

Child Death Review Report

Scottish Government Child Death Review Working Group

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SCOTTISH GOVERNMENT CHILD DEATH REVIEW WORKING GROUP

Consideration of a child death review system in Scotland: Report on findings

Executive Summary

The death of any child is a tragedy for families, and society would expect that the reasons for that death would be explored and lessons learned to reduce the chance of further deaths in children. Scotland has a considerably higher mortality rate in children and young people, in comparison to many other countries in Western Europe. A number of different formal and informal mechanisms already exist to examine some childhood deaths but there is considerable geographical variation across Scotland and mechanisms are often designed only for certain categories of childhood deaths. Some mechanisms produce epidemiological data that would be helpful in learning lessons at operational and strategic levels, locally and nationally, but data gathering is poorly coordinated.

The Scottish Government set up a Child Death Review Working Group to explore current practice in Scotland and to consider whether Scotland should introduce a collaborative multi-agency system for reviewing the circumstances surrounding the death of a child. Data generated from these reviews would inform policy and contribute to the prevention of child deaths in Scotland in the future.

Recommendation

The Working Group recommends that Scotland should introduce a national Child Death Review System which would:

- systematically review each death in a multi-agency forum. Any local learning would be implemented amongst relevant professionals and services. These reviews should be timely, appropriate and sensitive to the needs of bereaved families.
- collate a uniform data-set relevant to each child death for national analysis to inform national multi-agency learning and aid the development of national policy and
- identify factors which may reduce preventable childhood deaths.

In order to achieve this, a national multi-agency Steering Group should be established to make recommendations to the Scottish Government on implementation. The Steering Group should take into account pilot work currently underway which will inform the way the system is delivered.

The views and needs of families are of paramount importance in this process.

Background

1. Families who lose a child often find themselves involved in complex bureaucracy and may have considerable difficulty obtaining a clear account of why their child died.

Current Family Involvement

2. Families, who have closest knowledge of the lost child, have little opportunity to contribute to review processes. There are numerous anecdotal examples from front-line clinicians that the post-bereavement care, communication, timescales and outcomes of any review, are very unsatisfactory for many families. There continue to be long delays before families are informed of post-mortem findings and involvement of medical practitioners in appropriately 'translating' those findings is not consistent. In stark contrast to a model of professionals working with parents during their child's life, it seems that a family's views, information and questions are sometimes not afforded priority after their child has died. This compounds their grief and loss. The quotes below illustrate some of these parental views:

'Being told the outcome of the Post Mortem by police officers was inappropriate. They had no medical training and were therefore unable to answer our questions about the cause of death and the answer provided, namely that our son choked on his vomit was incorrect.'

'We feel very strongly that a family who loses a child needs special consideration. They need access to medical professionals. We had that through our own efforts rather than through any system that was in place. Without that we would have been completely lost.'

'We were left with the distinct impression that there was no protocol or accepted way of dealing with our tragic circumstances.'

Child Death Review Working Group

3. A Child Death Review Working Group was set up to explore current practice in the review of child deaths in Scotland, and to consider whether Scotland should introduce a system for reviewing the circumstances surrounding the death of a child, in order to identify preventable causes of death which could improve child mortality rates in Scotland in the future.
4. The Working Group met 5 times between September 2012 and November 2013. It carried out a mapping exercise of: reviews and audits currently undertaken in Scotland; the deaths examined; data sources and data dissemination; and communication and support for families. The Chair visited the University of Oxford to learn lessons from the MBRRACE-UK

system (Mothers and Babies: Reducing Risk through Audits and Confidential Enquiries across the UK) and also visited the Child Death Overview (CDOP) manager in Merseyside (see paragraph 24). The information in this report was also drawn from publicly available online sources, discussions with staff involved in reviewing child deaths in Scotland and from a survey of Child Health Commissioners within Scotland.

5. The Working Group considered whether Scotland should introduce a national system for reviewing the procedures and circumstances surrounding the death of a child in order to improve:
 - Local process/collation and coordination
 - Communication and support to families
 - Strategic process – learning from deaths and disseminating that learning.
6. The group consisted of representatives from NHSScotland, the Royal College of Paediatrics and Child Health, Police, Crown Office, Procurators Fiscal Service, Scottish Cot Death Trust, University of Dundee and the Scottish Government.

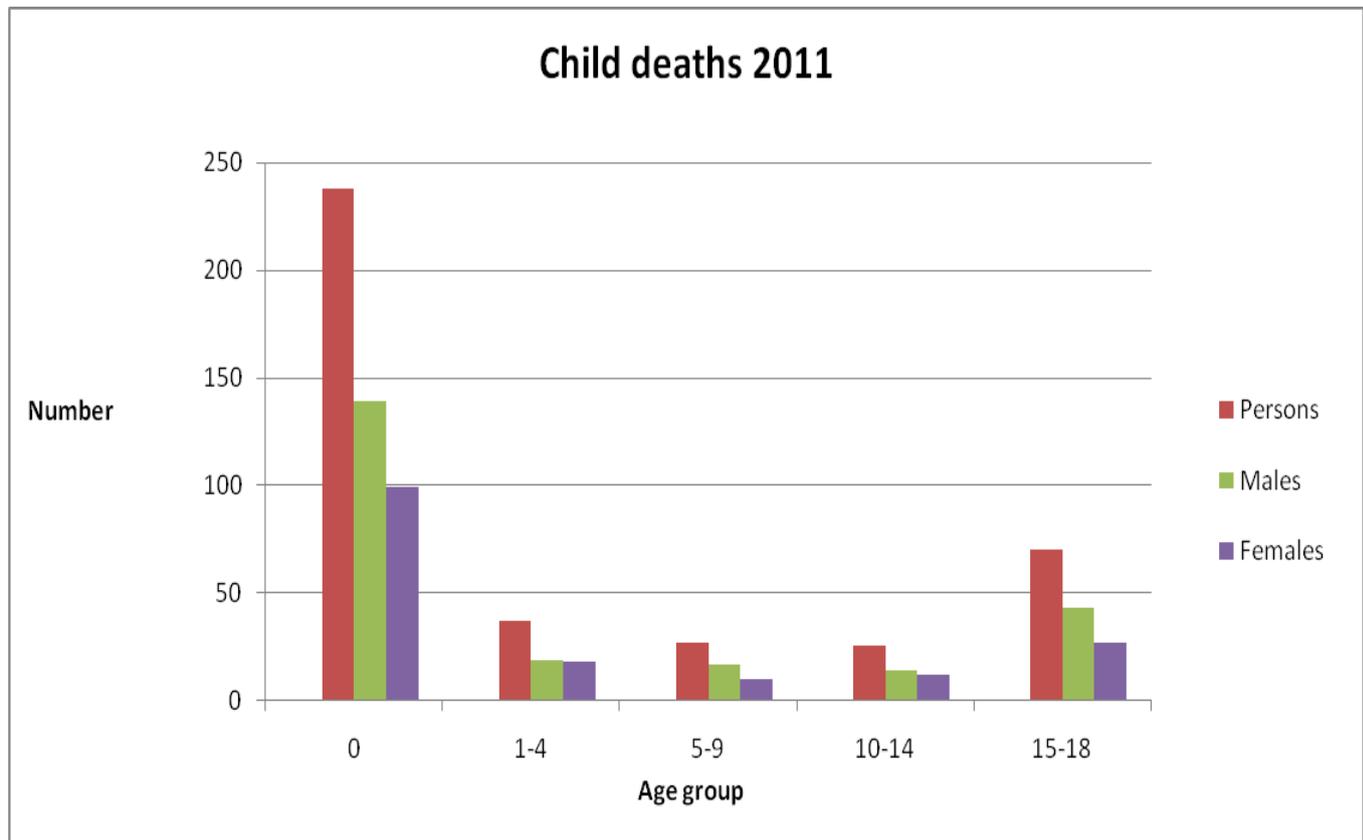
Contribution to Scottish Government Strategic Objectives and Current Policy

7. This work contributes to the Scottish Government’s “Healthier” strategic objective and in particular to the Healthier outcomes of “We live longer, healthier lives”; “We have improved the life chances for children, young people and families at risk”; and “Our children have the best start in life and are ready to succeed”.
8. The potential development of a child death review system for Scotland should link to current Scottish Government early years and child health policies in addition to child protection policies (e.g. *It’s Everyone’s Job to make sure I’m alright*¹) and should promote integration of good practice across health, social care and justice systems. By enabling the detection and modification of preventable factors involved in child deaths, it will also inform the work of the Early Years Collaborative to ensure that all children have the best start in life and are ready to succeed.
9. It will assist with the Early Years Collaborative’s Stretch Aim of reducing infant mortality by 10% by 2015 (from 3.7 per 1,000 live births in 2010 to 3.1 per 1,000 live births in 2015)² There are also important links between child death reviews, the Scottish Patient Safety Programme³ and the protection of children in the community in terms of learning being disseminated widely across agencies.

Epidemiology of child deaths in Scotland

10. In Scotland each year, there are roughly between 350 and 450 deaths of people aged under 18, with most of them occurring in children aged under 1. Of the other age-groups, 15-18 has the largest number of deaths: each of the 1-4, 5-9 and 10-14 age-groups has relatively few deaths (Figure 1).

Figure 1: Child deaths in Scotland 2011, by sex.



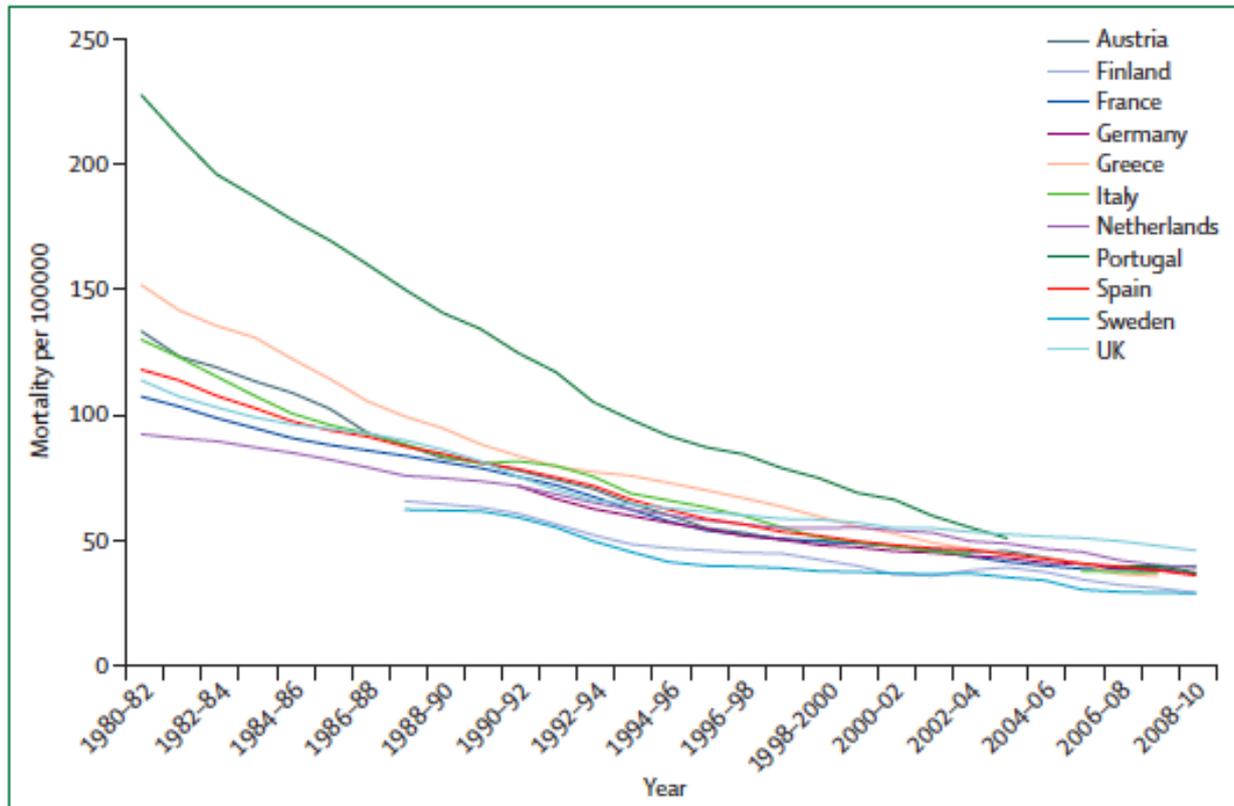
Source: GROS⁴

11. Causes of death in 0-1 age range bracket are usually related to prematurity and congenital abnormalities and causes in the 15-18 age range relate largely to trauma including road traffic accidents and teenage suicide.

