

Dadansoddi ar gyfer Polisi



Analysis for Policy



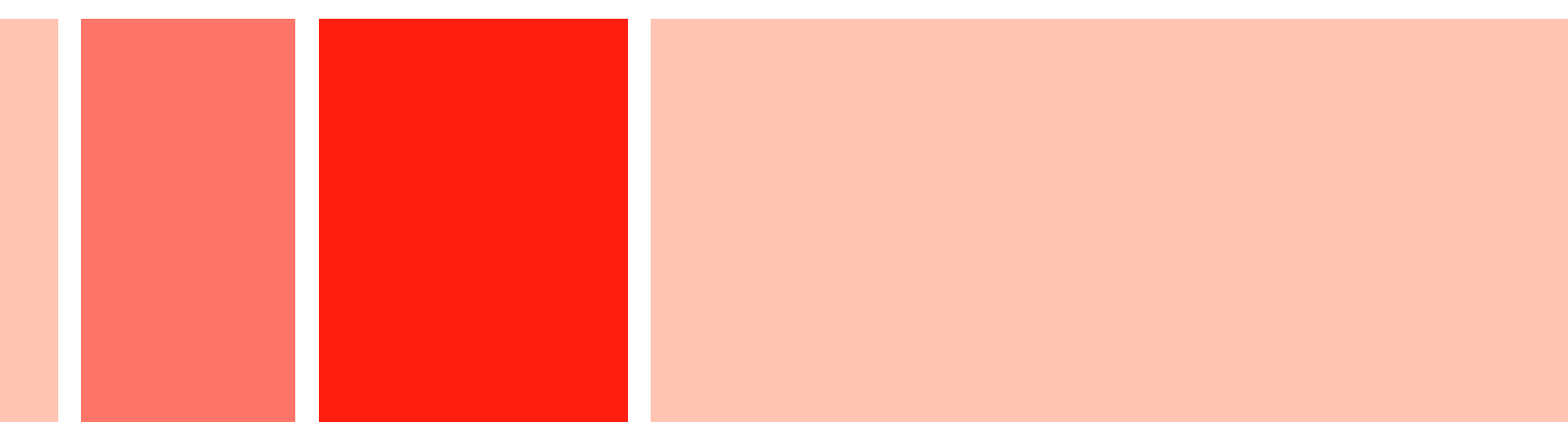
Llywodraeth Cymru
Welsh Government

www.cymru.gov.uk

Ymchwil gymdeithasol
Social research

Number: 10/2012

Evaluation of the Child Death Review Pilot Project in Wales



Evaluation of the Child Death Review Pilot Project in Wales

Cordis Bright Ltd

Views expressed in this report are those of the researcher and not necessarily those of the Welsh Government

For further information please contact:

Name: Julie A Lane

Department: Knowledge and Analytical Services

Welsh Government

Cathays Park

Cardiff

CF10 3NQ

Tel: 029 2082 5999

Email: julie.lane@wales.gsi.gov.uk

Welsh Government Social Research, 2012

ISBN 978 0 7504 7309 6

© Crown Copyright 2012

Table of contents

2	Introduction.....	5
3	Methodology.....	7
4	Findings: the evaluation's key objectives	10
5	Findings: the evaluation's specific objectives	14
6	Recommendations	24

Executive summary

1. This report contains the findings and recommendations of the external evaluation of the Child Death Review Pilot Project in Wales. The evaluation was carried out by Cordis Bright between June and December 2011, and is based mainly on 18 face-to-face interviews and 49 telephone interviews with stakeholders, as well as a review of relevant project documentation.

Key findings

2. The Child Death Review Pilot Project was seen as a very valuable process by all stakeholders interviewed as part of this evaluation.
3. The approach of conducting thematic reviews was seen as promising. However, stakeholders identified some areas for improvement in the way thematic reviews were conducted. For example, interviewees thought that more robust recommendations were needed for the reviews to have a greater impact. In addition, interviewees commented that more attention should be paid to the way the findings of the reviews are disseminated.
4. The research also showed that the work to establish an annual overview of child deaths in Wales received less attention than the work on the thematic reviews. The majority of interviewees thought that the annual report for 2010 produced by the Child Death Review Team had not been very useful in its current format.
5. During the pilot phase, there appears to have been a lack of commonly shared and detailed Terms of Reference for the Child Death Review Pilot Project. This is likely to have caused some of the issues identified as part of this research.
6. The Child Death Review Pilot Project encountered some difficulty in locating and accessing data. This was due to data about child deaths being held by a wide range of organisations, and reluctance by some

organisations to share information due to concerns about data protection. As a response, the Child Death Review Team developed innovative ways of collecting data.

Recommendations

1.1 The following recommendations are based mainly on Cordis Bright's overall evaluative judgement, which in turn draws heavily on the findings of the primary and secondary research conducted during the evaluation.

1.2 Recommendation 1: Consider continuation of funding for the Child Death Review Process

We would recommend that the Welsh Government considers funding the Child Death Review Project into the future, subject to establishment of clear outcomes and Terms of Reference. We recommend that this funding is then reviewed against the agreed outcomes after an appropriate period of time.

