# Sudden, unexpected deaths in Infancy and Childhood Thematic Report

Wednesday 14th December 2022

Presented by Professor Peter Fleming

NCMD
National Child Mortality Database

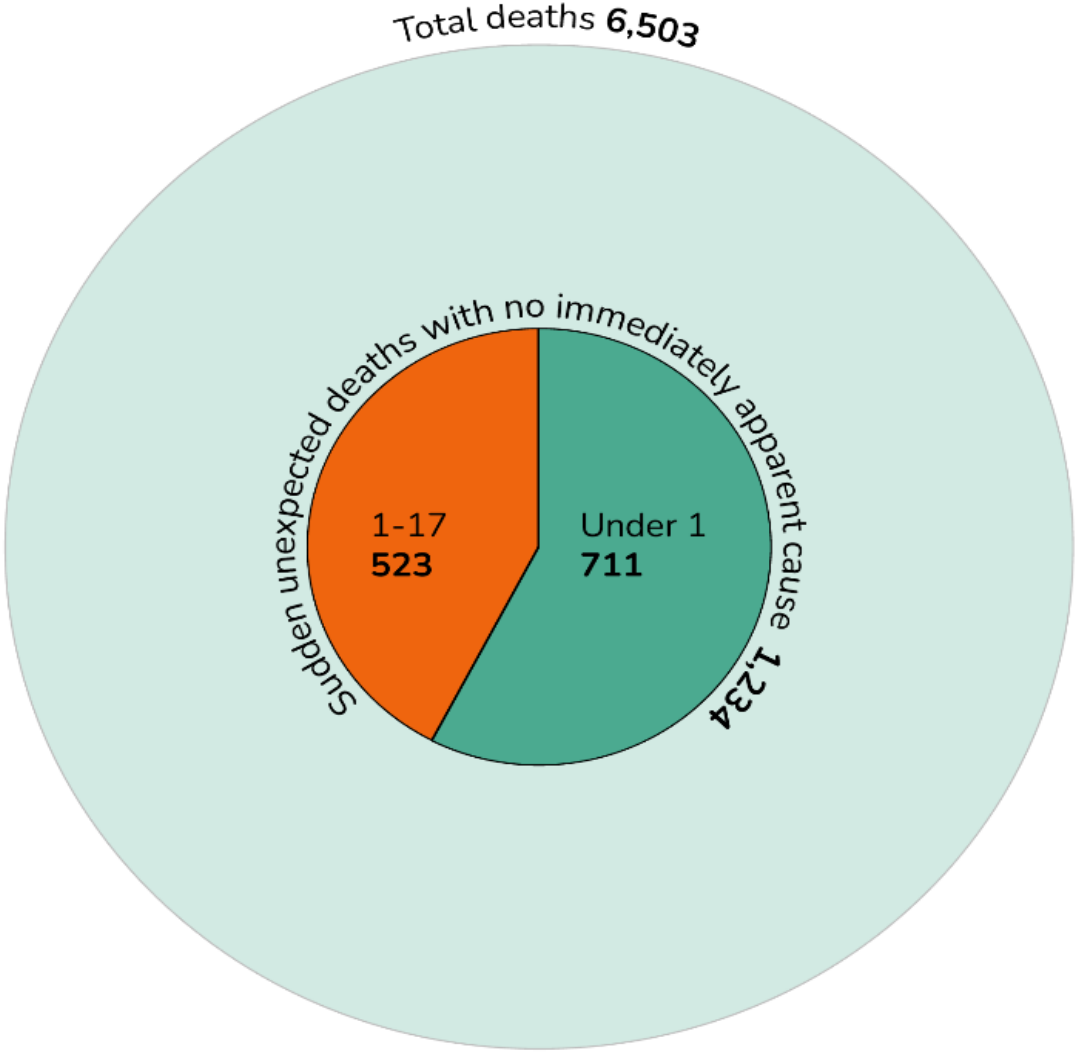
Knowledge, understanding and learning to improve young lives

# Overview of the report

- This report looks at all children who died suddenly and unexpectedly between April 2019 and March 2021
- Following the analysis on all children who died suddenly and unexpectedly, the report breaks the data down in two ways:
  - By age group (under 1 year and 1-17 years)
  - By whether the death went on to be explained or remained unexplained after full investigation

- Total deaths notified to NCMD in the 2 year period (1 April 2019 to 31 March 2021) and the proportion that were sudden, with no immediately apparent cause, by age group

