

NCMD

National Child Mortality Database

Knowledge, understanding and
learning to improve young lives

Infection related deaths of children and young people in England

National Child Mortality Database Programme Thematic Report

Data from April 2019 to March 2022

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Authors

- Brian Hoy^{1*}
- Sylvia Stoianova^{1*}
- Tom Williams^{1*}
- David Odd^{1,2}
- James Fraser¹
- Vicky Sleep¹
- Adam Finn³
- Peter Fleming¹
- Ashley Sharp⁴
- Alicia Demirjian⁴
- Theresa Lamagni⁴
- Shamez Ladhani⁴
- Ron Daniels⁵
- Oliver Plumb⁶
- Claire Donovan⁷
- Jenny Ward⁸
- Rachel Rowlands⁹
- Katherine Naish¹⁰
- Emily Handley-Cole¹⁰
- Louisa Whit¹⁰
- Karen Luyt¹

*authors have contributed equally

1. National Child Mortality Database, University of Bristol
2. School of Medicine, Division of Population Medicine, Cardiff University
3. Infection and Immunity, Bristol Medical School, University of Bristol
4. The UK Health Security Agency
5. The UK Sepsis Trust
6. Group B Strep Support
7. Meningitis Now
8. The Lullaby Trust
9. University Hospitals of Leicester NHS Trust
10. Learning Disability and Autism Programme, NHS England

Partners



Contact us

National Child Mortality Database Programme

Level D, St Michael's Hospital,
Southwell Street, Bristol BS2 8EG

Email: ncmd-programme@bristol.ac.uk

Website: www.ncmd.info

Twitter: @NCMD_England

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Executive summary

Key findings

- There were 1,507 infection related child deaths between 1 April 2019 and 31 March 2022 (3 years); an overall rate of 4.20 deaths per 100,000 children per year. This was the equivalent of 15% of all child deaths in this period.
- In 37% (n=553) of these deaths, the infection was thought to be a complete and sufficient explanation of death (6% of all child deaths).
- The risk of death varied according to the age of the child. Children under 1 year of age were more at risk of dying from infection than any other age group. Over half (61%) of deaths where infection was thought to provide a complete and sufficient explanation of death occurred in children under 1 year of age, with a further 16% of deaths between 1 and 4 years.
- Risk also varied by the ethnicity of the child. Children from an Asian/Asian British or black/black British ethnic background were at higher risk, with children from a Pakistani ethnic background at the highest risk of all.
- Children living in urban areas had a higher risk of dying from infection than those in rural areas. The chance of dying of infection in the most deprived neighbourhoods was twice that of those living in the least deprived neighbourhoods.
- Overall, in 90% of the infection related deaths the child had an underlying health condition, including 68% who had a life-limiting condition (e.g., cerebral palsy), and 22% who had another underlying health condition (including prematurity). 10% had no underlying health condition.
- In children where infection provided a complete and sufficient explanation of death, nearly a quarter (24%) had no underlying health condition.
- Of the 425 children aged 5 to 17 years who died with infection, a high proportion (67%) had a learning disability. In the cases where the infection provided a complete and sufficient explanation of death, 52% of the children in this age group had a learning disability. Pneumonia (lower respiratory tract infection) was identified in 75% of the deaths of children with a learning disability.
- Bacterial infection was implicated in nearly half (43%) of all deaths where infection provided a complete and sufficient explanation of death and where a pathogen was identified. In such cases, viral infection (including with coronavirus) was implicated in 27% of deaths and fungal in 3%.
- For deaths where infection provided a complete and sufficient explanation of death, 35% were associated with pneumonia (lower respiratory tract infection).

- While a seasonal variation of death from infection is well recognised in England, this appears to have been disrupted by the COVID-19 pandemic, with no rise in deaths over the winter of 2020/21. Overall numbers of infection related deaths over the most recent winter of 2022/23 were the highest since NCMD started collecting data.

Of 843 completed child death reviews where the child died between 1 April 2019 and 31 March 2022, and the CDOP categorised the death as 'infection' or 'perinatal infection' (either primary or secondary category of death):

- Modifiable factors were identified by CDOPs in 36% of child death reviews categorised as infection or perinatal infection; this was higher (42%) for deaths where infection was considered to be the primary category of death. From all factors recorded as relevant to the child's death, the ones most frequently selected as modifiable were in the service provision domain.
- 36% of child death reviews recorded issues related to service provision as a contributory factor (a factor that may have contributed to the vulnerability, ill-health, or death of the child); more than half of these reviews (n=159) identified service provision to be a modifiable factor.
- The most common contributory factors within the service provision domain recorded were in relation to initiation of treatment and identification of illness in the child, and following guidelines. They were the two most common modifiable factors reported across all four domains. Examples included lack of clinical recognition of the deteriorating child, delays in treatment, and failure to escalate for a timely senior review. Other service provision factors included poor communication within or between agencies, and with families; this included factors where parental concerns were not listened to and acted on by healthcare professionals.
- Challenges for parents with access to services (e.g., where services were available but there were challenges in supporting families to access them) were recorded, alongside challenges around access to services during the COVID-19 pandemic.
- Other contributory factors also included risk factors in the mother during pregnancy (e.g., smoking, maternal infections and ill health, obstetric and delivery complications) and factors that relate to the child's health history which increase vulnerability to infection, including prematurity, underlying health conditions and learning disabilities. Reviews also recorded the importance of vaccination uptake to help protect babies and children.

Recommendations

These recommendations are aimed at multiple organisations as they are wide-ranging and require a cross-departmental and cross-government approach to address, due to the multi-agency nature of the NCMD data. They reflect issues and gaps identified by the analysis in this report and all the organisations listed should take action on the recommendations relevant to them. This may require collaborative/integrated working with other organisations in deciding on specific tasks to meet the overall aims that these recommendations set out.

1. Ensure coherent and aligned guidelines on infections and administering anti-microbial treatments are developed and followed across services delivering early care to children (General Practice, Ambulance Service, and NHS Acute Trusts), investigate the barriers to not following them, and develop and disseminate this further learning (NHS England). Health professionals must be provided with education and tools (risk-assessment triage tools and appropriate diagnostic tests such as pulse oximetry) to support the early diagnosis of infection and sepsis and to identify the deteriorating child, with bespoke tools for high-risk groups. Examples of such tools include:

- The [STARWAVE](#) risk assessment tool
- [Spotting the Sick Child learning tool](#)
- [National paediatric early warning system \(PEWS\) charts](#)

Action by: Ambulance Service, NHS England Children and Young People Policy Team, NHS England Medical Directorate, NHS England Workforce Training and Education Directorate

2. Ensure that recognition of infants and children who are at a higher risk of death from infection* is included within guidance and training. Healthcare professionals must be alerted to this risk and a low threshold for urgent transfer to hospital, senior review and early initiation of treatment should be considered.

*Children who are at higher risk include those with underlying health conditions, children with a learning disability, children from ethnic minorities, children with parents who smoke or abuse alcohol/substances, and children currently or previously known to social care.

Action by: NHS England Workforce Training and Education Directorate and Royal College of Paediatrics and Child Health

3. Commission research to develop, validate and trial risk-assessment tools for triage and urgent referral/treatment of patients with symptoms and signs of infection and sepsis, including tools for specific high-risk groups. Commission research with healthcare professionals and systems into the barriers to recognising and managing sepsis and review effectiveness and specificity of current

sepsis guidance.

Action by: National Institute for Health and Care Research, National Institute for Health and Care Excellence, NHS 111

4. Investigate further and gain better understanding of the barriers to accessing services by parents when their child may be presenting with signs and symptoms of infection, and how these can be overcome.

Action by: Royal College of General Practitioners, Royal College of Emergency Medicine

5. Listen to and act on parental concerns about their baby's or child's health as per the NICE guideline [NG194](#). Ensure appropriate escalation to a timely senior review.

Action by: all healthcare professionals at primary and secondary care settings

6. Increase public awareness of potentially significant symptoms and signs of infection, particularly in infants. For example, by encouraging widespread use by healthcare professionals, parents and carers of the [Baby Check App](#) as recommended by NICE (NG194), the [NHS Website](#), [Healthier Together](#), and including information on this in the personal child health record (red book). For babies and older children, the [Caring for children with coughs leaflet and website](#) (recommended on the Royal College of General Practitioners' [TARGET antibiotic stewardship website](#)) provides information for parents on common symptoms, types of illnesses, when to see a doctor and how to care for their child. All resources should be available in multiple languages. Emergency departments should ensure appropriate guidelines and parental advice leaflets, in multiple languages, are available to families of children who are discharged into the community, and that any patient re-presenting to the emergency department, should be seen by a senior clinician.

Action by: NHS England Medical Directorate, Institute of Health Visiting, The Family Nurse Partnership and Early Years teams at the Office for Health Improvement and Disparities, UK Health Security Agency

7. Ensure that all children and families are offered all vaccinations their child is eligible for, and are supported appropriately to consider and take up the offer. Increase awareness of the [national children's vaccination schedule](#) and [Green Book Guidance](#) amongst child health services, including community paediatricians and primary care.

Action by: Royal College of Paediatrics and Child Health, Royal College of General Practitioners, Integrated Care Boards, NHS England Immunisations Team, NHS England Learning Disability and Autism Programme, Institute of Health Visiting

8. Ensure that any additional needs are identified prior to a child attending for vaccination so that person-centred reasonable adjustments can be accommodated where needed.

Action by: local providers of immunisation services and primary care

9. Ensure that any written and oral information and advice on immunisations is accessible to all groups and local communities and made available widely, and in multiple languages, to all parents, carers and young people, in order that an informed decision can be made. Support from local immunisation services, children's health services, local community leaders and community outreach partners can be helpful in disseminating information and providing reassurance to parents who may be hesitant in accepting any vaccination offer.

Action by: Royal College of Paediatrics and Child Health, Royal College of General Practitioners, Integrated Care Boards, NHS England Immunisations Team, NHS England Learning Disability and Autism Programme, Institute of Health Visiting, The Family Nurse Partnership at the Office for Health Improvement and Disparities, local immunisation services and primary care

10. Support and develop initiatives to improve health and reduce disparities and mitigate the social determinants such as housing, as well as risk factors such as smoking and obesity, all being associated with increased mortality risk from infection in children.

Action by: Office for Health Improvement and Disparities, Integrated Care Boards, NHS England Children and Young People Policy Team

11. Commission future research focusing on improvements in diagnosing specific causes and on the mechanisms underlying the much higher infection mortality rates in infancy. Further research should study the complex interaction of deprivation, ethnic disparities and underlying health conditions, and inform maternal vaccine implementation work and future perinatal vaccine research.

Action by: National Institute for Health and Care Research

12. Continue to develop data linkages between NCMD and other national datasets, including lab-confirmed infections within the Second Generation Surveillance System (SGSS) dataset at the UK Health Security Agency.

Action by: NHS England Children and Young People Policy Team, UK Health Security Agency





Introduction

Infections are caused by microorganisms such as bacteria, viruses, parasites and fungi. They commonly spread from person to person in different ways and this determines what precautions can be taken¹. Infections are common and for most people the risk of severe illness is low. However, some groups of people, for example those with weak immune systems due to a medical condition or treatment they are receiving, are at higher risk of infection, or of more severe illness due to infection².

Globally, infectious diseases, including pneumonia, diarrhoea, malaria and sepsis remain the leading causes of death for children 1 month to 9 years of age. Access to basic lifesaving interventions such as adequate nutrition, vaccinations, and treatment for common childhood diseases can save many young lives³. European research (including data from the UK) into life-threatening infections in children admitted to hospital with sepsis and severe infection has shown that the disease burden is mainly in children under 5, and that many cases are vaccine preventable, and sensitive to commonly available antibiotics⁴. A main limitation in this analysis was that, despite the availability and application of clinical procedures for microbiological diagnosis, the causative organism remained unidentified in approximately 50% of patients.

In early 2020, SARS-CoV-2 spread quickly around the world causing the global COVID-19 pandemic. The risk of this virus to children and young people has previously been quantified⁵. While all-cause child mortality significantly reduced during the first year of the pandemic (2020-21), probably from the measures put in place to reduce the spread of SARS-CoV-2, mortality returned to pre-pandemic levels the following year (2021-22)⁶.

The National Child Mortality Database (NCMD) [child death review data release in 2022](#) reported that of the deaths allocated a primary category of death (the uppermost selected category of death) as either 'infection' or 'perinatally acquired infection', the Child Death Overview Panel (CDOP) concluded that over 40% had modifiable factors identified. Modifiable factors are those that may, by means of a locally or nationally achievable intervention, be modified to reduce the risk of future child deaths.

This NCMD thematic report aims to identify common characteristics of children and young people who died with and because of an infection, investigate factors associated with these deaths and identify common themes, to help inform policymakers, commissioners, those providing services to children and young people, and those involved in reviewing deaths of children and young people.

1 WHO (2023)
2 UKHSA (2023)
3 WHO (2023)
4 Martín-Torres et al (2018)
5 Smith et al (2022)
6 Odd et al (2022)

How to read this report

The National Child Mortality Database (NCMD) Programme was established to collate and analyse data on all children in England who die before their 18th birthday.

This report includes child deaths where infection may have contributed to the death and those where infection provided a complete and sufficient explanation of death. Further information on how these deaths were identified, and limitations of this report, are described in the [Technical Information document](#). The tables containing the data presented throughout this report can also be found in the [Tables document](#).

The analysis of child (0-17 years) deaths within this report has been split into three sections:

- The first section reports the number of suspected infection related deaths at notification, that occurred between 1 April 2019 and 31 March 2023 (4 years).
- The second section reports the number and characteristics of infection related deaths that occurred between 1 April 2019 and 31 March 2022 (3 years).

- The third section reports the contributory factors and learning from the child death reviews that were categorised as infection (either primary or secondary category of death) by Child Death Overview Panels (CDOPs).

