Infection related deaths of children and young people in England

Presented by Dr David Odd

NCMD
National Child Mortality Database

Knowledge, understanding and learning to improve young lives

The National Child Mortality Database

The NCMD Programme was established to collate and analyse data on all children in England who die before their 18th birthday.

Aims

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

Introduction

- Infections are caused by microorganisms such as bacteria, viruses, parasites and fungi.
- Infections are common and for most people the risk of severe illness is low.
  - Some at higher risk of infection
  - Some at higher risk of severe illness.

- 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 quantified.

How to read the report

- 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.

- Divided into 3 sections:
  1. Context: the number of suspected infection related deaths at notification (April 2019-March 2023) (4 years).
  2. Characteristics: Details of infection related deaths between April 2019-March 2022 (3 years).
  3. Learning: The contributory factors and learning from the child death reviews that were categorised as infection by CDOPs (3 years)

General Methodology

- Population
  - All child (before 18th birthday) deaths where the CDOP in England were planning to, or had already, reviewed the death
  - This includes a small number of deaths that occurred abroad, and of children not usually resident in England
  - The dataset used within this report was extracted on 3rd May 2023
  - Pathogens/clinical conditions were coded with information available in the system.
  - ONS census data (2021) were used as denominators to calculate risk of death, including ethnicity and other population sub-groups

General Methodology

- Risks of death were calculated per 100,000 children, per year
- Data was assumed to follow a Poisson distribution.
- Data reported from CDOPs within the statutory child death data collection forms was used for this analysis.
- The child's postcode of residence was linked to the Index of Multiple Deprivation and other geographic measures
- Underlying health conditions were identified using a combination of data recorded in NCMD and through linked Hospital Episode Statistics (HES) data.

Other limitations

- The time period includes the COVID-19 pandemic and lockdown periods
  - It was not a typical period for many infections

- Deaths were included if
  - Infection considered a cause or contributor at notification

  OR
  - After full review, the CDOP categorised the death as infection or perinatal infection

- Some deaths without a completed review (18%), where there was no evidence of infection at notification, may turn out to be caused by an infection.

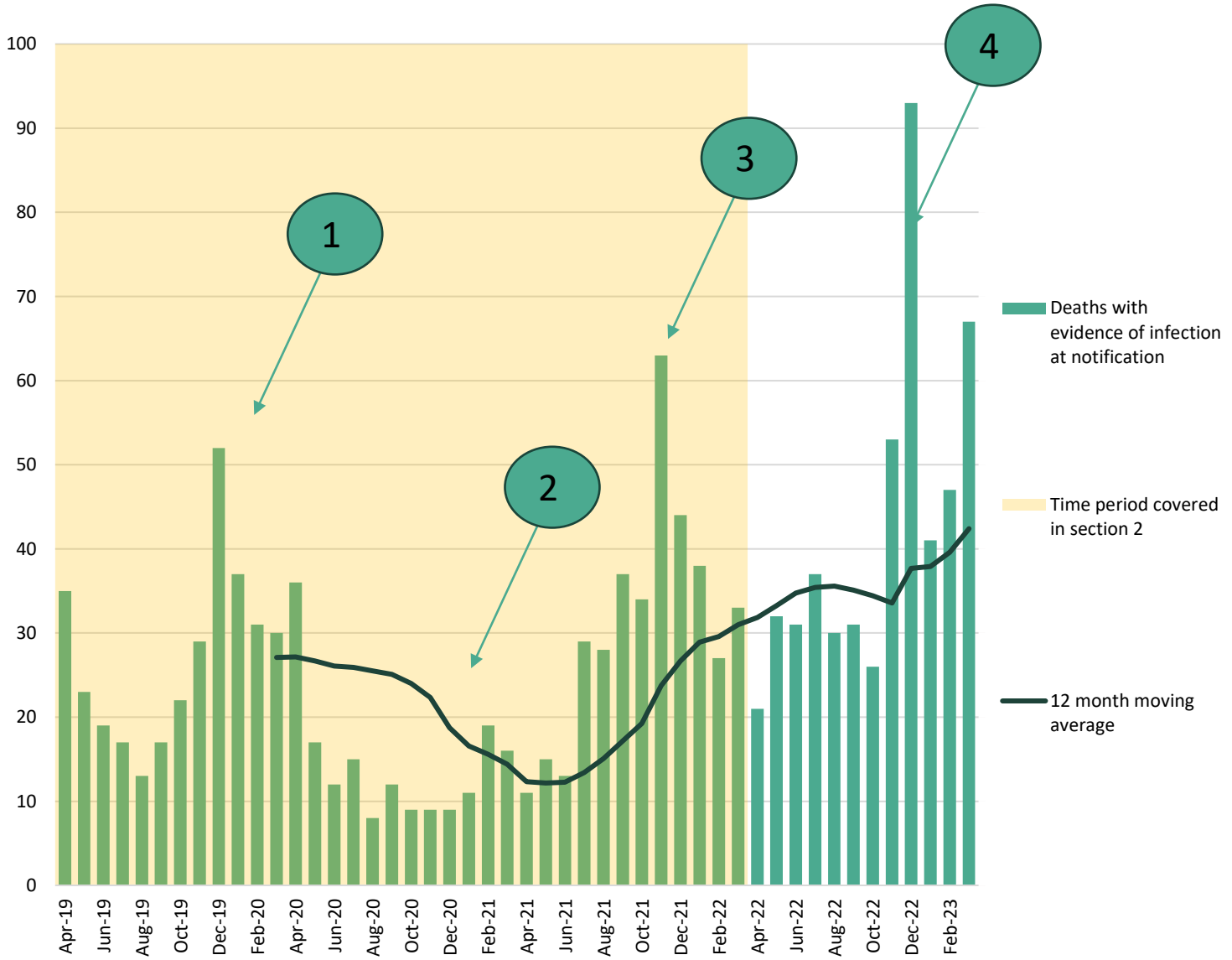
Section 1: Variations in incidence of child deaths with infection

- Deaths between April 2019 and March 2023 were included where 'infection' was coded at notification by two or more of the NCMD clinical team.
- Some deaths, not immediately related to infection at notification, will not be included.
- Data reported here are likely to be an underestimate (and different to Sections 2 & 3)
- Consistent throughout the period, and previous work
- Designed to show changes over time.

Section 1: Variations in incidence of child deaths with infection

- The seasonal variation in infectious deaths in children is well recognised
- … Actual rates and impacts throughout the year are often poorly quantified.

1. The NCMD data shows a clear peak in the winter months of 2019/20.
2. BUT no rise in deaths is seen over the winter of 2020/21
3. 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
4. A further rise in number of deaths across the most recent winter of 2022/23.



Infection related deaths of children and young people in England. NCMD Programme [2023]

Section 2: Infection related deaths

- Deaths between April 2019 and March 2022 where:
  - Where the death was coded as 'infection' at notification by two or more of the NCMD clinical team
  - 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 related deaths of children and young people in England. NCMD Programme [2023]

Section 2: Infection related deaths

All Infection Related Deaths

- Death was coded as 'infection' at notification

OR

- CDOP allocated as ‘infection’ or ‘perinatal infection’.

Infection provided a **complete and sufficient explanation** of death.

At CDOP review the death was primary classified as **Infection** or **Perinatal Infection**

OR

If not reviewed, most likely hierarchical code

1. Suicide
2. Substance Abuse
3. Trauma
4. Malignancy
5. Underlying Medical Condition
6. Intrapartum event
7. Preterm Birth
8. Infection
9. SUDIC

Infection **contributed** to the death

At CDOP review the death was not primary classified as infection or perinatal infection

OR

If not reviewed, coded as ‘infection’ but ‘not the highest code’

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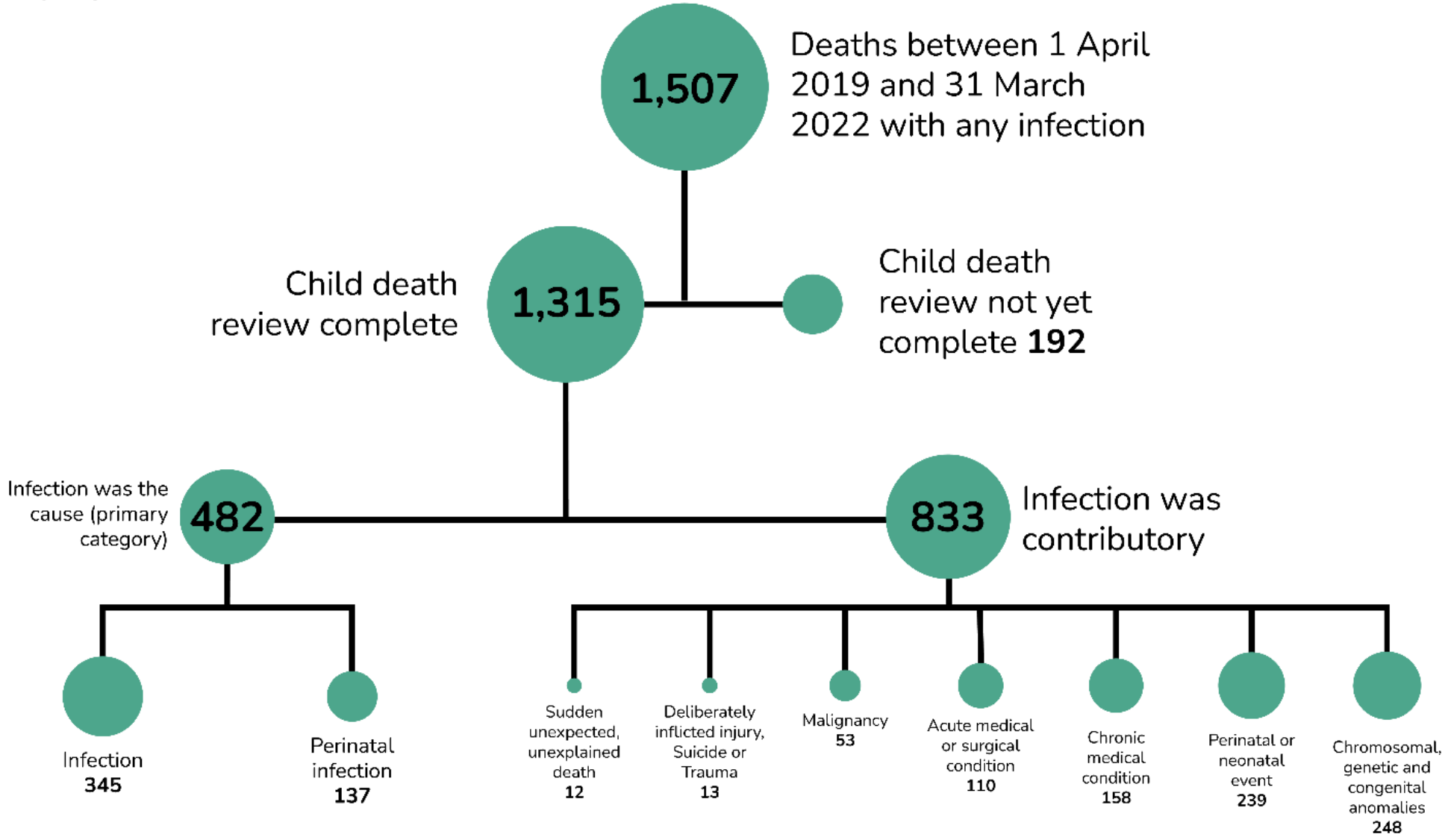
NCMD National Child Mortality Database

The Population



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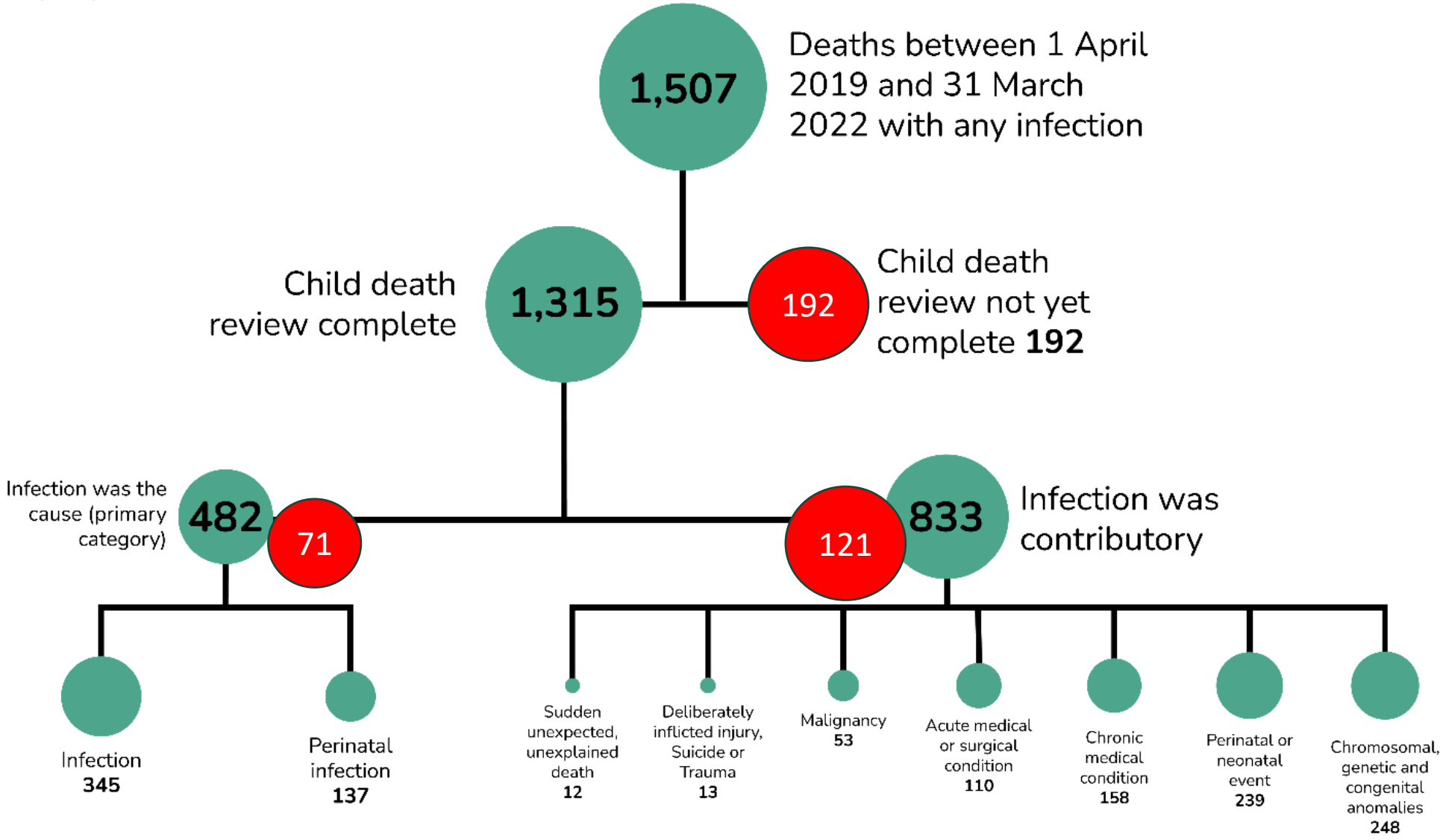
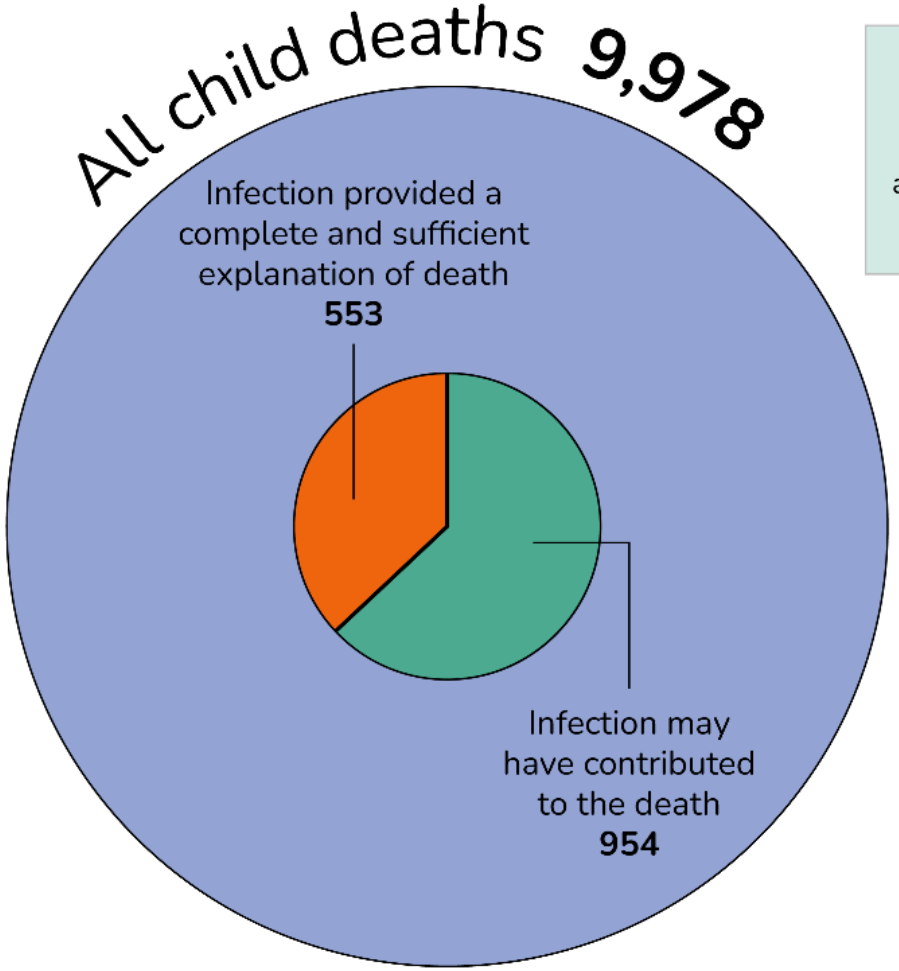
The Population



