

Preventing child deaths: what do administrative data tell us?

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Background

The UK has one of the highest child mortality rates in Western Europe: four in every 1000 children die before the age of one year; compared to two per 1000 children in Finland. Likewise, the mortality rate for 1-14 year olds in the UK is 10.4/100,000 children compared to 8.3/100,000 in Sweden.¹ Since the UK has a universal health care system, and comparable levels of per capita income, as these Scandinavian countries, a substantial proportion of deaths in children in the UK are likely to be preventable. This raises the question of what policies we should prioritise in order to lower child mortality rates in the UK most rapidly. Data on child deaths are crucial to answering this question. In the November issue of *Archives*, Garstang,² in an editorial linked to a paper by Firth et al³, argues that a national dataset collated from Child Death Overview Panels (CDOP), will allow us to '*understand better why children die in the UK and reduce our child mortality*'. In this commentary, we compare data collected by CDOPs to mortality data collected via linked civil registration and administrative data systems. We propose that important lessons for preventing child deaths can already be drawn from analyses of mortality records linked to other administrative datasets, and at relatively low cost. Targeted use of detailed investigations into the circumstances of child death could be guided by and enhance findings from administrative data but the priority should be greater use and wider linkage of these data to inform strategies to prevent child deaths.

Child Death Overview Panels

There are approximately 4000 deaths in children less than 18 years old in England every year.^{4,5} The circumstances of each of these deaths will be reviewed by one of 148 Child Death Overview Panels (CDOPs). A CDOP has 12 panel members on average, who include paediatricians, other clinicians, and professionals from social care, education and criminal justice.^{2,6} The aim of CDOPs is to identify modifiable factors that may have prevented a child from dying, and through the review process identify and inform interventions or practices that can prevent future deaths in children. Importantly, local review of deaths can highlight events or practices that should not be happening, irrespective of the need to decide whether the event contributed to causing the death or not.⁷

However, CDOPs may be remote from the team who would benefit from experiencing local learning. For example, CDOPs review the 48% of child deaths that occur in the first month of life,⁵ despite a finding that half of CDOP paediatricians consider hospital-based reviews more suitable for such early deaths.⁸ This detailed review of every death, irrespective of cause, is time consuming for all professionals and administrative staff involved, and therefore costly for financially stretched local authorities. A report into the workings of CDOPs estimated that a panel member spent a median of 5.1 hours reviewing each death, and that each administrative staff member spent 34.7 hours on each death reviewed.⁶

Despite the considerable input from highly stretched professionals in the CDOP process, there has been no formal evaluation of whether CDOPs have led to a reduction in child deaths overall, or informed specific interventions that have been effective in reducing deaths from specific causes. An evaluation of confidential enquiries, which uses similar methodology to CDOPs, found no evidence that detailed case reviews reduce mortality at a population level.⁹

As Garstang² highlights, a key challenge of generating learning for child death prevention through the CDOP process is that although CDOPs have been mandated to collect data from 2008, the Department for Education (DfE), who oversee CDOPs, have not implemented a standardised national data collection system. This is particularly well demonstrated by the data collected by CDOPs on 'modifiable' factors (presumably the key data item collected, given the CDOP remit). Modifiable in the

CDOP context means that panel members are asked to *'consider whether the Review has identified one or more factors across any domain [factors intrinsic to the child, factors in social environment, in physical environment, and in service provision] which may have contributed to the death of a child and which might, by means of locally or nationally achievable interventions, be modified to reduce the risk of future child deaths.'*¹⁰ This definition appears to be highly open to interpretation by individuals and panels. We agree with Garstang that it is very surprising that only 46% of 101 suicide or deliberate self-harm deaths in children were considered to involve modifiable factors in 2016/17.¹¹ In contrast, the Office for National Statistics (ONS) considers all deaths from injuries avoidable, using a definition based on International Classification of Diseases (ICD-10) coding.¹²

Following a national consultation in 2016,¹³ the Healthcare Quality Improvement Partnership commissioned a national child mortality database to collect CDOP data nationally using common data definitions. This is a welcome development, particularly since professional input may be largely wasted unless data are collated nationally. Yet, a fundamental challenge remains: CDOP data will still only represent a case series of deaths without controls. Although a new national CDOP database may include more detailed information about children who died, it will still be impossible to carry out studies to identify risk factors for child deaths without data on children who did not die. These types of studies are crucial in order to inform prevention strategies. This is demonstrated by Frith et al's analysis,³ which was limited to comparing rates of parental consanguinity between congenital anomaly and non-congenital anomaly deaths. The odds ratios from their study do not tell us about how important consanguinity is as a risk factor for deaths in children. This would have required linking data on all children in the Born in Bradford cohort to CDOP data. Such linkage would also have informed us of the relative contribution of consanguinity as well as other risk factors, including maternal smoking or age. Even with a nationally standardised dataset, the CDOP data on their own are extremely difficult to interpret without the ability to link the data to a denominator on all children exposed to a particular risk factor.