Where possible, risks of death were calculated per 100,000 children, per year, and are presented alongside their appropriate 95% confidence intervals (displayed as error bars on charts) throughout this report. [ONS census data \(2021\)](#) for 0-17 year olds (or adjusted to represent the appropriate age group and other characteristics) were used as denominators to calculate risk of death, including ethnicity data.

To ease reading and reduce repetition, the following terms are used interchangeably:

- » “infection related death”, “infection caused or contributed” and “children dying with infection”
- » “complete and sufficient explanation of death” and “complete and sufficient cause of death”
- » “death where infection may have contributed to the death” and “deaths where infection may have been contributory”

Glossary of Terms

Term	Definition
Category of death	Category of death is assigned in each child death review during the CDOP meeting depending on the likely cause of death. The classification of categories is hierarchical, where the uppermost selected category will be recorded as the primary category and others as secondary categories (should more than one category be selected)
CDOP	Child Death Overview Panel
Contributory factor	Factors determined by the CDOP that may have contributed to vulnerability, ill health or death of the child
Diagnostic overshadowing	The General Medical Council defines diagnostic overshadowing in the context of learning disability as “symptoms of physical ill health that are <u>mistakenly attributed</u> to either a mental health/behavioural problem or as being inherent in the person’s learning disabilities”
Domain A: Characteristics of the child	Factors in the child (and in neonatal deaths, in the pregnancy). Includes factors relating to the child’s age, gender and ethnicity; any pre-existing medical conditions, developmental or behavioural issues or disability, and for neonatal deaths, the mother’s health and wellbeing

Domain B: Social environment including family and parenting capacity	Factors relating to family structure and functioning and any wider family health issues; provision of basic care (safety, emotional warmth; stimulation; guidance and boundaries; stability); engagement with health services (including antenatal care where relevant); employment and income; social integration and support; nursery/preschool or school environment
Domain C: Physical environment	Factors relating to the physical environment the child was in at the time of the event leading to death, and for neonatal deaths, the mother's environment during pregnancy. Includes poor quality housing; overcrowding; environmental conditions; home or neighbourhood safety; as well as known hazards contributing to common childhood injuries (e.g., burns, falls, road traffic collisions)
Domain D: Service provision	Issues in relation to service provision or uptake for any agency. Includes any issues relating to identification of illness, assessment, investigations and diagnosis; treatment or healthcare management; communication or teamwork within or between agencies; and organisational or systemic issues. Includes underlying staff factors, task factors, equipment, and work environment, education and training, and team factors
Infant	A child under 1 year of age
Life-limiting condition	Life-limiting conditions (LLCs) are those for which there is no reasonable hope of cure. Children and young people with LLCs may die from other conditions or complications such as infections that might not prove fatal in other children. Some of these conditions cause progressive deterioration rendering the child increasingly dependent on parents and carers
Mode of death	The sequence of events preceding the death, rather than the underlying cause of the death
Modifiable factor	Factors where, if actions could be taken through national or local interventions, the risk of future child deaths could be reduced
Place of death	The place where the child is believed to have died regardless of where death was confirmed. Where a child is brought in dead from the community and no signs of life were recorded during the resuscitation, the place of death should be recorded as the community location; where a child is brought in to hospital following an event in the community and is successfully resuscitated, but resuscitation or other treatment is subsequently withdrawn, the place of death should be recorded as the location within the hospital where this occurs
Sepsis	Sepsis is a clinical syndrome resulting from a dysregulated immune response to an infection.
Vaccination	Vaccination is a simple, safe, and effective way of protecting people against harmful diseases, before they come into contact with them. Vaccines train a person's immune system to create antibodies, just as it does when it's exposed to a disease. Most vaccines are given by an injection, but some are given orally (by mouth) or sprayed into the nose

1. Variations in incidence of child deaths with infection

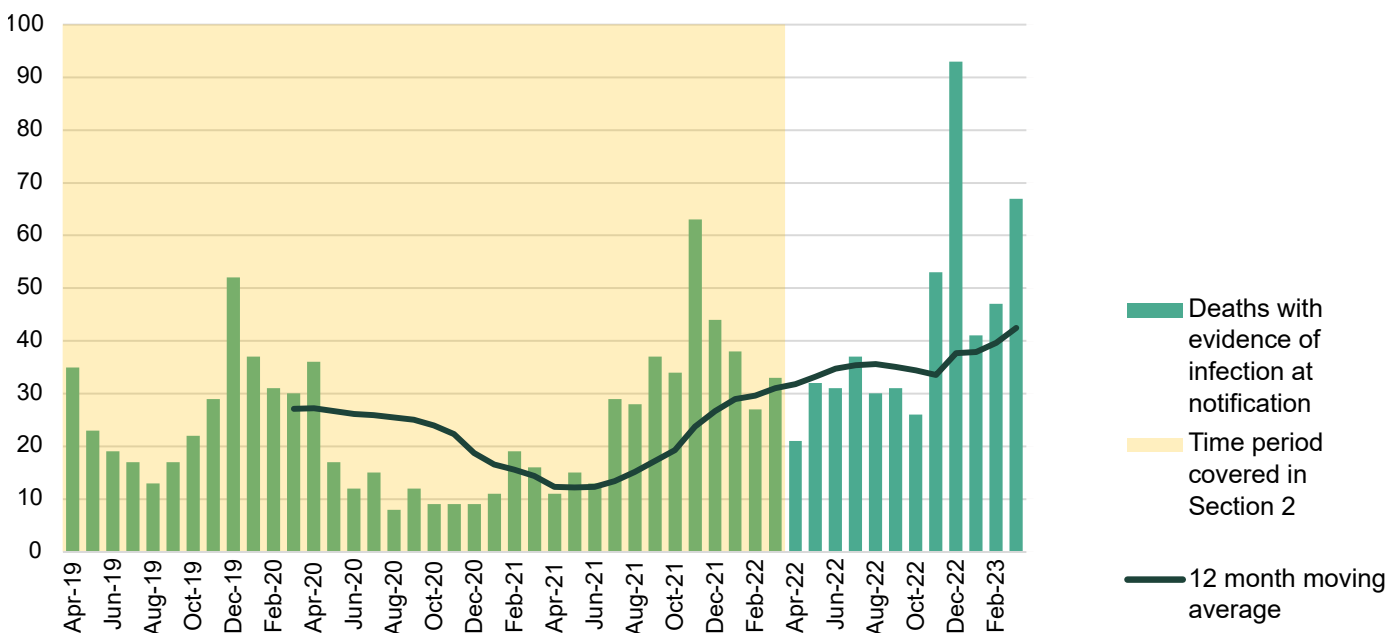
The incidence shown in Figure 1 is based on information recorded at 48 hours in the notification form submitted to NCMD, for deaths occurring between 1 April 2019 and 31 March 2023 (4 years). This means the deaths that were not immediately related to infection at notification but, following investigations were found to be infection related, will not be included within Figure 1. Therefore, data reported here are likely to be an underestimate and different to the data reported in Section 2, but are consistent throughout the period and with previous work, and are designed to show changes over time.

The seasonal variation in infectious deaths in children is well recognised⁷ although the actual rates and impacts throughout the year are often poorly quantified⁸. The NCMD data in Figure 1 is consistent with this, showing a clear peak in the

winter months of 2019/20. Importantly, no rise in deaths is seen over the winter of 2020/21; the period of lockdown and social restrictions put in place in response to the COVID-19 pandemic. However, a rise in deaths is seen again in the winter of 2021/22, which fails to return to previous summer levels in the subsequent spring/summer, with a further rise in number of deaths across the most recent winter of 2022/23.

This overall increase in deaths due to infection, and the apparent variability of the cycle, highlights the importance of the learning and recommendations presented within this report. In order to ensure the majority of deaths due to infection are captured, the analysis of characteristics in Section 2 has been limited to deaths up to 31 March 2022.

Figure 1: The number of suspected infection related child deaths at notification, by month of death



⁷ UKHSA (2022)
⁸ Lipsett et al (2021)

2. Infection related deaths

This second section reports the number and characteristics of infection related deaths that occurred between 1 April 2019 and 31 March 2022 (3 years). The time period includes the COVID-19 pandemic, where measures (e.g., lockdowns, school closures) were put into place to stop the spread of

COVID-19 and had an impact on transmission and variation in infections in circulation. Therefore, this was not a typical period for many infections, and consideration should be given to this throughout this report.

Cohort identification

Infection related deaths

Includes deaths where infection provided a complete and sufficient explanation of the death, or where the infection may have contributed to the death. All infection related child deaths were identified where the death was coded as 'infection' at notification by two or more of the NCMD clinical team, or where, after full review, the CDOP allocated the primary or secondary category of death as 'infection' or 'perinatal infection'. This includes any deaths where the initial notification was coded as infection, but the CDOP did not categorise the death as infection, and vice versa.

Infection provided a complete and sufficient explanation of death

Either where the death was coded as 'infection' by two or more of the NCMD clinical team at notification, or where the CDOP categorised 'infection' or 'perinatal infection' as the primary category of death. Deaths included within this cohort were attributed to the effect of a primary infection that directly caused the death (e.g., pneumococcal sepsis). This could occur in a child without any underlying health conditions, but could also occur in a child with an underlying health condition (e.g., sickle cell disease) that made them more vulnerable to this infection (and could be considered a contributory factor to the infection).

These deaths are included in Section 2A and 2C, and the characteristics of only these deaths are reported in Section 2B.

Infection may have contributed to the death

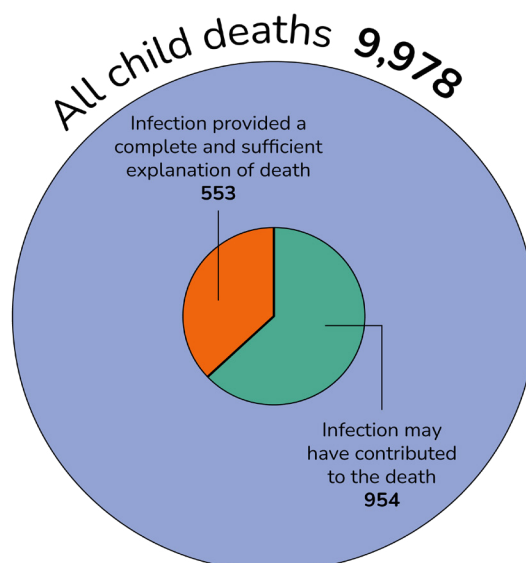
Any death where the infection was related to the death, but it did not provide a complete and sufficient explanation of death (i.e., those deaths that were infection related, but where infection did not provide a complete and sufficient explanation of death). For example, a death from an infection in an immunocompromised child undergoing chemotherapy for malignancy, would be included within this cohort, even if the infection was the final event leading to death.

These deaths are included in Section 2A and 2C.

More information about the identification and limitations of these cohorts can be found in the [Technical Information document](#).

Over the 3 year period, there were 1,507 deaths where infection either caused or contributed to the death of the child. **Sections 2A and 2C report all infection related deaths.**

Deaths over 3 years where infection contributed or caused the death, were approximately 0.01% of the total child population



In 553 (37%) deaths, an infection provided a complete and sufficient explanation of death. **Section 2B reports this group only.**

In 954 (63%) deaths, an infection may have contributed to the death (but may not have been sufficient in itself to have caused the death).

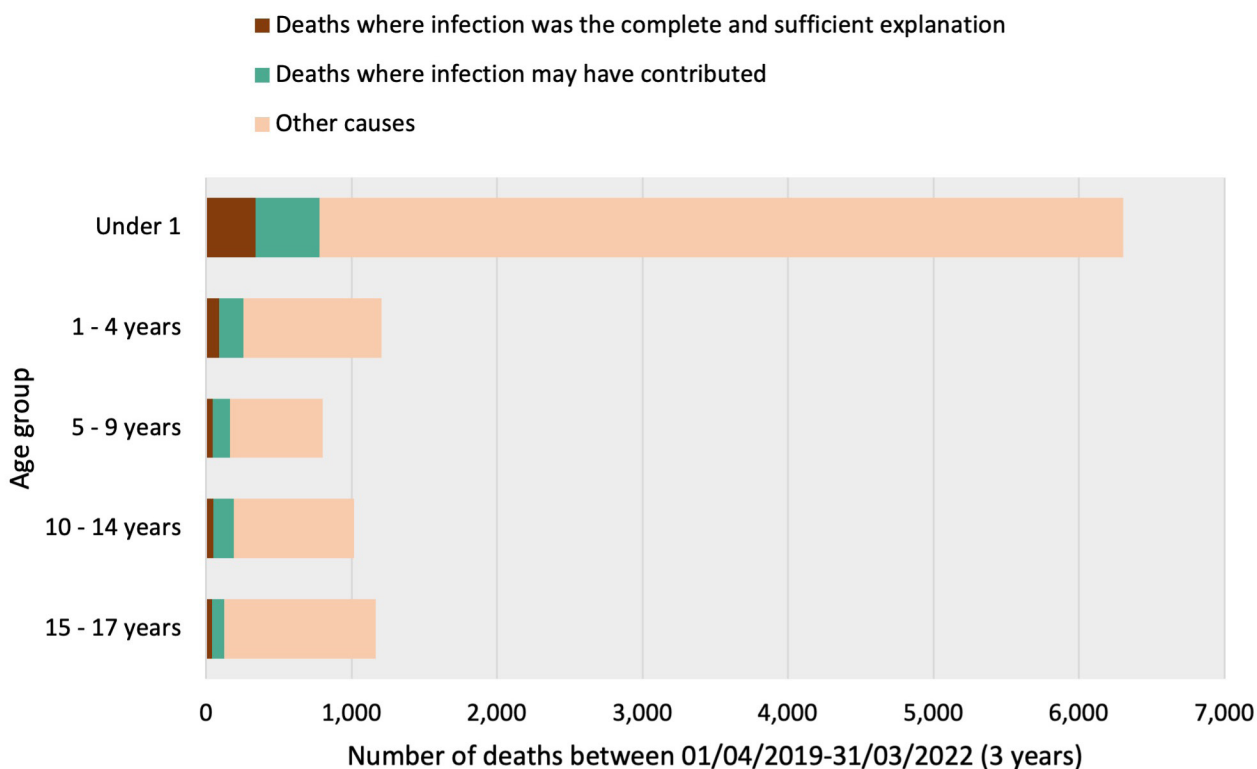
Infection related deaths in the context of all child deaths

This section summarises the number of infection related deaths as a proportion of **all** child deaths (0-17 years of age).

