IWC

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To: Chief Executive of HSS Trusts
Consultant Pathologists
Directors of Public Health of HSS Boards

HSS(MD) 6/00

27 March 2000

Dear Colleague

ORGAN RETENTION: INTERIM GUIDANCE ON POST-MORTEM EXAMINATION

As you know there is great public concern about this area of clinical care and bereaved relatives need to be given the clearest information possible about what they should expect if a post-mortem examination is requested.

The CMO in England is conducting an investigation into organ and tissue retention to consider what the issues are and what needs to be done taking into account the recommendations from the Bristol and Alder Hey Inquiries.

Meanwhile, this interim guidance sets out the action that NHS Trusts have been advised to take to ensure that practice in this area is improved and HSS Trusts in Northern Ireland should take similar action. There will be a final report in September following which comprehensive advice will be issued and which will supersede this interim guidance.

Yours sincerely

Hayble

HENRIETTA CAMPBELL (Dr)



INTERIM GUIDANCE ON POST-MORTEM EXAMINATION

Scope

This Interim Guidance deals with:

- the procedures relating to post-mortem-examinations,
- obtaining consent to the examination and the retention of organs or body parts;
- their respectful disposal.

Context

Organ and tissue retention at post-mortem examinations is a matter of serious public concern. The reports of events considered by the Bristol and Alder Hey inquiries have had a great impact not only on the parents of young children but also the bereaved families of adults where post-mortem examination was required.

The importance of post-mortem examination

All the groups and individuals who have made tepresentations recognise fully, that the post-mortem is critically important in:

- informing relatives, clinicians and the legal authorities about the cause of
- telling bereaved families about the possibility of acquired and genetic diseases where care and treatment may be required.

They also appreciate that appropriate examination of organs and tissue at postmortem is essential in:

- improving clinical care;
- maintaining clinical standards;
- increasing our understanding of disease;
- in supporting clinical research and training.

The Chief Medical Officer's [England] investigation

Because of this the Secretary of State asked the Chief Medical Officer (CMO) in England to carry out a full investigation into this area of clinical practice, looking at the implications for the NHS as a whole. This investigation is exploring the extent of organ and tissue retention at post-mortem in NHS Hospital Trusts, guidelines and local protocols for obtaining 'consent', and the arrangements in place for the disposal of organs and tissues kept for examination after death. CMO [England] will

be reporting to Ministers in September 2000 and definitive guidance to the NHS will follow.

Action: improved standards

It is however clear that standards in this area of clinical practice within the NHS should improve immediately and become more transparent, particularly communication with the bereaved and obtaining their 'consent'. This interim guidance sets out what NHS Trusts must do now in advance of the CMO England's report to Ministers.

INTERIM GUIDANCE

All NHS Hospital Trusts should:

- 1. Ensure that all staff who have contact with bereaved relatives have proper understanding of and respect for the rights of the dead, and are appropriately trained in handling:
 - patient confidentiality, which persists even after death;
 - any wishes they may have made in life about post-mortem examination or organ and tissue donation;
 - the wishes of spouses or relatives and executors of the dead person.
- Have transparent systems in place to support and monitor compliance with the Human Tissue Act 1961
- 3. Designate a named individual in the Trust who will be available to provide support and information to families of the deceased where a post-mortem examination may be required, whether this is requested by a hospital doctor or the Coroner*. This person should trained in the management of bereavement and in the purpose and practice of post-mortem examinations and be responsible for:
 - consulting spouses or relatives if a post-mortem is requested by the treating clinician, in accordance with the Human Tissue Act 1961;
 - ensuring that spouses or relatives are fully informed of the implications of a post-mortem examination required by the Coroner*;
 - obtaining 'consent' to post-mortem examination through a signed form (see annex) which provides clear written information about:

what the examination entails which organs and tissues may be retained and why how this might impact on the funeral arrangements and

