Healthcare Improvement Scotland

care inspectorate

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

Guidance on completing the core review data set (CRDS) and SUDIC data subset

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April 2026	Amended main content following user feedback. Introduction of specific questions: • Resident local authority at time of death • “Other” question within each contributing factors sections • Further questions relating to adverse childhood experiences within family and social environment contributing factors. Amendment to specific questions: • Clarifying answers as to the degree of family involvement in the review process. Added Appendix 2: Guidance on completing the data subset for sudden, unexpected deaths of infants and children (SUDIC).

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Introduction

Healthcare Improvement Scotland and the Care Inspectorate co-host the National Hub for reviewing and learning from the deaths of children and young people. The programme uses a multidisciplinary and multi-agency approach, focused on using evidence to deliver change, and ultimately aims to reduce deaths and harm to children and young people. We want to ensure the death of every child and young person is reviewed to an agreed minimum standard.

Reviews are conducted into the deaths of all live born children up to the date of their eighteenth birthday, or twenty-sixth birthday for care leavers who are in receipt of continuing care or aftercare at the time of their death.

The National Hub aims to:

- ensure that the death of every child in Scotland is subject to a quality review
- improve the experiences of and engagement with families and carers, and
- share learning from current review processes across Scotland that could direct action to help reduce preventable deaths.

Core review data set (CRDS)

The National Hub’s CRDS has been developed for use by NHS boards and local authorities/health and social care partnerships (HSCPs) when reviewing deaths of children and young people, to collect key information about the child or young person to learn from their death. It provides a standardised template, so the same information is collected for every death, supporting national analysis to enhance opportunities for learning from deaths.

The information from the CRDS should be securely entered into the online portal as the review into the death of a child or young person is progressing or alternatively, it can be entered once the review concludes. The data set should be completed following the deaths of all children and young people that meet the National Hub’s reporting criteria, regardless of what review process has been followed.

The CRDS is not intended to replace existing review processes. As part of your review process, following notification of the death of a child or young person the organisation(s) should determine the most appropriate review process. The review process should capture the relevant information for completion of the CRDS.

All questions in the CRDS should be completed. Where information is not known or not applicable, there will be options to identify this. No identifiable information other than the details of the child or young person should be entered in the CRDS form. If any identifiable information is entered into the online portal, that information will be anonymised by the National hub. You may find it helpful to begin completing the CRDS as you go through the review process. However, it should only be submitted on completion of the review process.

Please contact us if you need any further advice about completing or uploading the CRDS to the portal at HIS.CDRNationalHub@nhs.scot

The CRDS will be reviewed periodically, taking account of the learning from reviews and feedback from NHS boards and local authorities.

Prerequisites

Before services can upload and submit a Core Review Dataset to the National Hub online portal, users will need to create an account. First email the National Hub generic inbox (his.cdrnationalhub@nhs.scot) requesting permission to access the portal for a specific region (health board or local authority). You will then be given instructions on how to create an account.

1. Creating a New National Hub Form

When creating a new National Hub submission form in the online portal, you will be given the option to select either a Core data set, or a Core data set + SUDIC.

For any death that has been categorised as a sudden unexpected, unexplained death, and occurred **on or after 1 January 2026,** select “Core data set + SUDIC”. For all other deaths, including those that were categorised as sudden unexpected, unexplained death that occurred prior to 1 January 2026, select “Core Data set”.

If the wrong option is initially selected, Question 2.14 will allow for the SUDIC subset to be included or removed based on the answer chosen.

2. Demographics and background information

Further guidance on specific questions in this section is provided below.

Resident Board and Local authority at time of death

The NRS Board and Local Authority of residency should be selected from the drop-down list. In instances where the person was a resident of a health board of local authority outside of Scotland (For example, *the person was an English resident who was visiting Scotland*) then the “Other” option should be selected and the information relating to board of residence written in the open text box.