12. Child mortality rates fare particularly poorly in the UK compared to the rest of Europe. In the UNICEF report "*Child Wellbeing in rich countries*" (2013)⁵ compared the UK with all other European countries, indicating that the UK is in the bottom one third for infant mortality rates.

13. A recent report in *The Lancet*⁶ also published child mortality data for the UK and other western European countries from 1980 onwards. While it is immediately obvious that there have been falls in child mortality over the last 30 years, there are readily apparent disparities in those rates between countries (figure 2).

Figure 2: Trends in mortality in children aged 0-14 years in 11 European countries, 1980-2010



Trends in mortality in children aged 0-14 years in 11 European countries, 1980-2010
 Source: Lancet 2013: 381:1224-34: 6-12 April 2013⁶ WHO Mortality Database, 2012. Data are directly standardised rates.

14. Taking Sweden as a base-line with the lowest child mortality, the UK has the greatest 'excess mortality' of any country in western Europe (figure 3). By way of example the UK has five times the mortality rate for asthma compared to either Sweden, Portugal, Finland, Italy, Austria, Germany or Spain and there has been no fall in 'intentional injury' including assaults and suicides in the UK in the last 30 years.

Figure 3: Child mortality rates in the 15 pre-2004 countries of the European Union and excess child deaths compared with Sweden

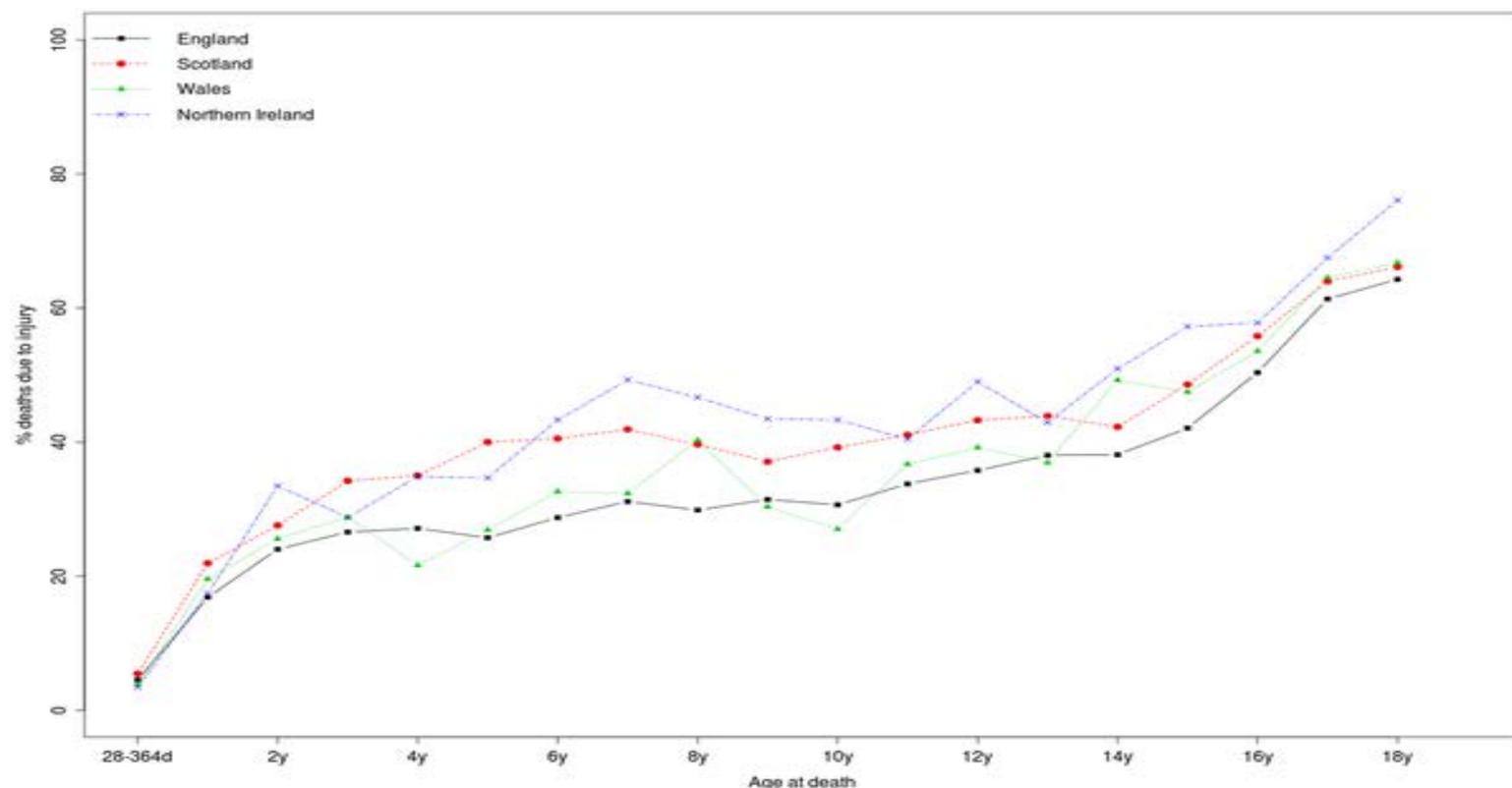
	Mortality (directly standardised rate)	Yearly excess deaths compared with Sweden
Sweden	29-27	0
Luxembourg	26-50	0
Finland	30-27	9
Spain	37-40	545
Greece	37-86	135
Germany	37-88	815
Italy	38-07	683
France	38-25	962
Austria	39-09	106
Ireland	39-78	98
Netherlands	40-66	292
Portugal	40-73	176
Denmark	42-69	121
UK	47-73	1951
Belgium	47-77	304

7

Source: Lancet 2013; 381:1224-34; 6-12 April 2013 WHO Mortality Database, 2012.2 Directly standardised rate data show all-cause mortality per 100 000 children aged 0–14 years and are 5 year means for 2006–10, except for France and Luxembourg (2005–09), Denmark (2002–06), Belgium (1998–99; 2004–06), Italy (2003; 2006–09); and Portugal (2003; 2007–10). Data for excess deaths are absolute numbers. An estimated 6198 deaths would have been avoided if the child mortality rate across the 15 pre-2004 countries of the European Union was the same as that in Sweden.

15. A recent report by Healthcare Quality Improvement Partnership (HQIP) Clinical Outcome Review Programme (CORP): Child Health confirmed there are variations too between the 4 nations: Scotland has the greatest 'excess mortality' from injuries over the age of 10 years with 146 additional deaths compared to England (figure 4).⁸

Figure 4: Percentage of child deaths due to injury by country and age at death, 1980–2010



Source: PLoS (Public Library of Science)

16. Child deaths are more common in areas of socio-economic deprivation. Children from deprived areas and from families with low socioeconomic status have higher rates of child mortality and death from injury.^{9,10,11,12} Pre-term delivery is strongly associated with socio-economic deprivation and with infant mortality, and the gap in the rate of preterm births between different socio-economic groupings has widened over the last four decades in the UK.

Existing review processes and surveillance systems in Scotland

17. Currently there are a variety of processes and mechanisms (statutory, regulatory, investigative, procedural, internal to agencies and multi-agency, formal and informal). These include:

Local hospital mortality reviews

18. There are numerous and varied informal and formal mechanisms that operate in different Health Board areas, to review a child's death. There is however no consistent process across Scotland, and no consistent multiagency groups which review all child deaths. Reviews that do take place may or may not reach conclusions about lessons to be learned, but sharing of those lessons more widely seems to be limited.
19. There are some groups of children where a process is more established. Perinatal morbidity and mortality meetings have run for many years and some paediatric units review all in-hospital deaths. These reviews are limited because they impact only on hospital health-care staff and there is limited evidence of sharing of lessons learned across health services.

Multi-agency child death reviews

20. There are some multi-agency review processes but these are confined to particular groupings of children. Significant Case Reviews are carried out by the local Child Protection Committees, after serious harm or death caused by child abuse. However not every child death where child protection concerns were known to have existed is subject to a Significant Case Review in Scotland. Infants who have suffered 'sudden and unexpected deaths in infancy' (SUDI) are reviewed through a multiagency process. NHS Boards have a responsibility to ensure that the meeting takes place with the appropriate professionals and that the SUDI Review summary sheet is completed and sent to Healthcare Improvement Scotland (HIS). The Care Inspectorate has a statutory duty to carry out reviews into deaths of Looked After Children and can make recommendations for other services, although these may not be implemented.

Procurator Fiscal Inquiries

21. At a national and regional level there are investigations by the Procurator Fiscal after certain deaths under the aegis of the Scottish Fatalities Investigations Units (SFIU).
22. The Procurator Fiscal may instruct expert opinion and will review all information relevant to the death whether from the Care Inspectorate or other sources. While there is no formalised process for dissemination of lessons learned such information would be provided to the organisations involved.

Existing Data collection and surveillance systems

23. The National Records of Scotland (NRS) and the Information Services Division (ISD) collect death certificate data and a variety of health-related information surrounding deaths in Scotland but there is limited clinical detail. There is on-going concern about the accuracy of death certificate data¹⁴ and no structured mechanism to feed collated data back to Health Boards.

However each of Scotland's Health Boards does receive a weekly data bundle with mortality data, some premortality data on every patient who has died in that area and on every patient normally resident in that area who has died elsewhere in Scotland. The potential exists to link the child mortality data received from NRS with the child's full medical history and some social data although the facility and capacity to do this currently varies across Scotland.

24. The new UK-wide MBRRACE-UK (Mothers and Babies Reducing Risk through Audit and Confidential Enquiries across the UK) collaboration is, from April 2013, collecting data from all maternity and neonatal care units in order to investigate maternal deaths, stillbirths and infant deaths.¹⁵ Scottish data will be separately analysed in addition to the UK report and will be used to inform the new patient safety programme in maternity services – the Maternity and Children's Quality Improvement Collaborative (MCQIC)³ - and the Early Years Collaborative² as well as to inform units at a local level.

Child Health Commissioners' Questionnaire of current practice

25. In a survey, Child Health Commissioners described a series of review processes occurring at a Health Board level but with no standardised template listed to align these processes in a unified way to promote learning. As above, there were some examples of good multi-disciplinary working within health but outside the Significant Case Review process and Sudden Unexpected Death in Infancy (SUDI) review, there were few examples of multi-agency review. Child Health Commissioners were generally in favour of a more formalised child death review process across Scotland.

Child death review systems: Evidence from other countries

England

26. There are 148 Local Safeguarding Children Boards in England and 93 Child Death Review Overview Panels (CDOPs). From 2008¹⁶ CDOPs have had statutory responsibility for the provision of 'Rapid Response Teams' and 'Child Death Overview Panels' were organised on a local authority basis with input from appropriate clinical staff from health. Local teams operate under the auspices of Child Safeguarding which is usually local authority led (and is similar to Scotland's Child Protection Committees).

27. A recent review of all CDOPs in England can be found at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/246562/DFE-RR303.pdf. This report makes several recommendations to improve child death review data collection and structure/process.

Recommendations from English child death review report (2013)¹⁷

- CDOPs must continue to be locally based and to have a local focus in order to continue their work with local services and agencies to ensure both the provision of data needed for the CDOP process and to ensure that recommendations for service improvements are locally relevant and acted upon locally.
- A national database should be established to enable the collection, analysis, interpretation and reporting of CDOP data at a national level.
- The database and the associated standardised data collection tools required to ensure high quality data are collected must be designed in collaboration with CDOP staff to ensure that they meet the CDOP data needs and local analysis requirements whilst a sub-set of the data is made available for national analysis.
- The database should be commissioned from a provider who is experienced in national data collection and analysis and has the requisite clinical skills to interpret the findings and to issue appropriate alerts and alarms when necessary as well as producing an annual national report.
- Links must be established with other national data collections and child health intelligence networks to ensure maximum benefit is derived from the data collected and the recommendations made.
- The continuation in some places and re-establishment in others of regional meetings is essential to ensure shared learning across CDOPs continues. Funded national meetings would also support one element of shared national learning and the goal of making better use of child death review data. Such meetings could be stand alone or form part of the remit of a national database provider.

