University Hospitals of Morecambe Bay NHS Foundation Trust

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Author / Title: Lindsay Pinch, Bereavement Nurse Specialist	**Responsibility:** Bereavement Services and HTA Working Group chaired by Trust DI for the HTA
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Which Principles of the NHS Constitution Apply? **Please list from principles 1-7 which apply** 1,2,3,4,5,7	**Which Staff Pledges of the NHS Constitution Apply?** **Please list from staff pledges 1-7 which apply** 1,2,3,6,7

Does this document meet the requirements of the Equality Act 2010 in relation to Race, Religion and Belief, Age, Disability, Gender, Sexual Orientation, Gender Identity, Pregnancy & Maternity, Marriage and Civil Partnership, Carers, Human Rights and Social Economic Deprivation discrimination? **Yes**

Document for Public Display: *Yes * Please delete as required

Reference Check Completed by…Joanne Shawcross Date…11/09/2014.

To be completed by Library and Knowledge Services Staff

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BEHAVIOURAL STANDARDS FRAMEWORK

To help create a great place to work and a great place to be cared for, it is essential that our Trust policies, procedures and processes support our values and behaviours. This document, when used effectively, can help promote a workplace culture that values the contribution of everyone, shows support for staff as well as patients, recognises and celebrates the diversity of our staff, shows respect for everyone and ensures all our actions contribute to safe care and a safe working environment - all of which are principles of our Behavioural Standards Framework.

Behavioural Standards Framework – Expectations 'at a glance'

1. SUMMARY

University Hospitals of Morecambe Bay NHS Foundation Trust is licensed by the Human Tissue Authority for the undertaking of post-mortem (PM) examinations and associated activities (License number 12356). The Human Tissue Authority is established by the Human Tissue Act (2004)[1] as the regulatory body for all matters concerning the removal, storage, use and disposal of human tissue, including post-mortem examinations. http://hta.gov.uk/

Consent for post mortem examination is a sensitive subject for both those requesting it and those granting it. The Consent process should be as straightforward as possible to minimize the risk of additional distress or confusion.

This Procedure sets out recommended practice for all those involved in communicating with families or others close to those who have died and with mothers of fetuses for the purposes of seeking consent for a post mortem examination. For fetuses fathers should be involved where possible but, by law, it is only the mother who can give consent.

2. PURPOSE

This Standard Operating Procedure (SOP) stipulates the mandatory arrangements for taking consent for hospital post mortem examination.

This SOP describes the procedure for taking Consent for Hospital Post Mortem Examination

Implementation of the SOP will lead to :

- Consistent practice

3. SCOPE

Duties of staff within University Hospitals of Morecambe Bay are to follow this Standard Operating Procedure.

It is the responsibility of those staff that are required to take Consent for Hospital Post Mortem Examination to ensure that they are appropriately trained and have a record of their attendance at training provided.

Consent is necessary for all Hospital Post Mortems. The Human Tissue Act[1] defines individuals appropriate to give consent. Please check this prior to request. (appendix 1)

Consent for post mortem examination must only be sought by individuals who have undertaken full training.

Prior to seeking consent the consent taker should liaise with the pathologist as in complex cases as there may be additional information required.

4. STANDARD OPERATING PROCEDURE

4.1 Consent forms

The correct consent forms for adults or children/babies must be used.
http://mbhci/C2/Mortuary/default.aspx

University Hospitals of Morecambe Bay (UHMBT) consent form from 18 years upwards.
(Found in mortuary handbook under- POST MORTEM EXAMINATION CONSENT FORM)

Manchester form for babies/children up to the age of 18years
(Found in mortuary handbook under- Service Level Agreement UHMBFT)

4.2 Information

The appropriate information leaflets for adults, children/babies must be given to the person consenting and time given for them to read and formulate any questions. Therefore allowing them to make an informed consent. You will be seeking consent at a time when parents/relatives are distressed and vulnerable.

It is very important that there is clinical input into the consent process, as only a clinician/midwife who has been involved in the care of the deceased will be able to explain the reasons for requesting a post mortem examination to the family. The presence of a familiar clinician/midwife is also reassuring to the family when consent is being requested.

