NCMD
National Child Mortality Database

Knowledge, understanding and learning to improve young lives

The Contribution of Newborn Health to Child Mortality across England

National Child Mortality Database Programme Thematic Report

Data from April 2019 to March 2021

Published July 2022

www.ncmd.info

HQIP

Authors

- David Odd[1,2]
- Tom Williams[1]
- Sylvia Stoianova[1]
- Vicky Sleap[1]
- Nikki Glover[3]
- Grace Rossouw[1]
- Sarah Harris[4]
- Caroline Lee-Davey[5]
- Charlotte Bevan[6]
- Peter Fleming[1]
- Karen Luyt[1]

1. National Child Mortality Database, Bristol Medical School, University of Bristol, UK
2. School of Medicine, Division of Population Medicine, Cardiff University, UK
3. UCL Partners
4. Child Bereavement UK
5. Bliss
6. Sands

Partners

Contact us

National Child Mortality Database (NCMD) Programme

Level D, St Michael's Hospital,
Southwell Street, Bristol BS2 8EG

Email: ncmd-programme@bristol.ac.uk
Website: www.ncmd.info
Twitter: @NCMD_England

Acknowledgements

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

Supported by: Nick Cook, James Harle and Kate Hayter from the NCMD team.

With thanks to:

Helen Mactier, Consultant Neonatologist and Honorary Clinical Associate Professor and President of the British Association of Perinatal Medicine, for reviewing the report and for the helpful contributions

Wendy Tyler, Consultant Neonatologist and Honorary Treasurer of British Association of Perinatal Medicine, for reviewing the report and for the helpful contributions

Nigel Simpson, Consultant Obstetrician and Gynaecologist at the Leeds Teaching Hospital NHS Trust and Associate Professor at the University of Leeds, for input into the key findings and learning points related to antenatal care and labour

Kate Fitch from Tommy's and Robert Wilson from the Joint Sands/Tommy's Policy Unit for their helpful comments on the recommendations on the prediction and prevention of preterm birth

Jane Coyne from Greater Manchester Treating Tobacco Dependency Programme, and Samantha Neville from Greater Manchester Heath and Social Care Partnership, for the case study on the Greater Manchester's Smokefree Pregnancy programme

The South West Operational Delivery Network Team for the PERIPrem case study

CleverMed for linking data from NCMD with data from the BadgerNet system

Forget Me Not Children's Hospice, and their families, for sharing their photos.

The families who shared their stories for inclusion in this report so that we may learn, and improve services provided in the future

All Child Death Overview Panels (CDOPs) and Child Death Review Professionals who submitted data for the purposes of this report and for their continued support with information to NCMD for the national analysis and learning from child deaths in England

Contents

Foreword

When a child dies, the event triggers a cascade of emotions in the people who care for that child – their family, but also the health and social care professionals who have worked with them. Guilt is often a dominant emotion. Guilt that important opportunities might have been missed. Guilt that if everyone had worked a bit harder, the tragedy might have been avoided. Guilt that if we could turn back time, then things might have been different. The loss of a child's life is devastating.

"Across agencies, across health, education, social care and justice, we need to work together to consider every opportunity to improve. I am convinced that collectively we can make a difference."

Dr Camilla Kingdon

This report into the contribution of neonatal illness to childhood mortality is starkly revealing. The headline that up to 70% of deaths in children under 10 years had a contributory neonatal illness speaks to the importance not just of the neonatal period, but of maternal health and wellbeing too. It reminds us that child health is determined even before conception, and that maternal smoking and obesity, for example, are crucial public health issues that need focus and attention. The data also reminds us that newborn babies are more likely to be unwell when their mothers are in abusive relationships or have mental health conditions.

This report is a powerful tool. It gives those of us who feel the pain of guilt after a child's death the chance to understand how often there are 'modifiable factors' at play: up to a third of deaths have factors that could be modified, and in these cases a different outcome might have been possible. For bedside nurses and doctors, for public health doctors, for health service planners and commissioners, and for politicians, this report presents an opportunity to learn from these tragic cases and consider where interventions might prevent future deaths.

But it also gives us a clear signal that collaboration is needed to understand how and when we can act to prevent death. With children who had a neonatal illness being 14 times more likely to die all the way up to their 10th birthday, it's clear that a whole-system approach will be central to tackling mortality. Across agencies, across health, education, social care and justice, we need to work together to consider every opportunity to improve. I am convinced that collectively we can make a difference. Let's rise to the challenge.

Dr Camilla Kingdon

President of the Royal College of Paediatrics and Child Health

Consultant Neonatologist

1. Executive summary

The death of a baby or child is devastating and life changing. Each death represents a precious life lost and has a huge impact on the health and well-being of bereaved parents, the wider family, friends, and the community.

When a child dies, at any age, the cause of their death may have originated in an event that occurred in, or around, the time that they were born. It may be that they were born prematurely (born before 37 weeks gestation) or that, even if born around their due date, they suffered a brain injury, commonly through the lack of oxygen, or infection. This report aims to understand patterns and trends in child deaths where an event before, or around, the time of birth had a significant impact on life, and the risk of dying in childhood. It also includes thematic analysis of the modifiable factors (those factors that, had they been different, may have prevented the child from dying) identified in the reviews of these children's deaths by Child Death Overview Panels (CDOPs). The CDOPs are responsible for carrying out the statutory child death review process which ensures that any child in England who dies before their 18th birthday has a multi-agency review of their death, to help prevent further child deaths.

The analysis of perinatal deaths, occurring as a result of birth events or neonatal conditions, is already the subject of a number of audits and reports looking at perinatal mortality, covering different aspects of this challenging area:

- The Perinatal Mortality Review Tool (PMRT) is used to review the deaths of babies who die within the first 28 days after birth. Use of the PMRT is recommended for neonatal deaths but it can be used to review post-neonatal death. All Trusts use the PMRT to review their perinatal deaths and the vast majority of neonatal deaths (in excess of 95%) are reviewed using the PMRT.
- MBRRACE-UK: Mothers and Babies: Reducing Risk through Audits and Confidential Enquiries across the UK surveillance data also provide valuable surveillance on babies who die in the first 28 days after birth, as well as stillbirths and late miscarriages. Since 2013 their reports have shown that ethnic minority babies, and babies from areas of high social deprivation, have a higher risk of dying around the time of birth, compared to British-born White babies, and babies born in less deprived areas. The findings from the recent thematic report of the National Child Mortality Database (NCMD) Programme on Child Mortality and Social Deprivation are consistent with the MBRRACE-UK data.
- In addition, the National Neonatal Audit Programme (NNAP) also reports neonatal deaths, but is limited to admissions to, and deaths on, NHS neonatal units. The NNAP Annual Report on 2020 data suggests that mortality rates for very preterm babies vary widely between neonatal units and networks across the England and Wales.

- The Healthcare Safety Investigation Branch also investigate early neonatal deaths when the baby died within the first week of life (0-6 days) of any cause. Eligible babies include all term babies (at least 37 completed weeks of gestation) born following labour.

To complement these projects, the NCMD collects data on all children who die after birth, and before their 18th birthday. The reporting of deaths is rapid (normally within 48 hours of the event) and a statutory requirement. The NCMD annual report in 2021 highlighted the large contribution of preterm birth to child mortality, and that preterm birth may be the leading cause of child mortality in England[1]. This new thematic report provides a deeper analysis to try to understand the likely impact of neonatal conditions in both early and later child mortality, and what modifiable factors may exist. This is crucial information if we are to reduce our excessive infant and child mortality rates in England and prevent more children from dying.

In this report, NCMD looks at all children who needed additional care after they were born, and subsequently died in infancy or later in childhood. This includes deaths that occurred in both neonatal and paediatric intensive care units, hospital wards, deaths that occurred at home, in children's hospices or elsewhere in the community, or outside of England (including abroad). The report also describes learning from reviews of child deaths caused by **perinatal/neonatal events**.

Key findings

The contribution of perinatal events to child mortality

- For babies born alive, at or after 22 weeks gestation, who subsequently died before 10 years of age between 1 April 2019 and 31 March 2021, half of the deaths occurred in children over one month old.
- Children who received additional care after birth (neonatal care) made up 83% of children who died before their 1st birthday, 38% of deaths in the next 4 years, and 27% of deaths between the ages of 5 and 9.
- There is a clear association between childhood death following neonatal illness and learning disabilities. Over half of the children who died also had learning disabilities.
- From a public health perspective, it is possible that neonatal illness contributes to 72% of all deaths under 10 years of age.
- Improvements in perinatal care to reduce neonatally acquired conditions (e.g., reduction in preterm births, or brain injury sustained around the time of birth), or the impact of them (e.g., preterm brain injuries) are likely to have broad benefits to children, society, and healthcare institutions, across at least the first decade of life.

Reviews categorised by CDOPs as a perinatal/ neonatal event

For child deaths reviewed by a CDOP between 1 April 2019 and 31 March 2021, and categorised as a *perinatal/neonatal event*:

- Immaturity/prematurity related conditions caused 78% of deaths, 13% were caused by perinatal asphyxia, 4% were caused by a perinatally acquired infection, and 4% were due to other causes.
- In 17% of deaths, there was planned palliative care, and, of these deaths, the majority (93%) occurred within a hospital trust.
- Modifiable factors were identified in 34% of deaths.
  - » 20% identified a modifiable factor within the characteristics of the child, including pregnancy factors. The most common factors were smoking in pregnancy or the household, and maternal obesity, both of which increase the chance of premature birth and complications for the baby.
  - » 7% identified a modifiable factor within the child's social environment. Challenges with access to services, domestic abuse, and mental health conditions of parents/ carers were the factors most commonly recorded by CDOPs.
  - » 11% identified a modifiable factor relating to the provision of services. The majority of these related to the lack of suitable or timely involvement by an appropriate service. Factors relating to poor communication and information sharing, and resource and equipment issues, were also recorded.
- Learning points or issues were identified in almost half (49%) of child death reviews. Themes included: the need to improve identification of risk factors for preterm birth and optimisation of antenatal steroid and magnesium sulphate use to protect preterm babies, improving birth management and newborn resuscitation to prevent newborn brain injury, effective screening and management of domestic abuse and other social issues, and timely transfer to appropriate services. A recurring theme was that of barriers to communication and lack of access to translation/interpreting services, and the importance of bereavement support and services for families.

Recommendations

The impact of neonatal illness is broad and pervasive across the first few years of childhood, not just in the first year of life. Where evidence exists to reduce the burden of neonatal illness, resources for universal implementation and improvement work could prevent substantial numbers of child deaths.

The recommendations described below are based on the analysis of the characteristics of the children who have died, and the modifiable factors and learning points as identified and recorded by the CDOPs.

Prediction and prevention of preterm birth

1. Make prevention of preterm birth a priority. Social initiatives to reduce or mitigate the social determinants (e.g., smoking, obesity, and deprivation) require resources and support. Commissioners should seek to reduce deprivation and housing insecurity, by integrating advice on employment, benefits and housing into maternity services, using health justice partnership and/or social prescribing models. Dedicated preterm birth clinics and implementation of evidence-based packages to predict and prevent preterm birth, as implemented through the Saving Babies' Lives Care Bundle, would ensure the best possible care to women according to their individual risk. The Maternity and Neonatal Safety Improvement Programme is supporting the implementation of a Preterm optimisation programme, which consists of a range of evidence-based interventions aimed at improving the outcomes in babies born prematurely.

Action by: Department of Health and Social Care, NHS England, Maternity Disparities Taskforce, Commissioners

2. Audit the implementation of the Overseas Visitor Charging Regulations to minimise the deterrent effect of charging for maternity care and to ensure correct application of exemptions.

Action by: NHS Trusts

3. Prioritise new research exploring the prevention of preterm birth. In particular, further work around social inequalities and the associations between ethnic group and this common cause of childhood death, need exploring[30].

Action by: Research Funders and Commissioners, Department of Health and Social Care, NHS England, National Institute for Health Research

4. Ensure that the NICE Quality Standard QS116, which covers services for domestic violence and abuse in adults and young people, is used to improve the quality of care provided in this area.

Action by: All Antenatal Care Services, Primary Care, Police, Social Care

Optimisation of the baby prior to and following preterm birth

5. Ensure vulnerable infants are born in an appropriate unit[2]. Linked obstetric, maternity and neonatal networks with joint responsibility for the care of the mother and baby, before and after birth, alongside national systems to easily identify the best place to provide care before a high risk baby is born, should be considered.

Action by: Commissioners and Providers of Maternity and Neonatal Care Services, Department of Health and Social Care, NHS England, NHS Integrated Care Boards, Integrated Care Systems

6. Ensure broad and equitable implementation of evidence-based care bundles and single interventions (e.g., antenatal corticosteroids and magnesium sulphate) that reduce the impact of preterm birth in line with element 5 of Saving Babies' Lives Care Bundle Version Two and as delivered through The Maternity and Neonatal Safety Improvement Programme. Delivery of all evidence-based therapies should be supported and benchmarked and compared between healthcare providers.

Action by: Commissioners and Providers of Perinatal and Community Care Services, NHS England

Improving perinatal care to reduce mortality and brain injury after birth

7. Ensure broad and equitable implementation of evidence-based bundles, care packages and single interventions that reduce the incidence and impact of brain injury around birth. Delivery of all evidence-based therapies should be supported and benchmarked between healthcare providers. In addition, the effective use of the Newborn Early Warning Trigger and Track (NEWTT) tool can reduce the severity of illness for babies who deteriorate after birth.

Action by: Commissioners and Providers of Maternity and Neonatal Care Services, NHS England

8. Implement and deliver new research and programmes to reduce perinatal brain injuries, e.g., the Avoiding Brain Injury in Childbirth programme. Hypoxic-ischaemic brain injury may be preventable by targeted antenatal intervention and the impact reduced through prompt neonatal interventions. In addition, no established treatments exist for infants with intracranial haemorrhage (ICH) to reduce long term burden.

Action by: Department of Health and Social Care, NHS England, National Institute for Health Research

9. Ensure hospital and community based staff are competent with basic neonatal resuscitation and are aware of the importance of early escalation of concerns in line with the Core Competency Framework.

Action by: NHS Trusts

Community and Social Interventions

10. Ensure all parents of infants born preterm or of low birthweight are given targeted advice and support on reducing the risk of sudden unexpected, unexplained death in infancy (SUDI)[3]. The association between preterm birth and later sudden unexpected, unexplained death in childhood (SUDIC) is well recognised, with a third of unexplained deaths occurring in infants who needed extra care after birth.

Action by: Commissioners and Providers of Postnatal Care, Health Visiting Services, Antenatal Services, Neonatal Hospital and Community Staff, Family Nurse Partnerships

11. Improve parental and professional awareness of risk factors in children with learning disabilities (particularly the need for good nutrition, maintaining activity levels, avoidance of constipation, and appropriate responses to respiratory infections)[4].

Action by: Commissioners and Providers of Healthcare Services to Children with Learning Disabilities, Local Authorities, Educational Providers, Social Care

12. Ensure staff are aware of the importance of interpreting services being provided by professional interpreters at all stages of care, alongside provision of interpreting and translation services in NHS Trusts and all healthcare services that provide care for women during pregnancy and beyond.

Action by: NHS England, Commissioners and Providers of Maternity and Child Healthcare Services, All Service Providers

13. Implement provision of resources within the NHS as described in the Health and Care Act 2022 alongside programs such as the National Bereavement Care Pathway for Pregnancy & Baby Loss to identify where palliative care is needed, antenatally or later, support the counselling and genetic counselling of parents and care-givers, and deliver holistic palliative care for the child, the family and the clinical team.

Action by: Commissioners of NHS Care

Additional Data Collection and Processes

14. Ensure that parents' views are sought and recorded as part of the child death review process. There was limited information from the CDOP process regarding parents' own views and concerns about their child's care during their child's life and death. The Child death review statutory and operational guidance requires parents' views to be sought and included in the process, however this is not yet happening in all cases. It will be important to find ways to improve this in future to help guide initiatives and support, for instance by using the Parent Engagement Materials provided by the Perinatal Mortality Review Tool Programme and training provided by Sands.

Action by: Child Death Review Professionals, Child Death Overview Panels

15. Ensure there is adequate multi-agency input into data collection and reviews so that social environment factors, e.g., factors relating to safeguarding and deprivation, are appropriately collected and included for review.

Action by: Child Death Review Professionals, Child Death Overview Panels

This report will inform what further policies or interventions may be required to reduce the number of children who die or are left severely disabled as a result of events occurring in the perinatal period.

2. Introduction

The death of a child around the time of birth is one of the biggest contributors to childhood mortality in the developed world, with 42% of all child deaths in England occurring when the child was under 28 days old[1]. The consequences for children who survive serious birth events or neonatal conditions are often long-term with life-long disability[5] and subsequent premature death in childhood, through the association with respiratory and neurological conditions[6].

Previous work has suggested that very low and low birthweight babies have higher risks of mortality throughout childhood[7]. While the impact of preterm birth (for babies born earlier than 37 weeks gestation) and perinatal brain injury is recognised, the wider impact on childhood mortality and the role and impact of specific pathologies (including spontaneous or medically instigated preterm birth) is unclear.

This report aims to quantify the population impact of birth events and neonatal conditions in England, and their contribution to longer term childhood mortality.

The findings and learning from the report will inform what further policies or interventions may be required to reduce the number of children who die or are left severely disabled as a result of events occurring in the perinatal period, and we will make recommendations based on our findings.

The NHS Long Term Plan sets explicit targets to reduce preterm births, and halve neonatal mortality and serious brain injury, by 2025. In addition, NHS England released version 2 of the Saving Babies' Lives Care Bundle in March 2019 with the aim of providing detailed information for providers and commissioners of maternity care, on how to reduce perinatal mortality across England. The care bundle brings together five elements of care that are widely recognised as evidence-based or best practice. They are:

- Reducing smoking in pregnancy
- Risk assessment, prevention and surveillance of pregnancies at risk of fetal growth restriction
- Raising awareness of reduced fetal movements
- Effective fetal monitoring during labour
- Reducing preterm birth and optimising care when preterm delivery cannot be prevented

This report did not target impacts or changes initiated by the COVID pandemic, although broad impacts on perinatal care in England are reported elsewhere[8].

2.1. How to read this report

Section 3 presents analysis on children who died in England before their 10th birthday, between 1 April 2019 and 31 March 2021. The section focuses on comparing the characteristics of deaths in infancy to those who die in childhood and identifying the proportion of children who die after neonatal illness across childhood.