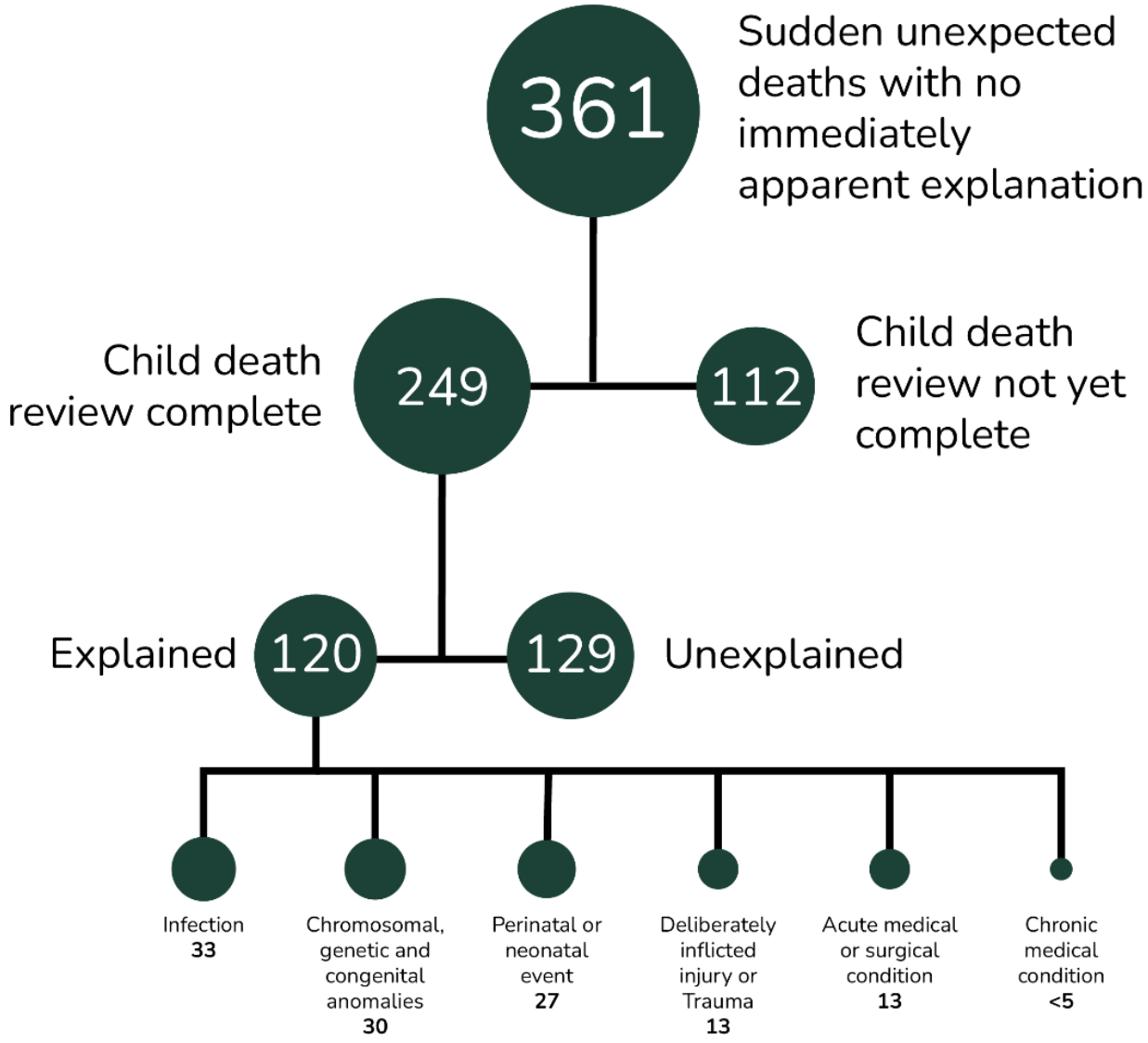
- National figures for unexpected deaths have not previously been reported anywhere, for any country. The figures published previously have been only for the final identified “cause” of death – not for the presentation as unexpected.



# What do we know about Under 1s?

- Of the 711 sudden and unexpected infant deaths between April 2019-March 2021, 70% were aged between 28 and 364 days, and 57% were male.
- Infant death rates were higher in urban areas, and the most deprived neighbourhoods. There were no changes in demographics across the 2-year period.
- We then conducted a more detailed review of all deaths during 2020 for which the full investigations had been completed.
- For sudden and unexpected infant deaths that occurred during 2020 and had been fully reviewed by a CDOP (n=249), 52% were classified as unexplained (i.e. Sudden Infant Death Syndrome (SIDS)), and 48% went on to be explained by other causes e.g. metabolic or cardiac conditions.
- There were 129 sudden unexpected and unexplained infant deaths in 2020 that had been reviewed by a CDOP by 28 June 2022 and remained unexplained after full investigation.
- There was a higher proportion of **unexplained** deaths of males (64%) than females (36%), which was not observed in deaths that went on to be explained where sex proportions were approximately equal (51% female, 49% male).

