

Inspections and reviews To drive improvement



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

National guidance when a child or young person dies

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## Introduction

#### Background

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>.

There is currently no national system to support reviewing and learning or to share national learning across all deaths and not all deaths are reviewed. We also know that the quality of reviews varies across services, and across Scotland.

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 and the Care Inspectorate are working together to deliver the aims outlined in the next section.

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.

The National Hub wants to ensure the death of every child and young person is reviewed to 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.

Whilst organisations are able to establish their own structure and process for reviewing the deaths of children and young people, they should ensure the local processes align to this guidance in order to enable good practice and lessons to be reflected and shared at a national level.

Organisations must ensure an infrastructure is in place that outlines all stages of the review process; from notification of the death, to carrying out the review, to sharing the learning locally and nationally.

<sup>1</sup> National Records of Scotland. Vital Events Reference Tables: <u>www.nrscotland.gov.uk/statistics-and-datastatistics-by-theme/vital-events</u>

<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

## National Hub

It is understood that the quality of reviews varies across services and across Scotland. While the National Hub aims to identify trends 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 and ensure consistency is applied to all reviews. The National Hub will operate in the context of existing review arrangements.

The aims of the National Hub are to:

- Ensure that the death of every child in Scotland is subject to a quality review:
  - develop methodology/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.

The National Hub will:

- work with NHS boards and local authorities and request updates on the progress of reviews
- establish a national learning system to facilitate learning and disseminate best practice across health and social care including a community of practice
- securely manage data submitted to the National Hub
- use the information submitted to the National Hub to inform thematic reviews, and
- publish an annual report.

The National Hub will not:

- carry out individual child death reviews, or
- collate or publish identifiable information.

#### National Hub criteria

The National Hub has been tasked with ensuring reviews are conducted on all deaths of live born children up to the date of their 18<sup>th</sup> birthday, or 26<sup>th</sup> birthday<sup>3</sup> for care leavers who are in receipt of aftercare or continuing care at the time of their death.

This includes Scottish children and young people who die outside Scotland, and children and young people who die in Scotland that do not reside in Scotland. It also includes live-born babies where a death certificate has been issued. In the event that the birth is not attended by a healthcare professional, organisations may carry out initial enquiries to determine whether or not the baby was born alive. If these enquiries determine that the baby was born alive, the death must be reviewed.

For the avoidance of doubt, it does not include stillbirths, late foetal loss, or terminations of pregnancy (of any gestation) carried out within the law<sup>4</sup>.

- Stillbirth: baby born without signs of life after 24 weeks gestation
- Late foetal loss: where a pregnancy ends without signs of life before 24 weeks gestation
- Cases where there is a live birth after a planned termination of pregnancy carried out within the law are not subject to a child death review.

#### **Reporting to National Hub**

The National Hub is working with National Records Scotland to implement a process to ensure all deaths of children and young people are notified to NHS boards, local authorities and the National Hub. This will enable reporting organisations and the National Hub to check that all eligible deaths are being reviewed. NHS boards will also be required to report quarterly to the National Hub on the progress of reviews. This guidance will be updated to reflect the new process when available.

Once the lead organisation has carried out a review into the child or young person, it should also complete all relevant sections of the National Hub core review data set using Healthcare Improvement Scotland's Customer Relationship Management (CRM) system. Separate guidance will be available for this system.

The CRM system will be able to accept documents to be attached such as action plans.

<sup>&</sup>lt;sup>3</sup> The Children (Scotland) Act 2014 introduced a new duty on local authorities to provide continuing care and extended eligibility for the receipt of aftercare to all categories of young people who cease to be looked after on or after their 16<sup>th</sup> birthday up until their 26<sup>th</sup> birthday.

<sup>&</sup>lt;sup>4</sup> The Abortion Act 1967.

# Purpose of this guidance

'Systematic review of all child deaths is grounded in respect for the rights of children and their families, and aimed towards the prevention of future child deaths<sup>5</sup>.'

This guidance sets out the processes when responding to, and reviewing, the death of a child or young person. It sets out the review process and infrastructure required to support local systems from notification to reporting on the death of a child or young person, including governance and key elements that make a quality review. It takes account of the need to consider how to keep family and carers at the centre of the process and provided with opportunities to be involved in and informed about all aspects of the review process.

It provides key steps to ensure consistency when reviewing the circumstances surrounding the death of a child or young person and identify key learning that will positively contribute to ways to prevent or reduce future, preventable deaths.

This guidance has been developed with input from the National Hub expert advisory group that includes representation from service-based stakeholders, professional organisations, third sector organisations representing children and families and policy makers. We have also collaborated with colleagues from the rest of the UK and we took into account NHS England's child death review forms when developing the National Hub core review data set, mirroring key information such as categorisation of death to allow for comparable data collection across the nations.

We understand a range of review processes already exists and this guidance does not intend to duplicate. More information on the other types of reviews that NHS boards and local authorities currently undertake to support learning improvement can be found in Appendix 1: Types of review, along with the criteria that apply for these review processes.

#### Who is this guidance for?

This guidance is aimed at any health and care professionals from NHS boards, local authorities and health and social care partnerships who will have a role in reviewing the circumstances around the death of a child or young person. This includes chief executives and chief officers, chief officer groups and senior management teams. Other organisations who review such circumstances may also find this guidance helpful.

<sup>5</sup> Fraser et al. 2014. Learning from child death review in the USA, England, Australia, and New Zealand.

# Engaging with family and carers

Every family is entitled to have their child's death sensitively reviewed and professionals have a duty to support and engage with families at all stages in the review process. In some cases this will be to identify the cause of death and to ensure that lessons are learnt that may prevent further deaths of children and young people. In circumstances when the death was anticipated and not preventable, it is important to ensure that the experiences of the child or young person were positively managed and that anticipatory wishes of the child, young person and family were met. Engaging in this process must not make things worse for the family at this already extremely difficult time.

All staff have a duty to support family members and carers after the death of their child or young person with kindness and compassion. If questions have been raised about the quality of care provided, organisations have a responsibility to explain what has happened, to apologise as appropriate, and to identify what lessons may be learnt to reduce the likelihood of the same, or similar, incidents happening again.

