Research - Understanding Ethics

VicHealth Koori Health Research and Community Development Unit

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INTRODUCTION

This is a report of our second Community workshop which was called ‘Research – Understanding Ethics’, held in June 2000 at the Aborigines Advancement League, in Thornbury, Melbourne. About 30 people attended. A number of Kooris spoke about their experiences of research and ethical issues. We felt that many people in the Community would be interested in the talks that were given at the workshop, and the ideas that people shared. Workshop participants were also asked to think about the ethics of a gammin research proposal which was presented as a case study. This case study and the discussion around it have been included in the report.

All sessions at the workshop were tape-recorded and transcribed. The transcripts have been edited slightly to make it easier for readers who were not at the workshop to understand what was being talked about. This report does not set out to represent the views of the Koori Community in general, but to open up discussion on the ethics of Koori health research and Community control of Koori health research.

The workshop agenda was developed to provide plenty of opportunities for learning from each other by getting people to talk about their experiences - the positives and negatives. We hope you enjoy this Community Report and find it useful.

Acknowledgments
We would like to thank all of the members of the Ethics Planning Group who put together the agenda for the workshop: Joan Vickery, Ron James, Paul Stewart, Lisa Thorpe and Reg Thorpe.
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THE DAY’S AGENDA

Introduction and Welcome
Ian Anderson

Issues to consider for Aboriginal health research ethics committees
Salina Bernard

Ethics, protocols and methodologies of research in the Koori Community
Esme Saunders

BREAK

What is a Memorandum of Understanding and why do we have them?
Rick Henderson

Group Discussion with Panel of Morning Presenters

LUNCH

Presentation of Case Study
Ian Anderson

Small Group Discussions

BREAK

Panel Discussion...Where to from here?
Welcome and Background to the Workshop

Ian Anderson

On behalf of the VicHealth Koori Health Research and Community Development Unit at the University of Melbourne I’d like to welcome everyone here this morning. This workshop came out of some work last year and some discussions that we had as part of our Community development program. As you probably know, the Unit was set up in partnership with VACCHO and one of our key briefs is to facilitate discussion in the Koori Community around various research issues and particularly to enable us to learn more about what works and what doesn’t work in Koori health research.

Last year we held a workshop at Rumbalara which was called ‘We Don’t Like Research - But in Koori Hands it Could Make a Difference’ (see report of this workshop listed in References). A number of people here today were actually at that workshop. One of the reasons we held that workshop was to give people a chance to talk about what are the sorts of things that we need to know, what sort of skills we need, or what sort of resources we need, to actually have ultimate control of Koori health research. One of the issues that people raised on that day was really about ethics. I guess if we think about the current history of Aboriginal health research, a lot of the arguments have been about ethics, on issues such as:

- exploitation
- control over research
- usefulness of research
- confidentiality
- informed consent
- ownership and control of data.

There was an earlier workshop back in 1987 organised by the Menzies Foundation and the NHMRC and attended by about 30 Aboriginal Community representatives. That really for the first time put the issue of ethics on the Aboriginal health research agenda (NHMRC 1988). That workshop came about in part due to the activism of Aboriginal people working in health. We wanted to have control over the research, and if it was going to be useful to us we wanted to deal with things like confidentiality, informed consent, and the ownership and control of data. That workshop resulted in the first set of guidelines around ethics being developed by the NHMRC (1991) and there’s a copy of those Guidelines available in this Report – Appendix One.

We take very seriously these issues of ethics and wanted to use today to challenge the ways we approach research and some of the broader issues. A number of us round this table are working with researchers or wanting to do research in our programs or services. This workshop provides an opportunity to think about how we are going to deal with these issues in our workplace. After lunch we’d like to actually workshop some of these issues in small groups through a particular case study that we’ve made up to illustrate some of the ethical issues. We want to use that as a basis for working out what sort of resources and practical guidelines are really needed in the Community.

We’d like to make today as informal and discussion-oriented as possible. We’d like to make a tape recording of the talks and discussions unless anyone wants the tape turned off for any particular reason, and then we will do so. We hope to produce a Community report, as we did with our last workshop. We want to make these reports available to other people in the Community so they can get the benefit of some of the discussions that took place in each of the workshops.
I thought I would tell you what is required of the VAHS Ethics Committee, and about the administration and other support that is required to maintain an ethics committee. When the Health Service's Ethics Committee commenced we were only dealing with internal research projects. Since then - well, over the years - a great number of external projects have come in for consideration which has meant that our Ethics Committee had to rethink its role, where it was going, and the direction it was taking, and the guidelines upon which it made its decisions. That has put us in a bit of a bind - the guidelines have changed, the requirements of the committees have changed, the responsibilities have changed or increased, and it has meant that there is a whole lot of extra work that is required of our Ethics Committee.

Like an incorporated association, I just might add, there are guidelines which govern an ethics committee, and these guidelines talk about your make-up, who has to sit on the committee, how often you have to report, what sort of leeway you have, what sort of guidelines you have to have, and those are all things that our committee simply hasn’t had the time to develop. Another thing is, there are guidelines for the number of members on the committee. Some have to be professional people like lawyers and doctors and so on, and the time that these people can actually spend on the committee’s work is limited. So, those are the sorts of things, if you’re thinking about establishing an ethics committee, you really need to put some time into it.

One of the changes to the Health Service’s Ethics Committee was the composition. When we first established the committee, it consisted of a lay man, a lay woman, a lawyer, a doctor with research experience, and a minister of religion. Now, in our case we asked the Australian Health Ethics Committee to consider whether or not they would have an Elder in place of a minister, which is more appropriate for us, and they agreed to that. In the new guidelines they have actually changed that. If you don’t want a minister you can have an Elder, if it is more appropriate.

Since then the composition of the committee is now seven, and it consists of a chair person as a separate position, a lay man, a lay woman, a minister of religion or an Elder, a doctor with research experience, a doctor with counselling type experience, and a lawyer.

We have had a problem with filling the Elder’s position. Auntie Iris was our original Elder and she was studying at the time, but it was very difficult for her to turn up to all of the meetings. So, getting to meetings and getting the group together has been a really difficult task for our little committee. But it is a very important committee and it has the potential to do a lot in the Aboriginal Community in terms of research.

The other thing that has come up to our Ethics Committee is procedures and policies and guidelines. Over the last few years we have made every decision almost on an ad hoc basis and we refer to the Aboriginal guidelines coming from the NHMRC (see Appendix One) but those guidelines are so very broad that they don’t allow us or give us any specific guidance. Also, they don’t reflect the diversity within Victoria or the differences in the different Community areas and the differences in people’s views about different things. What might be acceptable in Melbourne as an ethical practice may not be considered ethical in a country region, and so those guidelines are so broad-based that we’ve found it is very difficult to use them on every occasion and to come to a conclusion about whether a project may be or may not be ethical.
So out of many years’ discussion again, we’ve decided we need to draw up guidelines to provide a basis for researchers, so that when they are applying to our Ethics Committee for ethical endorsement for their projects, that they’ve got a guide to follow.

Some of the issues we need to deal with include the need to develop a protocol between the Ethics Committee and the Health Service itself. We’ve had research proposals come in to the Ethics Committee, where the researchers have said that they are working with the Aboriginal Health Service in Fitzroy, and that they are setting up a project committee, and so on, and that it is all endorsed by the Victorian Aboriginal Health Service. The Ethics Committee needs to get confirmation from the Health Service saying that they do endorse and support the project, that they are involved in it and that it’s all right with them. So that we can then finally give an endorsement to the researchers saying ‘That’s okay, you’ve proven your case, everything is in line, and you are right to go ahead’, basically.

Some of the difficulties we have experienced can hold things up for long periods of time. Another thing we have found with some of the projects coming forward from within the Health Service is that they are asking us for approval on an ongoing project, but we can feel under pressure because if we don’t endorse the project ultimately it will put people we know out of employment. So that, I think, has brought up the need for the Ethics Committee to have some sort of independence, and I mean, we are all blackfellas and we can be biased by somebody else’s possible hardship. So that’s something else that also needs to be considered when you’re establishing an ethics committee.

There are a million and one different things that you need to consider but the biggest thing is the need for administrative support. Like I said earlier, you’ve got a number of professional people that sit on your committee. It is very difficult for them to make the meetings, and at times there are a lot of phone decisions that need to be made. You might have three members of the Ethics Committee at a meeting, which is quite all right according to the guidelines, but the others need to be consulted before a decision is made by the whole Committee. So you need someone with arms and legs to pick up the phone and make the phone calls. You need someone with arms and legs to type the letters and the responses. You need someone to type the decisions made and the minutes of the meeting. You need someone to record all the information that needs to go the Australian Health Ethics Committee at the end of the year, it’s like an audit.

Another thing that has come up, too, recently they have changed the guidelines for monitoring. When we first established the Health Service Ethics Committee, you didn’t have to monitor projects and the two projects we did have running we chose to monitor because they were in-house projects. Under the new guidelines you have to actually monitor all projects that you endorse which means, again, you need someone with arms and legs to do the ground work, which is something that we don’t have. Fortunately the Health Service provided support through a worker who is employed on other projects. But that is a heavy load for someone who is already employed on a full-time basis doing other work.

We have to have a procedure for complaints. We don’t have that. We also need to have written guidelines for suspension of projects. When we are not satisfied through the monitoring process that a project is carrying on according to its original methodology, the Ethics Committee can suspend the project, and there’s a whole heap of work involved in doing that.

The other thing is, where we give ethical endorsement to a project and that project causes some damage of some sort in a Community, it is the Ethics Committee that is liable to a degree for giving that endorsement. So issues around insurance and
payment to Committee members and all that sort of stuff has recently come up which, for me personally, as the chairperson it scares me. But they are the sorts of things that you need to consider if you are thinking about establishing an ethics committee.

One last thing you need to consider is if you are thinking about research in a Community organisation, you have to establish your own ethics committee or have your research assessed by some other university or hospital-based ethics committee. Every research proposal that goes up these days has to be endorsed. If you are talking about Community-based research you have to establish your own ethics committee.

**Discussion**

In the discussion people were advised that the VAHS had set up the Ethics Committee because they had a research proposal of their own and they felt it was inappropriate that it had to be approved by a hospital or university ethics committee (such as the Ethics Committee at St Vincent’s Hospital).

Dealing with ethics committees, or setting up your own committee can cause real dilemmas for Community organisations. One of the problems is that how ethics committees are set up is based on how a university works, not how a community organisation works. People talked about having a statewide Aboriginal Ethics Committee and how that could work but suggested that there could be conflicts of interests. Another problem was that a Community controlled organisation could make decisions that the Community back in their own town might disagree with. People agreed that independence in making ethical decisions is very important. It was suggested that there might be other models working in other states that we could learn from.
Developing ethical protocols and methodologies of research in the Koori Community from the perspective of working in a University

Esme Saunders

I am currently the Research Manager at the Institute of Koorie Education at Deakin University in Geelong. I have been in the position since January 2000.

I want to talk about the Deakin University, Institute of Koorie Education, Ethics, Protocols and Methodologies 1994 Discussion Paper (see Appendix Two), but before I do that I want to talk to you briefly about how the research program at the Institute came about and how this Discussion Paper came about.

The Institute of Koorie Education is interested in collaborative research - collaborative research between the Aboriginal Community and the Institute, and between non-Indigenous researchers and the Institute. The research program at the Institute came about because of the Community-based education program that we have at the University. The students study in their Communities and come down to the University on an intensive basis every five or six weeks.

As that teaching program has grown, we have a lot of our students who have gone through the undergraduate program and are back doing post-graduate and masters degrees. These post-graduate courses usually have a research unit in them. So, we are now looking at how we conduct research, and the research program at the Koorie Institute has developed naturally as part of the education program.

Research is not something that we had suddenly decided to tack on to the program. It’s been brought about because there is a need for it with the students. We don’t have a research unit as such. We have a research program because our program is across all of the Institute's programs working together. Our research program does not stand alone. It is actually part of the Institute's program.

