

# NCMD

National Child Mortality Database

Knowledge, understanding and  
learning to improve young lives

## Second Annual Report

**National Child Mortality Database Programme**

**Data from April 2019 to March 2020**

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Insights from NCMD's first  
year of national child death  
review data collection

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Photographs of bedroom scenes by Katie Wilson for The Childhood Trust's Bedroom of London Exhibition.

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# Contents

<b>Foreword</b>	<b>4</b>
<b>1. Executive summary</b>	<b>5</b>
1.1 Introduction	5
1.2 Methods	5
1.3 Key findings from the data	5
1.4 Recommendations	6
<b>2. Introduction</b>	<b>8</b>
2.1 About NCMD	8
2.2 CDOP transitional arrangements	8
2.3 Child mortality surveillance in response to COVID-19	10
2.4 Notification alert system	11
2.6 Support and guidance for child death review professionals	13
2.7 Parent, Patient and Public Involvement in the NCMD's programme of work	13
2.8 About the data included in this report	14
<b>3. Deaths occurring between 1 April 2019 and 31 March 2020</b>	<b>15</b>
3.1 The number of child death notifications	15
3.2 Infant and child death rates	15
3.3 Age, sex and ethnic group	17
3.4 Place of death	19
3.5 Social deprivation	19
3.6 Gestational age at birth	20
3.7 Review and categorisation of deaths occurring between 1 April 2019 and 31 March 2020	22
<b>4. Deaths reviewed between 1 April 2019 and 31 March 2020</b>	<b>23</b>
4.1 The number of child death reviews	23
4.2 Mode of death	24
4.3 Social Care and Child Safeguarding Practice Reviews	25
4.4 Primary category of death	26
<b>5. Details of modifiable factors identified in deaths reviewed between 1 April 2019 and 31 March 2020</b>	<b>30</b>
5.1 Most frequent modifiable factors across all child deaths	32
5.2 Modifiable factors by category of death	37
<b>6. Positive examples of care, support and child death review</b>	<b>39</b>
<b>7. Next steps: Enhanced child death review data collection, national analyses and sharing of learning</b>	<b>41</b>
<b>8. Further information</b>	<b>42</b>
8.1 Information for parents, carers and families	42
8.2 Related publications	43
<b>9. Glossary of terms</b>	<b>44</b>
<b>10. References</b>	<b>46</b>
<b>Appendices</b>	<b>47</b>
Appendix A: Additional tables	47
Appendix B: Methodology and limitations	52
Appendix C: List of regions, CDOPs and Local Authority areas	58
Appendix D: Category of death descriptions	62
Appendix E: Modifiable factor analysis form domain descriptions	63

# Foreword

Every child death is heart-breaking. Families, friends and others who knew the child are devastated by these events and their lives are changed immeasurably. As a society it is incumbent upon us to learn from these tragedies and to identify ways in which we can change things to reduce the number of children who die in the future. The National Child Mortality Database (NCMD) was set up with this very aim in mind and this report gives a valuable source of information for providers of services, commissioners and policymakers to support evidence-based decision making to improve the health and well-being of children.

This report shows the work of the programme during a period of great change and transition for those working in the field of child death review. Implementation of new statutory guidance and the merging of Child Death Overview Panels (CDOPs) from 92 down to 58 created challenges, and colleagues across agencies rose to the occasion and continued to deliver the process, enabling NCMD to fulfil its part in our collective ambition to understand why children die.

Following the emergence of COVID-19 the NCMD team set up the only population level real-time surveillance system of child mortality in the world. The ability to have not only demographic details on children who die, but multi-agency information on the circumstances of their death, within 48 hours of it occurring has shown its value time and again. The intelligence provided by this system has undoubtedly saved lives during the pandemic and has been vital in informing policy and decision-making at a national level.

During the review of each death, modifiable factors are identified, and for the first time since the start of the child death review process in 2008, these factors have been collected nationally and analysed in this report, allowing us to see key areas for improvement. Among the most commonly identified modifiable factors are poor communication and information sharing between agencies. This is an issue across the board for all agencies who provide services to children.

“As a society it is incumbent upon us to learn from these tragedies and to identify ways in which we can change things to reduce the number of children who die in the future”

**Professor Karen Luyt,  
NCMD Programme Lead**

CDOPs have shown in their reviews that this can contribute to children's vulnerability and is something we must all work to improve. As professionals working within or providing services for children, we all have a part to play in reducing the number of children who die. I therefore encourage policy makers, public health services, service planners and commissioners to use the data in this report to inform and support change in their areas.

**Professor Karen Luyt  
NCMD Programme Lead**



# 1. Executive summary

## 1.1 Introduction

The second National Child Mortality Database (NCMD) annual report includes data from the first year of the child death review national data collection in England. The report provides descriptive analysis of the characteristics of the children who have died from 1 April 2019 to 31 March 2020. In addition, it analyses the information from the completed child death reviews during the same period, which also includes some deaths that occurred before 1 April 2019. The data analyses and the underlying data quality are presented in the context of the CDOPs transitional arrangements and the more up-to-date information on the development of the NCMD programme of work.

## 1.2 Methods

Child deaths in England are reported to the Child Death Overview Panels (CDOPs) by individual professionals and organisations across all sectors involved in the child death review, as per the statutory requirements outlined in [Working together to safeguard children \(2018\)](#) and the [Child death review statutory and operational guidance \(2018\)](#). The child death review process aims to improve the experience of bereaved families and professionals involved in caring for children and ensure that information from the child death review process is systematically captured in every case, to enable learning to prevent future deaths. Nationally agreed [data collection forms](#) are used by the CDOPs for the notification, reporting and analysis stages of the child death review process and to submit data to NCMD. The notification of all child deaths to NCMD should happen within 48 hours from the time of death. CDOPs are required to continue to subsequently provide additional information to NCMD as collected during the child death review process and at its completion.<sup>1</sup>

The data, as submitted by the CDOPs using these national forms, have been collated and used by NCMD to summarise and present the national findings for the period covering 1 April 2019 to 31 March 2020. These data and analyses form the main body of this report. In addition to the information gathered from the completed review forms, this report presents for the first time national categorisation and analysis of modifiable factors and sub-categories of death. This work has been carried out using relevant clinical expertise. The aim is to provide insightful information on the more specific causes of death and the factors related to them, to help inform actions to reduce the number of children who die.

<sup>1</sup> Department of Health and Social Care, National Child Mortality Database: transitional arrangements



3,347 child deaths occurred in the year 1 April 2019 to 31 March 2020, equating to approximately 28 child deaths for every 100,000 children living in England

## 1.3 Key findings from the data

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

- There were 3,347 child deaths that occurred in the year 1 April 2019 to 31 March 2020, equating to approximately 28 child deaths for every 100,000 children living in England.
- Of the children who died, 63% (n=2,102) were infants (under 1 year of age) and 42% (n=1,411) were under 28 days of age. The infant mortality rate for this period was 3.4 infant deaths per 1,000 live births.
- Where ethnicity was recorded (78%, n=2,596), 62% (n=1,605) were of children from a White ethnic group, 19% (n=502) were from an Asian or Asian British background, 9% (n=227) were from a Black or Black British background, and 7% (n=172) were from a Mixed background. Further work is needed to ensure that ethnicity is recorded for all deaths and to place these numbers in context.
- There were approximately three times as many deaths for children who were resident in the most deprived neighbourhoods (n=1,066) compared to the least deprived neighbourhoods (n=359). Further analysis using a model that adjusted for population density is included in the NCMD report on [Child Mortality and Social Deprivation](#).
- Where gestational age at birth was known for infants (below 1 year) who died (n=1,788), 69% (n=1,238) were born preterm (before 37 weeks).
- Where place of death was known (n=3,244), 78% (n=2,525) of deaths occurred within a hospital trust and 22% (n=719) occurred outside of a hospital.

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

*These deaths were reviewed during the year, but the deaths occurred across a number of years. There is partial overlap with the cohort of children in the 'Deaths occurring' analysis if the death was both notified and reviewed in this reporting period.*

- There were 2,738 child deaths that were reviewed in the year ending 31 March 2020.
- A category of *Perinatal/Neonatal* event was recorded for the largest proportion of deaths reviewed (31%, n=860). Where sufficient information was available, 33% (n=277/851) identified modifiable factors.
- Of all deaths categorised as *Perinatal/Neonatal event*, 77% (n=661) were immaturity/prematurity related deaths, meaning that deaths due to immaturity/prematurity accounted for 24% of all child deaths reviewed.
- The categories of death with the highest proportion of reviews with modifiable factors were *Sudden unexpected unexplained death* (75%, n=164/219), *Deliberately inflicted injury, abuse or neglect* (72%, n=43/60), *Trauma or other external factors* (69%, n=80/116) and *Suicide or deliberate self-inflicted harm* (57%, n=60/105). Deaths that were categorised as *Malignancy* had the lowest proportion of reviews that identified modifiable factors (5%, n=11/212).
- The most common modifiable factors recorded by CDOPs for all child death reviews in order of frequency were:
  1. Smoking by a parent or carer
  2. Quality of service delivery
  3. Unsafe sleeping arrangements
  4. Substance and/or alcohol misuse by a parent or carer
  5. Maternal obesity during pregnancy
  6. Challenges with access to services
  7. Poor communication and information sharing
  8. Domestic abuse
  9. Poor home environment
  10. Consanguinity (parents are known blood relatives to each other)
  11. Mental health condition in a parent or carer

## 1.4 Recommendations

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

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

2. 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.

**Action by: Department of Health and Social Care**

3. Continue to notify NCMD of all child deaths to ensure complete case ascertainment. Registrars of Deaths to notify CDOPs of all deaths of children under 18 years of age, to ensure that CDOPs know about all deaths of children in their area.

**Action by: Child Death Review Professionals, Child Death Overview Panels, Registrars of Deaths**

4. Support availability and access to complete ethnicity and gestational age at birth data at the point of notifying a death to NCMD.

**Action by: Child Death Review Professionals, Child Death Overview Panels, NHS England, Department of Health and Social Care**

5. 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.

**Action by: Hospital Trusts, Service Planners, Commissioners and Policy Makers at local and regional level**

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

**Action by: Policy Makers, Public Health Services, Service Planners and Commissioners at local and regional level, Local Government, Police and Crime Commissioners**

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**

## Child deaths (England): Age

1 Apr 2019 to 31 March 2020

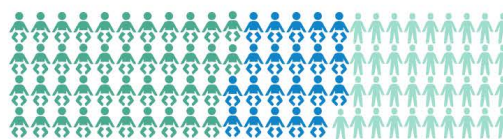
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**42%** under 28 days old

**21%** between 28 and 364 days old

**37%** 1 year and over



## Child deaths (England): Deprivation

1 Apr 2019 to 31 March 2020

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most deprived



approx.

**3X** DEATHS

least deprived

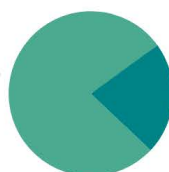


## Child deaths (England): Location

1 Apr 2019 to 31 March 2020

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22%  
outside  
hospital setting



## Child deaths (England): Prematurity

1 Apr 2019 to 31 March 2020

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**69%** infant deaths  
(under 1 year old)  
are born preterm  
(before 37 weeks)





## 2. Introduction

### 2.1 About NCMD

The National Child Mortality Database (NCMD) collects data on the deaths of all live-born children in England who die before their 18th birthday. The purpose of collating information nationally is to ensure that deaths are learned from, that learning is widely shared and that actions are taken, locally and nationally, to reduce the number of children who die.

The programme was established and is delivered by the University of Bristol, in collaboration with the University of Oxford, University College London (UCL) Partners and the software company QES. It also includes representation from bereaved families through the NCMD charity partners: Child Bereavement UK, The Lullaby Trust and Sands.

For further background on NCMD please visit [our website](#).

### 2.2 CDOP transitional arrangements

In July 2018, Department for Education (DfE) published the statutory document Working Together To Safeguard Children. Its purpose was to support the new child death review partners (CDR partners) in the transition to a new system of multi-agency arrangements for child death reviews. The CDR partners are local authorities (LAs) and Clinical Commissioning Groups (CCGs). The guidance aimed to help them understand the requirements and to plan and manage their work in the transitional period. CDR partners were tasked with delivering these arrangements via a Child Death Overview Panel (CDOP) or equivalent entity.

100% of CDOPs started submitting data to NCMD in the first year of the national data collection

From 29 June 2018, the CDR partners had up to 12 months to agree arrangements for the review of each death of a child normally resident in their area, including arrangements for the analysis of information about deaths reviewed. They were required to publish their plans for the new arrangements and, at the end of the 12-month period, they then had up to three months to implement their new arrangements. Therefore, all new arrangements were required to be implemented by 29 September 2019.



It is important to note that during some part of the year that this report refers to (April to September 2019), CDOPs were still going through the process of transition to their new arrangements. This had an impact on their ability to progress cases through the CDR process, particularly in areas where there were changes in staffing or new people involved in the process.

As part of their new arrangements, CDOPs were required to organise in such a way so they cover a child population that would enable them to typically review at least 60 child deaths each year. This resulted in a reduction in the number of CDOPs in England – from 92 to 58 CDOPs after the transitional arrangements were complete.

This was recommended in order to better support thematic learning and to identify potential safeguarding or local health issues that could be modified, in order to protect children from harm. A full list of CDOPs mapping to local authority areas and regions is available in [Appendix C](#).

Figure 1 shows the current CDOPs and their geographical boundaries across England.



**Figure 1: The geographical boundaries of Child Death Overview Panels in England as of 1 April 2020**

1. Barnsley
2. Bedfordshire
3. Birmingham
4. Black Country
5. Blackpool, Blackburn with Darwen & Lancashire
6. Bolton, Salford & Wigan
7. Bradford
8. Bury, Rochdale & Oldham
9. Cambridgeshire & Peterborough
10. Coventry, Solihull & Warwickshire
11. Cumbria
12. Derby & Derbyshire
13. Doncaster
14. Durham & Darlington
15. East Riding of Yorkshire
16. Essex, Southend & Thurrock
17. Gloucestershire
18. Hampshire, IoW, Portsmouth & Southampton
19. Herefordshire & Worcestershire
20. Hertfordshire
21. Hull
22. Kent & Medway
23. Leeds
24. Leicester, Leicestershire & Rutland
25. Lincolnshire
26. Manchester
27. Merseyside
28. Milton Keynes
29. Norfolk
30. North & South of Tyne
31. North Central London (Barnet, Camden, Enfield, Haringey & Islington)
32. North East London (Barking, Dagenham, Havering & Redbridge)
33. North East London (Waltham Forest, East London & the City)
34. North West London
35. Northamptonshire
36. Northern Lincolnshire
37. Nottinghamshire & Nottingham City
38. Oxfordshire & Buckinghamshire
39. Pan Berkshire
40. Pan Cheshire
41. Pan Dorset & Somerset
42. Pan Sussex
43. Rotherham
44. Sheffield
45. Shropshire, Telford & Wrekin
46. South East London (Bexley, Greenwich & Lewisham)
47. South East London (Bromley, Lambeth & Southwark)
48. South West London
49. South West Peninsula
50. Staffordshire & Stoke-on-Trent
51. Suffolk
52. Surrey
53. Swindon & Wiltshire
54. Tameside, Trafford & Stockport
55. Tees
56. Wakefield, Calderdale & Kirklees
57. West of England
58. York City & North Yorkshire



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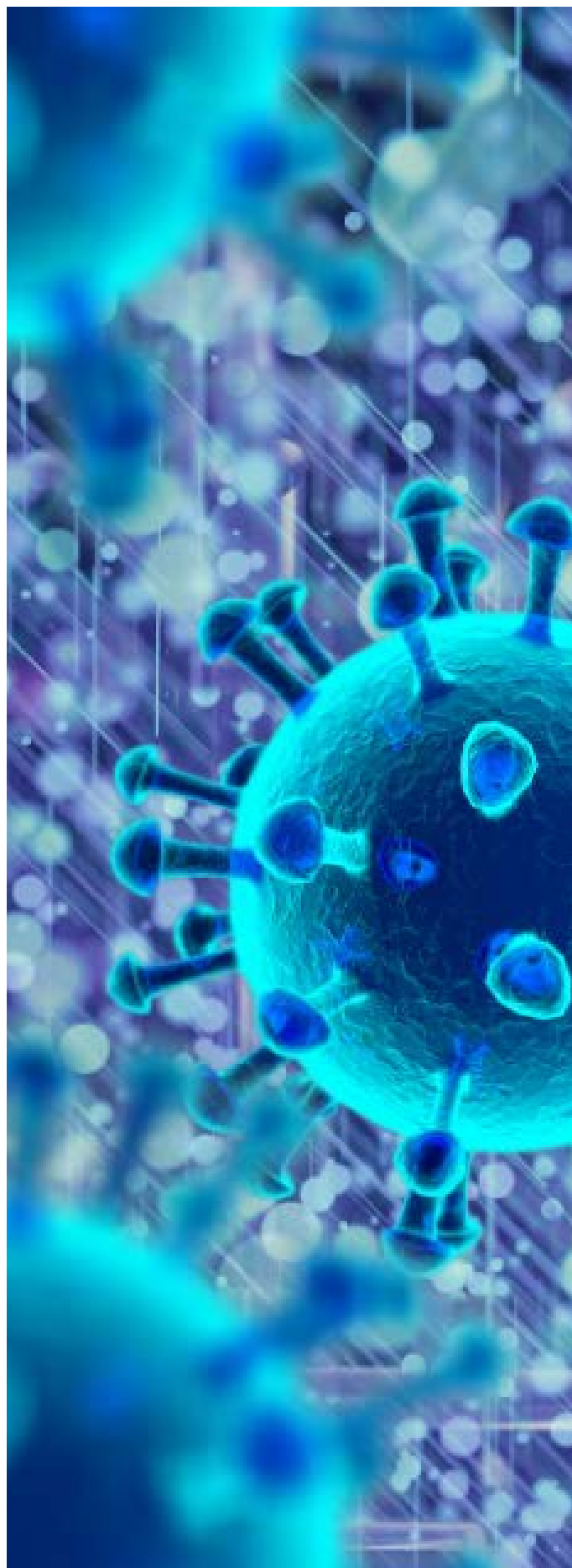
In addition to the transitions to their new arrangements, CDOPs also had to navigate two additional changes during this time. The first was significant changes to the statutory forms associated with the CDR process. These forms were changed during a consultation, which also resulted in the publication of the [new Child Death Review Statutory and Operational Guidance \(England\)](#). The second was the launch of NCMD and the requirement to submit data to the national database, which represented a new stage in the CDR process. The NCMD team was available to support CDOPs during these changes and 100% of CDOPs started submitting data to NCMD in the first year of the national data collection.

### 2.3 Child mortality surveillance in response to COVID-19

The emergence of COVID-19 during the early months of 2020 proved to be one of the biggest global challenges faced in our lifetime. The statutory requirement to notify NCMD of all child deaths within 48 hours provided an opportunity for the NCMD team to set up a real-time surveillance system to monitor the impact of the virus on child mortality in England. The system was designed, created, tested and deployed into the database in under two weeks. The statutory [child death notification form](#) was modified from 1 April 2020 to include a COVID-19 specific module. Data linkage with the COVID-19 test results held at Public Health England was established to ensure the COVID-19 status of all children who died is confirmed.

#### NCMD data helped to guide the NHS response to the COVID-19 pandemic

This enabled NCMD to carry out a more rapid review of all child death notifications and feedback commenced to key stakeholders within NHS England to quantify the impact of the pandemic, and the corresponding social changes, on childhood mortality. These data have helped and continue to guide the NHS response to the COVID-19 pandemic, identifying important features of the direct and indirect effects of the virus to guide policy changes at national level. In addition, further analyses on COVID-19 and child mortality will follow in future reports.



