We don’t like research...
But in Koori hands it could make a difference

VicHealth Koori Health Research and Community Development Unit
Introduction

This is a report of our first Community workshop, which was called ‘We Don’t Like Research – But in Koori Hands it Could Make a Difference’. This workshop was conducted in co-operation with the VACCHO, the Department of Rural Health (University of Melbourne, Shepparton) and the Rumbalara Aboriginal Co-operative (Shepparton) in November 1999. We would like to thank a number of people in the Community, Aunty Melva Johnson, Paul Briggs, Jan Muir, Rick Henderson and all the speakers.

We felt that many people in the Community would be interested in the talks that were given at the workshop. Workshop participants also contributed to a great deal of discussion and made suggestions about ways to increase Koori involvement in and control of health research. This has been summarised and 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 ways of improving health research practice for the Koori Community.

This is our first Community report. We hope you enjoy it and find it useful. Our next Community report will be about our second workshop, ‘Research – Understanding Ethics’, which was held in June 2000.
## CONTENTS

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>WHO WAS AT THE WORKSHOP</td>
<td>4</td>
</tr>
<tr>
<td>BACKGROUND</td>
<td>5</td>
</tr>
<tr>
<td>THE DAY’S AGENDA</td>
<td>6</td>
</tr>
<tr>
<td>WELCOME TO COUNTRY</td>
<td>7</td>
</tr>
<tr>
<td>THE MORNING SESSION: INTRODUCTIONS AND SMALL GROUP WORK</td>
<td>8</td>
</tr>
<tr>
<td>Justin Mohamed: Rumbalara Aboriginal Co-operative, Shepparton</td>
<td>9</td>
</tr>
<tr>
<td>Ian Anderson: VicHealth Koori Health Research and Community Development Unit, University of Melbourne</td>
<td>10</td>
</tr>
<tr>
<td>Small Group Work</td>
<td>11</td>
</tr>
<tr>
<td>THE MID-MORNING SESSION: STORIES OF Koori Community-Initiated Projects</td>
<td>12</td>
</tr>
<tr>
<td>Health Outcomes Agreements - Raelene Fennell</td>
<td>13</td>
</tr>
<tr>
<td>The Young People's Project - Paul Stewart</td>
<td>15</td>
</tr>
<tr>
<td>THE AFTERNOON SESSION: MORE STORIES OF Koori Community-Initiated Projects</td>
<td>16</td>
</tr>
<tr>
<td>The Well Persons' Health Check - Bev Greet</td>
<td>17</td>
</tr>
<tr>
<td>Ethics: What Do We Mean and What is Acceptable? - Salina Bernard</td>
<td>19</td>
</tr>
<tr>
<td>THE LATE AFTERNOON SESSION: SMALL GROUP REPORT-BACK AND PANEL DISCUSSION</td>
<td>21</td>
</tr>
<tr>
<td>Small Group Report-Back</td>
<td>21</td>
</tr>
<tr>
<td>Panel Discussion</td>
<td>27</td>
</tr>
<tr>
<td>Conclusion</td>
<td>28</td>
</tr>
<tr>
<td>WORKSHOP EVALUATION</td>
<td>29</td>
</tr>
<tr>
<td>ABBREVIATIONS</td>
<td>31</td>
</tr>
<tr>
<td>REFERENCES</td>
<td>32</td>
</tr>
</tbody>
</table>
Who was at the Workshop

Jenny Alford  Dja Dja Wrung Aboriginal Co-operative, Bendigo
Graham Atkinson  Yuruga Enterprises Pty Ltd, Melbourne
Neville Atkinson  Rumbalara Football/Netball Club, Shepparton
Les Baksh  Rumbalara Football/Netball Club, Shepparton
Tom Baksh  Rumbalara Football/Netball Club, Shepparton
Ali Barr  VicHealth, Melbourne
Salina Bernard  VACCHO, Melbourne
Luke Burchill  University of Melbourne
Marlene Burchill  Family Preservation, Shepparton
Dorothy Campbell  VicHealth, Melbourne
Fay Carter  ACES, Melbourne
Judy Cue  Mungabareena Aboriginal Corporation, Wodonga
Raelene Fennell  Dja Dja Wrung Aboriginal Co-operative, Bendigo
Carole Fraser  Southern Health Care Network, Melbourne
Melanie Fraser  Health Services Commission, Melbourne
Anne Garrow  VAHS, Melbourne
Bev Greet  VACCHO, Melbourne
Glennis Hansen  Goulburn Valley Base Hospital, Shepparton
Rick Henderson  Department of Rural Health, Shepparton
Lyn Maher  Community Options, Shepparton
Karen McMillan  Mungabareena Aboriginal Corporation, Wodonga
Luke Murray  Centre for Indigenous Education, University of Melbourne
Michael Murray  VAHS, Melbourne
Jacqui Randall  VicHealth, Melbourne
Gill Rea  Institute of Koorie Education, Geelong
Dick Soman  VAHS, Melbourne
Rosie Smith  Aboriginal Health Service, Hobart
Paul Stewart  VAHS, Melbourne
Alistair Thorpe  VAHS, Melbourne
Alma Thorpe  RUIMHER, Melbourne
Kate Torpey  Institute of Koorie Education, Geelong
Marc Williams  VACCHO, Melbourne
Anke van der Sterren  VAHS, Melbourne

And from the VicHealth Koori Health Research and Community Development Unit

Ian Anderson
Angela Clarke
Kim Humphery
Asmira Korajkic
Linda Lethbridge
Michael Otim
Lisa Rasmussen

Apologies

Vicki Briggs  Anti-Cancer Council, Melbourne
Ron James  Koori Health Unit, Department of Human Services, Melbourne
Melva Johnson  Echuca Health House
Barb McEwan  Koori Hospital Liaison Officer, Bendigo
Robynann Morgan  OATSIH, Melbourne
Phil Morrissey  University of Melbourne
Jenny Muir  Koori Hospital Liaison Officer, Ballarat
Ralph White  Sport and Recreation, Melbourne
Joan Vickery  Koori Diabetes Service, Melbourne
Background
The workshop was held at the Rumbalara Aboriginal Co-operative in Shepparton, Victoria on 24 November 1999. About 40 people attended. Rumbalara was a great place to have the workshop. This was a day for Koori researchers to present and discuss their work and/or involvement in research activities and for others to voice their concerns about research itself. Both Community Elders and young Community members spoke of their experiences and offered opinions.

Goals of the Workshop
• Look at and listen to the Koori Community’s concerns about research
• Look at the barriers to Community control in health research
• Look at things that would facilitate Community control in health research
• Look at strategies that would strengthen Community participation in and control of health research

As Ian Anderson said in explaining the purpose of the workshop:
Today was an outcome of some discussions that we at the VicHealth Koori Health Research and Community Development Unit in Melbourne have been having with the Department of Rural Health, up here in Shepparton. We have been talking about involving the Koori Community in research, and about assisting the Community to take control of research in the area of health. One of the things that we thought would be very important to do was to start to listen to some of the stories of people who have had experience over the last five to ten years in research and evaluation initiatives. We thought it would be valuable to talk about some of the benefits of Koori involvement in research, as well as some of the risks and dangers.

In line with this emphasis on listening to the stories of others and sharing ideas about how to increase Koori involvement in and control of research, the workshop was designed to be both informative and productive. The day’s activities thus included individual presentations, question and answer sessions, group activities and a panel discussion, with ‘time out’ for more informal discussion over tea, lunch and an end of day BBQ. This mixture of seminars, group activities and socialising worked well – although it proved to be a long day!
The Day’s Agenda

Traditional Welcome
Aunty Liz Hoffman

Introductions
Justin Mohamed - Rumbalara Aboriginal Co-operative
Ian Anderson - VicHealth Koori Health Research and Community Development Unit

Small Group Work – Learning from the past
Why don’t we like research? What are the good and bad things that have made it possible for Community controlled health research?

