Victorian Aboriginal Ethics Project Report

A Community Report from
Onemda VicHealth Koori Health Unit

Paul Stewart and Priscilla Pyett
5. Six models for increasing Aboriginal control of health research ethics .................................................. 15
Model 1: Victorian Aboriginal Ethics Committee ........................................... 16
Model 2: Aboriginal Ethics Adviser(s) .............................................................. 18
Model 3: Register of Trusted Experts .............................................................. 20
Model 4: Project-specific Ethics Advisory Group ........................................... 22
Model 5: Aboriginal Health Research Ethics Advisory Committee ........... 24
Model 6: Aboriginal representation on Human Research Ethics Committees .................................................. 26
6. Discussion ........................................................................................................ 28
6.1. Issues not addressed by this project ............................................................... 28
6.2. Where to from here? ..................................................................................... 28
7. Recommendations ............................................................................................. 29
References ........................................................................................................... 30

Acknowledgments
This project was funded by the Victorian Health Promotion Foundation (VicHealth). We thank VicHealth for its understanding and continued support for a project that was intended to take six months but has needed more than three years to be carried out respectfully and completed in accordance with culturally appropriate processes and protocols.

We thank Jill Gallagher, the Chief Executive Officer (CEO) of the Victorian Aboriginal Community Controlled Health Organisation (VACCHO), and staff from the OneMDa VicHealth Koori Health Unit (formerly the VicHealth Koori Health Research and Community Development Unit), in particular Ian Anderson and Angela Clarke for their valuable support and input into the project.

We also thank all the Victorian Aboriginal Community organisations that supported this project in various ways, and the individual participants who contributed to the consultations and in-depth interviews. The VACCHO Members’ Meeting, the VACCHO Executive, and members of staff at the Centre for Health and Society and OneMDa provided valuable feedback on earlier progress reports and on the final draft of this report, and we thank all those individuals for their input.

Finally, we would like to acknowledge the assistance and financial support of the Cooperative Research Centre for Aboriginal Health in the publication of this report.

This report was prepared by Paul Stewart and Priscilla Pyett. Paul Stewart is a Taungurung man from central Victoria, and is employed as a Project Officer with the OneMDa VicHealth Koori Health Unit at The University of Melbourne. Priscilla Pyett is a Senior Research Fellow at OneMDa and has also been working as a researcher at VACCHO for the past two and a half years.
List of participants

This list includes all individuals who were consulted or interviewed during the project, those who attended the Community consultations, and those who provided feedback on the models and on the report:

Ali Brookes                      Gwenda Black                      Marlene Drysdale
Alma Thorpe                      Ian Anderson                      Maxine Harradine
Alvin Chong                      Isabel Ellender                  Michael Murray
Amanda Gillick                   Jemmies Handy                    Nicole Waddell
Angela Clarke                    Jill Gallagher                    Petah Atkinson
Anke van der Sterren            Joan Vickery                      Peter Waples-Crowe
Anne Garrow                      Jon Willis                       Raylene Fennell
Bill Genat                       Karlene Dwyer                    Renee Owen
Bill Roberts                     Kate Murphy                      Ron James
Carmel Marshall                  Kelvin King                      Salina Bernard
Craig Edwards                    Ken Knight                       Sharon Charles
Daniel James                    Laura Thompson                    Sharon Cruse
Daniel McAullay                  Leeanne Wright                   Shaukat Esufali
Dick Sloman                      Leonie Ireland                   Shaun Ewen
Edlyn Jimenez-Santos            Lisa Thorpe                      Sue Darby
Felicia Dean                     Lynette Russell                  Tanya Garling
Geraldine Atkins                Lynn Gillam                      Trevor Edwards
Grant Drage                      Marilyn Kelly                    Warren Weeks
Gregory Phillips                 Mark Saunders                     Wendy Holmes

Acronyms

ACCHO  Aboriginal Community Controlled Health Organisation
CEO    Chief Executive Officer
CRCAH  Cooperative Research Centre for Aboriginal Health
HREC  Human Research Ethics Committee
NACCHO National Aboriginal Community Controlled Health Organisation
NHMRC National Health and Medical Research Council (of Australia)
VACCHO Victorian Aboriginal Community Controlled Health Organisation
VAHS  Victorian Aboriginal Health Service
VKHRCDU VicHealth Koori Health Research and Community Development Unit
(now known as Onemda VicHealth Koori Health Unit)

Executive summary

The Victorian Aboriginal Ethics Project was conducted by Onemda VicHealth Koori Health Unit (formerly the VicHealth Koori Health Research and Community Development Unit or VKHRCDU) in partnership with VACCHO and with funding from VicHealth. The overall aim of the project was to find out how Aboriginal people could have more control of the ethics of research that is carried out in, or impacts on, Aboriginal Communities in Victoria. The project collected information from Community consultations, individual interviews and focus groups with key people, and a literature review.

The outcome of the project was to develop options for VACCHO to consider. Six models were developed. Each model offers advantages to the Aboriginal Community in Victoria, and different models may suit different Communities at different times. Some models are easy to implement immediately, while others would require significant planning and funding to support implementation and ongoing activities. The six models are:

- **Model 1: Victorian Aboriginal Ethics Committee**
- **Model 2: Aboriginal Ethics Adviser(s)**
- **Model 3: Register of Trusted Experts**
- **Model 4: Project-specific Ethics Advisory Group**
- **Model 5: Aboriginal Health Research Ethics Advisory Committee**
- **Model 6: Aboriginal representation on Human Research Ethics Committees**

A properly constituted Victorian Aboriginal Ethics Committee would be registered with the National Health and Medical Research Council (NHMRC) and would have the same authority as any Human Research Ethics Committee (HREC). This model does have the potential to give Aboriginal people control over research conducted in Victoria, but it is also the model that requires the most resources from the Victorian Aboriginal Community in terms of time, personnel and administrative support, and it has a heavy burden of paperwork. VACCHO members need to consider the strengths and weaknesses of each of the models before deciding how to progress with this issue.

It is hoped that this report will contribute usefully to an ongoing dialogue about how research ethics can be better managed for the benefit of the Victorian Aboriginal Community.
1. Introduction

The Victorian Aboriginal Ethics Project commenced in April 2002 and has been carried out by Onemda VicHealth Koori Health Unit in collaboration with VACCHO. The main aim of the project was to develop options for VACCHO to consider ways of assessing the ethics of health research involving Aboriginal participants or research likely to affect Aboriginal Communities in Victoria. The main objective of this project has been to find ways of giving Aboriginal people in Victoria more control of the ways in which research is being conducted in their Communities. The project addressed the following key questions:

- How are Aboriginal research proposals currently assessed for ethics?
- Should Aboriginal people have more control?
- How could the ethical assessment of research projects be done better? (more effectively, more appropriately, with more Aboriginal involvement and control?)
- What models exist in Australia and elsewhere for Indigenous involvement in the process of ethical review?
- What are the advantages and disadvantages of each model for the Aboriginal Community in Victoria?
2. How ethics became an issue in the Aboriginal Community

The need for the involvement of Aboriginal people in medical and research ethics comes out of the historical relationship between Aboriginal people and non-Aboriginal people since the invasion of our country more than 200 years ago. This history has been one of destruction, dispossession and exploitation which has cast us as the most powerless and disadvantage group in this country today (Flick 1994).

