

1-1-2000

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### Recommended Citation

Tina Piper, "The Collusion of Law and Science in the Piracy of Human Genes" (2000) 9 Dal J Leg Stud 237.

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## **THE COLLUSION OF LAW AND SCIENCE IN THE PIRACY OF HUMAN GENES**

TINA PIPER

### **I. INTRODUCTION**

Advances in biotechnology over the last decade have created a demand for biological resources by transnational corporations. The search for biological resources has primarily focused on acquiring these resources from indigenous communities and countries of the South. However, the means by which these biological resources are obtained is exploitative and often tantamount to theft (or, as it is commonly known, biopiracy). As a result of communities attempting to prevent this theft and corporations seeking more international legitimacy for their "bioprospecting", "bioprospecting contracts" are more frequently being concluded between governments and corporations. Through the prism of current events in Iceland, I will demonstrate that bioprospecting contracts resolve little; they merely rename and reformulate an old crime into a new shape of exploitation which may be even more insidious than earlier forms of biopiracy. The events in Iceland will illustrate the problems inherent in encouraging governments to conclude contracts, and will show that a contract is only as good as the terms negotiated. The example of Iceland will also highlight the flexible and polymorphous nature of biopiracy as well as the myriad types of damage it can inflict on a community. Finally I will discuss how the law, science and language each play a role in both obscuring international acts of biopiracy and maintaining existing power inequalities.

## II. THE CONTEXT OF BIOPIRACY

### 1. The role of the life industry in the exploitation of genetic resources.

#### *i. Transnational corporations acquire genetic resources through various methods*

Transnational corporations mine genetic resources (bioprospect)<sup>1</sup> through various intermediaries, called collectors. Collectors are primarily individuals prospecting for public collections,<sup>2</sup> academic researchers from universities, or private prospectors or “brokers” affiliated with a corporation. In addition, private Non-Governmental Organizations (NGOs) have also mediated between corporations wishing to bioprospect and the communities possessing resources.<sup>3</sup>

Genetic resources are acquired by any means possible. Collectors often take resources without properly informing the community, by securing the “consent” of the peoples from whom they are taking the resource. The research and commercial purposes of the sample collection are not explained, therefore this consent is not considered to be informed by general legal standards.<sup>4</sup>

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<sup>1</sup> “Bioprospecting” or “biodiversity prospecting” is defined by D.A. Posey & G. Dutfield, *Beyond Intellectual Property, Toward Traditional Resource Rights for Indigenous Peoples and Local Communities* (Ottawa: International Research Development Centre, 1996) at 227 [hereinafter Posey] as:

The search for and collection of biological material for commercial purposes. The areas where prospecting takes place are usually species-rich environment, such as tropical forests and coral reefs.

<sup>2</sup> Both persons contracted by and officials of government funded agencies.

<sup>3</sup> Posey, *supra* note 1 at c. 1. However, industry has been exploiting the trusted position of NGOs in communities. For example, Pharmacogenetics (a supplier of genetic resources to the life industry) is partially owned by a private, voluntary agency called the Pan-American Development Foundation (PADF). PADF plans to use its contacts with indigenous communities, developed over 30 years, to obtain access to genetic bioresources. (RAFI Communiqué, “Bioprospecting/Biopiracy and Indigenous Peoples”, online: RAFI <<http://www.rafi.ca/web/allpub-one.shtml>> (date accessed: November 15, 1999) [hereinafter *Bioprospecting/Biopiracy*]).

<sup>4</sup> Worthy of particular mention here is the U.S. case of *Moore v. University of California Board of Regents* 793 P.2d 479 (Cal. 1990). The California Supreme Court held that Moore had a cause of action against his physician who had removed excess spleen and blood samples

*ii. The bioprospecting contract: one method of acquiring genetic resources*

A recent trend in the bioprospecting of genetic resources is that which creates legally enforceable agreements between source communities<sup>5</sup> and bioprospectors. These agreements can be material/information transfer agreements, licensing agreements and/or covenants.<sup>6</sup> A material/information transfer agreement provides that in exchange for biological resources, information and the right to

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and used them to develop a highly profitable cell-line. The doctor had breached his fiduciary duty by not obtaining informed consent, since he had not disclosed his **research and commercial interests** in Moore's spleen and blood cells.

An example in the bioprospecting context, involving both academic researchers and falsely obtained consent is that of the Guaymi. The claim of falsely obtained consent arose from a research project conducted by Panamanian scientists in collaboration with the U.S. National Institutes of Health and the Centre for Disease Control. Researchers were interested in the human T-lymphocyte virus (HTLV) known to be a primary causative agent in human T-cell leukemia. The Guaymis and other Amerindian peoples are commonly infected with this virus. The virus was obtained in the following manner, as described by the president of the General Congress of the Ngobe-Bugle (Guaymi):

Doctors came to the communities of Pandilla in small groups and started to collect indigenous blood, pretending that the indigenous people were suffering from a mortal disease and that the blood study was necessary to investigate the malformation or type of disease they suffered. Participants were given a small pill to compensate for the loss of blood.

The researchers found an unusual strain of the HTLV in a sample from a Guaymi woman which they applied to patent in 1990 in the U.S. and worldwide. However the patent application was abandoned after NGOs, such as RAFI and the World Council of Indigenous People, and the Guaymi people protested, the researchers citing the high cost of the patent claim. Throughout, the researchers claimed the Guaymi woman had given her "oral informed consent" even though she was not informed of the potential patent application and subsequent commercialization. (Posey, *supra* note 1 at 26 and 34; RAFI Communiqué "The Patenting of Human Genetic Material: Who owns the human genome? Patenting the human cell lines of indigenous people.", online: RAFI <<http://www.rafi.ca/web/allpub-one.shtml>> (date accessed: October 30, 1999). See also N. Roht-Arriaza, "Of Seeds and Shamans: The Appropriation of the Scientific and Technical Knowledge of Indigenous and Local Communities" (1996) 17 Mich. J.Int. L. 919. [hereinafter *Seeds and Shamans*]).

<sup>5</sup> "Source community" is the term used throughout this paper to refer to the community that supplies genetic resources.

<sup>6</sup> Posey, *supra* note 1 at 73. See also *Seeds and Shamans*, *supra* note 4; T. Greaves, *Intellectual Property Rights for Indigenous Peoples: A Sourcebook* (Oklahoma City: Society for Applied Anthropology, 1994) [hereinafter Greaves]; World Resources Institute, *Biodiversity Prospecting: Using Genetic Resources for Sustainable Development*. (Washington: WRI Publications, 1993).

commercialize findings (including the right to obtain patents),<sup>7</sup> source communities receive a share of royalties, up-front benefits or payments from a fund. Licensing agreements do not involve a transfer of possession; rather, source communities negotiate the specific proprietary rights that a corporation can have over its biological resources in exchange for a one-time licensing fee. Covenants dictate principles that parties must adhere to, in addition to the strict commercial arrangements generally provided for in contracts.

Bioprospecting contracts have been internationally sanctioned by government agencies such as the U.S. Congressional Research Service,<sup>8</sup> and non-governmental research organizations, such as the World Resources Institute.<sup>9</sup> Most significantly, however, the *Convention on Biological Diversity*<sup>10</sup> explicitly endorses bilateral contracts between government and industry to control prospecting of a country's genetic resources in the following provisions:

*Article 15*

1. Recognizing the sovereign rights of States over their natural resources, the authority to determine access to genetic resources rests with the national governments and is subject to national legislation.
4. Access, where granted, shall be on mutually agreed terms....<sup>11</sup>

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<sup>7</sup> Often involving the source "communities agreeing to collect, identify, process, resupply and in some case conduct further research in a laboratory on a supply of samples." (Posey, *supra* note 1 at 68).

<sup>8</sup> J. Axt, et al., *Biotechnology, Indigenous Peoples and Intellectual Property Rights* (Congressional Research Service: The Library of Congress, 1993).

<sup>9</sup> W. Reid, et al., *Biodiversity Prospecting: Using Genetic Resources for Sustainable Development* (Washington: WRI/IUCN/UNEP Global Biodiversity Strategy, World Resources Institute, 1993).

<sup>10</sup> (1992) 31 I.L.M. 818. Entered into force December 29, 1993, signed by 163 countries and ratified by 173 countries (UNEP Gen. Distribution Sheet, Convention on Biological Diversity, November 3, 1999).

<sup>11</sup> The important provisions of the Convention on Biological Diversity (for the purposes of this paper) are:

*Art. 2 Definitions*

"*Genetic material*" means any material of plant, animal, microbial or other origin containing functional units of heredity.

"*Genetic resources*" means genetic material of actual or potential value.

*Article 3. Principle*

States have... the sovereign right to exploit their own resources...

Bioprospecting contracts are being concluded between transnational corporations and government actors,<sup>12</sup> however the degree of proliferation and use of these contracts is unclear because of the “private” nature of the commercial dealings.<sup>13</sup>

The *Convention on Biological Diversity*<sup>14</sup> has enumerated international standards for bioprospecting contracts. Other documents, such as the *Covenant on Intellectual, Cultural and Scientific Resources*,<sup>15</sup> while not advocating contractual bioprospecting relations, have developed standards and codes of ethics for bioprospecting

*Article 15. Access to Genetic Resources*

5. Access to genetic resources shall be subject to prior informed consent...
6. Each Contracting Party shall endeavour to develop and carry out scientific research based on genetic resources... with the full participation of, and where possible in, such Contracting Parties.
7. Each Contracting Party shall take legislative, administrative or policy measures...with the aim of sharing in a fair and equitable way the results of research and development and the benefits arising from the commercial and other utilization of genetic resources with the Contracting Party providing such resources. Such sharing shall be upon mutually agreed terms.

*Article 19. Handling of Biotechnology and Distribution of its Benefits*

1. Each Contracting Party shall take legislative, administrative or policy measures, as appropriate, to provide for the effective participation in biotechnological research activities by those Contracting Parties... which provide the genetic resources for such research, and where feasible in such Contracting Parties.
2. Each Contracting Party shall take all practicable measures to promote and advance priority access on a fair and equitable basis by Contracting Parties, especially developing countries, to the results and benefits arising from biotechnologies based upon genetic resources provided by those Contracting Parties. Such access shall be on mutually agreed terms.

<sup>12</sup> The most recent examples of private bioprospecting contracts are summarized in *Seeds and Shamans*, *supra* note 4 at 958.

<sup>13</sup> According to RAFI: “there may be hundreds of bilateral agreements that are shrouded in relative secrecy and receive no public scrutiny.” (*Bioprospecting./Biopiracy*, *supra* note 3).

<sup>14</sup> Also known as the *Biodiversity Convention* and *Convention on Biodiversity*.

<sup>15</sup> Established by the Global Coalition for Biological Diversity (in Posey, *supra* note 1 at 175) [hereinafter the *Covenant*] The *Covenant* recognizes several categories of resource that are worthy of protection and compensation by corporations. These include:

- 7 - Biogenetic resources that originate (or originated) on indigenous lands and territories
- 9 - Classificatory systems of knowledge, such as traditional plant taxonomies.

contracts to protect indigenous peoples and local communities and make them aware of what can be demanded and expected within the contractual relationship.<sup>16</sup>

The following procedural and substantive conclusions can be drawn about the content of a bioprospecting contract. Procedurally, the two parties to a bioprospecting contract are the collector and the industry. The collector, as outlined above, can be a government, private individual, non-profit organization or for-profit corporation. The collector will increasingly be government as Article 15 of the *Biodiversity Convention* encourages contracts with government and transnational corporations prefer contracting with governments.<sup>17</sup> The bioprospecting contract must include provisions governing access to the bioresources and terms governing the supply, particularly the quality and availability, of bioresources.<sup>18</sup> The bioprospecting contract must specify compensation of the collector. Compensation can take the form of advance payments, payment of a licensing fee, royalty payments (usually 1-3% of the value of net sales of a product derived from the

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<sup>16</sup> For a discussion of a model contract see S.R. King, in Greaves, *supra* note 6. See also *The Contract between the Collector and the Government Parties*, available from the Third World Network, online: TWN <<http://www.southbound.com.my/souths/twn/twn.htm>> (date accessed November 15, 1999).