Infection related deaths of children and young people in England. NCMD Programme [2023]

Section 2: Infection related deaths

- 1,507 deaths where infection either caused or contributed to the death of the child.
    - 553 (37%) deaths: infection provided a complete and sufficient explanation of death.
    - 954 (63%) deaths: infection may have contributed to the death

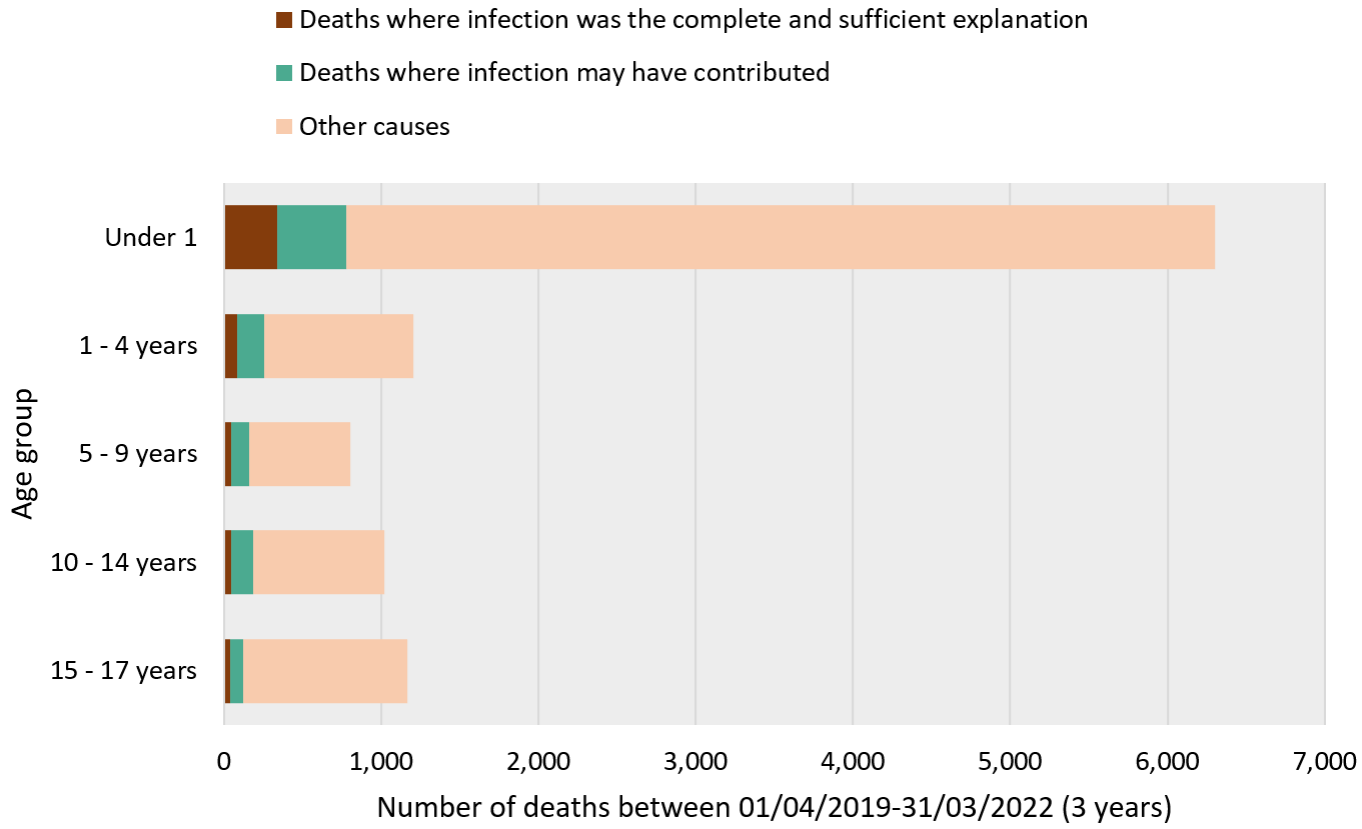


Deaths over 3 years where infection contributed to or caused the death, were approximately 0.01% of the total child population

Infection related deaths of children and young people in England. NCMD Programme [2023]

Section 2: Infection related deaths

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

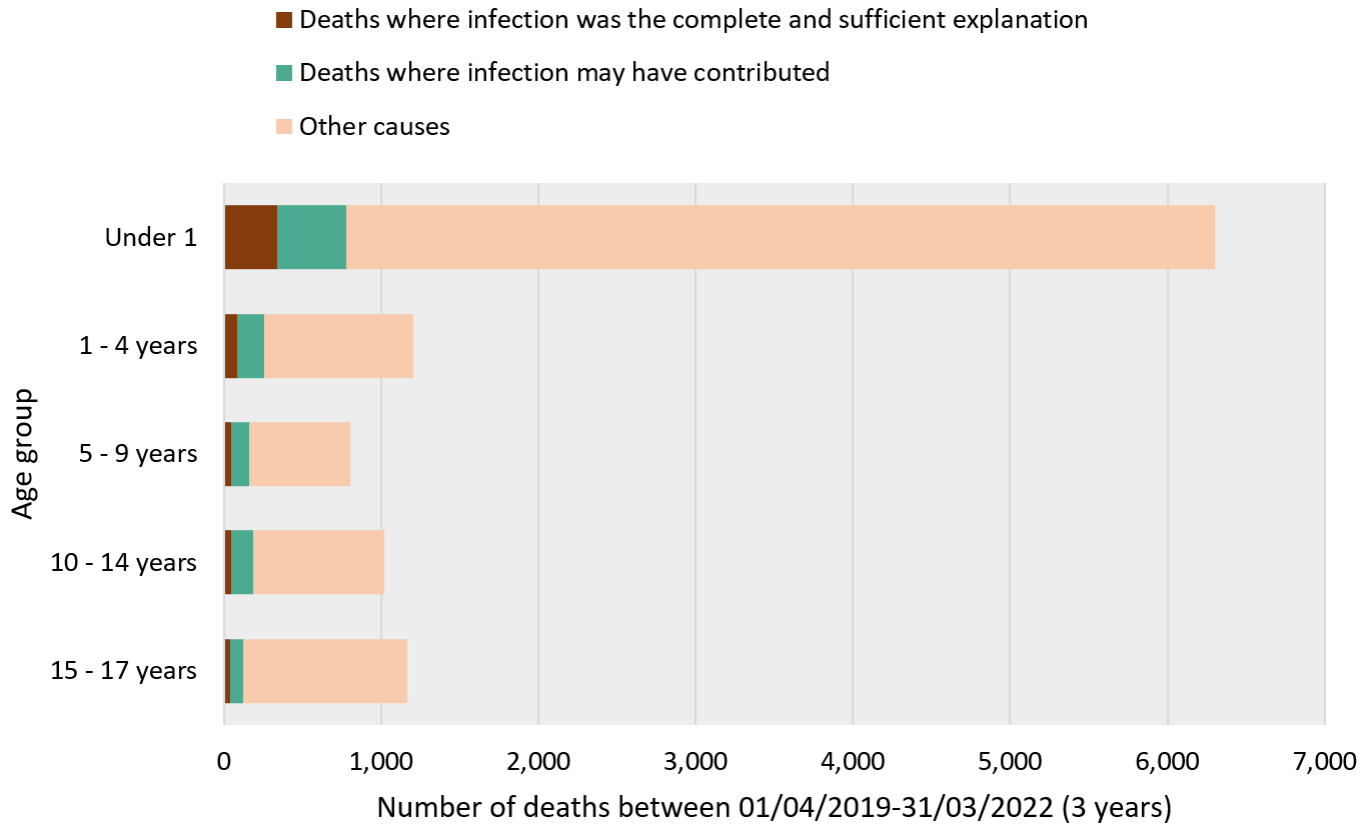


Infection related deaths of children and young people in England. NCMD Programme [2023]

Section 2: Infection related deaths

- In 15% of all child deaths between April 2019 and March 2022 (3 years) the death was infection related.

- The proportion of infection related deaths by age was:
  - Infants - 12%
  - 1-4 years - 25%
  - 5-9 years - 24%
  - 10-14 year olds - 21%
  - 15-17 year olds - 12%

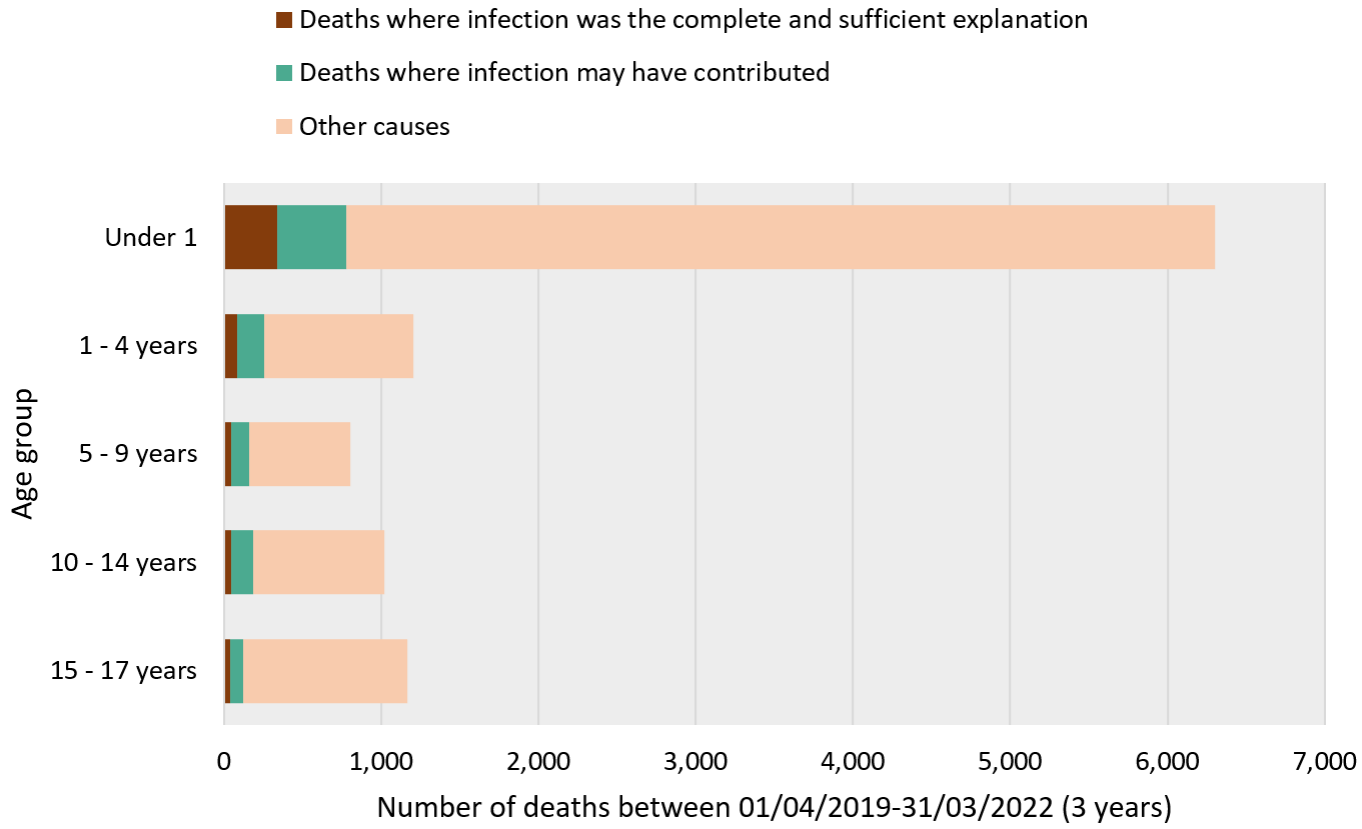


Infection related deaths of children and young people in England. NCMD Programme [2023]

Section 2: Infection related deaths

- In 6% (n=553) of all child deaths, infection provided a **complete and sufficient explanation** of death.

