

2.2.1 Reciprocity

A mutual obligation exists among members of Aboriginal and Torres Strait Islander families and communities to achieve an equitable distribution of resources, responsibility and capacity and to achieve cohesion and survival of the social order. This mutual obligation extends to the land, animals and other natural elements and features. In contemporary settings the value of reciprocity continues in various forms, and may vary between locations. Examples include the redistribution of income, benefits from the air, land and sea, and the sharing of other resources such as housing.

In the research context, reciprocity implies inclusion and means recognising partners' contributions, and ensuring that research outcomes include equitable benefits of value to Aboriginal and Torres Strait Islander communities or individuals. (Recognition of contribution is discussed below under Respect.) Reciprocity requires the researcher to demonstrate a return (or benefit) to the community that is valued by the community and which contributes to cohesion and survival. It is important to remember that Aboriginal and Torres Strait Islander Peoples may place greater or lesser value on the various returns than researchers. Reciprocity involves exchange although in the context of research this often involves unequal power relationships. In negotiating the conduct of research, Aboriginal and Torres Strait Islander communities have the right to define the benefits according to their own values and priorities.

Benefits may not take only one form or be immediate. Some benefits may be available to participating Aboriginal and Torres Strait Islander communities, to Aboriginal and Torres Strait Islander Peoples more generally or to the wider community as well. They must, however, be valued by the participating community. It is also important that unethical inducements in the provision of service are not linked to agreements about research.

The implications of reciprocity extend to all those involved in the potential research enterprise. HRECs can contribute by promoting real rather than superficial engagement between partners to the endeavour. Examples have been cited where an HREC was able to mediate an outcome where mistrust had emerged because of superficial engagement between communities and researchers. The engagement of other stakeholders such as service providers may also help build real engagement focussed on outcomes of benefit to Aboriginal and Torres Strait Islander communities.

When research involves Aboriginal and Torres Strait Islander Peoples, researchers and HRECs need to consider how the research proposal demonstrates the value of reciprocity, taking into account the following components:

- *Inclusion*

Inclusion, the basis for mutual obligation, describes the degree of equitable and respectful engagement with Aboriginal and Torres Strait Islander Peoples, their values and cultures in the proposed research.

- *Benefit*

Benefit in this context describes the establishment or enhancement of capacities, opportunities or outcomes that advance the interests of Aboriginal and Torres Strait Islander Peoples and that are valued by them.

Demonstrating reciprocity

Participating communities, researchers and HRECs should consider:

- How the proposed research demonstrates intent to contribute to the advancement of the health and wellbeing of participants and communities.
- Whether the proposal links clearly to community, regional, jurisdictional or international Indigenous health priorities and/or responds to existing or emerging needs articulated by Aboriginal and Torres Strait Islander Peoples.
- The nature of benefits for participants or other Aboriginal and Torres Strait Islander communities, and whether there is evidence of clear and truthful discussions about the potential benefit of the research proposal prior to approval.
- Whether the researcher has demonstrated willingness to modify research in accordance with participating community values and aspirations.
- Whether the proposed research will enhance the capacity of communities to draw benefit beyond the project, eg through the development of skills and knowledge or through broader social, economic or political strategies at local, jurisdictional, national or even international level.

Allied National Statement requirements¹⁴

NS 1.14 All research proposals must be so designed as to ensure that any risks of discomfort or harm to participants are balanced by the likely benefit to be gained.

NS 1.4 Each research protocol must be designed to ensure that respect for the dignity and well being of the participants takes precedence over the expected benefits to knowledge.

2.2.2 Respect

Respect for human dignity and worth as a characteristic of relationships between people, and in the way individuals behave, is fundamental to a functioning and moral society. Within Aboriginal and Torres Strait Islander cultures respect is reinforced by and in turn strengthens dignity. A respectful relationship induces trust and co-operation. Strong culture is a personal and collective framework built on respect and trust that promotes dignity and recognition.

Respectful research relationships acknowledge and affirm the right of people to have different values, norms and aspirations. Those involved in research processes should not be blind to difference.

Also essential to a respectful research relationship is the recognition of the contribution of others and the consequences of research. Contributions to the research enterprise come in a variety of connected forms and all should be respected. The trust, openness

¹⁴ The relevant sections in the *National Statement* are reproduced in full under these headings. The paragraph numbers are preceded by the initials 'NS'.