1.1 Recommendation 2: Develop and agree clear Terms of Reference

We suggest developing and agreeing clear Terms of Reference that define what the Child Death Review Process aims to achieve, what the outputs will be, and mechanisms for reporting and disseminating findings. Apart from the work on thematic reports, the aims and objectives should include a clear focus on the production of a database and annual overview of child deaths in Wales.

1.2 While the Child Death Review process is rightly led and hosted by Public Health Wales, it is important to view it as an ongoing and wider process that incorporates perspectives from social services and safeguarding. Essential contributions could and should be made from agencies working across these fields, with additional input from policy colleagues and other partner agencies. Ongoing and effective cooperation between agencies is essential for the long-term success of the Child Death Review process. The composition of the Steering Group, leadership of

the Child Death Review Team and operational practices should reflect the wider health and safeguarding focus.

1.3 Recommendation 3: Put appropriate governance arrangements in place

We suggest that a steering group is created to provide governance arrangements and accountability. It is our view that membership of the steering group should be balanced, with equal representation from the Welsh Government as the funder and Public Health Wales as the Child Death Review Team's host organisation, and additional members from partner agencies and organisations. In addition, we believe that the Chair should have a background that combines expertise in safeguarding, public health and child health.

1.4 Recommendation 4: Amending the Child Death Review Team's operational practices

Cordis Bright has developed suggestions on how the operational practices of the Child Death Review Team may be improved. These are detailed in the main body of the report, including recruiting a suitable candidate to the (currently vacant) post of the project's clinical lead. The lead should possess a good knowledge not only of child health and safeguarding, but also of public health and epidemiology, as well as skills in the effective presentation of research findings. Other recommendations by Cordis Bright concerning operational practices include ensuring the right mix of panel members for thematic reviews, and redesigning the forms used for ascertainment to reflect the priorities in the Terms of Reference.

1.5 Recommendation 5: Explore the possibility of giving the Child Death Review Process statutory powers

The research did not reveal a need to establish a statutory framework for undertaking CDRs. However, we recommend that further consideration is given to introducing a statutory framework in relation to the collection of, and access to, data relating to child deaths.

2 Introduction

- 2.1 In May 2008, the Minister for Health and Social Services agreed that the National Public Health Service for Wales (now Public Health Wales) be commissioned to establish a pilot study to inform the development of Child Death Reviews in Wales. The National Child Death Review Pilot Project started in July 2009.

- 2.2 The aim of the Child Death Review Pilot Project was to collect, analyse and review information about child deaths in Wales with a view to identifying common and preventable factors. A National Child Death Review Team was set up within Public Health Wales to manage the pilot project, and governance arrangements were provided through a multi-agency Task and Finish Group. The Child Death Review Team has been responsible for arrangements to ascertain and record child deaths in collaboration with a range of partners, including Local Safeguarding Children Boards, Registrars and Coroners. Child Death Panels were established to review the data collected and to identify key themes within the data which may represent preventable factors contributing to a child's death. Depending on the nature of the deaths being investigated, panels comprised representatives from child health, education, police, public health, social services, Children in Wales and the Children's Commissioner for Wales.
 - 2.2.1 In May 2011, the Welsh Government commissioned Cordis Bright to conduct an evaluation of the Child Death Review Pilot Project in Wales. The evaluation was tasked to focus on the Child Death Review Pilot Project's effectiveness in establishing national reviews of child deaths with the aim of identifying preventable factors that can lead to improved safeguarding of children in Wales. The fieldwork for the evaluation took place between June and November 2011.

- 2.3 This report provides the findings of the research undertaken. The rest of this report is structured into four parts: details of the methodology for this

evaluation are described in section 3. Section 4 provides information on the evaluation's main findings. Findings on the evaluation's specific aims are discussed in section 5. Finally, section 6 contains Cordis Bright's recommendations on how the Child Death Review Project could be improved in the future.

3 Methodology

Overview

- 3.1 The methodology for this evaluation was developed and agreed in conjunction with the Welsh Government. It consisted of a review of strategic documents and reports, 18 face to face interviews with stakeholders directly involved in the Child Death Review Pilot Project and 49 telephone interviews with a wider range of stakeholders.

Initially, the methods for the evaluation included an online survey to 200 stakeholders working across health and social care in Wales, focusing on the outputs of the Child Death Review Pilot Project. The survey was scheduled to take place during June and July 2011, and was to be followed up by up to 40 telephone interviews. However, the reports produced by the Child Death Review Team were not released until October 2011, and it was decided that these reports would only be made available to around 70 stakeholders on a restricted basis for the purpose of the evaluation and receiving feedback. This meant that it was not possible to conduct a survey and follow-up interviews in the timescales available. Therefore, it was agreed to modify the methodology, and contact all the recipients of the reports directly, asking them to participate in a telephone interview. A total of 49 telephone interviews were subsequently conducted. This change of methodology meant that the number of research participants was lower than initially planned but this was the best approach available given the timescales of the project.

Individual research elements

- 3.2 For the review of strategic documents and reports relating to the Child Death Review, the Welsh Government provided Cordis Bright with relevant documentation including a Project Initiation Document, an update on the project which was submitted to the Welsh Government,

information on the Procedural Response to Unexpected Deaths in Childhood (PRUDiC) and reports and documents produced by the Child Death Review Team.

