

National Hub for Reviewing and Learning from the Deaths of Children and Young People

Data overview report

March 2024

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Published March 2024

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Introduction

The death of every child and young person is devastating and families, friends, carers, and communities feel the impact deeply.

Scotland has one of the highest mortality rates for under-18s in Western Europe, with around 300 children and young people dying each year ⁽¹⁾. It has been estimated that around a quarter of those deaths could be prevented ⁽²⁾.

Commissioned by Scottish Government, Healthcare Improvement Scotland, in collaboration with the Care Inspectorate, established a National Hub for Reviewing and Learning from the Deaths of Children and Young People (National Hub). Focusing on using evidence to deliver change, the National Hub ultimately aims to help reduce preventable deaths and harm to children and young people by:

- ensuring that the death of every child¹ in Scotland is subject to a quality review
- improving the experiences of, and engagement with families and carers, and
- channeling learning from reviews across Scotland that could direct action to help reduce preventable deaths ⁽³⁾.

We are pleased to introduce this first National Hub data report. This should be read in conjunction with the [National Hub Overview Report](#) ⁽⁴⁾ which was published in February 2023 and sets out the steps taken to establish the National Hub, the stakeholders who contributed to this and our activities and learning during the first year of implementation. More information about the National Hub's key activities and milestones can be found in Appendix 1.

This data report builds on our previous learning and notes the progress made since then as new arrangements to review child deaths become embedded across Scotland. The report summarises national child death data for a single year from **1 April 2022 to 31 March 2023**. This is followed by an overview of learning from child death reviews carried out by NHS boards and local authorities / Health and Social Care Partnerships (HSCPs) from the start of National Hub data collection on 1 October 2021 to 31 March 2023. The report concludes with a summary of key learning points and recommendations.

We are extremely grateful to all those supporting this crucial work, particularly at a time of unprecedented pressures, including the longer-term impacts of the Covid-19 pandemic, the effects of which are still being experienced. Without the commitment and efforts of staff across NHS boards and local authorities / HSCPs, partner agencies and importantly, the voices of bereaved families, this report would not be possible.

¹ National Hub guidance, page 2: Reviews should be conducted on the deaths of all live born children up to their 18th birthday, or 26th birthday for young people who are in receipt of continuing care or aftercare at the time of their death.

Data analysis: summary of National Records of Scotland data

This section gives an overview of deaths that occurred between **1 April 2022 and 31 March 2023** of children aged between 0-17 years and young people in receipt of continuing care or aftercare services at the time of their death, up to the age of 26 years. This reporting period allows for alignment and comparison with the other UK nations.

Data in this section are published with permission of National Records of Scotland (NRS) which registers all deaths in Scotland and publishes official statistics.

Deaths of children under 18

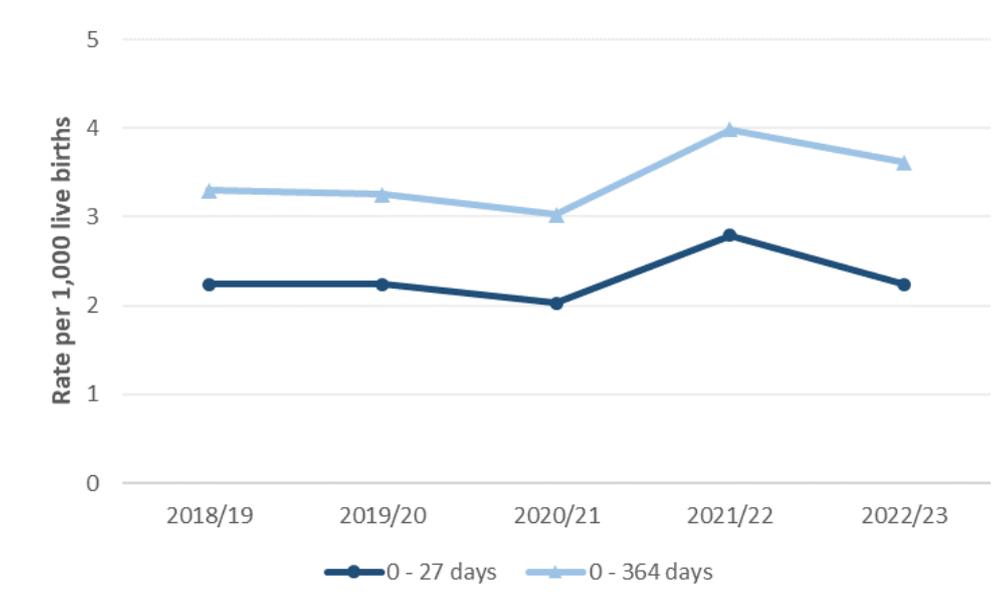
There were **280 deaths** of children aged between 0-17 years in Scotland between April 2022 and March 2023. Based on the latest mid-year population estimate for 2021, this is a rate of 27.3 deaths per 100,000 children ⁽⁵⁾. The National Child Mortality Database (NCMD) recently reported an estimated rate of 31.8 deaths per 100,000 children in England for the same year ⁽⁶⁾.

In 2022/23, 59% of child deaths in Scotland occurred in the first year of life and, of those, two thirds occurred in the neonatal period (0-27 days). An increase in the infant death rate (0-364 days) for 2021/22 compared to the preceding three years was due to an increase in neonatal deaths, and this increase in neonatal deaths has been the focus of a [Neonatal Mortality Review](#) ⁽⁷⁾ by Healthcare Improvement Scotland.

In 2022/23, the neonatal death rates in Scotland returned to rates like those observed between 2018/19 and 2020/21. However, at the time of writing this report, provisional data from January to September 2023 suggest a return to higher neonatal death rates in 2023.

Infant death rates decreased in 2022/23, along with neonatal death rates, but remained higher than those observed between 2018/19 and 2020/21.

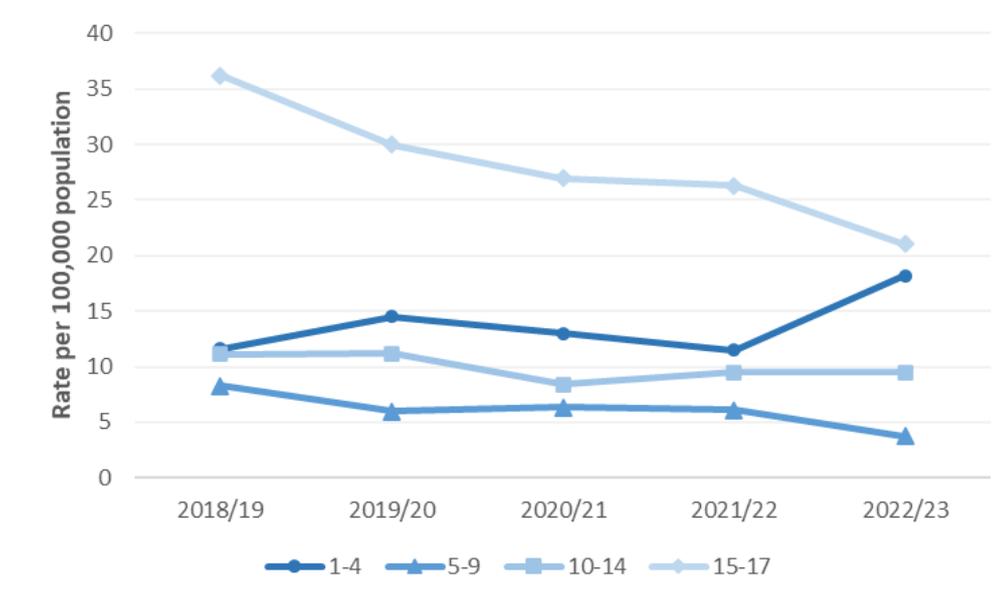
Figure 1: Rate of infant and neonatal deaths per 1,000 live births for 2018/19 to 2022/23



Source: National Records for Scotland Vital Events

For children aged between 1-17 years in 2022/23, the highest death rate was for older children aged between 15-17 years (21 per 100,000 population), though this rate has been steadily falling over five years. The death rate in children aged between 1-4 years increased in 2022/23.

