

NCMD

National Child Mortality Database

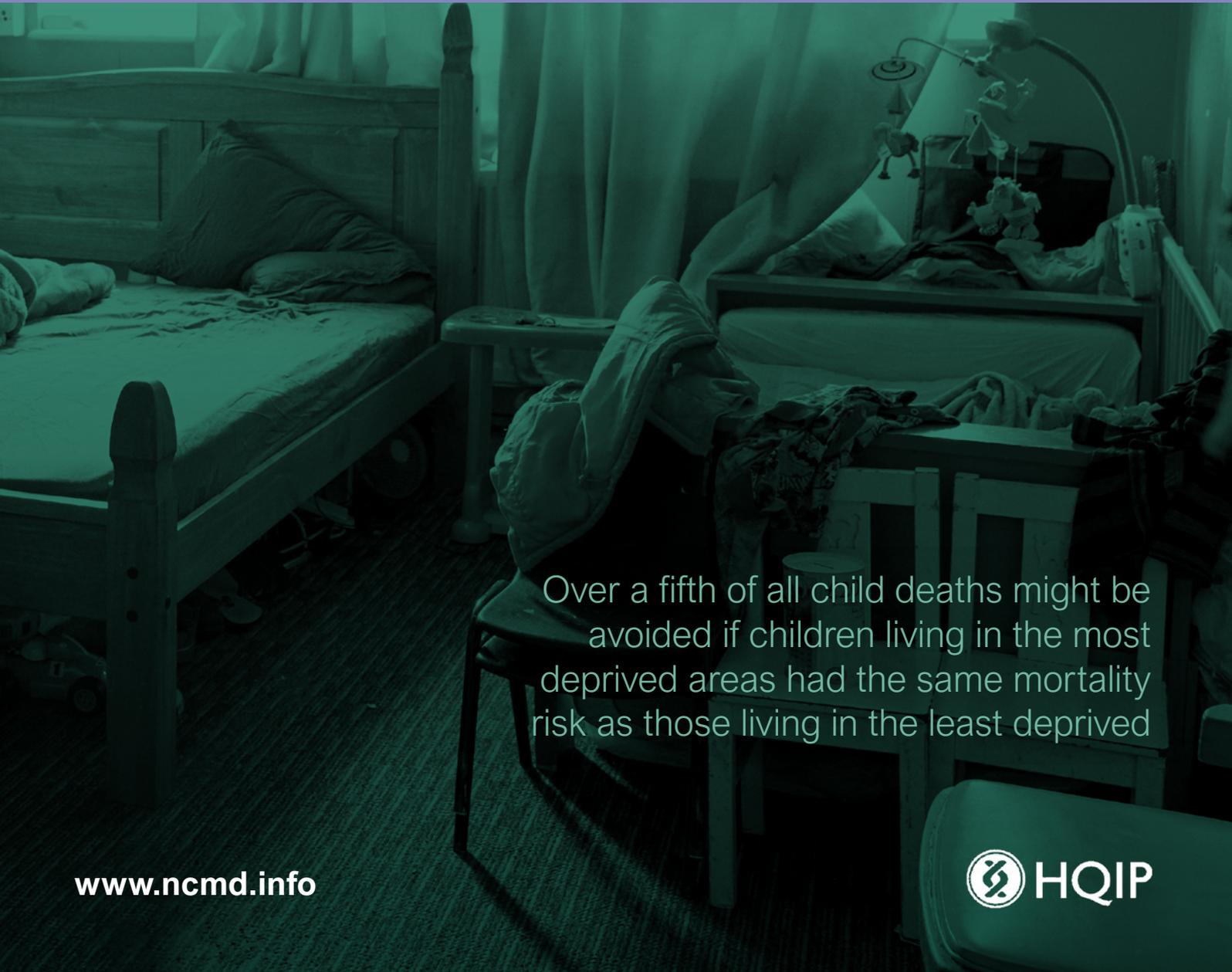
Knowledge, understanding and
learning to improve young lives

Child Mortality and Social Deprivation

National Child Mortality Database Programme Thematic Report

Data from April 2019 to March 2020

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Over a fifth of all child deaths might be avoided if children living in the most deprived areas had the same mortality risk as those living in the least deprived

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Foreword

Every child death is a tragedy. If unavoidable it can, depending on beliefs, be put down to bad luck, fate, the universe out of kilter, God's will. But if avoidable, there is a different sense. It should not have happened. "They" should have been able to do something about it. Perhaps "they" should be turned into "we". We, organised public health, the health care system, a well-functioning society should have been able to do something about it.

In the 1970s, Abe Adelstein was chief medical statistician at the Office of Population Censuses and Surveys (later part of ONS). Commenting on the Confidential Inquiry into Maternal Deaths, that provided an estimate of avoidable deaths, he said: the Inquiry has a limited conception of 'avoidable'; they think of it as something a doctor does, or does not do, to a patient. He wanted a more expansive view, examining causes in society and inequalities.

The present report takes just such a broader view of 'avoidable' by focussing on deprivation. In a rich society, deprivation should be avoidable – particularly of the kind that leads to deaths of infants and children. Infant mortality is a particularly sensitive indicator of the effects of social determinants of health.

"In a rich society, deprivation should be avoidable – particularly of the kind that leads to deaths of infants and children"

Professor Sir Michael Marmot
UCL Institute of Health Equity

To gain a sense of avoidable infant mortality, perhaps we should ask what 'should' the infant mortality rate be. One way of answering that question is to look at the country with the lowest infant mortality rate. Had we asked that question in 1970, the answer might have been 11 per 1000 live births, the rate in Sweden. We might have judged that any excess over 11 was avoidable. At the time the UK rate was 18. By 2017, the UK rate had dropped to 3.9 per 1000 live births, impressive. But perhaps the rate 'should' have been lower still – 1.9, the rate in Finland.

As this report makes clear, we are moving in the wrong direction. Infant mortality has risen over the last 4 years, particularly among families in more deprived areas. Extending the age range to under 5 mortality, in 2019 the UK ranked 22 out of 23 Western European countries. The report offers rising child poverty in the UK as a potential explanation.

A different way of assessing avoidability of infant and child deaths is to examine the relation with deprivation. Here, the relation is strong. In one of the analyses, the report shows that for each decile of deprivation, going from least to most deprived, on average, the mortality risk is relatively 10% higher. It means the rate is over twice as high in the most deprived decile compared to the least. The report calculates that if the child mortality rate in the most deprived half of the population was reduced to that of the least deprived half, 23% of child death could potentially have been avoided.

We could be even more ambitious. Given that the relation between deprivation and child deaths is graded – the greater the deprivation the higher the mortality rate – we could extend that calculation. There is reason enough to think that the association between deprivation and mortality is causal. Instead of taking the practical option of comparing the most deprived half with the least deprived half (as done in the report), what if we took the least deprived 20% as the benchmark, and ask how many child deaths could be avoided if the more deprived 80% had the low rate of the best-off quintile. The figure would likely be closer to a third of all child deaths which could be avoided by reducing deprivation.

If that sounds utopian – how could we have the most deprived 80% achieve the low rate of the least deprived 20% - then consider that infant mortality in 1970 was 18 per 1000, and just under 50 years later it was 3.9. Such improvement is possible. Indeed, specific factors judged to be avoidable were more common the greater the deprivation. The reason the UCL Institute of Health Equity followed the WHO lead in speaking not just of inequalities but of inequities is to capture the idea that those inequalities that are judged to be avoidable by reasonable means, and are not avoided, are inequitable. Putting them right is a matter of social justice.

Two further strengths of this report are welcome. First, texture is given to the statistical link between deprivation and death by case histories. The harrowing accounts of child loss both illustrate how the causation works and where intervention might have saved lives. The illustration that such intervention is possible is another strength. For example, the Manchester Reducing Infant Mortality Strategy has five priority themes: quality of services, maternal and infant wellbeing, addressing the wider determinants of health, keeping children safe from harm, and providing support for those bereaved by baby loss.

In December 2020, the Institute of Health Equity produced a report, *Build Back Fairer: the COVID-19 Marmot Review*. The central message of our report was that we must not go back to the status quo of early 2020. As we emerge from the pandemic, we should be seeking to build a fairer society with equity of health and well-being at its heart. Taking the actions that will lead to reduction in avoidable inequalities in child mortality will be central. The present report, by drawing attention to what is possible, plays a vital part.

Professor Sir Michael Marmot FRCP

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Executive summary

The data presented in this report represent babies, children and young people who have died. We recognise that the death of each child is a devastating loss that profoundly affects bereaved parents as well as siblings, grandparents, extended family members, friends and professionals. No two deaths are the same, but by pooling the information from all deaths, we can better understand if and how deprivation is associated with an increased risk of dying. The value of this work is to derive learning from each child's death to inform policy to improve the life chances of future children.

Key findings

1. There was a clear association between the risk of death and the level of deprivation for children who died in England between April 2019 and March 2020. This association appeared to exist for all categories of death except malignancy.
2. On average, there was a relative 10% increase in risk of death between each decile of increasing deprivation.
3. Over a fifth of all child deaths might be avoided if children living in the most deprived areas had the same mortality risk as those living in the least deprived. This translates to over 700 fewer children dying per year.

4. The proportion of deaths with identified modifiable contributory factors increased with increasing deprivation; with factors relating to the social environment being the most frequently reported.
5. At least 1 in 12 of all child deaths reviewed in 2019/20 had one or more factors related to deprivation identified at review.
6. There were exemplar projects highlighting how CDOPs had developed local strategies, informed by recurring review themes and local learning, to reduce infant mortality.

Recommendation

Use the data in this report to develop and monitor the impact of future strategies to reduce social deprivation and inequalities.

Action by: Policy Makers, Public Health Services, Service Planners and Commissioners at local and national level.



Clear association between the risk of death and the level of deprivation

Key findings

Child Mortality and Social Deprivation

April 2019 to March 2020

NCMD
National Child Mortality Database



CLEAR ASSOCIATION between **RISK OF DEATH** and level of **DEPRIVATION** (all categories except malignancy)



Relative **10% INCREASE** in **RISK OF DEATH** between each decile of increasing deprivation (on average)



>1 in 5 CHILD DEATHS might be **AVOIDED** if children living in most the deprived areas had the same mortality risk as those living in the least deprived



INCREASED PROPORTION of deaths with modifiable contributory factors with **INCREASING DEPRIVATION**



1 in 12 CHILD DEATHS reviewed in 2019/20 identified **1 OR MORE** factors related to **DEPRIVATION**



EXEMPLAR PROJECTS highlighting strategies informed by recurring themes and local learning to **REDUCE MORTALITY**

RECOMMENDATION

Use the data in this report to **DEVELOP** and **MONITOR** the **IMPACT** of future strategies to **REDUCE SOCIAL DEPRIVATION** and **INEQUALITIES**

ACTION BY: Policy Makers, Public Health Services, Service Planners and Commissioners at local and national level

1. Why was this work undertaken?

The NHS Long Term Plan sets out a strong commitment for action to improve wellbeing through tackling the wider factors that have an impact on health including social deprivation and inequalities.

The health of a nation is determined in large part by how society is organised and how well it functions. Measures that reflect national health include the average number of years people live, and how well vulnerable people are protected from things that harm their health and wellbeing. Babies, children, and young people are among the most vulnerable in society.

Early child development plays a major role in affecting future life chances and health throughout the life course.¹ The younger the age the stronger the effects of external factors such as poverty and deprivation. Indeed, the quality of a whole society is often expressed through the health of its youngest. For example, the infant mortality rate (IMR), which is the number of children dying under one year of age in a given year, per 1,000 live births, is commonly used to indicate country-level development and social functioning. Monitoring IMRs over time and comparing them between countries is an important policy lever, since IMR is one of the main single measures of a nation's health and health care systems' quality, as well as the wider public health, societal, economic, and environmental determinants.² IMRs in the UK had been continuously decreasing since the 1990s, but, in recent years, progress has slowed down and there has been no further improvement since 2014.^{3,4} Indeed, the IMR has risen over the past four years, but closer examination by socio-economic group reveals that children from deprived backgrounds may be differentially affected by this rise.⁵ In addition, the Global Burden of Disease Study reported the under 5 mortality rate in the UK in 2019 as 4.1 per 1000, the second highest amongst the 23 countries in Western Europe (average 3.4 per 1000), after Malta.⁶ A potential explanation is the rising child poverty in the UK, given the widespread and consistent associations within and between countries.⁷ It should be acknowledged that publications have also shown that the recent IMR in the UK is related to a significant increase in the number of live births being registered at gestations below 24 weeks^{8,9}. Further closer analysis of the neonatal mortality trends, i.e. by gestational age at birth and any potential local and regional variations in neonatal care and birth registration practices, is becoming increasingly relevant for policy-makers and health practitioners for monitoring the progress against the NHS Long Term Plan's ambition to halve the neonatal mortality rates.