When a child or young person dies it is important that family members and carers are offered bereavement support. While the support available and how this is accessed varies across Scotland, the National Hub would expect every family be offered bereavement support. Further information about national organisations offering bereavement support can be found at Appendix 2: National Bereavement links.

All bereaved families should be given a single, named point of contact. The main responsibilities for this key contact are to:

- be a reliable and accessible point of contact for family members and carers after the death
- help co-ordinate meetings between the family members, carers and professionals as required
- provide information on the review process and any investigations that relate to the child or young person, including liaising with the Crown Office and Procurator Fiscal Service (COPFS) or Police Scotland family liaison officer
- ensure that their questions are effectively addressed, and provide feedback to the family afterwards, and
- signpost to expert bereavement support if required.

In circumstances where a child or young person has died, and abuse or neglect is known or suspected, it is acknowledged that such events will be challenging for agencies and staff involved, however bereavement support should be in place throughout the entirety of the review process.

We are working with third party organisations to discuss ways of engaging with family members and carers throughout the review process. We will continue to develop this section and update links to other guidance when it is available.

### Governance

Good governance systems will have clear lines of accountability and clearly defined roles and responsibilities to support the reviewing and learning from the deaths of children and young people. This includes providing opportunities for staff at all levels to take part in appropriate learning and development and recognising the time required for people to participate in reviews. They should also ensure robust and integrated systems are in place to learn from reviews and identify themes, trends or patterns in order to make improvements to reduce risks and improve quality of care.

Most deaths of under 18s are due to health conditions. Governance arrangements should usually be led by the NHS board in partnership with local authorities to ensure there is a multi-agency approach. However, in reviewing deaths it is important to consider both health and social care aspects and in some cases it may be most appropriate for the review to be led by the local authority.

NHS boards, working in partnership with local authorities, should have the following in place to support governance systems for the review of deaths of children and young people:

- a lead for reviewing and learning from the deaths of children and young people, and
- a governance group (or designate an existing group), working in partnership with local authorities, 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.

NHS boards should ensure, through their clinical lead and governance group, that:

- they know the number of children and young people from their NHS board area who die
- an appropriate and quality review is carried out for live born children up to the date of their 18<sup>th</sup> birthday who die; working in collaboration with other agencies, third-sector organisations and NHS boards as relevant
- they liaise with local authority child death leads to identify and ensure that an appropriate and quality review is carried out for care leavers up to their 26<sup>th</sup> birthday who are in receipt of aftercare or continuing care at the time of their death
- timescales for carrying out reviews are monitored
- improvement plans from reviews are progressed, and
- learning from reviews is shared for the purpose of improvement.

It will be important that the nominated clinical leads have time protected in their job plan to ensure this process is properly implemented and embedded.

#### **Governance principles**

All organisations are accountable for effective governance and learning following the death of a child or young person. The following principles build on the clinical and care governance framework<sup>6</sup>.

Organisations should:

- work in an open and transparent manner to support a just culture.
- have relevant mechanisms and governance in place to consider and monitor reviews of the deaths of children and young people. This includes identifying the most appropriate review process for each death and ensuring reviews are carried out to a high quality.
- have systems for their senior leadership team to receive regular briefings on the detail of significant issues, trends and other analysis of the deaths of children and young people. This includes consideration of such information during an organisation's Board meetings.
- ensure their senior leadership team receives summary information, including the number of reviews taking place beyond recommended timescales, to gain assurance that appropriate action and learning has been, or is being, taken to reduce risks and to understand the impact on individual families/carers and staff.
- offer timely, compassionate and meaningful engagement with bereaved families and carers in relation to all stages of responding to a death.
- ensure that the contribution of family members, carers and frontline staff remains central to improving standards of care. This includes taking account of the views and questions raised by family members and carers and staff in all reviews and findings being shared with those involved.
- ensure sufficient numbers of staff have appropriate skills through specialist training and protected time as part of their contracted hours to review deaths.
- monitor the implementation of improvement plans including the effectiveness of any changes made following a review and that these are embedded across all relevant areas locally and at national level as appropriate.
- share relevant learning across the organisation and with other organisations and agencies where this could be useful. This includes proactively sharing emerging risks and learning with peers in an open, transparent and timely way.

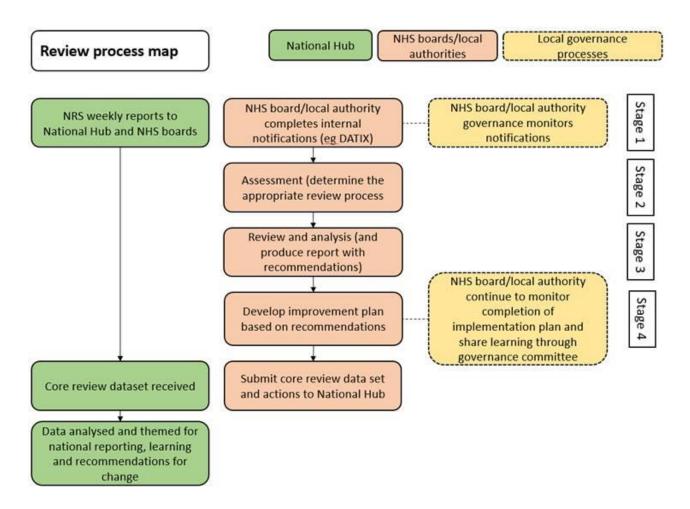
<sup>6</sup> Scottish Government. Clinical and Care Governance Framework. October 2015. Viewed at 6 July 2020. https://www.gov.scot/publications/clinical-care-governance-framework/

## Carrying out a quality review

The organisation undertaking the review must be clear and transparent from the outset that the purpose of the review is to learn and make improvements. Organisations should have a just culture that is open, supportive and focused on continuous learning and improvement. Reviews should be proportionate to the likely learning. They should obtain sufficient information to understand 'what happened and why' and determine the quality of the care provided. The review process should be carried out in a way that is flexible and relevant to the individual circumstance of the death, without incurring excessive workload. The review process can identify good practice that should be shared or learning points that are not directly related to the death that could have an impact on improving the system.