- 3.3 Between June and October 2011, 18 face to face interviews were conducted, including with former and current members of the Review Team, the Task and Finish Group, the individual panels, as well as with stakeholders with an involvement in the production of reports or provision of information for the Child Death Review process. Interviewees were selected through purposive sampling, in that they were suggested by the Welsh Government and Public Health Wales on the basis of the involvement they had had in the process. This method of sampling meant that interviewees were drawn from different partner organisations and had varying levels of involvement with the process. The interviews followed a template agreed with the Welsh Government, and lasted between 1-1.5 hours. Interviewees were assured that the discussion would be confidential and responses anonymous. In addition, interviewees were briefed about the purpose and scope of the interview in advance in order to ensure informed consent.
- 3.4 A total of 49 telephone interviews were conducted with a wide range of stakeholders across Wales. These interviews were aimed at establishing what professionals working in health and social care thought about the reports produced by the Child Death Review Team. For this purpose, two reports were released to a group of approximately 70 stakeholders on a restricted basis on 10 October 2011. The reports were accompanied by a letter stating that Cordis Bright would be inviting stakeholders to participate in interviews focusing on the reports. All 70 stakeholders were subsequently contacted and asked to participate in a telephone interview, which typically lasted between 30 minutes and one hour. The interviews followed a semi-structured interview template agreed with the Welsh Government, and took place between 12 October and 4 November. It should be noted that since potential research participants were alerted to the possibility of being interviewed, they may

have read the reports specifically with a view to providing feedback on them. Therefore, it is possible that responses may have differed if research participants had read the reports as part of their usual routine.

- 3.5 Information from the semi-structured interviews was transferred to spreadsheets and analysed thematically at different stages throughout the evaluation. For the final analysis, researchers compared notes and information collected for individual themes, and overall findings and conclusions were agreed between the whole team. The interviewees' differing levels of involvement with the Child Death Review Pilot Project - and the variety of organisations and professional perspectives they represented – meant that views could not be directly compared and contrasted.
- 3.6 Overall, the methodology used for this report relied heavily on qualitative methods and data. This was due to the limited number of stakeholders involved in the Child Death Review process to date, and the timescales to which the evaluation was delivered. However, as the research engaged with a significant proportion of individuals with knowledge of and contact with the Child Death Review process in Wales, we believe that the evaluation's findings represent an accurate picture of the Child Death Review Team's achievements to date.

4 Findings: the evaluation's key objectives

The evaluation's key aims and objectives

This section addresses the main objectives that this evaluation was tasked with, namely to assess the Child Death Review Pilot Project in relation to:

- its effectiveness in establishing national reviews of child deaths (with the aim of identifying preventable factors that can lead to improved safeguarding of children in Wales)
- its effectiveness in setting in place a system to identify child deaths in Wales.

The effectiveness of establishing national review of child deaths

4.1 Based on the fieldwork conducted for this evaluation, we conclude that the thematic approach to identifying preventable factors in children's deaths is very promising. It has raised awareness of these factors among practitioners in Wales. However, interviewees did identify a number of issues that should be addressed in the future for the thematic reviews to have a greater impact.

4.2 Areas for improvement identified by stakeholders included:

- A more effective and transparent process for choosing topics for review. Due to the pilot nature of the project, topics had so far been chosen on an opportunistic basis.
- A further area for improvement was the composition of the panels that were convened to review children's deaths on a thematic basis. Several interviewees commented that the panel composition could have been more balanced to include a wider range of professional perspectives.

- In addition, the Child Death Review Team's reports were not seen to include robust recommendations, and in their present form would contribute to learning and awareness only. Interviewees did not feel that the reviews would have a lasting impact.
- Finally, interviewees felt that robust mechanisms for dissemination of findings and reports should be agreed (detailed findings are set out in section 5 below. We have included recommendations on how these could be addressed in section 6 of this report.).

The effectiveness of setting in place a system to identify child deaths in Wales

4.3 The Child Death Review Team has worked hard to establish a system of ascertaining and recording child deaths. The approach adopted by the team of capturing/recapturing information from a variety of sources was widely seen as the right one by stakeholders. However, the objective of developing this data into a robust annual overview of child deaths seems to have received less attention than the work on the thematic reviews, and is under-developed. As a result, a large number of interviewees did not think that the overview of child deaths provided in the annual report for 2010 was very useful to them. A large majority of stakeholders thought that the data in the 2010 annual report could have been presented in a more accessible way. In addition, the data could have been interrogated and explored to greater effect, as in its present form it provided very limited insight.

4.4 Interviewees' views on the annual report for 2010 were reflected in the lack of clarity about the level of detail to be collected for every child death in Wales. The systems used for the Child Death Review Team were over-ambitious in that they aimed to ascertain highly detailed information. The team had mixed success at overcoming considerable barriers in securing access to this information. As a result, the desired level of detail could only be collected for a relatively small number of children. Discussions with stakeholders suggest that the Child Death

Review Team should review the data it wishes to collect on child death, with the aim of agreeing a smaller and simpler dataset that would be easier to collect and more robust in nature. Although it would have a narrower focus, this new dataset would enable the Child Death Review Team to produce an annual report which is of greater value to stakeholders across Wales (this is explored in greater detail in section 5, and we have provided recommendations for how this system could be improved in section 6).

