



Assessing Research for True Partnership

Based on: **WARDLIPARINGGA: Aboriginal Research in Aboriginal Hands. 2014**

Modified by Chris Perry (Chair of CAHREC) and NPYWC (2018)

Assessing research for true partnership

<p>Principle 1</p>	<p style="text-align: center;">PRIORITIES</p> <p style="text-align: center;">Research should be conducted on priorities arising from and endorsed by the Aboriginal community to enhance acceptability, relevance and accountability</p>		
<p>Priority setting</p>	<p>Priorities set in negotiation with NPYWC</p>	<p>There are national and population specific priorities applicable to the demographical area advocated by NPYWC</p>	<p>Priorities predetermined with little relevance to NPYWC</p>
<p>Input from NPYWC</p>	<p>Occurred at development stage. Was crucial to study design, or formed basis for the collaboration</p>	<p>NPYWC consulted in the process of developing the study design</p>	<p>None at all</p>
<p>Timing of first formal meeting</p>	<p>During development of research design, prior to funding application (or ethics, where this comes first)</p>	<p>During development of research design, prior to ethics submissions (or funding, should this come first)</p>	<p>Design completed, funded and approved by HREC prior to approaching NPYWC</p>



Principle 2	INVOLVEMENT		
	The involvement of Aboriginal people and organisations is essential in developing, implementing and translating research		
Level of consultation	Consultations with NPYWC which directly informed the study design	NPYWC is satisfied with the level of consultation that occurred	No consultation with NPYWC, before requesting formal support
Formal research agreement	Formal research agreement with NPYWC in place, or intended, prior to commencing work	Formal research agreement with NPYWC negotiations in process while seeking to commence study	No formal research agreement with NPYWC being attempted
Aboriginal reference group	Established as part of preparation for research	Intending to establish a specific Anangu Reference Group	No intention of facilitating an Anangu Reference Group
Principle 3	PARTNERSHIP		
	Research should be based on the establishment of mutual trust, and equivalent partnerships, and the ability to work competently across cultures		
Translation and dissemination of research	Research outcomes dissemination plan undertaken with NPYWC. Translation into language where feasible	Researchers open to the potential of creating a dissemination plan	No dissemination plan being considered by the researchers for this project
Employment of cultural mentors or Aboriginal Researchers	Detailed and budgeted, where possible Anangu staff are utilised	Discussed but not in detail	Not described within the study design
Reasonable cost recovery for participation	Funds to cover NPYWC resources and participants' time included in project budget	Limited funds available to support contribution of NPYWC to research	No funds available to support NPYWC or participants' resources



<p>Principle 4</p>	<p style="text-align: center;">RESPECT</p> <p style="text-align: center;">Researchers must demonstrate respect for Aboriginal knowledge, Aboriginal knowledge systems and custodianship of that knowledge</p>		
<p>Awareness of Aboriginal knowledge systems</p>	<p>Anangu knowledge systems are an integral part of the research</p>	<p>Anangu knowledge systems are mentioned but not embedded in the research</p>	<p>No understanding or scope to adapt research where required</p>
<p>Awareness of specific research guidelines for (health) research involving Aboriginal peoples</p>	<p>Is aware of, and works according to Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research (NHMRC), or comparable</p>	<p>Is unaware of such specific guidelines, but is receptive to learning and embedding this thinking in the study</p>	<p>No awareness</p>
<p>Principle 5</p>	<p style="text-align: center;">COMMUNICATION</p> <p style="text-align: center;">Communication must be culturally and community relevant and involve a willingness to listen and learn</p>		
<p>Respecting Aboriginal time and space</p>	<p>The study design acknowledges context of research and details flexibility in timelines and budgeting</p>	<p>Study design includes contextual elements which will enable timeframes and budgets to probably be met</p>	<p>The study design timelines are rigid and tight with no ability to modify</p>