As set out in the governance section, each organisation is required to nominate a lead to liaise with the National Hub on all deaths that meet the criteria and ensure that an appropriate review is carried out. We will work with your organisation's nominated lead to ensure these processes are in place.

A single point of contact for the family members and carers should be clearly defined at the outset, as set out in the Engaging with family and carers on page 6.



#### Stage 1: Initial reporting and notification

#### Notification

Organisations are responsible for ensuring a robust system is in place for the notification and recording of the death of every child and young person in their area. This notification should prompt a discussion around the type of review required to be carried out and follow a structured review process through to completion.

#### Consideration of any parallel processes

Depending on the circumstances, reviews into the deaths of children and young people may run parallel to other investigatory processes or proceedings. Such as, a review by the COPFS or criminal investigation carried out by Police Scotland. Efforts should be made to minimise duplication of effort and ensure, as far as is practicable, that the various processes are complementary, even if their purpose is somewhat different. In both these circumstance, early communication is key. If the decision had been made to carry on with your review of the death of a child or young person, both processes must remain separate, and not be compromised during any parallel review.

Effective co-ordination and communication is essential to avoid unnecessary delay and additional distress or confusion for staff and families. More information about national organisations and their review processes can be found in Appendix 3.

At the outset of the review process consideration should be given to whether a collaborative approach is needed. The lead organisation, such as the NHS board of residence of the child, should contact the other organisation(s) and agree the scale of their involvement. This could be providing information or documentation or being part of the review team.

#### When a death occurs out with your NHS board area

Children or young people who reside in one NHS board area, may die in another NHS board area. A child or young person could be supported in one local authority area and may die in other local authority area, or even a child or young person from outside Scotland could die in Scotland.

A structured system must be put in place to ensure the lead of the child or young person's area of residence is notified of the death. These deaths will be registered under the NHS board area where death took place. Once the new process of notification between NRS, the appropriate NHS board and the National Hub is established, that NHS board will be notified of the death. It will then be their responsibility to ensure a decision is made between all relevant organisations as to which organisation will lead the review. While it is strongly encouraged that all organisations that were involved in the child or young person's care contribute to the review, one will have overall ownership of responsibility for the process and outputs. However, all involved organisations will be responsible for implementation of actions and outcomes where relevant and applicable.

#### When a death occurs overseas

When a child or young person, who is a resident of Scotland, dies overseas, we would expect it to be the responsibility of the residing NHS board to conduct a review to the best of their ability.

You may learn about the death from a variety of sources, such as the Foreign and Commonwealth Office, media, family members or GP. The review into the death of a child or young person that occurs overseas can be challenging. We would encourage any NHS board to contact the National Hub for further guidance.

These deaths would be registered where the death took place and therefore would not be in the data supplied by the new NRS process. We will work with colleagues from the Death Certification Review Service, to ensure deaths abroad that are reported to the service of children and young people who usually reside in Scotland are notified to the appropriate NHS board.

#### **Expected deaths**

An expected death is the death of a child or young person that was anticipated following on from a period of illness that has been identified as terminal, including where no active intervention to prolong life is ongoing. It is expected that a person with a life limiting or life threatening condition will die prematurely although, it is not possible to anticipate when, or in what manner they will die.

Effective end of life care does not stop when a child or young person dies but involves wide-ranging and sensitive care after death. The review process provides an opportunity to examine the circumstances of the child or young person's palliative care needs and support prior to their death. Reviewing the circumstances of a child or young person's death and the period leading up to this can provide significant learning. The review could include:

- looking at the end of life and anticipatory care planning
- reviewing if the child, young person or family's wishes were fully taken into account
- aspects of the end of life care which went well
- aspects of the end of life care which could be improved
- support provided to the family prior to and after the death.

# Stage 2: Assessment – determining the appropriate review process

When an organisation is notified about the death of a child or young person there should be clear governance arrangements and processes in place to determine the appropriate review mechanism. Engagement must take place early in the process with any other organisations involved in the child or young person's care to reach a decision about the most suitable review process. All organisations and agencies involved should work together to undertake one single review wherever this is possible and appropriate. The rationale for deciding which review process should be carried out should be clear, take into consideration any statutory, legal or national requirements, and be

reached in a timely manner. More information on the other types of reviews that NHS boards and local authorities currently undertake to support learning improvement can be found in Appendix 1: Types of review, along with the criteria that apply for these review processes.

#### Stage 3: Review and analysis

A robust review should use best practice review techniques and methodologies. Methodologies should be briefly, but clearly set out in the review report. Those leading reviews should have up-to-date training and be competent in review methodologies and techniques including systems analysis and report writing.

#### Family involvement

All contact should consider the impact of the death of a child or young person and work sensitively with the family to ensure no additional distress is caused to them.

In the majority of cases, organisations should inform the family members and carers of any review of the death of a child or young person and invite them to contribute to the review process in accordance with their wishes. The review provides an opportunity to meaningfully consider their views and any concerns or queries they may have about the care they and their child received. A personalised supportive approach should be taken. If family members and carers are not involved, the reasons should be recorded. Processes should be in place that enables family and carers to receive feedback following the review process, including feedback on the review findings and any learning to improve future practice or systems.

#### Staff involvement

Staff who were involved in the child or young person's care provide an important source of information. The review process provides an opportunity to consider their perspective and experiences in identifying the factors that contributed to any interventions or the delivery of care. Staff should be made aware that a review is taking place and be clear about their role in the review process. They should also be given appropriate support throughout the review by their organisation.

#### **Review team**

The membership of the review team should take into the account the specialties and disciplines involved in the child or young person's health and social care. The organisation should ensure that individuals with all the relevant expertise according to the circumstances of the death are involved in the review. The review team should be multidisciplinary and include members who were not involved in the care provided to the child or young person. Members of the review team should have sufficient time allocated for preparing for, and attending review meetings.