Conclusion: The Child Death Review Pilot Project's progress against its main objectives

- 4.5 Overall, the evaluation has shown that all stakeholders thought that the aims and the work of the Child Death Review Pilot Project in Wales are important. The thematic approach to the review of child deaths seems to be worth developing further. A number of areas for improvement have been identified, and recommendations for how these can be addressed have been laid out below.
- 4.6 The evaluation also found that, for the Child Death Review Process to be effective, it is vital to produce a robust annual overview of the number, and the circumstances, of Child Deaths in Wales which could guide the future choice of topics and identify trends over time. As the overview produced to date has not been seen as useful by stakeholders, we believe that this element of the Child Death Review Process should be re-emphasised.
- 4.7 We have explored in the sections below how a lack of clarity of the Child Death Review's Terms of Reference contributed to some of the issues identified as part of the research. However, it should be emphasised that the Child Death Review Pilot Project was a new initiative, and it is normal for a pilot project to recalibrate its operational practices after a trial period. Therefore, we believe that should clearer governance arrangements, aims and objectives be developed in the future, the Child

Death Review Process in Wales has the potential to have a real impact on the understanding about child deaths in Wales.

5 Findings: the evaluation's specific objectives

5.1 This section provides additional details on the evaluation's main findings, and address the specific objectives set out in the specifications for this evaluation.

Terms of Reference

5.2 The evaluation found that the protocols for the Child Death Review Pilot Project were underdeveloped. Interviewees' views on what the pilot could and should achieve differed, and we could not find a unifying set of protocols or Terms of Reference to which the Task and Finish Group and the Child Death Review Team worked.

5.3 The Project Initiation Document (PID, produced in July 2008) sets out protocols and objectives in some detail. However, we believe that the PID was overly prescriptive. For example, the PID defines operational practices for the Child Death Review Team that seem unrealistically ambitious given that these practices were yet to be established and trialled. For example, the PID suggests that the panels would be meeting to review child deaths approximately twice a month. In addition, the processes described in the PID seem similar to those used in England. However, the PID does not sufficiently consider the differences between the England and Wales approach. For example, in England the process is driven locally by Child Death Overview Panels connected to individual Local Safeguarding Children Boards, while Wales has adopted a national approach which is further removed from front-line agencies. The somewhat unrealistic expectations towards the pilot outlined in the PID meant that it was of limited use as a guideline for the pilot.

5.4 Indeed, we found limited evidence that the PID was actually used as a blueprint for the operation of the pilot, and it was difficult to see which documents or Terms of Reference had been used in its place. We believe that this lack of agreed protocols or Terms of Reference

contributed to some of the difficulties the project encountered, for example the delay in publishing the reports, and the fact that the annual database of deaths was not pursued as vigorously as the thematic reviews.

Accountability

- 5.5 Based on the available evidence, it appears as if accountability for the Child Death Review Pilot Project could have been stronger. In particular, there were no governance arrangements in place after the Task and Finish Group disbanded in January 2011. In addition, even before this, no clear Terms of Reference existed which would have allowed for effective monitoring of progress.

Leadership and management

- 5.6 Interviewees agreed that leadership and management of the Child Death Review Team had been highly committed, and that the personal contribution of staff had been a key factor in the project's successes. Several research participants in a range of different agencies mentioned that they had had personal contact with the Child Death Review Team, either through meetings or because the Team's clinical lead or manager had given a presentation or attended a meeting to provide information on the Child Death Review Process.
- 5.7 However, a small number of interviewees taking part in the face-to-face interviews stated that they thought that there had been a strong health focus among the leadership of both the Task and Finish Group and the Child Death Review Team, and that a multi-agency perspective had not always sufficiently been taken into account.
- 5.8 The evaluation also found that difficulties in recruitment to posts within the Child Death Review Team had impacted on the ability of the team to deliver as effectively as it could have. For instance, the Child Death Review Team did not have a dedicated clinical lead for several months,

and several interviewees reported that it was not possible to attract a suitable dedicated candidate due to uncertainty over the project's future. The dedicated post of Support Officer within the Child Death Review Team was also vacant for some time. This meant there were periods when the Child Death Review Team's manager was the only dedicated member of staff working on the project. While additional valuable support and input was provided by external colleagues, this was in addition to their usual job commitments.

The Child Death Review Team's operational practices

- 5.9 **The panels:** Panel members generally reported that the panel worked well, with informed contributions from highly qualified participants. Several interviewees who took part in the panels commented that they were very impressed by the calibre and knowledge of the assembled panel members. All interviewed panel members thought that the concept of thematic reviews by a panel of experts was the right approach to take, as this would allow for the discussion of a larger number of cases than local reviews. In addition, discussing topics at a national level made it easier to bring together dedicated experts rather than having to replicate the panels on a smaller level locally.
- 5.10 However, a small number of interviewees who had taken part in the panel discussions reported that the panels had had a health/paediatric bias, and they felt that this had made it more difficult for them to contribute effectively.
- 5.11 **Ascertainment of child deaths:** The research suggested that the main focus of the Child Death Review Team's considerable efforts was on the thematic reviews. The second main objective – the creation of the child death database and overview of child deaths in Wales – was pursued less systematically and with less success. The majority of interviewees stated that the 2010 annual report produced by the Team was of limited usefulness. We believe that one of the reasons for this was that the

Child Death Review Team was over-ambitious, in that the team aimed to record a high level of detail for every child death in Wales. This is not too dissimilar from the work of the Child Death Overview Panels in England, which are located at Local Safeguarding Children's Board level and are tasked with reviewing every child death in the LSCB area. However, it should be noted that the Child Death Overview Panels in England have greater resources at their disposal, and the process in England is not directly translatable to a Wales context.

