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## Researching Aboriginal health: experience from a study of urban young people's health and well-being

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### Abstract

European colonisation had a devastating effect on the health and well-being of indigenous people in Australia. The history of Aboriginal health research has reflected the history of colonisation; research has understandably been viewed with distrust. The need for accurate statistics and improved understanding of health problems is clear, but obtaining them is not easy. In this paper we describe the first stage of a study of the health and well-being of urban young people that was initiated and carried out by the Victorian Aboriginal Health Service (VAHS), a community controlled organisation. This longitudinal study aims to describe the prevalence and incidence of a range of health problems, to explore their interrelated determinants, and to increase the capacity of the VAHS to carry out research. The process of planning and carrying out this study raised a number of interesting ethical, cultural and methodological issues. These issues include the establishment of an appropriate and properly constituted local ethics committee, the difficulty of obtaining a representative sample, the need for ongoing negotiation, attention to language, the use of a subject-generated identity code, and the need to recruit a wide range of peer interviewers. Achievements include a series of community reports of the findings, the establishment of a cohort of young people for a longitudinal study; a shift in attitudes toward research; a strengthened network of young Kooris; increased use of the health service by young people and the establishment of an after-hours clinic service and meeting place for young people. The aim of this analysis of our achievements and constraints is to assist others planning similar research, and to demonstrate the value for process and outcomes of research conducted under Aboriginal community control. © 2002 Elsevier Science Ltd. All rights reserved.

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### Introduction

Australian Aboriginal<sup>1</sup> people and their organisations have had reason to be suspicious of research, which has

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<sup>1</sup>The terms 'Aboriginal' and 'indigenous' are problematic because they refer to first nation's people who have in common the experience of colonisation, but whose experiences are also very different. In Australia the terms refer to the many different

often been conducted without their consent or involvement (Holmes & Thorpe, 1996; Anderson, 1994). The history of Aboriginal health research has reflected the

(footnote continued)

peoples and language groups who were living in Australia at the time of European settlement, including the Aboriginal peoples of the continent and the Torres Strait Islander people. Koori is a generic term that the Indigenous people from the south-east corner of the continent use to refer to themselves. However, increasingly Koori people use and identify with their specific language, country and/or family name.

history of colonisation. Aboriginal people's first experiences of research were of anthropologists who "collected" and represented their culture (Tuhiwai Smith, 1999, pp. 66–67) and measured their body parts to draw conclusions about their "primitive" intelligence (Brough Smith, 1975, Appendix 8; Bert, 1889). Then, for many years, medical researchers focused on prevalence studies (Lake, 1992). Aboriginal people have been examined, measured and asked questions (Guest, O'Dea, Hopper, Nankervis, & Larkins, 1992). They have been passive subjects rather than participants, without the opportunity to correct misinterpretations. Too often the studied community has not received study results, and the problems remain unaltered, while the researchers are perceived to have benefited (Hunter, 1992). Thus, it is not surprising that Aboriginal people have often experienced research as another form of exploitation.

In recent years, there has been a number of examples of more participatory health research in Aboriginal communities. Some studies have been initiated and controlled by Aboriginal health services; others have been collaborations between academic organisations and Aboriginal organisations (McKendrick, Cutter, MacKenzie, & Chiu, 1992; Gray, Morfitt, Ryan & Williams, 1997; Eades, Read, & the Bibbulung Gnarnep Team, 1999; Miller, Torzillo, & Hateley, 1999).

There are challenges in undertaking research in Aboriginal communities, and scope for the process to be harmful or beneficial. There are likely to be practical and logistical difficulties, problems related to communication and collaboration, and difficulties arising from different priorities and cultural attitudes (Manderson, Kelaher, Williams, & Shannon, 1998). Accounts of research experiences that contribute to contextually relevant methodological development are therefore important. There has been discussion of methodological issues in cross-cultural research related to various migrant ethnic groups in Australia (Small, Yelland, Lumley, & Rice, 1999). Although some of these issues are relevant to Aboriginal research, the different dynamics resulting from the colonial history of relationships also impact on the research process. The need for Aboriginal research guidelines has been recognised (Donovan & Spark, 1997; Miller & Rainow, 1997; Eades et al., 1999). However, some have suggested that this need is most critical in remote area contexts because of "adherence to traditional Aboriginal culture", distance from research institutes and poor health status due to the physical environment (Donovan & Spark, 1997 p. 90). There has also been an assumption that carrying out research in Aboriginal communities is simply a matter of non-Aboriginal researchers applying standard methodologies, but with cultural sensitivity (Donovan & Spark, 1997). We reject these assumptions. We agree with those such as Langton (1994); Rowse

(1996); and Tuhiwai Smith (1999) who argue that new approaches are needed. We hope to contribute to the elaboration of a research approach that addresses issues that have been identified by the indigenous community, in the literature and through our research experiences.

In this paper, we describe how we undertook a study of the health and well-being of young Koori people in Melbourne. The study is unusual in several ways: it was initiated and is being carried out by the Victorian Aboriginal Health Service (VAHS), a community controlled organisation; it has an urban setting; it establishes a cohort to allow longitudinal research and it combines qualitative and quantitative research methods. The process of planning and carrying out this study raised a number of interesting ethical, cultural and methodological issues.

### **Background to the study**

European colonisation has had a devastating impact on the lives of Aboriginal people. They have been displaced, subject to policies that removed children and split families, institutionalised, discriminated against and deprived of control (Anderson, 1988). The resulting poor state of Aboriginal health has been widely documented (Australian Bureau of Statistics (ABS)/ Australian Institute of Health and Welfare (AIHW), 1999; Ring & Firman, 1998). For the period 1991–96, life expectancy of Aboriginal and Torres Strait Islander people at birth was about 57 years for males and 66 years for females (ABS/AIHW, 1999). One way that Aboriginal people have resisted continuing discrimination and marginalisation has been to create their own community service organisations, such as the VAHS, with a board elected by the community and operating within a Koori cultural environment. The VAHS runs a range of clinical and health promotion programs which allows opportunity to engage directly with their concerns and information needs.

