



SCOTTISH EXECUTIVE

Legislation relating to hospital  
post-mortem examinations:  
Analysis of consultation  
responses

Health Department



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**LEGISLATION RELATING TO HOSPITAL  
POST-MORTEM EXAMINATIONS:  
ANALYSIS OF CONSULTATION RESPONSES**

**Linda Nicholson  
The Research Shop**

**Scottish Executive Social Research  
2004**

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## **ACKNOWLEDGEMENTS**

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Linda Nicholson  
December 2004

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## EXECUTIVE SUMMARY

A Scottish Executive Health Department consultation on the legislation relating to hospital post-mortem examinations took place between 24 November 2003 and 27 February 2004. A consultation paper was issued to which 29 responses were received from a range of professional organisations and individuals.

The paper sought comments on proposals for new legislation relating to hospital post-mortem examinations. It outlined specific questions which highlighted changes to the Human Tissue Act 1961 in Scotland and drew on the recommendations in the Phase 2 report of the Independent Review Group on the Retention of Organs at Post-Mortem<sup>1</sup>. The proposals also take account of parallel consideration of the law in the rest of the UK relating to human organs and tissues.

The consultation coincided with the launch of another related consultation in Scotland on the retention of organs at post-mortem examinations. This latter consultation drew on the recommendations in the Phase 3 report of the Review Group and is the subject of a separate analysis report<sup>2</sup>. Proposals for updating the Anatomy Act 1984 in the Scottish context were also subject to consultation and a further report has been completed containing an analysis of the respective responses<sup>3</sup>.

The consultation document was structured around 3 main topics:

- Who should authorise hospital post-mortem examinations?
- What safeguards should require to be in place?
- What penalties should be imposed if any person performs a hospital post-mortem without proper authorisation?

Although a relatively small volume of responses was received, these were submitted by respondents representing a wide range of different consultee sectors with NHS bodies and Trusts comprising the largest group of respondents.

The general mood of responses was one of concern over ensuring that legislative changes maintained an appropriate balance between preserving the rights of the deceased and their families, whilst permitting a reasonable and useful level of hospital post-mortem examination to continue.

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<sup>1</sup> A copy of the main documents reviewed by the Review Group and its reports are on the Review Group's website at [www.show.scot.nhs.uk/scotorgrev](http://www.show.scot.nhs.uk/scotorgrev)

<sup>2</sup> Retention of Organs at Post-Mortem: Analysis of Responses to the Consultation on the Review Group's Phase 3 Report (Scottish Executive)

<sup>3</sup> Anatomy Act 1984: Analysis of Consultation on Existing Provisions and Licensing Arrangements (Scottish Executive)

## **SUMMARY OF VIEWS EXPRESSED**

### **Who Should Authorise Hospital Post-Mortem Examinations: Public Interest (Chapter 4)**

- The majority of those who commented envisaged circumstances under which there may be sufficient “public interest” to warrant a hospital post-mortem without authorisation.
- The most commonly cited context for such practice was in the event of a possible public health risk where a quick diagnosis may be deemed necessary.
- Most commentators made suggestions for additions and amendments to the list of purposes for which a hospital post-mortem examination can be undertaken. A recurring request was for “research” to be added to the list.
- There were mixed views on whether “genetic testing” required to be added, with a few respondents considering that this may already be covered by the existing elements.

### **Who Should Authorise Hospital Post-Mortem Examinations: Children Under-16 (Chapter 5)**

- No clear consensus of views emerged in relation to the question of circumstances in which the views on authorisation of one parent should be allowed to prevail, indicating perhaps, the difficult ethical and social issues involved.
- The most commonly cited reason for proceeding with a post-mortem on the authorisation of only one parent was in situations where the results of the post-mortem may have implications for surviving family members.
- Where the hospital has been dealing with only one parent and is aware that the other parent is still alive, respondents tended to support the view that the hospital should make efforts to trace the absent parent.
- Where parents are separated or otherwise in dispute, a common view was that the parent who provided the child with the majority of care should be the first to be approached by the hospital.

### **Who Should Authorise Hospital Post-Mortem Examinations: Mature Children (Chapter 6)**

- Few comments were received relating to the issue of views expressed by mature children.
- The most common response was that the safeguards proposed for mature children were appropriate.

### **Who Should Authorise Hospital Post-Mortem Examinations: Adults (Chapter 7)**

- Respondents provided general support for the proposals relating to authorisation of post-mortems by adults.
- Most respondents appeared to be in favour of permitting orally expressed wishes of the deceased to prevail.
- Many respondents considered that where verbal authorisation was given, there should be witnesses to the decision and formal written recording of the deliberations.
- There were differences in opinion over whether surviving relatives should be able to over-turn a previously expressed wish of the deceased.
- Where a hospital holds a written note of the deceased's wishes but the relatives say that the deceased subsequently changed their mind, consultees were split on which of these wishes should prevail with no clear recommendation emerging.
- Overall, respondents liked the general structure of the proposed next of kin hierarchy although various amendments were suggested.
- A substantial body of respondents requested that "friend of long standing" be added to the list.

### **Obtaining Authorisation (Chapter 8)**

- Respondents were almost evenly split between those who considered it best not to prescribe the forms in new legislation and those who recommended formal, legal prescription of the forms.
- Reasons given by those opposing formal prescription focused on the need to retain flexibility for changes to evolve.
- Reasons for legislative prescription of the forms included the need to establish consistency and remove ambiguity.

### **Consequences of Authorising a Post-Mortem Examination (Chapter 9)**

- The majority of those who commented advocated making the status of organs, tissue blocks and slides beyond doubt in legislation.
- The overwhelming majority of commentators were in favour of a separate authorisation in respect of research.
- On balance, respondents were in agreement with the approach set out in the consultation paper regarding honouring a deceased's wishes against disclosure of post-mortem results.
- However, one recurring view was that disclosure of details should be permitted in cases where the results of the post-mortem have implications for living relatives.

### **Miscellaneous Issues (Chapter 10)**

- Of the minority of respondents who commented, all reported the triggers of the penalties for infringement to be sufficiently clear.
- The majority view was that the penalties proposed for infringement were too harsh.

- A recurring comment was that the system of penalties should recognise the difference between deliberately flouting the rules and simple error.
- The issue of the relationship between the Anatomy Act 1984 and the Human Tissue Act 1961 received very little comment.
- There were mixed views on whether the two Acts should be united and replaced by a unified Act, or whether the link between them should be broken or overlaps rationalised.

## CHAPTER 1: BACKGROUND TO THE CONSULTATION

### THE CONSULTATION

The consultation on the legislation relating to hospital post-mortem examinations was launched by the Health Minister on 24 November 2003. Over 100 copies of the consultation paper were distributed to a wide range of people and organisations in the public, private and voluntary sectors<sup>4</sup>.

The paper sought comments on proposals for new legislation relating to hospital post-mortem examinations. It outlined specific questions which highlighted changes to the Human Tissue Act 1961 in Scotland and drew on the recommendations in the Phase 2 report of the Independent Review Group on the Retention of Organs at Post-Mortem<sup>5</sup>.

The consultation coincided with the launch of another related consultation on the retention of organs at post-mortem examinations. This latter consultation drew on the recommendations in the Phase 3 report of the Review Group and is the subject of a separate analysis report<sup>6</sup>. Proposals for updating the Anatomy Act 1984 in the Scottish context were also subject to consultation and a further report has been completed containing an analysis of the respective responses<sup>7</sup>.

The proposals for changes to the legislation relating to hospital post-mortem examinations take account of parallel consideration of the law in the rest of the UK relating to human organs and tissue in view of the recognised need to ensure broad consistency of approach in relation to such a sensitive subject<sup>8</sup>.