I want to now have a look at what the ethical matters are so that you can think more about them. I’ll walk you through the Discussion Paper. If you have any questions at the end, I’ll answer them.

The Introduction to the Discussion Paper is what I have already said. We’ve reached a point where we recognise that research is an important area that we have to go into and we want to go into research in the right way. We don’t want to do research that is wrong. All of us have been victims of research that’s been done wrong. We know that in the Aboriginal Community we have had policies placed upon us that are a result of bad research or a bad interpretation of research. In some instances the research has been quite fine, there has been nothing wrong with the findings, but what happens to the Koori Community as a result of findings has not been advantageous for the Community. I can talk about one piece of research where that happened and that was the Miller report. If you remember back to those days, Mick Miller said in the report that there were too many institutions who were taking advantage of Aboriginal students and not giving them accredited courses. The report also said there were too many “Mickey Mouse courses”, and with that DEET immediately cut out any Abstudy for students who wanted to attend the so-called “Mickey Mouse courses”. At that time, a lot of Aboriginal students were people who were coming from the home for the first time. They would come out and do woodworking or sewing or something to get them out of the house. Having an educational background, we were really happy with that. But because of the research findings the government immediately cut that out.

It was not Mick Miller’s fault, the way he said it was right. Too many times universities and other institutions have taken advantage of Aboriginal people. They were offering courses that weren’t going to get Aboriginal people anywhere but at the same time there was a need for those sorts of courses for some of our people. That was an example of where the research was fine but the interpretation by government was not fine.

We’ve been victims of bad interpretations over, and over, and over and over again and that’s been a real problem in research. Talking about ethics committees, they’ve got a real dilemma because really a researcher can put all the fine words down on paper and present it to the ethics committee and that researcher might put down really genuine ethics but the bottom line is: What happens at the end of the day? How does that researcher present their report? Who do they give it to and how do people use it? And they are things that in some way we have got no control over. We can only say it sounds fine to us, but that’s something that neither the ethics committee nor the Community has any control over.

The other thing I want to say is this is an area where the Aboriginal Community needs to trust a little bit and it’s been an area where we’ve been really hurt and burnt badly, but if we want to get anywhere in the area we have to start trusting. It’s the only way we are going to get anywhere.

The Institute of Koorie Education is committed to research activities that advance the processes of empowerment and self-determination for Indigenous people. Without that we are not interested. Simply go away, see you later. If it doesn’t advance the process of empowerment and self-determination we are not interested. The Institute recognises that in addition to ethical matters which apply generally to all researchers in Koori research, there are also specific ethical matters for researchers anticipating being involved in Koori research that they need to consider. These specific matters arise from an appreciation of the history of past research practices into Aboriginal and Torres Strait Islander affairs which have been exploitative and, in so many cases, of little value to the families, clans and communities associated with the research. And that’s been a problem as we’ve said in the Discussion Paper. Too many researchers have just been out to exploit Aboriginal people.

**Ethical matters primarily for Koori researchers**

Now, as Kooris, we sometimes think we’re not subject to these guidelines because we are Kooris. But as Koori researchers we also need to be respectful of the following understandings, attitudes and practices. The first is one that we all know - that every Koori Community is different, and Community members expect that their Community be treated as unique in its own country.

If I go up to Bairnsdale and want to carry out research there, and I am from Shepparton originally, I am not going to just get in the door because I am Koori. And because I come from Shepparton, I am not going to know immediately how that Community operates. I know a lot of people from the Community but they are different from Shepparton. We’re different. Our mob is different. We carry out things differently. We do things differently. So as a Koori researcher, when I go down there, I have to recognise that. Koori outsiders to another Koori Community’s country are expected to be respectful of that Community’s cultural and political practices and knowledge. Also, Communities may not be impressed with implicit comparisons with other Communities. We might think, ‘Oh yeah, we do it like this in Shepparton so naturally you are going to do it like this in Melbourne’. That is not necessarily the truth.

Community consultation takes time. You need to sit down and listen, rather than take on a controlling role. Our education system today - and I am talking about mainstream...
education - it really encourages us to speed up the processes. If you’ve got a question and you want an answer, you want it now. You don’t want to sit down and listen. Too often you’ve only got an hour to do this, you haven’t got all day and you don’t want to sit down and just take time to listen. It takes time to get things out of the Koori Community - even with other Kooris. They are not going to tell me anything quicker than anybody else. I might get it in Shepparton, because they know me, but I won’t get it anywhere else.

Community members expect consultation to influence the way people work together. Consultations must be reflected in actions. You need to listen to the people and respond to their ideas and ways of working. You need to work to embed the research processes into the accepted Community lifestyle and rhythms. The Community’s past and present will influence the character of the project and the research. Every Community has had past practices that have influenced them differently. If you read about all the massacres that went on down in Bairnsdale, and around Gippsland, you will realise that for that Community, the past practices are different from those in Shepparton. There are some massacre sites up around the Yorta Yorta Nation area but not as many as went on down in Gippsland. So there are going to be past practices that will influence the present, and they do influence the present. So we have to respond to those past practices as well.

The most valuable resource people for any research project are already living in the Community. This is really important. They are the people who know the information. They are the people who live the information and they are the people who are able to access the information that is needed for the project.

You need to recognise and accept the expertise within the local Community and facilitate people to become participants in the project. We have always tried in education to involve local people in anything that we do, because we know that they are the people who have the expertise in the local Community. The success or failure of the project will ultimately be decided within the authority structure of the Koori Community. Now, if the Community closes its doors on you, you soon know it, don’t you, because that’s it. If someone in that Community closes its doors, you are out - you are not going to get anything. So, you really have got to work with the authority structure within the Community.

Koori research for self-determination involving Koori researchers affiliated with a university is uncharted territory. Avoid thinking that you are already an expert in Koori research just because you are a Koori. One of the problems you can have as a Koori researcher is that you ‘know’ the answer to the problem, because really we don’t, nobody does. In mainstream research you have to know the answer before you do the research. Isn’t that ridiculous? You’ve got the idea - you’ve got the answer in your head already. You suspect that this is the answer and so you pose the question and you’re going out to find out the answer. With us Kooris it is even worse because we know. We know there’s a drug problem or we know there is this problem or that problem and we know what causes it. But really research is about being open-minded. It is really about not assuming that you are an expert before you get out there. In particular, you are not an expert just because you are Koori.

Kooris with European-derived education qualifications may experience ambivalent and contradictory responses from Community members. Your academic qualifications don’t mean as much to the Koori Community as it does to non-Koori communities. That is the truth. Academic qualifications are recognised by non-Kooris. But academic qualifications are something that you have to fight against and get over in the Koori Community because they are really a bit suspicious of people who are qualified. It is probably not as bad today as it was, mind you, that is improving over the years.
Koori Community members expect to be involved in open and equal communication about projects which affect their lives. You can’t be gammin.2 You can’t go and pretend to people - you’ve got to be open. People know when you are not honest. Aboriginal people really know when you are not sincere.

Koori researchers must interact across the Community, be respectful of family and kinship obligations and appreciating the politics of the Community from a Koori prospective. Language is both a means of empowerment and oppression. The way we talk can either put someone down or build them up. We know when we want to exclude people from our conversation. We just change the way we speak.

Koori Communities do not necessarily discriminate between personal and professional identities when judging a person’s character and worthiness of respect. Individualistic approaches to researcher roles will run counter to Koori Community values about Koori identity and appropriate ways of behaving. Kooris really are a co-operative group of people. One of the most important aspects of our culture is kinship and the group mechanism. Individual approaches sometimes turn people off.

So those are the ethical matters for Koori researchers in the Discussion Paper.

**Ethical matters for non-Koori researchers**

The ethical issues for non-Koori researchers arise from an acceptance that Koori research must now be inclusive of Koori Community interests. A non-Koori researcher should ask themselves: Why are you doing it? What are you doing it for? What are you getting out of it? At the end of the day, what is it that the Community is getting out of it? Research must be non-invasive of Koori people’s lived experiences and cultural practices. Non-Koori people don’t realise this but we are a bit strange like this, I reckon. We don’t want to tell too much, and we are a bit wary about what you know and what you don’t know. I know, going to school there were a lot of things that I would not tell non-Kooris - like my best friend might have been non-Koori but they didn’t get to know half the things that I didn’t want them to know. So it’s very different. Non-Koori researchers really must be non-invasive. The research must be non-exploitative of Koori knowledge. If you just want to come and find out something, so you can go away and use it, you are not going to get anywhere. Or you shouldn’t get anywhere. Research must move from the positioning of Kooris as objects of others’ enquiries to research paradigms which attempt to redress the oppressed, marginalised and ‘border’ reality of Koori Nations in contemporary Australian society and within the society’s academic institutions. What this means is that non-Koori researchers must move from - ‘We want to do it for our own reasons’ - to - ‘We want to do it because it is better for this Community. It is going to improve things. It is going to help. It is going to assist and support.’

Other important ethical matters relate to cross-cultural sensitivities. Non-Koori researchers will be required to respect Koori cultural practices which include:

- ‘family’ as a centering concept and the various obligations associated with particular kin relationships;
- personal as distinct from professional relationships in establishing conditions for further interactions;
- the significance of Elders and Community-based organisations in Community life;
- the need for extended time-frames in which decisions are made and the collective nature of those decisions;
- the status of individual autonomy within a cultural system of collective responsibility for social action;

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2Gammin is an Aboriginal language word meaning untrue or pretending.
• the first languages of Kooris as the languages of authentic communication amongst Community members;
• the concept of ‘women’s business’ and ‘men’s business’; and
• the publication of only appropriate pictorial material and texts.

I could sum all that up by saying you’ve got to have knowledge and understanding of the Koori people. It is no good going in and researching people you’ve got no idea about - no understanding about how they operate. If you don’t know any of those things, you may as well give it the flick. Because you are not going to get anywhere and the research that you do get will not be true research. You will not get true answers and you will have an outcome that is not based on what’s really happening. And that will hurt the Koori Community more than anything and it will hurt you as a professional academic researcher.

Protocol matters in Koori research

Protocol is really about consultation in establishing projects. Consultation is a key principle of protocol. Really consulting with people. Consulting with the people that you are going to research. Looking at the project that you are going to be involved with: whether it really is viable; whether it really is going to do anything at the end of the day; whether it’s going to help anybody. The key concept associated with empowering Koori research is Community consultation and participation. Involving local Koori Community researchers. Involving local people, but as in people participating in the research itself.

Ownership and publication of research data

This is very important. The ownership of Koori research really belongs to the Koori Community as well as the researcher. Too often in the past, the problems that came about were because people have not shared ownership of the end result. Any information you get from another person means that they are part of the ownership. And the publication of that data is really important. It is really important what happens to the data at the end of the day because that can have an effect on what happens after the research is published. All Koori research projects should begin from the assumption that:

• research material and data will remain the property of the Koori Community concerned;
• projects may only be conducted according to principles negotiated and agreed with Koori Communities at the outset;
• prior to the publication of research data or reports, the approval of the publication texts by the relevant designated consultative Koori organisation is required;
• publication of the research data will include details of the joint university/community context of the research and the role of the Koori Community in formulating the direction and work of the project.

Post-research obligations of research teams

The researchers will be expected, at the very least, to return to the Community information based on the joint research projects, and inform Community members fully of the research outcome in a format and language appropriate to the Communities involved in the research project. Too often people come into the Community and do research and you never see them again. You might go into a university library one day and read the research but that’s about it. They don’t ever give it back. They don’t ever say, ‘Well, this is what we found; it might help you or your Community.’

Should the media solicit comments from researchers once the work of their joint
projects are in the public arena, researchers should first seek consent of the Communities concerned. Media comments should be sensitive and restricted to the research issues of the project. That’s really important. I’ve read some crap. Real crap in the papers based on the research somebody has done and they’ve really come out and said this great big statement and applied it generally to the Koori Community and it’s been crap. It’s very important that any media comments go back to the Community first.