#### Scope of the review

The scale, scope and timescale for the review must be agreed at the outset of the review process and documented in the terms of reference to help you consider:

- how best to support and engage with the family members and carers following the death and throughout the review process
- ensuring all relevant agencies are represented and have input into the review
- ensure timescales for reviews are met
- other parallel processes being conducted at the same time
- how improvement plans from reviews are to be monitored and completed, and
- how key learning from reviews are to be shared and acted upon for the purpose of organisational learning and improvement.

Decisions on the scale and scope of the review may need to be revisited as new information comes to light. Adopting a proportionate approach enables the aims of the review process to be met in a way that is flexible and relevant to the situation under review, without incurring excessive workload and is concluded in a timely manner.

#### Gathering and analysing information

Information sources gathered for a review to support informed judgements can include:

- a clinical and/or care history derived from relevant case records
- a timeline or narrative of the events relevant to, and preceding the death (chronology)
- statements and observations from key people involved
- perspectives of family members and carers and any questions they have
- relevant local policies and procedures
- any relevant national policies
- physical evidence, including photographs and environment layout where appropriate
- background information such as staff rotas and availability of staff, and
- relevant clinical and professional guidance documents.

Reviews should aim to be proportionate, which means that different reviews will require different amounts of information assembled to achieve their aims. Information needs may also change as the analysis progresses.

Reviews should use a structured and consistent approach. A systems approach using defined tools and techniques will identify the contributory and modifiable factors, details of the care provided and any lessons that could inform service improvement or reduce the risk of further deaths. A variety of tools, such as cause and effect charts, process mapping, fishbone diagrams and contributory factor frameworks, can be used. At least one member of the review team should be trained in review methodologies and their application. Where this is not possible, support from central clinical governance, risk management or quality improvement teams should be sought.

#### The report

The report should present the key findings, learning and recommendations of the review and be shared with everyone involved in the care and death of the child or young person. The report should clearly identify the findings of the review that are key to making local improvements and national recommendations where necessary. This should include identifying practice that contributed positively to the care of the child or young person, or that may assist in the prevention or reduction of deaths of children and young people.

The roles and responsibilities of each member of the review team must be clear, including identifying a lead reviewer, and should be documented.

It is good practice to write a review report that can be used for many purposes, such as sharing with those involved in the review process and family members and carers. Writing anonymised reports from the start would help, rather than redacting identifiable information about individual staff or family members at a later point.

Organisations will have local processes for the review and approval of reports and recommendations either through clinical governance structures or management team structures.

#### **Recommendations and findings**

The review team should consider how the recommendations and findings will support changes in practice and quality improvements. Recommendations and findings must make clear what they aim to improve or how they will minimise risk. The recommendations should indicate the timescale for completion.

Recommendations made should follow the SMARTER approach and be:

- Specific (what is to be done and how it can be carried out)
- Measurable (must be defined in a way that can be measured to ensure it had an impact)
- Accountable (all actions must be assigned to someone who will be accountable for completion)
- Reasonable (realistic and achievable)
- Timely (consider competing priorities and available resources)
- Effective (will it make a difference?), and
- Reviewable (should enable effective monitoring through governance processes).

#### Stage 4: Improvement planning and monitoring

A review into the death of a child or young person, no matter how well it is carried out, serves little purpose if the lessons learnt are not used to improve services, enhance practice and reduce risk at

a local and national level. Organisations should ensure arrangements are in place to share learning, improvements and best practice from reviews of the deaths of children and young people across services, the wider organisation and nationally as appropriate. The use of short learning summaries or 7-minute briefings can be helpful ways to share key learning points.

Reports relating to thematic learning should be collated over specific timeframes to assist and inform wider service and organisation improvement programmes aimed at preventing deaths of children and young people.

If the findings and recommendations from the review have highlighted a need for improvements, an improvement plan should be developed. This may require other organisations and agencies to act collaboratively to achieve them.

It is not necessarily the responsibility of the review team to produce the improvement plan as they may not be best placed to produce detailed action plans and management responses. Improvement plans should be developed by those with the responsibility for making the agreed changes and who, therefore have control and responsibility for implementation. This may be the team, department or service area where the death took place. It could also be a corporate management team or partnership level if a consistent corporate and strategic response is required.

The improvement plan should set out how each recommendation from the review will be implemented, monitored and measured, and identify how learning is shared. The plan should include responsible owners, timescales for delivery and review dates. Final plans should be shared with those previously involved in the care of the child through identified local processes.

# Appendix 1: Types of review

#### **Adverse Event Reviews**

An adverse event is defined as an event that could have caused (a near miss), or did result in, harm to people or groups of people. All organisations should have a management system for reporting, reviewing and learning from all types of adverse events.

Adverse event reviews are not about apportioning blame. The aim is to be open and honest with people when things do go wrong and offering an apology as soon as an event has been identified. A review of the care provided determines whether there are learning points for the organisation or organisations to improve the service. Organisations then need to implement the improvements identified to support a greater level of safety for all people involved in its care systems.

**Significant adverse event reviews (SAERs)** are carried out following events that have resulted in unexpected death or harm. These are focused on analysing factors that have contributed to the circumstances of the event. We understand this type of review is usually applied to suicide reviews and drug related deaths.

#### Death of a Looked After Child

Under regulation 6 of the Looked After Children (Scotland) Regulations 2009, local authorities have a duty to notify Scottish Ministers and the Care Inspectorate of the death of a looked after child and make arrangements to carry out a review. Local authorities are required to submit written notification within 24 hours of any death of a looked after child to Care Inspectorate. Within 28 days, the local authority require to send the Care Inspectorate a detailed report and supporting information. A copy of the death certificate should be forwarded to the Care Inspectorate as soon as it is available.

The Scottish Ministers will, through Care Inspectorate or any other relevant agency or body, advise the local authority about their conclusions and indicate what, if any, further action they will take or require the local authority to take. The Scottish Ministers may take steps to:

- examine the arrangements made for the child's welfare during the time he or she was looked after
- assess whether action taken or not taken by the local authority may have contributed to the child's death
- identify lessons which need to be drawn to the attention of the local authority immediately concerned and/or other authorities or other statutory agencies
- review legislation, policy, guidance, advice or practice in the light of a particular case or any trends emerging from deaths of children being looked after.

