



Department
for Education

Child death reviews: improving the use of evidence

Research Brief

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Contents

1. Introduction and aim	3
2. Key findings	3
3. Background	4
4. Methods	5
5. Further findings and discussion	6
6. Recommendations	8

1. Introduction and aim

Child Death Overview Panels (CDOPs) are responsible for reviewing the deaths of children in England. As part of this process information about each death is collected by the CDOP. The Department for Education (DfE) commissioned the National Perinatal Epidemiology Unit to undertake a study to investigate how to make better national use of the information collected through the child death review processes.

2. Key findings

- CDOP staff and chairs responded to the study enthusiastically; the passion they feel for their work in child death prevention was evident in their engagement and individual responses.
- CDOPs were established to have a local focus; this is an important strength. Thus, the majority of learning, recommendations and actions arising from child death reviews happen locally and for many recommendations this is wholly appropriate.
- There is evidence of beneficial regional sharing and learning between some CDOPs with meetings to exchange knowledge, information and concerns, and develop similar preventive approaches. However, this is not a universal activity. Furthermore, because of the demise of Regional Government Offices (RGOs) and NHS restructuring, organisations, such as RGOs and strategic health authorities, which arranged regional meetings in some areas in the past, no longer exist; regional leadership has yet to re-emerge.
- There is little evidence of co-ordinated national learning and sharing other than through events arranged by organisations such as the Lullaby Trust¹; currently there is no other active focus of national leadership.
- Of major concern is the management of the information which CDOPs collect. Despite the extensive amount of data collected by CDOPs only a quarter use a completely computerised system for information management with the rest using a mixed manual and computerised approach. Only 65% of CDOPs have a system which integrates their administrative data with panel findings. Over 80% of CDOPs use only Excel spread-sheets to manage their data; this has major limitations in terms of utility, ease of data extraction and analysis. This is reflected in the finding that 50% of CDOPs feel their data systems are inadequate for their needs. Concerns about data quality (identified by nearly three-quarters of CDOPs), completeness and inconsistency in data definitions across CDOPs were also identified. Many CDOPs using Excel clearly wish to develop a better database but are impeded by their limited, or lack of, access to information technology (IT) support.

¹ The Lullaby Trust was formerly the Foundation for the Study of Infant Death

- It emerged during the interviews that the reason why, when being established, many CDOPs chose to store their data using Excel spread-sheets was their expectation from early discussions that a national data collection system would be introduced. There is clear frustration and deep disappointment with the continuing lack of a proper national data system.
- Seventy percent of CDOPs thought that more information should be collected and analysed nationally and although 50% of CDOPs indicated ways in which they use the information published by DfE there is little enthusiasm for extending the amount and type of information currently collected by DfE.
- CDOPs vary hugely in size with the smallest participating CDOP reviewing only 10 child deaths per year and the largest 150 per year (median 45). 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 therefore necessarily limited by the (fortunately) small number of child deaths which occur in even the largest CDOP.
- The informal CDOP email network is the only mechanism CDOP staff currently have to communicate with all other CDOPs. Even with the most enthusiastic participants this informal approach to national case identification of new or excess causes of death is a very poor and risky substitute for a formalised alert and alarm system based on properly collected and analysed national data. The risk of relying on this informal system is that newly emerging preventable deaths are not identified and the chance of preventing future deaths is missed.
- The findings from this study highlight the missed opportunities to capitalise on the strong local structures and vital local focus of CDOP work by the failure to collect, analyse and disseminate local CDOP data nationally. There was a clear and vociferous call from CDOP staff and chairs for a proper national system of collecting, analysing and reporting CDOP data which would enable appropriate alerts and alarms to be issued and which would provide a focus for national information sharing and learning.

3. Background

Local Safeguarding Children Boards (LSCBs) in England were statutorily required to establish local CDOPs by April 2008 to review the deaths of all children from birth up to 18 years normally resident in their area.

The primary purpose of CDOPs is to review individual deaths to inform strategic planning on how “best to safeguard and promote the welfare of the children in their area.” To support the CDOP function and using templates provided by DfE, every CDOP collects information about each child who dies including the conclusions of the panel review. Limited aggregated and anonymised data are submitted to DfE who report each year’s data annually.

4. Methods

The study was conducted December 2012 through March 2013. Questionnaires were emailed to all CDOP co-ordinators to collect representative data, following which a series of telephone and face-to-face interviews were conducted with CDOP co-ordinators, managers and chairs. Initial findings were shared with an Advisory Group, which was convened by DfE and met once.