Approaches to identifying local and national trends

5.12 To date, the database created does not go back far enough to allow for the identification of trends over time. A majority of interviewees that we interviewed about the annual report for 2010 also thought that the information provided in the annual report would need more detail and structure to be useful in the future. This meant that local trends could also not be established. As numbers were low for individual health boards, they may be of limited use.

Identification of the key themes for review

5.13 Apart from the report on suicides, with which the pilot project was tasked from the outset, topics for review were mainly chosen opportunistically and on the basis of whether they may yield interesting results. However, as the project was still in a pilot stage, this was a necessary response to the fact that the database/overview had to be developed first before it could be used to identify topics for review.

5.14 The majority of stakeholders agreed that in the future, the choice of topics should generally be data-led, and based on the figures provided in annual reports to be produced in the future. However, it is worth noting that interviewees thought that topics should not solely be chosen on the basis of the highest numbers of death per category. There should be some flexibility to allow for topics which appear to have the potential for

preventing deaths.

Data access and data sharing

- 5.15 Data access and data sharing proved to be a challenging task for the Child Death Review Team, and the Team worked hard to access information through a wide variety of sources. This capture/recapture approach was widely seen as positive and worthwhile. Most interviewees generally agreed that the information required was not held within any one organisation, and that a wide range of sources should be used for ascertainment of deaths and the details surrounding them.
- 5.16 There was evidence of an uneven application across Wales by a number of organisations of the existing mechanisms for gathering and sharing information, for example the Procedural Response to Unexpected Deaths in Childhood (PRUDiC) guidelines and the Welsh Accord on the Sharing of Personal Information (WASPI). However, this was to be expected, as these protocols are still in the process of being fully implemented. During the interviews, it also became clear that the uneven application of data protection regulation and confidentiality rules was creating some of the difficulties for the ascertainment process. Partner agencies were not always confident that information could be shared with the Child Death Review Team. In addition, practitioners from partner agencies stated that it was not uncommon for them not to be in the possession of the information being requested. This could be indicative of the particular people we spoke to. Further research would be required in order to explore this in more depth.
- 5.17 The question of the level of information to be provided and collected was raised by a number of interviewees. A number of interviewees that had had direct involvement with the Child Death Review Team thought that the level of information required should be revisited, as they felt that currently, they were being asked to provide a high level of information which they did not always possess, and which also may never be

analysed further by the Child Death Review Team. This group of interviewees favoured a more streamlined collection of data.

Exploring the need to introduce a legislative framework

5.18 There was a consensus among face to face and telephone interviewees that the Child Death Review Team should be enabled to access a wider range of information. An improved flow of information would enable more accurate ascertainment and also more detailed analysis during the thematic reviews.

5.19 Interviewees' opinions differed as to how the flow of information could be improved, and to a degree depended on the professional background of the research participant. Those closely involved with the Child Death Review Process (a minority of interviewees) were strongly in favour of statutory guidance placing an obligation on partner agencies to supply information to the Child Death Review Team automatically. This would mean that (for instance) Coroners, Registrars and Local Safeguarding Children Boards would have a duty to pass on details about a child's death to the Child Death Review Team. However, the evaluation also interviewed a range of stakeholders who would have to provide this information. Several interviewees from this group commented that they did not always hold information beyond basic biographical data, as they may not have had significant involvement with the child that had died. If they did hold this information, supplying it would create an additional burden for their organisations. Therefore, these interviewees favoured a solution by which they would supply any information they held upon request. However, it should be noted that this evaluation only engaged with a minority LSCB coordinators in Wales, and it could not be determined how widely this opinion was held.

5.20 Most interviewees (across different groups of interviewees) agreed that a clarification of the Child Death Review Team's status would be helpful, as currently there was perceived to be some confusion over whether

information could be shared with them. This clarification could take the form of spelling out that the Child Death Review Team was an interested party in proceedings surrounding a child's death, and that certain information could be shared with them.

Lessons to be learnt from patterns of child deaths, and usefulness of information produced to the safeguarding agenda

5.21 The Child Death Review Team's annual report for 2010 and a report on young people taking their own life were discussed with 49 stakeholders from across Wales.

5.22 **The report on young people taking their own lives (the report on suicides):** The majority of interviewees thought that the report on suicide had identified interesting and appropriate issues, although a small number of interviewees commented that a number of conceptual models were missing from the report. For example, one interviewee commented that a functional analysis of the issues raised would have been helpful. Some interviewees also commented that they felt that the report should have been clearer about its limitations based on the number of cases reviewed being quite limited.