Administrative data

There is another source of data on child deaths in England. ONS collate data on all child deaths, based on data collected on death certificates. ONS mortality records have been collected nationally since the latter half of the 19th century, using standardised ICD coding for causes of death since 1911.¹⁴ Apart from causes of death, the death certificate captures dates of death and registration, place of death and residence and socio-economic classification (of the child if aged 17, or of the mother or father if the child is aged 16 years or less). Mortality records from ONS do not require additional resource since death registration is a legal requirement in the UK and data about the death are collected routinely through the civil registration system. The ONS have previously estimated the cost of their production of child mortality statistics as £10,000-£50,000 annually.¹⁵

ONS mortality data are particularly valuable for informing policies to prevent child deaths when linked to other ONS or National Health Service (NHS) datasets that contain information on risk factors for all children born in England. For example, ONS routinely link NHS birth notification, and ONS birth and death records to produce data on infant mortality rates according to birth weight, gestational age and maternal age.⁴ NHS Digital routinely link Hospital Episode Statistics (HES- the national hospital database for England¹⁶) to death registration and recently also birth registration data. Of particular importance when answering questions about risk factors for child mortality is the ability to develop birth cohorts with either national coverage, or national representativeness, in administrative data to examine risk factors for child deaths. It is also possible to link the baby's record to their mother's in these datasets to determine the role of maternal characteristics and health status on the risk of death in children.¹⁷

We have demonstrated the value of these data for informing policies to prevent child deaths in a number of studies using linked hospital and mortality data. Using such a birth cohort of children born in England, which we compared to a similar Swedish birth cohort, we examined why child mortality is so high in England compared to Sweden.¹⁸ We showed that 77% of differences in neonatal mortality and 68% of post-neonatal mortality could be accounted for by adverse birth characteristics: low birth weight, congenital anomalies and premature birth. These findings provide clear policy direction in terms of how to prevent childhood deaths: support women before and during pregnancy to improve birth outcomes. We have also demonstrated, using a birth cohort from Scotland, that children with chronic conditions are at increased risk of deaths from respiratory tract infection, and to a lesser extent, sudden unexpected deaths.¹⁹ These studies examined mortality in children less than five years old. As further years of hospital and mortality data become available in England, we and others will be able to undertake research to identify risk factors throughout the early life course which increase the risk of death in older children. This is already possible in Scotland, where linked birth registration, death registration and hospital admission data are available for individuals born from the early 1980s onwards.

Linked, administrative data sources therefore provide data on all deaths, and risk factors for all children in the population (that is, children who died and those who did not) at relatively low cost. However, administrative data does not provide the same level of detailed information about the death as a CDOP, Serious Case Review (SCR)²⁰, or a coroners' report.

In addition, administrative data have some specific challenges. For example, while ICD10 coding for causes of death may be unreliable²¹ we have demonstrated that such challenges can be overcome by linking mortality data to the child's preceding hospital records. By applying this method to mortality record for children who died in England, Scotland and Wales between 2001 and 2010, we were able to establish that 71% of children who died between age 1 and 18 years of age had at least one underlying chronic condition.²² When we used linked hospital data in combination with cause of death data recorded on death certificates, we found that neurological conditions were the most common type of conditions children died with (present in 38.5% children who died). Had we used the underlying cause of death alone, cancer would have been the most common chronic condition among children who died. This highlights that many of the shortcomings of death registration data can be overcome by linkage to other data sources.

Further, methods to link administrative databases may result in errors. The deterministic linkage methods used by NHS Digital to link hospital records over time have a false match rate of 0.2% (that is, multiple individuals being allocated one ID number), and a missed match rate of 4.1% in children (that is, the same individual being allocated multiple ID numbers). However, sensitivity analyses can be used to evaluate the impact of concerns about linkage error on results,²³ and probabilistic linkage methods can be used to reduce missed match rates.²⁴

What would be the additional value of national CDOP data collection?

