

National Child Mortality Database - Written evidence (PRT0060)

1. Background, and organisational Information

The National Child Mortality Database (NCMD) national data collection and analysis system is the first of its kind anywhere in the world. It records comprehensive data, standardised across a whole country (England), on the circumstances of children's deaths. The purpose of collating information nationally is to ensure that deaths are learned from, that learning is widely shared and that actions are taken, locally and nationally, to reduce the number of children who die.

The programme was established and is delivered by the University of Bristol, in collaboration with Anna Freud, UCLPartners and the software company QES. It also includes representation from bereaved families through the NCMD charity partners: Child Bereavement UK, The Lullaby Trust and Sands. The programme is funded by NHS England and commissioned by HQIP. The National Child Mortality Database (NCMD) commenced data collection on 1st April 2019.

The House of Lords Select committee has placed a call for evidence to support the committees' inquiry on the prevention, and consequences of preterm birth in England. Among others, the committee is focusing on the following topics directly aligned with the aims, objectives, and outcomes of the NCMD.

Variation in care and health inequalities

- The ethnic and socioeconomic inequalities seen in relation to preterm birth and how these could be reduced.

Below we give an overview of how our work addresses the above issues.

2. Summary of Existing NCMD Work

Previous work by the NCMD has worked to triangulate the impact of deprivation and ethnicity (as major determinants of inequalities) with child mortality¹. Recent analysis of all deaths of infants (children under 1) in England between the 1st of April of 2019 and 31st March 2022 showed stark associations with underlying measures of inequalities². Infant mortality was strongly associated with maternal ethnicity, with mothers from Asian and Asian British families having around a 60% increase in the chance of their baby dying from preterm birth by 1 year of age, compared to mothers from white backgrounds. The increased risk in Black and Black British mothers was even higher, with over a two-fold increase in the risk of having a baby die of prematurity. This association persisted, and indeed, barely changed, even after taking into account the local levels of deprivation the families lived in, and didn't measurably vary across the country. We know that women from Asian and Asian British, and Black and Black British backgrounds are more likely to have preterm deliveries; and much of the increased risk disappeared, when adjusting for the likely risk of giving birth to a child preterm – suggesting that increased mortality seen in these groups is because of increased levels of preterm birth, rather than increased death after these births.

However, we also know that deprivation has an added impact worsening existing inequalities, and that the chance, after a preterm death, that a modifiable contributory factor is identified is higher in the most deprived areas, compared to the least deprived¹. This same work, reviewed the underlying components of deprivation and overall neonatal death, and identified that local employment levels and opportunities, and household overcrowding, homelessness, and housing affordability, were the most important factors.

Finally, while many of these preterm infants die in the first few weeks of life, the impact of their preterm birth is substantial across their childhood³, with ex-preterm infants having increased risk of death at least until 10 years of age, and likely beyond. This work suggested that, of all the

childhood deaths below 10 years of age, 46% were caused by preterm birth, with the major additional neonatal conditions contributing to these deaths being necrotising enterocolitis (and inflammatory disease of the bowel seen in preterm babies) in 9.3%, intracranial haemorrhage (bleeding, commonly in the fluid spaces, in the brain) in 7.4%, and lung disease in 5.6% of all these deaths. We know from this work that the children who die after preterm birth, are two or more times more likely to have behavioural or developmental disorders, cerebral palsy, chronic neurological disease, and chronic respiratory disease.

