NCMD
National Child Mortality Database
Knowledge, understanding and learning to improve young lives

Sudden and Unexpected Deaths in Infancy and Childhood

National Child Mortality Database Programme Thematic Report

Data from April 2019 to March 2021
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HQIP

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Cover image: Beyond Limitations, a sculpture in bronze resin by artist John O'Connor

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Foreword

Every child's death is a tragedy and when a child dies suddenly the family desperately needs to know what happened. Back in 2004, I chaired a Working Group for the Royal College of Pathologists and the Royal College of Paediatrics and Child Health, after a public outcry concerning a number of mothers who were cleared of causing the deaths of their babies. Our mandate was to review procedures when an infant died and to advise on the best practice in such investigations. It was important to restore reality and remind the world that in the majority of cases where a child dies unexpectedly and suddenly nothing untoward has taken place and it is only in a small number of cases there is any unlawful cause. As a result, we advocated the introduction of a Multi-Agency Protocol: to understand why a baby died it was vital that all the agencies concerned worked together, shared information and kept the families included at every stage and worked with thoroughness but also care and compassion. It became clear that a number of factors increased the risk of Sudden Unexplained Death in Infants, including the sleeping position of the infant, the sleeping arrangements, young maternal age, parental smoking, socio-economic deprivation, and poor housing.

In 2016, the Report was revisited, and the Protocol further developed, with greater recognition of the sudden deaths of older children between the ages of one and seventeen and of the problem with having multiple agencies collecting data and working in silos. It was the insightful work of the team at University of Bristol led by Peter Fleming that drew attention to the need for a centralised collation of information. As a result, the National Child Mortality Database (NCMD) was established on a statutory footing in 2018 to collect and analyse data on all child deaths in England.

This new report shows the force of the Bristol team's wisdom. The statutory nature of the database means that all child deaths are promptly notified to the small, committed team and it enables a level of research that would not have been possible otherwise. Contact is commonly made with local teams to facilitate appropriate investigation and provide support for bereaved families. The NCMD team have been able to look at how and why these children died, how investigations were carried out after their deaths and have asked what can be learned from the investigations into contributory factors or factors which, if modified, could have created a different outcome.

The report, covering the two-year period from 2019 to 2021, is unique in two ways. It is the first national report to have investigated all unexpected deaths of infants and children – not just those that remained unexplained. And it is also the first national review of the "multi-agency investigation process" into unexpected deaths.

One striking finding is that in the unexpected deaths of children between 1 and 17 there is a high incidence of a family history of convulsions. Inexplicably it is as strong for those children whose deaths are fully explained by an underlying medical condition as for those whose death remains unexplained.

What this tells us is that research in this area is now a priority. It is crucial that we identify those factors which contribute to unexpected death in children over one year old.

I pay tribute to the NCMD team and all those committed professionals who are carrying on this important work. I strongly urge the powers-that-be to provide adequate resources to enable this vital research.

Baroness Helena Kennedy KC

Executive Summary

When a child dies suddenly and unexpectedly, it represents a devastating loss for the parents, wider family and the child's whole community. The figures detailed in this report represent precious lives lost and many families who endure the life-long impact of the lack of an explanation for why their child died.

This analysis focuses on all children in England who died suddenly and unexpectedly after birth and before their 18th birthday in the period 1 April 2019 to 31 March 2021. The terms "sudden unexpected death in infancy" (SUDI) for children under 12 months of age, or "sudden unexpected death in childhood" (SUDC) if the child was 12 months of age and older, are used by professionals to refer to this event. Some of these children's deaths went on to be explained after a post-mortem examination and other investigations. This means a cause for their death was identified. However, the majority remained unexplained even after all investigations were concluded. These deaths of infants under one year of age are often described as being due to "sudden infant death syndrome" or SIDS. This term was originally defined by Beckwith in 1969 as 'the sudden death of any infant or young child which is unexpected by history, and in which a thorough post-mortem examination fails to demonstrate an adequate cause of death'[1]. This is the term used when it is not known why the baby died. For deaths of children between 1 and 17 years of age, which remain unexplained despite a thorough investigation, the term 'Sudden Unexplained Death in Childhood' (also abbreviated to SUDC) was defined more recently by Krous et al in 2005[2]. In current practice there is a range of terms used to describe and certify this category of death in older children, such as Sudden Arrhythmic Death Syndrome (SADS) if the child is in their teens or has a cardiac medical history.

The demographic characteristics of SIDS families are similar across geographical and cultural boundaries. More deaths occur in males and among vulnerable infants with lower birthweight, shorter gestation or other neonatal problems as was shown in the NCMD thematic report "The Contribution of Newborn Health to Child Mortality across England". There is a strong correlation with young maternal age and having more children, and the risk increases with multiple births, single motherhood or a complicated obstetric history. SIDS occurs across the social strata but has consistently been more common in socio-economically deprived families and particularly among infants of parents who smoke[3]. The risk of SIDS is reduced by placing babies to sleep on their backs on a firm, flat surface. Deaths of children who die suddenly at 12 months of age or older, and whose deaths remain unexplained are not well understood, and the sleep related risk factors for infant deaths do not apply. However, there is evidence to suggest an association with febrile seizures in this age group, with a higher proportion of families reporting a history of febrile seizures than is known to occur in the general population[4]. The great majority of these children are found prone (face down) after death, even when this was not their usual sleeping position[1].

This report aims to quantify the number of sudden unexpected deaths of infants and children in England, the proportion of these deaths that remain unexplained following review by a Child Death Overview Panel (CDOP), and the demographics and characteristics of these children.

The findings and learning from the report will inform policies and interventions required to reduce the number of children who die, and recommendations will be made based on the findings.

Key findings

- Of all infant and child deaths occurring between April 2019 and March 2021 in England (n=6503), 30% (n=1924/6503) occurred suddenly and unexpectedly, and of these 64% (n=1234/1924) had no immediately apparent cause.

Sudden and unexpected infant deaths (under 1 year)

Deaths of infants between April 2019 and March 2021 whose death was sudden and unexpected with no immediately apparent cause.

- Of the 711 sudden and unexpected infant deaths between April 2019-March 2021, 70% were aged between 28 and 364 days, and 57% were male. Infant death rates were higher in urban areas, and the most deprived neighbourhoods. There were no changes in demographics across the 2-year period.
- In order to identify potentially contributory or other factors, in particular within the infant sleep environment, it was necessary to review in detail those deaths for which the full CDOP investigations had been completed. We have therefore taken all deaths during 2020 for which the full investigations had been completed for more detailed review. For sudden and unexpected infant deaths that occurred during 2020 and had been fully reviewed by a CDOP (n=249), 52% were classified as unexplained (i.e., Sudden Infant Death Syndrome (SIDS)), and 48% went on to be explained by other causes e.g., metabolic or cardiac conditions.

Unexplained infant deaths (under 1 year)

Deaths of infants between January 2020 and December 2020 that remained unexplained after investigations and the CDOP review. This time period was chosen as the updated data collection forms were more fully established, and enough time had elapsed since December 2020 for most CDOP reviews to have taken place to determine whether or not the death could be explained.

- There were 129 sudden unexpected and unexplained infant deaths in 2020 that had been reviewed by a CDOP by 28 June 2022 and remained unexplained.
- The majority (80%) of unexplained deaths were of infants aged between 28-364 days; the median age of death was between 8-11 weeks.
- There was a higher proportion of **unexplained** deaths of males (64%) than females (36%), which was not observed in deaths that went on to be explained, where sex proportions were approximately equal (51% female, 49% male).

- A significantly larger proportion of unexplained deaths were of infants living in the most deprived neighbourhoods (42%) than those in the least deprived neighbourhoods (8%).
- A joint agency home/scene visit was carried out by professionals for 65% of unexplained infant deaths, and a single agency response (usually police only) was recorded for a further 34%, and in 1% there was no agency response visit carried out by professionals after the death.
- The unexplained deaths were strongly associated with low birthweight, prematurity, multiple births, larger families, admission to a neonatal unit, maternal smoking during pregnancy, young maternal age, parental smoking and parental drug misuse. The profile of vulnerability surrounding the birth characteristics was even more marked among the explained deaths.
- Where it was known, 98% (n=124/127) of unexplained deaths occurred when the infant was thought to be asleep, and of those, 52% (n=64/124) of deaths occurred while the sleeping surface was shared with an adult or older sibling.
- Of the 64 deaths where the sleeping surface was shared, for 60% this sharing was unplanned and at least 92% were in hazardous circumstances e.g., co-sleeping with an adult who had consumed alcohol or on a sofa.
- Of the 124 deaths that occurred during apparent sleep, at least 75% identified one or more of the following risk factors related to the sleeping arrangements: put down prone (face down) or side; hazardous co-sleeping; inappropriate sleeping surface when sleeping alone; inappropriate items in the bed.
- Modifiable factors were identified by CDOPs in 87% of the reviews. The most common modifiable factors reported were unsafe sleeping arrangements, smoking in pregnancy or in the household and alcohol or substance use by a parent or carer.
- Learning points or issues were identified in 85% of reviews. Themes included: the importance of families understanding the risk of SIDS for their specific situation, the importance of health visitors viewing the sleep environment when they visit the home and the importance of high quality care being provided to families after the death of their infant.

Sudden and unexpected deaths of children 1-17 years

Deaths of children between April 2019 and March 2021 whose death was sudden and unexpected with no immediately apparent cause.

- Of the sudden and unexpected child deaths between April 2019 and March 2021, death rates were highest among the 1-4 year and 5-17 year age groups and in the most deprived neighbourhoods. The most marked change across the two years was a reduction in the number of sudden unexpected deaths of 1–4 year olds during the COVID-19 pandemic.
- For sudden and unexpected deaths that occurred during 2020 and had been fully reviewed by a CDOP (n=204), 84% went on to be explained by other causes e.g., cardiac condition. The proportion of deaths of 1-17 year olds that remained unexplained after review (16%) was lower than that of infants (52%).

> Of all infant and child deaths occurring between April 2019 and March 2021 in England, 30% occurred suddenly and unexpectedly and of these, 64% had no immediately apparent cause.

Unexplained deaths of children 1-17 years

Deaths of children between January 2020 and December 2020 that remained unexplained after investigations and the CDOP review. This time period was chosen as the updated data collection forms were more fully established, and enough time had elapsed since December 2020 for most CDOP reviews to have taken place to determine whether or not the death could be explained.

- There were at least 32 unexplained deaths in 2020 of children aged 1-17 years; 22 children aged 1-4 years and 10 children aged 5-17 years. Whilst unexplained deaths of infants show a marked male excess, there was an equal split of sex in unexplained deaths of older children.
- Where data were available (n=30), there was a history of convulsions recorded in 27% of children whose deaths remained unexplained in this age group. This incidence was similar to children whose deaths went on to be explained, which emphasises the potential importance of understanding the aetiology and potentially contributory factors to convulsions (febrile and other) in children.
- Where it was recorded (n=14), a joint agency home/scene visit was carried out by professionals in 7 deaths, a single agency response (usually police only) was recorded for 5 deaths and in 2 deaths there was no agency response visit carried out by professionals after the death.
- Learning points or issues were identified in 75% of child death reviews in this age group. Themes included: the importance of following the statutory guidance for Joint Agency Response when a child dies suddenly and unexpectedly. This ensures families are well supported, and the right information is collected to support investigations and future research in this area.

Recommendations

Recommendation 1: Ensure there is a robust system in place for identifying families living in unsatisfactory housing conditions and for prioritising them within housing allocation schemes. This should include carrying out appropriate checks to ensure that housing conditions (including temporary and emergency accommodation) are suitable for babies and their carers.

Action by: Department for Levelling Up, Housing and Communities, Local Authorities

Recommendation 2: Consider revising the prioritisation criteria for housing allocation schemes to recognise that families with infants under 2 years of age must have enough room for safe use of a full-size cot to support them to follow safer sleeping advice[5].

Action by: Department for Levelling Up, Housing and Communities, Local Authorities

Recommendation 3: Ensure safer sleep advice is personalised to the individual circumstances of each family, and that support addresses both the environmental and psychological barriers to following advice, to reduce the risks of sudden unexpected, unexplained death in infancy. Professionals discussing safer sleep advice should be aware of the high number of deaths in which unplanned co-sleeping took place in a hazardous environment so they can ensure that every family gets advice for such situations.

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

Recommendation 4: Consider use of validated Safer Sleep Assessment Tools to identify families with infants at higher risk of SIDS. This will support Health Visitors, Social Workers, GPs and Adult Mental Health Services to identify vulnerable families and provide enhanced support. This should include seeing where the infant sleeps during home visits and providing person-centred advice for families depending on their individual circumstances.

Action by: Local Authorities, Safeguarding Children Partnerships, Children's Services, Health Visiting Services, GPs and Providers of Adult Mental Health Services

Recommendation 5: Ensure that health visitors and midwives in the CORE20PLUS5 areas have enhanced staff numbers to allow for support and training to deliver individualised safe sleeping advice. This will utilise the NHS England Core20PLUS5 approach to reducing health inequalities and current multi-disciplinary training.

Action by: Maternity Transformation Partnership, Local Authorities, Commissioners of Maternity Services, Commissioners of Health Visiting Services, NHS England

Recommendation 6: Prioritise research on sudden unexpected and unexplained deaths of children over 1 year of age to identify potentially modifiable factors so professionals can work to prevent these deaths.

Action by: Department of Health and Social Care, NHS England, National Institute for Health and Care Research (NIHR), Genomics England, Office for Health Improvement and Disparities, Royal College of Paediatrics and Child Health

Recommendation 7: Ensure there is robust and consistent national training available on the child death review statutory process, SIDS, SUDC and available resources. This will contribute to high quality support for families and good quality information collection to improve the evidence base for research on SIDS and safer sleep, and on sudden unexplained death in childhood (SUDC) and association with febrile seizures.

Action by: Department of Health and Social Care, NHS England, National Child Mortality Database

Recommendation 8: Ensure agencies responsible for conducting the statutory Joint Agency Response are compliant with national guidance including the joint attendance of police and healthcare professionals to facilitate appropriate support of families and achieve good quality data collection.

Action by: National Police Chiefs Council, Commissioners of Joint Agency Response processes, NHS England, Department of Health and Social Care

Recommendation 9: Prioritise measures to reduce poverty and deprivation with a particular emphasis on families with children in line with the recommendations in the Health Equity in England: The Marmot Review 10 Years On report.

Action by: Department of Health and Social Care, Department for Levelling Up, Housing and Communities

Recommendation 10: Ensure evidence and incentive based smoking cessation programmes, such as those utilised by the Maternity Transformation Programme, are offered to people considering pregnancy or who are pregnant. This should include following NICE guideline NG209 on smoking cessation

Action by: Integrated Care Systems, NHS England

How to read this report

As there are marked differences in the demographics of sudden and unexpected deaths for infants under 1 year old and children aged 1-17 years, this report focuses on these age groups separately.

The first section gives a brief overview of all infants and children who died suddenly and unexpectedly at any age between 1 April 2019 and 31 March 2021 in England.

The second section focuses on deaths of infants (children under 1) where the death was sudden and unexpected with no immediately apparent cause and occurred between 1 April 2019 and 31 March 2021 in England. It also includes more detailed analyses on the proportion of these deaths that occurred in the full calendar year of 2020 that went on to be explained by other causes or remained unexplained after CDOP review. This particular year was chosen as enough time has elapsed since December 2020 for most CDOP reviews to have taken place and for CDOPs to determine whether or not the death could be explained. A full calendar year was chosen so comparison with certain characteristics could be made with Office for National Statistics (ONS) published data. The section also presents learning from the CDOP reviews of unexplained infant deaths, including what modifiable factors were recorded.

The third section analyses data on sudden and unexpected deaths of children who were aged 1-17 years at the time of their death. This section describes the characteristics of these children who died between 1 April 2019 and 31 March 2021 in England. It includes the proportion of these deaths during 2020 that went on to be explained, or that remained unexplained after CDOP review. The section presents learning from the CDOP reviews of unexplained deaths in children aged 1-17 years.

Mortality rates have been presented throughout this report using different populations. The infant mortality rate has been calculated using the ONS data for live births in 2019 and 2020, and the rate is presented per 1,000 live births. The mortality rate of children who were aged 1-17 years has been calculated using data from the ONS mid-year population estimates for 1-17 year olds in 2019 and 2020 and is presented per 100,000 children in this age group.

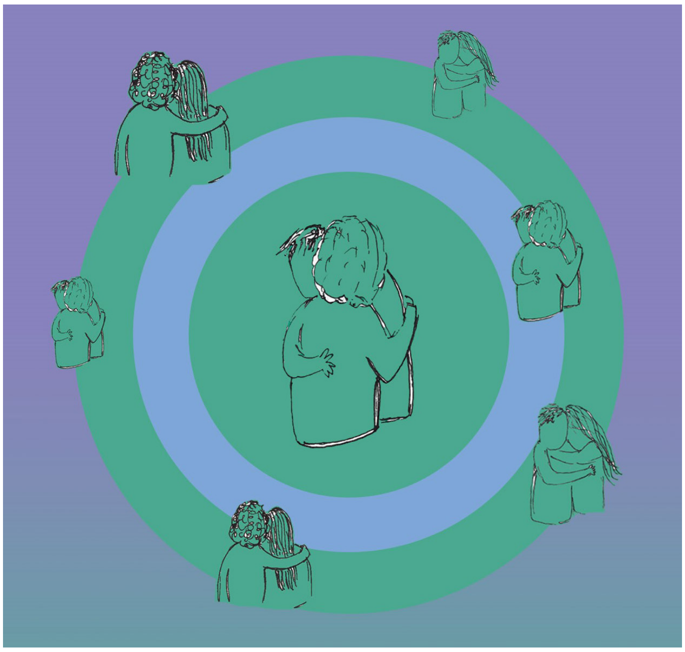
Definitions used in this report

Term	Definition
Sudden *unexpected* death in infancy (SUDI)	is a descriptive term used at the point of presentation for the death of an infant (under 1 year) whose death was not anticipated as a significant possibility 24 hours before the death, or where there was a similarly unexpected collapse leading to or precipitating the events which led to the death[6]. SUDI is not a causal classification of death and does not have an International Classification of Diseases (ICD) code. Once all investigations are complete, SUDI deaths will divide into those for which we have a clear diagnosis (explained) and those for which we do not have a diagnosis (unexplained, also known as SIDS (Sudden Infant Death Syndrome)).
Sudden unexpected, *unexplained* death in infancy	are deaths that remained unexplained at the end of the CDOP review. These deaths were assigned the category of "Sudden unexpected, unexplained death" by the CDOP on the statutory analysis form. The definition of this category is: *"Where the pathological diagnosis is either 'SIDS' or 'unascertained'"*.
Sudden *unexpected* death in childhood (SUDC)	is a descriptive term used at the point of presentation for the death of a child aged 1-17 years whose death was not anticipated as a significant possibility 24 hours before the death, or where there was a similarly unexpected collapse leading to or precipitating the events which led to the death[6]. Once all investigations are complete, these deaths will divide into those for which we have a clear diagnosis (explained) and those for which we do not have a diagnosis (unexplained).
Sudden unexpected, *unexplained* death in childhood	are deaths of children aged 1-17 years that remain unexplained at the end of the CDOP review. This excludes Sudden Unexpected Death in Epilepsy (category 5). These deaths were assigned the category of "Sudden unexpected, unexplained death" by the CDOP on the statutory analysis form.
Infant	A child under one year of age
Child	A child between 1 and 17 years

Information on how each of these cohorts of deaths were identified in this report can be found in the Methodology section.

1. Sudden and unexpected infant and child deaths (0 – 17 years)

This section presents the numbers of infants and children (0-17 years) who died suddenly and unexpectedly between 1 April 2019 and 31 March 2021 (24 months).



It is important to note that national figures for unexpected deaths have not previously been reported anywhere, for any country. The figures published previously have been only for the final identified "cause" of death – not for the presentation as unexpected.

How many infants and children (0-17 years) died suddenly and unexpectedly?

Of 6,503 deaths notified to NCMD during the two-year period, 30% (n=1924) were sudden and unexpected at the time of death, or at the time of the incident leading to death (Table 1). This includes deaths due to trauma e.g., vehicle collisions, drownings and falls and those which were suspected suicides.

Of these sudden and unexpected deaths, an immediately apparent potential cause was evident at the point of notification to NCMD for 36% (n=690), whilst 64% (n=1234) presented suddenly and unexpectedly with no immediately apparent cause (i.e., 19% of all child deaths).

Out of 1,234 sudden unexpected deaths with no immediately apparent cause, 44% (n=547) had at least one other potential category assigned at notification (underlying health condition, infection, malignancy, intrapartum or pre-natal event, preterm), but were included in this first group for analysis. This approach was taken to ensure that all sudden unexpected deaths were captured regardless of whether the child had another condition identified at notification that may turn out to be the major contributory cause of the death.

The analysis in this report focuses on sudden unexpected deaths with no immediately apparent cause. This group excludes any deaths identified as suspected trauma, suicide and substance misuse at the point of notification. However, the group of deaths that were initially categorised as having no immediately apparent cause may include some that are later found to be confirmed as trauma, suicide or substance misuse at the CDOP review.