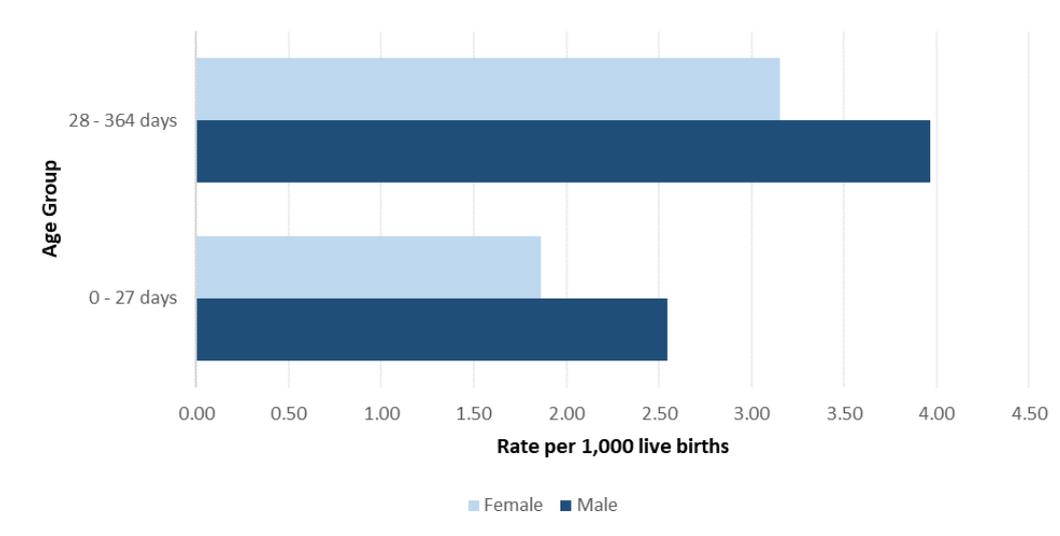
Figure 2: Rate of child deaths per 100,000 population by age group for 2018/19 to 2022/23



Source: National Records for Scotland Vital Events and Mid-Year Estimates

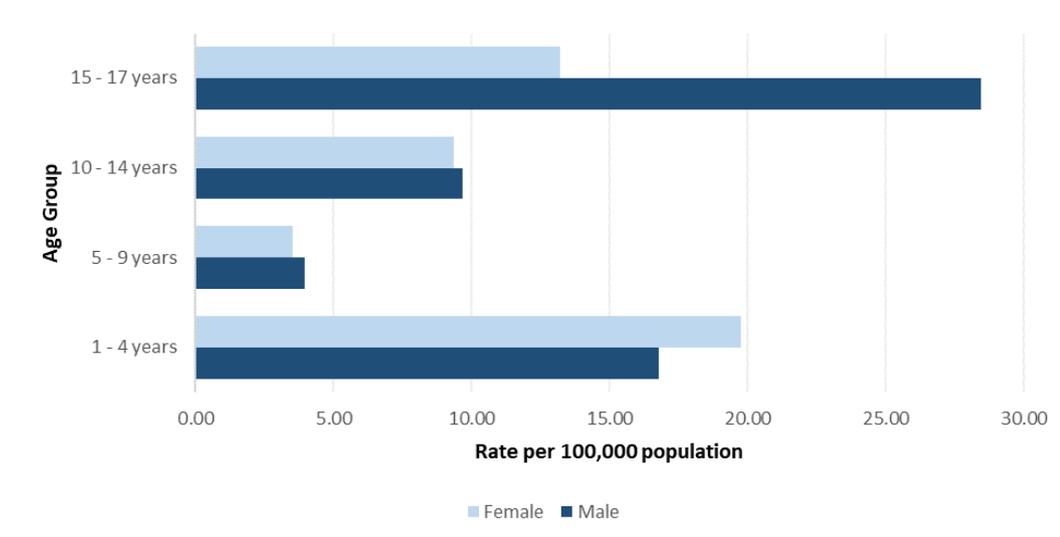
There were more child deaths of males than females, with 58% of child deaths occurring in males. Rates varied between males and females within age groups. In 2022/23, males had a higher rate within infants and also in young people aged between 15-17 years. The biggest difference between males and female is in the 15-17 years age group where the male rate is more than twice that for females.

Figure 3: Rate of infant death per 1,000 live births by age group and sex for April 2022 to March 2023



Source: National Records for Scotland vital events

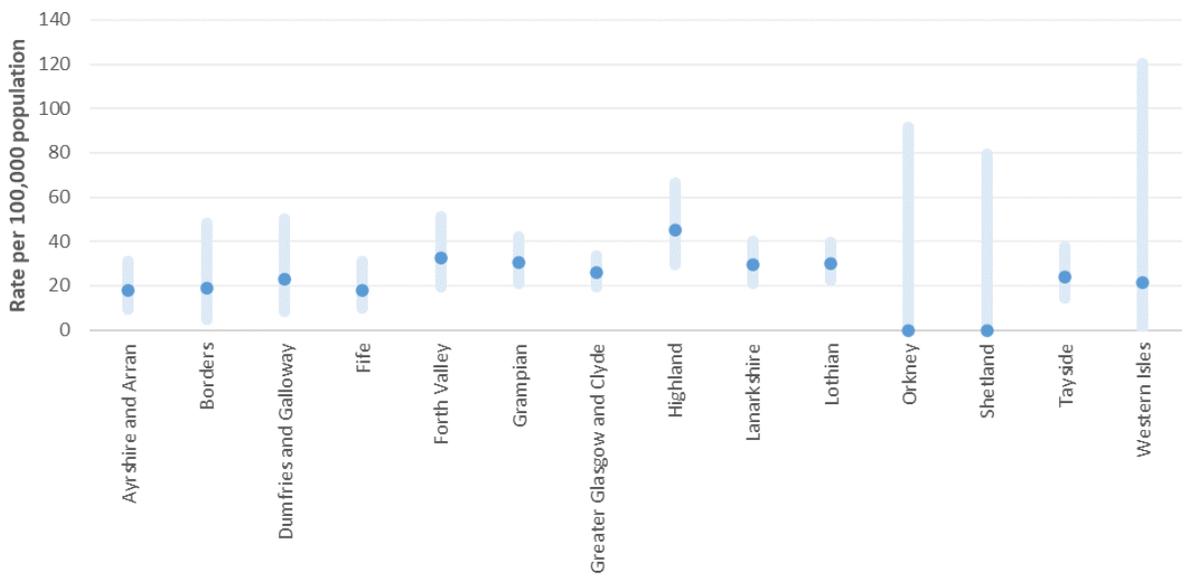
Figure 4: Rate of child death per 100,000 population by age group and sex for April 2022 to March 2023



Source: National Records for Scotland vital events and 2021 mid-year population estimates