<sup>17</sup> Industry also prefers to deal with institutional (i.e. governmental) collectors since government involvement makes collection more stable, reliable and ultimately more profitable. Transnational pharmaceuticals have enumerated the following criteria:

[W]hat are the qualities of the ideal collector?

- supervision by qualified scientists and access to taxonomic expertise to properly identify samples
- sound management and administration
- stable political and economic conditions in the collector's country
- a literate and skilled local population
- assurance that the collector institution will continue to function at least for the term of the contract
- national and/or international organizations...possess the expertise and authority to obtain such materials from whatever source.

S.A. Laird, "Contracts for Biodiversity Prospecting" in *supra* note 9 at 106. [hereinafter Laird].

The final quality directly addresses the confluence of the interests of the ruling/governing class of a society and the interests of transnational pharmaceutical industry. The government can be used to give legitimacy and legalize the actions of these industries, removing them from the scope of inquiry and discussion (see discussion *infra*).

<sup>18</sup> C.J. Hunter, "Sustainable Bioprospecting: Using Private Contracts and International Legal Principles and Policies to Conserve Raw Medicinal Materials" (1997) 25 Boston College Environmental Affairs L. Rev. 129 at 162.

bioresources which are the subject of the contract)<sup>19</sup> and non-monetary arrangements (such as technology transfer or training of local personnel).<sup>20</sup> The contract must also provide for a means of enforcing its provisions.

Substantively, the contract must operate within the framework of principles established at international law for bioprospecting contracts. Contracts must ensure that bioresources are obtained with the informed consent of the source community.<sup>21</sup> In addition, the contract must provide for the equitable sharing of profits between the contracting parties,<sup>22</sup> confidentiality of any information transmitted between the parties<sup>23</sup> and must ensure, to the extent possible, that scientific research and commercialization of products occurs in the country providing genetic resources.<sup>24</sup> The *Covenant*, in particular, elaborates principles for independent monitors, stating that they must “have no conflict of interests”, “...professional qualifications and relevant experiences” and “must practice full information disclosure”.<sup>25</sup>

*iii. The debate regarding bioprospecting contracts: fictions and realities of the private contracting regime.*

The eager embrace of bioprospecting contracts by transnational corporations must be viewed with suspicion. The contracting regime is not a value-neutral medium where “contracts [are] based on mutual agreement... and the creation of a contract [is] the result of a free choice unhampered by external control...”<sup>26</sup> The contracting regime can legitimize potentially coercive relationships with the patina of objectivity and formal equality while masking the inherent inequalities

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<sup>19</sup> Laird, *supra* note 9 at 111.

<sup>20</sup> Laird, *supra* note 9 at 108. See also Posey, *supra* note 1 at 68.

<sup>21</sup> *Biodiversity Convention* (Art. 15.5), the *Covenant* (Basic principle I) and model contract (Art. 3(d)).

<sup>22</sup> *Biodiversity Convention* (Preamble, Art. 1, Art. 8 and Art. 19) and *Covenant* (Basic principles I).

<sup>23</sup> *Covenant* (Basic Principles IV) and model contract Art. 9.

<sup>24</sup> *Biodiversity Convention* (Art. 15.6) and the *Covenant* (Basic Principles I and IX).

<sup>25</sup> The *Covenant* (Principles XIV-XVI).

<sup>26</sup> For a discussion of the contracting regime see P. Atiyah, *An Introduction to the Law of Contract*, 3d (London: Clarendon Press, 1981) at 4.



of the contracting relationship.<sup>27</sup> Bioprospecting agreements are characterized as the result of fair bargaining and consent between equal contracting parties, while removing the agreements from public scrutiny and regulation. In addition, the use of the contracting regime to regulate bioprospecting uses “the master’s tools”<sup>28</sup> (or contracts) with which transnational corporations are very familiar, instead of creating new (more equal) relationships between source communities and transnational corporations. Bilateral bioprospecting contracts also discourage the development of multilateral agreements, involving coalitions of countries, which would level the bargaining field.<sup>29</sup> Ultimately, bioprospecting contracts legalize the otherwise unlawful taking of genetic resources. The following table compares the rationalizing beliefs underpinning bioprospecting contracts as compared to the reality of those contracts:

**TABLE 2: UNPACKING THE BIOPROSPECTING CONTRACT: MECHANISM OF EQUALITY OR COERCION?**

Belief	Reality
<ul style="list-style-type: none"> <li>Parties can contract as equals and agree on mutually beneficial terms. Terms can be flexibly molded to the contingencies of each commercial situation.</li> </ul>	<ul style="list-style-type: none"> <li>There is inequality of bargaining power between most entities and transnational corporations, especially in terms of legal resources, ability to bargain and enforce terms, scientific knowledge of the value of resources and language differences.<sup>30</sup></li> </ul>

<sup>27</sup> Support for this view can be found in B. Conklin, “A Contract” in R. Devlin, ed., *Canadian Perspectives on Legal Theory* (Toronto: Emond Montgomery Publications, 1991) and I. Ayres, “Fair Driving: Gender and Race Discrimination in Retail Car Negotiations” (1991) 104 *Harvard L. Rev.* 817.

<sup>28</sup> U. Franklin, “The Sandbox and the Tools” in *Women in Scholarship: One Step Forward, Two Steps Back* (Proceedings of the Royal Society of Canada: 199) at 37-39.

<sup>29</sup> *Bioprospecting/Biopiracy*, *supra* note 3.

<sup>30</sup> *Seeds and Shamans*, *supra* note 4 at 960. An example from RAFI recounts how a bioprospecting contract was to be concluded between Washington University and Peru’s Aguaruna and Huambisa Council (CAH) of indigenous peoples. However, Washington University refused to provide a Spanish translation of the contract in spite of a “multimillion dollar project budget.” (RAFI Communiqué: “Biopiracy Update: A Global Pandemic”, online: RAFI <<http://www.rafi.ca/web/allpub-one.shtml>> (date accessed: October 30, 1999).

Belief	Reality
<ul style="list-style-type: none"> <li>• Contracts allow for clarity and disclosure in relationships between communities and corporations.<sup>32</sup></li> </ul>	<ul style="list-style-type: none"> <li>• Contracts mask the reality that bioprospecting will occur regardless of whether a contract is completed or not, and if parties do not agree to the industry's terms, the industry will seek a more "appropriate" partner.<sup>31</sup></li> <li>• Bioprospecting contracts contain ambiguous and expansive language, which strip the contract of meaning and benefit.<sup>33</sup></li> <li>• Because of the private contractual nature of relationships, such contracts are not public domain and are difficult to monitor by countries or the <i>Convention</i>.<sup>34</sup></li> </ul>
<ul style="list-style-type: none"> <li>• Contracts clearly establish the relationship as legal.</li> </ul>	<ul style="list-style-type: none"> <li>• There are no defined contractual standards for bioprospecting contracts; any standards are likely to be defined by industry.<sup>35</sup></li> <li>• Importantly, parties cannot control the activities of individuals or businesses not a party to the contract.<sup>36</sup></li> </ul>

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<sup>31</sup> *Ibid.* In the Washington University contract with Peru, the CAH did not consent to the contract. Despite this rejection, Washington University researchers unilaterally started collection of genetic resources and were reportedly looking for a more "appropriate" indigenous partner. As RAFI states "The de facto definition of a [...] partner increasingly appears not to be based on representation or legitimacy of indigenous organizations; but rather their malleability to the corporate and research interests of ICBG."

<sup>32</sup> Laird, *supra* note 9 and *supra* note 18.

<sup>33</sup> See Searle, *infra* note 40.

<sup>34</sup> This lack of disclosure means that exploitative deals are not open to public review and censure; as a result, widely-accepted norms are not established (*Bioprospecting/Biopiracy*, *supra* note 3).

<sup>35</sup> "By and large, the terms and conditions under which indigenous peoples might benefit financially are controlled by Northern corporations..." (*Bioprospecting/Biopiracy*, *supra* note 3).

<sup>36</sup> Laird, *supra* note 9.

Belief	Reality
<ul style="list-style-type: none"> <li>Mutually beneficial compensation can be arranged through royalties of 1-3% of sales or a product developed from local resources.<sup>37</sup></li> </ul>	<ul style="list-style-type: none"> <li>Royalty payments of 1-3% are “meagre” at best compared to the profit and financial resources of life industry corporations.<sup>38</sup></li> <li>Royalties are often not available to the parties who made the contribution.<sup>39</sup></li> <li>Language in contracts can be worded to avoid paying royalties if possible.<sup>40</sup></li> </ul>
<ul style="list-style-type: none"> <li>Compensation can also be provided through advance payments.</li> </ul>	<ul style="list-style-type: none"> <li>In practice, advance payments are generally inadequate in comparison to the access that the company enjoys.<sup>41</sup></li> </ul>
<ul style="list-style-type: none"> <li>Licensing agreements can allow parties to retain control over their resources and prevent commercial exploitation, by providing for a one-time fee payment.<sup>42</sup></li> </ul>	<ul style="list-style-type: none"> <li>Licensing agreements remove any sense of responsibility for the resource and provide inadequate compensation if a product is developed.<sup>43</sup></li> </ul>
<ul style="list-style-type: none"> <li>Non-monetary benefits accrue to source communities such as education, training, technology and exposure.</li> </ul>	<ul style="list-style-type: none"> <li>Non-monetary benefits is a way of legitimizing the exploitation of cheap South labour.<sup>44</sup></li> </ul>

<sup>37</sup> Laird, *supra* note 9 at 114.

<sup>38</sup> RAFI documents a contract agreement between Merck and INBio which provides unspecified royalties, estimated to be 1-3%. Merck contracted with the Costa Rican Instituto Nacional de Biodiversidad (INBio) to give INBio a “2 year research budget of \$1.135 million, an undisclosed share of royalties on any resulting commercial products, and technical assistance and training to establish in-house capacity for drug research.” (*Bioprospecting/Biopiracy*, *supra* note 3). The World Resources Institute has estimated that fair compensation for Costa Rica’s resources would require approximately a 40% royalty rate (Laird, *supra* note 9 at 111).

<sup>39</sup> See *supra* note 6 for a lengthy discussion of methods of resolving this problem.

<sup>40</sup> Under the contract between Searle and Washington University and Peru, Searle would not be obliged to pay royalties if “the biological activity of an active agent was in the public domain or was known or otherwise available to Searle, as evidence by Searle’s written records, prior to Searle’s discovery of the biological activity of the active agent in a Plant Extract.” Royalties (of a total possible amount of 0.2-1%) are only payable by Searle if 1) the final product actually incorporates a plant extract and 2) the final product is for the same purpose as it was used by Indigenous People. In addition, after payments to intermediaries and other costs, the maximum possible royalties that the Indigenous People could receive is 0.125% (of a total royalty of 1%). (*Bioprospecting/Biopiracy*, *supra* note 3).

<sup>41</sup> An example of this is that in the Merck-INBio agreement, Merck provided an advance payment of \$1.135 million to INBio. As RAFI points out, since Costa Rica possesses 5-7% of global biodiversity, at that rate the biodiversity of the South could be exploited for \$10 million / year. (*Bioprospecting/Biopiracy*, *supra* note 3).

<sup>42</sup> Posey, *supra* note 1 at 70. I found no recorded licensing agreements.

<sup>43</sup> *Supra* note 18 at 171.

<sup>44</sup> *Bioprospecting/Biopiracy*, *supra* note 3.

*iv. The communities providing genetic resources are harmed by bioprospecting*

Bioprospecting from communities harms the source communities in many ways. Some of the most common deprivations and damages to the source community are the following:<sup>45</sup>

- Communities providing genetic resources are often coerced by their governments and international trade agreements into paying elevated prices for products (because of patent royalty costs) that exist within their communities.
- The increased dependence on expensive manufactured products (such as pharmaceuticals) alienates source communities from traditional healing methods, increasing the community's dependence on pharmaceutical products.
- Cultural beliefs about what can be possessed and what constitutes property are violated by legal impositions of property rights.

The exploitative actions of bioprospecting, processing and commodification of genetic resources are individually and collectively called biopiracy.

