Iceland

The case of a national human genome project

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Iceland has been the site of complex and controversial events between 1996 and 1999. DeCode Genetics, a start-up genomics company, has burst on the local and global scenes with a project to map the genome of the Icelandic people as part of a larger medical database. It will do so by using a unique combination of the most advanced gene mapping strategies for locating multi-factorial diseases, clinical records dating back to 1915, and a genealogical database that seeks to locate all living Icelanders, as well as a substantial proportion of those who have ever lived, on a computerized database. Both of us are studying these developments, the expansion of the company, the construction of the database, and the public debates surrounding them in both Iceland and elsewhere. As we begin our fieldwork in Reykjavík and our observations of the global ecumene of biotechnology, the human genome industry, and the world of mass media, we have been engaged in discussions about a number of key themes and issues. What kind of anthropology is it that concerns itself with such developments? What is the relationship between this type of anthropology and ethnographic practice? Since ethical concerns, debates and conflicts are central to the object of study what is the best way to take up those issues? Is there such a thing as ethical neutrality in such cases and if so, is it desirable to adopt such a stance? If not, what does that mean for anthropological practice? We present a preliminary discussion of these issues below just at the moment that our research is beginning. We welcome our colleagues' reflections, suggestions and critiques. As with the weather in Iceland, we know that unknown and changeable conditions await us.

DeCode Genetics

DeCode Genetics Inc. was founded in 1996. The company was funded by venture capital funds coordinated in the United States. Of course, in this moment of globalizing capitalism such monies have no nationality. There is, however, an insistent desire to give money a nationality, especially by spokespeople for 'ethics', largely as a means of attributing 'responsibility' for its effects. Ethnographically, this discourse of ethics and responsibility, and a subject to whom they might be attributed, is a core component of what might be called contemporary genomic machinery. Although deCode is legally a United States company (most biotech companies in the world are given a fictitious Delaware location for legal, tax and patent advantages), it operates entirely in Iceland and has had majority Icelandic ownership from its foundation. Later on, deCode strengthened its financial position through a business arrangement with the pharmaceutical giant, Hoffmann La Roche. After nine months of national debate, in December 1998, the Icelandic Parliament passed a bill authorizing the construction of a national medical database. The licence to construct the database would be open to competition, the licensee would finance it, and the resulting database would belong to the National Health Service with the licensee retaining privileged rights to commercialize it for 12 years.

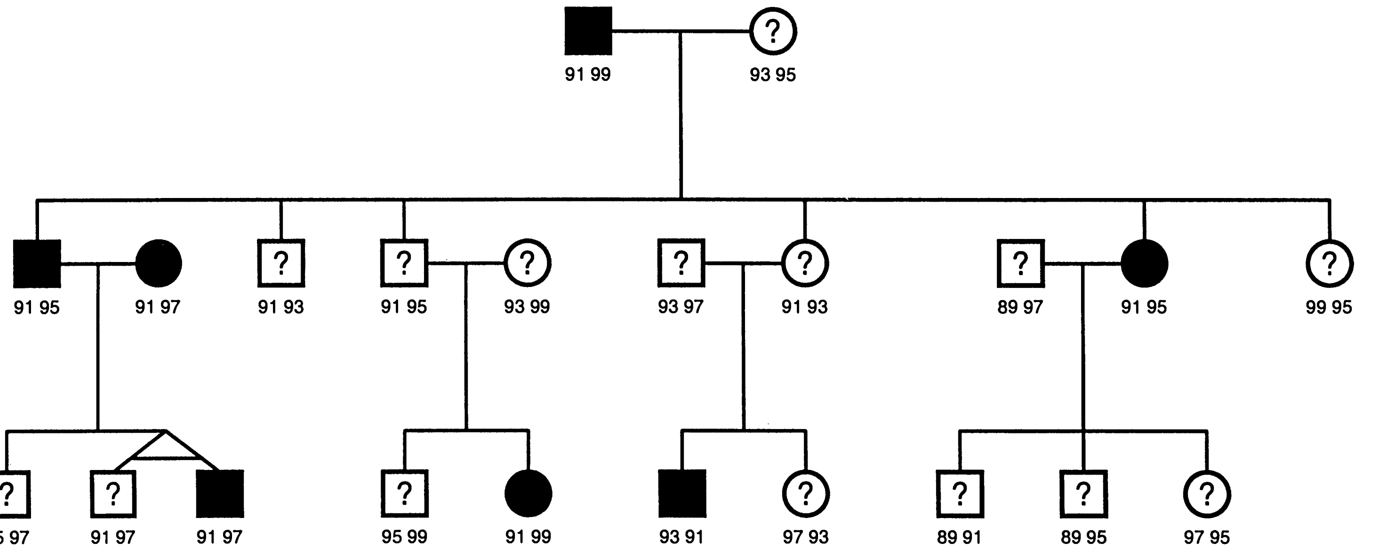
Now deCode is expected to receive the licence and the construction of the database is under way. The deCode project is plausible and scientifically promising in Iceland because the population has been small (275,000 today but 50,000 as late as the 19th century), relatively homogenous and comparatively isolated, and because Icelanders have a passion for keeping genealogical records.[1] This passion relates to many factors of anthropological interest, but unlike the Mormons who have an equally detailed devotion to family records, the motivation in the Icelandic case does not turn on religion, nor do the records cover a recently diasporic community.

