

Chapter 13

Department of Health and Children

13.1 The Post-Mortem Inquiry

Background to the Inquiry

In 1999 parents of children who had died at Our Lady's Hospital for Sick Children, Crumlin began to query the hospital's practice in the area of removal and retention of organs. By late March 2000, approximately 1,700 enquiries had been received from parents by the major hospitals. Concerns were expressed that the removal and retention of organs was not covered by informed consent. A particular concern related to the extraction of pituitary glands from deceased children. Our Lady's Hospital for Sick Children, Crumlin, confirmed that correspondence on its files indicated that its laboratory had participated in extracting pituitary glands from deceased children which were then supplied to a pharmaceutical company to manufacture a human growth hormone for the treatment of children.

In December 1999, parents of children whose organs had been retained by Our Lady's Hospital and by Cork University Hospital formed a support group called Parents for Justice (PFJ).

In April 2000 the Government decided to establish a non-statutory inquiry which would review post-mortem policy, practice and procedure in the State since 1970 particularly relating to organ removal, retention and disposal by reference to prevailing standards both within the State and in other jurisdictions. An inquiry was established with the intention that work would be completed in two phases

- The first phase of the Inquiry would culminate in a report which was to be available within six months.
- On receipt of this report, the Minister for Health and Children (the Minister) would table a motion that the second phase of the Inquiry would be undertaken by the Oireachtas Joint Committee on Health and Children. The Committee has powers to discover documents and compel witnesses under the Committees of the Houses of the Oireachtas (Compellability, Privileges and Immunities of Witnesses) Act 1997.

A chairman was appointed by the Minister on 11 April 2000 subject to approval of the terms and conditions of employment by the Minister for Finance.

The Form of the Inquiry

Detailed discussions took place with PFJ and its legal advisors in a bid to agree an appropriate format for the inquiry. PFJ lobbied for the establishment of a statutory inquiry with full powers of compellability, privileges and immunities of witnesses. However, the Minister favoured a non-statutory format for the following reasons

- The needs and concerns of PFJ could be met by this route
- It could be speedily established
- It could be flexible in its approach and less rigid in its implementation
- It would be relatively informal and less adversarial
- It would not be as debilitating on the provision of vital hospital services
- It could deal with these painful issues over a shorter period of time.

Additionally, the Minister expressed concerns that many parents might not be open to the prospect of going before an open and public tribunal to talk about the traumatic event of the loss of a child. While some parents would want to participate in such a forum there might be many others who might not wish to do so. At that stage, PFJ went along with this proposal on the basis that the Minister gave a written

commitment that there would be a second phase – the Oireachtas Joint Committee on Health and Children which would constitute the statutory phase. The Committee could decide whether to conduct hearings in relation to the report and, if it considered it appropriate to do so, to avail of powers to call witnesses as appropriate. Ultimately, however, it was not possible to conduct the second phase through an Oireachtas committee in the manner originally envisaged.⁴⁷

Objectives of the Inquiry

Although pressure groups, such as PFJ, lobbied to make the Inquiry as extensive as possible the Government proposed to confine the remit of the Inquiry in order to ensure timely completion. At the time the Government decided to establish the Inquiry in April 2000 its objectives were set out as follows

- To independently establish the full facts in regard to past practice relating to post-mortem examinations and to address the issues (removal, retention, disposal, storage and consent) raised by parents and by the PFJ group.
- To restore full public confidence in hospitals and in the necessity for post-mortem examinations including organ and tissue retention for such purposes as further diagnosis, teaching and research.
- To provide public assurance that any previous practice which might be judged unacceptable will not recur. An inquiry would provide for publicly acceptable protocols to apply to all hospitals where post-mortem examinations are carried out.
- To establish the full facts relating to some hospitals' confirmed participation in the extraction of pituitary glands from deceased children and the supply of these glands to a pharmaceutical company to produce a growth hormone for the treatment of children.

