(Re)presenting Human Population Database Projects: virtually designing and siting biomedical informatics ventures

[case studies: * Iceland Health Sector Database * Gene Trust ™ * BioBank UK]

Pei P. Koay

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Richard M. Burian, Committee Chair
Timothy W. Luke
Saul E. Halfon
Megan M. Boler
Ann F. La Berge

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Blacksburg, Virginia

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ABSTRACT

This dissertation examines the politics of representation in biotechnosciences. Through web representations, I examine three emerging endeavors that propose to create large-scale human population genomic databases to study complex, common diseases and conditions. These projects were initiated in different nations (US, UK, and Iceland), created under different institutional configurations, and are at various stages of development. The websites, which are media technologies do not simply reflect and promote these endeavors. Rather, they help shape these database projects in which the science is uncertain and the technologies not yet built. Thus, they are constitutive technologies that affect the construction of these database projects.

More needs to be done to explore how to interpret the 'virtual' realm and how it relates to the 'real' world and specific situations. By bringing hypertextuality into the analysis, I explore how knowledges, practices, and subjectivities are created. By adapting the methods of a number of science and technology (STS) authors, I develop a more dynamic lens in which to investigate web representations and 'emerging' biomedical projects. My concern however, is not only in what represents what, but how representations are constructed. The power of the latter derives from its invisibility.

In re-conceptualizing representation and new media technologies, I show that these sites are techno-social spaces for creating knowledge, specific ways of seeing, and practicing biomedicine today. The narrowing time/space between generating data, releasing information, and incorporating publics into their endeavors raises crucial issues as to how biomedicine is represented and how broader audiences are engaged.

In the dominant discourses, these projects are all situated within biomedical, (post)genomic, and information revolutions. Here, they hang on the technological object, the database, with the ability to contain what we are coming to understand as life/genetic/bio information. Through the moves of both treating these databases as part of a complex system and investigating them through a lens of representation, I begin to include potential participants and broader audiences into the analysis. Informatic bodies, populations, and subjects are co-created at, by, and through these sites as the developing database projects and information are (re)presented.

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A dissertation is a group effort, but all shortcomings of this project remain mine alone.

PREFACE

I continue to be fascinated by the world wide web. I remember when my world was internet free, although my memory rapidly fades. I remember entering the graduate student room at Victoria College in the University of Toronto sometime in 1995, where a friend was so excited to show me something called MOSAIC (what turned out to be the precursor of Netscape). I thought, 'That's nice.' At the time, I was working on my master's thesis on a history of organ transplantation in the United States. I was interested in the history of the body and medicine. The internet was another – a (n)ether- world to me. Little did I know that this, or similar interfaces, would mediate so much of my life, less than two years later.

Today, I likely spend more time on the web than 'anywhere' else. My time spent 'there' has only increased since arriving at Virginia Tech in the fall of 1999. Prior to this, living in the East Village in New York, I found myself drawn more to other worlds. But in Blacksburg, Virginia, my life online proved fruitful in the sense that it spawned my interest in bioinformatics, an interface of computers, biology, genes, and information technosciences. I became and continue to be fascinated by efforts to create technosciences of the body, but here with 'collecting, storing, and manipulating information.'

My interest in these human genomic database projects arose from the *promise* by its promoters, specifically the promise of personalized, individualized, *and* preventive medicine and health care. In this same breath, the advocates invoke the notions of the revolutionary and uncertain sciences and technologies as well as public acceptance and involvement needed to make this promise come true. What drives my study is a desire to make some sense of how the co-construction of objects and subjects works in these endeavors while concurrently invoking and deferring this promise. What makes these projects work – in the sense of being developed – now?

Scholarly works investigating the life sciences and the evolution of the body have primarily focused on genetic metaphors even in the invocations of information. A number have been devoted to the metaphors of text, for example, DNA as the 'book of life.' Others have studied the metaphor of maps and blueprints. In addition, a number of other studies have focused on the technologies of genetic engineering. Recently, others have focused on computer technologies. In this project, I highlight a media/ communicating/ representing

technology, the internet, especially its web aspects. However, I also wanted to bring into focus the absent subjects (potential participants and large publics) into the analysis.

As I dove into the cases I examine here, the *potential* participants (as individuals, specific populations, and broader publics) continued to emerge. In a speech at the Institute of Human Genetics, Alan Milburn, the Secretary of State for Health in the United Kingdom, stated that in order for Britain to succeed in the world of genetic medicine, "We need to secure public approval for progress…."[1] The necessity of public involvement is emphasized by the advocates of genetic medicine, especially of the sorts of projects that I study here. Specifically, in this dissertation, the *references* to potential participants drove me to become concerned with the relations and associations created, emerging, and invoked between technological objects and subjects, between information and bodies. Who were these participants, individuals, and populations?

The three endeavors that I study are all emerging, public biomedical informatics technoscientific endeavors. However, all are in different stages of development. A multiple case approach permits me to highlight the specificity of each project, but not necessarily the aspects that its promoters hope to highlight. These projects have not been uncontroversial. Not altogether surprising in that they constitute emerging, developing and uncertain, biomedical technosciences. However, this is true only in some respects. Promoters, investigators, and media have also been keen to highlight the differences in these projects, but here in my investigation, differences and similarities were deployed to help sponsors' (re)present their endeavors to broader audiences and potential participants. These representations focus on the construction of physical databases, the issue of consent in collection practices, and the use of information.

In the case of bioinformatics and genomics, histories of these emergent forms of science and technology are in some sense speeding past us. What do I mean by this? We are all aware of the industry of popular science books and media stories about the future of genomic medicine and life science research. However, these types of stories also occur in scientific and technical literature as well as business and investor reports and in policy circles.

[1] This speech was given at the International Centre for Life, in Newcastle-upon-Tyne, Britain on April 19, 2001 to launch and welcome this new Institute of Human Genetics and to highlight the achievements and future of Britain's genetic services to its population. A transcript of the speech can be found at the UK's Department of Health website <<http://www.doh.gov.uk>>.

The international Human Genome Project, or rather projects, is/are described as the big science of the twentieth century both in popular and scientific/ technical literature, laying the foundation for future biomedicine but emerging from past scientific and technological achievements in molecular genetics. Genomics is called the science of the late twentieth century, and post-genomics the science of the new millennium. Histories, current events, trends, and prospects collapse into the (re)presentation of 'genomic medicine' (individualized, personalized, and preventive medicine) and materialize in human genomic databases. These projects bring together individuals, populations, genes, environment, sciences, technologies, popular science, culture, promises and fears. Their dominant narratives, though, have been restricted to a story of the rapid growth of information technologies in the 1980s that finally permitted the theoretical aspects of population genomics to be borne out.

The historian of science, Kurt Danziger gives the example of how certain aspects of psychology's history are chosen when history focuses on specific individuals or specific events.[2] If we follow the narrative (above) of large-scale database projects, that is, as primarily the handmaidens of molecular biology, we arrive at this certain reality and coherence of these endeavors.

In this project, I use virtual representations, concerned with the web sites and invocations in, by, and through them of these endeavors, information, and participants. Focusing on the web presence of these projects, I illustrate that they are productive and increasingly important sites of investigation to explore interfaces, collaborations, and competition of varied investments and investors in bioinformatic projects. Information technology has generally been viewed in the genetic research realms as a medium, a communication or representing technology, for scientific work. Here, I suggest that a more complex frame around representing technologies is needed in studies in the biomedical life sciences today. Further, this project takes seriously the spatialization (space and time dimensions) of the web. The web aspects highlight the need to rethink the conventional categories – public/private, science/technology, and virtual/real – that have been used to frame these projects. I highlight the employment and deployment of these categories, not only in the language of promoters of the projects, but (re)produced in web practices.

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[2] Kurt Danziger, *Constructing the Subject: Historical Origins of Psychological Research*, New York: Cambridge University Press, 1990.

However, if we begin on less certain material grounds – in cyberspace, we may locate the dis/connections, the fragmentations, and anxieties of such schemes. The inevitability of these projects does not emerge. Rather, I highlight the hard work involved to create and maintain the coherences of the projects. We will be able to draw attention to narratives about what these particular biomedical informatics life sciences are practicing today and where we are imagined to take our place in, by, and through them. Rather than merely imagining or watching these machinations, I hope to suggest that we might find ways to intervene. I hope to suggest that we might create and actively participate in representing ourselves and our world(s) in more varied imaginations of life, health, and futures. Here, I do this by disturbing the dominant narrative by approaching my analyses of these endeavors through another lens.

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The Human Genome Project (also known by its initials HGP), an 'international' effort to sequence the human genome, is often mobilized in efforts to explain the future of medicine to broader publics. The international human genome is an aggregate sequence map of several human genomes and is sometimes presented as the blueprint for human life. Scientists tell us that there is very little variation from one human genome to another. The fact that the international HGP's human genome is composed of several genomes, instead of one, contributes to its symbolic appeal as representative of the universal human. However, while there is little variation in human genomes, there are variations nonetheless. Proponents of genomic medicine argue that the sequence variations in groups and individuals are the keys to rational, predictive, and/or personalized medicine.

The search for variations and the quest for rational medicine entail population-based approaches and the creation of large-scale human genomic population databases.[1] Through these projects, comprehensive information and biological material from individuals and populations are collected and stored in data– and bio–banks. Even though the Human Genome Project has become a defining international symbol of life and medical sciences research today, other emerging human genome database projects are important sites to engage.[2] There are enormous efforts to establish such databases even though the research of genomics is still highly experimental and its technologies underdeveloped.

While the 'universal' human genome may seem abstract, population database projects aim to represent and bring genomics into individuals' homes. These large-scale database projects are public science. Like the HGP, they, too, are made of assemblages and networks of private and public institutions and various sectors ranging from biotech, pharmaceuticals, managed care, media, computer, and information technologies and governmental agencies and organizations. However, sponsors of genomic database research aim to further identify their projects with citizens, (nation)-states, patients, individuals, and

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[1] See the special theme issue 'Human Genomics/Genetics,' *JAMA* (Journal of the American Medical Association,' eds. Jeanette M. Smith, et al., (November 14, 2001).

[2] For its international significance see for example, the document "Universal Declaration on the Human Genome and Human Rights." An online version can be found at UNESCO's website <<http://www.unesco.org/human_rights/hrbc.htm>>.

families. While the science and the technologies are highly technical and complex, broader publics are to play some role(s) in the efforts.

Figure 1 [from Aravinda Chakravarti, Figure 1 "Single nucleotide polymorphisms: to a future of genetic medicine," *Nature* 409 (February 2001): 822-3, online http://www.nature.com/cgi-taf/DynaPage.taf?file=/nature/journal/v409/n6822/full/409822a0_fs.html]

The idea that sequence and/or genetic information is bringing about a transformation of the dominant paradigm of biomedicine can be experienced online in the United States' Department of Energy's website devoted to the HGP.[3] At the beginning of the new millennium, sequence drafts of the human genome were announced, one public, one private.[4] Simultaneously, government officers, corporate executives, renowned scientists, and the media, also announced to the 'world' that a revolution in medicine was happening, heralded as a new dawning of 'genomic' or 'post-genomic' medicine.[5] Sequencing genomes – non-human and human – would accelerate biomedical research, by "allowing researchers to attack problems in a comprehensive and unbiased fashion."[6] Diseases would be understood by their causes not their symptoms.

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[3] DOE's Human Genome Project website can be found through the following address: <<http://www.ornl.gov/TechResources/Human_Genome/home.html>> [last accessed April 20, 2003].

[4] See the special issues on the human genome, *Science* 29: 5507(February 16, 2001) and *Nature* 409 (February 15, 2001) for the private and public versions, respectively.

[5] See Svante Pääbo, "The Human Genome and Our View of Ourselves," *Science* 29: 5507(February 16, 2001): 1219-20, Leena Peltonen and Victor A. McKusick, "Dissecting Human Disease in the Postgenomic Era," *Science* 29: 5507(February 16, 2001): 1224-29, and James M. Jeffords and Tom Daschle, "Political Issues in the Genome Era," *Science* 29: 5507(February 16, 2001): 1249-51.

[6] International Human Genome Sequencing Consortium, "Initial Sequencing and analysis of the human genome," *Nature* 409 (February 15, 2001): 860.

Data– and database–driven medicines, healthcare, and lifestyle management would be based on more precise scientific and rational judgment.[7] Here, this so-called 'revolution in medicine' is associated with a number of high tech, high-profile scientific achievements from the creation of genome chips, databases, and supercomputers, mapping of the human genome, and the infrastructure for an information superhighway. The mediation of life through (genomic) databases works to sustain a more precise, more pure, more unbiased representation of disease, life, and reality.

Like those who currently represent the international Human Genome Project, the sponsors and partners of these large-scale human population database endeavors are increasingly in the position to shape understandings, practices, and uses of life, health, and disease. They too work to sustain and extend these supposedly more precise and unbiased representations of life, disease, and wellness into the everyday.

In this dissertation, I show that the work done to represent genomic population database projects to broader publics is constitutive of sponsors' aims to *establish* these endeavors. Genomic database sciences are in the making. Here, I will show that their websites are rich opportunities for analyses of the work in action. Like the online resources for the international human genome projects provided by the National Institutes and Health and the Department of Energy in the United States and the consumer resources for health and medical information such as WebMD or the Mayo Clinic, the virtual sites of the database projects that I examine in this dissertation illustrate attempts to (re)define life, health, wellness, disease, and genomic medicine. Specifically, they work to (re)present the databases, the populations they use as their sources, the potential participants, and recipients, and the meanings and uses of genetic information. These all come into play in the database projects' websites. Further, they do this in extremely singular ways that are specific to their 'virtual' and 'real' sites and their specific databases.

These virtual representations have their own ways of producing practices and ways of seeing that are enrolled in representing these bioinformatics endeavors and in defining their objects and subjects. These ways have to do with how representations of various objects and subjects relate to one another. These in turn have to do with how potential

[7] See John Bell, "The new genetics in clinical practice," *BMJ* (British Medical Journal) 316 (February 21, 1998): 618-20.

visitors are envisioned, how they are envisioned to relate to information, and how they are envisioned to understand what it means to use the world wide web in these endeavors.

These virtual spaces are increasingly important ones, where what is valuable information and/or knowledge about life and health are constructed. The websites of the sponsors are representations of these informatic endeavors, but they are also more than this. They are social technoscientific spaces in which meanings, concepts, and practices for genomics are made. In these sites, technnoscientific objects and subjects are co-produced. (Re)presentations of the databases, populations, participants, disease, life, and genetic information are negotiated and constructed.

I position this project within the literature of politics of science, located specifically within the science and technology studies field. My approach maintains that representations of science are politics by other means.[8] Through this approach, it is acknowledged that normative and ethical aspects are constitutive, that is, they are integral components of any representation of science. Subsequently, this means even bioinformatic sciences – driven by data and/or quantitative schemes. Databases themselves are representational technologies. There is then a double notion of representation at play in this dissertation that I will discuss further below (see Sec 1.5).

Other spaces of representation could have been observed, but my approach to these biomedical informatic projects is to ask us to accept these virtual spaces as rich opportunities for engaging a currently emerging, yet increasingly highlighted mode of representation that is still little understood. Further, these are spaces that can have more normative effects on their visitors than any textbook on medical genomics. However, websites, unlike a physical book, are ephemeral, but a fact that can add to their power rather than diminish it. Therefore, what is also acknowledged in this project is that the websites (that is, specific spaces of representations) have their own normative effects.

1.2 > Matters of (re)presentation

This is a study about the ways in which bioinformatics, in particular, genomic biomedicine is currently being made. It is an analysis of some mechanisms through which

[8] See Bruno Latour, *We have never been modern*, Cambridge: MA: Harvard University Press, 1993.

(large-scale human genomic databases/genomic medical research) work to establish their place in the life sciences today. My project explores how the representations of bioinformatics interact with and shapes its objects and subjects. Unlike other analyses of representations of emerging technoscientific endeavors, mine does not speak to the politics of the future or regulations for the construction of these databases. Instead, this study tells how these projects, at, by, and through their representational acts, are done today.

Specifically, it examines the character of website representations of a growing area of biomedical technoscientific projects to understand how and to what extent the web contributes to these endeavors. My study contributes to informing the discussion of representations of emerging technosciences, disturbing the supposed transparency between those engaged in creating such projects and the public.

Current discussions either take for granted that the rapidly increasing quantity and availability of information (particularly with the world wide web) bring about more transparency of these biomedical projects, both public and private, or are uncritical in this area. *These websites work as important technosocial spaces through which concepts and practices are created, produced, and negotiated in attempts to establish what may or may not constitute acceptable explanations for moving forward with their projects.*

My argument is not that people 'believe' the websites'/initiators' claims about the endeavors. It is not a cause/effect analysis that attempts to answer how many actually believe or how many are persuaded to volunteer because they viewed the virtual sites. Furthermore, my argument does not attempt to get at what the initiators' *really* mean. Rather, it is an attempt to explore issues of representation (especially representations of the medical life sciences) and specific aspects of electronic media technologies.

In the cases I examine here, individuals and/or populations are solicited and enrolled as sources of information, prior to the establishment of significant manifest evidence for the effectiveness of genomic medicine as individualized medicine. The initiators needed neither a/the material technology nor the certainty of this genomic science to represent the project to broader audiences or potential volunteers. For me, this is an interesting issue, which I explore in detail in this dissertation. In a current climate of anxieties over privacy and security, *how do these biomedical informatics projects become established?*

In employing representations, or rather to borrow and adapt Latour's uses of the terms 'representation' and 're-presentations,' I develop (re)presentations.[9] I do this to illustrate that these websites stand in for absent or deferred objects. By absent objects I mean those that are physically non-present, unseen, and deferred. Further, moving from objects to representations, analyzing the website's (re)presentations, I also put representations to work. I illustrated instances of how these are deployed through the websites to do at various times types of boundary work. [Also see Section 1.6 and Figure 2 in that section for a diagram explaining how multiplicity, fragmentation, and coherences can coexist in virtual representations.]

In this dissertation, I am illustrating a *politics of what* rather than the traditional politics of who/whom. The 'politics of who' focuses on the question, 'who decides?' While not unimportant, it is not the most productive question in approaching these emerging technosciences for the issues I pursue them here. As others have shown, the move to a 'politics of what' helps turn our attention to enactment, that is, to what *is being* practiced.[10] By making this move, I shift the future-oriented discourses that have come to dominate and surround genomic medicine to genomic medicine as it is being practiced now.

Further, by shifting the politics to questions of what, a *politics of how* emerges. In fact, the questions are linked. By employing a 'politics of what' to look at what represents what, the issue over 'how to represent?' emerges. Here, I can illustrate boundary work and difference-making at, by, and through the sites. In particular, I found that boundary work of representations is conducted through various technologies of representation deployed through the website: design, spatial arrangement, text, hypertext. Further, these various means circulating in a site contribute to a coherence of these bioinformational projects that make them appear if not more real, then at least more realistic.

The move to examine representation is to demonstrate through these case studies that representations are not merely 'representations' of these projects. The websites are not merely reflections or only metaphors of these endeavors – although they can at times and spaces be these as well. Instead, in this project, I show that these websites also generate technosocial spaces, specific configurations for generating technoscientific narratives,

[9] I discuss Latour's uses of representation and re-presentation in chapter 2.
[10] See Annemarie Mol, *The Body Multiple: ontology in medical practice*, Durham, NC: Duke University Press, 2002.

concepts, and structures for practices. I look at multiple cases in order to illustrate that these are specific and produced in local sites. Further, I contend that their presence on the web does not remain solely in the virtual dimension.[11] What I mean by this is that they have real consequences, or affectivity. They are in fact contributing to the proliferation of what I will call, for now, informatic bodies.

As noted earlier, I take a multiple case studies approach. I focused on three projects: the Iceland Health Sector Database, BioBank UK, and the Gene Trust.[12] These large-scale population database projects entail collecting large amounts of various forms of information about individuals. They are intended to provide additional data to existing databases. Their sponsors contend that they will facilitate the construction of more precise descriptions of genetic causes of common disease and conditions. Essentially, as some of the sponsors in the cases here state, the idea of large data sets in genetics disease research here amounts to the law of large numbers. They provide the statistical force to their claims of causation and/or association to disease.

Existing genomic databases, in particular those produced through the international human genome projects, which include human and non-human sequence databases, are now described as merely raw data, compared to a list of parts. Knowing how they work, or function, is beyond what the human genome sequence can do alone. More information is required in order to get a better picture, or rather, to complete the analogy above, create a vehicle. In other words, the databases of the human genome project(s) are missing non-sequence information. Therefore, advocates of genomic medicine, as personalized and predictive medicine, call out for large collections of comprehensive data, inclusive of gene/genome sequence information as well as physiological, physical, medical, health, and

[11] See J. Macgregor Wise, *Exploring Technology and Social Spaces*, Thousand Oaks, CA: SAGE, Publications, 1997: 54.

[12] Although I consider only three projects here, other national or regional initiatives are in the works, or explored (e.g. Tonga, Singapore, Estonia, Newfoundland, China). These are organized in different ways but they are so far generally financed in part by sale of data access and intellectual property rights. These large-scale projects have been the subject of some controversy. There are also other smaller-scale projects, such as the Avon Longitudinal Study of Parents and Children, which studies gene-environment interaction in childhood infection, asthma, allergies, and development.

family history, drug response, lifestyle, and dietary information of individuals, to supplement existing biobanks and databanks.[13]

To obtain these kinds of information, sources are required. This means participants, voluntary or otherwise. Populations and individuals are (re)presented. Further, in the (re)presentational endeavors, broader publics are addressed by initiators. However, individuals from these publics are entreated to accept not just the physical projects but the whole conceptual scheme. They too may be potential participants one day. They are addressed, but not necessarily actively engaged at the projects' virtual sites. The websites achieve a relevancy, becoming primary devices where actors, actants, and artifacts make legitimizing claims to target subjects, larger audiences, and potential allies. These might be scientific, or natural scientific, claims, but not necessarily. Furthermore, in working these efforts into their (re)presentations of their endeavors, subjectivities emerge.

For example, in the DNA Sciences case, the site works as a type of limited public witnessing of the company's practices – a kind of window into the world. It also aims to recruit not just individual volunteers, but to make these same individuals recruiters for the company's own aims. However, in the UK case, in order to enroll a broader constituency, the project's sponsors provide a half-hearted appeal directly to the general public, and a more vigorous appeal to other expert groups and the state apparatus. The UK Department of Health already provides genetic services and is the keeper of the state's national health services. In some large ways, by involving such UK government groups, the potential to expand the project and initiate infrastructural supports helps to establish the endeavor. In both cases, particular individual participants are created, less than actively engaged in their development, online/offline.

Despite the mantras of participation and transparency and some limited negotiation through the pages/spaces of the virtual sites, they are seldom a principal place of exchange for those engaged in theory/practice of database science. The publics rarely become actually

[13] Trained professionals take blood or DNA samples. Biomaterials and information from past records already electronically recorded, in either public or private databases, are also included in some of these schemes. However, other information will be obtained from individual volunteers through one or more of the following: self-reporting via questionnaires, interviews by phone or face-to-face, doctors' visits, and possibly direct inputting. In order to replace these sources with precise observation, the creators provide some guidelines/ instructions to physicians/nurses. The instructions emphasize careful, daily recording of data, using instruments as much as possible. How this may play out in the field is a different matter that will require further examination once these schemes are operational.

engaged or even privy to scientific theories about genetics and disease or to continuing scientific disputes, for example, about the utility of heterogeneous or homogeneous population samples or about research methodology. Nor are they permitted into the current disputes and discussions about the difficulties of database construction, either from the position of translatability of the various types of information or in terms of issues of security. In other words, the broader publics and/or potential volunteers, visiting these websites, seldom become direct participants through them – even in the one site used explicitly for recruitment and public education – that is, DNA.com.

Nevertheless, I still contend that the drive for public acceptance by those engaged in these projects make the representative power of the sponsors/project's web presence at least a central node to the expanding of *some* understanding, *acceptance*, and *practices* of biomedical informatic database research. By promoting participation and a genomic vision not only of medicine, but of life itself, the virtual sites are involved in creating and establishing biomedical technoscience. They are involved in constructing a kind of science communication and societies/populations/individuals – that to different degrees accept these practices of genomic science.

I argue that the current dominant representations of these endeavors, which focus on the technological artifact – the construction of the databases – are inadequate to capture what these endeavors do today. In this project, by closely examining three current projects and their representations on the world wide web, I shift attention away from database construction itself and focus it on communication. This is a departure from the current analyses of such projects. I problematize the virtual/real (future) framework in emerging technoscience discussions today. Here, in this framework, issues are deferred for tomorrow, when the technologies solidify and the science is more robust.

I suggest that what might be taken into account in developing broader discussions on emerging technosciences are the following: multiplicity, contingency, and relations. These shed more light on the transformations that take place as the databases are constructed. (Re)presenting at, by, and through these sites also helps to highlight the roles that multiplicities play in creating coherences and incoherences. In examining web sites of these endeavors, the idea of '(re)presenting' helps to elucidate the boundary work – the different layers of ordering in the (re)presentation of individuals, populations, participants, and site visitors. Although these (re)presentations may seem like, at times, inconsistencies or

contradictions, they all may be necessary to create a more realistic endeavor, that is, one that coheres. Still, (re)presenting also highlights anxieties that emerge for the actants involved in constructing their objects and/or subjects.

I borrow this term 'multiplicity' from John Law and Annmarie Mol. Multiplicity, for them, means that there are several layers of order rather than the conventional notion of one. In these sites, then, I mean that there are multiple orders and that we can examine them by looking to the (re)presentations made by, at, and through these sites. Further, these (re)presentations illustrate that these can be overlapping multiplicities, negotiated and contested. Therefore, the co-existence of multiplicities is illustrated when these varieties are located (e.g. frames, discourses, styles) in specific configurations in, at, by, and through these sites. In other words, the (re)presentations are contingent upon a number of varied factors, and it is the fragile assemblage of these multiplicities that create the coherence of a database project.[14]

Information, particularly genetic information as it is (re)presented by the advocates of these databases, is being made and negotiated today, as is the construction of the experimental subject. In particular, the representations point to specific *relational* structures between experiment(er) and subjects – as individuals and/or populations. These are being constructed through these virtual spaces as are 'ways of seeing' genomic medicine, health, and life itself for potential volunteers, participants, individuals, and citizens of these industrialized societies.[15]

For example, through the DNA Sciences website, consumer and internet privacy frame 'information' for the site visitors, but these also circulate with genetic and biological frames. In deCODE's site, efforts are made to dissociate genealogical information from the Iceland population – to appropriate it for the company's efforts. However, at the same time/space, it is circulated at the site in efforts to associate the Icelandic people with deCODE's aims.

Further analyses that focus on relations and processes, at the level of language/technology through the mode of electronic mediated communication, provide another dimension to these emerging bioinformatic endeavors, which until now has been

[14] See the introduction to John Law and Annmarie Mol, eds., *Complexities: Social Studies of Knowledge Practices*, Durham, NC: Duke University Press, 2002.
[15] I borrow the term 'ways of seeing' from John Berger, *Ways of Seeing*, New York: Penguin Books, 1989.

largely ignored. Through this project, I provide an alternative perspective from which to analyze emerging biomedical technologies. The discursive frame allows me to explore the limits of effectiveness in these specific representational acts and (re)presentations of genomic information, databases, and subjects. Further, it helps me highlight the difficulties of traditional modernist dualist frameworks, especially those of science/society, and science/technology, as well as the more recent, virtual/real, which have been used to frame these endeavors in public discussions. By borrowing from a number of science studies and cultural studies perspectives, I contend that these virtual sites are real sites, in the sense of doing real work, of altering biomedical technoscientific practices.

The sponsors of these three endeavors centrally place the collection of data and construction of genomic and other databases within their overall schemes to study genetic roles in common disease and/or conditions. The dominant public discussions about large-scale human population database projects have come to circle around issues of data and the use of data in databases: database security (resolved primarily through legislative database acts) and individual/community (group) consent as the source(s) of information for these databases (discussed in terms of international guidelines on informed consent and/or medical data guidelines). These focus on social impacts of the projects. In other words, these dominant issues and proposed resolutions take for granted that these projects will be implemented.

These are important matters, but in this dissertation, I want to explore an approach to understanding and discussing the endeavors as they work today. Through the lens of their web presence as presented by their main sponsors, I treat these sites as technosocial spaces. I pay particular attention to both language and technology (of representation) to explore the boundaries between virtual and real. I investigate the use of the boundary work involved in these (re)presentations and temporal and spatial disturbances that may come into play by using various modes of representation.

I highlight the negotiated processes in envisioning and characterizing these endeavors over time/space. I will show the constructions of scientific subjects in relation to (re)presentations of their database projects. For example, using its website as a narrative window, DeCODE remakes the Icelandic population, relocating individuals from this population into deCODE's historical timeline and the company's future. DNA Sciences (re)configures altruistic-cyber savvy recruit(er)s to genomic consumers. BioBank's site works

to configure passive British publics and potential subjects and recipients for an envisioned national flagship project that will place the UK in the center of a genomics world. These (re)presentations take place in relation to shifts or changes in the sponsors' worlds, which I highlight. The seemingly timeless and spaceless character of the website work to efface these shifts and create a single order, but by examining these sites at a close and local level, I will show that tensions and multiple orders exist.

1.3 > Constructing manageable subjects

New technologies enable rapid processing of genetic information. This is one of the main explanations as to how sequencing of the human genome in the international Human Genome Project(s) 'finished' as quickly as it has. By identifying genes and understanding their biological functions, scientists ideally believe they can discover the causes of many of the physical disorders that arise when genetic variations occur. However, sequence data, lately described as merely raw material, do not provide information about function. Enter genomics. *Genomics* can be broadly defined as the study of genes and their function. It includes the study of the DNA sequence that contains an organism's complete genetic code. *Population genomics* extends this investigation to large groups of people. Along with genomics is pharmacogenomics. Generally, *pharmacogenomics* is the application of genomics research to drug discovery and development.

This could be done in a number of ways. For instance, a number of public organizations and biotechnology start-ups believe they can fill the gap in the phenotypic genetic side of the gene function-disease equation by creating databases of patients and patient samples. In other words, they think that they will be better able to describe and pinpoint precisely the functions of genes in causing disease. However, to do this, they state that they need to be able to combine numerous types of information about many individuals *at a large-scale* in order to obtain sufficiently powerful statistical correlations between genes, environmental and lifestyle variables, and common conditions. The claim here is that genetic epidemiology has come of age with the current state of computing power, and with that pharmacogenomics.

The three projects examined in my study attempt to fill this gap in a number of ways. Some promise access to almost 'proprietary' national or regional populations accompanied

by documented individual medical histories (e.g. deCODE). Others target genetic and disease-associated data from much broader populations by way of internet strategies, especially in obtaining samples and consent directly from consumers (e.g. DNA Sciences).

Access and ownership of patient records remain significant issues. There are also the challenges of getting the requisite number of patients as well as developing accurate, usable disease histories. All these challenges are currently in the forefront of scientific, political, and ethical discussions. The issues over the composition of specific populations, homogeneous or heterogeneous, and the difficulties over harmonizing vast types of information are being handled primarily behind closed doors. Meanwhile, the projects storm ahead.

Those involved in creating large-scale human population databases are also already locating and taking various approaches to *commercializing their databases*, because the value that drug firms will place on disease-associated gene data is uncertain. Those sponsors involved in such endeavors have focused initially on high-value diagnostics to create target-discovery businesses and to sell their data along with associated software and services (e.g. deCODE genetics).

Human genetics is now playing a major role in drug research and development. Of particular importance for this purpose is the development and use of population and family data collections designed to track down disease genes and loci.[16] There is story-telling going on through the web presence of the projects. The larger dominant narrative is that this re-emergent strategy of population genetics is consequence of the completion of a rough draft of the Human Genome Project plus the rapid growth of publicly accessible databases of human genetic variations (single nucleotide polymorphisms, or SNPs) and new DNA genotyping technology. It is an interesting note that none of the websites mention the troubled Human Genome Diversity Project or the private database ventures.

Critics describe the initiators of these efforts as racing to mine a population's DNA.[17] This claim may not be strong enough. The databases to be constructed here are complex, centralized databases. They may comprise all or some of the following: DNA samples, gene data, lifestyle and personal information, environmental and family history, medical records,

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[16] John Bell, "The new genetics in clinical practice," *British Medical Journal* 316 (February 21, 1998): 618-20. Bell, at the time this article was published, is Nuffield professor of clinical medicine, U. Oxford and, although he holds no equity, he sits as a non-executive member on the board of Oxagen, a genomic biotechnology center.

[17] See Lewontin, Richard C., "People are Not Commodities," [op ed], *The New York Times* (January 23, 1999).

and genealogical records. In other words, they are mining much more than just DNA. What is at stake here is whether what they mine is worth more to them, the individual, population, or some third-party. However, what this amounts to is how genetic information is represented by whom and for whom. *This is politics by other means.* (Re)presentations are embodied through and by the sites as much as representation can be embodied by and through human actants.[18]

My argument is not that there may not be some valuable genetic information that emerges from these databases. A more fruitful question is to ask whether or not these schemes have been adequately thought through in relation to alternative methods at combating these common lifestyle 'problems' that these sponsors hone in on. Effective alternatives might be low tech. It is elucidating that in discussions about environmental changes, these discussions focus on individuals making lifestyle changes, rather than possibilities of, say, making broader environmental changes.

The major claim by the sponsors of these projects is that cross-referenced, centralized, and/or integrated databases containing massive amounts of individuals' information will be the resources that allow them to get into the business of discovering genes associated with so-called common diseases, to develop novel genetic diagnostic tests, and, maybe, to develop new or tweak old drugs tailored to individuals or sub-populations. In the end, these population genetic studies require human populations, and *managing people is what these projects' initiators hope to specialize in.* Here genomics is information management. However, it is first necessary to define these people and populations specifically suited to these projects. Here genomics is experimental science. For the genomics proponents the increasing trend is to think, not of information, which is viewed as easily reproduced, manipulable, and transportable, but of *human subjects as the limiting resource in drug target discovery and recipients of genomic information.*[19]

In this dissertation, I examine three projects in various stages of development, in different locales, and scales. The first is the IHD (Iceland Health Sector Database) created through a private-public hybrid by a private company, deCODE genetics, and the state of Iceland. It hopes to include the entire population, including past and future generations, of

[18] I borrow this phrase 'politics by other means' from Bruno Latour. See Latour's *We have never been modern*, Cambridge, MA: Harvard University Press, 1993.
[19] See, for example, Juan Enriquez's book, *As the Future Catches You: How Genomics & other Forces are changing your Life, Work, Health, & Wealth*, New York: Crown Business, 2001.

the Iceland. The second is the Gene Trust, led by the fully private endeavor in California, DNA Sciences. Using a consumer- and web-based recruitment strategy, the company, initially, sought for its database a population of 30-100,000, but it eventually settled for about 12,000. Lastly, I examine BioBank UK, the public project sponsored by the UK's Medical Research Council, the private charity The Wellcome Trust, and the National Health Services. This scheme aims to include roughly 500,000 British middle-aged residents.

As we will see, the company, DeCODE genetics won the right to create a national health care database of computerized medical data. The company thinks it has the resources needed to conduct large-scale genetic studies by combining Iceland's well-documented, genealogical records and its own collection efforts. BioBank, as a state and/or public effort in the UK will create its own centralized bio-genomic database/study/framework. This effort will accomplish its current proposed goals with data from only a portion of its population without the genealogy in the deCODE database. The UK databases created will be combined with the medical records of the National Health Services records, and would have the capacity to expand and encompass the rest of its population.

Such nationwide database opportunities are few. Private companies take a number of different approaches in their efforts to acquire phenotypic (non-genetic) information and DNA. These include large prospective epidemiological studies, clinical trials, networks of physicians, and direct consumer appeals. The last of these is exemplified by the DNA Sciences case. DNA Sciences' envisions combining their efforts with the efforts of their recruits to recruit their own families into its aims. A common approach has been to access populations with a disease of interest by way of collaborating with academia. DNA Sciences also does this with the University of Utah, gaining access to the Utah population dataset. However, a lot of academic research tends to be centered on specific diseases. Such research has less broad and/or consumer appeal and, therefore, has been viewed as limiting in current private and public efforts. Accordingly, a growing trend in the population business is to assemble much broader databases covering several disease areas.

Many of the new start-ups are building businesses around patient samples and medical records in order to create associations between genes and common diseases. DNA Sciences is trying to commercialize its database by focusing first on diagnostic discoveries and alliances. Then, it will look for genes that can predict a person's chance of developing a

certain disease. Of course, importantly, the diseases in question are currently treatable or have drugs in the pharmaceutical pipeline.

By offering patients such predictive disease information, a genomics company could obtain, in return, patient specimens, genotype them, then, offer them to drug companies for use in clinical trials or other research programs and/or sell consumers genotype data relating to their own health status, alerting them to diseases to which they may be predisposed, to diseases they may have before symptoms appear, or to drugs to which they may have an adverse reaction.

DNA Sciences solicits members of the public over the World Wide Web as part of its Gene Trust Project. Through its DNA.com web site, the company ascertains personal and family health profiles from individuals. If an individual's profile matches one of the company's disease-associated genotype database needs, then the individual will be invited to donate a blood sample. In this manner, DNA Sciences hopes to gather large numbers of patients for similar disease association studies. It has been criticized for not going through the normal intermediary of a doctor or clinical investigator. The biotech company is going directly to patients and obtaining informed consent by asking patients to click through a web-based consent form – at least for the non-gene contributions.

