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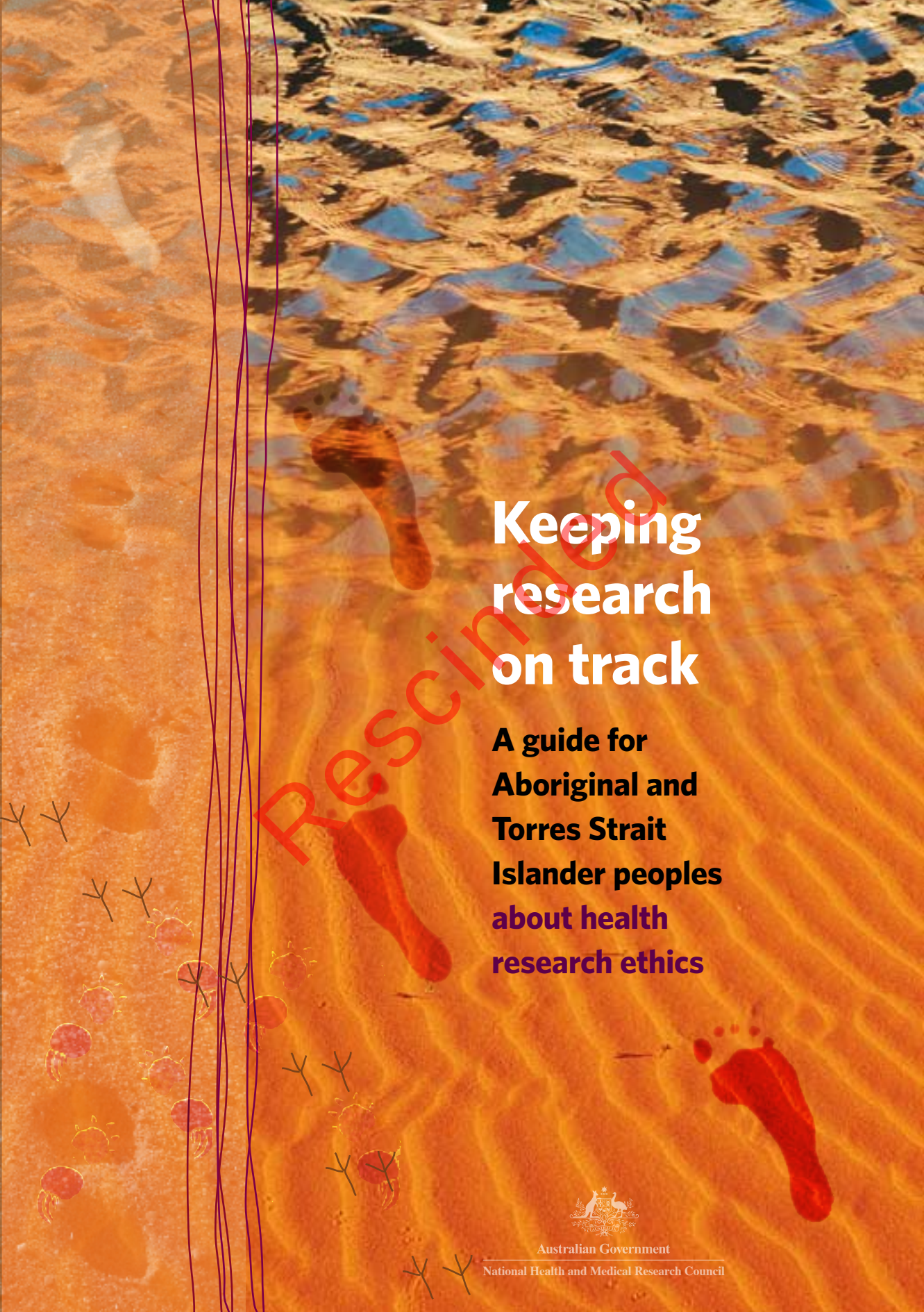
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Keeping research on track

**A guide for
Aboriginal and
Torres Strait
Islander peoples
about health
research ethics**



Australian Government

National Health and Medical Research Council

Rescinded



Making research work for us

Over the years there has been a lot of research undertaken in our communities into aspects of Aboriginal and Torres Strait Islander health and well being. Sometimes the outcomes from this research have not always benefited Aboriginal and Torres Strait Islander peoples and communities.

This booklet is about helping people to become familiar with the stages in the research journey. It helps us to understand the steps that we need to follow in order to make the research work for us.

Aboriginal and Torres Strait Islander peoples have a right, and indeed a responsibility, to be involved in all aspects of research undertaken in our communities and organisations. Referring to this booklet when making decisions about health research can help make sure that the research journey respects our shared values as well as our diversity, our priorities, needs and aspirations; and benefits Aboriginal and Torres Strait Islander peoples as well as researchers and other Australians.

For some communities and organisations this material could be told using other cultural ways such as through paintings, radio recordings, dance or plays. >> see page 45 >>

This booklet contains all the information that is relevant to Aboriginal and Torres Strait Islander peoples to help us make sure that any research undertaken in our communities:

- respects our shared values
- is relevant to our priorities, needs and aspirations
- develops long term ethical relationships with researchers, institutions and sponsors.

The information in this booklet comes from 2 key national publications which set out the ground rules for the ethical conduct of health research involving people.

National Statement on the Ethical Conduct of Research Involving Humans (NHMRC, 1999) and *Values and Ethics: Guidelines for ethical conduct in Aboriginal and Torres Strait Islander health research* (NHMRC, 2003).

>> see Source Documents page 34 >>

A committee of the National Health and Medical Research Council (NHMRC), the Australian Health Ethics Committee (AHEC), working together with M Squared Research Assisted Design, is responsible for developing this booklet for all Aboriginal and Torres Strait Islander peoples.

>> see Who is the NHMRC? page 44



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Joining in the research journey:

This story shows how you can make research work for your community or organisation by becoming involved in each step of the research journey.

Working in partnership with the researchers from the very start can help you to create many benefits for your community or organisation.

An Aboriginal community from a remote area participated in a health research project. The aim of the research was to compare the health of children before and after they were treated for scabies; and to see whether improved housing, infrastructure and additional health services helped to improve children's health.

How the community joined in the research

- The first step was for Council to give their agreement for community-wide participation in the project, and ask for Ethics Committee (HREC) approval. >> see page 5 >>
- A health management committee worked with the research team throughout the research journey.
- Researchers came to meetings with the Council and other service agencies to make sure that everyone understood the health significance of treating and preventing scabies.
- Some community members trained as researchers on the project.
- The community requested that the consent forms for children to participate in the program be written in local language as well as English.
- Throughout the project the researchers talked with community members about the aspects of everyday life that can cause the spread of disease, like inadequate housing, lack of health services, overcrowding, poor sewerage and visits between communities.

A success story

The outcomes

As a result of participating in the research project the community received:

- home repairs, improved sewerage and additional health services
- improved on-going health outcomes for the children, that flowed into other communities through strong cultural links
- new knowledge and understanding of:
 - the importance of community involvement in research
 - how to prevent the spread of infectious diseases
 - how to achieve improved hygiene, health and living standards.

These benefits were specific to this project and this remote community. The benefits from research projects in a city or rural community may be very different. However, the same principles of community involvement can be used anywhere.

Why it worked for that mob and could work for you!