In 15% (n=1507/9978) of all child deaths between 1 April 2019 and 31 March 2022 (3 years), the death was infection related. The highest proportion of infection related deaths was in the 1-4 years (25%) and 5-9 years (24%) age groups, followed by 10-14 year olds (21%), infants (children under 1 year) (12%) and 15-17 year olds (12%) (Figure 2).

In 6% (n=553/9978) of all child deaths, infection provided a complete and sufficient explanation of death. Similarly to all infection related deaths, the highest proportion of deaths where infection provided a complete and sufficient explanation of death was in the 1-4 years age group (8%), followed by the 5-9 years age group (6%), 10-14 year olds (5%), infants (children under 1 year) (5%) and 15-17 year olds (4%).

Figure 2: The total number of child deaths and infection related child deaths between 1 April 2019 and 31 March 2022, by age group



Further information on other causes of child death can be found in the [Child Death Review Data Release](#)

2A. Characteristics of children who died where infection may have contributed or caused the death

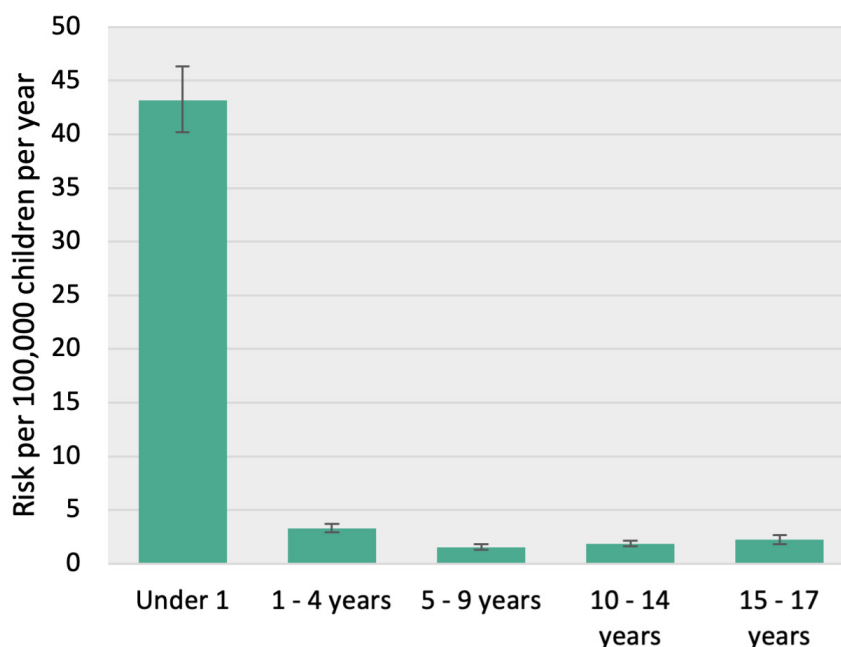
This section reviews the characteristics of all children where their infection may have contributed to or caused their deaths, between 1 April 2019 and 31 March 2022 (3 years).

It includes the child deaths also reported in section 2B (where infection provided a complete and sufficient explanation of death), but also includes those where infection may have contributed to the death, but may not have provided a complete explanation. This group of deaths is also defined as infection related deaths.

Age, sex, and ethnicity (Tables 1, 2)

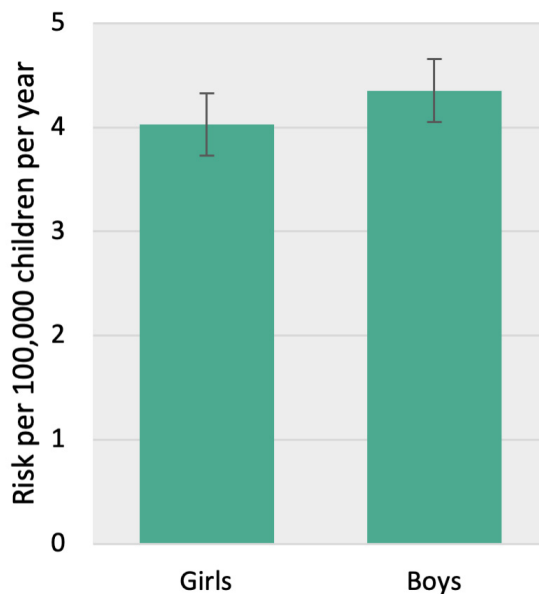
The largest number of deaths and the highest risk occurred in infants (children under the age of 1 year) (43.18 deaths per 100,000 infants), which was over 10 times that of all other age groups and also of the risk for all 0 – 17 year olds (4.20 per 100,000 children) (Figure 3).

Figure 3: Risk of infection related child death between 1 April 2019 and 31 March 2022 (3 years), by age group



Boys (4.35 per 100,000 children) and girls (4.03 per 100,000 children) had a similar risk of death (Figure 4).

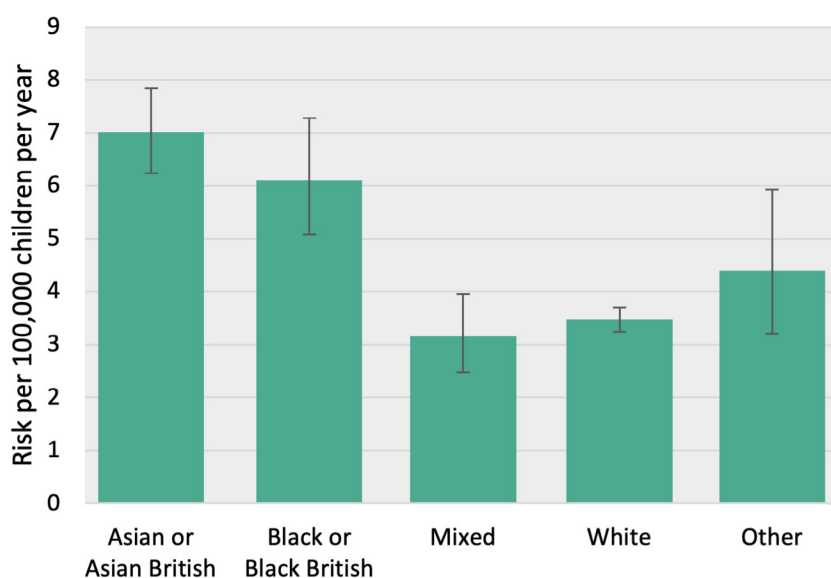
Figure 4: Risk of infection related child death between 1 April 2019 and 31 March 2022 (3 years), by sex



The risk of death did appear to vary by the ethnicity of the child. Children from an Asian or Asian British (7.02 per 100,000 children) and black or black British (6.11 per 100,000 children) background had the highest risk compared to children from a mixed (3.16 per 100,000 children) or white (3.48 per 100,000 children) ethnic background (Figure 5).

Within these groups, children with the highest risk of death were those who were described as being from a Pakistani (9.33 per 100,000 children), any other Asian (8.84 per 100,000 children), or African (6.88 per 100,000 children) ethnic background (Table 2). Further analysis is needed to investigate this disparity.

Figure 5: Risk of infection related child death between 1 April 2019 and 31 March 2022 (3 years), by ethnicity



Area, region and deprivation (Table 3)

The risk of infection related death varied according to whether the child lived in a rural or urban area. The risk for children living in urban areas (4.33 per 100,000 children) was higher than for those living in rural areas (3.24 per 100,000 children)

(Figure 6), and the number, and risk of death, increased with worsening measures of deprivation (Figure 8). The risk of death of children resident within each region ranged from 3.64 per 100,000 children to 5.28 per 100,000 children (Figure 7).

Figure 6: Risk of infection related child death between 1 April 2019 and 31 March 2022 (3 years), by rural/urban area of residence

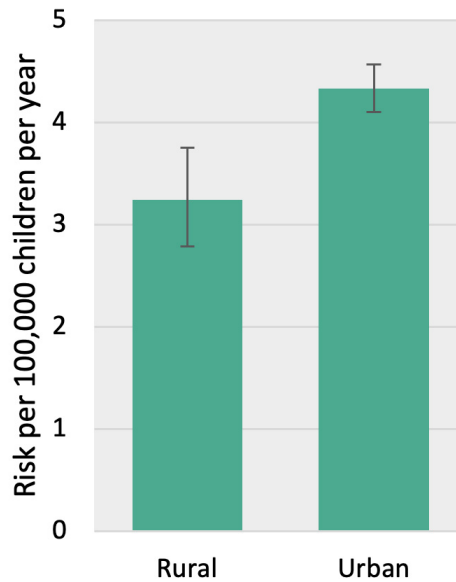


Figure 7: Risk of infection related child death between 1 April 2019 and 31 March 2022 (3 years), by region

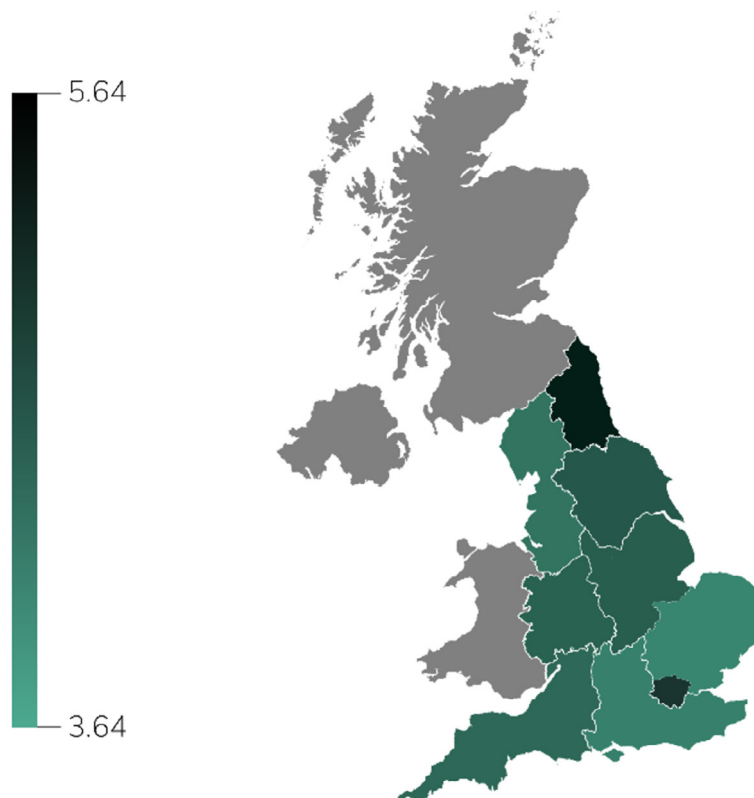
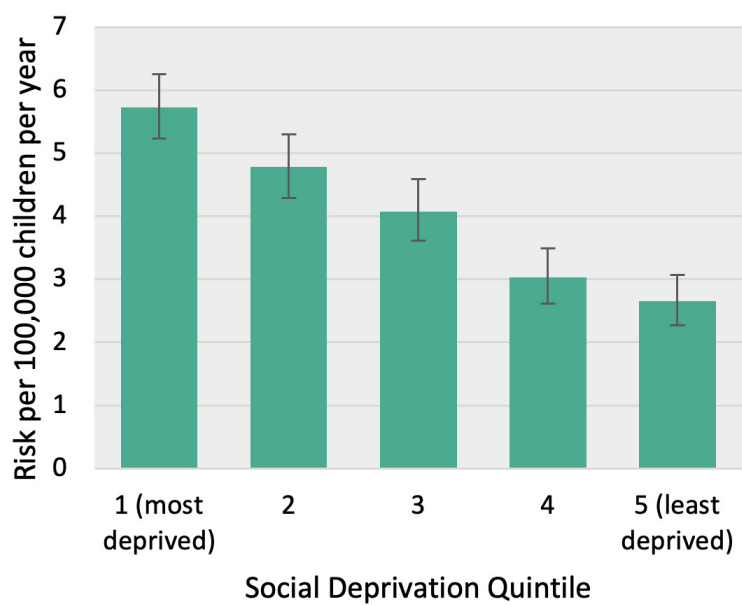


Figure 8: Risk of infection related child death between 1 April 2019 and 31 March 2022 (3 years), by deprivation quintile





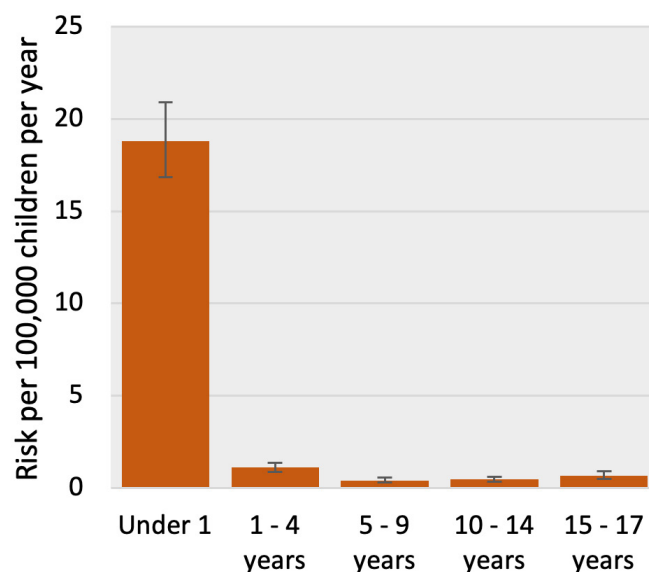
2B. Characteristics of children who died where infection provided a complete and sufficient explanation of death

This section reviews the characteristics of all children where infection provided a complete and sufficient explanation of death between 1 April 2019 and 31 March 2022 (3 years). Numbers are lower than those seen above (37% of all infection related deaths), but general patterns are similar for most characteristics.