Quick. Easy. Convenient. Strikingly all of the projects' sponsors emphasized – to various extents – their own efforts in making the steps for volunteering as efficient and invisible as possible. Perhaps the most striking was that in (re)presenting its endeavor, deCODE emphasized this aspect the least. BioBank initiators' conceive 'mobile units' that can temporally set up shop in neighborhoods – quickly in and out – to collect blood, physical measurements, and validate questionnaires. DNA Sciences takes non-gene information over the internet. Blood samples are taken from one of many satellite centers across the nation. DeCODE works with physicians to mediate individual's participation. The participants, here, never have to physically enter the company's grounds. Of course, these are all initial efforts. There is also follow-up. And after participating as information subjects, there is also the promise that tomorrow the individual will be on the receiving end. As we saw in the BioBank case, an educational infrastructure is currently being developed.

Pharmaceutical companies seem somewhat positive that the data obtained using these population approaches will have considerable value in drug discovery. This is seen through the number of collaborative efforts and license agreements between biotechnology

firms and large pharmaceutical industries, such as in the $12 million agreement between deCODE and the Swiss pharmaceutical giant, Hoffmann La-Roche. However, although there is a growing emphasis in work on creating diagnostic tests and drug targets, the question over whether such data will provide the basis for a business in consumer genomics remains elusive. In their representations, (through disclaimers) the sponsors defer genomic medicine for tomorrow. However, this does not mean efforts were not made to (re)present genomic living.

Creating a population of consumers seems well underway, at least online. The internet is already a huge resource for consumer health information. DNA Sciences is allied with the largest and one of the most popular consumer healthcare website's Healtheon/WebMD. The Healtheon/WebMD deal provides DNA Sciences with access to select populations of people. Many of these individuals, who post in the site's online discussion boards, identify themselves as having specific conditions. DNA Sciences through its internet-consumer-health-information association found another resource for its aims. However, more broadly, through this site, the company aims to educate the broader publics about the importance of genes and common disease and to define targetable consumer populations for specific drugs or therapies.

For the sponsors of Biobank, the current aims are to enroll its publics into a broader, more general process of establishing a genomic infrastructure in the UK. Currently, web visitors are addressed as potential experimental subjects in a flagship project that may propel the nation into the genomic spotlight. For deCODE, a mix of both the DNA Sciences consumer efforts and BioBank's efforts can be located in their (re)presentational acts.

The various large-scale population endeavors are specific configurations of varied partners, populations, and histories, the 'biomedical technoscientific imperative' narrative remains the same for them. The data needs to be interpreted. What the sequencing of the human genome has provided is the raw material. Biomedicine needs to interpret this data, that is, to link it to personal information, on a grand scale. What is at stake for them is the future of containing, defining, and securing *their* human genomic information, that is, (re)presenting *some population and/or individuals*. The absent object today may be the database, but tomorrow it may be embodied and process-oriented information, or rather knowledge and experiences, in medical understandings of health, disease, and life itself.

Although alternative narratives exist, the dominant narratives exclude themand do no prove them space. The enormous complexities of gene-environment interactions are lost even in the same breath that the sponsors acknowledge them.[20] The projects' representations exclude the needs of (re)educating and (re)disciplining 'lively' bodies by (re)defining and (re)building infrastructure, language, communication, and knowledge. These processes cannot begin and end at the mapped human genome. The matters at stake are self-knowledge of health, what counts as valuable information (raw data or knowledge and experience?), what is to be decided, and how these get to be determined and represented, by and for whom. Securing and containing a database today will not guarantee health, nor secure, less anxiety-ridden relations tomorrow.

1.4> Genomic medical visions & practices

I highlight the relationships (re)presented among the databases, potential participants, and information in human population database projects in the continued efforts to converge aspects of the medical life sciences, computer sciences, and internet technologies. In studying aspects of these convergences (and divergences), I was struck by how issues and aspects of communications and representations were central, yet not central in engagements with bioinformatics.

Bioinformatics proponents tout the centrality of human genomic population databases for continued and productive medical genetics research. We have seen a number of such projects arise in the past half decade and plans of more to come. While a number of individuals have been critical of these databases, the critiques and potential fixes are fractured, divided into dichotomous discussions over genetics versus databases, private versus public, individual versus community information, commodification versus non-

[20] See for example Lily E. Kay, *Who Wrote the Book of Life?: a history of the genetic code*, Stanford, CA: Stanford University Press, 2000, Evelyn Fox Keller, *The Century of the Gene*, New York, Oxford University Press, 2000, and Donna Haraway, *Modest Witness@Second_Millennium_FemaleMan©_Meet_Onco Mouse™: Feminism and Technoscience*, New York: Routledge, 1997. For a more general discussion, see Barbara Katz Rothman, *Genetic Maps and Human Imaginations: The Limits of Science in Understanding who We Are*, NY: WW Norton, 1998. For alternatives to the complexity of the organism see Ruth Hubbard and Elijah Wald, *Exploding the Gene Myth*, Boston: Beacon Press, 1993. Lewontin, Richard C., *Biology as ideology : the doctrine of DNA*, NY : Harper Perennial, 1992 and *The Triple Helix: Gene, Organisms, and the Environment*, Cambridge, MA: Harvard University Press, 2001.

commodification. In contrast, I examine the web-related roles of information, knowledge, and representation in this arena in the hopes of engaging these projects in a less fractured and more productive manner.

In the last half of the past century, many proponents assumed that the heart of the life-sciences is information. The current mantra in genomics is that the heart of its database research is the collection of information. Some advocates of genomics argue that an organism can be known through the collection of salient information – genetic and environmental. Through such comprehensive information gathering, researchers can know the organism rationally. At a broad level, genomic database endeavors envision the collection of an organism's information, collecting both genetic *and* non-genetic information. Similarly to databases for individual organisms, there has been a turn to create large-scale human population genomic databases, especially for biomedical research, with collections that attempt to be comprehensive.

These human population genomic database projects rely on the assumption that they can 'fully' represent the organism. These databases aim to encompass all or some of the following kinds of information about individuals: genetic, medical, lifestyle, and genealogical, which raises the question what salient of 'comprehensive' information can mean. Linked to these endeavors are the aims to standardize, quantify, and manipulate the varied forms of information in the supposed aim to produce truly precise, rational, and predictive knowledge.

This information still must be chosen, organized, and made compatible with a database, and perhaps also with other databases. In a human population genomics project, what information is important enough to be included, excluded, represented, and (re)-presented? How will we be represented? Who will do the choosing and representation? Furthermore, in population genomics, it is necessary to choose individuals whose data will be used for a given project/database/study. Equally important in these endeavors are wider publics and participants. Further the support and participation begins well before the construction of a physical database and well before the strengths and limitations of genomic medicine (interpreted as personalized or individualized and preventive medicine) are fully understood.

How representations are made is important, for it is constitutive in furthering an understanding of emerging biomedical technoscientific productions. In some circles, the turn

to genetics has been described as the beginning of a medical revolution or medicine for the new millennium. Others describe this convergence of the molecular sciences and medicine as the formation of a new field, the new biomedicine, in which medicine will finally be rationalized. Advocates claim that twenty-first century medicine will be based on preventive health care and personalized medicine.[21]

The increasing role or, rather, interrelationship between industry, academic, and state science in regard to genomic medicine was generally acknowledged, in all three cases, not only by the private but also by the public sectors. There was a sense that we can both control and contain the commercial scenario and that it is in fact ultimately necessary in order to deliver on the *promises* of individualized medicine. Even the sponsors of the public BioBank took these positions. The large scale centralized human population databases *and networks* are woven into these schemes. The promises of genomic medicine are deferred in all three cases, although, as expected, DNA Sciences and deCODE promised to make the time of deferral as short as possible. In fact, the promises hang on those of the databases themselves.

The major claims concerning genomic medicine are that they will yield more personalization, and therefore, more individual choices about one's own health, prevention, and longer-term (if not short term) cost-effectiveness. In the cases I examined here, personalized medicine, in the sense envisioned by the sponsors of these projects, amounts to market medicine. What is valued are not the aims of supporting self-understanding and social relations. Rather, value is what is value-able in terms of capital although in the guise of valuable information. Individual personal information is supposedly traded for personal service (deferred for now) and altruistic serving of future victims of conditions of concern.

In this study, individual choice is problematized. In my examination, I question DNA Sciences' claim to be opening up individual choice. By shifting the focus to relations, the question to ask is, 'freedom to choose what?' DNA Sciences seeks to reproduce a certain

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[21] Tom Meade, the director for the Medical Research Council (MRC) Epidemiology and Medical Care Unit in London and chairman of the MRC Working Group projects that the results will likely be two-fold:

1. Preventive medicine: the results will provide information on how lifestyles can be altered to improve health and
2. Personalized drugs: giving birth to a new specialty – pharmacogenetics – where genetic information is used to match patients to drug therapies that work best for them <<http://www.biomedcentral.com/news/20010221/05> >

See, also for another example, F.C. Kafatos, "A revolutionary landscape: the restructuring of biology and its convergence with medicine," *The Journal of Molecular Biology* 319:4(2002): 861-7.

vision – a genomic (genetic) one through dna.com, WebMD, Discoveryhealth, and its recruit/ers. Further, the long-range and long-term visions of individuals logging-on, ringing in, or seeing a health care provider, to access their genetic predisposition charts from a database, should call attention to how much individual choice or understanding about one's own health is really embraced in these schemes.

Attempts are already being made to standardize these databases with other genomic and informational databases. In the public and/or private sectors, the race now is to set the standards, in terms of infrastructure, protocols, practices, technologies, analytical tools, and disease classification/identification for the rest (of us?). These aspects gain greater importance as bio/health/life/medical informatics sciences continue to make efforts at expanding faster and more efficiently (invisibly) into public and private life/lives in the new millennium, and its sponsors continue (re)presentational efforts of their endeavors, translating and transforming them into life itself. However, from the database projects I examine here, these seem more likely to represent efforts of information management rather than the scientific studies, research, and/or medicine (re)presented to their broader audiences. I show that each project's web presence emphasizes specific aspects and configurations of web technologies that target and assume specific audiences. These sites then also work to create group identities.

These extra-scientific matters do not 'taint' database science. They are constitutive to making genomics (genomic medicine) what it is today.[22] The power to represent genomic medicine, genomic information, and human bodies emerges not from science alone, but singular assemblages in which individual and collective subjectivities are constructed. 'Genetic information' is the effect of specific assemblages at play in the websites. The specific assemblages, or configurations, modify our the ways of thinking about the human body, populations, genetics, information, and databases; their relational roles with one another in their redefinitions; and the ways potential participants are to perform their roles in these informatic endeavors both online and offline.

[22] Another interesting question is whether genomics database research is information management or experiment or both.

1.5 > Definitions

Virtual spaces

In the past decade, proponents of bioinformatics developed a number of sources that provided biologists guides to bio-computing. There are now materials on the World Wide Web, as well as textbooks, symposia, and conferences. Textbooks in the early to mid-1990s aimed to demonstrate to the then-uninitiated biologist how to use online databases, specifically how to perform searches, use e-mail, newsgroups, and MOOs.[23] Today, these guides increasingly focus on bio-computing on the web. In other words, the focus is on graphic-user-interfaces. Both bio-informaticians and biologists argue that biologists will find the visual oriented interfaces much easier to understand, use, and navigate. The idea, paraphrasing one bioinformatician, is to make the technologies, the databases and software, as invisible to the biologist as possible.

Currently, the movement to increasing integration of certain aspects of the life sciences with computer science *and* communication technologies continues at the public and private, university and industry levels. A number of studies already exist on the connection between the life sciences and computer sciences. Primarily, though, the focus of these studies is on computational biology, the technical aspects of databases, their software, and the relations between these latter technologies and biologists. In the technical writings on technologies for biologists, the virtual aspects are dominated by database talk, software tools and computational mathematics.

In this project, I work in a tripartite configuration among computing sciences, life sciences, and internet technologies. As we will see later, other authors, such as the historian, Timothy Lenoir, have considered the relations, or the confluences, of computer sciences and life sciences. The association between databases and genomic populations might be considered primarily through this lens. However, I contend that the websites of these and associated endeavors must be included in attempts to understand the relations between databases and their populations, life and computer sciences, and the multiple ways in which 'information' is understood.

The websites are public performances and political structures. Their roles in these genomic endeavors are more easily ascertained when considered as social spaces. On the one

[23] See for example the edited volume by Simon R. Swindell, et al., *Internet for the Molecular Biologist*, 1996.

hand, they provide venues to present the projects to multiple audiences. They serve as venues for proponents to persuade potential allies to enroll in their endeavors and to reinforce current allies to stay on their course. On the other hand, and more interesting, websites also serve non-rhetorical functions. They are important in defining, or characterizing, both the individuals and the population for their database projects. They are new actants in these informatic research systems, integral to the practices of database research and science and to an understanding of what these endeavors are today and what they may mean tomorrow.

As noted above, the databases cannot be perceived as monolithic entities. We will see that even the company, deCODE genetics, slips in the statement that the databases are part of their research system while simultaneously avoiding an explicit definition of 'database.' However, I contend that the research systems in these projects extends beyond the array of in-house (or off-line) computers and software. Further, the amorphousness and elaborateness of these projects are difficult to consider if only their bricks and mortar realms, hardware, and tissue samples are taken into account. Accordingly, in this dissertation I explore how virtuality is understood and used to make components (from the databases, populations, genetic information, and genomics research) of the projects *real*stic.

Genomic population database projects

Efforts to create some form of large-scale human genomic databases exist in countries such as Tonga, Singapore, Estonia, Sweden, China, the United Kingdom, the United States, Canada, and Iceland. Iceland's project, by the company deCODE, is likely the most famous case and, to date, the most developed. However, we must examine what 'developed' means here and how we are (re)configured in these developments.

Population genomics is not altogether new, but genomic information companies, such as deCODE genetics, integrate population genomics and informatics for their national/regional database efforts. As such, these companies and project initiators require access to pre-existing public databases as well as devising their own. These databases are not all genetic in character. Some contain public health information. Others contain historical, familial, medical, and lifestyle information. Still others contain technical and scientific literature. What is actually part of theirs and what they mean by database are, at times,

obfuscated by the sheer number and seemingly disparate sources used. Further, these projects are all in collaborative or alliance partnerships with one or more pharmaceutical companies, hospitals, foundations, biotech and software companies, universities, and governments.

While several countries are now actively pursuing the national/regional genomic population projects with public funding and public health records, the United States is not. However, the more interesting observation is that it may not have to. A private company, DNA Sciences, stands out as the closest to a national/regional database. It is a large-scale human genomic database endeavor referred to by its creators as The Gene Trust. However, many other genomics companies, not only those envisioning national/regional databases, as dealt with here, use portions of U.S. population (especially Mormon, Appalachia, and various American Indian populations) in their own research. Further, many of these private companies, such as DNA Sciences, combine, or seek to combine, their smaller privately-held databases with public databases.

Of all the projects, whose websites I have surveyed so far, DNA Sciences' is the most elaborate. These others include: BioBank UK (Wellcome Trust), Iceland Health Sector Database - IHD (deCODE genetics), Estonia Genome Project (Estonian Genome Foundation), Sweden (Uman), Newfoundland (Gemini-Genomics, Sequenom), and The Gene Trust (DNA Sciences). DNA Sciences stands out from the other projects studied here in several respects. Of particular interest here are their views of population and their recruitment method. Unlike many of the others (e.g. deCODE, Uman, Gemini-Genomics), DNA Sciences emphasizes a diverse population for its database (databases?), people of all ages, ethnic/racial backgrounds, and health states are encouraged to 'volunteer' to be part of The Gene Trust. However, only those in the United States are qualified. Other projects listed above emphasize the special-ness of their 'homogeneous' populations created by the founder effect.

Many of the comprehensive databases have yet to physically exist. Even when built, there is no totality – no end product. Information (e.g. continual monitoring of medical and lifestyle information) from all the various sources will need to be continually incorporated and integrated and built on. The need to create generational and familial networks is also salient. This seems to be the phase that DNA Sciences is moving towards in building up their database. The former CEO, Hugh Rienhoff encouraged Gene Trust 'participants' to

enlist their family members to also become 'volunteers.' However, participants do not only play a role in production. Here, the next phase of genomic medicine emerges. Personalized medicine/medical companies, such as Genaissance and DNA Sciences, plug into the already existing, but shifting, convoluted networks to create a generation and generations of consumers.

A tension exists, on the one hand over the newness of these sciences, their potential, the shifting and instability of these projects and where they may lead in the future, and on the other hand, the established research and technologies. The constantly changing configuration and entities related to these projects are stabilized when these projects form ties to established foundations especially public institutions and states. The need for these databases is explained through histories of population genetics and the way in which Mendelian genetics works to locate variation. Many project sites provide direct links or references (e.g. deCODE) to scientific journals to which their scientists have written papers. Further, these projects do not emerge or start from scratch. Many use and cite as justification for their proposed databases, pre-existing pedigree studies (e.g. of Mormon population in Utah for the Gene Trust) to aid in their analyses.

Are these *genomic* population databases or rather something else or something more? In other words, does genomics link the population with the databases and their endeavors? The need, according to their proponents, is to locate genetic variation especially in common, complex diseases and conditions. Therefore, there is the need for large database sets, integrated multi-informational sources, and recruiting, either diverse populations (DNA Sciences) or homogeneous ones (deCODE genetics).

The CEO of deCODE, Kári Stefánsson, stated that "The Icelandic population contributes simply by being what it is."[24] My reading of Stefánsson's position is that there exists, self-evidently, an 'Icelandic population' and, self evidently, this 'population' works best in genomic studies searching for the roots of causation of common disease. However, my question here is the following: Is the connection between these databases to a population self-evident?

[24] Stefánsson quoted in E. Dorsey, "Roche deCODE's Icelandic population in $200m deal," *Nature Biotechnology* 16, 1028-9 (March 1998).

What does a genomic population database look like?

Are genomic population databases simply then a 'collection of data arranged for ease and speed of search and retrieval?' Such a definition of a regional/national human genomic database does not tell us much about the relations between the database and the population. It might tell us about the relationship between data and the database, but I think not since data and databases do not have a natural connection. Data must still be converted into a form that can be processed by a computer. It also does not say much about how the data is obtained and the database constructed.

We can take the case of the efforts by the company deCODE genetics. The company never explicitly defines what a database is. Rather, on the corporate website, the company describes the Icelandic Health Sector Database (IHD) as part of their Combined Data Processing system (DCDP). DeCODE hopes to convey to readers of the site that the database is simply a recordkeeping tool. It is a simple public health database with one exception: the scope. The IHD will be nationwide. However, what is truly innovative is their DCDP, which incorporates several databases, although there is little elaboration about the relations among the databases. Rather, on their site, deCODE describes the system thusly,

> The linkage of these three resources [genetic, genealogical, health information] will create a powerful analytical tool called the deCODE Combined Data Processing system (DCDP). The DCDP is expected to open up new avenues of medical research and facilitate the development of technologies leading to:
>
> - Faster diagnostics, allowing for earlier treatment or changes in lifestyle.
> - Customized treatments, specific to disease subtype and with a lower risk of side-effects.
> - Better-informed, more cost-effective disease management strategies.
> - More accurate drug-targeting, leading to more effective, tailor-made treatment regimes,

linking the DCDP to potential commercialization efforts.

In 'Databases in Genomic Research,' William Gelbart begins "Genomic databases are public windows on the high-throughput genomic projects." Gelbart divides genomic databases into two categories: generalized and specialized. In the first, he includes databases such as GenBank, EMBL, and DDBJ, which sequence data for nucleic acids, and PIR and SwissProt, which are archives of polypeptide sequences. He describes these generalized databases as including and representing information on particular classes of molecules, without any phylogenetic or functional exclusions. The other category of databases, specialized (or 'expert domain'), is more limited. It may be organized around a specific

model organism or type of biological function, for example protein family databases. However, he points out that neither group of databases contain only genome project information, rather "they are a mosaic of data from genome projects intermixed with those from the broader scientific community." For instance, deCODE's database will be composed of three integrated database sources: genealogical, medical, and genetic. Therefore, this comprehensive database will be composed of three categories in which specific information about the Icelandic individuals will be deposited.

In describing a genomic database for *E. coli*, David Mount and Bruce Schatz characterize a 'total information database' for an organism as including 'all of the information on that organism.' They elaborate,

> The data will include information on DNA and protein sequences; genetic, physical, and cytological maps, genes and their mutant phenotypes; protein and RNA products and their properties; biochemical or developmental pathways; regulatory circuits, literature references; and many other types of data, as needed to describe the organism fully.[25]

The idea here is similar to the database projects under investigation in this study. Comprehensive databases are necessary and not just databases with genetic information in order to achieve 'total information' about populations. Still, deciding what needs to be included *and* how they are related one another in order to describe the organism 'fully' will require some determination on the part of the investigators.

Constructing populations & individuals: multiple technosocial scientific objects/subjects

In a critique of the Human Genome Diversity Project, medical and cultural anthropologist, Margaret Lock states that the main problem from the start was the idea of human 'population.' She writes, "far from being a readily definable natural fact (it) is a contested concept both politically and biologically." She then asks, in epidemiological studies, including genomic ones, "How, therefore, should one go about locating and

[25] David W. Mount & Bruce R. Schatz, Ch. 9 "A Genomic Database for Escherichia coli: Total Information on a Given Organism,' *BioComputing: Informatics and Genome Projects*, ed. Douglas W. Smith, San Diego: Academic Press, 1994: 249.

specifying the boundaries of the populations to be sampled?"[26] She then turns to the question of why. She argues that there is a continued emphasis on race, ethnicity, nationalism, and human difference today in epidemiological analysis because of the emphasis on visible differences in our society today. She writes, "phenotypic difference, in particular that which constitutes physical appearance, remains in the cultural imagination as a seductive, perhaps indispensable folk categorization…."[27]

I do not disagree with Lock, but I focus on a different issue. Lock's interest is in the question of who: 'who gets to decide who is included?' In this project, I focus on the 'how' rather than the 'who' or the 'why' questions. How do database projects continue to focus on and naturalize these categories of race, ethnicity, and nationality? By pursuing *this* 'how' question, the question (which, at times, may point to a seemingly conflicting pursuit) is raised: How, when, and where do these projects reinforce the notions of individual difference (designer drugs/personalized medicine), special populations, and/or unified humanity?

All of these projects latch onto the strengths of genetic science and computational mathematics and technologies, stabilizing the projects to various extents. The current importance of bio-information and health/medical pursuits gives these projects even more credibility. The web's virtual nature aids in redefinition of space, time, and bodies and permits the projects a certain amount of fluidity. The question I pursue in this dissertation is whether current public discussions that focus on problems of identifying who, that is, who decides, might be inadequate here.

The dominant representations of the population databases work together to veil the reinforcement of certain assumptions about what populations mean. By turning to a politics of what and investigating the shifting representations of these different projects, we will see that new categories of populations are constructed through them. These constructions are not always based on the visual, the exterior, or the clearly bounded. On the one hand, the sites create forms of populations inclusive of cyberculture, consumer culture, patient groups, and/or citizenship. On the other hand, they also create an ideal of an individual participant

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[26] Margaret Lock, "The Human Genome Diversity Project: A Perspective from Cultural Anthropology," *Human DNA: Law and Policy: International and Comparative Perspectives*, eds. Bartha Maria Knoppers, Claude M. Laberge, and Marie Hirtle, The Hague: Kluwer Law International, 1997: 231-2.
[27] Ibid., 229-38.

that emphasizes individual or personal choice as well as altruism. In other words, individual and collective subjectivities are co-produced. I highlight how scientific and technological objects are made and show how they are multiple, relationally, and locally constructed.

Politics of informatic representation: points of departure

The recognition that these are comprehensive databases highlights my departure points for this project. As I will elaborate in chapter 2, I problematize 'genomic databases.' I want to point out here, though, that because they are comprehensive, the relations between the databases and the population are much more complex than simply a collection of genetic data and even of other data. These complex relations lead to my second point of departure. These human genomic databases in keeping with being comprehensive, are also ongoing. Therefore, I maintain that the individual potential participant must also be brought into the analysis. They are also actants. The individual may be an actant different from a certain population, but she may also be part of that population or populations. It follows that asking the conventional political questions of who/whom is inadequate. Therefore, in this project, I focus on examining the production of representations rather than identifying exactly who is permitted to represent. My efforts are, as I stated earlier, more in accord with a politics of what rather than a politics of who/whom.

The third point of departure takes off from the position that there is a strong virtual connection to these genomics projects. This might be highlighted by turning to a discussion by the sociologist of science, Paul Martin. Martin, who has studied the UK's BioBank project to some extent, provides us with a discussion of the governing of these databases in the United Kingdom. He points to the connection between these population databases or data banks with tissue banks. In the BioBank UK case, I will problematize this association between the digital information and material samples. By turning to virtual representations of these projects, I examine the tensions that arise when the genomic databases are considered as virtual endeavors, but also associated with real, or physical, bodies.

Martin also points to what he calls the new research system. These are systems brought together through the new genomics, which center on the production, use, and

commodification of genetic information and knowledge.[28] This highlights my fourth point of departure. I problematize 'genetic information,' rather than accept it unproblematically. What is genetic information? By asking this question, I am concerned with the following: Does what 'genetic information' means, and how it is deployed change within these projects and virtual spaces? Are genetic data and genetic information the same as genetic knowledge? Is what is produced, what is used, and what is commodified, the same?

1.6 > a note on representing websites

The web is different from traditional print. It lacks the tangibility, stability, and linearity of the traditional print document. However, the web is not one technology. In this project, the web representations are specific to each project. There are various technologies within this technology of representation: hypertext, external and internal links, various forms of visual imagery, text, and forms of documentation. These can all be mobilized within one site. As a relatively new mode of communication, it presents itself in different ways, whether in the narrativity of deCODE's site, the news/updating approach that the BioBank pages take on, or the e-commerce/virtual community approach of the GeneTrust.

These aspects of story-telling, news updates, e-commerce, and virtual community are also aspects of how websites are practiced. They are also manifestations of what we think the web is about, as an around-the-clock news source, commercial tool, community space, and a form of expression. The sponsors here employed all these devices to represent their projects, which is indicative of who they believed their audiences were or who they envisioned their audiences to be. Furthermore, they employ these devices with the various modes of web communication, such as hypertext, rapid redesign, and interactivity, in specific configurations, all within a supposedly self-contained space for the projects. The endeavors take on a kind of stability even though the sponsors adapt their representations to offline changes and shifts in themselves and their projects.

In analyzing the websites, I borrow Latour's ideas of representation and absent objects. In the next chapter, I will discuss in more detail Latour's analysis of representational

[28] Paul Martin, "Genetic Governance: the risks, oversight and regulation of genetic databases in the UK," *New Genetics and Society*, 20:2 (2001): 171.

regimes through paintings, but in his discussion, he talks about how representations stand in for what he calls absent objects. I borrow this term 'absent,' or deferred, objects and what I mean are those that are physically unseen, not present, or not materialized. However, I modify Latour's concept of representation in order to highlight aspects of distribution and reciprocal (re)presentations of various objects and subjects. Further, I modify them in order to situate changes both in the conventionally understood, 'real' world and 'virtual' worlds. Here, I developed a heuristic to help me do so.

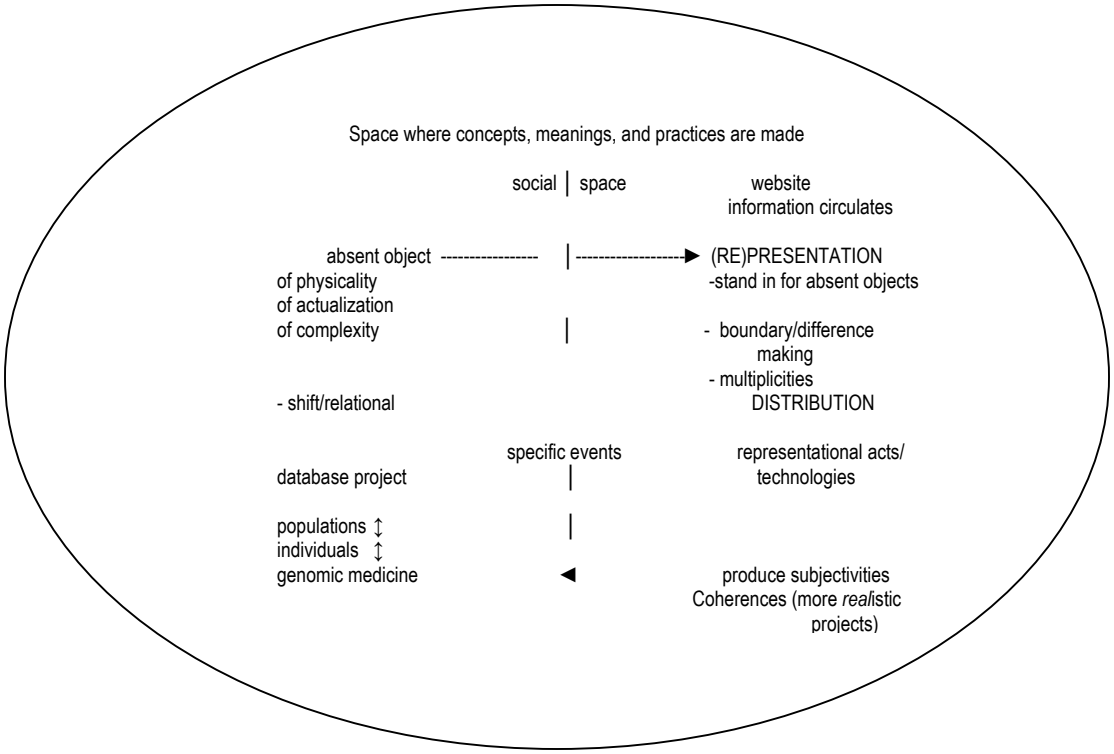

Figure 2 Representing Websites

In this space in which emerging biomedical informatic technoscience is represented, the left side indicates the various absent objects in these emerging projects. These can and do shift. The double arrows indicate that the shifts are relational as the various objects are (re)presented and as specific events occur in the 'real worlds' of the project's sponsors, for example, a shift in the company's business and/or research strategy. These shifts and relational (re)presentations are (re)created in the 'virtual worlds' of websites, technosocial spaces in which 'genetic information' is also (re)presented, (re)produced, and (re)created. Concepts, meanings, and practices are made. These are not linear, causal effects, but are closer to circulation and re-circulation. Here, in these spaces, in which politics of representation are enacted, subjectivity – both individual and collective – are created as the projects are also made more *real*istic.

In moving from objects to the space of (re)presentation [the websites], I demonstrate through these case studies that produced are not merely 'representations' of these projects

and their objects. The websites are not merely reflections or only metaphors of these endeavors – although they can at times and spaces be these as well. Instead, in this project, I demonstrate that these websites are also spaces, for generating and circulating specific technoscientific narratives, concepts, and practices.[29] They are spaces in creation of being.

As I stated above, I want to go farther than Latour and pursue issues of distribution and difference-making as well as the relational (re)presentations that are achievable through this mode of communication. So I put representations to work, by illustrating how these are deployed through the websites to do a type of boundary work, in which representations of the endeavors are created and distributed to certain audiences at certain times of the project. I do this by shifting in and out and through the dualist framework of the virtual and real dimensions. I locate what I believe are key moments to the specific projects and use these to mark or triangulate changes made in the websites. I do this to highlight the difference-making or shifts in the sponsors' representations, conducted through and deployed by various technologies: for example, design, spatial arrangement, text, hypertext, and file formats. These affect the representations of the databases, but these also result in changes in how other objects/subjects, especially potential participants, recipients, and information are represented.

1.7 > chapters represented

The sponsors of these uncertain endeavors must (re)present these endeavors to various audiences, but coherency(ies) must be made to produce (more) solid projects. It is not my contention that all of these (re)presentations emerge solely from the creators of these projects, or that they are performed linearly. I suggest that these projects are locally contingent, but fragmented, which the web and their sites at times conceal. In reconceptualizing representation and media technologies, I illustrate that these sites work at producing specific ways of seeing *and* practicing 21st century health.

[29] See J. Macgregor Wise, *Exploring Technology and Social Spaces*, Thousand Oaks, CA: SAGE, Publications, 1997: 54.

In chapter 2, I provide a more technical discussion of the science studies literature from which I borrow. I provide an explanation of (re)presentation and absent and deferred objects, especially in relations to my aims to examine complexity, multiplicity, and relationality in emerging technosciences. The chapter elaborates on studying representations of *emerging* technosciences and technologies of representation and the relations between the two, particularly for this project on web representations. Specifically, I discuss my move to bring hypertextuality into an analysis of bioinformatic projects today. Other forms of representation might have been examined but my turn to virtual ones uses and explores a current techno-cultural force which both produces and undermines the coherence and stability of these bioinformatic endeavors today.

The next three chapters are my case studies in which I illustrate and intervene in these productions and disturbances. Although each of the case studies can be read on its own, the DeCODE project sets up the other cases. The project was dominantly shaped as a problem of constructing a secure and private database. I examine the creators' virtual representations of their endeavors in an effort to illustrate that genomic database research is constructed through hard work. It is a complex assemblage built out of a network and (re)configuration and (re)presentation of relations, concepts, and practices that include efforts to address and enroll broader publics and/or potential (experimental and practicing) subjects. I illustrate the co-production of the endeavors and of their participants, and highlight the anxieties of these virtual representations by putting representations to work to illustrate boundary work, narrative (re)making, and fragmentation.

DeCODE uses its website to provide a revisionist account of the controversies that surrounded the company and the state of Iceland's aims to create a large-scale human population database. This account involved (re)presenting its endeavors, but I illustrate how deCODE's survival entails (re)presentations not only of its database project and the deCODE controversy, but also of the Iceland population, genomic practices, and its company. Through narrative (re)making at its website and in these (re)configurations, DeCODE presents itself as the critical node for the Icelandic population to understand their past, present, and future. In these moves, the company must continue to address (potential) participants. Through various web technologies, this site works to maintain a coherent, stable picture of the deferred technoscientific object (the comprehensive database for genomic medicine). However, even though the site does not interactively engage the site

visitor, by a close examination of the website, I show that tensions are produced and can be highlighted in its virtual (re)presentational endeavors. These tensions illustrate the anxieties for a potential visitor as the website works to produce a space in which potential bioinformatic participants, that is, informatic bodies are constructed.

Unlike the deCODE site, DNA Sciences' website works explicitly as an educational site and recruiting tool for its database endeavor. The company claims to make genetics real for ordinary people by providing them the opportunity to directly be involved in genetic research. In this chapter, I aim to illustrate the boundary work and schizophrenia that goes on in DNA.com as shifts and uncertainties plague this venture-capital backed start-up. Originally, the site predominantly stood in for its database project, the Gene Trust. However, after a shift in the company's strategy from research to business, the space for the (re)presentation of the Gene Trust was submerged and DNA Sciences emerged dominantly. In these moves, the company must continue to address and (re)present its potential participants/patients/consumers/internet users and supply value to its potential and current commercial partners. In this site, the use of certain aspects of this new mode of communication – networking, the ideas of interactivity, virtual community, e-commerce – are particularly enrolled to help solidify the project.

The last of the three projects I examine here, BioBank UK, is in the earliest stages of development – a 'conceptual phase.' Its three main sponsors highlight the importance of public engagement in this process. In particular, the site uses the world wide web as a prompt informational/news technology to suggest that its sponsors are keeping the British public well updated about its endeavor. However, in efforts to create a *real*stic endeavor, I illustrate the anxieties produced in establishing how representations are put to work in order to define the project. As it works to help solidify the project, the web presence is made to (re)present the endeavor in multiple ways to the British publics, to other potential funders, and the British state. In this process, specific relations between the study/database experiment and its potential data subjects/patient/recipients of outcomes are constructed in the (re)presentational acts.

These virtual representations have their own ways of producing practices and ways of seeing that are enrolled in representing these bioinformatics endeavors and that are constitutive in defining these latter objects. These ways have to do with how representations of various objects and subjects relate to one another. These in turn have to do with potential

visitors are envisioned, how they are envisioned to relate information, and how they are envisioned to understand how it means to use the world wide web.

The dissertation highlights this work because current public discussions concerning the construction and use of these databases have large ignored the ways in which these representations produce meanings and practices.[30] 'Genetic information' is the effect of specific assemblages. Each project's site enrolls and intertwines specific aspects of web cultures and technologies. For example, certain understandings of 'privacy' or hypertext, that target and assume specific audiences, are intertwined with articulations of genetic information and genomic medical science. Each case also illustrates that the projects emerge from distinct and fragile configurations drawn from scientific, technological, nationalistic, capitalistic, and global discourses and practices.

