

**Dissemination of information gained by post-mortem examination
following unexpected death of children in hospital**

Background Paper

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Introduction

1. Questions posed by the Inquiry appear to assume that uniform and specific protocols for the recording and dissemination of necropsy-derived information have been in place for very many years. This is not the case. Before attempting to answer your questions, it is appropriate to consider what we know of practices in the past.

Background

2. The earliest information available in respect of in-hospital deaths in children comes from the report of the National Confidential Enquiry into Perioperative deaths [within 30 days of surgery], which in 1989 looked at deaths in children in England (1). Of 295 deaths where information was made available to the Enquiry, 224 [76%] were reported to a Coroner but a post-mortem examination was instructed in only 130 [58%] cases. Amongst the cases not investigated by a Coroner, or not so reported [165 cases], permission was sought from the family in 110 and granted in 83. The commonest reason for not seeking permission for necropsy was that it would not contribute to better understanding of the case. This view has been shown to be invalid in several studies and review of clinical records suggested that it was also the case here.
3. The time taken for a post-mortem report to reach the surgeon was less than one week in two thirds of hospital post-mortems but for less than one-half of Coroners' cases. About 12% of hospital reports were outstanding after four weeks, as were 32% of reports on Coroners' cases.

4. The standard of the report itself was reviewed and considered high in 54/170 and very high in 60/170. This reflects the high proportion of post-mortem examinations performed by specialist pathologists. Additional information revealed by the examination was found in 31/44 non-cardiac deaths and was thought significant in 27 cases.
5. With the establishment of Clinical Pathology Accreditation (UK) Ltd (CPA) in 1992, protocols [Standard Operating Procedures, SOPs] relating to the content and timeliness of distribution of Post-mortem reports were drawn up by individual departments in advance of departmental review. This included rapid dissemination of information relating to a 'working diagnosis' to Clinicians in respect of their patients, in the form of a brief note, pro forma or preliminary report, to form the basis of discussions with relatives, before the Post-mortem report itself was completed. In the case of children, where there is always a need for ancillary investigations, including extensive, systematic histological examination, microbiology, detailed examination of the brain or cytogenetics, this takes several weeks. Locally, it was suggested to my colleagues that an appointment should not be offered to parents within six weeks of the death of their child.
6. It was and is usual to send a copy of the post-mortem report only to the medico legal authority and the designated clinician. It was my practice to send a copy to the referring clinician if the child had been admitted initially to another hospital. When the Accreditation process had been in place for a number of years, there was a slow move towards a consensus in the content of protocols related to post-mortem examinations between departments, promoted by comments from the reviewing team.
7. In 1993, in response to complaints about the standard of some Post-mortem reports, particularly, I recall, those performed on instruction from Coroner or Procurator Fiscal on adults, the Royal College of Pathologists produced 'Guidelines for the Production of Post-mortem Reports' (2), a short booklet distributed to relevant Members and Fellows of the College, indicating a minimum content of such reports. This document was advisory, not compulsory. This was the first attempt to introduce

some sort of uniformity into an area with very wide standards of personal practice. In children in England and Wales, style and content of post-mortem reports has also been influenced by Multicentre studies of unexpected infant death, which have introduced more conformity of approach and have had a knock-on effect on the investigation of deaths of older children (3, 4).

8. Practices in the production of reports have evolved locally and within departments, the style and content of reports varied widely between Pathologists, reflecting enthusiasm, experience and time available. The same is true for the dissemination of information, the only legal requirement being to provide a Cause of Death and subsequently a report, to the Coroner or Procurator Fiscal in cases investigated on their behalf and to the Regional Medical Officer in cases of certain infectious or industrial diseases. From the Pathologists' point of view, further dissemination of information about the death would be the responsibility of the attending clinician and, I expect, would vary from institution to institution. The other person regularly informed, via the clinician, would be the families' General Practitioner.

9. In Scotland, those hospital deaths requiring notification to the Procurator Fiscal were detailed in Deaths and the Procurator Fiscal (5). Most of those deaths, particularly in children, are subject to post-mortem examination although a formal investigation [Fatal Accident Inquiry, FAI] will be conducted in only a minority. The instigation of an FAI depends on the circumstances of death including any complaints from family or others. Following an FAI, a Sheriff will make a written determination, which will be issued to the CEO and Medical Director of the institution concerned and may contain recommendations about changes to practice.

