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for Education

Child death reviews: improving the use of evidence

Research Report

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Jennifer J Kurinczuk & Marian Knight

**National Perinatal Epidemiology Unit
University of Oxford**

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Glossary of terms

| | |
|--------------|--|
| CDOP | Child Death Overview Panel |
| Child death | Death of a child from birth to the 18 th birthday as defined by the Working Together to Safeguard Children, 2013. |
| CEMACH | Confidential Enquiry into Maternal and Child Health |
| CMACE | Centre for Maternal and Child Enquiries (CMACE superseded CEMACH) |
| DfE | Department for Education |
| DH | Department of Health |
| Infant death | Death of a child from birth to <1 year of age |
| LA | Local Authority |
| LSCB | Local Safeguarding Children Board |
| MBRRACE-UK | Mothers and Babies - Reducing the Risks through Audit and Confidential Enquiries |
| NPEU | National Perinatal Epidemiology Unit, University of Oxford |
| SCR | Serious Case Review |

Statement of related interests

Jenny Kurinczuk and Marian Knight have been commissioned by the Healthcare Quality Improvement Partnership, on behalf of the Health Departments of the four UK nations, to deliver the Maternal, Newborn and Infant Clinical Outcome Review Programme; the MBRRACE-UK collaboration has been established to run this programme. MBRRACE-UK involves the collection of surveillance information about all infant deaths in the UK.

Jenny Kurinczuk is also a member of the programme board of CHR-UK which is responsible for delivering the Child Health Clinical Outcome Review Programme which is similarly commissioned by the Healthcare Quality Improvement Partnership.

1. Background

The concept of child death reviews is not a new one; systems for review have been set in place in a number of countries including in the US where reviews were established in some States in the late 1970s (Johnson & Covington 2011). In the UK particular types of child deaths have been reviewed for some time in some regions, for example the Avon area (Fleming et al, 2004), and some deaths were reviewed in specific regions as part of the CEMACH 'Why Children Die: A Pilot Study' (Pearson 2008).

Enshrined in national legislation for the first time in England, Local Safeguarding Children Boards (LSCBs) were required to establish local Child Death Overview Panels (CDOPs) by April 2008, and subsequent national guidance and regulations have served to unify some operational aspects (*Working Together to Safeguard Children*, 2010) with the guidance having been recently updated (*Working Together to Safeguard Children*, 2013). Under the Children Act (2004) all Local Authorities in England have a statutory duty to set up a CDOP to review the deaths of all children from birth up to 18 years of age who are normally resident in their area. CDOPs are the responsibility of Local Safeguarding Children Boards (LSCBs) and some LSCBs 'share' CDOPs thus (at the time of writing) there were 93 CDOPs responsible to 148 LSCBs; on-going amalgamations mean that the exact number is difficult to specify at any one point in time. Central Government responsibility and oversight is located in the Department for Education.

The primary purpose of CDOPs is to review individual deaths, to identify modifiable causes to inform strategic planning on how "best to safeguard and promote the welfare of the children in their area" (*Working Together to Safeguard Children*, 2010) – that is, to learn lessons and put the lessons into practice to prevent future deaths. To meet these ends and to support the operational functions of the CDOP each CDOP collects information about each child death in their area including the conclusions of the panel review. A series of data collection templates for use by CDOPs are provided by the DfE and are available to download from the DfE website (Department for Education, 2013). Aggregated anonymised data are submitted once each year to the Department for Education who report each year's data centrally on an annual basis. Individual CDOPs report their own data in their own annual report, some of which make a public version available. The quality of data returned and the proportion of child deaths reviewed have improved year on year (Department for Education, 2012). Evidence of local actions and their impact comes from reviewing individual CDOP annual reports, conference presentations (FSID conference, 2012) and from the published literature (Sidebotham et al, 2011).

2. Aims and objectives

The aim of this proposal was to conduct a short project (4 months) to meet the DfE tender specification (Appendix A) by addressing the following objectives as given in the specification:

- Investigating how to make best use of the data currently collect by individual CDOPs which will include evaluating a series of options including:
 - Commissioning detailed research by independent contractors to identify key trends and national lessons learnt;
 - Developing a national database drawing on information already collected which could be analysed regularly;
 - Developing new standardised national data collection forms;
 - Making better use of informal links across CDOPs.
- Estimating the associated costs to the Department for Education (DfE) and the CDOPs of the proposed options and proposing different models of how this might be paid for
- Determining what information should be collected from or shared across CDOPs on a regular basis to learn national lessons
- Investigating the most efficient way to share information, lessons learned and best practice.

To meet the objectives the study was designed to address the following research questions which were given in the tender specification:

- I. How are data currently collected, stored, analysed and used by CDOPs?
- II. How do CDOPs Chairs and Co-ordinators think the data they have collected could be used by the DfE, CDOPs and external bodies to reduce child deaths?
- III. How can the data available be used to identify national trends and patterns, particularly unusual events occurring in a locality which might otherwise be regarded as a one off tragic accident which might in fact be repeated elsewhere?
- IV. Should the DfE collect data from CDOPs on a regular basis and with what frequency, and if so at what level of aggregation, what data items should be collected and how could the data be used to highlight issues and reduce child deaths?
- V. How could CDOPs make better use of informal networks to share information and learning?
- VI. What cost savings can be identified?

- VII. What actions and recommendations have CDOPs made which have been successful, and are the impacts monitored and shared with other CDOPs?
- VIII. What evidence is there that national lessons are being learned and to what extent are the recommendations and actions of CDOPs focused at the local, regional and national level?

3. Methods

The study was conducted between December 2012 and March 2013.

3.1 Study design

The research objectives were met by using two different methods. First, an e-mail survey was conducted with questionnaires sent to all CDOPs across England with the aim of collecting representative data to address the more quantitative of the research aims. Second, a series of broad ranging telephone and face-to-face interviews with a sample of CDOP co-ordinators, managers and chairs was conducted.

The information from the questionnaire survey enabled purposive sampling of the CDOPs for the interviews based on characteristics of the different CDOPs including some interviews with staff from CDOPs that did not respond to the e-mail survey. The final aspect of the study was a small number of informal interviews with other stakeholders who have an interest in the collection, collation and use of child death data for the prevention of child deaths; these interviews provided background information and the findings are not specifically reported here. An Advisory Group (Appendix B) convened by the DfE met once, and at the meeting and subsequently in writing the members provided advice and comment.

3.2 Email survey methods

3.2.1 The questionnaire

A straightforward questionnaire was developed in consultation with DfE staff, which was a simple Word document designed for completion and return electronically (Appendix C). The questionnaire was designed to collect information to directly address all the research questions to some extent with the exception of (vi) “What cost savings can be identified?”

The questions were a mixture of purely factual questions with some opinion based questions. Where appropriate, pre-specified options were provided in order to minimise the requirement to provide free text answers; although section 3, which asked about actions and recommendations resulting from CDOP reviews, consisted wholly of free text answers.

The questionnaire was divided in the following five sections:

1. **Information about the CDOP.** These were largely factual questions concerning operational aspects of the CDOP which required a mixture of numerical, categorical and open text responses.

2. **Notification and handling of information about child deaths.** These were largely factual questions which required a mixture of numerical, categorical and open text responses.
3. **Actions and recommendations resulting from CDOP reviews.** This section required open text responses with the suggestion that some of these responses could be 'cut and pasted' from the CDOP annual report, although others did require specific answers.
4. **Whether and how further use can be made of the information collected by CDOPs.** These questions required a mixture of categorical and open text responses.
5. **Exploring the issues further.** This section asked the respondents to indicate their willingness and the willingness of their colleagues to be interviewed for the purposes of the project; there was also an opportunity to provide any further information they felt appropriate.

The data collected included specific details about the individual CDOPs and were therefore not collected anonymously. Confidentiality was assured to the questionnaire recipients and consent to participate in the survey was implied by completion and return of the questionnaire.

3.3.2 Despatch and return of completed questionnaires

CDOPs were identified from the list of CDOP contacts published on the DfE website in November 2012. A total of 94 separate CDOPs were identified as serving the 148 LSCBs across the country. During the course of the survey one CDOP merged with another so that the final number invited to participate was 93.

The questionnaire was emailed as an attachment with an individual personalised email to the CDOP co-ordinator for each CDOP together with a covering letter (Appendix D) explaining the purpose of the survey and providing other details. The questionnaires were emailed in early December 2012. The completed questionnaires included in the analysis were returned by the end of February 2013 following a maximum of two reminder emails.

3.3 Interview methods

A series of broad-ranging telephone and face-to-face interviews was conducted with 11 CDOP co-ordinators/managers/chairs. The purpose of the interviews was to collect a greater depth and richness of information than can be collected in a largely quantitative survey questionnaire with the intention of developing a deeper understanding of the relevant issues through the views and experiences of the interviewees [Mason, 2002]. The interviews, as a qualitative process, were not able to provide representative data. The intention was to focus on collecting additional information to aid further understanding of the issues raised in the questionnaire responses.

All the interviews were carried out by a single interviewer (JJK), audio recorded (with the permission of the interviewee), and transcribed verbatim by a single audio-typist. The interviews were conducted using a combination of an initial narrative component to encourage the interviewees to freely describe their views and experiences of the use and value of CDOP data and how better use could be made of the data nationally. This element of the interview tended to be discursive with the interviewer responding to the comments made by the interviewee and on occasion asking further questions for clarification and to aid understanding. The narrative phase was followed by a semi-structured, prompt-led phase to pick up on topics and questions not covered in the initial discussion and also to further probe issues raised earlier; in some interviews all the salient points were covered in the course of the narrative phase. An initial prompt-guide was developed with reference to the original research questions and the responses to the survey questionnaire; the guide was further refined as the interviews progressed. A copy of the final prompt guide is given in Appendix E.

The questionnaire survey responses were used to purposively sample the CDOPs to ensure that a range of CDOPs were included. The characteristics used for sampling purposes included: the size of the population covered by the CDOP; coverage of predominantly inner city, urban, and rural populations; geographical representation across the country; and other characteristics associated with CDOP activities which emerged from the survey data, for example both similar and different methods of working compared to the generality of CDOPs. For those CDOPs where we had a completed survey questionnaire only those co-ordinators/managers/chairs who had indicated a willingness to be interviewed (which was the majority) were approached.

A total of 10 CDOPs who responded to the survey were initially approached for interview. No response to the personal email invitation was received from two potential interviewees; eight interviews were carried out with this group of CDOP co-ordinators, managers and chairs.

A sample of non-responders to the questionnaire survey was also approached to be interviewed. This was on the basis of trying to obtain information from the less responsive group and to assess the representativeness of the survey respondents. The sample was selected on the basis of a combination of geography to ensure that sufficient information was collected from CDOPs covering a predominantly rural area; the size of the CDOPs in order to include examples of CDOPs which dealt with a large number of LSCBs; and on the advice of Sarah Wolstenholme (Safeguarding and Vulnerable Children's Analysis Team, Department for Education) who is responsible for collecting the DfE annual return information from CDOPs.

A total of 11 'non-responder' CDOPs were initially approached on this basis with a single email; no further contact was attempted with those who did not respond. A total of three interviews were conducted with this group of CDOP co-ordinators, managers and chairs.

At the Advisory Group meeting a decision was made to explore further the expectations regarding a national database, by approaching a small number of CDOPs who had indicated in their questionnaire responses that they felt that further national data should be collected. Three further interviews which concentrated solely on this narrower focus were therefore carried out.

The intention had been to follow the original tender specification and conduct ~ 20 telephone interviews and ~ 6 face-to-face more in-depth interviews. However, the intention had also been to carry out as many interviews as needed until no new themes were emerging (theoretical data saturation), to carry out two further interviews to confirm that data saturation had been reached and then to stop. Due to pressure of time, availability of respondents due to holidays and the location of respondents, only one interview was conducted face-to-face; nevertheless detailed and in-depth interviews were possible on the telephone.

It became apparent that no new themes were emerging after the first eight interviews. A total of 11 interviews were carried out between 13th February and 7th March 2013; with the duration of the interviews ranging from 20 to 60 minutes with a median of 45 minutes.

The three subsequent focused interviews were carried out on the 15th and 16th April 2013 and lasted for about 25 minutes each. Thus a total of 14 interviews were conducted although the latter three had a narrower focus compared with the initial 11 which were more broad-ranging.

3.4 Data handling and analysis

Completed questionnaires were coded using pre-specified numerical codes for responses where this was appropriate; open text responses which could be quantified were coded into post-hoc categories based on the responses; other responses were dealt with as text. The data were entered into a Microsoft Excel spread-sheet and checked for accuracy against the original questionnaires. A purely descriptive analysis was carried out. Categorical data are presented as frequencies. Continuous numerical data are presented primarily as medians as the data for most variables was heavily skewed, with the minimum and maximum values given as the range.

Analysis of the qualitative survey data and the interviews was based broadly on the Framework Analysis approach (Richie & Spencer, 1994). Following reading and re-reading of the interview transcripts the open text themes were indexed manually and categorised under the broad themes and sub-themes.

3.5 Ethical considerations

By the nature of the project which involved information collected from professionals only the ethical considerations were not overly onerous; research ethics committee approval was therefore not sought. The research was nevertheless conducted according to the ethical and research standards prescribed by the Medical Research Council and other regulatory and advisory bodies. Throughout participants were treated with dignity and respect and their data were kept confidential and secure.

Consent to participate in the email survey was implied by completion and return of the questionnaires. Verbal consent to participate in interviews was sought and recorded at the start of the interview, in particular permission was sought to audio-record the interviews and this was made clear in the invitation email and confirmed at the start of each interview.