Wales

28. A similar process for Child Death Reviews has been established in Wales.

Northern Ireland

29. Northern Ireland has a review process and a safeguarding board. Models for a child death review process are being studied in Northern Ireland with a view to implementing a national system.

Other countries

30. The USA, Canada and New Zealand in particular have well established Child Death Review Systems. There is now considerable experience in these other high income countries who have shown that a process of reviewing all child deaths in the population can both identify preventable deaths and reduce mortality rates in certain populations. For example, data collated across the USA has resulted in changes in state law on swimming pool design, on road junctions, identified areas where child protection systems are functioning inadequately, resulted in enhanced 'Back to Sleep' advertising campaigns. This has evidenced reductions in maltreatment deaths due to better targeting of resources and the development of better mechanisms for the identification of children at risk. The US system has been of particular interest to other nations seeking to develop child death review processes because of its simple and inexpensive process¹⁸ The National Centre for Child Death Review Policy and Practice (www.childdeathreview.org/) has provided a rich source of detailed data that can be used to direct public health policy for children.

31. There is now a credible body of literature going back ten years affirming the efficacy of reviewing all child deaths in a process which collects and collates standard data and translates that data and recommendations into local and national policy initiatives.^{19,20,21,22.}

Resource Implications

32. In England, Safeguarding is delegated to local authorities. Child Death Overview Panels are resourced through this funding. The publication of the Child Death Research Report¹⁷ (October 2013) calculated the size of designated budget from local authorities to CDOPs has a median of £51,762 (range £9,750 – £200,000). The report also provides a basis for calculating the hours of professional time and administrative time for each child death review. With the number of hours of professional time spent reviewing each child death being a median of 5 hours (range 1.3-14.2 hours) and the number of administrative staff time being a median of 34.7 hours (range 10.4-195.4 hours) per child death reviewed.

33. At this stage, costs or a funding source have not yet been identified for a Scottish national process.

Key elements of a Child Death Review (CDR) system

34. The key elements of a CDR system are:

1. A local CDR process includes:
 - local notification of child deaths, collation of available information, identification of further data needed
 - convening a multi-agency CDR panel, with core and case-specific membership to share and collate information about the circumstances around an individual child's death, to create a narrative account of the circumstances
 - the completion of an agreed national standardised data-set for each child's death
 - timely and appropriate involvements of bereaved families
 - mechanism for local dissemination of learning
2. A national process includes:
 - learning lessons, developing good practice, disseminating information and implementing change across agencies
 - Collating and disseminating local and national data to identify common themes on avoidable deaths and
 - Establishing a strategic group which examines data trends and reviews recommendations to make appropriate recommendations to policy makers and public health.

35. Any implementation of a child death review system in Scotland should take account of other processes including: SCRs, SUDI reviews, neonatal or paediatric mortality review processes, patient safety programmes and may be further informed by the results of the death investigation carried out by the Procurator Fiscal.

36. The system should avoid duplication of existing data collection and use data linkage techniques to provide a comprehensive child death dataset for Scotland.

37. The system should maximise all opportunities to prevent child deaths.

Options to consider for Scotland

1. Maintain the Status Quo: no changes to present systems and process
2. Adapt existing models of review for child deaths
3. Develop a national model for reviewing Child Deaths in Scotland

1. Maintain the Status Quo : no changes to present systems and process

Advantages	Disadvantages
<p>There are a number of review processes of varying number and quality across Scotland that may be able to be adapted into a national system.</p> <p>Continue to utilise 'high level' mortality data provided into UK-wide systems e.g. MBRRACE.</p>	<p>There is no standardised process to learn lessons from childhood deaths or to gather detailed data on the causes and circumstances of the death.</p> <p>Families of children who have died may find the status quo unacceptable.</p> <p>There is now data indicating variation in mortality rates in the 4 countries of the UK. Without appropriately detailed Scottish mortality data little can be done to identify causes and patterns of mortality and allow opportunity to reduce mortality rates.</p>

2. Adapt existing models of review for child deaths

- A. The Significant Case Review system used by local Child Protection Committees.
- B. SUDI Toolkit process used for cot deaths.
- C. New process for Adverse Incident Reporting systems by HIS.
- D. Use existing models of data collection to identify patterns of death in under 18s.

A. The Significant Case Review (SCR) system used by local Child Protection Committees

Advantages	Disadvantages
<p>This is an established multi-agency process that examines some, though not all, child protection deaths in considerable detail.</p> <p>New guidance will ensure that the Care Inspectorate will become the repository for SCR reports in Scotland and be responsible for dissemination from the reports.</p>	<p>The SCR process is prolonged and complex.</p> <p>The process is currently being reviewed in Scotland. Revised guidance is scheduled to be published in late Spring 2014.</p> <p>Only a small minority of deaths in childhood are related to child protection issues and so this process would not capture the majority of child deaths.</p> <p>There is limited involvement of families, although recent research in England, in relation to family involvement in maltreatment case reviews, found that contrary to professionals' views, families were keen to participate in reviews, their desire for something to be redeemed from the tragedy over-riding their concern of further distress. (Morris et al., 2013)²³</p>

B. HIS process used for reviewing sudden unexpected deaths in infancy (SUDI process)

Advantages	Disadvantages
<p>This is an established multi-agency process with defined roles and responsibilities for all involved and appears to be like a confidential enquiry.</p>	<p>Detailed and time-consuming data collection form, with qualitative and quantitative items, is not user-friendly.</p> <p>The SUDI process is designed for a specific category of infant deaths and would be unlikely to be appropriate for the significant heterogeneity of children and young person's deaths across a wide age range. While there is a data collection process, there has been no formal analysis and national report.</p> <p>The significant heterogeneity of childhood and young persons' deaths outside infancy, can complicate data requirements. While there is a data collection process, there has been no formal analysis and national report.</p>

C. HIS Adverse Incident Reporting systems ²⁴

Advantages	Disadvantages
<p>This is a national system that applies consistent definitions and a standardised approach to adverse event management across NHS Scotland. It aims to learn from adverse events and promote patient safety.</p>	<p>It is designed to capture health-related adverse incidents only. There is limited multi-agency involvement and it cannot take account of the significant number of child deaths that occur outside healthcare settings, e.g. as a result of road traffic accidents (RTA).</p> <p>Many childhood deaths will not be applicable for an adverse incident framework.</p>

D. Use existing models of data collection to identify patterns of death in under 18s, in collaboration with HQIP NHS England. Data sources include:

- death certification data from NRS and ISD data
- National perinatal data collection linking into MBRRACE-UK
- SUDI data collection – HIS.

Advantages	Disadvantages
<p>Utilisation of existing data collection systems will improve accuracy of data capture and decrease overlap with any new data collection systems.</p>	<p>Systems have varying levels of development and maturity.</p> <p>These systems are generally designed to capture, for surveillance purposes, 'high-level' health service related data. As such, they cannot provide the level of detail needed to adequately review a child's death (like a confidential enquiry).</p> <p>Most cannot capture data outside health although data linkage with education and social care systems are developing in one Health Board area.</p>

3. Develop a national model for Scotland reviewing Child Deaths in Scotland

Set up a steering group to develop a national child death review process in Scotland and to identify costs and funding which will be informed by pilot work currently being undertaken (Appendix 8, Tayside pilot). The model includes:

- A multi-agency care pathway and set of standards for use in the event of childhood deaths in Scotland.
- A multi-agency CDR panel to meet to review and collate appropriate data relevant to the death of a child or young person. This is being piloted at Health Board level but without prejudice to other geographical or organisation groupings.
- A pilot of a working dataset allowing:
 - a. appropriate gathering of data
 - b. integration with other existing datasets and
 - c. the ability to feed into national and international data collection.
- A framework of agreed standards for communication with families about the process and outcomes. This would include how, when, and who.

Advantages	Disadvantages
<p>A consistent system across Scotland which enables data collection and analysis, dissemination of themes and informing policy with the potential to reduce child and young people mortality.</p> <p>Informed and sensitive communication with bereaved parents.</p> <p>Putting into practice lessons learned from the pilot of the CDR process.</p>	<p>Time taken to set up a national process.</p>

Recommendation

38. The Child Death Review Working Group recommends Option 3: 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 (see Appendix 8) which will inform the way the system is set up and the most cost effective way of delivering the components.

Child Death Review Group Membership

Dr Kate McKay (Chair)	Senior Medical Officer, Scottish Government
Dr Rob Ainsworth	Forensic Pathologist, NHS Lothian
Dr Vicky Alexander	Consultant Paediatrician, NHS Tayside
Ms Denise Bruce	Crown Office and Procurator Fiscal
Ms Claire Burnett	Office Manager, Royal College of Paediatrics & Child Health
Mr David Crawford	Crown Office and Procurator Fiscal
Dr Julia Egan	Professional Advisor for Public Health, Early Years and Children's Services, Scottish Government
Dr Clair Evans	Paediatric and Perinatal Pathologist, NHS Greater Glasgow and Clyde
Dr Marjorie Johnston	Public Health Registrar, NHS Grampian, seconded to Scottish Government
Dr Martin Kirkpatrick	Consultant Paediatric Neurologist, NHS Tayside
DCI Adrian Lawrie	Police Scotland
Dr Alyson Leslie	School of Education, Social Work and Community Education University of Dundee
Dr John McClure	Scottish Cot Death Trust
Dr Jillian McFadzean	Consultant in Anaesthesia and Intensive Care, NHS Lothian
Dr John O'Dowd	Consultant in Public Health Medicine, NHS Greater Glasgow and Clyde
Dr Rachael Wood	Information Services Division
Mrs Mary Sloan	Child & Maternal Health, Scottish Government
Mr Anthony Christie	Child & Maternal Health, Scottish Government (until October 2013)
Mrs Emily McLean	Child & Maternal Health, Scottish Government (from October 2013)

Role and Remit

To establish if there is a need for a national framework to achieve the following:

1. A system for reviewing child deaths across Scotland in a consistent manner in order to reduce the number of [unexplained] child deaths.
2. The provision of clear learning points from the process which links into SG policy and enables quality improvement across all services.

Objectives

- Review all existing, available data collected by local and national mechanisms across all agencies involved in the investigation and clinical care up to and after the child's death.
- Consider who holds the data and who it can be accessed by and how.
- Review all investigation and audit of child deaths: look at the causes of death and establish what kind of deaths are currently not subject to any formal review process.
- Map the processes involved in investigating and collating information and who carries out this investigation or review.
- Understand the process of audit and governance after child deaths and child death review to examine whether learning, practice and policy change is implemented.
- National and international systems: look at other similar pieces of work being carried out in Scotland and the UK in order not to replicate this work, ie Scottish Paediatric Patient Safety Programme, SUDI process, Clinical Outcomes Review Programme.
- Consider standards for communication and support to families.

The Steering Group will be expected to:

- Review and agree the work plan of the project.
- Oversee the progress of the project and provide support and advice as required.
- Ensure wide communication of the project within individual networks to ensure buy-in from the wider NHS and other stakeholders.
- Sign off the final report.

Resources to support this work:

The Child and Maternal Health Division will oversee and provide secretariat support to the group. Other partners (SUDI /ISD) will provide specific time-limited support.