Ethnicity

The ethnicity of children born in Scotland to parents of a particular ethnicity should be recorded as the ethnicity of the parent.

For example: *A child born in Scotland to Polish parents would typically be recorded as White: Polish on official forms in Scotland, according to Scottish Government guidance. While the child is also likely a British citizen, the "White Polish" category is used to identify the Polish population within Scotland.*

Was the child/young person a looked after child (LAC) or in receipt of aftercare or continuing care at the time of death

Looked after children and young people

Under the Children (Scotland) Act 1995, ‘looked after’ children are defined as those in the care of their local authority. There are many reasons children may become looked after, including:

- they face abuse or neglect at home
- they have disabilities that require special care
- they are unaccompanied minors seeking asylum, or have been illegally trafficked into the UK, and
- they have been involved in the youth justice system.

A looked after child or young person must fall into one of the following categories:

- be living at home and subject to a compulsory supervision order (looked after at home),
- be living in kinship care, foster care, or a residential care setting and subject to a compulsory supervision order (looked after away from home)
- be accommodated by a local authority by a voluntary agreement (under S.25 of the Children (Scotland) Act 1995). This includes children and young people who receive a series of short-term overnight breaks only
- be subject to permanence orders granted by a court, and
- be subject to an order, authorisation or warrant made by the relevant authorities under Chapters 2,3, or 4 or Part II of the Children (Scotland) Act 1995.

Continuing Care and Aftercare

A care leaver is a young person aged 16 or over who is no longer ‘looked after’ by a local authority but continues to need support.

The term ‘*Continuing Care’* refers to a local authority’s duty under *Section 26A of the Children (Scotland) Act 1995* to provide young people who are at least aged 16 years and whose final ‘looked after’ placement was in foster, kinship or residential care with the same accommodation and other assistance as was being provided by the local authority immediately before the young person ceased to be looked after. It provides a more graduated transition out of care, reducing the risk of multiple simultaneous disruptions occurring in their lives while maintaining supportive relationships.

The term ‘*Aftercare*’ refers to the advice, guidance and support provided to young people leaving local authority care under *Section 29 of the Children (Scotland) Act 1995*, to help them transition to independent living. This support is available to all care leavers aged 16 to 25 years and can include financial, educational and housing assistance, along with support for employment and wellbeing.

The review team should confirm with the relevant local authority whether this question applies to the child before completion. Any review of a looked after child or young person in receipt of aftercare or continuing care must include local authority representatives.

Was this child/young person known to the justice services at the time of death?

This question relates to children over the age of 12 who, at the time of their death, were in receipt of a statutory or voluntary criminal justice service. This includes young people on statutory court orders, or those who are diverted from prosecution. The service would be delivered by a justice social work service or commissioned third sector organisation.

It is possible that NHS staff may not be aware of this information unless, as part of the child or young person's plan, they were working with social work colleagues to improve and support the child or young person's wellbeing and manage risks. The child or young person would be known to social work services, this is an example of when an initial multi-agency discussion following notification of the death would be helpful in identifying those directly involved in supporting the child or young person.

3. Circumstances of the death

This section captures information on the nature and manner of the death. Further guidance on specific questions in this section is provided below.

Place of death

The place of death should be recorded as the place where the child or young person is believed to have died, regardless of where death was confirmed. In situations where a death has taken place in the community and recorded in hospital during resuscitation, the place of death should be recorded as the community location. In situations where a child or young person is brought to hospital following an event in the community and is successfully resuscitated, but resuscitation or other treatment is subsequently withdrawn, the place of death should be recorded as the hospital where this occurs.

Summary account of the circumstances leading to the death

This is a free text section that asks you to provide a summary of relevant information of the circumstances leading to the death. The form provides further detail on what should be included. If you are not sure whether something is relevant, please include it anyway, as often small details can help to identify important learning.