Sudden unexpected deaths with no immediately apparent cause

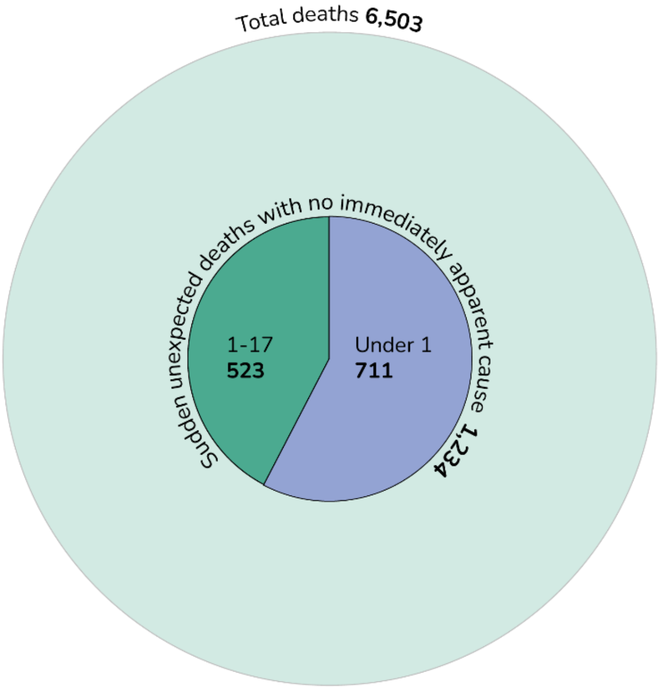


Table 1: All sudden and unexpected infant and child deaths between 1 April 2019 – 31 March 2021, by suspected category of death at the point of notification

Number of deaths		Under 1				1 – 17 years			
		2019-20		2020-21		2019-20		2020-21	
	Total n	n	Rate per 1,000 live births (95% CI)	n	Rate per 1,000 live births (95% CI)	n	Rate per 100,000 1 – 17 year olds (95% CI)	n	Rate per 100,000 1 – 17 year olds (95% CI)
Total deaths (all causes)	**6503**	**2162**	**3.54 (3.39-3.69)**	**1986**	**3.39 (3.25-3.55)**	**1274**	**11.17 (10.57-11.80)**	**1081**	**9.41 (8.92-10.06)**
All unexpected deaths	1924	397	0.65 (0.59-0.72)	396	0.68 (0.61-0.75)	581	5.09 (4.69-5.53)	550	4.79 (4.43-5.24)
Trauma/ Suicide/ Substance misuse deaths	690	32	0.05 (0.04-0.07)	50	0.09 (0.06-0.11)	297	2.60 (2.32-2.92)	311	2.71 (2.43-3.05)
Sudden unexpected deaths with no immediately apparent cause	1234	365	0.60 (0.54-0.66)	346	0.59 (0.53-0.66)	284	2.49 (2.21-2.80)	239	2.08 (1.84-2.38)

Data source: NCMD; ONS live births; ONS mid-year population estimates

See methodology for more information on cohort identification

CI = Confidence interval

2. Infants (under 1 year)

2.1. Sudden and unexpected infant deaths (under 1 year)

This section describes the demographics of sudden and unexpected infant deaths between April 2019 and March 2021 with no immediately apparent cause at the point of notification of the death. These deaths will not all remain unexplained once all the necessary investigations have been completed.

What were the demographics of infants who died suddenly and unexpectedly?

There were 711 sudden and unexpected infant deaths with no immediately apparent cause across the two-year period, a rate of 0.59 deaths per 1,000 live births (Table 2). The majority of these deaths (70%) were in the 28-364 day age group (0.42 per 1,000 live births) and there was a higher prevalence of males (0.66 per 1,000 live births).

Death rates by ethnicity ranged from 0.78 per 1,000 live births for infants described as Black or Black British, to 0.53 per 1,000 live births for White infants, and 0.38 per 1,000 live births for infants described as Other ethnicity.

As previously reported[7], more deaths occurred in infants living in the most deprived neighbourhoods of England, in comparison to the least deprived. The number of deaths increased with increasing deprivation quintile; and the death rate for infants living in the most deprived neighbourhoods (0.88 per 1,000 live births) was almost three times that of infants living in the least deprived neighbourhoods (0.32 per 1,000 live births). The death rate was also higher in urban areas (0.60 per 1,000 live births) than rural areas (0.42 per 1,000 live births).

Death rates by region of residence ranged from 0.82 to 0.45 per 1,000 live births for sudden unexpected infant deaths.

Table 2: Sudden and unexpected infant deaths with no immediately apparent cause between 1 April 2019 – 31 March 2021, by demographics

	Number (%) of deaths	Live births (2 years)	Rate (95% CI) per 1,000 live births per year
Age at death	**711**	**1,195,700**	**0.59 (0.55-0.64)**
0 – 27 days	213 (30%)	1,195,700	0.18 (0.16-0.20)
28 – 364 days	498 (70%)	1,195,700	0.42 (0.38-0.45)
Sex	**711**		
Female	304 (43%)	582,131 (49%)	0.52 (0.47-0.58)
Male	407 (57%)	613,569 (51%)	0.66 (0.60-0.73)
Ethnic group[2]	**638**		
Asian or Asian British	76 (12%)	146,901 (13%)	0.52 (0.41-0.65)
Black or Black British	47 (7%)	60,008 (5%)	0.78 (0.58-1.04)
Mixed	53 (8%)	81,080 (7%)	0.65 (0.49-0.86)
White	451 (71%)	846,525 (73%)	0.53 (0.48-0.58)
Other	11(2%)	29,180 (3%)	0.38 (0.19-0.67)
Deprivation[1]	**705**		
1 (most deprived)	269 (38%)	307,410 (26%)	0.88 (0.77-0.99)
2	181 (26%)	267,413 (22%)	0.68 (0.58-0.78)
3	127 (18%)	233,131 (19%)	0.54 (0.45-0.65)
4	70 (10%)	206,083 (17%)	0.34 (0.26-0.43)
5 (least deprived)	58 (8%)	181,663 (15%)	0.32 (0.24-0.41)
Area[1,3]	**705**		
Rural	68 (10%)	160,315 (13%)	0.42 (0.33-0.54)
Urban	637 (90%)	1,060,456 (87%)	0.60 (0.55-0.65)
Region[1]	**705**		
North East	23 (3%)	50,657 (4%)	0.45 (0.29-0.68)
North West	105 (15%)	156,349 (13%)	0.67 (0.55-0.81)
Yorkshire and The Humber	94 (13%)	114,197 (10%)	0.82 (0.67-1.01)
East Midlands	53 (8%)	95,936 (8%)	0.55 (0.41-0.72)
West Midlands	100 (14%)	129,730 (11%)	0.77 (0.63-0.94)
East of England	66 (9%)	131,722 (11%)	0.50 (0.39-0.64)
London	114 (16%)	229,585 (19%)	0.50 (0.41-0.60)
South East	92 (13%)	184,528 (15%)	0.50 (0.40-0.61)
South West	58 (8%)	102,996 (9%)	0.56 (0.43-0.73)

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

CI = Confidence interval

[1] Derived from child's postcode of residence

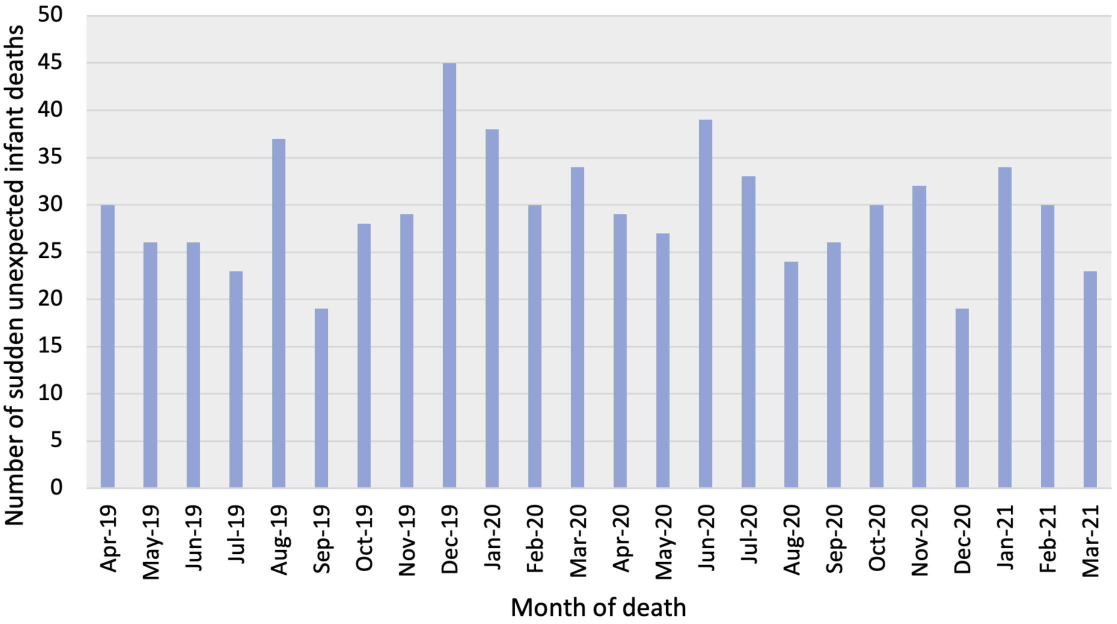
[2] Ethnicity is grouped based on groupings used in the 2011 Census. 'Other' includes 'Arab' and 'Any other ethnic group'.

[3] Population data used for urban/rural is based on mid-year population estimate for children under 1

Slightly fewer infant deaths occurred in 2020-21 (n=346) in comparison to 2019-20 (n=365), but the demographics of infants were similar when comparing the two years (Appendix A; Table 20).

The number of deaths in each month varied from 19 to a peak of 45 in December 2019, but this peak was not seen again in December 2020 (Figure 1) and there was no obvious seasonal pattern.

Figure 1: Sudden and unexpected infant deaths with no immediately apparent cause between 1 April 2019 – 31 March 2021, by month of death



Data source: NCMD
N=711

Table 2 provides the sudden unexpected infant death rates for different demographic characteristics, but more helpful interpretation can be made if the deaths are split into those with explained and unexplained causes. Section 2.2 does this for the calendar year of 2020 so we can specifically make a broad comparison with data collected on live births by the ONS for that year.

2.2. Sudden unexpected deaths in infancy during the calendar year 2020 (unexplained vs explained)

This section presents demographics on sudden and unexpected deaths of infants with no immediately apparent cause that occurred between 1 January 2020 and 31 December 2020, and where the CDOP had reviewed the death and categorised it as **'Sudden unexpected and unexplained'** by 28 June 2022.

This time period was chosen so that enough time had elapsed since December 2020 for most deaths to have undergone a CDOP review, however, it is important to note that not all deaths in 2020 had a completed review which means numbers presented throughout this section will be underestimated.

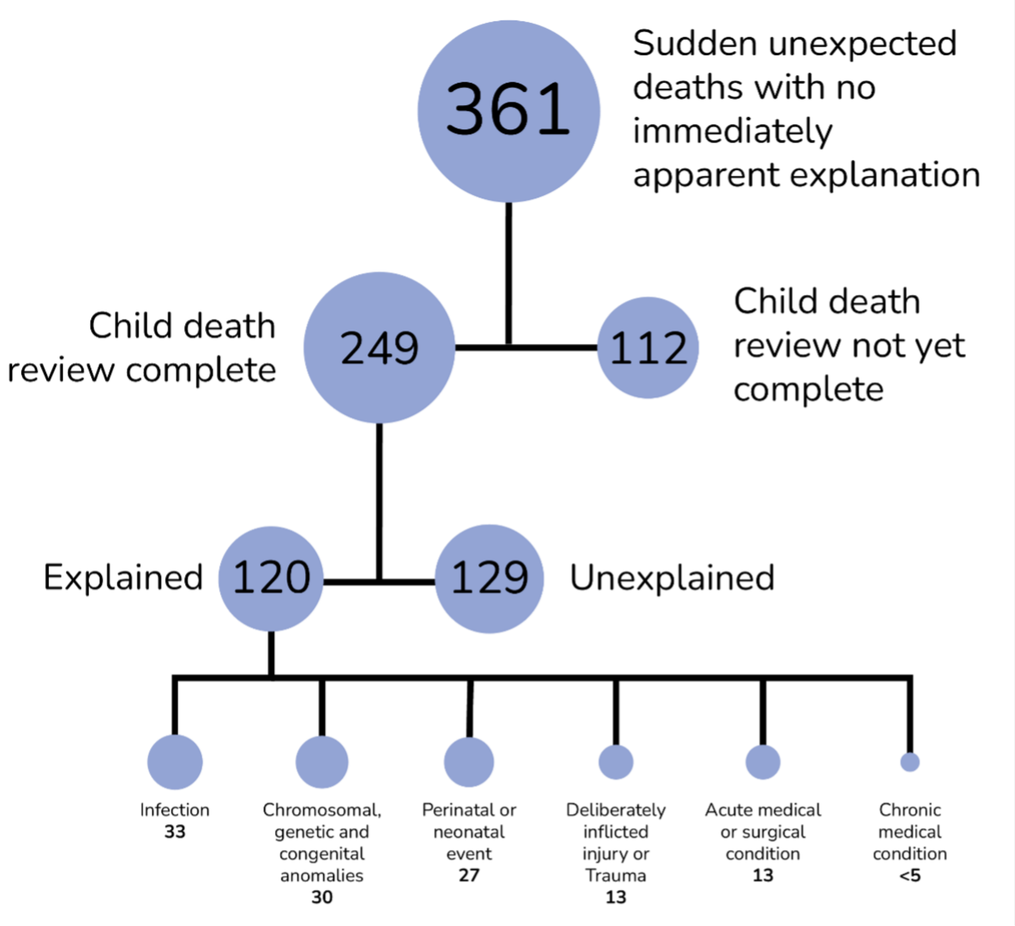
During the review, CDOPs either agree an explanation for the cause of death or determine that the death remains unexplained. The section compares demographics of those sudden and unexpected infant deaths that went on to be explained, and demographics of deaths that remained unexplained at the end of the CDOP review.

What proportion of sudden and unexpected infant deaths with no immediately apparent cause in 2020 remained unexplained following CDOP review?

Of the 361 sudden and unexpected infant deaths that occurred **during 2020**, 69% (n=249) had been reviewed by a CDOP by 28 June 2022. Child death reviews take on average around one year to complete but 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, and receipt of the final report from the local child death review meeting.

As only 69% of the deaths had been reviewed, this means that the numbers presented throughout this section will be an underestimate of the true incidence.

Figure 2: Sudden and unexpected deaths of infants with no immediately apparent cause in 2020, by CDOP category of death



Data source: NCMD

- reviewed before 28 June 2022
- data on suicide or self-inflicted harm not presented as not applicable for this age group
- in two thirds of deaths categorised as Chromosomal, genetic and congenital anomalies, the child was known to have the condition prior to death
- there were no deaths that went on to be reviewed as Malignancy

Of the deaths that had been reviewed, 52% (n=129/249) were classified as unexplained, and 48% (n=120/249) went on to be explained by other causes (Figure 2).

How do the demographics of infants whose death remained unexplained compare to those whose death went on to be explained?

There were 129 deaths of infants during 2020 that remained unexplained following review, of which 20% (n=26) occurred in the neonatal period (<28 days) and 80% (n=103) were aged 28-364 days (Table 3 and Figure 3). A higher proportion of these deaths in the neonatal period were explained (64%, n=47/73) than those in the post neonatal period (41%, n=73/176).

The overall male preponderance (57%, n=142/249) was limited to the unexplained deaths (64%, n=83/129). In the explained deaths the sex proportions were approximately equal (51% female and 49% male).

Of the unexplained deaths, 87 (71%) infants were described as being from a White ethnic background, 17 (14%) were from a mixed background, 9 (7%) were Black or Black British and 8 (7%) were Asian or Asian British.

The number of unexplained infant deaths in urban or rural areas was similar to the corresponding proportion of live births. Whilst 26% of births in 2020 were of infants living in the most deprived neighbourhoods, there was a higher prevalence of both explained deaths (34%, n=40) and unexplained deaths (42%, n=54) of infants in the most deprived neighbourhoods.

Table 3: Demographics of sudden unexpected infant deaths in 2020 by whether the death was explained/unexplained following CDOP review

	Number (%) of deaths		
	Explained	**Unexplained**	**Live births (2020) % comparison[1]**
Age at death	**120**	**129**	
0 – 27 days	47 (39%)	26 (20%)	-
28 – 364 days	73 (61%)	103 (80%)	-
Sex	**120**	**129**	
Female	61 (51%)	46 (36%)	49%
Male	59 (49%)	83 (64%)	51%
Ethnic group[2]	**111**	**122**	
Asian or Asian British	19 (17%)	8 (7%)	13%
Black or Black British	12 (11%)	9 (7%)	5%
Mixed	6 (5%)	17 (14%)	7%
White	74 (67%)	87 (71%)	72%
Other	0 (0%)	1 (1%)	2%
Area[3]	**119**	**129**	
Rural	12 (10%)	17 (13%)	13%
Urban	107 (90%)	112 (87%)	87%
Deprivation[3]	**119**	**129**	
1 (most deprived)	40 (34%)	54 (42%)	26%
2	28 (24%)	33 (26%)	22%
3	25 (21%)	21 (16%)	19%
4	14 (12%)	11 (9%)	17%
5 (least deprived)	12 (10%)	10 (8%)	15%
Region[3]	**119**	**129**	
North East	1 (1%)	5 (4%)	3%
North West	15 (13%)	12 (9%)	15%
Yorkshire and The Humber	22 (18%)	22 (17%)	13%
East Midlands	9 (8%)	14 (11%)	7%
West Midlands	10 (8%)	20 (16%)	15%
East of England	13 (11%)	15 (12%)	10%
London	24 (20%)	22 (17%)	16%
South East	13 (11%)	11 (9%)	13%
South West	12 (10%)	8 (6%)	8%

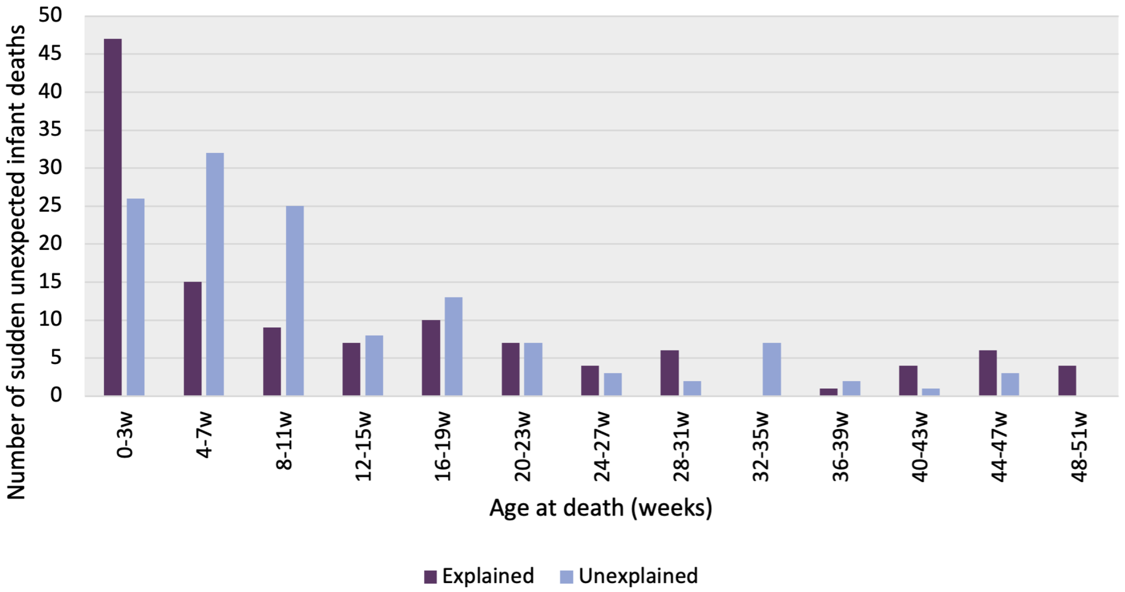
Data source: NCMD; ONS live births; IMD (2019)

1 ONS Birth characteristics (2020)

2 Ethnicity is grouped based on groupings used in the 2011 Census. ‘Other’ includes ‘Arab’ and ‘Any other ethnic group’.

3 Derived from child’s postcode of residence

Figure 3: Sudden and unexpected infant deaths with no immediately apparent cause in 2020, by age at death (weeks) and whether the death was explained/unexplained following CDOP review



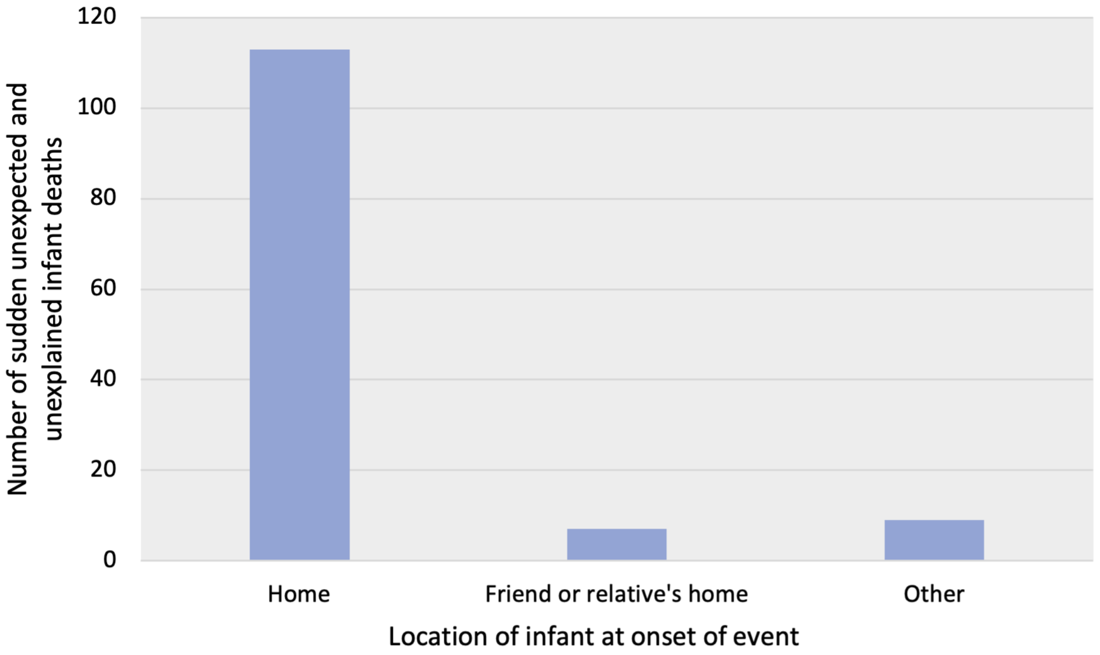
Data source: NCMD

N=249

In 88% (n=113) of unexplained infant deaths, the onset of the event that led to death occurred at home, 5% (n=7) occurred at a friend or relative's home, and 7% (n=9) occurred elsewhere (Figure 4). Out of the 16 deaths occurring outside the infant's home environment, 12 were thought to have occurred around the time the infant was thought to be asleep.