BREAK

Stories of Koori Community-Initiated Projects
Health Outcomes Agreements - Raelene Fennell
The Young People’s Project - Paul Stewart

LUNCH

More Stories of Koori Community-Initiated Projects
The Well Persons’ Health Check - Bev Greet
Ethics: What do we mean and what is acceptable? - Salina Bernard

BREAK

Small Group Report-Back – Learning from our experiences
How do we build Koori Community ownership of research? What are the barriers to this occurring? What skills broadly need developing?

Panel Discussion – Where to from here?
Aunty Alma Thorpe and Ian Anderson

BBQ
Welcome to Country

Aunty Liz Hoffman

It's a pleasure to be here and to see some familiar faces and to welcome you to our land, the Yorta Yorta land. We now make this welcome a process, in order to make people aware of the land that you are on.

What you are doing about health is very important, number one or number two after the land research that we have been involved in over the past three years. So I want to welcome youse all here and to just explain how we, as Aboriginal people, have suffered in the past, particularly with health.

It was never done right for Aboriginal people right from the beginning. So, here, we have got ourselves researchers to make an effort to correct some of the things that have been done in the past. What we have been doing also is trying to correct some of the issues to do with Aboriginal health which is number one in this Community, in the Aboriginal Community, because we are losing too many people. I lived on Cummeragunja, and I am back there again at the moment living on Cummera trying to correct the health situation as well as look after the land. And one of the things I think that this can achieve, and we are hoping to achieve, is that it will correct a lot of the problems and the faults that were made in the past.

Welcome, and all the best in your endeavours to continue your research. Thank you.
The Moming Session: Introductions and Small Group Work

Justin Mohamed, the Administrator of the Rumbalara Aboriginal Co-operative, presented the first talk of the day. Justin joined in welcoming everyone to Rumbalara and spoke about the involvement of the Co-operative in research activities. This was followed by Ian Anderson speaking about the establishment and role of the VicHealth Koori Health Research and Community Development Unit within the University of Melbourne.

Following Ian’s talk the workshop broke up into small groups in order to discuss the history of health research in the Koori Community over the last three decades and to construct a ‘History Wall’ of key events and research issues. This small group work was designed to collectively identify Koori attitudes to research and some of the areas of health research in which Kooris had taken control over the last 30 years. Groups were asked to identify the positives and negatives of research and suggest both barriers and possible strategies to increasing Community control of research activity. Each group used butchers paper and texta to list these attitudes, the positives and negatives, barriers and strategies. Later in the day, the sheets were placed up around the room and members of each group talked through the themes identified.
Justin Mohamed: Administrator, Rumbalara Aboriginal Co-operative, Shepparton

I would like to welcome everyone here today. When I heard that this workshop was going to be held at Rumbalara I was very excited because Rumbalara Aboriginal Co-operative has been involved in research projects from a number of different areas but mainly around health. Also with regards to the Department of Rural Health, we have been very much involved in the establishment, the beginning of the idea, of having a Department of Rural Health in Shepparton - and Rumbalara was seen as a key player in the Community in having that Department placed here.

So we have been very much involved, and when the universities are involved, usually research comes hand in hand with this, and our organisation has had joint research programs with Melbourne University and other institutions and individuals. Some of them have been positive and some haven’t been so positive over the years, and that I think is what this workshop is about. What can come out of this workshop is that there is more positive research which is done for Aboriginal Communities, and I think that the way to get positive research is when you get outcomes at the end of it and the research doesn’t stay on the shelf and get left there to collect dust, but that there are outcomes for the Community which will improve health and whatever other areas there may be.

With the name ‘We don’t like research but in Koori hands it could make a difference’, that created a little bit of discussion with people I spoke to and so forth, so whoever thought of the name, it got people thinking about what research really is and who it benefits. And I think that in the past that has been a little bit of a grey area for people doing the research, which was benefiting mostly them and losing the real focus which should be that when you research a group of people in an area it really needs to benefit the people which it is designed to help, where the research is taking place.

For people who haven’t been at Rumbalara before, hopefully at lunch time, if you would like, I could get someone to show you around and see what services we provide here. We provide a range of services from health to family services, aged care, community housing, youth and community justice programs, so we have kind of got a wide range of programs. But as Aunty Liz was saying, health is our main area of work here at Rumbalara and all the other programs that have come along since then have come to complement the health of the Aboriginal Community here in the Goulburn Valley.

So, once again, I would like to thank you. I hope that you enjoy your day up here and I hope that this is a very productive workshop.
I would like to talk a little bit more about our role as the University of Melbourne. There are now three areas of work occurring within the University around Koori health and it is very exciting to see the number of Kooris actually starting to work at the University of Melbourne.

For some time, a couple of years, there has been the Resource Unit for Indigenous Mental Health Education and Research (RUIMHER) at the University, working around issues of mental health. More recently, the Department of Rural Health in Shepparton has been created and it has a brief to work collaboratively with local people, and to build educational and research initiatives. It has recently employed Jan Muir and Rick Henderson as two of the growing number of Koori workers within the Faculty of Medicine.

And in June this year the VicHealth Koori Health Research and Community Development Unit was launched. Basically what the Unit is about is firstly looking at any areas of research which we can do that will be useful in terms of improving primary health care for Kooris in Victoria. The other task that we have is to actually think about how we work to create partnerships with Communities, but partnerships that are meaningful in the sense of everyone being equal partners.

What has really shaped a lot of my thinking about this is my experience over the years, which came a lot out of the Victorian Aboriginal Health Service. When I was first a student and actually worked for a while as a health worker, I remember at that time that there was a project going on which became somewhat controversial - which involved both the Victorian Aboriginal Health Service and another health organisation. What was troubling about this project was that the researcher involved was very well-intentioned and would talk to me about those good intentions but continuously miscommunicated or did not communicate well with the Community organisations that he was working with. It resulted in a lot of people being kind of burnt in a lot of ways, and organisations were burnt as well.

Over the years, that was kind of what people would talk about as the usual experience of research - of having someone come into the Community, pinch all this information and run away, and people never hearing again about it. A lot of people were feeling really quite exploited. But it was some years later, when some of the workers at the Health Service started to get actively involved in research projects, that it started to dawn on me how important this part of our work was. In one of the projects, which Lisa Thorpe and Julie Phillips were involved in around child health promotion, I remember one of those workers actually saying to me one day that one of the benefits of the project was that it really changed her mind about what happens. She had started to realise that she had certain assumptions from the Community about bed-wetting - and the research challenged her views. I thought then, that was kind of interesting because it is a way of showing how, when you systematically look at issues and ask people and talk to people, it can challenge you and challenge your own views about the world. But the other thing that was really important about such research is that it provided a process where we could learn about what we were doing; was it working, was it good, did the Community find the way that we were delivering programs useful, are there ways that we could do better? And it was that latter thing that I thought was the most important about learning for ourselves, about developing better ways that we could deliver services and programs and doing that in a way in which we could have some control over the information and what happened to that information.

I guess it was that set of different experiences - some of them were very negative and some of them were very positive - that challenged me to think over the years about how we actually build skills, build capacities and build the ability within the Community to actually take control of some of the research. And so, when organisations such as Rumbalara or the Victorian...
Aboriginal Health Service or Dja Dja Wurrung have an idea and say, ‘Look, we think that we would like to look at an emerging issue in the Community and we think that we could use some research type methods to understand that issue a bit more’, then people should feel able to know what is required, who they could get in to do the research, and feel able to take control of that process.

