

[Hospital and/or Trust/Health Board name plus NHS logo]

Perinatal post-mortem consent form

Your wishes about the post-mortem examination of your baby

This form has been developed by Sands in consultation with the Human Tissue Authority (HTA) to meet the requirements of the Human Tissue Act 2004. Any substantive changes to the main body of this form should be checked with the HTA.

Sands, November 2024

Template Perinatal Post-Mortem Examination Consent Form

Note for NHS staff taking consent - this page should be removed before the consent form is shared with parents.

This form applies to hospital consented perinatal post-mortem examinations only. This covers examinations for fetuses and babies from 12 weeks gestation up to birth, and babies who were aged up to 28 days old when they died.

The form should be completed jointly by those with parental responsibility and the consent taker, as part of an informed consent discussion. Parents should not be asked to complete the form independently.

The form should be adapted for local use. This template form covers the most widely available post-mortem examinations and tests. The form includes the option of a minimally invasive post-mortem examination. If this is not available, the option should be removed from the form. If any additional post-mortem investigations are available, e.g. MicroCT examination, additional consent will be required and the detail of this should be added to this template form.

Where a post-mortem investigation is being carried out via mutual aid between Perinatal Pathology Units, additional consent may be required according to the investigations available at the Perinatal Pathology Unit providing mutual aid.

Parents should be advised, as part of the consent process, where the post-mortem is expected to take place (if known). If the location is not known or it changes, parents should be informed of this and updated when the location is finalised.

Please note that the Perinatal Pathology Unit will triage all referrals for hospital consented post-mortems in line with [Royal College of Pathology autopsy practice guidelines](#) and [NHS England Perinatal Pathology Commissioning Policy](#) to confirm that a post-mortem is clinically indicated.

Please do not proceed with taking consent if you have not received training as otherwise the consent form may be invalid, and this is likely to cause delays. This includes ensuring that you have read the Human Tissue Authority's Codes of Practice A and B (available at www.hta.gov.uk/hta-codes-practice-and-standards-0) and you are compliant with your Trust's policies and requirements relating to post-mortem consent.

Contact details for Perinatal Pathology Unit (for staff only):

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.....

Key contacts for parents

Changing your mind about a post-mortem being carried out on your baby

After you sign this form, you have up to 24 hours in which you can change your mind about anything you have agreed to. This is because post-mortems need to be performed as soon as possible after death. **If you want to change your mind you must contact:**

[Name] [tel.]

[Job Title]

[Department].....

Parents must contact the above person:

before [time] on [date]

If the named person is unavailable, please contact:

[Name] [tel.]

All other questions

Except for the circumstance of changing your mind within 24 hours (see above), if you have any other questions about the post-mortem process, you should contact the following:

Main contact:

[Name] [tel.]

[Email].....

[Job Title]

[Department].....

Secondary contact (if main contact not available):

[Name] [tel.]

[Job Title]

[Department].....

Changing your mind about the retention of tissue, DNA or genetic material.

If you have given consent in sections 2 or 3, for the retention of tissue, DNA or genetic material, you can withdraw consent at any time in the future by contacting:

[Name] [tel.]

[Job Title]

[Department].....

[Email].....

Post-Mortem Examination Consent Form

Your wishes about the post-mortem examination of your baby/child

Mother	Baby/Child
Last name	Last name
First name(s)	First name(s)
Address	Date of birth
	Date of death (if liveborn)
Hospital no.	Hospital no.
NHS no.	NHS no.
Date of birth	Gender (if known)
Consultant	Consultant
Father / Partner / other Person with Parental Responsibility	Address (if different from the mother's)
Last name	
First name(s)	
Preferred parent to contact, tel. no.:	
Religion:	
Any additional needs: language, interpreter	
.....	
.....	

How to fill in this form:

- Please show what you agree to by writing **YES** in the relevant boxes. Write **NO** where you do not agree.
- Record any specific requests/concerns in the Notes to Section 4
- Sign and date the form. The person taking consent will also sign and date it. You should be offered a copy of the signed form.