The VAHS has recognised that gathering reliable information is essential for programme and policy planning, and has conducted a number of research projects on health issues of concern to the community (McKendrick et al., 1992; Holmes, Phillips & Thorpe, 1997a, b). The study of young urban Kooris' health and well-being, planned in 1995, was prompted by several factors. A project addressing child health promotion had recently been completed and, in the evaluation, the community had asked for a new focus on the problems of young people. The National Health and Medical Research Council (NHMRC) called for submissions for Aboriginal research projects, and there were staff members with research experience able to prepare a successful proposal.

The project is based within the Health Promotion and Research Unit of the VAHS under the direction of the Board of Directors. The research team consisted of one half-time Chief Investigator (non-Aboriginal), one part-time Chief Investigator (Koori), a half-time Research Fellow (non-Aboriginal), a full-time young Research Officer (Koori), and the manager of the Unit (Koori). The non-Aboriginal Chief Investigator had worked in both clinical and public health roles at the VAHS for many years and was familiar with and known by the community. The Research Fellow also had experience in Aboriginal health. An advisory committee of three external academics was appointed to provide occasional technical support and advice.

### Aims of the study

Longitudinal studies produce particularly valuable data to inform health promotion interventions (Adams, 1994), but to our knowledge ours was the first such study in an Aboriginal community. Good quality health data that relates to Victorian Koori communities and to urban Aboriginal communities are sparse (ABS, 1998a, b). A review of published reports of Aboriginal health studies found that only 13% were from urban communities, although the 1996 census showed that 30.3% of Aboriginal Australians live in urban centres of 100,000 or more (National Aboriginal and Torres Strait Islander Health Clearing House (NATSIHC), 1999).

Little about the development of health risk or resilience among Aboriginal youth has been documented. Brady (1993, p. S57) has observed that among Aboriginal youth “stress itself is associated with vulnerability to ill-health: stressors such as poverty, families disrupted by alcohol use or violence, frequent bereavement, pressure from relatives and from a sometimes hostile and racist environment have their effect”. Anderson (1988) has pointed out that Aboriginal young people confront issues such as finding work, pregnancy and child rearing, coming to terms with identity and general survival at an earlier age than most non-Aboriginal adolescents. Detailed knowledge of these transitions is crucial for the design of effective interventions.

The aims of the study are to:

- describe the prevalence and incidence of the health problems of Melbourne Aboriginal youth aged between 12 and 25 years and to explore the interrelated determinants of these problems;
- describe the variables associated with resilience and vulnerability in this population; and to
- characterise the development of risk factors for both physical and mental ill-health and determine whether they track over time.

The findings are being used to improve the design of interventions to promote the health of Aboriginal youth, and thereby the health of the community. A further aim of the project is to increase the capacity of the VAHS to carry out research, and to plan, implement and evaluate health promotion projects.

### Choice of study design and approach

An advantage of developing a research funding proposal within an Aboriginal community controlled health service is that there is opportunity for non-Aboriginal researchers and Aboriginal health workers to contribute together to the study design. This occurs within existing structures for community governance. When other research models are followed, consultation often begins only once the study has been designed. Aboriginal colleagues have a different perspective on research; their understanding of the community means they have a good sense of what is likely to work or fail in practice. It is important that these ideas are incorporated into the study design. The suspicion generated by past research practices can also hinder Aboriginal organisations when they wish to gather their own data. We found that the term “research” creates barriers so we used the terms “gathering information” and “study”. Others have recorded similar reaction to the word “research” in indigenous communities (Tuhiwai Smith, 1999; Colin & Garrow, 1998).

In this study, we explore a range of risk and resiliency factors. The diagram (Fig. 1) illustrates the theoretical basis of the study. It recognises that the proximal risk factors, such as poor diet and smoking, have underlying causes in common, which are the consequences of European displacement and acknowledges the range of strengths or protective factors in the Aboriginal community. It emphasises the feedback loop between ill-health and risk factors, and the contribution of lack of control to both risk factors and ill-health. Modifying risk factors requires understanding of the context in which they operate.

We chose to establish a longitudinal cohort study because such studies provide dynamic information about the determinants of health and well-being, and allow estimation of the incidence of conditions such as hepatitis C. To obtain prevalence of a number of conditions and risk factors we decided to obtain a random sample so that the first round of data collection would also provide cross-sectional data.

We planned a qualitative first stage with a series of focus group discussions (FGDs) with young people, and in-depth interviews with adults in the community who had contact with young people. This would enable us to define clearly the research questions and to design an effective research questionnaire. As Black (1994, p. 425)

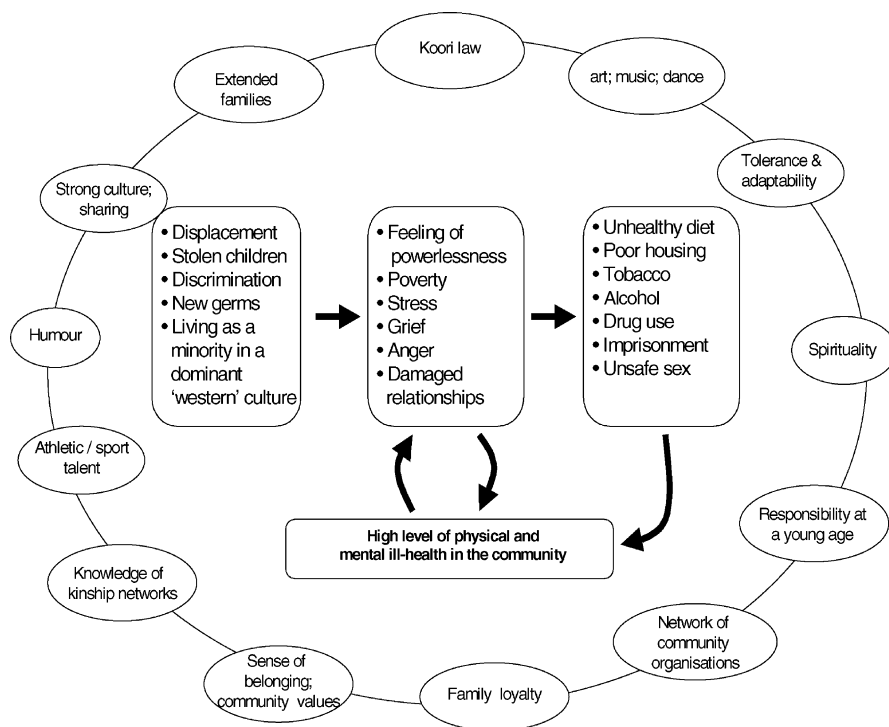


Fig. 1. A model for the development of risk and resilience.

wrote, “qualitative research can assist quantitative work by identifying the appropriate variables to be measured. Too often people start measuring before they fully understand the underlying issues and thus may not target the appropriate factors”.