The initial consultation period ran from 24 November 2003 until 27 February 2004 although a small number of responses were received after this date and have been included in this analysis. A press release helped publicise the consultation paper which was made available on the respective websites of the Review Group and the Scottish Executive. In announcing the consultation the Minister said:

*“I am pleased to announce that Scottish cabinet has agreed to the publication of a consultation on legislative proposals for hospital post-mortem examinations.*

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<sup>4</sup> A copy of the consultation paper is at [www.scotland.gov.uk/consultations/health/legislationpm.pdf](http://www.scotland.gov.uk/consultations/health/legislationpm.pdf)

<sup>5</sup> A copy of the main documents reviewed by the Review Group and its reports are on the Review Group’s website at [www.show.scot.nhs.uk/scotorgrev](http://www.show.scot.nhs.uk/scotorgrev)

<sup>6</sup> Retention of Organs at Post-Mortem: Analysis of Responses to the Consultation on the Review Group’s Phase 3 Report (Scottish Executive)

<sup>7</sup> Anatomy Act 1984: Analysis of Consultation on Existing Provisions and Licensing Arrangements (Scottish Executive)

<sup>8</sup> Broad details of the legislation which is proposed for the rest of the UK can be found at [www.doh.gov.uk/tissue](http://www.doh.gov.uk/tissue)

*The fundamental objection of families concerning past practice was the failure to involve them in decisions about their dead child. Many parents clearly feel the need to continue to protect the child after death, and for them past post-mortem practice was seen as a betrayal of the protective role.*

*One of the main aims of the new proposed legislation must be to place the sense of control in the hands of the parents when the question arises of a hospital post-mortem examination on a baby or young child”*

The consultation paper highlighted specific issues on which views were invited. These were:

- Who should authorise hospital post-mortem examinations?
- What safeguards should require to be in place?
- What penalties should be imposed if any person performs a hospital post-mortem without proper authorisation?

Altogether 29 responses to the consultation were received and have been included in this analysis of responses<sup>9</sup>. The responses will inform the preparation of advice to Ministers on the comments received on the proposal to change the Human Tissue Act 1961 in Scotland.

## **CONTEXT**

The consultation arose from the recommendations made by the Review Group on the Retention of Organs at Post-Mortem. Further context is provided by the review of relevant legislation elsewhere in the UK and the desire to maintain a general consistency in approach across jurisdictions. The current legislation governing hospital post-mortem examinations is the Human Tissue Act 1961. The need has been identified for updating the law to meet modern requirements and expectations. The Review Group undertook the ground work for a revised legislative framework and the consultation seeks views on the Executive’s proposals which resulted.

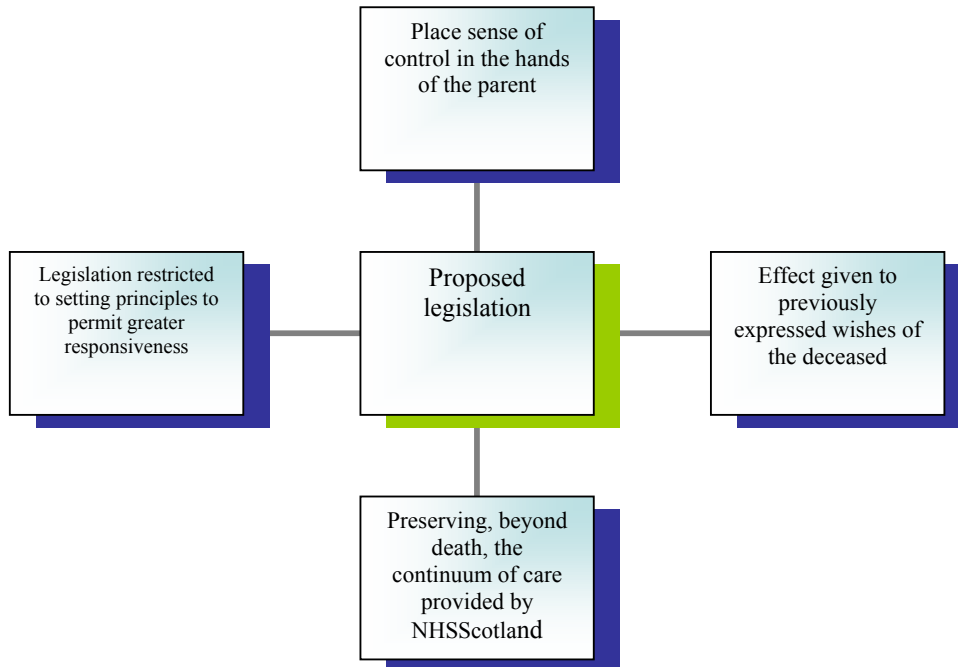
In analysing the responses to the consultation it has been important to bear in mind the principles which underpinned the development of proposed legislation. These are displayed overleaf in Figure 1.

In addition to these principles, the framing of the proposals reflects current, broader concerns relating to aspects of health care provision in the 21<sup>st</sup> Century. For example, the proposal to replace the notion of “consent” with one of “authorisation” is consistent with the preservation of the privacy and intimacy of the family unit.

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<sup>9</sup> A list of respondents is in Annex 1.

**Figure 1: Principles underpinning proposed legislative changes to Human Tissue Act 1961**



The shift in language also promotes the modern construct of patients and carers as equal partners in health care decisions and, it is proposed, will assist in restoring public confidence in the hospital post-mortem examination process.

Full written responses to the consultation have been made publicly available by the Review Group unless the respondent has specifically requested otherwise.

**The remainder of the report presents the “story” of the consultation, - the consultation process (Chapter 2), the approach to analysis of responses (Chapter 3), and the findings of the analysis (Chapters 4-10).**

## **CHAPTER 2: THE CONSULTATION PROCESS**

### **TIMING OF CONSULTATION**

The consultation became “live” on 24 November 2003 and closed officially on 27 February 2004 (although a few responses were received after this date and have been included in this analysis). The scale of the consultation was wide in terms of the range of bodies consulted, but relatively small-scale in terms of the number of responses received. Consultees included organisations in the public, private and voluntary sectors. Staff in the Health Planning and Quality Division of the Scottish Executive’s Health Department supported the exercise.

### **NATURE OF CONSULTATION**

The consultation paper comprised a 12 page document<sup>10</sup> containing specific questions which highlighted the proposed changes to the Human Tissue Act 1961. It posed 14 formal questions which sought views on the 3 key areas of:

- Who should authorise hospital post-mortem examinations?
- What safeguards should require to be in place?
- What penalties should be imposed if any person performs a hospital post-mortem without proper authorisation?

Consultees were invited to respond to the questions on these areas and also to feel free to comment on whichever aspects of the paper they wished.

### **DISTRIBUTION AND ADVERTISING OF CONSULTATION DOCUMENT**

To launch the consultation over 100 copies of the consultation paper were distributed to a wide range of people and organisations in the public, private and voluntary sectors.<sup>11</sup> Further copies were sent out on request. Consultees were invited to share the invitation to comment with others and the consultation was advertised on both the Scottish Executive and the Review Group’s websites.

### **WHO WERE THE RESPONDENTS?**

The full list of the 29 respondents is documented in Annex 1. Respondents could be grouped into broad categories as shown in Table 1.

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<sup>10</sup> See [www.scotland.gov.uk/consultations/health/legislationpm.pdf](http://www.scotland.gov.uk/consultations/health/legislationpm.pdf)

<sup>11</sup> See Annex 2 for list of consultees.

**Table 1: Respondents by Category**

<b>Respondent Category</b>	<b>No.</b>	<b>% of total</b>
NHS Body/Trust	7	24.1
Educational Body	5	17.2
Professional Representative Group	5	17.2
Academic	4	13.7
Professional Individual Response	3	10.3
Campaign Group	1	3.4
Advisory Committee	1	3.4
Research Council	1	3.4
Private Sector	1	3.4
Faith Group	1	3.4
<b>Total</b>	<b>29</b>	<b>100</b>

NB Percentages may not add exactly to 100% due to rounding

Although the consultation attracted only 29 responses, the respondents represented 10 different consultee sectors. The largest group of respondents comprised various NHS bodies and trusts (24% of total). Educational bodies and professional representative groups respectively formed the next largest categories of respondent.

### **Gaps in Respondent Type**

A scan of the consultee list along with a review of the respondent organisations revealed one particular gap in respondent as being the voice of representative minority ethnic organisations. One faith group responded to the consultation but many other viewpoints may also have been of relevance. This latter observation is consistent with respondent gaps noted in other similar consultation exercises.

### **Naming Respondents**

After discussion with the client consultation team, the convention adopted for this consultation has been to preserve anonymity of individual respondents and organisations by attributing their comments and quotes to their unique reference number combined with an abbreviation to represent the grouped respondent category to which they fitted. In this way, individual requests for anonymity are met and a further depth is added to the analysis by providing some contextual information about the respondent type. The terms used to describe the different category of respondent are as follows:

NHS Body or Trust	NHS
Educational Body	Educ
Professional Representative Group	Prof Rep
Professional Individual Response	Prof Individ
Campaign Group	Cam
Advisory Committee	Ad Com
Research Council	RC
Private Sector	Priv
Faith Group	Faith

## **NATURE OF RESPONSES**

The structure of the consultation document provided a significant steer in promoting a relatively consistent form of response. The document's format of relevant background followed by question for each topic of interest helped considerably in facilitating a consistency in response structure. Respondents chose which topics to respond to. Their responses ranged from one paragraph submissions to relatively long arguments documented over several pages. The general mood of responses was one of concern over ensuring that legislative changes maintained an appropriate balance between preserving the rights of the deceased and their families, whilst permitting a reasonable and useful level of hospital post-mortem examination to continue.