So, in part today’s workshop is about trying to take more control over the research agenda. The other objective really is to provide a bit of a forum through which we can discuss issues related to Koori health research and to identify activities that will strengthen Community participation in and control of research. Some of these activities will be work that the Unit will need to do over the next few years, and some of these activities will be work that may be picked up by other organisations such as VACCHO, or even local organisations such as Rumbalara.

The idea at the end of the day is that if research and evaluation does have a place, then it has to occur in a way that Communities have control over the agenda and have control over determining the benefits of those activities. That is a really short account of my experience around research and I am sure, and know actually, that there are a lot of other experiences in the room here.

**Small Group Work**

At this point the workshop divided into small groups to discuss the history of Koori health research and Koori control of research activities. Each small group was asked to address the questions:

- How do we build Koori Community ownership of research?
- What are the barriers to this occurring?
- What skills broadly need developing?

The outcome of these discussions is reported in the final section of this report.
The Mid-Morning Session: Stories of Koori Community-Initiated Projects

Following morning tea, the workshop came together once again as a larger group and heard two talks about projects in Koori Community organisations. In this session, Raelene Fennell, the Health Promotion Co-ordinator at the Dja Dja Wrung Aboriginal Co-operative in Bendigo, spoke about researching and implementing the Dja Dja Wrung Health Outcomes Agreement and outlined some of the issues arising from this process. Paul Stewart, from the Victorian Aboriginal Health Service in Melbourne, then spoke about the ‘Young People’s Project’, a Koori controlled research project on the health and well-being of young Kooris aged between 12 and 25. People at the workshop showed a lot of interest in these presentations and each talk was followed by a short time for questions and discussion.
I am not from Bendigo but I have been living in Bendigo for the past twenty-seven to thirty years. I am the Health Promotion Coordinator at Dja Dja Wrung and have been employed there for just over twelve months. I will talk on a project that I have been involved in as part of my employment - and this project was to do with the Health Outcomes Agreement at Dja Dja Wrung.

When the Co-op at Dja Dja Wrung was opened they did talk about a health service but that hasn’t happened until recently - as a result of the Health Outcomes Agreement that I have been working on.

I’m not sure if people know what a Health Outcomes Agreement is, so I will give you a little bit of history. The Health Outcomes Agreement comes from a document called Achieving Improved Aboriginal Health Outcomes that was released in 1997. One of the principles that this document did take into account was that improving health for Aboriginal people can only be achieved when Aboriginal people and organisations are empowered to act on their own behalf, and that Aboriginal health services should have the resources that are available.

Health Outcomes Agreements have three major functions:

- to contribute to the implementation of the Koori Health Reform Strategy in Victoria;
- to provide a framework in which the Aboriginal health services appointed by regional departments of Human Services can involve mainstream agencies in developing agreed strategies for meeting the needs of Aboriginal people; and
- to set out funding arrangements for individual Aboriginal health services.

A funding arrangement is an arrangement that is negotiated, and these funding arrangements will contribute to rationalising and simplifying separate service agreements with Commonwealth and State Government Departments. The main thing was that a Health Outcomes Agreement would be used in the negotiation of service agreements between the Department and mainstream services.

Now, I will briefly go into the process of how we got to where we are today. This is my story about what I have been involved in. Some research that was done in Bendigo resulted in a report called the Health Needs Analysis. Marc Williams put that report together and he was employed at Dja Dja Wrung and worked in conjunction with the Department of Human Services. He did a survey of our local Community in Bendigo, and that covered Castlemaine, Heathcote and Maryborough. Marc put out a survey of questions in December 1997 and people were asked to fill out that survey. The answers highlighted what our health needs were.

The findings that came out of the Health Needs Analysis related to access to primary health care services and some key health issues. The main concerns were respiratory diseases, diabetes, health screening, spiritual and emotional well-being, and appropriate ante-natal classes for young women. With access to primary health care, we began looking at making a GP accessible at our local Co-operative. That was one of the recommendations that came out of that research. Then there was the task of targeting agencies that we felt could deliver services from our organisation - for instance, who we were going to approach to find a GP for our service. There was also the issue of nurses for the young mums, and we were looking at other agencies we could start talking to.
So we approached five agencies: GP Divisions, Bendigo Health Care Group, Council, Loddon Mallee Women’s Health Service, and Community Health Bendigo. At first, we were unsure of how we were going to approach these agencies, but we thought we’d send them a letter and try and get representatives from each of those organisations. So we got them to a meeting in December 1998. At this meeting we were asked to show evidence for why we wanted the things we were asking for. What they instantly wanted was data. At that time, we did not have a copy of the Health Needs Analysis. So we set up another meeting and this time we made sure we had the report of the Health Needs Analysis with us, because they didn’t want to discuss anything until we had information and data to prove what we were asking for. So we handed them the report and they read through that.

I was the head of the negotiating group with these five agencies. Every time we met, we talked about what we could achieve from working together. Each of the other organisations wanted to get something out of working with us, and we wanted something from each of them. What we talked about needing for our Community came out of the Health Needs Analysis. That report backed up what we were asking for. If it was approached the right way, people from the other organisations would come back and make suggestions. It was a lot of hard work while we were doing it. We signed off on the Health Outcomes Agreement on the 30th of August 1999.

After we signed off, I thought ‘Wow, that hard work’s done’, but then we had to establish a working group to monitor our outcomes. Because we signed off for twelve months, we had to make sure that whatever we did in the next twelve months was done according to the Agreement. So we got various people on the working group who had been involved in negotiating the Agreement, to make sure that we do achieve some outcomes with it. It was important that we had Koori people on that working group, so that we are still in control and we don’t let other people take control and say how they want it to be done. Because it is our research that we did, and we know what we wanted out of it, we didn’t want anyone coming and telling us what we should have. I got to know those people and they knew where we’re coming from, so it’s become like a partnership as well.

What we got out of the Agreement was a GP for a session one day a week. We have three GPs who want to work at our Co-operative and we are going to roster it. So that is one thing we are monitoring - or just seeing how that goes. We also got two Nurse Practitioners. One is from Loddon Mallee Women’s Health, and she will be working specifically with women’s issues. Another is from Community Health Bendigo. She is really flexible and is well known in our Community, and she will be working with both males and females. We also got a Maternal and Child Health Nurse who will be working in our organisation. The hospitals will be topping up Medicare for our people for the twelve months, and we will have to re-negotiate in twelve months and just see how that goes. We are going to be monitoring the outcomes for each of these arrangements.

Because the Department of Human Services is involved in the Agreement, and have been involved in it from the start, I have had to sit down with people from the Department of Human Services and go through what targets they set for us - especially with the maternal and child health service because we don’t have a benchmark to start off with. We wanted to make sure that the targets are not set too high and that we keep things at a level that is realistic. We don’t want to commit to anything that we do not feel is achievable at this stage.

We were the first organisation in the Loddon Mallee region to sign off on a Health Outcomes Agreement. On the whole, it has been a really positive experience and a good process for our organisation to go through, and we are in what I call the ‘baby stage’ at the moment, so we can only grow!
I am employed at the Victorian Aboriginal Health Service working on a Young People’s Project. We are doing a study that looks at the health and well-being of young Kooris aged between 12 and 25. I am going to take you through the journey of actually where the Project has been and what we have achieved and what we mucked up on.

The Young People’s Project came out of an evaluation of the Child Health Promotion Project that was done in about 1994/95. A part of the Child Health Promotion Project evaluation was to go back to the Community and ask them what was the next thing we should be looking at in relation to health. And the Community came up with: young people and drug use in the Community. So we started in 1996 with collecting information from focus group discussions with a number of people, especially young Kooris who were homeless, employed, unemployed, and at school. We also interviewed key people. Those people were identified as people who had a lot of contact with young people - through things like sporting activities, and grandmothers, who have a lot of contact with their grand-children, and so forth. But a part of this stage of the research was gathering as many Koori names of young people aged 12-25 within the metro area. We thought, ‘Let’s find out where they are’, to begin with.