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and engagement of participating communities and individuals is as important as the scientific rigour of the investigation. A respectful relationship is fundamental to a sustainable research relationship. Such a relationship will require ongoing attention to cumulative decisions of participating communities and to the engagement of individuals.

The structures and processes for negotiating community involvement vary. Researchers should inform themselves about local structures and seek to engage with these in a spirit of respect and integrity. Where Aboriginal and Torres Strait Islander institutional structures exist, these should be used as the best means of community and institutional engagement by researchers, both in dealing with communities and in seeking HREC approval.

It is critical that respect underlies all aspects of the research process, especially sensitive negotiations such as those related to publication of research findings. Here, sensitivity may arise from tensions between on the one hand, the independence and integrity of research and, on the other, the risk of vilification and exploitation of Aboriginal and Torres Strait Islander Peoples. In addition researchers should not make the publication of research findings a greater priority than feedback of findings to the community in an appropriate and understandable way.

Respectful relationships require that agreements are made at the outset of any research project which make clear when, how and who will engage in the research process. In this way the value positions of all parties can be equally respected.

When research involves Aboriginal and Torres Strait Islander Peoples, researchers and HRECs need to consider how the research proposal demonstrates the value of respect, taking into account the following components:

- *Respect of people and their contribution*

Respect acknowledges the individual and collective contribution, interests and aspirations of Aboriginal and Torres Strait Islander Peoples, researchers and other partners in the research process.

- *Minimising difference blindness*

Respectful research relationships acknowledge and affirm the right of people to have different values, norms and aspirations. Those involved in research should recognise and minimise the effect of difference blindness through all stages of the research process.

- *Consequences of research*

Researchers need to understand that research has consequences for themselves and others, the importance of which may not be immediately apparent. This should be taken into account through all stages of the research process.

Demonstrating respect

Participating communities, researchers and HRECs should consider:

- Whether the proposal responds to the diversity of Aboriginal and Torres Strait Islander Peoples and communities, including the way decisions are made.

- How the proposal acknowledges the individual and collective contribution of Aboriginal and Torres Strait Islander Peoples.
- How the researchers propose to minimise the effects of difference blindness on and in the research process.
- How the research proposal engages with Aboriginal and Torres Strait Islander Peoples' knowledge and experience.
- Whether appropriate agreements have been negotiated about ownership and rights of access to Aboriginal and Torres Strait Islander Peoples' intellectual and cultural property.
- Whether the processes of reaching agreement demonstrate engagement with the values and processes of participating communities.
- Whether the participating communities have expressed satisfaction with the research agreement and decision making processes.
- Whether in reaching agreement with participating communities all relevant issues including management of data, publication arrangements and the protection of individual and community identity have been adequately addressed.

Allied National Statement requirements

NS 1.2 When conducting research involving humans, the guiding ethical principle for researchers is respect for persons which is expressed as regard for the welfare, rights, beliefs, perceptions, customs and cultural heritage, both individual and collective, of persons involved in research.

NS 1.7 Before research is undertaken, whether involving individuals or collectivities, the consent of the participants must be obtained, except in specific circumstances elsewhere in this Statement [see paragraphs 1.11, 6.9, 14.4, 15.8, 16.13].

The ethical and legal requirements of consent have two aspects: the provision of information and the capacity to make a voluntary choice. To conform with ethical and legal requirements, obtaining consent should involve:

- (a) provision to participants, at their level of comprehension, information about the purpose, methods, demands, risks, inconveniences, discomforts and possible outcomes of the research (including the likelihood and form of publication of research results); and
- (b) the exercise of voluntary choice to participate.

Where a participant lacks competence to consent, a person with lawful authority to decide for that participant must be provided with that information and exercise that choice.

NS 1.8 A person may refuse to participate in a research project and need give no reasons nor justification for that decision.

NS 1.9 Where consent to participate is required, research must be so designed that each participant's consent is clearly established, whether by a signed form, return of a survey, recorded agreement for interview or other sufficient means.

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In some circumstances and some communities, consent is not only a matter of individual agreement, but involves other properly interested parties, such as formally constituted bodies of various kinds, collectivities or community elders. In such cases the researcher needs to obtain the consent of all properly interested parties before beginning the research.

NS 1.10 The consent of a person to participate in research must not be subject to any coercion or to any inducement or influence which could impair its voluntary character.

NS 1.12 A participant must be free at any time to withdraw consent to further involvement in the research. If any consequences may arise from such withdrawal, advice must be given to participants about these before consent to involvement in the research is obtained.

