

# THE GENOGRAPHIC PROJECT: TRADITIONAL KNOWLEDGE AND POPULATION GENETICS

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## I Introduction

With the advent of the genetic revolution, Indigenous peoples have expressed particular concerns about 'biopiracy' – the unauthorised collection, screening, and use of genetic products taken from Indigenous peoples and from their land for commercial purposes. Victoria Tauli-Corpuz, Chairperson of the United Nations Permanent Forum on Indigenous Issues, has noted that '[b]iopiracy has been taking place and is still happening in many of our communities'<sup>1</sup> and that it 'includes, among others, the collection and patenting of our traditional knowledge and genetic materials found in our bodies, medicinal plants, seeds, animals and microorganisms found in our territories'.<sup>2</sup> In observing the public debate over the international problem of biopiracy of plant genetic resources, Ikechi Mgbeoji has commented:

Various factors have congregated to arouse a huge interest, indeed a controversy, with regard to the legal ownership of plant genetic resources and the knowledge associated with the uses of plants. This controversy has elicited calls for the creation of a regime dealing with access to and equitable sharing of the benefits of plant genetic resources. These issues are often conflated in what has become known as the issue of 'indigenous peoples knowledge'. The debate has often implicated a variety of issues, such as the imposition of Eurocentric legal concepts, the impact of globalization, and emerging norms on legal control of knowledge. In addition, the debate has raised issues pertaining to the prevailing ideology of 'civilization' and 'development' and its impact on biological and cultural diversity.<sup>3</sup>

There have been a number of infamous cases of alleged 'biopiracy' in relation to agricultural biotechnology.<sup>4</sup> For example, patents have been lodged over turmeric,<sup>5</sup> basmati rice,<sup>6</sup> Nap Hal wheat,<sup>7</sup> and the neem tree.<sup>8</sup> In addition to concerns about biopiracy of plant genetic resources, concerns have been raised over the patenting of genetic

material of Indigenous communities in Panama<sup>9</sup> and Papua New Guinea.<sup>10</sup> There has been much debate about the ethical propriety of gene prospecting in remote and isolated populations<sup>11</sup> such as the inhabitants of Tristan da Cunha<sup>12</sup> and Iceland.<sup>13</sup> Such controversies have contributed to an atmosphere of distrust towards the genetic study of Indigenous communities. There has been much academic and policy discussion at the local, national, and international level about the best means to protect traditional knowledge.<sup>14</sup> Within this literature, there has been significant interest in genetic research involving Indigenous communities.

It has been argued that there is a need for stronger ethical protocols by universities, funding agencies, and government agencies to guide research in this field. For instance, the Australian Law Reform Commission observed that:

Social and ethical concerns can be addressed most effectively through direct regulation of the use and exploitation of patented inventions, or through regulation of research activities that lead to the development of inventions, rather than through excluding particular subject matter from patentability.<sup>15</sup>

Kathy Bowrey suggests that ethical protocols can be influential: 'Whilst this effect is not assured, over time protocols do have the capacity to influence change in ways that differ to stringent bureaucratic or legislative programs.'<sup>16</sup>

Other policy-makers have called for reforms and amendments to intellectual property laws – in particular, patent law.<sup>17</sup> There has also been a push to supplement patent law with recognition of the bioethical principles of informed consent and benefit-sharing. This raises the issue of whether such principles should be mandated, or whether regulation should be voluntary.

Indigenous activists have called for the development of *sui generis* legislation to protect Indigenous interests in genetic resources.<sup>18</sup> This would require mandatory consultation and informed consent in respect of research and exploitation of genetic resources. This would also involve recognition of Indigenous communities' legal rights to own, control, and benefit from their genetic resources (including DNA extracted from skeletal remains). Solidifying these rights would necessitate some form of benefit sharing agreement.

This article recognises that the debate over biological research involving Indigenous communities is a contentious and emotional area. There are strong divisions of opinion, both between scientific researchers who believe that their scientific work is of universal value, and Indigenous communities who have well-founded fears of biopiracy. Charles Furniss has charted the contours of this debate:

The debate is a fascinating one. On one side are some of the world's most distinguished anthropologists and geneticists, striving to find answers to fundamental questions about our species' origin and searching for cures to a host of genetic diseases. Their research, they say, is of universal value to humanity. On the other side are some of the world's most endangered communities, who are struggling to preserve their cultural integrity, to retain their ancestral lands and, in some cases, to survive. Such research, they argue, is a new chapter of an old story of extractive, 'helicopter' science, where researchers from wealthy countries have profited from indigenous knowledge and culture while their subjects have received no benefit. Not only does it abuse indigenous peoples' human rights, they say, its results could have dire implications for their future security.<sup>19</sup>

It is contended that such acrimonious conflict and deep-seated mistrust has been exacerbated by a lack of clear legal rules and ethical protocols on traditional knowledge. It is argued that such disputes over genetic research involving Indigenous communities could be allayed through the development of clear, workable and fair legal rules and ethical protocols. It is submitted that there is a need for large scale biology projects to be driven by community-based participation research, and the principles of co-learning, mutual benefit, and long-term commitment.<sup>20</sup> There is a need for ethical protocols to be underpinned by legal protection of the principles of informed consent and benefit-sharing in national regimes. Furthermore, there is a need for over-

arching international rules on the protection of Indigenous knowledge and heritage.

This article considers the debate over patent law, informed consent, and benefit-sharing in the context of biomedical research in respect of Indigenous communities. In particular, it focuses upon three key controversies involving large-scale biology projects and Indigenous populations. These case studies are indicative of the tensions between research organisations, Indigenous communities, and funding agencies. Section two of the article considers the aims and origins of the Human Genome Diversity Project ('HGDP'), and criticisms levelled against the venture by Indigenous peak bodies and anti-biotechnology groups. It examines the ways in which the United Nations Educational, Scientific, and Cultural Organization ('UNESCO') has grappled with questions of patent law, informed consent, and benefit sharing in relation to population genetics. Section three focuses on *Tilousi v Arizona State University*<sup>21</sup> and *Havasupai Tribe v Arizona State University*.<sup>22</sup> These matters involved a direct claim by the Havasupai tribe as well as a separate claim by individual members against Arizona State University and its researchers for using genetic data for unauthorised purposes. The cases raise questions about informed consent, negligence, and the broader issue of human rights. Section four explores the legal and ethical issues raised by the Genographic Project.<sup>23</sup> It considers the aims and objectives of the venture, and the criticisms levelled against it by Indigenous communities and anti-biotechnology groups. It examines the response of the United Nations Permanent Forum on Indigenous Issues to the Genographic Project and then charts the debate over the protection of traditional knowledge in various international fora. The article concludes by recommending a number of measures to better regulate large-scale biology projects involving the participation of Indigenous communities.

## II The Human Genome Diversity Project

In 1984 Luigi Luca Cavalli-Sforza and his collaborators, Ken and Judy Kidd of the Yale University Genetics Department, along with anthropologist Barry Hewlett of Washington State University, started a pilot program to produce cell lines from a number of Indigenous populations throughout the world. The first collaborative effort was the generation of cell lines from African Pygmies of the Central African Republic and north-eastern Zaire.<sup>24</sup> A laboratory at Yale University

was able to grow cultures from such samples and provide an initial idea of genetic variation.