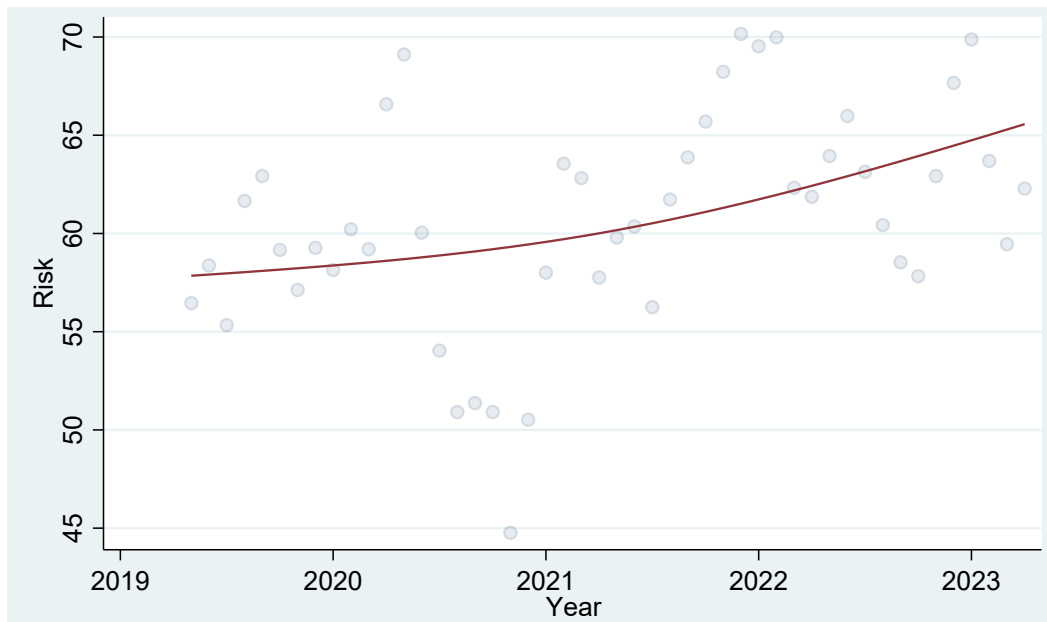
From an NCMD review of vulnerability more than a third (38%) of infants dying of Sudden Infant Death Syndrome (SIDS or “Cot Death”) were born preterm.⁵

The increased vulnerability of SIDS infants identified in previous studies has become more marked. The infants who died in 2020 of SIDS were more likely to be preterm (29.6% vs 19.3%, $p=0.012$) compared to historical studies in England.⁶

3. Unpublished NCMD data for evidence call

The numbers of deaths from prematurity have been increasing across the last four years (2019-2023). Using the NCMD data, and restricting to deaths of children born alive, at, or over 22 weeks of gestation, we estimate that there were 699 deaths between 1st April 2019 to 31st March 2020, 661 for the same period 2020-21, 757 in 2021-22, and 743 in 2022/23. Overall, this is an average rise of 3% per year (Figure 1).

Figure 1: Monthly deaths after preterm birth, April 2019 to March 2023, with trend-line (Source NCMD unpublished data).



Trend for deaths from preterm birth: RR 1.03 (1.00-1.07) per year.

This trend appears to be continuing through to the most recent NCMD real-time data analysis (deaths up to January 2024), with the increases in preterm deaths seen exclusively in children from non-White minority ethnic groups (Figure 2), and in the most deprived areas (Figure 3).

Figure 2: Deaths from prematurity trends by ethnic groups (2019-2024) - Source NCMD unpublished data.