Use flow chart to guide the consent process. (Section 4.5)

Work through checklist for taking consent. Appendix 1

For children/babies please read and ensure you are familiar with the referral process and consent document found in Service Level Agreement UHMBT within the mortuary handbook before approaching parents.

Read relevant advice for completing consent form.
Appendix 2 for adults,
Appendix 3 for babies/children.

Choose a quiet room where you will not be disturbed. Consent is a process, not an event. The process may involve several conversations, questions and explanations in preparation for the formal consent being recorded. Breaking bad news guidance and communication strategies may be helpful.
http://hiv.ubccpd.ca/files/2012/09/Summary-on-Breaking-Bad-News.pdf

http://www.gmc-uk.org/guidance/good_medical_practice/communicate_effectively.asp

Once the form has been completed and signed, two photocopies should be made and distributed as follows: -
• Original to be given to the relatives

• A copy to be sent to Pathology/Mortuary
• A copy to be filed in the Notes

If a PM is offered and consent declined, a consent form must always be completed to record that decision, then a copy given to the person from whom consent was sought and the remaining copies filled in the notes.

4.3 Cytogenetics

May be requested with or without a post-mortem. In either case the procedure is the same.

To go to Manchester each specimen requires a completed Genetics referral form only and NO OTHER form should accompany the specimen The specimens should NOT go to Histopathology

The form is available at:
http://www.mangen.co.uk/CubeCore/.uploads/Lab%20Documents/Useful%20documents/joint_referral_form.pdf

- The specimen is viable up to 7 days after delivery if in saline and in a fridge.
- 5cm of umbilical cord should be sent (NOT CORD INSERTION). No clamp or other equipment should be present. The specimen should NOT be in formalin.
- Tissue is kept in Manchester for possible future tests and the clinical member of staff completing the form signs to say that the parents are aware of this. No other consent is required.
- If a specimen is taken and will not get to Manchester before 5pm that day it should be put in sterile saline and kept in a fridge.
- The specimen should go via the appropriate Pathology reception (FGH or RLI) and can be refrigerated in reception.

4.4 Individuals Eligible to Give Consent

The Human Tissue Act (2004)[1] states for babies and children:

- Only parents or those with parental responsibility can consent to the post mortem examination of a baby.
- The mother's signature is essential if the baby has died before birth. If the mother has died then the case will be referred to the Coroner. If the mother is too unwell then there needs to be communication with Paediatric pathology in Manchester and a discussion with the family. A hierarchy of qualifying relationships will apply (see below).
- Where the father is present, it is preferable to have both parents' signatures recorded.

The Human Tissue Act (2004)[1] defines appropriate consent for adult post mortems as:-

- The consent of the deceased person, who may give or refuse consent before death.

- The consent of a nominated representative appointed by the deceased person to deal with this issue. The authority of the nominated representative to act on the deceased's behalf in this matter must be verified.

- The consent of someone who stood in a "qualifying relationship" to the deceased person immediately before that person died. There is a hierarchy of qualifying relationships, in descending order as follows:

    1. Spouse or partner (including civil or same sex partner)
    2. Parent or child
    3. Brother or sister
    4. Grandparent or grandchild
    5. Niece or nephew
    6. Stepfather or stepmother
    7. Half-brother or half-sister
    8. Friend of long standing