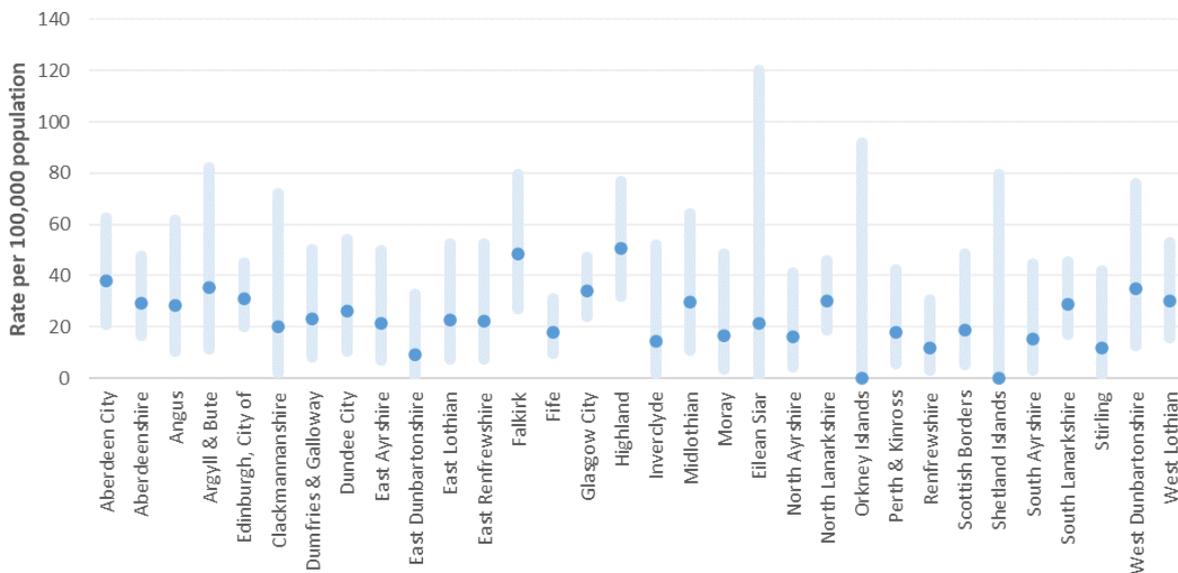
In 2022/23, the rate of child deaths by NHS board of residence ranged from 0 to 45.2 per 100,000 population aged between 0-17 years; and the child death rate by local authority of residence ranged from 0 to 50.9 per 100,000 population aged between 0-17 years. Confidence intervals show the range in which rates could have occurred by chance and must be taken into account when comparing rates for different areas, particularly areas with small populations where confidence intervals are much wider. With a 95% confidence interval there is only a 5% chance of rates occurring outside the interval. The variation in rates could also be partially due to areas having different populations. For example, some areas have higher deprivation which is linked to high child mortality.

Figure 5: Rate of child deaths per 100,000 population by NHS board of residence for April 2022 to March 2023, with 95% confidence intervals



Source: National Records for Scotland vital events and 2021 mid-year population estimates

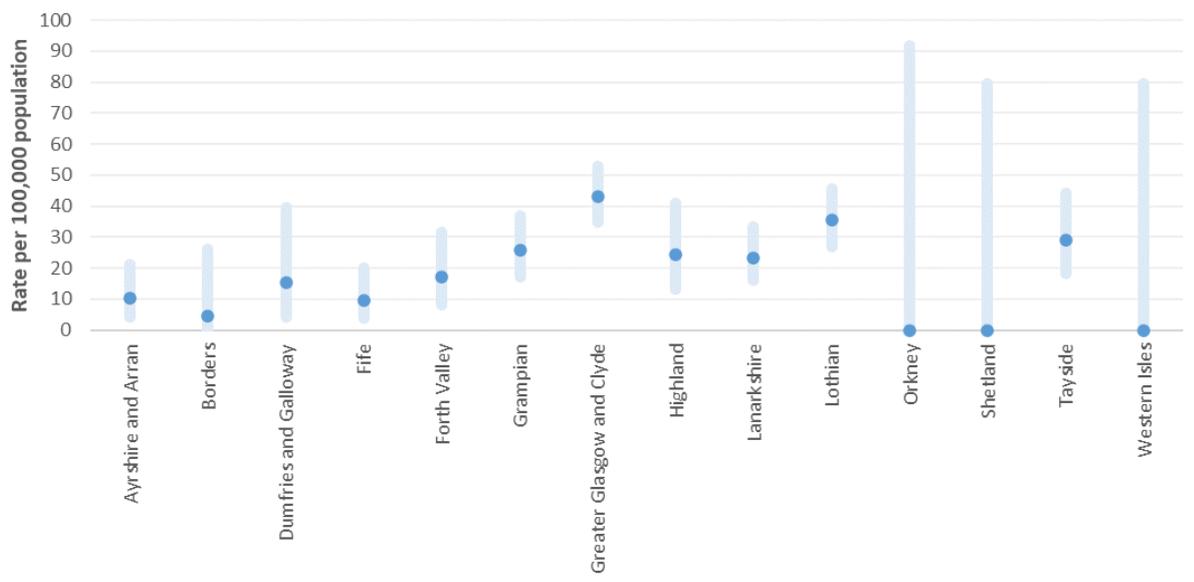
Figure 6: Rate of child deaths by local authority of residence for April 2022 to March 2023, with 95% confidence intervals



Source: National Records for Scotland vital events and 2021 mid-year population estimates

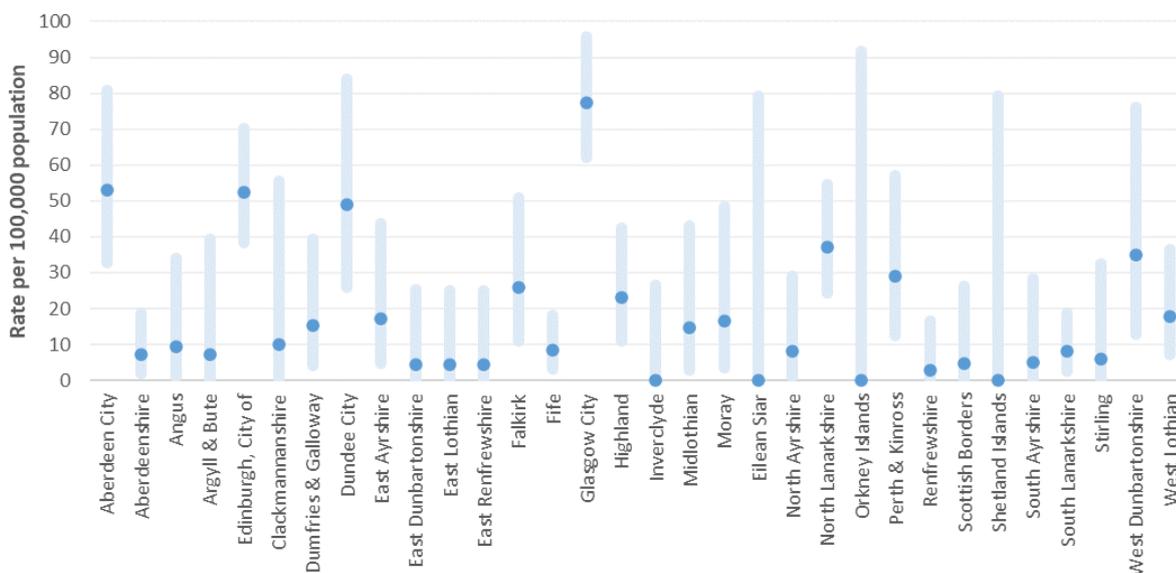
When based on location of death, the child death rate varied more widely; from 0 to 43.2 per 100,000 population for NHS boards and 0 to 77.5 per 100,000 population for local authorities. This is expected as areas with specialist care facilities receive more critically unwell children from across the region and Scotland. This mainly explains why NHS boards and local authorities, with large specialist hospitals, have some of the highest child death rates when based on the area where the death occurred.

