

## **Guidelines on autopsy practice**

## Fetal autopsy after termination of pregnancy or fetal loss associated with congenital anomaly

**DRAFT February 2024** 

Series authors: Dr Esther Youd, Clinical Lead for Autopsy Guidelines

Dr Ben Swift, Forensic Pathology Services, Oxon

Specialist authors: Dr Tamas Marton, Birmingham Women's and Children's Hospital

**NHS Foundation Trust** 

Dr Beata Hargitai, Birmingham Women's and Children's Hospital

**NHS Foundation Trust** 

Dr Flora Jessop, Cambridge University Hospitals NHS Foundation

Trust

Dr J Ciaran Hutchinson, Great Ormond Street Hospital NHS

Foundation Trust

Professor Christoph Lees, Imperial College Healthcare NHS Trust Dr Tracey Johnston, Birmingham Women's and Children's Hospital

**NHS Foundation Trust** 

Unique document number	G193
Document name	Guidelines on autopsy practice: Fetal autopsy after termination of pregnancy for congenital anomaly
Version number	V1
Produced by	The specialist content of this guideline has been produced by: Dr Tamas Marton MD, FRCPath, PhD, Consultant Perinatal Pathologist, Birmingham Women's and Children's Hospital Foundation Trust and Department of Obstetrics and Gynaecology, Semmelweis University, Faculty of Medicine; and Department of Pathology, Forensic and Insurance Medicine, Semmelweis University, Budapest, Hungary
	Dr Beata Hargitai, MD, Affiliate Member of RCPath, PhD, Consultant Perinatal Pathologist, Birmingham Women's and





	Children's Hospital Foundation Trust and Department of Obstetrics and Gynaecology, Semmelweis University, Faculty of Medicine; and Department of Pathology, Forensic and Insurance Medicine, Semmelweis University, Budapest, Hungary  Dr Flora Jessop, Cambridge University Hospitals NHS Foundation Trust  Dr Ciaran Hutchinson, Great Ormond Street Hospital NHS Foundation Trust  Professor Christoph Lees, Imperial College Healthcare NHS Trust  Dr Tracey Johnston, MD, FRCOG, Birmingham Women's and Children's Hospital NHS Foundation Trust
Date active	February 2024
Date for full review	February 2029
Comments	In accordance with the College's pre-publications policy, this document will be on the Royal College of Pathologists' website for consultation from 28 February to 27 March 2024. Responses and authors' comments will be available to view on publication of the final document.  Dr Brian Rous  Clinical Lead for Guideline Review

The Royal College of Pathologists 6 Alie Street, London E1 8QT

Tel: 020 7451 6700 Fax: 020 7451 6701 Web: <u>www.rcpath.org</u>

Registered charity in England and Wales, no. 261035 © 2024, the Royal College of Pathologists

This work is copyright. You may download, display, print and reproduce this document for your personal, non-commercial use. Requests and inquiries concerning reproduction and rights should be addressed to The Royal College of Pathologists at the above address. First published: 2024.

### **Contents**

Fore	word		4	
1	Introducti	on	6	
2	Consent.	Consent		
3	Clinical in	formation relevant to the autopsy	9	
4	The autor	osy procedure	10	
5	Specific h	nealth and safety aspects	13	
6	Limited or less invasive post-mortem examination in the context of termination of pregnancy for fetal abnormalities			
7	Organ retention13			
8	Autopsy report14			
9	Coding1		15	
10	Criteria for audit16			
11	Reference	es	18	
App	endix A	Exemplar autopsy request form	20	
App	endix B	Autopsy-related SNOMED CT codes	24	
App	endix C	Summary table – Explanation of grades of evidence	26	
App	endix D	AGREE II guideline monitoring sheet	27	



NICE has accredited the process used by the Royal College of Pathologists to produce its guidelines. Accreditation is valid for 5 years from 25 July 2017. More information on accreditation can be viewed at www.nice.org.uk/accreditation.

For full details on our accreditation visit: www.nice.org.uk/accreditation.

#### **Foreword**

The autopsy guidelines published by the Royal College of Pathologists (RCPath) are guidelines which enable pathologists to deal with non-forensic consent, coroner's and procurator fiscal post-mortem examinations in a consistent manner and to a high standard. They are intended primarily for the profession; some technical content may be distressing for the lay audience.

The guidelines are systematically developed statements to assist the decisions of practitioners and are based on the best available evidence at the time the document was prepared. Given that much autopsy work is single observer and one-time only in reality, it has to be recognised that there is no reviewable standard that is mandated beyond that of the FRCPath Part 2 exam or the Certificate of Higher Autopsy Training (CHAT). Nevertheless, much of this can be reviewed against ante-mortem imaging and other data. This guideline has been developed to cover most common circumstances. However, we recognise that guidelines cannot anticipate every pathological specimen type and clinical scenario. Occasional variation from the practice recommended in this guideline may therefore be required to report a specimen in a way that maximises benefit to the pathologist, coroner/procurator fiscal and the deceased's family.

At the time of drafting these guidelines, there is some uncertainty around workflow and the optimisation of patient pathways, despite great efforts by regional units to maintain service provision. Relevant additional material, including a parent pathway, is being drafted by NHS England, which aims to optimise the pathway and experience for parents at what is a very difficult time. Timely communication with parents via appropriate channels is critical to providing status updates regarding the examination and its findings, and providing answers for families experiencing great distress. Reference to these materials should be made, where required.

There is a general requirement from the General Medical Council (GMC) to have continuing professional development (CPD) in all practice areas and this will naturally encompass autopsy practice. Those wishing to develop expertise/specialise in pathology are encouraged to seek appropriate educational opportunities and participate in the relevant external quality assurance (EQA) scheme.

The guidelines themselves constitute the tools for implementation and dissemination of good practice.