3.6 Advisory Group

An advisory group was convened by DfE to provide advice to the project team and on the interpretation of the findings. A single meeting was held on 20th March 2013 and the members provided written comment and advice on the final report. Members of the advisory group are listed in Appendix B.

4. Findings

The findings from the two different methods of data collections are presented together. The qualitative findings from both the interviews and questionnaires are used to illustrate the quantitative results.

The findings from the interviews fall into three broad themes:

- operational arrangements of the CDOPs
- data issues
- learning, actions and communication

with a series of 25 sub-themes (Appendix F). These three overarching themes have been used to structure the presentation of the findings.

4.1 Questionnaire response and invitations for interview

Questionnaires were sent to a total of 94 CDOP co-ordinators; during the data collection period one CDOP merged with another thus the final number of potential respondents was 93. A total of 54 completed questionnaires were returned giving a response of 58%.

Fourteen interviews were conducted in total; these included eleven interviews with individuals involved with CDOPs from which a completed questionnaire had been returned and three interviews with individuals involved with CDOPs from which a questionnaire had not returned. Some of the individuals interviewed are involved with more than one CDOP thus overall, combining the different sources of data, information was obtained from a total of 59 CDOPs which represents 63% of CDOPs overall, covering 100 (68%) of the 148 LSCBs.

From the questionnaire responses alone information was collected from CDOPs which cover populations in which an estimated total of 2,775 child deaths occurred in the year April 2011 through March 2012 (calculated from the questionnaire responses). By comparison with the total number of deaths 0-17yrs in England reported by the Office for National Statistics as registered in 2011 this covers an estimated 64% of all child deaths.

4.2 Characteristics of the CDOPs who responded to the questionnaire

One of the themes common to some degree to all aspects of the findings of this study is the extent of the variation between CDOPs in most aspects of their arrangements and operations. This most likely reflects the genesis of CDOPs with local arrangements set in place based on local interpretation of the 'Working Together' guidance and which has evolved since the first CDOPs were established. As one interviewee reported:

“.....people agreed that if they were re-starting it now, they may do it slightly differently and maybe follow the model where it [Ref: the CDOP team] is based in the acute [Ref: health] sector.”

Table 4.1 summarises the characteristics of the CDOPs who responded to the questionnaire and the populations they serve. The majority of CDOPs who responded relate to one LSCB (59%), nearly one-fifth relate to two LSBCs, just less than one-sixth relate to three, and the final four CDOPs relate to four or more LSCBs.

As a consequence of local arrangements, with over 40% of CDOPs covering more than one LSCB, and the variation in size of LSCBs, the child population for which individual CDOPs are responsible range from as few as 35,500 to nearly 1.7 million with the median at just over 125,000 (Table 4.1). These arrangements, together with underlying geographical variations in mortality rates, are reflected in the number of child deaths for which each CDOP is responsible for reviewing each year: the overall median number of deaths which occurred in April 2011 through March 2012 is 45 but this ranged from 10 to 150.

The populations which the CDOPs serve are also characterised in geographical terms since this is likely to have consequences in terms of the risk of child deaths for some types of deaths. Given the general distribution of the population in England and the size of the areas covered by many CDOPs it was not surprising to find that 30% of CDOPs cover mixed city, urban and rural populations and nearly two-thirds (63%) cover some combination of city, urban and rural. Only 7% of responding CDOPs serve a predominantly rural population.

Table 4.1 Characteristics of the child death overview panels (CDOPs) and the population which they serve (n=54)

| Characteristics | Number | Percentage |
|--|------------------|------------|
| Number of LSCBs to which the CDOP relates: | | |
| One | 32 | 59% |
| Two | 10 | 19% |
| Three | 8 | 15% |
| Four or more | 4 | 7% |
| Total population of children aged 0-17yrs served by the CDOP: | | |
| Median | 125,468 | -- |
| Range | 35,500-1,674,300 | -- |
| Total number of deaths of children aged 0-17 deaths which occurred in the CDOP population April 2011-March 2012: | | |
| Median | 45 | -- |
| Range | 10-150 | -- |
| Geographical area served by the CDOP: | | |
| Predominantly a city area | 5 | 9% |
| Mixed city and urban area | 8 | 15% |
| Predominantly/completely an urban (not city) area | 9 | 17% |
| Mixed city, urban and rural area | 16 | 30% |
| Mixed urban and rural area | 12 | 22% |
| Predominately a rural area | 4 | 7% |

4.3 Operational arrangements of the CDOPs

4.3.1 Staffing and panel membership

The operational arrangements of the CDOPs also reflect a wide variation with the first of these variations being the title of staff working in CDOPs. In common with the DfE listing of CDOP contacts the term 'CDOP co-ordinator' was used throughout the questionnaire, it is however clear that this term is not used universally and also the meaning of this title varies from CDOP to CDOP with some co-ordinators having a purely junior administrative role whereas others are managers and others still have a much broader professional remit, for example, some are the 'single point of contact' (SPOC). A small number (7%) of CDOPs had more than one person designated in the co-ordinator role and these were the larger CDOPs (Table 4.2). Information was also sought about other support for running the CDOP and just over half of CDOPs receive some additional support which, for some of the larger CDOPs, was substantial, for example, an additional full-time-equivalent member of staff.

The variation between CDOPs continues with the professional background of the CDOP Chair. Whilst nearly two-thirds of CDOPs from which data were received are chaired by a public health professional (the majority being Directors of Public Health), 13% of CDOPs have an independent chair, 9% are chaired by the designated nurse or safeguarding nurse, 7% are chaired by the designated doctor or a paediatrician more generally, and 9% are chaired by a range of other professionals.

Nearly three-quarters of responder CDOPs run just one panel, one-fifth run two panels and three CDOPs run three panels. These additional panels were largely referred to as sub-panels and the vast majority were established to review neonatal deaths although one was designated as an 'expected medical deaths audit' and the term 'pre-viable' audit was also used.

The review of neonatal deaths clearly varies from CDOP to CDOP and this was an issue about which several people who were interviewed held strong views as illustrated by the following quotes:

".....in some places neonatal reviews are just looked at by a neonatologist who says there is no issue. And then they just put those ... those deaths as not preventable and that's the review. That isn't, in my view, what the Child Death Review process is supposed to be about and isn't a full review and definitely in our experience in [*name of CDOP*] we are doing proper neonatal reviews, but if you do them properly and gather information from obstetric and midwifery and other agencies, you We have had in the last two or three years, we've had as many preventable deaths in the neonatal grouping as in the other areas. But the issues that are interesting and have definitely presented quite significant challenges and some recommendations have all been about obstetrics and midwifery."

"We get an awful lot of neonatal notifications and one of the big things is that it always gets marked as prematurity and I suppose again that is a very broad term."

".....and we kind of went down that line because when we used to do them at panel, we got so bogged down in all the neonatal cases... I think it was that we didn't have the expertise round the table....."

Other CDOPs which have not set up sub-panels to look at neonatal deaths have taken a different approach:

"Another area that we actually sort of collect data on specific group is neonates and we have just reviewed them all together, once a year."

"So equally the review of the cases is not consistent. So, for example, in [*name of one CDOP*] their CDOP does not fully review any expected deaths or any neonatal deaths. Both cases are reviewed by a sort of sub-set of the panel, which have

sort of less people attending. But those cases are reviewed in full in [*name of another CDOP*].”

Table 4.2 Operational structures of the child death overview panels (n=54)

| Operational structures of the panels | Number | Percentage |
|---|-----------------|------------|
| Co-ordinator support for the panel: | | |
| Number of co-ordinators: | | |
| One co-ordinator | 50 | 93% |
| Two or more co-ordinators | 4 | 7% |
| %FTE co-ordinator time: | | |
| Median | 60% | -- |
| Range | 15% - 220% | -- |
| Additional support provided to assist the CDOP: | | |
| Yes | 29 | 54% |
| No | 25 | 46% |
| Designation of the CDOP Chair: | | |
| Public health professional ¹ | 35 | 63% |
| Designated doctor/Paediatrician | 4 | 7% |
| Designated/safeguarding nurse | 5 | 9% |
| Independent chair | 7 | 13% |
| Other ² | 5 | 9% |
| Total | 56 ³ | |
| Number of panels run by the CDOP: ⁴ | | |
| One panel | 43 | 74% |
| Two panels | 11 | 20% |
| Three panels | 2 | 6% |
| Total | 56 ³ | |
| Number of main panels members: | | |
| Median | 12 | -- |
| Range | 7 - 22 | -- |
| Number of 'sub-panel' members ⁴ : | | |
| Median | 6 | -- |
| Range | 2 - 12 | -- |

1. Many, but not all, public health (PH) professionals were either Directors of PH or Consultants in PH

2. Two directors from clinical commissioning groups (CCGs), one manager from an acute trust, one manager from a cluster and one manager from the police service

3. There is a total of 56 here because one CDOP covering three LSCBs has three chairs, one for each LSBC area and panel even though the CDOP reports itself as operating as a single CDOP

4. CDOPs with a second or third panel predominantly refer to them as the main panel and a sub-panel

The number of main panel members and their professional backgrounds also varies widely. The median number of main panel members is 12 but this ranges from 7 to 22. Different terminology, often related to managerial roles, which was used to describe people probably undertaking the same role made identifying the individual professionals represented on panels difficult. From the survey data it was only possible to identify four professional groups which are common to all the CDOPs panels: paediatricians, nurses, police officers and social care workers. Although public health professionals are present on the vast majority of CDOPs and indeed chair the majority of panels, they are not universally represented and even when listed their engagement in some places appears limited:

“You know, there isn’t a lot of linking in with public health; it’s very dependent on your local public health people, and..... There is no, sort of guidance about that. There’s no structure for it. And my experience is, a lot of public health people aren’t really interested.”

“We struggle with getting Public Health there. I think recently they have been there once. We have had them sort of 10% of the time perhaps.”

Similarly obstetric and midwifery staff are far from universally represented despite the fact that in 2011 49% of all child deaths 0-17yrs occurred in the neonatal period and a proportion of these deaths will inevitably be related to aspects of care during pregnancy, labour and delivery. Twenty-seven (50%) of the main panels had a midwifery member whereas from the information given it was not possible to identify a single main panel member who was an obstetrician. Of the 13 CDOPs which also have a sub-panel seven (54%) have a midwifery member and three (23%) have an obstetric member. Some of these difficulties are illustrated by the following interview comments:

“We found it very difficult to get anybodywe got a midwife but we couldn’t get a neonatologist or a physician along.”

“..... It is very difficult to get the hospital clinicians at all.”

“.....so we have been holding joint meetings once a year in our local hospital trust and we insist that they bring along an obstetrician and gynaecologist ... an obstetrician and a neonatologist and then we actually go through sort of a few of our neonatal death cases..... and then we can actually have a proper conversation which we cannot do otherwise.”

Despite the difficulties faced by some CDOPs positive aspects of the membership of panels and the panel operations were mentioned by several interviewees and are illustrated by the following comments:

“And because we have got – I think we’ve got the right people around the table, they do tend to bring out things that I would not necessarily see in social care and we’ve got the police and they are really good at attending, so we have got all the

different aspects and we can bring in other people who aren't, although we haven't really needed to, to be honest.”

“So it does feel that it has taken a while, but it is a very confident panel now in terms of the decision... I think because the people know each other they feel happier to make those challenges. So they know it is a safe challenge and that it is not going to go any further.”

“Child death reviews have always been seen as important within [*name of place*] and examination of causes of Infant/child deaths has been taking place since 1996 in Public Health within [*name of PCT*]. Membership of the panel has had a core membership group dating back to those days.”

4.3.2 CDOP funding and resourcing arrangements

In terms of the funding arrangements of the CDOPs a specific question was asked as to whether the CDOP has a designated budget. Just less than two-thirds of CDOPs indicated they have a designated budget for their CDOP (Table 4.3). The size of budget varies widely with a median value of just under £52,000 per annum but ranging from just less than £10,000 to £200,000. The use made of the budget also varies widely (Table 4.3); salary costs of CDOP staff was the most frequently mentioned item by 32 of the 33 CDOPs with a designated budget. Some CDOPs indicated they pay for the time of the chair, other members of their CDOP panel and designated doctor costs; thus whose time is being paid for from the designated budget varied widely across CDOPs. Use of the designated budget for activities such as prevention campaigns was mentioned by only four (12%) CDOPs.

The designated budget figures must be interpreted with some caution because clearly for those CDOPs without a designated budget similar, and certainly staff, costs were being met from a budget even if this was not made explicit to the CDOP staff through a designated budget. Furthermore, those CDOPs with very small budgets clearly were only required to use these for primarily dissemination activities and not to fund staff, the costs for which were obviously being met from elsewhere as illustrated by the following:

“The manager's role is hosted by health (although the manager is an officer of the LSCB) and the post sits within community health, as does the admin role. There is 1 SUDIC Doctor – community based. They do not provide an on call service. They are not paid for from the CDOP budget. We have seven named nurses who as part of their full time safeguarding posts undertake home visits with the police – they are not paid for out of the CDOP budget.”

In view of the difficulty of interpreting the budget figures the issue of resources devoted to the CDOP process was also explored from the perspective of time spent reviewing cases and the time spent by the CDOP staff running the whole process required to support the panel reviews. One major cost which is not covered directly by CDOP budgets in most

instances is the costs of the time spent by chairs and panels members which are presumably met by their employing organisations. To estimate this contribution the number of person-hours spent reviewing child deaths was calculated by multiplying the number of panel members by the frequency and duration of meetings. From this it was estimated that a total of ~386,670 professional person-hours were spent by the CDOP panel members reviewing ~2,775 child deaths at the individual CDOP level; this equates to a median of ~5.1 person-hours spent in panel reviews for each child death reviewed with a range from 1.3 to 14.2 person-hours (Table 4.3).