A systematic review examining the relationship between social factors and early childhood health and developmental outcomes provides strong evidence that factors such as neighbourhood deprivation, lower parental income and unemployment, lower educational attainment, lower occupational social class, heavy physical occupational demands, lack of housing tenure, and material deprivation in the household are all independently associated with a wide range of adverse health outcomes.¹⁰ For the early years, the evidence relating to social deprivation and death is strongest for infant mortality (child deaths under the age of 1 year), however Marmot¹¹ has demonstrated clear associations between socio-economic status and life expectancy, as have Dorling et al¹² and many others.

The under 5 mortality rate in the UK in 2019 was the second highest in Western Europe

The National Child Mortality Database (NCMD) Programme was established in 2018 to collate and analyse data on all children in England, who die before their 18th birthday, with statutory death notifications required within 48 hours. The data are collated from the 58 regional Child Death Overview Panels (CDOPs) in England who carry out detailed analysis of the circumstances of death and the modifiable factors relevant to the death as part of the child death review (CDR) process with the aim of identifying common themes to guide learning and inform actions to reduce future child deaths.¹³

1 Marmot et al, 2008

2 Trust, T. N. Infant and neonatal mortality, 2020

3 Taylor-Robinson et al, 2019

4 Office for National Statistics, 2018

5 Wickham et al, 2016

6 Lozano, Fullman, Mumford et al, 2019

7 Cheung R., 2018

8 Davis PJ et al, 2018

9 Nath S et al, 2020

10 Pillas et al, 2014

11 Marmot, 2020

12 Dorling et al, 2007

13 Child death review: statutory and operational guidance, 2018 (<https://www.gov.uk/government/publications/child-death-review-statutory-and-operational-guidance-england>)

The CDR process is statutory, with the Children Act 2004 mandating the review and analysis of all child deaths so the circumstances of death that relate to the welfare of children locally and nationally, or to public health and safety, are identified and understood and preventive actions are established. The NCMD provides a valuable resource for learning from child deaths at national level, using the strong evidence of the detailed information collected and analysed from the CDR process to inform policies to drive improvements in child health and wellbeing.

The NCMD legal basis to collect confidential and personal level data under the Common Law Duty of Confidentiality has been established through the Children Act 2004 Sections M - N, Working Together to Safeguard Children 2018 and associated Child Death Review Statutory & Operational Guidance.

The NCMD legal basis to collect personal data under the General Data Protection Regulation (GDPR) without consent is defined by GDPR Article 6 (e) Public task and 9 (h) Health or social care (with a basis in law).

This is the NCMD Programme's first thematic report, aiming to investigate and quantify the characteristics of children who have died since the launch of the national data collection and analysis system on 1st April 2019. It aims to identify if social deprivation is associated with childhood mortality and if apparent socio-economic inequalities appear to be less or more important for the different sub-groups of the population and the different causes of death. It also presents for the first time national analysis on modifiable factors, as identified in the child death review, by looking at the proportion of children with modifiable factors by deprivation decile.

The preliminary analyses carried out by the NCMD since the start of the national data collection, identified a detrimental effect of social deprivation on all causes and categories of death, across all ages, with the most profound effect in deaths in children under the age of 1. A working group drawing in expertise in epidemiology, neonatology, child health and public health was set up by the NCMD team to explore this topic further. The group was also advised by the appropriate Parent, Patient and Public Involvement (PPPI) representatives from the NCMD partner charities: The Lullaby Trust, Sands and Child Bereavement UK, as well as by the Child Poverty Action Group. A consultation took place with the wider NCMD stakeholders' groups and the NCMD Professional Advisory Group, which recommended that a report on social deprivation should be prioritised as one of the first NCMD thematic reports. This recommendation was formally supported by NHS England. Since all deaths must be notified to NCMD within 48 hours, this results in a complete and prompt dataset of childhood deaths, and with the rich clinical and social information it contains, it presents a valuable opportunity for NCMD to explore the effect of social deprivation on child mortality using a reliable source of all child deaths in England for 2019/20.

Anonymised vignettes are included in this report. They describe real children and families, but some of their details have been modified to protect their identity.



2. Quantitative analysis of NCMD data

2.1. How to read this section

This work aims to calculate the number (n) of children in each category of deprivation (each decile), and then calculate their risk of dying over the 2019/20 year, 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. The analysis then tests if any differences 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 the exposure (in this case, deprivation) was not present. The median interquartile ranges (IQR) are also included showing the middle value of the deprivation deciles.

Strong evidence that the number of deaths increased with increasing levels of deprivation

2.2. How we carried out this work

Aim

The aim of this work was to identify, and quantify, any association between measures of deprivation and childhood mortality in the data reported to the National Child Mortality Database (NCMD) over the 2019/20 year. Data was downloaded from NCMD on 30th September 2020 and included deaths which occurred, or were reviewed by, a Child Death Overview Panel (CDOP) between 1st April 2019 and 31st March 2020.

Cohorts

The main analysis was based on deaths occurring between 1st April 2019 and the 31st March 2020, for which NCMD has complete coverage. A comparison between the number of deaths notified to NCMD and those reported by ONS from the death registrations was performed, with more complete coverage of all deaths in 2019 than the corresponding ONS data.

This is likely due to the fact that deaths are reported to NCMD within 48 hrs, while death registration takes a long time in some cases (e.g., undergoing coroner's investigation or inquests). The main analysis was therefore based on deaths occurring from 1st April 2019 up to 31st March 2020 for which NCMD has complete coverage; however, not all of these deaths will have had a review completed by a CDOP. This is because it can take several months for the review to take place, for instance in sudden, unexpected deaths, requiring investigation by the coroner. In addition to deaths occurring during the year, a second cohort was identified which included deaths that were reviewed by a CDOP between 1st April 2019 and 31st March 2020 as more detailed information including category of death is available once the CDOP review is complete. The deaths included in this cohort occurred at any time before 31st March 2020. All analyses were repeated on this second cohort. For clarity, these cohorts are referred to throughout this report as "Cohort 1: Reported deaths" and "Cohort 2: Reviewed deaths". Due to this temporal difference in completing reviews of complex and sudden unexpected deaths, their relative contribution is expected to be different between Cohorts 1 and 2.

Measurement of deprivation

Using the residential address of the child as recorded in the NCMD, each household was linked to its corresponding English indices of deprivation (2019), which is calculated using 7 main domains (income, employment, education, health (physical and mental health), crime, access to housing and services, and living environment) and is calculated down to the scale of around 1,500 people.¹⁴ Each area is then placed in one of 10 deciles, containing approximately the same number of people across England, with increasing measures of deprivation (a common approach for work using the indices, and recommended for most research (<https://www.gov.uk/government/statistics/english-indices-of-deprivation-2019>)). For this work, deciles were coded with 1 being the least, and 10 the most deprived.

Additional datasets

Two further sources of data were linked using the smallest geographic level of the deprivation index (the Lower Super Output Area (LSOA)).

- Lower Layer Super Output Area population estimates mid-2019: Population estimates of age and gender are available from ONS, estimating the number of male and female children for each year of age in each LSOA¹⁵
- Classification of each LSOA into either Rural (Rural town and fringe, Rural village) or Urban (Urban city and town, Urban major conurbation)¹⁶

¹⁴ McLennan et al, 2019

¹⁵ Lower layer Super Output Area population estimates (supporting information). 2020

¹⁶ Rural Urban Classification (2011) of Lower Layer Super Output Areas in England and Wales. 2018

Exploratory variables

For the primary exploratory analysis, variables included were:

- Age at death, categorised as <1 year, 1-4 years, 5-9 years, 10-14 years and 15-17 years
- Sex (male, female, or data missing)
- Area of residence (urban or rural)

Additional data from child death review process

- Ethnic group was recorded by the CDOP teams with a range of possible replies and categorised for the analysis as White, Black, Asian, Mixed or Other. These categories reflect those that are used in the [child death notification form](#), where data on ethnic group is collected.
- The CDOP is responsible for identifying any modifiable factors in relation to the child's death. Modifiable factors are those which may have contributed to the death of the child and which might, by means of a locally or nationally achievable intervention, be modified to reduce the risk of future deaths.
- Data on whether modifiable factors were identified, were available for deaths that had been reviewed by a CDOP, however, the details of such factors were only required to be collected as part of the child death review process from 1st April 2019 onwards. Therefore, it was only possible to analyse the details of the modifiable factors in a subset of Cohort 2. Modifiable factors were categorised as:
 - » Factors Intrinsic to the Child: Behavioural factor, emotional factor, clinical condition, mental health condition, developmental disorder, other.
 - » Factors in the Social Environment: Safeguarding factor, behavioural factor/clinical condition/mental health condition/developmental disorder in a significant person in the child's life, family/cultural factor, other.
 - » Factors in the Physical Environment: Household safety, public safety, vehicle or transport factor, other.
 - » Factors in Service Provision: Organisational factors (education, communication, equipment, environment), human factors, local and national commissioning, other.
- Category of death was available for any deaths which had been reviewed by a CDOP (definitions for each category can be found in [the child death review analysis form](#)). Due to small numbers in many groups and to aid interpretation, categories were grouped as:
 - » Trauma and suicide: Including deaths caused by deliberately inflicted injury, abuse, or neglect, external trauma (such as traffic accidents) and suicide or deliberate self-inflicted harm. Of note, the trauma category is broad for pragmatic reasons (e.g. small numbers and the lack of intent in some accidental deaths) and so any interpretation of possible causal pathways should be cautious

- » Malignancy
- » Medical condition: Acute medical or surgical condition; Chronic medical condition; Infection
- » Congenital anomalies: Chromosomal, genetic and congenital anomalies
- » Perinatal: Perinatal/neonatal event
- » Sudden unexpected, unexplained death (SUDIC)

Analysis

Initially the research population was reviewed, and demographics summarised. The percentage of deaths by each deprivation decile was calculated in total, and by the recorded category of death, along with summary median and interquartile range. Evidence of a difference between the deprivation measure, and evidence of any trend in proportions by increasing deprivation decile were tested using a nonparametric test for trend across ordered groups.¹⁷ The proportion of children with modifiable factors identified in the review, by deprivation decile, was also derived.

A total of 3,347 childhood deaths that occurred between April 2019 and March 2020 were reported to the NCMD

Due to the distribution of children and their demographics being unequal across deprivation deciles, to test if death rate was changing by decile, Poisson regression models were used to estimate the relative risk of death for each increasing decile of deprivation. The population distribution of demographic factors was derived using ONS data for each LSOA resulting in a dataset with the predicted numbers of children at each age, sex and rural area. The risk of death was then derived using a Poisson regression model, to estimate the relative risk of death for each decile of deprivation. The model was then repeated, additionally adjusting for the other known underlying population characteristics (sex, age and area) of each LSOA; and then repeated for each reported category of death individually. Next, for all deaths, the relative risk for those children in the lowest vs the highest 5 deciles, adjusting for sex, age and rural / urban area was derived. The latter estimates were used to derive the population attributable risk fraction for children living in the most deprived 5 deciles. Due to rapid changes in which infants around borderline viable gestations may be defined as stillbirths (and hence not reported to the NCMD) or alive, but too preterm to survive⁸, the analysis was repeated excluding all those children who died in the first, or second day of life. Finally, the main regression model was repeated, using a measure more specific to childhood deprivation ([Income Deprivation Affecting Children Index \(IDACI\)](#)).

17 Cuzick, 1985

2.3. What we found

Cohorts investigated

Cohort 1: Reported deaths. A total of 3,347 childhood deaths that occurred between April 2019 and March 2020 were reported to the NCMD, of which 3,227 (96.4%) were successfully linked to deprivation deciles (Table 1).