In the conclusion, I speak further to the issues of addressing and enrolling broader publics in these representations, the construction of information in these genomic endeavors, and the construction of experimental objects/subjects. In particular, I claim that in all these virtual representations, publics and/or participants must be addressed and enrolled, although, I demonstrate that they do not necessarily have to be engaged in any critical way with the project. I argue that in attempting to solidify and/or make these emerging genomic endeavors/experiments (predominantly absent objects) more *real*istic, that

[30] Generally, analyses of the representations of science fall under two camps: science inside and science disseminated to the public. The latter – sometimes referred to, as the study on the 'popularization of science' has been a burgeoning topic in recent years. See the works (cited in the bibliography) by Dorothy Nelkin and Susan Lindee, Celeste Michelle Condit, José van Dijck, Jon Turney. Many authors, like van Dijck, acknowledge that there is traffic between the two. Van Dijck's insightful analyses on the popularization of genetics, discusses the proliferation and (re)circulation of images from the latter half of the 20th century. However, she does not see the production of these images and imaginations as science-in-action, maintaining the dichotomy. By turning to websites/spaces, where multiple discourses and practices emerge and (re)circulate, my dissertation attempts to analyze representations of science without imposing this artificial dichotomy. Further, rather than focus on images and imaginations, or ideas, I aim to also show that the websites are spaces where genomic practices emerge as well. This is important in that while sometimes images and metaphors are the first to proliferate, other times they are not. She points out that today, we might expect that new images like 'networks' or processing systems would be used to illustrate the acknowledged complexity of the genome. However, she argues that predominantly, 'computer programs' proliferate popular discourse. Van Dijck's admits that her work is retrospective. We may notice later the proliferation of network metaphors. However, I show that emerging may not be a 'network' metaphor in the specific sites that I examine. Rather, it is the practices of networking that are emerging. These practices resolve the problem of the 'fixed flows of information' highlighted in the program metaphor used by continual updates and statistical fixes.

is, more coherent, the websites work to (re)present the projects. In the process, they must (re)present their potential participants/subjects as well. For example, deCODE's need for a specifically Icelandic population is not based on genetic homogeneity alone. Rather, as we will see, the website works to displace the history of the Icelandic population with its own. The site must marshal a number of actants and resources, including web technologies, in order to create a more *real*stic project to its site's visitors.

In working to solidify these projects, that is, in establishing their inevitability, embodied bodies/individuals are increasingly displaced. The Icelandic individual's personal and family history is displaced by a concept of genetic informational flows and fragmented into discrete data crunched in deCODE's hyper-technologized system. By focusing on these virtual representations, I examine the problematic dichotomization of the virtual and the real, and the resistances to the representational acts at, by, and through these bioinformatic sites. For example, the private company, DNA Sciences must interact with its Gene Trust participants, at least those selected for studies which utilize their DNA samples, if only through the mediation of a collaborating partner. In the conclusion, by borrowing from a number of other writers, I expand on my discussion of resistances to and anxieties created by increasing efforts to create bioinformatic bodies in everyday life.

2.1 > Virtual sites

2.1.1> Representing promises, absence, and deferment

Genomic medicine promises individualized or personalized medicine and healthcare through a revolutionary new paradigm of molecularized and rationalized frameworks for understanding disease. Although there is little concrete evidence to date that genomics has led to better medicine or health, some of the proponents of genomic medicine even say it is today's medicine as well as tomorrow's. This is clearly rhetorical hubris. However, it drives home – in this hyper-capitalist, technologically-driven, progress-oriented industrialized place and time – that the much-stated mantra that 'the future is now' takes shape in many aspects of our lives, including health.

This idea is further illustrated in the seeming necessity and inevitability of pursuing and establishing human genomic population databases for medical research. In these schemes larger publics are needed to 'participate' as subjects, objects, and allies of these technoscientific ventures. Therefore, proponents of such endeavors must represent them to broader audiences. They cannot do this based on empirical evidence of genomic medicine. Even if the future is now, the promises of genomic medicine are not in existence now. Yet, the number of such projects is growing. Vast amounts of money, infrastructure, and scientific effort and work are put into these projects. Governments, states, populations, citizens, are heavily invested in these endeavors.

Rather than follow the future-oriented and social consequence models that frame many political, policy, and ethical discussion on genomics, I argue that we need to address what these bioinformatics projects are doing today even though many of their objects and subjects are deferred or absent from our purview. Because genomic medicine is future-oriented and promise-making, it seems a likely candidate for deferred critical thought on the matter, or mattered body.[1] It illustrates the roles of new representational technologies in the

[1] Media representations of these endeavors have been somewhat mixed, invoking the misuse of information while simultaneously invoking the 'revolutionary' improvement of medicine. Some public understanding of science, politics of science, and policy studies discuss the possible social impacts that may emerge, once the databases are built and revolutionary treatments developed. Further, the authors of these studies have addressed issues of

production of its knowledge and practices. Further, it illustrates their role in solidifying these informatic endeavors. Because none of the studies referred to above have focused on critically characterizing the web's influence and roles in establishing these emerging biomedical informatic projects, they miss an important factor in how genomics is made real and realistic today – not tomorrow.

As I show, through the case studies, one of the major problems with the frameworks of revolutionary and emerging science is that while these projects are new in some ways, they are also old in others. They sustain many of same reductionist, objectifying, and dualist modernist frames (re)presented in the life and medical sciences today and tomorrow. My claim is not that these databases will not yield 'useful' information. They certainly may. Instead, I highlight the need to examine them at local levels, asking what these projects do today – not tomorrow. By framing this question in terms of the present, defining genomic medicine, genetic information, populations, experiments, and subjects are seen to be in the making. These are being defined conceptually and in practice – all in the midst of our increasing drive to create various forms of bio-value, not in and through the abstract, but by and throughout the living body. These biomedical informatics pursuits seek to define, enroll, and entwine many living bodies into their projects.

By turning to the virtual representations, I highlight the need not only to take the materialities of communication more seriously, but also to take *relationality* more seriously. I claim that how we communicate through the internet lays a constitutive role in the making and solidifying of these new biomedical informatics sciences and practices. We might think of the world wide web as further producing 'virtual perception' in the sense of both thinking and practice.[2] In this way, representation is also treated dynamically. We are speaking in terms not only of image-making but also performance. Here, I use this idea in exploring the co-production of subjectivities in these biomedical informatics sites, showing that as site visitors and/or potential participants, we are not only caught in 'virtual perception,' but also aid in the creation and solidification of this perception.

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representation in participation, regulation, and ethical protocols in the development of these projects. See the literature cited in the deCODE controversy (chapter 3).

[2] I borrow this term 'virtual perception' from Katherine Hayles and will return to her discussion of it in Chapter 6. See Katherine Hayles' How we became postmodern: virtual bodies in cybernetics, literature, and informatics, Chicago: University of Chicago Press, 1999.

'Personal choice' does not mean active participation nor does it mean absolute freedom to choose. The proponents of these projects make many promises, in particular, the development and delivery of individualized medicine and personalized health management. However, they also claim that individuals will be partners and collaborators in these endeavors. By turning to case studies, I am able to examine in local spaces the sponsors' virtual representations of their endeavors, and to show that attempts are made to inscribe the marks and practices of certain identifications in and through these entirely absent bodies – internet users, buying consumers, dutiful citizens, financially constrained individuals, potential patients, and manageable subjects.

In representing their projects to broader audiences on the web, the sponsors 'invite' site visitors, to assemble an identity and role for themselves within their deferred endeavors. However, I aim to capture specific configurations in which there are constraints to such assemblages created by human and nonhuman actants.[3] In doing so, I highlight the relational (re)presentations of (genomic) information, genomic medicine, genomic databases, and the participants (as individuals or populations). The specific assemblages, or configurations, modify both the ways of thinking about the human body, genetics, information, databases, and their relational roles with one another, and the way potential participants are to perform their roles in these endeavors.

While the websites are conceived by some of the sponsors as sites for practicing their work, the science and the databases themselves are, like the bodies and dicine they seek, largely absent. There is work being done, but what seems to be forgotten here is that bioinformatic information, like news-related information, requires a medium or media. It needs to be embodied in order for it to be meaningful. In other words, this information needs to interpreted within this or these contexts to be understood. The three projects that I examine place too much hope in the absence of their own scientific and technological objects and envision too little as to what their actual subjects may contribute to their own understandings of and practices towards health and wellness.

[3] In these time-spaces of hypermedia, self-assemblage is not a distant concept or practice. In these virtual spaces re-making oneself is understood as a common occurrence. Therefore, borrowing these practices from the virtual realm seems quite 'natural' in these (re)presentations.

The problem with bodies in these virtual spaces (and therefore also in my project) is that they are largely absent both in the websites and in the endeavors. These are literally the absent objects, in the first case, for the obvious reason that these are virtual spaces and in the latter because these are emerging projects. By this I mean that they are either in the planning or very early stages. However, it is not only the envisioned or future body that concerns me here. It is the living body today. In fact, I insist that the bodies cannot be ignored. Further, although largely absent, bodies can be brought into the analysis.

Here, instead of the argued active role of participating individuals, I contend that these endeavors predominantly maintain and extend the modernist vision of the universal body. This is the body that is objectified, containable, manageable, and bounded. Active individuals – but not necessarily seen bodies (as highlighted throughout most of my dissertation) which are mostly absent – must be included at some points of these projects. However, whether seen or not, they are quickly translated out as they are transformed by scientists, states, networks, computers, and corporations. The knowledges, stories, and information, these individuals tell in print, voice, and body are digitized, coded, aggregated, disaggregated, validated, and thus transformed. In the future, although not the in the present version, they are supposed to be returned back to the individual in some prescriptive form – for medicine and/or of lifestyle management.

Biomedical informatics assumes that an organism can be known best through information about its body, its environment, and their interaction. It makes the problem that of ascertaining the right and best information from its sources, that is, its 'human subjects.' Best information is understood through a positivist lens that is, it is seen as the most objective, pure, and thus expertly validated. In effect, genomic medicine as rationalized medicine displaces the problem of individualized, messy, unpredictable illness. The de-contextualized data, derived from questionnaires and physical measurements, incorporate and yield a different mode of action for policymakers, scientists, public health workers than information obtained through actual interaction between scientists, doctors, public health workers, and patients.

2.2 > Emerging biomedical technosciences

2.2.1 > Public science: Large-scale human genomic population databases

According to proponents of genomic medicine, a primary purpose of human population genetics in medical research is to locate specific gene/s that are associated with specific diseases. In genetics, at present, single gene or 'simple,' but rare genetic diseases benefit the most from such work. That most diseases are complex, largely emerging from multiple genes, possibly in interaction with each other and the environment, makes this genetically-driven approach to common disease research difficult.

Still, the so-called post-industrialized worlds, primarily, North America and Northern and Western Europe (and some parts of Eastern Asia) are in the midst of an explosion of research and development of new scientific approaches and technologies into the area of 'common diseases' and genetics. One such approach is the development and implementation of large-scale human population databases. Here, a purpose of these databases in genomic medical research is essentially to ascribe a specific gene/s to a *common* disease/condition.

The production of the infrastructures of these database schemes is a complex undertaking. It requires interdisciplinary practices and knowledges, new collaborations. It is subject to widespread criticism about access, ownership, privacy and security issues. However, attempts to undertake such efforts clearly continue at a rapid pace on many fronts. Salient questions to ask, then, are 'How are the promoters of such endeavors moving toward their goals?' And, 'how are they coordinating their efforts?' Attempts to address issues of large-scale human population database projects, such as those that concern me here, are clearly in accord with biomedical and life science research goals.

The emerging practices of bioinformatics are central to the efforts of today's life and medical sciences. Nonetheless, there is skepticism on some fronts about what is sometimes described as the marriage of the life, medical, and computer sciences. One ground for skepticism is supplied by arguments about genetic reductionism. Another critique concerns security of the databases. This the second technological argument, is the dominant one. However, neither of these critically engage the communicative roles of media technologies, i.e. the internet, and the role of communication in constituting the subjectivities of various actants and the practices of the emerging biotechnosciences.

A number of other attempts have been made to problematize and critique DNA database activities in this arena of genetic medical research. Attempts are made from a number of fronts: scientific (on the genetics), technical (on the database), medical (from

practitioners), legal and ethical, based on bioethics.[4] A number of science studies researchers, anthropologists, sociologists, historians, philosophers, etc. have also addressed these issues.[5]

None of these large-scale population databases (neither the ones I examine nor similar endeavors) are fully formed. Therefore, many may consider this question to be premature. In critical discussions of emerging biological technosciences, it is important to locate and engage the work in process in its formative stages. True, in the early stages of a project, it is difficult to keep one's hands around the projects. At least one of the cases I examine, the database is still in its planning stage.

One area in which to view, investigate, and engage with the emerging aspects of these sciences today and the varied actants is on the web. In the following chapters, I focus on the representations of these technosciences and the envisioned relations between information, experiment, and subjects. I also investigate the conceptual and material makings of 'information' as the projects' sponsors seek to enroll and engage potential volunteers and publics. I do this by examining how information is circulated at their sites in the sponsors' efforts to characterize their endeavors to broader audiences, who may be potential participants and/or potential recipients. These examinations in these websites help me to explore the creation of subjectivities in bioinformatics endeavors because these are sites in which enacted and disembodied practices and visions are produced – to some extent – by, for, and with broader audiences, including, especially, the visitors to the websites.

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[4] For some ethics and policy issues see, Vicki Brower, "Mining the genetic riches of human populations," *Nature Biotechnology* 16 (April 1998): 337-40; Janet Kaye and Paul Martin, "Safeguards for research using large scale DNA collections," *British Medical Journal* 321 (2000): 1146-9; For some genetics issues see, "Genetic studies: look no further than your own backyard," *TIG* 16: 10 (October 2000): 440, I.A. Eaves, et al., "The genetically isolated populations of Finland and Sardinia may not be the panacea for linkage disequilibrium mapping of common disease genes," *Nature Genetics* 25 (2000): 320-3; P. Taillon-Miller, et al., "Juxtaposed regions of extensive and minimal linkage disequilibrium in human Xq25 and Xq28," *Nature Genetics* 25 (2000): 324-8.; Technological issues see for example, Jennifer Fisher Wilson, "The Rise of Biological Databases, " *The Scientist* 16:6 (March 18, 2002): 34; Karen A. Frenkel, "The Human genome project and informatics: a monumental scientific adventure," *Communications of the ACM* 34: 11 (November 1991): 40-52.

[5] See, for example, Michael Fortun, "Projecting Speed Genomics," In Michael Fortun and Everett Mendelsohn, eds., *Practices of Human Genetics: International and Interdisciplinary Perspectives, Sociology of the Sciences Yearbook* Vol. 19. New York: Kluwer, 1999; Joan Fujimura and Michael Fortun, "Constructing Knowledge across Social Worlds: The Case of DNA Sequence Databases in Molecular Biology," Laura Nader, ed., *Naked Science: Anthropological Inquiry into Boundaries, Power, and Knowledge*. New York: Routledge, 1996. Also, see the literature on the Iceland case and emerging work on the UK project (e.g. see Kaye and Martin). For literature on the Iceland case, see the chapter 3 on the deCODE case.

2.2.2 > Circulating Information

I began this dissertation with the question, 'what are genomic databases?' I do not mean, 'what is a physical, technical database' but rather 'how do they come to be?' because these database projects belong to the category of *emerging* technosciences. Studying emerging technosciences present its own special set of difficulties. Chief among them is that the objects and subjects studied are in the making. How can we study or even talk about them? Here, I show we can. In this project, I suggest that the web can provide a useful and important resource for exploring and investigating them.

In this project, information is dealt with on two levels. Information is the stuff of genomics, the content, the *thing(s)*, the scientific objects, inside these databases.

> It became clear that a feature of biomedical genomics research which needs to be borne in mind is that it is as much about informatics and use of genetic and biomedical information as it is about access to and use of material samples.[6]

The importance of information, collecting, storing, and manipulating information is not given short shrift by the proponents of genomics. However, by providing a careful and close analysis of their representations, that is, of their information and news about their experiences with developing these endeavors, I want to illustrate how information is explained and deployed by the sponsors, in some cases even before data translations and manipulations can be imagined, that is, before constructing digitized information.

In particular, I investigate genetic 'information' in several life-information-driven endeavors, which aim to create large-scale population databases. This will be achieved through examining the representations and the relations made through the projects' web presence. In doing this, I contend that if we want to better understand and discuss these emerging biomedical technosciences, it is very useful to conceive of these projects/databases as hybrids. By this I mean that they are co-produced by a number of human and non human

[6] Tom Wilkie and Pat Spallone, quoted from the Medical Research Council and Wellcome Trust's Report *on the Workshop on Human Biological Sample Collections,* (November 1999): 3. Available through the MRC's website. <<http://www.mrc.ac.uk>>.

actants, but further they are complex constructions. In viewing them in this way I suggest the following:

1. We cannot merely stay focused on the 'technology.' Here, I mean on the physical object and in this specific case, the construction of the database. However, I also do not want to stay simply focused on the population that is to be studied. Rather, I suggest that a stronger consideration on *relations* and *processes* are especially needed. In particular, in this project, I turn to that of *communication*.
2. Even though we are speaking about *information*, we need to think about this in an especially complex manner. Information is presented in a number of ways in these endeavors. In my project, I want to examine how (genetic) information is circulated in the sponsors' websites, particularly in relation to their (re)presentations of their database projects and potential participants and/or populations.
3. Understanding the representations of these databases is important because these latter have not yet solidified into *the* physical objects or produced certain knowledge. In particular, I contend that their virtual representations are especially significant, in that they provide a lens to these bioinformational public endeavors, which can highlight process and dynamism. These virtual representations illustrate certain machinations of the project's multiplicity (elaborated below) – e.g. in which they are treated as resources, databases, collections, and studies. Yet, if we consider the websites as configured spaces, these multiple representations are seen, or are created, within a 'single moment.' This is so even though within the sites there are different 'orderings.'[7] I use these different orderings to refer specifically to distributive- and boundary- work in the sites. Law and Mol describe 'multiplicity' as "about coexistences at a single moment."[8] I borrow this idea in this project. In the moment, or rather within a website visit, multiplicity (produced in specific configurations or

[7] These terms are borrowed from Law and Mol. Law and Mol raise the concern over the simplification produced in idea of single order produced in modernist frameworks. In particular, they point to dualist frameworks. An example, might be abnormal/normal that expel complexity. Instead, they suggest a framework of orders occurring in single moments. They work towards this by putting the ideas of multiplicity and singularity to work. Their aim is to take complexity seriously and to go beyond the usual critiques of simplification that occur in technical and scientific practices. See John Law and Annmarie Mol, introduction, *Complexities: Social Studies of Knowledge Practices*, eds. John Law and Annmarie Mol, Durham, NC: Duke University Press, 2002. The works in the volume they edit aim to illustrate complexity at work.

[8] John Law and Annmarie Mol, *Complexities*: 7.

assemblages and made at specific times to site visitors) works to provide a sense of singular (whole and stable) endeavors. These 'moments' give these projects coherence and a *real*stic appeal.

4. In other words, I demonstrate that multiplicity is constitutive in establishing the coherence of these projects. These multiplicities are important in illustrating orderings and distribution – inclusion and exclusion – to certain representations of the projects. In creating coherences, for example of an object or project, several things are going on: structuring, ordering, including, and excluding. In the following, I attempt to illustrate these processes in the cases I study. By doing so, I hope to highlight co-production of *subjects* in these processes.

Specifically, I investigate the web presence of several emerging large scale human genomic database endeavors to get at:

a. how these projects are planned and practiced and narrated in, by, through some aspects of information technology,
b. how information is (re)presented, and
c. how relations between genetic population databases/collections/studies and individuals are constructed.

By exploring the web/cyber/internet presence of specific biomedical technoscientific ventures, a salient question might be stated as a starting point "What kinds of relations are created in each endeavor in, through, by certain conditions?" Another emerges – What are the conditions? Here, I want to take seriously that local conditions do matter and the relations are not inherent or inevitable. Rather, they are configured. They are an assemblage of human and non-human actants. These questions are important for exploring subjectivities in these projects. Further, in this dissertation, I want to address the creation of the databases and participants in a 'single moment,' instead of speaking about the emerging databases separately from populations and potential participants. These are co-produced and complex constructions.[9]

[9] David M. Levy in his book, *Scrolling Forward: Making Sense of Documents in the Digital Age*, about the nature of documents makes a similar observation in his comparison of print and online versions of Walt Whitman's *Leaves of Grass*. He surmises that in simply treating books or computers as 'information delivery vehicles', we contribute to the fetishizing of information and their modes of delivery. Rather, his approach to evaluating the merits of these modes of communication is to "look to *their* specific material conditions and to *ours*." (57) In his

2.2.3 Virtually (re)presenting and (in)forming bio-technosciences

Bioinformatics is generally defined as the study of how information technologies are used to solve problems in biology. About two decades old, its vision is prediction. Through the application of expert systems, artificial intelligence, and search tools – in development – structures and patterns are located *only* from data.[10] Increasingly, internet technologies – including email, the world wide web, cyberspace – are constitutive of the emergent practices and discourses of the life sciences and their associated institutions.[11] Textbooks are written and conferences and workshops run that aimed to increase awareness of students and researchers in the life science readying its students and current participants of applications of information and computer technologies (ICT) in their areas of research.[12]

Despite many popular and academic critiques and discussions which point to the commercial and consumer aspects and takeover of much of the web, in the work of the life sciences, information and computer technologies are still dominantly viewed as transparent technologies. I contend that communication technologies are not simply representing technologies (in the traditional sense), and that the websites are not simply devices of promotion for the creators of these endeavors. Rather, I suggest here an alternative investigative approach that takes seriously the idea that analysis of the complex, multidisciplinary, and emerging practices involved are necessary for characterizing the projects and their associated technologies.

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example, he provides personal observations about the anxieties he experiences in reading his own childhood print version of Whitman and a web reproduction.

[10] See for example, Minoru Kanehisa, *Post-Genome Informatics*, New York: Oxford University Press, 2000.

[11] For the increasing role of databases and online computer networks in the life sciences, see for example, M. Mitchell Waldrop, "On-line archives let biologists interrogate the genome," *Science* 269: 5229 (September 8, 1998): 1356-9; Nadia J. Martin, Tracy Primich, and Ruth A. Riley, "Accessing genetics databases," *Database* 17:1 (February 1994): 51-9. William M. Gelbart, "Databases in Genomic Research," *Science* 282: 5389 (October 23, 1998): 659.

[12] See for example of an early text, see *Internet for the Molecular Biologist*, eds. Simon R. Swindell, R. Russell Miller, and Garry S.A. Myers, Norfolk, England: Horizon Scientific Press, 1996. For a more recent volume, see Stuart M. Brown, *Bioinformatics: a biologist's guide to biocomputing and the internet*, Natick, MA: Eaton, 2000. For a historical perspective see Timothy Lenoir, "Shaping Biomedicine as an Information Science," in *Proceedings of the 1998 Conference on the History and Heritage of Science Information Systems*, eds. Mary Ellen Bowden, Trudi Bellardo Hahn, and Robert V. Williams, Medford, NJ: Information Today, Inc., 1999: 27-45. An online version of this paper can be found at Lenoir's homepage: <http://www.stanford.edu/dept/HPS/TimLenoir/shapingbiomedicine.html>.

In the essay, "Image Technologies and Traditional Cultures," the philosopher of technology, Don Ihde states, "The photograph, more than merely representing, 'teaches' a way of seeing."[13] We could extend his argument to the world wide web. It too is a media technology, Ihde's term, targeted towards various audiences and explicitly presenting various 'ways of seeing.' However, I do not think that Ihde goes far enough. Borrowing from science and technology studies, which analyze representation as practice, I will demonstrate that political work, in which ordering, structuring, and exclusions in practices, goes on. The aim of this project is not to ascertain intentionalities in the design of the website. Rather, the turn to the web representations provides a lens to explore the production of subjectivities (of site visitors, individual participants, and/or populations) in human bioinformatics projects in the communicative media technologies of the website examined in chapters 3-5.

I contend that the genetic/genomic population database in disease research – how they are understood, what they are becoming, and how practiced – are mediated by and mediate some notion of the web – especially in terms of information and our relations to information about ourselves – and how it is understood. The point is not that internet and computer technologies perniciously dominate life and medical sciences. Rather, it is that these databases are multiple and emergent, yet nonetheless, coherent and singular in their forms. I use their web presence to illustrate these claims.

2.3 > Technologies & Systems of Representation

2.3.1 Materialities of representation

I begin with a claim that, at least on a general level, science constructs its objects through a process of differential marking. In other words, scientists classify and categorize.[14] Further, systems of representation have rules and conventions about how they are organized. For example, such languages, as English have a specific grammatical framework, syntax, rules, etc. However, other systems of representation, such as painting, photography, television, and the World Wide Web also have rules.

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[13] Don Ihde, "Image Technologies and Traditional Cultures," Ch. 9 in *Technology & the Politics of Knowledge*, eds. Andrew Feenberg and Alastair Hannay, Bloomington: Indiana University Press, 1995: 151 (147-58).

[14] See Geoffrey C. Bowker and Susan Leigh Star, *Sorting Things Out*: Classification and its Consequences, Cambridge, MA: MIT Press, 1999.

Historian of science, Timothy Lenoir contends that the consideration of communication technologies and technologies of representation become fundamental if science is understood to create knowledge in this manner. Furthermore, he argues that science makes its object(s) of investigation stable through public forms for the construction and dissemination of meaning. In other words, for Lenoir, media are 'machines' that mediate and stabilize our representations. They are 'extensions of the senses' and 'create the space within which the scientific object exists in a material form.'[15] He states that,

> Media are not a mere supplement enabling the extension of research into areas where theory is insufficient to tread. Rather… attention to the materiality of inscriptions themselves will demonstrate the extent to which inscription devices actually constitute the signifying scene in technosciences.[16]

Following Lenoir, I contend that scientific representation is historically, locally, and socially situated. However, unlike Lenoir, I want to extend the semiotics and language/representational analyses. Here, I adopt certain aspects of actor network theory, especially those derived from John Law, Michel Callon, and Bruno Latour.[17] The first is the idea about *relational materiality*. John Law describes relational materiality as a "ruthless application of semiotics" or a "semiotics of materiality." This position emphasizes the relationality of entities. These entities are produced in relations. However, it goes further than traditional semiotics, applying this production to all materials – not just linguistic ones. In my project, I do this by taking up web technologies into my analysis of these database endeavors.

Second, is the idea of *performativity*. In the semiotic approach, entities achieve their form as a consequence of the relations in which they are located. However, the actor network (ANT) approach emphasizes that these entities are performed in, by, and through these relations. Performed in and by these relations, entities can be constrained, made durable and fixed, but never given, since, in principle, everything is uncertain and reversible, that is, never give in the order of things.

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[15] Timothy Lenoir, Inscribing *Science: Scientific Text and the Materiality of Communication*, ed. Timothy Lenoir, Stanford, CA: Stanford University Press, 1998: 12.
[16] Ibid., p. 12.
[17] See especially, the volume, *Actor Network Theory and After*, eds. John Law and John Hassard, New York: Routledge, 1997.

In other words, in this project I want to adopt the aspect of actor network approach that draws attention to more than language. In particular, I borrow Latour's focus on the way inscriptions and inscription devices are mobilized as part of the process of recruiting allies and constructing networks. However, I hope to contest an *a priori* claim that lurks in his analyses of technoscientific systems.[18] Technologies of representation of the web – especially hypertext – can be mobilized to create a sense of totality and seamless flow, but they can also be shown to fragment and create anxieties for their visitors.

Here, we may consider taking exception to Lenoir's claim. The question here is: do representing technologies always stabilize? Rather, I demonstrate that while the intention may or may not be to use them to do so, they may not accomplish this end. One alternative, as Rob Shields argues, is that at least one mediating technology, the World Wide Web, *always* destabilizes.[19] We may also take exception to such a totalizing claim. Rather, I consider the specificities and heterogeneous, or multiple, practices in which such technologies perform. Shields states,

> Pages are the most visible, machinic elements that deflect or attempt to channel the flow across the Net. It is not texts – as stable or even cut-up, but still clearly identifiable entities – but the movement of browsing that characterizes the World Wide Web, not the superficial stasis of the webpages themselves.[20]

This view positions the World Wide Web as something apart from the 'real' world. Shields speaks about the web as characterized by motion in an attempt to move away from metaphors of space and geography. He argues that while these metaphors are productive for getting at certain aspects about the web, they have contributed to views of the web as static and stable and flowing, thereby backgrounding the jumps, breaks, and disruption that characterize the web. Shields argues that these characterizations distinguish the web from traditional forms of modern representation, especially print. For Shields, hypertext links are the dominant instrument of the web and motion should be the dominant description.

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[18] For a more detailed discussion, see Latour's work on immutable mobiles see *Science in Action: how to follow scientists and engineers through society*, Cambridge, MA: Harvard University Press, 1987.
[19] Rob Shields, "Hypertext Links," *The World Wide Web and Contemporary Cultural Theory*, eds. Andrew Herman and Thomas Swiss, New York: Routledge, 2000 (Ch.7): 145-60.
[20] Ibid., p. 156.

While I am sympathetic to Shields' position, I find a 'totalizing' aspect of his argument, which I do not believe to be his intention. I suggest that closer, or rather more local, examinations provide rather different interpretations of the work that websites perform.

The dominant discourses are those of truth and relativism, in which representing technologies are presented as either mirroring nature/reality or as merely promoting individual or group point of views. In this project, I demonstrate how the web works in human genomic population databases in a way that does not fit the two dominant and polar discourses. Therefore, here, I pay attention to text and other methods of representation. However, what Shields' quote above implicitly points to is the relational aspect of the web, particularly in the 'browsing' of pages, and I attend to these as well.

2.3.2 World Wide Web: new regime of representation?

In "Opening one eye while closing the other… a note on some religious paintings," Latour discusses the concepts of regimes of representation and argues how a scientific regime displaces a religious one.[21] I would not go so far in discussing the world wide web, but I would suggest that its location in biomedicine and more broadly bioinformatics are presently contested. However, what we can find in Latour's piece is a helpful discussion of representation. I will describe it as differentiating between notions of representation, (re)presentation, and presentation.

Here, he describes representation in religious painting in the 15th century as meaning presenting anew *and* anew. He writes,

> A religious painting never offers direct access to the sacred. It is a renewed commemoration of what others – usually apostles or saints – said and saw. Were you to use this very painting to obtain information 'on how the historical Christ' looked you would be disappointed. And yet this *is* an exact *re-presentation* of Christ... (My italics) (21)

[21] Bruno Latour, "Opening one eye while closing the other… a note on some religious paintings," in *Picturing Power: Visual Depiction and Social Relations*, eds. John Law and John Whittaker, London: Routledge, 1988: 15-38.

This differs, Latour argues, from another type of representation forming and dominating at about this time. Here in describing Holbein's painting, 'The Ambassadors,' he writes about the terrestrial globe depicted,

> (The) globe… does also *represent* the earth, but what it means to represent has been deeply modified. The globe *stands in the place of the absent and large earth*, but it offers a reduced, manageable, and readable model of it. (Latour's italics) (22)

In other words, in this instance, the globe is *represented* in the previous instance Christ is *re-presented*. This difference is important to Latour because it reveals that what viewers can do with such representations is entirely different in these instances. According to Latour, both types of representations keep some aspect(s) intact but the aspects differ. In the new regime, represented in the second example above, relative distance is saved but in the old regime, metaphors, narratives, interpretations are saved.

Latour's discussion is lucid, but I would argue that his two regimes are totalizing and insufficient when turned onto the current (re)presentations of the biomedical technoscientific informatic projects considered here. However, it is not my intention to point out counter-instances to Latour's argument. Rather, it is to borrow his discussion of representation, here. For Latour's regimes of representation are especially helpful when we consider the time-scale of these emerging initiatives. Latour continues,

> In this new regime, the prefix 're-' of representation means that whatever is out there has already been inscribed, mapped, and drawn. The prefix 're-' is there to point out a two-way metonymic relation between the scale–model and the scale–one phenomena. It is not the ever-present that is presented anew, as in the old regime, but the realm of *absent*, distant, inaccessible, and unmanageable things that have already been mastered and dominated by sight *here*. The absent is made present *here*. The distant is brought *here*. The big is scaled down. The small scaled up. Places that one has never visited can be visited. We become familiar with the world once absent through the manipulation of its representatives and substitutes. (24)

What I borrow from Latour is the idea that the database – from the 'database projects' – offers a manageable, simplified version of these endeavors. Further, 'information' does the same for bodies/populations. I illustrate these moves through the virtual representations of these projects. In particular, I would argue that the websites when taken as a whole provide a

stand-in for the absence (or the actualization) of genomic medicine. Further, when examined more locally, their (re)presentational acts of their projects also illustrate the kind of representation described by Latour of manageable, inaccessible subjects/participants for these bioinformational endeavors.

To demonstrate the complexity of the projects and these machinations, I choose to stay close to these websites and I insist that hypertextuality appears in the analysis. I follow the works of Law, Latour, and Michel Foucault, and here described by Law and John Whittaker, "that it is the specificity of the methods by which politics is pursued that deserves study."[22]

From here, I differ with Latour. I want to get at concerns about distribution and so I focus in at the local level of specific websites. Here, I describe the work of inclusion and exclusion generally as boundary work. Geoffrey Bowker and Susan Leigh Star's *Sorting Things Out: Classification and its Consequences* may help us to start thinking about some of the issues here. Their aims are somewhat different from my own here, but their work on classifications does have some overlap. Bowker and Star are essentially concerned with large bureaucratic category making. They seek to understand how categories are made in large bureaucracies and kept invisible. This theme is important for my project, which examines web representations in terms of hierarchical schemes, as to what counts as knowledge, the roles of individuals and groups, and decision-making. In addition, my concerns overlap more specifically with their concerns with medical informatics and somewhat on disease classification. In this project, I focus on how classification schemes are emerging rather than how they are operationalized in bureaucratic environments, which their work focuses on.

Information is not knowledge. A major issue about the web and information is the issue of knowledge and classification. Bowker and Star's concept of invisible work in classification and categorization is helpful here. We know there is a lot of information on the web and this is and will continue to grow, but what does it all mean? How is it structured? Who is structuring it? The authors write, "finding information (on the Net) is much less of a

[22] John Law and John Whittaker, "On the art of representation: notes on the politics of visualization," in *Picturing Power: Visual Depiction and Social Relations*, eds. John Law and John Whittaker, London: Routledge, 1988: 180.

problem than assessing its quality – the nature of its categorical associations and by whom they are made."[23]

They point out that "The material force of categories appears always and instantly."[24] In regard to this view, I pay attention to the design of the websites and the work that they do in creating certain hierarchies and in the networks created. For example, I pay attention to hypertext links in order to highlight the associations, which emerge. Here, again, I follow Bowker and Star where "Every link in hypertext creates a category. That is, it reflects some judgment about two or more objects: they are the same, or alike or functionally linked, or linked as part of an unfolding series."[25]

In addition, my aims might be viewed as equivalent to Law and Mol's aim to devise a discourse of more than one but less than many.[26] In other words, it is to explore other ways of examining the practices of genomic population projects that do not collapse into simply issues of public/private science or into linear narratives of progress, from science to technology to the public nor to claim that anything goes. The virtual (re)presentations highlight the work involved in sustaining coherent projects and in ongoing negotiations of 'information' and potential participants, both online and offline.

Here, I borrow their ideas of multiplicities and coherences. The representations of these projects produce multiple orders. These are orders, for example, of style, discourses, and frames. By closely examining these websites, we can draw out these varieties. By doing so, we can see that the representations of the projects, the databases, the participants, the site visitor are not singular, but multiple. However, together presented in a site they present more coherent endeavors.

2.4 Notes on technologies of representation and the life sciences

The websites of these projects have been largely ignored. Even in many cyberspace and technology studies, information and computer technologies (ICT) are treated as simply transparent media. These studies divide up the analysis of its contents from its technology,

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[23] Geoffrey Bowker and Susan Leigh Star, *Sorting Things Out: Classification and its Consequences*, Cambridge, MA: MIT Press, 1999: 7.
[24] Ibid., p. 3.
[25] Ibid., p. 7.
[26] See John Law and Annmarie Mol, Introduction, *Complexities: Social Studies of Knowledge Practices*, eds. John Law and Annmarie Mol, Durham, NC: Duke University Press, 2002: 1-22.

that is, its mode or vehicle of transmission. Such studies tend to focus on inequality of access. No small problem or unimportant dilemma to be sure, but this project's focus is aimed elsewhere. In these ICT studies, the technologies become black-boxed. An argument I make in this project is that these technologies provide a productive avenue to consider multidisciplinary public/private individual/communal bioinformatic-biomedical endeavors and therefore need to be opened in new ways.

In an ethnographic study of laboratory work in a genetics laboratory, Christine Hine, provides us with a glimpse to how information technology (IT) is understood and used as an instrument of genetics. She interprets various genetics researchers' comments, and argues that these scientists use information technology strategically. Hine shows that information technology, computers, and IT developers are understood as primarily invisible within this laboratory setting. Further, she argues that the scientists' attitudes toward information technology and IT developers in their laboratory and work significantly contribute to an understanding of information technology as providing a transparent window on nature.[27]

In the DNA Sciences chapter, I carry this argument further in the sense that I extend the idea of the laboratory and extend Hine's use of information technology to the internet, not only databases. Further, rather than concentrate on physical practices, I attempt to illustrate how the practices are articulated by focusing on how information is conceived and circulated and knowledge constructed at, by, and through the sites. In doing so, I also extend the notion of scientific practice as well as the notion of scientific laboratory.