- The proportion of infection related deaths by age was:
  - Infants - 5%
  - 1-4 years – 8%
  - 5-9 years - 6%
  - 10-14 year olds - 5%
  - 15-17 year olds - 4%



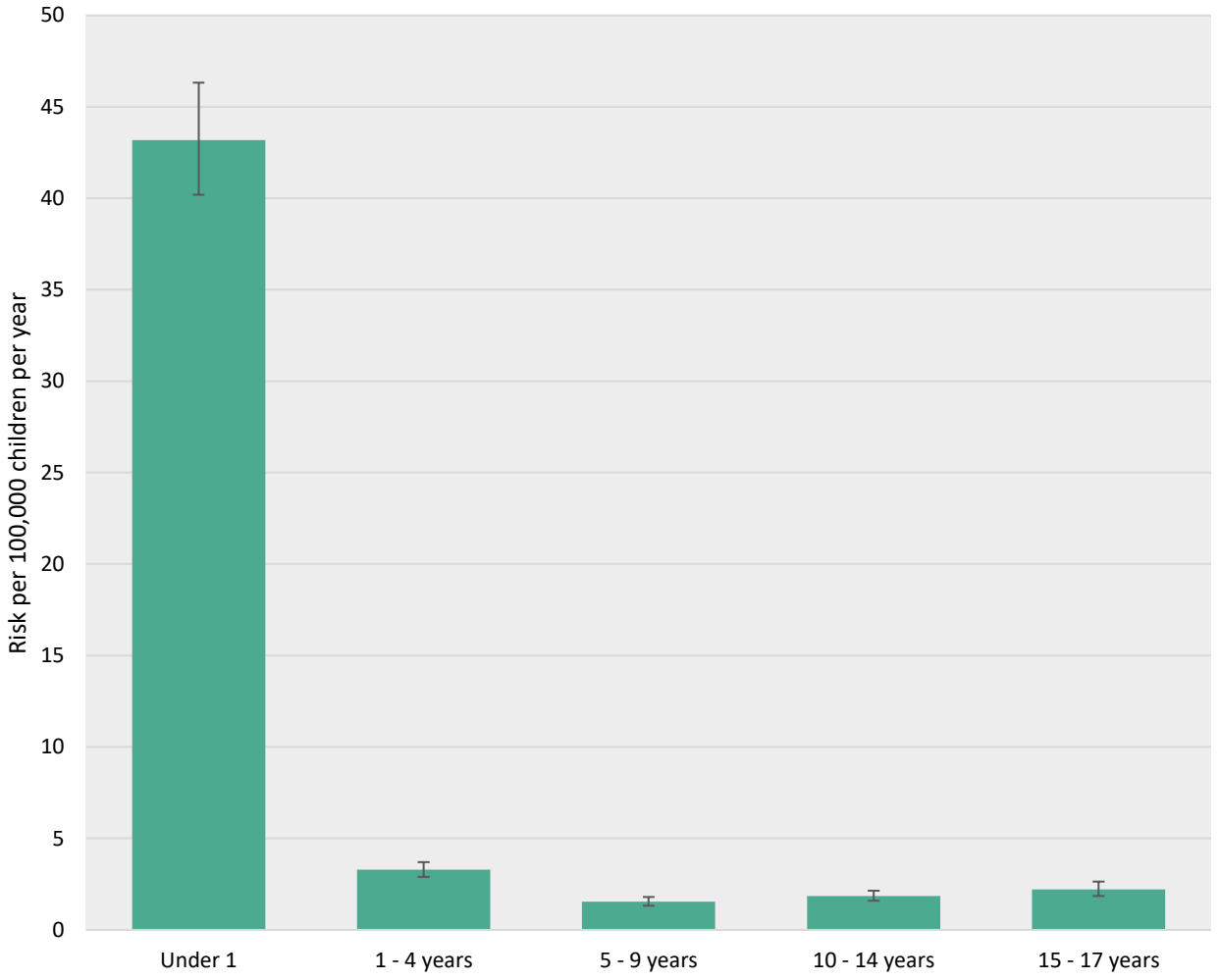
Infection related deaths of children and young people in England. NCMD Programme [2023]

Age

For all infection related deaths;

The largest number of deaths and the highest risk occurred in infants

Risk: 43.18 deaths per 100,000 infants per year



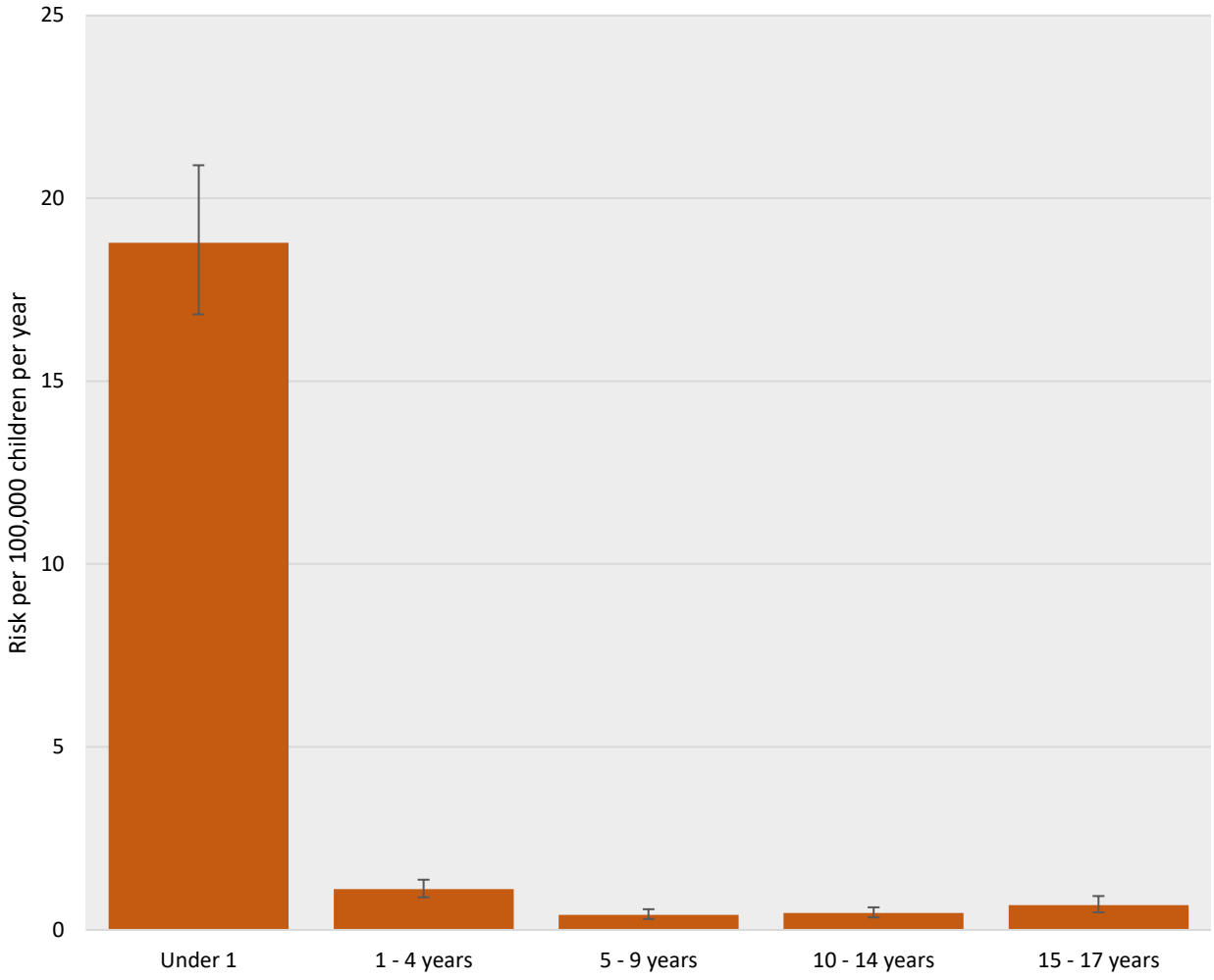
Infection related deaths of children and young people in England. NCMD Programme [2023]

Age

For deaths where infection was the **complete and sufficient explanation** of the death;

The largest number of deaths and the highest risk occurred in infants:

Risk: 18.78 deaths per 100,000 infants per year



Infection related deaths of children and young people in England. NCMD Programme [2023]

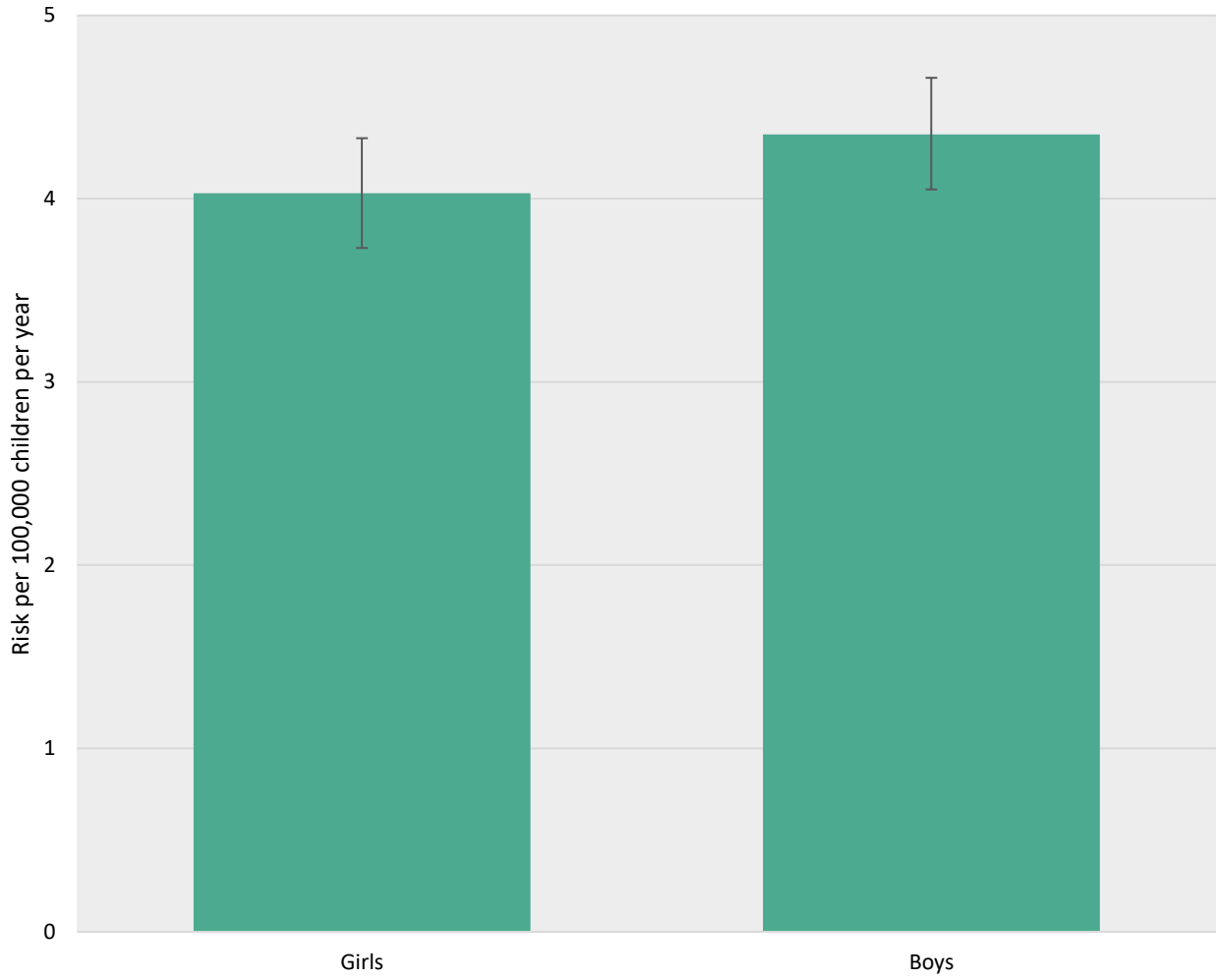
Sex

For all infection related deaths;

Boys: 4.35 per 100,000 children

Girls: 4.03 per 100,000 children

-> Similar risk of death.



Infection related deaths of children and young people in England. NCMD Programme [2023]

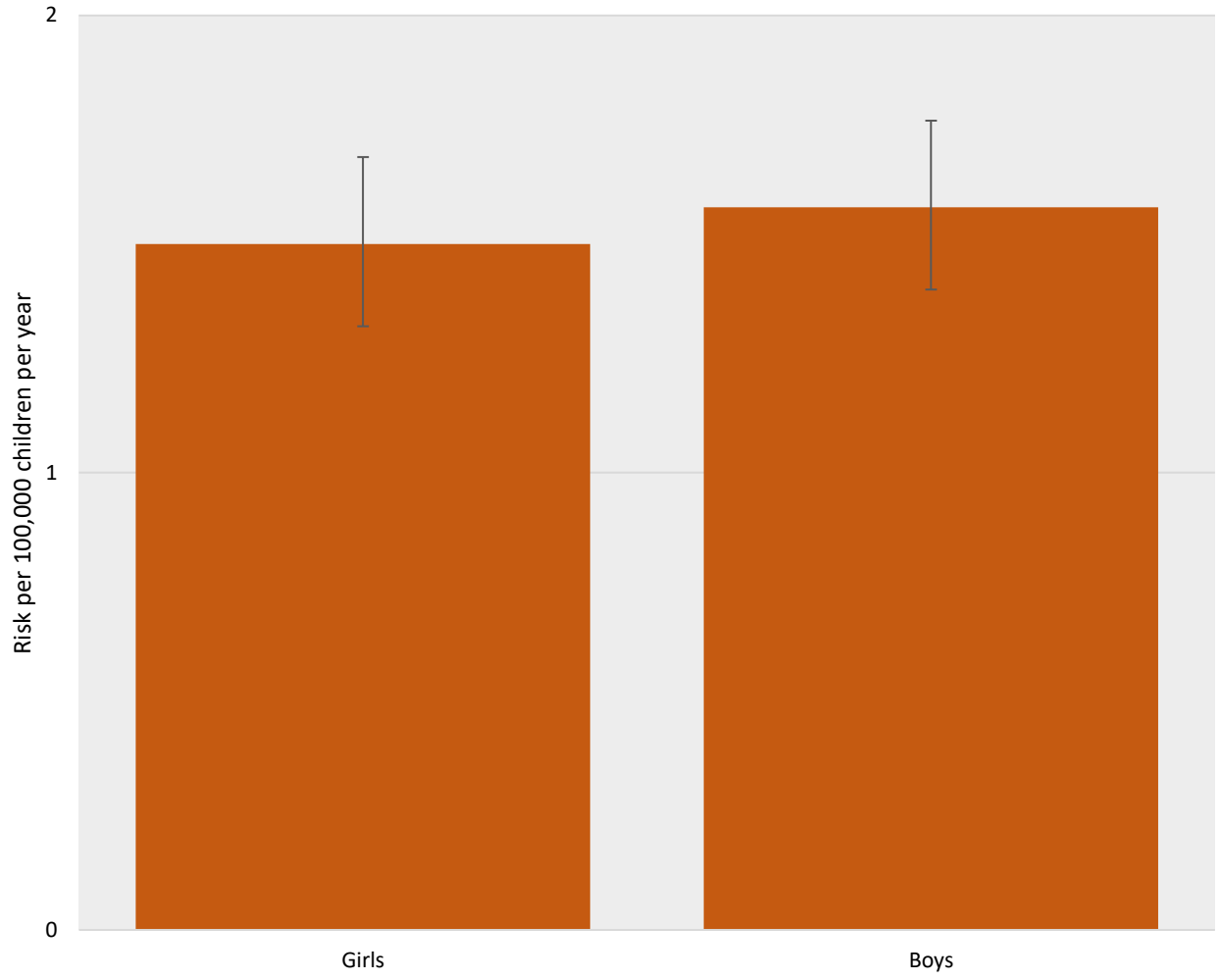
Sex

For deaths where infection was the **complete and sufficient explanation** of the death;

Boys: 1.58 per 100,000 children

Girls: 1.50 per 100,000 children

-> Similar risk of death.



Infection related deaths of children and young people in England. NCMD Programme [2023]

Ethnicity

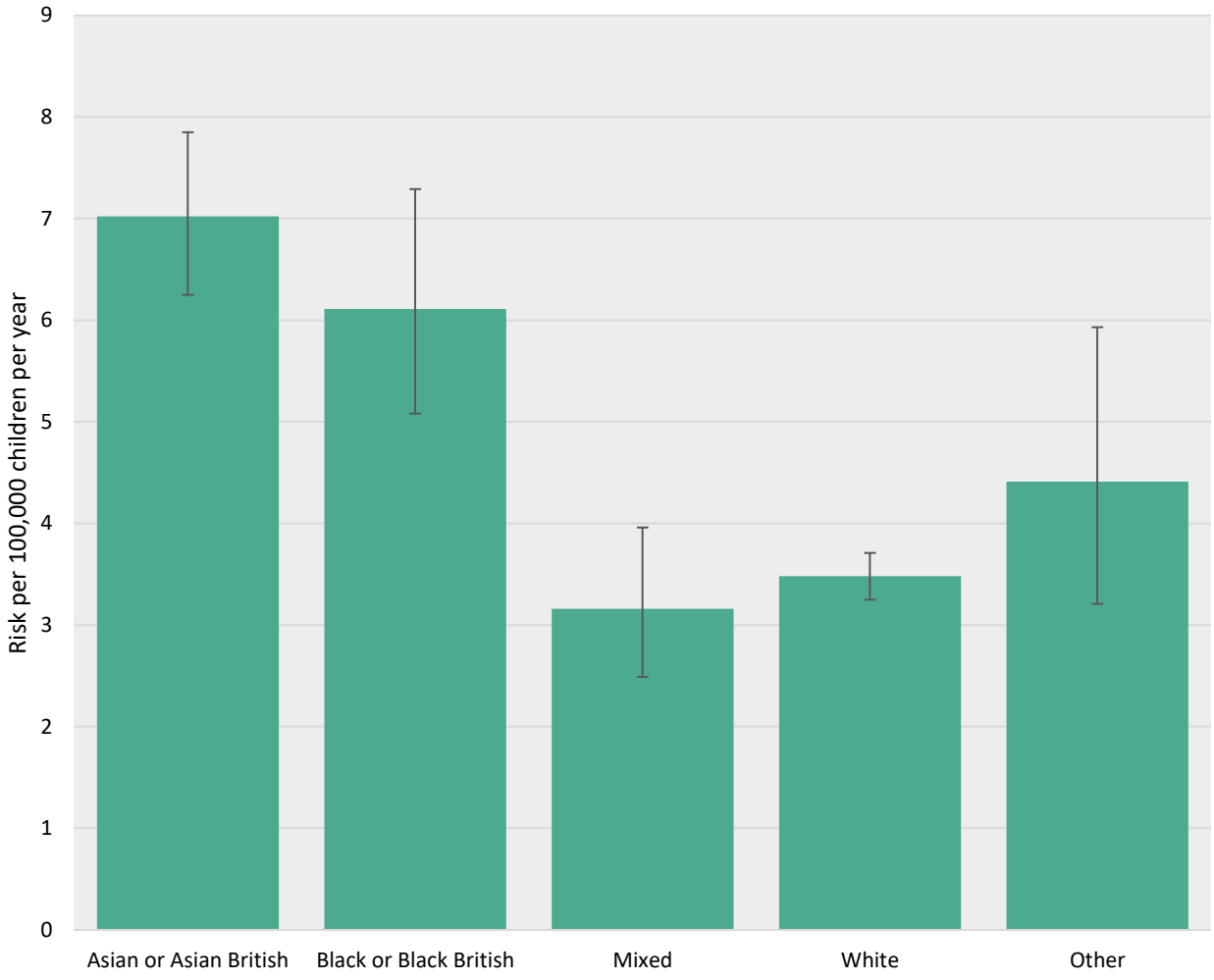
For all infection related deaths;

The risk of death did appear to vary by the ethnicity of the child.