2.2.3 Equality

One of the values expressed by Aboriginal and Torres Strait Islander Peoples and cultures is the equal value of people. One of the ways this is reflected is a commitment to distributive fairness and justice. Equality affirms Aboriginal and Torres Strait Islander Peoples' right to be different.

Equality as a value may sometimes be taken to mean sameness. However, Aboriginal and Torres Strait Islander Peoples hold strong beliefs that sameness is not equality. Aboriginal and Torres Strait Islander Peoples have sought the elimination of 'difference blindness' so that Aboriginal and Torres Strait Islander cultures can be appreciated and respected.

Crude or unsubstantiated assumptions of the value or vitality of Aboriginal and Torres Strait Islander cultures and societies have led Australian history in many instances to discriminate against Aboriginal and Torres Strait Islander Peoples. Such assumptions have created significant and longstanding difficulties that have at times been reflected in research practices. The marginalisation of Aboriginal and Torres Strait Islander cultures by the dominant society has created myriad inequalities that "pursue them from sphere to sphere in the form of stereotyping, discrimination and disregard."¹⁵

International and domestic studies have increasingly revealed a correlation between social and economic inequality and poor health. Research should seek to advance the elimination of inequalities. Equality is also a feature of the fundamental dignity of humanity. To treat people less favourably is not only unethical, but discriminatory.

Historically, Aboriginal and Torres Strait Islander Peoples have perceived the benefit as flowing principally to researchers and institutions.

When research involves Aboriginal and Torres Strait Islander Peoples, researchers and HRECs need to consider how the research proposal demonstrates the value of equality, taking into account the following components:

¹⁵ Miller D and Walzer M, *Pluralism Justice and Equality*, Oxford University Press, 1995

- *Valuing knowledge and wisdom*

Aboriginal and Torres Strait Islander Peoples value their collective memory and shared experience as a resource and inheritance. Researchers who fail to appreciate or ignore Aboriginal and Torres Strait Islander Peoples' knowledge and wisdom may misinterpret data or meaning, may create mistrust, otherwise limit quality or may overlook a potentially important benefit of research.

- *Equality of partners*

Ethical research processes treat all partners as equal notwithstanding that they may be different. In the absence of equal treatment, trust among research funders, researchers, host institutions, Aboriginal and Torres Strait Islander communities and other stakeholders is not possible. Without such trust ethical research is undermined.

- *The distribution of benefit*

The distribution of benefit stands as a fundamental test of equality. If the research process delivers benefit in greater proportion to one partner in the initiative than other partners, the distribution of benefit may be seen as unequal.

Demonstrating equality

Participating communities, researchers and HRECs should consider:

- Whether the ways that participating communities are included in the research processes demonstrate equality.
- Whether the research agreements have the strength necessary to sustain equality.
- Whether participating communities have understood and expressed satisfaction with the proposed research, its potential benefits and their distribution. Researchers therefore have a responsibility to ensure that the information that they provide is understood and usable in decision making by participating communities.

Allied National Statement requirements

NS 1.5 The ethical value of justice requires that, within a population, there is a fair distribution of the benefits and burdens of participation in research and, for any research participant, a balance of burdens and benefits. Accordingly, a researcher must:

- avoid imposing on particular groups, who are likely to be subject to over researching, an unfair burden of participation in research;
- design research so that the selection, recruitment, exclusion and inclusion of research participants is fair; and
- not discriminate in the selection and recruitment of actual and future participants by including or excluding them on the grounds of race, age, sex, disability or religious or spiritual beliefs except where the exclusion of inclusion of particular groups is essential to the purpose of the research.

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NS 1.6 The proportion of burdens to benefits for any research participant will vary. In clinical research, where patient care is combined with an intent to contribute to knowledge, the risks of participation must be balanced by the possibility of intended benefits for the participants. In other research involving humans that is undertaken solely to contribute to knowledge, the absence of intended benefits to a participant should justly be balanced by the absence of all but minimal risk.

2.2.4 Responsibility

Central to Aboriginal and Torres Strait Islander societies and cultures is the recognition of core responsibilities. These responsibilities include those to country, kinship bonds, caring for others and the maintenance of harmony and balance within and between the physical and spiritual realms. A key responsibility within this framework is to do no harm, including avoiding having an adverse impact on others' abilities to comply with their responsibilities. As well, one person's responsibilities may be shared with others so that they will also be held accountable.

