ORGANS RETAINED AT AUTOPSY

Ethical and Practical Issues

Advice of the Australian Health Ethics Committee to the Federal Minister for Health, Dr Michael Wooldridge, August 2001
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- fostering and supporting a high quality and internationally recognised research base;
- providing evidence based advice;
- applying research evidence to health issues thus translating research into better health practice and outcomes; and
- promoting informed debate on health and medical research, health ethics and related issues.

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1. Preface

In a letter dated 20 November 2000, the Federal Minister for Health and Aged Care, Dr Michael Wooldridge requested advice from the Australian Health Ethics Committee (AHEC) on what should be done about tissues and organs currently held by institutions as a result of autopsies.

The following subcommittee met on several occasions from February to July 2001 to develop draft recommendations.

Dr Christopher Cordner Chair, Member of AHEC
Dr Penny Brabin Psychologist, Vice-Chair of SANDS (Stillbirth and Neonatal Death Support) Australia
Ms Belinda Byrne Member of AHEC
Prof Bryan Campbell Member, National Health and Medical Research Council
Ms Michelle Daly Grief Counsellor, John Tonge Centre, Brisbane
Ms Helen McKelvie Manager Policy and Program Development, Victorian Institute of Forensic Medicine
Dr Paul Monagle Divisional Director, Laboratory Services, Royal Children’s Hospital and Royal Women’s Hospital, Melbourne
A/Prof Charles Naylor Chief Forensic Pathologist, John Tonge Centre, Brisbane
Dr Penny Mc Kelvie Head Anatomical Pathology Services, St Vincent’s Hospital, Melbourne
Mr John Vidas AHEC secretariat
Dr Kerry Breen The Chair of AHEC, has also provided advice.

Before AHEC finally considered the report, the subcommittee sought comments on the draft recommendations from a range of individuals and organisations. The subcommittee considered, and gratefully acknowledges, all the comments that were received.

It should be noted that the recommendations pertain to coronial as well as to non-coronial autopsies, and that they pertain only to tissues and organs taken at past autopsies. The need for changes to future autopsy practice is currently being considered by State and Territory Government agencies, with advice from relevant professional bodies.
2. BACKGROUND

Autopsy and organ retention practice in the United Kingdom

Widespread public concern about retention and use of organs and tissues following autopsy was first expressed in 1998/99 in the United Kingdom, when the Bristol Royal Infirmary Inquiry was examining evidence regarding the hospital’s paediatric cardiac surgery service.

The evidence included material on the retention and use of children’s organs as part of autopsy practice. The reaction to evidence that children’s organs had been retained at autopsy without the knowledge of the parents led to further government inquiries at other hospitals across the National Health Service, including Alder Hey Hospital in Liverpool.

The inquiries caused intense media interest in the parents’ responses, and highlighted deficiencies in both ethical and legal aspects of practice.

Autopsy and organ retention practice in Australia

Concerns have also been raised about autopsy and organ retention practice in Australia. In the early 1990s in Western Australia, next-of-kin concerns about coronial autopsies prompted an inquiry and legislative review that resulted in the inclusion of provisions dealing with organ retention practices in the new Coroners Act 1996 (WA). More recently, information made public in the eastern States and South Australia has triggered significant distress for next-of-kin, including many parents of deceased children and babies.

Current rules governing Australian practice of autopsy and of retention of organs and tissues are contained in State and Territory legislation passed in the late 1970s and early 1980s. These largely uniform Acts were based on recommendations of the Australian Law Reform Commission in its 1977 report on Human Tissue Transplants. Before the passage of these Acts, the common law (and limited statute law in Queensland and Tasmania) left uncertain many questions about the lawfulness of organ retention practices.

1 Transplantation and Anatomy Act 1979 (Qld); Human Tissue Act 1983 (NSW); Human Tissue Act 1985 (Tas); Human Tissue Transplant Act (REPH003) (NT); Human Tissue Act 1982 (Vic); Human Tissue and Transplant Act 1982 (WA); Transplantation and Anatomy Act 1978 (ACT); Transplantation and Anatomy Act 1985 (SA).
Next-of-kin consent has not been and is not required for the conduct of coronial autopsies. Under the current Acts, in some jurisdictions next-of-kin consent is required for non-coronial autopsies to be performed. However, in other jurisdictions ‘non-objection’ is sufficient. The removal of organs and tissues for diagnostic purposes as part of the autopsy is legally permissible under the next-of-kin’s consent or under the coronial order for the autopsy, even though in practice next-of-kin appear often not to have known that organs would be removed.

The laws also allow for tissues and organs removed for the purposes of autopsy, whether coronial or non-coronial, to be retained for other therapeutic, medical or scientific purposes without any consent having been sought or given by the deceased or the next-of-kin for that subsequent retention and use. This was an express consequence of Paragraph 165 of the Australian Law Reform Commission report of 1977 referred to above, which said that “(0)he procedures and characteristics of normal autopsies, and the beneficial uses to which tissues routinely removed during autopsies may be put, are such that the Commission unhesitatingly recommends some departure from the general principle of consensual giving upon which this report is based”. (As already indicated, the situation in Western Australia with respect to coronial autopsies changed in 1996.)