Epidemiology of child deaths in Scotland

1. Of 398 child deaths in 2011, the majority (60%) occurred in those aged under one year with most of these occurring within the first four weeks of life.⁴ The predominant factors associated with singleton neonatal deaths (ie within the first four weeks of life) are congenital anomalies and factors associated with prematurity, including respiratory disorders.⁹

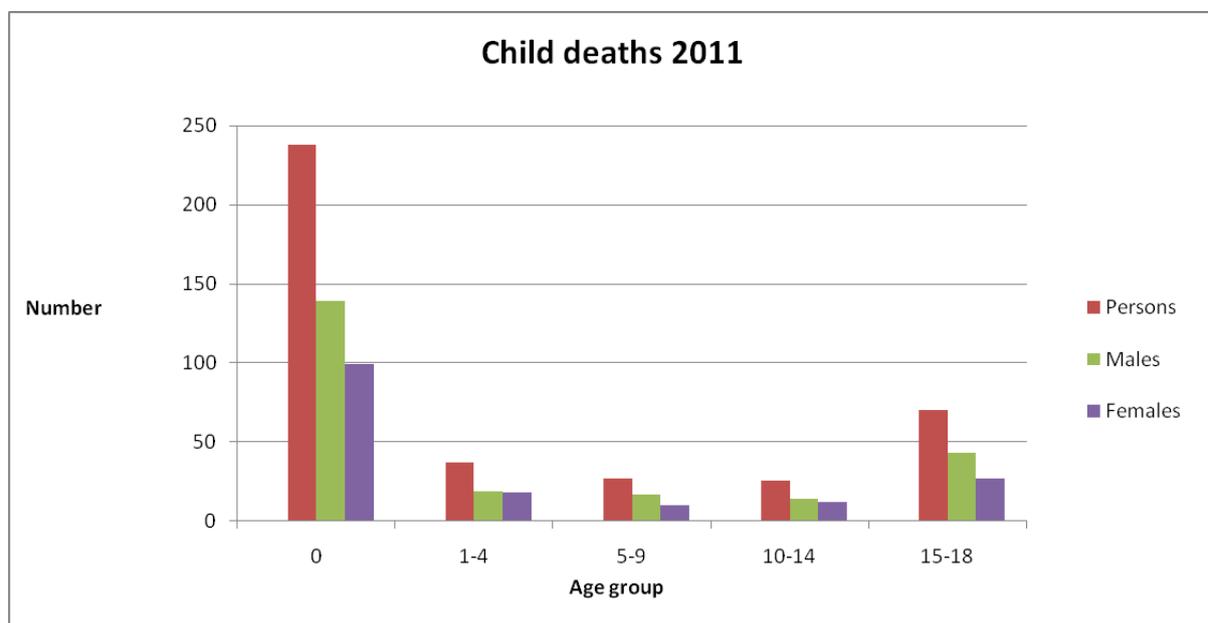


Figure 1: Child deaths in Scotland 2011, by sex. Source: GROS⁴

In children aged between 4 weeks and one year, sudden unexpected death is the most frequent cause of death although the number of deaths from sudden unexpected death in infancy (SUDI) has fallen over the past 15 years.

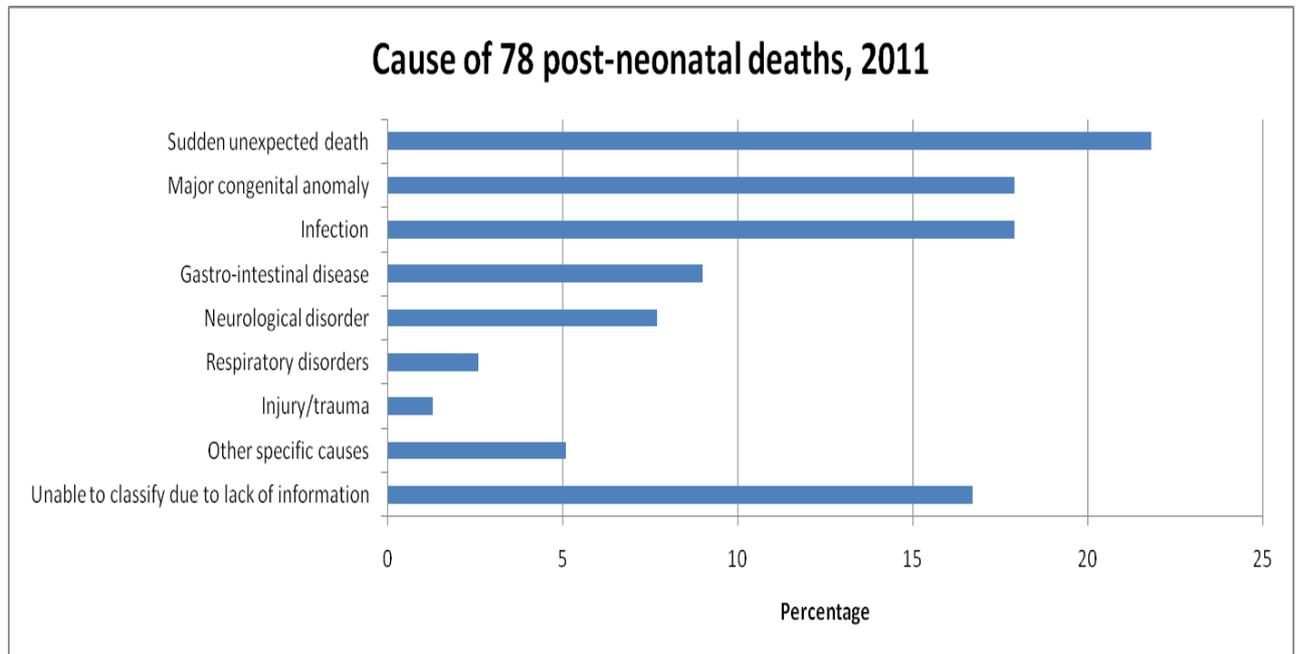
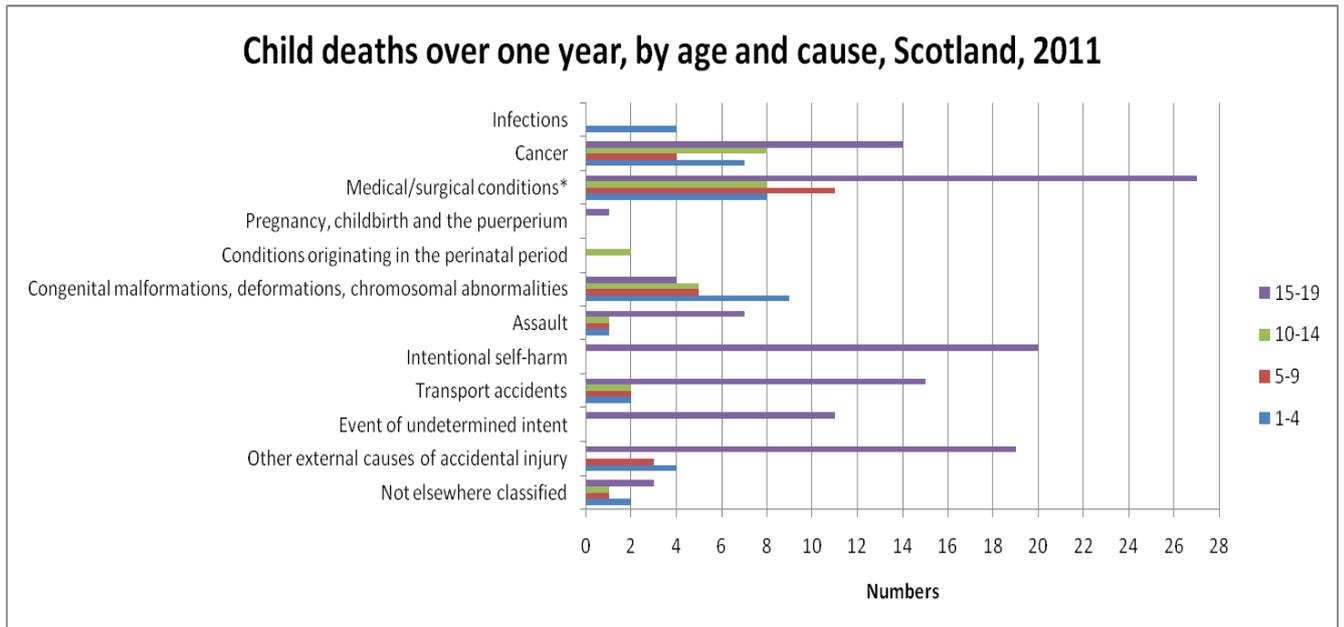


Figure 2: Causes of 78 post-neonatal (occurring after four weeks but before one year of life) deaths, Scotland, 2011. Source: ISD⁹

2. The second largest group of child deaths by age is the 15-18 year old category. Aside from medical and surgical conditions (which have been combined) the largest causes of death in 2011 in the 15-18 year old age group were due to external factors: “intentional self-harm”, followed by “other external causes of accidental death” and “transport accidents” (Figure 3).



* Includes: D50-89 III. Diseases of the blood and blood-forming organs and certain disorders involving the immune mechanism
 E00-90 IV. Endocrine, nutritional and metabolic diseases
 G00-H95 VI-VIII. Diseases of the nervous system and the sense organs
 I00-99 IX. Diseases of the circulatory system
 J00-99 X. Diseases of the respiratory system
 K00-93 XI. Diseases of the digestive system
 L00-99 XII. Diseases of the skin and subcutaneous tissue
 M00-99 XIII. Diseases of the musculoskeletal system and connective tissue
 N00-99 XIV. Diseases of the genitourinary system

Figure 3: Child deaths over one year, by age and cause, Scotland 2011 (note due to data available from GROS deaths in those aged 19 are included in this chart).
 Source: GROS⁴

3. There were nine child homicides in Scotland in 2011/12. The five-year average homicide rate has increased in the last two years, but is still lower than at any other point between 1981 and 2008/09.²⁷

4. All sudden, suspicious, accidental and unexplained deaths must be reported to Procurator Fiscal for investigation.²⁶ There were 190 reports to the Procurator Fiscal during the fiscal year 2011/12 in those aged under 18. This figure is around 51% of deaths in this age group. The majority of reports were for those aged less than one with the next largest category being those aged 16-17. There were 91 recorded Procurator Fiscal investigations completed in the same fiscal year (these may include investigations commenced in previous fiscal years). Very few progress to Fatal Accident Inquiries (FAIs). Over the period 2007 to 2013 there were 19 completed FAIs.

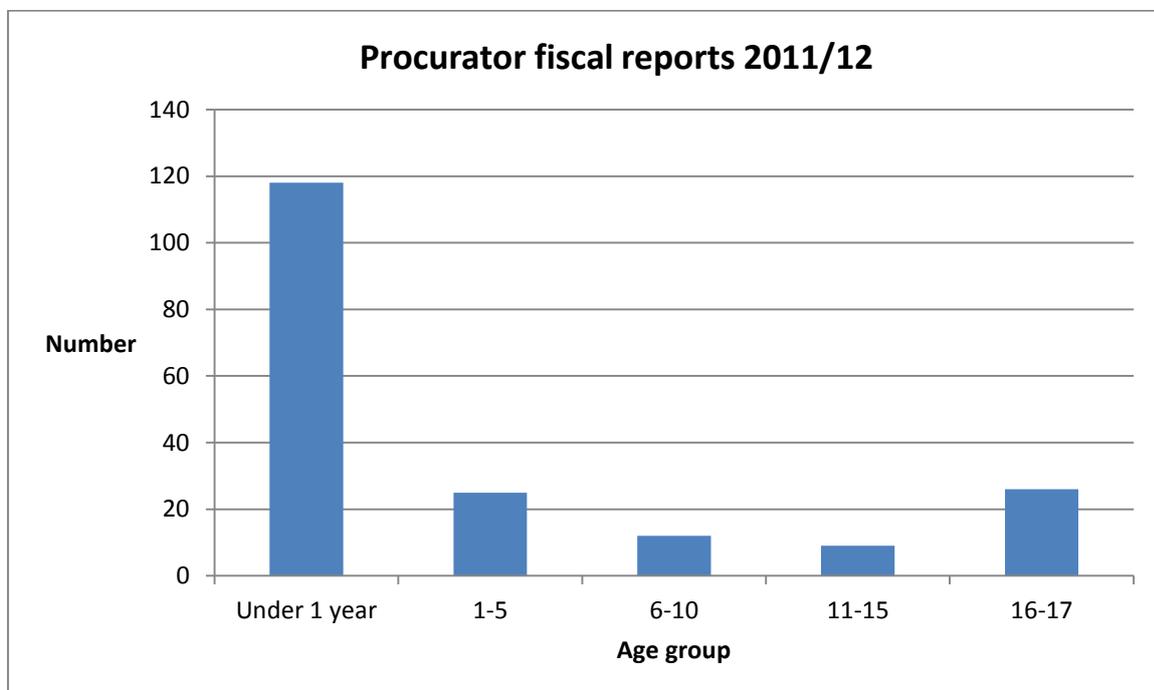


Figure 4: Reports to Procurator Fiscal 2011/12, Scotland, by age group.
Source: ad hoc query to Scottish Fatalities Investigation Unit

5. Differences in the death registration systems used in each nation may have an impact on the comparability of data between nations in the UK. However, National Society for the Prevention of Cruelty to Children analysis found that, in 2011, the rate of deaths due to assault and undetermined intent was highest in Scotland at 5.2 per million, followed by 3.9 per million in Northern Ireland and 3.6 per million in England and Wales. However, in all nations the average rate has decreased since the 1980s. For child suicides in Scotland, the five-year average rate has increased by 77% since 1984, however since 2003 the average rate has been on a downward trend. ²⁵