- Asian or Asian British (7.02 per 100,000 children)
- Black or Black British (6.11 per 100,000 children)
- Mixed (3.16 per 100,000 children)
- White (3.48 per 100,000 children)

Within these groups, children with the highest risk of death were those who were described as being from:

- Pakistani (9.33 per 100,000 children)
- African (6.88 per 100,000 children)



Infection related deaths of children and young people in England. NCMD Programme [2023]

Ethnicity

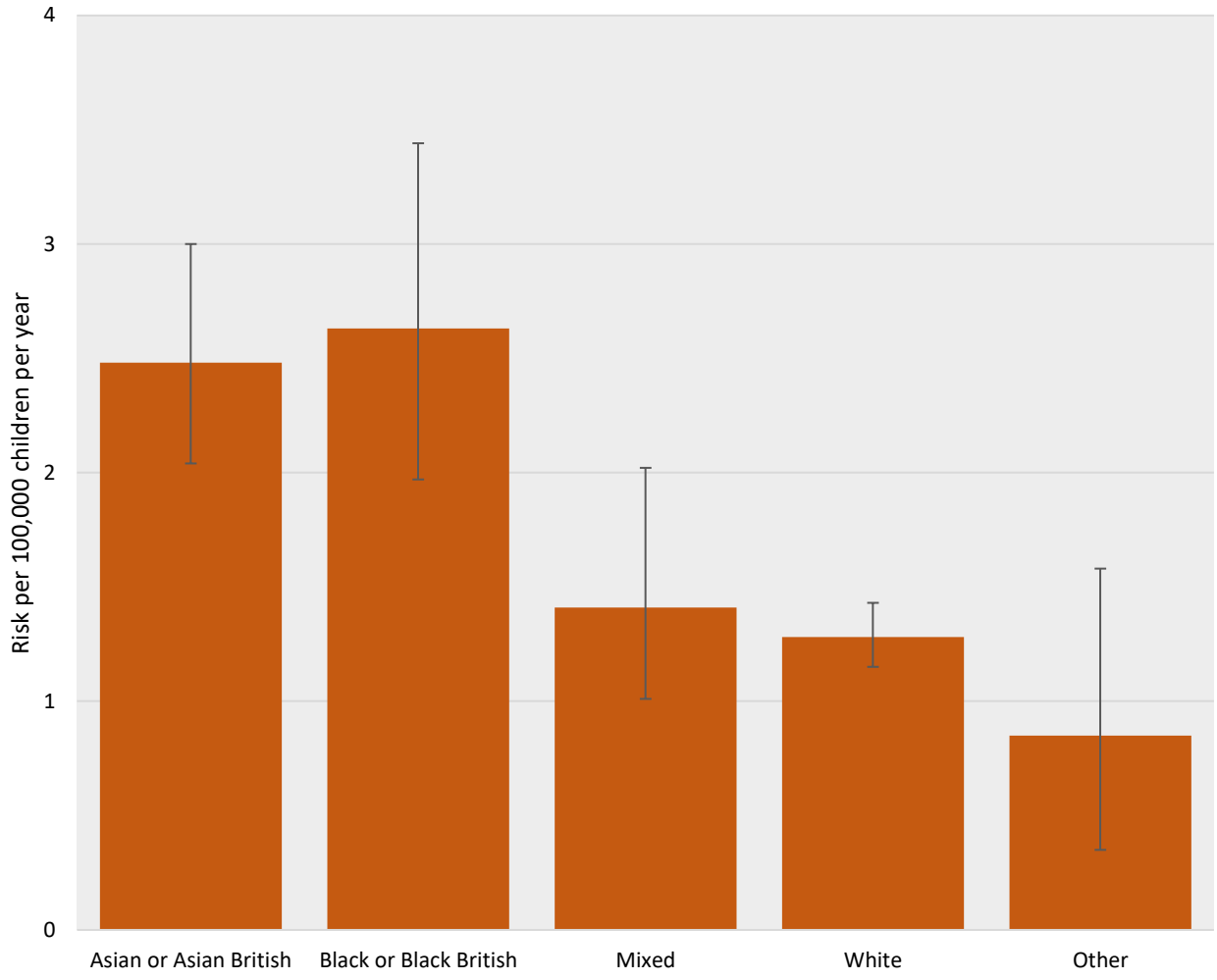
For deaths where infection was the **complete and sufficient explanation** of the death;

The risk of death did appear to vary by the ethnicity of the child.

- Asian or Asian British (2.48 per 100,000 children)
- Black or Black British (2.63 per 100,000 children)
- Mixed (1.41 per 100,000 children)
- White (1.28 per 100,000 children)

Within these groups, children with the highest risk of death were those who were described as being from:

- African (2.90 per 100,000 children)
- Pakistani (2.52 per 100,000 children)



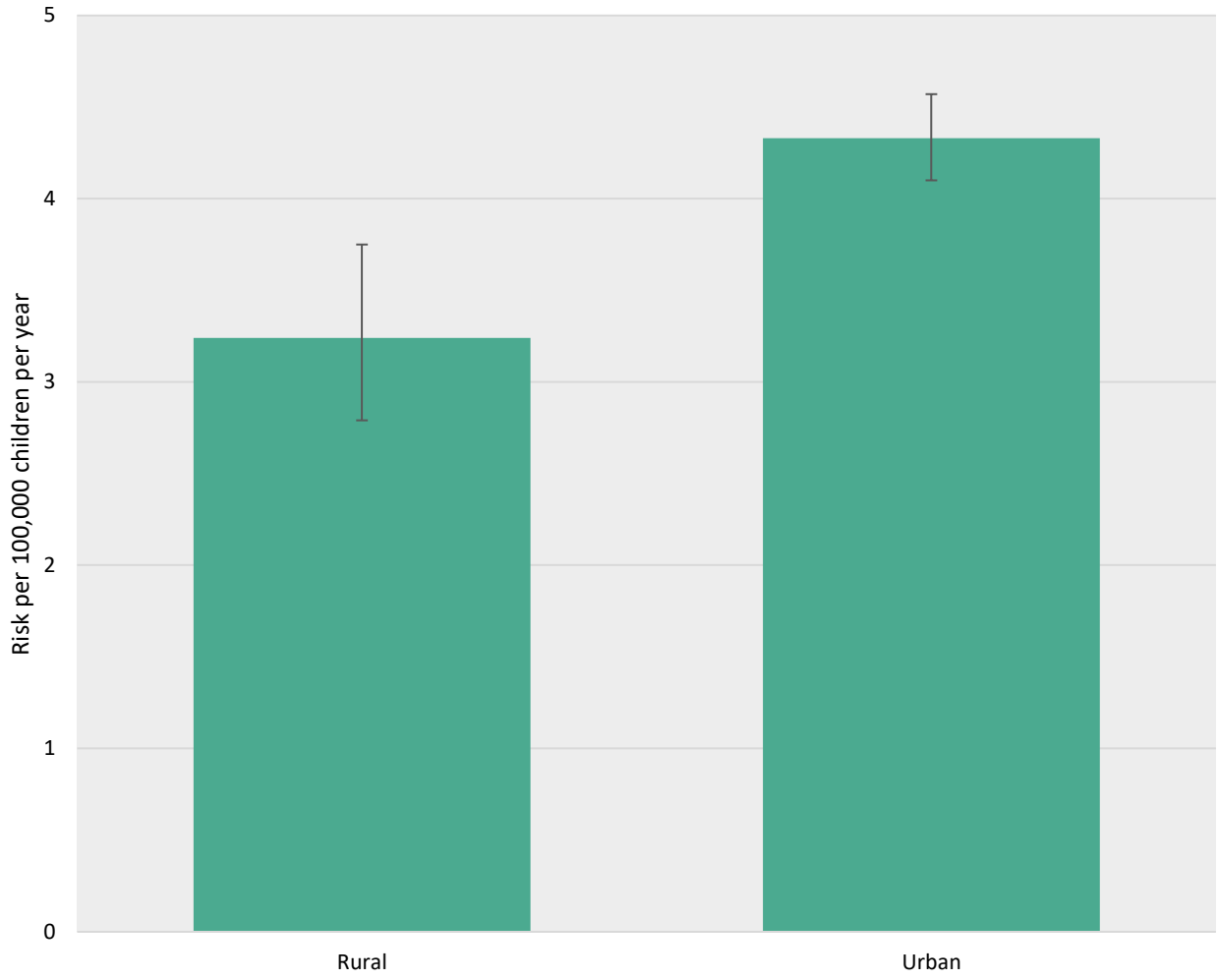
Infection related deaths of children and young people in England. NCMD Programme [2023]

Area

For all infection related deaths;

The risk of infection related death varied according to whether the child lived in a rural or urban area.

- Urban areas (4.33 per 100,000 children)
- Rural areas (3.24 per 100,000 children)



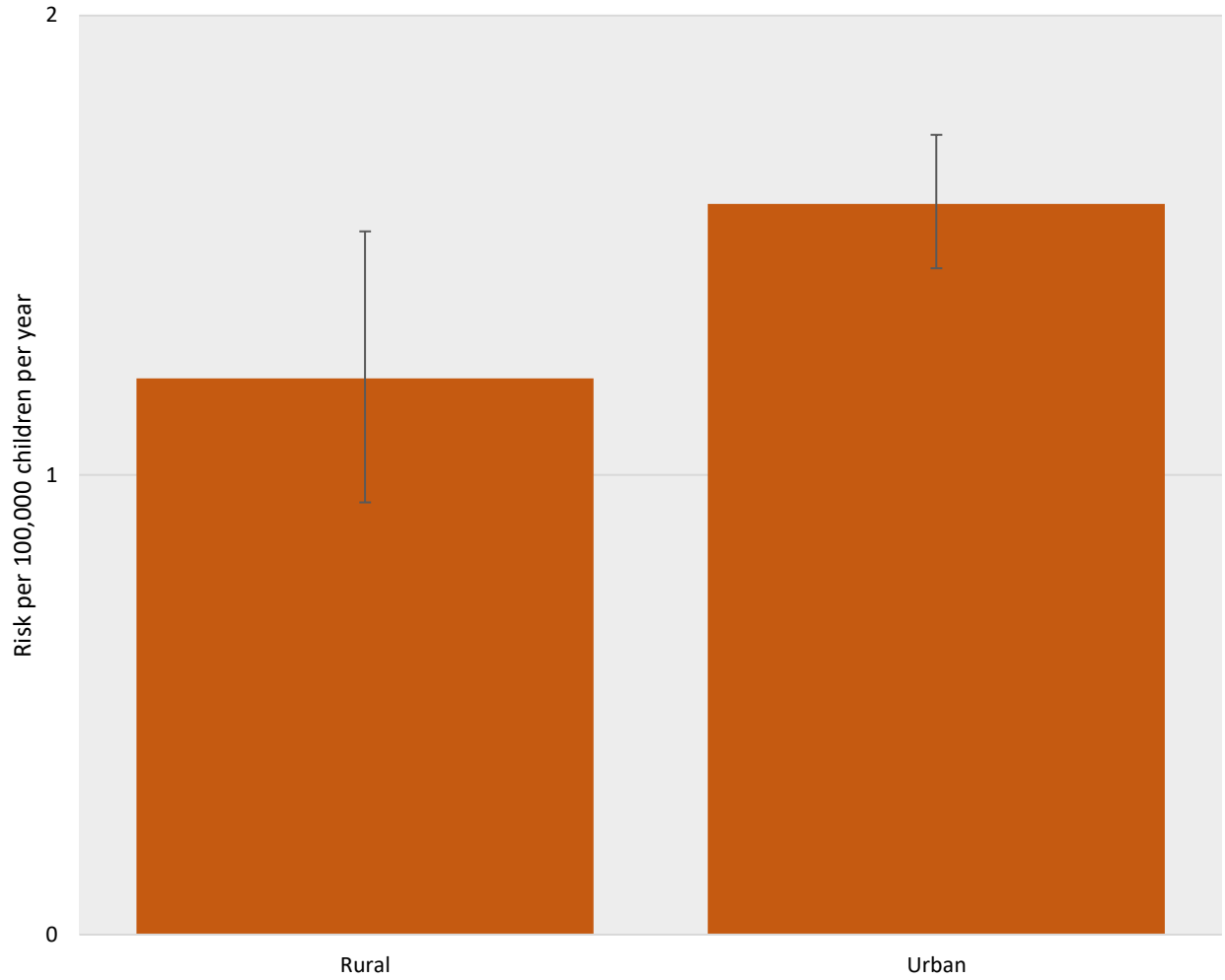
Infection related deaths of children and young people in England. NCMD Programme [2023]

Area

For deaths where infection was the **complete and sufficient explanation** of the death;

The risk varied according to whether the child lived in a rural or urban area.