**Methodological matters in Koori research**

The key issues for the Institute are:

- Of proposed research methodologies associated with Koori research, which ones seem to provide the potential to meet the ethical and protocol criteria of the field?
- What are the features of those research methodologies that diminish the ‘power over’ elements of the research experience for Koori participants?
- What are the features of those research methodologies that enhance the prospects of Koori realities being taken seriously by the research project?
- Are there research methodologies that contain elements of organisation, procedure, data collection, analysis and interpretation, and reporting that show a potential to be assimilated into the Koori cultural tradition?

In concluding, we see that the main issue is establishing research that is in the Community’s best interest - in the Koori Community’s best interest. Making sure that consultation occurs before that really gets to a stage of being a part of a research project. If you do go into a Community, making sure that you involve that Community, participating in the research actively. Not just sitting down in meetings and saying this is the project and this is what we are going to do, and see you later. But actually having people involved, local Community researchers involved as well. And coming back to the Community with the findings and giving feedback to the Community. And making sure that wherever the findings actually end up that they are going to end up benefiting the Community and not just yourself.
Developing a Memorandum of Understanding (MOU)

Rick Henderson

I am going to be talking about Memorandums of Understanding (MOU) and what they are. We have been working with the Rumbalara Football/Netball Club in developing an MOU which just sets out the principles and arrangements between the two organisations - the Department of Rural Health and the Rumbalara Football/Netball Club.¹

This MOU is in a draft format so by no means is this the last version. (The final version is in Appendix Three of this report.) An MOU is normally in five or six steps. The first one is the scope of the Memorandum. This sets out the principles and arrangements between the Department of Rural Health and the Rumbalara Football/Netball Club. The primary purpose of the MOU is to:

• enable the Rumbalara Football/Netball Club and the Department of Rural Health to evaluate the Healthy Lifestyles Program;

• enable the Rumbalara Football/Netball Club and the Department of Rural Health to undertake joint educational, research and health intervention programs, as defined by needs and demands; a broad definition of health is taken and understood to include social justice, leadership and other issues considered to be determinants of health in the Koori Community;

• enable agreed placements of students through the Department of Rural Health within the Rumbalara Football/Netball Club.

Also, in relation to some of what Esme was speaking about before is that the Rumbalara Football/Netball Club will enable the Department of Rural Health to access all material appropriate to the Healthy Lifestyles Program and related activities in the custody of the Rumbalara Football/Netball Club, under the terms of this Memorandum.

The Department of Rural Health will assist and support the Football/Netball club in undertaking health surveys among those associated with the club.

And the next point is the Rumbalara Football/Netball Club and the Department of Rural Health agree to work closely together to enhance health outcomes for the Koori Community as identified by the Football/Netball club, through culturally sensitive research, education and evaluation.

Some of the other things that we have looked at in this process is that the Koori Community will have access to the expertise of the Department of Rural Health in health related areas, and where necessary joint proposals will be generated to resource required activities.

Aims of the Rumbalara Football/Netball Club

The Rumbalara Football/Netball Club aims:

• To continue to build on and develop the Healthy Lifestyles Program, addressing

¹The Department of Rural Health (DRH) is a department in the Faculty of Medicine, Dentistry and Health Sciences at the University of Melbourne. The DRH is located in Shepparton. Its main aim is to improve the health and well-being of rural and Indigenous communities by providing leadership and excellence in collaborative, multi-disciplinary and culturally sensitive research and education.

The Rumbalara Football/Netball Club (RFNC) is the only Aboriginal football and netball club in Victoria and one of only a few in Australia. The RFNC would arguably be the largest Indigenous sporting club in Australia. The Club was established in 1972 and accepted into the Goulburn Valley Football League in 1997. The Club is followed weekly by a supporter base of approximately 500 people, directly influencing the 6,000 Aboriginal people in the Goulburn Valley and having an indirect impact on approximately 30,000-40,000 Kooris in Victoria and lower NSW. The club is also having a significant impact on the broader community sporting fraternities of northern Victoria. The Club’s vision is to build on the Community’s passion for sport to get people involved in a broad range of activities that promote health and emotional and spiritual well-being.

The RFNC is able to access and promote physical fitness among large numbers of the Koori Community through teams, members and supporters. Therefore the Club provides an excellent home base for the delivery of the Healthy Lifestyle Program.
community based issues in sport, which impact on health. These include food and nutrition, substance misuse, community relations, racism, leadership, reconciliation, job creation and education.

- To address the health, well-being and future aspirations of young Koori people in the local Community by providing quality information, education, positive role models and encouragement to meet their potential.

- To ensure that the Rumbalara Football/Netball Club is an established and secure part of the ongoing existence of the Koori Community in Shepparton.

- To continue to achieve and strive to excel as a sporting club, which is Community based and Community controlled.

- To continue to contribute to the health and well-being of the Koori Community, and the overall community in the wider Shepparton area.

- To specifically develop the role of the Rumbalara Football/Netball Club in providing information, advice and support to other Indigenous sporting clubs, Community groups and organisations.

- To provide cultural awareness information and education to mainstream sporting clubs and bodies and health agencies.

Aims of the Department of Rural Health

These are the aims of the Department of Rural Health. As you will see, this mission statement illustrates some of what Esme was talking about in regard to language and interpretation. The Department aims:

To catalyse and contribute to the demonstrable elimination of the differential in health status between Koori and non-Koori, and between rural and urban people by:

- undertaking research, education and evaluation and

- stimulating and supporting:
  - Community development
  - Community action
  - health promotion
  - service integration
  - rural and Indigenous health workforce development
  - delivery of quality health care.

Guiding principles

This MOU was initiated by the committee of the Football/Netball club, and we thought some guiding principles to help us along would be appropriate:

- Recognition of Yorta Yorta Nations as the Traditional Custodians.

- Mutual respect for the mission and goals of each organisation.

- The Koori Community through the Rumbalara Football/Netball Club will request Community control of all research and evaluation undertaken by the Department of Rural Health for and on behalf of the Rumbalara Football/Netball Club.

- The Department of Rural Health recognises the social and cultural expertise of the Rumbalara Football/Netball Club.

- The Rumbalara Football/Netball Club recognises the research and academic expertise of the Department of Rural Health.

- The recognition that adequate support is needed to facilitate the maximum input from the Koori Community and that is around the resources and those sorts of issues as well.

The next bit is around definitions and what ‘Koori people’ means: Aboriginal people from South East Australia.

This is about data collection and also publications:

- Research and evaluation undertaken will usually result in publication, the content
of which must be agreed to by both the Rumbalara Football/Netball Club and the Department of Rural Health.

• Data and materials to be stored at a site jointly agreed to by the Rumbalara Football/Netball Club and the Department of Rural Health prior to commencing each individual activity or project, and such a site must ensure both privacy and security for the Community and those involved.

Some of the other things which we have in the MOU are around ‘Koori related material’, that is, previous information about Koori people in the records held by both organisations - that’s the Football/Netball club and the Department of Rural Health. Another thing which we looked at is the provision of personal photocopies of relevant material.

We also deal with Dispute Resolution:

• In the event of a dispute, both parties will agree to mediation for conflict resolution. An external person who is acceptable to both parties may provide mediation.

There are a lot of things these days around research between Kooris and non-Kooris and a lot of the time Kooris go on a hand-shake or that sort of thing. I think a lot of Communities have been burnt by researchers or academics, and this part of the MOU sets out the principles and arrangements so that won’t happen again. Also, there is a section on Termination of Agreement: if a mediated outcome can’t be reached, or in the event that either party wishes to terminate the partnership, this can be done by providing the other party with thirty days written notice.

MOUs are not legally binding documents. It’s more or less, as I said, an honesty sort of working relationship which we have, the Department of Rural Health with the Football/Netball club. What we are trying to achieve at the Department of Rural Health is to do this with most of the organisations that we work with, and also the Rumbalara Aboriginal Co-operative. We also have a Koori health partnership committee in the Department of Rural Health which covers the region - Swan Hill across to Wodonga and down to Seymour. All those Communities have been invited to sit on the partnership committee, which decides how we do our business. What we are trying to do is to establish an MOU with every one of those organisations. So it’s in the process. We are also working with the VicHealth Koori Health Research and Community Development Unit to try and develop an MOU as well.

This MOU, as I said, will be the first of its kind with Melbourne University and an Aboriginal Community, and there’s a signing off on the MOU on the 6th of July in Shepparton. The Melbourne University hierarchy have got pretty well behind the concept as well.

2 This signing off was attended by a large number of people from Rumbalara, Shepparton, the DRH, VicHealth and other representatives of the University of Melbourne.
Discussion

In the Discussion people were told how the MOU came about. The Rumbalara Football/Netball Club had been running a Healthy Lifestyle Program funded by VicHealth and the Department of Human Services. They were looking for a process of evaluation and talking about evaluation with Melbourne University and the Department of Rural Health. The MOU was needed to outline a clear understanding of the relationship between the two organisations.

People talked about some of the problems of working with universities and working for the Koori Community. There are different expectations of how long it will take to deliver. Sometimes it is necessary to wait for the Community, which can be a long process. Waiting for the Community can hold up completion of a project and it can be a problem if it holds up further funding. The length of time a project takes can also be a problem for Community organisations where the Board keeps changing so you don’t know who to consult with when it comes to publications.

The difference between the language used by universities and way Kooris use words was discussed. Kooris are very conservative in our use of language – we use few words. Universities use a lot of words – as if they are preparing for battle, defending themselves.

Panel Discussion

Salina Bernard, Esme Saunders and Rick Henderson joined Ian Anderson for a discussion of issues that came out of all the morning’s talks. Some of the questions were around the importance of educating non-Aboriginal people about real Community consent. It isn’t easy for a university research ethics committee to understand and apply the NHMRC Guidelines. The committee will know the researcher has to consult with the Koori Community in person but they don’t know how to assess this. Many projects are still coming from people who have not had any contact with Koori Communities. Getting an MOU between an organisation and the Community is an important step. Even though an MOU is not a legal document, it will bind an organisation to the principles and obligations that have been agreed to.

People felt there should also be a review process during the project to review the methodology and the MOU.

There was discussion about the need to make Community organisations stronger so that they can own and control the research. People don’t know what research is and how it can benefit the Community. VAHS is currently the only Community organisation that employs researchers and owns the research. It was suggested that there may be a need for a course for Kooris to do research, to skill people up.
I get a sense that there’s a lot going on and a lot to work through and think through in terms of ethics. Even in terms of demystifying it and making the whole subject seem less ‘academic’. In a sense what we’ve really been talking about this morning is how do we make sure that we get a balance between the benefits from research at the same time as protecting people from the harms of research. So, this afternoon we wanted to work through – in smallish groups – a made-up case study, to try and illustrate some of the details of these issues.

In a lot of ways it doesn’t matter whether we have an ethics committee or whether you’re actually involved in research, most people who work in Koori health or in Koori organisations will be asked at different times to give an opinion about a particular research proposal. That research proposal might have come up from the organisation or it might have come from an outside researcher. We’ve talked about some of the different ways and some of the different tools that we can use in order to make sure that the Community is protected from potential harm. I think that it really does rely on Kooris taking control of the event and actually taking control of the decision making.

We’ll always have researchers working in universities who have got an interest in research work. We will probably always have a need to be able to call on researchers working in universities, but I’m increasingly convinced that one of the other important things is for Kooris in Community organisations to actually be directly involved in doing research themselves around the issues that they think are important. It has been my experience that once people start doing that in their own organisation they actually become a lot stronger in actually negotiating with outside researchers because people are more familiar with the issues, familiar with the language, and they’ve had to really think about things themselves.

I think one of the most challenging things about having a research ethics committee in an organisation where you are involved in the research is you’re suddenly realising, ‘No this is not just an issue for those fellas in universities.’ We’ve got to think about these issues ourselves and we’ve got to think about the challenges of what it means to be in a Community involved in a research project and actually be empowering ourselves to do our own research. So in a lot of ways it doesn’t matter at the end of the day whether it’s an ethics committee that’s answerable to the Community, or whether it’s a Memorandum of Understanding that you want to develop, or whether you want to encourage a particular research body to develop protocols for that research, it’s important that it’s Koori decision making that’s driving the process.