It has become clear that families, in giving consent to hospital autopsies or in being informed about a coronial autopsy, have often not been aware that the procedure may involve organs being removed and not returned to the body.

**Ethical considerations**

This document is concerned with ethical rather than legal aspects of institutional practices surrounding autopsy. This section briefly discusses some of the ethical aspects of these issues.

AHEC believes that many factors contributed to the situation to which these recommendations respond. The Australian Law Reform Commission, after extensive deliberation, produced the report in 1977 which gave impetus to new laws in States and Territories across Australia. This legislation, which anchored the practices surrounding autopsy that are now at issue, was debated and passed by the people's representatives in parliaments around the country. Many different groups contributed to confirming those practices, and even the community as a whole shares some responsibility for them.
This document in part reflects a sense of this widely shared responsibility. The main emphasis of the document, however, is on what now needs to be done by those institutions in which autopsies have previously taken place and organs have been stored.

The belated discovery that organs were removed at autopsy and not returned to the body has been painful for many families involved with an autopsy. The discovery has led some families to realise that what they thought crucial in order for someone they love to be laid to rest with due respect has not been done. Laying the dead to rest with due respect is a value universally shared, even though cultures, and also groups within a culture, may differ in their sense of which practices will manifest such respect. Not everybody shares the conviction that if possible human bodies must be buried or otherwise laid to rest with all their organs. All can recognise, however, not only that this conviction is very widely held, but also that it expresses a serious sense of respect for the dead.

Some families have experienced not only pain at what they have discovered, but also anger. This anger has at least two related sources. The first is these families’ sense that they have not been dealt with openly and honestly by medical staff, hospitals and other institutions. The second is that what was either concealed from them or passed over in silence prevented them from being able to lay their dead relative to rest with due respect. This lack of candour thus showed a failure to acknowledge what should have been recognisable as a matter of real importance to these families. In such cases families may also understandably think that this treatment of them also showed scant regard for their dead relative.

More could be said about these issues. In particular the various factors contributing to the practice of ‘not telling’ families could be distinguished and explored. Suffice it to say here that the treatment of families described above generates obligations and responsibilities, to which the recommendations in this report undertake to give shape.

**Aboriginal and Torres Strait Islander people**

Further recommendations on these matters that are sensitive to the distinctive concerns and needs of Aboriginal and Torres Strait Islander people need to be developed. Reasons for this include the high mortality rate among Aboriginal and Torres Strait Islander people, difficulties in the relationship between Aboriginal and Torres Strait Islander communities and the health service, and specific cultural beliefs among many such communities. AHEC is
seeking advice on how best to develop these further recommendations and will report to the Minister as soon as possible.

AHEC acknowledges that other ethnic and religious groups have beliefs which make these issues especially significant to them. Sensitivity to the various concerns of such groups is very important, but it is also compatible with recognising that the special history of Aboriginal and Torres Strait Islander people in Australia warrants separate attention to their concerns.

**Value of autopsy**

AHEC acknowledges and wishes to emphasise the value of autopsies and organ retention to individual families, to the practice of medicine, and to the community at large. The benefits include: allaying family fears about what they could have done to prevent the death; providing information about potential genetic disease that may have implications for family members; effective clinical audit; medical education and training; providing information about preventable causes of disease and accident and other public health hazards; contributing to research leading to improved health care; and transplantation of autopsy tissue. In addition, there are the forensic benefits of investigation of homicide, suspected homicide, other unexplained or suspicious deaths, and deaths apparently due to accident or injury.

The recommendations that follow in no way call the value of autopsies and organ retention into question. What they reflect is an appreciation of obligations arising from ethical shortcomings in some aspects of past practices.

**The main focus of concern**

Local experience as well as the UK reports strongly suggest that concern is focused on retention of whole organs, rather than on small samples of tissue routinely taken at autopsy for further testing. It seems that next-of-kin generally assume that an autopsy entails sampling on this scale as part of the investigation, and generally accept this practice. Much greater significance is attached to whole or substantial parts of organs, and AHEC’s recommendations are therefore centrally concerned with these.
3 SUMMARY OF RECOMMENDATIONS

Scope

These recommendations pertain to coronial as well as non-coronial autopsies. The recommendations concern the retention, use and disposal of tissues and organs removed at past autopsies only. Recommendations for change to future autopsy practice are outside the terms of the advice sought by the Minister, and therefore outside the scope of this document.

The recommendations are concerned generally with visually recognisable whole or substantial parts of organs or other body parts, which were removed at autopsy and not returned to the body. Except for Recommendation 10, the recommendations are not intended to apply to tissue samples taken as part of the autopsy investigation (e.g., tissue blocks, histology slides, retained small-tissue samples in formalin pots, samples of bodily fluids).

Sometimes, however, even these tissue samples may comprise a substantial part of a small whole organ (e.g., in the case of samples taken from infants). Next-of-kin may sometimes want information about such remains. While institutions need to be in a position to provide such information, these tissue samples are not intended to be subject to the audit referred to in Recommendation 1. The necessary information will usually be contained in an institution’s autopsy reports, and can be made available to next-of-kin upon request.