## **REFLECTIONS ON THE CONSULTATION PROCESS**

### **The Research View**

The consultation attracted a relatively small volume of responses but represented a wide range of respondent categories. Responses tended to follow closely the ordering of topics outlined in the consultation document which greatly facilitated the task of collating relevant views and analysing them in a systematic fashion. The consultation document appeared to be comprehensive with few additional themes emerging in the consultation process.

### **The Respondents' View**

A few respondents commented in general terms on the consultation paper and exercise. A selection of the positive comments follows:

*“most comprehensive document”* (4 NHS)

*“the proposed changes would bring much needed clarification and are welcome”* (6 Educ)

*“for the most part the approach is clear and sensible”* (18 Ad Com)

However, a few respondents expressed criticism of the consultation paper and exercise. One respondent considered the paper to be, *“at times a little difficult to follow”* (10 NHS). Another expressed disappointment that consultation was still taking place some 3 years since the publication of the Review Group's Phase 1 Report and 2 years since the, *“so called final report”*, was published (2 Acad).

A recurring view was that there appeared to be some uncertainty amongst professionals concerning hospital post-mortems which had, of late, had a negative impact on the level of post-mortems carried out. Some respondents considered that proposals to strengthen the rights of the public, coupled with more stringent penalties for infringement of

regulations, would likely lead to a further decline in the numbers of examinations proceeding.

## CHAPTER 3: APPROACH TO ANALYSIS

One of the challenges for any analysis of consultation responses is handling, in a systematic manner, any detailed free text material submitted by respondents. As previously stated, the responses to this consultation were relatively straightforward to assimilate for analysis as in general they followed the consultation paper structure in terms of their ordering of views. A comprehensive electronic framework for identifying and recording relevant comments from respondents was developed and a number of ground-rules established to ensure responses were prepared for analysis in a consistent and sensible fashion.

### ANALYTICAL FRAMEWORK

An electronic Excel database was used to store and assist analysis of the responses. This database enables the storage of either free text or numerical data in a systematic manner whilst providing the flexibility for framework amendments should these be required as the work progresses.

The fields used to record the material were based largely on the topics set out in the consultation paper. Once responses had been examined, a small number of additional fields were added to accommodate the further themes or sub-themes which arose. The result was a comprehensive list of fields which formed the headings for the consultation database of responses.

### GROUND-RULES

#### Quantitative Material

Although much of the analysis was based on descriptive free text, a limited amount of scope for quantitative analysis did exist and was exploited. Generally, this involved approximate counts of the numbers of respondents who commented on particular topics and, within these groups, the numbers of respondents holding particular views. However, because of the open nature of the consultation, which did not require people to provide a response on every issue, the approach of a few consultees in providing more general comments rather than responding to each question posed, and the way that respondents could “opt in” to their chosen response topics, **any quantification should be regarded as indicative rather than absolute.** In addition, it should be noted that **any statistics quoted here cannot be extrapolated to a wider population outwith the consultation population.**

#### Factual Accuracy

The views presented in this analysis have not been vetted in any way for factual accuracy. The opinions and comments submitted to the consultation may be based on fact or may, indeed, be based on what respondents perceive to be accurate from their perspective, but which others may interpret differently. It is important for the analysis to represent views

from all perspectives. The report may, therefore, contain analysis of responses which may be factually inaccurate, but are objective in terms of their reflection of strongly held perceptions.

**The following 7 Chapters document the substance of the analysis, presenting the main issues, arguments and other comments contained in the responses. These follow broadly the ordering of issues raised in the consultation paper.**

## **CHAPTER 4: WHO SHOULD AUTHORISE HOSPITAL POST-MORTEM EXAMINATIONS: PUBLIC INTEREST**

The specific issues raised in the consultation paper are looked at in turn below.

### **4.1 PUBLIC INTEREST REASONS FOR CARRYING OUT A HOSPITAL POST-MORTEM EXAMINATION**

#### **The consultation stated:**

The lawful undertaking of a hospital post-mortem examination is dependent, in everyday language, on getting “the consent” of the family concerned. The Review Group report pointed out, however, (paragraph 11) that there are technical reasons why the idea of ‘consent’ is inappropriate in the context of a post-mortem examination on a child, and expressed its reluctance (paragraph 12) to propose law reform based on wording which is inappropriate. It therefore sought an alternative concept, and strongly advocated the use of the word ‘authorisation’. This term is based on a recognition of the intimate bond between parents and children, the privacy of the family unit, and the right to prevent interference by third parties with the intimacy of the family relationship.

The use of the expression ‘authorisation’ recognises the role which parents must be given in making decisions about the way their children should be dealt with after death, as in life (paragraph 17 of report). Granting ‘authorisation’ also suggests an active decision taken by someone in a recognised position of power, whereas ‘consent’ implies a passive acceptance of something being proposed by someone else. This is therefore in keeping with the general move towards making patients and carers equal partners in health care decisions. A further consideration also has significant implications in the wider post-mortem examination context. ‘Consent’, to be valid in law, is generally expected to follow the provision of information, but many people, parents in particular, do not want to be given details about organ removal, retention and use. Since ‘authorisation’ is based on a power to make decisions, it can be given in the absence of any information being provided (paragraphs 17 and 44 of report).

The proposed legislation will therefore be based on ‘authorisation’, rather than ‘consent’ or ‘informed consent’ proposed for the rest of the UK. In order to help restore public confidence in the hospital post-mortem examination process, the effect will be that no hospital post-mortem examination can take place unless it has been authorised.

#### **The consultation asked:**

**Are there any circumstances (other than Fiscal cases) where there would be sufficient “public interest” reason for carrying out a hospital post-mortem examination in circumstances where there was no authorisation, either from the deceased or those closest to him/her in life?**

Twenty-four responses contained commentary of relevance. Of the 23 responses containing a clear view, 16 envisaged circumstances under which there may be sufficient

“public interest” to warrant a hospital post-mortem examination without authorisation from the deceased or those closest to the deceased.

The most commonly cited context for such practice was in the event of a possible public health risk where a quick diagnosis may be deemed necessary. The diagnosis of diseases such as CJD, AIDS and new types of neurodegenerative diseases was quoted in this respect (3 Acad) as was the possibility of toxin exposure (19 Educ).

A few respondents considered such practice permissible only where a health risk exists *and* no surviving relatives of the deceased can be found (9 Educ, 10 NHS, 11 NHS, 12 NHS, 17 Acad, 18 Ad Com, 22 Educ). Another view was that post-mortem should proceed only in circumstances where all efforts had been made to locate the deceased’s relatives (21 Priv).

Two other rationales for proceeding with “unauthorised” hospital post-mortems were provided. These were in cases which concerned a genetic disease which may affect others still living or may affect future generations (2 Acad, 25 NHS); and finally, where for practical reasons there was no time to contact relatives (e.g. if tissue needed to be put into liquid nitrogen as soon as possible) (1 Acad).

Those who could see no circumstances (other than Fiscal cases) where there would be sufficient “public interest” to proceed with an “unauthorised” hospital post-mortem represented a variety of consultee sectors (6 Educ, 13 NHS, 14 Educ, 16 Prof Indiv, 26 Cam, 28 Faith, 29 Prof Rep).

## 4.2 PURPOSES OF THE HOSPITAL POST-MORTEM EXAMINATION

### **The consultation stated:**

The new legislation should make clear the purposes for which a hospital post-mortem examination can be undertaken. These are:

- Determining the cause of death;
- Investigating the effect of the medical treatment (including the efficacy of drug treatment) of the deceased person;
- Obtaining information relevant to the health of someone still living;
- Education or training of those engaged in, or proposing to engage in, the care or treatment of patients

These purposes are consistent with the legislation proposed for the rest of the UK and are distinct from an anatomical examination conducted under the Anatomy Act 1984.

### **The consultation asked:**

**Is the list sufficiently comprehensive, or are there any other purposes requiring a hospital post-mortem examination which should be included in the legislation?  
Does any special provision need to be made in respect of genetic information?**

Twenty-three responses provided relevant commentary. One general comment was that perhaps the list did not need to be so prescriptive but could simply state that these are the usual reasons for post-mortem, leaving room for circumstances in the future (23 Prof Indiv). Four respondents considered that the list was sufficient as it stood (4 NHS, 12 NHS, 13 NHS, 16 Prof Indiv).