2.1. History of ethics and Aboriginal health research

Like other Indigenous Communities around the world, the Aboriginal Community in Victoria has become increasingly critical of the way research involving Aboriginal people has been conducted, particularly in the area of health. There are now many documented examples of Aboriginal health research where there has been insufficient consultation or involvement of those being researched, inadequate sensitivity to cultural issues, and little or no feedback of results to the Communities involved (McAullay, Griew & Anderson 2002).

Aboriginal health research conducted in Australia today is guided by ethical principles formulated during the 1980s and outlined in guidelines produced by the NHMRC (NHMRC 1991). The latest version of the guidelines for research with Aboriginal and Torres Strait Islander populations has been revised during the time this project has been conducted, and was finally released in 2003 as the Values and Ethics document (NHMRC 2003). Although the process of revising these guidelines involved a considerable amount of consultation with Aboriginal and Torres Strait Islander people around Australia, both the process and the content of the new guidelines have been subject to criticism from some sectors of the Aboriginal Community, particularly the National Aboriginal Community Controlled Health Organisation (NACCHO) (NACCHO 2003). The debate around these guidelines was acknowledged by participants in this project and is reflected in the data collected and reported in this document.

At the heart of the issue of ethical practice in Aboriginal and Torres Strait Islander health research is the question of how research proposals are assessed and monitored by ethics committees and what level of Indigenous control of ethics assessment is important. Like other Indigenous Communities, the need for the involvement of Aboriginal people in the research process is not new. People have expressed concern and often anger about a whole range of things such as:

• who to share the findings with;
• who actually benefits from much of the research undertaken;
• who does and should control the ‘research agenda’;
• who should own the data, and who should have access to it;
• who controls the use of the data;
• who determines the costs and benefits of research; and
• who should benefit from the results of research.

Unfortunately, not all researchers have applied these principles in research with Aboriginal people. For many years now there has been great concern within Aboriginal Communities and amongst some non-Aboriginal researchers about the processes of researching Aboriginal health issues. People have expressed concern and often anger about a whole range of things such as:

• to what extent do Aboriginal people actually ‘consent’ to being involved in particular research projects?
• who does and should control the ‘research agenda’?
• who actually benefits from much of the research undertaken?
• what happens to data about Aboriginal people after it has been collected?

In practice, ethics means that researchers should:

• respect people’s individual wishes;
• make sure that people are not harmed by research;
• only do research that will benefit the people or Community being researched;
• make sure people are fully informed about the aims and purposes of the research;
• keep people informed about the methods and the research processes being used;
• ensure confidentiality of individuals and Communities;
• negotiate ownership of data; and
• be concerned about the way the outcomes of the research may affect individuals or the Community.

2.2. Victorian Aboriginal Community workshops on research and ethics

A Community workshop entitled ‘We Don’t Like Research... but in Koori Hands it Could Make a Difference’ was conducted by the Victorian Koori Health Research and Community Development Unit (VKHRCDU) at Rumbalara in November 1999 (VKHRCDU 2000). The issue of research ethics was raised by many participants in presentations and in discussions, so a second Community workshop called ‘Research—Understanding Ethics’ was planned in partnership with VACCHO. This was held at the Aborigines Advancement League, Thornbury, Melbourne, in June 2000, and a report of this workshop was published in 2001 (VKHRCDU 2001).
2.4. Why we need to look at the role of ethics committees

HRECs in universities, hospitals and research organisations have been operating really only since the 1970s (Humphery 2003). All research funded by the NHMRC, and most health and medical research in Australia, must be assessed by a properly constituted HREC that is registered with the NHMRC. A registered HREC must abide by specific regulations about:

- membership of the HREC;
- roles and responsibilities of members;
- processes of assessment; and
- annual reporting requirements.

There are usually between ten to fifteen members on a HREC. These must include:

- a doctor or person with professional counselling experience;
- a lawyer;
- a minister of religion or Aboriginal Elder;
- a lay man;
- a lay woman; and
- a health researcher.

Decision-making is usually by consensus. If any member of the ethics committee has a query or is uncomfortable about any aspect of a proposal, those concerns are reported to the researchers who are required to address them. The researchers’ response is reported back to the ethics committee, which decides if all the committee members’ concerns have been addressed. It is not unusual for a research proposal to be returned to the researchers many times before approval is granted. However, the issues that might concern members of mainstream HRECs are not always the same issues that might be raised by Aboriginal Communities. The conventional model of Western research may represent values that are different from the values that are important to Aboriginal Communities. A recognition of the importance of different values underpins the Values and Ethics document, which was developed by the NHMRC in consultation with Aboriginal groups around Australia (NHMRC 2003).

2.5. Why it’s important for Aboriginal people to have more control of research ethics

At the ethics workshop, one of the Aboriginal presenters pointed out that although the Aboriginal Community in Victoria has been really hurt by past research experiences, research can be useful to the Community if it is done properly (VKHRCDU 2001). Ethics can be a very useful tool for Aboriginal Communities as it can:

- stop bad research;
- protect and respect the rights of individuals and Communities;
- minimise the risks of harm;
- protect confidentiality;
- maintain ownership of data; and
- promote good research.

Arising out of the discussions in the two Community workshops, it seemed that there was a need for VACCHO to consider whether there were different ways for the Aboriginal Community to have more input into research ethics and more control over how, when and why research is conducted in Aboriginal Communities in Victoria.

3. How the Victorian Aboriginal Ethics Project was conducted

3.1. Planning

Before the project commenced, there were a number of discussions between VACCHO and Onemda because the project would be a collaboration between the two organisations. Funding was sought and obtained from the Victorian Health Promotion Foundation (VicHealth). An Aboriginal Project Officer (Paul Stewart) was employed to carry out the main business of the project with assistance from staff at both Onemda and VACCHO. The Onemda research team has met regularly throughout the project with the CEO of VACCHO to obtain advice and to keep VACCHO informed of the progress being made. The VACCHO Executive and member organisations have been informed about the project regularly.

At the same time, a national project called ‘Promoting ethical research with Indigenous Communities’ has been conducted by the Cooperative Research Centre for Aboriginal Health (CRCAH) in parallel with the Victorian project. With the agreement of VACCHO and the CRCAH, some information has been exchanged to assist both projects.