The hours of CDOP staff time spent running all aspects of the process required to support the panel meetings was also estimated by multiplying the number of hours of staff time per week by 44 (number of working weeks in a year) and dividing by the total number of child deaths per year in each CDOP. From this it is estimated that a median of 34.7 person-hours are spent by CDOP staff running the entire CDOP process for every child whose death is reviewed (range 10.5 to 195 person-hours).

Table 4.3 Funding arrangements and person resources of the child death (n=54)

| Funding and resource arrangements for the panels | Number | Percentage |
|---|----------------------|------------|
| Designated CDOP budget: | | |
| Yes | 33 | 60% |
| No | 19 | 35% |
| Missing | 2 | 4% |
| Size of the designated budget (£) per annum: | | |
| Median | £51,762 ¹ | -- |
| Range | £9,750 - £200,000 | -- |
| Spending arrangements for the designated budget ² (n=33): | | |
| Salaries only | 20 | 61% |
| Salaries and activities | 12 | 36% |
| Training | 7 | 21% |
| Prevention campaigns | 4 | 12% |
| Admin, sundry items, accommodation costs | 1 | 3% |
| Non-recurrent IT costs | 1 | 3% |
| CDOP staff development | 1 | 3% |
| Commissioning research | 1 | 3% |
| Publications | 1 | 3% |
| Person-hours of professional time spent reviewing child death – hours per child death reviewed ³ : | | |
| Median | 5.1 hrs | -- |
| Range | 1.3 – 14.2 hrs | -- |
| Person-hours of CDOP staff time undertaking the CDOP work – hours of staff time per child death reviewed ^{4,5} : | | |
| Median | 34.7hrs | -- |
| Range | 10.4 – 195.4 hrs | -- |

1. Based on data from 30 CDOPs as three CDOPs who indicated they had a designated budget did not provide information about its value

2. Not mutually exclusive, thus percentages total more than 100%

3. Estimated individually for each CDOP by multiplying the number of panel members by the frequency and duration of panel meetings and dividing by the total number of child deaths per year in that CDOP

4. Estimated individually for each CDOP by multiplying the number of hours of staff time employed by 44 weeks (assumed average number of weeks worked per year) and dividing by the total number of child deaths per year in that CDOP

5. Based on 50 CDOPs for which the relevant data were provided

4.3.3 CDOP panel meeting arrangements

Main panel meeting are held with a varying degree of frequency with meetings on alternate months being the most common pattern, 46% (Table 4.4). Sixteen percent of CDOPs meet monthly and 4% only six monthly. One consequence of infrequent meetings is illustrated by the following interviewee who commented on the difficulty of consistency when panel meetings were held infrequently:

“So I just think we are ... we are terribly inefficient ... it feels terribly inconsistent, it often seems that the categorisation..... for some [Ref: meetings] we might be obsessed by one theme and another [Ref: meeting] it might be something else.”

Most commonly the meetings last for 3 hours (median) but this ranges from 2 hours to whole day meetings. Between three and 20 deaths are reviewed at each meeting with the median being seven. Of note a number of CDOPs hold special meetings occasionally. The estimate given above based on panel meetings and in Table 4.4 do not include the additional sub-panel meetings held most commonly to review neonatal deaths or other meetings held on occasion to review particular types of deaths.

Table 4.4 Operational management of the child death overview panel meetings (n=54)

| Operational management of the panel meetings | Number | Percentage |
|--|-----------------|------------|
| Frequency of main panel meetings: | | |
| Monthly (12/yr) ¹ | 9 | 16% |
| Nine meetings per year (9/yr) | 2 | 4% |
| Alternate months (6/yr) | 26 | 46% |
| Quarterly (4/yr) | 17 | 30% |
| Six monthly (2/yr) | 2 | 4% |
| Total | 56 ² | 100% |
| Duration of the main panel meetings: | | |
| Median (hrs) | 3 | -- |
| Range (hrs) | 2 - 7 | -- |
| Number of child death reviewed at each panel meeting: ³ | | |
| Median | 7 | -- |
| Range | 3 - 20 | -- |

1. Often miss at least one meeting in summer

2. There is a total of 56 here because one CDOP covering three LSCBs has three chairs, one for each LSBC area and panel even though the CDOP reports itself as operating as a single CDOP

3. This was often presented as a range from which we took the upper limit and is therefore likely to be an over-estimate rather than an under-estimate

4.4 Data issues

4.4.1 Receipt of information and data quality

Section 2 of the questionnaire asked about the process of notification of death and how the CDOP handles the data received. Modes of receipt of notifications include paper forms through the post, secure emails, secure faxes and telephone calls. Two CDOPs who completed the questionnaire are running web-based data entry systems and all notification and data are collected this way from the relevant agencies in their area.

Nearly three-quarters of CDOPs indicated that they have concerns about the quality of the information they receive about each child death (Table 4.5). A free text response box allowed the respondent to indicate their concerns; some gave more than one concern. The most common single concern was about the provision of incomplete data which was mentioned in 29 (54%) responses; this sometimes included incomplete information about the cause and circumstances surrounding the death, ethnicity in particular, and information about the parents and family. Other concerns include:

- lack of consistency in the data provided;
- the time taken to receive the information back;
- a lack of understanding about the role of CDOPs and their activities;
- the difficulty of obtaining information from GPs;
- the need to get information about the pregnancy, which for many deaths can be difficult to obtain.

Of note in relation to the latter in the past this information had been provided via the CMACE forms forwarded on by maternity and neonatal units. In the future MBRRACE-UK (the organisation which has replaced CMACE) data will be provided to CDOPs.

“Previously CMACE used to advise us of all neonates deaths wherever they occurred in the UK, this aided our ability to track these deaths greatly. We have done a lot of work revising systems and networks but are aware that it still seems possible to receive late notifications and we strive to avoid missing notifications.”

Table 4.5 Process of child death notification and data handling (n=54)

| Child death notification processes and data handling | Number | Percentage |
|--|---------------|-------------------|
| Any concerns about the quality of information received: | | |
| Yes | 39 | 72% |
| No | 15 | 28% |
| Use of an electronic administrative database: | | |
| Completely computerised admin system | 13 | 24% |
| Mixed manual and computerised system | 41 | 76% |
| Type of administrative database: | | |
| Excel spread-sheets ¹ | 44 | 82% |
| Access database | 10 | 18% |
| Adequacy of the administrative database: | | |
| Adequate | 27 | 50% |
| Inadequate | 27 | 50% |
| Use of template 'C' for documenting panel findings: | | |
| Yes | 52 | 96% |
| No | 2 | 4% |
| Of those using template 'C' extent of completion (n=52): | | |
| Complete all form 'C' | 42 | 81% |
| Partially complete | 8 | 15% |
| Varies | 1 | 2% |
| Missing | 1 | 2% |
| Use an electronic data base to collate panel findings: | | |
| Yes | 50 | 93% |
| No | 4 | 7% |
| Are the panel findings in a database which is integrated with the administrative database: | | |
| Yes | 35 | 65% |
| No | 19 | 35% |

1. Includes two CDOPs who collect the data using a web-based data entry application but then use Excel spread-sheets to store their data

Concerns in general about data quality and variations in quality were raised by most interviewees. These ranged from concerns about the quality of the information provided to CDOPs, how the information is dealt with and coded by CDOP (with lack of consistency between CDOPs frequently mentioned but inconsistency within the CDOP was also mentioned), through to concerns about the quality of information submitted in the annual return to DfE. The following quotes illustrate the strength of feeling that the interviewees generally expressed:

“I have grave concerns about the integrity of the data. That’s my big concern really. It doesn’t appear to be systematically collected and I have always felt there should have been an actual database.... I also felt that the co-ordinators are

taking responsibility for inputting this data and these co-ordinators really aren't supported. They are not given any training. There is no standardisation of how this data is collected and I am sure, as you know, the CDOPs across the country vary in size."

"Yeah and you know there is no standardisation. There is an inability really to answer any of the questions that we have. And there is no assurance or quality control about the data."

"But also I wonder how accurate this data is because nobody is entering it in the same way."

"..... I know, because of the work I do that many authorities are actually filling those returns in after a very minimal review."

"Yes. I think at the moment it is done so badly and so inconsistently that it is a waste of time and money..... I think if you wanted to do this properly, which I think if you want any sensible learning from it, you should be trying to do it properly and given the amount of money that is thrown at it. It is disrespectful to be honest for the children who have died, if you want to put it in bleak and emotional terms. I think that the way that it is done at the moment is so haphazard, it is so idiosyncratic.The CDOPthe whole thing..... The reviews, the organisation, who is on the panel, which data items they collect."

".....but for me as a Public Health person, the main thing is that if you are doing this sort of thing on a national basis, I think you should be doing it consistently."

4.4.2 Use of and changes to the national templates

Template 'C' is the most commonly used of the DfE data collection templates with 52 of the 54 CDOPs using the form 'C' although not all complete the entire form, nor do they necessarily enter the data from the form 'Cs' into their database (Table 4.5). Form C includes the cause of death and summary as well as details of the modifiable issues identified, learning points, recommendations and actions specific to the case.

Beyond the main form 'B' (the 'agency report' which collects identifying information, details of circumstances of the death, details about the child, family environment and circumstances, parenting and contact with services) there are 11 different condition-specific 'B' forms (b2 to b12). The use of the conditions-specific 'B' forms varies by form but overall about a third of CDOPs either do not use the condition-specific forms at all or only use them manually and do not computerise the data; about a quarter use them and partially computerise the data; about a third use them and computerise the data completely; and 4% did not respond to this question.

It was clear from the interviews that some CDOPs have modified the forms to make them more user friendly, for example, by reducing the number of questions which were

irrelevant to a particular agency. The following quotes from interviewees illustrate this point:

“All of the questions that are on the sort of statutory Form B are reflected in the Form Bs that we send out, but they are just reflected to the appropriate agencies who can answer them. Because if you send a 20 page form to somebody and they don't see the relevance, they are probably not going to spend the time to fill it out because they are very busy with other things. But you know if you just extract the questions they could have reasonably answered, and we have added a few other ones in that have become ones that our panel at the [*name of CDOP*] have felt necessary to be asked on different things. So like, you know, for example the ambulance service form that we use has just got the details of the time of the call, dispatch times and then, you know, specific details about the incident and where the child was taken and the resuscitation, as opposed to “Was this child on the Child Protection Plan?”The thing to mention here is that the ones we amended were done in conjunction with each agency. So we didn't sort of arbitrarily say “Because we are sitting in this office, we know what is best”. We had a meeting with our contacts in Social Care or our contacts in the ambulance service and we discussed which ones they felt they could reasonably answer and then that informed it.”

“ So we have kind of had to trim them down to actually what is needed from particular people “I just need this bit off you. Obviously if you have got anything else, please enter it.”

One of the interviewees, who is a paediatrician, also reflected on the contents of the forms from a clinical and data provider point of view:

“..... they are not very user friendly and people they send them out to don't send them back partly because they are so daunting. So we say things like, “Well just fill out the bits you know about”.....”

There was evidence that those CDOPs who had made modifications to the content of the templates had found a clear improvement in the speed, completeness and quality of data provision:

“But since we have been doing that, which has been 2010, we have had a huge increase in information gathered and hugely improved hit rate of getting those forms back.”

“And we have found a much better response rate from that. Because sometimes people were opening the pages and seeing there are 15 pages and thinking – ‘I can't do that'.”

Other CDOPs had however, held off making changes on the basis that they are waiting for a national process:

“And we’ve put off reviewing them [ref: the data collection templates] in [*name of CDOP*]- we’ve talked about changing and developing them – because we keep being told that there is going to be national process.”

4.4.3 Handling and processing CDOP data

Questions about how the CDOPs handle and process the data they receive were included in the questionnaire. Three-quarters of CDOPs indicated that they use a mixed manual and computerised system, and only a quarter use a completely computerised system (Table 4.5). However, these simple summary figures hide again a very wide variation in what having a ‘computerised system’ means. From one extreme this was a fully functioning Access database which is able to be interrogated to produce reports, through to keeping the information about child deaths in a series of Microsoft Word documents and having one Excel spread-sheet to track the cases. The most common electronic tool used to store data is Excel and more than four out of five CDOPs indicated that they store their administrative data in either one or a series of Excel spread-sheets.

Whilst 93% of CDOPs enter their panel findings into an electronic database, which is helpful for completing the DfE annual return and producing their local annual report, only 65% enter the data into a database which is integrated with their administrative database. For some this is explained by the fact that the administrative function is provided by one organisation and the person responsible for managing the panel findings and producing the annual report is based in a different organisation. Nevertheless this suggests a poor level of efficiency with presumably some data items having to be entered into the two separate systems thereby doubling the risk of errors and inconsistencies.

It is clear from the comments made in the questionnaire and interviews that data handling and manipulation is a major issue for many CDOPs; only 50% of respondents to the questionnaire indicated that they think their database is adequate for their needs (Table 4.5). But even a statement of adequacy was qualified by a number of questionnaire respondents:

“Adequate to a point – I have to store text information in other places e.g. a Word document contact sheet.”

“The spread-sheet is adequate for managing the local cases however it does not allow for any detailed analysis of information.”