The majority of those who responded made suggestions for additions and amendments to the list. Most commonly cited was the perceived need to include “**research**” or “ethically approved research” within the list (1 Acad, 2 Acad, 9 Educ, 11 NHS, 15 Prof Rep, 18 Ad Com, 19 Educ, 22 Educ, 24 RC, 25 NHS). Specific wording was suggested by one consultee: “*furthering knowledge and understanding of the condition(s) suffered by the deceased with a view to improving treatment and prevention in the future*” (1 Acad).

Another addition suggested, that **genetic testing**, was the topic of some discussion. A few consultees considered this to be an omission from the list (5 Prof Indiv, 21 Priv). Others however, suggested that such a reason may already be covered by the third purpose listed, that of obtaining information relevant to the health of someone still living (13 NHS, 17 Acad, 24 RC, 25 NHS).

Clearly this aspect of the list was ambiguous, with one respondent stating that they required more information on what might be meant by genetic information prior to addressing the question (29 Prof Rep). Another respondent suggested clarifying the difference between genetic information required to complete the post-mortem examination and genetic information available for analysis some time in the future (18 Ad Com). A further recommendation was that perhaps it could be made explicit that information relevant to the health of someone living may include the investigation of genetic information (19 Educ).

Three respondents identified the need to refer to the role of hospital post-mortem in **auditing** (14 Educ, 17 Acad, 20 Prof Rep). Two respondents raised the need to include within the list the purpose of **investigating pre-morbid illness** (3 Acad, 18 Ad Com).

Other suggestions for broadening the list included:

- Investigation of newly diagnosed disease (7 Prof Rep)
- To ascertain the presence of other diseases which may be either unsuspected or suspected clinically and which may be either directly relevant to the death or not related to the death but of interest for other medical reasons (14 Educ)
- To establish the extent/severity of disease (20 Prof Rep)
- To provide detailed facts for later discussion with the family (20 Prof Rep)
- To inform best medical practice (18 Ad Com)
- For the purpose of gathering epidemiological data (18 Ad Com)

## **SUMMARY POINTS**

- The majority of those who commented envisaged circumstances under which there may be sufficient “public interest” to warrant a hospital post-mortem without authorisation.
- The most commonly cited context for such practice was in the event of a possible public health risk where a quick diagnosis may be deemed necessary.
- Most commentators made suggestions for additions and amendments to the list of purposes for which a hospital post-mortem examination can be undertaken. A recurring request was for “research” to be added to the list.
- There were mixed views on whether “genetic testing” required to be added, with a few respondents considering that this may already be covered by the existing elements.

## **CHAPTER 5: WHO SHOULD AUTHORISE A HOSPITAL POST-MORTEM EXAMINATION: CHILDREN UNDER-16**

The specific issues raised in the consultation paper are looked at in turn below.

### **The consultation stated:**

The legislation should state clearly that no hospital post-mortem examination in respect of a child under the age of 16 should take place unless it has been authorised by a parent or the parents of the child. The only exception would be mature children (see paragraphs 20 and 21 of the consultation document).

These provisions should also cover the case of the mature child (see paragraph 22) who has expressed no views on the subject.

The legislation needs to determine how any disputes should be dealt with which might arise in cases where more than one parent is involved in the care of the child, or where there are others who have a legitimate interest in the deceased child. The Review Group took the view that failure to agree between or amongst them on the authorisation of a hospital post-mortem examination should render it unlawful for a post-mortem examination to be undertaken. The legislative proposals for the rest of the UK suggest, consistently with the existing law relating to consent, that if one parent consents, the post-mortem examination could go ahead.

### **5.1 CIRCUMSTANCES IN WHICH VIEWS OF ONE PARENT SHOULD PREVAIL?**

#### **The consultation asked:**

**Are there any circumstances in which the views of one parent should be allowed to prevail?**

Overall, 18 responses were of relevance. It was noticeable that no clear consensus of views emerged in relation to this question, indicating perhaps the difficult ethical and social issues involved. Indeed, one consultee commented that this question was really one for society at large and perhaps family lawyers (14 Educ). Other remarks were that such considerations were of increasing significance given the current fractured nature of many families (14 Educ) and in instances in which unmarried women did not wish to reveal the identify of the father of the dead child (26 Cam, 29 Prof Rep).

Two respondents stated simply that the situation should be as for the rest of the UK with one consenting parent enough to enable a post-mortem to proceed (11 NHS, 12 NHS). However, opposing views came from 4 consultees who argued that in cases of disagreement between parents, the post-mortem should not take place (6 Educ, 13 NHS, 20 Prof Rep, 26 Cam). One comment was that even if it was permissible to proceed in the event of disagreement, the threat of stiff penalties for malpractice might provide a strong disincentive to continue (14 Educ). Another respondent urged that whatever was decided, the system should be simple to understand because of the existence of such

penalties (5 Prof Indiv). A further view was that in cases of disagreement, if one argument reflected strongly held religious beliefs, then this should take precedence (7 Prof Rep).

The most commonly cited reason for proceeding on the authorisation of only one parent was in situations where the results of the post-mortem may have implications for surviving family members (7 Prof Rep, 9 Educ, 19 Educ, 22 Educ).

Where the main carer parent has given authority for the post-mortem and reasonable efforts have been made to locate the absent parent, then according to a few consultees the post-mortem should proceed (6 Educ, 14 Educ). A further circumstance was envisaged in which one parent may be under 16 years of age, in which it was recommended that the authorisation of the older parent should prevail (21 Priv).

Some consultees considered circumstances in which the views of neither parent should be taken. These included situations where both parents were under 16, in which case staff were urged to use discretion in seeking the views of the parents' older relatives (21 Priv), and where grandparents or others had been, of late, the main carers of the dead child (17 Acad, 16 Prof Indiv, 18 Ad Com).

## **5.2 OBLIGATION ON HOSPITAL TO SEEK VIEWS OF ABSENT PARENT?**

### **The consultation asked:**

**Where the hospital has been dealing with only one parent, and is aware that the other parent is still alive, what duty, if any, should there be on the hospital to seek the views of the other parent? Should the post-mortem examination be allowed to proceed on the authorisation of the one parent? If so, should that parent be the legal guardian of the child?**

Eighteen responses contained relevant commentary.

The most commonly expressed view was that efforts should be made by the hospital to trace the absent parent, but failing this the authorisation of the carer parent should be sufficient for the post-mortem to proceed (6 Educ, 7 Prof Rep, 9 Educ, 13 NHS, 16 Prof Indiv, 20 Prof Rep, 21 Priv, 22 Educ). Some respondents highlighted that authorisation should come from the legal guardian of the child (7 Prof Rep, 9 Educ, 16 Prof Indiv, 19 Educ, 22 Educ, 29 Prof Rep). An isolated view was that the parent will normally be the legal guardian of the child but not necessarily (1 Acad).

A slightly different emphasis was provided by one respondent who considered that in the event of the present parent refusing authorisation, then the hospital should seek the opinion of the absent parent as this may overrule the first opinion (12 NHS).

A few consultees stressed that it may not be necessary to attempt to trace missing relatives if the person most closely involved in the care of the child had given authorisation to proceed (1 Acad, 11 NHS, 18 Ad Com).

Two respondents outlined the need for what they saw as clearer definitions to be adopted. In particular, clarification was required in relation to the terms “parent”, “step parent” (5 Prof Indiv) and the status of grandparent authorisation in the absence of parents (5 Prof Indiv, 14 Educ).

### **5.3 PROTOCOL WHERE PARENTS ARE IN DISPUTE**

#### **The consultation asked:**

**Where the parents are separated, or otherwise are in dispute, what effect should that have on which of them is approached to authorise the post-mortem examination?**

To some extent, this question was referred to in the responses to the previous 2 questions. However, a minority of 10 respondents appeared to have addressed the issue specifically and their views are below.

The most common view was that the parent who provided the child with the majority of care should be approached first (7 Prof Rep, 13 NHS, 17 Acad, 19 Educ, 20 Prof Rep). Several respondents commented that in an ideal situation both parents should be approached, and certainly where they provided equal child care (12 NHS, 16 Prof Indiv, 19 Educ, 20 Prof Rep).

Other remarks were that the legal guardian should be the first to be approached for authorisation (9 Educ, 16 Prof Indiv, 22 Educ) or the parent who admitted the child to hospital would be the most appropriate to approach (1 Acad).

#### **SUMMARY POINTS**

- No clear consensus of views emerged in relation to the question of circumstances in which the views on authorisation of one parent should be allowed to prevail, indicating perhaps, the difficult ethical and social issues involved.
- The most commonly cited reason for proceeding with a post-mortem on the authorisation of only one parent was in situations where the results of the post-mortem may have implications for surviving family members.
- Where the hospital has been dealing with only one parent and is aware that the other parent is still alive, respondents tended to support the view that the hospital should make efforts to trace the absent parent.
- Where parents are separated or otherwise in dispute, a common view was that the parent who provided the child with the majority of care should be the first to be approached by the hospital.