We had previously found FGDs to be effective and acceptable to the community; the idea of sitting together discussing problems is familiar and an appropriate way to gather information. We found that it was important that Kooris facilitate the discussions and interpret the results. On one occasion a non-Aboriginal researcher was pleased with the results of a discussion but two Koori researchers separately concluded that the participants in that group had been saying what they thought the researcher wanted to hear.

We planned to develop a highly structured standardised questionnaire during the first stage of the project. From our experience we were aware that the use of questionnaires is problematic in the Aboriginal community. Questionnaires are often associated with officialdom. In the past being identified as Aboriginal by officials often had serious consequences, including removal of children, so that Kooris often respond to requests for information with fear, distrust or anger. Some Kooris may not read well enough to understand and answer the questions, but may be reluctant to say this to an outsider and so complete the questionnaire by guessing. Kooris tend not to like to refuse a request,

especially from another Koori, so may complete a questionnaire quickly, especially if they do not understand the purpose of the study. These cultural differences need to be taken into account when planning study methods.

During consultations young people were in favour of a questionnaire programmed on lap-top computer rather than on paper. Others have used computer-based questionnaires with success (Hibbert et al., 1996). Advantages of the use of computers include

- participants do not see branches that are not relevant to them, for example, if they answer that they have not been sexually active, they do not see the questions on sexual behaviour;
- a sense of privacy that increases honesty (Paperny, Aono, Lehman, Hammar, & Risser, 1990);
- time saved on data entry;
- answers can be downloaded directly to the statistics package for analysis avoiding the substantial problem of data entry error (Day, Fayers, & Harvey, 1998).

There was a need to limit the number of physical tests performed because of constraints of time, resources and acceptability. Since a new urine or tampon test had recently become available for chlamydia, gonorrhoea, and trichomonas that did not require a pelvic examination we asked young people whether we should include

this (Tabrizi, Paterson, Fairley, Bowden, & Garland, 1998). They told us that they would be keen to know how common sexually transmitted diseases (STDs) were in their community. The study design included measurement of blood pressure; weight and height; and a urine screen for protein, sugar and blood. For those over the age of 16 counselling and testing for blood-borne viruses and STDs were included.

We hoped to conduct two rounds of data collection a year apart in the first three years of the study.

### Mechanism for approval

We wanted the sensitive ethical issues raised by this study to be considered by representatives of the Aboriginal community rather than the Institutional Ethics Committees (IEC) of the local teaching hospital or university. The VAHS therefore established an IEC, constituted according to the guidelines of the NHMRC and registered with this Council. The IEC was made up of an elder, three women and three men from the community, a lawyer, and a medical practitioner with research experience. The NHMRC requires a “Minister of Religion” to sit on IECs. Traditionally, in the Koori community, the advice of elders has been sought on ethical and spiritual matters, and this continues today. Elders are closely in touch with community values and greatly respected by the community. The suggestion to appoint a respected elder rather than a Minister was approved by the NHMRC Australian Health Ethics Committee.

In addition to the initial scrutiny of the designs, the IEC monitors the conduct of the studies, can receive complaints in confidence from community members with concerns, and answers requests for advice from the project team. Before the IEC gave initial approval to the study of young people’s health and well-being they had three half-day meetings. Deliberations covered the nature of and need for research; control over publication of results; privacy concerns in relation to potential sources for a register of young people’s names; and a mechanism for obtaining consent from parents for young people under 16 years which would not prevent young people without parents from participating. They raised important questions in relation to making arrangements to provide support and counselling if young people became upset by topics raised in FGDs.

Many IECs have problems in locating funds to resource the administrative tasks associated with the Committee, and to pay members sitting fees. The VAHS has no funding identified for this purpose. We suggest that an amount for monitoring of ethical aspects of the research be added to the budget of research funding submissions. We feel that the existence of the IEC is also an important contribution to self-determination.

### Some key methodological issues

#### *Sampling strategy*

There are difficulties in obtaining a random sample for studies in the urban Koori community because there is no reliable estimate of the size of the community, and no adequate sampling frame exists that lists all Kooris in metropolitan Melbourne (ABS/AIHW, 1999, pp. 147–154). There are a number of contributing factors, including

- adverse experiences in the past may cause many Kooris to be unwilling to identify themselves or give contact details for official purposes,
- Kooris may choose not to register on the electoral roll because of political reasons,
- routinely collected data, such as birth and death registrations, provide unreliable estimates since Aboriginality is often not recorded (Koori Health Unit, 1995),
- community controlled organisations which have lists of their members with contact details are understandably reluctant to allow use of these lists for any purpose other than those directly connected with the organisation.

It is very important to understand the depth of feeling associated with privacy breaches in relation to identity or address. This can only be understood with a good knowledge of the policy of removal of children and the discrimination experienced by Aboriginal people for generations.

Since the mid-1970s the VAHS has kept a patient register. Some of those on the register with dates of birth in the age range 12–25 were seen as small children for immunisation and had not visited VAHS since. Many on the register had moved to other states or towns in Victoria; several were deceased, or were not Aboriginal. Despite these weaknesses the patient register is a valuable community asset for research. The study design had included plans to use the patient register as a sampling frame, which did not entail looking at patient files. However, the IEC decided that the list of names should not be used in this way, since patients had given their names only for the purposes of patient care.

Therefore, the research team decided to develop a list of young people’s names specifically for the research project, with informed permission from the young people. This took a long time and much effort, but there were several advantages to this process. Awareness of our project grew through our publicity for the list, which included a giant snake on the health service wall which was gradually coloured in to indicate progress. We were able to get in touch with young people to ask them to be on the list through a wide range of contacts.