The following quotes from interviewees further illustrate some of the problems that CDOPs face in storing and analysing data:

“One of our big problems, many of the CDOPs will use Excel spread-sheets, which are great, you know, if they only have twenty cases a year. For us we are having over [*mentioned a medium to large number*] cases and it is a nightmare and we are working on a database but that is just taking years and we are still not in a position to be able to interrogate this database. So that has a huge impact on

learning. And it is just a huge concern for me and for somebody that, you know, started off right at the beginning of all of this and you can feel it grow. I feel really disappointed, if I am honest, in the DfE because I really do think that was the tool that should have been put in place right at the beginning.”

“No, that is the problem we have got. At the moment we are still working part on spread-sheets and partly, you know, trying to develop this database.”

“To be quite honest it is a nightmare. And it was fine, you know, at the beginning of this programme we only had, you know, a few cases, then, you know, a spread-sheet was fine, you could do it manually. But now there are so many cases you can’t.”

“ there is no proper spread-sheet, it is just all free text, which means when you are analysing it, there is no sort of categorical data that’s consistent. It is a complete mess and I think that is the same in a lot of CDOPs, they just didn’t have the resources to put into it. And for me the main purpose of doing these things with death is about learning and sharing information.”

What then became clear through the course of several interviews was that the reason so many CDOPs started by using Excel spread-sheets (and thus have continued) was the expectation at the outset, from when CDOPs were first established, that a national database was going to be implemented:

“Right, well it had been the intention of the government from when the process first commenced in 2008 that there would be a national collation of the information that is submitted. Originally it was through all the information that is provided on the Form Bs And because we questioned when we were sent the template, how much details goes in there and the way it was laid out, it wasn’t particularly user friendly. And they told us at that time they were designed for uploading on to an electronic system. That’s why we started with Excel spread-sheets so we were expecting all that information at the point at which we inputted on to our local systems, that at some point we would have to upload that to a national system and that never happened.”

“And this was the one chance we had of collecting [Ref: national] qualitative and quantitative data and we are not ... I am sorry, it sounds very negative, but it is because I value the programme, I would like to see it done properly.”

Having started with predominantly Excel spread-sheets the capacity of most CDOPs to improve their data handling procedures was clearly limited in many cases by an inability to access proper information technology (IT) support:

“Because IT don’t have the time – they are giving us time in dribs and drabs”

“No IT support to maintain, design or update spread sheets to enable ease of entry and analysis. E.g. drop down boxes etc. for categorical data.”

As a consequence of these data handling problem it is clear that for some CDOPs that even completing the relatively limited annual data return to DfE is a major piece of work:

”that is a big piece of work, once a year, and because of the numbers of deaths that we have it is massive for us.”

“....so it is all paper based. The information is there but you have to go through it manually.”

The limitations of the local data systems also impacts on the ease with which some local annual reports can be produced.

“They can get the data in and I spend hours doing pivot tables and stuff and you know you should think I shouldn’t have to be I can do it of course I can, but it is an expensive use of Public Health Consultant’s time to be cleaning data and doing pivot tables [*to produce the annual report*].”

This contrasts quite starkly with the experience of one of the CDOPs who has a fully functioning Access database and the CDOP staff have sufficient IT skills to run reports themselves and to make changes to their database:

“Because I do ... every year I do an update to our databases and I just re-programme to reflect additional questions that the DfE ask in their return. And also questions, comments from the people who use the database in our office who say “that this would be better if it could do this or it would be better if we could have this drop down box” or whatever it might be. So every year there is sort of an updated version to make it a bit more useful and user friendly. And we find that works quite well, and we also find that, you know, when we get requests in from people for information, so we have requests sort of from the [*name of area*] Cancer Network and other people for figures on malignancy. It is extremely quick and easy to extract that information from the database, which is obviously what you want, isn’t it?”

4.4.4 Use of CDOP data and the DfE Child Death statistical releases

Aggregated data are requested by the DfE from CDOPs. The data are summarised and published by the DfE in an annual statistical release which in 2012 was entitled ‘Child Death Reviews’. A question was included in the questionnaire to seek information about how CDOPs use the information published in this annual statistical release (Table 4.6).

Two-thirds of CDOPs reported using the information provided by DfE in the annual statistical release although nearly 20% did not indicate the specific use they made of this information. Of those using the information benchmarking and comparison in their annual

report were the main uses reported, with the second use being as information for CDOP panel members. About a third of CDOPs thought the DfE collate enough information and half thought not enough information was collated by the DfE in this way.

Only scant details were given in open text answers about the use to which DfE statistical release information is put. However, the main types of comparisons appear to be with the process measures and the following was a typical response to the question of how the CDOP use the DfE statistical information:

“To compare the regional figures/findings with the national picture. Often this will be used to support the Annual Report findings. However, we have often questioned the validity of some of the figures on this report.”

“Well, I think at the moment it is very frustrating because the only ... the only information that is collected nationally is about process, not about outcomes..... because they don't ask you about any of the findings that you are finding from the process.”

“I actually think that the data skews are present because the data is all about process and it isn't about what you find from it. And there is actually, from the CDOPs that are doing it properly, a wealth of data that isn't being gathered or used in any way. It is all being kept in local CDOPs, where it is meaningless because the data numbers are too small for you to use it any meaningful way.”

Table 4.6 Use of CDOP data and Department for Education statistical release information (n=54)

| Use of data | Number | Percentage |
|---|--------|------------|
| Use of information from CDOPs published by DfE : | | |
| Yes, we use this information | 36 | 67% |
| No, we do not use this information | 11 | 20% |
| Missing response | 7 | 13% |
| How the DfE statistical return information is used (n=36): | | |
| For activity comparison/benchmarking ¹ | 23 | 64% |
| For information to the CDOP members | 6 | 17% |
| Indicated use, but no specific use given | 7 | 19% |
| Does DfE collate enough information nationally: | | |
| Not enough information is collated by DfE | 28 | 52% |
| Enough information is collated by DfE | 17 | 31% |
| Too much information is collated by DfE | 0 | 0% |
| Missing | 9 | 17% |
| Should more data should be collected and analysed nationally ² : | | |
| Yes | 38 | 70% |
| No | 8 | 15% |
| Missing | 8 | 15% |
| How the CDOP use their own information to identify trends ³ : | | |
| Informal regional and national CDOP network | 21 | 39% |
| Too few deaths to identify trends | 4 | 7% |
| Use the professional judgement & panel memory | 19 | 35% |
| Analyses of cumulated data over time | 8 | 15% |
| Missing | 4 | 7% |

1. Some mentioned using the information when they write the annual report
2. The question indicated that this question did not make any assumption about who might undertake this collection and analysis
3. Some CDOPs gave more than one response thus the total is greater than 100%

One fifth of CDOPs said that they don't use the DfE statistical release information at all and one in ten (13%) did not answer this question. The following quotes are typical of the answers to the question as to why they do not use the statistical release information:

"We are aware of and have read it but we have not identified a way of responding to or using the information."

"We are not convinced about its consistency and hence reliability."

"The information is not particularly helpful or relevant"

"The information collected seems to fulfil a data need rather being used in any practical, meaningful way."

“There is sparse data with inadequate details.”

“The information collected should be intelligent so that it can be used to make a difference rather than to audit what the CDOP are doing with their time.”

Similar views were reflected in the interviews:

“.....the national templates when you have sent them in you don't seem to get much. We send the information in but we don't really seem to get much back.”

“.....and the return that the DfE want is weird; it is just bizarre; total process.”

4.4.5 Data collection needs

When asked in a closed question 70% of CDOPs said that they thought more information should be collected and analysed on a national basis; this question was explicit about making no assumptions about who and how this type of data collection might occur (Table 4.6). In response to the next question as to how this might be achieved the single most common response to this open text question was “through the creation of a national database.” A sample of the many questionnaire responses is given below:

“A national database, which local CDOPs can update after they have reviewed cases and which could be used for their own data analysis as well as at a regional and national level.”

“Central database where CDOPs can input their deaths and this can be reviewed at a national level as to causes of death, local trends, recommendations, etc.”

“Central point for storing learning and recommendations could highlight deaths from what might seem a particularly unique set of circumstances but drilling down into the findings might identify issues relevant or of interest to other areas.

Existing information collated using Form Bs at local level is more than adequate, but it would be helpful to develop and roll out a national database (so consistent info from all areas) to upload local information for analysis by local and national public health statisticians/epidemiologists, etc.”

“By the use of a national database that allowed for real time input.”

“National online database/data collection.”

“It is the analysis of the information that is currently missing, the deaths in one area are often too few to draw many conclusions and make recommendations.”

Aspects of how a national data collection and the interpretation of the data might be achieved are illustrated by the following comment from an interviewee:

“..... but if I was given a freehand with it, I would say it needs to be linked to a university with some proper researchers who know what they are doing, not hobbyist like me..... Work out how much money you want to spend on it, either chose some sensible sites or do it properly nationally.”

“Need input from experts in data analysis to review national data.”

The strength of feeling about the need for national collation and comparison of data, and particularly the analysis of trends and the identification of newly emerging causes of death, also emerged through the responses to questions about how CDOPs use the information they collect to determine if a particular death is a one-off tragic event or part of a wider trend and how they use the information to examine trends over time. While most CDOPs attempt to identify trends the problem of small numbers is illustrated by the fact that in order to do so they mainly rely on the judgement and collective memory of the panel members (mentioned by 35%) to identify if a case is a one-off event and by using the informal national network of CDOP co-ordinators (39%) to identify if they have seen a similar case (Table 4.6). Interviewees also commented on this, as illustrated here:

“There is an internet group and people send out asking for information and we always contribute to that and we have a national newsletter. I think we are just a bit concerned that we might have one or two deaths here, we see in isolation but there might actually be one or two deaths in every area. There isn't really a very good mechanism for pulling together experiences of other areas or like that.”

“We started since very early, we started and it was one of the bigger LSCBs with about [*average number of children mentioned*] children. And even so the numbers are very small, it is a bit difficult to spot trends. I mean we would never spot a trend in cancer, for instance, because the numbers are too tiny. But nationally that would... you would. You would need to clean/collect the data much better one thing is prematurity but that is like we have 35%/40% of all deaths. But once you get to the rarer things you are never going to spot them.”

“Again, it is hard to know whether it is statistically significant because of the small numbers.”

“I suppose locally the issues we have, are when looking at our numbers, obviously what we want are small numbers, but that in turn brings issues with trying to bring together any meaningful data from them. So when we report back to the LSCB, they will ask us to say what impact we have made, how that has reduced deaths, and obviously because the numbers are small, it is very difficult to interpret that.”

“But again the numbers are so small, so even with getting Public Health in. And maybe there is nothing to be done but it just feels like we are missing that bit extra, that we have still got quite a limited picture. Whereas to have, I suppose, much more of a national picture may help people at the panel again to decide that

we actually feel comfortable or is there something else we could do? Or actually we should be taking this further and what those next steps would be.”

As the following interviewee reflected, for some CDOPs the small numbers effect and thus the inability to identify trends has led to challenges about the purpose and value of their CDOP:

“We’ve had a lot of challenges locally from the LSCB about the report and that kind of goes back to the data again. Because it is very much an overview and what they want to know is how many deaths did you prevent, what did we learn what did we do? And so there has been an awful lot of discussion. And one of the things with the new Chair, he is very, very clear about what you can [Ref: conclude] and what you can’t.”

“..... and they [Ref: LSCB] will say, as well, all the stuff about the safe sleeping. ‘The numbers did go down slightly. Well, obviously that impacted.’ But no you can’t justit would be lovely to think that we done that, but actually you would need a lot more data.”

“...although obviously that is teased out a bit when you then do it over three years and you do start to see some sort of themes coming through that. Although, as you rightly say, it is very difficult to sort of draw any conclusions from that with such small numbers.”

“And you know that is one of the things that when they did our review [Ref: the CDOP was reviewed], saying well you have to demonstrate value for money.”

The strength of feeling about the lack of national data from which more detailed information including outcomes and trends can be analysed also emerged from the narrative phase of the interviews. This is illustrated by the following, small selection, of available quotes:

“For me fundamentally coming here [Ref: arriving in post] and finding that there is no sort of aggregated information from national aggregated information, or sharing, or any sort of formal routes of sharing information does seem to make it sort of pointless. A bit like the maternal death survey, the numbers are so small that you cannot make any sense out of them locally, but, you know, there are a lot of lessons to be learnt across the country.”

“You won’t get any energy to review forms and make them more useful for purpose or whatever, unless people have some sense of it being used for a purpose. At the moment, with the best will in the world, with a CDOP that is really committed to it, who was doing it, before it actually was even, you know, in the pilot, we are struggling to maintain the energy to fill in all those blooming boxes, when we know that we do very little with them. So why continue?”

“I do think, I personally think that if there isn’t some sort of national collation of findings, people will stop doing it. It’s as simple as that.”

“Actually I think it is a [*expletive*] scandal. I nearly wrote to The Times, because I think it is such a scandal that really a lot of money has been spent setting up the CDOP. We have collected all this data and as far as I can see nobody has done anything with it. Well when you report centrally is... All we report centrally is the number of deaths and how many are preventable. Well, that’s not any use is it?”

4.4.6 The informal CDOP network

The questionnaire did not include any specific questions about the informal network of CDOP co-ordinators. However this was raised in the context of responses to several questions about data in the questionnaire and during the interviews. This is effectively an informal email network that CDOP co-ordinators use to contact other co-ordinators, for example, to share materials they have developed, but also to seek information about particular cases which they have seen in order to identify whether other similar cases have been seen elsewhere. Whilst in the absence of a more organised approach this provides a useful source of information and means of sharing several of the interviewees raised concerns and described the limitations of the network:

“And sometimes you do see people with the best of intentions are putting stuff out with advice attached that you may have very junior co-ordinators, you know, picking up on that advice and really I think that needs to be centrally co-ordinated and, you know, somebody that, you know has much more awareness and expertise being able to put out the right advice and smart stuff, rather than knee jerk reactions really.”