Inquiry Resources and Timing

In a letter to the Minister in February 2001 the chairman set out the terms under which the Inquiry team and the chairman were embarking on the Inquiry. The chairman indicated that

- She no longer thought it possible to complete the task within the six months originally agreed and asserted that it would take far longer because the Inquiry had become much more extensive, complex, and comprehensive than originally envisaged.
- She required the services of at least one Senior Counsel on a full time basis rather than on an ad hoc basis alone.
- She and two members of the legal team would be operating with flexibility. This would allow them to attend to legal work other than that of the Inquiry which she felt was necessary, in order to maintain connection with the Law Library and with their respective practices.
- She wished to be able to review these terms every six months.

Terms of Reference

The Terms of Reference were set out in a Public Notice issued on 23 March 2001 by the chairman together with her Interpretation of the Terms of Reference. The published Terms of Reference are set out in Figure 6.

⁴⁷ The Minister had stated that if it transpired that it was not possible to submit the final report to the Oireachtas Committee (whether as a result of the Abbeylara judgment or otherwise) he was committed to submitting it to another appropriate forum with statutory powers. When the final Madden report was published it was submitted to the Oireachtas Committee.

Figure 6 Terms of Reference of the Inquiry

To review all post-mortem examination policy, practice and procedure in the State since 1970, and in particular as it relates to organ removal, retention, storage and disposal by reference to prevailing standards both in and outside of the State. To examine the application of these policies, practices and procedures in hospitals, generally and in particular their application in the 11 named hospitals⁴⁸.

The Inquiry will address the hospitals' policies, practices and procedures in this area of organ removal, retention, storage and disposal, the necessity for such practices and the manner in which they were carried out. The Inquiry will take account of best practice regarding post-mortem examinations in and outside of the State together with the reasonable expectations of parents of deceased children and next of kin in such circumstances. In particular, the Inquiry will:

- Examine the hospitals' policies and practices relating to obtaining consent from parents and next of kin for post-mortem examinations, organ removal, retention, storage and disposal.
- Examine the hospitals' procedures and practices relating to retained organs, including the reasons for such retention, the hospitals' management of such retention and storage of organs (including record keeping) and of any other arrangements relating to such organs and the practices adopted for ultimately dealing with retained organs including any arrangements with pharmaceutical companies in relation to those retained organs.
- Review the nature and appropriateness of the hospitals' overall response to parents of children and next of kin of persons on whom a post-mortem examination was performed.
- Examine any specific cases in any hospital as it deems appropriate in relation to post-mortem examinations and post-mortem examination related matters.

However, it will be at the discretion of the Inquiry to examine any other relevant matters which arise in the course of the Inquiry in relation to post-mortem examination policy, practice and procedure in the State since 1970.

The inquiry will make its final report, including its findings, to the Minister for Health and Children within six months unless otherwise determined by the Minister. It will make recommendations to the Minister on foot of its findings.

The report will include confirmation that the Inquiry received all the information and co-operation from health agencies, persons employed therein and any other persons, which it considered necessary to form its opinions and to arrive at its conclusions. In the event of deficiencies arising in these areas, which the Inquiry considers materially limits the scope of its investigations the report will identify same.

The chairman's Interpretation of the Terms of Reference stated that she considered that the work of the Inquiry would extend to all post-mortem examinations wherever carried out. This set the scope of the Inquiry which would extend to an examination of the specifics of individual post-mortem examinations. The scope in the Interpretation also extended to all hospitals within the State in which post-mortem examinations were carried out and/or hospitals which requested, directed or authorised post-mortem examinations to be carried out at another location. The Interpretation stated that the Minister for Health and Children had determined that the time limit of six months for the final report no longer applied and that the inquiry would report to him within a period of 18 months unless otherwise determined by him.

⁴⁸ Temple St Children's Hospital, Coombe Women's Hospital, Our Lady's Hospital for Sick Children (Crumlin), National Maternity Hospital (Holles St), Rotunda Hospital, and the Major Academic Teaching Hospitals.

On 22 October 2002 the Minister, in Dáil Éireann, expressed some reservations about the scope of the terms of reference. He noted that to move to a statutory phase at that stage would not be achieved within the existing terms of reference, as these were too wide. He also noted that the problem which had by then arisen with the timeframe was related to the terms of reference.