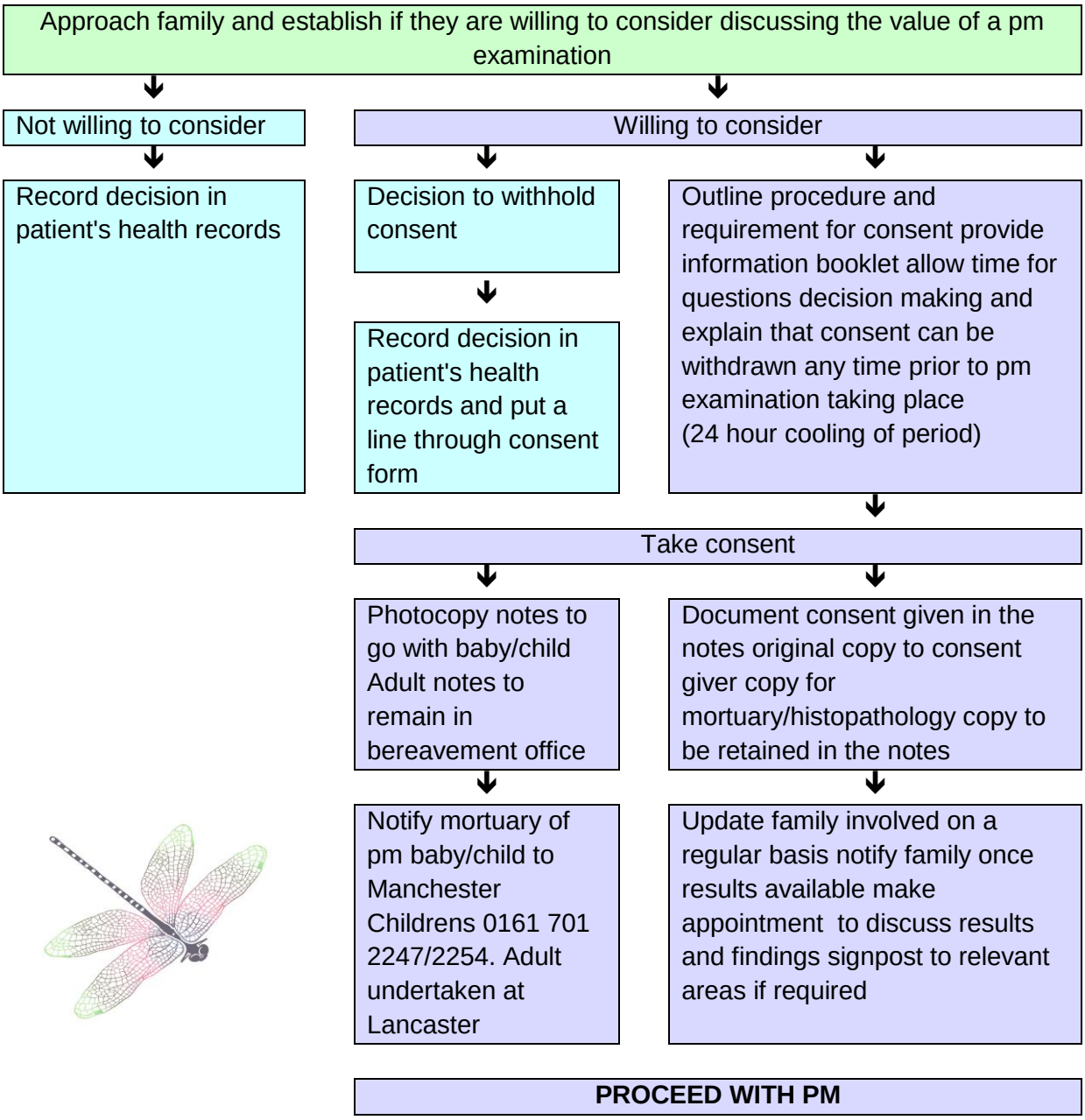
This hierarchy is intended to help those seeking consent to know who to approach, and in what order (the highest first).

There is no legal obligation to obtain consent from the immediate family or others in a qualifying relationship if proper consent from the deceased person or their nominated representative is in force. However, the hospital may prefer to discuss the existence and nature of this consent with the surviving relatives.

If a family member or those close to the deceased person object to the post mortem or tissue/organ retentions when the deceased person (or their nominated representative) has explicitly consented, clinicians and the trained individual should seek to discuss this issue sensitively with the family. Relatives should be encouraged to accept the deceased person's wishes and it should be made clear that they do not have the legal right to overrule those wishes.

