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# Scoping exercise report

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

August 2020



Scottish Government  
Riaghaltas na h-Alba  
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# Executive summary

Scotland has a higher mortality rate for under 18s than any other Western European country, with over 300 children and young people dying every year<sup>1</sup>. Around a quarter of those deaths could be prevented<sup>2</sup>. Every death of a child or young person deserves a review and by reviewing and learning from these deaths we may reduce the chances of future deaths.

There is currently no national system to support reviewing and learning, or to share national learning, and not all deaths are reviewed. We also know that the quality of reviews varies across services, and across Scotland. To address these issues a National Hub has been set up, co-hosted by Healthcare Improvement Scotland and the Care Inspectorate.

The National Hub conducted a baseline scoping exercise to investigate the different types of review being carried out into the deaths of children and young people. This considered the whole review process, and included information from the notification of a death, to the outputs from the review process, and how learning from reviews is shared, locally and nationally.

The resulting actions for the National Hub are summarised below.

**Action 1:** We will work with National Records of Scotland to develop a process to regularly provide relevant organisations with the information they require on the deaths of children and young people within their NHS board and local area.

**Action 2:** We will work with organisations during implementation of the new process to identify if their process for notification of the death of a child or young person requires any improvement.

**Action 3:** We will work with our expert advisory group and organisations to identify key elements of a quality review to ensure that all deaths of child and young people receive a review of equal quality.

**Action 4:** We will develop a core review dataset for organisations to use when reviewing the deaths of children and young people that would not otherwise receive a review through any other process.

**Action 5:** We will work with organisations during implementation of the new process to identify areas where improvements can be made to the review process. We will also work with other national organisations to highlight areas that are causing delays and identify any actions which need to be taken to improve the process.

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<sup>1</sup> National Records of Scotland. Vital Events Reference Tables 2018. Viewed 16 June 2020. [www.nrscotland.gov.uk/statistics-and-data/vital-events-reference-tables/2018/](http://www.nrscotland.gov.uk/statistics-and-data/vital-events-reference-tables/2018/)

<sup>2</sup> National Records of Scotland. Avoidable Mortality. 2018. Viewed 16 June 2020. [www.nrscotland.gov.uk/statistics-and-data/vital-events/deaths/avoidable-mortality](http://www.nrscotland.gov.uk/statistics-and-data/vital-events/deaths/avoidable-mortality)

**Action 6:** We will ask organisations to identify a lead for reviewing and learning from the deaths of children and young people in each NHS board and local authority area. The National Hub will engage with the nominated leads to support implementation of the new process.

**Action 7:** We will also ask NHS boards to set up (or designate an existing) governance group with responsibility for ensuring that every child and young person in each NHS board area receives a quality review in the event of their death and that learning is captured and shared from reviews.

**Action 8:** We will work with representatives from family and carer organisations, support organisations and voluntary organisations to understand what involvement families and carers would like in the review process. We will use this information to provide guidance to NHS boards and local authorities.

# Introduction

## Background

The Scottish Government requested a system be established for reviewing and learning from the circumstances surrounding the deaths of all children and young people in Scotland, based on a National Hub, with an aim to co-ordinate all current review activity. Healthcare Improvement Scotland, in collaboration with the Care Inspectorate, are the co-hosts of the National Hub programme.

The programme will use a multidisciplinary and multi-agency approach, focused on using evidence to deliver change, and ultimately aim to reduce deaths and harm to children and young people. Every child and young person has the right to a review in the event of their death that should be of an agreed minimum standard. Reviews should be conducted on the deaths of all live born children up to the date of their 18<sup>th</sup> birthday, or 26<sup>th</sup> birthday for care leavers who are in receipt of aftercare or continuing care at the time of their death.

## National Hub

It is understood that the quality of reviews of the deaths of children and young people varies across services and across Scotland. The National Hub aims to identify trends, from such reviews, that could alert professionals of possible areas of risk. It will also look to establish a minimum standard for carrying out reviews into the deaths of children and young people. The National Hub will operate in the context of existing review arrangements, rather than replace or duplicate these. Progress on the pilot year (April 2019-March 2020) of the National Hub has been reported to the Scottish Government. As a result of the current COVID-19 pandemic and following discussions between the National Hub and Scottish Government, the planned roll out and implementation of the new review system was postponed from 1 April 2020. This was done to avoid placing additional pressure on services and to maximise the availability of all health and social care staff to focus their priorities on responding to meet the challenges of the pandemic. The new child death review system will now be fully implemented on 1 April 2021.