Provisions in Regard to Procedures

By reason of the fact that the Inquiry was established on a non-statutory basis it had no powers of compellability, either in relation to the production of documents or information, or in respect of the attendance of witnesses before it. Consequently, it depended upon the voluntary co-operation of the many potential participants in its work. For this reason it was deemed necessary to obtain a consensus between all potential participants as to the procedures to be adopted. To this end a document entitled 'Memorandum on Procedures' was drawn up, in consultation with relevant parties, and issued on 3 August 2002 to all participants for signature and return. The memorandum outlined how the Inquiry proposed to conduct its work. Specifically it set out three stages to be completed.

- The first stage involved conducting research as well as obtaining information from all relevant individuals. This included taking submissions both oral and written, obtaining a sample of post-mortem examination records and records of consent.
- The second stage aimed to consider all the evidence and identify matters which might be in dispute.
- In the third stage it was planned to resolve these disputed matters of fact.

The Memorandum guaranteed the constitutional right to fair procedures to all those affected by its work. Moreover, the Inquiry stated that it would inform all affected persons of proposed criticisms contained in its report and would afford them a right of reply.

It is unclear how many hospitals agreed to be bound by these procedures but by 2 October 2002 only 62 of the 201 hospitals identified in the report had signed the Memorandum. Furthermore, only 65 of 402 parents and next of kin who had made written submissions to the Inquiry had signed as at that date. However, having regard to the level of co-operation obtained to that date the chairman did not regard the failure of participants to sign the memorandum as impeding the ability of the Inquiry to continue its work. A number of participants who had not signed the Memorandum provided full cooperation to the Inquiry.

Conduct of the Inquiry

The first phase of the Inquiry began on 5 March 2001. No provisions had been put in place for interim reporting as the report was expected to be delivered by September 2002. However, in August 2002 the chairman informed the Minister that the Inquiry was a long way from reaching the stage at which a report would be available having regard to the extensive scope of the terms of reference and the nature of the Inquiry. The Minister requested a progress report from the chairman. In response, the chairman submitted a Progress Report on 2 October 2002 which outlined the work already completed by the Inquiry team and set out the work that had yet to be completed. The Report also noted the response rate obtained from hospitals, individual parents and next of kin, and other relevant parties. However, the chairman was unable to give an estimate of the timescale required for the completion of the work of the Inquiry and the making of its report.

In October 2002 the PFJ expressed their dissatisfaction with the process in a meeting with the Minister and decided to withdraw. At the time, there were also concerns about the implications of the Abbeylara judgment. The Minister assured the PFJ, following legal advice, that the Abbeylara judgment should not affect phase one and that it could continue. In respect of phase two, his advice was that much would depend on the content of the report that would be presented to the Oireachtas Committee. Upon their withdrawal from participation in the Inquiry the PFJ also withdrew any submissions made to it by their

members. The Chairman informed the Minister, in November 2002, that she had sufficient involvement of parents and the Inquiry was continuing with its work.

In December 2002, the chairman indicated to the Minister that an interim report on paediatric hospitals would be provided by December 2003 which would be followed by reports on maternity hospitals and on general hospitals. Subsequently, in October 2003, the chairman, in a further progress report, informed the Minister that she would not be in a position to provide the interim report on paediatric hospitals by the end of the year.

During a review of all ongoing Tribunals and Inquiries the Attorney General wrote to the chairman on 16 July 2004 requesting an estimated date of completion. The chairman's response to this request did not give a definite timeframe for completion. Subsequently, it was agreed by Government on 1 September 2004 that the chairman should be requested to furnish the Minister with a final report not later than 31 March 2005 and that the Inquiry should then cease.

Output of Phase One of the Inquiry

On 31 March 2005, 54 bankers boxes of material were furnished to the Department of Health and Children. This material comprised a report running to 3,500 pages accompanied by 51 boxes of appendices including submissions from parents, next of kin, hospitals, health boards and professional bodies. The report dealt with the three Dublin paediatric hospitals and did not report on the other 198 hospitals identified in the progress report. However, evidence collected on these other hospitals was contained in the appendices. It was acknowledged in the report that it was not complete due to time constraints.