Q1. Between 1995 to date, what was/is the system of procedures and practices in the UK for recording, reporting and dissemination of information on unexpected deaths in hospital to the hospital within which the unexpected death occurs, the treating clinicians (including doctors and nurses), the Trust, Area Board and DHSSPS including the Chief Medical Officer?

10. As far as I am aware, there is no standard system of procedures and practices within the UK for reporting, recording and dissemination of information about in-hospital unexpected deaths.
11. The only common procedure is the issuing of a death certificate. This will be done, in most cases in England and Wales, by a Coroner if an investigation has been done on his behalf. When a post-mortem has not been instructed, a death certificate may be issued by the responsible clinician on instruction from the Coroner, or by the clinician, taking into account information from the pathologist when a hospital post-mortem has been performed. In Scotland, the death certificate is issued by the pathologist following necropsy, or by the responsible clinician following discussion with the Procurator Fiscal.
12. Deaths are discussed at meetings by the staff of individual units, particularly if the individual has been cared for in an Intensive Care Unit. Within a Trust, there may be channels for passing information routinely about unexpected deaths to the Medical Director. I am not aware of a requirement to pass information to other bodies.

Q2. Between 1995 to date, what was/is the system of procedure and practices in the UK for ensuring that the information on unexpected deaths in hospitals is/was analysed and that any lessons to be learned from those deaths feed/fed into the teaching and training of doctors and nurses and the care of patients?

13. There was and is no common procedure within Children's Hospitals and Paediatric units within Teaching Hospitals for the formal analysis of these deaths and for ensuring that lessons learned from the deaths is made widely available and incorporated by changes in practice throughout the Unit, far less introduced into formal training.
14. Pathologists will have presented cases of in-hospital child deaths at clinical meetings within the institution over many years, this was neither consistently done, nor was it mandatory. The meetings were not usually minuted.

15. It was not until 2002-3 that in Edinburgh, a formal meeting was convened to consider hospital deaths, except within Obstetric departments, where such meetings have been required by the Royal College of Obstetricians and Gynaecologists [RCOG] for many years. At the meetings to discuss in-hospital deaths, an opinion was expressed about the avoidability of death. No minutes of the meetings were subsequently distributed.
16. Information about the current situation in the UK from practising paediatric pathologists indicates that regular 'Death Meetings' are held in about half of units, all in children's hospitals. A decision about the avoidability of death was made in all but in only two units was it clear to the pathologist that meetings were minuted and that there was an established mechanism for dissemination of lessons learned.

Q3. Between 1995 to date, what is/was the system of procedures and practices in the UK for the accurate coding of deaths in hospitals, including how accuracy of coding is checked and verified, how accurate are death codes in general, who has responsibility for the coding of a death, on what basis and/or using what documents is the decision on coding of a death made, and how would inaccurate coding affect statistical analysis (e.g. by the National Confidential Enquiry into Perioperative deaths) of deaths in hospitals?

17. Coding of deaths in hospitals is performed by clerks in Medical Records departments, based on information from medical staff from the Unit to which the patient was admitted. Usually, the information is summarised briefly on the front of the patients' notes. The use of trained clerks for coding of this sort has been found to be accurate by a number of studies. The precise method of checking coding accuracy varies from institution to institution. Because coding itself is based on information from doctors, often junior staff, the likely source of error lies with them. Information for coding is entered on the front of medical notes at the time that discharge [or death] summary is made. A copy of the summary letter, as sent to the referring doctor, is retained within the medical notes and would be available to the clerk for checking should uncertainty arise about the meaning of the summary itself.
18. The responsibility for accuracy and timely submission of clinical information centrally for statistical purposes lies with the Medical Records Officer. Any

inaccuracies would affect Government-generated statistics. They would not, however, be likely to affect analyses such as the National Confidential Enquiry into Perioperative Deaths [NCEPOD], or the Confidential Enquiries into Stillbirths and Deaths in Infancy [CESDI] and its successors, as information for these studies is obtained on direct enquiry from the consultant concerned. In the case of NCEPOD, a questionnaire is sent to both surgeon and anaesthetist and a copy of the post-mortem report obtained. Furthermore, a local or regional contact person is appointed by the appropriate Royal College to ensure timely remittance of information by the named individual and direct contact made by study personnel in cases of ambiguity or suspected inaccuracy. This, together with group discussion of cases by appropriate professionals, makes inaccuracy in confidential enquiries unlikely.