## 2.4 Notification alert system

Alongside the real-time surveillance system, the NCMD team also implemented a case alert system, the purpose of which was to provide a mechanism for CDOPs to alert NCMD to any feature of a death that they thought was concerning or might need urgent action to prevent another death occurring. The alert system consists of a mandatory question which is included in both the notification and reporting form which the CDOP, or anyone submitting information to the CDOP, can use to alert the NCMD team. This functionality was implemented on 1 April 2020.

Alongside the technical aspect of the alert system, the NCMD team developed a process for the review of the alerts by the clinical and epidemiological experts within the NCMD Programme Operational Group. This allowed for a structured and regular review and decision on follow-up actions. Alerts requiring national action are escalated to NHS England for further agreement on any actions required. As part of this process, NCMD also established relationships with national charities and government agencies, such as the [Royal Society for the Prevention of Accidents \(RoSPA\)](#) and the [Medicines and Healthcare products regulatory agency \(MHRA\)](#), which have the remit to collate evidence and drive actions for the prevention of accidents, e.g. related to home safety and the safety of different products.

Work is ongoing on further developing and formalising the escalation process to include a wider national, multiagency approach in the review and actioning of case alerts and signals from the data, and in agreeing how sharing of learning can be best utilised to improve child safety.

### Recommendation 1

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

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

## 2.5 Data linkage

Data linkages between NCMD and other national data collection systems have also been brought forward during the pandemic. Data linkages have been intended from the inception and commissioning of the programme, but this became more immediate in the context of the pandemic and the need for more timely evidence to inform policies and actions to protect children from the virus. Data linkage was set up with Public Health England's virology database, which allowed NCMD to link with the COVID-19 test results for all children who die during the pandemic and carry out the real-time child mortality surveillance system as outlined above. Arrangements are also in progress to link to record level ONS data to ascertain the numbers of deaths as reported to NCMD and the death registration system. Once in place, this will help NCMD identify where the notification gaps may be so they can be addressed, and any potential ascertainment biases removed. This will further improve the reliability of the NCMD analyses and reporting findings. In addition, a national

data feed has been established from [BadgerNet](#), to help with completing the data on neonatal deaths. Alongside this, agreements are progressing for linking with the [Paediatric Intensive Care Audit Network \(PICANet\)](#) and the [NHS Digital Maternity Services Dataset](#).

All ongoing and intended data linkages are presented in the [NCMD data flow diagram](#).

The [Child Death Review Statutory and Operational Guidance](#) sets out the intention for neonatal deaths to be reviewed using the [Perinatal Mortality Review Tool \(PMRT\)](#) run by the [National Perinatal Epidemiology Unit \(NPEU\)](#) at University of Oxford. Work continues between the NPEU and NCMD teams to align the two systems so that data can flow from PMRT to NCMD. This will support the streamlining of the two systems and reduce duplication for professionals submitting data.



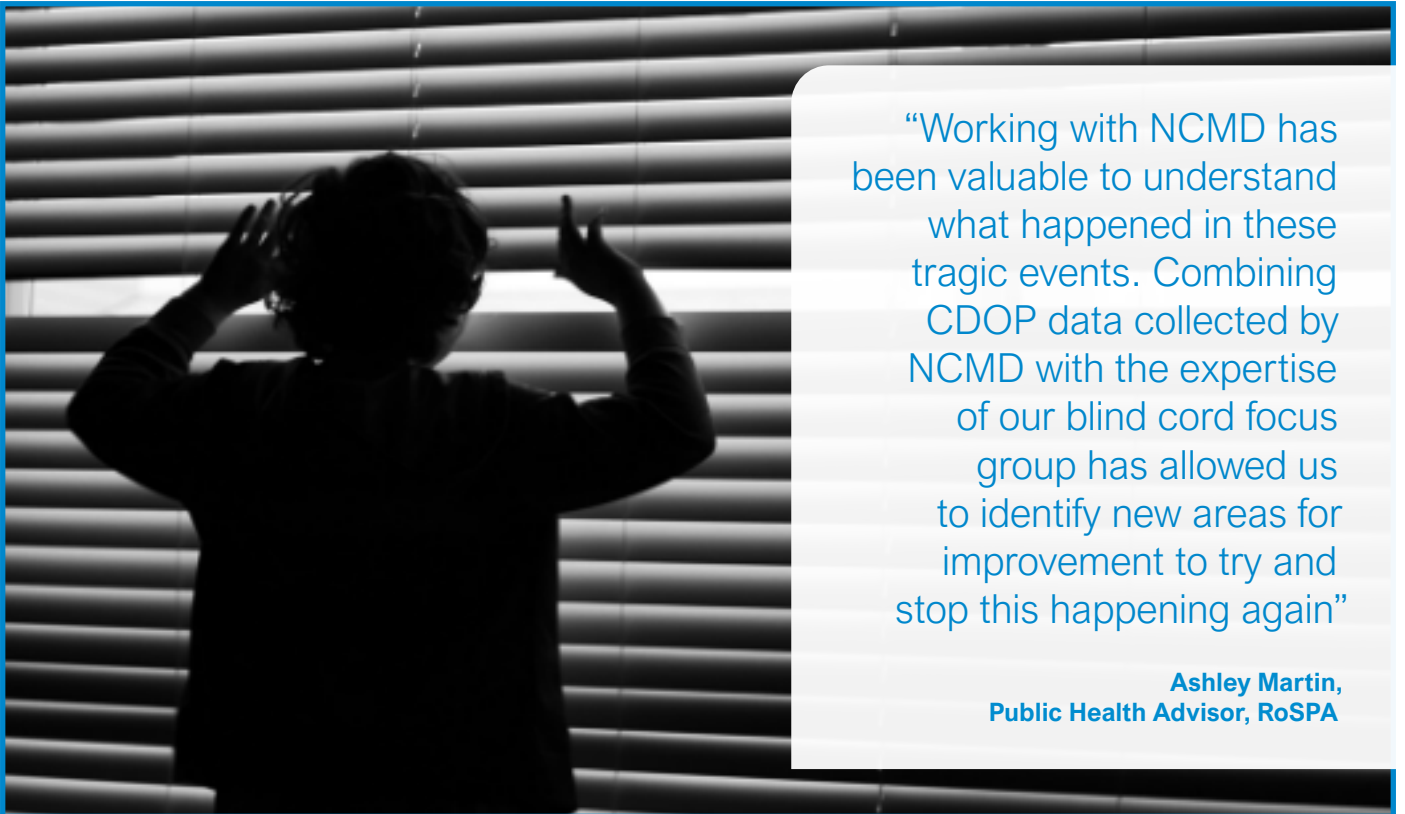
### Suicide in the pandemic

This briefing describes the findings from the NCMD real-time surveillance system (as outlined above) relating to child death by suicide in England during lockdown. By pooling information across all notifications of death, we aimed to identify any changes in incidence and common risk factors, and support public health responses to COVID-19 to balance interventions to control the spread of the disease against the impacts that such interventions may have on population health.

In the first publication on this, we reported on likely suicides between 1 January 2020 and 17 May 2020, comparing rates before and during lockdown (a comparison was also made with deaths occurring at a similar time in 2019).

This report found, among the likely suicide deaths reported after lockdown, that restriction to education and other activities, disruption to care and support services, tensions at home and isolation appeared to be contributing factors. As such, clinicians and services were made aware of the need for continued vigilance and support during periods of physical distancing, particularly among children and young people previously known to mental health services. It is important to note however, as child suicides are fortunately rare, that our analysis was limited on small numbers and interpretation was correspondingly limited.

For further information please visit the [NCMD website](#).



“Working with NCMD has been valuable to understand what happened in these tragic events. Combining CDOP data collected by NCMD with the expertise of our blind cord focus group has allowed us to identify new areas for improvement to try and stop this happening again”

**Ashley Martin,**  
Public Health Advisor, RoSPA

### Tackling deaths of children from blind cord strangulation

Prior to the commissioning of NCMD there had been some tragic deaths of young children strangled by blind and curtain cords. It was an issue of concern to CDOPs and those working in accident prevention such as RoSPA. However, until NCMD was launched there was no central way to identify these incidents and no standard set of information collected for every death. Therefore, when the NCMD alert function was launched, CDOPs were encouraged to highlight such occurrences to NCMD at the point of notification of the death so that action could be taken as soon as possible to prevent further tragedies from happening. Sadly, it was not long after the launch of the alert system that NCMD received information on several deaths involving blind and curtain cords.

In response to this, NCMD contacted RoSPA who responded by re-establishing their national blind cord focus group. This group of national experts included representatives from government, industry and manufacturing, retail and the charity sector. The group quickly identified what information was needed to understand why these events were occurring and NCMD was able to contact the CDOPs who had reported a death involving a blind or curtain cord and ask for some further detail about the type of blinds, their location in the house and the housing tenure. Following receipt of this information from the CDOPs, the group reviewed the details of each death and were able to identify two features which were not previously known.

- The events were occurring in many different places within the house. Previously they were thought to occur mainly in the bedroom.
- Some events were occurring in rented properties, and there is currently no legal requirement for landlords to provide cleats or other safety mechanisms for window blinds.

Having identified these issues, national action was taken by the group by writing to the Secretary of State for Housing, Communities and Local Government, asking for window blinds and cord-operated curtains to be added to the Housing Health & Safety Rating System (HHSR) to ensure that blinds in rented properties are correctly risk assessed. The group has also approached the National Residential Landlords Association to work with them to jointly communicate the importance of risk-assessing these common household items.

Finally, RoSPA, in conjunction with the British Blinds and Shutters Association, the Department for Business, Energy and Industrial Strategy and other partners have launched an awareness raising campaign to help families understand the risks and take action to make their blinds and cord-operated curtains safe. For more information on this please visit their website: [www.rospace.com](http://www.rospace.com)



## 2.6 Support and guidance for child death review professionals

A key component of the work of the NCMD team is to support child death review (CDR) professionals to provide the best quality and most complete data so that child deaths are reviewed robustly and maximum benefit from the analysis carried out by NCMD is ensured. It was agreed that a multi-dimensional approach to supporting CDR professionals would maximise opportunities for NCMD to engage with its primary group of stakeholders. Free webinars, regular newsletters and other resources are provided via the [NCMD website](#) to increase engagement with CDR professionals.

Despite the work carried out by the NCMD team, there remain significant gaps in support and training for CDR professionals, particularly as new staff are appointed into roles within the CDR community. Lack of support and training leads to challenges and inconsistencies in following the statutory CDR process, which may also be affecting how modifiable factors are identified and reported. When the process is not followed, poor quality and/or incomplete data are submitted to NCMD. This in turn limits what can be drawn from the data and limits NCMD's capacity to provide comprehensive and meaningful analyses ([Appendix B](#), e.g. the accuracy of the information submitted for category of death).

### Recommendation 2

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.

**Action by: Department of Health and Social Care**

### Webinars

The [webinar programme](#) started in November 2019 and to date there have been seven webinars, with attendance increasing each time. All the webinars are recorded, and links are provided to those CDOPs who were unable to attend. Each webinar includes a presentation and a live Q&A session at which CDR professionals can ask questions on any topic they choose. Listed below are examples of some of the topics discussed at the webinars:

- How to complete a good notification form
- Guidance for holding local child death review meetings
- How to deal with deaths of international patients who die in England
- Guidance on data retention for CDOP records
- Co-ordination of processes when a child lives in one area and dies in another
- How to adapt CDR processes in light of COVID-19
- How to address stillbirths and pre-viable gestation babies
- Guidance on local themed CDOP meetings
- Guidance on regional themed CDOP meetings

## 2.7 Parent, Patient and Public Involvement in the NCMD's programme of work

The NCMD Parent, Patient and Public Involvement (PPPI) group was established from the start of the programme in April 2018 and NCMD is committed to ensuring meaningful opportunities are provided for the engagement of parents, patients (in this case children) and the public in all work.

The NCMD team has worked with our charity partners and members of our PPPI group who have provided significant and valuable input to:

### Writing of NCMD thematic and annual reports

- [Child Poverty Action Group \(CPAG\)](#) played a key role in the development of the NCMD thematic report on child mortality and deprivation.
- [Papyrus](#) is the UK charity for prevention of young suicide, and NCMD continues to work with them on the forthcoming NCMD suicide thematic report to ensure the voices of children and their families are reflected.

Engagement with both of these charities has been essential in understanding the lived experiences of families in the UK today and has provided important additional context in which the data can be analysed.

### Analysis of data submitted by CDOPs through the alert system

The [Royal Society for the Prevention of Accidents \(RoSPA\)](#) has assisted NCMD by setting up a national focus group to analyse data from deaths involving blind cords. With representation from government offices, industry and retail it has been possible to identify important information to support accurate and up-to-date messaging to families on safety and prevention in this area.

### Development of an NCMD information postcard for families

In June 2019 a PPPI stakeholders meeting was held to ask for input on the best way of providing information on the programme to families. The meeting benefitted from representation from a wide range of charities and the discussion was helpful in steering this piece of work at an early stage. Following the meeting, the NCMD partner charities were vital in establishing the right content and images for use on the postcard. The postcards have been made available to families via CDOPs and through the NCMD website [here](#).

### Development of guidance for professionals on how to engage families in the CDR process

NCMD produced guidance for professionals on how to hold an effective CDR meeting. The [guidance](#) provided practical advice on how to ensure the meeting met the requirements of the statutory guidance, including the input of families to those discussions. The NCMD charity partners helped to write a section of the guidance entitled "Ensuring the family's perspective is included".



“NCMD is a really important resource that works to support CDR professionals”

**CDOP Lead for Child Death**  
(NCMD survey, Oct 2020)

## 2.8 About the data included in this report

The data cover two cohorts presented in two separate sections of the report. The first section analyses data on children that were notified to NCMD as having died between 1 April 2019 and 31 March 2020. The second section analyses information from the reviews of children whose death (which may have occurred before April 2019) was reviewed by a CDOP between 1 April 2019 and 31 March 2020.

It is important to note that the CDOP reviews of child deaths might not have been completed in the same year as when deaths occurred. Therefore, the population of children reported in these cohorts were separate but partially overlap (deaths that both occurred and were reviewed within the same year were included in both cohorts).

The analyses in this report use data which were collected and submitted by CDOPs on infants and children who died. These data have been analysed alongside other datasets and key findings and recommendations are presented.

The aim of the report is to present the profile of the deaths notified / reviewed across England. The proportions presented on the characteristics of the children by sex, ethnicity and region of residency are limited in interpretation by a number of factors: the out-of-date reference population from the last population census in 2011, the incomplete data on ethnicity, the quality of the reporting in the first year of national data collection and the limited scope within this work to investigate the factors and causal pathways involved.

Further details on the methodology and limitations for these analyses are outlined in [Appendix B](#). Throughout this report, ‘child’ is used to refer to a child aged from 0 up to their 18th birthday (0 – 17 years), and an ‘infant’ is defined as a child from birth until their first birthday.

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.

# 3. Deaths occurring between 1 April 2019 and 31 March 2020

This section of the report focuses on the number of deaths and provides descriptive analysis on the demographics of children who died between 1 April 2019 and 31 March 2020.

## 3.1 The number of child death notifications

**3,347**

The NCMD received 3,347 notifications of child deaths from CDOPs in England where the date of death of the child was between 1 April 2019 and 31 March 2020.

Although the numbers were relatively consistent throughout the year, there were slightly more child deaths in the winter months, with December being the month where most deaths occurred (n=327). In contrast, the month in which the lowest number occurred was June, where there were 235 deaths (Figure 2).

As NCMD only started collecting data on 1 April 2019 it is not possible to make a comparison to previous years' data to analyse how the number of deaths might be changing. Trend analysis of NCMD death notification data will be included in future NCMD annual reports.

## 3.2 Infant and child death rates

The overall child death rate and infant death rate presented here have been calculated using different populations. The child death rate includes all children who died between 0 – 17 years of age and has been calculated using data from the 2019 mid-year population estimate for 0 – 17 year olds.<sup>2</sup> The child death rate is presented per 100,000 population.

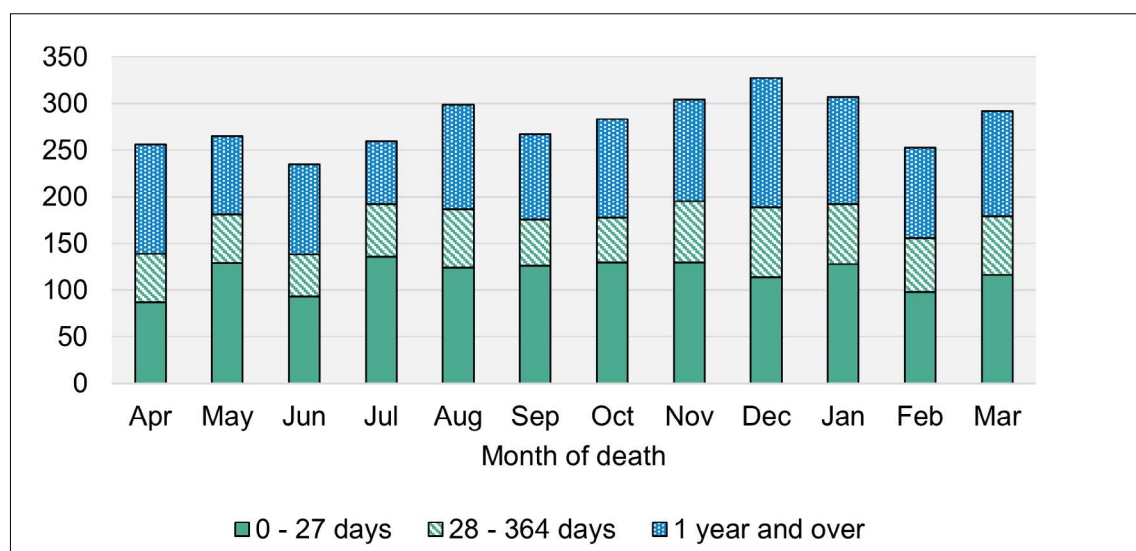
The infant death rate (deaths of children under 1 year of age) has been calculated using data for live births<sup>3</sup>, and the rate is presented per 1,000 live births. Whilst these rates are presented at regional level, there may be significant differences in rates between CDOPs within each region.

### Recommendation 3

Continue to notify NCMD of all child deaths to ensure complete case ascertainment. Registrars of Deaths to notify CDOPs of all deaths of children under 18 years of age, to ensure that CDOPs know about all deaths of children in their area.

