

Understanding Research

MODULE THREE



SAHMRI
South Australian Health &
Medical Research Institute



MARRIGUNDJA
Indigenous Research



The Australian Indigenous Doctors' Association Ltd
100 Years On

Slide 1 – Module Three: Effective Research Collaborations

If you can't find a satisfactory and reliable answer within the peer reviewed or grey literature, you may wish to commission research to be undertaken on your behalf. In this module we discuss some important values and ethical issues which should be considered when working with a research partner. We also identify the type of issues which may need to be addressed within formal agreements between yourselves and the researcher or researcher's organisation prior to beginning the collaboration.

Module Three

Effective Research Collaborations

Study Guide: Chapter Three

Slide 2 – It is important to remember you can...

Choosing the right research partner is never easy, particularly as there are a number of universities, private research organisations and consultants who have previously or are currently undertaking Aboriginal and Torres Strait Islander health research. The organisation you choose to partner with has implications for the way in which the research will be conducted and the types of agreements that you may enter into. For example, not all consultants will be required to seek ethics approval. Different organisations will also have different agreements in regards to who owns the intellectual property which is used in, and/or created by the research that is undertaken.

Primary healthcare services are also often approached by researchers with invitations to participate in research collaborations. As this can be resource intensive and a costly undertaking for healthcare services, often requiring additional infrastructure and a time commitment from you and your colleagues it is important to assess the request in detail.

It is important to remember that healthcare services may:

- choose not to collaborate with researchers,
- decide to discontinue the collaboration at any time, for any reason; and/or
- seek advice from an ethics committee if they are not satisfied with the conduct or outcome of the research.

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Slide 3 – Who sets the agenda?

Researchers have a particular set of priorities which are important to their academic career. These include the amount of grant funding that is awarded to them and the number of peer reviewed journal articles that they publish. Sometimes, the needs of the participants or healthcare services are forgotten or downgraded in an attempt to meet these academic responsibilities. It is therefore important from the very beginning of any collaboration to ensure that healthcare services and the communities they serve play a significant role within the governance structure and they are able to drive the research agenda.

One way of identifying researchers who would make a good partner is to ask them about the way in which they have previously worked and the values they have and continue to apply to the research they undertake.

Who sets the agenda?

It is important from the very beginning of any collaboration to ensure that healthcare services and the communities they serve play a significant role within the governance structure and they are able to drive the research agenda.

Slide 4 – Ethical values and standards

Not all researchers will be obliged to seek ethics approval from a human ethics committee. While universities and most research institutes usually have strict guidelines around seeking approval from not only their internal ethics approval but also where appropriate, Aboriginal and Torres Strait Islander specific committees before commencing the research, consultants may not always adhere to the same requirements. We suggest that these approval processes are essential and necessary in all instances to ensure the rights of participants and you as a collaborating party are protected.

Rather than one set of ethical values, research involving Aboriginal and Torres Strait Islander peoples need to consider a range of issues which could be thought of as a hierarchy.

Ethical values and standards

Context specific values, standards and guidelines - for example the Wardliparingga Accord which extend the national guidelines

Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research (NHMRC 2003)

National Statement for Ethical Conduct in Human Research (NHMRC 2007)

Slide 5 – As a start...

At a minimum, the National Health and Medical Research Council (NHMRC) has developed the '*National Statement for Ethical Conduct in Human Research*' [15] which includes a set of core values which must be considered and addressed **when conducting all research** involving human participants.

Research Merit and Integrity

This value includes ensuring the research methods are appropriate, are based on a thorough study of the current literature, and designed to ensure respect for the participants. Research should also be conducted by appropriate qualified and experienced researchers and use facilities and resources appropriate for the research. Importantly, researchers must be committed to searching for knowledge and understanding, following recognised principles, conducting research honestly and disseminating and communicating results

Justice

This value includes ensuring the inclusion of participants, the process of recruiting and the distribution of benefits is fair. In addition, there should not be an unfair burden on participation.

Beneficence

This value includes ensuring the benefit of the research justify the risks of harm to participants and where there is no benefit, the risks to the participants should be lower than would be ethically acceptable. In addition, researchers are responsible for designing the study to minimise harm, telling participants about both the benefits and risks and ensuring the welfare of participants.

Respect

This value includes respect for human beings for their intrinsic value and respect for the individuals' right to confidentiality and privacy.

As a start.....

- Research merit and integrity
- Justice
- Beneficence
- Respect

Slide 6 – In addition...

The 'Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research' [16] and the companion document 'Keeping research on track. A Guide for Aboriginal and Torres Strait Islander peoples about health research ethics' [17] provide the next important level in the hierarchy of ethical values and standards. These two documents, which were developed in collaboration with Aboriginal and Torres Strait Islander communities, identify six core values which Aboriginal and Torres Strait Islander societies see as essential for conducting research involving Aboriginal and Torres Strait Islander peoples.

- **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.

In addition.....



