



## Development of guidelines for non-Indigenous people undertaking research among the Indigenous population of north-east Victoria

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NOT ONLY IS INDIGENOUS HEALTH in Australia poor,<sup>1-4</sup> “there is widespread agreement that knowledge about the health status of the Aboriginal population is inadequate”.<sup>5</sup> Some Indigenous health research has been of immense use in designing and evaluating interventions which have improved the health status of Indigenous people, especially at the local level.<sup>6,7</sup> Consequently, high-quality, proactive, participatory research is needed.<sup>8,9</sup>

Because there are few Indigenous healthcare professionals and researchers in Australia, non-Indigenous researchers are involved in Indigenous research. Ensuring these researchers work in culturally appropriate and non-exploitative ways is a key concern.<sup>2,10,11</sup> This article documents an approach that developed a partnership between researchers and Koorie communities in parts of northern Victoria and southern New South Wales. It extends previous guidelines about general research issues (cultural beliefs, language, privacy and questioning approaches)<sup>12,13</sup> by describing how community research has been appropriately undertaken. This is more innovative, comprehensive and in addition to agreements between specific Indigenous organisations and researchers,<sup>14</sup> for it develops a culturally sensitive and outcome-based policy for non-Indigenous researchers before partnerships are entered into.

### Setting

The multidisciplinary Department of Rural Health (DRH), University of Melbourne, was established in 1999. One of its three objectives is to assist in reducing the health differential between Indigenous and non-Indigenous people.<sup>15,16</sup> The DRH was sited in Shepparton, partly because the area has the largest Indigenous population in Victoria outside Melbourne (estimated 6000 Indigenous residents).<sup>17</sup> This includes communities in Shepparton/Mooroopna, Barmah/Cummeragunja, Echuca/Moama, Kerang, Swan Hill and Albury/Wodonga. One community is a small town of mostly Aboriginal residents, and the others have Indigenous residents living among the non-Indigenous

### ABSTRACT

- The Department of Rural Health, University of Melbourne, has developed a framework for conducting research in partnership with Indigenous communities.
- The framework addresses past inappropriate research practices, incorporates cultural understandings, and outlines culturally appropriate protocols.
- The four parts of the framework are a committee to initiate, direct and oversee all research projects; a Koorie Team to guide research; a set of research guidelines; and a policy for the department.
- The framework has been used to develop strong relations with Koorie communities and conduct various health projects.

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population. These communities have high rates of diabetes, heart disease and depression (about 40%–50% for each), compounded by huge rates of unemployment, very low completion of high school, alcohol and drug issues, low incomes and low self-esteem.<sup>18,19</sup> Exact rates for many of these are lacking at the community level and it is likely that many unidentified health issues also exist.

Indigenous communities in this region have had negative experiences with research projects due to the lack of community control, lack of local benefits, and interpretation of data in isolation from social context.<sup>9,13,20</sup> Therefore, a framework was developed to build a partnership between local Indigenous communities and the new academic department.

### The Indigenous research framework

#### *Establishment of the partnership committee*

The Koorie Health Partnership Committee (Box 1) was established in 1999. All Koorie organisations in the region were invited to join the committee, which meets bi-monthly to identify health priorities, develop specific projects and review the activities of the DRH, communities and individual organisations. The committee has initiated projects on topics including cross-cultural issues, workforce, and a “bush tucker” project in which nutritional, cultural and legal aspects of traditional foods can be examined. Members of the partnership committee have also been on selection committees for new appointments to the department and acted as advisers to the Koorie Team.

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### **Establishment of a Koorie Team in the department**

The DRH established a Koorie Team, accountable to the partnership committee and the Koorie communities. Team members carry out tasks set by the partnership committee and work with researchers to develop programs aimed at improved Koorie outcomes. The Koorie Team has connections with the Koorie Health Research and Community Development Unit at Melbourne University and gains additional support from elsewhere within the university, but is supported mostly by the local communities.

### **Guidelines for Koorie research**

The partnership committee recognised the need for written protocols to guide non-Indigenous members of the DRH in working within Koorie communities. In consultation, the Koorie Team developed guidelines to ensure that members of the DRH are informed of appropriate actions and negotiation within Koorie communities and organisations. The guidelines are also intended to develop trust, reinforce the integrity of the DRH and maintain robust relationships with local communities that can withstand some difficulties (eg, funding that only partially meets partnership committee objectives). The guidelines also protect non-Indigenous researchers, maintaining their neutrality.

The guidelines are based on general research guidelines, the National Health and Medical Research Council (NHMRC) *Guidelines on Ethical Matters in Aboriginal and Torres Strait Islander Health Research*,<sup>13</sup> and the input of researchers and the partnership committee.

### **Community consultation**

Koories work and act collectively, so each community must be consulted about any research being proposed within it. The following steps outline the appropriate consultation process.

- In preparing a proposal, the project group should first seek approval from the Board of Directors of the Koorie community organisation. The project group should present a written proposal and discuss the project with the Koorie organisation and any others deemed appropriate.