For example, summary account (child with a life-shortening condition): *The child was diagnosed with a brain tumour six months before death, following two weeks of headaches and vomiting. The child presented to the GP and was referred to paediatrics for further investigation. At that time, a scan revealed an astrocytoma. The child was referred to the oncology service and received treatment. Unfortunately, the disease progressed and, following discussion with the family, it was decided that they would be transferred to palliative care. An anticipatory care plan was completed* *with the family, and their choice was for the child to die at home. They were discharged home one week before death with a package of community nursing support and some medication for pain relief. On the day before death, the child deteriorated and required additional pain relief. The child died the following morning with parents present.*

Subgroup selection

If, when the form was created, “Core Data set + SUDIC” was selected, or if “SUDIC” was chosen as an answer for question 2.1, an additional tab labelled “S” will be visible.

This tab will contain the subset questions that are to be completed if the cause of death has been classified as Category 10: Sudden, unexpected, unexplained death in childhood and has occurred after 1 January 2026.

For deaths categorised as SUDIC that occurred prior to 01st January 2026, question 2.14 relating to subgroup selection should be answered as “Not Applicable”, and the subset not completed.

Guidance on the SUDIC subgroup questions can be found in Appendix 2.

4. Family and carer involvement

This section captures information on the involvement of families and carers in the review process and the support provided to them. This covers whether:

- the family were informed of the review
- they had the opportunity to ask questions
- questions raised by the family were addressed in the review, and
- feedback was provided to the family following the review.

It also asks for details of what bereavement or other support was offered to the family and carers, including the child or young person’s brothers and sisters where appropriate.

5. Review meeting

This section captures information on the membership of the review team and the date that the review report was approved by the relevant local leadership and governance group.

If the review team holds more than one review meeting, the date of the first meeting of the team should be entered in this section.

The range of agencies or services represented at review meetings will vary. In situations where a service has been represented at meetings and is not included in the list of services, this can be recorded in the ‘Other’ box.

6. Contributory factors: child or young person, family and social environment, physical environment and service provision

For all these sections, the review team should use all the information available to determine whether each factor was present in the life of the young person. If present, the review team should then use the information available and use its clinical and professional judgment to determine whether each factor may have contributed to vulnerability, ill-health or death of the young person and grade them accordingly. It is important to look beyond the child's clinical care when reviewing their death and to consider the wider public health factors which may have been evident during the child's life and/or impacted on their death.

The combination of drop-down boxes and free text should allow you to move through this section, while still allowing expansion of issues where relevant. When describing the factor in the free text section, a sentence is usually better than a single word. Such as, "*there was a delay in the ambulance service attending as the incident was in a remote location, which was difficult to find"* is more helpful than *"ambulance delayed*". There is also an "Other" option in each section to capture any other factors or issues not covered by the specific options. This should be graded at the level of influence that is highest for any of the other issues present. Any factors noted in the free text section should be graded, if possible.

In instances where the answer to all questions is either "information not available" or "factor not identified" use the buttons at the top of each section to automatically populate the section with those responses.

The numerical contributing factor sections should not be used to record good practice, or factors that have had a positive impact on the individual. Instead, this information could be included in either the free text boxes below each numbered factor or, in Section 11.2: Good practice identified from the review.

Contributory factors: child or young person

The purpose of this section is to find out as much as possible about the child or young person. However, for neonates, this covers any medical or mental health condition(s) in the mother and any relevant information about the pregnancy and obstetric history. The “Other Child or Young Person issue” question and subsequent free text section can be used to capture issues not covered by the individual questions.

Consider factors relating to the child or young person’s age, gender and ethnicity, any pre-existing medical conditions, developmental or behavioural issues or disability.

Where the death is of a looked after child, please include the following in the free text section.