This afternoon we want to spend a bit of time on the case study and then come back together as a group at the end of that process and have a small panel discussion where we talk about ‘Where to from here?’ We hope that we’d finish at about 3pm but we’d particularly like to make sure that we have a good panel discussion at the end of the day so that we can draw out some of the threads of the discussion today.

I am going to hand out copies of the gammin case study on ‘Koori Kids’ Ear Disease’. We all know that Koori hearing and ear health is a really important issue, particularly with young kids, and it has an impact on kids’ learning. We have drawn on all sorts of different experiences and tried to make this case study as realistic as possible. Although some participants (or readers) might be reminded of a certain situation or think you recognise your own Community, I want to assure you that this was definitely a made-up case study.

Gammin is an Aboriginal language word meaning untrue or pretending.
**GAMMIN CASE STUDY – KOORI KIDS’ EAR DISEASE**

The Board of Directors of the ‘Red River Aboriginal Co-operative’ have asked for your advice on the ethics of a research project. The Co-op is a small Aboriginal Community controlled organisation in a rural town. The Board was approached in writing by researchers from the ‘University of South East Australia’ in November 1999 to ask if the Board would support a research project on Koori kids’ ear disease. You are a health worker that works for the Co-op and are a member of the Ethics Committee that is examining this project. You know that while some of the Board members have the usual doubts about research, some members of the Board are quite keen on this one. It is planned to be a part of a larger national study developed in collaboration with the National Aboriginal Community Controlled Health Organisation; and involves a couple of well-known Koori workers in the project.

**BACKGROUND:**

In October 1998 the Research Team from South East University met with the Administrator and the Senior Health Worker to discuss a possible research project in Koori kids’ ear disease. This was a very general discussion. The Administrator of Red River Co-op talked generally about issues of working in Koori Communities, such as the need for consultation and so on. Present at the meeting were two well known Kooris who work in health (from Melbourne) and who are going to be a part of the Research Team. No meeting notes were taken. The Research Team felt that this was generally a good discussion. The Research Team was invited back to discuss this further. A follow-up letter was sent by the Research Team thanking the Administrator for meeting with them, and for the Administrator’s support for the project.

In the written proposal that was presented to the Red River Co-op Board in November 1999 the Research Team outlined the project. The aims of the study were to:

- review current approaches to management of ear disease in Koori kids;
- determine the prevalence of ear disease and hearing problems from a group of Koori kids who present to the Co-op for other reasons;
- make recommendations about how to improve the management of ear disease and hearing problems in Koori kids.

As a part of the research project the researcher will:

- review all the files of under fives held by the Co-op;
- check the ears and hearing of all kids that present to the Co-op for other services;
- refer kids with identified problems for treatment and further assessment;
- return in six months to check the ears and hearing of all kids that had problems identified in the initial survey.

The findings of this study will be written up and a Community report provided to the Co-op.

Data will also be included in the national analysis that is also been undertaken by the University of South East Australia in collaboration with NACCHO.

**You are a member of the Ethics Committee that is examining this project. What will your advice to the Board be?**
Small Group Work: Stage One - What else do you need to know?

The workshop participants were divided into 4 groups to discuss the case. Little mistakes - or even large ones - had been deliberately written into the case study. The idea was that these mistakes would not be too obvious but that people would pick them up in the small groups. People were asked to think what else they needed to know about the proposed project in the case study.

When people returned to the large group Ian played the role of a non-Koori researcher named ‘Jeff’ who was very keen to do research with the Koori Community but didn’t have much experience with Kooris. ‘Jeff’ answered the questions put to him by the small groups.

All groups questioned the content of the support letter in the case study. Everyone felt that too many assumptions had been made by the researchers. For example, the researchers assumed that support had been given to the project. However, there was no evidence of any Community consultation around the project. People also noted the long time between October 1998 (when the researchers had met the Administrator of the Co-op) and November 1999 (when they wrote the letter). Things would have changed over that time. The Administrator and other staff may have changed. Others at the Red River Co-op may feel differently about the project.

People wanted a lot more information about the proposal before they could consider whether it should go ahead. Their questions are shown on the next page.
QUESTIONS ABOUT THE GAMMIN CASE STUDY PROPOSAL

- Whose project is it? (NACCHO? the Co-op? the University? the researchers? the Community?)
- Who initiated it? Why is it being done?
- How many Communities will be involved in this project?
- Has any Community consultation taken place?
- Is ear disease a priority for Red River?
- Where did they get their information about Koori kids in this area having ear disease - that the way we manage it needs to be improved?
- How much is the project worth and how's it funded?
- Why did the researchers pick the Red River Community?
- Who will have access to files? What information are they taking out of files? Will parents be asked to give informed consent for this? Is there another way of gaining this information?
- How will this study add to existing knowledge about the problem? Will it actually change things for the local Community? Will it do something about the problem?
- How will the local Community be involved in the research? Will it be possible to employ any Koori researchers on the project?
- Will this project skill local workers?
- Will there be any ongoing resources for the Community after the research ends? Any long term sustainability and support?
- Who owns the data? Will the Community have any editorial rights over the information?
- Where is the information going? Who is going to be using it and how?
- Who will the recommendations be made to?
- Will any identifiable information be collected and used? How will data be reported? Will the Red River Community be identified in the National study?
- How did the project get funded without ethical approval? Do you already have ethical approval from elsewhere?
- Surely a sample of only 4 Communities is not an enough for a National study?
- Have the NHMRC Guidelines for researching with ATSI Communities been considered?
- Do the researchers have any sort of relationship with VACCHO or NACCHO?
- How does this project fit into the national picture?
- How will it benefit the local Community, considering it's a broader study involving other organisations?
- What sort of follow up and referral process will there be? (Issues around appropriate services, access to services, etc)
- How accurate are the testing processes and how will they handle healthy children who are wrongly diagnosed?
- How do the researchers plan to report back to the Community?
- What is the time frame for the project?
- Who are the chief investigators? Who supervises the project? Who will be doing face to face things?
- Will there be any Red River staff involvement - for continuity?
- Can the University clearly identify its methodology? Where is the project design? Not enough concrete information.
- Isn’t this research biased towards kids who are sick?
Small Group Work: Stage Two - What are the possible harms and benefits of this proposal?

When all their questions had been answered, people were asked to return to their small groups and to list all the possible harms and benefits of the research project proposed in the case study.

People were asked to think about this from the perspective of:

- the individual research subject (a kid who has their ears checked by the research team)
- the study population (Koori kids who might have their ears checked)
- the Community (Koori Community in Red River)
- the organisation (Red River Co-op)

All the harms and benefits that people thought of are listed on the next two pages.

People were also asked to think about ways to minimise harm. Each group was asked to focus on one of these four areas of concern:

**Group 1 - Confidentiality**
- What are the possible confidentiality issues in this project?
- What could be done to protect the confidentiality of research subjects?
- Do you have any recommendations for the research team on this issue?

**Group 2 - Informed Consent**
- What do we mean by informed consent?
- What are the possible issues relating to informed consent in this project?
- What should be done to protect informed consent?
- Do you have any recommendations for the research team on this issue?

**Group 3 - Consultation and strengthening Community participation**
- Has there been adequate consultation on this project?
- How do we know if consultation is adequate?
- Do you have any recommendations to the research team about how to strengthen Koori participation in the project?

**Group 4 - Ownership and publication of data**
- What are the general issues and problems with the ownership and publication of data that needs to be addressed in this project?
- Do you have any recommendations to make about the ownership and publication of data regarding this project?
HARMS

- Agreeing to the Project at this stage could set a precedent that does not allow for proper consultation
- Possible breaches of confidentiality - Information in files being accessed
- No continuity of care after research
- Some children may be wrongly identified as having ear disease which will cause unnecessary distress
- Children with ear disease may be identified but not followed up - practical issues of access may be a problem
- Stereotypes may be reinforced through reporting in the media and through the way the findings are reported
- External researchers - Melbourne ‘Johnny come lately’ research team have no experience with Koori Communities
- Examiners’ knowledge of and sensitivity to Koori children in the Community is unknown
- Possibility of research draining Community resources
- Possibility of over-researching the Community (What other research and programs are already being conducted?)
- Exploitation – information going to National report
- Loss of empowerment - people as the subjects of research
- This Project just measures – it offers no solution after the research has been done
- If nothing is done about the problem as a result of the research – the research will have been done for nothing
- Questionnaires could be intrusive
- Invasion of privacy can open up other aspects of people’s lives which could lead to other consequences or further interventions
- Research can raise trauma for the Community – people often have to go over and over similar stories
- Research can be judgemental - just show people failing, if not done properly
- If unsuccessful the Community will be blamed
- Could result in a loss of $$$ if there is a negative result
- Not addressing the cause
- Structural issues may not be addressed - reinforcing blame in the Co-op and in the Community leads to a cycle of failure and blame if people are not empowered to come up with a solution
BENEFITS

• Identify kids with hearing problems – find out how much ear disease there is in the area
• Benefits of children having their ears checked and being treated
• Fix problems before they get worse
• Child ear health improvement
• Better school outcomes – possibly
• Training of local Community workers in ear health care
• Individual, family and Community benefit
• Locally training researchers
• Demonstrate Community needs
• Produce valuable information
• Self-determination – if Community can oversee the whole process
• Other factors may be identified eg smoking in the home, infections
• Set up health promotions
• More funding and resources may be allocated for child ear health, hearing programs and general health programs
• Identify current resources
• Increase Community knowledge and awareness of the problem - leading to a better program - leading to preventive behaviour
THESE ARE THE SUMMARIES OF WHAT EACH GROUP THOUGHT ABOUT THE FOUR AREAS OF CONCERN:

CONFIDENTIALITY ISSUES

- Who is going through the files and where?
- Who will have access to the data once it is collected?
- Where and how is the data stored?
- What is the examination procedure - private examination vs ‘meat market’?
- How will the results be given to the family?
- How will the privacy around other issues recorded in files be retained?
- How will parents be assured about confidentiality?
- How will data be identified?

ISSUES AROUND INFORMED CONSENT

- Must be informed that other researchers will have access to the data because it is part of a National study
- Must be clear about the Co-op’s role in the research
- Language must not be too wordy and not use too many big words
- Should be told who you can complain to about any aspect of the research
- Who would explain the project to the parents or guardians?
- Must be able to withdraw at any time
- Who will explain the process to a child?
- Must not be worded to encourage participation – as if people would miss out on something if they don’t agree – it is unethical to pressure parents to participate
ISSUES AROUND CONSULTATION AND STRENGTHENING COMMUNITY PARTICIPATION

- Community needs to be informed as the project goes along
- Question of whether researchers should pay for knowledge held in the Community
- Issues of payment or inducements to participate – people should be reimbursed for their time and for travel costs

ISSUES AROUND OWNERSHIP AND PUBLICATION OF DATA

- Confidentiality
- Editorial rights
- Authorship
- Recognition
- Acknowledgment
- Ownership
- Analysis
- Collaboration
- Language/interpretation
- Dissemination
- Copyright/intellectual property rights
Report Back and Group Discussion

When everyone was asked to return to the large group, all the ideas and suggestions from the smaller groups were discussed. The large group was asked what recommendations they would make to the Board at the ‘Red River’ Co-op.

Two key issues were identified:

• Is it a Community priority?
• There must be Community involvement through a steering committee.

People also asked:

• If ‘Red River’ says no to the proposal, won’t the researchers just go to another Community and do it there?

In general people felt they could not decide without proper Community consultation. However, they suggested a number of recommendations that could be made to the Board.

**RECOMMENDATIONS**

• Have a Community meeting to form an advisory committee
  - to consider the project
  - to oversee and monitor the whole process
  - to report quarterly to Community

• Develop a MOU

• Develop other ways of keeping Community informed about all stages of the project

• Ensure privacy for examinations of kids

• Don’t do the systematic file review - only review files for specific concerns and with consent of parents

• If looking at files, have a Co-op worker relay the information from the files

• Local Community must be involved in the whole process: design, implementation, evaluation
SUMMARY

Ian Anderson

The purpose of the case study was to illustrate some of the decisions facing an ethics committee and to illustrate that you don't always have all the information on the table when you are asked to make those decisions. Working through the case study, you can see that there are a range of things you can put in place that can actually minimise the potential harm of the research. You could establish an advisory committee for the project, develop MOUs, employ Koori researchers on a project, and have Community meetings. But it's not always clear-cut - it is often a very difficult juggling act.