The aim of this section is to investigate how many of these deaths are associated with neonatal illness, and how many are in the 1st year after birth, compared to those who die later in childhood, as well as the possible causes and reasons why they die.

Within this section, '**neonatal illness**' refers to children who either died in the first day of life, or needed admission to a neonatal unit for additional care shortly after birth; including support for prematurity. The phrase '**neonatal condition**' refers to a specific disease, disorder or condition (preterm birth, low birthweight, intracranial haemorrhage, congenital abnormalities, hypoxic-ischaemic encephalopathy, necrotising enterocolitis) diagnosed during the neonatal period.

We calculate the number (n) of children in different groups, their risk of dying, and how this might be greater or lower than others, i.e., their relative risk (RR). A relative risk of 2 means the child has twice the chance of dying compared to another child. We can test if any differences we see are unlikely to be due to chance using the p-value (which gives the probability that there is no true difference despite what numbers we may see), and the 95% confidence interval (CI) (which gives a range of numbers where we can be 95% sure the true value lies). The population attributable risk fraction is also calculated, which is a way of estimating how many deaths may be avoided if those children with the exposure (in this case needing additional care after birth) had the same risk of death as those who didn't.

Section 4 describes data and learning reported from child death reviews in England that were completed between 1 April 2019 and 31 March 2021, where *perinatal/neonatal event* was selected by CDOPs as the primary category of death. Some of these deaths occurred in earlier years.

3. The contribution of perinatal events to child mortality

This section of the report analyses data from child deaths between 1 April 2019 and 31 March 2021, reported to NCMD, and limited to children born alive after 22 weeks gestation, and who subsequently died before their 10th birthday. The aim of this work is to investigate how many of these deaths across the first 10 years of childhood are associated with neonatal illness, as well as the specific neonatal conditions that may be responsible, and the reasons for the deaths.

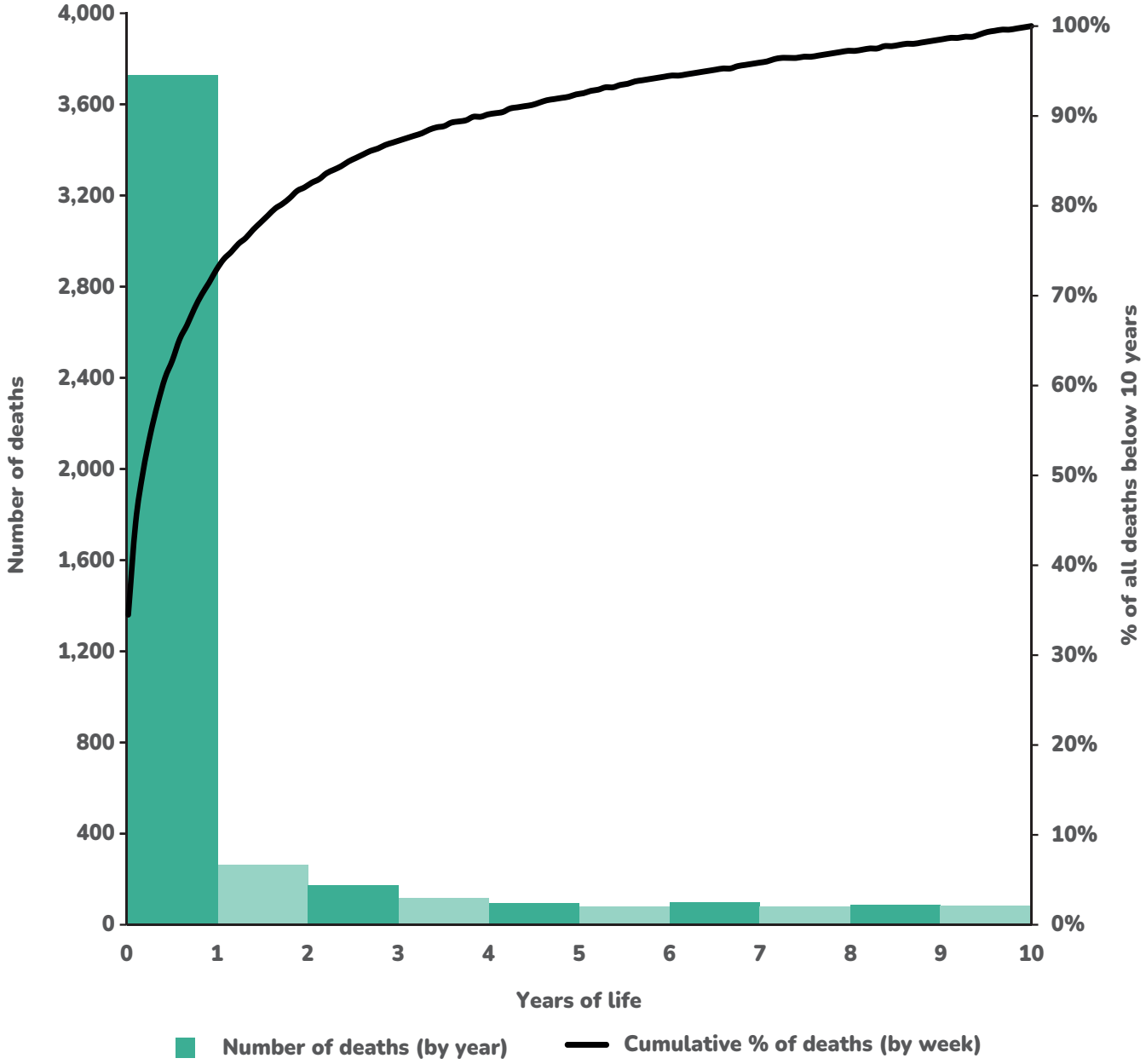
3.1. Data and population used

Initially, the data from all deaths reported to NCMD, that occurred between 1 April 2019 and 31 March 2021 (24 months), were identified. NHS numbers, included in the child death notification form, were sent to CleverMed to match with records on BadgerNet (an electronic patient data management platform used by neonatal units in the UK). This was to identify whether the child had been admitted to a neonatal unit at any time after birth, and if so, if a BadgerNet data record existed. If a record existed, the discharge summary for each episode of care was returned to NCMD and linked to the NCMD record. Where more than one admission was identified (e.g., where an infant was born in one hospital, and subsequently transferred to another for a higher level of care, repatriation or capacity issues) there were often multiple entries recorded for birth information. In such instances, the first entry was used (e.g., the record from the hospital of birth). For text strings containing diagnoses or possible causes of death, strings were combined to include all available diagnoses and codes.

3.2. Characteristics of the childhood deaths under 10 years of age

This section reports the frequencies and characteristics of the children who died, split by their age group (less than 1 year, 1-4 years, and 5-9 years). A total of 4829 children died before their 10th birthday, after being born at or after 22 weeks gestation, between 1 April 2019 and 31 March 2021 (a 24-month period). In total 2784 (57.7%) of these children were linked to a BadgerNet record. The numbers of deaths were higher at younger ages, with 1666 deaths in the first week of life, dropping to 8 deaths in the 52nd week, and fewer than 5 deaths in the week before the child's 10th birthday. Figure 1 shows the number of deaths per year over the first 10 years of life (green bars and left-hand axis), alongside the proportion of all deaths that have occurred by that point (black line right-hand axis). Around half (n=2406 (50%)) of all deaths before the age of 10 years had occurred by 4 weeks of age, and three quarters (n=3730) had occurred by 1 year of age; with then much smaller numbers of deaths occurring every week over the next 9 years.

Figure 1: Number of deaths and proportion of all deaths before 10 years of age, by age at death



The sex of the children varied by the age of death, but all other demographics (Table 17; Appendix B) appeared to be different between deaths in different age categories.

3.3. Proportion of childhood deaths after having neonatal illness across England

This section reports on the proportion of childhood deaths (under 10 years of age) associated with neonatal illness after birth. The main outcome was an overall measure of neonates requiring additional medical care immediately after birth. This was derived by identifying all children who had received neonatal care in a neonatal unit after birth, in addition to those who died in the first day of life prior to admission ('Neonatal Illness'). The overall proportion of deaths with evidence of neonatal illness was identified and tested to see if the proportions differed across demographic measures (using the Chi^2 test) and to see if the patterns observed were different for children below 1 year of age, and over 1 year of age (using Likelihood Ratio Test).

Who is dying after neonatal illness?

Overall, 71.6% of children who died under the age of 10 years had evidence of neonatal illness. This was higher in those children who died under 1 year of age (82.7%) than between 1 and 9 years (33.9%) ($p<0.001$) (Table 1). While there were fewer deaths of girls compared to boys across all age groups, the proportion of children with evidence of neonatal illness was higher in girls than boys, (73.1% vs 70.0%), and this appeared similar across the ages investigated ($p_{interaction}=0.578$).

Table 1: Proportion of deaths in children aged less than 10 years in England with evidence of neonatal illness, 1 April 2019 to 31 March 2021, overall, and split by sex

	All Ages (0-9 years)	p-value*	Age at death		p-value
			<1 year	1-9 years	
All deaths linked to neonatal illness	**3456 (71.6%)**	**-**	**3083 (82.7%)**	**373 (33.9%)**	**<0.001**
					$P_{interaction}$**
Sex		0.019			0.578
Female	1570 (73.1%)		1402 (84.0%)	168 (35.2%)	
Male	1825 (70.0%)		1624 (81.4%)	201 (33.0%)	

Number are n (%). Due to small numbers, comparisons are between deaths under and over 1 year of age

* A p-value is a measure of the probability that an observed difference could have occurred just by random chance. The lower the p-value, the greater the statistical significance of the observed difference

** $P_{interaction}$ is the probability that the relationship between neonatal illness and age is different for males and females

The proportion of deaths with evidence of neonatal illness also appeared to be associated with the ethnic group of the child (p=0.008); with the highest proportion in Black or Black British children (77.2%), and the lowest in those where the child's ethnicity was defined as Mixed (70.5%), White (70.5%), and Other (64.0%) (Table 2).

This profile changed with the age of the children, with the highest proportion in the older children (1-9 years) being seen in the Asian or Asian British ethnic group (37.5%), and the two lowest ethnic groups being Black or Black British (28.4%) and Other (14.3%).

Table 2: Proportion of deaths in children aged less than 10 years in England linked to neonatal illness, 1 April 2019 to 31 March 2021, split by ethnicity

	All Ages (0-9 years)		Age at death		
			<1 year	1-9 years	
	Number (%)	**p-value***	**Number (%)**	**Number (%)**	**$P_{interaction}$****
Ethnicity*		**0.008**			**0.003**
Asian or Asian British	**586 (74.6%)**		**511 (87.2%)**	**75 (37.5%)**	
Black or Black British	**271 (77.2%)**		**252 (88.7%)**	**19 (28.4%)**	
Mixed	**186 (70.5%)**		**167 (80.7%)**	**19 (33.3%)**	
Other	**73 (64.0%)**		**68 (86.1%)**	**5 (14.3%)**	
White	**1897 (70.5%)**		**1679 (81.1%)**	**218 (35.2%)**	

Number are n (%). Due to small numbers, comparisons are between deaths under and over 1 year of age

* Ethnicity is grouped based on groupings used in the 2011 Census

* A p-value is a measure of the probability that an observed difference could have occurred just by random chance The lower the p-value, the greater the statistical significance of the observed difference

** $P_{interaction}$ is the probability that the relationship between neonatal illness and age is different for different ethnic groups

The proportion of deaths with evidence of neonatal illness also appeared to be associated with the region of England the children lived in (p=0.022), with the highest proportion in the West Midlands (76.8%) and London (73.4%), and the lowest in the North East (68.3%), South East (69.4%) and South West (69.3%) (Table 3 and Figure 2).

Again, this profile changed with the age of the children (p=0.008), with the highest proportion in the older children (1-9 years) being seen in the West Midlands (42.5%), East Midlands (39.0%) and South West (39.1%), and the lowest in London (26.8%) and the South East (27.9%).

Table 3: Proportion of deaths in children aged less than 10 years in England linked to neonatal illness, 1 April 2019 to 31 March 2021, split by region

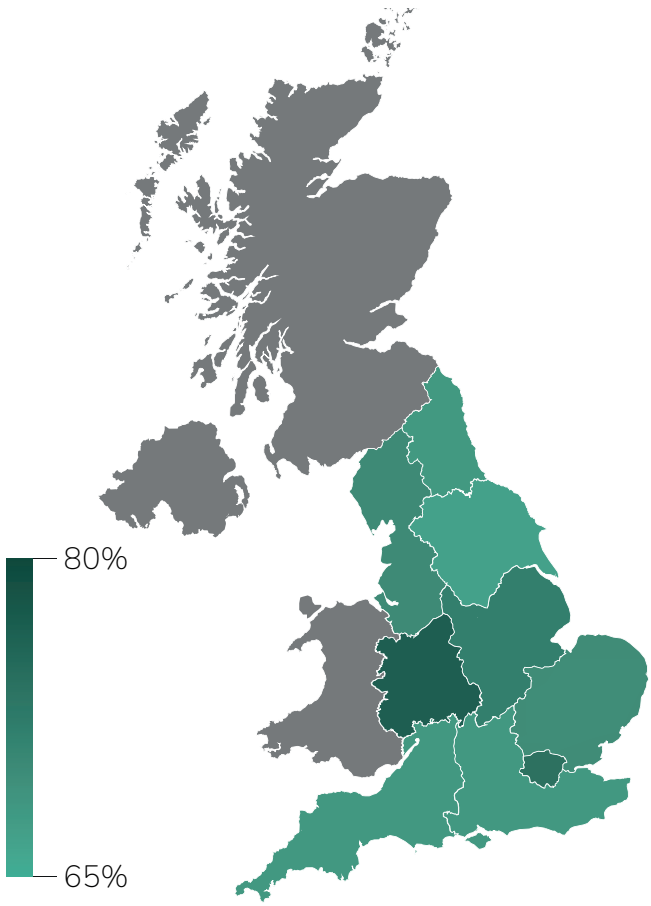
	All Ages (0-9 years)	p-value*	Age at death		$P_{interaction}$**
			<1 year	1-9 years	
Region		**0.022**			**0.008**
East Midlands	284 (73.0%)		252 (82.1%)	32 (39.0%)	
East of England	325 (70.5%)		282 (81.7%)	43 (37.1%)	
London	651 (73.4%)		599 (86.4%)	52 (26.8%)	
North East	144 (68.3%)		127 (82.5%)	17 (29.8%)	
North West	493 (71.4%)		437 (80.9%)	56 (37.1%)	
South East	443 (69.4%)		399 (83.1%)	44 (27.9%)	
South West	250 (69.3%)		214 (79.6%)	36 (39.1%)	
West Midlands	496 (76.8%)		445 (84.6%)	51 (42.5%)	
Yorkshire and Humber	370 (67.9%)		328 (78.9%)	42 (32.6%)	

Number are n (%). Due to small numbers, comparisons are between deaths under and over 1 year of age

* A p-value is a measure of the probability that an observed difference could have occurred just by random chance The lower the p-value, the greater the statistical significance of the observed difference

** $P_{interaction}$ is the probability that the relationship between neonatal illness and age is different for different regions

Figure 2: Proportion of child deaths linked to neonatal illness by region (Children aged 0-9, who died between 1 April 2019 and 31 March 2021)



Although the number of deaths was greater for children living in the more deprived deciles, the proportion of deaths after neonatal illness appeared to be similar across 5 categories of deprivation (IMD) (p=0.131) (Table 4). However, this did appear to differ by the age of the child, with little variation in deaths under 1 year of age; but a clear difference in older children, with the proportion of children with evidence of neonatal illness much higher in the most deprived neighbourhoods in comparison to the least deprived neighbourhoods (40.8% vs 29.9%) ($p_{interaction}$=0.054).

Table 4: Proportion of deaths in children aged less than 10 years in England linked to neonatal illness, 1 April 2019 to 31 March 2021, split by social deprivation decile

Characteristic	All Ages	p-value**	Age at death		$P_{interaction}$***
			<1 year	1-9 years	
IMD*		**0.131**			**0.054**
1-2 (Most deprived)	1224 (74.0%)		1083 (82.8%)	141 (40.8%)	
3-4	793 (70.9%)		720 (80.7%)	73 (32.2%)	
5-6	619 (70.8%)		554 (84.1%)	65 (30.2%)	
7-8	439 (70.9%)		388 (84.7%)	51 (31.7%)	
9-10 (Least deprived)	344 (68.9%)		304 (83.3%)	40 (29.9%)	

Number are n (%). Due to small numbers, comparisons are between deaths under and over 1 year of age

* Index of Multiple Deprivation (IMD)

** A p-value is a measure of the probability that an observed difference could have occurred just by random chance
The lower the p-value, the greater the statistical significance of the observed difference

*** $P_{interaction}$ is the probability that the relationship between neonatal illness and age is different for different measures of deprivation

What are children dying of after having neonatal illness?

The category of death for this group of children was identified from data received from the Child Death Overview Panels (CDOPs) in England, who carry out a detailed review of the circumstances of death in all cases. While the CDR process is statutory it can sometimes take some months to complete, and so these detailed data, with a category of death, were only available for 2484 (51.4%) children included in this part of the analysis (those who died between 1 April 2019 and 31 March 2021, and below 10 years of age when they died). As part of the process, the CDOP allocate a primary category of death (for definitions, see Appendix D). Due to small numbers, those who died of suicide or deliberate self-inflicted harm, deliberately inflicted injury, abuse or neglect, and trauma, were also excluded from this analysis and not presented (n=55). For all causes of death, children who had had neonatal illness had a different profile to those who hadn't, in all age categories (Table 5). In order to assess whether children who had previously had neonatal illness appear overrepresented in any categories, the proportion of children expected to have had neonatal illness in the population was estimated to be 15.4% (using data derived from Neonatal Data Analysis Unit (NDAU) data[9]).

