Healthcare Improvement Scotland

care inspectorate

National Hub for reviewing and learning from the deaths of children and young people

Data release: Year ending 31 March 2024

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Contents

Introduction

Purpose of the National Hub

Healthcare Improvement Scotland and the Care Inspectorate have hosted the National Hub for reviewing and learning from the deaths of children and young people (National Hub) since October 2021. By ensuring that the death of every child in Scotland is subject to a quality review and that bereaved families and carers are engaged in those review processes, the National Hub aims to identify and share learning from reviews and help reduce preventable deaths.

About child death reviews

Reviews are conducted into the deaths of all live born children between 0-17 years, and young people up to the age of 26 years who are in receipt of continuing care or aftercare services at the time of their death.

The National Hub worked with stakeholders to create national guidance for NHS boards and local authorities to use when reviewing the deaths of children and young people in Scotland. The guidance recommends keeping family and carers at the centre of the review process and provides key steps to ensure consistency when reviewing the circumstances surrounding the death.

Information from each review is captured in a core review dataset (CRDS). Each NHS board and local authority or health and social care partnership (HSCP) area across Scotland uploads completed CRDS to a secure online reporting portal, which allows the National Hub to analyse review data at a national level.

Presenting the data

Following publication of its Data overview report in March 2024, the National Hub is pleased to introduce this first, annual data release, which summarises child death data from National Records of Scotland (NRS) from 1 April 2023 to 31 March 2024 and compares it to historic data by financial year from 1 April 2019. This release also summarises findings from child death review data from the start of National Hub data collection on 1 October 2021 to 31 March 2024. It provides an overview of currently available data which, over time, will inform future thematic child death reports. These reports will focus on factors we identify as having the greatest potential for change. In this data release, 'child' can mean a baby, child or young person.

Data analysis: summary of National Records of Scotland (NRS) data

This section offers an overview of child death data from NRS from 1 April 2023 to 31 March 2024 and compares it to historic data by financial year from 1 April 2019. It encompasses children aged between 0-17 years and young people in receipt of continuing care or aftercare 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 NRS, which registers all deaths in Scotland and publishes official statistics.

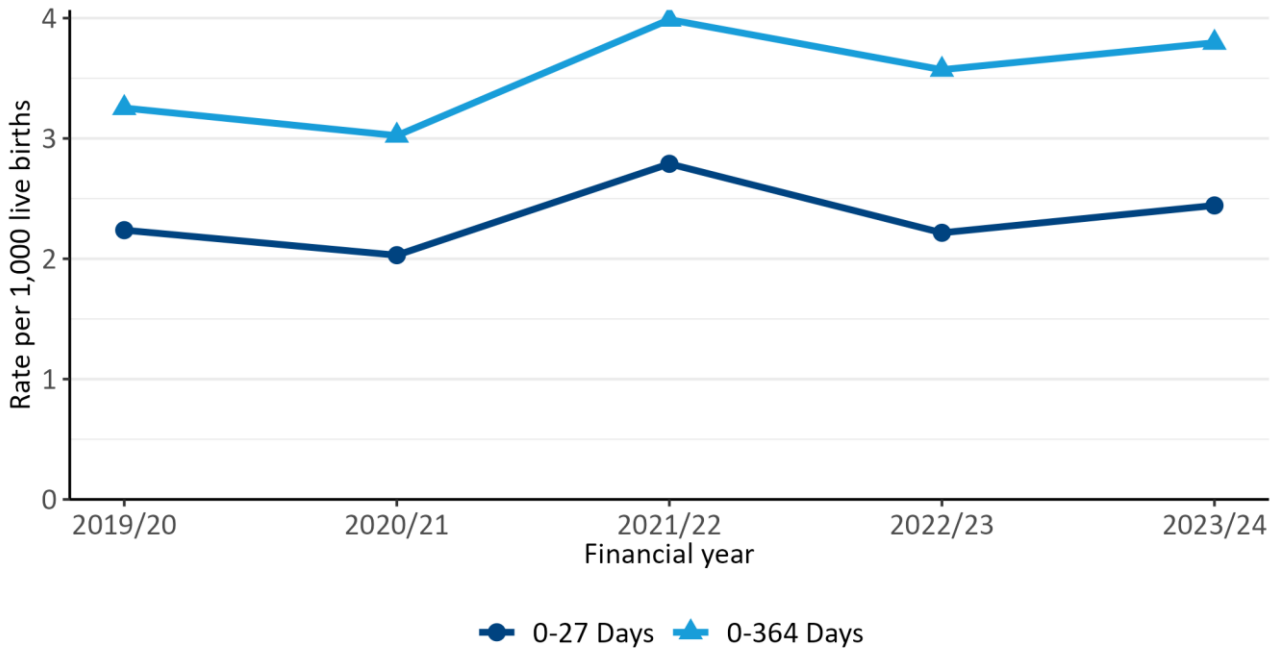
Deaths of children under 18

There were 297 deaths of children aged between 0-17 years in Scotland between April 2023 and March 2024. Based on the latest mid-year population estimate for 2023, this is a rate of 29.3 deaths per 100,000 children.

Age

Infant and neonatal death rates for 2023/24 are below the rates observed in 2021/22 but higher than those observed previously (Figure 1.1).

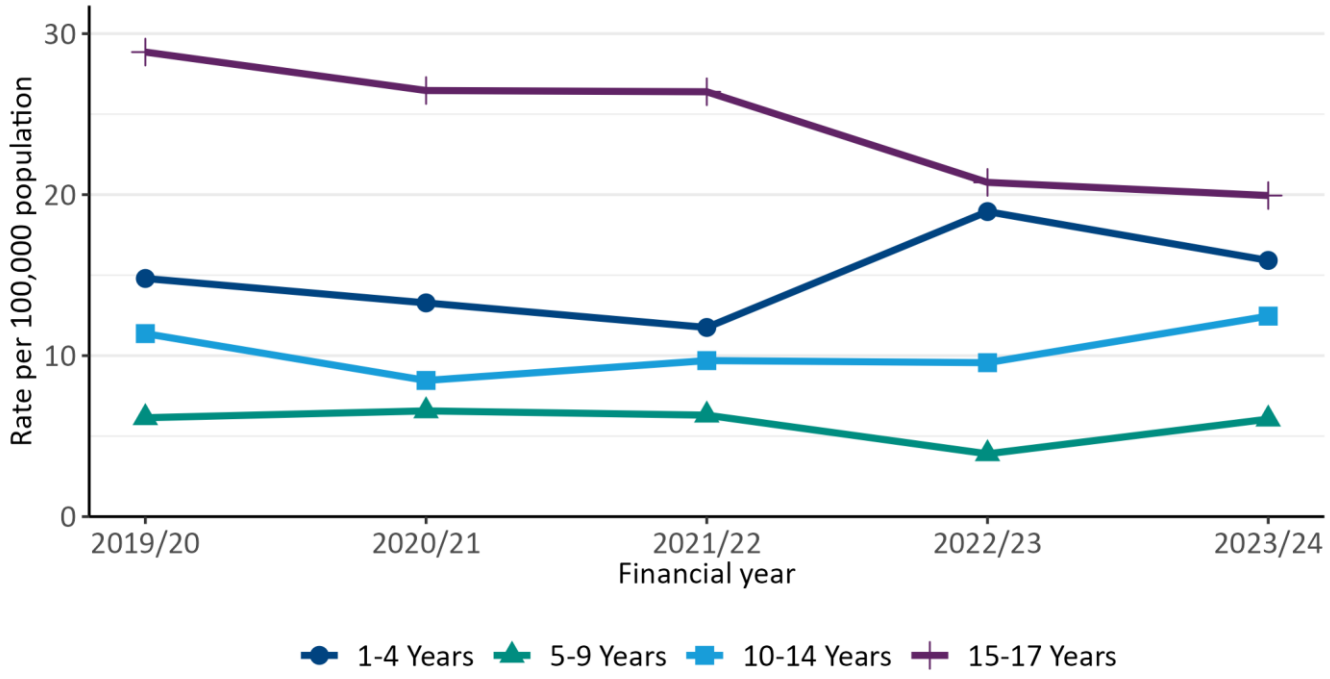
Figure 1.1: Rate of neonatal and infant deaths by financial year



Source: National Records of Scotland vital events

For children aged between 1-17 years the highest death rates were for older children aged between 15-17 years (20 per 100,000 population), though this rate has been steadily falling over five years. The death rate in children aged between 1-4 years fell in 2023/24 after increasing in 2022/23. Death rates for both 5-9 years and 10-14 years have remained relatively consistent over five years (Figure 1.2).

Figure 1.2: Rate of child deaths by age group and financial year

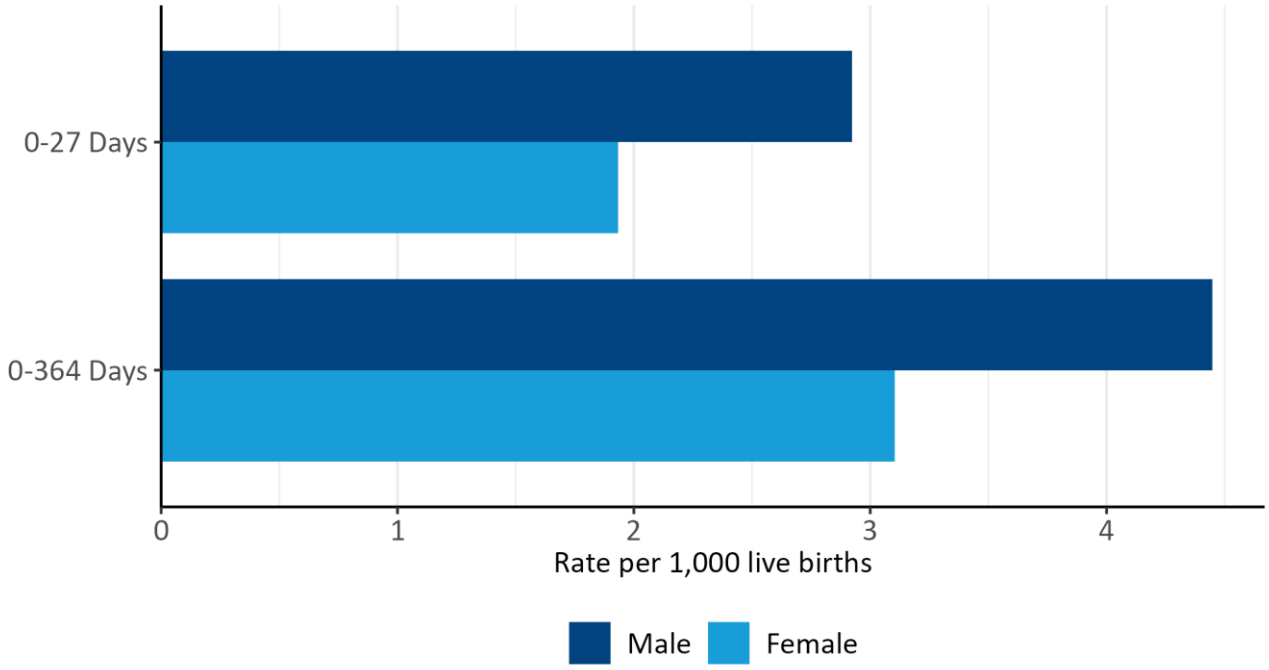


Source: National Records of Scotland vital events and mid-year population esimates

