

**FINAL REPORT:
REMOVAL AND RETENTION OF ORGANS AND TISSUE
FOLLOWING POST-MORTEM EXAMINATIONS**

A Report to the Minister for Health

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1.0 Introduction

1.1 Relevant background

In March 2001, a hotline was established by the Minister for Health to allow the relatives of a deceased person to raise queries about the conduct of post-mortem examinations, and in particular about any retention of organs and tissue following post-mortem examinations.

The process implemented by the Department of Health to investigate the queries which were raised by callers to the hotline was described in the *Interim Report to the Minister for Health on the Investigation into the Removal and Retention of Organs and Tissue following Post-Mortem Examinations in Western Australia* ("the *Interim Report*") (see Annexure A).

In the *Interim Report* the three stages of the investigation were described as follows:

1. The investigation of the specific queries, concerns and complaints which have been registered with the Department.
2. A review of current post-mortem practices and procedures in Western Australia under existing legislation.
3. Consideration of the need for any amendments to existing legislation, changes to procedures or implementation of new procedures, relating to the conduct of post-mortem examinations.

After the release of the *Interim Report* in June 2001, 22 additional cases were registered with the Department of Health for investigation (see Annexure B).

This brought the total of individual cases registered with the Department to approximately 60. Most of the investigations have now been finalised. Of the later cases registered, 11 cases are not yet finalised, but will soon be finalised.

The queries and concerns which were raised in the additional cases registered since the *Interim Report* are similar to those which were raised in the earlier cases, and which were described in the *Interim Report*.

The review and consideration of the practices, procedures and legislation (referred to in the *Interim Report* as stages 2. and 3. of the investigation) has now been completed and is the subject of this *Final Report*.

1.2 Other relevant activities

In June 1998, the Secretary of State for Health (UK) established an inquiry into paediatric cardiac services at the Bristol Royal Infirmary ("the Bristol Inquiry"). In May 2000, the Bristol Inquiry issued an interim report on the removal and retention of organs and tissue during post-mortem examinations.¹

In December 1999, as a result of evidence given at the Bristol Inquiry, an inquiry was established into the removal, retention and disposal of organs and tissue at the Royal Liverpool Children's ('Alder Hey') Hospital ("the Alder Hey Inquiry"). In November 2000, the Alder Hey Inquiry issued its report.²

In September 2000, the Minister for Health and Community Care (Scotland) established an Independent Review Group to consider post-mortem examination practices, particularly in relation to organ and tissue retention. In January 2001, the Independent Review Group issued its first report.³

In February 2001, the Chief Medical Officer (UK) issued advice on the removal and retention of organs and tissue at post-mortem examination which drew on the results of the Bristol and Alder Hey Inquiries.⁴ Its intention was to: "provide definitive advice which will enable a new beginning and start the process of restoring public confidence."⁵

¹ The Bristol Royal Infirmary Inquiry (2000) *Interim Report - Removal and retention of human material* (<http://www.bristol-inquiry.org.uk>)
² The Royal Liverpool Children's Inquiry (2000) *Report* (<http://www.rlcinquiry.org.uk/index.htm>)
³ Independent Review Group (2001) *Report of the Independent Review Group on the Retention of Organs at Post Mortem* (<http://www.show.scot.nhs.uk/scotorgrev>)
⁴ Department of Health (UK) (2001) *The Removal, Retention and use of Human Organs and Tissue from Post-Mortem Examination ("CMO(UK) Advice")* (<http://www.doh.gov.uk/orgretentionadvice>)
⁵ *CMO(UK) Advice* at p. 3 (Chapter 1, para 14).

In October 2000, an interim policy on consent as it related to post-mortem examinations was issued by the Director-General (NSW Department of Health),⁶ and a review process was commenced in that State. In March 2001, the Chief Health Officer (NSW) issued an interim report on organ and tissue retention following post-mortem examinations in that State.⁷

In August 2001, reports on specific investigations relating to organ and tissue retention conducted in New South Wales⁸ and South Australia⁹ were issued.

In November 2000, the Minister for Health (Cth) requested the Australian Health Ethics Committee ("AHEC")¹⁰ to provide advice on the ethical and practical issues relating to organs retained following a post-mortem examination. That advice, including recommendations, has recently been finalised by AHEC.

Policy guidelines relating to organ and tissue retention have also been issued by the Royal College of Pathologists (UK)¹¹ and the Royal College of Pathologists of Australasia,¹² and the issues involved have been the subject of ongoing review by such professional bodies.¹³

As a result of the various inquiries, investigations and reviews which have been conducted in the last few years, the issues relating to post-mortem examinations and organ and tissue retention have now been the subject of very detailed and extensive consideration.¹⁴

⁶ NSW Health (2000) *Interim Policy on Consent Associated With Post-Mortem Examination* (<http://www.health.nsw.gov.au/health-public-affairs/publications/policies/interimpolicy.html>)

⁷ NSW Health (2001) *Interim Report into the retention of tissue & organs following post-mortems in NSW* (<http://www.health.nsw.gov.au/whatsnew>)

⁸ Bret Walker SC (2001) *Inquiry into Matters Arising from the Post-mortem and Anatomical Examination Practices of the Institute of Forensic Medicine: Report* (<http://www.health.nsw.gov.au/health-public-affairs/forensic>)

⁹ BM Selway QC (2001) *Report into the Retention of Body Parts after Post-Mortems* (<http://www.dhs.sa.gov.au/documents/publications/BodyParts.pdf>)

¹⁰ AHEC is a committee of the National Health and Medical Research Council ("NHMRC"), established under the *National Health and Medical Research Council Act 1992* (Cth). It has the function of providing advice to the NHMRC on ethical issues relating to health.

¹¹ The Royal College of Pathologists (March 2001) *Guidelines for the retention of tissues and organs at post-mortem examination* (http://www.rcpath.org/news/tissue_retention.pdf)

¹² The Royal College of Pathologists of Australasia (July 2001) *Autopsies and the Use of Tissues Removed from Autopsies* (<http://www.rcpa.edu.au/images/pdf/PolicyProcedureManualOct2000.pdf>)

¹³ For example, the Royal College of Pathologists of Australasia has held workshops to discuss the issues involved, and develop appropriate guidelines, in March 2001 and May 2001.

¹⁴ As Mr Selway QC, the Solicitor-General for South Australia, noted in his recent report: "Whatever the position may have been five years ago there is now a surfeit of information on the legal and ethical issues relating to post-mortems and the retention of body tissues available for those that wish to seek it." (BM Selway QC *Report into the Retention of Body Parts after Post-Mortems* at 8)

The central theme which has emerged, in a relatively consistent way, from those inquiries, investigations and reviews is:

- (a) that the relatives of a deceased person need to be given an adequate opportunity to participate in the decision-making involved in any post-mortem examination which may be carried out in relation to the deceased person;
- (b) that an appropriate level of communication with the relatives of a deceased person about any post-mortem examination is critical to any informed involvement by them in the decision-making process; and
- (c) that unless the law, and relevant practices and procedures, operate to adequately secure such an opportunity for relatives, the post-mortem examination system will be significantly out of step with current community expectations.

2.0 The Post-Mortem Examination

In its simplest terms, a post-mortem examination is a medical examination carried out on the body of a deceased person after death.¹⁵ Sometimes, this process of examination is described as an 'autopsy'¹⁶ (less commonly as a 'necropsy'.)¹⁷ In this *Report* the description 'post-mortem examination' will be used.¹⁸

¹⁵ Each year, there are approximately 130,000 deaths in Australia, and approximately 12,000 deaths in WA. Approximately 15% of those deaths will result in a post-mortem examination. The majority of those post-mortem examinations (ie 85%-90%) will be coronial post-mortem examinations. In WA there are approximately 1500 coronial post-mortem examinations carried out each year.

¹⁶ The term has the literal meaning of 'seeing with one's own eyes; personal observation' and in this context refers to the dissection of a dead body so as to ascertain the cause or extent of disease processes by actual inspection, as distinct from other forms of diagnosis (see *Shorter Oxford English Dictionary*).

¹⁷ The term refers to the surgical examination of a dead body (see *Shorter Oxford English Dictionary*).

¹⁸ This is the term which has been adopted by the *Coroners Act 1996* (WA) (see for example s34), the *Human Tissue and Transplant Act 1982* (WA) (see for example s25) and the *Anatomy Act 1930* (WA) (see for example s20). It was also the term adopted by the former coronial legislation (see for example *Coroners Act 1920* (WA) s40).

2.1 Classification of post-mortem examinations

It is common to classify post-mortem examinations into those that are carried out under the jurisdiction of, and for the purposes of, a coroner and those that are not carried out under that jurisdiction and for that purpose.

The terminology varies. However, the former are usually described as 'coronial post-mortem examinations' and the latter are usually described either as 'hospital post-mortem examinations' or 'non-coronial post-mortem examinations' (less commonly as 'consent post-mortem examinations'). In this *Report* the descriptions 'coronial' and 'non-coronial' will be used to classify the two different kinds of post-mortem examination.

While the genesis and rationale of 'coronial' and 'non-coronial' post-mortem examinations are different, and there are some aspects of the procedures carried out which tend to differ,¹⁹ the basic post-mortem examination procedures are similar in the 'coronial' and 'non-coronial' context.

2.1.1 Coronial post-mortem examination

A coroner is given the jurisdiction to investigate certain kinds of death in our community,²⁰ namely any death which:

- (i) appears to have been unexpected, unnatural or violent;
- (ii) appears to have resulted, directly or indirectly, from injury;
- (iii) occurs during, or as a result of, an anaesthetic;²¹

¹⁹ For example, the external examination is usually much more detailed in a coronial post-mortem examination, the internal examination is often more thorough as well (not necessarily based only on the examination of organs as is usually the case for non-coronial post-mortem examinations), and the pathologist carrying out a coronial post-mortem examination is not able to rely to any great extent on pre-existing clinical history (as is usually the case for the pathologist carrying out a non-coronial post-mortem examination). Also, toxicology tests are almost routine in coronial post-mortem examinations, but very rare in non-coronial post-mortem examinations.

²⁰ *Coroners Act 1996* (WA) s19 (1); s3 (defn. of "reportable death"). The former legislation, the *Coroners Act 1920* (WA), which applied until 7 April 1997, gave to a coroner similar jurisdiction (ie in relation to deaths which appeared to have been violent or unnatural or sudden with an unknown cause or while the person was in a prison or mental health institution): see *Coroners Act 1920* (WA) s6.

²¹ In the latter case only if the death was not due to natural causes: *Coroners Act 1996* (WA) s3 (para (c) of the definition of "reportable death").

- (iv) is of a person who was 'held in care', or appears to have been caused or contributed to while the person was 'held in care';²²
- (v) appears to have been caused or contributed to by any action of a member of the Police Force of the State;
- (vi) is of a person whose identity is not known;
- (vii) where a death certificate has not been issued by a medical practitioner.

Where a coroner assumes the jurisdiction to investigate a death, the coroner is required to attempt to determine the identity of the deceased, how the death occurred, the cause of the death and any other particulars which are required to enable the death to be registered.²³

Where the death is of a person who was 'held in care', a coroner is also required to comment on the quality of the supervision, treatment and care of the person.²⁴

In any case, the coroner is also entitled to comment on any matter connected with the particular death, including public health or safety or the administration of justice.²⁵

A coroner may, to assist in the investigation of a death, direct that a post-mortem examination be carried out on the body of the deceased.²⁶

In many cases, a post-mortem examination will provide crucial information to the coroner about the death (whether by confirming, and/or excluding, the various possible causes or contributing factors to the death).

Therefore, in most cases which fall within the jurisdiction of the coroner, a direction will be given to conduct a post-mortem examination.²⁷ In this State, such a direction is given in approximately 90% of deaths which are investigated by a coroner.²⁸

²² A person is considered to be 'held in care' when in the custody of the prison service, the police service, the child welfare service, a drug and alcohol rehabilitation centre, mental health hospital or detained as a young offender: *Coroners Act 1996* (WA) s3 (defn. of "person held in care").

²³ *Coroners Act 1996* (WA) s25 (1).

²⁴ *Coroners Act 1996* (WA) s25 (3).

²⁵ *Coroners Act 1996* (WA) s25 (2).

²⁶ *Coroners Act 1996* (WA) s34 (1). The former legislation contained a similar power to direct that a post-mortem examination be carried out: *Coroners Act 1920* (WA) s40 (2).

²⁷ Indeed, the legislation assumes that in most cases a post-mortem examination will be necessary (see s20 (1) (b) of the *Coroners Act 1996* (WA) which requires a coroner, as soon as is practicable after assuming jurisdiction to investigate the death, to inform the next of kin of the deceased person that a post-mortem is likely to be performed on the body).

2.1.2 Non-coronial post-mortem examination

Where a person dies in a hospital,²⁹ but not in circumstances which would require a coronial investigation into the death, there may still be reasons to consider carrying out a post-mortem examination on the body of the deceased person.

The specific reasons may vary from case to case. However, the central purpose of a non-coronial post-mortem examination will usually be to allow a more detailed understanding to be obtained of the medical reasons for the death.

That more detailed information about the medical reasons for a death can be of benefit in a number of ways. For example:

- (i) it may assist in answering a specific question, or questions, about the disease process which is known to have led to the death;
- (ii) it may assist in determining whether the clinical diagnosis prior to death was accurate³⁰ and the treatment provided was appropriate;³¹
- (iii) it may assist in the understanding of disease processes which are not yet well understood, and the identification of disease processes which have not previously been identified;
- (iv) it may assist in the development of new or improved modes of treatment, including those which may prevent deaths in the future;

²⁸ Based on statistics from the 1999/2000 Annual Report of the State Coroner (1545 coronial deaths investigated; post-mortems directed in 1413 of those cases). In that year, objections by relatives to a post-mortem examination were lodged in only about 9% of cases, and 85% of those objections were accepted by the coroner (ie in less than 1% of the total cases in which a post-mortem examination was directed, was this done despite an objection by the relatives). In cases where an objection was lodged and ultimately accepted by the coroner, the relatives would usually have agreed with the authorisation of a limited post-mortem examination (ie external examination of the body only with the taking of blood and urine samples for an urgent limited toxicology analysis).

²⁹ Or the person's body has been brought to a hospital following death.

³⁰ Studies show that post-mortem examinations can often reveal findings which did not form part of the clinical diagnosis: BM Selway QC, *Report into the Retention of Body Parts after Post-Mortem* at 26.

³¹ The process to which this type of information may contribute is often referred to as 'clinical audit', which is a description usually applied to any systematic attempt to critically analyse the quality of clinical care for the purpose of identifying, and remedying, any deficiencies (sometimes the term 'quality assurance' is used to refer to this type of process).

- (v) it may assist in the education and ongoing training of medical practitioners (both clinicians and pathologists); and
- (vi) it may assist in identifying public health hazards.