The stakeholders consulted for this document were:

- British and Irish Paediatric Pathology Association (BRIPPA)
- Stillbirth and Neonatal Death Charity (Sands)
- The Royal College of Obstetrics and Gynaecologists (RCOG)
- Human Tissue Authority (HTA)
- The Coroners' Society of England and Wales
- Crown Office and Procurator Fiscal Service (COPFS) Scotland
- Coroner's Service for Northern Ireland
- The Home Office Forensic Science Regulation Unit and Forensic Pathology Unit and the British Medical Association.
- Pregnancy and Baby Charities Network.

The information used to develop this document was derived from current medical literature. Much of the content of the document represents custom and practice and is based on the substantial clinical experience of the authors. All evidence included in this guideline has been graded using modified SIGN guidance (see Appendix C). The sections of this autopsy guideline that indicate compliance with each of the AGREE II standards are indicated in Appendix D.

No major organisational changes or cost implications have been identified that would hinder the implementation of the guidelines.

A formal revision cycle for all guidelines takes place on a 5-year cycle. The College will ask the authors of the guideline to consider whether or not the guideline needs to be revised. A full consultation process will be undertaken if major revisions are required. If minor revisions or changes are required, a short note of the proposed changes will be placed on the College website for 2 weeks for members' attention. If members do not object to the changes, the changes will be incorporated into the guideline and the full revised version (incorporating the changes) will replace the existing version on the College website.

The guideline has been reviewed by the Professional Guidelines team, Death Investigation Committee, Forensic Pathology Specialty Advisory Committee and Lay Advisory Group. It will be placed on the College website for consultation with the

membership from 28 February to 27 March 2024. All comments received from the membership will be addressed by the author to the satisfaction of the Clinical Lead for Guideline Review.

This guideline was developed without external funding to the writing group. The College requires the authors of guidelines to provide a list of potential conflicts of interest; these are monitored by the Professional Guidelines team and are available on request. The authors of this document have declared that there are no conflicts of interest.

#### 1 1 Introduction

- 2 This is a new guideline that complements *G160 Guidelines on autopsy practice: Fetal*
- 3 autopsy following antepartum or intrapartum death of non-malformed fetuses and G161
- 4 Guidelines on autopsy practice: Fetal autopsy of 2nd trimester fetal loss (excluding
- 5 termination of pregnancy for congenital anomaly) and focuses on fetuses with structural
- 6 abnormalities of any gestational age.
- 7 Investigations following either planned delivery or termination of pregnancy for fetal
- 8 abnormality identified in the antenatal period may take several forms. It is essential that
- 9 the contribution from perinatal pathology services forms part of a multidisciplinary
- 10 approach prior to and following delivery.
- 11 The voice of bereaved parents has been central to producing these guidelines. Many
- bereaved parents want to access a post-mortem examination for their baby, seeking the
- possibility of answers, even if only to rule out some underlying conditions rather than elicit
- specific positive findings. Bereaved parents have told us that the post mortem can become
- an important part of their path through their grief. The post-mortem report can support
- difficult decisions about another pregnancy. It is, of course, extremely common for parents
- to feel protective and strongly connected to their baby the acute sensitivities and
- 18 emotional context make perinatal post mortem unlike any other investigative procedure.
- 19 The report authors have held the narrative of parents' vulnerabilities and wishes at the
- 20 heart of the discussions involved in producing these guidelines.
- 21 This guideline is particularly relevant to cases which present with structural abnormalities
- for which there is no unifying diagnosis. In these circumstances, parents should be offered
- a full, detailed autopsy. Macroscopic, radiological or histologic findings at post mortem
- 24 may well be additional to those identified antenatally and are key to providing as accurate

- 1 diagnosis/genetic counselling as possible. 1–3 Where possible, strong parental preferences
- 2 (as documented on the consent form or in the referral documentation) should be taking
- 3 into consideration by the responsible consultant.
- 4 The guidance provided in this publication is primarily directed towards supporting perinatal
- 5 pathologists in undertaking what may be described as conventional, dissection-based
- 6 autopsies. There is a considerable volume of evidence supporting less invasive autopsy,
- 7 and imaging modalities such as ultrasound (US), micro-computed tomography (micro-CT),
- 8 CT or magnetic resonance imaging (MRI) as effective investigations following termination
- 9 of pregnancy for fetal anomalies.<sup>4–7</sup> Currently, UK-based perinatal pathologists are trained
- in a dissection-based approach to fetal autopsy and lack local resources to expand their
- 11 practice into alternative methods. Should local resource permit, alternative approaches are
- not proscribed by these guidelines; the information from additional imaging should, in
- those circumstances, form part of the final post-mortem report.
- 14 In some cases, extensive prenatal investigation (US, MRI, comparative genomic
- 15 hybridisation [CGH] microarray, whole-exome sequencing [WES] or whole-genome
- sequencing [WGS]) will have yielded a partial and/or differential diagnosis. In such
- 17 circumstances, a detailed post-mortem examination can provide further valuable
- 18 information and should again be offered.
- 19 Fetal autopsy also represents an opportunity to identify concomitant diseases, and fetal,
- 20 maternal and placental conditions, particularly those with implications for subsequent
- 21 pregnancies (e.g. fetal growth restriction, malformation, maternal diabetes).
- In a minority of cases, prenatal diagnosis/screening has not been undertaken, with
- 23 anomalies only identified following delivery and neonatal death. These guidelines also
- 24 apply to this scenario, and parents should again be offered full post-mortem examination
- with genetic testing. Please note, however, that the clinicians providing care in these cases
- 26 should initially discuss the case with their local medical examiner teams, to consider
- 27 whether an MCCD (Medical Certificate of Cause of Death) should be issued or a referral to
- 28 HM Coroner should be made. Perinatal pathologists should undertake a consented post-
- 29 mortem examination only in circumstances where that discussion has been concluded and
- 30 an MCCD has been issued. (The medical examiner team equivalent in Scotland is the
- 31 Death Certification Review Service. In Northern Ireland, it is the Independent Medical
- 32 Examiner Service.)