In 1991 Cavalli-Sforza and a group of colleagues proposed the HGDP in a letter to the scientific journal *Genomics*.<sup>25</sup> He hoped that the venture would overcome some of the inherent limitations of the Human Genome Project:

The Human Genome Project would therefore be incomplete, and perhaps fail in a number of its most important aims, were we to take just one – or, more precisely, half of one – individual. As it stands, it is a formidable undertaking, so the study of individual variation should be planned with the maximum economy. It is unthinkable to fully analyse the sequence of nucleotides in a hundred or thousand individuals. An intelligent program, however, can hope to cover most of the significant individual variations, with a very modest expense, less than 1 percent of the whole budget. A group of colleagues and I have launched a proposal for such a program called Human Genome Diversity.<sup>26</sup>

Cavalli-Sforza and his colleagues had emphasised the urgent need for such a study: ‘The populations which can tell us most about our evolutionary past ... are being rapidly merged with their neighbours ... destroying irrevocably the information needed to reconstruct our evolutionary history’.<sup>27</sup> They observed that ‘[i]t would be tragically ironic if, during the same decade that biological tools for understanding our species were created, major opportunities for applying them were squandered’.<sup>28</sup> This call provided the impetus for the establishment of the HGDP.

Amade M’charek has said of the controversy surrounding the HGDP:

Whereas the proponents of the Diversity Project emphasized its mere scientific goals and the fact that it would refrain from economic exploitation of the genes and knowledge acquired, in the debates the project was constructed in a different manner. In these debates, the Diversity Project was linked with concerns about economic exploitation in terms of gene patenting and the development of expensive medication, with the development of ethnic weapons (‘gene-bombs’) and racism, with bio-piracy and bio-colonialism, and with a sheer interest in the history of populations rather than their futures. It seems that, however hard the projectors tried to purify their initiative, it became a focal point for various

different concerns that indigenous peoples and others have with biotechnology and the new genetics.<sup>29</sup>

This debate between the supporters of the HGDP and its critics is instructive.

### A The Human Genome Diversity Project

The HGDP aimed to collect DNA samples from over 500 linguistically distinct groups by taking blood and tissue samples from 25 individuals from each group with prior informed consent given at the individual or community level.<sup>30</sup> The leaders of the group explained the aims and objectives of the project thus:

The HGD Project is an effort by anthropologists, geneticists, doctors, linguists, and other scholars from around the world to document the genetic variation of the human species worldwide. This scientific endeavour is designed to collect information on human genome variation to help us understand the genetic makeup of all of humanity and not just some of its parts. The information will also be used to learn about human biological history, the biological relationships among different human groups, and may be useful in understanding the causes of and determining the treatment of particular human diseases.<sup>31</sup>

The HGDP emphasised that it had no intention to patent the blood samples that it collected: ‘At its international congress in September 1993, the Project decided that it would not profit from the samples or the data developed from them’.<sup>32</sup> The venture was committed to sharing the benefits of the research: ‘If any products were developed as a result of samples obtained from sample repositories or data banks operated by the Project, some reasonable financial benefits would flow back to the sampled populations.’<sup>33</sup> The HGDP stressed that it was not a commercial enterprise: ‘It seeks knowledge, not profit.’<sup>34</sup>

The leaders of the HGDP were conscious of the controversies that had arisen over the patenting of plant genetic resources held by Indigenous communities and developing countries: ‘Some advocates for indigenous peoples or the developing world have been concerned that the Project will be a human version of these plant-collecting expeditions’.<sup>35</sup> The HGDP sought to reassure the public that it was not simply engaged in bioprospecting, providing the qualified undertaking

that any commercial products that might emerge from the research would be subject to benefit-sharing:

Even if commercial products were created using the Project's samples, the HGD Project is committed to two propositions: (1) that financial benefits should not go to the Project and (2) that an adequate part of the financial gains, if any, must go back to the sampled populations. The best ways to implement those commitments are not yet entirely clear. Implementation depends on some complex issues of patent and contract law that have not been entirely resolved, as well as on some decisions by the sampled populations or their representatives on how best to proceed. The Project plans to make those implementation decisions after consultation with such representatives.<sup>36</sup>

The research group emphasised: 'The [HGDP] will not profit from the samples and it will do its best to make sure that financial profits, if any, return to the sampled populations'.<sup>37</sup> It observed that 'no population should take part in the Project because it expects to earn royalties from pharmaceuticals'.<sup>38</sup> Furthermore, it noted that 'the Project can promise to share with the sampled population the information derived from the samples about history, medicine, or other topics'.<sup>39</sup>

The North American Region of the HGDP prepared a model ethical protocol, laying out its principles in respect of informed consent and benefit-sharing; respect for the sampled population's culture; and adherence to international standards of human rights. The HGDP emphasised the need for the venture to meet the highest ethical standards:

The proposed HGDP is an exciting effort to increase our knowledge of the human family: its evolution, history, diversity, and essential unity. Its breadth may be unique among major scientific endeavours – it seeks to study our entire species in ways that will engage the attention of tens of millions of people. This scientific project intrigues people who are interested in origins, history, languages, cultures, medicine, and a host of other topics. In particular, anthropology, genetics, and molecular biology combine in the HGDP to reach out to an enormous audience, throughout the world. This breadth of the HGDP is one of the things that makes it even more crucial that it be conducted according to the highest ethical standards. There may be no other scientific project that has the capacity to touch so many lives and minds.<sup>40</sup>

The ethical protocol concluded: 'If the [HGDP] is conducted according to these principles, it should enhance not only humanity's knowledge of itself, but also humanity's interest in, knowledge of, and confidence in science'.<sup>41</sup> Nonetheless, it noted that '[i]f conducted poorly, without respect for and protection of the rights of those who participate, it may prove a disaster – not for humanity, but for science'.<sup>42</sup>

Writing in 2001, Henry Greely commented that 'the HGDP remains today, as it was nine years ago, largely at the planning stage, an unfunded ghost at the [Human Genome Project]'s lavish banquet'.<sup>43</sup> He sought to explain the relative failure of the HGDP as compared to the Human Genome Project:

Although the HGDP was criticized by indigenous organizations for being a front for predatory biomedical companies, it lost political clout because of its very limited biomedical implications. The HGDP does not plan to collect phenotypic or medical data; the data it will collect are to be limited to some ethnographic background information on the participants. Without phenotypic data, the HGDP's samples and data would have limited value for biomedical purposes. Although the HGDP's resource might help to determine whether particular alleles thought to be related to disease were common or uncommon in particular populations, it could not connect the alleles to medically important information.<sup>44</sup>

Greely concludes that the HGDP was never able to win support from either the National Institutes of Health or the United States Department of Energy because it lacked a clear medical focus. Furthermore, the HGDP was even more unattractive to research agencies because it was embroiled in the middle of various scientific and ethical controversies.

In recent times, Cavalli-Sforza has defended the continuing relevance of the HGDP and emphasised its medical significance: 'The HGDP collection is valuable not only for medical studies, but also for the study of other phenotypes'.<sup>45</sup> He has suggested that the HGDP deserved greater funding: 'Its potential uses in medicine, science and social problems such as racism are sufficiently important that the project should be continued and expanded'.<sup>46</sup>

## **B The Vampire Project**

The HGDP generated significant concern, with coalitions of Indigenous communities and anti-biotechnology groups

organising themselves on an international basis against it. In 1993 the anti-biotechnology group Rural Advancement Foundation International ('RAFI') released a communiqué concerning HGDP, in which it observed:

The sampling of human genetic material for scientific research, as currently being discussed by the Human Genome Diversity Project, has serious implications for indigenous peoples. Products and processes extracted from the collected material could have enormous commercial value. The material itself may be patentable even without further research. Will profits be made from the genes of poor people whose physical survival is in question? Who will have access to stored genetic material, and where will these collections be located? What benefits, if any, will accrue to the indigenous peoples from whom DNA samples will be taken?<sup>47</sup>

Elaborating upon such concerns, Hope Shand of RAFI argued that 'the Human Genome Diversity Project ... should not continue without full approval and participation of indigenous people's organizations, and without functioning under the auspices of a United Nations body'.<sup>48</sup> RAFI demanded that the HGDP immediately halt any collection efforts until such time as it had consulted representative Indigenous organizations. RAFI argued that Indigenous communities should participate fully in every aspect of the HGDP and enjoy the equivalent of veto power.