AHEC is aware that conventionally, the term ‘autopsy’ applies to the post-mortem examination of human beings already born and to the post-mortem examination of foetuses of 20+ weeks gestation, but not to the post-mortem examination of foetuses of less than 20 weeks gestation. The phrase ‘pathological examination’ is used in the latter context. Under the conventional understanding of the term ‘autopsy’, the recommendations would not apply to whole or parts of foetuses of up to 20 weeks gestation. However, AHEC is aware that some parents will be concerned about the storage and disposal of such foetuses. AHEC therefore intends its recommendations to apply also to foetuses of less than 20 weeks gestation.

Interpretation

• In order to avoid unduly complex sentences, the terms ‘organ’ and ‘organs’ will be used in the recommendations. These terms are intended to cover only visually recognisable:
— whole or substantial parts of organs or other body parts, which are retained after autopsy for any use,

— whole or substantial parts of foetuses regardless of gestation period,

• as described in the Scope, above.

• References to next-of-kin are to next-of-kin of deceased whose organs were retained. A hierarchy of senior, available next-of-kin is set out in relevant legislation in each jurisdiction.2 (AHEC recognises, however, that in some circumstances someone other than the next-of-kin may ethically be involved in the interactions to which the recommendations refer).

Recommendations

1. All institutions holding organs removed at autopsy for any purpose should, as soon as possible, undertake an internal audit both of those organs and also of records relating to past use and disposal or transfer of organs previously held.

   The audit should include as much of the following information as is reasonably possible:

   • Description of stored organs

   • Name and date of death of the deceased from whose body organs were removed

   • Whether the deceased was an Aboriginal or Torres Strait Islander

   • Any other available information on the cultural or religious alignment of the family

   • How relevant autopsy reports may be accessed

   • Where and how the organs are stored

   • Uses to which organs are currently put or intended uses (See also Recommendations 9 to 12)

   • Any specific benefits attributed to current or future use of organs

2 Transplantation and Anatomy Act 1979 (Qld); Human Tissue Act 1983 (NSW); Human Tissue Act 1985 (Tas); Human Tissue Transplant Act (REPH003) (NT); Human Tissue Act 1982 (Vic); Human Tissue and Transplant Act 1982 (WA); Transplantation and Anatomy Act 1978 (ACT); Transplantation and Anatomy Act 1983 (SA).
• Who has access to the organs and how this is regulated
• Name and contact details of person currently responsible for organs
• Description of records of past use and disposal or transfer of organs previously held

2. Institutions holding organs, or at which organs were retained at autopsy and then subsequently disposed of, should establish processes for responding to approaches from the next-of-kin. (See also Recommendation 6.)

Further guidance on responding to next-of-kin is provided in Appendix A of this document.

3. Institutions should not initiate contact with individual next-of-kin with information about stored organs.

4. Next-of-kin with concerns or questions about the conduct of an autopsy or the retention or disposal of organs should be invited, via the widespread dissemination of public information, to contact the responsible institution. This invitation should remain open indefinitely.

5. Responsibility for overseeing the dissemination of this information should lie with the Commonwealth Minister for Health in liaison with relevant State and Territory Government Departments, organisations and individuals, including community representatives.

6. Institutions have an obligation to provide for professional counselling for next of kin who need help in coming to terms with what they have discovered.

7. Next-of-kin should not incur any costs associated with an institution's response to their approach, including costs associated with disposal of organs. (See also Recommendation 8.)

8. In the absence of prior instructions from the deceased, institutions should seek to accommodate the wish of the next-of-kin about what is to be done with organs. This may be subject to negotiation if the wish seems unsafe, illegal or excessively onerous.

9. Institutions currently using organs retained at autopsy for educational and training purposes should review or, if necessary, develop policies to ensure respectful handling and use of the
organs. Attention should be given to ascertaining any specific concerns of different religious and ethnic groups about such handling and use.

10. Institutions should ensure that all research protocols proposing use of organs or tissue samples currently stored after autopsy are considered by a Human Research Ethics Committee (HREC).

(Some of the issues HRECs would need to take into account in considering such proposals are set out in the Discussion section of this document at page 18.)

11. Institutions currently holding organs where the identity of the deceased is known, and for which no further use is intended, should refrain from disposing of them for three years in the first instance, unless otherwise directed by the next-of-kin. Towards the end of this three-year period, the sub-committee of the Australian Health Ministers’ Advisory Council referred to in Recommendation 13 should review the need to extend this moratorium on disposal of organs. Where the identity of the deceased is still unknown after the audit referred to in Recommendation 1, organs may be disposed of respectfully.

12. Special consideration must be given to developing recommendations serving the distinctive concerns of Aboriginal and Torres Strait Islander people in the range of issues covered by this document. Until such recommendations are developed, institutions should not dispose of organs known or suspected to be from an Aboriginal or Torres Strait Islander unless directed to do so by the next-of-kin.

13. The Commonwealth Department of Health should, in conjunction with the States and Territories, develop methods of ensuring that institutions comply with these recommendations. The Australian Health Ministers’ Advisory Council should be asked to establish a sub-committee to oversee this process.
4. **DISCUSSION**

This section contains the reasoning leading to the recommendations.