PGD 280224 7 V1 Draft

- 1 With regard to live birth after termination of pregnancy, please see Chief Coroner
- 2 Guidance No. 45, February 2023.8
- 3 In cases of known (prenatally diagnosed) aneuploidy, post-mortem examination is of
- 4 doubtful value and should not routinely be offered.

#### 1.1 Target users of this guideline

- 6 The target primary users of this guideline are UK consultant and trainee
- 7 perinatal/paediatric pathologists. Recommendations will also be of value to pathologists
- 8 working outside the UK, obstetricians, neonatal paediatricians, fetal medicine consultants
- 9 and clinical geneticists, biomedical scientists and bereavement midwives.

#### 2 Consent

5

10

- 11 Consent must always be obtained for the hospital post-mortem examination of a baby,
- whether born alive or dead, and at any gestation.
- 13 Consent is also required for all genetic testing, including of placental samples. Local
- protocols should be established between clinical genetics and histopathology departments.
- 15 This will help to ensure that appropriate consent is in place prior to the release of tissue for
- 16 any genomic investigation.
- 17 The only time when parental consent/authorisation for a post-mortem examination on a
- baby is not needed is when a coroner or procurator fiscal orders a post-mortem
- 19 examination; this is unlikely to be relevant in the clinical context of these guidelines.
- 20 Regardless of the gestation, perinatal post-mortem examination may only be performed if
- 21 informed consent has been given by the mother, unless there are exceptional
- 22 circumstances, e.g. if she is too ill to consent. Wherever possible, in this situation, the
- 23 partner's consent/authorisation should also be sought.9
- 24 The consent process should be compliant with the requirements of the HTA's Code of
- 25 Practice: Code A: Guiding Principles and the Fundamental Principle of Consent. 10 In
- 26 Scotland, Human Tissue (Scotland) Act 2006 is in force and the consent process should
- 27 follow the legislation.<sup>11</sup>
- The autopsy consent form should be compliant with the model 'Consent form for perinatal
- 29 post mortem' developed by Sands, in conjunction with the HTA.<sup>12</sup> The pathologist
- performing the autopsy must see the completed consent form, either as a physical copy or

- 1 electronically, before commencing the autopsy. Any limitations on the scope of the autopsy
- 2 must be complied with.
- 3 Any concerns regarding the validity of the consent should be resolved before commencing
- 4 the autopsy.
- 5 The consent form indicates the maximal extent of the post-mortem examination that
- 6 should be performed. For some patients, if the responsible consultant considers that a
- 7 more limited examination can adequately answer the questions raised, the examination
- 8 may not include some of the components, in keeping with the latest NHS guidance. 13 This
- 9 depends on the specific features and history for each patient and is at the discretion of the
- 10 consultant pathologist responsible for the examination.
- 11 [Level of evidence GPP in line with statutory obligations.]

## 12 3 Clinical information relevant to the autopsy

- 13 The relevant clinical information (best obtained using structured request form, see
- 14 Appendix A) includes:
- patient identification details
- maternal age/date of birth
- maternal height, weight and BMI
- relevant medical and family history, including consanguinity
- obstetric history, previous pregnancies/deliveries, including previous fetal and neonatal
- 20 losses (if post-mortem examination had been carried out), malformation and growth
- 21 restriction and other complications
- history of current pregnancy, including:
- 23 estimated delivery date (gestation by date and by scan)
- 24 antenatal infection screen results, including cytomegalovirus, toxoplasma, HIV
- 25 abnormal findings from US or other antenatal investigations (copy of the US report
- is highly desirable, mandatory with antenatally diagnosed structural abnormalities)
- results of first trimester screening, non-invasive tests, chorionic villus sample (CVS)
- 28 and amniocentesis
- 29 any concerns regarding fetal growth/fetal monitoring

- the presence of complications, such as pregnancy-induced
   hypertension/preeclamptic toxaemia
- events leading up to intrauterine death and/or delivery (membrane rupture,
   maternal pyrexia, antenatal bleeding, last evidence of fetal heartbeat).

5 6

7

[Level of evidence – B.]

## 4 The autopsy procedure

- 8 This guideline refers specifically to planned delivery or termination of pregnancy for fetal
- 9 abnormalities identified in the antenatal period. <sup>2,14–17</sup>
- Whole body X-ray for gestational age assessment, malformation, etc. Recommended
- in all cases; mandatory for suspected skeletal dysplasia and multiplex developmental
- abnormalities. If available, this may be replaced or complemented by other imaging
- modalities e.g. CT, MRI.
- Photography is mandatory in all cases, particularly important to document external and
- internal abnormalities. Digital photography and secure storage should be available, in
- line with local trust/hospital information governance standards.
- Routine measurements should be taken (body weight, crown–heel length, foot length.
- 18 Consider taking: crown–rump length, occipito-frontal circumference, inner and outer
- canthal measurements). Abdominal circumference has not been validated as a post-
- 20 mortem measurement.
- Detailed external examination, including: fetal growth, soft tissue and muscle bulk,
- local/generalised oedema, pallor, dysmorphic features of the ears, eyes, facial
- proportions, patency of orifices (including choanae) and palatal fusion, limbs
- 24 (positional abnormalities, skin webs), hands and feet (fingers, toes, nails and creases)
- and external genitalia. Recording of negative findings is not required unless clinically
- requested or relevant.
- Cases being submitted for MRI/US scan/micro-CT examination should be examined
- by a pathologist and then transferred to appropriate imaging facilities before returning
- for further assessment, ideally with any available interim imaging reports. At this time,
- follow up with dissection-based autopsy (in line with parental consent) is appropriate,
- but may be omitted at the discretion of the examining pathologist in line with their
- 32 experience and expertise in these modalities.