This is not an exhaustive list of the potential benefits of a non-coronial post-mortem examination, and the extent to which they may be realised in any one case, or over a period of time as the result of the cumulative effect of a number of cases, will vary.³²

Sometimes the benefits can be seen to directly assist the relatives of the deceased person. For example, the post-mortem examination may assist the relatives simply by more precisely defining the causes of the death (this knowledge may assist some relatives in coming to terms with the death during the grieving process). It may provide comfort by confirming that no action on the part of the relatives could have prevented the death. It may assist by identifying, or excluding, the presence of some genetic component in the cause of death which could inform the decisions which relatives may themselves make in the future.³³

Sometimes the benefits can be seen to accrue more directly to the community as a whole.³⁴ In the *Interim Report into the retention of tissue & organs following post-mortems in NSW*, the Chief Health Officer (NSW) gave the following example:

"... Reye's Syndrome ... was first described by the paediatric pathologist, Douglas Reye, at the Camperdown Children's Hospital. Dr Reye made this discovery through comparison of tissue over 12 years in the 1950's and 1960's from children who had died unexpectedly from an acute febrile illness. This syndrome was later linked to aspirin use in children following chicken pox, influenza and viral fevers. All aspirin packaging in Australia and the United States now carries a warning against use for children and teenagers following these conditions. In 1980 there were 555 cases reported in the United States. Since warnings were introduced, this syndrome has diminished. From 1994 to 1998, there were fewer than 7 cases per year."³⁵

³² As the information brochure for relatives produced by the Royal College of Pathologists notes: "even the most detailed post-mortem investigation will often leave some questions unanswered."

³³ For example, a post-mortem examination on a deceased baby which either discloses, or excludes, some genetic problem may inform the decision of the parents about future family planning decisions.

³⁴ The reduction in the incidence of SIDS deaths and the characterisation of variant CJD are examples which have been cited in recent reports.

³⁵ *Interim Report into the retention of tissue and organs following post-mortems in NSW* at 1.4.

Sometimes the benefits to the community can be realised many years later (for example, by re-examining archived material in the light of new knowledge or with new investigative techniques such as DNA testing).

2.2 Post-mortem examination procedures

In this State, coronial post-mortem examinations are usually carried out at the State Mortuary, which is located at the Queen Elizabeth II Medical Centre.³⁶

Non-coronial post-mortem examinations are carried out at the following facilities:³⁷

- (i) Royal Perth Hospital Mortuary;
- (ii) State Mortuary (deceased patients from Sir Charles Gairdner Hospital);
- (iii) Princess Margaret Hospital Mortuary;
- (iv) King Edward Memorial Hospital Mortuary;
- (v) Fremantle Hospital Mortuary.

A post-mortem examination is carried out by a pathologist, or pathologists,³⁸ with the assistance of mortuary technicians. A pathologist is a medical practitioner whose specialist area of expertise is the study of disease processes, particularly the structural changes in the tissues and organs of the human body which may be caused by, or cause, the occurrence of disease processes.

A mortuary technician is a person who is trained to assist the pathologist with the technical (ie non-diagnostic) aspects of the post-mortem examination procedure, such as the opening of the body, the taking of body fluid samples, the removal and weighing of organs, and the reconstruction of the body at the conclusion of the post-mortem examination.

³⁶ Some coronial post-mortem examinations are still carried out in country hospitals where the death has occurred in a country area. However, this is not common. More often, in the case of a country death, the body would be transported to Perth to undergo a post-mortem examination at the State Mortuary.

³⁷ Where a death occurred in another metropolitan hospital (ie other than RPH, SCGH, PMH, KEMH or Fremantle Hospital), and a non-coronial post-mortem examination was required, the body would be transferred to one of these facilities.

³⁸ In most cases only one pathologist will conduct the post-mortem examination. However, in particular cases it may be necessary for pathologists with different areas of expertise to jointly perform a post-mortem examination (for example, a specialist paediatric pathologist may jointly perform a coronial post-mortem examination with a forensic pathologist where the deceased is a child). In other cases, the post-mortem examination may be performed jointly by a pathologist and a registrar in pathology (ie a person undertaking training towards a specialist qualification in pathology).

A post-mortem examination will be carried out as soon as possible after the death (usually within 2-3 working days). If the post-mortem examination is carried out within such a timeframe (ie soon after the death), the chances that useful information about the causes of death will be obtained will tend to be maximised.³⁹ Such a timeframe is usually also consistent with the wishes of the relatives to be able to proceed with the funeral within a reasonable period of time after the death has occurred.

2.2.1 Full post-mortem examination

The standard post-mortem examination is usually referred to as a 'full post-mortem examination',⁴⁰ and the process consists of three distinct stages:

- (i) the external examination;
- (ii) the internal examination; and
- (iii) microscopic examination and testing.

A post-mortem examination will commence with the external examination, which involves a careful visual inspection of the outside of the body. The pathologist will at this stage identify any potentially significant visual signs of disease or injury which can be seen on the outside of the body,⁴¹ and any signs of medical or surgical interventions prior to death.⁴² To assist in recording any potentially significant signs, photographs or x-rays may be taken at this stage.⁴³

³⁹ It is important, for diagnostic purposes, to be able to examine and sample body tissues before the natural post-death changes which occur in those body tissues have proceeded too far (where they have, this can obscure important information about the causes of death which might otherwise have been ascertained from examination and testing of the tissue).

⁴⁰ Sometimes this is referred to as a 'three-cavity post-mortem examination' (a description which refers to the three principal body cavities - cranial (skull), thoracic (chest) and abdominal (stomach/intestinal) - which are subjected to an internal examination): see for example Bret Walker SC *Inquiry into Matters Arising from the Post-Mortem and Anatomical Examination Practices of the Institute of Forensic Medicine - Report* at para. 166.

⁴¹ For example, bruising, cuts, scratches, evidence of a fracture etc.

⁴² For example, a recent surgical scar, puncture mark from an intravenous drip etc.

⁴³ External measurements such as height and weight are routinely also made at this stage, if they have not already been made upon receipt of the body at the mortuary.

When the external examination has been completed, the pathologist will commence the internal examination. This involves a detailed examination of all the organs which are found in the three principal body cavities, that is, the cranial (skull) cavity,⁴⁴ the thoracic (chest) cavity⁴⁵ and the abdominal (stomach/intestinal) cavity.⁴⁶

Access to these body cavities is usually obtained by making two incisions . One incision is made down the front of the body.⁴⁷ The other incision is made across the back of the scalp.⁴⁸ The chest plate is removed to give access to the thoracic cavity, and a portion of the skull is removed to give access to the cranial cavity.⁴⁹

The pathologist will then usually first carry out a visual inspection of the body cavities and organs before the organs are removed from the body. The purpose of this inspection is to identify any features of potential significance while the organs are still in situ and the body cavities undisturbed.⁵⁰

Any samples of body fluid which may later be required for the purposes of the third stage of the post-mortem examination process (ie microscopic examination and testing) will usually then be taken. The body fluids taken will depend on the circumstances of the case⁵¹ and the professional judgment of the pathologist. In coronial post-mortem examinations, they may include one or more of the following: blood, urine, bile,⁵² vitreous humour.⁵³ The quantity taken will vary from case to case, but each sample would usually be in the range 5mL-30mL.⁵⁴ In non-coronial post-mortem examinations, other fluids may be sampled.⁵⁵

⁴⁴ The organs include the brain and pituitary gland.

⁴⁵ The organs include the heart, lungs and thymus gland.

⁴⁶ The organs include the stomach, liver, spleen, kidneys, bladder and intestines.

⁴⁷ This incision usually commences behind each ear, joins at the centre of the chest and continues down past the navel to form a 'Y' shape.

⁴⁸ This incision is made above the hairline, which means that it can be sown up and is not noticeable once the body has been reconstructed after the post-mortem examination is completed.

⁴⁹ Both are replaced when the body is reconstructed at the completion of the internal examination.

⁵⁰ For example, the presence of accumulations of blood or other bodily fluids in particular areas, or the presence and location of devices which may be indicative of surgical or medical interventions carried out prior to the death (eg. endotracheal tube).

⁵¹ It is common in most coronial cases to refer samples of blood and urine (sometimes also bile) for toxicology testing (this testing seeks to identify the presence of any alcohol or drugs).

⁵² Fluid secreted by the liver to aid digestion which concentrates in the gallbladder. Where a sample is taken at post-mortem examination, it is taken from the gallbladder.

⁵³ Fluid found in the eyeball. Where a sample is taken at post-mortem examination a small quantity is extracted using a syringe.

⁵⁴ The amount taken is usually dictated by the needs of the testing procedures to which the fluids will later be subjected. For example, toxicology testing for the presence of alcohol and the range of common drugs will ordinarily require a sufficient quantity of blood and urine to be able to run a series

Each organ will then be removed from the body, and a number of the organs⁵⁶ will usually be weighed. The purpose of weighing the organs is to obtain an indication of whether they are within the usual ranges for a person of the deceased's age and size. This can be an important guide for the pathologist,⁵⁷ including in some cases by simply confirming that the organ weights are within the expected range.⁵⁸

Each removed organ will then be visually examined by the pathologist (this is sometimes referred to as a 'naked eye' or 'macroscopic' examination). That macroscopic examination will commence with an inspection of the external surface of the organ. However, it must always then progress to an inspection of the internal structure and appearance of the organ.⁵⁹ This is done by dissecting the organ (sometimes referred to as 'sectioning', 'slicing', or 'exposing a cut surface') and then examining the interior surfaces of the organ which are then revealed.

The extent of the dissection which may be required will depend on the structure of the particular type of organ, the circumstances of the particular case being investigated and the professional judgment of the pathologist.

For example, where the internal structure of a particular organ is relatively homogenous (for example, in the case of the liver) the dissection of the organ in one or two planes only may be sufficient to allow the internal structure to be adequately inspected.⁶⁰

of tests on small samples (1-2 mL), each of which will lead to the consumption of that portion of the sample.

⁵⁵ For example, serous fluid from the pleura (membrane surrounding the lungs), the peritoneum (membrane lining the abdominal walls), the pericardium (membrane surrounding the heart) and secretions (eg. from within the respiratory tract).

⁵⁶ Brain, heart, lungs, liver, kidneys, spleen, thymus gland, thyroid gland, adrenal glands.

⁵⁷ For example, a marked difference between the weight of an organ and the average range may point towards some potential abnormal condition in the organ (eg. in an adult) or some developmental problem (eg. in an infant or baby).

⁵⁸ In this respect, it is important to keep in mind that the investigation of a death often proceeds (particularly in coronial post-mortem examinations) by a process of careful and methodical exclusion of potential causes and contributing factors to the death. In that context, any finding, in relation to an organ or organs, that they are normal and not affected by a disease process or injury, is itself a significant finding for the exclusionary purposes of the investigation.

⁵⁹ Not all, or even many, of the features of potential significance will be apparent from an inspection of the external surface of the organ.

⁶⁰ At least, perhaps, where that kind of minimal dissection is sufficient to disclose to the pathologist that the organ is apparently normal in structure and appearance.

However, where the internal structure of the organ is more complex (for example, in the case of the heart which has a number of separate and distinct chambers) the organ will usually need to be dissected in a number of planes to allow it to be adequately inspected. For example, the brain is usually dissected for the purposes of visual examination in the coronal plane⁶¹ at regular intervals (usually 1cm) through its entire mass.⁶²

The circumstances of the case, and the judgment of the pathologist, will also affect the extent to which any organ needs to be dissected. For example, if during the course of the internal examination it becomes apparent to the pathologist that a particular organ is likely to be implicated in the reasons for the death, that organ may need to be dissected to a greater extent than it would be otherwise.⁶³

As each organ is macroscopically examined in this way, the pathologist will take any tissue samples (sometimes referred to as 'tissue blocks' or 'sections') which may later be needed for the purposes of the third stage of the post-mortem examination process (ie microscopic examination and testing). In this *Report* the term 'tissue block' will be used to refer to these tissue samples.

Each tissue block taken is usually very small, and represents a tiny fraction only of the total mass of the organ from which it is taken.⁶⁴ A typical tissue block would be, in surface area, about the size of a thumbnail and a few millimetres in thickness. It is analogous, in dimension, to a biopsy sample which might be taken from the tissue of a living patient for testing purposes.

⁶¹ The 'coronal plane' is that which divides the body longitudinally on the right-left axis (as distinct from the front/back axis).

⁶² In some cases, other organs may be similarly dissected at regular intervals to ensure that no significant pathology is missed.

⁶³ The purpose then being to more closely examine the potentially significant variations in the internal structure and appearance of that organ.

⁶⁴ It would almost invariably be less than 1% of the total mass of the organ. However, exceptions to this proportion may exist in the case of the minor organs of deceased babies where the total mass of the organ is often very small, so that the proportion that a standard sized tissue block bears to the organ from which it is taken may be higher. Indeed, in some very small deceased babies, one of the smaller minor organs (eg. pituitary gland) may be so very small that to attempt to dissect it at all to take a tissue block would disrupt the tissue to an extent which would render it unusable for diagnostic purposes, and it may therefore be necessary to take the whole organ as a tissue block.

The precise number of tissue blocks which are taken from each organ will again depend on the type of organ, the circumstances of the case and the professional judgment of the pathologist.⁶⁵ However, the total number of tissue blocks taken from all organs will in the usual case be in the region of about 15-30.⁶⁶

In broad terms, the pathologist will in taking such tissue blocks be aiming to ensure that they are sufficiently representative of the organs from which they are taken, so that the findings which may be made on later microscopic examination and testing can be taken as representative of the actual condition of the organs.⁶⁷

The tissue blocks are placed in formalin,⁶⁸ and are later processed by laboratory technicians and medical scientists into what are usually referred to as 'paraffin blocks' (sometimes just 'blocks' as in a reference to 'blocks and slides').⁶⁹ This is a small plastic cassette (about the size of a matchbox) in which a tissue block has been embedded and preserved in paraffin wax. In this *Report*, the term 'paraffin blocks' will be used to refer to tissue which has been preserved in this way.

Some tissue blocks may also be taken for the purpose of other specialist testing. For example, the testing carried out on relevant tissue blocks may include one or more of the following: microbiology,⁷⁰ virology,⁷¹ bacteriology,⁷² biochemistry,⁷³ toxicology,⁷⁴ cytogenetics,⁷⁵ mycology,⁷⁶ electron microscopy.⁷⁷

⁶⁵ Sometimes, additional small tissue samples may be taken from organs by the pathologist as 'reserve tissue' and kept in formalin in case it may later become necessary to process further paraffin blocks and create further slides of that tissue for the purposes of microscopic examinations, or to conduct tests on the tissue which may depend on it not having been preserved in paraffin wax. As with tissue blocks, such 'reserve tissue' would typically involve a small fraction only of the mass of the organ from which it was taken. If not subsequently required for process into paraffin blocks and slides, such tissue would be disposed of by incineration.