RAFI passed on its analysis of the HGDP to the World Council of Indigenous Peoples, Survival International, and the Third World Network. Taking heed of such warnings, Indigenous organisations trenchantly demanded that

the Human Genome Diversity Project and any other such scientific project cease any attempts to seduce or coerce participation in their projects through promises of benefits and financial gain in order to obtain consent and participation of indigenous peoples. We demand an immediate moratorium on collections and/or patenting of genetic materials from indigenous persons and communities by any scientific project, health organization governments, Independent agencies, or individual researchers. We demand that nation-state governments and their departments do not participate, fund or provide any assistance to the Human Genome Diversity Project or any related programs or seek to hold patents or otherwise benefit from the genetic materials taken from indigenous peoples.<sup>49</sup>

The coalition of Indigenous groups urged the international community and the United Nations 'to participate with Indigenous peoples in developing international policies and conventions which protect all life forms from genetic manipulation and destruction'.<sup>50</sup>

The Central Australian Aboriginal Congress re-named the HGDP 'the Vampire Project'. In its Position Paper the Congress observed:

The Vampire Project is legalized theft. The Vampire scientists are planning to take and to own what belongs to indigenous people... We must make sure that our people are not exploited once more by corporations, governments, and their scientists.<sup>51</sup>

Similar statements and declarations were made by other Indigenous communities and representative peak-bodies.<sup>52</sup>

Michael Dodson, Australia's first Aboriginal and Torres Strait Islander Social Justice Commissioner, condemned the HGDP, noting Indigenous people's central objections:

Our core objection to the Human Genome Diversity Project is not its potential to undermine our cosmology: that would hardly be something new; it happens in every aspect of our interaction with non-indigenous culture. It is the denial of our humanity, it is that the project would have our bodies the sites of exploitation as our lands have long been.<sup>53</sup>

Dodson maintained that 'the scientific community should have the humility to accept that, however good the intentions, the HGDP did not start with the correct approaches to nor respect for indigenous peoples in many cases'.<sup>54</sup> He commented: 'It is the scientific community that has the ethical obligation to start again, and to offer proper explanations in a context of respectful negotiation and a commitment to equality'.<sup>55</sup>

The HGDP has also attracted a chorus of academic disapproval and discontent. According to Jill McKeough:

While the HGP has highlighted the issues of patenting of gene sequences, gene therapies and other aspects of human life, the HGDP appears to be pursuing an aggressive patenting policy which, furthermore, has the overtones of all the worst aspects of colonialism.<sup>56</sup>

Stephen Gray notes that '[t]here have been protests about this project raised by a number of community groups, including those concerned at the discriminatory uses to which new scientific information of this type might be put'.<sup>57</sup> Cindy Hamilton alleged that '[p]rojects like the HGDP, despite its good intentions medically, occupy a position on a continuum of cultural imperialism that seeks to exploit indigenous communities while offering almost nothing in return'.<sup>58</sup> Annie Wu has observed the inherent 'oddity of patenting human cells [which] has aggravated and fuelled much hysterical controversy, not without good cause'.<sup>59</sup>

One of the most cogent criticisms of the HGDP comes from Bitu Amani and Rosemary Coombe:

Those concerned with issues of social justice quite properly ask why we should expect indigenous peoples to grant us access to their genetic resources in order to advance medical knowledge about the maladies of the privileged when we will not provide even the most basic of existing medicines or infrastructural resources to alleviate their suffering.<sup>60</sup>

It is the opinion of this author that some of the censure regarding the HGDP was well-founded. The HGDP was designed without proper community-based research participation. As a result, the protocols first developed in respect of informed consent and benefit-sharing were inadequate. While the fears of Indigenous communities, civil society groups, and academic commentators that the HGDP would involve the patenting of human genetic material were never realised there has, nonetheless, been significant activity in the field of gene patents by both companies and public research institutions.

### **C United Nations Educational, Scientific, and Cultural Organisation**

In the Autumn of 1995 Cavalli-Sforza went to UNESCO for an independent review of the HGDP's protocol. The UNESCO Subcommittee on Bioethics and Population Genetics ('Subcommittee') report highlighted concerns about the patenting of Indigenous genetic material: 'Patenting has become an issue in population genetics primarily in relation to the patenting of products derived from the genetic material of indigenous peoples'.<sup>61</sup> The report emphasised the need to obtain proper informed consent in relation to population genetics:

Various groups of indigenous peoples have expressed their irritation with past population genetics research which they claim has been conducted without prior consultation and in a way where consent was obtained in terms inconsistent with their cultural norms.<sup>62</sup>

It noted that while:

[t]he application of the ethical principle of informed consent and respect for integrity is a more complex process at the level of populations... [p]ractitioners of contemporary science do not always understand that the goals and aspirations of scientific projects may not always coincide with the goals and aspirations of particular cultures. It may not be ethically acceptable to some people to cooperate in the collection of saliva, skin, hair and blood samples for the purpose of storage and the establishment of 'transformed cell lines', samples which would be basically identical to the individual of origin which are then made available for study to scientists around the world.<sup>63</sup>

Consequently, the Subcommittee provided the following guidelines for conducting genetic research on populations:

The importance of obtaining consent from a study population is well recognised (even if not always practiced). Population genetics studies should be conducted by personnel with the appropriate qualifications, but only after informed consent has been given for any general medical examinations, and removal of blood samples (generally under 20ml) or other bodily samples. Such samples are taken to the home laboratory or other laboratories, and the components separated for analysis. The analysis of the samples requires specific consent that should be sought and given before samples are obtained (Baird, 1995). By the term 'specific' consent we mean it could include consent for complete genetic analysis of the DNA, or analysis for detailed purposes, but it should be clarified and informed.<sup>64</sup>

The Subcommittee stressed that there was a need for Indigenous communities to be properly represented in the management of population genetics research projects: 'The body entrusted with the responsibility of overseeing such research should include substantial and legitimate representation of the target populations'.<sup>65</sup>

The Subcommittee also discussed the importance of benefit-sharing:

It should be remembered that financial returns are not the only form of benefits of research results which could be returned to subjects of research. Perhaps a more important aspect is the return of information and research results to the communities from which data was collected. There are research projects, for example, which plan to write their research analyses and conclusions in popular form which are accessible to the communities so that they could be helpful to them in promoting concrete responses to particular problems.<sup>66</sup>

The Subcommittee also noted that 'general statements of possible benefits flowing from research projects to local populations, such as the HGDP's claims that it will lead to the development of scientific laboratories in local areas, should be formulated concretely and specifically so that it becomes obvious how this will happen.'<sup>67</sup>

The Subcommittee ultimately declined to provide specific support to the HGDP. Nonetheless, it sought to provide more guidance to population genetics research. In a letter to *Nature*, Professor Bartha Knoppers and her colleagues explained the findings of the UNESCO report:

What we did criticize was the planners' failure to anticipate the reactions of some groups of indigenous peoples to the HGDP, as well as the delay between the planning of the project and the release of detailed measures to explain how 'informed' consent would be obtained. However, obtaining informed consent is an ethical problem for many population research projects. The latest measures produced by the HGDP planners contain some of the most ethically sophisticated and detailed procedures for obtaining informed consent from individuals and groups in population genetics research.<sup>68</sup>