Q4. Between 1995 to date, what is/was the system of procedures and practices in the UK for the reporting and dissemination of information on the outcomes or lessons to be learned from Coroner's Inquests to the hospital where the patient was treated, other hospitals, the doctors and nurses, Trusts, Boards and the DHSSPS, including the Chief Medical Officer?

19. My understanding is that it is the Coroners' responsibility to communicate relevant information from inquests to Clinicians.
20. My own practice has been to obtain blanket permission from the Medico legal Authority to inform Clinicians, in advance of an inquest of post-mortem findings on their patients, in some areas, this is the responsibility of the Coroners' Officer. It is clear from my enquiries that other pathologists adopt the same approach, with verbal and then written information, transmitted.

Q5. Between 1995 to date, what was/is the system of procedures and practices in the UK for ensuring that the information on the outcomes or lessons to be learned from Coroner's Inquests is/was analysed and feeds/fed into the teaching and training of doctors and nurses and the care of patients?

21. I am not aware of any formal mechanism for ensuring that information from Coroners' Inquests was analysed and fed into teaching and training programmes. I

would expect that deaths subject to Coronial inquiry would be discussed in hospital death meetings, where they exist and that elsewhere would be discussed within the relevant unit.

Issues going forward



22. Before consideration of improvements to systems of notification and dissemination of information about unexpected deaths of children, it is important to consider the quality of the available information so that any efforts made to distribute it are worthwhile.
23. There are two important factors to be taken into consideration. The first of these is appropriate, timely clinical input. Whether they occur within or outwith hospital, many unexpected deaths will be in children with long standing problems, which may not always have been recognised (6). Whenever possible, a clinician should be present during the post-mortem examination to consider clinical events and, perhaps, to assist the pathologist in the interpretation of investigations which may have been undertaken, or point out those which have been omitted. A Coroner may be uncomfortable about the presence of the responsible clinician during an independent investigation. In this event, every effort should be made to engage assistance from an independent clinician. It is probably more important for the investigation of what are often complex cases at this stage than to have an independent clinician present at the Inquest. This does not seem to be a problem in Scotland, where many post-mortem examinations on unexpected deaths are performed in the hospital mortuary and attendance of clinicians is encouraged.
24. The second important consideration is the choice of pathologist. In my, perhaps biased, view, a pathologist with paediatric experience should always be involved. This is almost always the case in Scotland where a 'two doctor' investigation is usual following unexpected death in hospital, providing both paediatric and forensic expertise.
25. I appreciate that it is entirely within the Coroners' jurisdiction to appoint the pathologist and decide on the venue of the examination, but paediatric pathology

expertise and the use of hospital mortuaries, which in many instances have better facilities for the appropriate investigation of child deaths, is likely to maximise the information gained. Use of the hospital mortuaries also facilitates clinician attendance.

26. It is encouraging to find, from my colleagues in the UK that the involvement of paediatric pathologists has become much more common and that the involvement of two pathologists in cases of suspected criminal intent or malpractice is increasing.
27. Unexpected deaths in children are infrequent and processes to disseminate information and lessons learned should be all-inclusive, but not unduly onerous, using existing channels wherever possible. The obligation of Local Authorities to set up Local Safeguarding Children's Boards [Safeguarding Board for Northern Ireland; Whole Wales Initiative] which in turn are obliged to set up Child Death Overview Panels seems to be an appropriate means of collating and disseminating information about unexpected deaths using a minimum data set which should include necropsy-derived information which has been found to provide 'new and extremely important information' in 18/42 deaths where the post-mortem report was available in a recent review (6). This should enable appropriate cases to be reviewed in depth and facilitate pooling of information so that lessons are learned more quickly. The pilot study 'Why Children Die' (6) has demonstrated the feasibility of this approach. Given the relatively small number of deaths when compared to perinatal deaths where information is collected on a regular basis, there is no reason why data on older children should not be similarly collected.
28. There are important roles for the Royal College of Paediatrics and Child Health [RCPCH] in the process of analysis of information and translating the information into education and practice. The College might encourage the setting up of regular Death Meetings in all units where children are admitted and, indeed be persuaded to make such meetings mandatory for recognition of training, as has the RCOG in respect of Perinatal Mortality Meetings. The RCPCH is probably the best vehicle for ensuring that lessons learned are fed in to training and practice. It has already shown itself well able to produce and disseminate timely practice guidance.