“..... there are different things that come around, saying have you had incidents of this, which are so informal and it is up to you whether you get back to them and say “yes” or “no” really. But there are things that people in different areas who think it is appropriate, raise and send them all to the CDOP. Something is happening informally but nothing is being pulled together properly.”

“.....and then there is some ad hoc stuff about the weird and the wonderful that people write saying has anybody had patio doors fall on people? And things like that. And then ... so unless there is some consistent way of doing it, I don’t get any feeling that anyone taking any central control of that.”

“And the issues with that are they don’t have to respond if they don’t want to, so it is not a very accurate picture and you kind of have that thing about resources, thinking we’re going to do this and [*name of a person*] might say we are doing this and [*name of a place*] might say we are doing something else.”

“We had one particular death, which I guess was more sensitive than most and emailed round saying has anyone has anything similar and a couple of people

came back saying “Yes but we won’t share” because they were very mindful about where they wanted that information to go. Some areas said that they were thinking about doing a campaign, others weren’t. And again, I guess it is that mixed message because it is at times like that you think well actually there would be some merit in, I guess, getting a national lead on ‘should we do anything with this’? What is the wider picture? Because it very much felt like we’d got one view, somebody else had got a slightly different view again ...”

“.....but I have to confess that even sometimes when I have got something positive to say, it drops to the bottom of my list because we have got so much other work to do.”

4.5 Learning, actions and communication

The questionnaire included a series of questions seeking open text responses designed to: explore the type of recommendations and actions which have resulted from CDOP reviews and the impact these recommendations have had; identify examples of local activities and actions which might be suitable for sharing more widely with either neighbouring CDOPs or nationally and those which only have local relevance; understand the formal and informal links between CDOPs and local serious care review (SCR) panels and how CDOPs make use of SCR findings; find out whether and how CDOPs contribute to national learning; and to find out whether CDOPs staff think further use could be made of local CDOP data and the recommendations which panels make.

4.5.1 Local recommendations, actions and impacts

The vast majority of questionnaire respondents gave detailed examples of the recommendations and actions which have resulted from the learning from the CDOP reviews; quite a number gave extensive examples by quoting directly from their annual report. The following vignette represents a mixture of responses from different CDOPs but overall is typical of the type of responses the majority of CDOPs gave to the questions about recommendations and actions:

- SIDS prevention campaign focusing on day time sleeping place and position and the identification of high risk families;
- A change in procedures for the health visiting service in contacting families who do not attend appointments for immunisations;
- Specific road traffic safety measures in a particular area;
- Review of palliative services and care pathways for children with life limiting conditions;
- Develop a suicide prevention strategy for teenagers;

- To write to all [*named groups of individuals*] in schools to highlight that all pupils excluded for drugs should be referred to appropriate drug support agencies.

The majority of CDOPs gave examples of learning resulting in recommendations and actions which were very specific to their local services and circumstances, for instance, a recommendation about specific road safety measures in a particular location and a recommendation to review local palliative services and care pathways. However, these were generally given alongside other examples which could clearly be generalised to some extent in terms of their action, for example, a SIDS prevention campaign, writing to schools in relation to drug use and the need to refer pupils excluded from school for drug use to appropriate drug support agencies.

Examples of impacts are similarly drawn from examples given by many CDOPs and are summarised in the vignette below. Although the examples given below related to a variety of aspects the overriding finding is that the majority of impacts relate to clinical/social service organisation and delivery, and relate to service improvements.

- The Local Safeguarding Children Board has made suicide prevention integral to its priorities.
- Changes have been made to existing pathways in caring for children and young people.
- Practical steps have been taken to improve road signage on the [*name*] Road.
- The [*name*] LSCB has vulnerable babies as one of their 2012/13 priorities. This will raise awareness with both professionals and the public around issues e.g. co-sleeping, alcohol and smoking.
- CDOP manager now attends the [*name*] Road Safety Group, therefore, creating stronger links.
- All women booked to deliver in the local NHS trust now have a Pre-CAF [Ref: common assessment framework] assessment record identifying risk of domestic violence, thinking about what needs to be done if they have other children and need admitting etc.

During the course of the interviews the issue of where across the three domains of safeguarding, clinical/social service organisation and delivery, and public health, the majority of recommendations and actions lie was specifically explored. The following illustrate typical responses:

“I think the other thing about the whole process as a general thing is I feel that although there is a bit of a mismatch now between whether we are reviewing child deaths from a sort of social and safeguarding implications of them, or whether it is safeguarding thing. Or, because most obviously 35-40% of them are going to be neonatal, premature babies, all of them, that are expected deaths and should we

be reviewing them. I don't know whether you can build it into this? Whether that is a good use of time or whether that should be done somewhere else?"

"I went to the [*name of another CDOP*] CDOP and the [*name of another CDOP*] CDOP and they tended to have much more of a public health focus than they existing in [*name of own CDOP*]. I am not sure why that was because the Consultant in Public Health had been chairing the meetings, but it didn't feel like a predominantly safeguarding thing, which I think it should do."

"We haven't had many safeguarding ones, interestingly. We have just got our first newest case review for about, I think it is about, three years..... I think most recommendations are clinical. Public health certainly has two or three public health.....public health recommendations to be taken forward."

".....and actually the majority of them are probably on the clinical side. There is a much smaller number on the public health and safeguarding side."

Several respondents to the questionnaire reflected here again, in response to these questions, the difficulty in demonstrating impact in terms of child deaths prevented:

"The total number of deaths is small so measuring impact is difficult. However one good example is continuing work around safe sleeping and the introduction of a safe sleeping risk assessment and training for frontline staff."

4.5.2 Local actions suitable for sharing more widely

The examples given of local activities and actions which might be suitable for sharing more widely with either neighbouring CDOPs or nationally were fewer in number than those which only have local relevance. However, examples relating to materials developed for local campaigns to prevent sudden infant deaths, to improve bereavement and palliative care services, and activities around specific teenage suicides are three areas which were cited with examples of learning and sharing which is already going on and could be expanded further if there was a mechanism for doing so. Most of the shared learning is with neighbouring CDOPs or CDOPs in the same region which already have formal or semi-formal arrangements to work together, but there are also examples where CDOPs have identified other CDOPs with similar problems in different parts of the country and have organised joint meetings to discuss the particular issue and to share learning and actions.

There was evidence of quite a lot of 'regional activity' with some areas having regular and frequent 'regional' meetings to share experiences, to discuss cases and to identify common learning and actions. In some parts of the country this is well established and these types of activities have carried on in recent times. However, it is also clear that these types of meeting are not universal; some CDOPs do not appear to participate in this kind of regional sharing at all or did in the past but recent meetings have not been organised. The demise of Government Regional Offices and Strategic Health Authorities

who took the lead in organising some of these meetings were cited as reasons why some regional meetings have stopped happening:

“With the demise of Local Government Officers there has also been an end to the regional CDOP Chairs/Coordinators meetings in our area and so there is no ‘formal’ sharing at the moment as there is no-one coordinating this.”

Evidence of clear benefit of these types of regional activities was cited in the questionnaire responses and includes amongst others: sharing good practice, the capacity to start to identify unusual patterns and types of death, sharing management protocols and policies which have been developed to avoid duplication of effort, and dissemination of findings and recommendations.

4.5.3 Formal and informal links between CDOPs and SCR panels

National data collected by DfE suggests that 1% of the child death reviews completed in 2011-12 were also subject to a serious case review (Department for Education, 2012). In relation to the Serious Case Review (SCR) panels there was a wide variation in terms of the relationship between the SCR panel and the CDOP. At one extreme, there was little interaction and the CDOP just receives the SCR report to integrate into the CDOP process and at the other extreme there is a close working relationship between the two panels with some individuals, for example the designated doctor, being a member of both panels. Where mentioned the sequence of events for most CDOPs is that they will wait until the SCR panel review was complete so that their findings can be incorporated into the CDOP review process. The two extremes of operation are illustrated by the following quotes from two questionnaire respondents:

“We have agreed with LSCB chairs relatively recently that the panel will receive the full report of any SCR or other form of local review following the death of a child. There is learning as a result across the three areas that make up our panel. I consider that there is more we could do but have to negotiate what is properly our responsibility as against that of the LSCB. We have never liaised with the SCR panel.”

“In our area, members of the CDOP are also members of SCR Panels therefore information sharing is very good. Lessons learnt are disseminated to other localities present in the CDOP (there are 3 localities within the [name] CDOP).”

4.5.4 National learning from CDOP findings and data

In response to the question about what CDOPs and their local partners do to contribute to national learning from their local panel findings 19 (35%) did not respond to the question; and 20 (37%) responded but gave either an answer which indicated that they do not do anything to contribute or gave an example of either local or regional learning.

The types of responses where national action has been attempted by 15 (28%) of CDOPs and has been successful in some cases are illustrated below:

“HPA [Ref: Health Protection Agency]* initiative relating to meningitis will be cascaded nationally” [*Note HPA is now part of Public Health England]

“Our Safer Sleeping Guidance has been acknowledged nationally by FSID.”

“The [*name of service*] Fire Service put posters on fire engines which strongly encouraged people to make sure babies and children were strapped into car seats. Fire engines from this service cover a large part of the geographical area of [*name of area of the country*]. We have been in discussion with British Waterways over canal safety, but with little effect. Window safety discussed with Child Accident Prevention Trust (CAPT). CONI [Ref: Care of Next Infant] data submitted as part of national evaluation. This could be enhanced but would need a national database to be effective – also resources to analyse and effect sharing.”

“[*Name of place*] has liaised effectively with HEFA (Human Embryology and Fertilisation Authority) re [Ref: regarding] number of deaths of babies conceived with medical intervention- often as twin embryos- and number who died. Promoted research results of single embryo fertilisation. There has been a definite reduction of deaths of babies who were conceived with medical intervention, but we are not able to prove that this was due to these interventions.”

Frustration about the lack of a proper mechanism for feeding into national learning or some means of national co-ordination was also evident in some of the responses where examples of national actions were not given but the reasons why were noted. The issue of the need for national collation and information sharing, to provide a central focus for action again emerged in these responses:

“SIDS deaths for example is a national issue which is borne out by the number of CDOPs that have conducted local campaigns and whilst I accept there should be local ownership to a degree my expectation is that where themes, modifiable factors and recommendations are consistently identified there should be some national recognition of this and steps taken to address these on a national level. I have been to a number of national conferences and this comes up every time which I think reflects the frustration of CDOPs.”

“We complete the DFE annual return and respond to national emails via the CDOP coordinator network. There is currently no other mechanism for national learning, a database would certainly be welcomed and national workshops/ conferences would also be useful.”

“The findings and recommendations are all fed through the LSCB mechanism and are reported centrally. CDOP are limited to a mandatory annual report and we do

feel there should be a better mechanism for sharing our learning and actions taken in response to the recommendations.”

“Without the use of a national database this is difficult although regular sharing does contribute to CDOP review through e-mail correspondence.”

“At present this is done through completing the DfE Annual Returns and responding to enquiries that are sent informally across the national network of CDOP Coordinators.”

“Not formally but [*name of place*] has good contacts with national CDOP coordinators. However, there is a danger that national and local trends will not be identified if there is not a more formal method of information sharing.”

“And I know we had a case recently where a child died of [*rare preventable cause*]. And that has been a big one nationally, but trying to get data about how many children nationally have been affected by this sort of issue is problematic.”

“....without any national data collection, it is extremely difficult to get action at a national level taken forward.”

5. Discussion

The response to this study by many CDOP co-ordinators, managers and chairs was enthusiastic and the passion that individuals working in CDOPs feel for their work in child death prevention came through in their responses to many questions and during the course of the interviews.

However, with a response of 58% to the questionnaire survey the representativeness and thus the generalisability of the findings to all CDOPs must be considered. Importantly some information, either through the questionnaire and the interviews or the interviews alone, was available from 63% of CDOPs which relate to 68% of LSCBs. Findings which can be directly compared with the national data published by DfE include the average number of CDOP meetings per year and the average number of child deaths reviewed at each meeting (Department for Education 2012). Reassuringly the survey results reflect very closely the national figures for both of these aspects. Furthermore the findings from the small number of interviews conducted with CDOP staff where a questionnaire had not been returned indicated that the non-responder CDOPs are not materially different in terms of their activities and staff views from responder CDOPs. This suggests that the findings reported here are likely to be representative of English CDOPs in general and can be generalised across all CDOPs in England with some confidence.

CDOPs were established to have a local focus and this has clearly been successful on many levels. The variation in organisation which ranges from differences in the size of the CDOP, the size of the panels, the number of staff, the frequency and duration of meeting between CDOPs is one reflection of this localism. Local arrangements have been developed to make the process work locally, and to suit the local services and agencies with which the CDOPs work. Relationships with the local service providers are essential to ensure that the information necessary to conduct panel reviews is provided to CDOPs and although there is some evidence of delays and concerns about completeness and data quality these issues can only be addressed realistically at a local level. Making local modifications to the national data collection templates is one means by which some CDOPs have improved both the speed of return of information and its completeness. The local arrangements which have been developed have also served to ensure that CDOP recommendations are implemented in ways which are relevant to local service provision and local circumstances and many examples of this were given in both the questionnaires and the interviews.