It is important that families are supported to follow safe sleep advice for every sleep, including when staying somewhere other than their normal place of residence.

Figure 4: Sudden unexpected and unexplained infant deaths in 2020, by location of infant at onset of event



Data source: NCMD

N=129

Other includes; hospital, mother and baby unit, public place, temporary accommodation, foster care home.

Unexplained deaths are strongly associated with low birthweight, prematurity, multiple births, larger families, admission to a neonatal unit and maternal smoking during pregnancy.

What were the birth characteristics of the infants?

Of the infants whose death remained unexplained, 29% (n=34/118) were born with a low birthweight (under 2500g), 28% (n=36/127) were born prematurely (<37 weeks gestation), 8% (n=10/129) were a twin or higher multiple, and 44% (n=44/101) were born to a mother with 3 or more previous births (Table 4). Smoking in pregnancy was recorded in 50% (n=57/113) of these deaths and 28% (n=36/127) had been admitted to a neonatal unit after birth.

A comparison of the unexplained deaths with population data mirrors previous observations from UK SIDS case-control studies[6,8] in that the unexplained deaths are strongly associated with low birthweight, prematurity, multiple births, larger families, admission to a neonatal unit and maternal smoking during pregnancy.

This profile of vulnerability surrounding the birth characteristics is even more marked among the explained deaths, over 43% (n=43/100) of whom were of low birthweight, 40% (n=47/118) were born prematurely and 48% (n=57/118) had been admitted to a neonatal unit.

At a population level, maternal smoking during pregnancy has fallen over recent decades to 11%[9] but is three-fold higher among the explained deaths (32%) and five-fold higher among the unexplained deaths (50%).

Birth characteristics (prematurity, low birthweight, neonatal care) were most prominent in the explained group but were also evident in the unexplained group compared to the rest of the population. Socio-economic and environmental factors (smoking, alcohol, drugs, higher order births, young mothers, parental mental health problems, Children's Social Care involvement, abuse/neglect and family violence) were all more prominent in the unexplained group.

Table 4: Sudden and unexpected infant deaths in 2020, by birth characteristics and whether the death was explained/ unexplained following CDOP review

	Number (%) of deaths		
	Explained	**Unexplained**	**Population comparison (%)**
Deaths in 2020	**120**	**129**	
Birthweight[1]	**100**	**118**	
<1500g	15 (15%)	9 (8%)	1%
1500-1999g	14 (14%)	6 (5%)	1%
2000-2499g	14 (14%)	19 (16%)	5%
2500-2999g	20 (20%)	33 (28%)	17%
3000-3499g	24 (24%)	30 (25%)	37%
3500g+	13 (13%)	21 (18%)	40%
Prematurity[1]	**118**	**127**	
<32 weeks gestation	18 (15%)	9 (7%)	1%
32-36 weeks gestation	29 (25%)	27 (21%)	6%
37 weeks+ gestation	71 (60%)	91 (72%)	93%
Multiple birth[1,6]	**108**	**129**	
Twin or higher	8 (7%)	10 (8%)	3%
Live births (including this child)[2]	**84**	**101**	
1 birth	30 (36%)	34 (34%)	44%
2 births	33 (39%)	23 (23%)	34%
3 births	13 (15%)	25 (25%)	13%
4+ births	8 (10%)	19 (19%)	8%
Smoking[3]	**107**	**113**	
During pregnancy	34 (32%)	57 (50%)	11%
Neonatal care[4,5]	**118**	**127**	
Admitted to neonatal unit following birth	57 (48%)	36 (28%)	15%

Data source: NCMD

1 ONS Birth characteristics (2020)

2 ONS Live births by number of previous live-born children and age of mother, England (2020); 1 added to ONS data to account for current birth.

3 NHS Digital Smoking status at time of delivery, where it was known (2020)

4 C. Gale, K. Ougham, S. Jawad, S. Uthaya, and N. Modi, 'Brain injury occurring during or soon after birth: annual incidence and rates of brain injuries to monitor progress against the national maternity ambition 2018 and 2019 national data', Neonatal Data Analysis Unit, Imperial College London, 2021. [Online]. Available here.

5 Defined for NCMD data by a record existing in BadgerNet. See Methodology section for more information.

6 Where answered in sudden unexpected deaths supplementary reporting form or the child had an inpatient hospital admission at any time with an ICD-10 diagnosis code Z383-Z388. See Methodology section for more information.

What was the social environment background of the infants?

Of the infants whose death remained unexplained, 36% (n=43/119) were born to mothers under 25, 17% (n=22/126) were known to social care, 45% (n=56/125) were recorded as living in a household with violence, and for 14% (n=15/109) of deaths abuse or neglect concerns were noted (Table 5). For the background of the parents, 56% (n=70/124) of parents were known to have mental health problems, 69% (n=83/121) were smokers, 35% (n=42/120) were known to misuse drugs and 22% (n=25/116) were recorded to misuse alcohol. Although the prevalence of these factors is most marked in the unexplained group, for most of these factors, prevalence in the explained group was also higher than in the general population.

From the limited population data available, unexplained deaths are strongly associated with young maternal age, parental smoking and parental drug misuse. Other markers of social disruption including whether the family is known to social care services, abuse or neglect concerns, household violence, alcohol misuse and issues with parental mental and physical health appear particularly high; factors that are pertinent to explained deaths but even more marked among the unexplained deaths. These findings are similar to the risk factors reported in families with additional needs in the National Child Safeguarding Practice Review Panel report[10].

Table 5: Sudden and unexpected infant deaths in 2020, by social environment characteristics and whether the death was explained/unexplained following CDOP review

	Number (%) of deaths		
	Explained	**Unexplained**	**Population comparison (%)**
Age of mother at birth of child[1]	**113**	**119**	
Under 20	10 (9%)	13 (11%)	3%
20 – 24 years	28 (25%)	30 (25%)	13%
25 – 29 years	28 (25%)	32 (27%)	27%
30 – 34 years	27 (24%)	26 (22%)	34%
35 or older	20 (18%)	18 (15%)	24%
Known to social care[2]	**119**	**129**	
Yes, at the time of death	12 (10%)	22 (17%)	-
Child Protection Plan or Child in Need or Looked after child	8 (7%)	15 (12%)	4%
Previously known	17 (14%)	21 (16%)	-
Not known to social care	90 (76%)	86 (67%)	-
Family members known to be smokers[3]	**117**	**121**	
Mother or Father	48 (41%)	83 (69%)	14%
Family members known to have any physical health problems/ disabilities[4]	**117**	**119**	
Mother or Father	40 (34%)	38 (32%)	21%
Sibling	4 (3%)	12 (10%)	9%
Family members known to misuse drugs[5]	**116**	**120**	
Mother or Father	18 (16%)	42 (35%)	9%
Family members known to misuse alcohol	**116**	**116**	
Mother or Father	12 (10%)	25 (22%)	-
Family members known to have any mental health problems	**117**	**124**	
Mother or Father	45 (38%)	70 (56%)	-
Abuse/neglect concerns	**105**	**109**	
Yes	8 (8%)	15 (14%)	-
Household violence	**120**	**125**	
Yes	32 (27%)	56 (45%)	-

Data source: NCMD

1 ONS Birth characteristics (2020)

2 Characteristics of children in need (2021)

3 ONS Adult smoking habits in England (2020)

4 Family Resources Survey: financial year 2020 to 2021

5 ONS Drug misuse in England and Wales (2020)

Further supplementary data on sudden unexpected and unexplained infant deaths

This section presents data on sudden unexpected and unexplained infant deaths that was collected by CDOPs on the supplementary reporting form for sudden unexpected deaths.

Of the sudden unexpected and unexplained infant deaths, 60% (n=61/101) were reported to have been breast-fed for at least one day, and 39% (n=44/114) were still breast-feeding up to the time of death. In comparison, for all live-born term babies born in 2020-21, 73% were reported to receive breast milk as the first feed[11]. 13% (n=16/120) of infants were not seen alive for more than 6 hours before they were found (Table 6). In the 24 hours preceding death, signs of an illness (e.g., cold or viral symptoms) were recorded for 31% (n=37/120) of infants and 14% (n=11/79) were recorded as having a previous unexpected death in a close relative.

Table 6: Sudden unexpected and unexplained infant deaths in 2020

	Number (%) of deaths
Breast-fed	**101**
>1 day	61 (60%)
Breast-fed	**114**
At time of death	44 (39%)
Hours since last seen alive	**120**
Observed at time of death	7 (6%)
<1 hour	19 (16%)
1 - <2 hours	20 (17%)
2 - <4 hours	33 (28%)
4 - <6 hours	25 (21%)
6+ hours	16 (13%)
Illness identified in last 24 hours	**120**
Yes	37 (31%)
Previous deaths	**79**
Previous unexpected infant/ child death in first/second degree relative[1]	11 (14%)
Blood or blood-stained fluid around face	**100**
Yes	49 (49%)

Data source: NCMD

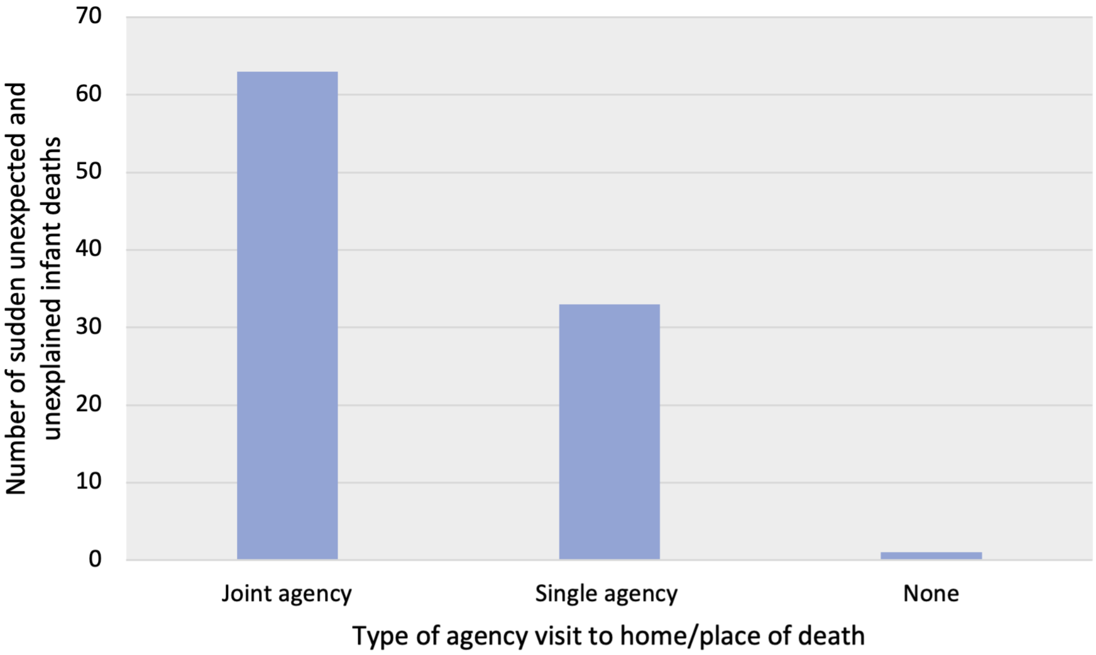
[1] For example; a parent, sibling, grandparent, aunt, uncle or cousin.

Home/scene visit carried out by professionals after death

The child death review statutory and operational guidance states that a coordinated multi-agency response (on-call health professional, police investigator, duty social worker), should be triggered if a child's death is sudden and there is no immediately apparent cause. The full process for a Joint Agency Response is set out in the Sudden unexpected death in infancy and childhood guidelines. One component of the Joint Agency Response is a joint visit to the infant or child's home or place of death.

Where the information was provided, a joint agency home/place of death visit was recorded for 65% (n=63/97) of unexplained infant deaths, and a single agency (usually police) home/place of death visit was recorded for a further 34% (n=33/97) (Figure 5). For one death there was no home/place of death visit carried out by professionals after the death.

Figure 5: Sudden unexpected and unexplained infant deaths in 2020, by agency visit to home/place of death



Data source: NCMD

N=97

In 32 deaths this data on whether a joint agency response visit to the home/place of death took place was not known or not complete.

Sleep related sudden unexpected and unexplained infant deaths

Of the 127 sudden unexpected and unexplained infant deaths where it was known, 124 (98%) occurred around the time the infant was thought to be asleep (Table 7).

Whilst over half of infants were found unresponsive in the morning hours (53%, n=65/122), deaths were not limited to the night-time hours and occurred throughout the 24-hour period.

In 11% (n=13/123) of deaths the infant was sleeping on a sofa, 29% (n=27/95) were placed on their front or side to sleep and there was a change of routine noted in 49% (n=26/53) of the deaths.

In 52% (n=64/124) of deaths the infant was sharing the sleep surface with another person; this cohort is reported on in the section in this report on co-sleeping.

Table 7: Sudden unexpected and unexplained infant deaths in 2020 where the death occurred when the infant was thought to be asleep

	Number (%) of deaths
Unexplained infant deaths occurring during apparent sleep	**124**
Time of day child found unresponsive	**122**
06.00- <12.00	65 (53%)
12.00- <18.00	8 (7%)
18.00- <24.00	14 (11%)
24.00- <06.00	35 (29%)
Place of sleep	**123**
Adult bed	63 (51%)
Cot, crib, carry cot, Moses basket	36 (29%)
Sofa[4]	13 (11%)
Other sleep place[1]	11 (9%)
Sleeping position at beginning of sleep	**95**
Supine (Back)	61 (64%)
Prone (Front)	13 (14%)
Side	14 (15%)
Other	7 (7%)
Sleeping position when found	**95**
Supine (Back)	47 (49%)
Prone (Front)	36 (38%)
Side	6 (6%)
Other	6 (6%)
Change of normal routine	**53**
Yes	26 (49%)
Dummy (pacifier)	**58**
Used during final sleep	10 (17%)
Temperature	**43**
Concerns about overheating[2]	23 (53%)
Carers sleeping in same room	**87**
Yes	69 (79%)
Sleep positioning device[3]	**110**
Yes	10 (9%)
Sharing sleeping surface with another person	**124**
Yes	64 (52%)

Data source: NCMD

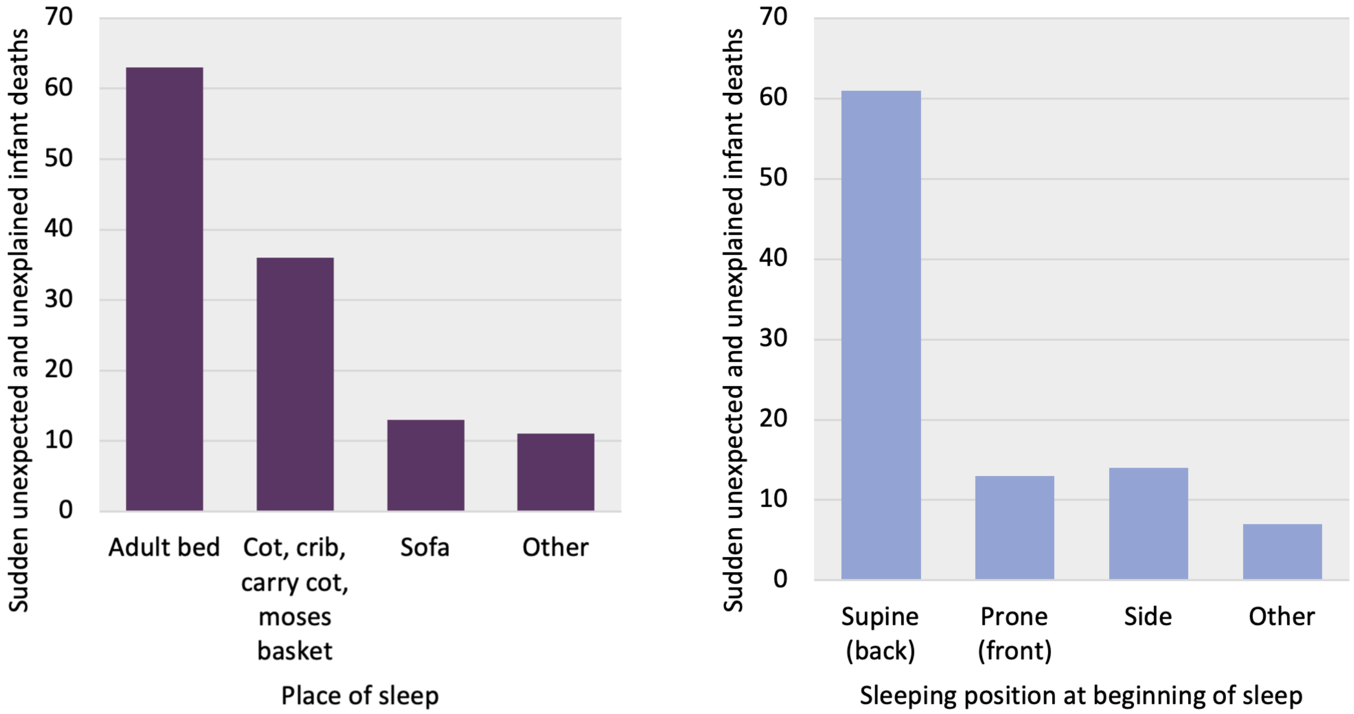
[1] Includes pod, nest, pram, travel cot, three-sided baby bed attached to adult bed, sling or baby carrier, and any other sleep environment.

[2] Expert review of the records for each of these deaths identified that evidence of overheating was not consistently recorded by professionals responding when the child died. The Avon Clinico-pathological classification system describes the possibility of overheating when two or more of the following are present: very soft surface, excessively heavy wrapping/ clothing, head covered, excessive heating or in direct sunshine, on soft cushion, pillow or bean bag.

[3] A sleep positioning device is defined as something designed to hold the baby in a particular position, e.g., a foam wedge or device with straps. Examples reported here included use of pillows/ cushions alongside other devices.

[4] 12 infants were co-sleeping with another adult and 1 infant was sleeping alone.

Figure 6a and 6b: Sudden unexpected and unexplained infant deaths in 2020, by place of sleep and sleeping position at beginning of sleep



Data source: NCMD
N=123

Data source: NCMD
N=95

Risk factors in sudden unexpected and unexplained infant deaths occurring during apparent sleep

Using previous literature, four risk factors known to increase the risk of unexplained infant deaths were identified in the deaths that occurred during apparent sleep. These were:

1. **Put down prone or side** – identified where the sleeping position at beginning of the final sleep was recorded as prone or side.
2. **Hazardous co-sleeping** – identified where the sleeping surface was shared with another person and:

   a) the sleeping surface was a sofa or chair, or

   b) the adult had consumed any alcohol or drugs (including medication that may cause drowsiness, whether prescribed or not), or

   c) the mother smoked in pregnancy or person sharing sleep surface was a smoker, or

   d) the infant was less than 12 weeks old and was born before 37 weeks gestation or weighed under 2500g.

   Where data was missing factors a-d were assumed not to be present. This may lead to an underestimate of the presence of some risks.
3. **Inappropriate sleeping surface when sleeping alone** – identified where the infant was sleeping alone and the place of sleep was recorded as a parental bed, bunk bed, large soft cushion, pod/nest, or baby bouncer/swing.
4. **Inappropriate items in the bed** – identified where cot bumper, pillows, toys, blankets, other items, or the use of a sleep positioning device was recorded.

The denominators used in Table 8 are the number of sudden unexpected and unexplained infant deaths that occurred around the time the infant was thought to be asleep. Missing data or where data was ‘not known’ was excluded for each risk factor, apart from hazardous co-sleeping where the denominator used was all unexplained infant deaths occurring during apparent sleep.

The risk factor with the highest prevalence in these deaths was hazardous co-sleeping (48%, n=59/124) (Table 8). There were also deaths where the infant was put down prone or side to sleep (28%, n=27/95), put on an inappropriate surface to sleep (12%, n=15/123), or where there were inappropriate items in the bed (20%, n=22/109).

Table 8: Sudden unexpected and unexplained infant deaths in 2020 where the death occurred when the infant was thought to be asleep, by risk factors present

Risk factor	Number (%) of deaths
Put down prone or side	27/95 (28%)
Hazardous co-sleeping[1]	59/124 (48%)
Inappropriate sleeping surface when sleeping alone	15/123 (12%)
Inappropriate items in the bed	22/109 (20%)

Data source: NCMD

[1] Hazardous co-sleeping is defined as co-sleeping with any person where a) the sleeping surface was a sofa or chair, or b) the adult had consumed any alcohol or drugs (including medication that may cause drowsiness, whether prescribed or not), or c) the mother smoked in pregnancy or person sharing sleep surface was a smoker, or d) the infant was less than 12 weeks old and was born before 37 weeks gestation or weighed under 2500g. Where data was missing the factor was assumed not to be present.

The frequency of how many of these four risk factors were present in each death was also calculated.