Through a literature review and a survey that were conducted for the CRCAH project, we learned what ethics committees do around Australia. This helped inform the main consultation phase of this project.

3.2. Literature review

A comprehensive literature review (using Australian and international literature) was conducted by Daniel McAullay, Robert Greiw and Ian Anderson for the CRCAH project and published in 2002. This has provided important background information for the Victorian project. Similarly, a discussion paper produced by Kim Humphery (2003) on the development of the NHMRC’s Guidelines on Ethical Matters in Aboriginal and Torres Strait Islander Health has provided useful information. Another useful report was by Queensland researchers Rhonda Kelly and Cieran O’Fairchealáigh (2001). Their report includes a table showing Aboriginal representation on ethics committees in Australian universities.

3.3. Information gathering

To get the project off on the right track, the Project Officer began a process of consultation with individuals and organisations around Australia to gather background information about ethics and Aboriginal health research. Issues that were raised by these discussions also helped inform the main consultation phase of the project.

3.4. Community consultation

Letters were sent to all VACCHO member organisations to give all Victorian Aboriginal Communities the opportunity to discuss issues relating to research ethics. Representatives from VACCHO member organisations and any other interested Community members were invited to attend a Community consultation to discuss the best way for Aboriginal Communities to have control over the ethics of health research projects that affect their Communities. People were invited to discuss any issues they had in regard to research projects or ethical practices within their regions.
Three Community consultations were conducted. These consultations covered all areas of the State, although not all Communities were able to send representatives to the consultations, which were held in Bendigo, Geelong and Bairnsdale. A total of about thirty participants attended these consultations (see List of Participants, page 2).

The consultations focused on these five core questions:

1. Who would you trust for advice on research ethics?
2. Do we need an Aboriginal ethics committee? How many ethics committees/where?
3. Who should be on the ethics committee? How would your Community be represented?
4. Who’d put their hand up to be on an ethics committee from your Community?
5. How would an Aboriginal ethics committee gain the support of:
   - The Aboriginal Community around the State?
   - Your Community?
   - The non-Aboriginal research community?

Participants were asked to workshop a couple of scenarios. Each consultation group developed a unique set of suggestions for ways of assessing Aboriginal research ethics. A preliminary analysis of all material gathered so far helped to develop a range of options which were presented to key people for feedback and discussion.

3.5. Individual in-depth interviews

The Project Officer organised individual in-depth interviews or small group discussions with fourteen key people, the majority of whom had been consulted in the early information-gathering phase of the project. These included:

- Aboriginal Elders;
- Aboriginal CEOs of Community organisations;
- Aboriginal and non-Aboriginal people involved in or with ethics committees; and
- Aboriginal and non-Aboriginal people with an interest in ethics and ethical processes.

The aim of these interviews was to gather specific information that relates to how an Aboriginal ethics committee would work within Victoria and what other options there are for Aboriginal people to have more control of research ethics.

3.6. Putting all the information together

All the information collected for this project was collated and analysed by the Project Officer and other members of the research team with advice and support from VACCHO. Six different models for Aboriginal input into assessing ethics had been identified by the Community in the consultation process. From the literature review, the Community consultations and the individual interviews, we made lists of the strengths and weaknesses of each model. These were also workshopped with Aboriginal and non-Aboriginal researchers who have experience in ethics and on ethics committees.

3.7. Presenting the findings to VACCHO

A preliminary report on the findings from the project was presented to a VACCHO Members’ Meeting in November 2004. The six models were discussed, with strengths and weaknesses of each model outlined. The project team was requested to develop the models in sufficient detail for the VACCHO Executive and VACCHO member organisations to consider. This report is the final outcome of the project, and outlines the six models in detail in Section 5. It is hoped that this report will contribute usefully to an ongoing dialogue about how research ethics can be better managed for the benefit of the Victorian Aboriginal Community.
4. What the project found

4.1. What happens now around Australia?

From a survey of 228 registered HRECs that was conducted for the CRCAH project in 2002, we learned that only two Aboriginal ethics committees existed in Australia at that time and neither was in Victoria. Another two Aboriginal ethics committees were identified that were actually sub-committees to a registered HREC. Eleven HRECs said they always refer projects to an Aboriginal sub-committee. Thirty HRECs said they would co-opt an Aboriginal person onto the committee to assess an Aboriginal proposal, and forty said they would refer to an Aboriginal expert who is not a member of the committee. Many HRECs said they rarely or never review projects involving Aboriginal and Torres Strait Islander Communities (Shibasaki & Stewart 2004).

4.2. What happens now in Victoria?

Of the 228 registered HRECs in Australia, sixty-four were in Victoria. Only forty-three (67 per cent) of these responded to the CRCAH survey. No response was received from the VAHS Ethics Committee, which had operated for a relatively short time in the 1990s. There is no institutional ethics committee in Victoria that has Aboriginal control. Only two (2/43) HRECs in Victoria said they have a permanent position for an Aboriginal representative. In some cases (5/43) Aboriginal people are co-opted onto ethics committees to assess Aboriginal projects; other HRECs (12/43) said they consult Aboriginal ‘experts’ or Aboriginal members of staff at the relevant university or hospital where the ethics committee is situated (Shibasaki & Stewart 2004). So, for example, this project had to be assessed by the HREC at The University of Melbourne, which has no Aboriginal members and relies instead on seeking advice from Aboriginal staff at the university.

When a research proposal involves Aboriginal people, the researcher is obliged to consult with the relevant Aboriginal Community and seek approval for the project before it is assessed by an HREC. However, the Aboriginal Community is not funded or acknowledged in the process. During the consultation and information gathering phases of this project, we learned that in most cases the role of reviewing a research proposal is taken up by the CEO within an Aboriginal Community Controlled Health Organisation (ACCHO). Reviewing a research proposal can be extremely time consuming as applications are lengthy and may require clarification on technical matters as well as consideration of ethics in relation to Community consultation and protocols. This often means further consultation with Aboriginal organisation staff, boards of directors, Aboriginal Community members and researchers. In some instances, a CEO may feel confident and have the time needed to review a research proposal. But ethics is often alienating to Community members and research is not a high priority in an organisation providing direct services. If the CEO does not feel confident or does not have the time or the interest in the research being proposed, the project may be turned down without having been properly considered as to whether it might offer some benefit to the Community. Another scenario that was reported during the consultations was that a project could be approved simply because there was an Aboriginal student or researcher involved, but people recognised that an Aboriginal researcher is no guarantee that they know what the Aboriginal Community wants or how to carry out research that is ethical and relevant to the Community.