So, once we got all of this information through focus group discussions, and developed all of these topic areas, we started to develop a questionnaire and to look at how we should be asking these questions. We looked at stuff like sex, drugs, alcohol, school, employment, culture, mental health issues, and how comfortable young Kooris feel about who they actually are and how they fit into today’s society. We tried to get them to have as much input into the questionnaire as possible. We asked them: Is this a good question? Is this the right language? Do you understand it, don’t you understand it? And so forth. So we tried to get their input and that’s been the whole focus of the Project, of getting young people’s input.

Some of the questions were very sensitive and upsetting at times, but the young people felt that this was their way of voicing their own opinions and a way to get people to listen to them.

We developed a data collection procedures manual. It was a manual that assisted peer interviewers; they were the young people who were recruited to collect all of this data from other young people in our random sample. That procedures manual was to assist peer interviewers and to address any problems that they might come across when they were collecting data. At the same time it was about learning new things, because a part of the questionnaire was a health section, so peer interviewers were doing blood pressure, urine testing, and measuring height and weight. We drew a random sample of 400 and collected 174 young people’s questionnaires.

One of our findings showed that what tended to happen at the Health Service was that – how can I best explain this? An example, one day a young girl said, ‘What if I take a day off and come to the Health Service and if I come to have a pregnancy test and see Auntie there and the first thing she says is “Hey, how ya goin’, what you doin’ ’ere?”’. That was one of things that young people told us, and one of our outcomes is the need to have an after hours clinic just for young people on a Wednesday night.

Today the Victorian Aboriginal Health Service employs 10 to 12 young people and we’ve got friends coming in visiting for lunch, all the Adolescent Mental Health Team, and more young Kooris are coming in to see the doctors or whoever. Part of our research has involved taking blood pressure, urine tests, and all that was offered to people under sixteen. The blood tests were offered only to those over the age of sixteen. So, as a part of the research process we had to see every individual at least three times. The interviewers would go out and do the questionnaire, and then bring the kids in to see the doctors who did all the tests, HIV, hepatitis etc., and took all the samples – and then the young people had to come back in to get their results.

We also established a newsletter to make us known and influence young people about taking control over their own lives. There were some principles that we tried to work with: Aboriginal involvement, control, consultation, negotiation, understanding, holistic approach to Aboriginal health, links to programs, but also to be very sensitive to our cultural and social issues.

I think that the most important thing for this Project, which has taken us three or four years to get where we are, is that without the support of the Health Service, the environment of the Health Service, of all of these people coming in and being able to walk down those corridors and say, ‘Gee, that lady, I need to find her son, how do I do that?’; just being able to have that sort of involvement from within the Health Service, it probably would not have happened within a mainstream organisation, never would have. So that is one of the bonuses of being based in the Health Service, and we acknowledge all the people who have been involved the Project. And that’s the journey of the Young People’s Project at the Health Service.
The Afternoon Session: More Stories of Koori Community-Initiated Projects

It was really good being in a Koori environment at Rumbalara. It was good to take a break for lunch and wander outside. The group returned in the afternoon to listen to the two final talks of the day. Bev Greet, a member of the Sexual Health Team at VACCHO, spoke about the experiences of the team in helping develop a Victorian Indigenous Sexual Health Strategy. Bev outlined the activities of the team, and lessons learned in piloting a ‘Well Persons’ Health Check’ in Morwell in 1999. Following this, Salina Bernard, Chair of the VAHS Health Research Ethics Committee, spoke of her experiences in becoming involved in ethics committee work and some of the issues arising from the establishment of the VAHS committee. Once again, these two talks sparked interest and there was a lengthy group discussion both of the usefulness of ‘Health Checks’ and the role of research ethics committees.
Initially I would like to introduce you to the sexual health team at VACCHO. It’s myself, Jill Gallagher, Marc Williams and Michael Murray from the Victorian Aboriginal Health Service (VAHS), all of us are part of our sexual health team. Our responsibility overall is to develop a Victorian Indigenous Sexual Health Strategy, and within that we have also been developing programs and various workshops etc.

The background to this is that there was a National Indigenous Sexual Health Strategy, which Ian Anderson was involved in. The Strategy came out in 1997 and the main aim of the Strategy is to increase the detection, treatment and care of blood-borne viruses, meaning HIV, Hep C and also STDs. In line with the National Strategy, the proposed Victorian Sexual Health Strategy aims to reduce the infection rate of STDs within the Aboriginal Community, but to also increase access to detection, treatment and care of blood-borne viruses.

We only started a year ago at VACCHO and are attempting to ascertain the incidence of STDs in the Victorian Aboriginal Community. When we initially started, we found that there were very few statistics for this. So the reports leave incredible gaps, not only with HIV but with STDs in relation to Aboriginal Communities. And we thought that part of our role would be to develop data in relation to STDs in Victoria, seeing that there were so little stats, and that we would maybe have to paint a picture or get a plan and actually develop a database of statistics around HIV, STDs and Hep C.

Through Dr Kit Fairley we learnt of a new project that was first piloted in Weipa up in Cape York, called the ‘Well Persons’ Health Check’. It’s a holistic approach to health and the idea was to pilot it in Victoria, which we did in July in Morwell. Obviously if you said to people, ‘Come and get your STDs, HIV and Hep C checked here’, no-one would come. So we piloted the Well Persons’ Health Check, and the idea was to follow the principles of holistic health care. So we encouraged people to have all sorts of tests. Included in the package was eye testing for diabetes, a lifestyle questionnaire, blood pressure, and we also offered things like pap smears.

So the Well Persons’ Health Check was to detect and treat some elements that are prevalent within the Community, to gather statistics on illness within Communities, and to identify possible hot spots. The identifiable information will be kept by Melbourne Sexual Health Centre and the pathology results were only known to pre and post care counsellors from Melbourne Sexual Health Centre. That’s in relation to the STDs, Hep C and HIV. The Community gains were statistics regarding prevalence of illness in the Community, data to support funding applications, the identification of service needs for local Communities, and identified training needs for health workers.

Just to give you a little idea of the set-up, people would come into the Co-op, register their name and details about themselves, and then they would have a lifestyle interview which is around their smoking, drinking, and exercise, and then have measurements: height, weight, blood pressure. Then we called in VACCHO’s eye program. They came in and they had trained up the health workers to use the eye machine, testing eyes for retinopathy problems. Obesity showed up to be a problem in the Community.

Through Dr Kit Fairley we learnt of a new project that was first piloted in Weipa up in Cape York, called the ‘Well Persons’ Health Check’. It’s a holistic approach to health and the idea was to pilot it in Victoria, which we did in July in Morwell. Obviously if you said to people, ‘Come and get your STDs, HIV and Hep C checked here’, no-one would come. So we piloted the Well Persons’ Health Check, and the idea was to follow the principles of holistic health care. So we encouraged people to have all sorts of tests. Included in the package was eye testing for diabetes, a lifestyle questionnaire, blood pressure, and we also offered things like pap smears.

So the Well Persons’ Health Check was to detect and treat some elements that are prevalent within the Community, to gather statistics on illness within Communities, and to identify possible hot spots. The identifiable information will be kept by Melbourne Sexual Health Centre and the pathology results were only known to pre and post care counsellors from Melbourne Sexual Health Centre. That’s in relation to the STDs, Hep C and HIV. The Community gains were statistics regarding prevalence of illness in the Community, data to support funding applications, the identification of service needs for local Communities, and identified training needs for health workers.