**Action by: Child Death Review Professionals, Child Death Overview Panels, Registrars of Deaths**

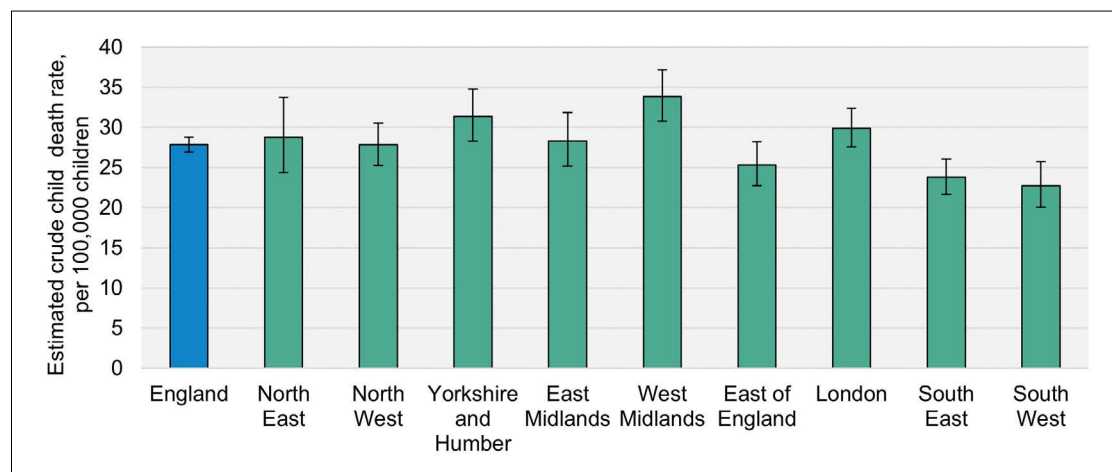
**Figure 2: The number of child death notifications received by Child Death Overview Panels by month of death and age at death, year ending 31 March 2020**



Data source: NCMD  
n=3,347

<sup>2</sup> Office for National Statistics. 2019 mid-year population estimate  
<sup>3</sup> Office for National Statistics. 2019 live births data

**Figure 3: The estimated crude child death rates per 100,000 population by region, year ending 31 March 2020**



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

I represents 95% confidence intervals

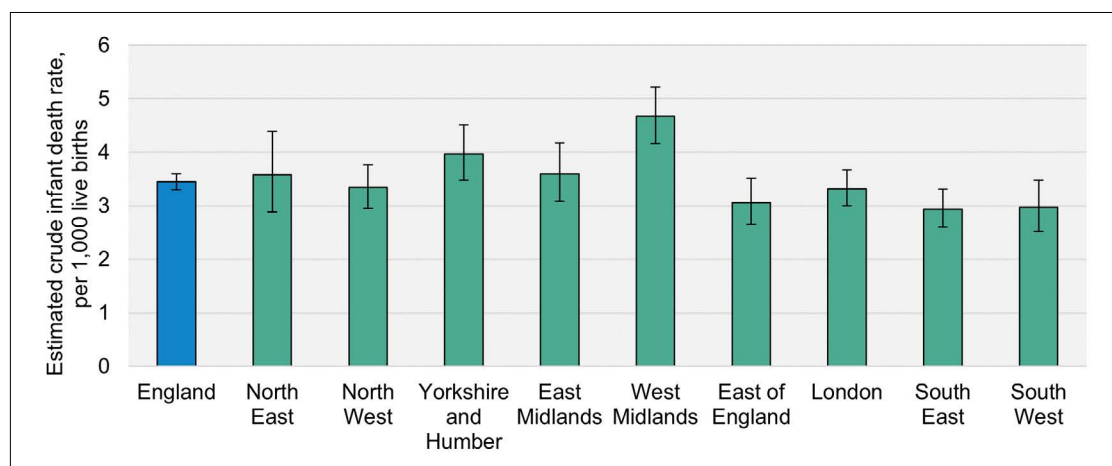
Regions are ONS regions that have been mapped to responsible CDOPs that will complete reviews, a mapping list is available in [Appendix C](#)

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).

Across England, there were an estimated 27.8 (95% confidence interval (CI) 26.9-28.8) child deaths per 100,000 population of children (Figure 3). The differences between regions were not particularly marked, ranging from 22.8 (95% CI 20.0-25.7) to 33.9 (95% CI 30.8-37.2) child deaths per 100,000 population.

For the death rate of infants under the age of 1 year (infant death rate) in England, there were an estimated 3.4 deaths per 1,000 live births (95% CI 3.3-3.6) (Figure 4). The differences between regions ranged from 2.9 (95% CI 2.6-3.3) to 4.7 (95% CI 4.2-5.2) infant deaths per 1,000 live births.

**Figure 4: The estimated crude infant death rates per 1,000 live births by region, year ending 31 March 2020**



Data source: NCMD, 2019 live births (ONS)

I 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.



### 3.3 Age, sex and ethnic group

## Child deaths (England): Age

1 Apr 2019 to 31 March 2020

NCMD  
National Child Mortality Database

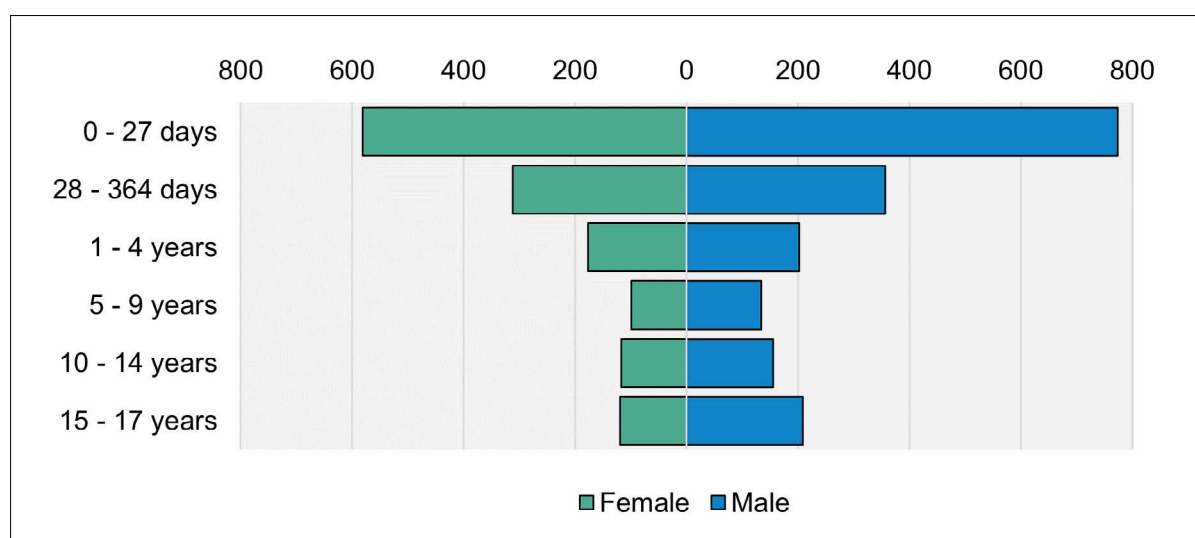
**42%** under 28 days old  
**21%** between 28 and 364 days old  
**37%** 1 year and over



42% (n=1,411) of 3,347 deaths occurred during the first 27 days after birth and a further 21% (n=691) of deaths occurred when the baby was aged between 28 and 364 days, meaning deaths of infants accounted for 63% (n=2,102) of all child deaths (see Table 10 in [Appendix A](#)). The lowest number of deaths occurred for children aged between 5 and 9 years (7%, n=237).

There were more males than females who died in each age group (Figure 5), particularly for deaths under 28 days (males n=774; females n=581) and between 15 and 17 years (males n=209; females n=119).

**Figure 5: The number of child death notifications received by Child Death Overview Panels 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

Overall, the child's sex was recorded in 97% (n=3,236) of death notifications and, of these, over half (n=1,831, 57%) were male. When adjusting for the fact that there were more males born than females<sup>4</sup>, as expected the child death rate for

males remained higher than the child death rate for females (Table 1). This difference is consistent with what is reported by ONS<sup>5</sup> every year and observed in most countries in the world<sup>6</sup>.

<sup>4</sup> Office for National Statistics. Births in England and Wales: summary tables, 2019

<sup>5</sup> Office for National Statistics. Deaths registered by single year of age, UK, 2020

<sup>6</sup> Roser, Ritchie and Dadonaite, 2013

**Table 1: The estimated crude child death rates per 100,000 population by sex, year ending 31 March 2020**

Sex	Number of deaths	Population (0-17 years)	Estimated crude child death rate, per 100,000 children (95% CI)
Female	1,405	5,857,616	24.0 (22.7 – 25.3)
Male	1,831	6,165,952	29.7 (28.4 – 31.1)

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

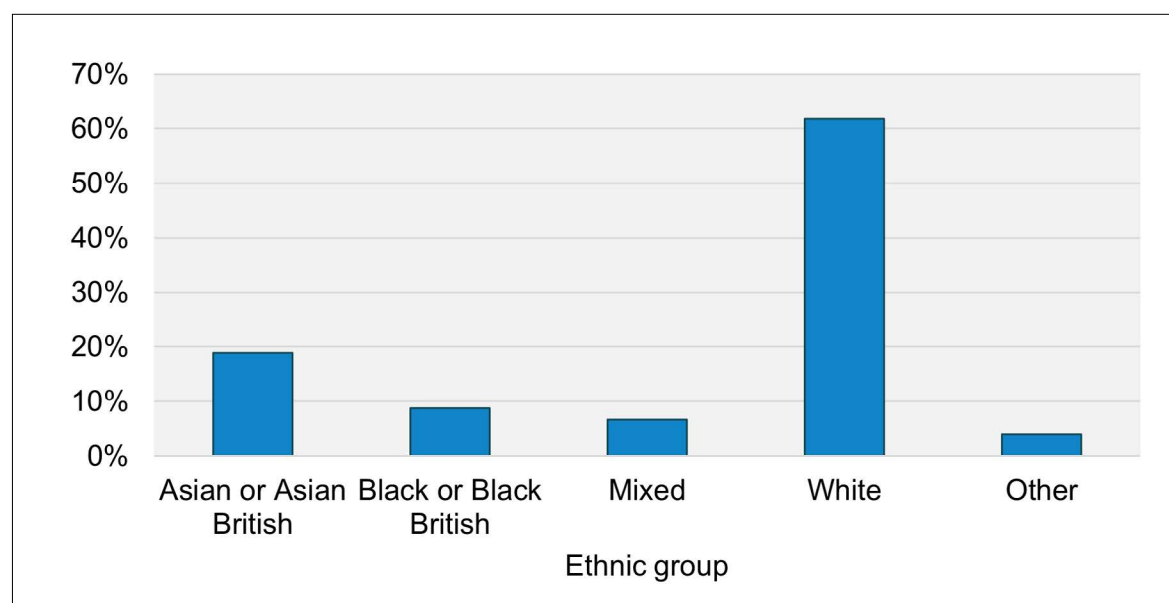
In 111 cases sex was not known or incomplete

Ethnic group was recorded in 2,596 (78%) death notifications. Of these, 62% (n=1,605) of deaths were of children who were recorded as being from a White ethnic group (Figure 6), 19% (n=502) of deaths were of children from an Asian or Asian British background, 9% (n=227) were from a Black or Black British background and 7% (n=172) were from a Mixed background.

In the data published following the latest census data collected in 2011, 79% of the child population (0 – 17 years) were White, 10% were Asian or Asian British, 5% were Black or Black British, 5% were from a mixed ethnic group and 1% were described as being from any other ethnic group. However, this census data on ethnicity was collected 8 years prior to the 2019-20 deaths data included here and covers both England and Wales; and therefore, may not accurately represent the current population structure of England. More reliable population data being available and improved data completeness in NCMD will allow for comprehensive analysis on death rates between ethnic groups (See Section 7).



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



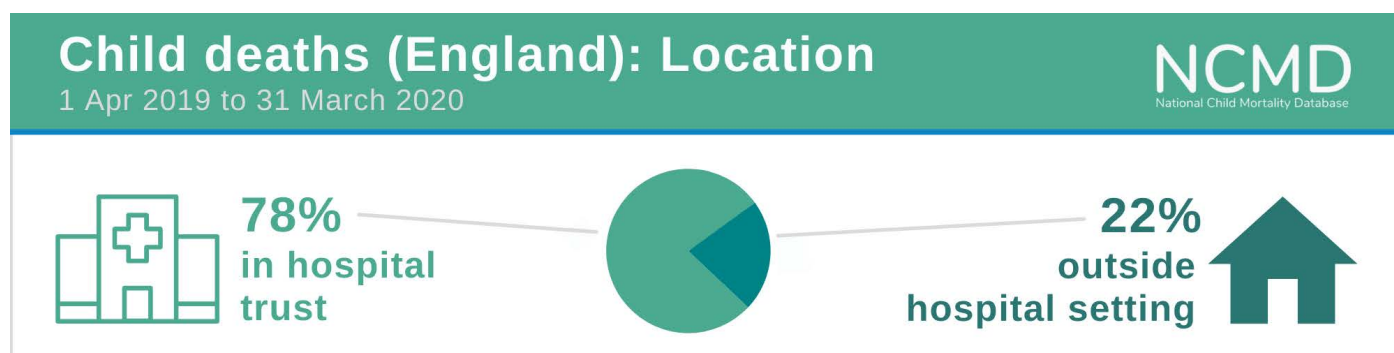
Data source: NCMD

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

### 3.4 Place of death



The place of death is defined at data collection as where the child is believed to have died regardless of where death was confirmed. The place of death was recorded in 3,244 (97%) deaths and the majority (78%, n=2,525) of these occurred within a hospital trust, and a quarter (25%, n=821) of all deaths occurred on a neonatal unit (Table 2). 22% (n=719) of all deaths occurred outside of a hospital, including 418 (13%) which occurred at home and 142 (4%) which occurred within a hospice.

**Table 2: The number of child death notifications received by Child Death Overview Panels 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%)
<b>Total</b>	<b>3,244 (100%)</b>

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](#)

### 3.5 Social deprivation

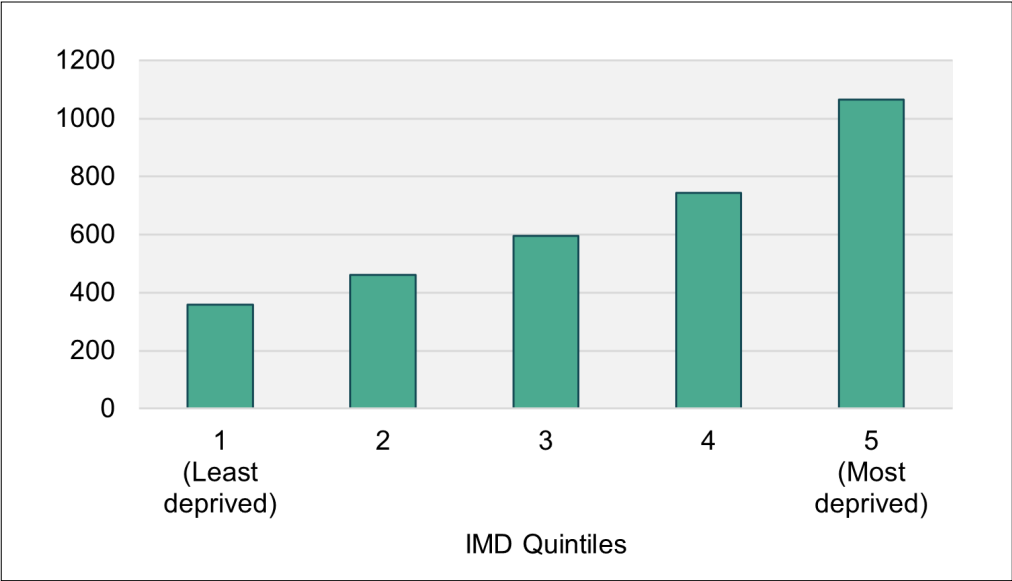
The NCMD published a thematic report on [Child Mortality and Social Deprivation](#) in early 2021 which aimed to identify whether social deprivation is associated with childhood mortality. It also explored if apparent socio-economic inequalities appear to be less or more important for the different sub-groups of the population and the different categories of death.

For the analysis here of the possible link between social deprivation and mortality, the postcode of each child was linked to its corresponding [Index of Multiple Deprivation \(IMD 2019\)](#) which is calculated to the granularity of around 1,500 people. Each neighbourhood is ranked from most deprived to least deprived, which are then divided into five equal sized groups (quintiles). Whilst these quintiles hold an equal number of neighbourhoods, they represent similar but not equal numbers of children and, in general, more children live in more deprived areas. (See the report published by the NCMD on [Child Mortality and Social Deprivation](#) for further analysis using a model that adjusted for population density.)

More deaths were associated with children living in the most deprived neighbourhoods of England, in comparison to the least deprived (Figure 7). The number of deaths increased throughout each increasing deprivation quintile; there were approximately three times as many deaths of children who were resident in the most deprived quintile (n=1,066) compared to the least deprived quintile (n=359).



**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

# Child deaths (England): Deprivation

1 Apr 2019 to 31 March 2020

most deprived

£ £ £ (1,066 deaths)

approx. **3X DEATHS**

least deprived

(359 deaths) £ £ £ £ £

3.6 Gestational age at birth

Gestational age at birth is presented as the number of weeks\*days.

CDOPs and CDR professionals follow the statutory child death review guidance<sup>7</sup> which states that all live births of any gestational age need to be reviewed and notified to NCMD. Out of the 1,355 deaths that occurred during the neonatal period (under 28 days of age), gestational age at birth was completed for 1,301 (96%) deaths (Table 3). Of these, over half (53%, n=696) were born at an extremely preterm gestational age (before 28 weeks). An additional 303 (23%) deaths occurred at later preterm gestations (28+0-36+6 weeks); in total, 77% (n=999) of infants dying in the neonatal period were born prematurely (before 37 weeks).

When reviewing all deaths of infants where gestational age was recorded (n=1,788), 69% (n=1,238) were babies who were born at a premature gestational age (before 37 weeks).

A breakdown of gestational age by place of death can be found in [Appendix A](#) (Table 12).



<sup>7</sup> Department of Health and Social Care, Department for Education. Child Death Review Statutory and Operational Guidance



**Table 3: The number of infant death notifications received by Child Death Overview Panels by gestational age at birth in weeks and age group at death, year ending 31 March 2020**

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

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

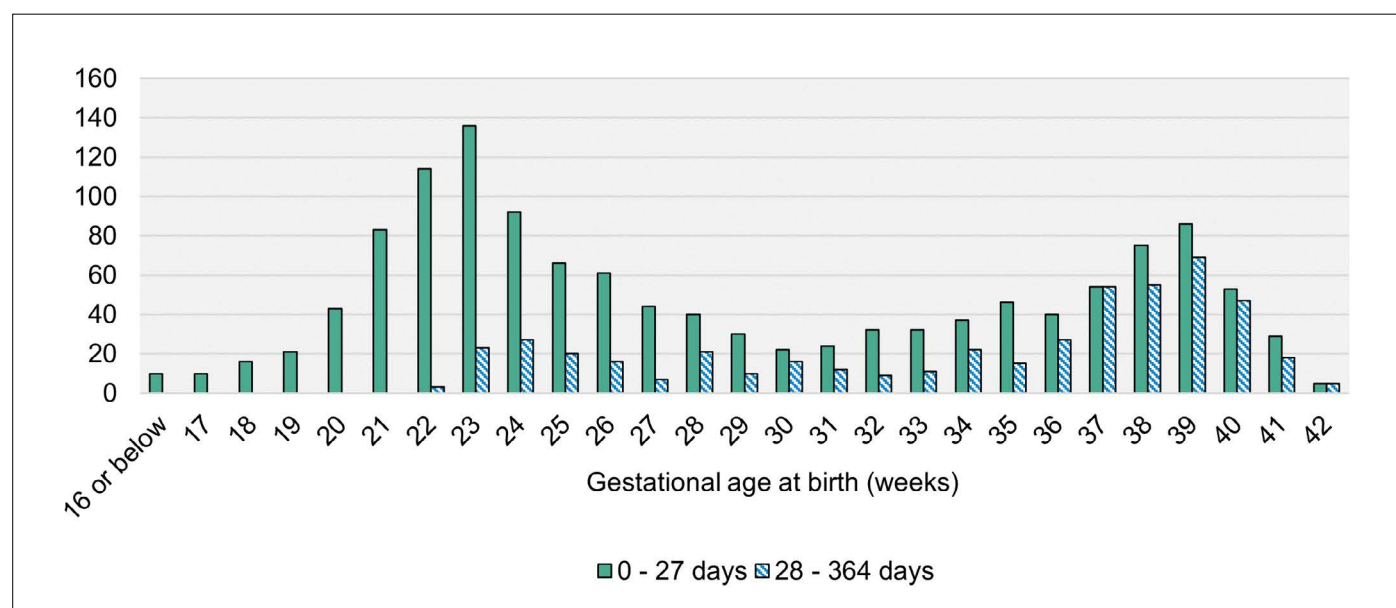
Data only presented for deaths of infants (<1 year)

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)

The distribution of number of infant deaths by gestational age at birth is shown in Figure 8.

**Figure 8: The number of infant death notifications received by Child Death Overview Panels by gestational age at birth (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)

## Child deaths (England): Prematurity

1 Apr 2019 to 31 March 2020

**NCMD**  
National Child Mortality Database

**69%** infant deaths  
(under 1 year old)  
**are born preterm**  
(before 37 weeks)



## Recommendation 4

Support availability and access to complete ethnicity and gestational age at birth data at the point of notifying a death to NCMD.