Figure 7: Rate of child deaths per 100,000 population by NHS board of death for April 2022 to March 2023, with 95% confidence intervals



Source: National Records for Scotland vital events and 2021 mid-year population estimates

Figure 8: Rate of child deaths by local authority of death for April 2022 to March 2023, with 95% confidence intervals



Source: National Records for Scotland vital events and 2021 mid-year population estimates

NRS classify the underlying cause of death based on information collected on the child’s death certificate together with any additional official information. Deaths that require further investigation as to the cause of death, for example by the Procurator Fiscal, are often initially coded as ‘Sudden unexpected, unexplained death’ then later updated with a confirmed cause of death.

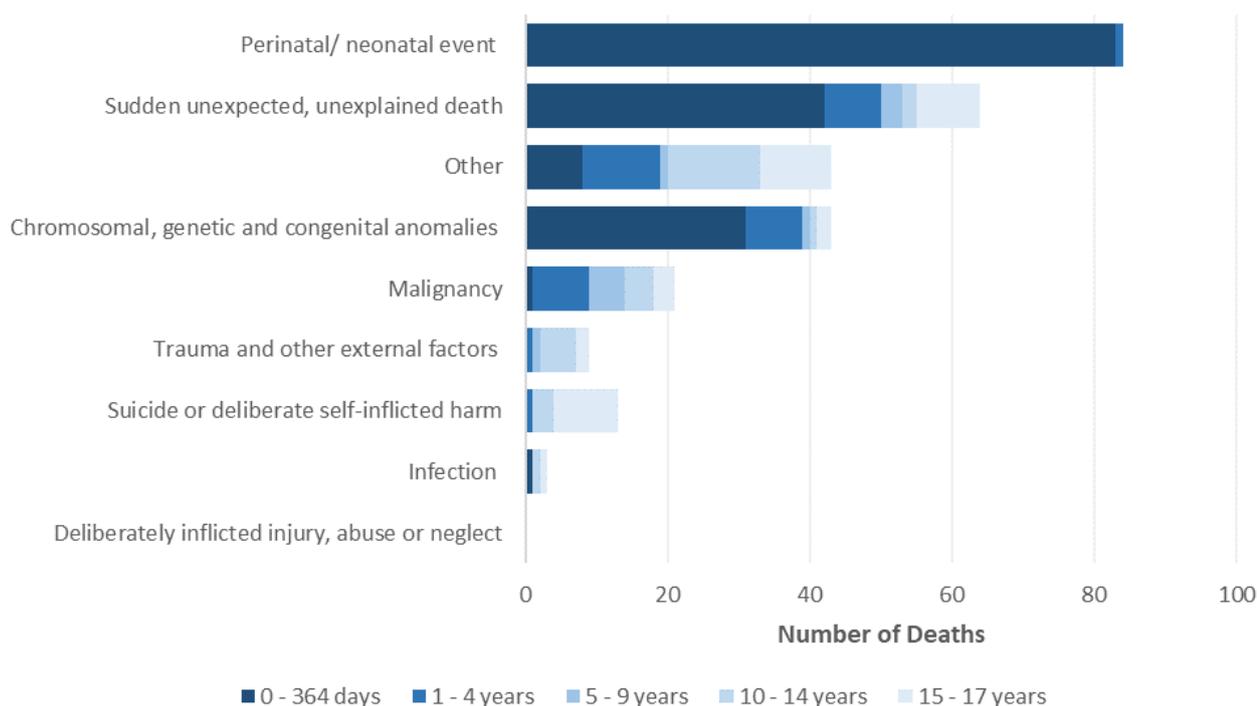
Data for 2023 used in this report has not yet been updated with confirmed cause of death, and data for 2022 was marked as provisional, due to the time delay inherent when Procurator Fiscal investigations are required.

The majority of deaths in children aged between 0-17 years were due to a ‘perinatal or neonatal event’ (30%), due to the largest proportion of deaths occurring in the neonatal period. The second highest number of deaths were due to ‘Sudden unexpected, unexplained death’ (23%), however a number of these will be re-defined once investigations have concluded.

The most common causes of death were:

- ‘Perinatal / neonatal event’ - for children aged under 1
- ‘Other’ - for children aged between 1-4 years (which includes respiratory disorders, epilepsy, metabolic disorders, anoxic brain damage, and sequelae of stroke)
- ‘Malignancy’ - for children aged between 5-9 years
- ‘Other’ - for children aged between 10-14 years (which includes epilepsy, intestinal disorders, cerebral palsy, disorder of the brain, cardiomyopathy, intracerebral haemorrhage and cerebrovascular disease), and
- ‘Suicide or deliberate self-inflicted harm’ - for children aged between 15-17 years.

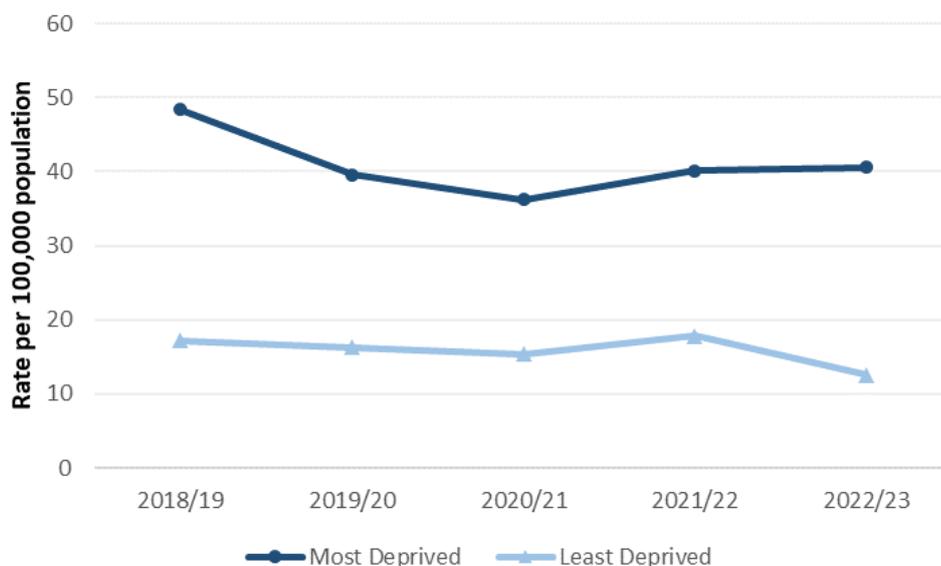
Figure 9: Number of child deaths by cause and age group April 2022 to March 2023



Source: National Records for Scotland vital events and 2021 mid-year population estimates

The recording of ethnicity information in data about deaths of children aged between 0-17 years was around 75% in 2022/23, with the remaining not provided. This makes analysis of child deaths by ethnicity very unreliable, especially for less common ethnic groups. The rate of deaths in the most deprived areas remains well above that in the least deprived areas and, in 2022/23, the gap increased further due to a fall in child deaths in the least deprived group.

