# Clinical Practice Guideline for Care Around Stillbirth and Neonatal Death

## Section 4

## Perinatal Autopsy Including Placental Assessment

**Version 3.1, March 2018**

***Endorsed by***

# SECTION 4
# PERINATAL AUTOPSY INCLUDING PLACENTAL ASSESSMENT

## 4.1 Introduction

The perinatal autopsy remains the gold standard in diagnostic evaluation of the causes of perinatal death[1-3]. Information gained from an autopsy can assist in the understanding of events surrounding the death and enable consideration of potential risk recurrence and appropriate management strategies in future pregnancy planning. Despite the value that perinatal autopsies offer, two challenges persist; low autopsy rates and the quality of post-mortem examinations.

This section of the update of the guideline has been undertaken through a partnership between PSANZ and the NHMRC Stillbirth Centre of Research Excellence in Stillbirth.

To view further information on the described guidelines in this section of the PSANZ Clinical Practice Guideline for Care Around Stillbirth and Neonatal Death see *Appendices G-Q.*

## 4.2 Objective of this section

The main objective of section 4 of the PSANZ Clinical Practice Guideline for Care Around Stillbirth and Neonatal Death is to assist clinicians to improve standards for perinatal autopsy examination. This includes communication with parents, which directly affect autopsy rates.

For further information regarding communication with parents after a perinatal death please refer to Chapter 3 - Psychological and social aspects of perinatal bereavement.

## 4.3 What has changed in this update?

In this update, based on the findings of an updated literature review, the recommendations have remained unchanged. We have revised the formatting and reduced duplication across the different sections of the guidelines to enhance readability.

## 4.4 Purpose of perinatal autopsy

The purpose of any autopsy examination extends beyond diagnosis of the cause of death[4-9].

The main purposes of an autopsy are to:

- Identify an accurate cause of death[4,5,7,9]
- Exclude some potential causes of death[10]
- Identify disorders that have implications for counselling and monitoring in future pregnancies[10-16]
- Provide other information related to the death, including excluding possibilities that may alleviate feelings of guilt [1,8,9,11,16]
- Obtain tissues for genetic tests (see *Appendix S – Components of the genetic autopsy for investigations of metabolic disorders)*
- Assist grieving by helping parents' understanding of the events surrounding the death [1,11,16,17]
- Contribute to research, for example, by the recognition of new disease entities and expansion of knowledge on known diseases[14,15,18-24]

- Inform clinical audit of perinatal deaths, including deaths due to iatrogenic conditions[20] and to confirm antenatal diagnoses or suspected fetal pathology[21,22]
- Teach pathologists and medical students[10,11,25]
- Avoid inaccuracies in data on causes of death for audit activities and subsequent public health policy[26-29].
- Inform medico-legal processes, for example, provide information in coronial investigations or cases of litigation[10,16].

### Value of an autopsy including placental examination

The autopsy examination remains the gold standard for identifying cause of perinatal death[1,2]. The value of a perinatal autopsy has been demonstrated in several studies where the information obtained changed diagnoses or provided important additional findings[17,21,30-38]. A review of 27 studies found that perinatal autopsy revealed a change in diagnosis or additional findings in 22% to 76% of cases[30]. Another review of 53 studies, across a broad range of health care settings, on diagnostic errors detected at autopsy demonstrated a median error rate of 23.5% for major errors (clinically missed diagnoses involving a principal underlying disease or primary cause of death) and 9% for Class 1 errors (major error that, had they been detected during life, "would", "could", "possibly" or "might" have affected patient prognosis or outcome). This study also showed some decrease in error rate over time however the rate remained sufficiently high, supporting the ongoing use of autopsy [39]. Value from an adequate numbers of perinatal autopsies to ensure standards in perinatal pathology has also been suggested[40].

A systematic review concluded that pathology of the placenta, cord, or membranes is attributed as a cause or contributory to stillbirth in 11% to 65%[41]. Placental histopathology can be causal and associated with factors associated with causing neonatal morbidity and mortality including: fetal growth restriction; pre-eclampsia; infection; conditions as a result of hypoxia such as necrotising enterocolitis and cerebral palsy; and infants who fail to respond to resuscitation[23,37]

### Pathways to an autopsy

An autopsy results from one of two major pathways: with parent consent or mandated by the coroner. Informed parental consent is essential for any post-mortem examinations that are not coroner-mandated (see Section 3).