Although many informal definitions of biopiracy abound, there is no precise legal definition.<sup>46</sup> Biopiracy has been defined narrowly to encompass only the theft of plant genetic resources<sup>47</sup> or broadly to include the taking of biological resources and knowledge.<sup>48</sup> Some definitions of biopiracy include as victims only indigenous peoples,<sup>49</sup> or Third World or developing communities,<sup>50</sup> while others broadly state that it can be perpetrated by large corporations against any community or individual.<sup>51</sup> The means of theft are just as broadly defined; some

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<sup>45</sup> Generally taken from: *Seeds and Shamans*, *supra* note 4; *Enclosures of the Mind: Intellectual Monopolies*. Prepared for the Community Biodiversity Development and Conservation Program. (DesignCo, 1998) at 75. [hereinafter *Enclosures*]; *Biopiracy/Bioprospecting*, *supra* note 3; V. Shiva, *Biopiracy: the Plunder of Nature and Knowledge* (Boston: South End Press, 1997) [hereinafter *Shiva*].

<sup>46</sup> J. Odek, "Bio-Piracy: Creating Proprietary Rights in Plant Genetic Resources" (1994) 2 J. Intell. Prop. L. 141 at 145.

<sup>47</sup> *Supra* note 18 at 139.

<sup>48</sup> *Enclosures*, *supra* note 45 at 5.

<sup>49</sup> *Supra* note 18.

<sup>50</sup> *Shiva*, *supra* note 45 at 5; *supra* note 46 at 145 respectively.

<sup>51</sup> *Bioprospecting/Biopiracy*, *supra* note 3.

assert that it must involve intellectual property rights<sup>52</sup> while others merely stipulate that goods must be developed and marketed without adequate compensation.<sup>53</sup>

From the definitions in the literature, the basic thread of biopiracy is an expression by source communities of an entitlement to their biological genetic resources,<sup>54</sup> which have been stolen and profited from (using any means, such as intellectual property rights) by a third party who has little or no entitlement, depriving the source community of appropriate compensation, other benefits and/or human rights. The definition of biopiracy must address the exploitation of existing power imbalances, be they South-North, developing-developed, indigenous-national government or national government-transnational corporation.

## 2. The international community's (lack of) response to biopiracy

To date, the theft of biological resources, or biopiracy, has neither been named nor condemned by the international legal community in binding legal documents. However, declarations and recommendations, primarily from indigenous peoples' organizations, have named the crime, in particular the *Indigenous People's Earth Charter*,<sup>55</sup> the COICA/UNDP Regional Meeting on Intellectual Property Rights and

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<sup>52</sup> *Enclosures*, *supra* note 45.

<sup>53</sup> *Supra* note 18 and 46.

<sup>54</sup> *Supra* note 18 at 139. This is demonstrated by the specific definition of the term in relation to the topic under discussion. For example, in Hunter's discussion of the Merck-INBio agreement to exchange plant genetic resources, he defines biopiracy as the "exploitation of indigenous peoples to locate and understand the uses of medicinal plants and then to develop and market drugs derived from those plants while returning little or no compensation from sales of the drug to indigenous peoples."

<sup>55</sup> Posey, *supra* note 1. World Conference of Indigenous Peoples on Territory, Environment and Development (25-30 May 1992), expressed by the Indigenous Peoples of the Americas, Asia, Africa, Australia, Europe and the Pacific at Kari-Oca Villages in Brazil. Of note is Art. 61:

Indigenous peoples must consent to all projects in our territories. Prior to consent being obtained the peoples must be fully and entirely involved in any decisions. They must be given all the information about the project and its effects. Failure to do so **should be considered a crime** against the indigenous peoples. The person or persons who violate this should be tried in a world tribunal within the control of indigenous peoples set for such a purpose. This could be similar to the trials held after World War II [emphasis added] (see also Arts. 70(b), 99, 102).

Biodiversity<sup>56</sup> and the UNDP Consultation on the Protection and Conservation of Indigenous Knowledge.<sup>57</sup> These documents, and others, have recommended and elaborated upon measures to prevent the appropriation of indigenous community resources.<sup>58</sup> Two non-binding declarations, the *Universal Declaration on the Human Genome and Human Rights*<sup>59</sup> and the *Draft Declaration on the Rights of Indigenous*

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<sup>56</sup> Posey, *supra* note 1. Held in Santa Cruz de la Sierra, Bolivia, 28-30 September 1994. Under "Basic points of agreement" the document states:

8. Prevailing intellectual property systems reflect a conception and practice that is... Usurpatory, in that it is essentially a **practice of theft...**

13. The prevailing intellectual property systems **must be prevented from robbing us**, through monopoly rights, of resources and knowledge in order to enrich themselves and build up power opposed to our own. [emphasis added]

<sup>57</sup> Posey, *supra* note 1. Also known as the *Sabah Statement*, Sabah, East Malaysia, 24-27 February 1995. In the section entitled "Specific points raised on indigenous knowledge and intellectual property rights (IPR)" the document states:

Indigenous knowledge and resources are being eroded, exploited or appropriated by outsiders in the likes of transnational corporations (TNC's), institutions, researchers, and scientists who are after the profits and benefits gained through monopoly control.

**The technological method of piracy** is too sophisticated for indigenous peoples to understand, especially when indigenous communities are unaware of how the system operates and who are behind it. [emphasis added]

See the *Beijing Declaration of Indigenous Women*, which states: "Bioprospecting, which is nothing but the alienation of our invaluable intellectual and cultural heritage through scientific collection missions and ethnobotanical research, is another feature of recolonization." *Beijing Declaration of Indigenous Women*, NGO Forum, United Nations Fourth World Conference on Women, Huairou, Beijing, Peoples Republic of China, Aug. 30-Sept 8, 1995, online: <<http://www.web.net/~csc/text/Beijing.htm>> (date accessed: November 21, 1999).

<sup>58</sup> See the Rio Declaration on Environment and Development; Agenda 21; the Charter of the Indigenous-Tribal Peoples of the Tropical Forests, Penang, Malaysia, 15 February 1992; the Mataatua Declaration on Cultural and Intellectual Property Rights of Indigenous Peoples, June 1993; Recommendations from the Voices of the Earth Congress, Amsterdam, Netherlands, 10-11 November 1993; UNDP Consultation on Indigenous Peoples' Knowledge and Intellectual Property Rights, Regional Consultation on Indigenous Peoples' Knowledge and Intellectual Property Rights, held in April 1995 in Suva, Fiji.

<sup>59</sup> Online: UNESCO <<http://www.unesco.org/ibc/uk/genome/projet/index.htm>> (date accessed: December 1, 1999). For example, the preamble states: "Recognizing that research on the human genome and the resulting applications open up vast prospect for progress... but emphasizing that such research should fully respect human dignity, freedom and human rights, as well as the prohibition of all forms of discrimination based on genetic characteristics."

*Peoples*,<sup>60</sup> have attempted to address issues integrally related to biopiracy without naming or confronting the crime, by respectively recognizing individual and indigenous peoples' rights relating to genetic resources.

The only binding legal document that has attempted to address issues of exploitation and biopiracy is the *Biodiversity Convention* discussed above. However, opinions are divided as to whether it promotes or discourages biopiracy.<sup>61</sup> The *Convention* encourages equitable sharing of resources, yet provides no mechanism to ensure this sharing will occur. It contains no binding code of conduct for bioprospectors, nor does it control access to biological resources. The *Convention* encourages mutual agreements and supports intellectual property rights over technologies, two provisions which aid the life industry more than source communities. Most importantly, the *Convention* does not condemn or even acknowledge prior exploitation and biopiracy of biological resources.

The lack of official recognition of biopiracy by non-indigenous peoples is complemented by a strengthening of the mechanisms of biopiracy through the WTO-Trade-Related Aspects of Intellectual Property (TRIPS) agreement which requires "developing" countries to adopt intellectual property legislation for plant varieties and microorganisms.<sup>62</sup> As RAFI states: "the effect of this imposition will be to legalize and facilitate the North's appropriation of resources and knowledge from the South... legitimat[ing] the piracy of community innovations on a global scale."<sup>63</sup>

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<sup>60</sup> This document specifies that indigenous peoples are entitled to full ownership and control of cultural property and that "they have the right to special measures to control, develop and protect their sciences, technologies and cultural manifestations, including human and other genetic resources, seeds, medicines, knowledge of the properties of fauna and flora..." (Part VI, Art. 29) U.N. Commission on Human Rights, Sub-Commission on the Prevention of Discrimination and Protection of Minorities, 46<sup>th</sup> Sess., Agenda Item 15, U.N. Doc. E/CN.4/Sub.2/1994/2/Add.1 (1994).

<sup>61</sup> See Posey, *supra* note 1 for a discussion of how the *Biodiversity Convention* will limit biopiracy. See *Enclosures*, *supra* note 45 for a discussion of how the *Biodiversity Convention* encourages biopiracy.

<sup>62</sup> Online: World Trade Organization <<http://www.wto.org/wto/intellect/4-ipstan.htm#5>> (date accessed October 23, 1999). Art. 27(b) of TRIPS states: "However, Members shall provide for the protection of plant varieties either by patents or by an effective *sui generis* system or by any combination thereof."

<sup>63</sup> *Enclosures*, *supra* note 45 at 8. See also *Shiva*, *supra* note 45.

### III. A CASE-STUDY OF BIOPIRACY: THE ACTIONS OF deCODE GENETICS IN ICELAND

Iceland is a northern-European nation; its genetic resources are a wealth of genetic samples, medical records and publicly available genealogies which document the genetics of Iceland's homogeneous population. Its biopirates are a start-up genetic biotechnology company, deCode, that received a \$200 million equity investment from Hoffman La Roche, a transnational corporation in the life industry. The Icelandic government concluded a contractual licensing agreement with deCode which allows unlimited access to Icelanders' genetic resources. It will be shown that although the names and places may vary, the perpetrators (corporations), the victims (source communities with valuable genetic resources), the modes of exploitation and the damage caused by bioprospecting are disturbingly similar.

The situation of Iceland will also demonstrate how the creation by governments of bioprospecting contracts, a method that is thought to remedy or minimize the occurrence of biopiracy, poses no barrier to biopirates. Instead, the implementation of bioprospecting contracts may lead to further exploitative situations since, as a "legal" agreement, the contract is unassailable. The Icelandic situation will illustrate that the bioprospecting contract, eagerly embraced by industry and treaty-makers, changes the form but not the substance of biopiracy. It will also show that vesting control of genetic resources in government is perilous since government's interests are more in line with corporations than with those of their people. Iceland will further illustrate that bioprospecting contracts negotiated between governments and industry do not guarantee "equitable sharing"<sup>64</sup> of resources; the terms of the contract are only as good as those negotiated.

Iceland also serves as an exposition of the many forms of damage that biopiracy can wreak on the source community. It will be shown that the Icelandic peoples' human rights to privacy and informed consent, and rights to adequate compensation have been denied. It will also be demonstrated that the biopirates have made promises they cannot keep to the Icelandic people.

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<sup>64</sup> See *Biodiversity Convention*, *supra* note 10.



As biopiracy is a specialized type of theft with no precise legal definition,<sup>65</sup> to demonstrate that the Icelandic situation is biopiracy, I will show that it fits the elements of traditional theft and the specialized situation of biopiracy.

### **1. The life industry is interested in Iceland:**

A former resident of Iceland, Kari Stefansson, established deCode Genetics (hereinafter deCode) in 1996, as a small start-up biotechnology company specializing in genetic research. Although the company claims 70% ownership by Icelanders,<sup>66</sup> it is a wholly owned subsidiary of a Delaware paper corporation and was initially funded by \$12 million of investments from American and European venture capitalists,<sup>67</sup> whose representatives comprise five of the six members of the Board of Directors of deCode.<sup>68</sup> In February 1998, deCode accepted a \$200 million equity investment from Hoffmann-LaRoche (Roche), a transnational Swiss-based pharmaceutical company, to enable it to research the genetic causes of twelve common diseases.<sup>69</sup>

DeCode will compile Icelanders' medical records, genealogy and genetic data in a centralized database to facilitate discovering the genetic processes that cause disease. As a representative from Roche stated, this research will help the life industry "make drugs".<sup>70</sup> In addition, the life

<sup>65</sup> Whereas theft has a precise legal definition.