Table 1. Characteristics of the populations investigated

Characteristics	N*	Cohort 1: Reported deaths in 2019/2020 n** (%)	N	Cohort 2: Reviewed deaths in 2019/2020 n (%)
All Deaths	3227		2688	
Categories of death known	1363 (42.2%)		2688 (100%)	
Medical/surgical		232 (17.0%)		477 (17.7%)
Congenital anomalies		373 (27.4%)		665 (24.7%)
Trauma and suicide		73 (5.4%)		279 (10.4%)
Malignancy		136 (10.0%)		210 (7.8%)
SUDIC		68 (5.0%)		212 (7.9%)
Perinatal/neonatal event		481 (35.3%)		845 (31.4%)
Category of death unknown	1864 (57.8%)		0 (0%)	
Modifiable factors identified	1500	395 (26.3%)	2688	842 (31.3%)
Year of death, median (range)		2019 (2019-2020)		2018 (2012-2020)
Age of death	3227		2688	
<1 year		2033 (63.0%)		1675 (62.3%)
1-4 Years		377 (11.7%)		322 (12.0%)
5-9 Years		232 (7.2%)		211 (7.8%)
10-14 Years		267 (8.3%)		227 (8.4%)
15-17 Years		318 (9.9%)		253 (9.4%)
Sex	3188		2670	
Male		1802 (56.5%)		1505 (56.4%)
Female		1386 (43.5%)		1165 (43.6%)
Area	3227		2688	
Rural		395 (12.2%)		328 (12.2%)
Urban		2832 (87.8%)		2360 (87.8%)
Ethnicity	2563		2390	
White		1589 (62.0%)		1554 (65.0%)
Asian or British Asian		481 (18.8%)		427 (17.9%)
Black or British Black		226 (8.8%)		188 (7.9%)
Mixed		171 (6.7%)		136 (5.7%)
Other		96 (3.7%)		85 (3.6%)

*N=denominator; **n=numerator.

Percentages may not add up to 100% due to rounding.

The most common age at death was less than 1 year (63.0%) and more boys than girls died (56.5% vs 43.5% respectively). The majority of children lived in areas defined as urban (87.8%) and most were of a white ethnic background (62.0%). As not all of these deaths had yet been reviewed by a CDOP, the category of death was not available for the majority of children (57.8%), but where it was available, perinatal/neonatal event (35.3%) was the most common category.

Cohort 2: Reviewed deaths. A total of 2,738 deaths among children were reviewed by a CDOP during the year, of which 2,688 (98.2%) were linked to deprivation deciles. Although these deaths were reviewed by a CDOP in the year from 1st April 2019 to 31st March 2020, the actual year of death ranged from 2012 to 2020, with a median year of death of 2018. All deaths reviewed had a category of death allocated, of which the most common was a perinatal/neonatal event (31.4%).

The demographic characteristics between the two cohorts were similar. Modifiable factors were identified in 26.3% of Cohort 1, and in 31.3% of Cohort 2.

Cohort 1: Reported deaths – deaths that occurred between April 2019 and March 2020

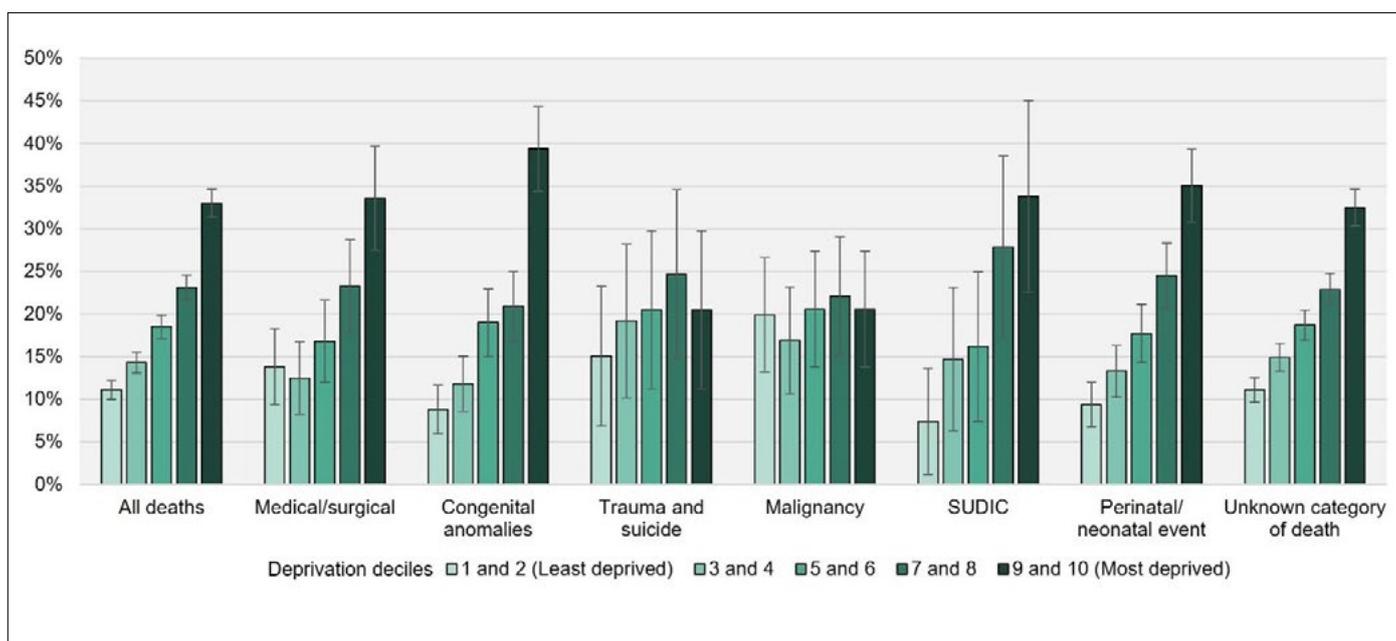
Deaths were more common among children living in the most deprived areas with a median decile of deprivation of 7 (IQR 4-9) (Table 2). There was strong evidence that the number of deaths increased with increasing levels of deprivation ($p=0.003$). This was similar for all categories of death, except trauma and suicide ($p=0.174$) and malignancy ($p=0.296$), although likely due to smaller numbers, a straight gradient across all deciles is less clear for some of the other categories (e.g., Medical/surgical) (Figure 1). There was also strong evidence that the proportion of deaths, where a modifiable factor was identified, increased with increasing deprivation ($p=0.004$) (Table 2).

Table 2. Category of death and modifiable factors by deprivation in Cohort 1: Reported deaths in 2019/2020

Measure	Deprivation Decile						P _{trend} *
	1 and 2	3 and 4	5 and 6	7 and 8	9 and 10	Median (IQR)	
All deaths	359 (11.1%)	461 (14.3%)	597 (18.5%)	744 (23.1%)	1066 (33.0%)	7 (4-9)	0.003
Medical/surgical	32 (13.8%)	29 (12.5%)	39 (16.8%)	54 (23.3%)	78 (33.6%)	7 (4-7)	0.014
Congenital anomalies	33 (8.8%)	44 (11.8%)	71 (19.0%)	78 (20.9%)	147 (39.4%)	7 (5-9)	0.003
Trauma and suicide	11 (15.1%)	14 (19.2%)	15 (20.5%)	18 (24.7%)	15 (20.5%)	5 (3-7)	0.174
Malignancy	27 (19.9%)	23 (16.9%)	28 (20.6%)	30 (22.1%)	28 (20.6%)	5 (2-7)	0.296
SUDIC	5 (7.4%)	10 (14.7%)	11 (16.2%)	19 (27.9%)	23 (33.8%)	6 (3-8)	0.014
Perinatal/neonatal event	45 (9.4%)	64 (13.3%)	85 (17.7%)	118 (24.5%)	169 (35.1%)	7 (4-9)	0.003
Not yet reviewed/unknown	206 (11.1%)	277 (14.9%)	348 (18.7%)	427 (22.9%)	606 (32.5%)	7 (4-9)	0.003
Modifiable factors							0.004
No	119 (74.8%)	163 (79.1%)	225 (80.1%)	249 (70.7%)	349 (69.5%)	7 (4-9)	
Yes	40 (25.2%)	43 (20.9%)	56 (19.9%)	103 (29.3%)	153 (30.5%)	8 (5-9)	

*Nonparametric test for trend across ordered groups. Percentages may not add up to 100% due to rounding.

Figure 1. The proportion of deaths in each pair of deprivation deciles for all deaths and across each category of death, including 95% confidence intervals. (Cohort 1)



The number of deaths reported and reviewed, alongside the predicted number of children in each decile¹³, is shown in Table 3. Using this population distribution in a Poisson regression model, on average, there is a relative risk (RR) of 1.10 (95% CI 1.09-1.12) of dying for each increase in the deprivation decile; this means that on average the relative risk of death overall increased by 10% for each increasing decile of deprivation (Table 4). The relative risk of death increased by between 9% (RR 1.09 (95% CI 1.05-1.15)) and 16% (RR 1.16

(95% CI 1.12-1.20)) for deaths from medical/surgical disease, congenital anomalies, SUDIC and perinatal categories, as well as for those currently uncategorised ($p < 0.001$); these results were statistically significant and thus unlikely to be due to chance (Table 4). Adjusting for age, sex and area of residence had no material impact on the findings. There was no evidence of an association between deprivation and relative risk of death by trauma and suicide ($p = 0.452$) and malignancy ($p = 0.671$).

Table 3. Predicted number of children per decile, and number of deaths reported and reviewed in 2019/2020

Deprivation Decile	Predicted Child Population	Number of Deaths Reported	Number of Deaths Reviewed
1	1,116,263	168	125
2	1,094,322	191	168
3	1,080,106	229	198
4	1,073,447	232	185
5	1,119,929	279	224
6	1,135,362	318	252
7	1,180,707	342	315
8	1,294,342	402	329
9	1,376,490	477	370
10	1,487,319	589	522

Figures are total numbers.

Table 4. The relative risk of death for each increase in deprivation decile by category of death in Cohort 1: Reported deaths in 2019/2020

	n	Unadjusted		n	Adjusted*	
		RR 95% CI	p		RR 95% CI	p
All Deaths	3227	1.10 (1.09-1.12)	<0.001	3188	1.09 (1.07-1.10)	<0.001
Category of death						
Medical/surgical	232	1.09 (1.05-1.15)	<0.001	231	1.09 (1.04-1.15)	<0.001
Congenital anomalies	373	1.16 (1.12-1.20)	<0.001	368	1.14 (1.10-1.19)	<0.001
Trauma and suicide	73	1.01 (0.93-1.09)	0.781	73	1.03 (0.95-1.12)	0.452
Malignancy	136	0.98 (0.93-1.04)	0.534	136	0.99 (0.93-1.05)	0.671
SUDIC	68	1.14 (1.04-1.24)	0.003	68	1.13 (1.03-1.24)	0.009
Perinatal/neonatal event	481	1.13 (1.09-1.17)	<0.001	474	1.10 (1.06-1.14)	<0.001
Not yet reviewed/unknown	1864	1.10 (1.08-1.12)	<0.001	1838	1.08 (1.07-1.10)	<0.001

* Adjusted for age, sex and rural profile.

Estimating the risk of death (adjusted for age, sex and area), and comparing the risk of death in the most deprived 5 deciles, versus the 5 least deprived, gave compatible results to the main analysis (RR 1.51 (95% CI (1.40-1.63)) with a population attributable risk fraction of 22.2% (95% CI 18.3%-26.0%). A total of 752 of the deaths in Cohort 1 occurred on the first or second day of life; excluding these gave compatible results with the main analysis in both the unadjusted (n=2475; RR 1.10 (1.08-1.11)) and adjusted (n=2462; RR 1.09 (1.07-1.11)) analyses. Repeating the analysis using the Income Deprivation Affecting Children Index (IDACI) gave compatible results to the main analysis (RR 1.08 (1.06-1.09)).

Cohort 2: Reviewed deaths – deaths that were reviewed by a CDOP between April 2019 and March 2020

Repeating the analysis for all children who had a completed death review between April 2019 and March 2020 gave mostly similar results to the first analysis. Similar to the first cohort, there was also strong evidence that the proportion of deaths where a modifiable contributory factor was identified increased with increasing deprivation (p=0.003) (Table 5).