The aims of the National Hub are to:

- Ensure that the death of every child and young person in Scotland is subject to a quality review:
  - develop 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 review process, and
  - improve the quality and consistency of existing reviews.
- Improve the experience and engagement with families and carers.
- Channel learning from current review processes across Scotland that could direct action to help reduce preventable deaths.

An expert advisory group has been established to provide external advice on the operational methodology and the range of products being developed and delivered by the National Hub. The expert advisory group has representation from service-based stakeholders, professional organisations, third-sector organisations (representing children and families) and policy makers. The group will be consulted throughout implementation of this work for specialist advice and support to ensure the buy-in and ownership of external stakeholders.

## Scoping exercise

We conducted a baseline scoping exercise to investigate the different types of reviews currently being carried out across health and social care.

In August 2019, we wrote to 48 organisations (NHS boards and local authorities) and received responses throughout September and October 2019. We received returns from all 14 territorial NHS boards, one special NHS board and 11 local authorities. Some organisations submitted a joint response.

We hoped to gain a better understanding of the entire review process, including:

- information from the notification of a death
- outputs from the review process, and
- how learning from reviews is shared (locally and nationally).

We also wanted to identify potential gaps and consider why some deaths are not reviewed. This exercise built on the Scottish Government's Child Death Review Working Group Child Death Review Report<sup>3</sup>. The working group carried out a survey in 2013 with child health commissioners, to identify work being undertaken that related to the review and prevention of the deaths of children and young people in Scotland.

The results of this scoping exercise have provided a map of how reviews, into the deaths of children and young people, are currently conducted in Scotland. This has allowed us to consider what methodology is required to ensure that every child and young person has a robust review carried out following their death.

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<sup>3</sup> Scottish Government Child Death Review Working Group. Child Death Review Report. 2014. Viewed 16 June 2020. <https://www.gov.scot/publications/child-death-review-report>

# Findings from the scoping exercise

When reviewing the responses to our scoping exercise, some key themes were identified. These themes have been outlined below along with actions for the National Hub programme.

## Notification system

We asked NHS boards and local authorities how their organisation is made aware of the death of a child or young person. We were told that organisations received notification through a wide variety of methods (see appendix 1) with no single, consistent, systematic process.

A wide range of sources were highlighted by those who responded, which reflects the many different areas of public services who interact with children and young people. Seven respondents fed back they receive reports from National Records of Scotland (NRS). These reports contain information on deaths that have occurred in their area. NHS boards had arranged to receive the report from NRS at different intervals; some weekly, others quarterly.

Responding organisations told us of a variety of different ways they are informed of a death that has occurred out with their area.

**Action 1: We will work with National Records of Scotland to develop a process to regularly provide relevant organisations with the information they require on the deaths of children and young people within their NHS board and local area.**

**Action 2: We will work with organisations during implementation of the new process to identify if their process for notification of the death of a child or young person requires any improvement.**

## Existing reviews

We were told of a range of reviews that are already taking place to review the deaths of children and young people. On examining the information, we found variation in a number of areas between the many different reviews identified by the respondents. This included:

- membership of review teams
- format of the reviews
- outputs from review
- family and carer involvement, and
- time to complete reviews.

A number of reviews currently taking place are required to be undertaken by legislative or best practice guidance. The format of these reviews is dictated by national guidance and any reports are submitted to the relevant national organisation. Other types of review are carried out by organisations in accordance with local processes, such as specialty or departmental review meetings. It was clear from responses that more work is required to understand the content and

format of these reviews. This will provide the National Hub a greater understanding of whether these reviews meet the required minimum standard.

**Action 3: We will work with our expert advisory group and organisations to identify key elements of a quality review to ensure that all deaths of child and young people receive a review of equal quality.**

We also identified that organisations could not assure themselves, or us, that every child and young person receives a review in the event of their death.

**Action 4: We will develop a core review dataset for organisations to use when reviewing the deaths of children and young people that would not otherwise receive a review through any other process.**

We asked organisations how they record reviews they have completed. All the respondents told us that they use an electronic system to store and record the information. However, they also told us that they use multiple systems including excel, DATIX, shared folders, to store the information.