Having community members involved in the research from the beginning led to many benefits for the community. The outcomes were broader than the researchers' original intention because the community negotiated for greater outcomes to meet their needs.

Being involved encouraged the community to:

- set things up properly to meet local health priorities and needs
- accept ownership of the research project and of achieving improved health and living standards
- watch the whole process to keep the research on track for the community
- jointly author the report at the end of the research.

Community partnership with the research team helped the researchers:

- to understand Aboriginal structures and family values
- to embrace flexibility and negotiation
- to feed back the results of research in culturally appropriate ways.

Use this booklet to check out the steps your community needs to take at each stage of the research journey and make research work for you.

What are human research ethics?



Aboriginal and Torres Strait Islander cultures operate within defined ethical frameworks. Many people may not be familiar with the terms used by researchers.

Here are the usual definitions for the terms: ethics, research ethics, ethical research, and research benefits.

Understanding the jargon

What are ethics?

Ethics is about beliefs, and the way we think and behave. It is about the rules of behaviour and human duty, morals and values: that is, understanding right and wrong, justice and injustice, good and bad, and doing the right thing.

What are human research ethics?

Human research ethics are a set of principles to help guide researchers to develop and do research in a way that is safe, respectful, responsible and of high quality.

What is ethical human research?

Ethical research is a research project in which each of the 8 steps of the research journey >> see pages 15-29 >> are considered ethically acceptable (human rights protected) by all stakeholders involved (research team, research participants, research communities/organisations and other interested community members).

What is human research benefit?

A research benefit is another way of talking about a positive outcome that results either directly or indirectly from the research. The benefit may be immediate, short term or long term, local or Australia-wide.

Examples of research benefits for Aboriginal and Torres Strait Islander peoples may include: employing community members on the project team, improvements to health services, or a focus on communities' and organisations' priorities for additional services.

HRECs What are they?

Human Research Ethics Committees (HRECs) are responsible for the ethical review of research. They check whether research proposals respect basic human rights and shared values, and have high quality methods, skilled people and resources to do the research.

HRECs are generally located within universities, research organisations and sometimes regional hospitals and health departments. Some States and Territories have Aboriginal HRECs.

>> see page 40 >>

Communities can request which HREC should be a part of the research approval process. Some HRECs have Aboriginal sub committees.

HRECs will receive research progress reports and applications to change the approved research process for those projects it has approved. An important part of any research agreement is to identify an HREC contact person. Establishing a relationship with this contact person can help community and organisational representatives feel confident about raising any concerns they may have about the way the research is progressing.

Getting on track ...

This booklet aims to empower Aboriginal and Torres Strait Islander peoples to get the most out of research projects.

Why this booklet was developed

During 2002, NHMRC held a series of national workshops and received submissions to consider Aboriginal and Torres Strait Islander health research issues. Three important messages came out of this process:

- The need for improving the way researchers work with Aboriginal and Torres Strait Islander peoples.
- The need for developing the research capabilities of Aboriginal and Torres Strait Islander peoples.
- The need to improve our awareness of our rights as participants in the research journey.

>> see *NHMRC Road Map* page 35 >>



Keeping research on track

The best way to keep research on track is for researchers and participants to work together to develop long term partnerships based on trust and shared values.

This booklet will help us to work out whether any proposed research is relevant, ethical and appropriate by:

- identifying our most important shared values
>> see page 8 >>
- listing our rights to participate in all stages in the research journey
>> see page 10 >>
- outlining the 8 common steps of the research journey and listing key questions we may need to ask at each stage
>> see page 15 >>
- providing a check list of the steps community members may follow to keep the research on track
>> see pages 28-29 >>

Thinking about research

The main thing is not to be scared about participating in the research journey. We have done it for years. Research is part of Aboriginal and Torres Strait Islander traditions.

Today it is important to negotiate with the researchers right from the start about the what, why, how and who questions for the research project.

Meetings with the researchers are ongoing throughout the project.

Think about how this might happen for your community or organisation.

You could have:

- a local steering committee
- a community reference group
- a cultural mentor who keeps everything on track
- research assistants who train with and work alongside the researchers.

>> see pages 16-21 >>

Our most important values

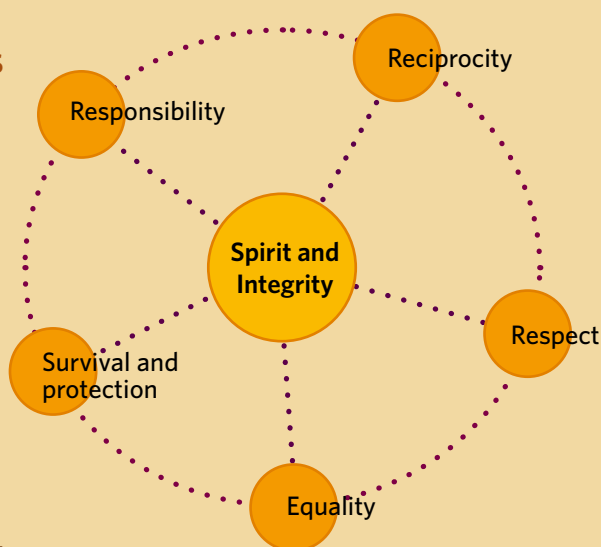
Aboriginal and Torres Strait Islander societies each have their own established and respected values and protocols, and unique ways of expressing their different values.

There are however six common values that have been identified as being important to all Aboriginal and Torres Strait Islander peoples (core values).

Each community or organisation has the right to express how these core values, and any unique values, will be addressed in research.

Spirit and Integrity

This is the most important value that joins all our Aboriginal and Torres Strait Islander peoples' values together. The first part, Spirit, is about the on-going connection (continuity) between our past, current and future generations. The second part, Integrity, is about the respectful and honourable behaviours that hold Aboriginal and Torres Strait Islander values and cultures together.



Reciprocity

Our way of shared responsibility and obligation is based on our diverse kinship networks. This process in our communities keeps our ways of living and family relationships strong. These responsibilities also extend to the care of the land, animals and country and involve sharing benefits from the air, land and sea, redistribution of income, and sharing food and housing.

Respect

Respect for each other's dignity and individual ways of living is the basis of how Aboriginal and Torres Strait Islander peoples live. Within our cultures, respect strengthens dignity, and dignity strengthens respect. A respectful relationship encourages trust and co-operation. Strong culture is built on respect and trust, and a strong culture encourages dignity and recognition, and provides a caring and sharing environment.

Equality

Aboriginal and Torres Strait Islander peoples recognise the equal value of all individuals. One of the ways that this is shown is in our commitment to fairness and justice. Equality affirms and recognises Aboriginal and Torres Strait Islander peoples' right to be different.

Survival and protection

We continue to protect our Aboriginal and Torres Strait Islander cultures, languages and identity. Recognition of our shared cultural identity, which is based on our shared values, is a significant strength.

Responsibility

All Aboriginal and Torres Strait Islander communities recognise the same most important (core) responsibilities. These responsibilities involve country, kinship bonds, caring for others, and the maintenance of cultural and spiritual awareness. The main responsibility is to do no harm to any person, or any place. Sometimes these responsibilities may be shared so that others may also be held accountable.



Our rights to participate in research

It is important to think about our rights, responsibilities and expectations if our communities and organisations are going to participate in or conduct research.