Local authorities should also be aware of their duties to notify the Care Inspectorate without delay of the death of any service user who has died while the care service was being provided, and of the circumstances of the death, including a looked after child. This is in regulation 21 of the Regulation of Care (Requirements as to Care Services) (Scotland) Regulations 2002, S.S.I. 2002/114.

#### Deaths of young people in receipt of after care

Under Section 29 (10) (b) of The Children (Scotland) Act 1995 (amended by the Children and Young People (Scotland) Act 2014), if a local authority becomes aware that a person who is being provided with advice, guidance or assistance by them under this section has died, the local authority must as soon as reasonably practicable notify Social Care and Social Work Scotland (known as the Care Inspectorate). Reviews should be conducted on the deaths of all care leavers who are in receipt of aftercare at the time of their death.

# Deaths of young people in continuing care up to their 26<sup>th</sup> birthday

Under Section 26 A (10) (b) of The Children (Scotland) Act 1995 (as amended by the Children and Young People (Scotland) Act 2014), if a local authority becomes aware that a person being provided with continuing care has died, the local authority must as soon as reasonably practicable notify Social Care and Social Work Improvement Scotland (known as the Care Inspectorate). Reviews should be conducted on the deaths of all care leavers who are in receipt of continuing care at the time of their death.

#### Death in Prison Learning, Audit & Review (DIPLAR)

DIPLAR<sup>7</sup> is the joint Scottish Prison Service and NHSScotland process for reviewing deaths in custody. It provides a system for recording any learning and identified actions and is held within 2 weeks of a death. DIPLAR enables the Scottish Prison Service to contribute to the national suicide prevention policies and develop the evidence base through a reporting and learning system that analyses all suicide reviews to promote learning and improve strategies throughout Scotland.

#### Drug Related Deaths (DRD)

Drug-related deaths in Scotland are recorded and examined by local critical incident monitoring groups who often collaborate with the police and Procurator Fiscal to identify such cases in their local area. Each area has a data collection co-ordinator who works closely with the local critical incident monitoring group and other key partners to collate the information on each drug-related death. Data collected from all drug related deaths from NHS boards is recorded on the national DRD dataset which is managed by Public Health Scotland.

<sup>&</sup>lt;sup>7</sup> Scottish Prison Service. 2018. Death in Prison Learning, Audit & Review (DIPLAR) Process Guidance. Viewed at 28 July 2020. <a href="https://www.sps.gov.uk/Corporate/Publications.aspx">www.sps.gov.uk/Corporate/Publications.aspx</a>

#### **Duty of Candour**

The organisational Duty of Candour procedure is a legal duty which sets out how organisations should tell those affected that an unintended or unexpected incident appears to have caused harm or death. They are required to apologise and to meaningfully involve them in a review of what happened.

When the review is complete, the organisation should agree any actions required to improve the quality of care, informed by the principles of learning and continuous improvement.

They should tell the person who appears to have been harmed (or those acting on their behalf) what those actions are and when they will happen.

#### **Fatal Accident Inquiries**

A Fatal Accident Inquiry (FAI) is a type of court hearing which publically inquires into the circumstances of a death. It will be presided over by a Sheriff and will normally be held in the Sheriff Court. If the death has happened as a result of an accident while at work or if the death happened while in legal custody, for example in prison or police custody, a Fatal Accident Inquiry will normally be held. FAIs can be held in other circumstances if it is thought by COPFS to be in the public interest to do so.

When considering how an FAI may impact your review into the death of a child or young person, communication must be made with your local COPFS office. In most circumstances a robust, timely review will help COPFS when deciding whether to progress to an FAI. Circumstance may be different in every case.

#### Learning reviews

The overall purpose of a learning review, previously known as initial case reviews or significant case reviews, is to bring together agencies, individuals and families in a collective to learn from what has happened in order to improve and develop systems and practice in the future and thus better protect children and young people. A Child Protection Committee will undertake a Learning Review in the following circumstances.

When a child has died or has sustained significant harm or risk of significant harm as defined in the <u>National Guidance for Child Protection in Scotland</u> and one or more of the following apply.

- Abuse or neglect is known or suspected to be a factor in the child's death or the sustaining of or risk of significant harm
- The child is on, or has been on, the Child Protection Register (CPR) or a sibling is or was on the CPR or the child was looked after by, or was receiving aftercare or continuing care from the local authority. This is regardless of whether or not abuse or neglect is known or suspected to be a factor in the child's death or sustaining of significant harm, unless it is absolutely clear to

the Child Protection Committee that the child having been on the CPR or looked after has no bearing on the case

• The child's death is by suicide, alleged murder, culpable homicide, reckless conduct, or act of violence **and** one or more from the above apply

The key guidance for carrying out this type of review is the **National guidance for child protection** committees for conducting a significant case review<sup>8</sup> (Scottish Government, 2015) - To be replaced by new National Guidance For Child Protection Committees – Undertaking Learning Reviews when available.

The recently published Protecting children and young people: Child Protection Committee and Chief Officer responsibilities<sup>9</sup> states that chief officers groups should be advised by the chair of the Child Protection Committee of any cases that should be considered in respect of meeting the criteria for warranting a review. Once agreed that there is a need to undertake a review, the Child Protection Committee should consider and agree how the review will be undertaken, who should lead the review and ensure that appropriate communication of the case has taken place in respect of key contacts.

#### Mortality and Morbidity reviews

The Mortality and Morbidity process describes the review of incidents from the initial event to the mortality and morbidity meeting and implementation of identified actions or outcomes.

A mortality and morbidity meeting is a unique opportunity for caregivers to improve the quality of care offered through case studies. They provide clinicians and members of the healthcare team with a routine forum for the open examination of adverse events, complications, and errors that may have led to illness or death in patients.

Mortality and morbidity meetings are also known as mortality and morbidity reviews or conferences, case conferences or clinical teaching conferences. The term 'patient safety' or 'quality improvement' or 'quality assurance' (or a similar variant) is occasionally appended as a prefix.

Mortality and morbidity meetings support a systematic approach to the review of patient deaths or care complications to improve patient care and provide professional learning. The meetings give ownership to clinical teams and offer a direct opportunity to improve care delivery in a timely manner.