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		
Benefits of contributing	Study directly addresses a priority topic of NPYWC in a meaningful way	Benefits exist in this project but the benefit is not equitable to NPYWC or its members	NPYWC sees no tangible benefit for itself or its members by contributing to this project
The burden of contributing	NPYWC's contribution to the research is well defined, and resources are paid for from the project funds	Plans to discuss how researchers can enhance the capacity of NPYWC to respond to researcher's request	NPYWC is being asked to contribute to this research as an open ended request
Training for local community members or researchers	Detailed and budgeted	Discussed but not in detail	Not described within the study design
Principle 7	OWNERSHIP Researchers should acknowledge, respect, and protect Aboriginal intellectual property rights and transparent negotiation of intellectual property use and benefit sharing should be ensured.		
Nature of the knowledge and data being requested	Researchers have negotiated issues relating to intellectual property rights and ownership over research materials to the satisfaction of NPYWC	Researchers have not planned for but have given assurances to have negotiations with NPYWC to negotiate an outcome	Researchers assume that data/materials derived from the research project will be retained and owned by their auspicing institution
Understanding of how participants data/information will be used by researchers and securely stored	Researchers have provided clear documentation about how privacy and confidentiality of research materials and data will be handled	Researchers have explicit protocols describing privacy and confidentiality provisions without contextualisation to Central Australian values	Researchers have no protocols in place describing systems to maintain the privacy and confidentiality of people's contribution to the research project
Future use and storage of participant data and materials	Researchers have provided clear documentation about the governance	Researchers have limited governance structures in place but have given an	No governance structures surround the storing and use of data or biological



	structures which will hold the data and biological materials of individuals for the life of the project	undertaking to develop structures in accordance with best practice in the domain	materials into the future
Consenting issues	Specific and time limited consent for the use of research data and materials is being requested	Extended consent to reuse research data / materials, for a specific time frame is being requested	Unspecified consent to reuse research data/materials is being requested
Secondary use of research data or biological materials	No reuse of research data or materials is being considered by researchers. [Secondary use or use beyond the original consent may be undertaken only following re-consent, but is not foreseen at time of original consent]	Researchers are actively foreshadowing to re-consent individuals for use of their data / material for a purpose not originally agreed to in the original project	No intention to re-consent individuals for permission to use their data / material for a purpose not originally agreed to in the original project
Principle 8	CONTROL Researchers must ensure the respectful and culturally appropriate management of all biological and non - biological research materials		
Sensitivity of the collection of biological materials is understood and clearly addressed	Researchers are acutely aware of the problematic nature of this and have in place compelling justification of the benefits for holding such materials	Researchers are aware of the historical experiences of communities and individuals and are willing to negotiate about how this might need to occur	Researchers are not aware of the historical experiences of communities and individuals within Central Australia and see its collection as unproblematic
Sensitivity of the collection of biological materials is understood and clearly addressed, continued	Researchers have engaged in transparent negotiations and developed appropriate handling and governance arrangements through formal and full consent of individuals and their communities	Researchers are aware of the problematic nature of holding biological materials into the future without developed protocols and wish to develop these as the project develops	Researchers consider themselves to be the sole owner of data or materials contributed to by participants to a research project with no accountability back to the source individual or community for future use



<p>Withdrawal from consent or study participation is possible at any stage</p>	<p>Researchers have protocols for the withdrawal and/or destruction of biological materials if directed to by community representatives, or individual participants</p>	<p>Researchers have protocols for the withdrawal and/or destruction of biological materials derived from national document without consultation from local representatives</p>	<p>No ability is present for contributing individuals or institutions to have any input into the continued storage and use of their biological materials</p>
<p>Principle 9</p>	<p align="center">KNOWLEDGE TRANSLATION AND EXCHANGE</p> <p align="center">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</p>		
<p>The format of the research outcomes will have immediate utility for NPYWC</p>	<p>Researchers have a detailed process how the research project will be used to inform policy and practice for the benefit of the research population, and have taken into account how NPYWC would use the results for these purposes</p>	<p>There is potential for this research to be published but no dissemination plan as the basis for any form of knowledge translation component</p>	<p>There is risk that this research remains unpublished or disseminated to inform policy or practice. There are no agreed reporting timelines to NPYWC</p>
	<p>Researchers have a detailed dissemination plan that includes strategies to feedback meaningful information to the communities with whom the research was undertaken</p>	<p>Researchers state they will only distribute the outcomes of the research to those individuals or institutions who request it</p>	<p>Researchers are not intending to re-visit communities at the completion of the project or in any way communicate meaning outcomes of the project</p>