The questionnaire collected information about the CDOP; notification and handling of information; actions and recommendations; and whether and how further use can be made of CDOP data. Fifty-four (58%) completed questionnaires were returned from the 93 CDOPs which cover 148 LSCBs; a descriptive quantitative and qualitative analysis was performed. Interviews were conducted with 11 CDOP staff/chairs to collect a greater depth and richness of information. The interviews were audio-recorded and transcribed verbatim for analysis; interviewing continued until theoretical data saturation was reached. Analysis of the qualitative data was based on the Framework Analysis approach.

Of the 11 interviewees eight were from CDOPs which responded to the questionnaire and three were from CDOPs which did not. Following the Advisory Group meeting three additional short interviews were conducted with CDOP staff/chairs who had indicated in their questionnaire they felt that further national data should be collected. Thus, a total of 14 CDOP staff/chairs were interviewed.

Overall, information was obtained from 59 CDOPs which represents 63% of CDOPs, covering 100 (68%) LSCBs and 64% of all child deaths. Comparison of findings with DfE published data and interviews with CDOP staff/chairs who had not returned the questionnaire indicates that the non-responder CDOPs are not materially different from responder CDOPs. This suggests that the study findings can be generalised across English CDOPs with some confidence.

5. Further findings and discussion

CDOPs were established to have a local focus. The variation in arrangements is one reflection of this localism. There were many differences between CDOPs reported:

- the size of the CDOPs (covering a child population of 35,500 to 1.7million; median 125,000);
- the number of panel members (range 7 to 22 members; median 12);
- the number of CDOP staff (range 15% FTE to 220% FTE²; median 60% FTE);
- the frequency of meetings (range monthly to six monthly; median alternate months);
- the duration of meetings (range 2 to 7 hours; median 3 hours).

An average³ of five person-hours of professional time is spent by CDOPs reviewing each child death (range 1.3 to 14.2 hours). The process to support CDOP operations is complicated and requires a high and sustained level of administrative and managerial support; current data systems in many CDOPs add to rather than reduce this complexity.

Arrangements have been developed to ensure CDOP processes suit the local services and agencies with which the CDOPs engage; relationships with local service providers are essential to ensure the information necessary to conduct panel reviews is submitted. While there is some evidence of delays and concerns about data completeness and quality these issues can only be addressed at a local level. Some CDOPs have improved completeness and speed of return of information by making local modifications to the national data collection templates.

Some CDOPs have experienced difficulties in recruiting appropriate panel members with obstetricians being notably under-represented despite neonatal deaths accounting for nearly half of all child deaths. A related issue is the variation in neonatal deaths reviews with some panels undertaking minimal review whereas others undertake full review leading to recommendations.

CDOPs provided examples of recommendations and actions which have resulted from the learning from the CDOP reviews. The majority of these have a local focus and most frequently relate to clinical issues, and the delivery and organisation of clinical services.

Some duplication of effort across CDOPs was evident, for example in the production of information materials. Some sharing of findings and materials does occur but duplication could be minimised further with better formal mechanisms for sharing. This would, however, result in only a small cost saving since the proportion of designated CDOP budgets spent on information materials is small.

² Some panels have less than and some more than one full-time equivalent (100% FTE) member of staff

³ This average was estimated as the median not the mean

Holding national meetings would achieve some aspects of national information sharing. Central government funded meetings would be one way of ensuring such meetings happen without having to rely on the support of small charities. Another option posed in the project brief was independent research using existing CDOP data. This would however, have serious limitations given the variation in data collection and storage, and likely variation in participation. Consequently this would be an expensive, complex, retrospective activity which would require repeating regularly to be of value. Furthermore, concerns about aspects of existing 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 data items thereby improving data quality. Prospective electronic data collection, with appropriate regulatory authorisation, would allow linkage to other national child data leading to further understanding of the antecedents of child deaths and thus potentially prevention of a greater number.

Such a database could be designed to support local CDOP data analysis and production of local reports as well as national analysis. A national database located in an appropriate centre of excellence could also provide a focus for shared learning between CDOPs; it could act as a central repository for information materials to reduce duplication of effort; and also include a discussion forum to support the regular exchange of information and ideas between CDOP staff. Annual reports could be launched at national meetings to further enhance shared national learning.

6. Recommendations

- CDOPs must continue to be locally focused in order to continue their engagement with local services and agencies to ensure both the provision of data needed for the CDOP process and so that their recommendations 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 standardised data collection tools must be designed in collaboration with CDOP staff to ensure that they meet 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 issue appropriate alerts and alarms as well as producing a national annual 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 facilitate shared learning across CDOPs. Funded national meetings would support one aspect of shared national learning and could be stand alone or form part of the remit of a national database provider.



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