An ethics committee would normally pick up on a lot of the issues that have been raised today, but they won't pick up on the importance of making informed consent forms in Community-friendly language. You could make a recommendation that there be a Koori Health Worker there to explain the consent form to participants. Another approach people have used in other Communities is to have a video for consent. This would show every step of the research process so people can actually see what is going to happen before they sign a consent form.

It could be useful to get another researcher to look at the proposal and assess it - to see if it is good quality research. At the end of the day, even if it is a Community priority, if the results will be meaningless because the research has not been properly planned and carried out, then you’ve wasted everyone's time. It can be difficult for a Community ethics committee to make that sort of assessment. Often you don’t have enough information in the proposal that is put up to the committee. You actually need to go back to the researchers and ask them to respond to certain questions.
FINAL PANEL SESSION: WHERE DO WE GO FROM HERE?

The day ended with an open discussion, helped along by Elders Joan Vickery and Kevin Coombs. People were asked to think about research and training issues, and where to go from here in relation to the role of ethics committees.

Panel members congratulated the Unit on putting these workshops together and suggested that there should be more workshops and training for Aboriginal people all around the state. People sometimes feel that they have to go through with a research project just because NACCHO is involved, or other Communities are involved, but every Community has the right to decide whether it gets involved in research or not. Workshops like this are a way of providing information to people, showing people that they have the right to make decisions for their own Community. People can ask for more information, they can say ‘no’ to the researchers, or they can say ‘Hang on a minute, you need to this, or you need to that’.

One panel member said that Aboriginal organisations and Aboriginal people shouldn’t be scared of research because if it’s done properly it will back up what the organisation is trying to achieve. Research can provide evidence that you can take to the government to put a case for further funding.

As a Koori researcher, you still need advice and support from other researchers, from ethics committees and from people in the Community. There was further discussion about the need for more specific and practical guidelines for researchers and for Communities. People also discussed the possibility of a central ethics committee and how VACCHO and NACCHO might be involved.
WORKSHOP EVALUATION

16 people who attended the workshop completed our short evaluation forms. Here is a summary of what people said about the workshop.

1. How did you find out about the workshop?

About the same number of people had heard about the workshop through letters, leaflets and from others.

2. The Unit intends to hold workshops every 3 or 4 months – would anything make it easier for people to attend?

People made these suggestions:
- Plenty of notice to get time off
- Formal approaches to Koori organisations to encourage release of staff
- Rotating venues so people would not have to travel for more than 2 hours
- Clear agendas for morning and afternoon so that people could attend half-days

3. Was the ‘all-day’ agenda suitable? Was the day too long/too short? Did the workshop cover too much or too little?

Most (14) participants found the day just right, the information interesting and the coverage good. People felt they had the opportunity to participate. One participant found the day too long and the topic was a bit dry. One suggested that a half-day workshop might be more convenient.

Other comments included:
- A second day might help to follow through on what was raised today
- The workshop did not stick to its agenda but this was OK because there was lots of relevant discussion
- The case study was good in breaking up the day and allowing small group work, but having this earlier in the day might be good

4. Which session(s) did you find most interesting/useful, and why?

People liked the presentations by Esme, Rick and Salina, and the open discussion around ethics. Most of the participants said they found all sessions useful and interesting. Half found the case study session the most useful because ‘it brought out real issues that everyone could relate to’.

5. What kind of sessions do you like best – talks, group discussions, panel discussions?

Most people liked the variety of sessions because they generate discussion and help you to reflect on different aspects of the information. Some preferred group sessions.
6. Overall, did you find the day useful? Did you feel comfortable attending? How could we improve these kinds of workshops?

Only one participant said they had found it difficult to have input at first but other participants felt comfortable at the workshop. One said: ‘The group was great and I felt comfortable taking about these issues in this group.’

People suggested some ways of improving the workshops:

- More presentations by Koori researchers
- An opportunity for people to talk about research they are involved in
- Hold more workshops
- Would like people to hand out printed notes and speak to the main points
- Wider range of Koori people attending these workshops in future
- Maybe a video, guest speakers
- Less distance between the tables and the presenters
- Some more discussion about what constitutes research would be helpful
- Learning about the structure and steps to take in the research process
- Ask local Communities their issues, problems and solutions

7. Would you attend other workshops in the future? What topics would you like to see discussed at future workshops?

Almost everyone said they would attend more workshops. The following topics were suggested:

- Confidentiality
- In-house examples of research
- Research projects, current and past research projects
- How to write research briefs, funding applications, get funding to conduct research in an area that they need researching
- Different methods of research and the ethical implications
- How are Community organisations going to prepare for research
- Putting ethics into practice – practical implications
- Commercialisation of ethics – charging for ethical services and advice
- Use of data for different projects through the years (ethical implications)
- Ethics of copyrighting and charging for data collection and use
- Use of ‘consultation’ by governments - classification as research and political implications of this for funding to co-ops
- Government use of knowledge and information from program reports – ethical aspects and practical implications of how Communities and governments work together
- Underlying principles of ethics – should they include self-determination, empowerment, capacity building, etc?
ABBREVIATIONS

AAL   Aborigines Advancement League
MOU   Memorandum of Understanding
NACCHO National Aboriginal Community Controlled Health Organisation
NHMRC National Health and Medical Research Council
OATSIH Office of Aboriginal and Torres Strait Islander Health
RFNC  Rumbalara Football/Netball Club
RUIMHER Resource Unit for Indigenous Mental Health Education and Research
VACCHO Victorian Aboriginal Community Controlled Health Organisation
VAHS  Victorian Aboriginal Health Service
VKHRCDU VicHealth Koori Health Research and Community Development Unit

REFERENCES


VicHealth Koori Health Research and Community Development Unit (2000). We Don’t like Research … But in Koori hands it could make a difference. Melbourne, VicHealth Koori Health Research and Community Development Unit, University of Melbourne.
APPENDIX ONE

GUIDELINES ON ETHICAL MATTERS IN ABORIGINAL AND TORRES STRAIT ISLANDER HEALTH RESEARCH

Approved by the 111th Session
Of the National Health and Medical Research Council,
Brisbane, June 1991

NATIONAL HEALTH
AND MEDICAL RESEARCH COUNCIL

(Extract: pages 6-8)

NEW DEVELOPMENTS

In several states, Institutional Ethics Committees (IEC) have been established within Aboriginal and Torres Strait Islander controlled organisations. These committees can decide on ethical approval of research proposals initiated by workers within the Aboriginal and Torres Strait Islander controlled organisations or on proposals from institutions that do not have an IEC. These committees can also be invited to advise on, and facilitate deliberations on ethical matters for research proposals on Aboriginal and Torres Strait Islander communities and groups which have been initiated by workers from other institutions.

FORMAT

The guidelines are presented under the following headings;

• Consultation
• Community Involvement
• Ownership and Publication of Data

GUIDELINES CONCERNING ABORIGINAL AND TORRES STRAIT ISLANDER HEALTH RESEARCH

In assessing a research proposal involving study of Aboriginal and Torres Strait Islander individuals or communities, an Institutional Ethics Committee (IEC), in addition to assessing whether the proposal conforms to the NHMRC statement of Human Experimentation and Supplementary Notes, shall satisfy itself that:
CONSULTATION

1. In the preparation of the research proposal, the researcher has sought advice not only from State, Territory and Federal Aboriginal and Torres Strait Islander Health agencies, but also from local community-controlled Aboriginal and Torres Strait Islander health services and agencies.

2. The Aboriginal and Torres Strait Islander community, or appropriate community controlled agency able to represent the Aboriginal and Torres Strait Islander group which is the focus or context of research, has indicated that the research being proposed will be potentially useful to the community in particular or Aboriginal and Torres Strait Islanders in general, and will be conducted in a way that is sensitive to the cultural and political situation of that community.

3. The researcher has obtained written documentation of consent from the communities in which it is proposed to conduct research and where this has not been possible, the reasons should be documented.

In such circumstances, informed consent should be shown to have involved:

(a) provision of information in a form accessible to community members and able to be readily understood by them. This information should have included details of the collection and analysis of data, and the drafting and publication of reports. It should also list any potential costs to the community as well as potential benefits;

(b) face-to-face discussions with community groups and individuals concerned wherever possible and where this has not been possible, the reasons should be documented;

(c) the allowance of sufficient time for the community and the individuals concerned to assimilate and respond to the information offered;

(d) demonstration of a process for obtaining free consent from individuals as well as written evidence of consent by the community-at-large;

(e) provision of information to participants that consent may be withdrawn at any time.

COMMUNITY INVOLVEMENT

4. Members of the Aboriginal and Torres Strait Islander community being studied will be offered the opportunity to assist in the research and will be paid for the assistance, and the funds to support that assistance are included in the research budget proposal. Specifically, Aboriginal and Torres Strait Islander women, as advised by the community, will be involved when research deals with women’s or children’s health issues; and the specific cultural and social needs of Aboriginal and Torres Strait Islander men will be similarly recognised.

5. The researcher has accounted for any resources which may be made use of in the conduct of the research, has costed these in the research proposal, and has demonstrated a process for reimbursing the community and/or individuals for any such costs.

6. The researcher recognises the right of the community to request further information about aspects of ongoing research, and accepts that changes in research protocols, procedures or methodologies will require further negotiations with the community and consent for that change by the community or an agency nominated by the community. The IEC must also be notified and be given the opportunity to approve changes to the research protocol.

7. The researchers and IECs must observe the requirements for surveillance of research set down in Supplementary Note 1 of the NHMRC Statement on Human Experimentation and Supplementary Notes, as published from time to time.
OWNERSHIP AND PUBLICATION OF DATA

If there is any reason to expect that there may be a misunderstanding between researchers and Aboriginal and Torres Strait Islander research subjects over the conduct of research, the ownership of raw data or the rights to publication of research findings, these matters must be discussed and negotiated and preferably agreed upon by both parties before the research begins.

8. Following completion of data collection and analysis, and before any publication or presentation of this data, a summary of the findings will be reported to the community as a whole. Details of findings relevant to their health or well-being will be confidentially conveyed to individuals who participated together with counselling as appropriate.

9. If a researcher wishes to use the information or blood or tissue samples gathered in the course of research for any purpose other than for which consent was obtained, further permission must be sought from the community.

10. The return of identifiable raw data, its destruction, or secure storage on completion of the research, should be negotiated with the community, or its nominated representative or agency, prior to the commencement of the research.

11. Results will not be published in a form which permits identification of individual subjects. Results which identify a particular Aboriginal or Torres Strait Islander community will not be published without permission from that community or from a community-controlled agency able to represent that community.

12. Pictorial material will be made only with the consent of the local community and will be handled in accord with their wishes.

13. Proper acknowledgment will be given to individuals and communities who took part in the research.

14. Whenever practicable, Aboriginal or Torres Strait Islander assistants who contributed to the research will be involved in the preparation of publications and will be acknowledged. Publication acknowledgment shall be in accordance with the NHMRC Statement on Scientific Practice.

15. Should the media solicit comments from researchers, once their work is in the public arena, researchers should first seek the consent of the community concerned. Comments to the media should be sensitive and professional and should focus on the research issues under consideration.
APPENDIX TWO

DEAKIN UNIVERSITY
INSTITUTE OF KOORIE EDUCATION
KOORIE RESEARCH PROGRAM
Ethics, Protocols and Methodologies

Discussion Paper
December, 1994

Mary Atkinson (Chairperson, Board of the Institute of Koorie Education), Wendy Brabham (Director of the Institute of Koorie Education), John Henry (Institute of Koorie Education/Faculty of Education), David James (Vice-Chancellor, Ballarat University)

1. Introduction

The Institute of Koorie Education has, to date, had a primary focus on establishing equity education programs for Koorie students enrolling at Deakin University. This work has evolved through several staged and is now a distinctive feature of the University’s curriculum and teaching practice. As is the case with innovative developments in teaching practice, especially those breaking new ground in conceptualisation, the distinction between teaching and research becomes blurred.