### Coroner-mandated autopsy

The purpose of a coroner's autopsy is to determine the cause of death, and specifically whether it was natural or unnatural. Each jurisdiction has reasons for notification and so it is important to reference the Coroner's act for your state or territory. Some examples are:

- Babies dead on arrival at hospital
- Unattended stillbirths
- Deaths after an operation, anaesthetic or invasive procedure
- Deaths as a result of accident
- Unnatural, criminal or suspicious deaths, e.g. neglect, abuse, poisoning
- Deaths caused by drugs, prescribed or otherwise
- Deaths as a result of medical mishap
- Deaths in which the doctor is uncertain of the cause of death and unable to confidently complete the death certificate
- Unexpected death on the ward[10].

If there is any doubt as to whether a death should be referred to the coroner, discussion with an experienced coronial officer or with the coroner is advised.

Coroners should ideally arrange for paediatric pathologists to perform the autopsy[4], and provide results to relevant clinicians rather than use general or forensic pathologists.

The Coroner's act for each state and territory can accessed via the relevant links listed:

| State/Territory | Web site address/URL |
|---|---|
| **Victoria** | http://www.coronerscourt.vic.gov.au/find/legislation/ |
| **South Australia** | https://www.legislation.sa.gov.au/LZ/C/A/CORONERS%20ACT%202003.aspx |
| **Queensland** | https://www.legislation.qld.gov.au/LEGISLTN/CURRENT/C/CoronersA03.pdf |
| **New South Wales** | http://www.legislation.nsw.gov.au/#/view/act/2009/41/whole |
| **Western Australia** | https://www.slp.wa.gov.au/legislation/statutes.nsf/main_mrtitle_201_homepage.html |
| **Tasmania** | http://www.thelaw.tas.gov.au/tocview/index.w3p;cond=;doc_id=73%2B%2B1995%2BAT%40EN%2B20160707000000;histon=;pdfauthverid=;prompt=;rec=;rtfauthverid=;term=;webauthverid= |
| **Northern Territory** | http://www.austlii.edu.au/au/legis/nt/consol_act/ca120/ |
| **Australian Capital Territory** | http://www.legislation.act.gov.au/a/1997-57/ |
| **New Zealand** | http://www.legislation.govt.nz/act/public/2006/0038/latest/whole.html |

## 4.5 Different types of autopsy

Autopsies are generally defined in terms of their extent. The "gold standard" is the 'classical' conventional or full autopsy, which involves the combination of review of the clinical notes and maternal investigations, placental examination and examination of the baby. In a full autopsy examination of the baby includes external examination (including measurements and clinical photographs), radiological investigations, evisceration, dissection and organ examination including detailed histological evaluation. Other special tests like microbiology, molecular karyotyping/cytogenetics and molecular studies may also need to be performed. All other forms of autopsy are compared to the full autopsy in terms of the level of examination and degree of invasiveness[3].

Less invasive autopsies (LIA) include all post-mortem examinations that take an approach other than a full autopsy. LIA include limited and minimally invasive or non-invasive autopsies. Limited

autopsies take an organ-specific approach and usually require some form of surgical incision. For example, the examination involves an incision to look at the heart or brain only. Minimally invasive autopsies (MIA) do not make a large surgical incision but use a laparoscopic or keyhole approach to obtain organ samples with radiological guidance. Non-invasive autopsies (NIA) use no internal examination, but instead rely on the detailed external, placental and umbilical cord examinations and external measurements, skin/needle blood sampling, clinical photography, and radiological investigations that are performed. Radiology may also include conventional radiographs, computed tomography, or magnetic resonance imaging[42,43] (see 4.13 below). Stepwise post-mortem may include sampling tissue immediately after death (for example for metabolic reasons) then performing the full autopsy.

## 4.6 Autopsy rates

While data to establish an optimal perinatal autopsy rate is lacking, the Working Party of the Royal College of Pathologists[5] recommended a rate of 75%. However, perinatal autopsy rates have steadily declined over recent years to rates much lower than this recommendation in many regions. A 2.8% per year decline over the decade 1990-1999 was reported by one tertiary setting in the UK [17]. Reports of perinatal autopsy rates more than a decade ago ranged from 33% to 67% [17,23,24,44]. An analysis of perinatal deaths in Australia from 2011-2012 showed an overall perinatal autopsy rate of 38.7% (42.3% stillbirth and 28.2% neonatal deaths). Over half (57.5%) of all perinatal deaths were recorded as not having an autopsy performed [45].