- Urban areas (1.59 per 100,000 children)
- Rural areas (1.21 per 100,000 children)

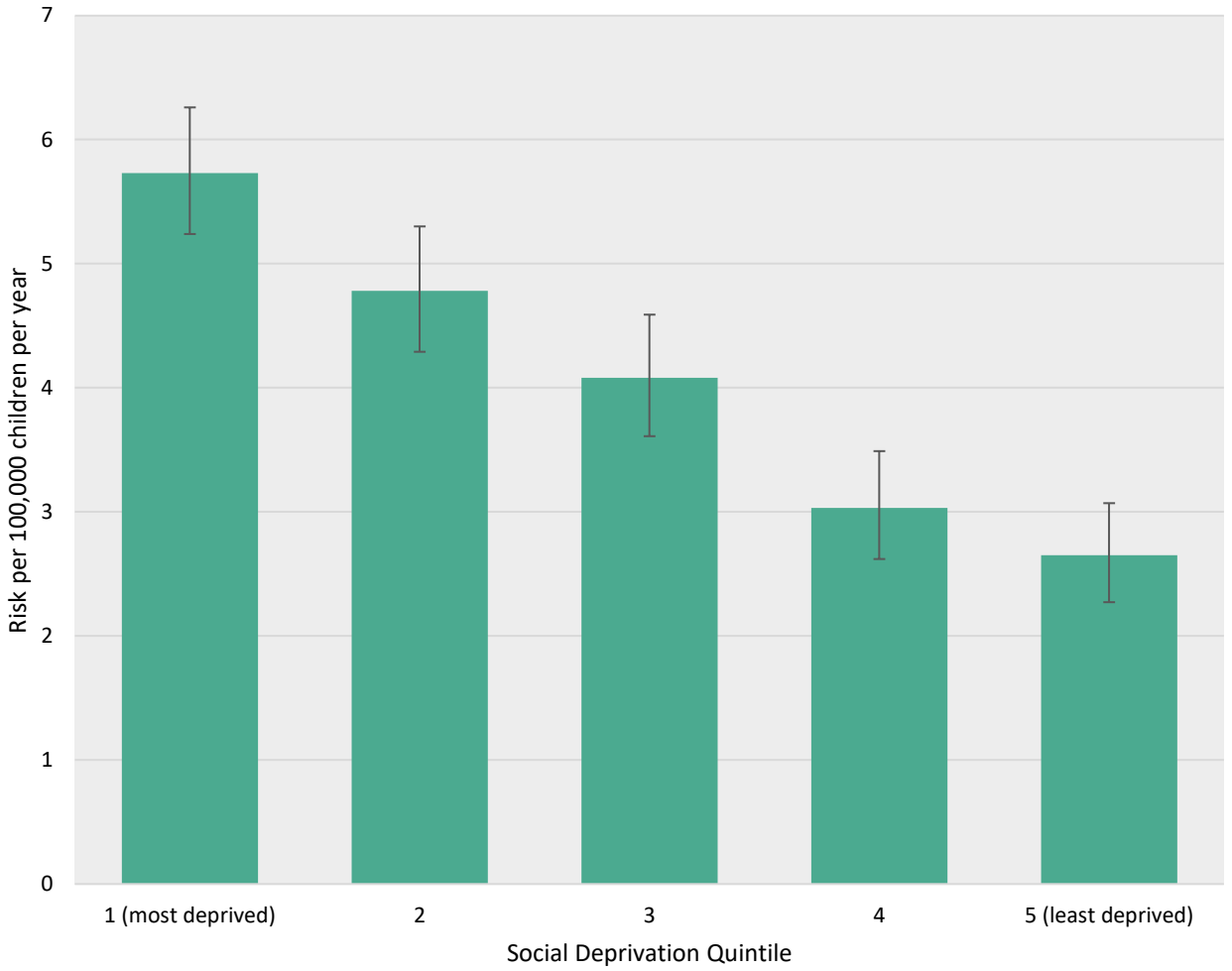


Infection related deaths of children and young people in England. NCMD Programme [2023]

Deprivation

For all infection related deaths;

The risk of infection related death and the number, and risk of death, increased with worsening measures of deprivation.



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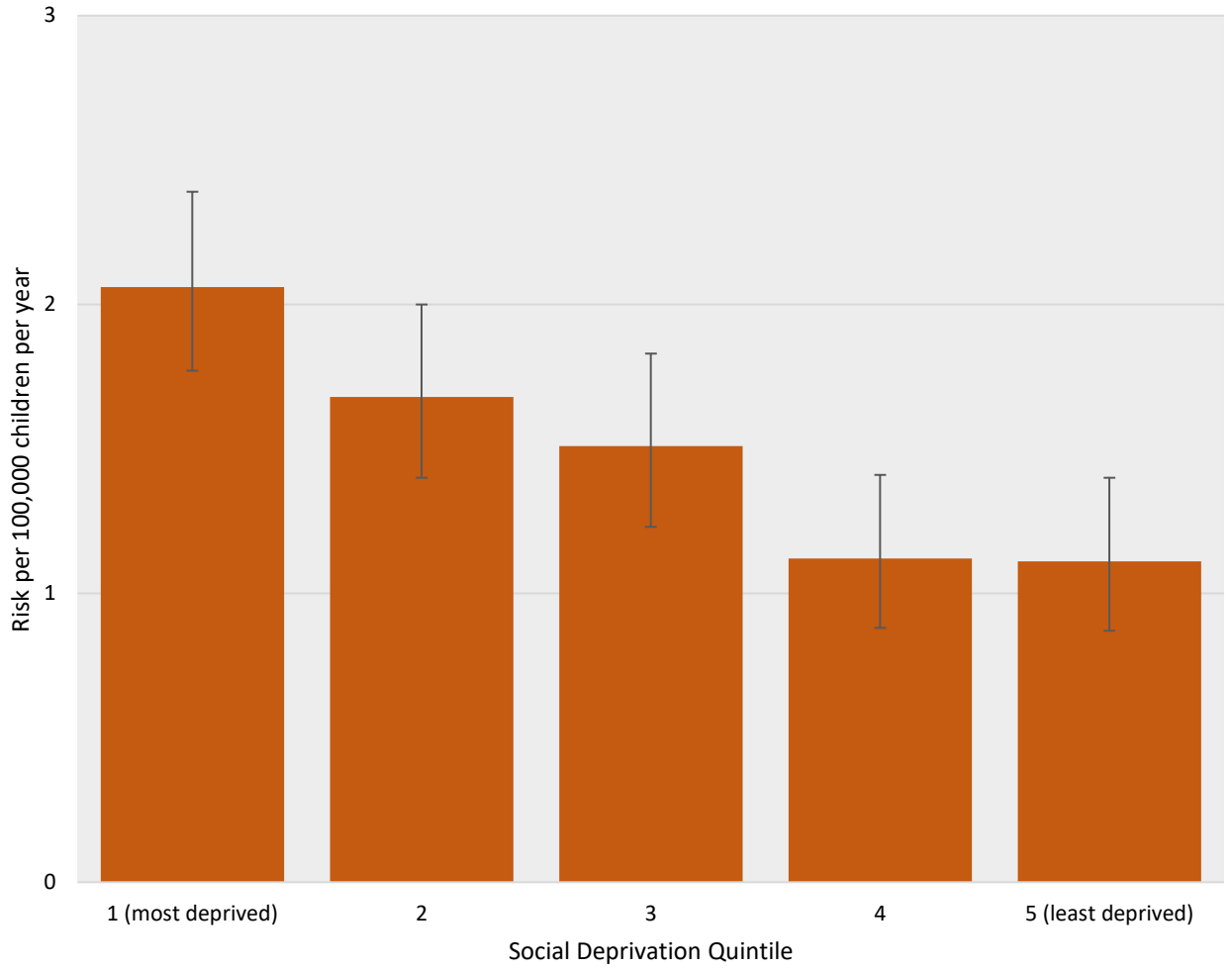


Infection related deaths of children and young people in England. NCMD Programme [2023]

Details of the infections and their clinical presentations

- Summarises the organisms involved, and the manner in which the child presented to healthcare.
  - This work does not differentiate between community and hospital acquired infections.
- Pathogens and clinical conditions were identified using a combination of free text searching of information recorded within NCMD, followed by confirmation by the NCMD team.
  - Notification details
  - Infection supplementary reporting form
  - Contributory factors recorded by the CDOP
  - Cause of death (medical certificate and CDOP cause of death)

Infection related deaths of children and young people in England. NCMD Programme [2023]

Details of the infections and their clinical presentations

- The list was not exhaustive: aimed to capture the majority of the main pathogens and conditions, therefore some pathogens may not be reported.

- Iterative process: a set of all records where a pathogen/condition was found was validated by the NCMD team, to confirm that the detected free text refers to evidence of the expected pathogen/condition; any incorrect matches picked up in error were removed.

Infectious pathogens

At least one infectious pathogen was identified in 56% (n=841) of infection related deaths using information recorded in NCMD

In 21% (n=320), more than one pathogen was identified.

However, even where infection appeared to provide a **complete and sufficient explanation** of death, in 35% (n=196) deaths, no organism was clearly identified.

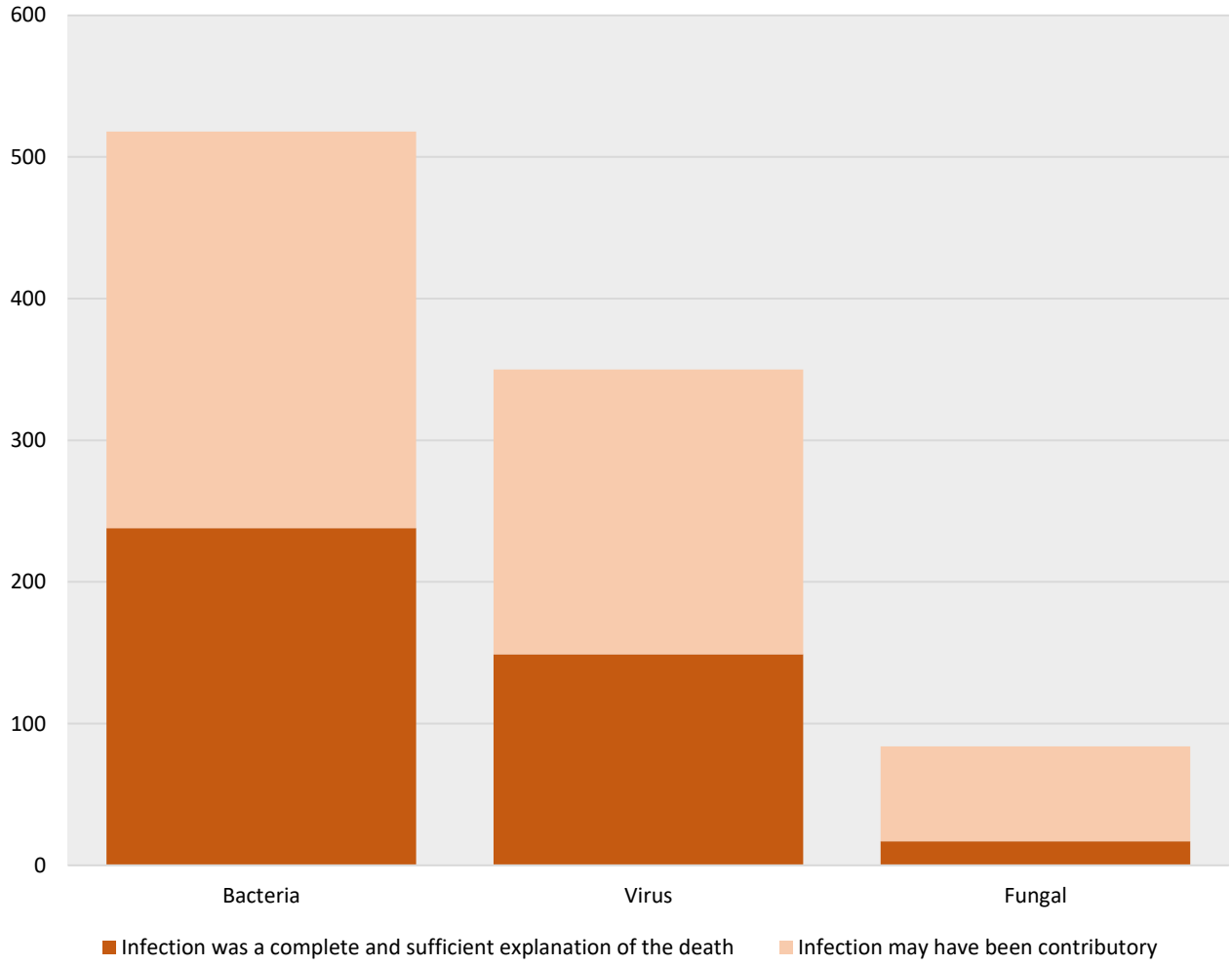
All Infection Related Deaths	1507
Any pathogen identified	841 (56%)
1 pathogen identified	521
2 pathogens identified	255
3+ pathogens identified	65

Infectious pathogens

Bacterial infection was reported in 34% of deaths and in 43% of the deaths where infection provided a complete and sufficient explanation.

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

6% (n=84) cases of fungal infection were identified, 3% (n=17) where infection provided a complete and sufficient explanation.



Infection related deaths of children and young people in England. NCMD Programme [2023]

Bacteria

Gram negative bacteria were recorded in 21% of infection related deaths,

- 72% of these identified in children under the age of 1 year.

	Complete and sufficient	Contributed	Total
Total deaths	**553**	**954**	**1507**
Bacteria (all)	**238 (43%)**	**280 (29%)**	**518 (34%)**
Streptococcus (all)	**101 (18%)**	**45 (5%)**	**146 (10%)**
Streptococcus (group A)	21	11	32
Streptococcus (group B)	49	21	70
Streptococcus pneumoniae (pneumococcal)	24	8	32
Streptococcus (Other or unspecified)	8	5	13
Gram negative bacteria	**107 (19%)**	**202 (21%)**	**309 (21%)**
E-coli	43	58	101
Pseudomonas	16	64	80
Haemophilus influenzae	9	3	12
Other gram negative bacteria	57	110	167
Other Bacteria	**45 (8%)**	**58 (6%)**	**103 (7%)**
Listeria	2	0	2
Meningococcal sp.	13	2	15
Staphylococcus sp.	22	34	56
Enterococcus sp.	8	22	30
Tuberculosis (TB)	*	*	2

Infection related deaths of children and young people in England. NCMD Programme [2023]

Bacteria

Streptococcus species infections were reported in 10% deaths, including:

- Group B Streptococcus (GBS) which was recorded in 70 deaths (93% of which were of children under 1).
- 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 2022/23.
- Pneumococcal infections, caused by the Streptococcus pneumoniae bacteria, were identified in 32 deaths

Meningococcus is a bacterium that can cause meningitis or sepsis. It was present in 15 deaths

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Staphylococcus sp.	22	34	56
Enterococcus sp.	8	22	30
Tuberculosis (TB)	*	*	2

Bacteria

Vaccinations are available, and free, for a significant minority (12%) of the bacteria seen

- Streptococcus pneumoniae
- Haemophilus influenzae
- Meningococcal
- Tuberculosis (TB)

Notably, several GBS vaccines for pregnant women are currently under development globally, which aim to protect the baby during pregnancy and birth.

Antibiotics are generally effective against all of the bacteria seen in this work

- Early delivery is often needed
- Broad, or inappropriate, use can lead to drug-resistant infections in the population.

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Enterococcus sp.	8	22	30
Tuberculosis (TB)	*	*	2

Infection related deaths of children and young people in England. NCMD Programme [2023]

Virus

- Viruses were reported in 23% of all deaths and in 27% of the deaths where infection provided a complete and sufficient explanation.
- Most common was coronavirus (109 deaths)
- Many others with >30 deaths
  - HSV
  - Influenzae
  - CMV
  - Enterovirus
  - Adenovirus
  - RSV

	Complete and sufficient	Contributed	Total
Total deaths	**553**	**954**	**1507**
Virus	**149 (27%)**	**201 (21%)**	**350 (23%)**
Herpes simplex virus (HSV)	28	9	37
Influenzae	17	16	33
Parainfluenzae	11	17	28
Varicella zoster virus (VZV)	5	3	8
Coronavirus	45	64	109
Metapneumovirus	6	17	23
Cytomegalovirus (CMV)	7	27	34
Respiratory Syncytial Virus (RSV)	18	22	40
Enterovirus	17	23	40
Adenovirus	15	24	39
Human immunodeficiency virus (HIV)	0	0	0

Virus

Vaccinations are available, and free for at least some of the population, for a significant minority (41%) of the virus seen:

- COVID-19 (SARS-CoV-2) was the cause of all coronavirus infections in this report.
- Influenza virus was recorded as the cause of death in 33 cases.

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.
- The Joint Committee on Vaccination and Immunisation (JCVI) have recently advised that an RSV maternal or newborns immunisation programme is cost-effective and should now be developed; discussions are taking place nationally as a consequence.

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Cytomegalovirus (CMV)	7	27	34
Respiratory Syncytial Virus (RSV)	18	22	40
Enterovirus	17	23	40
Adenovirus	15	24	39
Human immunodeficiency virus (HIV)	0	0	0

Virus

Chickenpox (varicella zoster virus) was recorded in eight deaths, including five deaths where infection provided a complete and sufficient explanation of death.

- 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 in specific circumstances

Effective antivirals are available for some of the other viruses seen here (e.g. Herpes Simplex Virus (HSV) and HIV).

No child died of HIV in the 3 years reported.