5.23 The main point of criticism on the report on suicides was that the recommendations and lessons learnt could have been more specific. Stakeholders thought that it would be more useful if recommendations were more substantial and included appropriate action points, as so far they were seen to be mainly generic. In addition, interviewees felt that reports by the Child Death Review Team may not be the most effective way of communicating and disseminating findings and recommendations effectively. However, interviewees did not necessarily see this as the task of the Child Death Review Team and the panel itself – there was a sense that for the reports to have a real impact, recommendations would need to be developed in conjunction with agencies or bodies with

greater influence over implementation, e.g. the Welsh Government or Public Health Wales, depending on the topic.

5.24 A number of interviewees also commented that the report on suicides could have established a clearer link between current policy and initiatives in the area under review, as they felt that they had not been given sufficient consideration. In addition, interviewees felt that a shorter executive summary would have made the reports more accessible to practitioners with limited time to read the reports.

5.25 These factors meant that in its present form, the impact of the report on suicides would be limited to raising awareness of issues – only a minority of interviewees thought that the report had the realistic potential to lead to real changes.

5.26 **The Child Death Review Team's annual report for 2010:** Asked about the annual report that had been produced for 2010, most interviewees thought this had been of limited use, and would have a limited impact. This was mainly due to the Results section within the report consisting mainly of tables of rates of child death per 100,000 children. This was not seen as very accessible for people with no or only limited statistical training. Most interviewees thought that additional narrative and analysis could and should have been provided to explore these figures in more detail. In addition, interviewees were very interested in actual numbers and causes of child deaths, which had not been provided. Trend data was requested by many interviewees, although they also realised that this would be built up over time. Several interviewees also commented that future annual reports should include an executive summary. If changes and improvements were to be made, all interviewees agreed that an annual report on child deaths would be highly valuable.

Effectiveness of the project's communication

5.27 Research participants that had been in contact with the Child Death Review Team agreed that the Team had been very effective at building very good working relationships with a wide group of stakeholders across Wales. Many interviewees who were not directly involved with the project said that they had had contact with the Child Death Review Team through presentations, networking events or meetings that one of the Team members had attended, including with LSCB coordinators, staff within Health Boards, Coroners and members of the police. This personal presence was seen as very useful for partnership working.

Method of disseminating reports

5.28 Although the reports were seen as useful by most interviewees, a core of interviewees questioned the value of disseminating them in their present form. This was mainly due to these interviewees thinking that the reports themselves were not sufficiently focussed on recommending changes or actions. The multi-agency workshop held with stakeholders tried to address this, but interviewees did not think that the findings from the workshop added value to the recommendations.

5.29 A number of interviewees suggested that the reports would be more widely read, and would have carried more weight, if they had been disseminated by the Welsh Government, potentially in the form of a response which could be published after the reports had been submitted. Some interviewees also suggested that the Welsh Government could endorse the reports. However, this would not address the issue of how recommendations would be developed.

5.30 A number of interviewees noted that there had been a significant delay in the releasing of reports, which impacted negatively on the wider project's communication. We believe that this was due to the absence of agreed and shared Terms of Reference, which could have spelt out the

responsibilities of the Welsh Government and Public Health Wales in more detail.

6 Recommendations

- 6.1 Cordis Bright has developed five main recommendations for how the project could be amended and improved in the future. While drawing heavily on the primary and secondary research conducted for this evaluation, the recommendations are ultimately based on Cordis Bright's overall evaluative judgement.
- 6.2 The following table shows an overview of the recommendations, with additional details provided below.

Overview of recommendations

#	Recommendation
1	Consider continuation of funding for the Child Death Review Process
2	Develop and agree Terms of Reference
3	Put appropriate government arrangements in place
4	Amending the Child Death Review Team's operational practices
5	Explore possibility of giving Child Death Review Process statutory powers

Recommendation 1: Consider continuation of funding for the Child Death Review Process

- 6.3 We recommend that the Welsh Government considers continuing the provision of funding for the Child Death Review Process in Wales. This is due to the clear feedback received from stakeholders stating that the process is very valuable and should be continued. In order to be able to attract a suitable candidate to lead the Child Death Review Team, it would be advisable to agree funding for more than one year.
- 6.4 Decisions on the level of funding provided should be reviewed once new Terms of Reference have been agreed, and have been implemented for one year.

Recommendation 2: Develop and agree Terms of Reference

6.5 We recommend that Terms of Reference are developed that more clearly define the Child Death Review Process, along with its aims and objectives. These should be agreed between Public Health Wales and the Welsh Government. We would suggest that the Terms of Reference include the following considerations:

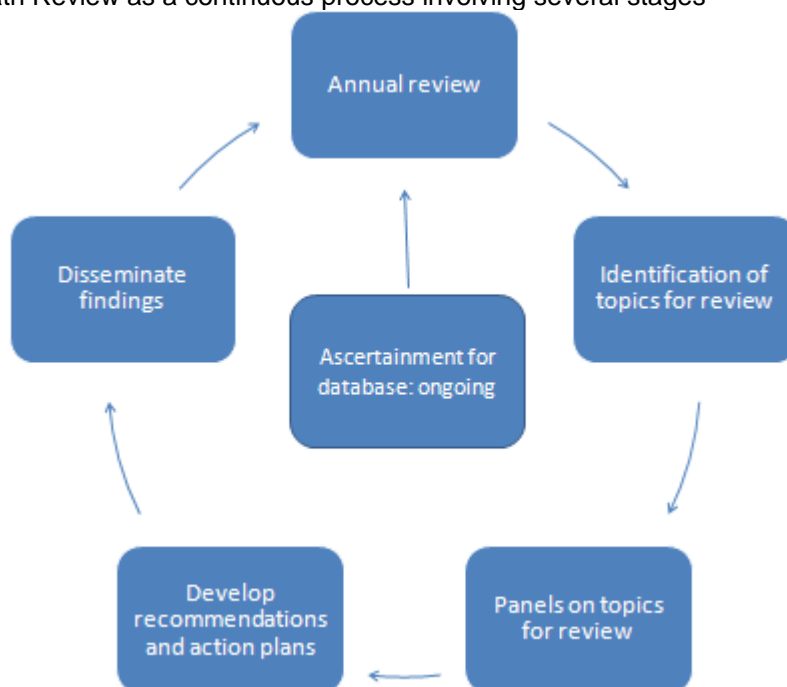
Ensure that Child Death Review process includes both thematic reviews and a robust database and overview of Child Deaths

6.6 An annual overview of the number and causes of child deaths provides an essential starting point for the identification of significant topics, clusters and trends over time. We therefore recommend that the Terms of Reference underline the importance of producing the database and accompanying annual overview as one of the main aims of the Child Death Review Process.

The Child Death Review Process should be defined as going beyond the work of the Child Death Review Team

6.7 Child Death Review is an interdisciplinary process, which should be understood as going beyond the work of the Child Death Review Team or the Steering Group providing governance arrangements. Therefore, we would suggest that in the development of Terms of Reference, thought is given to the roles other agencies and bodies, such as the Welsh Government, the police, Local Safeguarding Children Boards and the third sector can play in the process. In particular, this includes the process of developing robust recommendations and action plans after thematic reviews, and disseminating findings appropriately.

Figure 1: Child Death Review as a continuous process involving several stages



6.8 In addition, we would like to emphasise that the Child Death Review Process is a truly interdisciplinary undertaking. In its overall aim to identify factors that could lead to children’s deaths being prevented, the process draws on medical expertise, a public health methodology as well as safeguarding approaches (depending on the topic under review). Therefore, it is important that the process is not too narrowly defined as belonging to only one of these areas.

A clear mechanism through which robust recommendations and action plans are developed and disseminated

6.9 The research has shown that stakeholders think that the reports on the thematic reviews need to provide robust recommendations and action points in order to be effective. However, it may not be possible to develop these recommendations at the panels themselves. Therefore, we believe that it is necessary to ensure that the Child Death Review Process does not end with the production of reports. Instead, we suggest that the Terms of Reference include a specific focus on the development and dissemination of robust and relevant recommendations, in order for the process to continue and have a real

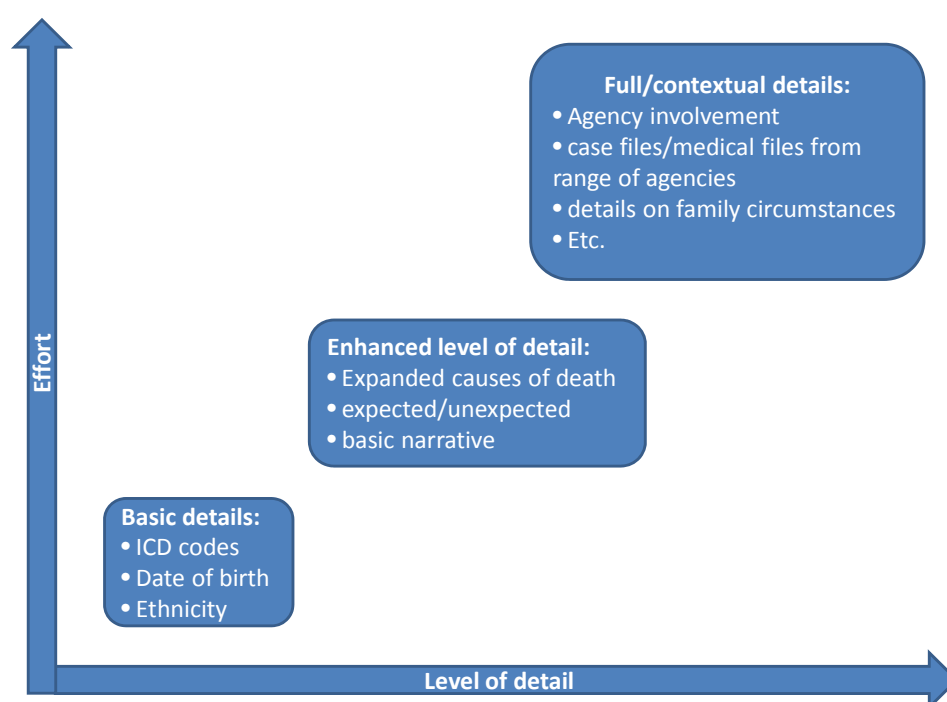
impact. The approach taken on this will depend on the nature of, and audience for, the recommendations.