CDOP panels vary hugely in size. Some CDOPs have experienced some difficulties in recruiting appropriate members to their CDOP panels with obstetricians being a group notable by their low level of representation despite the fact that neonatal deaths account for nearly half of all child deaths. Related to this is the whole issue of how neonatal deaths are reviewed with some panels undertaking minimal review and other undertaking full review and making recommendations about service improvements as a consequence. Despite the fact that central guidance on dealing with the dilemma of how to review neonatal deaths has been issued confusion and different local approaches

persist suggesting that either the guidance or how it is expressed might benefit from review.

One aspect of CDOP functions which is clearly of concern is the management of the data which the CDOPs collect. The use of Excel spread-sheets for the long term storage of information of this type is concerning for several reasons including the capacity when using Excel spread-sheets to inadvertently change data items, and to sort the data by individual column(s) and thereby irretrievably disrupt the integrity of the data. It is clear that the capacity of some CDOPs to even return the limited information requested annually by DfE is severely limited by the limitations of Excel spread-sheets as the primary means of manipulating their data. In addition a number of CDOPs have an almost completely manual system of data storage. There was also evidence that a substantial proportion of CDOPs have separate data storage for administrative information and the panel findings leading to an inevitable duplication of effort and doubling the risk of data errors for pieces of information common to both systems.

Many of the CDOPs using Excel clearly wish to develop a better database system but are impeded by their limited or lack of access to the necessary IT support to do so. The experience of these CDOPs contrasts sharply with the experience of CDOPs who run properly integrated Access databases and have the capacity to modify their database and run reports to generate selected outputs rapidly. The experience of the latter CDOPs gives an insight into what might be possible and the potential benefits of having a properly functioning national database.

It became evident from a number of interviews that the reason why CDOPs had chosen to store their data using Excel spread-sheets when they were establishing their local processes was their expectations from early discussions that a national system of data collection was going to be introduced. There was clear frustration and disappointment with the limited information which is collected by DfE and this was evidently not what CDOPs were expecting from the outset. Whilst the statistical releases produced by DfE based on the annual returns of data by CDOPs are used by about half of CDOPs who also indicated how they used the information, their use is clearly limited by the content. The content of the releases was noted by several interviewees as primarily focusing on process rather than outcomes and was described by one participant as “essentially an audit of CDOP activity.” There is limited scope and there little evidence of enthusiasm on the part of CDOPs for extending the amount of this type of information collected in this way by DfE.

The capacity of CDOPs to use their own data to examine time trends and identify one-off causes of death versus an emerging pattern is by definition limited by the (fortunately) small number of child deaths and child deaths of particular types which occur in even the largest of the CDOPs. As a number of interviewees commented the absence of national data to enable examination of individual causes of deaths means it is simply not possible to identify the difference between a one-off cause and an emerging trend other than to resort to contacting other CDOP co-ordinators through the informal email network. While

this has resulted in the identification of specific causes of death, for example nappy sack suffocation (Benyon & Hayes, 2012), Benyon reported the extensive effort and prolonged time it took to identify other deaths from the same cause elsewhere using the informal e-mail network and searching for news reports of cases (Benyon & Hayes, 2012). This resulted in a delay in identifying this cause of death as an emerging concern and thus before preventive action could be taken.

The informal CDOP email network is the only mechanism that CDOP staff currently have to communicate with all other CDOP staff across England. The risk of relying on such an informal system is that preventable causes of deaths are not identified and the chances of preventing future deaths are missed. One interviewee also noted with concern that advice was being issued through this route and questioned the veracity of some of the advice. Even with the most enthusiastic participants this informal approach to national case identification is a very poor and risky substitute for a formalised alert and alarm system based on properly collected and analysed national data.

Not surprisingly with the main focus of CDOP activity being very local the majority of learning and actions happen at the local level and for the many of the findings and recommendations CDOPs make this is wholly appropriate. The main focus of findings relate to clinical service delivery and organisation resulting in local service improvements. Some of the findings and service improvements relate to services for children with life limiting conditions and palliative care rather than the prevention of death. However, it seems wholly appropriate that if a death cannot be prevented then the focus should be on providing services to ensure a 'good death'. An improvement in bereavement services is one service improvement mentioned by a number of interviewees and in questionnaire responses which has resulted directly as a consequence of CDOP recommendations.

Some duplication of effort across CDOPs was evident, for example in the production of materials for staff such as health visitors. Some sharing of materials and findings does occur but duplication of effort could be minimised further with better formal mechanisms for sharing information and ideas. This would result in some cost savings, although based on the proportion of designated CDOP budgets which are spent on 'campaign' or information materials, which is small, the cost savings would by necessity also be relatively small.

There was evidence of regional sharing and learning which, in the interviews and responses to the questionnaire, was clearly a beneficial way of sharing information, issues, concerns and preventive approaches. However, such regional sharing and learning is not occurring universally and the recent restructuring of health service and the demise of local government offices has led to the loss of some (but not all) of this regional activity which these organisations took responsibility for organising in some areas. It is to be hoped that somewhere in the newly emerging structures that this responsibility will once again be reassumed. At present is not clear where the drivers for this will come from although the wholesale move of public health staff from the NHS into local authorities may help this process. Public health specialists are involved in the

majority of CDOPs and will appreciate the need for review and sharing of findings and activities at a population level above that of most CDOPs given the inherent problems of basing conclusions and actions on the small numbers of deaths reviewed in most CDOPs.

There was little evidence of national learning going on other than through events arranged by organisations such as the Lullaby Trust (formerly the Foundation for the Study of Infant Death – FSID). A small number of CDOPs have sought to engage with national bodies such as the Human Fertilization and Embryology Authority but without a more formal mechanism for this type of engagement they are at risk of being a lone voice in the wilderness. In the absence of additional national data collation holding national meetings would be one approach to achieving some elements of national data sharing. At present the funding of such meetings tends to rely on the voluntary sector, for example the meeting run by the Lullaby Trust in 2012. Meetings run and funded by central government would be one way of ensuring such meetings happen without having to rely on the support of small charities.

Extensive time and resources are devoted to ensuring that the deaths of all children are reviewed thoroughly through the CDOP process. With an average of five person-hours of professional time being devoted to the review of each child death in the panel process it is clear this statutory responsibility is taken very seriously by LSCBs. It is also clear that the whole process to support the operations of CDOPs requires a high and sustained level of administrative and managerial support. The process is complicated, the collection and manipulation of information to support the panel reviews is detailed and lengthy, the final analysis of CDOP data required to produce local annual reports is complex, and the reporting and implementation of recommendations is time consuming. Furthermore, current data systems in most CDOPs add too rather than reduce this complexity. It is important that LSCBs recognise the complexity at all levels and that the process of providing support to CDOPs is not seen as a purely administrative one which can be undertaken solely by relatively junior clerical staff.

The overall findings from this study highlight the missed opportunities to capitalise on the strong local structures and vital focus of work at the local level by the failure to collect, analyse and disseminate the data CDOPs collect locally at a national level. Frustration and anger best describe the feeling expressed in the questionnaires and in the interviews about the lack of a national database. When CDOPs were first established expectations of a national database were raised and staff in CDOPs now feel very let down and disappointed by the failure to implement a properly functioning national data collection. It is essential that the work of CDOPs continues at the local level since it is at this level that service improvements will be achieved. However, this goal is entirely compatible with the goal of prospective data collection and analysis of CDOP data at the national level. A national database has the potential to reap benefits in terms of the analysis of the causes and circumstances surrounding all child deaths; to examine geographical and time trends; to identify newly emerging patterns of causes of death; and from which properly

evaluated and data driven alerts and alarms could be issued. In the long term interventions to reduce child deaths developed as a consequence of being able to examine child death data properly could also be robustly evaluated if national data are available. Finally it is essential to emphasise that none of this is possible for individual CDOPs dealing with just their own data.

An alternative to a national database and one option posed as part of the research questions in the tender specification for this study would be the commissioning of detailed research by an independent contractor to identify key trends and national lessons learnt using existing CDOP data. The first difficulty with this approach is that it is evident that at present, because of a lack of clear definitions and standardisation across CDOPs, different data items are collected by CDOPs and apparently similar data items are collected and coded according to different working definitions. Second, the data are currently held in over 80 different databases and some CDOPs don't actually have anything resembling an electronic database; thus the extraction and merging of the electronic data to create a single database for analysis would be far from a trivial technical exercise. The latter point may lead to incomplete participation and thus the data collated would not be 'national'. Finally, this could only be conducted as a one off retrospective activity and once concluded would provide no future improvement to the quality and availability of CDOP data unless repeated at regular intervals; this would be a complex and costly option and furthermore concerns about data quality and thus the veracity of any conclusions would inevitably remain.

In contrast a national database would provide the impetus, focus and necessity for the standardisation of the data items collected and coded by CDOPs thereby improving the quality of data collection. If the data were collected prospectively using modern methods of electronic data capture at the individual child level with complete identifiers, and with appropriate regulatory authorisation for linkage purposes, this has the potential to lead to the capacity to link to other sources of national data, for example hospital inpatient data, thereby extending the value and outputs from the data and leading to a better understanding of the antecedents of child deaths and thus the capacity to prevent a greater number of deaths. Such a database could be designed to support local data analysis and production of local reports as well as enabling analysis at the national level. A national database located in an appropriate centre of excellence could also provide a focus for shared learning between and across CDOPs. Part of the database function could be to act as a central repository for information materials to reduce duplication of effort, it could also include a discussion forum to support the regular exchange of information and ideas between CDOP staff including individual CDOP recommendations; and the annual analysis and release of the national report could be launched at national meetings organised by the database team.

The design of any national database and the data items to be collected must include input from CDOP staff and not be imposed in a 'top down' fashion. A primarily 'bottom up' approach to the design is the only way to ensure the system is fit for purpose, will be

used to its maximum advantage by the CDOPs and thus the quality of data collected will be high. A detailed scoping of the content of a national database was beyond the capacity of this short project but would be an essential step, in collaboration with CDOPs, to maximise functionality for both local and national users of the data.

Finally making links with the newly established National Child and Maternal Health Intelligence Network and relevant national data collections will be vital to ensure that the data will be used for the maximum benefit of children.

6. Recommendations

- 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.

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Appendix A – Summary of Tender Specification

Purpose/objectives

The key aim of the study is to recommend the most cost effective options for making the best use of the information held by CDOPs and thereby help practitioners to understand and share the lessons on how best to prevent child deaths.

The study will:

- Investigate how to make best use of the data collected by CDOPs. This will include evaluating the suitability of the following options:
 - detailed research which would be carried out on a regular basis by independent contractors to identify key trends and national lessons learned;
 - developing a national database which draws on information which already exists and could be analysed on a regular basis;
 - developing new standardised national data collection forms (which may also be applicable to SCRs) to be submitted to the department on an annual basis; and
 - making better use of informal links across CDOPs.

There is no presumption that any one of these options should be followed, therefore the merits of all options should be investigated alongside other options which are suggested by the CDOPs who are interviewed.

- Estimate the associated cost to the department and CDOPs of the proposed options;
- Determine what information should be collected from/shared across CDOPs on a regular basis to be able to learn national lessons; and
- Investigate the most efficient ways to share information, lessons learned and best practice.

To achieve these objectives, the research will address the following key research questions:

- How are data currently collected, used, stored and analysed by CDOPs?
- How do CDOPs think the data they have collected could be used by the department, CDOPs and external bodies to reduce child deaths?
- How can the data available be used to identify national trends and patterns? How can we identify issues which at a local level may appear to be a one off tragic accident but actually immerge to be a wider issue when the information is collected and analysed nationally?

- Should the Department collect data from CDOPs on a regular basis? – Should this be aggregate or child level? What data items should be collected?
- How could these data be used to highlight issues and reduce child deaths?
- How frequently should they be collected?
- How could CDOP make better use of informal networks to share information and learning?
- What cost savings can be identified? Could costs be saved by running joint campaigns? Or by sharing market research? Or sharing designs/items used for awareness raising? Are these lessons to be learned nationally from campaigns which haven't been successful?
- What actions and recommendations have CDOPs made which have been successful? Do CDOPs monitor this and are these lessons shared nationally?
- What evidence is there that national lessons are being learned? Are the recommendations and actions of CDOPs focused at a local level or are they also at a regional or national level?

Methodology

This will be a relatively small scale study. Views from approximately 20 CDOPs will be gathered on what more the department, external organisations and CDOPs themselves could do to make better use of the data. Details on how these CDOPs currently collect, store and analyse the data they hold about individual child deaths will also be collected. We anticipate that this will be done via telephone interviews with the appropriate person within the CDOP (CDOPs chairs and/or co-ordinators.) These CDOPs will be selected to ensure a range is included with regard to size and rural/urban location.

In-depth interviews will be undertaken in a small number (approximately 6) of these CDOPs to gather more detailed information from CDOP chairs and co-ordinators to help identify potential national patterns, one-off concerns that could potentially be national issues, how they would like to see information shared nationally and across CDOPs and suggestions of cost savings.

Outputs

There will be two main outputs from this research:

- A full report to DfE which will be published as part of the Department's research report series; and
- A short 2000-word summary of the research, to follow the standardised format of a DfE Research Brief.