**Action by: Child Death Review Professionals, Child Death Overview Panels, NHS England, Department of Health and Social Care**

### 3.7 Review and categorisation of deaths occurring between 1 April 2019 and 31 March 2020

The child death notification form, on which the data in this section are based, collects information on the *suspected* cause of death. This is completed using information available in the 48 hours after the death occurs and is therefore subject to change after discussion with the medical examiner and in some cases, completion of the post-mortem examination process and investigation by the coroner. NCMD does not therefore report these data as they remain unconfirmed until completion of the child death review process.

740 (22%) of the child deaths which occurred between 1 April 2019 and 31 March 2020 were reviewed by a CDOP in this time period (the data for these cases are included within [Section 4](#)).

The majority (78%, n=2,607) of these deaths had not been reviewed by a CDOP by 31 March 2020. This is because each review takes at least several months to complete and this time can vary depending on the circumstances of the death. Factors that can contribute to a longer length of time between the death of a child and CDOP review include: the return of reporting forms from professionals, the completion of the final post mortem report by the pathologist, undertaking of a coronial or criminal investigation or a Child Safeguarding Practice Review (formerly known as Serious Case Review), and receipt of the final report from the local child death review meeting. Once these deaths have been reviewed by a CDOP, they will be included in the review cohort of future NCMD annual reports.

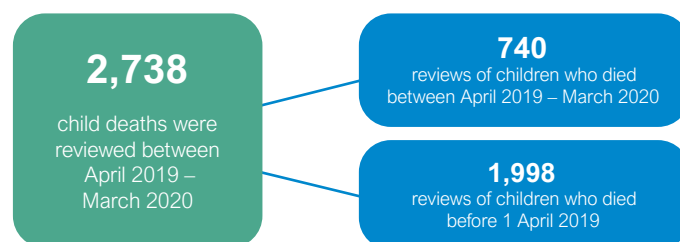
Notification to NCMD immediately after death includes basic demographic data and the suspected cause of death. The CDOP offices then undertake a data collection process and the cause and category of death is confirmed once the case has been reviewed by CDOP some months later.

In future years, the NCMD will be able to report on confirmed category of death for each defined year when deaths occurred.



## 4. Deaths reviewed between 1 April 2019 and 31 March 2020

This section focuses on data from the completed child death reviews by the CDOPs where the child death review took place between 1 April 2019 and 31 March 2020 (the child may have died in previous years). CDOPs in England must review all deaths of children normally resident in the local area and, if they consider it appropriate, any non-resident child who has died in their area.



### 4.1 The number of child death reviews

2,738 child deaths were reviewed by CDOPs in England between 1 April 2019 and 31 March 2020. Of these, 27% (n=740) were reviews of children who died within the same year and 73% (n=1,998) were reviews where the child died before 1 April 2019.

The number of completed reviews in 2019-20 decreased by 16% (n=512) from the previous year (Table 4). This is potentially due to fewer CDOP meetings taking place whilst they were working under transitional arrangements. In addition, many CDOP meetings were cancelled in March 2020 due to the response to the COVID-19 pandemic. Further breakdown of these data is presented in [Appendix A](#) (Tables 13 and 14).

**Table 4: The number of child death reviews completed and the number of reviews where modifiable factors were identified by Child Death Overview Panels by region, years ending 31 March**

Region	Number of reviews completed (Years ending 31 March)					Number (%) of reviews completed which were assessed as having modifiable factors* (Years ending 31 March)				
	2016	2017	2018	2019	2020	2016	2017	2018	2019	2020
<b>England</b>	<b>3,665</b>	<b>3,575</b>	<b>3,595</b>	<b>3,250</b>	<b>2,738</b>	<b>863 (24%)</b>	<b>974 (27%)</b>	<b>1,015 (28%)</b>	<b>965 (30%)</b>	<b>862 (31%)</b>
North East	151	157	130	135	110	27 (18%)	39 (25%)	45 (33%)	35 (25%)	41 (37%)
North West	546	582	565	490	366	161 (29%)	176 (30%)	215 (38%)	200 (41%)	164 (45%)
Yorkshire and Humberside	407	414	380	315	348	115 (28%)	126 (30%)	130 (34%)	100 (31%)	128 (37%)
East Midlands	296	280	310	230	214	67 (23%)	74 (26%)	95 (31%)	65 (27%)	79 (37%)
West Midlands	489	444	595	485	408	96 (20%)	125 (28%)	150 (25%)	140 (28%)	102 (25%)
East of England	358	303	300	305	234	108 (30%)	98 (32%)	85 (29%)	70 (22%)	66 (28%)
London	555	600	605	600	484	108 (19%)	125 (21%)	125 (21%)	170 (28%)	116 (24%)
South East	545	500	455	465	342	91 (17%)	130 (26%)	110 (25%)	115 (25%)	96 (28%)
South West	318	295	255	225	232	90 (28%)	81 (27%)	60 (24%)	80 (37%)	70 (30%)

Data source: NCMD, LSCB1 Return 2018/19

Regions are ONS regions that have been mapped to responsible CDOPs who will complete review, a mapping list is available in [Appendix C](#)

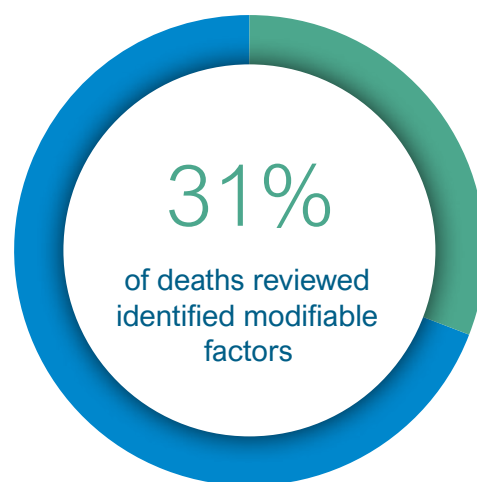
\*The denominator used to calculate the percentage is the total number of all deaths reviewed. This methodology was kept for 2020 to be consistent with previous years' data publications. There were 23 deaths in 2020 where there was insufficient information to determine modifiable factors



During the review, the CDOP is responsible for identifying any modifiable factors in relation to the child's death. Such modifiable factors are defined as factors which, by means of nationally or locally achievable interventions, could be modified to reduce the risk of future child deaths.

Out of the 2,738 reviews completed by CDOPs, 31% (n=862) identified one or more modifiable factors (Table 4). This percentage is comparable to the figure reported in 2018-19, but the proportion of reviews identified with modifiable factors continues to increase each year and in total, by 7% since 2015-16. The cohort of deaths reviewed in any given year depends on multiple factors, including how quickly the information can be gathered for each death, the progression and completion of parallel processes such as the coronial process and the number of CDOP meetings held by the panel reviewing the case. It is therefore difficult to comment on the apparent increase in the number of deaths with modifiable factors as this could be due to random variation within the deaths reviewed in the 2019-20 year. Once all the deaths that occurred in 2019-20 have been reviewed, further analyses can be performed to look at modifiability by year of death.

The proportions of reviews that identified modifiable factors are reported in each table throughout this section and the details of these modifiable factors are presented within [Section 5](#).



## 4.2 Mode of death

The mode of death (this is the sequence of events preceding the death, rather than the underlying cause of the death) was recorded in 2,091 (76%) reviews. Of these, for 37% (n=773) the death resulted from *withholding, withdrawal, or limitation of life-sustaining treatment* (Table 5). For a further 26% (n=535) of deaths planned palliative care was recorded as the mode of death.

**Table 5: The number of reviews completed by Child Death Overview Panels by mode 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
Mode of death	n (%)	n (%)	n (%)
Brainstem death	48 (2%)	47 (2%)	19 (40%)
Unsuccessful cardio-pulmonary resuscitation	453 (22%)	446 (21%)	202 (45%)
Found dead	282 (13%)	282 (14%)	167 (59%)
Planned palliative care	535 (26%)	535 (26%)	76 (14%)
Withholding, withdrawal, or limitation of life-sustaining treatment	773 (37%)	767 (37%)	217 (28%)
<b>Total</b>	<b>2,091 (100%)</b>	<b>2,077 (100%)</b>	<b>681 (33%)</b>

Data source: NCMD

In 647 cases, data for the mode of death were not known or incomplete



### 4.3 Social Care and Child Safeguarding Practice Reviews

Of the 1,876 (69%) reviews where social care information was known to and reported by the CDOPs, the NCMD received information on 254 (14%) children who were known to social care at the time of their death, with 176 (9%) children having had previous input, and 1,446 (77%) without any record of previous social care involvement (Table 6). Of the 254 children who were known to social care, 41% (n=104) had modifiable factors identified in the review. 41 children were on a child protection plan at the time of death, and a high proportion (78%, n=32) of these reviews identified modifiable factors.

A Child Safeguarding Practice Review (previously Serious Case Review) in England is conducted when a child is seriously harmed, or dies, as a result of possible abuse or neglect as outlined in *Working together to safeguard children (2018)*. The review identifies how local professionals and organisations can improve the way they work together. Out of the number of child death reviews completed throughout the year, NCMD received information that a Child Safeguarding Practice Review was carried out for at least 48 child deaths (Table 7). Of these, 79% (n=38) identified modifiable factors in the review.

**Table 6: The number of reviews completed by Child Death Overview Panels by social care status, 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
Known to social care	n (%)	n (%)	n (%)
Yes, at the time of death	254 (14%)	253 (14%)	104 (41%)
Child protection plan <sup>a</sup>	41 (2%)	41 (2%)	32 (78%)
Looked after child <sup>a</sup>	25 (1%)	25 (1%)	12 (48%)
Child in need <sup>a</sup>	105 (6%)	105 (6%)	31 (30%)
Other <sup>a</sup>	118 (6%)	117 (6%)	47 (40%)
Previously, but not at time of death	176 (9%)	174 (9%)	78 (45%)
Not at all	1,446 (77%)	1,429 (77%)	407 (28%)
<b>Total</b>	<b>1,876 (100%)</b>	<b>1,856 (100%)</b>	<b>589 (32%)</b>

Data source: NCMD

In 862 cases, data for the child's social care status was not known or incomplete

<sup>a</sup>Each child death review included under 'Yes, at the time of death' can be known to social care in multiple ways and therefore these totals will not sum to the total of reviews

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

Due to a change in data collection and CDR processes in the year ending 31 March 2020, there were more incomplete data for social care status than in previous years

**Table 7: The number of reviews completed by Child Death Overview Panels by Child Safeguarding Practice Review status, 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
Child Safeguarding Practice Review (CSPR)	n (%)	n (%)	n (%)
A CSPR took place	48 (2%)	48 (2%)	38 (79%)
A CSPR did not take place	2,445 (98%)	2,424 (98%)	776 (32%)
<b>Total</b>	<b>2,493 (100%)</b>	<b>2,472 (100%)</b>	<b>814 (33%)</b>

Data source: NCMD

In 245 cases, child safeguarding practice review data was not known or incomplete

## 4.4 Primary category of death

CDOPs are required to assign a category to each death during the review. The classification of categories is hierarchical, where the uppermost selected category will be recorded as the primary category, should more than one category be selected. A description of these categories can be found in [Appendix D](#).

Deaths categorised as perinatal/neonatal events had the highest overall number of reviews that identified modifiable factors

31% (n=860) of deaths reviewed recorded a primary category of *Perinatal/neonatal event*, and a further 25% (n=676) recorded a primary category of *Chromosomal, genetic and congenital anomalies* (Table 8). These two categories combined represented over half (56%) of the reviews completed. Deaths categorised as *perinatal/neonatal events* had the highest overall number of reviews that identified modifiable factors (n=277, 33%).

221 (8%) of deaths reviewed were categorised as *Sudden unexpected and unexplained*, and where sufficient information was available (n=219), 75% (n=164) identified modifiable factors, the highest proportion across all categories. There were 119 (4%) reviews categorised as *Trauma or other external factors*, where 56 of these were deaths from the result of a vehicle collision.

There were 212 (8%) deaths with a primary category of *Malignancy*. This category had the lowest proportion (5%, n=11) of deaths identified as having modifiable factors across all categories.

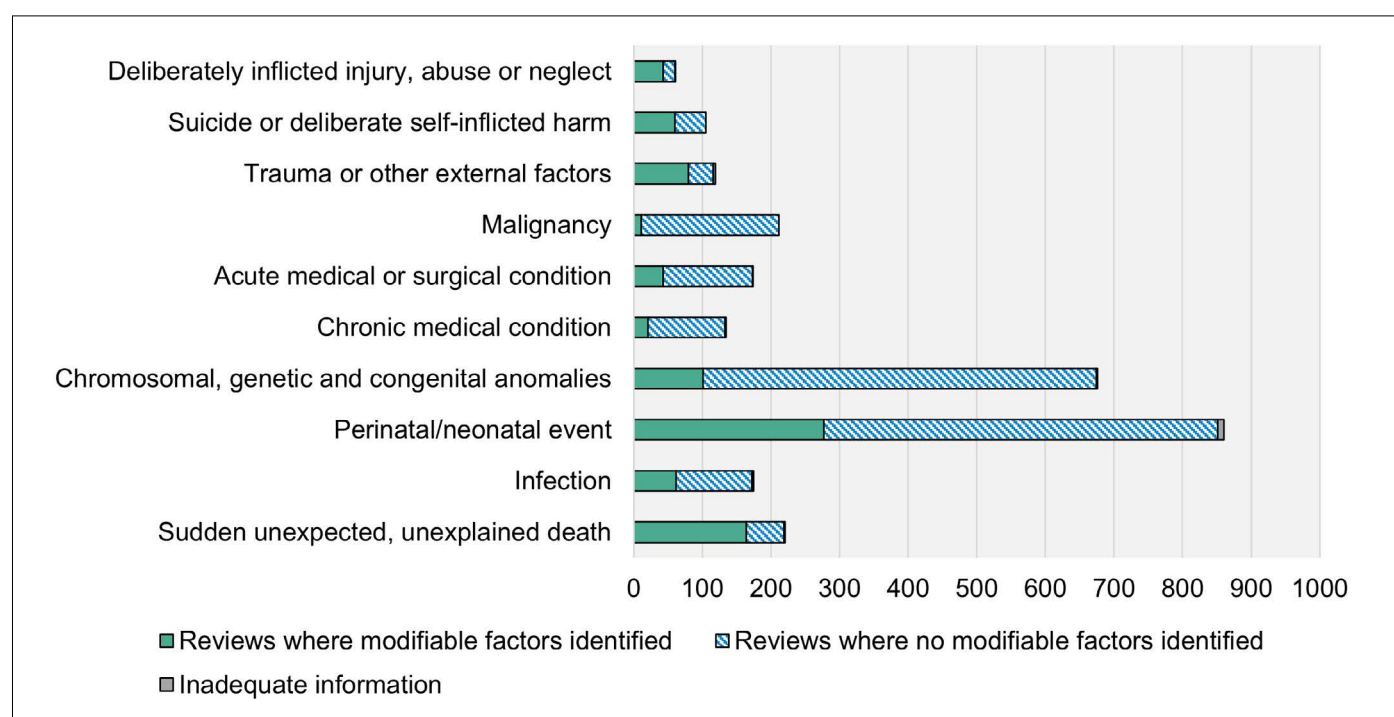
The highest proportion of deaths with modifiable factors were identified (all over 50%) within the categories: *Sudden unexpected and unexplained death* (75%, n=164/219), *Deliberately inflicted injury, abuse or neglect* (72%, n=43/60), *Trauma or other external factors* (69%, n=80/116) and *Suicide or deliberate self-inflicted harm* (57%, n=60/105). A forthcoming NCMD thematic report on suicide will explore this topic in detail and is due to be published later this year.

In addition to the category of death, based on information provided by the CDOPs, NCMD were able to sub-categorise some of these death categories to provide a more granular level of detail. For further methodology please see [Appendix B](#).

The details of the modifiable factors identified and reported to NCMD are presented within [Section 5](#) of the report.

Figure 9 presents the overall number of reviews by category of death and the proportion of these that identified modifiable factors.

**Figure 9: The number of reviews completed by Child Death Overview Panels by primary category of death and whether modifiable factors were identified, year ending 31 March 2020**



Data source: NCMD  
n= 2,738

**Table 8: The number of reviews completed by Child Death Overview Panels 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%)
<b>Total</b>	<b>2,738 (100%)</b>	<b>2,715 (100%)</b>	<b>862 (32%)</b>

Data source: NCMD

There were 23 deaths where panels had insufficient information to determine if there were modifiable factors in the child's death. In some cases, this was because it was not possible to gather further information. For example, if the coroner was unable to conclusively determine the cause of death. In other cases, it was because of difficulties in obtaining accurate information, for example when a child died abroad and limited information was provided to the panel

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

## Perinatal/neonatal events

With deaths categorised as Perinatal/neonatal events being responsible for the largest proportion of death reviews (31%, n=860), work was undertaken to determine the sub-categories for these deaths. A total of 819 (95%) had sufficient information to further sub-categorise the death; with 80% (n=657) being immaturity/prematurity related, 13% (n=105) related to perinatal asphyxia, and 5% (n=38) due to perinatally acquired infection.

28 out of the 38 deaths categorised as due to perinatally acquired infection had a confirmed bacterial or viral infection. 12 infants died following an infection by a gram-negative bacteria (including five following a confirmed *Escherichia coli* infection) while fewer than 5 infants died as a result of Group B streptococcal infection in the first week of life.

The vast majority (77%, n=74) of deaths in children born after 37 weeks gestation were due to perinatal asphyxia; with sentinel events of out of hospital delivery, placental abnormalities and antepartum haemorrhage being reported.

### Recommendation 5

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.

**Action by: Hospital Trusts, Service Planners, Commissioners and Policy Makers at local and regional level**

**Table 9: The number of reviews categorised as *Perinatal/Neonatal event* by Child Death Overview Panels by sub-category and gestational age at birth, year ending 31 March 2020**

Sub-category	Reviews categorised as <i>Perinatal/Neonatal event</i> (Year ending 31 March 2020)		
	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%)
<b>Total</b>	<b>723</b>	<b>96</b>	<b>819 (100%)</b>

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)

## Category of death by age group

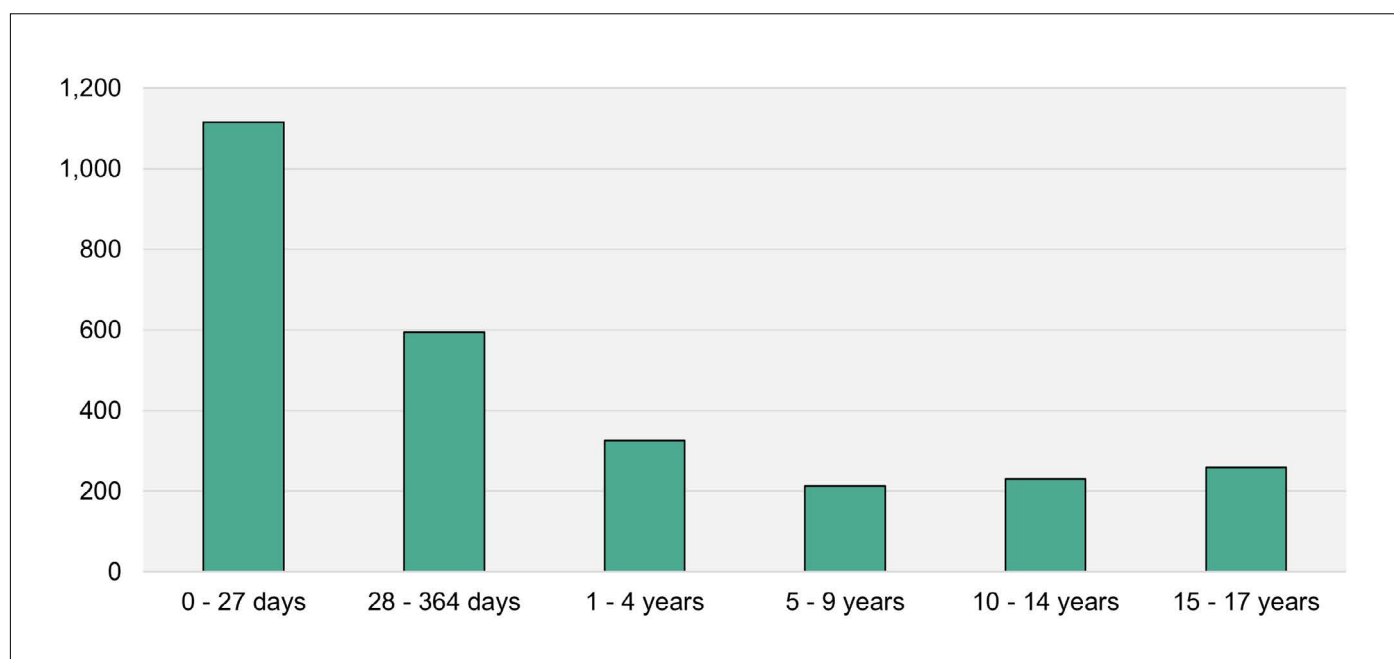
Figure 10 presents the number of child death reviews by age group and figure 11 presents the proportion of reviews in each age group by category of death. Some categories of death in figure 11 have been combined to aid interpretation.