Table 5: Categories of death, split by the presence, or not, of neonatal illness

Age and Category of death	No neonatal illness	Neonatal illness	p-value**
<1 year			**<0.001**
Malignancy	11 (50.0%)	11 (50.0%)	
Infection	37 (46.3%)	43 (53.8%)	
Acute medical or surgical condition	11 (27.5%)	29 (72.5%)	
Chromosomal, genetic and congenital anomalies	86 (13.8%)	535 (86.2%)	
Chronic medical condition	10 (19.2%)	42 (80.8%)	
Perinatal/neonatal event	23 (2.6%)	867 (97.4%)	
Sudden unexpected, unexplained death	117 (67.2%)	57 (32.8%)	
1-4 years			**<0.001**
Malignancy	63 (88.7%)	8 (11.3%)	
Infection	28 (70.0%)	*	
Acute medical or surgical condition	11 (44.0%)	14 (56.0%)	
Chromosomal, genetic and congenital anomalies	48 (45.7%)	57 (54.3%)	
Chronic medical condition	15 (31.9%)	32 (68.1%)	
Perinatal/neonatal event	*	*	
Sudden unexpected, unexplained death	*	*	
5-9 years			**0.002**
Malignancy	79 (87.8%)	11 (12.2%)	
Infection	12 (75.0%)	*	
Acute medical or surgical condition	25 (75.8%)	8 (24.2%)	
Chromosomal, genetic and congenital anomalies	38 (67.9%)	18 (32.1%)	
Chronic medical condition	17 (56.7%)	13 (43.3%)	
Perinatal/neonatal event	*	*	
Sudden unexpected, unexplained death	*	*	

Numbers are n (%).

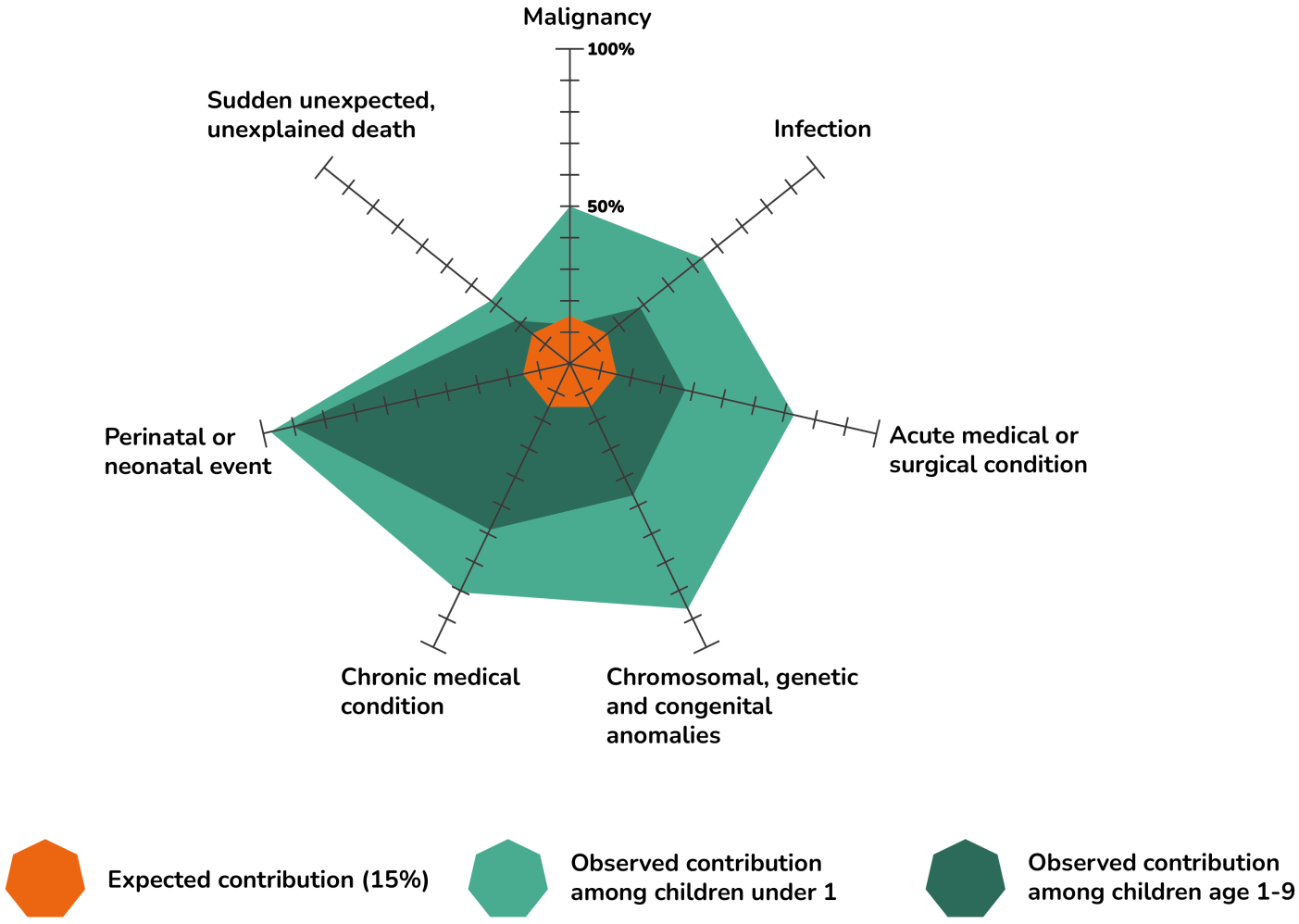
* Absolute number less than 5, or where it can be derived from other data

** A p-value is a measure of the probability that an observed difference could have occurred just by random chance. The lower the p-value, the greater the statistical significance of the observed difference

Overall, children with previous neonatal illness accounted for 1776/2429 (73.1%) of all deaths reviewed, with around half of these deaths categorised as *Perinatal or neonatal events* (n=876). However, the number of children with neonatal illness also appeared to be higher than expected for deaths categorised as *Infection* (59/136 (43.4%)), *Acute medical or surgical conditions* (51/98 (52.0%)), *Chromosomal, genetic and congenital anomalies* (610/782 (78.0%)), *Chronic medical conditions* (87/129 (67.4%)), and *Sudden unexpected, unexplained death* (63/201 (31.3%)).

The proportion of children with deaths from *Malignancy* (30/183 (16.4%)) seen in children with neonatal illness was similar to the estimated population prevalence (of 15.4%). Figure 3 shows the proportion of deaths occurring in children who had had neonatal illness, split by the category and age of death.

Figure 3: Observed contribution of children with neonatal illness to overall mortality (by age and category of death) compared with the proportion of children in the population estimated to have neonatal illness ("Expected contribution")



Do the children dying after neonatal illness have particular disabilities?

During the CDOP process, data on whether the child had learning disabilities, or other disabilities, are collected in the statutory reporting form. Diagnosis of learning disabilities is challenging under the age of 4, and so these data have not been reported for those in the lowest two age categories in this work. Children who died after neonatal illness were more likely to have had a learning disability (if 5-9 years), or learning disabilities or other developmental impairment or disability (all age categories) than those who died without preceding neonatal illness (Table 6).

Table 6: Proportion of deaths with learning disabilities or other developmental impairment or disability, split by age and neonatal illness

Disabilities identified during Review	Age at death		
	<1 year	1-4 years	5-9 years
Learning disabilities identified			
Neonatal Illness	-	-	71/120 (59.2%)
No evidence of Neonatal Illness	-	-	107/320 (33.4%)
p-value*	-	-	<0.001
Learning disabilities or other developmental impairment or disability			
Neonatal Illness	209/3083 (6.8%)	140/253 (55.3%)	82/120 (68.3%)
No evidence of Neonatal Illness	30/647 (4.6%)	93/406 (22.9%)	134/320 (41.9%)
p-value	0.043	<0.001	<0.001

* A p-value is a measure of the probability that an observed difference could have occurred just by random chance
The lower the p-value, the greater the statistical significance of the observed difference

How many children are dying after neonatal illness?

In this section we have estimated the relative risk of dying after neonatal illness in 3 age periods, compared to those unaffected in the neonatal period, and calculated an estimate for the overall population impact (i.e., the proportion of deaths attributable to neonatal illness). See Appendix A for more information.

Absolute risk of death is low, with children after neonatal illness having an annual risk of 1.7% in the first year of life but dropping to 0.02% between 5 and 9 years. Within this overall low risk of death, children who had neonatal illness were 14 times (RR 13.82 (95% confidence interval of 13.00-14.71)) more likely to die before their 10th birthday than those unaffected by neonatal illness (Table 7). If the risk of mortality in this group was reduced to the same as the rest of the population, then 66.4% (95% confidence interval of 64.9%-67.9%) of childhood deaths might be avoided. Comparable results were seen when looking at the different age bands, with the risks of dying after neonatal illness decreasing as age increased. However even in children between 5 and 9 years old, those who had been admitted to neonatal units had a doubling of the risk of death compared to their peers; and likely contribute to 14.3% (95% confidence interval of 9.7%-18.6%) of all deaths during this later age period.

Table 7: Relative Risk of death, and estimated population impact, of neonatal illness on all cause child mortality before 10 years, over a 2 year period of 1 April 2019 to 31 March 2021

Age at death	Neonatal Illness		No Neonatal Illness		Relative Risk (95% CI)	Population Attributable Risk Fraction (95% CI)
	Deaths	Est Population at risk*	Deaths	Population		
All ages (0-9 years)	3456	1,874,997	1373	19,296,082	13.82 (13.00-14.71)	66.4% (64.9% to 67.9%)
<1 year	3083	190,478	647	1,030,532	25.78 (23.69-28.06)	79.4% (78.0% to 81.8%)
1-4 years	253	749,049	406	4,118,801	3.69 (3.12-4.37)	29.3% (24.3% to 33.9%)
5-9 years	120	935,470	320	5,146,749	2.08 (1.72-2.52)	14.3% (9.7% to 18.6%)

*Derived from ONS 2019 Population Estimates, and estimated for number of children at risk over 24 months

What Neonatal Conditions appear to be responsible?

To identify the overall impact of neonatal illness, and which neonatal conditions were contributing to the increased childhood mortality, a number of specific neonatal conditions were identified; either from the BadgerNet record, or from the NCMD record if the death occurred in the first day of life. We identified the presence, or absence, of the derived neonatal conditions, and their frequency in each age group (i.e., the number of children of each age who died with that specific characteristic):

- Preterm: Children born at a gestational age below 37 weeks, or those with a coded admission definition of preterm in the BadgerNet record
- Low birthweight: Babies born at term with birthweight below 2500g
- The two common causes of perinatal brain injury: Neonatal hypoxic-ischaemic encephalopathy (HIE) and Intracranial haemorrhage (ICH)
- Necrotising Enterocolitis (NEC)
- Congenital Abnormality

For more information on the text used to identify these neonatal conditions, see Appendix A and Appendix E.

The proportions of children dying in whom one of these neonatal conditions was identified, and comparisons between the ages of children, were tested using the Chi^2 Test.

In total, 82.7% of deaths in the first year of life were associated with evidence of neonatal illness; 38.4% between 1 and 4 years, reducing to 27.3% for deaths between 5 and 9 years (Figure 4 and Table 8). When investigating specific neonatal conditions, 60.2% of children who died under 1 year of age had evidence of preterm birth in their records. This reduced for deaths of older children ($p<0.001$), where 13.9% of children who died between 5 and 9 years had evidence of preterm birth. There was an association between age at death and all other neonatal conditions identified here, and with the composite measures ($p<0.001$). A total of 8.3% of deaths of infants (less than one year of age) were associated with HIE and this reduced to 3.0% in deaths of children between 5 and 9 years of age, while for 16.1% of infant deaths there was a record of ICH.

Figure 4: Proportion of deaths, by the presence of any neonatal condition, by age (years) at death

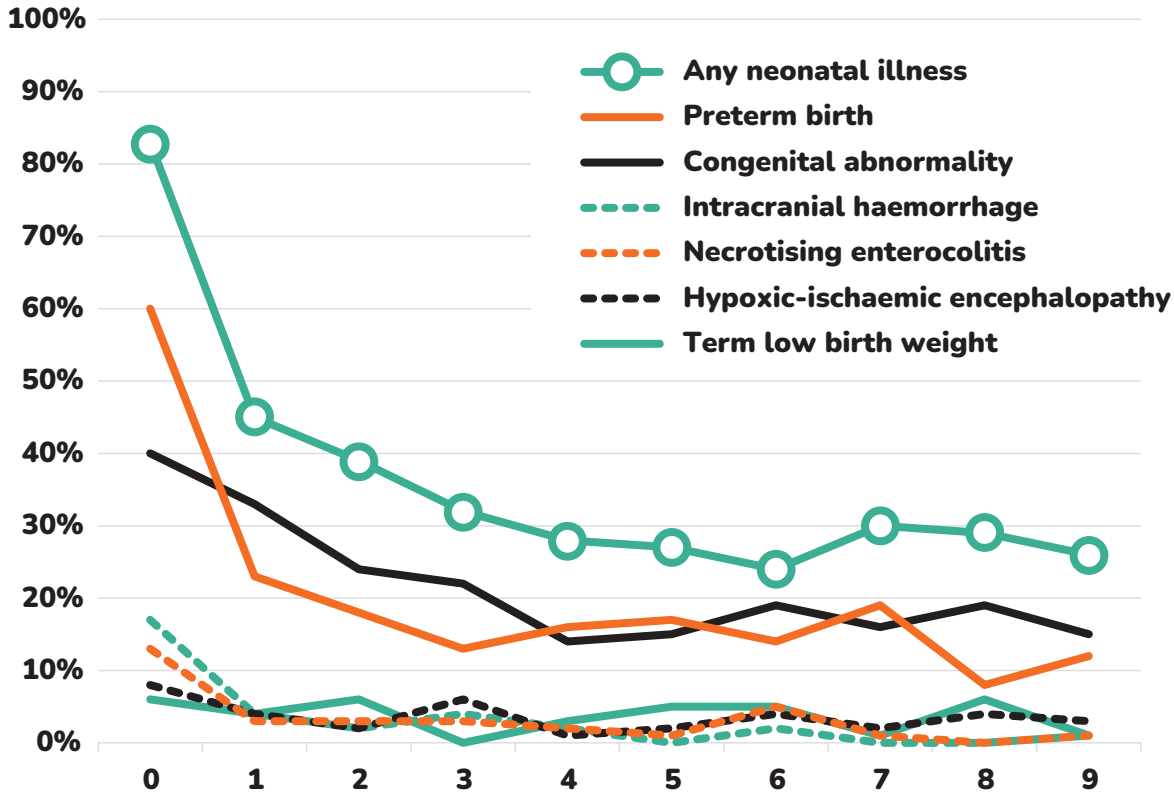


Table 8: Neonatal conditions of all deaths of children aged less than 10 years in England, 1 April 2019 to 31 March 2021, split by their age at death

Characteristic	Age at death			p-value**
	<1 year	1-4 years	5-9 years	
All deaths	**3730**	**659**	**440**	**-**
Any Evidence of Neonatal Illness	3083 (82.7%)	253 (38.4%)	120 (27.3%)	<0.001
Specific Neonatal Conditions*				
Low Birthweight (Term births only)	223 (6.0%)	24 (3.6%)	16 (3.6%)	0.011
Preterm	2244 (60.2%)	124 (18.8%)	61 (13.9%)	<0.001
Hypoxic-Ischaemic Encephalopathy	304 (8.3%)	18 (2.7%)	14 (3.2%)	<0.001
Congenital Abnormality	1503 (40.3%)	171 (26.0%)	75 (17.1%)	<0.001
Intracranial Haemorrhage	600 (16.1%)	19 (2.9%)	-	<0.001
NEC	401 (10.8%)	19 (2.9%)	-	<0.001

Number are n (%)

* Children without evidence were assumed to not have the characteristic

** A p-value is a measure of the probability that an observed difference could have occurred just by random chance
The lower the p-value, the greater the statistical significance of the observed difference

3.4. Interpretation

The majority of deaths of children under 10 years of age occur in the first few days of life, with most happening before 4 weeks of age. However, the impact of adverse perinatal events appears to persist throughout childhood, with increased overall risk of childhood death, particularly from underlying illness attributable to conditions identified in the neonatal period. From a public health perspective, it is possible that neonatal disease contributes to 66% of all deaths of children under 10 years of age.

A higher proportion of deaths of girls was associated with neonatal events throughout the first 10 years of life, and for girls, deprivation was more strongly associated with deaths after one year of age than in the first year. The variations in the risk of deaths from neonatal illness across different ethnic groups and regions of England are complex, and in this report, we have not been able to derive the risk of death for each measure. Consequently, interpretation should be cautious and further work is urgently needed.

Children who needed additional care after birth had a different profile to those with no evidence of problems, at all ages, and even in the oldest children they appeared to have higher than expected risks of dying of infection, acute or chronic medical or surgical conditions, and SUDIC. They were also more likely to have learning and other disabilities than children who died without neonatal illness.

Evidence of neonatal illness was common in those children who died in the first year of life. However, children who were admitted to neonatal units after birth also made up 38% of deaths in the next 4 years, and 27% of deaths between 5 and 9 years, with individual risk for death substantially above those of their peers who appeared to be well after birth.

Changes in perinatal care, to reduce disease (e.g., reductions in preterm births, or brain injuries), or the impact of them (e.g., preterm brain injuries) are likely to have broad benefits to children, society and healthcare institutions across at least the first decade of life. Effective evidence-based perinatal interventions to reduce preterm mortality and brain injury exist (BAPM Toolkit; PERIPrem), however significant regional variation in clinical use has been noted (NNAP Report 2020). The PERIPrem evidence-based perinatal care bundle has achieved a reduction in preterm mortality and brain injury in the South-West region after implementation (see Case Study). New research in prevention and treatment of perinatal disease is urgently needed; however despite over 20% of the population of England being below the age of 18, and the profound life-long benefits of early health, only 5% of research funding in England is directed to projects in this group[10]. Preterm birth and its consequences may be the biggest, potentially modifiable, specific component of increased mortality, although brain injury around birth also appears to have a substantial impact. However, there is little progress in the UK government's ambition to reduce brain injuries around birth[9], although hypoxic-ischaemic brain injury may be preventable by targeted antenatal intervention[11], and the impact reduced through prompt neonatal interventions [12], [13]. In addition, while no established treatments exist for infants with intracerebral haemorrhage (ICH) to reduce long term burden[14], some show promise. The impact of congenital abnormalities is also large, with 17% of later (5-9 years) deaths being associated with a neonatally identified congenital abnormality. However, while a heterogeneous group, the majority may also be preventable[16]. Improving understanding about genetic inheritance among families and healthcare professionals and improving access to culturally-sensitive genetics counselling is also important; it can empower affected families and reduce unexpected affected births[17].