Figure 10: Rate of child deaths per 100,000 population by quintile deprivation level for 2018/19 to 2022/23



Source: National Records for Scotland vital events and 2021 mid-year population estimates

Deaths of looked after children and young people receiving continuing care or aftercare services

There is little quantitative evidence on how the health of care experienced children (the term widely used to describe any person who has experience of being in care, regardless of their placement length, type or age) compares with other children in Scotland. A recent population-wide study however, found that care experienced children and young people are, on average, more likely to face adverse health events, including higher deaths compared to the general population ⁽⁸⁾.

In supporting Scotland's Promise ⁽⁹⁾ to care experienced children and young people, the National Hub includes all looked after children and young people in receipt of continuing care or aftercare services at the time of their death within the criteria for a child death review.

There is a statutory requirement for local authorities to notify the Care Inspectorate of the death of a looked after child or young person in receipt of continuing care or aftercare services. Care Inspectorate notification data has therefore been used to inform this section of the report.

There are many, often complex, reasons why a child or young person becomes looked after. Usually, it is to protect them from harm, improve the quality and consistency of care they receive and promote their wellbeing and life chances. In the context of this report, children and young people can be looked after:

- when their parents enter into a voluntary agreement with a local authority to provide regular overnight short breaks ⁽¹⁰⁾. This is typically when children and young people (under the age of 21 years) have complex and enduring disabilities and such arrangements form part of a package of family support

- when children and young people (under 18 years) become subject to a compulsory supervision order made by a child’s hearing because of child protection concerns.

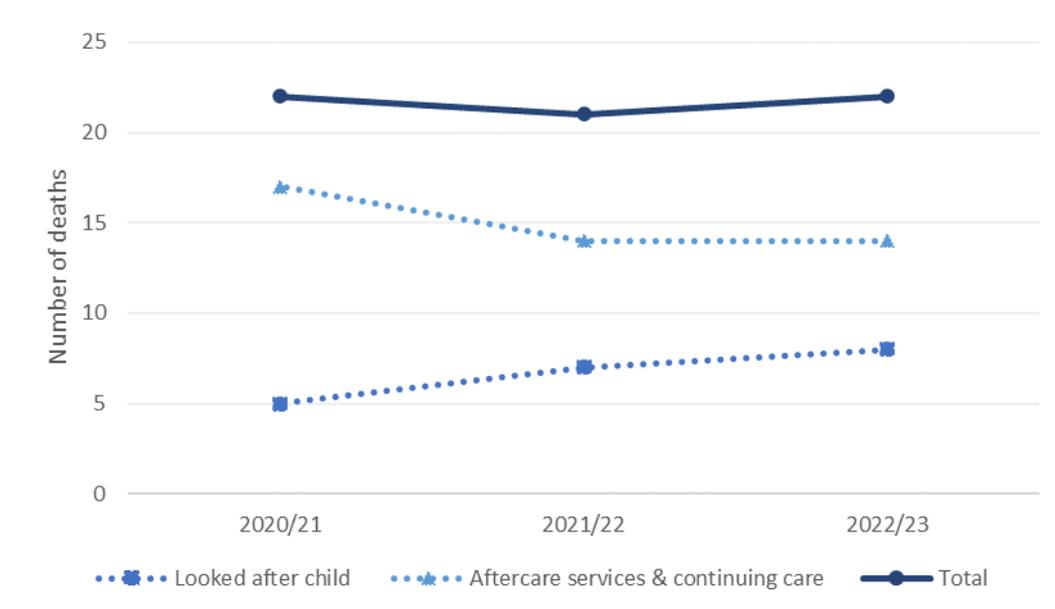
In recognition of the need to improve the life chances of looked after children and young people, the Children (Scotland) Act 2014 ⁽¹¹⁾ strengthened transition arrangements for young people leaving care placements. It introduced a new duty on local authorities to provide continuing care and extended eligibility for the receipt of aftercare up to the age of 26 years. The Care Inspectorate began receiving notifications of the deaths of this group of young people in 2015.

As of 31 July 2022, 12,596 children were looked after, 696 young people were in a continuing care placement and 4,108 were in receipt of aftercare services ⁽¹²⁾.

Between April 2022 and March 2023, the Care Inspectorate received notification of the deaths of eight looked after children and 14 young people in receipt of continuing care or aftercare services. This is roughly in line with the number of deaths reported to Care Inspectorate in the years 2020/21 and 2021/22 ⁽¹³⁾.

Due to the small numbers of these deaths and to protect their identity, we considered the deaths of this group of children and young people over a three-year period. Of the 65 deaths reported between April 2020 and March 2023, there were 20 deaths of looked after children and 45 deaths of young people in receipt of a continuing care placement or aftercare services.

Figure 11: Number of child deaths for looked after children, and young people in receipt of continuing care and aftercare services, for 2020/21 to 2022/23



Source: Care Inspectorate notification of child deaths data

Many of the characteristics of these deaths mirror those reported in the Care Inspectorate publication on the deaths of looked after children in Scotland 2012-2018 ⁽¹⁴⁾. Observed common themes in deaths occurring between April 2020 and March 2023 are noted below.

Looked after children and young people

Over the three-year period, half of the deaths of looked after children were due to medical illnesses or life shortening conditions. For the remainder of looked after children, the reported cause of death included suspected suicide, drug-related death, and traumatic death. A very small number of deaths were recorded as unascertained or unexplained pending the outcome of further investigations.

Young people in receipt of continuing care or aftercare services

Over the three-year period, 45 deaths of young people in receipt of continuing care or aftercare services were notified to the Care Inspectorate. Most of these deaths were reported as drug-related or suspected suicide, with a significantly greater number of deaths among young men than young women. By far, most deaths were of young people receiving aftercare services.

While it is vital we learn lessons from the deaths of this group of children and young people, the limited data available at this time, particularly in relation to young people leaving care, has prevented any meaningful analysis. As more detailed information is gathered by the National Hub through individual child death reviews, we will begin to gain a greater understanding of the lives of these children and young people, the circumstances surrounding their deaths, and the actions necessary to deliver change and reduce future preventable deaths.

Data analysis: early findings from child death reviews

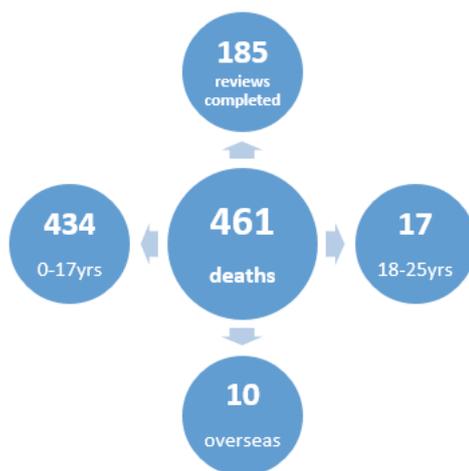
The death of every child and young person in Scotland should be subject to a review. National guidance ⁽¹⁵⁾ for NHS boards and local authorities / HSCPs with a role in reviewing the circumstances around the death of a child or young person, sets out the systems and processes necessary to respond to and review each death. Reviews should conclude with the completion of a core review dataset (CRDS) ⁽¹⁶⁾ which is submitted to the National Hub via an online reporting portal.