- Child’s legal status:
    - Section 25 (Voluntary agreement) Children's (Scotland) Act 1995
    - Compulsory Supervision Order Section 83 Children's Hearing (Scotland) Act 2011
    - Interim Compulsory Supervision Order Section 86 Children's Hearing (Scotland) Act 2011
    - Residence Order Section 11 Children's (Scotland) Act 1995
    - Permanence Order Section 80 Adoption & Children (Scotland) Act 2007
- Child's residence at time of death:
    - Living at home with parent(s)
    - Kinship care
    - Foster care
    - Living in children's house
    - Secure care
    - Residential education placement
    - Residential health placement/hospital
    - Children's hospice
    - Homeless

Contributory factors: family and social environment

The purpose of this section is to find out as much as possible about the family and social background of the child or young person and any adverse childhood experiences that may have had an influence on their life. Consider information relating to all individuals living within the household, the child's wider social environment (such as friends) and parenting capacity and supervision. You may need to consider two households if the child regularly spends time in more than one household.

In this section you can document whether the experience or 'voice' of the child heard was heard. You should record details here of any social isolation, interaction with peers, bullying, abuse or other experiences the child may have had, which involved people in their social circle.

In terms of areas for improvement, it is helpful to know if the family was able to meet the child or young person's needs. If not, in what way were they not being met? If the family needed to engage with a particular service or bring the child to appointments and could not do so, try to describe the barriers to better engagement. For example, *financial situation, language barriers*.

You can also include positive details, in the free text section, about how the family supported the child and family relationships and friendships in the child or young person's life and the positive aspects of the household in which they lived.

Contributory factors: physical environment

This section collects information about any ways in which the child or young person's physical environment may have been a feature that led to vulnerability, ill-health or death.

This section asks questions relating to the physical environment that the child or young person was in at the time of the event leading to death, or the mother during pregnancy, including: poor quality housing; overcrowding; environmental conditions; home or neighbourhood safety.

The section for "Other physical environment safety issues" can be used to record details of any product or equipment issues. This could be:

- a malfunction of equipment, such as medical equipment
- a product being used in a way other than expected, such as using a stairgate in a door frame rather than on the stairs, or
- an instance where a product or piece of equipment has contributed to the death, such strangulation on blind cords, suffocation on nappy sacks.

This section could also be used to record factors such as *whether first responders had difficulties finding the scene or accessing the address,* for example, *obtaining access to blocks of flat*s.

Other factors you may want to consider in this section include whether there was unsecured and easy access to medicines in the family home, or if the weather conditions or road layout were a factor in a road traffic collision.

Contributory factors: service provision

The purpose of this section is to obtain further detail on the services provided to the individual or family. Where possible you should consider information relating to every service the child or young person had contact with in their life.

It is important to include any challenges around accessing a service in the areas for improvement. Had the child's needs been fully assessed, and the most appropriate service identified? Were there delays in the child receiving a service in response to identified needs? If so, why was this? This might be because the service needed is not yet provided, or because it needs to be expanded. It is also important to include the reasons why it may have been difficult for the child or family to access the service, for example, *was it difficult to get to?*

It is also important to note any challenges relating to communication and or information sharing. This could be within or between agencies but could also be between agencies and the child or young person and their family or carers. It should include details of the cause of these challenges, if known.

In situations where a child or young person received palliative care, you should consider whether the death took place in the location of choice, and if not, why?

This is the place to record any concerns the family may have expressed about any services.

As well as areas for improvement, you should include positive examples, in the free text section, such as where services have worked well with each other and the family, examples of where a service has gone 'above and beyond' to provide what was needed, or where services have been particularly innovative in helping to support a child.

9. Modifiable factors

The review team should consider whether the review has identified one or more factors across any sections that may have contributed to the death of the child or young person, and which might be modified to reduce the risk of future deaths. Details should be provided of any modifiable factors that are identified.

All modifiable factors should be reflected in the contributing factors section. For example, *if the review team identified issues with the services escalation of care that, if amended, could have changed the outcome* or *reduced the risk in the future* this should be described in the "Modifiable Factors" section and in "Service Provision Contributory Factors" section.