Case Study PERIPrem

Perinatal Excellence to Reduce Injury in Premature Birth (PERIPrem) project

Background: In England, the NHS Long Term Plan aims to realise a 50% reduction in neonatal mortality and brain injury by 2025. In response, the Perinatal Excellence to Reduce Injury in Premature Birth (PERIPrem) project was launched in April 2020 and developed out of a shared vision to reduce brain injury and mortality in preterm babies in our South West region (population 5.6 million). Co-production and implementation of this perinatal care bundle continued right through the pandemic. The high-level aim is to improve survival free of brain injury in preterm infants. The project was funded and supported by the West of England and South West Academic Health Science Networks (AHSNs), in partnership with the South-West Operational Delivery Network (ODN), and uses Quality Improvement (QI) methodology. PERIPrem is a collaboration of all the 12 perinatal units in the South West, with a high level of engagement with obstetricians, midwives, neonatologists/paediatricians and neonatal nurses. The PERIPrem care bundle and tools were co-produced by the 12 perinatal teams and our parent partners, supported by Quality Improvement (QI) coaches and clinical leads. Parents with lived experience of preterm birth and neonatal intensive care are partners on the PERIPrem project team. They innovated by producing the PERIPrem multi-lingual baby passport and have been passionate advocates and advisors. Families helped to engage and encourage our perinatal teams throughout the pandemic by telling their stories about their experiences of PERIPrem.

Each of the 11 elements of the care bundle is evidence-based, and the combined benefit to preterm infants is an estimated 50% reduction in mortality and severe brain injury. A comprehensive set of measurement tools was developed, enabling each unit and the entire region to measure improvement in uptake of each of the elements/interventions, at patient level, at monthly intervals.

The implementation was modelled on the exemplar PReCePT Programme, which was successfully scaled-up into all (155) maternity trusts in England. Resources (QI/implementation tools, learning materials, coaching tools, run chart templates and PERIPrem baby passports) are available for free download from the PERIPrem Website. PERIPrem uses the same clinical leadership model developed in PReCePT, with a dedicated funded nurse and midwife champion in each unit, supported by a unit obstetric and neonatal consultant and regional clinical leads with overall oversight. The teams are supported by AHSN QI coaches, to help focus development and refining of the elements in the care bundle. A regional community of practice developed, connected through virtual "Share and Learn" sessions. PERIPrem was planned to be delivered face-to-face using the principles of an IHI Breakthrough Series Collaborative. Unfortunately, it also timed with the advent of the global COVID-19 pandemic.

In order to deliver PERIPrem during this challenging time, our strategy pivoted - all engagement was via online platforms either as direct one-to-ones or shared learning events. This model had some positive unintended consequences: unit level clinicians were more accessible and could build in PERIPrem sessions into their working day; sessions could be recorded for later play back; teams from different units could meet and collaborate; regular subject matter topic experts could be seconded to the project to support the delivery of specific perinatal interventions.

PERIPrem placed parent partners at the heart of the programme to ensure co-production. Parent partners are members of the PERIPrem steering group alongside lead clinicians and representatives from maternity and neonatal systems, contributing to strategic development. Our parent partners are hands on with design and development of parent facing resources and have led "share and learn" sessions for perinatal staff and provided a link to wider patient networks:

"Being a parent rep on the PERIPrem steering group has been one of the most empowering journeys I have taken as a Mum of a pre-term baby. Seeing my ideas incorporated into the design and roll out of the PERIPrem bundle has been incredibly rewarding. It's knowing that I have made a personal difference"

PERIPrem Parent Partner

Measurement and Evaluation: Perinatal teams in all 12 Trusts were asked to collect data to measure for improvement using a bespoke PERIPRem QI data collection tool which allowed real-time assessment of optimal care, as well as aggregating data at Trust, sub/regional level. This data provided teams with the opportunity to celebrate successes and identify further opportunities for continuous improvement. This data was supported by a quarterly dashboard commissioned from the South West Neonatal ODN, pulling anonymously aggregated data directly from the neonatal electronic patient record to serve as an effective quality check for NNAP nationally reported data sets. PERIPRem was independently evaluated by the South West AHSN using convergent parallel mixed methods.

Data on adherence to the pathway was analysed for 693 babies born between Nov 2020 and July 2021 across 12 perinatal centres in the South West and compared to 2019, using mixed effects binary logistic regressions. Regional Vermont Oxford Network (VON) data was used to analyse mortality and severe brain injury (defined as cystic periventricular leukomalacia or severe intraventricular haemorrhage). The outcome data in 2020 were compared with baseline data from 2014-2019, using a chi-squared test. To evaluate implementation and develop recommendations for future spread, self-report questionnaires of psychological safety and teamwork were completed, alongside qualitative semi-structured interviews. Qualitative data was analysed using a combination of framework and thematic analysis.

Outcomes: Between 2019-21 the percentage of interventions received by mothers and babies increased by 23 percentage points (55% to 78%). Delivery of all 11 interventions improved (range 8%-63%), with statistically significant improvements in correct place of birth for extremely preterm babies, antenatal steroids, optimal cord management, thermoregulation, early caffeine, early breast milk, multi-strain probiotics and prophylactic hydrocortisone. A 34% reduction in severe brain injury (p=0.02) and a 22% reduction in mortality (p=0.15) was noted between 2014-2019 and 2020 (implementation phase). Linear mixed models indicated a statistically significant improvement in team function, situation monitoring and communication within teams. Interviewees described that capability, motivation and opportunity acted as barriers and enablers to implementing the care bundle.

Conclusion: Through a cohesive and coordinated QI approach, perinatal teams across a large region of England were able to successfully implement an 11-intervention perinatal care bundle and reduce rates of preterm mortality and severe brain injury. This was achieved through improvements in perinatal team culture and teamwork, increasing knowledge and skills, having strong leadership and access to the right evidence-based resources. Above all else, the key was having a care bundle that was evidence-based backed by a supportive and credible PERIPrem team. This evaluation has provided evidence-based knowledge and recommendations, which has advanced our understanding about the processes that underpin successful implementation of a perinatal care bundle.

As a large regional pilot, PERIPrem offers a replicable opportunity to be spread to other geographical areas and clinical specialities; in particular, we have invested in developing perinatal team culture, recognising that to improve safety, multi-disciplinary team working must be optimised. If these improvements can be replicated across all English regions, this would translate as at least 220 fewer preterm infant deaths and 340 fewer preterm babies developing brain injury per year in England*.

* Gale C, Statnikov Y, Jawad S On behalf of the Brain Injuries expert working group, *et al* Neonatal brain injuries in England: population-based incidence derived from routinely recorded clinical data held in the National Neonatal Research Database *Archives of Disease in Childhood - Fetal and Neonatal Edition* 2018;103:F301-F306.

4. Child death reviews

The cohort of data described in this section is based on reviews that were completed by a CDOP between 1 April 2019 and 31 March 2021; the deaths of some of these children occurred in earlier years.

4.1. Background

There were 5326 child (0-17 years) deaths that were reviewed by a CDOP between 1 April 2019 and 31 March 2021 (the death may have occurred in earlier years). Figure 5 shows the number of child death reviews by category of death.

32% (n=1726) of reviews were categorised as *Perinatal or neonatal event*. This category was responsible for the largest proportion of child death reviews.

Figure 5a: Number of child death reviews by primary category of death and age at death, where the review occurred between 1 April 2019 and 31 March 2021

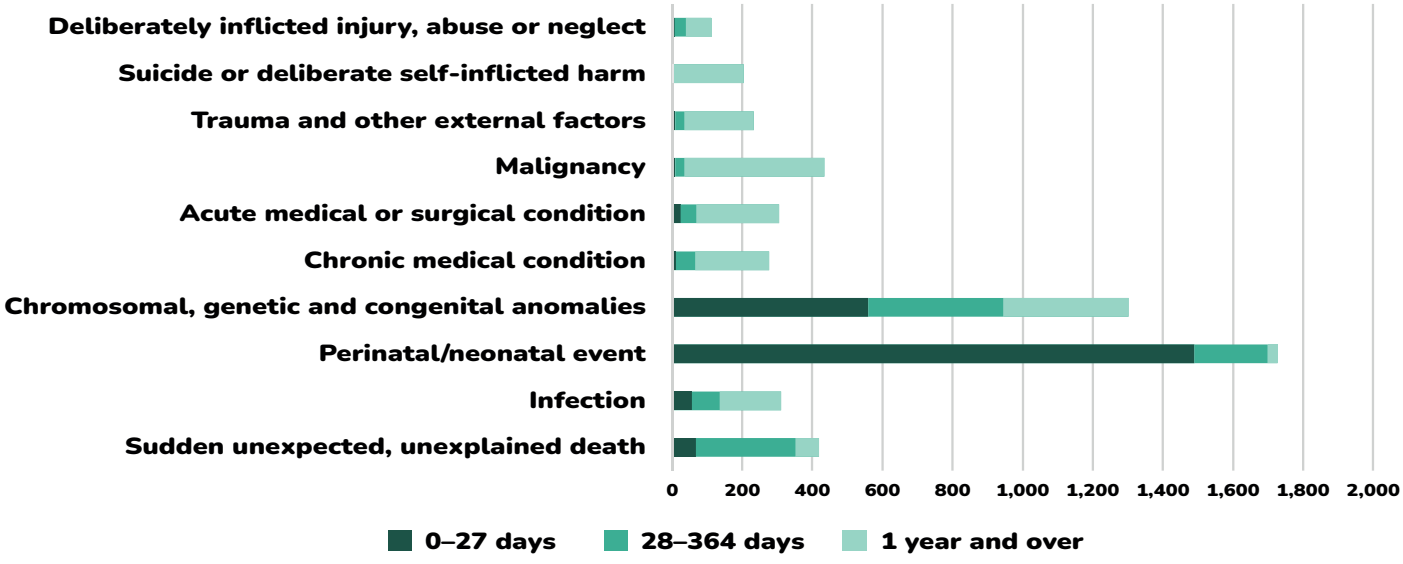
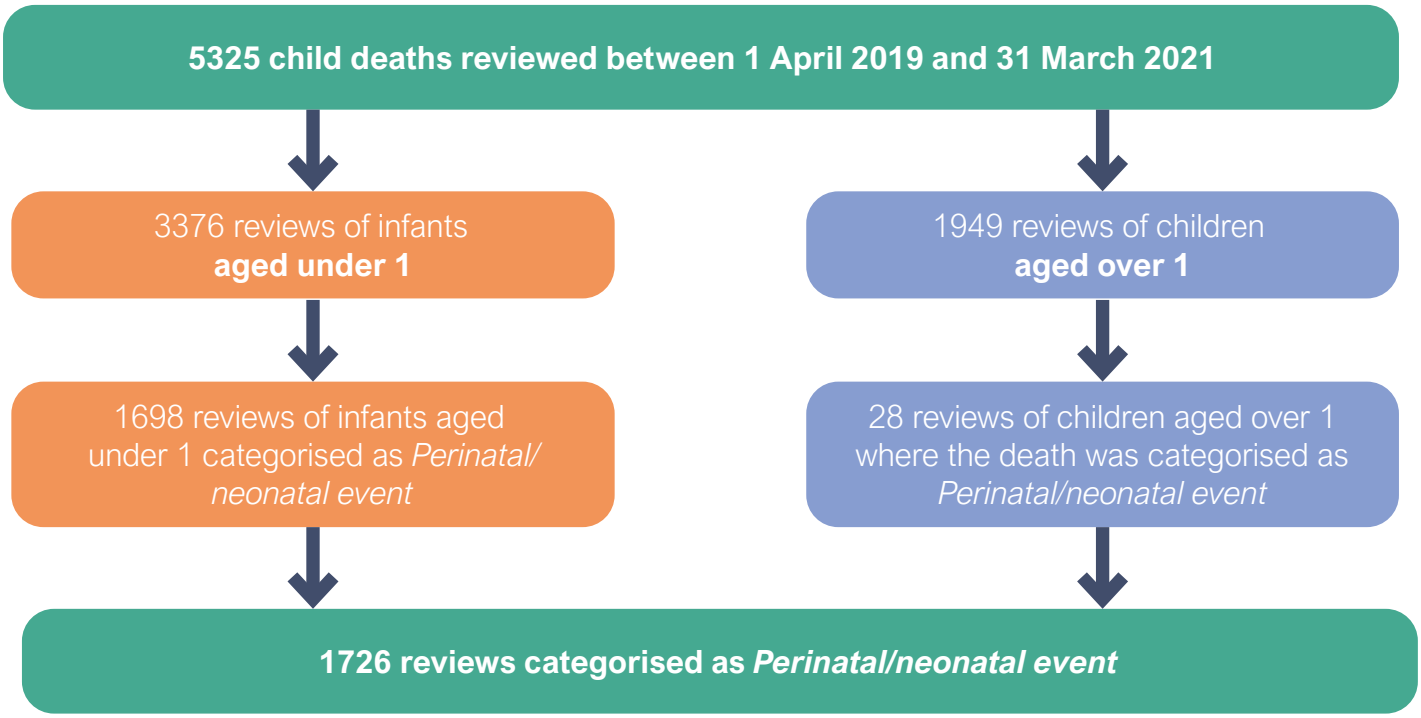


Figure 5b: Flow diagram of child deaths reviewed between 1 April 2019 and 31 March 2021



Of the 1726 perinatal/neonatal reviews, over half (58%, n=1004) were of children who died between 1 April 2019 and 31 March 2021, and 42% (n=722) of the reviews were where the child died before 1 April 2019.

4.2. Characteristics of perinatal/neonatal event child death reviews

This following analysis in this section of the report analyses data from child death reviews where:

- the child death review was completed between 1 April 2019 and 31 March 2021, regardless of when the child died
- the CDOP assigned the primary category of death as being due to a *Perinatal/neonatal event*

Perinatal/neonatal event is defined on the Child Death Review Analysis form as:

> Death ultimately related to perinatal events, e.g., sequelae of prematurity, antepartum and intrapartum anoxia, bronchopulmonary dysplasia, necrotising enterocolitis, post-haemorrhagic hydrocephalus, irrespective of age at death. It **includes** cerebral palsy without evidence of cause, and **includes** congenital or early-onset bacterial infection (onset in the first postnatal week).

The uppermost selected category is chosen as the primary category of death. Therefore, this analysis only includes reviews where categories appearing above *Perinatal/neonatal event* (categories 1 – 7; Appendix D) were not also chosen at the review.

Sub-category of death

When CDOPs select the category *Perinatal/neonatal event* during their review, they must then choose from 4 sub-categories of death. These sub-categories are:

- Immaturity/prematurity related
- Perinatal asphyxia
- Perinatally acquired infection
- Other

In total, across the two years there were 1726 child death reviews categorised as *Perinatal/neonatal event*. 78% (n=1342) of these were immaturity/prematurity related, 13% (n=220) were caused by perinatal asphyxia, and 4% (n=72) were caused by a perinatally acquired infection in the first 7 days of life (Table 9).

Table 9: Number of reviews categorised as *Perinatal/neonatal event* by sub-category and age at death, where the review occurred between 1 April 2019 and 31 March 2021

	Number (%) of child death reviews that were completed between 1 April 2019 and 31 March 2021			
	0 – 27 days	28 – 364 days	Over 1 year	Total
Immaturity/prematurity related	1153	179	10	1342 (78%)
Perinatal asphyxia	192	13	15	220 (13%)
Perinatally acquired infection	68	*	*	72 (4%)
Other	54	9	*	64 (4%)
Total	**1490**	**208**	**28**	**1726 (100%)**

*Absolute number less than 5, or where it can be derived from other data

28 reviews were excluded where sub-category of death was not known or unclear

Place of death

The place of death is defined at data collection as where the child is believed to have died regardless of where death was confirmed.

Over half (52%, n=891) of deaths occurred on a Neonatal Unit, and 32% (n=552) occurred on a labour ward or delivery suite (Table 10). Overall, deaths that occurred within a hospital accounted for 97% (n=1644) of deaths categorised as *Perinatal/neonatal event*.

Table 10: Number of reviews categorised as *Perinatal/neonatal event* by place of death, where the review occurred between 1 April 2019 and 31 March 2021

Place of death	Number (%) of child death reviews that were completed between 1 April 2019 and 31 March 2021
Home	28 (2%)
Hospice	20 (1%)
Hospital trust	1644 (97%)
Emergency Department	32 (2%)
Hospital ward	67 (4%)
Labour ward/delivery suite	552 (32%)
Midwifery Unit	37 (2%)
Neonatal Unit	891 (52%)
PICU	59 (3%)
Other hospital area (Operating Theatre, AICU)	6 (<1%)
Other	8 (<1%)
Total	**1700 (100%)**

26 reviews were excluded where place of death was not known/not stated

"Other" includes abroad and public place

Mode of death

The mode of death (this is the sequence of events preceding the death, rather than the underlying cause of the death) was recorded in 1349 (78%) reviews. This question is included in the statutory child death reporting form and only one option from the list can be selected. There is some overlap in the options that can be selected. For example, "withholding, withdrawal, or limitation of life-sustaining treatment" overlaps with "unsuccessful cardio-pulmonary resuscitation" and with "planned palliative care". In some instances, more than one of these options might apply to the child's death, however for the purposes of this section, we have described the option selected in the record submitted by the CDOP.

Where it was known, 67% (n=900) of deaths resulted from withholding, withdrawal, or limitation of life-sustaining treatment (Table 11) and in 15% (n=204) of deaths, unsuccessful cardio-pulmonary resuscitation was recorded as the mode of death. Palliative care is an approach that improves the quality of life of patients (adults and children) and their families, who are facing problems associated with life-threatening illness. Planned palliative care was the mode of death for a further 17% (n=233) of deaths, demonstrating the importance of the availability of palliative care services. It prevents and relieves suffering through the early identification, correct assessment, and treatment of pain and other problems. It ensures that families are offered meaningful and realistic choices for the care of their baby or child, and can help support decisions on critical care and the family's wishes at the end of the life of their baby or child.