### Why the decline in autopsy rates?

Consent is the major limiting factor to achieving adequate autopsy rates[16,46]. Consent for autopsy is difficult for both clinicians and parents. Parents are confronted by a proposed process that appears intrusive, and that requires them to understand detailed consent procedures when they are in a state of grief[10] while clinicians are reluctant to place further burden on parents[47].

Adverse publicity generated from inquiries into autopsy practices in the United Kingdom over retained organs[48-50] and the inquiry at the NSW Institute of Forensic Pathology[51] are believed to have adversely influenced clinicians' willingness to seek consent and parents' acceptance of the procedure[52,53]. Practice improvements resulted from the NSW inquiry but complexity in the consent process also increased, which may have created an additional deterrent for clinicians[8]. However, clinician reluctance to seek consent because of the added burden placed on families may be misplaced. A survey of UK parents found significantly more parents who did not have an autopsy were dissatisfied with their decision (OR=2.43, 95% CI 1.53-3.87)[54]. The low autopsy rate may also indicate that clinicians are ambivalent about the value of an autopsy[10,55,56] or may be reluctant to discuss difficult issues with families where no pre-existing relationship exists

Other factors identified as possibly affecting clinicians' willingness to approach parents for consent for autopsy include: lower gestational age at death[17,57]; clinician discipline and seniority [16,57]; and workforce shortages[8].

Khong *et al* found that obstetricians and neonatologists were less averse to seeking consent for perinatal autopsies than midwives and neonatal nurses who were more influenced by those factors unfavourable to consent-seeking[16]. Obstetricians and neonatologists surveyed considered nurses and midwives influential in parents' decision-making about autopsy[16].

Provision of educational opportunities for all members of clinical teams, both formal (during undergraduate and post graduate training) and informal (through day-to-day positive reinforcement from clinical leaders) is crucial to increasing the rates of perinatal autopsy.

***Section 4 Recommendations***

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| **1** | Clinicians should discuss the value of an autopsy with parents in all cases of perinatal death and offer them the option of the procedure. |
| **2** | To increase the rates of perinatal autopsy:<br>• Clinicians should collaborate with pathologists and parent based organisations to raise public awareness of the value of perinatal autopsy and to advocate for high standards in perinatal autopsy at local and government level.<br>• Clinical leaders should promote formal and informal educational opportunities for clinicians on: post-mortem examination procedures; the potential benefits of an autopsy; compassionate counselling and obtaining parental consent; and address specific local barriers to the conduct of perinatal autopsy.<br>All clinicians providing maternity and newborn care should attend the IMproving Perinatal Mortality Review and Outcomes Via Education (IMPROVE) Workshops educational program (https://sanda.psanz.com.au/improve/). |
| **3** | Seek advice from the coroner or an experienced coronial officer if any doubt exists as to whether a death should be referred to the coroner. |

## 4.7 Costs of a post-mortem examination and transport

Diverse arrangements exist across Australia regarding payment for autopsy[8]. The cost of autopsy are estimated to be around $1500[58] – $2600[59]. Currently the post-mortem examination of a stillborn baby is not adequately covered under Medicare and consequently the costs for the post-mortem examination need to be covered either by the institution state health departments or their designated authorities.

***Recommendation***

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| **4** | Clinicians need to be aware of costs associated with transferring an infant from non-metropolitan areas to tertiary centres for autopsies within their region and inform parents of any personal cost implications relevant to their decision-making. |

## 4.8 Quality of perinatal autopsies and minimum standards

Research on the quality of perinatal autopsies is limited however the available data suggests that approximately half may not reach minimum standards[23,55,60]. Approaching parents for consent when a quality post-mortem service is not available raises important ethical questions[2] that demand attention to the requirements of minimum standards.

