

# **Child Death Reviews**

## **Scottish Government Steering Group Report**

**March 2016**

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## EXECUTIVE SUMMARY

One Thousand One Hundred And Nine (1,109) deaths of people, aged 0–18 years, were registered in Scotland, in the years 2011, 2012 and 2013. The end of life does not mean the end of care.

Scotland has a higher mortality rate in children and young people compared to many other Western European countries. In Scotland each year, there are approximately between 350 and 450 deaths of people aged under 18, with most of them occurring in children aged under one year old.

Modifiable factors, preventable factors and lessons at different levels ought to be learnt, considered and acted upon from these life ending events.

Every child death deserves a review. The overarching purpose of the review will be to ensure that information is collected and learning shared which may prevent future child deaths or contribute to child health and wellbeing.

An economic methodology which can be used to quantify the value of a life saved, or death avoided, is the “value of prevented fatality” approach – “VPF”. This approach is taken by the United Kingdom Department for Transport to monetise prevented road and rail fatalities. It is based on an estimated willingness to pay to avoid a casualty, taking into consideration a range of factors. The current estimated cost per casualty, from 2013, amounts to a VPF of One Million Seven Hundred And Forty-Three Thousand Pounds Sterling (£1,743,000), per life.

The recommendations of this report cost far less.

Scottish Ministers, in 2014, accepted the recommendation of the Child Death Reviews Working Group report<sup>1</sup> - that Scotland should introduce a national Child Death Review System and that a Steering Group be established to develop the process and to identify costs and funding.

A Child Death Reviews Steering Group was established and met on 5 occasions from January to June 2015. The strong desire of the Steering Group is that a Child Death Review process should be instigated with minimal delay. Subject to the detail of this report, the Steering Group’s recommendations are summarised below and set out in full in Chapter 6:

- a. A Scottish national child death reviews system should be established comprising one National Resource Centre [the NRC], along with 3 regional offices, based in the North, West and East areas of Scotland. This should be an independent system – independent of existing structures.
- b. Reviews should be conducted on the deaths of all live born children up to the date of their 18<sup>th</sup> birthday and for care leavers in receipt of aftercare or continuing care at the time of their death, up to the date of their 26<sup>th</sup> birthday.

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<sup>1</sup> <http://www.gov.scot/Publications/2014/04/5599>

- c. National Records of Scotland/NHS Central Register should be commissioned to inform the NRC of all deaths registered in Scotland up to the date of the 18<sup>th</sup> birthday.
- d. Local Authorities should be commissioned to inform the NRC of all deaths of care leavers in receipt of aftercare or continuing care up to their 26th birthday at the time they notify the Care Inspectorate.
- e. The review system should review deaths of children and young people, who die in Scotland and who are resident in Scotland. This would include, for example, students studying in full time education, and deaths in hospices. Arrangements should be put in place for a Scottish child dying outside Scotland, and for a child dying in Scotland who does not reside in Scotland.
- f. Reviews should be conducted in a collaborative manner across all agencies and with a learning approach. Reviews are not to establish professional blame or responsibility. Reviews are to consider modifiable and preventable factors, with a purpose of learning lessons to prevent avoidable deaths. Other processes, e.g. criminal investigations or significant case reviews should take place prior to a child death review, with the outcomes of these processes informing the child death review process.
- g. Child Death Review Panels (CDRPs) should meet monthly, reviewing approximately 10 deaths at each meeting; with monthly meetings generally alternating between neonatal reviews and older child/young person death reviews.
- h. The National Resource Centre should notify the relevant Regional Office of deaths to be reviewed within 2 days of notification of the death. The Child Death Review process should commence with the issuing of a request for information from relevant agencies by the Regional Office, within 7 working days of notification from the NRC. The desired conclusion of the process ought to be attained within 4 months, for the majority of reviews. The process requires inherent flexibility.
- i. Family engagement is a central element of the process, if appropriate and desired by the family, following the guidance notes annexed to this report.

## CHAPTER 1 INTRODUCTION and MODEL

1.1 Although the number of child deaths in Scotland has decreased in recent years, Scotland has a higher mortality rate in children and young people compared to many other Western European countries. In Scotland each year, there are approximately between 350 and 450 deaths of people aged under 18 years, with most occurring in children aged under 12 months of age, and those aged 16 years and over.

	2007	2008	2009	2010	2011	2012	2013	2014	2007-11 average	2008-12 average	2009-13 average	2010-14 average
Under 1	272	253	235	218	238	217	186	207	243	232	219	213
Age 1-14	120	103	98	90	90	93	83	81	100	95	91	87
Age 1-18	251	226	208	193	160	153	155	134	208	188	174	159
Under 18 (0-17)	462	433	410	371	369	348	322	328	409	386	364	348
Age 15-18 (inc)	131	123	110	103	70	60	72	53	107	93	83	72

Extracted from <http://www.nrscotland.gov.uk/statistics-and-data/statistics/statistics-by-theme/vital-events/deaths/deaths-time-series-data>

1.2 Currently in Scotland there are reviews of deaths carried out in certain circumstances, in different fora, using different data collection processes. There is no consistent process for reviewing a child's death. There is no uniform approach. There are a number of different formal and informal mechanisms that exist but there is considerable geographical variation across Scotland, and mechanisms are often designed only for certain categories of childhood deaths. Uniform data collection and the sharing of any lessons, at local and/or national level are inconsistent, or not present. Examples of reviews include a Sudden and Unexpected Death in Infancy (SUDI) review; a Significant Case Review by Child Protection Committees; Adverse Event Review or a Fatal Accident Inquiry (FAI); there can be criminal or civil proceedings; hospital mortality and morbidity reviews; neonatal reviews; there exist a number of different fora using different information, operated by different agencies, with legitimate and different purposes. An overview would suggest some lack of uniformity in approach though clearly different fora do have different purposes. There would be considerable wisdom – where at all possible – for data collection to become more standardised. For example upon the death of a child, information, collected in one uniform method, could clearly assist different fora. This is not to limit the purposes and duties of the different agencies but is to assist in uniform recording, uniform standards, and the avoidance of duplication.

1.3 The Scottish Government set up a Child Death Review Working Group to explore the current practice of reviewing child deaths in Scotland and to consider whether Scotland should introduce a national, collaborative, multi-agency system. Scottish Ministers accepted the recommendation in the Working Group's report<sup>2</sup>

<sup>2</sup> [www.scotland.gov.uk/Publications/2014/04/5599](http://www.scotland.gov.uk/Publications/2014/04/5599)

“that Scotland should introduce a national Child Death Review System and that a Steering Group be established to develop the process and to identify costs and funding, taking into account a pilot which is currently underway [Ruby Reviews, University of Dundee] which will inform the way the system is set up and the most cost effective way of delivering the components.”

1.4 A Child Death Reviews Steering Group was established, chaired by David Jack, Advocate. It comprised representatives from:

- Care Inspectorate
- Child Health Commissioners
- College of Emergency Medicine
- Convention of Scottish Local Authorities (COSLA)
- Crown Office and Procurator Fiscal Service
- Faculty of Public Health
- Healthcare Improvement Scotland
- Information Services Division, National Services Scotland, NHS Scotland
- Paediatric Pathology
- Police Scotland – also representing Family Liaison Officers
- Royal College of Emergency Medicine, Scotland
- Royal College of Paediatrics and Child Health (RCPCH)
- Royal College of Psychiatrists in Scotland
- Scottish Ambulance Service
- Scottish Government Child and Maternal Health
- Scottish Government Child Protection
- Scottish Government Senior Medical Officer
- Scottish Neonatal Consultants Group
- Social Work Scotland
- Third Sector
- University of Dundee Fatality Investigation and Review Studies (pilot of child death reviews). (see Annex 1)

1.5 The remit of the Steering Group was to establish a national framework for reviewing child deaths in Scotland and to determine the age range and deaths to include and exclude. The Group agreed all deaths of children and young people up to the date of their 18<sup>th</sup> birthday and care leavers in receipt of aftercare or continuing care, who die up to the date of their 26<sup>th</sup> birthday, should be reviewed. The function of the framework proposed is to review the circumstances surrounding the death in a nationally uniform manner, and in a collaborative, inquisitorial, multi-agency, and “no blame” approach. The framework should operate within the context of the number of existing review arrangements and should not duplicate this work. It is not part of the remit of this Steering Group to re-organise existing structures. In any event, the purpose of a Child Death Review is different. The desired outcomes of the framework are to:

- Improve communication with families;
- Gather accurate information and implement consistent reporting of the cause and manner of each death;

- Identify significant risk factors and trends to be disseminated locally and/or nationally; and inform Scottish Government policy in order to reduce the number of child deaths;
- Identify and alert implications for others and/or for future births; and
- Improve inter-agency responses in the investigation and structured review of child deaths.

1.6 A very significant number of the deaths are in the 0-1 year age bracket. Such deaths can often be related to prematurity and congenital abnormalities. Establishing the cause and manner of death for these children can be relatively straightforward. For older children with life limiting conditions and complex needs, and for young people who die through self-harm, drug and alcohol-related deaths and accidental deaths, the factors that may have contributed to the death are far broader and very varied. There is a need:

- for every death to be subject to a Child Death Review Panel review as existing structures do not necessarily cover all deaths.
- for multi-agency child death reviews.
- for an initial process at local level to consider all deaths to inform Child Death Review Panels.
- for different input to child death reviews of neonatal, and other, deaths.
- for a Child Death Review Panel to have flexibility to seek information and expertise as appropriate in the circumstances.
- to identify modifiable or preventable factors from deaths.
- for local and national collation of modifiable factors, trends, causes and circumstances to inform education and learning.

None of the above affects existing structures, nor is it duplication.

1.7 The Steering Group met on 5 occasions between January and June 2015. A briefing paper was circulated wider than the Group members following the first 4 meetings. Comments were received, collated and considered. Annex 2 provides a list of the agencies involved in this process.

1.8 The *Children and Young People (Scotland) Act 2014*, furthers the Scottish Government's ambition for Scotland to be the best place in the world to grow up by putting children and young people at the heart of planning and services, and ensuring their rights are respected across the public sector. The duties of the Act upon Ministers and others, promote that ambition. There is clear purpose to improve services and to support children. It puts in statute access to a Named Person and for a single, coordinated, planning process to be put in place.

1.9 The *Getting it right for every child*<sup>3</sup> approach seeks to ensure focus on the child and a uniformity of process and approach. This includes working across organisational boundaries and maintaining child focus. There is a desire for a consistency in data collection.

1.10 No child death should miss being reviewed.

### **Purpose of a Child Death Review**

1.11 The purpose of a Child Death Review will be to:

- evaluate information about a child's death;
- consider the child's wellbeing concerns; relevant family and environmental aspects; relevant parenting aspects; service provision and delivery;
- engage with relevant family as appropriate;
- categorise the likely cause of death;
- consider any modifiable factors in relation to the death;
- identify lessons to be learnt from a child's death;
- inform local and national learning of child death issues.

### **National Child Death Review model for Scotland**

1.12 The recommendation is that there should be one Child Death Reviews National Resource Centre (NRC) – ideally hosted within existing public sector (NHS) infrastructure, though preserving its independence and independent scrutiny. This would be the headquarters of the Scottish national system. It ought to initially have staff of one full time coordinator, one full time data analyst and one full time administrator. Additionally there should be 3 Regional Child Death Reviews Offices situated in the North, West and East areas of Scotland. Such a broad geographical layout is already used by other national agencies, such as Police Scotland, the Procurator Fiscal Service and the Scottish Ambulance Service. The geographical layout would also meet with a very broad division of likely workload. Each Regional Office ought to initially have staff of one full time coordinator and one full time administrator.