⁶⁶ Of course, in very complex cases the total number of tissue blocks may be much higher (as the number is always dictated by the need to obtain a representative microscopic picture of the potentially relevant changes in the organs and tissue prior to death). For example, in complex coronial cases, the total number of tissue blocks could be in the region of 50-100.

⁶⁷ For example, it would be common to take at least one tissue block from each of the significant structures in the heart (ie left ventricle, right ventricle, septum).

⁶⁸ A chemical solution containing a mixture of formaldehyde and water, which is used in pathology laboratories to preserve human tissue (ie 'preserve' in this sense means to prevent any further post-death changes in the structure and appearance of the tissue).

⁶⁹ The tissue blocks would usually need to be left in the formalin for at least 3-4 days before they could be processed into paraffin blocks.

⁷⁰ The identification of micro-organisms.

⁷¹ The identification of viruses and viral diseases.

⁷² The identification of bacteria and their toxins.

⁷³ The identification of the biochemical makeup of tissue.

Tissue blocks taken for the purposes of this type of testing are usually either wholly consumed during the testing process, or disposed of as clinical waste⁷⁸ when the testing is complete and a report on the results of the testing has been issued.

In coronial cases, a quantity of the liver is often also taken for the purposes of toxicology testing (usually approximately 100-200 grams). The contents of the stomach are also usually retained for this purpose.

Once the organs have been macroscopically examined, and relevant tissue blocks and body fluid samples taken for later microscopic examination and testing, the organs would be returned to the body of the deceased person by placing them back in the body cavities.⁷⁹ The previously removed chest plate and portion of the skull would then be replaced and the incisions sewn up by the mortuary technician.⁸⁰

The post-mortem examination procedure to this point usually takes about 1- 2 hours, but it can take more than 3 hours, and sometimes up to 6-8 hours.⁸¹ The body can usually (after reconstruction) be released to funeral directors on the same day or the day following.⁸² Everything possible is done to avoid any delay to the funeral.

However, in some cases, the pathologist may consider that it is necessary to retain a whole organ for the purpose of later specialist examination.

In this respect, the brain has always presented a particular problem for pathologists. That is because the brain is an organ which is soft and lacks a firm structure in its natural state. This has particular implications for the macroscopic examination of a brain, and the taking of relevant tissue blocks for later microscopic examination.

⁷⁴ The identification of alcohol, drugs and poisons.
⁷⁵ The identification of genetical abnormalities in cells.
⁷⁶ The identification of pathological changes caused by fungi.
⁷⁷ Examination of cellular structures in tissue with the use of a (high magnification) electron microscope.
⁷⁸ That is, by high temperature incineration.
⁷⁹ However, it is not possible in doing this to return each organ to its pre-removal location.
⁸⁰ The mortuary technician will be responsible generally for the reconstruction of the body at the conclusion of the internal examination prior to its release to funeral directors.
⁸¹ Such a longer period of time is commonly taken in the case of a coronial post-mortem examination involving the investigation of a suspected homicide (in rare cases of this type an internal examination may need to be conducted over a number of days).
⁸² In coronial cases, the authorisation of the coroner is required before the body can be released.

Although it is possible to dissect the brain in the fresh state (and obtain some information from such a dissection), an optimal examination can usually only be made once the brain tissue has been 'fixed' (ie hardened by chemical pre-treatment) in a formalin solution for a period of days. Once the tissue has been fixed in this way, the anatomical structure of the interior of the brain is preserved and the brain can then be dissected by making the thin regular slices which will allow all of the relevant anatomical areas of the brain to be examined and correlated with any findings made as a result of that examination.⁸³

The examination of the brain is sometimes performed by a specialist neuropathologist.⁸⁴ Neuropathology is that part of the discipline of pathology which is concerned with the study of diseases of the central nervous system (ie the brain and spinal cord).

The process of fixation of a brain has usually taken in the region of 2-3 weeks. In both coronial, and non-coronial, cases this time period has been shortened in more recent times to about 7 days by using more concentrated formalin.⁸⁵ However, even this period of time is usually incompatible with the standard time of 2-3 days between the death and release of the body following post-mortem examination to funeral directors. There is then a practical problem with the examination of brain tissue (ie that unless it is first fixed it is possible that important pathological findings may be missed).

In particular cases, other organs may need to be retained and examined after a process of fixation to properly investigate a potential disease or injury.

The pathologist will dictate a post-mortem report at the completion of internal examination. The report will summarise the findings made as a result of the macroscopic examination. In non-coronial cases, it will also include a summary of the clinical findings.⁸⁶

⁸³ It is important, in examining brain tissue, to be able to identify not only an abnormality but also the precise anatomical location of the abnormality (the various areas of the brain having distinct functions).

⁸⁴ In coronial cases, a brain which has been retained for fixation and later examination will almost always be examined by a neuropathologist. If it is examined in an unfixed state at the time of the internal examination, this will be done by the pathologist carrying out the coronial post-mortem examination. In non-coronial cases, a brain retained for examination after fixation may be referred to a neuropathologist if indicated, but would otherwise be examined by the attending pathologist.

⁸⁵ A 40% solution (formaldehyde to water) is used rather than the standard 10% solution.

⁸⁶ These are the findings which were made as a result of clinical diagnosis prior to the death.

In coronial cases, the pathologists also provide a brief interim report to the State Coroner immediately after the internal examination has been completed. In non-coronial cases, a summary of the findings is usually made available to the requesting doctor within 24 hours. A final post-mortem report is made once the microscopic examination and other investigations are completed.⁸⁷

To allow for the necessary microscopic examination to be carried out, each paraffin block is used by the laboratory technician to create one or more microscope slides. This is done by cutting a very thin section off the paraffin block which is then stained (to better bring out the structure of the tissue under the microscope⁸⁸) and set on a microscope slide. Exactly the same procedure is used to prepare slides from biopsy samples taken from living patients. In this *Report* the term 'microscopic sections' will be used to refer to sections which are cut off paraffin blocks and set on microscope slides.

It is currently a condition of accreditation for each pathology laboratory in this country to retain paraffin blocks and microscope slides for not less than 20 years after they are created.⁸⁹ It is the standard practice, both in this country and overseas, to retain paraffin blocks indefinitely.

The microscopic sections are later examined under microscope by the pathologist.⁹⁰ This is part of the third stage of the post-mortem examination, and is usually referred to as 'histopathology' or 'microscopy'.

It involves a microscopic analysis of the structure and composition of the tissue or material, and is used by the pathologist to confirm or exclude the provisional diagnoses which were made at the time of the external and internal examination, and arrive perhaps at new conclusions which only a microscopic examination of the tissue will show.

⁸⁷ This will usually comprise the report originally dictated, with any amendments or additions which may be necessary as a result of the microscopic examination and other investigations. The time it will take to finalise the post-mortem report varies from case to case, depending in part on how soon tissue blocks can be processed into slides, and other testing and investigations completed (it can take up to 6 months in the more complex cases).

⁸⁸ Different types of stains are used to bring out different types of cell structure under a microscope (which can be why more than one slide is prepared from the one paraffin block).

⁸⁹ The pathology laboratories are required to comply with the standards set by the National Pathology Accreditation Advisory Council which include that paraffin blocks, microscope slides and reports are retained for not less than 20 years.

⁹⁰ There may be a few weeks between the conclusion of the post-mortem examination and the time when the microscope slides can be examined by the pathologist.

The pathologist will prepare a separate report (sometimes referred to as a 'histopathology report') on the results of this microscopic examination of the tissue.

2.2.2 Limited post-mortem examination

The term 'limited post-mortem examination' is usually used to describe an examination of the deceased person's body which is in some way more limited than the standard post-mortem examination procedure which has been described above.

The options for a limited post-mortem examination may, for example, include:

- (i) an internal examination which is limited only to the organ, or organs, which are thought to have been directly involved in the death;⁹¹
- (ii) an internal examination which is limited to a particular body cavity, or cavities;
- (iii) an internal examination which is performed only through a pre-existing surgical incision; or
- (iv) an external examination only.⁹²

The limited post-mortem examination is something which can usually only be considered in the non-coronial context.⁹³ It is also, being less than comprehensive to a greater or lesser extent, a form of examination which carries with it the potential risk that not all information of possible relevance will be identified. The more limited the examination, the greater that risk is likely to be in a particular case.⁹⁴

⁹¹ The information brochure for relatives produced by the Royal College of Pathologists provides the following example of such a limited post-mortem examination: "For example, if someone has died of a stroke then only the brain and blood vessels supplying the brain might be examined."

⁹² Which may be supplemented by other external techniques such as radiology.

⁹³ A coronial post-mortem examination, being a comprehensive investigation into the causes of death, will in most cases need to involve a full post-mortem examination. However, as noted earlier in this *Report* (see fn. 27) in that relatively small number of cases where a coroner upholds an objection by the relatives to a full post-mortem examination, there may still be a limited post-mortem examination authorised by the coroner which is limited to an external examination of the body and the taking of blood and urine samples for toxicology analysis.

⁹⁴ Indeed, in some cases, a very limited post-mortem examination may be considered to be of little or no value in obtaining relevant information about the death.

3.0 The Legal Context

3.1 The *Coroners Act 1996* (WA)

Where a death is of a kind which falls within the jurisdiction of a coroner, the decision as to whether or not to direct a pathologist to carry out a coronial post-mortem examination is ultimately one for the coroner who assumes jurisdiction.⁹⁵ It could not be otherwise in a coronial system which depends on the independent investigation by the coroner of the circumstances of the deaths which fall within that jurisdiction.⁹⁶

However, the *Coroners Act 1996* (WA) ("*Coroners Act*") is notable for the extent to which it nevertheless requires a coroner who assumes such jurisdiction to investigate a death to, as soon as it is practicable to do so, provide relevant information about the process to the relatives of the deceased person.⁹⁷ That information must also be provided in a language and a form which is likely to be understood, and in writing where practicable.⁹⁸ In the present context, the most relevant of those items of information are probably:

- (i) that a post-mortem examination is likely to be performed on the body; and
- (ii) that there is a possibility that tissue may be retained after the completion of the post-mortem examination where it is necessary to investigate the death.⁹⁹

A coroner may direct the pathologist carrying out a coronial post-mortem examination to remove 'tissue' (including whole organs)¹⁰⁰ from the body of the deceased person, for such period as the coroner directs, if this appears to be necessary to investigate the death.¹⁰¹

⁹⁵ Subject only to any contrary order by the Supreme Court on an appeal against the carrying out of such a post-mortem by the senior next of kin of the deceased: *Coroners Act 1996* (WA) s37.

⁹⁶ And the consequent safeguarding of the public interest that the community has in those deaths being the subject of such an independent investigation.

⁹⁷ *Coroners Act 1996* (WA) s20 (1).

⁹⁸ *Coroners Act 1996* (WA) s20 (2).

⁹⁹ *Coroners Act 1996* (WA) s20 (1) (b) and (h). Other information which must be provided is: that the body is under the control of the coroner; that while the body is under the control of the coroner the next of kin may view the body, and may touch the body unless the coroner determines that it is undesirable or dangerous to do so; that a doctor chosen by the senior next of kin may be present at any post-mortem examination; that there is a right to object to a post-mortem examination and the manner in which such an objection may be made; that there is a right to request a post-mortem examination; that a coronial counselling service is available to the next of kin.

¹⁰⁰ This term is defined broadly by the *Coroners Act 1996* (WA) to include: "an organ or part of the human body or a substance extracted from, or part of, the human body" (s3 (defn. of "tissue")).

¹⁰¹ *Coroners Act 1996* (WA) s34 (2).

Where such a direction is given, this will authorise the pathologist to remove tissue in accordance with the direction.¹⁰² However, any tissue removed for this purpose must be dealt with in accordance with the coroner's directions and any relevant guidelines.¹⁰³

In this way, the *Coroners Act* allows a coroner to maintain specific control over the retention of any organ beyond the time at which the internal examination is completed. That control can be exercised by the coroner in the following ways:

- (i) by deciding whether or not, in any particular case, to authorise the retention by the pathologist of an organ for further examination;
- (ii) by imposing time limits on the period for which any organ may be retained for further examination; and
- (iii) by requiring that any organ be dealt with in accordance with any other directions given, or guidelines issued, by the coroner.

The way in which this legislative scheme works in practice (and in particular the way in which relatives are involved in the decision-making process) will be outlined in the following chapter of this *Report* which deals with practices and procedures.

For present purposes, it suffices to note that the legislative scheme for coronial post-mortem examinations is based on the principle that tissue will only be retained where this is considered necessary by a coroner to investigate the death, and in that event the coroner will maintain specific control over any such retention.

The only exceptions to this principle, under the *Coroners Act*, are:

- (i) where tissue is removed by the pathologist in accordance with the written permission of the deceased person;¹⁰⁴ or

¹⁰² *Coroners Act 1996* (WA) s34 (3) (a).

¹⁰³ *Coroners Act 1996* (WA) s34 (6).

¹⁰⁴ The coroner is required, in this situation, to ensure that, before the tissue is removed, the senior next of kin of the deceased is informed in writing what tissue is to be removed and is given a chance to view the written permission of the deceased: *Coroners Act 1996* (WA) s34 (7).

- (ii) where tissue is removed by the pathologist in accordance with the written informed consent of the senior next of kin of the deceased¹⁰⁵ which specifies the tissue which may be removed and the 'non-coronial' purpose for which the tissue may be removed.¹⁰⁶

These exceptions preserve, in the case of a coronial post-mortem examination, the opportunity for the deceased (by prior written authorisation) or the next of kin to authorise the removal and retention of tissue where this would not otherwise be required for the purposes of the investigation of the death.

It follows that, under the *Coroners Act* scheme, tissue can only be retained at the completion of a coronial post-mortem examination for one of two purposes:

- (i) for the purpose of properly investigating the death (ie for a necessary 'coronial purpose'), and with the authorisation of, and in accordance with the directions given by, the coroner; or
- (ii) for some other purpose (ie for a 'non-coronial purpose') with the prior written authorisation of the deceased or the senior next of kin, and in accordance with any limitations¹⁰⁷ imposed by those persons.

3.2 The *Human Tissue and Transplant Act 1982* (WA)

The *Human Tissue and Transplant Act 1982* (WA) was first enacted in 1982. It came into operation on 1 March 1983.¹⁰⁸

¹⁰⁵ The senior next of kin are in order, and depending on their respective availability: spouse (including de facto spouse); son or daughter over 18 years; parent; brother or sister over 18 years; executor or personal representative; person nominated by the deceased to be contacted in an emergency: *Coroners Act 1996* (WA) (s3 (defn. of "senior next of kin") & s37 (5)).