We asked NHS boards and local authorities about their timescales for completing a review. We were told that most areas do not routinely capture data that details the time taken to complete a review. However, many did comment that reviews can take a long time to complete. The reasons for this included:

- insufficient resource
- delays in receiving post mortem examination results
- lack of administration support
- availability of information
- delays from the procurator fiscal, and
- availability of staff to attend meetings.

The National Hub recognises that timely reviews are of benefit to the organisations and bereaved families.

**Action 5: We will work with organisations during implementation of the new process to identify areas where improvements can be made to the review process. We will also work with other national organisations to highlight areas that are causing delays and identify any actions which need to be taken to improve the process.**

## Governance

We asked NHS boards and local authorities if they had a lead person responsible for the reviews of the deaths of children and young people. We received a mixed response. On reflection the wording of the question left room for interpretations. Some areas identified no overall lead. Others provided details of how responsibility has been split by subject or age group. For example,



perinatal, sudden unexpected death in infants (SUDI), and drug-related deaths. From the information we received we could see that there was a gap in organisations identifying a lead for older children and young adults who did not require a significant case review.

We also found that overarching governance structures were not in place that would ensure the quality of the reviews taking place and that learning was being captured and shared. Organisations told us it could be difficult to share lessons with all relevant staff in a co-ordinated manner. They told us learning was shared in a variety of ways including:

- learning notes and summaries
- department meetings
- morbidity and mortality meetings for educational purposes
- bulletins and newsletters
- learning events
- seven minutes briefings
- staff debriefs, and
- governance committees.

**Action 6: We will ask organisations to identify a lead for reviewing and learning from the deaths of children and young people in each NHS board and local authority area. The National Hub will engage with the nominated leads to support implementation of the new process.**

**Action 7: We will also ask NHS boards to set up (or designate an existing) governance group with responsibility for ensuring that every child and young person in each NHS board area receives a quality review in the event of their death and that learning is captured and shared from reviews.**

## Engagement with families and carers

The National Hub recognises the importance of families and carers in the review process. We asked organisations how they communicated with families around the review of the death of their child or a decision not to review the death. We received a variety of responses with many areas stating that this would be documented within the case notes or on DATIX. It was not clear how organisations engage families in the review process in a consistent manner. However, it was identified by several NHS boards and local authorities as an area they would like to improve.

**Action 8: We will work with representatives from family and carer organisations, support organisations and voluntary organisations to understand what involvement families and carers would like in the review process. We will use this information to provide guidance to NHS boards and local authorities.**

# Findings from the pilot sites

In order to progress this national system, three NHS boards; NHS Lanarkshire, NHS Lothian and NHS Tayside, have been working with the Scottish Government and the National Hub to evaluate existing systems when reviewing the death of children and young people and compare local and national processes. The aim of the exercise was to:

- evaluate current systems, such as, what reviews are being carried out/not carried out, family engagement and which agencies are involved
- examine what aspects of current systems could work well at a national level and where there would be challenges
- identify and carry out tests of change that will improve upon current review systems, whilst considering national fit
- look at an example of existing software to determine potential suitability and draw comparisons with current systems (electronic or otherwise), and
- share learning across the three pilot sites, Scottish Government and National Hub.

An interim report (covering October 2018-March 2019) and a final report (covering March 2019-September 2019) have been produced. Due to the sensitive nature of the topic and the information contained, the reports were only shared with Scottish Government, the National Hub and the three pilot sites.

We are grateful to the three pilot sites for the considerable work carried out and recognise the important contribution their work has made. The pilot exercise has provided significant insight into how reviews into the deaths of children and young people are currently conducted in Scotland. The following provides a summarised overview of feedback from the pilot sites.

## Data

The pilot sites provided information on notifications and data collection following the death of a child or young person.

### Notification systems

All pilot sites are notified of the deaths of children and young people, from their NHS board area, by NRS. The pilot sites outlined how they are working to gather and disseminate information regarding the deaths of children and young people to ensure they have a complete picture and no deaths are missed.

One pilot site advised that, on receipt of NRS data, the NHS board's information services department uploads the dataset to an internal data storage system. Following this, a notification is sent to the medical records department, which is responsible for updating the relevant clinical systems that the patient has died. There is an internal system of notifications to ensure relevant staff are made aware of a child's death.