Just to give you a little idea of the set-up, people would come into the Co-op, register their name and details about themselves, and then they would have a lifestyle interview which is around their smoking, drinking, and exercise, and then have measurements: height, weight, blood pressure. Then we called in VACCHO’s eye program. They came in and they had trained up the health workers to use the eye machine, testing eyes for retinopathy problems. Obesity showed up to be a problem in the Community.

Through Dr Kit Fairley we learnt of a new project that was first piloted in Weipa up in Cape York, called the ‘Well Persons’ Health Check’. It’s a holistic approach to health and the idea was to pilot it in Victoria, which we did in July in Morwell. Obviously if you said to people, ‘Come and get your STDs, HIV and Hep C checked here’, no-one would come. So we piloted the Well Persons’ Health Check, and the idea was to follow the principles of holistic health care. So we encouraged people to have all sorts of tests. Included in the package was eye testing for diabetes, a lifestyle questionnaire, blood pressure, and we also offered things like pap smears.

So the Well Persons’ Health Check was to detect and treat some elements that are prevalent within the Community, to gather statistics on illness within Communities, and to identify possible hot spots. The identifiable information will be kept by Melbourne Sexual Health Centre and the pathology results were only known to pre and post care counsellors from Melbourne Sexual Health Centre. That’s in relation to the STDs, Hep C and HIV. The Community gains were statistics regarding prevalence of illness in the Community, data to support funding applications, the identification of service needs for local Communities, and identified training needs for health workers.

Just to give you a little idea of the set-up, people would come into the Co-op, register their name and details about themselves, and then they would have a lifestyle interview which is around their smoking, drinking, and exercise, and then have measurements: height, weight, blood pressure. Then we called in VACCHO’s eye program. They came in and they had trained up the health workers to use the eye machine, testing eyes for retinopathy problems. Obesity showed up to be a problem in the Community.

Through Dr Kit Fairley we learnt of a new project that was first piloted in Weipa up in Cape York, called the ‘Well Persons’ Health Check’. It’s a holistic approach to health and the idea was to pilot it in Victoria, which we did in July in Morwell. Obviously if you said to people, ‘Come and get your STDs, HIV and Hep C checked here’, no-one would come. So we piloted the Well Persons’ Health Check, and the idea was to follow the principles of holistic health care. So we encouraged people to have all sorts of tests. Included in the package was eye testing for diabetes, a lifestyle questionnaire, blood pressure, and we also offered things like pap smears.

So the Well Persons’ Health Check was to detect and treat some elements that are prevalent within the Community, to gather statistics on illness within Communities, and to identify possible hot spots. The identifiable information will be kept by Melbourne Sexual Health Centre and the pathology results were only known to pre and post care counsellors from Melbourne Sexual Health Centre. That’s in relation to the STDs, Hep C and HIV. The Community gains were statistics regarding prevalence of illness in the Community, data to support funding applications, the identification of service needs for local Communities, and identified training needs for health workers.
problems in the Community so that proper services can be planned for the future, and we wanted to ensure that confidentiality was respected. That was one of the reasons why we called in the Melbourne Sexual Health Centre, because they are not part of the Community, people felt comfortable about them coming on board and doing post-test counselling. The Melbourne Sexual Health Centre is highly regarded for its confidential nature and so they were very excited to join with us as part of the program. They have an outreach program - so that was a part of their outreach program.

It worked really well and, in fact, we are now going to be doing the next Well Persons’ Health Check in March in Mildura with the Melbourne Sexual Health Centre on board. We also called upon the Department of Epidemiology at the Alfred Hospital to develop a database documenting the results because we didn’t have the expertise to develop the database and analyse the data, which they did. VACCHO still own it so they can’t do anything with it, they can’t use it for publications or anything. Obviously, the Melbourne Sexual Health Centre had the identifiable data because they needed it. There were two ways which people could get their results. They were given a card at the end of the day where they could ring a 1800 toll free number to get their results. But with HIV and Hep C you cannot give those results over the phone anyway, so they organised for themselves to come back. The nurses came back two weeks after the Well Persons’ Health Check, so that people could follow up on those tests, and get their results and also get treatment if needed. All treatment was free. Everything was free to the Community actually. The benefits of the Well Persons’ Health Check is the holistic approach, the way it was packaged and how it was monitored - I suppose, sexual health within a holistic framework, and confidentiality is guaranteed.

The sexual health team within VACCHO would like to implement a Well Persons’ Health Check throughout the Victorian Aboriginal Community. We would like to take it around to two sites within each region and, as I said, we are doing one in Mildura in March and then we are going to Lake Tyers in May because it was a bit far for the Lake Tyers mob to come up and we thought it more appropriate to base ourselves down there.

Two hundred and thirty-five people came through the first Well Persons’ Health Check and the blood test was optional. We were amazed how many did have it. I can’t remember the exact figures, but more than 90% of the people had the blood test. And it was interesting about the teenage stuff because we actually took anyone over 13, but a lot of them aged 13, 14, 15 actually came with their parents which was a bit strange and there were questions like ‘Are you having sex?’ The child would not actually give out that information in front of their mums sitting there, you know.

One of the things that we have asked for that will be happening towards the end of the year, we are actually getting one more person on our team to be the person that goes to the Community one month before and say one month after to help link with those people who have been diagnosed. If there are no services at the Co-operative, this link-up person will tell them where they can go, like, to refer them on to a Hep C counsellor if that is what they need, or to other support services that they might need. So there is potentially more follow-up, I think. With Morwell, because it was a pilot program, there was a problem we didn’t foresee or really think about which was, ‘Well, what are we going to do once someone has got a Hep C diagnosis?’, particularly Hep C because it’s not a matter of giving them a pill.

Long term we are taking a tour over the State over the next eighteen months. It is hoped then that each Co-operative will be able to run their own Check once a year, and that they actually do it. Not that we need to be a part of it. All of those health workers that were at every one of those stations during the first Health Check were trained up in that area, and they will be able to run their own Well Persons’ Health Check once a year.

The Well Persons’ Health Check is not all we have been doing. We have been running workshops in Co-operatives to raise awareness of how people think about their sexual health. The other thing that came out of the Well Persons’ Health Check is that a large percentage of people who had their eyes tested, who had diabetes, needed glasses - and they all now have glasses.
Ethics: What Do We Mean and What is Acceptable?

Salina Bernard
Chair, Victorian Aboriginal Health Service Health Research Ethics Committee, Melbourne

I will try and give you a bit of a background on the establishment of it, but I have been involved with the Committee for the last four years and, I think, the last three years as Chairperson.

That Ethics Committee is based at the Victorian Aboriginal Health Service in Fitzroy. Maybe Ian Anderson could elaborate a bit more on the establishment of it, but as I understand it, the Health Service was approached hundreds of times over the years from external researchers to do research on Aboriginal Communities, whether in Melbourne or elsewhere, and it got to the point where the Health Service realised that it is in a position where it can be a part of and participate in research being undertaken on Aboriginal people across the State.

Anyway, the first two studies that we were asked to look at were the Injecting Drug Use Study as well as the Young People’s Project which Paul talked about before. Basically, the Committee was established to endorse or reject the ethical soundness of those proposals and their research methodology, which meant that we had to read through a hell of a lot of paper and come to some sort of conclusion about whether we thought the research was going to be appropriate and acceptable to the local Aboriginal Community that was going to be researched. In both of the proposed projects we actually thought that some of the points, like blood testing and informed consent, and that sort of stuff, wasn't really right and, particularly with the Young People’s Project, we thought that parents might have some qualms about parts of it, like their kids getting blood tested and not being notified if their children were diagnosed with a Hepatitis or HIV or some other illness. So after lengthy discussion and reference to the NHMRC guidelines (which I might add has a lot of gaps and needs to be re-drawn), but using those guidelines as a standard, we went through the projects and discussed what we thought was ethical for our own people compared to non-Aboriginal people. In the end we gave endorsements to those projects, but we also gave advice about where we were not happy with certain parts of them - and advised that endorsement would not be provided unless these things were changed and resubmitted to the Ethics Committee. And so they were the two original proposals that we looked at.