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<sup>3</sup> <http://www.gov.scot/Topics/People/Young-People/gettingitright>



## Role of the National Resource Centre.

1.13 The NRC should be informed through National Records of Scotland/NHS Central Register/Local Authorities/the Care Inspectorate of the deaths subject for review. The NRC, which may have a management committee if so required, should have the role of central governance of the national child death review system. The NRC should also have a role in instigating the review by informing the appropriate regional office closest to the residence of the deceased child or young person who will then commence the process. The NRC should have overall strategic accountability for regional offices including: assuring a uniformity of process; assuring the effectiveness of learning opportunities; assuring that reviews occur; budgeting; finance; undertaking national policies and issues; quality assurance; receiving final reports of completed reviews; and collating and reporting learning to facilitate national changes in policy and practice where required. The NRC should have the ability to audit and adapt procedures to promote the development of the national CDR system.

## Role of the Regional Office

1.14 The role of the Regional Office will principally be to provide the operational and delivery processes which support the monthly Child Death Review Panels. The Regional Office staff will recruit and identify Panel members, including the Chairs. They will request the information from agencies prior to the Panel meetings to provide secretariat for the Panel, liaise with the Chair, serve the Panel, record the decisions of the Panel, seek to initiate local learning, advance national learning and feedback to the NRC, against a number of process outcomes.

## Interface with other review processes

1.15 There are existing review mechanisms such as, though not exhaustively: hospital mortality and morbidity reviews; neonatal reviews; FAIs; SUDI reviews; Significant Case Reviews; Court Processes; Child Protection Committee Reviews, and Adverse Events Reviews. Each has its own purpose. A Child Death Review will not replace these mechanisms. A Child Death Review may use the results and information from these sources if reasonably available in the conduct of its purpose. A Child Death Review may request information from any pertinent source. It may adjourn consideration of a case, as it sees fit. It may seek specific expertise to assist its function, as it sees fit. It may use and rely upon the findings of previous considerations of the death.

## Information gathering

1.16 The Child Death Review process will gather information from relevant sources regarding the death, in a consistent manner throughout Scotland. An example of potential forms for the gathering of information is at Annex 3. Supplementary forms for specific types of death may be developed if required.

1.17 The recommendation from the Steering Group is that there is one specific form used for the initial notification of the death to the NRC and from the NRC to the Regional Office (Form 1). There should be one form used for gathering appropriate

information from relevant external sources (Form 2) and there should be one form used for the review conclusion (Form 3).

- These forms should be used consistently.
- These forms may be amended by the NRC in collaboration with relevant parties.
- As stated at paragraph 1.2 there would be considerable wisdom in a uniformity of approach, or an amalgamated approach, to information gathering across the different agencies involved in the consideration of child deaths.
- CDRPs should be able to seek information from, for example, Mothers and Babies: Reducing Risk through Audits and Confidential Enquiries across the UK (MBRRACE) or other agencies as they see fit.

## CHAPTER 2 CHILD DEATH REVIEW PANELS

2.1 Consistency of approach is desirable. It is anticipated that the system will likely require adjustment as experience informs the process and thus the issue of flexibility is inherent to the process. A collaborative and learning based approach is considered essential.

2.2 The Steering Group considered that reviews ought to be held within the geographical locality of the relevant Regional Office. Multi-agency input to the review will be essential. A Review Panel member must not be involved in the review of a case with which they were associated. Multi-agency and multi-disciplinary participation is required.

2.3 As stated, it will be the role of the National Resource Centre to support and resource the 3 Regional offices. It will be the role of the Regional Offices to organise, support and provide the secretariat for the Child Death Review Panels (CDRPs).

2.4 It is envisaged that each Regional Office will hold one CDRP each month. It is for the Regional Office, in collaboration with the NRC, to establish CDRPs for their geographical area. The Panels should alternate monthly between reviewing neonatal deaths (up to 28 days of life) and other deaths. Regional Offices may have a pre-Panel meeting with Chairs as they see fit to discuss Panel input, Panel membership, agendas and all matters pertinent to the Panel.

2.5 Reviews should be multi-agency and multi-disciplinary.

2.6 An individual cannot participate in the death review of a child with which they were associated, either professionally or otherwise.

2.7 The proposed model recommends that review Panels for neonatal deaths and deaths of infants in neonatal units may comprise of:

Chair

a representative from the 3 Managed Clinical Networks for Neonates

Neonatal Consultant

Obstetrician

Midwife

Local Authority/Social Work representative, depending on circumstances

Primary Care representative

Public Health

One Lay Member from the Third Sector/bereavement services

The Regional Coordinator

The Regional Administrator

Others who may be called on as required, include:

Adult services which may have been involved with the parents

Police

Pathology

Scottish Ambulance Service.

Flexibility will be required when deciding which deaths are reviewed by a 'neonatal' Panel. For example, it may be more appropriate for babies dying of SUDI before 28 days to be reviewed by the Panel for older children whereas babies dying of complications of prematurity after 28 days, may best be reviewed by the neonatal Panel.

2.8 The proposed model recommends that review Panels for other deaths may comprise of:

- Chair
- Public Health representative
- Paediatrician/secondary care representative
- Lay member from the Third Sector/bereavement services
- Mental health services representative, ie a Child and Adolescent Mental Health Services lead clinician
- Local Authority/Social Work representative
- Education representative
- Named Person representative
- Safeguarder representative
- The Regional Coordinator
- The Regional Administrator

Others who may be called on as required, include:

- Neonatologist
- Police
- Palliative care
- Substance misuse services.

2.9 Chairs are to be of a senior, professional level, similar to medical consultant grade or above. They do not require to be of a medical discipline. This position should evoke independence, trust, quality and accountability. The suggested model is that whilst the Chair position ought to be a remunerated position, as is that of the Coordinator and Administrator, the other personnel on a Panel are not. Employing organisations may require to be compensated for the attendance of Panel members at review meetings. All those present ought to receive reasonable travel expenses as required. The precise roles and responsibilities of staff, Chair and Panel members ought to be determined at the implementation stage.

### **Timescales And Process For Notification**

2.10 The National Resource Centre will be informed of child deaths from National Records of Scotland/NHS Central Register/Local Authorities/the Care Inspectorate. Within 2 working days of that notification, the NRC is to inform the Regional Office of the death. Within 7 days from that notification the Regional Office will commence the process of gathering information on the death from relevant agencies and sources. Additionally within that period the Regional Office will identify and record the identity of the Family Engagement Person, as outlined in this report. Thereafter the process of gathering relevant information will proceed. There may be a pre-Panel meeting or further requests for information as appropriate. It is desired that the CDRP will conclude a case within 4 months from initial notification to it. In some cases this

timeframe may not be appropriate because of issues such as pathology reports, criminal or civil legal procedures etc. The CDRP may seek further information or adjourn consideration of a case as it sees fit in the circumstances, but a clear record of each consideration of a case, and the outcome of it, must be recorded by the Regional office. The reasons for cases not being concluded within 4 months should be recorded by the regional office and considered by the National Resource Centre.

2.11 Following each Review Panel, the Regional Office will record its conclusions. The Regional Office will retain the conclusions. A partially anonymised version (ie name removed but CHI number retained) will be prepared and sent to the NRC who will use that information for the purposes of collation, consideration, national learning, reporting in an anonymised manner and identifying issues to inform practice and policymaking.

2.12 Whilst local input and knowledge within the Review Panel is essential to understand local service responses and culture, it is equally essential that broader objective input and knowledge should be present to allow a balance and flow of knowledge. Regional Offices will comprise a pool of suitable professionals for CDRPs thus allowing for different experiences and knowledge; and avoiding excessive onerous duties resting on a few.

2.13 Whilst a death may have been the subject of discussion at a SUDI review/significant case review or similar forum, this primary process does not take the place of the CDRP. The CDRP should have the information of previous considerations before it – but it still requires to conduct and conclude on the child death for its own purposes and functions. Some deaths will not have been previously considered and thus a CDRP will be important, and in any event the purposes of the CDRP are different and separate from other processes.

2.14 Uniformity of process, consistency in data outcomes, uniformity of information, and the uniformity of the consideration process of a CDRP is essential. It is known that in the English Child Death Overview Panel (CDOP) system, some CDOPs adapt forms and to varying extent adapt their processes. It is considered that this weakens the trends and scope for learning both locally and nationally from Child Death Reviews. It will be the role of the NRC to manage the uniformity of the process to advance local and national learning.

## **Learning From Reviews**

2.15 National learning from collated information will be an essential component of this model and system. It is seen as a vital element of the process in reducing child deaths, responding to risk and danger, and learning through the deaths of children that there is a robust system for the collation of the results of CDRPs. The clear purpose is to reduce deaths in children and to learn locally and nationally through reviews. The NRC should develop a process to advance this clear intent. This ought to incorporate at least reporting to Scottish Ministers and others each year, on the results of reviews, trends, local and national issues, and on all matters that may affect policymaking and practices.

2.16 The national child death review system will be a novel opportunity for learning in Scotland. This report clearly endorses that and advances such a model. As this will be a new venture it is also reasonably anticipated that lessons may be learnt as the system develops and as the system and CDRPs are implemented. Thus the NRC should have the ability to amend and adjust matters as it sees fit in the interests of the main purposes of the review system. The NRC may require to have a management committee to assist in this process. It is accepted that some flexibility will be required in the operations of CDRPs, however the NRC must ensure that a uniformity of approach and structure is maintained.