Knoppers noted that many of the issues raised in the report, such as the commercialisation and use of the results of the collected DNA and cells applied to the whole of population genetics research. She noted that '[t]he resolution of biotechnology patents and "genetic prospecting" was not a subject for our subcommittee to resolve, but we urge the clarification of this issue by a global body'.<sup>69</sup> Diplomatically, Knoppers observed, '[t]he fact that our report did not endorse any particular population genetics project is not a criticism of the HGDP'.<sup>70</sup> Rather, she concluded that '[it] is our personal view that the role given to us by UNESCO could better be served, as could science, by the establishment

of a separate ethical committee available to all population genetics researchers'.<sup>71</sup>

In October 2003, UNESCO, pursuant to Knoppers' advice, received a mandate to draw up a declaration setting out fundamental principles in the field of bioethics.<sup>72</sup> A suitable declaration was drafted by a multi-disciplinary advisory group under the chairmanship of Justice Michael Kirby of the High Court of Australia.<sup>73</sup>

In October 2005, the member states adopted the *UNESCO Universal Declaration on Bioethics and Human Rights 2005* ('*UNESCO Declaration*').<sup>74</sup> The Director-General, Koïchiro Matsuura, explained the intent of the Paris Declaration:

By drawing on the 1948 *Universal Declaration of Human Rights*, the new *Universal Declaration on Bioethics and Human Rights* clearly enshrines the specific domain of bioethics in international human rights law. Under this aegis, it deals with ethical issues raised by medicine, life sciences and associated technologies as applied to human beings, taking into account their social, legal and environmental dimensions. It is thus conceived as a set of general provisions and principles that, first, allow for a better evaluation of the implications of the ethical issues at stake and, second, provide assistance in decision-making in this field. It does not aim to resolve all the bioethical issues presently raised and that evolve from day to day.<sup>75</sup>

The recitals recognise that 'ethical issues raised by the rapid advances in science and their technological applications should be examined with due respect to the dignity of the human person and universal respect for, and observance of, human rights and fundamental freedoms'.<sup>76</sup> Moreover, the recitals observe 'that it is necessary and timely for the international community to state universal principles that will provide a foundation for humanity's response to the ever-increasing dilemmas and controversies that science and technology present for humankind and for the environment'.<sup>77</sup> There has been some hope that the international instrument will have a bearing on intellectual property issues such as gene patents and access to essential medicines.<sup>78</sup>

The *UNESCO Declaration* recognises, in its recitals, 'that unethical scientific and technological conduct has had particular impact on indigenous and local communities'.<sup>79</sup> The proclamation also stressed 'the need to reinforce international cooperation in the field of bioethics, taking into account

in particular the special needs of developing countries, indigenous communities and vulnerable populations’.

A number of the general provisions of the *UNESCO Declaration* are relevant to scientific research involving Indigenous communities. Article 3 emphasises the need to respect human dignity, human rights, and fundamental freedoms. Article 4 notes: ‘In applying and advancing scientific knowledge, medical practice and associated technologies, direct and indirect benefits to patients, research participants and other affected individuals should be maximized and any possible harm to such individuals should be minimized.’ Article 6(c) provides: ‘In appropriate cases of research carried out on a group of persons or a community, additional agreement of the legal representatives of the group or community concerned may be sought.’ Article 8 observes: ‘Individuals and groups of special vulnerability should be protected and the personal integrity of such individuals respected.’ Article 12 requires that ‘[t]he importance of cultural diversity and pluralism should be given due regard.’ Article 15(a) provides that ‘benefits resulting from any scientific research and its applications should be shared with society as a whole and within the international community, in particular with developing countries’. Article 22(a) provides: ‘States should take all appropriate measures, whether of a legislative, administrative or other character, to give effect to the principles set out in this Declaration in accordance with international human rights law.’ Moreover, it suggests that such measures should be supported by action in the spheres of education, training and public information.

### **III *Tilousi v Arizona State University and Havasupai Tribe v Arizona State University*<sup>80</sup>**

The litigation arising out of the conduct of genetic researchers affiliated with Arizona State University, *Tilousi* and *Havasupai*, has raised important questions about the duties and responsibilities of geneticists in respect of research involving Indigenous populations.

The following extract describes the genesis of the litigation:

South of the Grand Canyon in Arizona, in a valley that roads still don’t reach, the Havasupai tribe has for centuries lived a cloistered existence in the high desert. Isolation in a geological wonderland has allowed the tribe’s 600-plus current members to protect their ancient culture. But the flipside is a restricted gene pool that has given the Havasupai

one of the highest incidences of type 2 diabetes anywhere in the world. Such populations offer geneticists the chance to discover rare gene variants underlying disease that would be difficult to detect in more diverse groups. And in the early 1990s, with the tribe’s blessing, a team from Arizona State University (ASU) in Tempe began searching for a genetic cause of the Havasupai’s diabetes. Instead of a genetic breakthrough, the research project has spawned lawsuits claiming \$75 million in damages, filed by tribal members who claim that their rights were infringed.<sup>81</sup>

The Havasupai tribe from the Grand Canyon in Arizona sued Arizona State University claiming misuse of blood and genetic samples taken for diabetes research.

#### **A *Arizona State University Research***

In 1989 social anthropologists John Martin and Daniel Benyshek, together with geneticist Therese Markow, established a proposal to study diabetes in the Havasupai tribe. The project had three key components: diabetes education; collection of blood samples from tribal members for research; and genetic testing to identify an association between certain gene variants and diabetes among Havasupai people.

Between 1989 and August 1990 Martin and Markow sought approval for the diabetes project from the seven-member tribal council of the Havasupai tribe. On May 14 1990 Martin sought a letter from the tribe endorsing the project’s research protocol. The Havasupai tribe stressed that the tribal council had only permitted the research project on the basis that it would focus on diabetes.

In 1991 Arizona State University’s human subjects committee of the Institutional Review Board approved the research. It is worth noting, though, that Markow’s research began prior to receiving official approval. The study was conducted with university funds, a \$US90 000 grant from the National Alliance for Research on Schizophrenia and Depression in New York, and small grants from the National Science Foundation and the National Institutes of Health.

In the period to 1994, Martin, Benyshek and Markow obtained nearly 400 blood samples from more than 180 donors. Markow also obtained more than 100 medical charts from the Supai Health Clinic in the Supai Village to identify patients with schizophrenia, according to court records. Researchers



also collected handprints from test subjects in 1992, claiming they would be used in the diabetes study.

The research gave rise to a number of publications.<sup>82</sup> In 1997, Martin and Benyshek published a study about Havasupai nutritional habits in the *Journal of the American Dietetic Association*. The researchers drew a link between that and diabetes. In 1997, Therese Markow published a paper in the journal, *Tissue Antigens*,<sup>83</sup> saying Havasupai genes have more in common with Asian people than with South American tribes.

In 1999 Markow left Arizona State University and became the director for the University of Arizona's Centre for Insect Science. She took the remaining Havasupai samples with her to Tucson, even though tribal members had been promised in writing that their blood would remain 'under lock and key' at Arizona State University.<sup>84</sup> Markow sent the Havasupai samples to researchers around the nation – including to scientists at Stanford University and a for-profit pharmaceutical laboratory in California. A renowned scientist at the pharmaceutical lab later gave some of his samples to a doctoral candidate working on migration studies.

## **B The Havasupai Tribe's Complaints**

In 2002, Daniel Garrigan, a PhD student in another lab at Arizona State University, used blood samples provided by Therese Markow to examine genetic variability among the Havasupai. In early 2003 Garrigan had a manuscript accepted by the journal *Genetics* detailing markers in the Havasupai that were sufficiently variable to use in the search for genetic predispositions to diabetes. In March 2003, Garrigan delivered a lecture on the topic as part of his defence of his doctoral dissertation.

