

Ethical Framework

Two traditions of thought combine to form the ethical foundation of *The Genographic Project*. For a project of this kind; each tradition is necessary. However, neither is, by itself, sufficient. Thus the core requirements of each tradition must be satisfied if an acceptable ethical ‘benchmark’ is to be achieved. Of these traditions, one line of thinking is derived from what might best be described ‘modern research ethics’; the other is a product of Indigenous experience and thinking.

An Indigenous Framework for Ethical Research

One of the core principles expressed across the world’s Indigenous communities is that authority to speak on behalf of any group is fundamentally local and limited. That is, indigenous people have a highly developed sense of the boundaries that restrict how any one person or group might represent the views and interests of another. While broad representative structures can be established by consent, these structures will usually have only conditional authority. It is against this background that *The Genographic Project* has sought and adopted an Indigenous ethical framework for its research – specifically that articulated by Professor Mick Dodson¹. While Professor Dodson’s ideas cannot be taken as representing the position of all indigenous people, we believe that the core of his argument is an authentic expression of Indigenous concerns and requirements. Given that one of his central principles privileges local, community-based, decision-making – we think that his framework includes the proper degree of flexibility needed to respect the views of diverse indigenous communities around the world.

In regard to Professor Dodson’s paper, the following principles have informed the development of *The Genographic Project*:

Indigenous scepticism is a product of centuries of exploitation

The impetus for the development of an Indigenous Framework for Ethical Research is the product of many centuries of exploitation. Having had their lands colonised and cultures marginalised, many Indigenous people have an understandable fear that scientists now wish to ‘colonise’ and exploit their bodies. This fear is compounded by the experience, of many, of a fundamental lack of respect in which indigenous people have been treated as less than fully human ‘specimens’ for research.

This has not only been the experience of Indigenous people. Indeed, the members of marginalised communities amongst the colonisers have also been treated as objects of

study. However, the development of ethical considerations (such as the principle of ‘respect for persons’) has seen a new concern for human rights being extended to the marginalised ‘kin’ of the colonisers – while excluding Indigenous communities. Indeed, some researchers still fail to take into consideration the core, ethical requirements of Indigenous communities – thus reinforcing a climate of scepticism about researchers in general.

Indigenous people are expert managers of mixed modes of knowing

In one form or another, every human society recognises and values knowledge as a human good. Indigenous communities are no different – and have a refined capacity to develop and manage diverse forms of knowledge within a single cultural environment. Typical forms of knowledge include (but are not limited to): cosmological, mythological, historical, spiritual, aesthetic, scientific (based on observation and experience), mathematical ... and so on. For example, a single species of plant may be known of in very different ways. It might feature in a creation story (perhaps the final embodiment of a being once capable of changing form). At the same time, the plant may be known for its medicinal properties – with this knowledge being developed using standard scientific procedures of observation and experiment over time. Finally, the plant may play a role in and therefore be known and understood, in ritual or aesthetic terms. While each mode of knowing will represent different perspectives, Indigenous people integrate these different ways of knowing into their lives. This capacity even extends to the management of competing narratives. For example, Indigenous people living over an extended area may have quite different creation stories that offer competing explanations for how the world came to be. Indigenous people tend to respect such differences – recognising different narratives as alternatives that can coexist without one threatening the integrity of the other. While committed to their different ways of knowing, Indigenous people tend not to suffer from the arrogance of other groups that would proclaim their narrative as being the sole expression of truth.

Indigenous people operate on the basis of relationships rather than ‘contracts’

In many societies, the development of legal contracts has been encouraged as an alternative to the establishment of relationships. In theory, this is supposed to facilitate agreements between strangers – where negotiated and enforceable rules are meant to serve as a substitute for personal bonds of understanding. The reality is that most people recognise that good relationships are more important than well-drafted contracts. This is even true in societies with a strong tradition of contract law.

However, it is a common factor in Indigenous societies that a formal contract can never count as a substitute for a proper relationship based on mutual respect. As such, agreements between total strangers are hardly possible – and where they do exist, is usually evidence of some imposition. Instead, Indigenous communities place a high premium on issues of trust borne out of mutual respect. Interactions amongst new acquaintances will often require a mutually trusted third party to effect introductions. None of this is to suggest that apparent strangers are unable quickly to form bonds of trust. The integrity of a person can be rapidly assessed. However, the more usual pattern requires time to pass before a relationship will form.

Reciprocity is a fundamental aspect of Indigenous relationships

It is a common aspect of Indigenous societies that a network of relationships provides an effective guarantee of the welfare of all. That is, the survival of any one individual may depend on the support of each for all others. In one sense, reciprocity is not so much a matter of intentional agreement between people as a consequence of integrated bonds of kinship. However, admission to the world of Indigenous people (at their election) is rarely, if ever, a 'one way street'. Rather, there is an expectation that, irrespective of the purpose of the relationship, it be understood as bringing in to existence reciprocal obligations – often extending to and from an extended network that may include the community as a whole.

Researchers are expected to engage in advocacy in support of Indigenous people's aspirations

One of the most significant disappointments for Indigenous people has been the number of researchers who have failed to engage in advocacy in support of the communities they have studied. The advocacy sought often relates to support for the legitimate aspirations, of Indigenous people, for the preconditions of cultural integrity. These preconditions can include claims for self-determination, land rights, the preservation of language and customs, and so on.