The need to add names to the list led to the production of a regular newsletter to keep young people informed about the project and related activities. Nevertheless, despite the interest generated, after several months we had only 400 names on our study list. We therefore asked the IEC whether we could send a letter out to those on the VAHS patient register in the relevant age group to inform them of the new after-hours clinic for young people, and include the information that we would add their name to the study list unless they objected. The IEC agreed to the proposal noting that it was crucial to the success of the study. No objections were received from young people so the names from the VAHS register were added to the study list from which we drew our random sample. The final list contained the names of 1116 young people. The Australian Bureau of Statistics estimates a population of approximately 10,000 Aboriginal or Torres Strait Islander people in metropolitan Melbourne (ABS, 1994). Given the age structure of the Aboriginal population we could expect 2500 (25%) of these to be in the 12–25 year age group.

Because we had data on which to base an estimate of the prevalence of hepatitis C we used this variable to calculate that a minimum sample size of 200 would allow us to estimate the prevalence of hepatitis C within a 95% confidence interval. We used an expected prevalence of 10% for hepatitis C, assuming that 35% of the estimated 30% that have injected drugs would be infected (Crofts et al., 1993). We knew that a large proportion of those on the final list might not be eligible and that we would have difficulty in finding many of the young people to participate in the study so we drew a random sample of 425. We asked young people at the Dulap Bininang Meeting Place, an initiative of the project that provides after-hours access to health care for young people, to pull numbers out of a box for the random sample. Of these 425 young people, we were able to determine that 113 (27%) were ineligible because they no longer lived in metropolitan Melbourne, they were not Aboriginal, or they had died. Of the 312 remaining in the sample we were unable to contact 104 (33%). It is likely that some of these were also ineligible to participate. Only 29 (9%) of the young people with whom we made contact declined to participate in the study. A total of 176 young people agreed to take part; 174 questionnaires and health checks were completed. Therefore, the response rate within the original sample was at least 56% (176/312). Because we do not know the number in our random sample that was eligible to participate we cannot calculate an exact response rate.

Despite this relatively low response rate we are confident that the 174 young people that took part are representative of the larger population of young Aboriginal people in metropolitan Melbourne. The distribution of age, sex and suburb on our register was similar to that of the Australian Bureau of Statistics

estimates. We used a wide variety of methods and networks to contact young people and those we were able to contact did not differ from those in the sample that we were not able to contact in terms of age, gender or suburb of residence.

#### *Recruitment and training of peer interviewers*

The interviews and FGDs gave us several suggestions for how to undertake the questionnaire survey, including advice to use peer interviewers:

You probably should have a Koori person with you. A young person who knows what's going on, they can generally say, "Come on cuz, if you don't want to answer it doesn't matter, but we'd like you to answer. That's what it's all about" and they talk in their own language...

We recruited a total of 18 young people as peer interviewers. They were of different ages, both sexes, living in a range of suburbs, and representing different family groups and networks. We trained them to administer the questionnaire and conduct a health check, and provided each with a detailed manual. They received payment for each interview and for their expenses. Some had large social networks and completed many interviews; others had smaller networks and did not feel comfortable to approach young people that they did not know. Some had little time to trace potential participants because of study, work or family commitments. We were able to recruit more peer interviewers without difficulty and felt that the larger number was not a problem because they reached a wide range of young people from different backgrounds with their varied networks. The use of peers also helped to raise awareness of the study in the community, and participants could complete the questionnaire at a time that suited them, not just within working hours.

An important principle of our research approach was that we did not want to impose on young people. This presents an interesting tension, because valid study findings depend on a high response rate. Peer interviewers tended to be reluctant to try to persuade young people who declined to take part in the health check component. In discussing this issue they suggested that checking whether another time might be more convenient would be acceptable, as would leaving a phone number for the young person to get in touch if they changed their minds. They agreed that it was important to allow an informed choice by explaining at the outset the reasons for the study, that it belongs to the community, and that we could only obtain a true picture of young people's health if most on the random list agreed to take part. But saying this to persuade someone who had already indicated that they were

unwilling was perceived as applying undesirable pressure. McMasters (1996) has pointed out that Aboriginal people may feel under pressure to participate when asked directly by researchers, but feel more free to decline when asked by peers. We could add that peers, probably because they are both more sensitive to subtle indications of lack of willingness and less concerned about the implications of a poor response rate, are less likely to pressure participants than Aboriginal or non-Aboriginal researchers. However, our experience suggests that young people are more likely to be genuinely willing to participate in a study when asked by a peer.

### Identifying code

To maintain confidentiality while allowing linking of questionnaires we developed a participant generated identity code, called a Hogben number (Honig, 1995). A sequence of questions is devised, which enables the participant to write down a series of numbers or letters to produce a unique identifying code. When the same questions are asked in the same order at subsequent rounds of data collection the participants' answers will produce the same unique identity code.

The use of Hogben numbers assured participants of confidentiality. Identity codes cannot be "lost" because they can be generated at any time when the participant answers the list of questions. However it is interesting to note that it was difficult to select questions that all young Kooris would be able to answer, and that would not be likely to change over time. We asked a representative group of young people for their ideas about questions for the Hogben number. After much discussion they chose the following five:

- "What is the third letter of your first name?" The first letter would have made it possible to identify the person and the second letter is often a vowel and so would be the same for many young people.
- "What is the first letter of the first high school (secondary school) that you attended?" Young Kooris may change school frequently, but they thought that they would be able to remember the name of the first high school that they attended.
- "What is your day of birth (e.g. 06,23)?"
- "Are you male or female?"
- "What is the first letter of the place where you were born?" This is an important fact for Aboriginal people and all the participants were able to answer this question.

This results in a six-character code such as *NW03FW*. This process for producing unique identifiers worked very well. Only two participants generated the same identity code—and they were twins! The code was generated again when blood or urine specimens were

taken and matched those generated for the questionnaires.

### Progress of the research

#### *Qualitative stage*

During 1996, 15 FGDs were conducted with a total of 80 young people. FGDs were held in a number of locations to provide representatives of different age groups, different family groups, school attendees and non-attendees, employed and unemployed, parents, and those living independently. We also interviewed 15 key people from the community who have contact with young Kooris through their work, or through personal commitment. We used the term "key people" rather than "key informant" which has unfortunate connotations. Prior to FGDs, interviews, and questionnaire administration we gave participants written details of familiar health workers and professional counsellors whom they could contact if they felt upset. The FGDs worked well, except with the younger boys who sometimes seemed shy when talking with an older facilitator.