In practice it will be unusual for consent to come from either the deceased person or nominated individuals. Consent for hospital autopsies usually comes from those in qualifying relationships. When consent is based on the indication of someone who stood in a qualifying relationship careful consideration should be given before proceeding on the basis of one person's consent if other family members express strong objections (e.g. if a spouse has no objection to organs being retained but everyone else in the family objects)

4.5 Flow chart



5. ATTACHMENTS	
Number	**Title**
Appendix 1	Checklist for Taking Post Mortem Consent
Appendix 2	Advice for Completing the Adult Consent Form
Appendix 3	Advice for Completing Baby/Child Consent
Appendix 4	Equality and Diversity Impact Assessment Tool

6. OTHER RELEVANT / ASSOCIATED DOCUMENTS	
Unique Identifier	**Title and web links from the document library**
Corp/SOP/002	Cytogenetic Testing SOP http://uhmb/cs/tpdl/Documents/CORP-SOP-002.docx
	http://mbhci/C2/Mortuary/default.aspx

7. SUPPORTING REFERENCES / EVIDENCE BASED DOCUMENTS **References in full**	
Number	**References**
1	Great Britain (2004) Human Tissue Authority 2004. Available at: https://www.legislation.gov.uk/ukpga/2004/30/contents (accessed 11/09/2014)

8. DEFINITIONS / GLOSSARY OF TERMS	
Abbreviation or Term	**Definition**
DI	Designated Individual for HTA for UHMBT
HTA	Human Tissue Authority
UHMBT	University Hospitals of Morecambe Bay NHS Foundation Trust
FGH	Furness General Hospital
RLI	Royal Lancaster Infirmary
PM	Post Mortem

9. CONSULTATION WITH STAFF AND PATIENTS	
Name	**Job Title**
Lindsay Pinch	Bereavement nurse
Celia Sykes	Midwife bereavement specialist
Consultant Obstetricians & Gynaecologists UHMBFT (circulation for comments)	
Band 7 and above midwifery staff UHMBFT (circulation for comments)	
Non-consultant obstetricians / gynaecology medical staff ST3 and above UHMBFT (circulation for comments)	

10. DISTRIBUTION PLAN	
Dissemination lead:	Lindsay Pinch
Previous document already being used?	Yes
If yes, in what format and where?	Electronic- Heritage
Proposed action to retrieve out-of-date copies of the document:	• Replace document on the Trust Intranet – Policy Library
To be disseminated to:	
Document Library	
Proposed actions to communicate the document contents to staff:	Include in the UHMB Weekly News – New documents uploaded to the Document Library
	Distribute to Pathology staff through Q-pulse

11. TRAINING		
Is training required to be given due to the introduction of this policy? *Yes / No * Please delete as required		
Action by	**Action required**	**Implementation Date**

12. AMENDMENT HISTORY				
Revision No.	**Date of Issue**	**Page/Selection Changed**	**Description of Change**	**Review Date**
2			Formatting revised	01/08/2017
2.1	30/10/2017	Page 3	BSF page added	01/08/2017
2.2	20/12/2017		Review date extended (207/2017)	01/04/2018
2.3	16/07/2018		Review date extended (097/2018)	01/10/2018

Appendix 1: Checklist for Taking Post Mortem Consent

Checklist for taking post mortem consent

NHS
University Hospitals of Morecambe Bay
NHS Foundation Trust

Deceased patient name		*Affix addressograph label if available*	
Address			
Patient DOB			
Hospital number			
Interview with (name)		Relationship to patient	
Date of interview		Time	
Those seeking consent should ensure that the consent interview covers the following			

I confirm that I am the appropriate person to seek consent for the post mortem examination under the human tissue act 2004 and have under gone the relevant training Tissue donation has been discussed if appropriate	
I have checked that the person consenting is the appropriate person (Only parents or those with parental responsibility can consent to the examination of a baby. The mothers name is essential if the infant died before birth(stillbirth) Where the father is present it is preferable to have both signatures)	
The person giving consent has stated that they understand the post mortem examination procedure, including the removal, storage of tissues and organs including blocks and slides and the various purposes for which they may be used including cytogenetics	
Options for what will happen to the body and any material removed ie for teaching purposes, returning tissues and organs to the body for burial or cremation following examination	
Where the post mortem examination will take place when and by whom The individuals who will be present ie pathologist anatomical technicians	
The benefits of a post mortem and the questions to be addressed and the possible outcomes if any of the examination . Where applicable alternatives ie limited post mortem or x rays	
Information about tests needed histology, toxicology, microbiology and whether these may delay the process. Reassurance the examination will be held at the first available opportunity and should not ordinarily cause delay to the funeral	
The options for giving and refusing consent for any particular storage and retention of organs and tissues and for their particular use. Information on the cooling of period of 24 hours where consent can be withdrawn	
Notify the pathologist mortuary staff regarding the post mortem and any special requirements of the family Provide the pathologist with a detailed clinical history in the case of a baby ante/intra partum notes photocopied and sent with the body	
I have documented in the notes that a post mortem examination has been agreed or refused and informed the consent giver when, to whom and how the results of the examination will be made available	
I have checked the consent form for accuracy of personal details and that all decisions are clearly recorded. Photocopied the consent form the original for the consent giver, a copy for the notes and the pathology department	