The assignment or inheritance of responsibilities within communities functions to ensure the order and survival of individuals, families and whole communities. Survival includes maintaining the bonds and relationships between people and between them and their environment. It also encompasses responsibilities in respect of spiritual domains. A transparent accountability regime ensures the timely and appropriate discharge of responsibilities.

When engaging Aboriginal and Torres Strait Islanders Peoples in the research enterprise, researchers carry responsibilities in addition to the science of their inquiry. The nexus between their research and community life brings responsibilities for which they or those of the community with whom they work may be held accountable. Ethical research occurs when harmony between the sets of responsibilities is established, participants are protected, trust is maintained and accountability is clear.

When research involves Aboriginal and Torres Strait Islander Peoples, researchers and HRECs need to consider how the research proposal demonstrates the value of responsibility, taking into account the following components:

- *Doing no harm*

There is a clear responsibility for researchers to do no harm to Aboriginal and Torres Strait Islander individuals or communities and also to those things that they value.

- *Accountability*

Researchers and participating communities need to establish processes to ensure researchers' accountability to individuals, families and communities, particularly in relation to the cultural and social dimensions of Aboriginal and Torres Strait Islander life.

Demonstrating responsibility

Participating communities, researchers and HRECs should consider:

- What measures are identified to demonstrate transparency in the exchange of ideas and in negotiations about the purpose, methodology, conduct, dissemination of results and potential outcomes/benefits of research.
- How provision is made for appropriate ongoing advice and review from the participating community, including mechanisms to monitor ethics standards and to minimise the likelihood of any unintended consequences arising from or after the research project.
- What does the proposal say about timely feedback obligations to communities and whether that feedback is relevant to the expressed concerns, values and expectations of research participants and communities.
- How the proposal demonstrates agreed arrangements regarding publication of the research results, including clear provisions relating to joint sign off for publication and the protection of individual and community identity if appropriate.
- Whether there is clarity about the demand on partners created by the proposed research and the potential implications for partners arising from it.

Allied National Statement requirements

- NS 1.1** The guiding value for researchers is integrity, which is expressed in a commitment to the search for knowledge, recognised principles of research conduct and in the honest and ethical conduct of research and dissemination and communication of results
- NS 1.3** In research involving humans, the ethical principle of beneficence is expressed in researchers' responsibility to minimise risks of harm and discomfort to participants in research projects.
- NS 1.13** Every research proposal must demonstrate that the research is justifiable in terms of its potential contribution to knowledge, and is based on a thorough study of current literature as well as prior observation, approved previous studies, and where relevant, laboratory and animal studies.
- NS 1.18** The results of research (whether publicly or privately funded) and the methods used should normally be published in ways which permit scrutiny and contribute to public knowledge. Normally, research results should be made available to research participants.
- NS 1.19** Where personal information about research participants or a collectivity is collected, stored, accessed, used, or disposed of, a researcher must strive to ensure that the privacy, confidentiality and cultural sensitivities of the participants and/or collectivity are respected. Any specific agreements made with the participants or the collectivity are to be fulfilled.

2.2.5 Survival and Protection

Aboriginal and Torres Strait Islander Peoples continue to act to protect their cultures and identity from erosion by colonisation and marginalisation. A particular feature of Aboriginal and Torres Strait Islander cultures and these efforts has been the importance of a collective identity. This collective bond reflects and draws strength from the values base of Aboriginal and Torres Strait Islander Peoples and cultures.

Aboriginal and Torres Strait Islander Peoples do not intend to forego the distinctiveness of their cultures. Barriers between research and Aboriginal and Torres Strait Islander Peoples have been created for example where some researchers or institutions have ignored or sought to undermine this distinctiveness. The repeated marginalisation in research of Aboriginal and Torres Strait Islander values has reinforced these barriers over time creating a ‘collective memory’ that is an obstacle to research today. Researchers will need to make particular effort to deal with the perception of research held by many Aboriginal and Torres Strait Islander communities as an exploitative exercise. They will need to demonstrate through ethical negotiation, conduct and dissemination of research that they are trustworthy and will not repeat the mistakes of the past.

As noted throughout, the distinctive cultures and community life of Aboriginal and Torres Strait Islander Peoples rests at the heart of these guidelines. It is, therefore, essential that researchers engage with Aboriginal and Torres Strait Islander communities collectively, not just with individuals.