<sup>66</sup> This goal was reached in June of 1999 when the original interests sold some of their shares to The Icelandic Investment Bank, The National Bank of Iceland, The Agricultural Bank and Hof Holding Company to vest "approximately" 70% ownership in Icelanders (Online: deCode <<http://www.decode.is>> (date accessed: November 2, 1999). Note that the major shareholders are not individual citizens but banks.

<sup>67</sup> These include Advent International, Atlas Venture, Arch Venture Partners, Falcon Technologies, Medical Science Partners and Polaris Venture Partners (R.C. Lewontin, "People are not Commodities", *New York Times* (January 23, 1999)).

<sup>68</sup> Online: deCode <<http://www.decode.is/company/index.html>> (date accessed: November 2, 1999).

<sup>69</sup> Online: deCode <[http://www.decode.is/e\\_news1\\_releases.htm](http://www.decode.is/e_news1_releases.htm)> (date accessed: November 2, 1999). E. Marshall notes: "Roche Holding of Base announced it would pay \$200 million over the next five years for research by an obscure firm in Reykjavik called deCode Genetics, which at the time had no products, no clients, and less than a year's operating experience." (E. Marshall, "Iceland's Blond Ambition: A Nordic Country Cashes in on its Isolated Gene Pool", online: Mother Jones <[http://truher.mojones.com/mother\\_jones/MJ98/marshall.html](http://truher.mojones.com/mother_jones/MJ98/marshall.html)> (date accessed: November 15, 1999) [hereinafter Marshall]).

<sup>70</sup> *Ibid.* Once genetic processes that underlie disease have been identified, pharmaceutical companies can design drug treatments which anticipate diseases and sell them to patients before diseases have even occurred.

industry hopes to use deCode's research to aid the development of "pharmacogenomics", a system whereby the most suitable persons for clinical trials of drugs are selected by genetic testing. If the drug were successful in treating their condition, it would be marketed to people whose genetic profiles matched those of the trial group. Pharmacogenomics results in huge financial savings for pharmaceutical companies by reducing the volume of clinical trials that must be conducted.

## 2. Why Iceland is of interest to the life industry

Iceland<sup>71</sup> is a valuable resource to life industry bioprospectors because its genetic homogeneity and meticulous historical and genealogical records allow comprehensive genetic research.

Iceland's present population is largely descended from a small number of Nordic and Gaelic explorers who settled the island in the seventh century A.D..<sup>72</sup> Since that time, most Icelanders have married and reproduced with the descendants of those original settlers, leading to a high level of genetic homogeneity among Icelanders. Few people have emigrated to Iceland due to its harsh environment and living conditions. The genetic homogeneity of the island has increased due to disease and natural disasters,<sup>73</sup> which further restricts the genetic variation of Icelanders.<sup>74</sup>

<sup>71</sup> Iceland is an isolated Northern European nation whose population is about 270 000.

<sup>72</sup>Note that contrary to the assertions of the popular media that Iceland possesses a genetically homogeneous population descended from the Vikings, the Gaelic portion of the genetic mixture is estimated at greater than 50%. (E. Arnason, Letter to the Editor, *The New York Times*, online: Mannvernd <<http://www.mannvernd.is/english/articles/ea.nytimes.html>> (date accessed: November 15, 1999)) [hereinafter Arnason].

<sup>73</sup> In the 1400's the Black Death killed two thirds of the population. In addition, the residents were subject to smallpox and finally in the late 1700's the volcano Hekla erupted. The volcano spewed ash over pastures and fields, disrupting agriculture and causing a severe famine. Marshall, *supra* note 69.

<sup>74</sup> Icelanders also enjoy uniformity in their good standard of living, living conditions and diets. (A. Berger, "Private company wins rights to Icelandic gene database.", online: *British Medical Journal* <<http://www.bmj.com/cgi/content/short/318/7175/11>> (date accessed: November 12, 1999) [hereinafter Berger]).

Alternate explanations for the attractiveness of the Icelandic population have been proposed, in particular J.H. Edwards believes:

It is not genetic homogeneity which makes Iceland so attractive for the study of these disorders. It is the genetic heterogeneity of its individuals, much enriched by Celtic genes from a few slaves and many women,

In addition to the homogeneity of the genetic pool, Icelanders have kept meticulous records of their genealogy and ancestry; records can be traced to the seventeenth century and comprehensive records have been kept since the 1840's.<sup>75</sup> Since 1915, the Icelandic healthcare service has been collecting detailed medical records and since the Second World War it has collected tissue samples from Icelandic healthcare users.

### 3. How the life industry is accessing Icelanders' genetic resources

DeCode's rights to Iceland's genetic information are created by legislation passed by the Icelandic parliament in 1998, entitled an *Act on a Health Sector Database* (see Appendix A).<sup>76</sup> The objective of the Act is "to authorise the creation and operation of a centralised database of non-personally identifiable health data with the aim of increasing knowledge in order to improve health and health services".<sup>77</sup> The Act aims to achieve this objective by concluding a bilateral bioprospecting contract between the government and deCode, without mentioning the corporate party specifically. The Act legislates with respect to five essential terms of the contract: the licensing regime, the access rights, enforcement provisions, the consent scheme and privacy requirements. The first three terms are procedural, whereas the consent and privacy requirements are more substantive.

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acquired by both consent and abduction, from the coastal regions of Ireland and North Britain. It seems likely that there is a majority of Celtic genes (Bjarnason et al. 1973), although this need not imply a majority of Celtic settlers. It is this innate variability, coupled with the high regional homogeneity in physique, culture, diet and other environmental features, that makes Iceland so attractive for the study of common disorders.

J.H. Edwards, "Decoding genes in Iceland", online: Mannvernd <[http://www.mannvernd.is/english/articles/04.12.1998\\_decoding\\_genes\\_john\\_edwards.html](http://www.mannvernd.is/english/articles/04.12.1998_decoding_genes_john_edwards.html)> (date accessed: November 12, 1999).

<sup>75</sup> These records were input into a computerized database funded by the Atomic Energy Commission in the U.S. in the sixties, a database that has since been maintained by the University of Iceland and University Hospital. (*Ibid.*) This record-keeping has resulted in a depth of knowledge to the extent that the family ties can be traced of 75% of all Icelanders that have ever lived. (J. Crosby, "Iceland: The selling of a nation's genetic code", online: Star Tribune <<http://www.startribune.com/cgi-bin/stOnLine/article?thisSlug=ice10&date=10-Feb-1999&word=iceland>> (date accessed: November 14, 1999)).

<sup>76</sup> [hereinafter the Act]. The legislation was passed in October 1998 with 37 for and 20 against, with 6 abstentions. (English version of legislation available online: Mannvernd <<http://www.brunnur.stjr.is/interpro/htr/htr.nsf/pages/gagngr-log-ensk>> (date accessed: October 23, 1999)).

<sup>77</sup> *Ibid.* Art. 1.

*i. Licensing scheme:*

The licensing scheme of the Act outlines the compensation terms of the bioprospecting contract. Article 4 authorizes the government to issue an exclusive license<sup>78</sup> to create a health sector database; the article also specifies that the licensee will pay all the costs of the licensing scheme, in particular the costs of monitoring the creation and use of the database and the costs of processing information for entry onto the database. The license is temporary (12 years at a time -Art. 5, no. 9) and cannot be transferred.<sup>79</sup>

A condition of the license is that the database must be located exclusively in Iceland.<sup>80</sup> This is further supported by Article 10, which provides that the database may not be transported out of Iceland and database processing must occur in Iceland. However, the legislation notes significantly that “[t]he licensee is authorised during the period of the licence to use the data on the database for purposes of **financial profit**, under the conditions laid down in this legislation and the licence.”<sup>81</sup>

*ii. Access rights:*

Legislative provisions also govern the supply, use and access to genetic resources. Article 6 provides that a three-person committee and the Data Protection Commission<sup>82</sup> will monitor the creation and operation of the health service database.<sup>83</sup> Article 7 provides that the actual medical information will be obtained through contracts with health institutions or self-employed health workers (i.e. doctors).

The licensee is **not** authorized to grant direct access to data on the database, however the licensee is entitled to process data in the database.<sup>84</sup> This information can be used to “develop new or improved

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<sup>78</sup> A license is defined by B. Ziff as “a permission to do that which would otherwise constitute a trespass. Such a privilege may be expressly conferred... or it may be implied.” (B. Ziff, *Principles of Property Law* (Scarborough: Carswell, 1996) at 274).

<sup>79</sup> Act, *supra* note 76 Art. 5.

<sup>80</sup> Act, *supra* note 76 Art. 5, no.1.

<sup>81</sup> Act, *supra* note 76 Art. 10 [emphasis added].

<sup>82</sup> Act, *supra* note 76 Art. 12.

<sup>83</sup> Especially adherence to the conditions of the licence and the legislation.

<sup>84</sup> Act, *supra* note 76 Art. 10.

methods of achieving better health, prediction, diagnosis and treatment of disease.”<sup>85</sup>

The government will have access to statistical data from the database<sup>86</sup> free of charge.<sup>87</sup> Article 9 confirms that this information can be used for the “making of health reports and planning, policy-making and other projects”. There is no specific provision for access by independent scientific researchers<sup>88</sup> or individuals.

### *iii. Enforcement terms.*

The license may be revoked with or without notice if the licensee violates the terms of the legislation or of the license. The license can also

<sup>85</sup> DeCode intends to use its access rights as follows: genetic information is obtained from individuals with the illnesses deCode hopes to research through collaborating physicians. The physicians obtain blood samples from these patients, then the patient’s identity is replaced with an encrypted ID. The sample is then sent for testing at deCode’s labs where its genetic profile or genotype is obtained. The genetic profile is then matched with medical records including “physical details, including a person’s disease status, age and weight” and family genealogical records (Marshall, *supra* note 69).

<sup>86</sup> Act, *supra* note 76 Art. 5, no. 7.

<sup>87</sup> Act, *supra* note 76 Art. 9.

<sup>88</sup> Act, *supra* note 76 Art. 4 provides that “[t]he minister and licensee may agree on further payments to the Treasury, which shall be devoted to promoting the health service, **research** and development.” [emphasis added]

Art. 6 makes a tangential reference to the role of the three person committee in determining:

[t]he sum to be paid by the licensee under the terms of para. 3 art. 4 shall be negotiated by the committee, as shall recompense in the form of access to data from the database for health institutions, self-employed health workers and their staff for purposes of **scientific research**. [emphasis added]

In addition, Art 5. No. 8 provides that:

[t]he licensee shall pay all costs of processing data from health institutions and self-employed health workers for entry onto the database. The data shall be processed in a manner that fulfills the needs of the relevant institution or self-employed health worker for a standardised information system, the needs of medical specialist fields and the requirements of health authorities, cp. Clause 7, and so that it can be used in **scientific research**. [emphasis added]

The Notes to the Bill do provide that: “the Bill provides that a special committee... will be able to grant scientists access to data from the database for use in scientific research; it is one of the conditions of the license being granted that the needs of scientists shall be taken into account in processing of data on the database.” (*Notes to the Bill*, online: Mannvernd <<http://mannvernd.is/english/laws/HSD.bill.html>> (date accessed: October 23, 1999) Part III, para. 4.) [hereinafter *Notes to the Bill*].

be revoked if the licensee becomes unable to operate the database.<sup>89</sup> The legislation provides in Article 14 for penalties of fines or imprisonment if the legislation or license is not adhered to. If the licensee violates the confidentiality/privacy policies then it must pay compensation to the person affected.<sup>90</sup>

*iv. Consent scheme:*

The supply of genetic resources to deCode does not require the informed consent of the patients whose data is being supplied. Rather, a patient must ask to have their data removed from the database. As stipulated in Article 8:

A patient may request at any time that information on him/her not be entered onto the health-sector database. The patient's request may apply to all existing information on him/her or that which may be recorded in the future, or to some specific information. Such a request must be complied with. The patient shall inform the Director General of Public Health of his/her wish...<sup>91</sup>

*v. Privacy scheme:*

The legislation attempts to protect the privacy rights of Icelanders. The security standards of the health care database are monitored by the Data Protection Commission.<sup>92</sup> Health care workers<sup>93</sup> encrypt personal data prior to its handling by the licensee in order to ensure confidentiality. This information is encrypted one-way to ensure that the coding cannot be traced by a de-coding key.<sup>94</sup> The licensee must develop guidelines for ensuring confidentiality in its processing of data, must ensure that "data are processed and connected in such a way that they cannot be linked to identifiable individuals" and cannot allow access to individual information.<sup>95</sup> All employees of the licensee are

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<sup>89</sup> Act, *supra* note 76 Arts. 13 and 15.