- 1 In practice, if the findings are discordant with the antenatal information, follow up
- 2 dissection is recommended, where consent permits.
- Incisions on the body should be placed with due regards to the requirement for
- 4 reconstruction. Standard incisions include typically T- or Y-shaped; an inverted Y-
- 5 shaped incision of the lower abdominal wall can be considered for assessment of the
- 6 internal lower abdominal wall.
- 7 Detailed systematic examination of other internal organs, including:
- 8 in-situ examination of the thoracic cavity (thymus, lungs, heart and great vessels)
- 9 with sequential segmental analysis of malformations
- 10 in-situ examination of abdominal organs and retroperitoneum; consider removing
- in continuity to assess abnormal structures crossing diaphragm; umbilical arteries
- 12 and vein, ductus venosus
- 13 weights of internal organs (recommended: brain [if examined], lungs, liver;
- 14 consider: kidneys, thymus, adrenals, spleen) to be compared with standard
- 15 reference tables as required
- 16 sampling for histology if indicated by clinical and pathological findings. Routine
- histological examination of macroscopically normal organs (in the absence of a
- clinical indication to sample the organ) shows low diagnostic low yield<sup>18</sup> but is at
- the discretion of the responsible consultant.
- 20 any abnormally formed organ should be sampled for histological assessment (e.g.
- 21 cystic kidney [with liver], lung)
- 22 muscle, if suspected fetal akinesia deformation sequence or another myopathy
- appropriate samples for bone histology for suspected skeletal dysplasia: long bone
- 24 (including growth plate), vertebral body consider skull/rib if indicated.
- 25 [Level of evidence C.]
- A record of the samples taken should be kept and tissue blocks and slides should be
- traceable within the laboratory, in line with the requirements of the HTA and the UK
- 28 Accreditation Service (ISO 15189).
- Quantitative fluorescent PCR (QF-PCR) and array studies (if not undertaken
- antenatally). Freezing tissue for DNA extraction should be considered; lung and/or
- 31 placenta may be preferable to autolysed liver (consider local consensus with the

PGD 280224 11 V1 Draft

- 1 genetic laboratory). Frozen tissue may be required in due course to support WES or
- 2 WGS. The current Genomic Laboratory Hub (GLH) guidelines should be followed by
- 3 the fetal medicine multidisciplinary team (MDT) collaborating with the pathologist.
- 4 (Wales: All Wales Genomics Laboratory; Scotland: Scottish Strategic Network for
- 5 Genomic Medicine [SSNGM] laboratories; Northern Ireland: Northern Ireland
- 6 Genomics Medicine Centre [NIGMC]).
- 7 Apply special dissection techniques where appropriate, photo-document the relevant
- 8 findings, and consider dissection under the camera/under water/short-term formalin
- 9 fixation.

10 11

12

[Level of evidence – GPP.]

#### 4.1 Central nervous system examination

- 13 Examination of the central nervous system (CNS) is mandatory in termination of
- 14 pregnancy for brain/CNS malformation or in cases of termination of pregnancy for
- 15 syndromic disease without unifying diagnosis. Formal CNS examination should be
- 16 considered in cases of incidental major internal anatomical abnormality.
- Median posterior or transverse scalp incision.
- Skull incisions to allow assessment of falx and venous sinuses.
- Observation of gyral pattern to assist gestational assessment.
- Consider removal under water (or direct in formalin) and perhaps in dura especially
- with marked autolysis: will permit weighing and assessment of gyral pattern.
- Consider referring the whole CNS for neuropathological examination in appropriate
- cases. This may include sampling peripheral nervous tissue (nerve root, peripheral
- 24 nerve, muscle, etc). Consultation with an appropriately experienced neuropathologist
- 25 may be helpful.

26 27

28

[Level of evidence – C.]

#### 4.2 Placental examination

- 29 Placental examination is an integral part of the perinatal post-mortem examination.
- 30 Submission to pathology with the baby is mandatory; non-conformances should be
- 31 monitored in line with local policies. Guidance for detailed examination of the placenta is
- 32 given in the *Tissue pathway for examination of the placenta*. 19

PGD 280224 12 V1 Draft

1 [Level of evidence – B.]

## 2 5 Specific health and safety aspects

- 3 The pathologist should be informed as part of the referral if there is a potential biohazard
- 4 risk.
- 5 Autopsy practice using universal precautions will significantly protect against accidental
- 6 transmission of infection, including HIV, SARS CoV-2 and other blood-borne viruses.

## 7 6 Limited or less invasive post-mortem examination in

- 8 the context of termination of pregnancy for fetal
- 9 abnormalities
- 10 Where consent for a full autopsy is not given, limited or less-invasive examination may be
- of value. Consent takers should be competent to counsel bereaved parents on the benefits
- 12 and limitations of this approach.
- 13 Examples of such examinations:
- autopsy limited to 1 or more body cavities
- examination excluding the brain or performing a CNS-only autopsy
- open or needle biopsy of specific internal organs (if available)
- external examination of the body with X-ray, photography and genetics (if indicated)
- placental examination only (with genetic testing if indicated)
- less/minimally invasive autopsy: external examination and imaging (CT, MRI if
- 20 available) alone or with targeted biopsies.<sup>17</sup>
- 22 [Level of evidence C.]

21

## 23 7 Organ retention

- 24 Short-term retention of organs to allow fixation does not require specific consent, provided
- 25 they are reunited with the body before release for burial/cremation.

PGD 280224 13 V1 Draft

- 1 Specific consent should be sought for long-term retention beyond the release of the body,
- 2 for the purpose of examining the organs. Consider for extracranial organs with congenital
- 3 malformations (particularly heart) if input is not available from a perinatal pathologist or
- 4 cardiac morphologist on site at the time of examination, and the abnormality cannot be
- 5 satisfactorily recorded by photography.
- 6 In practice, brain fixation for a minimum of 2–3 days in 20% formalin (± 5% acetic acid) will
- 7 usually produce sufficient fixation to allow adequate sectioning and block sampling to allow
- 8 the brain to be returned to the body before release for funeral. If there is doubt, consult the
- 9 local neuropathology team.
- 10 [Level of evidence GPP.]

