NCMD

National Child Mortality Database

Knowledge, understanding and learning to improve young lives

NCMD Second Annual Report

Professor Karen Luyt

University of Bristol

National Programme Lead NCMD

@KarenLuyt

The National Child Mortality Database

- Commissioned by HQIP on behalf of NHS England
- Led by University of Bristol in collaboration with partners
- The Lullaby Trust, Sands and Child Bereavement UK are our partner charities
- Started collecting data on 1 April 2019

Our Aim

To collate and analyse information nationally to ensure that deaths are learned from, that learning is widely shared and that actions are taken, locally and nationally, to reduce the number of children who die.

Child Death Reviews

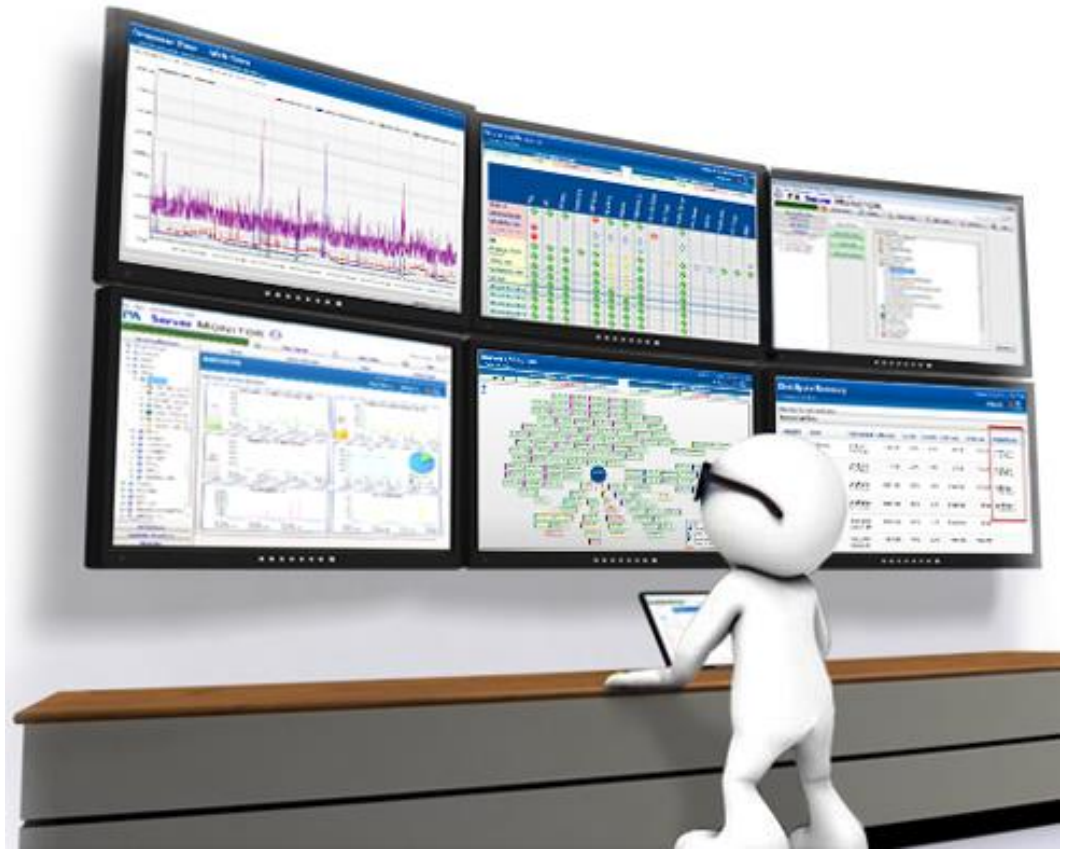
- Child Death Overview Panels (CDOPs) are tasked with reviewing deaths of children resident in their area
- There is a legal requirement to notify deaths to NCMD within 48 hours
- Following this a comprehensive, multi-agency information gathering process is carried out
- Information is collected on statutory forms and includes the views of families

NCMD Analysis

There are two ways in which data is analysed by NCMD. Real-time surveillance and analysis of reviewed data

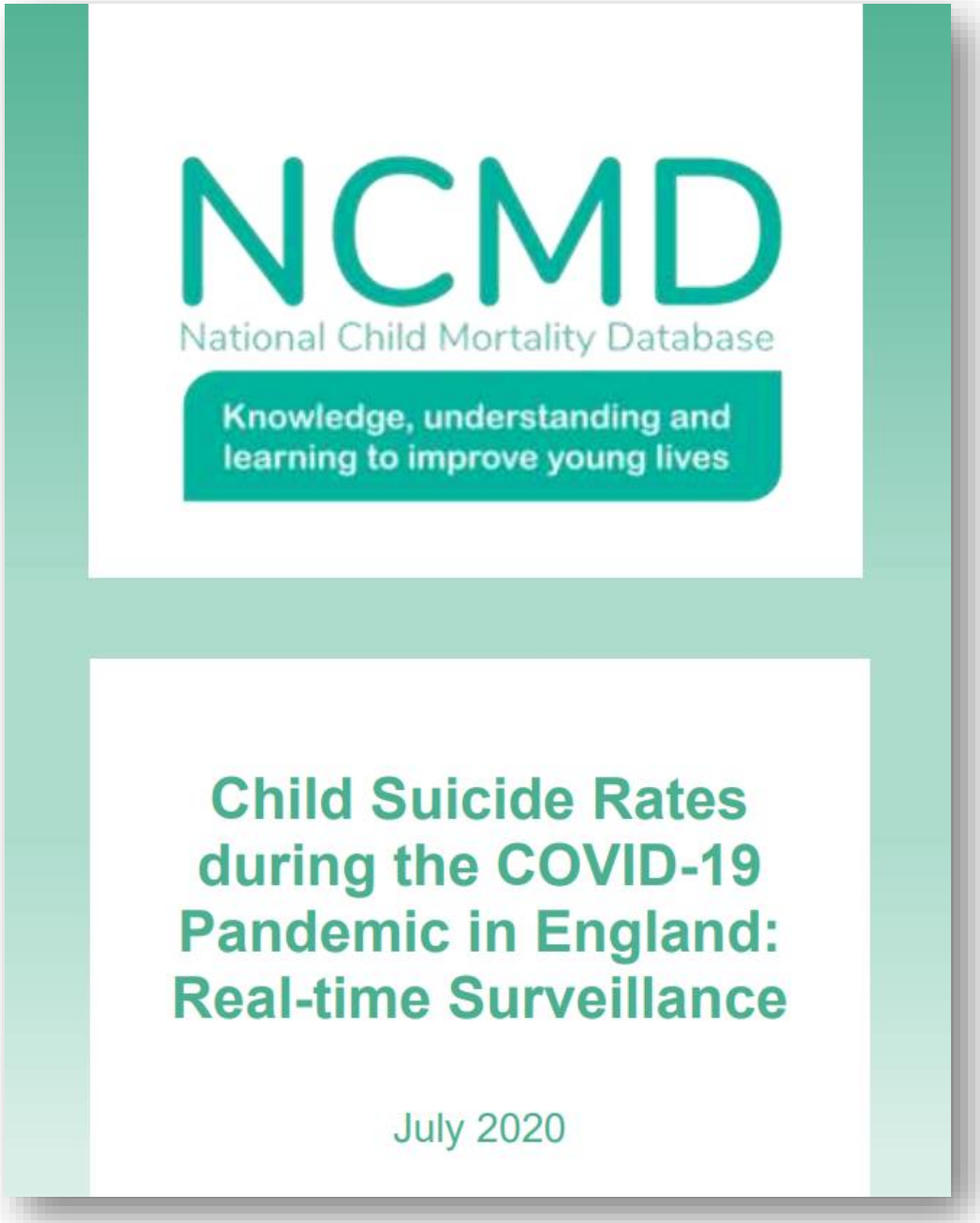
Real-time surveillance includes data from the 48 hour notification

Analysis of reviewed data includes the full dataset after review by CDOP (often not available until many months after death)



Publication Date: 10 June 2021

https://www.ncmd.info/2021/06/10/2nd-annual-report/



https://www.ncmd.info/2020/07/09/suicide-covid/

BMJ Journals

Archives of
Disease in Childhood

[Child mortality in England during the COVID-19 pandemic (bmj.com)]

https://adc.bmj.com/content/early/2021/06/21/archdischild-2020-320899.full

OPEN ACCESS

Child mortality in England during the COVID-19 pandemic

David Odd ,[1,2] Sylvia Stoianova,[1] Tom Williams,[1] Vicky Sleap,[1] Peter Blair,[1,3] Peter Fleming ,[1,3] Ingrid Wolfe,[4,5] Karen Luyt [1]

► Additional supplemental material is published online only. To view, please visit the journal online (http://dx.doi.org/10.1136/archdischild-2020-320899).