In addition, these sites can be seen as clinical research recruiting centers. These are public science projects, in the sense that they require participation from non-scientists. Therefore, I want to take up the roles (or envisioned roles) of volunteers/participaters/visitors in this project. Some of these are: consumer/volunteers, subjects/objects, and human subjects/experimental objects. The constructions and circulation of these identifications are explored, particularly in relation to time/space disturbances that the web may lend itself to. Thus the websites are *real* spaces in which representational acts are performed. The representations they produce stand in for absent

[27] Christine Hine, "Information Technology as an Instrument of Genetics," *Genetic Imaginations: Ethical, Legal, and Social Issues in Human Genome Research*, eds. Peter Glasner and Harry Rothman, Aldershot: Ashgate, 1998:41-56.

objects, for example, actual sites, physical database, genomic medicine, populations/bodies. The sites are spaces of production.

In the following case studies, I show the specific uses of the web and its associated methods of representation. As a new medium, with its own constitutive methods, its uses in representing science are ambiguous. Legitimacy, ownership, and access to information, knowledge, and its production are (re)configured in these modalities of representation. These technologies are legitimate sites of investigation in their own right. They cannot be assumed to be transparent, merely reflecting science, or rhetorical devices for those advocating or resisting certain sciences.

I draw attention to different modes of informational and representational technologies that can be used for difference-making. The creators of these projects can mobilize these to do boundary-, enrolling-, and legitimizing- work. For example, I highlight one section of a website, such as the <Disease Center> for the broader publics versus <Products & Services> for potential commercial partners at DNA Sciences site, <Publications> versus <Diseases> sections at deCODE's website, and expert workshops and report documents versus public fact sheets in the UK project. Further, I highlight how the design, layout, and links/associations made through and by the web sites contribute to the sponsors' representational acts of their endeavors and the audiences they seek or envision generally as means to create more *real*stic and/or projects that cohere. In producing mulitiplicity, these seemingly self-contained sites can (re)present coherent endeavors.

However, for the website visitor, or a potential participant in these endeavors, tensions can be produced. Hypertextual anxieties are found in the new and old technologies of representations converging in representational endeavors on the web. They are found in hypertext and hyperlinks that can be indicators for time/space disturbances, of tensions, and anxieties in the move from real to imagined spaces. Other forms of representation might have been closely examined, for example, print, video, or audio, but my turn to web representations is to use and critique a current techno-cultural force which both produces and undermines the coherence or stability of these bioinformatic endeavors today.

However, this project is not concerned with the intentionalities of its site designers. What I am concerned with is how subjectivities are created in these spaces and how these are

intertwined with the production of technoscientific knowledge and practices. Site visitors may embody these practices. This may be a period in time in which the tension can be highlighted better, in that these practices are still vaguely foreign for some of us more than for others. Here, I aim to capture some of these tensions.

The three case studies take up several issues of technology/language through their virtual (re)presentations. On the one hand, I suggest that the database endeavors are always in an unfinished state. There is no completeness or closure, even though the dominant discourse that surrounds these endeavors is in terms of security and containment. Information from individuals needs to be constantly updated and linked to them to some extent. On the other hand, the focus of this project is the virtual presence of these endeavors – in the area of the world wide web.

Here, I explore the connections between the virtual and actual sites of the sponsors of these endeavors and the sites used to (re)present the endeavors. In particular, I draw attention to associations made between a virtual site to its actual, physical site, for each endeavor: e.g. the use of maps & directions at DNA Sciences or the use of photos in deCODE. It is to locate once again, the tension between the actual and the virtual in these web representations of bioinformational projects that aim to be actualized, but are swimming in the sea of the virtual. The very work of these endeavors to collect 'types' of information about individuals, and then to translate, transform, and digitize that information will yield some virtually real information. However, how this information can be representative of an individual or even a population can only remain – at most – in the domain of virtually so.

3. 1 > Siting the DeCODE Genetics project[1]

DeCODE genetics, an Iceland-based genomics, health information company, was formed in 1996.[2] At that time, Kári Stefánsson, an Icelander, working as a neuropathologist at Harvard University in Boston, Massachusetts began this biotechnology venture. Stefánsson has been largely identified with the database endeavor, but, in this chapter, I engage the Icelandic project, focusing on the company's website rather than any one individual, as representing, (re)creating, and performing the project.[3]

I provide an argument, perhaps a plea as well, for the necessity to examine these bioinformational projects from a more techno-social perspective. I do not forget about the technological artifact, but I want to put it back into the technosociological process. In doing so, I suggest the need to develop other avenues of engagement, in which hypertextuality is brought into the analyses of representational endeavors. The websites could disappear tomorrow as could these projects, but still they remain important sites of engagement today. Specifically, in these cases they are important in efforts to understand the 'emerging' of

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[1] <<http://www.decode.com>> [Accessed and archived May 7, 2002]. In 2002, the English version could also be accessed at <<http://www.decodegenetics.com>>. According to Alexa Internet, a company that tracks and archives websites, this site has been online since May 19, 1998, while decode.com is relatively newer having been online since December 8, 1999. Further, the company reports that more sites link to the latter, 219, in comparison to 17 for the former while 157 sites link to the Icelandic version. [<<http://www.alexa.com>> last accessed July 24, 2002].

[2] The ambiguity of deCODE's status is an issue. Opponents of the endeavor point out that the company was incorporated in Delaware and the $12 million of venture capital originated from the U.S. Stefánsson describes the company as an Icelandic company. He argues that the majority of deCODE's approximately 500 employees are Icelandic, that it is headquartered in the capital, Reykjavik, and that its geno-typing laboratories are housed and operated there as well.

[3] That so much is written about Kári Stefánsson is itself interesting. Unlike the other two cases studied in this dissertation, the Iceland endeavor is not only linked but very much identified with a particular individual. This identification is made across the board from various media outlets to the literatures of bioethics, biotechnology, science, and science studies. Stefánsson is also very good at self-identifying himself with the project. In a recent interview in MIT's *Technology Review*, Stefánsson himself summed it up in the following manner: [D]on't forget that I come from Iceland. My family has lived in Iceland for 1100 years. There is a certain adaptation that has taken place. We fit this sort of wet, barren, dark corner of the North Atlantic. That does not necessarily mean I like every aspect of it, and I miss America a lot. It was a great place for me; this was a community that was extremely generous to me. I learnt an awful lot here. I'm running a company in Iceland that is fundamentally run on American philosophy. It fits pretty well there. ["Population Inc., Q & A: Kari Stefánsson," *Technology Review* (April 2001).]

emerging biomedical informatics science and research. They are important to relationally understand how certain practices that incorporate genetics, health, computers, and communication technologies seek to *establish* themselves while seeking to enroll and/or involve broader publics by co-constructing objects and subjects.[4]

DeCODE, a tiny start-up company, began with twenty employees. It became widely and internationally known from near its inception. The venture emerged on the front pages of popular media and discussion about this firm and its endeavor ended up on the agenda table of several government committees as well as academic conferences in the late 1990s. Throughout the 1990s, biotechnology companies were a dime a dozen. Why did this one receive so much attention by such a broad audience?

Its initial renown seems to have emerged from its combined endeavor with the state of Iceland to create a large-scale human genomic database covering the entire population of Iceland. The company described its plan to create a population database that cross-referenced medical, genealogical, and genetic information of all Icelanders. These various types of culled information were to come from individuals in the current population of Iceland, numbering about 275,000 today, but also past and future generations. In order to attempt such a project, the company required access to sources for all of this information.

Genealogical information in Iceland is widely available and deCODE set out to establish its own genealogical database of the Icelandic population. It still required the requisite resources for the medical/health and genomics component. Stefánsson approached the state of Iceland with his plan to obtain medical/health information. A proposal was put forward to partner with the government to create a comprehensive, computerized database with such information. A draft for an Iceland Health Sector Database act was on the table of the Althingi (the Icelandic Parliament) by 1998.[5] According to deCODE's website, that year, the number of its employees rose to one hundred, a five-fold increase barely two years after its inception.

This database project elicited great derision from a number of prominent academics, from the natural and social sciences and humanities, around the western world. By 1997, the

[4] The sites do this in terms of having pages deleted and replaced. Associations in the form of hypertext are also deleted or replaced. These may be virtual but they may also be more than this.

[5] The Icelandic Health Sector Database Act can be found in full text at the Icelandic Ministry of Health and Social Insurance website. <<http://www.althingi.is>>

deCODE/Althingi effort became internationally well-known *and* controversial.[6] The project became a popular subject in science media, cultural academics, and bioethics circles, at least online in Western Europe, the United States, and Canada. This popularity may have been helped along by a national organization in Iceland, called Mannvernd.[7] Icelandic, for 'Human Protection,' this organization became and continues to be a watchdog of the project and an on-line clearinghouse for information, providing such in Icelandic and, to the relief of many international critics, English.[8] International interest emerged from varied disciplinary, institutional, and non-institutional communities and individuals. Further, boundaries were drawn among the groups as to what kinds of questions could be asked by whom and about what – genetics, database, policy, law, medicine, and ethics. [9]

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[6] For science studies sources see Gísli Pàlsson and Paul Rabinow, "The Icelandic genome debate," *TRENDS in Biotechnology* 19:5 (May 2001) and 166-71; "Iceland: The Case of a National Human Genome Project," *Anthropology Today* 15:5 (1999): 14-8, Skúli Sigurdsson, "Yin-Yang Genetics, or the HSD deCODE Controversy," *New Genetics and Society* 20: 2 (August 2001): 103-17, Hilary Rose, "Gendered genetics in Iceland" *New Genetics and Society* 20: 2 (August 2001): 119--38; For bioethical discussion see George Annas, "Rules for Research on Human Genetic Variation – Lessons from Iceland," *New England Journal of Medicine* 342 (2000): 1830-3; Ruth Chadwick, "The Icelandic database – do modern times need modern sagas," *British Medical Journal* 319 (August 14, 1999): 441-4. For legal issues, see Henry T. Greely, "Iceland's Plan for Genomic Research: Facts and Implications," *Jurimetrics* 40 (Winter 2000): 153-91. Hróbjartur Jonatansson, "Iceland's Health Sector Database: A Significant Head Start in the Search for the Biological Grail or an Irreversible Error?" *American Journal of Law & Medicine* 26 (2000): 31-67 and D.E. Winickoff, "Biosamples, Genomics, and Human Rights: Context and Content of Iceland's Biobanks Act," *Journal of BioLaw and Business* 4:2 (2001): 11-7.

[7] While my focus has been on the initiators' sites, I have also attempted to follow their trails, if not their networks. In the case of the Iceland project, the initators' take us through networks of scientific publications and various, primarily, U.S. information clearinghouse and patients' groups. However, unlike the other two projects and their virtual sites, deCODE's project has an opposing force, which has followed its actions and intervened in a number of ways. This is the Icelandic organization, Mannvernd (the Association of Icelanders for Ethics in Science and Medicine), formed in direct opposition to its database project.

This association runs its own website and acts as a clearinghouse for deCODE database updates, but also for more general news about genetics research and medicine. Sources are obtained from and linked to around the (virtual) globe. Media, not only general and popular media in the United States, but also scientific and medical literature, cite this association. The international emergence of the Iceland project was no doubt raised in large part by this group.

[8] Mannvernd's website can be accessed at <<http://www.mannvernd.is>>.

[9] Feature stories about the company appeared in international media, from print, radio, and television. These were inseparable from Stefánsson. Several gave detailed biographies of his life. In the United States, lengthy stories appeared in a wide variety of nationwide print publications from the *New Yorker* and *Discover*, television magazine productions, such as CBS' 60 Minutes and ABC's Nightline, and radio, such as National Public Radio's 'Sounds Like Science' and 'Talk of the Nation.' Further, even local and state publications ran major stories on deCODE, some finding their way on the front page – even in New Jersey! In addition, stories and updates about deCODE and interviews with its creator, Stefánsson, were easily

During the late 1990s, the main public issues seemed to be those of database privacy and security, genetic discrimination once the database(s) are up and running, and public participation/volunteers in creating a genomics/medical database. These continue to be the focus. However, these issues revolve around the *potential* use of the database. Nobody seemed to ask – at the local level, 'what is a human population genomic database?' I do not mean in terms of its technical infrastructure. In fact, database specialists were asking biologists this question at the time, and continue to do so. Rather, the issue at stake might be put thusly, 'what – if anything – does an emerging genomic database *actually* do – now, today?' For me, this question raises the problems having to do with (re)presenting: building boundaries, categories, processes and structures in creating practices, concepts, identities, and identification, as much as with creating technological objects and things: databases and information.

What is the Icelandic Health Sector Database (IHD)? Yes, the IHD is an object of sorts. Here, I suggest that it is also more – and importantly, not other – than this.[10] I borrow Latour's ideas on representation in order to demonstrate how the IHD works as an absent object in the company's virtual representational endeavors. I do this to make a move that engages not only the question of 'what' but of 'how.' These virtual representational acts are constitutive to producing an understanding of these bioinformational projects and how they are practiced. Specifically, these large-scale population projects are public science, in the sense that they require broader support to continue – and it is these acts, and these audiences in which I am particularly interested.

In this dissertation, I focus especially on web and internet resources in my efforts to explore the concept of representation, and, in this chapter, several areas of the website are especially highlighted. These are the:

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found on the world wide web. See, for example, "Decoding a Nation's Genes," in *Popular Science*'s online edition: <<http://www.popsci.com/scitech/features/iceland/index.html>>. The Popular Science edition includes links including one to DeCODE's site. The June 18, 2002 *New York Times*' article is reprinted in the NYT online edition and includes a special interactive feature if a visitor logs on.

[10] Why is this difference important to capture? The Iceland database project triggered various discussions about public versus private science, privacy and security issues, and public and private knowledge. The discussions and debates focused on securing the database, an object, in which information from individuals is gathered, translated, and contained, and subsequently retrieved from scientists and researchers to produce knowledge. Additional understanding is needed here beyond an understanding of the technical structure of the IHD.

- home page – similar to a cover page,
- site map – similar to a table of contents,
- structure (of the website not the database), and
- 'contents.' – [In particular, discussions will focus on the IHD (deCODE, the Althingi, Iceland, populations, genetics, disease).]

The sociologists of science, John Law and Annmarie Mol develop the idea of an ontology of difference, which I borrow here. This allows me to illustrate the coordination of multiplicities and coherence through difference-making. In, at, through, and by the company's webspace, this coordination creates coherence and, at times, non coherences. The website provides a single moment and place in which a singular project emerges. Therefore, I show that these multiplicities are necessary in producing a singular project. These are needed to sustain and extend the IHD efforts.[11] The Iceland case/site emerges as an illustrative example of coherence and coordination through multiplicities, spatial and temporal disruptions, and fragmentation to create the endeavor. I argue that through such representational work, there is concomitantly the (re)presentation of an Icelandic population and potential participant.

Earlier, I discussed that the Iceland endeavor came under heavy scrutiny nationally in Iceland and transnationally, primarily from various professional organizations, media, and individuals. Some of the main charges levied against the health informatics company, deCODE, were that:

- Through its initial public offering, deCODE would effectively turn the Icelandic genetic heritage into a publicly tradable commodity. (See. e.g. Lewontin (*NY Times*))

[11] See John Law, *Aircraft Stories: Decentering the Object in Technoscience*, Durham: Duke University Press, 2002; Marc Berg and Annmarie Mol, edsl, *Differences in Medicine: Unraveling Practices, Techniques, and Bodies*, Durham: Duke University Press, 1998; John Law and Annmarie Mol, eds., *Complexities: Social Studies of Knowledge Practices*, Durham: Duke University Press, 2002.

- Its sample collection practices for the IHD are based on presumed consent. Critics argued that this basis was contrary to Iceland's own national as well as international standards of informed consent. (See e.g. George Annas (*NEJM*))[12]
- Securing the database and its contents (that is, its information)

I will illustrate through a study of deCODE's virtual site that while the IHD is directly presented in a strict sense as a medical records database of Iceland's entire population, for deCODE, another 'bigger' project is to create, in the larger database community's term, a comprehensive, database, not just of medical/health records, but of a database that can cross-reference varied types of information over generations of an entire nation: genealogical, genetic, and medical/health information. The even bigger project, in turn, would be a network with or distribution to a number of other databases. Further, in (re)presenting its endeavors, the site relationally (re)presents and in doing so redefines other technoscientific objects: its potential participants and 'genetic information.'

Eventually, in the Iceland case, the principal means of regulating the project was a database law to secure information for *the* Iceland database. This description of the project as simply a database one, framed public as well as academic discussions specific to the Iceland project and to the other cases presented in this dissertation.

The dominant discursive frame concealed other contentious issues. One issue in particular was that of Iceland's genealogical heritage. In deCODE's comprehensive database scheme, the company acknowledges that partnerships for accessing and some form of consent are necessary for ascertaining medical and genotypic information. However, the company maintains that Iceland's genealogical information is widely considered to be in the public domain and therefore requires no consent from the Icelandic population and/or individuals.[13] DeCODE's position is that the Icelandic genealogy is a common heritage. However, at the turn of the millennium, the company had been embroiled in a legal dispute

[12] There are many papers written about these controversies, primarily focused on the partnership between deCODE and the Icelandic state and the subsequent legislative act passed authorizing the database construction.

[13] <<http://www.decode.com>> Resources ► What is the IHD ► System Architecture and Data Security (from author's own archived site. May 7, 2002)

with another Icelandic company that had compiled much of Iceland's genealogical history, although this was not mentioned at virtual site.[14]

Rather than follow the representation of the endeavor through legislation, as many scholars have done, I pursue the project, as emerging practices in the life sciences, through a different avenue. By focusing on the internet, specifically the web, I illustrate some of tensions in the company's associations of the IHD, the company, and the Icelandic population through a mode of representation embraced in this industrial world. In particular, I focus on those tensions as they pertain to (genomic) information in the life sciences today (especially in genomics and bioinformatics), highlighting the processes in the narrative-making, relations-making, value-creating and the boundary work constitutive to these endeavors and a genomics vision. And in lieu of the dominant frame shaping much of the discussion of this bioinformatics project, in the following section, I turn to deCODE's virtual space to examine (re)presentations of events.

3.2 > Losing sight of a nation's body and bodies

3.2.1 > DeCODE's Genealogy Approach

What is deCODE's IHD project? In the public arena, it came to be described as a private/public scheme to turn a nation's genes into a commodity. Stefánsson made interview rounds in the midst of the Iceland database controversy supposedly to clarify this description. According to deCODE's officials and the Icelandic state, the Icelandic Health Sector Database (IHD), technically and strictly, is the medical/clinical records database. In December 1998, following deCODE's (re)presentation of the IHD, the Parliament passed legislation which also described it as a database, ultimately 'filled' with its population's non-gene information.[15]

However, what the visitor is confronted with through the company's website rather complicates this explanation. This might not be surprising. What is surprising is that the

[14] See deCODE's press release January 13, 2000 posted on their website and 2001 Annual Report: 33. For further discussion of collecting information for the three components of its database, see Appendix 1 of this chapter.

[15] The Althingi passed the HSD (Health Sector Database) Act sometimes referred to as the Icelandic Health Sector Database Act (and the acronym IHSD is used).

complexity does not emerge from a plethora of scientific, technical, mathematical, and/or computer jargon.[16] In the following, I want to pay attention to deCODE's (re)presentation of its endeavor in relations to the Iceland population and then its circulation and use of information.[17]

The website takes the question head on with its own section entitled <What is the IHD?>, located under the heading <Resources>. In this section, the IHD is located along side offline 'courses' provided by the company, hypertext links to locations of its researchers' publications, information about the company's interest in specific diseases, copyright information, and the company's policy on website privacy. Here, in this location and through these associations, a website visitor might infer that the site positions deCODE as the author/creator of this project. [See Fig.1]

This is further established when the visitor enters the sub-section <What is the IHD?>. The visitor is provided a description of deCODE's alliance with the Icelandic state. Here, there is an explanation of what the database should and can do, *as authorized by the Icelandic state*. This alliance was achieved through the legislative act and license provided by the Althingi and and the Department of Health and Social Security (DHSS), respectively. The license document is retrievable through deCODE's website, and the Althingi site and DHSS site are even linked here. Thus, deCODE (re)presentation of the IHD is further legitimized.

In this sub-section, then, what is the IHD?

> The database will collect information from anonymized patient records from Iceland's National Health Service and store the data in a secure computer system for clinical statistical analysis. The license also permits deCODE to cross-reference IHD data with the company's genealogical database and genotypic data obtained and analyzed with the informed consent of Icelandic donors. The linkage of these three resources will

[16] Further, deCODE, as represented by some of its key researchers including Stefánsson, goes to quite a bit of trouble to identify for us what the IHD is (as does the Iceland's parliament, the Althingi). In two different scientific journal articles, the company's scientists' elaborately describe the process of collecting data and the database's encryption and privacy system. Both papers even provide the same illustration with the caption, 'Methodology for encrypting personal identifiers in creating a population-based phenotypic list.'[16] Neither this process, nor illustration, is provided on deCODE's website.

[17] In this chapter, I focus investigate the website through January-December of 2002.

create a powerful analytical tool called the deCODE Combined Data Processing system (DCDP).[18]

Fig. 1 *DeCODE genetics' website outline (May 7, 2002)/ (Jan 26, 2002)**

Although DeCODE's site does have a search function and a simplified content (as described in the body of the chapter), at this date (May 7, 2002), it did not post a sitemap. Here, I have broken down the contents into its component pages. The homepage lists only the main headings in hypertext. These are: <Company> <Investors> <News> <Products> <Resources> and <Íslenska>.

- Company
  - Company Profile ---- The IHD – 'A Powerful Resource'
    - The Genealogy Approach
  - Business Model
  - Milestones
  - Management
  - Departments
  - Careers
  - Partners
- Investors
  - Stock Quote
  - Stock Chart
  - SEC Filings
  - Events
  - Reports
  - Contacts
  - Analyst Coverage
- News
  - Press Releases
  - News Archives
  - Events
  - Subscription
- Products ---- Genealogy Approach ---- Company Profile
  - Iceland HSD
  - The IHD Database
  - Gene Discovery
  - Functional Genomics
  - Database Services
  - Software
  - Pharmacogenomics**
- Resources
  - Open Courses
  - Publications
  - What is the IHD? ---- The DCDP
    - The License
    - System Architecture & Database Security
    - Oversight
  - Diseases
  - Copyright
  - Website Privacy
- Íslenska

Source: <<http://www.dna.com>>

The description reiterates the CEO's characterization of the IHD. However, the explanation enrolls science, technology, states, individuals, patients, contracts and licenses, ethics, history, and projections, but at the same time, it is also (re)presenting the already very public story.

[18] Page 68 of 822 – author's own archive of deCODE's site [downloaded May 7, 2002].

Further, the IHD is positioned here as one component of some larger public/private Iceland project, the DCDP. Strictly speaking, the 'IHD data' is the same as 'anonymized patient records' from the state's NHS. Cross-referencing this database with genealogical and genotypic data occurs through a new component of the company's, the DCDP.[19] This identification of the comprehensive database, the 'DCDP,' was absent from public discussions concerning the partnership with the state in the mid-/late – 1990s. Preceding this description of the IHD is deCODE's compressed narrative of events:

> On December 17, 1998, **Althingi**, the Icelandic parliament, approved **legislation** enabling the **Ministry of Health and Social Security** to grant a license to create and operate an Icelandic Health Sector Database. On January 22, 2000, Islensk erfdagreining, ehf., the Icelandic subsidiary of deCODE genetics, was awarded a 12-year license to build and run the IHD.[20]

DeCODE essentially provides the visitor with *its ending* of the story. Further, by the end of 2002, the links, this story, and the state license agreement with the Icelandic state have been effaced from the company's site, but in the following I will show that the Icelandic people are not forgotten in pursuing deCODE's endeavor. However, they must be redefined, re-identified, and/or transformed first into a value-able resource: aggregated genealogical information/database.

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[19] Technically, this would be the comprehensive database system. Issues about anonymization in the deCODE and other such comprehensive population database projects remain unresolved. For a debate that arose in the deCODE case about the technical problems of anonymity in such interlinked databases, see Nigel Duncan, "World Medical Association opposes Icelandic gene database," *British Medical Journal* 318 (April 24, 1999): 1096. Also see an exchange of letters that ensued from this article. These include: Gisli Ragnarsson, "Opposition to the Icelandic database is based on false information," *British Medical Journal* 318 (May 4, 1999): 1354, Ross Anderson, "Iceland's Medical Database is Insecure," *British Medical Journal* 319 (July 3, 1999): 59, and Gisli Ragnarsson, "Iceland's medical database will be secure," *British Medical Journal* (October 30, 1999): Rapid Response accessible at the *BMJ's* online journal site <<http://bmj.com/cgi/eletters/319/7201/59/b#5144>> [last accessed April 9, 2003]. Also see Tomas Helgason, "World Medical Association's Opposition to Icelandic Health Sector Database founded on Correct Information," British Medical Journal 318 (May 17, 1999): Rapid Response accessible at the *BMJ's* online journal site <<http://bmj.com/cgi/eletters/318/7194/1354#3171>> [last accessed April 9, 2003).

[20] Here, 'Althingi,' 'legislation,' and the Icelandic 'Ministry of Health and Social Security' are highlighted *and* hypertext. <<http://www.althingi.is>> [last accessed May 7, 2002].

But let us stay at the January/May 2002 site for now.[21] Here, the immediacy of deCODE's endeavor was also made clear: 'faster' and 'earlier' for 'efficiency' and 'change' so Iceland will not be left behind.

> The DCDP is expected to open up new avenues of medical research and facilitate the development of technologies leading to:
>
> - faster diagnostics, allowing for earlier treatments or changes in lifestyle.
> - Customized treatments, specific to disease subtype and with a lower risk of side-effects.
> - Better-informed, more cost-effective disease management strategies.
> - More accurate drug-targeting, leading to more effective, tailor-made treatment regimes.[22]

While the site's treatment of the question, 'What is the IHD?' briefly describes genealogical data, the website provides a separate division for the company's <Genealogy Approach>. The importance of genealogy is further illustrated in the website's architecture. It can actually be found through several avenues: found through its <Products>, it flows from the <Company> profile, and is linked to <The IHD Database>.[23] [See Fig. 1] DeCODE's 'genealogy database' is not described at a technical level. Unlike the medical and clinical database, the visitor is not told how the information is gathered into a computerized format.

But, here, instead, the visitor is treated to a description of a history of the Icelandic people and a characterization of the 'Icelandic population.' The Icelandic peoples' 'passion,' sometimes described as obsession, with genealogy is emphasized. DeCODE's role is one of sorter. Simply, the company organizes the extensive Icelandic genealogical records, translates

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[21] The May 2002 is the primary site in this study rather than the December 2002. The sites from January 2002 and May 2002 are almost identical. The text is updated, particularly in the news and investors' section, as expected. However, the design and structure are largely the same. In the pages I examine, I could have interchanged the pages, but for the sake of referencing I chose the later version. These sites, rather than the December 2002 site, also more closely resemble – at least in design – the site during the height of the 'Iceland controversy' in 2000-1. Here, in this chapter, I wanted to capture the (re)presentation and co-production of the IHD and Iceland population at this site, particularly as largely absent objects. These are presented especially in the January/May 2002 sites rather than the newer site. Further, these may well be (re)presented in the December 2002 site, but time constraints for this project prevented more detailed examination.

[22] Page 68 of 822 – author's own archive of deCODE's site [downloaded May 7, 2002].

[23] <<http://www.decode.com>> Company ► Company Profile ► Genealogy Approach (accessed May 7, 2002: 203).

it into digitized data, plugs it into a database in order to 'cluster patients with a particular disease sometimes into large extended families.' This Icelandic genealogical approach is then linked to the medical/clinical database. Further, within the same narrative, the visitor is told that the Icelandic people, in addition to their genealogical passions, are also excellent record-keepers. This is reflected in the Icelandic state's comprehensive medical record-keeping which the site points out dates back to the early 20th century.

The Icelandic genealogical approach is also linked to the genetic (component of the centralized) database, in which the company then compares the genotypes of both closely and distantly related disease sufferers. This, the visitor is told, is a much more efficient approach to isolating specific genes and/or mutations than among unrelated individuals. However, as the site reports itself, the real uniqueness of the company's approach is not the science, but the Icelandic population:

> DeCODE's research model marks an important step forward because the isolation of disease-causing genes has proven to be dauntingly difficult and complex in heterogeneous populations like those of continental Europe or North America. By contrast, an isolated population such as Iceland's – one containing little diversity and boasting extensive genealogies and medical histories – offers ideal conditions for the discovery of disease-genes.[24]

However, even though the Icelandic peoples have been working on its genealogy for hundreds of years, which is described to some extent on this page, the company transforms this genealogical resource into its own:

> The depth and comprehensiveness of deCODE's genealogical resources in Iceland are unrivalled by those available anywhere else in the world.[25]

DeCODE's version, through advanced computer technology and networking system, are unmatched, going beyond and (re)placing the hundreds of years of human record-keeping of Icelandic individuals of Icelandic genealogy into the company's narrative of deCODE.

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[24] Author's own archived site (Accessed May 7, 2002: 204).

[25] The deCODE genealogy database includes more than 680,000 records. According to the company, this covers more than half of all the Icelanders who have ever lived. More information can be found at deCODE's website.

However, the company lists the computerization of Iceland's genealogical records as one of its major <Milestones>. The site does not provide a link to its <Genealogical Approach> but it does provide one to its <IHD> here. Magnanimously, though, deCODE and its genealogical software collaborator, Frisk Software, have donated access to their genealogy database, which the named, 'The Book of Icelanders,' to the Icelandic nation.[26] In addition, they claim that they will eventually provide any individuals to the database. However, the database will be online, limiting access only to those who are World Wide Web-equipped.[27]

At this site/time/space, deCODE maintains a division between its IHD and the Iceland population, although attempting to establish a link, a bond, a mutual need. The site appeals to the Iceland's people. It can bring medicine and preventive healthcare to Iceland's population – 'faster' and more 'efficiently' with the population's information and participation. Here, deCODE is still in the timeline of Iceland's history, and deCODE works to enroll the Icelandic population in its endeavor.

3.2.2 > Subject/objects: (re)locating populations and communities

In the <Resources> section, and under the heading 'Open Courses,' the site explains that the company is directly, tangibly (offline), involved with the Icelandic public(s). The visitor is told that it is vital to the company's research and success to maintain close contact with 'ordinary citizens.' Just as we will see in the DNA Sciences project, in the next chapter, deCODE also asserts its 'dependence on the goodwill and trust' of its research base, here, the Icelandic people. Like the GeneTrust™ initiators, it plays the role of science educator online, although to a lesser extent. Rather, it offers public lectures to local 'ordinary citizens' of Iceland and provides lectures and shares teaching facilities with the University of Iceland and the University of Akureyi.

In a number of interviews, Stefánsson claimed that one of his aims through the database endeavor is to contribute to a restoration of national pride, science, and

[26] According to deCODE's virtual site, 'The Book of Icelanders' references 'Islendingabok.' This site provides a short history lesson to its visitor, informing him/her that this was the earliest preserved book of Icelandic history that was written around 1130 by Ari Thorgilsson the Learned. [accessed Dec. 4, 2002]

[27] Author's own archived site (Accessed May 7, 2002: 204).

achievement in Iceland. A form of this claim is reiterated in the company's mission in 2000.[28] DeCODE's headquarters, including its genomics laboratory, are in Iceland's capital, Reykjavik. It has invited 'thousands' of Icelanders to tour its facilities in an effort to maintain close contact, 'keeping the people informed and involved in its mission and activities.' There continues to be an Icelandic language division of the site. In an Icelandic version, it includes pictures of the facilities, and their construction, and surroundings that were not included in the English version. At the same time, deCODE's pharmaceuticals group is based in Chicago. Its biostructures group is based in Seattle. These groups conduct downstream development work on targets derived from deCODE's proprietary research in human genetics.[29] Attempts to forge various partnerships are not ignored on the website, since facilitating the creation of alliances is an explicit purpose of these biotechnology firms' sites.[30]

The company's claim to actively engage the Icelandic population is put into doubt here. The site works to secure more than an association with the Icelandic people. It seeks to make the Icelandic people identify with the company and not just to its endeavor. As we saw above, the work to enroll and (re)present Icelandic history into the company's own endeavors is produced not only in the text, but through the internal links, particularly the <IHD> links. These circle, or interiorize the links back into the site.

However, as the company expands, the (re)presentation of the Icelandic population (and its people) through the company's site is (re)distributed. External links also relocate certain aspects of Icelandic's history, population, and individuals within the political economy of global genomics and bioinformatics. By May 2002, deCODE had added <Pharmacogenomics> to its list of <Products> and expanded efforts to alliance-building. [See (**) Fig.1] The Iceland story (re)presented in the company's <Genealogy Approach> is further linked and distributed beyond deCODE's site. This is seen in the next two paragraphs on <The Company ► Partners>[31].

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[28] See footnote 23 (Mission statement posted at deCODE site 4.1.2000).
[29] See the company's news releases (especially July 2002).
[30] Many critics, however, point out that the company partners with many other international private firms and public institutions, providing more detail than I am able here to detail, about the machinations of biotechnology industry, which rely on such partnerships and alliances.
[31] <<http://www.decode.com>> [May 7, 2002].

Here, DeCODE genetics informs its website visitors that it seeks partnerships with a number of other organizations, seeking alliances with pharmaceutical companies, biotech firms, and healthcare institutions. At this page, the visitor is confronted with a list of its partners and abbreviated descriptions of the company's working relationships with particular organizations. Further, most of the organizations' names are in hypertext. These are not linked directly to more information about their relations. Rather, deCODE invites and provides the means for its visitors to travel to their partners' homepages in off-site links. Here, one can learn more – beyond their associations with deCODE – about Genmab, Applied Biosystems, Hospital and Physicians Collaborations, Partners HealthCare, Affymetrix, and F. Hoffmann-LaRoche.[32]

It appears that the world of biotech is as easy as a click of one's mouse. One need not physically travel or even make a long-distance call to Boston, Massachusetts to find out what Partners HealthCare is all about or Basel, Switzerland to discover Roche's work. While the company's network is represented as global and diverse here, there is a notable absence: the Icelandic population. While noted for 'certain unique qualities,' neither the Icelandic peoples nor the population are here with the company's <Partners>. They are not given active roles to demonstrate their uniqueness. However, as a public project and here, at its website – a public window – broader publics are addressed, and constructing a population of accepting database subjects is also at work. This constructing occurs only in certain spaces of deCODE's internal sections, which I turn to in the next section.

3.3 > Science Literature and Literary License

3.3.1 > Re(presenting) and Transforming Information and Text

[32] GenMab Biotech is a company, based in Denmark, that creates and develops antibodies for treatment; Applied Biosystems, based in California, is currently most known for producing instruments for DNA analysis, Partners HealthCare develops an integrated healthcare delivery system and was founded by Brigham and Women's Hospital in Boston and Massachusetts General Hospital, Affymetrix, based in California, is best known for producing 'gene chips,' and Hoffmann-La Roche is a Swiss pharmaceutical giant. While based in certain locations, the companies listed here have international locations and/or affiliations as well. See their websites for some of their current international locations and affiliations. <<http://www.genmab.com>>, <<http://www.appliedbiosystems.com>>, <<http://affymetrix.com>>, and <<http://www.roche.com>>.

'Information' takes center-stage, integral in genomic database research and by extension pharmacogenomics, and now more generally, in biomedical life sciences.[33] Genomics, as its pundits describe it, deals with and in data and/or information. They espouse the view that the life sciences are becoming information sciences to a broader audience.[34] These developments demand further examination of what we mean by data and information in specific contexts, and this requires an examination of what is represented, how it is represented, and to whom.

The display of public electronic resources is integral in the pursuits/performance of this start-up's project. Through the company's <Publications> section, a visitor can see for him or herself that its scientists publish – thus, virtually witnessing their expertise. Visitors are even led to the gateways in which these papers are housed, but access to full content may be guarded by other gateways (e.g. the operators of specific publisher's databases).

However, through another 'sub' space/section of its website, the visitor is always invited to 'participate' more directly in deCODE's science. Here, the visitor can learn more about deCODE's diseases, through the site's provisional resources on 'diseases.' The <Scientific Publications> and <Diseases> section are set up as separate subsections of its 'Resource' page. There are no hypertexts in its 'Scientific Publications' to the 'Diseases' section. However, there is an occasional link to a paper published by deCODE's scientists in the disease section, discussed below.

<Publications> 'Scientific Papers'[35]

In this section, the site announces and presents in hypertext, scientific literature that the company's researchers, including Stefánsson, publish dating back to 1997.[36] For this

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[33] For the centrality of 'information' in various life science work see e.g. Lily E. Kay, *Who wrote the Book of Life?: a history of the genetic code*, Writing Science Series, ed. Timothy Lenoir, Stanford, CA: Stanford University Press, 2000.

[34] See, e.g. Gary Zweiger, *Transducing the Genome: Information, Anarchy, and Revolution in the Biomedical Sciences*, New York: McGraw Hill, 2001.

[35] January and May 2002 websites.