Another pilot site told us that work was ongoing to establish the NRS data as the master data source for the death of a child or young person. In addition, they also use daily child health identifier (CHI) downloads, weekly CHI updates from Trak, and notifications from their DATIX system. This information is used to monitor death rates in the NHS board and DATIX reports are used to monitor the timeliness of review, and thus support the wider public health agenda.

### Data gathered for reviews

Pilot sites provided us with information on the various types of reviews that take place into the deaths of children and young people. These include perinatal mortality review, morbidity and mortality meetings, local adverse event review (LAER), drug death review, suicide review, initial case review (ICR), significant case review (SCR), significant adverse event review (SAER) and SUDI.

One pilot site told us that current systems of review are not comprehensive, and the nature and depth of any review depends on circumstances. Within this NHS board, all cases where there is child protection involvement are recorded in DATIX and are subject to briefing note review, SAER or multi-agency ICR/SCR processes. Informal reviews of cases are conducted for children with complex care needs and/or where death is expected. Learning across services is limited as no formal review process currently exists for these cases. Reports on formal review processes are provided to the relevant clinical governance committees for review of learning and to assure that any identified improvement actions have been delivered.

An exercise was carried out by a pilot site to identify gaps in the DATIX child death review process. Gaps were identified when children died out with the NHS board, either at other hospitals or abroad, and therefore would not have been alerted through the local DATIX system. The remainder had all received a review signed off by the associate medical director and associate nurse director. The level of review carried out was thought to be proportionate to the death. The pilot site identified a need to involve colleagues out with the speciality where the death occurred; this is now being addressed and delivered.

Another pilot site told us that many deaths are already reviewed in a variety of formats however, there is not a robust and consistent approach across review processes. Further work is required to ensure learning from reviews is shared and, when required, changes are embedded in practice.

### Deaths of young people aged 18-26 years

A pilot site told us that the local child health commissioner is notified weekly of all deaths up to the age of 26 years old. Some of these are reviewed through other services, for example mental health services or social work for looked after children. Another pilot site advised they have been unable to find a way to identify the deaths of young people, up to their 26<sup>th</sup> birthday, who have been receiving aftercare or continuing care services. Meetings have been arranged with leads for suicide reviews and drug death reviews in their NHS board, to cross check cases to see whether reviews were carried out, and gain understanding of how learning was shared.

## Stakeholders

A wide range of stakeholders have been involved in the pilot exercise. The pilot sites provided an overview of ongoing engagement with key stakeholders in the child death review process and identified areas where improvements have been made.

### Child death review groups

Two of the pilot sites had established governance groups to oversee child death reviews.

One had a child death review steering group to examine the clinical and administrative processes required to develop a comprehensive system for reviewing deaths of children and young people. The group is multidisciplinary and includes senior managers, clinicians from paediatrics, neonatology, the emergency department, child protective services, nursing and midwifery.

Another pilot site has a strategic NHS board-wide multi-agency child death review group in place, chaired by the NHS board's child health commissioner, and includes colleagues from Scottish Ambulance Service, Police Scotland and The Crown Office and Procurator Fiscal Service. This group has an important function in developing policies, as well as building relationships and sharing learning. A significant piece of work has been carried out to examine the need for more multi-agency involvement in local child death review processes. The NHS board has formalised links with community staff, such as health visitors, social work services and bereavement services to ensure shared vision and delivery. A short life working group has been established to review the current policy and co-ordinate delivery of the child death review action plan.

### Third sector involvement

A pilot site told us that, while feedback is gathered from families and carers after every death, wider service feedback is important to improve care around deaths of children and young people. Third sector partners provide a vital role in understanding these needs. Feedback from families and carers on their experience of the review process (following the loss of their child) is a standing item for their strategic child death review group. Representation on this group includes services that support families during early pregnancy loss, such as:

- dedicated charity memory box services
- neonatal services
- maternity service
- primary care
- mortuary services
- bereavement services
- funeral providers, and
- crematoria.

## Support for families and carers

A pilot site indicated that feedback from families and carers is a crucial part of all their reviews into the death of children and young people. A key contact is identified from the NHS board who will be known to the family for all deaths of children and young people, not including SUDI. This is either the child's consultant or community nurse. Different services manage this process in different ways. Some services contact parents by letter providing details of the review process and invite the family to raise any questions they would like answered as part of process. These are recorded and answered as part of the review meeting and then shared with the family. Information is shared in both face-to-face meetings with families, as well as by letter. The 'Being Open' principles are also used, which aids the open discussion about family experiences, as well as being important to ensure process and service improvement.

