CDR
Child Death Review
Database Development Project

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Database Development Project
England and Scotland

Final Report

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Glossary of terms

BMI	Body Mass Index
CBUK	Child Bereavement UK
CDOP	Child Death Overview Panel
CDRP	Child Death Review Panel
CDR	Child Death Review
Child death	Death of a child from birth to their 18th birthday, as defined by the Working Together Guidance, 2015[2] and the Child Death Review Steering Group in Scotland.[4]
DCSF	Department for Children, Schools and Families
DfE	Department for Education
DH	Department of Health
HQIP	Healthcare Quality Improvement Partnership
HSIB	Healthcare Safety Investigation Branch (England)
IAG	Independent Advisory Group
Infant death	Death of a child from birth to <1 year of age
ISD	Information Service Division (Scotland)
LA	Local Authority
LSCB	Local Safeguarding Children Board
Lullaby Trust	Formerly the Foundation for the Study of Sudden Infant Deaths
MBRRACE-UK	The collaboration which delivers the national Maternal, Newborn and Infant Clinical Outcome Review Programme.
NHSE	NHS England
NMDS	National Maternity Data Set (England)
NNCDOPs	National Network of CDOPs
NPEU	National Perinatal Epidemiology Unit, University of Oxford
NRS	National Records of Scotland
ONS	Office for National Statistics (England and Wales)
PBPP	Public Benefit and Privacy Panel (Scotland)
PICANet	Paediatric Intensive Care Audit Network
PMRT	Perinatal Mortality Review Tool
Sands	Stillbirth and neonatal death charity
SCR	Serious Case Review
Statistical neighbours	Populations with similar demographic and socio-economic characteristics but which are not necessarily geographically close
TIMMS	The Infant Morbidity and Mortality team, University of Leicester.

Acknowledgements

This project was essentially a consultation exercise and it would not have been possible to carry out the project without the goodwill and contribution of a very large number of people. We are very grateful to everyone who attended our consultation meetings, spoke to us in other circumstances or made a written submission. Everyone very willingly and enthusiastically participated and this exemplifies the commitment to the work, in which everyone we consulted is involved, in relation to the prevention of child deaths.

We would particularly like to acknowledge and thank the 25 bereaved parents who each participated in one of four consultation meetings with us, and the charities CBUK, Sands and the Lullaby Trust who organised and facilitated these meetings for us. We are very grateful to all the parents who attended the consultation sessions to discuss matters which are deeply personal and profoundly sad; this was a very courageous and generous act on their behalf.

The individuals who contributed to this project are listed in Appendix A

Executive Summary

Background

- In 2014 a total of 4,419 infants, children and adolescents died before their 18th birthday in England and Wales. In the same period 341 infants, children and adolescents died before reaching 18 in Scotland. While mortality rates for children and young people over the age of 5 are similar to the European average the rate in the under 4s places the UK in the bottom 25% of European countries; notably our relative position, particularly for infant and neonatal mortality, has substantially worsened since 1970.[1]

- Child Death Overview Panels (CDOPs) were statutorily established in England in 2008 under the aegis of Local Safeguarding Children Boards (LSCBs) with the responsibility of reviewing the deaths of all children (0 to <18yrs) in their resident population with one of their purposes being the identification of actions to prevent future child deaths.[2] At their inception there was a widespread expectation that a national database of information from all CDOPs would be created; despite a pilot being carried out the database was never established.

- Information about child death reviews undertaken (rather than child deaths *per se*) is collected centrally from CDOPs as aggregated annual returns to the Department for Education (DfE). The data are published in annual bulletins presenting cross-sectional data reporting on the process of reviews with limited information on outcomes. It is not possible from these bulletins to share learning, identify national actions needed to prevent future child deaths, nor to evaluate the impact of such actions.[3]

- Following the recommendations of the Child Death Reviews Working Group report that Scotland should introduce a national Child Death Review System, in 2014 the Scottish Government established a Steering Group to develop the process and identify costs and funding. The group met in 2015 and in March 2016 their report was published recommending the establishment of a National Resource Centre along with three regional offices to run multi-agency Child Death Review Panels (CDRPs) with the remit to review all child deaths to consider modifiable and preventable factors, with the purpose of learning lessons to prevent avoidable future deaths.[4]

- During the course of the development study reported here the Department for Education (DfE) in England, who have responsibility for safeguarding, commissioned an external, fundamental review of the role and function of LSCBs. Included in the review was the requirement to "identify what makes an effective Child Death Overview Panel (CDOP) and to explore what body is best placed to review child deaths to ensure that CDOPs are managed and held to account effectively."[5] This was a rapid review carried out by Alan Wood which concluded after three months in March 2016; the 'Wood' report was published in May 2016. Of particular note the review recommended that responsibility for CDOPs should move to the Department of Health[6]; this recommendation was accepted by the Government[7] with an announcement by the Minister of State for Children and Families that "We will put in place arrangements to transfer national oversight of CDOPs from the Department for Education to the Department of Health, whilst ensuring that the keen focus on distilling and embedding learning is maintained."[8]

Purpose and conduct of the development study

- This report presents the findings of a development project funded by NHS England (NHSE) and the Scottish Government to investigate whether and how it might be possible to create a national database of information collected in the course of child death reviews conducted by CDOPs in England and the CDRPs, which were recommended in Scotland during the course of the development project.

- The project was conducted primarily as a series of consultations with individuals and organisations involved in child death reviews and/or with an interest in the data which would flow from a national database. This included bereaved parents, third sector organisations which represent parents and families, representatives from CDOPs in England, medical royal colleges and professional organisations, LSCBs, the police, coroners, researchers, and the Child Death Review Steering Group in Scotland. We also met with the Executive Group of the National Network of CDOPs (NNCDOPs) on two occasions; this is a group of representatives of CDOPs which self-formed to develop leadership and collaboration across CDOPs. We also consulted on issues of data privacy and security, and the technical issues surrounding the creation and maintenance of a national electronic database.

- We consulted with a total of 25 bereaved parents, 131 individuals representing 109 organisations concerned with child death and received written submissions from nine researchers in the field. In February 2016 we attended and presented at the second National CDOP conference organised by the NNCDOPs Executive.

Findings

Views on the creation of a national child death review database

- There was overwhelming support for the creation of a national child death review database; with only one conditional exception, everyone with whom we consulted was wholly in favour of such a database being created. Importantly this included all the bereaved parents we met. Indeed several of the parents we met objected to the fact that such a database did not already exist.

- At no stage did we have to convince anyone, including bereaved parents, of the benefits that would arise from having a national database. Parents in particular were keen to ensure that where possible future child deaths would be prevented to avoid anyone else experiencing the suffering they had endured; they implicitly understood the valuable contribution that a national database would make to the achievement of this goal.

Design and operations of local CDOPs data management systems and the national database

- There are currently 92 CDOPs in operation in England who are responsible to 148 LSCBs; of note, at the start of the project there were 89 CDOPs and during the course of the project one CDOP disaggregated. Previously there were instances of CDOP aggregation (e.g. the Merseyside and Pan-Dorset CDOPs were created through coalescence of smaller CDOPs). Although a Local Authority responsibility, CDOPs are variously hosted in both Local Authority and Health Service settings. The size of individual CDOPs, based on the population they are responsible for and thus the number of child deaths they review, varies widely as do the resources available to them. In a previous survey we identified that individual CDOPs who responded to the survey reviewed between 10 and over 150 deaths per year.[9] Notably the information technology (IT) facilities available to CDOPs to manage the extensive amount of information they collect about each child who dies is also highly variable.[9] The majority have access to relatively limited IT systems with many managing with a combination of Excel spreadsheets and Word documents. This situation arose from the early expectations of the creation of a national database so that initial investment in IT systems was not considered an appropriate or necessary use of resources.[9] The current situation is becoming increasingly problematic as data cumulate over the years; there was some evidence that a small number of CDOPs had deleted their historic data which is of considerable concern.

- Some of the larger CDOPs have had the resources to invest in more sophisticated IT systems and one IT company in particular has recently been working with a small number of the larger CDOPs to develop a bespoke system which specifically meets their data management needs. This system, which is now in use in four CDOPs with three in start-up, collects case notifications and information about the child using a bespoke, web interface. It enables the CDOP staff to more easily acquire and manage the information needed for presentation at the CDOP panel meetings, to generate reports and to submit their annual return to DfE.

- Whilst all CDOP staff we consulted were in favour of the creation of a national database this was only if it did not create additional data entry work. This could be achieved by the development of an integrated software system on a hub and spoke model, which would include functions to support the data management requirements of local CDOP day-to-day activities as well as collating at a national level a portion of the data collected locally, thereby creating the national database. This concept was overwhelmingly supported by CDOP staff. Importantly, the CDOPs who already have more sophisticated data management systems, who are satisfied with their current system, would still wish to provide data to the national database by being able to upload their data into the database.

- The capacity to upload existing historical data was also identified as an essential feature. This would ensure that the valuable data collected since 2008 are not lost and that data collection is not effectively starting again eight years after the establishment of CDOPs.

Benefits arising from the creation of a national database

- The goal of any national database would be to cumulate the data from all CDOPs across England and CDRPs across Scotland, to create an actively managed national database of key data items and information. The benefits of such a system, as identified by the consultees were to:
    - Improve our understanding of how and why children die, including identifying newly emerging causes of death;
    - Identify how future deaths might be prevented;
    - Share the learning that arises from local reviews;
    - Guide the implementation of preventive actions;
    - Enable the evaluation of the effectiveness of preventive actions;
    - Improve services for children with life limiting conditions for whom premature death is an inevitable consequence of their condition.

- Consultees identified the following activities which a national database would enable which are not possible under the current locally-based arrangements:
    - Calculation of mortality rates and condition-specific mortality trends over time with meaningful numbers of cases;
    - Comparison of rates and trends between geographical areas and 'statistical neighbours' (who have populations with similar demographic and socio-economic characteristics but are not necessarily geographically close);
    - Identification of clusters of deaths;
    - Identification of newly emerging causes of death and issuing of alerts and alarms;
    - Identification of potential new risk factors for specific causes of death;
    - Enabling specific cases to be identified to enable research into the risk factors for, and the circumstances and causes of child death;
    - Systematic sharing of learning, actions and resources aimed at prevention.

What data should be held in the national database?

- During the consultations with CDOP staff we took a 'first pass' view of what data items they thought should be included in the national database. In the summary of these findings we also included the data requirements identified by the Scottish Steering Group. This should not be regarded as a definitive list and will need to be re-evaluated and integrated with standardisation work currently being undertaken by the NNCDOPs Executive group. Ideally this would be carried out during the planning stage of the national database and once the standardisation work is complete. The vast majority of consultees took the view that the national database should contain data at an individual child level rather than aggregated data, although reporting should be on an aggregated level with small number suppression to ensure that individual children and their families were not identifiable from the information published.

- The single most contentious issue we discussed with all consultees was consideration of whether the data held in the national database should be identifiable or anonymised. The entire spectrum of perspectives was expressed from the view that the data held nationally should be fully identifiable through to the data being completely anonymised. It was also clear from these discussions that there is not a single shared view of what the terms ‘identifiable data’ and ‘anonymised data’ actually mean.

- The inclusion of identifiers and the purpose and value of their inclusion were explored in detail with all groups. Bereaved parents in particular, generally took a more permissive view of the inclusion of some specific identifiers for example, NHS number, date of birth, date of death and postcode (the latter to derive measures of socio-economic deprivation). They took a less permissive view regarding name and address. Of note, some parents thought that all identifiers should be held nationally with one parent expressing the view that identifiability was not an issue since “Nothing can be worse than the death of your child.” Parents also acknowledged the fact that there is a wide range of causes of death and some parents may be less willing to have their information shared, especially if they were implicated in some way in their child’s death. Parental consent to the inclusion of data, particularly identifiable data, in the database was also explored. The fact that some parents would not consent was seen as problematic since a national database which does not include all deaths was seen as an important limitation. Parental electronic notification when an individual child’s information was used was suggested as a desirable attribute.

- Factors which influenced parent thinking on the issue of identifiability included the fact that the vast majority of those consulted were not previously aware of the existence of CDOPs, their purpose and activities, the fact that their child’s death would have been discussed by their local CDOP and that their local CDOP holds information about them and their child. Further considerations of concern to them included data security, who would have access to the identifiable information and how the findings from the database would be presented.

- Representatives from CDOPs and other stakeholders similarly expressed the whole range of views on the issue of identifiability. Many CDOP representatives could see the value of including identifiers, facilitating the capacity to link the information from CDOPs to other sources of additional information, enabling a richer picture of the causes and circumstances of child deaths to be developed which would be particularly valuable for analyses at national level.

- Other reasons to enable linkage identified by CDOP representatives and other consultees included:
    - Research purposes to reduce child deaths;
    - The opportunity to identify recurrent child deaths which occur within the same family in different parts of the country when families move around;
    - To facilitate data sharing for individual cases where the death occurred outside the area of residence and for which the ‘resident’ CDOP is responsible for the review but the information to be reviewed has to come from another CDOP.

- The counterviews expressed by CDOP representatives and other consultees included:
    - The fact that CDOPs owe a duty of care to parents and this extends to not sharing data which may make them and their child identifiable;
    - That CDOPs 'own' the data, that a national database would be solely for the benefit of CDOPs and thus there would never be any need to include identifiers because no use would ever be made of this information;
    - That any data breach would be more serious because it could include the personal identifiers;
    - Identifiability may be of concern in situations where legal proceedings were underway in relation to particular families.

- Following detailed discussions it was clear that for some CDOP representatives, the benefits of allowing identifiable data to be held in the national database out-weighed the potential risks and counter arguments, but others took the opposite view. The balance of views after discussion, although not quantified by 'voting', was generally more in favouring of enabling some identifiers to be held in the national database than not. However, it was also clear that this issue could potentially be a 'deal breaker' for some CDOPs in terms of their 'participation' in the national database.

The legal basis for data sharing

- In order for identifiable data to be included in a national database there would need to be a legal basis for the sharing, collection and processing of those data. We therefore explored this particular issue further.

- Consent provides the strongest legal basis for the collection and sharing of identifiable data. Parents in particular expressed concerns about how and when consent might be sought and by whom. The fact that not all parents would give consent was of concern to them as this was seen as particularly problematic by leading to incomplete information thus seriously limiting the value of the database.

- The legal basis enabling CDOPs in England to use and process identifiable data is clear and comes from the statutory powers enshrined in the National Children Act 2004,[10] which is operationalised through Regulation 6 of the Local Safeguarding Children Board Regulations 2006 (made under section 14(2) of the Children Act 2004),[11] and is outlined in the Working Together Guidance.[2]

- In addition to consent, we identified two further potential legal gateways to enable CDOPs in England to share identifiable data with the national database and to enable the national database to receive, hold and process identifiable data both from CDOPs and from other data sources.

- The first is the Children Act 2004 which makes explicit, for England, under section 12(5) that the "Secretary of State may by regulations make provision in relation to the establishment and operation of any database or databases under this section." Further sections outline in detail the circumstances in which such a database can be established but they broadly relate to section 10 (Co-operation to improve well-being) and section 11 (Arrangements to safeguard and promote welfare). We presume that it was under these provisions that the operation of the original national database was planned. However, the Regulations required to enact section 12(5) for the purposes of the creation of a national child death database were never laid before Parliament and this would be needed before this route could be relied upon as the legal basis for establishing a national database which contains identifiable data.