## Sudden and unexpected deaths, with no immediately apparent cause of those under 1 year of age in 2020, by CDOP category of death



# What do we know about Under 1s?

- A joint agency home/scene visit was carried out by professionals for 65% of unexplained infant deaths, and a single agency response (usually police only) was recorded for a further 34%, and in 1% there was no agency response visit carried out by professionals after the death.
- The unexplained deaths were strongly associated with low birthweight, prematurity, multiple births, larger families, admission to a neonatal unit, maternal smoking during pregnancy, young maternal age, parental smoking and parental drug misuse. The profile of vulnerability surrounding the birth characteristics was even more marked among the explained deaths.

# Sleep environment

- Where it was known, 98% (n=124/127) of unexplained deaths occurred when the infant was thought to be asleep, and of those, 52% (n=64/124) of deaths occurred while the sleeping surface was shared with an adult or older sibling.
- Of the 64 deaths where the sleeping surface was shared, for 60% this sharing was unplanned and at least 92% were in hazardous circumstances e.g. co-sleeping with an adult who had consumed alcohol or on a sofa.
- Of the 124 deaths that occurred during apparent sleep, at least 75% identified one or more of the following risk factors related to the sleeping arrangements: put down prone (face down) or side; hazardous co-sleeping; inappropriate sleeping surface when sleeping alone; inappropriate items in the bed.

# Modifiable Factors in Under 1s

| Modifiable Factor | % of cases where it was recorded as modifiable by CDOPs |
|---|---|
| Unsafe sleeping arrangements | 72% |
| Smoking in pregnancy or in the household | 48% |
| Alcohol or substance misuse | 27% |
| Quality of service provision | 14% |
| Poor home environment | 8% |
| Domestic or child abuse / neglect | 6% |

# Issues and Learning for Under 1s

**Safe Sleeping**

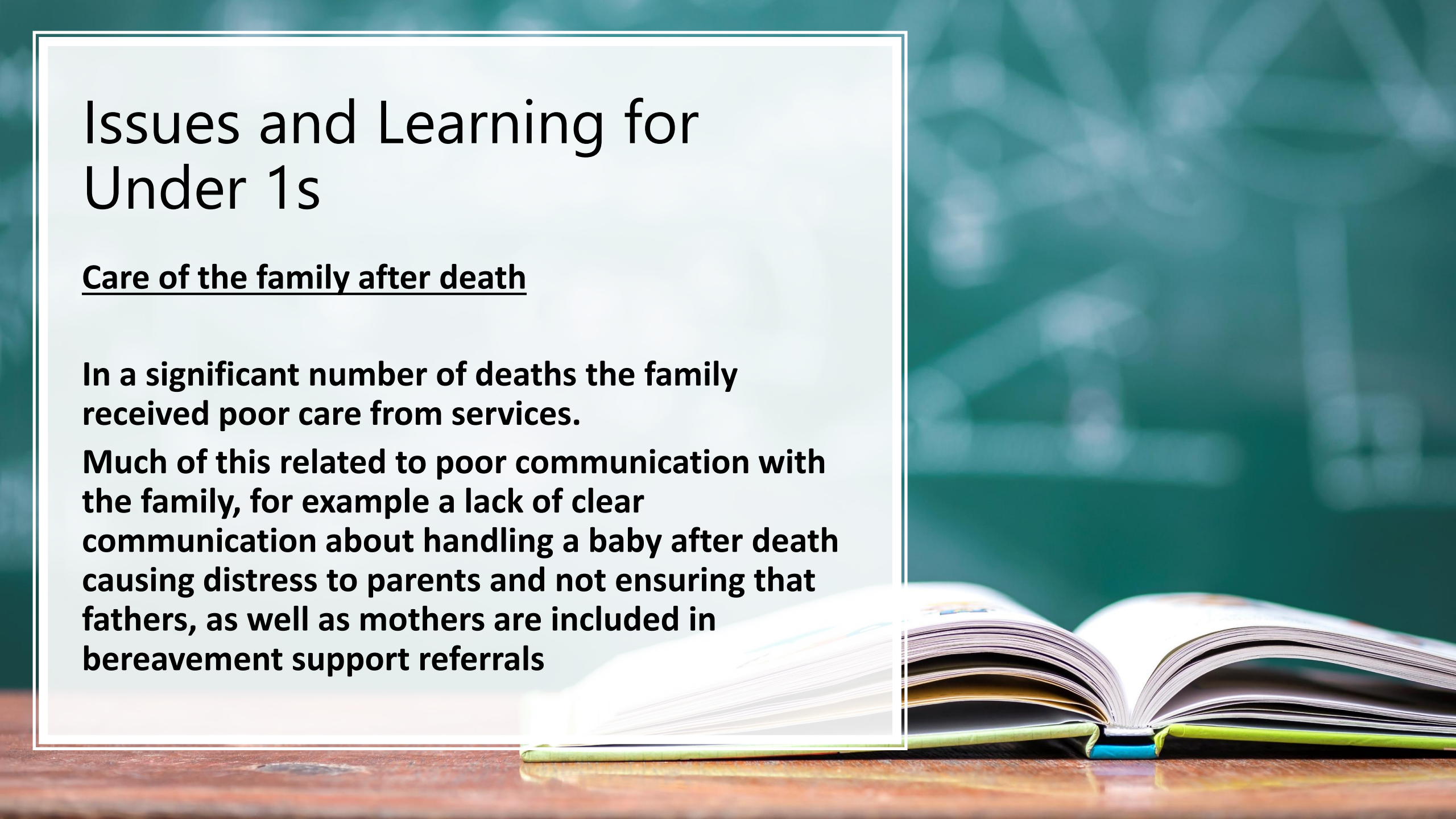
- **A strong theme identified was the importance of families understanding the risks of SIDS for their specific situation and the need to create a safe sleeping space for their infant.**
- **This included understanding the risks when they have a change in their normal routine, such as going to a party, or staying at another family member's house**
- **The importance of health visitors viewing the sleep environment when they visit the family home. Seeing the sleep environment provides an opportunity to support the family to understand any specific risks for their set-up.**