Table 5. Category of death and modifiable factors by deprivation in Cohort 2: Reviewed deaths in 2019/2020

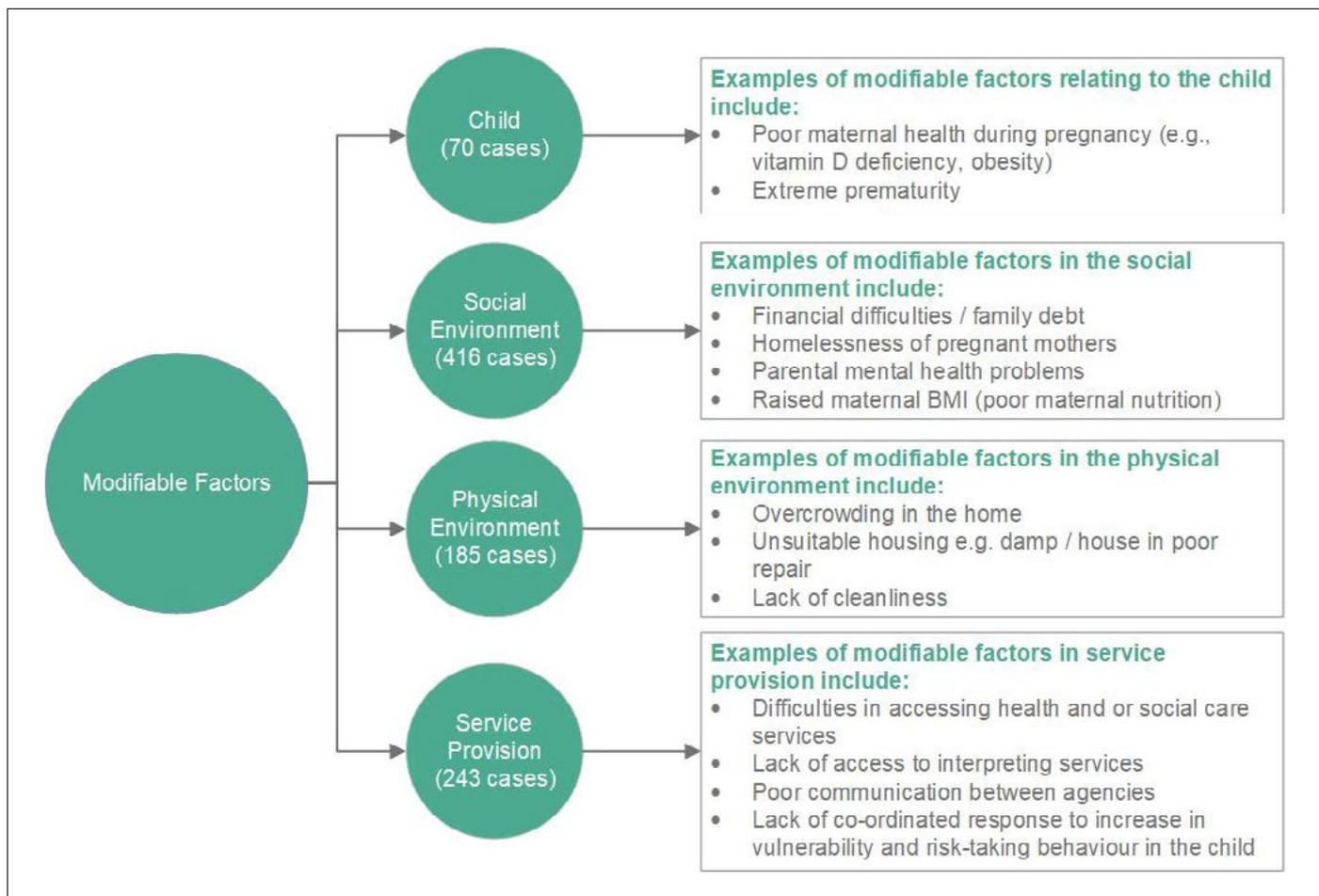
Measure	Deprivation Decile						p _{trend} *
	1 and 2	3 and 4	5 and 6	7 and 8	9 and 10	Median (IQR)	
All deaths	293 (10.9%)	383 (14.2%)	476 (17.7%)	644 (24.0%)	892 (33.2%)	7 (4-9)	0.003
Medical/surgical	60 (12.6%)	61 (12.8%)	83 (17.4%)	131 (27.5%)	142 (29.8%)	7 (4-9)	0.006
Congenital anomalies	60 (9.0%)	71 (10.7%)	117 (17.6%)	147 (22.1%)	270 (40.6%)	7 (5-9)	0.003
Trauma and suicide	44 (15.8%)	52 (18.6%)	38 (13.6%)	59 (21.1%)	86 (30.8%)	6 (3-9)	0.074
Malignancy	38 (18.1%)	41 (19.5%)	42 (20.0%)	36 (17.1%)	53 (25.2%)	5 (3-8)	0.326
SUDIC	17 (8.0%)	30 (14.2%)	44 (20.8%)	48 (22.6%)	73 (34.4%)	7 (4-9)	0.006
Perinatal/neonatal event	74 (8.8%)	128 (15.1%)	152 (18.0%)	223 (26.4%)	268 (31.7%)	7 (4-9)	<0.001
Not yet reviewed/unknown	-	-	-	-	-	-	
Modifiable factors							0.003
No	222 (75.8%)	269 (70.2%)	351 (73.7%)	425 (66.0%)	579 (64.9%)	7 (4-9)	
Yes	71 (24.2%)	114 (29.8%)	125 (26.3%)	219 (34.0%)	313 (35.1%)	8 (5-9)	

*Nonparametric test for trend across ordered groups.
Percentages may not add up to 100% due to rounding.

Of the 842 deaths where modifiable factors were identified, details were recorded in 686 cases (examples given in Figure 2). Of these, 416 deaths had at least one modifiable factor identified in “Factors in the Social Environment”, and these were more common with increasing deprivation ($p=0.004$).

In addition, 70 deaths had at least one modifiable factor identified in “Factors Intrinsic to the Child” ($p_{trend}=0.237$), 185 with “Factors in the Physical Environment” ($p_{trend}=0.009$), and 243 with “Factors in Service Provision” ($p_{trend}=0.007$).

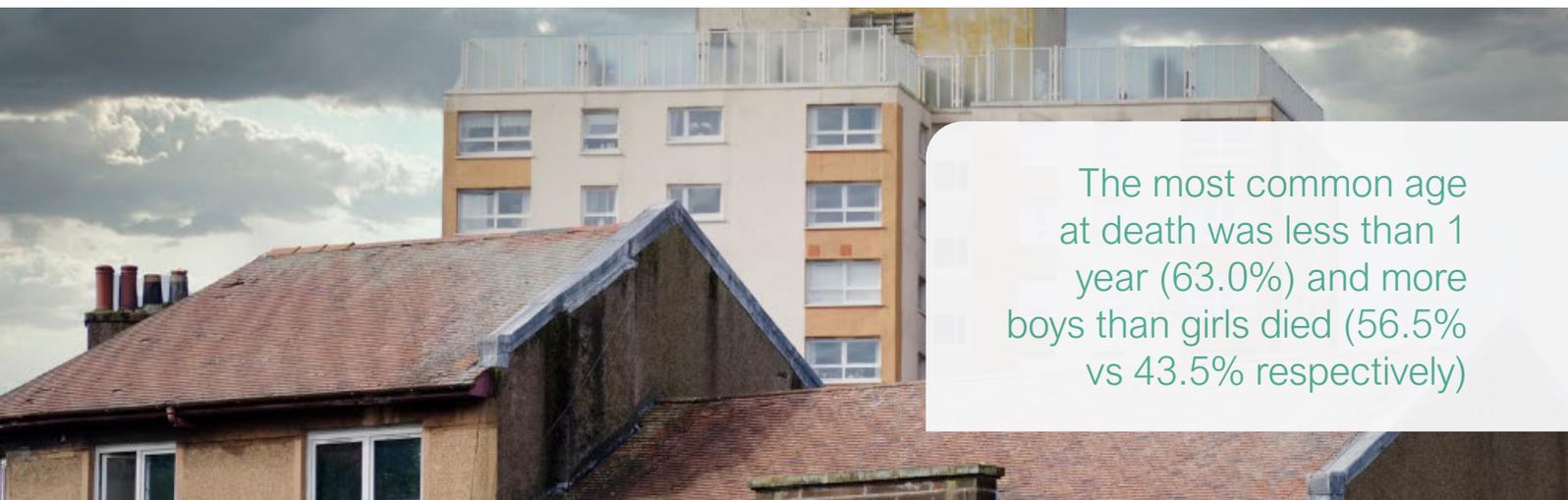
Figure 2. Numbers and examples of modifiable factors identified in Cohort 2



N.B. The number of cases presented in the figure does not sum to total number of cases reported due to some cases having a modifiable factor in more than one category.

The regression models also produced similar results, although in this second cohort with the larger numbers in this group we were also able to identify a significant 7% increase in the relative risk of death by trauma or suicide for each unit

increase in deprivation decile (Adjusted RR 1.07 (1.03-1.12), $p=0.002$) (Table 6). The result for deaths from malignancy was essentially unchanged.



The most common age at death was less than 1 year (63.0%) and more boys than girls died (56.5% vs 43.5% respectively)

Table 6. The relative risk of death for each increase in deprivation decile by category of death in Cohort 2: Reviewed deaths in 2019/2020

Reviewed		Unadjusted			Adjusted*	
	n	RR 95% CI	p	n	RR 95% CI	p
All deaths	2688	1.11 (1.09-1.12)	<0.001	2670	1.09 (1.08-1.11)	<0.001
Category of death						
Medical/surgical	477	1.09 (1.06-1.13)	<0.001	476	1.09 (1.06-1.13)	<0.001
Congenital anomalies	665	1.17 (1.14-1.21)	<0.001	658	1.15 (1.12-1.19)	<0.001
Trauma and suicide	279	1.05 (1.01-1.10)	0.012	279	1.07 (1.03-1.12)	0.002
Malignancy	210	1.00 (0.95-1.04)	0.868	210	1.00 (0.96-1.05)	0.914
SUDIC	212	1.13 (1.08-1.19)	<0.001	211	1.10 (1.05-1.16)	<0.001
Perinatal/neonatal event	845	1.11 (1.09-1.14)	<0.001	836	1.08 (1.05-1.11)	<0.001
Unknown	0	-		0	-	

* Adjusted for age, sex and rural profile.

Estimating the risk of death (adjusted for age, sex and area), and comparing the risk of death in the most deprived 5 deciles, versus the 5 least, gave compatible results to the main analysis (RR 1.54 (95% CI 1.41-1.67)); with a population attributable risk fraction of 23.1% (95% CI 19.0%-27.2%).

Over a fifth of all child deaths might be avoided if children living in the most deprived areas had the same mortality risk as those living in the least deprived

2.4. Summary of this section

There is an overall clear gradient of increasing childhood mortality at all ages by increasing deprivation in England, which is not explained by sex, age or rural/urban location. The only exception to this is deaths from malignancy, which show little evidence of any relationship with deprivation. The proportion of deaths with identified modifiable factors also increased with increasing deprivation; with factors relating to the social environment being the most numerous reported. Over a fifth of all child deaths (23%) might be avoided if children who are among the most deprived half of the population had the same mortality risk as the least deprived. This translates to over 700 fewer children dying per year.



3. Qualitative, thematic analysis of completed child death reviews

3.1. How we carried out this work

Rationale

The circumstances explaining a child's death are often extremely complex, and the CDOP review process involves compiling an extensive qualitative dataset, including factors that may have contributed to the child's ill-health, vulnerability or death. Which of those contributory factors are identified by the CDOP as modifiable then influences the learning points and recommendations for actions. In addition, quantitative analysis linking up postcode data to indices of deprivation scores has the limitation of not bringing to light the fact that there may be people experiencing social deprivation even if they live in overall less deprived areas. Qualitative research is therefore an essential complement to the quantitative analysis presented in the first section of this report. An initial review of the free text information was carried out for Cohort 2 (n=2,738) to identify the deaths with potential factors related to deprivation. The current child death review data collection forms do not have specific questions related to deprivation to allow for a more complete and structured analysis of this information. Therefore, a method was developed to carry out an initial review of this information. The aim was to gain a better understanding of the specific circumstances and deprivation related factors that the child may have experienced during their life and of the potential links between these and the chain of events that led to each child's death.