- The second potential legal gateway is through an application to the Secretary of State under Section 251 of the NHS Act 2006[12], again this only applies to England and not Scotland. Section 251 (s251) of this Act allows the Secretary of State to make regulations to set aside the common law duty of confidentiality for defined medical purposes. The Regulations that enable this power are the Health Service (Control of Patient Information) Regulations 2002.[13] The potential limitation of these provisions to enable the establishment of a national child death review database containing identifiable information hinges on demonstrating that there is no practicable alternative (such as consent), the identifiable data are needed, the purposes can be regarded as 'medical purposes' and whether the information shared can be regarded as 'patient information'. As regards the latter, the definition of patient information has recently been extended to incorporate information about social care as well as health care.[14] As regards medical purposes these are defined broadly to include the "management of health and social care services" as well as "preventative medicine, medical diagnosis, medical research, the provision of care and treatment." It would be necessary to make a s251 application to test whether the extended provisions would cover all child deaths and thus enable the sharing of national identifiable data with the national database. Importantly, even with s251 approval parents will be able to choose to opt out of having their and their child's data included in the national database.

- The Scottish Government Steering Group recommended that the child death review process should be implemented in Scotland without delay and therefore should not await legislation for its establishment.[4] Inclusion of identifiable data from Scotland in an English and Scottish national database would therefore also require an appropriate legal gateway in Scotland. Other than consent, an application to the Public Benefit and Privacy Panel (PBPP) for Health and Social Care for Scotland may provide an appropriate route although without making an application it is not clear whether this route would cover all child deaths.

Additional benefits flowing from the creation of a national database

- From our discussions with CDOP representatives and the work of the NNCDOPs Executive it is clear that there is a lack of standardisation of the data collected across different CDOPs. Although all CDOPs use the templates provided by DfE[15], modifications to the data items and the collection of additional data items has led to different definitions for some data items being used. For example, different CDOPs use different definitions of ethnicity. In order to 'pool' data in a national database, the data held in the national database will need to be collected using the same standard definitions thereby improving the quality and ensuring comparability and consistency of the data collected.

- There is an evident lack of national leadership for CDOPs and in some places a lack of regional leadership leaving some CDOPs functioning as isolated, stand-alone entities. Whilst there was leadership in the past, the re-organisation of the health service in 2012 and at the DfE has led to a loss of regional leadership in many places (with some notable exceptions) and certainly at a national level. It has only been through the efforts of particular committed individuals that the National Network of CDOPs has recently been established in order to provide leadership, collaboration and much needed support for CDOP staff. The creation of a national database would have the capacity to provide a further, welcome and essential focus of national leadership both at the level of the database and by Senior Responsible Officers at both the Department of Health and NHS England taking a leadership role. This is needed to set priorities; refine the CDOP processes, define the data to be collected, and agree the national dataset; provide training; disseminate the learning arising from reviews; and to interact with and influence the relevant agencies to take the necessary action for change at a national and regional level to ensure that national learning is translated into reduced child mortality rates.

- The active management of the national database would enable:
    - An enhanced communication function with the issuing of alerts and alarms in relation to unusual and newly emerging risk factors and causes of death;
    - Provision of a communication platform for the sharing of information between CDOP co-ordinators;
    - Sharing and mutual reviewing of cases to support consistent reviewing processes across CDOPs;
    - Sharing learning and prevention resources developed as a consequence of the findings of local reviews;
    - Publication of bulletins and other means of communicating the findings from the national database, for example interactive comparative tables, of the sort available on the ChiMat website.[16]

Recommendations for implementation

- We strongly recommend that a national child death review database is established.

- We strongly recommend that the national database should include identifiable information to optimise the function and benefits arising from the database thus maximising our capacity to prevent future child deaths.

- We strongly recommend therefore that the legal basis for the sharing of identifiable data without consent in England and the mandatory contribution of data by CDOPs is pursued through the provisions in the Children Act 2004. The move of the responsibility for CDOPs from the Department for Education to the Department of Health will require a legislative change and this presents an opportunity to incorporate the creation of the national database as part of these changes. An application to the Secretary of State for approval through the s251 mechanism of the NHS Act 2006 could be pursued as a limited alternative. A parallel application to the Public Benefit and Privacy Panel in Scotland would need to be made for the same purpose.

- The creation of a national child death review database, together with the proposed move of the responsibility for CDOPs to the Department of Health and the inception of the Healthcare Safety Investigation Branch (HSIB) in England presents a clear opportunity to consider the whole process of child death reviews, particularly in relation to deaths which occur in hospital. This should include who reviews which deaths, to which degree of detail, when this review should take place and who should communicate the findings to parents.

We recommend the following for inclusion in the specification of a national child death review database for England and Scotland:

Function

- The data system developed must include provision for a local data management system for CDOPs who wish to adopt a more sophisticated system than they have at present.

- We propose an integrated data management software system based on a hub and spoke model to develop local data management systems for local CDOPs/CDRPs with a real time connection to a national data management hub (see Figures 2 & 3). This will provide a more appropriate local data management system than is currently available to many CDOPs and importantly, avoid the need for duplicate data entry.

- The data system must be compatible with a range of computer operating systems and web browsers that meet appropriately stringent security requirements but facilitate access from a range of organisations to enable case notification and data provision to CDOPs/CDRPs to occur electronically. Accessibility for individuals with a disability will also need to be incorporated into the design.

- The national database must be actively managed with strong clinical leadership by which we mean the data must be scrutinised routinely to identify potential newly emerging causes of death and to enable alerts and alarms to be issued.

- Account must be taken of the fact that the majority of CDOPs have very limited, if any, resources at all to pay for a local data management system.

Data input

- The national database must include information about all child deaths in England and Scotland regardless of whether the review of each death has been completed.

- The data management system must allow for CDOPs who are satisfied with their current data management system to upload their data into the national data management hub and thus contribute to the national database; it should also be designed to allow the legacy data to be uploaded.

- Primarily the data flowing into the national database would be quantitative. However, consideration should be given to the inclusion of free text information arising from the narrative of panel discussions and currently recorded in 'Form C'. This would be for the purpose of enabling thematic, topic-based reviews of the rich qualitative data which is summarised following the panel discussions. It would also enable text searches for specific, potentially newly emerging, risk factors and causes of death.

Governance, regulation and management

- The creation and function of the national database must involve all relevant stakeholders, most particularly bereaved parents must be closely involved in the design and oversight of the operation of the database from the outset.

- Strong leadership of the central database management team is essential. This should have the capacity to provide national leadership for the whole programme and most particularly to ensure that required actions to prevent future child deaths are disseminated through to the relevant agencies for action and change.

- Data security is an essential priority and must be assured with risk minimisation protocols developed in parallel with the software development.

Outputs and access to data

- No identifiable data should be published in any of the outputs from the national database.

- CDOPs and CDRPs should have access to pre-specified reports of their own data, the ability to specify their own ad hoc reports and to access aggregated data to allow comparison of their data with their statistical neighbours and other comparators. Outputs available to CDOPs and CDRPs should be available at a regional as well as local level.

- A range of public outputs from the national data could include an annual report, regular bulletins dealing with specific topics, and pre-specified tables of aggregated data downloadable from the public facing website of the national database.

- Data access, including access by bone fide researchers, must be supportive and not prohibitive and will require a transparent access protocol which is developed with stakeholders and the data controller as an early priority.

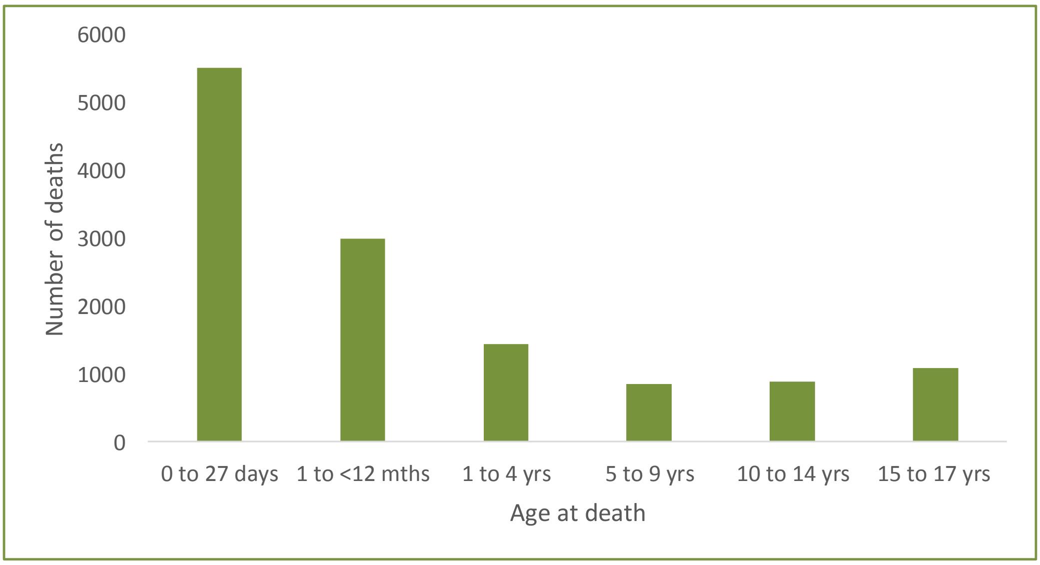
- Ideally analysis of the national data would replace the need for annual returns to the DfE. Until this point data for the annual return to DfE should be easily accessible by individual CDOPs.

Finally, we strongly recommend that improvements are made in the information provided to bereaved parents about the existence, purpose and function of CDOPs. This consideration is a key recommendation in the Scottish Steering Group report[4] and should happen in England regardless of the establishment of a national database. However, the establishment of a national database should enable the information given to parents about CDOPs, CDRPs and the national database to be more consistent across the country and to be informed by parent involvement, which <u>must</u> form an integral part of all aspects of the development and establishment of a national child death review database.

1. Background

In 2014 a total of 4,419 infants, children and adolescents died before their 18th birthday in England and Wales. In the same period 341 infants, children and adolescents died before reaching 18 in Scotland. In common with our high perinatal mortality rates comparisons of rates of death of infants, children and adolescents with other high income countries places England, Scotland, and indeed the whole of the UK, in an unfavourable light. A study of mortality rates comparing the UK with 15 other European countries showed that whilst mortality rates for children and young people over the age of 5 were similar to the European average, the rate in the under 4s places the UK in the bottom 25% of European countries.[1] What is also particularly salutary is that our relative position, particularly for infant and neonatal mortality, has worsened substantially since 1970.

Figure 1. Total number of child deaths in England and Wales by age at death, 2012 to 2014*



*ONS death registration data

Figure 1 show the total number of child death by age at death in England and Wales 2012 to 14. These figures are based on death registration data published by the Office for National Statistics (ONS). A more detailed analysis of child deaths was published in the Lancet series by Sidebotham *et al* (2014).[17] The figures illustrate the periods of a child's life where the child is at greatest risk of death. Broad categorisations of cause of death published by the Office for National Statistic are helpful in that they illustrate the types of causes of death at different ages. However, this information is not sufficiently detailed to provide guidance as to how we might reduce mortality, which deaths might be avoidable and what actions are required to prevent future similar deaths.

There is a long standing history of detailed scrutiny of the deaths of individual children in North America and New Zealand with the goal of identifying and implementing actions to prevent future child deaths.[18] Child death reviews (CDR) were instituted more recently in Australia, England and Wales, with planning underway in Scotland[4] and there are similar discussions taking place in Northern Ireland. Whilst broadly seeking to achieve the same outcome the means of achieving this varies between these jurisdictions, and apart from in New Zealand, even within these jurisdictions.[18]

Child Death Overview Panels (CDOPs) were introduced in England by statute[10]; each Local Safeguarding Children Board (LSCB) was required to have a CDOP in place by April 2008.[11] Responsibility for LSCBs and CDOPs, as part of the children's safeguarding agenda originally sat within the Department for Children, Schools and Families (DSCF), passing to the Department for Education (DfE) when this department was created in 2010. Varying levels of guidance on the operation of CDOPs has been provided through the 'Working Together' guidance which has been modified a number of times since its original publication.[2]

When CDOPs were originally introduced there were plans to bring together the information about child deaths and the outcomes of their review collected by individual CDOPs into a national database. Plans were advanced as far as a pilot phase before being cancelled in ~2010. In anticipation of the establishment of a national database many CDOPs have used relatively rudimentary information systems to meet their case management needs and to collate the information required for the annual DfE return, their own annual report and any other outputs.[9]

A survey of CDOP co-ordinators in 2012 identified that 75% of the survey responders were using a mixture of manual and computerised administration systems to manage the information required to conduct their panels and whilst 93% used a computer database to record their panel findings, this was only integrated with their administrative database in 65% of CDOPs.[9] The most commonly used 'electronic data system' was a series of excel spreadsheets combined with Word documents with most of the information arriving into the CDOP in paper form; very few CDOPs who responded had a more sophisticated information management system. As part of the same survey it was established that there was an overwhelming desire for the establishment of a national CDOP database.

In 2014, in response to the findings of the report from the 2012 survey[9] NHS England and the Scottish Government asked the Healthcare Quality Improvement Partnership (HQIP) to commission a development project to investigate whether and how it might be possible to establish a child death review national database to support the goal of reducing child deaths. Following an external bidding process a collaboration between the National Perinatal Epidemiology Unit, University of Oxford (Kurinczuk) and the TIMMS team in the Department of Health Sciences, University of Leicester (Draper and Field) were awarded the 18 month contract, starting on the 1st February 2015, to carry out the development project; the findings are reported here.

Following the recommendations of the Child Death Reviews Working Group report that Scotland should introduce a national Child Death Review System, in 2014 the Scottish Government established a Steering Group to develop the process and identify costs and funding. The Steering Group met on five occasions between January and June 2015, which was during the early period of the development project reported here, and their report was published in March 2016. They recommended the establishment of a National Resource Centre along with three regional offices to run multi-agency Child Death Review Panels (CDRPs) with the purpose of learning lessons to prevent avoidable future deaths.[4]

During the course of the development study reported here the Department for Education (DfE) in England, who have responsibility for safeguarding, commissioned an external, fundamental review of the role and function of LSCBs. Included in the review was the requirement to "identify what makes an effective Child Death Overview Panel (CDOP) and to explore what body is best placed to review child deaths to ensure that CDOPs are managed and held to account effectively."[5] This was a rapid review carried out by Alan Wood which was concluded in March 2016 after a three months review period; the 'Wood' report was published on the 26th May 2016. Of particular note the review recommended that responsibility for CDOPs should move to the Department of Health[6]; this recommendation was accepted by the Government[7] with an announcement by the Minister of State for Children and Families that "We will put in place arrangements to transfer national oversight of CDOPs from the Department for Education to the Department of Health, whilst ensuring that the keen focus on distilling and embedding learning is maintained."[8]

2. Aims

The aim of the development project was to investigate whether and how it would be possible to develop a 'national' database for England and Scotland to collect information from the child death reviews which are carried out in England by Child Death Overview Panels (CDOPs) and from the child death review process which was being planned in Scotland during the course of the development project.

3. Methods

The project was conducted largely as a series of consultations with the intention of consulting with:

- Those directly involved in the child death review process and specifically individuals involved in dealing with the information needed to carry out the reviews and the data generated by the reviews;
- Individuals and organisations which have oversight of the child death review process;
- Individuals and organisations, including third sector organisations, which would make use of the data that would be generated by a national child death review database;
- An expert in data sharing and information governance;
- An expert in developing national IT systems;
- The Scottish Child Death Reviews Steering Group;
- Bereaved parents;
- Other interested parties.

In total we consulted with a total of 25 bereaved parents, 131 individuals representing 109 organisations concerned with child death and received written submissions from 9 researchers in the field.

3.1 CDOP visits

We made two preliminary visits to the Merseyside and the Bristol CDOPs to gain a more detailed understanding of the day-to-day operational activity of CDOPs in preparation for the wider CDOP consultation meetings. During the CDOP consultation period we also visited the Kent CDOP to see their new web-based electronic data management system in operation. Kent CDOP has been working with the company QES to develop a bespoke, data management system to support their CDOP activities. When we visited the system was live although they had not yet used data from the system in a CDOP panel meeting; this was due to happen imminently.