## **Legislation**

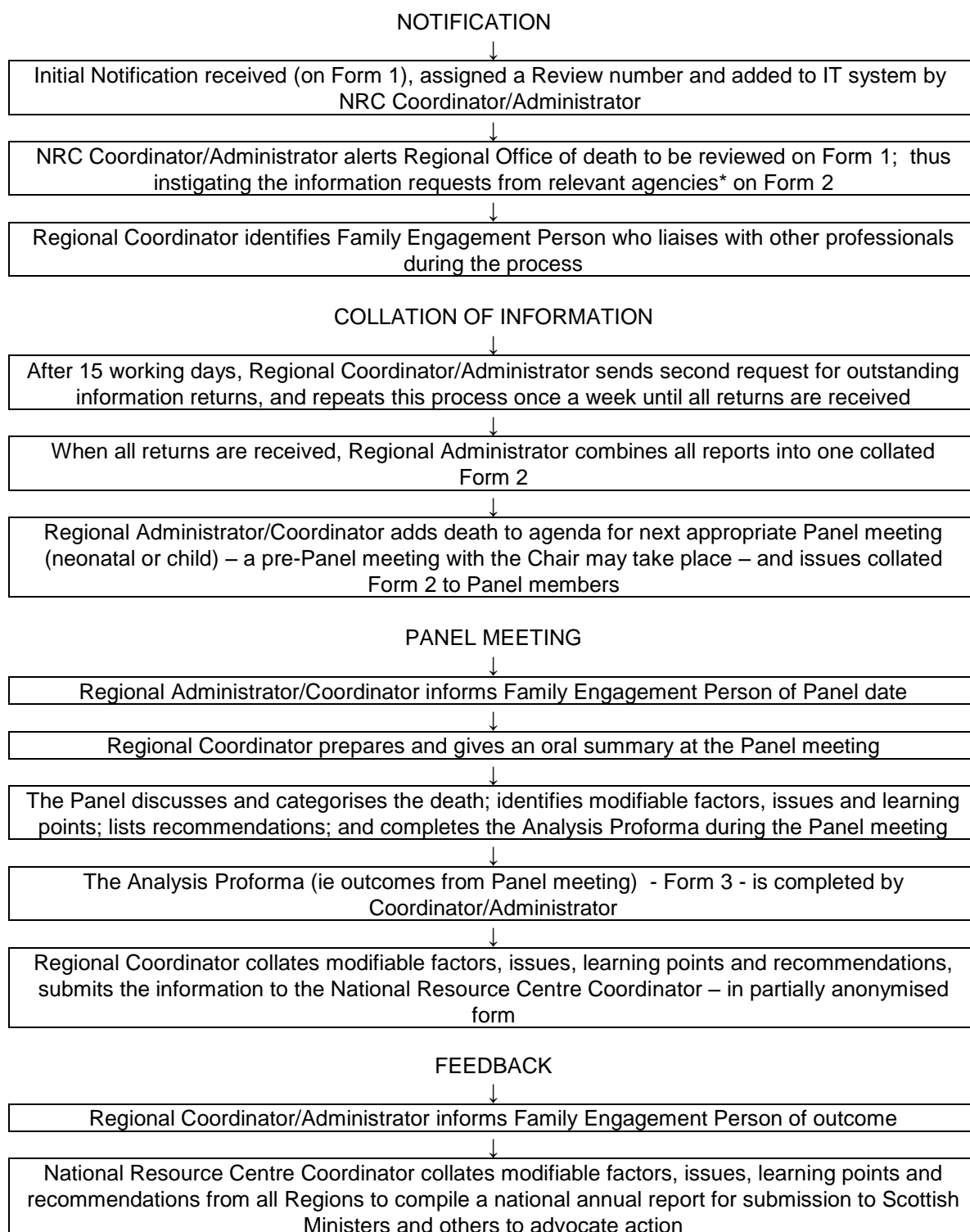
2.17 The steering group considered the need for legislation to implement this system and ensure its outcomes. There existed strong feeling within the group that legislation was the only sure method of introducing the system. The delay this would create was also considered and the recommendation is that a Child Death Review process ought to be commenced initially without legislation. It ought to be commenced by way of a “Chief Executive Letter” which issues guidance to health boards regarding policy to be implemented on a non-statutory basis. A similar practice for local authority and other agencies’ involvement should also be adopted. As matters evolve, or should the system not commence, then consideration should be given to drawing up a Memorandum of Understanding or a Partnership Agreement with agencies. Legislation would also then be seen as increasingly necessary. The strong desire of the Steering Group is that a Child Death Review process should be instigated with minimal delay.

## **Procedure**

2.18 The flow chart on the following page is a suggested outline of procedural steps for the operation of Child Death Review Panels. These are not mandatory. It is presented to assist in the understanding of the roles and steps that are recommended. It will be seen that information can flow from a CDRP both toward a local learning setting and toward a national learning setting. The importance for lessons to assist both locally and nationally is a central aim of the process. It is known that in other jurisdictions national learning is not as well developed as is desired. It is sought to avoid that in Scotland. Suggested templates/checklists for running Child Death Review Panels can be seen at Annex 4.

2.19 The suggested domains and criteria the CDRPs should consider are set out at Annex 5.

## Child Death Reviews in Scotland flowchart



\* For example, requests for information could be sent to the following agencies:

- Neonatal deaths: maternity hospital; GP; health visiting; school health (if older siblings); social work services; Named Person; Lead Professional; police; voluntary organisations; other as appropriate
- Child/young person deaths: all of the above (with the exception of maternity unless SUDI); children's/general hospital; youth offending; other as appropriate

## CHAPTER 3 NOTIFICATIONS, DATA and CASE MANAGEMENT

### Death Notifications to the National Resource Centre

3.1 The Scottish national child death review system should review all deaths of children/young people who are resident in Scotland. The deaths of all live born children, including sudden and unexpected deaths in infancy (SUDIs) up to the 18<sup>th</sup> birthday, and up to the 26<sup>th</sup> birthday of a care leaver in receipt of aftercare or continuing care should be reviewed. Other processes, e.g. criminal investigations, significant case reviews should take place prior to a child death review, with the outcomes of these processes informing the child death review process.

3.2 A death which occurs in Scotland must be registered within 8 days of the date of death by the Registrar of Births, Deaths and Marriages. The law allows a death to be registered in any registration district in Scotland. A death can be registered by any relative of the deceased, any person present when the person died, the deceased's executor or other legal representative, the occupier of the property where the person died, or if there is no such person, anyone else who knows the information to be registered. If the death has been reported to the Procurator Fiscal, registration is open-ended. There can be exceptions with the written authority of the Registrar General. Once a death is registered it is public information.

3.3 All deaths registered are examined by a district examiner. By arrangement and in accordance with legislation, National Records of Scotland (NRS)<sup>4</sup> can share information about a death after the registration of the death has been recorded in its central database. This is done electronically and can be transmitted daily, on the stroke of midnight, or weekly.

3.4 There are two National Records of Scotland (NRS) IT systems which could notify the National Resource Centre of child and young people deaths. The Registrar General is the Data Owner of both systems. One system is for Civil Registrations of events, the second is the NHS Central Register (CR). NHS CR could notify the CDR national resource centre of all deaths in the 0-18 year age range. If the NHS CR system were to provide information, an application would have to be submitted to the Public Benefit and Privacy Panel for Health and Social Care. The scrutiny process is operated across Scotland by a newly formed Public Benefit and Privacy Panel for Health and Social Care.

3.5 The legislation NRS has to take into account before agreeing to share the information includes the Social Security Act 1987, and the Local Electoral Administration and Registration Services (Scotland) Act 2006. The legislation covers who NRS can share data with, what the data can be used for and facilitates straightforward data-sharing arrangements with public bodies. However this can take time to set up and can encounter difficulties if IT systems are not compatible.

3.6 Assuming that appropriate authorisations are obtained (and, if necessary, regular payments for the work involved are made), NRS could provide information

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<sup>4</sup> <http://www.nrscotland.gov.uk/>



about all deaths registered in Scotland, of those aged up to their 18<sup>th</sup> birthday, or of all those aged up to their 26<sup>th</sup> birthday. However, other mechanisms would have to be put in place, to identify the deaths in the age range of 18-25 years who were care leavers in receipt of aftercare or continuing care at the time of death, as that death would not be formally marked in the registration system's records as the death of a care leaver in receipt of care. The National Health Service Central Register (NHSCR) could identify which deaths of people aged 18-25 were deaths of care leavers. However, to do this, NHSCR would have to be kept up-to-date (by the organisations which provide the care) regarding who was in receipt of care, in order that NHSCR could "flag" such people in its database and hence be able to inform the child death National Resource Centre (NRC) when any of them died aged 18-25. Alternatively, or in addition, as the deaths of care leavers in receipt of aftercare or continuing care are notifiable by law to the Care Inspectorate, arrangements could be put in place for Local Authorities to inform the National Resource Centre of these deaths at the same time as they inform the Care Inspectorate, providing the NRC has a secure email address.

3.7 If the death of a Scottish child or young person occurs in another UK country, it would be registered in the country where death occurred and not in Scotland. Similarly, deaths occurring in Scotland of individuals who are normally resident in other UK countries will be registered in Scotland by NRS. Arrangements should be put in place for the Scottish National Resource Centre to notify the appropriate country of a death of one of its nationals in Scotland, and for the NRC to be informed of the death of a Scottish child or young person in another UK country.

3.8 Regarding the deaths abroad of Scottish children and young people, an agreement could be put in place, with the necessary protocols on information sharing etc, for the Healthcare Improvement Scotland (HIS) Death Certification Review Service (DCRS) to inform the NRC Coordinator when the deceased child or young person has been repatriated for burial or cremation in Scotland. DCRS may also be able to provide clinical background information relevant to the death. This should avoid the need for the national Coordinator to contact the Foreign and Commonwealth Office (FCO). NRC should have the ability to revise systems to address the particular circumstances for reviewing child deaths that occur outside the UK.

3.9 Therefore, the deaths of children and young people up to the age of their 18<sup>th</sup> birthday, and for those up to their 26<sup>th</sup> birthday in respect of a care leaver in receipt of aftercare or continuing care at the time of death could be notified to the NRC by respectively National Records of Scotland/NHS Central Register and Local Authorities/the Care Inspectorate.

## **Data Issues**

3.10 The NRC ought to receive the notification of death as referred to above. It should then notify the Regional Office related to the child's residence. The Regional Office would then require to gather information to inform Panel discussions, which it would organise and provide secretariat. Panels would then generate summary output reports/data on each case for collation, analysis and dissemination at national level. This process is to allow for both local and national level learning.

3.11 It is recommended that a simple 3 form approach is used. This would be similar to the system used by the English CDOPs.

3.12 **Form 1** would be the initial notification form used by the agencies to inform the NRC of the death. Form 1 should also be used by the NRC to inform the Regional Office of the death which would be the notification for them to proceed with seeking and gathering information relevant to the purpose and function of the review Panel.

3.13 **Form 2** would be the information gathering template form. This would be sent to all relevant agencies by the Regional Office in the process of collating information for the Panel. Agencies would complete what information they can on this form and return it to the Regional Office. For example: a general practitioner might complete certain information that is requested on the form; if there has been a SUDI review then information from it could be inserted; a health visitor may complete certain information. Agencies would complete information on this form as it is known to them and would be expected to complete only the sections relevant to them. The Regional Office would collate all relevant information onto one "master" Form 2 for each death. This is the information before the Review Panel and would then be used for the Review Panel.

3.14 **Form 3** would be the summary output review form. It would contain essential information on the details and conclusion of the review including the Review Panel outcome. Form 3 would be kept as a record of the review by the Regional Office and, in a partially anonymised format, be sent to the NRC for use in their function of considering, reporting, and national learning. Supplementary forms for specific types of death may be developed if required.

3.15 Sample data forms for Child Death Reviews, ie Forms 1, 2 and 3, are set out in Annex 3.

3.16 Form 3 would be the final conclusions and learning summary report prepared at the end of a Review Panel meeting. Form 3 would be retained by the Regional Office for collation of local learning as it thought appropriate and submitted to the National Resource Centre, as stated above. It will be the only information retained on cases at both local and national level. The data items included will therefore form the basis of all analysis of modifiable factors influencing child deaths, and local and national learning.

3.17 During a Child Death Review Panel meeting, the Panel will require to consider and conclude upon an evaluation of the information of the death; to identify lessons to be learnt therefrom; and to inform an understanding of all child deaths in Scotland. The Group has considered and recommends, for that process, the approach of considering 4 specific domains, ie:

- Factors intrinsic to the child;
- Factors in the child's family and social environment;
- Factors in the child's wider/physical environment; and
- Factors in relation to service provision/delivery.

3.18 Each of these 4 domain headings will require to be considered and evaluated in the review process, by determining their level of influence in the circumstances of the death. A different number is attributed to each domain pertinent to the level of influence. This is to assist with local and national learning. Annex 5 explains this analysis process. The conclusions of the Panel on these domains should be reported on Form 3 in both a numerical and, as appropriate, free text manner.

3.19 The Child Death Review Panel will also categorise the cause of death/likely cause of death, taking into account the death certificate and other information, following the categories in the Analysis Proforma (Annex 5); and categorise and identify any modifiable factors that could have led to preventable factors arising. Annex 5 is a classification list, and aid, for use by the Panel in this process. The conclusions of the Panel should be reported on Form 3.

3.20 The process recommended above is similar to the English CDOP system which was considered by the steering group. It was viewed in operation by the Chair and supporting staff. It allows for both local and national learning. Additionally it may provide for learning across the UK. Scottish local and national learning is a central aim of the process. The use of the system recommended has that as one of its primary aims.