Age, sex, and ethnicity (Tables 4, 5)

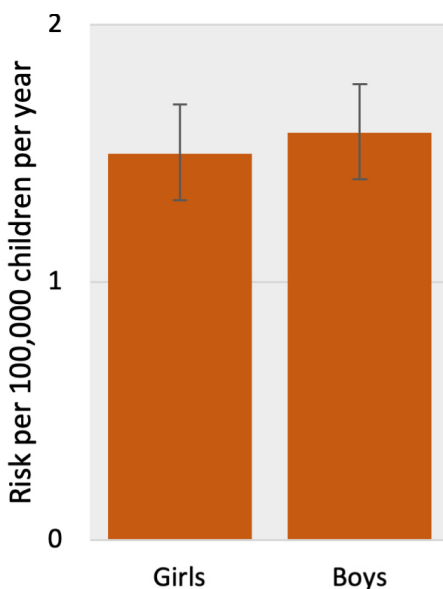
In children where infection provided a complete and sufficient explanation of death, the risk of death was highest in infants (18.78 deaths per 100,000 infants), which was over 10 times higher than for all other age groups and the rate for all 0 – 17 year olds (1.54 per 100,000 children) (Figure 9).

Figure 9: Risk of child death between 1 April 2019 and 31 March 2022 (3 years) where infection provided a complete and sufficient explanation of death, by age group



Boys and girls had similar risks of death overall (1.58 vs 1.50 per 100,000 children) (Figure 10).

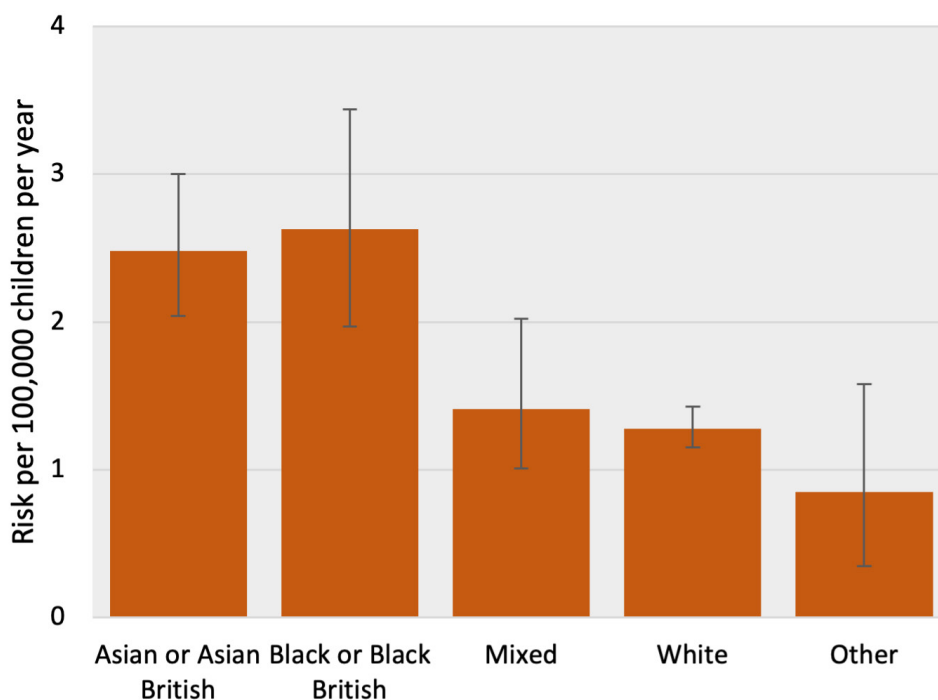
Figure 10: Risk of child death between 1 April 2019 and 31 March 2022 (3 years) where infection provided a complete and sufficient explanation of death, by sex



The risk of death did appear to vary by the ethnicity of the child. Patterns of ethnicity were also similar to section 2A. Children from a black or black British background (2.63 per 100,000 children) and Asian or Asian British background (2.48 per 100,000 children) had the highest risk of death in comparison to children from a mixed (1.46 per 100,000 children) or white (1.28 per 100,000 children) ethnic background (Figure 11). Within these groups, the highest

risk of death was in children described as African (2.90 per 100,000 children), Pakistani (2.52 per 100,000 children), or having any other Asian (3.77 per 100,000 children) ethnic background (Table 5). Higher proportions of both adults and children from Asian or black ethnic backgrounds have been reported to have died from COVID-19^{9,5}. These ethnic groups also have higher rates of early-onset neonatal sepsis due to Group B *Streptococcus*¹⁰.

Figure 11: Risk of child death between 1 April 2019 and 31 March 2022 (3 years) where infection provided a complete and sufficient explanation of death, by ethnic group

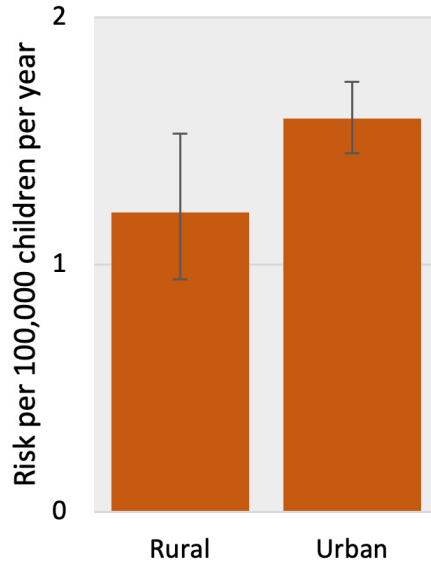


9 Nafilyan et al (2021)
10 Collin et al (2022)

Area, region, and deprivation (Table 6)

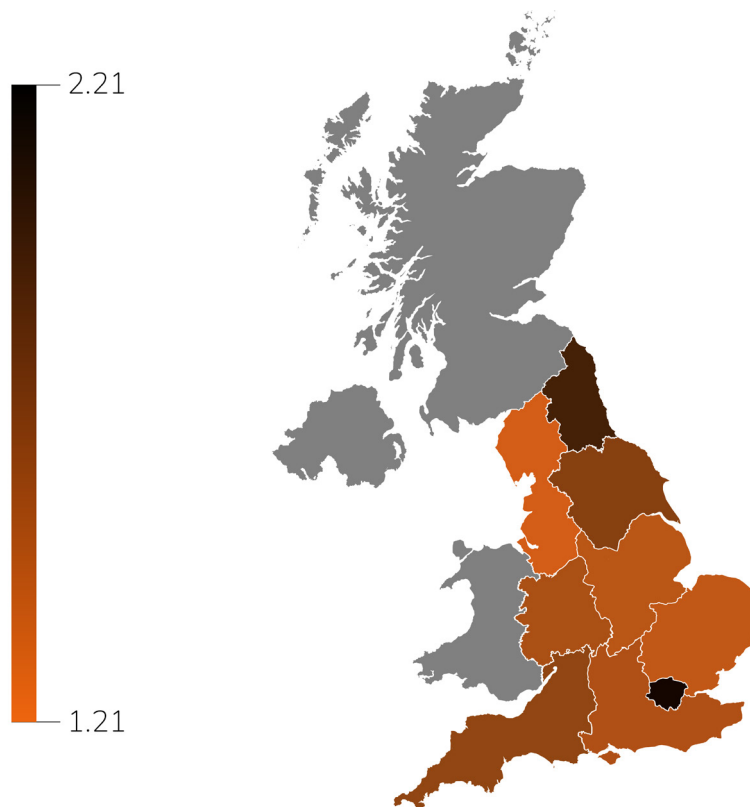
The risk of death was higher for children living in urban areas (1.59 per 100,000 children) than in rural areas (1.21 per 100,000 children) (Figure 12).

Figure 12: Risk of child death between 1 April 2019 and 31 March 2022 (3 years) where infection provided a complete and sufficient explanation of death, by rural/urban area of residence



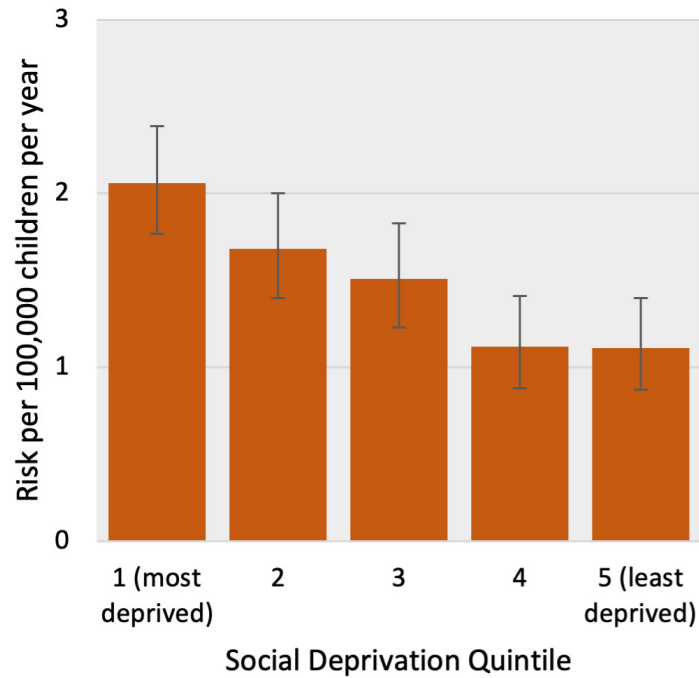
In children where death provided a complete and sufficient explanation of death, the risk of death by residence within each region of England ranged from 1.21 to 2.17 per 100,000 children (Figure 13).

Figure 13: Risk of child death between 1 April 2019 and 31 March 2022 (3 years) where infection provided a complete and sufficient explanation of death, by region



The risk of death was highest for those living in the most deprived neighbourhoods (2.06 per 100,000 children), and decreased as levels of deprivation reduced, with the least deprived neighbourhoods having the lowest risk (1.11 per 100,000 children) (Figure 14).

Figure 14: Risk of child death between 1 April 2019 and 31 March 2022 (3 years) where infection provided a complete and sufficient explanation of death, by deprivation quintile



2C. Details of the infections and their clinical presentations

This section reviews all infection related deaths, and summarises the organism or organisms involved or implicated, and the manner in which the child presented to healthcare.

This work does not differentiate between community and hospital acquired infections. Further information on this is included in the [Technical Information document](#).

Infectious pathogens (Tables 7, 11, 13)

Information within NCMD was reviewed for pathogens listed in the cause of death, contributory factors, or circumstances leading to death. More information on how they were confirmed to be involved or implicated in the death, and coded, can be found in the [Technical Information document](#).

Tables 7 and 11 report the infectious pathogens identified in children where there was evidence of infection preceding death. At least one infectious pathogen was identified in 56% (n=841/1507) of infection related deaths using information recorded in NCMD, and in 320 (21%), more than one pathogen was identified. However, even where infection appeared to provide a complete and sufficient explanation of death, in 196 (35%) deaths, no organism was clearly identified.

Bacteria

Gram negative bacteria were recorded in 309 (21%) infection related deaths (Figure 15), with 223 (72%) of these identified in children under the age of 1 year (Table 11). *E. coli* was most common, and reported in 101 deaths. *Haemophilus influenzae* is a species of bacteria that can cause infections. It was reported in 12 deaths. It is not the same organism as the influenza virus “flu”. One type, *Haemophilus influenzae* type b (Hib), can cause severe life-threatening infections, and can be prevented with vaccination. Babies and children are most at risk of getting seriously ill and vaccines are available against Hib as part of the [NHS vaccination schedule](#) for children.

Streptococcus species infections were reported in 146 (10%) deaths, including [Group B Streptococcus \(GBS\)](#) which was recorded in 70 deaths (65 of which were of children under 1 (Table 11)). GBS is one of the many bacteria that normally live in our gut and which usually cause no harm. However, in newborns, it can be invasive and cause severe illness. Pregnant women with GBS can spread the bacteria to their infants before or during childbirth. Most babies with a GBS infection make a full recovery with prompt treatment, which means early detection and treatment is vital while ongoing clinical trials are recruiting to identify the best way to screen mothers and treat babies. [NICE guideline \[NG195\]](#) makes recommendations for pregnant women and for the prevention

of early-onset infection before birth, including guidance specific to GBS ([Neonatal Infection QS75](#) is currently being updated and due to be published in December 2023). Several GBS vaccines for pregnant women are currently under development globally, which aim to protect the baby during pregnancy and birth.

While most high-income countries routinely test all pregnant women for GBS bacteria, there is ongoing debate in the UK as to the best approach to GBS infection prevention. Since 2003 the [UK National Screening Committee \(NSC\)](#) has [recommended against a population screening programme](#) as they consider there to be insufficient evidence of its benefit. A major clinical trial, the [GBS3 Trial](#), is currently examining whether routine testing is more effective than the UK's current risk-factor approach to preventing GBS infection in newborn babies. Due to report in 2025, the UK National Screening Committee has committed to considering its results when complete. There is a British Paediatric Surveillance Unit study in Phase 2 application stage that would survey invasive Group B streptococcal (iGBS) disease in British and Irish infants less than 90 days of age, following up on a 2000-01 study (before the introduction of risk-factor prevention in 2003), and a 2014 surveillance study.

There is also longer-term research continuing into the development of a maternal vaccine against GBS, which will prevent GBS stillbirths, early onset and late onset GBS infection, maternal infections and preterm births caused by GBS. GBS is recognised by the World Health Organisation as a key pathogen to address in their [Defeating meningitis by 2030 global road map](#).

Levels of awareness of GBS remain concerningly low among new and expectant mothers, with [2023 polling](#) finding that while most (95%) had heard of the infection, fewer than two-thirds (62%) felt confident recognising symptoms in a baby, and 66% would like to learn more about GBS from their healthcare professional.

Group A *Streptococcus* infection was recorded in 32 deaths across the 3 years, and was recently seen as a significant cause of disease in the winter of 2022/23¹¹. In the general population, most Group A *Streptococcus* infections are not serious and can be treated with antibiotics, but on rare occasions the infection can cause significant morbidity and be life-threatening. Prevention is therefore important; the [NHS website](#) provides information on the measures that individuals can take to avoid infections.