All FGDs and interviews were taped, transcribed and coded. Categories for coding were developed by a group of Koori workers. The FGDs and interviews helped us to understand the underlying issues and informed the development of the questionnaire; they also raised awareness of the project, and enabled the research team to identify some areas requiring immediate attention. For example, there are a number of reasons why young people tend not to use services at the VAHS: most young people are healthy and some feel more comfortable to go to a clinic or health centre where they are not known. Young people feel self-conscious. They worry about confidentiality; for example, that they may be seen and questioned by a family member at VAHS. They also mentioned difficulties in understanding doctors and in being understood by doctors or older health workers. They suggested a separate clinic for young people.

We therefore collaborated with the local Yarta Wirta youth group to provide a young people's clinic and meeting place at the VAHS after usual hours on one evening a week. About 30 young people attend each week. Staff and volunteers plan a variety of activities, including trips to the gym, swimming pool and bowling alley. Homework tuition is also available and the young people receive a home-cooked nutritious dinner each week. The Fitzroy Stars Aboriginal Community Youth Club Gymnasium (FSACYCG) contribute staff and a vehicle. Doctors and younger health workers are available to chat with young people, provide advice and information in an informal way, and offer confidential counselling, for example in relation to behaviour change, hepatitis C and HIV testing. Each

week, several young people ask to see the doctor. Almost all have now had dental check-ups and treatment. The young people chose to name the program “Dulap Bininang” which means “Proud Cousins” in the Woiwurrung language (Dixon & Blake, 1991).

The qualitative findings have been used to explain and complement the quantitative survey results in a series of community reports. For example, the survey results suggested that the move from primary to secondary school is a key time to take up smoking, and the analysis of the FGD transcripts provided several reasons for this, as well as reasons why some young people did not take up smoking. These reasons can inform messages for primary school children to discourage them from starting to smoke.

#### *Quantitative stage*

In developing the questionnaire we reviewed those used by researchers from the Gatehouse Survey (Centre for Adolescent Health, 1997), “Don’t be shame if you don’t play the game” from the Indigenous Health Program (University of Queensland, undated), and the Urban Indian Youth Health Study (University of Minnesota, undated).

The questionnaire included questions on the following topics: personal characteristics; general health characteristics; access to and use of health care services; substance use; symptoms of depression and other mental illness; suicidal ideation and attempts; infection with blood-borne viruses; injuries; sexual and reproductive health; food choices; eating disorders; and contact with police and criminal justice system.

We pre-tested the questionnaire with a representative sample of 22 young people at Camp Jungai, an Aboriginal-run rural camp in central Victoria. Participants signed consent forms and the parents of those under 16 years also gave written consent. Several VAHS health workers and the researchers attended the camp. The friendly, relaxed and supportive atmosphere meant that the young people could talk to each other or to one of the adults present if they felt upset by the questionnaire or any of the discussions. The camp was held over three days, which enabled us to test and discuss the questionnaire, as well as other issues related to the data collection including the acceptability of the health check; the best way to contact young people; preference for computer or paper questionnaire; acceptability of testing urine for STDs; and acceptability of blood tests for hepatitis C. The questionnaire proved to be very acceptable, even though it took some young people more than an hour to complete. Some said that they found some of the questions upsetting, but they added: “*It gives us a chance to be honest. You need to know these things.*” The young people enjoyed themselves and made new friends; several expressed interest

in training as peer interviewers and showed great support for the project. Modifications suggested at Camp Jungai were incorporated into the questionnaire.

Young people in the random study sample were informed by letter of their selection and invited to attend the Dulap Bininang Meeting Place to undertake the questionnaire. Portable computers were also available so that the peer interviewers could deliver the questionnaire at participants’ homes. Young people from the random sample who could not read well had the questionnaire read to them, but made their own responses. Data collection also took place with small groups at other community centres.

The computer-administered questionnaire was popular and there were few difficulties. Both peer interviewers and participants liked the chance to use computers rather than paper. Consent for the second round of data collection was requested from each participant at the time of the first round.

The peer interviewers measured blood pressure, weight and height, and undertook the urine screen. They asked participants over the age of 16 years to come to the VAHS to see one of the study doctors for counselling and testing of blood and urine if they were willing. One hundred and forty young people were offered screening for hepatitis B and C, and HIV antibodies (blood), and chlamydia, gonorrhoea and trichomonas (urine or tampons). We developed separate consent forms for each test so that young people could decline single tests if they wished. Nineteen (13.6%) declined to see the doctor and so were not counselled. After pre-test counselling seven declined the blood test but agreed to have their urine tested for STDs. Six declined to give a urine or tampon specimen but were tested for blood-borne viruses. Participants were asked to return to the VAHS to receive their results and post-test counselling.

All data were entered into the statistical package SPSS, cleaned and checked. Simple frequencies and cross tabulations were determined. We also categorised certain variables and explored associations between different health-compromising behaviours and social factors, and between identifiable “resiliency factors” and a range of outcomes, using multiple logistic regression. In many instances it has been possible to make comparisons with all Victorian youth, and with North American native young people (Coffey, Ashton-Smith, & Patton, 1998; University of Minnesota Adolescent Health Program, 1992).

A series of community reports and journal articles are being produced which combine the qualitative and quantitative findings. A report and poster showing our findings about the strengths and protective factors of young Kooris were displayed at the VAHS 25th anniversary celebrations. The results are being shared with community members and organisations, various



government departments and other interested groups and organisations.

### *Constraints*

Several factors hindered the progress of the study. The start of data collection was delayed by the need to program the questionnaire. As expected, high mobility made it very difficult to contact many of the young people. Fewer than half lived at the addresses we had, and although we could trace many through community networks, this took time. The project team members are VAHS staff, so they are often drawn into assisting clients. During the first stage of the study there were major changes in the management and administration of the organisation. The peer interviewers varied in their commitment and in the time they could offer. Frequent changes of staff caused interruptions and the need to spend time on recruitment. The project had four different Research Fellows, which affected continuity. Koori researchers are affected by the same problems that affect their community, which may influence their work. In the second year there was high turnover in the Koori researcher position which had an adverse effect on data collection. It was often difficult to arrange for the participants to see the doctor after completing the questionnaire. They had to be willing to make themselves available again to the study, and the participants were spread across metropolitan Melbourne, often at some distance from the VAHS and with limited access to transport. In several cases the doctors visited participants at their home for the counselling and testing. Much time was spent establishing responses to the findings, e.g. the Dulap Bininang Meeting Place.