The proportion of deaths that were classified as *External causes* (*Deliberately inflicted injury, abuse or neglect, Suicide or deliberate self-inflicted harm, Trauma or other external factors*) increases with age. Over half (53%) of children between 15 and 17 years of age died of *External causes* in the deaths reviewed in this period. The proportion of deaths categorised as *Perinatal/neonatal event* decreases as age group increases, with 65% of the deaths reviewed where the child was aged under 28 days categorised as *Perinatal/neonatal event*. Perinatal causes were felt to be the primary category of death in 2% (n=17) of deaths over 1 year of age. Deaths which were classified under *Acquired natural causes* (*Malignancy, Acute medical or surgical condition, Chronic medical condition, Infection*) accounted for the largest proportion of deaths for each age group between 1 and 14 years.





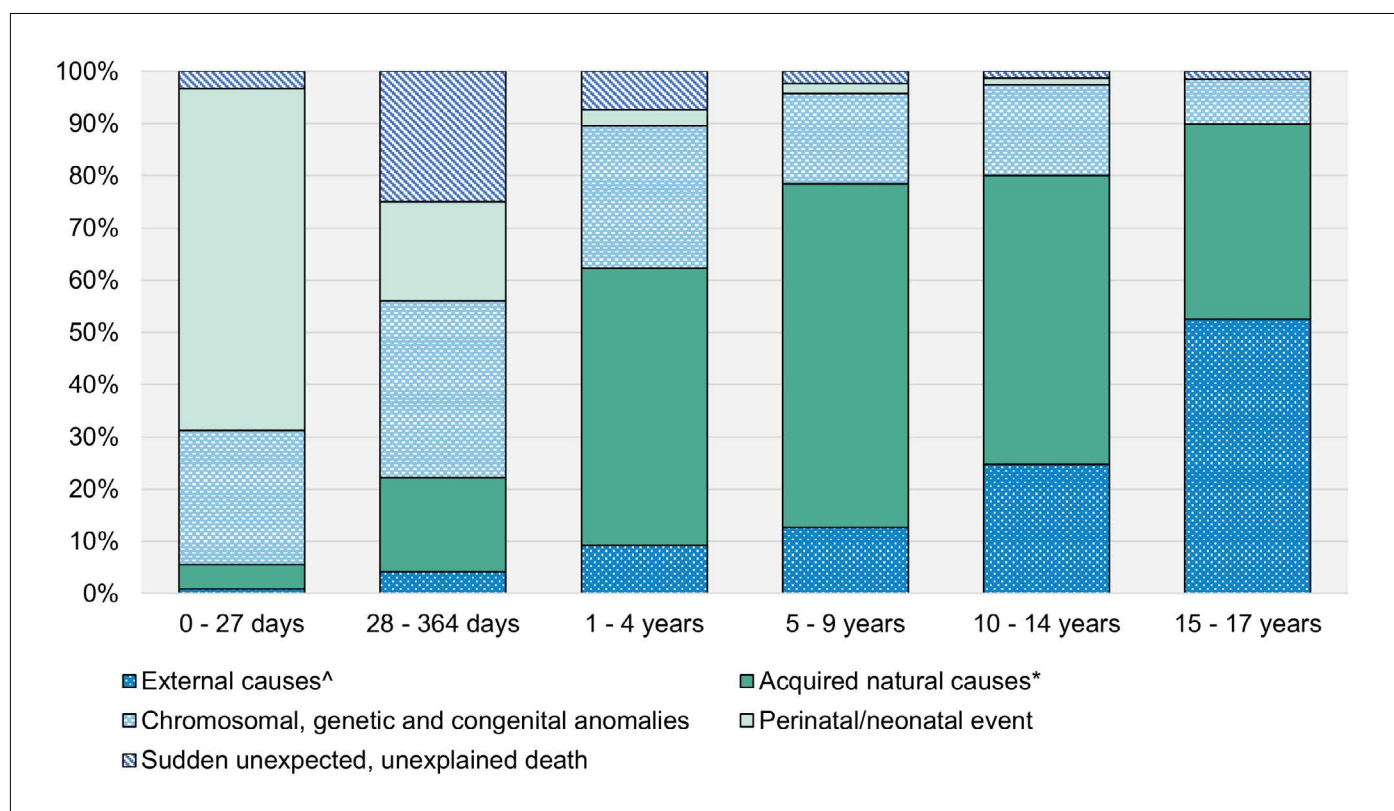
**Figure 10: The number of reviews completed by Child Death Overview Panels by age group, year ending 31 March 2020**



Data source: NCMD

n= 2,738

**Figure 11: The proportion of reviews completed by Child Death Overview Panels in each age group by category of death, year ending 31 March 2020**



Data source: NCMD

n= 2,738

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

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

<sup>\*</sup>Acquired natural causes: Malignancy, Acute medical or surgical condition, Chronic medical condition, Infection

# 5. Details of modifiable factors identified in deaths reviewed between 1 April 2019 and 31 March 2020

**Modifiable factors are defined as:**

“Factors which may have contributed to the death of the child and which might, by means of a locally or nationally achievable intervention, be modified to reduce the risk of future deaths.”

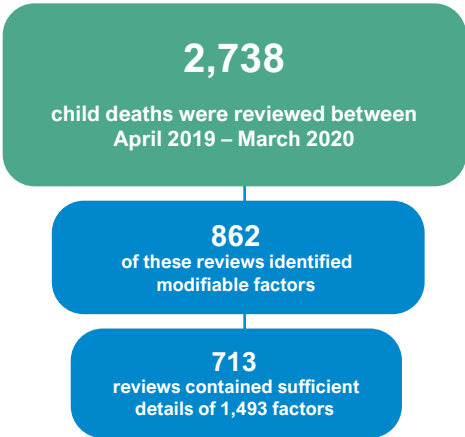
Working Together to Safeguard Children (2018)

This section focuses on the details of the modifiable factors that were recorded by CDOPs who are responsible for identifying whether there were any modifiable factors in relation to the child’s death. Changes introduced to the statutory data collection forms from April 2019 required CDOPs to list the modifiable factors they identified. Prior to this, CDOPs were not required to collect this information and therefore children in this cohort whose deaths occurred prior to 1 April 2019 had no details of the modifiable factors listed. This means that the interpretation of the analysis in this section is limited to the number of deaths where the list of modifiable factors was provided. Where the details of the modifiable factors were provided, these were reviewed and categorised by the NCMD team using the available information to interpret the context. Previous publications on child death review data focused on presenting the proportion of cases that identified modifiable factors. NCMD built on this by carrying out a more detailed analysis to identify and describe these factors from the free text information provided by the CDOPs.

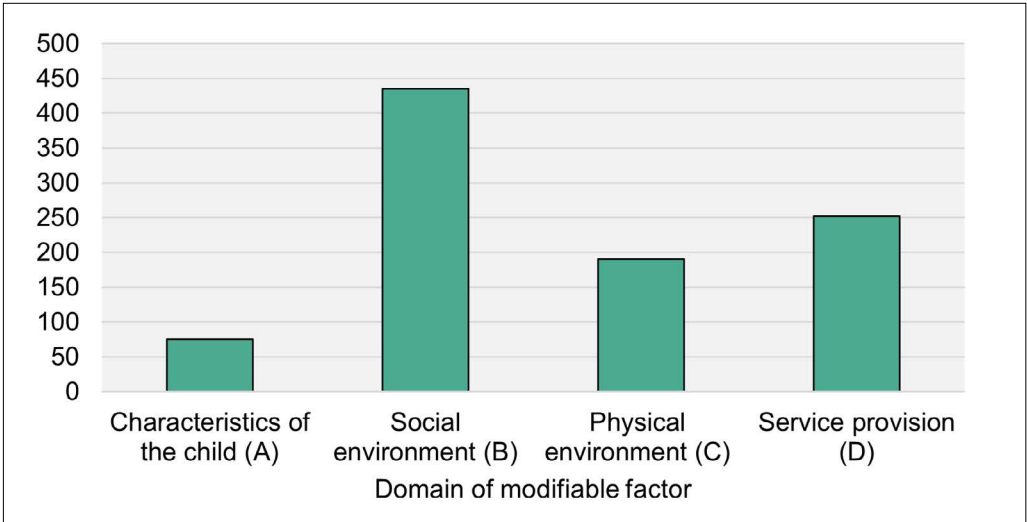
It is important to note that the information reported within this section is what CDOPs across England have recorded at their panel meetings and subsequently submitted to NCMD as modifiable factors.

Whether a factor is deemed to be modifiable is dependent on the circumstances of the death and the interpretation of the modifiable factors may vary across CDOPs. This analysis only covers those factors that were assessed as modifiable by the CDOP; these factors may have been present in more deaths but were not deemed modifiable in those cases by the reporting CDOPs.

More than one modifiable factor was identified by the CDOPs in many of the reviews. The interaction of multiple factors can increase the impact of these factors and vulnerability to death compared with what the impact might have been if there was only one factor present. It should be noted that these factors may be related to the cause of death (e.g. if the child dies from a vaccine preventable infection), or the child’s vulnerability or ill-health (e.g. if the child suffers from a respiratory condition and lives in a household where individuals smoke). They have been identified as potentially modifiable by an intervention which, once in place, could reduce the risk of future child deaths either directly, or by reducing the elements which increase children’s vulnerability and/or ill health.



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



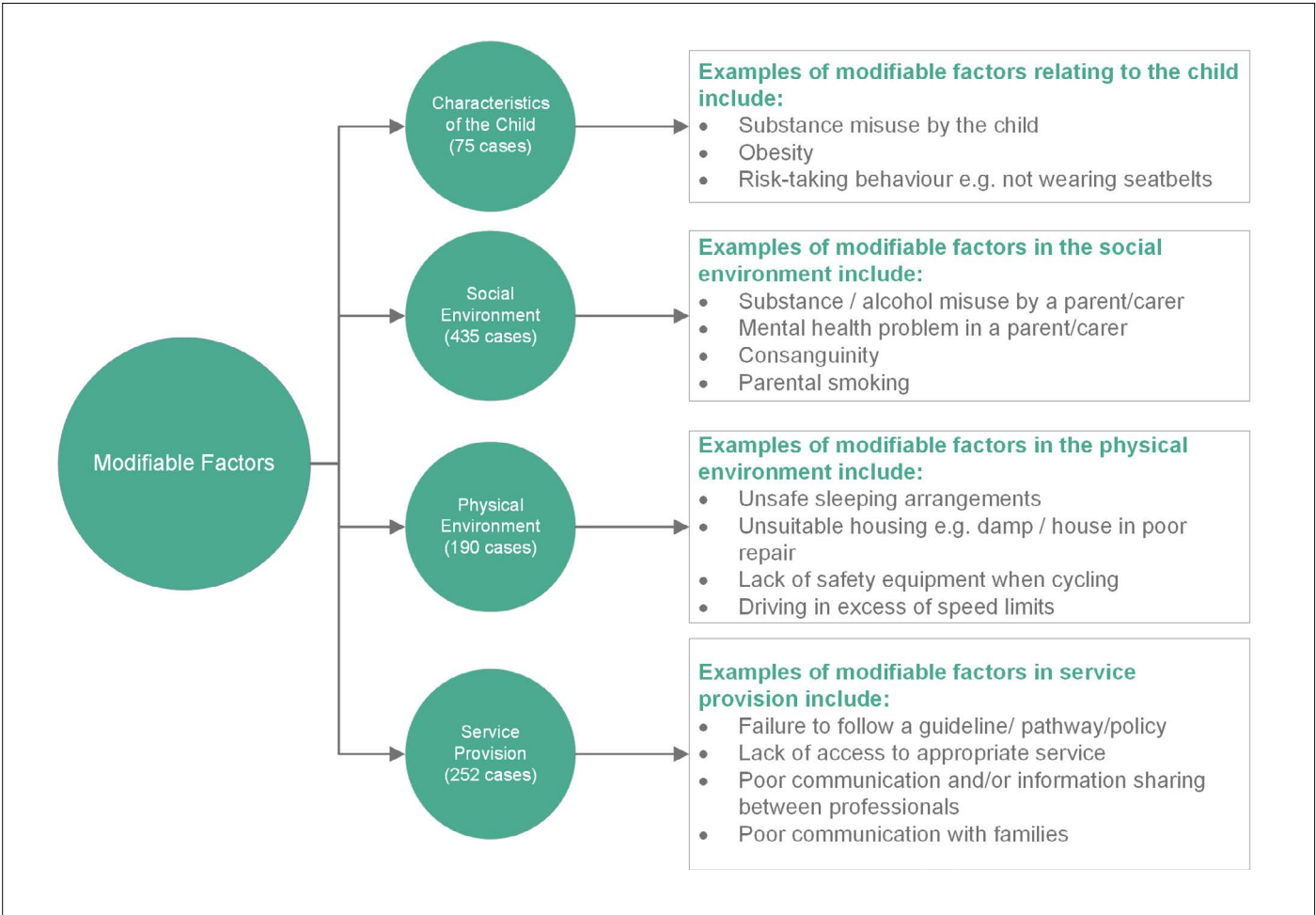
Data source: NCMD  
n= 713  
The number of reviews in each domain do not sum to the total as 239 reviews had a modifiable factor in more than one domain

Out of the 862 cases where modifiable factors were identified, sufficient details of these factors were submitted for 713 (83%) cases. There were 1,493 factors recorded in total, which was on average 2 factors per case.

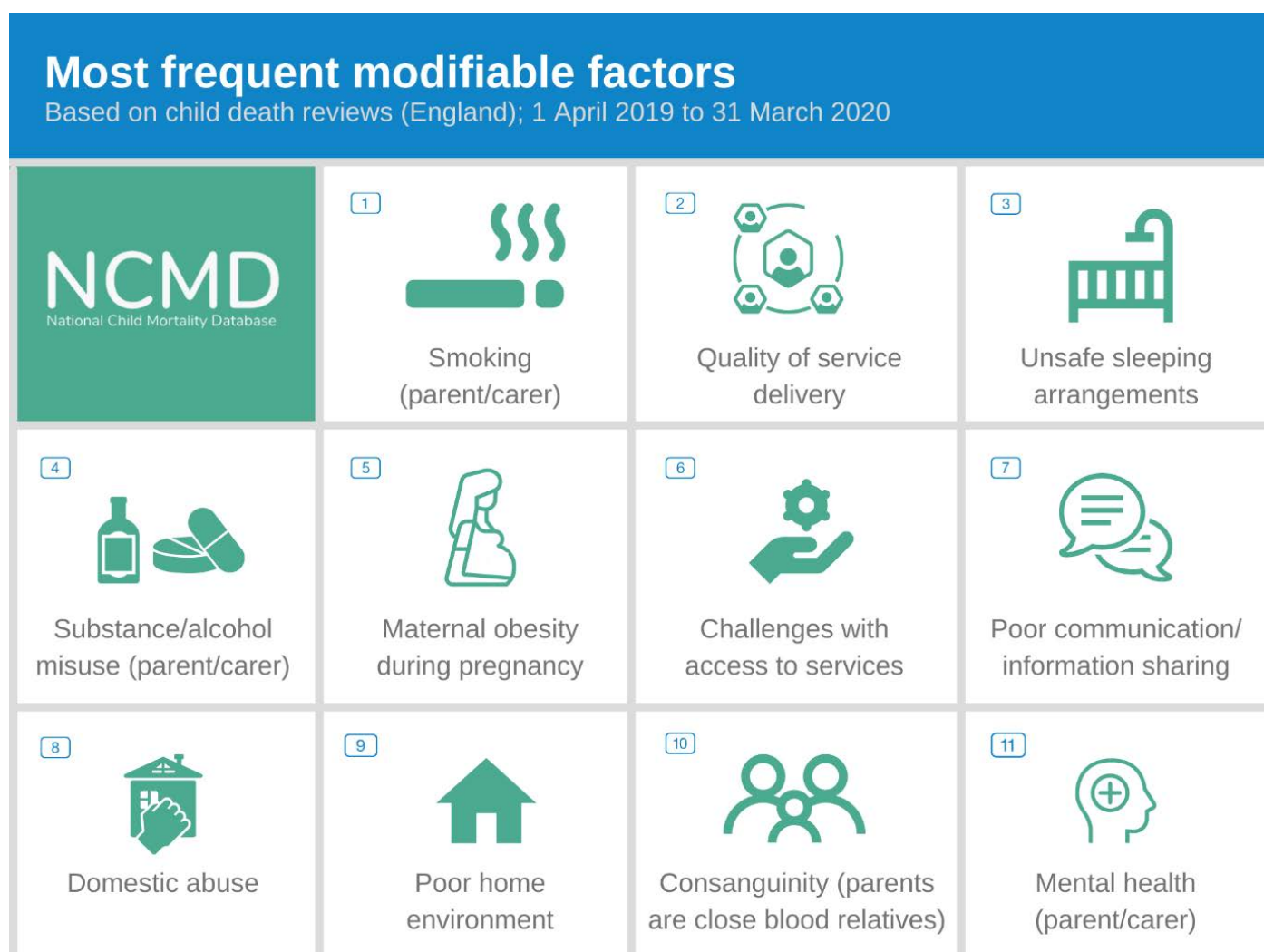
Of the 713 reviews with sufficient details of modifiable factors submitted to NCMD, over half (61%, n=435) of these reviews identified at least one factor in the social environment, 252 (35%) identified a factor in service provision, 190 (27%) identified a factor in the physical environment, and 75 (11%) identified a factor in the child that was deemed by the CDOP to be modifiable (Figure 12).

A description of each domain is available in [Appendix E](#).

The diagram below shows some examples of modifiable factors identified by CDOPs during their reviews:



## 5.1 Most frequent modifiable factors across all child deaths



For all child deaths that were reviewed during 2019-20, the most frequently recorded modifiable factors are listed below. These are all factors which were present in 30 reviews or more.

Interventions to further reduce these modifiable factors and their significant impact on child health could prevent future child deaths.

### 1. Smoking by a parent or carer

Smoking was reported as a modifiable factor in 226 deaths. This included smoking during pregnancy and smoking by anyone in the child's household. The [NHS Live Well web page](#) includes information about the risks of smoking and how to protect family members from second-hand smoke. Pregnant women exposed to passive smoke are more prone to premature birth and their baby is more at risk of low birthweight and Sudden Infant Death Syndrome (SIDS). Children who live in a cigarette smoke filled environment are at higher risk of breathing problems such as asthma and allergies.







"It is vital that professionals understand safe infant sleeping arrangements and give families accurate evidence-based information. Advice should be tailored to individual family circumstances with an explanation that bed-sharing is only a risk factor when in the presence of other factors such as smoking, alcohol and drug use, but that falling asleep on a sofa or an armchair with a baby is always dangerous. Almost all parents sometimes fall asleep whilst feeding a baby at night, so even if they do not plan to routinely bedshare, parents should be advised how to make their bed safe for the baby if they fall asleep unintentionally."