1 **Audit of stored organs and related records**

There are two main reasons for recommending an audit of stored organs and related records. The first is the need to minimise the likelihood of future dramatic revelations about organ collections, which could cause continuing distress to bereaved families. Undertaking an audit would make all relevant information about stored organs available as part of a considered process.

The second reason for auditing is to place institutions in a position to provide accurate information to next-of-kin with concerns about organs removed at autopsy, and either subsequently disposed of or still retained. In the UK, institutions with different operating and record-keeping systems were required to report in a standardised way and to a standard deadline. While this approach allowed for an overall picture to be gained, it did not necessarily serve to place institutions in the best possible position to provide accurate information to next-of-kin. To this end, AHEC considers that individual institutions should undertake their own internal audits of stored organs and related records, within some general guidelines.

Individual auditing will allow institutions to take account of their own particular circumstances while being as comprehensive and accurate as possible. For example, an institution may have retained organs that are now part of private collections or which have been lent or transferred to other institutions. Institutions and individuals should communicate where necessary and co-operate in compiling as complete an audit as possible. This audit should allow information about organs that are still being held to be readily available to next-of-kin who approach the institution.

Institutions should also establish processes to enable ready access to records of cases in which organs may have been retained after autopsy and then disposed of, or used for research or other purposes, so that this information can be conveyed to next-of-kin upon request.

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5 In the light of public concern expressed about events at the Bristol Infirmary and at Alder Hey Hospital, British hospital pathology services and medical schools were subject to a standardised audit of their organ collections. The intention of the audit was to determine the size and nature of the collections. The audit concluded that at the end of 1999, pathology services were holding approximately 54,300 organs, body parts, still birth or foetuses from autopsies conducted between 1970-1999.
Some information that it would be useful to discover from an audit may not be available in every institution. Auditing should be as thorough as practicable, within the limitations of the institution’s records.

As stated earlier, AHEC does not intend tissue samples routinely processed as part of the autopsy investigation (e.g. tissue blocks, histology slides, retained small-tissue samples in formalin pots, samples of bodily fluids) to be subject to this audit. It is enough that institutions’ autopsy reports make it possible for available information about such samples to be given to next-of-kin upon request. If the information sought requires re-examination of the tissue blocks or other samples, this re-examination can be undertaken at that time.

Recommendation 1

All institutions holding organs removed at autopsy for any purpose should, as soon as possible, undertake an internal audit both of those organs and also of records relating to past use and disposal or transfer of organs previously held.

The audit should include as much of the following information as is reasonably possible:

• Description of stored organs
• Name and date of death of the deceased from whose body organs were removed
• Whether the deceased was an Aboriginal or Torres Strait Islander
• Any other available information on the cultural or religious alignment of the family
• How relevant autopsy reports may be accessed
• Where and how the organs are stored
• Uses to which organs are currently put or intended uses (See also Recommendations 9 to 12)
• Any specific benefits attributed to current or future use of organs
• Who has access to the organs and how this is regulated
• Name and contact details of person currently responsible for organs
• Description of records of past use and disposal or transfer of organs previously held

2 Responding to approaches from next-of-kin

The audit is a necessary preliminary to institutions being able to respond helpfully to bereaved families. Institutions will need to ensure that any staff undertaking these responses have the particular skills and training necessary for the responses to be open, honest, sensitive and informative. In addition, there should be staff involved with a sufficient level of authority to assure next-of-kin that their concerns and requests will be acted on.

In some institutions, those who respond may also be best placed to undertake the counselling referred to in Recommendation 6.

As already noted, AHEC is seeking advice on the development of recommendations responding to the distinctive concerns of Aboriginal and Torres Strait Islander people. Until these recommendations are developed, institutions holding organs known or suspected to be from Aboriginal and Torres Strait Islander people should keep lines of communication open with local Aboriginal Medical Services.

Recommendation 2

Institutions holding organs, or at which organs were retained at autopsy and then subsequently disposed of, should establish processes for responding to approaches from the next-of-kin. (See also Recommendation 6.)

Further guidance on responding to next-of-kin is provided in Appendix A of this document.

3 Direct contact with next-of-kin

Should institutions only stand ready to respond to approaches from next of kin, or should they initiate direct contact with next of kin? In considering this difficult question AHEC was mindful of events in the UK. In particular, the report of The Royal Liverpool Children’s Inquiry included material describing the process undertaken by the Alder Hey Hospital in directly contacting families with information about organs having been retained from their
children’s autopsies. This process was criticised for causing unwarranted distress, which in some cases had disastrous consequences for the families.

Many families have said that they would have preferred not to know, or that they were not yet ready to know, about their children’s organs having been retained. A direct approach from an institution with information about retained organs would, for such families, be unwelcome and might even have a devastating effect. A letter or telephone call merely inviting the family to contact the relevant institution for information could easily be interpreted as implying that the institutions holds organs from their child. Even if not interpreted in this way, such communication could still be an unwelcome reminder of past events.