Carletta Tilousi recalls being outraged that Garrigan had used the blood samples in his research without the permission of the Havasupai tribe. She recalls attending his dissertation defence:

He spoke about how the DNA of this isolated, intermarried group of people – us – was unique, and how my people had migrated to Arizona from Asia. I knew we wouldn't have given this guy or anyone permission to do that study. I started to think, 'How dare this guy challenge our identity with our own blood, DNA.' Then I remembered when many

of us gave blood years ago for a diabetes project. I wondered if this was the same blood.<sup>85</sup>

In the question-and-answer period, Tilousi questioned whether Garrigan had the authority to conduct the research: 'I said, "I'm from the Havasupai tribe, and I want to know if you asked us permission to do this study"''.<sup>86</sup> Garrigan replied that he did not.<sup>87</sup>

John Martin also objected to the use of the material in the doctoral dissertation. After the thesis showdown he apparently informed Garrigan that he viewed the Havasupai data as his intellectual property and warned him to '[s]top, or there will be repercussions'.<sup>88</sup> Martin complained to Arizona State University human subjects committee, alleging that the research had covered areas that the tribe had not agreed to. After the Committee dismissed this complaint, Martin wrote to Arizona State University president Michael Crow and other university officials alleging that Markow had misused tribal DNA samples by sending them for analysis of their human leukocyte antigen ('HLA') genes to two laboratories in California.

In 2003 the Arizona State University commissioned a report by independent investigators Stephen Hart, a Phoenix lawyer, and Keith Sobraske.<sup>89</sup> The report was a compendium of interviews. It contained no firm findings of misconduct, but acknowledged that there were issues with project administration, record-keeping, and the knowledge of the tribe as the nature of the research that would be undertaken.

## **C Lawsuit**

In February and March 2004 members of the Havasupai tribe filed two lawsuits against Arizona State University, the Arizona State University Institutional Review Board, the Arizona Board of Regents, and three researchers: Therese Markow, John Martin, and Daniel Benyshek.<sup>90</sup> One lawsuit was filed by the tribe itself; the other involved 52 members of the tribe. Carletti Tilousi observed:

They challenged our identity and our origins with our own blood and without telling us what they were doing ... We aren't just Indians griping about whatever. If this were someone else's blood being misused, I think it would hit home for them, too.<sup>91</sup>

The tribe alleged that researchers collected 400 blood samples from them for researching diabetes, and undertook additional unauthorised research on those samples regarding schizophrenia, inbreeding and population migration. The lawsuit also maintained that the Arizona State University researchers allowed 'wholesale transfer of blood samples from laboratory to laboratory and university to university for over a decade to the extent that many blood samples cannot be accounted for at this time'.<sup>92</sup> The tribe's suit also alleged that the Institutional Review Board failed to stop the mishandling and transfer of the blood samples to laboratories and research institutions across the country. The findings of research involving the blood samples appeared in 23 scholarly papers and 15 publications dealing with 'schizophrenia, inbreeding and theories about ancient human population migrations from Asia to North America'.<sup>93</sup>

The lawsuit claimed that Arizona State University researchers 'went beyond all possible bounds of decency ... so as to be atrocious and utterly intolerable in a civilized community'.<sup>94</sup> The Havasupai tribe was concerned that the research on schizophrenia and inbreeding stigmatised them. Bill Freeman, a physician and former director of research for Indian Health Service, observed:

Schizophrenia is a stigmatizing condition, and we're not talking about tomorrow's stigmatization, especially with a small tribe like [the Havasupai] ... No one wants to be known as the, quote, 'crazy tribe.' Doing that kind of research without specific permission from the subjects is a real harm.<sup>95</sup>

Tilousi and others argued that Markow and her colleagues implied that the Havasupai were descendants of people who entered the Americas via the Bering Strait after the existence of Indians in South America was established. This directly contradicts the Havasupai belief that human beings originated in the Grand Canyon. The Havasupai have expressly indicated that they would not have authorised the migration research because it conflicted with their religious origin story. Professor Louise Baca of Argosy University in Phoenix posed the issue in the following way: 'Think of how devastating it would be to learn that you unknowingly gave your blood for studies that went against your entire belief system of origin.'<sup>96</sup>

The Havasupai contend that Arizona State University has engaged in 'genetic piracy'.<sup>97</sup> According to the tribe's attorney:

The heart of our complaint is whether we are going to ... monitor human research and human researchers. That's something that's not resolved in Arizona, whether the researchers who are working on human subjects have a duty to those subjects to treat them fairly.<sup>98</sup>

Drawing upon the independent report prepared for the Arizona State University,<sup>99</sup> the complaint in the case of *Tilousi* listed six causes of action against the university:

1. Breach of fiduciary duty. In particular, the tribe observed that there was a lack of informed consent, and there were inadequate procedures for vulnerable subjects such as children, people with mental illness, and people whose main language was the tribal language.
2. Fraud, misrepresentation, and fraudulent concealment.
3. Intentional or negligent infliction of emotional distress.
4. Conversion.
5. Violation of civil rights.
6. Negligence, gross negligence and negligence per se.

The plaintiffs requested the court to hold the defendants jointly and severally liable for \$US25,000,000 in compensatory damages and \$US25,000,000 in punitive damages. Further, the plaintiffs requested that the judge enjoin any further research activity or publication involving the blood samples.

In a statement responding to the lawsuit filed by individual tribal members, Arizona State University spokesman Virgil Renzulli disputed the allegations and said the university 'will vigorously defend itself'.<sup>100</sup> He argued that an ASU researcher came across the mishandling of the blood samples and reported it to officials. ASU then launched an independent investigation to track the blood samples and return them to the original donors or their families. General counsel Nancy Tribbensee, observed: 'Despite the various public relations campaigns of the Havasupai, the litigation appears to be going in favor of the positions advanced on behalf of the universities'.<sup>101</sup>

The Arizona State University has also been working with the Inter Tribal Council of Arizona regarding issues of research in American Indian communities. Executive director of the council, John Lewis, observed: 'Several tribe representatives, including the Havasupais, met with

President Crow to state our concerns and do something to prevent this in the future'.<sup>102</sup>

The National Congress of American Indians, which represents 250 tribes, has passed a resolution in support of the Havasupai tribe, saying it had a right to have its informed consent on the research sought: 'NCAI admonishes Arizona State University and the state of Arizona for the apparent fraud on the Havasupai Indian Tribe'.<sup>103</sup> Many tribes have also contributed financially to the lawsuit.

The dispute between the Havasupai tribe and Arizona State University has highlighted the limitations of ethical protocols governed by universities. Juan A Avila Hernandez notes that the litigation has highlighted the need for community-led regulation of the conduct of research: 'This scandal exposed once again the need for tribal governments and Native American communities to get involved in regulating research on human subjects'.<sup>104</sup> In light of the research scandal at Havasupai, William Freeman from the Northwest Indian College says that the need for tribal colleges and universities ('TCUs') to review research is paramount: 'An [Institutional Review Board] that's Indian-focused would help ensure that to the extent possible, harm is done neither to individuals nor to the community'.<sup>105</sup>

*Havasupai* has been transferred from a United States District Court to the Maricopa County Superior Court. In May 2007, a Maricopa County Superior Court judge dismissed a lawsuit against the University of Arizona, Arizona State University and researchers claiming they misused blood samples from Havasupai tribal members.<sup>106</sup> However, tribal officials said they plan to refile the suit and take the case to the Arizona Court of Appeals. A second case, by individual members of the tribe seeking damages for alleged misuse of their samples, is still awaiting trial. Whatever its outcome, the case will have wider implications for the standards of informed consent and benefit sharing required in respect of population research dealing with Indigenous communities.