The Committee is made up of one doctor, one lawyer, one layman, and one laywoman, and a minister of religion. As I understand it, when we first approached the NHMRC to register we said that a minister of religion wasn’t really appropriate to sit on an Aboriginal Ethics Committee. So we ended up having that changed to an Aboriginal Elder, which worked well for us, although it is a big load and lot of reading and a big responsibility. So as a consequence that position has stayed vacant for a bit, but for us the NHMRC were quite open to us changing that representation on the Committee.

What we have found over the last four years is that research can mean one hundred and one different things. You can have research where people are ringing up saying, ‘Hey I’m doing my thesis and I am wanting to do a bit on Aboriginal people, what do I do? I need ethical approval and it has to come to this Committee and what do I do?’ and also internal stuff at the Victorian Aboriginal Health Service where issues come up with research projects currently being undertaken.
There are other external research projects that have happened and we’ve had a number of proposals that have come in from everywhere and they just want to get Aboriginal endorsement on their proposals. Sometimes they are so far-fetched because of misunderstanding and ignorance. There are other external research programs that don’t actually need to go through the Ethics Committee at all.

I found that Aboriginal Community controlled research is the most beneficial research that can be done because it has the involvement, commitment and the participation of the local people which can open up the doors for the researchers. Without those people and those networks and that commitment, the research is going to go nowhere and you are going to have poor research findings. You are going to have research that provides you with information that is wrong, that is usually documented in a way that is biased and doesn’t represent the views and needs of the people being researched. Generally this is pretty poor research and just shouldn’t be done. Negotiating with Aboriginal people to undertake the research is essential, getting them involved and employing them as Research Assistants, so they are involved in the whole process of research: they are involved in the planning, they are involved from the very beginning, from that you get an easier path to research.

The Ethics Committee has been operating for four years and we are trying to be more active in how we expand the responsibilities of the Ethics Committee. Its scope needs to be broadened, not just sit within the Victorian Aboriginal Health Service, because there are a number of organisations that could benefit from using the Ethics Committee. It’s also a good way of supporting Aboriginal Communities themselves, and provides opportunities to say: ‘Don’t be scared of research, if it’s in your hands and it’s in your control then you can get the grants for it and you can bring in the people who you want to do the research, and then it can work in your favour.’ We are currently talking about redeveloping our guidelines and possibly accessing grants to further develop the Ethics Committee - as there is a place for it.
The Late Afternoon Session: Small Group Report-Back and Panel Discussion

The final session of the day was designed to bring the workshop to an end through a group discussion of the many issues that had arisen throughout the day in relation to Koori involvement in research. Each small group (formed earlier in the morning) reported back on their discussion of Koori health research. Using the butchers paper ‘History Wall’ placed up around the room, people talked through Koori attitudes to research, the positives and negatives of the research process and how Koori control of and involvement in research can be increased. Discussion was helped along by Aunty Alma Thorpe and Ian Anderson who responded to the various issues raised.

Small Group Report-Back

In this session people shared their ideas about the history and future of research in Koori Communities. Each small group had also been asked to address these questions:

• How do we build Koori Community ownership of research?
• What are the barriers to this occurring?
• What skills broadly need developing?

The variety of responses to these questions were written up in point form on butchers paper. All the ideas and issues raised in the small groups have been put together on the following pages.
The ‘History Wall’

What are the good and bad things that have made it possible for Community controlled health research?

**POSITIVES**

**1967**
- Referendum – Citizenship

**1968**
- Aborigines Welfare Board replaced by Ministry of Aboriginal Affairs (theoretical shift from welfare-driven policy to one of self-determination starting)
- Starting point of lobby groups
- Political/Social activism strong

**1970s**
- Tent Embassy
- Emergence of political movements in the State
- Land rights
- Legal rights
- NACNACC had direct link to Federal Politicians
- NAIHO established
- Emergence and strengthening of Community organisations in and around Victoria and interstate:
  - Rumbalara Co-op
  - Aborigines Advancement League (AAL actually started 1932)
  - VAHS
  - Redfern Aboriginal Medical Service
  - Aboriginal Legal Service
  - Aboriginal Educational Consultative Group (became VAEAI)
  - Housing Co-op
  - Hostels
  - Fitzroy Stars Gym
- Key Player AAL & others committed to Koori Health
- Cultural Heritage Acts
- Cultural material handed back to Communities
- Redefinition by Commonwealth of Aboriginality (to include self-identity and Community acceptance)
- Culturally relevant guidelines for research developed
- Aboriginal people who fought for service establishment were really researchers
  (but used a different word):
  - doing the groundwork
  - doing needs analysis
  - getting Community involvement
- Committed people who gave services
- Community was becoming united, wanted Community control
- Strength of Kooris – ability to fight for rights
- Improved political awareness
- Expansion of services that were required
  (through consultation/research)
- Partnerships with professionals
- Community controlled organisations enabled people to resist research imposed by Government or students

**1980s**
- Researchers employed by Aboriginal Community organisations
- Learning process, setting up guidelines for control
- People who struggled to continue and set up organisations were researchers
- Criterion was researcher being an Aboriginal person
- Significant growth in Aboriginal services
- Many reports/reviews undertaken
  - Deaths in Custody
  - National Aboriginal Health Strategy
- Mabo Case commenced
  - highlighted land rights, culture
- Fitzroy Stars Football Club
- Fred Hollows
- Koori Kollij established
- Increased our profile, confidence, recognition
- Koori Units established at the Universities
- Research undertaken in partnership with Koori organisations (Wronski Report, Cameron & Debelle, McKendrick)
- Partnerships developed/enhanced
- First Koori Medical student in Victoria
- Establishment of more organisations
- Development of strategies to improve access to services, education, etc
- Government goals and targets developed for NAHS
- ‘Link up’ (NSW) for Stolen Generation
- Change in law/s
1970s

- Aborigines Welfare Board replaced but theoretical only
- Still an oppressive structure
- Backlash against Aboriginal rights
- Outside community not seeing the needs of Aboriginal people
- Difficult to make outside community aware
- Struggle to get Aboriginal people to see or acknowledge our needs or differences
- Fighting to establish proper services eg. housing
- Struggle against outside opposition
- Having to prove ourselves

1980s

- Do not celebrate ‘88
- Deaths in custody
- Coe case lost (NSW)
- Still under resourced
- Recommendations from reports/reviews not implemented
- Government lacked political will
- Tokenistic
- Services not delivered in a culturally appropriate manner, ie ‘Welfare’ was merely renamed ‘Community Services’
- Research was an excuse for inaction
- Getting employment hard for Aboriginal people
- Pressure to co-opt Communities into the numbers game, with the agenda set by government
- White education system and white definitions of ‘academic’

1990s

- Continued poor health status of Aboriginal people
- Marginalised by Government policy
- Effects of oppression has caused the sickness

NEGATIVES

1990s

- ATSIC established (amalgamation of DAA and ADC)
- NHMRC established guidelines for Aboriginal research
- VAHS Ethics Committee
- VACH/OACCH established and subsequently resourced
- Child Health Promotion Project
- VKHRCU established
- Young People’s Project (VAHS)
- Injecting Drug Use Project (VAHS)
- Department of Rural Health, Shepparton, developed with a Koori focus
- Health Promotions VAHS
- Rumbalara Football/Netball Club
- OATS WH established
- Mabo, Wik/native title
- Stolen Generations Inquiry
- Evaluation of NAHS
- Memes research in NT
- ‘Bringing them home’ report
- Master of Applied Epidemiology (in Indigenous Health) at ANU
- Ethics guidelines development
- NHMRC devoted some special funding for Aboriginal Health research
- Self-determination and Community Control recognised as credible
- Health Outcomes Agreement
- Framework Agreement
- Yorta Yorta land claim
- Holistic approach recognised
- Influence on policy and strategy continues
- United front – political alliances politically informed and strong
- Working towards reconciliation
Some Koori Views on Research