With national administrative data already available for research into child deaths and the opportunity to link different administrative data sources for all children in the country, what might be the added value of CDOP data? Ultimately, this very much depends on data quality, the additional data items collected, and the ability to apply standardised definitions (of for example 'modifiable factors') nationally. We suggest that linkage to ONS mortality data or other administrative data sources is absolutely crucial in order to assess CDOP case ascertainment and data standards. For example, it

appears from Firth's study that recording of ethnic group in CDOP data is unreliable compared to maternal questionnaires.³ Linkage to Hospital Episode Statistics and NHS Birth Notification data would allow triangulation of ethnic group information. We also note that although a national CDOP dataset is expected within the next few years, it will take many further years of data collection to allow analyses of time trends in different types of death, or of the proportion of deaths involving less common contributing factors.

One potential advantage may be more timely availability of data. Mortality records in England, particularly for older children, are subject to substantial delays incurred by the need for coroner referrals or inquests.²⁵ However, since one in four CDOP reviews takes longer than 12 months to complete,¹¹ timeliness of CDOP reviews currently does not appear to be any better than for ONS mortality records. We have previously shown that indicating whether a death is expected or not would be extremely useful for indicating which deaths are amenable to healthcare intervention.¹⁹ Clinician reporting of deaths to CDOP as expected or unexpected, could therefore be useful for filtering deaths for CDOP investigation and would provide important information that could be linked to death certificates.

Combining analyses of administrative data and detailed in depth reviews

With limited evidence regarding whether CDOPs are leading to reductions in child deaths, we question whether mandated reviews of, and duplicated data collection from, a case series of all child deaths is an efficient use of scarce local authority resources. Others²⁶ have raised the duplication of effort between CDOPs, SCRs and coroner investigations. Local scrutiny of deaths can provide information on circumstances at the death scene, child care, parental risk factors, and contacts with services that can inform local practices. Routine analyses of linked data and clinician and/or coroner reporting of whether deaths were expected or not can be used to identify cases for more in depth scrutiny by local authorities. Rather than make CDOPs comprehensively review all deaths, CDOPs would provide added value if they focussed on selected deaths that are not also reviewed elsewhere, for example as SCRs. To further reduce duplication of effort, a selective system of death review by local authorities could be combined with reviews in hospital based meetings of deaths in hospital or in children with life-limiting conditions.⁸ Selection of deaths requiring CDOP review requires work with Public Health England, NHS Digital and ONS to develop rapid analyses that could identify deaths with minimal delays.

Instead of waiting for a highly expensive CDOP dataset that consumes scarce senior staff time, we suggest maximising the potential of linked administrative datasets for research into, and monitoring of, child deaths. This will involve linkage between further routinely collected data sources, including Census records (which will provide self-reported data on socio-economic position, housing, family resources and health status), stillbirth records (which will allow the study of perinatal mortality), and education data (which can identify education-related risk factors for deaths, such as school performance or absenteeism). The data should also be easier to access for child health researchers and national and local government analysts. In England, linkage between ONS birth and stillbirth registration, death registration and HES data for research purposes currently requires approval by three committees (an NHS Research Ethics Committee, the Confidentiality Advisory Group, and the Independent Group Advising on the Release of Data). In Scotland or Wales, only one committee review is required. A welcome development would therefore be to introduce such a streamlined data application process in England.

A large number of high quality datasets, routinely collected as part of NHS care or local authority business are already available to support policy development to prevent child deaths. Rather than relying on future, costly CDOP data, improved access and use of linked administrative databases will

save both money and children's lives without further delays. CDOPs could then focus on far fewer deaths where scrutiny of circumstances would provide useful information for local services.

Contributors

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Competing interests

All authors use administrative health data from the Office for National Statistics, NHS Digital, and other UK data providers extensively in their research.