As the completion of the first comprehensive and detailed genetic maps of homo sapiens approaches, it has become scientifically and culturally clear that such a 'consensus' map is only a first step.[2] Homo sapiens is diverse, and understanding that diversity is vital for many reasons, among them the fact that the role played by genetic diversity could well play an important role in understanding disease and health.

DeCode has been the focus of controversy from the start. On the international scene there has extensive coverage, in the world press and on major TV channels, of the company, its charismatic director (Kári Stefánsson), the scientific project, and the database deCode proposes to construct. This coverage has used deCode to illustrate the potential dangers and concerns as the media currently thematizes them. Understandably, Icelanders have been even more attentive. There have been some 700 newspaper articles in the press, 150 television programmes, a series of town meetings, and endless discussion and debate both within the Parliament and in the shopping centers, cafes and dinner tables of Iceland. Our institutes at Berkeley and Reykjavík have jointly established a web site – http://sunsite.berkeley.edu/biotech/iceland/ – where media material and public documents relating to the mapping of the Icelandic human genome are made available and on which a reflective and informed discussion about it can take place.

There are many dimensions to the conflicts surrounding deCode and the database. The similarities and differences in public discourse on the issues involved constitute an interesting anthropological problem in its own right. While a detailed analysis cannot be provided at this stage, a preliminary outline is essential for contextualizing the debates in question. The 'national' debates taking place in the major media around the world are clearly interlinked. It seems, however, that the concerns and the intensity of the debates vary somewhat from one place to another. Thus, the debate in the German press seems to draw some heat from earlier concerns with eugenics and racial purification. The British discourse, on the other hand, seems partly informed by rapidly growing fears of genetically modified food, 'Frankenstein food' as it has been called. And American critics tend to focus on money and humanitarian ethics.

Equally, Icelandic discourse has its own contours and trajectories which we are only beginning to map and to understand. The database has raised important concerns about ethical protection, the principle of informed consent, and the power to regulate genetic information. Thus, the Association of Icelandic Physicians claims it violates the relation of trust between physician and patient since it operates on the basis of the principle of presumed (rather



A hypothetical genealogical tree involving a complex disease with a potential genetic link. Finding the common denominator for the patients involved (indicated by solid symbols) may help to establish the genetic link and the source (in this case a male ancestor). (Image courtesy of deCode.)

than informed) consent (people can refuse to be included in the database and so far 11,500 Icelanders have withdrawn). One might add that deCode's current research efforts all operate on the basis of fully informed consent obtained through patient groups. The debate also reveals concerns about potentially dramatic changes in the practices and structures of Icelandic bioscience and medicine. Some academics have alleged that restrictions of access to information and resources implied in the privileged contract of deCode with the Icelandic state will inevitably result in the stagnation of bioscience. DeCode argues that there are no restrictions for non-commercial research, that the database will make possible much more research in Iceland and that many new positions will be created for research both within the company and at the University of Iceland. Critics further argue that the first bill issued to Parliament was premature and that the scientific community and the general public had not been properly consulted. DeCode rejoins that the second bill ratified by Parliament meets or exceeds international standards and that all the reasonable criticisms were taken into account.