3.2 CDOP consultations

At the outset of the CDOP consultation phase there were 89 CDOPs in operation. Of note after the completion of our consultations one CDOP had disaggregated into separate CDOPs thus returning to the previous total of 92.

We conducted 13 separate consultation meetings with groups of CDOP representatives in various locations around the country: Leicester, Newcastle, Sheffield (two meetings), Bristol, Manchester, Oxford, Birmingham (two meetings) and London (four meetings). Individuals from all CDOPs were invited to attend a local meeting; if they were unable to attend that meeting they were offered the opportunity to attend one of the other meetings. Three additional meetings were held beyond those originally planned, at the end of the consultation period in the hope that all 89 CDOPs would have been able to send a representative to one meeting; unfortunately, despite these additional offers six CDOPs were unable to attend. Thus, overall we consulted with 99 individuals representing 83 (93%) of the 89 CDOPs in operation during the consultation period. Following the consultations a draft report based on the consultation meetings was circulated for comment to all CDOPs, including those who were unable to send a representative to the meetings.

The CDOP consultations each took the form of a face-to-face meeting which lasted between 3 to 4½ hours. Following an introduction of the background and aims of the development project the project team posed a series of questions to the CDOP representatives and discussion ensued. Notes of the discussion points were taken by the team members present.

The questions discussed were:

Local CDOP functions

- The design of a national database could include functions to support local CDOP day-to-day activities for CDOPs as well as collating data nationally, would this be of use to support their CDOP?
- If such functions would be of use, who would they want having access to enter (not change or extract) data?
- What information do they collect locally, do they still use the DfE templates, have they modified the DfE templates and if so what data items have they added?

National database

- What would they see as the main purposes of a national database containing data from all CDOPs?

- What are the main questions a national database could answer that current local information cannot?
- What would be the main outputs from a national database that would be of use to them and/or others?
- Are there any other functions that could be supported by the presence of a national database that is, the national database would provide a platform for?
- In terms of data being entered into the database, what level of detail would need to be included?
    - Aggregated data?
    - Individual level data?
- What information, and in what format would that information, need to go into a national database?
  To address this point we used the current DfE templates/forms (B, supplementary B forms and the C form) and asked the CDOP representatives to go through the forms and indicate which particular data items would be of value for inclusion in the national database to meet the purposes of a national database which they had outlined in the earlier discussion.
- Should the information in a national database be anonymous?
    - Would the information need to be anonymous?
    - Would there be any benefits to including individually identifiable information?
    - Would there be any difficulties with including identifiable information in a national register?
- What else we need to consider which had not already discussed?

As anticipated, many of the points made in the discussions were made in each consultation meeting. Specific new points were made in all the meetings we held, even in the later meetings new points were still being raised. The final question in particular about ‘other considerations’ led to quite a number of new discussion points. In reporting the findings we have incorporated these new discussion points in the relevant sections rather than reporting them separately.

3.3 Consultation with other stakeholders

We held one consultation meeting with a group of stakeholders who can broadly be described as representatives from organisations who provide data used in the CDOP process and organisations which would have an interest in the information that could be generated by a national CDOP database; quite a number of representatives fell into both groups. Representatives were from the medical royal colleges, professional organisations, the third sector, Public Health England, the association of Chairs of LSCBs, the police and the Department of Business, Innovation and Skills. A representative from the coronial service was not able to attend, so this discussion took place by telephone.

The meeting followed a similar format to the face-to-face CDOP consultations. Following an introduction of the background and aims of the project the project team posed a series of questions to those attending and these were addressed in small group discussions. Notes of the discussion points were taken by the team members present.

The questions discussed were:

National database

- What would they see as the main purposes and uses of a national CDOP database?
    - The use by their own organisation
    - Broader purposes and uses by other organisations
- What outputs would they want to see?
- How would they like to be able to access the information from a national CDOP database?
- The national database would contain a sub-set of all the data collected by individual CDOPs Should the data included in the national database be:
    - Anonymous?
    - Could/should the data contain identifiable information (names, addresses, postcodes, dates of birth, NHS number)?
- Are there any benefits to collecting identifiers?
- Are there any disadvantages and/or risks to collecting identifiers?
- What else needs to be considered which has not already been discussed?

3.4 Consultation with bereaved parents

We held four face-to-face consultation meetings with groups of bereaved parents; we met with a total of 25 parents. The meetings were organised and facilitated by Child Bereavement UK (CBUK), the Lullaby Trust and Sands which are all third sector organisations who work with and represent bereaved parents; the parents who attending the meeting were members or used the services of these three charities (Appendix B – parent information leaflet).

We started with an introduction of the background and aims of the project which included a description of the function and purpose of CDOPs. We then posed a series of questions followed by a discussion period with the project team members present. The team members then left the room for a period to allow parents to discuss the various questions and their conclusions were then fed back when the team members re-joined the parents. Notes were taken by the team members.

The questions discussed were:

Child death overview panels

- Were they aware of the CDOP process and activities?
- And if so – have they had any involvement in the process?

National database for child death review information

- What are their views on the idea of having a national database of the information collected by CDOPs (access and security safeguards will be in place)
- How do they feel about the creation of such a database?
- Do they see any value in such a database?
- Would they object to such a database being created?
- Would they object to information about their child and family (limited family information) being included?

What sort of data should be held?

- Assuming that all the appropriate security and access safeguards are in place should the information on the database be anonymous or should it include identifiable information such as:
    - NHS number?
    - Name?
    - Address?
    - Postcode?
    - Date of birth?
    - Date of death?
- How would they feel about the inclusion of information regarding their child and family (very limited) including identifiable information being submitted to a national database?
- What else needs to be considered which has not already been discussed?

3.5 Consultations with the Scottish Child Death Review Steering Group

We held four teleconferences with the Child Death Review Steering Group in Scotland (David Jacks [Chair]; Kate McKay; Rachael Wood). This enabled us to keep mutually appraised of the progress of each project. The Scottish Steering Group developed a list of data items they proposed would be collected as part of the review process. We included this list alongside the data items identified by the CDOP representatives as needing to be included in the national database. The Steering Group presented their report to the Scottish Government during the course of the development project and it was published in March 2016[4] enabling us to make reference to their findings in relation to our recommendations.

3.6 Consultation with the Executive Group of the National Network of CDOPs

We also met with the Executive Group of the National Network of CDOPs on two occasions; this is a self-formed group of representatives of CDOPs who have been brought together by Dr Nisar Mir, community paediatrician and assistant coroner in Cheshire. They have organised two national conferences, one of which we attended in February 2016 and presented the work of the development project. As well as trying to develop a network, provide leadership and engage CDOPs in collaborative work, the executive group have been reviewing the data collected by CDOPs to refine the information, the number of data items, to reduce the volume and to standardise the data definitions used particularly in relation to modifiability.

3.7 Consultation with researchers

We carried out a remote consultation with researchers with an interest in the field of child death and child death reviews. We identified researchers working in the UK through existing knowledge and review of the recent child death review literature acknowledging that this was likely to generate an incomplete list of interested researchers. The researchers were sent a short email questionnaire which contained the following questions:

National database

- What do you see as the main purpose and uses of a national CDOP database? Please answer this from both a general and a research perspective.

- A national database is likely to include only a sub-set of all the data collected by CDOPs. In broad terms what data do you think should be included in the national database? Should the data be collected by the national database in an aggregated format or as individual level data?
- Assuming appropriate data security controls and information governance arrangements are in place should the data in the national database include personal identifiers?
- What do you see as the risks and benefits of including identifiable data?
- What other issues should we consider?

3.8 Consultation with a data sharing and information governance expert

We met once and had a further teleconference with Dr Mark Taylor, Senior Lecturer in Law, at the University of Sheffield who is an expert in the law relating to data protection, data sharing and confidentiality. This discussion provided very helpful insights in relation to data sharing issues, particularly the issue of sharing of identifiable data and the legal basis of such sharing, and information governance in general.

3.9 Consultation with an expert in developing national data collection systems

We met with Peter Smith, Senior Programmer on the MBRRACE-UK programme, NPEU, University of Oxford to discuss potential configuration of a national database. Because at this stage no final decisions had been made about how the database might be configured he was able to provide only general advice, plus advice on the process of the specification of the database and the steps involved.

3.10 Wales – Child Death Review process

The commissioning brief did not include Wales. However, in order to take account of the Welsh Child Death Review process we consulted with Dr Rosalind Reilly on one occasion. There is also a representative from Wales on the Executive Group of the NNCDOPs who was present at one of our consultation meetings with the group.

4. Findings and implications

The detailed findings from the various consultations are given in Appendices C (CDOPs), D (other stakeholders), E (parents), and F (researchers). The data items which were identified for inclusion in national database are given in Appendix G. Of note this list must be regarded as a ‘first pass’ look and will need to be combined with the findings of the standardisation work carried out by the self-established National Network of CDOPs and if data from Scotland is included in the national database then further consultation with the Scottish Government and the Information Services Division Scotland will be required.

In this section we present the broad findings from the consultations and discuss the issues in terms of the practicalities of the creation of a national CDOP/CDRP database. We also discuss the issue of whether the data included in the national database should include personal identifiers, discussing the benefits and potential risks of this approach, and the associated information governance issues.

4.1 Support for a national child death review database

We found overwhelming support for the creation of a national child death review database; with only one conditional exception, everyone with whom we consulted was wholly in favour of such a database being created. Importantly this included all the bereaved parents we consulted. Indeed several of the parents we met objected to the fact that such a database did not already exist.

At no stage did we have to convince anyone, including bereaved parents, of the benefits that would arise from having a national database. Parents in particular were keen to ensure that where possible future child deaths would be prevented to avoid anyone else experiencing the suffering they had endured; they implicitly understood the valuable contribution that a national database would make to the achievement of this goal.

4.2 How a national database might operate

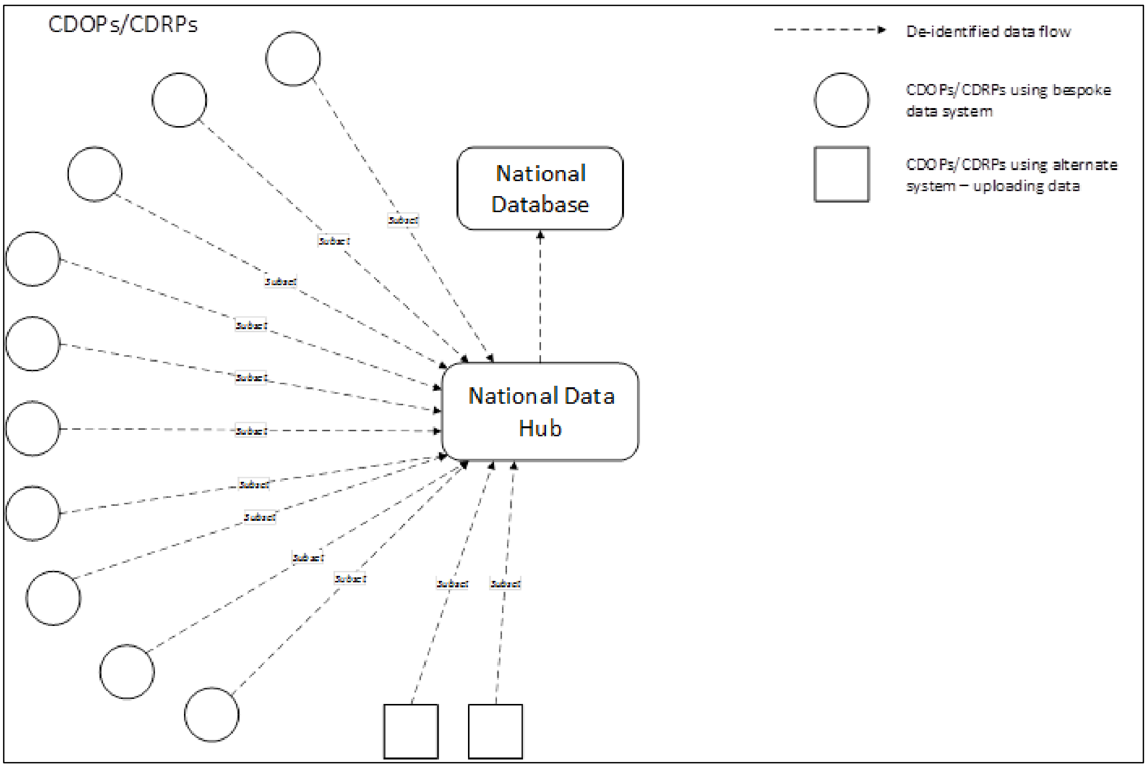
The vast majority of local CDOPs currently operate with very basic information management support. This lack of investment in IT systems arose from the inception of CDOPs when a national database was anticipated. Subsequent investment has not been forthcoming for the majority even at a time when funding for CDOPs was ring-fenced, which is no longer the case. The consequences of this are that:

- The introduction of a national database must not involve additional data entry burden for CDOP staff;
- The majority of CDOPs would not be in a position to contribute to the cost any of local system incorporated as part of a new national system.

To meet these requirements we propose the development of an integrated data management system on a hub and spoke model where the new national database comprises a software system which supports local data management for those CDOPs which require this support. A subset of the data collected locally would be fed into a national data hub and through to the national database in real time (Figures 2 & 3). Importantly the system would also need to the capability to receive data uploads from CDOPs who are satisfied with their existing data system and also to upload the existing historical data currently held by CDOPs.

The model illustrated in Figure 2 would require sharing of only de-identified data. Under this model key data items which are also identifiers e.g. date of birth and data of death, would need to be shared but could be truncated (e.g. month and year of birth rather than full date of birth). However, limiting the sharing of these identifiers would introduce some constraints on the analyses and thus outputs from the data and thus limit the potential benefits that could follow the introduction of a national database.

Figure 2: Proposed hub and spoke model for an integrated data management system for local CDOP data and the central national database hub – model sharing de-identified data only



A hub and spoke model has the advantage that the data items collected will be pre-defined using standard agreed definitions which can be applied consistently across all CDOPs/CDRPs. Currently different definitions for apparently the same data item are used in different places thus limiting any potential direct comparisons; this inconsistency will need to be eliminated in a national system. The definition of data items will draw on the 'first pass' view taken as part of this development project, but should also draw more heavily on the detailed work undertaken by the NNCDOPs Executive Group and the Scottish Government Steering Group.

An important feature of the national database is that it would not contain all the information which is collected locally to support the individual CDOP processes. This follows the principle of collecting a 'small', tightly defined and complete dataset on every death, rather than collecting a larger but inevitably incomplete set of data. There are two main reasons for following this principle:

- CDOPs collect an extensive amount of information which would realistically never be analysed and published nationally;
- Whilst the majority of information is and could be collected using agreed standard definitions across all CDOPs there are always likely to be local concerns and interests which would potentially lead to the collection of specific items to meet such local concerns but which would not be a national priority.

The national CDOP/CDRP database could however, have the capacity to receive electronic data downloads to incorporate information which goes beyond that which is currently collected by CDOPs or is currently collected in a paper form at present. To maximise both the prevention of deaths locally and the capture of the richest possible dataset nationally, consideration needs to be given to the linkage of data from other informative sources.