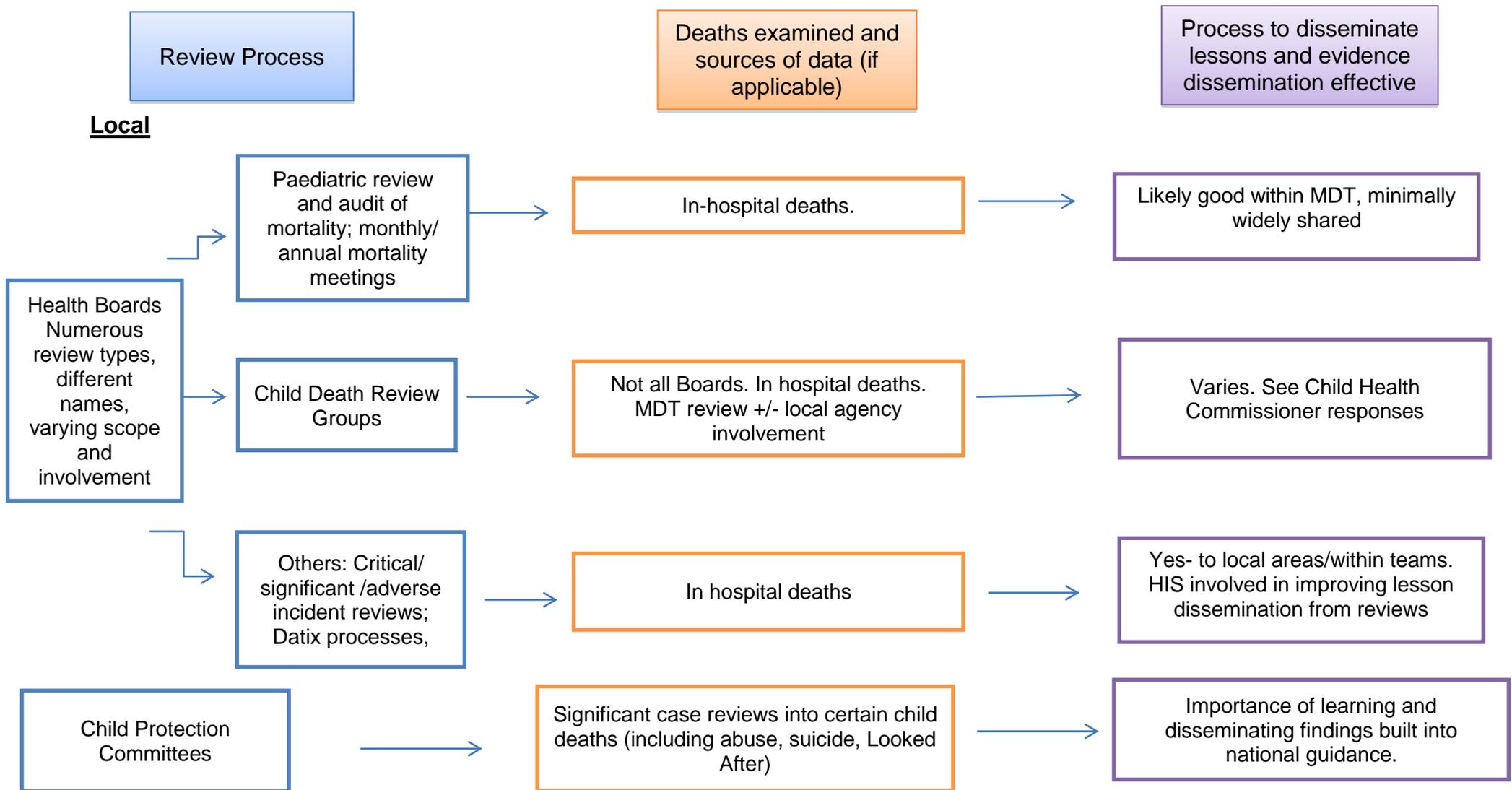
6. Rates of child deaths due to injury have decreased over the past three decades but recent research suggests they may be higher in Scotland compared to England. ²⁷

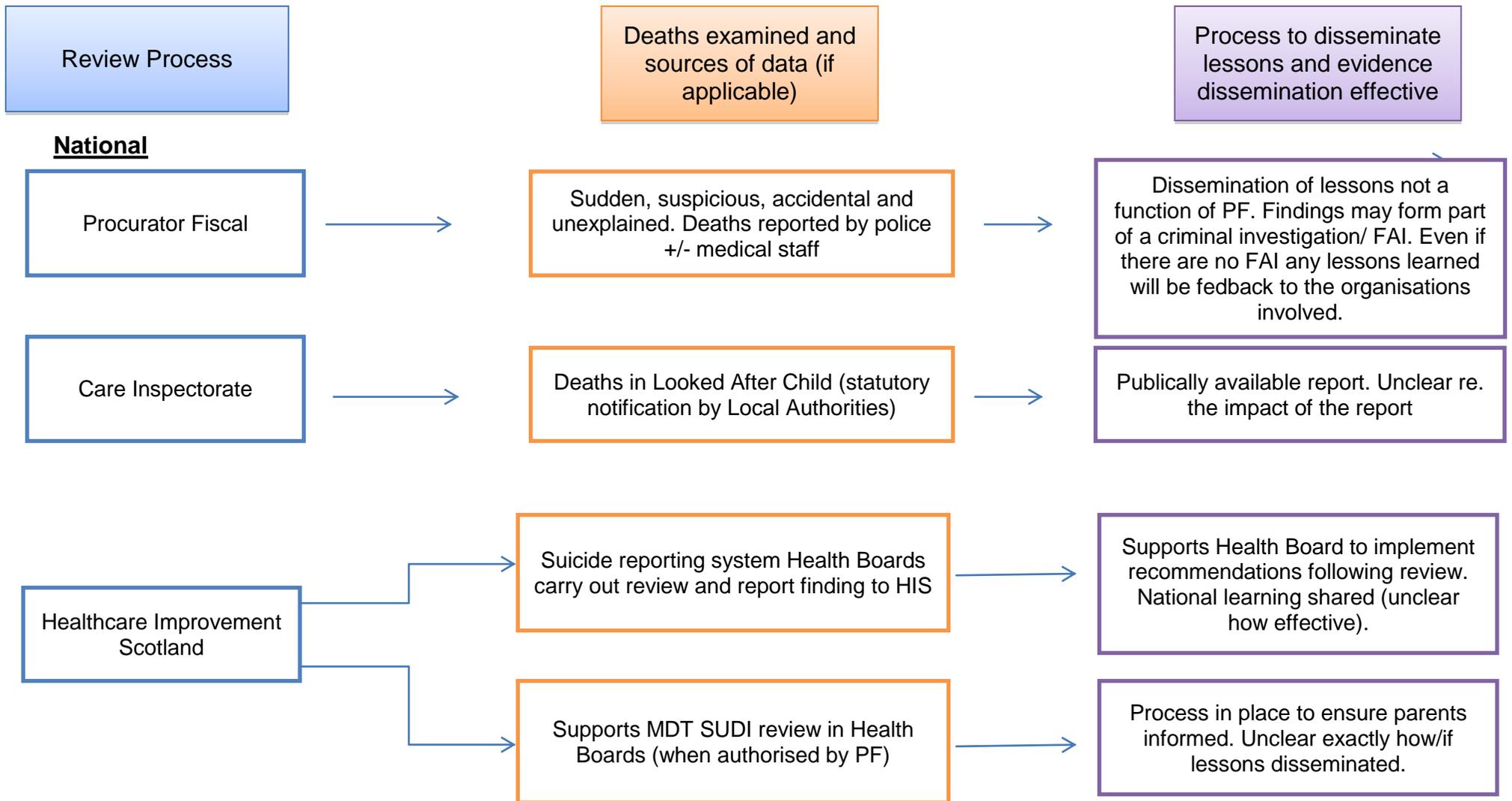
7. There are significant inequalities in deaths in children. There is an association between obesity, smoking and deprivation with stillbirth and infant death, ¹⁰ and evidence has consistently shown a link between socioeconomic status and child mortality ^{12,28}. Deaths in children from injury may have fallen over the thirty years, but this is less so for children from families with lower socioeconomic status. ¹²

Review and surveillance processes in Scotland

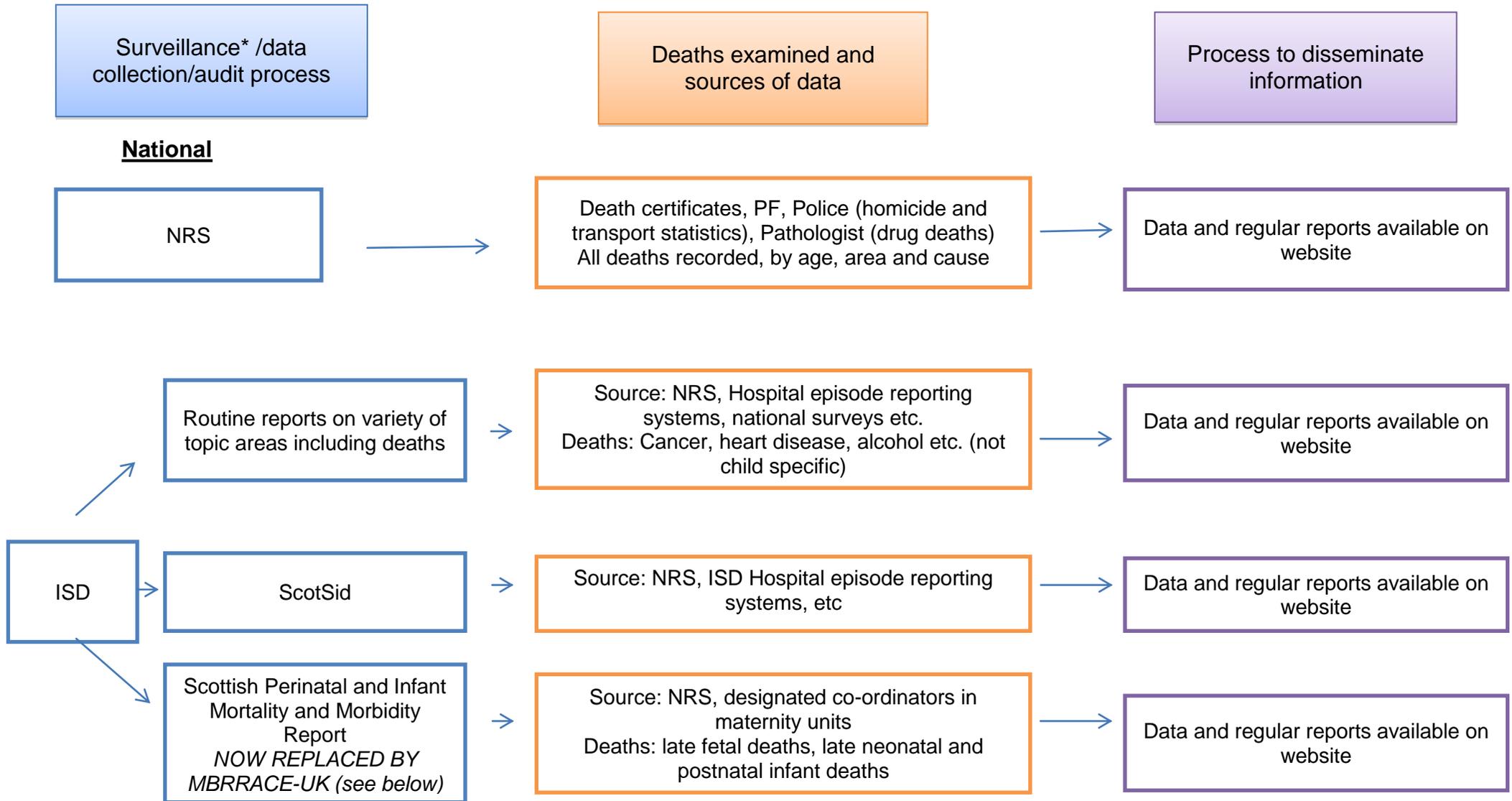
Abbreviations: MDT, multi-disciplinary team; HIS, Healthcare Improvement Scotland; SUDI, Sudden and unexpected death in infancy; NRS, National Records of Scotland; ISD, Information Services Division; PF, Procurator Fiscal; ScotSid, Scottish Suicide Information Database; MBRRACE-UK, Mothers and Babies Reducing Risk through Audit and Confidential Enquiries across the UK