### **Outcomes**

A series of community reports have been prepared that describe: strengths and protective factors; cigarette smoking; substance use; sexual health and relationships; pregnancy and parenting; mental and emotional health and resiliency factors; nutrition and exercise; oral health and access to health and dental care services; confronting issues: anger; violence; criminal activity; contact with police and corrective services; education and employment; and money and housing. These contain quantitative estimates of the frequency of the problems as well as provide an understanding of the context of the problems illustrated with verbatim quotes by young people. They also include suggestions for action. Journal articles are also in preparation. These reports will be valuable to different program areas within the VAHS, to other Aboriginal community organisations, and to mainstream service providers and policy makers. The process of the study has already increased awareness of the

issues that face young people, and we expect that our results will trigger ideas for new responses and stronger services.

A significant outcome is that we have established a cohort for a longitudinal study. Adams (1994, p. 127) has argued that while public health research has grown in the areas of cross-sectional studies and large-scale data bases, there has been a dearth of Australian cohort studies: “True cohort studies are still few and far between as cost and logistics all too often militate against their establishment.” There is still much that we do not understand about the causes of the high prevalence of heart disease and diabetes in Aboriginal communities. A cohort study with rounds of data collection at intervals should provide important data.

We have observed that the study has contributed to a shift to a more positive attitude towards research among Aboriginal policy makers and staff, and increased the capacity to gather information for monitoring and evaluation, and to answer specific operational questions.

A further significant outcome has been the strengthened network of young Kooris. Several Koori health workers and young people have been trained in research and public health skills. They have gained confidence and now play important advocacy and management roles in a range of community organisations.

An outcome of the successful participation of young people in the study process was that their presence at the health service increased. Peer interviewers were trained and young people attended for interviews and health checks at the health service. Other young Kooris would then come in to meet their friends. The increased presence of young people has meant that in turn more young people feel comfortable to come to the health service and to make use of the services available. There are also now more young people employed by the VAHS.

A further benefit of the process of this project is that 121 young Kooris living in Melbourne have received pre and post-test counselling in association with testing for blood-borne viruses. Such counselling may lead to behaviour change, and certainly provides young people with important information.

The Dulap Bininang Meeting Place, despite lack of funding, has been a success and has led to collaboration with the FSACYCG and Yarta Wirta Youth Group. Experience at the Dulap Bininang Meeting Place has resulted in the introduction of a new model of clinical consultation at the VAHS. We found that in the informal atmosphere of the Meeting Place young women often asked whether they could be seen by the doctor with two or three of their friends. In these consultations each young woman might mention a health problem or question, and seemed to feel more confident with the doctor than if they had been alone. Young people undergo a transition from attending the doctor with a

parent to initiating a consultation on their own. The option to attend the doctor in a small group might ease this transition and encourage them to seek health care.

The VAHS now has a large collection of resource materials on indigenous youth issues which has been used by academics, students and by Aboriginal and non-Aboriginal health workers.

## Conclusions

We suggest that this research model offers one possible approach to improving Aboriginal health research practices. Tuhiwai Smith (1999, pp. 115–116) proposes that if research is to contribute to decolonisation there must be an agenda that is focused strategically on the goal of self-determination of indigenous peoples. This model is important because it fits with the principles of self-determination, as well as increasing the likelihood of valid findings. Our experience with sampling shows that although there are obstacles such as lack of population denominators and means to assess representativeness, Aboriginal communities also have strengths, such as close and extensive networks and organisation-based registers, that they can harness to improve the quality of research. We believe that validity was also increased because question guides and questionnaires were developed and checked by a range of Aboriginal people and because participants were more likely to trust the research team, and therefore more willing to take part and to give honest answers. The importance of trust has also been emphasised by Voyle and Simmons (1999) reporting their experience of evaluation with an urban indigenous community in New Zealand.

Opportunities for genuine community involvement occur more readily when a study is based in a community organisation. Non-Aboriginal researchers are employed by and accountable to the community through the elected board. Community members call in to chat with the Koori researcher and stay to add their suggestions to the work. Arranged meetings often fail, but in a community space such as the VAHS there are often opportunities to consult, pre-test materials, and check interpretations with a wide range of community members. A sense of participation and ownership was encouraged in many small ways throughout the study: for example, developing the Hogben number, drawing the random sample, helping with publicity, adding to the register.

However, it is not easy for community organisations to undertake research. There is a need for continual communication between the research team and the management of the organisation, and between the research team and the study participants, in this case the young people, who may have different perspectives

about the study activities. We found that the young Koori researchers played a key role in this ongoing negotiation because of their understanding of the dynamics within the community. There is also a need for continued negotiation between the research team and staff in other program areas. Community organisations are subject to frequent crises, which cause distractions, delays and disrupt the continuity of a study. Study activities may be seen as less of a priority than service delivery. Our experience confirms that of others who have noted that undertaking research in cross-cultural settings has “major implications for study costs and timelines” (Small et al., 1999, p. 385).

The NHMRC has produced guidelines on ethical matters in Aboriginal and Torres Strait Islander research, which emphasise the need for consultation, community involvement and clarification of ownership and publication of data (National Health and Medical Research Council, 1991). We believe that the thorough scrutiny of the Aboriginal IEC facilitated the ethical conduct of this research, and demonstrated that such committees can be established, officially registered and function well. Many IECs have problems in locating funds to resource the associated administrative tasks. We suggest that an amount for monitoring of ethical aspects of the research be added to the budget of research funding submissions. We feel that the existence of the IEC is also an important contribution to self-determination.

We found the ability to call informally on the members of the Academic Advisory Committee for advice when needed was more valuable than the formal meetings, which took much time to organise. Support from the Macfarlane Burnet Centre for Medical Research was also valuable. When partnerships or collaborations are planned there should be discussions to clarify ownership of data, including issues such as where, how, and for how long data will be stored, and how it may be accessed, and control of publication, for example whether the Board, representing the community, will have the right to veto publication, edit, or simply comment on articles. The agreement should be documented.