<sup>&</sup>lt;sup>8</sup> Scottish Government. 2015. National Guidance for Child Protection Committees for Conducting a Significant Case Review. Viewed at 23 June 2020. <u>https://www.gov.scot/publications/national-guidance-child-protection-committees-</u> <u>conducting-significant-case-review/</u>

<sup>&</sup>lt;sup>9</sup> Scottish Government. 2019. Protecting children and young people: Child Protection Committee and Chief Officer Responsibilities. Viewed at 23 June 2020. <u>https://www.gov.scot/publications/protecting-children-young-people-child-protection-committee-chief-officer-responsibilities/</u>

Effectively run audit and peer review processes, incorporating analysis of mortality and morbidity cases, contribute to improved patient safety and professional development.

#### Perinatal Mortality Reviews

The <u>Perinatal Mortality Review Tool</u> (PMRT) supports standardised perinatal mortality reviews across NHS maternity and neonatal units on the deaths of babies from 22+ week's gestation to 28 days after delivery. These are reviewed using the Mothers and Babies Reducing Risk through Audits and Confidential Enquiries (MBRRACE) and PMRT.

The PMRT has been designed following these principles.

- There should be comprehensive and robust review of all perinatal deaths from 22+0 days gestation until 28 days after birth; excluding termination of pregnancy and those with a birth weight <500g if the gestation at birth is not known.
- Such reviews should be conducted using a standardised nationally accepted tool, ideally webbased, that includes a system for grading quality of care linked to outcomes.
- A multidisciplinary group should review each case at a meeting where time is set aside for doing the work.
- There should be scope for parental input into the process from the beginning.
- An action plan should be generated from each review, implemented and monitored.
- The review should result in a written report which should be shared with families in a sensitive and timely manner.
- Reporting to the NHS board executive should happen regularly and result in organisational learning and service improvements.
- Findings from local reviews should feed up regionally and nationally to allow benchmarking and publication of results, and thereby ensure national learning.

#### Police Investigations & Review Commissioner (PIRC)

The Police Investigations & Review Commissioner can investigate the following.

- Incidents involving the police, directed by the COPFS. These include deaths in custody and allegations of criminality made about police officers.
- Serious incidents involving the police, at the request of the Chief Constable or the Scottish Police Authority. These include the serious injury of a person in police custody, the death or serious injury of a person following contact with the police or the use of firearms by police officers.
- Allegations of misconduct by senior police officers of the rank of assistant chief constable and above, if requested by the Scottish Police Authority.
- Relevant police matters which the commissioner considers would be in the public interest.
- At the end of an investigation, the commissioner can recommend improvements to the way the police operate and deliver services to the public in Scotland.

#### Sudden Unexpected Death in Infancy (SUDI)

SUDI is the term used to describe sudden and unexpected death in infancy. A SUDI is deemed to have occurred where there is no known pre-existing condition which would make the death predictable.

Since the cause of death is not known, a death certificate cannot be issued and the death is not able to be registered. It is therefore routine practice that all SUDIs are reported to the Procurator Fiscal, on whose behalf the police will act. This practise is well established and the police will automatically be informed of the death by the Scottish Ambulance Service or Emergency Department. Investigations, which include a post-mortem examination may take several months. In some cases a cause of death may be found during post-mortem examination, but for many the post-mortem examination will not explain the death. The term SUDI may therefore be given as a classification of death on the death certificate, as the death is still unexplained. Healthcare Improvement Scotland will then notify the designated SUDI paediatrician in each NHS board when the Procurator Fiscal has authorised a review to proceed. Reviews are undertaken as per CEL21 (2013) using the <u>SUDI toolkit</u> process on all unexpected deaths up to 24 months. You will also find bereavement support links to support families on the SUDI toolkit.

A SUDI review is a multidisciplinary meeting held shortly after the final post-mortem examination report is available, which may be several months after the infant has died. The main participants may include a paediatrician, pathologist, GP, health visitor, community midwife, social worker and any other professional relevant to that particular SUDI. The purpose is to discuss all aspects of the death, including possible causes or contributing factors to see what lessons can be learned and to plan support for the family, particularly in identifying support needs for any future pregnancies.

# Appendix 2: National bereavement programmes of work

#### Bereavement charter for Scotland

In April 2020 the first <u>Bereavement charter for Scotland</u> was launched. It contains 15 statements which describe what the best bereavement care and support should look like. Additional guidance is provided for the following groups and individuals:

- children and young people
- learning disabilities and degenerative neurological conditions
- pregnancy loss, stillbirth and neonatal death, and
- bereavement following suicide.

The charter and accompanying guidance attempts to describe what good bereavement support can look like and the difference it can make.

#### National bereavement care pathway (NBCP)

The vision of the <u>National Bereavement Care Pathway</u> (NBCP) is to increase the quality of bereavement care and reduce local and national inconsistencies so all bereaved women, partners and families in Scotland receive compassionate, person centred care.

The evidence-based pathways are designed to be used by all healthcare professionals and staff involved in the care of bereaved families.

# Appendix 3: National organisations that may link or input to your review

Other organisations and agencies have a duty to investigate certain types of deaths. In many cases, the death will also be reported to the Crown Office and Procurator Fiscal Service (COPFS). Some organisations, such as the Care Inspectorate, are required to provide quality assurance on reviews carried out by organisations.

#### **Adult Protection Committees**

Adult Protection Committees (APCs) have a central role to play in taking an overview of adult protection activity in each council area and making recommendations to ensure that adult protection activity is effective. APCs have a range of duties, which include:

- reviewing adult protection practices
- improving co-operation
- improving skills and knowledge
- providing information and advice
- promoting good communication

Local Adult Protection Committees will carry out <u>Significant Case Reviews</u> (SCR) in circumstances where an adult has been abused or neglected resulting in serious harm or death.

#### **Care Inspectorate**

The Care Inspectorate is the independent scrutiny, assurance and improvement support body for social care and social work in Scotland. It regulates and inspects social care and social work services. It is a legal requirement that the death of a person using a care service is reported to the Care Inspectorate. Local authorities are also required to notify the Care Inspectorate of the death of a looked after child, the deaths of young people receiving aftercare provision and deaths of young people in continuing care.