Signature		Designation	

Appendix 2: Advice for Completing the Adult Consent Form

Advice for completing the Adult consent form

Patient Details

- By law we must record the name and details of the deceased, including their hospital number. (Please complete fully and correctly in clear, printed handwriting)

- Ensure the person consenting has received all the information you need to make a decision.

Part 1: Post mortem examination: full or limited
Agreement to a full post mortem examination

The pathologist, working to standards set by the Royal College of Pathologists, will remove and examine all the major internal organs and will take samples of tissue and fluid (such as blood) for later examination in detail. The organs are then returned to the body (although they cannot be returned to their original position).

A full examination would not in any way prevent you from viewing the body in the mortuary after the post mortem has taken place. Not all assessments can be made only with the naked eye and so it may be necessary to retain samples of tissue for later study under the microscope, or for other investigations. These are small pieces of tissue (usually less than 2.5cm across), which are placed into wax blocks, from which microscope slides are made. With consent, these would normally be retained as part of the pathology record.

Limited post mortem examination
This could involve removal and examination only of those organs directly involved in the deceased's illness. This may, however, mean that no information will be available about possible abnormalities present in other organs, but which may have contributed to death. If they wish to limit the examination in any way, for example to only part of the body, please explain the restrictions to the person asking for consent so they can be recorded on the consent form.

Part 2: Retention of tissue samples
With consent, the hospital will store tissue samples removed during the post mortem as part of the deceased's medical record. The tissue is made into blocks and slides for examination under a microscope. Blocks and slides can be stored indefinitely and so can be very useful because ways of examining tissues improve year on year. Storing blocks and slides enables them to be reviewed in the future either in the light of further medical information or on behalf of the family.

Tissue blocks and slides may also be used in training doctors and other health professionals and for quality assurance and audit purposes. Training doctors may be on a one to one basis or at meetings where the treatment of the deceased may be discussed. Tissue samples may be needed to check on standards in a hospital pathology service. These uses require your consent.

With consent, tissue blocks and slides can be used in research which may benefit other people in the future. When a new disease or health problem emerges, examination of tissue on a wide scale may provide clues about how and why the disease emerged – and how to respond. Independent regional committees, working to national guidelines, must approve any research to make sure it is ethical, and that sufficient consent has been given. Tissue must not be used for research without your agreement.

You may choose that tissue samples are not retained for any reason meaning that further investigations will not be possible in the future. It is not possible to guarantee how long it will be before tissue samples can be disposed of or returned but it may be several weeks. As the slides are made of glass it may not be possible for crematoriums to cremate them. If they do not agree to the tissue samples being retained, document if the hospital will dispose of the samples lawfully by hospital incineration or they wish to have them returned to the funeral director.

Part 3: Retention and disposal of organs for diagnosis
Sometimes organs need to be preserved with chemicals before samples can be taken.

With permission an organ or part of an organ might also be retained for use in research or medical education. If the organ shows a particularly clear example of a specific illness, it may play an important role in the education of medical students, doctors and nurses. If specific organs or parts of organs are retained for a long period, it will not be possible for the tissue or organs to be buried or cremated with the deceased.

Once the examination has been completed, they need to decide what happens to any retained organs or tissue:

- They can donate the retained organs for research into related disease and medical education, after which they will be disposed of lawfully by hospital incineration.
- They can ask the hospital to dispose of the organs lawfully by hospital incineration.
- They can delay the funeral so that organs and tissue may be returned to the body for burial or cremation. However this can take several weeks or longer
- They can ask for any organs and tissue that have been retained to be returned to the funeral director. This would be for a separate cremation or burial.