Both *Tilousi* and *Havasupai* demonstrate the reluctance and unwillingness of United States courts to provide adequate legal protection of the need for informed consent and benefit-sharing.<sup>107</sup> It has been difficult to establish a cause of action under traditional doctrines such as breach of fiduciary duties; fraud; emotional distress; conversion; breach of civil rights; and negligence. The litigation between the Havasupai Tribe and the Arizona State University has

provided further impetus for law reform to provide for greater protection of research participants and Indigenous communities in genetic research.<sup>108</sup>

#### IV The Genographic Project

Launched in April 2005, the Genographic Project ('Project') is a five-year genetic anthropology study that aims to map historical human migration patterns by collecting and analysing DNA samples from over 100 000 people across five continents. The leader of the project is Dr Spencer Wells, a scientific adventurer and explorer-in-residence of the National Geographic.<sup>109</sup> He has explained the mission of the Project:

We want to learn the why of history. Why did people move? Why did these people look a little bit like those people? Why did they speak the same language or a different language? We want to place the genetic information in the context of history and anthropology.<sup>110</sup>

The Project has large ambitions:

The goal of the Genographic Project is to help people better understand their own history, learn about ancient migratory paths our ancestors took to populate the planet, and discover how, in spite of our diverse appearances, we all are part of the same family tree and share common origins.<sup>111</sup>

Despite efforts to address ethical concerns, the Genographic Project has been embroiled in public controversy. There has been criticism that the Project has repeated the failings of past endeavours, such as the HGDP and the Arizona State University genetic research. The Project is a large-scale collaboration between various public and private entities, involving the participation of Indigenous communities. There is particular concern that the venture has not been driven by the needs and aspirations of traditional groups, though the Project has sought to provide safeguards in respect of the informed consent, privacy, and confidentiality of research participants. It has also established a fund to provide benefits to Indigenous communities. Nevertheless, the Indigenous Peoples Council on Biocolonialism remains concerned about the sufficiency and adequacy of such measures. While the research institutions involved in the Project have sought ethical approval for research protocols from institutional review boards,<sup>112</sup> the Project has not

received support from representative international bodies such as the United Nations Permanent Forum on Indigenous Issues.

## A The Journey of Man: A Genetic Odyssey

The Project describes itself in the following terms:

Our genes allow us to chart the ancient human migrations from Africa across the continents. Through one path, we can see living evidence of an ancient African trek, through India, to populate even isolated Australia. But to fully complete the picture we must greatly expand the pool of genetic samples available from around the world. Time is short. In a shrinking world, mixing populations are scrambling genetic signals. The key to this puzzle is acquiring genetic samples from the world's remaining indigenous and traditional peoples whose ethnic and genetic identities are isolated. But such distinct peoples, languages, and cultures are quickly vanishing into a 21st century global melting pot.<sup>113</sup>

The Genographic Project has three core components. First of all, the Project is based on field research. Spencer Wells and a group of scientists from 10 research centres have sought to collect blood samples from Indigenous and traditional populations, and analyse key genetic markers to obtain indications of ancient migratory patterns. The Australian Centre for Ancient DNA is involved in the study through providing analysis of DNA from ancient remains.<sup>114</sup> Second, the Project has a public participation and awareness campaign. Members of the general public can take part in the project by purchasing a Public Participation Kit and submitting their own cheek swab sample, allowing them to learn about their own migratory history. The project has created a human mitochondrial DNA database from such samples.<sup>115</sup> Finally, the Project has a Genographic Legacy Project. Sales from the proceeds of the Public Participation Kits will support education and cultural preservation projects among participating and other Indigenous and traditional groups. According to Wells, '[w]e will help empower Indigenous groups on a local level while helping to raise awareness on a global level of the challenges and pressures facing these communities.'<sup>116</sup>

The Project, with \$US40 million in funding, is another example of a spectacular large-scale biology project. It involves collaboration between various private and public entities. The National Geographic Society is providing overall

coordination for the project, including management of field operations, the sale and distribution of the Participation Kits, the Project Web site and other related activities. A team of IBM researchers, scientists and technicians designed the technical infrastructure for the project, providing computational biology and research expertise, and driving exploratory research programs related to data compilation and analysis. The Waitt Family Foundation has provided critical funding to underwrite the Project's field research, which will form the basis of its findings. The Project has an advisory board chaired by Dr Luigi Luca Cavalli-Sforza, the same geneticist who led the HGDP. The board is also comprised of representatives of the various funding agencies, a range of scientists, ethicist Simon Longstaff, and Australian lawyer and Indigenous advocate Tammy Williams.

The Project has provided a commitment that it will protect the privacy of research participants, make data publicly available, and not patent the results of the research. Wells is conscious of the complex ethical and legal questions associated with research. He wrote in his book *The Journey of Man* about the distrust of Indigenous communities towards scientists:

With the realization that their cultural identity is being eroded, though, many indigenous populations are now refusing to participate in scientific studies. A history of colonial exploitation, with incidents such as the horrendous medical experiments inflicted on the Australian Aborigines in the mid twentieth-century, has understandably led many indigenous people to be wary of scientists. Activists have also reasserted ancient taboos on ancestor disinterment, asking for archaeological material to be returned for proper burial. These cultural taboos can, and do, extend to giving samples for genetic studies. In a way, we are trying to excavate the past from the blood of people living in the present – an activity that can be interpreted as voyeuristic (or worse). A desire for cultural privacy, perhaps combined with the suspicion that the scientific results may not agree with their own beliefs, is leading more and more indigenous groups to choose not to participate.<sup>117</sup>

Wells concluded that 'scientists have a responsibility to explain the relevance of their work to the people they hope to study, in order for their participation to become what it really is – a collaborative research effort'.<sup>118</sup> He noted that 'only then we can regain some of the trust that we have lost'.<sup>119</sup>

In response to criticism from Indigenous communities, Spencer Wells insisted that the Project could not be likened to the unsuccessful HGDP or 'vampire project':

When the Human Genome Diversity Project was first discussed 14 years ago, the language of DNA and genetic anthropology was foreign to all but a few scientists. Today that language is more familiar to many of us, and many of the ethical and privacy issues are more clearly understood and respected by the global community. The Genographic Project is designed with strict protocols that assure the anonymity of all participants. The project has been approved by the University of Pennsylvania's institutional review board and follows all agreed international protocols for research on human subjects. Helping communicate indigenous people's stories and promoting preservation of their languages and cultures is very much a part of the National Geographic Society's mission and has been for more than 117 years. In addition to answering questions of scientific interest, we feel it is imperative to give something tangible back to the participating communities through Genographic's legacy project, which will include educational activities and cultural preservation projects.<sup>120</sup>

Wells noted that the Project had raised more than \$US500 000 for legacy projects, and stated, '[w]e sincerely believe this may be the last generation for many Indigenous populations and we are eager to collaborate with them to help us all understand the connections among us and to preserve their fragile cultures.'<sup>121</sup>

The Project denies that it is involved in bioprospecting:

The Genographic Project research centers will release the resulting genetic data (on an anonymous and aggregate basis) into the public domain to promote further research. The genetic data will be treated as discoveries, rather than inventions, and will not be patented. The scientific consortium comprised of the ten regional research centers will author scientific papers based on their analysis. At the time of publication, the data associated with the research will be made public. At the end of the Project, the findings will be released into the public domain. The Genographic Project is a non-profit effort and its noncommercial focus is fully supported by all its partners.<sup>122</sup>

The Project has emphasised that it involves no medical research: 'The samples collected from the Indigenous and

traditional peoples as well as the samples submitted by the general public via the Public Participation Kits will be analysed for historical and anthropological data'.<sup>123</sup> Furthermore, no pharmaceutical companies are involved.<sup>124</sup> The Project's mandate strictly prohibits any commercialisation of genetic material gathered during the life of the Project and subsequently: 'In terms of legal restraints, the contractual agreements that are in place with all Project partners explicitly prohibit the commercialization of any genetic material volunteered for the Project'.<sup>125</sup> Furthermore, '[c]ontractual clauses call for termination and expulsion from the Project in case of material breach'.<sup>126</sup>