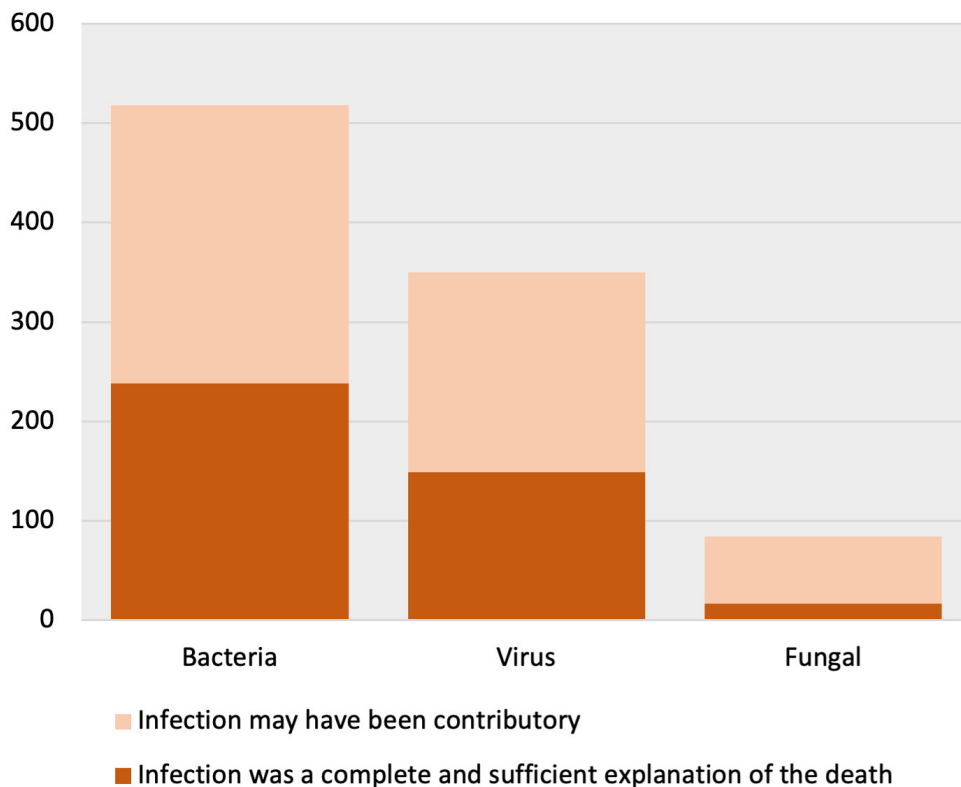
Pneumococcal infections, caused by the *Streptococcus pneumoniae* bacteria, were identified in 32 deaths, of which an infection provided a complete and sufficient explanation of 24 deaths. The [pneumococcal vaccine](#) (or pneumonia vaccine) protects against some serious and potentially fatal infections.

11 UKHSA (2022)

Meningococcus is a bacterium that can cause meningitis or sepsis. It was present in 15 deaths, for 13 of which the infection provided a complete and sufficient explanation of death. The number of cases has greatly diminished over the last 23 years, partly due to successful vaccine programmes in infancy and adolescence.

Antibiotics are generally effective against all of the bacteria seen in this work. However, early delivery is often needed and broad or inappropriate use can lead to unnecessary side effects¹² in individuals, and an increase in drug-resistant infections in the population.

Figure 15: Number of infection related child deaths between 1 April 2019 and 31 March 2022, by pathogen identified



Viruses

Viruses were reported in 350 (23%) deaths, and 149 (27%) of the deaths where infection provided a complete and sufficient explanation of death (Figure 15).

Respiratory syncytial virus (RSV) is a viral infection which is very common and spreads easily. It can cause a cough or cold and in young children it can cause bronchiolitis. Bronchiolitis is a common chest infection that affects babies and children under 2 years. It is usually mild and can be treated at home but it can be serious (further information on symptoms, treatment and when to seek help is available on the [NHS website](#)). RSV is the most common viral cause of pneumonia and a leading cause of hospitalisation due to acute lower respiratory infection, especially in infants and young children. RSV was recorded in 40 deaths over the 3 year period and was identified where infection provided a complete and sufficient explanation of death in 18 cases. An RSV vaccine, and other preventative therapies are available, but are currently not routinely offered at a population level. However, the Joint Committee on Vaccination and Immunisation (JCVI) have

recently advised that an RSV immunisation programme, that is cost-effective, should be developed for newborns and infants¹³; discussions are taking place nationally as a consequence.

Herpes simplex virus (HSV) is another common viral infection, and is a common cause of blisters or cold sores. It was present in 37 deaths; 24 of which were neonatal (babies under 28 days) deaths. Neonatal herpes is an HSV infection in a young baby. It is rare but can be very serious and cause death or long-term neurological problems. Perinatal management can help prevent neonatal herpes infection in newborn infants and an effective drug (acyclovir) also exists.

Cytomegalovirus (CMV) is a related virus and is often also seen in the newborn period or in children with immune problems. It was identified in 34 deaths including seven deaths where infection provided a complete and sufficient explanation of death.

¹² Aversa et al (2021)

¹³ Department of Health & Social Care (2023)



schedule. This should be a 2-dose programme offering vaccination at 12 and 18 months of age using the combined MMRV (measles, mumps, rubella and varicella) vaccine.

COVID-19 (SARS-CoV-2) was the cause of all coronavirus infections in this report. Further work on this is published elsewhere⁵, but this was the most frequent virus reported in this cohort (n=109).

No child died of HIV in the 3 years reported.

Fungal infections

84 cases of fungal infection were identified, and provided a complete and sufficient explanation of 17 deaths. Fungal infections are rarely seen in children with normal immune systems but are seen in infants after birth at the earliest gestations and in children who are immunocompromised. Anti-fungal drugs exist but treatment is often complex and prolonged.

Tables with a further breakdown of infection pathogens by age group, underlying health condition, and learning disability, are available in tables 11, 13, 15 and 17.

Clinical conditions (Tables 8, 12, 14)

This section reports on clinical conditions, describing how infections presented to parents, carers and healthcare workers. The clinical conditions reported here may not have caused the death, but there was evidence of the presence of the condition in the events preceding death. In 52% of deaths a single condition was identified using information recorded in NCMD, and in 6% of deaths more than one condition was identified (n=91/1507).

Pneumonia and lower respiratory tract infection was the most common condition reported (n=593) (Figure 16). Pneumonia is a form of acute infection that affects the lungs. When someone has pneumonia, the alveoli (small sacks that make up the lungs, that fill with air when a healthy person breathes) are filled with pus and fluid, making breathing difficult and limiting oxygen intake. Pneumonia is the single largest infectious cause of death of children worldwide. It can be caused by viruses, bacteria or fungi and the most common pathogens are *Streptococcus pneumoniae*, *Haemophilus influenzae* type b (Hib) and respiratory syncytial virus¹⁵.

Meningitis and encephalitis are most common in babies and children and require prompt treatment. They were recorded in 126 deaths across the 3 years, with 77 deaths of children under 1 year (Table 12). Vaccinations are available that offer some protection against pneumococcal and meningococcal meningitis, and effective antibiotics are available for most organisms.

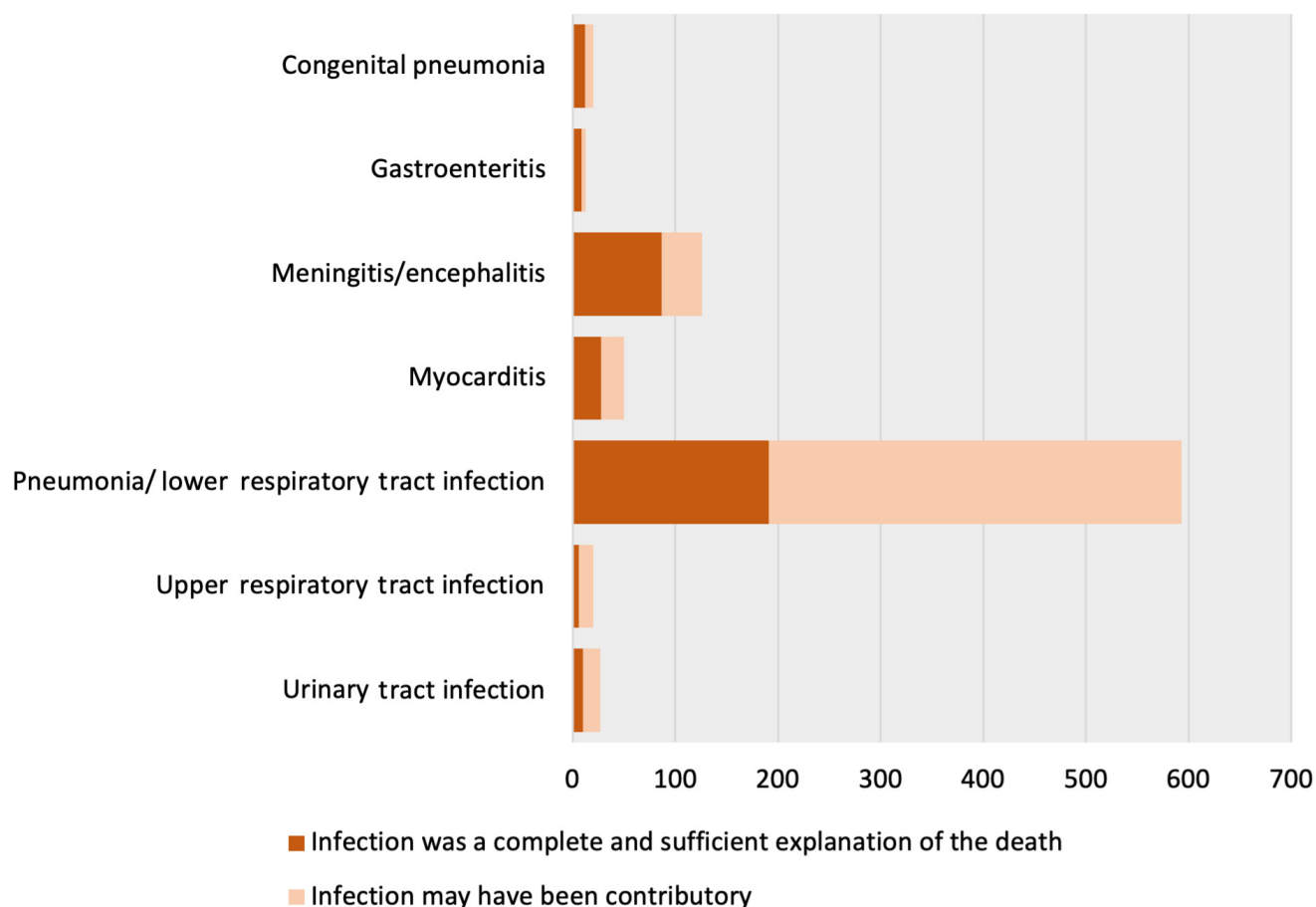
A breakdown of clinical conditions by age group, underlying health condition, and learning disability, is available in Tables 12, 14, 16 and 18.

“The Flu” caused by the influenza virus was recorded in 33 deaths. Babies, very young children and those with other underlying health conditions are at greater risk of serious illness and complications due to influenza. Flu vaccines are a safe, effective method to reduce the risk of influenza infection and serious illness and are offered every year to children, and expectant mothers, which helps to protect them and others who are vulnerable.

Chickenpox (varicella zoster virus) was recorded in eight deaths, including five deaths where infection provided a complete and sufficient explanation of death. This included deaths where the child died of chickenpox and also where the child died due to a secondary bacterial infection. Chickenpox is a common childhood infection which is usually mild, and complications are rare. However it can also increase the risk of other serious infections (e.g., group A *Streptococcus* (GAS) infection). Almost all children develop immunity to chickenpox after infection, so most only catch it once. It may however, lead to shingles (herpes zoster) later in life through reactivation of dormant virus. Chickenpox can also cause complications during early and late pregnancy. A chickenpox vaccine is available but is not currently part of the routine childhood vaccination schedule. It is only available on the NHS to adults and children who are in close contact with someone who has a weakened immune system, or as part of public health management of mixed outbreaks of GAS and chickenpox¹⁴, in those at risk of serious illness if they catch chickenpox. Protection is by decreasing the opportunity for transmission to those who may become seriously unwell should they become infected, although active anti-viral drugs such as acyclovir also exist. The Joint Committee on Vaccination and Immunisation (JCVI) published a report on 14 November 2023 recommending a universal varicella (chickenpox) vaccination programme to be introduced as part of the routine childhood

¹⁴ UKHSA (2023)
¹⁵ WHO (2022)

Figure 16: Number of infection related child deaths between 1 April 2019 and 31 March 2022, by identified clinical condition at presentation



Sepsis

Sepsis is a clinical syndrome resulting from a dysregulated immune response to infection. The primary source of infection may arise in the bloodstream (e.g., meningococcal bacteraemia), lung (e.g., pneumococcal pneumonia), or other body systems. Septic shock should be considered a subset of sepsis in which underlying circulatory, cellular and metabolic abnormalities contribute to a greater risk of mortality than that posed by sepsis alone. In clinical practice, septic shock is usually the final common pathway in patients in whom sepsis is described as providing a complete and sufficient explanation of death, although this may not be apparent until peri- or post-mortem results are available.

In this report, it was difficult to distinguish children with sepsis from known sources (e.g., lower respiratory tract), versus those with sepsis from unknown sources but bacteria (e.g., *neisseria meningitidis*) identified only in blood, versus those with sepsis from an unknown source entirely. Across the entire cohort (n=1507) the clinical signs of sepsis were reported in 701 deaths and in 478 cases this was the only clinical condition/presentation identified and may well represent the only clinical evidence of infection by the time the child presented to healthcare. It is not completely understood why some people develop sepsis in response to these common infections whereas others do not. It can be difficult to identify evolving signs of sepsis but concerned members of the public

should call 999 or go to the nearest Emergency Department. The National Institute for Health and Care Excellence (NICE) provides guidance for people with sepsis, their families and carers, and for healthcare professionals, on the recognition, diagnosis and early management of sepsis, and training resources are also available from The UK Sepsis Trust.