## 11 8 Autopsy report

- 12 Units may choose, if resources allow, to issue a provisional report giving details of the
- macroscopic findings shortly after the examination of the body, followed by a final report
- when all histology and other tests have been completed. Alternatively, only a single, final
- 15 report may be produced.
- 16 The report should include the following sections, where performed:
- demographic and identification data
- details of autopsy consent and limitations
- 19 body weight
- body measurements with relevant reference values
- list of main findings
- 22 clinicopathological summary (final report)
- summary of clinical history
- systematic description of external and internal findings and placental examination
- organ weights with relevant reference values and ratios
- details of ancillary tests taken (and results in final report)
- histology (final report)

- list of histology tissue blocks and retained organs and tissues, if applicable (final
- 2 report).

3

4 [Level of evidence – GPP.]

#### 5 8.1 Clinicopathological summary

- 6 The summary should include:
- 7 reference to the gestational age at delivery (and death, if applicable)
- reference to previous losses/terminations of pregnancy, their outcome and relevance
- 9 to the current pregnancy loss
- for termination of pregnancy, concordance or discordance of findings with the clinical
- 11 history and prenatal testing, likely/possible unifying diagnosis and recommendation for
- 12 genetic referral or further tests if appropriate
- identification of those cases with an increased risk of recurrence and
- 14 requirement/possibility of additional testing
- results of MDTs, such as the clinical genetics MDT and its outcome, including
- molecular genetic diagnosis. In these cases, an addendum report or reports would be
- 17 appropriate.

18

19 [Level of evidence – GPP.]

### 20 9 Coding

- 21 The autopsy procedure and principal findings should be coded according to the SNOMED
- 22 CT system using appropriate body structure, finding, disorder and morphologic
- 23 abnormality codes for SNOMED CT or appropriate T (topographic) and M (morphologic)
- for older versions of SNOMED (local protocols should be followed).
- 25 Of note, SNOMED ceased to be licensed by the International Health Terminology
- 26 Standards Development Organisation from 26 April 2017; the authors recognise that NHS
- 27 England aspires to fully transition to SNOMED CT.
- 28 The requirement to enable SNOMED CT content in secondary care systems is yet to be
- 29 fully achieved, although it is known that many providers have SNOMED CT enabled EPR
- 30 systems in place. SNOMED CT is used in many different healthcare settings
- internationally and an NHS-approved fundamental standard (SCCI0034). SNOMED CT

- 1 gives clinical IT systems a single shared language, making the exchange of information
- 2 between systems easier, safer and more accurate. It contains all the clinical terms needed
- 3 for the whole NHS, from procedures and symptoms through to clinical measurements,
- 4 diagnoses, medications and pathological findings.
- 5 The NHS Digital SNOMED CT UK browser can be accessed for free.
- 6 A non-exhaustive list of autopsy-related SNOMED CT codes is provided in Appendix B.

#### 7 10 Criteria for audit

- 8 The following standards are suggested criteria that might be used in periodic reviews to
- 9 ensure a post-mortem examination report meets national standards. The phase of the
- 10 autopsy examination (pre-analytical, analytical and post-analytical) assessed by the
- 11 standard is included.
- 12 Supporting documentation:
- standards: supporting documentation was submitted with the body in 95% of cases
- 14 [pre-analytical]. (NB: it is recommended that an autopsy should not be commenced in
- the absence of clinical information.)
- standards: 95% of submitted information is satisfactory, good or excellent [pre-
- 17 analytical
- standards: a correctly completed autopsy consent form, meeting national requirements
- is submitted with 95% of cases [pre-analytical]. (NB: an autopsy must not be
- commenced unless the pathologist has seen a physical copy of the consent form and
- 21 it is correctly completed.)
- standards: 100% of autopsy reports must include all of the sections detailed in section
- 23 15, within the limits of parental consent and extent of the examination determined by
- the responsible consultant (above) [analytical]
- standards: in 100% of autopsy reports, the information documented is satisfactory,
- good or excellent [analytical]
- standards: in 100% of autopsy reports, the clinicopathological summary is clear and
- concise and, when appropriate, contains the information detailed above [analytical]
- standards: 80% of autopsy reports are completed within the turnaround times agreed
- with local clinical teams, excluding cases where turnaround time is compromised by

- 1 testing outside of the control of the responsible consultant (e.g. genetic array,
- 2 neuropathological examination) [post-analytical]
- standards: 100% of autopsy reports are communicated to referring centres using
   secure email (e.g. nhs.net email) or encrypted email [post-analytical]
- standards: 100% of autopsy cases are coded appropriately according to local
   guidelines [post-analytical].

For reference, the NHS specifications (from the 2013/2014 standard contract for perinatal pathology<sup>20</sup>) are as follows:

60% of final reports for routine post-mortem examination will be issued to referrers within 42 days of examination and 90% should be issued within 56 days. This will exclude those cases in which there may be a specialist referral opinion required (e.g. neuropathology) or very complex metabolic or genetic testing required.

These are mandatory contractual requirements of units commissioned to provide perinatal pathology services and are important measures of service quality and outcomes. The authors recognise that paediatric and perinatal pathology services have ongoing staffing and associated operational challenges and where services are shorthanded or otherwise under provisioned, or are providing mutual aid to other units, specific audit targets will be agreed between commissioners and clinical teams, but with the view that all units should be working towards the standards set out in the service specification.

The authors recognise that many units are inadequately staffed with either pathologists or anatomical pathology technologists. Failure to achieve targets is unlikely to reflect the performance of individual pathologists but may indicate the need for a managerial review of local systems in place to ensure timely reports, and measures such as mutual aid should be considered. Where services are shorthanded or otherwise under provisioned, temporary audit targets should be agreed with clinical teams and outsourcing of reporting or other measures should be considered.