Although the survey was sent to every registered HREC, and follow-up letters were mailed twice to non-respondents, we recognise that not all HRECs returned the completed survey. We had a total response rate of 71 per cent but there may have been other Aboriginal ethics committees that did not participate in the survey.

4.3. What are the main issues for VACCHO to consider?

It was clear that Aboriginal Communities in Victoria want Aboriginal people to have more control of how ethics is assessed when the research affects their Communities. There was strong support for a State-wide Aboriginal-controlled ethics committee but people also recognised the burden of time and resources that would be involved. It would also be difficult for a State-wide ethics committee to represent every Aboriginal Community. In an ideal situation, each Community could have its own ethics committee, or at least a regional ethics committee for Aboriginal projects. So there is a need to balance Community control against overburdening every Aboriginal Community in Victoria.

Five common themes came up consistently when people were asked to think about having a Victorian Aboriginal health ethics committee:

• What are the skills that are required to be an ethics committee member?
• How will the committee be made up?
• How will the committee be resourced?
• What role will the committee play?
• How will the committee gain the support of the Aboriginal Community and the research community?

Other important issues that arose included:

• the need to stop researchers from ‘Community-shopping’ (taking their projects from one Community to another);
• the need for briefing papers and clear pro formas to make reviewing simpler;
• the need for training about ethics for Aboriginal Community members;
• the need for a central register of research projects (past and present, approved and rejected); and
• the need to protect the Aboriginal Community from insensitive research or inappropriate timing of research.

During the Community consultations, six different models were developed to endeavour to increase the involvement of Aboriginal people in health research ethics in their Community. Each of these models offers the Aboriginal Community in Victoria different levels of control over research proposals and how research is conducted in the relevant Community. In considering each model, VACCHO and its member organisations need to consider four key issues that were raised throughout this project: representation, resources, expertise and power. These issues are outlined in the following table.
Key issues arising from Community consultations

5. Six models for increasing Aboriginal control of health research ethics

These six models were developed from the Community consultations held around Victoria, with input from the individual interviews, and with feedback from VACCHO member organisations and Aboriginal and non-Aboriginal researchers who have experience in ethics and on ethics committees. While each of the six models offers advantages to the Aboriginal Community in Victoria, there are also disadvantages in terms of the burden of time, resources and personnel needed. Different models may suit different Communities at different times. Some models are easy to implement immediately, while others would require significant planning and funding to support implementation and ongoing activities.

Representation
- Local versus central
- How are rural and urban Aboriginal Communities to be represented?
- Would the Aboriginal representative be accountable to:
  - their own Community?
  - other Aboriginal Communities?
  - their workplace (university, hospital, etc.)?
  - an ACCHO?

Resources
- Time
- Costs
- Personnel
  - number of Aboriginal Community people needed
  - maintaining membership
- Infrastructure
  - venue for meetings
  - administrative support
  - photocopying, stationery, telephone and mail-out
  - organising travel and accommodation for meetings
- Training

Expertise
- Skills, expertise and experience needed
  - medical
  - legal
  - technical
  - ethical
  - literacy
- Interest from Community
- Priority for Community

Power
- Formal recognition and authority
- Confidence to manage researchers, HRECs, universities, hospitals, NHMRC
- Support for process from:
  - Aboriginal Communities
  - HRECs
  - Aboriginal and non-Aboriginal researchers
  - NHMRC
  - government departments
  - other health services and non-government organisations
Model 1: Victorian Aboriginal Ethics Committee

A Victorian Aboriginal Ethics Committee would be properly constituted, State-wide and registered through the NHMRC, but it would be Aboriginal controlled. The membership of the Victorian Aboriginal Ethics Committee would meet the minimum requirements for a HREC, with an additional Aboriginal Elder (so that there would be one male and one female) and additional Aboriginal membership, which would vary according to the projects being assessed. The membership proposed by Community members in the consultation was as follows:

- doctor with research experience;
- lawyer;
- Aboriginal lay man;
- Aboriginal lay woman;
- Aboriginal male Elder;
- Aboriginal female Elder;

plus

- Aboriginal researcher;
- five VACCHO representatives (nominated and elected through the VACCHO membership);

plus

- representative(s) from Aboriginal Communities involved in any project affecting them.

Ideally all members would be Aboriginal but this may not always be possible or practical. However, at all times the Victorian Aboriginal Ethics Committee must have both an overall Aboriginal majority and an Aboriginal majority for a quorum at any meeting. Because the model proposed is for a State-wide Victorian Aboriginal Ethics Committee, it is important to outline processes that would be required to ensure local Aboriginal Community input and control over research affecting their own Community. The Victorian Aboriginal Ethics Committee would consult the local Aboriginal Community on any proposal affecting that Community and seek representatives from that Community to sit on the committee while the proposal is assessed. In order to build knowledge and expertise across a range of topics, the committee would also need to seek advice from additional scientific, medical or technical experts when appropriate. The processes followed by the Victorian Aboriginal Ethics Committee would be the same as those required by the NHMRC for any registered HREC. This would require transparency in decision-making and reporting. At the same time, the Victorian Aboriginal Ethics Committee would be required to adopt a bureaucratic model, which may not suit ACCHOs.

Funding would be essential to support the administration costs of the Victorian Aboriginal Ethics Committee and to cover out-of-pocket expenses for members from around the State.
Model 2: Aboriginal Ethics Adviser(s)

Aboriginal Ethics Adviser positions would be established in Aboriginal Community organisations or at VACCHO. Dedicated recurrent funding would be essential to train and support these positions. This would build Aboriginal research capacity and knowledge of ethical processes. The Aboriginal Ethics Adviser(s) would be seen as the first point of call for the CEO of an ACCHO, and for researchers and HRECs, to seek advice and assistance with a research proposal or any other research concern. The Aboriginal Ethics Adviser(s) could then call on a broader network of Aboriginal and non-Aboriginal professional experts.

The responsibility of an Aboriginal Ethics Adviser would be to provide all Victorian ACCHOs and mainstream organisations with advice and support on health research matters affecting the Aboriginal Community in Victoria. Aboriginal Ethics Adviser(s) could also play a brokerage and advocacy role between an ACCHO, researchers and HREC. This would be a two-way process, providing culturally relevant advice to researchers and HRECs and playing an important brokerage role on behalf of Aboriginal Communities in Victoria. The Aboriginal Ethics Adviser(s) could also guard against Aboriginal Communities being over-researched.

The role of the Aboriginal Ethics Adviser(s) would include checking and monitoring Community consultation and informed consent processes, culturally appropriate methods, data ownership, and the relevance and benefits of the research to the Aboriginal Community in Victoria. They would consult the relevant Aboriginal Community and may send the researcher to consult the Community. They could request that the researcher presents a user-friendly document for the Aboriginal Community to review and processes involved in the project. They could also keep a register of all research conducted in Victorian Aboriginal Communities and of projects that have not been approved by Victorian Aboriginal Communities.