[36] The literature that concerns scientific publication in science studies is relatively large. However, much less has been done on electronic publication. A study that focuses solely on the scientific literature in traditional print format from deCODE's scientists and what is available online and/or cited on the company's site could be done, specifically in regard to the status of bioinformatics. This is not within the scope of this project.

study, it is important to highlight the following issues about visual versus textual information, audience, format and design, and speed and accessibility.

Print publication is considered the standard method for publishing scientific literature. As might be expected, specific scientific communities hold specific publications as key to their fields and their members tend to read, refer to, and cite these. However, there are several internationally read journals, among them *Nature* and *Science*, that are perused by a general scientific and science media audience. These journals provided considerable reportage on the progress of the deCODE/Althingi project. Several articles also appeared in two standard, western medical journals, *British Medical Journal* and the *New England Journal of Medicine*. In addition, Stefánsson also published an early paper on the project in the first online medical journal, *Medscape*.

The multidisciplinarity of the database project can be illustrated in the range of journals that deCODE's scientists publish. The site presents the interested site visitor, a publication list, under the heading 'Scientific Papers.' Not all of its scientists' papers are presented. The list is updated when new, key papers are published. This is especially clear in the regular email news releases to investor and corporate information listservs. Any explanation of the key importance of new papers is sometimes provided in news releases from the public relations firm or in-house public relations personnel.

In addition, subscribers may, at times, also have access to pre-published papers. However, while a few online articles are available free of charge for some brief time-span, even these generally revert to subscription fee access. Electronic journal databases, such as SciMed and Medline, have existed for some years on the internet, prior to the generally accessible world wide web. These now exist publicly on the web, which makes such scientific literature indices and journals easier to access. Specifically, access to full content to some journals (with online content) is available. However, it is available only to those with internet access and subscriptions to journals with online content.[37] These representative articles demonstrate the company's researchers' expertise and inclusion in and collaboration with those in the larger scientific, especially genetics community.

[37] Such access could be personal but it could also be through some institutional access.

DeCODE's <Diseases>[38]

There is, however, no detailed explanation of the company's approach to studying common diseases at its website. Neither is there a detailed definition of disease. Although, if the site's visitors can access the published papers in the scientific journals above, they may be able to locate for themselves a more detailed position on common diseases, as complex entities. In addition, the company's CEO has offered his own rendition of the company's approach,

> When you're dealing with very complex conditions, like common diseases, you basically have to do it in a systematic manner. We are currently studying these diseases with very clear, probably often utterly wrong, ideas of what the disease is, what constitutes the disease, and where the margins between two diseases are. But when you look at these diseases unbiased by anything other than the data and the instruments that you have, you uncover fascinating things… [39]

The company's 2001 annual report also offered this explanation of current methods of studying common diseases and the company's alternative.

In this approach, the power of the database is an imperative. The larger the numbers crunched, the stronger the association, and the more 'revealing'/determining of what diseases *actually* are. However, also important is the databases ability to link to other databases. Here is one example:

> In view of the complexity of the preeclampsia-trait, finding relatively little overlap between the five-genome scans is maybe not particularly surprising. It is a fairly typical finding for genome-wide scans of complex traits performed in relatively small sample sizes. Merging raw data of published scans on a web-site and joining forces between groups studying the genetic background of preeclampsia might therefore greatly enhance the power of linkage studies to find maternal susceptibility genes in the future.[40]

In this article, DeCODE's researchers hold a view that the complexity of preeclampsia is best understood through a computerized database. Specifically, it is best understood through a computerized database equipped with a lot of raw power and ability to link with databases

[38] January and May 2002 websites.
[39] Kari Stefánsson, interview with EMBO reports (European Molecular Biology Organizaton) 21:11 (November 11, 2001): 965 (964-7).
[40] "A genome-wide scan for preeclampsia in the Netherlands," August MA Lachmaijer, et al. (including Augustine Kong, Jeff R. Gulcher, Kári Stefánsson), *European Journal of Human Genetics* 9 (2001): 763

from around the globe. However, some one, or *some thing*, must be able to transform as well as aggregate the 'raw data.' Consequently, for deCODE what is also necessary is a powerful system, hardware *and* software.

Therefore, it is not surprising that the ubiquitous 'we' have got the concept of disease (or an understanding/construction of disease) wrong. It is not surprising to find a 'Disease' section, which covers those of deCODE's research interests in specific conditions and explanations for what these diseases *actually*, or 'really' are.[41] In this section, the site visitor finds that deCODE researches many diseases, each introduced here. The sorts of information and the design of the presentation vary to some extent, but there are some general themes that emerge from examining the different presentations. It is worth noting that while Stefánsson and some of the company's researchers go to some considerable length in discussing disease in interviews and some of its scientific publications, here, there is no additional information about how some of the conditions presented are contestable as diseases nor, as mentioned earlier, does the site provide information about what is meant by disease.[42]

Rather, unproblematically, this section of the website presents 47 conditions on which the company currently conducts research or has some interest in. These are categorized into types of diseases:

> autoimmune disease, cardiopulmonary disease, cancer, central nervous system disease, eye disease, women's health, metabolic and other diseases, and lastly a category for other research projects.[43]

The visitor to the deCODE site can find an explanation of these categories as well in the <Products> section since this section on <Diseases> is directly accessible, that is linked, from there. Noting that deCODE's 'diseases' can be found in the company's <Products>

[41] DeCODE's databases may be able to tell us what diseases actually are but can they tell us what they potentially may be?

[42] Further, none of the other sites that I present in this study raise the issue over the question as to whether or not genetic disease is as easily expanded to the conditions or 'common diseases' that the company has their eyes on.

[43] This last category also has the entry, longevity. This area of study is also of interest in the GeneTrust™ and UK BioBank projects. As another note, in a more recent access date to the company's site [July 7, 2002], another entry can be found: research on the origins of Icelanders.

section further highlights 'diseases' ambiguous status as understood in a supposed unbiased way, as the company intends, and/or manufactured.

In order to present the company's progress in studying these 'common diseases,' a chart is provided with the following headings, on the horizontal:

'Linkage analysis' 'Locus identified' 'Disease gene isolated'

The conditions are listed, on the vertical, within specific categories, above, and checks are made under the headings, presumably indicating the tasks that the company's researchers have accomplished. The site explains that the company's gene discovery program is focused on identifying the genetic factors of some 40 diseases, having already mapped around some 20 disease genes, and announced the identification of three specific disease genes.[44]

The conditions listed in this chart are all presented in hypertext, linking them to individual pages, with cursory summaries of the 'disease.' Some entries also provide some cursory information of the work that deCODE has done in the area. Many of these entries provide statistics on how prevalent, or rather in the company's words, 'common' the disease is, especially in North American and European populations. The visitor is provided with additional sources of information about the 'disease.' These are in the form of hypertext that link to another site and, on occasion, a hypertext link to PubMed's citation of a paper written by deCODE's scientists. Generally, the off-site links tend to be to national organizations or information clearinghouses from the United States.

In describing this resource section on diseases, I highlight several characteristics. The first deals with audience. Although the site states that this section is for patients, students, and those interested in the company's research, the information provided is rather minimal in content. In the case of the publications list, the ability to access the full documents suggest who this site 'works' most for, at least in terms of accessing information. Second, there is a classification scheme for disease that its designers offer up in which the conditions are constructed. Third, the links are another area in which boundaries are created and categorization occurs.

Further examination of the specific content of each topic illustrates three characteristics: first, that the overall theme of these 'diseases' or conditions is emphasized as

[44] These numbers are based on the author's archived sited accessed May 7, 2002.

'common.' Common apparently means having relatively high prevalence for western, industrialized populations, since these are the populations cited in these sections. In particular, if statistics are cited, they are generally for the American population.[45] Second, in a general description of either symptoms and/or risk factors, the latter are then linked to comments on the disease's cause(s) and its heritability. Third, in discussing cause and inheritance, the site will, when applicable, provide a brief description of any work that the company's scientists have conducted or information about its prospective research or published findings on the company's research on common diseases for which genetic predispositions or causes are suspected.

References to work that deCODE's researchers conducted or are conducting are, for the most part, general in content. There may be mention of its scientists having conducted a genome wide scan or identifying a genetic locus, or a specific gene, for a specific disease. Occasionally, a link to a citation of its researchers' papers is provided, but this, too, is infrequent. In order to keep up with deCODE's work on specific diseases, a visitor might also visit its 'News' site. Here, visitors can peruse new and archived press releases and sign-up to have these directly sent to them via email.

DeCODE does not specifically use its website as a news or education tool (in the sense that the other two endeavors' sites do – as we will see) for the general audience or even the Icelandic patient/database population.[46] Still, its design and content are more useful for certain audiences than for others. The company intends for Icelandic individuals to use, at least, the resource section, especially, that of the section on 'Diseases,' in which Icelandic resources are sometimes provided. These are local Icelandic associations and patient organizations, some of which are in the Icelandic language.[47] Further, although it also does

[45] The resource section does not provide any citations for the sources of the statistics or where general information about the topics can be found. It is likely that statistics that state American population in actuality means the U.S. population, but there is no citation to confirm this assumption.

[46] Although many of its pages are allocated to 'News and Investors' (include press releases and investor information such as stock quotes and SEC filing reports). In a newer reconstruction of its virtual site (12.04.2002), 'News and Investors' division survives, where 'Resources' does not. Although, certain aspects are 'streamlined' into other divisions, for instances 'Diseases' is shifted into a new division, 'Science and Research.'

[47] In a recent visit to the company's website, the Icelandic version contains a glossary of genetic terms. This was not provided in the English version. See <<http://www.decode.is>> [last accessed March 15, 2003].

not specifically intend its website as a clinical recruiting tool, individuals can find a sample copy of an informed consent form can be found in its website.

In this section, <Diseases>, the site also works to extend its network to a much larger and broader patient/consumer/client population. However, this means not only extending its technology (which has come to be symbolized broadly as the IHD). It must also works to weave an Icelandic history, culture, and population into the extending network and sites (and sights) of deCODE. In a world of human large-scale database science, populations are understood as the limiting resource.[48]

3.4 > Site of (re)production/presentation

3.4.1 > Making the Map of Life… a Blueprint for Health…

The divisions and subdivisions of the company's virtual site discussed above existed during the tail-end of the deCODE controversy. However, in late September 2002, deCODE announced its plans to implement a scheme to achieve positive cash flow by the end of that year. Effective immediately, the company reduced the number of its employees worldwide from 650 to 450. Further, it announced that its aims were to increase productivity through stronger utilization of its automation processes.[49] By December 2002, the divisions in <Resources> were streamlined and both <Publications> and <Diseases> were shifted into a new division <Science and Research>. The latter becoming <Disease Projects> [See Fig. 2].

In the emerging technoscience of genomic medicine, websites are sites of (re)presentation, boundary-work, and negotiation. Unlike a policy document, a scientific article, a commercial brochure, and/or an investor's report, sponsors' cannot linearly define and characterize their projects on line. We cannot assume that the representations of the database and information through these websites are stable, contained, and/or containable. In this particular instance, by investigating this hypertextual endeavor, I highlighted tensions in what are assumed to be stable representations of the endeavor and the Icelandic

[48] <<http://www.decode.com>> [last accessed January 15, 2003].
[49] <<http://www.decode.com>> [Press release from September 27, 2002].

population's role in it. Rather, fragmentation, time/space disturbances, and boundary making mark this site.

Fig. 2 deCODE's site (re)vision

By December 2002, deCODE's website went through a major transformation in visual design, content, and reorganization. The website contains a site map and the two areas that of major interests in relation to the previous site are in the divisions <Products and Services> and the new division <Research>

<Products & Services>
- Target Discovery
- Pharmacogenomics
- Clinical Genome Miner™
- Genotyping
- Structural Biology
- Pharmaceutical Services
  - Drug Discovery
  - Drug Development
  - Drug Delivery
- Clinical Services

<Science & Research>
- The deCODE Population Approach
  - Unique Resources
  - Participation
- Drug and Diagnostic Discovery
- Disease Projects
- Publications

See deCODE's site map <<http://www.decode.com>> [Accessed December 4, 2002]

The work produced in the virtual spaces is not bounded by the virtual dimension. Entering the company's homepage (before the newer December 2002 version), the visitor is confronted with the statement: 'Making the Map of Life… a Blueprint for Health' boldly written in white text contrasted against a warm, deep life-affirming blood red background.[50] However, what might be more visually immediate are photo cutouts of individuals seemingly happily entering (or already within) deCODE's site. If an individual visits the site often, s/he will find that there are several of these photos with individuals of various ages. On any given day, the photos change. On one access date [<<http://www.decode.com>> July 29, 2002], the photo was that of what appeared to be a grandmother and her grandson. In this case, the two blonde, beaming, healthy individuals appear to be coming in, comfortably entering, deCODE's site, from the viewer's right hand side of the screen.[51]

[50] Prior to the winter of 2002.
[51] To compare the differences in visual styles of the homepages, see the APPENDIX in the back of the dissertation [Diagrams 1 and 2].

These cut-out photos of individuals are superimposed over the faintly repeated letters, ACTG. The letters symbolizing the base pairs need no explanation here. A subtle, curved line, reminiscent of the familar double helix, border the 'contents,' separating the list from the centrally-placed phrase, 'Making the Map of Life….a Blueprint for Health.' Very little text appears on this homepage (compared with the two other cases in this dissertation). Interpretation is left to the visitor. Unarguably, the central statement is a direct reference to the genome, and we can safely assume specifically the human genome. Further, the human genome can be taken here as the standard for health. On another level, though, the phrase might be taken to allude to making genomics (including all its genomes, practices, technologies, knowledges, industries) the standard for 21st century medicine. Proponents for genomics medicine have worked hard to create a natural association between the genome and health. Their histories begin with the international Human Genome Project (see Gene Trust and BioBank UK as well). Questions that remain unanswered though are: 'why the genome?' 'what is the genome and/or genomic information in regards to health?' 'who defines health?' and 'who will make the genome a blueprint?' These questions are not exclusive. A secondary statement, which appears on deCODE homepage as well, 'Decoding the Language of Life,' provides another clue to the referent for the larger first statement. It is deCODE who will decide and who can turn the mass of 'raw' data into real and useful knowledge (for certain individuals and communities) by (re)presenting what is to be relevantly represented.

DeCODE does not use its website to actively recruit volunteers to its database project. As we saw in the first section, it does not need to. However, I still contend that its website is a critical node in its endeavor. Engaging deCODE's site, we might (re)consider this mission as 'Making *a* Map of Life (deCODE's map)… a Blueprint for Health.' DeCODE's site is meant as a source of information about the company for various audiences. In some capacity it is meant to persuade. However, more critically, it (re)educates or rather *disciplines*. How these acts work in various circumstances are relevant to visitors and non-visitors of these virtual spaces. The site (re)presents and creates versions of genomic visions of health, disease, identity, and relations, both on- and offline in its efforts to create value-able information.

Visually, the sense of totality is stronger in deCODE site prior to the December 2002 site. The format is kept the same on each of the company's webpages. The deCODE

site leads the visitor to various internal links throughout the company's site, and the internalizing of the IHD link works to draw the visitor in. However, the visitor can also be shuttled or offered transport and sometimes guidance to other 'outside' sites. Hypertext-ing can take the visitor to one of its partner's sites such as Hoffmann-La Roche's homepage or guided, through the direct link to the clinical or pharmacology page at Encode's site. On the one hand, the visitor is left to make an association through the hypertext link, which demonstrates a break in the seemingly seamless flow of the company's webpages, which are grouped together through their similar graphic format, the same red border, and the ever present, but backgrounded image of the grandmother and grandson, on every page. On the other hand, while not a network, in the sense of moving fluidly or in the sense of an enclosed system, the website is not a completely free space or a space in which frontier-like work can go on.

The boundary work is illustrated at the level of the structure of its contents, but also in the format in which the contents are presented. The company's (re)presentation of its genomics approach in its scientific <Publications> differs from that of this approach as described through its <Diseases> section. The latter is less technical and more reliant on hypertext. In addition, an association of the genealogical approach to the <Company's profile> is different than its association of it, grouped in the <Resources> section. The hypertext links and clicks that move visitors to other spaces, pages and other sites, are indicative of the breaks in time and history.

This temporal dimension is as important aspect as the spatial. I suggest that websites present a potential for renewal and remaking while simultaneously presenting the opportunity for collective forgetting – or rather, the making of collective forgetting easy. This aspect fits in well with many biotechnology and internet firms. In the industries associated with these, biotechnology and internet companies come and go at dizzying speeds. Webpages, content, and links can be added, deleted, altered without much reference or thought to pre-existing pages that are not updated. Further, these changes and deletions alter, that is, reconfigure the space that existed before.

As I noted, with deCODE's website, a virtual re-launch of the company occurs in late 2002. Preceding this time, the company's virtual site remained mostly consistent, subject

only to updates. Taking a look at the changes in its main headings in the six month period between May 2002 and December 2002 is revealing:

Company Investors News Products Resources Íslenska
[01.26.2002 and 05.07.2002]

Products & Services News & Investors Science & Research Company [12.04.2002]

On a literal level, this reflects the company's implementation of its new plan, its increasing emphasis on its alliance-building and partnership–making, as well as its increasing focus on allowing these partners and the company to create products and services, now or at least as soon as possible. <Resources>, a section aimed at the larger audiences, is dissolved. Its components streamlined into other divisions.

These directions (towards increasing speed, efficiency, and alliance-building) of the life and medical sciences today are an important trend to track in and of themselves. However, what is of particular interest to me in this study is the reconfiguration of the IHD in this (re)presentation of deCODE('s) endeavor. Here, in the new (site-map) scheme, the IHD is absent replaced by deCODE's 'Population Approach.' [Compare Fig. 1 and Fig. 2] The Icelandic population (re)presented by deCODE's new website is completely appropriated by deCODE – beyond even the earlier genealogical information of the Iceland population.

The company appeals to the Icelandic population throughout the earlier website (May 2002) presenting aspects of its history and genealogy. DeCODE and the IHD were represented as a part of Iceland's timeline, that is, a part of Iceland's history. However, by December 2002, deCODE completely stands in for the IHD/DCDP and Iceland's timeline is replaced by deCODE's. It becomes the definitive space for the Icelandic population to fulfill its future and understand its past and present. Importantly, I mean by this the experiences and knowledge in all Iceland's embodied individuals, and not those fragmented into information and turned into bits and bytes. These machinations, however, are integrally woven into the (re)presentations of practices for these new medical life sciences *and* deCODE in its making. For the individual, understanding disease, health, and wellness will

require bio/health informatics companies, like deCODE, to mediate an individual's knowledge of himself, his family, his experiences, and his gene information.

There is no doubt that there is a lot of rhetoric in the deCODE site.[52] However, throughout this study, it is my contention that these websites can and should be engaged beyond simply housing rhetoric or merely displaying advertisements.[53] Two aspects are particularly striking in illustrating the anxieties in the deCODE case of virtual (re)presentational acts today that I want to highlight before moving onto a discussion of the circulation of information at its site in the next section.

One is the juxtaposition of the scientific literature and the text and visuals/design of the website. DeCODE's site highlights the anxiety in the emerging biotechnosciences. Its site works to incorporate new communication technologies and create 'legitimate' scientific practices and knowledge. The site seeks to address (but not necessarily engage) the broader public, yet simultaneously, the site seeks to be a node for serious scientific disciplines to converge. An example of this is found in the <Publications> section, where multi-disciplined hypertext scientific publications from the company's researchers are presented.

Second, and related to the first aspect, the layers and links built onto and into the website are aspects of note. On the one hand, together, they present a narrative that the company puts forward, of its past, present, and future. On the other hand, while what information and how the sites (re)present information can be interpreted as just rhetorical, the sites (its website at different times) do work beyond those that are merely persuasive. DeCODE's site does work that (re)produces some aspects of 21st century medical science, creating associations in links with specific off-sites, incorporating 'instantaneously' and immediately their history and work into its own and distributing what is appropriates and transforms in a seamless ease through its networks. However, again, these same aspects of the world wide web highlight anxieties.

There are temporal and spatial disruptions that cannot be completely reined into the totalizing and classificatory system created through deCODE's virtual site. There may be rogue visitors. However, although montage-like and interactive, the web is still not a free-for-all for its visitors, the company, or the site itself. There are constraints as well as freedom to choose (dis)order on the web. For example, we saw this in the (earlier) site's attempt for

[52] Stefánsson, himself, has pointed out the importance of myth in Icelandic culture.

more structure in its <Diseases> and <Publications> sections. A linearity and hierarchy, similar to that of today's conventional print book may not exist on the web, but neither is there total freedom to choose.

3.5 > (Re)presenting bioinformation

3.5.1 > Decoding genetic information

DeCODE's virtual site (re)presents gene information in the frames of information in the cybernetic sense of data, signal, and transmission and also information as thing.[54] Here, it is reduced to family data (flows).[55] In the same breath, it describes information imbued with various understandings.

Further problematic is the view that information is a thing that flows seamlessly through networks and is containable in boxes. The emphases on stability and seamlessness are pervasively represented throughout the site. Genetics is bioinformatics, as stated elsewhere by the company's CEO:

> Our way of approaching the study (of complex disease) is to use a population that has some very important qualities – the most important one being that the genealogical data, the data on the genealogy of the nation, is relatively complete. When you're researching human genetics, you're researching the information that goes into the making of man and there's a flow of information from one generation to the next. The genealogy shows the different avenues by which the information flows.[56]

Presenting, representing, and securing the centrality of information – of data – is not lost as deCODE cites its achievements, aims, and visions of disease, science, and life. However, in

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[54] In the cybernetic view, information is stripped of meaning.

[55] Science studies scholars, historians, and philosophers of biology have described the increasingly central position of information in the life sciences (although fewer works characterize that same move in biomedicine). Here, they have especially illustrated the utility of the metaphor of information in the work of molecular biologists. See, e.g. the works of Lily E. Kay, *Who Wrote the Book of Life?,* Stanford: Stanford University Press, 2000 and Evelyn Fox Keller, *Refiguring Life*, New York: Columbia University Press, 1995. Others have pointed out the dissolution of the metaphor to the literal use of information. See especially Donna Haraway, *Modest Witness*, New York: Routledge, 1997.

[56] Kari Stefánsson, Interview, Leo Gough, *Investing in Biotechnology Stocks*, New York: John Wiley & Sons, 2001: 31.]

addition to treating information as object here, also unlike the cybernetic theory of information, Stefánsson imparts meaning into information.

The new (medical) life sciences, including areas of bioinformatics, genomics, and proteomics, are increasingly described as the convergence of biology, computer, and communication sciences. Computer technology is at the forefront of deCODE's endeavors. In deCODE's vision of genetics, computer power will mediate us towards understanding life, health, and a blueprint for living. In its <Milestones> division, the company highlights that:

> • deCODE had finished building its 'world-leading high-throughput genotyping facility,'
> • developed 'automated software algorithms for data capture, analysis, and interpretation,' and
> • constructed a 'computerized genealogy database covering the Icelandic population.'

However, these milestones are associated with the claims that deCODE has:

> • identified the location of twenty locations for disease-causing genes and
> • identified more than 20 specific candidate disease genes,

How these actually work for the Icelandic individuals is still unknown – preventive and individualized medicine is still deferred. However, for deCODE it is

> • filing patents on 'more than 350 targets identified through the company's proprietary datamining products.'

The idea of 'information flows' is not a new view in molecular biology. The view that families provide a useful means to follow that vertical flow of information from generation to generation is also not new. Specifically, for deCODE, the keys to the company's uniqueness are the completeness of Iceland's genealogical records, translated through its computerization/digitization of these records, and then transformed for itself and its partners through its powerful, speedy, and efficient information systems and proprietary analytical tools and software.

The virtual site captures the next step of Stefánsson's definition of genetics as the study of 'information flows' from one body to the next of *its* Icelandic people, the essence flowing through these bodies, culminating in the latest population. This deCODE's site (re)presents as best captured through its innovative technological system, the DCDP.

On the same webpage as <What is the IHD?>, the visitor is also provided with more internal hyperlinks to more information about the IHD. These hypertext links – <DCDP> <'The License> <System Architecture> and <Data Security> and <Oversight> – are gateways into other areas of this site. They are openings which enter deeper, or cycle back, into deCODE's supposed self-contained, private world, that will provide the visitor further access and explanation to discovering what is the IHD. The visitor cannot stop at this page labeled as <What is the IHD?> for a complete explanation. Rather, she must enter into the DCDP section. Here, she finds a window into the company's physical workplace, a photo of workers found among rows of computers. The deCODE Combined Data Processing System (DCDP) is then explained in the future tense. The visitor is told that it,

> "will be the first system in the world capable of cross-referencing genetic, phenotypic and genealogic data on a large scale."[57]

Here, the visitor is also given a more extensive but still highly limited account of technical aspects about how the gathered information will be processed.

DeCODE's site here highlights the importance of its proprietary software and computer technologies in the company's work in sorting out data. The site is peppered with photos of laboratory workers at computer terminals and surrounded by large mainframe computers. Qualified end-users – 'scientists, healthcare professionals, Icelandic authorities and deCODE customers and partners' – pose specific queries through some software program. This program will process the request. The physical or hardware system, held by deCODE, will give these users, the ability, or in the company's words, 'power,' to build more complete models than those currently available of the 'actual' interplay among genes, disease, and the environment.

[57] Resources ►What is the IHD? ► The deCODE Combined Dataprocessing System (DCDP)

However, in the site's (re)presentation of the genealogical approach/IHD/DCDP system, gene, genetic, and non-genetic information collected from the Icelandic people are aggregated, made digital, easily transportable, translatable, transformable, and subsequently, value-able by deCODE and maybe valued by its global partners. In other words, the virtual site captures the emergence of a horizontal flow/expansion of gene information to health, medical, pharmaceutical, family, personal, national, and global information. In the world of cyberspace, hypertext also creates a sense of association, flow, timelessness, and totality in which Icelandic gene information flows into genetic information, non-genetic information, and finally digital information – a data object – collected, housed, and transformed within deCODE's system (re)presented through decode.com. However, as we have seen, on closer examination, hypertextuality reveals time/space disruptions, fragmentation/boundary work, and effacing/collective forgetting.

3.5.2 > Decoding de(CODE)'s science & practices

In the above paragraph, I mentioned that information is collected from individuals, but where are they in this picture of information flows? What do they contribute? Scientists at deCODE, including Kári Stefánsson, contend that complex diseases are diagnosed on consensus criteria, in which diagnosis results from the combination of symptoms. The company, therefore, begins by defining a disease, 'broadly, but rigorously.'[58] Having established which complex and common diseases to study, deCODE proceeds by locating individuals, through health-care institutions in Iceland, with the disease. Tissue samples are taken and these alleles are run through the Icelandic genealogy database. According to the company, this will permit its researchers to find out which families have had the disease. Furthermore, deCODE contends that what is 'revealed' is 'what it is in the phenotype that has passed through the generations.'

In interview after interview, Stefánsson resists the description of the Icelandic Health Sector Database (IHD) as a gene database. Asked to comment about the controversy over the IHD, he states,

[58] EMBO interview with Stefánsson. Nov. 2001.

> One of the interesting misunderstandings this past year has been about the database on healthcare in Iceland that we have been licensed to build. It does not contain any genetic data, it doesn't contain any biological samples, any DNA or anything like that.[59]

Similar to the company's site, he describes the IHD as a comprehensive medical and clinical information database. DCDP is forgotten here (the links broken to the gene and genealogical information?). This is epidemiological research, according to Stefánsson, and this is why presumed consent is warranted. Asked, 'what kind of healthcare information is collected?,' his response is that it has run of the mill epidemiological information gathered and used for decades by public health institutions and research, specifically,

> diagnosis, treatment, prognosis, measurement of values in blood…It is the kind of vital healthcare information that has been used for the past century to do epidemiological research. This is simply the healthcare information that people use to run healthcare institutions.[60]

Stefánsson argues that the international and (Icelandic) rules for using this type of information do not require informed consent. But is it just a health information database? Stefánsson himself continues,

> The people who say that collecting healthcare information into our *centralized database* without informed consent is in violation of international standards are talking nonsense. There is not a single place in the world where people are required to obtain informed consent for the use of such information [my italics].

Centralized can be taken in two ways. It could be the centralized information of the medical/health records database and/or the larger centralized database system which links medical/health, genealogical, and gene information. In other words, it might refer to the human population genomics database. It seems reasonable to consider the IHD in a more complex manner, that is, in the latter sense above, particularly in light of the primacy of the

[59] Leo Gould, *Investing in Biotechnology Stocks*, New York: John Wiley & Sons, 2001: 25.
[60] Gould: 26.

company's work, which is to locate the genetic variation, and its business plan, which is to create value for its varied partners. [61]

The importance of these complex databases of networking and cross-referencing, in studying common/complex diseases is pointed out by Stefánsson himself. Analysis into these diseases of industrial society today begins with a complex set of data, which 'defies the use of the classic hypothesis-driven scientific approach.' He continues,

> This alternative is to take every data point from your data text and juxtapose it with every other data point, looking for the best fit. This is not easy for the unaided human mind, which cannot handle a large number of data points, but the modern computer is ideal for the job. [62]

Specifically, what is emphasized in deCODE's approach is that genetics is bioinformatics, in which genetics is the study of the flow of information. Stefánsson espouses this,

> If you stop looking at genetics as a collection of molecular tricks, and take it for what it is, you find that it is bioinformatics. It is information that in most cases remains constant from generation to generation. Special creationists say, 'In the beginning was the word' – they just forget to mention that the word is written in the nucleotide of DNA.[63]

From this perspective, information appears singular. In the discussions above, the database is foregrounded. By considering (re)presentations of the company's endeavor through its site, the focus turns from securing information to the creating of such a singular 'information' from disparate objects and subjects. The flows and translatable and transformable characteristics are as important as the consistent and singular characteristics, but it is the latter that are most securable. However, in interviews, Stefánsson disaggregates these himself.

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[61] Here, Stefánsson disaggregates and aggregates the databases into their component parts; he takes them to be decentralized or centralized at his convenience. If we take the IHD, in the strict sense of the medical/clinical database alone, it loses its utility for the company's aims and the assumptions of this kind of genomic medical research. Stefánsson is using the frame of database construction to his advantage as he does in his discussions about information.

[62] Gould: 32.

[63] Stefánsson, interview with Robert W. Wallace, "Opportunity not exploitation: valuing the Icelandic genome," [Update] *DDT* (Drug Discovery Today) 3:8 (August 1998): 357.

Securing human medical-genomic databases is at the forefront of public debates in the creation of emerging large-scale population database projects. In the IHD case, the public (international) debates revolved largely around issues of private/public in several senses. In particular, these were those of public versus private science and public (common) information versus private (individual) information. These coalesced into policy debates over privacy, security, access, and ownership of the database.

In the same interview above, Stefánsson concedes that there are privacy and security risks to individuals, but he contends, "The risk that is taken is only informational risk."[64] Human volunteers are transformed into data subjects. The company's strategy depends on obtaining individual's profiles and then matching them with the genealogy and health care records of the Iceland population in order to create a comprehensive database. As described earlier, in the overall comprehensive database research strategy, the notion is that the collection of the 'whole organism,' at least in terms of information, will yield better knowledge.

The public debates, from the late 1990s to the early part of this millennium, over the IHD were concerned in large part with the problem of database security. Therefore, this was also of some concern to the company as illustrated through the portions of the site that discuss 'Oversight' and 'The license,' which work to legitimate the company's endeavor. However, all of these discussions as well as the eventual answer provided by the Iceland Act on the HSD, presume that the IHD is simply a physical object, a high-powered but still material technology, which aids deCODE's (genomics) science. As such, it is securable and containable, and what it contains is simply 'information.'

If we return to one version of its site, the company mission statement asserts:

> We believe that certain unique qualities of the Icelandic population - together with our advanced bioinformatics and high throughput genotyping facility - place deCODE at a competitive advantage, which will in turn create value for the company and our partners. [65]

This is located centrally in the <Company Profile> webpage. From the beginning of deCODE's existence, it maintained the position that the Icelandic population is genetically

[64] Gould: 27.
[65] DeCODE genetics <<http://www.decode.com/company/>> accessed June 28, 2002.

homogeneous and as such the ideal population for an efficient approach to establishing genetic links to common diseases. (The wording has since shifted to 'relatively genetically homogeneous.') Further, the company maintains that specific cultural and historical peculiarities of the state of Iceland, the Iceland people, and the geography of Iceland's land create its singular environment. It is this singularity that makes the entire Icelandic population as the resource, the raw material, for the contents, that is, the information, of its centralized database.[66] As Stefánsson put it in 2001,

> I think that genetic homogeneity is overrated. It helps. But the big advantage we have is the genealogy of the entire nation in a computer database. When you are studying genetics, you are studying information that flows from one generation to the next. Genealogy gives you the avenues by which the information flows. I think our biggest advantage is that we have access to this information.[67] [68]

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[66] The genetic and non-genetic homogeneity of an Icelandic population is contested by a number of other researchers. In other cases, the usefulness of homogeneous populations in large-scale population databases are raised. See, for example, E. Árnason, et al., "Genetic Homogeneity of Icelanders: Fact or Fiction?" *Nature Genetics* 25 (August 2000): 373-4, Bijal P. Trivedi, "Icelanders, a Diverse Bunch?" Genes & Genomes (8.11.00) <<http://www.celera.com/celerascience/news/articles/08_00/Icelanders.cfm>> (accessed 10.21.00), A. Abbott, "Manhattan versus Reykajavik," *Nature* 406 (2000): 340-2, B. Anderson and T. Zoega, "Icelandic genetics," *Nature Biotechnology* 12 (June 1999): 517, J. H. Edwards, "Unifactorial models are not appropriate for multifactorial disease," *British Medical Journal* 318 (May 15, 1999): 1353, Ricki Lewis, "Iceland's Public Supports Database, But Scientists Object," *The Scientist* 13: 15 (July 19, 1999): 1, and M. Enserink, "Opponents Criticize Icelandic Database," *Science* 282 (1998): 859.

[67] Stefánsson, interview conducted by Holger Breithaupt, "Health care and privacy," [Interviews] *EMBO reports* (European Molecular Biology Organization) 2:11 (January 2001): 965.

[68] In deCODE's approach, population genomics is the more accurate method when it comes to firmly establishing a relationship between genes and so-called common diseases. A flawed, or mutated, gene marks the passage of disease from one generation to the next as it is transferred from one generation to the next and along the various branches of a family tree. Proponents of this approach believe that they can pinpoint the ancestral founders of a mutation ('founder's effect') and that they can find that gene's normal counterpart. Furthermore, they believe that they can map the association with a specific disease and/or condition by comparing genealogical records with DNA extracted from an extended family. Iceland in northern Europe, Tonga, an island in the South Pacific, pockets of Utah in the United States, and Newfoundland, Canada as well as other isolated locations are thought by some researchers as primary places for such (re)constructions. These scientists argue that these locations offer special populations to search for 'disease' genes. In particular, populations who live in and come from these regions are believed to increase the odds of locating these genes by providing smaller, clearer 'pools,' to search. This research into the 'founder effect' is not entirely new, but these scaled-up efforts, based on genomic technologies, were thrust into the spotlight in the late twentieth century.
Many other researchers think that the task is difficult, if not next to impossible, because of current living conditions. The reasons given are that after decades of immigration, families are

In the quotation above, Stefánsson foregrounds well the uniqueness of the Icelandic cultural heritage, not its biological one, while simultaneously back grounding the physical database that is (re)presented through certain mechanisms of the company's website. In a recent version of its virtual site, discussion of the database is virtually equated with discussion of the company's genealogy approach and the Icelandic population.[69] However, the circulation of 'information' through the company's site, highlights not the Icelandic population's unique qualities and its individuals' experiences and knowledge, but the genotyping and bioinformatics in the creation of usable value or value-able information. It is supposedly understood, from the quote above, that the manipulations and processing of the database (once properly configured and in existence) will create value for partners of varied interests. The site stands in for the unseen, deferred physical database in mediating the translations, or rather transformations, of a unique population's genealogy, history, and culture to a standardized technoscience's flow of information. However, the importance of the Icelandic population is not taken lightly. The visitor does not need to see (or experience) the physical database to witness its legitimacy. Rather, its legitimacy is now established through its association (its near equivalency) with the Icelandic population (the limiting resource), with its long-experience in expert record-keeping and information-gathering. Meanwhile, the IHD/DCDP remains (re)presentable as secure, private, and unseen.

3.5.3 > Real… really

In the Iceland database project, many critical analyses exist from a number of disciplinary angles. A number of science studies researchers, bioethicists, legal experts, scientists, and media critiqued the efforts.[70] These critiques primarily deal with database privacy and security issues, ownership of information, and human subjects research and

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scattered across continents. In addition, over many years, marriages, partly outside the local community, have made it extremely difficult for researchers to use genealogy to reconstruct a disease or a condition's lineage. See Cavalli-Sforza for literature in this area. For example, see L.L. Cavalli-Sforza, *Genes, People, and Languages*, translated by Mark Seiestad, New York: North Point Press, 1st ed., 2000.

[69] Last accessed 12.04.2002.