Our right to commission research that meets our priority needs

There are many ways that this could be done. You could approach your local Aboriginal Health Service, Aboriginal and Torres Strait Islander units in your local university or local research organisations and Aboriginal health sections in local, State and Federal governments. It is important to note that not all Aboriginal Health Services or other community-based organisations have the time or resources to provide assistance but they might be able to provide further contacts.

Our right to say no up front

There may be occasions where researchers approach communities or organisations with research proposals whose questions and/or outcomes do not address your priorities. In such a case it is OK to say No.

Our right to say yes

A community, organisation or person has the right to say Yes to be involved in research.

Our right to negotiate a different focus for the research

There might be times when communities and organisations are approached by researchers to become involved in their research program. You may need to ask: Does the proposed research promise outcomes that will address some of our priority needs? Does it comply with our cultural ways?

You have the right to negotiate how your communities/organisations will participate in the research to achieve your goals.

Our right to say no or request more time to talk about the research proposal

You don't have to participate in research and you have the right to refuse to do so. If you request more time to talk it might mean that the researchers may need to go somewhere else to do the research. You might also wish to explore the research topic with other researchers when people are ready to do so.

Our right to expect that our culture and values (beliefs) are respected

Making sure that the research processes, timelines and expected outcomes are appropriate to our communities' shared culture and values is important. >> see page 8 >>

The *Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research* document >> see page 34 >> supports the expectation that Aboriginal and Torres Strait Islander peoples should have their culture and values respected.

This document refers to past policies and laws imposed without seeking guidance from or listening to the views of our peoples.

It recognises that Aboriginal and Torres Strait Islander peoples do have connection to their past. Aboriginal and Torres Strait Islander societies draw strength from the body of knowledge, values and wisdom, from our heritage and also from the lived experiences of colonisation.

Our rights continued

It is better to agree on the processes and outcomes of research **before** the research commences.

Our rights if the trust with the researchers is broken

We have the right to:

- go back to the HREC contact person for help << [see page 5](#) <<
- contact the Health Ombudsman or Health Care Commissioner in your state or territory (refer to the telephone book for the contact number)
- contact the Human Rights and Equal Opportunity Commission.
>> [see page 41](#) >>

Our right to have input into the research agenda

We have the choice of:

- going along with external research agendas such as the *NHMRC Road Map* document >> [see page 35](#) >>
- establishing our own research agenda
- working in partnership with the researchers to make sure the research has a positive outcome and meets our communities'/ organisations' needs and expectations
- making some research a low priority.

Our right to check on the researcher's track record

When communities or organisations employ researchers to work with them it is good practice, as part of the recruitment process, to check on the researcher's track record of working with Aboriginal and Torres Strait Islander peoples.

This will help the community to make sure that the research team has the required knowledge and experience to work in partnership in a way that acknowledges our culture and values.

>> [see page 32](#) >>

Our right to expect that the way we do things in our communities/ organisations is respected during the research process

This can be monitored by setting up a local steering committee to arrange frequent feedback between the research team and community members.

Our right to negotiate a formal research agreement

This agreement should cover intellectual property rights >> see page 14 >> benefits, publication, translating research findings/outcomes, use of community or organisational facilities, conflict resolution processes, monitoring of progress milestones and any other matters the communities/ organisations feel are important.

The World Health Organization (WHO) has an example of a formal research management agreement that may be useful to consider >> see page 41 for a WHO website address >>

Our right to seek advice and support to help us negotiate formal research agreements

If your community or organisation would like to participate in research but do not feel confident about your resources, you have the right to seek advice and ask for assistance to negotiate agreements.

For example, your community/ organisation might require interpreters during the negotiations and the researchers should engage interpreters to aid this process.

There are a range of organisations that may be able to assist.
>> see pages 40-41 >>

Our right to delay or stop (terminate) the research

If there is a breach of the formal research agreements, or of the way your community and organisation would like things done, you have the right to stop (terminate) or suspend the research. Sometimes these long delays might put the research project at risk because of the funding requirements. The researcher will need to work through this.



Intellectual property

Aboriginal and Torres Strait Islander cultural and intellectual property has been described as the:

'...rights...that exists in the cultural practices, resources and knowledge systems of Indigenous peoples, and that are passed on by them in expressing their cultural identity.'

The Australian Institute of Aboriginal and Torres Strait Islander Studies *Guidelines for Ethical Research in Indigenous Studies* (2000)

>> see page 35 >>

Put more simply, this means ... anything that is written, spoken or created by Aboriginal and Torres Strait Islander peoples, whether it is a story, a painting, a sculpture, an object, a dance, a song, or music (cultural practices), and any knowledge of our land, culture or kinship that is used to express our cultural identity, is our intellectual property.

It is acknowledged that Aboriginal and Torres Strait Islander peoples' intellectual property continues to grow with all contemporary creative and original works that have been based on Aboriginal and Torres Strait Islander cultural heritage.

Additional information about intellectual property management for your organisation can be found at www.nhmrc.gov.au/funding/policy/ipmanage.htm

The 8 steps of the research journey

This guide to the 8 steps in the research journey will help people who are involved in negotiations about research to make sure that the research is relevant to communities'/organisations' priorities, needs and aspirations.

Each step describes what needs to happen and lists key questions to ask.

Use the questions like a checklist to keep the research on track, ethical and appropriate. This process will also help to maintain relationships with the research team.

Regardless of who comes up with the research idea or who does the research, >> see page 31 >> it is important to think about whether or not the research is right (ethical and appropriate) for our communities/organisations.

This thinking should happen throughout the research journey (process).

The best way to keep research ethical and appropriate is by asking questions at each of the 8 steps in the research process. >> see pages 16–29 >>

Not every research project will have all the 8 steps, and the steps may not always happen in the same order.

Sometimes we may skip a step.

Other times we may need to take a step back, and ask the questions again so that we can maintain trust and be confident that the research process is on the right track for us.

Some of the questions are specific to that particular step of the research. Other questions may be asked at any time throughout the course of the research to help monitor progress.



1 Building relationships

The first step in any research journey is about building relationships. This refers to both the researchers and the community/organisation members getting to know one another.

As well as being the first step in the journey, it is important to maintain relationships throughout the whole research journey.

In talking with one another and talking about how strong working relationships can happen with researchers, it is important to talk about our values and ways of doing things (protocols).

<< see pages 8-9 <<

During this stage we need to think about whether or not the research team has the knowledge, skills and experience to do this research.

>> see page 32 >>

After we have established relations we are ready to move to the next step. The communities/organisations can then decide whether to:

- go ahead with the proposed research
- go ahead with the research but with changes to the processes, outcomes or even how the research question is framed; or
- not go ahead with the research.

<< see our rights to participate, pages 10-13 <<

QUESTIONS TO ASK OURSELVES

- Are we ready to enter into this relationship?
- Are the researchers respecting our values and ways of doing things (protocols)? << see pages 8–9 <<
- Have we explained our community's or organisation's standards of behaviour and respect (protocols and processes) to the researchers?
- Have we made it clear to the researchers that we can and will suspend or even stop (terminate) the research project if it is not meeting our ethical and cultural standards? << see pages 11, 14 <<
- Have we chosen a cultural mentor to guide and work alongside the researchers? >> see page 33 >>
- Have we made sure that the researchers have allocated resources to funding the work of our cultural mentor?
- Have the researchers given the communities/organisations enough time to be involved in ways that are acceptable to our peoples? If not, are we still willing to be involved?