### **Electronic Case Management System**

3.21 The Certification of Death (Scotland) Act 2011 confers a responsibility on Healthcare Improvement Scotland (HIS) to review a proportion of Medical Certificates of Cause of Death (MCCDs) annually for quality and accuracy. The Act also places a responsibility on National Records of Scotland (NRS) to randomly select and transmit those relevant MCCDs for review to the Death Certification Review Service (DCRS).

3.22 HIS contracted NHS National Services Scotland Information Technology (NSSIT) (which develops IT systems for national projects) to develop an electronic case management system (eCMS) to support the new national Death Certification Review Service (DCRS). The DCRS is based within NHS24 premises and the eCMS was built using an existing application (SUGAR CRM) already used to support a number of other NHS24 services.

3.23 The DCRS undertakes the reviews of MCCDs in real time. The reviews must be concluded before the death registration can be completed and the funeral can take place. To minimise adverse impact on people who are bereaved it was important that the design of the supporting IT infrastructure streamlined the process of electronically transferring MCCDs selected for review from NRS to the DCRS. Significant development work has been undertaken to develop the NRS system to select MCCDs (both manually and electronically completed MCCDs) based on certain parameters, and to build an electronic interface between NRS and the eCMS.

3.24 Aspects of the work already completed by NSSIT and NRS in terms of systems development, and the range of joined up processes that have been mutually agreed and operationalised, could potentially be transferable to support the operation of a national child death review system.

3.25 NHS Central Register could also set up a database with high quality demographic information. It could identify and include those in receipt of aftercare or continuing care up to the 26<sup>th</sup> birthday. It would not be for NHSCR however to request and collate information on the death/deceased.

### **Timescale**

3.26 It is estimated it would take approximately 12-18 months to set up a child death review IT system, if the existing medical examination of death certificates IT system were to be adapted.

3.27 For access to the NHS Central Register, applications to the Public Benefit and Privacy Panel for Health and Social Care will normally be concluded within 30 working days of submission, not including any time elapsed whilst awaiting a response for further information. Where an application requires review by a full committee meeting, the process will take longer to conclude.

### **Costs**

3.28 Adapting an existing NSSIT system could potentially cost in the region of £300,000 - £400,000. Creating a new system would cost considerably more. The costs of utilising the NHSCR system would be determined and negotiated once the child death review system requirements had been developed.

3.29 It is recommended that the adaptation of an existing system is most desirable, and ought to be the favoured approach.

## **CHAPTER 4 FAMILY ENGAGEMENT**

4.1 For the families of children who die in Scotland each year, there is a huge variation in the circumstances of these deaths, the number of professionals involved with a family, the communication that takes place following their child's death and the support the family is offered. Active engagement of bereaved parents, so far as appropriate and desired, should be a central feature of the process. A family's ability to begin to grieve for their child, accept their death and begin to live without their child is affected greatly by their experiences with professionals soon after their child dies<sup>5 6</sup>.

### **Informing parents/carers about the CDR process**

4.2 Parents/carers can value open and honest discussions, through direct contact, to inform them of what will happen and to feedback what has happened<sup>7</sup>. Parents/carers should know from the outset what the review process is and its purpose. Parents/carers should be informed that their child's death will be reviewed. They may have significant information and questions to contribute to the review process, thus parental input forms could be made available for this purpose. These forms should be uniform to the national process.

4.3 Upon the Regional Office commencing to request information from relevant sources, it should be agreed and documented who the person liaising with the parents/carers will be. Engagement should commence at this point. Support should be available throughout the child death review process, with the parents/carers kept informed of progress. Face-to-face meetings should be offered, as a standard.<sup>8</sup> Documents and signposting to electronic information should be used to support direct contact, but not as the sole or preferred source of communication for families.

### **Appointing a family liaison professional**

4.4 In each individual circumstance, an appropriate professional should be identified to support the family through the process by the Regional Office, and that appointment should be recorded by them. This role should be termed as the Family Engagement Person. The appointed and appropriate professional should be known to the family, preferably with an already established relationship and a level of trust. Without being exhaustive such persons are likely to be: a General Practitioner; Social Worker; Health Visitor; Midwife; Paediatrician; Community Psychiatric Nurse; or Nurse.

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<sup>5</sup> Meert KL et al. Examining the needs of bereaved parents in the pediatric intensive care unit: a qualitative study. *Death Studies*. 2009, 33(8):712-740.

<sup>6</sup> de Frain JD, Ernst L. The psychological effects of sudden infant death syndrome on surviving members. *J Fam Pract*. 1978;6:985-9.

<sup>7</sup> Bruno Michon et al. Death of a child: Parental perception of grief intensity – End-of-life and bereavement care. *Journal of Paediatrics and Child Health*. 2003 Jul-Aug; 8(6): 363-366.

<sup>8</sup> Garstang J et al. What do bereaved parents want from professionals after the sudden death of their child: a systematic review of the literature. *BMC Pediatrics*. 2014 Oct 15;14:269.

4.5 Feedback to family members should be restricted to those who have a right to know. Information imparted to them may be sourced from review reports. Careful consideration on a case-by-case basis should be given to the family's needs, wishes and personal circumstances when feeding back review outcomes.

### **Explaining the CDR process to the family**

4.6 Professionals supporting parents and family members should inform the following:

- The objective of the child death review process is not to allocate blame, but to learn lessons.
- The purpose of the child death review is to help prevent further such child deaths.
- The remit of a CDR meeting is a discussion on each child's case.

Reference to paragraph 1.11 of this report may assist.

4.7 Relevant information may be sought from parents/carers prior to the CDR meeting. They should know that any information provided about their child will be treated with sensitivity, respect and with confidentiality. Only those who require information and who sit on a Review Panel will see that information. The results and conclusion of a Review Panel will be anonymised, thus preserving confidentiality.

4.8 Parents/carers should be advised that aggregated anonymised information from reviews will be used to inform learning, policymaking issues, public health campaigns etc. Parents/carers should be informed of the outcome of their own child's review meeting. They should be asked if they wish to be informed when national reports are being published so that they may source the report. The Regional Offices would assume this task.

4.9 If parents/carers have any concerns about the review process and wish to discuss these, they should be provided with contact details of the NRC Coordinator.

### **When should engagement begin?**

4.10 Early communication between key professionals to form an agreement as to who is to liaise with the parents/carers, and at what key points, will be essential. This should be supported by the Regional Office. Parents/carers should be aware as early as possible of the processes which follow their child's death.

4.11 Additionally, parents/carers should be offered information on local, regional and national charities who can offer them bereavement support. A Child Death Review pamphlet explaining the process with relevant information should be available.

4.12 Where a child is born with a medical condition and it is expected the child will die in the neonatal period (first 28 days of life), it is likely that support will be provided

by staff in the hospital setting<sup>9</sup>. In such a circumstance it may appear appropriate for a member of that staff to be the Family Engagement Person. In any expected child death there may be key health professionals involved with the family, who are appropriate for that role.<sup>10</sup>

4.13 When a child dies suddenly and unexpectedly, whether in the neonatal period or any time after, many different professionals will be involved with the family<sup>11</sup>. A professional point of contact for the Child Death Review process should be appointed. A member of staff, within a hospital where the child was taken, may be appointed as a named point of contact for the parents/carers and will provide them with the information and follow up, as required. However not all children who die are taken to hospital and arrangements should be put in place to identify a professional point of contact in these circumstances. In all circumstances a Family Engagement Person should be appointed, who should link with other professionals to ensure the parents/carers are kept informed.

4.14 Where the death of a child may have an impact on future pregnancies or on the health of existing siblings, it will be an explicit part of the review process that it is confirmed whether parents have already been linked with relevant professionals.

### **When families do not engage**

4.15 The complexity of parental bereavement and an understanding of why parents might be deemed “hard to reach” is pertinent. The death of a child is a traumatic event that can have long-term effects on the lives of parents.<sup>12</sup> Parents do not expect to outlive their children and rarely is a parent prepared for a child's death. The length of life does not determine the size of the loss. The death of a child alters every aspect of family life.

4.16 The death of a sibling is a profound loss for a child and other family members, and grief is equally profound. It takes many forms, can be intense and can lead to further harm.

4.17 The Family Engagement Person will require to be aware of the many reasons why parents may not be responsive. People have different reactions and feelings after the death of a child and may grieve the loss in different ways. Useful resources such as the draft guidance note (see Annex 6) offers some background information to the professional appointed to support a family.

4.18 Any communication with parents/carers should consider significant days such as the child's birthday, anniversary of death, dates when they may have been

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<sup>9</sup>Endo K et al. Palliative Medicine. Interventions for bereaved parents following a child's death: A systematic review. 2015 Jul;29(7):590-604. E.pub 2015 Mar 24.

<sup>10</sup> deCinque N et al. Bereavement support for families following the death of a child from cancer: experience of bereaved parents. Journal of Psychosocial Oncology. 2006;24(2):65-83.

<sup>11</sup> Ryan R. Loss in the neonatal period: Recommendations for the pediatric health care team. In: Woods JR, Esposito Woods JL, editors. Loss During Pregnancy or in the Newborn Period: Principles of Care with Clinical Cases and Analyses. Pitman: Jannetti Publications Inc; 1997. pp. 125–57.

<sup>12</sup> Dent A et al. A study of bereavement care after a sudden and unexpected death. Archives of Disease in Childhood. 1996 Jun;74(6):522-6.

starting school or graduating – these can be common triggers for grief. The needs of a family may alter over time and the Family Engagement Person ought to offer further information at a later date if this is considered appropriate.

4.19 The Steering Group considered family members should not attend Child Death Reviews. They should, however, be engaged in the process, if so desired, through the Family Engagement Person.



## CHAPTER 5 RESOURCES and COSTINGS

### Introduction

5.1 The Child Death Review Panel Steering group considered that it did not possess the expertise to address resources adequately. The group was content for the Chair and Scottish Government support staff to meet with individuals who would be able to assist. The group however was aware of the costing of the University of Dundee pilot child death review project of 2014. That report contained certain details regarding the pilot costs. The Chair, support staff and others, have taken advice and input from the Scottish Government Health Finance, eHealth and Analytics Division in connection with the details provided here. Additionally, the COSLA input to the group assisted in considering this matter.

5.2 As mentioned above, the University of Dundee Fatality Investigation and Review Studies Team ran a child death reviews pilot (referred to as Ruby Reviews) in early 2014. In *An Account of the Tayside Ruby Reviews, March-April 2014*, it stated that the Child Death Overview Panel (CDOP) system in England appeared to be demanding of time and resources (RCPCH, 2008) (Sidebotham et al., 2011). The CDOP system had required government seed funding and 3-year operating costs of £55.2m over its first 3 years (CDFS, 2008). A considerable proportion of these costs tended to derive from aspects of the English statutory and child protection frameworks not present in Scots law or operating arrangements. The size of CDOPs' budgets<sup>13</sup> vary widely with a median value of just under £52,000 per annum but ranging from just less than £10,000 to £200,000. Only 60% of CDOPs had a designated budget.

5.3 The costings associated with the University of Dundee Ruby Review process were reviewed but they were not considered to be relevant, given the different approach developed by the Steering Group.

### Potential Costings

5.4 These costings are an overview for the Child Death Review Panel system outlined in this report. The majority of the costing methodology is based on previous modelling work undertaken for the Certification of Death (Scotland) Act 2011 and provides indicative figures. Modelling centres around the composition of staff involved with managing and undertaking the review Panels. As staff costs are the biggest cost item, the composition of Panel membership and frequency of Panels significantly affects overall costs.