Method

The CDR data collection forms do not directly ask whether there were any specific factors, either present, or contributory and / or modifiable relating to poverty and social deprivation. Therefore, the NCMD team were reliant on the CDOPs offering this information through free text fields on the forms. A search was performed looking for key words relating to deprivation from the CDOP reports to enable a thematic analysis of the circumstances of a child's death. Key words were agreed initially through discussions with CDOP colleagues, the NCMD deprivation report working group and from information in the literature. The key words used were: *poverty, deprivation, overcrowding, foodbank, hardship, destitution, malnutrition, starvation, free school meals, working tax credit, universal credit, financial support, housing, accommodation issues (living in shelter and other temporary places), delays in benefits, homelessness, unemployment, debt, vulnerability*. These words were used to search the database to identify all deaths in which one or more of these key terms were mentioned in the record. From the initial extract, based on these search terms, 212 deaths were returned, and these data were then validated. This validation was achieved by reviewing the deaths in which key terms were identified and establishing whether the terms were used in the context of deprivation.



The 212 deaths were further grouped into the following themes:

- Family debt
- Financial issues
- Free school meals
- Government benefits
- Homelessness
- Housing
- Low income
- Malnutrition
- Overcrowding
- Unemployment
- Vulnerability

The next step was to further analyse these data by introducing the additional search terms: *delay, recommendation, action* and *improvement* to assess whether there were any potentially more direct links between deaths where deprivation was present and the outcome.

At least 1 in 12 of all child deaths reviewed in 2019/20 had one or more factors related to deprivation identified at review

All details of the babies and children reported here are fully anonymised; all identifiers have been changed and some other key details, that may enable identification, have either been removed or changed. However, the descriptions here relate to real people and their lived experiences.

3.2. What we found

The initial analysis demonstrated that approximately 8% (212/2,738) of all child deaths reviewed in 2019/20 had at least one factor related to deprivation present in the detailed information from the record. In other words, 1 in 12 children had experienced one or more factors related to deprivation during their life as noted in the circumstances relating to their death.

One of the main themes identified in these 212 death records was housing issues, with the most common concerns being *lack of cleanliness*, *unsuitable accommodation* (e.g., *overcrowding*) and *maintenance issues* (e.g., *damp/mould or house being in poor repair*). There were 123 deaths where a housing issue was identified. This also included families being based in temporary accommodation, or frequently moving to a new house, creating an unstable living environment for the child.

There were also 33 babies and children in which homelessness was specifically mentioned, either related to the father, mother, or child. Factors which contributed to homelessness were mental health conditions in a parent or caregiver (15/33) and financial issues (13/33), and in some instances both factors were present (5/33). Homelessness most commonly affected pregnant mothers, who went on to give birth to babies who subsequently died, families with young children, and young people having left or been forced out of their family home.

Another common factor associated with housing issues was overcrowding. There were instances noted where residents significantly outnumbered bedrooms frequently leading to unsuitable and unsafe sleeping arrangements, particularly for babies.

Family debts and financial problems were also identified as common themes relating to deprivation. In some cases, family debt had a considerable impact.

Cohort 2 also included deaths of children with chronic health conditions, complex needs and learning disabilities. Review of these child deaths showed that families experienced gaps and difficulties in accessing services, preventing the child from receiving the correct equipment, housing, or financial support. This is particularly evident in the death of Samayra below, where the CDOP affirmed the following learning point: “Poor housing - the importance of suitable housing for children with additional needs, and for housing [representative] to be invited and to attend multi-agency meetings so that housing needs can be reviewed in relation to the impact of health needs and impact on life expectancy”.

3.3. Limitations

The main limitation of this analysis is that this is not an exhaustive list of all the deaths where deprivation may be present as it is based on the key words used in the search criteria being recorded in the record submitted to NCMD. As such, the figures in the results and conclusions section above, are likely to represent the minimum number of deaths where these factors were present. However, this approach allowed us to identify some of the individual stories presented here and to inform work on further refining the national data collection. For instance, the NCMD team will be working on improving future data collection to include more specific questions on factors related to poverty and deprivation in the child’s life. In addition, we noted that there was no specific focus on mental health related issues (known to be related to deprivation factors e.g. [housing](#)) as identified in the reviews of these cases and this warrants further work.

Samayra

Samayra was primary school aged when she died from a chronic health condition. She had complex health needs and required full time care from Mum together with input from a number of agencies over the years. She was able to attend a special school where she was very much part of the school community and she also had support from social services. She had all relevant equipment and therapy plans in place to promote independence and function.

Mum was a single parent, she coped very well but was unable to work due to her own health problems and Samayra’s care requirements and relied on benefits to manage. They had experienced long-term housing issues. When Samayra was born, they were in a first-floor council flat with steep stairs. They were moved to a small ground floor flat when Samayra’s problems and needs became evident but were once again waiting to move to housing that better met Samayra’s accessibility and care needs. The property was not wheelchair accessible and the doorways were not wide enough to accommodate Samayra’s equipment, including her wheelchair, within the home, which meant that her wheelchair and other equipment had to be kept outside the flat in a communal hallway. Samayra required hoisting but due to the lack of space in the flat, hoisting could only be provided in the bedroom and Mum had to carry Samayra round the rest of the flat. The bathroom was also not suitable for her needs. The local area was not wheelchair friendly and this impacted on Samayra accessing the community and attending appointments.

Interpretation and action

CDOP felt this child’s quality of life and that of her mother was affected by her poor housing. Although professionals wrote in support of the house move, the housing team was not included in multi-agency meetings and it is unclear if they understood the impact the poor housing had on Samayra’s life and that of her mother. The housing team were invited to meet with CDOP to discuss these issues and to set up a process to ensure they are invited to future multi-agency meetings where there is an unmet housing need.

4. Exemplar case studies from Child Death Overview Panels

Child Death Overview Panels (CDOPs) were invited to put forward examples of projects that were developed out of CDOP recommendations and local learning, focused on reducing modifiable factors around social deprivation. These exemplar case studies are important to highlight the value of CDOPs in influencing changes in local and regional policies. While it is too early to measure impact in changes in mortality from the national data collection, the processes are now in place and as a result of the CDOPs' work, outcomes are monitored and reported to enable wider system learning and national policies.

4.1. Reducing infant mortality – Manchester CDOP *Manchester reducing infant mortality strategy (2019 - 2024)*

Summary

The Manchester Reducing Infant Mortality Strategy (2019-2024) provides information on current trends, patterns and risk factors associated with infant mortality in Manchester. It highlights a picture of infant mortality rates increasing since 2011-13 following a long period of year-on-year reductions.

Background

Infant mortality is an indicator of the overall health of a population. It reflects the relationship between the causes of infant mortality and upstream determinants of population health such as economic, social and environmental conditions. In order to try to reverse the trends in infant mortality rates in Manchester and ensure that those who experience baby loss get the support they need a multi-agency strategy was implemented.

The work to develop the strategy was led by the Manchester Population Health and Wellbeing Team who established a multi-agency steering group to oversee the implementation of the strategy. The steering group included key partners with a role to play in the delivery of the strategy and influencing others including maternity services, health visiting services, strategic housing, early help, early years, Child Death Overview Panel (CDOP), safeguarding and voluntary, community and social enterprise organisations.

The strategy reflects local and national evidence including the experiences of professionals and families in Manchester. It incorporates analysis of trends, data and research relating to infant mortality, locally and nationally including data from the Manchester CDOP, the North West Sector Led Improvement Project on Infant Mortality 2016 and the Maternity Experiences in North Manchester Research.

Aims

The aim of the strategy is to reduce the rates of infant mortality in Manchester, and improve the health and wellbeing of pregnant women, mothers and infants, and to provide compassionate support for families that are bereaved following the loss of a baby.

Objectives

Using five priority themes, objectives and actions were set to reduce infant mortality, improve maternal and infant health, and support those bereaved. Services recognised the complexity and interrelatedness of the work required, and agreed to co-ordinate activities across key areas:

1. Quality, safety and access to services
 - Increase engagement with antenatal services and promote the benefits of antenatal care
 - Appropriate assessment and referral during pregnancy, and support during birth
 - Improve take-up of flu vaccinations for pregnant women
 - Genetic counselling/genetic literacy for individuals and communities with a need
 - Improve access to IVF and raise awareness about the risks of IVF treatment abroad
2. Maternal and infant wellbeing
 - Support women to stop smoking and promote smoke-free homes
 - Support maternal mental health and wellbeing
 - Reduce maternal obesity and improve nutrition
 - Encourage and support breastfeeding
 - Alcohol and substance-misuse support in pregnancy and postnatally
3. Addressing the wider determinants of health
 - Support efforts to reduce and mitigate against poverty (the most important determinant of a child's health)
 - Housing - focus on the private-rented sector to ensure that housing is safe and warm and meets basic standards for mother and baby
 - Identify and address inappropriate environments
 - Working with Homeless Families Services to support vulnerable mothers and infants

4. Safeguarding and keeping children safe from harm
 - Continue to educate on safe sleeping and support those most vulnerable with additional help
 - Help parents to keep a safe home environment
 - Prevent unintentional injuries (e.g., scalds and falls)
 - Reduce the damage of abusive head trauma
 - Support pregnant women/mums experiencing domestic abuse

5. Providing support for those bereaved and affected by baby loss
 - A system-wide approach to making things as easy as possible for bereaved families
 - Increase knowledge about bereavement services to improve signposting
 - Strengthen pathways to ensure people who have had a loss receive enhanced support for their next pregnancy
 - Increase the skills and confidence of the wider workforce to talk about bereavement
 - Minimum standards of care for bereavement support

Launch

To coincide with Safer Sleep Week (March 2019), Manchester Health and Care Commissioning arranged three launch events to enable colleagues to find out more about the strategy and how they could contribute. Events were held in Manchester City Centre, North and South which were aimed at those working in senior roles, managers, operational staff, volunteers and anyone with an interest in reducing infant mortality in Manchester.

Launch events were supported and opened by senior leaders:

- Barry Gillespie, Consultant in Public Health, Chair of the Manchester Child Death Overview Panel
- Councillor Garry Bridges, Executive Member for Children and Schools
- Councillor Sarah Judge, Assistant Executive Member for Skills Culture and Leisure

Each event had good attendance from a range of multi-agency practitioners and engagement from services, with approximately 150 attendees in total.

Outcome

The prevention of infant mortality is delivered through key statutory health and social care services, e.g., maternity services, neonatal units, health visiting, children's social care, as well as public and voluntary services, and society as a whole. There are also a number of established programmes and services directly supporting the strategy:



Manchester Vulnerable Babies Service: This service, provided by Manchester University Foundation Trust, was established in 2004 to address the rising number of sudden infant deaths. It provides targeted case planning to meet the needs of individual families, involving them in their package of support. The service works with and takes referrals from all professionals and volunteers who work with parents and babies.

