

Appendix 6

Relatives' Questionnaire

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HUMAN ORGANS INQUIRY

Relatives' Written Contribution

**Please return as soon as you are able to do so to, preferably before
30 June 2001:**

**Human Organs Inquiry
Enterprise House
4th Floor
55-59 Adelaide Street
BELFAST
BT2 8FE**

**If, but only if, you wish to remain anonymous, please detach this front
page and you need not sign at the end.**

Name:

Address:

**Phone No: - Home -
 Work -**

E-mail:

**The Inquiry acknowledges, with thanks, permission from the Royal
Liverpool Inquiry to adapt its Questionnaire.**

Human Organs Inquiry Relatives' Written Contribution

On 22 March 2001 the Minister for Health, Social Services and Public Safety Ms Bairbre de Brún announced the establishment of the Human Organs Inquiry. It has been set up to review past and current post mortem policy and practice, with a particular focus on organ removal, retention and disposal.

There are 2 types of post mortem. Hospital post mortems, in general terms, are carried out where those who have been responsible for the care of a patient think it would be helpful to study the cause of that patient's death in more detail. Secondly there are post mortems carried out on the instructions of a coroner to establish the cause of a person's death. The consent of the relatives is not required for coroners' post mortems and organs and other materials may be retained for the purpose of further inquiries to establish the cause of death. Coroners' post mortems do not fall within the Inquiry's Terms of Reference except to the extent that organs have ultimately been retained in hospitals and there is an issue about what then happens to them. The focus of the Inquiry's work will be on hospital post mortems and how organs have been removed, retained and disposed of.

As a key part of its work the Inquiry wants to consult as widely as possible. The more it is told and finds out about concerns about past and current practice, the better will be its position to report to the Minister on those practices and to make recommendations for the future. If you have had experience of past post mortem practice your contribution would be of great value to us and we want to hear from you. If you are prepared to share that information with us you may find the enclosed Questionnaire a useful way of doing so. The more questions you answer the better, but it is entirely up to you to decide which of the questions you want to answer. You are also entirely free to submit any information you want in a different format if you would find that easier. In addition it would help the Inquiry to see copies of any relevant correspondence you have had with a Trust or hospital.

The Inquiry is committed to openness in its proceedings and for that purpose has established its own website (<http://www.hoi-ni.org>). We expect to include all of the information we receive on our website. Much of it may also be referred to in our report to the Minister. Where replies are published, details of all personal information will be removed so as to allow for complete anonymity for those involved. That way, you need not worry about your personal details being put on the website or in the report. However we would not publish anything without your full permission. In order to be on the safe side, if you do not make your wishes clear, we will assume you would prefer us not to publish what you send us.

Please tick this box if you are content for your anonymised completed version of this statement to appear on the Inquiry's website and in its final report.

The work of the Inquiry may require it to follow up your response to this Questionnaire by asking doctors, hospitals or others for details about your case or for a response to any claims made by you. This cannot be done properly unless the Inquiry gives those involved the details including names, dates of death, etc.

Please tick this box if you are content for the Inquiry to discuss your case with any doctors, hospitals or others if the Inquiry feels it is necessary to do so.

We are aware that if you do decide to provide us with information, it may add to any distress which you have already suffered. The Inquiry staff will be pleased to help you or answer any general questions that you may have. In addition you can get help from the Relatives Reference Group which has been set up by the Minister specifically to give advice and support to parents and other relatives. That Group can be contacted through its Secretary at 19 Bedford Street, Belfast, BT2 7EJ or on freephone 0800 328 5420 or by e-mail at ehssc1@yahoo.co.uk.

This form is divided into four sections:

- Section 1 deals with general information about your child or other relative.
- Section 2 deals with hospital post mortem examinations. If you were asked by a hospital to sign a form, then your child or relative almost certainly had a hospital post mortem.
- Section 3 deals with your feelings and views about what happened and how you think these procedures should be dealt with in the future.
- Section 4 gives you a chance to make any points or raise any issues which are not referred to in Sections 1-3.

You should try to complete as many Sections, and questions within each Section, as you can but you do not have to do so. Do not worry if you are unsure, just tell us that this is the case or leave the space blank.

Please give your answer in the space below each question. If you do not have enough space for your answer, please carry on at the end of the continuation sheet.

Section 1 - General Information

- 1.1 What was the name of the person who died? Was he/she your child or another relative?

If another relative:

- 1.2 What was his or her relationship to you?
- 1.3 When and where did your child or relative die?
- 1.4 What caused the death of your child or relative?
- 1.5 How, where and when were you told (eg, at the hospital, by telephone, through a message given to you by another relative or someone else) that a post mortem was to be carried out?
- 1.6 Who told you (eg, doctor, nurse or other)?
- 1.7 Can you remember what you were told at this time? (Please tell us what you remember and anything that you said.)