Transfer of your baby/child for post-mortem examination

In most cases, your baby will need to be transferred to another hospital where the post-mortem examination will take place. Once the location is known, you will be told.

Please be assured that your baby will always be treated with care and respect.

Section 1: Your decisions about a post-mortem examination

This form lists the different types of post-mortem examination. The consultant pathologist will only carry out the investigation/s you have given your consent for.

The different levels and types of tests and examinations are summarised below, and in Appendix 1 of this form. You can decide the maximum level of examination that can be carried out. If you need more detail please ask for more information from the person taking consent.

Within the limits that you agree to, the consultant pathologist will work out the level of post-mortem that will be carried out. They will consider which investigations and tests will be most helpful. For example, for some babies a focused post-mortem examination is enough to answer the questions about what happened.

If you do not consent to a complete / full post-mortem but the pathologist thinks that a more invasive investigation could provide the most information, you will be contacted by the hospital and asked if you wish to consent to this.

The pathologist will never perform more extensive investigations than you have agreed to.

Please consent to the maximum level of examination you agree can be carried out.

- i. **A complete / full post-mortem.** This includes: an external examination; examining all the internal organs via incisions; examination of small samples of tissue; examination of placenta (afterbirth) where relevant/available; imaging and medical photographs. Tests may also be done for infection and other problems.

☐ **I/We agree to a complete / full post-mortem examination.**

OR

- ii. **A minimally invasive post-mortem examination.** This includes: an external examination; examination of the internal organs of the body usually via a key-hole surgery approach; examination of placenta (afterbirth) where relevant/available; imaging and medical photographs. In some cases it may be possible to take small tissue biopsies under imaging guidance alone to answer certain specific questions.

☐ **I/We agree to a minimally invasive post-mortem examination.**

OR

- iii. **A focused post-mortem (or limited post-mortem).** This includes: an external examination; examining the internal organs in the area(s) of the body that you agree to; examining small samples of tissue; examination of placenta (afterbirth) where relevant/available; imaging and medical photographs. Tests may also be done for infection and other problems.

☐ **I/We agree to a focused post-mortem examination.**

Please indicate what **can** be examined: ☐ **head**

☐ **chest and neck**

☐ **abdomen**

☐ **placenta only**

other

OR

- iv. **An external / imaging examination (non invasive examination).** This includes: an external examination; examination of placenta (afterbirth) where relevant/available; imaging and medical photographs. No incisions will be made or biopsies taken.

☐ **We agree to an external post-mortem examination with / without MRI**

Section 2: Genetic testing

To examine the baby's chromosomes or DNA for a possible genetic disorder or condition, as part of the post-mortem, the pathologist may take small samples of skin, other tissue and/or samples from the placenta (afterbirth).

With your agreement, this material will be kept as part of the medical record so that it can be re-examined to try to find out more if new tests or new information become available. This could be especially useful if you think you may have another baby in the future.

Please note, genetic testing is a separate process which may require additional tests.

☐ **I/We agree to genetic testing of samples of skin, other tissue and/or the placenta.**
If samples should not be taken from any of these, please note this below.

☐ **I/We agree to the genetic material being kept as part of the medical record for possible re-examination.** See Section 6 Item 7 for more information.

Notes to Section 2 if required

Section 3: Tissue samples

Section 3 covers additional separate consent that you may decide to give. It will not affect what you have already agreed to above, what is done during the post-mortem, or the information you get about your baby, but it may be helpful for others in the future.

With your agreement, the tissue samples taken from your baby or placenta may also be examined for quality assurance and audit of pathology services to ensure that high standards are maintained.

☐ **I/We agree to the tissue samples being kept and used for quality assurance and audit.**

Tissue samples, medical images, and other information from the post-mortem can be important for training health professionals. Identifying details are always removed when items are used for training.