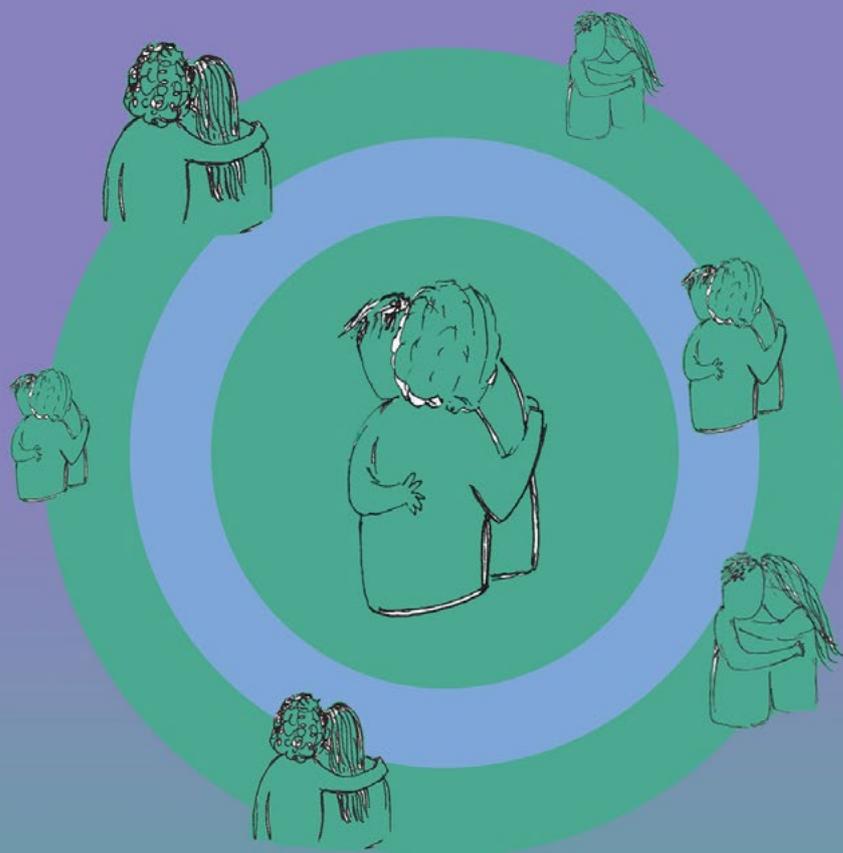
Baby Clear Programme: Baby Clear is a key part of the Greater Manchester Strategy to make smoking a thing of the past. The overall aims of the programme are to reach a target of no more than 6% of women smoking at the time they give birth by 2021, and ultimately for no woman to smoke during her pregnancy. Key programme elements are carbon monoxide (CO) monitoring of all pregnant women at booking (all midwives specially trained), referral to specialist stop smoking support within 24 hours for ongoing support to quit, and a risk-perception interview for those who have not quit at the first scan.

ICON Programme: ICON is a new programme which addresses the damage of abusive head trauma by using a simple four-point message delivered by health professionals through strength-based conversations to parents:

- I** = Infant crying is normal, and it will stop
- C** = Comfort methods can sometimes soothe the baby, and the crying will stop
- O** = it's Okay to walk away if you have checked the baby is safe, and the crying will stop
- N** = Never ever shake or hurt a baby.

Evaluation and monitoring

Focus and priorities are informed in a dynamic way by learning from national and local research, CDOP, and child safeguarding practice reviews. The effectiveness of this approach will be evaluated, and performance/outcomes monitored.



“Following a long period of year-on-year reductions, Manchester has seen a concerning increase in infant mortality and we were determined to halt this trend. Using national and local data, we were able to highlight emerging patterns and trends associated with infant mortality. This five-year strategy is a clear indication of Manchester’s collective commitment to ensuring a reverse in the rise of infant mortality. By co-ordinating efforts across the city, we are confident we can start to see a downward trend once again”

Barry Gillespie
Consultant in Public Health,
Chair of the Manchester Child Death
Overview Panel

4.2. Safer Sleep for Baby Campaign – Accessible for all Blackburn with Darwen, Blackpool and Lancashire CDOP

The Lullaby Trust (2018) tells us more than 200 babies die suddenly and unexpectedly every year in the UK. Over the years there has been a significant reduction in infant deaths largely due to an increase in evidence-based knowledge and practice. Despite this, rates within pan-Lancashire (Blackburn with Darwen, Blackpool & Lancashire) remain high and are consistently higher than the national average.

The Safer Sleep for Baby Campaign was re-launched in 2020 in recognition of the fact that unsafe sleeping arrangements are a feature in a number of sudden and unexpected childhood deaths in Lancashire.

Lancashire is made up of 12 distinct districts. Additionally, there are 2 Unitary Authorities within the geographic region of Lancashire, each diverse and with significant distinct differences, including population, demography, geography, ethnic composition and levels of deprivation.

It was clear from the deaths reviewed by the CDOP, that not all our target audience could understand the publications due to the language used or the way it was written. This was a modifiable factor and it was decided that this needed addressing.

Aims

To ensure the Safer Sleep for Baby Campaign is accessible for all parents and carers across Lancashire and to respond to the unmet need in terms of providing language variations to meet the requirements of those where English was not a first language.

It was also felt that due to the learning difficulties of some parents that a simpler version could be used in partnership with messages given by professionals.

Objectives

To provide resources and materials in the four most used additional languages in Lancashire.

To provide resources and materials to meet the needs of the visually impaired and those who have learning difficulties.

Approach

The tools have been used as a backup resource when working with Asylum Seekers or with parents where English is a second/additional language or there is a learning difficulty.

The information is universally available to families and the languages covered are Polish, Punjabi, Arabic, and Urdu. The approach taken is a multi-agency one so that colleagues in midwifery, early help and health visiting and other services can provide the relevant information at the earliest point.

Planning and delivery

Once funding for the materials had been secured, a small task and finish group convened. The group linked in with the Translation Project Manager at DA Languages who organised for the 6-steps posters to be translated and proofread by a second linguist.

To produce the 'Easy Read' posters the group met with a local Community Engagement Officer who had links to groups in the community. Once we had a draft document, the local officer shared and discussed the new design within local communities and the voluntary group of visually impaired and blind people to make sure the poster met their requirements.

Outcome

Allowing parents to access the information in their own language has meant that there is no room for error in interpretation, in addition to where there is cultural perception of safer sleep i.e. swaddling babies and not having baby with the care giver night or day. The messages were received clearly and the visuals reinforced messages. Where we have been aware that a parent or parents have learning difficulties the "easy read" version has allowed a professional to use this as a follow up to the demonstration and conversation that has taken place. This has provided reinforcement of the messages.

Impact

Although it is difficult to measure impact when a result is prevention, the impact of these interventions was that we have not seen an increase in baby deaths where language or learning difficulty have been identified. This will be monitored through the CDOP data going forwards.

Next steps

The SUDIC Prevention Group have just secured additional funding to expand the range of languages available to parents and carers across Lancashire.

Key messages to take away

Pathways to these versions of the safer sleep materials are in place; this means that wherever possible the families can be supported with understandable resources that meet their needs.

We need to ensure the quality of the data collected as part of the Child Death Review process. This data will help when identifying inequalities and ensure these are pushed through as a priority when statutory partners are planning their considerations going forward. This is particularly important for the diverse Lancashire profile, to gain a better understanding of child deaths locally.

5. Conclusions

This report sets out strong evidence of a persistent relationship between childhood mortality and social deprivation in England; backed up by other published evidence of widespread and consistent associations between poverty, social deprivation, and death. The nature and strength of the association between social conditions and health outcomes merits close examination, in order to make reasoned recommendations. These are questions of transdisciplinary research, not reasonably amenable to testing in a traditional biomedical, clinical, or public health trial. Bradford Hill's criteria for investigating association or causation provides an essential framework to guide our thinking and recommendations for action.¹⁸ The cause of an outcome may be direct or indirect; the crucial question is whether we can influence outcomes by changing environments, including social factors. Bradford Hill sets out a series of criteria to use when a clear association is found, as it is here, when such an association is beyond what might be expected by chance, and how to guide determining that the likeliest explanation is causation and therefore to make recommendations to act. Bradford Hill's first criterion is strength of association.

The data collected and analysed by the NCMD provides a valuable addition to the evidence base needed to inform policies to improve child health and wellbeing

As has been shown in this report, and in countless other research papers and reports, there is a strong association between social deprivation and death. Second, consistency. The association between social deprivation and death has been demonstrated again and again, in diverse countries, populations, and ages.

Third, specificity. There are specific causes of death that are more or less associated with social deprivation, for example in this report we showed that deaths from malignancy are not clearly socially patterned compared with deaths from other causes. However, every other cause of death we examined is clearly related to social deprivation. Biological gradient is another criterion; Figure 1 in our report clearly demonstrates that the risk of death increased for each increasing decile of deprivation. Finally, plausibility and coherence are demonstrated vividly through the findings for the individual deaths which are described in detail. Each account tells a story of complex intertwined risks that led to death.

Bradford Hill's own words, from 1965, sum up the state of knowledge regarding social deprivation and childhood mortality described in this report, and with which we make our recommendations for action. *"All scientific work is incomplete - whether it be observational or experimental. All scientific work is liable to be upset or modified by advancing knowledge. That does not confer upon us a freedom to ignore the knowledge we already have, or to postpone the action that it appears to demand at a given time."*

The NHS Long Term Plan sets out a strong commitment for NHS action to improve prevention through tackling the wider determinants of health, including social deprivation and inequalities. Exploring the effects of deprivation on child mortality highlights important characteristics and learning to help inform national and local government agencies commissioning services for families and children. The NHS has an important role to play in tackling wider factors, along with local authorities, public health, and crucially central government. The data collected and analysed by the NCMD provides a valuable addition to the evidence base needed to inform policies to improve child health and wellbeing.

6. Recommendation

Use the data in this report to develop and monitor the impact of future strategies to reduce social deprivation and inequalities.

Action by: Policy Makers, Public Health Services, Service Planners and Commissioners at local and national level.



¹⁸ Hill, 1965

7. Potential interventions to reduce inequalities

The patterns of mortality seen in this report, along with more detailed information around the deaths (in particular, perceived modifiable factors) helped identify the following priority areas for further work or opportunities for intervention. Our findings point to the need for a cross-government consensus and initiatives to improve child health, wellbeing and survival and ensure best start in life for all children by reducing inequalities.^{19,20} Strong local leadership is vital for an effective cross-agency approach to improve maternity and early years services, reduce child mortality and to ensure that governance arrangements are in place so that local areas can work together to deliver reductions in child mortality.²¹

Child health programmes, such as the [Healthy Child Programme](#) in England, are designed to target services in order to reduce health inequalities. They are universal in reach and targeted in approach. The [Healthy Child Programme 0 to 19](#), led by health visitors, offers a core programme of prevention and health promotion to all families (starting in the antenatal period) and a range of early intervention services for different levels of risk and assessed need. The programme assesses the health and wellbeing of children in the context of the family and the home environment, identifying additional needs and working across services to put the required support into place.

Service coverage needs to be sufficient to enable equitable access and maintenance of a clinically qualified, skilled workforce to protect and promote children's health in a non-stigmatising, family friendly manner. There is also evidence that structured home visiting intervention programmes such as [Flying Start Wales](#), and the [Maternal Early Childhood Sustained Home-visiting \(MECSH\)](#), currently being trialled in some areas of the UK, may also be successful in improving children's outcomes.²² However, with the recent significant changes to the way public health is delivered in England along with an historic 31.8% reduction in health visitors in England's NHS over the last 5 years,²³ reviewed investment in these flagship programmes is likely needed.

Collaboration with children, young people and their parents and carers, is key to the co-production of a cohesive NHSE child health strategy. They require a seamless and integrated healthcare system that is well connected to other support they need; and a system which focuses on prevention and early intervention. Primary prevention services such as parenting support and preparation for parenthood need to be designed so that they match the needs of service users.

Appropriate levers and incentives should be developed and extended to drive improvements in treatment and care for children and young people, alongside a workforce strategy specific to children and young people to ensure professionals have the right knowledge and skills to meet their needs.

¹⁹ Public Health England Strategy, 2020 – 2025

²⁰ Royal College of Paediatrics and Child Health (RCPCH), 2020

²¹ Public Health England, 2015

²² Goldfeld et al, 2018

²³ NHS Digital, 2019

David

David was a young teenager who was involved in a road traffic collision as a pedestrian. He lived in an area without a park or play facilities so had been with a group of friends playing next to a main road. David ran across the road to retrieve something from the carriageway and did not survive the injuries he sustained in the collision.

David lived at home with his family. Both his parents struggled with their mental health and both had received care from mental health services in the past. Neither was employed and the family was living solely on benefits. They lived in council accommodation and had been supported to move to a bigger property due to overcrowding. They had a difficult relationship with their neighbours who had made some complaints about noise.

David struggled to engage at school and had periods of not attending. He struggled to feel that he belonged at the school and he saw school, and teachers within it, as an establishment that should be challenged. He also had some contact with the police. He himself also struggled with his mental health and had reported that he at times felt low and had previously self-harmed.