It is true that reluctance to give people distressing information about the actuality of autopsies played a part in producing the situation to which these recommendations respond. It might seem that Recommendation 3 merely perpetuates the same practice. But this is not so. It is a mistake – an understandable mistake, but a mistake nevertheless – to suppose that the best way to rectify what happened must be directly to impose on people information that once was withheld from them.

On a very practical level, it is likely also to be difficult for institutions to be sure they can actually make direct contact. Records of next-of-kin addresses kept by institutions may no longer be accurate, especially in cases where the death occurred many years ago. Family circumstances may have changed: parents of a deceased child may have divorced, remarried or died. Sending potentially distressing information into an unknown context is very intrusive.

For all these reasons AHEC recommends that institutions should not make direct contact with next-of-kin with information about stored organs.

**Recommendation 3**

**Institutions should not initiate contact with individual next-of-kin with information about stored organs.**

4 Inviting approaches from next-of-kin

The other side of the issue discussed above is the risk that some parents or other next-of-kin who want to know what has happened may not get to do so. AHEC judges that the best way to minimise the chance of this happening
is to have an extensive, thoughtful and carefully organised public information process. This should include a general invitation to next-of-kin to approach the relevant institution with any concerns or questions they may have about the conduct of an autopsy.

Experience of several members of the sub-committee strongly suggests that the sensitivity with which this process is carried out will make a big difference to the readiness of next-of-kin to approach institutions. The process will have to be multi-lingual and sensitive to the needs and concerns of different religious and ethnic groups. Representatives of these groups should be involved in the setting up of the process.

Some next-of-kin will take considerable time to come to terms with the knowledge that information may be available to them about organ retention. They therefore may not arrive at a decision to approach the relevant institution for months or perhaps even years. For this reason it should be made clear that the invitation does not have a time limit.

**Recommendation 4**

Next-of-kin with concerns or questions about the conduct of an autopsy or the retention or disposal of organs should be invited, via the widespread dissemination of public information, to contact the responsible institution. This invitation should remain open indefinitely.

5 **Responsibility for publicity**

Clearly, the process of providing the public with the relevant information will need to be handled very carefully. AHEC considers that the Commonwealth Minister for Health should take responsibility for this process, having available to him the resources, skills and experience needed for this type of exercise. This includes being well-placed to consult with those who have experience dealing with families in these circumstances, as well as with relevant State and Territory Departments and institutions to ensure appropriate timing and co-ordination of publicity with institutions’ readiness to respond.

As already mentioned, it is also very important that both the content of the publicity and the way it is disseminated are sensitive to the differences among the cultural, religious and other groups who need to be reached.
It should be noted that Recommendations 3, 4 and 5 still allow considerable latitude to individual institutions in the way they publicise the kind of information they have available. For instance, an institution might have one of its members speak about autopsy issues on radio. Or it might decide to print its own leaflets and distribute them in local doctors’ surgeries. Both initiatives are still crucially different, however, from directly contacting an individual next-of-kin because the institution has information about retained organs that is specifically relevant to him or her.

Furthermore, some institutions may be ready to receive inquiries, and to respond helpfully to them, earlier than other institutions. It is important that such institutions are free to publicise the information they have available before the centrally-generated process referred to in Recommendations 4 and 5 gets under way, provided they give careful consideration to the ways in which they go about doing this.

Recommendation 5

Responsibility for overseeing the dissemination of this information should lie with the Commonwealth Minister for Health in liaison with relevant State and Territory Government Departments, organisations and individuals, including community representatives.

6 Providing counselling services for next-of-kin

From its own experiences and from the UK reports, AHEC is aware that many next-of-kin will want and benefit from professional counselling in coming to terms with discoveries about organ retention. In some cases, finding that there is no information about organs that have been disposed of could be a reason for a next-of-kin to seek counselling. Given that the practices of institutions have significantly contributed to the need for such counselling, AHEC considers that institutions should take responsibility for making it available.

In some cases next-of-kin may not be able, or may not wish, to undertake counselling provided directly by the institution (for example, where next-of-kin live far away, or where their experiences have left them distrusting the institution). In these cases, the institution should arrange for counselling to be provided by a professional who is acceptable to the next-of-kin.
The counselling process may uncover unresolved grief, or other issues, reaching beyond the institution’s responsibility. For this reason, there may in some cases need to be negotiation between institutions and next-of-kin about the duration of counselling provided for by the institution.

**Recommendation 6**

*Institutions have an obligation to provide for professional counselling for next of kin who need help in coming to terms with what they have discovered.*

**7 Next-of-kin not to incur costs**

In the UK some families with concerns about autopsies and organ retention were forced to make Freedom of Information requests, or to pay for the costs associated with hospitals accessing their records. There was also variation in the experiences of families who chose to cremate or bury retained organs. In some cases, these costs were borne by families. In other cases, the relevant institution took this responsibility.

Next-of-kin have not been responsible for creating the situation from which such costs may arise. AHEC believes they should not be responsible for meeting those costs.

Some institutions may be concerned about the resource implications of this recommendation, especially as it relates to costs of cremation and burial of retained organs. However, in the experience of the Royal Children’s Hospital in Melbourne, which has taken responsibility for such costs since October 2000, the choices made by families are such that very few cases incur costs of any significance. In any event, meeting these costs should be seen as part of what is involved in discharging obligations arising from practices that may have caused pain for bereaved families.