## **CHAPTER 6: WHO SHOULD AUTHORISE A HOSPITAL POST-MORTEM EXAMINATION: MATURE CHILDREN**

### **The consultation stated:**

The Review Group noted that section 2(4) of the Age of Legal Capacity (Scotland) Act 1991 provides that those under 16 may have the capacity to make legally-binding decisions about medical treatment, where, ‘in the opinion of the medical practitioner attending him, he is capable of understanding the nature and possible consequences of the procedure or the treatment’. This is re-inforced by section 15(5) of the Children (Scotland) Act 1995, which provides that a person may act as a child’s legal representative only where the child is incapable of acting on his or her own behalf. Where the child acquires capacity and is below the age of 16, the parent or guardian loses the right to act in respect of a particular transaction. This was the approach the Review Group wished to adopt: that by the age of 16 everyone is assumed to be capable of providing the necessary authority and that a child below that age who, while living, is competent to make that decision may do so.

The new legislation should therefore make clear that any views expressed by the mature child about a hospital post-mortem examination should be respected. These would be subject to the same conditions as apply to adults (paragraph 22). The adult version of the authorisation form devised by the Review Group should be used, and will contain provision for a statement by those closest to the child in life that the child had indeed expressed such a wish. Implementation of this approach would mean that the mature child’s wishes should be upheld, even in the face of objections by one or both parents, or anyone acting in *loco parentis*.

Where the mature child left no such expression of intent, the role of the parents should be the same as in relation to children under 16 as set out in paragraphs 16 – 18 of the consultation document (see paragraph 37 of Review Group report).

### **The consultation asked:**

#### **Are any further safeguards required?**

Although 16 responses were of relevance to this issue, few provided any comments of substance. The most common response was that the safeguards proposed for mature children were appropriate (11 respondees).

A few queries were raised. One consultee questioned the logic in a mature child being considered competent to authorise a post-mortem yet not competent to complete the authorisation form, this being the role of “*those closest to the child in life*” (14 Educ). Another query asked whether in circumstances where a child has consented to donate organs for transplantation, could this be taken as a wish to contribute to medical knowledge through a post-mortem against the wishes of their parents (17 Acad)? A final query asked whether the safeguards covered the giving of authorisation by the child for stillbirth or neonatal deaths (29 Prof Rep)?

Two further consultees provided additional comments. Firstly, that there might be a case for considering whether the taking of a specific sample for testing (e.g. for a genetic disorder) could be authorised by a child, even if they do not wish to have a post-mortem (19 Educ). Secondly, it was suggested that a safeguard should be in place to ensure that a doctor could not bend the will of a child due to that child feeling grateful for the work of that doctor or for any other reason (26 Cam).

#### **SUMMARY POINTS**

- Few comments were received relating to the issue of views expressed by mature children.
- The most common response was that the safeguards proposed for mature children were appropriate.

## **CHAPTER 7: WHO SHOULD AUTHORISE A HOSPITAL POST-MORTEM EXAMINATION: ADULTS**

The specific issues raised in the consultation paper are looked at in turn below.

### **7.1 VERBALLY EXPRESSED WISHES**

#### **The consultation stated:**

People over the age of 16 in Scotland are able to make decisions for themselves about medical procedures, and should therefore be able to make decisions about a hospital post-mortem examination and the subsequent use of the body, or parts of it. Respecting the autonomy of the competent individual is one of the key principles which should underpin the new legislation in Scotland. This is consistent with the approach being taken for the legislation affecting the rest of the UK. While it is at present still very unlikely that an adult will request a post-mortem examination on him or herself, the possibility should nevertheless be recognised in the legislation. The expressed wishes of the individual adult, competently made before death, should therefore take priority over the wishes of surviving relatives.

Given the centrality of respecting those wishes, it is essential that the new legislation should provide for the manner in which those wishes can be expressed. Section 1 of the 1961 Act authorises removal of body parts where the deceased has expressed a wish that his body may be used for medical education or research or for therapeutic purposes. Section 1(1) provides that such wishes can be expressed in writing at any time, and there should be a similar provision in the new legislation. It also provides that such wishes can be expressed orally in the presence of 2 or more witnesses (aged over 16) during the person's last illness. The Review Group acknowledged that it was unclear whether section 1(1) applied to post-mortem examinations, but went on in their report to assume that it did. The Review Group did not subscribe to the view that only written agreement is valid when the decision is made in the absence of a final illness (paragraph 43 of Phase 2 report). The legislation should therefore provide that a competent verbally expressed intention at any stage of adult life should be sufficient in law to permit the deceased's wishes to be fulfilled.

The Review Group noted (paragraph 42 of its report) that an approach based on the complete autonomy of the competent individual might seem to be harsh. In order to obviate or minimise any potential distress to surviving relatives, the Review Group went on to stress the importance of accompanying this approach with a campaign directed at those who may wish to make such a declaration, to encourage them to discuss their wishes freely and fully with those who will ultimately be asked about the deceased's intentions. The campaign should also emphasise the importance of recording those wishes in a readily accessible place and form.

#### **The consultation asked:**

**Is there general support for the approach set out above, especially in relation to wishes which have been expressed verbally when the person was not in their final**

**illness? If so, what would be the best mechanisms for setting out whose responsibility it should be to record the deceased's verbal wishes, and where are they to be recorded? Where the deceased recorded his or her views, whether orally or in writing, should this be regarded as any other form of advance statement to be given effect to?**

Overall, 21 responses contained commentary of relevance to these issues.

General support for the proposals was expressed by a third of those who commented. Whilst it was difficult to quantify views precisely, most respondents appeared to be in favour of permitting orally expressed wishes of the deceased to prevail (although it was not clear from most responses whether consultees were referring to wishes expressed during their final illness or prior to this). A few dissenting voices argued that only written authorisation should be acceptable (5 Prof Indiv, 11 NHS, 14 Educ) or should be established if at all possible (17 Acad). One argument for this approach was that pathologists may be most reluctant to perform post-mortems without the deceased's written authorisation (17 Acad).

The focus of most of the commentary concerned the mode of recording verbal wishes and safeguards to ensure their validity. Many respondents considered that where verbal authorisation was given there should be witnesses to the decision and formal written recording of the deliberations. It was suggested that witnesses could be a parent, guardian or close friend (9 Educ, 22 Educ), or perhaps a lawyer (9 Educ), a physician (12 NHS) or someone not personally concerned with the patient or the hospital (26 Cam). Suggestions for recording the decision included GP records (3 Acad, 5 Prof Indiv), and/or hospital records (18 Ad Com, 9 Educ, 22 Educ).

Some stressed the importance of recording decisions on formal, standardised documents (29 Prof Rep, 19 Educ) with the authorisation entered onto a single, up-to-date database (3 Acad) or held in a readily accessible place and form (3 Acad). Another suggestion was for carrying the authorisation on some form of donor card which could be attached to GP notes and hospital records (3 Acad, 5 Prof Indiv). It was considered by one respondent that the onus should rest with patients to ensure that their wishes are recorded clearly (20 Prof Rep).

Differences emerged between those who urged that any previously expressed wishes of the deceased should be respected (7 Prof Rep, 28 Faith) and the view that there may be a case for surviving relatives to over-turn this decision (11 NHS - perhaps where the deceased believed he/she was suffering from an inherited or acquired disorder which might have implications for surviving family members and had expressed the wish that a post-mortem examination should not be performed).

There was some support for the idea of educating the public on the issues via a publicity campaign. This was envisaged as being targeted at people from an early age and accompanied by accessible methods by which decisions could be recorded (NI cards, ID cards, driving licence (26 Cam)). However, one view was that even if supported by

extensive publicity campaigns it was unlikely that open discussions amongst relatives would take place (14 Educ).

Finally, one respondent, though expressing general support for the proposals in principle, considered that there may be real practical difficulties in their implementation (23 Prof Indiv). They envisaged the necessity of a central register, checked by a dedicated person within a Trust or a Bereavement Officer, but thought that wishes may still be overlooked, for example if the deceased died on holiday or in another health region.

## 7.2 CHANGES OF MIND

### **The consultation stated:**

The current legal requirement in section 1(1) (which relates to the authority to remove body parts and not to post-mortem examinations) to make reasonable inquiries as to whether or not these wishes have been withdrawn should apply to authority for post-mortem examinations. This information should be sought from whoever would have the power to authorise a post-mortem examination.