Some hold the view that the barriers to undertaking rigorous research in Aboriginal communities relate predominantly to cultural differences between researchers and researched (Kamien 1999a,b; Donovan & Spark, 1997). For example, Kamien (1999b, p. 23) has suggested that there is a conflict between the culture of the academic research community “to report the ‘truth’ as found by the researcher” and that of the Aboriginal communities’ culture of community ownership and desire to control the research process. Our experience, and that of others (Eades et al., 1999; Larson, 1996), suggests that there need not be such conflict. Aboriginal organisations undertaking research have just as much

interest in obtaining valid and meaningful results as the academic community, but retain the right to own the results and approve articles for publication, not in order to “censor”, but to ensure that they are aware of information being disseminated about their community and to avoid the harmful stereotyping that has occurred in the past. In our experience, the concern of Aboriginal representatives is that research results be reported with reference to the context, that confidentiality be maintained, and that Aboriginal people not be portrayed as passive victims.

We agree with Langton (1994) and Rowse (1996) when they argue for the importance of dialogue between Aboriginal and non-Aboriginal people working together. The research team has Aboriginal and non-Aboriginal members, working in an Aboriginal setting. We believe that our intercultural conversations about the research have helped us to build together new understandings about research and the research process, and that this has been facilitated because the dialogue takes place within an Aboriginal community controlled organisation.

It is sometimes suggested that quantitative research methods are not participatory (Stringer, 1996). We find that a combination of qualitative and quantitative methods provides complementary information, and can be carried out in a participatory way. Some questions are best answered with quantitative methods; young people expressed their wish to know the frequency of different behaviours and health problems in their community. Aboriginal organisations need to have the capacity to use a range of research methods. We believe that the way a study is conducted affects participation more than the methods used.

Conducting the research within a community controlled health service meant there was a capacity to act on findings and implement responses, such as the Dulap Bininang Meeting Place, during the research. This reflects Miller and Rainow's (1997, p. 96) experience that “If you are doing a survey on old people's needs be prepared to collect firewood”. Because of the range of programs there are opportunities for findings to influence planning and program implementation.

We recommend that similar research initiatives be supported by funding agencies as an important component of efforts to address the poor health status of Aboriginal communities. We agree with Redman (1996) that a national research strategy is needed that could establish a contract or targeted funding mechanism, which acknowledges that such research takes time and encourages researchers to develop the relationships that facilitate effective research. Our experience shows that, despite inevitable constraints, it is possible to implement rigorous research methods in an appropriate and acceptable way to collect useful Aboriginal health data. We hope that this analysis will assist others planning

similar research and demonstrate the value for process and outcomes of research conducted under Aboriginal community control.

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### References

- Adams, T. (1994). Long live Australian cohort studies. *Australian Journal of Public Health*, 18(2), 127.
- Anderson, I. (1988). *Koorie health in Koorie hands—An orientation manual for Aboriginal health care providers*. Health Department, Victoria.
- Anderson, I. (1994). Ethics and health research in Aboriginal communities, *Proceedings of conference. Researching health care: Methods, ethics and responsibility*. St. Vincents Hospital, Melbourne.
- Australian Bureau of Statistics. (1994). *Census of population and housing: Aboriginal community profile, 1991, Victoria, statistical division: 05 Melbourne*. Cat. no. 2722.2, ABS, Canberra.
- Australian Bureau of Statistics. (1998a). *Census of population and housing: Aboriginal and Torres Strait Islander people, Victoria, 1996*. Cat. no. 2034.0, ABS, Canberra.
- Australian Bureau of Statistics. (1998b). *Census of population and housing: Aboriginal and Torres Strait Islander people, Victoria, 1996*. Cat. no. 2034.2, ABS, Canberra.
- Australian Bureau of Statistics and Australian Institute of Health and Welfare. (1999). *The health and welfare of Australia's Aboriginal and Torres Strait Islander peoples*. Cat. no. 4704.0, ABS/AIHW, Canberra.
- Bert, P. (1889). *First year of scientific knowledge*. London: Relfe brothers.
- Black, N. (1994). Why we need qualitative research. *Journal of Epidemiology and Community Health*, 48, 425–426.
- Brady, M. A. (1993). Health issues for Aboriginal youth: Social and cultural factors associated with resilience. *Journal of Paediatrics and Child Health*, 29(Suppl. 1), S56–S59.