While the previous section of the report considers data over the fiscal year 2022/23, this section summarises initial findings extracted from completed CRDS for children and young people who died between 1 October 2021 and 31 March 2023. It provides cumulative information over an 18-month period and begins to offer some insight into the lives and deaths of children and young people as revealed by their individual reviews and information provided by the CRDS.

A range of established processes were already in place to review some child deaths prior to the creation of the National Hub; for example, adverse events and learning reviews. It was recommended that existing review arrangements, where relevant, should be followed ⁽¹⁷⁾ or a single child death review undertaken, the aim being to avoid multiple reviews and to provide clarity for families and staff. Irrespective of the review process followed, the standardised CRDS should be completed following the review and submitted to the National Hub.

During the 18-month period, from 1 October 2021 to 31 March 2023, 461 children and young people died: 434 children between 0-17 years; 17 young people between the ages of 18 and 25 who met the criteria for the National Hub programme; and 10 children, ordinarily resident in Scotland, who died overseas and whose deaths were therefore not registered with NRS. 185 child death reviews and CRDS' were completed by NHS boards, local authorities/HSCPs and their partners.

Figure 12: Overview of child deaths and reviews completed between 1 October 2021 to 31 March 2023



Source: National Hub online reporting portal

Data limitations

It is to be expected that there will be a lag in time between the date of the child's death and conclusion of the review process. External factors, such as lengthy waits for the outcomes of statutory investigations can further delay the completion of a review and subsequent CRDS. The limited amount of data available means that we are not yet able to comment on themes or trends, and more information is required to allow meaningful analysis. Nonetheless, we can begin to draw some emergent messages from the data as outlined below.

Category of death

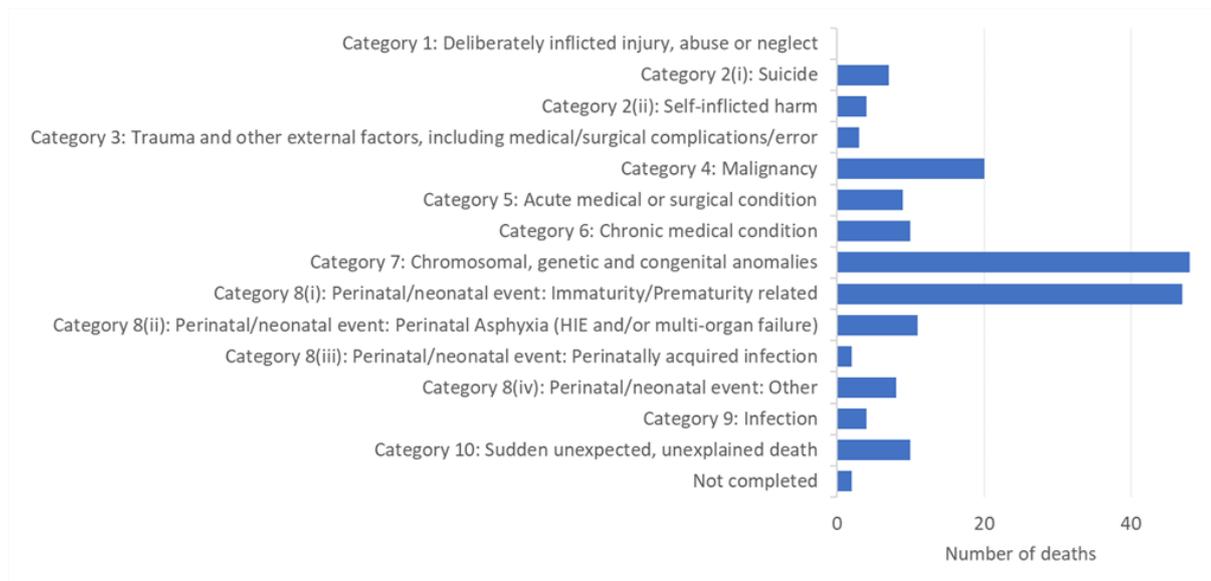
The categorisation of death recorded in the CRDS makes clearer the underlying reason for a child's death, including sub-categorising the largest group, perinatal and neonatal deaths. Categories can differ from the medical certificate cause of death and are agreed by the local review team at the end of the process. The categories in the CRDS align to those recorded by NCMD, which allows us to compare Scottish data with other UK regions.

Perinatal and neonatal related deaths form the largest category of deaths, with those due to prematurity making up the largest subcategory within this. 'Chromosomal, genetic and congenital abnormalities' is the second largest category, reminding us that the root cause of a child's medical complexity often arises from these seminal issues.

At the end of the review process, there were still 10 deaths that remained unexplained. The introduction of improved genetic testing (whole genome sequencing) might help to determine the cause of some of these deaths in the future.

A very small number of deaths were categorised as primarily due to infection. The four nations' rapid review of invasive Group A Streptococcus (iGAS) covered deaths due to this specific organism ⁽¹⁸⁾.

Figure 13: Categories of death as recorded on the CRDS for deaths between 1 October 2021 and 31 March 2023



Source: National Hub online reporting portal

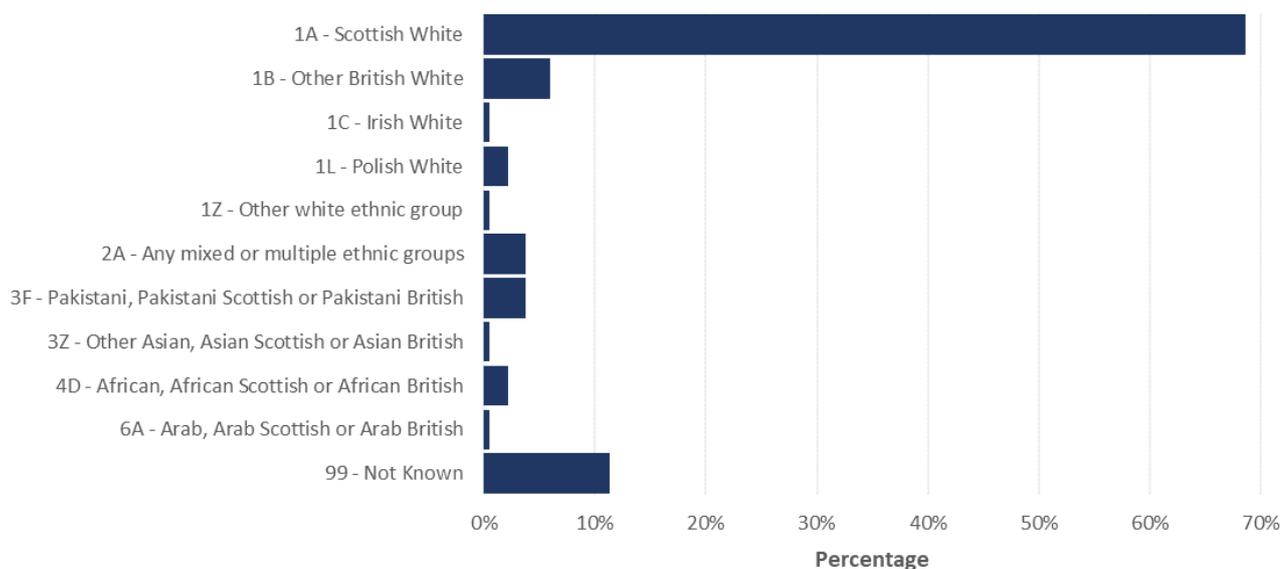
Ethnicity

While NRS data indicated recording of ethnicity at 75%, this was better documented in the CRDS, where the child's ethnicity was recorded in 89% of cases. Almost 78% of children and young people who died were of Scottish white or another white ethnicity. This was followed by smaller numbers of children from minority ethnic groups (11%). A further 11% were recorded as not known.