Counsel from the Attorney General's Office were retained to read and analyse the report at a total cost of €21,800. Arising out of this review certain legal issues were identified. In a letter written to the Tánaiste and Minister for Health and Children in April 2005 the Attorney General stated that the report could not be published for legal reasons due to issues relating to natural justice.

Cost of Phase One

At the outset the costs had been estimated to be of the order of €1.9m. However, by 31 March 2005 when the report was submitted the total cost of the Inquiry had risen to over €13m. Table 44 outlines the costs of the Inquiry.

Table 44 Costs incurred by Inquiry

Cost Category	€m
Office Fit out costs	1.19
Rent of Premises	1.10
Legal costs (Inquiry Team)	7.70
Administrative Costs ⁴⁹	3.80
Total	13.79

A total of €7.7m was incurred on legal costs. These fees were incurred as set out in Table 45.

⁴⁹ These included salaries, office administration, heat power, light, maintenance, cleaning, security etc.

Table 45 Legal Costs

Recipients	Number	Cost €m
Chairman	1	2.5
Full-time Barristers	2	3.1
Part-time Barristers	3	1.1
Solicitor	1	1.0
Total	7	7.7

UK Inquiries

No inquiries of this scale have previously been undertaken on organ retention issues in Ireland or the UK. The two inquiries which were undertaken in the UK dealt with single hospitals and are therefore not directly comparable in terms of timescale and cost.

- An inquiry into the management of the care of children receiving complex surgical services at the Bristol Royal Infirmary was established in June 1998 and disclosed that following post-mortem examinations, the organs of children who had died were removed and retained by the hospital. The Inquiry was conducted by a Chairman who was a Professor of Health Law, Ethics and Policy, and assisted by a Professor of Medicine, a Director of Nursing, and a Director of a Centre for Family Law. An interim report of the Inquiry investigating the removal and retention of organs was published in May 2000.
- An inquiry into Alder Hey Children's Hospital in Liverpool, which was established in December 1999, found that the organs of a large number of children were retained without the consent of parents or next of kin. The Alder Hey Inquiry was conducted by a Chairman who was a Queen's Counsel, and assisted by a Consultant Paediatric Pathologist, and a Chief Officer of a Community Health Council. This Inquiry extended only to one hospital and reported in nine months.

In contrast to the UK inquiries, the Irish Inquiry relied heavily on legal expertise. Two full-time barristers, three part-time barristers and a solicitor made up the bulk of the Inquiry's resources. No other area of expertise was represented on the team. However, the advice of several experts was sought throughout the life of the Inquiry. The advice of a statistician was sought but does not appear to have been used.

Appointment of Legal Expert to prepare Report

In May 2005, following the advice of the Attorney General, the Government approved the appointment of a legal expert to prepare a report on key issues relating to post-mortem practice and procedures by 21 December 2005. The final report was completed and presented to the Minister by the reporting deadline and at the total cost of €436,000.

The specific terms of reference for this work were

- To inquire into policies and practices relating to the removal, retention and disposal of organs from children who had undergone post-mortem examination in the State since 1970.
- To inquire into allegations that pituitary glands were removed from children undergoing post-mortem examination for sale to pharmaceutical companies within and outside the State.
- To examine professional practice in relation to the information given to children's parents in respect of the removal, retention and disposal of tissue and organs and the appropriateness of practices of obtaining consent.

- To review the manner in which hospitals responded to concerns raised by bereaved families relating to post-mortem practices carried out on children.
- To make recommendations for any legislative and/or policy change as deemed appropriate in relation to post-mortems on children.

For the purpose of her report 'child' or 'children' refers to those born alive and less than twelve years of age at the date of death.

In conducting this work, the objective pursued by the expert was to make findings on facts about post-mortem procedure in the hospital system. The expert's report found that post-mortem examinations were carried out in Ireland according to best professional and international standards and that no intentional disrespect was shown to the child's body. In relation to the extraction of pituitary glands the expert concluded that there was no known commercial motive on the part of any hospital or its staff. The root causes of the controversy had been a lack of communication with parents as to why organs were retained, the difference in perspective as to their symbolic significance and the legislative vacuum on the role of consent in post-mortem examinations. The report recommended the enactment of clear and unambiguous legislation to ensure that such practices cannot happen again.