<sup>90</sup> Act, *supra* note 76 Art. 17.

<sup>91</sup> Act, *supra* note 76 Art. 8.

<sup>92</sup> Act, *supra* note 76 Art. 5 no. 2 and Art. 12.

<sup>93</sup> The Act also provides that the recording and processing of data will be carried out by individuals professionally qualified in the health sector (Act, *supra* note 76 Art. 5, no. 3).

<sup>94</sup> Act, *supra* note 76 Art. 7.

<sup>95</sup> Act, *supra* note 76 Art. 10.

strictly bound to a confidentiality agreement, which does not terminate when their employment ends.<sup>96</sup>

*vi. Comparison to general principles governing bioprospecting contracts:*

The Act legislates the terms of a bioprospecting contract. In accordance with the spirit of the *Biodiversity Convention*, the contract is between government and a corporation.<sup>97</sup> The legislation specifies supply, access, compensation and enforcement terms; however its access terms are too vague and do not clearly state that access will be enjoyed by parties other than the government or deCode.<sup>98</sup> The Act violates the standard terms for bioprospecting contracts by not providing for the informed consent of the source community. The Act does legislate privacy requirements; however, as will be demonstrated,<sup>99</sup> these provisions are far from adequate to protect the source community. The Act does not provide for the “equitable sharing of benefits”<sup>100</sup> of the contract since deCode keeps all financial profit derived from the database with no benefits to Icelanders (like royalties) other than the licensing fee. The Act does adhere to the substantive principles of the bioprospecting contract by ensuring that the company is based in and the database is processed in Iceland; however, there is no control over the processed material once bought by a transnational pharmaceutical company. The legislation also contains no terms regulating deCode’s potential to obtain intellectual property rights over Icelandic genes.

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<sup>96</sup> Act, *supra* note 76 Art. 11.

<sup>97</sup> It must be noted that the *Biodiversity Convention* does not refer to human genetic resources. As outlined in Posey, *supra* note 1 at 171: “Any possibility that the [*Biodiversity Convention*] could be interpreted to include human genes as genetic resources was eliminated at the Second Conference of the Parties, in November 1995, which decided that “human genetic resources are not included within the framework of the Convention” (UNEP 1995. Report of the Second Meeting of the Conference of the Parties to the Convention on Biological Diversity (UNEP/CBD/COP/2/19). UNEP, Geneva.) However, the Convention establishes an international norm for bioprospecting contracts. See K.H. Ching, “Indigenous Self-Determination in an age of Genetic Patenting: Recognizing an Emerging Human-Rights Norm” (1997) 66 *Fordham L. Rev.* 667 [hereinafter Ching] and *supra* note 18.

<sup>98</sup> For a discussion of the uncertainty surrounding access to Icelandic genetic resources see: Electronic responses, “Exclusive tools for the future”, online: *British Medical Journal* <<http://www.bmj.com/cgi/eletters/318/7175/11>> (date accessed November 13, 1999).

<sup>99</sup> *Infra* section 3.35.

<sup>100</sup> See *Biodiversity Convention*, *supra* note 10.

Furthermore, the Act does not legislate the percentage ownership of deCode by Icelanders. Generally, the Act falls short of the international practice and the articulated norms of a bioprospecting contract.

#### **4. This contracting scheme and the actions of deCode and the national government constitute biopiracy**

However, the agreement between Iceland and deCode is more than just an unfair contract. It is international theft, an act of biopiracy that is not being condemned by the International or Icelandic community.

Black's law dictionary defines theft as:

The act of stealing. The taking of property without the owner's consent... The taking of personal property belonging to another, from his possession, or from the possession of some person holding the same for him, without his consent, with intent to deprive the owner of the value of the same, and to appropriate it to the use or benefit of the person taking...<sup>101</sup>

Theft	Biopiracy <sup>102</sup>	Iceland
1. The taking of personal property belonging to another from her possession	<ul style="list-style-type: none"> <li>• Biopirates prospect biological resources (such as blood and skin cells) that belong to source communities.</li> </ul>	<ul style="list-style-type: none"> <li>• deCode has bought monopoly rights to the medical records, genealogy and genetic samples collected by the public health service of Iceland from Icelanders</li> </ul>
2. Without consent	<ul style="list-style-type: none"> <li>• Material is taken from source communities either without informing the community or without ensuring there is informed consent.</li> </ul>	<ul style="list-style-type: none"> <li>• Medical information is automatically included in the database without the informed consent of patients.</li> </ul>

<sup>101</sup> *Black's Law Dictionary*, 6<sup>th</sup> ed., s.v. "theft".

<sup>102</sup> Information about biopiracy is generally derived from the discussion at page 4.



Theft	Biopiracy <sup>102</sup>	Iceland
<p>3. With intent to deprive the owner of value of the same</p>	<ul style="list-style-type: none"> <li>• Source communities do not receive profits from resources they have collected and cultivated for centuries.</li> <li>• These communities are then required to pay market rates for products derived from their resources, which often (as is the case with drugs) are not applicable to their illnesses.</li> <li>• However, they are still required to maintain the source locations of these resources intact for further extraction</li> <li>• The dependence on products of the life industry removes self-reliance and independence of these communities.</li> <li>• Privacy rights are violated since private knowledge is made public.</li> </ul>	<ul style="list-style-type: none"> <li>• Icelanders' privacy rights will be violated by the public health sector database.<sup>103</sup></li> <li>• Discoveries obtained from the health care database are not applicable to individual Icelanders since the database is "non-personal".</li> <li>• There is no realistic guarantee that there will be any benefits to Iceland because of the project, either in terms of free drugs or shareholder returns</li> <li>• The deCode database will eliminate funding and resources from locally held databases which treat Icelanders for diseases.</li> </ul>
<p>4. To appropriate it to the use or benefit of the person taking.</p>	<ul style="list-style-type: none"> <li>• Corporations realize the profits from patent royalties and selling access rights to final products.</li> </ul>	<ul style="list-style-type: none"> <li>• deCode has the potential to make a huge financial profit from selling processed information from the database.</li> <li>• deCode will also profit from creating its own specialized database and its plans to obtain patents on genetic discoveries from the database, neither of which is controlled by the legislation.</li> </ul>

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<sup>103</sup> I am arguing here that Icelanders will lose the value of their private medical records which lies in their confidentiality and private nature.

*i. The taking of personal property belonging to another*

Like typical bioprospectors, deCode has taken genetic resources from the source community of Iceland.<sup>104</sup> This requires the commodification<sup>105</sup> and subsequent acquisition of rights of possession to Icelanders' genetic resources, achieved through the formally unassailable legalistic mechanism of acquiring monopoly rights through a contractual licence.<sup>106</sup> Thus deCode has obtained the right to exclusive physical possession of Icelandic genetic resources without a physical

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<sup>104</sup> Ownership of human genetic material is a contested issue in the international arena. The *Convention on Biological Diversity* specifically excludes human genetic materials from its purview, hence it is not explicitly within the mandate of government to legislate ownership of human genetic material. The *Universal Declaration on the Human Genome and Human Rights* provides no guidance, stating merely in Article 4 that "[t]he human genome in its natural state shall not give rise to financial gains." There has been speculation (Ching, *supra* note 43 at 717) that ownership of human genetic material could be founded on a claim of self-determination, thus extending the international right of self-determination beyond its current purview. As Ching states "The term self-determination has been imbued with the idea of bodily integrity and could be applied to allow for greater control of the individual over her body." See also G.J. Simpson, "The Diffusion of Sovereignty: Self-Determination in the Post-Colonial Age" (1996) 32 *Stan. J. Int'l L.* 255 and E. Kolodner, "The Future of the Right to Self-Determination" (1994) 10 *Conn. J. Int'l L.* 153. Both advocate expanding the right of self-determination.

Intellectual property law in the United States (significant because most transnational corporations have strong links with the U.S.) provides that genetically engineered microorganisms, plants, animals, genes and human cell lines are all patentable, or subject to **legal** ownership. As RAFI states "biotechnology has advanced so rapidly in recent years that there is now virtually no life form which does not have...potential as the subject of patent application." (*Enclosures, supra* note 45 at page 15 quoting S.I. Hirst, "Biopatents: A Sense of Order" (1992) 10 *Trends in Biotechnology*). However (at least in the U.S.) the human source of genetic material has no presumptive right of ownership and had no property rights over removed genetic material, as was held in *Moore (supra* note 4).

<sup>105</sup> See *supra* note 67 where Lewontin states that the government of Iceland has made "its entire population into a captive biomedical commodity." See J.P. Berlan, "From agricultural genetics to the looting of the Icelandic health system", online: Mannvernd <<http://www.mannvernd.is/english/articles/jpb.looting.html>> (date accessed: November 6, 1999) and J.P. Kahn, "Attention Shoppers: Special Today – Iceland's DNA", online: CNN <<http://www.cnn.com/HEALTH/bioethics/9902/iceland.dna/template.html>> (date accessed: November 5, 1999) [hereinafter Kahn].

The property discourse is further reflected in commentary on the situation where the Icelandic health sector database is compared to a commercial fishing ground (Kahn). The commodification of Icelandic medical resources is of great concern to the World Medical Association (see *infra* note 129).

<sup>106</sup> It may be held that the licence does not give exclusive possession to deCode; rather the license allows access to other parties, hence deCode has not taken or does not possess the Icelandic genome. This argument is supported neither by the legislation nor by prevailing

taking.<sup>107</sup> Like standard acts of biopiracy, deCode has prospected genetic resources (both records and physical samples) that have been cultivated over centuries by the diligence of Icelandic health care workers and the tax dollars of Icelandic citizens. The link to Iceland is so strong that the collected genetic resources have even been called part of “Iceland’s national identity”.<sup>108</sup>

*ii. Without his or her consent*

Medical records used by deCode in the commercial development of the health sector database have not been obtained through informed consent.<sup>109</sup> The legislation removes the requirement for informed consent by stipulating that consent to the release of medical records is

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commentary. DeCode has the right to process the data for commercial profit and is required to exclude all other users from direct access to the database, with the exception of limited access rights retained by the Ministry of Health (see above discussion). The restriction of access has thus created monopoly rights in deCode Genetics a fact confirmed by Dr. Hartl who states “once a body for data becomes proprietary, or requires permission for access, that access is very hard or very time consuming to get.” (Dr. Hartl, Letter to B. Andersen, online: Mannvernd <[http://www.mannvernd.is/english/articles/22.10.1998\\_daniel\\_hartl-e.html](http://www.mannvernd.is/english/articles/22.10.1998_daniel_hartl-e.html)> (date accessed: October 22, 1999) [hereinafter Hartl]). The conferral of monopoly rights is further supported by Dr. M.G. McInnis (“The Assent of a Nation: Genethics and Iceland”, online: Mannvernd <<http://www.mannvernd.is/english/articles/>> (date accessed: October 30, 1999) at 1 [hereinafter McInnis]) and Berger, *supra* note 74 where the author states: “[m]uch of the growing opposition to the bill stems from the **monopoly** it clearly gives to a single company so that no other biotechnology or pharmaceutical company will have access to the data.” at 1 [emphasis added]. See also Kahn, *ibid* and B. Andersen, “The only issue is scientific advances” (online: Mannvernd <<http://www.mannvernd.is/english/news/bogi.in.response.to.wp.html>> (date accessed: October 14, 1999)).

<sup>107</sup> deCode’s CEO is also interested in pirating Iceland’s micro-organisms; he intends to start a second company to study the extremophile bacterium which can be found in Iceland’s hot springs and glaciers. This microbe is useful for chemical and food processing. (C. Loizos, “The doctor is kin”, *The Red Herring* (July 1998), online: Red Herring Magazine <<http://www.redherring.com/mag/issue56/stefansson.html>> (date accessed: November 13, 1999)).