Table 11: Number of reviews categorised as *Perinatal/neonatal event* by mode and place of death, where the review occurred between 1 April 2019 and 31 March 2021

	Number (%) of child death reviews that were completed between 1 April 2019 and 31 March 2021					
	Neonatal Unit	Labour ward/ delivery suite	Other hospital area	Hospice	Other	Total
Withholding, withdrawal, or limitation of life-sustaining treatment	517	265	96	7	7	892 (67%)
Planned palliative care	116	73	23	12	5	229 (17%)
Brainstem death	*	*	*	*	*	6 (<1%)
Unsuccessful cardio-pulmonary resuscitation	96	67	35	*	*	202 (15%)
Found dead	*	*	*	*	*	6 (<1%)
Total	**732**	**408**	**156**	**19**	**19**	**1334 (100%)**

*Absolute number less than 5, or where it can be derived from other data

392 reviews were excluded where either question was not answered/not known

"Other hospital area" includes; ED, AICU, Hospital ward, Midwifery unit, PICU, Theatre

"Other" includes; Home, Abroad, Public place, Other residence

Social Care

At least 80 (6%) children were known to social care at the time of their death (Table 12), of whom 29 (2%) were a child in need and 23 (2%) were on a child protection plan. Children might be known to social care for a number of different reasons, e.g., because they have complex medical conditions resulting in additional needs or, in a very small number of cases, for safeguarding/child protection reasons.

This includes the responsibility to safeguard some babies prior to their birth where risks or vulnerability have been identified. In such cases, work is carried out in the antenatal period to help minimise any potential harm through early assessment, intervention and support. Health agencies, Children's Social Care and other agencies working with the mother and her family, are responsible for planning, assessment and any actions required to safeguard the unborn baby.

Table 12: Number of reviews categorised as *Perinatal/neonatal event* by whether the child was known to social care, where the review occurred between 1 April 2019 and 31 March 2021

Known to social care	Number (%) of child death reviews that were completed between 1 April 2019 and 31 March 2021
Yes	80 (6%)
Child protection plan	23 (2%)
Looked after child	*
Child in need	29 (2%)
Other	48 (3%)
Previously, but not at time of death	42 (3%)
Not at all	1321 (92%)
Total	**1443 (100%)**

Each child can be known to social care in multiple ways and therefore the figures may not sum to the total

283 reviews were excluded where the question was not answered/not known.

"Other" includes but is not limited to children who were known to: early help services, disabled children's services, or adoption and fostering services

See Glossary for definitions

4.3. Modifiable factors

CDOPs are responsible for identifying any modifiable factors in relation to the child's death during their review. These are defined as factors which may have contributed to the death of the child, and which might, by means of a locally or nationally achievable intervention, be changed to reduce the risk of future deaths.

Whether a factor is thought to be modifiable depends on the circumstances of the death, and the interpretation of what factors are modifiable may vary across CDOPs. **This analysis only covers those factors that were assessed as modifiable by the CDOP; these factors may have been present in more deaths but were not thought to be modifiable in those cases by the reporting CDOPs.** It is important to note that the information reported within this section is what CDOPs across England have recorded at their panel meetings and subsequently submitted to NCMD as modifiable factors.

The number of factors present may sometimes correlate to how vulnerable a child is considered to be. The factors recorded by CDOPs might relate to the cause of death (e.g., if the child dies from a vaccine preventable infection), or the child's vulnerability or ill-health (e.g., if the child suffers from a respiratory condition and lives in a household where individuals smoke). Factors are assessed as being modifiable if there is an intervention which, once in place, could reduce the risk of future child deaths either directly, or by reducing the elements which increase children's vulnerability or ill health.

Out of the 1,711 reviews categorised as *Perinatal/neonatal event* where there was adequate information for CDOPs to make a judgement whether modifiable factors were present or not, 581 (34%) of these identified modifiable factors (Table 13). This proportion was highest for deaths caused by perinatal asphyxia (52%, n=113/219), than any other sub-category.

Table 13: Number of reviews categorised as *Perinatal/neonatal event* by sub-category and modifiable factors identified, where the review occurred between 1 April 2019 and 31 March 2021

	Number of child death reviews that were completed between 1 April 2019 and 31 March 2021	Number (%) of reviews that identified modifiable factors
Immaturity/prematurity related	1329	412 (31%)
Perinatal asphyxia	219	113 (52%)
Perinatally acquired infection	72	28 (39%)
Other	91	28 (31%)
Total	**1711 (100%)**	**581 (34%)**

15 reviews were excluded where the CDOP indicated that inadequate information was available to make a judgement on modifiable factors (see Section 5. Limitations for further details on these cases)

Modifiable factors domains

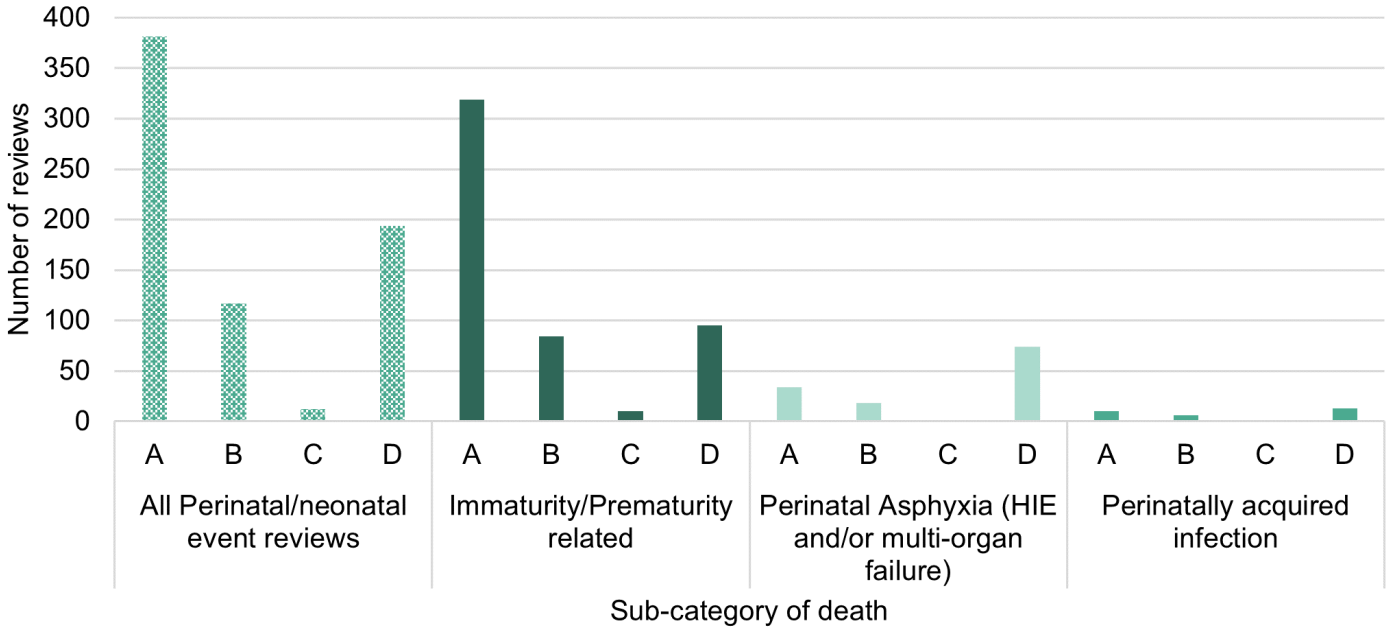
During the review of each death, CDOPs record factors they identify under one of 4 domains on the child death analysis form. The 4 domains are:

- Domain A: Characteristics of the child (including pregnancy factors)
- Domain B: Factors in the social environment including family and parenting capacity
- Domain C: Factors in the physical environment
- Domain D: Factors in service provision

See Glossary for the descriptions of the factors included in each domain.

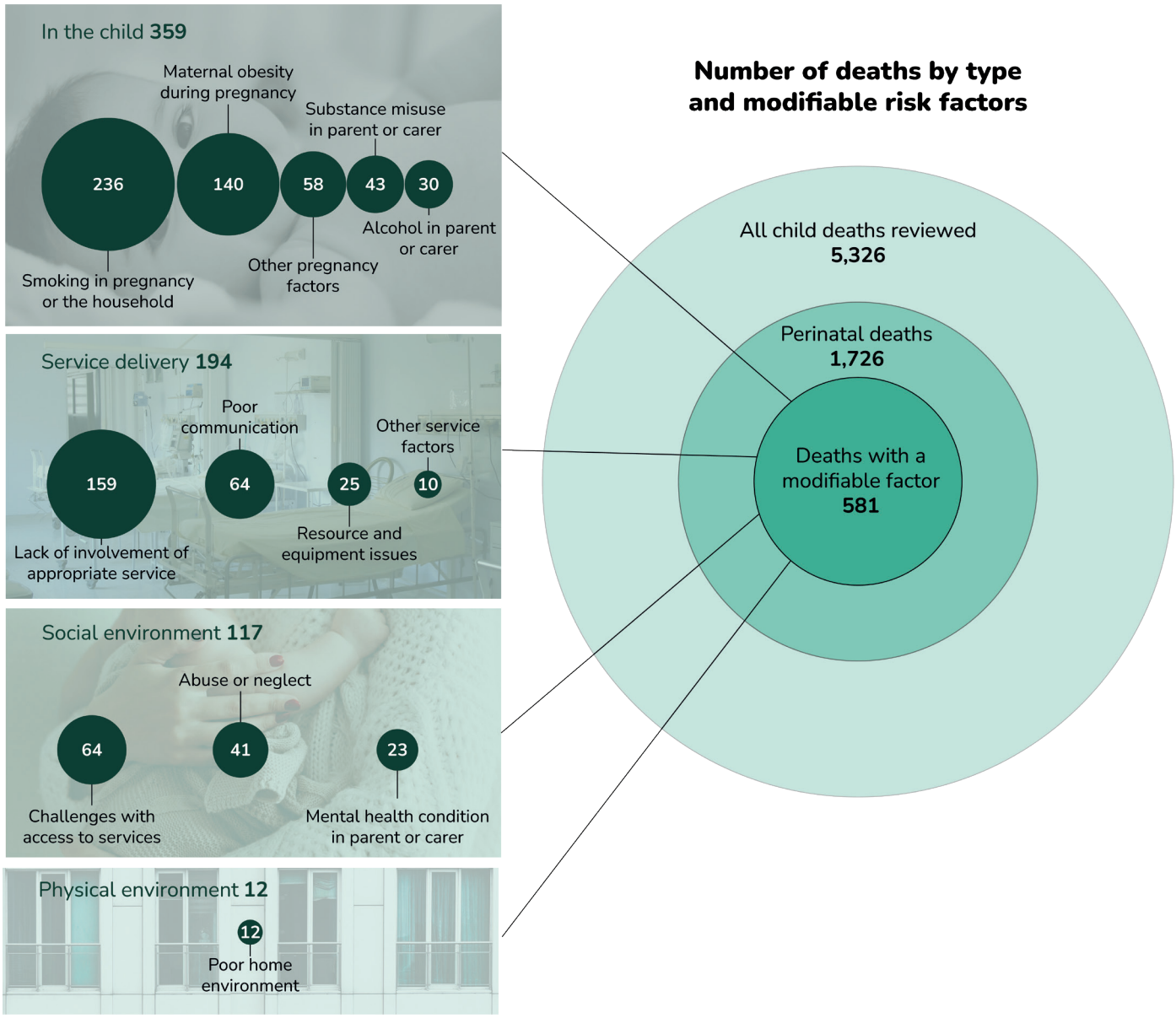
Figure 6 shows the number of reviews categorised as *Perinatal/neonatal event* with modifiable factors by domain and sub-category. For immaturity/prematurity related deaths, the number of reviews with modifiable factors in the characteristics of the child and pregnancy factors was the highest (n=319), followed by service provision (n=95) and the social environment (n=84). For deaths caused by perinatal asphyxia, modifiable factors were identified the most in the service provision domain (n=74). While the total amount of reviews for perinatally acquired infections was lower than other sub-categories, most modifiable factors were reported in service provision (n=13) and the characteristics of the child (n=10).

Figure 6a: The number of deaths with at least one modifiable factor identified in each domain by sub-category, where the review occurred between 1 April 2019 and 31 March 2021



A = Characteristics of the child (including pregnancy factors)
B = Social environment
C = Physical environment
D = Service provision

Figure 6b: Summary infographic showing the number of deaths that identified modifiable factors



Please note 'Perinatal deaths' refers to deaths categorised as *Perinatal/neonatal event*

Domain A: Characteristics of the child (including pregnancy factors)

Of the reviews where there was sufficient information to determine modifiable factors (n=1711), 359 (21%) reviews reported at least one modifiable factor within the characteristics of the child or pregnancy related factors.

Table 14: Number of reviews categorised as *Perinatal/neonatal event* by modifiable factor identified in the characteristics of the child, where the review occurred between 1 April 2019 and 31 March 2021

Modifiable factor	Number of child death reviews that were completed between 1 April 2019 and 31 March 2021
Smoking in pregnancy or in the household	236 (14%)
Maternal obesity during pregnancy	140 (8%)
Other pregnancy factors	58 (3%)
Substance misuse in parent or carer	43 (3%)
Alcohol misuse in parent or carer	30 (2%)

Smoking, alcohol and substance misuse outside of pregnancy would usually be reported under the social environment domain. However, in some instances it was not possible to tell whether it occurred antenatally or postnatally, and so the factors were combined under Domain A for this report due to the impact on the child at birth. See Section 5. Limitations for more information.

Smoking in pregnancy or in the household

Smoking in pregnancy or in the household was reported as a modifiable factor in 236 reviews (Table 14), the majority of which related to smoking in pregnancy.

The NHS Live Well web page includes information about the risks of smoking and how to protect family members from second-hand smoke. Pregnant women exposed to passive smoke are more prone to premature birth and their baby is more at risk of low birthweight.

Children who live in a cigarette smoke-filled environment are at higher risk of breathing problems such as asthma and allergies. The Saving Babies' Lives Care Bundle version 2 provides a practical approach to reducing smoking in pregnancy, including the use of carbon monoxide testing for all women at the antenatal booking appointment and as appropriate throughout pregnancy, and referral for support from trained stop smoking advisors.

Greater Manchester's Smokefree Pregnancy programme

Smoking in pregnancy remains a key public health concern and is the single biggest risk factor for adverse outcomes in pregnancy, including complications during labour, increased risk of miscarriage, premature birth, low birthweight and stillbirth. Quitting smoking before week 16 of pregnancy provides the greatest benefits, but quitting at any stage will benefit both mother and baby.

The Greater Manchester Smokefree Pregnancy Programme aims to reduce the number of women smoking during pregnancy and has been supporting pregnant smokers and their partners to quit since early 2018.

The programme uses the babyClear model to implement NICE guidance, along with an evidence-based incentive scheme. The core elements of the programme include investment in:

- Workforce development: recruitment of specialist stop smoking midwives and maternity support workers, along with comprehensive training for all maternity staff. Empowering the maternity workforce to have open and honest conversations about the risks of smoking and use of carbon monoxide (CO) monitors to test for exposure to tobacco smoke, as well as facilitating immediate referrals to the specialist maternity stop smoking service.
- Equipment: carbon monoxide (CO) monitors are used across all 10 boroughs of Greater Manchester, and an innovative digital platform that streamlines data collection allows maternity staff to spend more time on patient care and less time on administrative tasks.
- Targeted incentives and interventions: an evidence-based incentive scheme for those who would find it hardest to quit and Risk Perception Intervention (RPI) for those who do not accept the referral to the maternity stop smoking service and continue to smoke.

Outcomes

Latest data from NHS Digital shows Smoking at the Time of Delivery (SATOD) rates have fallen by around a quarter in the past four years – down from 12.6% in 2017-18 to 9.8% in 2020-21.

As of January 2022, the maternity stop smoking services across Greater Manchester are seeing a 75% four-week quit rate and more than 2,000 babies have been born smokefree, with an average birthweight 200g more than those born to mothers who continue smoking throughout pregnancy.

Katie and Jack's story

Katie and Jack have been together from the age of 15. Both smoked before they met and at one point were smoking around 40 cigarettes a day each. They had their first baby 10 years ago when they were both 18. Although they cut down, they both continued to smoke throughout the pregnancy and their baby was born four weeks premature and had a low birthweight.

A couple of years ago Katie became pregnant with their second child and this time she was much more worried about smoking. During her prenatal journey she was referred to the maternity stop smoking service.

After being given advice on stop smoking treatments Katie decided e-cigarettes were the best option for her and also bought one for Jack so they could quit together. Their second pregnancy went well, and Katie had to be induced early as the baby was getting too big.

Katie said: "The dramatic birthweight difference between both my boys shows just what a difference smoking when pregnant can make. Quitting has really put my mind at ease."

Tierney-Rose's story

Tierney-Rose, 21, started smoking when she was just a teenager and tried to quit many times, before quitting for good when she became pregnant with her first baby in spring 2019. She said: "I had smoked for almost six years and knew I would need help to quit. So, when I was asked if I smoked at my first midwife appointment, I was honest and said yes. I told the midwife that I desperately wanted to quit, and I was relieved to find that I would receive stop smoking support as I wanted to do everything I could to ensure that my baby was safe and well.

"I was referred to the stop smoking service and they were so supportive and took the time to listen to everything that was going on in my life at the time. With their support I got through the tough times and I've now been smokefree for two years. Without the support I really don't think I would have been able to quit."

Maternal obesity during pregnancy

CDOPs recorded maternal obesity as a modifiable factor in 140 reviews during this period (Table 14); the second most common modifiable factor reported. Being very overweight (or obese) when pregnant can increase the chances of some complications for the mother of the baby such as gestational diabetes, high blood pressure and pre-eclampsia. It can also increase the chances of complications for the baby such as being born prematurely. Being obese can also sometimes make it difficult to see the baby clearly on antenatal scans, which makes it harder for doctors to detect if anything is wrong with the baby during pregnancy, and can impede accurate monitoring of the baby's heartbeat before and during labour. Other issues identified by the CDOPs are lack of appropriate referrals, and that maternal BMI is sometimes unknown at the review meeting. The statutory reporting form has been updated to allow the collection of this information for CDOPs in future.

Substance or alcohol misuse in a parent or caregiver

CDOPs recorded substance or alcohol misuse as a modifiable factor in 73 deaths reviewed during the period (Table 14), the majority of which were reported to be during pregnancy. Research shows that illicit drug use, misuse of prescription drugs, or alcohol use during pregnancy can have severe health consequences for the baby. This is because many substances pass easily through the placenta, so substances that a pregnant woman takes also reach the baby[18]. Effects of using some drugs could be long-term or sometimes fatal to the baby. These include fetal growth restriction, preterm birth and later developmental disorders[19].

Other pregnancy factors

Any other factors related to pregnancy are included in this domain. The most commonly recorded factor in this group was maternal diabetes, which was recorded as a modifiable factor in 20 deaths reviewed by CDOPs (Table 14); this was followed by obstetric or underlying health conditions which was recorded in 19 deaths reviewed by CDOPs. Other examples included within this group are low maternal BMI (being very underweight), IVF treatment and risks associated with a high or low maternal age.