In total, 75% (n=93/124) of the deaths had one or more of the risk factors presented above recorded; 52% (n=65) had one, and 23% (n=28) had at least two or more risk factors (Table 9). In 25% (n=31) there were no known risk factors reported, however this proportion is affected by missing data and is likely to be lower if all data fields were fully completed.

Table 9: Sudden unexpected and unexplained infant deaths in 2020 where the death occurred when the infant was thought to be asleep, by number of known risk factors present

Minimum number of risk factors present[1]	Number (%) of deaths
No risk factors reported	31 (25%)
1 risk factor reported	65 (52%)
2 or more risk factors reported	28 (23%)
Total sudden unexpected and unexplained infant deaths occurring during sleep	124

Data source: NCMD

[1] For any deaths where data was missing or not known for any risk factor, the risk factor was assumed not to be present, therefore numbers here should be interpreted as a minimum and will likely be underestimated.

Co-sleeping

Of the sudden unexpected and unexplained infant deaths that occurred during apparent sleep, the sleeping surface was shared with an adult or older sibling in 52% (n=64/124) of deaths (Table 10).

Of these co-sleeping deaths (n=64), hazardous co-sleeping circumstances were recorded in 92% (n=59) of deaths and, where information was available, unplanned co-sleeping was seen in 60% (n=28/47) of co-sleeping deaths (Table 10). There were no co-sleeping deaths where we could be fully confident that there were no hazardous risk factors present; the 5 deaths that were not identified as hazardous all had missing data for at least one of the factors.

Table 10: Sudden unexplained infant deaths in 2020 where sleeping surface was shared with another person

	Number (%) of deaths
Sharing sleeping surface with another person	**64**
Planned or unplanned co-sleeping	**47**
Planned	19 (40%)
Unplanned	28 (60%)
Person sharing sleep surface	**64**
Father	33 (52%)
Mother	57 (89%)
Sibling(s)	12 (19%)
More than 1 person	36 (56%)
Place of sleep	**64**
Adult bed or other place	52 (81%)
Sofa	12 (19%)
Alcohol/drug use (including medication that may cause drowsiness, whether prescribed or not) of person sharing sleep surface (within the last 8 hours)	**47**
Alcohol	19 (40%)
Illicit drugs	10 (21%)
Prescribed drugs	9 (19%)
Any of the above	32 (68%)
Smoking	**64**
Person sharing sleep surface was a smoker	43 (67%)
Smoking during pregnancy	**56**
Yes	33 (59%)
Birth characteristics	**64**
Aged under 12 weeks and born premature or low birthweight	18 (28%)
Hazardous co-sleeping[1]	**59/64 (92%)**
Co-sleeping with none of the hazardous risk factors present[2]	**0**

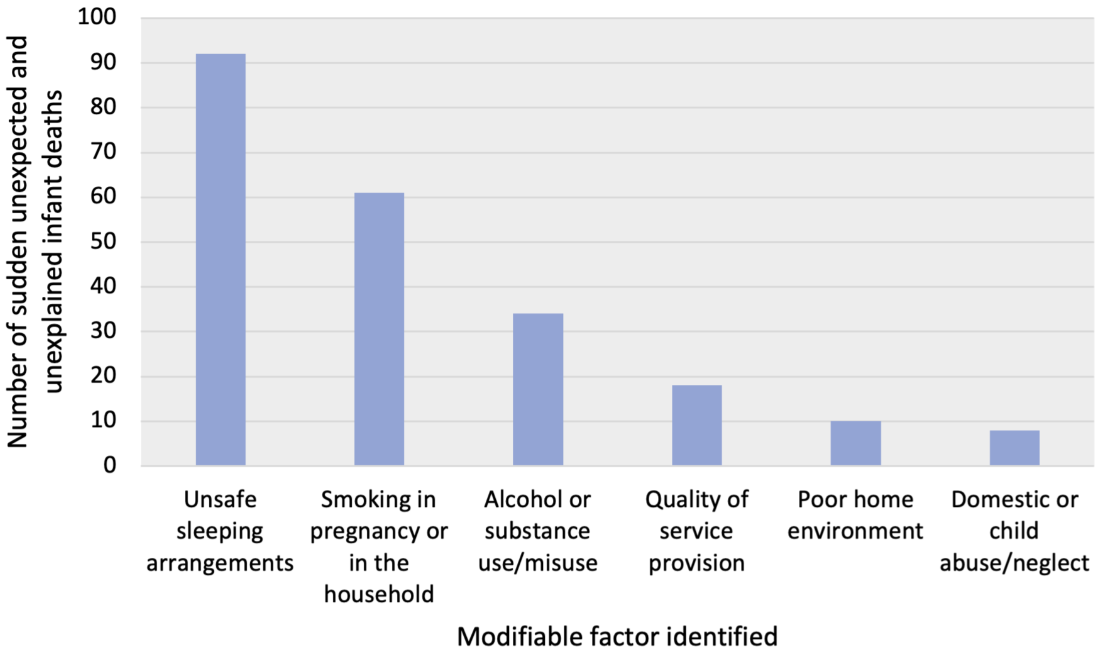
Data source: NCMD

[1] Hazardous co-sleeping is defined as co-sleeping with any person where sleeping place was on a sofa or chair, or the adult had consumed any alcohol or drugs (including prescribed medication), or the mother smoked in pregnancy or person sharing sleep surface was a smoker, or the infant was less than 12 weeks old and was born before 37 weeks gestation or weighed under 2500g. Where data was missing the factor was assumed not to be present.

[2] where data on all risk factors was completed.

Whilst there is no definition of overlaying used in the Child Death Review data collection forms, overlaying has been previously defined as a *witnessed account of a person on top of or against an infant, obstructing the infant's airway*[12]. Although overlaying was identified by CDOPs as a potential contributory factor in several deaths, the evidence on which this was based was very limited, and most commonly it referred to a death having occurred in circumstances in which overlaying was a possibility, but there was no evidence to state that overlaying actually occurred.

Figure 7: Sudden unexpected and unexplained infant deaths in 2020, by modifiable factor recorded



Data source: NCMD

The number of deaths in each column do not sum to the total number of deaths as each death can have multiple modifiable factors identified

1 review was excluded as there was inadequate information in order to determine modifiable factors

What modifiable factors were identified by CDOPs?

Modifiable factors are defined in Working Together to Safeguard Children (2018) 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".

Where the CDOP had sufficient information to determine modifiable factors (n=128), 87% (n=111) of the reviews identified at least one modifiable factor in these deaths. This proportion is higher than any other category of death[13]. Whilst the cause or causes of unexplained deaths are not known, research has shown that there are some factors, such as those described in this section, that may increase the risk of such deaths occurring.

Unsafe sleeping arrangements

Unsafe sleeping arrangements were recorded as a modifiable factor in 92 (72%) deaths of children who died suddenly and unexpectedly and whose death remained unexplained after CDOP review. An example of an unsafe sleeping arrangement is where an adult is sleeping on a sofa or armchair with a baby. Some parents choose to share a bed or other sleep surface (known as co-sleeping) with their babies, and this is not a modifiable factor when done without hazards. However, co-sleeping on a sofa or armchair can increase the risk of SIDS by 50 times[8], making this an unsafe practice. Co-sleeping in an adult bed where the parents have consumed alcohol, taken drugs or smoked has also been shown to be extremely unsafe as well as sleeping with young infants (less than 12 weeks) who were born preterm or low birthweight[14].

Sections 1.3.13 and 1.3.14 of NICE guideline NG194 on postnatal care provides information for professionals on discussion of bed-sharing with parents.

Smoking in pregnancy or in the household

Smoking was reported as a modifiable factor in 61 (48%) deaths. This included smoking during pregnancy and smoking by anyone in the child's household. Smoking cigarettes during pregnancy or after birth increases the risk of SIDS. Mothers who smoke 1-9 cigarettes per day during pregnancy are more than 4 times as likely to have a baby die due to SIDS than a mother who did not smoke at all during her pregnancy[15].

NICE guideline NG209, covers support to stop smoking for those aged 12 years and over. It includes recommendations to identify pregnant women who smoke and to provide support for women to stop smoking during and after pregnancy. Routine carbon monoxide testing should be offered at all antenatal appointments to assess exposure to tobacco smoke along with an opt-out referral to receive stop-smoking support.

The guidance also provides recommendations on follow-up for those referred to a stop-smoking service which includes addressing any factors that prevent pregnant women from using stop-smoking support including:

- A lack of confidence in their ability to stop smoking
- Lack of knowledge about the services on offer
- Difficulty accessing them
- Lack of suitable childcare
- Fear of failure and concerns about being stigmatised.

Research shows that intensive NHS smoking cessation treatments are effective in helping people to stop smoking[16]. The Lullaby Trust provides advice on how to keep your baby smoke free. The NHS Better Health webpage gives advice for those who want to stop smoking.

Alcohol or substance use/misuse

Alcohol or substance use/misuse was recorded as a modifiable factor in 34 (27%) deaths. This included both previous alcohol or substance use by a parent or carer, and alcohol or substance use by a parent or carer at the time the child died. Alcohol consumption is not a risk factor for SIDS if there is no co-sleeping. However, parents who have consumed alcohol should not co-sleep with their baby. The risk of SIDS is higher if the infant is co-sleeping with one or more adults who have consumed drugs or alcohol. This includes both illicit drugs and prescription drugs where there has been a recent change in dosage or medication.

Quality of service provision

The NCMD Second Annual Report showed that for children whose deaths remain unexplained there are fewer modifiable factors relating to service provision recorded than for most other types of death. This will often be because they have not needed to access any services prior to their death, or because their interaction with routine services has been as expected. However, quality of service provision was recorded as a modifiable factor by CDOPs in 18 deaths (14%). Examples of issues in the quality of service provision include lack of face-to-face contact or assessment by services due to COVID-19 restrictions, lack of access to appropriate resuscitation equipment in the community and lack of appropriate referral during pregnancy to enhanced midwifery service.

Further detail on issues highlighted by CDOPs in this area is recorded in the learning points section of this report.

Poor home environment

Poor home conditions were reported as a modifiable factor in 10 deaths (8%). Concerns reported included overcrowding, lack of cleanliness, houses in poor repair and the presence of damp and/or mouldy conditions. Further analysis showed that in 34 reviews, there was recorded evidence related to homelessness, temporary accommodation and threats of eviction (n=15), overcrowding (n=13), poverty and deprivation (n=6). This means that nearly 30% (n=34/129) of the infant deaths in this cohort were in families experiencing poverty and deprivation, homelessness or living in temporary accommodation. A question was added to the child death statutory reporting form from 1 April 2021 asking whether there was any indication that the child / child's family lived in poverty and/or deprivation. The answer was recorded as “Yes” in 8 of the infant death records included in this cohort where this information was available (n=30).

The NCMD thematic report on Child Mortality and Social Deprivation showed a clear association between the risk of death and the level of deprivation in the cohort examined for all types of death, including children whose deaths remain unexplained, and the Health Foundation showed that overcrowding is highest for those with low incomes[5]. The circumstances and environment relating to deprivation can make following safer sleep advice more difficult. For example, families living in overcrowded conditions may have no choice but to sleep together in an unsafe environment, e.g., families not having enough space for a full-size cot for the baby to sleep in. Households with lower incomes are more likely to be overcrowded and living in an overcrowded household is associated with worse health outcomes. Section 166A(3) of the Housing Act 1996 makes provision for local authorities to give preference in their housing allocation schemes to people occupying insanitary or overcrowded housing or otherwise living in unsatisfactory housing conditions. In this context the lack of space to safely use a full-sized infant cot is an “unsatisfactory” housing condition. In addition, local authorities can also give high priority to particular descriptions of people who fall within the statutory reasonable preference categories and have urgent housing needs. This includes families in severe overcrowding which poses a serious health hazard.

Domestic or child abuse/neglect

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. CDOPs recorded domestic abuse or child abuse/neglect as a modifiable factor in 8 (6%) deaths. These are not deaths which were directly caused by abuse or neglect. They represent children where abuse or neglect was identified as present in the child’s life and may have been a contributory factor.

What issues and learning points were identified by CDOPs?

Evidence of issues and learning points identified by CDOPs were recorded in 85% (n=110/129) of deaths during the CDOP review.

Safe sleeping

CDOPs routinely review whether and how safe sleeping advice has been given to families who lose an infant suddenly and unexpectedly and there were many deaths where there was documented evidence that these discussions had taken place. A strong theme identified was the importance of families understanding the risks of SIDS for their specific situation and the need to create a safe sleeping space for their infant. This included understanding the risks when they have a change in their normal routine, such as going to a party, or staying at another family member's house. The National Child Safeguarding Practice Review Panel report "Out of Routine: A review of sudden unexpected death in infancy in families where the children are considered at risk of significant harm" was published in June 2020. The report highlights the challenges in supporting vulnerable families to follow safer sleep advice and offers recommendations for how to address this issue for high-risk populations.

CDOPs recorded evidence of the use of Safer Sleep Assessment Tools in supporting discussions with parents. There were also several examples of the need for safer sleep advice to be available in the parents' first language and with pictorial information.

The second strong theme to emerge from CDOP reviews was recognising the importance of health visitors viewing the sleep environment when they visit the family home. Seeing the sleep environment provides an opportunity to support the family to understand any specific risks for their set-up. During this visit, it is important to ask if they plan for the baby to sleep anywhere else in the house or if the baby will be sleeping at any other friends or family members' homes so that safe sleeping advice can also be provided to those people e.g., grandparents.

The Lullaby Trust provides a number of resources on safer sleep on their website, for families and for professionals. There is no advice that guarantees the prevention of SIDS or SUDC, but parents should be informed that, by following safer sleep advice, it is possible to significantly lower the chance of this tragedy occurring. It is therefore important for midwives, health visitors and other professionals working with families during pregnancy and around the time of birth to discuss safer sleep advice. This advice should be followed up by the midwife after the birth, by the health visitor in the early weeks of the baby's life and again by GPs at the six week baby check (NICE guideline NG194). It is essential that all professionals in touch with parents and visiting the family home make sure that the messages are understood by them, and do not assume that someone else has already offered leaflets or other materials.

The impact of COVID-19 and the public health measures implemented to reduce the spread of the virus

The public health measures introduced to help stop the spread of COVID-19 included several national lockdowns which meant the way that all agencies delivered their services changed. During the review of these deaths, CDOPs identified a number of effects of the pandemic and the public health measures which had an impact on families. These included:

- Inability of healthcare professionals to interact with families in person affecting the dissemination of information.
- Increased numbers of patients not attending phone appointments with their GP, possibly due to healthcare professionals calling from withheld numbers.
- Delays in registration of a new baby with a GP.
- Families being unable to accompany their child to the mortuary or go and visit them after death.
- Post-mortem report findings being shared virtually and inquests taking place virtually making it difficult for families to attend.
- Stopping face to face bereavement counselling sessions.

The Maternal Mental Health Alliance reported that 65% of local authorities in England redeployed at least one Health Visitor during the pandemic. CDOPs noted that this particularly affected first time parents. The University College London report on the Impacts of COVID-19 on health visiting in England highlights that a high proportion of antenatal and early postnatal contacts were delivered by phone or video call in early 2020. However, some face-to-face visits did continue, in particular where families were assessed as being vulnerable or in clinical need.

The Parent-Infant Foundation Babies in Lockdown Report highlighted that two thirds (68%) of parents said their ability to cope with their pregnancy or baby had been adversely affected by COVID-19 and only 11% of parents of children under 2 reported that they had seen a health visitor face to face in early 2020.

However, the lockdown measures also affected the routines of family life. The impact of social isolation led to some parents becoming anxious about COVID-19 and not wanting to have face to face calls. Coping with the loss of a child when in lockdown, without access to networks of families and friends, was also identified as a significant challenge. In addition, CDOPs highlighted the experience of families who were forced to rearrange their home environment to accommodate working from home, meaning safe sleeping practices could not be followed for daytime naps.

Care of the family after death

The care families receive following the death of their child is of paramount importance. Chapter 6 of the Child Death Review Statutory & Operational Guidance lays out the support that should be offered to families in these circumstances. However, CDOPs identified a significant number of deaths where the family received poor care from services. Much of this related to poor communication with the family, for example a lack of clear communication about handling a baby after death causing distress to parents, and not ensuring that fathers, as well as mothers are included in bereavement support referrals. CDOPs also highlighted the importance of Emergency Departments ensuring that resuscitation areas are clear of all non-essential people, including inpatients where possible, to minimise additional distress for the family. For GPs, the learning identified related to the importance of adding a flag to GP records for affected family members following a child death to alert any practitioner to the bereavement. Finally, delay in the receipt of the final post-mortem report was documented as causing distress to multiple families. The national shortage of paediatric pathologists in England continues to influence the time taken for families to receive answers about why their child has died and to be referred for other investigations.

Poor communication and information sharing

CDOPs recorded multiple examples of poor communication both within and between services and between professionals and families. Particular challenges occurred in circumstances where families had moved house from one area to another and the new area had not received complete information relating to the family's health or social care background. Within healthcare services, it was noted that an additional challenge is experienced when different information technology systems are used. CDOPs also gave importance to accurately documenting weights, reviewing growth charts, and recognising and responding appropriately to faltering growth in infants.

Good Practice
CDOPs also recorded several examples of good practice in their local areas. For example:

- Emergency Department teams ensuring staff involved in unsuccessful resuscitation of infants and children are given the opportunity for an immediate "hot de-brief" to provide an opportunity for everyone involved to begin to acknowledge and process the emotional impact, and to reflect and identify any immediate learning points from what has happened.
- GPs offering all children under 5 years old a face-to-face appointment straight away, instead of having a telephone appointment first.
- Health visiting services offering a tailored service to vulnerable families.
- Healthcare services recognising that each new child in a family is an opportunity for professionals to share new evidence and updates with families on safer sleeping.

3. Children aged 1 to 17 years

3.1. Sudden and unexpected deaths of children aged 1 to 17 years

This section describes the demographics of sudden and unexpected deaths of children aged 1 to 17 years with no immediately apparent explanation between 1 April 2019 and 31 March 2021. These deaths will not all remain unexplained once all of the necessary investigations have taken place.

What were the demographics of children aged 1 to 17 years who died suddenly and unexpectedly?

There were 523 sudden and unexpected deaths of children across the two-year period where there was no immediately apparent cause, a rate of 2.28 deaths per 100,000 1-17 year olds (Table 11). Death rates were highest among the 1–4 year olds (3.46 per 100,000 population) and the 15-17 year olds (3.02 per 100,000 population).

The number of deaths increased with increasing deprivation quintile; and the death rate of those living in the most deprived neighbourhoods (3.41 per 100,000 population) was almost three times that of the children living in the least deprived quintile (1.15 per 100,000 population). This is the same trend as seen for sudden unexpected deaths of infants.

When comparing changes across the two years, the most marked change was a reduction in the number of sudden unexpected deaths of 1–4 year olds during 2020-21, the first year of the COVID-19 pandemic (Appendix A: Table 21, and Figure 8).

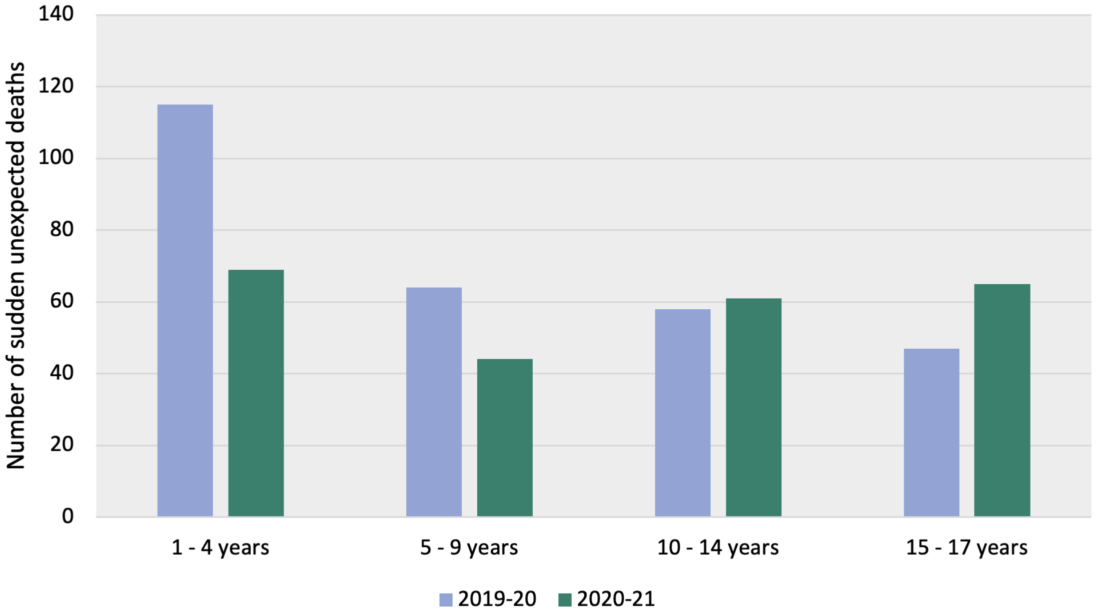
Table 11: Sudden and unexpected deaths with no immediately apparent cause of children aged 1 to 17 years, between 1 April 2019 – 31 March 2021, by demographics

	Number (%) of deaths	Estimated population of children same age (2 years)	Rate (95% CI) per 100,000 1-17 year olds per year
Age at death	**523**	**22,896,085**	**2.28 (2.09-2.49)**
1 – 4 years	184 (35%)	5,318,313 (23%)	3.46 (2.98-4.00)
5 – 9 years	108 (21%)	7,077,664 (31%)	1.53 (1.25-1.84)
10 – 14 years	119 (23%)	6,789,825 (30%)	1.75 (1.45-2.10)
15 – 17 years	112 (21%)	3,710,283 (16%)	3.02 (2.49-3.63)
Sex	**522**		
Female	228 (44%)	11,153,460 (49%)	2.04 (1.79-2.33)
Male	294 (56%)	11,742,625 (51%)	2.50 (2.23-2.81)
Area[1]	**519**		
Rural	63 (12%)	3,545,933 (15%)	1.78 (1.37-2.28)
Urban	456 (88%)	19,350,152 (85%)	2.36 (2.15-2.59)
Deprivation[1]	**519**		
1 (most deprived)	186 (36%)	5,454,357 (24%)	3.41 (2.94-3.94)
2	116 (22%)	4,718,453 (21%)	2.46 (2.03-2.95)
3	93 (18%)	4,318,777 (19%)	2.15 (1.74-2.64)
4	75 (14%)	4,143,656 (18%)	1.81 (1.42-2.27)
5 (least deprived)	49 (9%)	4,260,842 (19%)	1.15 (0.85-1.52)
Region[1]	**519**		
North East	28 (5%)	1,013,763 (4%)	2.76 (1.84-3.99)
North West	76 (15%)	2,975,270 (13%)	2.55 (2.01-3.20)
Yorkshire and The Humber	62 (12%)	2,227,502 (10%)	2.78 (2.13-3.57)
East Midlands	38 (7%)	1,912,724 (8%)	1.99 (1.41-2.73)
West Midlands	69 (13%)	2,474,354 (11%)	2.79 (2.17-3.53)
East of England	58 (11%)	2,567,865 (11%)	2.26 (1.72-2.92)
London	97 (19%)	3,846,937 (17%)	2.52 (2.04-3.08)
South East	58 (11%)	3,762,580 (16%)	1.54 (1.17-1.99)
South West	33 (6%)	2,115,090 (9%)	1.56 (1.07-2.19)

Data source: NCMD; ONS mid-year population estimates

[1] Derived from child's postcode of residence

Figure 8: Sudden and unexpected deaths with no immediately apparent cause of children aged 1 to 17 years, by age and year of death



Data source: NCMD
N=523

Of the children who died suddenly and unexpectedly, 66% (n=320) were reported as being of White ethnic background, 17% (n=81) were Asian or Asian British, 10% (n=47) were Black or Black British, 6% (n=27) were of mixed ethnicity, and 3% (n=13) were reported as other ethnicity (Table 12).