With the appropriate design of the system, some of this additional information could come from the capacity of the electronic data management system to receive information from other systems currently operating and those currently under development. Examples of data available currently which could be fed into the hub and spoke model as electronic feeds include:

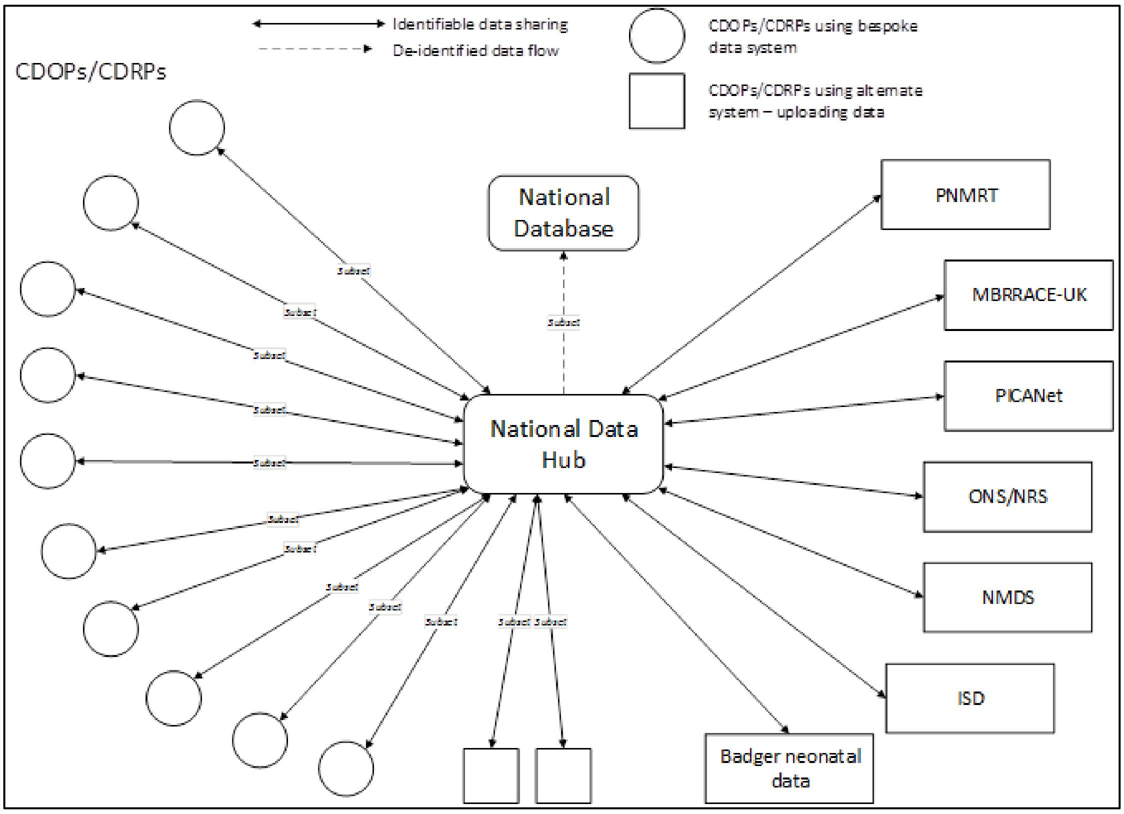
- Data from the national surveillance of perinatal deaths collected by MBRRACE-UK;
- Elements of the clinical data collected by the Badger data system which is in widespread use in neonatal units around the UK;
- Elements of the data collected from all paediatric intensive care units in the UK by the Paediatric Intensive Care Audit Network (PICANet);
- The clinical discharge data for neonates, infants and children collected by ISD Scotland.

Examples of systems in development and early start-up include:

- Data arising from the Perinatal Mortality Review Tool (PMRT) which is being funded by the Department of Health England and Scottish Government (and Welsh Government) and currently being commissioned by HQIP;
- Data being collected from local maternity data system by the National Maternity Services Data set in England.

The inevitable consequence of the ability to receive and process these data feeds is that this would have to be organised by a central data processing hub and will involve the use of data containing personal identifiers. Whilst this does not necessarily mean that personal identifiers would be included in the data designated as the ‘national database’, it does mean that the central software development and management team would have to have access to personal identifiers and thus these could not just be kept within the local CDOP systems. This proposed model, which is illustrated in Figure 3, would maximise the data available to both local CDOPs and the national database. However, this brings us to the most contentious issue of the consultation, that of the need for personal identifiers to be accessible beyond the local CDOP data management systems.

Figure 3: Proposed hub and spoke model for an integrated data management system for local CDOP data and the central national database hub – model sharing identifiable data to enable linkage and data sharing with other sources



4.3 Access to and need for personal identifiers beyond the local CDOP/CDRP systems

The single most contentious issue we discussed with stakeholders of every description was the issue of whether the data held in the national database should be identifiable or anonymised. The entire spectrum of perspectives was expressed from the view that the data held nationally should be fully identifiable through to the data being completely anonymised. It was also clear from these discussions that there is not a single shared view of what the terms ‘identifiable data’ and ‘anonymised data’ actually mean. This has important implications for future communications about the national database.

The inclusion of identifiers and the purpose and value of their inclusion were explored in detail with all groups. Bereaved parents in particular, generally took a permissive view of the inclusion of some specific identifiers for example, NHS number, date of birth, date of death and postcode (the latter to derive measures of socio-economic deprivation). They took a less permissive view regarding name and address. Of note, some parents thought that all identifiers should be held nationally with one parent expressing the view that identifiability was not an issue since “Nothing can be worse than the death of your child.”

Parental consent to the inclusion of data in the national database was also explored. Parents acknowledged the fact that there is a wide range of causes of death and some parents may be less willing to have their information shared especially if they were implicated in some way in their child's death. Concerns were also expressed about how and when consent might be sought and by whom. The fact that some parents would not consent was seen as particularly problematic since a database which does not include all deaths was seen as a serious limitation. Parental electronic notification when an individual child's information was used was suggested as a desirable attribute.

Representatives from CDOPs and all other stakeholders expressed the whole range of views on the issue of Identifiability. Many CDOP representatives could see the value of including identifiers as enabling the capacity to link the information from CDOPs to other sources of additional information, resulting in a richer picture of the causes and circumstances of child deaths.

Additional reasons to enable linkage identified by CDOP representatives and others included:

- Research purposes;
- The opportunity to identify related child deaths which occur in the same family in different parts of the country when families move around;
- To enable the capacity to 'share' information on cases where the death occurred outside the area of residence and for which the 'resident' CDOP is responsible for the review but the information to be reviewed has to come from another CDOP.

The counterviews expressed by CDOP representatives and other consultees included:

- The fact that CDOPs owe a duty of care to parents and this extends to not sharing data which may make them and their child identifiable;
- That CDOPs 'own' the data, that a national database would be solely for the benefit of CDOPs and thus there would never be any need to include identifiers because no use would ever be made of this information;
- That any data breach would be more serious because it could include the personal identifiers;
- Identifiability may be of concern in situations where legal proceedings were underway in relation to particular families.

Following detailed discussions it was clear that for some CDOP representatives, the benefits of allowing identifiable data to be held in the national database out-weighed the potential risks and counter arguments, but others took the opposite view. The balance of views after discussion, although not quantified by 'voting', was generally more in favour of enabling some identifiers to be held in the national database than not. However, it was also clear that this issue could potentially be a 'deal breaker' for some CDOPs in terms of their 'participation' in the national database.

4.4 The use of information containing personal identifiers

We took the view that to maximise the benefit of a national CDOP/CDRP database it would be necessary to be able to incorporate by linkage and data downloads, data from other sources. To do this it would be necessary for personal identifiers to be made available to the central programming and system management team in the national data hub, although it would be possible that only de-identified data would then be included in the dataset designated as the national database. However, regardless of the distinction between the national data hub (the operational centre) and the national database a firm legal basis for the sharing of identifiable information without consent would be required assuming that a wholly consented model was not practicable for the reasons discussed above. For this reason we explored in some detail the possible ways in which such a legal basis could be established.

4.4.1 Situation in England

The legal basis enabling CDOPs in England to use and process identifiable data without consent is clear and comes from the statutory powers enshrined in the National Children Act 2004[10], which are operationalised in Regulation 6 of the Local Safeguarding Children Board Regulations 2006 (made under section 14(2) of the Children Act 2004)[11], and outlined in the Working Together Guidance.[2]

In addition to consent, we identified two further potential legal gateways to enable CDOPs in England to share identifiable data with the central hub of a national data system without consent and to enable the hub to receive, hold and process identifiable data both from CDOPs and from other data sources.

The first is the Children Act 2004 which makes explicit, for England, under section 12(5) that the "Secretary of State may by regulations make provision in relation to the establishment and operation of any database or databases under this section." Further sections outline in detail the circumstances in which such a database can be established but they broadly relate in this regard to section 10 (Co-operation to improve well-being) and section 11 (Arrangements to safeguard and promote welfare). We presume that it was under these provisions that the operation of the original national database was planned. However, the Regulations required to enact section 12(5) for the purposes of the creation of a national child death database were never laid before Parliament and this would be needed before this route could be relied upon as the legal basis for establishing a national data hub/national database which contains identifiable data. Through this route it would also be possible to mandate the sharing of information by all agencies concerned.

However, to achieve this would require support from the relevant government department which, with the planned change in arrangements,[7,8] will be the Department for Health. Engagement at the highest level would be required to make the national child death review database a priority for a Minister and the civil servants who would undertake the drafting, the identification of an appropriate instrument which is in the legislative calendar for their inclusion, and support in parliament when the regulations are laid. The latter might be garnered from the All Party Parliamentary Group for Children and the Children's Commissioner and building on the response to a parliamentary question about child deaths by the Prime Minister when he said "…..but I can tell her that NHS England is going to fund a project to develop a national child death review information system to try to drive more information."[19] Ministerial support from the Department of Health might be built on the desire to see the national 'Halve it' ambition relating to neonatal deaths and neonatal brain injury achieved. The move of the responsibility for CDOPs from the Department for Education to the Department of Health will require a legislative change and this presents an opportunity to incorporate the creation of the national database as part of these changes.

The second potential legal gateway is through an application to the Secretary of State under Section 251 of the NHS Act 2006[12]; again this only applies to England (and Wales). Section 251 of this Act allows the Secretary of State to make regulations to set aside the common law duty of confidentiality for the sharing of patient information for defined medical purposes. The Regulations that enable this power are the Health Service (Control of Patient Information) Regulations 2002.[13] The potential limitation of these provisions to enable the establishment of a national child death data system containing identifiable information hinges on demonstrating that there is no practicable alternative (such as consent), that identifiable data are needed, the purposes can be regarded as 'medical purposes' and whether the information shared can be regarded as 'patient information'. As regards the latter, the definition of patient information has recently been extended to incorporate information about social care as well as health care.[14] As regards medical purposes these are defined broadly to include the "management of health and social care services" as well as "preventative medicine, medical diagnosis, medical research, the provision of care and treatment." It is not immediately clear that information about all child deaths would meet the requirements for s251 support. It would therefore be necessary for a s251 application to be made to test whether the extended definition of patient information and the current definition of medical purposes would be interpreted as covering all child deaths and thus enabling the sharing of national identifiable data on all deaths with the national data system. Importantly, even with s251 approval parents will be able to choose to opt out of having their and their child's data included in the national database.

4.4.2 Situation in Scotland

The recommendation of the Scottish Government Steering Group is that the child death review process should be implemented in Scotland without delay and therefore should not await legislation for its establishment.[4] Other than via consent the inclusion of identifiable data from Scotland in an English and Scottish national database would therefore also require an appropriate legal gateway in Scotland. An application to the Public Benefit and Privacy Panel (PBPP) for Health and Social Care for Scotland may provide an appropriate route although without a test application it is not clear whether, as in the case of a s251 application in England, this route would cover all child deaths.

4.5 Other benefits of a national child death review database

From our discussions with CDOP representatives and the work of the NNCDOPs Executive it is clear that there is a lack of standardisation of the data collected across different CDOPs; consistency in the attribution of modifiability is a particular problem both across and within CDOPs. Although all CDOPs use the templates provided by DfE modifications to the data items and the collection of additional data items has led to different definitions for some data items being used. For example, different CDOPs use different definitions of ethnicity. In order to 'pool' data in a national database, the data held in the national database will need to be collected using the same standard definitions thereby improving the quality and ensuring comparability and consistency of the data collected.

There is an evident lack of national leadership for the work and direction of CDOPs and in some places a lack of regional leadership leaving some CDOPs functioning as isolated, stand-alone entities. Whilst there was leadership in the past the re-organisation of the health service in 2012 and at the DfE has led to a loss of regional leadership in many places (with some notable exceptions) and certainly at a national level. It has only been through the efforts of particular committed individuals that the National Network of CDOPs has recently been established. The creation of a national database would have the capacity to provide a further, welcome and essential focus of national leadership both at the level of the database and by Senior Responsible Officers at both the Department of Health and NHS England taking a leadership role. This is needed to set priorities;

refine the CDOP processes, define the data to be collected, and agree the national dataset; provide training; disseminate the learning arising from reviews; and to interact with and influence the relevant agencies to take the necessary action for change at a national and regional level to ensure that national learning is translated into reduced child mortality rates.

The active management of the national data would allow for an enhanced communication function with the issuing of alerts and alarms in relation to unusual and newly emerging risk factors and causes of death and could be developed to provide a communication platform for the sharing of information between CDOP co-ordinators. Such a function could be used to enable sharing and mutual reviewing of cases to support consistent reviewing processes as well as sharing learning and prevention resources developed as a consequence of the findings of local reviews.

4.6 Information for and the role of bereaved parents

It was evident from our discussions with bereaved parents that the vast majority were not previously aware of the existence of CDOPs, their purpose and function, the fact that their child's death would be been reviewed at their local CDOP panel and that their local CDOP holds information about them and their child. Similarly, few of those parents whose child died in hospital were aware that a review of their child's death would most likely have taken place. Parents initially expressed a mixture of shock and surprise, and some appeared initially affronted when we described the CDOPs to them; they then reflected that they were pleased that 'someone' was taking the death of their child seriously. Their reactions serve to underline the fact that any development of a national database must involve bereaved parents at every stage from the outset; that is, from the earliest point of development when the design is considered and planning starts, all the way through to oversight of the operation of the national database once established.

5. Recommendations

- We strongly recommend that a national database of information from child death reviews is established. The lack of such a database is impeding our capacity in England and Scotland to understand fully the causes and circumstances of child deaths, to fully identify modifiable factors, to put in place local, regional and national actions to prevent future deaths and thereby reduce our national child mortality rates.

- We strongly recommend that the national database should include identifiable information to optimise the function and benefits arising from the database thus maximising our capacity to prevent future child deaths.

- We strongly recommend therefore that the legal basis for the sharing of identifiable data without consent in England and the mandatory contribution of data by CDOPs is pursued through the provisions of the Children Act 2004. The move of the responsibility for CDOPs from the Department for Education to the Department of Health will require a legislative change and this presents an opportunity to incorporate the creation of the national database as part of these changes. An application to the Secretary of State for approval through the s251 mechanism of the NHS Act 2006 could be pursued as a limited alternative. A parallel application to the Public Benefit and Privacy Panel in Scotland would need to be made for the same purpose.

- The creation of a national child death review database, together with the proposed move of the responsibility for CDOPs to the Department of Health and the inception of the Healthcare Safety Investigation Branch (HSIB) presents a clear opportunity to consider the whole process of child death reviews in England, particularly in relation to deaths which occur in hospital. This should include who should review which deaths, to which degree of detail, when this review should take place and who should communicate the findings to parents.

We recommend the following for inclusion in the specification of a national CDOP/CDRP database for England and Scotland:

5.1 Function

- The national child death review database must be designed to improve the local data management for CDOPs in England which, with a small number of notable exceptions, in general have poorly functioning systems, and to support the system of CDRPs when established in Scotland. It must also have the capacity to receive uploads of data from those CDOPs with more developed and satisfactory existing systems and to integrate the existing legacy data. The new national database must not add to the data collection burden of CDOP staff.