# Issues and Learning for Under 1s

**Care of the family after death**

**In a significant number of deaths the family received poor care from services.**

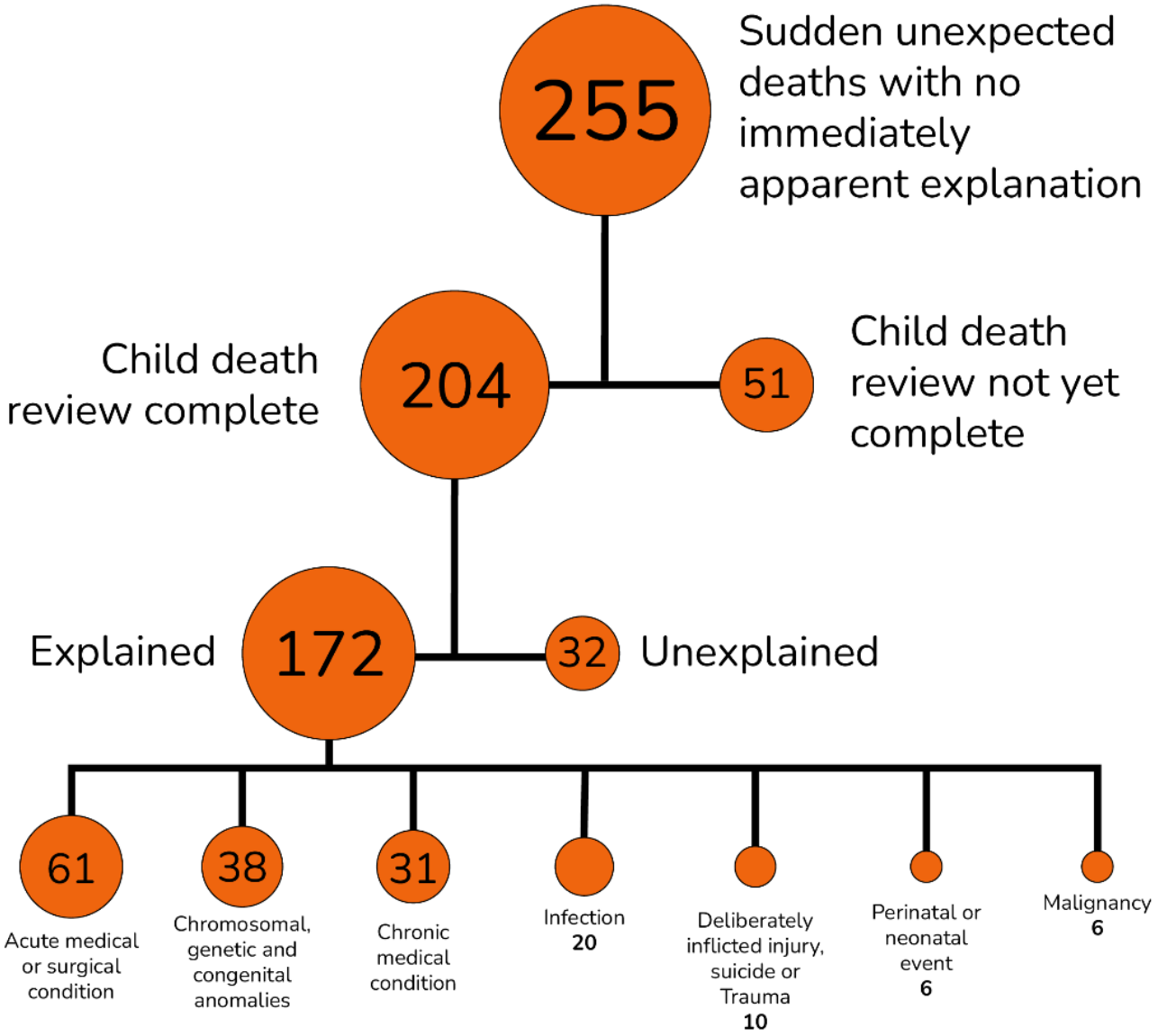
**Much of this related to poor communication with the family, for example a lack of clear communication about handling a baby after death causing distress to parents and not ensuring that fathers, as well as mothers are included in bereavement support referrals**