QUESTIONS TO ASK THE RESEARCHER

- Who are the research team (including students)? Which organisations are they from?
- Why were we approached?
- What other communities/organisations were invited to be involved in the research? What were their concerns and why?
- Are the researchers aware of current issues in our communities?
- Does the proposed research allow time and resources for the research team to get to know Aboriginal and Torres Strait Islander peoples before they start collecting data?
- How can members of our communities/organisations be involved in the research?
- Will Aboriginal and Torres Strait Islander peoples get formal and/or informal qualifications from being on the research team? If so, how?
- Which HREC has been identified and who is the HREC contact person? << see page 5 <<

2 Conceptualisation—thinking

The second step, developing the research idea or conceptualisation, is where we explore all aspects of the research.

This stage is where we think broadly about what we want (planning), what the researchers want, how the research might benefit our community or organisation, and what risks there might be.

This is the time to explore all the possibilities to make sure that we understand each other and get the most out of the research.

It is a time for us to share in shaping the research to meet our needs.

Things to think about include the:

- focus of the research
- management of the project including steering or advisory committees
- our levels of participation
- skills development for Aboriginal and Torres Strait Islander peoples
- outcomes from the project.

It is also important to maintain (continue developing) the relationships that we established in the first step.

IS THE RESEARCH RIGHT FOR US?

- What is the aim of the project?
- Does everyone understand what the project is about?
- Do we need an interpreter?
- Is there a clear description in plain or local language of the proposed project that everyone can understand?
- Are all the details of how the research process will run clearly explained?
- When will the research start? Is this negotiable?
- Has the project already been to an Ethics Committee?
<< see page 5 <<
- Has the Ethics Committee been informed about relevant Aboriginal and Torres Strait Islander values?
- Are there appropriate community/organisational and individual consent processes in place? >> see page 36, 38 >>
- What measures are there to protect our confidentiality and privacy?

QUESTIONS ABOUT RISKS AND BENEFITS?

- Is this research a priority for our communities/organisations?
- Does this research meet our priorities and goals?
- Who is funding the research?
- What are we getting out of the research?
- What are the researchers getting out of this research?
- What are the risks if we participate in the research?
- What are the social, cultural and physical benefits to:
 - individuals? (financial, social, health)
 - organisations? (human, financial, resources)
 - communities? (survival and protection, reputation)
- What are the costs to individuals, organisations and communities? (inconvenience)
- Can our communities/ organisations afford these costs? If not, what can we do?

3 Development and approval

The third step, development and approval, is where the research team and the communities/organisations work out all the final details.

Three things to do:

- 1 Provide a letter of community/organisation support.

>> see page 36 >>

- 2 Jointly develop the ethics application for approval.
- 3 Develop the Research Agreement and make sure that everyone understands it.

It is good practice to have a **written agreement** between the research team and the communities/organisations about what the research project will look like. This is called a 'research agreement'. The World Health Organization's website address provides a sample research agreement.

>> see page 41 >>

Ask the researchers for, or work with them to write, a clear explanation of the agreement so that everybody understands what the proposed research is all about.

Letter of support

Once everyone understands the research question, agrees with the details of how the research will be done, and has read and is happy with the 'ethics application form', then it is time for us to provide a letter giving community/organisation support. This letter will go with the researcher's application to the HREC for final approval of the project.

Do not provide a letter of community/organisation support for the project if the people are not happy with every detail. Wait until the necessary changes have been made.

Do not start the research without ethics approval.

QUESTIONS ABOUT FINAL DETAILS

- Are the methods for research culturally and personally appropriate?
- What does the funding cover (human resources, equipment, office space, etc)?
- What is expected 'in kind' (use of the communities'/organisations' time, resources, equipment etc) ?
- What are the communities/ organisations expected to pay for?
- Who will be on the steering or advisory committee?
- Is there a clear description (plain or local language) of the process and outcomes that the researchers expect?
- Are there agreed arrangements for suspending or stopping the research? << see page 13 <<
- If body parts or specimens are collected as part of the research what happens to these at the end?
- Do we understand what is meant by 'informed consent'? >> see page 36 >>
- Have the researchers given us Informed Consent Forms that we can easily understand?
- Are we happy to provide a letter of support for the research?
- Have we named a HREC contact person in the Research Agreement?
- Will there be any opportunity for employing and training Aboriginal and Torres Strait Islander peoples?
- How is the data (research information) to be stored?
- Is the data being linked to any other data?
- How may the data be used in the future? Who may use the data? Who is the contact for this?
- Who owns the data?
- Can the communities/ organisations use the data?
- Does the proposal clearly state community benefit?
- What situations or outcomes would trigger the need for renegotiation between the communities/organisations and the researchers?
- How will the results of the research be published?
- What opportunities are there for checks and balances?
For example, will the researchers be reporting to and liaising with the communities/organisations at each step in the research journey?

4 Data collection and management

The fourth step, data collection and management, is when information is being collected during the research. Data may take many forms. >> see page 37 >>

REMEMBER! Feedback between the researchers and communities and organisations should continue through all stages of the research journey.

Information (data) may be collected from many places including health records, people, statistical collections and other sources. Data collection may also include blood samples.

Management of the data collection process includes:

- getting consent from each individual to participate in the research
 - ensuring that all the information collected is kept private (confidential) and where appropriate de-identified.
- >> see pages 36-37 >>

Community feedback

It is good practice to have regular meetings to discuss progress, concerns and issues.

KEEPING THE RESEARCH ON TRACK

The following questions will help you think about monitoring the project and may be asked at any time throughout the course of the research.

- Do we have regular feedback meetings that talk about everybody's point of view (researchers, participants, organisations involved, other community members)?
- Is the time frame for the project on track (target)?
- Are there any difficulties so far?
- Do participants feel that they are able to give their informed consent (photo use, specimen use, testing with children etc)?
- Are enough people involved?
- Is there anything stopping our community members from participating?
- What are the outcomes to date?
- Do we need to make any changes to the process written down in the Research Agreement between the researchers and the communities/organisations?
- Are the communities'/organisations' protocols/processes being observed?
- Is the research running to budget?
- Does everyone still understand what this research is about and where it is going?
- How and where is the data being stored?
- Is the data only being used for this project as agreed?

5 Analysis—looking at the meaning

The fifth step, analysis, is when the research team looks at the information that has been collected to see what it shows and what it means.

Both the researchers and the community/organisations need to talk about what the information which has been collected means for each of them.

It is important to understand the results of the research and to talk about what this means for the community or organisation.

QUESTIONS TO ASK

- What are the processes for analysis of data (and future re-analysis)?
- What is the role of the community /organisation in the analysis and interpretation of the data?
- Do we understand and agree with what the researchers say the research means?
- Are the findings important to our communities/organisations?
- What happens if we disagree with the research teams' interpretation?

6 Report writing

Step six, report writing, is about putting the information (findings) together to tell the story.

This includes explaining what has been learnt in this study, discussions about these findings and some recommendations.

It is important for the communities/ organisations to have input at this stage to make sure that the information is presented in ways that are culturally appropriate.

It is also important that the report acknowledges community contribution, authorship and intellectual property, as stated in the Research Agreement.