¹⁰⁶ The coroner may direct a pathologist, in this situation, not to cause tissue to be removed as authorised by such a next of kin if satisfied that the removal would be contrary to or inconsistent with wishes expressed in writing by the deceased person: *Coroners Act 1996* (WA) s34 (4).

¹⁰⁷ For example, as to the tissue which may be removed and the non-coronial purpose (eg. therapeutic, medical, teaching or scientific) for which it may be removed.

¹⁰⁸ The legislation was based, as was similar legislation in other States, on model legislation contained in the 1977 report of the Australian Law Reform Commission - *Report No. 7 - Human Tissue Transplants*.

If a non-coronial post-mortem examination is to take place under the *Human Tissue and Transplant Act*, a number of requirements need to be met. They can be summarised as follows:

1. The "designated officer"¹⁰⁹ for the hospital must first authorise that non-coronial post-mortem examination.¹¹⁰
2. The power to give such an authorisation is subject to the following conditions:
 - (a) that the "designated officer" has reason to believe, after having first made all inquiries as are reasonable in the circumstances, that the deceased patient had, during his or her lifetime consented to a post-mortem examination and had not revoked that consent (ie there was some 'positive indication of consent');¹¹¹ or
 - (b) that the "designated officer" has no reason to believe, after having first made all inquiries as are reasonable in the circumstances, that:
 - (i) the deceased patient gave any positive indication either way,¹¹² during his or her lifetime, of his or her attitude to the possibility of a post-mortem examination after death; and

¹⁰⁹ A medical practitioner who has been nominated by the chief medical administrator of the hospital to discharge this role, and whose nomination has been approved for that purpose by the Executive Director, Public Health: see *Human Tissue and Transplant Act* s3 (1) (defn. of "designated officer") & s4.

¹¹⁰ The "designated officer" can authorise a post-mortem for the purpose of: ascertaining the cause or extent of any pathological condition that may be present in the deceased patient, ascertaining whether the deceased patient was affected by a prescribed condition of health (however none are currently prescribed) and/or for teaching pathology: *Human Tissue and Transplant Act* s25 (1).

¹¹¹ The wording of the provision refers in the alternative to 'expressing a wish' and 'consenting to'. They are different ways of referring to the one concept which involves some positive indication of agreement to a possible post-mortem examination.

¹¹² Whether a 'consent' or an 'objection'.

- (ii) the "senior available next of kin"¹¹³ has any objection to the proposed post-mortem examination; or
 - (c) that the "designated officer":
 - (i) has no reason to believe, after having first made all inquiries as are reasonable in the circumstances, that the deceased gave any positive indication either way, during his or her lifetime, of his or her attitude to the possibility of a post-mortem examination after death; and
 - (ii) is unable, after having made all inquiries as are reasonable in the circumstances, to ascertain the existence of any "next of kin", and/or their whereabouts, and/or whether any of them (whose existence or whereabouts can be established) have any objection to a post-mortem examination.
3. If, such an authorisation is given, then it will only authorise the medical practitioner to whom it is given,¹¹⁴ to do certain things, that is:
- (a) to conduct such examination of the body of the deceased patient as is necessary for the purpose for which the examination was authorised (for example, the purpose of ascertaining the cause or extent of a pathological condition); and
 - (b) to remove "tissue"¹¹⁵ from the body of the deceased patient if that removal is necessary for the purpose of the examination.

¹¹³ This term is defined by the *Human Tissue and Transplant Act* in very similar terms to the definition of "senior next of kin" which is used by the *Coroners Act* (ie. spouse, son or daughter over 18 years, parent, brother or sister): see *Human Tissue and Transplant Act* s3 (1) (defn. of "senior available next of kin").

¹¹⁴ Who must be a medical practitioner other than the "designated officer" (ie a "designated officer" cannot give such an authorisation to himself or herself): see *Human Tissue and Transplant Act* s28 (1).

¹¹⁵ Under the *Human Tissue and Transplant Act*, the term "tissue" is defined broadly to include an organ or part of the human body or a substance extracted from, or from a part of, the human body: *Human Tissue and Transplant Act* s3 (1) (defn. of "tissue").

If authorisation for a post-mortem examination is given, and tissue is removed for the purpose of the examination then s28 (2) of the *Human Tissue and Transplant Act* operates so as to grant a further authority to use tissue removed from the body for one of four specified purposes: therapeutic, medical, teaching or scientific purposes.¹¹⁶

As was noted in the *Interim Report*, this provision means that organs and tissue removed for the purposes of a non-coronial post-mortem examination can be retained for those specified purposes without any legal requirement to consult further with the next of kin about any such retention of organs or tissue. This reflected the view reached by the Australian Law Reform Commission in 1977. It is now widely recognised that this is not a view which is consistent with current community expectations.

In 1997, the *Human Tissue and Transplant Act* was amended to allow for Codes of Practice to be issued which would set standards and provide guidance in relation to matters of detail (such as how consent procedures in relation to non-coronial post-mortem examinations should be implemented by hospitals).¹¹⁷

3.3 The *Anatomy Act 1930 (WA)*

The *Anatomy Act 1930 (WA)* ("the *Anatomy Act*") is separate and distinct from, and does not in any relevant way overlap with, the post-mortem examination provisions of either the *Human Tissue and Transplant Act* or the *Coroners Act*.¹¹⁸

¹¹⁶ This implemented the conclusions of the Australian Law Reform Commission in its 1977 Report that such tissue should be available for such use without requiring further specific consent to be obtained for this from the next of kin. Prior to the *Coroners Act 1996*, a similarly worded provision (s28 (3) of the *Human Tissue and Transplant Act*) gave a similar authority - subject to any contrary order by the coroner - in relation to tissue removed for the purposes of a coronial post-mortem examination. That provision was repealed as part of the *Coroners Act 1996* consequential amendments.

¹¹⁷ *Human Tissue and Transplant Act* ss 32A & 32B. A Code of Practice Working Party was established after these amendments, and a report was prepared which included a draft code relating to post-mortem examinations. However, no code of practice has yet been issued. This *Report* recommends that a code of practice now be issued to provide the appropriate guidance to hospitals.

¹¹⁸ This is apparent, in particular, from s20 of the *Anatomy Act* which provides that nothing in it: "shall be construed to extend to or to prohibit any post mortem examination of any human body required or directed to be made by a competent legal authority", such as the coroner (coronial post-mortem examination) or a 'designated officer' (non-coronial post-mortem examination).

Although the techniques of examination may in some respects be similar, the primary purpose of the post-mortem examination is to identify the presence of disease or injury, whereas the primary purpose of the anatomical examination is to simply delineate the internal anatomical structure of the human body.

The focus of the anatomical examination is then primarily on the educational and training benefits which accrue to society from enabling students (the future medical practitioners, health professionals and scientists) to directly observe the anatomical structure of the human body.

The *Anatomy Act* deals, essentially, with those cases in which the whole body of a deceased person is transferred to an authorised school of anatomy for the purpose of such anatomical examination.

Under the *Anatomy Act*, a person may, prior to death, direct that his or her body be used for such a purpose after death.¹¹⁹ However, the *Anatomy Act* also provides that this will not occur where the surviving husband or wife or nearest known relative, or any one of the nearest known relatives which are 'kin in the same degree' do not consent.¹²⁰

There is also authority under the *Anatomy Act* for licensed persons at hospitals or persons with lawful possession of the body to transfer for anatomical examination¹²¹ but only subject to any expressed objection prior to death and again subject in any event to the consent of the surviving relatives (ie same procedure in this respect as described above).

It follows that, under the *Anatomy Act*, an anatomical examination cannot take place unless one of the following situations applies:

- (i) both the deceased (by prior direction) and the next of kin (by subsequent consent) are agreeable to such an examination taking place; or
- (ii) the deceased has not expressed objection (prior to death) and the relatives (by subsequent consent) are agreeable to such an examination taking place.

¹¹⁹ *Anatomy Act* s10.

¹²⁰ There is also an obligation placed on the "authority" with possession of the body to direct the attention of such relatives to the provisions of the *Anatomy Act* and obtain consent (if it is given) in writing: *Anatomy Act* s11.

¹²¹ *Anatomy Act* s8 and s9.

In both situations, the agreement of the relatives is made a necessary pre-condition to any anatomical examination taking place. In this respect, the *Anatomy Act* can be regarded as a consent-based legislative scheme.

In practice, as explained in the following chapter, bodies are only received for anatomical examination where the deceased has made a specific prior direction (ie has in advance bequeathed his or her body for such use - is a 'registered donor') and the relatives are agreeable to this taking place.

4.0 Practices and Procedures

4.1 Coronial post-mortem examinations

The Coroner's Office will notify the relatives of a deceased person if a coronial post-mortem examination is required, and consult with the relatives if it may be necessary to retain an organ for further examination at the completion of the internal examination.

If the pathologist considers that it may be necessary or desirable for the investigation of the death to retain an organ in the short term, the organ will be retained temporarily and placed in formalin. The Coroner's Office will then be informed of the pathologist's professional judgment that in the circumstances of the particular case the short term retention of the organ for further examination is either 'required' or 'recommended'.

In such cases, a counsellor at the Coroner's Office will then consult with the relatives of the deceased person, and obtain their views on such a short term retention of the organ.¹²² The State Coroner, or his delegate, will then decide to either authorise the short term retention of the organ, or decline to authorise that retention. While the views of the relatives will be taken into account in making that decision, it is ultimately one for the coroner.

Where the coroner declines to authorise the short term retention of the organ, this decision will be conveyed to the State Mortuary. The organ will then be removed from its temporary storage in formalin, macroscopically examined (and the relevant tissue blocks taken) and then returned to the body of the deceased, which will then be released to funeral directors for cremation or burial.

¹²²

Because of the requirements of the *Coroners Act* to provide information to the relatives, they will already have been informed before the post-mortem examination that this may be a possibility.

In those cases where the coroner authorises the short term retention of an organ,¹²³ the coronial counsellor will discuss with the relatives the options for disposal of the organ upon the completion of the further examination. Those options will include:

- (i) delaying the funeral so that the organ can be returned to the body before cremation or burial of the body; or
- (ii) having the organ collected by funeral directors for later separate cremation, or for later burial with the body.

The effect of these practices and procedures is to ensure that the relatives are made aware, from the very beginning, of any possible short term retention of an organ, given an opportunity to express their views on that course of action, and are made aware of the options for disposal in the event that such a short term retention is authorised by the coroner.

In short, it is a system which allows the relatives to be informed of what is happening and to have some involvement (to the extent that this is possible given the dictates of a coronial system of investigation) in the decision-making process in relation to any short term retention of an organ which may be necessary.

4.2 Non-coronial post-mortem examinations

In each of the hospitals which carry out non-coronial post-mortem examinations in this State, a form is used to record the details relating to the authorisation to carry out the post-mortem examination under the *Human Tissue and Transplant Act*.

The forms are described in various different ways: 'Request, Consent and Authority for Post Mortem';¹²⁴ 'Authority for Post Mortem Examination';¹²⁵ 'Autopsy Consent and Request Form';¹²⁶ 'Consent for Autopsy Examination';¹²⁷ 'Post Mortem Request Form'.¹²⁸

¹²³ This is usually for not more than about 10 days. The organ which would most commonly need to be retained is the brain, and a form of rapid 'fixation' is used to shorten the time which it would otherwise take to fix the brain tissue so that it can be dissected and examined (this is done by increasing the concentration of the formalin solution (from about 10% formaldehyde to about 40% formaldehyde).

¹²⁴ Royal Perth Hospital.

¹²⁵ Sir Charles Gairdner Hospital.

¹²⁶ Princess Margaret Hospital.

¹²⁷ King Edward Memorial Hospital.

¹²⁸ Fremantle Hospital.

The forms also differ in some respects as to matters of detail.¹²⁹ However, each form includes, with either the same or very similar wording, the following key sections:

- (i) a consent by next of kin;
- (ii) a statement by requesting doctor; and
- (iii) an authority for post-mortem examination.

Those key sections (taking the Royal Perth Hospital form as a typical and sufficiently illustrative example) are in the following form:

CONSENT BY NEXT OF KIN

1. Signed Consent

I consent to a post mortem examination of the above named.

Signed _____ Relationship to Deceased _____

OR

2. Verbal Consent

Verbal consent has been given by:-

(Name and Relationship of Next of Kin)

for a post mortem examination of the above named deceased.

Signed _____ Date _____

(Signature of Doctor)

STATEMENT BY REQUESTING DOCTOR

I have made reasonable inquiries and:-

- (1) Have no reason to believe that the deceased person during his/her lifetime expressed an objection to a post mortem examination.
- (2) Have reason to believe that the above consent was given by the deceased person's senior available next of kin.

Signed _____ Date _____

(Signature of Doctor)

¹²⁹

For example, some include some information on the form itself for relatives about the post-mortem examination process and its potential benefits (ie PMH and KEMH).

AUTHORITY FOR POST MORTEM EXAMINATION

I, _____

(full name of doctor)

having the powers of a designated officer delegated to me under the Human Tissue and Transplant Act 1982, authorise a post mortem examination to be performed on the above named deceased.

Signed _____ Date _____

(Signature of Doctor)

It will be apparent that this type of form is consistent with the requirements of the *Human Tissue and Transplant Act*, and is in fact designed in a way which substitutes consent of the senior available next of kin for apparent non-objection by that person. In other words, in practice it is the specific consent of the senior available next of kin which is sought when a non-coronial post-mortem examination is being considered (and it is this which demonstrates to the 'designated officer' the absence of objection by that person of which the *Human Tissue and Transplant Act* speaks).

However, this type of form does not (in itself) necessarily ensure that the decision of the senior available next of kin to give consent to the carrying out of the post-mortem examination will be a particularly informed decision.

For example, it is unlikely that a person without some medical training and/or experience will know what a post-mortem examination actually is, beyond perhaps that it involves some form of medical examination carried out on a dead body. It is also unlikely that such a person would know that the retention of an organ, or organs, may be a necessary part of a full post-mortem examination.

These are two examples only of the kind of information which may be unknown to the non-medical person at the time that he or she (as the senior available next of kin) may be asked to consider giving consent (ie confirming non-objection) to the carrying out of a post-mortem examination on a deceased relative.

They are examples of the kind of information which may be considered by the senior available next of kin to be relevant to the decision which they are being asked to make. Unless the hospital takes steps to ensure that the senior available next of kin is able to obtain that kind of information it is unlikely to be known to that person before the decision is made.

The forms in use have assumed that the responsibility for obtaining consent from the senior available next of kin will generally be that of the treating clinician (ie the person referred to in the forms as the 'requesting doctor').

However, the level of seniority of the clinician to whom this task may fall in any particular case will probably vary (as will that person's level of knowledge about post-mortem examination procedures). The time immediately following a death is also usually one of heightened emotion for the relatives (and the particular clinician may, or may not, by experience be well qualified to undertake the task of providing detailed information about a post-mortem examination in those circumstances).