**Recommendation 7**

*Next-of-kin should not incur any costs associated with an institution’s response to their approach, including costs associated with disposal of organs. (See also Recommendation 8.)*
8 Meeting next-of-kin requests about organ disposal

Next-of-kin should be given the opportunity to decide what should happen to organs currently being held, unless an institution has an agreement with the now-deceased person about what is to be done with the organs. In some cases next-of-kin may choose to allow institutions to continue to use the organs unconditionally, or with conditions, such as that they are contacted in the event that the organs are no longer useful.

Where next-of-kin request that organs be disposed of or returned, institutions should ensure that any relevant laws, health and safety issues or other requirements are discussed with the next-of-kin. (Such laws and issues include: State and Territory legislation covering cremation and burial, including requirements about foetuses of different gestation periods; law and practice regarding disposal of organs retained as part of a coronial investigation; and hazards associated with dealing with chemicals such as formalin, in which organs may be stored.)

Institutions should provide next-of-kin with suitable options for disposal of organs. These should include making arrangements via a funeral director for cremation and burial services, in addition to any other methods routinely used by the institution that are acceptable to next-of-kin.

Experience so far suggests that requests by next-of-kin for disposal of organs will hardly ever involve excessively onerous demands upon an institution. But should an institution think a request to involve such demands, negotiation may be necessary.

Recommendation 8

In the absence of prior instructions from the deceased, institutions should seek to accommodate the wish of the next-of-kin about what is to be done with organs. This may be subject to negotiation if the wish seems unsafe, illegal or excessively onerous.

9 Organs stored for educational and training purposes.

The UK reports, the experience of AHEC and sub-committee members, and anecdotal evidence all suggest that there is significant public and next-of-kin support for the principle of using stored organs for education and training that will provide on-going benefits to the wider community.
Institutions should make sure they have policies to ensure respectful handling and use of the organs. Advice may be sought from professional and community representatives and ethics committees. Such policies should include details about maintenance to minimise damage and about providing information to students and trainees on the source of the organs. The privilege attached to using them should be made clear. Policies should also take account of the possibility that next-of-kin may request return or disposal of an organ in a teaching collection (in accordance with Recommendation 8).

Recommendation 9

Institutions currently using organs retained at autopsy for educational and training purposes should review or, if necessary, develop policies to ensure respectful handling and use of the organs. Attention should be given to ascertaining any specific concerns of different religious and ethnic groups about such handling and use.

10 Research use of currently stored organs and tissue

Some organs retained without knowledge or consent of next of kin are currently being used in research, and further requests for use of such organs in research may be made. This raises obvious ethical questions. AHEC considers that proposals for research involving organs or tissue samples stored following autopsy should be considered by a Human Research Ethics Committee (HREC).

At present, research using human material from autopsies is specifically excluded from the purview of the National Statement on Ethical Conduct in Research Involving Humans (1999), since additional guidelines or legislation may apply. Even so, some HRECs may wish to consider whether some of the principles underlying Chapter 15 of that document, entitled ‘Use of Human Tissue Samples’, are helpful to them in this context. The following suggestions may also be of some help to HRECs in thinking about how to respond to research requests to make use of stored material from autopsies.

Consent of those whose tissue is used for research is standardly a requirement of research approval by HRECs. Such consent will usually not have been given by those whose organs or tissues are held by institutions after autopsy. HRECs might then decide that consent from next-of-kin is sufficient. But, for the same reasons that apply in the case of Recommendation 3 above, researchers should not approach next-of-kin who may not know of the
existence of a stored organ to seek their consent for the research use of such organs or other tissue. HRECs will have to decide whether the requirement of consent for use of such organs and tissue in research is then to be waived.

Some HRECs may think that the decision must be no, and therefore that they cannot approve the research in these cases. HRECs who think the decision could possibly be yes, should then consider at least the following two questions. First, is there reason to suppose that the deceased or the next-of-kin would have refused consent? The onus would be on researchers to show that the organs or tissues they proposed to use do not come from, for example, people belonging to groups with religious or cultural beliefs that would prompt refusal to consent. Secondly, HRECs should consider how the proposed research may affect the appearance or integrity of an organ about which a next-of-kin might subsequently inquire.

It is worth noting that research requests to use organs that have been stored for some time since autopsy are rare, although requests to use other tissue samples are more common, and becoming increasingly so.

**Recommendation 10**

**Institutions should ensure that all research protocols proposing use of organs or tissue samples currently stored after autopsy are considered by a Human Research Ethics Committee (HREC).**

11 Disposal of organs

In the UK and here in Australia, some next-of-kin have expressed regret that retained organs were disposed of before they came to know of the retention. Some would have wanted to be involved in deciding how to dispose of the organs. For others, even the recovery of an organ would have given them something to ‘connect’ with, and thus to help them come to terms with their grief. (This is especially relevant in cases involving neonatal deaths and stillbirths, where past hospital practice discouraged or disallowed physical contact with the dead baby.)