The Care Inspectorate has a quality assurance role for reviewing the effectiveness of the processes for conducting a review of a death of looked after child carried out by local authorities. They provide feedback to Child Protection Committees on individual learning reviews to support continuous improvement. The Care Inspectorate also undertakes thematic reviews of deaths of looked after children and learning reviews completed in Scotland, reporting nationally on key learning for the benefit of national learning, policy and practice change.

#### Children's Hospices Across Scotland (CHAS)

CHAS offer a full family support service for babies, children and young people with life-shortening conditions. This includes palliative care, family respite and support – through hospices, homecare services and hospital presence. A child or young person may die while receiving care from CHAS or in their hospice premises. We would expect the child's usual resident, local NHS board or local authority to lead in the review of the death however CHAS should be fully involved in the process.

CHAS also has a research, advocacy and education role in informing improvements in children's palliative care to offer the highest levels of care and support.

#### **Child Protection Committees Scotland**

Child Protection Committees Scotland has a pivotal role to play, in conjunction with the Scottish Government and other partners in the protection of children across the country, by supporting the development and delivery of efficient and effective processes, common standards, and continuous improvement.

Local Child Protection Committees will carry out learning reviews into the death of a child or young person who have died or been significantly harmed within a child protection context. A learning review is a multi-agency process to support professional and organisational learning and to promote improvement in future inter-agency child protection practice. More information about undertaking learning reviews can be found on page 18.

#### COSLA

COSLA is a councillor-led, cross-party organisation who champions councils' vital work to secure the resources and powers they need. COSLA works on councils' behalf to focus on the challenges and opportunities they face, and to engage positively with governments and others on policy, funding and legislation.

Scotland's National Suicide Prevention Action Plan, *Every Life Matters*, contains 10 actions which together aim to reduce the suicide rate in Scotland by 20% by 2022 from the baseline level in 2017. Action 10 of the plan commits to the development of appropriate reviews into all suicide deaths and ensure the learning is shared with the National Suicide Prevention Leadership Group and partners and acted upon. COSLA has now begun to develop a model that will enable a multi-agency approach to reviewing deaths by suicide. This will gather information from health (including mental health, primary care and emergency departments), local authority (including social care, housing and criminal justice), Police Scotland, Scottish Ambulance Service, third sector and families and carers. This work will help provide a better, more timely understanding of the factors which may have contributed to an individual's suicide.

#### **Crown Office and Procurator Fiscal Service**

All sudden and unexpected deaths, including suicides must be reported to the Crown Office and Procurator Fiscal Service (COPFS) for investigation.

The Lord Advocate has the responsibility for investigating deaths that require further explanation. The Procurator Fiscal, acting on behalf of the Lord Advocate, receives reports of deaths in certain circumstances. Within COPFS, the Scottish Fatalities Investigation Unit is a specialist unit responsible for carrying out fatal accident inquiries (FAIs).

COPFS works closely with Police Scotland and the roles are complementary, and regular dialogue and co-operation enables problems and issues to be dealt with efficiently and effectively.

All deaths where the circumstances are thought to be suspicious must be reported to the Procurator Fiscal. The Procurator Fiscal will instruct Police Scotland to investigate the circumstances and consider whether criminal charges should be brought which may lead to a prosecution.

The Procurator Fiscal in Scotland has an investigative role and can provide instructions and directions to the police in connection with their investigations. This happens particularly in serious cases, where the police work very closely with the Procurator Fiscal. In cases of sudden, suspicious and unexplained deaths, the Procurator Fiscal has responsibility during the early stages of the investigation to arrange a post mortem examination by forensic pathologists.

#### Healthcare Improvement Scotland

All NHS boards are required to notify Healthcare Improvement Scotland when a category 1<sup>10</sup> significant adverse event review (SAER) is commissioned. The national notification system will allow data to be collated and analysed centrally which will facilitate the recognition of trends and themes at a national level and to inform the planning of national improvement programmes and to support greater consistency in the management and review of the most serious adverse events that occur in healthcare services.

Healthcare Improvement Scotland's Learning from adverse events through reporting and review: A national framework for Scotland<sup>11</sup> focuses on sharing any learning that could inform service improvement and any learning that could inform organisations' adverse event management processes to improve the quality of care delivered.

Healthcare Improvement Scotland is also notified of suicides of people who have been in touch with mental health services 12 months prior to their death. Once the review has been carried out, a

<sup>11</sup> Learning from adverse events through reporting and review: A national framework for Scotland. 2019. Healthcare Improvement Scotland. Viewed on 20 July 2020:

<sup>&</sup>lt;sup>10</sup> Category I – events that may have contributed to or resulted in permanent harm, for example unexpected death, intervention required to sustain life, severe financial loss (£>1m), ongoing national adverse publicity.

www.healthcareimprovementscotland.org/learning from adverse events/national framework.aspx

learning summary should be submitted, which is published on the Suicide Review Community of Practice <u>website</u>.

#### Adverse Events Community of Practice

Healthcare Improvement Scotland hosts a community of practice <u>website</u> to support care providers to share learning for improvement following adverse events reviews.

#### **Mental Welfare Commission**

The Mental Welfare Commission for Scotland has statutory powers to carry out investigations when concerns are raised about the care or treatment of somebody with a mental illness, learning disability or related conditions.

From 1 January 2020, all deaths of people subject to mental health detention or a community based order under the 2003 Act of the Criminal Procedure (Scotland) Act and all homicides committed by people with recent contact with mental health services should be notified to the Mental Welfare Commission. This is to ensure complete and proportionate system of review for all deaths in detention, irrespective of the cause, in collaboration with other agencies.

#### **Police Scotland**

It is the responsibility of Police Scotland to investigate and report all deaths to COPFS that fall into the following categories:

- suspicious death any death where the circumstances are unknown and give cause for concern (such as age of deceased, location, circumstances, intelligence, lifestyle)
- accidental deaths including deaths resulting from falls and industrial accidents
- drug misuse
- incidents of suicide
- deaths occurring as a result of neglect or fault
- deaths in legal custody
- any death where the identity of the deceased is unknown and cannot be readily ascertained
- any death of a child or young person under 18 years, which is unexplained (or fits any of the other criteria mentioned), or
- any death as directed by COPFS.