The potential weakness in the system then would seem to be that too much reliance is placed on the treating clinician to provide relevant information to the relatives about the post-mortem examination process, at a time when most relatives are likely to be in an emotional state which makes it very difficult for them to properly take that information in.

There also does not seem to be any convenient mechanism by which the person giving the final authorisation (ie "designated officer" or delegate) can satisfy himself or herself about the quality of the information which may have been provided to the relatives prior to their consent being obtained.

In many cases, the clinician may provide all the relevant information, the relatives will make an informed decision, the post-mortem examination will be carried out accordingly and no difficulties (beyond those associated with the death itself) will be experienced by the relatives.

However, this type of system leaves open the possibility of other outcomes. Those cases in which relevant information is not provided (or is provided but is not properly taken in), the relatives make a decision without the benefit of what they consider relevant information, the post-mortem examination is carried out (and perhaps organs retained) and the relatives later discover that there was a gap between what they expected to happen and what

did happen. Therein lies the potential for significant emotional distress. The system should be designed to ensure that this type of outcome cannot happen.

In this respect, it should be noted that Princess Margaret Hospital for Children and King Edward Memorial Hospital have in recent times developed more detailed information leaflets and consent forms which are designed to ensure that any decisions made by the relatives with respect to a non-coronial post-mortem examination (and any possible organ retention) will be sufficiently informed decisions. Other hospitals are awaiting the guidance on these issues which will be provided by the recommendations of this *Report*.¹³⁰

4.3 Anatomical examination

There are currently three licensed schools of anatomy under the *Anatomy Act*:

- (i) the Department of Anatomy & Human Biology at the University of Western Australia ("UWA Department");
- (ii) the School of Biomedical Science at the Curtin University of Technology ("Curtin School"); and
- (iii) the School of Human Anatomy at Murdoch University ("Murdoch School").

The UWA Department undertakes the central role under the *Anatomy Act* in terms of registering the details of any person who decides that they wish to donate their body after death for the purpose of anatomical examination.¹³¹

If a person expresses interest in making such a bequest, he or she will be provided with relevant information about what is involved in making such a bequest, and will be able to discuss any questions about the process with the Department's Bequest Secretary.

¹³⁰ It should also be noted that Royal Perth Hospital developed an information pamphlet for relatives in 1993 to assist in addressing the need for relatives to understand the post-mortem examination process.

¹³¹ There are at any one time approximately 5,000 - 7,000 persons registered with the UWA Department as persons who wish to make such a body bequest after death. If the Curtin School receives any enquiries from persons about making such a bequest they will be referred to the UWA Department for registration at that facility.

If the person elects to make a bequest, a form is completed with relevant details and signed by the donor and the person is then registered within the Department's record-keeping system.¹³² Donors are requested to make their next of kin aware of their intentions with regard to the bequest, and are also provided with a donor card.¹³³

When a registered donor dies, the UWA Department will determine whether or not to accept the body for anatomical examination. Bodies cannot be accepted where:

- (i) the death is being investigated under the jurisdiction of the coroner;
- (ii) the body of the deceased has been the subject of a non-coronial post-mortem examination;
- (iii) the body of the deceased has undergone recent surgery (ie has not yet healed after a surgical operation);
- (iv) the body of the deceased is, or may be, affected by a contagious disease;
- (v) the body is unsuitable for embalming.

Where a body is suitable for acceptance by the UWA Department, but the relatives of the deceased person are not willing for it to be received for anatomical examination, the body is not accepted by the UWA Department.¹³⁴

The number of bodies received each year by the UWA Department varies, but currently averages at about 20-25 bodies per year. Upon receipt at the UWA Department, the bodies are embalmed.¹³⁵ The UWA Department transfers approximately 5-6 bodies each year to the Curtin School for anatomical examination at that facility.¹³⁶

¹³² The form allows the donor to indicate whether or not there is agreement to the indefinite retention of any part of the body for research and teaching purposes.

¹³³ This alerts any person reading it to the fact that the person has bequeathed their body after death, and asks that the Bequests Secretary be notified of the death of the card holder. Donors are able to withdraw the bequest at any time by notifying the UWA Department.

¹³⁴ In most cases, relatives appear to be willing to comply with the wishes of the deceased person (and therefore do not object to the receipt of the body for anatomical examination).

¹³⁵ This process usually takes 1-2 days.

¹³⁶ The bodies are transferred to the Curtin School after they have been embalmed. No bodies are currently transferred to the Murdoch School, which does not carry out any dissections (specimens only are provided by the UWA Department to the Murdoch School).

The bodies are kept by the UWA Department and the Curtin School for up to the prescribed 3 year time limit and used for the education of students undertaking courses in relevant disciplines which require an understanding of anatomy (which can include medicine and surgery, nursing, human biology, physiotherapy, public health, occupational therapy, medical imaging, pharmacy etc).¹³⁷

When the body is no longer required, or at the expiry of the 3 year time limit, the UWA Department makes appropriate arrangements with funeral directors for the body to be collected for the purposes of cremation or burial.¹³⁸ At that time, the relatives are notified so that they may attend the funeral.

It is only where there has been prior agreement from the donor and next of kin that body parts may be retained by the UWA Department or the Curtin School as specimens for longer term research and teaching purposes.

In some cases, although not commonly, the relatives of a donor may request that the body be returned before the 3 year time limit. In those cases, the UWA Department will then arrange for that earlier return for cremation or burial in accordance with that request.

5.0 Other Issues

5.1 Enquiries relating to past post-mortem examinations

The process for dealing with specific queries in relation to past post-mortem examinations was described in the *Interim Report*. It involves an analysis of past records and discussions with individuals involved where still available. The earlier the case, the more difficult it usually is to answer queries with precision.

However, it should remain possible for relatives to raise such queries about past post-mortem examinations, and to have them answered to the extent that this is possible. It is expected that this service will be provided on an ongoing basis by the relevant hospitals (in

¹³⁷ However, only a small percentage of the students who are educated using bodies donated for anatomical examination would actually be involved in performing dissection. The other students would be educated by having access to bodies and specimens which had already been dissected by specialist technicians. The institutions ensure that students who are permitted access to such material are registered to do so, are carefully supervised and comply with strict codes of conduct.

¹³⁸ The bodies which are transferred to the Curtin School are returned in the first instance to the UWA Department, which makes all the arrangements for the return of bodies for cremation and burial and the notification of relatives.

relation to non-coronial post-mortem examinations) and by the Coroner's Office (in relation to coronial post-mortem examinations).

5.2 Paraffin blocks and slides

It will be apparent from the description in Chapter 2 of this *Report* that paraffin blocks and microscope slides contain human tissue (respectively tissue blocks and microscopic sections) which is taken at the time of a post-mortem examination, and which is analogous to a biopsy sample.

The tissue ordinarily represents a tiny fraction of the total mass of the organ from which it is taken. In the form of paraffin blocks and slides it is considered by the accreditation body for pathology laboratories to represent an indispensable part of the medical record of the post-mortem examination.

Paraffin blocks are retained indefinitely, and microscope slides for not less than 20 years, as a matter of standard pathology practice both around Australia and overseas.¹³⁹ The paraffin blocks and microscope slides from pathology studies of tissue taken from living patients (eg. biopsies and diseased tissue removed during surgical operations) are preserved and retained in just the same way.

In the experience of those who have dealt with queries from family members in this State, the issue of the retention of paraffin blocks and slides does not seem to have been an issue of major concern to relatives. Neither does it appear to have been the main concern in most of the other enquiries and investigations in other States and overseas. Rather, and as might be expected, the concerns of relatives have tended to focus on the retention of either whole or substantial parts of organs without their knowledge or consent.¹⁴⁰ It would appear to be generally accepted that the indefinite retention of paraffin blocks and slides is an integral part of the post-mortem examination process.

¹³⁹ The reasons for doing so include: the ability to audit the work of pathologists by having the conclusions checked by other pathologists and the ability to test the tissue (eg. DNA testing) in the future in order to answer other questions which may be raised by relatives (eg. genetic susceptibilities).

¹⁴⁰ Particularly, as might have been expected, in relation to those organs such as the heart and brain which tend to have a particular emotional resonance for relatives.

5.3 Existing collections of retained organs

It is clear that, over the years, specimens of organs and tissue removed for the purpose of post-mortem examinations have been retained on occasions for teaching and scientific purposes as authorised by the relevant legislation at the time, and that many specimens are still retained for those purposes today. It is likely that in some cases those specimens were retained without the knowledge of the deceased person's relatives because of the lack of any statutory requirement for specific consent in those circumstances.

This raises a question as to whether contact should now be initiated with the relatives of a deceased person to discuss their wishes concerning any further retention of such specimens, or the disposal of the specimens.

It has been recognised, for example by the Scottish Review Group and the Australian Health Ethics Committee ("AHEC"), that as a matter of principle it is not appropriate to initiate contact with the relatives of a deceased person who has undergone a post-mortem examination. Such contact, when not initiated by the relatives, can simply cause unwanted distress in relation to issues of bereavement which the relatives may have no wish to revisit.

However, it may equally cause distress if relatives do in the future initiate a query and then learn that organs which are now retained from a past post-mortem examination were subsequently disposed of without their knowledge, and without the opportunity to decide how the organs should be disposed of (by cremation or burial).

The recommendation of AHEC (and this is consistent in principle with the recommendations of the Scottish Review Group) is to address this issue by adopting the following general procedure:

- (i) impose a moratorium for a period of time on the disposal of any currently retained organs, except in accordance with the directions of the relatives of a deceased person (AHEC has recommended 3 years);
- (ii) ensure that the public is aware that during that moratorium period enquiries may be made about retained organs;

- (iii) respond to any enquiries which may be made, and act in accordance with the wishes of relatives where the enquiry relates to a retained organ;
- (iv) allow institutions to make arrangements for the respectful disposal of retained organs which are subject to the moratorium period at the conclusion of that moratorium period.¹⁴¹

5.4 Medical research

Among the decisions which the relatives of a deceased person may make, as part of the process of making an informed decision about a non-coronial post-mortem examination (or in making a decision about organs not required to be retained for the purposes of a coronial post-mortem examination), is that of permitting organs or tissue to be retained for medical research.

As the Chief Medical Officer (NSW) has noted:

"It is undisputed that the retention of body parts from post-mortem examinations for research and other purposes has yielded immeasurable benefits to the understanding of human disease processes. It is of little doubt that the knowledge gained through such research has improved the quality of life in all tiers of society through substantial gains in the ability to prevent, detect and treat many diseases."¹⁴²

It is to be expected that some relatives (and some deceased persons by way of prior direction) will wish to contribute to the continued advance of medical knowledge which can be achieved by such research.

Such a decision may include one of the following:

- (i) a decision to allow an organ to be retained initially for diagnostic purposes, and then to be retained for possible medical research;

¹⁴¹ AHEC has indicated that it will review the situation at the conclusion of the 3 year moratorium period in order to determine whether there is any need to extend that period. AHEC has not currently specified in any detail the criteria which should be applied by institutions at the end of that 3 year period in determining whether or not to dispose of any retained organs which have not been the subject of a specific enquiry or specific direction for disposal.

¹⁴² *Interim Report into the retention of tissue & organs following post-mortems in NSW* (2001) at 1.4.

- (ii) a decision to allow an organ to be retained for medical research (whether or not there is any requirement that the organ be retained for diagnostic purposes).

Such permission may be limited as to the type of research which may be carried out on the retained organ or it may be more general. It may be limited as to the time for which the organ may be retained for research purposes or it may allow indefinite retention for this purpose. It may be given on condition that some feedback on any research be provided to the relatives, or it may be given on the basis that no such feedback is sought.

The specific type of permission granted could therefore be expected to vary from case to case. However, it has been recognised¹⁴³ that it is appropriate to make the permission of the relatives only one of the necessary steps in obtaining approval for any research use of human tissue obtained from post-mortem examinations.

The other step should be for the proponent of the medical research proposal to obtain the approval of the relevant institutional research ethics committee. Such an ethics committee is able to assess such things as: the bona fides of the researcher; the scientific merit of the proposal; and the steps which will be taken to maintain appropriate confidentiality.

It provides a mechanism by which any decision by relatives (or the deceased by prior direction) to permit the use of retained organs or tissue for research purposes can be made in the knowledge that independent evaluation by an ethics committee will also be a condition of such use of any retained organs or tissue.

6.0 Conclusions

6.1 General comments

It is clear that those recommendations of the *Report of the Committee of Inquiry into Aspects of Coronial Autopsies* ("the Honey Report") which were designed to secure for the relatives of deceased persons involved in the coronial process an appropriate degree of knowledge about, and involvement in, that process have been realised with the enactment of

¹⁴³ For example, the provisional recommendations of the Australian Health Ethics Committee would require ethics committee approval to any research. In the coronial sphere, the coroner has established an ethics committee to advise on research proposals (the permission of relatives is also made a necessary pre-condition under that system of ethics approval).

the *Coroners Act 1996* (WA), the guidelines and directions issued by the State Coroner, and the practices and procedures implemented by the Coroner's Office.

In the *Interim Report* it was stated that:

"In our opinion, the 1992 *Report of the Committee of Inquiry into Aspects of Coronial Autopsies* (usually referred to as the *Honey Report* after the Chairperson of the Committee, Colin Honey) represented a most comprehensive examination of the coronial system of post-mortems in Western Australia. It investigated and reported on the issue of organ and tissue retention and drew attention to the issues that the callers to the hotline have raised in the current investigation.

After the *Honey Report* was released and with the subsequent enactment of the *Coroners Act 1996* the practices and procedures have been greatly improved. In the new coronial system family members are kept informed about post-mortem procedures and, in particular, about any retention of organs required for examination. As a result the family members are able to make choices about funeral arrangements which accommodate family wishes."

The relevant features of the new coronial procedures (most of which have now been in place since early 1997) have been described earlier in the *Report*. The preliminary views expressed in the *Interim Report* are confirmed. It is not apparent that any relevant changes are required in relation to the system of coronial post-mortem examinations (which can rightly be regarded as representative of current 'best practice' in relation to these issues¹⁴⁴).

No recommendations for change in relation to the system of coronial post-mortem examinations are therefore made in this *Report*.

While the *Anatomy Act* can be said to be relatively old legislation,¹⁴⁵ it is already based on the fundamental principle of consent to the anatomical examination of the body (from the deceased and next of kin) and in practice would seem to operate adequately to secure the interests of relatives (and deceased persons prior to death) in being properly informed about what such an anatomical examination will involve prior to the 'donation' of the body. In addition, no concerns have been raised, in the cases investigated by the Department, about the operation of the system for anatomical examination (all cases investigated have related to coronial and non-coronial post-mortem examinations).