# What do we know about 1-17 year olds?

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

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



# What do we know about 1-17 year olds?

- There were at least 32 unexplained deaths in 2020 of children aged 1-17 years; 22 children aged 1-4 years and 10 children aged 15-17 years. Whilst unexplained deaths of infants show a marked male excess, there was an equal split of sex in unexplained deaths of older children.
- Where data were available (n=30), there was a history of convulsions recorded in 27% of children whose deaths remained unexplained in this age group. This incidence was similar to children whose deaths went on to be explained, which emphasises the potential importance of understanding the aetiology and potentially contributory factors to convulsions (febrile and other) in children.
- Where it was recorded (n=14), a joint agency home/scene visit was carried out by professionals in 7 deaths, a single agency response (usually police only) was recorded for 5 deaths and in 2 deaths there was no agency response visit carried out by professionals after the death.

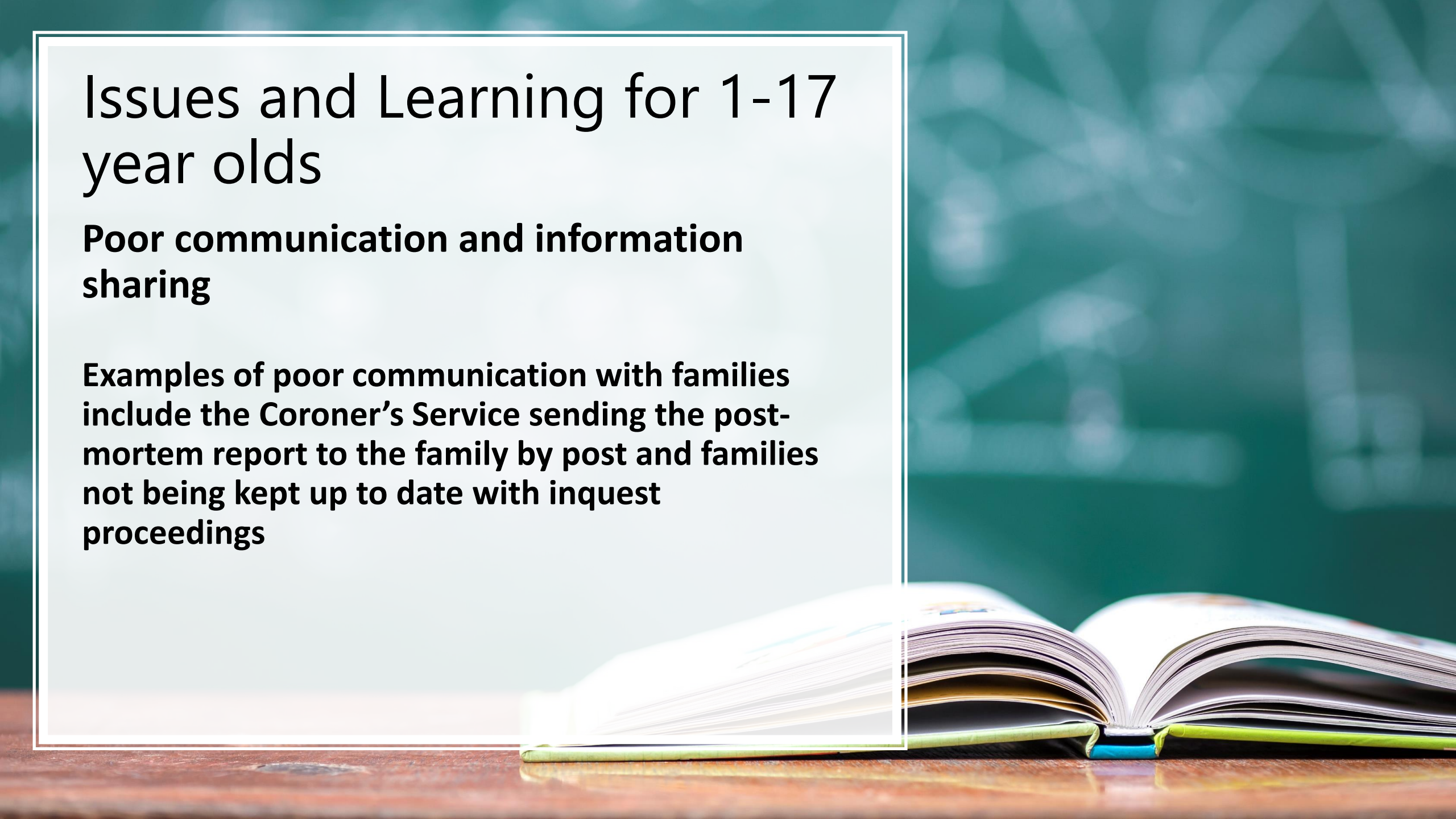