Domain B: Social environment

Of the reviews categorised as *Perinatal/neonatal event* where there was sufficient information to determine modifiable factors (n=1711), 117 (7%) reviews reported at least one modifiable factor within the social environment.

Table 15: Number of reviews categorised as *Perinatal/neonatal event* by modifiable factor identified in the social environment, where the review occurred between 1 April 2019 and 31 March 2021

Modifiable factor	Number of child death reviews that were completed between 1 April 2019 and 31 March 2021
Challenges with access to services	64 (4%)
Domestic or child abuse/neglect	41 (2%)
Mental health condition in parent or carer	23 (1%)

Challenges with access to services

Challenges in accessing any service was reported by CDOPs as a modifiable factor in 64 deaths (Table 15). The issues reported here relate to challenges in accessing any service, e.g., social care, health, or education. Where a challenge in accessing a service has been recorded in this domain, it relates to instances where services are available, but there are challenges in supporting families to access them. Marginalised families may be disadvantaged or difficult to reach and are often under-served because of their limited engagement with services. As a result, they frequently experience poorer health and social outcomes. Examples reported by CDOPs include poor engagement with antenatal services, late booking for the pregnancy, and concealed pregnancies in which no antenatal care was accessed.

Ann's Story

Ann is a woman who came to Maternity Action for help after getting a bill of £10,000. She is currently challenging it on the grounds of destitution.

Her first baby died soon after birth.

My name is Ann. My first pregnancy was really challenging, and quite depressing and stressful because I knew I was here without leave to stay.

When I found out I was pregnant, I didn't want to go to the doctors because I didn't know how much it would cost and how I would pay.

One day, I felt a lot of pain and knew I had to go to hospital. They knew I didn't have my leave (I came in with a visiting visa) and it was as if I had a tag on me, a tag that said 'she's just a thing'. I wasn't looked after, I wasn't cared for. My baby was coming for three days, and they kept saying 'we're going to get you to the baby hospital' because I was about 28 weeks at that point.

But nothing happened, they just left me. I kept telling the lady "please I'm in pain, I'm in pain." And she just kept giving me a stronger painkiller and left me.

In the morning when they came to check me I used the loo and when I wiped I felt a lump below. The minute I came back the group of doctors who came to check me said "Oh I think the baby's coming".

I gave birth to my baby, Nima, but she was stuck in between for a long time. They had all sorts of machines going and I didn't know what was going on. The group of doctors just gave her to me, they knew she was dying – she literally turned blue in my hand and that was it. Later, while I was still holding her, a lady from the overseas charging office came and said 'Oh if you sleep on our bed tonight we're going to charge you'. I felt like I wasn't even a human, that I was just no one.

I buried my baby in a graveyard in London. It's peaceful there. I try and go to visit her when I can.

Coming in contact with Maternity Action has been a great relief for me because I didn't know you could have such support. If I'd have known I could have had such support I think my daughter would have still been alive right now. I don't think I would have been treated like I was."

Domestic or child abuse / neglect

Exposure to domestic abuse or violence in childhood is a type of child abuse and was reported as a modifiable factor in 41 deaths reviewed by CDOPs (Table 15). The NSPCC children's charity defines domestic abuse as any type of controlling, coercive, threatening behaviour, violence or abuse between people who are, or who have been in a relationship, regardless of gender or sexuality. It can include physical, sexual, psychological, emotional or financial abuse. It is important to note that the deaths included in this group were from a variety of causes and the domestic abuse did not necessarily directly lead to the child's death. Domestic abuse during pregnancy puts a pregnant woman and her unborn child in danger as it can trigger placental abruption, leading to fetal distress and maternal emergency. It increases the risk of miscarriage, infection, premature birth, low birthweight, and injury to or death of the baby. The charity Refuge provides a 24 hour, freephone, national domestic abuse helpline on 0808 2000 247.

Mental health condition in a parent or carer

CDOPs recorded this as a modifiable factor in 23 cases reviewed during this period (Table 15). Having a baby is a big life event and it is natural to experience a range of emotions during pregnancy, however for some people these feelings can start to have an impact on their day-to-day life, and this may mean they are experiencing a mental health problem such as depression or anxiety.

This may make it difficult for them to cope with family life. Many parents and carers with mental health problems are able to manage their condition and minimise its impact on their children, particularly if they are able to access appropriate support; however for some, they may for example find it difficult to control their emotions and behaviour around their children, or recognise and respond to their children's emotional or physical needs. The charity Mind has further information on this on their website.

Domain C: Physical environment

Poor home environment

This was reported as a modifiable factor in 12 deaths reviewed during the period. Research has shown an association between severe housing insecurity during pregnancy and low birthweight and/or preterm birth[20]. In addition, there is growing evidence on the negative effects associated with unhealthy housing situations, including crowding, frequent moves, cold homes (fuel poverty) and damp/mouldy conditions[21]. CDOPs recognised the importance to health and well-being of housing provision and conditions, and they reported a poor home environment as a modifiable factor in 12 perinatal/neonatal deaths reviewed. The most common concerns were lack of cleanliness, overcrowding, houses in poor repair and the presence of damp and/or mouldy conditions. There were also instances of homeless pregnant women reported.

Domain D: Service provision

Of the reviews where there was sufficient information to determine modifiable factors (n=1711), 194 (11%) reviews reported at least one modifiable factor within service provision.

Table 16: Number of reviews categorised as *Perinatal/neonatal event* by modifiable factor identified in service provision, where the review occurred between 1 April 2019 and 31 March 2021

Modifiable factor	Number of child death reviews that were completed between 1 April 2019 and 31 March 2021
Lack of suitable or timely involvement by appropriate service	159 (9%)
Poor communication and information sharing	64 (4%)
Resource and equipment issues	25 (1%)
Other service provision factors	10 (1%)

Lack of suitable or timely involvement by appropriate service

CDOPs recorded modifiable factors relating to lack of suitable or timely involvement by a service in 159 deaths reviewed during the period (Table 16). The majority of these were related to the provision of healthcare services. This included maternity services, other hospital services and primary care. The issues identified in this section relate to circumstances where something did not happen, or it happened at the wrong time. For example, appropriate actions were not taken to enable adequate risk assessment of the mother during her delivery, or referral to the appropriate specialist service did not occur. By incorrectly assigning a mother to a low-risk pathway, maternity providers limit the intensity of fetal monitoring that the baby receives and may be caring for a mother and her baby without access to all the necessary resources.

Poor communication and information sharing

CDOPs recorded examples of poor communication and poor information sharing both within and between services, and between services and families, in 64 deaths reviewed in the period (Table 16). This includes episodes where escalation for review by a senior clinician did not occur or was not timely, where CDOPs recorded the importance of effective and early escalation of concerns (antenatally, labour, neonatal and postnatal), in the learning of the review.

Other factors included poor co-ordination of care between hospital trusts and poor contemporaneous documentation of clinical information across all areas of care (antenatal events, in labour, neonatal admission and care and postnatal).

Poor documentation was also highlighted in the review in relation to resuscitation. Learning from these reviews included the importance of clear SBAR (situation, background, assessment, recommendation) communication. Factors also included lack of availability or use of an interpreter service, and instances where the correct information was not given to pregnant women, e.g., around seeking urgent medical attention when experiencing reduced fetal movements.

Resource and equipment issues

In 25 deaths, CDOPs recorded a resourcing or equipment issue as a modifiable factor in the review which can affect the outcome of the child (Table 16). Examples include insufficient bed capacity within neonatal intensive care units, inadequate staffing levels or skill mix, faulty equipment, or appropriate equipment not being available.

Gemma's story

Our baby was due in March 2020. It was my first pregnancy, and everything was completely fine right up until about 36 weeks, when I developed a liver condition called obstetric cholestasis. This condition carries a small chance of stillbirth in late pregnancy, and so I was advised that it would be best to have an induction at 38 weeks.

My husband and I followed this advice, and I went into hospital on 28th February 2020 to be induced. At about 8pm they sent my husband home, and I was left on the antenatal ward. This was a difficult period; I was starting to have contractions, I was in pain and I felt very scared and alone. When I asked for help, I got the impression that I was basically expected to take the pain relief and get on with it – childbirth is painful.

At around 3am I asked the midwife to come. She said that I still was only 1cm dilated so I could have some pethidine. She also said that it wouldn't be that long, so I could call my husband Nick. We only live about five minutes away from the hospital, so he was there very quickly. Once he got there, they monitored the baby's heart rate for a short time to check that everything was OK, and then gave me the pethidine.

The hospital has since lost all record of this monitoring, so we have no way of knowing if everything was actually OK at that stage. During our antenatal classes we had also been told that you shouldn't be given pethidine if you are close to giving birth as it can make the baby sleepy. I still wonder if the administration of this drug had an impact on our baby's recovery. Between 3am and 6am my waters broke. Nick went to get the midwife to come back, as we had been left by ourselves on the antenatal ward for most of this time. Although I was in active labour, the hospital was understaffed so were unable to accommodate me on the labour ward.

When the midwife came, just before 6am, she realised that the baby's heartbeat was dropping and she pressed the emergency button. We were then rushed through to a labour room. Our baby, Barney, was born 17 minutes later, at 6.05 am, with the help of a suction cup. We found out later that I had had a placental abruption while in labour, so he hadn't been getting enough blood or oxygen.

They took Barney to one side straight away and began attempting to resuscitate him. They were working on him for about an hour. We now know, from the Healthcare Safety Investigation Branch (HSIB) report, that during this time they delayed calling in a more senior doctor and failed to give him the blood transfer that he needed in a timely manner and began to cool him when they shouldn't have, making him dangerously cold.

Once they did get him back round, they took Barney upstairs to the special baby unit, and then a couple of hours later my husband and I were allowed to go and see him. We held his hand and spoke to him, and he opened his eyes and looked at us. I am so grateful that we got to have that moment of connection with him. We were told that they were going to stabilise him and then transfer him to a different hospital who were specialist in cooling and brain damage prevention because he had been without oxygen for so long.

While the transfer team went to get him ready, we were taken to a different room. About 20 minutes later they came back to say that he had had a heart attack and they had been working on him again, but they couldn't revive him. We had to go and say goodbye at that point. We were taken back into the room just as they were pronouncing him dead and that is a moment that will continue to haunt me.

Afterwards we met with the bereavement midwives and the consultant and they tried to explain what had happened. We were able to spend three days in the Sands Butterfly Bereavement Suite at the hospital with Barney, which while difficult also helped us so much. His grandparents were able to come and visit and hold him and the Sands photographer took some pictures of him which we really treasure. The postmortem didn't find anything wrong other than the abruption, which meant that he hadn't been able to get enough oxygen, otherwise he would have been a perfectly healthy baby boy.

It was explained to us there would be an independent report from HSIB as well as the hospital report, because of the nature of what had happened. The report was obviously really hard because it threw up a lot of things that we didn't know at first: being left unmonitored on the antenatal ward and the mistakes during resuscitation meant that the outcome for Barney could have been different if things had been handled differently, so it was a bit of a shock. We'd assumed everyone had done their best and they had, but there were still failings in care which we weren't aware of.

We have since had another baby boy. His pregnancy and birth were, as you would expect, very stressful. He was born via a planned Caesarean section. On arriving at the hospital for this, we were told that they were four midwives understaffed. Had it not been for two excellent midwives who had come in to support us on their day off, I think we would have turned around and gone home. My experience through both births has really made me lose confidence in the healthcare system, there are some excellent individuals doing their best, but the system doesn't work. We would have liked to have had another child, but are now reconsidering it, as the stress and risks that come with it seem too high.

4.4. Learning points from CDOPs

As part of the review into child deaths, CDOPs are required to list any learning points that have been identified and taken forward for local action. These are recorded within the same field as issues and may include, for example, the absence of certain key persons from the CDOP discussion or the lack of key documents. Learning points should be reflected on with reference to wider agency, regional, and national bodies. CDOPs are responsible for ensuring that these learning points are disseminated locally.

Learning points or issues were identified at a local level in almost half (49%, n=846/1726) of reviews by CDOPs. This proportion was higher for reviews categorised as perinatal asphyxia (60%, n=138/220) and infection (56%, n=40/72), than for immaturity/prematurity related reviews (46%, n=617/1342).

Details of learning points recorded by CDOPs were extracted, reviewed and grouped by themes presented under each of the stages of the care pathway: antenatal, labour, neonatal and postnatal. The team then identified key words to facilitate a search of all learning points raised by CDOPs. The results of the key word search were then validated and coded against the themes to ensure the learning points were categorised based on the correct context.

Learning identified in relation to antenatal care

CDOPs identified a number of areas of challenge in relation to antenatal care. These included poor identification of risk factors for preterm birth, such as IVF with multiple pregnancies, multiple births, raised BMI, drug use and domestic abuse. When such risk factors were not identified or were identified late, this resulted in mothers not being referred to the appropriate service, not receiving consultant-led care, or ineffective screening and management during pregnancy.

78% (1342/1726) of reviewed deaths were classified as immaturity/prematurity related (Table 9). A specific issue recorded by CDOPs was the failure to identify women at high risk of preterm birth, through lack of knowledge of previous maternal cervical pathology and lack of routine monitoring of cervical length measurements. This meant that preterm birth was not predicted, and high-risk women did not have access to targeted interventions, e.g., cervical suture.

CDOPs also highlighted the importance of follow-up plans for maternal test results to enable effective screening and management, for example for vaginal and urinary tract infections (UTIs), in deaths due to preterm birth and neonatal infection.

Where it was known, domestic violence/abuse in the household was reported in 14% of the child death reviews (n=217/1559). The NHS pregnancy support webpage highlights that pregnancy can be a trigger for domestic abuse and existing abuse may get worse during pregnancy or after giving birth. CDOPs recorded challenges relating to effective screening and management of domestic abuse, and other social issues.

From review of deaths due to perinatal asphyxia, CDOPs reported that there was a need for raising awareness of the importance of maternal monitoring of fetal movements and access to effective escalation plans when abnormalities were detected.

Rosie and Leo's story

This was my second pregnancy, and it was really straightforward. The only slight concern was at my 12 week scan, they did the nuchal test and it showed that my risk of having a baby with Trisomy 21 was significantly higher than the average woman at my age. We did a harmony test, and the results came back that it was very unlikely the baby would have any of the trisomies.

Leo was born at 31 weeks gestation. We knew he was going to be born early about an hour before he arrived. I started bleeding in the morning due to a partially abrupted placenta. The doctors initially said that I might get to 36 weeks, but my cervix started to dilate, and Leo had to be delivered that day.

Looking back, I was really scared. I had no experience of prematurity before, and it hadn't crossed my mind. I'm the oldest of four siblings who were all born late. Then I felt more reassured as the doctors were saying that 31 weekers have a good chance of survival without long term difficulties. Then I felt kind of excited to meet our baby but wondered if I should feel guilty for being excited. I went into early labour and then Leo was delivered by emergency caesarean section.

Leo lived for three weeks. When Leo was born at around 7pm he was whisked away to NICU and was initially put on CPAP, and not ventilated. He was then sent for routine genetic screening – they weren't worried at this point, although for the first 12 days there were lots of problems that kept cropping up. We weren't getting clear answers and needed to wait for the MRI and genetic screening results, which then had been sent to a brain specialist in London.

The MRI showed the extent of the diagnosis – and it was really devastating news. It was the worst moment - I felt that my life had shifted – I was in disbelief and shock. I couldn't really process it at the time.

Leo's case was very rare - he had a deletion on his sixth chromosome - his deletion was particularly long and touched other genes, which was very severe and linked to his brain. Genetic counselling showed that Leo's condition had a 1/100,000 to 1/200,000 chance - the doctors had no experience of that condition – they were also in shock and trying to figure it out.

After receiving the test results, I held Leo all afternoon and then the next few days had lots of different meetings with consultants and then we made the decision to end life support.

Leo got to go outside, which was a really beautiful moment. We went to get a hot chocolate with two of the neonatal nurses and one of the specialist brain consultants. They had a massive bag of things. At that point during the pandemic, you could only have six named visitors under Covid regulations, however the staff said that anyone could come at any time - they understood that we didn't have much time with him.

They lifted off the top of the incubator and got him dressed in clothes, which was really special. He felt so much more like our baby – somehow less fragile. Having those special moments was so important, especially having the chance to go outside of the hospital.

Leo's death has had an enormous impact on every part of our lives – a lot of it has been sadness and grief, however, it has also had a positive impact.

I was particularly worried about my eldest son, James (born in 2018) having lost a brother. When it happened, he was so little, so he didn't quite understand, but now that he's a little older he does and is obsessed with death, in a straightforward, child-like way. This is probably because he has been exposed to death in such an overt way at a young age. He uses phrases like 'who will look after me when Daddy dies?' and 'Mummy, when is Daddy going to die?'

For my wider family it has brought them closer together and encouraged us to forget petty things and small annoyances. They now put things in perspective and see that family and health are the things that matter.

My health anxiety has gotten worse, and I struggle to rationalise things because Leo's genetic disorder was such a small chance. I find the idea of leaving my new baby, Henry, (born 2021) with a nanny quite scary – I definitely feel more protective. I also felt a sense of guilt when I gave birth to Henry, almost like I was replacing Leo.

I feel that I'm not necessarily brave but that I've dealt with something really tough and found strength within myself. I am lucky to have a huge support system and I feel able to bond with other people who have experienced loss.

In the longer term, Leo's death has provided clarity and perspective. Sometimes people assume that when you lose a baby that you would get over it by having another one, but you never get over it. I think wider society should talk about grief more. It's not something that goes away, or you can get over - you are changed forever. Developing understanding is important.

After Leo died, they discovered that they'd missed something at the 20-week scan, and I would have been offered a termination if this had been seen. However, I'm thankful that they missed it, so I was able to meet and spend time with Leo.

I think that being monitored for cervical shortening and being screened for Group B Strep (GBS) is incredibly important. I found out I had GBS when I was pregnant with Henry.

I have had support and therapy from the NHS for the last two years and have also received help from Bliss, Sands and Tommy's. During my third pregnancy with Henry, I had lots more support, was assigned a midwife and had around 17 scans throughout my pregnancy.