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Virus	**149 (27%)**	**201 (21%)**	**350 (23%)**
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Cytomegalovirus (CMV)	7	27	34
Respiratory Syncytial Virus (RSV)	18	22	40
Enterovirus	17	23	40
Adenovirus	15	24	39
Human immunodeficiency virus (HIV)	0	0	0

Fungal Infections

- In 6% cases a fungal infection were identified
  - Provided a complete and sufficient explanation of 3%
- Fungal infections are rarely seen in children with normal immune systems but are seen in infants
  - After birth at the earliest gestations
  - Children who are immunocompromised.
- Anti-fungal drugs exist but treatment is often complex and prolonged.

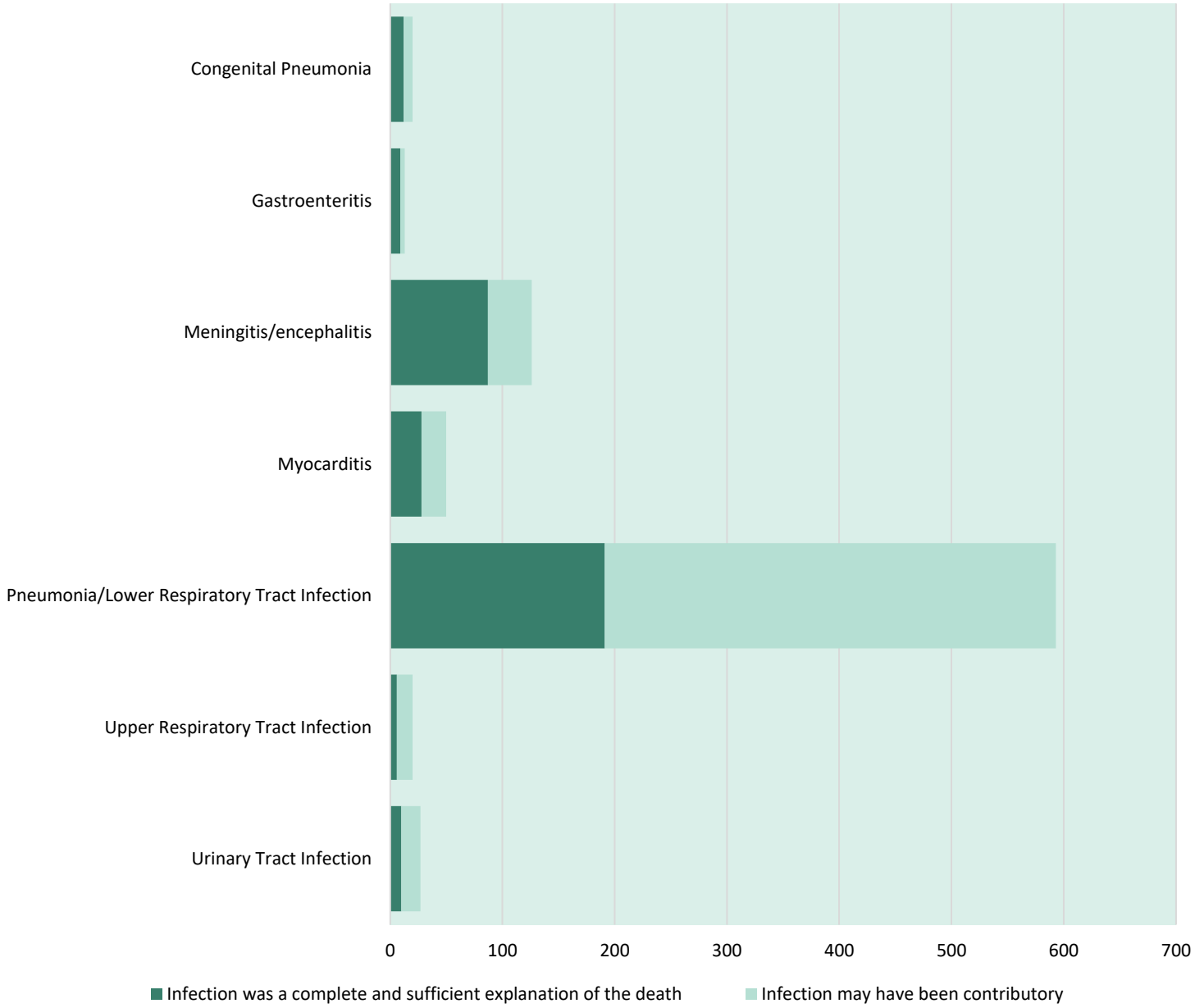
Infection related deaths of children and young people in England. NCMD Programme [2023]

Clinical conditions

- This section reports the 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
  - In 6% of deaths more than one condition was identified

Clinical conditions

- Pneumonia and lower respiratory tract infection was the most common condition reported.
- Meningitis and encephalitis are most common in babies and children



Infection related deaths of children and young people in England. NCMD Programme [2023]

Sepsis

- Sepsis, Septicaemia and Septic shock were often difficult concepts to identify from the data
- In this report, it was difficult to distinguish
  - Sepsis from known sources (e.g., lower respiratory tract)
  - Sepsis from unknown sources but bacteria identified only in blood
  - 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
- A proposed national Paediatric Early Warning System (PEWS) for England is due to be launched autumn 2023

Underlying health conditions

- Underlying health conditions can increase the vulnerability of a child to an infection.
- Life-limiting conditions (LLCs) are those for which there is often no reasonable hope of cure.
  - Some may be life-threatening conditions
  - However some may be curative (e.g. cancer).
- Children and young people with LLCs may die from infections that might not prove fatal in other children.
- Life-limiting conditions for each child were identified either through linking to ICD-10 diagnosis codes within Hospital Episode Statistics data (HES), 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 conditions.

Underlying health conditions

- Of all infection related child deaths, 90% had an underlying health condition
    - 76% of these deaths the infection was thought to be a complete and sufficient explanation of the death.
    - LLC in 68% of all infection related deaths.
    - Preterm or perinatal in 17%
- 10% of children had no underlying condition
    - Complete and sufficient deaths: 24%
    - Contributed: 2%

	Complete and sufficient	Contributed	Total
Total deaths	**553**	**954**	**1507**
Underlying health condition	**423 (76%)**	**938 (98%)**	**1361 (90%)**
Life-limiting condition	275	749	1024
Preterm or perinatal event	124	135	259
Other underlying health condition	24	54	78
No underlying health condition	**130 (24%)**	**16 (2%)**	**146 (10%)**

Infection related deaths of children and young people in England. NCMD Programme [2023]

Children between 5-17 years with a learning disability

- 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.
- People of all ages with a learning disability have increased risks of hospital admission and death from COVID-19 and other infections
    - Some **co-morbidities** may increase susceptibility to infection (rather than the learning disability itself).
    - However…. health inequalities/systems factors likely also increase susceptibility to serious illness and/or death following infection:
        - Delayed assessment, diagnosis and treatment
        - Difficulties reporting pain
        - Communicating with professionals
        - Understanding the importance of assessment/treatment).
- Of all infection related deaths, there was a high proportion of children with a learning disability (67%).
    - Where the infection provided a complete and sufficient explanation of death: 52% had a learning disability.
    - Where infection contributed to death: 72% had a learning disability.

Infection related deaths of children and young people in England. NCMD Programme [2023]

Section 3: Learning from CDOP completed child death reviews

- This section focuses on the outcome of completed child death reviews by CDOPs where the child died between April 2019 and March 2022

- Restricted to reviews where 'infection' or 'perinatal infection' was considered to be the primary or secondary category of death

Infection related deaths of children and young people in England. NCMD Programme [2023]

Section 3: Learning from CDOP completed child death reviews

843 reviews were categorised by the CDOP as 'infection' or 'perinatal infection' either as the primary or secondary category of death

Infection was the primary category of death in 41%

Perinatal infection was the primary category of death in 16%

Either were listed as a secondary category in 43%

Infection related deaths of children and young people in England. NCMD Programme [2023]

Contributory and modifiable factors

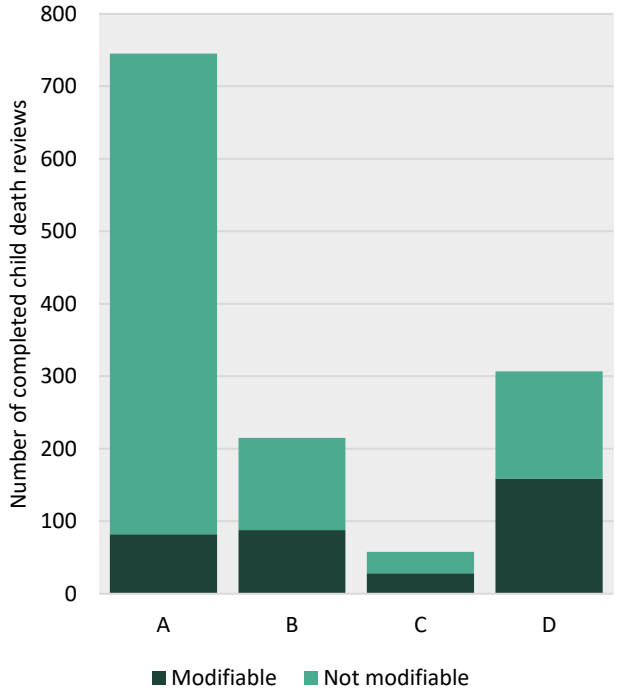
- **Contributary**: Contributory factors are factors that may have contributed to vulnerability, ill health or death.
- **Modifiable**: Modifiable factors are contributory factors that may, by means of a locally or nationally achievable intervention, be modified to reduce the risk of future child deaths.

- **Modifiable** factors were identified at review in 36% of child death reviews;
  - In 42% of deaths where ‘infection’ was considered the primary category of death
  - In 41% of deaths where ’perinatal infection’ was considered the primary category of death
  - In 28% of deaths where either were considered a secondary category of death.

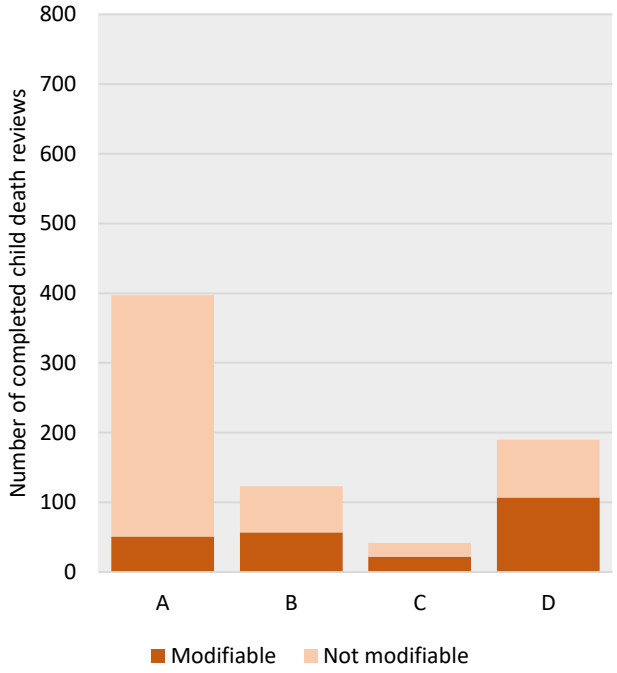
Infection related deaths of children and young people in England. NCMD Programme [2023]

Contributory and modifiable factors

All deaths categorised as infection (n=843)



Infection was the primary category (n=482)

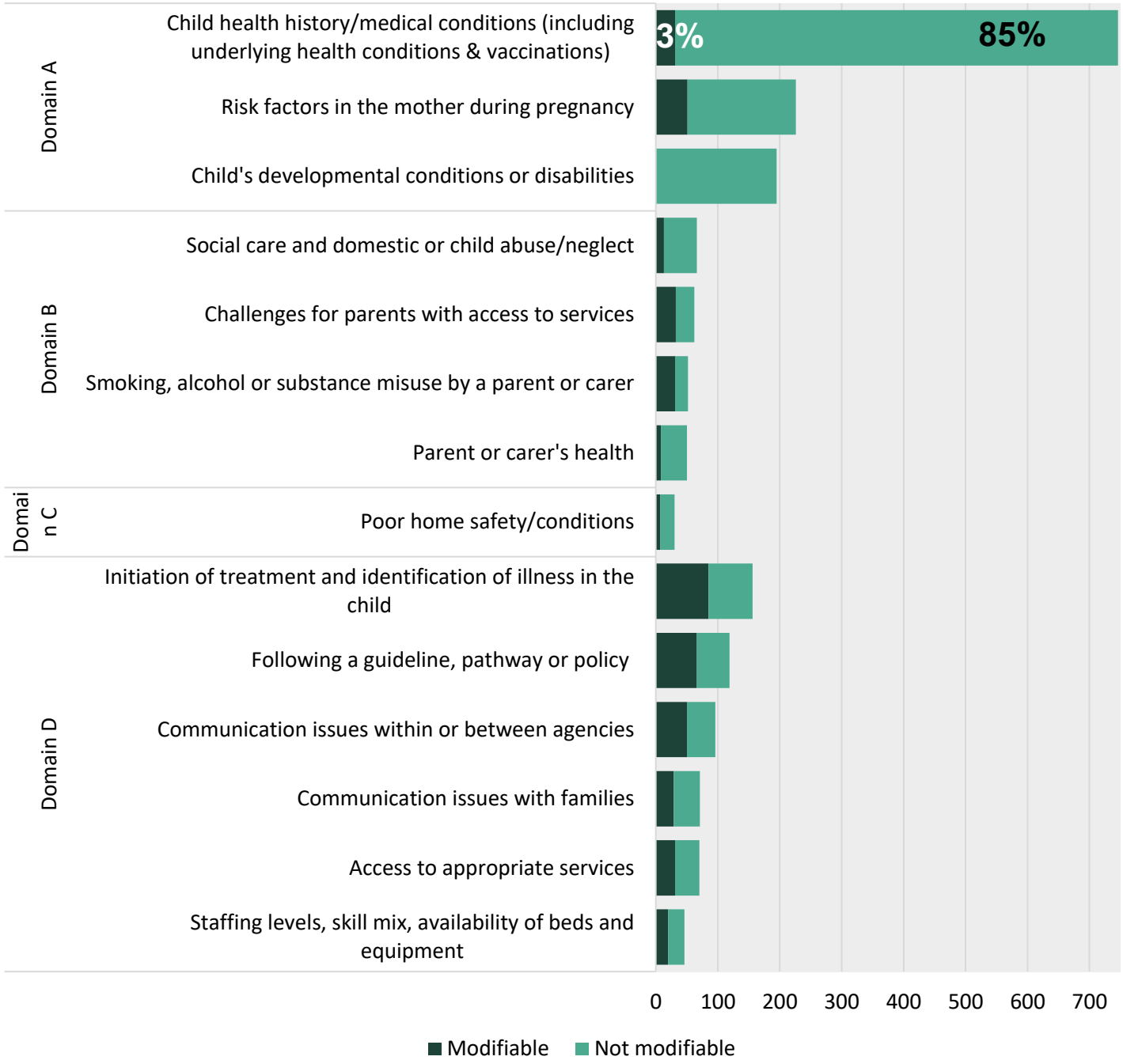


A = Characteristics of the Child, B = Social environment, C = Physical environment, D = Service provision

Infection related deaths of children and young people in England. NCMD Programme [2023]

Characteristics of the Child

- Prematurity or low birth weight was recorded as a contributory factor in 30% of reviews.
- The CDOP recorded a baby or child not being immunised, or there being a delay, in 3% reviews.
- Themes
  - Parental choice, logistical issues, or circumstances in the child's background.
  - Especially noted in children with complex needs