[70] For literature on the controversy, see the citations from footnote #2.

informed consent. As mentioned earlier, most of these studies focus specifically on the legislative act and consent, some other critiques focus primarily on Stefánsson. Science studies scholars richly contextualized deCODE's project and some researchers reflexively analyzed their own roles and their disciplines' roles in the debates.[71]

There have also been some critiques about deCODE's research approaches, in particular, its assumptions of the genetic homogeneity of the Iceland population. Further, the utility of homogeneous populations in the kind of research the company is involved in has been recently criticized. The concerns are about the generalizability of genetic homogeneity to the world population (at least the western one). In addition, others have been critical of what might be described as the company's hand in too many cookie jars. Most traditional pharmaceutical and even biotechnology companies tend to focus on a limited number of disease/conditions. DeCODE works on and is interested in over forty and the list grows.

However, the debates over these primarily scientific issues in genetics have been far fewer than over other issues, which have been grouped more with ethical and social concerns. Some of these discussions deal with the technical aspects of database design, but these debates concentrate mainly on issues about privacy and security maintenance. In the last two years (2000-2), deCODE's website focused heavily on its right to create and operate an IHD. Further, it focused on security and containment issues. These representations of the endeavor as the making of a technological object, embrace discourses of information, totality, efficiency, and futurism that are left unengaged. The discourse(s) on (genomic) medicine, health, and life may be at least what is partially at stake. DeCODE's website illustrates the site's work at stabilizing a kind of (discursive) reality of these through a systems of difference-making and multiplicity.

In an earlier study of the Icelandic database project, I alluded to a 'realness,' that is an effective existence, of the project regardless of the existence of the physical database.[72]

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[71] See especially the anthropological works of Gisli Pàlsson and Paul Rabinow's "Iceland: The Case of a National Human Genome Project," *Anthropology Today* 15:5 (1999): 14-8, Hilary Rose's "Gendered genetics in Iceland" *New Genetics and Society* 20: 2 (August 2001): 119—38, and Skúli Sigurdsson's "Yin-Yang Genetics, or the HSD deCODE Controversy," *New Genetics and Society* 20: 2 (August 2001): 103-17. The historian of science Michael Fortun also has written about the case, "Experiments in Ethnography and Its Performance," posted on Mannvernd's website: <<http://www.mannvernd.is/english/articles/mfortun.html>>.

[72] Pei Koay, "Icelandic (Ad)'ventures: new research? new subjects? new ethics?," *Advances in Bioethics* 8 (forthcoming).

While certain aspects may be digitized, genetic and/or personal information cannot be disembodied from individuals and retain the exact same meaning and/or value. In this sense, deCODE sets the standard for value. Further, even digitized, how data/information can be contained in a meaningful way is problematic. Collapsed into 'information' and flowing through networks, there is a sense of seamless ease in deCODE's representation of its database endeavor, which even Stefánsson in interviews cannot maintain/contain.

3.6 > (Re)presenting representation…..

In this chapter, I illustrated the tensions created in representing deCODE's genomic (IHD/DCDP) database/information especially in relations to the Icelandic population and individuals through this virtual and digital mode of communication. Political debates over deCODE's venture led to the construction and subsequent passing of the Iceland Health Sector Database Act. This document, while regulating the construction and maintenance of the IHD highlights an area in these new fields of informatics, especially biomedical informatics, which is overlooked among the various critics of the consent rules and privacy and security regulations. These are the configurations between experiment(er) and patient and the place and understanding of information in these schemes in increasingly hyper-informational environments. Through deCODE's and the Iceland's parliament, individual patients do not *actively participate* in research conducted under the Database Act.[73] Rather, they are data participants/donors.

Proponents of this project, deCODE officials, and Iceland's parliament presented the case for presumed consent in the construction of the IHD. This argument was based on conventional understandings of human experimentation in medical research. However, as I point out in this chapter, what it means to 'actively participate' in medical research needs some redefining and extensive amounts of re-thinking. However, also needed is more attention to relations between body, history, identity, and information. According to the state of Iceland, health and medical information from individual Icelanders are not subject to proprietary claims. It is the state that collects, organizes, manages, and stores the information. Thereby, in effect, it is the state, here, that creates value and *real*(?) knowledge?

[73] See Database Act (1998).

Further, under current regulation, while the state does not own individual's health and medical information, it is its steward.[74]

Stefánsson maintains that the population of Iceland is already receiving real value from his company and its endeavor. He contends that the company has jumpstarted a new industry – of biotech – in a country that had previously relied on fishing. Further, it repatriated a large number of Icelandic scientists back to their homeland, although, as cited earlier, it laid off over 200 of its employees in the autumn of 2002 in efforts to achieve positive cash flow.[75] In addition, the company's license agreement with pharmaceutical companies, such as that with Roche, specifies that the pharmaceutical company will provide any drugs produced on the basis of research emerging from the population to the entire Icelandic population for free. Stefánsson stated that it "provides a symbolic gesture towards the population."[76] The question of whether or not this remains largely symbolic is a legitimate, real issue. The reality of such an event may be closer in the virtual realm than in the realm of the living Icelander today.

While the Icelandic population are (re)presented in deCODE's site in terms of their genealogical data and medical records, I argue that the Icelandic population is not regarded as an audience to actually *actively engage* with. Perhaps, Stefánsson's position that they are already receiving value from the company and that they are already "thoroughly behind the company" settles the matter.[77] It may also be the fact that the company's access to both kinds (genealogical and medical) of information is secure as of today. In terms of genetic information from Icelandic individuals, deCODE also has access to biological material from which gene information can be extracted. The company does not directly approach individuals from the current population to ascertain gene information. According to its CEO, this is an issue of maintaining privacy. The site does make some appeal to them with the presence of sample copy of an informed consent form. However, access will come when individual Icelanders visit their doctors and routine biological tests are performed. Samples

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[74] The earlier version of the Database Act, then the Bill, was worded more strongly, implying ownership. This was strongly criticized by other members and the bill reworded before passed in December 1998.

[75] Since most biotechnology firm are small, relying on alliances, partnerships, and now automation to pursue their work, 200 is a large number.

[76] Robert W. Wallace, "Opportunity not exploitation: valuing the Icelandic genome," [Update] *DDT* (Drug Discovery Today) 3:8 (August 1998): 356.

[77] Kari Stefánsson, Interview, Robert W. Wallace, "Opportunity not exploitation: valuing the Icelandic genome," [Update] *DDT* (Drug Discovery Today) 3:8 (August 1998): 355.

will be taken and then made available to the company. Further, individuals can be proactive and volunteer samples. Samples from future generations seem somewhat more easily secured than those of this current generation since these biological materials will be automatically taken unless parents explicitly object.

I still contend that the drive for public acceptance by those engaged in these projects make the *(re)presentative* power of the web presence at least a central means to expand *some* understanding and *acceptance* of database research. Further, it enables the web presence to be a space in which some negotiation of what it means to do genomic database research. In the deCODE case, publics are not completely forgotten, but their place and role(s) have changed. Although (a la Haraway) the 'lively' bodies of individuals that make up the population, that is the Icelandic population, may be forgotten, the company's site still works to negotiate the Iceland population's place and role(s) in a scheme of deCODE's version of a genomics world.

As of the winter of 2002, neither deCODE nor its partner, Frisk Software, had provided the genealogical database online to the Iceland population, although they already put it to work in deCODE's research.[78] In terms of the other components of its centralized database, on the one hand, the information currently flows only one way, from the Iceland population to the IHD/DCDP. Personalized/preventive medicine is deferred. Therefore, other strikingly absent objects are health endeavors that work for and with Iceland's individuals. On the other hand, an understanding of gene information expands to genetic information (incorporating information of *all* aspects of life?). Mediated by some of the most advanced computer technologies in the world, deCODE secures the relations between its experiments and data subject(s), particularly as a population. Further, a nation's (or people's) genealogical/health/gene information may even provide avenues for continued scientific and economic progress and prosperity for industry and states through deferred value-making. This lesson is taught here in deCODE's site, but also by the broader biotech sector. The visitor can observe some of the transformations and exchange of information at the company's virtual site, but fuller and/or alternative representations of such complex

[78] After completing the writing of this chapter, I ascertained that the company did release an Icelandic version of the database on January 19, 2003. This launch date was posted on a message board: <<http://iceland-usa.org/wwwboard/messages/52.html>> by Friðrik Skúlason. It can be accessed through deCODE's website. When I last visited, the site in early April of 2003, the interface was only provided in Icelandic (an English version is in the works). The database is free of charge, but it requires an Icelandic ID number.

endeavors require a few more lively bodies. They also require a few more interactive, engaging sites to actualize alternative values of emerging knowledge and practices about life, health, and disease, rather than merely value-able information flows and disembodied information.[79]

[79] Or might it just be an overflow of information? As many of the proponents, as well critics of these genomic medical endeavors, point out themselves in their more candid and/or lucid moments, scientists do not yet know if any therapeutic outcome will emerge from the deluge of data and information collected.

CHAPTER 3 > APPENDIX 1 >
How are DNA Samples/ Medical/Genealogical/Genetic Information Collected?

DeCODE's virtual site works at maintaining and furthering the divisions between medical and health information, genealogical information, and genetic information, or rather, material. The association between genetic information and genetic material is another complex issue in light of privacy and security issues and digitalization of biological information.[80]

DeCODE

▼ Identifies which common/complex disease to study and approach

Notifies physicians in Iceland working with patients with that disease

▼ DeCODE/physicians draw up a protocol and send to:

Data Protection Committee (government body)
and Ethics Committee

▼ If committees approve protocol

Physicians' institutions prepare patients' medical records

▼ List of chosen patients and encrypted records with medical information sent to

DeCODE's laboratories and statisticians

▼ Compare medical information to family trees in deCODE's genealogy database, narrow down and identify chosen families for their study on the initial disease chosen for study.

Physicians receive list of families

▼ Notify these families and ask them to participate in deCODE's study

Families accept

▼ Sign consent forms

Physicians take tissue/DNA sample from patients

▼ Encrypted

Sample and encrypted code sent to DeCODE

[80] Perhaps, it is the case that gene information needs to be differentiated from genetic information, which might include phenotypic as well as genotypic information.

The website also describes how specific component information will be gathered. In particular, there is a lengthy (by website standards) explanation for where 'Clinical Data from the Icelandic Healthcare System' comes from. It is in collecting this information that the company uses presumed consent. One source of this data already comes from a centralized data system run from Iceland's government,

> Under the terms of the IHD license, deCODE is allowed to gather and process medical information, environmental exposure information and resource-use information from the Icelandic healthcare system.

In order to maintain and update the data, deCODE will continue to also collect data from a network of health professionals in Iceland,

> The IHD will receive medical records data prepared in each participating healthcare institution. This selected information is expected to include the most salient details of patients' medical and social histories, such as records on allergies, risk-factor exposure, hospital admissions, diagnostic work-ups and results, diagnoses, procedures performed during patient visits, surgical interventions, and pharmaceutical treatments and outcomes. All medical information will be anonymized and assigned encrypted identification tags by a government-controlled encryption service even before it is forwarded to the database. Once entered in the IHD, all data will be stored using state-of-the-art identity encryption and data protection systems. Likewise, query parameters will be designed to ensure that individuals cannot be identified by their medical records.

The IHD, here then, is also updated and secured, a comprehensive medical information warehouse after a translation (or transformation?) from medical records supplied through this work bestowed, or allocated, to the health practitioners in Iceland. However, in relation deCODE's missions, it must be more than this.

When describing 'The Genealogy Data' and 'Genotypic Data,' the significance of the IHD is as part a transformative system of multi-databases rather than a contained, comprehensive medical records system,

> The DCDP will utilize the same genealogy data that deCODE uses in its current discovery programs.

And,

> In accordance with applicable regulations, deCODE plans to analyze the genotypes of Icelanders who consent to have their genotypic data stored and cross-referenced with the IHD. [81]

The IHD seems to simultaneously expand and contract in this section… Singular. Linked. Static. Transforming. Collecting. Collection… of information. In terms of its DCDP, each component is explained, here, and, as alluded to above, each is described to varying degrees. The genealogical and genotypic components are described, in more detail, elsewhere within the site (discussed later), but under different circumstances. What are highlighted in the section <What is the IHD?'> are the manners in which the different information are characterized and configured with one another.

For the medical and genotypic components of this centralized database, partners', or others', active involvement in the exchange and production of the information and project are explained. However, the extraction of genealogical data requires no reference to partnerships. In addition, in its discussion of various forms of consent that deCODE uses in obtaining these forms of data, the company maintains that the genealogical information is widely considered to be in the public domain and therefore requires no consent, and it would seem, no alliances.[82] DeCODE's position is that the Icelandic genealogy is a common heritage. Although not mentioned at its virtual site, the company has been embroiled in a legal dispute with another Icelandic company that had compiled much of Iceland's genealogical history.[83]

Another significant aspect to highlight is not only the vagueness of how these supposed three different types of information are centralized through the DCDP, but how these will be cross-referenced. It is not just centralization of the databases that makes the deCODE approach important. The proprietary-quality of its technologies prevent deCODE from revealing more than that the DCDP is relational. In particular, it depends on the client's/researcher's/clinician's needs. It is assumed here that deCODE can configure and turn these disparate sources into something of 'value' for its clients, but on another level,

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[81] <<http://www.decode.com>> Resources ► What is the IHD ► The deCODE Combined Data Processing System (DCDP)

[82] <<http://www.decode.com>> Resources ► What is the IHD ► System Architecture and Data Security (from author's own archived site. May 7, 2002)

[83] See deCODE's press release January 13, 2000 posted on their website and 2001 Annual Report: 33.

deCODE cannot reveal what the database can provide because it cannot know what it can provide.[84]

[84] For a biotechnology investor's definition of value see George Wolff's *The Biotech Investor's Bible*, New York: John Wiley & Sons, Inc., 2001: 29-32.

CHAPTER 3 > APPENDIX 2 >
Events of deCODE genetics (M = Milestones, DeCODE website May 7, 2002)

9th century A.D.	Vikings settle in Iceland
1400s	Outbreak of bubonic plague in Iceland reduces the population from 70, 000 to 25, 000, increases the population's genetic uniformity.
1700s	Eruptions of the volcano Hekla, which broad widespread famine to Iceland, and also boosts the population's genetic uniformity
1915	Iceland's national health service begins, with universal access, and systematic medical record-keeping established by the state.
1996 August	deCODE incorporates in Delaware; receives $12 m in venture capital from seven US venture capital companies; starts its research with 20 employees (M)
1998 February	deCODE enters a research collaboration and license agreement with Swiss pharm-giant, Hoffman -La Roche, to identify genetic causes of twelve 'common' diseases. (M)
1998 April	Health Sector Database bill first introduced in the Althingi, debated and withdrawn (reintroduced in with revisions in September 1998)
1998 December	HSD Act passed by a vote of 38 to 23
2000 January	deCODE employees reach 300 (M)
2000 January	deCODE and Frisk Software (Fridrik Skulason ehf.) announce that the company's genealogy database 'The Book of Icelanders' will be eventually be made open to consultation by the public. (M)
2000 January	deCODE is awarded a license to create the Icelandic Health Sector Database (IHD) and commercially operate it for twelve years. "The IHD will collect healthcare data from anonymized patient records from the Icelandic healthcare system, and deCODE plans to use the database to support its disease-gene research and to develop healthcare informatics and privacy protection products." (M)
2000 May	Icelandic Parliament passes the Icelandic Biobanks Act
2000 July	deCODE completes its initial public offering (IPO) of common stock and shares begin trading on the Nasdaq and Easdaq exchanges (M)

2000 November	deCODE launches Encode as a pharmacogenomics subsidiary CRO (contract research organization); founded in early 1999.
2001 April	deCODE employees reach 500 (M)
2001 July	deCODE and Affymetrix sign an agreement to develop DNA-based tests using deCODE's population-based approach to pharmacogenomics and Affymetrix's GeneChip® technology. The tests will focus on common conditions including high cholesterol, depression, asthma, hypertension, breast cancer, schizophrenia and migraine. The clinical work will be performed by Encode. (see deCODE press release 07.24.2001)
2001 July	deCODE signs a 3-year license with Applied Biosystems to adapt deCODE's genotyping software suit for integration with Applied Biosystems laboratory management software to move towards integrating analytical tools with laboratory management and automation systems. (see deCODE press release 07.19.2001).
2001 July	Roche Diagnostics announce they will use deCODE's Clinical Genome Miner™, an in silico platform for genomics research. (see deCODE press release 07.16.2001).
2001 November	deCODE announces files patents on 350 drug targets (M)
2002 September	deCODE announces plans to achieve positive cashflow from its research and services operations in 2003 and in accordance lays off approximately 200 employees (from a total of about 650), mostly from its gene research division in Reykajavik. The company will refocus on utilizing its automation technologies and software development in 'absorbing these changes' and reductions. (See deCODE's press release 09.27.2002).

4.1 > The Gene Trust™

4.1.1 > on solid ground?[1]

In May of 1998, venture capitalist physician, Hugh Y. Rienhoff formed a tiny, privately held health information firm, Kiva Genetics in California. Just over two years later, on July 17, 2001, the company re-emerged as DNA Sciences. Newly minted, the company also recruited, the geneticist, Raymond White, as its Chief Scientific Officer.[2] On August 1, 2000, two weeks later, DNA Sciences launched a project named the Gene Trust. It made a bit of a splash – landing an article in the *New York Times* – on that very date.[3]

According to the company, the project's goal was to create a large scale human population database combining gene information with lifestyle information and family and medical history of individual volunteers from the United States. The launch of the Gene Trust was a means of publicizing the project commercially but it was also a recruitment strategy – a call to the American public to volunteer for its endeavor. This, individuals could do simply by logging onto the company's website at www.DNA.com.[4] Less than a year after the launch, the company announced that it had registered 10,000 individuals.[5]

While more clinical studies projects are using the internet to recruit volunteers, DNA Sciences is currently (as far as I can gather) the broadest.[6] Further, it not only recruits potential donors and/or volunteers at its website, it also gathers personal and medical information over the internet. After going through their four-step registration process, an

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[1] Logo Copyright © 2002 DNA Sciences, Inc. All rights reserved.

[2] Raymond White worked as the Executive Director of Utah's Huntsman Cancer Institute and Professor of Human Genetics at the University of Utah. He is a specialist in cancer genetics and was involved in developing molecular tools for constructing a map of genetic markers for the Human Genome Project. His roles in the creation of the HGP are highlighted in Robert Cook-Deegan's *The Gene Wars: Science, Politics, and the Human Genome*, New York: W.W. Norton, 1994.

[3] "A Start-Up Recruits People to Donate DNA to Science," *New York Times* (August 1, 2000): A1; Andrew Pollack, "Company Seeking Donors for a 'Gene Trust,' *New York Times* (August 1, 2000: Business section.

[4] This homepage is from an early site archived at the Wayback machine <<http://www.archive.org>>, dated January 2001.

[5] Company spokesperson's claimed they expected less than half this number in the first year. Initially, they suggested a total of 100,000 -300,000 individuals, but as we will see the company stopped registering people at much smaller number.

[6] Traditionally, patient recruitment techniques, in the United States, have been through hospitals and doctors. This supposedly served as a means to mediate, along with other technologies, such as informed consent forms and new institutional structures designed to safeguard the patients and research subjects' interests.

individual can expect that the company will keep the information indefinitely whether or not that individual is also invited to donate a blood sample.

While traditional methods of patient recruitment for pharmaceutical firms tend to entail mediation and monitoring from hospitals and doctors, DNA Sciences appeals directly to the public, or consumers. Patients or those with known diseases/conditions are not their primary aim, but potential customers with potential diseases/conditions. That these are primarily American (U.S.) consumers is especially highlighted by the diseases/conditions that the company chooses to study. These currently include coronary heart disease, Type II diabetes, asthma, and multiple sclerosis. These, as the company points out, are conditions that are most prevalent in the United States.[7]

The company's site masthead is 'fulfilling the promise.' 'Which promise today does the Gene Trust project (work to) fulfill? - A promise towards some understanding of better health and wellness? Or is it a promise/contract to create value-able information for certain pharmaceutical partners?'

In this chapter, the main issue is the same as in the other two cases: representations in emerging biomedical technosciences. I argue that subjectivities are made through the company's representational acts on the web. However, these reflect and refract the company's offline changes. I employ '(re)presentation' to illustrate how the site stands in for absent objects, in particular the physicality and technicalities of the database. In terms of this, I speak to the specific concerns of the construction of biomedical technoscientific objects, subjects, and practices in relationship to potential recruits and the broader public.

The turn to the web presence will help me highlight certain features, especially anxieties and contradictions hidden in the conventional frameworks of private/public, virtual/real, and 'emerging' that dominates public discussions of these projects. In this chapter, several areas of the website are highlighted. These are:

- homepage and contents bar
- structure/design
- 'contents'/text

I focus on the location of the Gene Trust (in the company's virtual space) over time as the company (re)presents its endeavor and/or aims. In particular, I want to illustrate

[7] See DNA Sciences (333-53306), IPO Plan (S-1) to Securities and Exchange Commission (January, 05, 2001). Available at the SEC's website <<http://www.sec.gov>>.

specific anxieties produced in these projects. In addition, I also want to highlight the schizophrenia of the company's website. The site, at times, seems to present itself as an online patient/participant community and, at other times, to (re)present the company, DNA Sciences. I will highlight the roles its web presence plays, in efforts to stabilize, maintain, and extend the company's position. In examining how DNA.com is put to work and in putting DNA.com to work, my aim is to demonstrate constructions of techno-social relations and the co-production of participants and the boundary-work involved in this representational endeavor.[8]

Within the machinations and shifts in the company/virtual site, [See Fig. 1] I take up specific issues regarding the representation of DNA Sciences' project, its building of support networks, the Gene Trust, the circulation/uses of (genetic) information, and the characterization and expectations of the 'volunteers.' DNA Sciences differs from the other two cases I examine in this project in that it is a completely private and commercial endeavor and it explicitly uses its website, to recruit and educate volunteers.

Here, in the company, the website, and the Gene Trust, DNA Sciences purports to make (genetic) science real for ordinary people and directly include them in its quest, largely because it provides individuals transparency, choice, and a voice. In joining the Gene Trust, the individual is putting her genes to work. Further, DNA.com is both an education center and 'online patient network' in which recruits can check on how the company is doing. In addition, according to the company, volunteered personal information remains the individual's. The database, then, will simply act as (or represent) a pool of data – an overall computerized resource of genetic profiles of thousands of individuals – that DNA Sciences' researchers and their affiliates might use in studies of any number of the twenty-plus conditions that the company is looking into – for the consumer.

In this chapter, I want to show that DNA.com is a space in which, in spite of surface appearance, recruits are co-constructed with genomic science and put to work to help establish this venture-backed start-up company. This is an experimental project, and it is here – at the virtual - that I base an exploration of how, when, and where un/certain knowledges, practices and processes, associations and relations of an unseen, emerging, experimental genomic databases are put to work to create singular technoscientific projects.

[8] I primarily examine the site after the company's shift in 2001. Unless noted the text, in particular comes from an archived site from January 27, 2002.

Fig. 1 A DNA Sciences/Gene Trust Timeline

May 1998 A small biotechnology firm, Kiva Genetics, is started a life science venture capitalist physician, Hugh Y. Rienhoff.

March 6, 2000 The company makes a $35 million/5 yr-period deal with Healtheon/WebMD to provide genomics information to WebMD*health* and WebMD*practice*.

mid-July 2000 The company recruits Raymond White as Chief Scientific Officer & changes name to DNA Sciences.

August 1, 2000 The company officially launches a project named the Gene Trust. The project described as a large scale human population database endeavor. The launch lands a story in the *NY Times* largely for the company's overall method of volunteer recruitment: online through its website.

09.07.00 *

THE GENE TRUST / ABOUT US / DISEASES & CONDITIONS / DNA BASICS / FORUMS / PRIVACY

September 20, 2000 DNA Sciences announces that it would begin genetic studies in three areas of its research interest: breast cancer, asthma, and colon cancer:

December 18, 2000 enters an agreement to acquire PPGx. This is a pharmacogenetic testing and services company. It is now a wholly-owned subsidiary of DNA Sciences. Six months later, its name was changed to DNA Sciences Laboratories.

January 5, 2001 The company files for IPO (initial public offering) with the SEC (Securities and Exchange Commission).

May 1, 2001 Expanding its reach internationally, the company announces its opening of a new facility in Cambridge, England.

July 19, 2001 The company announced 10, 000 individuals registered to join the Gene Trust. Four days later, on July 23, and less than six months after its IPO bid, the company withdraws its $125 M plan for IPO.

September 20, 2001 About two months after its IPO plan withdrawal, the company announces the resignation of Hugh Rienhoff as chief executive officer and a 'new phase' focusing on more 'viable commercial opportunities.'

10.31.01 [01.27.2002] [05.07.2002] *

PRODUCTS & SERVICES/ SCIENCE & DISCOVERY/ OUR COMPANY/ FAMILY GENETICS/ DISEASE CENTER/ GENE TRUST

11.22.2002 *

CAPABILITIES&SERVICES/ SCIENCE& DISCOVERY/ OUR COMPANY/ FAMILY GENETICS/ DISEASE CENTER / GENE TRUST

Figure 1 See Appendix 1 for additional and more detailed events.
* DNA Sciences' website's general hypertext outline of its sites contents as (re)presented on its homepage.

4.2 > DNA Sciences' Gene Trust and trust in genes

4.2.1 > Old aims, new variables

Why the Gene Trust? This is DNA Sciences and behind DNA.com and the Gene Trust is the company's claim that genetic associations can be precisely made thus permitting the establishment of individual susceptibility to common disease,

> DNA Sciences is focused on identifying the genetic basis of common disease susceptibility, disease progression and response to drug treatment. In particular, we are researching variations that are important in common disease and conditions.

Its business/science is gene identification. Specifically, it aims to establish individual differences by producing numbers that illustrate increased variants in DNA sequences in afflicted/affected people. This is not a minor point of DNA Sciences.

Through the Gene Trust Project, DNA Sciences planned to recruit participants primarily over the web to help create a large-scale human population genomic database. In order to build its population base, the company's approach was to contact and work with individuals *directly* rather than to recruit specific populations, specific publics, groups, or communities via the mediation of doctors or interest groups. This approach actually meant that individuals would contact the company. The relationship would in essence be a virtual one – over the web – without face-to-face interaction.

This strategy differed from the traditional approaches taken by other biotechnology and pharmaceutical companies that tended to establish populations *based* on patient, geographic, and/or ethnic characteristics.[9] The company's database would be inclusive of diverse Americans from all over the country, healthy or otherwise. What they needed from participants was information for their studies. This included not only gene information (or sequence data) – derived from a blood/DNA sample – but contact, lifestyle, medical, and family history information. If DNA Sciences is doing genetic research on disease, the

[9] At about the time of DNA Sciences announcement, a rival company, deCODE Genetics and the Icelandic government were in the limelight as they announced collaborative plans to create a national genetic and medical database that would be based on most of the Icelandic population. Although not well received by many in the news media nor embraced by all in the various international academic communities, ethical, political, scientific, and medical, deCODE's project certainly brought much attention to an imperative of large scale population database research with the future of medicine, wellness, and drug development.

question, then, is 'in its collection scheme, why is the company collecting all this non-genetic information from healthy individuals?'

There are two trends that need to be taken note of in human genomics medical research today. First, is the trend to study what have come to be called common diseases. These are conditions that are thought by scientists to be complex, emerging from several genes interacting with each other and with the environment. This leads to a second general trend in the new genetics, or genomics, which is the emphasis that genes are complex. Researchers must take gene-environment interaction into account.[10] Trying to disentangle this is currently no small problem in the world of genomics.

In its website, the company acknowledges complex gene-environment interaction. Most diseases, it states "may arise from a complex combination of genetic influences and environmental influences,"

> we are in the early stages of a genetic revolution in medicine. Many of the genetic diseases that we understand arise from large health effects of mutations in a single gene. But most diseases probably arise from the effects of variations in **several** genes, combined with a variety of environmental influences. As we learn more about genetics, we will begin to understand these complex interactions. We will no doubt learn that genetics plays a role in nearly all diseases.[11]

This quote comes from an article called 'Nature and Nurture' found in DNA.com's <FAMILY GENETICS> center, its public education site. Here, genomics is new and complex but not insurmountable at least for DNA Sciences. It does not aim to understand the complexity, but find genes associated with common conditions. Further, a company spokesperson here explains a participant's role in its pursuits.

> One of the problems with all types of genetic studies is that environmental factors play a role in most diseases. That is, some people may develop a given disease, not because of their genes, but because of some non-genetic factor – for example, diet. These factors cloud our picture of the genetics and we

[10] Gene-environment is meant in the local, cellular sense *and* in the much broader environmental sense.

[11] Dna.com's "Nature and Nurture" article found at the dna.com's Family Genetics > DNA Basics > How DNA Works > Nature and Nuture, WebMD's Family Genetics and Discovery Health Channel's Family Genetics Encyclopedia. [last accessed November 22, 2002].

> need to take them into account when we perform our studies. This is why we have detailed questionnaires as part of the Gene Trust – the more information we have about participants, the easier it is to identify disease susceptibility genes.[12]

According to DNA Sciences, it has figured out that environment is noise that needs to be (and can be?) filtered out. The idea that information about the object/subjects must be comprehensive is in the (re)presentation of the Gene Trust. In this (re)presentation, the Gene Trust works to push genetic science forward. Gene-environment interaction is now mainstream in the genetics disease world. However, it is through the Gene Trust via DNA Sciences that this view might be (re)visioned and put into action.

4.2.2 > And so the GeneTrust is launched

As expected, just after the official launch of The Gene Trust, its web presence at its site was prominent. Displayed on the company's homepage, a large clickable icon of the letter **g** compelled individuals to 'JOIN NOW.'[13] When initially launched the company aimed to draw potential recruits simultaneously into their website *and* their Trust/trust. The site focused on having individuals interact with the website/company online. At that time, the website's content bar lists the Gene Trust first, followed by several other hypertext categories displaying the DNA Sciences/DNA.com/Gene Trust's major themes.

THE GENE TRUST | ABOUT US | DISEASE & CONDITIONS | DNA BASICS | FORUMS | PRIVACY [14]

The company asked recruits to fill in pre-scripted questionnaires and send them in online. These include queries concerning lifestyle, medical conditions, family and health history. The questionnaires were self-administered. Geneticists have been skeptical of the DNA Sciences approach. One concern has been its direct recruitment of participants. A major contention, here, has been that experts view self-reporting by individuals as imprecise.

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[12] Interview with Hywel B. Jones, Director of Genetics at DNA Sciences, "The Gene Trust: After Your Donation," (aired August 7, 2000 <<http://www.dna.com>>)
[13] <<http://www.dna.com>> [accessed September 8,2000].
[14] <<http://www.dna.com>> [accessed September 8, 2000].

A genetics professor from Emory University, Stephen Warren, was quoted as stating, "What people know about their own family history is not very precise or accurate. It's more or less hearsay, or family lore that's been passed down and that's the opposite of what we would like to obtain, which is very precise clinical data."[15]

In reply to such criticisms, the company not only claims to acknowledge the importance of personal experience, unlike traditional researchers, in turning these criticisms around, the company insists it trusts its 'collaborators' to self-report, to be self-historians, or rather, to self-administer questionnaires of the company's own devise.[16] Rienhoff, while CEO, insisted that volunteers can be accurate about such matters as those the geneticist refers to above. The issue over such questionnaires is further clouded by the fact that it is not altogether clear from the company's description of its research approach, the exact procedures for how Gene Trust registrants' responses are used in genetic studies.[17]

Although we may be more skeptical about DNA Sciences' approach, the fact remains that there still is no clear answer in the scientific literature as to how to use such non-gene information nor is there a clear answer in the technical database literature as to how to link such information to gene information (or sequence data). Currently, the direction DNA Sciences seems to be taking is that collecting various forms of non-gene information about an individual into a database will allow its researchers to filter out at least those variables and the result will produce the desired gene information.

Therefore, genetic material is not the only thing needed from individuals and not the only source of information that the company seeks. Its approach entails not only the extraction of DNA and biological material from an individual, but tracking him/her over time/space, collecting myriad glimpses of his/her life from historical and current events. All of which then needs to be converted into a cross-reference-able form. Finally, gene functions can be found. For all our acceptance of complexity – complex interactions of genes and environment – DNA Sciences illustrates that for many of us our desire for control predominates.[18] Regardless of the fact that neither an explanation for how these various

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[15] Quotation from CNN, "Charting the gene pool: CA firm banks on volunteers to further DNA study," (March 26, 2001) <<http://www. cnn.com>>.

[16] And, in fact, the move to disembody experience is made by the individual.

[17] CNN, "Charting the gene pool: CA firm banks on volunteers to further DNA study," (March 26, 2001) <<http://www. cnn.com>>.

[18] Asked whether the company's studies would include the combined affect of genetics and the environment, Ray White, Chief Scientific Officer of DNA Sciences, stated, "Not in the

forms of information will be compatible or combined with one another nor even the algorithms and methods for yielding results. Regardless of the fact that these are merely snapshots of an individual's experiences (at least for now), knowledge, and life – mediated, translated, and purified – and, in a word, body-less.

These contentions are not raised in DNA Sciences discussion of The Gene Trust. However, a company spokesperson states that in this genomic database research, individual's information is in some sense just not that important. According to Joseph Lough, who states,

> Genetics is intrinsically a statistical subject. What we're looking for is a difference in the frequency of certain alleles (variants of a gene) between people who have the disease and people who do not. Because these differences are very small, we need a large number of people to participate in each. Many diseases are thought to be polygenic (multiple genes are involved), and this makes statistics very complex. To analyze the data arising from these studies can require huge amounts of computer power.[19]

Lough raises the issue of analyzing the data, but technical aspects about a population database are virtually non-existent for the broader publics in the company's (re)presentation of the endeavor. The mention of its database, which was referred to in its SEC Filing report, as DNA BASE, is not found at its website at all.

The statistical aspect is further formulated by Nanette Newell, an ethics and privacy policy consultant for the company, who states,

> the kinds of experiments that DNA Sciences is doing do not rely on any one person's results. It's a statistical analysis of many people's information that

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beginning. Our first challenge is to identify the genetic variants that cause susceptibility. But the question is an excellent one because that will enable us in the future to more readily identify the environmental agents that are also components of the disease. I think it will be very important at that point to do those studies. Because that is almost certainly going to be an important avenue for intervention through a change of lifestyle. Our problem now is that we don't know what individuals are likely to be responsive to which lifestyle or diet changes. It is very frustrating because there is good evidence that both genetics and lifestyle or environment are major components of our most serious diseases." - interview, "Genetics What's Next," (orig. air date: July 31, 2000), <<http://www.dna.com>>)

[19] Interview with Hywel B. Jones, Director of Genetics at DNA Sciences, "The Gene Trust: After Your Donation," (originally aired August 7, 2000 <<http://www.dna.com>>).

> gives us the info we're looking for, so it's the group of people that's valuable to the company. [20]

Implied here is that individuals are irrelevant to the work of the DNA Sciences. Yes, the individual participants are informational subjects, but once translated from individuals' genetic, medical, health, lifestyle and/or family history they are data points for the company's numbers' crunching. Through some approach, not elaborated at its site, aggregated information from genotyped DNA samples from volunteer-consumers are to be linked with their personal, health, and history information, but how this will be meaningfully brought back to the individual is problematic.

In its discussion of collection efforts, mainly through its Privacy Policy document, The Gene Trust Project (re)presented, attempts to tap into a culture of anxiety about privacy as well as savvy-ness of web frequenters when it comes to recruiting, obtaining personal information, and alleviating doubts about security issues. On the one hand, the company appeals to potential recruits on the level of privacy and ownership of information. On the other hand, it appeals to a sense of anonymity. It claims that individual's information is the person's own and that individual identity can be safely masked through population genetics/genomics. Genetic privacy and identification are circulated, but discussed here as one and the same as digital information. However, the output, the results (which are at best hypothetical) are of individual, consumer importance. In this case, then, consumer privacy and identification are circulated in this space.

According to the site, personally identifiable information about individuals remains the property of individual consumer-patient volunteers. This is reiterated again by a company spokesperson,

> Some companies have decided that their personally identifiable information is property of the corporation. DNA Sciences has obviously adopted a different position. We will not share personally identifiable information with a third party, without explicit consent from the individual.[21]

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[20] Interview with Joseph W.H. Lough and Nanette Newell, "The Gene Trust: Privacy Issues," (originally aired September 5, 2000 <<http://www.dna.com>>).
[21] Interview with Joseph W.H. Lough and Nanette Newell, "The Gene Trust: Privacy Issues," (originally aired September 5, 2000 <<http://www.dna.com>>).

In its Privacy Policy document, though, the company states that this means information that would allow a third party to contact the donor. Health and family information is supposedly, in the company's terms, "de-identified," meaning contact information has been de-linked from it. Individuals, in the company, however will have the ability to link them back together. The company, in a sense, reclassifies all these forms of information into its own categories of what an individual gives the company: personal and family health information and what the individual owns: contact information. Keeping these separate seems highly problematic.

The company plans to take the information its consumer-volunteers submit, translating, digitizing, aggregating, sifting, analyzing, transforming, and ultimately creating new information, which only then will be of monetary value to anyone, from consumers, health care providers, physicians, third party payers (e.g. insurance companies), to pharmaceuticals. Personal information becomes privately value-able information for the company and its commercial partners. However, according to the company this is when it is transformed into aggregate form. At this point, the company seems to be speaking beyond the individual and in the realm of population. Its online Privacy Policy suggests, the importance of digital bio-information here shifts from its identification with individuals to populations. In the next section, I want to deal more with the company's collection methods. In doing this, I will also highlight the tensions between various forms of information and between descriptions of populations and individuals. The company puts to work these descriptions and constructed relations to create a sense of security for the potential recruit.

