



Attachment A: Definitions

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1. PREAMBLE

Ninti One is dedicated to improving conditions for remote-dwelling Australians and it recognises that there have been past instances of Aboriginal and Torres Strait Islander peoples' knowledge and intellectual property being misappropriated and exploited. The Ninti One Board also recognises that Ninti One's objectives will only be achieved by working in equitable partnership with Aboriginal and Torres Strait Islander people. Such partnerships include knowledge sharing in research and potentially the creation of new intellectual property. Ninti One acknowledges that Aboriginal and Torres Strait Islander communities and groups have their own protocols and that these must be observed, understood, respected and engaged with as an essential, ongoing part of the research process. The philosophy of working together in partnership is important to Aboriginal and Torres Strait Islander people and is reflected in the commitments of the Board structure and enacted through shared Board and committee memberships.

It is a requirement of the Ninti One Agreement that all participants be aware of this Protocol as a working document. It should be used together with other Ninti One resources:

Guides for researchers:

- Aboriginal and Torres Strait Islander Research Engagement Protocol
- Free Prior Informed Consent procedures (<u>Briefing Paper #7</u>)
- Schedule of rates of pay for Aboriginal and Torres Strait Islander workers in research
- <u>Guidelines to good manners</u> when working with Aboriginal and Torres Strait Islander people in research
- Guide to Partner Intellectual Property in Ninti One
- · Ninti One Guide to Agreements
- Ninti One Agreement

Guides for Aboriginal and Torres Strait Islander communities and organisations:

- Community guide to this Protocol (forthcoming)
- Plain language briefing papers on Intellectual Property laws

Internal research management tools:

- IP register
- · Ethics register
- · Audit and Risk management sub-committee of the Board
- Commercialisation and Utilisation Plan

2. PURPOSE

This Protocol is a resource to guide researchers toward best practice in ethics, confidentiality, equitable benefit sharing and in managing research information. It sets out the ways in which Ninti One research with Aboriginal and Torres Strait Islander people should be conducted and how Aboriginal and Torres Strait Islander knowledge and intellectual property will be managed throughout the research process.

Ninti One recognises that working in a cross-cultural context is complex. In particular, where research projects involve Aboriginal and Torres Strait Islander knowledge and intellectual property, special attention is needed to ensure that these are handled appropriately.

This protocol also needs to be read in conjunction with the Guide to Partner Intellectual Property in Ninti One, as this outlines the ways in which IP and Commercial Project IP are managed.

3. **DEFINITIONS**

For definitions of terms used in this Protocol, refer to Attachment A, Definitions of Terms.

4. GUIDING PRINCIPLES

This Protocol will be developed to ensure its consistency with best practice in existing and emerging standards, including internationally and within Australia. It will have reference to such international standards as the UN Declaration on the Rights of Indigenous Peoples, the International Society of Ethnobiology Code of Ethics, and the Bonn Guidelines on Access to Genetic Resources and Benefit Sharing.



4.1 Ethics

Researchers must respect local Aboriginal and Torres Strait Islander ethical protocols.

All projects in which Aboriginal and Torres Strait Islander people participate, and that involve Aboriginal and Torres Strait Islander knowledge, Aboriginal and Torres Strait Islander intellectual property, and other intellectual property, will only be carried out if they have received ethical clearance from the relevant committees (such as university ethics committees). They should also meet appropriate ethical standards, consistent with those such as the Australian Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS) *Guidelines for Ethical Research in Indigenous Studies* (2000), the *National Statement on Ethical Conduct in Human Research* (2007), and any others developed, and subsequently adopted by the Ninti One Board.

4.2 Confidentiality

Where requested by Aboriginal and Torres Strait Islander knowledge holders and/or owners, researchers, including students, will observe confidentiality of this knowledge and/or of Aboriginal and Torres Strait Islander intellectual property. This is an over-riding requirement to all other clauses in this Protocol and is supported by the Centre Agreement. All researchers must be made aware of and accept this requirement before engaging in any activity in Ninti One. Any breach of confidentiality will be handled by the appropriate Ninti One mechanisms and processes.

4.3 Free Prior Informed Consent

All projects that involve Aboriginal and Torres Strait Islander people, and Aboriginal and Torres Strait Islander knowledge and practices, must ensure that free prior informed consent processes have been carried through. This means that:

- Aboriginal and Torres Strait Islander participants in the project have been fully informed about the project, and have a clear understanding of the purpose, methodology, and intended outcomes of the research, including potential risks, uses and possible commercialisation options
- Adequate opportunities and timeframes have been provided for Aboriginal and Torres Strait
 Islander participants to make their own decisions about the research and whether they will
 participate. This may be either as individuals or through their communities and organisations
- Consent is an ongoing engagement between the community and the researcher. Subject to local circumstances, it can be suspended or withdrawn.



4.4 Benefit-sharing

Research must produce direct benefits to Aboriginal and Torres Strait Islander people and reinforce Aboriginal and Torres Strait Islander peoples' self-determination through their full and ongoing active participation and negotiation in the decision-making process for research planning and implementation according to local priorities. Benefit sharing is an ongoing process of negotiation and must be embedded in the processes of free prior informed consent.