**Professor Peter Fleming**  
University of Bristol

## 2. Quality of service delivery

The quality of service delivery was reported as a modifiable factor in 147 deaths. It is important to note that modifiable factors identified in the Service Provision domain can relate to any agency providing services to children. This includes healthcare services, education services, social care services and law enforcement and youth justice services. The issues identified here relate to circumstances where something did not happen or happened at the wrong time, and where the service delivered was of poor quality. For example, CDOPs regularly reported issues with a failure of professionals to follow a specific guideline or policy. These are instances where guidance/policies were available but were not followed by professionals in health, social care and education. Examples include failure to follow up on missed appointments and failure to follow appropriate guidelines for labour and delivery.

## 3. Unsafe sleeping arrangements

CDOPs reported unsafe sleeping arrangements as a modifiable factor in 122 deaths. These were almost all noted in sudden, unexplained infant deaths. The current [NICE guidance](#) highlights that the cause or causes of such deaths are not known and it is possible that many factors contribute, but some factors are known to make such deaths more likely. The guidance gives advice on the association between co-sleeping and SIDS and the circumstances in which the association is likely to be greater. An example of an unsafe sleeping arrangement is where an adult is co-sleeping on a sofa or armchair with a baby. The leaflet [Caring For Your Baby At Night: A Guide for Parents](#), is a resource covering a range of topics including safe sleeping environments and is endorsed by UNICEF, The Lullaby Trust, the Royal College of Midwives (RCM), the Institute of Health Visiting (iHV) and the Community Practitioners and Health Visitors Association (CPHVA). Additionally, The Lullaby Trust provides further information on [How to reduce the risk of SIDS](#).

## 4. Substance and/or alcohol misuse by a parent or carer

Substance misuse was more commonly recorded than alcohol misuse in this group. Substance and/or alcohol misuse by a parent or carer was reported as a modifiable factor in 96 deaths reviewed by CDOPs during this period, with the majority of cases relating to parental or carer use of recreational drugs. This also included some cases of drug and alcohol use during pregnancy. The most common categories of death where this was identified as a modifiable factor were *Sudden unexpected, unexplained death* and *Perinatal or neonatal event*. The [NSPCC](#) highlights that parents or carers who misuse drugs can have chaotic, unpredictable lifestyles and may struggle to recognise and meet their children's needs. This may result in their children being at risk of harm.

## 5. Maternal obesity during pregnancy

The body mass index (BMI) is a measure that uses height and weight to work out if a person's weight is healthy. In 82 occurrences, CDOPs stated that the mother was reported to have a significantly high BMI during pregnancy and recorded this as a modifiable factor. CDOPs commented on the difficulty in seeing the baby clearly during antenatal scans in women with high BMI, which can also lead to difficulties in identifying problems with the baby's development such as cardiac problems or other congenital anomalies, and can lead to medical problems (e.g. gestational diabetes) in the mother. Obesity may also increase the risk of pre-term delivery or contribute to increased risk of a large baby with subsequent delivery complications.<sup>8</sup>

## 6. Challenges with access to services

Challenges in accessing any service was reported as a modifiable factor in 77 deaths. The issues reported here relate to challenges in accessing any service, e.g. social care, health or education. They are broadly split into two groups. The first group are issues with availability or capacity of services and examples include lack of bed capacity at intensive care units and age criteria for screening for certain health conditions. The second group relates to issues where services are available, but there are challenges in supporting families to access them. Marginalised families may be disadvantaged or difficult to reach and are often under-served because of their limited engagement with services. As a result, they frequently experience poorer health and social outcomes.<sup>9</sup> Examples reported by CDOPs include poor engagement with antenatal services and compliance with medication regimen.

## 7. Poor communication and information sharing

This was reported as a modifiable factor in 75 deaths. There were many examples reported by CDOPs of poor communication and information sharing, both between professionals and between professionals and families. Examples include poor information sharing between primary care, community services and education, and sharing of information across county and regional boundaries. Poor family communication included lack of information sharing with wider caregivers and family members; in some cases information was shared only with the mother of the child. Inadequate communication of risk to families was also highlighted.

## 8. Domestic abuse

The NSPCC defines domestic abuse as any type of controlling, coercive, threatening behaviour, violence or abuse between people who are, or who have been in a relationship, regardless of gender or sexuality. It can include physical, sexual, psychological, emotional or financial abuse. Exposure to domestic abuse or violence in childhood is a type of child abuse and was reported as a modifiable factor in 50 deaths reviewed by CDOPs during the year. It is important to note that the deaths included in this group were from a variety of causes and the domestic abuse did not necessarily directly lead to the child's death. CDOPs reported instances of domestic abuse where children were present at the time of the incident, and cases where the child was in another room and overheard the abuse or saw the consequences of it afterwards.

## Rayana

Rayana was a baby girl who was born prematurely following a complicated pregnancy.

The family were visiting the UK on student visas and Rayana was well when the family arrived. The family opted not to pay an NHS surcharge when they got their visas, which meant that the family were not entitled to free NHS treatment. After a few months of being in the UK, Rayana became ill and required treatment in hospital. Following this episode of care, the family received a large hospital bill which created significant financial hardship and distress for them. A little while later, shortly before the family were due to return to their country of origin, Rayana became unwell and eventually collapsed at home and sadly could not be resuscitated. It was felt that the hospital bill relating to the previous admission prevented the family from seeking medical assistance sooner.

## Learning and actions

The CDOP felt earlier presentation to healthcare services may have made a difference to the outcome in this case and recorded this as a modifiable factor. Good practice was noted in that the Trust Overseas Visitors Manager attended the CDR meeting. The family's visa clearly stated that they would not receive free health care. They were required to pay a one-off charge for the first 3 weeks of treatment, and then a daily charge thereafter. Non-payers are reported to the Department of Health which would affect future visa applications. Unfortunately, it seems that the cost implications placed on the family may have deprived Rayana of the care she required, until it was too late. NHS charges are dropped upon a patient's death.

<sup>8</sup> Norman, Reynolds and Symposium, 2011

<sup>9</sup> Hui et al, 2020



Neonatal deaths represent the highest proportion of child deaths by age group. Approximately half of the deaths that we review at CDOP are those of neonates. Identifying and challenging the barriers to women accessing timely maternity care is of paramount importance. In 2017 a significant amendment was made to the National Health Service charging regulations for overseas visitors; maternity care became chargeable at 150% of the NHS tariff for anyone that is not 'ordinarily resident' in England.<sup>10</sup> If a debt in excess of £500 has not been paid and no repayment plan agreed, hospitals will share this information with the home office. There is evidence that fear of charges can lead to delayed presentation to maternity services, and reduced attendance for antenatal care. This has contributed to adverse pregnancy outcomes, including deaths as noted in the MBRRACE-UK 2019 report.<sup>11</sup>

In Greenwich, London, the CDOP learnt that charging fees for maternity care has been a barrier to accessing necessary antenatal care for some of the most vulnerable women, exacerbating racial, gender and socioeconomic inequalities in our society. Our CDOP contacted the NCMD about our concerns that no data was being routinely collected on adverse neonatal and infant outcomes associated with this barrier to care. Our concerns were met with immediate engagement and we have worked collaboratively with the NCMD to instate a routine data collection field on child death reporting forms from April 2021, which asks whether charges may have delayed care. Collecting this data at a national level will allow a true picture to be built of the scale of this problem. Locally, we have engaged our local trust in a process of change to implement the charging regulations in as sensitive and compassionate a manner as possible. This includes communication that overcomes language barriers, more stringent measures to identify exemptions, clear signposting to support services, and raising the threshold for involvement of debt collectors. Going forward, we hope that CDOPs across England will scrutinise the process employed by their local hospitals to implement charging regulations. In doing this, we can act to ensure that the inevitable harms of charging user fees for maternal care are reduced.

**Dr Nikesh Parekh (CDOP Chair and public health medical associate, Greenwich)**  
**Sophie Russell (Consultant midwife, Queen Elizabeth Hospital, Woolwich)**

<sup>10</sup> The National Health Service, Charges to Overseas Visitors, 2004  
<sup>11</sup> Knight et al, 2019



## 9. Poor home environment

There is a growing evidence on the negative effects associated with unhealthy housing situations, including crowding, frequent moves, cold homes (fuel poverty) and damp/mouldy conditions<sup>12</sup>. CDOPs recognised the importance to health and well-being of housing provision and conditions and they reported a poor home environment as a modifiable factor in 40 deaths reviewed this year. The most common concerns were lack of cleanliness, overcrowding, houses in poor repair and the presence of damp and/or mouldy conditions. There were also instances reported of families living in temporary accommodation or undergoing frequent moves creating an unstable living environment for the child.

## 10. Consanguinity (parents are known blood relatives to each other)

Close relative marriage, often marriage between cousins, is common around the world.<sup>13</sup> It is also preferred among some families and communities in the UK. Since blood relatives are more likely to carry the same gene variants than unrelated people, a higher incidence of autosomal recessive genetic disorders ensues. This manifests as higher population rates of congenital abnormality, infant and child mortality. The elevated risk is often exaggerated and the great majority of births to cousins are not affected by autosomal recessive genetic conditions. Risk clusters in families, and research shows that access to genetic information, counselling and testing is often poor for people in families where deleterious gene mutations exist. CDOPs reported the presence of consanguinity as a 'modifiable' factor in 33 deaths reviewed this year. The majority of these were categorised as deaths due to chromosomal, congenital, or genetic anomalies. Unlike other child deaths, most deaths caused by autosomal recessive genetic conditions are not avoidable through medical treatment or better care of the pregnant woman or child. Instead, reducing these deaths implies reducing conceptions and/or reducing the number of affected babies being born (i.e. termination of pregnancy). Clearly, both the decision to become pregnant and to terminate a pregnancy are personal choices with significant moral and religious considerations. Further work is therefore needed to clarify whether deaths of babies to consanguineous couples were anticipated, that is, whether it was the couple's choice to proceed, and whether couples are receiving access to the information and support they need to make such difficult decisions in an informed manner. The labelling of consanguinity in-and-of-itself as a modifiable risk factor should be refined in future CDOP reporting, since the key focus must be on the presence of genetic mutations that present risk.



## 11. Mental health condition in a parent or carer

Modifiable factors in the social environment are collected and reviewed by CDOPs to understand the circumstances in which the child was living and whether anything in those circumstances may have created additional vulnerability or had an impact on the child's ill-health or death. The presence of a mental health condition (e.g. depression or anxiety) in a parent or carer was reported as a modifiable factor in 30 deaths. In some cases, it has been highlighted that children themselves have caring responsibilities for other family members. Research suggests that the caring role has an impact on the child's education, health, wellbeing, social opportunities and employment prospects.<sup>14</sup>

### Recommendation 6

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

**Action by: Policy Makers, Public Health Services, Service Planners and Commissioners at local and regional level, Local Government, Police and Crime Commissioners**

<sup>12</sup> Ormandy, 2014

<sup>13</sup> Khan, Salway, 2020

<sup>14</sup> Joseph et al, 2020



## 5.2 Modifiable factors by category of death

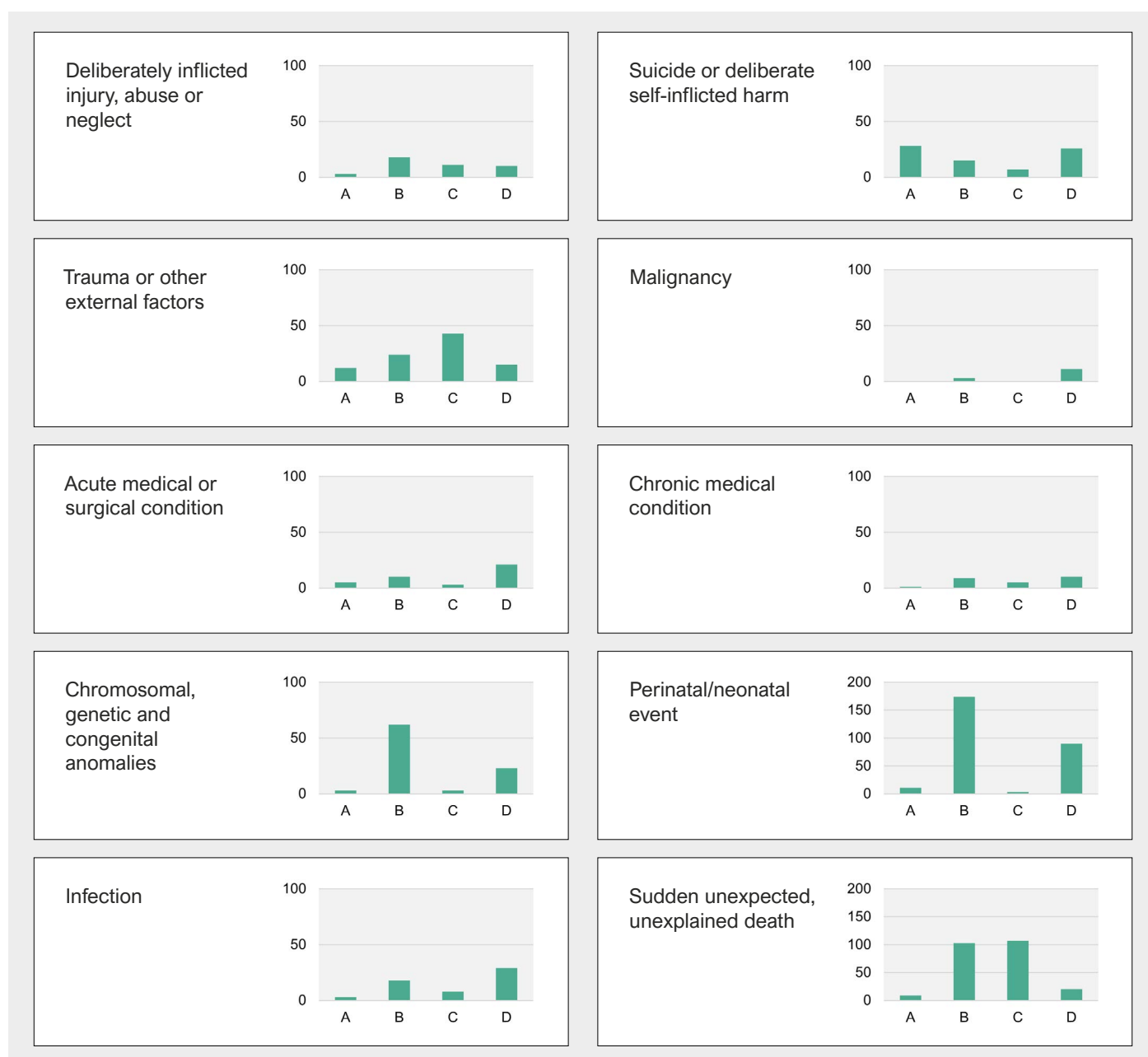
Figure 13 shows the profile of modifiable factors across domains for each category of death. This indicates in which domains these modifiable factors are being identified more frequently than others and the differences of these profiles across each category of death.

### Modifiable factors identified in deaths categorised as Perinatal/neonatal event

There were 242 reviews which submitted details of modifiable factors where the category of death was *Perinatal/Neonatal*

event and 174 of these reviews identified a modifiable factor in the social environment where the most frequent factors were: smoking by a parent or carer, raised maternal BMI during pregnancy, substance and/or alcohol misuse by a parent or carer, domestic violence, challenges with access to services and unbooked pregnancies. 90 reviews identified a modifiable factor within the service provision domain, including 59 reviews identifying factors in relation to gaps in service provision, and 26 reviews identifying factors in relation to poor communication.

**Figure 13: The number of deaths with at least one modifiable factor identified in each domain in reviews completed by Child Death Overview Panels, year ending 31 March 2020**



Data source: NCMD

A = Characteristics of the child, B = Social environment, C = Physical environment, D = Service provision

## Liam

Liam was born extremely prematurely. He developed an infection from which he could not recover, and he died at a few days of age.

This was Mum's first pregnancy, and she is a non-smoker with no medical problems. She booked for this pregnancy late but there were no issues until she went into spontaneous pre-term labour. She contacted the midwife who advised her to go to the hospital. When she got to the hospital, she was given a dose of steroids to help the baby to breathe more easily when he was born. Mum's labour progressed very quickly, and Liam was born soon afterwards. Liam needed some help to breathe when he was born but he quickly stabilised and was transferred to the neonatal unit. At two days old, Liam started to develop some problems and the doctors were concerned that he might have an infection, so he was given antibiotics. However, there was a delay in both the prescribing of the antibiotics and in Liam receiving them. It was noted that the department was extremely busy, and the delay occurred during the handover from one shift to the next.

### Modifiable factors (service provision – education)

The CDOP recorded that the modifiable factor in this case was the delay in prescribing and administration of antibiotics and noted that antibiotics should be given within one hour of the decision.

### Modifiable factors identified in deaths categorised as Sudden Unexpected and Unexplained

There were 140 reviews which contained sufficient details of modifiable factors where the category of death was *Sudden Unexpected, Unexplained Death*. 107 identified factors in the physical environment, where most factors reported were relating to unsafe sleeping arrangements (including unsafe sleeping surfaces, high temperature of room, loose bedding/blankets, prone sleeping position of the baby), unsafe co-

sleeping, and a home environment which was overcrowded, unsafe or unclean. 103 of these reviews also identified modifiable factors within the social environment, where these factors mostly related to smoking by a parent or carer, substance and/or alcohol misuse by a parent or carer, and safeguarding factors such as domestic violence and child abuse/neglect.

## Emily

Emily died of Sudden Infant Death Syndrome (SIDS) when she was a few days old. Emily was well after she was born. She was breast-feeding and all her checks were normal. On the evening before her death, she was with her parents on the sofa at home. The family fell asleep on the sofa with Emily in the crook of Dad's arm. This is their normal routine. When he awoke Emily was in the same position. He realised she was not breathing and called an ambulance, however unfortunately she could not be resuscitated.

Both parents are smokers and are known to misuse drugs and alcohol. Mum reported to the midwife that she was using drugs and alcohol during her pregnancy. She declined a referral for substance misuse and a referral for smoking cessation support. Mum has also had mental health problems in the past. She attended some of her antenatal appointments, but this was patchy.

Dad had drunk a number of cans of alcohol during the evening before Emily died and Mum had taken her prescribed medication.

### Modifiable factors (unsafe sleeping, substance misuse, smoking and alcohol use)

CDOP recorded the modifiable factor as the combined impact of prescribed methadone for Dad and prescribed medication for Mum combined with Dad's alcohol use and co-sleeping on a sofa.

## 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**

### Fazal

Fazal was born with a rare congenital anomaly. He was placed on a palliative care pathway and received support from the children's community nursing (CCN) team. With this support, his parents were able to provide excellent care and symptom management.

His family report they were well supported by agencies prior to and after his death.

#### Positive aspects of service delivery and examples of excellent care

There was excellent multi-disciplinary care involving key agencies in the hospital and in the community who worked well collaboratively. This led to the formation of an outstanding package of home care and support, which was assembled at short notice and continued for over 6 months. The continuing care team went above the basic requirements to support this family.

Excellent communication and joined up working between palliative care services, primary care, community nursing teams and pharmacies. Any issue identified was quickly rectified to try to ensure a seamless provision of care for Fazal. All the members of the team were thanked for their hard work and dedication. This was a sentiment also shared by Fazal's parents.

### Samuel

Samuel had multiple complex medical conditions.

During his admission there were several multi-disciplinary team meetings to discuss his end of life care which enabled his end-of-life plan to be modified regularly as his condition changed.

#### Positive aspects of service delivery and examples of excellent care

All teams involved in Samuel's care were praised for their excellent teamwork and their clear and sensitive communication with the family. The support provided by the ward staff in Samuel's final admission was exceptional, particularly as child death on a hospital ward is a rare occurrence. The care provided to Samuel demonstrated how by ensuring all the teams involved in his care were involved as soon as he was admitted really helped in delivering excellent service.