A recent report by NCMD ⁽¹⁹⁾ highlighted an increase in the number of infant deaths of black and Asian ethnicity during 2022/23 compared to the previous year and a widening of inequalities between children from the most and least deprived neighbourhoods of England.

We will continue to monitor ethnicity and deprivation rates of child deaths in Scotland to establish whether a similar pattern is emerging here.

Figure 14: Ethnicity as recorded on the CRDS for deaths between 1 October 2021 and 31 March 2023



Source: National Hub online reporting portal

Location of death

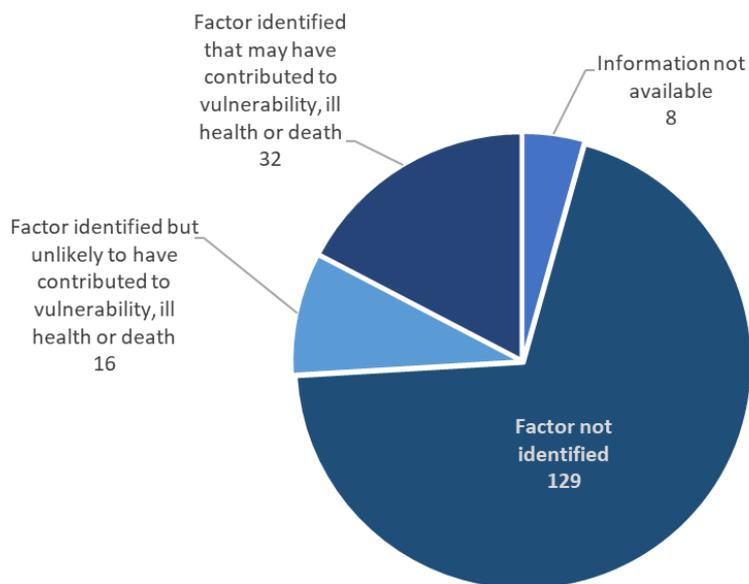
70% of children and young people whose deaths were reviewed, died within a hospital setting, with a further 5.5% dying in a hospice. Fewer children died at home (17%); however, it was not yet possible to establish if these deaths were anticipated or unexpected, or whether this was the preferred location for expected deaths. A further 7% of children died in other locations such as in a community setting or outside Scotland.

Developmental impairment or learning disability

Just over a quarter of children and young people whose deaths were reviewed, were recorded as having a developmental impairment or learning disability, and in most cases (66%), this was thought to have contributed to their vulnerability, ill health, or death. This group will include children with extremely complex health and social care needs and multiple co-morbidities; however, it does not lessen the impact or the desire to change outcomes.

This correlates with previous studies ⁽²⁰⁾ which have shown that children with learning disabilities are at least 12 times more likely than other children of the same age to die in childhood and that adults with learning disabilities are twice as likely to die from preventable illnesses. For a small number of children who died, information about disability was not recorded.

Figure 15: Developmental impairment or learning disability as recorded on the CRDS for deaths between 1 October 2021 and 31 March 2023



Source: National Hub online reporting portal

Modifiable factors

This section of the CRDS allows review teams to identify factors which might, by means of a locally or nationally achievable intervention, be modified to reduce the risk of future death of a child / young person in similar circumstances. Most reviews (79%) identified no modifiable factors in the child's death; however, in 17% of reviews factors were identified that may have contributed to the child's vulnerability, ill health or death. In less than 5% of reviews, review teams found there to be insufficient information to make a judgement about this.

This aspect of the CRDS provides significant information about practice and systems, and where change and improvement may help reduce preventable deaths. NCMD data for 2022/23 suggests that around 30% of all child deaths in England have recorded modifiable factors such as smoking or substance misuse (by parent / carer), unsafe sleeping arrangements, challenges with access to services, or poor home environment. The small number of deaths where modifiable factors were recorded for Scottish children (31 children), limits our ability at this time to comment on themes or make recommendations.

There is a key role for the National Hub to collate and analyse the modifiable factors captured within datasets and to highlight emerging trends or patterns of concern. As we gain further insight into these factors and their relationship to different cause of death groups, we will share this learning nationally to inform and to influence, where relevant, practice and policy change.

Bereaved families' experiences

While reviews enable services and the wider health and social care system to learn and make improvements in care, they are also designed to give parents as much information as possible about their child's death. Knowing how and why their child died can help parents and carers begin to make sense of what happened.

Our report on families and carers experiences of the review process following their child's death ⁽²⁰⁾ found that many families had benefitted from compassionate care and support from those who knew their child well. However, this was not the experience of all families, and others felt that they did not always understand the review process or how they could contribute to it. Some families did not know whether there had been a review of their child's death, and if there had been, what the findings were. In our recommendations, we highlighted the importance of involving and supporting families throughout the review process in a way which is flexible, sensitive, and family-centred. Having in place a key contact or single point of contact was central to ensuring families had direct access to those involved in carrying out the review.

From our dataset information, we found that almost all families (94%) were offered bereavement or other forms of support following their child's death. Over three quarters of families were informed that a review would take place and were supported to contribute to the review process, and 70% of families received feedback following their child's review. It was a concern that almost a quarter of families were not aware that a review would be taking place, and therefore did not have the opportunity to raise questions about their child's end of life and death, or to comment on positive aspects of care. This issue requires to be addressed as a priority by those responsible for carrying out reviews.

Practice change and improvement

From our meetings with NHS boards and local authorities, engagement with other national organisations and our initial review of CRDS submissions, we identified positive examples of practice change and improvement. While not universal to all areas, it was encouraging to hear about creative and innovative practice developments taking place. For more information, contact the National Hub at his.cdrnationalhub@nhs.scot or register with our community of practice.

<p>Supporting families</p>	<ul style="list-style-type: none"> • Improved written information for bereaved families and carers about child death reviews and how they can contribute to the process. • Enhanced memory-making for families following the death of their child. • Investment in bereavement support services. • Better awareness of the need for different types of support for families. • Key contact for families and carers to maintain contact throughout the review process.
<p>Planning end of life care</p>	<ul style="list-style-type: none"> • Improved visibility of children’s anticipatory care plans on electronic systems. • Improved communication between primary care and secondary care teams for children with life shortening conditions.
<p>Improving systems</p>	<ul style="list-style-type: none"> • Improved systems and practices that support greater partnership working across agencies, information sharing and joint reviews. • Systems in place to ensure all child deaths are reviewed (this now includes groups of children and young people whose deaths would not necessarily have been reviewed previously). • Local agreements to ensure appropriate transfer of children’s bodies where this is required after deaths in the community.
<p>Sharing learning</p>	<ul style="list-style-type: none"> • Production of a board-specific child death review report with a public health focus. • Early steps linking learning from local child death reviews with strategic children’s service planning groups and other strategic partnerships. • New approaches to share learning within and across services and organisations.
<p>Collaborating across borders</p>	<ul style="list-style-type: none"> • Good collaboration with cross-border child death review processes for children who die in England, or children normally resident in other parts of the UK who die in Scotland. • Improved collaboration with other UK nations, for example supporting the rapid review of invasive Group A Streptococcus death and the development of guidelines for when a child dies abroad.