5. PRACTICES

5.1 Survey, scoping and collection

Any Aboriginal and Torres Strait Islander knowledge and/or other types of information collected or disclosed to researchers in the course of a research project will not be published or commercialised or used in any other way without:

- Ensuring the free prior informed consent of Aboriginal and Torres Strait Islander participants
- Ensuring that this knowledge and information is surveyed, documented and recorded and/or collected in accordance with the wishes of, and full participation of the relevant Aboriginal and Torres Strait Islander persons, communities and organisations
- In the case of publications, ensuring the Board, as delegated to the Executive Management Team, has provided prior written approval for the proposed publication
- In the case of commercialisation, ensuring the Board has provided prior written approval for the proposed commercialisation activities.

5.2 Storage, access, and publication

Data relating to Aboriginal and Torres Strait Islander intellectual knowledge and practices, Aboriginal and Torres Strait Islander intellectual property, and personal and other information relating to Aboriginal and Torres Strait Islander individuals, and communities and/or organisations provided to, and/or collected or created by researchers in the course of projects:

- Will be held in accordance with relevant legal, ethical, and Aboriginal and Torres Strait Islander community and cultural guidelines, including the Information Privacy Principles contained in the Privacy Act 1988 (Cth)
- Will recognise local keeping places and knowledge centres. Subject to negotiation and consultation, research products will be deposited with communities, and stored and retrieved in accordance with community protocols



- Will be stored and/or archived in appropriate and sensitive ways, in consultation with, and with the free prior informed consent of relevant Aboriginal and Torres Strait Islander people
- If stored and/or archived, must be appropriately and clearly documented, indexed and catalogued, in consultation with the relevant Aboriginal and Torres Strait Islander people
- Once stored and/or archived, must be accessible upon request by Aboriginal and Torres
 Strait Islander people with interests and rights in the data
- Subject to legal or ethical requirements, must be destroyed on the request of the providers of
 the information or on the request of those who according to traditional law have the authority
 to make that decision or when specifically required to do so by the Board or by a properly
 constituted Ethics Committee
- Will not be published in any form that allows for identification of the Aboriginal and Torres
 Strait Islander persons or communities involved without the specific written approval of the
 Aboriginal and Torres Strait Islander persons or communities involved
- Will not be used for any purpose other than for which it was collected without the free prior informed consent of the Aboriginal and Torres Strait Islander persons who originally provided the information or of those persons authorised by the relevant communities to make that decision
- Will not be used or published in a manner that is likely to adversely affect the interests of the
 particular research participants, particular Aboriginal or Torres Strait Islander communities or
 of Aboriginal or Torres Strait Islander people generally
- May be published in a form that does not allow for identification of the Aboriginal and Torres
 Strait Islander persons or communities involved if the initial informed consent obtained from
 such persons or communities permitted such publication
- Efforts will be made to co-author publications with Aboriginal and Torres Strait Islander
 participants and other researchers who are authors, and/or who have contributed in other
 ways to the project.

5.3 Return and feedback

Researchers should ensure that there is appropriate and relevant feedback of plans, knowledge and research products, including all intellectual property to all Aboriginal and Torres Strait Islander people with interests in the project. In returning and depositing final products of research to communities, researchers will recognise local keeping places and knowledge centres, and store and retrieve materials in accordance with community protocols. Feedback and return of results and project information will be provided to all Aboriginal and Torres Strait Islander participants in ways that are relevant, accessible and meaningful.



5.4 Use, including commercialisation

The Board will ensure that no commercialisation takes place until they have ensured that the Aboriginal and Torres Strait Islander people and communities who have rights and interests in such material have had opportunities to decide whether to provide their free prior informed consent to such commercialisation. Implicit within this Board approval is that appropriate ethical, confidentiality and free prior informed consent procedures have been followed, as outlined at 4.1, 4.2, 4.3 and 4.4.

6. EQUITABLE BENEFIT-SHARING

Aboriginal and Torres Strait Islander people have a right to expect that research conducted on their lands and in their communities will be of benefit to them. See the Aboriginal and Torres Strait Islander Research Engagement Protocol for an outline for negotiating equitable benefit sharing, as this also may extend to non-monetary benefits. The precise terms of benefit-sharing will be determined by negotiation, in accordance with the principles of free prior informed consent by all participants on mutually agreed terms initially and as the research develops.

6.1 Benefit-sharing and commercialisation

Ninti One acknowledges the complexities and the ethical concerns with regard to evaluating Aboriginal and Torres Strait Islander knowledge and practices, and Aboriginal and Torres Strait Islander intellectual property, especially in the engagement process with Aboriginal and Torres Strait Islander and other researchers. Benefit sharing with Aboriginal and Torres Strait Islander people based on their knowledge contribution to projects that have the potential to yield revenue streams will be negotiated on a project-by-project basis with the starting arrangement being equitable sharing of net benefits for both Ninti One and Aboriginal and Torres Strait Islander parties. Revenue from any commercialisation by Ninti One that becomes the Company's Participating Share (after other equity partners of Ninti One have been paid their share) will be allocated into a separate account, which will be used to fund research of a priority to the interests of remote-dwellling Aboriginal and Torres Strait Islander people within the general aims of Ninti One.