The family had also expressed their thanks to the team and have said that they could not imagine being treated, supported or cared for any better.

## Holly

Holly was born with a birth defect which required complex surgery. Following her surgery, she had a difficult course and sadly died at a few months of age.

Holly's birth defect had been picked up early when Mum went for an antenatal scan and this enabled the midwifery team to ensure that Holly was born in the hospital most equipped to help her when she was delivered.

Following her surgery, Holly spent time on the Paediatric Intensive Care Unit (PICU) as she needed a high level of care. The nurses and junior doctors caring for her were vigilant and incisive in monitoring her and when they noticed concerning symptoms, they made effective use of the Paediatric Early Warning Score (PEWS) chart and requested the presence of a senior consultant to review Holly straight away.

The CDOP noted these as positive aspects of service delivery.

## Harry

Harry was involved in a road traffic collision and sadly did not recover from his injuries. This was a serious incident involving a number of vehicles. The ambulance service and the police and fire services responded. A Clinical Supervisor and Ground Commander were deployed along with double crewed ambulances, rapid response vehicles, the Air Ambulance and H.M. Coastguard who were in the area. This ensured individuals with all the necessary skills were on scene quickly to render assistance.

The CDOP noted an exceptional response to the initial 999 call from the numerous services involved. Services worked together collaboratively to ensure the care provided to all those involved in the collision was of the highest standard.

## Mateo

Mateo was born with a combination of birth defects which were sadly at the more severe end of the spectrum. He required ongoing treatment to ensure he could breathe properly which required a number of complex procedures. Eventually, following discussion with Mateo's family, it was agreed that a referral would be made to palliative care services who could support him to have a good quality of life at home before his death. The lead home carer was hugely supportive during this time and the family felt they were invaluable.

The CDOP commended the lead home carer and noted the outstanding work by the occupational therapist in the provision of equipment which enabled Mateo to be at home. In addition, the respiratory nurses recognised the family's wishes for Mateo and organised for these to be met.

## Elena

Elena was a teenager who collapsed suddenly while out on a walk with her family. She suffered a cardiac arrest due to an underlying heart condition, from which she did not recover.

After Elena's death, her family, including her younger sibling were supported to access bereavement services. Her sibling was struggling to talk about what had happened to Elena and was supported to attend a local sibling support group and the family were also signposted to Winston's Wish and some bereavement charity blogs. The school also offered lots of support to Elena's sibling.

It was reported that the family liaison coordinator arranged a day trip for the family, something which the mother said Elena would have loved.





## 7. Next steps: Enhanced child death review data collection, national analyses and sharing of learning

With the NCMD national data collection and analysis still in its infancy, work is ongoing on the continuous improvements in the data completeness and quality by further developing the statutory data collection forms. In addition, there are a few areas that have been identified in this report which warrant further analysis and investigation. Consequently, we recommend:

1. Ensuring continuous case ascertainment and establishing data linkage with ONS death registration data sources to validate the overall number of death notifications submitted to NCMD.
2. Investigating potential regional differences in infant and child death rates by carrying out further, more detailed analysis (e.g. exploring the relationship between gestational age and infant and childhood deaths). Complete data on gestational age at birth will be needed from the CDOPs and through data linkages with ONS and NHS Digital.
3. Investigating the apparent disproportionate number of Black and minority ethnic groups deaths in England once more recent data on the population by ethnic group are available. In addition, explore any links with social inequalities and deprivation and establish an ongoing measure to assess mortality rates by deprivation quintile.
4. Improving the quality and analysis of the contributory and modifiable factors data by providing further support to the CDOPs in completing the data collection. For instance, the flow of how the information is asked in the analysis form can be restructured so that the CDOPs can complete whether a contributory factor was deemed to be modifiable or not.
5. Introducing sub-categories of death within the child death analysis form to enable CDOPs to select the relevant sub-category of death. This will standardise the data collection and facilitate more timely and detailed national analysis and reporting of the related sub-categories of deaths. Perinatal/neonatal event sub-categories were introduced into the analysis form from April 2020 so data can be provided at this level in future annual reports and to allow more detailed analysis, reporting and recommendations.
6. Considering future thematic analysis on neonatal/perinatal events, the leading cause of child death, with appropriate data linkage to additional data sources (e.g. BadgerNet) to enable better understanding around areas that are potentially modifiable.
7. Agreeing and formalising a case alert and signal escalation process protocol across the multiagency landscape so that the sharing of learning can be best utilised to improve child safety.

## 8. Further information

### 8.1 Information for parents, carers and families

Engaging with bereaved families in meaningful ways is of paramount importance for the NCMD programme. A number of steps have been taken to help parents, carers and family members to understand both what NCMD does and how the data is used:

- NCMD website ([www.ncmd.info/families](http://www.ncmd.info/families)) – There is a dedicated section of the NCMD website specifically for bereaved families, which can be found from the main home page. This section summarises the CDR process and the role of NCMD, provides information about how data are stored, and signposts families to relevant further information.
- Frequently Asked Questions ([www.ncmd.info/faqs](http://www.ncmd.info/faqs)) – There is a set of available FAQs for families, covering topics including the aims of NCMD, the CDR process, how data are collected, stored and used, and where to obtain further information. These have been reviewed by and had input from our partner charities to ensure that they meet the needs of bereaved families.

“One of the things you want most when your child dies is learning so that another parent doesn’t go through the same devastating experience”

#### Bereaved mother

- Postcard – NCMD have produced a postcard which explains the database, and is intended for distribution by CDOPs toward the end of the CDR process. This card contains first-level information, and informs families where they can find out more.
- Public engagement – A dedicated network of organisations and charities that support bereaved families has been set up to review the outputs from NCMD and ensure that there is continual engagement with bereaved families in meaningful ways.



*a lasting legacy*

### CARE pledge for bereaved families

All of the listed activity has been underpinned by the C-A-R-E pledge to bereaved families, which is publicly shared and adhered to in everything undertaken by NCMD:

**Core** – Your data will be used solely for our core purpose of learning lessons to improve and save lives.

**Anonymous** – NCMD will never publish information where you or your child can be identified.

**Relevant** – NCMD will only collect relevant data, including personal information about your child and their death.

**E-safety** – All data is held according to strict data protection guidelines and, as such, is safe and secure.

## 8.2 Related publications

Child death reviews: year ending 31 March

This publication can be found at the following websites:

- 2020: <https://www.ncmd.info/2020/11/12/cdr-data-2019-20/>
- 2018 and 2019: <https://digital.nhs.uk/data-and-information/publications/statistical/child-death-reviews/2019>
- 2017 and earlier: <https://www.gov.uk/government/collections/statistics-child-death-reviews>

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Child death review forms

The data collection forms used to gather information on child deaths can be found here: <https://www.gov.uk/government/publications/child-death-reviews-forms-for-reporting-child-deaths>

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Child death review statutory and operational guidance

The child death review statutory and operational guidance can be found here: <https://www.gov.uk/government/publications/child-death-review-statutory-and-operational-guidance-england>

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Child death review process

For information on the child death review processes, see Chapter 5 of the 'Working Together to Safeguard Children' document which can be found here: <https://www.gov.uk/government/publications/working-together-to-safeguard-children--2>

## 9. Glossary of terms

AICU	Adult Intensive Care Unit
BadgerNet	BadgerNet is a clinical information system which forms a continuous care record for neonatal and paediatric care
BMI	Body mass index – a measure that uses your height and weight to work out if your weight is healthy
Category of death	Category of death is assigned in each child death review during the CDOP meeting. The classification of categories is hierarchical where the uppermost selected category will be recorded as the primary category should more than one category be selected
CDOP	Child Death Overview Panel
CDR	Child Death Review
CDR partners	Child death review partners (Clinical Commissioning Groups and Local Authorities)
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
CI	Confidence Interval proposes a range of plausible values for the true parameter
DfE	Department for Education
eCDOP	Bespoke case management system for child death reviews
HQIP	Healthcare Quality Improvement Partnership
Infant	Defined as a child under 1 year of age
LA	Local Authority
LSCB	Local Safeguarding Children Board
Median	A measure that determines the middle value in a given list of values in ascending order
Mode of death	Defined as the sequence of events preceding the death, rather than the underlying cause of the death
Modifiable factor	Defined as where there are factors which, by means of nationally or locally achievable interventions, could be modified to reduce the risk of future child deaths
MBRRACE-UK	Mothers and Babies: Reducing Risk through Audit and Confidential Enquiries



NCMD	National Child Mortality Database
Neonatal death	A neonatal death happens in the first 28 days after birth
Neonatal Unit	An intensive care unit specialising in the care for babies with the highest need for support. Includes Neonatal Intensive Care Units, Local Neonatal Units, Special Care Baby Units
Notification	A statutory requirement to submit an initial notification of death to the CDOP and NCMD in the hours immediately following the death of a child
NPEU	National Perinatal Epidemiology Unit, University of Oxford
NSPR	National Safeguarding Practice Review
ONS	Office for National Statistics
Place of death	The place where the child is believed to have died regardless of where death was confirmed. Where a child is brought in dead from the community and no signs of life were recorded during the resuscitation, the place of death should be recorded as the community location; where a child is brought in to hospital following an event in the community and is successfully resuscitated, but resuscitation or other treatment is subsequently withdrawn, the place of death should be recorded as the location within the hospital where this occurs
PICU	Paediatric Intensive Care Unit
PMRT	Perinatal Mortality Review Tool
QES	IT partner in the NCMD collaboration
Quintiles	Five equal groups into which a population can be equally divided
Registered death	Death of child aged 0-17 who were resident in England, as recorded by the Office for National Statistics
Review	A child death review is the responsibility of the child death review partners and the purpose is to identify any matters relating to the death, that are relevant to the welfare of children in the area or to public health and safety, and to consider whether action should be taken in relation to any matters identified. A child death review is a statutory requirement
Safeguarding	Safeguarding means protecting a person's health, wellbeing and human rights; enabling them to live free from harm, abuse and neglect
UCLP	UCL Partners, Quality Improvement partner in the NCMD collaboration

## 10. References

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# Appendices

## Appendix A: Additional tables

**Table 10: The number of child death notifications received by Child Death Overview Panels by age group, sex and ethnic group, year ending 31 March 2020**

	Number (%) of deaths
<b>Age group</b>	
0 – 27 days	1,411 (42%)
28 – 364 days	691 (21%)
1 – 4 years	389 (12%)
5 – 9 years	237 (7%)
10 – 14 years	280 (8%)
15 – 17 years	339 (10%)
<b>Total</b>	<b>3,347 (100%)</b>
<b>Sex<sup>+</sup></b>	
Female	1,405 (43%)
Male	1,831 (57%)
<b>Total</b>	<b>3,236 (100%)</b>
<b>Ethnic group<sup>^</sup></b>	
Asian or Asian British	489 (19%)
Black or Black British	227 (9%)
Mixed	172 (7%)
White	1,605 (62%)
Other	103 (4%)
<b>Total</b>	<b>2,596 (100%)</b>

Data source: NCMD

+In 111 cases, data for the child's sex were not known or incomplete

<sup>^</sup>In 751 cases, data for the child's ethnic group were not known or incomplete

Ethnicity is grouped based on groupings used in the 2011 Census

**Table 11: The number of infant and child death notifications received by Child Death Overview Panels by region and estimated crude death rates, year ending 31 March 2020**

Region	Infants (aged under 1 year)			Children (aged 0 – 17 years)		
	Number of deaths	Live births in 2019	Estimated crude infant death rate per 1,000 live births (95% CI)	Number of deaths	Population (0-17 years)	Estimated crude child death rate, per 100,000 children (95% CI)
England	2,102	610,505	3.4 (3.3-3.6)	3,347	12,023,568	27.8 (26.9-28.8)
North East	92	25,742	3.6 (2.9-4.4)	153	532,057	28.8 (24.4-33.7)
North West	267	80,020	3.3 (2.9-3.8)	435	1,563,460	27.8 (25.3-30.6)
Yorkshire and Humberside	231	58,281	4.0 (3.5-4.5)	367	1,169,941	31.4 (28.2-34.7)
East Midlands	176	48,986	3.6 (3.1-4.2)	284	1,002,649	28.3 (25.1-31.8)
West Midlands	308	65,982	4.7 (4.2-5.2)	440	1,299,803	33.9 (30.8-37.2)
East of England	206	67,409	3.1 (2.7-3.5)	341	1,346,457	25.3 (22.7-28.2)
London	391	117,897	3.3 (3.0-3.7)	607	2,032,427	29.9 (27.5-32.3)
South East	275	93,664	2.9 (2.6-3.3)	468	1,969,297	23.8 (21.7-26.0)
South West	156	52,524	3.0 (2.5-3.5)	252	1,107,477	22.8 (20.0-25.7)

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

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.



**Table 12: The number of infant death notifications received by Child Death Overview Panels by gestational age at birth in weeks and place of death, year ending 31 March 2020**

Place of death	Gestational age at birth (weeks <sup>+days</sup> )						Total
	<22	22 <sup>+0</sup> -23 <sup>+6</sup>	24 <sup>+0</sup> -27 <sup>+6</sup>	28 <sup>+0</sup> -36 <sup>+6</sup>	37 <sup>+0</sup> -41 <sup>+6</sup>	≥42	
Home	*	*	*	23	49	*	79
Hospice	*	*	*	11	32	*	46
Hospital Trust	177	268	325	404	449	7	1630
<i>A&amp;CU</i>	*	*	*	*	*	*	*
<i>Emergency Department</i>	*	*	6	34	79	*	123
<i>Hospital ward</i>	5	6	*	12	36	*	63
<i>Labour ward/delivery suite</i>	149	113	47	56	38	*	404
<i>Midwifery Unit</i>	15	7	*	7	7	*	36
<i>Neonatal Unit</i>	6	127	257	243	164	*	800
<i>PICU</i>	*	12	10	47	120	*	190
<i>Operating Theatre</i>	*	*	*	*	*	*	12
Other	*	*	*	*	*	*	10
<b>Total</b>	<b>180</b>	<b>272</b>	<b>328</b>	<b>439</b>	<b>536</b>	<b>10</b>	<b>1765</b>

Data source: NCMD

In 337 cases data for the child's gestational age and/or place of death were not known or incomplete

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

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

Other includes abroad, public place, school and any other place

**Table 13: The number of child death reviews completed by Child Death Overview Panels by age group, sex, and ethnic group, 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
	n (%)	n (%)	n (%)
<b>Age group</b>			
0 – 27 days	1,116 (41%)	1,106 (41%)	328 (30%)
28 – 364 days	594 (22%)	591 (22%)	247 (42%)
1 – 4 years	326 (12%)	321 (12%)	74 (23%)
5 – 9 years	213 (8%)	211 (8%)	43 (20%)
10 – 14 years	230 (8%)	229 (8%)	72 (31%)
15 – 17 years	259 (9%)	257 (9%)	98 (38%)
<b>Total</b>	<b>2,738 (100%)</b>	<b>2,715 (100%)</b>	<b>862 (32%)</b>
<b>Sex*</b>			
Female	1,188 (44%)	1,176 (44%)	379 (32%)
Male	1,532 (56%)	1,521 (56%)	482 (32%)
<b>Total</b>	<b>2,720 (100%)</b>	<b>2,697 (100%)</b>	<b>861 (32%)</b>
<b>Ethnic group<sup>^</sup></b>			
Asian or Asian British	436 (18%)	433 (18%)	97 (22%)
Black or Black British	191 (8%)	191 (8%)	43 (23%)
Mixed	137 (6%)	136 (6%)	47 (35%)
White	1,582 (65%)	1,570 (65%)	562 (36%)
Other	89 (4%)	87 (4%)	21 (24%)
<b>Total</b>	<b>2,435 (100%)</b>	<b>2,417 (100%)</b>	<b>770 (32%)</b>
<b>Year of death</b>			
2015-16 or earlier	17 (1%)	17 (1%)	12 (71%)
2016-17	86 (3%)	85 (3%)	46 (54%)
2017-18	353 (13%)	349 (13%)	156 (45%)
2018-19	1,542 (56%)	1,531 (56%)	493 (32%)
2019-20	740 (27%)	733 (27%)	155 (21%)
<b>Total</b>	<b>2,738 (100%)</b>	<b>2,715 (100%)</b>	<b>862 (32%)</b>

Data source: NCMD

\*In 18 cases, data for the child's sex were indeterminate, not known, or incomplete

<sup>^</sup>In 303 cases, data for the child's ethnic group were not known or incomplete

Ethnicity is grouped based on groupings used in the 2011 Census

**Table 14: The number of reviews completed by Child Death Overview Panels by category of death and age group, year ending 31 March 2020**

Category of Death	Reviews completed (Year ending 31 March 2020)						
	% of age group within category						
	0 – 27 days	28 – 364 days	1 – 4 years	5 – 9 years	10 – 14 years	15 – 17 years	Total (% of all deaths)
Deliberately inflicted injury, abuse or neglect	5 (8%)	17 (28%)	*	8 (13%)	7 (11%)	20 (33%)	<b>61 (2%)</b>
Suicide or deliberate self-inflicted harm	*	*	*	*	18 (17%)	87 (83%)	<b>105 (4%)</b>
Trauma or other external factors	5 (4%)	8 (7%)	26 (22%)	19 (16%)	32 (27%)	29 (24%)	<b>119 (4%)</b>
Malignancy	*	13 (6%)	52 (25%)	63 (30%)	51 (24%)	29 (14%)	<b>212 (8%)</b>
Acute medical or surgical condition	11 (6%)	28 (16%)	39 (22%)	27 (16%)	35 (20%)	34 (20%)	<b>174 (6%)</b>
Chronic medical condition	8 (6%)	24 (18%)	25 (19%)	26 (19%)	28 (21%)	24 (18%)	<b>135 (5%)</b>
Chromosomal, genetic and congenital anomalies	287 (42%)	201 (30%)	89 (13%)	37 (5%)	40 (6%)	22 (3%)	<b>676 (25%)</b>
Perinatal/neonatal event	730 (85%)	113 (13%)	10 (1%)	*	*	*	<b>860 (31%)</b>
Infection	29 (17%)	42 (24%)	57 (33%)	24 (14%)	13 (7%)	10 (6%)	<b>175 (6%)</b>
Sudden unexpected, unexplained death	37 (17%)	148 (67%)	24 (11%)	5 (2%)	*	*	<b>221 (8%)</b>
<b>Total</b>	<b>1,116 (41%)</b>	<b>594 (22%)</b>	<b>326 (12%)</b>	<b>213 (8%)</b>	<b>230 (8%)</b>	<b>259 (9%)</b>	<b>2,738 (100%)</b>

Data source: NCMD

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

## Appendix B: Methodology and limitations

The data within this report was extracted from NCMD on 30 September 2020. The report presents data that was submitted by CDOPs to NCMD. As NCMD is newly established, the data collection continuing and with some transitional arrangements still ongoing, more data may be submitted retrospectively. Updated figures and analyses will be presented with the next and subsequent NCMD annual reports. The figures reported are those after data was checked by the NCMD team. This includes exclusion of cases that did not meet the criteria for child death review (e.g. small numbers of reported stillbirths or termination of pregnancies) and removal of any duplicates. From May - July 2020 the NCMD team contacted CDOPs to confirm that the data held was correct:

- 52 CDOPs confirmed that the data held was correct
- 3 CDOPs were unable to submit so partial data (i.e. only data which they had submitted) were included for analysis
- For a further 3 CDOPs, the NCMD team was unable to confirm whether the data submitted were correct. These data have been included but are unconfirmed

## Data completeness

Table 15 shows the percentage completeness of data fields in NCMD, for the two cohorts reported within this report. This is only a list of key fields and is not an exhaustive list of all data fields in NCMD. Some of the incomplete data is because the information was not known to the notifier, rather than the response being left blank. Some incomplete data has been increased due to CDOP transitional arrangements and the changes in data collection forms.