Given the current NHMRC guidelines, as outlined in the Values and Ethics document (NHMRC 2003), researchers and HRECs may greatly appreciate the opportunity to consult the Aboriginal Ethics Adviser(s). The NHMRC could be informed that all research affecting Aboriginal Communities in Victoria. The Aboriginal Ethics Adviser(s) could then call on a broader network of Aboriginal and non-Aboriginal professional experts.

Aboriginal Ethics Adviser(s) would be accountable to the Aboriginal Community throughout Victoria and to the local Aboriginal Community on specific projects. Their role would be to represent the best interests of VACCHO or the local ACCHO on health research issues. Aboriginal Ethics Adviser(s) would advocate on behalf of an ACCHO while remaining neutral in local Community issues.

Key strengths:
- accountability to the Aboriginal Community in Victoria;
- supports local Aboriginal Community organisations;
- builds Aboriginal Community capacity in research and ethics;
- can educate mainstream research processes;
- could obtain NHMRC support; and
- could develop relationships with HRECs in Victoria.

Key weaknesses:
- requires ongoing funding for position(s);
- requires ongoing training;
- research still needs HREC approval;
- requires ongoing investment, commitment and interest in ethics; and
- needs NHMRC endorsement.

Expertise

The Aboriginal Ethics Adviser(s) would build up knowledge and expertise and become an increasingly valuable resource to Aboriginal Communities, researchers and HRECs. They would learn what research is happening in Aboriginal Communities around Victoria and assist with dissemination of research from one Community to another. It is important to recognise that there may be very few people able to fill these positions without first undergoing training in ethics and research.

Power

The role of the Aboriginal Ethics Adviser position(s) would need to be clear to ACCHOs throughout Victoria and a policy would need to be put in place to deal with issues like conflict of interest and accountability to VACCHO and its member organisations. Although the Aboriginal Ethics Adviser position(s) would not carry the authority of a registered HREC, the role could be strengthened if the position was endorsed by the NHMRC. HRECs and researchers would learn to respect the advice given by an Aboriginal Ethics Adviser.

Key strengths:
- accountability to the Aboriginal Community in Victoria;
- supports local Aboriginal Community organisations;
- builds Aboriginal Community capacity in research and ethics;
- can educate mainstream research processes;
- could obtain NHMRC support; and
- could develop relationships with HRECs in Victoria.

Key weaknesses:
- requires ongoing funding for position(s);
- requires ongoing training;
- research still needs HREC approval;
- requires ongoing investment, commitment and interest in ethics; and
- needs NHMRC endorsement.

Resources

A significant financial commitment would be essential to support the Aboriginal Ethics Adviser position(s) and provide ongoing training. This could be cost-effective, as it would reduce the time currently spent on assessing research proposals by CEOs and staff in ACCHOs. The Aboriginal Ethics Adviser(s) could also provide timely and efficient advice to researchers and save time wasted by HRECs assessing projects that have not been approved by Aboriginal Community organisations. However, consideration needs to be given to how the Aboriginal Ethics Adviser(s) will be supported in their role and what mechanisms would be needed to ensure that they are able to sustain their activities.

It is likely that the workload and responsibility would be too much to place on one Aboriginal Ethics Adviser. It would be important for the positions to be funded externally and for the Aboriginal Ethics Adviser(s) to be independent of Aboriginal Community organisations.

Model 1: Aboriginal Ethics Adviser

Aboriginal Ethics Adviser positions would be established in each Aboriginal Community organisation and funded by the Australian Research Council (ARC). Dedicated recurrent funding would be essential to train and support these positions. This would build Aboriginal research capacity and knowledge of ethical processes. The Aboriginal Ethics Adviser(s) would be seen as the first point of call for the CEO of an ACCHO, and for researchers and HRECs, to seek advice and assistance with a research proposal or any other research concern. The Aboriginal Ethics Adviser(s) could then call on a broader network of Aboriginal and non-Aboriginal professional experts.

The responsibility of an Aboriginal Ethics Adviser would be to provide all Victorian ACCHOs and mainstream organisations with advice and support on health research matters affecting the Aboriginal Community in Victoria. Aboriginal Ethics Adviser(s) could also play a brokerage and advocacy role between an ACCHO, researchers and HREC. This would be a two-way process, providing culturally relevant advice to researchers and HRECs and playing an important brokerage role on behalf of Aboriginal Communities in Victoria. The Aboriginal Ethics Adviser(s) could also guard against Aboriginal Communities being over-researched.

The role of the Aboriginal Ethics Adviser(s) would include checking and monitoring Community consultation and informed consent processes, culturally appropriate methods, data ownership, and the relevance and benefits of the research to the Aboriginal Community in Victoria. They would consult the relevant Aboriginal Community and may send the researcher to consult the Community. They could request that the researcher presents a user-friendly document for the Aboriginal Community to review and processes involved in the project. They could also keep a register of all research conducted in Victorian Aboriginal Communities and of projects that have not been approved by Victorian Aboriginal Communities.

Given the current NHMRC guidelines, as outlined in the Values and Ethics document (NHMRC 2003), researchers and HRECs may greatly appreciate the opportunity to consult the Aboriginal Ethics Adviser(s). The NHMRC could be informed that all research affecting Aboriginal Communities in Victoria. The Aboriginal Ethics Adviser(s) could then call on a broader network of Aboriginal and non-Aboriginal professional experts.

Aboriginal Ethics Adviser(s) would be accountable to the Aboriginal Community throughout Victoria and to the local Aboriginal Community on specific projects. Their role would be to represent the best interests of VACCHO or the local ACCHO on health research issues. Aboriginal Ethics Adviser(s) would advocate on behalf of an ACCHO while remaining neutral in local Community issues.

Key strengths:
- accountability to the Aboriginal Community in Victoria;
- supports local Aboriginal Community organisations;
- builds Aboriginal Community capacity in research and ethics;
- can educate mainstream research processes;
- could obtain NHMRC support; and
- could develop relationships with HRECs in Victoria.

Key weaknesses:
- requires ongoing funding for position(s);
- requires ongoing training;
- research still needs HREC approval;
- requires ongoing investment, commitment and interest in ethics; and
- needs NHMRC endorsement.

Resources

A significant financial commitment would be essential to support the Aboriginal Ethics Adviser position(s) and provide ongoing training. This could be cost-effective, as it would reduce the time currently spent on assessing research proposals by CEOs and staff in ACCHOs. The Aboriginal Ethics Adviser(s) could also provide timely and efficient advice to researchers and save time wasted by HRECs assessing projects that have not been approved by Aboriginal Community organisations. However, consideration needs to be given to how the Aboriginal Ethics Adviser(s) will be supported in their role and what mechanisms would be needed to ensure that they are able to sustain their activities.