Please note you should NOT record something in the "Modifiable Factors" section that you have not listed in one of the "Contributory Factors" sections.

10. Categorisation of death

This section asks the review team to choose the category it considers best to describe the circumstances of the death. This is a hierarchical list of categories, if more than one category could reasonably be applied, the highest up the list should be marked. Please note only ONE category should be marked.

While your choice of category does not have to match the registered cause of death, sometimes it will. The review team should consider all the factors that have been identified and consider why the child died. For example, *the registered cause of death recorded for a child that was trafficked in a shipping container might be dehydration, but the child died because they were trafficked. Therefore, the categorisation of death will be Category 1: Deliberately inflicted injury, abuse or neglect.*

11. Summary and actions

This section is about learning and improvement, and how you will apply learning from the review to improve outcomes for children and their families. It is therefore important that you capture and record the learning points and actions in a succinct and informative way.

You should list the key actions arising from the review. These should be actions that are relevant to practice change or may be of national interest and should flow from the learning points identified from the review. This should include learning relevant to Scotland where reviews span another UK nation.

A learning point should make sense as a standalone statement and should present the case for change. It should identify what the problem or issue is, why this is the case, and what and how this needs to change. All learning should be added to the CRDS even if this did not contribute to the child's death as this can help identify the scale of any service provision issues more widely.

The final question in the template asks about ongoing support for family and carers: record any follow-up support offered to the family and any longer-term plans to support families whose needs may change over time. For SUDI reviews, this should include details of support for future pregnancies.

The CRDS will be subject to review and will take account of the learning from reviews and feedback from NHS boards and local authorities.

Appendix 1: Additional points to consider when reviewing the death of an older young person (18-25 years)

The CRDS has been designed to capture data in relation to children and young people across all age groups. Indicators have, where appropriate, been aligned with those used in the rest of the UK to enable nation-wide comparisons. In recognition of the wider scope of the programme in Scotland, where the criteria for a review includes young people in receipt of continuing care or aftercare at the time of their death, additional consideration should be given to the following sections of the CRDS.

2. Circumstances of the death

Summary account of the circumstances leading to the death

Responses in this section will vary depending on a range of factors, for example, *if the young person's death was expected or not, if there were underlying health conditions, or where the death occurred*. It is likely that older young people or young adults with experience of care will have had support from a range of services, often for a significant period during their lives. A summary of the circumstances leading to their death, which may form the summary section of the review report, is likely to provide all the necessary information.

3. Family and carer involvement

Any other significant relationships should be considered for example, *partner, spouse and brother or sister* and how their views have been included in the review process.

4. Review meeting

The range of agencies or services represented at review meetings will vary. For older young people, it is more likely that adult services may have been involved in some aspects of their care. Where adult services have been represented at meetings and are not included in the list of services in the template, this can be recorded in the 'Other' box.

Reference to education in this section can include further education; reference to mental health services can include both child and adolescent mental health or adult mental health services.

5-8. Contributory factors: child or young person, family and social environment, physical environment and service provision

For all these sections, the review team should use all the information available to determine whether each factor was present in the life of the young person. If present, the review team should then use the information available and use its clinical and professional judgment to determine whether each factor may have contributed to vulnerability, ill-health or death of the young person and grade them accordingly.

The combination of drop-down boxes and free text should allow you to move through this section, while still allowing expansion of issues where relevant. There is also an “Other” option in each section to capture any other factors or issues not covered by the specific options. This should be graded at the level of influence that is highest for any of the other issues present. Any factors noted in the free text section should be graded if possible.

5. Child or young person

This section asks about factors intrinsic to the young person. After completing the level of influence section, use the free text box to give your views on the impact of these factors on the young person’s vulnerability, ill-health or death.

6. Family and social environment

This section asks about the adverse events which may have occurred in the young person’s early childhood years. While this may not be significant at the time of death, it will be important to understand the context of the young person’s formative years and how they shaped their life experiences.