*In some projects, project organisers have held or attended community meetings to gain the perspectives of community members. In other projects, the input of local boards, the partnership committee and a project steering committee has been viewed as adequate.*

- Project outcomes should be negotiated between, and mutually agreed upon by, the project group and the community organisation before any research begins.

*Existing projects negotiated outcomes at the start of each project during community consultations, some aiming to improve the health of study participants, some to establish healthcare programs, and others to provide recommendations for existing healthcare programs.*

- A nominated representative of the local Koorie community with the appropriate authority (designated by the community and related to the project) should represent the community to liaise with the project group and monitor the implementation of these guidelines.

### **1: Organisations in the Koorie Health Partnership Committee**

Allinjarra Aboriginal Cooperative (Kerang): Cultural centre with a range of support and healthcare programs.

Bangerang Cultural Centre (Shepparton): Keeping Place, cultural centre, community education for Koorie and other communities.

Department of Rural Health, University of Melbourne (Shepparton): Research, university education, training, community development.

Goulburn Valley Aboriginal Women's Resource Group (Shepparton): Koorie women's group to provide support, information and develop women's programs.

Koorie Economic Employment and Training Agency (Shepparton): Training and employment program with non-Indigenous businesses/organisations.

Local Aboriginal Education Consultative Group (Shepparton): Works with primary and secondary schools to support Koorie students. Offers preschool and daycare.

Mungabareena Aboriginal Cooperative (Wodonga): Cultural centre with a range of support and health care programs.

Rumbalara Football Netball Club (Shepparton): Football and netball club participating in 'mainstream' league; also runs a health promotion program.

Rumbalara Aboriginal Cooperative (Mooroopna): Cultural centre with a range of support programs and an Aboriginal Health Service.

Savina Morgan Health Centre (Cummeragunja): Aboriginal Health Service.

Swan Hill and District Aboriginal Co-operative (Swan Hill): Cultural centre with a range of support and health care programs.

- All research proposals require written documentation of consent and support from the Koorie organisation or community in which the research is to be conducted.

- The project group is responsible for ensuring that Koorie organisations and participants are fully aware of the research process and the use of any tools and equipment. Cultural protocols must be followed when using videotape recording, audiotape recording, multimedia images or other visual or voice recordings.

### **Community involvement**

The Koorie community and relevant Koorie organisations should remain involved in the activity throughout the entire research project, from design to implementation of outcomes.

- It is recommended that a project steering committee or reference group be established to oversee the research. Gender must be respected: Koorie women, as advised by the community, will be involved in women's issues, Koorie men in men's business. The specific cultural and social needs of elders and children also need to be recognised.

- Individuals involved in a project steering committee or reference group should be paid a fee, negotiated between the two parties.

### **Administration of local ethical review for research**

There might be a need and resources for a local Koorie ethics committee. If this is not possible, the following local structures are likely to prevent problems arising.

■ The ethics committee reviewing the research proposal should include two Koorie people (to avoid tokenism and intimidation) to assess the need for referral to a Koorie community group.

■ A local Koorie community group with cross-community representation should be convened to assess any additional local Koorie community issues (history, social context, etc) in relation to any proposal. This group is likely to include greater representation than the initial group consulted.

*In some projects, the partnership committee has had sufficient breadth to fulfil this role.*

**Supervision of individuals inexperienced in working in the Koorie community**

Non-Indigenous researchers need to be supervised to ensure their actions are culturally appropriate. It is recommended that a Koorie worker be employed to advise the project organisers of these issues and to accompany non-Indigenous researchers in the community. The local Koorie representative should oversee the activity of non-Indigenous people working in Koorie communities.

*A Koorie project worker or research assistant has usually been employed on projects, sometimes both a man and a woman, to work with both men and women in the community.*

**Data storage and retention**

Koorie communities believe they have the right to own data collected in their community. However, because of the strong ties within Koorie communities, individual research participants must not be put in jeopardy in their own community for their contributions. Thus, while the community controls the use of the data and how and where they are reported, communities do not have access to individual-level data (such as an interview transcript) which might compromise confidentiality. In the past, the Koorie Team has held the data, but all reports stemming from the research are controlled by the community.

■ Projects must be conducted according to data principles negotiated and agreed with Koorie communities at the outset.

■ Research material and data remain the property of the Koorie community.

■ Before publication of research data or reports, the draft texts must be approved by the designated consultative Koorie organisation.