5.5 The proposed model for Child Death Reviews (CDRs) at present comprises of the following:

- The National Resource Centre – ideally hosted within existing public sector (NHS) infrastructure though preserving its independent position; with 3 regional

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<sup>13</sup> Information extracted from *Child Death Reviews: improving the use of evidence – Research Report*: Jennifer J Kurinczuk and Marian Knight: October 2013  
[https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/246562/DFE-RR303.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/246562/DFE-RR303.pdf)

offices in the North, West and East of the country – also ideally hosted within existing public sector (NHS) infrastructure though preserving its independent position.

- Total staff envisaged amount to 4 coordinators and 4 administrators in full time positions, across these 4 centres, plus one data analyst.
- Chairs of Review Panels ought to be remunerated (at senior level, paid pro rata). This resource may be transferred from other NHS resources.
- It is proposed that there would be broadly one Panel each month, in each Regional Office, and Panels would comprise of *circa* 10 people – compensated for travel and expenses but without additional compensation.
- The cost arising from time dedicated to Panels by members other than the Chairs would constitute an opportunity cost to their regular employer and this was discussed at paragraph 2.9. Currently, there is no provision made for compensating regular employers for this cost and the potential for compensation would need to be discussed further, but could be similar to the costs for Child Protection and Care proceedings, and Adoption and Fostering Panels.

5.6 A possible set of minimum and maximum pay ranges based on NHS Agenda for Change (AfC) pay scales, is set out below.

Staff grade assumptions	Min	Equivalent to approx.	Max	Equivalent to approx.
Coordinator	AfC band 8c, incl. on-cost full time	£77,100	Med Consultant, incl. on-cost, full time	£138,600
Admin	AfC Band 3, incl. on-cost, full time	£22,800	AfC Band 5, incl. on-cost, full time	£29,200
Local coordinators	AfC Band 5, incl. on-cost, full time	£29,200	AfC B7, incl. on-cost, full time	£45,200
Local assistants	AfC Band 3, incl. on-cost, full time	£22,800	AfC Band 5, incl. on-cost, full time	£29,200
Local reviewers	AfC band 8c, incl. on-cost, pro rata	£350	Med Consultant, incl. on-cost, pro rata	£630
Data analyst	AfC band 6, incl. on cost, full time	£37,500	AfC band 8b, incl. on cost, full time	£64,200

5.7 The table that follows provides an overview of potential cost implications. The column labelled 'Year 1' shows the costs in the first year and gives an early indication of how staff cost will play a proportionately greater role than implementation costs as the number of staff increases. The column labelled 'PC over 30 years' provides Present Costs (PC) of these cost implications over a time period of 30 years.

5.8 Ideally in a full cost benefit analysis (CBA), PC would be set against the Present Value (PV) i.e. the sum of monetised benefits, aggregated over the same

time period, in order to arrive at a Net Present Value (NPV). However, as is discussed in the section on benefits below, it is very difficult in this case to estimate a representative value for benefits and only indicative values are presented.

5.9 There are a number of items in the costing model which have been based on the initial analysis for the Certification of Death (Scotland) Act 2011, such as changes to National Records of Scotland (NRS) databases and the development of a training module, and which have been updated, where possible, to the current model. They are provided as indicative costs.

<b>Total Cost in year 1 and after 30 years</b>	<b>Current model costings</b>	
	<b>Year 1</b>	<b>PC over 30 years</b>
<b>Recurring costs</b>		
Total training and replacement	£0	£0
Total Salary cost	£480,189	£9,140,768
Total Running costs	£41,178	£783,854
<b>Total recurring</b>	<b>£521,367</b>	<b>£9,924,621</b>
<b>Start-up costs</b>		
Total Initial Accommodation Costs	£17,550	£17,550
Non-IT programme management	£330,000*	£330,000
IT Changes and Support	£357,000*	£357,000
Advertising/information cost	£10,000	£10,000
Development of e-learning Module	£57,500	£57,500
<b>Total start-up</b>	<b>£772,050</b>	<b>£772,050</b>
<b>Total</b>	<b>£1,293,417</b>	<b>£10,696,671</b>

\* these are indicative figures based on the medical reviews of death certificates and may be less than stated

5.10 Regarding running costs - all costs are also based on previous modelling undertaken for Certification of Death (Scotland) Act 2011 and are for indicative purposes. Travel claims are based on a transport model; including relevant deaths per annum; Scottish Government mileage compensation at £0.40 per mile. There is an assumption that each Panel will incur travel expenses for each Panel member. Annual IT, telephony cost is as advised by Scottish Government IT in 2009/10.

5.11 In respect of start-up costs – item costs are as advised by Scottish Government Buildings and Maintenance, as at June 2015.

5.12 IT and support costs are also based on previous modelling undertaken for Certification of Death (Scotland) Act 2011 with system change to include change to NRS databases and forms.

5.13 The estimated cost of IT changes and support in the first year are substantial. These are driven by the complexity and scale of the system in addition to the number of different stakeholders and potential users that will need to access and use the new system. The cost estimate includes Project Management, Analysis, Developer, Testing, Hosting and Security costs which all need to be factored into developing and implementing any new system.

5.14 Please note that no estimate has been given for ongoing/longer term running costs although this can usually be estimated (as a starting point) as 10% of the implementation costs.

5.15 Other costs have been addressed as:

- Job advertising cost - these are non-linear with the number of posts included in model and can range from £2,000 -20,000 per post;
- Advertising/information cost – estimated at £10,000;
- Development of e-learning module – estimated at £57,000 - £65,000;
- Training cost of involved staff – considered to be included in on-going NHS Education for Scotland (NES) cost.

## Benefits

5.16 When considering the estimated costs of Child Death Review implementation it is important to also consider potential benefits from having CDRs in place. The main anticipated benefit of CDRs would be a reduction in the future number of preventable child deaths. Child Death Reviews would influence subsequent practice and policy, with the lessons learned from the reviews.

5.17 A Lancet<sup>14</sup> review on child death in high-income countries noted that “locally, a systematic approach to inquiry can lead to better understanding of how and why a child died [...] a diagnosis is invaluable to a bereaved parent and might allow them to undergo counselling for future pregnancies.” Further that “Child Death Reviews greatly increase understanding of how and why children die, provide a framework for detailed investigation of unexpected deaths, contribute to better accuracy in coding cause of death, provide a framework for the formal assessment of modifiable factors.”

5.18 It is beneficial to give estimates of the value of prevented child deaths, to put the CDR implementation costs into perspective. There are a number of possible approaches to this, including the Value of a Prevented Fatality (VPF) approach and measuring Quality Adjusted Life Years (QALYs).

5.19 Value of a Prevented Fatality (VPF) is the approach taken by the UK Department for Transport (DfT) to monetise prevented fatalities from road and rail traffic, and is based on estimated willingness to pay, encompassing all aspects of the valuation of casualties, including the human costs, which reflect pain, grief, suffering; the direct economic costs of lost output and the medical costs associated with road accident injuries. The current estimated cost per casualty (fatality) from 2013 is £1.743m<sup>15</sup>.

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<sup>14</sup> Petrou et al (2014) *Child deaths: inequity and inequality in high-income countries*, Lancet Vol 384, No 9946, p.831-833

<sup>15</sup> DfT: Reported Road Casualties in Great Britain: 2013 Annual Report

[https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/359311/rrcgb-2013.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/359311/rrcgb-2013.pdf)

5.20 An alternative calculation would be to assess the value of the years of life lost given average healthy life expectancy and life expectancy, using the Quality Adjusted Life Year (QALY) approach. A rough calculation using a cost per year of £60,000, healthy life expectancy of 60.8 and life expectancy of 77.1 years and taking the average number of years lost from deaths of those aged between 0-17, would give a value of life lost of about £3.681m.

5.21 There are various ranges given in the literature for the proportion of child deaths with avoidable (modifiable) factors or that were entirely preventable. Below are a number of estimates for this range:

- Lancet<sup>16</sup>: A 2006 confidential enquiry into deaths of children [...] identified avoidable factors in 31 (26%) deaths of 119 cases reviewed with potentially avoidable factors noted in a further 51 (43%) cases.
- Lancet<sup>17</sup>: In 2009, 66,000 children younger than 5 years died in high-income countries [...] up to a quarter of these deaths could be considered preventable.
- Lancet<sup>18</sup>: In England, of 4061 child death reviews that were completed in 2010-11, investigators noted that 800 (20%) had modifiable factors.
- DoE<sup>19</sup>: 22% of child death reviews (823 reviews) identified as having modifiable factors, a slight increase from 20% in the year ending 31 March 2011.

5.22 A Scottish Government study into *The Financial Impact of Early Years Interventions in Scotland*<sup>20</sup> found that short term savings from investing in early years/early interventions from pre-birth to aged five suggest that there are potential net savings of up to £37.4k per annum per child in severe cases and of approximately £5.1k per annum for a child with moderate difficulties in the first 5 years of life. There are potential medium term net savings to the public sector, that can be realised 10 years after the early years period. In the longer term, a failure to effectively intervene to address the complex needs of an individual in early childhood can result in a nine fold increase in direct public costs, when compared with an individual who accesses only universal services. Interventions based on CDR learning could potentially contribute to realising these savings.

5.23 The above estimates show that, even if Child Death Reviews prevent one death a year, they may represent good value for money. If the proportions above were applicable and between 22% and 26% of deaths could be prevented, in Scotland with an estimated 322 deaths in 2013 this would equate to between 71 and 84 potentially avoidable deaths.

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<sup>16</sup> www.thelancet.com Vol 384 September 6, 2014

<sup>17</sup> ibid

<sup>18</sup> ibid

<sup>19</sup> ibid

<sup>20</sup> <http://www.gov.scot/Topics/Research/by-topic/children-and-young-people/FinancialImpactEarlyYears>

5.24 It is expected that Panel members will be involved from a wide range of backgrounds, and some may require to be freed from their day job for the days on which Panels take place. A full economic analysis would need to take into consideration the opportunity cost of the productive output forgone by these staff. In April 2013 the gross median weekly earning for full-time employees in Scotland was £508.30, equating to a median daily earning of about £102. Applying this to 8 Panel members not fully employed on CDRs, across 36 Panels in one year would give an opportunity cost of staff time of about £29,300.

5.25 There will, of course, also be wider costs and benefits such as the additional service need (e.g. emergency and other health services) by a child whose death was prevented. These are however extremely difficult to quantify and are not addressed at this stage.

5.26 Taking into account the points above, a national child death review process represents good value for money.

## CHAPTER 6 RECOMMENDATIONS

These recommendations are submitted on the basis that Scottish Ministers, in 2014, accepted the recommendation of the Child Death Reviews Working Group report - that Scotland should introduce a national Child Death Review System.

The Child Death Reviews Steering Group, with reference to the contents of this report, respectfully recommends:

1. A Scottish national child death reviews system should be established comprising one National Resource Centre (NRC), along with 3 Regional Offices, based in the North, West and East areas of the country.
2. This should be an independent system – independent of existing structures, though it may be hosted within existing infrastructure.
3. Child Death Reviews should be conducted at Child Death Review Panels (CDRPs) to review the deaths, of all live born children up to the date of their 18<sup>th</sup> birthday; and for care leavers in receipt of aftercare or continuing care at the time of their death, up to the date of their 26<sup>th</sup> birthday.
4. National Records of Scotland/NHS Central Register/Local Authorities/the Care Inspectorate should be commissioned to inform the NRC of the deaths of said persons registered in Scotland.
5. The review system should review deaths of children and young people, who die in Scotland and who are resident in Scotland. Arrangements should be put in place for a Scottish child dying outside Scotland, and for a child dying in Scotland who does not reside in Scotland.
6. Reviews should be conducted in a collaborative manner and with a learning approach. Reviews will not be to establish professional blame or responsibility. Reviews will be to consider modifiable and preventable factors, with the purpose of learning lessons, locally and nationally, to prevent avoidable deaths.
7. A Family Engagement Person should be appointed in all cases for the purposes outlined in this report. That appointment and engagement should commence at the start of the review process. Families should not attend review Panels but should be engaged in the process through the Family Engagement Person.
8. Child Death Review Panels may meet and conduct the review process in accordance with the suggested contents of this report.
9. Review Panels should be multi-agency and multi-disciplinary.
10. Uniformity of process, consistency in data outcomes, uniformity of information collection, and the uniformity of the consideration process of a CDRP will be essential.