Age and sex

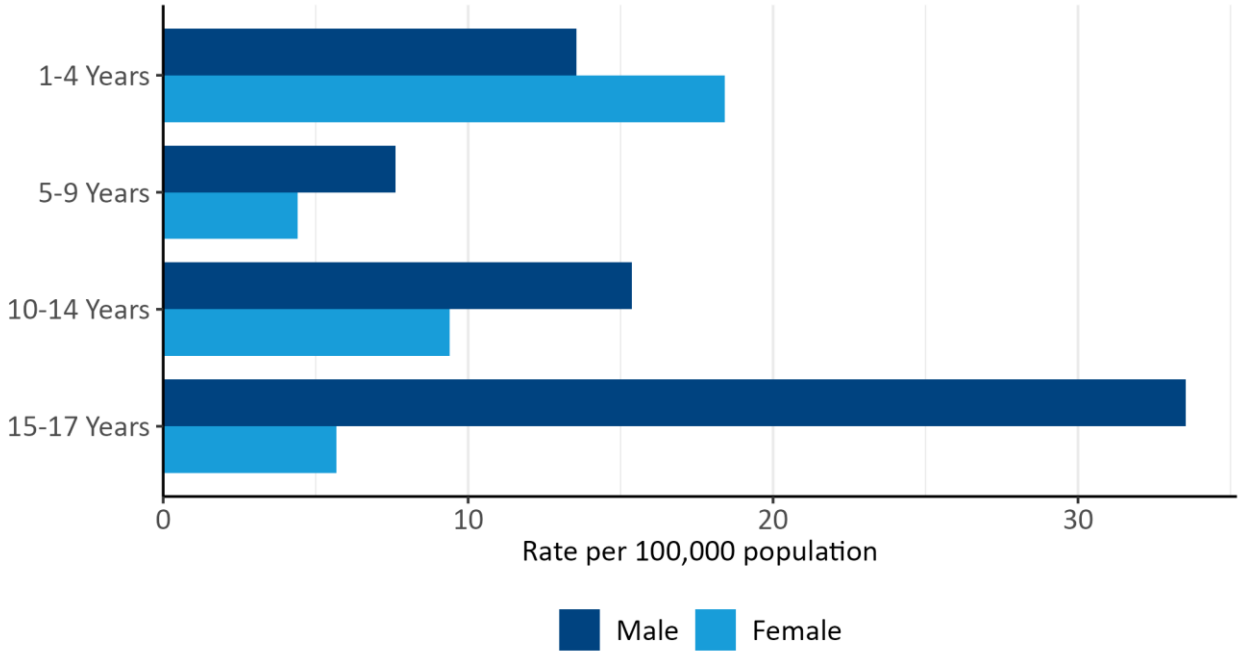
Rates varied between males and females within age groups. In 2023/24, males had a higher rate in all age groups except 1-4 years. The biggest difference between males and females is in the 15-17 years age group where the male rate is more than five times that for females (Figure 1.3 and 1.4). The difference in death rate between males and females in this age group is consistent with previous years.

Figure 1.3: Rate of neonatal and infant deaths by age group and sex in 2023/24



Source: National Records of Scotland vital events

Figure 1.4: Rate of child deaths by age group and sex in 2023/24

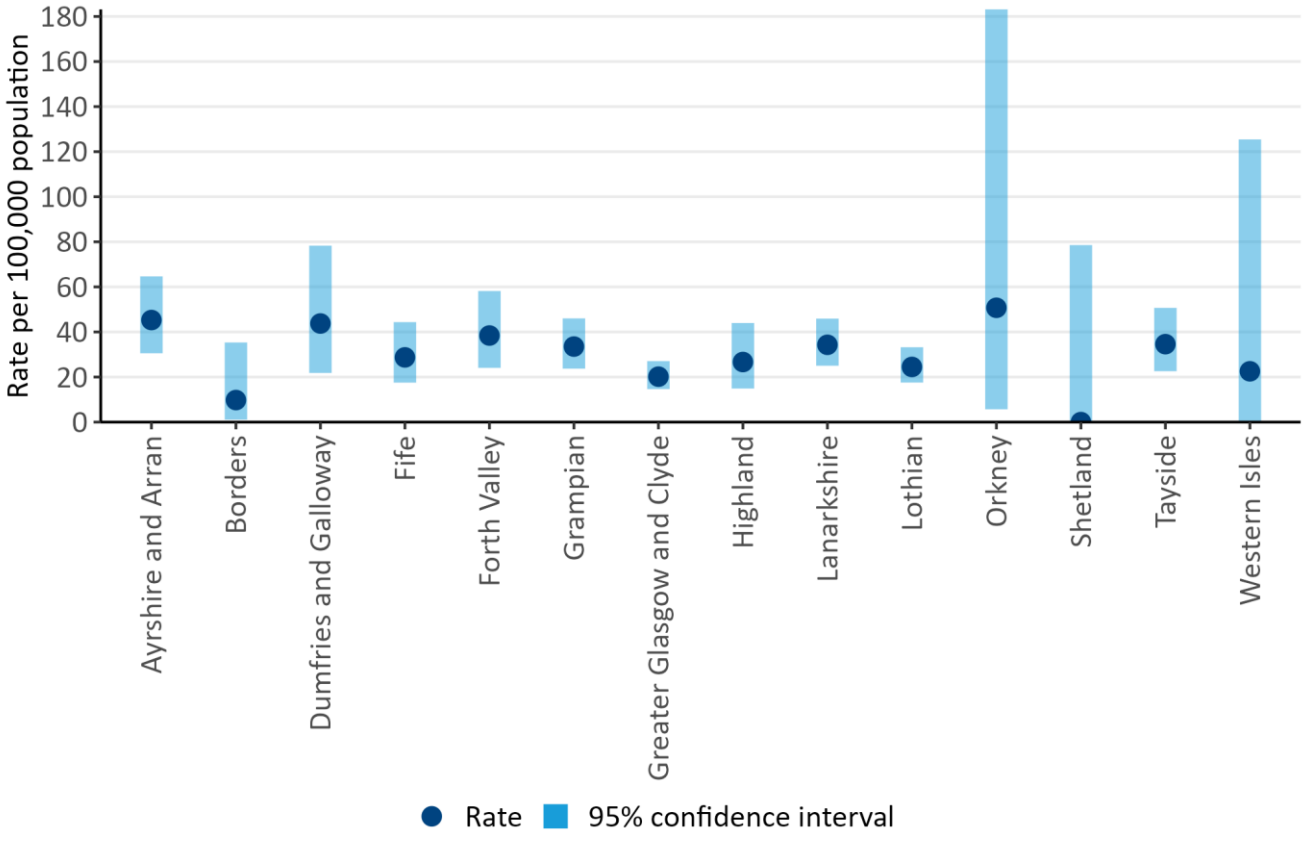


Source: National Records of Scotland vital events and mid-year population esimates

Area of residence

In 2023/24, the rate of child deaths by NHS board of residence ranged from 0 to 50.7 per 100,000 population aged between 0-17 years (Figure 1.5). Confidence intervals show the range in which rates could have occurred by chance and must be considered 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 range. The variation in rates could also be partially due to areas having different populations. For example, some areas have higher levels of deprivation which is linked to higher child mortality.

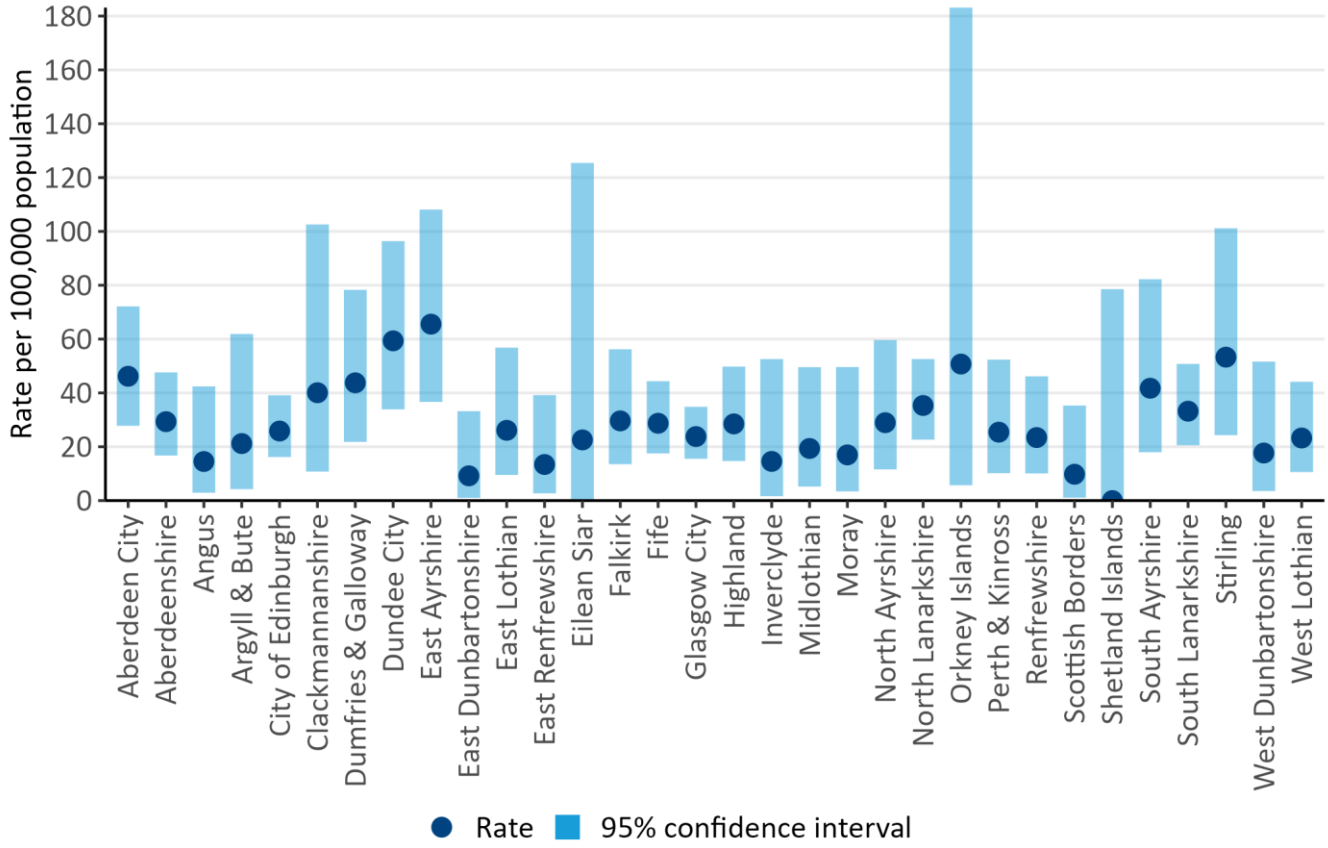
Figure 1.5: Rate of child deaths per 100,000 population by NHS board of residence for 2023/24, with 95% confidence intervals



Source: National Records of Scotland vital events and mid-year population esimates

The child death rate by local authority of residence ranged from 0 to 65.5 per 100,000 population aged between 0-17 years (Figure 1.6).