Interpretation and action

Collectively, the CDOP felt that these features paint a picture of David and his family living in deprived and challenging circumstances with no local facilities for children to play safely. The culmination of these features was thought likely to have contributed to risk-taking behaviour and vulnerability for this young person. There were several points of contact with services where there were missed opportunities to provide constructive support and help for David and his family. The CDOP review of David's death identified this lack of a co-ordinated multi-agency response to provide targeted support for this child as a modifiable factor. Since the review of David's death, a new multi-agency approach to vulnerable young people is now in place with a high level of information sharing, use of risk indicator tools and identification of a lead worker.

Kofi

Kofi died from Sudden Infant Death Syndrome (SIDS). Mum was a single parent with other children to look after who have learning difficulties. Mum had some hearing difficulties, was a smoker and had also had some periods of depression. She suffered from a chronic health condition and was not able to work because of this, so she had to rely on benefits in order to live. The family live in a ground floor council flat. This is a small flat and the older children used the bedrooms while Mum slept in the sitting room on the sofa. Kofi slept in a Moses basket next to the sofa where Mum slept. The house generally showed signs of a family living in poverty with few floor coverings and general poor repair. Mum had moved to the area from elsewhere in the country due to her experience of domestic violence and therefore her family were not nearby and could not easily help to support her. The family had experienced some difficulties with racism and disability discrimination in the area they lived.

Interpretation and action

Poverty, racism, and other forms of marginalisation have been identified as key social drivers of disease and poor overall health ([The Commission on Social Determinants of Health, World Health Organisation, 2018](#)). Poverty is also associated with previously documented risk factors for SIDS in multiple settings, such as lower maternal educational level,⁴³ unmarried status, and younger age.⁴⁴ Socio-economic position is fundamentally linked to health because it provides access to an extensive array of health-promoting resources such as money, information, social support, and network connections. When faced with health risks, individuals with these resources have more opportunities to protect themselves than those constrained by limited resources.⁴⁵

43 Sosnaud, 2017

44 Spencer, Logan, 2004

45 Link, Phelan, 2005

7.1. The social factors of health

The circumstances and environment in which people live have a major effect on their physical and mental health. They can create or block opportunities to make healthy choices. As stated in the [PHE Strategy 2020 to 2025](#) "for most people, the ingredients for a healthy life include a good education, a good job, a decent place to live and friends and family to care for and about. This demands a joined-up approach where all parts of society work together to create inclusive growth and healthier and more productive communities".

Income

Low income is the main measure of social deprivation leading to a range of other deprivations.²⁴ As our study demonstrates, the most deprived children are at a greater risk of dying than the least deprived. Urgent action is needed to respond to this by increasing the generosity of benefits for children, such as child benefit.

As a result of austerity and looking forward to the likely economic impact of the COVID-19 pandemic, people are becoming poorer. Cuts to social security benefits have hit families with children hard. In particular, they are reducing the incomes of the most vulnerable who are at the greater risk of poverty: lone parents, families with babies and young children, larger families, those with a disability, and those in low-paid work.²⁵

Intervention opportunities

- Set and monitor child poverty targets to ensure wealth is distributed fairly to areas of need.¹⁸

- Increase child benefit payments to all families with one or more children as a universal and protective measure that is constant and reliable when other forms of income may vary. Child benefit has lost almost a quarter of its value (23%) over the last 10 years. An increase of £10 per month per child would reduce child poverty by 5%.²⁶

A subsequent focused deprivation analysis of the 2020 and 2021 NCMD data should be considered. It will be even more important to focus on this topic in the context of the expected economic impact of the COVID-19 pandemic.

Housing

Ensure affordable, available, and safe housing for all. Appropriate housing for families with babies and young children is essential to meet basic needs. Unsuitable and poor housing is a recognised risk factor for sudden unexpected death in infancy.²⁷

Intervention opportunities

- Review of housing policies with particular emphasis on families with disabled children.
- Improve communication between housing, health services and social care.
- Social and housing policies should ensure that social networks are maintained. Vulnerable mothers and their children should be kept close to their extended family who provide the main support network.
- Ensure housing services are represented in multi-agency service and care planning meetings and reviews such as [Team Around the Child/Family](#).

24 Cooper, Stewart, 2017

25 Tucker, 2017

26 Sinha, Lee, Bennett et al, 2020

27 Department for Education death in infancy review, 2020

Yasmin

Yasmin died from Sudden Infant Death Syndrome (SIDS). She was from a large extended family who lived together in one home due to housing issues. Due to overcrowding in the home, both parents slept on sofas each with one of their children and this is where Yasmin was when she died. The rest of the family slept upstairs. The property only had an outside toilet. There were no concerns around parenting capacity and the parents engaged well with health services.

Mum was a full-time Mum to her children and Dad was employed. Mum suffered with mental health problems in the past and Dad had been known to misuse alcohol.

Interpretation and action

The CDOP concluded that the issues the family faced with housing were a factor in the outcome for this baby. The family did not have suitable accommodation and the property was overcrowded, which likely led to these dangerous sleeping arrangements. As part of the analysis of this death the CDOP identified learning and took an action to explore alternative messages around risks of co-sleeping on a sofa and other risk factors, which could have more impact and influence behavioural change amongst parents and carers.

Education and childcare

Our findings echo those of the Marmot review ten years ago which recommended that equity be placed at the heart of national decisions about education policy and funding.²⁸

Intervention opportunities

- Further investment in early years education to reduce the attainment gap and improve the long-term productivity of the economy. Invest in high quality early years education and childcare in order to support child development and out of school childcare through extended schools so children can take part in enriching activities and parents are able to work.
- Increase levels of spending on early years and as a minimum meet the Organisation for Economic Cooperation and Development (OECD) average and ensure allocation of funding is proportionately higher for more deprived areas.²⁹
- Improve availability and quality of early years services, including Sure Start and Children's Centres, in all regions of England.
- Ensuring good emotional wellbeing support for all children and young people e.g. by the NHS-funded mental health services and school- or college-based Mental Health Support Teams (NHS Mental Health Implementation Plan 2019/20 – 2023/24).

Nutrition

Optimal nutrition during pregnancy and the early years of a child's life contributes to perinatal health and normal child development. Balanced nutrition during human development is of critical importance for normal growth, physical development as well as later health and wellbeing and for reducing the risks of many chronic diseases. In the UK we know that many women consume poor quality diets, which result on the one hand in nutritional deficiencies and on the other, in overweight and obesity (BMA Board of Science, 2013).

Less healthy diets are more common among women of low educational attainment, and among women who have low incomes and who are food insecure. Mothers living in the most deprived areas have consistently lower rates of initiating and continuing breastfeeding compared to those in the least deprived areas in England.²⁹

Intervention opportunities

- Ensure advice about healthy weight and nutrition and supplementation in pregnancy is targeted to women at higher risk and is accessible. For example, use of social media, video guides, pictorial and translated material.
- Access to good and affordable nutrition for all children via universal free school meals.
- Educating parents and carers around making safe and healthy food choices for their children e.g., early years settings.
- Work with service users to co-create interventions which will meet the needs of local communities.
- Dietary patterns run in families and the diet of babies and young children tends to be similar to that of mothers. It is likely that interventions such as nutrition education in schools, parenting support or early years settings which improve the diets of young women will also lead to improved diets for their children.
- The Healthy Start scheme provides support for eligible women and children through provision of food vouchers and vitamin supplements and needs to be promoted widely.
- Effective implementation of existing national strategies for breastfeeding support³⁰ and healthy weight during childhood.³¹

²⁸ Marmot, 2010

²⁹ RCPCH, 2020

³⁰ RCPCH, 2020

³¹ RCPCH, 2020

Living environment

Several meta-analyses have demonstrated that home safety education and provision of safety equipment helps families make homes safer³² and the creation and maintenance of safe neighbourhoods provides safe environments for children and young people inside and outside their homes.³³

Intervention opportunities

- Enhance joined up working between hospital emergency departments, social care, health visitors, school nurses and General Practitioners so families who would benefit from such advice and provision can be targeted effectively.
- Families with children identified as being at higher risk of injury should receive home safety assessments, advice and referral to safety equipment schemes.³⁴
- Embed educative approaches within existing services such as early help team giving empowering information about safe bath times or a breastfeeding supporter advising about safe sleep.
- Training in injury prevention should be provided for healthcare and early years professionals.³⁵
- Parents and local authorities can be empowered to work with organisations such as [Playing Out](#) to seek Temporary Street Play Orders to give children a safe outdoor place to play³⁶ and implement strategies to improve air quality.
- Improvements to transport links to facilitate better access to services.

Felix

Felix died from an infection in infancy. He lived with his parents and young siblings. They were a warm and loving family with positive relationships between the parents and children. Mum was a full-time Mum and Dad was long-term unemployed, so the family were dependent on benefits. Both parents had difficult and unstable childhoods themselves and had limited parenting skills, but they used the few local community resources available to them. They moved to be closer to Mum's family who were very supportive and helped out. However, they were isolated as they did not have a car and had to rely on very limited public transport or taxis to transport them around day to day. This cost them a great deal of money in getting to and from appointments for their children and led to them being in significant debt. Their home was overcrowded and the conditions they lived in were cluttered. The family had tried to improve things for the children by making some alterations to the home to create separate spaces for the children. The family lived in financial hardship and consequently faced constant insecurity and uncertainty in their lives.

Felix had been unwell for a couple of days before he died. His parents were worried and took him to hospital. The hospital is some distance from their house and involves a 45-minute bus journey. The doctor kept Felix in for a few hours to watch him. His parents were allowed to take him home in the early hours of the morning and with no buses running the family had to get a taxi home. Before they left the hospital, the doctor advised them to return if anything changed or if they were worried. But without the financial resources to pay for another taxi the parents did not return.

Interpretation and action

In this case, Felix was exposed to the impact of his family's poverty experiencing the inequality in access to healthcare services by virtue of not being able to pay for transport. Closer enquiry by the medical and nursing staff should have identified that this family had no easy means, particularly in the middle of the night, of bringing Felix back should his condition deteriorate.

32 Kendrick et al, 2012

33 Korkodilos, 2016

34 NICE, 2010

35 Public Health England, 2018

36 Play England, 2016



7.2. Health and wellbeing

Promoting maternal health and wellbeing has the capacity to prevent ill health and early death by improving maternal health as well as reducing preterm birth and infant mortality. Supporting young people to adopt healthy behaviours that can help to prevent poor health, remains one of the top challenges for the public health system. Despite progress in reducing rates of smoking, it is still the leading cause of premature death in England with a disproportionate impact on low income and vulnerable groups ([PHE strategy 2020-25](#)).

Intervention opportunities

- Provide accessible and tailored to needs education, advice, and support for new mothers / parents around antenatal health, safe sleeping and recognising illness.
- Offer intensive support to those experiencing, or most likely to experience, problems – such as intensive home visiting, preschool education or childcare.³⁷ One of the potential roles for Health Visitors or Family Nurse Partnership practitioners is to identify unsafe environmental conditions and inform housing and social care departments of the needs of families with young infants.
- Implement new models for identifying and supporting pregnant smokers to quit across NHS services ([PHE strategy 2020-25](#), page 22).
- Strengthen the Health Visiting workforce so variability of services across regions does not continue.
- Implement the modernised [Healthy Child Programme](#) that includes screening, immunisation, oral health, reviews of child development and support and guidance in parenting and mental health ([PHE strategy 2020-25](#), page 26).
- Develop healthy places for families that help to reduce inequalities, vulnerability and adversity experienced by children and parents ([PHE strategy 2020-25](#)) e.g., investing in [Children's Centres](#).