☐ **I/We agree to anonymised tissue samples, images and other relevant information from the post-mortem being kept and used for professional training.**

Tissue samples, medical images, and other relevant information from the post-mortem can also be useful in research into different conditions and to try to prevent more deaths in the future. All research must be approved by a Research Ethics Committee.

☐ **I/We agree to tissue samples, images and other relevant information from the post-mortem being kept and used for ethically approved medical research.**

You can withdraw consent for any of the above at any time in the future. To do so, please contact the person/department detailed in on the **Key Contacts** page at the start of this form, in the box labelled 'Changing your mind about the retention of tissue, DNA or genetic material'.

Section 4: Consent from person(s) with Parental Responsibility

☐

I/We have been offered written information about post-mortem examinations.

☐

I/We understand the possible benefits of a post-mortem examination.

☐

My/Our questions about post-mortem examinations have been answered.

☐

I have reviewed the contents of this form and I am content that they accurately reflect my/our wishes.

Notes to Section 4: Parent requests

Please write here any specific requests you wish to make in relation to the post-mortem investigation. Your request will be considered by the pathologist but please note that ultimately, the pathologist will determine the extent of the post-mortem examination that is performed in line with the consent that you have provided and the specific details of your case.

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Mother's name (Print): Signature

Other person with Parental Responsibility: Name (Print).....

Signature

Date Time

Section 5: Consent taker's statements, to be completed and signed at the time of consenting.

- ☐ I have read the written information offered to the parents/those with Parental Responsibility.
- ☐ I believe that the parent(s)/those with Parental Responsibility has/have sufficient understanding of a post-mortem and (if applicable) the options for what should be done with tissue and organs to give valid consent.
- ☐ I have recorded any variations, exceptions and special concerns.
- ☐ I have checked the form and made sure that there is no missing or conflicting information.
- ☐ I have explained the time period within which parents can withdraw or change consent and have entered the necessary information at the beginning of this form.

Name Position/Grade

Department

Contact details (Department tel. and Ext/Bleep)

Signature Date Time

Interpreter's statement (if relevant)

- ☐ I have interpreted the information about the post-mortem for the parent(s)/those with Parental Responsibility to the best of my ability and I believe that they understand it.

Name Contact details

Signature Date Time

Section 6: Notes for the consent taker

1. "Responsibility for obtaining consent should not be delegated to untrained or inexperienced staff. Anyone seeking consent for hospital post-mortem examinations, should have relevant experience and a good understanding of the consent procedure. They should have been trained in dealing with bereavement and in the purpose and procedures of post-mortem examinations. Ideally, they should have also witnessed a post-mortem examination." (Human Tissue Authority, Code of Practice B, 2017).
2. Consent must be given by those with Parental Responsibility. Please note that pregnancy losses under 24 weeks gestation are considered the mother's tissue and therefore, the mother (or person with Power of Attorney with health and welfare, or legal advocate) has to give consent. Losses of over 24 weeks are stillbirths. This requires the consent of the person with parental responsibility which automatically falls to the mother. A father/partner does not automatically have parental responsibility, unless there is another named person with parental responsibility – for example where the mother lacks capacity or the child is in local authority care. Please see [Code A - Guiding principles and the fundamental principle of consent.pdf \(hta.gov.uk\)](#) for further information.
3. Written information about post-mortems should be offered to all Parents/those with Parental Responsibility before you discuss the form with them.
4. If the parents/those with Parental Responsibility have a specific request that you are not sure about, contact the pathologist **before the form is completed. Any specific parent requests should be clearly documented in the Notes to Section 4.**
5. Make sure that an appropriate time and date is entered in the *Changing your mind* section at the beginning of the form, and the parent(s)/those with Parental Responsibility understand what to do if they change their minds. The post-mortem should not begin unless this section is completed. **It is your responsibility to ensure that, if the parent(s)/ those with Parental Responsibility change their minds, they will be able to contact the person(s) or department entered on this form.** If the parents do not want a copy of the form, they should still be given written information about changing their minds.
6. Write the mother's or the baby/child's hospital number in the box at the foot of each page of the form. For a baby who was born dead at any gestation use the mother's hospital number; for a baby who was born alive use the baby's hospital number.
7. **Sections 2 and 3: Genetic material and tissue samples:** If the parents/those with Parental Responsibility do not want tissue samples or genetic material kept as part of the medical record, explain the different options for disposal (below) and note their decisions in the relevant section.