Figure 1.6: Rate of child deaths per 100,000 population by local authority of residence for 2023/24, with 95% confidence intervals

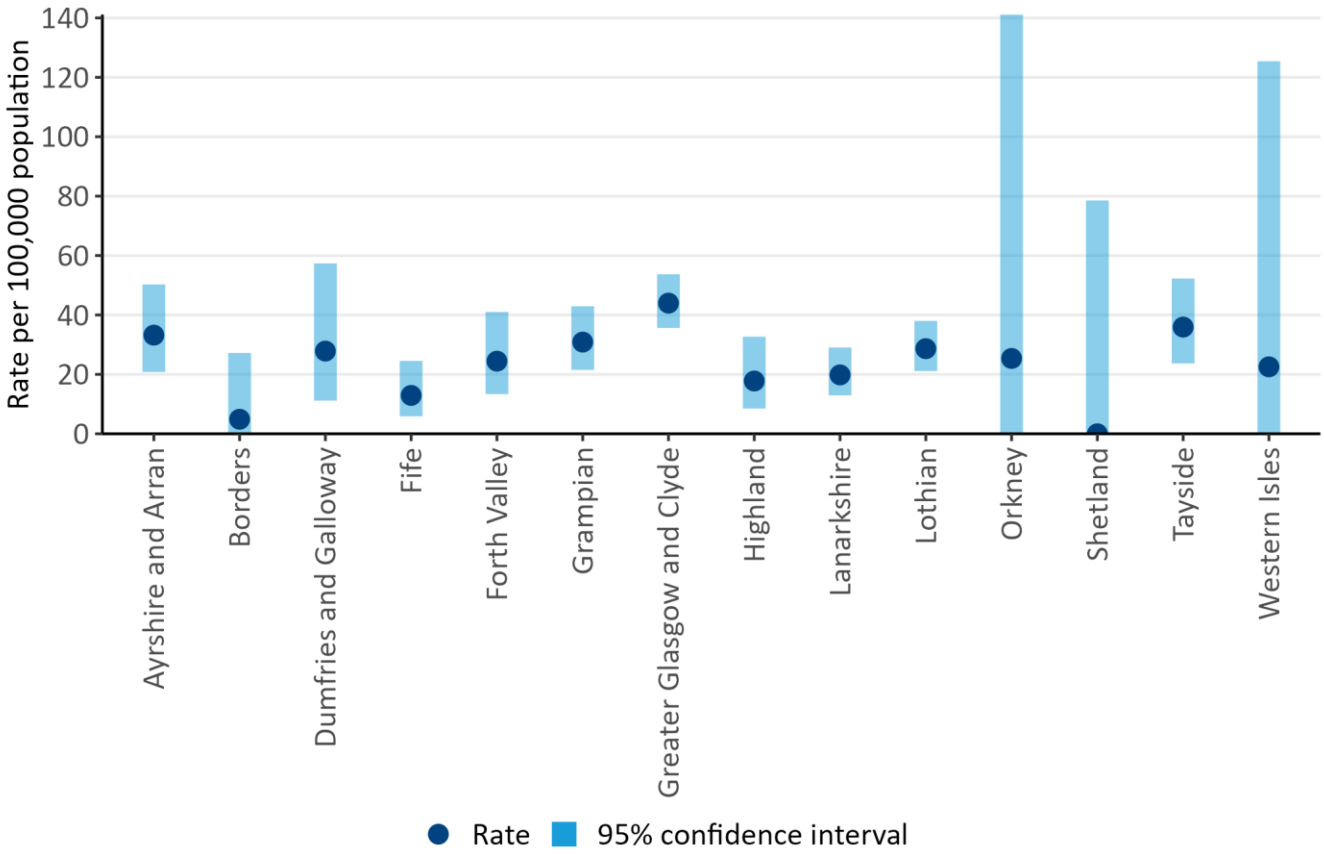


Source: National Records of Scotland vital events and mid-year population esimates

Area of death

When based on location of death, the child death rate varied from 0 to 44 per 100,000 population for NHS boards (Figure 1.7). NHS boards with large specialist hospitals have some of the highest child death rates when based on the area where the death occurred. This is expected as areas with specialist care facilities receive more critically unwell children from across the region and Scotland.

Figure 1.7: Rate of child deaths per 100,000 population by NHS board of death for 2023/24, with 95% confidence intervals



Source: National Records of Scotland vital events and mid-year population esimates

Cause of death

NRS codes each death for underlying cause using the ICD-10 (International Classification of Diseases 10th revision) from information available on the death certificate. Deaths that require further investigation as to the cause of death are often initially coded as 'sudden unexpected, unexplained death' then later updated with a confirmed cause of death. Data for 2024 used in this report has not yet been updated with confirmed cause of death.

Most deaths in children aged between 0-17 years were due to a 'perinatal or neonatal event' (32%), due to the largest proportion of deaths occurring in the neonatal period. The second highest number of deaths were due to 'chromosomal, genetic and congenital anomalies' (20%) (Figure 1.8).

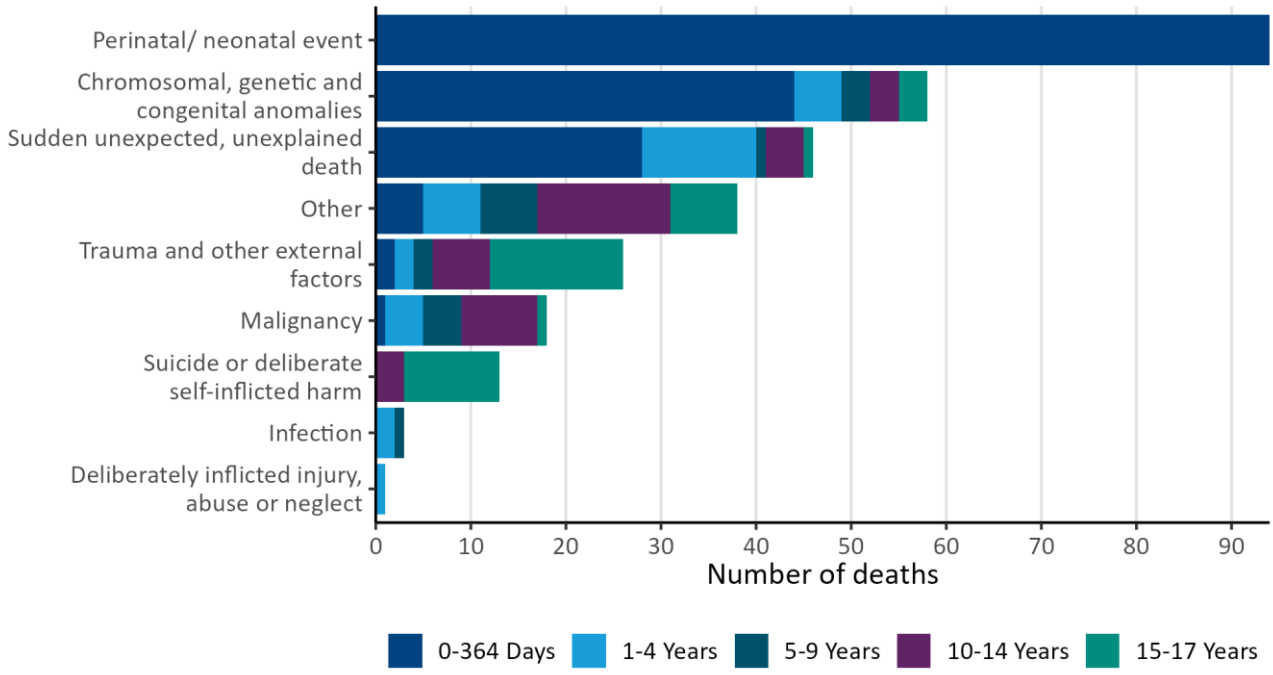
The most common causes of death for each age group were:

- ‘Perinatal/neonatal event’ - for children aged under 1
- ‘Sudden unexpected, unexplained death’ - for children aged between 1-4 years
- ‘Other’* - for children aged between 5-9 years
- ‘Other’* - for children aged between 10-14 years, and
- ‘Trauma and other external factors’ - for children aged between 15-17 years.

** ‘Other’ currently includes acute medical or surgical conditions, and chronic medical conditions.*

Further information on the ICD-10 codes used for these cause of death groupings can be found in the data tables.