The post-mortem examination of an infant is very different to that performed on an adult[5,61-63], and ideally should be performed by a paediatric pathologist. Pathologists with paediatric training find a higher incidence of causes of death in infants[64], provide a much higher proportion of adequate reports[65,66], and the causes of death based on perinatal/paediatric pathologists reports are infrequently revised by the Confidential Enquiry into Stillbirths and Deaths in Infancy (CESDI) review panel[67]. There are currently no guidelines for Australia and New Zealand on quality and minimum standards for perinatal autopsies. Until the availability of such guidelines, the Guidelines on Autopsy Practice produced by the Royal College of Pathologists should be used for guidance[4].

Appropriate clinical information is an essential part of a good quality post mortem. The history of the pregnancy, results of antenatal investigations and circumstances of perinatal loss are vital in determining the relevant questions to be addressed by the post mortem and enable judicious use of investigations (please refer to *Appendix I – Autopsy clinical summary form*). Transportation of the baby to a centre with appropriate perinatal pathology expertise should be offered to parents where this expertise does not exist in the birth facility. Transport should be arranged with a registered undertaker.

There is growing use of new molecular techniques in the assessment of perinatal deaths. Chromosomal microarray is fast becoming standard practice as it detects a significant number of pathological changes not seen with standard karyotyping, although balanced chromosomal translocations and triploidy may not be detected[68]. However, this is a developing technology and the range of normal and pathological variants are yet to be established. Interpretation can be time consuming. Next generation sequencing is already used diagnostically with large studies funded in the US and under discussion in the UK and Australia for more routine[69]. Material like cartilage or skin can be used for these techniques. This needs to be retained and should be included in the consent process.

Following recent reviews the use of microarray is becoming standard[68]. Identification of previously undiagnosed genetic disorders always was part of the post mortem process making a full informed consent difficult. However the parents should be informed that material for DNA and genetic tests is likely to be retained, and should be if there are features suggesting a genetic cause. Consent for further genetic testing may be sought by the genetics team after the autopsy using material retained at autopsy.

Specific autopsy protocols have been developed for examinations when genetic metabolic disorders are suspected[70] and in the event of a Sudden Unexpected Deaths in Infancy[71]. Please refer to these protocols for full details.

(*Please see Appendix Q – Suspected genetic metabolic disorders)*

*(Please see:*

- *Appendix O – RCPath guidelines for autopsy investigation of fetal and perinatal death*
- *Appendix Q – Suspected genetic metabolic disorders*
- *Appendix I – Autopsy clinical summary form*

## ***Recommendations***

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| **5** | The Guidelines on Autopsy Practice produced by the Royal College of Pathologists[5] should be used for guidance on minimum standards until guidelines for Australia and New Zealand are developed. |
| **6** | Specific protocols developed for post-mortem examination in the event of Sudden Unexpected Death in Infancy and death with suspected genetic metabolic disorders should be followed. |
| **7** | A perinatal/paediatric pathologist should perform or supervise all perinatal post-mortems. Clinicians should request autopsies from the service providing the highest quality. |
| **8** | Transport to a centre with appropriate expertise should be arranged to ensure that all perinatal post-mortem examinations are of sufficient quality. Transport should be arranged with a registered undertaker. |
| **9** | A comprehensive maternal history should accompany the baby for a post-mortem examination including:<br>• Clinical/obstetric history including relevant previous obstetric history<br>• Copies of all ultrasound reports9<br>• Copy of the death certificate if available<br>• Copy of amniocentesis report if available. |

## 4.9 Post-mortem reporting

A preliminary report is usually available within three days of the examination, and should include a summary of the clinical history, samples taken and further tests requested, and macroscopic findings. The final report may take up different times in different jurisdictions; up to eight weeks in most cases although more complex genetic or metabolic workups can take six to 12 months. The post-mortem report includes demographic details, a clinical summary, and findings of the external and internal examination including: organ weights; microscopic findings; results of ancillary examinations such as cytogenetics; microbiology; radiology a summary of findings; a commentary to suggest the most likely pathophysiological pathway; and a cause of death if appropriate. Other details ideally recorded are mode of identification, a list of samples taken, a record of X-rays and photographs taken, and details of the consent and any limitations imposed[10].

Delays with and poor communication of results can be a source of much distress to parents[72,73]. Establishing clear processes and timelines for informing parents of results may help to alleviate such distress.