Pilot sites also told us they are looking to improve the family liaison service and ensure families are kept informed of the progress of a review and links have been made with the NHS board's head of spiritual care to discuss bereavement care and family support

## Tests of change

Several tests of change ideas were generated and carried out during the pilot exercise, which concentrated on examining current systems and processes. Some of these tests of change are outlined below.

### Recording and reporting

A database has been developed by a pilot site to collect data on all deaths of children and young people aged 0-25 years. This allows staff to produce a report on a quarterly basis with agreed data fields. The report has been through a number of iterations to ensure they are clear, accurate and meaningful to support the review processes.

### Social work links

The same pilot site has made links with social work departments to determine the best method of accessing information on the social work status of children and young people. The team were able to identify young people who were known to social work services, the reason for contact with social work services and the date of last contact. Categories for 'reason known to social work' have been refined over time and fields added, as the overall database and report has developed.

### Engagement with health visitors

Since the launch of the health visitor pathway, which sets out the minimum core home visiting programme to be offered to all families by health visitors, links have been strengthened with families. Health visitors provide a vital link in the process of reviewing the deaths of children and young people, as many are children known to their service. One pilot site planned to add health visitors to the list of professionals who are required to be part of the core child death review processes in neonatal and SUDI. A small-scale test of change was carried out and was successful. To date, the small numbers of health visitors involved have provided valuable input to the child death

review process. As with any change, communication takes time, however this is part of the pilot site's action plan.

# Conclusion

A key aim of the National Hub for Reviewing and Learning from the Deaths of Children and Young People is to channel learning from current review processes across Scotland that could direct action to better understand and reduce preventable deaths.

This scoping exercise has enabled a better understanding of the different types of review being carried out into the deaths of children and young people across Scotland and how reviews are currently being conducted and learning is shared. The findings have helped identify the key priority areas and specific actions to focus our work that will be taken forward with stakeholders. This includes the development of a robust methodology and implementation of a consistent review process that ensures every child and young person in Scotland has a quality review carried out following their death.

The findings also highlight the considerable variation in engaging families and carers in the review process and how we need to bring a consistent approach to the process. Understanding what involvement families and carers want in the review process, and how their views can be incorporated in a consistent manner, will ensure that they are appropriately engaged and included.

As we have outlined, there is currently no national system to support reviewing and learning or to share national learning. As such, further work will be taken forward by the National Hub to ensure that mechanisms are in place so that learning from reviews into the deaths of children and young people is captured locally and shared nationally. Our aim is to bring about improved practice change for children and families and facilitate action to help reduce preventable deaths.

For further information about the National Hub, please visit our [website](#) or contact us at [hcis.cdrnationalhub@nhs.net](mailto:hcis.cdrnationalhub@nhs.net).

# Appendix 1: Systems of notification

One question in our scoping questionnaire was 'How your organisation is made aware of the death

Emergency department	BadgerNet	CHI download report	Child and adolescent mental health services (CAMHS)
Child protection department	Clinical lead	Crown Office and Procurator Fiscal Service	DATIX
Drug related death co-ordinator	Education department	Email	Emergency services
GP	Health visitor, school nurse, community nurse	Head of midwifery	Local authority
Local incident reporting system	Media or social media	National Records of Scotland (NRS)	On-call paediatrician
Paediatric ward	Parents of child or young person	Pathologist	Police Scotland
Public health returns	Scottish Cot Death Trust	Social work department	Special care baby unit
Staff from another hospital	SUDI paediatrician	TrakCare	Word of mouth

of a child or young person'. We have listed the many different ways NHS boards and local authorities told us they received notification of the death of a child or young person in their area.



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or email [contactpublicinvolvement.his@nhs.net](mailto:contactpublicinvolvement.his@nhs.net)

## Healthcare Improvement Scotland

Edinburgh Office  
Gyle Square  
1 South Gyle Crescent  
Edinburgh  
EH12 9EB  
0131 623 4300

Glasgow Office  
Delta House  
50 West Nile Street  
Glasgow  
G1 2NP  
0141 225 6999

[www.healthcareimprovementscotland.org](http://www.healthcareimprovementscotland.org)