Proponents of the database argue that the debate seems to come as close to being a democratically arrived at decision as we are likely to see, pointing out that there has been substantial discussion for months about the issues involved in both Parliament and in the mass media, and that the bill that finally was adopted represented a significant improvement in terms of the ethics of consent, privacy, security and research. (The act that was finally passed is available on our web site in English and Icelandic). Also, it is pointed out that a biotech company that currently employs 250 people has and will have a significant effect on the entire Icelandic scientific community, a significant proportion of whom have been obliged to leave Iceland to find employment and many of whom are now returning to work in deCode (and perhaps other such companies that may appear, as has happened with software). Those in favour of the database observe that Icelandic physicians opposing the database are partly motivated by 'professional' concerns with territorial control and that the authority of the medical establishment remains too strong. There is a significant and ironic gap, they point out, between current bioscientific and medical practices in Iceland (the practices of many of deCode's main opponents) and the types of protection of privacy and provisions for informed consent appropriately demanded for deCode.

Although the debates about deCode and its database reflect particular local concerns, perhaps the dominant outside focus has been on issues that are often elided: the fact that a private company proposes to construct a genomic map of the Icelandic people (as part of a State-owned and operated database) and to commercialize information contained in it. This strategy has been confused (with more or less good faith) with 'selling Icelandic DNA'. While such concerns with capital, national sovereignty, and property rights are evident in the tension in the Icelandic deCode debate between the political left and right, between neo-communitarians and advocates of common property arrangements, on the one hand, and, on the other, adherents of private property and the free market, the lines of political division around the database issue are neither so clear nor simple. Thus, for example, not all Icelandic physicians are on the 'left' and not all patient groups are on the 'right'.

How did we arrive at this ethnographic scene? In 1998,

1. Recent research in biological anthropology, based on DNA analysis and demographic studies, indicates that while Icelanders are more homogeneous than most other European populations they are nevertheless surprisingly heterogeneous for a small island population; see Helgason et al. 2000. On the relative importance of kinship and friendship in Iceland and the historical significance of genealogical records, see Durrenberger and Pálsson 1999.

2. The maps of the human genome produced today are called 'consensus' maps because multiple labs contribute sections to them using DNA drawn from a large number of different individuals. There is a central co-ordination of disparate sequence.

3. The collective aim of the project, which has just been launched, is to understand how and why Europeans moralize the way they do about the marketing of bodily components and biomedical information and to what extent the criteria for legitimacy differ from one population to another. The more we know about the extent and nature of cultural diversity, the better the consequences of that diversity can be reconciled in a variety of areas, including legislation, research-, and funding policy. The views expressed in this article are not necessarily representative for the project as a whole. The authors alone are responsible for any flaws and errors there may be.

the Institute of Anthropology of the University of Iceland, began a lecture series on 'The Boundary Between Nature and Society' that addresses central questions related to developments such as these, focusing on the nature/culture and body/society interface in the modern age, its theoretical and practical implications. These themes constituted a coherent extension of the on-going research at the Institute on environmental anthropology and the long standing Icelandic debate about fishing rights, the commodification of a natural resource that still constitutes most of Iceland's exports (Helgason and Pálsson 1997). The lecture series is also in line with a major comparative European project, 'Bodily Commodities: Ethical Concerns About Biotechnology and Market Exchange in Europe', organized by the Institute and coordinated by Gísli Pálsson.[3] The first speaker in the lecture series was Paul Rabinow who at this point was completing a manuscript – *French DNA, Trouble in Purgatory* (1999) – based on ethnographic fieldwork in Paris during 1995 at the leading French genome mapping laboratory, the Centre d'Etude du Polymorphisme Humain (CEPH). Earlier he published a book about a Nobel Prize winning invention made at one of the original start-up companies in California (Rabinow 1996a), as well as a collection of more theoretical writings on power and knowledge (1996b). Rabinow delivered his public lecture in Reykjavík in October 1998. During his stay in Reykjavík, he and Pálsson discussed the idea of an international project on deCode and the medical database. Such a collaboration moved rapidly from an idea to a reality over the next six months.