- We recommend an integrated software system on a hub and spoke model to develop local data management systems for local CDOPs/CDRPs with a real time connection to a national data management hub from which the national database is derived. This would support all the local CDOP data management activities including the collection of data using standardised terms across all CDOPs and avoid duplicate data entry. The data would be partitioned to enable the flow of a selected subset of the data in real-time thereby creating the national database. The Paediatric Intensive Care Audit Network (PICANet) uses this model of data collection. See Figures 2 and 3 (paragraph 4.2) for two possible models of operation.

- The data system must be compatible with a range of computer operating systems and web browsers that meet appropriately stringent security requirements but facilitate access from a range of organisations to enable case notification and data provision to occur electronically. Accessibility for individuals with a disability will also need to be incorporated in the design.

- The national database must be actively managed with strong clinical leadership by which we mean the data must be scrutinised routinely to identify potential newly emerging causes of death and to enable alerts and alarms to be issued.

- Account must be taken of the fact that the majority of CDOPs have very limited, if any, resources at all to pay for a local data management system.

5.2 Data inputs

- The national database must include information about all child deaths in England and Scotland regardless of whether the review of each death has been completed.

- The data management system must allow for CDOPs who are satisfied with their current data management system to upload their data into the national data management hub and thus contribute to the national database; it should also be designed to allow the legacy data to be uploaded.

- Primarily the data flowing into the national database would be quantitative. However, consideration should be given to the inclusion of free text information arising from the narrative of panel discussions and currently recorded in 'Form C'. This would be for the purpose of enabling thematic, topic-based reviews of the rich qualitative data which is summarised following the panel discussions. It would also enable text searches for specific, potentially newly emerging risk factors and causes of death.

5.3 Governance, regulation and management

- The creation and function of the national database must involve all relevant stakeholders, most particularly bereaved parents must be closely involved in the design and oversight of the operation of the database from the outset.

- Strong leadership of the central database management team is essential. This should have the capacity to provide national leadership for the whole programme and most particularly to ensure that required actions to prevent future child deaths are disseminated through to the relevant agencies for action and change.

- Data security is an essential priority and must be assured with risk minimisation protocols developed in parallel with the software development.

5.4 Outputs and access to data

- No identifiable data should be published in any of the outputs from the national database.

- CDOPs and CDRPs should have access to pre-specified reports of their own data, the ability to specify their own ad hoc reports and to access aggregated data of their statistical neighbours and other comparators. Outputs available to CDOPs and CDRPs should be available at a regional as well as local level.

- A range of public outputs from the national data could include an annual report, regular bulletins dealing with specific topics, and pre-specified tables of aggregated data downloadable from the public facing website of the national database.

- Data access, including access by bone fide researchers, must be supportive and not prohibitive and will require a transparent access protocol which is developed with stakeholders and the data controller as an early priority.

- Ideally analysis of the national data would replace the need for annual returns to the DfE. Until this point data for the annual return to DfE should be easily accessible by individual CDOPs.

Finally, we strongly recommend that improvements are made in the information provided to bereaved parents about the existence, purpose and function of CDOPs; this consideration is a key recommendation in the Scottish Steering Group report. This should happen in England regardless of the establishment of a national database. However, the establishment of a national database should enable the information given to parents about CDOPs, CDRPs and the national database to be more consistent across the country and to be informed by parent involvement, which must form an integral part of all aspects of the development and establishment of a national child death review database.

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Appendix A – Individuals who contributed to the development project and the consultation meetings

We would like to thanks the following individuals who contributed to the development project:

Cath Rounding and Beth Lawson who provided administrative support to the project.

Ann Chambers, Ann Rowland, Katie Koehler, and Sue Clachers, from CBUK; Charlotte Bevan and Roopal Shah from Sands; and Francine Bates and Jenny Ward from The Lullaby Trust, all of whom enabled and facilitated our meetings with bereaved parents.

David Jacks [Chair], Kate McKay and Rachael Wood, Child Death Review Steering Group in Scotland and Mary Sloane who organised our teleconferences.

Nisar Mir [Chair] and other members of the Executive Group of the National Network of CDOPs who met with us on two occasions to discuss their work on standardisation.

Irene Wright and Helen Fleming-Scott, Merseyside CDOP, Vicky Sleap, Bristol CDOP and Sue Gower and Sue Gibbons, Kent CDOP all of whom hosted us for a visit to their CDOP.

Nick Chinn and Rob Taylor from QES Software Solutions whom we met on our visit to the Kent CDOP.

Mark Taylor, Senior Lecturer in Law, University of Sheffield, who provided helpful advice in relation to data protection, data sharing and confidentiality.

Peter Smith, Senior Programmer, MBRRACE-UK, National Perinatal Epidemiology Unit, University of Oxford, who provided helpful advice and discussed models for the potential configuration of a national database.

Rosalind Reilly, with whom we discussed the Welsh child death review processes.

Bereaved parents

We met with 25 bereaved parents who each participated in one of four consultation meetings with us. We are very grateful to all the parents who attended the consultation sessions to discuss matters which are deeply personal and profoundly sad; this was a very courageous and generous act on their behalf.

Six parents did not wish or did not give permission to be thanked by name.

We would like to thank the following parents: Dawn Allen mother of Henry, Charlotte Bevan mother of Hope Williams, Nicola Carlin and Christopher Carlin parents of Lily, Vicky Constable mother of Nathaniel Octave, Susan Down mother of Emily Louise Down, Chandni Freer and Patrick Freer parents of Aaron Freer, Pauline James mother of Paul James, Aneta Jankowska mother of Nathan George White, Nathalya Kennedy mother of Danny Ray Kennedy, Andrea Kerslake mother of Elliot, Susan Palmer mother of Anna Ceridwen Palmer, Jackie Parkinson mother of Samuel James Parkinson, Emma Smith mother of Nyah, Leanne Smith and Jack Reader parents of Oscar Reader, Christina Walker mother of Antoinette Maria Walker and Heather Wicks mother of Simon Wicks.

CDOP representatives

We are very grateful to the individuals who attended our CDOP consultation meetings representing their CDOPs; their participation was fulsome and enthusiastic.

CDOP representative	CDOP represented
Kailash Agrawal	Tees
Lavinia Armotrading	Hammersmith, Fulham, Kensington, Chelsea & Westminster
Stacey Attenborrow	Rotherham
Greg Barbosa	Dudley
Colin Barker	Derbyshire
Jaki Bateman	Sandwell
Lorraine Beckford	Sutton Merton
Karen Bennett	Sheffield
Sarah Bennett	Richmond
Shelley Birch	Tameside, Trafford, Stockport
Roselyn Blackman	Barking & Dagenham
Ben Brown	Doncaster
Debbie Brown	Sandwell
Ruth Byrne	Sheffield
Julia Caldwell	Calderdale
Emma Chawner	York City and North Yorkshire
Hayley Cheesman	Surrey
Monica Clarke	Redbridge
Nicola Clarke	Bradford
Louise Clarkson	Bradford
Simon Corkill	Barnet
Helen Craddock	Milton Keynes
James Crompton	Lambeth and Southwark
Susie Crook	Worcestershire
Cat D'angelo	Oxfordshire
Stephanie Davern	Bury, Rochdale and Oldham
Danielle Dawson	Blackpool, Blackburn, Lancashire
Dennis Wilkes	Birmingham
Nicola Docherty	Camden
Sophia Dougall	Warwickshire
Rick Dowell	Pan Dorset
Allison Duggal	Enfield
Cathy Eccersley	Kingston Upon Hull

David Elliman	Haringey
Carol Evason-Coombe	SW Peninsula
Moira Fahy	Manchester, and representing Bolton
Vicki Fearne	Pan Dorset
Helen Fleming-Scott	Merseyside (Knowsley, Liverpool, Sefton, St Helens, Wirral)
Helen Fowler	Dudley
Carole Furlong	Harrow
Joanna Garner	Bradford
Stacey Gilham	North East Lincolnshire
Shakira Gordon	Havering
Lou Gostling	Norfolk
Sue Gower	Kent
Karen Guest	Pan Dorset
Carol Hamilton	Ealing/Hillingdon
Bernie Harrison	Bedford, Central Bedfordshire & Luton
Julie Hartley	Calderdale
Alison Henderson	Wakefield
Zoe Hiett	Somerset
Nicky Hoyles	Kirklees
Amanda Hugill	Darlington & Durham (2 CDOPs)
Jayne Hurd	North Lincolnshire
Lisa Hydes	Leicester, Leicestershire & Rutland
Evelyn Irving	Suffolk
Jill May	Bexley
Fiona Johnson	East Sussex
Lynda Jones	Lincolnshire
Farhana Khan	SW Peninsula
Mick Lay	Tameside, Trafford, Stockport
Helen Leahey	Lewisham
Janet Levett	Essex, Southend & Thurrock
Nia Lewis	Croydon
Faith Lindley-Cooke	Staffs & Stoke on Trent
Kerry Littleford	Hackney & City
Dara Lloyd	Coventry, Solihull & Warwickshire (3 CDOPS)
Anne MacKenzie	Cheshire East
Christine Martin	Tower Hamlets
Debbie Mawson	Nottingham City
Sean May	Gateshead
Helen McElroy	Medway Towns

Lesley Mellor	Milton Keynes
Paul Menkenzi	Kent
Simon Meyrick	Herefordshire
Sharon Mitchell	Cumbria
Cynthia New	Surrey
Ene Odeh	Newham
Kitty Paques	Cambridgeshire Peterborough
Margaret Pugh	West Sussex
Jill Rennie	North of Tyne
Bob Ross	Nottinghamshire
Phillipa Scott	Hertfordshire
Jenny Selway	Bromley/Bexley
Kelly Slade	Wandsworth
Vicky Sleap	West England, Swindon & Wiltshire and Gloucestershire
Jo Smith	Merseyside [Wirral]
Margo Smith	East Riding of Yorkshire
Ruth Stevens	Leeds City Council
Hamira Sultan	Derbyshire
Oosman Tegally	Brent
Hannah Tellam	Tower Hamlets
Mark Tester	Barnet
Lorna Tunstall	Berkshire [Reading Slough Windsor Wokingham]
Hilary Walker	Buckinghamshire
Alison Wood	Shropshire/Telford&Wrekin
Cherylynn Wray	Barnsley

Broader stakeholder group

We are grateful to the broader stakeholder group who attended our stakeholder consultation meeting, provided a written submission or spoke to us in an alternative context:

Organisation	Name	Role
Public Health England	John Battersby	Programme Director, Child and Maternal Health (ChiMat) Intelligence
Sands (the stillbirth and neonatal deaths charity)	Charlotte Bevan	Senior Research and Prevention Advisor
Association of Independent LSCB Chairs	Richard Burrows	NE Regional Director, Northumberland LSCB. Representing LSCB Chairs

Police service	Yvette Connolly	National Injuries Database Adviser Specialist Operations / National Injuries Database
Bliss (for babies born too soon too small or too sick)	Caroline Davey	Chief Executive
Multiple Births Foundation	Jane Denton	Chief Executive
British Association of Perinatal Medicine	Alan Fenton	President
Child Death Reviews, Bristol	James Fraser	Consultant in Paediatric Intensive Care, Bristol
Royal College of Midwives	Mervi Jokinen	Practice and Standards Professional Adviser
British Association for Community Child Health	Anne Livesey	Community Paediatrician, Sussex community NHS Trust
NCT	Sarah McMullen	Head of Research
ROSPA	Sheila Merrill	Head of Public Health
National Network of CDOPs	Nisar Mir	Paediatrician and Assistant Coroner for Cheshire; Chair, Executive Group NNCDOPs
British Association of Perinatal Medicine	Lisa Nandi	Executive Secretary
Muslim Bereavement Support Service	Mohamed Omer	
Group B Strep Support	Jane Plumb	Chief Executive
Department for Business, Innovation and Skills	Michael Porter	Single Market Product Safety
National Society for the Prevention of Cruelty to Children (NSPCC)	Gwynne Rayns	Development Manager
Society of Coroners	Andre Rebello	Secretary
Twins and Multiple Births Association	Keith Reed	Chief Executive, TAMBA
Royal College of Paediatrics and Child Health	Rachel Rowlands	Consultant Paediatric Emergency Medicine
Royal College of Nursing	Fiona Smith	Professional Lead Children and Young People
Institute of Health Visiting	Karen Stansfield	Head of Department, Education and Quality, Institute of Health Visiting
Lullaby Trust	Jenny Ward	Director of Services
Paediatric Intensive Care Society	Peter Wilson	President
Police Service	Stuart Wratten	Metropolitan Police

Researchers

We asked a number of researchers in the field to contribute to a virtual consultation and are grateful for the written submissions from the following individuals:

Name	Role
James Fraser	Consultant Paediatric Intensive Care, Bristol Royal Hospital for Children
Lorna Fraser	Paediatric Epidemiologist, University of York.
Ruth Gilbert	Professor of Clinical Epidemiology, Institute of Child Health, University College, London. (Submitted in collaboration with colleague Pia Hardelid, ICH, UCL)
Ian Maconochie	Paediatric Clinical Academic, Imperial College, London
Catherine Powell	Safeguarding and Child Protection Consultant
Sharon Vincent	Reader in Child Welfare, Department Social Work and Communities, Northumbria University
Russell Viner	Professor of Adolescent Health, Institute of Child Health, University College London
Martin Ward Platt	Honorary Clinical Reader in Neonatal and Paediatric Medicine, Newcastle University

Independent Advisory Group

We are grateful for the support and guidance of the members of the HQIP appointed Independent Advisory Group:

Name	Role
Stuart Logan	Chair IAG; Professor of Epidemiology, University of Exeter
Jacqueline Cornish	Representing NHS England
Cynthia Davies	Representing the Department for Education, England
Helen Duncan	Representing Public Health England
Katy Lindfield	Representing the Department of Health, England
Kate McKay	Representing the Scottish Government
Miguel Marcos dos Santos	Representing the Department for Education, England
Irene Wright	Merseyside CDOP
Sinead Magill	Observer from the Northern Ireland Government
Heather Payne	Observer from the Welsh Government
Rosalind Reilly	Observer from the Welsh Government

Healthcare Quality Improvement Partnership (HQIP)

This development project was commissioned on behalf of NHSE and the Scottish Government by HQIP. We are very grateful for the advice and support of Jenny Mooney, without whom this project would not have come to fruition. Tina Strack and Vivien Seagrove attended consultation meetings and provided other very helpful advice and support.

Appendix B – Parent leaflet developed with Charlotte Bevan, Sands

- Example used for the meeting organised by Sands

CDR
Child Death Review
Database Development Project

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Consulting Parents – information for you

We are a group of researchers from the Universities of Oxford and Leicester. We are working on a project to look at whether it's possible to set up a national database of information about babies and children who have died. The purpose of this database would be to ensure there is learning from the causes and circumstances of children and baby deaths across England. This is so that similar tragedies can be prevented in the future.
The project is called the 'Child Death Review Database Development Project'.

About the Child Death Review Database Development Project

The aim of this project is to see whether and how it might be possible to develop a 'national' database for England to collect information centrally, which is already collected at a local level from the reviews of the deaths of babies and children. The reviews are carried out by Child Death Overview Panels (CDOPs), which have been carrying out this work since 2008.

The ultimate goal is to prevent the deaths of as many babies and children as possible; this short-term development project is the first step on the way to developing a national information resource needed to support this goal.

Child Death Overview Panels (CDOPS) in England are made up of experts who look at every baby or child who has died in their geographical area and review what happened. They are legally required to do this. This is to try to learn from the deaths of babies or children in order to prevent future babies and children dying from the same causes. The information that is currently collected during this process is held by each of the 89 individual CDOPs around England. At the moment there is no way of gathering that information together to make sense of it on a national or even a regional basis.

A national database that could securely store selected information about every death which is reviewed would mean that experts would be able to examine the information and identify where national lessons can be learned. This would mean that, where we could, we would be able to put strategies in place to prevent future deaths.