Learning identified in relation to labour and birth

CDOPs have reported areas of challenge in relation to care and management provided during labour and at delivery. Issues related to timely transfer to appropriate services, e.g., in utero transfer to a hospital with a tertiary neonatal unit able to provide a higher level of care for the baby. CDOPs collect data on whether the baby is born in a hospital able to provide the appropriate level of care. Of the 635 reviews where this question was answered, 12% (n=76) stated that the baby was not delivered in an obstetric centre with a neonatal unit able to provide the appropriate level of care. Multiple reasons were identified for this, including the mother being in advanced stages of labour and maternal complications making it unsafe to travel, and lack of referral unit capacity.

Failure to administer corticosteroids and magnesium sulphate to eligible women in suspected or established preterm labour to reduce the risk of preterm brain injury and mortality (NICE Guidance NG25) was also identified as a learning point. Of 445 reviews where this question was reported as applicable and an answer was recorded, in 171 reviews (38%) women were not given magnesium sulphate and for 139 of them a reason was given, e.g., rapid/emergency delivery or planned palliative care after delivery. In 7 cases magnesium sulphate was not considered and in 24 there was no reason given.

In addition, CDOPs identified the following:

- The need for effective triaging of potential admission telephone calls when women contact the maternity unit. Documentation of these calls is important and should ideally be done using a proforma, and by a trained professional.
- The importance of early consultant obstetric input in high-risk births.
- The need for dynamic risk assessment during labour. This includes adapting the timing of intermittent auscultation based on the risk assessment.
- The importance of effective CTG monitoring for women in labour or with antenatal concerns. This includes the use of fresh eyes, and escalation for senior review as required.
- The importance of effective management of malpresentation including vaginal breech presentation. Malpresentation can increase the chance of needing an assisted delivery, which may increase the chance of complications for the baby and the mother.
- The need for effective management plans and documentation to be in place for resuscitation, where the baby is expected to be compromised.
- The need for all providers of maternity and neonatal care to be competent in basic neonatal resuscitation and to have access to appropriate resuscitation equipment.
- The need for prompt escalation to senior staff when support is required with neonatal resuscitation.

Learning identified in relation to the neonatal period

CDOPs recorded learning related to the need for:

- Effective thermal management at delivery, during resuscitation, on admission to a neonatal unit and during transfer between units. This relates to situations where the baby gets too cold or too hot. Issues relating to thermal management were reported in at least 31 reviews. Newborn babies regulate body temperature less efficiently than adults and they can lose heat more easily. The smaller and more premature the baby, the greater the risk of illness and death.
- Effective endotracheal intubation during advanced resuscitation.
- Prompt and early identification and treatment of sepsis, including administration of antibiotics within 1 hour.

Learning identified in relation to the postnatal period

Areas of learning were noted by CDOPs in relation to the postnatal period. These included:

- The effective use of the Newborn Early Warning Trigger and Track (NEWTT) tool. This tool can be used by healthcare professionals to identify babies at risk of clinical deterioration following birth. Through early identification and intervention this can reduce the severity of illness for some babies.
- The importance of ensuring that babies showing any symptoms of respiratory compromise have oxygen saturation monitoring as part of their assessment.
- The importance of sending the placenta for histology where there is suspected fetal compromise.

Cross-cutting themes

Communication and language

A recurring theme recorded by CDOPs relating to all stages of the care pathway was barriers to communication and lack of access to translation/interpreting services. Language barriers and interpreter issues were mentioned in at least 21 reviews. More specifically, one of the reported issues was difficulties in translation, where CDOPs recorded the importance of using formal, expert interpreters for all appointments, ensuring the language spoken was documented, and that information leaflets were made available in multiple languages.

The lack of accessible and high-quality interpreting services was a common issue for women without English language skills. High-quality interpreters are lacking in mental healthcare, in GP surgeries and at different points along the maternal healthcare pathway. This leads to poor communication between women and maternity services providers, which has been described as leading to lack of trust resulting in poorer access to, and engagement with services[22], [23].

Bereavement support and services

The importance of bereavement support and services for families, and ensuring detailed information is provided to parents on the PMRT and child death review processes, was also recorded throughout the reviews.

The statutory child death reporting form has been updated so information on whether bereavement support was offered to the family is available for the CDOP review. This in turn helps ensure that effective bereavement support services are in place. The implementation of the National Bereavement Care Pathway for Pregnancy & Baby Loss, or a similar process, will help to improve the quality of bereavement support for families.

5. Limitations

Data throughout this report are based on data that have been submitted to NCMD by CDOPs. As CDOPs were still going through the process of transition to their new arrangements during the period that is included within this report, there was some impact on the completeness and quality of data submitted to NCMD. NCMD is dependent on accurate data entry by the CDOPs, and in particular, category of death is presented within the report as it was submitted by the CDOP.

Case ascertainment

The Child Death Review Statutory and Operational Guidance requires CDOPs to review the deaths of all babies who are live born. This applies even if their gestational age at birth is less than 24 weeks. Clinical guidance is available on determination of signs of life following spontaneous births before 24+0 weeks gestation.

It is noted in Working Together (2018) guidance that there is a responsibility on registrars of deaths to notify CDOPs of all deaths of children under 18 years of age, to ensure that CDOPs know about all deaths of children in their area. It is important that CDOPs regularly cross-reference their data with local registrars to provide assurance that all child deaths are being reported and reviewed.

Linkage to BadgerNet and coding neonatal conditions

This work is based on statutory data reported to NCMD, which was linked to routine patient electronic record data used by all neonatal units in England. Previous work has shown good validation and coverage of both data sources[8], [24]. Diagnostic criteria were based on previously published work, and where possible population estimates (used in the estimates of risk) were derived from the same source. Limitations in this work are likely conservative, and relate to missing of diagnoses (e.g., missing gestational age data) or evidence of neonatal care (NHS numbers were available on 96% of deaths in NCMD). In both cases the results are likely an underestimation of the impact of neonatal health on child mortality (e.g. using the sum of children identified as having one or more specific neonatal condition identifies slightly more infants than those admitted to neonatal units (n=3635), with a correspondingly higher RR estimated than in the primary analysis (all ages: RR 16.73 (15.68-17.87)), under 1 year: RR 37.71 (34.23-41.55), between 1 and 4 years: RR 3.70 (3.12-4.38), between 5 and 9 years: RR 2.08 (1.73-2.52)).

We were also limited in the range of which children we could investigate. We limited the work to babies born at or after 22 weeks gestation, as recognition and registration below this age is likely inconsistent[25], and further work including stillbirths in any measures of population impact would be useful. In addition, the BadgerNet system was not routinely used across England before 2009, and so we restricted the work to children who were born at or after 22 weeks gestation and died before their 10th birthday. As with the previous limitation, the impact of neonatal health on mortality is likely underestimated in this report as a result.

These factors may be differential across regions of the UK, and so interpretation when comparing between regions should be done cautiously.

Supplementary reporting form

Changes were introduced to the statutory data collection forms from 1 April 2019 which required further information from CDOPs to be submitted to NCMD, including the introduction of supplementary reporting forms. Prior to this, CDOPs were not required to collect this information and therefore this has had an impact on data where the child died prior to 1 April 2019. The information collected within the supplementary reporting form (deaths on a neonatal unit, delivery suite or labour ward) is used to inform the CDOP review and is also submitted to NCMD for national analysis. For the reviews across the two years, the form was partially or fully completed for 43% of Perinatal/neonatal reviews (Table 18; Appendix C). This proportion was higher for the deaths that occurred after the implementation of NCMD and had been reviewed by a CDOP: 52% for deaths in 2019-20, and 70% for deaths in 2020-21. The introduction and changes in statutory forms and guidance likely contributed to poorer completion rates for earlier deaths.

After an initial assessment of these data, the large quantity of missing data for the reviewed cohort meant that there were difficulties in the interpretation of these data. However, these data were used to aid interpretation of modifiable factors and learning points. CDOPs and CDR professionals should continue to improve the completion rate of supplementary reporting forms, which will contribute to a higher quality of review and national analysis in future.

Contributory and modifiable factors

Some improvements to the data collection were introduced from April 2021 which enabled CDOPs to specify whether each contributory factor submitted was perceived to be modifiable by the CDOP. This aimed to ensure consistency of factors in the data collection process.

For example, 51% of modifiable factors recorded in the Perinatal/neonatal reviews were not recorded as a contributory factor graded as a 2. Whilst the general completeness of recording at least one contributory factor (any grade) for Perinatal/neonatal reviews was excellent (97%), further work is now required for NCMD to facilitate better data quality and consistency around contributory and modifiable factors reported across all CDOPs, and ensure these data are suitable for national analysis and reporting. Across all CDOPs, 46% of contributory factors were recorded across more than one domain. This indicates that there is a need for more clarity and guidance for CDOPs, to increase consistency, reporting and grading of contributory factors. Improvements should be made to the statutory analysis form and data collection systems to ensure the way CDOPs record and submit data to NCMD is clear, consistent, and efficient.

For example "smoking" was commonly listed as a modifiable factor, however, on some occasions it was often not clear whether this was smoking by the mother during pregnancy, after pregnancy, or other smoking in the household. In addition, this will also help to standardise the identification of factors across CDOPs, and enable better national reporting on specific risk factors during pregnancy, e.g., maternal diabetes.

Smoking, alcohol and substance misuse outside of pregnancy would usually be reported under the social environment domain. However, in some instances it was not possible to tell whether it occurred during pregnancy and so the factors were combined under Domain A for this report due to the impact on the child at birth. This is different to the NCMD Second Annual Report where these factors were presented under Domain B. The planned changes to the way contributory and modifiable factors are recorded in NCMD will help improve the consistency of this reporting in future.

6. Glossary of terms

AICU	Adult Intensive Care Unit
BadgerNet	BadgerNet is a clinical information system used by neonatal units in the UK which forms a continuous care record for neonatal and paediatric care
BMI	Body mass index – a measure that uses your height and weight to work out if your weight is healthy
Category of death	Category of death is assigned in each child death review during the CDOP meeting. The classification of categories is hierarchical where the uppermost selected category will be recorded as the primary category should more than one category be selected
CDOP	Child Death Overview Panel
CDR	Child Death Review
CDR partners	Child death review partners (Clinical Commissioning Groups and Local Authorities)
Domain A: Characteristics of the child	Factors in the child (and in neonatal deaths, in the pregnancy). Includes factors relating to the child's age, gender and ethnicity; any pre-existing medical conditions, developmental or behavioural issues or disability, and for neonatal deaths, the mother's health and wellbeing
Domain B: Social environment including family and parenting capacity	Factors relating to family structure and functioning and any wider family health issues; provision of basic care (safety, emotional warmth; stimulation; guidance and boundaries; stability); engagement with health services (including antenatal care where relevant); employment and income; social integration and support; nursery/preschool or school environment
Domain C: Physical environment	Factors relating to the physical environment the child was in at the time of the event leading to death, and for neonatal deaths, the mother's environment during pregnancy. Includes poor quality housing; overcrowding; environmental conditions; home or neighbourhood safety; as well as known hazards contributing to common childhood injuries (e.g., burns, falls, road traffic collisions)
Domain D: Service provision	Issues in relation to service provision or uptake for any agency. Includes any issues relating to identification of illness, assessment, investigations and diagnosis; treatment or healthcare management; communication or teamwork within or between agencies; and organisational or systemic issues. Consider underlying staff factors, task factors, equipment, and work environment, education and training, and team factors
Child	A young person aged from 0 up to their 18th birthday, excluding stillbirths and planned terminations of pregnancy carried out within the law
Child in need	Defined under the Children Act 1989 as a child who is unlikely to achieve or maintain a reasonable level of health or development, or whose health and development is likely to be significantly or further impaired, without the provision of services; or a child who is disabled
Child protection plan	A child protection plan is made when a child is judged to be at risk of significant harm, significant harm being a level of harm that affects the health, welfare and development of the child
CI	Confidence Interval proposes a range of plausible values for the true parameter
HQIP	Healthcare Quality Improvement Partnership
ICH	Intracranial haemorrhage
Infant	A child under 1 year of age
Looked after child	A child who has been in the care of their local authority for more than 24 hours is known as a looked after child. Looked after children can be: • Living with foster parents; • Living in a residential children's home; or • Living in residential settings like schools or secure units

LSCB	Local Safeguarding Children Board
Median	A measure that determines the middle value in a given list of values in ascending order
Mode of death	The sequence of events preceding the death, rather than the underlying cause of the death
Modifiable factor	Factors which, by means of nationally or locally achievable interventions, could be modified to reduce the risk of future child deaths
MBRRACE-UK	Mothers and Babies: Reducing Risk through Audit and Confidential Enquiries
NCMD	National Child Mortality Database
Neonatal death	A neonatal death happens in the first 28 days after birth
Neonatal Unit	An intensive care unit specialising in the care for babies with the highest need for support. Includes Neonatal Intensive Care Units, Local Neonatal Units, Special Care Baby Units
Notification	An initial notification of death to the CDOP and NCMD in the hours immediately following the death of a child, which is a statutory requirement
NPEU	National Perinatal Epidemiology Unit, University of Oxford
Perinatal/neonatal event	Perinatal/neonatal event is defined on the Child Death Review Analysis form as: *"Death ultimately related to perinatal events, e.g., sequelae of prematurity, antepartum and intrapartum anoxia, bronchopulmonary dysplasia, necrotising enterocolitis, post-haemorrhagic hydrocephalus, irrespective of age at death. It* ***includes*** *cerebral palsy without evidence of cause, and* ***includes*** *congenital or early-onset bacterial infection (onset in the first postnatal week)."*
Place of death	The place where the child is believed to have died regardless of where death was con-firmed. Where a child is brought in dead from the community and no signs of life were recorded during the resuscitation, the place of death should be recorded as the com-munity location; where a child is brought into hospital following an event in the com-munity and is successfully resuscitated, but resuscitation or other treatment is subse-quently withdrawn, the place of death should be recorded as the location within the hospital where this occurs
PICU	Paediatric Intensive Care Unit
PMRT	Perinatal Mortality Review Tool
Preterm birth	A baby born before 37 weeks of pregnancy
p-value	A p-value is a measure of the probability that an observed difference could have occurred just by random chance. The lower the p-value, the greater the statistical significance of the observed difference
$P_{interaction}$	Is the probability that the relationship being tested varies by another factor
Review	A child death review is the responsibility of the child death review partners and the purpose is to identify any matters relating to the death, that are relevant to the welfare of children in the area or to public health and safety, and to consider whether action should be taken in relation to any matters identified. A child death review is a statutory requirement
Safeguarding	Protecting a person's health, wellbeing and human rights; enabling them to live free from harm, abuse and neglect
SUDIC	Sudden unexpected, unexplained death in childhood

7. References

[1.] T. Williams *et al*., 'NCMD second annual report. National Child Mortality Database (UK)', 2021. [Online]. Available: https://www.ncmd.info/wp-content/uploads/2021/06/NCMD_2nd_Annual_Report_June-2021_web-FINAL.pdf

[2.] K. Helenius, N. Longford, L. Lehtonen, N. Modi, and C. Gale, 'Association of early postnatal transfer and birth outside a tertiary hospital with mortality and severe brain injury in extremely preterm infants: observational cohort study with propensity score matching.', BMJ, vol. 367, p. l5678, Oct. 2019, doi: 10.1136/bmj.l5678.

[3.] C. E. Leach *et al*., 'Epidemiology of SIDS and explained sudden infant deaths. CESDI SUDI Research Group', Pediatrics, vol. 104, no. 4, p. e43, 1999.

[4.] P. Heslop, P. Blair, P. Fleming, M. Hoghton, A. Marriott, and L. Russ, 'Confidential Inquiry into premature deaths of people with learning disabilities', Department of Health, 2013.

[5.] C. J. L. Murray *et al*., 'Disability-adjusted life years (DALYs) for 291 diseases and injuries in 21 regions, 1990-2010: a systematic analysis for the Global Burden of Disease Study 2010.', Lancet Lond. Engl., vol. 380, no. 9859, pp. 2197–2223, Dec. 2012, doi: 10.1016/S0140-6736(12)61689-4.

[6.] K. Luyt *et al*., 'Ten-year follow-up of a randomised trial of drainage, irrigation and fibrinolytic therapy (DRIFT) in infants with post-haemorrhagic ventricular dilatation.', Health technology assessment (Winchester, England), vol. 23, no. 4. England, pp. 1–116, Feb. 2019. doi: 10.3310/hta23040.

[7.] W. J. Watkins, S. J. Kotecha, and S. Kotecha, 'All-Cause Mortality of Low Birthweight Infants in Infancy, Childhood, and Adolescence: Population Study of England and Wales.', PLoS Med., vol. 13, no. 5, p. e1002018, May 2016, doi: 10.1371/journal.pmed.1002018.

[8.] D. Odd *et al*., 'Child mortality in England during the COVID-19 pandemic', Arch. Dis. Child., p. archdischild-2020-320899, Jun. 2021, doi: 10.1136/archdischild-2020-320899.

[9.] C. Gale, K. Ougham, S. Jawad, S. Uthaya, and N. Modi, 'Brain injury occurring during or soon after birth: annual incidence and rates of brain injuries to monitor progress against the national maternity ambition 2018 and 2019 national data', Neonatal Data Analysis Unit, Imperial College London, 2021. [Online]. Available: https://www.imperial.ac.uk/media/imperial-college/medicine/dept-medicine/infectious-diseases/neonatology/2018-2019-Brain-injury-occurring-during-or-soon-after-birth-NATIONAL-DATA-280121.pdf

[10.] N. Modi *et al*., 'A healthy nation: strengthening child health research in the UK.', Lancet Lond. Engl., vol. 381, no. 9860, pp. 73–87, Jan. 2013, doi: 10.1016/S0140-6736(12)61818-2.

[11.] T. Draycott *et al*., 'Does training in obstetric emergencies improve neonatal outcome?', Bjog, vol. 113, no. 2, pp. 177–182, 2006.

[12.] P. D. Gluckman *et al*., 'Selective head cooling with mild systemic hypothermia after neonatal encephalopathy: multicentre randomised trial', Lancet, vol. 365, no. 9460, pp. 663–670, 2005.

[13.] D. V. Azzopardi *et al*., 'Moderate hypothermia to treat perinatal asphyxial encephalopathy', N Engl J Med, vol. 361, no. 14, pp. 1349–1358, 2009.

[14.] L. Mahoney, K. Luyt, D. Harding, and D. Odd, 'Treatment for Post-hemorrhagic Ventricular Dilatation: A Multiple-Treatment Meta-Analysis', Front. Pediatr., vol. 8, p. 238, 2020, doi: 10.3389/fped.2020.00238.