QUESTIONS TO ASK

- What types of reports or publications are being prepared? Will there be a written report, journal paper, conference paper, presentation, audio/visual CD or community report? Will there be a combination of reports?
- Have we given consent to use photos?
- How will we be involved to comment on the design, structure and drafts of the reports?
- What will happen if our communities/organisations are unhappy with any of the reports or with the way the reports have been written up?
- Who is the author, co-authors?
- How will the communities/ organisations be recognised or acknowledged? (This should not be in conflict with individual and community concerns about identification).
- Has the funding body got any specific report writing requirements?

7 Dissemination—sharing the results

The seventh step, dissemination, is about sharing the findings of the research with other communities, organisations, policy makers and funding bodies. This may be done in many ways, such as community meetings, stakeholder meetings, conference presentations, radio interviews, newspaper articles and publications in journals.

The results of research

The results of health research can be used in different ways, for example, to improve health and living arrangements, or to develop health policies.

To get outcomes for Aboriginal and Torres Strait Islander peoples it is important to tell the story (research findings) to the right people.

The research results can be used to lobby government departments.

QUESTIONS TO ASK

- Will there be a media launch?
- Who will be the media contacts?
- Will the researchers follow up important findings from the research to get good outcomes for our communities like better health services?
- Will the research budget cover the costs of printing reports and media broadcasts?
- Does the funding body have any special dissemination requirements about releasing the reports?
- Will there be a Plain English Community Report?

8 Learning from our experience

The eighth step is about looking at (evaluating) the research process from the community or organisational perspective.

This is a very important step and gives us information about how to improve the next formal Research Agreement.

It might also identify other important research questions, and consider whether knowledge transfer has been effective.

What is knowledge translation?

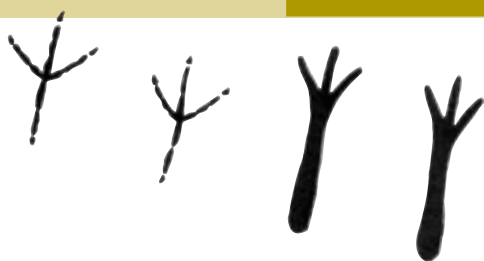
Knowledge translation is the process of joining in and so understanding the 8 steps of the research process, knowing the questions to ask at each stage and understanding the many outcomes.

We can use what we have learned (knowledge translation) to negotiate future research projects.

We can use the outcomes of the research to lobby or advocate for policy or service delivery changes.

QUESTIONS TO ASK

- What was good about this journey?
- What have we learned?
- What can we do better next time?
- Where to next?



Keeping the research on the right track

The 8 steps research process Researcher's tasks

1

Establishing relationships

- Contact and meet the Aboriginal Council members or appropriate Aboriginal organisation
- Meet local key people
- Find out about our protocols
- Contact and visit local Aboriginal organisations

2

Conceptualisation—thinking and planning

- Explaining the big research picture
- Negotiation and decision making
- Work with communities to fill out ethics approval form to go to HREC

3

Development and approval—finalising the Research Agreement

- Finalise the Research Agreement
- Sign Research Agreement when everybody is happy
- Jointly develop the ethics application for approval. Do not start without ethics approval.

4

Data collection and management

- Training Aboriginal and Torres Strait Islander peoples
- Working ethically with participants to collect data

5

Analysis—working out what the data means

- Look at the information that has been collected to see what it means
- Prepare the findings in a clear statement that everybody can understand
- Hold community meetings and get feedback on the analysis

6

Report writing

- Maintain constant relationships with communities/organisations when writing all reports
- Acknowledge all local co-authors
- Meet funding body's needs for report writing

7

Dissemination—sharing the findings or research results

- Present findings to community
- Publish and broadcast the findings

8

Learning from our experience

- Help the communities/organisations to work out the effectiveness of their involvement at each stage of the research process

Overview of community involvement

Community/organisational involvement

More information

- Prepare a list of our communities'/organisations' codes of behaviour (protocols and values) for the researchers
- Prepare a list of priority issues
- Choose a cultural mentor to work along side the researchers
- Community and organisational feedback into the appropriateness of research
- Select the HREC contact person

<< see pages 16-17 <<
<< see pages 8-9 <<

>> see page 33 >>
>> see pages 32-33 >>
<< see page 5 <<

- Negotiation and decision making
- Feedback into appropriateness of research agenda
- Assess risks and benefits of proposed research

>> see pages 18-19>>

- Make sure there is a clear explanation of the Research Agreement which all community members can understand
- Request different approaches if need be
- Jointly develop the ethics application for approval.
- Provide a letter of community/organisation support

>> see pages 20-21 >>

- Research participants sign individual consent forms
- Community/organisational participation
- Regular meetings with researchers to discuss progress

>> see pages 22-23 >>

- Attend community meetings to make sure we understand the meanings derived from the data
- Talk about whether the findings are important to our communities/organisations
- Make sure any meanings that are important to us are included in the findings

>> see page 24 >>

- Get communities/organisations involved to prepare and present report information.
- Check that the communities/organisations are properly acknowledged
- Check that we agree with all the reports
- Ask for a Plain English Community Report

>> see page 25>>

- Make sure that the research findings are presented to the communities/organisations first, before being broadcast outside

>> see page 26 >>

- Evaluate if this research has been good for us
- Identify the good and not so good outcomes
- Is there anything we would change next time?

>> see page 27 >>

About research and researchers

Research is a process where people with the right skills look for answers to a specific issue or situation, or describe a situation. The researchers gather information (data collection), and then look at the meaning of that information (analysis). The results are written up in a report, and the key findings are shared with other people (dissemination). The results may be used in different ways. Finally, the project will be looked at (evaluation) to see if the research was worthwhile.

Common types of research

- **Surveys (descriptive)**
Surveys involve collecting information about people or communities in an organised way. They include using questionnaires or interviews to ask people about issues that are important to their health and well being.
- **Experiments (analytical studies)**
These are scientific studies that may include testing a new medicine or way of treating a disease.
- **Quantitative (numbers)**
Involves counting and measuring, eg, the number of cigarettes smoked each day, or weight and blood pressure readings.
- **Qualitative (stories)**
Involves describing, eg, the views people have about alcohol use in their community. The information might be obtained from a focus group or a one-on-one interview.
- **Evaluation**
A research process used to decide the worth or value of something, eg, a new approach to providing support to mothers with young babies, or a new drug to treat diabetes.

Health research may be:

- suggested (proposed) by an outside researcher or organisation
- commissioned by the government
- commissioned by a community
- suggested and undertaken by a local community organisation.

Ways of starting research

- **Researcher driven research**
When researchers select a topic, approach communities/ organisations, and ask permission to do the research.
- **Government requested research**
Research may be carried out in partnership with government departments, mining companies, pharmaceutical companies, universities, research institutes and other private businesses.
- **Community requested research**
When communities or organisations identify the topic, approach a researcher and ask them to do the research.
- **Community driven research**
When an organisation or community use their own research team to undertake research that the organisation/community has identified as important.

Finding out about researchers

If we are looking for a researcher to undertake a project, or if we have been approached by a researcher to be involved in a project, we need to decide if the researcher is right for us.

3 things to check about the researcher:

- knowledge, skills and capabilities
- resources and budgets
- experience working with Aboriginal and Torres Strait Islander communities.

CHECKING OUT THE RESEARCHER

Use this checklist to find out if a researcher is right for us.