Spencer Wells has insisted that there will be no commercial applications arising from the Project:

We are not going to be patenting any of the genetic information and no one will be able to patent this information just from that data. We're not collecting clinical data, nor are we examining markers that have any known medical relevance. This is data that will tell us about historical migration patterns and patterns of genetic diversity.<sup>127</sup>

Wells has denied that the involvement of IBM suggests a commercial motive: 'The Genographic database will be very complex, with both anthropological and genetic data, and IBM sees this as a real data-mining challenge. This is not a for-profit enterprise for them, although they may develop a new algorithm.'<sup>128</sup>

## **B Indigenous People's Council on Biocolonialism**

The Indigenous Peoples Council on Biocolonialism ('Council') was alarmed at the launching of a new global genetic research project that will focus on the collection of Indigenous peoples' DNA. Executive director Debra Harry expressed concerns about the similarities between the Project and the HGDP:

This is a recurrent nightmare. It's essentially the same project we defeated years ago. Some of the actors are different, but also some are the same. With the founder of the [Human Genome Diversity Project] serving on this new project's advisory committee, I can't help but think this is simply a new reiteration of the [Human Genome Diversity Project].<sup>129</sup>

The Council has raised a number of specific concerns about the Project:

1. The Project's speculation about the history of human migration potentially challenges the creation stories of Indigenous peoples. Noting the Project's objectives, Marla Big Boy, a Lakota attorney on the Council's board, commented:

Our creation stories and languages carry information about our genealogy and ancestors. We don't need genetic testing to tell us where we come from ... We will not stand by while our ancestors are desecrated in the name of scientific discovery.<sup>130</sup>

Harry has expressed concern that research into Indigenous peoples' history and human migration could undermine Indigenous peoples' claims to their ancestral lands:

Where people have very insecure rights to their territories, to their mechanisms of control of their lives and futures, then we are sceptical about what use would be put to reinterpretation of their links with their lands.<sup>131</sup>

2. The Council has expressed doubt over whether the Project strictly adhered to the principles of free and prior informed consent with both individuals and Indigenous communities. Harry observed:

If the Genographic Project were a true partnership, as they claim, they would have sat down with indigenous peoples to find out whether there was any genetic research that could address our current needs, and not just the interests of Western science. You have to start at that point, rather than after the project has been designed.<sup>132</sup>

Harry has questioned whether the benefits accorded to research participants matched the risks involved in taking part in the Project. She has expressed dissatisfaction with the Genographic Legacy Fund, characterising it as 'an add-on that is effectively a coercive mechanism to encourage people to participate [which] is totally unethical'.<sup>133</sup> Indeed, '[i]f they had a true altruistic motivation to protect indigenous cultures, they wouldn't be asking for something in return'.<sup>134</sup>

3. The Council expressed concern about the commercialisation of human genes: 'Even if the Genographic Project does not pursue commercial development of the genetic material, others with access to the materials may do so in the future.'<sup>135</sup> Harry has questioned whether the genetic database developed by the Genographic Project could be exploited by commercial third parties: 'What's to stop some

company from taking information from the Genographic database and using it for commercial purposes without compensation to the original donors?'<sup>136</sup>

4. The Council was horrified at the prospect of genetic research being carried out by the Australian Centre for Ancient DNA on the ancient remains of Indigenous people. Harry reiterated the point that taking genetic material offended the religious and spiritual beliefs of some Indigenous peoples: 'One of our big issues with this study is that it promotes research on the remains of our ancestors, which of course requires destructive analysis'.<sup>137</sup> This reflects wider concerns about scientists conducting genetic research on the ancestral remains of Indigenous people.<sup>138</sup>

5. The Council also expressed concern that the Project would be an example of racist science, turning Indigenous people into scientific curiosities. Le`a Kanehewho, legal analyst of the Council, commented:

It's interesting how in the past racist scientists, such as those in the eugenics movement, did studies asserting that we are biologically inferior to them; and now, they are saying their research will show that we're all related to each other and share common origins. Both ventures are based on racist science and produce invalid, yet damaging conclusions about Indigenous cultures.<sup>139</sup>

Harry has expressed a determination 'to stop projects that treat us as scientific curiosities'.<sup>140</sup> The Council called for an international boycott of IBM, Gateway Computers (the source of the Waitt Foundations' funds), and National Geographic until the Project was abandoned.

The concerns expressed by the Council were echoed by a number of regional Indigenous groups. In Australasia, for instance, a number of Indigenous activists, lawyers and academics raised concerns about the Project. Michael Mansell of the Tasmanian Aboriginal Centre was guarded: 'Scientists always say they are not interested in politics but the results of their research are open to political manipulation'.<sup>141</sup> Paul Reynolds of Auckland University said he and many other Maori feared that the Project would undermine traditional beliefs about New Zealand's original settlement by Pacific seafarers:

This is arrogant science ... It relates directly to the minimisation and the disintegration of indigenous people's

rights. They are making the assumption that science is the only truth, but there are a whole lot of knowledges. Our stories have been around for centuries.<sup>142</sup>

Aroha Mead of Victoria University doubted that the Project would be able to meet ethical standards or obtain the informed, collective consent of Indigenous people. She observed that '[t]he human story might be written in genes from a scientific point of view but the human story from a cultural point of view is actually written in our culture, it's in our language, it's in our art, it's in our dance, it's in our tradition'.<sup>143</sup> Wellington lawyer Moana Jackson said Indigenous peoples should question the project's motives: 'I'm sure part of it will be to try to strengthen some of the existing theories about the arrival of Indigenous peoples in various countries, and that has a sordid history because it has been used to diminish Indigenous rights'.<sup>144</sup> According to Le'a Mali Kanehe, a Kanaka Maoli attorney from Honolulu in Hawaii, '[t]here is nothing that a map of our genome would tell us about ourselves culturally; we know who we are and where we come from'.<sup>145</sup>

The Project has also been criticised by anti-biotechnology groups. Bob Phelps of Gene Ethics questioned the intentions of the leaders of the Project: 'They're making sure that their DNA doesn't disappear, instead of saying these people are of value and are entitled to survive in their own right, aside from their genetic material'.<sup>146</sup> Hope Shand of the ETC Group observed that the Project is in fact more dangerous than the HGDP because it lacks accountability to public funding agencies:

The proposed Genographic Project is like the vampire strikes back ... But it's much bigger and more dangerous [than the] HGDP because it's privately funded by deep-pocketed institutions, with no accountability to sampled communities or international governance.<sup>147</sup>

Jim Thomas of the ETC Group awarded the Project 'a Captain Hook Award for Biopiracy' in 2006.<sup>148</sup> He observed that the venture had 'the potential for genetic discrimination, the threat to privacy and to the rights of Indigenous People and uncertainties surrounding informed consent and intellectual property'.<sup>149</sup>

Spencer Wells dismissed the concerns of the Indigenous Peoples Council on Biocolonialism:

Groups and individuals can choose to participate in the project or not. It's a collaborative process. Consent has to be given at an individual level and a group level. We're not going to wander into a village and start poking people in the arm and collect samples. We will explain what will be done with samples and what the information could be when it comes back from the lab. I think if those involved in (the Indigenous Peoples Council) really understood what we're trying to do, they would not object to it, even if they might choose not to participate.<sup>150</sup>