Together and separately we have conducted extensive interviews with some of the key players in the Icelandic debate about deCode and the database. In the meantime, the Institute of Anthropology in Reykjavík has been compiling a comprehensive archive of the local and international press as well as official documents relating to deCode and the database. DeCode genetics, it is an understatement to say, is a 'phenomenon' of local and global interest. The simple fact that a whole population will be genetically mapped, that a start-up company from a tiny country should become a world class scientific and business competitor in two years, that an entirely literate, relatively homogeneous, group of citizens would debate such an issue and come to a decision (with whatever shortcomings any democratic decision may inherently contain) surely is of general significance. It follows that it should be of anthropological interest. In fact the deCode case and the ethnographic study of it provide an apt opportunity to address fundamental questions about anthropological representation, ethics and practice.

Anthropology reborn yet again?

Today is hardly the first time that anthropology has been confronted with the need to re-invent its subject matter, its methods, its ethics. Such critical examination, and the crises it provokes at times, has been a recurrent event within anthropology. A decade or two after decolonization of the major European powers, anthropology (the 'child of colonialism' as it was later dubbed) was subject to intense criticism because of its presumed preoccupation with isolated, timeless tribal societies. Anthropology, some of the critics argued, was a discipline fatefully shaped by the forces of the past and the power of the dominant. Peter Worsley, in a far-sighted article in 1966 entitled 'The end of anthropology?', questioned whether anthropology had any future at all. In his reasoning, with the dissolution of the colonial regime and the political independence of 'third world' countries, the context of most anthropological field research at the time, the discipline was fated to wither away. Decolonization meant there was no longer an ethnographic object, an Other to be perused by detached and distant observers; there was no longer a fundamental division between the West and 'the rest'. In short, anthropology had become obsolete.

History proved Worsley to be both right and wrong. He was right that the then standard ethnographic practice was increasingly archaic. The post-colonial critique of anthropology gained important momentum with the publication of a well-known collection of essays edited by Talal Asad (1973). Worsley was wrong, on the other hand, in seeing this condition as inevitably leading to the end of the discipline. Unexpectedly, ethnography and anthropology have been thriving during the last quarter of a century in many places, while some social sciences, especially sociology, have experienced a prolonged disciplinary crisis. The reasons for this are not quite clear. It may be the case that anthropology has been allowed to slip into the intellectual vacuum left by sociology because of the latter's loss of prestige. Whatever the institutional survival mechanisms, the vigour of anthropology is underlined by the fact that Worsley himself has continued to write important works many of which would properly count as anthropological (see, for example Worsley 1997).

Equally in 1966, another and perhaps more comprehensive challenge was posed to anthropology, a challenge that somewhat surprisingly has great force today. Michel Foucault attempted to demonstrate in *The Order of Things* that the very figure of 'Man' was a historically situated discursive invention less than two hundred years old, not a millennial fact that anthropology simply took up as its object of study. Foucault famously concluded his book by wondering:

> If those arrangements were to disappear as they appeared, if some event of which we can at the moment do no more than sense the possibility – without knowing either what its form will be or what it promises – were to cause them to crumble, as the ground of Classical thought did, at the end of the eighteenth century, then one can certainly wager that man would be erased, like a face drawn in sand at the edge of the sea (1970: 370).