Define the scope and amount of information to be collected for the database and thematic reviews

6.10 The data collection for the child death database and the thematic reviews should be viewed separately. Child deaths to be reviewed at the panel require a high level of detailed information to be collected. However, the same level of information is not necessary for the child death database. This means that ascertainment for the child death database could be streamlined, and a high level of detail (for example, the information from the PRUDiC proceedings) only collected for deaths to be reviewed at the panels. This would reduce the effort necessary to assemble the Child Death database.

6.11 Figure 2 shows a model detailing different levels of data that can be collected. Our suggestion would be that the Child Death Review Team assembles an 'enhanced' dataset on all child deaths, which could include expanding on the 'basic' information it receives from the ONS and adding details gained from the Welsh Paediatric Surveillance Unit and other sources. 'Full' or 'contextual' details would then only be collected for the cases discussed during thematic panels.

Figure 2: Conceptual model for future collection of Child Death Review data



6.12 While this would mean that there would be a delay in gathering detailed information, it would also allow the Child Death Review Team to focus on assembling a highly valid dataset, albeit with limited information (as opposed to a dataset which contains a wider range of information on a lower number of cases). The amount and scope of information to be collected for the database will be determined by the Terms of Reference to be developed. The annual overview should then provide information on the categories to be agreed.

Recommendation 3: Put appropriate governance arrangements in place

6.13 We recommend that a new Steering Group is created (or the Task and Finish Group revived) in order to provide governance and oversight for the Child Death Review Process. The Steering Group could be tasked with ensuring that appropriate Terms of Reference are developed and agreed – the work plan for the Child Death Review Team could then be based on the Terms of Reference agreed.

6.14 We believe that it would be beneficial to ensure that membership of any steering group to be created is balanced between representatives of the Welsh Government and Public Health Wales. Further agencies and organisations that could be involved in the Steering Group include representatives from Local Safeguarding Children Boards and their partner agencies such as, Health Boards, Local Authorities and the police as well as other organisations such as Children in Wales, the Children’s Commissioner for Wales and the NSPCC.

6.15 In order for the Steering Group to be able to provide the appropriate level of oversight and strategic direction, we suggest that the group’s Chair should have a thorough understanding of health issues, public health as well as safeguarding.

Recommendation 4: Amending the Child Death Review Team’s operational practices

6.16 The Child Death Review Team has already made very significant progress towards ascertaining Child Deaths. In order to increase the effectiveness of the team’s work in the future, we would suggest the following changes to the team and its operational practices.

Recruiting a suitably qualified lead and support officer

6.17 Should future funding be agreed by the Welsh Government, a suitably qualified lead for the Child Death Review Team should be recruited (as this post has been vacant for several months). We would recommend that the individual should have an understanding of clinical issues and paediatrics, as well as a very good grasp on epidemiology. We would also stress that the team’s lead should be able to demonstrate a commitment to and good understanding of safeguarding issues, in order to reflect the multi-disciplinary nature of the Child Death Review Process. The lead will also be responsible for drafting the project’s main outputs in the form of reports. Therefore, individuals should be able to

demonstrate skills in this area. In addition, the vacant post of Support Officer of the Team should be filled.

Amend forms used for data collection

6.18 The Child Death Review Team should continue its efforts in collecting data, especially its very valuable system of capture/recapture. Links should be maintained (and if need be formalised) with sources of data such as the Welsh Paediatric Surveillance Unit (WSPU), the Office for National Statistics, Welsh Demographic Services, the All Wales Perinatal Survey and Patient Episode Data Wales. The data collection should reflect the two main aims of the Child Death Review Process – creation of a database, and thematic reviews – and forms should be adjusted accordingly.

Ensuring effective panel discussions

6.19 The expert panels undertaking the thematic reviews have provided very valuable work in identifying factors and issues contributing to children's deaths. However, we believe that these panels could be more effective if the membership was more evenly balanced between clinicians/paediatricians and other panel members from police, education, LSCBs and voluntary organisations. The exact composition of the panel will depend on the topic under review. This is in line with our view that the Child Death Review process must be seen holistically, and encompassing a wide range of agencies and partners in order to have a real impact and lasting effect.

6.20 In addition, we would strongly recommend that individuals with appropriate expert knowledge of existing policy and initiatives are recruited to the panels for relevant reviews. For example, for a review of road traffic accidents, this may be a Welsh Government representative with detailed knowledge of the Road Safety Strategy for Wales. This would ensure that the panel could draw on information on the current

policy and state of service provision, thus reducing the likelihood of duplication.

Recommendation 5: Explore possibility of giving Child Death Review Process statutory powers

6.21 We would recommend that options are explored that facilitate the Child Death Review Team's ability to collect data from partner agencies. Rather than placing statutory obligations on other agencies to notify the Child Death Review Team automatically, we would at this stage recommend that the Child Death Review Team receives the right to request information. The exact nature of the Child Death Review Team's powers to request information will depend on the depth of information the team will be required to collect, which will be determined alongside the new Terms of Reference.