6.2 Aboriginal and Torres Strait Islander Trustees

When commercial revenue funds have accumulated from the Company's Participating Share payments, the Aboriginal and Torres Strait Islander members of the Board will establish an Aboriginal and Torres Strait Islander Trustees group to manage and distribute these funds. The Board will establish, or cause to be established, a charter of operation of the Trustees group. The



Aboriginal and Torres Strait Islander Trustees group, in consultation with the Board, will determine the research priorities for which the funds will be used.

7. MONITORING, REPORTING AND IMPLEMENTATION

It is a requirement that effective measures are taken to ensure this Protocol is properly implemented in all research projects. Ongoing monitoring and reporting will be conducted throughout the duration of the project through milestone and annual review reports. Ninti One will ensure that any breach in ethics and confidentiality is handled appropriately using relevant processes.

8. BREACHES OF THE PROTOCOL

Ninti One will ensure that any breach in ethics and confidentiality is handled appropriately using fair and equitable processes, currently through referral to the management of Ninti One.

Potential penalties and sanctions are:

- Withdrawal of research funding
- Written censure with consequent damage to credibility of researchers
- Suspension of contracts or permission to conduct research
- Withdrawal of communities and families from the research.

Breaches of ethics and confidentiality will be referred to the Board for appropriate action.

9. CONTINUAL IMPROVEMENT

With the full participation of Aboriginal and Torres Strait Islander people involved in research projects, research within Ninti One will be informed by ongoing developments in ethical standards for defining and handling Aboriginal and Torres Strait Islander knowledge and IP. A continual improvement process in research projects will ensure ongoing ways to integrate formal scientific methods with local Aboriginal and Torres Strait Islander knowledge/s. Ninti One will examine new relevant models that are consistent with international standards, such as articulated in the United Nations Convention on Biological Diversity. The Board may update this Protocol to reflect these improvements.



ATTACHMENT A - DEFINITIONS OF TERMS USED IN THIS PROTOCOL

Aboriginal and Torres Strait Islander Knowledge

Refers to the totality of cultural heritage of Aboriginal and Torres Strait Islander people, as this is defined by Aboriginal and Torres Strait Islander people. This is an inclusive and dynamic body of practices and traditions, encompassing both tangible and intangible elements. It allows for a diversity of situations, uses and meanings. It is based on collective rights and interests, is passed on through generations, and is closely linked to land and identity.

Background Intellectual Property

This is the intellectual property that all participants bring to a project at the start. The actual nature of this IP will be described in schedules to a Project Agreement. In general, background IP refers to notes, documents, reports and other materials relating to a project that are in existence prior to the commencement of a project. In practical terms, background IP may be said to include Aboriginal and Torres Strait Islander knowledge as defined above, as this is the property of Aboriginal and Torres Strait Islander people that is in existence prior to the commencement of a project.

Intellectual Property

Refers to products, works and inventive processes that result from Ninti One research projects, that are subject to, or potentially subject to protection under conventional intellectual property rights laws. These laws include the *Copyright Act (1968)*, *Patents Act (1990)*, *Plant Breeder's Rights Act (1994)*, *Trade Marks Act (1995)* and the *Designs Act (2003)*.

Confidentiality

Refers to the privacy of the individual with whom the researcher is working. Any information imparted by an individual will be kept between the researcher and that individual, unless it is clear that it is public and open information. The participant in a research project should be told at the start of the project that the researcher will protect their privacy and confidentiality.

Ethics

The key principles that guide ethics are respect, equality, responsibility, research merit and integrity, justice, reciprocity, free prior informed consent and collaboration. The two important documents that researchers working with Aboriginal and Torres Strait Islander people in Australia follow are the *National Statement on Ethical Conduct in Human Research* (2007), and the

NINTI* ONE:

Guidelines for Ethical Research in Indigenous Studies by the Australian Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS 2011).

Free Prior Informed Consent

Refers to the process of providing full and relevant information to Aboriginal and Torres Strait Islander people about the risks and benefits of research projects prior to the commencement of the project, in order to allow Aboriginal and Torres Strait Islander people to make informed decisions whether or not to consent to the project. This consent can be withdrawn at any time without penalty.

Agreement

The contractual agreement that establishes the Unincorporated Joint Venture (UJV) of DKCRC, as well as empowering the formation of a company (Ninti One Limited) to hold the Intellectual Property produced by the Centre's activities and to provide administrative services to the Centre. The Centre Agreement is signed by all the Partners and such other partners as wished to be part of it ('Supporting Partners').

Commonwealth Agreement

This contractual agreement commits the Essential Partners to deliver Ninti One's obligations in return for Commonwealth funding and is signed by the Essential Partners and the Australian Government.

Company's Participating Share

The Centre Agreement sets out that the Company (DKCRC) receives commercialisation revenue as determined in accordance with clauses 33.6 and 33.7. These clauses state that the Company's share of revenue is calculated in proportion to the total value of Centre resources (other than Participant contributions) divided by the total value of Centre and Participants' contributions.