A plain language report (PLR) may be helpful to parents[8]. A copy of the PLR, if available, and full autopsy report should also be sent to the GP. Autopsy reports should not be sent directly to the parents but provision should be made to discuss the findings with the parents, even if the results are inconclusive[74]. Parents should be advised in instances where, based on the findings of investigations, a revised death certificate may be be submitted. Such discussions should take

place at a suitable venue (e.g., away from antenatal clinics). Parents should be advised in instances where, based on the findings of investigations, a revised death certificate will will be submitted.

***Recommendations***

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| **10** | Guidelines for post-mortem reports produced by the Royal College of Pathologists[4] should be used as a guide for reporting of perinatal post-mortem examinations. |
| **11** | Ideally, a preliminary post-mortem report should be forwarded to the referring clinician within three working days of the post-mortem. The final report should be forwarded to the referring clinician ideally within eight weeks of the autopsy. |
| **12** | The post-mortem report should be made available to the parents at a time when the primary care clinician is present to discuss the findings. |
| **13** | A Plain Language Report (PLR) should be available to parents on request. |
| **14** | A request for the General Practitioner (GP) to receive a copy of the report (including the PLR, if available) should be explicit on the request form, as they are the main care provider on discharge. |

## 4.10 Communication and consent

All hospital perinatal autopsy examinations require written consent from parent(s) following informed discussion[47], although little is known on the best ways to inform parents making decisions about autopsy or other post-mortem examinations and we rely on the knowledge and experience of those involved at the time[75]. Such knowledge and experience can be highly variable among health professionals[54].

The influences on parents' decision-making regarding autopsy are complex and diverse[72,73,76]. Assumptions need to be avoided as barriers perceived by clinicians are often different from those reported by parents [72]. Parents are often overwhelmed and need clear, easily understandable and structured information presented verbally and in written form [72]. Parents should be given written information explaining autopsies to assist in their decision about an autopsy examination for their baby (please refer to *Appendix M – Infant autopsy consent brochure*). The extent of the examination including retention of organs and DNA needs to be clearly explained and documented in the consent form. Options for a full, limited or stepwise autopsy should be explained. Parents need to be counselled that limited autopsy may result in the loss of important information. Written consent from parents is also required for peri-mortem investigations such as clinical photographs, tissue and blood sampling by cardiac puncture. Written consent is not required for histopathological examination of the placenta, however parents should be informed that this is a part of the routine investigation that may provide valuable information[77].

Parents want to know why their baby died and a desire for information is a strong motivating factor for consent to autopsy; concerns about the invasiveness of the procedure and a desire to

protect the baby from unnecessary harm are major barriers to consent (Lewis et al., 2017). A UK survey that included 460 parents, found professional advice influenced the decisions about autopsy for more than one in five parents (22%). The majority of parents were satisfied with their decision related to autopsy, although those who did not have an autopsy were more likely to be dissatisfied[54]. Regret is more common among parents who have not had an autopsy even when a cause of death is not found, although sample sizes are commonly small or skewed[54,78,79]. Informed discussion with the parents should include the possibility that a cause of death may not be found, but that the information obtained may benefit other babies in the future. Clinicians need to be aware of religious and cultural beliefs and values which may influence parents' decisions[8,11]. It is important and appropriate to ask parents what is important to them.

Where possible, consent from parents should be sought by an experienced clinician who has rapport with them. Responsibility for obtaining informed consent lies with the primary attending physician[2,10] and in most cases the consultant clinician should approach the parents, although this may be delegated to another attending clinician (e.g. midwife, nurse)[80]. Clinicians seeking consent should be prepared to answer in a sensitive manner questions about what actually happens to the baby during the procedure and how the baby may look after the examination[80]. Therefore, all clinicians seeking consent should have in-depth knowledge of post-mortem procedures and, preferably, have witnessed several autopsy examinations. Discussion with parents about consent for all post-mortem examination needs to take into account the importance of partnerships in decision making[81]. Parents are likely to need practical information about the process and the implications of their decision, such as advice on how long the baby can remain in the hospital or be taken home without adversely affecting post-mortem results, whether they will be able to see the baby again, and if any costs might be involved.

(*Please refer to Appendix N – Information for health professionals seeking consent*.

### *Recommendations*

**15** Where possible, a senior clinician who has established a rapport and understanding with the parents should discuss the value of an autopsy and offer the option of the procedure. Such clinicians should have high level communication skills and knowledge of all post-mortem examinations, and preferably witnessed several perinatal autopsies.