- **Yarn with your mob**
Use community networks to learn if the researcher has worked successfully with Aboriginal and Torres Strait Islander peoples before.
- **Ask the researcher**
Talk directly to the researcher about other projects they have done with Aboriginal and Torres Strait Islander communities or organisations.
Consider whether the researcher has enough resources and support to do the research in a way that meets our needs and expectations.
- **Referees**
Ask the researcher to provide referees (contacts) for past projects.
- **Ask for a cv**
Get a copy of the researcher's academic qualifications and history of their previous research and work experience.
- **Publications**
Check whether the books, journal articles and experience of the researcher are relevant to the proposed research topic.

Issues with 'new' researchers

Not all researchers have had experience in Aboriginal and Torres Strait Islander health research. It can be as difficult for established researchers with no previous experience of working with Aboriginal and Torres Strait Islander peoples as it is for junior researchers to show proof of relationships with Aboriginal and Torres Strait Islander communities.

While it is not essential that a researcher has already worked with Aboriginal and Torres Strait Islander peoples, it is important that a 'new' researcher is able to show:

- A commitment to relationships with key individuals or organisations within the community.
- An understanding of our shared cultural values, and specifically how the host communities/organisations express these values in relation to health research.
- The intention, where possible and appropriate, to employ local researchers and community members in the research process.
- An understanding of the potential and actual difficulties that Aboriginal and Torres Strait Islander peoples face when working in research.

Working with 'new' researchers

Sometimes it can be good to work together (collaboratively) with a 'new' researcher who has no previous experience with Aboriginal and Torres Strait Islander peoples. The outside researcher brings knowledge, education and research skills, which they share with us, and we bring local cultural and research knowledge, which we share with them.

A good way to help a new researcher fit in is to work together using a cultural mentor program. The cultural mentor may be a local researcher who works between the community and the outside researcher, joining in all stages of the research.

Partnerships between the researchers, cultural mentor and community benefit everyone.

- The researchers develop knowledge and an understanding of working with Aboriginal and Torres Strait Islander peoples.
- The community mentor develops further research skills.
- The community gets both the research outcomes, and a practical understanding of the research journey.

Further reading

Source documents

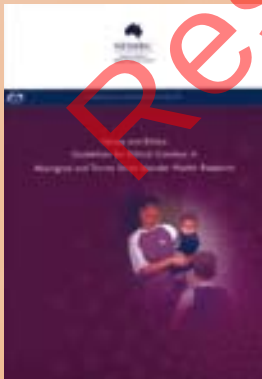
Information in this booklet was taken from the following key NHMRC documents. All NHMRC guidelines are reviewed every five years to ensure they remain in line with current thinking and expectations about research directions. Because of these reviews people are advised to check the status of these documents on the NHMRC website. The status and authority of these documents is set out under the *National Health and Medical Research Council Act 1992*.



1 *National Statement on Ethical Conduct of Research Involving Humans* (NHMRC, 1999)

This document sets out the ground rules for all publicly funded research that all researchers in Australia must follow when conducting research that involves human participation.

www.nhmrc.gov.au/publications/synopses/e35syn.htm



2 *Values and Ethics: Guidelines for ethical conduct in Aboriginal and Torres Strait Islander health research* (NHMRC, 2003)

This publication, developed through national consultations, introduces special requirements for developing and conducting research in a manner that is respectful and inclusive of Aboriginal and Torres Strait Islander values and culture.

The ethical principals outlined in this publication are based on 6 core values identified during the consultations as being important to Aboriginal and Torres Strait Islander peoples.

www.nhmrc.gov.au/publications/synopses/e52syn.htm

Useful publications

The following resources offer guidance on research processes.

Guidelines for Ethical Research in

Indigenous Studies (Australian Institute of Aboriginal and Torres Strait Islander Studies 2000) www.aiatsis.gov.au/corp/docs/EthicsGuideA4.pdf

Joint NHMRC/AVCC Statement and Guidelines on Research Practice

(NHMRC, 1997)

This document lays down expectations for good practice in research.

Our Culture: Our Future

www.icip.lawnet.com.au

This document has information about intellectual property and copyright.

The NHMRC Road Map: A strategic framework for improving Aboriginal and Torres Strait Islander health through research (NHMRC, 2003)

This document was developed from information gathered during a series of workshops and submissions undertaken in 2002 to consider Aboriginal and Torres Strait Islander health research issues. A balance of Aboriginal and Torres Strait Islander and non-Aboriginal views are represented. It identifies key research areas important to improving Aboriginal and Torres Strait islander health and well being.

www.nhmrc.gov.au/publications/synopses/r28syn.htm

Other NHMRC publications

The following publications are all available from the NHMRC website www.nhmrc.gov.au/publications.

Human Research Ethics Handbook (NHMRC, 2001)

National Principles of Intellectual Property Management (NHMRC, 2001)

Statement on Consumer and Community Participation in Health and Medical Research (NHMRC, 2002)

When Does Quality Assurance in Health Care Require Independent Ethical Review? (NHMRC, 2003)

To seek other relevant current NHMRC publications from the index:

www.nhmrc.gov.au/publications/index.htm#2



Glossary of terms

AHEC: Australian Health Ethics Committee, one of the four principal committees of the NHMRC.

>> see page 44 >>

Analysis: when the research team look at the information they have collected to see what it shows and what it means. >> see pages 24-25 >>

Community: may include a group or organisation; a term used to describe a shared view amongst Aboriginal and Torres Strait Islander peoples of groups based on culture, language, geography or common interests.

Community/organisational support: a group or organisation saying 'Yes' (giving voluntary agreement) to participate in research. They do this only after they have a good understanding of everything that is involved.

Community protocols and standards: cultural and societies' ways of doing things (codes) to protect and preserve the well being of the societies, for example, asking permission to enter communities, and dressing the right way.

Conceptualisation: 2nd step of the research journey, where you think more about the research questions, and how the project can best be done.

Confidentiality: when you are given private information about somebody else, not using that information for any purpose other than for which it was given.

Copyright: ownership of anything you have created. The legal right granted to an author, composer, playwright, publisher, or distributor to exclusive publication, production, sale, or distribution of a literary, musical, dramatic or artistic work.

Cultural Intellectual Property: the protection of cultural knowledge, cultural expressions, cultural ideas and cultural materials.

Cultural mentor: a community or organisation member, funded by the research project, to make sure that the researchers stay on the right path, and that the project remains within cultural bounds and remains safe for everyone involved.

Data: information (words, numbers, specimens, papers, blood and tissue samples, audiovisual recordings, art work) collected during research processes to help answer the research questions.

Data collection and management: 4th step of the research journey, the time when all the information (data) is collected, and how that data is used.

>> see pages 22-23 >>

Development and approval: 3rd step of the research journey, when the research team and communities or organisations work together to finalise how the project will run, who will do the work (research team), who is part of the research team (researchers and/or community members), who controls it (steering/ advisory committee) and who funds it.

>> see pages 20-21 >>

Dissemination: the 7th step of the research journey where the research team tells everyone the results (research findings). This can be done in many places, through scientific meetings, conference presentations, scientific journals and community meetings. >> see page 26 >>

Equality: fairness, equal opportunity.

Ethics: your beliefs, the way you think and behave: that is, understanding right and wrong, justice and injustice, good and bad, and doing the right thing. >> see page 4 >>

Glossary continued

Ethical human research: a research project in which each of the 8 steps of the research journey >> see pages 15–29 >> are considered acceptable (human rights protected) by all stakeholders involved (research team, research participants, research communities/organisations and other interested community members).

