



RESPONSE TO CONSULTATION DOCUMENT

POST MORTEM EXAMINATIONS

GOOD PRACTICE IN CONSENT AND THE CARE OF THE BEREAVED

1.0 Introduction

The four Northern Ireland Health and Social Services Councils were established to represent the interests of health and social services users in Northern Ireland. Our aims are to make public services more responsive to users' and carers' needs, to give the public an opportunity to influence decisions to advocate on their behalf, and to provide advice and support to people who wish to express their dissatisfaction with the services they receive.

Within this remit we have provided advice and assistance to members of the public about matters relating to the provision of informed consent right across the spectrum of health and social services. We have been involved in complaints which clearly demonstrate that, particularly in the clinical setting, it is often the case that people are not being provided with sufficient information to enable them to make decisions about treatment options from a position in which they are in possession of all required and relevant information.

2.0

The Human Organs Inquiry was established in March 2001 as a result of revelations about post-mortem practice in Northern Ireland. Most of the complaints that had been received concerned the lack of information given to next of kin about what a post-mortem involves and what subsequently happens to parts of the body which have been removed and retained. As a consequence the validity of any consent to a post-mortem, if obtained at all, cannot be informed consent because it was not given from a position of full and adequate information.

Specifically with regard to consent and post-mortem practices in the future The Human Organs Inquiry recommended that:

“Uniform standard consent forms (adult and child) should be used throughout Northern Ireland in conjunction with standard relative information booklets and professional guidance notes”.

The Inquiry cautioned against the possibility of producing consent forms which were either inaccessible or more importantly which exceed the level of detail and information which is either necessary or practical, given the traumatic and emotionally distraught circumstances of next of kin when presented with post-mortem examination consent forms. After consulting with the Relatives Reference Group and medical professionals, the Inquiry proposed new consent forms which were attached as Appendices 11 & 12 in the Report.

With regard to consent for post-mortem forms and supporting documents, the Inquiry recommended:

“...that within six months of the completion of this Inquiry the Department should produce these documents and the Relatives’ Reference Group should be engaged by the Department to contribute to and comment upon any drafts and the final version”.

It is against these recommendations and our experiences in dealing with matters relating to consent and in our direct involvement with relatives who were directly affected and traumatised as a result of the revelations about organ retention that we intend to respond to this document.

3.0 Response to Questions:

Q. 1 – Do you consider that these consent forms should be introduced throughout the HPSS?

We believe that there is an urgent need for the introduction of new consent for post-mortem forms throughout the HPSS. We are however disappointed in the delay in producing them, contrary to the recommendation by the Human Organs Inquiry that they should be produced by November 2002.

Q.2 Do you consider that relatives will find the consent forms easy to understand. If not, do you have any suggestions for improving them?

We believe that the consent forms are easily understood and although they contain significantly more detail than those proposed by the Inquiry Team we support the inclusion of as much information on the forms as is necessary to ensure a complete understanding of the issues for which consent is requested. However, references to consent for Coroners Post Mortem examinations should be removed as this is not required.

There are however a number of suggestions for improving the layout of the consent forms that we would propose for consideration. Some of these proposals are applicable to all the consent forms in the document, and others may be specific to a particular form:

Under 3. **CONSENT** (page 57) it states that:

“A post mortem examination can be full or limited in extent and the hospital staff will explain this choice and what it means to you”.

We propose that the form should contain a section which requires a tick for confirmation that this **has been explained** to the relatives as opposed to stating that this will be explained. This should be fully explained to relatives before the consent form is given for completion.

We also propose that the **I do not consent** to a post mortem examination section of the form should be the first section in the form which would relieve relatives who do not wish to consent to a post mortem from the possible distress associated with reading the form.

Under **section 5** once again we propose that the **I do not consent** section should be first.

Under **section 6** – same proposal.

Under **section 8** – I want the hospital to dispose of the organs in a lawful and respectful way following completion of the post mortem report. Our view is that as the information booklet describes this method lawful disposal as by incineration then this description should be included under the appropriate section in the consent form.

Q.3 Do you consider that relatives will find the information booklets easy to understand? If not, what suggestions do you have for improving them?

We do consider that relatives will find the information booklets easy to understand. They are clear and informative and, although we feel that the information will be distressing to read and consider, it is important that relatives are fully aware of the facts regarding post mortems, and thus able to give or refuse informed consent. The information contained in these booklets should be available in other formats and languages.