Local and National child death review processes in Scotland diagram

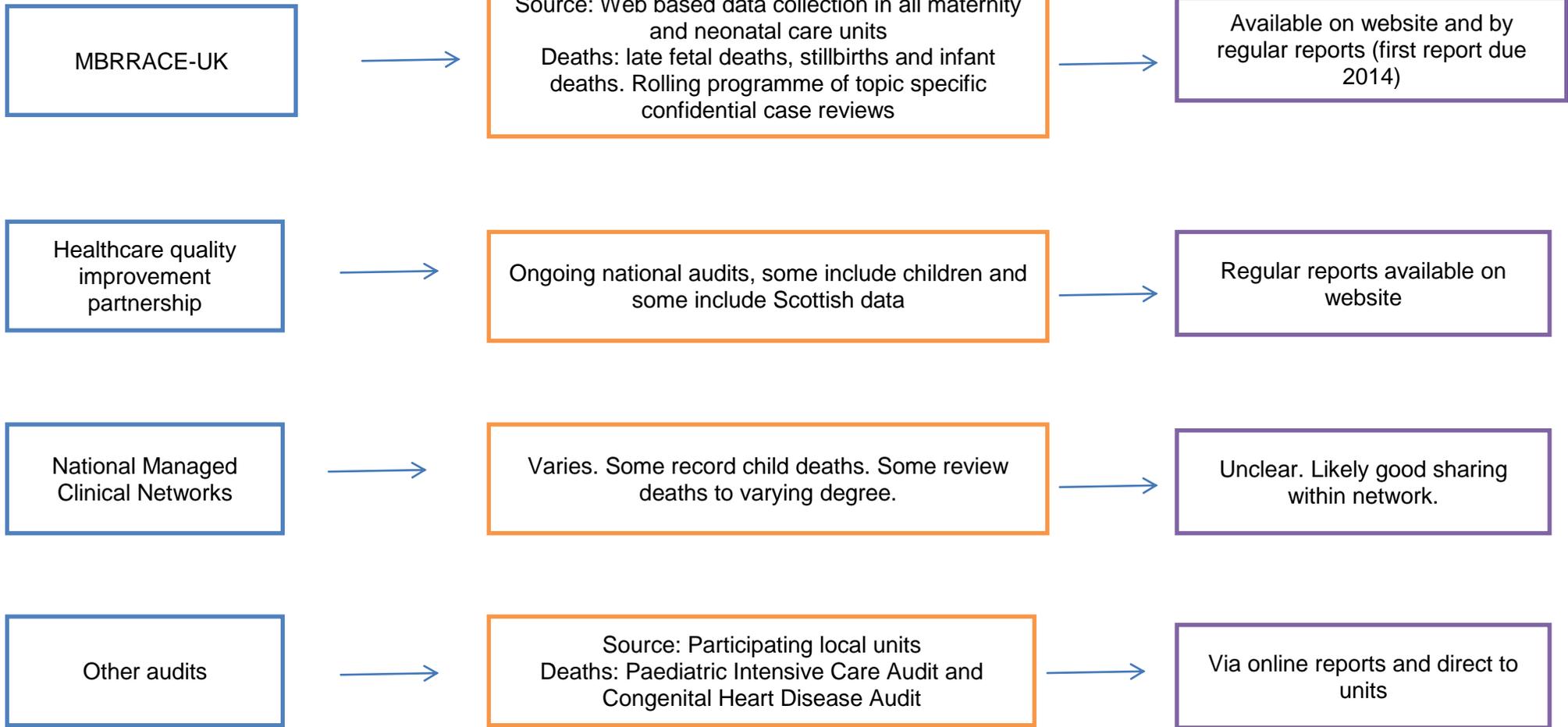




National child death data collection and surveillance systems including audit diagram



Other systems



*Surveillance definition: gathering, analysing, and interpreting data and disseminating findings

Child death review processes- text to accompany above diagrams

1. Interviews with healthcare staff (including Child Health Commissioners, a Paediatric Pathologist, a Consultant in Public Health Medicine and a Paediatrician) and a written survey of all Child Health Commissioners in Scotland reveal there are numerous varied review processes occurring in Health Board areas following the death of a child. Critical/significant/adverse incident reviews occur in all Boards and it appears that lessons learnt are shared effectively within local teams. Some Boards have specific “Child Death Review groups” but these vary in terms of scope, membership and lesson dissemination. Many Boards have regular audits of mortality (including Paediatric review and audit of mortality) and whilst lessons are shared effectively within teams there appears to be less sharing more widely.
2. The diagram also details national level review processes which occur following the death of a child, including investigation by the Procurator Fiscal after certain deaths, review by the Care Inspectorate following the death of a looked after child, specific suicide and sudden and unexpected deaths in infancy (SUDI) reviews led by Healthcare Improvement Scotland (HIS) and the significant case reviews carried out by local multi-agency child protection committees for certain child deaths. Common to most of these reviews is the lack of evidence that lessons learned are effectively shared more widely.
3. The SUDI Review²⁹ is a multidisciplinary case discussion which is held after the final post-mortem examination report is available which may be several months after the infant has died. The process involves assessing the circumstances of the death, including detecting possible causes or contributing factors, with the aim of identifying what lessons can be learned. Additionally, support for the family is considered, particularly in relation to future pregnancies.
4. The group is generally made up of a paediatrician, pathologist, GP, health visitor, community midwife, social worker and any other professional relevant to that particular infant death. Boards have a responsibility to ensure that the meeting takes place with the appropriate professional and that the SUDI Review summary sheet is completed and sent to HIS.
5. No Boards have a specific multi-agency group which reviews all child deaths. The closest to this are the Significant Case Reviews carried out by the local Child Protection Committees. The Scottish Government requires every Local Authority area to have a Child Protection Committee, bringing together key agencies that work with children and their families. Child Protection Committees do not have a statutory basis, however their role and functions are set out in the national guidance. They consist of representatives from a range of backgrounds including the police, health services, local authorities, children services and relevant voluntary agencies. Child Protection Committees have the overall strategic role for the continuous improvement of child protection

policy and practice in their local areas. This includes carrying out Significant Case Reviews after significant events. These significant events include child deaths where:

- Abuse or neglect is known or suspected to be a factor in the child's death
- The child is on, or has been on the Child Protection Register or a sibling is or was on the Child Protection Register
- The death is by suicide or accidental death
- The death is by alleged murder, culpable homicide, reckless conduct, or an act of violence
- The child was Looked After by the Local Authority³⁰

6. The importance of learning from significant case reviews is built into national guidance³⁰. However, it is unclear how effective this is as there is no evidence either way.

Data collection and surveillance systems

7. The diagram details the work carried out by the National Records of Scotland (NRS) in collecting data on the number and cause of deaths in Scotland. The Information Services Division (ISD) carries out a number of surveillance roles and reports may include child deaths. Additionally it hosts the Scottish Suicide Information Database which will include child suicides when they occur.

8. The UK wide MBRRACE-UK (Mothers and Babies Reducing Risk through Audit and Confidential Enquiries across the UK) collaboration was appointed by the Healthcare Quality Improvement Partnership (HQIP) to provide a national programme of work investigating maternal deaths, stillbirths and infant deaths, including the Confidential Enquiry into Maternal Deaths¹⁵. MBRRACE-UK will collect data from all maternity and neonatal care units about maternal deaths, stillbirths and infant deaths.

9. MBRRACE-UK replaces the ISD Scottish Stillbirth and Infant Death Survey. All units in Scotland are now registered for the web based data collection process. Scottish data will be separately analysed in addition to the UK report and will be used to inform the new patient safety programme in maternity services – the Maternity and Children's Quality Improvement Collaborative³ - and the Early Years Collaborative as well as to inform units at a local level².

10. There are other national and local audits occurring which may include child deaths, for example audits of various health issues from HQIP and from the national and local managed clinical networks. Reports are often made available online but the extent to which learning points or issues are disseminated more widely is unclear.

Child Health Commissioner responses

In May 2013, the Child Health Commissioners within each territorial Health Board in Scotland were sent a questionnaire survey with regards to child death review processes in their area. 12 out of the 14 territorial NHS Boards participated in this Child Death Review Audit. The questions are below with a summary of the responses.

OPERATIONAL ASPECTS
Does your Health Board area have a child death review group?
<p>3 Boards do have a child death review group 8 Boards do not 1 Board was unsure.</p> <p>Comments from Boards who said no or were unsure:</p> <ul style="list-style-type: none"> • 2 Boards reported not formally called that but have a multi-disciplinary process • One Board is developing a morbidity/mortality review meeting within paediatrics which will fulfil some of the roles of such a group: another reported all hospital deaths are reviewed through a mortality review process • One Board has a Significant Clinical Incident Review Group, all paediatric deaths in the children's hospital are reviewed by the Chair of PRAM (Paediatric review and audit of mortality) and any unexpected paediatric deaths trigger a review under Significant Clinical Incident process, the Board's child protection forum examines Significant Case Reviews where there is a child protection issue and clinical governance groups examine Datix reports • One Board reported cases are looked at individually by the paediatric named consultant • 4 Boards reported child protection committees would instigate reviews where appropriate
If yes can you describe its role, remit and membership?
<p>1 Board reported annual multi-disciplinary childhood mortality meeting to review all post-neonatal deaths in infancy and childhood 3 Boards reported meetings took place to learn lessons 1 Board reported the remit was to review any unexpected child death in relation to child protection. 1 Board reported role is to ensure governance of child protection. 2 Boards reported Significant Incident procedure would be followed. 1 Board reported PRAMS monthly meetings – cases are selected and presented for discussion. Chair of PRAMS also leads the local risk group and links PRAMS' identified issues into the risk agenda. 1 Board reported its perinatal mortality group is a multi-disciplinary child death review group. Membership varied – medical staff, paediatricians; head of paediatric services; paediatric nursing, A&E, anaesthetic staff; regional PICU colleagues, child protection, pathologist, clinical directors, consultant relevant to specialty, clinical risk manager, critical incident response group involvement, other members identified relevant to individual cases</p>

Do you have a Paediatric review and audit of mortality (PRAM) in place?
8 Boards have a PRAM in place 4 Boards do not
Within the Paediatric setting, do any other reviews occur following a child death?
Boards reported other reviews occur when appropriate: <ul style="list-style-type: none"> • SUDI (Sudden Unexpected Death in Infancy) reviews • SUDiC (Sudden Unexpected Death in Children) • Child Death Review processes • Child protection procedures • Perinatal reviews • Significant case review/event, Adverse Event Review • PICU reviews • Individual service reviews • DATIX process • Regular departmental/multi-professional meetings, multi-disciplinary/multi-agency reviews, de-brief meetings, peer review meetings • Maternity Services Clinical Governance Forum • Reported via MBRRACE
If yes can you describe these in terms of their roles, remits and membership?
Role and remit as per: <ul style="list-style-type: none"> • Child protection procedures • SUDI/SUDiC protocols • Perinatal mortality meetings • Child death review process • Significant case review process/significant event analysis meeting to discuss learning points and put action plans in place • De-brief meetings for staff catharsis and fact-finding to inform significant event review • Feedback from PICU • Establish events and identify/share learning points across agencies Membership includes staff concerned, SUDI paediatrician, GP, pathologist, paediatric and obstetric consultants, associated nursing and midwifery staff, obstetricians, neonatal nurses, multi-disciplinary, consultant who leads on quality and safety, emergency medicine, anaesthetics, PICU, primary care staff, social workers, education, police, procurator fiscal, public health
Out with the Paediatric setting are you aware of any specific reviews occurring following a child death, for example in Psychiatry following a child suicide?
6 Boards reported specific reviews occurred, eg Significant Clinical Incident Review Group, Significant Case Reviews for child protection, Initial Case Review or Serious Case Review for child on child protection register/LAC or known child protection concerns, reviews led by specialist children's services, reviews led by the Ambulance Service, CAMHS Mental Health Critical Incident/Pathway following Suicide/Unexplained Death reporting processes. 4 Boards reported no specific reviews occurred 1 Board reported no child suicides
If yes can you describe these in terms of their role, remit and membership?
Adverse significant event policy, significant case review if potential child protection issue, Mental Health Critical Incident Review, family and community support,