- It has a bad history
- It is a suspicious process
- It is not based on outcomes of benefit to the Koori Community, but based on what the researchers want from it
- It has generally ‘taken away’ and not ‘given back’ to the Koori Community
- It has ‘studied’ the most highly researched people in the world
- It has been involved in producing information which is used against Koori Communities (Native title cases etc.)
- It potentially divides Communities/groups
- It has no use/meaning to the Community
- It is necessary to acquire funding for health services
- It should be run by the Community
- It should be owned and totally controlled by the Community
- It should be initiated by the Community
- It needs to have a clear grasp of what Community control means today
- It should be modelled on ‘Participatory Action Research’
- There are other ways to describe research – study, information gathering
- It should be culturally and socially sensitive and take into account the historical context of particular Communities
- It needs to result in positive outcomes for Koori Communities
- It requires rigorous negotiation for the achievement of good outcomes
- It should be governed by a set of guidelines for research and include the full involvement of Aboriginal people
- It needs to confront the issue of who gets employed as researchers: Aboriginal/non Aboriginal?

- Where does the Aboriginal consultant fit in?
- It needs to be flexible about defining ‘qualifications’ and ‘experience’
- It needs to be sensitive about how information might be held by specific groups (men, women, Elders)
- It needs to take account of the gender of researchers
- It should have Ethics Committee approval before beginning
- It needs to be understandable to the Community
- There should be clear guidelines for the way results are published to avoid misuse of information
- Bad research has a biased perspective
- Good research is culturally appropriate in terms of feeding back information and facilitating Community action

Some Koori Views on Research

We don’t like research... but in Koori hands it could make a difference
Barriers to Koori Community Control of Research

- Lack of recognition by government, funding agencies, universities of a Koori way of doing research
- Lack of
  - funding
  - resources
  - access to resources
- Conflict of ideas
  - what is research?
  - who is going to own it?
  - storage of data – where? how? by whom?
- Institutions want recognition and ownership of research
- Lack of knowledge of right protocols to follow
- Lack of skills and understanding of what research is and why it is done
- Lack of training and skills development for Kooris in research
- Need to meet the inappropriate requirements of governments and funding agencies, reports and timelines etc.
- Funding restriction – restricts Community controlled research, undermines Community control
- Difficulty in having applied action research accepted by funding bodies (who are bound up in funding ‘pure’ research)
- Short-term funding for research (often illness specific)
- Lack of existing data to support research proposals
- Lack of baseline data for comparison
- Lack of understanding of academic language
- Lack of consultation
- Lack of reward
- Lack of confidence – need for reinforcement of positives, skills, recognition (credibility) of Koori knowledge
- Fear of
  - being ripped off
  - misappropriation
  - being misunderstood
  - being misrepresented
  - being identified (confidentiality)
- Lack of representation on decision-making bodies
- Nothing changes – no benefits
- Tokenistic
- Lack of successful models (need promotion of good practice research)
- Lack of trust (need for partnerships)
- It gets done to you – rather than by you or with you
- History – academia
- Ignorance
  - of principles of research
  - of qualifications and skills of Aboriginal people
- Culturally inappropriate research methodology
- Paternalistic views of researchers
- Racism
  - blatant
  - insidious
  - institutionalised
  - systemic
- Continued subordination of Aboriginal people
- Differences between funding bodies and Community organisations in
  - approach to research
  - aims and objectives
  - expectations
  - timelines
  - philosophies
  - understanding of health
- Qualitative data not quantitative
- Confidentiality burn out
- Lack of trust in research internally
- Internally conducted research not seen as credible externally
- Not recognising relationship between health service delivery, planning and research
Activities/Strategies to Increase Community Controlled Research

- Local/State-wide forums – give Communities opportunity to discuss research issues
- Increased awareness of
  - funding opportunities
  - rounds of funding
  - where to go for funding
- Produce and promote existing Community-controlled research
- Koori people to work alongside non-Koori researchers training
- Increased training/skill development
- Change academic research ‘culture’
- Community-controlled organisation should approach universities instead of the other way round
- Promotion of an Aboriginal Ethics Committee
- Body which looks at the broad issues of research – coordinating body
- Holistic approach
- Recognition of
  - history
  - impact of loss
  - bio-psycho-social context
  - environmental factors
  - cultural factors
  - spiritual factors
  - kinship breakdown
- More skilled Indigenous people
- Recognition of life experience, not university qualifications
- More Kooris in parliament/local government
- Shift from external activism to internal activism (ie. within government)
- Community education and support
- Increase in support including: financial, education and training, skills development, knowledge
- Information sharing
- Koori representation and participation in all stages of research
- Advocacy
- Promotion of best practice models
- Self evaluation (ongoing)
- Action research
- Self-determination, empowerment, equal sovereignty
- Acknowledgment of us as a people and that we are a nation within a nation
- Intellectual property
- ‘Pay the rent’ proper resources in Koori hands
- Recognising our philosophy of good health as a holistic perspective
- Outcomes need to be monitored by Community
- Ideas come from Community
- Community endorsement – the Community needs to want it
- Properly resourced research
- Promote good research that has been done
- More culturally appropriate forms of research, broader holistic approach (ie. emotional and spiritual well-being centres, performing arts)
- True Community control
- Support services for workers/carers people in Community involved in research
- More discussion, more understanding of the meaning of research, evaluation and inquiry
- Development of a database on Aboriginal health research (would need protocols around registering; would need resources)
Panel Discussion

The final session produced a lively discussion of many of the issues that had been raised during the day. Aunty Alma Thorpe and Ian Anderson responded to people’s comments.

People agreed on the need for Koori Community involvement in research and for more Community control of future health research activities. The importance of asking Communities for permission to do research was also discussed.

Aunty Alma talked about the history of Aboriginal activism and the way Indigenous Community health services were fought for. There was also discussion around government funding for Aboriginal health and the need for monitoring mainstream services and hospitals, making them more accountable for the way they spend the money that is allocated for Aboriginal health.

Ian asked if people had any ideas about ways to change academic culture and the way universities think about and do research. People suggested there was a need for:

- more Aboriginal people to be involved at the academic level;
- methodology training to include how to do good cross-cultural research;
- training in cross-cultural programs to be made an essential requirement for academic promotion;
- cross-cultural training at all levels – from kindergarten on – because it’s no use leaving it too late to change people’s attitudes;
- a holistic approach to research instead of isolating issues for each research project.

Aunty Alma: ‘Research’, as you said, it’s a dirty word in Aboriginal Communities. What does research actually mean and what analysis gets done? Also, why do we have to beg for money to do research ourselves when we’re talking about self-determination?

It’s very hard to come up with a clear definition of how we’re going to go about research or what we want, because we need, first of all, to be clear about our rights in relation to health.

Some research that was done with a Community organisation found that the illnesses of Aboriginal people are caused by oppression, by deprivation, and by sadness, which causes the whole of your body to be sick. So how do you combat that first instead of just picking at holes here and trying to fix it up there? We’ve tried to kick the goals but the goal posts have moved every time.