Evaluation: 8th step of the research journey. Looking at whether the research was worthwhile.
>> see page 27 >>

Findings: see Research findings

HAC: Health Advisory Committee, one of the four principal committees of the NHMRC. >> see page 44 >>

HREC: Human Research Ethics Committee. >> see page 4 >>

Individual consent (informed consent): when you say 'Yes' to do something or be involved in something once you have a good understanding of everything that is involved. You also have the right to say 'No'.
>> see page 10 >>

In-kind: a way of providing support without money (time, buildings, machines, transport, reference group, mentoring etc) to a research project.

Intellectual property: original creative works in literary, artistic, industrial and scientific fields that can be protected either by copyright or trademarks.

Knowledge translation: processes where knowledge is created and shared understandings are exchanged within the group and wider to help improve or change something. In research this might occur throughout the time the project is running and after the project is finished to help improve services, or change policy, or seek more funding. << see page 27 <<

LC: Licensing Committee, one of the principal committees of the NHMRC.
>> see page 44 >>

NHMRC: National Health and Medical Research Council, peak funding body for health and medical research.
>> see page 44 >>

Privacy: protecting someone's personal information. Control over the extent, timing, and circumstances of sharing oneself (physically, behaviourally, or intellectually) with others.

Reciprocity: a two way process. The sharing of skills, knowledge, goods and services that creates responsibility within a relationship where the sharing becomes a mutual obligation. For example, I share openly with you and that's what I expect back.

Report writing: 6th step in the research journey. Writing down what the research team found out in their analysis of the data collected during the research process.

Research: a process where people explore and describe the 'How', 'What', 'If' and 'Why' questions of an issue or situation.

Research benefits: the positive outcomes that come, either directly or indirectly, from the research.

Research ethics: the application of principles of ethics to the involvement of humans in research.

Research findings: the conclusions or results from a study, evaluation or investigation.

Research methods: the planned way of doing research using different skills, knowledge and processes that are usually guided by the type of study.

Research outcomes: processes where knowledge is created and shared understandings are exchanged within the group and wider communities to help improve or change something. In health research this might occur throughout the time the project is running and after the project is finished to help improve services or change policy or seek more funding..

Research protocol: the rules, roles, policies and procedures that will be followed within a specific research project.

Respect: the way we show that we value someone or something.

Values: our belief systems and ways of doing things. << see pages 8-9 <<

Helpful organisations

These organisations may be able to assist Aboriginal and Torres Strait Islander peoples who are involved in negotiations about health research.

The National Health and Medical Research Council (NHMRC)

www.nhmrc.gov.au

For queries about Aboriginal and Torres Strait Islander research and research funding
phone 1800 500 983

For queries about AHEC, local and currently registered HRECs or other general ethical issues

Email ahec.nhmrc@nhmrc.gov.au
phone 02 6289 9575

Australian Indigenous HealthInfoNet

www.healthinfonet.ecu.edu.au

Australian Institute of Aboriginal and Torres Strait Islander Studies

www.aiatsis.gov.au

Australian Indigenous Doctors Association

www.aida.org.au

World Health Organization

You can download a
Sample Research Agreement from
www.treatycouncil.org/about11.htm

United Nations Permanent Forum for Indigenous Peoples (website)

[www.unhchr.ch/indigenous/forum.
htm](http://www.unhchr.ch/indigenous/forum.htm)

National Aboriginal Community Controlled Health Organisation (NACCHO)

This national Aboriginal health
organisation represents Aboriginal
Community Controlled Health Services
throughout Australia.

Their website is:
www.naccho.org.au

For your local or state organisation see
your local telephone directory.

Office for Aboriginal and Torres Strait Islander Health (OATSIH)

Australian Government Department of
Health and Ageing
phone 02 6289 5291
email oatsih.enquiries@health.gov.au

Universities

See your local telephone directory.
Many universities have Aboriginal and
Torres Strait Islander Centres that might
be able to provide assistance.

Aboriginal Medical/Health Services (AMS, AHS)

See your local telephone directory.
State and territory community based
AMS and AHS may not have the time
or resources to be able to provide
assistance, but they may be able to
put you in touch with other research
contacts.

The following site has some useful links
to other sites:

[www.doctors.healthon-net.com/
abhealth/ablinks.htm](http://www.doctors.healthon-net.com/abhealth/ablinks.htm)

Human Rights and Equal Opportunity Commission

GPO Box 5218, Sydney NSW 1042
02 9284 9672 Toll free 1300 369 711.

Congress of Aboriginal and Torres Strait Islander Nurses (CATSIN)

email catsin@bigpond.net.au

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Consultations and events to develop this booklet

Organisations

- : Wuchopperen Health Service Cairns, July 2004
- : Queensland Aboriginal and Islander Health Forum, July 2004
- : Australian Institute of Aboriginal and Torres Strait Islander Studies, August 2004
- : Winnunga Nimmityjah Aboriginal Health Clinic and Health Service, ACT, August 2004
- : South West Aboriginal Medical Service, Bunbury, November 2004
- : Derbarl Yerrigan Health Service, Perth, November 2004
- : Hobart University Indigenous Centre, November 2004
- : Torres Strait & Northern Peninsula Area Regional Authority, April 2005
- : Ceduna Koonibba Aboriginal Health Service Inc, May 2005
- : Port Lincoln Aboriginal Health Service, May 2005
- : Central Australian Aboriginal Congress, June 2005
- : Centre for Remote Health, Alice Springs, June 2005
- : NHMRC Indigenous Forum, August 2005
- : NHMRC Aboriginal and Torres Strait Islander Research Working Group, August 2005
- : Australian Health Ethics Committee, December 2004 and July 2005

Presentations

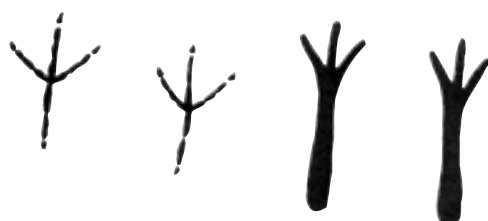
- : National Indigenous Researchers' Forum, Newcastle, November 2004

Key informants

- : Ms Juanita Sherwood
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- : Ms Stephanie Bell
- : Ms Pat Anderson
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- : Dr Shane Houston