Figure 1.8: Number of child deaths by cause and age group 2023/24

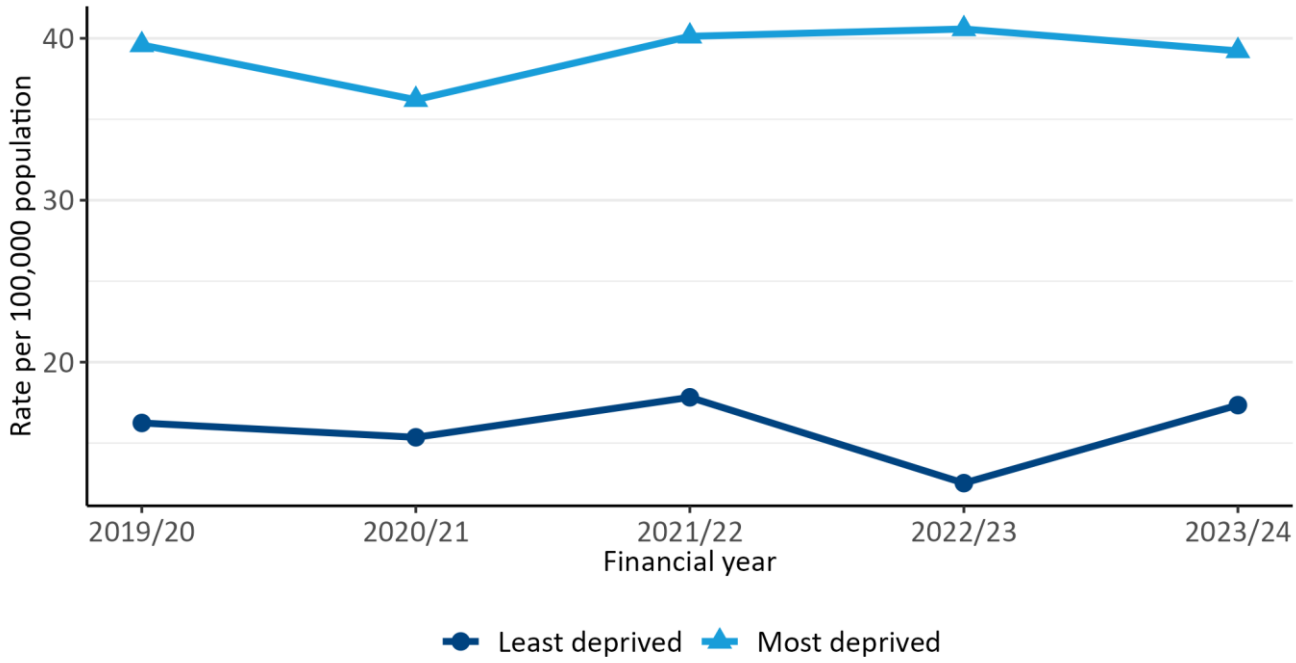


Source: National Records of Scotland vital events

Deprivation

The rate of deaths has remained highest for the most deprived areas. In 2023/24, the gap between least and most deprived returned to that observed before 2022/23 when the gap widened (Figure 1.9).

Figure 1.9: Rate of deaths for the most and least deprived areas by financial years



Source: National Records of Scotland vital events and mid-year population esimates

Ethnicity

The recording of ethnicity information in data about deaths of children aged between 0-17 years was around 70% in 2023/24, with the remaining not provided. This is similar to the previous year and makes analysis of child deaths by ethnicity unreliable, especially for less common ethnic groups. The National Hub has begun working with PHS to explore whether ethnicity information from health records can be used to enhance ethnicity information about deaths of children.

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

Under the Children (Scotland) Act 1995, looked after children are those in the care of their local authority who are either 'looked after' at home or away from home.

In Scotland, all children living with foster carers, kinship carers or in residential care on or after their 16th birthday are entitled to remain in the same place with their same carers up until their 21st birthday, or they can request advice, guidance and assistance, or aftercare support from their local authority, up to the age of 26 years (Children and Young People (Scotland) Act 2014).

The most recent Scottish Government data reported that as of 31 July 2024:

- 11,844 children were looked after – down 2% since 31 July 2023 (12,084) and down 24% since 2013-14 (15,600).
- 1,115 young people were in continuing care. This is 22% of those who were eligible for continuing care at the time of ceasing to be looked after (4,985).
- 4,454 (48% of those eligible) were receiving aftercare services on 31 July 2024 – up 7% on 31 July 2023 (4,151).

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

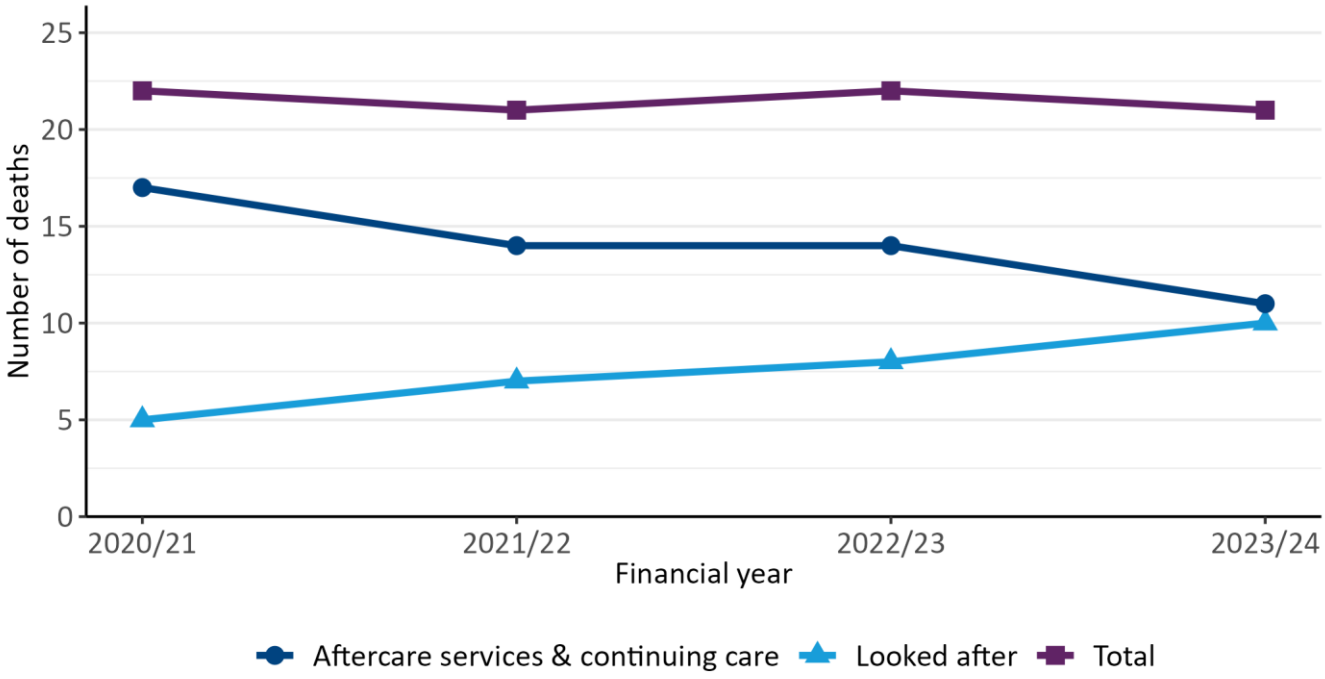
From April 2020 to March 2024, the total number of deaths across all care groups remained stable, with some very minor fluctuations in the data. During this four-year period, the Care Inspectorate received notification of the deaths of 30 looked after children and 56 young people who were in receipt of a continuing care placement or aftercare services (n=86) (Figure 1.10).

Between April 2023 and March 2024, there were ten deaths of looked after children. Half of these deaths were associated with underlying or complex health conditions. Other reported causes of death included suspected suicide, suspected drug related or were unascertained. Children's ages ranged from under one to 17 years, with half of all deaths occurring in the 16-17-year age group.

The number of deaths of young people who were in receipt of continuing care or aftercare services at the time of their death fell slightly from 14 in 2022/23 to 11 in 2023/24. There were no reported deaths of young people receiving continuing care during 2023/24. All deaths during this reporting period related to young people receiving aftercare support. The characteristics of the deaths of these young people mirrored those reported in previous years i.e. there were significantly more males than females, and ages ranged from 16-25 years. The reported cause of death varied, with just over half recorded as suspected suicide or suspected drug related. Other causes of death were reported as unexplained/unascertained, accidental, or due to an underlying health condition.

Caution should be exercised when interpreting this data due to the small numbers.

Figure 1.10: Number of deaths of looked after children and young people in receipt of continuing care and aftercare services, 2020/21 to 2023/24



Source: Care Inspectorate notification of child deaths data

Data analysis: findings from child death reviews

Between 1 October 2021 and 31 March 2024, NRS notified the National Hub of 724 child deaths under the age of 18, and the Care Inspectorate confirmed that there were 26 deaths of young people aged between 18 and 25 who were in receipt of continuing care or aftercare services. Notifications were relayed to the health boards and local authorities of residence and death, that subsequently undertook the reviews, involving other areas and agencies as appropriate for each review.

In addition, the National Hub was notified, primarily by health boards, of the deaths of 18 children that occurred outside of Scotland. The local services were asked to complete a CRDS because these children were residents of Scotland.

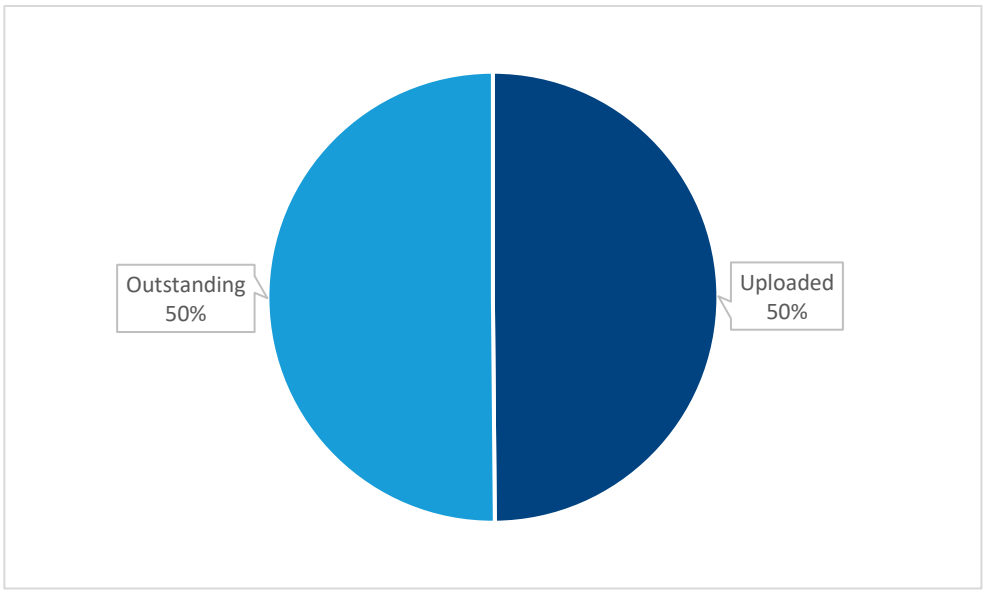
Whilst the previous section of this release considers NRS data between April 2019 and March 2024, this section summarises initial findings extracted from completed CRDS for children and young people who died between 1 October 2021 and 31 March 2024. It provides cumulative information over this period and begins to offer some insight into the lives and deaths of children and young people as revealed by their individual reviews.