Key learning points and recommendations

This first data report provides an overview of both national data and information gathered from completed child death review datasets. As noted throughout the report, the National Hub is still in its early stages of data collation, and limitations in our data means that we are not yet able to comment on widespread themes or trends. As our evidence base grows and further data becomes available, we will provide more comprehensive analysis of findings and where relevant, any recommendations for action to help reduce preventable deaths.

The national data has highlighted important messages that will require further review and exploration to better understand the reasons why children in Scotland die in childhood.

Key learning from the data so far:

- a. Perinatal and neonatal related deaths formed the largest category of deaths, with those due to prematurity making up the largest subcategory within this. Rates of infant and neonatal deaths have fluctuated over the previous five years. Following an increase in neonatal deaths reported during 2022, Scottish Government commissioned Healthcare Improvement Scotland to carry out a review. While out with the scope of this report: the review ⁽²¹⁾ and a subsequent reported increase in infant deaths observed by Public Health Scotland during 2023; highlight the need for continued attention and action to review and understand the reasons behind the fluctuations in death rates for this group of infants. (Recommendation 1)
- b. The second highest number of deaths for children 0-17 years was due to ‘sudden, unexpected, unexplained death’, with most occurring in children under 1 year. While some of these deaths will be re-defined once investigations have concluded, further analysis is needed to understand the factors associated with sudden, unexplained deaths in childhood. In line with national guidance around safer sleeping, we would encourage those working with families with very young children to follow this advice ⁽²²⁾. (Recommendation 1)
- c. Encouragingly, the death rate among older children and young people aged between 15-17 years has been steadily falling over the past five years. However, it was a concern that suicide and self-harm was recorded as the leading cause of death, and that overall, deaths of boys were more than double that of girls in this age group. A report on suicide among young people in Scotland ⁽²³⁾ highlighted that suicide was the leading cause of death among children and young adults aged between 5-24 years, accounting for one in four (25.7%) lives lost, during the period 2011 to 2020. It also highlighted that those across the 5-24 age group who died by suicide were less likely to have had contact with a healthcare service in the period before death, compared to older adults who died by suicide. Collaboration with other national organisations with a responsibility for reducing child deaths by suicide is vital if we are to optimise learning from these tragic deaths and inform actions which may help to reduce such deaths in the future. (Recommendation 1)

- d. There was an increase in 2022/23 from previous years in the death rates of 1-4-year-olds, with a range of causes of death, including sudden, unexplained death. While it is too soon to determine the significance of this increase, we will continue to review this data in collaboration with other national organisations. (Recommendation 1)

Recommendation 1

NHS boards, children's services planning partners and other relevant national organisations should work together to identify any improvements that can be made to the existing systems for responding to early signals in the data. Signals may indicate a significant increase or decrease in deaths of children or young people at a local and / or national level. Early identification could help to improve understanding of any emerging contributory factors and ensure timely response or share learning. This should include consideration of the wider public health factors associated with these deaths, as well as learning from relevant developments in other parts of the UK.

- e. A key part of the review process is the identification of modifiable factors by review teams. These are the factors which might, by means of a locally or nationally achievable intervention, be modified to reduce the risk of future death of a child or young person in similar circumstances. A more comprehensive analysis of modifiable factors, as they relate to different cause of death groups, will become the focus of National Hub activity as more information is obtained. To support this, NHS boards, local authorities / HSCPs and partnerships with responsibility for carrying out child death reviews should ensure that careful consideration is given to this section of the CRDS and ensure complete and well-considered dataset information is provided. (Recommendation 2)
- f. Elements of the NRS data and the CRDS were not always fully completed which made analysis of important aspects of the data less reliable. For example, the ethnicity of the child was not always recorded consistently in the NRS data or the CRDS. NHS boards, local authorities / HSCPs and partnerships with responsibility for carrying out child death reviews should ensure they fully complete the CRDS prior to submission. (Recommendation 2)

Recommendation 2

NHS boards, local authorities / HSCPs and partnerships with responsibility for carrying out child death reviews should ensure that core review dataset information, including ethnicity, is completed fully. Particular attention should be given to modifiable factors given their potential to reduce preventable deaths.

- g. Most deaths among young people who had left care but continued to receive a service from the local authority were because of suspected suicide or were drug-related, with a significantly greater number of deaths among young men than young women. By far, most deaths were of young people receiving aftercare services. Data about the circumstances of the lives and early deaths of this group of young people was limited. A thematic review should be carried out by the National Hub when more information becomes available (Recommendation 3).

Recommendation 3

The National Hub, in collaboration with other relevant national organisations, should carry out a thematic review into the deaths of looked after children and young people in receipt of a continuing care placement or aftercare services. This should be carried out at a time when more information becomes available.

- h. Of the 461 child deaths which have occurred since the National Hub launched in October 2021, 40% of children who died had their reviews completed by NHS boards / local authorities. Many more reviews are in progress. Encouragingly, we note that children and young people whose deaths may not have been reviewed previously were now having the circumstances of their lives, and deaths, reviewed. In a climate of competing priorities and workforce challenges, NHS boards, local authorities and their partners were working hard to prioritise this work as they recognised the importance of learning lessons from each child's death. Local areas were keen to improve their understanding of the data and how they compared with other areas and nationally. The National Hub will have a key role in supporting further development of this work. (Recommendation 4)

Recommendation 4

The National Hub should strengthen and improve the current data systems to support NHS boards and local authorities to analyse and compare data at local and national levels.

- i. Reassuringly, almost all families and carers were offered bereavement or other support following the death of their child. While most families were involved in their child's review, there remained a significant proportion who were not. Some families were unaware of the child death review process and their right to contribute to this. This issue requires to be addressed as a priority by those responsible for carrying out reviews. (Recommendation 5)

Recommendation 5

NHS boards, local authorities / HSCPs and partnerships with responsibility for carrying out child death reviews should review local child death review policies and practice to ensure bereaved parents and carers are informed about their child's review and supported to contribute to the review process.

Appendix 1

National Hub key activities and milestones

2020	<ul style="list-style-type: none">• Published report on scoping exercise.• Established stakeholder groups and engagement.• Recruited pathfinder sites in NHS Lothian, NHS Tayside and NHS Lanarkshire.
2021	<ul style="list-style-type: none">• Published National Guidance for reviewing child deaths.• Developed a core review dataset (CRDS) with guidance and training.• Built a network of implementation leads responsible for establishing local systems in each NHS board and local authority / HSCP.• Consulted, tested and refined the National Hub model and guidance with stakeholder groups and pathfinder sites.• Formed an online Community of Practice for those involved in child death reviews to share ideas and learning.• Established secure systems for processing deaths data from National Records of Scotland (NRS).• Launched the National Hub child death review process on 1 October 2021.• Launched a survey to gather views of bereaved families and carers.
2022	<ul style="list-style-type: none">• Published the report: When a child dies: Learning from the experiences of bereaved families and carers ⁽²⁴⁾.• Established quarterly meetings with counterparts across the four UK nations.• Gained approval from NHS Scotland for the National Hub to receive and process data from NHS boards.• Delivered two rounds of engagement meetings with local area child death leads to identify positive practice developments and share learning across Scotland.
2023	<ul style="list-style-type: none">• Launched our online reporting portal to collect CRDS.• Published our Overview report: Year 1• Published an information booklet: Supporting families in Scotland with the child death review process• Presented our work at the Royal College of Paediatrics and Child Health and Scottish Paediatric Society conferences.• Co-hosted our first learning event with third sector partners titled: What matters to families?

Appendix 2

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Published March 2024

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