<p>bereavement counselling, Critical Incident Review, Suicide Review Policy</p> <p>Role and remit as per Scottish Government guidance for Child Protection.</p> <p>Membership includes lead clinician determined by the circumstances, CAMHS, psychology, educational psychology, Associate Medical Director, Clinical Director, General Manager</p>
<p>Are child deaths which are “expected” (for example following a long illness) routinely reviewed in your Health Board?</p>
<p>4 Boards reported “expected” child deaths are routinely reviewed 6 Boards reported they are not 1 Board was unsure and 1 Board was unsure for acute services.</p>
<p>If yes can you describe these reviews in terms of their role, remit and membership if not already covered above?</p>
<p>Annual mortality meeting, as per Child Death Review process, PRAMS, Significant Event Analysis meetings, exploring need to set up Child Death Review Group.</p>
<p>Are there any multi-agency groups (involving Health, Social Work, the Police and/or others) which review child deaths?</p>
<p>9 Boards reported yes 2 Boards reported no</p>
<p>If yes can you describe these in terms of their role, remit and membership if not already covered above?</p>
<p>Child protection committee review sub-group, significant/serious case reviews, child protection committees, formal meetings to discuss child protection deaths and SUDI.</p> <p>Membership can be multi-disciplinary including health, social work, police, lead paediatricians for child protection</p>
<p>Does your Health Board area have any other processes in place to review child deaths not covered here?</p>
<p>3 Boards reported yes 8 Boards reported no</p>
<p>If yes, can you describe these in terms of their role, remit and membership?</p>
<p>Potentially as part of HSMR (Hospital Standardised Mortality Ratios) patient safety programme, other mechanisms such as significant untoward incident investigation, discussed at Clinical Governance and Risk Management Group, SUDI</p> <p>Membership of the groups includes lead paediatrician, pharmacist, dental, GP, Scottish Patient Safety Programme representative, Out-of-Hours, paramedics, social work, A&E, primary/secondary care, pathologist, SUDI paediatrician/review officer</p>
<p>STRATEGIC ASPECTS</p>
<p>Are the lessons identified from any of the reviews listed above disseminated and acted upon by the relevant agency involved?</p>
<p>10 Boards reported yes adding:</p> <ul style="list-style-type: none"> • As per child death review process and Child Protection Committee review subgroup • definite room for improvement • reported widely and action plans drawn up and reviewed to ensure implementation • recommendations circulated to specialist children’s service managers to

<p>discuss with staff and implement</p> <ul style="list-style-type: none"> • actions implemented by child protection groups • recommendations reviewed to include consideration of wider learning, action plans generated and tracked for completion • paediatric patient safety bulletin • reports reviewed by local quality improvement teams, child protection or serious incident reports considered by Board Joint Management Team and followed up. Actions form an Action Plan • Learning from Significant Case Reviews shared by relevant agency. Recommendations discussed at child protection executive group where actions will be agreed
<p>Are you aware of lessons being shared with <i>other</i> areas/agencies after any of the reviews listed above?</p>
<p>7 Boards reported yes 1 Board reported no 1 Board was unsure 2 Boards reported yes but not for all reviews Lessons were shared with Child Protection Committees and CPC Review subgroup, Clinical Management Teams, Multidisciplinary Teams</p>
<p>If yes, which reviews does this occur for, how are lessons shared and who are they shared with?</p> <ul style="list-style-type: none"> • SUDI, occasionally other deaths if significant point identified • SUDI learning points correlated and disseminated via Healthcare Improvement Scotland Health takes the lead role in reviewing all child deaths, anonymised report discussed at Child Protection Committee review subgroup. Learning shared with staff involved • As part of Child Protection Committee process • Recommendations circulated to Director of Women and Children's Directorate, Child Protection, Director and Clinical Director of sector in which incident occurred • Multi-agency or multi-disciplinary reviews. Significant case review lessons shared with local authorities or multi-agency • According to individual circumstances. • Newsletter for GPs • Shared via Clinical Governance and Risk Management Group meetings • Child protection reviews shared with social work and police following child protection guidelines and procedures • Serious Case Review findings/recommendations shared with Healthcare Governance and Risk Management committee. • Procurator Fiscal and frontline staff may also be appraised • Departmental meetings • Child protection training updated and specific staff group training needs identified and training programmes implemented where required • Lessons shared via Child Protection Committee for dissemination to key staff within each agency.

Do you feel lessons learned from child deaths are *effectively* disseminated to other areas and agencies (for example changes are made in response to learning points identified)?

6 Boards said yes

1 Board said no

2 Boards were unsure

One Board reported Yes for specialist children's services, currently being audited for child protection and no, could improve, for acute services.

If yes, can you describe for which reviews this occurs and give examples as to what enables the process to be effective?

- One Board reported learning lessons from avoidable accidents eg dangers of loops on blinds, co-sleeping and raising awareness or making changes.
- One Board reported all child deaths were reviewed or discussed by the Child Protection Committee review sub-group. Lessons learned/actions taken included improving the communication pathway
- One Board reported within specialist children's services, recommendations are circulated within the Board and an audit of implementing recommendations is in development.
- Three Boards reported lessons from Significant Case Reviews are shared and action plans developed - multidisciplinary.
- One Board reported lessons learned from suicide reviews are circulated to Operational Management Groups who then consider and agree how best to implement/disseminate learning. Child Protection Serious Case Reviews are shared with all agencies, action plans are monitored and reviewed.
- One Board reported following a high profile review, its procedure for the Unseen Child and failure to attend appointments had been reviewed.

If lessons are not shared/ not effectively shared, do you feel that there is a need for a process to ensure that this does occur?

9 Boards responded yes with comments:

- Useful to have central collation of findings so patterns can be identified
- Ensure support in place for the family and timely identification of any child protection concerns
- Multiagency learning points, for child protection and other child deaths, eg those with chronic health needs often had social care involvement. Are we good at changing things to prevent children dying in accidents?
- Joint debriefs help with learning and with supporting staff as well as improving feedback to parents. Child deaths would benefit from SUDI approach – families appreciate an agreed pathway for information and support that indicates they are not alone and offers hope that others have survived the loss of a child
- Standardised process would be welcome
- Learning and improvement to better manage risk
- A process to ensure learning points and actions plans are acted on to potentially improve children's services and to facilitate feedback/counselling with parents would be helpful
- There may be value in an overarching group to ensure that everything that could have been done has been done across all relevant agencies
- A nationally agreed process would be helpful.

1 Board was unsure

Finally, do you have any comments not covered by the questions above? In particular do you have any comment on the proposal to consider setting up a Child Death Review process in Scotland?

Comments included:

- Strongly support CDR process – to set best practice regarding inter-agency analysis of all child deaths, not only those where significant case reviews are instigated for child protection
- A nationally agreed procedure and standards would be helpful
- There should be local and national components
- A CDR process in Scotland would potentially provide significant learning points for all agencies involved which would improve children’s services in Scotland
- The process could review expected and unexpected deaths, and also look at child deaths in the community which involve the Child Protection team
- People who know the family well should be involved
- The CDR process in the United States could be useful in Scotland
- Would welcome guidance on involving families in CDR process
- CHAS holds debrief sessions – currently discussing models of care with them. CHAS should be involved
- Consideration should be given to potential effect of the Managed Clinical Networks that may result in children dying in Health Board areas other than their place of residence – this could affect who is involved in the review of deaths and the legal processes
- The needs of families who suffer the death of an adolescent may be relevant, especially in relation to suicide and risk behaviour but the death may present to adult services
- Essential to have administrative resource allocated to ensure the process works effectively
- Needs to be a balance between child protection procedures and other aspects – SUDI work could be taken into account

Effectiveness and structure of Child Death Review Process: literature review

1. This section details the results of a non-systematic scoping review of the literature carried out in April 2013 and designed to rapidly appraise the available evidence as to the effectiveness and most appropriate structure of a child death review process.
2. In April 2008, new procedures for reviewing child deaths were instituted across England and each local authority was required to establish a child death overview panel to review all deaths of children from birth to 18 years. There are also well-documented processes in countries such as the United States^{13,18,20,33,38} and New Zealand.
3. There is no widely accepted definition or approach taken towards carrying out a child death review. However, the process tends to involve a multiagency review of child deaths with the aim of better understanding how and why a child dies, and the findings being used to take action to prevent other deaths.
4. Evidence suggests that having a robust child death review process can be an effective way of identifying and addressing preventable factors.^{31,32,33,34} One paper drew together numerous examples of the benefits of a child death review process demonstrating it can positively influence policy and legislation, change organisational structures and practice, mobilise communities, strengthen individual knowledge and skills, educate communities and influence individual case management³¹.
5. A comprehensive overview of the approaches taken in reviewing child deaths was carried out by the Dartington Social Research Unit on behalf of the Scottish Executive in 2005.³⁵ The report summarises the features of a good system, and these include having political and senior professional backing, having clarity over what the review is seeking to do and clarity over how it fits in with other agencies and investigations (for example police investigations). Additionally it stated that the recommendations made following a review should be realistic, useful and disseminated widely.
6. A report by the Confidential Enquiry into Maternal and Child Health (CEMACH) highlighted some areas of importance in relation to the new child death review responsibilities arising in England as a result of Chapter 7 of “Working Together to Safeguard Children” in 2008. Chapter 7 details that there should be in depth review of all unexpected child deaths.* CEMACH had previously found that there were avoidable factors in around half of deaths falling outside those which would be

* Deaths can be categorised as expected or unexpected. An unexpected death is “the death of an infant or child (less than 18 years old) which was not anticipated as a significant possibility for example, 24 hours before the death; or where there was a similarly unexpected collapse or incident leading to or precipitating the events which lead to the death.”³⁸

classified as being “unexpected” and therefore recommend that as many child deaths as possible should be reviewed in as much depth as possible¹⁷.

7. Additionally, CEMACH had found that multidisciplinary panels with full access to case notes were essential for the identification of avoidable factors. The independence of the panel was highlighted as a key factor in enabling it to carry out its duties effectively³⁶.

8. The CEMACH statement about multi-disciplinary panels was also made in a mixed methods study of early Child Death Review panels in England³⁷. It also reflects the recommendations of the National Maternal and Child Health Center for Child Death Review in the US³⁸. The importance of a degree of independence of the process was highlighted in another paper, which stated that whilst having panel members with local experience is useful, independence can be achieved through having for example an independent chair³².

9. One US study quoted a number of anecdotal pieces of evidence of the impact of effectively disseminating the recommendations following a child death review, for example a child death review team worked with industry to place warning labels on large buckets following a series of child drownings. However, it also found that child death review teams were better at assessing problems than proposing effective recommendations³³.

10. Limitations highlighted in a non-systematic review paper examining the US system included child death review teams having insufficient resource to carry out their role and the lack of formal criteria by which the reviews may be evaluated. The paper also discusses the importance of defining whether a child death review is carried out as part of the investigative process into a child’s death or as a separate retrospective review not feeding in to the investigation. The benefits or drawbacks of either approach are not discussed³³.

Child Death Overview Panels (CDOP) in England

Overview of “Working Together to Safeguard Children: A guide to inter-agency working to safeguard and promote the welfare of children, March 2013”¹⁶.