Audit Concerns

For the year ending 2005, expenditure on tribunals and inquiries under the aegis of the Department of Health and Children (Subhead E) amounted to approximately €44.4m. Some €1m of this charge related to Post-Mortem Inquiries bringing the total legal and administrative costs of the Post-Mortem Inquiries to €12m. These costs do not include office fit out costs and rental costs which are charged to other subheads of the vote or the costs incurred by hospitals and health boards (now the HSE) in responding to the inquiry.

It is recognised that there is a delicate balance to be achieved when inquiries are undertaken. On one hand, the facts must be established through an objective and independent process while, on the other, there needs to be a cost effective inquiry which gathers sufficient relevant and reliable evidence to enable the State to address the issues and concerns which arise. This would suggest the importance, at the outset, of focusing attention on certain key features of inquiries

- agreeing the general scope of the Inquiry and specific, focused and unambiguous terms of reference
- establishing a methodology based on achieving cost effective evidence-gathering focused on defined Inquiry issues
- providing for review milestones and reporting deadlines.

Queries to the Department

Arising out of these concerns I asked the Accounting Officer what steps were taken at the outset of the Inquiry and during its course by the Department to reduce the exposure of the State to cost escalation and to ensure timely reporting. I also enquired as to what lessons have been learned in regard to the conduct of this Inquiry in the areas of scope setting, methodology and the establishment of review milestones and reporting deadlines, and the extent to which such lessons have been or are capable of being applied to other Inquiries. I also asked the Accounting Officer for his best estimate of the costs incurred by the Health Service Executive (formerly the Health Boards) and of hospitals in connection with the Inquiry.

Accounting Officer's Response

With regard to the role of the Department in reducing the risk to the State of cost escalation and ensuring timely reporting the Accounting Officer informed me that it is necessary to address this question in the

context of the position that obtained in 1999/2000 when issues in relation to post mortem practice and organ retention came to public attention. This was a highly emotional issue for parents and the motives of the hospitals and clinicians involved were being questioned, particularly in relation to the extraction of pituitary glands. There were demands that where appropriate those involved be “named and shamed” and many believed that the Department itself was at least partially culpable for what had occurred.

The Government Decision in April 2000 was that a non-statutory inquiry should be conducted by a senior counsel, who would act independently of the Department. The terms and conditions of the Inquiry chairman were approved following consultations with the Attorney General and the Department of Finance in accordance with the arrangements that applied generally to Inquiries at that time. The Government also approved the terms of reference of the Inquiry subject to any modifications which the Minister considered necessary following consultation with key parties. In February 2001 at a meeting with the chairman the Minister confirmed that the interpretation of the terms of reference was strictly a matter for the chairman. At that stage it was agreed to extend the timeframe for her work from six months to 18 months i.e. until September 2002.

At a meeting with PFJ shortly after the Government decision to establish the Inquiry, the Minister assured the group that the workings of the Inquiry were independent of him and of the Department, and that there was no question of dictating to the chairman what she should or should not do. In this context it was essential that the Inquiry was completely independent in carrying out its investigation, particularly as the Department itself was under investigation.

At the outset of the Inquiry, the Department had no reason to believe that the task could not be completed within the six-month time-scale that was originally envisaged. For example, the then most recent Tribunal of Inquiry into the Blood Transfusion Service Board which the Department had dealt with and which was equally emotionally-charged had been completed within 5 months. In the light of this, the six month time-scale seemed reasonable.

Considerable delays were experienced in obtaining suitable accommodation for the Inquiry, which ultimately did not become available until January 2001 despite the best efforts of the Department and the OPW. In addition, there were difficulties in sourcing clerical and administrative staff to assist the Inquiry. The combination of these factors meant that the Inquiry only became operational in March 2001.