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.

Core review datasets completed

As of 1 March 2025, CRDS have been completed and uploaded to the National Hub's online reporting portal for 361 (50%) of the 724 deaths (Figure 2.1). The following figures are based on those completed cases.

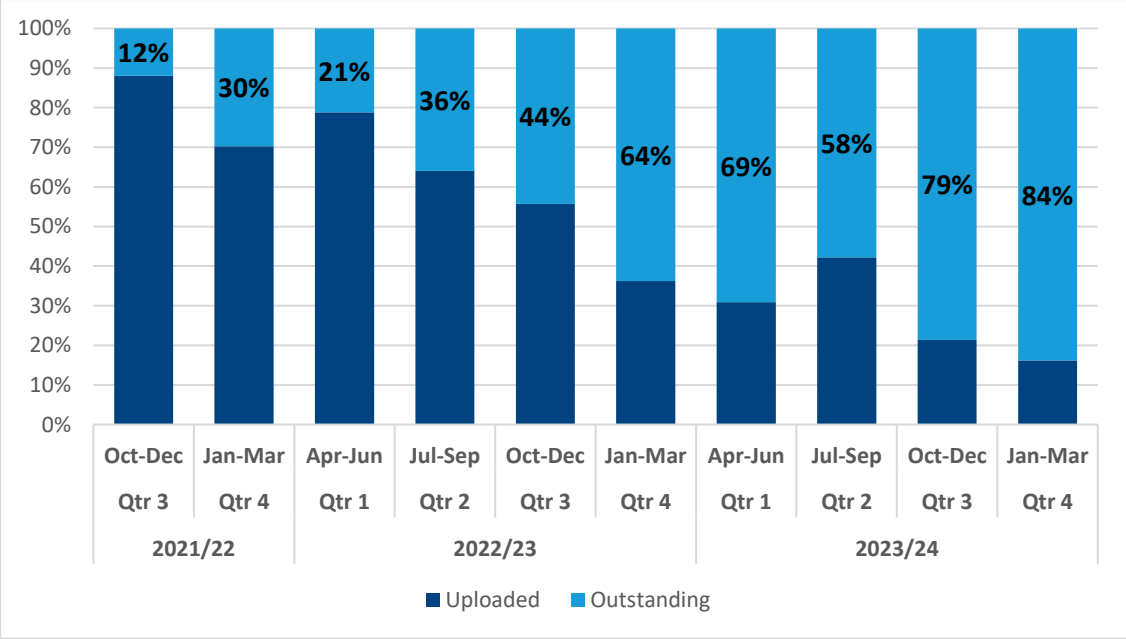
Figure 2.1: Proportion of completed vs outstanding CRDSs uploaded to the online reporting portal



From the 149 child deaths recorded in the partial data collection period October 2021 to March 2022, CRDSs have been completed for 118 (79%). This completion rate decreases to 58% (n=161) in 2022/23 and 28% (n=82) in 2023/24 (Figure 2.2).

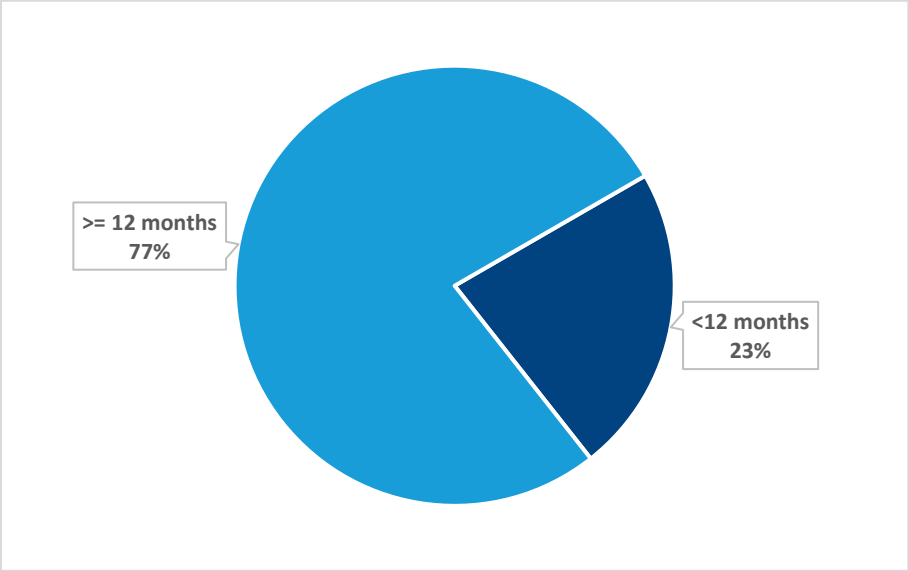
The lower numbers of total child deaths recorded for the data collection period 2021/22 is reflective of the National Hub being launched on 1 October 2021. Therefore, data was collected from only the last two quarters of that financial year.

Figure 2.2: Proportion of completed CRDSs by financial year and quarter



Of the 361 completed CRDS, 23% (n=82) were uploaded to the portal within 12 months of the death occurring (Figure 2.3).

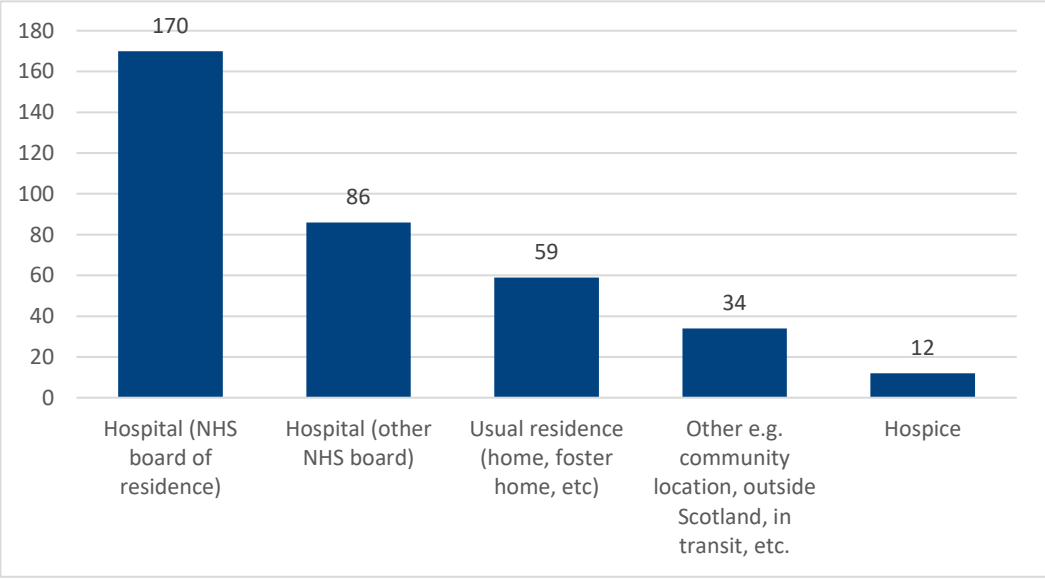
Figure 2.3: Proportion of CRDS completed within 12 months



Location of death

Almost half of the CRDS completed were for individuals who died at a hospital in their board of residence (47%, n=170). Almost a quarter (24%, n=86) were for deaths that happened in a hospital in another health board, 16% (n=59) within their usual residence, 9% (n=34) in the community, in transit or outside of Scotland, and 3% (n=12) in a hospice (Figure 2.4).

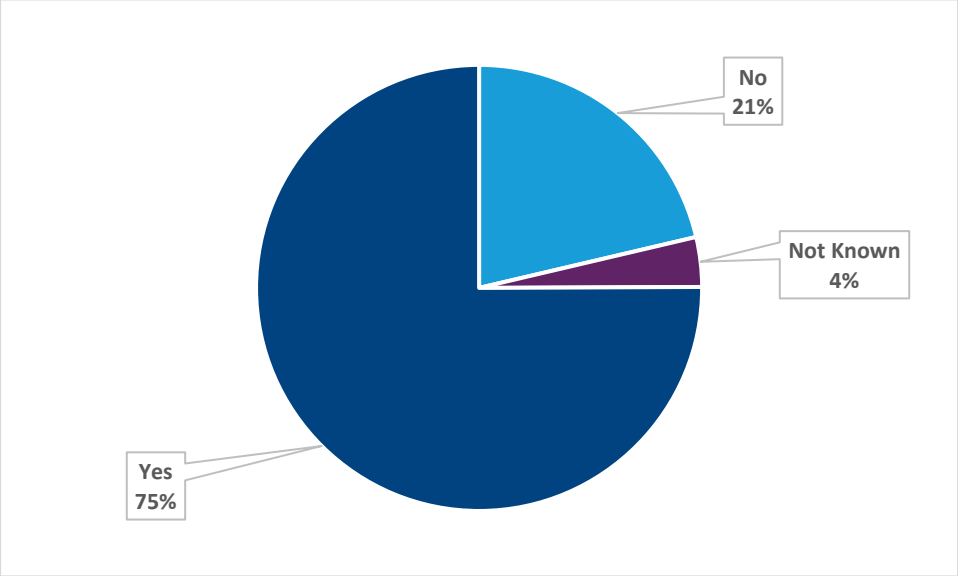
Figure 2.4: Location of child or young person when they died



Informing families and carers

Families and carers were notified about the intention to complete a review in 75% of instances (n=271). In 13 cases (4%) it was not recorded on the CRDS whether family had been notified or not (Figure 2.5).