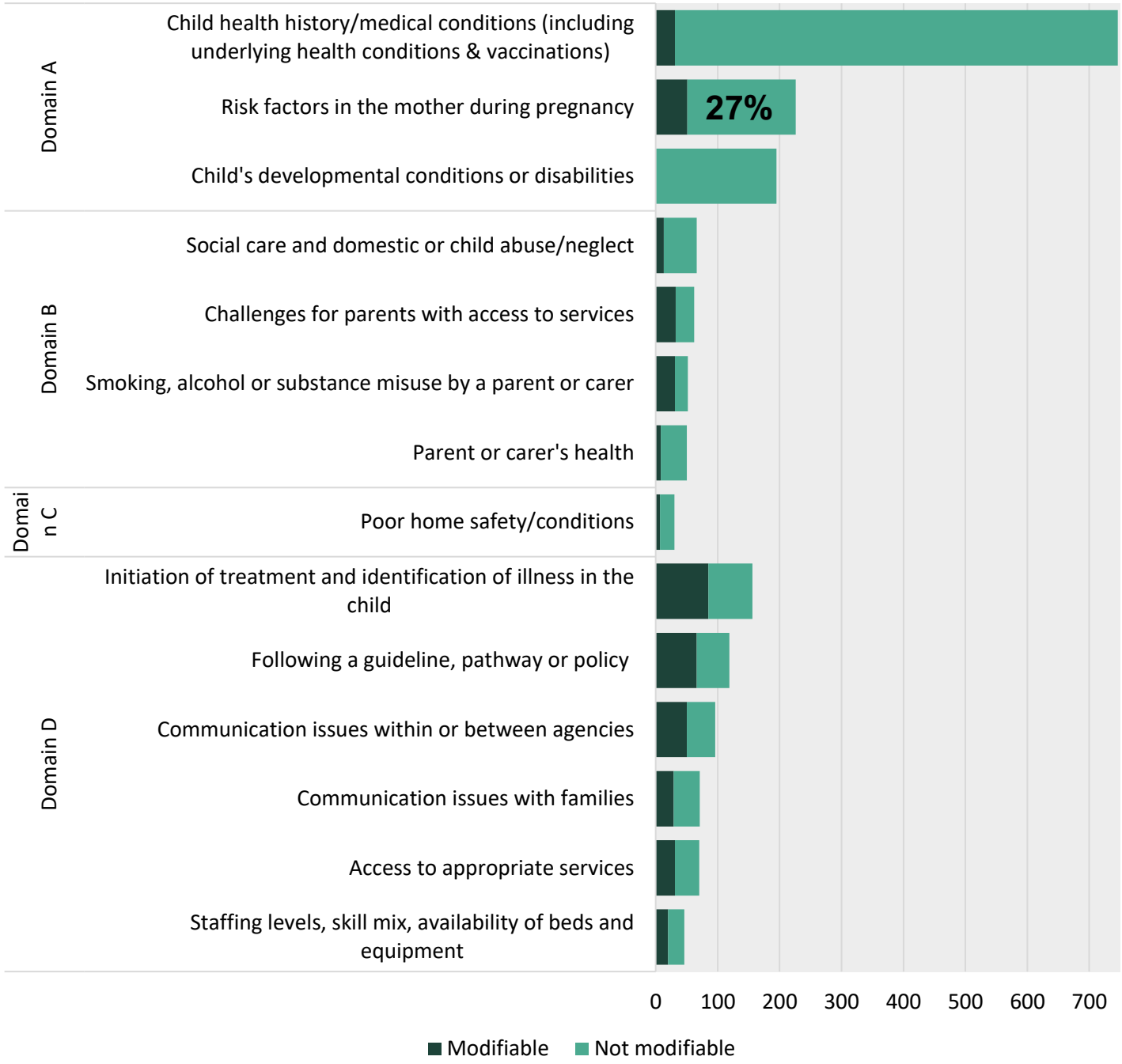


Infection related deaths of children and young people in England. NCMD Programme [2023]

NCMD National Child Mortality Database

Characteristics of the Child

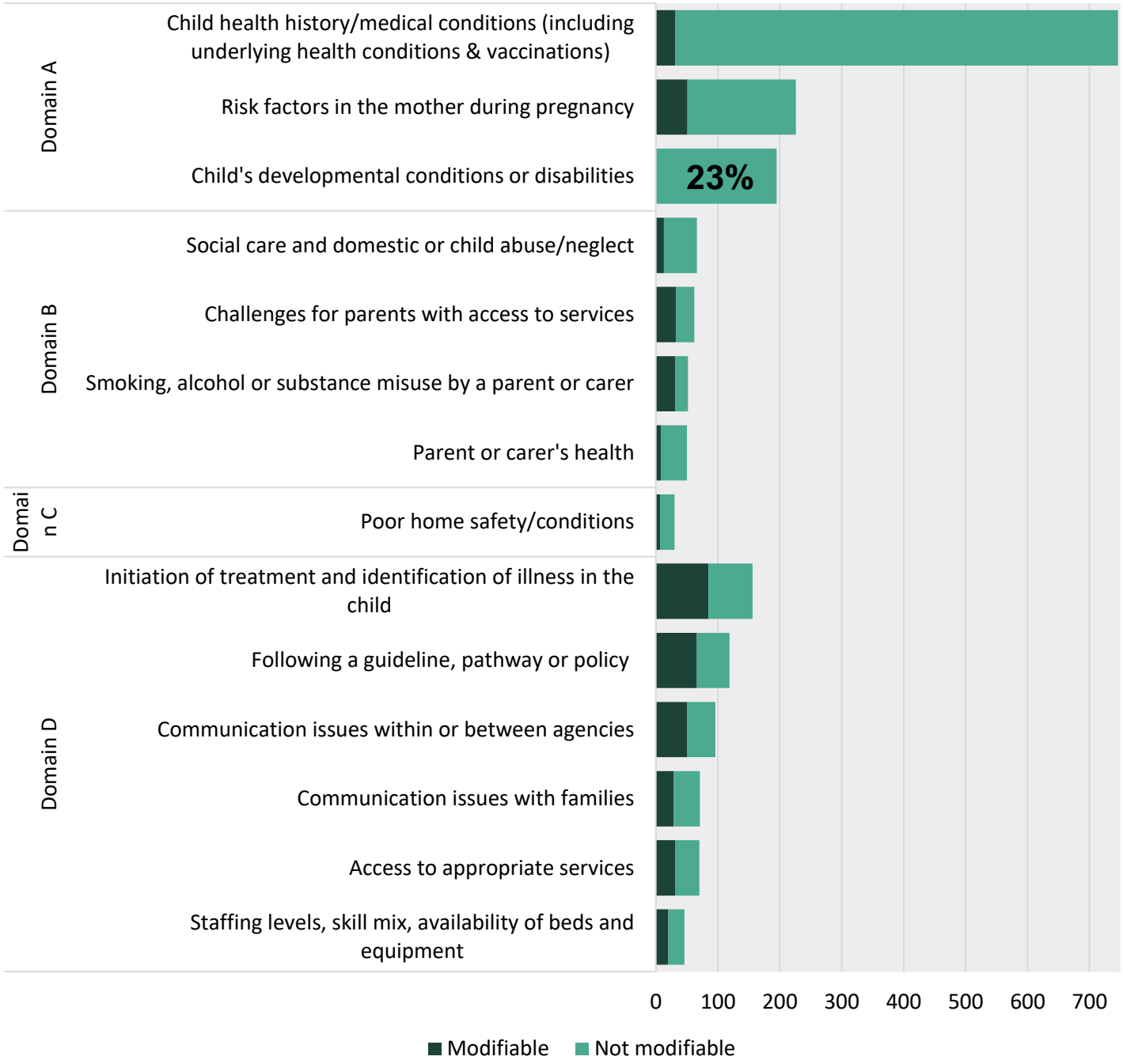
- Risk factors included:
  - Maternal infections
  - Smoking in pregnancy
  - Twin or multiple pregnancy
  - Maternal health (e.g., high maternal BMI, maternal diabetes, gestational diabetes)
- Themes identified:
  - Midwifery workforce shortages
  - Ineffective communication between the maternity and neonatal teams
  - Lack of clear clinical leadership and multidisciplinary working.
  - Need for better knowledge and screening for HSV and CMV



Infection related deaths of children and young people in England. NCMD Programme [2023]

Characteristics of the Child

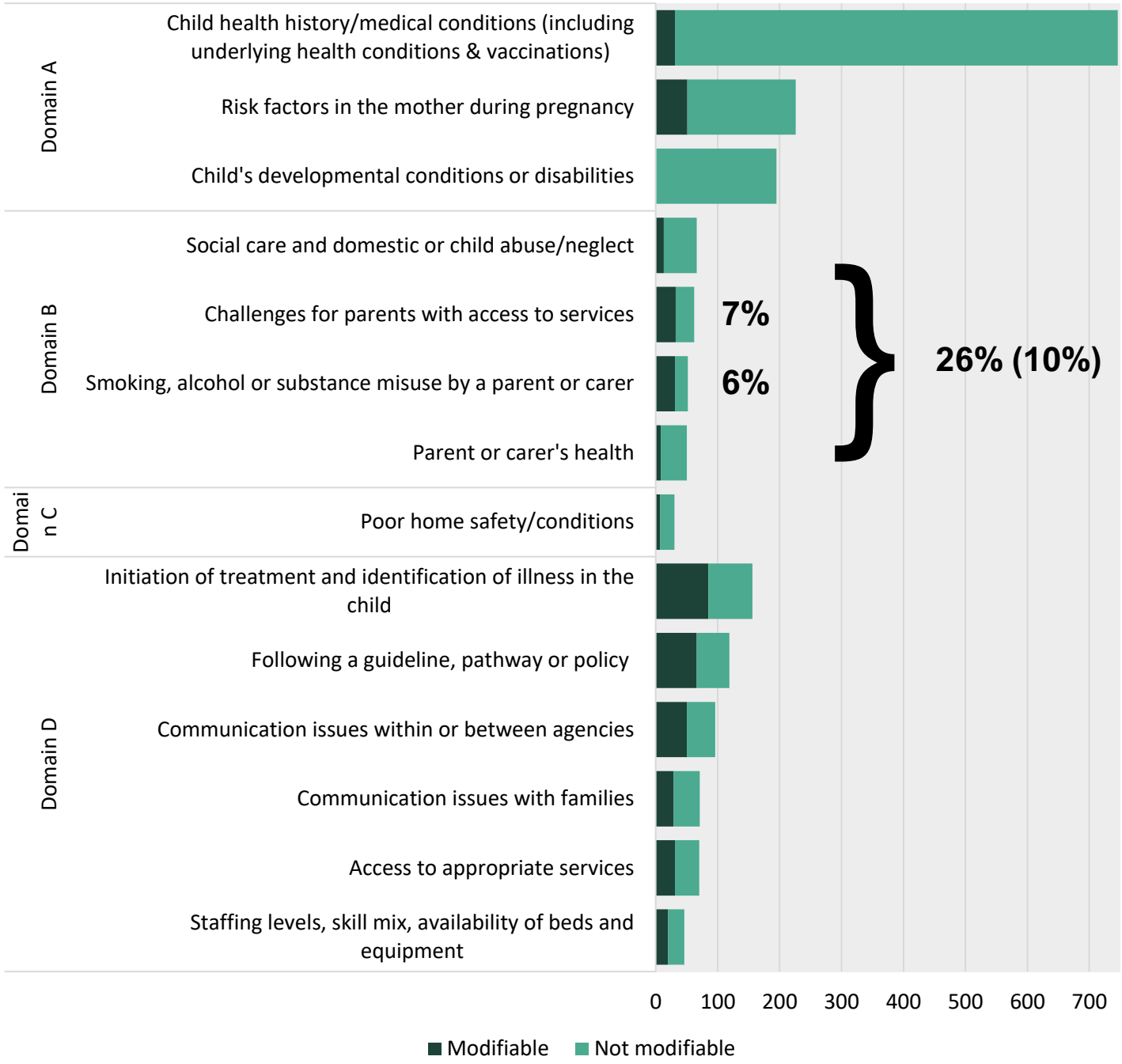
- In those children with learning disability the review identified modifiable factor in 25%, e.g.:
  - Initiation of treatment and identification of illness including escalation of care
  - Communication factors
  - Access to appropriate services including impact of COVID-19 pandemic on services.



Infection related deaths of children and young people in England. NCMD Programme [2023]

Social environment

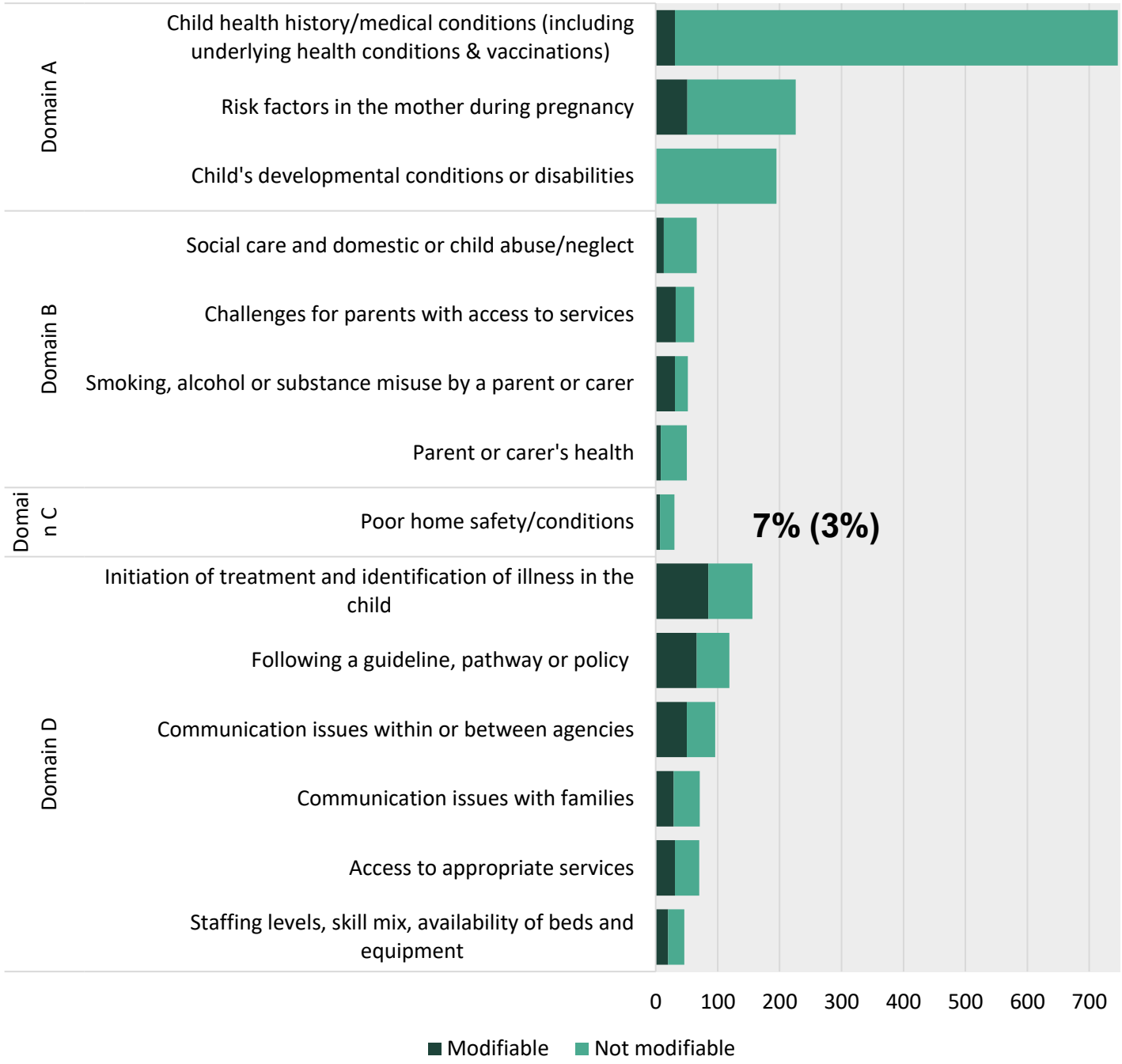
- Themes:
  - Lack of services, or challenges accessing them
  - Access to services due to COVID infections, lockdown restrictions, and telephone appointments.
  - Challenges for families in recognising a deteriorating child, which result in a consequent delay in presentation to healthcare services.