One workshop participant commented on the lack of any national understanding of the structural problems that keep Aboriginal Communities in poor health. He said that stories about Aboriginal health in the media tend to focus either on total despair or on Fred Hollows. It is as if the only positive thing to say about Aboriginal health is that Fred Hollows worked in the Communities and did something about eye disease. This gives a message that you can fix anything if you’ve got the right equipment. There was discussion about the way stories like these make people in the mainstream community feel comfortable but it doesn’t do anything to change the structural problems. If you even hint at addressing the big issues the mainstream community just says ‘Too hard! Too hard!’

Aunty Alma: In some Communities where eye and ear disease was bad, all they needed was clean water because in some areas there was only one tap for 500 people.

Ian: One point I can pick up on, from the discussion so far is the principle of ‘No research without doing something about the problem’. If you actually read all the Aboriginal health research that’s been done over the last 30 years, the best way to describe it is 30 years of describing the problem. I think that what has been very disabling about research is that it has been predominantly descriptive. We’ve got to think of ways of insisting that the research agenda shifts much more towards actually describing solutions.

Aunty Alma: One thing I think we should look at is all the inquiries that have gone on in the last few years and what has come out of them. Isn’t an inquiry a form of research as well? You’ve got the Deaths in Custody and the Stolen Generation Inquiries, they cost thousands, millions of dollars all these inquiries. But the thing is, our people are tired of these things, they’re saying: ‘What, again? What do we actually get out of it?’ Inquiries don’t mean a thing if nothing gets changed.
Conclusion

After a long day of thinking and talking about many important issues, the workshop was brought to a close by Ian Anderson. In his closing comments, Ian summarised the main points arising from both the individual presentations and group discussions. He also spoke about the need to continue the momentum towards challenging and taking control of research, and of the Unit’s role in doing this: what activities and strategies are needed that the Unit can help in developing, that would support Community controlled research. Ian thought it was important to acknowledge that this had been a Community workshop on research with all Koori presenters. This workshop was the beginning of a process and it had shown that there was a need for more discussion around issues of ethics and models of partnership, and so on. It was important to have discussions and even arguments around these issues in a Community context. It was also very valuable to be able to learn about the historical context with people from different generations.

As an outcome of the workshop, the Unit promised to produce this Community report, and to make it available to all the workshop participants and to organisations and individuals in the Koori Community.

Ian closed the day by thanking Rumbalara, the Department of Rural Health and particularly Rick Henderson and Jan Muir, the Unit team, all the presenters, Aunty Alma Thorpe and everyone who attended. Everyone was invited to stay on for a BBQ.
Workshop Evaluation

We wanted to check out what people’s views on the workshop were, and to incorporate them next time we run a workshop. We handed out a short Evaluation Sheet towards the end of the day in which we asked people to comment on a number of issues. Fifteen people filled in these forms for us.

What we learned from the Evaluation

Being our first Community workshop there was quite a bit of trial and error on our part. We were pleased that feedback was pretty positive. We were keen to make the day useful to everyone who came to the workshop but the feedback suggested that maybe we had made the day too busy. One of the strong messages on the day was about giving people plenty of notice so that they can make plans to attend future workshops.

Here are the questions we asked on the Evaluation Sheet and a summary of people’s responses:

1. **How did you find out about the workshop?**
   Most people had found out about the workshop either through a leaflet or personal letter. A few heard about it from other people.

2. **The Unit intends to hold workshops every 3 or 4 months – would anything make it easier for people to attend?**
   A number of people suggested that workshops should be held in a ‘roving’ number of centres involving both country and city locations. There should be at least six weeks notice for each workshop.

3. **Was the ‘all-day’ agenda suitable? Was the day too long/too short? Did the workshop cover too much or too little?**
   Almost all the people who responded to the evaluation felt that the ‘all-day’ agenda was good. A number of people suggested that the day was a bit too ‘packed’ or that not enough time was available for a full discussion of a number of the issues raised.

4. **Which session(s) did you find most interesting/useful, and why?**
   - Sessions involving Elders talking about the history of research
   - The question sessions
   - The final session because it focused on strategies for action
   - Community projects

5. **What kind of sessions do you like best - talks, group discussions, panel discussions?**
   Many people thought that there should be an emphasis on group and panel discussions and more time for questions.

6. **Overall, did you find the day useful? Did you feel comfortable attending? How could we improve these kinds of workshops?**
   Everyone who responded felt that the day was very useful. Some suggested changes to the seating layout. People felt comfortable and found the discussion groups very inclusive. (See other comments next page)
7. Would you attend other workshops in the future? What topics would you like to see discussed at future workshops?

Everyone who responded said they would attend another workshop.

Topics people would like to see covered in the future included:
- Research skills and methods
- Research ethics
- National research issues
- Education issues
- Holistic health models
- Racism
- Relationship between research and practice
- Health promotion

Here are some of the other things that people said:

The involvement of younger people in these workshops is essential for education and future programs.

Excellent workshop – great participation. All presenters and participants gave a huge amount. Very productive discussion.

Should be an opportunity for ‘tangible’ as opposed to ‘general’ or ‘simplistic’ solutions.

Gave an insight into ‘peeling back the issues’ that people (researchers) need to know.

The workshop always opened more things to consider and explore.

The final session was the most useful when we talked about actual strategies to improve Community-controlled research.

The small group discussions keep us active.

The seating could have been set out a bit better – became a little crowded.

Good – a lot needed to be discussed and was.

Getting hard to think towards the end.
Abbreviations

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>AAL</td>
<td>Aborigines Advancement League</td>
</tr>
<tr>
<td>ACES</td>
<td>Aboriginal Community Elders Services</td>
</tr>
<tr>
<td>ADC</td>
<td>Aboriginal Development Corporation</td>
</tr>
<tr>
<td>ATSIC</td>
<td>Aboriginal and Torres Strait Islander Commission</td>
</tr>
<tr>
<td>DAA</td>
<td>Department of Aboriginal Affairs</td>
</tr>
<tr>
<td>KODE</td>
<td>Koori Opendoor Education</td>
</tr>
<tr>
<td>NAC</td>
<td>National Aboriginal Conference</td>
</tr>
<tr>
<td>NACC</td>
<td>National Aboriginal Consultative Council</td>
</tr>
<tr>
<td>NACCHO</td>
<td>National Aboriginal Community Controlled Health Organisation</td>
</tr>
<tr>
<td>NAHS</td>
<td>National Aboriginal Health Strategy</td>
</tr>
<tr>
<td>NAIHO</td>
<td>National Aboriginal and Islander Health Organisation</td>
</tr>
<tr>
<td>NHMRC</td>
<td>National Health and Medical Research Council</td>
</tr>
<tr>
<td>OATSIH</td>
<td>Office of Aboriginal and Torres Strait Islander Health</td>
</tr>
<tr>
<td>RUIMHER</td>
<td>Resource Unit for Indigenous Mental Health Education and Research</td>
</tr>
<tr>
<td>VACCHO</td>
<td>Victorian Aboriginal Community Controlled Health Organisation</td>
</tr>
<tr>
<td>VAEAI</td>
<td>Victorian Aboriginal Education Association Incorporated</td>
</tr>
<tr>
<td>VAHS</td>
<td>Victorian Aboriginal Health Service</td>
</tr>
<tr>
<td>VKHRCDU</td>
<td>VicHealth Koori Health Research and Community Development Unit</td>
</tr>
</tbody>
</table>
References

ANCARD (1997)
Working Party on Indigenous Australians’ Sexual Health

Nutrition of Aboriginal infants and children in the Murray Valley.
Medical Journal of Australia, 144 Suppl: S5-8.

Department of Human Services Victoria in partnership with the Victorian Aboriginal Community Controlled Health Organisations Incorporated (1997).


Guidelines on Ethical Matters in Aboriginal and Torres Strait Islander Health Research. Canberra: NHMRC.