- Brough Smith, R. (1975). Physical description of Coranderrk inhabitants. In A. Massola (Ed.), *Coranderrk. A history of the Aboriginal station* (Appendix 8, pp. 75–76). Kilmore: Lowden Publishing.
- Centre for Adolescent Health. (1997). *Gatehouse survey term 1, 1997*. Centre for Adolescent Health, Royal Children's Hospital, Parkville.
- Coffey, C., Ashton-Smith, C., Patton, G. (1998). *Victorian adolescent health cohort study report: 1992 to 1998*. Centre for Adolescent Health, Royal Children's Hospital, Parkville.
- Colin, T., & Garrow, A., (1998). *Thinking, listening, looking, understanding and acting as you go along* (2nd ed.). Alice Springs: Council of Remote Area Nurses of Australia Inc.
- Crofts, N., Hopper, J.L., Bowden, D.S., Breschkin, A.M., Milner, R., & Locarnini, S.A. (1993). Hepatitis C virus infection among a cohort of Victorian injecting drug users. *Medical Journal of Australia*, 159 (4), 237–241.
- Day, S., Fayers, P., & Harvey, D. (1998). Double data entry: What value, what price. *Controlled Clinical Trials*, 19, 15–24.
- Dixon, R.M.W., & Blake, B.J. (Eds.). (1991). *Handbook of Australian languages*, vol. 4. *The Aboriginal language of Melbourne and other grammatical sketches*. Melbourne: Oxford University Press.
- Donovan, R. J., & Spark, R. (1997). Towards guidelines for survey research in remote aboriginal communities. *Australia and New Zealand Journal of Public Health*, 21(1), 89–94.
- Eades S.J., Read A.W. & the Bibbulung Gnarnep Team. (1999). The Bibbulung Gnarnep Project: Practical implementation of guidelines on ethics in indigenous health research. *Medical Journal of Australia*, 170(3), 433–436.
- Gray, D., Morfitt, B., Ryan, K., & Williams, S. (1997). The use of tobacco, alcohol, and other drugs by young aboriginal people in Albany, Western Australia. *Australia and New Zealand Journal of Public Health*, 21(1), 71–76.
- Guest, C. S., O'Dea, K., Hopper, J. L., Nankervis, A. J., & Larkins, R. G. (1992). The prevalence of glucose intolerance in aborigines and Europids of southeastern Australia. *Diabetes Research and Clinical Practice*, 15, 227–235.
- Hibbert, M. E., Hamill, C., Rosier, M., Caust, J., Patton, G., & Bowes, G. (1996). Computer administration of a school-based adolescent health survey. *Journal of Paediatrics and Child Health*, 32(5), 372–377.
- Holmes, W., & Thorpe, L. (1996). Establishing an institutional ethics committee for Aboriginal health research. *Human research ethics committee's institutional providers conference*, Adelaide, April 1996.
- Holmes, W., Phillips, J., & Thorpe, L. (1997a). Initiation and duration of infant feeding in the Melbourne Aboriginal community. *Australia and New Zealand Journal of Public Health*, 21(5), 500–503.
- Holmes, W., Thorpe, L., & Phillips, J. (1997b). Influences on infant feeding practices in the Melbourne Aboriginal community. *Australia and New Zealand Journal of Public Health*, 21(5), 504–510.
- Honig, F. (1995). When you cant ask their names: linking anonymous respondents with the Hogben number. *Australia and New Zealand Journal of Public Health*, 19(1), 94–96.
- Hunter, E. (1992). Feedback: towards the effective and responsible dissemination of Aboriginal health research findings. *Aboriginal Health Information Bulletin*, 17, 17–21.
- Kamien, M. (1999a). The Bibbulung Gnarnep Project: practical implementation of guidelines on ethics in indigenous health research, letter. *Medical Journal of Australia*, 171, 389–390.
- Kamien, M. (1999b). Letter to the editor. *New Doctor* 71, 23.
- Koori Health Unit. (1995). *Koori health counts*. Koori Health Unit, Public Health Division, Victorian Government Department of Human Services, Melbourne.
- Lake, P. (1992). A decade of Aboriginal health research. *Aboriginal Health Information Bulletin*, 17, 12–21.
- Langton, M. (1994). Aboriginal art and film: The politics of representation. In P. Poynton (Ed.), *Aboriginal Australia: Land, law and culture; Race and Class* (special issue) 35(4), 89–106.
- Larson, A. (1996). *What injectors say about drug use: Preliminary findings from a survey of indigenous injecting drug users*. IDU project working paper no. 2, Australian Centre for International and Tropical Health and Nutrition, University of Queensland.
- Manderson, L., Kelaher, M., Williams, G., & Shannon, C. (1998). The politics of community: Negotiation and consultation in research on womens health. *Human Organization*, 57, 222–229.
- McKendrick, J., Cutter, T., MacKenzie, A., & Chiu, E. (1992). The pattern of psychiatric morbidity in a Victorian urban Aboriginal general practice population. *Australian and New Zealand Journal of Psychiatry*, 26, 40–47.
- McMasters, A. (1996). Research from an Aboriginal health workers point of view. *Australia and New Zealand Journal of Public Health*, 20(3), 319–320.
- Miller, P., & Rainow, S. (1997). Don't forget the plumber; research in remote Aboriginal communities. *Australia and New Zealand Journal of Public Health*, 21(1), 96–97.
- Miller, P. J., Torzillo, P. J., & Hateley W. . (1999). Impact of improved diagnosis and treatment on prevalence of gonorrhoea and chlamydial infection in remote Aboriginal communities on Anangu Pitjantjatjara lands. *Medical Journal of Australia*, 170(9), 429–432.
- National Health and Medical Research Council, NATSIHC. (1991). Guidelines on ethical matters in Aboriginal and Torres Strait islander health research. National Health and Medical Research Council, Commonwealth of Australia, Canberra.
- Paperny, D. M., Aono, J. Y., Lehman, R. M., Hammar, S. L., & Risser, J. (1990). Computer-assisted detection and intervention in adolescent high-risk health behaviors. *Journal of Pediatrics*, 116(3), 456–462.
- Redman, S. (1996). Towards a research strategy to support public health programs for behaviour change. *Australia and New Zealand Journal of Public Health*, 20(4), 352–358.
- Ring, I. T., & Firman, D. (1998). Reducing indigenous mortality in Australia: Lessons from other countries. *Medical Journal of Australia*, 169, 528–533.
- Rowse, T. (1996). *Traditions for health*. North Australia Research Unit, The Australian National University, Canberra and Darwin.

- Small, R., Yelland, J., Lumley, J., & Rice, P. (1999). Cross-cultural research: Trying to do it better. *Australia and New Zealand Journal of Public Health*, 23(4), 385–390.
- Stringer, E. T. (1996). *Action research: A handbook for practitioners*. Thousand Oaks, CA: Sage.
- Tabrizi, S. N., Paterson, B. A., Fairley, C. K., Bowden, F. J., & Garland, S. M. (1998). Comparison of tampon and urine as self-administered methods of specimen collection in the detection of *Chlamydia trachomatis*, *Neisseria gonorrhoeae* and *Trichomonas vaginalis* in women. *International Journal of STD and AIDS*, 9(6), 347–349.
- Tuhiwai Smith, L. (1999). *Decolonizing methodologies. Research and indigenous peoples*. Dunedin: Zed Books Ltd.
- University of Minnesota Adolescent Health Program. (1992). *The state of native American youth health*. Minneapolis.
- University of Minnesota. (undated). *Urban Indian youth health survey*. Indian Youth Resiliency Impact Study, School of Nursing, Minneapolis.
- University of Queensland. (undated). *Don't be shame if you play the game*. Indigenous Health Program, University of Queensland, St Lucia.
- Voyle, J. A., & Simmons D. (1999). Community development through partnership: promoting health in an urban indigenous community in New Zealand. *Social Science & Medicine*, 49(8), 1035–1050.