It is likely that the workload and responsibility would be too much to place on one Aboriginal Ethics Adviser. It would be important for the positions to be funded externally and for the Aboriginal Ethics Adviser(s) to be independent of Aboriginal Community organisations.

Model 2: Aboriginal Ethics Adviser(s)

Aboriginal Ethics Adviser positions would be established in Aboriginal Community organisations or at VACCHO. Dedicated recurrent funding would be essential to train and support these positions. This would build Aboriginal research capacity and knowledge of ethical processes. The Aboriginal Ethics Adviser(s) would be seen as the first point of call for the CEO of an ACCHO, and for researchers and HRECs, to seek advice and assistance with a research proposal or any other research concern. The Aboriginal Ethics Adviser(s) could then call on a broader network of Aboriginal and non-Aboriginal professional experts.

The responsibility of an Aboriginal Ethics Adviser would be to provide all Victorian ACCHOs and mainstream organisations with advice and support on health research matters affecting the Aboriginal Community in Victoria. Aboriginal Ethics Adviser(s) could also play a brokerage and advocacy role between an ACCHO, researchers and HREC. This would be a two-way process, providing culturally relevant advice to researchers and HRECs and playing an important brokerage role on behalf of Aboriginal Communities in Victoria. The Aboriginal Ethics Adviser(s) could also guard against Aboriginal Communities being over-researched.

The role of the Aboriginal Ethics Adviser(s) would include checking and monitoring Community consultation and informed consent processes, culturally appropriate methods, data ownership, and the relevance and benefits of the research to the Aboriginal Community in Victoria. They would consult the relevant Aboriginal Community and may send the researcher to consult the Community. They could request that the researcher presents a user-friendly document for the Aboriginal Community to review and processes involved in the project. They could also keep a register of all research conducted in Victorian Aboriginal Communities and of projects that have not been approved by Victorian Aboriginal Communities.

Given the current NHMRC guidelines, as outlined in the Values and Ethics document (NHMRC 2003), researchers and HRECs may greatly appreciate the opportunity to consult the Aboriginal Ethics Adviser(s). The NHMRC could be informed that all research affecting Aboriginal Communities in Victoria. The Aboriginal Ethics Adviser(s) could then call on a broader network of Aboriginal and non-Aboriginal professional experts.

Aboriginal Ethics Adviser(s) would be accountable to the Aboriginal Community throughout Victoria and to the local Aboriginal Community on specific projects. Their role would be to represent the best interests of VACCHO or the local ACCHO on health research issues. Aboriginal Ethics Adviser(s) would advocate on behalf of an ACCHO while remaining neutral in local Community issues.
Model 3: Register of Trusted Experts

The Register of Trusted Experts model is a list of experts who are known and trusted by the Victorian Aboriginal Community and can be called upon on a needs basis by an ACCHO when assistance is required with reviewing a research project. The Register of Trusted Experts would form an important part of the information-gathering process for the CEO of an ACCHO who may be assessing whether this research will benefit the Aboriginal Community. The role of the Register of Trusted Experts would be to review and provide feedback and recommendations to an ACCHO about a research proposal, and to assist the ACCHO to monitor the research process if necessary.

The Register of Trusted Experts would be established by an individual ACCHO and should be revised and added to continually to ensure the best possible representation. It could be made up of any number of experts from within or outside the Aboriginal Community and from a wide range of fields, for example, lawyers, Aboriginal liaison officers, doctors, researchers or Aboriginal Elders. A CEO could also use trusted experts to form a Project-specific Ethics Advisory Group (see Model 4). A State-wide Register of Trusted Experts could also be compiled if ACCHOs wanted to share their resources. However, experts trusted by one Aboriginal Community may not be trusted by others.

Representation

Trusted experts would be selected by an ACCHO to suit the individual needs of a local Aboriginal Community. Selection would be based on the expert’s educational background, expertise and experience of working with Aboriginal Communities. A weakness of this model is when an ACCHO has a limited number of trusted experts to call upon, as this may limit the quality of advice available. If this is the case, the ACCHO may seek a recommendation for a trusted expert from another ACCHO.

Resources

Establishing a Register of Trusted Experts is a low-cost exercise that requires minimal administration. The initial stages of developing a register would require ACCHO representatives to meet and map out their networks of trusted experts from various disciplines. Experts would be called on a needs basis, which should mean only occasionally seeking their advice for specific projects.

Expertise

Having a Register of Trusted Experts would enable an ACCHO to obtain valuable advice quickly from a range of individuals who have the best interests of the Aboriginal Community at heart.

A concern of this model is the value a CEO places on the research advice of one trusted expert. Therefore, it is important that a CEO obtains advice on the research project from a variety of trusted experts to ensure that the research project meets the needs of the local Aboriginal Community. It is also important that an ACCHO does not solely rely on the ethical advice of a non-Aboriginal trusted expert, especially if the local Aboriginal Community is not consulted.
Model 4: Project-specific Ethics Advisory Group

When a researcher approaches an ACCHO, or when an ACCHO wants to carry out some research of its own, an Ethics Advisory Group could be set up for the specific project. Each project could have a steering group and an Ethics Advisory Group, which would assess and monitor the project’s research ethics. An ACCHO could develop a core group of people, which would build up experience over time, and then add specific individuals for each new project. Members would be chosen for their expertise in the local Aboriginal Community or on the topic to be researched. The Ethics Advisory Group need not meet all the time but could be kept informed and members could be consulted individually on matters relating to their own areas. Because it is locally based, once it is set up for a specific project the Ethics Advisory Group could provide advice and assistance to the researcher(s) with minimal time delays.

It would be the responsibility of an ACCHO to determine the membership of the Ethics Advisory Group, which may include the following people: Aboriginal Elders, Aboriginal health workers, Aboriginal Community members and a general practitioner or other experts relevant to the specific project, such as, lawyers, medical experts or a researcher known and respected by the local Aboriginal Community. This may be difficult in smaller organisations but it may also suit organisations that only have occasional research projects in their Communities.

The role of a Project-specific Ethics Advisory Group would be to work alongside a HREC to assess and monitor the ethical and cultural issues of one specific research project on behalf of an ACCHO and the local Aboriginal Community. The Ethics Advisory Group could provide relevant ethical and cultural advice on the research project, as they would have local knowledge and awareness of Community issues. The HREC would assess the technical and scientific components of this specific research project and take responsibility for the complaints and paperwork associated with the research project. The Ethics Advisory Group would need to develop a relationship of mutual trust and support with a relevant HREC; both bodies would be strengthened if the HREC recognises the authority of the Ethics Advisory Group.