STATEMENT

The information contained in the Report, is to the best of my knowledge, true at the time of writing.

Signed  Date 

Dr JW Keeling

Addendum

I have been asked to give an opinion on the following:

In a situation where it is found, for example at a Coroner's Inquest, that the cause of death is other than that stated on the original death certificate, what in my view is, or should be, the subsequent effect on (a) the original death certificate (b) the issue of coding and other hospital notes and records.

(a) If the cause of death is changed, then a further certificate should be issued. This is done in the case of infants dying suddenly and unexpectedly, when usually, a certificate is issued to enable death registration, immediately following the postmortem examination, but before the results of histological and other investigations are available. The initial cause of death in these cases often reads 1a Undetermined. This is amended later and a further certificate issued to the parents. As far as I am aware, the registered cause of death is not changed. This is unfortunate, as it affects National death statistics. A means of change to the registration is desirable.

(b) The changed cause of death may find its way into the hospital notes, in the form of a communication from the Coroner, but I am not aware of any procedures to ensure that coding would be changed as a matter of course.

References

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 - 3 Knowelden J, Keeling JW, Nichol. A multicentre study of post-neonatal mortality. London Crown Copyright 1984.
 - 4 Fleming P, Blair P, Bacon C, Berry J. Sudden unexpected deaths in infancy. London The Stationery Office.2000.
 - 5 Crown Office. Death and the Procurator Fiscal. Crown Office. 1998
 - 6 Pearson GA (Ed). Why children die: a pilot study 2006, England (South West, North East, West Midlands), Wales and Northern Ireland. London. CEMACH. 2008.
- Additional reading
- Berry J. Sudden death of children in hospital. in Busuttill A, Keeling JW. Paediatric Forensic Medicine and Pathology. Hodder Arnold 2008 pp363-384.

Curriculum Vitae - Dr JW Keeling FRCPATH, FRCP(Edin), FRCPCH

I was Consultant Paediatric Pathologist, Lead Consultant, Paediatric Pathology, in the Department of Pathology, New Royal Infirmary, from 2003 to Dec 2004. After that, I continued in a locum capacity until August 2005. Previously, I was Head of Department, Paediatric Pathology, Royal Hospital for Sick Children, Edinburgh; Honorary Senior Lecturer, University of Edinburgh from 1989 until 2003. I was Consultant Paediatric Pathologist, John Radcliffe Hospital, Oxford from 1974-1989.

I have performed more than 2500 post-mortems on babies, infants and children and regularly investigated sudden deaths for HM Coroners and Procurators Fiscal. I have appeared in Court as an expert witness in cases involving alleged injury to children for both prosecution and defence and in litigation cases involving perinatal problems.

I was review pathologist for the Sheffield Multicentre Study of postneonatal infant deaths (A multicentre study of postneonatal mortality, Knowlton J, Keeling JW, Nicol JP, HMSO 1984). I am author of many book chapters on aspects of neonatal and infant pathology and editor of Fetal and Neonatal Pathology, Springer-Verlag London, Heidelberg, 1987, 2ed 1994, 3ed 2001, the 4th ed 2007. I am co-editor (with Prof A Busuttill) of Paediatric Forensic Medicine and Pathology, Hodder Arnold, London 2008.

I was pathology assessor to the National Perioperative Deaths Enquiry (NCEPOD) when it addressed the problem of perioperative deaths in children (1988-1990). I was a member of the National Advisory Body of the Confidential Enquiry into Stillbirths and Deaths in Infancy (CESDI) from 1992-2003 and was a member of the CMO's Expert Working Group on Cot Death Theories. I was a Paediatric Pathology expert to the Bristol Royal Infirmary Inquiry and a member of the Inquiry panel for the Royal Liverpool Children's Inquiry.

I served as an elected member of Council of the Royal College of Pathologists from 1987-90 and 1992-95. I was founding chairman of the Specialty Advisory Committee on Prenatal, Perinatal and Paediatric Pathology to the College (1993-1995).

I have been President of the Paediatric Pathology Society.

I was President of the International Paediatric Pathology Association from 2002 to 2004.

I was a member of the Home Office Policy Group for Forensic Pathology from 2003 to 2006.

I have published more than 100 papers.

I am still actively involved in research projects into aspects of Perinatal and Infant death, my last paper was published in 2010.