4.2.3 > An appealing ease

The participant in DNA Sciences' Gene Trust is made out through its site to be the post-industrial consumer-volunteer. In the company's narrative, life is complicated. DNA Sciences makes an appeal, especially to healthy recruits, by offering to do the hard work. The cyber-savvy individual, who lives a busy fast-paced life can simply compile all her information about life, family, health, physical attributes (and perhaps later a small blood sample), turn it over to DNA Sciences and not worry about it. It is the individual's choice to make. DNA Sciences offers to alleviate her of her anxieties and worries over health, disease, and the future.

DNA Sciences claims that participation is easy. The company emphasizes that the donation of a sample of blood will only have to be done once, minimizing time and effort on the part of the individual:

> It only takes minutes to join the Gene Trust Project, but your contribution is nothing less than heroic.[22]

The blood sample will be taken by an independent, but 'qualified health professional.' This professional will be located in proximity to the volunteer/consumer, again minimizing time and effort. Although not referred to at the site, it turns out that a phlebotomy services company, Hooper Holmes, based in Basking Ridge, New Jersey was signed on by DNA Sciences in the summer of 2000 to provide nationwide services. Further, it is in these locations that informed consent services will be conducted, rather than with DNA Sciences itself.[23]

Although the website suggests that the aim is to make the collection efforts and blood sample procedure as quick and painless for its volunteers as possible, with a 'one time' only blood sample, its CEO Rienhoff had stated,

> with the permission of the Gene Trust member, we can periodically inquire, perhaps once a year, as to whether their health status has changed. An important feature of the Gene Trust as a web-based communication tool is that, with participants' permission, we can establish a long-term relationship.[24]

However, facilitated by DNA.com, its 'online patient network,' DNA Sciences promises that the volunteer's part is uncomplicated.

> If you're interested in joining us, click the link below to register. It's a simple process… [25]

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[22] <<http://www.dna.com>> Home > The DNA Sciences Gene Trust Project > How we're doing [accessed 10.31.2001].
[23] See the August 16, 2000 press release from Hooper Holmes last web access May 15, 2002 <<http://www.ir.connect.com/hh/>>
[24] Interview with Hugh Y. Rienhoff, Jr. "The Gene Trust: An update from the CEO," orig. aired September 14, 2000, <<http://www.dna.com>>]
[25] <<http://www.dna.com>> Home > The DNA Sciences Gene Trust Project > How we're doing [accessed 10.31.2001].

Recruits never have to set foot in its California headquarters to participate. However, the experimental site seems to smoothly expand from within DNA Sciences facilities, through and by the Internet, and into the volunteers' homes. The website tells its visitors that joining the Gene Trust Project is a simple process. However, even in the unlikelihood that DNA Sciences' pharmacogenetics and genetic diagnostic schemes succeed in more precisely establishing drug efficacy and higher risk individuals for certain conditions, the individual practices of genomic medicine impact on an individual's decision on taking certain drugs, having certain preventive surgeries, and making certain lifestyle changes. Further, these are directly linked to the company's commercialization efforts. The move from participant to consumer is clearer here.

The examples above highlight the distorting of the virtual and non virtual relational aspects between the individuals who volunteer and the experiment/er (Gene Trust/DNA Sciences). The site's language of a web-based consumer focus conveys a log-on to the virtual realm and log-off to your real world. However, the initial volunteering of one simple blood sample ('one-time donation of blood') and a few questions online may become a lifelong relationship (if the company lasts) or at least (again if the company lasts) periodic inquiries for additional information over the long term.

The idea of establishing a long-term relationship with individuals is furthered in the site's supposed attempts to present a virtual space that brings together individuals from across the states, into a virtual, non-geographical place – that is, a community. [See Fig. 2 for membership information. The early idea was that a real community exists here at the site. According to DNA Sciences, it wanted to hear what you say- as a patient (?), collaborator (?), and/or consumer (?) All of these identifications circulate in DNA Sciences' site. However, it provides a portion of the company's virtual space for individuals to post. It reserves the right to use an individual's comments and actions in its space for its own research/purposes. The company's site increasingly addresses the visitor in terms of his/her consumer wants and desires to have genetics made less abstract (the kind of genetics in the public sector) and made more real – in the form of diagnostic tests and targeted medicines. The difference in

the homepages of its new site in relation to the old site should at least be an indicator of where the individual is in the company's current sight/site.[26]

Fig. 2. The road to 'Gene Trust membership'
(a re-construction)

Attempts to register online suggest that there are several levels of 'membership.' Joining the first level, 'basic registration,' permits the registrant access to the chat rooms, bulletin boards, online discussions, and public discussions, moderated by 'experts.' Now part of DNA.com, an individual signs up to be part of an online community. In return, the registrant provides her name, email address, and zip code. DNA Sciences states that two types of information are collected:

a. *contact information*. After an individual has reached this level of online access, s/he is shown the rules of compliance with the company (community's) chat room policies and, **another request to join the Gene Trust**.
b. *shared information* while in chat rooms and bulletin boards, maintained by the company. ('Personal Information DNA Sciences Collects').*

According to the company, since these are public forums, any information provided by an individual here is public since they are public forums, and may be collected for the company's research and business activities. It notes that at stage (a), DNA Sciences compiles registration information into non-personal and aggregate information, or statistics, as well as for research purposes, specifically to ascertain the numbers of visitors to their site. The latest 'Facts' about the Gene Trust illustrate one use of 'your personal information':

'The Gene Trust Project already has volunteers from 50 states!'**
'To date, over 250,000 people have visited the Gene Trust.'**

Here, personal information becomes not just research material but is enrolled – in aggregate – to do work for the company and promote the Gene Trust. At the level of 'basic registration,' no direct genetic information or tissue/blood samples are gathered. This is preserved for a second level of membership. Members at this level will provide additional information to the company:

a. **more detailed contact information** than that which was necessary at the basic level of registration.
b. through a self-administered questionnaire provided by the company, the individual will provide information about the his/her **health and health history of family members**.

The responses to these questionnaires are not automatically inputted into computer databases. Researchers of the company scrutinize them. Those individuals whose answers match a specific profile, specifically, match a study currently conducted by the company's researchers, will then be asked to **donate a sample of their blood**. This constitutes the highest level of volunteer.

In DNA Sciences, the blood sample will be taken by an independent, but 'qualified health professional.' This professional will be located in close proximity to the volunteer/consumer, again minimizing time and effort.

The blood samples are then sent back to DNA Sciences' laboratories, and after being assigned an 'anonymous code,' they will be evaluated, and the **gene information** extracted will become part of DNA Sciences' ongoing and 'extensive genetic studies.' Anonymous, here, is not complete de-identification and therefore not de-personalization of the information, in the company's sense of personal. It is rather encoded. Therefore, at the very least, specific personnel at the company can still match the blood sample with the donor.

* See DNA Sciences Privacy Policy <<http://www.dna.com>>
** <<http://www.dna.com>>

Further, the site presents DNA Sciences as a protector, mediator to other companies, and transformer of the varied information that individuals provide. According to

[26] See Diagrams 3 and 4 in the APPENDIX of diagrams at the end of the dissertation for the older and newer sites, respectively.

the company, personal information as it defines is the individual's.[27] DNA.com works to ensure that,

> your registration and personal and family health information is protected from unauthorized individuals externally as well as internally. [DNA Sciences Privacy Policy posted on its website].

The company not only works to make its collection processes uncomplicated for the individual, it is doing the hard work in order to minimize the individual's effort. However, individuals are encouraged to contribute to forums, and to update personal information. For volunteers, while there is no ownership and no access to the 'locked box' database, the website is available to them. Individuals are provided IDs and passwords and, at their convenience, can log onto the site, in the privacy of their own homes.[28] Participants should feel secure that their personal information is as safely monitored, maintained, and held by DNA Sciences as consumers, when providing their credit card information by Amazon.com.

> Our security arrangements do not make it possible for us to allow anyone, including you, to access your information over the Internet. [DNA Sciences Privacy Policy].

The fact that the actual database is a sight unseen even to its volunteers should alleviate any fears of security breaches.

However, what the promises of security mean is problematic. Public discussions, in the United States, about these types of database schemes have emphasized security and the construction of the database. There is also the related issue of privacy. DNA Sciences works at one level on an individual consumer model, both in terms of recruitment and in terms of end-sales. And as such, the company has made great efforts to discuss publicly – in a consumer privacy model – the security and containment of all information from registered consumer-volunteers. However, the company circulates genetic information within this

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[27] The wording of personal information varies elsewhere in the privacy policy, "We promise never to share personally identifiable information – information that can be used to contact you – with any person or entity outside DNA Sciences without your express consent, unless legally required…."

[28] The company later reassessed that this idea is no longer plausible, given the design of its security system.

frame. Allaying anyone's fears regarding a breach of privacy, Nanette Newell, an ethics and privacy policy consultant for the company, stated,

> Some specifics include keeping information on offline computers that are not connected to the Internet. They are kept in secure rooms that are locked, alarmed, have video cameras, motion sensors. None of the info is available even within the company. One's personal information is only linked to one's genetic information via a complex encryption code, so that to link the person's personal info with their genetic info is very difficult.[29]

The website is a space in which the company can interchange 'gene information' with 'private' and 'personal information.' It is also a space in which the company can put into circulation both 'genetic privacy' with 'personal information' – even if genetic material or gene information is not collected on line.[30] The interchange between genetic and internet privacy is also reflected in the discussion with Lough, in which he responds to the question, 'Where are we (in the United States) with national *genetic* laws?':

> I expect that during the next administration, no matter who is elected, *Internet privacy* will be at the top of their agenda and we will see some strong enforceable laws.[31]

However, for now, DNA Sciences will protect and take care of the individual's sequence data, genetic, personal, historical, medical, familial information, secured and fully contained in its Gene Trust/DNA Sciences. Nanette Newell makes this clear,

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[29] Interview with Joseph W.H. Lough and Nanette Newell, "The Gene Trust: Privacy Issues," (originally aired September 5, 2000 <<http://www.dna.com>>).

[30] See DNA Sciences' IPO filing in which 'DNA samples' and information are stated to be collected on line. "We may be unable to attract a sufficient number of participants to the project because of concerns regarding the privacy of genetic and personal information provided to us over the Internet." [DNA Sciences' IPO, S-1: 10] The ambiguity of what is meant by genetic information is also seen here: "Those interested in participating in the Gene Trust project are asked to complete a profile that includes their own health information, medical histories and family disease histories. Individuals can update their information on an ongoing basis. …Over time, we expect to develop a large, active database containing this information and the genetic information we derive from the DNA samples... We retain full ownership of all data collected and generated through our Gene Trust project." [DNA Sciences' IPO, S-1 IPO: 42.] <<http://www.sec.gov>>.

[31] Interview with Joseph Lough and Nanette Newell, "The Gene Trust: Privacy Issues," (originally aired September 5, 2000 <<http://www.dna.com>>).

> It's important to understand that the genetic information is not online. It's kept in secure offline computers that have what are know as 'one-way drops.' So someone enters their personal info on the website, and it comes into the secure computer. It's called a one-way drop. It has numerous firewalls and protections.[32]

Here, genetic information seems to be interchanged with personal information. Is it less (or more) than sequence data and/or gene information? Newell's comment seems to suggest that there is a tension in keeping the (terms?) or really these various forms of (gene, genetic, personal, private) information meaningfully separate.

In fact, although it may be called The Gene Trust project, according to DNA.com, issues of collecting genetic/blood material, storing, and securing samples are deferred for offline events. Its main document for information collections is its 'Privacy Policy' site, but this handles only information collected by/through the website. DNA Sciences itself does not come into contact physically with the recruits who provide blood samples. Rather the company contracts out the responsibility of blood sample extraction (as we saw earlier Hooper Holmes), and it is also this company that handles informed consent contracts with those recruits who provide samples.

Further, here, DNA.com is simply a one-way interface, in which the potential collaborator is really just an information source. In order to establish strong security of information, the site/Gene Trust here is represented as something less than an interactive community/collaborative effort. This becomes more apparent in Rienhoff's statement, in response to whether privacy seems to be an important concern for the Gene Trust's volunteers,

> People who have major concerns about privacy might not be reassured doing anything is confidential on the web, whereas people who understand the meaning of our privacy and security policies are comfortable.[33]

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[32] Interview with Joseph Lough and Nanette Newell, "The Gene Trust: Privacy Issues," (originally aired September 5, 2000 <<http://www.dna.com>>).
[33] Interview with Hugh Y. Rienhoff, Jr. "The Gene Trust: An update from the CEO," (orig. aired September 14, 2000, <<http://www.dna.com>>).

I do not know how many individuals understand the *meaning*, or rather meanings, of these policies, or believe that these policies establish privacy. However, Rienhoff, here, attempts to shift the responsibility of trust to its potential volunteers and the responsibility of security not to the company, but to the participant/consumer and internet user.

These verbiages among the company's spokespeople embody the similar circulations, in the company's ether space of genetic, gene, personal, and private information. The company's website, including its posted Privacy Policy document, give an appearance of the ease – a flow – between gene/tic material/information to personal identifying information to lifestyle, health, and family experiences to information and digital data that DNA Sciences seeks. However, as we saw earlier in this section, this is only an apparent ease.

These pronouncements should indicate the anxieties a visitor may feel in attempting to identify what s/he is volunteering, lending, and/or giving away to the company. S/he may wonder even whether her/his information can even be parsed out into these categories in a meaningful manner. In the next section, I want to explore further how the representational endeavor may put the visitor at additional ease by putting the representation to boundary work.

4.3 > Building futures

4.3.1 > Changing spaces

The website has gone through a number of different spatial arrangements, especially its homepage, and by 2001 the Gene Trust figured less prominently. The company halted registration after it had collected about 12,000 registrations, rather than the projected 100,000. After it announced halting registration, The Gene Trust is simply, with no explanation, located differently. In fact, a visitor to the company's homepage would find a complete overhaul and regrouping of the company/site's divisions.

PRODUCTS&SERVICES | SCIENCE&DISCOVERY | OURCOMPANY | FAMILYGENETICS | DISEASE CENTER | GENE TRUST[34]

[34] <<http://www.dna.com>> [accessed October 31, 2001].

However, we also need to take into account that in July of 2001, the company pulled out of its initial public offering plan. Then, in late September of 2001, the company saw a massive reshuffling and overhaul of its management, employees, and business plan. The firms' creator, Rienhoff 'resigned' as chief executive officer (CEO). To take over the day-to-day operations, Harvard MBA graduate, Steven B. Lehrer, who was the former chief business officer, replaced him. Lehrer assumed the post of chief operating officer (COO), and changes were made in board structure as a director, James D. Watson, also resigned.

Further, the company's announced a shift from research to a more commercial focus, in particular into pharmacogenetics.[35] Although the company sent out press releases concerning the above shifts, there was no re-launch of a new company.[36] However, in its website, specifically, its homepage, the company re-presented its 'new' self. Out with the old dna.com, the education and online patient network, that was focused on providing forums and message boards. Instead, the (re)presentation of the company expands into the Gene Trust's site. DNA Sciences re-introduces itself: <WHO WE ARE>. Although this 'switch' to a business focus was announced just one year after the Gene Trust's launch, by then over 10,000 individuals had registered.[37] Further, it was not long after the company's shifts that it also decided it had collected an adequate number of registrations at least for the time being.

While changes were made to the website, what has remained rather stable, though, in both content (here meaning substantive text) and arrangement is the <Gene Trust> section. Its subheadings include: 'Origins of the Gene Trust' 'How it works' 'The Gene Trust Bill of Rights' and 'How we're doing.' They have all remained unchanged within the two years since the Project's launch.[38] Here in this newly designed site, the visitor (currently 2002) cannot sign up, but s/he can find out how DNA Sciences' Gene Trust is doing and how it works, but s/he can also find out how individuals' who have joined the Gene Trust work in and for

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[35] This commercial side of the company is presented as conducted separately by DNA Sciences *Laboratories* (DSL). DNA Sciences *Laboratories* was previously PPGx, Inc., a firm that provided research information to pharmaceutical companies. However, it became a wholly-owned subsidiary of DNA Sciences, which entered into an agreement to acquire PPGx in December of 2000. See DNA Sciences press release, "DNA Sciences enters agreement to acquire PPGx, Inc." (December 18, 2000).

[36] See DNA Sciences press release "DNA Science appoints new leadership, Increases focus on commercial opportunities." (September 20, 2001).

[37] Since then, the homepage has gone through another major change. [last accessed. However, the time-frame for this project prevents me from more in depth analysis. [November 21, 2002]

[38] At least, this is true of the times I frequented the site through those two years.

DNA.com/ DNA Sciences. Here, this section provides a window for individuals and recruits to check up on the company's progress in its Gene Trust efforts. Here, the recruit should perhaps feel s/he is collaborating in the company's endeavors.

4.3.2 > New Sites - Contributing to a genetics revolution?

After the DNA.com space was overhauled, the amount of corporate information expanded at its homepage. The site's arrangement and content altered, and the themes were also expanded. This entailed new descriptions with more information about the company's involvement in <SCIENCE & DISCOVERY> and providing <PRODUCTS & SERVICES>.[39] [See Fig. 1].

The Gene Trust would only be one component of the company's research aims, and in fact is not the only database it uses. In its new division <SCIENCE & DISCOVERY>, the Gene Trust Project is explained as linked to the company's other sources of population data the Utah population database, and to family linkage datasets.[40] With the established population resource at the University of Utah, this start-up company establishes its affiliation with a public, academic institution. Further, in this section, the company cites its use of a combination of established past approaches as the basis of its genetics research:

> We expect to be successful through our approach by applying proven techniques to families that are orders of magnitude larger than those used for previous studies.

The company claims that its scientific approach is well-grounded, for instance, in the sense that family linkage datasets have been used for a long time. Therefore, what they are doing is not so new as to be completely experimental. In this same moment, the company does emphasize the innovativeness of its approach – *access* to extremely large and heterogeneous populations:

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[39] In this presentation of a split/schizophrenic identity, the site's focus is on a 'new' strategy from information to tangible product (drug) interests. However, this does not contradict DNA Sciences early statement on how the company makes money.

[40] Science and Discovery > Our Approach > How DNA Sciences recruits Participants [January 26, 2002].

> What sets DNA Sciences apart from previous gene discovery efforts is the company's access to extremely large populations in which we can map genetic markers.

In this light, the company's Gene Trust project is less innovative, less emerging than expected, its origins linked to the so-called revolution brought about by the public, international human genome projects.[41]

Now, part of this genetics revolution, the DNA Sciences is willing to bring the ordinary person – who has wanted to do this all along – with them as an active participant. In announcing their 10,000-mark of Gene Trust registrants, Rienhoff remarked, "This milestone reflects America's widespread interest in being part of the genetics revolution…."[42] The idea of the early DNA.com site was to provide a virtual space as both an educational site and an 'online patient network.' However, upon registering, an online visitor becomes a 'volunteer.' The virtual site becomes a dynamic high-tech tool that permits the ordinary individual to become involved in science. In the company's words, 'the ordinary becomes extraordinary' – and the *virtual*-site becomes a *real*-site for doing science. The recruit could actually participate online. However, after the revamping of the company, the site undergoes some changes. In addition, one year after this strategy shift, the company re-emerged again as more than a health information company. It had become a 'leader in pharmacogenomics,' shifting from primarily providing/creating information to creating drug products."[43]

For Rienhoff, the 'genetics revolution' will do no less that transform medicine. According to Stefánsson from the Iceland project, Meade from the UK, and Rienhoff from DNA Sciences, genetics will turn a symptom-based medical approach to a preventive approach to medical research and healthcare. At DNA.com, *genetics* may be 'transforming healthcare,' but DNA Sciences is 'fulfilling the promise.'[44] The questions, though, are 'transforming how?' 'what promise?' and 'fulfilling a promise to whom?'

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[41] See, the site's 'Origins of the Gene Trust,' which links the project to the HGP. <<http://www.dna.com>>.
[42] PR Newswire <<http://www.prnewswire.com>> (July 19, 2001).
[43] <<http://www.dna.com>> [accessed 4.2002].
[44] The company's mantra, in a masthead above the company's name, was 'genetics Transforming Healthcare.' This title, in a rather understated presentation, topped the homepage (as stated above). Its implication and the role of DNA Sciences in such a transformation were centrally situated in the 'Genetics' corner. It is a shift from the

4.3.3 > Fulfilling the promise

In its division, <PRODUCTS & SERVICES>, the visitor learns about the company's clinical and research services. The site provides some details about its genetic and diagnostic testing in its <Clinical services> pointing out the company's access to traditional laboratories as well as high-tech capabilities and expertise. Its ability to perform clinical services quickly is highlighted. Also highlighted is the fact that although it may be a relatively small company (or because of this attribute), its clinical capabilities are globally available and globally attuned through strategic alliances. The company also describes <Research services>, targeted primarily to drug discovery companies, such as traditional pharmaceutical ones. The company's current goals are to aid the refinement of drugs already marketed or under development for common diseases/conditions. [45]

According to the company, then, its population databases, although heterogeneous, or rather, because of this fact, can be used especially to make queries at the level of geographic and ethnic categories:

> drug targets and related pathway proteins can be sequenced for variations in the general population across diverse geographic and ethnic backgrounds in both affected populations of patients as well as unaffected control populations. This includes access to a database of common and rare sequence variations in many genes along with clinical associations where they exist.[46]

In this section of the site, like that of <SCIENCE AND DISCOVERY> section, the company describes the Gene Trust in terms of a population although only implicitly and in

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(re)presentation of the company in which the roles of DNA Sciences were as mediator, educator, and patient advocate.' Currently, the site's mantra is '*fulfilling the promise*.' [last accessed November 18, 2002].

[45] In particular, DNA Sciences works in the areas of pharmacokinetics and pharmacodynamics. Pharmacokinetics can be briefly defined as how a body processes a drug. Pharmacodynamics defined as how a drug affects a disease. Rienhoff distinguishes DNA Sciences from other companies working in pharmocogenetics in that it is looking at "the heritable components that influence disease susceptibility and disease course and therapeutic response in a given disease." [Quoted by Celia M. Henry, "Pharmacogenomics," *Chemical Engineering News* 79: 33 [cover story] August 13, 2001: 37-42.

[46] <<http://www.dna>> Archived website of dna.com. See dnasciences.pdf p. 54.

combination with its other sources. According to the company, the heterogeneity in DNA Sciences' Gene Trust population distinguishes it here from other's population resources. This section of the site, however also reconfigures its population base into sub (specifically 'ethnic') populations/categories. The company

> offers access to a proprietary database for insight into the prevalence of genetic polymorphisms among ethnic groups. Using our large reference population, we can accurately determine the frequencies of new genetic variants in Caucasian, African-American, Hispanic and Asian populations.[47]

DNA Sciences configures individuals' information into an aggregate format, but the database not only stores information, it transforms these into usable knowledge for the pharmaceutical firms reconfiguring information. Usable knowledge, here, consists of determining gene variants, not in terms of the individual, but within some populations, based on some ethnic scheme, which is undeveloped at this site. This approach is currently of special interest for the pharmaceutical industry developing drugs:

> In addition to understanding that genetic variation defines us as individuals, it is important to understand that genetic variation also defines populations. This understanding is of key importance to the pharmaceutical industry; if 'the right drug for the right patient' is unrealistic, the right drug for the right population might be a more achievable goal.'[48]

The current idea in the industry of pharmacogenomics is that, by establishing a relationship between genetic susceptibility to a condition with an associated drug, its efficacy might be refined to a specific individual, and if not, at least some population. This is still in experimental stages, but this is one glimpse (and one of very few) into how the Gene Trust population/database is envisioned to 'create value.'

Similar to its 'clinical services,' the company emphasizes the broad reach of its 'research services.' This utility of its databases for determining variation across broad

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[47] <<http://www.dna>> Archived website of dna.com. See dnasciences.pdf p. 54.

[48] Elizabeth C. Jazwinska, "Exploiting human genetic variation in drug discovery and development," *TRENDS Guide to Genetic Variation and Genomic Medicine*, eds. Robert Shields, Arianne Heinriche, and Meran Owen (March 2002): S32 (S30-6).

geographic and ethnic populations fits well with the company's efforts to keep its business options open, to attempt to reach a broader, global audience, and, possibly, to create transnational collaborations. However, the company was more explicit, in its Securities and Exchange Commission report, about its efforts to market and, therefore, to study diseases/conditions of most interest to individual American (i.e. U.S.) consumers and pharmaceutical companies. For the goal of individualized medicine, certain categories of populations are still required to explain variation, that is, differences in individuals *and* populations (as reflected in the quote above). The company currently plans to market genetic test kits to physicians and individual consumers in the United States, but pharmacogenetics also has broader appeal and market.

After this change in strategy, the website's emphasis, through <PRODUCTS & SERVICES> and <SCIENCE & DISCOVERY>, is even more strongly focused on the company's ability to locate genetic variation across geographic and ethnic lines through its heterogeneous reference population. In other words, at a scientific level its large-scale population database is distinguished from others, like Iceland's more homogeneous database, by its heterogeneity. The scientific debates over the usefulness of heterogeneous and/or homogeneous populations in studying complex conditions appeals to different interests, individuals, researchers, industries, and nations at different times. The tide continues to shift, but these disputes are bypassed at DNA.com.

However, in other domains of the site, the company points to the character of its individuals in attempting to establish the uniqueness of the Gene Trust. DNA Sciences points to recruitment methods. Furthermore, the Gene Trust population may not be identified as homogeneous as others – genetically – but it is uniquely American in its individuals' altruism and its volunteers' beliefs in scientific and technological progress and internet savviness.[49]

[49] This uniqueness, however, is rather different than emphasizing uniqueness of its 'expression' or definition, the latter seen in the deCODE Genetics case, whose officials emphasize the uniqueness of its resource – the Icelandic population.

4.3.4 > An orientation on Gene Trust: (re)presenting a vision

The information above about the research and clinical services of the company are provided in a simplified, but rather traditional, professionally-based manner. There are no links nor even bibliographies or references to its researchers' papers or to the company terms as established past approaches to gene discovery or population genetics.[50] I would argue, though, that the <Clinical> and <Research> is intended primarily for professional and allied audiences. This is further suggested from both the company's changes and the rearrangement of its homepage [Sept. 7, 2000 to October 31, 2001, See Fig. 1] in which <PRODUCTS & SERVICES> appears only after the company's shift in business plans from 'research' to 'applied' strategy. DNA Sciences, instead, provides a separate site for individual consumers and a more general public.

For DNA.com creating individual consumers/ patients/ collaborators/ cyber-volunteers/ participants is important as well. According to the company, personal information, in a blood sample donation, and personal health and family history, through accurate self-reporting, are important. In fact, they are even integral to the company's research in validating genetic findings using linkage analysis. This may be the case. However, more directly and immediately, having an individual's profile makes the consumer market in diagnostic testing more appealing to the company as well. However, information in the raw forms provided by an individual recruit does not yet constitute valued information for the company. As stated in the company's SEC IPO report,

> Even if we are successful in developing these products and services, we do not expect our diagnostic tests to be available for commercial sale for many years. In addition, there may be no market for our diagnostic tests because of lack of patient and physician acceptance….[51]

Completion of the cycle requires a negotiated effort with the potential consumer.

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[50] The company is in the midst of applying for patents on its intellectual property, which includes its approach to establishing a database, which it refers to as DNA BASE. Until then, the company maintains its closed position and lack of public documentation about its research and its specific methods and approaches. [See the DNA Science's SEC initial public offering filing report].

[51] DNA Sciences (333-53306), IPO Plan (S-1) to Securities and Exchange Commission (January, 05, 2001): 8. Available at the SEC's website <<http://www.sec.gov>>.

The company's site, therefore, continues to aim at educating its potential volunteers, perhaps to facilitate better reporting, but more importantly to get potential consumers to adopt a genomic vision of health. In order to facilitate the transformation of this information to value-able information, dna.com (re)creates a different reference database and basis for its data-based approach. <THE DISEASE CENTER>[52] is DNA Sciences' site for a public education initiative on genetics and disease.[53] At the 'Center' visitors are provided with information on more than 20 common diseases and conditions from 'breast cancer,' 'eating disorders,' 'obesity,' to 'Parkinson's'. Here, one can find 'News' from Reuters, the Associated Press, and the company's partner, WebMD. In addition, one can also find 'in-depth interviews with the world's leading experts' in either text or audio in 'Gene Talk' and a 'Disease Reference' guide with 'quick and easy overviews' of each of the diseases 'complete with illustrations and additional resources.'

This is a treasure trove of general information about common conditions *and* their genetic components. However, the entries in this online database emphasize the connections between genetics and disease, providing simple illustrations of the genetics involved. The 'Center' does not present controversial issues among various biological and medical communities. It does not even provide references to actual studies that the company is conducting or hopes to conduct. It does, though, provide additional citations to genetic studies that present cases for correlations between genes and these disorders.[54] For example, in the case of eating disorders, the site (re)presents a study on the association between anorexia and bulimia to genes in a twin studies case. The reader is reminded that environment plays a role – in each of the conditions they select for inclusion in their

[52] At the company entrance, apart from defining who they are by what they provide, the company orients the visitor to their site. To the left, is its DISCOVERY PLATFORM and to the right, there is a way to THE GENE CENTER. Beneath the hypertext, DISCOVERY PLATFORM, on the lower left of the page is the hyperlink text, urging, 'Call now to learn more about our laboratory offerings.' It is aimed at potential clients and professional collaborators. THE GENE CENTER is a resource center for general information about genetics, inheritance, and disease. Here, the visitor discovers 'How genetics can affect your family's health' under FAMILY GENETICS and find an 'easy-to-use online guide to common diseases and conditions' in which you can 'visit a DISEASE CENTER.' A quick link box even permits the visitor to select a specific disease. <<http://www.dna.com>> [05.07.2002].

[53] A number of biotechnology sites provide simplified disease definition resources, glossaries, and DNA/Genetics basics sites within their sites.

[54] These are linked directly, if available online, (usually to Medline). However, as those who have used Medline know, this may only provide the user – without journal subscriptions – of this database access to a citation or abstract – rarely the full article.

reference guide – but genes dominate the discussion. For 'eating disorders,' the center finds that there are no such causes that are 'proven.' However, it is noted that "Better understanding of the genetic roots of eating disorders will make it easier to identify and understand the environmental factors." This should not be forgotten since, lastly, The 'Center' then makes an appeal for these visitors to consider 'joining' the Gene Trust project.

The diseases in this reference guide also happen to be the disease conditions the company is interested in studying. The Gene Trust Project began with an initial plan to study twenty diseases. The Gene Trust, as a database of compiled individual genetic profiles, is supposed to facilitate – in fact 'speed up' – the process of finding genetic causes for common conditions. It is not only the individual DNA samples combined with specific historical information about those samples, the company is interested in. It is also the pool of the *large number* of such individual samples with associated information *and* the ability to manipulate and alter their associations with one another. Here, the analogy of the genomic database project as a mere warehouse, or even a biobank, begins to lose ground.

The fact that the database is not used for a specific study and/or disease area contributes to DNA Sciences' desire to collect information of such varied sorts. Further, as alluded to above, the company's strategy is to focus on complex diseases and conditions prominently of interest to certain populations of the United States.[55] These are unproblematically revealed as:

> Alzheimer's, Asthma, Autism, Breast Cancer, Cardiac Disease, Colon Cancer, Crohn's, Diabetes (Type 2), Eating disorders, Epilepsy, Hearing Loss, Heart Disease, Long QT Syndrome, Lupus, Multiple Sclerosis, Obesity, Osteoporosis, Pancreatic Cancer, Parkinson's, Prostrate Cancer, Psoriasis, Rheumatoid Arthritis, and Scleroderma.

Indeed, as the above show most of these conditions and diseases are not rare diseases, but common conditions. In addition, and not so incidentally, many of these are labeled today as 'lifestyle' diseases/conditions. Furthermore, they also happen to be diseases/conditions with established therapeutics or therapeutics already under investigation by prominent pharmaceutical companies.

[55] This is found within the company's SEC initial public offering filing report.

From the time of its initial public appearance online, the company's representatives repeatedly characterized one of the company's primary aims as general public education in the area of genetics, focusing especially on the relations between genetics and disease.[56] While individuals who initially register at the site and those who are then permitted to donate blood samples are likely interested in some specific condition, perhaps one with which they themselves or family members are afflicted, the call for recruits was/is also aimed at individuals who are currently healthy. Altruism is again invoked the closing plea to join the Trust. Visitors are told that they can help themselves, their families, and even others (if the disease does not afflict anyone in their family) not only by joining the Trust but also in donating time and money to charities that help those with the condition.

4.3.5 > DNA.com/Gene Trust/DNA Sciences

In a recent site, DNA Sciences describes a component of its work as "operating a comprehensive website at DNA.com,"[57] in which the company addresses two functions: a foray into science education, as an "online destination for news and information about genetics and health," and a recruitment center providing, "an opportunity to become involved in genetics research through the Gene Trust Project."[58] This differs from its earlier description and website, in which DNA.com was presented as primarily a portal for individuals to participate in discussion forums and message boards. The efforts in 2002 were primarily to explain and simplify the genetics of disease for the ordinary individual. In its <DISEASE CENTER> and <FAMILY GENETICS>, DNA Sciences establishes relations

[56]This case also illustrates that DNA Sciences initial and continued strongest public appearance is primarily online. In regards to corporate biotechnology's role in public life science education, more work needs to be done in this area. DNA Sciences is not the only corporate entity involved in such efforts. Celera is another company that works hard in this area. Further, many of these efforts are not only web-based or in providing news content. Other private and public entities with research and financial interests are increasingly involved in public education of science. See, for example, the American Museum of Natural History's the 'Genomic Revolution,' underwritten by a number of biotech companies. <<http://www.amnh.org>>.

[57] <<http://www.dna.com/ourCompany>> last accessed May 7, 2002.

[58] <<http://www.dna.com/ourCompany>> last accessed May 7, 2002. The company also recruits non-web-based participants by advertising through print ads and post. [See Interview with Hugh Y. Rienhoff, Jr. "The Gene Trust: An update from the CEO," orig. aired September 14, 2000, <<http://www.dna.com>>]

among genes, heredity, and common diseases/conditions (perhaps part of its scheme for making genetics real for ordinary people).

DNA Sciences' officials, other proponents of such database schemes, bioethicists, and critics claim that these ventures must rely on the altruism of individuals to register. There is no payment for their involvement and the company representatives, including Rienhoff, while still CEO, have publicly stated that the company may take many years before (or if) tangible results emerge from its research. However, the company promises to provide patients with any information and/or free services that result from their research. How this will fit in with alliances with other companies is unclear. Indeed, the matter of whether or not any such information or service will surface in their volunteers' lifetime is a serious question.

But a company representative, Hywel Jones, director of genetics, turns this around by sharing this risk with ordinary people:

> One of the novel aspects of the Gene Trust is that by using the web, people can be directly involved in helping increase our understanding of the genetics of common disease.[59]

Rienhoff, while still CEO, reiterates Jones' description of how the company perceives the relations between the Gene Trust and its web presence, but goes further in establishing the company's role in making science available for 'real people' to be directly involved:

> The success of the Gene Trust Program is a credit to the willingness of web users, who've heard about us, to roll their sleeves and participate. It's in fact a measure of the goodwill and trust that is present in people across the United States.[60]

Its recruits are enlightened volunteers who have been waiting for this opportunity – to be part of, as the company's genetic revolution in medicine. This web-based approach is described as both an altruistic, collaborative scheme with the everyday wo/man in America

[59] Interview with Hywel B. Jones, Director of Genetics at DNA Sciences, "The Gene Trust: After Your Donation," [originally aired August 7, 2000 <<http://www.dna.com>>].
[60] Hugh Y. Rienhoff, Jr., M.D., "The Gene Trust: an update from the CEO," DNA.COM Live Events (September 14, 2000). <<http://www.dna.com>>.

and a consumer-driven project. The company spokespeople go so far to (re)present its history and the central role of its private endeavor in the timeline of genetics.

The company provides a series of 'forums' or rather Q/A's that they call DNA.COM 'Live Events.'[61] Here, various geneticists, physicians, genetic counselors, bioethicists, researchers and other professionals from both within and outside the company are interviewed. These are archived and accessible to anyone with the proper equipment, hardware, software, and connection, on its website. Through these 'Live Events,' several DNA Sciences' representatives have talked about the company's work.

The forums have the effect of integrating the company's work into the broader scientific communities, a corporate 'story time.' In one interview, Hywel Jones, links its Gene Trust project specifically to the international Human Genome Project(s) (HGP) efforts, stating that

> In 1989, a massive worldwide research effort called the HGP set out to create a map of all the DNA within an organism – this map is called the human genome, and the information it contains will open the door to new ways of diagnosing, treating, and possibly even preventing disease.