NHS England in partnership with the Royal College of Paediatrics and Child Health and the Royal College of Nursing is developing a new NHS warning system to spot deterioration in children's health faster. It includes a specific escalation pathway for sepsis. This is modelled on the Academy of Medical Royal Colleges' statement on the initial antimicrobial treatment of sepsis V 2.0 which matches either the early warning score, clinical intuition or parental concern to a specific escalation (rather than individual vital sign criteria which are known to be poorly specific/sensitive). It also extends the antibiotic response time to 3 hours if shock isn't present, safely balancing the need for treatment with reducing unnecessary antibiotic prescription. The national paediatric early warning system (PEWS) observation and escalation charts are part of the SPOT (system wide paediatric observation tracking) programme of work. This will expand over the next 1-3 years from inpatient wards to Emergency Departments and the community, ultimately addressing some of the system and communication issues described in this report.

Underlying health conditions (Tables 9, 15, 16)

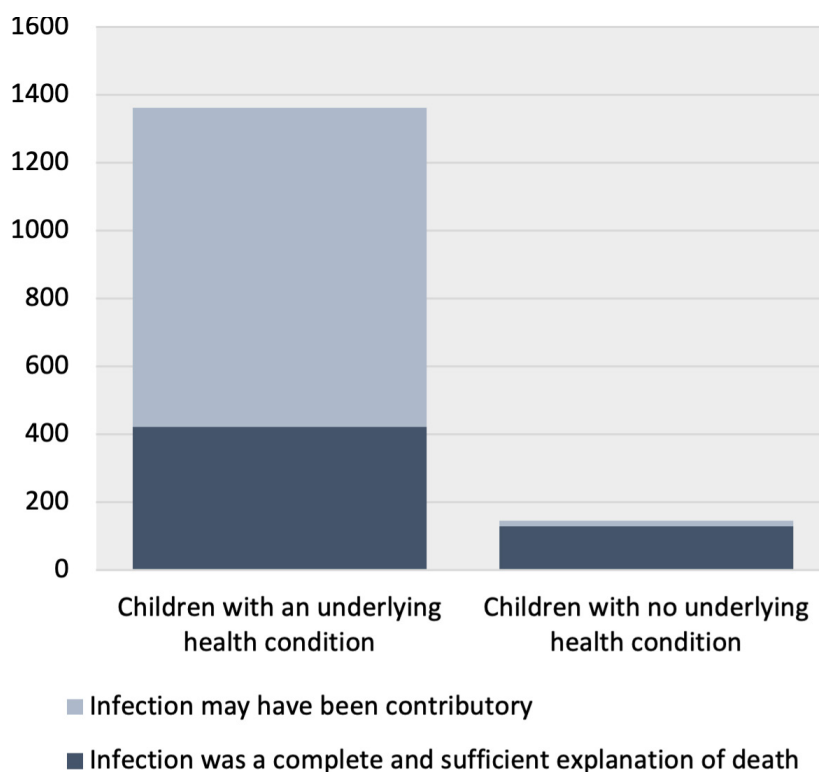
Underlying health conditions can increase the vulnerability of a child to an infection. Life-limiting conditions (LLCs) are those for which there is no reasonable hope of cure. Children and young people with LLCs may die from other conditions or complications, such as infections, that might not prove fatal in other children. Some of these conditions cause progressive deterioration, rendering the child increasingly dependent on parents and carers¹⁶.

Life-limiting conditions for each child were identified either through linking to ICD-10 diagnosis codes within Hospital Episode Statistics data, or where the life-limiting condition supplementary form was completed during the child death review. Chosen ICD-10 codes were consistent with those identified in previous research on children with life-limiting conditions¹⁷. This list also includes life-threatening conditions (those for which curative treatment may be feasible but can fail; for example, cancer) and can be found in the [Technical Information document](#).

Of all infection related child deaths, 90% (n=1361) had an underlying health condition, and in 423 of these deaths the infection was thought to be a complete and sufficient explanation of the death (Figure 17). The child had an LLC in 68% (n=1024) of all infection related deaths. Other underlying health conditions included prematurity (born before 37 weeks gestation) and perinatal events (n=259). In 10% (n=146) of deaths the child had no underlying condition, 130 of which were where the infection was a complete and sufficient explanation of death.

Where infection provided a complete and sufficient explanation of death, 423 (76%) deaths had an underlying health condition. 275 (50%) children in this cohort had a life limiting condition, and 124 (22%) of these were linked to perinatal (birth) events e.g., prematurity. However, in 130 (24%) cases, the child appeared to not have any underlying health problem. Of these 130, 50% (n=65) were under 1 and 50% (n=65) were between 1-17 years.

Figure 17: Number of infection related child deaths between 1 April 2019 and 31 March 2022, by presence/absence of underlying health condition



The likelihood of identifying a pathogen, and the profile of those identified, appeared similar between those children with, or without an LLC (Table 15), but lower respiratory tract infections appeared to be a more common clinical condition in children with an LLC (45%, n=462/1024) than in children without (27%, n=131/483) (Table 16).

Viral infections were identified in 25% (n=252/1024) and fungal infections in 7% (n=72/1024) of children with an LLC; a higher proportion than in deaths of children without an LLC (20% and 2% respectively).

¹⁶ Together for Short Lives (2018)

¹⁷ Fraser et al (2021)

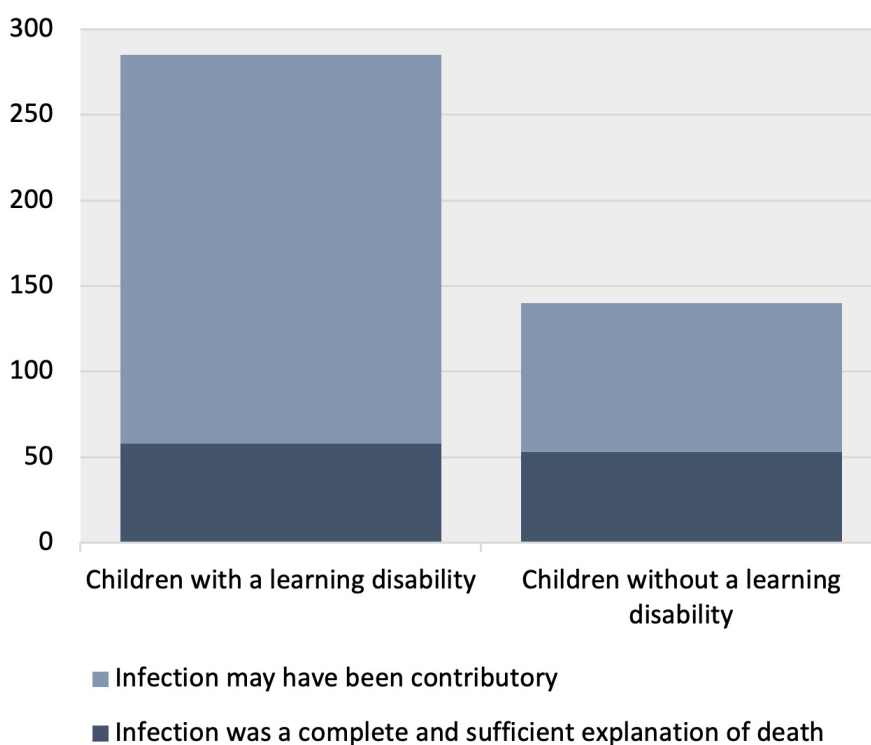
Children between 5-17 years with a learning disability (Tables 10, 17, 18)

Previous research has shown that people of all ages with a learning disability had increased risks of hospital admission and death from COVID-19¹⁸, and the risk was even greater for people from minority ethnic groups¹⁹. It is likely comorbidities, as reported in the Confidential Inquiry into the deaths of people with learning disabilities (CIPOLD) study²⁰, may increase susceptibility to infection, rather than the learning disability itself. Furthermore, health inequalities/systems factors likely also increase susceptibility to serious illness and/or death following infection, such as diagnostic overshadowing, unconscious bias and lack of reasonable adjustments, as

well as factors relating to the learning disability itself. This can lead to delayed assessment, diagnosis and treatment (e.g., difficulties reporting pain, communicating with professionals, and understanding the importance of assessment/treatment)²⁰.

Diagnosis of a learning disability is less common before 4 years of age, and so the following data have only been reported for children aged between 5 and 17 years. Of all infection related deaths, there was a high proportion of children with a learning disability (67%, n=285/425). In cases where the infection provided a complete and sufficient explanation of death, 52% (n=58/111) of children had a learning disability. In cases where infection contributed to death, 72% (n=227/314) had a learning disability (Figure 18).

Figure 18: Number of infection related deaths in children aged 5 – 17 years between 1 April 2019 and 31 March 2022, by whether the child had a learning disability



A pathogen was less commonly identified in children with a learning disability (44%, n=124/285), than in those without (71%, n=100/140) (Table 17). Viral infections were most common and were identified in 27% (n=77/285), followed by bacterial infections identified in 20% (n=58/285), and fungal infections in 4% (n=12/285) of children with a learning disability.

Similar to children with life limiting conditions, pneumonia or a lower respiratory tract infection was the most common condition identified (75%, n=215/285) in the deaths of children with a learning disability, compared to 25% (n=35/140) of deaths of children without a learning disability (Table 18).

Further breakdown of data relating to infection pathogens and clinical conditions in children with a learning disability is available in Tables 17 and 18.

An upcoming thematic report on all deaths of children with a learning disability will analyse characteristics, themes, and causes of death in depth. This thematic report will be published by NCMD in 2024 and will include learning identified from the child death reviews.

¹⁸ Williamson et al (2021)

¹⁹ Public Health England (2020)

²⁰ Heslop et al (2014)



3. Learning from CDOP completed child death reviews where death was categorised as Infection

This section focuses on the outcome of completed child death reviews by CDOPs where the child died between 1 April 2019 and 31 March 2022 and the review had been finalised by 3 May 2023.

During the review, CDOPs are required to categorise the likely cause of death using a hierarchical schema, where more than one category can be selected. Where more than one category is applied, the uppermost selected category will be recorded as the primary category and others as secondary categories. The category of death hierarchal schema can be found in the [statutory analysis form](#).

The reviews included in this section include reviews where 'infection' or 'perinatal infection' was considered to be the primary category of death (i.e., the likely cause), and also reviews where either of these categories were selected as a secondary category of death (these reviews will have had another category selected as the primary category of death). Those where infection was categorised as a primary category were included under the cohort 'infection provided a complete and sufficient explanation of the death' in Sections 2B and 2C. Those where infection was categorised as a secondary category were included under the cohort 'Infection may have been contributory', and thus included in the wider cohort reported in Sections 2A and 2C.

Analysis was restricted to deaths that were categorised as 'infection' or 'perinatal infection' by the CDOP to ensure learning reported by CDOPs was relevant to infection deaths. Further information on the methodology used for defining this group is included in the Technical Information document. For infection related deaths (reported in Section 2), 87% (n=1315/1507) had been reviewed by a CDOP. Of those, 843 reviews were categorised by the CDOP as 'infection' or 'perinatal infection' either as the primary or secondary category of death. As 87% of the deaths had been reviewed, the numbers presented throughout this section will be an underestimate of the true incidence over the 3 years, and focus is therefore on proportions. It can often take time, sometimes over a year, for the whole child death review process to be completed. This is because the CDOP review is the last review to happen following other proceedings that may be required, e.g., coroner's inquest, criminal trial, child safeguarding practice review or domestic homicide review.

Of the 843 death reviews included in this section, 43% (n=360) were for children who died in 2019-20, 28% (n=240) for children who died in 2020-21 (the year of the start of the COVID-19 pandemic), and 29% (n=243) for children who died in 2021-22. 'Infection' was the primary category of death in 41% (n=345) of reviews, 'perinatal infection' was the primary category of death in 16% (n=137) of reviews, and either were listed as a secondary category in 43% (n=361) of reviews.

Contributory and modifiable factors identified by CDOPs

During the review, CDOPs are required to determine contributory factors across domains specific to the child, the social and physical environment, and service delivery. Each factor is then graded with a relevance, to identify any factors which 'may have contributed to vulnerability, ill health, or death of the child'. The role of the CDOP is also to determine which of these factors are assessed as 'modifiable'; factors that may, by means of a locally or nationally achievable intervention, be modified to reduce the risk of future child deaths. Many factors can be assessed as contributory to the death; however, not all will be assessed to be modifiable.

Contributory or modifiable factors recorded that 'may have contributed to ill-health, vulnerability, or death of the child' were included in the analysis. Data on both contributory and modifiable factors are presented, to show all factors which

may have contributed and whether they were assessed to be modifiable by the CDOP.

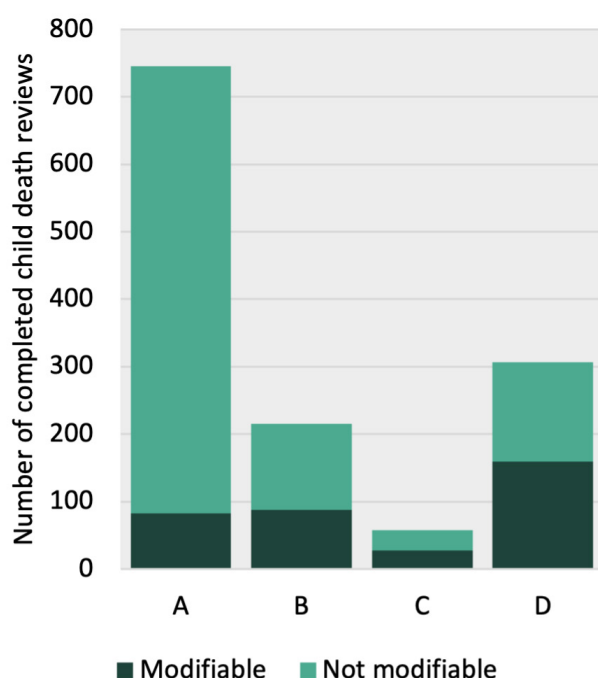
Overall, modifiable factors were identified at review in 36% (n=304/843) of child death reviews; namely, in 42% (n=146/345) of deaths where 'infection' was considered the primary category of death, in 41% (n=56/137) of deaths where 'perinatal infection' was considered the primary category of death, and in 28% (n=102/361) of deaths where either were considered a secondary category of death.