# Modifiable Factors in 1-17 year olds

- Where the CDOP had sufficient information to determine modifiable factors (n=31), 35% (n=11) of the reviews identified at least one modifiable factor in unexplained deaths of children aged 1-17 years.
- This proportion was lower than that of infants which is likely to be due to the lack of evidence base surrounding the unexplained deaths of older children.
- Sudden and unexplained death in childhood is a rare event. The evidence base around contributory factors is weak. In the longer term NCMD data could feasibly be utilised in case control studies to further our understanding of causation of these rare events.
- Due to small numbers of deaths that identified modifiable factors, details of these modifiable factors are not reported to protect the identity of the children.

# Issues and Learning for 1-17 year olds

**Poor communication and information sharing**

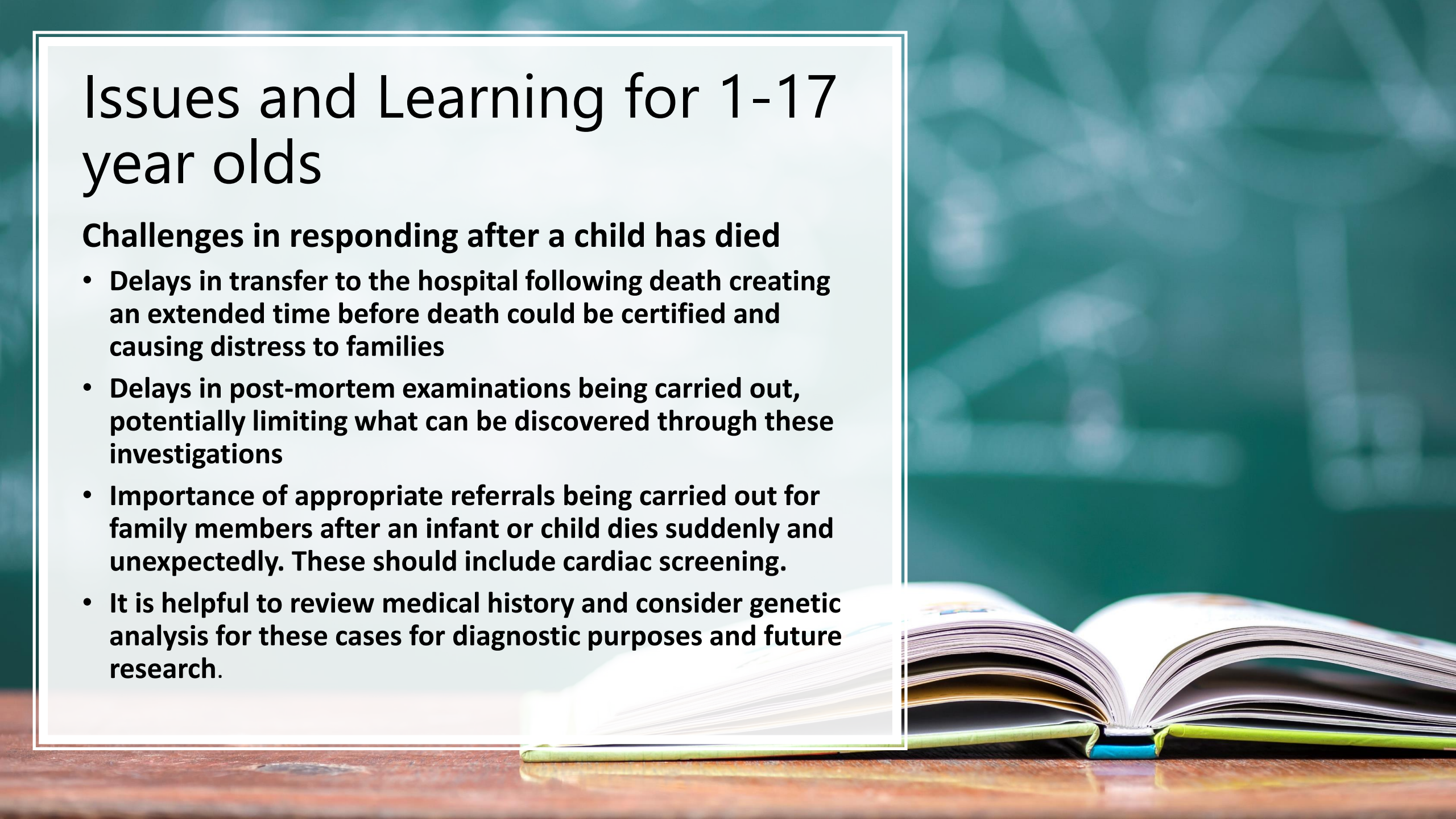
**Examples of poor communication with families include the Coroner's Service sending the post-mortem report to the family by post and families not being kept up to date with inquest proceedings**