Having Project-specific Ethics Advisory Groups in local Aboriginal Communities could build Aboriginal Community knowledge about how research is done and about the outcomes of the research. However, it may be difficult to build expertise if each project has a different Ethics Advisory Group. The Ethics Advisory Group also has the potential to build trust about research within its own Aboriginal Community, which in turn could facilitate good research and useful outcomes both now and in the future.

- **Representation**
  - The major strength of a Project-specific Ethics Advisory Group is that it is made up of local Aboriginal and non-Aboriginal members who are respected within the Community. Members would be selected by the local Aboriginal Community. However, members need to have the availability and time to provide a valuable contribution to the Ethics Advisory Group to ensure it is an effective group.

- **Resources**
  - Another strength is that the resources needed to support a Project-specific Ethics Advisory Group are less than for a full ethics committee. However, in order to operate effectively, the Ethics Advisory Group would require some time and money for meetings and administration.

- **Expertise**
  - The Project-specific Ethics Advisory Group has the ability to attract Aboriginal and non-Aboriginal experts with local knowledge and experience from various disciplines. The right type of expertise on the Ethics Advisory Group is a crucial factor to ensure that the research project is ethical and can be realistically carried out to the benefit of the Aboriginal Community.

- **Power**
  - A Project-specific Ethics Advisory Group would have considerable power in relation to local Aboriginal Community issues and protocols. However, the Ethics Advisory Group does not have the same authority as a registered HREC and, therefore, can only provide ethical advice and recommendations to a HREC. This is a significant weakness as the ACCHO and Aboriginal Community can only rely on the goodwill of researchers and HRECs to seek approval and recommendations from the Ethics Advisory Group. It could be difficult for Aboriginal Community members of the group to challenge ‘experts’ in scientific or medical fields. To manage disagreements, the Ethics Advisory Group would need to develop a conflict resolution process.

- **Key strengths:**
  - project specific;
  - targets appropriate expertise;
  - locally based; and
  - minimal resources needed.

- **Key weaknesses:**
  - no authority over HRECs;
  - may not have required expertise;
  - smaller Aboriginal Communities may have limited access to experts; and
  - difficult to challenge ‘experts’.
Model 5: Aboriginal Health Research Ethics Advisory Committee

The Aboriginal Health Research Ethics Advisory Committee would be a State-wide committee but would not be registered with the NHMRC. The main reason for not making it a properly constituted ethics committee is to avoid the bureaucratic requirements and the heavy burden of paperwork associated with being a registered HREC. However, the Aboriginal Health Research Ethics Advisory Committee would seek to make it mandatory for all HRECs and researchers in Victoria to consult with it.

The role of the Aboriginal Health Research Ethics Advisory Committee would be to provide advice, training and advocacy on ethical issues relating to Aboriginal health research. The committee would provide advice to ACCHOs, to researchers and to HRECs on ethical issues involving Victorian Aboriginal Communities. The committee would review the ethics of a health research proposal and could also keep track of health research projects involving Victorian Aboriginal Communities. However, each research proposal would still have to be assessed by a registered HREC and the researcher would have to consult with the local Aboriginal Community for approval. The Aboriginal Health Research Ethics Advisory Committee would liaise with the relevant HREC and keep the local Aboriginal Community informed of processes.

The Aboriginal Health Research Ethics Advisory Committee would consist of Aboriginal and non-Aboriginal members who have experience in specific areas of health research and have an understanding of Aboriginal Communities in Victoria. This committee would co-opt local Aboriginal people when a research proposal involving their local area is presented. The Aboriginal Health Research Ethics Advisory Committee would be of benefit to all Victorian Aboriginal Communities, as the committee would act as a safeguard to ensure that the researched Community is involved in the ethical review process. The committee could steer researchers to the appropriate Aboriginal Community and to the appropriate person to be consulted. The committee could also warn Aboriginal Communities about research it has not approved and guard against Communities being over-researched. However, the Aboriginal Health Research Ethics Advisory Committee should not be seen as a gatekeeper.

The Aboriginal Health Research Ethics Advisory Committee could function more effectively if one, or more, of the other models was established. For example the Aboriginal Ethics Adviser(s) could take on an important liaison role between the Aboriginal Health Research Ethics Advisory Committee and the local Aboriginal Community. The committee could develop a network of technical experts to advise Aboriginal Communities, or members of the Register of Trusted Experts could be co-opted onto the Aboriginal Health Research Ethics Advisory Committee. The committee could suggest that an ACCHO set up a Project-specific Ethics Advisory Group, if appropriate. Or it could require that a HREC co-opt an Aboriginal representative from a specific Aboriginal Community to review a project involving that Community.

Represenation

The Aboriginal Health Research Ethics Advisory Committee would need to have Aboriginal members from all around Victoria. However, it is also crucial that there be representation from the local Aboriginal Community to ensure that its needs are considered when a research project requires ethical approval. The Aboriginal Health Research Ethics Advisory Committee would need a process of taking advice from local Aboriginal Communities.

Resources

Funding would be required to support the committee and compensate members for out-of-pocket expenses. Even though this committee would not have all the administrative costs of a HREC, in order to operate effectively it needs someone to take responsibility for setting up meetings and maintaining partnerships with HRECs and Aboriginal Communities in Victoria. Aboriginal Ethics Adviser(s) could be part of the Aboriginal Health Research Ethics Advisory Committee. Because the research proposals still need to be assessed by a HREC, researchers could find the process involving the Aboriginal Health Research Ethics Advisory Committee too slow, especially if the project goes back and forth between committees and the Aboriginal Community in the consultation process.

Expertise

The most important function of the Aboriginal Health Research Ethics Advisory Committee is to have input into the ethical review process of a research project that involves Aboriginal Communities in Victoria. The Aboriginal Health Research Ethics Advisory Committee would need to seek members who have a variety of expertise and experiences in health research (including members of the local Aboriginal Community) to ensure that appropriate advice can be given and that research projects are thoroughly reviewed.

Power

The Aboriginal Health Research Ethics Advisory Committee does not have the same authority as a HREC, therefore it cannot formally give ethical clearance to a research proposal. However, the committee could seek to make it mandatory for all HRECs and researchers in Victoria to seek ethical approval from the Aboriginal Health Research Ethics Advisory Committee. Clear guidelines about processes for consulting the Aboriginal Health Research Ethics Advisory Committee would be needed for researchers to follow.

Key strengths:
- Aboriginal membership;
- involves local Aboriginal Communities; and
- builds Aboriginal Community capacity.