A small proportion of deaths of children or young people are 'expected or anticipated' due to medical explanation or illness and are considered non-suspicious. However, even in circumstances where a child or young person has a life-limiting condition and their death is expected, the timing of that death cannot be clearly determined. Police Scotland may need to obtain more information on such deaths to inform the PF (if reportable), or make an assessment whether the death requires further investigation.

Deaths of children or young people that are 'unexplained or unascertained' cannot be categorised as non-suspicious. These deaths are likely to require a police investigation to establish a cause of death.

When a child or young person dies, Police Scotland will appoint a suitable trained child death senior investigating officer (SIO) who will:

- conduct a thorough and proper investigation
- provide an appropriate and proportionate response to the circumstances presented, ensuring the preservation and recovery of relevant evidence
- facilitate effective inter-agency information sharing and collaborative working, and
- ensure the safety and wellbeing of any other children or young people.

As part of any child death enquiry, the investigation team will make contact with the relevant local authority and NHS board, as part of normal information gathering. If the child or young person who has died had surviving siblings, then an Interagency Referral Discussion (IRD) will be held, as soon as reasonably practicable, to facilitate sharing of information, risk assessment and decision making around the needs of the surviving siblings.

# Appendix 4: Other available guidance

Resource	Source viewed at 28 July 2020
Adult Protection Committee guidance	https://www.gov.scot/publications/interim- national-framework-adult-protection- committees-conducting-significant-case- review/pages/16/
Adverse Events Community of Practice: NHS boards tools, templates and guidance including learning summaries	http://www.knowledge.scot.nhs.uk/adverse- events/nhs-board-tools-templates-and- guidance.aspx
Healthcare Improvement Scotland Being Open Guidance 2015	http://www.healthcareimprovementscotland. org/our_work/governance_and_assurance/le arning_from_adverse_events/being_open_gui dance.aspx
NHS Lothian's Being Open pack	http://www.knowledge.scot.nhs.uk/media/CL T/ResourceUploads/4067101/Being%20Open %20Test%20Pack.docx
SPSO How to Make a Good Apology	https://www.spso.org.uk/sites/spso/files/com munications material/2018%20SPSO%20Apol ogy%20Guidance.pdf
Effective Communication about Adverse Events in Maternity Units	http://www.knowledge.scot.nhs.uk/media/CL T/ResourceUploads/4084759/c70766d7-2524- 4fb3-8e98-4fb9642e3220.pdf
Significant adverse event reviews: Information for staff	http://www.knowledge.scot.nhs.uk/adverse- events/adverse-events-toolkit.aspx
Who should participate in a suicide review	http://www.knowledge.scot.nhs.uk/media/CL T/ResourceUploads/4084792/2c40793d-031f- 4693-84f0-7ae1e6b86eee.pdf
Areas to consider in your review reports (SRLS)	http://www.knowledge.scot.nhs.uk/media/CL T/ResourceUploads/4084840/9d0dcb73-7eca- 427a-a19f-4fa0d96fe954.pdf
Expectations of a suicide review	http://www.knowledge.scot.nhs.uk/media/CL T/ResourceUploads/4084838/50bfdbec-e377- 4791-9edb-682c44f43f2b.pdf
Gathering and analysing information from a review	http://www.knowledge.scot.nhs.uk/media/CL T/ResourceUploads/4084795/5408f9ce-55bf- 4f6c-b790-82f40858d5d3.pdf
How to chair an effective review	http://www.knowledge.scot.nhs.uk/media/CL T/ResourceUploads/4084796/5e689e60-9199- 46af-a46f-3cfa034f433b.pdf

Participating in a review	http://www.knowledge.scot.nhs.uk/media/CL T/ResourceUploads/4084797/bfa98c14-7030- 4265-922a-249f1cfe838c.pdf
Recommendations for action	http://www.knowledge.scot.nhs.uk/media/CL T/ResourceUploads/4084798/8f919ca1-9b76- 4ab6-af9a-e67c6f083490.pdf
SMARTER Recommendations	http://www.knowledge.scot.nhs.uk/media/CL T/ResourceUploads/4084839/13371ca7-c84c- 43e1-adb9-eee9b83687aa.pdf
From plan, to change, to improvement	http://www.knowledge.scot.nhs.uk/media/CL T/ResourceUploads/4084803/6f279e4e-4ac8- 4108-962b-d45e45cf3eb3.pdf
Turning recommendations into improvements	http://www.knowledge.scot.nhs.uk/media/CL T/ResourceUploads/4084799/b8023561-402c- 4cf8-b893-1d7e88224ab0.pdf
Making it safe to learn	http://www.knowledge.scot.nhs.uk/media/CL T/ResourceUploads/4084802/98416921-8566- 4ade-a411-47e24fa5eb0c.pdf
Making sure family members and carers are involved in the suicide review	http://www.knowledge.scot.nhs.uk/media/CL T/ResourceUploads/4084801/3123d32b-f2b3- 461e-9535-506165e71a8c.pdf
Guiding principles for sharing information from adverse event reviews	http://www.knowledge.scot.nhs.uk/media/CL T/ResourceUploads/4058634/20150113%20G uiding%20Principles%20for%20Sharing%20Inf ormation%20from%20Adverse%20Event%20R eviews.pdf
Safety Checklist - Questions everyone should ask about safety	https://www.gov.scot/publications/safety- checklist-questions-everyone-ask- safety/pages/3/
NHS England – engaging with bereaved families	https://www.england.nhs.uk/ourwork/part- rel/nqb/national-guidance-for-nhs-trusts- engaging-with-bereaved-families/
NHS England – learning from death template policy	https://improvement.nhs.uk/resources/learni ng-deaths-nhs/#h2-data-collection-and- reporting
Scottish Government's Thematic Review of Fatal Accident Inquiries	https://www.gov.scot/publications/thematic- review-fatal-accident-inquiries/
Learning reviews guidance	When available