[1]National Child Mortality Database, Bristol Medical School, University of Bristol, Bristol, UK
[2]School of Medicine, Division of Population Medicine, Cardiff University, Cardiff, UK
[3]Centre for Academic Child Health, Population Health Sciences, Bristol Medical School, University of Bristol, Bristol, UK
[4]School of Life Course Sciences, Department of Women and Children's Health, King's College London, London, UK
[5]Evelina London Children's Hospital, London, UK

Correspondence to
Dr Karen Luyt, National Child Mortality Database, Bristol Medical School, University of Bristol, Bristol BS2 8EG, UK; karen.luyt@bristol.ac.uk

Received 13 October 2020
Accepted 25 April 2021

ABSTRACT

Objectives Using the National Child Mortality Database (NCMD), this work aims to investigate and quantify the characteristics of children dying of COVID-19, and to identify any changes in rate of childhood mortality during the pandemic.

Design We compared the characteristics of the children who died in 2020, split by SARS-CoV-2 status. A negative binomial regression model was used to compare mortality rates in lockdown (23 March–28 June), with those children who died in the preceding period (6 January–22 March), as well as a comparable period in 2019.

Setting England.

Participants Children (0–17 years).

Main outcome measures Characteristics and number of the children who died in 2020, split by SARS-CoV-2 status.

Results 1550 deaths of children between 6th of January and 28 June 2020 were notified to the NCMD; 437 of the deaths were linked to SARS-CoV-2 virology records, 25 (5.7%) had a positive PCR result. PCR-positive children were less likely to be white (37.5% vs 69.4%, p=0.003) and were older (12.2 vs 0.7 years, p<0.0006) compared with child deaths without evidence of the virus. All-cause mortality rates were similar during lockdown compared with both the period before lockdown in 2020 (rate ratio (RR) 0.93 (0.84 to 1.02)) and a similar period in 2019 (RR 1.02 (0.92 to 1.13)).

Conclusions There is little to suggest that there has been excess mortality during the period of lockdown. The apparent higher frequency of SARS-CoV-2-positive tests among children from black, Asian and minority ethnic groups is consistent with findings in adults. Ongoing surveillance is essential as the pandemic continues.

What is already known on this topic?

- Childhood SARS-CoV-2 disease may present in a variable way, often without clear respiratory symptoms, and so in many cases ascertainment is difficult.
- There are concerns of a hidden impact of SARS-CoV-2 on the health of newborns, infants and children.
- The relationship of COVID-19 disease and common chronic diseases of childhood, such as asthma, age and ethnic group, remains unclear.

What this study adds?

- Child mortality was lower in 2020 than in 2019 with little to suggest that there has been an excess mortality among children during the period of lockdown.
- Children who died and had a positive result for SARS-CoV-2 were more likely to be older and from ethnic minority groups.
- We found little to suggest an over-representation of children with underlying health conditions.

Despite the unprecedented research efforts arising from the pandemic, few data have been published on the overall direct and indirect disease impact on child mortality. Standard national mortality registration does not have complete ascertain-

Key findings

Deaths **occurring** between 1 April 2019 and 31 March 2020

There were 3,347 child deaths in the period, equating to approximately 28 child deaths for every 100,000 children living in England.

63% were infants (under 1 year of age) 42% were under 28 days of age. The infant mortality rate for this period was 3.4 infant deaths per 1,000 live births.

78%, of deaths had ethnicity recorded. 62% were from a White ethnic group, 19% were from an Asian or Asian British background, 9% were from a Black or Black British background, and 7% were from a Mixed background.

There were approximately three times as many deaths for children who were resident in the most deprived neighbourhoods compared to the least deprived neighbourhoods.

Where gestational age at birth was known for infants (below 1 year) who died, 69% were born preterm (before 37 weeks).

Where place of death was known, 78% of deaths occurred within a hospital trust and 22% occurred outside of a hospital.

Key findings

Deaths **reviewed** between 1 April 2019 and 31 March 2020

There were 2,738 child deaths reviewed in the period

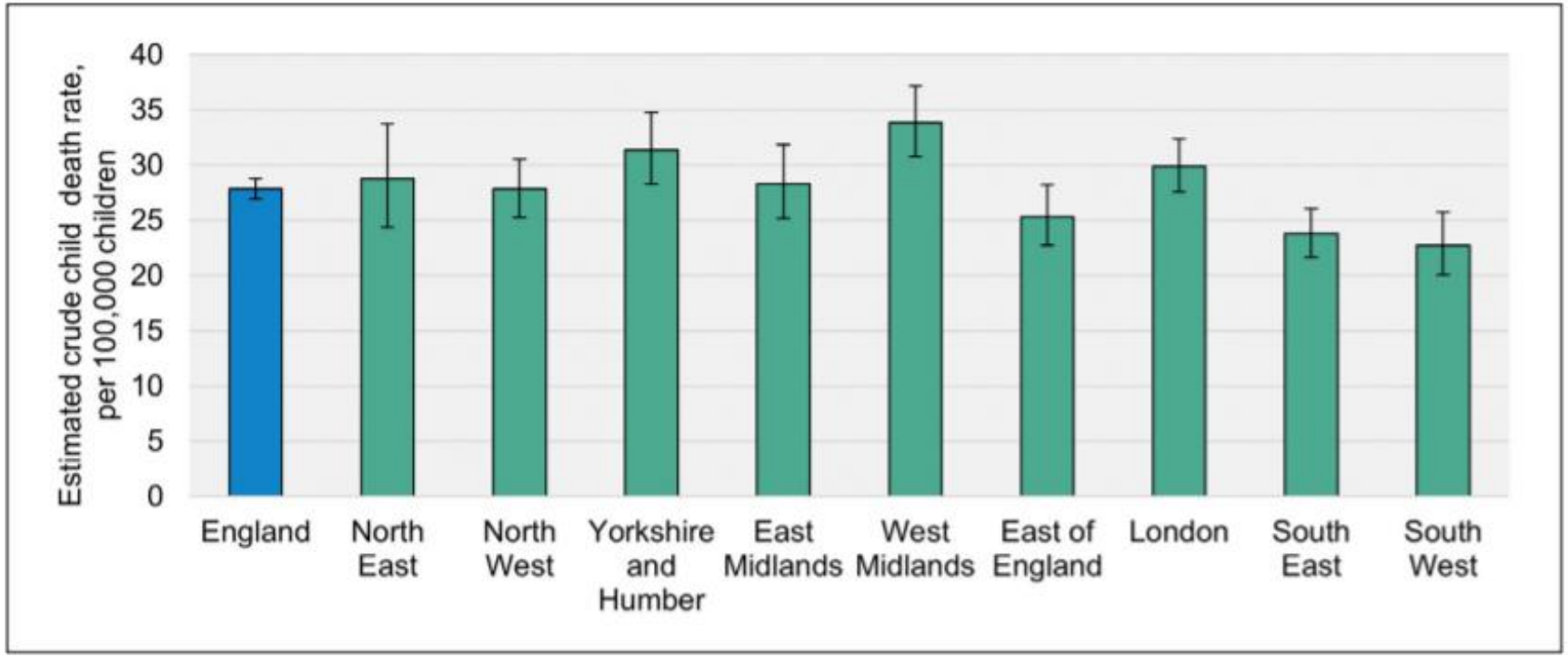
A category of Perinatal / Neonatal event was recorded for the largest proportion of deaths (31%). Where sufficient information was available. 33% identified modifiable factors.