If disposal is requested, it will usually take place a year later. This is to ensure that the family have the opportunity to ask for further testing. This often happens 6-8 months later. The options are: disposal by a specialist hospital contractor; returned to Hospital for a later burial / cremation / collection by chosen funeral director; or release to the parents themselves. They cannot be returned to the body but can accompany in a small box. This option may delay collection of their baby/child.
8. Send the completed form to the relevant pathology department, offer a copy to the parent(s)/those with Parental Responsibility, and put a copy into the mother's (for a stillbirth or miscarriage) or the baby/child's medical record.
9. Record in the clinical notes that a discussion about the post-mortem examination has taken place, the outcome, and any additional important information. This should include recording in the notes where parents have declined a post-mortem.

Appendix 1 – description of different post-mortem examinations

A complete / full post-mortem	This includes an external examination, then via two or more incisions, examining all of the internal organs, examining small samples of tissue under a microscope, a range of imaging techniques as appropriate (E.g. X-rays, CT, Micro CT, MRI, ultrasound) and medical photographs. Tests may also be done for infection and other problems. The placenta (afterbirth) where relevant and if available will also be examined.
A minimally invasive post-mortem examination	This includes an external examination, a range of imaging techniques as appropriate (E.g. X-rays, CT, Micro CT, MRI, ultrasound), medical photographs and examination of the internal organs of the body that you agree to, usually via a “key-hole surgery” approach. This will only involve a small incision for the endoscope; no large incisions will be made. The placenta will also be examined if available. In some cases it may be possible to take small tissue biopsies under imaging guidance alone to answer certain specific questions.
A focused post-mortem (or post-mortem with limitations)	This involves fewer investigations than a complete/full or minimally invasive post-mortem examination but depending on the circumstances, may often answer specific questions. A focused post-mortem includes an external examination, examining the internal organs in the area(s) of the body that you agree to, examining small samples of tissue under a microscope, and imaging (E.g. X-rays, CT, Micro CT, MRI, ultrasound), and medical photographs. Tests may also be done for infection and other problems and the placenta will also be examined where relevant and if available.
An external / imaging examination (non invasive examination)	This involves fewer investigations than a complete/full or minimally invasive post-mortem examination but depending on the circumstances can often answer specific questions. An external/imaging examination includes an examination of the outside of your baby/child’s body plus a range of imaging techniques as appropriate (E.g. X-rays, CT, Micro CT, MRI, ultrasound) and medical photographs but no incisions will be made or biopsies taken. The placenta will also be examined if available.

This matrix summarises the information in the table above

Examinations that may be part of the post-mortem	Type of post-mortem			
	Complete / Full	Minimally invasive	Focussed	External
Examining the outside of the baby's body	X	X	X	X
A range of imaging techniques, as appropriate, and dependent on local availability (E.g. X-rays, CT, Micro CT, MRI, ultrasound)	X	X	X	X
Medical photographs	X	X	X	X
Examining all the internal organs, via two or more incisions	X			
Examining internal organs in specific areas that you agree to, via an incision			X	
Examining the internal organs that you agree to, usually via keyhole surgery, involving a small incision for a laparoscope, or needle biopsies under imaging guidance		X		
Examining small tissue samples under a microscope	X	X	X	
Tests may be done for infection and other problems	X	X	X	X
Examining the placenta (if it is available)	X	X	X	X