Promoting maternal health and wellbeing has the capacity to prevent ill health and early death

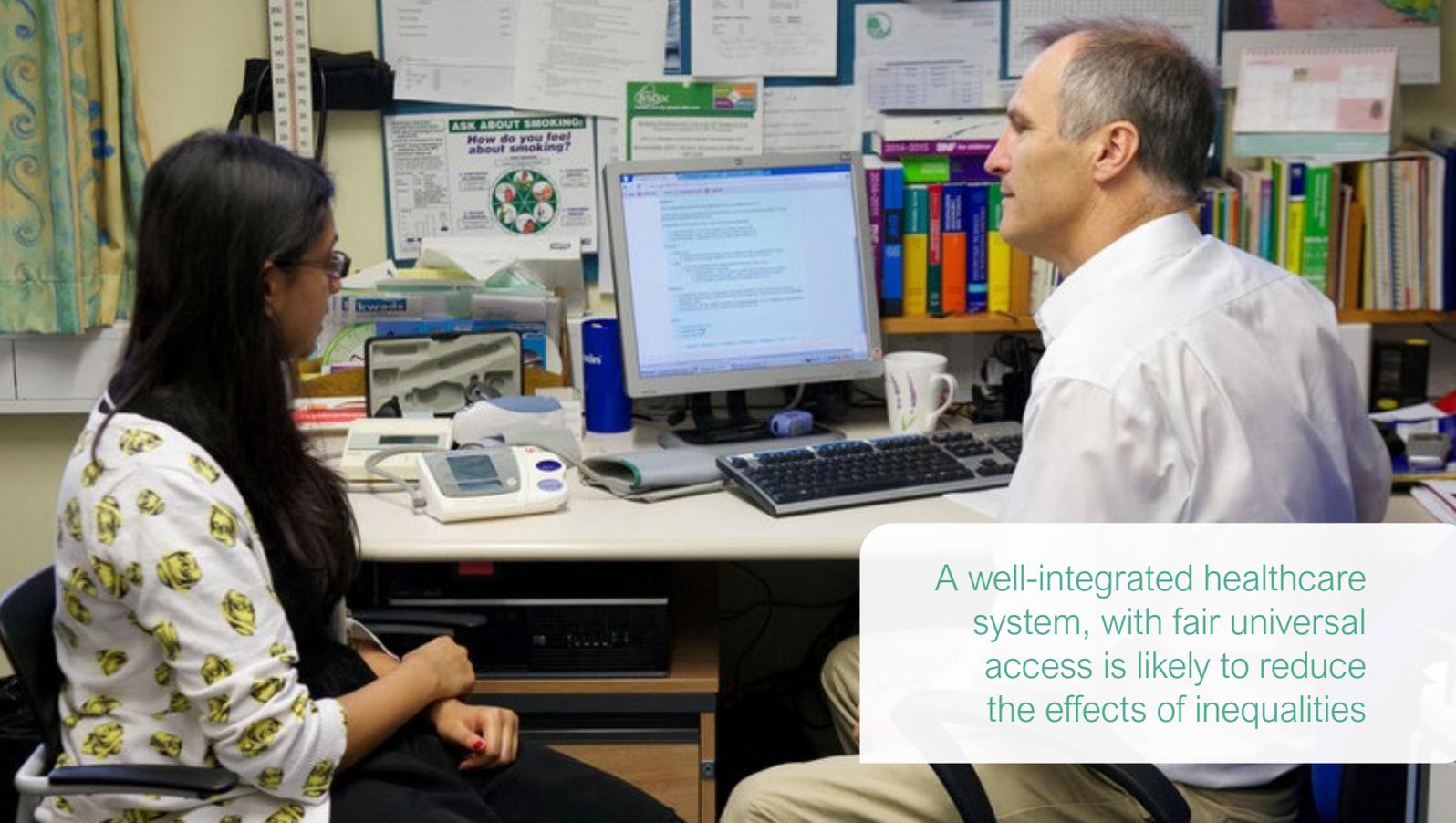
Ruby

Ruby was born extremely prematurely and lived for only a few minutes. Her Mum had experienced several child deaths before Ruby; the babies had all died soon after birth and had been reviewed by the CDOP. For this pregnancy, Ruby's Mum had not booked for antenatal care. Ruby was born at home following a difficult birth with no healthcare professional present. Mum had several risk factors for premature birth including smoking during pregnancy, having had a previous very premature baby, not engaging with maternity services in the past and being socio-economically deprived. She and her partner (Ruby's Dad) had a number of other issues which made them both very vulnerable and social services had been involved with the family for many years.

Interpretation and action

CDOP felt that Mum was an extremely vulnerable adult and agreed to complete an adult safeguarding referral.

³⁷ Scottish Government, 2018



A well-integrated healthcare system, with fair universal access is likely to reduce the effects of inequalities

7.3. Health care services

Development of a well-integrated healthcare system, with fair universal access is likely to reduce the effects of inequalities seen in this report.

The NHS Long Term Plan commits to making sure everyone in England has the best start in life, by improving care for patients over the next 10 years; specific aligned goals are:

- Reducing neonatal deaths by 50%.
- Providing extra support for expectant mothers at risk of premature birth.
- Ensuring most women can benefit from continuity of care through and beyond their pregnancy, targeted towards those who will benefit most.
- Expanding support for perinatal mental health conditions.
- Increasing funding for children and young people’s mental health.

The NHS Long Term Plan sets out a delivery plan by doing things differently: “we will give people more control over their own health and the care they receive, encourage more collaboration between GPs, their teams and community services, as ‘primary care networks’, to increase the services they can provide jointly, and increase the focus on NHS organisations working with their local partners, as ‘Integrated Care Systems’, to plan and deliver services which meet the needs of their communities” and by backing our workforce: “we will continue to increase the NHS workforce, training and recruiting more professionals”.

Primary care

Intervention opportunities

- Further developing partnership and advocacy for families. Support GPs to see the family holistically, to continue working with other health professionals, community services, education and social care for relief and improvements.³⁸
- The “You’re Welcome” criteria³⁹ have been shown to help with young people’s access to GPs while promoting visibility and accessibility of support services for emotional and mental health within schools, addressing issues of stigma by providing confidential and universal services such as clinics with appropriately trained school health nurses.
- Health Visiting: Invest in the Health Visiting workforce to ensure the equitable delivery of the Healthy Child Programme across the country⁴⁰, alongside improving health literacy to improve immunisation uptake and appropriate use of health services such as emergency departments. Ensure health information is provided in an accessible format e.g., plain English, pictorial and translated material and that families in temporary accommodation or who have recently had a change to their living arrangements with a young child are targeted for preventive and supportive health services such as community midwifery and health visiting.

³⁸ Gilbert et al, 2012

³⁹ Department of Health UK Government, 2011

⁴⁰ HM Government, 2021

Jamie

Jamie was born extremely preterm at 24 weeks gestation and died on the day he was born. Mum booked appropriately for this pregnancy under consultant led care as she had a history of substance addiction. She was a smoker and continued to smoke cigarettes during this pregnancy. She reported a past history of mental health problems. Mum and Dad had a difficult relationship with frequent episodes of domestic abuse, including during this pregnancy. Mum reported housing issues and it was documented that she lived in poor conditions.

During this pregnancy there was spontaneous rupture of her membranes at 22 weeks gestation and antibiotics were commenced. She was admitted to hospital for a period of inpatient care one week later and following her discharge home she attended the Day Assessment Unit for regular checks. She was re-admitted with abdominal pain to her local hospital two days before Jamie was born and treated for a suspected urinary tract infection. Preterm labour was suspected and then Jamie was born quite suddenly on the antenatal ward. He was resuscitated after birth by the paediatric team and admitted to their local neonatal unit. He was cold on admission. He was ventilated for severe lung disease and transferred by the regional neonatal transport team to the tertiary level neonatal intensive care unit (NICU). He died within 24 hours due to immature lung disease, infection and severe intraventricular bleeds.

Interpretation and action

Earlier diagnosis of preterm labour might have initiated the antenatal preterm optimisation pathway with timely antenatal steroids and in utero transfer to the network's perinatal centre with a tertiary level NICU. These interventions reduce both mortality and severe intraventricular bleeds in extremely preterm babies, therefore are considered potentially modifiable factors.

Maternal smoking is considered a contributory factor in preterm birth and is potentially modifiable by having access and the support of smoking cessation services.

Secondary care

Overarching policies such as the [NHS Long Term plan](#), which commits to halve neonatal mortality by 2025, will have a significant impact on reducing infant mortality. This, along with other National programmes, and consistent implementation of NHS policy by every NHS Trust / healthcare provider will reduce child mortality. By eliminating variation in the quality of healthcare provision for pregnant mothers, babies and children, between regions and NHS Trusts, equality in access will be assured.

Intervention opportunities

Evidence-based policies/programmes, which require universal implementation across the NHS include:

- Evidence-based action plan in [the Neonatal Critical Care Transformation Review](#). For instance, ensuring the birth of all extremely preterm babies in tertiary level units will reduce neonatal mortality significantly; with one or more additional babies surviving for every 20 mothers transferred into a tertiary unit.⁴¹ In 2019 there was unwarranted regional variation in ensuring the optimal place of birth for every extremely preterm baby ([National Neonatal Audit Report 2019](#)).
- [Saving Babies Lives \(version 2\)](#) care bundle to reduce preterm birth and implement evidence based perinatal optimisation where preterm birth is inevitable. For instance, optimal use of antenatal steroids in preterm birth reduces mortality due to immaturity by 30%.⁴² In 2019, there was both unwarranted hospital level and regional variation in antenatal steroid use for eligible preterm births ([National Neonatal Audit Report 2019](#)).

- [Getting it Right First Time \(GIRFT\)](#) policy for maternity, neonatal and paediatric services. For instance, investing in the workforce in paediatric and neonatal care settings, as highlighted in the [RCPCH GIRFT reports](#).

7.4. Data sharing

Implementing digital developments in child health records, using the infrastructure for real-time data sharing between clinical settings, so that records are more comprehensive, and families only need to tell their stories once. Consider extending this messaging infrastructure to enable data sharing between health, education and social care settings.



41 Helenius et al, 2019

42 Roberts, Brown, Medley et al, 2017

8. Next steps: Enhanced child death review data collection and national analyses

Currently the child death review form contains a free text area where social deprivation related factors are noted if considered by the CDOP review panel. However, there are no specific and prompting questions for possible factors relating to social deprivation, and improvements in collecting these data in a standardised format would assist in more detailed analysis of future deaths. Future NCMD deprivation analyses will need to explore the information collected in the circumstances of death and modifiable factors in greater detail. Feasibly, this is where the richest information to help understand the link between social deprivation, inequalities, adverse childhood events, poverty and child mortality might be found. However, there are challenges in how these data are collected in the child death review process at present.

Specific and structured questions related to social deprivation should be included in the child death review reporting form

To achieve a more systematic collection and analysis of the contributory and modifiable factors, specific and structured questions related to social deprivation should be included in the child death review reporting form. The aim is to provide a prompt in the system to ensure that CDOPs consider poverty and social inequalities as they review the deaths.

Consequently, we recommend:

- Restructuring the order in which the information is collected and recorded in the analysis form to provide the mechanism for a more guided review process of contributory factors. This will reduce the variability in how the modifiable factors are understood and used by the CDOP reviewers, and lead to improved data quality to assist with deeper analyses concerning the circumstances of death and modifiable factors.
- Addition of specific questions about factors mapped to the sub-domains of the English indices of deprivation.
- Additional training and guidance in completing the forms and new domains.

Subsequent focused deprivation analyses by NCMD on the 2020, 2021 and 2022 data should be considered to monitor the impact of system interventions. It will be even more important to focus on this topic in the context of the expected economic impact of the COVID-19 pandemic.

In addition, future thematic reports from NCMD should consider deprivation as a cross-cutting theme and include a focused section on the role and impact of deprivation in their findings.

9. Glossary of terms

CDOP	Child Death Overview Panel
CDR	Child Death Review
Child	Defined as a child aged from 0 up to their 18th birthday, excluding stillbirths and planned terminations of pregnancy carried out within the law
NCMD	National Child Mortality Database
Infant mortality	Defined as deaths that occur in the first year of a child's life
IQR	Interquartile range is the range between the upper quartile (Q3) and the lower quartile (Q1) values in the data
Modifiable factor	Defined as a factor which, by means of nationally or locally achievable interventions, could be modified to reduce the risk of future child deaths
p-value	The probability that there is no true difference despite the numbers that can be seen
p_{trend}	p-value for trend
Population attributable risk fraction	Defined as the proportional reduction in population disease or mortality that would occur if exposure to a risk factor were reduced to an alternative ideal exposure scenario (e.g., no tobacco use)
RR	Relative risk. The relative risk (also known as risk ratio [RR]) is the ratio of risk of an event in one group (e.g., exposed group) versus the risk of the event in the other group (e.g., nonexposed group)
SUDIC	Sudden unexpected, unexplained death in childhood
95% CI	95% confidence interval is a range of numbers where we can be 95% sure the true value lies

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