Of all deaths categorised as Perinatal / Neonatal event, 77% were prematurity related, meaning that prematurity accounted for 24% of all child deaths reviewed.

The highest proportion of reviews with modifiable factors were Sudden Unexplained death (75%), Deliberately inflicted injury (72%), Trauma (69%) and Suicide (57%).

Malignancy had the lowest proportion of reviews that identified modifiable factors (5%).

Estimated Crude Child Death Rates per 100,000 population by region, year ending 31st March 2020



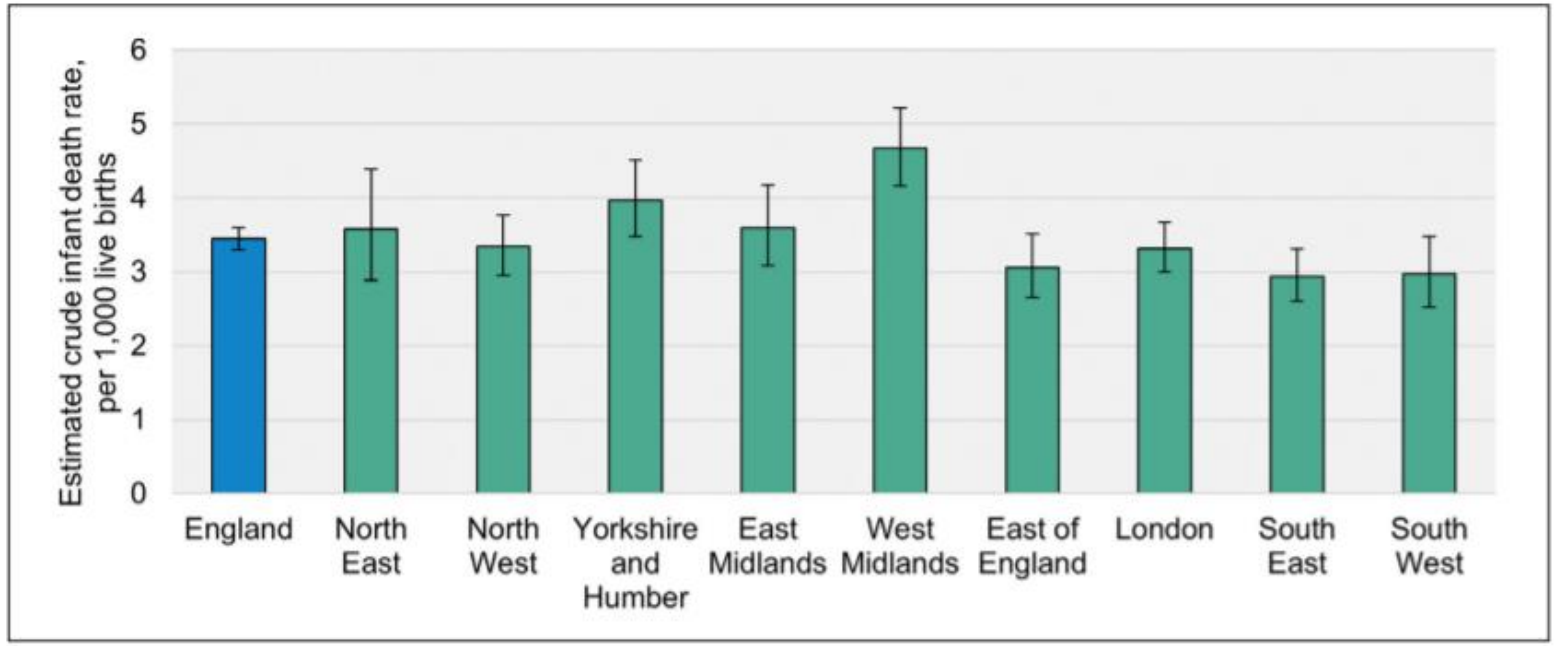
Data source: NCMD, 2019 mid-year population estimate (ONS)

[represents 95% confidence intervals

Regions are ONS regions that have been mapped to responsible CDOPs that will complete reviews, a mapping list is available in Appendix C

Data here include the number of death notifications submitted to NCMD. There were a small number of CDOPs who did not submit all of their data in the first year of national data collection. This will have an impact on regional and national rates presented here. This therefore does not allow for comparisons between these regional rates and for formal statistical analyses to be carried out. The regional rates will start to become meaningful when every CDOP is submitting complete data and with 2-3 years' data (when confidence intervals will be smaller).

Estimated Crude Infant Death Rates per 1,000 live births population by region, year ending 31st March 2020



Data source: NCMD, 2019 live births (ONS)

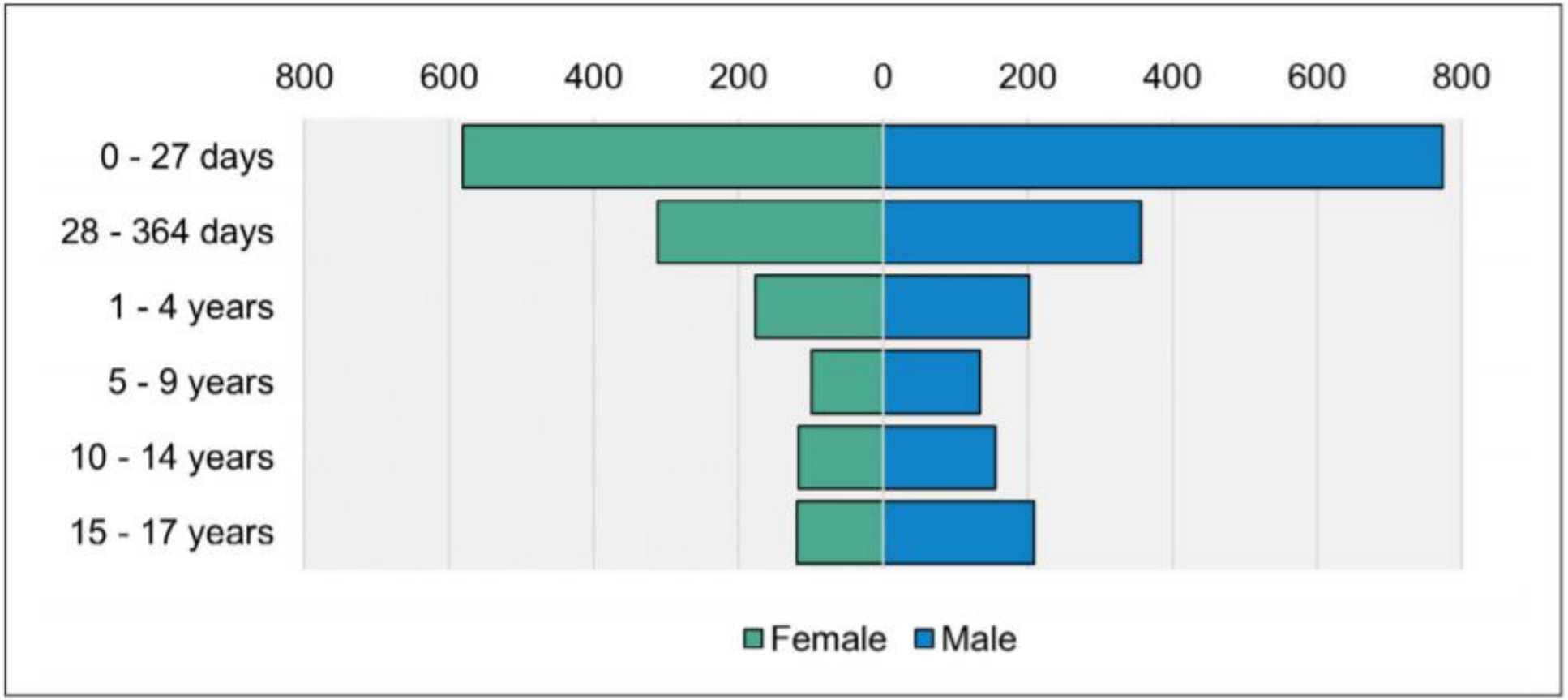
[represents 95% confidence intervals

Regions are ONS regions that have been mapped to responsible CDOPs that will complete reviews, a mapping list is available in Appendix C.