Appendix B – Membership of the advisory group

Members who attended the advisory group meeting to discuss the draft report and emerging findings

Peter Sidebotham, Associate Professor in Child Health, University of Warwick,
Consultant Paediatrician, Warwickshire Community Health

Irene Wright, Merseyside CDOP Manager, Liverpool Safeguarding Children Board

Susie Crook, CDOP Manager, Worcestershire CDOP

Christine Humphrey, Department of Health

Members who provided written comment on the final report

Irene Wright, Merseyside CDOP Manager, Liverpool Safeguarding Children Board

Susie Crook, CDOP Manager, Worcestershire CDOP

Nicky Brownjohn, Associate Director for Safeguarding (CWHH)/Designated Nurse for
Safeguarding Children (Westminster, Kensington and Chelsea; Chair, Pan-London
CDOP Chairs' Group

Appendix C – Copy of the email questionnaire

'How to make better use of information from child death reviews nationally'

Questionnaire

Please return your completed questionnaire by email to:

lynne.roberts@npeu.ox.ac.uk

If you prefer to complete the questionnaire by hand, please print it out ensuring that you have expanded the text boxes in the tables sufficiently to complete your answers and return your completed questionnaire by post to:

Lynne Roberts
National Perinatal Epidemiology Unit
University of Oxford
Old Road Campus
Headington
Oxford OX3 7LX

If you have any queries or you would like any further information about this project please either email:

jenny.kurinczuk@npeu.ox.ac.uk **or** lynne.roberts@npeu.ox.ac.uk

or

telephone: 01865 289719



Thank you

Section 1: Information about you and your CDOP

The first section of questions asks for details about you, your CDOP, the population your CDOP serves and the support available for the running of your CDOP

| Questions | | Please add your responses into these boxes | |
|-----------|---|--|--|
| 1.1 | As the person/people involved in completing this questionnaire please give your name(s) and email address(es): | <i>If more than one person was involved in answering the questionnaire, please give both names and email addresses</i> | |
| 1.2 | What is/are your designation(s)? <i>For example CDOP Co-ordinator and CDOP Chair</i> | <i>If more than one person was involved in answering the questionnaire, please give the designation of both people</i> | |
| 1.3 | What is the name of the CDOP about which you are giving information? | | |
| 1.4 | How many Local Safeguarding Children Boards (LSCBs) does your CDOP relate to? | | |
| 1.5 | What is/are the name(s) of the LSCB(s) to which your CDOP relates? | | |
| 1.6 | What is the total child population of the area which your CDOP serves? | <i>Please include all children up to their 18th birthday</i> | |
| 1.7 | How many child deaths occurred in your CDOP area in the period 1 st April 2011 to 31 st March 2012? | <i>Please include all the deaths you have been notified about regardless of whether they have all undergone panel review</i> | |
| 1.8 | Please indicate which of the following best describes the area which your CDOP serves: | <i>Please delete as appropriate:</i> Predominantly a city area | |

| | | | |
|------|--|---|--|
| | | <p>A mixed city and urban area Predominantly an urban (but not city) area A mixed city, urban and rural area A mixed urban and rural area Predominately a rural (but not remote) area A remote rural area Other – <i>please describe:</i></p> | |
| 1.9 | a. Do you have a single CDOP panel or more than one CDOP panel, for example a neonatal sub-panel in addition to your main panel? | <p><i>Please delete as appropriate:</i></p> <p>We have a single panel – <i>please go to 1.10</i> We also have a second panel or a sub-panel – <i>please go to 1.9b</i></p> | |
| | b. If you have more than one panel or a sub-panel please indicate the different activities your panels cover: | | |
| 1.10 | Please give the name and designation of your CDOP Chair: <i>For example Dr Jane Doe, Consultant in Public Health</i> | | |
| 1.11 | How many core members are there on your CDOP panel? <i>This excludes co-opted members who may be invited to discuss specific issues or cases</i> | <i>If you have more than one panel or a sub-panel please answer separately for the different panels:</i> | |
| 1.12 | Please list the core panel membership of your CDOP by giving the designation (but not names) of each member - please indicate if there is more than one member with the same designation <i>For example two community paediatricians:</i> | <i>If you have more than one panel or a sub-panel please list them separately for the different panels:</i> | |
| 1.13 | How often does your CDOP usually meet? | | |
| 1.14 | On average how long does each CDOP meeting last? | | |
| 1.15 | On average how many child deaths would your panel review in a typical meeting? | | |
| 1.16 | Do you have a single CDOP Co-ordinator or is this role shared? | <p><i>Please delete as appropriate:</i></p> <p>Single Co-ordinator</p> | |

| | | | |
|------|--|---|--|
| | | Shared Co-ordinator role | |
| 1.17 | What proportion of time, expressed as a proportion of a full-time equivalent post (%FTE), is designated for the role of Co-ordinator for your CDOP? | <i>If this is a shared role please indicate the %FTE for each person</i> | |
| 1.18 | a. Apart from the Co-ordinator, Chair and panel members, do you have any other support to assist in running your CDOP? | <i>Please delete as appropriate:</i> Yes, we have other support – <i>please go to 1.18b</i> No, we have no other support – <i>please go to 1.19</i> | |
| | b. If yes, what proportion of time expressed as a proportion of a full-time equivalent post (%FTE), is designated for the other support for your CDOP? Please also indicate the type of support provided: | | |
| 1.19 | a. Do you have a designated budget for your CDOP? | <i>Please delete as appropriate:</i> Yes, we have a designated CDOP budget – <i>please go to 1.19b</i> No, we do not have a designated CDOP budget – <i>please go to 1.20</i> | |
| | b. In round figures how much is your designated CDOP budget? | | |
| | c. What do you mainly spend your CDOP budget on? | | |
| 1.20 | Please give any other information about the Chairing and membership of your panel, the CDOP Co-ordinator(s) role, other support and any other arrangements which you think would assist us in understanding how the running of your CDOP is organised and supported: | | |

Section 2: Notifications and handling of information about child deaths

The second section of questions asks for details about how you receive information about child deaths in your area and how this information is processed and used

| Questions | | Please add your responses into these boxes | |
|-----------|---|---|--|
| 2.1 | How do you receive the initial notification of a death, is this by mainly phone or mainly by receipt of a completed agency report form (Form B) or other paperwork? | <p><i>Please delete as appropriate:</i></p> <p>Mainly by phone Mainly by receipt of a completed Form B or other paperwork A mixture of both</p> | |
| 2.2 | Do you have any concerns about the quality of the information and/or the completeness of the information you are provided with about each child? | <p><i>Please delete as appropriate:</i></p> <p>Yes, we have concerns about information quality and/or completeness— <i>please go to 2.2b</i> No, we have no particular concerns about information quality and/or completeness – <i>please go to 2.3</i></p> | |
| | b. What particular concerns do you have about information quality and are there any particular gaps in the information you receive? | | |
| 2.3 | a. Do you use an electronic administrative database to manage the collation and tracking of case notifications and data collection forms or do you use a manual system? | <p><i>Please delete as appropriate:</i></p> <p>We use a completely manual system – <i>please go to 2.3b</i> We use a completely computerised system – <i>please go to 2.3c</i> We use a mixed partly manual and partly computerised system – <i>please go to 2.3c</i></p> | |
| | b. Are there any barriers to the implementation of an electronic administrative system? | <p><i>Please go to 2.4</i></p> | |
| | c. What type of database do you use? <i>For example an Excel spreadsheet or a database written in Access</i> | | |

| | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
|--|---|--|--------------------------------|--------------------------|-------------------|-------------------|--------------------------------|--------------------------|--------------------------|-------------------|-------------------|--------------------------------|--------------------------|--|-------------------|-------------------|--------------------------------|--------------------------|--|-------------------|-------------------|--------------------------------|--------------------------|---------------------------------|-------------------|-------------------|--------------------------------|--------------------------|--------------------|-------------------|-------------------|--------------------------------|--------------------------|--------------------------|-------------------|-------------------|--------------------------------|--------------------------|---------------------|-------------------|-------------------|--------------------------------|--------------------------|--|-------------------|-------------------|--------------------------------|--------------------------|-----------------------------|-------------------|-------------------|--------------------------------|--------------------------|------------------------------|-------------------|-------------------|--------------------------------|--------------------------|-----------------------------|-------------------|-------------------|--------------------------------|--------------------------|
| | d. Is your database adequate for your needs or do you think you would benefit from improvements to your database ? | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| | e. Do you share your database with one or more other CDOPs or do you use the same database as another/other CDOPs? | <p><i>Please delete as appropriate:</i></p> <p>No, we have our own system – <i>please go to 2.4</i></p> <p>Yes, we <u>share</u> a system with one or more other CDOPs – <i>please go to 2.3f</i></p> <p>Yes, we <u>use the same</u> system as one or more other CDOPs – <i>please go to 2.3f</i></p> | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| | f. Please describe the database sharing arrangement you have with one or more other CDOP(s)? | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 2.4 | For the DfE templates which you use, please indicate which templates you only use manually (<i>for example to discuss at CDOP meetings</i>) and which templates you use and then also enter the information collected on the template into an electronic data base: | <i>Please delete as appropriate:</i> | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| | <table border="1"> <tr> <td>Form B</td> <td>Do not use at all</td> <td>Use manually only</td> <td>Partially computerise the data</td> <td>Computerise all the data</td> </tr> <tr> <td>Form b2 – neonatal death</td> <td>Do not use at all</td> <td>Use manually only</td> <td>Partially computerise the data</td> <td>Computerise all the data</td> </tr> <tr> <td>Form b3 – child with a known life limiting condition</td> <td>Do not use at all</td> <td>Use manually only</td> <td>Partially computerise the data</td> <td>Computerise all the data</td> </tr> <tr> <td>Form b4 – sudden unexpected death in infancy</td> <td>Do not use at all</td> <td>Use manually only</td> <td>Partially computerise the data</td> <td>Computerise all the data</td> </tr> <tr> <td>Form b5 – road traffic accident</td> <td>Do not use at all</td> <td>Use manually only</td> <td>Partially computerise the data</td> <td>Computerise all the data</td> </tr> <tr> <td>Form b6 – drowning</td> <td>Do not use at all</td> <td>Use manually only</td> <td>Partially computerise the data</td> <td>Computerise all the data</td> </tr> <tr> <td>Form b7 – fire and burns</td> <td>Do not use at all</td> <td>Use manually only</td> <td>Partially computerise the data</td> <td>Computerise all the data</td> </tr> <tr> <td>Form b8 – poisoning</td> <td>Do not use at all</td> <td>Use manually only</td> <td>Partially computerise the data</td> <td>Computerise all the data</td> </tr> <tr> <td>Form b9 – other non-intentional injury</td> <td>Do not use at all</td> <td>Use manually only</td> <td>Partially computerise the data</td> <td>Computerise all the data</td> </tr> <tr> <td>Form b10 – substance misuse</td> <td>Do not use at all</td> <td>Use manually only</td> <td>Partially computerise the data</td> <td>Computerise all the data</td> </tr> <tr> <td>Form b11 – apparent homicide</td> <td>Do not use at all</td> <td>Use manually only</td> <td>Partially computerise the data</td> <td>Computerise all the data</td> </tr> <tr> <td>Form b12 – apparent suicide</td> <td>Do not use at all</td> <td>Use manually only</td> <td>Partially computerise the data</td> <td>Computerise all the data</td> </tr> </table> | | | Form B | Do not use at all | Use manually only | Partially computerise the data | Computerise all the data | Form b2 – neonatal death | Do not use at all | Use manually only | Partially computerise the data | Computerise all the data | Form b3 – child with a known life limiting condition | Do not use at all | Use manually only | Partially computerise the data | Computerise all the data | Form b4 – sudden unexpected death in infancy | Do not use at all | Use manually only | Partially computerise the data | Computerise all the data | Form b5 – road traffic accident | Do not use at all | Use manually only | Partially computerise the data | Computerise all the data | Form b6 – drowning | Do not use at all | Use manually only | Partially computerise the data | Computerise all the data | Form b7 – fire and burns | Do not use at all | Use manually only | Partially computerise the data | Computerise all the data | Form b8 – poisoning | Do not use at all | Use manually only | Partially computerise the data | Computerise all the data | Form b9 – other non-intentional injury | Do not use at all | Use manually only | Partially computerise the data | Computerise all the data | Form b10 – substance misuse | Do not use at all | Use manually only | Partially computerise the data | Computerise all the data | Form b11 – apparent homicide | Do not use at all | Use manually only | Partially computerise the data | Computerise all the data | Form b12 – apparent suicide | Do not use at all | Use manually only | Partially computerise the data | Computerise all the data |
| Form B | Do not use at all | Use manually only | Partially computerise the data | Computerise all the data | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| Form b2 – neonatal death | Do not use at all | Use manually only | Partially computerise the data | Computerise all the data | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| Form b3 – child with a known life limiting condition | Do not use at all | Use manually only | Partially computerise the data | Computerise all the data | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| Form b4 – sudden unexpected death in infancy | Do not use at all | Use manually only | Partially computerise the data | Computerise all the data | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| Form b5 – road traffic accident | Do not use at all | Use manually only | Partially computerise the data | Computerise all the data | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| Form b6 – drowning | Do not use at all | Use manually only | Partially computerise the data | Computerise all the data | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| Form b7 – fire and burns | Do not use at all | Use manually only | Partially computerise the data | Computerise all the data | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| Form b8 – poisoning | Do not use at all | Use manually only | Partially computerise the data | Computerise all the data | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| Form b9 – other non-intentional injury | Do not use at all | Use manually only | Partially computerise the data | Computerise all the data | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| Form b10 – substance misuse | Do not use at all | Use manually only | Partially computerise the data | Computerise all the data | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| Form b11 – apparent homicide | Do not use at all | Use manually only | Partially computerise the data | Computerise all the data | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| Form b12 – apparent suicide | Do not use at all | Use manually only | Partially computerise the data | Computerise all the data | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 2.5 | Please list what information is generally presented for review at your CDOP panel meeting: <i>For example, the Form B, a copy of the post-mortem report</i> | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 2.6 | a. Does your CDOP panel use the DfE analysis proforma (Form C) to document the findings of your CDOP panel discussions? | <p><i>Please delete as appropriate:</i></p> <p>Use Form C to document panel findings – <i>please go to 2.7.c</i></p> | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |

| | | | |
|-----|---|---|--|
| | | No, we do not use Form C - <i>please go to 2.7b</i> | |
| | b. How do you document the findings of your CDOP panel discussion? | <i>Please go to 2.8</i> | |
| | c. Do you complete all of Form C or only parts of Form C? | <i>Please delete as appropriate:</i> We complete all of Form C We complete <u>only some</u> parts of Form C | |
| 2.7 | a. Do you use an electronic database for the collation and storage of the <u>findings</u> from your panel discussions? | <i>Please delete as appropriate:</i> Yes, we use an electronic system – please go to 2.8c No, we use a manual system – please go to 2.8b | |
| | b. Why do you not use an electronic database and would you prefer to have one? | <i>Please go to 2.8f</i> | |
| | c. Is this database integrated with the administrative information into a single database or is this a separate database? | <i>Please delete as appropriate:</i> Yes, this is integrated with the administrative database No, this is separate database | |
| | d. Who is responsible for maintaining and entering the information from the panel discussions into the database? | | |
| | e. What is the main purpose(s) of the database? | <i>Please delete as appropriate (more than one answer may be relevant):</i> For completing the annual return to the Department for Education For generating the CDOP annual report For recording and monitoring actions/recommendations For other purposes – <i>please describe what these are:</i> | |
| | f. Who carries out the analysis of your CDOP data to enable you to produce your annual report? | | |

| | | | |
|------|--|---|--|
| 2.8 | How do you use the information you have collected to determine if a particular death is a one-off tragic accident or if there might be a wider trend? | | |
| 2.9 | Do you use the information you collect to examine trends in child deaths over time? | <i>Please delete/complete as appropriate:</i> Yes we examine trends over time No we don't examine time trends | |
| 2.10 | Please give any other information about how you receive, process and use information about child deaths which you think would assist us in understanding how these activities are organised for your CDOP: | | |