Given that Foucault defined 'Man' as the place where the discourses of Life, Labour and Language intersect, one must conclude that he too was premature in his death announcement. Some have seen the ongoing developments in biotechnology (as well as globalizing capitalism and informatics) as ominous, perhaps heralding a second and more fundamental end of anthropology, in its destructive effect upon humanity and nature. The problem is pertinent: *Does current uncertainty about what constitutes life, a species, the human etc., undermine the relevance of the discipline? Or will the growing anxieties surrounding these matters make anthropology even more vital and central than ever before?*

We think these questions are linked and make possible a creative new tension between ethnography and anthropology. As ethnographers, we must invent ways of describing the emergent practices and discourses of the life sciences and their associated institutions. As anthropologists, we must reflect on and question the meaning and implications of these practices. We already see ample evidence that ethnography is thriving. The extensive work on reproductive technology shows the theoretical and practical relevance of fine-grained ethnographic work (see, for example, Strathern 1992). We are hopeful that anthropology can take a central place in thinking through what it means to be human today.

In recent years, humans have been confronted (as a result of their own activities) with a nature very different from that experienced by previous generations. For one thing, biotechnology has revolutionized the capacity for altering DNA material, raising new and fundamental 'anthropological' questions. Although anthropologists have argued for a long time that the human body and nature are inextricably social (Descola and Pálsson 1996), it is a cliché today to say that a new power to modify them is with us and that they are increasingly commodified and subject to market exchange. Clichés are often substantially true but never entirely adequate. One needs to get close to the things themselves and see what is happening before making grander and grander pronouncements about the future. After all, venture capitalists and many of their political opponents are both engaged in hyping projected futures, be they glorious or horrific. Anthropology's challenge is to take such representations of the future as social facts that circulate and produce effects. Following the work of Niklas Luhmann (1998), one might say that the future is constantly being decided today.

In this light, it is quite appropriate to explore such issues in the Icelandic context. Let us take up a recent example of the politics and ethics of representation to illustrate some of the pitfalls of skirting basic ethnographic work while rushing to draw global conclusions. An example is what happens even to as distinguished and theoretically sophisticated a critic of overextended claims of genetic determinism as Professor Richard Lewontin, a population geneticist at Harvard. Early this year (23 January), Lewontin published an opinion piece, 'People are not commodities', in the New York Times condemning the decision of the Icelandic Parliament last December to construct a centralized medical database. There Lewontin asserts that Icelanders have been misinformed about the fundamental issues involved and that they fail to realize what is best for them. The sidebar of his incendiary piece reads 'A setback for informed consent in health research'.

No one is proposing a return of slavery and this trope is deployed for its rhetorical shock value. More substantively, some nine months of public debate preceded the vote. And much of this coverage was thorough and critical and a strong physician- and biology-based lobby remained passionately opposed. Lewontin's characterization of the vote in Parliament as 'narrowly passed' is aberrant – the vote was 37 to 20 with 6 abstentions. A series of opinion polls, both formal and informal, indicate that the general support for the bill is even higher. This decision was clearly the product of informed democratic consent, whatever one may think of the substance of the bill. If one then wants to question the appropriateness of democratic procedures for such matters, as some of the bill's opponents do, that is another matter. Such a critique of democracy would, of course, necessitate accepting a subject position of technocratic authority or humanitarian universalism that are themselves the topics of lively critique.

It is important to keep in mind, as already mentioned, that there have been two different versions of the bill presented to Parliament, the first in March 1998 and a second extensively revised version passed in December 1998. Unfortunately, Lewontin relied on an outdated bill (the later version was available to him on the web). There was heated debate and criticism within and outside Parliament, especially over the protection of individual records. Changes were introduced to the first version so as to bring it up to and even beyond the European Union's strict standards. It should be underlined that these standards far surpass those currently in place for Icelandic physicians and medical researchers today. This point is often neglected by critics. It certainly does not mean that such standards should not be in place, only that they should apply generally. In sum, the medical database legislation places Iceland at the high edge of a world curve of standards. Furthermore, in addition to specifying criminal penalties for anyone who violates a patient's privacy, there is a clause in the bill specifying that the licensee stands to lose its licence if it violated those provisions of the bill concerned with privacy.

