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

Guidance on completing the core review data set

March 2022

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Introduction

Healthcare Improvement Scotland, in collaboration with 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 will ultimately aim 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 will be conducted into the deaths of all live born children up to the date of their 18th birthday, or 26th 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 by:
 - developing a methodology and documentation to ensure all deaths of children and young people, that are not subject to any other review, are reviewed through a high quality and consistent process, and
 - improving the quality and consistency of existing reviews,
- improve the experiences and engagement with families and carers, and
- sharing learning from current review processes across Scotland that could direct action to help reduce preventable deaths.

Core review data set

The National Hub core review data set has been developed for use by NHS boards and local authorities when reviewing deaths of children and young people, to collect key information about the child or young person in order 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 core review data set should be securely inputted through the online portal once the review into the death of a child or young person is complete. 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 core review data set 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 core review data set.

All questions in the core review data set 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 core review data set form. You will find it helpful to begin completing the core review data set 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 the core review data set at HIS.CDRNationalHub@nhs.scot

The core review data set will be reviewed every year taking account of the learning from reviews and feedback from NHS boards and local authorities.

1. Demographics and background information

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

Age at death

This should be completed as follows:

- for infants up to 28 days, in days
- for children between 1 to 12 months, in months, and
- for children and young people over 1 year, in years.

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

This question relates to children or young people 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 would be an example of where 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.

2. 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. When 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. When 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.

Example summary account (child with a life-limiting condition):

The child was diagnosed with a brain tumour 6 months before death, following 2 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 1 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.

3. 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 were raised at 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.

4. Review meeting

This section captures information on the membership of the review team and date the review report was approved by the relevant 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. 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.

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

Within these sections, the review team should use all the information available to them to conclude, for each factor listed, if they have enough evidence to determine whether or not each factor was present in the life of the child or young person. If present, the review team should then use the information available to them, and their clinical and professional judgment, to determine whether each factor may have contributed to vulnerability, ill-health or death of the child or 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. 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". If you have noted factors in the free text section you should also try to grade them if possible.

The free text section can also be used to record positive factors and we would encourage you to do so.

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 conditions in the mother and any relevant information about the pregnancy and obstetric history. The free text section can be used to capture issues not covered in the 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. Was the voice of the child heard? You should record details here of any social isolation, interaction with peers, bullying or other experiences the child may have had, which involved people in their social circle.

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, in particular, 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 terms of areas for improvement, it is helpful to know if the family were 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 was not able to do so, try to describe the barriers to better engagement. For example, financial situation, language barriers.

You can also include positive details 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.

You should 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 stair-gate 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 as strangulation on blind cords, suffocation on nappy sacks.

You should also record factors such as whether first responders had difficulties finding the scene or accessing the address, for example obtaining access to blocks of flats.

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.

For sudden and unexpected deaths of infants (SUDIs) you should consider the details of where the child was sleeping at the time of death. It should include whether the child was co-sleeping (sleeping with another member of the family) and if so, where - in bed, on a sofa or armchair.

Contributory factors: service provision

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

You should include positive examples as well as areas for improvement, 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.

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.

When 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.

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 of children or young person. Details should be provided of any modifiable factors identified.

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 they feel best fits 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. Only ONE category should be marked.

While your choice of category does not have to match what is recorded as the registered cause of death, sometimes it will. The review 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 in order 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.

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 core review data set 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. Record if the family had a designated key contact or co-ordinator, and if so, how effective was this in supporting the family and ensuring meaningful engagement with the review process.

Appendix 1: Additional points to consider when reviewing the death of an older young person, or adult

The core review data set 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 criterion for a review includes young people or young adults in receipt of continuing care or aftercare at the time of their death, additional consideration should be given to the following sections of the core review data set.

2. Circumstances of the death

2.13 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 of time 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 or young adults, 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. Child or young person

This section asks about factors intrinsic to the young person or young adult. 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 or young adult'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 or young adult'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 or young adult's formative years and how they shaped their life experiences.

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

Factors in social environment – the 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 or young adult 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 or young adult supported in school or further education, employment, training programme?
- Parenting and caring responsibilities – Did the young person or young adult 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 or young adult's housing environment. For example was it comfortable and safe or was the young person or young adult "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 the young person or young adult's 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.

The core review data set will be subject to review on an annual basis and will take account of the learning from reviews and feedback from NHS boards and local authorities.