To claim that the Institute of Koorie Education has not had a research agenda in the past is to misrepresent the work of affiliated academic staff. However, it is true to say that the Institute of Koorie Education has reached a point in its development whereby its research activities need to be recognised as constitutive of an emerging Koorie research program. There is a need now to recognise formally the research profile of the Institute of Koorie Education and to develop guidelines for an expansion of this important component of the Institute’s academic activities.

2. Research and the Empowerment of Indigenous Australians

The Institute of Koorie Education is committed to research activities which advance the process of empowerment and self-determination for Indigenous people. This is a fundamental principle for research conducted under the auspices of the Institute of Koorie Education.

There are important issues to resolve or, more appropriately, to work towards resolving for the Institute of Koorie Education and University generally while establishing a Koorie research program which supports and contributes to self-determination agenda of Indigenous Australian communities. These issues relate to research ethics, to research protocols and to research methodologies. These issues are typically not restricted to one area but interconnect across the ethical, procedural and methodological areas. It is, however, useful to identify the key issues and appropriate guidelines under each area, as a way forward in this discussion of Koorie research policy for the Institute.
3. Ethical Matters in Koorie Research

There are matters which apply to any consideration of research ethics and which therefore apply equally to Koorie research. These matters are covered by the University’s existing research ethics policy.

However, the Institute of Koorie Education recognises that in addition to ethical matters which apply generally to all researcher’s in Koorie research, there are specific ethical matters for researchers anticipating involvement in Koorie research projects to consider. These specific matters arise from an appreciation of the history of past research practices into Aboriginal and Torres Strait Islander affairs which have been exploitative and, in so many cases, of little value to the families, clans and communities associated with the research.

Koorie communities have become highly critical and cynical about research as an activity; and rightly so. Their experience of research has been one of paternalistic probing, of being constructed by disciplines that are presented and portrayed as impenetrable sources of knowledge and power (white mythologies?), of being written about, and of others gaining status on their backs. More specifically, Koorie communities have experienced the processes by which non-Koorie researchers have appropriate Koorie cultural knowledge to become “experts” about them. These portrayers and purveyors of appropriate and reconstructed Koorie knowledge have, in the past, damaged the processes of cultural reproduction in Koorie families and their communities. They have also carried messages about Aboriginality to non-Aboriginal Australia unrepresentative of Koorie cultural truths.

The contemporary context of Koorie research is one framed and informed by the past experiences of Koorie communities to the research community of Australian universities and others, and by the self-determination agenda of Indigenous Australians. It is from within this context that the Institute of Koorie Education identifies ethical issues relevant to Koorie research.

As a beginning point in this discussion of ethics in Koorie research the Institute of Koorie Education makes it clear that Koorie research is conceptualised through the Institute’s equity work in Koorie higher education. Equity in Koorie education at Deakin University has meant in practice the involvement of both Koorie and non-Koorie academic staff in collaborative teaching work. Similarly, equity in Koorie research will mean that in the development, implementation and reporting of Koorie research projects Koorie and non-Koorie researchers will be involved as equal participants. Ethical considerations then apply to all researchers involved in the research of the Institute, whether the researchers be Koorie or non-Koorie.

The Institute further believes that these issues can be discussed most usefully by initially identifying those ethical matters particularly pertinent to Koorie researchers involved in Koorie research, and those most pertinent to non-Koorie researchers. While it is recognised that these two sets of ethical matters are not entirely discrete to one group of the other, the issues do however usually present within projects in culturally specific ways. With this in mind, these matters are discussed below separately as the primary focus for, firstly, Koorie researchers, and then as the primary focus for non-Koorie researchers.

(a) Ethical matters primarily for Koorie researchers

The ethical matters for Koorie researchers participating in Koorie research arise from their difficult position of undertaking a role that has been defined in the past, and still in the present, through forms of institutional life which have served the cultural interests of colonial Australia. Koorie researchers face continually the moral dilemma that their involvement in Koorie research may perpetuate the past exploitation of their communities by the dominant non-Indigenous cultural tradition of Australia into the future. For Koorie researchers, the ethical matters of importance are those which focus on the re-definition of their role as researchers so that the cultural and political
interests of Koorie communities come to the fore as the primary purpose of Koorie research projects. The ethical questions for Koorie researchers are: What are the most appropriate protocols, and how should Koorie researchers behave so that Koorie interests are protected and advanced?

The Institute accepts that the detailed answers to these questions will emerge as actual research projects proceed. However the Institute, upon advice from community members, accepts that Koorie researchers will be more helpful to communities involved in Koorie research when their orientation to their role is respectful of the following understandings, attitudes and practices:

- Every Koorie community is different and community members expect that their community be treated as unique in its own country
- Koorie outsiders to the community’s country are expected to be respectful of the community’s cultural and political practices and knowledge;
- Communities may not be impressed with implicit comparisons with other communities; avoid as uninvited “in my area or in Community ‘such-and-such’ this is what’s happening’ type of input;
- Community consultation takes time; sit down and listen rather that take on a controlling role whereby the project is run purely to outsiders’ timetables and agenda;
- Community members expect consultation to influence the way people work together; consultations must be reflected in actions; listen to the people and respond to their ideas and ways of working, work to embed the work of the project into the accepted community lifestyle and rhythms;
- The community’s past and present will influence the character of the project and the research; be sensitive to the accustomed ways of working through issues in the community, be sensitive to the history of the community and to community developments already in place, assist people to inform the project through their history and developments;
- The most valuable resource people for the project will be living in the community itself; recognise and accept the expertise within the local community and facilitate people to become participants in the project;
- The success or failure of the project will ultimately be decided within the authority structure of the Koorie community; respect the authority of the elders in the community and be prepared to take direction from their advice;
- Koorie research for self-determination involving Koorie researchers affiliated with universities is uncharted territory; avoid thinking that you are already an expert in Koorie research just because you are a Koorie;
- Koories with European-derived education qualifications may experience ambivalent and contradictory responses from community members during the introductory phase of a project; recognise that your academic qualifications give you no automatic access to the most appropriate research protocols with Koorie communities, these are likely to be a hinderance to your work in community-based projects if flaunted, status in Koorie communities is not related to an academic education;
- Koorie community members expect to be involved in open and equal (symmetrical) communication about projects that effect their lives; accept and facilitate the need for open and equal interactions with community members, interactions which secure community input into defining the actual work of the research project;
- Koorie researchers must interact across the community respectful of family and kinship obligations and appreciating the politics of the community from a Koorie perspective; although committed to social and political issues, Koorie researchers must avoid involvement in local political issues which could be interpreted by sections of the community as partisan support;
Language is both a means of empowerment and oppression; Koorie researchers need to communicate the work of the project and its potential outcomes in language that is accessible to community members; avoid exclusive, esoteric language and always use culturally acceptable forms of communication;

Koorie communities do not necessarily discriminate between personal and professional identities when judging a person’s character and worthiness of respect; be open to the community as a Koorie person, be accountable at a personal level for your actions in the project and avoid presenting yourself to community members only through professional and institutionally defined roles.

Individualistic approaches to researcher roles will run counter to Koorie community values about Koorie identity and appropriate ways of behaving; attempts to define your researcher role as one which contributes to a communitarian approach to research.

The researcher role for Koories will be informed by Koorie cultural values. The ethical matters of paramount importance for Koorie researchers are those which impinge on this process. How does one move forward in the field of Koorie research without putting at risk one's integrity as a Koorie person or one's responsibilities to family, clan and community?

(b) Ethical matters primarily for non-Koorie researchers

The ethical issues for non-Koorie researchers arise from an acceptance that Koorie research must now be inclusive of Koorie community interests. It must be non-invasive of Koorie people's lived experience and cultural practices. And it must be non-exploitative of Koorie knowledge. It must move from the positivistic position of Koories as objects of others' enquires to research paradigms which attempt to redress the oppressed, marginalised and ‘border’ reality of Koorie nations in contemporary Australian society and within this society’s academic institutions. ‘Power over’ issues are central to the ethics of Koorie research. Koorie research defined in this way addresses the issues of excellence, the validation of Koorie cultural reproduction processes and the knowledge produced, the generation of new knowledges, and the importance of critical analyses and public commentaries form the perspective of Koorie empowerment.

Two ethical matters of paramount significance for non-Koorie researchers involved in Koorie research arise from an acknowledgment and understanding, firstly, of Koorie cultures and, secondly, of the history of Koorie community involvement in research projects.

The first ethical matter relevant primarily to the code of behaviour of non-Koorie researchers is that of researcher cross-cultural sensitivity, that is, researcher, preparedness to honour culturally different values, needs, practices and perspectives. While participating in Koorie research projects, researchers will be required to respect Koorie cultural practices which include, amongst other:

- ‘family’ as a centering concept and the various obligations associated with particular kin relationships;
- personal, as distinct from professional, relationships in establishing conditions for future interactions;
- the significance of elders and community-based organisations in community life;
- the need for external time frames in which decisions are made and the collective nature of those decisions;
- the status of individual autonomy within a cultural system of collective responsibility for social action;
- the first language of Koories as the languages of authentic communication amongst community members;
• the concepts of ‘women’s business’ and ‘men’s business’; and,
• the publication of only appropriate pictorial material and texts (eg. Not including names or photographs of deceased persons, nor referring to individuals according to eurocentric constructs of Aboriginality where these acts offend community sensibilities)\(^1\).

These cultural sensitivities should also be framed within an understanding of the impact of the Koorie nations’ history of dispossession, marginalisation and alienation over the past two centuries on the contemporary social, economic, cultural and political circumstances of Koorie people.

Secondly, there is the matter of the historical experience of Koorie communities with the research community of non-Aboriginal Australia. These experiences and the relationships established have, in many cases, been structured through the colonial metaphor in which Koories became the objects of research projects over which they had no control other than to choose whether to accept or reject the overtures of the researchers. In the past, the power imbalance between the white and black communities of Australia has meant that outright rejection was never a viable option. Consequently, Koories have been subjected to highly intrusive, exploitative and eurocentric research which has reinforced the ideologies of colonial Australia. This research has not served the interests of Koorie communities through critical understanding of their socio-political circumstances; it has however, served to build academic reputations within the research community and universities.

The researcher for non-Koories will be informed by an acknowledgment and understanding of the above ethical matters. How does one move forward in the field of Koorie research without repeating the past exploitation of Koorie communities, but now under the rubric of empowerment and self-determination?

How does one balance personal and professional interests through research without putting at risk one’s commitment to supporting Koorie community cultural and socio-political aspirations?

(c) Koorie Research Committee

The Institute of Koorie Education seeks to establish the conditions under which the conduct of exemplary, cultural appropriate, non-invasive, non-exploitative and empowering Koorie research becomes a reality within the University. It is proposed that a Koorie research committee be established by the Board of the Institute of Koorie Education to advise and assist researchers, and to evaluate the appropriateness and acceptability of Koorie research proposals within the ethical framework discussed under (a) and (b) above. This committee would work closely with the University’s Ethics Committee advising that committee on all projects involving Koorie persons, families, clan or communities\(^2\).

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\(^1\) Refer to the Appendix to this document for explanatory notes and amplification.

\(^2\) The Institute of Koorie Education advises the University that the concept of ‘Koorie Community’ has a clear, though fluid definition within this document. The definition is one acceptable to Koorie members of the Board of the Institute. Community is a collective of Koorie families with shared cultural, social, economic and political interests. For certain purposes communities may come together into larger wholes. It is therefore appropriate to refer to local communities, regional communities and state or territory communities without contradiction. Individual Koories are, for the purposes of this document, members of communities. Koorie research projects involving this University intersect with the lives of Koories through association with their communities whether, local, regional, or state and territory. The position the Institute of Koorie Education is advancing through this document is that the University should become involved in Koorie research when Koorie communities, identified by Koorie participants themselves, seek to be partners in research projects with the University.
4. Protocol Matters in Koorie Research

The ethical issues in research generally, and in Koorie research specifically, provide a set of reference points for establishing appropriate protocols for Koorie research. The protocols for Koorie research are statements of the transactions between the researchers and the associated Koorie community. These transactions become the procedural guidelines for enacting research projects. Procedural guidelines are considered under headings which mark the general stages in a sequential unfolding of an idealised research project.