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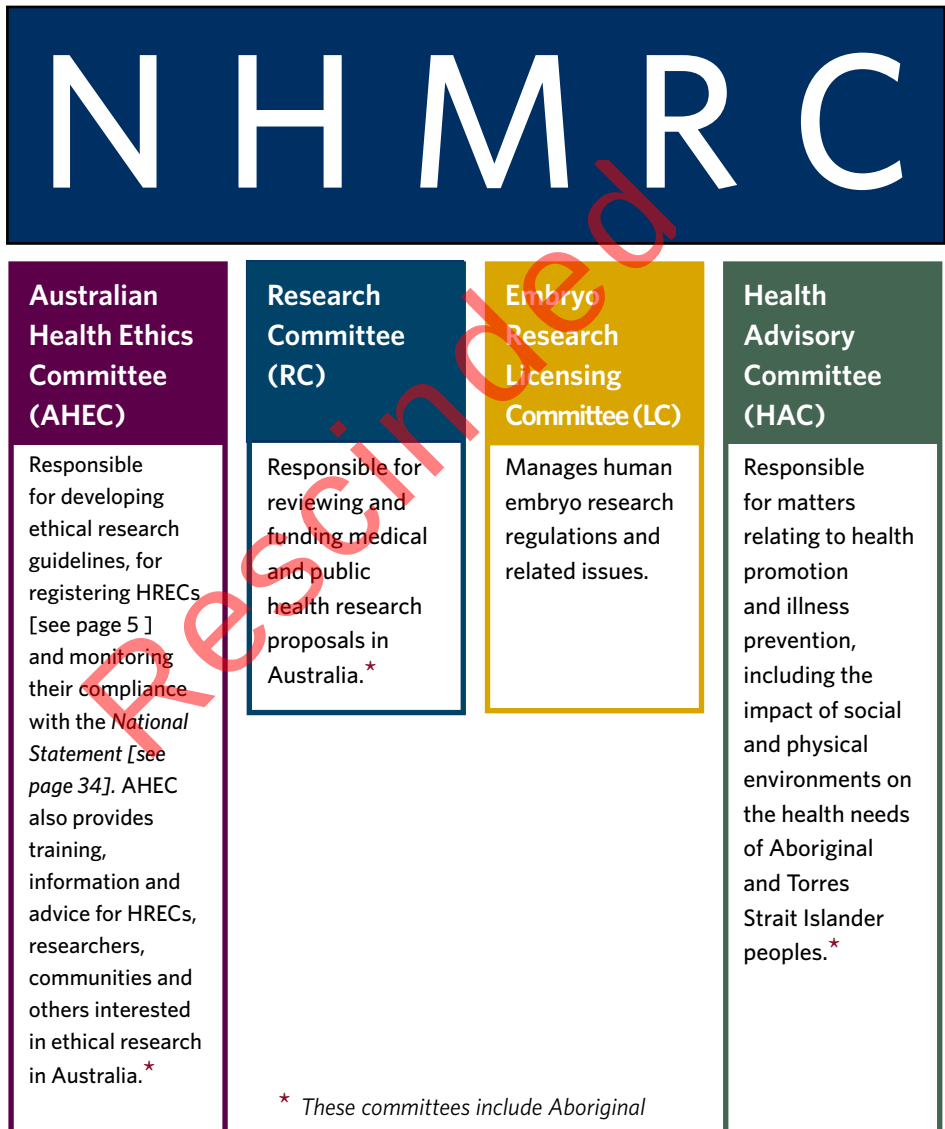
- : Ms Terry Dunbar
- : Mr Daniel McAullay
- : Ms Dallas Young
- : Ms Yvonne Cadet-James
- : Dr Margaret Scrimgeour
- : Ms Christine Franks
- : Mr Michael Duffy
- : Ms Mouli MacKenzie
- : Ms Emma Vanian



The National Health and Medical Research Council

NHMRC is the peak funding body for medical and health research in Australia. It is responsible to the Commonwealth Minister for Health.

It has four main committees.



* These committees include Aboriginal and Torres Strait Islander members with knowledge about Aboriginal and Torres Strait Islander health research.

How can we make the best use of this booklet in our communities and organisations?

During the pilot testing of this document there were some requests to produce this booklet in different languages and formats. It is not possible or appropriate for a national organisation like NHMRC to take responsibility for translating this information for specific communities across Australia.

Some excellent suggestions to make this information locally relevant are:

- Meet with local communities to discuss how best to pass the information on.
- Establish small local working groups to make a painting or video of the research and ethics story.
- Train local people to talk in first language about the contents of this booklet.
- Conduct workshops across larger local regions.



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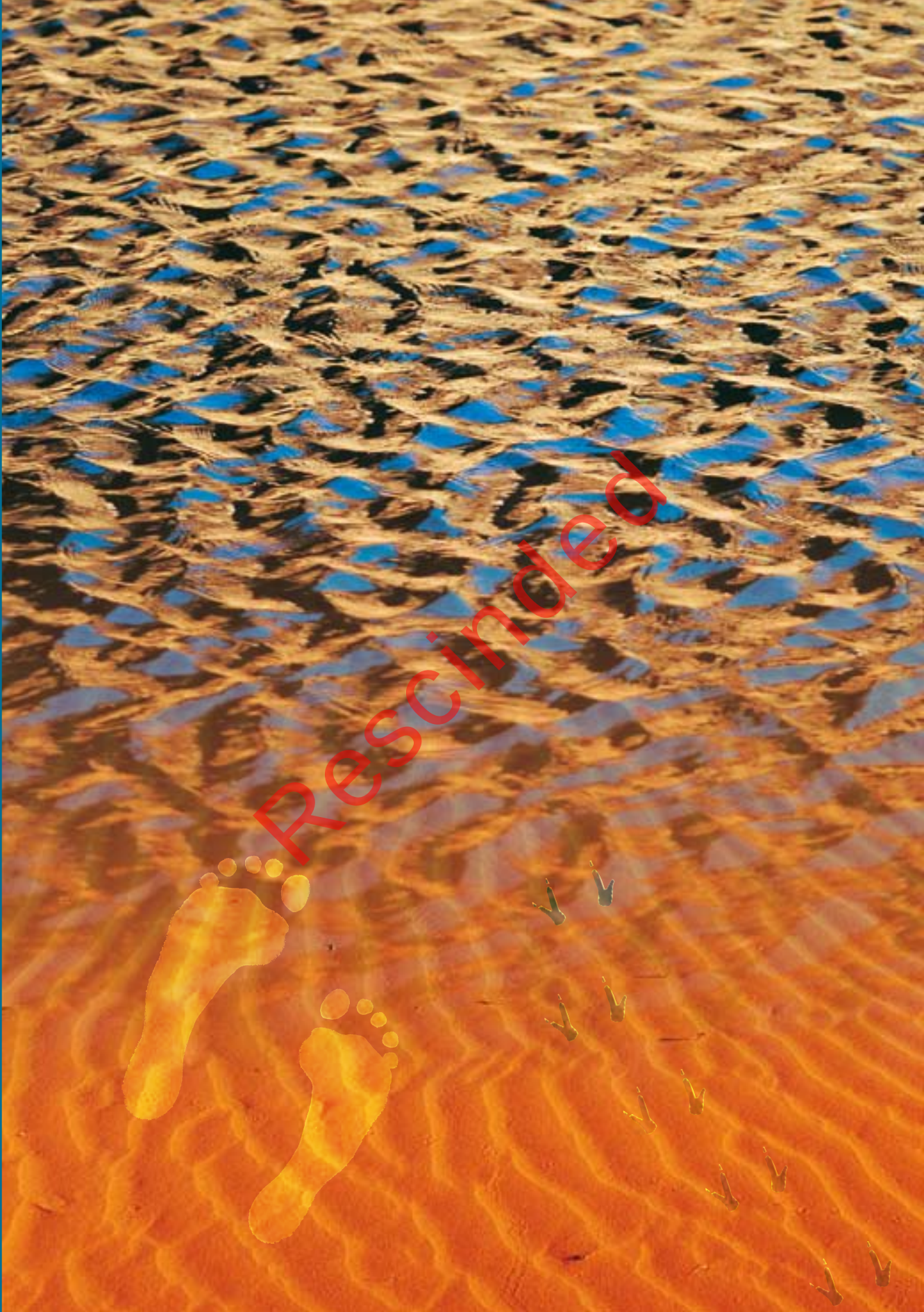
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