[15.] M. N. Cizmeci *et al*., 'Randomized Controlled Early versus Late Ventricular Intervention Study in Posthemorrhagic Ventricular Dilatation: Outcome at 2 Years.', J. Pediatr., vol. 226, pp. 28-35.e3, Nov. 2020, doi: 10.1016/j.jpeds.2020.08.014.

[16.] A. E. Czeizel, 'Birth defects are preventable', Int. J. Med. Sci., vol. 2, no. 3, pp. 91–92, 2005, doi: 10.7150/ijms.2.91.

[17.] S. Salway, 'How should health policy and practice respond to the increased genetic risk associated with close relative marriage? results of a UK Delphi consensus building exercise', BMJ Open 2019;9:e028928. doi: 10.1136/bmjopen-2019-028928

[18.] H. E. Jones and A. Fielder, 'Neonatal abstinence syndrome: Historical perspective, current focus, future directions.', Prev. Med., vol. 80, pp. 12–17, Nov. 2015, doi: 10.1016/j.ypmed.2015.07.017.

[19.] R. E. Azuine *et al*., 'Prenatal Risk Factors and Perinatal and Postnatal Outcomes Associated With Maternal Opioid Exposure in an Urban, Low-Income, Multiethnic US Population.', JAMA Netw. Open, vol. 2, no. 6, p. e196405, Jun. 2019, doi: 10.1001/jamanetworkopen.2019.6405.

[20.] K. M. Leifheit *et al*., 'Severe Housing Insecurity during Pregnancy: Association with Adverse Birth and Infant Outcomes.', Int. J. Environ. Res. Public. Health, vol. 17, no. 22, Nov. 2020, doi: 10.3390/ijerph17228659.

[21.] D. Ormandy, 'Housing and child health', Paediatr. Child Health, vol. 24, no. 3, pp. 115–117, Mar. 2014, doi: 10.1016/j.paed.2013.08.009.

[22.] Pregnancy and Complex Social Factors: A Model for Service Provision for Pregnant Women with Complex Social Factors. London: RCOG Press, 2010.

[23.] 'Guidance for Commissioners: Interpreting and Translation Services in Primary Care', NHS England, 2018. [Online]. Available: https://www.england.nhs.uk/publication/guidance-for-commissioners-interpreting-and-translation-services-in-primary-care/

[24.] C. Battersby, Y. Statnikov, S. Santhakumaran, D. Gray, N. Modi, and K. Costeloe, 'The United Kingdom National Neonatal Research Database: A validation study.', PloS One, vol. 13, no. 8, p. e0201815, 2018, doi: 10.1371/journal.pone.0201815.

[25.] P. J. Davis, A. C. Fenton, C. J. Stutchfield, and E. S. Draper, 'Rising infant mortality rates in England and Wales{—}we need to understand gestation specific mortality', BMJ, vol. 361, 2018, doi: 10.1136/bmj.k1936.

[26.] D. McLennan, S. Noble, M. Noble, E. Plunkett, G. Wright, and N. Gutacker, 'The English Indices of Deprivation 2019: Technical Report. Ministry of Housing, Communities and Local Government.', 2019.

[27.] C. Gale, Y. Statnikov, S. Jawad, S. N. Uthaya, and N. Modi, 'Neonatal brain injuries in England: population-based incidence derived from routinely recorded clinical data held in the National Neonatal Research Database', Arch. Dis. Child. - Fetal Neonatal Ed., Oct. 2017, [Online]. Available: http://fn.bmj.com/content/early/2017/10/22/archdischild-2017-313707.abstract

[28.] C. Battersby, T. Santhalingam, K. Costeloe, and N. Modi, 'Incidence of neonatal necrotising enterocolitis in high-income countries: a systematic review.', Arch. Dis. Child. Fetal Neonatal Ed., vol. 103, no. 2, pp. F182–F189, Mar. 2018, doi: 10.1136/archdischild-2017-313880.

[29.] 'Birth characteristics 2019', Office for National Statistics (UK), 2019. [Online]. Available: https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/livebirths/datasets/birthcharacteristicsinenglandandwales

[30.] MBRRACE-UK. Rapid report 2021: Learning from SARS-CoV-2-related and associated maternal deaths in the UK, 2021.

8. Appendices

Appendix A: Additional methodology and technical information

Gestational age was recorded from the NCMD or BadgerNet data as available. In addition, the CDOPs also report baseline characteristics of the child, with the following data derived from the child death notification form: sex of individual, ethnic group (Asian or Asian British, Black or Black British, Mixed, White, Other, or Unknown), age at death, region in which the death occurred, and (from the child's home postcode) the Index of Multiple Deprivation, a measure of local deprivation [26] (on a score of 1-10) with a lower value suggesting greater deprivation.

Neonatal conditions were identified using data from the initial notification form sent to NCMD, CDOP review, or BadgerNet record. Gestational age was recorded from the NCMD or BadgerNet data as available; and secondarily categorised into 5 categories (less than 24 weeks, 24 to 31 weeks, 32 to 36 weeks, 37 to 41 weeks and 42 and above weeks of completed gestation at birth). In addition, infants with a gestational age at birth below 37 weeks, or those with a coded admission definition of preterm in the BadgerNet record, were defined as preterm.

Children without evidence of premature birth were assumed to not be preterm. Birthweight was also derived from the NCMD or BadgerNet data. Term gestation (37 weeks or over) low birthweight infants were identified by those with a recoded birthweight below 2500g or a coded admission as "Low Birth Weight" in the BadgerNet record. The infant was identified as having likely hypoxic-ischaemic encephalopathy (HIE), intracranial haemorrhage (ICH), from text codes (Appendix E) identified from BadgerNet fields (Principal Diagnosis at Discharge, Neurological Diagnosis, Cause of Death (1a, 1b or 2), Principal Reason for Admission, Cause of death) in the discharge record, or NCMD codes (Notification Details, Suspected Cause of Death, Cause of death (1a, 1b or 2)) if death occurred in the first day of life. The presence of any congenital anomalies was identified as per the BadgerNet record, or the presence of one of more text codes (Appendix E:). HIE, ICH text was based on previously published work [27], [28].

The population at risk (i.e., all children) was derived from Office of National Statistics 2019 estimates [29]. Population frequencies in the older age groups were modelled using observed frequencies of death in younger children.

Appendix B: Additional data tables

Table 17: Demographics in all deaths of children aged less than 10 years in England, 1 April 2019 to 31 March 2021, split by their age at death.

Characteristic	N	Age (Years)		
		<1	1-4	5-9
All deaths	**4829**	**3730**	**659**	**440**
Sex	**4753**			
Male		1996 (54.5%)	354 (54.3%)	256 (58.7%)
Female		1669 (45.5%)	298 (45.7%)	180 (41.3%)
IMD*	**4765**			
1/2 (Most deprived)		1308 (35.5%)	213 (32.9%)	133 (30.5%)
3/4		892 (24.2%)	129 (19.9%)	98 (22.5%)
5/6		659 (17.9%)	134 (20.7%)	81 (18.6%)
7/8		458 (12.4%)	89 (13.8%)	72 (16.5%)
9/10 (Least deprived)		365 (9.9%)	82 (12.7%)	52 (11.9%)
Ethnicity**	**4205**			
Asian or Asian British		586 (18.2%)	126 (21.7%)	74 (18.6%)
Black or Black British		284 (8.8%)	30 (5.2%)	37 (9.3%)
Mixed		207 (6.4%)	38 (6.5%)	19 (4.8%)
Other		79 (2.5%)	20 (3.4%)	15 (3.8%)
White		2070 (64.2%)	368 (63.2%)	252 (63.5%)
Region	**4829**			
East Midlands		307 (8.2%)	47 (7.1%)	35 (8.0%)
East of England		345 (9.3%)	59 (9.0%)	57 (13.0%)
London		693 (18.6%)	127 (19.3%)	67 (15.2%)
North East		154 (4.1%)	32 (4.9%)	25 (5.7%)
North West		540 (14.5%)	103 (15.6%)	48 (10.9%)
South East		480 (12.9%)	93 (14.1%)	65 (14.8%)
South West		269 (7.2%)	57 (8.7%)	35 (8.0%)
West Midlands		526 (14.1%)	70 (10.6%)	50 (11.4%)
Yorkshire and Humber		416 (11.2%)	71 (10.8%)	58 (13.2%)

* Index of Multiple Deprivation

** Ethnicity is grouped based on groupings used in the 2011 Census

Appendix C: Quality, completeness and timeliness

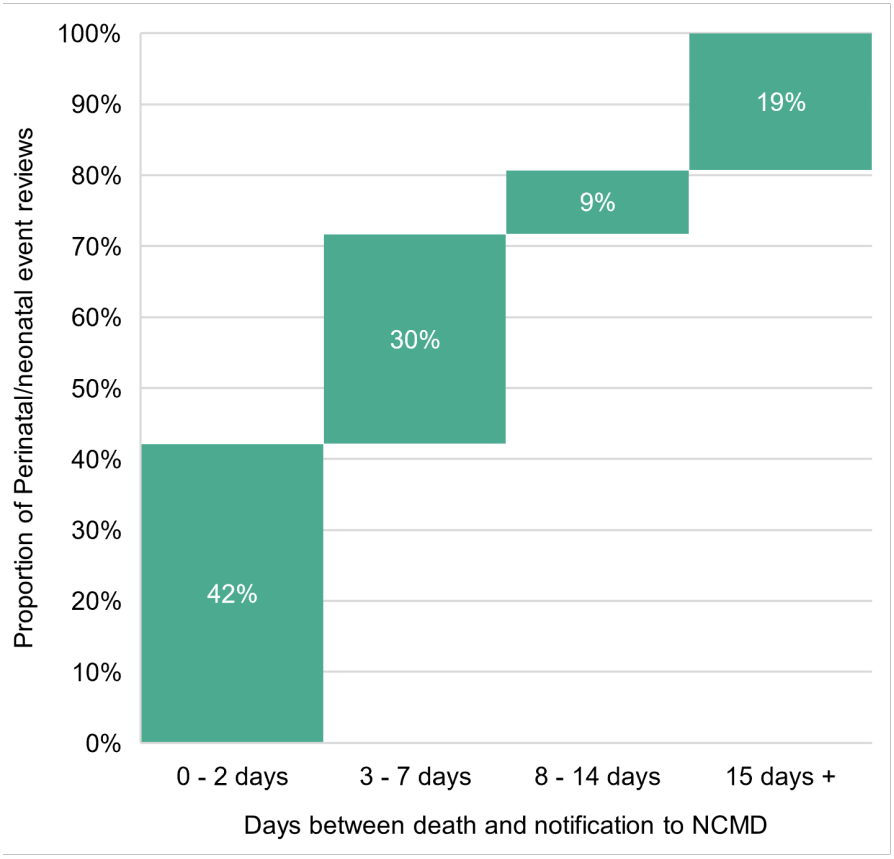
Timeliness of NCMD notification and review data

Timely notifications to NCMD are important to enable effective real-time surveillance of child and infant mortality.

Of the 1004 Perinatal/neonatal child death reviews where the death occurred after the launch of NCMD (1 April 2019), the median number of days for the death to be notified to NCMD was 3 days.

41% (n=407) were notified to NCMD in 2 days or less and a further 29% (n=296) between 3 and 7 days (Figure 7). Overall, 81% (n=797) of these deaths were notified to NCMD within two weeks of the death occurring. There was an increase in the timeliness of notifications to NCMD in 2020-21, the second year of data collection, where 59% were notified to NCMD within 2 days or less. Please note that this does not adjust for weekends or non-working days where CDOPs would not process a death notification to NCMD.

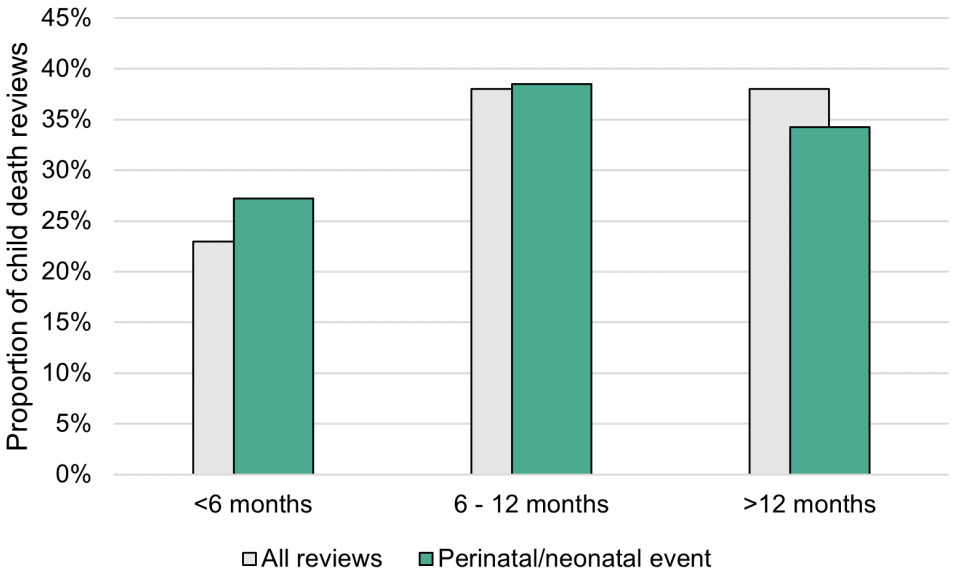
Figure 7: Time between death and notification to NCMD of reviews categorised as *Perinatal/neonatal event*



Completion of reviews

For the review to complete, the median time taken for Perinatal/neonatal reviews was approximately 9 months (282 days). 27% (n=470) took less than 6 months, 39% (n=665) took between 6 months and 1 year and 34% (n=591) took over 1 year to complete (Figure 8). There was a higher proportion of Perinatal/neonatal reviews that took less than 6 months in comparison to all child death reviews (27% and 23% respectively).

Figure 8: Time taken to complete child death reviews, where the review occurred between 1 April 2019 and 31 March 2021



CDOPs are provided with a quarterly data report from NCMD which summarises their data and completeness of key data fields.

The reports serve as a prompt to review data accuracy and completeness.

Table 18: Proportion of reviews with a supplementary form completed for reviews categorised as *Perinatal/neonatal event* and where the review occurred between 1 April 2019 and 31 March 2021, by year of death

	Year of death			
	2018-19 or before	2019-20	2020-21	Total
Deaths reviewed with supplementary form* partially or fully completed	187 (26%)	413 (52%)	149 (70%)	749 (43%)
Total	722	790	214	1726

*Deaths on a neonatal unit, labour ward or delivery suite supplementary form

Appendix D: Category of death descriptions

Table 19: Name and description for each category of death on the child death review analysis form in hierarchical order

Category	Name of category	Description of category
1	Deliberately inflicted injury, abuse or neglect	This includes suffocation, shaking injury, knifing, shooting, poisoning & other means of probable or definite homicide; also deaths from war, terrorism or other mass violence; includes severe neglect leading to death.
2	Suicide or deliberate self-inflicted harm	This includes hanging, shooting, self-poisoning with paracetamol, death by self-asphyxia, from solvent inhalation, alcohol or drug abuse, or other form of self-harm. It will usually apply to adolescents rather than younger children.
3	Trauma or other external factors, including medical/ surgical complications/error	This includes isolated head injury, other or multiple trauma, burn injury, drowning, unintentional self-poisoning in pre-school children, anaphylaxis & other extrinsic factors. Also includes proven medical and surgical complications or errors as the primary cause of death. Excludes Deliberately inflected injury, abuse or neglect. (category 1).
4	Malignancy	Solid tumours, leukaemias & lymphomas, and malignant proliferative conditions such as histiocytosis, even if the final event leading to death was infection, haemorrhage etc.
5	Acute medical or surgical condition	For example, Kawasaki disease, acute nephritis, intestinal volvulus, diabetic ketoacidosis, acute asthma, intussusception, appendicitis; sudden unexpected deaths with epilepsy.
6	Chronic medical condition	For example, Crohn's disease, liver disease, immune deficiencies, even if the final event leading to death was infection, haemorrhage etc. Includes cerebral palsy with clear post-perinatal cause.
7	Chromosomal, genetic and congenital anomalies	Trisomies, other chromosomal disorders, single gene defects, neurodegenerative disease, cystic fibrosis, and other congenital anomalies including cardiac.
8	Perinatal/neonatal event	Death ultimately related to perinatal events, e.g., sequelae of prematurity, antepartum and intrapartum anoxia, bronchopulmonary dysplasia, necrotising enterocolitis, post-haemorrhagic hydrocephalus, irrespective of age at death. It includes cerebral palsy without evidence of cause, and includes congenital or early-onset bacterial infection (onset in the first postnatal week).
9	Infection	Any primary infection (i.e., not a complication of one of the above categories), arising after the first postnatal week, or after discharge of a preterm baby. This would include septicaemia, pneumonia, meningitis, HIV infection etc.
10	Sudden unexpected, unexplained death	Where the pathological diagnosis is either 'SIDS' or 'unascertained', at any age. Excludes Sudden Unexpected Death in Epilepsy (category 5).

Appendix E: Identification of neonatal conditions

Table 20: Text used to identify certain neonatal conditions

Hypoxic Ischaemic Encephalopathy (HIE)	Intracranial Haemorrhage (ICH)	Congenital Abnormalities	Necrotising Enterocolitis
moderate neonatal encephalopathy	subdural haemorrhage	congenital	necrotising enterocolitis
severe neonatal encephalopathy	cerebral haemorrhage	transposition great arteries (TGA)	necrotizing enterocolitis
hypoxic ischaemic encephalopathy (HIE)	intracranial haemorrhage (ICH)	renal agenesis	NEC
hypoxic-ischaemic encephalopathy	subarachnoid haemorrhage	hypoplastic right heart syndrome	
hypoxic ischemic encephalopathy	tentorial tear due to birth injury	hypoplastic left heart syndrome	
hypoxic-ischemic encephalopathy	post-haemorrhagic hydrocephalus (PHVD)	diaphragmatic hernia (CDH)	
hypoxic-ischemia encephalopathy	intraventricular haemorrhage	trisomy	
hypoxic brain injury	intracerebral haemorrhage		
hypoxic ischaemic brain damage			

National Child Mortality Database (NCMD)

Level D, St Michael's Hospital
Southwell Street
Bristol, BS2 8EG

Email: ncmd-programme@bristol.ac.uk
Website: www.ncmd.info
Twitter: @NCMD_England