Other requirements
If they have any particular requests or concerns, please write them on the consent form. You should also record any special instructions on the consent form.

Sometimes there is a requirement arising from the post mortem examination for genetic testing of tissue samples. In the case of unexpected deaths in adults, this is to help us investigate conditions such as inherited cardiac conditions, since these would not have been diagnosed in life.

Right to change their mind and signing the form
Please explain if they change their mind before the post mortem has taken place they can modify or withdraw consent even after signing. Please contact the as soon as possible and not later than 5pm by telephone 01524 583793/583794 for Lancaster, Kendal and Barrow (Histopathology offices) as soon as possible and not later than 5pm on the day after you have signed this form(Monday to Friday or by 5pm Monday if you signed at the weekend). Please do not hesitate to contact the above numbers and ask to speak to a pathologist if you have any questions.

Appendix 3: Advice for Completing Baby/Child Consent

Advice for completing baby/child consent

Section 1
Please complete fully and correctly in clear, printed handwriting

Section 2
Self-evident

Section 3

- Ensure this section is filled in; if consent is for a limited post mortem; please say exactly what the examination is to be limited to. If there is any doubt about what is possible or appropriate **do** speak to a pathologist to clarify.
- If you have discussed post mortem consent with parent(s) who then decide not to consent to the examination, please go to part 11 only.
- ****** The section allowing time for the person *(Mother, Father or relative)* giving consent to change their mind(s) and **must** be completed. This is a requirement of the HTA guidance. The post mortem will not go ahead unless this section is completed. You need to fill in name and contact details of the member of staff that the Mother, father or relative can contact. The date and time should be 24 hours from consent. The Post Mortem will not be carried out until the specified time and date has passed.

Section 4
Self-evident

Section 5
Self-evident-
NB genetic testing may only be carried out in this region if there is an indication for it (if congenital abnormalities are present, if the baby is not macerated and if the interval between delivery and receipt of the specimen by cytogenetic is less than 5 days); it may be more appropriate to take specimens for these investigations here

Section 6
Self-evident
NB images are not be taken in all cases;
Section 7
Organ retention- note that this is unlikely to be helpful in the majority of perinatal post mortems- but might be useful in some circumstances – please discuss with a pathologist if required.

Section 8
Self-evident

Section 9
If it possible to have a staff member as a witness this is desirable.

Section 10
Who can give consent? Note that in the case of an infant who has not lived it must be the **mother only – not the father or other relative.**

However where the deceased infant of any gestation has had a separate existence no matter how brief (and is therefore classed as a **live birth**), the HTA guidance states that one person with parental responsibility may give consent (though clearly if possible the matter should be discussed between and agreed by both parent(s))

Section 11
To be filled in only if there is refusal for Post Mortem examination as specified in section 3. Not applicable if a Post Mortem is to be carried out.

Appendix 4: EQUALITY & DIVERSITY IMPACT ASSESSMENT TOOL

		Yes/No	Comments
1.	**Does the policy/guidance affect one group less or more favourably than another on the basis of:**	No	
	• Race		
	• Ethnic origins (including gypsies and travellers)		
	• Nationality		
	• Gender		
	• Culture		
	• Religion or belief		
	• Sexual orientation including lesbian, gay and bisexual people		
	• Age		
	• Disability - learning disabilities, physical disability, sensory impairment and mental health problems		
2.	**Is there any evidence that some groups are affected differently?**	No	
3.	**If you have identified potential discrimination are there any exceptions - valid, legal and/or justifiable?**	N/A	
4.	**Is the impact of the policy/guidance likely to be negative?**	No	
4a	**If so can the impact be avoided?**	N/A	
4b	**What alternative are there to achieving the policy/guidance without the impact?**	N/A	
4c	**Can we reduce the impact by taking different action?**	N/A	

If you have identified a potential discriminatory impact of this procedural document, please refer it to the HR Equality & Diversity Specialist, together with any suggestions as to the action required to avoid/reduce this impact.

For advice in respect of answering the above questions, please contact the HR Equality & Diversity Specialist, Extension 6242.