While acknowledging that '[t]here are some sensitive ethical issues with the testing of the remains of ancient people',<sup>151</sup> Wells gave the assurance that '[w]e will approach the descendants and get fully informed consent'.<sup>152</sup> However, he noted that '[i]n some cases, it's not clear what particular tribal group has a claim because of the age of the remains'.<sup>153</sup> Wells also pointed out that some of the Project's Indigenous participants have been greater supporters. Sougoui, a member of the Toubou people in northern Chad, observed that 'the Genographic Project is a great opportunity for us, the Toubou, because we are a people who are extremely interested in our origins'.<sup>154</sup> Wells contends that '[t]he genetic story is not meant to replace group beliefs or oral traditions but to complement them, leading to a fuller sense of where we all come from'.<sup>155</sup> Rather, '[t]he goal is ultimately to connect people from around the world into one family, showing how our ancestors took their long journey from Africa to where we live today'.<sup>156</sup>

### C United Nations Permanent Forum on Indigenous Issues

Commenting on the Project, Steve Kinnane of the Australian Institute of Aboriginal and Torres Strait Islander Studies expressed surprise that the international project had not consulted the relevant United Nations agencies:

There's not necessarily a great historical relationship with the scientific community ... I would have expected for instance a project this size would have engaged with the Permanent Forum on Indigenous Issues in the United Nations.<sup>157</sup>

Indeed, the Council has forwarded a petition to the United Nations Permanent Forum on Indigenous Issues ('UNPFII') containing the names of 868 Indigenous persons, Indigenous rights activists and other supporters calling for an end to the Project.

Spencer Wells maintains that such opposition to the Project is confined to a minority of Indigenous activists:

Eighty-two per cent of the 868 signatures on the IPCB petition were from North America and signed in direct response to an inaccurate summary of the project's aims and methodologies. Many of them were from academics or indigenous rights advocates, and not from indigenous people *per se*. There are an estimated 300 million indigenous people in the world today, so 868 isn't a huge number. On the other hand, we have 8,000-plus indigenous people from around the world who have already participated.<sup>158</sup>

Wells is eager to point out that the Project wanted to engage in an open dialogue: 'We've spoken to many of the people who were involved in drafting [the UNPFII recommendation] and are more than happy to have open consultations in the future to explain the project's progress and methodologies'.<sup>159</sup>

In August 2005, the fifth session of UNPFII recommended that the World Health Organization and the Human Rights Council conduct an investigation of the aims, objectives, and operations of the Project, and report upon whether Indigenous peoples and communities had provided free, prior and informed consent to the research activities.

Victoria Tauli-Corpuz, chairperson of UNPFII, observed that the members of UNPFII believed that the Project had failed to obtain full and proper informed consent from the relevant institutions and representative bodies:

During the meeting of the Permanent Forum ... many of the members who are leaders of their own organisations from different countries – including some where the project has already made collections – were raising this point [that they hadn't been consulted]. They were saying: 'We don't know about this project and we don't believe its claims in terms of what it can achieve. We've had experiences in the past of our genetic materials being collected without our knowledge, so we don't like this project.'<sup>160</sup>

Tauli-Corpuz noted that '[i]t is impossible for all Indigenous peoples to be aware of all the implications of this project ... so there is a danger that the consent process could be manipulated by interested parties'.<sup>161</sup> She observed that it is essential that Indigenous people be fully involved in the design and oversight of the Project: 'It is our responsibility as Indigenous institutions to know what all the possible

implications are for Indigenous peoples and to have a regulatory function'.<sup>162</sup>

Tauli-Corpuz also questioned whether the Project would be of benefit to Indigenous communities and peoples. She commented that many Indigenous peoples currently have far more pressing concerns:

All over the world we are being killed, we are being displaced. And while this is going on, the Genographic Project is spending millions of dollars on a study that hopes to show the patterns of population migrations. It's hard to see how this is a collaboration. Why don't they bring that money to us and ask us what we really need?<sup>163</sup>

Tauli-Corpuz has also questioned whether migration studies are of interest to Indigenous communities: 'Most Indigenous peoples have our own genealogies, our own myths and stories about where we came from',<sup>164</sup> adding that, '[i]n fact, that is an important part of what makes us Indigenous, because we know we have historical accounts of where our people came from'.<sup>165</sup>

In light of such controversies, there has been much debate about the desirability and feasibility of an international treaty to provide protection of traditional knowledge under the framework of intellectual property in a number of international forums – including the World Trade Organization,<sup>166</sup> the World Intellectual Property Organization,<sup>167</sup> the United Nations Conference on Trade and Development,<sup>168</sup> the Convention on Biological Diversity,<sup>169</sup> the International Union on the Protection of New Varieties of Plants, the Food and Agriculture Organization,<sup>170</sup> and UNESCO.<sup>171</sup>

Frustrated by the limitations of such initiatives, UNPFII has instead called for the comprehensive protection of Indigenous cultural heritage.<sup>172</sup> Victoria Tauli-Corpuz has argued that there is a need for a holistic approach to the protection of Indigenous cultural heritage:

We look at our heritage from a comprehensive moral and human rights perspective. Our right to our heritage which includes, among others, traditional knowledge and our genetic materials, cannot be delinked from the bundle of civil, political, economic, social and cultural rights which we are entitled to enjoy. All these rights flow seamlessly into each other. Thus the desegregation of our rights as if these can be treated as separate issues and the breaking up of our



heritage to be handled by different international bodies is creating multiple problems for us. Those among us who are participating with the WIPO and the CBD have asked, time and again, that the link between traditional knowledge, biodiversity and genetic resources with territorial and resource rights and the right to self-determination be acknowledged and established.<sup>173</sup>

The UNPFII has supported a rights-based approach to the protection of Indigenous cultural heritage, challenging 'the WIPO and the WTO to explore what they can do as individual institutions or jointly with other UN bodies to be more holistic, development-oriented, and rights-based in the way they address these issues'.<sup>174</sup>

As an appropriate model, UNPFII supports the *United Nations Declaration on the Rights of Indigenous Peoples* 2006 ('*Declaration on the Rights of Indigenous Peoples*'). Article 31 paragraph 1 of the *Declaration* provides:

Indigenous peoples have the right to maintain, control, protect and develop their cultural heritage, traditional knowledge and traditional cultural expressions, as well as the manifestations of their sciences, technologies and cultures, including human and genetic resources, seeds, medicines, knowledge of the properties of fauna and flora, oral traditions, literatures, designs, sports and traditional games and visual and performing arts. They also have the right to maintain, control, protect and develop their intellectual property over such cultural heritage, traditional knowledge, and traditional cultural expressions.<sup>175</sup>

Article 31 paragraph 2 emphasises the need for state protection: 'In conjunction with indigenous peoples, States shall take effective measures to recognize and protect the exercise of these rights'.

## V Conclusion

The Project, the HGDP, and the Arizona State University diabetes project were each undermined by mutual distrust between scientific researchers and Indigenous communities regarding the legal and ethical issues of intellectual property, informed consent and benefit-sharing. In the future, a number of measures need to be put in place in respect of large-scale biology projects. First, large-scale biology projects involving Indigenous populations should involve community-based participation research.<sup>176</sup> Such ventures should be guided

by the principles of co-learning, mutual benefit, and long-term commitment. There is a need to address larger issues of power, privilege, participation, community consent, racial and ethnic discrimination, and the role of research in social change. Second, ethical protocols managed by universities, funding agencies and governments have been insufficient by themselves to deal with concerns about genetic piracy. There is a need for greater legal protection of the principles of informed consent and benefit-sharing in national regimes. The *UNESCO Declaration* provides a blueprint for such legal and administrative regimes. Third, the large-scale biology projects all illustrate the need for clear, workable, and accessible international rules on the protection of Indigenous knowledge and heritage. The *Declaration on the Rights of Indigenous Peoples* could provide a workable template enabling a holistic approach to the protection of traditional knowledge and Indigenous cultural heritage.

## Endnotes

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