Our consultations

In order to get this work right we are consulting with a wide range of people. This group of people includes those who are familiar with CDOPs and their work, health care professionals, related charity and support groups, bereavement specialists and of course bereaved parents themselves.

How can parents help?

We wish to include your views about the development of a national database that would contain information about the deaths of babies and children when we produce our report from this project.

continued overleaf

We want to make sure that parents' views are truly represented from first-hand accounts, and not merely based on our own assumptions about how parents might feel.

That's why we are holding a series of meetings with parents so that we can find out about your views of the proposals to develop this national database. By attending one of these meetings and sharing your views, you can make a contribution to these discussions.

What will happen at the meeting?

The meeting will begin with an introduction by a member of the team. This will not only provide some background information about Child Death Reviews, but also an update on the project's progress so far, and what our next steps will be. We will discuss the key things that we need to think about in developing the database, in order to get your views on these issues.

We will then have a short coffee/tea break; this will allow you some time to think about what you have heard and to talk to the other parents.

After the break, we will gather together again, answer any questions and then discuss issues further. In the discussions we want to hear about what you think about the proposals, but if you think of things later you can always contact us after the meeting and let us know then.
The meeting is likely to last 2-3 hours, and a light lunch will be provided towards the end of the meeting.

How we use the information from the meeting

We will take notes during meeting so that we can refer back to them when drafting our report and recommendations. We will not identify anyone in any of our reports.

Any sensitive personal experiences that are also shared during the discussions will be treated as completely confidential and will not be reported. If while attending the meeting, parents feel upset or distressed at all, there will be support available.

Expenses

We are sorry that we are not able to pay you for coming to the meeting but we can cover the costs you have incurred, including travel and any child care costs.

You will need to support any claims for reimbursement with tickets and receipts, so please save them. We will give you a claim form and envelope at the meeting, do please send it to the project co-ordinating office, so that we can reimburse you.

Questions?

If you have questions at this point then we will be very happy to help, so do get in touch with us by telephone or email (*please see the details at the top of the letter*).   Alternatively you can ask your support organisation for help; if necessary they can get in touch with us on your behalf.
See https://www.npeu.ox.ac.uk/cdr for more information about the project.

Jenny Kurinczuk, Elizabeth Draper & David Field
[Project Investigators]

Brenda Strohm
[Project Manager]

Thank you for taking the time to read this information,
maybe we will have the pleasure of meeting you at one of our meetings.

Appendix C – Report of the consultation with CDOP representatives

Child Death Review
Database Development Project
England and Scotland

Preliminary Report of the Consultation Meetings with representatives from Child Death Overview Panels

Jennifer J Kurinczuk
Brenda Strohm
National Perinatal Epidemiology Unit
Nuffield Department of Population Health
University of Oxford

Elizabeth S Draper
David J Field
Department of Health Sciences
University of Leicester

January 2016

Aims

The aims of the development project are to:

- Establish whether and how it might be possible to establish a national database of data from child death reviews;
- To develop a blueprint for how this might be achieved.

For the avoidance of doubt, the development project is not intended to actually develop and set up the national database.

Methods

The project was conducted largely as a series of consultations with the intention of consulting with:

- Those directly involved in the child death review process

  and specifically individuals involved in dealing with:

  - Information needed to carry out the reviews
  - Data generated by the reviews

This short report presents the findings of the consultations with representatives from Child Death Overview Panels (CDOPs) carried out in a series of 13 group meetings.

The CDOP consultations took the form of face-to-face meetings which lasted between 3 to 4½ hours. Following an introduction of the background and aims of the project the project team posed a series of questions to the CDOP representatives and discussion ensued. Notes of the discussion points were taken by the team members present.

The questions discussed were:

Local CDOP functions

- The design of a national database could include functions to support local day-to-day activities for CDOPs as well as collating data nationally; would this be of use to support their CDOP?
- If such functions would be of use, who would they want to have access to enter (not change or extract) data?
- What information do they collect locally, do they still use the DfE templates, have they modified the DfE templates and if so what data items have they added?

Proposed national database

- What would they see as the main purposes of a national database containing data from all CDOPs?
- What are the main questions a national database could answer that current local information cannot?

- What would be the main outputs from a national database that would be of use to them and/or others?
- Are there any other functions that could be supported by the presence of a national database; that is, for what else could the national database provide a platform?
- In terms of data being entered into the database, what level of detail would need to be included?
    - Aggregated data?
    - Individual level data?
- What information, and in what format, would that information need to be entered into a national database?
  To address this last point we used the current DfE templates/forms (B, supplementary B forms and the C form). We asked the CDOP representatives to go through the forms during the course of the meeting and indicate which particular data items would be of value for inclusion in the national database to meet the purposes of a national database, which they had outlined in the earlier discussion.
- Should the information in a national database be anonymous i.e. de-identified?
    - Would the information need to be anonymous?
    - Would there be any benefits to including individually identifiable information?
    - Would there be any difficulties with including identifiable information in a national register?
- What else might we need to consider, which had not already been discussed?

Whilst, as anticipated, many of the points made in the discussions were made in each consultation meeting, specific new points were made in all the meetings we held, even in the later meetings one or two new issues emerged. The final question in particular about other considerations led to quite a number of new discussion points. In reporting the findings we have incorporated these new discussion points in the relevant sections where possible.

Findings

By the nature of the discussions held at the consultation meetings, the information we collected from the discussions is largely qualitative in nature. We did not attempt to quantify (by counting) the number of specific responses. We have, however, included a general indication of whether particular responses were from a small number, most, or the majority of CDOP representatives.

Local CDOP functions:

a. Views about whether an integrated system, which would include functions to support the information requirements of local CDOP day-to-day activities as well as collating data nationally, would be of use to CDOPs:

- **This suggestion was overwhelmingly welcomed by the vast majority of CDOP representatives;**

- There is a small number of CDOPs who have relatively sophisticated data management systems, who are happy with their current information management and would wish to interact with the national database element of the system by being able to **upload their data into the system;**

- Consideration should be given to transferring the existing data into any new system.

The suggestion was overwhelmingly welcomed provided that:

- There would not be a cost incurred by CDOPs (many of which have not been able to update their existing information systems because of lack of funds and access to IT support);
- The system is easily accessible and intuitive to use with features to ease data entry and avoid data entry errors e.g. drop down boxes, range checks and similar features;
- Training would be provided with the implementation of any new information system;
- The system will meet all their local information management functions so that they would not have to develop additional data collection systems, for example additional spreadsheets;
- Double keying of data (duplicate data entry) would be avoided;
- The data would be securely partitioned so that not all the data needed for local CDOP activities would be included in the national database;
- Automated email reminders for late returns would be included to reduce administrative workload for CDOP staff;
- The system developed is adaptable and flexible to enable future development and changes;
- The system would be able to interact with software specifically designed for individuals with accessibility needs;
- The system could work with most common web browsers and accommodate updates to them, as well as working with older systems that may persist in some premises with limited IT facilities and support.

b. **Assuming the successful development of an integrated system, what were the views of individual CDOPs concerning who should have access to enter information (but not extract data)?**

- **There were mixed views concerning this question;**

- The majority indicated that a system where individuals providing the notifications of deaths and subsequent information could log on via a secure web-based system would be of great benefit – with specific requirements as noted below;

- A small number of individuals felt that they would not be able to engage their local data providers in such a system. In addition, because information comes from so many sources the CDOP staff are required to make sense of the data and would therefore be best placed to be the only individuals interacting with the data entry.

For those supporting an integrated system the following would be required:

- Security and data confidentiality would be paramount;
- Individuals from agencies providing notifications and information would only be able to enter data, not extract or change existing data;
- Support with training for external data providers would be needed and provided centrally rather than locally;
- CDOP staff would have overall and full control of the data;
- CDOP staff would need to be able to enter information about deaths where external agencies were not able to do so. They would also need to be able to update the data held as further information became available.

c. **The collection of information by CDOPs locally: whether they use the DfE templates, whether they have modified the DfE templates and if so what data items they have added**

- **The responses to this question varied considerably;**

- A small number of CDOPs use the templates exactly as provided by DfE and have made no changes to the questions or the format of the forms;

- A number of the CDOPs continue to use the questions in the templates but have modified how they present the forms to the agencies and individuals from whom they seek information;

- A substantial number of the CDOPs have both modified the way in which they present the forms to agencies and have also modified the questions and/or added new questions; Some CDOPs have created completely new sub-Form Bs, with considerable detail included e.g. neonatal forms, emergency service and ambulance service forms.

- No one indicated that they had 'deleted' questions from the templates but very few CDOPs actively pursued the collection of all data items and very few used the 'supplementary B forms' in their current format.

The specific additional new data items added include questions about:

- Consanguinity*;
- Nature of the consanguineous relationship;
- Maternal Body Mass Index (BMI);
- Details of antenatal care;
- Previous pregnancies and outcomes (live/stillbirth, miscarriage, termination);
- IVF and/or other assisted conception;
- Age at conception;
- Maternal hypertension;
- Female genital mutilation;
- Streptococcus B infection;
- Genetic counselling;
- Bereavement care;
- Unsafe sleeping and/or sleeping conditions;
- Known to social care;
- More specific smoking data – at conception, during pregnancy, at delivery, postnatal;
- Honour killing;
- Child sexual exploitation;
- People trafficking;
- Occupation;
- Prematurity;
- Non-engagement with recommended services;
- Recent history of service use, child and/or mother, visits to GP, HV, Emergency Department etc.;
- Transfer between hospitals during care;
- Documentation of discrepancy between CDOP Review result and Coroner's verdict.

A small number of CDOPs mentioned additional contextual information they have been collecting:

- Use of near-miss data (from Emergency Departments) to identify potential trends: e.g. use of headphones by cyclists which masks noises that could indicate danger;
- Resuscitation outcomes from Emergency Departments and Ambulance Service to identify possible episodes of unsuccessful suicide and serious self-harm.

*Note consanguinity was added to the DfE templates during the course of the consultation period

The national database

a. **Views as to the main purposes of a national database and the main questions which could be answered by a national database that cannot be answered with the information which is currently available:**

The data which would become available from a national database would enable:

- There to be information about sufficient numbers of cases of individual causes of death to draw meaningful conclusions and to make meaningful comparisons;
- The introduction of more standardisation of data items and their definitions thus enabling pooling of data of the same standard;
- Identification of trends in mortality rates over time to be examined;
- Identification of variations between populations – geographical patterns and distributions;
- Identification of clusters of cases e.g. suicides or deaths as a result of self-harm;
- Single tragic accidents to be distinguished from newly emerging causes of death;
- The description of the characteristics of the children who die and their families to enable identification of risk factors;
- Comparisons of local and regional mortality rates between populations with similar characteristics; for example, similar levels of deprivation, ethnic mix, ‘statistical neighbours’ etc.;
- Active management and ongoing surveillance of the data to allow formal alerts and alarms to be issued;
- To provide more informative, detailed information than is currently published in the DfE annual bulletins.

The potential benefits of having these data available:

- Benchmarking between areas (local and regional) with similar populations – enabling sharing of experiences of prevention activities;
- Benchmarking of CDOP processes e.g. time from death to completion of panel review;
- Identification of where efforts in prevention need to be focused;
- The identification of clustered events which may be related e.g. copycat self-harm;
- Identification of particular at-risk groups which could form one element of focusing efforts in prevention;
- Identification of risk factors which again could form the focus of preventive efforts;
- Identification of seasonal risk factors (sleeping in car seats during Christmas visiting, pool/water related risks of drowning in summer etc.)
- Identification of the national burden of death from particular causes so that national action can be taken - it is very difficult to argue locally for prevention campaigns on the basis of a small number of local cases whereas once the figures are collated nationally a more compelling argument can be made;
- Identification at an earlier stage of increases in cause-specific mortality enabling preventive actions to be put in place much earlier;
- Identifying newly emerging causes of death. Previous examples include blind cord strangulation, nappy sack inhalation, methadone ingestion, button battery and nicotine solution (for e-cigarettes) ingestion, and babies sleeping overnight in car seats. Alerts and alarms could be issued to highlight new concerns;

- To identify areas of good practice;
- To enable deaths to be placed in context, e.g. those children who are homeless when they die, multiple cases in one family over time and across geographical boundaries;
- National evaluation and subsequent audit of preventive actions;
- With a greater strength of evidence available from national data this could potentially lead to the development of new legislation to prevent future deaths;
- Ongoing use of the data will improve the quality of the data;
- Greater scope for future research projects;
- Comparison with non-UK data to increase learning;
- Linkage to other sources of national data to increase the utility of data analysis on a national basis;
- Facilitation of responses to Freedom of Information enquiries.

b. Views about which outputs from a national database of use to CDOPs and others

- A national annual report;
- Regular bulletins throughout the year;
- Themed reports or bulletins highlighting/targeting particular topics;
- The ability to 'interrogate' the data directly using pre-specified data items from which sets of tables can be generated – the CHIMAT* tables were used as an illustration;
- The ability to 'interrogate' the raw data (although this would not include identifiers), the access to which would be securely controlled on an authenticated role basis;
- The ability of CDOPs to download their own data in different formats to support, for example, the generation of the CDOPs' own annual reports and reports for others;
- Reduction of the burden of collating data from various sources in order to carry out meaningful analyses locally;
- The DfE returns being replaced by 'centrally' generated reports and if not this system would enable the DfE annual return to be generated with greater ease;
- Alerts and alarms being issued for newly emerging causes of death and significant increases in known causes of death;
- Data validated at point of entry would reduce data cleaning burden for CDOP staff.

***Available at: http://atlas.chimat.org.uk/IAS/dataviews/**

c. Views about which other functions could be supported by the presence of a national database

The national database could provide a platform for:

- Resources developed by individual CDOPs for sharing with other CDOPs, e.g. information leaflets and other means of dissemination of information used locally which could be shared for use by other CDOPs;
- Sharing of national reports and information e.g. providing links to the newly published report on traumatic head injury in children*
- Access to up-to-date statistics;
- A virtual forum for exchanging information and allowing discussion;
- Sharing learning and good practice between CDOPs including recommendations and local action plans;
- Sharing of training packages and courses;
- A means of sharing learning from rapid review processes and serious case reviews;
- Directory of CDOP contacts to support communications between CDOPs in general;
- Directory of contacts with particular expertise for consultation
- Directory of CDOP websites with links to their annual reports;
- Publicising annual meetings and conferences;
- Standardisation of practices of CDOPs to improve consistency of data collection and the interpretation of modifiable factors:
    - Allow inter-CDOP exchange of cases to assess reliability and consistency, and for comparison of review findings;
    - Provide generated quality assurance ‘test cases’ for CDOPs to review, in order to compare results and identify areas that need more guidance to improve inter-CDOP consistency;
    - Practice in relation to review of pregnancy losses at less than 24 weeks gestational age.
- Developing and supporting a network of CDOPs to help reduce the isolation in which some CDOP co-ordinators work;
- Debate on areas of practice that vary between CDOPs, e.g.
    - structure of panels and selection of members;
    - acquisition of parental consent;
    - Parental involvement in the review process, if/ how/when they are informed about its progress.
- Providing a focus of national leadership which is currently lacking (having been present in the past);
- Guidance on specific issues, for example what to do about deaths that are out-of-area, abroad, during travel between countries and in Scotland;
- Dissemination of coronial rule 43 safety notices;
- Interchange with third sector stakeholders e.g. relevant charities and voluntary organisations with links to their websites and resources;
- Information areas for the general public as well as CDOPs and other professional groups;
- FAQ pages.