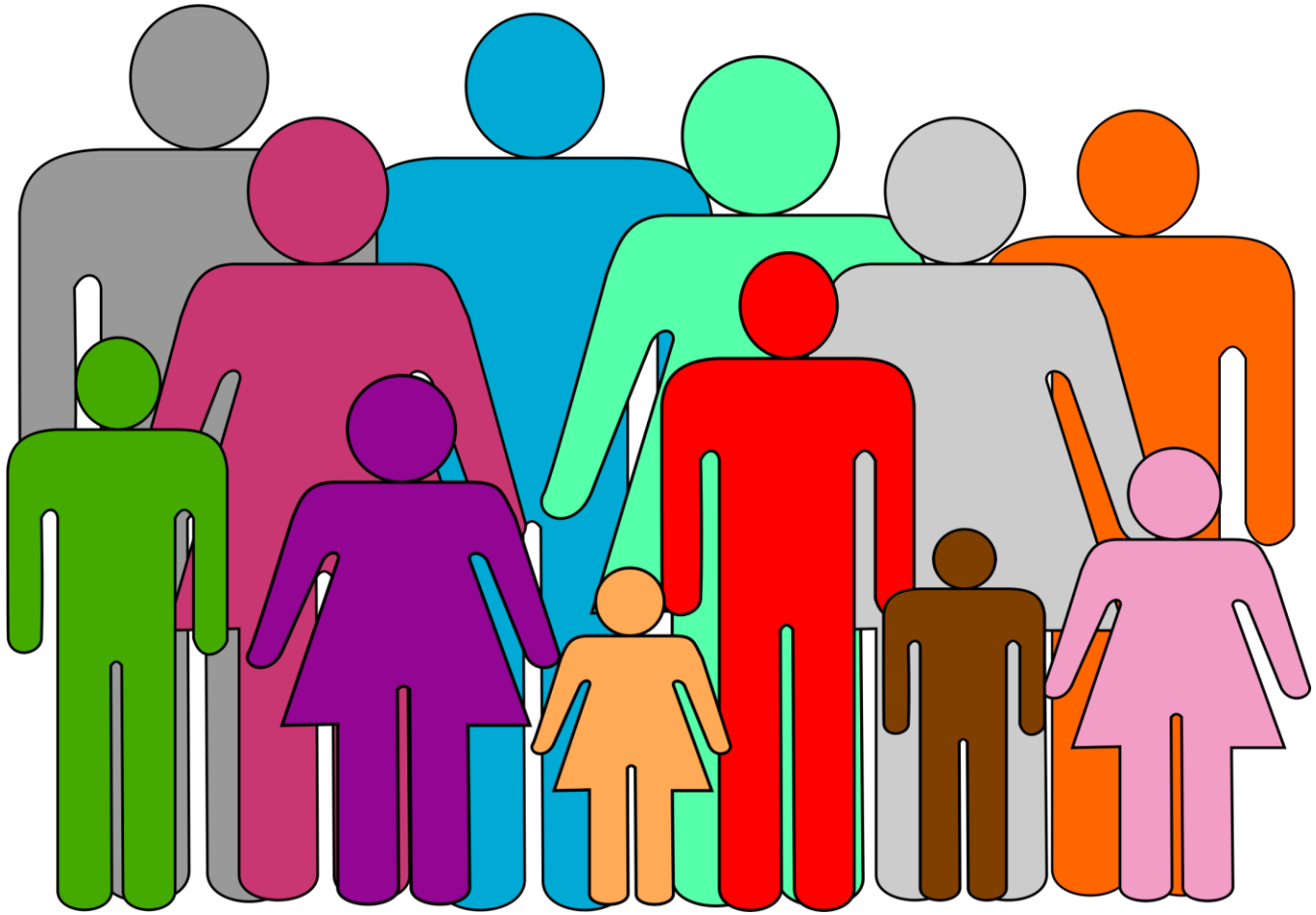
# Issues and Learning for 1-17 year olds