### **The consultation asked:**

**What provision should be made if the hospital holds a written note of the deceased's wishes but the relatives say that the deceased subsequently changed his or her mind? Are the relatives to be asked to provide anything to support their statement, or is an assertion on their part to be considered sufficient?**

Twenty responses contained commentary of relevance to these issues.

In general, respondents acknowledged that the issues raised by the situation described were "difficult" (3 Acad) and "sensitive" (16 Prof Indiv) to address. And indeed consultees were split on how best to tackle such a situation, with no clear recommendation emerging.

Two commentators remarked that each case was different and that there should be room allowed for hospital discretion in the light of the circumstances (1 Acad, 20 Prof Rep).

Many consultees felt that any written expression of the deceased's wishes should take precedence over relatives' orally expressed wishes if the former had not provided any further indication of a change of view (3 Acad, 5 Prof Indiv, 18 Ad Com, 21 Priv, 22 Educ, 26 Cam).

Another opinion was that the expression of the deceased should prevail except where relatives could provide firm evidence of a change of view of the deceased (such as their oral wish witnessed by multiple people or hospital staff) (2 Acad, 8 NHS, 9 Educ, 12 NHS, 17 Acad, 19 Educ).

Contrasting with these views were those of consultees who recommended that the balance should lie in favour of respecting the relatives' wishes (11 NHS, 13 NHS, 23 Prof

Indiv, 29 Prof Rep). One comment was that the views of the living should be able to override the wishes of the dead, particularly as it is the living who have an interest in knowing why the deceased has died, not the deceased (11 NHS).

### 7.3 NEXT OF KIN “HIERARCHY”

#### **The consultation stated:**

The new legislation should make clear that where the deceased was not known to have expressed any views, or had not nominated a representative, it would be the “next of kin” who would be able to authorise a hospital post-mortem examination.

It is proposed that the new legislation should define the “next of kin” by means of a hierarchy. It is proposed to follow that set out in section 254 of the Mental Health (Care & Treatment) (Scotland) Act 2003, which is as follows:

- (a) spouse, including registered civil partner
- (b) partner (including same-sex and unmarried couples)
- (c) child
- (d) parent
- (e) brother or sister
- (f) grandparent
- (g) grandchild
- (h) uncle/aunt
- (i) niece/nephew
- (j) person who has been living with the adult for 5 years or more

The “next of kin” would be the person whose relationship to the deceased was highest in the list above. This is broadly equivalent to the list proposed in the legislation for the rest of the UK, except that the list in that legislation included “friend of long standing” as the final category.

#### **The consultation asked:**

**Is there general support for the approach set out above? How workable is it? Are there any additions or subtractions which should be made to the list? Are there any changes which should be made to the order? Should “friend of long standing” be included? If so, how long should the friendship have lasted?**

Twenty-two responses provided commentary of relevance. Overall, consultees liked the general structure of the list and the approach outlined, with one comment that it would be beneficial to build in the flexibility to amend the list as appropriate (perhaps by subordinate legislation (5 Prof Indiv)).

#### ***How workable is the list?***

In terms of practicalities of its working, a few issues were raised. These were:

- On occasions, the hierarchy will not work as a particular person on the list will not be available (3 Acad)
- What would happen if the person who had been the main carer for the deceased was lower down the list than others? (11 NHS)
- The list should provide guidance only as, for example, blood relatives may have more pressing reasons for wishing a post-mortem than a spouse (17 Acad)
- What if a person lower down on the list urgently needed information from a post-mortem for their own health? (20 Prof Rep)
- What if a couple were separated but not divorced? (26 Cam)

***Are there any additions or subtractions which should be made?***

A number of more detailed points were made relating to aspects of the list. These comprised:

- Need sharper definition of “partner” (11 NHS, 14 Educ, 29 Prof Rep). For example, what about former partners, divorcees?
- Add “long standing” to (b) (12 NHS)
- It should be made clear that “child” refers to the nature of the relationship and not the age of the person (10 NHS)
- What about half-siblings? (14 Educ)
- Extend “parent” to include foster parents, legal guardians (21 Priv)
- Switch the relative positions of grandparent and grandchildren where the latter are over 16 (21 Priv)
- Switch the relative positions of uncle/aunt and niece/nephew where the latter are over 16 (21 Priv)
- Add “cousin” to the list (24 RC)

***Should friend of long standing be included?***

Eleven respondents articulated their view that “friend of long standing” should be added to the list. Two consultees commented that this brought the added benefit of being consistent with UK legislation (7 Prof Rep, 20 Prof Rep).

***How long should the friendship have lasted?***

There were mixed views expressed. It was commented that defining a set time was difficult (24 RC) and that perhaps no time limit should be specified (18 Ad Com). Of the 4 consultees who recommended a time limit, 3 considered 5 years or more to be appropriate (8 NHS, 13 NHS, 17 Acad), whilst the remaining view was for longer than one year (19 Educ).

**SUMMARY POINTS**

- Respondents provided general support for the proposals relating to authorisation of post-mortems by adults.
- Most respondents appeared to be in favour of permitting orally expressed wishes of the deceased to prevail.

- Many respondents considered that where verbal authorisation was given, there should be witnesses to the decision and formal written recording of the deliberations.
- There were differences in opinion over whether surviving relatives should be able to over-turn a previously expressed wish of the deceased.
- Where a hospital holds a written note of the deceased's wishes but the relatives say that the deceased subsequently changed their mind, consultees were split on which of these wishes should prevail with no clear recommendation emerging.
- Overall, respondents liked the general structure of the proposed next of kin hierarchy although various amendments were suggested.
- A substantial body of respondents requested that "friend of long standing" be added to the list.

## CHAPTER 8: OBTAINING AUTHORISATION

### **The consultation stated:**

The vehicle for obtaining authorisation will be the standard authorisation forms which the Review Group has been developing as part of its third phase of activity. It is not intended to refer to these forms on the face of the primary legislation, since that would make it too cumbersome to change them.

### **The consultation asked:**

#### **Should the forms be prescribed in Regulations made under the new legislation?**

Twenty two responses were of relevance. Of these, 12 considered that on balance it would be best not to prescribe the forms in new legislation. The remaining 10 consultees recommended the formal, legal prescription of forms.

Reasons given by those opposing formal prescription of the forms focused on the need to retain flexibility for changes to evolve (17 Acad, 24 RC). However, there was a concern that even if the forms were not prescribed under the new legislation there should still be an emphasis on standardisation of detail and authorisation practice.

Reasons given by those in favour of legislative prescription of the forms included the need to establish national consistency (2 Acad, 7 Prof Rep, 9 Educ, 22 Educ) and to remove any ambiguity over authorisation (14 Educ). One idea was that prescription could cover the minimum information and authorisation required but not the appearance of the forms which could be left to local discretion depending on circumstances (19 Educ).

A small number of other views were expressed. One concerned prescribing the forms but not in primary legislation (18 Ad Com). Another suggested incorporating the forms into Codes of Practice which could be subject to periodic review (10 NHS). A final recommendation was for use of National Standards to provide benchmarks for the forms, again, subject to regular review (23 Prof Indiv).

### **SUMMARY POINTS**

- Respondents were almost evenly split between those who considered it best not to prescribe the forms in new legislation and those who recommended formal, legal prescription of the forms.
- Reasons given by those opposing formal prescription focused on the need to retain flexibility for changes to evolve.
- Reasons for legislative prescription of the forms included the need to establish consistency and remove ambiguity.

## **CHAPTER 9: CONSEQUENCES OF AUTHORISING A POST-MORTEM EXAMINATION**

The specific issues raised in the consultation paper are taken in turn below.

### **9.1 AUTHORISATION SUFFICIENT FOR RETENTION OF BLOCKS AND SLIDES?**

#### **The consultation stated:**

As the Review Group points out, the creation of slides for examination under the microscope represents the logical end of a thorough post-mortem examination, and provide a permanent record of it. The slides are generally stored indefinitely as part of the patient's medical record. As noted, the standard authorisation forms are being drafted on the basis that authorisation carries with it the understanding that the carrying out of a full post-mortem examination involves keeping small tissue samples and slides, and may involve taking photographs, X-rays and scans, all of which would be kept as part of the medical record and used for medical education, training, audit and research.

The Review Group proposed in its Phase 2 report that the new legislation should contain a provision putting beyond doubt that tissue blocks and slides retained from a properly-authorized post-mortem examination form part of the deceased's medical record. It also wanted the new legislation to provide that if proper authorisation had been obtained, interest in the blocks and slides should pass to the hospital authorities, who may retain and use them for purposes of medical education, training, audit and research. That use would be subject to the general rules regarding confidentiality and proper ethical approval of any proposed research.