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* http://www.hqip.org.uk/public/cms/253/625/19/305/07013-Head-Injury-Report FINAL.pdf?realName=3vIB0q.pdf

d. Views about the level of detail of the data which should be included in the national database

- **The vast majority of CDOP representatives felt that individual level data would need to be included in the national database in order for the full benefits of the database to be realised;**

- One or two representatives felt that only aggregated data would need to be included.

e. Views about which information and data items should be included in the national database

To address this question we asked the CDOP representatives to use the current DfE templates to indicate which individual data items would need to be included in the national database in order for the database to be used to generate the outputs from which they would benefit (see item b page 8 above). The selection preferences for data items from the main Form B have been collated and are reported in the appendix of this preliminary report.

f. Views about whether information included in the national database should be held as de-identified information or whether there would be any benefits from including individually identifiable information

- **This was the single most contentious issue that we discussed;**

- Views were expressed which spanned the whole spectrum, from the view that data transferred to the national database should be completely de-identified and the identities of the individuals should never be available outside the individual CDOP team, through to the view that, with appropriate safeguards and access controls, the national database should contain fully identifiable data about both the child and parents.

We, and other CDOP representatives, specifically challenged the view that the national database should only contain de-identified information and the following views of the benefits and risks emerged:

Potential benefits:
- There are benefits to including identifiable information (with all the appropriate safeguards and access controls) which include the capacity to link the CDOP data to other sources of information about individual children, for example, mortality information from the Office for National Statistics to ensure that all deaths have been included, hospital episode statistics information to investigate interactions with health services on a population level, education information to identify specific characteristics of children who die;
- It would enable the capacity to identify related child deaths which occur in the same

family in different parts of the country as families move around;
- It would give the capacity to 'share' cases where the death occurred outside the area of residence and for which the 'resident' CDOP is responsible for the review but the information to be reviewed has to come from another CDOP.

Counterview:

- CDOPs owe a duty of care to parents and this extends to not sharing data which may make them and their child identifiable;
- That CDOPs 'own' the data, that a national database is solely for the benefit of CDOPs and thus there would never be any need to include identifiers because no use would ever be made of them;
- Any data breach would be more serious as it would include the personal identifiers.

Conclusion for some CDOP representatives:

- Following detailed discussions it was clear that for some CDOP representatives, the benefits of using identifiable data out-weighed the potential risks and counter arguments, but others took the opposite view. The balance of views after discussion, although not quantified by counting, was generally more in favour of using identifiable data than not. However, it was also clear that this could be a 'deal breaker' for some CDOPs in terms of participation in the national database.

Other issues raised in relation to identifiable data (although these are in fact generally more generic issues relating to data sharing):

- 'Ownership' of the data once included in the national database needs to be clarified;
- The basis of data sharing needs to be clarified. For example the management of data which come from other organisations who have shared the information with the CDOP and the capacity of CDOPs to onward share this information needs to be clarified;
- There was not a clear shared understanding amongst the CDOPs of what an identifier is, for example, several representatives who were not in favour of including identifiers felt that full postcode of residence needs to be included in the national database so that area-based measures of deprivation can be derived and geographical mapping can be carried out;
- The responsibility for information security and governance would need to be made very clear i.e. the 'gate keeping' functions would have to be robust and explicit from the outset;
- Access to NHS numbers was not universal and posed a particular difficulty for CDOP co-ordinators who are based in a social care rather than in a health service location.

g. Additional points and questions raised which do not fit under the headings above

- What would DfE's role in the national database be and would they have to 'sanction' its establishment?
- The data would have to be 'actively' managed and it would need to be clear who had oversight of the database and the data;
- A steering committee would be required to ensure that the data are managed and used appropriately;
- There are other information resources which are not being used to maximum benefit for children for example, information held by the police; might it be possible for some of this information on relevant cases to be included beyond that which is already collected by CDOPs?
- Aspects of current data quality and standardisation is questionable and if the data are going to be used then this will motivate improved standardisation and data completion – the more the data are used the better the quality of the data;
- Death abroad presents a particular challenge to CDOPs – it is not clear how a national database might actually help but that the capacity to share practice with respect to these deaths would be helpful, was evident from the discussions in the consultation sessions;
- The interactions that different CDOPs have with their Coroners were reported to be as hugely variable and the relationship varied from being extremely close and supportive to CDOPs experiencing difficult relationships and consequently having difficulties obtaining coronial data;
- The involvement of specialists is needed to develop data items for use in relation to specific deaths, e.g. deaths from poisoning;
- A mechanism for 'uploading' the historical data is needed to ensure that the new national database does not start from a point of having zero data when several years of historic data are already stored locally;
- There is variation in terms of when different CDOPs take cases to panel, some wait until the conclusion of an inquest and others do not; similarly with the conclusion of serious case reviews. Unless this variation is managed consistently in terms of what data are made available to the national database and when, it will result in variations in reporting across the country which are unrelated to mortality rates;
- Some individuals expressed the view that the database would require mandatory participation to ensure that every CDOP contributes data and only then would it be truly national;
- The national database being hosted by organisations such as Public Health England (PHE), NHS England (NHSE), the Health and Social Care Information Centre (HSCIC) and the Department of Health (DH) was thought by some to be a means of increasing confidence in the security of the data. Others expressed the counter view that hosting by one of these organisations may actually reduce public confidence;
- There is a need for a national steer on the duration of record retention by CDOPs as some CDOPs are already deleting their historical data;
- Consider what would happen if a Freedom of Information request were raised;
- Any access to the database (or data extracts from the database) for research would have to be overseen by a scientific committee; relevant regulatory and ethics committee approvals would also be required.

Appendix:

Data item identified for inclusion in the national database by different proportions of CDOP representatives (n=77)

	Proportion of CDOP representatives who indicated the item was required for inclusion		
	25-49%	**50-74%**	**75+%**
Form B			
Notifying details about the child			
• Full name of the child	*		
• Date of birth		*	
• Date of death		*	
• Sex			*
• NHS number		*	
• Address	*		
• Postcode	*		
Agency report provided by			
• Name of agency	*		
Summary of the case and circumstances leading to the death			
• Notifier's understanding of the cause of death	*		
• Mode of death		*	
• Death expected/unexpected			*
• Medical certificate of cause of death issues			
• Referred to the coroner		*	
• Post-mortem carried out			*
• Inquest held		*	
• Registered cause of death			*
• Location of the child at the time of the event of condition which led to the death			*
• Location of the child when death was confirmed		*	
• Specific list of events known to have occurred – these are the categories of the supplementary B forms			*
• Circumstances of the death - narrative	*		
Information about the child			
• Birth weight			*
• Gestational age at birth		*	
• Last known weight	*		
• Last known height	*		
• Any known medical conditions at the		*	

time of death			
• Any known developmental impairment or disability at the time of death		*	
• Any medication at the time of death		*	
• Education/occupation		*	
• Ethnic group			*
• Religion	*		
• Factors in the child - narrative	*		
Family and environment			
• Mother’s details (not clear which)		*	
• Father’s details (not clear which)		*	
• Significant others details (not clear which details)		*	
• Sibling details (not clear which details)		*	
• Was the child/family an asylum seeker			*
Further family information			
• Parent or significant other smoker			*
• Parent or significant other disability			*
• Parent or significant other physical health issues			*
• Parent or significant other mental health issues			*
• Parent or significant other substance misuse			*
• Parent or significant other alcohol misuse			*
• Parent or significant other known to the police			*
• Mother and father are blood relatives			*
• Known domestic violence in household			*
• Factors in the family and environment – narrative	*		
Parenting capacity			
• Child’s residence at the time of death		*	
• Carer (direct care) at the time of death		*	
• Child subject to child protection plan (CPP)[1]			* (100%)
• Category of most recent CPP			*
• Child subject to any statutory order (SO)			*
• Category of most recent SO			*
• Child assessed as in need under section 17 Children Act 1989			*
• Any siblings subject to any SOs			*
• Factors in the parenting capacity – narrative	*		

Service provision – details of agencies involved			
• Primary health care		*	
• Secondary or tertiary hospital services	*		
• Community services	*		
• Hospice services		*	
• CAMHs		*	
• Police		*	
• LA Children's services		*	
• Education	*		
• Connexions	*		
• Probation	*		
• Other	*		
• Identified unmet needs/gaps in services	*		
• Identified difficulties in family engagement with services	*		
Critical or serious incident review			
• Death subject of a formal critical incident review		*	
• Any other internal agency investigation	*		
• Death subject of a serious case review			*
Issues for discussion – narrative	*		

Appendix D – Report of the consultation with the broad stakeholder group

Findings

This consultation was carried out as a face-to-face meeting with a group of stakeholders who can be broadly characterised as representatives from organisations who provide data used in the CDOP process and organisations who would have an interest in the information which could be generated by a national CDOP database; quite a number of representatives fell into both groups. Following an introduction of the background and aims of the project the project team posed a series of questions to those attending and these were addressed in small group discussions with team members taking notes which are summarised here.

Ahead of discussing the specific consultation questions, as part of the introduction we had a general discussion where the following views were expressed:

Initial general discussion points

- Long-standing wish for a national database – resulting in stagnation of old systems or independent upgrading in isolated cases – increasing need for standardisation;
- Feeling of pointlessness if data are submitted but minimal feedback or output occurs as a result:
    - Tertiary level hospitals are especially aware of this;
- Need for standardisation – of practice, definitions, interpretation of modifiability;
- Dislike (among some at least) of early categorisation about expected/unexpected death – can determine the pathway of process from the outset, not always appropriately;
- Need to be able to access more easily the rich source of data within submitted form Bs and Cs;
- Families' awareness and involvement – variable, often unaware of CDR process triggered by child's death; standardise and improve communication with parents – throughout process and at conclusion;
- Help families understand how data about them are processed, if and when anonymised
- Information leaflet to inform parents and public – currently needs updating, need for more frequent review, especially if processes change. Improve dissemination of such information;
- Case review – quality control needed, variation needs to be eliminated;
- Burden of data collection – improved linkage to existing data sources could reduce this;
- Eliminate and avoid double entry of data, duplication of workload;
- Improve motivation of those providing the data;
- Identification and alerting of emerging new causes and trends of deaths;
- Look to good practice abroad – e.g. availability of button battery deaths data in U.S.;
- RoSPA and BIS for example can only gather data informally or via media – accurate and up to date data/evidence/proofs needed to support their work – under-reporting currently likely to be the case;
- Coronial data – better collaboration and output of information needed – look to areas with good practice, in relation to suicide cases especially.

Q1. What would you see as the main purposes and uses of a national CDOP database?

- **Use by your own organisation**
- **Broader purposes and uses by other organisations**

Supplementary questions:

- **What outputs would you like to see?**
- **How would you like to be able to access the information from a national CDOP database?**

Purposes and uses of a National CDOP database

- National dissemination of 'Why do babies die in hospital';
- Safety of products;
- To look into the variability of the investigation into different types of deaths e.g. approaches to different types of murder;
- Improve the quality of care in general – specifically to look at quality of case reviews nationally;
- Early identification of emerging problems;
- Investigating the circumstances surrounding birth and subsequent death;
- Potential for data linkage;
- Standardisation of data items and analysis e.g. modifiable factors, expected /unexpected deaths;
- Share lessons learned nationally across all agencies – identifying both poor and best practice;
- Facilitation of local quality of care reviews;
- Streamlining of existing systems;
- Act as a means of reducing duplication of data entry and review processes;
- Allow on line data entry and facilitate regular feedback to clinical teams and families;
- Regular essentially epidemiological (annual) reports with large area geographical patterns and time trends (perhaps based on ODNs?);
- Dissemination of lessons learned;
- Act as an important resource for research;
- Identification of public health messages;
- FOI requests and parents' requests – assist processing?
- Platform for CDOPs: contact information, general communication, exchange of resources, co-ordination of training;
- Monitoring of care delivered in 3rd sector as well as that provided by NHS.

Outputs from the national database

- To drive improvements – frequency of modifiable factors (once clearly defined!) – importance of learning and sharing best practice;
- To investigate geographical variations at regional and individual CDOP level – including investigation of processes;
- Start with small and simple – develop over time once early reports understood;
- To investigate trends;
- Target outputs at specific audiences: parents, lay public, professionals.

Additional issues

- Build on best practice – evidence for improvements;
- Requires ample resources to support team to provide data analysis and deal with data requests;
- Harness political drive – link to Jeremy Hunt's* 50% reduction in neonatal deaths (*Secretary of State for Health).

How would you like to be able to access the information?

- Standardised tables to be developed and fed back to CDOPs / stakeholder organisations;
- To investigate potential new / emerging risks – ensure flexibility of database;
- Highlighting emerging issues using an on line discussion forum accessible by CDOP teams. Need to develop a strategy for dealing with spurious links ("serious case analysis section");
- Formal requests – could be via local CDOP or using a central request system. These will be limited by the capacity of the analytical team so there will be a queuing process and IG issues will be dealt with at this stage;
- Regular reports providing national and local data to provide a 'surveillance' function. Need to determine what level of data will be freely available and what is only available to individual CDOPs. Analysis / reporting to be managed by central team;
- Require an 'Oversight' body – (IAG / Steering group etc.) to select focus for central team. This should be a process that all stakeholder organisations can feed into;
- Develop a restricted site and a publically available site for outputs;
- CDOP / CDOP staff could register as individual users with permissions set for their organisation;
- Would like to be able to request data relating to specific product / product misuse – to answer parliamentary questions and investigate potentially linking data with MHRA?
- Reporting of timing of pathology – flag shortage of perinatal pathologists.

Q2. The national database would contain a sub-set of all the data collected by individual CDOPs

- **Should the data included in the national database be:**
    - **Anonymous?**

or

- **Could/should the data contain identifiable information (names, addresses, postcodes, dates of birth, NHS number)?**

Supplementary questions:

- **Are there any benefits to collecting identifiers?**
- **Are there any disadvantages and/or risks to collecting identifiers?**

- Despite everyone seeing the potential benefits of identifiable data there was a complete spectrum of views about whether the data at a national level data should identifiable with some individuals indicating that the data should be fully anonymised through to the view that all the data should completely identifiable with every range in between;
- Even where it was thought data should be anonymised age, IMD and the first half of the post code would be acceptable for inclusion;
- For those whose view was that the national data should be fully anonymised - the overwhelming reasons for the view that data should be fully anonymised were that:

    - Having identifiable data in a first phase of implementation carried too many political risks. Hence it was better to take the benefits that could come from anonymous data and then reconsider the collection of national identifiable data in perhaps 5 years. Identifiable data flowing between local services and the local CDOP office remained essential to achieve adequate feedback to families and clinicians;
    - There is no reason to have identifiable data in the national dataset and to do so would violate the duty of care to patients by CDOPs;

- Detailed discussion and clarification highlighted that there was widespread misunderstanding around the issues of confidentiality / wider data sharing and also that there had been no real consideration of the wider issues.

Benefits of identifiers

- Data linkage with HES, Education, Social Services etc. to enhance the uses of the data;
- Epidemiological investigations;
- Transparency agenda;
- Investigation of clusters using time and space data – geography, case definition / diagnosis / dates of birth and death;
- Also discussed checking of data / going back to cases to check details. This should be done at local CDOP level so should not really impact on national database requirements;
- Facilitate quality assurance at CDOP level.

Disadvantages and risks

- Use of identifiers raises issues of confidentiality;
- Some misunderstanding of issues around data sharing and how this would not include individual identifiers;
- Presentation of data around rare outcomes – dealing with small numbers to prevent identification of individuals (data suppression);
- Require safe haven;
- Potential to inhibit CDOP participation – blame culture. This seemed to stem from the fact that the group were interpreting identifiers as including the name of the CDOP etc.