11. Child Death Review Panels should not duplicate work from other review structures, eg hospital mortality or morbidity reviews, neonatal reviews, SUDIs, FAIs etc. There is a need for an initial process at local level to consider all deaths to inform Child Death Review Panels. Child Death Review Panels should endeavour to use all available information, including the findings of other review mechanisms, in the conduct of their review.
12. The review process should commence within 7 days of the notification to the Regional Office. The Review Panel should convene and, where possible, conclude within 4 months from the commencement of the process. It is understood that some circumstances will prevent that timeframe being fulfilled in which cases the reasons for delay beyond 4 months should be recorded and considered by the National Resource Centre.
13. Information could be notified, collected and retained in a small number of documents, such as in the Forms 1, 2, and 3 outlined in this report.
14. The analysis of potential influential factors to a death may follow, among other factors, the considerations of the domain factors and categorisations, outlined in this report.
15. Modifiable or preventable factors from deaths should be recorded, considered and acted upon locally and nationally. This report outlines how that may be done.
16. It is recommended that adapting an existing IT system is a desirable, and ought to be the favoured, approach. This is likely to be the most economic and compatible approach.
17. The proposed system suggests 9 full time employment positions, with Panel Chairpersons being remunerated, on a pro rata basis.
18. Funding, as outlined in this report, should be made available to proceed with the Scottish Ministers' acceptance that Scotland should introduce a national Child Death Review System.
19. Legislation is not the desired method of instigating a Child Death Review system, due to likely issues of delay. A "Chief Executives' letter", used for implementing non-statutory policies is preferred, at this stage. A similar practice for local authority and other agency involvement should be adopted.
20. The process of data collection, and the data that is collected, on the death of a child and young person, ought to become more uniform, across the numerous Health Boards and agencies involved.
21. A Management Committee for the proposed NRC ought to be constituted to establish the NRC, to act upon its objectives, and to be accountable for its actions, objectives and budget.



**MEMBERSHIP, ROLE AND REMIT****CHILD DEATH REVIEW STEERING GROUP****Membership**

David Jack, Chair	Advocate
Lynsay Allan	Scottish Cot Death Trust
Julie-Clare Becher	Scottish Neonatal Consultant Group
Amanda Britain	University of Dundee Fatality Investigation and Review Studies (Ruby Reviews pilot of child death reviews)
Jen Browning	Royal College of Emergency Medicine, Scotland
Jane Byrne	Healthcare Improvement Scotland
Kirsty Craig	Scottish Government Child and Maternal Health
Sally Egan	Child Health Commissioners
Jill Fletcher	Scottish Ambulance Service
Ron Gray, on retirement replaced by John O'Dowd	Faculty of Public Health
David Green	Crown Office and Procurator Fiscal Service
William Guild, on retirement replaced by Scott Cunningham	Police Scotland (also representing Family Liaison Officers)
Jacquelyn Jennett	Social Work Scotland
Jacqueline Lamb	Children in Scotland
Elaine Lockhart	Royal College of Psychiatrists Scotland
Martin Kirkpatrick	Royal College of Paediatrics and Child Health (RCPCH)
Kate McKay	Scottish Government Senior Medical Officer
Ann McMurray	Stillbirth and Neonatal Deaths (SANDS)
Amanda Murphy	Paediatric Pathology
Robert Nicol/Kathy Cameron	Convention of Scottish Local Authorities (COSLA)
Mary Sloan	Scottish Government Child and Maternal Health
Judith Tait	Care Inspectorate
Donna Turnbull	Scottish Government Child Protection Information Services Division, National Services Scotland, NHS Scotland
Rachael Wood	

## **ROLE AND REMIT**

To establish a National Framework for reviewing child deaths in Scotland which achieves the following:

1. A system for reviewing child deaths across Scotland in a consistent manner in order to reduce the number of child deaths.
2. The provision of clear learning points from the process which links into Scottish Government policy and enables quality improvement across all services.
3. Improve communication with bereaved families.

## **Objectives for the National Framework**

- Ensure the accurate identification and uniform, consistent reporting of the cause and manner of every child death in Scotland
- Determine the age range and deaths to include and exclude
- Improve inter-agency responses in the investigation of child deaths
- Improve inter-agency responses in the structured review of child deaths
- Determine who will host (hold) the data, who it can be accessed by and how, IT system to use, core dataset to be captured
- Determine governance: area of review teams, who is responsible for ensuring a review takes place/identifying cases, arrangements if child dies outwith area or outwith Scotland
- Determine arrangements for review, including information gathering, confidentiality, venue, recording, standardised forms and agenda
- Determine standards for communication and support to families to improve the quality, timeliness and method of information sharing with families in the aftermath of a child death and through the review process
- Identify and manage implications for other family members
- Identify significant risk factors and trends in child deaths
- Determine dissemination of learning from reviews, including increasing public awareness and advocacy for the issues that affect the health and safety of children
- Ensure the process does not replicate other work carried out in Scotland and the UK, i.e., Scottish Paediatric Patient Safety Programme, SUDI process, RCPCH Clinical Outcomes Review Programme.
- Consider the need for statutory legislation to ensure a national Child Death Review System is put in place.

The Steering Group will be expected to:

- Review and agree the work plan of the project
- Attend meetings, provide support and advice as required

- Contribute to the development of a Child Death Review process by attending meetings and by email between meetings
- Ensure wide communication within individual networks to ensure buy-in
- Contribute to and sign off the final report.

Resources to support this work:

The Scottish Government Child and Maternal Health Division will oversee and provide secretariat support to the group. Other partners will be asked to contribute as necessary.

**RECIPIENTS OF BRIEFING PAPERS**

Children with Exceptional Healthcare Needs (CEN) Network

Children's Hospice Association Scotland (CHAS)

Consultant Forensic Pathologist

Directors of Public Health

Faculty of Forensic & Legal Medicine

Mothers and Babies Reducing Risk through Audits and Confidential Enquiries across the UK (MBRRACE)

National Records of Scotland (NRS)

NHS Borders Nurse Consultant Vulnerable Children

NHS Grampian Pathology

NHS Health Scotland

People Experiencing Trauma and Loss (PETAL)

Royal College of General Practitioners (RCGP)

Royal College of Obstetricians and Gynaecologists (RCOG)

Royal College of Paediatrics and Child Health (RCPCH)

Royal Society for the Prevention of Accidents (RoSPA)

Scottish Child Law Centre

Scottish Children's Reporter Administration (SCRA)

Scottish Government Better Life Chances Unit

Scottish Government Chief Medical Officer

Scottish Government Chief Social Work Officer

Scottish Government Child Protection

Scottish Government Community Safety Unit

Scottish Government Courts, Judicial Appointments Policy And Central Authority Unit

Scottish Government Directorate for Finance, eHealth and Analytics

Scottish Government Health Protection (Medical Reviews of Death Certificates)

Scottish Government Looked After Children Unit

Scottish Government Maternal and Infant Health

Scottish Government Solicitors - Food, Children, Education, Health and Social Care

Scottish Government Transport, Accessibility and Road Safety

Scottish Information Commissioner

Scottish Public Health Observatory (SPHO)

University of Dundee Fatality Investigation and Review Studies (Ruby Reviews pilot of child death reviews)

## NOTIFICATION and DATA COLLECTION FORMS

## Annex 3

Data items for Child Death Review forms		Form 1	Form 2	Form 3
Data item	Coding structure/comments	Initial notification	Information gathering template	Summary review output data
<b>Child identifiers and demographics</b>				
CDR unique case reference number			✓	✓
CHI number		✓	✓	✓
NRS death registration identifiers		✓		✓
NRS registration district		✓		✓
NRS registration year		✓		✓
NRS entry number		✓		✓
First forename		✓	✓	
Second forename		✓	✓	
Surname		✓	✓	
Previous forename		✓	✓	
Previous surname		✓	✓	
Date of birth	DD/MM/YYYY	✓	✓	✓
Gender	M/F	✓	✓	✓
Address of usual residence		✓	✓	
Postcode of usual residence		✓	✓	✓
Alternative postcode	Eg if child lives between two homes or has recently moved	✓	✓	✓
Country of residence		✓		
Area of usual residence	NHS Ayrshire & Arran			✓
	NHS Borders			✓
	NHS Dumfries & Galloway			✓

	NHS Fife			✓
	NHS Forth Valley			✓
	NHS Grampian			✓
	NHS Greater Glasgow & Clyde			✓
	NHS Highland			✓
	NHS Lanarkshire			✓
	NHS Lothian			✓
	NHS Orkney			✓
	NHS Shetland			✓
	NHS Tayside			✓
	NHS Western Isles			✓
	Rest of UK			✓
	Outwith UK			✓
Country of birth		✓	✓	✓
Length of time in Scotland prior to death	YY/MM		✓	✓
Ethnicity	See code list	✓	✓	✓
At the time of death, was the child:			✓	✓
Member of a travelling family	Y/N		✓	✓
Unaccompanied asylum seeker	Y/N		✓	✓
Member of asylum seeking family	Y/N		✓	✓
Recognised as homeless	Y/N		✓	✓
Looked after child	Y/N		✓	✓
On child protection register	Y/N		✓	✓
<b>Respondent identifiers</b>				
Individual registering the death		✓		
Forename		✓		
Surname		✓		

Address		✓		
Postcode		✓		
Date of registration	DD/MM/YY	✓		
Doctor certifying the death		✓		
Forename		✓		
Surname		✓		
Business address		✓		
Business contact telephone number		✓		
Consultant responsible for deceased as a patient		✓		
Registered GP		✓		
Forename		✓		
Surname		✓		
Surgery address		✓		
Each individual completing information gathering template			✓	
Forename			✓	
Surname			✓	
Job title			✓	
Place of work			✓	
Address			✓	
Postcode			✓	
Tel			✓	
Email			✓	
Date of completion	DD/MM/YY		✓	
<b>Circumstances of the death</b>				
Type of death	Neonatal death		✓	



May trigger additional type specific data collection forms.	Death of a child with a life limiting condition		✓	
	SUDI		✓	
	Road traffic accident		✓	
	Drowning		✓	
	Fire/burns		✓	
	Poisoning		✓	
	Other non-intentional injury		✓	
	Substance misuse		✓	
	Apparent homicide		✓	
	Apparent suicide		✓	
Death expected ie death anticipated as a significant possibility in 24 hours before the death (or before the collapse that precipitated the events leading to death)	Y/N		✓	
Medical certificate of cause of death issued	Y/N	✓	✓	
Registered cause of death		✓	✓	
la		✓	✓	
lb		✓	✓	
lc		✓	✓	
ld		✓	✓	
le		✓	✓	
Death referred to Procurator Fiscal?	Y/N	✓	✓	
Post mortem intended or carried out?	Y/N	✓	✓	
Post mortem carried out?	Y/N		✓	
Other reviews conducted on death			✓	