There is of course a stricter sense of 'informed consent'. Iceland has a national health care system that covers all Icelandic citizens. Hence the risks to the people in Iceland of such a project are rather different than they would be in other places such as the United States where such basic protections are lacking. It is worth noting that in Iceland, as in many other countries, patient groups are very strongly in support of genomics projects. It may be that their hopes for what genomics can bring in terms of short-term therapeutic advance are unrealistic, but they certainly are informed by any reasonable definition of the term. Perhaps Icelanders' hopes have been driven by an over generous faith in the grand narratives of science.

Lewontin and British novelist Simon Mawer's companion piece in the New York Times, 'Iceland, the Nation of Clones', are both troubling examples of what we anthropologists have come to call 'Orientalism'. Edward Said argued that one of the mainstays of Western imperialism was its ability to represent the other in a manner that fixed stereotypes of some essential inferiority (and depravity) and denied the rest of the world the right to (or at times, the ability for) rational discourse and self-representation. Although Said's original use of the term has been criticized as being too categorical, it does provide conceptual help in highlighting certain representational practices. Thus, Lewontin heaps scorn on the corruption of Mexico and Indonesia; he expresses his shock that 'a northern European' nation has been duped by a capitalist plot that he can see through 'even from thousands of miles away' at Harvard. Three paragraphs later Lewontin proclaims Iceland 'does begin to sound like Mexico'. Actually it begins to sound like Cambridge, Massachusetts, and the ever-growing number of biotech companies and governmental reform missions, that Harvard and MIT professors are associated with. It also sounds exactly like Orientalism. Disdain for democracy and deploying contemptuous representations of other people is bad politics, bad ethics and contributes to the corruption of truth. Unlikely as it may appear to them, even powerful Americans profiting from their positions at world centres of prestige and power might have something to learn from those 'thousands of miles away'. If people are not commodities, as Lewontin maintains, why treat them as if they were, assuming that they are mere pawns in the games of self-interested investors and (other) prestigious professors? Lewontin's piece is a small example of how moralism and ethnocentrism can blind.

One of the central contributions of anthropology to such issues is to explore how and why people moralize and why the responses may differ from one context to another, to provide a comparative understanding of what may be referred to as the 'moral landscapes of modernist regimes' (Helgason and Pálsson 1997).

Moral landscapes

Recent developments in biotechnology have opened up an entirely new biological and cultural world in which a multitude of different kinds of bodily components, such as blood, genes, gametes, enzymes, tissues and organs, can be isolated and produced for medical and scientific purposes. These developments have taken place in a social environment where the partnership of science and the market is considered to be the most efficient means of advancing knowledge and human wellbeing. As a result,

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newly identified bodily components are quickly absorbed into the market place where they are exchanged in the form of commodities. To further the search for genetic diseases, radically new kinds of commodities are being created: genealogies, medical records, and genetic characteristics of individuals and entire populations. Such commodities are considered to provide the impetus for the rapid progress of scientific knowledge and competitive industry. The partnership of the market and biotechnology is seen to herald a fascinating new era in which humans are finally able to crack the code of life and cure every conceivable disease at minimum cost.

These are transnational developments occurring at an exponential rate. However, they exhibit considerable cultural diversity. Within Europe, for instance, attitudes towards the human body and its marketing vary widely and for a variety of reasons. These differences can be observed at different levels, nationally, ethnically, and locally, as well as internationally. One point of difference is the extent to which it is morally 'right' or 'permissible' to remove, reproduce, and market as commodities the components of the human body as well as information about them. Although in each and every context, a clear distinction is made between the permissible and unethical, the line separating the two seems to vary from one context to another. A comparative research on people's responses to the development of biotechnology and the moral landscape which they constitute provides a better understanding of the market and the economic system in question as well as the options available for informing decisions and regulating production and consumption.