In order to maximise opportunity for next-of-kin to be involved in decision-making about organs that are currently held, AHEC recommends that, where the identity of the deceased is known, institutions refrain from disposing of organs for a period of three years in the first instance. Where the identity of
the deceased remains unknown after the audit referred to in Recommendation 1, organs may be disposed of respectfully.

It must be acknowledged that a degree of arbitrariness attaches to any particular length of time for which it is specified that organs should be held. AHEC judges, however, that holding organs for an initial three-year period should help accommodate those next-of-kin who may not feel ready for some time to approach an institution. The publicising of a specific length of time for which organs will be retained may also provide a helpful horizon for those same people in their thinking about whether and when they might want to approach the institution.

Institutions may dispose of organs within the three-year period if instructed to do so by the next-of-kin.

Towards the end of the three years, an assessment should be made about whether the moratorium on disposal of organs should be extended. Factors bearing on the decision will include the number of inquiries institutions have had and are continuing to have, and other information arising from the audit and inquiry processes. AHEC considers that such an assessment should be made by a centralised body such as the sub-committee of the Australian Health Ministers' Advisory Council, referred to in Recommendation 13.

**Recommendation 11**

Institutions currently holding organs where the identity of the deceased is known, and for which no further use is intended, should refrain from disposing of them for three years in the first instance, unless otherwise directed by the next-of-kin. Towards the end of this three-year period, the sub-committee of the Australian Health Ministers' Advisory Council referred to in Recommendation 13 should review the need to extend this moratorium on disposal of organs. Where the identity of the deceased is still unknown after the audit referred to in Recommendation 1, organs may be disposed of respectfully.
12 Concerns and needs of Aboriginal and Torres Strait Islander people

As indicated earlier, there are specific issues affecting Aboriginal and Torres Strait Islander people which AHEC recognises need to be addressed in further recommendations. Advice is currently being sought on these issues and recommendations will be forwarded to the Minister as soon as possible.

Recommendation 12

Special consideration must be given to developing recommendations serving the distinctive concerns of Aboriginal and Torres Strait Islander people in the range of issues covered by this document. Until such recommendations are developed, institutions should not dispose of organs known or suspected to be from an Aboriginal or Torres Strait Islander unless directed to do so by the next-of-kin.

13 Compliance with these recommendations

It is very important indeed that there be ways of ensuring that institutions comply with these recommendations. AHEC considered various possible approaches to trying to ensure compliance, including changes to processes of accreditation and to annual reporting requirements of institutions, and legislation. All involve difficulties of application, which AHEC did not consider itself to be in the best position to resolve.

The Minister for Health in the UK has established a statutory agency, the Retained Organs Commission, to deal with issues arising from the various local and national inquiries into autopsy and organ retention practices. AHEC believes a body such as this to be a sensible idea, even if not on the same scale as has been found necessary in the UK. AHEC therefore recommends that a sub-committee of the Australian Health Ministers’ Advisory Council (AHMAC) be established to oversee the development of measures to ensure compliance with these Recommendations.

AHMAC is an appropriate body for this function because it has representation from health departments from all Australian jurisdictions, and also because it is likely to play a central role in co-ordinating reform of autopsy and organ retention practices around the country. Although AHMAC does not have jurisdiction over all institutions that have collections of organs stored after
autopsy, (e.g., universities and other educational institutions), it will be able to take account of the need to involve relevant parties in the membership of the sub-committee.

Recommendation 13

The Commonwealth Department of Health should, in conjunction with the States and Territories, develop methods of ensuring that institutions comply with these recommendations. The Australian Health Ministers’ Advisory Council should be asked to establish a sub-committee to oversee this process.
APPENDIX A

Guidance for handling next-of-kin inquiries about organ retention

The guidance in this Appendix is based on the experience of the Royal Children’s Hospital in Melbourne, which has been dealing intensively with next-of-kin inquiries about autopsies and organ retention since October 2000. The guidance is not definitive, but is offered on the basis that it may assist other institutions with practically implementing some of the Recommendations contained in the main part of this document. Obviously, individual circumstances in each institution will play a part in determining how useful this guidance is.

Basic principles and mechanisms

- Information should normally be given only to the deceased person’s next-of-kin unless next-of-kin gives written authorisation to provide information to others.
- Next-of-kin should be made to feel that their inquiries are welcome and will be dealt with openly and honestly.
- All facts particular to a case should be verified before any information is provided to next-of-kin. This includes checking case files and any other relevant information sources and cross-checking against any institutional database.
- Information should be provided in a sensitive manner, but should be explicit, rather than censored in any way. Relevant explanation of terms and procedures should be included and there should be capacity to support the next-of-kin through the whole process. Face-to-face meetings are therefore recommended.
- If requested, all details should be provided in written form, after the verbal explanation.
- An apology for hurt caused by institutional procedures can be given without assigning blame or acknowledging liability.
- Institutions should have a nominated team to deal with all next-of-kin inquiries. The team should include medical staff and those with qualifications and experience in counselling/bereavement support. The team could be area based, involving a number of institutions.
• All calls and correspondence should be directed to the specific team. All relevant personnel should be notified to ensure consistency of approach. This includes the switchboard, mailroom, all relevant departments within the institution, and the Freedom of Information officer. The team’s contact details should be widely publicised and readily available within the institution.