Section 3: Actions and recommendations resulting from CDOP reviews

The third section of questions asks for details of what actions and recommendations have resulted from the panel reviews conducted by your CDOP

| | | |
|-----|---|--|
| 3.1 | <p>We are interested in hearing about the recommendations and actions which have resulted from the findings of your CDOP panel reviews. Please can you either give a small number of examples or recent recommendations and actions or list the recommendations and actions from one of your recent annual reports which you might be able to cut and paste into here.</p> <p><i>Answer:</i></p> | |
| 3.2 | <p>We are interested in hearing about the impact of CDOP recommendations and actions. What impact do you think your CDOP recommendations and actions have had? Again, for ease you might be able to cut and paste the relevant section describing this from one of your recent annual reports.</p> <p><i>Answer:</i></p> | |
| 3.3 | <p>We are interested in finding out about examples of local activities and actions resulting from CDOP recommendations which might be suitable for sharing more widely, either with other CDOPs in your area or nationally. If you are able, please give an example of an activity of this kind which you shared with another/other CDOP(s) or which might have been suitable for sharing.</p> <p><i>Answer:</i></p> | |
| 3.4 | <p>We are interested in findings out about activities and actions arising from local panel reviews which have specific relevance to the local panel area and child population rather than having wider relevance. If you are able, please give an example of an activity which would only have specific relevance to your CDOP area services and child population.</p> <p><i>Answer:</i></p> | |
| 3.5 | <p>We are interested in formal and informal links between CDOPs which allows the sharing of information and/or sharing of recommendations and actions. Do you have any formal or informal links with other CDOPs to enable sharing of information and/or sharing of recommendations and actions? If so please can you describe how these links operates:</p> <p><i>Answer:</i></p> | |

| | | |
|-----|--|--|
| 3.6 | <p>We are interested in the formal and informal links between CDOPs and local Serious Case Review (SCR) panels and how CDOPs make use of SCR findings.</p> <p>Do you have any formal or informal links to SCR panel(s), including neighbouring SCR panels, to enable sharing of lessons learnt from SCR recommendations? If so please can you describe how these links operate:</p> <p><i>Answer:</i></p> | |
| 3.7 | <p>We are interested in what CDOPs and their local partners do to contribute to national learning from their local panel findings and recommendations and whether this could be enhanced in the future.</p> <p>Do you have any examples of recommendations you have made which you feel have contributed to national learning? If so please can you describe this/these:</p> <p><i>Answer:</i></p> | |
| 3.8 | <p>We are interested in whether you think further use could be made of the information you collect and the recommendations you make.</p> <p>Do you think that you make maximum use of the information you collect and the recommendations you reach locally? And if not, in what way do you think more use could be made of this information</p> <p><i>Answer:</i></p> | |
| 3.9 | <p>We are interested in any other comments you have.</p> <p>Please give any other information about how you use local information and recommendations that you think would assist us in understanding how this happens in your CDOP and any other comments you would like to make relating to the issues covered in this section:</p> <p><i>Answer:</i></p> | |

Section 4: Whether further use can be made of the information collected by CDOPs

The fourth section of questions asks for your views on whether further use can be made of the information collected by CDOPs and if so how this might be achieved

| Questions | | Please add your responses into these boxes | |
|-----------|--|--|--|
| 4.1 | a. We are aware that a lot of information about child deaths is collected locally, but only aggregated data are collated nationally and published on the Department for Education website. Do you use the information published by the DfE on their website? | <p><i>Please delete as appropriate:</i></p> <p>Yes, we use this information – <i>please go to 4.1b</i> No, we don't use this information – <i>please go to 4.1c</i></p> | |
| | b. What do you use the information on the DfE website for? | | |
| | c. Is there any reason why you don't use the information published on the DfE website? | | |
| 4.2 | Do you think that DfE collate too much information about child deaths, just enough or not enough? | <p><i>Please delete as appropriate:</i></p> <p>Too much information Just about the right amount of information Not enough information</p> | |
| 4.3 | a. Do you think there is scope for collecting more information and analysing the data at a national level? <i>This does question does not make any assumptions about who might do this.</i> | <p><i>Please delete as appropriate:</i></p> <p>Yes, more information should be collated and published nationally – <i>please go to 4.3b</i> No, sufficient information is collated and published nationally – <i>please go to 4.4</i></p> | |
| | b. How do you think the collation and analysis of more information from CDOPs nationally could be achieved? | | |
| 4.4 | What role do you think local CDOPs should play locally, regionally and nationally in the dissemination of learning from the child death information held locally? | | |
| 4.5 | Please give any other comments about your views on how | | |

| | | | |
|--|---|--|--|
| | information about child deaths collected locally could be further used to prevent child deaths. | | |
|--|---|--|--|

Section 5: Exploring the issues further

Finally, as part of this DfE funded project we would like to explore some of the issues touched on in the questionnaire further by carrying out telephone interviews and face-to-face interviews with a small sample of CDOPs Co-ordinators and Chairs

| Questions | | Please add your responses into these boxes | |
|-----------|---|---|--|
| 5.1 | If selected would someone from your CDOP be willing to be interviewed either by phone or in person: | <p><i>Please delete as applicable:</i></p> <p>Co-ordinator: Yes – phone interview Yes – phone or face-to-face interview No - would prefer not to be interviewed</p> <p>Chair: Yes – phone interview Yes – phone or face-to-face interview No - would prefer not to be interviewed</p> | |
| 5.2 | Please provide any further information or comments about any of the issues covered in the questionnaire and any other areas, which will failed to ask questions about, which you feel would be helpful for us to know about | | |

Thank you for your assistance

Please email the completed copy to:

lynne.roberts@npeu.ox.ac.uk

Appendix D – Covering letter for the first emailing of the questionnaire

NAME

CDOP Co-ordinator

NAME OF CDOP

3rd December 2012

Dear NAME,

Re: Department for Education funded project to investigate the use of information from child death reviews and how this might be enhanced nationally

We are writing to invite you and your CDOP Chair to participate in a project funded by the Department for Education (DfE) which is designed to investigate how information about child deaths collected by Child Death Overview Panels is currently used locally and how the information might be further used nationally to enhance the prevention of child deaths. If you were at the FSID CDOPs conference in June you might recall that Tim Loughton, the then Children's Minister announced that this project would be commissioned by DfE.

The first stage of this project is the collection of information from all the CDOPs across England which is designed to enable us to better understand the workings of CDOPs, how data are collected and used locally, and to find out the views of CDOP Co-ordinators and Chairs about how better national use might be made of the information collected by CDOPs.

The second stage of the project will involve a series of telephone interviews with willing CDOP Chairs and Co-ordinators to add to the information collected in the questionnaire. This will help us to further understand the issues faced by CDOPs and the views of Chairs and Co-ordinators of how to ensure that not only are local lessons being learned but that national learning is taking place and that maximum benefit is being derived from the work of CDOPs.

The attached questionnaire is designed to collect the information for stage one of the project and we would be grateful if you would complete the questionnaire and return it by email to: lynne.roberts@npeu.ox.ac.uk by Friday 14th December. If you prefer to complete the form by hand please print it out (ensuring that you expand the free text boxes sufficiently for your purposes), complete and post the form to Lynne Roberts at the National Perinatal Epidemiology Unit at the address given below.

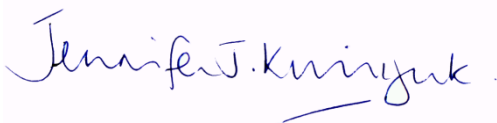
We anticipate that some questions will be best answered by CDOP Co-ordinators and some questions by the CDOP Chair. We estimate it will take each of you about 20-30 minutes to answer all the questions. We apologise for the short times scales but this is only a four month project and the responses to the questionnaire will guide how we conduct the interviews and the questions we ask, so we would appreciate if you are able to return the completed questionnaire by the deadline.

Whilst we are not collecting the information anonymously we can assure you that the information you provide will be treated in the strictest confidence. The results produced from the analysis will be presented primarily as tables in a report to the DfE. Free text answers will be used to illustrate the quantitative findings. Where free text answers are quoted we will ensure that the quotes are de-contextualised and are thus unattributable so that it will not be possible to identify individuals and particular CDOPs from the results presented to DfE. We are in this capacity acting as independent researchers.

If you have any questions or feel that you may have difficulty completing the questionnaire we would be happy to discuss this with you. Please do not hesitate to call Jenny Kurinczuk on 01865 289719 or you can email at jenny.kurinczuk@npeu.ox.ac.uk

With very best wishes

Yours sincerely



Jennifer J Kurinczuk
Professor of Perinatal Epidemiology
Director, NPEU
Honorary Consultant in Public Health
Tel: 01865 289719
Email: jenny.kurinczuk@npeu.ox.ac.uk



Marian Knight
NIHR Research Professor in Public Health
Honorary Consultant in Public Health

Appendix E – Copy of interview prompt guide

Telephone and face-to-face interview prompt guide topics:

Opening comment for the narrative section of the discussion:

We're conducting a study funded by the Department for Education to identify how better use can be made nationally of the information from child death reviews in order to be more effective in the prevention of child deaths.

So what I'd like to do is to first ask you for your reflections on this aim, to have a conversation and then secondly if there are any particular areas that we haven't covered I have a few specific questions, although we might end up having covering most of these in the course of the conversation already.

Specific follow-up topics:

1. The need for improved IT technology and support to use local data to maximum benefit locally
2. Usefulness of the DfE templates for data collection
3. The importance of the qualitative element of the information collected and collated locally
4. How the data they collect is or could be used and shared with neighbouring CDOPs and if this doesn't happen, why doesn't it happen
5. What do they need to be able to identify with more certainty unusual patterns and trends in deaths in their 'area'
6. To what extent the recommendations and actions of their CDOP are focused at the local versus regional versus national level
7. How learning points and actions plans can be shared with neighbouring CDOPs and wider afield to the national level. What is in place to do this now, is this adequate and how can this be improved
8. What do they need (if anything) to be more effective in the prevention child deaths
9. If data were to be collated nationally, what data should be collected, to what level of detail and identifiability, and who should have access; how might this be achieved and what role would they see for DfE
10. If you could choose one single thing to do to prevent child deaths what would it be?

Appendix F – Qualitative analysis themes

1. Operational arrangements for the CDOPs

- 1.1 Neonatal reviews
- 1.2 Data quality/consistency
- 1.3 Value of the panel process/panel operations and variation
- 1.4 Difficulty of getting some professionals involved

2. Data issues

- 2.1 Modifications to the national templates
- 2.2 Data quality/consistency
- 2.3 Views about using excel spreadsheets
- 2.4 Web access data entry
- 2.5 Lack of IT resources to improve the local data systems
- 2.6 DfE information and making the DfE return & the frustrations
- 2.7 How to identify unique cases and spotting trends/small number problems
- 2.8 What is missing/disappointments/national database

3. Learning and actions

- 3.1 Impact of lack of resources
- 3.2 Concerns about the current email alert system
- 3.3 Main focus of the local learning
- 3.4 The three domains issue (clinical SDO, public health, safeguarding)
- 3.5 Example of good local activities
- 3.6 Examples of local learning recommendations and actions
- 3.7 Impact of the background of the Chair
- 3.8 Role of Public Health
- 3.9 Value of shared learning
- 3.10 Difficulties of funding shared meetings
- 3.11 Missed opportunities for shared learning
- 3.12 Learning not going beyond the local or regional
- 3.13 Duplication of effort



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for Education

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The views expressed in this report are the authors' and do not necessarily reflect those of the Department for Education.

Any enquiries regarding this publication should be sent to us at Richard White, Ground Level, Sanctuary Buildings, Great Smith Street, London, SW1P 3BT / email:

richard.white@education.gsi.gov.uk

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