(a) Consultation and Establishing Projects

The ‘birth’ of projects in Koorie research is a crucial stage in the determination of their essential form and direction. Projects ‘invented’ by outsiders to Koorie communities and their sphere of intellectual and political activity will have a diminished probability of meeting the criteria of appropriateness and acceptability as judged by the Koorie Research Committee of the Institute of Koorie Education. The issue here is that of a research agenda being imposed upon the Koorie Community and coopting the community’s interests to serve primarily the interests of the researcher.

Community and coopting the community’s interests to serve primarily the interests of the researcher.

The problem is that the act of formulating a research proposal independently of the Koorie community participants and then presenting the polished proposal to community participants, has the effect of disempowering these participants from the outset. Through this all too conventional and usually bureaucratically driven strategy, the Koorie participants are placed in the invidious position of, at best, tinkering with something that carries the authority of the academic institution and its eurocentric cultural form. By this strategy there is an imbalance in the contribution level of the Koorie participants built into of the project from the beginning, and the research becomes structured through non-Koorie cultural perspectives and practices.

Koorie research proposals are always presented with the good intention of benefiting community interests. As argued above, this claim has so often been unfulfilled in the past. The expression of good intentions is a necessary but insufficient condition for participation in Koorie research.

The key concept associated with empowering Koorie research is community consultation and participation. But, once again, it is necessary to be cautious about researcher claims to have consulted fully with relevant community people. The Institute of Koorie Education endorses the principle of Koorie self-determination as fundamental to the consultation/negotiation process in Koorie research. This principle is translated into the enacting principles of joint authority and joint management over the development, implementation and evaluation of Koorie research projects approved by the Institute’s Koorie Research Committee. As with the development of Koorie education initiatives within the University, the application of these principles to Koorie research will include the research program of the Institute under the Higher Education Agreement between the University and the Victorian Aboriginal Education Association Inc.

In order to weaken the possibility of a primarily University-centred agenda being imposed onto Koorie communities through Koorie research projects, the Koorie Research Committee will favour Koorie research projects established jointly by the University and communities. Joint research projects are those developed from a synthesis of concerns and interests of the Koorie community made known to the University and the research interests of the University academic community. The Institute of Koorie Education will function as a research ‘consultancy or broker’ between Koorie communities and its affiliated University academic staff. Research projects will be formulated out of this consultancy relationship and the close and detailed consultation and negotiation entailed.

In addition, it is the Koorie Research Committee’s view that consultation in Koorie research is an ongoing process throughout the life of any project. The principles of joint authority and joint
management mean that community consent may be withdrawn at any point in the life of a project if the contracted commitments of the researchers are not being satisfactorily adhered to. Relevant to ongoing community consultation is the commitment to appropriate and full communication.

Communication in the context of Koorie research requires that communities must be provided with all relevant information and explanations of any research proposal including the intent, methodology, evaluation and potential use. This information must be comprehensible to the community involved and researchers must also comply with any request from relevant community organisations for further information. These obligations remain for the duration of any research project.

Consultation requires researchers to respect community processes of decision-making allowing sufficient lead-time for communities to consider proposals. In addressing this requirement, researchers must ensure that they do not act in a pre-emptive manner nor seek access to community sub-groups or individuals without respect for cultural protocols.

(b) Community Involvement in Research Projects and Implementation of Research

Clearly, community involvement with Koorie research projects is to be beyond the level of objects to be researched. Koorie research projects will as a matter of definition involve Koorie community participants. This is the case even with historically focused projects. The issue here is the status of Koorie community participants within the work of the projects. A further level of community involvement to be considered is that of employing Koorie research assistants from communities in which projects are located. The position adopted by the Institute of Koorie Education is that these levels of involvement for community members are limited, minimalist, and therefore may well be insufficient as safeguards for the ethical matters raised earlier.

The Koorie Research Committee adopts the view that Koorie community involvement in the conduct of Koorie research should be beyond the minimalist circumstances above. As already stated, equity in Koorie research requires the involvement of Koorie researchers as full and equal members of research teams. Research are those members of a research team involved in decisions over research design, in the conduct of the research, and, importantly, in the theoretical, conceptual and publishing work of the project. The Koorie Research Committee endorses the condition that Koorie research involves Koorie researchers. But the issue of appropriate levels of Koorie community involvement is not resolved by the inclusion of Koorie researchers in project teams.

Koorie researchers may be from different communities to those participating in the research. When Koorie researchers are from the participating communities, research colleagues may assume to Koorie researchers a position of authority over community matters where only limited cultural rights for making decisions affecting the community exist for individual people. There is also the issue of Koorie researchers’ authority status in their communities based on age and gender. The status a Koorie researcher has amongst project team members may not be equivalent to that person’s status in the community.

The Koorie Research Committee adopts the view that Koorie community involvement in the conduct of Koorie research is to be formalised through the identification of an existing Koorie organisation as the Koorie community’s designated consultative Koorie organisation to the research project. These designated organisations will function as advisory groups and mentor to groups to research teams involved in Koorie research.

Proposals for Koorie research will be expected to indicate the form and the timing of community involvement structured through the designated consultative Koorie organisations in the conduct of the research.
(c) Ownership and Publication of Research Data

This is the area of Koorie research about which Koories are particularly wary and sensitive. Researchers have, in the past, typically violated Koorie communities’ sense of ownership over cultural property through their personal and individualistic appropriation, reconstruction and publication of knowledge shared. This practice has been very damaging to the continuity and practice of Koorie cultures and has also served to increase feelings of powerless and oppression amongst individual Koories.

The issue of ownership and publication of data are sensitive matters for the universities also. Universities of a western liberal tradition guard jealously their freedom to undertake intellectual work and to report to outcomes of such work relatively unencumbered by external restrictions. Deakin University belongs to this great tradition.

The Institute of Koorie Education seeks to map a pathway of reasonable practice in this area of data ownership and publication. There are already precedents, although some may claim unfortunate ones, whereby caveats on the ownership and publication of research data exist. Aside from the laws covering misrepresentation and libel, caveats have been placed on the data resulting from research sponsored by particular agencies, including governments. The point to be made from these precedents is that Koorie communities may not be seeking caveats over the ownership and publication of research data in excess of what, for some existing non-Koorie research, is already routine practice.

The Koorie Research Committee adopts the view that the issues of data ownership and publication are matters that must be included in the formulation stage of a research project. Negotiations and agreements will be reached between the research team and the participating Koorie community at this formulation stage. Included will be agreements over ownership of data, rights of publication of research outcomes, and specific embargoes.

In order to put in place a uniform base position on this potentially contentious issue from which research teams and Koorie communities can negotiate the specific conditions for individual projects, the Institute of Koorie Education adopts the following set of principles. All Koorie research projects should begin from the assumption that:

- Research material and data will remain the property of the Koorie community concerned;
- Projects may be conducted according to principles negotiated and agreed with Koorie communities at the outset;
- Prior to the publication of research data or reports, the approval of the publication texts by the relevant designated consultative Koorie organisation is required;
- Publication of the research data will include details of the joint University/community context of the research and the role of the Koorie community in formulating the direction and work of the project;
- In preparing acknowledgments, the proper accreditation of participation and assistance of Koorie communities, individuals and organisations will be noted;
- Results of research will not be published in a form that permits the identification of individuals without their consent;
- Data will not be used for any purpose other than that for which consent was gained unless further permission is given by the relevant designated consultative Koorie organisation; and,
- The return, storage or destruction of data will be negotiated with the relevant designated consultative Koorie organisation before data collection begins and again at the completion of the data collection phase of projects.
Negotiation agreements between designated consultative Koorie organisations and research teams over the ownership and publication of research data will be lodged with the finalised research contracts to be filed by the Koorie Committee of the Institute.

(d) Post-Research Obligations of Research Teams

Researchers entering into a research relationship with Koorie communities must be mindful of their continuing obligations to those communities. These obligations require researchers to be respectful of the trust Koorie community participants have placed in them. This trust has been given by people who have been, and continue to be, vulnerable to oppressive forces in Australia usually not fully appreciated by non-Koorie university academics.

As an expression of reciprocity to the trust given, researchers will be expected, at the very least, to:

• Return to communities information based on the joint research projects and inform community members fully of the research outcomes in formats and language appropriate to the communities involved with the research projects; and.
• Should the media solicit comments from researchers once the work of their joint projects are in the public arena, researchers should first seek consent of the communities concerned. Media comments should be sensitive and restricted to the research issues of the projects.

(e) Research Project Budgets and Employment

In the development of the final submission for a research project the development of the project budget will be a joint enterprise involving the Research Team and the designated consultative Koorie organisation. This will be done after the designated consultative Koorie organisation members have full access and knowledge to the budget and funding guidelines for the proposed research.

Community resources must not be used for the research project without prior agreements. Costs to be incurred, or incurred, by the community or by members of the community from the conduct of research projects must be built into the budget submission.

Koories working in research projects will be employed under the University's awards system. Contracts of employment when agreed upon must be accompanied by evidence of the employee's understanding of the contract and agreement.

5. Methodological Matters in Koorie Research

The research methodologies applicable to Koorie research would need to be compatible with the ethical and protocol issues raised in the above sections. In addition, the methodologies must be appropriate for meeting both the Koorie community needs being addressed by the research, and the intellectual requirements of the University in terms of theory development and conceptualisation.

As an important element of its research program, the Institute of Koorie Education seeks to develop Koorie research methodologies. The Institute recognises that Koorie research methodologies will become established as researchers adapt their projects to the multiple, and, perhaps at times, seemingly contradictory agenda of this new field. Koorie research methodology development will undoubtedly draw on the insights becoming available from the research on research being carried out by other marginalised and oppressed sections within western society. Relevant to this discussion are the publications of poststructuralists, post modernists, feminist researchers and the recent developments and critiques of participatory social action research and critical theory.
The key methodological issues for the Institute at this stage in the establishment of its research program are:

- Of proposed research methodologies associated with Koorie research, which ones seem to provide the potential to meet the ethical and protocol criteria of the field?
- What are the features of those research methodologies that diminish the ‘power over’ element of the research experience for Koorie participants?
- What are the features of those research methodologies that enhance the prospects of Koorie realities being taken seriously by the research project?
- Are these research methodologies that contain elements of organisation, procedure, data collection, analysis and interpretation, and reporting that show a potential to be assimilated into the Koorie cultural tradition?

Developments in Koorie research methodology will be through the endorsement of Koorie research projects by the Koorie Research Committee of the Institute. Endorsement will be given to those projects with methodologies from which the Koorie Research Committee believes answers to these key methodological issues may be forthcoming.

This research methodology development strategy relies heavily on monitoring, reviewing and evaluating Koorie research projects undertaken by researchers and Koorie communities under the auspices of the Institute of Koorie Education. This will be the meta-research project of the Institute in Koorie Research.

6. A summary of the Process to assist Koorie Research at Deakin University through the Institute of Koorie Education

[Diagram of the research process]

- Koorie Community: Researchable issue(s) identified, Research Consultancy sought, Koorie organisation designated as the consultative organisation for the Research Project
- Deakin University: Institute of Koorie Education, Koorie Research Committee, Consultancy Offered, Research Team Identified

Joint Research Project Proposal Development
Project Agreement Negotiated

Project Approval
Monitoring and Review
Publication of texts Approval Process
Publication
Post-Research Obligations

Project Evaluation
7. Research Project Submission and Approval Procedure

The above discussion of Koorie Research to be conducted within the University under the auspices of the Institute of Koorie Education leads to the following procedure for the submission and approval of projects.