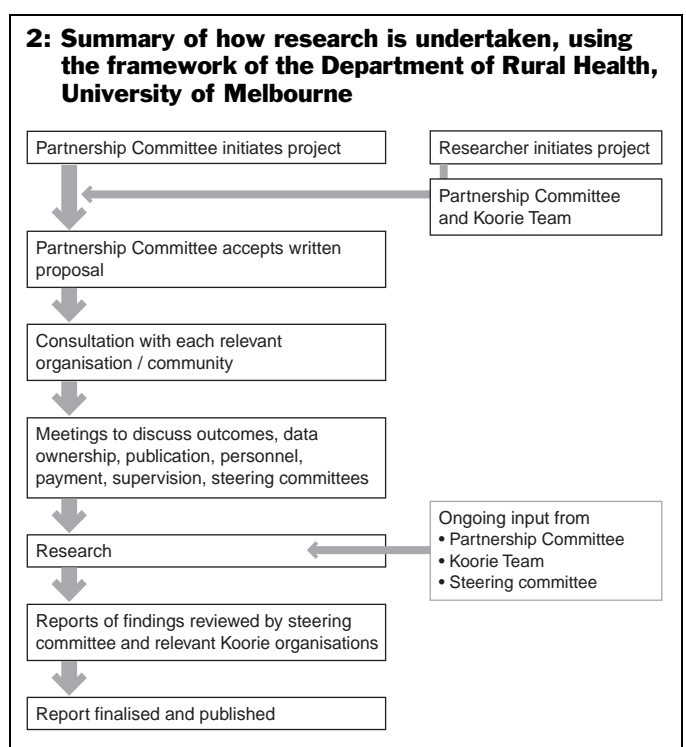
■ Publication should include details of the joint research and community context of the research and the role of the Koorie community in formulating the direction and work of the project.

■ Acknowledgements should include proper accreditation of participation and assistance of the Koorie community, individuals and organisations.

■ Results must not be published in a form that permits the identification of individuals without their consent.

■ Data will not be used for any purpose other than that for which consent was gained, unless further permission is given by the designated consultative Koorie organisation.

■ The return, storage or destruction of data will be negotiated with the designated consultative Koorie organisation



before data collection begins and again at the completion of the data collection.

*In projects to date, the raw data have been held by the Koorie Team at DRH (for confidentiality) and copies of interview transcripts have been given to specific interviewees. Research reports are given to the community and relevant organisations, after discussion, and these are owned by the community. Generally, communities insist on constructive reporting and tend to reject reports that could be politically damaging. Communities and organisations maintain the right to ask for further analysis and other information from the project to assist in addressing their own goals. Academic publications tend to be written by DRH members, but are approved by the partnership committee and relevant communities and organisations before submission for publication.*

**Departmental policy**

It became DRH policy that all activities with Koorie communities must be discussed with the Koorie Team, who then inform the partnership committee. It also became policy that all activities follow these guidelines, be culturally and historically sensitive, and aim to improve Koorie health outcomes — the priority is to benefit communities rather than researchers.

**Application of the framework**

The DRH framework means that research is undertaken with consultation before, during and after the project (Box 2). Usually a Koorie research assistant is employed to assist with consultation and data collection and analysis. Payment of study participants and steering committee members has not been common, but research assistants and project officers are paid.

Although the process appears straightforward, the complexity cannot be overstated. For example, different Koorie organisations often have different expectations of outcomes, and levels of involvement, interest and commitment. Because of the holistic nature of such research, many organisations are usually involved, with unclear boundaries and changing requests. Further, the guidelines sometimes challenge scientific procedures or call for researchers to negotiate sampling, data collection techniques and presentation of results.

The usual university ethics approval is still required.<sup>21,22</sup> Ethics committees have agreed on requirements to date, including steering committees, employing Koories, storage of data with the Koorie Team, written consent, the role of the partnership committee, ongoing consultation and approval of all reports. Our framework extends general ethical requirements, calling for research to be culturally sensitive and accepted as necessary and useful by the communities of the participants. This gives communities the power to decide what research should be undertaken, a voice on how research is conducted, and control over presentation of the findings.

## Conclusions

Participatory research is increasingly being used in a variety of settings among indigenous communities in Canada, the United States, Sweden, South Africa and New Zealand.<sup>2,12,23-25</sup> The approach presented here, in conjunction with others,<sup>9,13</sup> should provide a positive starting point for negotiation between Indigenous communities and researchers in other regions of Australia.

Rather than develop one-off Koorie research projects, the DRH has developed a framework to promote partnership with Koorie communities in research, education, employment and community development. This framework reflects the Indigenous holistic view of health and the relationship between physical health outcomes, the social determinants of health and the need to respect the integrity of each Indigenous community. Most importantly, ongoing negotiations allow flexibility within the guidelines — they are adapted to each project and allow for the development of new phases and extensions to previous projects.

As relationships between DRH and Koorie communities have strengthened, the workload for the partnership committee and Koorie Team has increased dramatically. Including Koories in most health research has meant the partnership committee and Koorie Team are involved in most research at the DRH. In addition, despite inclusive processes and openness of information, local political and family histories still raise issues. The partnership committee, Koorie Team and researchers can find themselves between conflicting family groups or perceived to favour some families or organisations over others. The challenge for outsiders to understand and address this, and for insiders to work between them while living in these communities, remains.

The growth and use of evidence for developing and implementing sustainable interventions to improve Indigenous health is urgently required. Our framework addresses

the key concern of undertaking this while respecting history and Indigenous cultures.

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