<sup>108</sup> The connection between the medical information and the Icelandic population is so strong that one commentator stated: “Comprehensive hereditary and health care information for a whole nation, in a format in which every individual and his/her characteristics can most likely be identified! Nothing less than Iceland’s national identity is at stake!” (B. Pálsson & S. Thorgeirsson, “Decoding Developments in Iceland” (1999) 17:5 *Nature Biotechnology* 407 at 407) [hereinafter Pálsson].

<sup>109</sup> A further irregularity (in addition to lack of informed consent) is that the licensee (i.e. deCode) is “exempt from procedures to which other researchers must comply such as obtaining permission of the specially appointed independent national Bioethics Committee. Instead the Minister of Health shall issue rules for a special interdisciplinary (in-house?)

*implied* unless the patient expressly withholds consent.<sup>110</sup> Once the patient refuses to allow her medical information to be used, information entered earlier cannot be withdrawn – the refusal is not retroactive.<sup>111</sup> Hence Icelanders can neither expressly consent to the use of their medical records in the creation of the database, nor can they consent to the manner in which their genetic information will be used in research.<sup>112</sup>

The lack of informed consent is compounded by the potential for coercion of consent (or misinformed consent) since the commercial database was legislated into existence by the government.<sup>113</sup> The participation of government enhances the legitimacy and may encourage participation in the database.<sup>114</sup> People might participate solely because the creation of a database by government implies a public interest and a corresponding public benefit.<sup>115</sup>

The government asserts that the reason for dispensing with informed consent is to ensure the quality of the database, since some people might **not** consent to allowing their information to be used.<sup>116</sup>

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ethical committee to evaluate research carried out within the company as well as questions posed to the database by others. The Bioethics Committee will only be informed afterwards.”: T. Helgason, “Editorial: New Legislation on Health Database Threatens Personal Autonomy and Freedom of Research” (1999) 99 *Acta Psychiatrica Scandinavica* 313.

<sup>110</sup> Genealogies of Icelanders are public domain and genetic data is obtained from patients who consent to its use in research.

<sup>111</sup> McInnis, *supra* note 106 and B. Andersen “Hijacked Medical Records” *The Washington Post* (Saturday February 6, 1999) A20.

<sup>112</sup> Patients may have ethical concerns about the commercial applications of research based on their genetic information.

<sup>113</sup> Hartl, *supra* note 106. It is even alleged in Iceland’s major newspaper that the passage of legislation was facilitated by:

a contribution worth as much as half a million US dollars, from deCODE Genetics... It is alleged that the Independence Party accepted 20 million IS krona and the Progressive Party 17.5 million to grease the company’s momentum and especially to help the bill on the centralized health database clear the Althing [Parliament]. At the passing of the bill into law, the stocks of deCODE rose to thirty times their original price...

V. Jóhannesson, *Morgunblaðið* (November 2, 1999). Online: Mannvernd <<http://www.mannvernd.is/english/articles/>> (date accessed: October 22, 1999).

<sup>114</sup> J-P Berlan, “From Agricultural Genetics to the Looting of the Icelandic Health System”, online: <<http://www.mannvernd.is>> (date accessed November 1, 1999). [hereinafter Berlan].

<sup>115</sup> Which in this case does not exist – see discussion *infra* section 3.43.

<sup>116</sup> *Supra* note 88. As the *Notes to the Bill* state: “In the first place, it is possible to create a database of personally identified or identifiable data, which would be entered on the database

This possibility of refusal to consent should only **increase** the need for informed consent. However, the government believes that

Clearly it would cost great effort, time and money to gain consent from every individual in a data collection envisaged here. This finance could otherwise be used to ensure confidentiality and build up the dispersed database.

The government has consented to abandoning Icelanders' informed consent in the interests of increasing the value of the database. Only deCode benefits from the increased value of the database. The inherent perversion is that the government has placed the commercial interests of a private corporation over the individual human rights of its citizens.<sup>117</sup>

The protection of the right to informed consent is embodied in a vast number of international agreements and conventions. The most significant of these are the European Community Directive 95/46 on the *Protection of Individuals With Regard to the Processing of Personal Data And on the Free Movement of Such Data*,<sup>118</sup> the *Universal Declaration on the Human Genome and Human Rights*,<sup>119</sup> and the Nuremburg Code.<sup>120</sup> The government of Iceland has received a strongly

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with the consent of all the individuals in question... The disadvantage is that **participation might be less, so that the database would be of less value.**"

<sup>117</sup> Citizens also do not have the rights to know or correct their records.

<sup>118</sup> EC Directive 95/46/EC on the protection of individuals with regard to the processing of personal data and on the free movement of such data (the Official Journal of the European Communities, 23 November 1995 No L. 281 at 31). It includes the following definition of "consent" in Article 2(h): "the data subject's consent" shall mean any freely given specific and informed indication of his wishes by which the data subject signifies his agreement to personal data relating to him being processed."

Article 8 of the Directive then provides that:

1. Member States shall prohibit the processing of personal data... concerning **health** or sex life.
2. Paragraph 1 shall not apply where: (a) the data subject has given his explicit consent to the processing of those data... [emphasis added].

<sup>119</sup> *Supra* note 59. Article 5(b) states: "In all cases, the prior, free and informed consent of the person concerned shall be obtained." The declaration was adopted unanimously by the General Conference (October 21 – November 12, 1996), comprising representatives of UNESCO's 186 Member States which include Iceland.

<sup>120</sup> *Trials of War Criminals before the Nuremburg Military Tribunals under Control Council Law No. 10*, v. 2 (Washington, D.C: U.S. Government Printing Office, 1949). The Code states:

1. The voluntary consent of the human subject is absolutely essential. This means that the person involved... should be so situated to be able to exercise free power of choice, without the intervention of any

worded recommendation from the European Union and European Economic Area<sup>121</sup> (EEA) Data Protection Commissioners to:

reconsider the project in light of the fundamental principles laid down in the European Convention on Human Rights, the Council of Europe Convention 108 on Data Protection and Recommendation (97)5 on medical data, and the EC Directive 95/46 on the protection of personal data.<sup>122</sup>

However, there are no *binding* international agreements to which Iceland is a party that would compel it to require informed consent.

*iii. With intent<sup>123</sup> to deprive the owner of the value of the same*

An act of theft or biopiracy must disadvantage its victims. Icelanders have been deprived of their privacy rights by the

element of force, fraud, deceit, duress, over-reaching, or other ulterior form of constraint or coercion; and should have sufficient knowledge and comprehension of the elements of the subject matter involved as to enable him to make an understanding and enlightened decision...

Other influential documents that have embodied the requirement for informed consent are:

- *Convention on Biological Diversity* (1992), *supra* note 10 Art. 15(5) 5 “Access to genetic resources shall be subject to prior informed consent of the Contracting Party providing such resources, unless otherwise determined by that Party.”
- *Draft Declaration of the Rights of Indigenous Peoples* (1994), *supra* note 60 Arts. 12, 27 and 30.
- *U.S. Code of Federal Regulations*, Protection of Human Subjects, Title 45, Part 46 (*supra* note 45).

<sup>121</sup> “The EEA Agreement links Iceland, Norway and Liechtenstein to the EU Internal Market through the creation of the European Economic Area in which uniform rules regarding the four freedoms, competition, state-aid and public procurement apply.” (Online: European Free Trade Association <<http://www.efta.int/structure/>> (date accessed: November 28, 1999)).

<sup>122</sup> Green Group in the European Parliament, News Release “Iceland’s Parliament to Vote on Commercial Exploitation of Genetic Database.” (8 December 1998) [hereinafter Green Group]. Note however that the government believes it has adequately addressed these concerns. See *Note to the Bill*, *supra* note 88 Part II “European law and international obligations.”

<sup>123</sup> I do not specifically address the issue of intent since I believe that it plays a small role in the debate about the appropriation of the cultural and medical resources of a population. I am supported in this contention by Whitt who states:

It is important that biocolonialism not be held to turn on intent. Whether or not a specific practice is biocolonialist depends on the consequences of agency, not the agent’s intent – whether the agents in question are scientists, corporations or nations.

bioprospecting contract between deCode and the government. Both the government<sup>124</sup> and deCode<sup>125</sup> claim that they have adequately addressed privacy concerns, primarily by encrypting data one-way, creating a supervisory Data Protection Commission and imposing strict confidentiality obligations on all employees of health institutions which will handle personal data.

However, international law-making and policy bodies, scientists and specialists in the field of data protection believe that the database will violate Icelanders' privacy rights. Dr. Ross Anderson<sup>126</sup> concluded that there was a high risk of privacy violations because the database contains information about genealogy and health, is accessible to large transient populations of commercial subscribers, will be highly accessible to government and contains a large volume of information consolidated in one database. Anderson concluded that:

The measures which are proposed to limit the scope of users' enquiries, and to provide technical protection in other ways, **are not credible**. There is not even enough information about the proposed use of the database to determine whether effective protection measures are feasible.<sup>127</sup> [emphasis added]

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L.A. Whitt, "Indigenous Peoples, Intellectual Property and the New Imperial Science" (1998) 23 Oklahoma City University L. Rev. 211 at 213. [hereinafter *Imperial Science*]

<sup>124</sup> The government clearly believes that it has fully addressed all privacy concerns. In the *Notes to the Bill*, *supra* note 88, it outlines how it had commissioned a software company, Stiki ehf., to recommend a highly secure form of encryption. In addition, it has established the Data Protection Commission, has adopted the EEA definition of personal data and has encrypted the data one-way. All employees (either of health institutions or deCode) who encrypt and handle data are subject to strict confidentiality restrictions and any violations of confidentiality will be penalized. DeCode will only be allowed to transmit information that has been processed to other companies and the government has limited access to the database to ensure that "it will not be possible to pick out individuals or small groups." The government also plans to have the privacy provisions independently reviewed prior to implementation. (*Notes to the Bill*, *supra* note 88 Part III no. 2).

<sup>125</sup> DeCode states that a master list linking names and personal identifiers will be located at the company, but will only be accessible to deCode employees with a Data Protection Commissioner present. (Marshall, *supra* note 69).

<sup>126</sup> Dr. Ross J. Anderson is a world specialist in computer security and personal privacy in medical information systems at Cambridge University (Online: Ross Anderson <<http://www.cl.cam.ac.uk/users/rja14/>> (date accessed: October 30, 1999)). He was hired by the Icelandic Medical Association to review the data protection provisions of the health sector database.

<sup>127</sup> *Ibid.* Anderson's contentions were challenged unconvincingly by Hakon Gudbjartson of deCode Genetics (Online: deCode <<http://www.decode.is/>> (date accessed: November 28, 1999)).

Dr. Anderson's concerns about invasion of privacy rights have been echoed by the European Union and EEA Data Protection Commissioners (who have implied the database may violate both the European Convention on Human Rights and *Convention for the Protection of Individuals with regard to Automatic Processing of Personal Data*).<sup>128</sup> The World Medical Association<sup>129</sup> has also raised concerns about privacy violations. Within Iceland, the Icelandic Office for Human Rights<sup>130</sup> and independent scientists have also raised their voices in dissent. The scientists are concerned because Iceland has a relatively small population and families are easily identifiable.<sup>131</sup> The database will require correlation of family data – hence these families will be easily discerned due to their socially known relationship patterns.<sup>132</sup>

The right to privacy is a fundamental human right. It is enshrined in Article 12 of the *Universal Declaration of Human Rights* which states: “[n]o-one should be subjected to arbitrary interference with his privacy... Everyone has the right to the protection of the law against

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<sup>128</sup> Green Group, *supra* note 122. The *Convention for the Protection of Individuals with Regard to Automatic Processing of Personal Data*, *infra* note 136.

<sup>129</sup> N. Duncan, “World Medical Association Opposes Icelandic Gene Database” (1999) 318 *British Medical Journal* 1096 at 1096. The WMA agrees with the grounds proposed by the Iceland Medical Association for opposing the database on the following grounds:

1. Invasion of privacy
2. Breach of patient/physician trust
3. Lack of independent review mechanisms
4. Abuse of patient consent
5. Disregarding of established scientific standards
6. Use of medical records as a commodity, and
7. Creation of a centralized database of an entire population.