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References

1. Organisation for Economic Co-operation and Development. Child mortality, 2013 (or nearest year). *Health at a Glance: Europe 2016* 2016; (23/04/2019). <https://www.oecd-ilibrary.org/social-issues-migration-health/health-at-a-glance-europe-2016/child-mortality-2013-or-nearest-year-health-glance-eur-2016-graph44-en> Accessed: 24/04/2019
2. Garstang J. Challenges of research using data from child death overview panels. *Arch Dis Child* 2018;103(11):1008-09. doi: 10.1136/archdischild-2018-314821
3. Firth C, Petherick E, Oddie SJ. Infant deaths from congenital anomalies: novel use of Child Death Overview Panel data. *Arch Dis Child* 2018;103(11):1027-32. doi: 10.1136/archdischild-2017-314256
4. Office for National Statistics. Child mortality statistics, 2016. 2018 <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/datasets/childmortalitystatisticschildhoodinfantandperinatalchildhoodinfantandperinatalmortalityinenglandandwales> Accessed: 13/02/2019
5. Office for National Statistics. Deaths registered in England and Wales, 2016. 2017 <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/datasets/deathsregisteredinenglandandwalesseriesdrreferencetables> Accessed: 13/02/2019
6. Kurinczuk JK, M. Child death reviews: improving the use of evidence. 2013 https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/246562/DFE-RR303.pdf Accessed: 13/02/2019
7. NSPCC. Learning from case review briefings; 2018 <https://learning.nspcc.org.uk/case-reviews/learning-from-case-review-briefings/> Accessed: 24/04/2019
8. Allen L, Lenton S, Fraser J, et al. Improving the practice of child death overview panels: a paediatric perspective. *Arch Dis Child* 2014;99(3):193-96. doi: 10.1136/archdischild-2013-305085
9. Angelow A, Black N. The use and impact of national confidential enquiries in high-income countries. *BMJ Quality & Safety* 2011;20(1):38-45. doi: 10.1136/bmjqs.2010.040477
10. Department for Education. Child death reviews: forms for reporting child deaths; 2018 <https://www.gov.uk/government/publications/child-death-reviews-forms-for-reporting-child-deaths#history> Accessed 24/04/2019
11. Department for Education. Child death reviews: year ending 31 March 2017. 2017 https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/627206/SFR36_2017_Text.pdf Accessed: 13/02/2019
12. Office for National Statistics. Avoidable mortality in the UK. 2018 <https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/causesofdeath/datasets/avoidablemortalityintheuk> Accessed: 13/02/2019
13. Kurinczuk JS, B; Field, D; Draper, ES; . Child Death Review Database Development Project England and Scotland: Final Report. 2016 https://www.npeu.ox.ac.uk/downloads/files/cdr/CDRDDP%20Final%20Report_July%202016.pdf Accessed: 13/02/2019
14. The National Archives. Historic Mortality Datasets; 2019 <http://discovery.nationalarchives.gov.uk/details/r/C15263> Accessed 24/04/2019
15. Office for National Statistics. ONS Consultation on Statistical Products 2013. 2013 <http://www.ons.gov.uk/ons/about-ons/get-involved/consultations-and-user-surveys/consultations/statistical-products-2013/ons-consultation-on-statistical-products---questionnaire.pdf> Accessed: 13/02/2019
16. Herbert A; Wijlaars L ZA, Cromwell D, Hardelid P. Data Resource Profile: Hospital Episode Statistics Admitted Patient Care (HES APC). *Int J Epidemiol* 2017 doi: <https://doi.org/10.1093/ije/dyx015>
17. Harron K, Gilbert R, Cromwell D, et al. Linking Data for Mothers and Babies in De-Identified Electronic Health Data. *PLoS One* 2016;11(10):e0164667. doi: 10.1371/journal.pone.0164667
18. Zylbersztejn A, Gilbert R, Hjern A, et al. Child mortality in England compared with Sweden: a birth cohort study. *The Lancet* 2018;391(10134):2008-18. doi: 10.1016/S0140-6736(18)30670-6

19. Verfurden ML, Gilbert R, Sebire N, et al. Avoidable mortality from respiratory tract infection and sudden unexplained death in children with chronic conditions: a data linkage study. *Arch Dis Child* 2018;103(12):1125-31. doi: 10.1136/archdischild-2017-314098
20. Sidebotham P. What do serious case reviews achieve? *Arch Dis Child* 2012;97(3):189-92. doi: 10.1136/archdischild-2011-300401
21. Devis TR, C; . Death certification and the epidemiologist. *Health Statistics Quarterly* 1999;1:21-33.
22. Hardelid P, Dattani N, Gilbert R. Estimating the prevalence of chronic conditions in children who die in England, Scotland and Wales: a data linkage cohort study. *BMJ Open* 2014;4(8):e005331. doi: 10.1136/bmjopen-2014-005331
23. Harron KL, Doidge JC, Knight HE, et al. A guide to evaluating linkage quality for the analysis of linked data. *Int J Epidemiol* 2017;46(5):1699-710. doi: 10.1093/ije/dyx177
24. Hagger-Johnson G, Harron K, Goldstein H, et al. Probabilistic linkage to enhance deterministic algorithms and reduce data linkage errors in hospital administrative data. *J Innov Health Inform* 2017;24(2):891. doi: 10.14236/jhi.v24i2.891
25. Office for National Statistics. User guide to mortality statistics; 2018
<https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/methodologies/userguidetomortalitystatisticsjuly2017#registration-of-deaths> Accessed 24/04/2019
26. Mecrow IO, LM. The value of Child Death Overview Panels (CDOP) remains unproven (response to Allen et al). *Arch Dis Child* 2014 [online only]
<https://adc.bmj.com/content/99/3/193.responses>