• The following information should be obtained at the initial inquiry:
  - Name of inquirer
  - Name of deceased
  - Relationship of inquirer to deceased
  - Date and time of inquiry
  - Deceased’s date of birth and date of death
  - Inquirer’s contact details (any confidentiality issues should be ascertained, e.g., is it OK to leave a message on an answering machine, are there members of the household who are not to know of inquiry?)
  - Any specific concerns

• Next-of-kin should be told when to expect further contact from the team, i.e., how long will it take to check the case details? Once the information is available, a member of the team should make contact with the next-of-kin to arrange an appointment at which the information can be conveyed and questions asked and answered.

• Meetings with next-of-kin should not take place where the deceased may have been cared for, or in a laboratory environment. If information is to be provided by telephone, having a support person on-site for the next-of-kin should be considered (i.e., suggest that the next-of-kin arrange to have someone they trust with them at the time of the pre-arranged call).

• Care should be taken to ensure that the information given is accurate and questions are answered honestly and openly.

• Next-of-kin should be offered follow-up counselling, and support from the institution.

• As noted earlier, AHEC is seeking advice on the development of recommendations responding to the distinctive concerns of Aboriginal and Torres Strait Islander people. Until these recommendations are developed, institutions holding organs known or suspected to be from Aboriginal and Torres Strait Islander people should keep lines of communication open with local Aboriginal Medical Services.
Information categories

Organs retained at autopsy fall into three main categories: organs held by an institution; organs retained for diagnostic purposes that have been subsequently disposed of; and organs retained for research purposes that have been subsequently disposed of. The following are suggestions for information in these three categories that should be kept on an institutional database to assist in responding to next-of-kin inquiries.

Organs held by an institution

(mostly as for audit in Recommendation 1 above)

- Description of stored organs
- Names and dates of death of the deceased from whose body organs were removed
- Whether the deceased was of Aboriginal or Torres Strait Islander descent
- Any other available information on the cultural or religious alignment of the family
- How relevant autopsy reports may be accessed
- Where and how the organs are stored
- Uses to which organs are currently put or intended uses
- Any specific benefits attributed to current or future use of organs
- Who has access to the organs and how this is regulated
- Name and contact details of person currently responsible for organs

Organs retained for diagnostic purposes, subsequently disposed of

Sometimes there will be no specific information available to be given in response to an inquiry about a particular autopsy. In that case, institutions should be ready to offer general information about diagnostic organ retention and disposal practices, with as much detail as possible that is relevant to the time and kind of autopsy about which the inquiry was made:
For example only:

Between 1960 and 1980 all routine autopsies performed at “XXX” Hospital included retention of the brain, which was fixed in formalin so that thorough neurological examination could be done. This did not happen if:

• The autopsy was limited to specific organs not including the brain, to comply with the instructions of next-of-kin or the requesting doctor
• The autopsy was on a still-birth where the infant died before delivery and thorough examination of the brain was not possible

Between 1960 and 1980 hearts were retained at autopsy in the following case categories:
• …..etc.

When the examination of organs retained at autopsy was completed, the organs were disposed of, or transferred elsewhere, in the following manner:

• 1960-1980: hospital incineration as for surgical tissue
• 1981-2000: off-site incineration by contractor
• Other: e.g., sent to Institution “X” for research use

**Organs retained for research purpose, subsequently disposed of**

In addition to responding to inquiries about specific cases, institutions should provide general information about research use of organs retained at autopsy:

• Project title
• Investigator
• Year(s) in which organs retained and used
• Type of organs retained and used
• Whether consent was obtained from deceased/next-of-kin
• Whether an institutional ethics committee approved use of the organs
• Manner of disposal
The National Health and Medical Research Council

The National Health and Medical Research Council (NHMRC) is a statutory body within the portfolio of the Commonwealth Minister for Health and Aged Care, established by the National Health and Medical Research Council Act 1992. The NHMRC advises the Australian community and Commonwealth; State and Territory Governments on standards of individual and public health, and supports research to improve those standards. The NHMRC advises the Commonwealth Government on the funding of medical and public health research and training in Australia and supports many of the medical advances made by Australians.

The NHMRC also develops guidelines and standards for the ethical conduct of health and medical research. The Council comprises nominees of Commonwealth, State and Territory health authorities, professional and scientific colleges and associations, unions, universities, business, consumer groups, welfare organisations, conservation groups and the Aboriginal and Torres Strait Islander Commission.

The Council meets up to four times a year to consider and make decisions on reports prepared by committees and working parties following wide consultation on the issue under consideration. A regular publishing program ensures that Council’s recommendations are widely available to governments, the community, scientific, industrial and educational groups.

The Council publishes extensively in the following areas:

- Aged care
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- Clinical practice guidelines
- Communicable diseases
- Dentistry
- Diabetes
- Drugs and poisons
- Drug and substance abuse
- Environmental health
- Ethics – Animal
- Ethics – Human
- Health procedures
- Health promotion
- Infection control
- Men’s health
- Mental health
- NHMRC – National Health and Medical Research Council
- Nutrition
- Public health
- Research
- Sport/Injury
- Women’s health
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