Under **Different Options** we would seek clarification as to what “other professional” will discuss the post mortem examination with the relatives. Also under paragraph 4 (p.16) it states that

“If necessary before the discussion with the family, the responsible clinician should contact the pathologist....”

Would this not be essential as a clinician would not know the detail of what organs were retained and for what purpose? Families dealing with such a sensitive and distressing issue need to receive accurate information from well informed individuals. They also need to be reassured at such an emotional time. A meeting with the pathologist should be offered if the relatives wish.

Under **x-rays and other images** at page 65 there is no inclusion of “if you object to images being used in this way, you must say so” as there is at page 51.

Under organ **retention/disposal** section in information booklets there is no reference to the costs to parents/relatives if retained organs are later returned for a separate cremation or burial. In the consent form this is referred to but only as a footnote. A clearer reference is required. Another perspective is that if a hospital requests the post mortem for research/teaching then they should bear the cost.

Q.4 Do you think that the information provided in the guide is clear and easy to understand? If you have suggestions for improving it please tell us.

We believe that the information provided is clear and easy to understand.

Q.5 Are there any further areas which you feel should be covered in this document?

We believe that this document satisfactorily covers all relevant issues pertaining to consent for post mortem examinations.

Q.6 Do you think that the information provided in the care plan is clear and easy to understand? If you have any suggestions for improving it please tell us.

We believe that the information in the care plan is clear, comprehensive and easy to understand.

Q.7 Are there any further areas which you feel should be covered in this document?

We believe the document to be comprehensive.

Q.8 Do you think that the proposed documentation may have an adverse impact on equality of opportunity and/or good relations for any of the categories listed in Section 75 of the Northern Ireland Act 1998.

We believe that a consistent and rigorous application of the principles and procedures contained in this document will ensure compliance, insofar as can be anticipated, with the requirements of Section 75 of the Northern Ireland Act 1998.

Q.10 Do you think that any additional guidance is required for specific groups?

We believe that the guidance proposed is sufficient for all specified groups. We do however have concerns that the code does not deal as such with the support and information that hospitals should offer to dying patients and feel that if there is no code of practice there could as a result be a lack of uniformity across the sector. (page 10)

Q.11 To what extent do you think that the guidance adequately addresses human rights issues?

The expectation is that best practice in the health service already respects the European Convention on Human Rights. The new good practice initiatives can only serve to enhance the human rights of those who have or will suffer the trauma of bereavement.

4.0 General Comments

Concerns that relatives may be charged for the provision of a post mortem report. (p.12). How much would this be and is it not or should it not be provided for under NHS?

Concerns about the term “designated named individual” (p.16). If each trust has their own guidelines about this there is a potential for an inconsistent approach across the service.

Any human “material” handed over needs to be done in a very sensitive any caring manner. Guidance on how this should be done should be given to staff. Such material should be handed over in a casket. (Para 2 – page 18).

Under Results from a Coroner’s Post Mortem Examination (Page 20) the last sentence of paragraph 2 states “Help in interpreting the report should be provided by a relevant clinician”. Relatives should not be subjected to a member of staff who is not familiar with their case and should be able to discuss concerns with someone who has the knowledge to answer the questions that relatives may ask.

Para. 2 (page 22)

“A summary of this information should be made available in written form for the family to take away with them.” Under these circumstances it may be difficult to take in all that has been said and consequently a copy would be most useful for relatives.

First bullet point (page 23)

Why should it be of preference to hand over any remaining tissue or organs to funeral directors? Should this choice not be for the relatives concerned?

Concerns that the following paragraph at 1b.4 (p.29) should be included under essential criteria rather than desirable criteria:

“There is a designated member of staff, appropriately trained, whose primary function is to be a point of contact for relatives, to ensure completion of all appropriate forms and co-ordinate communication between the clinical staff, pathologists and relatives”.

Joint Health & Social Services Councils Response

The choice between essential and desirable could perhaps be left optional for smaller hospitals and the person trained for this primary function could also undertake other tasks.

There needs to be confirmation of receipt of organs from sending to receiving site and even internally from department to department. There needs to be a better system for tracking of records and safety mechanisms are required. (3e.2 ‘ page 37)

Will the consent forms and information booklets be evaluated and reviewed?

Who will monitor that standards are met?