(i) All research proposers, whether Koorie community-based or University-based will consult with the Director of the Institute of Koorie Education and the Chair of the Institute's Koorie Research Committee prior to the submission of an interim project proposal.

(ii) Upon the advice of the Director of the Institute of Koorie Education and the Chair of the Institute's Koorie Research Committee, the Koorie Research Committee will either recommend or not recommend that the proposed research be conducted under the auspices of the Institute.

(iii) Proposers of interim proposals not recommended may be advised to resubmit according to guidelines set down by the Koorie Research Committee.

Proposers of recommended interim proposals will be advised and supported by the Koorie Committee in establishing a Joint Research Project Proposal Development Team consisting of members of the to-be-involved community(ies) [the designated consultative Koorie organisation] and members of the University [the Research Team]

(iv) The joint Research Project Proposal Development Team will develop the full research proposal according to the guidelines for Koorie Research of the Institute of Koorie Education

(v) The full proposal will be submitted to:

- The relevant Koorie community organisation(s) via the designated consultative Koorie organisation for approval, and
- The Koorie Research Committee of the Institute of Koorie Education via the Research Team for recommendation to the Board of the Institute.

(vi) Upon receiving approval from the relevant Koorie community organisation(s) and the Board of the Institute of Koorie Education, the proposal will be an approved research project to be conducted under the auspices of the Institute of Koorie Education. The approved research project may then be submitted for further approval to other relevant bodies internal and external to the University if required.

(vii) Approved research projects will have provision for on-going monitoring and review by the Koorie Research Committee and the relevant designated consultative Koorie organisation. Progress reports will be submitted to these bodies according to a format and frequency negotiated during the project approval process.

(viii) Approved research projects will include provision for negotiated release of research findings for publication. The negotiated release provision will involve both the Koorie Research Committee and the relevant designated consultative Koorie organisation.

(ix) Approved research projects will include an agreement by the Koorie Research Team to be evaluated fully and publicly by the Koorie Research Committee.

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3 Post-graduate students seeking to undertake research topics in Koorie affairs will be accommodated within the general procedures for Koorie research project submission and approval. Projects involving students as researchers will be drawn from existing projects for which approval has been granted. The existing approved projects will be larger host projects within which student projects will become a smaller topic. Students' research supervisors will be affiliated with the Institute of Koorie education and will direct students to research topics for which Koorie community support exists. Approval for students' projects, as part of larger ongoing approved research projects, will be expedited through the Research Committee of the Institute and the designated consultative Koorie organisations. Students' research will be monitored as an aspect of the larger host projects.
References

In the preparation of this document ideas from the following papers were taken up.

Australian Institute of Aboriginal and Torres Strait Islander Studies, Research Grants: Information and conditions for Applicants, Canberra, 1990.


National Health and Medical Research Council, Guidelines on Ethical Matters in Aboriginal and Torres Strait Islander Research, Canberra, 1991.

The Koori Centre, The University of Sydney Aboriginal Education Centre, Principles and Procedures for the Conduct of Research, University of Sydney, 1992.

APPENDIX

Cross-Cultural Sensitivity and Koorie Cultural Practices: Explanatory Notes

As stated in the body of the document, a domain of ethical matters for non-Koorie researchers involved in Koorie research centres on researcher cross-cultural sensitivity; the preparedness of the researcher to honour culturally different values, needs, practices and perspectives. Cross-cultural sensitivity in Koorie research for non-Koories typically involves a decentering from cultural perspectives associated with being a member of a dominant and all pervasive culture in which ‘to be like me’ is taken for granted as the acceptable and respectable way of expressing one’s humanity. Non-Koorie researchers are, by their educational experiences, schooling, socialisation and status, usually successful adherents of the dominant culture of their country. They are likely to be more ethnocentric in practice than they may be prepared to admit. Thus for non-Koorie Australians, cross-cultural sensitivity in Koorie research will require a process of cultural decentering from the dominant, all pervasive Anglo-Celtic Australian cultural tradition: for others, this cultural decentering will be from, for example, European, North American or Asian cultural frames of reference.

Cross-cultural sensitivity, and the associated cultural decentering process, requires of non-Koorie researchers a preparedness to undergo a highly personalised form of learning. One does not become ‘decentred’ without becoming involved in cross-cultural interactions in which one’s social security, demeanour, self-assurance, and let it be said, manipulative power, drawn from years of social intercourse based on refined knowledge of an accustomed set of cultural rules and etiquette, is put at risk. If non-Koorie researchers are not prepared to embark on this form of learning, with its attendant potential for some social embarrassment and, perhaps a measure of mild humiliation, and its inherent struggles to understand ‘perplexing’ social behaviours based on a different cultural logic while resisting ‘plausible’ ethnocentrically-based explanations, then their involvement in Koorie research must be questioned.

Cross-cultural sensitivity is essentially an attitude and orientation to cultural difference through which one attempts to be respectful of cultural ways not shared and to understand the significance of these initially ‘foreign’ ways in the lives of others.

Cross-cultural sensitivity becomes an issue of importance in community interactions when there exists a power imbalance between the communities involved. In Koorie research, non-Koorie researchers will, unavoidably, be representatives of the more powerful community. Cross-cultural sensitivity for non-Koorie researchers means attempting to shift the power imbalance.
conventionally structured into non-Koorie/Koorie relationships in a direction which facilitates an empowerment of Koorie participants involved in these relationships. Non-Koories may feel ‘uncomfortable’ or anxious when relationships between themselves and people with whom one has only ever had social interactions (even if only vicariously) as a cultural oppressor begin to be defined more equitably. When Koories respond to non-Koories in these situations ‘imputing’ meanings that were never ‘intended’ then one’s commitment to becoming cross-culturally sensitive is being put to the test. These are crucial learning moments for non-Koories. These are the opportunities from which to take up the challenge of cultural decentering and to begin to understand how the cultural domination and marginalisation of Koorie communities can be maintained through well meaning and generous non-Koories behaving ‘normally’.

A short, and clearly incomplete, list of Koorie cultural practices is included on page 40 of this report as examplars of practices researchers will be required to respect in Koorie research.
The Institute of Koorie Education included these significant though selected cultural practices as a starting point for non-Koories naive to the Indigenous cultures of Australia. Those non-Koorie researchers prepared to embark on the learning required to become cross-culturally sensitive in circumstances involving Koorie communities will embark on a life-long program of coming to appreciate the cultural practices listed and many more besides. This program of cultural decentering, vital to constructive participation in Koorie research, will be built upon personal relationships with Koorie individuals and their families.

For particular Koorie research projects, the Koorie Research Committee of the Institute of Koorie Education, in negotiating with potential members of the research team, may deem it necessary for interested non-Koorie researchers to attend a Koorie cultural awareness program as part of their preparation for involvement in the project itself. These cultural awareness programs would be a service to the University offered by the Institute.
APPENDIX THREE

MEMORANDUM OF UNDERSTANDING
Between the Department of Rural Heath, University of Melbourne
And Rumbalara Football Netball Club
For the period 6/7/2000 - 5/7/2001

1. Scope
This Memorandum of Understanding sets out the aims to be pursued through placements and programs to be agreed upon by the Department of Rural Health (DRH) and the Rumbalara Football Netball Club (RFNC).

The primary purpose is to:
• Enable the RFNC and DRH evaluate the Healthy Lifestyles Program.
• Enable the RFNC and DRH undertake joint educational, research and health intervention programs as defined by need and demand. A broad definition of health is taken and understood to include social justice, leadership and other issues considered to be determinants of health in the Koorie community.
• Enable agreed placements of students through the DRH within the RFNC

The RFNC will enable the DRH to access all material appropriate to the Healthy Lifestyle Program and related activities in the custody of the RFNC under the terms of this memorandum.

The DRH will assist and support the RFNC in undertaking health surveys among those associated with the club.

The RFNC and the DRH agree to work closely together to enhance health outcomes for the Koorie community as identified by the RFNC, through culturally sensitive research, education and evaluation.

This Memorandum of Understanding is not intended to be a legal agreement but is a statement only of the parties’ understanding of the parties’ aims. The placement and programs contemplated by this Memorandum of Understanding are subject to a formal contract being entered into between the parties.

The Koorie community will have access to the expertise of the DRH in health related areas. Where necessary, joint proposals will be generated to resource required activities.

Research and evaluation undertaken will usually result in publication, the content of which must be agreed to by both the RFNC and DRH.

Data and materials will be stored in a site jointly agreed by RFNC and DRH prior to commencing each individual activity/project. Such a site must ensure both privacy and security for the community and those involved.
Aims of the RFNC

The RFNC is the only Aboriginal football and Netball club in Victoria and one of only a few in Australia. The RFNC would arguably be the largest Indigenous sporting Club in Australia. The club was established in 1972 and accepted into the Goulburn Valley Football League in 1997. The Club is followed weekly by a support base of approximately 500 people, directly influencing the 6,000 Aboriginal people in the Goulburn Valley and having an indirect impact on approximately 30,000-40,000 Koories in Victoria and lower NSW. The club is also having a significant impact on the broader community sporting fraternities of northern Victoria. The Club’s vision is to build on the community’s passion for sport to get people involved in a broad range of activities that promote health and emotional and spiritual well-being.

The RFNC is able to access and promote physical fitness among large numbers of the Koorie community through teams, members and supporters. Therefore the Club provides an excellent home base for the delivery of the Healthy Lifestyle Program (HLP).

The RFNC aims:

• To continue to build on and develop the HLP, addressing community based issues in sport, which impact on health. These include food and nutrition, substance misuse, community relations, racism, leadership, reconciliation, job creation and education.

• To address the health, well-being and future aspirations of young Koorie people in Local community by providing quality information, education, positive role models and encouragement to meet their potential.

• To ensure that the RFNC is an established and secure part of the ongoing existence of the Koorie community in Shepparton.

• To continue to achieve and strive to excel as a sporting club, which is community based and community controlled.

• To continue to contribute to health and well-being of the Koorie community, and the overall community in the wider Shepparton area.

• To specifically develop the role of the RFNC in providing information, advice and support to other Indigenous sporting clubs, community groups and organisations.

• To provide cultural awareness information and education to mainstream sporting clubs and bodies and health agencies.

Aims of the Department of Rural Health

To catalyse and contribute to the demonstrable elimination of the differential in health status between Koorie and non-Koorie, and between rural and urban people by:

• Undertaking Research, Education and Evaluation and

• stimulating and supporting

• Community development

• Community action

• Health promotion

• Service integration

• Rural and Indigenous health workforce development

• Delivery of quality health care
2. Guiding Principles

2.1 Recognition of Yorta Yorta Nations as the Traditional Custodians
2.2 Mutual respect for the mission and goals of each organisation.
2.3 The Koorie community through the RFNC will request community control of all research and evaluation undertaken by the Department of Rural Health for and of behalf of the RFNC.
2.4 The DRH recognises the social and cultural expertise of the RFNC.
2.5 The RFNC recognise the research and academic expertise of the DRH.
2.6 Recognition that adequate support is needed to facilitate the maximum input from Koorie communities.

3. Definitions

“Koorie people” means Aboriginal people from South East Australia.
“Koorie related material” includes information about Koorie people in records held by the RFNC and Department of Rural Health.

4. Provision of personal photocopies of relevant material

Fees for photocopying requested by Koorie people (or their accredited agents) under this memorandum shall be waived by the RFNC. This arrangement will be monitored to assess its impact on the workload and resources of the RFNC and will be reviewed annually.

Individuals who obtain photocopies of material accessed under this memorandum acknowledge that it is their responsibility to safeguard the privacy of third party personal information contained in those copies.

The photocopying of any Koorie related material requested shall only be undertaken by the RFNC.

5. Dispute Resolution

In the event of a dispute, both parties will agree to mediation for conflict resolution. An external person who is acceptable to both parties may provide mediation.

6. Termination of Agreement

If a mediated outcome cannot be reached, or in the event that either party wishes to terminate the arrangement, this can be done by providing the other party with 30 days notice in writing.

Paul Briggs
President
Rumbalara Football Netball Club

Professor David Simmons
Head of Department
Department of Rural Health