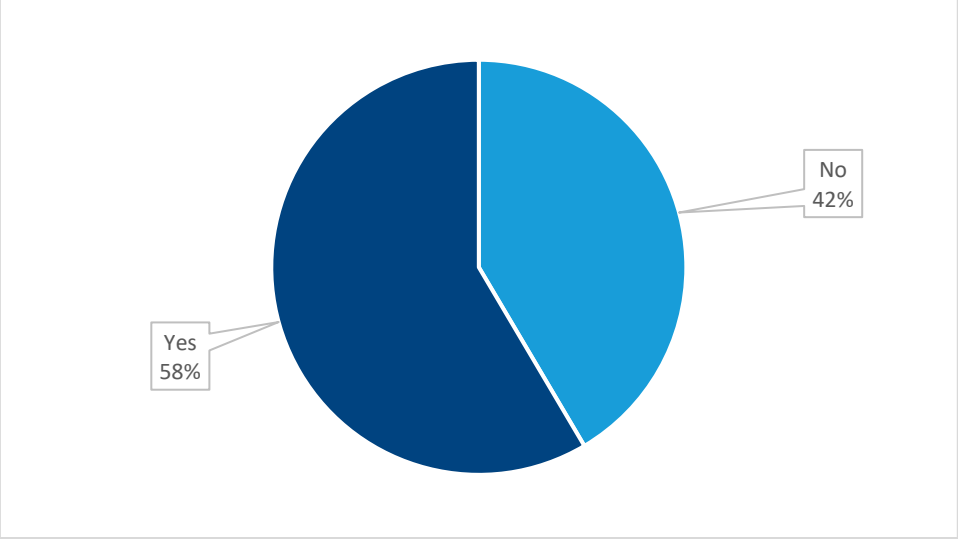
Figure 2.5: Proportion of families and carers informed of their child's review



Expected and unexpected deaths

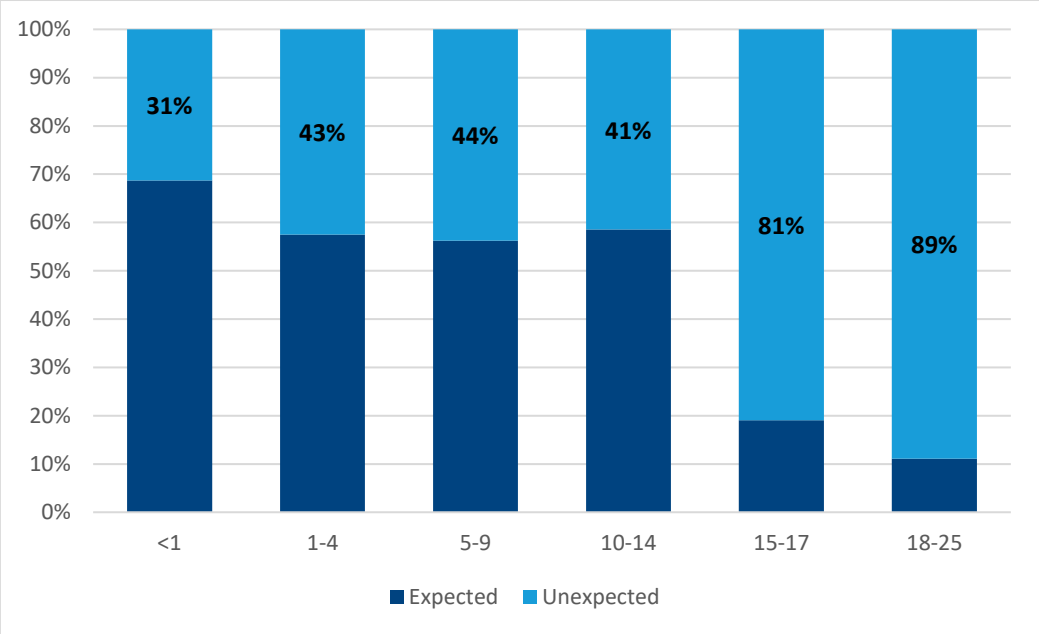
From the 361 completed CRDS, the death was expected in 58% (n=210) of cases (Figure 2.6).

Figure 2.6: Proportion of CRDS that indicated whether or not the death was expected at the time



The proportion of deaths that were expected decreases as age increases, from 69% of deaths for under 1-year olds being expected, 56-59% of those aged 1-4, 5-9 and 10-14, 19% of 15-17-year-olds and 11% of 18-25-year-olds (Figure 2.7).

Figure 2.7: Proportion of expected and unexpected deaths, by age group

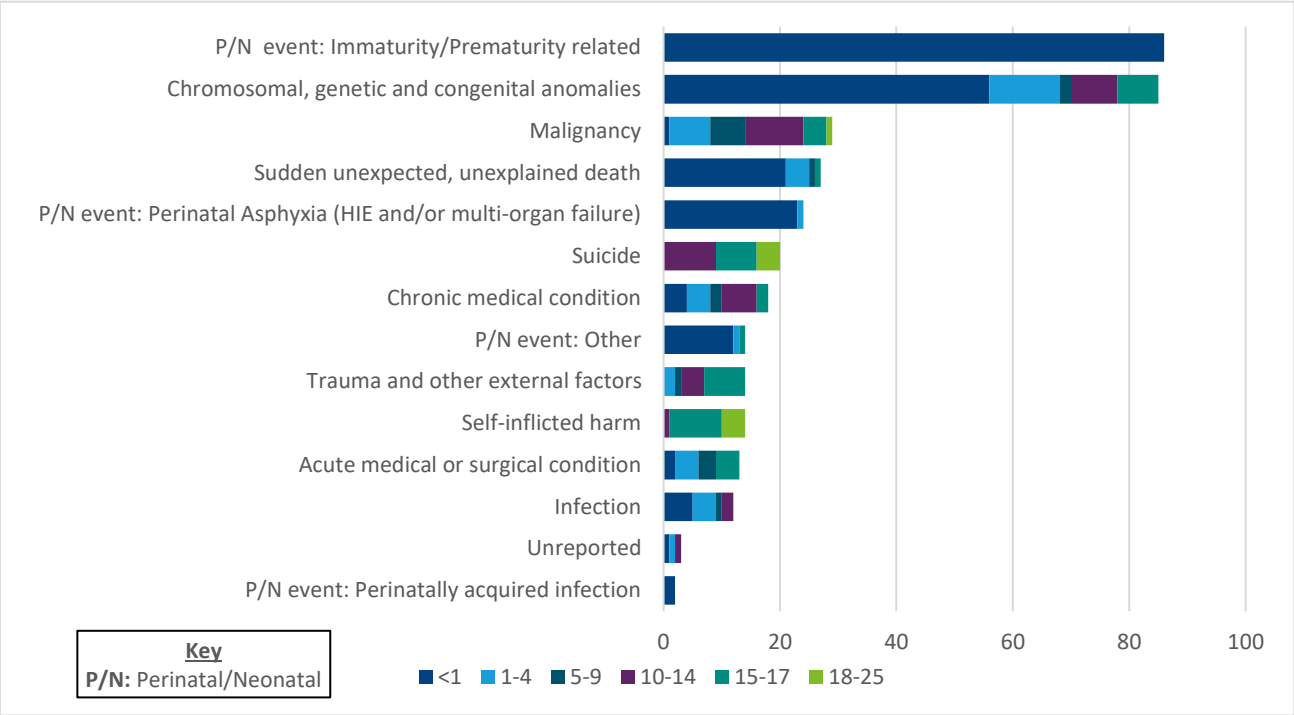


Category of death

As part of the review process, the review team categorises why the child died. These categories are based on the National Child Mortality Database (NCMD) *Category of Death: Clarification* (2021) to allow future national comparisons.

The most common category of death for deaths that occurred between October 2021 and March 2024 was *Perinatal/Neonatal Event: Immaturity/Prematurity related,* which accounted for 40% of all deaths for children under 1 year old, and 24% (n=86) of total deaths. This was followed by *Chromosomal, genetic and congenital anomalies* (24%, n=85*), Malignancy* (8%, n=29), and *Sudden unexpected, unexplained death* (7%, n=27) (Figure 2.8).

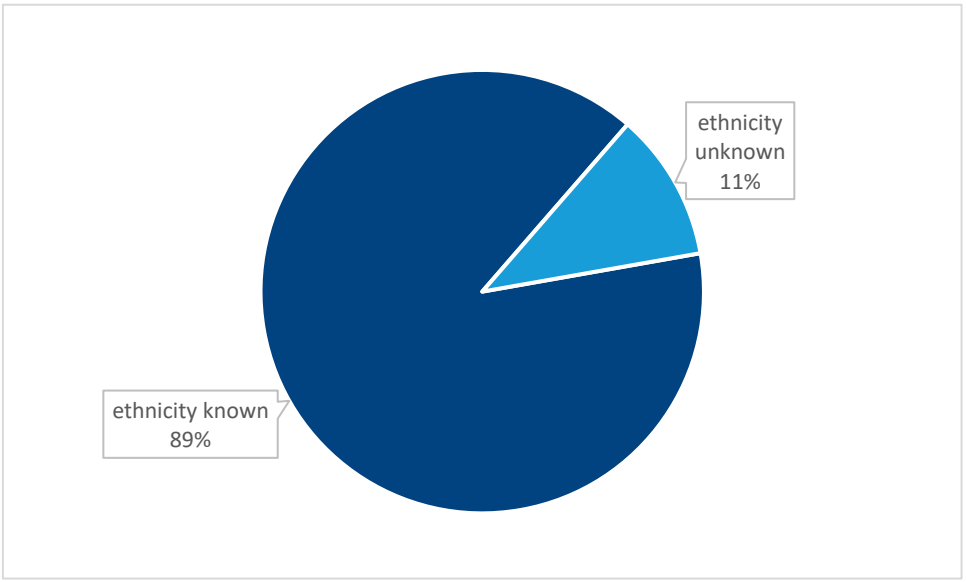
Figure 2.8: Categories of death, by age group



Ethnicity

From the 361 completed CRDS, 89% (n=321) reported the ethnicity of the child or young person. The highest population within this number was *White Scottish* (75%, n=242). 11% (n=29) of completed CRDS reported ethnicity was *Not known* (Figure 2.9).

Figure 2.9: Proportion of CRDS that reported ethnicity



Review outcomes: contributory and modifiable factors

Contributory factors

The CRDS asks review teams to consider a list of individual intrinsic, family, social, environmental, and service provision factors that may have contributed to the vulnerability, ill-health or death of the child or young person. For each of these contributing factors, reviews must grade the level of influence they have had on the individual's death. The list of contributory factors can be found in sections 5-9 of the CRDS.