The first formal indication that the Inquiry was running behind schedule was in August 2002 when the chairman advised the Minister that the Inquiry was a long way from reaching a stage at which a report would be available and she sought an extension of the time-scale for the Inquiry. At the request of the Minister the chairman submitted a Progress Report in October 2002 which indicated that the chairman was not in a position to estimate the timescale for completion of the work of the Inquiry and that she considered that it would be some considerable time before the report could be completed. The Minister and the Department were concerned at the absence of a definitive time scale. Considerable thought was given to possible options to expedite the Inquiry, including the possibility of effecting changes in the terms of reference. Having taken advice, the Minister came to the conclusion that it would not be practicable, at that stage, to revise the terms of reference or to replace the Inquiry with some new structure. One of the primary concerns was that any such change could invalidate the work done to date such as interviews with witnesses and could mean having to start the investigation afresh. A further concern was that any move to alter the terms of reference might fuel demands from PFJ for a statutory Tribunal of Inquiry.

Having decided against a change in the terms of reference, the Minister, at a meeting with the chairman and her legal team in December 2002, stressed the need to expedite the investigation. It was agreed that a report on paediatric hospitals would be provided by the end of 2003, to be followed by reports on maternity hospitals and general hospitals at six month intervals. The chairman indicated that her legal team would need to be augmented in order to achieve these revised deadlines. The Department sought sanction from the Department of Finance for an increase in the legal staffing but this was not

forthcoming. In the light of this, the chairman advised the Minister in June 2003 that the deadline of end 2003 for the completion of the report on paediatric hospitals might not be achievable. However, she undertook to keep the matter under review with a view to making a more definitive statement within the following two months or so. In the event, on 16 October 2003 the chairman wrote to inform the Minister that she would be unable to furnish the report by the end of that year. Her letter, which was accompanied by a 12 page progress report, did not specify when it was anticipated that the report would become available. The Minister met with the chairman and her legal team on 17 November 2003 and expressed his concern that the deadline for the paediatric hospital report would not be met.

In April 2004 the Inquiry advised that, with some exceptions, it was at the end of the second stage of its work in relation to the paediatric hospitals i.e. the information gathering was complete and the issue of analysing the information and establishing which matters remained in dispute had been concluded. The Inquiry was next to consider the third and final stage of its work, which was the resolution of matters in dispute and the conclusion of the Report. The Inquiry added that it was keeping in mind the need to be in a position to commence the work in relation to the maternity hospitals as soon as the paediatric report was completed.

In July 2004, the Attorney General, on behalf of the Government, conducted a review of all Tribunals and Inquiries then in being to establish their likely completion dates. On 1 September 2004 the Government decided, *inter alia*, that the chairman should be informed that the Inquiry should furnish to the Minister for Health and Children not later than 31 March, 2005 a Final Report based on all information and evidence obtained by and available to the Inquiry at that time and that the Inquiry would then cease to exist.

With regard to the lessons learnt the Accounting Officer stated that, although the terms of reference were approved by the Government, it would have been preferable if the capacity to interpret these, and to provide input to the methodology to be employed, had been reserved. However, for the reasons set out above, this was not possible in this instance.

It would have been preferable if the contractual arrangements with the chairman and her legal team had been so structured as to provide certainty for early completion of the work. However, the terms and conditions were set in accordance with the arrangements that applied generally to Inquiries at that time and it is not clear that it would have been possible to secure the services of the relevant people on any other basis.

It would have been preferable if provision had been made for interim progress reports. Had this been the case, the Department would have been alerted at an earlier stage that there were problems with the timeframe for the Inquiry. However, when it became evident in October 2002 that it would be some considerable time before the report would be presented, the Minister decided that it would not be practicable, at that stage, to revise the terms of reference or to replace the Inquiry with some new structure. Accordingly, regular interim reports would not necessarily have changed the outcome.

With regard to the costs incurred by the HSE (formerly the Health Boards) the Accounting Officer informed me that the Department provided specific funding for Inquiry-related expenditure to the Eastern Regional Health Authority (and subsequently the Health Service Executive), which, for the period 2000-2005, amounted to €6,350,000. The Department does not have information in relation to expenditure incurred by health boards/ hospitals outside the former ERHA region.