#### **The consultation asked:**

**Is the authorising of the post-mortem examination sufficient in itself to allow for the retention of any organs, tissue blocks and slides as part of the medical record, or would it be better if the status of such material were to be put beyond doubt in the legislation? Should there be separate authorisation in respect of research?**

#### ***Authorisation of post-mortem examination sufficient***

Nineteen responses appeared to contain comments of relevance.

It was difficult to distinguish in many of the responses the precise views of the consultees regarding the separate issues of using legislation to put authorisation beyond doubt, or accepting the authorisation of the post-mortem examination as an authorisation for the retention of any organs, tissue blocks and slides. Several, urged that the position must be made clear and put beyond doubt, but it was not clear whether they felt that this could be done without legislation.

Overall, 14 respondents advocated making the status of the material beyond doubt. Of the others, it appeared that the respondents considered that the authorisation form could specify the status of material (3 Acad, 9 Educ, 12 NHS, 20 Prof Rep), perhaps by including tick boxes relating to each purpose for which a post-mortem examination may be undertaken (5 Prof Indiv).

***Should there be separate authorisation in respect of research?***

Of the 17 responses where a clear recommendation could be identified, the overwhelming majority (13) was in favour of separate authorisation in respect of research. Where reasons were provided in support of the view expressed, these included allaying people's fears over "secret" research being undertaken without their knowledge (14 Educ) and to respect particular faiths where such practice would not be permitted (28 Faith). One suggestion was that the request for specific authorisation could be accompanied by a statement of benefits which could accrue from future research (24 RC).

Of the four respondees (1 Acad, 11 NHS, 19 Educ, 20 Prof Rep) who recommended that no separate authorisation for research should be sought, a reason provided by one was that highlighting research may put people off authorising a post-mortem at all (20 Prof Rep). Another consultee urged that authorisation should be supported by reassurances that any future research will be subject to clearance through appropriate ethical procedures (19 Educ).

## **9.2 RIGHTS OF ACCESS TO FINDINGS OF HOSPITAL POST-MORTEM**

**The consultation stated:**

There appears to be no automatic right of access to the findings of a hospital post-mortem examination on the part of those closest to the adult deceased, because issues of confidentiality appear to survive death. The NHS Quality Improvement Scotland standards presume (Standard 1) that the information in a post-mortem examination report must be made available promptly so that discussion can take place as soon as possible after death with clinical staff involved in the case, and with the relatives. The Review Group was concerned about the situation where an adult deceased had expressed a wish that his clinical status should not be disclosed after death, and it is proposed that the legislation should provide for that wish to be honoured. That provision should also apply to the mature child.

**The consultation asked:**

**Is there general support for this approach, which is consistent with the fundamental principle that the wishes of the competent adult should be respected after death?**

Twenty one responses were of relevance to this issue which one consultee described as one of the most contentious and difficult of the consultation (18 Ad Com). Two other respondents outlined what they saw as difficulties: one understood that relatives already have legal access to case records (3 Acad); and another saw a tension between the right for confidentiality, and the rights of those family members for whom there may be significant implications arising from the post-mortem (13 NHS).

On balance, respondents were in agreement with the approach set out in the consultation paper. Thirteen consultees recommended that where the deceased had expressed the right for confidentiality then that should be honoured. This was seen as being consistent with other aspects of medical practice (2 Acad).

A suggestion was that relatives should be informed of the deceased's request for confidentiality at the time of authorising the post-mortem (5 Prof Indiv). Another comment was that respecting confidentiality should not preclude the discussion of a case amongst professionals (18 Ad Com).

One recurring view was that disclosure of details should be permitted in cases where the results of the post-mortem have implications for living relatives (8 NHS, 11 NHS, 19 Educ). Another point made was that unless the deceased had specifically requested confidentiality, then the default should be in favour of disclosure of information as withholding it may reinforce the public perception that there was something to hide (6 Educ).

Finally, 2 respondents suggested that the best approach would be for the decision to be at the hands of clinical discretion (17 Acad) or be up to an independent authority to judge (26 Cam).

#### **SUMMARY POINTS**

- The majority of those who commented advocated making the status of organs, tissue blocks and slides beyond doubt in legislation.
- The overwhelming majority of commentators were in favour of a separate authorisation in respect of research.
- On balance, respondents were in agreement with the approach set out in the consultation paper regarding honouring a deceased's wishes against disclosure of post-mortem results.
- However, one recurring view was that disclosure of details should be permitted in cases where the results of the post-mortem have implications for living relatives.

## CHAPTER 10: MISCELLANEOUS ISSUES

The remaining issues raised in the consultation paper are taken in turn below.

### 10.1 PENALTIES FOR INFRINGEMENT

#### **The consultation stated:**

Any person who performs, or induces the performance of a hospital post-mortem examination without the relevant authorisation shall be guilty of an offence, and shall be liable to a penalty, which would be either imprisonment, or a fine, or both.

Any person who performs, or induces the performance of a hospital post-mortem examination on an adult or a mature child who was known to have expressed a wish that no such post-mortem examination should be undertaken shall be guilty of an offence, and shall be liable to a penalty, which would be either imprisonment, or a fine, or both.

Any person who retains without appropriate authorisation human material obtained at a hospital post-mortem examination shall be guilty of an offence and shall be liable to a penalty, which would be either imprisonment, or a fine, or both.

Any person failing to adhere to the terms of any authorisation, whether relating to the performance of a post-mortem examination or the retention of organs, tissue blocks or slides, shall be guilty of an offence and shall be liable to a penalty, which would be either imprisonment, or a fine, or both.

The legislation proposed for the rest of the UK will contain penalties for equivalent actions, and the intention would be to make sure that the level of penalty was consistent across the UK. In Scotland, it would be expected that allegations of contraventions of these penalty provisions would be reported to the police for investigation with a view to submitting a report to the procurator fiscal if appropriate.

#### **The consultation asked:**

**Are the triggers of the penalties sufficiently clear? Views on the severity of the same penalty in each case would be welcomed. Should the level of penalty be the same in each case, or are there grounds for distinguishing them and therefore making any of them attract a severer penalty?**

Twenty-three responses were of relevance to these issues.

One general view to emerge was that a balance needed to be struck between dealing appropriately with misconduct, whilst not discouraging professionals from undertaking post-mortem examinations.

Of the 7 consultees who responded specifically on the triggers, all reported them to be sufficiently clear. There were, however, mixed views expressed on the severity of the penalties proposed. The majority view was that the penalties were too harsh. Up to three years imprisonment was seen as excessive (9 Educ, 22 Educ) with the penalties and threat

of criminal conviction too onerous for minor infringements (14 Educ, 13 NHS). For some, the General Medical Council was a more appropriate route for infringers (3 Acad, 18 Ad Com, 11 NHS). One comment was that penalties were not desirable but were required politically (25 NHS). However, in contrast, 2 consultees considered the proposed penalties to be adequate (12 NHS, 16 Prof Indiv), with another attracted to maintaining consistency with the rest of the UK (5 Prof Indiv). Again, an opposing view was that such penalties created an inconsistency with the rest of the healthcare profession (14 Educ).

Some respondents provided relatively pragmatic recommendations on shaping the penal framework to accommodate different levels of infringement. A recurring comment was that the system should recognise the difference between deliberately flouting rules and simple error (5 Prof Indiv, 23 Prof Indiv, 27 Prof Rep). Others envisaged the need for gradations of penalties to take into account mitigating factors such as acting in good faith (17 Acad), where the professional had reason to believe they could proceed (20 Prof Rep), or where the infringement was made by a trainee whilst under the supervision of a consultant (17 Acad). Other comments were that levels of penalty should reflect the type of tissue involved, with unauthorised post-mortems and handling of whole organs attracting stiffer penalties than infringements associated with blocks and slides (8 NHS, 13 NHS). In the light of such considerations, one comment was that the system could become too cumbersome to administer with detailed checking of authorisations required at each stage (19 Educ).

Detailed changes to wording of the proposals were advocated by several consultees particularly in relation to paragraph 41 of the consultation document (second whole paragraph in shaded section above). Comments were:

- As the wording stands the pathologist could be found guilty even if he knows that the deceased had changed their mind on opposing the post-mortem (1 Acad)
- Clause 41 to change to "...or a mature child who was known to him or her to have expressed ..." (13 NHS)
- Para 41 is too vaguely phrased – could doctors be prosecuted for not acting on attributed verbal wishes? (14 Educ)
- Para 41 – not sure what is meant by “induces the performance of a hospital post-mortem” - the wording is too simplistic (19 Educ)
- Concerned over the drafting of para 41 in relation to the level of knowledge which should be attributed to the person performing the examination. Criminal proceedings should only follow where the person conducting the post-mortem know they were proceeding without proper authorisation (27 Prof Rep)
- Para 43 is too vague (27 Prof Rep)
- Para 40 – status of “relevant” authorisation needs to be defined (14 Educ)

One final comment was that in addition to holding professionals to account, relatives should also face penalties if they supply false information for the authorisation form (2 Acad).