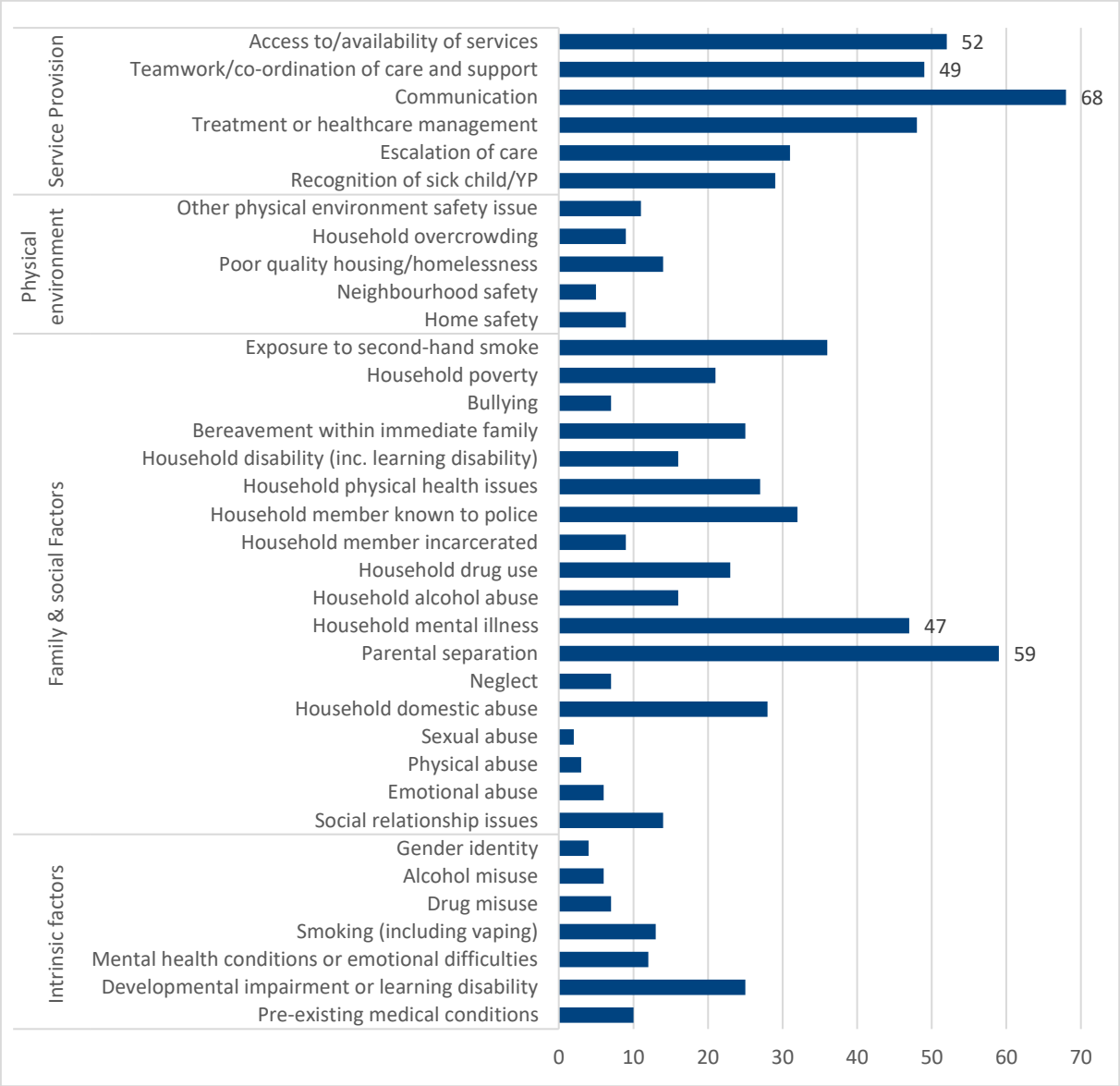
The level of influence is graded on a 4-point scale:

- 0 - information not available
- 1 - factor not identified
- 2 - factor identified but unlikely to have contributed to vulnerability, ill-health or death; or
- 3 - factor identified that may have contributed to vulnerability, ill-health or death.

Level 2 contributory factors

Level 2 factors were identified a total of 780 times across the 361 completed CRDS. *Communication* was the most identified (n=68), followed by *parental separation* (n=59) and *access to services* (n=52), *coordination of care* (n=49) and *treatment or healthcare management* (n=49) (Figure 2.10).

Figure 2.10: Level 2 contributory factors

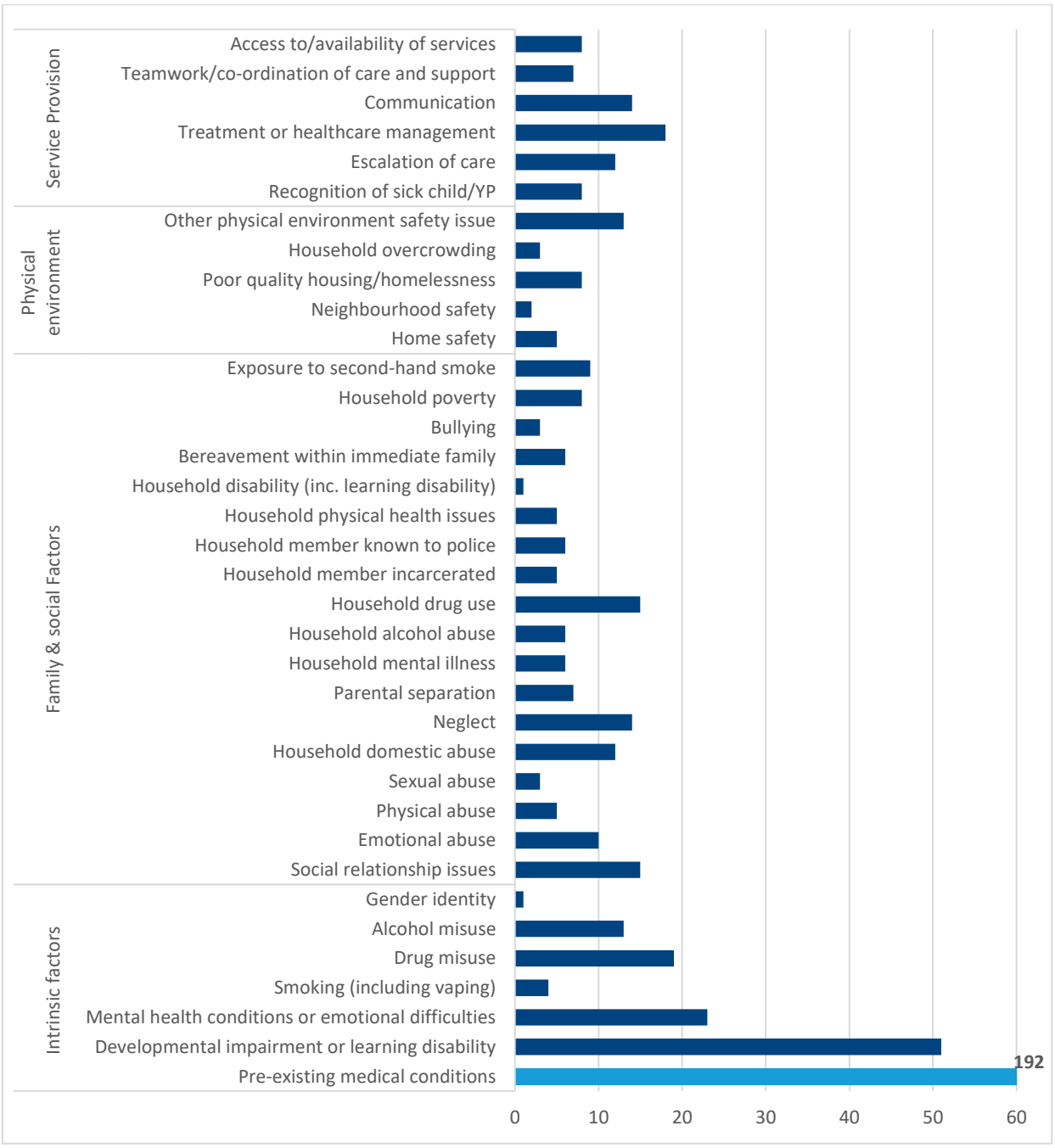


Level 3 contributory factors

Level 3 factors were identified a total of 405 times across the 361 completed CRDSs. *Pre-existing medical conditions* appeared most frequently (n=192: cropped below for figure readability). Secondly, *developmental impairment or learning disability* (n=51), followed by *mental health condition or emotional difficulties* (n=23) and *drug misuse* (n=19). These factors all fell within the *intrinsic/individual* category.

Outside of this group, *treatment and healthcare management* (n=18) was the factor most identified, then *household drug use* (n=15) and *social relationship issues* (n=15), *communication* (n=14) and *neglect* (n=14) (Figure 2.11).

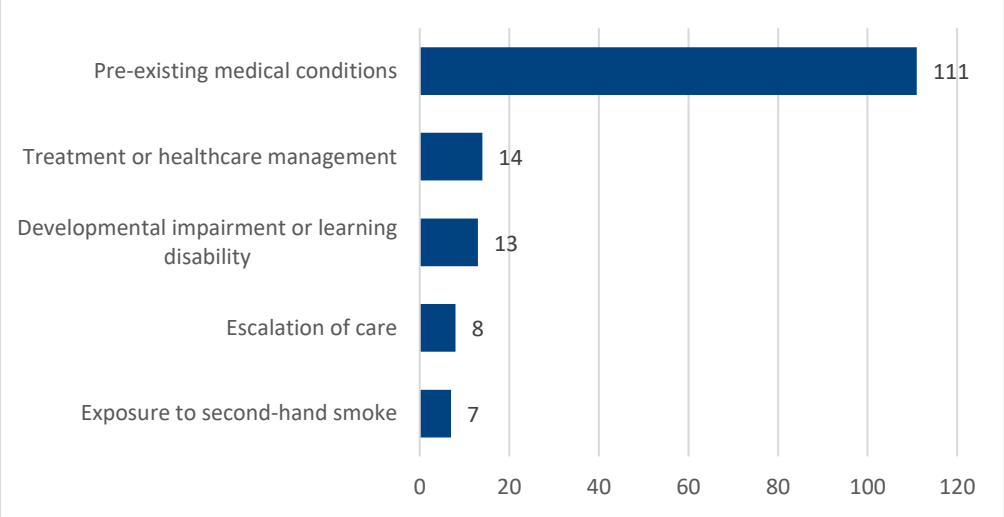
Figure 2.11: Level 3 contributory factors