¹⁴⁴ Always allowing for the particular restrictions imposed by a system of coronial investigation in which decision-making must usually ultimately reside, in the public interest, with the coroner.

¹⁴⁵ Enacted in 1930 (and borrowing language and concepts from much earlier legislation), it has been subject to minimal amendment since that time.

No recommendations for change in relation to the system of anatomical examinations are therefore made in this *Report*.

The recommendations which follow relate only to the current system of non-coronial post-mortem examinations. They are designed to close whatever gap may still exist between community expectations and the practices and procedures in this area. They are consistent with, and reflective of, similar ideas and recommendations which can be found in the documents produced by the many inquiries, investigations and reviews which have been conducted in the last few years (and to which reference was made in the Introduction to this *Report*). They do not assume that significant steps have not already been made by the relevant hospitals to make similar changes (the contrary would appear to be the case).

6.2 Summary of conclusions

The main conclusions of the *Report* are as follows:

- (a) that the current system of coronial post-mortem examinations, as enacted in the *Coroners Act 1996* and implemented by way of appropriate practices and procedures since that time, ensures that relatives of the deceased person have an appropriate degree of knowledge about, and involvement in, that process and that changes in this area do not therefore appear to be necessary;
- (b) that the current system of anatomical examinations is based on the principle of consent, and no problems with its operation in practice are apparent, and that changes in this area do not therefore appear to be necessary;
- (c) that the current system of non-coronial post-mortem examinations needs to be more explicitly based on the principle of informed decision-making by relatives of the deceased person, and the implementation of those decisions by hospitals, and that changes in this area are necessary to ensure that the aims of that principle are achieved.

7.0 Recommendations

7.1 Guiding Principles

The recommendations are informed by the following guiding principles:¹⁴⁶

1. That the relatives of a deceased person should be treated at all times with appropriate sensitivity and due respect.
2. That the relatives of a deceased person should be given the opportunity to consider a non-coronial post-mortem examination (in an appropriate case).
3. That the relatives of a deceased person should be given the opportunity to make informed decisions about a non-coronial post-mortem examination, without any pressure to make those decisions in a particular way.
4. That the informed decisions made by the relatives of a deceased person in such a case should be respected and fully implemented by the hospital.
5. That it should be possible to monitor the implementation by the hospital of the informed decisions made by the relatives of a deceased person.
6. That a hospital should answer to the best of its ability any queries which the relatives of a deceased person may have in relation to a non-coronial post-mortem examination previously carried out at the hospital.
7. That a hospital should comply to the best of its ability with any requests which may be made by the relatives of a deceased person in relation to tissue or organs retained at the hospital from any non-coronial post-mortem examination previously carried out at the hospital.

7.2 Communication with relatives

It is not possible to generalise either about the personal and individual reaction that relatives will have to the death of a loved one, or about their likely attitude to the possibility

¹⁴⁶

It is not of course suggested that the principles represent an exhaustive list of those which could be formulated. See for example the list in *The Removal, Retention and use of Human Organs and Tissue from Post-mortem examinations - Advice from the Chief Medical Officer (UK)* at 37.

of a non-coronial post-mortem examination being carried out on the body of the deceased or the possibility of tissue (including whole organs) being retained as a result of such a post-mortem examination (whether for diagnostic or other purposes).

Therefore, any system for communicating with relatives about these issues needs to be sufficiently flexible to be able to respond appropriately to the different needs that relatives may have at what will always be a very difficult time.

For some, perhaps many, the preference may be to discuss these issues (if at all) with the treating clinician. It will often be that person who has had the most ongoing contact with the relatives prior to the death. However, that person may not always be sufficiently familiar with post-mortem examination procedures to provide the relatives with all relevant information.

For others, the preference may be to discuss these issues with the pathologist who will perform the proposed post-mortem examination. However, that person is unlikely to have the same rapport with the relatives as the treating clinician. Some relatives may wish to later discuss the findings of any post-mortem examination with the pathologist.

For others again, the preference may be to discuss these issues with a non-medical person such as a hospital-based social worker, a bereavement counsellor or a religious adviser. However, that person again may lack sufficient knowledge about post-mortem examination procedures to be able to provide the relatives with all relevant information.

Each of these persons may, in a particular case, have an important input into the process by which the relatives are informed about the post-mortem examination process, assisted in arriving at decisions with which they are comfortable, and provided with appropriate emotional support, both during and after those decisions are made.

However, no one person will in all cases be the person who is best placed to provide the information and support that the relatives of a deceased person may require. For that reason, a 'team-based' approach would seem to be the most appropriate model (being the most flexible).¹⁴⁷ In this model, the particular expertise of clinicians, nurses, pathologists, social

¹⁴⁷ This model was supported by the Scottish Review Group: *Report of the Independent Review Group on the Retention of Organs at Post Mortem* (2001) at para. 82.

workers, counsellors, and religious advisers can each be called upon as and when, and to the extent, which is required in the particular case.¹⁴⁸

However, introducing this type of flexibility into the communication process carries with it the risk that relevant information will not, through inadvertence, be provided to the relatives. If a number of people participate in the process of communicating with the relatives, it is always possible that one or more of them may not provide some relevant information because they assume that someone else has already done so. For that reason, any 'team-based' approach needs to be co-ordinated by one person who will ultimately be accountable for ensuring that in each case nothing has been missed.

Such a co-ordinator would be able to:

- (i) arrange for the relatives to be provided with the necessary information, in an appropriate setting and at an appropriate time,¹⁴⁹ which will enable them to reach informed decisions in relation to any post-mortem examination;¹⁵⁰
- (ii) ensure that any post-mortem examination is not authorised until the relatives have had the opportunity to receive and consider the necessary information and reach informed decisions;¹⁵¹
- (iii) ensure that appropriate records are kept in each case;¹⁵²

¹⁴⁸ For example, a relative is discussing the issues with a clinician but wishes to be provided with more detail about the possibility of a limited post-mortem examination (how it could be done, what would be the implications of that for the answers which may be obtained about the death). To address that request, the pathologist is brought in to discuss that issue with the relative.

¹⁴⁹ The need to perform any post-mortem examination as soon as possible after the death will impose some restrictions on how appropriate the timing for such decisions can ever be in any case (it is not a decision that can be left for many days - the time for any useful post-mortem examination will then have passed).

¹⁵⁰ This might involve the co-ordinator providing verbal and written information and arranging for discussions with other relevant personnel (clinician, pathologist etc).

¹⁵¹ For example, the co-ordinator could review with the relatives all the necessary information (to ensure that it has been received and is understood) before any consent form was signed. Although this might mean that issues are traversed twice (eg. once by the clinician and once by the co-ordinator), this will always be preferable to anything being missed. The co-ordinator could then certify to the "designated officer" that all the relevant information had been provided and apparently understood by the relatives.

¹⁵² For example, of the information which was provided to relatives, of the relevant decisions made by the relatives, and of the carrying into effect of those decisions by the hospital. Such centralised record-keeping would also allow for statistics to be kept on a yearly basis which would allow a 'snapshot' to be obtained in relation to the rate of non-coronial post-mortem examinations from year to year (and in particular whether such things as better public education and the provision of more

- (iv) be an ongoing point of contact at the hospital for the relatives;¹⁵³
- (v) follow up any requests for further information on behalf of the relatives with the appropriate personnel;¹⁵⁴
- (vi) assist with the ongoing improvement of practices and procedures over time;¹⁵⁵
- (vii) assist with any process of public education which might be undertaken about the nature of, and benefits of, the non-coronial post-mortem examination.

Such a post-mortem co-ordinator, dedicated either fulltime or part-time to that task, would also represent over time a stock of 'corporate knowledge' about the post-mortem examination process (this can otherwise be lost as clinicians and pathologists move from hospital to hospital).

Those involved in seeking permission from relatives should never assume that the relatives will have any, or any particular, level of knowledge about the issues which may need to be discussed with them. The starting point should always be an assumption that nothing is known by the relatives about those issues.

Those involved in seeking permission from relatives should also never assume that the relatives will not wish to be informed about an issue because it may cause them some emotional distress. The starting point should always be an assumption that the relatives will want, and will need, to know about those issues which may affect their decisions, even where the information may cause them some emotional distress.

detailed information to relatives may arrest the decline in the rate of non-coronial post-mortem examinations).

¹⁵³ In case the relatives may later wish to obtain any further information, or to have information previously provided clarified, or to check on the progress or result of any examinations or investigations or on compliance with any directions made about the use or disposal of organs and tissue etc.

¹⁵⁴ For example, finding out from the pathologist what technical terms in the post-mortem findings mean and passing that on to the relatives.

¹⁵⁵ For example, such a person might over time realise that some terms used in the information booklets provided to relatives were not usually well understood by relatives and thereby contribute to the process of improving the language which was used to make it better understood by relatives.

However, those involved in seeking permission from relatives should always give adequate respect to the right of the relatives not to know about any matters of detail which they may be content to have left unexplained,¹⁵⁶ where the relatives indicate that the provision of that level of detail is not necessary for them to make the decisions.

Relatives should always be provided with written information about the issues in relation to which they need to be informed prior to the making of any decision, and written confirmation of the decisions which they have made (including any decisions to impose conditions or restrictions on what may take place). It may be difficult to take in information delivered verbally and it is therefore important that information in writing to the same effect is available for the relatives to take away, and perhaps read and re-read, before making the relevant decisions.

Relatives should always be provided with a convenient ongoing point of contact from where information, clarification or confirmation can later be sought or sourced.

The hospital should always be satisfied that the relatives have received the necessary information, and made informed decisions, before any non-coronial post-mortem examination takes place. The hospital should also always ensure that any decisions made by relatives about the use or ultimate disposal of retained organs or tissue are carried into effect, and that it is always able to check that this has been done.

Another important aspect of communication with relatives will be providing feedback on the findings of a post-mortem examination in an appropriate form (ie in a form which the relatives are able to understand). This may involve supplying the relatives with a copy of the report and an opportunity to discuss, and have the findings explained by, a medically trained person (clinician, pathologist, general practitioner).¹⁵⁷ It might involve the preparation of an additional 'plain english' post-mortem report for the relatives in some cases.

7.3 Accountability and audit

¹⁵⁶ As the Scottish Independent Review Group noted: "Naturally, there will be some relatives who wish neither to receive information about the post-mortem nor to be told what may become of the organs after post-mortem, and their right not to receive this information must also be respected.": *Report of the Independent Review Group on the Retention of Organs at Post Mortem* at para. 10.

¹⁵⁷ This will usually need to be a person with a good understanding of the pre-mortem course of treatment (eg. the treating clinician), as the significance of post-mortem findings often depends on being able to correlate post-mortem findings with pre-mortem treatment.

Any system which has as its primary goal the implementation of the informed decisions of relatives, must include procedures which will allow the implementation of those decisions to be checked and confirmed (both by the hospital - 'internal audit' - and by others - 'external audit').

This does not involve any assumption that the decisions of relatives will be disregarded by the hospital (the appropriate assumption will be to the contrary). However, relatives are entitled to have confidence that their decisions will be implemented, and this can only be guaranteed by a system in which the implementation of those decisions can be subject to scrutiny.

For this reason, the first requirement must be adequate record-keeping. It is this which will provide a basis for checks to be made when (as will be inevitable) the staff involved change over time. The information provided to the relatives must be documented. The decisions made by the relatives must be documented. The implementation of those decisions must be documented.

It should, in the future, always be possible for the hospital to determine quickly and conveniently the answer to any relevant question which may be asked about a non-coronial post-mortem examination carried out at the hospital. In particular, it should be possible to demonstrate by written records that what was done at the time of the post-mortem examination, and subsequently, followed the decisions made by the relatives at the time that permission was originally given by the relatives.

A hospital should, by maintaining the appropriate records, be able to report on a periodic (eg. yearly) basis to the Chief Medical Officer, Department of Health in a de-identified manner on matters such as: the number of non-coronial post-mortem examinations carried out; the number of cases in which organs were retained; the purposes for the retention of any organs; whether any organs are still retained; whether, and how, any organs retained at the time of the previous report have been disposed of and how.

It should, by means of such record-keeping, be possible for the hospital to maintain an up to date register of any organs or substantial tissue which is retained from time to time (and to track its use or ultimate disposal in accordance with the decisions made by the relatives). If considered appropriate, the information contained in the register could be coded so that it is

de-identified but can be linked if necessary to the particular specimen and records relating to the post-mortem examination.

It should also then be possible for the Chief Medical Officer, Department of Health to conveniently review the circumstances of any particular case in the event (which should be unlikely in a system based on informed decision-making by the relatives) that any query, concern or complaint is raised by a relative at some future point in time.

7.4 Other issues

While there are always some benefits in standardisation, it would seem sensible to allow hospitals some flexibility in the development of documentation to give effect to the recommendations in this *Report*.

In particular, the development of written information about post-mortem examinations and revision of consent forms is a task which may be left to each of the hospitals to address in the context of their own particular situations. As noted, considerable work in this area has already been done in Princess Margaret Hospital and King Edward Memorial Hospital.

However, there is in allowing such individual approaches a need to ensure that all critical items of information are included in any information booklet which may be developed by each hospital for the relatives of a deceased person. There is a similar need to ensure that any consent forms developed provide scope for all the critical decision-making to be recorded.

It is therefore considered appropriate that a system of approved information booklets and approved consent forms be adopted. By this means, hospitals would be able to develop their own documentation and have it approved from time to time by the Chief Medical Officer, Department of Health. This would enable the Chief Medical Officer to ensure that any documentation in use from time to time was appropriate.

This approach may work towards standardisation, but leaves room for some flexibility in the approach of each particular hospital.

Many of the changes to practices and procedures have already been implemented, to a greater or lesser degree, in hospitals in this State. A degree of enforceability can, and should, be given to them at this time by issuing a Code of Practice under the *Human Tissue and*

Transplant Act. The Code of Practice which it is recommended be issued under the *Act* is Annexure C to this *Report*.

This will be sufficient to ensure that the practices and procedures relating to non-coronial post-mortem examinations in this State follow the principle of informed decision-making by relatives until changes can be made to the *Human Tissue and Transplant Act* to bring it more into line with that principle. Relevant parts of the *Human Tissue Amendment Bill 2001 (NSW)*¹⁵⁸ are likely to provide an appropriate template for those changes to the *Human Tissue and Transplant Act*.

7.5 Recommendations

The specific recommendations made in relation to non-coronial post-mortem examinations are as follows:

1. That the practices and procedures of hospitals should always be designed to ensure that the relatives of a deceased person will be able to make informed decisions about a non-coronial post-mortem examination, and in particular:
 - (a) about whether or not to agree to a post-mortem examination being carried out on the body of the deceased person;
 - (b) about whether or not to agree to a full post-mortem examination, or some more limited form of post-mortem examination;
 - (c) about whether or not to agree to any organ (or substantial part of an organ) being retained at the completion of an internal examination;
 - (d) about whether or not to agree to any retained organ (or substantial part of an organ) being used for a non-diagnostic purpose (such as research, education, or therapeutic use);
 - (e) about how and when any retained organ (or substantial part of an organ) should be disposed of by the hospital (eg. return to the body prior to burial or cremation where this may be possible, separate cremation or burial, incineration).