Slide 7 – And also...

There are also values and guidelines developed at state, regional and/or local levels. You could check with the state peak Aboriginal Community Controlled Organisation or the National Aboriginal Community Controlled Organisation to find out what could apply in your particular context. For example, in response to a call from Aboriginal communities and researchers within South Australia, Wardliparingga Aboriginal Research Unit has developed a set of nine principles based on national and international best practice frameworks and guidelines for conducting research with Indigenous peoples.

PRINCIPLE 1. PRIORITIES: Research should be conducted on priorities arising from and endorsed by the Aboriginal community to enhance acceptability, relevance and accountability.

Principle 2. INVOLVEMENT: The involvement of Aboriginal people and organisations is essential in developing, implementing and translating research.

Principle 3. PARTNERSHIP: Research should be based on the establishment of mutual trust, and equivalent partnerships, and the ability to work competently across cultures.

Principle 4. RESPECT: Researchers must demonstrate respect for Aboriginal knowledge, Aboriginal knowledge systems and custodianship of that knowledge.

Principle: 5. COMMUNICATION: Communication must be culturally and community relevant and involve a willingness to listen and learn.

Principle 6. RECIPROCITY: Research should deliver tangible benefits to Aboriginal communities. These benefits should be determined by Aboriginal people themselves and consider outcomes and processes during, and as a result of, the research.

Principle 7. OWNERSHIP: Research should acknowledge, respect, and protect Aboriginal intellectual property rights and ensure transparent negotiation of Intellectual Property use and benefit sharing.

Principle 8. CONTROL: Research must ensure the respectful and culturally appropriate management of all biological and non-biological research materials.

Principle 9. KNOWLEDGE TRANSLATION AND EXCHANGE: Sharing and translation of knowledge generated through research must be integrated into all elements of the research process to maximise impact on policy and practice.

And also.....



Slide 8 – The Research Agreement

Regardless of which research organisation you choose to collaborate with it will be important to clearly identify what you expect from your research partner and what your research partner expects from you. Often this starts with an open and frank discussion. We would also suggest that general points discussed are outlined in writing. The agreed principles should then be formalised within a Research Agreement addressing key issues included in the remainder of this module.

The Research Agreement

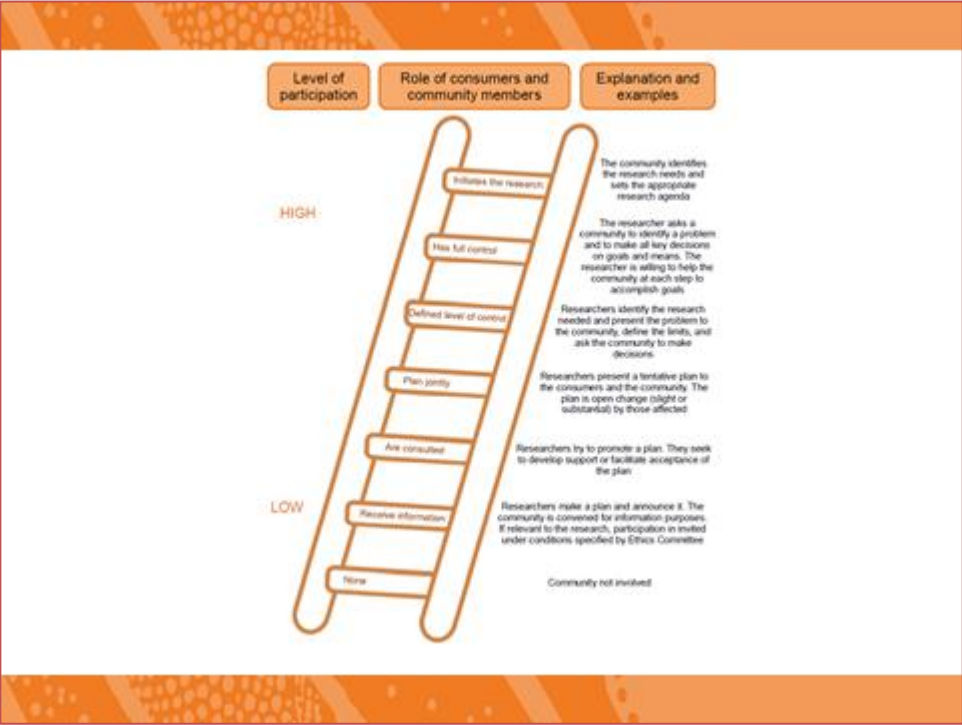
- Roles and responsibilities
- Opportunities to strengthen capacity
- Ownership of intellectual property
- Application of values
- Ensuring quality outcomes

Slide 9 – Research collaborations

Roles and responsibilities of each party should be clearly identified within both the discussion document and the Memorandum of Understanding. In particular, your level of involvement in the study should be agreed upon.

Levels of participation can range from almost no input to a level whereby the health service or the community sets the agenda and is highly involved in the study.