Preterm Birth deaths by Ethnic group

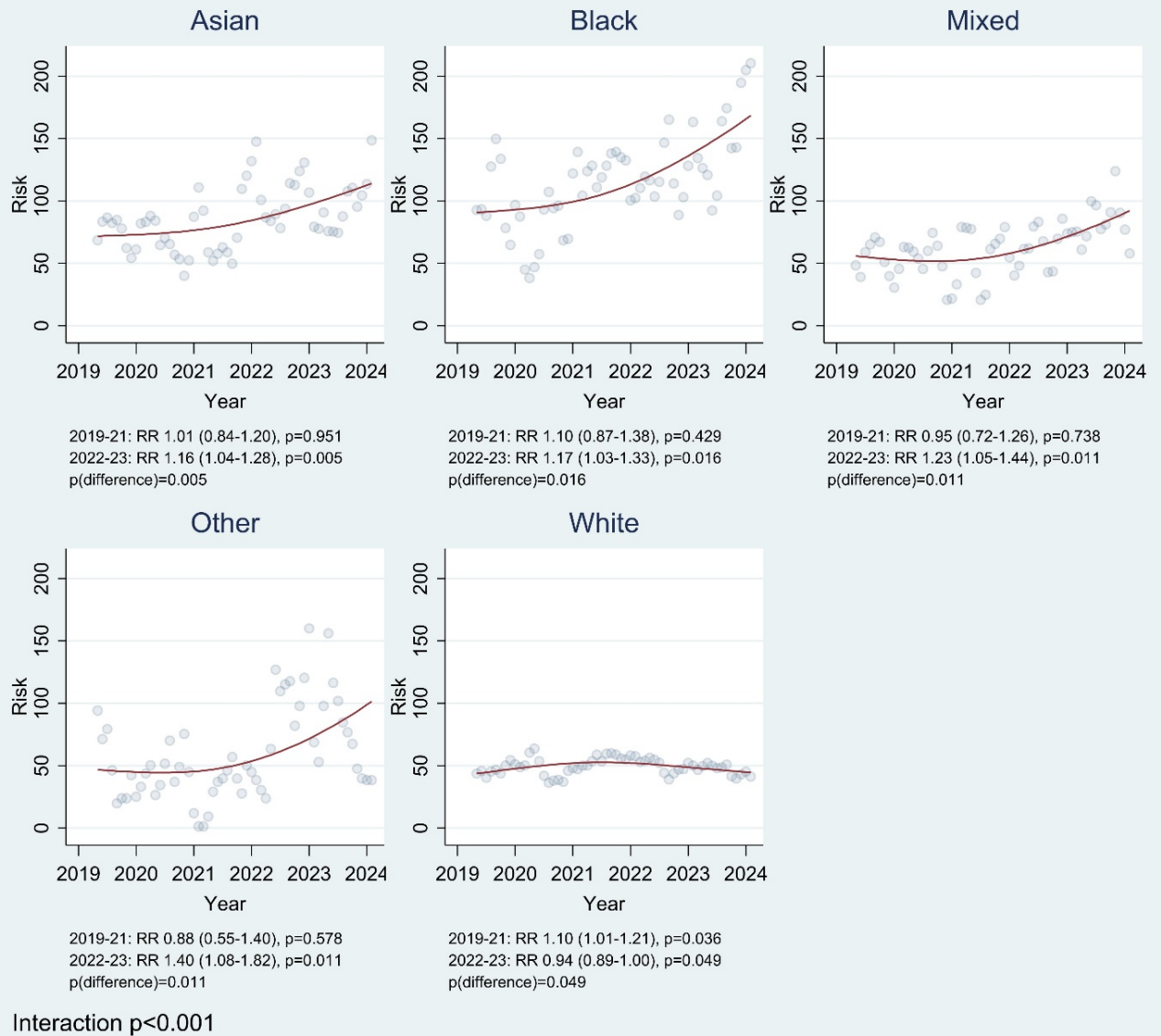


Figure 3: Deaths from prematurity trends by index of multiple deprivation (IMD) quintile (2019-2024) – Source NCMD unpublished data.