## 11 References

- 1. Cassidy A, Herrick C, Norton M, Ursell P, Vargas J, Kerns J. How does Fetal Autopsy after Pregnancy Loss or Termination for Anomalies and other Complications Change Recurrence Risk? *Am J Rep* 2019;9:1:30–35.
- Gowda M, Paranthaman S, Jacob SE, Thiagarajan M, Godipelli L. Role of Autopsy in Diagnosis and Genetic Counselling of Congenital Malformations: a Prospective Analytical Study. *J Fetal Med*. 2019;69–79.
- 3. Hauerberg L, Skibsted L, Graem N, Maroun LL. Correlation between prenatal diagnosis by ultrasound and fetal autopsy findings in second-trimester abortions. *Acta Obstet Gynecol Scand* 2012;3:386–390.
- 4. Hutchinson JC, Kang X, Shelmerdine SC, Segers V, Lombardi CM, Cannie MM *et al.*Postmortem microfocus computed tomography for early gestation fetuses: a validation study against conventional autopsy. *Am J Obstet Gynecol* 2018;218:4:445–445.
- 5. Shelmerdine S, Langan D, Sebire NJ, Arthurs O. Diagnostic accuracy of perinatal post-mortem ultrasound (PMUS): a systematic review. *BMJ Paediatr Open* 2019;3:1.
- Thayyil S, Sebire NJ, Chitty LS, Wade A, Chong W, Olsen O et al. Post-mortem MRI versus conventional autopsy in fetuses and children: a prospective validation study. Lancet 2013;20:223–233.
- Shelmerdine SC, Simcock IC, Hutchinson JC, Guy A, Ashworth MT, Sebire NJ et al.
   Postmortem microfocus computed tomography for noninvasive autopsies: experience in >250 human fetuses. Am J Obstet Gynecol 2021;224:103.
- 8. Courts and Tribunal Judiciary. *Chief Coroner's Guidance No.45 Stillbirth, and Live Birth Following Termination of Pregnancy*. Accessed July 2023. Available at: <a href="https://www.judiciary.uk/guidance-and-resources/chief-coroners-guidance-no-45-stillbirth-and-live-birth-following-termination-of-pregnancy/">www.judiciary.uk/guidance-and-resources/chief-coroners-guidance-no-45-stillbirth-and-live-birth-following-termination-of-pregnancy/</a>
- Human Tissue Authority. Sands guide for consent takers: seeking consent for the post mortem examination of a baby. Accessed May 2023. Available at: <a href="https://www.hta.gov.uk/guidance-professionals/regulated-sectors/post-mortem-post-mortem-model-consent-forms/sands">https://www.hta.gov.uk/guidance-professionals/regulated-sectors/post-mortem-post-mortem-model-consent-forms/sands</a>
- Human Tissue Authority. Codes of Practice. Accessed May 2023. Available at: <u>www.hta.gov.uk/codes</u>

- 11. Acts of Scottish Parliament. *Human Tissue (Scotland) Act 2006*. Accessed February 2024. Available at: <a href="www.legislation.gov.uk/asp/2006/4/contents">www.legislation.gov.uk/asp/2006/4/contents</a>
- 12. Human Tissue Authority. *The Sands perinatal post mortem consent package*.

  Accessed May 2023. Available at: <a href="www.hta.gov.uk/guidance-professionals/regulated-sectors/post-mortem/post-mortem-model-consent-forms/sands">www.hta.gov.uk/guidance-professionals/regulated-sectors/post-mortem/post-mortem-model-consent-forms/sands</a>
- 13. NHS England. Interim Clinical Commissioning Urgent Policy Statement: Perinatal post-mortem investigation of fetal and neonatal deaths (England, Scotland and Wales).
  Accessed May 2023. Available at: <a href="www.england.nhs.uk/publication/perinatal-post-mortem-investigation-of-fetal-and-neonatal-deaths-england-scotland-and-wales/">www.england.nhs.uk/publication/perinatal-post-mortem-investigation-of-fetal-and-neonatal-deaths-england-scotland-and-wales/</a>
- 14. Boyd PA, Tondi F, Hicks NR, Chamberlain PF. Autopsy after termination of pregnancy for fetal anomaly: retrospective cohort study. *BMJ* 2004;17:137.
- 15. Dickinson JE, Prime DK, Charles AK. The role of autopsy following pregnancy termination for fetal abnormality. *Aust N Z J Obstet Gynaecol* 2007;6:445–449.
- 16. Godbole K, Bhide V, Nerune S, Kulkarni A, Moghe M, Kanade A. Role of fetal autopsy as a complementary tool to prenatal ultrasound. *J Matern Fetal Neonatal Med* 2014;1688–1692.
- 17. Shelmerdine SC, Arthurs OJ, Gilpin I, Norman W, Jones R, Taylor AM *et al.* Is traditional perinatal autopsy needed after detailed fetal ultrasound and post-mortem MRI? *Prenat Diagn* 2019;8:818–829.
- 18. Lewis C, Hutchinson JC, Riddington M, Hill M, Arthurs OJ, Fisher J et al. Minimally invasive autopsy for fetuses and children based on a combination of post-mortem MRI and endoscopic examination: a feasibility study. Health Technol Assess 2019;46:1–104.
- 19. The Royal College of Pathologists. *Tissue pathway for histopathological examination of the placenta*. Accessed May 2023. Available at:

  <u>www.rcpath.org/profession/guidelines/cancer-datasets-and-tissue-pathways.html</u>
- 20. NHS England. 2013/14 NHS Standard Contract for Perinatal Pathology. Accessed May 2023. Available at: <a href="https://www.england.nhs.uk/wp-content/uploads/2013/06/e12-perinatal-path.pdf">www.england.nhs.uk/wp-content/uploads/2013/06/e12-perinatal-path.pdf</a>