Authority is local and conditional

For many Indigenous people, authority arises out a complex and inter-dependent web of relationships to people, land and culture (law and lore). Even though such webs may intersect, they are invariably grounded in local points of presence. Given this, Indigenous people are deeply reluctant to speak on behalf of others. Where they do so with consent, then the authority to do so will always be conditional. For example, in Australia, specific individuals may be selected to represent a community at a regional forum but know that they have no authority to speak about some other person's 'country'. Furthermore, some matters may be mandated by custom and practice and therefore be beyond any person's exercise of discretion.

Consent may be communal in character

One effect of this is that where discretion can be exercised, then agreement tends to be by consensus – and consent is ultimately a matter for local people to give or withhold as they think fit. This principle applies equally in matters subject to either communal or individual decision-making. Finally, those who are authorised to decide a particular matter will also be able to decide any further issue relating to the same matter.

Application of the indigenous framework to *The Genographic Project*

Genographic Project research protocols include the following features:

- Informed consent procedures include the possibility of communal and/or individual consent.
- Informed consent to participate in the research implies a linked right to control the mode of communal or personal access to information arising from the research. For example, those responsible for giving communal consent may determine the extent (if any) to which research findings are conveyed to the community and the form in which this information is communicated. Where individuals provide informed consent, then they may determine the flow of information for themselves.
- The collection of blood samples is not a strict requirement of the project. Communities and individuals have a broad range of options to choose amongst in relation to the collection of DNA samples. While the collection of a blood sample will provide the greatest amount of DNA, alternatives include buccal (cheek) swabs the use of a non-invasive mouth wash (using ordinary water). Indigenous people may elect to provide a sample using any of the available techniques – or not to participate at all.
- Principal Investigators are required to be (and are) sensitive to the fact that knowledge generated by the project may give rise to narrative accounts that function as an alternative to some traditional accounts of the origin of the cosmos (including people). All project participants understand that scientific narratives do not have priority over other types of narrative – and that Indigenous communities will determine the extent (if any) to which such narratives might complement their existing world views.
- *The Genographic Project* has established the *Genographic Legacy Fund*. The purpose of this fund is to provide tangible benefits to Indigenous communities in support of their aspirations to promote and protect their cultures. The details of the operation of the *Legacy Fund* are contained in the Charter established for this purpose. The Charter provides considerable flexibility in the choice of applications that might receive funding. Thus, Indigenous communities can apply for financial support for a broad range of purposes that could assist their preservation and/or development. The process of selecting projects makes specific provision for advice from indigenous people who are an integral part of the steering committee.

Modern Research Ethics

The development of procedural and institutional arrangements to consider the ethical dimension of research proposals (especially in relation to research involving humans) has become an established feature of project design. The assessment of research applications is typically conducted by a disinterested committee with its members applying a formally sanctioned ethical framework.

The development of institutional ethics committees (or their equivalents in different jurisdictions around the world) is, in part, a response to incidents of serious abuse by

scientists (or pseudo-scientists) in past times. For example, one of the most notorious cases involved the ‘pseudo-science’ of people, like Mengele, in Germany during the Third Reich. However, deliberation about the ethical constraints that ought to govern research is also a product of long-standing traditions of requiring that the legitimate ‘end’ of discovering new knowledge be served by ethical ‘means’.

What people now understand as being unethical research was not always the product of malevolent intentions. In many cases, researchers failed to reflect on practices that were uncritically accepted as ‘normal’. Thus, much that is worthy of condemnation today was once the product of unthinking custom and practice. The failure to reflect on the ethical dimension of some research practices was also, on occasions, the product of a convenient process of rationalising what was done by researchers for reasons of self-interest. Like others, researchers can be tempted not to look too closely at troubling questions which, if investigated, might prevent or delay them from realising their scientific objectives.

This is where the role of a disinterested ethics committee can be so crucial. While having a proper regard for the ‘good’ of knowledge, an ethics committee has an overriding duty to ensure that core principles are applied in the design of research protocols.

It is worth noting that the principles applied by ethics committees are, for the most part, a product of what might be called ‘Western’ cultural paradigms. For example, the notion of ‘informed consent’ is typically applied to individuals. As noted above, such standards may not always be consistent with Indigenous cultures.

Modern Research Ethics and *The Genographic Project*

- It is a requirement of *The Genographic Project* that all research protocols be approved by independent ethics committees established by institutions (typically universities) located in the regions occupied by the project’s Principal Investigators.
- In some regions, approval by institutional ethics committees is just the first step. A number of countries also require formal approval by government appointed committees – some of which are established specifically to protect the interests of Indigenous people.
- To the extent the project includes the collection and analysis of ancient DNA, where kinship affiliations can be determined accurately, then samples will only be taken with the consent of the descendant community.

- Finally, given the explicit and limited objective of *The Genographic Project* its Directors have established core requirements that all project participants must accept as a formal condition of their involvement. The most important of these are that:
 - No medical research will be conducted using the DNA samples collected for this project
 - No patents will be sought as a result of this research
 - All research findings will be held for public benefit
 - All samples collected will be held under strict conditions maintaining confidentiality and may not be used for any purpose inconsistent with the strictly limited scientific objectives of the project.
 - Participants may, at any time, withdraw or modify their consent and may exercise discretion over the storage, return or destruction of their sample and/or any identifiable data arising from the project.

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Dodson, M (1997) *Indigenous Social and Ethical Issues: control of research and sharing of benefits*, an address to the Indigenous Concerns Symposium, Fremantle (unpublished)

Dodson, M. & Williamson, R. (1999) "Indigenous Peoples and the Human Genome Diversity Project" in *Journal of Medical Ethics*, Vol 25, pp. 204-208

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Reference to the work of Professors Dodson and Williamson does not imply that they support the research objectives of the Genographic Project.