<sup>130</sup> The Icelandic Office for Human Rights: “1. The bill must contain a clause prohibiting that information, not necessary for the purpose of the health sector database, is included in the database.” (Excerpts from the opinion about the Health Sector Database given to Althing, the Icelandic Parliament, online: Mannvernd <[http://www.mannvernd.is/english/articles/02.12.1998\\_office\\_for\\_human\\_rights.html](http://www.mannvernd.is/english/articles/02.12.1998_office_for_human_rights.html)> (date accessed: November 2, 1999)).

<sup>131</sup> Palsson, *supra* note 108.

<sup>132</sup> J. Edwards, “Decoding Genes in Iceland” (Online: Mannvernd <<http://www.mannvernd.is/english/articles/>> (date accessed: November 4, 1999)). Professor Edwards is a biochemistry professor at Oxford University in England. Edwards outlines the implications of this information. He believes that the database will identify information about these families, whose total removal of identity would be virtually impossible if the data is to maintain its coherency, such as “disability, diagnosis and the likelihood of future disease, but could, and should, include data on infections...”



such interferences or attacks.” Binding international agreements such as the *International Covenant on Civil and Political Rights*<sup>133</sup> (ICCPR) and the *European Convention for the Protection of Human Rights and Fundamental Freedoms*<sup>134</sup> contain similar protections.<sup>135</sup> In particular, the Council of Europe *Convention for the Protection of Individuals With Regard to Automatic Processing of Personal Data*<sup>136</sup> states in its preamble that:

Considering that it is desirable to extend the safeguards for everyone’s rights and fundamental freedoms, **and in particular the right to the respect for privacy**, taking account of the increasing flow across frontiers of personal data undergoing automatic processing; [emphasis added]

Source communities are often deprived of any benefits from the resources they have provided, because the life industry does not create

<sup>133</sup> (1966), 999 U.N.T.S. 171. Iceland has ratified the ICCPR.

<sup>134</sup> (1950) E.T.S. No. 5. Iceland has ratified the *European Convention*. Article 8 states:

1. Everyone has the right to respect for his private and family life, his home and his correspondence.
2. There shall be no interference by a public authority with the exercise of this right except such as is in accordance with the law and is necessary in a democratic society in the interests of national security, public safety or the economic well-being of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others.

The European Court of Human Rights has consistently interpreted the protections broadly, while narrowly defining the restrictions. The protections of Article 8 have been expanded to encompass the acts of private persons (not just government) where it appears that government should have prohibited those actions. The Data Commissioners have concluded that the court could order the imposition of data protection laws if data were improperly processed to the detriment of the data subject (Rolv Ryssdal, *Data Protection and the European Convention on Human Rights in Council of Europe Data Protection, Human Rights and Democratic Values*, XIII Conference of the Data Commissioners 2-4 October 1991 41-43. (1992)).

<sup>135</sup> Other influential international agreements that protect the right to privacy are the *American Convention on Human Rights* (Signed Nov. 22, 1969, entered into force July 18, 1978, O.A.S. Treaty Series No. 36, at 1, O.A.S. Off. Rec. OEA/Ser. L/V/II.23 dec rev. 2.) and the *American Declaration of the Rights and Duties of Man* (O.A.S. Res XXX, adopted by the Ninth Conference of American States, 1948 OEA/Ser. L./V/I.4 Rev (1965)).

<sup>136</sup> (1981) E.T.S. No. 108 [emphasis added]. Iceland has ratified this convention.

*Article 1 – Object and purpose*

The purpose of this convention is to secure in the territory of each Party for every individual, whatever his nationality or residence, respect for his rights and fundamental freedoms, and in particular his right to privacy, with regard to automatic processing of personal data relating to him (“data protection”).

drugs that treat their diseases. In Iceland, the results obtained by deCode cannot be traced to individual Icelanders (who have funded the collection of data through their public health-care system<sup>137</sup>) since doing so would have reduced the commercial value of the database. The *Notes to the Bill* recount how the government decided to develop a non-personally identifiable database (that does not require informed consent) because it would spend less time and money, as opposed to a personally identifiable database which could be traced to individuals and provide them with health information.<sup>138</sup> However, Icelanders are still required to fund and supply the collection of their medical records, genealogies and genes.

To facilitate the theft of resources biopirates often make promises. They have, for example, promised drugs “at cost” to the population that provided plant resources;<sup>139</sup> they have also promised royalties to source communities (however, these royalties, if paid, rarely reach the actual community).<sup>140</sup> DeCode has used the same strategies in Iceland. Stefansson, the CEO of deCode, has promised that he will only license genes discovered to drugmakers if they promise to provide drugs developed from the genes free to Icelanders.<sup>141</sup> However, this is an “empty” promise;<sup>142</sup> it is not realistic if one compares the bargaining power of deCode with any transnational pharmaceutical company. There are other problems. How could one prove that a drug was based solely on the discovery of one gene?<sup>143</sup> If the drug companies use genetic information for “pharmacogenomics”, then there is no drug produced, merely a reduction in the number of clinical trials.<sup>144</sup>

<sup>137</sup> Berlan, *supra* note 114.

<sup>138</sup> *Notes to the Bill*, *supra* note 88: “The advantage [of a personally identifiable database] is that data can easily be traced to individuals if necessary for health or other reasons... a non-personally identifiable database may be built up... **The disadvantage is that it is not possible to trace individuals who might be in need of health care.**” [emphasis added].

<sup>139</sup> *Enclosures*, *supra* note 45.

<sup>140</sup> King, *supra* note 6 addresses this problem by suggesting various royalty-returning schemes.

<sup>141</sup> W.W. Gibbs, “Natural-born guinea pigs. A start-up discovers genes for tremor and psoriasis in the DNA of inbred Icelanders”, online: Scientific American. Technology and Business <<http://www.sciam.com/1998/0298issue/0298techbus3.html>> (date accessed: October 21, 1999) [hereinafter *Guinea Pigs*].

<sup>142</sup> *Ibid.*

<sup>143</sup> This problem has been discussed extensively in *Bioprospecting/Biopiracy*, *supra* note 3.

<sup>144</sup> Other considerations are what kind of restrictions will be placed on the provision of drugs (i.e. will drugs only be provided to people who can prove their information was used in

Stefansson has also “promised” that 70% of shares in deCode will be owned by Icelanders, hence Icelanders will receive indirect royalties through share dividends. However, an unspecified proportion of these shares are owned by both state-run and privately owned commercial banks and deCode plans to trade shares publicly.<sup>145</sup> If this occurs, there will be no restriction on ownership of shares; capital gains realized from increased value in shares will not even be taxed in Iceland.<sup>146</sup>

Biopiracy often robs a source community of its self-reliance by making the community dependent on expensive manufactured products (such as medicines). In Iceland, the creation of the health sector database will likely lead to an erosion of high quality research by local scientists for local problems based on specialized databases due to the diversion of public funds to maintaining deCode’s database.<sup>147</sup>

Biopiracy can also affect the identity and harmony of communities in disparate and unique ways. For example, as recognized by the Icelandic Office for Human Rights,<sup>148</sup> Icelanders are at risk of increased discrimination due to the monopoly over their medical records granted to deCode.<sup>149</sup> There is also the intangible damage done to Icelandic’s

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the database)? If deCode is not permitted to patent the gene, then how could it control access and **require** free drugs from a pharmaceutical company?

<sup>145</sup> Pálsson, *supra* note 108. Shares are not currently traded publicly as a search of the Iceland stock exchange has concluded (Online: Iceland Stock Exchange <[http://www.vi.is/vsm\\_vthi/owa/disp.birta?pk=1307](http://www.vi.is/vsm_vthi/owa/disp.birta?pk=1307)> (date accessed: November 18, 1999)) and the New York Stock Exchange (Online: NYSE <<http://www.nyse.com/international/international.html>> (date accessed: November 18, 1999)).

<sup>146</sup> The company processing the database does not even have to be an Icelandic legal entity (Act, *supra* note 76 Art. 5, no.1; see also in Principal amendments no. 3 *Notes to the Bill*, *supra* note 88). In addition, the Board of Directors who direct the operations of deCode Genetics are representatives of the venture capital interests and pharmaceutical companies: Pálsson, *supra* note 108.

<sup>147</sup> An example of this is the Cancer Registry, currently funded by the Surgeon General and the Cancer Society. Thorlacius et al. provide an example of the innovative Icelandic research conducted based on the Cancer Registry: (1998) 352 *The Lancet* 1337-39).

<sup>148</sup> *Supra* note 130. In its recommendations for improvements to the Bill, stated: “5. [A] law prohibiting the discrimination of individuals, families or groups based on health information is preferable.”

<sup>149</sup> Kahn, *supra* note 105. For example the Icelandic population could be shown to be at high risk for a particular disease due to the presence of a genetic mutation that increases the risk of acquiring that disease. However, the presence of that genetic mutation does not necessarily predispose them to that disease, rather it merely indicates that scientists discovered their particular genetic mutation first. However inferences could easily be drawn that the population was genetically predisposed to a certain disease and result in discrimination in the provision of insurance and employment.

cultural and national identity upon realization that their identity is a commodity to be traded and exploited. Furthermore, trust between doctor and patient is eroded when patients know their medical records can be commercialized without their consent.<sup>150</sup>

*iv. To appropriate it to the use or benefit of the person taking*

Bioprospectors profit from the commodities they extract by obtaining patent (monopoly) rights on the products and processes they “discover” and develop. Since corporations have monopoly rights, they are free to provide unique products and profit from those products for 17-25 years without concern for competition. Hence they are able to sell products at artificially contrived high prices. DeCode has been provided with monopoly access to medical records, genealogy and genetic data, acquired through public funds, of a population uniquely suited to genetic research. DeCode’s only substantial cost is the expense of building the database, which has been funded by Roche. The potential for financial profit is demonstrated by the dramatic increase in deCode’s share values (from \$1 per share at start-up in 1997 to \$22 per share in May of 1999<sup>151</sup>).

DeCode is also creating its own specialized database, called the Genotypes, Genealogy, Phenotypes and Resources (GGPR) collection.<sup>152</sup> Access to this database will be sold to the life industry; thus deCode has effectively created monopoly property rights over information from the health sector database, since this new database will not be subject to the licensing agreement. DeCode also plans to patent any genes that it discovers;<sup>153</sup> the acquisition of monopoly rights over those genes will lead to future profits.

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<sup>150</sup> Arnason, *supra* note 72. Also the encouragement of “genetic nationalism” within Iceland and the myth of a “pure Aryan race” to lure investors may also negatively impact the Icelandic cultural and national identity.

<sup>151</sup> Pálsson, *supra* note 108.

<sup>152</sup> Marshall, *supra* note 69. Which will be used to “identify families in which specific diseases occur, trace the inheritance of the disease over several generation, and rapidly identify the genetic basis of the disease.”

<sup>153</sup> *Guinea Pigs*, *supra* note 141.

#### IV. WHY ARE THE INTERNATIONAL COMMUNITY AND ICELAND OBLIVIOUS TO THIS CRIME?

Whereas the international community<sup>154</sup> has clearly labeled the exploitative acts of the life industry as “biopiracy”,<sup>155</sup> Icelanders have not characterized the actions of deCode as such. Nor have they labeled their government as a collaborator in this piracy. Why has this characterization not entered the debate, either in the international or Icelandic community? I believe the answer lies in the powerful legitimizing and mediating force of the “the law”, science and language.

##### 1. The powerful justification of “the law”, science and language:

The law provides the necessary validation for the actions of the government and deCode through the powerful public perception of the law as just and equitable, a protector of public interest and of the community.<sup>156</sup> The law is held to express the values of the community and mediate competing interests to reach a fair resolution.<sup>157</sup> The commonly held belief that the law will resolve a situation in the best interests of citizens and their communities has perpetuated this injustice.

The law then provides the perfect vehicle for imposing the will of the corporation and government on the population of Iceland. The law mediates and presents the acquisition of proprietary rights by deCode as the outcome of a fair, rational, just and objective decision-making process that is in the best interests of the community while obfuscating

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<sup>154</sup> I am referring here primarily to countries of the South, Indigenous Peoples and those who write and comment about biopiracy and biotechnology.