1. CDOPs became a statutory function in April 2008 because of Section 13 of the Children Act 2004 in England required each local authority to establish a Local Safeguarding Children Board (LSCB) for their area. The Act specified the organisations and individuals which should be represented on LSCBs. A LSCB is responsible for developing, monitoring and reviewing child protection policy and procedures, practice issues and making sure training is available to everyone working with children. This includes ensuring that a review of each death of a child normally resident in the LSCB’s area is undertaken by a Child Death Overview Panel (CDOP).
2. The objective of the child death review process is not to allocate blame, but to learn lessons and therefore help to prevent further such child deaths (if the death contained preventable factors). The responsibility for determining the cause of death rests with the coroner or the doctor who signs the medical certificate of the cause of death. It is not the responsibility of the CDOP.
3. The LSCB is responsible for ensuring that a review of each death of a child normally resident in the LSCB’s area is undertaken by a CDOP. This remains the case if a child has been in contact with organisations from more than one LSCB area prior to their death (although these other organisations should cooperate in undertaking the review). For looked after children, the LSCB of the Local Authority looking after the child will take the lead for conducting the child death review. The LSCB should also ensure they use other avenues such as the media to find out when a child normally resident in their area dies abroad.
4. The CDOP fixed core membership will be made up of those from the organisations represented on the LSCB. There is flexibility to co-opt other professionals for certain types of death when relevant. There should be a Public Health and Child Health professional on the CDOP and the chair should be the LSCB Chair’s representative. The chair should not be involved directly in providing services to children and families in the area.
5. One or more LSCBs can choose to share a CDOP. CDOPs responsible for reviewing deaths from larger populations are better able to identify significant recurrent contributory factors.
6. The functions of the CDOP include:
 - “reviewing all child deaths up to the age of 18, excluding those babies who are stillborn and planned terminations of pregnancy carried out within the law;
 - collecting and collating information on each child and seeking relevant information from professionals and, where appropriate, family members;

- discussing each child's case, and providing relevant information or any specific actions related to individual families to those professionals who are involved directly with the family so that they, in turn, can convey this information in a sensitive manner to the family;
- determining whether the death was deemed preventable, that is, those deaths in which modifiable factors may have contributed to the death and decide what, if any, actions could be taken to prevent future such deaths;
- making recommendations to the LSCB or other relevant bodies promptly so that action can be taken to prevent future such deaths where possible;
- identifying patterns or trends in local data and reporting these to the LSCB;
- where a suspicion arises that neglect or abuse may have been a factor in the child's death, referring a case back to the LSCB Chair for consideration of whether a Serious Case Review is required;
- agreeing local procedures for responding to unexpected deaths of children; and cooperating with regional and national initiatives – for example, with the National Clinical Outcome Review Programme – to identify lessons on the prevention of child deaths.”¹⁶

Report on visit to Merseyside Child Death Overview Panel, July 2013

1. As part of the Child Death Review scoping process, Dr Kate McKay and Dr Marjorie Johnston visited the Merseyside Child Death Overview Panel (MCDOP) team in Liverpool in July 2013. The following is a summary of the findings of that meeting. The meeting was hosted by Irene Wright, CDOP manager for the Liverpool LSCB and Merseyside CDOP. Some of the summary has been supplemented by visiting the Liverpool Local Safeguarding Children Board (LSCB) website.³⁹

2. The details of the CDOP process will vary in every area and there is scope for the process to fit round the needs of that area. For example the frequency of the CDOP meetings and whether LSCBs choose to merge with surrounding areas may depend on the number of deaths occurring in an area. The following describes the process and organisation of the Merseyside CDOP.

History of the Merseyside CDOP

3. Each of the five Merseyside LSCBs set up their own CDOPs which functioned until 2011. In April 2011 four Merseyside CDOPs, Liverpool, St Helens, Sefton and Wirral merged to form the Merseyside CDOP (MCDOP). The fifth is considering joining this larger CDOP.

CDOP process

Background

4. The MCDOP has one CDOP manager. Each separate area within the MCDOP has a part-time administrator with one overall whole time administrative manager.

5. There were 85 deaths reviewed last year. There are monthly panel meetings, reviewing around 6 to 9 deaths each. There is no meeting in August and December to account for staff holidays. As the majority of deaths are neonatal, every third meeting is a neonatal death CDOP (with current plans to make this every second meeting).

Process

6. There are Child Death Paediatric Liaison Nurses within local hospitals. Part of their role is to ensure that each child death is reported to the CDOP. In addition to this they inform the community and other hospitals to allow them to modify their records accordingly and in a timely manner. If the death occurs in the community there is a process in place whereby the "safeguarding lead" within a GP practice will inform the Paediatric Liaison Nurse.

7. The Paediatric Liaison Nurse informs the CDOP by filling in a specific form online on the "Sentinel system" (see below for more details). This notifies the CDOP

team who then notify a number of relevant agencies via email and ask them to complete an agency return on Sentinel. This form is 17 pages long and contains detailed information about all factors relating to the death, including family factors. The majority of the form involves selecting pre-determined options and there is space available for free-text completion.

8. The agencies required to complete the form vary depending on the type of death. For neonatal deaths it will include social care, General Practice, secondary care and the police. For non-neonatal deaths, youth offending services and mental health are also included. The agencies will be given the details of family members where possible, allowing them to check whether they have had any contact with the family, as well as the child.

9. The CDOP team then merge all agency returns into a single report for the CDOP panel to view. Panel members are emailed a notification and case number and log on to a secure server where they can read the report in advance of the meeting.

Panel members

10. In the MCDOP, the meetings are chaired by a Consultant in Public Health. There tends to be 12-16 panel members. They have a fixed core membership to review cases, with flexibility to co-opt other relevant professionals as and when appropriate. The members are:

- Consultants in Public Health
- Consultant Paediatricians (Neonatologists for the neonatal CDOPs)
- Legal Services
- Children's Services
 - Social Care
 - Education
- Designated Nurse
- Merseyside Police
- CDOP/Specialist Nurse
- Bereavement Services
- Lay Members (x2)

The CDOP meeting

11. CDOP panel meetings last around three hours. The case is summarised and presented to the group. An analysis proforma is used to guide panel members with the aim being to decide whether there are modifiable or non-modifiable factors involved in the child's death. If there are modifiable factors then recommendations are put in place to attempt to address these.

Systems: Sentinel

12. This system was developed by the MCDOP with a private provider. It allows the completion and submission of the initial notification form by the Paediatric Liaison

Nurse and generates a case number (see below for more details). It is the system where each agency completes and submits the agency return form. It is also where the completed analysis proforma is submitted after the CDOP panel meet. It can provide additional benefits - for example the Paediatric Liaison Nurse can tick an option to let other agencies know of the child's death.

13. Information sharing agreements and safeguards were put in place prior to Sentinel being used for the CDOP process. For data security there is an audit trail showing who has accessed a particular file. Training was provided by the CDOP manager and administrative manager to all agencies involved in completing the Sentinel forms.

14. The system can provide simple quantitative analysis of the data entered. The development of this feature is still in progress. The qualitative aspects of the data collection form are used to inform the report which goes to the CDOP panel. This data do not get collated at a national level as this would be too difficult to analyse. However, they are helpful for informing the report.

15. As the form is online, any revisions can be made immediately and the updated form will be immediately in use for the next user.

16. This is a system developed by MCDOP, however other areas in England are showing interest in using it.

Funding requirements

17. This section is in no way deemed complete and is drawn from discussions with the MCDOP coordinator. Specific costings are not provided.

18. In order for the process to be successful, funding is required for:

- Dedicated CDOP coordinator and administrative support (in this case for an area in which around 85 deaths per year occur there is requirement for one CDOP coordinator, one administrative manager and four part time administrators)
- IT system which allows notification of a child's death, the collection of all relevant data, which is secure, which ensures relevant individuals and agencies are notified of a new case report, and from which data can be readily drawn for analysis
- Protected time for panel members - not only for CDOP meetings but time to read documents in advance of meetings.

19. Additional desirable aspects for which funding would be required:

- Psychological support for panel members

20. It is assumed there would be no other capital costs (e.g. existing building space can be used to house the team). There may be cost savings in combining local areas into a regional panel, however we do not have evidence for this.

21. This does not include recurrent costs such as for paper and other consumables.

Governance

22. The MCDOP produces a quarterly and annual report which is made available to all areas. Each council area has a CDOP sub-group to scrutinise their performance. There is performance management by the LSCB.

23. The Department for Education are notified of all reviews and do a cross-check of death notifications. The Department for Education produce a regular report which combines data from all CDOP returns nationally.

24. The Department for Education also has a CDOP contacts list which allows CDOPs to contact other CDOPs. There is no formal mechanism for sharing lessons but if a modifiable factor is identified which could have national implications it can be shared with other CDOPs through this route.

25. There is no formal national level review or inspection of CDOPs (although they may be part of Ofsted reviews of LSCBs).

Links to other reviews

26. The MCDOP manager did not feel that there was any way of adding the CDOP process on to existing child death review processes for example health reviews, as these reviews vary significantly from area to area. Having a separate child death review process is felt to be more effective.

27. There is no requirement for other agencies to share results of their internal reviews - for example hospital department critical incident reviews - although most do. The panel do not have powers to demand to see these reviews and it was felt that having these powers may be helpful.

28. If there is a serious case review or criminal investigation the CDOP will be suspended until these are complete.

Other points

- The panel members, including the chair, are not necessarily independent. The MCDOP manager gave an example where having by chance a Paediatrician from another area on a review panel meant that they highlighted a concern with the care provided and perhaps this may not have occurred if the Paediatrician had come from that particular area.
- A benefit of a merged CDOP is that it allows there to be a rota for panel members - for example there are three paediatricians who only need to attend two non-neonatal CDOPs per year. This assists with continuity and also may help reduce staff burnout.
- The MCDOP have arranged for psychological support to be available to panel members if required. This is thought to be very important.

- Panel members feeling able to challenge any aspect of the review process is seen as being crucial to ensuring modifiable factors are not missed.
- One of the local Coroners is a very positive force and will use his powers to gain additional information if the panel itself has not managed. For example he has ensured GPs complete the agency return form, even when they have asked to be paid for it. Therefore it may be possible to use existing powers to strengthen the child death review panel's ability to gain information.
- There is no formal mechanism to re-visit the recommendations made to check that a particular agency or body has made changes with regards to modifiable factors identified in a child's death.

Tayside Pilot of Child Death Review Model: Lead Researcher: Dr Alyson Leslie

The Fatality Investigation and Review Studies team (FIRST) at University of Dundee, in collaboration with the School of Medicine and with the support of NHS Tayside, are piloting a model of child fatality review in Tayside between January and March 2014. The project is jointly funded by Scottish Government and the University of Dundee Alumni Fund.

The project will use the Ruby Model, an adapted version of the “elegantly simple” child death review process first rolled out in the US and subsequently adopted in other nations including Canada and New Zealand. At the heart of this model are the story of the child, their lives and circumstances of their death and the contributions of family and professionals who knew them and treated them.

A short multi-agency meeting will review each death and will determine whether it was preventable and what recommendations, if any, can be made to reduce the likelihood of similar deaths. Alongside this qualitative data, over 300 data elements will be collected on each child from death certification details and other records. Funding from Tayside Medical Science Centre is allowing the development of software which captures National Records of Scotland data and uses it to populate the data collection tools which are completed at the multi-agency review meeting. The data is then stored in a database in the Health Informatics Centre (HIC) at Dundee, one of only four UK-wide Farr Institutes (centres of excellence and exceptional resources in the management, storage, analysis and linkage of data). Dundee HIC co-ordinates the UK network.

A multi-agency stakeholder group from across Tayside is being established to support and inform the pilot work and to review and take forward recommendations from reviews.

Part of the Alumni Fund grant is being used to employ a part-time family liaison worker to support the recently bereaved families who are contributing to the pilot, to capture their insights and recommendations and to ensure their views and voices are heard in the review meeting. The liaison worker will also feedback to families from the review.

The dataset collected in the child death review pilots in Tayside is being compiled in conjunction with stakeholders and expert clinicians. Drawing on other work being undertaken by FIRST, discussions are underway with other Child Death Review projects across the UK which are exploring capacity for data linkage. The work being undertaken in relation to Significant Case Review datasets in Scotland and work across the UK on child fire fatality data collection is also being studied, to ensure compatibility where possible.

Resource implications of the Ruby Model will be identified and the process will be costed as part of the pilot study. The pilot research group will report to Scottish Government on their experience and findings in April 2014.

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Glossary

CDOP	Child Death Overview Panel
CDR	Child Death Review
CORP	Clinical Outcome Review Programme
CP	Child Protection
CPC	Child Protection Committee
CPU	Child Protection Unit
FAI	Fatal Accident Inquiry
FIRST	The Fatality Investigation and Review Studies Team
HIC	Health Informatics Centre
HIS	Healthcare Improvement Scotland
HQIP	Healthcare Quality Improvement Partnership
ISD	Information Services Division
LAC	Looked after children
LSCB	Local Safeguarding Children Board
MBRRACE	Mothers and Babies Reducing Risk through Audit and Confidential Enquiries
MCQIC	Maternity and Children's Quality Improvement Collaborative
MDT	Multi-disciplinary team
NRS	National Records of Scotland
PF	Procurator Fiscal

PRAM	Paediatric Review and Audit of Mortality
RCPCH	The Royal College of Paediatrics and Child Health
SCIR	Significant Clinical Incident Review
ScotSid	Scottish Suicide Information Database
SCR	Significant Case Review
SUDI	Sudden and unexpected death in infancy
SUDiC	Sudden and unexpected death in childhood
UNICEF	United Nations Children's Fund



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