Preterm Birth deaths in England by Deprivation



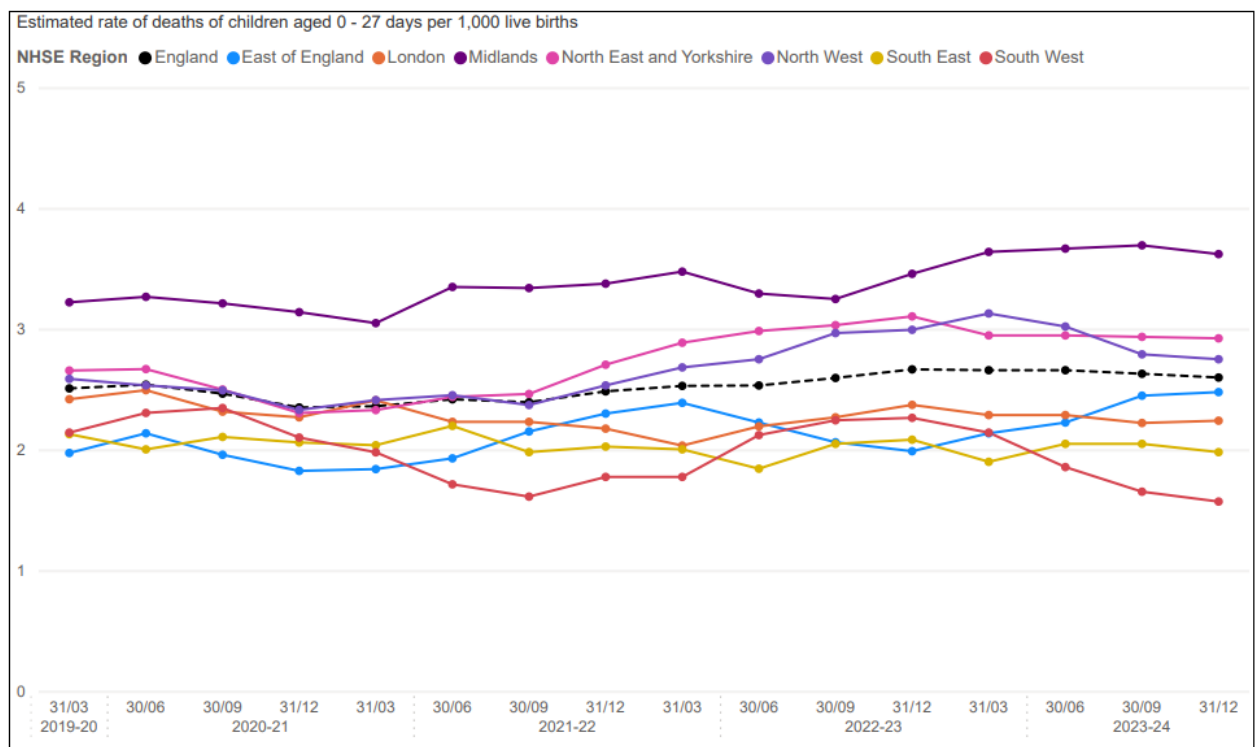
Interaction p=0.043

4. Regional Variation in Neonatal Mortality

Neonatal mortality is primarily driven by preterm birth and complications of prematurity.⁴ The neonatal mortality rate is rising, with large variation

across the regions of England (Figure 4). The South-West region had the lowest neonatal mortality in England in 2023. The PERIPrem care bundle (see case study, reference 3, p21), focused on reducing preterm mortality was implemented in South-West England in 2020. The two regions with the highest neonatal mortality rate (Midlands and North-East) will be supported by their respective Health Innovation Networks to implement PERIPrem from April 2024.

Figure 4: Neonatal Mortality Rate England by regions (April 2019 to December 2023) – Source NCMD unpublished data.



*ONS Live births 2022 was used to calculate estimated rates for all years

5. Relevant Multi-sector Recommendations from NCMD commissioned thematic reports³

Prediction and prevention of preterm birth

5.1 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

5.2 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

5.3 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.

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

Optimisation of the baby prior to and following preterm birth

5.4 Ensure vulnerable infants are born in an appropriate unit. 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

5.5 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

5.6 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

5.7 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

5.8 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

5.9 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). 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

5.10 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

6. References

1. Odd D, Stoianova S, Williams T, et al. What is the relationship between deprivation, modifiable factors and childhood deaths: a cohort study using the English National Child Mortality Database. *BMJ Open* 2022;12(12):e066214. doi: 10.1136/bmjopen-2022-066214 [published Online First: 20221209]
2. Odd DE, Stoianova S, Williams T, et al. Race and Ethnicity, Deprivation, and Infant Mortality in England, 2019-2022. *JAMA Netw Open* 2024;7(2):e2355403. doi: 10.1001/jamanetworkopen.2023.55403 [published Online First: 2024/02/12]
3. Odd D, Williams T, Stoianova S, et al. The Contribution of Newborn Health to Child Mortality across England.: National Child Mortality Database (UK); 2022 [Available from: <https://www.ncmd.info/wp-content/uploads/2022/07/Perinatal-FINAL.pdf>].
4. Odd D, Williams T, Stoianova S, Rossouw G, Fleming P, Luyt K. Newborn Health and Child Mortality Across England. *JAMA Netw Open*. 2023;6(10):e2338055. doi:10.1001/jamanetworkopen.2023.38055
5. A thematic review of vulnerability, which increases the risk of poor outcomes, in infants by [NCMD Programme](#) | Sep 28, 2023

[Vulnerability in infants: a study of sudden and unexplained deaths \(ncmd.info\)](https://www.ncmd.info)

6. Pease A, Turner N, Ingram J, *et al.* Changes in background characteristics and risk factors among SIDS infants in England: cohort comparisons from 1993 to 2020. *BMJ Open* 2023;**13**:e076751. doi: 10.1136/bmjopen-2023-076751

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