Contemporary anthropology consistently finds itself confronted with complex moral landscapes of this kind. As we think more about ethics and morality as social facts it leads us to reformulate some of the classical principles of anthropological ethics. Traditionally anthropologists have prided themselves on suspending ethical judgement until late in (or after) fieldwork: ideally, anthropologists have attempted to 'get it right' before passing judgement on others' practices (a moment that often never arrived). When anthropology was most concerned with combating ethnocentrism, it seemed to be necessary to avoid any premature judgment in advance. Such neutrality, informed by a profound ethical premise of the worth of all cultures, has been held to be necessary to carry out fieldwork at all. And surely we need to be reasonably open to the exotic and the unknown; if we think we know all the answers in advance, what would be the point in doing fieldwork? Imagine a Euro-American fieldworker in, say, the Highlands of New Guinea who publicly proclaims on arrival in broken Tok Pisin that she can't stand atheism, witchcraft, shamans, premarital sex, ancestor worship ... and the rest of it!

Many things have happened in world anthropology in the last several decades. To refer to *Writing Culture* (Clifford and Marcus 1986) as one locus of discussion, it seems clear that the idea of separate cultures with clear and distinct boundaries is not one that many anthropologists would defend. With its demise, the place for the anthropologist as an outside observer scientifically analysing the 'other' has also come under intense scrutiny. It follows that the assumption of a universal ethical system based on tolerance has, at the very least, taken new political and epistemological turns. This short piece is not the place to analyse such changes and most readers will themselves be actively engaged in working through these changes in their own work and lives. The demise of the 'island culture' concept and its associated ethnographic practice is nowhere more pertinent than in Iceland (Pálsson 1996). Although exoticizing images of Iceland certainly proliferate (as its tourism grows and as busy experts judge it 'from thousands of miles away'), as in so many other places around the world, the macro-forces of capitalism, of science, of technology, of communication and information technologies, are found on every street corner and in every home in Iceland. Iceland has a thriving music industry as well as software companies. And now it has deCode Genetics as well.

Anthropology is confronted with a twin challenge today: First, how to study the social and cultural formations arising from the intersections of new biosciences, new forms of representation, and an extremely fluid system of global capital. Secondly, the fracturing of anthropology (the weakening of the 'four-field' approach in North America and the persistence of the dualistic structure of European anthropology) will be overcome only when social anthropologists learn more biology as our richer and more powerful colleagues have urged us to do. However, the converse is even more compelling: molecularly inclined anthropologists must accept the fact that social biology (with its social Darwinist underpinnings and discourse) is more appropriate to the 19th century than the 21st where nature and its inequalities will be social ones as much as they are natural. Both camps must come to see that in order to understand the knowledge they are producing they must themselves become more fully anthropological in the broadest sense of the term. Such a vision is neither nostalgic nor utopian. We can already find examples of such synthesis in the study of medical anthropology (Lindenbaum and Lock 1993) and environmental anthropology (Ingold 2000). We are convinced that the time is ripe for a molecular anthropology that includes scientific, technological, political, cultural and ethical dimensions.

The problem facing anthropologists about to embark on a study of deCode and similar phenomena in the contemporary world is how to situate themselves in this work. George Marcus has recently argued (1998) that anthropologists are moving from a relationship of 'rapport' with their informants to one of 'complicity'. Complicity is an ethically and epistemologically much more complex term than rapport and one that no doubt many anthropologists will feel less immediately comfortable with. But the old tropes of rapport associated with earlier relations of ethnographic production are now too closely tied to a colonial context that often facilitated it but was too infrequently analysed, to a presumed psychological relationship in which only one member spoke and wrote, to a view of two cultures facing each other across a clear divide. Complicity blurs and complicates these niceties even if it does not entirely eliminate them. To even have access to the kind of work we are proposing one must confront a set of questions and queries posed by informed, literate and demanding interlocutors. How does one begin with the 'native's point of view' in such situations? Or are we ready to abandon this imperative? Or only apply it when we are dealing with the dominated of the world? We are not proposing that complicity become the master trope of an anthropology of the modern world. We will most certainly need a range of such terms adequate to a range of different types of relationships that will be forged. In sum, we will need a new anthropological imaginary as well as politics, epistemology and ethics.□

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