(concluded/ongoing)				
Critical incident review	Y/N		✓	
SUDI review	Y/N		✓	
Significant case review	Y/N		✓	
Fatal accident inquiry	Y/N		✓	
Other, eg Adverse Event Review, Medical certificate of cause of death (MCCD)?			✓	
Cause of death - provisional description			✓	
Circumstances of death - provisional description			✓	
Date of death	DD/MM/YYYY	✓	✓	
Time of death	00.00-24.00	✓	✓	
Age at death	YY/MM	✓	✓	
Place of death - address		✓	✓	
Place of death - postcode		✓	✓	
Place of death - type	Neonatal unit		✓	
	A&E		✓	
	Paediatric ward		✓	
	ICU/HDU		✓	
	Psychiatric hospital/unit		✓	
	Hospice		✓	
	Family home		✓	
	Other private residence		✓	
	Residential care setting		✓	
	School/nursery		✓	
	Public place		✓	
	Outwith Scotland		✓	
	Other		✓	

	Not known		✓	
Date of event leading to death			✓	
Time of event leading to death			✓	
Place of event leading to death - address	If applicable eg onset of acute medical condition or injury that lead to the death		✓	
Place of event leading to death - postcode			✓	
Place of event leading to death - type			✓	
<b>Child's medical history</b>				
Gestation at birth	WW (completed weeks)		✓	
Birthweight	In gms		✓	
Multiple birth	Singleton		✓	
	Twin		✓	
	Triplet or more		✓	
Perinatal issues			✓	
Developmental issues/disability			✓	
Physical health issues			✓	
Mental health issues			✓	
Child on medication at time of death	Free text		✓	
Alcohol or substance misuse			✓	
Summary of factors intrinsic to the child that are relevant to the death	Free text		✓	
<b>Child's educational history</b>				
Child's education/occupation status	Not yet in education		✓	
	Early education and childcare		✓	
	School		✓	
	Further/higher education		✓	
	Left education – employed		✓	

	Left education – unemployed		✓	
School/nursery attended	Name, address, postcode		✓	
<b>Family/carers and household</b>				
Number of adults living in child's usual place of residence			✓	
For each adult			✓	
Date of birth/age	DD/MM/YY or YY		✓	
Gender	M/F		✓	
Relationship to child			✓	
Health or social issues?	Eg physical health, mental health, disability, alcohol or substance misuse		✓	
Number of children living in child's usual place of residence			✓	
For each child			✓	
Date of birth/age	DD/MM/YY or YY		✓	
Gender	M/F		✓	
Relationship to child			✓	
Health or social issues?	Eg physical health, mental health, disability, alcohol or substance misuse		✓	
Other carers living elsewhere			✓	
For each carer			✓	
Date of birth/age	DD/MM/YY or YY		✓	
Gender	M/F		✓	
Relationship to child			✓	
Health or social issues?	Eg physical health, mental health, disability, alcohol or substance misuse		✓	

Other siblings living elsewhere			✓	
For each sibling			✓	
Date of birth/age	DD/MM/YY or YY		✓	
Gender	M/F		✓	
Relationship to child			✓	
Health or social issues?	Eg physical health, mental health, disability, alcohol or substance misuse		✓	
Was the child ever looked after or on the child protection register?	Y/N		✓	
Have any siblings ever been looked after or on the child protection register?	Y/N		✓	
Summary of factors in the child's family, household, and wider social environment that are relevant to the death	Free text		✓	
<b>Services involved with child</b>				
Were the following services involved with the child at the time of death (or during the final illness)?	Primary health care		✓	
	Secondary health care		✓	
	CAMHS		✓	
	Hospice		✓	
	Early education and childcare		✓	
	Education		✓	
	Social work		✓	
	Scottish Children's Reporter Administration		✓	

	Other		✓	
Summary of factors relating to the services being provided to the child/family that are relevant to the death	Free text		✓	
<b>Delivery of review</b>				
Date of CDR	DD/MM/YYYY			✓
Duration	H, MM			✓
Agencies/specialties represented at review meeting	Primary health care			✓
	Neonatology			✓
	Paediatrics			✓
	Child and adolescent mental health			✓
	Public health			✓
	Ambulance service			✓
	Other healthcare			✓
	Police			✓
	Fire service			✓
	Procurator Fiscal			✓
	Social work			✓
	Early education and childcare			✓
	Education			✓
	Family representative			✓
	Other			✓
Family involvement in review	Submitted written information			✓
	Review findings to be provided to family in written format			✓
	Review findings to be discussed with family			✓

Information gathering template available from	Primary health care			✓
	Secondary health care			✓
	CAMHS			✓
	Hospice			✓
	Early education and childcare/Education			✓
	Social work			✓
	Other			✓
<b>Outcome of review</b>				
Cause of death - final description	Free text			✓
Cause of death - classified	Deliberately inflicted injury, abuse or neglect			✓
	Suicide or deliberate self-inflicted harm			✓
	Trauma and other external factors			✓
	Malignancy			✓
	Acute medical or surgical conditions			✓
	Chronic medical condition			✓
	Chromosomal, genetic and congenital anomalies			✓
	Perinatal/neonatal event			✓
	Infection			✓
	Sudden unexpected, unexplained death			✓
Factors that may have contributed to the child's death	<i>Categorise each specific category marked 0-3 as</i>			
	0 No information available			
	1 No factors likely to have contributed to death			
	2 Factors identified that may have contributed to death			
	3 Factors identified that provide a complete and sufficient explanation for the death			

<b><i>Intrinsic to child</i></b>				
Summary	Free text - include strengths and difficulties			✓
Perinatal issues	Free text / 0-3			✓
Acute physical illness	Free text / 0-3			✓
Chronic physical illness	Free text / 0-3			✓
Emotional / behavioural / mental health condition	Free text / 0-3			✓
Developmental problem or disability	Free text / 0-3			✓
Alcohol or substance misuse	Free text / 0-3			✓
<b><i>Child's Family and social environment</i></b>				✓
Summary	Free text - include strengths and difficulties			✓
Poor parenting / supervision	Free text / 0-3			✓
Child abuse / neglect	Free text / 0-3			✓
Physical health of parent / carer	Free text / 0-3			✓
Mental health of parent / carer	Free text / 0-3			✓
Alcohol or substance misuse by parent / carer	Free text / 0-3			✓
Domestic violence in home	Free text / 0-3			✓
Family breakdown	Free text / 0-3			✓
Family finances	Free text / 0-3			✓
<b><i>Child's wider/physical environment</i></b>				✓
Summary	Free text - include strengths and difficulties			✓
Home safety	Free text / 0-3			✓
Other physical environment safety issue	Free text / 0-3			✓
Bullying	Free text / 0-3			✓
Gang culture	Free text / 0-3			✓
Wider social and policy environment	Free text / 0-3			✓
<b><i>Service provision/delivery</i></b>				✓
Summary	Free text - include strengths and difficulties			✓



Recognition of sick child	Free text / 0-3			✓
Team working/coordination of care and support	Free text / 0-3			✓
Access to/availability of services	Free text / 0-3			✓
<b>Summary and actions</b>				✓
Case summary	Free text			✓
Issues relating to the delivery of the review	Free text eg agencies not represented information not submitted to panel			✓
Modifiable factors identified?	The panel has identified one or more factors which may have contributed to the death and which, by means of locally or nationally achievable interventions, could be modified to reduce the risk of future child deaths - Y/N			✓
Modifiable factors identified - description	Free text			✓
Learning points	Free text			✓
Recommendations	Action			✓
	Relevant agency			✓
	Level (local/regional/national)			✓
Refer death to another agency	Police			✓
	Procurator fiscal			✓
	Health and Safety Executive			✓
	Serious Case Review panel			✓
	Other?			✓
Follow up plans for the family	Free text			✓

## **Code list for ethnicity**

### **Group A - White**

- 1A - Scottish
- 1B - Other British
- 1C - Irish
- 1K - Gypsy/Traveller
- 1L - Polish
- 1Z - Other white ethnic group

### **Group B - Mixed or multiple ethnic groups**

- 2A - Any mixed or multiple ethnic groups

### **Group C - Asian, Asian Scottish or Asian British**

- 3F - Pakistani, Pakistani Scottish or Pakistani British
- 3G - Indian, Indian Scottish or Indian British
- 3H - Bangladeshi, Bangladeshi Scottish or Bangladeshi British
- 3J - Chinese, Chinese Scottish or Chinese British
- 3Z - Other Asian, Asian Scottish or Asian British

### **Group D - African**

- 4D - African, African Scottish or African British
- 4Y - Other African

### **Group E - Caribbean or Black**

- 5C - Caribbean, Caribbean Scottish or Caribbean British
- 5D - Black, Black Scottish or Black British
- 5Y - Other Caribbean or Black

### **Group F - Other ethnic group**

- 6A - Arab, Arab Scottish or Arab British
- 6Z - Other ethnic group

### **Group G - Refused/Not provided by patient**

- 98 - Refused/Not provided by patient

### **Group H - Not Known**

## **List for place of event leading to death and place of death**

- |                           |                          |
|---------------------------|--------------------------|
| Acute hospital            | Family home              |
| Neonatal unit             | Foster home              |
| A&E                       | Other private residence  |
| ICU/HDU                   | Residential care setting |
| Psychiatric hospital/unit | School/nursery           |
| Paediatric ward           | Public place             |
| Hospice                   |                          |
| Outwith Scotland          |                          |
| Other                     |                          |
| Not Known                 |                          |

## TEMPLATES AND CHECKLISTS

### CHILD DEATH REVIEW PANEL MEETING: [Date]

#### PLAN AND CHECKLIST

	ITEM	BY WHOM AND NOTES	DONE
1	Dates of meetings for a Calendar year to be set in October of previous year		
2	The Pool of Panel members to indicate which meetings they will attend – ensure representative from each specialty will attend each meeting		
3	Venue(s) to be booked for each meeting		
<b>Before each meeting</b>			
4	Remind Panel the date of meeting		
5	Remind Panel members it is their responsibility to arrange for another member (from the Pool in their specialty) to attend if they cannot attend in person		
6	Check venue booking		
7	Deaths to be reviewed identified, ie those whose information has been received		
8	Issue agenda and collated information forms to Panel members		
9	Prepare summaries to present at meeting		
10	Arrange parking if appropriate		
11	Arrange catering		
12	Inform security/reception of Panel members attending		
13	Ensure laminated Explanation of Analysis Proforma domains/ categories sheets are available for each Panel member		
14	Ensure confidentiality statement is available at meeting		
15	Ensure Chair has a copy of the Analysis Proforma for completion during meeting		
16	Checklist for meeting		
17	Attend meeting Administrator to take notes		

## CHECK LIST FOR DAY OF MEETING

Date:

Time:

Venue:

Child Review References:

	Action	By Whom	Done?
1	Room lay out – sufficient chairs, refreshments	Administrator to check	
2	Ensure reception has visitor list	Administrator	
3	List of attendees	Administrator to bring	
4	Confidentiality statement available	Administrator to bring	
5	Confidentiality statement signed by all		
6	Give Chair an Analysis Pro Forma for each death	Administrator/Coordinator	
7	Take short notes (in case of later queries on decisions)	Administrator	
8	Agree entries on Analysis Pro Forma for each death	Chair	
9	All papers to be collected from Panel members and shredded at end of meeting	Administrator/Coordinator	
10	Outcome and findings of review to be added to the electronic Analysis Proforma	Administrator/Coordinator	