¹⁵⁸

NSW Bills (<http://www.parliament.nsw.gov.au/prod/web/PHWeb.nsf/Bills>).

2. That the practices and procedures of hospitals should always be designed to ensure that the informed decisions of the relatives of a deceased person (in relation to a non-coronial post-mortem examination and any organ retention which may be agreed to by the relatives):
 - (a) are always strictly implemented; and
 - (b) can be shown to have been implemented (ie. by maintaining adequate records of both the decisions of the relatives and their implementation.)

3. That the practices and procedures of hospitals should always be designed to ensure that the relatives of a deceased person are treated with appropriate sensitivity and due respect, and in particular:
 - (a) so that the relatives are able to make any necessary decisions within a timeframe and setting, and with the emotional support, which will minimise any undue distress; and
 - (b) so that there is no pressure placed on the relatives by the hospital to make any necessary decision in a particular way.

4. That each hospital carrying out non-coronial post-mortem examinations appoint an appropriate person (or persons) to perform the duties of a post-mortem co-ordinator with responsibilities such as the following:
 - (a) arranging for relatives to be provided with the information which will enable them to reach informed decisions;
 - (b) ensuring that any non-coronial post-mortem examination is not authorised by a "designated officer" unless and until the relatives have had the opportunity to reach informed decisions;
 - (c) ensuring that appropriate records are kept in each case (both of the decisions made by relatives and the implementation of those decisions);
 - (d) being an ongoing point of contact for relatives, and following up on their behalf any requests for further information;

- (e) assist with developing improved procedures over time, and with any process of public education about the nature of, and value of, non-coronial post-mortem examination;
- 5. That information booklets, and consent forms, are developed by hospitals carrying out non-coronial post-mortem examinations which will assist in giving effect to the principle of informed decision-making by relatives about all relevant aspects of non-coronial post-mortem examinations.
- 6. That each hospital carrying out non-coronial post-mortem examinations ensure that appropriate records are kept in relation to the informed decisions of relatives, and their implementation, and maintain an appropriate register of retained organs.
- 7. That each hospital report on a periodic basis to the Chief Medical Officer, Department of Health on the number of non-coronial post-mortem examinations carried out and any organs retained with permission of the relatives.
- 8. That each hospital respond to any queries raised about organ retention from past post-mortem examinations, but not initiate contact with any relatives who have not raised queries.

9. That each hospital refrain from disposing of any organs currently retained from past post-mortem examinations (except where this is done in accordance with the instructions of the relatives) for a period of 3 years (which is the period identified by the Australian Health Ethics Committee as appropriate in its recent recommendations).

7.6 Implementation of recommendations

It is considered that the appropriate steps to take, in implementing the recommendations are as follows:

1. Issue the Code of Practice under the *Human Tissue and Transplant Act*. (Provide for the Code of Practice to come into operation after a period of 1-2 months to allow hospitals sufficient time to have information booklets and consent forms prepared and approved by the Chief Medical Officer, Department of Health.)
2. Draft amendments to the *Human Tissue and Transplant Act 1982 (WA)* to more explicitly change its focus to incorporate informed decision-making by relatives in relation to all relevant stages of the non-coronial post-mortem examination process, including the retention of organs. (Give consideration to the recent NSW Amendment Bill as a guide to such amendments).
3. Ensure that each hospital carrying out non-coronial post-mortem examinations appoints an appropriate person (or persons) to perform the role of post-mortem co-ordinator for that hospital, and implements a system of record-keeping and reporting of the kind recommended in this *Report*.
4. Ensure that each hospital carrying out non-coronial post-mortem examinations has in place procedures to respond to any queries which may be raised by relatives about organ and tissue retention in past non-coronial post-mortem examinations carried out at the hospital.

5. Ensure that each hospital imposes a moratorium on the disposal of any retained organs from past non-coronial post-mortem examinations (except any which are already the subject of disposal directions from the relatives) for a period of 3 years (the time period nominated by the Australian Health Ethics Committee).
6. Monitor any recommendations which are made, and guidelines which are finalised, at the national level, through the work of the Australian Health Ethics Committee and the Australian Health Ministers' Advisory Council, to ensure that the practices and procedures in this State are consistent with that national approach.

Professor Bryant Stokes AM
Acting Commissioner of Health

2 October 2001

Annexure A: Copy Interim Report

INTERIM REPORT TO THE MINISTER FOR HEALTH ON THE INVESTIGATION INTO THE REMOVAL AND RETENTION OF ORGANS AND TISSUE FOLLOWING POST-MORTEM EXAMINATIONS IN WESTERN AUSTRALIA

BACKGROUND

Earlier Events

On 5 March 2001, the *Interim Report into the retention of tissue and organs following post-mortems in NSW* was released (a report from the Chief Health Officer, NSW Health to the New South Wales Minister for Health).

The process which led to that *Interim Report* commenced on 10 October 2000 when the New South Wales Minister for Health set up an information line for members of the public in that State, and was itself apparently prompted by events in the United Kingdom, in particular the Royal Bristol Infirmary Inquiry and the Royal Liverpool Children's Hospital ('Alder Hey') Inquiry.

In February 2001, drawing on the results of those inquiries, the Chief Medical Officer for the United Kingdom had published an advice entitled *The Removal, Retention and use of Human Organs and Tissue from Post-mortem examination*.

On 18 March 2001, the *Sunday* program and the *60 Minutes* program broadcast reports which alleged that improper practices in relation to post-mortem examinations had occurred at the Glebe Mortuary in New South Wales.

The Minister's Response

On 21 March 2001, the Minister for Health for WA announced that a 24 hour toll free telephone hotline would be set up to allow members of the public in this State to request information, express any concerns and make any complaints in relation to the conduct of post-mortem examinations.

The Minister for Health also announced that an investigation would be undertaken into post-mortem examination practices relating to organ and tissue removal and retention, and into the adequacy or otherwise of existing legislation and procedures.

The investigation is being undertaken by a team comprised of officers from the Crown Solicitor's Office and the Health Department of Western Australia ("the Department") as a co-operative and a consultative endeavour.

The Telephone Hotline

On 22 March 2001, the hotline commenced operation and the Department began taking calls and recording any requests for information, concerns and complaints.

Principally through the hotline, but also in some cases as a result of written communications with the Department or referrals from hospitals or the Coroner's Office, a total of 34 cases are currently registered with the Department for investigation.

Of those cases, 26 (ie approximately 75%) involved enquiries about post-mortem examinations carried out under the coronial system ("coronial post-mortems"), and 8 (ie approximately 25%) involved enquiries about post-mortem examinations carried out, or thought by the person making the enquiry to have perhaps been carried out, within the hospital system ("hospital post-mortems").

By arrangement with the State Coroner, the investigation team is examining those cases which involve coronial post-mortems during the period prior to the enactment of the *Coroners Act 1996* (WA), as it was considered that the Department would have access to the relevant records and be able to make the necessary enquiries, and be able to consult with the Coroner's Office if required. Enquiries received by the Department relating to coronial post-mortems from after the enactment of that legislation are referred to the Coroner's Office for investigation.

We note that prior to the establishment of the Department's hotline, the Coroner's Office received a number of enquiries relating to coronial post-mortems (both pre and post-1996) which that Office has investigated. Therefore, those enquiries are not referred to in this report.

The Time Period

The hospital post-mortem cases registered with the Department relate to deceased persons whose respective dates of death range from 1961 through to 2000. The earliest coronial post-mortem case was from 1969.

The Nature of the Concerns

Each of the enquiries was made by a close relative of the deceased person.

The issues raised by most callers related to the retention, or possible retention of organs and tissue, following a post-mortem examination on a family member without the knowledge or consent of the next of kin. We detail later in this report a statistical breakdown of those concerns.

Many callers stated that their call was not a complaint as such, but just involved a wish to know what had happened, or know more about what had happened and why, in relation to the deceased person.

Other issues raised by the callers related to the following:

- in non-coronial cases whether a post-mortem examination was carried out on the deceased person;
- why it was necessary to retain organs or tissue;
- the duration of retention of organs or tissue;
- the lack of information and communication at the time when the post-mortem examination was carried out and since that time;
- the lack of information generally regarding the procedures and justification for post-mortem examination.

The Legal Context

The relevant legal contexts, as they relate in particular to the degree of involvement of the next of kin, should also be briefly noted. A more detailed exposition of the relevant law will be included in the final report.

Prior to April 1997 (when the *Coroners Act 1996 (WA)* ("the *new Coroners Act*") came into operation), coronial post-mortem examinations were regulated by the *Coroners Act 1920 (WA)* ("the *former Coroners Act*") and the *Human Tissue and Transplant Act 1982 (WA)* ("*HTT Act*").

The effect of those statutory provisions was to make the carrying out of a coronial post-mortem examination depend on the direction of the Coroner, and to authorise the retention of organs and tissue removed for the purposes of such a post-mortem examination for therapeutic, medical, teaching or scientific purposes, subject to any order to the contrary by the Coroner. There was no legal requirement to consult the next of kin about retention of organs and tissue.

Under the *new Coroners Act* organs and tissue may be removed and retained at the direction of the Coroner where this is necessary to investigate the death. However, any such organs and tissue may only be retained for such period as the Coroner directs in the particular case.

The *new Coroners Act* also provides for a process by which the senior next of kin can authorise the retention of tissue and organs for a specified purpose (eg. therapeutic, medical, teaching or scientific). That is now an alternative potential source of the necessary legal authority to retain tissue and organs from a coronial post-mortem examination.

Since March 1983, hospital post-mortem examinations have been regulated by the *HTT Act*, the effect of which is to make the carrying out of a post-mortem examination depend on authorisation being granted by a person within the particular hospital who had been appointed as a "designated officer" under the *HTT Act*. However, that authorisation cannot be given by the "designated officer" in any case where the senior next of kin objects.

Under the *HTT Act* organs and tissue removed for the purposes of a hospital post-mortem examination can be retained for specified purposes (therapeutic, medical, teaching or scientific). There is no legal requirement to consult with the next of kin about retention of organs and tissue.

THE INVESTIGATION PROCESS

The Tasks and Their Priority

The investigation is being carried out on three levels:

1. The investigation of the specific queries, concerns and complaints which have been registered with the Department (ie the 34 cases).
2. A review of current post-mortem examination practices and procedures in Western Australia under existing legislation.
3. Consideration of the need for any amendments to existing legislation, changes to procedures or implementation of new procedures, relating to the conduct of post-mortem examinations.

Priority has been given to task 1 (ie investigating the specific cases) as it is appreciated that the recent media attention has, in most if not all of those cases, generated considerable anxiety amongst those relatives of deceased persons who have raised queries, concerns and complaints.

Once task 1 is completed, or completed in the majority of cases, the attention of the investigation team will increasingly focus on the broader issues (ie tasks 2 and 3), an endeavour which will require and involve considerable consultation with relevant persons (including where they are willing to provide input, the family members who have registered specific queries, concerns and complaints).

Investigation of Cases (Task 1)

Once the caller had contacted the Department telephone line, the relevant details were recorded by the hotline operators on a confidential basis.

Follow up telephone contact was then made as soon as possible by a senior investigating officer at the Department to acknowledge receipt of the enquiry and confirm the matter would be investigated and to provide an ongoing point of contact (whether by phone or by face to face meeting as the caller might wish).

A follow up letter was also sent confirming that information shortly after that first telephone contact.

Each matter was thoroughly investigated by initially searching for and examining the relevant files held at, for example, PathCentre, the Coroner's Office, the Ministry of Justice and the relevant hospital (in hospital cases).

Enquiries were also made, in writing and at interview, with relevant persons and organisations. We wish to acknowledge the high degree of co-operation received, and still being received from those individuals and organisations.

Provisional Results of Investigation (Task 1)

As at today's date, the greater part of the investigation side of each of the 34 cases has been completed. In some cases further work is required to clarify outstanding issues or to address further queries which might be raised by the family members.

We include below a table which summarises, in a general and de-identified form, the nature of the enquiries and the results of the investigations. It should be noted that in some cases the results are provisional only, pending further enquiries and clarification.

Nature of Enquiries

Caller unaware of whether post-mortem examination was carried out, and if so whether any organs or tissue retained	Caller aware that post-mortem examination was carried out, but wanted to know whether any organs or tissue retained	Caller aware that post-mortem examination was carried out, and aware that organs and/or tissue retained, but wanted additional information and/or explanation
3 (ie 9% of total cases)	16 (ie 47% of total cases)	15 (ie 44% of total cases)

Results of Investigations - Total Cases (34)

No post-mortem examination carried out	Post-mortem examination carried out, but no organ and/or tissue ¹⁵⁹ retained	Post-mortem examination carried out, and organ and/or tissue retained	Pending further enquiries to establish whether or not organ and/or tissue retained
3 (ie 9% of total cases)	3 (ie 9% of total cases)	25 (ie 74% of total cases)	3 (ie 9% of total cases)

Results of Investigations - Coronial Cases (26)

No post-mortem examination carried out	Post-mortem examination carried out, but no organ and/or tissue ¹ retained	Post-mortem examination carried out, and organ and/or tissue retained	Pending further enquiries to establish whether or not organ and/or tissue retained
0 (ie 0% of coronial cases)	2 (ie 8% of coronial cases)	21 (ie 81% of coronial cases)	3 (ie 11% of coronial cases)

Results of Investigations - Hospital Cases (8)

No post-mortem examination carried out	Post-mortem examination carried out, but no organ and/or tissue ¹ retained	Post-mortem examination carried out, and organ and/or tissue retained
3 (ie 37.5% of hospital cases)	1 (ie 12.5% of hospital cases)	4 (ie 50% of hospital cases)

The results can be briefly summarised as follows:

- in 31 of the 34 cases investigated a post-mortem examination was carried out;
- in at least 25 of those 31 cases, organs and/or tissue were retained;
- in the majority of cases, the organ retained was the brain;
- in the majority of cases the retained organs were subsequently cremated although the time at which this occurred varied;
- in most if not all of the 25 cases it appears that the family was not aware at the time of the post-mortem examination, or before the funeral, that organs and/or tissue were retained;

¹⁵⁹

In this context, the term 'tissue' does not include samples of tissue taken for testing and/or microscopic examination. Such very small samples of tissue are routinely taken, tested and/or examined, and stored as part of standard, and worldwide, pathology procedures.

- in the 15 cases where the callers were previously aware of organ and/or tissue retention the period between the post-mortem examination and the time at which they became aware varied;
- at this stage, it does not appear that any organs and/or tissue were retained contrary to the legal requirements which applied at the time.