## **Appendix A** Exemplar autopsy request form

CLINICAL INFORMATION FOR FETAL / PERINATAL POST MORTEM

Mother (sticker if av	ailable)	Fetu	ıs / Infant (st	icker if available)	
Family Name:	First D.o.	ily Name: Name: B.: / / No	D.o.D: / /		
Please carefully complete this form. Any missing information could potentially delay or alter the findings.  Parts 1, 2 and 3 ALL require completion for EVERY referral made.  REFERRING HOSPITAL:  HOSPITAL OF BIRTH (if different):  (Please include history / notes from previous hospitals)  CONSULTANT OBSTETRICIAN:  CONSULTANT PAEDIATRICIAN:  Part 1. MOTHER'S DETAILS  (ALL fields for this section are MANDATORY for ALL requests please)					
Ethnic origin:	Ethnic origin: Father's ethnic origin (if known)				
Consanguinity between	parents? Y/N	Blood group:		_	
Maternal height:	cm	Booking weight:	kg	BMI:	
Obstetric History: PREVIOUS PREGNAN	ICIES				
Date 1. 2. 3. 4. 5. 6. 7.	Gestation	Delivery	Sex	Outcome	

Were there any complications with any previous pregnancies (this current pregnancy excluded)?\* Yes / No / Not known – if yes, specify

This form consists of 4 pages. All require your attention.

<sup>\*</sup>Further space for writing is provided on p4 of this form.

Please carefully complete this form. Any missing information could potentially delay or alter the findings.

	RENT PREGNAN or this section are			L reques	ets please)	
Booked/Unb	ooked LMP:			EDD:		
Gestation: b	y dates:/	40 by scan:	/	40 weeks	s	
Were there a Doppler result Medications		ening results	? (If yes		Fetal growth issues and u	uterine artery
Date	Indication (e.g. dating / anomaly, etc.)	Gestation	Findin	•	report if abnormal)	
1.						
3.						
4.						
	agnostic procedur ampling or other in					
Was this a to Any history of Was there a Was there p Was there a Is there anyto pathologist?		ance regardin	detaile	If so, how Y/N If BP = BP = regnancy d in the form	that you would like to tel	h?

N.B. Would this PM examination be classed as an infection risk to relevant staff? Y/N

## This form consists of 4 pages. All require your attention.

Please carefully complete this form. Any missing information could potentially delay or alter the findings.

Part 3: LABOUR & DELIVERY DETAILS Have you completely filled part 1 & 2? An	y missing information ca	n alter the findings.
1) Was this a TOP? Y/N a) If TOP – Feticide Y/N If so, method 2) Was this a miscarriage (i.e. pregnancy 3) Was this an IUD > 24 weeks' gestation If so, when was the last documented evid 4) Was this an intrapartum or neonatal de What was the presenting part? Vertex / E b) Rupture of membranes: dateti c) 1st stagehmin 2nd :hmin d) Abnormal fetal monitoring or suspected	loss <24 weeks' gestation (i.e. macerated stillbirth) lence of fetal / infant viableath (i.e. fresh stillbirth / libreach / Other ime Augmentation	o? Y/N ility / fetal heart beat? ve birth)? Y/N (Syntocinon): Y/N
e) DELIVERY: Spont. / Assisted (forceps	s / ventouse) / CS (electiv	re / emergency). Date
f) Apgars: 1st min 5th min		
Did labour commence spontaneously / die	d it require induction?	
Date of induction, if applicable:		Date of delivery:
Liquor: Normal / reduced volume / increas	sed volume.	Abnormal liquor colour?
Was there antepartum haemorrhage?		Was there maternal pyrexia, concerns re: maternal infection
The infant or fetus	Any notable abnormaliti	es in the fetus / infant at time of
Male ♂ Female ♀ Indeterminate	delivery*:	
Birth Weight (g):		
*Frontlean angles is much deleter to without and	1 - f 1  - f - w	

Part 4: For LIVEBORN infants ONLY (i.e. Neonatal deaths):

Have you completely filled parts 1, 2 & 3?

RESUSCITATION procedures employed:

NEONATAL PROBLEMS & PROCEDURES:

BRIEF SUMMARY OF LATER SYMPTOMS / TREATMENTS AND MAJOR INVESTIGATIONS (including CPAP / ventilation, IV therapy, fits, episodes of collapse, pneumonia, pneumothorax, bleeding problems, type of feeding, etc.)

Surfactant: Y/N

\*Further space for writing is provided on p4 of this form.

<u>Attention please:</u> If this was a complex course, please consider sending YOUR summary and interpretation of events. Sending photocopies of the notes or the complete set of notes may be acceptable, but not advisable for optimal practice.

SUSPECTED CAUSE(S) OF DEATH: DEATH REGISTERED AS (if applicable):

ANY OTHER RELEVANT INFORMATION / SPECIAL POINTS TO BE NOTED AT POST MORTEM:

## This form consists of 4 pages. All require your attention.

PGD 280224 22 V1 Draft

<sup>\*</sup>Further space is provided for writing on p4 of this form.

<sup>\*</sup>Further space for writing is provided on p4 of this form.

Please carefully complete this form. Any missing information of findings.	ould potentially delay or alter the
Please do not hesitate to contact us should you have any quer form.	ies regarding the completion of this
Person completing form:No	Contact number / bleep
(Please PRINT)	
Copy of report to be sent to:	
Consultant obstetrician: (Mr/ Ms/ Mrs/ Dr)(Please PRINT)	and/or
Consultant paediatrician:(Please PRINT)	
Thank you for carefully completing all relevant parts of this formattention please.  May we remind you that any missing information could potential	
Notes for any further relevant information and short narrative of the c	linical synopsis:

ALL BABIES AND PLACENTAS SHOULD BE SENT FRESH IN LEAKPROOF, OPAQUE CONTAINERS UNLESS

THERE IS AN INFECTIOUS HAZARD (in this case phone to discuss whether the specimen should be fixed in 10% formalin before transportation)

IT IS ESSENTIAL TO SEND THE PLACENTA WITH A FETUS / INFANT.