As recent data on the population by ethnicity is not available, comparisons to the population should be treated with caution due to limitations of the population data (based on 0-17 years for England and Wales data from the 2011 census).

Table 12: Sudden and unexpected deaths with no immediately apparent cause of children aged 1 to 17 years, between 1 April 2019 – 31 March 2021, by ethnic group

	Number (%) of deaths	Proportion of population of 0 – 17 year olds (2011)
Ethnic group[1]	**488**	
Asian or Asian British	81 (17%)	9%
Black or Black British	47 (10%)	5%
Mixed	27 (6%)	5%
White	320 (66%)	80%
Other	13 (3%)	1%

Data source: NCMD; Census (2011)

[1] Ethnicity is grouped based on groupings used in the 2011 Census. 'Other' includes 'Arab' and 'Any other ethnic group'.

Table 11 provides the sudden and unexpected child death rates for different demographic characteristics, but more helpful interpretation can be made if the deaths are split into those with explained and unexplained causes. Section 3.2 does this for the calendar year of 2020 so we can specifically make a broad comparison with data collected on livebirths by the ONS for that year.

3.2. Sudden unexpected deaths of children aged 1 to 17 years during the calendar year 2020 (unexplained vs explained)

This section presents data on sudden and unexpected deaths of children aged 1-17 years with no immediately apparent cause that occurred between 1 January 2020 and 31 December 2020, and where the CDOP had reviewed the death and categorised as 'Sudden unexpected and unexplained' by 28 June 2022.

This time period was chosen so that enough time had elapsed since December 2020 for most deaths to have undergone a CDOP review, however, it is important to note that not all deaths in 2020 had a completed review which means numbers presented throughout will be underestimated.

During the review, CDOPs either agreed an explanation for the cause of death or determined that the death remains unexplained. The section compares demographics of both sudden and unexpected deaths that went on to be explained, and demographics of deaths that remained unexplained at the end of the CDOP review.

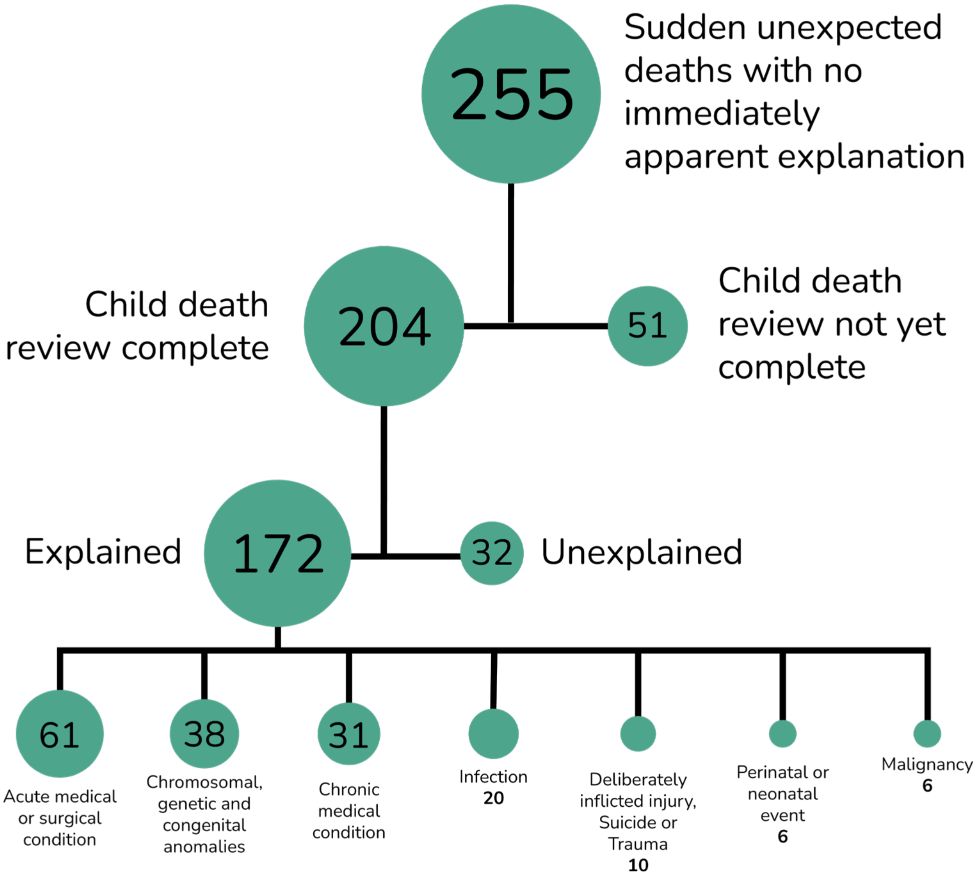
What proportion of sudden and unexpected deaths with no immediately apparent cause in 2020 of children aged 1 to 17 years remained unexplained following review?

Of the 255 sudden and unexpected deaths with no immediately apparent cause that occurred during 2020, 80% (n=204) had been reviewed by a CDOP by 28 June 2022 (Figure 9). Child death reviews take on average around one year to complete but 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, and receipt of the final report from the local child death review meeting.

As only 80% of the deaths had been reviewed, this means that the numbers presented throughout this section will be an underestimate of the true incidence.

Of the sudden and unexpected deaths in 2020 that had been reviewed, 16% (n=32/204) were classified as unexplained, whilst 84% (n=172/204) were explained by other causes, as shown in Figure 9. Thus, the proportion of unexpected deaths of children 1-17 years with no immediately apparent cause that remained unexplained (16%) after review was lower than that for infants (52%).

Figure 9: Sudden and unexpected deaths with no immediately apparent cause of children aged 1 to 17 years in 2020, by CDOP category of death



Data source: NCMD

- reviewed before 28 June 2022
- In 84% of deaths categorised as Chromosomal, genetic and congenital anomalies, the child was known to have the condition prior to death.

How do the demographics of children whose death was sudden unexpected and unexplained, compare to those that went on to be explained?

Unexplained deaths of children aged 1-17 years are fortunately rare, so the analysis is based on small numbers. Numbers and percentages presented throughout this section should be interpreted with caution.

In total, there were 32 unexplained deaths of children aged 1-17 years; 22 were aged 1-4 years and 10 aged 5-17 years (Table 14). Children aged 1 year accounted for the largest proportion of these deaths (n=11), followed by children aged 2 (n=7), with the numbers of deaths of children reducing to fewer than 5 in each of the following age years.

It is important to note that, whilst unexplained deaths of infants show a marked male excess, this was not seen in unexplained deaths of children aged 1-17 years.

Whilst 24% of 1-17 year olds were living in the most deprived neighbourhoods in 2020, there was a higher prevalence for both explained (36%, n=61) and unexplained deaths (32%, n=10) in the most deprived neighbourhoods.

Table 14: Demographics of sudden and unexpected deaths of children aged 1-17 years, with no immediately apparent cause in 2020 by whether the death was explained/unexplained following CDOP review

	Number (%) of deaths		Proportion of population in 2020 within each demographic
	Explained	Unexplained	
Age at death	**172**	**32**	
1 – 4 years	44 (26%)	22 (69%)	23%
5 – 17 years	128 (74%)	10 (31%)	77%
Sex	**172**	**32**	
Female	76 (44%)	16 (50%)	49%
Male	96 (56%)	16 (50%)	51%
Ethnic group[2]	**167**	**32**	
White	112 (67%)	21 (66%)	80%
Other Ethnicities	55 (33%)	11 (34%)	20%
Area[1]	**172**	**31**	
Rural	20 (12%)	3 (10%)	15%
Urban	152 (88%)	28 (90%)	85%
Deprivation[1]	**171**	**31**	
1 (most deprived)	61 (36%)	10 (32%)	24%
2	42 (25%)	6 (19%)	21%
3	29 (17%)	7 (23%)	19%
4	23 (13%)	6 (19%)	18%
5 (least deprived)	16 (9%)	2 (6%)	19%

Data source: NCMD; ONS mid-year population estimates (2020); IMD (2019); Census (2011)

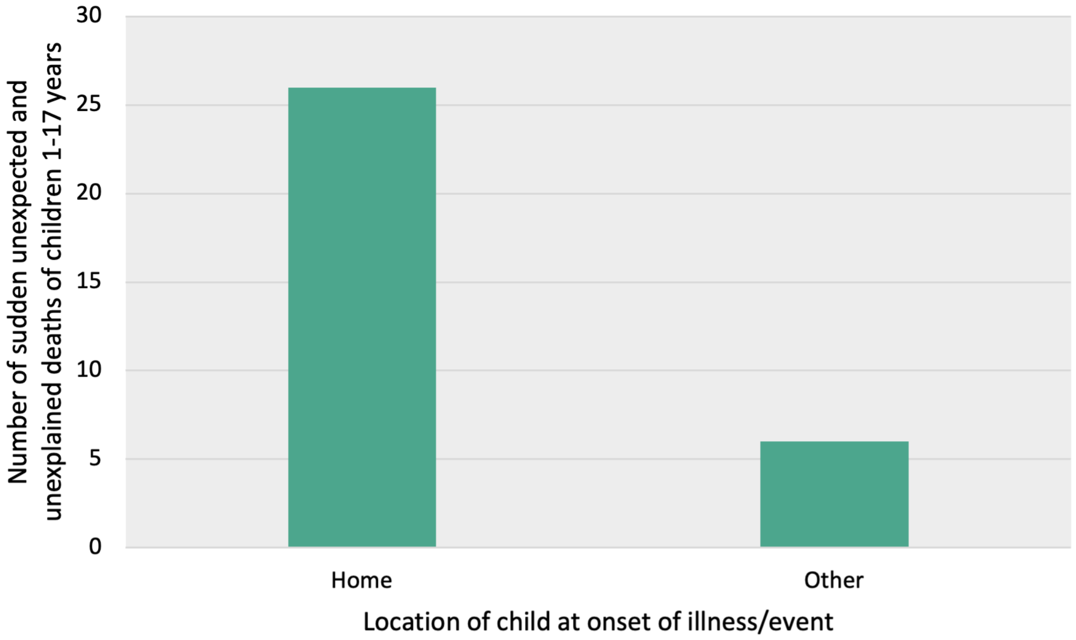
[1] Derived from child's postcode of residence

[2] Population by ethnicity used for 0-17 year olds from Census (2011) data. 'Other Ethnicities' includes 'Asian', 'Black', 'Mixed' and 'Other' ethnic groups.

Data on region not presented due to small numbers

In 81% (n=26) of unexplained deaths, the onset of the illness/event that led to death occurred at home and 19% (n=6) occurred in other locations outside of the child's home (Figure 10).

Figure 10: Sudden unexpected and unexplained deaths of children aged 1 to 17 years in 2020, by location of the child at onset of illness or event that led to death



Data source: NCMD

N=32

Other includes; school or nursery, public place, care home, friend's or relative's home.

What were the birth characteristics of the children?

Where the characteristics were known in the unexplained deaths, 20% (n=5/25) were born prematurely, 21% (n=6/28) of mothers smoked during pregnancy, 17% (n=4/24) had been admitted to a neonatal unit after birth and fewer than 5 children were born at a low birthweight (Table 15). Observations of associated birth characteristics of unexplained infant deaths were not seen in the unexpected and unexplained deaths of older children.

Table 15: Sudden and unexpected deaths of children aged 1 to 17 years in 2020, by birth characteristics and whether the death was explained/unexplained following CDOP review

	Number (%) of deaths	
	Explained	**Unexplained**
Deaths in 2020	**172**	**32**
Birthweight	**45**	**17**
<2500g	22 (49%)	3 (18%)
2500g+	23 (51%)	14 (82%)
Prematurity	**100**	**25**
<37 weeks gestation	27 (27%)	5 (20%)
37 weeks+ gestation	73 (73%)	20 (80%)
Multiple birth[2]	**141**	**31**
Twin or higher	6 (4%)	*
Smoking	**134**	**28**
During pregnancy	19 (14%)	6 (21%)
Neonatal care (1 – 9 age group only)[1]	**82**	**24**
Admitted to neonatal unit following birth[1]	33 (40%)	4 (17%)

Data source: NCMD

[1] defined by a record existing in BadgerNet. Data presented for 1-9 years age group only as the BadgerNet system was not routinely used across England before 2009. See Methodology section for more information.

[2] Where answered in sudden unexpected deaths supplementary reporting form or the child had an inpatient hospital admission at any time with an ICD-10 diagnosis code Z383-Z388 coded. See Methodology section for more information.

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

What was the social environment background of the children?

Where the social environment characteristics were known in the unexplained deaths, 19% (n=6/32) were known to social care compared to 28% (n=48/172) of the explained deaths (Table 16). Proportions of deaths where parents were smokers, had physical health problems or disabilities, and/or misused alcohol or drugs, were similar across the unexplained and explained deaths, however, small numbers of unexplained deaths make interpretation of data limited.

There was a higher proportion of parental smoking, drug and alcohol misuse, parental mental health issues, and household violence in the deaths of infants in comparison to children aged 1-17 years.

Table 16: Sudden and unexpected deaths of children aged 1 to 17 years in 2020, by social environment characteristics and whether the death was explained/unexplained following CDOP review

	Number (%) of deaths	
	Explained	**Unexplained**
Age of mother at birth of child	**139**	**24**
Under 25	45 (32%)	6 (25%)
25 or older	94 (68%)	18 (75%)
Known to social care	**172**	**32**
Yes at the time of death	48 (28%)	6 (19%)
Child Protection Plan or Child in Need or Looked after child	35 (20%)	4 (13%)
Previously known	41 (24%)	8 (25%)
Not known to social care	83 (48%)	18 (56%)
Family members known to be smokers	**149**	**31**
Mother or Father	35 (23%)	8 (26%)
Family members known to have any physical health problems/ disabilities	**160**	**30**
Mother or Father or Sibling	67 (42%)	14 (47%)
Family members known to misuse drugs	**158**	**31**
Mother or Father	20 (13%)	6 (19%)
Family members known to misuse alcohol	**159**	**30**
Mother or Father	7 (4%)	*
Family members known to have any mental health problems	**161**	**30**
Mother or Father	47 (29%)	12 (40%)
Abuse/neglect concerns	**162**	**28**
Yes	6 (4%)	*
Household violence	**165**	**32**
Yes	35 (21%)	10 (31%)

Data source: NCMD

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

Disabilities and medical conditions

The child death review statutory data collection forms collect information on learning disabilities, pre-existing medical conditions and whether there is a history of convulsions (including febrile convulsions) in the child and the family background.

In 41% (n=13/32) of unexplained deaths the child was reported to have a pre-existing medical condition, the proportion of which was higher for the explained cohort (77%, n=131/171) (Table 17). Similar levels of signs of illness being identified in the last 24 hours of life were recorded between the explained and unexplained cohorts (51% and 46% respectively). Half (n=5/10) of the children aged 5-17 years whose death remained unexplained were reported to have a learning disability. This is higher than the population prevalence of children in England with a learning disability, which was estimated at 2.5% in 2015[17].

Previous research has shown that febrile convulsions may be associated with sudden unexplained deaths of children[4,18]. The prevalence of febrile seizures in the general population is 2-5%[4] and consistent with previous studies, 27% (n=8/30) of children whose unexpected death remained unexplained in 2020 had a documented history of seizures. 32% (n=52/163) of children whose unexpected deaths were explained were also known to have had a previous convulsion. These explained deaths include Sudden Unexpected Death in Epilepsy (SUDEP), other neurological deaths, and sudden deaths of children with underlying health conditions.

Table 17: Sudden and unexpected deaths of children aged 1 to 17 years in 2020, by previous convulsions and whether the death was explained/unexplained following CDOP review

	Number (%) of deaths	
	Explained	**Unexplained**
Learning disability (5 – 17 years only)[1]	**126**	**10**
Yes	73 (58%)	5 (50%)
Pre existing medical condition	**171**	**32**
Yes	131 (77%)	13 (41%)
Convulsions (including febrile convulsions)[2]	**163**	**30**
Yes	52 (32%)	8 (27%)
Illness identified in last 24 hours	63	**26**
Yes	32 (51%)	12 (46%)

Data source: NCMD; Hospital Episode Statistics

[1] Diagnosis of learning disabilities is challenging under the age of 4, and so reporting has been limited to children aged 5-17 years.

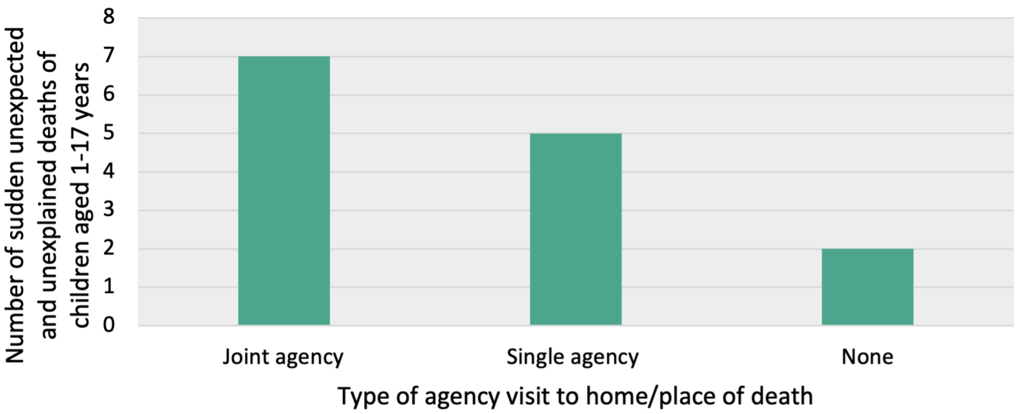
[2] Where answered in sudden unexpected deaths supplementary reporting form or the child had an inpatient hospital admission at any time with an ICD-10 diagnosis code R56 coded in any position. See Methodology section for more information.

Home/scene visit carried out by professionals after death

The Child Death Review Statutory and Operational Guidance states that a coordinated multi-agency response (on-call health professional, police investigator, duty social worker), should be triggered if a child's death is sudden and there is no immediately apparent cause. The full process for a Joint Agency Response is set out in the Sudden unexpected death in infancy and childhood guidelines. One component of the Joint Agency Response is a joint visit to the infant or child's home or place of death. Where it was recorded (n=14), a joint agency visit to the home/place of death took place in 7 deaths, and a single agency visit (usually police) was recorded for a further 5 deaths (Figure 11). For 2 deaths there was no home/place of death visit carried out by professionals after the death.

> A history of convulsions was recorded in 27% of children whose deaths remained unexplained in this age group. This incidence was similar to children whose deaths went on to be explained.

Figure 11: Sudden unexpected and unexplained deaths of children aged 1 to 17 years in 2020, by agency visit to home/place of death



Data source: NCMD

N=14

Sleep related deaths of children aged 1 – 17 years

Of the 32 sudden unexpected and unexplained deaths of children aged 1 -17 years, 22 (69%) were known to have occurred around the time the child was asleep (Table 18). Fewer than 5 were co-sleeping with another adult at the time of their death. Where it was recorded, 43% (n=6/14) of children were found on their front.

National data collected on unexplained deaths of older children is limited and most data collected within the statutory reporting form focuses on known risk factors for infant deaths.

Table 18: Sudden unexpected and unexplained deaths of children aged 1 to 17 years in 2020

	Number (%) of deaths
Sudden unexpected and unexplained deaths of 1 – 17 year olds	**32**
Unexplained deaths occurring during apparent sleep	**22 (69%)**
Sleeping position when found	**14**
Supine (Back)	7 (50%)
Prone (Front)	6 (43%)
Other	1 (7%)

Data source: NCMD

What modifiable factors were identified by CDOPs?