When reviewing the death of a care experienced young person, social work assessments and reports will likely include information about their early childhood experiences.

Factors in social environment – the “Other” option and free text box

Suggested areas to consider in this section include the following:

- Engagement with services or support networks; was help available to prepare for and manage independent living?
- Family networks and relationships; was the young person in a relationship, co-habiting or married? Was there any ongoing support from family members? What was their relationships with friendship groups (if known and relevant) and others who provided care or support?
- Education and employment status; was the young person supported in school or further education, employment, training programme?

- Parenting and caring responsibilities; did the young person have parenting responsibilities; biological children; living with a partner who had children; caring responsibility for brothers or sisters; caring responsibility for other family members?

7. Physical Environment

In addition to the guidance provided, consider the young person's housing environment. For example, *was it comfortable and safe or was the young person "sofa surfing", in temporary accommodation, supported lodgings, homeless accommodation or own tenancy?* What was the young person's view of the help they received to transition to independent living, if known. Were there aspects of the community environment which may have been a factor in their death?

8. Service provision

Factors to consider in this section include:

- the extent to which need and risk was assessed
- access to services, in particular mental health or addictions services
- how well transitions were planned and managed between child and adult services
- the extent to which services were meeting identified needs
- communication between agencies and services, and
- support available out with normal working hours.

Appendix 2: Guidance on completing the data subset for sudden, unexpected deaths of infants and children (SUDIC)

What it's for

To support completion of the child death review CRDS, a supplementary form aims to gather more detailed information on deaths categorised as SUDIC (aged 0-18 birthday).

When and how to use it

The SUDIC form should be used for relevant deaths **from 1 January 2026**. For deaths prior to that date, please select the CRDS dataset option in the portal and only complete that dataset.

The SUDIC subset should be completed in all cases where the death fulfils Category 10: deaths that are sudden, unexpected and unexplained.

Due to the nature of the information requested, you may find it helpful to circulate a PDF or hard copies of the form to relevant stakeholders (e.g. Scottish Ambulance Service (SAS), Police Scotland, social work) to begin capturing information immediately following the death, where possible.

All questions should be completed as fully and accurately as possible. Where information is not known or not applicable, there will be options to identify this. As with the CRDS, no identifiable information other than the details of the child or young person should be entered on the SUDIC form.

Questions are grouped as follows:

- All deaths (all ages)
- If the child was found dead during or just after a sleep (all ages)
- If the child was found dead during or just after a sleep (under one year old)
- All deaths of children under 1 year old

The online portal will automatically calculate the age of the child from the 'Date of Birth' and 'Date of Death' questions in the demographics section of the CRDS and only display the questions applicable to that age. For this reason, please ensure that the dates of birth and death are entered accurately before continuing with the subset questions.

Bereavement support

The National Hub recommends the National Bereavement Care Pathway (NBCP) for all staff who are involved in the care of bereaved families and carers. See the Sudden and Unexpected Death in Infancy (SUDI) Pathway and the Bereavement Care Standards.

Question-specific guidance

Question S.1.2 asks whether the child experienced a previous brief resolved unexplained episode (BRUE), also known as acute life-threatening event (ALTE).

BRUE is defined as an episode in an infant less than 12 months old characterized by:

- < 1 minute duration (typically 20-30s)
- Followed by return to baseline state
- Not explained by identifiable medical conditions

Includes one or more of the following:

- Central cyanosis/pallor
- Absent, decreased or irregular breathing
- Marked change in tone (hyper or hypotonia)
- Altered level of consciousness

ALTE is an older descriptive term based on an event that is frightening to the observer including a combination of: apnoea, colour change, change in muscle tone, choking or gagging.

If there are any other questions for which you need further guidance – or if you have a suggestion for improvement - please email his.cdrnationalhub@nhs.scot so we can answer your query and update this guidance document.

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