CDOPs are provided with a quarterly data report from NCMD which summarises their data and completeness. The reports serve as a prompt to review data accuracy and completeness.

**Table 15: The percentage completion rate of data fields in reviews completed by Child Death Overview Panels, year ending 31 March 2020**

	% completeness
Deaths occurring between 1 April 2019 – 31 March 2020	
NHS number	95%
Date of birth	100%
Date of death	100%
Sex	97%
Postcode	97%
Ethnic group	78%
Place of death	97%
Hospital of death <sup>^</sup>	88%
Gestational age at birth (weeks) (infant deaths only)	85%
Gestational age (weeks) (all deaths)	61%



	% completeness
Deaths reviewed between 1 April 2019 – 31 March 2020	
NHS number	88%
Date of birth	100%
Date of death	100%
Sex	99%
Postcode	99%
Ethnic group	89%
Place of death	99%
Hospital of death <sup>^</sup>	70%
Gestational age at birth (weeks) (infant deaths only)	90%
Gestational age at birth (weeks) (all deaths)	61%
Where was the child at the onset of the illness or incident that led to their death?	99%
Is this child's death subject to a Serious Case Review (child protection) / local or national Child Safeguarding Practice Review?	91%
Mode of death	76%
Were any of the following events known to have occurred?	75%
Social care status	69%
CDOP meeting date	100%
Contributory factor recorded (at least one)	93%
Were any modifiable factors identified?	100%
Details of modifiable factors <sup>+</sup>	83%
Category of death	100%

Data source: NCMD

<sup>^</sup> Where place of death was recorded as hospital

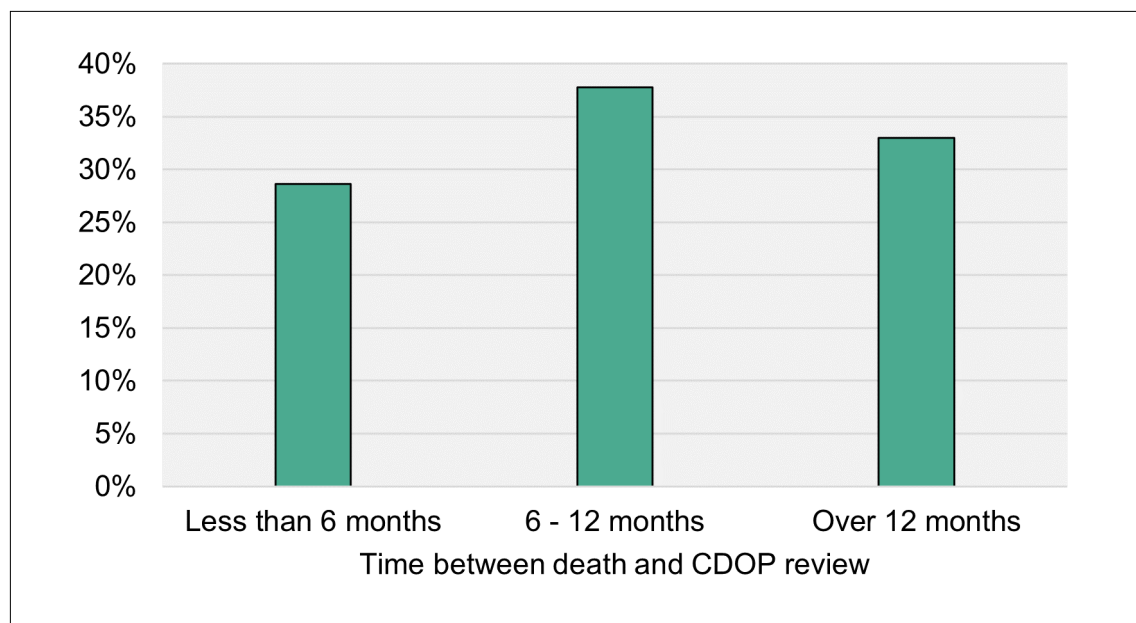
<sup>+</sup> Where modifiable factors were identified

Data submitted as not known are counted as incomplete within the table

### Time taken to complete CDOP review

The median time between the date of death and the date of the CDOP review was 275 days. 38% of reviews took between 6 and 12 months to complete, and 33% took over 12 months to complete (Figure 14).

**Figure 14: The percentage of reviews completed by Child Death Overview Panels by the number of months between the date of death and the date of the Child Death Overview Panel review, year ending 31 March 2020**



Data source: NCMD  
n=2,738

### Case ascertainment and CDOP uptake

The aim for the first and second year of the programme was to achieve 25% and 50% of CDOPs submitting data to NCMD respectively. Within the first year of data collection of the NCMD, the year 2019-20 (the second year of the programme), all 58 CDOPs submitted data for both the notifications and reviews cohort. All CDOPs continue to submit data to NCMD on an ongoing basis.

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

**Table 16: The number of death notifications received and the number of reviews that were completed by Child Death Overview Panels, year ending 31 March 2020**

CDOP	Number of death notifications submitted to NCMD	Number of reviews that were completed and submitted to NCMD <sup>^</sup>
Barnsley	14	17
Bedfordshire	47	5
Birmingham	141	176
Black Country	107	84
Blackpool, Blackburn and Lancashire	108	92
Bolton, Salford and Wigan	63	28

CDOP	Number of death notifications submitted to NCMD	Number of reviews that were completed and submitted to NCMD^
Bradford	68	41
Bury, Rochdale and Oldham	7	29
Cambridge and Peterborough	46	31
Coventry, Warwickshire and Solihull	79	75
Cumbria	23	21
Derby and Derbyshire	70	50
Doncaster	21	14
Durham and Darlington	32	20
East Riding of Yorkshire	15	*
Gloucestershire	30	23
Hampshire and Isle of Wight	105	56
Herefordshire and Worcestershire	22	13
Hertfordshire	66	57
Kent and Medway	106	83
Kingston upon Hull	28	10
Leeds	58	75
Leicester, Leicestershire and Rutland	59	31
Lincolnshire	28	29
Manchester	62	41
Merseyside	91	73
Milton Keynes	15	19
Norfolk	42	35
North and South of Tyne	88	70
North Central London	82	56
North East London (Barking & Dagenham, Havering and Redbridge)	55	44
North East London (Waltham Forest, East London and the City)	98	65
North West London	151	137
Northamptonshire	35	20
Northern Lincolnshire	13	12
Nottinghamshire and Nottingham City	92	84
Oxfordshire and Buckinghamshire	54	52
Pan Berkshire	54	22
Pan Cheshire	45	45
Pan Dorset and Somerset	64	54
Pan Sussex	81	56

CDOP	Number of death notifications submitted to NCMD	Number of reviews that were completed and submitted to NCMD <sup>^</sup>
Rotherham	13	35
Sheffield	38	39
Shropshire, Telford and Wrekin	27	19
South East London (Bromley, Lambeth and Southwark)	62	38
South East London (Bexley, Greenwich and Lewisham)	75	61
South West London	84	83
South West Peninsula	70	84
Southend, Essex and Thurrock	104	88
Stockport, Tameside and Trafford	36	37
Stoke on Trent and Staffordshire	64	41
Suffolk	36	18
Surrey	53	54
Swindon and Wiltshire	37	26
Tees	33	20
Wakefield, Calderdale and Kirklees	67	56
West of England	51	45
York City and North Yorkshire	32	45

Data source: NCMD

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

<sup>^</sup> The figures in this column represent deaths that were reviewed during the year, but the deaths occurred across a number of years. There is partial overlap with the cohort of children in the column 'Number of death notifications submitted to NCMD' if the death was both notified and reviewed in this reporting period.

### Sub-category classification

Deaths categorised as *Trauma or other external factors*, *Acute medical or surgical condition* or *Perinatal/neonatal event* were further sub-categorised to present additional information on the national data, which is frequently asked for by the CDOPs and CDR professionals. For this work, the free text information as reported by the CDOPs around the circumstances of death and the Medical Cause of Death was reviewed to determine the relevant sub-category. In addition, some of the cases required further validation by relevant clinical expertise.

The deaths categorised as *Perinatal/neonatal event* were reviewed and the underlying cause was sub-categorised by:

- Immaturity/prematurity related: Deaths that were the result of immaturity/prematurity related complications or where preterm birth likely led to an infection (deaths after 7 days of life) as well as other complications of immaturity/prematurity. This included those who were asphyxiated at birth as a result of being born prematurely.
- Perinatal asphyxia: Deaths of children who were born at term gestation (37 weeks or over) where there was evidence of perinatal asphyxia, or where there was evidence that perinatal asphyxia was the underlying cause in a child born at a preterm gestation.
- Perinatally acquired infection: Deaths of children as a result of perinatally acquired infection (where the infection was within the first week of life), or where there was evidence that an infection led to preterm birth. Children born preterm who developed sepsis along with other complications of prematurity/immaturity were not included in this group.
- Other: Other cause or perinatal event.
- Unclear: Cases were sub-categorised as unclear where there was insufficient information regarding the perinatal event. Deaths initially classified as unclear were reviewed by an expert working group and classified into one of the above categories if possible.



### **Modifiable factor coding**

The NCMD team developed a coding schema to review and code the data submitted on modifiable factors for cases that had been reviewed by a CDOP ([Appendix E](#)). All factors were coded as they were submitted to the NCMD. The data was initially coded, and then this was reviewed and validated by the NCMD manager and the NCMD clinical team if required.

### **Limitations**

All data is based on data that has been submitted to the NCMD by CDOPs. As CDOPs were still going through the process of transition to their new arrangements, there was some impact on the completeness and quality of data to NCMD, particularly in areas where there were changes in staffing or new people involved in the process. The NCMD is aware of at least 3 out of 58 CDOPs that did not submit all death notifications or reviews to NCMD, so some totals may be underestimated.

In addition, denominators used to calculate rates (e.g. child death rate) are based on population estimates, and in particular, comparisons using ethnicity data should be treated with caution due to limitations of the comparator data (based on England and Wales data from the 2011 census). Additional data from the next census (2021) will allow for a more reliable comparison in future reports.

The NCMD is dependent on accurate data entry by the CDOPs, and in particular, category of death is presented within the report as it was submitted by the CDOP. As seen in the Neonatal/Perinatal event sub-categorisation analysis, it is likely that in a minority of cases the category of death submitted to the NCMD may not be consistent with the description of the category ([Appendix D](#)). Further work with the CDOPs and more clarity on the online data collection form to improve data consistency is underway.

## Appendix C: List of regions, CDOPs and Local Authority areas

**Table 17: List of regions mapped to CDOPs and Local Authority areas**

Region	Child Death Overview Panel	Local Authority area
<b>East Midlands</b>	Derby and Derbyshire	Derby
		Derbyshire
	Leicester, Leicestershire and Rutland	Leicester
		Leicestershire
		Rutland
	Lincolnshire	Lincolnshire
	Northamptonshire	Northamptonshire
	Nottinghamshire and Nottingham City	Nottingham
		Nottinghamshire
<b>East of England</b>	Bedfordshire	Bedford Borough
		Central Bedfordshire
		Luton
	Cambridge and Peterborough	Cambridgeshire
		Peterborough
	Hertfordshire	Hertfordshire
	Norfolk	Norfolk
	Southend, Essex and Thurrock	Essex
		Southend
		Thurrock
	Suffolk	Suffolk
<b>London</b>	North Central London	Barnet
		Camden
		Enfield
		Haringey
		Islington
	North East London	Barking and Dagenham
		Havering
		Redbridge
	North East London (WELC)	Hackney and City
		Newham
		Tower Hamlets
		Waltham Forest
	North West London	Brent
		Ealing
		Hammersmith and Fulham
		Harrow
		Hillingdon
		Hounslow
		Kensington and Chelsea
		Westminster

Region	Child Death Overview Panel	Local Authority area
London continued	South East London BGL	Bexley
		Greenwich
		Lewisham
	South East London	Bromley
		Lambeth
		Southwark
	South West London	Croydon
		Kingston upon Thames
		Merton
		Richmond upon Thames
		Sutton
		Wandsworth
North East	Durham and Darlington	Darlington
		Durham
	North and South of Tyne	Gateshead
		Newcastle upon Tyne
		North Tyneside
		Northumberland
		South Tyneside
		Sunderland
	Tees	Hartlepool
		Middlesbrough
		Redcar and Cleveland
		Stockton on Tees
North West	Blackpool, Blackburn with Darwen and Lancashire	Blackburn with Darwen
		Blackpool
		Lancashire
	Bolton, Salford and Wigan	Bolton
		Salford
		Wigan
	Bury, Rochdale and Oldham	Bury
		Oldham
		Rochdale
	Cumbria	Cumbria
	Manchester	Manchester
	Merseyside	Knowsley
		Liverpool
		Sefton
		St Helens
		Wirral
		Isle Of Man
	Pan Cheshire	Cheshire East
		Chester and Cheshire West
		Halton
		Warrington
	Stockport, Tameside and Trafford	Stockport
		Tameside
		Trafford

Region	Child Death Overview Panel	Local Authority area
South East	Hampshire and Isle of Wight	Hampshire
		Isle of Wight
		Portsmouth
		Southampton
	Kent and Medway	Kent
		Medway Towns
	Milton Keynes	Milton Keynes
	Oxfordshire and Buckinghamshire	Buckinghamshire
		Oxfordshire
	Pan Berkshire	Bracknell Forest
		Reading
		Slough
		West Berkshire
		Windsor and Maidenhead
		Wokingham
	Pan Sussex	Brighton and Hove
		East Sussex
		West Sussex
	Surrey	Surrey
South West	Gloucestershire	Gloucestershire
	Pan Dorset and Somerset	Bournemouth, Christchurch and Poole
		Dorset
		Somerset
	South West Peninsula	Cornwall
		Devon
		Isles of Scilly
		Plymouth
		Torbay
	Swindon and Wiltshire	Swindon
		Wiltshire
	West of England	Bath and North East Somerset
		City of Bristol
		North Somerset
		South Gloucestershire
West Midlands	Birmingham	Birmingham
	Black Country	Dudley
		Sandwell
		Walsall
		Wolverhampton
	Coventry, Warwickshire and Solihull	Coventry
		Solihull
		Warwickshire
	Herefordshire and Worcestershire	Herefordshire
		Worcestershire
	Shropshire, Telford and Wrekin	Shropshire
		Telford and Wrekin
	Stoke on Trent and Staffordshire	Staffordshire
		Stoke on Trent



Region	Child Death Overview Panel	Local Authority area
Yorkshire and Humberside	Barnsley	Barnsley
	Bradford	Bradford
	Doncaster	Doncaster
	East Riding of Yorkshire	East Riding of Yorkshire
	Kingston upon Hull	Kingston upon Hull
	Leeds	Leeds
	Northern Lincolnshire	North East Lincolnshire
		North Lincolnshire
	Rotherham	Rotherham
	Sheffield	Sheffield
	Wakefield, Calderdale and Kirklees	Calderdale
		Kirklees
		Wakefield
	York City and North Yorkshire	North Yorkshire
		York City

## Appendix D: Category of death descriptions

**Table 18: Name and description for each category of death on the child death review analysis form in hierarchical order**

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

## Appendix E: Modifiable factor analysis form domain descriptions

**Table 19: Name and description for each domain and sub-domain used to code modifiable factors**

Domain	Sub-domain	Examples and information
<b>Characteristics of the child</b>	Behavioural factor	Examples include: risk taking behaviour by the child, smoking by the child, alcohol misuse by the child, different presentation to people online than in person, accessing information which enables suicide or self harm or negatively affects mental health, school attendance issues
	Emotional factor	Examples include: Isolation, bereavement, lack of social support, loss of key relationships, poor or dysfunctional relationship with relative or friend, social/identity issues
	Clinical condition (excluding mental health condition and developmental disorder)	Examples include: disease, comorbidity, prematurity, congenital anomaly, allergy, complications or poor response to treatment, findings at post-mortem Excludes: mental health condition, learning disability
	Mental health condition	Examples include: depression/low mood, anxiety, eating disorder, post traumatic stress disorder, suicidal ideation or previous suicide attempt
	Developmental disorder	Examples include: Autism, ADHD, learning disability
	Other	This category should only be used for a small number of factors
<b>Social environment</b>	Safeguarding factor	Examples include: domestic abuse, physical, emotional or sexual abuse, neglect, female genital mutilation, inadequate parenting/supervision, on child protection plan, other safeguarding involvement with social care, child reported missing
	Behavioural factor in a significant person in the child's life	Examples include: alcohol misuse, smoking, substance abuse, poor emotional attachment with child, poor control of medical condition by a parent or carer, late booking for pregnancy
	Clinical condition (excluding mental health and developmental disorder) in a significant person in the child's life	Examples include: existing clinical condition, maternal health in pregnancy, high/low maternal BMI, infection Excludes: mental health condition, learning disability
	Mental health condition in a significant person in the child's life	Examples include: depression/low mood, anxiety, eating disorder, post-traumatic stress disorder, bipolar disorder, emotional dysregulation. Also includes parental mental health during pregnancy
	Developmental disorder in a significant person in the child's life	Examples include: Autism, ADHD, learning disability
	Family/cultural factor	Examples include: English not first language, consanguinity, other cultural practices, financial pressures/hardship
	Other	This category should only be used for a small number of factors

Domain	Sub-domain	Examples and information
<b>Physical environment</b>	External trauma factor (deaths that occur as the result of an external event)	Examples include: animal attack, terrorism, natural disaster, homicide where child is not known to perpetrator Excludes: vehicle or transport related deaths (see vehicle or transport related factor below)
	Household safety (including relative or friend's home)	Examples include: anything relating to safety within the home of the child or the home of the caregiver who has responsibility to make the environment safe. Unsafe sleeping practices, access to medicine/poison, nappy sacks, blind cords, falls from windows, burns, lack of / poor fencing surrounding garden pond or pool, building work, stair gates, smoke alarms, button batteries, housing issues e.g. unclean/chaotic environment/overcrowding
	Public safety (factor relating to environment outside household)	Examples include: anything relating to safety within the community e.g. drowning in public body of water (e.g. river, lake, public swimming pool), falls from playground equipment or within public parks, public equipment or product fault/failure, poor compliance with health and safety regulations Excludes: drowning within home garden pond or swimming pool (see Household Safety)
	Vehicle or transport related factor	Examples include: road/rail management and design, any factors related to a vehicle involved in the child's death (trains, tractors, motor vehicles including mo-peds, motorcycles, bicycles, skateboards, aeroplanes) which may include speeding, poor driving conditions, road camber, potholes, faulty seatbelts, seatbelt absent or not working correctly, child safety locks, airbags, helmets, protective clothing, black box devices etc.
	Other	This category should only be used for a small number of factors
<b>Service provision</b>	Organisational factor - Education	Examples include: gaps in service provision, failure to follow recognised guidelines or pathway, failure to recognise clinical symptoms / severity of illness / deteriorating patient, failure to record or document accurate observations or information or to do appropriate investigations, drug errors, training not provided, out of date or ineffective
	Organisational factor - Communication	Examples include: Poor communication and/or information sharing within or between professionals / organisations, poor communication/information sharing with the family, no interpreter available
	Organisational factor - Equipment	Examples include: Equipment not available or faulty, inappropriate equipment used
	Organisational factor - Environment	Examples include: inappropriate skill mix, low staff to patient ratio, fatigue (excessive working hours/lack of staff breaks), bed occupancy levels
	Human factor	In relation to the individual practitioner when organisational factors do not predominate. Includes: all examples included within "education" where staff member judged to have received sufficient training, failure of judgement, failure in performing task
	Local & National policy / commissioning	Examples include: No policy/guidance available, challenges with transitions between paediatric and adult services, lack of access to a service (e.g. service not available or service unfunded)
	Unimmunised	Examples include: cases where a child was unimmunised, and this was found to be a modifiable factor in relation to the child's circumstances or death
	Other	This category should only be used for a small number of factors
<b>Insufficient info</b>	Insufficient Info	Insufficient Info

# NCMD

National Child Mortality Database

Knowledge, understanding and  
learning to improve young lives

## National Child Mortality Database (NCMD)

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