Common contributory factors

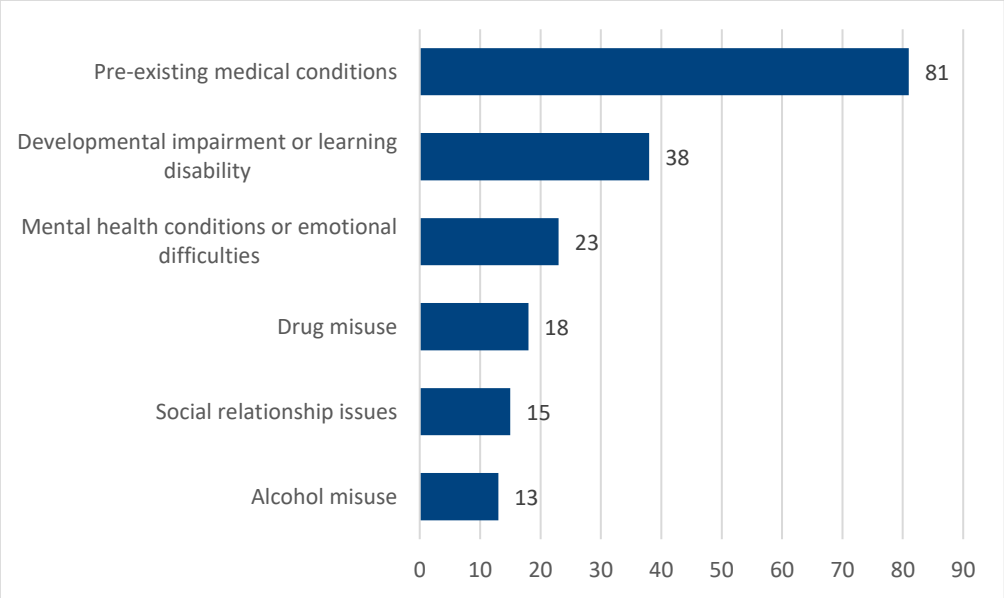
The most common recorded level 3 contributory factors of deaths in infants under 1 year old were *pre-existing medical conditions* (n=111), followed by *treatment or healthcare management* (n=14), and *developmental impairment or learning disability* (n=13) (Figure 2.12). The total number of deaths of under 1s was 213.

Figure 2.12: Most common level 3 contributory factors in under 1s



The most common recorded level 3 contributory factors of children and young people aged 1 year or older was *pre-existing medical conditions* (n=81), *developmental impairment or learning disability* (n=38) and *mental health or emotional difficulties* (n=23) (Figure 2.13). The total number of deaths of children aged 1 and over was 148.

Figure 2.13: Most common level 3 contributory factors in ages 1 and over



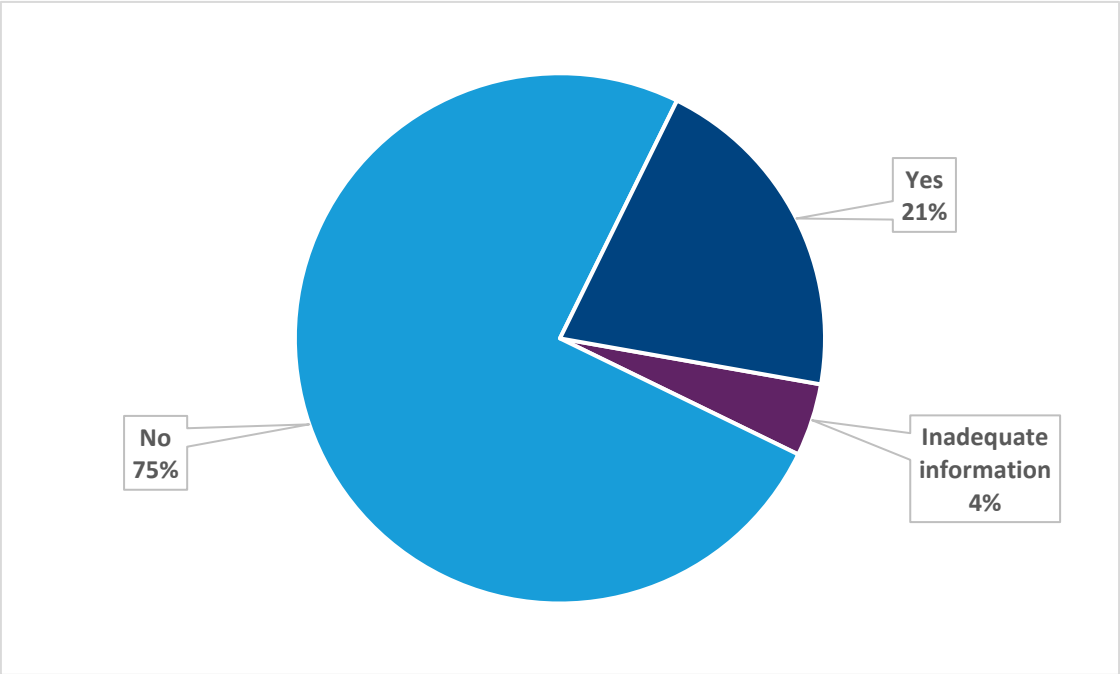
Modifiable factors

Review teams make a judgement as to whether factors have been identified 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.

The presence of these modifiable factors was answered as either yes, no, or inadequate information upon which to make a judgement.

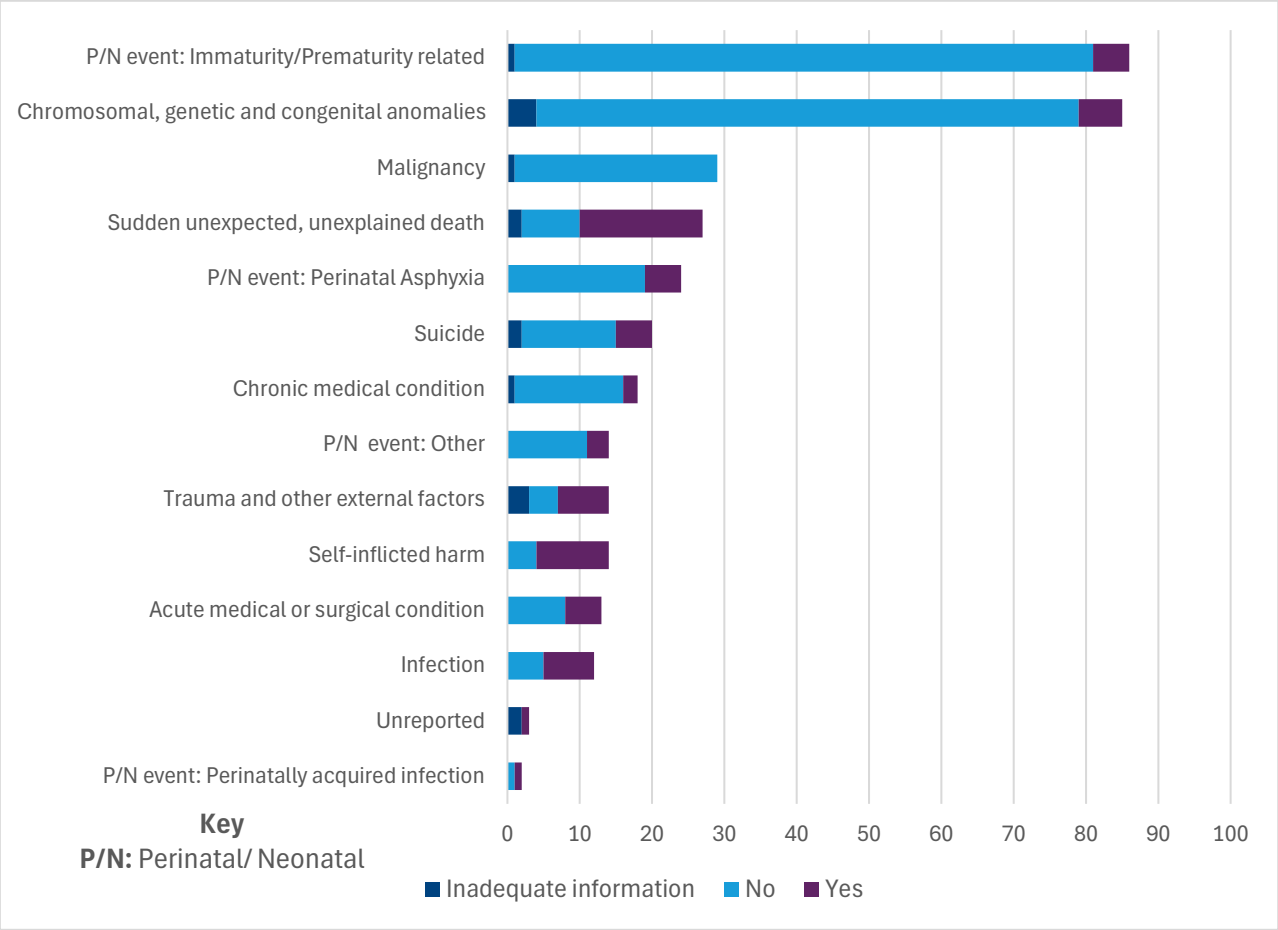
21% (n=74) of completed CRDSs had modifiable factors, the highest proportion of these being in children aged 1 and over. There was inadequate information upon which to make a judgement in 4% (n=16) of cases (Figure 2.14).

Figure 2.14: Modifiable factors recorded on CRDS



Deaths categorised as *self-inflicted harm* (71%, n=10/14) had the highest number of modifiable factors followed by *sudden unexpected, unexplained deaths* (63%, n=17/27), *infection* (58%, n=7/12) and *trauma and other external factors* (50%, n=7/14) (Figure 2.15).

Figure 2.15: Modifiable factors by category of death



Further information

This first National Hub Data release marks a new approach to how the National Hub reports child death data. It offers a statistical summary which includes data produced by NRS from 1 April 2023 to 31 March 2024 together with the findings from child death review data from the start of National Hub data collection on 1 October 2021 to 31 March 2024.

The National Hub will produce an annual data release. Over time, and as our data become more comprehensive, our intent is to produce thematic child death reports. These reports will focus on factors we identify as having the greatest potential for change.

The National Hub will continue to engage with NHS boards, local authorities and partnerships to encourage and support timely submission of child death review data.

Find out more about the National Hub's work on the Healthcare Improvement Scotland website. You can download resources for professionals involved in reviews as well as information about reviews for bereaved families and carers.

We welcome queries or feedback on this Data release, or any aspect of our work. Email HIS.CDRNationalHub@nhs.scot

Resources

1. Vital Events Reference Tables 2023 - National Records of Scotland (NRS)
2. National Hub for reviewing and learning from the deaths of children and young people
3. National Hub's National guidance when a child or young person dies (October 2021)
4. Supporting documents - Children's Social Work Statistics: Looked After Children 2023/24 - gov.scot
5. Children (Scotland) Act 1995
6. Children and Young People (Scotland) Act 2014
7. Category of death: Clarifications - National Child Mortality Database
8. National Hub Core Review Dataset: October 2021

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