## 10.2 LINKS BETWEEN RELATED LEGISLATION

### **The consultation stated:**

As noted above (paragraph 1), a separate consultation exercise is being carried out in respect of the Anatomy Act 1984. That covers both the effect on current arrangements in Scotland of the changes proposed in the new legislation affecting the rest of the UK and a widening of the scope of the Act to permit the training of surgeons in interventional skills and procedures. Under the proposals for the rest of the UK, the 1984 Act and the Human Tissue Act 1961 would be repealed and replaced by a single legislative and regulatory regime.

There is, however, a specific question about the relationship between the Anatomy Act 1984 and the Human Tissue Act 1961. Section 1(5) of the 1984 Act states ‘If part of a body is authorised under section 1 of the Human Tissue Act 1961 to be removed for purposes of medical education or research, that section (and not this Act) applies to the removal and use of the part, even if the education or research consists of or involved anatomical examination...’. The consultation process should help to rationalise the relationship between the 2 pieces of legislation.

### **The consultation asked:**

**If this link between the 2 areas of existing legislation is to continue in the new legislation, how can the various components best be rationalised?**

This issue attracted very little comment with only 10 consultees addressing the question. Four of these consultees considered that the consultation exercises and revisions to the legislation provided an opportunity to break this link between the Acts (1 Acad, 9 Educ, 22 Educ, 23 Prof Indiv). Two respondents maintained that the 2 separate Acts should be united and replaced with a consolidated Act (5 Prof Indiv, 13 NHS). The remaining commentators envisaged the Acts kept separate but the link rationalised so that studies on the same specimen of post-mortem tissue is not covered by different legislation (24 RC), and pre-consent for one does not preclude donation after death for the other (17 Acad). One suggestion was for relevant clauses in each Act to refer to the others respectively (29 Prof Rep).

The consideration of the future respective legal positions of Scotland and England and Wales prompted a few comments relating to cross-border consistency. Some support was provided for the development of different legislation, in particular the proposals in Scotland for the use of the term “authorisation” and the different provisions for dealing with organ transplantation (6 Educ, 18 Ad Com). However, a common view was that it was preferable to maintain a UK wide consistency wherever possible to prevent difficulties arising, say, when relatives died in hospitals across the border or where professionals wished to take up posts or training in other jurisdictions (10 NHS, 11 NHS, 20 Prof Rep, 23 Prof Indiv, 24 RC).

## **SUMMARY POINTS**

- Of the minority of respondents who commented, all reported the triggers of the penalties for infringement to be sufficiently clear.
- The majority view was that the penalties proposed for infringement were too harsh.
- A recurring comment was that the system of penalties should recognise the difference between deliberately flouting the rules and simple error.
- The issue of the relationship between the Anatomy Act 1984 and the Human Tissue Act 1961 received very little comment.
- There were mixed views on whether the two Acts should be united and replaced by a unified Act, or whether the link between them should be broken or overlaps rationalised.

## **ANNEX 1: LIST OF RESPONDENTS**

Academy of Royal Colleges and Faculties in Scotland  
Professor J Bell, Prof J Ironside and Dr C Smith, Neuropathology, University of Edinburgh  
British Medical Association Scotland  
Common Services Agency  
Dunira Strategy – Business Consultants (Public Ethics)  
Professor S Fleming, Professor of Cellular & Molecular Pathology, University of Dundee  
Professor D Graham and Dr S Robinson, Department of Neuropathology, University of Glasgow  
Justice for the Innocents (Parent Support Group)  
The Law Society of Scotland  
Dr J MacKenzie, Consultant Neuropathologist, Grampian University Hospitals NHS Trust  
E Hunter, Physiotherapy Representative, National Allied Health Professionals Committee  
Professor D Levison, Professor of Pathology  
PGB McNeill  
Medical Research Council  
Dr R Nairn, Department of Pathology, Crosshouse Hospital  
Bereavement Group, NHS Lothian University Hospitals Division  
North Glasgow University Hospitals NHS Trust  
Pathology Department, North Glasgow University Hospitals NHS Trust  
Retained Organs Commission  
Royal College of Midwives UK Board for Scotland  
Royal College of Nursing Scotland  
Royal College of Pathologists – Scottish Regional Council  
Royal College of Physicians of Edinburgh  
Royal College of Physicians and Surgeons of Glasgow  
Scottish Association of Histotechnology  
Scottish Council of Jewish Communities  
Scottish Medical and Scientific Advisory Committee  
Dr P Simpson, President, Royal College of Anaesthetists  
M Tweedie, Service Re-Design Manager, Southern General Hospital

## **ANNEX 2: LIST OF CONSULTEES**

Action for Sick Children  
Action of Churches Together in Scotland  
Africa Centre Scotland  
Agency for Inter-faith Relations Churches Together in Scotland  
Asian Concern  
Asian Welfare Association  
Associated Presbyterian Churches of Scotland  
Association for Children with Heart Disorders  
Association Church of Scotland Churches  
Association of Clinical Pathologists Baptist Union of Scotland  
Bangladesh Welfare Council  
British Medical Association Scottish Office  
British Paediatric Pathology, Scottish Branch  
Church of Scotland  
Church of Scotland National Association for Welfare of Children in Hospital  
Citizens Advice Scotland  
Clinical Standards Board for Scotland  
Commission for Racial Equality  
Conference of Scotland Council of Christians and Jews  
Crown Office (Edinburgh)  
CRUSE Bereavement Care  
Department of Forensic Medicine & Science, University of Glasgow  
Department of General Practice, Edinburgh University  
Department of Health, London  
Department of Pathology, Western Infirmary, Glasgow  
Edinburgh & District Chinese Association  
Ethics & Advisory Committee, Royal College of Paediatrics & Child Health  
Evangelical Alliance Scotland Faculty of Advocates (Edinburgh)  
The Free Church of Scotland  
The Free Presbyterian Church of Scotland  
General Medical Council  
Health & Community Care Committee, Scottish Parliament  
Hospital Chaplains Association  
Human Genetics Commission  
Justice for the Innocents (Parent Support Group)  
Law Society of Scotland  
Local Health Councils  
Local Medical Research  
Local Research Ethics Committees  
Medical & Dental Defence Union of Scotland  
Medical Research Council  
MRC Social & Public Sciences Unit, University of Glasgow  
National Association of Funeral Directors  
Neuropathology Department, University of Edinburgh  
NHS Trusts' Patients Councils

NHS Trust Chief Executives  
NHS Trust Medical Directors  
Office of the Chief Rabbi  
The Patients' Association  
Procurator Fiscals Society  
Professor D Pounder, Ninewells Hospital & Medical School  
Reformed Presbyterian Church of Scotland  
Reform of Synagogues of Great Britain  
Religious Society of Friends (Quakers)  
Retained Organs Commission  
Royal College of Anaesthetists  
Royal College of General Practitioners  
Royal College of Nursing, Scottish Branch  
Royal College of Paediatrics and Child Health  
Royal College of Pathologists  
Royal College of Pathologists (Scotland)  
Royal College of Physicians & Surgeons of Glasgow  
Royal College of Physicians of Edinburgh  
Royal College of Surgeons of Edinburgh  
Scottish Association of Health Councils  
Scottish Committee, Royal College of Pathologists  
Scottish Cot Death Trust (Parent Support Group)  
Scottish Council for Voluntary Organisations: Voluntary Sector Health Network  
Scottish Deans Medical Curriculum Group  
Scottish Episcopal Church  
Scottish Ethnic Social & Cultural Organisation Council  
Scottish Inter-Faith Council  
Scottish Law Commission  
Scottish Medico-legal Society  
Scottish Neonatal Consultants' Group  
Scottish Organisation Relating to the Retention of Organs (SORRO) (Parent Support Group)  
Scottish Partnership Forum  
Scottish Parents for a Public Inquiry into Organ Retention  
Scottish Regional Council, Institute of Biomedical Sciences  
Stillbirth and Neonatal Death Society (SANDS) (Parent Support Group)  
Strathclyde Police  
UK Central Council for Nursing, Midwifery & Health Visiting  
United Free Church of Scotland

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