At a minimum, you may consider setting up a Reference Group at the beginning of the planning stage in order to review and agree on the questions to be addressed, the way in which the study will be conducted as well as providing advice and guidance around the interpretation of research findings. This Reference Group could also oversee the dissemination of study findings as well as assist in developing policies and make decisions concerning any future use of the data collected.



Slide 10 – Opportunities to strengthen capacity

One of the benefits of being highly involved with and embedding community members, yourself and your colleagues within the study team is that the research capacity of your organisation is strengthened. This type of collaboration is also of benefit to the researchers as community members and healthcare staff will contribute by:

- providing a deeper understanding of the cultural norms, beliefs and attitudes of the participants,
- facilitating a greater acceptance of the researcher within the research setting but also contributing to a shared understanding of perspectives; and
- achieving a deeper awareness of contextual issues and ultimately a more informed body of research.

Any agreement to include either healthcare providers or community members as researchers in the study should be articulated in the research agreement together with appropriate rates of pay.

It is also important to ensure that the contributions made by healthcare services as a whole, individual healthcare providers and community members involved in the research are appropriately acknowledged in other ways. It may also be appropriate for healthcare providers to be authors on any publications that are produced as a result of the research and funded to present at conferences. In addition, you may wish to ensure that the healthcare service is able to have direct input or at provide feedback on a final report prior to dissemination.

Opportunities to strengthen capacity

Also.....

- provide a deeper understanding of the cultural norms, beliefs and attitudes of the participants,
- facilitate a greater acceptance of the researcher; and
- achieving a deeper awareness of contextual issues and ultimately a more informed body of research.

Slide 11 – Intellectual property

The Research Agreement should also define the ownership of any intellectual property collected and/or developed through the research partnership. This can include, but may not be limited to the data as well as study outcomes. The following quote highlights one of the many problems that Aboriginal and Torres Strait Islander people continue to face when participating in research.

Unfortunately, intellectual property law only protects products or tangible outcomes that people produce such as paintings and sculptures. Stories and other cultural knowledge are not protected until they are written down. Therefore, it is important to think about what type of intangible objects will be shared with researchers as the study progresses and clearly define who will own and who will be entitled to determine how they will be used after they are turned into tangible products in the form of reports, papers and books.

Intellectual property

When Aboriginal and Torres Strait Islander peoples participate in research projects and share their knowledge with researchers, then their ideas, cultural information, words, language and stories are written down or recorded.

Slide 12 – Ensuring values, ethical responsibilities and quality outcomes

At a minimum, two types of documents need to be developed before the study begins. The first is the Study Plan sometimes referred to as a “research protocol”. This should define in practical terms how the values applicable to your study will be addressed throughout the study. In addition, the Study Plan will also outline:

- who will undertake the research including any health centre staff and/or community members,
- who will participate in the research; and
- how the research will be conducted.

An Ethics Application is also required when undertaking any research involving human participants. Applying for ethics approval forces researchers to ensure that their research to think about their ethical obligations. Depending on where and with whom the research is conducted, approval may be required from a number of ethics committees, many of whom will have their own ethics application. All ethics approvals will need to be received in writing prior to commencing the study.

You may not wish to be involved with writing either the Study Plan or the Ethics Applications. However, you should be given the opportunity to review all of these documents in order to ensure that they incorporate the values and meet the ethical standards that your organisation requires. We would recommend that your right of review is specifically articulated within the Discussion Document and the Memorandum of Understanding.

An established system which ensures that appropriate processes and procedures are in place to manage the research process is essential. **Good Clinical Practice** (GCP) is one of the many international recognised quality guidelines for researchers. Implementing and then complying with the GCP guidelines ensures that the rights, safety, and well-being of participants are protected and the findings of research are both reliable and credible.

Ensuring values, ethical responsibilities and quality outcomes



Slide 13 – Key Messages

Key messages from Module Three are:

1. There are a number of different organisations that you can collaborate with to undertake research. Choosing the right one is important.
2. The needs of the participants and the healthcare service must be considered first and foremost prior to, during and after completion of the research.
3. Although not required by all organisations, we believe that approval from all appropriate Aboriginal and Torres Strait Islander human research ethics committee is an essential pre-requisite to any research project.
4. A formal agreement with the organisation you are collaborating should be established and clearly state:
 - Roles and responsibilities of each party including who is responsible for the provision of the resources required.
 - Capacity strengthening opportunities for community members and healthcare providers who are involved in the research.
 - Ownership of any pre-existing as well as any newly developed intellectual property.
 - Details of how the research will be conducted and how the quality of the research will be ensured.

Key messages

- Choose the right research partner
- Ensure the needs of the participants and the healthcare service are first and foremost
- Develop a formal agreement which clearly states:
 - Roles and responsibilities
 - Capacity strengthening opportunities
 - Ownership of intellectual property.
 - Details of how the research will be conducted and how the quality of the research will be ensured.