Modifiable factors are defined in Working Together to Safeguard Children (2018) 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”.

There is currently no evidence base to suggest that there are any known risk factors for unexplained deaths in the 1-17 year old age group. However, the child death review requires CDOPs to record whether there were any modifiable factors identified for all deaths, regardless of cause or age. Modifiable factors are still collected for this age group, which could highlight known risk factors for sudden unexplained infant deaths alongside service delivery or public safety issues such as effective community resuscitation, if the CDOP felt the factor could be modified to reduce the risk of future child deaths.

Where the CDOP had sufficient information to determine modifiable factors (n=31), 35% (n=11) of the reviews identified at least one modifiable factor in unexplained deaths of children aged 1-17 years. This proportion was lower than that of infants which is likely to be due to the lack of evidence base surrounding the unexplained deaths of older children.

Sudden and unexplained death in childhood is a rare event. The evidence base around contributory factors is weak. In the longer term NCMD data could feasibly be utilised in case control studies to further our understanding of causation of these rare events.

Due to small numbers of deaths that identified modifiable factors, details of these modifiable factors are not reported, to protect the identity of the children.

Unsafe sleeping arrangements

CDOPs recognised unsafe sleeping arrangements as modifiable factors in fewer than 5 deaths; these included concerns about overheating, unsafe sleeping surface, and co-sleeping following alcohol consumption. The deaths that these issues were recorded in, were all children in the 1–4 year age group. Fewer than 5 were sharing the sleep surface with another person.

What learning points/issues were identified by CDOPs?

CDOPs record learning points identified during their review of the death. Evidence of learning points/issues identified by CDOPs were recorded in 75% (n=24/32) of deaths of children aged 1 to 17 years during the review. Within this age group there were three main areas of learning:

Impact of COVID-19 and the public health measures put in place to control the spread of infection

CDOPs recorded a number of factors relating to lockdown measures that they identified as contributing to the vulnerability of children. These included barriers to families accessing healthcare services due to changes in the way they were delivered during the first national lockdown. Specific examples included lack of availability of GP appointments, increased time for emergency services to attend and deliver care and families not being able to accompany the child to hospital when death had been pronounced at home. However, there were also examples of good practice recorded by CDOPs including review of children in residential placements to assess the need to add them to the shielding list and to review whether remaining in their placement would create a higher risk of infection.

Poor communication and information sharing
CDOPs recorded multiple examples of poor communication and information sharing between agencies and with families. Examples of poor communication with families include the Coroner's Service sending the post-mortem report to the family by post and families not being kept up to date with inquest proceedings. There were also areas of improvement identified for police including ensuring regular communication with the family, early return of property (when appropriate) and consideration of how the property is returned.

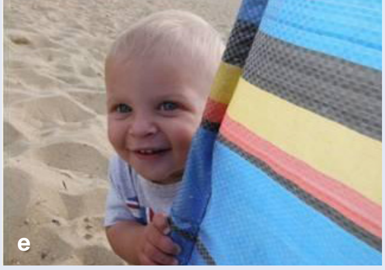
Cross border working was also recognised as presenting a challenge to agencies working with children, with examples of poor information sharing when families moved from one area to another and when children were discharged from one service to another. Examples include lack of timely and accurate communication between secondary and primary care following discharge from hospital.

Challenges in responding after a child has died
The multi-agency guidelines for care and investigation of Sudden, unexpected deaths in infancy and childhood and the Child Death Review Statutory & Operational Guidance (2018) lay out the processes to be followed when a child dies.

CDOPs recorded incidents of delays in transfer to the hospital following death, creating an extended time before death could be certified and causing distress to families and delays in post-mortem examinations being carried out, potentially limiting what can be discovered through these investigations.

CDOPs also noted the importance of appropriate referrals being carried out for family members after an infant or child dies suddenly and unexpectedly. These should include cardiac screening. Molecular autopsy or genetic investigations in sudden unexplained deaths is inconsistent, yet research has revealed pathogenic variants in 9% of cases[19]. It is helpful to review medical history and consider genetic analysis for these cases for diagnostic purposes and future research.

In addition to these three areas of learning, CDOPs reviewed a number of deaths of children with complex medical needs who died suddenly and unexpectedly. It is important to recognise that children with such conditions, even if on a palliative care pathway, may die at a time other than expected and those children and their families should benefit from the same investigations as any other child who dies suddenly and unexpectedly.



a: Amy
b: Roxie (p.49)
c: Rosie
d: Claire and Harry (p.46)
e: Yianni
f: Rex
g: Patrick
h: Liam
i: Anonymous (p.45)
j: Louis
k: Frankie
l: Elliot (p.48)

Personal stories

Little Baby Edward

Edward Thomas Kirton was my first baby. I had been diagnosed with PCOS so the doctor said I might struggle to get pregnant naturally. But as soon as I came off the pill I fell pregnant almost immediately which was a real shock but I was delighted! The pregnancy was straightforward, I had the usual sickness during the first trimester but after that I was well and really looked forward to the arrival of my first baby. I got everything ready but wasn't expecting him to be early but then, when I was 37 weeks pregnant I went to bed on the Saturday evening and woke up an hour later and my waters broke much to my shock! I went straight into the hospital but they sent me home as I wasn't in active labour. Frustratingly nothing then happened for 48 hours until the Monday evening when the contractions came fast. I went into hospital and was already 6cm dilated but when they examined me they realised he was breech so I was sent for an emergency caesarean, much to my dismay, I desperately wanted a natural birth but the midwife wouldn't allow it. So, after 3 nights with no sleep, at 3.36am Baby Edward was born. He was perfect, 7lbs 7oz and absolutely beautiful. I adored him.

Sadly at exactly 24 hours later a midwife noticed his blood sugar was low and he was taken to NICU where they found an infection. He was very unwell, the infection was probably caught in the time between my waters breaking and his birth. He was put on very strong anti-biotics and was kept in an incubator. It was heart breaking but I was so proud of him for fighting the infection and after a week in NICU I was allowed to bring him home. It was wonderful and, despite being utterly exhausted, I was delighted to have my son at home with me. He was just so beautiful.

Dear Edward suffered from reflux which meant feeding him was a challenge as he was sick all the time. This meant he didn't sleep and also he wasn't putting on weight. I was under a consultant who recommended aged 4 months putting him on solid food as it would be easier for him to digest. After that he was a different baby, happy, contented, smiley, giggly, and just made me the happiest lady in the world. I am so so glad we had those happy 2 months.

When he was 6 months 4 days old we went to stay with some friends for the night. Edward had been lovely in the day as usual, and I was very proud of him. I put him to bed in their cot at around 7pm and he went to sleep. His dad then went in and fed him when he woke around 3am.

I woke up around 5.30 as that was the time Edward usually woke up but I couldn't hear him so I thought maybe my friend was treating me to a lie in so I went back to sleep. When I woke at 6.30 I thought I would just check on him. When I walked into his room I knew immediately what happened. I screamed and my friend ran in and called the ambulance. The rest of that morning is a blur, thankfully, as I couldn't go through it again.

People think losing a baby is the worst thing that can happen to you, and all I can say is that it is infinitely worse than anyone can ever imagine. The physical loss as I used to hold him all day, the emotional loss of never seeing him again, and the social loss as it changes all the relationships around you. It is truly hell on earth and I wouldn't wish it on anyone.

The Lullaby trust were the only thing that got me through. Being able to speak to someone who understood was vital to me as while my friends and family tried, they didn't really know the depths of the pain. I also found the CONI scheme invaluable when, very luckily I went on to have my 2 other children, Barney and Sarah.

I will never, ever get over losing Edward. He is and always will be my first born and he is as important to me as my other children. But, through them, I have found some happiness again.

A personal story of a family's experience of sudden unexpected and unexplained death in infancy

When my husband and myself decided to start a family we thought it would be easy and enjoyable, but after months and months of trying it didn't seem the case. Eventually we decide to give up trying and then to our surprise I fell pregnant. This was our first pregnancy and we was over the moon and so excited. The pregnancy wasn't easy, I suffered really bad with sickness to the point I ended up in hospital with Hyperemesis gravidarum and had to be put on a drip overnight, the hospital also requested for me to have an early scan just in case it was due to carrying twins as they run in the family. All was confirmed it was just one baby. I was due the 1st February 2014 but went over due and after 2 failed sweeps I was induced. On the 12th February 2014 our healthy little girl arrived. Darcey was the name we gave her and she was a very healthy baby. She was such a happy and content little girl, she loved listening to music and one of her favourite songs was "clean bandit rather be". During our time together we went on a little caravan holiday in Clacton and had a fab time. A few days passed and little did we know the worst thing was going to happen, something no parent ever thinks would. It was Sunday 20th July and Darcey woke up just like every morning very happy and smiley. It was around 9/9.30am and had her bottle, my husband was at work early that morning and arrived home just as she was finishing her bottle, he said I'm going to get an hour's sleep and I said that's fine Darcey seems a little tired so she can have a nap while you do. I had things downstairs that needed doing e.g., clean bottles, washing and hoovering then we was planning on going out shopping once we was all up and dressed. I laid Darcey back down to sleep around 10am and went downstairs, 15 minutes later I went up and checked on her and she was still asleep so continued with bits downstairs. I then went to check on her again at 10.30am and my life flashed before my eyes, my little girl was laying there lifeless and not breathing, her face was so pale, I screamed "Andrew wake up Darcey isn't breathing" (A vision I will never be able to erase from my mind) Andrew took her off me and he run downstairs and started CPR while I rang 999 within 5 minutes they had arrived. 45 minutes they was trying then told us we are going to take her to the hospital, again 45 minutes they was trying at the hospital then the doctor walked over and told us "I'm so sorry she has gone". The staff at the hospital were absolutely amazing, they was so supportive. One challenging part was being at the hospital being made to feel like I was a criminal, like myself or my husband had done something wrong or it was our fault. I understand the police had a job to do and Darcey was evidence but to us she was our little girl and being told we wasn't allowed to touch her until the inspector had been was heart breaking. 8 years on and we still don't understand why she passed away and why it was us. When she had a post-mortem they told us there wasn't anything wrong and she was a healthy happy little girl that fell sleep and just never woke up. One thing professionals could learn with this experience is looking more into if SIDS is a genetic thing as I'm the third generation in my family to have gone through this and when it went to the coroners court they said by my story it could quite possibly be genetic but on paper no because there isn't enough scientific evidence.

A personal story of a family's experience of SUDC

My daughter died suddenly and unexpectedly in January 2019. She was a happy, vibrant child who was enjoying school and making friends, and she loved playing with her older sister. A week before her death we had a party for her fifth birthday, and she ran around playing with all her new friends at a soft play. I will treasure the videos and photographs from that day forever.

The few days leading up to her death she seemed a little under the weather, but nothing to be concerned about. The day before she died, we had a meal with some friends and their children. During the meal my daughter developed a temperature and my husband ran out to a pharmacy to get Nurofen. She had had a febrile seizure the year before, and though the doctors had assured us it wasn't dangerous, we were still concerned. After the Nurofen she improved, the temperature subsided, and she carried on playing outside with her friends. We returned home and again she started to feel a bit warm before she asked for her dad to put her to bed.

Sometime in the night she came in and said she'd had a bad dream. She climbed into bed between us. A few minutes later she did a little cough, so my husband said: "Come on back to your own bed". He led her by the hand to her bed and she settled down.

The next morning, I woke up to find that she wasn't up. I thought she felt a little off yesterday, I'll let her have a lie in, and I might keep her off school if she's not well. Around ten minutes later I walked into her bedroom. She was face down. I tried to wake her but there was no response, and her hand was cold and purple. I turned her over in bed. She was dead, eyes open and a small amount of liquid coming from her mouth. I screamed for my husband and he started CPR. I phoned 999 and they sent an ambulance and the police. They tried CPR but she had already gone. The ambulance crew gathered downstairs in my lounge (birthday banners, cards and presents still filled the room) to tell me she was dead and that I would need to go to the hospital and to find someone to look after my other daughter.

The police and ambulance crew treated us with amazing care and compassion. I can't fault them. The lead policeman said, "We are all parents, this is tragic, our investigation ends here". He offered to go to my daughter's school to inform the head what had happened as it was school run time. They closed our street and told people to stay inside while we made our way to the ambulance. A young policeman accompanied us in the back of the ambulance. As we started our journey to the hospital he started to cry, a reaction that I found empathetic and comforting.

When the ambulance crew explained to the ER staff what had happened, they did that in front of us, and the words "The parents put her to bed with a fever" still haunt me. The hospital staff let us stay by my daughter's side for hours. I think I was waiting for her to wake up and for them to tell me it had all been a horrible mistake. We worried if we had given her Calpol before bed or felt her temperature she wouldn't have died – but the consultant reassured us there was nothing we could have done and saying "febrile seizures don't cause death".

We were asked if we wanted to have footprints and hair taken (we did) and if we would like to go home – they let us know that we were free to return to the mortuary that night to see her again. When we returned that evening, we were asked if we wanted to see 'the body'. I wish they had said 'your daughter' rather than 'the body'. The nurses came with us from the ER, and they were in tears with us. As with the policeman who accompanied us in the ambulance, this felt more natural to me than when the services are cold and impersonal. We left hospital with a couple of phone numbers on scraps of paper from the nurses.

That night, my other daughter started to feel a bit hot and I was on high alert and still am to this day that a similar thing could happen to her too. The consultant at the hospital had said if we ever felt worried, to bring her straight to them to have tests. We took her the next day. The consultant gave my other daughter a postcard of a painting of two children together. These personal moments meant a lot to us then and now.

After that there didn't seem to be any coordinated system for what to do with us or how to support us – I've since learned in some parts of the country there is a dedicated bereavement support nurse who liaises with the coroner for the family and helps guide them. This would have been hugely helpful.

Instead, we liaised with the coroner directly, and they told us about the post-mortem procedure and informed us on the form they send out that it is usual for people to tick the box that says samples should be destroyed. My husband filled out the report and ticked this box. It was only later, with information from SUDC UK, that I learned what this meant and was able to urgently contact the coroner and reverse what we had put on the form. I think parents need to be given more information on this section and its implications – telling them it is 'usual' to tick one box makes you feel it is somehow wrong to tick the other one. We were then told that her body would be released once 'the main organ (brain) is repatriated with the body'. This language was not appropriate for grieving parents, and a liaison officer I'm sure would have described it in less painful terms.

There were also some challenges in registering my daughter's death. When registering her death there were naming ceremony leaflets on the lady's desk right in front of me, which was upsetting. I was asked whether I was there when she died, which given that the death was sudden and unexpected, I couldn't have been.

In the weeks that followed I was struggling emotionally and unable to sleep with flashbacks and feelings of panic, but finding support was difficult. To this day I suffer from what I now know is post-traumatic stress disorder, and anxiety and sleeplessness affect others in my family. At the time however, the NHS Talking Therapies service said they couldn't help me. I tried to contact the bereavement support at the hospital but was told this had been cut due to lack of funding. I contacted support groups but felt I was constantly being redirected to another group by the people on the phone. Eventually I contacted Child Bereavement UK who gave me telephone support once a month for a year – and I now receive cognitive behavioural therapy to help with the PTSD which I self-referred myself for.

Sudden and unexplained deaths affect many families in the UK every year and we need answers. I have since found out that one third of SUDC children have had a febrile seizure in the past so I believe this may contribute to the deaths. To help find answers for ourselves and others, my family have participated in a USA based research study – but it's only through more effective data collection and funding for research that we will ever find out a reason. For now, we live in a state of shock that my daughter died, confusion as to what might have happened, and guilt that we could have done something to save her.

Harry Smith's story

Harry, our little boy, was born 19 July 2016 on the hottest day of the year! Eager to come into the world, he decided to arrive a few days before our planned caesarean. We had 20 months and 18 incredible days with our baby boy, until one Friday afternoon on the 6 April 2018, he went for his usual nap and didn't wake up. Our lives changed in that moment forever, we are heart broken and not a day goes by that I don't question why us, why Harry and why don't we know what happened during that 45-minute nap?

I want to tell you our story since that heart breaking and life changing day and how the actions of some have made our grief even harder to navigate. How decisions were made on our behalf, without explanation or consideration of our feelings, our vulnerability or the impact it has had on every part of our lives.

In the week leading up to Harry's death he had signs of a cold and was a little under the weather, but nothing that worried us. He woke up happy on the Friday morning, he had breakfast and was playing and causing chaos by pulling all the books off the bookshelf. We went to a local cafe, Harry was a little whingey and didn't want to sit in his highchair or eat his tea-cake which was unusual, but how many toddlers turn their nose up at food they would usually eat!? It was getting a bit late for his afternoon nap, and he looked tired in his buggy. I said to Harry "are you tired' and he nodded his head. So, I raced around the supermarket quickly and we went home, trying to keep him awake in the car seat. It was a warm day, so I stripped him down to his vest and put him in his sleeping sack, got him his drink of water and put him in his cot still awake. He had a little grumble but went to sleep quickly. 40 minutes later I went to wake him, and found him lying face down, very flat – I knew something was wrong straight away. As I rolled him over, I could see that his face and lips were blue and he was unresponsive.

I screamed and ran with him to our neighbour, thinking he was choking. I tried so hard to resuscitate him, as did the paramedics and doctors. We never got him back. I don't know if he had died in his cot, and I was too late, but it must have happened so fast. I just don't understand how a happy, healthy little boy, could go to sleep for his normal nap and never wake up again.

The day we lost Harry, we were initially spoken to by the coroner on call, social workers and the police. We were in complete shock and the formalities passed without us really engaging with them. I do remember we were left in a room for hours, and there must have been a shift change of staff, as no one even knew we were still there and when I asked to see Harry again, a nurse had already taken him away without us being told or being given the chance for a last goodbye. I have been haunted by this and the deep regret of not asking sooner or trying to find someone to let me be with my little boy again. The actions of that staff member have had a profound effect on us and I hope in the future other families are given more time to be with their little ones.

Harry's death was ruled as pneumonia. We have never accepted this because Harry did not appear sick before he died. It just didn't make sense to us. Over the next two years we fought for a better understanding of what happened, meeting with many paediatricians and doctors – none of whom agreed with the pathologist's report. I spent many hours doing research online to support my understanding of these conversations and Harry's post-mortem report, which was difficult but unavoidable when you don't have anyone to help facilitate conversations with medical professionals.

During this time, I was in regular contact with the registry office to explain why we hadn't registered Harry's death, to avoid prosecution. We also found support from SUDC UK and the SUDC Foundation, who gave us the opportunity to have a paediatric pathologist investigate Harry's case with the hope of getting some answers.

All I had to do to get this expert's second opinion was sign a release form for Harry's historical slides and tissue samples, which were taken during his post-mortem, to be released. The following day I received an email with the devastating news that on the instruction of the coroner, all Harry's remaining DNA and samples had been destroyed. I literally broke down, I could hardly breathe, it completely derailed me again. My husband and I felt utterly helpless.

I emailed the coroner's office to ask why Harry's samples had been destroyed, when we didn't remember being asked about what we would like done with Harry's tissues and DNA and we certainly never signed anything as his parents to allow this to happen. We now understand that it is not uncommon for a Coroner's office to take verbal consent and sign the form themselves. In our case we had one quick call from the coroner, where they asked what we wanted to happen to the tissues from Harry's organs that they no longer needed and if we would like them to be repatriated to Harry before his funeral. To hear someone, talk to you about your child's body like this stays with you forever – we agreed to the samples going back to Harry, but we didn't know exactly what this meant, or that it would lead to evidence we might need in future being destroyed.

A couple of days after receiving the email to tell me all Harry's samples had been destroyed, I was finally given the chance to talk to Harry's pathologist and explain why we didn't agree with his report. He told me: "You have not failed Harry" – I started to cry, it was such a relief to hear that from him. Once he had all the facts about how Harry was in himself that week and most importantly how he was happy and well on the day he died, he said "no wonder you didn't agree with my cause of death, you are right to question it." He said Harry would have been very poorly that week, not running around and playing if he had pneumonia. He said a lot of the information we provided was new to him. Harry's pathologist was so kind and empathetic, and he apologised for contributing to the guilt we felt.

Why did it take so long for this conversation to be facilitated? Why wasn't the pathologist given all the information? Does the coroner's office understand how powerful their silence is to grieving parents? We sat by the phone waiting and waiting for news, and when we did get a call back, we felt the replies were unhelpful and vague, lacking in tact and empathy.

To anyone working with bereaved parents we ask you to please listen to our voices, please feel our pain and remember that there is a whole other side to grief and loss that you don't often see. What you say and do has a profound effect on families grieving and trying to come to terms with the impossible loss of a child.

Elliot's Story

Elliot was 2 years and 9 months when I put him down for his afternoon sleep. He never woke up. He wasn't ill in any way, just a usual toddler runny nose. The ambulance came and they took Elliot into the back and closed the doors. We were left on the street whilst they worked on him. I was making all possible deals with the universe for Elliot to be ok, I was begging him to wake up. I felt incredibly guilty that they thought I had done something to Elliot. It didn't take much for that seed to grow and grow. They opened the doors, asked us to get in and we set off.

We arrived at hospital and were taken into A&E. They took Elliot into a cubicle and told us what everyone was there to do – I didn't take it in – but I did appreciate they made the effort to engage. We were asked to wait in the corridor. No separate room, no seats – just a corridor with others around. When a nurse came out of the cubicle and starting walking towards me I just knew – I kept backing away, thinking, if she doesn't get to me, then she can't tell me. I ran out of space and hit the wall; the nurse said, 'we have to stop this now'. That's how I was told my beautiful and amazing little boy was dead. We spent the next 6 hours in and out of the A&E cubicle with him. There was no offer of a separate room, no privacy – just a plastic chair with Elliot in my arms.