Data here include the number of death notifications submitted to NCMD. There were a small number of CDOPs who did not submit all of their data in the first year of national data collection. This will have an impact on regional and national rates presented here. This therefore does not allow for comparisons between these regional rates and for formal statistical analyses to be carried out. The regional rates will start to become meaningful when every CDOP is submitting complete data and with 2-3 years' data (when confidence intervals will be smaller).

Initial comparisons between the published ONS 2019 child death registrations data and NCMD were undertaken by the NCMD team; this estimated that there were approximately 20% more neonatal (0-27 days of age) deaths registered than were reported to NCMD. This is only an estimated difference as the published ONS data covers death registrations from January to December 2019, whereas the NCMD annual report covers deaths reported from April 2019 to March 2020.

Number of notifications received by CDOPs by age group and sex, year ending 31 March 2020

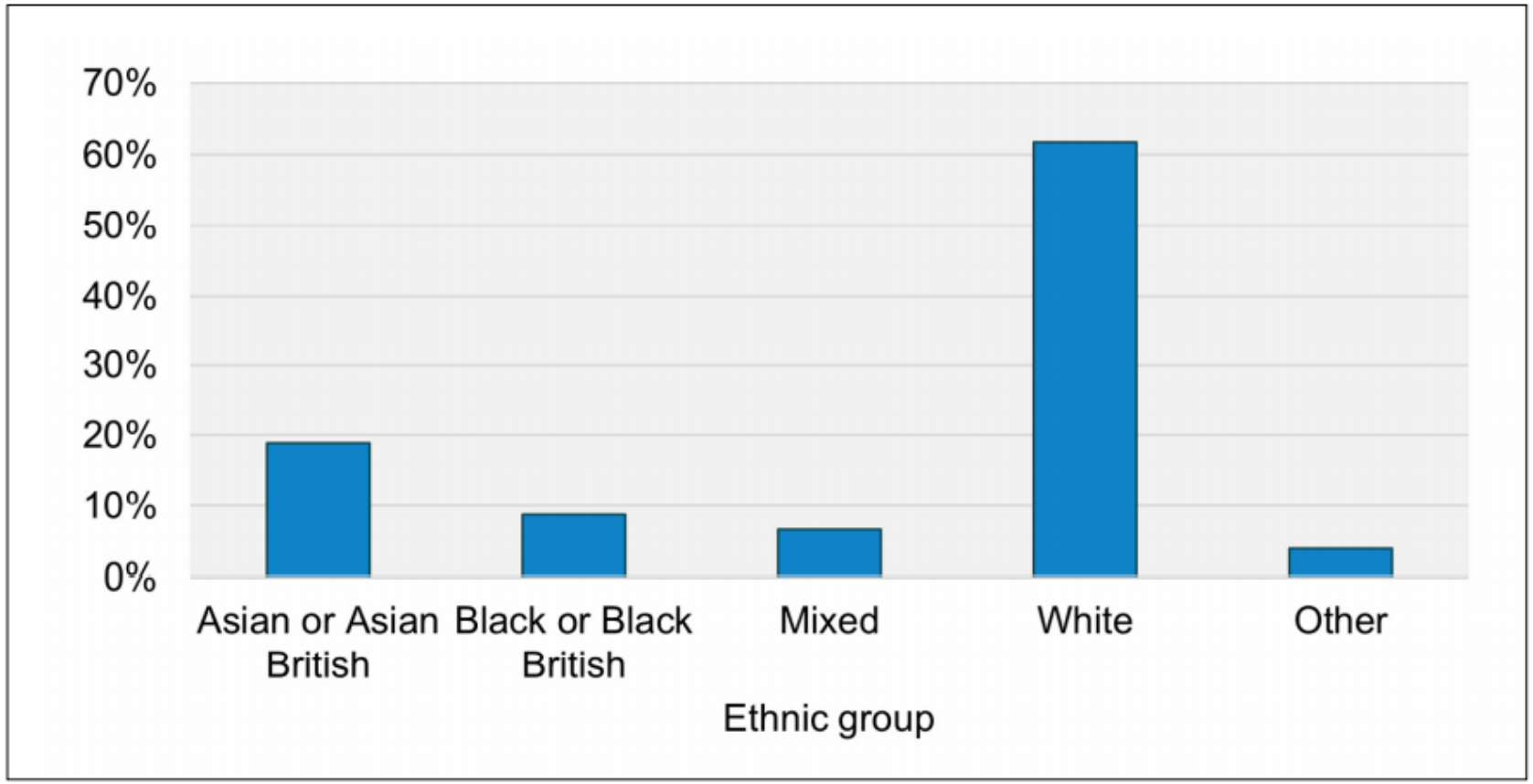


Data source: NCMD

n= 3,236

In 111 cases data for the child's sex was not known or the data was incomplete

Figure 6: The proportion of child death notifications received by Child Death Overview Panels by ethnic group, year ending 31 March 2020