Communication of Results of Investigation (Task 1)

The current priority is communicating the relevant information back to each person who initiated an enquiry. This communication will be either by meeting in the first instance or by letter with the option of a follow up meeting.

These approaches are being made with awareness that bereaved families may be caused further distress on receiving new information. As a support measure, experienced professionals in grief counselling have been consulted and retained by the Department. The services of the counsellors to provide support are offered to families if they wish at the time information is conveyed or for private sessions of counselling at a subsequent date.

As far as is possible, the families will be provided with sufficient information to answer their questions and any further questions they may have. All will receive formal written confirmation of the results of the investigation.

In the very small number of cases where an organ has been retained without the family's knowledge and has not yet been cremated, arrangements will be made for cremation or burial in accordance with the family's wishes.

Review of Current Practices/Procedures (Task 2)

As noted above, a common issue raised by the callers was the retention of organs and tissue following post-mortem examination without the knowledge or consent of the deceased's relatives.

It is proposed to investigate whether this occurs under current practices and whether policies and procedures with regard to obtaining informed consent for post-mortems are satisfactory at the present time.

In our opinion, the 1992 *Report of the Committee of Inquiry into Aspects of Coronial Autopsies* (usually referred to as the *Honey Report* after the Chairperson of the Committee, Colin Honey) represented a most comprehensive examination of the coronial system of post-mortems in Western Australia. It investigated and reported on the issue of organ and tissue retention and drew attention to the issues that the callers to the hotline have raised in the current investigation.

After the *Honey Report* was released and with the subsequent enactment of the *Coroner's Act 1996* the practices and procedures associated with coronial post-mortems have been greatly improved. In the new coronial system family members are kept informed about post-mortem procedures and, in particular, about any retention of organs required for examination. As a result the family members are able to make choices about funeral arrangements which accommodate family wishes.

In relation to hospital post-mortems, it is proposed that consultation will take place with hospitals, professional groups and agencies to ascertain:

- current practices and procedures regarding the information provided to next of kin when obtaining consent for post-mortem examination;
- the circumstances in which organs and tissue are retained under the *Human Tissue and Transplant Act 1982* (WA).

Although no callers raised any concerns or queries in relation to bodies donated to schools of anatomy under the *Anatomy Act* it is proposed to investigate the practices and procedures associated with this legislation in light of the potential for similar issues to arise in this area.

Review of Legislation (Task 3)

The final stage of this investigation will include a review of the relevant legislation and consideration of the need for any amendment:

Human Tissue and Transplant Act 1982 (WA)

Anatomy Act 1930 (WA)

Coroner's Act 1996 (WA)

This will include consideration of the amendments to the *Human Tissue and Transplant Act 1982* in 1997 which allowed for the development and enforcement of codes of practice for the purposes of facilitating the administration of that Act.

FINAL REPORT

It is expected that the further investigations will be completed and the final report presented to the Minister for Health by 31 July 2001.

RELEASE OF INTERIM REPORT

At this stage, the investigating team is in the process of communicating the results of the investigation to the families and anticipate that this process may not be complete for several weeks.

It is considered that the media attention that may be prompted by release of this Interim Report could have the potential to cause additional distress to the families at this particular time. It is therefore recommended that the Interim Report not be released while the process of communicating with the families is continuing.

Peter Panegyres
**Crown Solicitor for the
State of Western Australia**

Alan Bansemer
Commissioner of Health

Date: 17 May 2001

Annexure B: Additional Cases

After the release of the *Interim Report*, a further 22 cases were registered with the Department of Health for investigation (14 of which related to coronial post-mortem examinations). The nature of the enquiries was as follows:

Nature of Enquiries

Caller unaware of whether post-mortem examination was carried out, and if so whether any organs or tissue retained	Caller aware that post-mortem examination was carried out, but wanted to know whether any organs or tissue retained	Caller aware that post-mortem examination was carried out, and aware that organs and/or tissue retained, but wanted additional information and/or explanation
2 (ie 10 % of cases)	12 (ie 50% of cases)	8 (ie 40% of cases)

Of those 22 cases, 1 case related to a post-mortem examination carried out in New South Wales and was referred to the NSW Department of Health.

There were also 2 cases involving coronial post-mortem examinations carried out after the *Coroners Act 1996*, which were referred to the Coroner's Office. In 2 other cases, the callers subsequently requested that the matter not be investigated.

Of the remaining 17 cases, there were 3 cases in which no post-mortem examination had been carried out.¹⁶⁰ Those callers have received a report on that outcome of the investigation into their queries.

Of the remaining 14 cases, investigations are complete and the callers have been advised of the outcome in a further 4 cases. The investigation of the other 10 cases has not yet been finalised.

¹⁶⁰ These were the two cases in which callers had been unaware of whether a post-mortem examination had been carried out, and a further case in which the caller had mistakenly thought that a post-mortem examination has been carried out.

Annexure C: Code of Practice

Code of Practice

Issued by the Executive Director, Public Health, with the approval of the Minister for Health, under Section 32A (1) of the *Human Tissue and Transplant Act 1982* (WA).

Citation

1. This code of practice may be cited as the *Non-Coronial Post-Mortem Examinations Code of Practice 2001*.

Commencement

2. This code of practice will come into operation on [a date to be determined].

Application

3. This code of practice applies to any non-coronial post-mortem examination.

Definitions

4. In this code of practice, the following words have the following meanings:

"approved consent form" means a consent form which has been approved by the Chief Medical Officer;

"approved information document" means an information document which has been approved by the Chief Medical Officer;

"Chief Medical Officer" means the person who holds, or acts in, the position of Chief Medical Officer, Department of Health;

"consent form" means a document used by a hospital carrying out non-coronial post-mortem examinations to record the informed decisions of the senior available next of kin and other matters relevant to the authorisation of such a post-mortem examination;

"designated officer" has the same meaning as set out in the *Human Tissue and Transplant Act 1982*;

"diagnostic purpose" means for the purpose of arriving at a diagnosis in relation to the cause or extent of any pathological condition which may be present in the body of the deceased;

"disposal" and "disposed of" in relation to an organ includes incineration by the hospital or contractors, and release to funeral directors for cremation or burial;

"information document" means a document used by a hospital carrying out non-coronial post-mortem examinations to provide relevant information to the senior available next of kin about post-mortem examination practices and procedures;

"informed decision" means a decision by the senior available next of kin which has been made after that person has been provided with relevant information about post-mortem examination practices and procedures;

"non-coronial post-mortem examination" means any post-mortem examination carried out on the body of a deceased person which is not carried out at the direction of a coroner made under the *Coroners Act 1996*;

"non-diagnostic purpose" means any purpose other than a diagnostic purpose, and includes:

- (a) the purpose of medical research;
- (b) the purpose of teaching;
- (c) the purpose of therapeutic or medical use;

"organ" includes any whole, or substantial part of, a human organ;

"post-mortem co-ordinator" means, in relation to a hospital, the person (or persons) appointed by a hospital in accordance with clause 4. of this Code of Practice;

"senior available next of kin" has the same meaning as set out in the *Human Tissue and Transplant Act 1982*;

General guidelines

5. Each hospital in the State which carries out non-coronial post-mortem examinations shall take all reasonable steps to ensure that:
 - (a) its practices and procedures allow the senior available next of kin of a deceased person to make informed decisions about:

- (i) whether or not to agree to a non-coronial post-mortem examination being carried out on the body of the deceased person;
 - (ii) whether or not to agree to a full post-mortem examination or some more limited form of post-mortem examination;
 - (iii) whether or not to agree to any organ being retained at the completion of the internal examination (whether for diagnostic and/or non-diagnostic purposes);
 - (iv) how and when any organ retained at the completion of the internal examination should be disposed of by the hospital;
- (b) its practices and procedures will enable the senior available next of kin (and any other relatives of the deceased person) to be treated with appropriate sensitivity and due respect, and in particular:
- (i) so that the senior available next of kin is able to make any necessary decisions within a timeframe and setting, and with the emotional support, which will minimise any undue distress;
 - (ii) so that there is no pressure placed on the senior available next of kin to make any necessary decisions in a particular way;
- (c) the informed decisions of the senior available next of kin about any such matters are respected and implemented by the hospital.

Post-mortem co-ordinator

6. Each hospital in the State which carries out non-coronial post-mortem examinations shall have a person, or persons, appointed to be a post-mortem co-ordinator.

General responsibilities of post-mortem co-ordinator

7. A post-mortem co-ordinator shall have the following general responsibilities:
- (a) arranging for the senior available next of kin to be provided with the information which will enable that person to reach informed decisions about the matters referred to in clause 5 (a) of this code of practice;

- (b) ensuring that a non-coronial post-mortem examination is not authorised by a designated officer unless and until the senior available next of kin has had the opportunity to reach informed decisions about the matters referred to in clause 5 (a) of this code of practice;
- (c) ensuring that appropriate records are kept, in each case, of the decisions made by the senior available next of kin in relation to the matters referred to in clause 5 (a) of this code of practice, and of the implementation of those decisions by the hospital;
- (d) being an ongoing point of contact for the senior available next of kin (or other relatives) in relation to any requests for further information about any matter relating to a non-coronial post-mortem examination carried out on the deceased person.

Notification to be given to the post-mortem co-ordinator

8. A post-mortem co-ordinator shall be notified, as soon as is practicable, whenever a non-coronial post-mortem examination is being considered.

Preliminary action by post-mortem co-ordinator

9. When a post-mortem co-ordinator is notified that a non-coronial post-mortem examination is being considered, that person shall take steps to ensure that:
- (a) the senior available next of kin of the deceased person is identified;
 - (b) the senior available next of kin is provided with an approved information document and approved consent form;
 - (c) the senior available next of kin is given an adequate opportunity to read and consider the approved information document and approved consent form and to discuss their contents with any other relatives;
 - (d) the senior available next of kin is given an adequate opportunity to have any questions answered about the contents of the approved information document and approved consent form, or about any other aspects of the non-coronial post-mortem examination.

Subsequent action by post-mortem co-ordinator

10. When the post-mortem co-ordinator is satisfied that the senior available next of kin has had the opportunities referred to in clause 9. (c) and (d) of this Code of Practice, that person shall:
 - (a) ascertain from the senior available next of kin whether the deceased person had given any indication during his or her lifetime of his or her attitude to the possibility of a post-mortem examination after death;
 - (b) ascertain from the senior available next of kin whether he or she agrees to a post-mortem examination being carried out on the body of the deceased person.
11. If the post-mortem co-ordinator is informed by the senior available next of kin that the deceased person had expressed an objection during his or her lifetime to a post-mortem examination after death, no further action shall be taken by the hospital.

Consent form procedure

12. Where the senior available next of kin agrees to a post-mortem examination being carried on the body of the deceased person, the post-mortem co-ordinator shall ensure that:
 - (a) an approved consent form is completed and signed by the senior available next of kin;
 - (b) the approved consent form includes a record of all relevant decisions made by the senior available next of kin (including any limitations or conditions which may be placed by the senior available next of kin on the post-mortem examination and/or any retention of organs following the internal examination);
 - (c) the approved consent form includes certification from the post-mortem examination co-ordinator that all relevant information has been provided to the senior available next of kin so that informed decisions could be made (and that the approved consent form is not submitted to the designated officer until that has been certified);
 - (d) a copy of the approved consent form is provided to the senior available next of kin if and when it has been endorsed with the authorisation to perform a post-mortem examination by the designated officer.

Action by designated officer

13. A designated officer shall not authorise the carrying out of any non-coronial post-mortem examination unless he or she has been provided with a completed approved consent form (which includes the certification from the post-mortem co-ordinator referred to in clause 12 (c) of this code of practice).

Feedback to relatives

14. The post-mortem co-ordinator shall ensure that the senior available next of kin has an opportunity to receive appropriate feedback on the findings of any post-mortem examination which has been carried out on the body of that deceased person.

Record-keeping

15. The post-mortem co-ordinator shall ensure that, in relation to each case where a non-coronial post-mortem examination is considered, an adequate record is kept of:
 - (a) who was identified as the senior available next of kin;
 - (b) when an approved information document and approved consent form was given to the senior available next of kin;
 - (c) any questions raised by the senior available next of kin about the contents of the approved information document, approved consent form or about any other aspects of the non-coronial post-mortem examination, and the answers given to those questions;
 - (d) any information provided by the senior available next of kin about the attitude of the deceased, prior to death, to the possibility of a post-mortem examination;
 - (e) any decisions made by the senior available next of kin in relation to the matters referred to in clause 5 (a) of this code of practice;
 - (f) the implementation by the hospital of any decisions made by the senior available next of kin in relation to the matters referred to in clause 5 (a) of this code of practice.

16. The post-mortem co-ordinator shall ensure that there is maintained at the hospital, and kept up to date, in relation to any non-coronial post-mortem examination which is carried out after the date on which this code of practice comes into operation, a register which includes the following information:
 - (a) a description of any organ retained;
 - (b) an indication of when the non-coronial post-mortem examination to which the organ relates was carried out and the deceased person on whom it was carried out;
 - (c) an indication of when the approved consent form was signed, and any limitations placed by the senior available next of kin on that retention;
 - (d) an indication of any use of that retained organ (ie for diagnostic purposes and/or non-diagnostic purposes as may have been authorised by the senior available next of kin) and when any such use was completed;
 - (e) an indication of how and when any retained organ was disposed of by the hospital.
17. An extract from the register maintained in accordance with clause 14 of this code of practice, containing the details which relate to any retained organs from a particular deceased person, shall be provided by the hospital on request to any senior available next of kin of that deceased person (or other person authorised by the senior available next of kin).
18. The register maintained in accordance with clause 14 of this code of practice shall be open to inspection at any time by the Chief Medical Officer, or any officer of the Department of Health who may be authorised in writing by the Chief Medical Officer.

Reporting

19. The post-mortem co-ordinator shall ensure that on or before the 30th day of June in each year, a report is provided to the Chief Medical Officer which includes the following information:
 - (a) the number of non-coronial post-mortem examinations which were carried out at the hospital during the period since the 1st day of July of the preceding year;
 - (b) the number of non-coronial post-mortem examinations during that period in which an organ, or organs, were retained at the completion of the internal examination;

- (c) the number of non-coronial post-mortem examinations during that period in which an organ, or organs, were retained for diagnostic purposes;
- (d) the number of non-coronial post-mortem examinations during that period in which an organ, or organs, were retained for non-diagnostic purposes (and a percentage breakdown of the types of non-diagnostic purposes for which organs were retained);
- (e) the number of organs from non-coronial post-mortem examinations during that period which were disposed of during that period (and a percentage breakdown of the method of disposal which was used);
- (f) the total number of organs which are still retained at the hospital from non-coronial post-mortem examinations carried out during that period.