1.8 Did anyone speak to you about the post mortem examination generally?

If so: Who was it (eg, doctor, nurse, pathologist, or other)?

1.9 Did anyone tell you where the post mortem examination would take place?

If so: Please specify.

If not: Where did you expect that it would take place?

1.10 So far as you know, when did the post mortem actually take place?

1.11 Was an explanation given for the post mortem examination?

If so: By whom and what did they say?

1.12 Were you asked if you had any questions?

If so: Do you remember what you asked and what you were told? (Please tell us as much as you can remember).

1.13 Were you given any written information?

If so:

- What sort of document was it?

- What do you remember that it said? (If you still have the written information, please provide a copy).

Section 2 - Hospital Post Mortem Examinations

- 2.1 Were you given a chance to think about it or get advice before you gave any "consent"?

If so: How long did you have?

- 2.2 Did you get any advice?

If so: Who from and what advice did they give you?

- 2.3 Did anyone explain to you that you could refuse to consent to a Hospital post mortem?

- 2.4 Did anyone tell you that you could **agree** to a Hospital post mortem examination to look for the cause of death, but **not agree** to the retention of organs (including the brain) for "medical purposes" ("medical purposes" means for treatment, medical education or research)?

2.5 Were you asked to sign a consent form?

If so:

- Did you read the form that you were asked to sign?

 - What did you say when you were asked to sign the form?

 - Did the form make it clear to you that there were two types of Hospital post mortem, one which simply looked into the cause of death, and one which also gave permission for retention of organs (including the brain) for "medical purposes"?

 - If you read the form, or anyone mentioned the word "tissue" to you, did they tell you what it meant?

 - If you gave it any thought, what did you think "tissue" meant?
- 2.6 Did anyone tell you that whole organs, such as the heart, would be removed from the body?

If so: What organs did they tell you about?

2.7 Did they say what would happen to the organs?

If so: What did they say would happen to them?

If not: What did you think would happen to them when the post mortem examination was over?

2.8 Where were you when you signed the consent form (eg, ward, office, or other)?

2.9 Who was with you when you signed (eg, friend, family member or someone else)?

2.10 How long after (or before) the death were you asked to sign?

2.11 Did anyone tell you the result of the post mortem?

If so: Who told you and when?

2.12 Where were you when you were told?

2.13 What did they tell you was the result?

2.14 Did anyone tell you that the result might not be final because the organs had not yet been examined under the microscope?

2.15 Do you now feel that you fully understood why a post mortem examination was carried out? In your own words, tell us how you feel about the information that you were given.

3.6 If in person, who told you?

3.7 If a letter, who wrote to you?

3.8 If a telephone call, who spoke to you?

3.9 What organs or tissue were retained so far as you are aware?

3.10 Do you know what happened to the organs when they were retained?

3.11 Do you know if any of the organs or tissue have been disposed of?

If so: How were they disposed of, and how did you find out?

3.12 So far as you are aware have all the organs or tissue been returned?

If so: When were they returned and were they returned together?

3.13 So far as you are aware, are some organs or tissue still retained?

If so: Do you know or have you been told why?

If your child or relative's organs have been returned for burial or cremation:

3.14 Has the hospital ever told you whether tissue samples were taken at the time of the original post mortem?

If so: When were you told?

If tissue samples were taken prior to the original release of the body or later release of retained organs:

3.15 Did the hospital ask for your consent before those samples were taken?

3.16 If you know that organs or samples are still being retained by the hospital what do you wish to be done with them?

Hospital's response to organ retention:

3.17 How do you feel about the handling of your concerns by the hospital involved in your case or by other organisations?

3.18 Did you make an official complaint to the hospital at any stage?

If so: Please give details of who you made the complaint to, the nature of the complaint and the approximate date that it was made.

3.19 What progress has been made with the complaint? (Are you satisfied about the way in which the complaint has been handled? If you are not satisfied, please explain why).

3.20 Did you seek any help or assistance from a Health and Social Services Council in making a complaint?

If so: What help did you get and are you satisfied with that help?

If not: Why did you not seek help from a Council?

3.21 If your complaint has not yet been resolved, what would resolve it for you?

3.22 In light of your experiences, how do you think procedures can be improved in the future?

Section 4 – Any other points or issues

- 4.1 Is there anything else at all that you want the Inquiry to know? (You are free to raise any issue that you think is relevant to the Inquiry).**

Please tick this box if you are willing to meet with or be consulted by the Inquiry.

Signed Date

(Name in Capitals)