As soon as the nurse had uttered those words we were in a world of everyone else's processes and systems. We were no longer a family, Elliot was a 'case'. The Police on the night were great, let us stay together as a family with Elliot and they let the nurses ask most of the questions so we didn't have to keep repeating ourselves. We left the hospital that night, having to leave Elliot behind. We went into hospital as a family of 5 and came out as a family of 4 – the only support was an A5 yellow leaflet that started with, 'I'm sorry your baby/child has died'.

Elliot's death pushed us into a world of Police, Hospital, SUDIC and Coroner processes. No one explained what these processes were, why they were happening or what our role was. We were told it would take up to 12 weeks to establish a cause of death for Elliot. I was convinced I had missed something; I had been with Elliot every minute of the day. With each passing day and no news I grew more convinced that Elliot's death must somehow be my fault.

The areas of process that impacted the most were the Coroner's and the hospital's. We got a call from a Coroner's Officer 4 days after Elliot died to say that his death was still unexplained, so he had three options for us. First, we could have Elliot's body back after all the tests had been concluded and a cause was determined. This would delay the funeral for at least 3 months. Second, we could have Elliot's body back minus his heart and his brain. We could then have his funeral and his brain and heart back once a cause was determined. Third option was to have Elliot's body back minus his brain and heart and donate them to medical science. We were given the weekend to decide. How do you go from planning your son's 3rd birthday to organising a funeral with these 3 options?

There were significant delays with the Coroner's process and I had to constantly chase for information. One delay was with the Hospital who had not sent a key piece of information to the Coroner. I spoke to the Hospital who told me they had the letter, it just needed signing, but the person was away. I asked if it could be signed by someone else as the delay meant we didn't have an inquest date. I explained I was Elliot's mum and I wanted to know why my son had died. The exact words of the hospital staff were, 'sorry but we are concerned with the living not the dead'.

On one call to the Coroner's Office I was told I needed to be patient, Elliot's 'samples had been sent to Sheffield'. I had no idea why were they sending parts of Elliot to Sheffield? They said it was toxicology and Sheffield had the expertise. The tests would show if Elliot had digested something. I hung up and cried. I had no idea parts of Elliot would be sent anywhere, and now I was getting even more convinced I had missed something and that was why Elliot was never coming home.

One cause of huge stress was not knowing how we would be told about Elliot's death. Would something come in the post, a knock on the door, or a phone call? No one I asked could tell me – not even the Coroner's Office. Three months later, it came, a phone call – no warning, just 'Hello we have Elliot's cause of death'.

Two months later the initial cause of death was disputed by peers of the original Pathologist. He had determined Elliot had a brain tumour and a virus (unknown) had attacked his brain whilst he slept and because he had a tumour, as his brain swelled it put pressure on the brain stem which closed down Elliot's breathing and heart. We found out this original cause was disputed by a phone call one Friday evening – totally unexpected. We didn't even know Elliot's case was being reviewed.

The inquest took place 19 months later. We listened to two competing theories as to why Elliot died. The Coroner gave a natural causes verdict. He took the evidence of an expert witness and determined Elliot had died from a virus (unknown) that had attacked his brain whilst he slept, that nothing could have been done to save Elliot – even if he had been in hospital. He said he did not have a brain tumour. He concluded that this was 'the best guess' as to why Elliot had died as no virus had been properly identified (the only one in his system was the cold sore virus). I was devastated. I had waited 19 months and expected that the Inquest would give definitive answers and I came away with a 'best guess' offer. To this day I can't understand the verdict. Elliot wasn't ill, he had no temperature, he didn't cry – how can a virus do that in a split second?

A Consultant told me that what happened to Elliot was one in a million and hopefully that brings me comfort. No it doesn't. The devastation of losing Elliot is beyond any words I can put here. Our family was part of everyone else's process – no one was ever part of ours. Each different service did their bit and moved on. No one coordinated any of it for us, or explained what was happening or why. No one explained that the inquest may not be the holy grail of knowledge – that medical science doesn't always know the answers. Sitting, listening to people talk about Elliot in harsh medical terms and still not have a real answer; nearly 10 years on and I am still angry at the process.

Please talk to families, tell them what is happening and why. Be ready to repeat it if they don't take it in first time. Have an honesty – that everyone will do their very best to find out what happened – but sometimes we don't have all the answers. There is still a lot that we do not know. This honesty can help to reduce the guilt, fear and panic that are just some of the emotions and thoughts that you go through when you put your child for an afternoon sleep and they never wake up.

Claire and Roxie's Story

I'm Claire. I'm a daughter, a sister, a wife and a mother.

I'm 33 years old, a trained beauty therapist and nail technician. I've been married to Damian for 3 years, together for 8 years. I'm mother to 3 children Lennon (aged 12) Roxie (died aged 1) and Lacey-Hope (aged 5)

I've found life to be a bit of a roller coaster, especially when my daughter passed away. If I had a penny for every time I've been asked how I 'do it' I'd literally be a millionaire!

I had my first child aged 21, Lennon. The relationship with Lennon's dad didn't work.

I met Damian in 2013 and for the first time ever knew it was meant to be! Shortly after I gave birth to my second child, Roxie.

We were a very happy family enjoying family life and many adventures together.

Roxie had just celebrated her first birthday and a couple of days after came out in spots around her mouth, which doctors confirmed was the virus called hand, foot and mouth. We were told it was common in children and very contagious. Roxie was quite poorly with the virus but doctors reassured us that, given a week, all would be fine and Roxie would be back to her normal self again.

After a week the virus had given Roxie a throat infection which she was given medicine for and almost straight away seemed loads better. She started getting back to her normal, cheeky, playful self.

A few days later Lennon woke us up at his usual time of 6am and we woke to find Roxie no longer breathing. She had passed away in her sleep.

We were in total disbelief; our beautiful little girl and Lennon's sister was no longer with us. We cannot describe the pain and our whole world had been turned upside down.

Doctors were unsure of Roxie's cause of death. After many months of waiting and specimens of Roxie's body being tested, we were told Roxie was wrongly diagnosed and in fact had come into contact with the cold sore virus. Pathologists believe the virus has spread to her brain and slowly shut it down resulting in her stopping breathing. We will never know why Roxie's body was unable to cope, as this was reported as unheard of for a child of 1 years old.

As Roxie's mother I became obsessed with finding out what had happened and researching/ googling, never satisfied with the answer. As a result, I have been diagnosed with severe anxiety disorder and severe OCD.

We focused on having another child, although I was on suicide watch (apparently procedure for a mother in the 1st year after death). I had to be put on a programme during pregnancy (cognitive behaviour programme) to help me. The whole pregnancy was horrendous, full of worry, anxiety, emotions, grief and trying to get on with everyday life! I was eventually told that I had to deliver the baby earlier as the worry of anxiety on my body was life threatening.

A year after Roxie passed away Lacey-Hope was born, our 'rainbow baby'. After every storm there is a rainbow, a rainbow of hope!

The amount of love I have for my children cannot be put into words.

My life events have caused many mental problems. I am in desperate need to be a 'normal parent.'

I find myself stood in the school playground observing others, jealous of how 'normal' their lives are. I know that there's no such thing as 'normal' but it doesn't stop me wanting it!

So, I'm here today still married (a few downs, but many ups); I have a 12 year old son just started high school (more over-thinking and worry) and a 5 year old that has learning difficulties and potential ADHD. But I'm still here!

I'm not telling this story so that you say: 'oh, poor Claire!' or because I want sympathy. I'm doing it to show that if I can do this, so can any other person! I know I'm not alone, and if anything, I will tell my story over and over again to help others. Life is hard work and sometimes you just need to know you're not on your own. The pain doesn't go away, and it doesn't get easier but if you have the fight inside you, then you can do this!

Best Practice Case Studies

1. Forget Me Not Children's Hospice

Losing your child suddenly is every parent's worst nightmare. Sadly, for around 70 families in West Yorkshire every year, a sudden illness, a car accident, a fire, a suicide, will make this a devastating reality. For many, their suffering is made even more unbearable by the shocking lack of bereavement support available across the UK. Left alone to deal with the police, hospital or coroner's office, and their experiences in the days and weeks after their child dies can cause lasting and grievous damage to their health and wellbeing.

With experience of supporting families through children's palliative care and into bereavement, the team at Forget Me Not Children's Hospice felt equipped to provide these families with specialised support and believe strongly that these families should be entitled to the same level of holistic bereavement care and support as other families whose child has died.

How we got here

We were approached by Elliot's Footprint, founded by John and Andrea Kerslake following their experience of leaving the hospital after their 2 year old son Elliot died suddenly, holding 'just a leaflet'. They had conducted research with other bereaved parents and the stark results revealed just how little support existed for these families. They were looking for a service that could fill this gap.

We developed our pioneering sudden and unexpected death in childhood (SUDIC) service in partnership with Elliot's Footprint. It was the first of its kind in the UK and it has continued to grow into the ground-breaking service we have in place today.

Initially, our plan was to employ one dedicated SUDIC worker. Their role would be to provide immediate and ongoing practical and emotional support to bereaved families through the first days, weeks and months after their loss. We recruited our SUDIC worker in November 2018 and started delivering SUDIC support in April 2019. Having evaluated how the support was working, we adapted the approach, fully embedding our SUDIC service into our family support team, enabling these families to access a wider offer of therapeutic support, including 1-1 bereavement support sessions, counselling, sibling support, peer-to-peer groups, creative art therapies and trauma therapies.

How it works

Referrals for families whose child dies suddenly or unexpectedly come from various sources, including West Yorkshire Police, A&E departments at local hospitals, coroners' officers and families themselves. Upon receipt of the referral, families are contacted within 48 hours of the referral and offered immediate support to navigate the numerous systems and tasks they face, such as liaising with mortuary staff, coroners, police officers and registrars. Our SUDIC keyworker will also support siblings, act as an advocate on families' behalf, contact workplaces and schools to explain what's happened, or simply act as a point of contact to explain processes to families who are bewildered and sometimes re-traumatised by the complexity of everything they face.

Families are also offered the opportunity access a private and comfortable space at our children's hospice, where they can spend time with their child, say their last goodbyes and capture lasting memories.

Every family's bereavement journey looks different, and the support that is offered is tailored to their needs. However, we have a tiered approach to family support which ensures we have clear pathways, assessments and processes that allow us to offer the right support, at the right time. Support for families is offered for up to two years' post bereavement, with families accessing various tiers of support as and when required. Families are also invited to attend annual remembrance events and use the memory garden at the hospice, where they can hang a keepsake, engraved with their child's name, on our memory tree. At the end of their formal support from Forget Me Not, families are invited to stay connected with us. They receive a newsletter with invites to relevant events, information about other services available and advice and guidance about navigating the world and the future as bereaved families.

Growing our SUDIC service

In June 2022, we were delighted to win the Children and Youth category at the National Charity Awards for our SUDIC service. This was a true honour to be recognised for pioneering and vital support for the children and families in our care and we dedicate this award to the families who allow us to stand at their side at the most difficult time of their life.

In July 2022 we formed a partnership with colleagues at West Yorkshire Police and our ambition is to ensure that every family who experiences the sudden death of a baby or child in West Yorkshire is offered our support. We'll also be offering training to police officers on how best to support families after a child's death.

As a charity, funding to enable us to continue to offer and grow this service is vital but not guaranteed. We receive no funding from the government or NHS for this service. So while we have various income streams which enable us to continue this work, much of that is reliant on the generosity of our local community, supporting us by shopping in our shops, fundraising and taking part in events.

The difference our support makes

"The SUDIC worker applied for a grant for us when our baby died. We were given £300 which was a great help as I could not work in those early days, and I'm self-employed."

"The SUDIC worker guided us through the planning of the funeral, as we were not even able to focus at the time. She helped us choose the funeral director, made those initial calls and suggested ideas, colour themes, music, poems and verses, even helped us to choose a florist. She gave us ideas to involve people who could not attend due to Covid-19 restrictions."

"The SUDIC worker was my only support after my baby's death when I was sectioned and placed in a mental health unit at the hospital. She was the only one who visited and liaised with my consultant and then kept my family up to date with my progress. I am so thankful."

"The SUDIC worker has helped support me with my request for a house move. I am struggling to live in that house anymore as that is where he died. She completed a form supporting my request and highlighting the urgent need. She is always there to listen."

"The SUDIC worker helped to gather a support network round my whole family after my 11yr old died. She was quick to update my GP, and I had twice weekly GP calls for extra support. The children receive sibling support and counselling from the hospice. I have attended peer support groups. I have also received EMDR therapy. I will be forever grateful; I couldn't have got through this without her."

2. Parents reaching out to parents

In Liverpool, the Parent Champion in the Community Project (October 2021 to March 2022) was set up to provide peer-led support to families in the most deprived areas, whose babies are most at risk of having severe bronchiolitis (a respiratory infection caused by Respiratory Syncytial Virus (RSV)). Suboptimal antenatal health, maternal smoking, low breastfeeding rates and poverty contribute to poor maternal and infant health, and cause bronchiolitis admission rates in Liverpool to be consistently twice the national average[20]. The project aims were to:

- Co-develop a free, evidence-based multi-format and multi-lingual toolkit for parents illustrating concerns about bronchiolitis.
- Help families to access support with housing quality, benefits, and food insecurity (socio-economic factors that worsen bronchiolitis).
- Empower and educate expectant/new parents to address severe bronchiolitis risk factors, make informed lifestyles choices and access help in enabling these.
- Educate parents in self-managing bronchiolitis and how and when to seek medical help.

Parent champions are parents from the local community who have experience of the issues being faced by parents in the area.

A qualitative evaluation (surveys and interviews) with parents and key stakeholders was undertaken and identified five main themes about the impact and value of the project; core to these was the way in which parents were reaching out to parents.

"We talk with parents. We take time and we give advice on prevention, and this doesn't happen at the doctors. They just say 'paracetamol, fluids, go home'. We can help parents in lots of ways, giving them reasons to trust us because they know we've helped with food vouchers, heating, smoking, so they can trust our advice about bronchiolitis" (Parent Champion)

Raising awareness and sharing knowledge

The central focus of the project was on raising awareness and knowledge among parents and helping health inequalities. This extended to raising awareness and knowledge among the staff at local Children's Centres as well as into the community (e.g., nurseries and other settings). Parent Champions built their knowledge about bronchiolitis within an initial interactive training session which prepared them for their role in disseminating the information. The parents they worked with talked about how the delivery of the information had been good and was pitched at the right level. The Parent Champions used videos showing a baby experiencing respiratory distress and parents identified these as being memorable and helpful. They also appreciated the leaflets. They all said that the information meant they felt more confident about looking after their baby if they had bronchiolitis. Although all the Parent Champions engaged with parents across a range of cultural backgrounds, parents whose first language was not English particularly valued engaging with Parent Champions who spoke their first language.

Creating connection, trust and confidence

The Parent Champions' ability to connect with parents came from their friendly and approachable manner and the trust they inspired and the way that they took parents' concerns seriously. The parents trusted the information the Parent Champions shared as being "better" or as much as if it was from a "GP or nurse". Several parents thought that Parent Champions' information was "more in depth than GP would be" and that their Parent Champion had "a special knowledge in the area and can see it from perspective of parents". The Parent Champions' experiences and sensitivity meant that parents trusted them to listen, not judge and not lessen their concerns and "never made me feel stupid like I did a couple of times in the hospital". This aligned with the hopes of the core project team who wanted the Parent Champions to "give us a foot into the world of mums we wouldn't see otherwise before too late".

Flourishing in their role as a parent champion

The Parent Champions themselves established good working relationships and created strong connections with parents, and within their own Children's Centres and in the wider community. They were trusted colleagues and they inspired confidence. The Children Centre Managers talked of how well the Parent Champions fitted into their teams. The Parent Champions brought many skills and experiences with them to their role, but it was also clear that their skills, capacities, confidence and sense of self as a Parent Champion had been augmented. All of them talked of finding their feet, feeling more confident (especially in more challenging situations) and having a deeper knowledge of the work of the Children's Centres, what resources were available and how to signpost parents to help with food vouchers, support with heating, and other help.

Rising to the challenges

The main challenge across the whole project related to the problems, delays and uncertainties around the recruitment process. However, this may be explained by the short time frame – six weeks – between applying for funding and the start of the project which left little time to prepare support services such as human resources for the recruitment of a new type of employee. This was a challenge for the core project team who noted that despite "communicating well with human resources [that] working in partnership and recruiting with a new organisation was tricky…as some of the processes are complex – lots of cogs in the wheel".

An initial challenge for the Parent Champions was the lack of resources such as leaflets and posters to support their work. However, they rose to this challenge and created and used their own leaflets (approved by the project manager). This was time consuming and there was a sense that the posters and leaflets would be better if they were standardised so parents moving from one centre to another would not be confused.

All Parent Champions had a project phone delivered to them at the start of the project and they relied on this for communication and sharing videos. However, it soon became clear that a tablet would be valuable as sharing videos in a group setting was near impossible via a phone screen. Tablets were ordered partway through the project and were delivered towards the end of the six-month period.

Two of the Parent Champions could speak a second language (Arabic, Polish) and their materials and sessions could be delivered in the parent's first language; this was seen as being "a definite bonus". However, it was also noted that there was a need for them to be available in other languages and it was noted that all the pictures showed a white family and were therefore not inclusive. One of the solutions that the Parent Champions used was a translation app on their phones; this was seen to be reasonably effective but not something they wished to fully rely on.

Knowledge is power, prevention is key

The Parent Champions wanted people in positions of power who fund Parent Champions in Liverpool and elsewhere, to know that the project worked because it was based on parents reaching out and empowering parents, and that the knowledge of the Parent Champions is "from living day to day and living through times like the parents are experiencing first-hand".

The importance of prevention was at the heart of the Parent Champions' role. They wanted the government to be aware that health promotion and prevention are not prioritised enough but are the basis for improving health; "prevention is a wonderful thing – people don't really focus enough on this… the benefit of keeping children healthy is for everyone. It helps keep family healthy – no days off school/work this helps create a healthier society – really beneficial for everyone". This reflected the core project team's ambition to improve health inequalities and their awareness that "health is one big tapestry, and respiratory health is part of wider geography of health – this is about everything from violence, parental well-being, poverty, smoking, and food insecurity".

Conclusions:

This project demonstrated that there is a clear need for parent-to-parent peer support; the Parent Champions and staff in the Children's Centres are keen to continue to deliver the service and the parents welcome the opportunity to learn and improve the lives and health of their children. The Parent Champions were clear that the 'government' (local and higher national levels) need to know that their engagement with parents can change not only the individual parents but also their community and their city. Participants across all stakeholder groups were interested not only in bronchiolitis (signs, symptoms and what to do) but also the wider factors associated with respiratory ill health such as poverty, poor housing, and air pollution.

The Parent Champion project has, through evaluation, been shown to be a viable means of delivering high quality information and awareness about bronchiolitis and related factors to parents who otherwise would not have this information. There is also evidence, direct from the parents, that they have used and shared this information and that their behaviour and decision-making have been positively informed and shaped by what they have learned. Qualitative evidence shows that Parent Champions working in these very deprived communities deliver effective health-related peer support to parents not only because of their communication skills and personal characteristics but also because they have similar life experiences to the parents; this means parents feel that they can be open with and trust the Parent Champions. In turn, this trust means other aspects of parents' lives have the potential to be changed (e.g., through finding out about other services such as fuel vouchers, housing, safe sleeping etc.).

Qualitative evaluation team:

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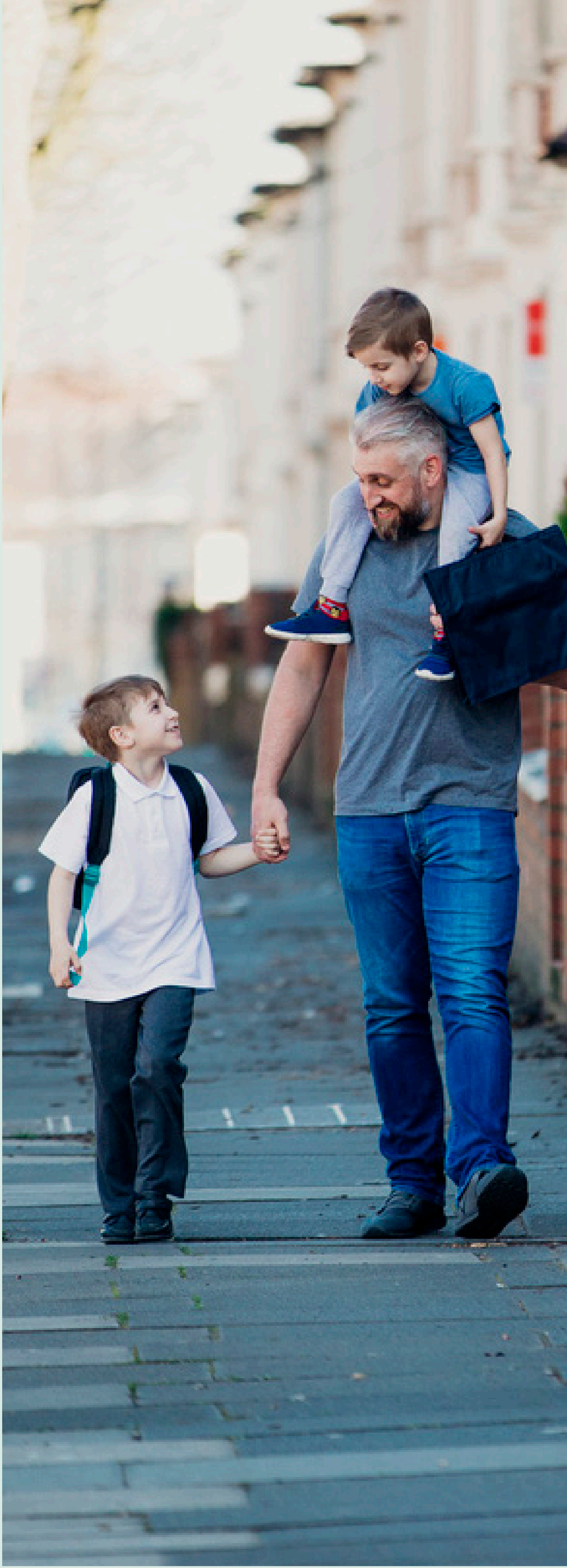
Implementation team:

Debi McAndrew, Children's Centre Strategic Lead, Liverpool City Council; Alice Lees, Paediatrician, Alder Hey Children's Hospital; and Prof. Ian Sinha, Consultant Paediatrician, Alder Hey Children's Hospital.