**Challenges in responding after a child has died**

- **Delays in transfer to the hospital following death creating an extended time before death could be certified and causing distress to families**
- **Delays in post-mortem examinations being carried out, potentially limiting what can be discovered through these investigations**
- **Importance of appropriate referrals being carried out for family members after an infant or child dies suddenly and unexpectedly. These should include cardiac screening.**
- **It is helpful to review medical history and consider genetic analysis for these cases for diagnostic purposes and future research**.



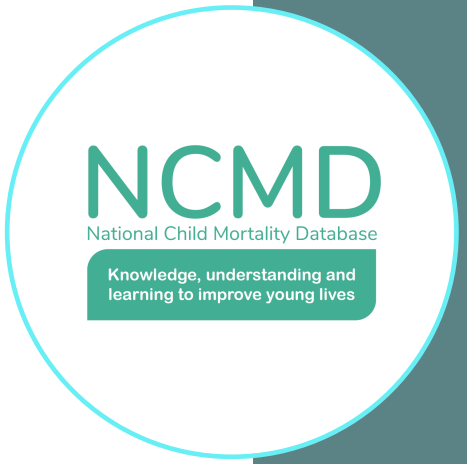
# Report Recommendations



# Housing

Ensure there is a robust system in place for identifying families living in unsatisfactory housing conditions and for prioritising them within housing allocation schemes. This should include carrying out appropriate checks to ensure that housing conditions (including temporary and emergency accommodation) are  suitable for babies and their carers. **Action by: Department for Levelling Up, Housing and Communities, Local Authorities**

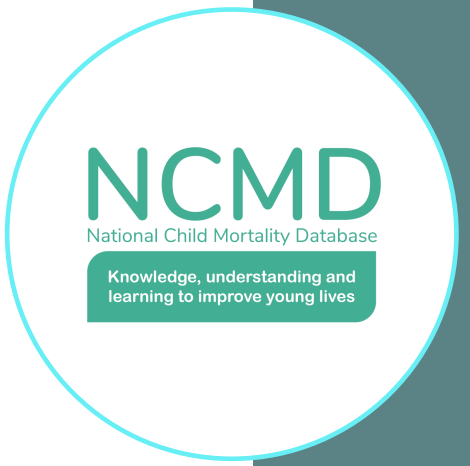
Consider revising the prioritisation criteria for housing allocation schemes to recognise that families with infants under 2 years of age must have enough room for safe use of a full-size cot to support them to follow safer sleeping advice. **Action by: Department for Levelling Up, Housing and Communities, Local Authorities**



# Poverty & Deprivation

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

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



# Sleep Environment

Ensure safer sleep advice is personalised to the individual circumstances of each family, and that support addresses both the environmental and psychological barriers to following advice, to reduce the risks of sudden unexpected, unexplained death in infancy. Professionals discussing safer sleep advice should be aware of the high number of deaths in which unplanned co-sleeping took place in a hazardous environment so they can ensure that every family gets advice for such situations. **Action by: Commissioners and Providers of Postnatal Care, Health Visiting Services, Antenatal Services, Neonatal Hospital and Community Staff, Family Nurse Partnerships, GPs and family support workers**

Consider use of validated Safer Sleep Assessment Tools to identify families with infants at higher risk of SIDS. This will support Health Visitors, Social Workers and GPs to identify vulnerable families and provide enhanced support. This should include seeing where the infant sleeps during home visits and providing person-centred advice for families depending on their individual circumstances. **Action by: Local Authorities, Safeguarding Children Partnerships, Children's Services, Health Visiting Services and GPs.**

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# Research

Prioritise research on sudden unexpected and unexplained deaths of children over 1 year of age to identify potentially modifiable factors so professionals can work to prevent these deaths. **Action by: Department of Health and Social Care, NHS England, National Institute for Health and Care**

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# Other

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

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

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

Action by: National Police Chiefs Council, Commissioners of joint agency response processes, NHS England, Department of Health and Social Care

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# Panel Discussion

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