Infection related deaths of children and young people in England. NCMD Programme [2023]

Factors in the physical environment

- Themes
  - Unclean or mouldy properties
  - Overcrowding
  - Temporary accommodation/Suitability of housing placements (esp. antenatal care and for families of children with complex health needs)



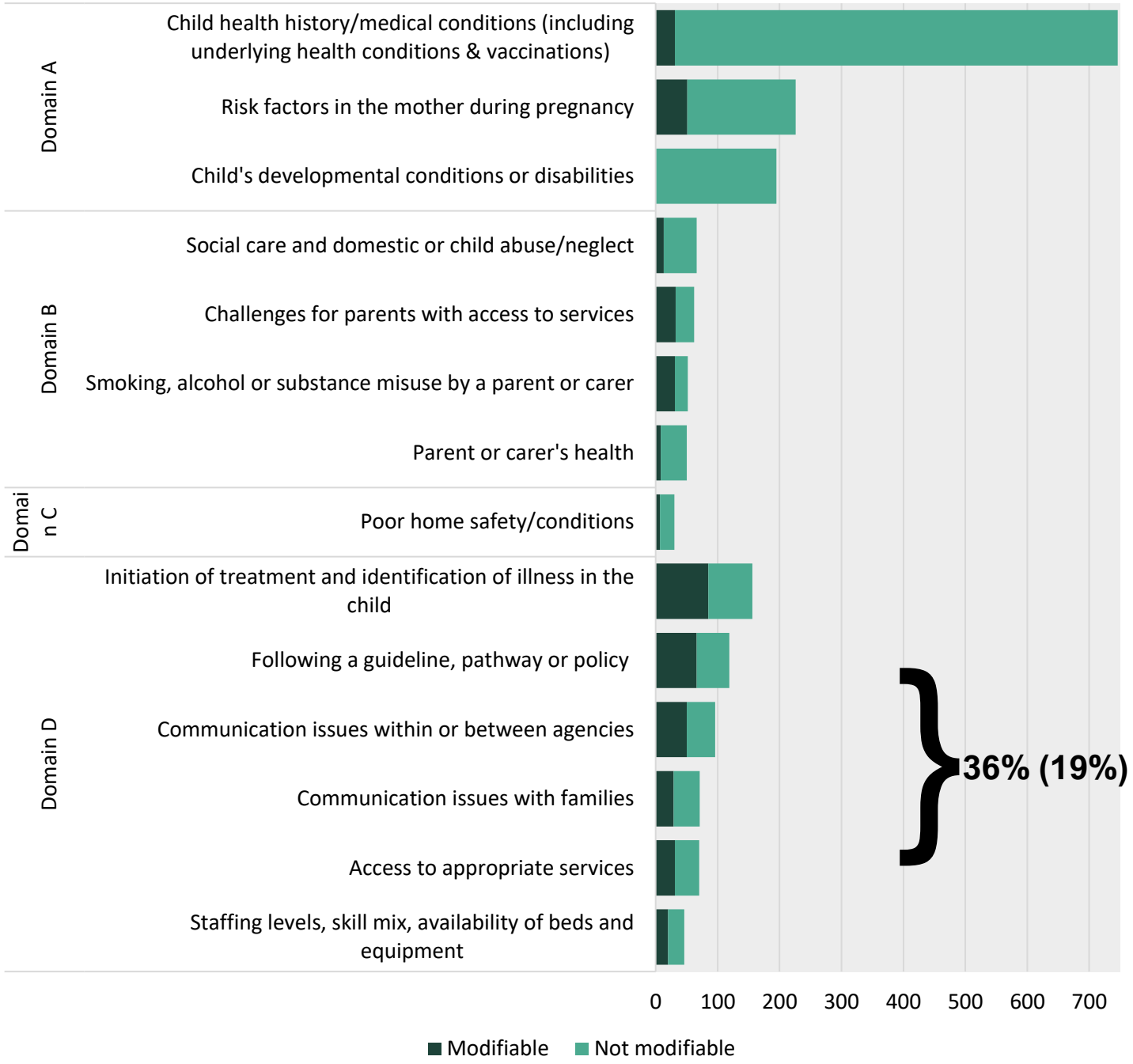
Infection related deaths of children and young people in England. NCMD Programme [2023]

NCMD National Child Mortality Database

Factors relating to service provision

Initiation of treatment and identification of illness themes:

- Issues with the diagnosis, treatment, and the availability of information.
- Lack of clinical recognition of the deteriorating child
- Failure to appropriately escalate for senior review.

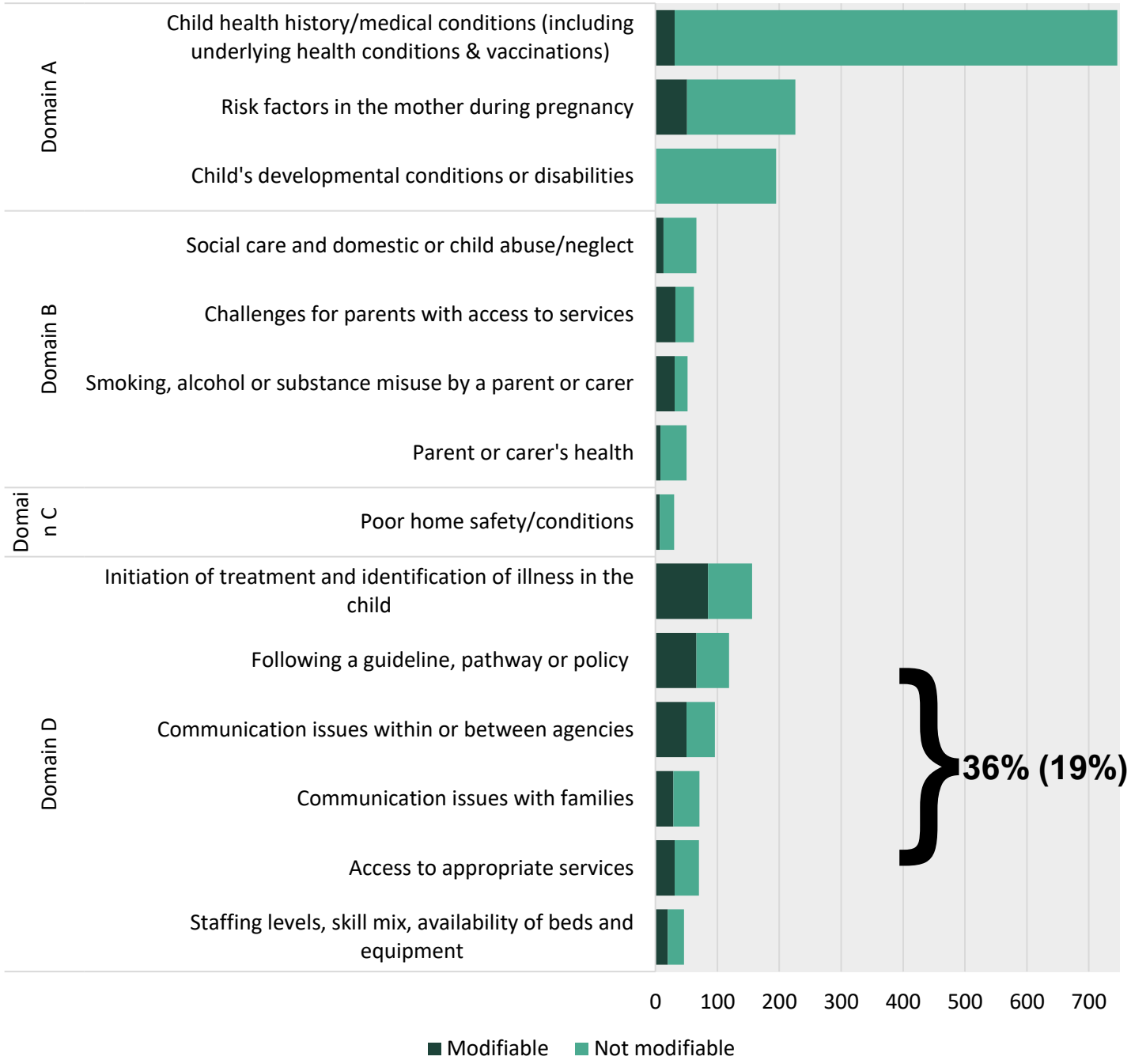


Infection related deaths of children and young people in England. NCMD Programme [2023]

Factors relating to service provision

Following a guideline, pathway or policy themes:

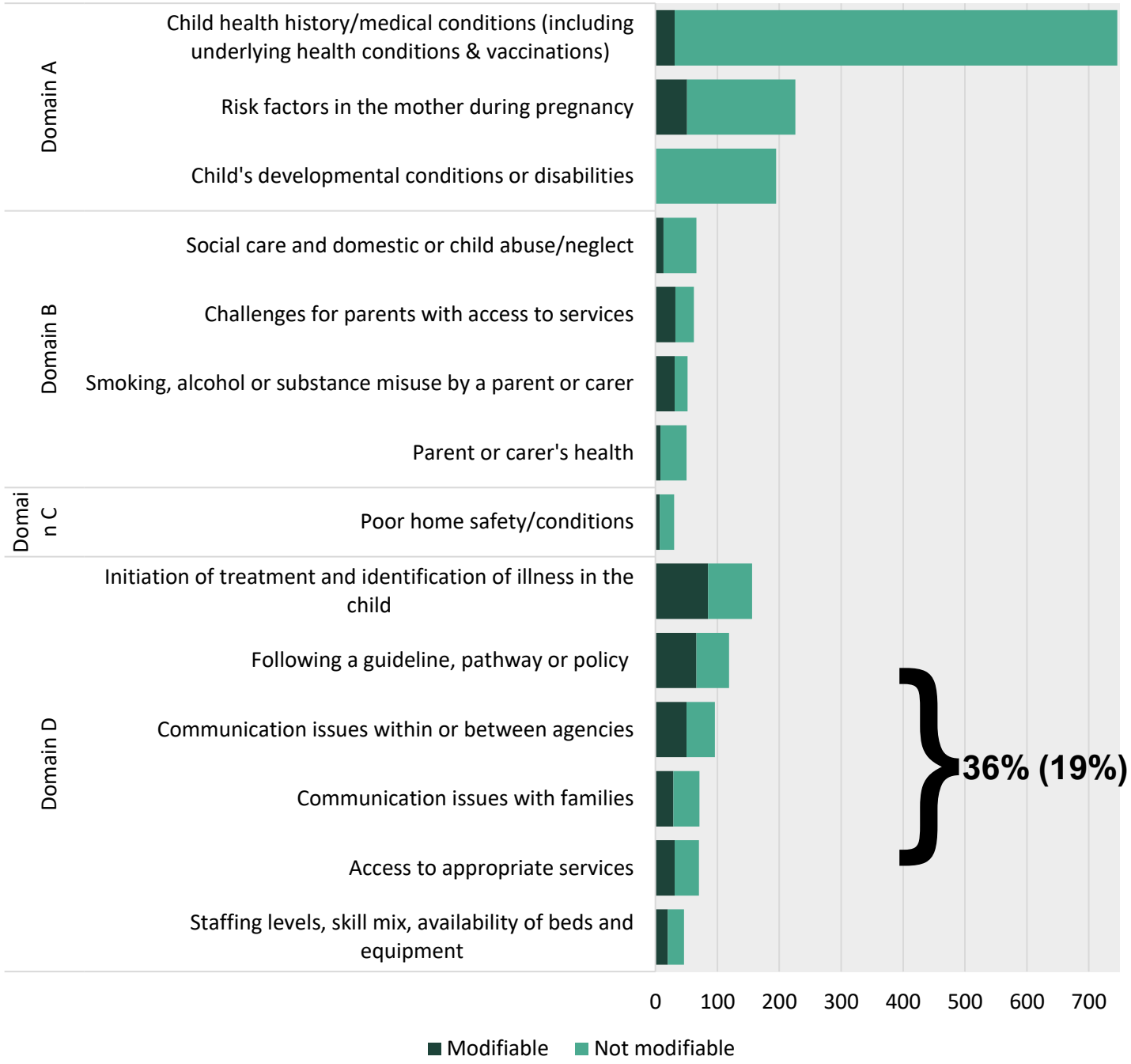
- Poor quality or no clinical assessment or review
- Unclear care pathways
- Where a guideline was available, but not followed.
- Where appropriate treatment was not started early enough



Infection related deaths of children and young people in England. NCMD Programme [2023]

Factors relating to service provision

- Communication issues within or between agencies were recorded in (11%)
- NHS 111 service, transfer, or availability of the ambulance service (2%)
- Issues related to staffing levels, skill mix, availability of beds and equipment (maternity and paediatric services) (5%)



Infection related deaths of children and young people in England. NCMD Programme [2023]

Domain D: Recognition of suspected sepsis

- Where it was applicable and answered:
  - 18% recorded that recognition of suspected sepsis was not timely
- For presentation in hospital:
  - 12% of reviews recorded a failure to deliver broad spectrum antibiotics within one hour [NICE Guidelines for Sepsis (NG51)].
  - 77% identified and recognised red flag symptoms
  - 8% had 1+ red flag symptoms not recognised
  - 15% had no red flag symptoms

Infection related deaths of children and young people in England. NCMD Programme [2023]

Deaths abroad

- 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.

→ 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.

Infection related deaths of children and young people in England. NCMD Programme [2023]

Key findings: Epidemiology

- There were 1,507 infection related child deaths between 1 April 2019 and 31 March 2022 (3 years)
- A likely overall rate of 2-4 deaths per 100,000 children per year.
  - This was the equivalent of 6-15% of all child deaths in this period.

- 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.
  - Where infection was thought to provide a **complete and sufficient explanation of death**, 50% of deaths occurred in children under 1 year of age

Key findings: Epidemiology

- 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
  - Children from a Pakistani and African 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.

Key findings: Epidemiology

- Overall, in 90% of the infection related deaths the child had an underlying health condition:
  - 68% who had a life-limiting condition (e.g., cerebral palsy)
  - 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 had no underlying health condition.

- Of the children aged 5 to 17 years, a high proportion (2/3) had a learning disability

  → Pneumonia was identified in ¾ of these deaths.

Infection related deaths of children and young people in England. NCMD Programme [2023]

Key findings: Epidemiology

- Bacterial infection was implicated in nearly half of all deaths
- Viruses (including coronavirus) were identified in a quarter.
- A third 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
  - No rise in deaths over the winter of 2020/21.
  - Deaths over the most recent winter of 2022/23 were the highest since NCMD started collecting data.

Infection related deaths of children and young people in England. NCMD Programme [2023]

Key findings: Child Death Reviews

- Modifiable factors were identified by CDOPs in 1/3 of child death reviews
  - This was higher 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 (D).

- The most common contributory factors within the service domain recorded were in relation to initiation of treatment and identification of illness in the child, and following guidelines.

Key findings: Child Death Reviews

- Challenges for parents with access to services 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)
  - Factors that relate to the child's health history, including prematurity, underlying health conditions
  - Learning disabilities

- Reviews also recorded the importance of vaccination uptake to help protect babies and children.

Recommendations

- These recommendations are aimed at multiple organisations
- They reflect issues and gaps identified with the analysis in this report
- This may require collaborative working with other organisations in deciding on specific tasks to meet the overall aims that these recommendations set out.

Recommendations

1. Ensure coherent guidelines on infections and administering anti-microbial treatments exist between services delivering early care to children and investigate the barriers to not following them.

Recommendations

2. Ensure that infants and children who are at a higher risk of death from infection are included within guidance and training.

Recommendations

3. Commission research with healthcare professionals into the barriers to following existing guidelines and potential solutions to improve education and training.

Recommendations

4. Investigate further to understand the barriers to accessing services by parents when their child may be presenting with signs and symptoms of infection.

Recommendations

5. Listen to and action on parental concerns about their baby's or child's health as per the NICE guideline NG194.

Recommendations

6. Increase public awareness of potentially significant symptoms and signs of infection, particularly in infants.

Recommendations

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.

Recommendations

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.

Recommendations

9. Ensure that any written and oral information and advice on immunisations is accessible to all groups and local communities and made available widely in order that an informed decision can be made.

Recommendations

10. Support and develop initiatives to improve health and reduce disparities and mitigate the social determinants such as housing, smoking and obesity.

Recommendations

11. Commission future research focusing on improvements in diagnosing specific causes and on the mechanisms underlying the much higher infection mortality rates in infancy.

Recommendations

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.

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