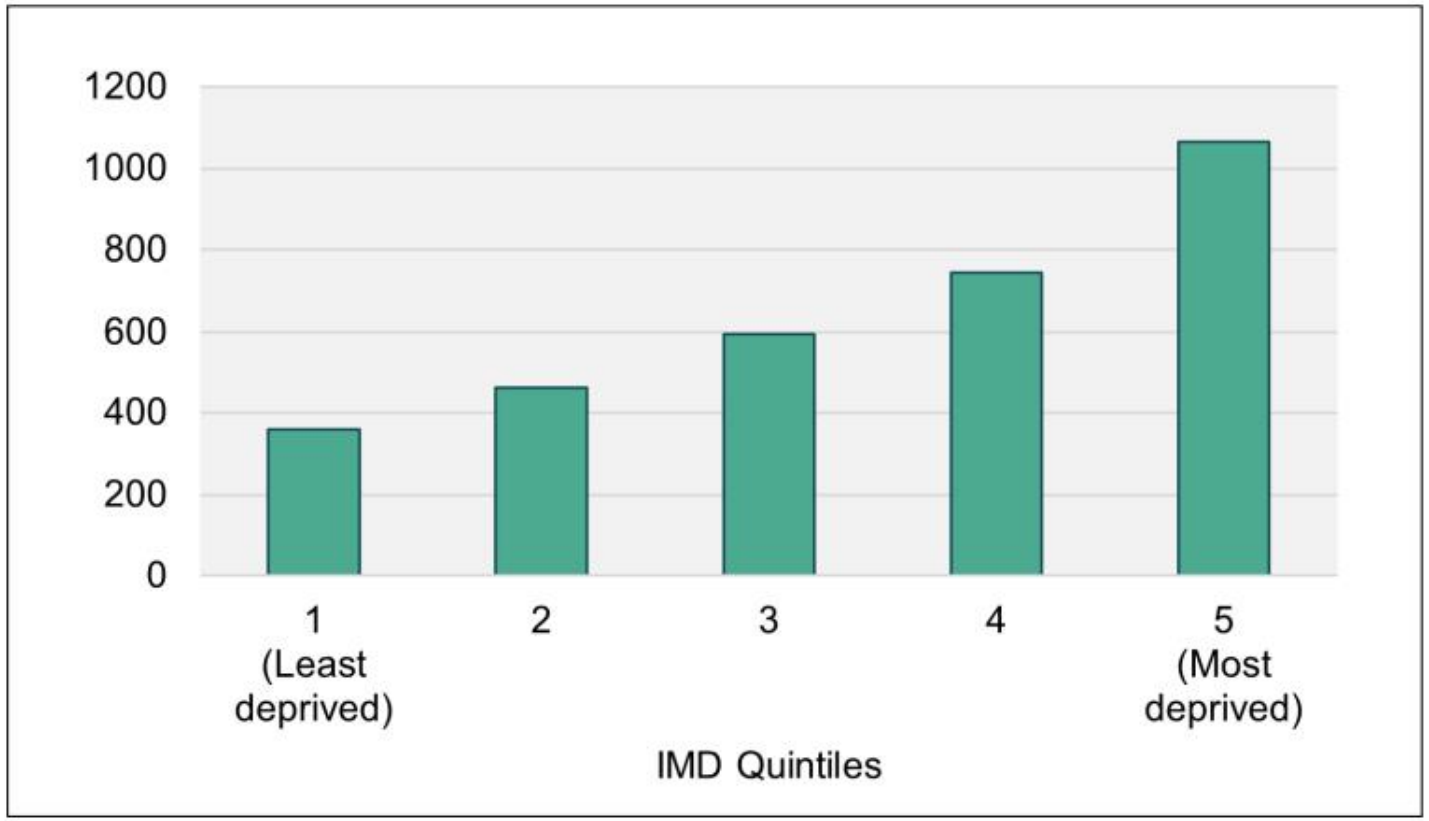
Data source: NCMD

n= 2,596

In 751 cases, data for the child's ethnic group was not known or incomplete

Ethnicity is grouped based on groupings used in the 2011 Census

Figure 7: The number of child death notifications received by Child Death Overview Panels by deprivation quintiles, year ending 31 March 2020



Data source: NCMD, IMD (2019)

n=3,227

In 120 cases, data for the child's postcode was not known or incomplete and therefore data linkage to IMD was not possible

NCMD National Child Mortality Database

Number of notifications received by CDOPs by place of death, year ending 31 March 2020

Place of death	Number (%) of deaths
Abroad	25 (1%)
Home	418 (13%)
Hospice	142 (4%)
Hospital Trust	2,525 (78%)
AICU	37 (1%)
Emergency Department	365 (11%)
Hospital ward	265 (8%)
Labour ward/delivery suite	435 (13%)
Midwifery Unit	38 (1%)
Neonatal Unit	821 (25%)
PICU	534 (16%)
Operating Theatre	30 (1%)
Other	27 (1%)
Public place	102 (3%)
School	5 (<1%)
Total	**3,244 (100%)**

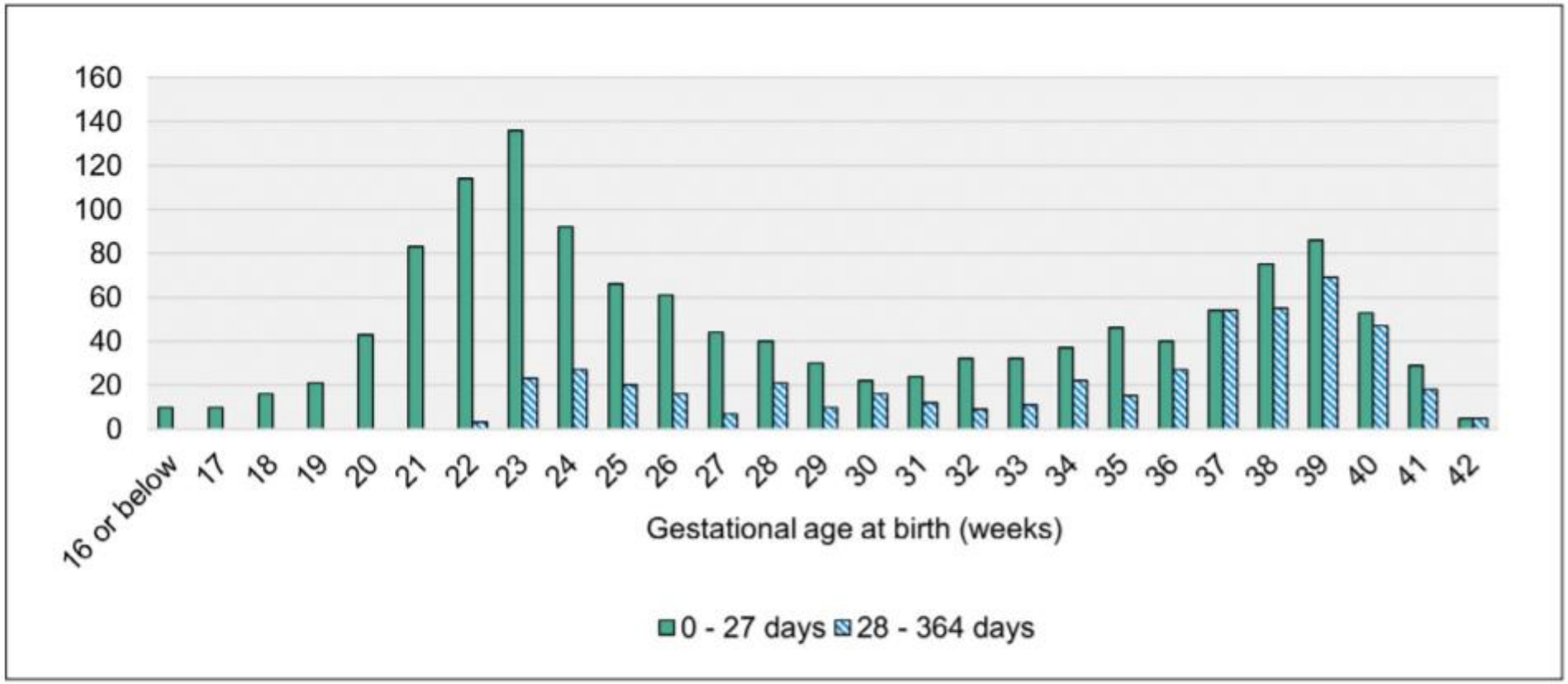
Data source: NCMD

In 103 cases, data for the child's place of death was not known or incomplete

AICU – Adult Intensive Care Unit, PICU – Paediatric Intensive Care Unit

The full definition of place of death is available in the Glossary of terms

Number of infant death notifications received by CDOPs by gestational age at birth in weeks and age group at death, year ending 31 March 2020



Data source: NCMD

n= 1,788

In 54 cases (0-27 days) and 260 cases (28-364 days), data for the child's gestational age were not known or incomplete

Data only presented for deaths of infants (<1 year)

Number of infant death notifications received by CDOPs by gestational age at birth in weeks and age group at death, year ending 31 March 2020

Gestational age at birth (weeks^{+days})	Number (%) of deaths		
	0 – 27 days	28 – 364 days	Under 1 year
<22	183 (14%)	*	183 (10%)
22^{+0}-23^{+6}	250 (19%)	26 (5%)	276 (15%)
24^{+0}-27^{+6}	263 (20%)	70 (14%)	333 (19%)
28^{+0}-36^{+6}	303 (23%)	143 (29%)	446 (25%)
37^{+0}-41^{+6}	297 (23%)	243 (50%)	540 (30%)
≥42	5 (<1%)	5 (1%)	10 (1%)
Total	**1,301 (100%)**	**487 (100%)**	**1,788 (100%)**