**16** Any clinician approaching parents for autopsy consent should discuss:

- Options for full, Less invasive autopsies (LIA), minimally invasive autopsies (MIA), Non-invasive autopsies (NIA) or stepwise post-mortem examinations
- Issues related to retained tissues, organs and DNA for genetic and other tests
- The value of autopsy
- Possibility that cause of death may not be determined
- Possibility that some potential causes of death could be excluded
- Information gained may not directly benefit the family but may benefit others
- Possible implications for future pregnancies
- The care and respect that will be given to the baby

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| **17** | Discussion with parents should be supplemented by written information explaining autopsies to help in their decision on autopsy for their baby. |
| **18** | When consent is obtained for specific organ/s to be retained for further examination, parents should be offered the option of either delaying the funeral until the organs can be returned to the body or specifying their preferred method of organ disposal. |
| **19** | Consent for the autopsy which clearly outlines the extent of the investigation should be recorded on an approved consent form, relevant to the jurisdiction. |
| **20** | Where possible the pathologist should be available to discuss the autopsy with the parents before and/or after the procedure and, where feasible, the requesting clinician should attend the autopsy and provide the parents with a preliminary report immediately after the examination. |

## 4.11 Placenta, membranes and cord histopathology

Examination of the placenta, membranes and cord should occur after all births. The placenta is also an integral part of the post-mortem examination and, ideally, all placentas should be retained for a few days after birth to allow for subsequent retrieval should an infant deteriorate. This may happen with sepsis or metabolic disorder[10]. The placenta, membrane and cord should be sent to the pathologist fresh and unfixed for histopathological examination once samples have been collected for cytogenetics and microbiology. A perinatal/paediatric pathologist should undertake the examination[23] . A standardised reporting form for placental histopathology is provided to enable high quality reporting (Please see *Appendix P – Placental histopathology reporting form*).

Placental examination by a perinatal/paediatric pathologist should be performed for specific maternal, placental, fetal and neonatal indications[82].

Maternal indications include:

- Systemic disorders such as an active autoimmune disease, uncontrolled diabetes, or other significant maternal disease that has affected the pregnancy
- Moderate or severe pre-eclampsia
- Intrapartum fever or infection
- Suspected chorioamnionitis
- Unexplained bleeding in the third trimester
- Excessive bleeding (more than 500ml)
- Placental abruption
- Severe maternal trauma
- Amniotic Fluid Index (AFI) abnormalities.

Fetal and neonatal indications include:

- Admission to neonatal intensive care
- Failure to respond to resuscitation
- Spontaneous or iatrogenic preterm birth
- Fetal compromise including growth restriction
- Severe cardiorespiratory depression at birth

- Signs consistent with congenital infection
- Severe growth restriction
- Diagnosis of hydrops fetalis
- Suspected severe anaemia
- Suspected or known major congenital abnormalities
- Death.

Placental indications include:

- Physical abnormality
- Abnormal placental size or weight for gestational age (small or large)
- Suspected vasa praevia
- Umbilical cord lesions
- Abnormal cord length.

***Recommendation***

**21** Placentas should be sent for examination by the perinatal/paediatric pathologist regardless of whether consent for an autopsy has been gained following stillbirths, neonatal deaths in the delivery room or birth of high risk infants.

## 4.12 Alternative investigations: When permission for autopsy is not obtained

If permission for an autopsy is not obtained, other less invasive testing may assist to establish whether any important abnormalities have been missed. These options should be offered to parents as these alternatives permit detailed investigation of the baby while respecting the wishes of parents[83]. However, a Working Group of the Royal College of Paediatrics and Child Health found little evidence for valid alternatives to the paediatric post-mortem[61]. Parents should be informed at the time of consent about the possibility of missing an important finding when a full post-mortem investigation is not undertaken. All alternative investigations are subject to the same requirements of informed consent as autopsy examinations.

### External examination

Examination by an experienced clinician (by a perinatal/paediatric pathologist, clinical geneticists or paediatrician) is of particular importance when an autopsy examination is declined[84]. Clinicians should discuss the importance of this examination with the parents and arrange for an appropriately skilled clinician to perform it.