## This form consists of 4 pages. All require your attention.

PGD 280224 23 V1 Draft

## **Appendix B** Autopsy-related SNOMED CT codes

The following codes are suggested for centres with SNOMED CT capabilities. Local coding procedures should be followed where SNOMED CT has yet to be implemented. The suggested lists below are not exhaustive but highlight examples of codes that could be used. The <a href="NHS Digital SNOMED CT UK browser">NHS Digital SNOMED CT UK browser</a> can be accessed for free.

Report for Procurator Fiscal (record artifact)

#### **General autopsy codes**

	Autopsy examination (procedure)
I	Coroner's autopsy (procedure)
I	Forensic autopsy (procedure)
I	Pediatric autopsy (procedure)

#### Specimen codes

308375000

309502007	Fetus specimen (specimen)	
725957005	Formalin-fixed placenta tissue specimen (specimen)	

#### Post-mortem imaging

717193008	Cone beam computed tomography (procedure)
699581005	Post mortem magnetic resonance imaging (procedure)
713599004	Post mortem ultrasonography (procedure)

#### **Fetal findings**

85811006	1	Autolysis (morphologic abnormality)
248200007	1	Dysmorphic facies (finding)
87309006		Death of unknown cause (event)
22033007	1	Fetal growth retardation (disorder)
289448000		Fetus normal (finding)
198901003		Macerated fetus (disorder)
85728002		Morphologic description only (finding)

723745006 | Morphological description only, with differential diagnosis (finding)

41962002 | Oligohydramnios sequence (disorder)

## **Placental findings**

4532008	1	Acute inflammation (morphologic abnormality)
84499006		Chronic inflammation (morphologic abnormality)
396343006		Funisitis (disorder)
65396000		Histiocytic infiltrate (morphologic abnormality)
125563001		Hyalinized fibrosis (morphologic abnormality)
55641003		Infarct (morphologic abnormality)
73728008		Maturation acceleration (morphologic abnormality)
50353005	1	Maturation deceleration (morphologic abnormality)
309162003	1	Normal histology findings (finding)
415105001	1	Placental abruption (disorder)
268585006	1	Placental infarct (disorder)
237292005	1	Placental insufficiency (disorder)
448485001	1	Specimen satisfactory for evaluation but limited by cellular degeneration (finding)
27696007	1	True knot of umbilical cord (disorder)
75798003	1	Twin dichorionic diamniotic placenta (disorder)
83787007		Twin monochorionic diamniotic placenta (disorder)
388604008	1	Villitis (disorder)
1155707008		High histologic grade
1155708003	3	Low histologic grade (qualifier value)
1155705000	)	Histologic grade cannot be assessed (qualifier value)

# Appendix C Summary table – Explanation of grades of evidence

(modified from Palmer K et al. BMJ 2008; 337:1832)

Grade (level) of evidence	Nature of evidence	
Grade A	At least 1 high-quality meta-analysis, systematic review of randomised controlled trials or a randomised controlled trial with a very low risk of bias and directly attributable to the target population or  A body of evidence demonstrating consistency of results and comprising mainly well-conducted meta-analyses, systematic reviews of randomised controlled trials or randomised controlled trials with a low risk of bias, directly applicable to the target cancer type.	
Grade B	A body of evidence demonstrating consistency of results and comprising mainly high-quality systematic reviews of case-control or cohort studies and high-quality case-control or cohort studies with a very low risk of confounding or bias and a high probability that the relation is causal and which are directly applicable to the target population or Extrapolation evidence from studies described in A.	
Grade C	A body of evidence demonstrating consistency of results and including well-conducted case-control or cohort studies and high- quality case-control or cohort studies with a low risk of confounding or bias and a moderate probability that the relation is causal and which are directly applicable to the target population or  Extrapolation evidence from studies described in B.	
Grade D	Non-analytic studies such as case reports, case series or expert opinion or Extrapolation evidence from studies described in C.	
Good practice point (GPP)	Recommended best practice based on the clinical experience of the authors of the writing group.	

## **Appendix D** AGREE II guideline monitoring sheet

The guidelines of the Royal College of Pathologists comply with the AGREE II standards for good quality clinical guidelines. The sections of this guideline that indicate compliance with each of the AGREE II standards are indicated in the table.

AGREE standard		Section of guideline
Sc	ope and purpose	
1	The overall objective(s) of the guideline is (are) specifically described	Introduction
2	The health question(s) covered by the guideline is (are) specifically described	Introduction
3	The population (patients, public, etc.) to whom the guideline is meant to apply is specifically described	Foreword, Introduction
St	akeholder involvement	
4	The guideline development group includes individuals from all the relevant professional groups	Foreword
5	The views and preferences of the target population (patients, public, etc.) have been sought	Foreword
6	The target users of the guideline are clearly defined	Introduction
Rigour of development		
7	Systematic methods were used to search for evidence	Foreword
8	The criteria for selecting the evidence are clearly described	Foreword
9	The strengths and limitations of the body of evidence are clearly described	Foreword
10	The methods for formulating the recommendations are clearly described	Foreword
11	The health benefits, side effects and risks have been considered in formulating the recommendations	N/A
12	There is an explicit link between the recommendations and the supporting evidence	Throughout
13	The guideline has been externally reviewed by experts prior to its publication	Foreword
14	A procedure for updating the guideline is provided	Foreword
CI	arity of presentation	
15	The recommendations are specific and unambiguous	Throughout
16	The different options for management of the condition or health issue are clearly presented	Throughout
17	Key recommendations are easily identifiable	Throughout

Applicability	
18 The guideline describes facilitators and barriers to its application	Foreword
19 The guideline provides advice and/or tools on how the recommendations can be put into practice	All appendices
20 The potential resource implications of applying the recommendations have been considered	Foreword
21 The guideline presents monitoring and/or auditing criteria	10
Editorial independence	
22 The views of the funding body have not influenced the content of the guideline	Foreword
23 Competing interest of guideline development group members have been recorded and addressed	Foreword