Data source: NCMD

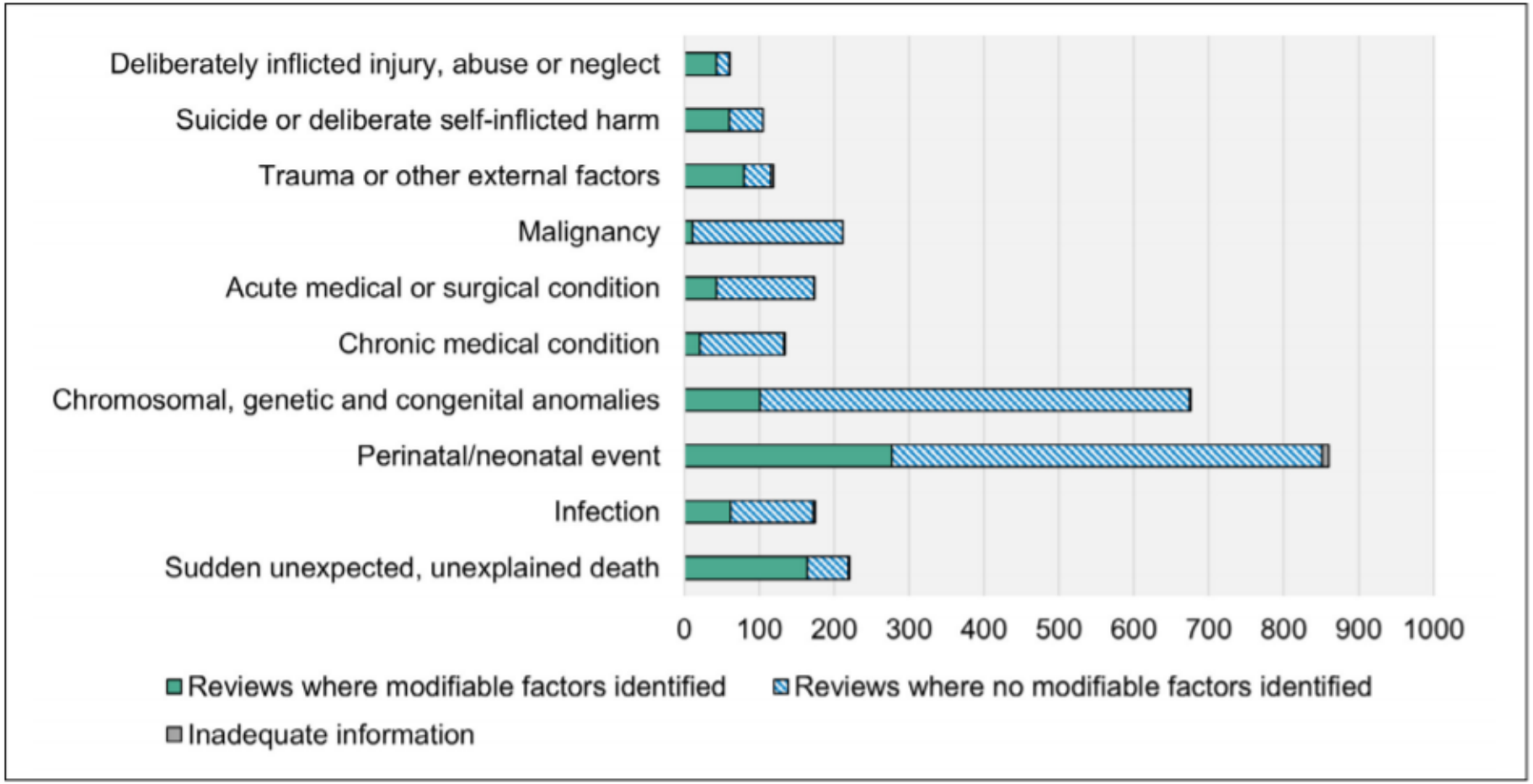
In 54 cases (0-27 days) and 260 cases (28-364 days), data for the child's gestational age were not known or incomplete

Data only presented for deaths of infants (<1 year)

Percentages may not sum to total due to rounding

* denotes that a figure has been suppressed due to small numbers (less than 5, including zero)

Number of reviews completed by CDOPs, by primary category of death, and whether modifiable factors were identified, year ending 31 March 2020



Data source: NCMD

n= 2,738

NCMD National Child Mortality Database

Number of reviews completed by CDOPs by category and sub-category of death, year ending 31 March 2020

	Reviews completed (Year ending 31 March 2020)	Reviews where the CDOP indicated that adequate information was available to make a judgement whether modifiable factors were present or not	Reviews with adequate information that identified modifiable factors
Category of death	n (%)	n (%)	n (%)
Deliberate inflicted injury, abuse or neglect	61 (2%)	60 (2%)	43 (72%)
Suicide or deliberate self-inflicted harm	105 (4%)	105 (4%)	60 (57%)
Trauma or other external factors	119 (4%)	116 (4%)	80 (69%)
Vehicle collision	56 (2%)	55 (2%)	36 (65%)
Drowning	12 (<1%)	11 (<1%)	6 (55%)
Fire, burns or electrocution	6 (<1%)	6 (<1%)	6 (100%)
Other non-intentional injury/accident/trauma	45 (2%)	44 (2%)	32 (73%)
Malignancy	212 (8%)	212 (8%)	11 (5%)
Acute medical or surgical condition	174 (6%)	173 (6%)	43 (25%)
Epilepsy	25 (1%)	25 (1%)	*
Asthma	14 (1%)	14 (1%)	9 (64%)
Diabetes	5 (<1%)	5 (<1%)	*
Other	130 (5%)	129 (5%)	28 (22%)
Chronic medical condition	135 (5%)	133 (5%)	21 (16%)
Chromosomal, congenital and genetic anomalies	676 (25%)	674 (25%)	101 (15%)
Perinatal/neonatal event	860 (31%)	851 (31%)	277 (33%)
Immaturity/Prematurity related	661 (24%)	654 (24%)	192 (29%)
Perinatal asphyxia	115 (4%)	115 (4%)	59 (51%)
Perinatally acquired infection	39 (1%)	39 (1%)	16 (41%)
Other	26 (1%)	25 (1%)	*
Unclear	19 (1%)	18 (1%)	6 (33%)
Infection	175 (6%)	172 (6%)	62 (36%)
Sudden unexpected, unexplained death	221 (8%)	219 (8%)	164 (75%)
Total	2,738 (100%)	2,715 (100%)	862 (32%)

Data source: NCMD

Number of reviews categorised as Perinatal / Neonatal event by CDOPs, by sub-category and gestational age at birth, year ending 31 March 2020

	Reviews categorised as *Perinatal/Neonatal event* (Year ending 31 March 2020)		
Sub-category	**Preterm (< 37 weeks gestation)**	**Term (37 weeks gestation +)**	**Total (% of all deaths)**
Immaturity/Prematurity related	657	*	657 (80%)
Perinatal asphyxia	31	74	105 (13%)
Perinatally acquired infection	25	13	38 (5%)
Other	10	9	19 (2%)
Total	**723**	**96**	**819 (100%)**

Of all deaths categorised as Perinatal / Neonatal event, 77% were prematurity related, prematurity accounted for 24% of ALL child deaths reviewed.