*Please refer to Chapter 5 - Investigation of stillbirths and Chapter 6 - Investigation of neonatal deaths for further details*

### Babygram

Parents who decline an autopsy should be provided with further information about and asked to consent to the use of a full body X-ray (babygram) as an alternative non-invasive investigation. A babygram may detect abnormalities (mainly skeletal) which may not be detected on an

external examination. The Wisconsin Stillbirth Service Program has estimated that approximately 20% of unselected stillborn babies will have abnormalities which are detectable on X-ray[84].

*Please refer to Chapter 5 - Investigation of stillbirths for further details.*

### Ultrasound scan

A detailed ultrasound examination of the infant at the time of confirmation of an intrauterine death or after the birth may identify fetal abnormalities not identified by an external examination[85].

*Please refer to Chapter 5 - Investigation of stillbirths for further details.*

### Magnetic Resonance Imaging (MRI)

Magnetic Resonance Imaging (if available) may be offered to parents who decline an autopsy investigation. The investigation should be undertaken as soon as possible after a stillbirth. Clinicians should explain to the parents that a full autopsy remains the gold standard as the MRI does not supply tissue samples and therefore important information may be missed.

A comprehensive overview presented the advantages and disadvantages of the post-mortem MRI[1]. The major advantages of post-mortem MRI included the non-invasive nature of the examination and the detection of pathologies and malformations of the central nervous system. The disadvantages included the lack of tissue sampling; limitations in detection of complex cardiac malformations, and other abnormalities (e.g. tracheo-oesophageal fistula, bowel perforations) which are undetectable by post-mortem MRI; and lack of experience in perinatal post-mortem MRI. The authors concluded that a full autopsy remains the gold standard; however, MRI may play an important role when an autopsy is declined [1].

More recent literature comparing MRI with autopsy in accurately identifying cause of death or most clinically significant abnormality in stillborn fetuses found that sensitivity for MRI was 69%, and specificity was 95%[86]. Following on from these results, one large study showed that concordance for detection of major pathological abnormalities between full autopsy and MRI is near 43% for stillbirth ≤24 weeks' gestation, and 63% for stillbirths >24 weeks' gestation[87]. However the discordance between MRI and full autopsy is relatively high, 23% for stillbirth ≤24 weeks' gestation, and 33% for stillbirths >24 weeks' gestation[87], suggesting that MRI only may not be an optimal substitution for full autopsy. Current ongoing studies are exploring yield of techniques combining computed tomography (CT) scans with MRI to guide biopsy sampling, so-called virtual autopsy[88]. It is possible that MRI in combination with additional techniques may provide an option for cause of death investigations when full or partial autopsy is declined

### Clinical photographs

Following consent from parents, clinical photographs should be taken for later review, particularly for births that occur in non-tertiary hospital settings. These photos are additional to the bereavement photographs and should not be given to the parents. They should be clearly labelled and filed in the medical record. The use of digital imaging for this purpose is optimal, however issues regarding storage and patient confidentiality should be considered.

*Please refer to Chapter 5 - Investigation of stillbirths and Chapter 6 - Investigation of neonatal deaths for further details.*

### Other alternatives to a full post-mortem examination

Post-mortem needle biopsy; laparoscopic autopsy and small incision access are other alternatives to a full post-mortem for focussed investigation of suspected abnormalities. Recent studies suggest that minimally invasive post-mortem examinations may be a valuable investigation to determine cause of death in stillbirth if a full post-mortem is declined[87].

***Section 4 Recommendation***

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| **22** | Consent should be sought from parents for less invasive testing if permission for an autopsy is not obtained, including: external examinations by skilled clinician; an MRI scan; babygram; ultrasound scan; post-mortem needle biopsy; laparoscopic autopsy and small incision access. |
| **23** | When an MRI scan is undertaken it should be undertaken as soon as possible after a stillbirth. |

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## 4.14 Section authors

Yee Khong, Vicki Flenady, Jane Dahlstrom, David Ellwood, Lisa Hui, Dell Horey, Lynn Sinclair, Jane Zucculo, Fran Boyle.

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## 4.16 Appendices

*Appendix I – Autopsy clinical summary form*

*Appendix M – Infant autopsy consent brochure*

*Appendix N – Information for health professionals seeking consent*

*Appendix O – RCPath guidelines for autopsy investigation of fetal and perinatal death*

*Appendix P – Placental histopathology reporting form*

*Appendix Q – Suspected genetic metabolic disorders*

*Appendix S – Components of the genetic autopsy for investigations of metabolic disorders*