Figure 19 shows the distribution of contributory factors recorded across all four domains, and the proportion of those that were classified as modifiable by the CDOP.

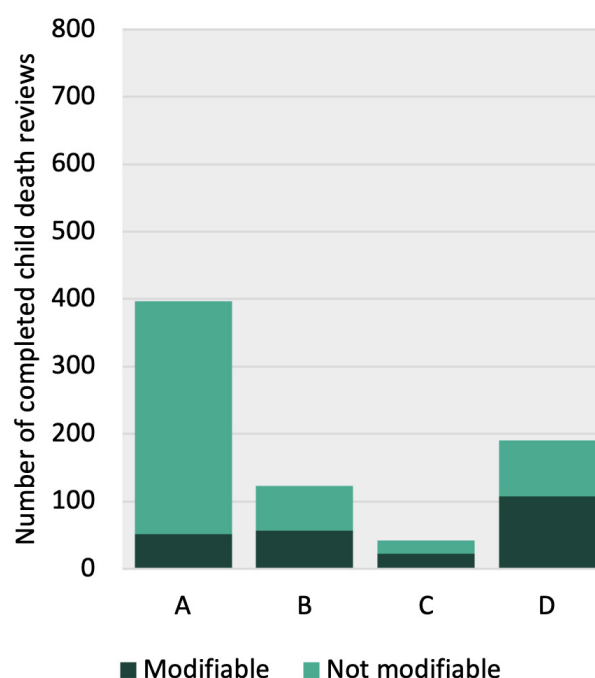
The interaction of multiple factors can increase the impact of these factors and vulnerability to death, compared with what the impact might have been if there was only one factor present.

Figure 19: Contributory factors recorded by the CDOP that may have contributed to the vulnerability, ill health or death of the child, for completed child death reviews by CDOPs where the child died with an infection

All deaths categorised as infection (n=843)



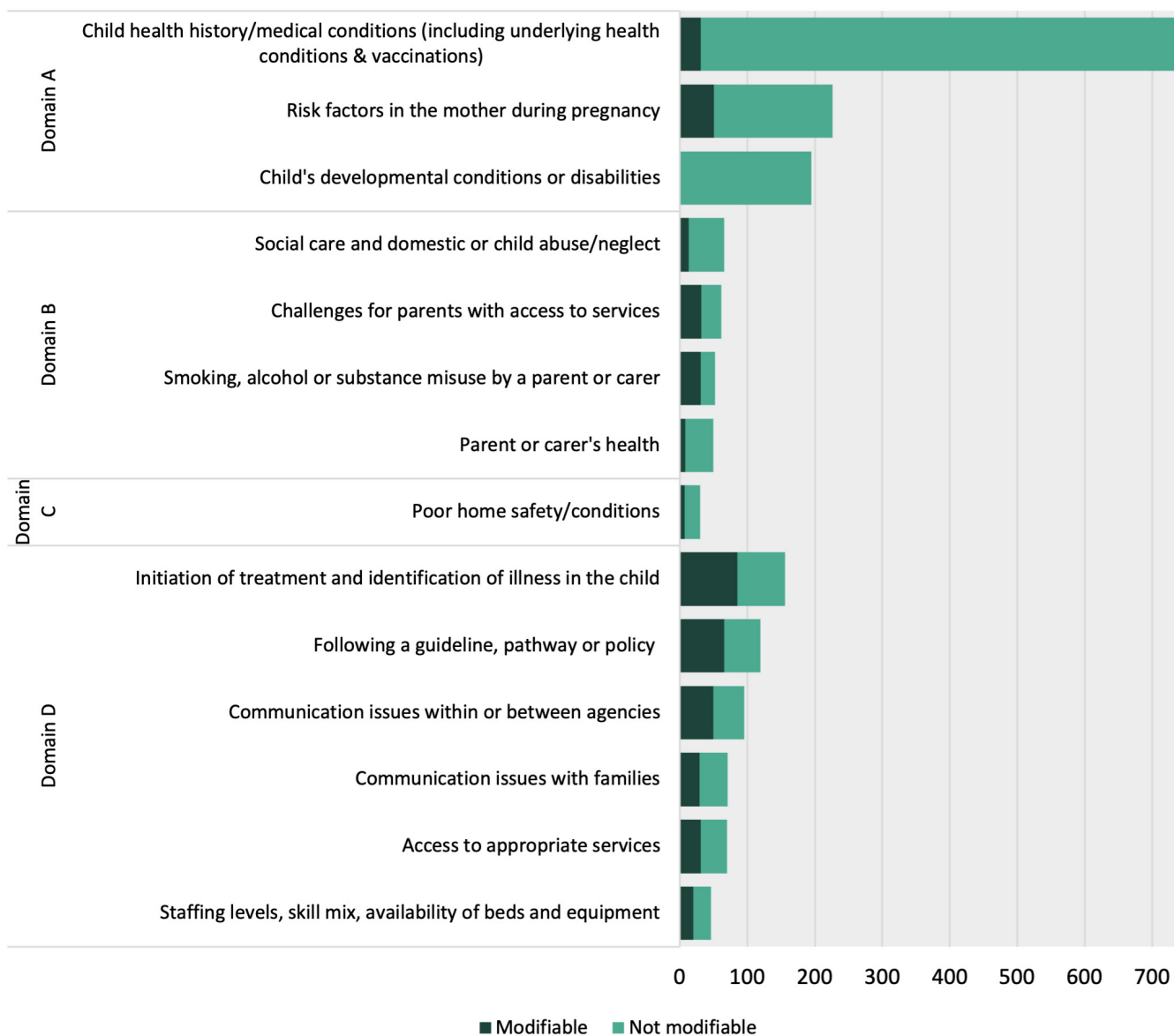
Infection was the primary category (including perinatal infection) (n=482)



- A** = Characteristics of the Child
- B** = Social environment
- C** = Physical environment
- D** = Service provision

Figure 20 shows the most commonly recorded contributory and modifiable factors by CDOPs. Further detail of these is provided in the subsections below, including CDOP learning points related to these factors.

Figure 20: Most frequently recorded contributory and modifiable factors recorded by CDOPs that may have contributed to the vulnerability, ill health or death of the child, for completed child death reviews where the child died with an infection



Factors intrinsic to the child or young person:

A contributory factor within the characteristics of the child was recorded in 88% (n=745/843) of reviews.

Child health history

Factors in relation to the child's health history or underlying health conditions were reported in 86% (n=724/843) of reviews. Most of these factors related to the acute illness and presenting infection of the child. Underlying health conditions

such as malignancy, congenital/genetic/chromosomal anomalies and other chronic health conditions (e.g., obesity) were also commonly recorded (46%, n=385). Initiatives are ongoing to address obesity and poor diet in children. Through the Healthy Food Schemes a nutritional safety net is provided to those families who need it the most. [Healthy Start](#), the [Nursery Milk Scheme](#) and the [School Fruit and Vegetable Scheme](#) together help more than three million children.

Other learning identified, included the need for earlier referral to specialist services from primary healthcare where advice was needed, where repeated or frequent presentations

occurred, or where automated systems had identified high risk presentations. Learning also included ensuring adequate equipment to assess children in all environments where they may be assessed (e.g., paediatric pulse oximeters that should be housed with the surgery emergency equipment), and knowledge and adherence to NICE guidelines (e.g., training and awareness of sepsis).

NHS England in partnership with the Royal College of Paediatrics and Child Health and the Royal College of Nursing has been developing a [new NHS warning system to spot deterioration in children's health faster](#) for over 3 years with pilots running across 15 sites. It includes a specific escalation pathway for sepsis. This is modelled on the Academy of Medical Royal Colleges' [statement on the initial antimicrobial treatment of sepsis V2.0](#) which matches either the early warning score, clinical intuition or parental concern to a specific escalation (rather than individual vital sign criteria which are known to be poorly specific/sensitive).

Prematurity or low birth weight was recorded as a contributory factor in 30% (n=255) of reviews. Premature babies are more susceptible to infections as their immune system is less developed. The [NCMD thematic report on the contribution of newborn health to child mortality across England](#) makes a number of recommendations on the prediction, prevention and management of preterm birth.

Learning disabilities

In the completed reviews of children aged 5 – 17 years, 62% were recorded as having a learning disability (n=151/245); a similar proportion to the overall cohort of deaths. 25% (n=37/151) of these reviews identified modifiable factors, which included 21 reviews where a modifiable factor in service provision was highlighted. Initiation of treatment and identification of illness including escalation of care (n=9), communication factors (n=9), and access to appropriate services including the impact of the COVID-19 pandemic on services (n=4), were recorded as modifiable factors. Learning included ensuring that the presence of a learning disability and reasonable adjustments are considered as part of the assessment by all services including out of hours providers. CDOPs also recorded modifiable factors in the reviews of children with a learning disability, around challenges for parents with access to services and engagement with families (n=4), and missed opportunities for vaccination (n=4).

Vaccinations

The NHS strongly recommends that babies and children are vaccinated. It is important that vaccines are given on time to provide best protection. If a child misses a vaccine, parents or carers should contact their GP who will organise for the child to have a catch up immunisation. All clinical staff, particularly health visitors, school nurses and primary care practitioners, should utilise opportunities to engage in discussions around the importance of vaccinations with parents or carers, to protect children against complications from infectious diseases. Availability of accessible information and communication is also essential to support this, as well as ensuring those children and young people who may be eligible

for vaccination at a younger age or eligible for additional doses of certain vaccines due to being at increased risk from certain serious disease, are identified and vaccinated by community paediatricians or primary care.

The CDOP recorded a baby or child not being immunised, or there being a delay in immunisations, as a contributory factor in 23 (3%) reviews. Reasons recorded for this included parental choice, and logistical issues around receiving the vaccine, such as problems with service provision or circumstances in the child's background. Findings from an English national surveillance sentinel network study show a fall and variation in the uptake of pneumococcal and measles, mumps and rubella (MMR) vaccines in children, and associated change in vaccine-preventable diseases across the first and second waves of the COVID-19 pandemic; this fall highlights ethnic, socioeconomic and geographical disparities in vaccines and risks widening health disparities²¹.

Missed vaccinations for influenza A and B was also recorded as a modifiable factor. CDOPs reported that influenza would have made children more vulnerable to bacterial infections (e.g., invasive streptococcal disease) and that it is possible that the influenza vaccine could have prevented deaths. Learning from CDOPs also highlights the importance of raising awareness in the general community that previously fit and well children can die from influenza, and that influenza is a potentially preventable condition if vaccinations are taken up.

There were also reviews of children with complex needs dying from infections where protection from infection and associated complications could have been provided via routine vaccination. CDOPs recorded the importance of encouraging parents to take up vaccination offers, and greater joined up processes between agencies of call and recall processes for children who have not received routine scheduled vaccinations (e.g., children may have missed immunisations due to being admitted to hospital or being abroad). Given the increased risk amongst particular groups of children, such as those with complex needs, those with particular co-morbidities, children with a learning disability and autistic children and young people, it is essential that any additional needs are identified prior to attendance so that person-centred reasonable adjustments can be accommodated where needed. This is particularly important for families of special educational needs and disability (SEND) children who may be more anxious and where adjustments will need to be tailored to take account of individual needs.

[Public Health England \(PHE\) national immunisation inequality strategy](#) makes recommendations for national and local actions to narrow inequalities in immunisation uptake.

An exemplary case study on local work undertaking a system wide approach in immunisations to address inequalities and other complex factors related to missed immunisations, is included in the Personal Stories and Case Study document accompanying this report.

21 Hoang et al (2022)



Factors in the social environment:

Social determinants of health (e.g., access to services) are non-medical factors that influence health outcomes and have an important influence on health inequities. As reported in Section 2B, the number, and risk of death, of children with evidence of infection increased with worsening measures of deprivation.

Social environment factors were recorded as a contributory factor in 26% (n=215/843) of child death reviews, including 88 reviews which identified them as being a modifiable factor. The subsections below provide further details on the main factors and CDOP learning points related to these issues.

Service access challenges for parents and carers

Challenges for parents to access services was recorded as a contributory factor in 7% (n=62/843) of CDOP reviews, including 32 reviews which identified this as modifiable. For example, there were instances where services were available but there were challenges in supporting families to access them.

Marginalised, disadvantaged or difficult to reach families are often under-served because of their limited engagement with services. As a result, they frequently experience poorer health and social outcomes. Examples reported by CDOPs included poor engagement with antenatal and postnatal services.

This also included challenges for families in recognising a deteriorating child (4%, n=33/843), which result in a consequent delay in presentation to healthcare services. It was recorded that the recognition of deterioration in a child with a learning disability or complex medical conditions is particularly challenging, as the child's response to illness may not be typical.

CDOPs also recorded challenges around access to services during the COVID-19 pandemic due to COVID infections, lockdown restrictions, and use of telephone appointments.

Parent or carer's health

Smoking, alcohol or substance misuse by a parent or carer that contributed to the vulnerability, ill health or death of the child, was recorded as a contributory factor in 6% (n=52/843) of child death reviews. Babies and children are vulnerable to the effects of parental and bystander smoking. Premature babies and those with underdeveloped lungs can be seriously affected by cigarette smoke.

Other factors were recorded relating to the parent/carer's health, including mental or physical health, as contributory factors in 6% (n=50/843) of CDOP reviews.

Social care and domestic or child abuse/neglect factors

Where it was recorded, the child was known to social care at the time of their death in 18% of CDOP reviews (n=153/832), and had been previously known in a further 15% (n=121/832) of CDOP reviews (Figure 21).