Methodology and Limitations

Cohort identification – Sudden and unexpected deaths

To obtain a provisional category of death, all child deaths notified to NCMD were coded contemporaneously by the same three independent coders to identify the most likely cause of death at the point the death was notified to NCMD.

The majority of the analysis on unexpected deaths focuses on **sudden unexpected deaths with no immediately apparent cause**. These deaths were identified by including any death categorised at the point of notification as SUDI/SUDIC at least once (regardless of any other categories assigned) but excludes Trauma/Suicide/Substance misuse deaths defined below.

This approach was taken to ensure that all sudden and unexpected deaths were captured regardless of whether the child had another condition identified at notification that may turn out to be the major contributory cause of the death. This approach will mean that more sudden unexpected deaths were identified in this report, than other work where a hierarchal methodology was applied[21].

In addition, Table 1 also includes data on the following groups:

All unexpected deaths – Any death categorised at notification as suspected SUDI/SUDIC, Trauma, Substance misuse, or Suicide at least once.

Trauma/Suicide/Substance misuse deaths – Any death categorised at notification as suspected Trauma, Substance misuse, or Suicide at least once.

Figure 12 shows a detailed flow diagram of the methodology of cohort identification included for analysis in this report.

Cohort identification – Sudden unexpected and unexplained deaths

Deaths included within the unexplained cohorts were all assigned the category 10 of "Sudden unexpected, unexplained death" by the CDOP on the statutory child death analysis form and finalised in the system at the date of data extraction. The definition of this category is: "Where the pathological diagnosis is either 'SIDS' or 'unascertained' or 'SUDC', at any age. Excludes Sudden Unexpected Death in Epilepsy (category 5)."

Data exclusions

Deaths identified that were stillbirths unattended by a medical professional were excluded from the data extract and the overall number of deaths.

Data cleaning

The dataset used within this report was extracted from the database on 28 June 2022. Missing or unknown data fields within the sudden unexpected deaths supplementary dataset were reviewed and string data and documents existing elsewhere in the system were used to re-code missing data. This was to ensure data was as complete as possible for reporting. Data which was completed by CDOPs remained unchanged.

Population estimates and live births data

ONS data for live births and mid-year population estimates were used as denominators to calculate rates of death. Data is published by ONS for each calendar year, therefore the 2019 calendar year was used to calculate rates in 2019-20 and the 2020 calendar year was used to calculate 2020-21, where applicable. Data related to population estimates, and in particular, comparisons using population ethnicity data should be treated with caution due to limitations of the comparator data (based on 0-17 years for England and Wales data from the 2011 census).

Data linkage

BadgerNet data

Data from the BadgerNet system (an electronic patient data management platform used by neonatal units in the UK) managed by CleverMed were used to identify the number of children admitted to a neonatal unit after birth. NHS numbers, included in the child death notification form, were sent to CleverMed to match with records on BadgerNet. This was to identify whether the child had been admitted to a neonatal unit at any time after birth, and if so, if a BadgerNet data record existed. Previous work has shown good validation and coverage of this data source[22]. Deaths, where NCMD had a valid NHS number that was sent to CleverMed, were included within the denominator, and those that returned a linked record from the BadgerNet system were included in the numerator (i.e., were admitted to a neonatal unit).

Hospital Episodes Statistics (HES)

Data from HES-ONS mortality data and HES admitted patient care were used in combination with NCMD data to supplement missing data on whether the child was a part of a multiple birth, and whether the child had any previous convulsions. Deaths in NCMD which could be linked to a record in HES-ONS data were included in the denominators and linked records which had a relevant ICD-10 diagnosis code in any position of any previous inpatient admission were included in the numerators.

Multiple birth – ICD-10 diagnosis codes Z383-Z388 in any position.

Convulsions – ICD-10 diagnosis code R56 in any position.

CDOP categorisation of death

NCMD is dependent on accurate data entry and categorisation by the CDOPs, and in particular, category of death is presented within the report as it was submitted by the CDOP.

For all ages, information submitted to NCMD for sudden unexpected deaths in 2020 that were categorised as explained as Categories 1 or 3 were reviewed by a clinical expert in the NCMD team. In 80% of these reviews, it appeared that most had been categorised on the basis that there was an unsafe sleep environment, and in several this probably contributed to the death, but no definite cause of death was found so these deaths should have been considered as Category 10 (Sudden unexpected, unexplained death).

Table 19 compares deaths of infants and children whose death was categorised by CDOP as 'Sudden unexpected and unexplained', by the ICD-10 underlying cause of death assigned in HES-ONS mortality data.

Table 19: Deaths in 2020 where the CDOP categorised the death as 'Sudden unexpected and unexplained', by underlying ICD-10 cause of death within Ill-defined and unknown causes of mortality listed in HES-ONS mortality data

	N(%)
Under 1	**111**
R95 or R99[1]	99 (89%)
Other underlying cause	12 (11%)
1 – 17 years	**26**
R96-R99[1]	16 (62%)
Other underlying cause	10 (38%)

Data source: NCMD; HES-ONS mortality data (NHS Digital)

In 24 deaths it was not possible to link the data to HES-ONS, or the underlying cause of death was not available.

[1] Descriptions of ICD-10 codes can be found at: https://icd.who.int/browse10/2019/en#/

Other limitations

Whilst notification of deaths to NCMD is very good, the time it takes for the child death review to conclude is often over a year and this will mean that the numbers included for sudden unexpected and unexplained deaths in 2020 will be conservative because not every death during that year had been reviewed at the time of analysis.

The numbers of deaths occurring between 1 April 2019 and 31 March 2022 (Table 1) is based on suspected category of death using information available at the point the death was notified to NCMD. This may be different to the final category of death assigned by the CDOP once the child death review is finalised.

It is important to consider that increasing completeness of notification forms across the years may contribute to any changes in numbers across the two years.

Data on consanguinity was considered for inclusion, however, numbers were too small to report.

Improvements required to data collection fields and child death reviews

Work by NCMD is ongoing to continuously improve the data completeness and quality by further developing the statutory data collection forms. This aims to better support and guide the CDR process and provide more granular and comprehensive data to support deeper understanding of all child deaths. Analysis of this cohort has identified the need for a number of improvements including:

- Introduction of new fields to collect the dates of post mortem examinations and the date of receipt of the final post mortem report by the CDOP. This will support CDOPs to consistently and robustly identify any delays experienced by families, related to the post mortem process.
- Development of a set of questions for children over 1 year of age, to include in the supplementary reporting form for Sudden and Unexpected Deaths. The current questions are designed based on risk factors identified for the under 1 year group and do not adequately capture the data needed in the older age group. This will support CDOPs in the review process and improve the evidence base for potential risk factors.
- Review and update questions on overheating to support consistent collection of data and review by CDOPs.
- Review and update mandatory fields on the supplementary reporting form for Sudden and Unexpected Deaths. This will improve data quality and completeness for these questions.

Completeness of supplementary reporting form

The sudden unexpected death supplementary form was completed for 77% (n=99/129) of infant deaths and 66% (n=21/32) of deaths of children aged 1-17 years. To ensure completeness within this report, missing or unknown data fields were reviewed and string data and documents existing elsewhere in the system were used to re-code missing data.

The lower completion rate for deaths of the older group may reflect that the majority of the questions on the supplementary reporting form relate to known risk factors for infant deaths and are often not relevant to deaths of children aged 1-17 years.

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Appendices

Appendix A: Additional data tables

Table 20: Sudden and unexpected infant deaths with no immediately apparent cause between 1 April 2019 – 31 March 2021, by demographics and year of death

	2019-20			2020-21		
	Number (%) of deaths	**Live births (2019)**	**Rate (95% CI) per 1,000 live births**	**Number (%) of deaths**	**Live births (2020)**	**Rate (95% CI) per 1,000 live births**
Age at death	**365**	**610,505**	**0.60 (0.54-0.66)**	**346**	**585,195**	**0.59 (0.53-0.66)**
0 – 27 days	108 (30%)	610,505	0.18 (0.15-0.21)	105 (30%)	585,195	0.18 (0.15-0.22)
28 – 364 days	257 (70%)	610,505	0.42 (0.37-0.48)	241 (70%)	585,195	0.41 (0.36-0.47)
Sex	**365**			**346**		
Female	161 (44%)	296,673 (49%)	0.54 (0.46-0.63)	143(41%)	285,458 (49%)	0.50 (0.42-0.59)
Male	204 (56%)	313,832 (51%)	0.65 (0.56-0.75)	203 (59%)	299,737 (51%)	0.68 (0.59-0.78)
Ethnic group[2]	**327**			**311**		
Asian or Asian British	42 (13%)	73,051 (12%)	0.57 (0.41-0.78)	34 (11%)	73,850 (13%)	0.46 (0.32-0.64)
Black or Black British	24 (7%)	30,475 (5%)	0.79 (0.50-1.17)	23 (7%)	29,533 (5%)	0.78 (0.49-1.17)
Mixed	28 (9%)	41,082 (7%)	0.68 (0.45-0.99)	25 (8%)	39,998 (7%)	0.63 (0.40-0.92)
White	228 (70%)	433,689 (73%)	0.53 (0.46-0.60)	223 (72%)	412,836 (72%)	0.54 (0.47-0.62)
Other	5 (2%)	15,816 (3%)	0.32 (0.10-0.74)	6 (2%)	13,994 (2%)	0.43 (0.16-0.93)
Area[1,3]	**362**			**343**		
Rural	39 (11%)	80,651 (13%)	0.48 (0.32-0.66)	29 (8%)	79,664 (13%)	0.36 (0.24-0.52)
Urban	323 (89%)	538,207 (87%)	0.59 (0.53-0.66)	314 (92%)	522,249 (87%)	0.60 (0.54-0.67)
Deprivation[1]	**362**			**343**		
1 (most deprived)	140 (39%)	157,749 (26%)	0.89 (0.75-1.05)	129 (38%)	149,661 (26%)	0.86 (0.72-1.02)
2	99 (27%)	136,439 (22%)	0.73 (0.59-0.88)	82 (24%)	130,974 (22%)	0.63 (0.50-0.78)
3	61 (17%)	119,115 (20%)	0.51 (0.39-0.66)	66 (19%)	114,016 (20%)	0.58 (0.45-0.74)
4	35 (10%)	105,007 (17%)	0.33 (0.23-0.46)	35 (10%)	101,076 (17%)	0.35 (0.24-0.48)
5 (least deprived)	27 (7%)	92,195 (15%)	0.29 (0.19-0.43)	31 (9%)	89,468 (15%)	0.35 (0.24-0.49)

	2019-20			2020-21		
	Number (%) of deaths	**Live births (2019)**	**Rate (95% CI) per 1,000 live births**	**Number (%) of deaths**	**Live births (2020)**	**Rate (95% CI) per 1,000 live births**
Region[1]	**362**			**343**		
North East	13 (4%)	25,742 (4%)	0.51 (0.27-0.86)	10 (3%)	24,915 (4%)	0.40 (0.19-0.74)
North West	45 (12%)	80,020 (13%)	0.56 (0.41-0.75)	60 (17%)	76,329 (13%)	0.79 (0.60-1.01)
Yorkshire and The Humber	47 (13%)	58,281 (10%)	0.81 (0.59-1.07)	47 (14%)	55,916 (10%)	0.84 (0.62-0.11)
East Midlands	24 (7%)	48,986 (8%)	0.49 (0.32-0.73)	29 (8%)	46,950 (8%)	0.62 (0.41-0.89)
West Midlands	63 (17%)	65,982 (11%)	0.95 (0.73-1.22)	37 (11%)	63,748 (11%)	0.58 (0.41-0.80)
East of England	34 (9%)	67,409 (11%)	0.50 (0.35-0.70)	32 (9%)	64,313 (11%)	0.50 (0.34-0.70)
London	60 (17%)	117,897 (19%)	0.51 (0.39-0.66)	54 (16%)	111,688 (19%)	0.48 (0.36-0.63)
South East	47 (13%)	93,664 (15%)	0.50 (0.37-0.67)	45 (13%)	90,864 (16%)	0.50 (0.36-0.66)
South West	29 (8%)	52,524 (9%)	0.55 (0.37-0.79)	29 (8%)	50,472 (9%)	0.57 (0.38-0.83)

Data source: NCMD; ONS live births; IMD (2019)

1 Derived from child's postcode of residence

2 Ethnicity is grouped based on groupings used in the 2011 Census. 'Other' includes 'Arab' and 'Any other ethnic group'.

3 Population data used for urban/rural is based on mid-year population estimate for children under 1.

Table 21: Sudden and unexpected deaths with no immediately apparent cause of children aged 1 to 17 years between 1 April 2019 – 31 March 2021, by demographics and year of death

	2019-20			2020-21		
	Number (%) of deaths	**Estimated population of children same age**	**Rate (95% CI) per 100,000 1-17 year olds**	**Number (%) of deaths**	**Estimated population of children same age**	**Rate (95% CI) per 100,000 1-17 year olds**
Age at death	**284**	**11,404,710**	**2.49 (2.21-2.90)**	**239**	**11,491,375**	**2.08 (1.82-2.36)**
1 – 4 years	115 (40%)	2,680,779 (24%)	4.29 (3.54-5.15)	69 (29%)	2,637,534 (23%)	2.62 (2.04-3.31)
5 – 9 years	64 (23%)	3,538,206 (31%)	1.81 (1.39-2.31)	44 (18%)	3,539,458 (31%)	1.24 (0.90-1.67)
10 – 14 years	58 (20%)	3,354,246 (29%)	1.73 (1.31-2.24)	61 (26%)	3,435,579 (30%)	1.78 (1.36-2.28)
15 – 17 years	47 (17%)	1,831,479 (16%)	2.57 (1.89-3.41)	65 (27%)	1,878,804 (16%)	3.46 (2.67-4.41)
Sex	**283**			**239**		
Female	126 (45%)	5,556,790 (49%)	2.27 (1.89-2.70)	102 (43%)	5,596,670 (49%)	1.82 (1.49-2.21)
Male	157 (55%)	5,847,920 (51%)	2.68 (2.28-3.14)	137 (57%)	5,894,705 (51%)	2.32 (1.95-2.75)
Area[1]	**282**			**237**		
Rural	39 (14%)	1,765,900 (15%)	2.21 (1.57 – 3.02)	24 (10%)	1,780,033 (15%)	1.35 (0.86-2.01)
Urban	243 (86%)	9,638,810 (85%)	2.52 (2.21-2.86)	213 (90%)	9,711,342 (85%)	2.19 (1.91-2.51)

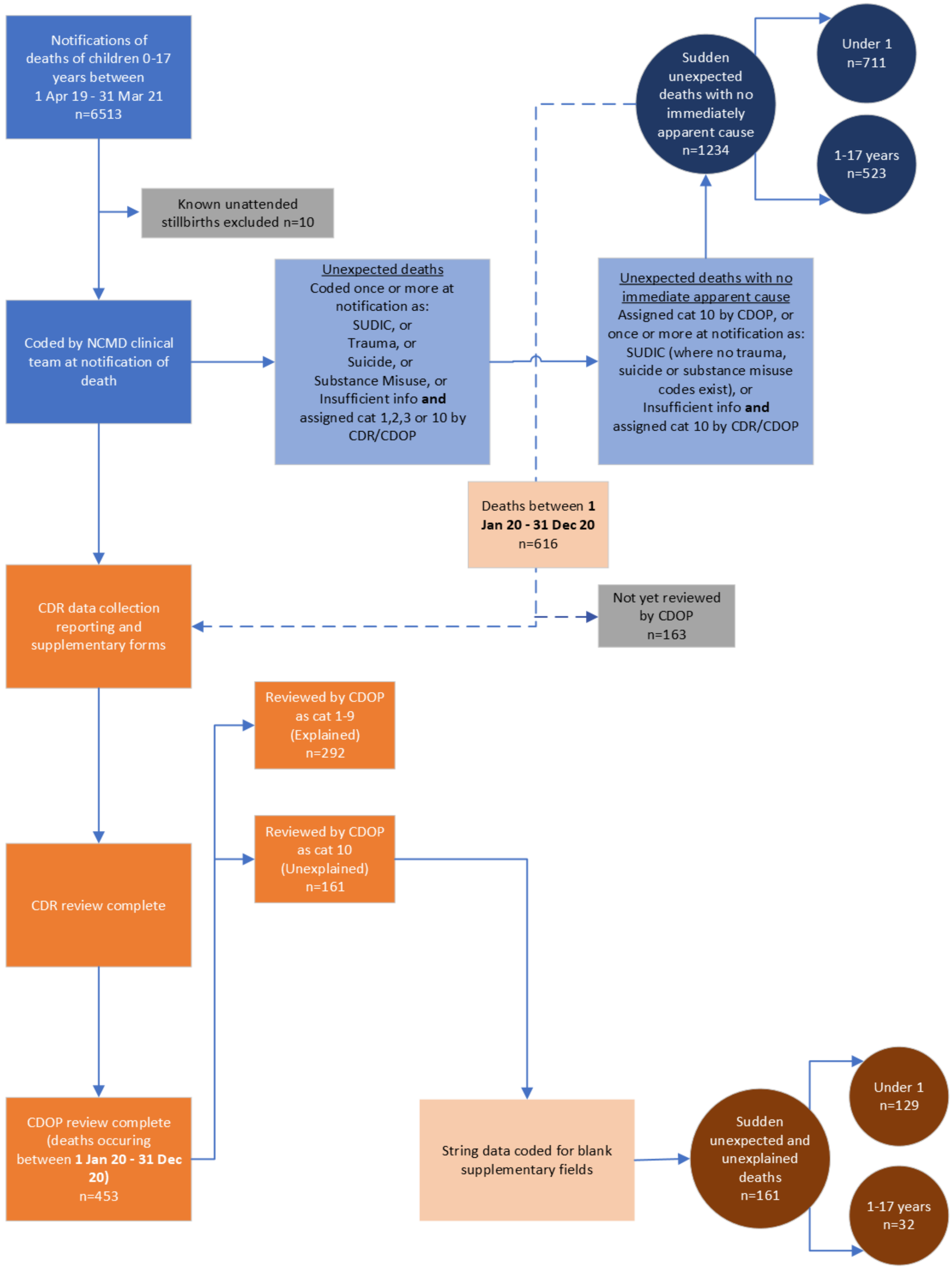
	2019-20			2020-21		
	Number (%) of deaths	Estimated population of children same age	Rate (95% CI) per 100,000 1-17 year olds	Number (%) of deaths	Estimated population of children same age	Rate (95% CI) per 100,000 1-17 year olds
Deprivation1	**282**			**237**		
1 (most deprived)	102 (36%)	2,719,725 (24%)	3.75 (3.06-4.55)	84 (35%)	2,734,632 (24%)	3.07 (2.45-3.80)
2	58 (21%)	2,351,101 (21%)	2.47 (1.87-3.19)	58 (24%)	2,367,352 (21%)	2.45 (1.86-3.17)
3	52 (18%)	2,148,752 (19%)	2.42 (1.81-3.17)	41 (17%)	2,170,025 (19%)	1.89 (1.36-2.56)
4	43 (15%)	2,061,214 (18%)	2.09 (1.51-2.81)	32 (14%)	2,082,442 (18%)	1.54 (1.05-2.17)
5 (least deprived)	27 (10%)	2,123,918 (19%)	1.27 (0.84-1.85)	22 (9%)	2,136,924 (19%)	1.03 (0.65-1.56)
Region[1]	**282**			**237**		
North East	12 (4%)	505,436 (4%)	2.37 (1.23-4.15)	16 (7%)	508,327 (4%)	3.15 (1.80-5.11)
North West	44 (16%)	1,482,202 (13%)	2.97 (2.16-3.99)	32 (14%)	1,493,068 (13%)	2.14 (1.47-3.03)
Yorkshire and The Humber	34 (12%)	1,110,717 (10%)	3.06 (2.12-4.28)	28 (12%)	1,116,785 (10%)	2.51 (1.67-3.62)
East Midlands	17 (6%)	953,011 (8%)	1.78 (1.04-2.86)	21 (9%)	959,713 (8%)	2.19 (1.35-3.34)
West Midlands	39 (14%)	1,233,040 (11%)	3.16 (2.25-4.32)	30 (13%)	1,241,314 (11%)	2.42 (1.63-3.45)
East of England	33 (12%)	1,278,333 (11%)	2.58 (1.78-3.63)	25 (11%)	1,289,532 (11%)	1.94 (1.25-2.86)
London	47 (17%)	1,914,587 (17%)	2.45 (1.80-3.26)	50 (21%)	1,932,350 (17%)	2.59 (1.92-3.41)
South East	37 (13%)	1,873,472 (16%)	1.97 (1.39-2.72)	21 (9%)	1,889,108 (16%)	1.11 (0.69-1.70)
South West	19 (7%)	1,053,912 (9%)	1.80 (1.09-2.82)	14 (6%)	1,061,178 (9%)	1.32 (0.72-2.21)

Data source: NCMD; ONS mid-year population estimates; IMD (2019)

1 Derived from child's postcode of residence

Appendix B: Methodology of cohort identification

Figure 12: Flow diagram of inclusion criteria for analyses



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