When research involves Aboriginal and Torres Strait Islander Peoples, researchers should describe and HRECs should consider issues of survival and protection including the following components:

- *Importance of values based solidarity to Aboriginal and Torres Strait Islander Peoples*

Aboriginal and Torres Strait Islander Peoples vigorously oppose the assimilation, integration or subjugation of their values and will defend them against perceived or actual encroachment. Researchers must be aware of the history and the continuing potential for research to encroach on these values.

- *Respect for social cohesion*

The importance of the personal and collective bond within Aboriginal and Torres Strait Islander communities and its critical function in their social lives.

- *Commitment to cultural distinctiveness.*

The cultural distinctiveness of Aboriginal and Torres Strait Islander Peoples is highly valued by them. Within the scope of these guidelines, researchers must find ways of working that do not diminish the right to the assertion or enjoyment of that distinctiveness.

Demonstrating survival and protection

Participating communities, researchers and HRECs should consider:

- Whether the research project contributes to or erodes the social and cultural bonds among and between Aboriginal and Torres Strait Islander families and communities.
- What safeguards are in place against the research project contributing to discrimination or derision of Aboriginal and Torres Strait Islander individuals or cultures.
- Whether the proposal respects the intrinsic values based expectations and identity of Aboriginal and Torres Strait Islander Peoples and communities including the balance between collective and individual identity.
- How the proposal contributes to the opportunity for Aboriginal and Torres Strait Islander Peoples to better advocate for or enjoy their cultural distinctiveness.
- What strategies have been identified to eliminate any threats to Aboriginal and Torres Strait Peoples' ability to enjoy their cultural distinctiveness.

2.2.6 Spirit and Integrity

This is an overarching value that binds all others into a coherent whole. It has two components. The first is about the continuity between past, current and future generations. The second is about behaviour, which maintains the coherence of Aboriginal and Torres Strait Islander values and cultures. Any behaviour that diminishes any of the previous five values could not be described as having integrity.

Aboriginal and Torres Strait Islander communities have demonstrated a continuity of values and bonds that has sustained and been sustained by the overarching value of spirit and integrity. This continuity has remained evident in individuals and communities despite changes in physical environment and behaviours. These bonds and values have often been the touchstone for personal or community level action to renew or protect identity, culture and life.

Aboriginal and Torres Strait Islander communities are not homogeneous. However, there are core values and principles that remain common across the cultural spectrum and Aboriginal and Torres Strait Islander Peoples will assert the dignity and worthiness of their particular efforts to protect and uplift their own.

Researchers are perceived as owing an obligation to the spirit and integrity of communities not just to individuals. It is clear that Aboriginal and Torres Strait Islander communities will look to see if what is proposed is consistent with their values. However, the responsibility to demonstrate consistency falls to those proposing research.

Community decision making based on shared values is an implicit part of spirit and integrity.

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When research involves Aboriginal and Torres Strait Islander Peoples, researchers should describe and HRECs should consider issues of spirit and integrity including the following:

- *Motivation and action*

This means that researchers must approach the conduct of research in Aboriginal and Torres Strait Islander communities with respect for the richness and integrity of the cultural inheritance of past, current and future generations, and of the links which bind the generations together.

- *Intent and process*

Negotiations with Aboriginal and Torres Strait Islander communities will need to exhibit credibility in intent and process. In many circumstances this will depend not only on being able to demonstrate that the proposal is in keeping with these guidelines, but also on the behaviour and perceived integrity of the proponents of research.

Demonstrating spirit and integrity

Participating communities, researchers and HRECs should consider:

- How the proposed research demonstrates an understanding of and agreement about the relationship between the proposed research and the community's cultural, spiritual and social cohesion, including workable timeframes.
- Whether the proposal recognises in the conduct and reporting of research the diversity of Australian Aboriginal and Torres Strait Islander People's cultures, including the mechanisms through which communities may make decisions.
- Whether the proponents of the proposal are able clearly to demonstrate personal integrity, specifically in the development of their proposal.
- Does the proposal demonstrate a commitment to working within the spirit and integrity of Aboriginal and Torres Strait Islander Peoples?

Allied National Statement requirements

NS 1.1 The guiding value for researchers is integrity, which is expressed in a commitment to the search for knowledge, to recognised principles of research conduct and in the honest and ethical conduct of research and dissemination and communication of results.

NS 1.2 When conducting research involving humans, the guiding ethical principle for researchers is respect for persons which is expressed as regard for the welfare, rights, beliefs, perceptions, customs and cultural heritage, both individual and collective, of persons involved in research.