RF Preliminary - INQ

whether archiving for research or legal reasons is required

- providing clear information about where any retained organs and tissues may be stored, why, for how long and the arrangements for reuniting retained organs or tissues with the body before burial where appropriate;
- allowing relatives time to consider what will take place and the
 opportunity to ask questions and talk the issues through (with the
 designated Trust individual or a senior member of the medical staff) before
 the post-mortem examination is carried out.
- 4. Provide clear written information to spouses or relatives, about the options for the disposal of organs, body parts and tissues retained at post-mortem, including arrangements for reuniting these with the body before the funeral.
- Ensure the disposal of retained organs and tissues of dead persons according
 to the Trust's agreed arrangements, in line with the legitimate prior wishes
 of the dead person and those of spouses and relatives.
- 6. Ensure that all doctors within the Trust, including locums, follow best professional practice in the management and conduct of all aspects of the postmortem examination whether this is requested by the doctor or by the Coroner. They should specifically take account of the Royal College of Pathologists' "Guidelines on the retention of organs and tissues at post-mortem" issued 23 March 2000. The accompanying leaflet on "Information about post-mortem examination for relatives" is also useful for clinicians and other staff when advising the bereaved.
- 7. Arrange for a copy of the signed post-mortem 'consent' form to be
 - an integral part of the post-mortem record;
 - · placed in the deceased patient's notes; and
 - · given to the relative who signed it.
- 8. Provide the treating clinician and/or dead person's General Practitioner with a full report of the post-mortem examination carried out in the Trust, whether the examination was at the request of the hospital doctor or Coroner*.
- Inform appropriate bereaved family members of the cause of death, if they
 wish to know, to help them complete the bereavement process taking full
 account of patient confidentiality, as it relates to the dead person.
- 10. Have proper transparent systems in place for the detailed recording of all post-mortem examinations carried out by pathology services, including:
 - · whether 'consent' was obtained;
 - which organs, body parts or tissues were retained;
 - how the retained organs and tissues were archived and/or disposed of.

- Allow access, free of charge, to those with an appropriate and legitimate 11. interest, to the post-mortem records taking due account of:
 - the express wishes the dead person may have made in life;
 - the right of the dead person to confidentiality;

 - the law and any impending legal process*;
 the public health implications of the post-mortem findings; and
 - the impact on immediate family and representatives.
 - * See Notes

RF Preliminary - INQ

Notes on this interim guidance:

This interim guidance will be reviewed in the light of the recommendations from the Chief Medical Officer England's investigation later this year.

In this interim guidance:

- 'consent' is in inverted commas to reflect everyday usage of the word, rather than any legal meaning or implication;
- the emphasis on involving spouses and relatives and seeking their agreement to post-mortem is in line with the terms of the Human Tissue Act 1961. It is good practice also to seek the agreement of unmarried partners where appropriate;
- the necessity to preserve the independence of the Coroner's investigations is fully recognised, and therefore post mortems requested by him/her do not require 'consent' and also take precedence over any prior wishes of the deceased or their relatives. However it is good practice to inform the families of the deceased about any such request from the Coroner, and the implications in terms of their rights and expectations, working closely with the Coroner's office. Coroners usually provide post-mortem reports to the treating hospital clinician or the general practitioner where requested, except in cases where this might prejudice the inquest or any criminal investigation.

Annex

Hospital Post Mortem Examination 'Consent' Form

All NHS Trust 'consent' forms used to seek the agreement of spouses/relatives to a post-mortem should include the following:

- agreement to a post mortem examination including retention of tissue samples for body fluids for laboratory investigation, to establish cause of the death and to study effects of treatment;
- agreement that this may involve the retention of organs or body parts;
- information on why the examination is required, and
- the possible impact on funeral arrangements

Relatives should be asked:

- whether they wish the examination to be limited to certain areas of the body;
- whether they would prefer that specific organs or tissues were not retained;
- whether they agree/disagree to the retention of organs for more detailed examination
- how they want the organs, tissues, or body parts disposed of upon completion of detailed examination e.g:
 - reunited with the body of the deceased
 - disposal by the hospital
 - retained for medical education and research
 - separate burial or cremation;
- whether the organs and tissues may be retained longer than specified if this is later required for diagnosis, training or research.
- whether tissues or organs may be kept for an unlimited amount of time for medical education or research.