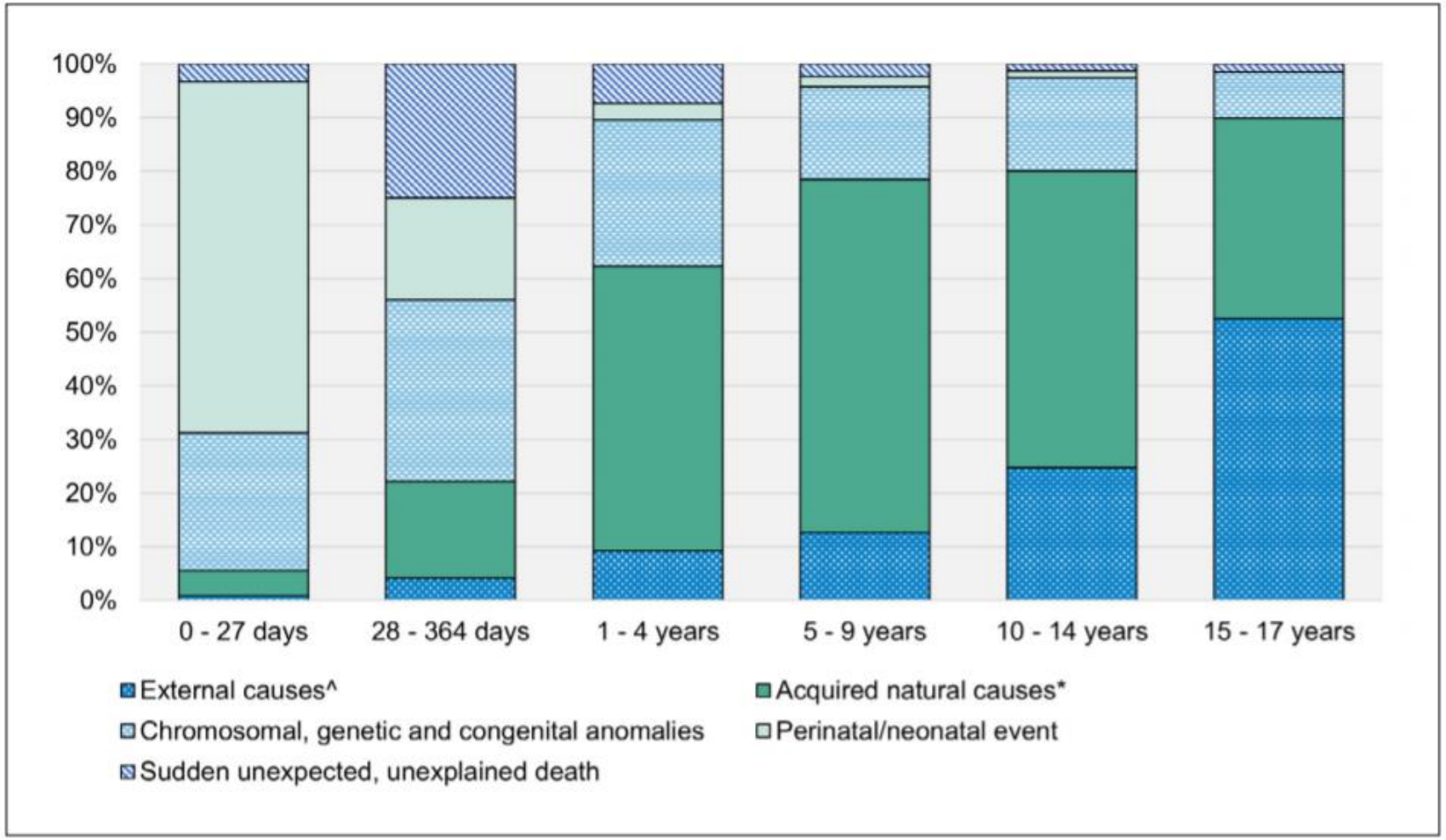
Data source: NCMD

In 19 cases the sub-category was unclear due to limited information and in a further 22 cases it was not possible to determine whether the child was born at a preterm or term gestational age

Other includes those who had other perinatal causes, including those such as meconium aspiration syndrome and hydrops fetalis

* denotes that a figure has been suppressed due to small numbers (less than 5, including zero)

Proportion of reviews completed by CDOPs, in each age group by category of death, year ending 31 March 2020



n= 2,738

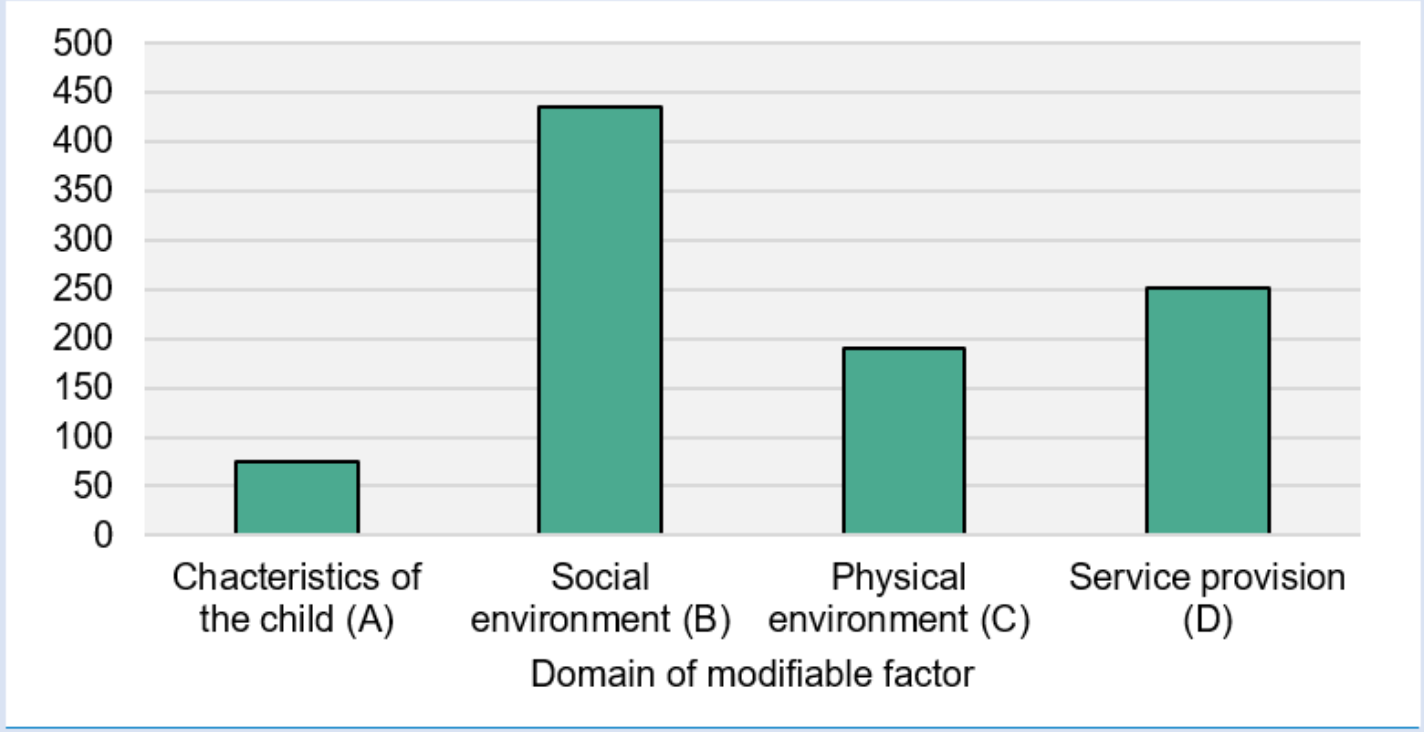
To aid interpretation and to avoid small numbers, the following categories have been combined:

^External causes: Deliberately inflicted injury, abuse or neglect, Suicide or deliberate self-inflicted harm, Trauma or other external factors

*Acquired natural causes: Malignancy, Acute medical or surgical condition, Chronic medical condition, Infection