Risk factors in pregnancy

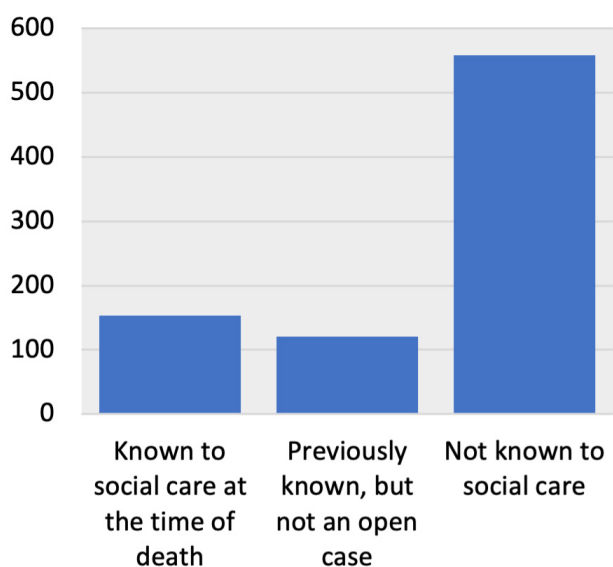
Risk factors in the mother during pregnancy or delivery were recorded in 27% of all reviews (n=226/843). These included maternal infections, smoking in pregnancy, twin or multiple pregnancy, maternal health (e.g., high maternal BMI, maternal diabetes, gestational diabetes), and obstetric and birth complications. Some vaccines are recommended in pregnancy, which help to protect both the mother and baby from infection.

Delivery and other obstetric complications were recorded as contributory factors in 15% (n=125) of reviews. Themes identified from CDOP learning included midwifery workforce shortages, ineffective communication (information sharing and handover) between the maternity and neonatal teams caring for the mother and baby, and lack of clear clinical leadership, comprehensive plans and multidisciplinary working.

The 2011 Royal College of Obstetricians and Gynaecologists (RCOG) guidelines recommend that women who present with reduced fetal movements on two or more occasions should have an ultrasound assessment of fetal growth, liquor volume and Doppler.

Learning from perinatal viral infections identified the need for better knowledge and screening for Herpes simplex virus (HSV) and cytomegalovirus (CMV). The NICE guidelines NG201 have clear guidance on giving written information to parents during the antenatal period about HSV, CMV and Group B Strep.

Figure 21: Number of completed child death reviews by CDOPs where the child died with an infection, by whether the child was known to social care



NB. In 11 cases data on social care were not known or missing

Social care and domestic or child abuse/neglect factors were recorded as having contributed to the vulnerability, ill-health or death of the child in 8% (n=66/843) of child deaths, including where the child was subject to neglect by an adult (n=24) and where there was other known domestic violence or abuse in the household (n=21). Domestic abuse during pregnancy puts a pregnant woman and her unborn child in danger as it can trigger placental abruption, leading to fetal distress and maternal emergency. In turn, this increases the risk of infection and premature birth.

Factors in the physical environment:

Physical environment factors were recorded as a contributory factor in 7% (n=58/843) of CDOP reviews, including 28 reviews which identified a modifiable factor.

Poor home safety/conditions

Factors most commonly recorded within the physical environment were related to poor home conditions and safety (4%, n=30/843). Factors reported included living environment deprivation (e.g., temporary accommodation or homelessness), unclean or mouldy properties, and poor living conditions e.g., overcrowding; and the impact this has on the capability of families to support children. Research from New Zealand has shown that reducing harmful housing exposures, particularly damp and mould, would reduce the hospitalisation rate of young children for acute respiratory infection by 19%²².

The [Department of Health and Social Care published guidance](#) on understanding and addressing the health risks of damp and mould in social and private rented homes.

Other factors included the suitability of housing placements and the effect of this on antenatal care, especially where there is exposure to smoke within the accommodation. CDOPs also raised concerns about the lack of appropriate housing for families of children with complex health needs, and the difficulties such families face in trying to undertake appropriate alterations to meet the needs of their children.

Outcomes from the reviews also recommended that practitioners working with families who reside in multi-occupancy households should be aware that landlords need to register these with the council, to ensure tenants have minimum standards as outlined in the [government guidance on private renting of houses in multiple occupation](#).

Factors relating to service provision:

Factors recorded here can relate to provision of services by any agency e.g., law enforcement, social care, healthcare (primary, secondary or tertiary care) or education. Of the child death reviews (n=843), 36% (n=307) recorded a contributory factor relating to service provision, including 159 reviews that identified a modifiable factor. The number of deaths with modifiable factors was higher in the service provision domain than any other domain.

22 Ingham et al (2019)

Quality of service delivery

The most common contributory factor recorded was in relation to the initiation of treatment and identification of illness in the child, which was recorded in 19% of reviews (n=156/843). It was recorded as a modifiable factor in 10% (n=85) of reviews. This included instances where there was an issue with the diagnosis, treatment, and the availability of information e.g., test results. There were also factors recorded where there was a lack of clinical recognition of the deteriorating child through triage or monitoring, which resulted in delays to treatment or appropriate referral being made. In 25 reviews, CDOPs recorded factors where there was a failure to appropriately escalate for a timely senior clinical review.

NICE Guidance [NG195] outlines that antibiotics should be offered during labour to women identified as having chorioamnionitis, or if a Group B streptococcal colonisation or infection has been detected during the current or previous pregnancy. These recommendations are also made in the Royal College of Obstetrics and Gynaecology Green-top Guideline No.36 on preventing early onset neonatal GBS disease (these are currently being revised and updated, with expected publication date in 2025). There were 13 neonatal deaths where there was a delay in administration of antibiotics, either to the mother or baby, in such situations. Contributory factors included issues in communication or delays around test results being received by the maternity team, and inappropriate antibiotics being given following poor communication about pathogens with antibiotic resistance.

Learning from CDOPs also highlighted that all observations of children must be documented, with any abnormalities escalated to an appropriate clinician prior to discharge. Emergency departments should ensure appropriate guidelines and parental advice leaflets are available to families of children who are discharged into the community, and that any patient re-presenting to the emergency department should be a red flag to clinical teams.

NICE guideline [NG194] makes recommendations for healthcare professionals on the symptoms and signs of illness in babies. They include listening carefully to parents' concerns about their baby's health as an important indicator of a possible serious illness in their baby. Healthcare professionals are also encouraged to use the Baby Check scoring system, which is also recommended for use by families and carers.

Issues relating to following a guideline, pathway or policy were recorded as a contributory factor in 14% of CDOP reviews (n=119/843), and in 8% (n=66) they were recorded as a modifiable factor. This included poor quality or no clinical assessment or review, unclear care pathways, and where a guideline was available, but not followed. There were also examples where appropriate treatment was not started early enough following inadequate assessment. CDOPs also recorded the importance of ensuring the correct interpretation of physiological observations, with respect to the age of the child.

Issues with staffing levels, skill mix, availability of beds and equipment were recorded as contributory factors in 5% (n=46/843) of CDOP reviews. These issues related to both maternity and paediatric services. In some instances, CDOPs

reported that workforce shortages and high workloads impacted the delivery and continuity of care.

In 2% (n=19) of reviews, CDOPs recorded issues with the NHS 111 service, transfer, or availability of the ambulance service. In some reviews, the emergency service response was complicated by excessive demand due to COVID-19. CDOPs recorded that delays in ambulance availability highlights the lack of ambulance resource nationally, which may lead to families deciding to transport the child to hospital themselves. Ambulance availability was also affected by excessive demand on the service and excessive delays in hospital handovers. Delays due to mis-categorisation or triaging of calls, system design, and ambulance routes were also recorded.

Factors relating to access to appropriate services for families were recorded in 8% (n=70/843) of CDOP reviews. These included issues with transfer, babies not being born in hospitals with appropriate level of care, un-commissioned services, and the impact of COVID-19 restrictions on face-to-face contacts.

Communication issues

Clear and timely communication between all professionals involved with the care of all children is essential. Communication issues within or between agencies were recorded in 11% (n=96/843) of CDOP reviews, including 50 modifiable factors. This highlights the importance of clear and timely documentation for all contacts.

Communication factors were also reported between professionals and families (8%, n=71/843), of which 29 were recorded as modifiable factors. In 15 reviews, the CDOPs recorded parental concerns about their baby's or child's health not being listened to and acted on by healthcare professionals as a contributory factor. CDOPs also highlighted the need for good signposting for parents and carers about when to seek medical attention, for women in pregnancy and children who are ill, to be available in multiple languages. The importance of clear and adequate written safety netting advice given to families on discharge was also recorded. Families should be provided with a written escalation care plan for what to do when a child with a life-limiting condition is unwell. These may also be logged with the local ambulance service so that if the family call an ambulance when the child becomes unwell, they are aware of the details of the escalation plan and what treatments they should or should not provide.

Timely recognition of sepsis, red flags, and administration of antibiotics

Sepsis is a life-threatening reaction to an infection, which happens when the immune system overreacts and starts to damage tissues and organs. It can be especially challenging to recognise in babies and young children (Symptoms of sepsis - NHS). NICE guidance NG51 recommends that clinicians think 'Could this be sepsis?' if a child presents with fever and symptoms or signs that indicate possible sepsis. Diagnosing sepsis in a neonate can be very challenging and neonatal sepsis can present with subtle signs, but can rapidly progress to multi-system organ failure.

The child death review process [supplementary reporting form for infection](#) asks questions about the recognition of suspected sepsis. Where it was applicable and answered, 18% (n=35/190) recorded that recognition of suspected sepsis was not timely, and for presentation in hospital, 12% (n=16/131) of reviews recorded a failure to deliver broad spectrum antibiotics within one hour, as documented within [NICE Guidelines for Sepsis \(NG51\)](#).

Where it was known, in 85% (n=112/131) of deaths where the child presented to hospital, there were one or more red flag symptoms for sepsis, and these were recognised in 77% (n=101/131) of deaths. However, in 8% (n=11/131) one or more red flag symptoms were present but not recognised, and in 15% (n=19/131) of the deaths where the child presented to hospital, there were no red flag symptoms.

CDOPs have recorded learning related to the early recognition of sepsis, including the need for undertaking a complete set of observations and utilising sepsis screening tools for all children presenting unwell with abnormal observations in accordance with [current NICE Guidelines for Sepsis \(NG51\)](#). CDOPs also reported the importance of earlier recognition and treatment of bacterial infections, recognition of abnormal vital signs as a marker of sepsis, timely assessment of children who trigger as needing earlier assessment using triage tools, and ensuring professionals take on board parental concerns. It is important that there is a consistent and robust approach in following sepsis protocols, including use of specific documentation, correct sample handling, and timely and appropriate treatment.

Deaths abroad

[Working Together to Safeguard Children \(2018\)](#) requires child death review partners to review the deaths of all children normally resident in their area. This includes children who die whilst they are abroad, for example, on holiday or visiting family. [The Child Death Review Statutory and Operational Guidance](#) provides advice on how to conduct a child death review investigation for a child who dies abroad, and this includes working with the Foreign Commonwealth and Development Office where necessary.

There were 17 child deaths abroad where infection was the primary category of death. Sepsis, pneumonia, COVID-19 and influenza were the most common pathogens or conditions identified, but data is limited on their role in these cases.

Infants and children may be more likely to be exposed to food and water borne illness during travel, due to their natural exploratory nature and hand to mouth habits. This is why the risk of infection may be higher in these groups. Learning from the CDOPs identified the need for appropriate travel advice and support for families of children with life-limiting conditions and complex needs when they travel abroad. For school trips abroad, schools should know how to access healthcare when abroad and undertake appropriate risk assessments, as well as raise awareness and provide training for teachers in recognising sepsis.





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

Data linkage between NCMD and SGSS data

Preliminary work was undertaken to explore linkage between the NCMD dataset and laboratory reports held within the UK Health Security Agency's (UKHSA) Second Generation Surveillance System (SGSS). Introduced in 2014, SGSS is UKHSA's primary method for collecting data on positive cases of infections of clinical significance and antimicrobial resistance from [laboratories across England](#).

Since October 2010, the 'Health Protection (Notification) Regulations (2010)' have [required diagnostic laboratories to notify UKHSA of the identification of specified causative agents in a human sample](#). In addition to this compulsory reporting, laboratories can voluntarily report a broader range of pathogens.

Data linkage was undertaken using NHS numbers to link NCMD records in the reporting period with SGSS records. Overall, 67% (n=1009/1507) of the infection related deaths identified in NCMD linked to a positive test within 28 days of death (or at post-mortem) within SGSS. Similar proportions could be seen for deaths where infection provided a complete and sufficient explanation of death (67%, n=371/553), and for deaths where infection may have contributed (67%, n=638/954).

There are several potential reasons why NCMD records might not have linked with SGSS records. One reason is that linkage depended on the availability of NHS numbers, which were only present in 96% of records. Next, for pathogens that are reported on a voluntary basis, there is varied reporting practice, so laboratory reports may not be captured in SGSS. Finally, there may be cases where no pathogen was identified, so there was no positive result.

Work is needed to develop our understanding of the relationship between NCMD and SGSS databases and to develop processes for routine linkage, to support collaboration in infectious disease surveillance and incident response.

Future research

Future research should utilise linked NCMD and UKHSA pathogen datasets to study the complex interaction of deprivation, ethnic disparities and underlying health conditions, and to inform maternal vaccine implementation work and future perinatal vaccine research.

Further investigation is required into the mechanisms underlying the much higher infection mortality rates in infancy, and improvements in diagnosing specific causes.

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NCMD

National Child Mortality Database

Knowledge, understanding and
learning to improve young lives

National Child Mortality Database (NCMD)

Level D, St Michael's Hospital
Southwell Street
Bristol, BS2 8EG

Email: ncmd-programme@bristol.ac.uk
Website: www.ncmd.info
Twitter: [@NCMD_England](https://twitter.com/NCMD_England)