The form should also include the following details:

- who is agreeing to the post mortem examination;
- what their relationship is to the deceased;
- who obtained and witnessed the agreement;
- what their position is within the Trust and their contact details;
- the date of the agreement.

POST MORTEM DECLARATION FORM

Patient's Name:		Hospital No: ,,,	
I the undersigned being the expatient, authorise a post mortem	xecutor/the nearest sur examination of the bod	viving relative/a relative of y of the deceased who died	the above-named on:
Date:			
Time of Death:	······		*******************************
			ک و اوس
Routine post mortem will invol study of the deceased's condition	lve removal and retenti	on, when necessary, of the	
As far as I can ascertain neither objection to a post mortem exam	er the deceased, during nination being carried ou	life, nor any close relative t.	e has expressed an
Signature:			
Signature:		;**************************************	
Relationship to deceased:			
Date:	7		***************************************
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RF Preliminary - INQ

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POST MORTEM

N	ame of Deceased	•	
••	V		
Pi	ovisional Diagnosis.		
D	ate of Death	and part of special process of the special part of the special par	
Is	a P.M. desired?		
н	as permission for a P.M. been obtained?		
Date	Signed Resident Med		·
I.H.A.			
.l.H.A. ospital	Surname and First Names	Hospital	No.
		Hospital Sex	No.
espital ard or Dept.	Surname and First Names Physician or Surgeon I hereby give consent to a Post Mortem examination being	Sex	Age
espital and or Dept.	Surname and First Names Physician or Surgeon	Sex carried out on the	Age
e of (address)	Surname and First Names Physician or Surgeon I hereby give consent to a Post Mortem examination being I am the nearest living relative of the deceased.	Sex carried out on the	Age
spital ord or Dept. e of (address)	Surname and First Names Physician or Surgeon I hereby give consent to a Post Mortem examination being	Sex carried out on the	Age
espital and or Dept. de of (address)	Surname and First Names Physician or Surgeon I hereby give consent to a Post Mortem examination being I am the nearest living relative of the deceased.	Sex carried out on the	Age ne body o

NORTHERN IRELAND REGIONAL PAEDIATRIC PATHOLOGY SERVICE

AUTOPSY AND BURIAL/CREMATION CONSENT FORM FOR FETAL, STILLBIRTH AND NEONATAL DEATHS

1,	
am t	the mother of
who	was born on
l cor give	nfirm that the autopsy has been discussed with me and that I have been n the Autopsy Booklet.
(Plea	ase read all sections below, clearly cross out the parts which do not apply sign the form):
Cons	sent for Autopsy
1. 2. 3. 4.	I give consent for a full autopsy to be performed on my baby, which I understand will include examination of the brain I give consent for only a limited autopsy to be performed on my baby — confined to head / chest / abdomen. I give consent for an external post mortem examination only. I do not wish an autopsy to be performed on my baby.
Rete	ntion of Organs
1. 2.	I give consent for the brain / heart to be retained for further examination if this is necessary to reach a diagnosis. I do not give consent for the heart / brain to be retained but I understand that the information in the autopsy report may be less than complete.
<u>Disp</u>	osal of Retained Organs:
1. 2.	I wish the retained organ to be returned to me for burial/cremation when the autopsy report is complete. I wish the hospital to arrange cremation of the retained organ when the autopsy report is complete.
Buria	al / Cremation
1. 2.	I wish to take my baby's body and I will arrange burial / cremation. I wish the hospital to arrange cremation of my baby.

Signed Date

ct.cp.nirpps.jan.2000.