Q3. Other considerations

- Improvement in the definitions used in the CDOP process and how they are applied consistently was seen as essential if the system is to produce meaningful data and outputs;
- The CDOP database would provide an opportunity to look at existing review processes and provide an opportunity to remove some duplication and also enable the introduction of more standardised processes in general so that, for example, feedback to parents of panel findings would be consistent across in England in terms of timescales, how it was provided and by whom;
- Key elements of the system included on-line data submission; data entry by senior staff and adequate IT support to CDOPs;
- The resources available to some CDOPs are currently inadequate in some areas and the database could only be introduced effectively if there is a minimum set of infrastructure and man-power available to all;
- The new database would have to be free;
- Repeatedly the point was made that without adequate resourcing the full potential of the database could not be realised;
- Avoidance of blame culture while learning from errors featured in discussions generally
- Leadership would need to occur at a national level in terms of allowing the data set to be dynamic and have the potential to focus and investigate emerging trends. This would essentially be a steering group with membership similar to those who attended the stakeholder meeting;
- There would be merit in amalgamating some of the existing CDOPs to permit more efficient use of resources and man-power. There would need to be discussion about optimal size;
- There seemed to be acceptance of a model with largish CDOP hubs (larger than now) exchanging identifiable data with local services for review purposes and then supplying anonymised data for analysis of epidemiological trends;
- There should be an easy system for researchers to request access to the anonymised data Again in this discussion the view that identifiable data should not be stored centrally was expressed although it was accepted that consent for use of anonymised data could be trialled;
- It was suggested that stillbirths that occurred as a result of some type of assault during pregnancy and perhaps all intra-partum deaths should also be collected by CDOPs;
- Develop a 2 phase system to include a rapid reporting of individual cases and then a final version of the data to include coroner’s information;
- Ability to add / amend database over time as new information emerges;
- Mandate timing of inquests – to within 6 months of death?
- Initial goals should be realistic, with a view to establishing an effective database sooner than later; expansion and improvement will ensue if database proves its worth from the start.

Appendix E – Report of the consultation with bereaved parents

Findings

We met with 25 bereaved parents who each participated in one of four consultation meetings with us. Following a discussion of the background to the project and role and purpose of CDOPs we discussed a series of specific questions. The following summarises the discussions.

Q1. Were you aware of the CDOP process and activities? And if so – have you had any involvement in the process?

A small number of the parents involved in the consultation had had their bereavement prior to the establishment of CDOPs in 2008.

Of those whose child had died since 2008 the majority were not aware of the existence of CDOPs and of those who were, only one had received any information directly from their CDOP and they had found this an unsatisfactory encounter. A couple of other parents had been told briefly about the CDOP by their GP at some stage but did not really understand the purpose of CDOPs.

Similarly, few of those parents whose child died in hospital were aware that a review of their child's death would most likely have taken place.

Parents initially expressed a mixture of shock and surprise, and some appeared initially affronted when we described the CDOPs to them and what they did. They then reflected that they were pleased that 'someone' was taking the death of their child seriously and were concerned to review what happened.

Parents expressed a desire to receive feedback from any reviews of their child's death and care.

Some parents also expressed a desire to be able to feed information into the CDOP process.

Support for parental involvement in the CDOP process should be provided.

Q2. What are your views on the idea of having a national database of the information collected by CDOPs? (access and security safeguards will be in place)

Supplementary questions:

- **How do you feel about the creation of such a database?**
- **Do you see any value in such a database?**
- **Would you object to such a database being created?**
- **Would you object to information about your child and family (limited family information) being included?**

Of concern to parents were what safeguards would be in place for the national database, who could access the data and what data would they be able to see.

However, with appropriate assurances on the issue of safeguards, all parents could see the value of a national database and would have no objection to information about them and their child being included in the database.

Some parents in fact objected to the fact that such a database did not already exist.

The general view was that anything which can reduce the chances of future child deaths is a good thing. They were very keen that other parents would not experience what they had experienced and could see that a child death review database would contribute to achieving this.

They were also keen that parents were not ‘judged’ for what had happened to their child.

In their view the data to be collected needs to be standardises and updated as more information becomes available e.g. coronial findings and post-mortem. And the data in the database will only be as good as the review which was conducted.

They also indicated that the legacy data should be included in any new database which starts so that all that information is not lost and we are not starting again from scratch.

The specific purposes of the database they described included:

- To enable research to be conducted to prevent future deaths;
- So that lessons learned can be disseminated;
- So that seasonal information about deaths is known;
- So that regional information about deaths is identified;
- For the provision of advice to parents;
- To improve support networks;
- To identify clusters of cases;
- To reduce variation in care;
- To share best practice;
- To describe trends and make comparisons including international comparisons.

Q3. Assuming that all the appropriate security and access safeguards are in place, the information on the database could be either anonymous or it could include identifiable information, by which we mean it would include information such as:

- **NHS number**
- **Name**
- **Address**
- **Postcode**
- **Date of birth**

The importance of identifiable data is that it could be linked with other sources of information and increase the value of the database enabling more questions to be answered.

How would you feel about information about your child and family (very limited) including identifiable information?

Parents expressed the whole spectrum of views about the inclusion of identifiers from indicating that they thought the database should be completely anonymous through to the view that the database should be fully identifiable.

One parent expressed the view that identifiability was not an issue for them since “Nothing can be worse than the death of your child.”

During the course of the discussions we indicated the purpose of each identifier following which there was a general sense that the inclusion of some identifiers was necessary, for example:
NHS number, date of birth, date of death and postcode (the latter to derive measures of socio-economic deprivation).

Parents generally took a less permissive view regarding the inclusion of names and addresses.

Some parents expressed the view that they wanted all their own identifiers to be included as this would maximise the value of the register.

Some parents expressed the principle that only as much information (including identifiers) should be used as is necessary.

Parents also acknowledged the fact that there is a wide range of causes of death and some parents may be less willing to have their information shared especially if they were implicated in some way in their child’s death.

Parental consent to the inclusion of data in the national database was explored.
The fact that some parents would not consent was seen as problematic since a database which does not include all deaths was seen as a serious limitation.

Generally consent was not thought appropriate, but it was thought very important to inform parents about the existence of the database and indeed CDOPs in general. The principle of opt out was discussed but again this came back to the fact that if substantial numbers of parents opted out then the database would not be complete thus seriously limiting its value.

Q4. What other issues should we consider?

Parental electronic notification when an individual child’s information was used was suggested as a desirable attribute.

Parents’ views about the database should be taken into consideration and not just the views of CDOPs, particularly on the issue of identifiers being included.

Parents need to be told about the CDOP process, to have the opportunity to feed into that process and to receive information about the findings. They also want parents to have support to enable them to be involved.

Appendix F – Report of the virtual consultation with researchers

Findings

This consultation with researchers was carried out as a virtual consultation where we identified a non-exhaustive list of researchers in the field of child death reviews and circulated a short questionnaire by email. The following summarises the themes from the questionnaires which were returned.

Q1. What do you see as the main purpose and uses of a national CDOP database? Please answer this from both a general and a research perspective.

1. Learning from preventable deaths;
2. Identification of themes and patterns;
3. Sharing good practice;
4. Provide a source of high-quality data:
    a. comparable data that can be used internationally, nationally and regionally
    b. that enable research to be conducted
5. Inform policy, strategy development and legislation;
6. Aid service planning;
7. Inform public health initiatives;
8. Identify and address inequalities;
9. Repository for CDOP data, also to be used as tool for CDOP administrative functions;
10. Enhance ONS data, not merely duplicate them;
11. Data linkage with other clinical databases;
12. Linkage of mortality data to other non-health databases (e.g. education, child protection);
13. Identify prognostic factors;
14. Audit over time for evidence of reduction in mortality rates;
15. Provide better information about children's palliative care services and their impact.

Q2. A national database is likely to include only a sub-set of all the data collected by CDOPs. In broad terms what data do you think should be included in the national database? Should the data be collected by the national database in an aggregated format or as individual level data?

1. Mixed views concerning content of database:
    a. Necessity for allowing for linkage to occur versus need for S.251 approval?
    b. Argument for small but 'robust and usable' versus argument for comprehensive / as much as possible;
    c. Necessity of obtaining as full a picture of child's death as possible;
2. Arguments for both individual data and aggregate data; but individual level data are essential to enable research to be conducted;
3. If Panel judgements to be used in research, consistency must be improved; guidance and rationale needed to guide their decisions, definitions;
4. Non-health data important – social services, geographic, educational, demographic;
5. Flexibility to allow temporary in-depth data collection (similar to British Paediatric Surveillance Unit data collection, for example);
6. Responses included some itemised and detailed suggestions with respect to the current B-forms (these have been saved and are available for future reference).

Q3. Assuming appropriate data security controls and information governance arrangements are in place should the data in the national database include personal identifiers*?
What do you see as the risks and benefits of including identifiable data?

1. Overall agreement that some identifiers are necessary; postcode specified in 5/6 responses and implied in 6th;
2. Robust information governance and S.251 approval necessary, with risk assessment and management;
3. IT capabilities can ensure secure permitted access to data by few individuals; appropriate controls would outweigh risks of holding identifiable data and bring many benefits;
4. Do not waste resources on collecting and storing data that are already publically available; add to them by including extra data not available at present and that could enhance research and analysis when linked;
5. Age at death important, either with DOB-DOD or calculated;
6. NHS number: mixed views on that specific item but other identifiers needed if not that.

Q4. What other issues should we consider?

1. Need for inclusion of retrospective data, otherwise it could be years before the database has developed the scope for successful scrutiny for trends and patterns;
2. Flexibility to respond to current research needs at a particular time;
3. Education of parents and public: that CDOPs exist, what they do, why and benefits to be derived;
4. Standardisation of processes and CDOP membership – higher quality data input and output will motivate users of system to provide data and then use them with confidence;
5. International collaboration to ascertain remedial interventions that could prevent deaths;
6. Identification of health events (e.g. surviving cardiac arrest) that result in poor health and subsequent early death;
7. Published research demonstrates the informative value of age and deprivation information derived from post-codes.

Appendix G – Summary of data items

Data item identified for inclusion in the national database by different proportions of CDOP representatives (n=77) – FORM B

	Proportion of CDOP representatives who indicated the item was required for inclusion		
Form B	**25-49%**	**50-74%**	**≥75%**
Notifying details about the child			
• Full name of the child	*		
• Date of birth		*	
• Date of death		*	
• Sex			*
• NHS number		*	
• Address	*		
• Postcode	*		
Agency report provided by			
• Name of agency	*		
Summary of the case and circumstances leading to the death			
• Notifier's understanding of the cause of death	*		
• Mode of death		*	
• Death expected/unexpected			*
• Medical certificate of cause of death issues			
• Referred to the coroner		*	
• Post-mortem carried out			*
• Inquest held		*	
• Registered cause of death			*

	Proportion of CDOP representatives who indicated the item was required for inclusion		
Form B	**25-49%**	**50-74%**	**≥75%**
• Location of the child at the time of the event of condition which led to the death			*
• Location of the child when death was confirmed		*	
• Specific list of events known to have occurred – these are the categories of the supplementary B forms			*
• Circumstances of the death - narrative	*		
Information about the child			
• Birth weight			*
• Gestational age at birth		*	
• Last known weight	*		
• Last known height	*		
• Any known medical conditions at the time of death		*	
• Any known developmental impairment or disability at the time of death		*	
• Any medication at the time of death		*	
• Education/occupation		*	
• Ethnic group			*
• Religion	*		
• Factors in the child - narrative	*		
Family and environment			
• Mother’s details (not clear which)		*	
• Father’s details (not clear which)		*	
• Significant others details (not clear which details)		*	

	Proportion of CDOP representatives who indicated the item was required for inclusion		
Form B	**25-49%**	**50-74%**	**≥75%**
• Sibling details (not clear which details)		*	
• Was the child/family an asylum seeker			*
Further family information			
• Parent or significant other smoker			*
• Parent or significant other disability			*
• Parent or significant other physical health issues			*
• Parent or significant other mental health issues			*
• Parent or significant other substance misuse			*
• Parent or significant other alcohol misuse			*
• Parent or significant other known to the police			*
• Mother and father are blood relatives			*
• Known domestic violence in household			*
• Factors in the family and environment – narrative	*		
Parenting capacity			
• Child's residence at the time of death		*	
• Carer (direct care) at the time of death		*	
• Child subject to child protection plan (CPP)[1]			* (100%)
• Category of most recent CPP			*
• Child subject to any statutory order (SO)			*
• Category of most recent SO			*
• Child assessed as in need under section 17 Children Act 1989			*

	Proportion of CDOP representatives who indicated the item was required for inclusion		
Form B	**25-49%**	**50-74%**	**≥75%**
- Any siblings subject to any SOs			*
- Factors in the parenting capacity – narrative	*		
Service provision – details of agencies involved			
- Primary health care		*	
- Secondary or tertiary hospital services	*		
- Community services	*		
- Hospice services		*	
- CAMHs		*	
- Police		*	
- LA Children’s services		*	
- Education	*		
- Connexions	*		
- Probation	*		
- Other	*		
- Identified unmet needs/gaps in services	*		
- Identified difficulties in family engagement with services	*		
Critical or serious incident review			
- Death subject of a formal critical incident review		*	
- Any other internal agency investigation	*		
- Death subject of a serious case review			*
Issues for discussion – narrative	*		

Data items identified for inclusion in the national database by different proportions of CDOP representatives (n=77) – FORM C

	Proportion of CDOP representatives who indicated the item was required for inclusion		
Form C	**25-49%**	**50-74%**	**≥75%**
Child's age at death			
Date of review			
Gender	*		
List of documents available for discussion	*		
Cause of death as presently understood	*		
Case Summary		*	
Domain - Child's needs		*	
Factors intrinsic to the child		*	
Acute / Sudden onset illness (specify)			*
Chronic long term illness		*	
Asthma		*	
Epilepsy		*	
Diabetes		*	
Other chronic illness Specify:		*	
Disability or impairment		*	
Learning disabilities Specify:		*	
Motor impairment Specify:		*	
Sensory impairment Specify:		*	
Other disability or impairment Specify:		*	
Other			*
Emotional / behavioural / mental health condition in the child Specify:			*

	Proportion of CDOP representatives who indicated the item was required for inclusion		
Form C	**25-49%**	**50-74%**	**≥75%**
Allergies Specify:			*
Alcohol/substance misuse by the child Specify:		*	
Domain - family and environment		*	
Factors in the family and environment			*
Emotional/behavioural/mental health condition in a parent or carer. Specify:			*
Alcohol/substance misuse by a parent/carer. Specify			*
Smoking by the parent/carer in household. Specify:			*
Smoking by the mother during pregnancy. Specify:		*	
Housing. Specify:			*
Domestic violence. Specify:			*
Co-sleeping. Specify:		*	
Bullying. Specify:		*	
Gang/knife crime. Specify:		*	
Pets/animal assault. Specify:			*
Consanguinity. Specify:	*		
Domain - parenting capacity	*		
Factors in the parenting capacity			*
Poor parenting/supervision. Specify:			*
Child abuse/neglect. Specify:	*		
Domain - service provision	*		
Factors in relation to service provision			*
Access to health care. Specify:			*
Prior medical intervention. Specify:			*
Prior surgical intervention. Specify:			*

	Proportion of CDOP representatives who indicated the item was required for inclusion		
Form C	**25-49%**	**50-74%**	**≥75%**
The CDOP should categorise the likely/cause of death using the following schema.			
Deliberately inflicted injury, abuse or neglect			
Suicide or deliberate self-inflicted harm			
Trauma and other external factors			
Malignancy			
Acute medical or surgical condition			
Chronic medical condition			
Chromosomal, genetic and congenital anomalies			
Perinatal/neonatal event			
Infection			
Sudden unexpected, unexplained death			*
The panel should categorise the 'preventability' of the death – tick one box.			
Modifiable factors identified		*	
No Modifiable factors identified			
Issues identified in the review		*	
Learning Points		*	
Recommendations			
Specific agency			
LSCB			
Regional			
National	*		
Follow up plans for the family, where relevant	*		
Possible Actions: Should this death be referred to another agency or Authority (e.g. Police, Coroner, Health and Safety Executive, Serious Case Review panel) for further investigation or enquiry? If so, please state			

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