<sup>155</sup> See *Shiva, supra* note 45; *supra* note 46; B. Burrows, “How Do You Spell Patent? P-I-R-A-C-Y?” (1994) 4 *Boycott Q.* 5; E. Bryant, “Corporate Patents or Global Piracy? African Oppose Privatization of Genetic Innovations” (1994) *African Farmer* 37.

<sup>156</sup> R.A. Belliotti, “The Legacy of Marxist Jurisprudence” in D. Caudill and S. Gold, eds., *Radical Philosophy of Law: Contemporary Challenges to Mainstream Legal Theory and Practice* (New Jersey: Humanities Press, 1995) [hereinafter Belliotti]. Belliotti comments, “Apologists portray a refined legal system as that which holds a community together, facilitates the progress of civilization and redeems us from the anarchy of a Hobbesian state of nature.”: *Ibid* at 11.

<sup>157</sup> *Ibid.* at 14: “Law interprets and resolves social conflicts and relationships, mediates the potentially disruptive tensions in economic substructures and issues authoritative proclamations which purport to be the product of an objective, neutral, rational process.”

its true effect.<sup>158</sup> This “monopoly on truth”<sup>159</sup> hides the fact that the law promotes minority interests of the governing class while sacrificing the interests of the population.<sup>160</sup> Law achieves this distortion by ignoring and marginalizing dissenting discourse as anti-health and anti-progress.<sup>161</sup> The mechanism chosen by the government, the licensing scheme, is implicitly held to be the best way of mediating the relationship between deCode and Icelanders because of its adoption as “the law”. The result of this process is best explained by Belliotti, who states:

The dominant ideology is filtered through a series of legal surrogates, purified of direct contamination by the ruling class, sanctified as the outcome of eminently fair procedures, and solidified as part of society’s core commonsense normative beliefs... citizens further internalize the decrees of law, and come to accept these judgments as their own... and **are thereby less likely to vent the rage necessary for meaningful social transformation.**<sup>162</sup>

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<sup>158</sup> For example, the *Notes to the Bill*, *supra* note 88, outline how the major supervisory committee of three will consist of one representative of deCode, one representative of the government and a third member from the health profession. In spite of facial neutrality (i.e. striking the committee) the committee substantially represents the interests of deCode and government.

<sup>159</sup> R. Devlin, “The Irish Hunger Strike” (1994) 17 *Windsor Yearbook of Access to Justice* 16.

<sup>160</sup> Belliotti, *supra* note 156.

<sup>161</sup> B.A. Arrigo, “Rethinking the Language of Law, Justice, and Community: Postmodern Feminist Jurisprudence” in *supra* note 156 at 89. “This juridical imperialism is constituted through law’s claim to truth manifested in its lofty vision of itself – even more striking than exercising power in concrete effects (judgments) is its ability to disqualify other non-legal experience or knowledge, or to relegate them to second-class status.” For an example of anti-health discourse see: Andersen, *supra* note 106 quoting deCode’s CEO saying “[w]e’re not going to let people die simply because it might be abused [referring to privacy rights].”

The “public health” justification has also been criticized by scientists who believe that the centralized database will be biased since individuals with serious diseases and from higher socio-economic classes will refuse consent. Information will not be properly correlated and corrected due to the volume of information. Therefore biased information will lead to biased results which may lead to recommendations of unnecessary or harmful treatments. (E. Arnason, “A biased database hurts people”, Lecture at the meeting of Mannvernd, at the Nordic House in Reykjavik, online: Mannvernd <<http://www.mannvernd.is/english/articles/>> (date accessed: November 3, 1999)).

<sup>162</sup> Belliotti, *supra* note 156 at 14 [emphasis added].

As a result of the passivizing and manipulative effect of law, Icelanders do not perceive the acts of the government and deCode as perpetuating theft.<sup>163</sup>

The subversion of justice is aided and abetted by language. The piracy of Icelanders' genetic resources is not named as theft but rather as a "public health" initiative. According to Dale Spender:

[D]ifficulty arises when one group holds a monopoly on naming and is able to enforce its own particular bias on everyone, including those who do not share its view of the world...<sup>164</sup>

The monopoly on naming is held by the governing class, which uses the legal system to label<sup>165</sup> through legislative and governmental acts. The power of naming highlights the lack of power in those who do not possess the tools to name. As Patricia Monture has stated: "Not being in control of the process of naming – that is defining who you are – serves as one of the most express examples of silencing that I can think of."<sup>166</sup> The piracy of Icelanders' genetic resources is not named as theft since those who would brand it as such do not possess the power to name. Hence it is not perceived of as theft and so the wrong committed cannot be acknowledged and redressed.

The government of Iceland and deCode have the power to name. They have called the database a "public health" initiative,<sup>167</sup> while criticizing those who label it otherwise as thwarting the course of medical research that will save lives. The government has branded deCode's rights to the genetic information as a "license" – a term which connotes flexibility and accessibility – while providing exclusive rights

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<sup>163</sup> The class dimension of this analysis is demonstrated by the proximity of deCode to the government of Iceland. The former president of Iceland is a member of deCode's Board of Directors (Lewontin, *supra* note 63, online: <<http://www.decode.is>> (date accessed: October 23, 1999)). The confluence between the ruling class of Iceland and the corporation deCode allows conduct which would be considered criminal in a setting not involving corporations to occur without attaching culpability. (See H.J. Glasbeek, "Why Corporate Deviance is Not Treated as a Crime – the Need to Make Profits a Dirty Word" (1984) 22 *Osgoode Hall L. J.* 393).

<sup>164</sup> *Man Made Language*, 2d ed. (London: Routledge & Kegan Paul, 1985) at 164.

<sup>165</sup> M.G. Salter, "The Rule of Power in the Language of Law" (1985) 7 *The Liverpool Law Review* 33.

<sup>166</sup> "Reflecting on Flint Woman" in R. Devlin, ed., *Canadian Perspectives on Legal Theory* (Toronto: Emond Montgomery, 1991) 351 at 354.

<sup>167</sup> See both the title of the legislation (a 'health' sector database) and the objectives: "increasing knowledge in order to improve health and health services."

to a company to develop, operate and profit from the use of the database. What rights have in fact been retained by the government? Language has abstracted Icelanders' identity, thus placing it within the province of "objective" decision-making.<sup>168</sup> By referring to their history as "genetic data" and their medical history as "health data" the government has succeeded in mystifying, de-personifying and removing Icelanders' identity from its social context. Once objectified, the "data" becomes a resource that can be consumed.<sup>169</sup>

The camouflage provided by law and language is further reinforced by science. Science presents itself as value-free and unencumbered by politics. Science appears objective, neutral and always progressive; it never seeks to exploit or dominate, it merely seeks knowledge and truth.<sup>170</sup> When issues of politics are raised with respect to science they are classified as "ethical"<sup>171</sup> (or individualistic) and dismissed without addressing the underlying social and collective (ultimately political) power dynamic.<sup>172</sup> As can be seen with deCode, violations of rights to informed consent and privacy are "ethical" issues, not evidence of commercial exploitation or theft, which must be subsumed to the value-neutral and unarguably 'progressive' force of science.

International law, primarily through TRIPS and the *Biodiversity Convention*, seeks to reformulate biopiracy in a legal discourse of contracts and intellectual property rights. Language is used to mask the exploitative nature of these forms by naming contracts as "mutually agreed upon terms" and by encouraging "equitable sharing of benefits".<sup>173</sup> Biopiracy is justified as necessary in the pursuit of neutral, rational and apolitical scientific goals.

<sup>168</sup> T. Isaac, "The Power of Constitutional Language: The Case Against Using 'Aboriginal Peoples' as a Referent for First Nations" 19 Queen's L.J. 415 at 422.

<sup>169</sup> C.J. Adams, *The Sexual Politics of Meat: A Feminist-Vegetarian Critical Theory* (New York: Continuum, 1990) at 47.

<sup>170</sup> *Imperial Science*, *supra* note 123 at 215.

<sup>171</sup> According to J.P. Berlan: "Because we do not confront these questions [biopatents] *politically*, we turn to ethics" ("The Commodification of Life" (1989) 41 Monthly Rev. 26 as cited in *Imperial Science*, *supra* note 123 at 217).

<sup>172</sup> In particular Whitt refers to "an apolitical ethics of science in which issues of power in ethics are ignored, or channeled into very narrowly envisioned accounts of **informed consent** and the violation of **individual autonomy**." [emphasis added]: *Imperial Science*, *supra* note 123 at 217.

<sup>173</sup> *Biodiversity Convention*, *supra* note 10.



## V. WHAT CAN ICELANDERS DO TO PREVENT THE THEFT OF COMMUNITY RESOURCES?

Icelanders can use “the master’s tools”<sup>174</sup> – in this case, the law – to assert their rights against the theft of their community resources. Icelanders could arguably make a complaint to the European Free Trade Association Surveillance Authority,<sup>175</sup> alleging a breach of Iceland’s commitments under the EEA not to grant monopoly rights.<sup>176</sup> Individuals within Iceland could petition the Human Rights Committee of the ICCPR, alleging a breach of the Article 17 right to privacy; individuals could also petition the European Court of Human Rights alleging a breach of their privacy rights under Article 8.<sup>177</sup> In Iceland itself, physicians could refuse to complete contracts and give information to deCode, thus thwarting the efforts to create the database.<sup>178</sup>

## VI. CONCLUSIONS

The international crime of biopiracy is of late acquiring more legitimacy as the *Biodiversity Convention*, and other international legal instruments, sanction the creation of bioprospecting contracts.

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<sup>174</sup> Franklin, *supra* note 28.

<sup>175</sup> The Surveillance Authority is established to ensure that member states comply with the EEA Rules, pursuant to the Agreement between the EFTA States on the Establishment of a Surveillance Authority and a Court of Justice (Surveillance and Court Agreement). The Authority is entitled to make unannounced inspections, impose fines and periodic penalties. If there has been an infringement of EEA rules, the Authority pursuant to a decision of the Court of Justice, can order an end to the infringement (online: European Free Trade Association <<http://www.efta.int/>> (date accessed: November 28, 1999)).

<sup>176</sup> More information on the EEA rules is available online: European Free Trade Association <<http://www.efta.int/>> (date accessed: November 28, 1999).

<sup>177</sup> It is unlikely that Icelanders could receive a decision from the International Court of Justice (ICJ) since there would have to be either a contentious issue between states or the U.N. General Assembly (or one of its Specialized Agencies) would have to ask the ICJ for an Advisory Opinion.

<sup>178</sup> There are indications that this may already be happening (online: Mannvernd <<http://www.mannvernd.is>> (date accessed: October 23, 1999)).

Removing biopiracy from the unregulated regime where exploitation could at least be discerned and named to the haven of contracts is a disturbing new trend that signals the increasing legalization and legitimization of the global theft of bioresources. Once biopiracy becomes shielded by the legal legitimacy of contracts, the fact that those contracts may be exploitative and unfair becomes the responsibility of the contracting parties and not worthy of international sanction. Hence, transnational life corporations are free to use legally obtained genetic resources to “fuel” the pharmaceutical research machine.

The Icelandic situation exposes the perils of vesting in government contractual rights over genetic resources by highlighting that the interests of government may be more akin to corporations than to those of their people. As well, the flexibility of contracts allows the negotiation of any terms the government desires. The comparison of Iceland’s contract with deCode to standard exploitative bioprospecting agreements underscores the inequity of the contract. Icelanders’ rights to informed consent and privacy of medical records have been violated; these particular legislative provisions would not withstand the scrutiny of even the standard bioprospecting contract, which is regarded by many as *de facto* piracy. The government of Iceland should have included contractual provisions which governed intellectual property rights over deCode’s findings. It also ought to have either included royalty provisions contractually or included a term in the contract which would guarantee that 70% of deCode’s shareholders be Icelandic. If deCode wanted to promise free drugs to Icelanders then the government should have captured that promise in the contract. If the government of Iceland only intended to grant a license, then it should have specified precisely the type of access to which other parties would be entitled.

The debate over biopiracy should not shift focus from the core questions concerning the legitimacy of the commodification of biological resources and the value of the industries which exploit them. Currently, transnational corporations have only rights and no obligations. Transnational corporations should be accountable for the social and economic consequences of their actions. We must act to both name corporate crimes and demand accountability for the actions of corporations by using the means we possess and by forging new tools in the crucible of our indignation.