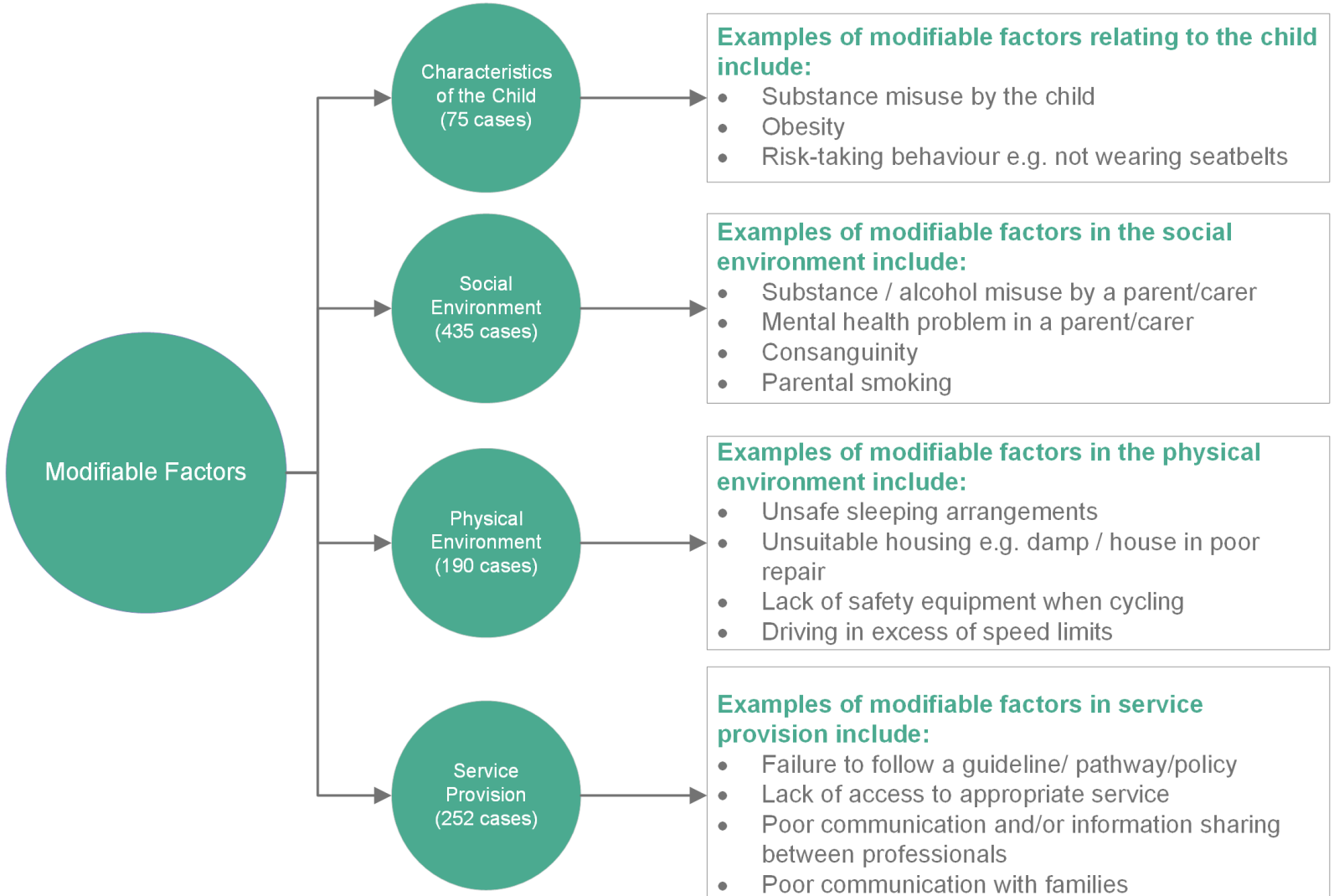
Modifiable factors identified by CDOPs

Figure 12: The number of child death reviews with at least one modifiable factor in each domain, year ending 31 March 2020

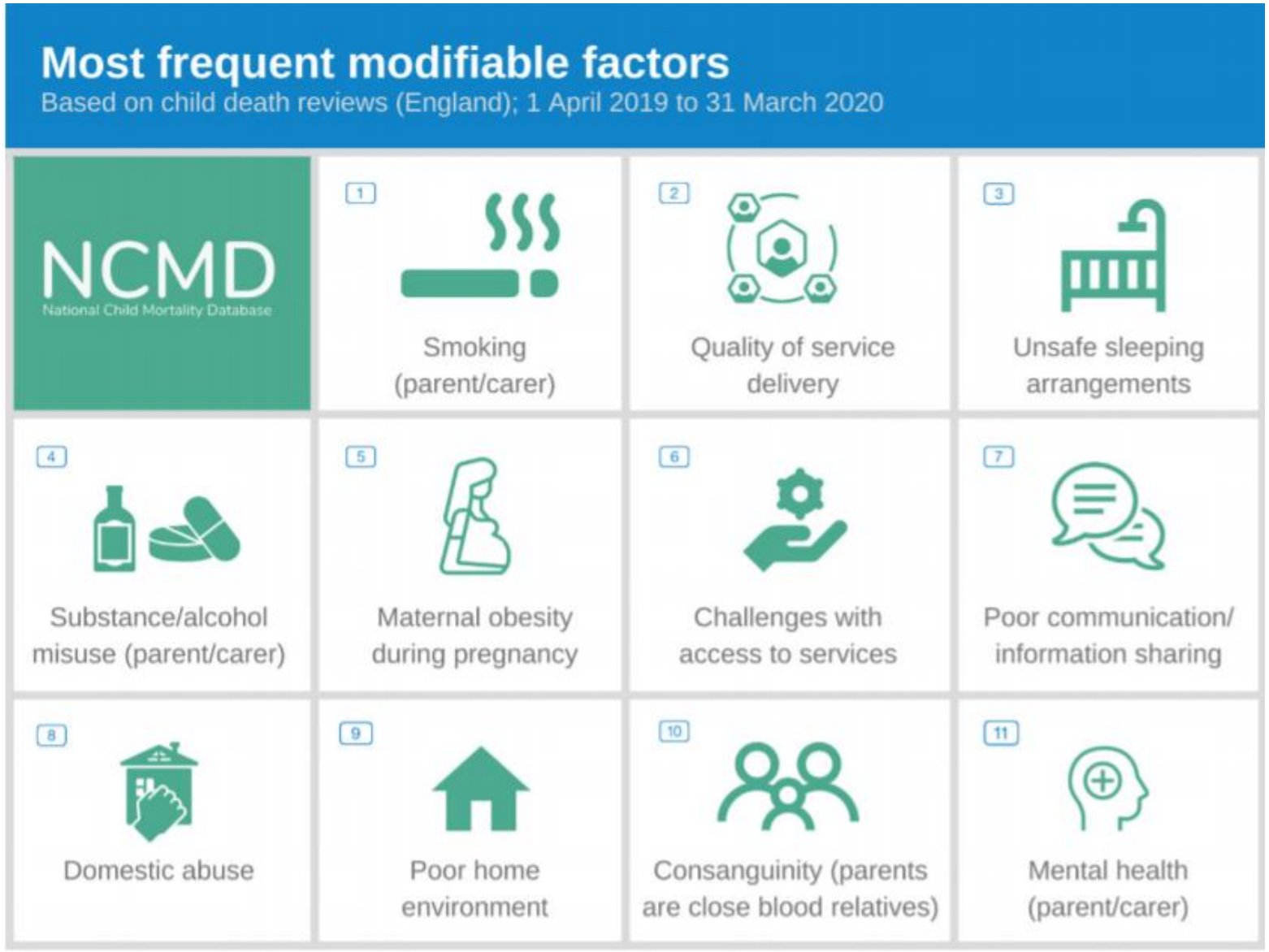


Data source: NCMD
n= 713
The number of reviews in each domain do not sum to the total as 239 reviews had a modifiable factor in more than one domain

Numbers and examples of modifiable factors identified by CDOPs



Key findings: Most Common Modifiable Factors



6. Positive examples of care, support and child death review

Whilst child death reviews aim to identify any factors relating to the child's vulnerability, ill-health and death and to consider whether action should be taken in relation to these factors, the statutory analysis form also encourages CDOPs to report and acknowledge positive aspects of service delivery and to give detailed examples of excellent care. On collating this information for all child death reviews during 2019-20, there were many examples of excellent coordinated multi-disciplinary care, regular engagement with families, compassionate end of life care and bereavement support for the families of the children who died. CDOPs often acknowledged these positive examples of care during the review and recognised key agencies and professionals across health and social care.

Recommendation 7

Continue to use the child death review process to highlight positive aspects of service delivery and to give detail of examples of excellent care as a powerful way of sharing best practice nationally.

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

Recommendations

Continue to use the NCMD child death case alert functionality to ensure regular and timely review of all alerts to inform immediate national learning and action, to ensure the safety of other children.

Consider creating, implementing and maintaining a system for structured and sustainable training, guidance and support for CDOPs and child death review professionals. This will standardise the CDOP processes and drive further improvements in the national data quality.

Integrate local learning and actions with information from this national report, to reduce the number of preterm births and improve outcomes after unavoidable preterm delivery.

Review the most frequent modifiable factors, as presented in this report, and consider how to address them at a local, regional and national level

Find Out More

1. Follow us on Twitter @NCMD_England
2. Visit our website www.ncmd.info
3. Read our report on Child Mortality and Social Deprivation
4. Read our report on Child Suicide Rates during the COVID-19 pandemic
5. Sign up to receive our regular newsletter
6. Look at our information for families


University of
BRISTOL


HQIP


UCLPartners


UNIVERSITY OF
OXFORD


QES


Sands
Stillbirth & neonatal death charity


the lullaby trust
safer sleep for babies – support for families


Child
Bereavement UK
REBUILDING LIVES TOGETHER