Key weaknesses:
- no authority over HRECs;
- may not have required expertise;
- committee members may need training;
- requires funding support;
- slows down process for researchers; and
- could be seen as a gatekeeper.
Model 6: Aboriginal representation on Human Research Ethics Committees

This model suggests that all HRECs would be required to have an identified position for an Aboriginal representative to review research projects that involve Aboriginal Communities in Victoria. The Aboriginal representative would have the option of being a permanent member of the HREC and reviewing all projects, or of being part of the review process only when projects involve Aboriginal Communities. Aboriginal representation would be of assistance to HRECs during the ethical review process to pick up on culturally sensitive issues, and to advise on appropriate processes of consultation with the local Aboriginal Community. The Aboriginal representatives could also provide links and contribute to good working relationships between HRECs and local Aboriginal Communities in Victoria.

It would be important for Aboriginal representatives to be provided with adequate training before joining the HREC. Because most HRECs are located in universities or hospitals, they can be very intimidating. The Aboriginal representatives would need self-confidence to question other members of the committee.

Key strengths:
- Aboriginal membership on all HRECs;
- low cost; and
- builds Aboriginal knowledge about research.

Key weaknesses:
- cannot represent all Aboriginal Communities;
- only one voice on the HREC;
- need confidence to challenge HREC;
- could be seen as tokenistic;
- a large time commitment required; and
- need a lot of people (sixty-four HRECs in Victoria).

Representation

A single Aboriginal member on a HREC cannot represent all Aboriginal Communities in Victoria. HRECs could also include local Aboriginal people from the Aboriginal Community where the proposed research is to be conducted, and possibly assign two positions on the committee. This would help to ensure the best possible representation and research outcomes for the Aboriginal Community.

Resources

Aboriginal representation on HRECs is a low-cost exercise, as the committee is already established and functional. However, as there are more than sixty HRECs across Victoria, there would need to be a number of Aboriginal people across the State to be available to review research projects. A significant time commitment would be required from Aboriginal representatives, as HRECs meet frequently (many HRECs meet monthly). Training should be provided for Aboriginal representatives before they join the committee.

Expertise

Aboriginal representation on HRECs would bring specific Aboriginal Community expertise and cultural knowledge to the committee. The Aboriginal representative would advise on appropriate consultation processes and ensure that the appropriate Aboriginal Community is involved in the consultation and approval process. The Aboriginal representative may feel that much of the review process is not relevant to his or her expertise, and that many of the scientific and technical aspects of the review process can be confusing.

Power

Aboriginal representation on HRECs could facilitate equal participation during the ethical review process. Aboriginal representatives would have to be confident people to challenge the other members of the committee about ethics and the processes used in the proposed research project. Aboriginal representatives could feel as if their positions are merely a tokenistic membership of the HREC.
6. Discussion

It is clear that there are advantages and disadvantages to each of the six models suggested in this report. VACCHO and its member organisations need to consider which models are most suitable, easiest to implement and most cost-effective, but also which models ultimately give Aboriginal people in Victoria the greatest control over the way research is done in their Communities. Some of the weaknesses outlined above could be addressed by VACCHO taking a strong advocacy role, for example, in informing the NHMRC of the preferred protocol that is to be followed by researchers wishing to conduct research in Victorian Aboriginal Communities.

6.1. Issues not addressed by this project

It is important for Victorian Aboriginal Communities to note that ethics approval is separate from Community approval. Whatever model is adopted for reviewing the ethics of research proposals, individual Community organisations have the right to approve or reject any research proposals involving their Communities. Under the current NHMRC guidelines, it is not clear whether researchers should seek Community approval before or after they seek ethics approval from a registered HREC. There are also problems when projects cover several different areas and may involve a number of Victorian Aboriginal Communities, or the whole State. How should researchers approach the different Communities that may be involved? These and other issues would need to be examined further when the models are developed in more detail. There is also no guarantee that a Victorian Aboriginal Ethics Committee would be able to function as a one-stop review process. Many mainstream institutions (such as universities and hospitals) require their researchers to seek approval from their own HREC. It is not clear how the mainstream HRECs would relate to a Victorian Aboriginal Ethics Committee. Which committee would grant approval first or finally?

Another issue that was beyond the scope of this project is the question of what sort of research projects should be submitted to a Victorian Aboriginal Ethics Committee, or to the Victorian Aboriginal Community, for approval. This question is often asked in relation to which projects should be covered by the Values and Ethics document (NHMRC 2003). So, for example, should a project be submitted to a Victorian Aboriginal Ethics Committee:

- when all (or most) of the participants are Aboriginal?
- when the project involves a Victorian Aboriginal Community?
- when there is a possibility that the project will include Aboriginal people as participants?
- when the project will have an impact on the Victorian Aboriginal Community?

6.2. Where to from here?

Whatever model(s) are adopted, the success of their implementation will depend on Aboriginal Communities in Victoria:

- investing in an ongoing commitment to ethics in health research;
- securing ongoing funding for Aboriginal control of ethical review;
- building knowledge, skills and experience around research ethics in the Aboriginal Community in Victoria;
- informing universities and other HRECs about protocols to be used in Victoria; and
- educating all researchers about Aboriginal ethical issues.

7. Recommendations

1. Consider options and ways to move forward with preferred model(s).
2. Consider ways of seeking funding to develop materials and mechanisms for dissemination to inform Community organisations of their rights in relation to research ethics under current guidelines.
3. Consider ways of seeking funding to develop materials and mechanisms for dissemination to inform HRECs in Victoria about issues raised by the Aboriginal Community during this project and ways that HRECs can more appropriately consult Communities and process ethics applications.
4. Identify current interest and expertise in research ethics in the Aboriginal Community in Victoria.
5. Establish a panel of experts to consider implementation and support for one or more of the models suggested in this report.
References


Kelly, R. & O’Faircheallaigh, C. 2001, Indigenous Participation in Managing University Research, Centre for Australian Public Sector Management, Griffith University, Nathan.


NACCHO 2003, NACCHO Newsletter, August.

#NHMRC 1991, Guidelines on Ethical Matters in Aboriginal and Torres Strait Islander Health Research, AGPS, Canberra.

#NHMRC 2003, Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research, NHMRC, Canberra.

**Shibasaki, S. & Stewart, P. 2004, Workshop Report: Aboriginal and Torres Strait Islander People Involved in Ethics, Cooperative Research Centre for Aboriginal Health, Darwin.

* VKRCDU 2000, We Don’t Like Research...But in Koori Hands it Could Make a Difference, VKRCDU, Melbourne.

* VKRCDU 2001, Research—Understanding Ethics, VKRCDU, Melbourne.

*These four documents are available from Onemda, and can also be obtained in PDF format from the website: <http://www.chs.unimelb.edu.au/koori/publications>.

#These two documents are available from the NHMRC or from its website: <http://www.nhmrc.gov.au/publications/index.htm>.

**This report is available from the Cooperative Research Centre for Aboriginal Health or from its website: <http://www.crcah.org.au/index.cfm>.
Notes