## CHILD DEATH REVIEW PANEL MEETING

DATE

TIME

VENUE

### AGENDA

1. Welcome and Introductions Chair
2. Confidentiality requirements Chair/All  
(all attendees to sign confidentiality statement)
3. Reminder of purpose of meeting and number of deaths to be reviewed Chair

For each case to be reviewed:

4. Introduction of death to be reviewed Coordinator
5. Share, question and clarify case information All
  - Child's life story
  - Lead up to incident/death
  - Health at time of death
  - Circumstances of death
  - Response and investigations
  - Aftermath support family/staff
6. Data collection – complete Analysis Proforma Chair
  - Factors in each of the domains in discussion with All
  - Allocate a category
  - Identify modifiable factors/note no modifiable factors
  - Identify issues
  - Identify learning points
  - Identify recommendations
  - Follow up plans for family
  - Possible Actions
7. Dates of next meetings:
  - Neonatal reviews
  - Child death reviews
8. Thank you and close

## CHECKLIST ASAP AFTER MEETING

1	Type up notes	Administrator	
2	Circulate notes to Panel meeting attendees [or just keep on record]	Administrator	
3	Input onto IT system the information recorded on Analysis Proforma for each death	Administrator	
4	Submit information recorded on Analysis Proforma for each death to national resource centre [if the centre cannot automatically access it]	Administrator	
5	Collate information on all child deaths	National Resource Centre Coordinator	
6	Analyse information on all child deaths	National Resource Centre Coordinator	
7	Prepare quarterly report for Region	National Resource Centre (?) Coordinator	
8	Prepare national annual report, submission to Scottish Ministers	National Resource Centre Coordinator	

## **CONFIDENTIALITY STATEMENT**

(to be agreed by host organisation and National Resource Centre)

### **Child Death Review Meeting**

**Date**

**Time**

**Venue**

The purpose of the Child Death Review (CDR) Panel is to conduct a thorough review of all child deaths in order to better understand how and why children die and to take action to prevent other deaths.

In order to assure a coordinated response that fully addresses all systematic concerns surrounding child deaths, all relevant data should be shared and reviewed by the CDR Panel, as permitted within the stipulations of the Data Protection Act 1998, including historical information concerning the deceased child, his/her family and the circumstances surrounding the death. Much of this information is protected from public disclosure.

In no case will any CDR Panel member disclose any information regarding CDR Panel discussions outside the meeting other than pursuant to the mandated agency responsibilities of that member. Public statements about the general purpose of the child death review process may be made, as long as they are not identified with any specific case.

The undersigned agree to abide by the terms of this confidentiality policy.

**OR**

**Information pertaining to the case being reviewed is confidential and must remain so to protect the identity of the child and the privacy of his/her family.**

I undertake not to disclose outside this meeting any identifiable information provided by participants, beyond what is necessary for the performance of my agency's legal responsibilities in relation to public protection.

<b>Name</b>	<b>Agency</b>	<b>Signature</b>

## ANALYSIS PROFORMA

The proforma should be used by the Child Death Review Panel (CDRP) to:

- Evaluate information about the child's death;
- Identify lessons to be learnt;
- To inform an understanding of all child deaths at a national level.

The CDRP meeting participants should analyse any relevant environmental, extrinsic, medical or personal factors that may have contributed to the child's death under the headings below.

### Domain - Factors intrinsic to the child

Include any known health needs; factors influencing health; development/educational issues; behavioural issues; social relationships; identity and independence; abuse of drugs or alcohol; note strengths and difficulties

[Factors include: acute/sudden onset illness; chronic long term illness (asthma/epilepsy/diabetes/other chronic illness); disability or impairment (learning disability/motor impairment/sensory impairment/other disability or impairment); emotional/behavioural/mental health condition; allergies; alcohol/substance misuse by the child]

### Domain - Factors in the child's family and social environment

Include family structure and functioning; including parental abuse of drugs or alcohol; wider family relationships; housing; employment and income; social integration and support; community resources; note strengths and difficulties

[Factors include: emotional/behavioural/mental health condition in parent or carer; alcohol/substance misuse; smoking in household; smoking during pregnancy; housing, domestic violence; co-sleeping; bullying; gang/knife crime; pets/animal assault; consanguinity]

### Domain – Factors in the child's wider and physical environment

Include issues around provision of basic care; health care (including antenatal care where relevant); safety; emotional warmth; stimulation; guidance and boundaries; stability; note strengths and difficulties

[Factors include: poor parenting/supervision; child abuse/neglect]

### Domain - Factors in relation to service provision/delivery

Include any identified services (either required or provided); any gaps between child's or family member's needs and service provision or delivery; any issues in relation to service provision or uptake

[Factors include: access to health care; poor medical intervention; poor surgical intervention]

The CDRP should analyse any relevant environmental, extrinsic, medical or personal factors that may have contributed to the child's death under the following headings.

For each of the four domains below, determine different levels of influence (0-3) for any identified factors:

- 0 - Information not available
- 1 - No factors identified or factors identified but are unlikely to have contributed to the death
- 2 - Factors identified that may have contributed to vulnerability, ill-health or death
- 3 - Factors identified that provide a complete and sufficient explanation for the death

This information should inform the learning of lessons at a local and national level.



**The CDRP should categorise the likely/cause of death using the following schema.**

This classification is hierarchical: where more than one category could reasonably be applied, the highest up the list should be marked.

Category	Name & description of category	Tick box below
1	<b>Deliberately inflicted injury, abuse or neglect</b> This includes suffocation, shaking injury, knifing, shooting, poisoning & other means of probable or definite homicide; also deaths from war, terrorism or other mass violence; includes severe neglect leading to death	<input type="checkbox"/>
2	<b>Suicide or deliberate self-inflicted harm</b> This includes hanging, shooting, self-poisoning with paracetamol, death by self-asphyxia, from solvent inhalation, alcohol or drug abuse, or other form of self-harm. It will usually apply to adolescents rather than younger children.	<input type="checkbox"/>
3	<b>Trauma and other external factors</b> This includes isolated head injury, other or multiple trauma, burn injury, drowning, unintentional self-poisoning in pre-school children, anaphylaxis & other extrinsic factors. <b>Excludes</b> Deliberately inflicted injury, abuse or neglect. (category 1).	<input type="checkbox"/>
4	<b>Malignancy</b> Solid tumours, leukaemias & lymphomas, and malignant proliferative conditions such as histiocytosis, even if the final event leading to death was infection, haemorrhage etc.	<input type="checkbox"/>
5	<b>Acute medical or surgical condition</b> For example, Kawasaki disease, acute nephritis, intestinal volvulus, diabetic ketoacidosis, acute asthma, intussusception, appendicitis; sudden unexpected deaths with epilepsy.	<input type="checkbox"/>
6	<b>Chronic medical condition</b> For example, Crohn's disease, liver disease, immune deficiencies, even if the final event leading to death was infection, haemorrhage etc. <b>Includes</b> cerebral palsy with clear post-perinatal cause.	<input type="checkbox"/>
7	<b>Chromosomal, genetic and congenital anomalies</b> Trisomies, other chromosomal disorders, single gene defects, neurodegenerative disease, cystic fibrosis, and other congenital anomalies including cardiac.	<input type="checkbox"/>
8	<b>Perinatal/neonatal event</b> Death ultimately related to perinatal events, eg sequelae of prematurity, antepartum and intrapartum anoxia, bronchopulmonary dysplasia, post-haemorrhagic hydrocephalus, irrespective of age at death. It <b>includes</b> cerebral palsy without evidence of cause, and <b>includes</b> congenital or early-onset bacterial infection (onset in the first postnatal week).	<input type="checkbox"/>
9	<b>Infection</b> Any primary infection (ie, not a complication of one of the above categories), arising after the first postnatal week, or after discharge of a preterm baby. This would include septicaemia, pneumonia, meningitis, HIV infection etc.	<input type="checkbox"/>
10	<b>Sudden unexpected, unexplained death</b> Where the pathological diagnosis is either 'SIDS' or 'unascertained', at any age. <b>Excludes</b> Sudden Unexpected Death in Epilepsy (category 5).	<input type="checkbox"/>

**The Panel should categorise the 'preventability' of the death – tick one box.**

Preventable child deaths are those in which modifiable factors may have contributed to the death. These are factors defined as those where, if actions could be taken through national or local interventions, the risk of future child deaths could be reduced.

<b>Modifiable factors identified</b>	The Panel have identified one or more factors, in any domain, which may have contributed to the death of the child and which, by means of locally or nationally achievable interventions, could be modified to reduce the risk of future child deaths	<input type="checkbox"/>
<b>No Modifiable factors identified</b>	The Panel have not identified any potentially modifiable factors in relation to this death	<input type="checkbox"/>
	Inadequate information upon which to make a judgement. <i>NB this category should be used very rarely indeed.</i>	<input type="checkbox"/>

**Guidance notes for a Family Engagement Person appointed through the Child Death Review process** (see Chapter 4)

As a national standard, the following ought to be developed:

- Within 7 days of notification of the death from the NRC, the Regional Office is to have agreed and documented the identity of the Family Engagement Person who will support the family; and when they intend to make contact with the parents/carers to discuss the CDR process.
- The appointed person should (wherever possible) already be known to the family.
- The appointed person should gather relevant information about support already in place for the family and link with key professionals from other organisations in this regard.
- The parents/carers should be offered face-to-face contact. If this is not their preference, then contact through an agreed method should be offered.
- Literature should also be offered to support what has been discussed regarding the CDR process and function.
- Correspondence to inform parents/carers of the Child Death Review process is not the preferred initial form of communication, but may have to be used where other methods of engaging have not succeeded.
- Parents/carers should be informed at each stage of the process and of any outcomes.
- Delays that may occur in the Review process should be explained to the parents/carers concerned.
- Parents/carers should have information about a person they can contact at regional or national level should they have any comments, complaints or questions.
- The Family Engagement Person offering support should have available a range of information on organisations to whom they may refer the family, for ongoing bereavement support.
- The Family Engagement Person should have an awareness of how the death of a child and the complex grief that this brings can affect the responses of parents/carers, and why they perhaps may seem to not wish to engage.

It is noteworthy that:

1. Information given only once may not be processed.
2. Parents/carers may suffer from extreme guilt and feel they have failed to protect their child.
3. Anger is often an outlet for the frustration felt by parents/carers and may be directed towards key people supporting them and imparting information to them.
4. Suicidal intent can be present and early professional intervention may be appropriate.
5. The questioning of, or a loss of faith or spiritual beliefs are common – the Family Engagement Person should be aware of sources from which relevant assistance may be sought in this regard.

**ABBREVIATIONS**

CBA	Cost Benefit Analysis
CDOP	Child Death Overview Panel (England)
CDR	Child Death Review
CDRP	Child Death Review Panel
COSLA	Convention of Scottish Local Authorities
DCRS	Death Certification Review Service
eCMS	Electronic case management system
FAI	Fatal Accident Inquiry
FCO	Foreign and Commonwealth Office
GP	General Practitioner
HIS	Healthcare Improvement Scotland
ISD	Information Services Division
MBRRACE	Mothers and Babies: Reducing Risk through Audits and Confidential Enquiries across the UK
MCCDs	Medical Certificates of Cause of Death
NES	NHS Education for Scotland
NHSCR	National Health Service Central Register
NPC	Net Present Costs
NPV	Net Present Value
NRC	National Resource Centre
NRS	National Records of Scotland
NSSIT	NHS National Services Scotland Information Technology
PC	Present Costs
PV	Present Value
QALYs	Quality Adjusted Life Years
RCPCH	Royal College of Paediatrics and Child Health
SG	Scottish Government
SUDI	Sudden Unexpected Death in Infancy
VPF	Value of prevented fatality



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