However, the company projects, if not an unreal then a distant relation between those efforts and us. The basic needs to be applied, the abstract to be grounded, and the utility of the HGP made manifest in medicine. Thus, Jones continues,

> But before this can happen, someone needs to take the information and make it relevant to real people. That's where DNA Sciences comes in. In creating the Gene Trust, our goal is to establish a huge database of information about people – physical characteristics, health histories, responses to treatment, etc. based on the genetic knowledge this will give us, we can drastically speed up the rate of medical advances.[62]

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[61] DNA Sciences enlisted Digital Planet, a broadband web services company that produces interactive content to create content "to brand DNA Sciences and create a global awareness of this groundbreaking project." [See <<http://www.biospace.com>> press release 9.14.00].

[62] Hywel B. Jones, 'The Gene Trust: After your Donation,' DNA.COM Live Events (August 7, 2000). <<http://www.dna.com>>.

Therefore, the company is working for the consumer and the individual is invited to watch through DNA.com. Corporate transparency wins the day?

4.3.6 > (net)working sites

However, for the company, reaching consumer/participants through DNA.com is not enough. It hopes to extend its network of volunteers. The way in which individuals or volunteers participate in the company's research is not presented as the valuable personal information they provide, whether in the form of their DNA samples or in their narratives of their personal and family histories. Here, as stated by Rienhoff, it is in their abilities to enroll other members of their family:

> We, now, are interested not only in volunteers, but we would like to focus also on families. We would like to figure out a way to have whole families participate, including multi-generations, as well as extended members of a family.[63]

The importance is in fulfilling the promise of a future for DNA Sciences. How?

> I think the simple way to get families to participate is for the initial member of the Gene Trust to encourage their families to contact the Gene Trust on their own. Perhaps there might be tools for families that could encourage families to participate.[64]

Here, participants are also envisioned as recruiters. However, DNA Sciences is also at work. It seems to already have found at least one tool for doing so in DNA.com, as we saw in its <DISEASE CENTER>, but it may have found another as well. It is in fact – to be participants and recruiters for DNA Sciences.

DNA Sciences' networking attempts to reach beyond individual collaborators to their Gene Trust Project. It was early March of 2000, when the company came to a $35m

[63] Hugh Y. Rienhoff, Jr., M.D., "The Gene Trust: an update from the CEO," DNA.COM Live Events (September 14, 2000). <<http://www.dna.com>>.
[64] Hugh Y. Rienhoff, Jr., M.D., "The Gene Trust: an update from the CEO," DNA.COM Live Events (September 14, 2000). <<http://www.dna.com>>.

agreement with WebMD.com, a commercial health information, news, and forum internet company, to provide consumer medical and health information on its website. In return, DNA Sciences would be permitted to prominently link and display advertising material about its work.[65]

> To build DNA Sciences Brand as the preferred provider of genetic-based information to consumers and physicians and to attract more people to its genetic research project known as The Gene Trust. By providing expertise in genetics and genomics-related content, DNA Sciences intends to build trust and demonstrate their long-lasting commitment to quality healthcare with WebMD users.[66]

In the agreement, DNA Sciences was to provide genetic information about health and disease for two components of this internet company. The first was WebMD*health*, which is aimed to provide medical information to the consumer market. The second was WebMD*practice*, which aimed to provide medical information for physicians. Some of the information provided on this site is identical to that found in it <DISEASE CENTER>. In keeping with the company's theme of kinship and family genetics, especially throughout its <DISEASE CENTER>, the two companies create *Family Genetics* on WebMD's site, where, when I last visited, 'Pharmacogenetics: Drugs for *your* genes' was prominently headlined.[67] The information provided here also (re)produces DNA.com's work on <FAMILY GENETICS>.

The question here is what kinds of information are the company and its partners (re)producing. Yes, the material at hand is on genetics and disease. I am not disputing the validity that genes have some function in diseases. The current description that almost all diseases have a genetic component is likely. By the same token, almost all diseases have an environmental component. How meaningful and/or useful this idea is is a serious question.

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[65] See DNA Sciences IPO filing report (Exhibit 10-6, Doc. 3, S-1A) to the SEC (filed January 25, 2001).

[66] <<http://my.webmd.com/dna>> [accessed November 19, 2002].

[67] *Family Genetics* is found not only at dna.com and WebMD's site. It is also found (re)produced through the Disney-owned Discovery Health Channel's site, although DNA Sciences is less prominently displayed as its content contributor. <<http://health.discovery.com/minisites/dna/dnabasics.html>> [last accessed November 22, 2002]

Even though the DNA Sciences site works to describe its <Family Genetics> and <Disease Center> as providing basic science material, it can be more easily interpreted with the idea that it is in a corporate site. However, a visitor viewing and engaging the material through WebMD produces a different reading. An advertisement of the Gene Trust appears, but there is a more serious (re)presentation of the project here. The issue I raise is whether the disease/genetics information, the genomic vision, and/or the visions of the immediate aims of the company and its partners can meaningfully be teased apart in the company's broader, public educational efforts. The Gene Trust, not as a physical object, but the company's visions and approach to disease are here in its networked <Family Genetics>.

4.4 > Consuming and (reproducing) DNA(Sciences') information

4.4.1 > building trust(in)' subjects

Why should a potential consumer/patient/volunteer trust DNA Sciences, or any such company, with his/her personal information? According to Mark A. Rothstein, director of the Health Law and Policy Institute at the University of Houston, "It boils down to a couple of simple questions… What do you know about the company, and are you willing to trust it with your highly personal medical information and genetic sample? Everything flows from that."[68] DNA Sciences is new. At the time the Gene Trust was launched, it was virtually unknown. Its venture is a completely private endeavor. Further, the primary relationship between consumer and company/ volunteer and researcher is virtually-based. Perhaps this latter aspect is a good thing?

Here, I want to return to privacy (re)presented by, at, and through the site in more detail and the spaces in which it is (re)presented. The company devotes a large chunk of space on its site to privacy concerns pertaining to private, personal information.

> DNA Sciences is not only a genetics discovery company but we are also highly focused on ensuring privacy and confidentiality of all study

[68] Quoted by Foubister, Vida, "Genetics firms seeking wide patient base," *AMNews* (October 9, 2000) <<http://www.amednews.com>>.

> participants – an indisputable need when operating in a sensitive area such as genetics.[69]

However, the company again invokes genetics in relation to issues of privacy and security. Privacy and ownership of genetic information have been important issues in the United States, increasingly contentious and much debated. However, the point I make here is to question the conflation between genetic material, genetic information, identifying information, and digital information. At dna.com, it appears that personal information that the site deals with had less explicit connection with genetics and more with identifying information.

This is seen in how it registers individuals for the Gene Trust database and in its Privacy Policy document. The outline of the registration processes, above, refers to pages/text from a version of their website available only while the company was actively recruiting.

However, the site's Privacy Policy page/document/statement which continues to be displayed online, reiterates that it is DNA Sciences that collects an individual's personal information *over the website*. The document classifies these into four types of information:

1. Survey information
2. Registration information
3. Anonymous information
4. Personal and health information[70]

These have nothing to do with gene information extracted from a material sample. DNA Sciences' Privacy Policy document is set up much like other internet/consumer privacy policy documents found on the web, warning website users about online policy. Subsequently, this entails an explanation of the limitations to which the company commits itself about sharing your/its information. The document states,

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[69] <<http://www.dna.com>> Home > Science and Discovery > FAQs [10.31.01].
[70] See DNA Sciences' privacy statement <<http://www.dna.com>> [Version 3 last modified Nov.28, 2001/accessed January 27, 2002].

> No one other than authorized DNA Sciences personnel will have access to the personally identifiable health and family information you supply to the Gene Trust without your express written permission. [DNA Sciences Privacy Policy]

The conflation of various types of information and connections between DNA.com's treatment of volunteers' personal information and consumers' information gathered by websites is further illustrated by its links to two other sites, TRUST·e and Health on the Net. Their seals/logos are prominently displayed on the Privacy Policy page of the site.[71] Created in 1995, The Health on the Net Foundation (HON) is a non-governmental Swiss organization that acts as a sort of consumer-health watch group. It produces a 'HON Code of Conduct for medical and health sites (HON)code'[72] Sites that comply with its code of eight principles are given its 'seal of approval,' much like the Good Housekeeping Seal, which are then displayed on those sites.[73]

TRUST·e is a privacy organization, founded by the Electronic Frontier Foundation (EFF) and the CommerceNet Consortium. Consumer focused its mantra is,

"Make privacy your choice."[74]

The organization name in hypertext is discretely displayed at the bottom of every one of dna.com's pages. However, it is not until the site visitor enters dna.com's privacy page that s/he find out the relationship between this site and TRUST·e. With a click of the button, the visitor is sent directly to the licensee validation page at TRUST·e.[75]

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[71] Links to these two organizations can be found on all of dna.com's pages.

[72] <<http://www.hon.ch/HONcode/Conduct.html>>.

[73] The foundation states that its mission is, "to guide lay persons or non-medical users and medical practitioners to useful and reliable online medical and health information. HON provides leadership in setting ethical standards for Web site developers." <<http://www.hon.ch/home.html>>.

[74] It describes itself as "independent non-profit privacy organization whose mission is to build users' trust and confidence in the Internet, and in doing so, accelerate the growth of the Internet industry." <<http://www.truste.org>> [last accessed November 19, 2002].

[75] Home > The DNA Sciences' Gene Trust Project > The Gene Trust Bill of Rights <<http://www.dna.com/privacyPage/>> TRUST·e's validation page is linked through its icon revealing that it "confirms that DNA.com is a licensee of the TRUSTe Privacy Program. …Because this web site wants to demonstrate its commitment to your privacy, it has agreed to disclose its information practices and have its privacy practices reviewed for

This trustmark and the HON seal can be found at a number of other sites, including WebMD's. A frequent browser and consumer of websites, especially consumer health and medical advice seekers will likely have glimpsed these seals and marks. It is unclear how many web site visitors actually read privacy policy documents. However, the formats of those with the TRUST·e trustmark are similar. The organization provides guidelines and a list of questions that the site must address concerning privacy and information, as dna.com does in its document. However, these deal with the collection of information over websites. This does not include genetic material or, rather, the information extracted from it.[76]

It seems, according to the company, a potential Gene Trust 'member' should trust it because (a) it is working for the consumer, (b) it has the ability to facilitate and create pharmaceutical developments faster and more efficiently (than public resources and other private ventures), (c) registrants will always own their personal information and (d) the *real* Gene Trust is offline, [77] (e) a public window to the company's world is provided, and (f) they trust their volunteer-patients, recruit(er)s, and cyber-savvy consumers.

Former CEO of DNA Sciences, Rienhoff, was reported to have commented early in their recruitment endeavors that those who are 'paranoid' about providing medical information would not participate. Instead, as he put it, "Patients who enroll in The Gene Trust are patients who want to have a relationship with the company."[78] Here, the company describes its participants as trusting users of the web and trusting patients of the company. In (re)presenting its GeneTrust/DNA Sciences endeavor through its site, the company constructs a subject, or rather a schizophrenic one.[79] DNA.com, in initially (re)presenting the

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compliance by TRUSTe. By displaying the TRUSTe trustmark, this web site has agreed to notify you of …" [last accessed November 17, 2002 – page last altered November 28, 2001].

[76] However, not elaborated at its site are offline collection procedures: where exactly DNA/blood samples of individuals are taken and how these relate to privacy issues. There is mention that the samples will be drawn by qualified professionals but who exactly these individuals will be is not publicly available. A visitor would have to do some off-site searching to find that *Hooper Holmes* was signed on in the summer of 2000 to provide nationwide services. See the August 16, 2000 press release from Hooper Holmes last web access May 15, 2002 <<http://www.ir.connect.com/hh/>>.

[77] Rather, the virtual site is presented as a reliable educational resource center for basic genetics and disease information and a space for volunteers' voices and action. However, the latter is limited to emailing 'the company' (no specific names are given) for further inquiries.

[78] Quoted by Foubister, Vida, "Genetics firms seeking wide patient base," *AMNews* (October 9, 2000) <<http://www.amednews.com>>. Foubister reports that within its first two months about 4, 500 people had registered.

[79] For 'constructing a subject,' see Kurt Danziger's *Constructing the Subject* (1990).

Gene Trust, comes to dominantly (re)present the company itself. Through these transformations of its site, this involved (re)presenting its recruit – an active volunteer, patient, participant, consumer, registrant, recruiter, collaborator, historian, cyber-savvy individual – perhaps citizen. The company even presents The GeneTrust Bill of Rights. [See. Fig. 3].

Fig. 3 DNA Sciences The Gene Trust Bill of Rights*

- Your personally identifying genetic information will never, under any circumstances, be sold or shared with anyone outside the Gene Trust.
- Once collected, your information will be made anonymous and all the Gene Trust researchers will use only anonymous information.
- We will never be a supplier of genetic information for employers or insurance companies.
- DNA Sciences and the Gene Trust are committed to understanding the genetics of disease and health. We will never be involved in or associated with practices such as cloning a human being.
- If you contribute information to one of the Gene Trust studies, and that study leads to a diagnostic test that might help you, you or your doctor will be among the first to have access to that test - free of charge.
- Even if you have contributed to the Gene Trust, you can choose to withdraw your participation at any time, for any reason, and without penalty.
- As a participant in the Gene Trust, we will provide you with updated information on the status of our studies. You will have access to all published material that comes from the Gene Trust.

Source: <<http://www.dna.com>> Copyright © DNA Sciences, Inc. All rights reserved. [Accessed 7.21.2002]

Further, the company is only interested in signing up anyone (in the US), healthy or not, interested in contributing to the progress of science and disease research.

> Consumers who wish to help advance the understanding of genetics' role in disease and wellness will be asked to join the Gene Trust…[80]

If we return to the company, two years after the launch of The Gene Trust, neither Rienhoff nor its initial chief scientific officer, Ray White, works for DNA Sciences. Rienhoff returned to work on other biotech venture capitalist endeavors.[81] His nominal presence and references to him have been effaced from the company's site. However, his ghost, or voice remained after his departure, in particular, in the stored 'Live Events' forums' audio and transcript files. This was also the case for White.

The same representation of the Gene Trust project, originally linked to Rienhoff's conception, remains at DNA.com. However, without a representation of Rienhoff, its

[80] <<http://www.dna.com>> Home > Science & Discovery > FAQs [accessed 10.31.2001].
[81] As of this writing, Rienhoff is a general partner of Vanguard Ventures and is on the board of directors of two biotechnology firms, Iconix and Apneos. White was appointed director the University of California, San Francisco, Ernest Gallo Clinic and Research Center in July of 2002.

origins are now exclusively recounted as emerging from the public Human Genome Project. In fact, according to the site, the project that mapped the human genome will still be needed. This information will 'open the door to new ways of diagnosing, treating, and possibly even preventing disease."[82] The Gene Trust is a project that continues the HGP project's aims, but brought home to the ordinary individual and made real and extraordinary by and through DNA Sciences. While, many biotech and genetic information start-ups, including DNA Sciences, turn to alliance-building with academic institutions and traditional pharmaceutical and computer companies, DNA Science goes even farther than other public or private by claiming to directly involve its potential participants. In fact, the publicly mapped genome is too abstract and too universally-centered for the average person. They will put *your* DNA to work for you.[83] DNA Sciences will make it real to the ordinary American individual. Yes – perhaps through consuming, trusting, and securing volunteers, their 'extraordinary' Trust continues simply – a genomic vision and practice of life.[84]

This may be a longer ride than dna.com/Gene Trust suggests to its potential recruits – depending on the *actual* life of the company and maybe even thereafter, depending on the GeneTrust/trust in genes. The website tells its visitors that joining the Gene Trust Project is a simple process. Even if DNA Sciences' pharmacogenetics and genetic diagnostic schemes succeed in more precisely establishing drug efficacy and higher risk individuals for certain conditions, the individual practices of genomic medicine impact on an individual's decision on taking certain drugs, having certain preventive surgeries, and making certain lifestyle changes.[85] However, dna.com/Gene Trust already develops and sustains certain work, practices, and relations. These are not necessarily contractual relations and physical spaces established between the company and individual. Instead they are (re)presenting complex

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[82] DNA.com locates the origins of the Gene Trust in 1989 with the 'worldwide research effort called the Human Genome Project.' <<http://www.dna.com>> Home > The DNA Sciences Gene Trust Project > Origins of the Gene Trust Project [10.31.01]

[83] "Put your DNA to work! Joining the Gene Trust Project helps the fight against disease." <<http://www.dna.com >> Home > The DNA Sciences Gene Trust Project [10.31.01]

[84] However, another origin story might incorporate the contentious Human Genome Diversity Project, in which efforts to (re)present 'extraordinary' populations in human genome project endeavors. See Donna Haraway, *Modest_Witness@Second_Millennium_FemaleMan©_Meet_ OncoMouse™: Feminism and Technoscience*, New York: Routledge, 1997 and Margaret Lock, "Interrogating the Human Diversity Genome Project," *Social Science of Medicine* 39:5 (1994): 603-6.

[85] See DNA.com's explication for Why DNA Sciences is needed.

understandings and relations between genetics and environment, actual experiment(er) and subjects, and health and living itself.

4.5 > The genomic, medical, and information revolutions

> The possibilities of The Gene Trust are literally endless." …. "We'll be studying dozens of diseases and conditions that affect millions of people. Who knows what we'll find, or how far this will take us. But we do know one thing: The Gene Trust will make a difference.[86]

As a privately held biotechnology firm, DNA Sciences is backed by venture capitalist George Soros, as well as Jim Clark, the founder of the web browser, Netscape, and the computer company, Silicon Graphics. Clark is on the board of directors of DNA Sciences. Clark perhaps provides a clue to his own reasons to support this *private* genetics/genomics endeavor when he wrote, in a *New York Times* op/ed about his intentions to give funds to create a biomedical engineering center at Stanford. At the time of this article, the United States Congress was embroiled in disputes about funding stem cell research. He decried what he considered the President and Congress' actions as "thwarting part of the intended purpose [of the] center by supporting restrictions on stem cell research and cloning."[87] Although only part of the planned center would be involved in such research and work, Clark decided to suspend part of the funds he intended to contribute for its construction.

Clark's interest and involvement in DNA Sciences is an illustration of an increasing interweaving of computer sciences, communication technologies, and medical life sciences. Specifically, it is an example of the current interest among those in computer and information technologies industries to fund and/or contribute in the area of genomics, but it is also an illustration of efforts to (re)establish the lines between what is best science, particularly in relation to what are public and private spheres, and not. DNA.com reaffirms that speed, efficiency, and rational and usable, or rather, value-able knowledge is better situated within private science/venture. Private ventures, such as DNA Sciences, claim that

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[86] <<http://www.dna.com>> Home > The DNA Sciences Gene Trust Project [10.31.01]
[87] Jim Clark, "Squandering our Technological Future," op ed, *The New York Times* (August 21, 2001).

public choice and scientific freedom in research and technological progress is actually more amenable here. Companies are more focused and consumer oriented and less constrained by public funds. Of course, in the world of biotechnology firms, a company's continued existence, mission, and strategic planning are generally highly unstable.

In January of 2001, DNA Sciences filed for initial public offering, planned at $125m, but in July of 2001, the company withdrew its registration. In its filing with the Securities and Exchange Commission (SEC), the company stated 'current market volatility' as one of its reasons as well as a change in business and financing plans.[88] Although the 'genomic revolution' was touted by the biotechnology pundits as at hand at the turn of the millennium, especially with the 'completion' of the sequencing of the human genome, or at least, the draft, biotechnology stocks were not stable.[89] The fact that most biotechnology companies are netting losses, much the way that internet companies were (are) reported to do so at the time, are highlighted by the latter fact. DNA Sciences has not produced a profit to date (year end 2002), but perhaps none of the biotechnology pundits expected it to.

Much of the hope (and/or hype) of bioinformatics and post-genomic medicine is in individualized/personalized medicine. The value of information (or informational values), here, according to the company, supposedly goes through important transformations.

> The knowledge we gain from The Gene Trust has the potential to change medicine forever. But we can't do it without your help. We need hundreds of thousands of volunteers to fill out a health survey and thousands who match a specific profile to donate a sample of their blood. From there we can begin to understand the true relationship between genetics and disease. If you're interested in joining us, click the link below to register. It's a simple process and you can opt out at any point.[90]

The genomic revolution for medicine advocates claim to acknowledge that geneticization does not work as a guiding principle anymore. It is not wrong that genes are prominent – it is just not enough to extract genetic information from gene samples. However, what is still implied here is that reductionism of disease, health, and life itself,

[88] Securities and Exchange Commission's website.
[89] For sources on the completion of the mapping of the human genome, see especially special issues of *Nature* and *Science* (February 2001).
[90] <<http://www.dna.com>> Home > The Gene Trust Project > Signing up [10.31.01].

through the understanding of the gene, is still possible. The idea now seems to be that this requires researchers capture everything (or virtually everything) about an individual.

Here, though, I explored how DNA Sciences virtually (re)presents its project The Gene Trust as it remakes and attempts to establish the project/itself. The company has enrolled this current scientific trend into its Gene Trust. Simultaneously, in its site it argues that individuals are better off, the more personal information is collected, aggregated, and then made accessible to private researchers and biotech. There could be more control, choice, efficiency and efficacy in medicine's development and healthcare in this private sector – specifically theirs since the ordinary individual is invited to come along in the genomics adventure as DNA Sciences works to fulfill its promise. In the process it must also attempt to make genomics medicine real to the individual – if not by building actual relations between itself and participants then by virtually constructing an information-dependent gene-trust subject – in the hopes of fulfilling its own promise.

CHAPTER 4 > APPENDIX 1
DNA Sciences' announcement of events

1998 May	The company, Kiva Genetics forms, initiated by Hugh Y. Rienhoff.
2000 July 19	The Gene Trust Project publicly announced; Recruits Raymond White as Chief Scientific Officer. (in this month the company changes its name to DNA Sciences)
2000 August	Gene Trust Project's official launch date
2000 August 16	DNA Sciences announces that it signed a joint agreement with Hooper Homes, Inc. to provide nationwide phlebotomy and informed consent services for the company's Gene Trust Project.
2000 September 14	Digital Planet, a B2B broadband web services company producing interactive content, will create and produce all of DNA Sciences live event programming for DNA.com.
2000 September 20	DNA Sciences announces that it would begin genetic studies in breast cancer, asthma, and colon cancer.
2000 October	Company reports that 4, 500 individuals register with the Gene Trust
2000 December 18	DNA Sciences enters an agreement to acquire PPGx (now a wholly owned pharmacogenetic testing and services subsidiary).
2001 January 5	DNA Sciences files for IPO (initial public offering) with the SEC (Securities Exchange Commission)
2001 May 1	DNA Sciences' announces the opening of a new facility, which included MCA certified laboratory for genetic research, in Cambridge, England.
2001 June 18	DNA Sciences changes the name of PPGx, Inc to DNA Sciences Laboratories.
2001 July 19	DNA Sciences announces it has registered 10, 000 Gene Trust participants
2001 July 23	DNA Sciences withdraws $125M IPO plan
2001 September 20	DNA Sciences announces 'new phase' to increase focus to more viable commercial opportunities in especially (application of genetics to clinical development of) pharmaceuticals and technology development (for genetic analysis).

2001 September 20 DNA Sciences announces that Hugh Y. Rienhoff, Jr., MD, resigns as Chairman and Chief Executive Officer (CEO). [PR Newswire]/ GenomeWeb describes the situation as a 'sacking.' Further, the resource Genome Web reported that the company intended to lay off about half of its workforce. [91]

Between this last date and the summer of 2002, a few announcements about studies and facility openings were made, but the company remained rather quiet.

[91] Hugh Y. Rienhoff is named as its primary initiator. When I began work on the project, he remained identified by DNA Sciences as a central player, a role also bestowed upon its chief scientific officer, Raymond White. As a University of Utah faculty member, White, was prominently involved in developing the Eccles Institute of Human Genetics, working as its co-director, and as executive director of the Huntsman Cancer Institute. Both Rienhoff and White are named in the DNA Sciences' initial public offering report to the SEC as essential to the company's success.

5.1 > Representations of BioBank/s

5.1.1 > An initial siting of Biobank: a UK Biomedical Venture

When I began studying this project, it was in its early planning stages. News of its rumblings came to me while preparing a paper on the Iceland database project and, according to media sources, it was the Iceland endeavor that spurred the development of the UK project. Subsequently, BioBank UK emerged in international public discourse in connection with discussions of the Iceland project in late 1999. These two were grouped together with others as large-scale national human genomic databases. However, in light of the controversies surrounding the Iceland database (see chapter 3), BioBank's advocates sought to dissociate it from Iceland's database in certain aspects. In fact, a number of media and academic studies framed their commentaries and suggestions for a UK population database in direct contrast to certain aspects the Iceland database design. This project has not been without its own critics, although criticism has been rather muted, especially in comparison with the Iceland project.

The prominent public representations of the BioBank case, as in the Iceland and other national database schemes, have revolved around issues of securing information. In particular, much attention has been focused on the security of the database and obtaining informed consent from the individuals who will provide certain personal, medical, and genetic information.[1] The sponsors for BioBank have continued to address these concerns throughout the planning of this project and state their claim of its transparency to the UK public. Thus, in this chapter, I want to ask of this emerging project, based on emerging and uncertain sciences and technologies, 'why and how is this project represented to a larger audience?'

[1] As the online newspaper, *GuardianUnlimited* reported, Alan Milburn, the UK's health minister, stated in January of 2002 that the government would not allow work to proceed on BioBank until issues of confidentiality, security of data, and patient's consent were addressed. James Meikle, "Biggest gene bank seeks 500,000 volunteers" (April 17, 2002). Several UK watchdog groups raised these 'scientific' and 'research' issues about these database projects. In particular, UK-based watchdog groups, with web visibility, such as GeneWatch <<http://www.genewatch.org>> and Human Genetics Alert <<http://www.hga.org>> have criticized the project for its lack of timely and adequate public consultation, debate, scientific validity, value-for-money, and independent oversight.

At the time that the project came to public light, there was no database nor was there a protocol, yet its sponsors emphasized their continued transparency to the wider audience and claim that the British publics were consulted in the conceptual phase of the project. The draft protocol was presented long after the public announcement of the endeavor and establishment of its web presence. The protocol was published on the web in March 2002 and is currently the definitive and the only detailed scientific/technical document of the project. Here, then, I want to investigate how the sponsors represent an emerging biomedical project and to whom. To do this, I engage the BioBank project, focusing on the project's two main sponsors' virtual (re)presentation. In particular, I focus on the shift before and after the draft protocol was published in the early spring of 2002.

In this chapter, I examine the main sponsors' websites to draw attention to the importance of virtual technologies/instruments of representations in the analysis. I focus in particular on:

- the placement of BioBank's virtual representation in its major sponsors' websites and the relationship between the two sites
- the timing of material – as updates – and the lack of updates
- the (re)presentation of the virtual sites in contrast to the draft protocol and other documents, expert reports, workshops.

In particular, I pay attention to the modes of information and their deployment. In considering the locations and timing of such presentations, I highlight the associations and boundaries made with various means of representation, online and offline, specifically in respect to envisioned participation of the proposed participants and broader publics to this endeavor. Lastly, I explore the processes of creating a certain kind of genetic information in this endeavor and the co-construction of this project's subjects in these representations.

5.2 > Creating BioBank

5.2.1 > (re)producing BioBank: the Wellcome Trust (WT) & UK's Medical Research Council (MRC)

Unlike the other two endeavors under discussion here, BioBank is envisioned as a public entity in the sense that it will be publicly owned and publicly managed. Making its public debut in the spring of 1999, BioBank UK, previously named the UK Population

Biomedical Collection, is a national population database initiative. Funding was earmarked in the amount of £45m in April of 2002 by its three major collaborators. Its largest funders are the UK's Medical Research Council (MRC) and the private British biomedical research charity, Wellcome Trust (WT), each contributing £20m.[2] Its third major collaborator, the UK Department of Health (DH), contributed £5m to the endeavor.

During its first three years, committees, workshops, and consultations resulted in reams of analyses focused on how to create this project. Since 1999, sponsors made early efforts to (re)present the initiative to a broader audience.[3] Its major funders 'house' BioBank's representational information within their websites, updating them on occasion. However, as late as January 2002, the substantive information was limited primarily to a brief summary page and a summary of a protocol workshop, which took place in November 1999.[4]

Unlike, either the Iceland or California projects, which at least in their initial 'outings' to the public, linked their endeavors to a leader, there are very few names directly associated with the project. I want to begin by looking at its sponsors representational endeavors of the project.[5] When the project was presented to the broader public, in the late spring of 1999, not much in the way of detailed information about the public was posted on the web. In the summer of 1999, the WT produced a short write up in its community newsletter, the *Wellcome News*. However, given that there are three main sponsors, is there one BioBank site?

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[2] The Medical Research Council has been mainly responsible for the UK Human Genome Mapping Programme (UK HGMP), including its Resource Centre and the programme on Genetic Approaches to Human Health. The private British charitable organization, the Wellcome Trust supports independent research laboratories in the UK and Europe, such as the Sanger Institute and Human Genome Organization (HUGO), Europe. Both are the main funders of the UK's human genome research.

[3] Early, here, must be put into some perspective. The period is less than three years. Since it does not have its own site, in order to locate the project at the Wellcome Trust's site or the others, the visitor would have to know what s/he is looking for. The best way to locate BioBank UK in cyberspace is through a web search engine, such as GOOGLE. GOOGLE's web engine works by popularity. A current search yields pages from the Wellcome Trust's site first.[3] As more online media stories about the project arose, many of the links to information about BioBank pointed to this site. These were provided by news media sites, especially online ones, for example that of the British Broadcasting Service (http://www.bbc.com), and eventually search engines, as noted above, but also from critics of the project, such as the groups, Genewatch.org and the Mannvernd.is.

[4] <<http://www.wellcome.ac.uk/>> [accessed January 28, 2002].

[5] Contact information is provided for Frances Rawle, from the Medical Research Council, and Alan Doyle, at the Wellcome Trust, but their positions are left unstated. In the foreword of the Report of the UK Population Biomedical Collection Protocol Development Workshop, they are identified as project managers of BioBank.

It turns out that BioBank's web presence is dispersed. Several sites present the project, although two are dominant.[6] Currently, its definitive presence and source of authoritative information reside in/through both the Wellcome Trust and Medical Research Center's sites, described in the next few pages. Both have been centrally involved in the international genome efforts. Well-established and well-known in the UK, both have strong presence on the web. In the following discussion I want to examine the design and placement of the BioBank pages in order to gain as sense of its location, and or position, of BioBank within its sponsors' own organizational websites.

The Wellcome Trust's site splits its pages into the following clickable four subheadings:

Biomedical Science Public Interest History of Medicine About the Trust[7]

These categories are located clearly across the top of the screen. The first three are indicative of the Wellcome Trust's history, providing a schematic reminder/enforcement of the organization's interests/interventions, as one of Britain's leading medical research funders. Its selling of some of its shares of Glaxo-Wellcome, Britain's leading pharmaceutical company, in recent years, has also made it a leading private funding organization in biomedical research.

BioBank's presence is not constitutive component to the Wellcome Trust site's homepage.[8] The Wellcome Trust's website embeds BioBank's presence within its site, but rather than fully integrating it, its pages are mostly an add-on. The BioBank pages are extremely static. They have no external links and very few internal links in relation to the rest of the Wellcome Trust's site.

However, since funding was committed, in the late spring of 2002, BioBank UK has been represented on the homepage. In a headline, the visitor is presented with the hypertext 'UK Biobank gets go ahead.' Underneath the headline are two hypertext links, 'Read the <press release> or <background information>.' The latter links the

[6] <<http://www.wellcome.ac.uk/en/1/biovenpop.html>> This page was accessed on August 27, 2002. See the *MRC's Annual Report* (2000-2001) and press release from April 29, 2002 from its website. <<http://www.mrc.ac.uk>>. See a version of the Wellcome Trust's BioBank homepage located in the APPENDIX at the back of this dissertation [Diagram 5].
[7] <<http://www.wellcome.ac.uk/>> [May 20, 2002].
[8] This is true up until the website's homepage was last accessed (October 7, 2002).

visitor to the main page for the project embedded in the Wellcome Trust's site. Next to this headline is a photograph of a bustling urban sidewalk, presumably representing the UK population. Clicking on the photo, an individual browsing this site is taken to 'fact sheets' about BioBank.

The BioBank project is not found at the WT's homepage, though, but rather through several hypertext links:

WT > Biomedical Science > Ventures > UK Biobank[9]

Not just medicine, but biomedicine – the set-up creates an association between the biomedical venture and BioBank. As a forward looking descriptor, 'venture' is described at the site as the 'Trust's major funding initiatives.'[10]

This appendage-like characteristic is more apparent when a visitor finds a very similar – almost mirror site – at the Medical Research Council's website.[11] [12] [13] BioBank's web pages are also embedded in the many pages of the Medical Research Council's website,

[9] <<http://www.wellcome.ac.uk/>> [May 20, 2002].

[10] The other ventures, the two times this page was archived, included, Synchrotron, Genome Campus, SNP Consortium, Wellcome Department of Cognitive Neurology, Cardiovascular Research Initiative, Clinical Research Facilities, Millennium Seed Bank, Developmental Biology Resource, Cancer Genome, Wellcome Trust Centres, ALSPAC (Avon Longitudinal Study of Parents and Children), and ENSEMBL (a database service providing researchers with access to automatic annotation of genomic data). [<<http://www.wellcome.ac.uk/en/1/biovenpop.html>> May 20, 2002].

[11] The Medical Research Council's site is located at the following web address: <<http://www.mrc.ac.uk/ >>. This national organization is funded mainly by the UK Government through the Office of Science and Technology (OST). It funds research but does not earmark funds for particular topics. Therefore, research proposals in all fields compete for available funding. The main consideration is that the research be directly related to health.

[12] MRC's mission statement is summarized on its site as follows: To encourage and support high-quality research with the aim of maintaining and improving human health; To train skilled people, and to advance and disseminate knowledge and technology with the aim of meeting national needs in terms of health, quality of life and economic competitiveness; and To promote public engagement with medical research. <<http://www.mrc.ac.uk/index/about/about-misssion.htm>>

[13] In November 2000, the UK's science budget allocations were announced for 2001-2004, which will increase MRC's income by £89 million over the three years. By 2003-4, its core funding from OST will be raised to £430 million each year. A large portion of these funds will go to genomics and related research and technologies. Of the funds, £65 million was awarded for genomics research, £8 million for health informatics, bioinformatics and e-science. It is within this genomics grant that the MRC will make its portion of initial investment of £20 million (matching the Wellcome Trust) for BioBank. [MRC Research Funding Strategy and Priorities 2001-2004 (March 2001) also see MRC's website.]

much like those at the Wellcome Trust.[14] The information about the project overlaps and is almost verbatim and structurally similar to the WT's. [See Fig. 1].

The design of the pages differs, reflecting and highlighting the overall design of the Medical Research Council's site instead.[15] Further, there are frames at both sites in which the logos are identified as belonging either to the MRC or the WT. In addition, while the texts are almost verbatim, there are some differences.

The main topics at the Medical Research Council's site are subcategorized in the following manner:

About MRC Public Interest Funding Current Research Strategy Publication[16]

BioBank can be found by clicking through the following:

MRC > Public Interest > Consultation > Biobank UK[17]

This orientation is different from the Wellcome Trust, which we saw in the last section as locating BioBank in its <Ventures> category. By placing the BioBank information with <Public Interest> and the subheading <Consultation>, the project here is associated with medical clinical trials.

There are several interesting aspects to note here. On the one hand, the MRC's and the Wellcome Trust's sites implicitly suggest independent claims by each organization to the project and its presentation. The project, itself, is situated within the aims and practices of each. This is not done through the text as such since the information provided is almost identical. Rather than have just one site for information about the project, the two organizations create almost equivalent 'fact sheets.' The topic headings are almost but not

[14] The MRC's website includes a site map of its entire site, which once clicked, provides the visitor with a schematic vertically linear hypertext outline of all the pages of its site, much like a book's table of contents. This is the easiest way to find BioBank's locations and how it is categorized here. It is found by name only under <News Archive> and <Consultation> [See <<http://www.mrc.ac.uk/index/sitemap.htm>> last accessed October 5, 2002].
[15] See the APPENDIX at the back of the dissertation [Diagram 6].
[16] <<http://www.mrc.ac.uk/>> [May 20, 2002].
[17] <<http://www.mrc.ac.uk/>> [May 20, 2002].

quite identical. Further, these pages are presented with the site's own schemes and designs [See Fig. 1]. Further, at both locations, the few hypertexts within their BioBank pages connect to different, but internal pages, circling back within each site. These links relate the project to specific initiatives of each organization.

On the other hand, a unified, or coherent, representation of BioBank is not lost in the separate presentations. The descriptions and texts in the pages, the information about BioBank, are almost verbatim. This (re)production creates, or at least reinforces, a coherent, authoritative, and authoritatively understood project, even if located in two different sites. However, both MRC and the Wellcome Trust are able to negotiate their own independent ideals and/or aspirations of the project, and hyperlink them to their own initiatives.

In fact, directly on the Wellcome Trust's BioBank pages is a hypertext link that takes the visitor directly to its big initiative on <Functional Genomics>.[18] In this instance, BioBank pages can be a boundary object, a shared concern of the Wellcome Trust and the Medical Research Council. The static text concerns what both organizations agree on – or agree to say to the public - as to what BioBank is, but each can secure its own interests to the project. This seems a win-win situation for establishing the 'developing' project as well. In the instance of the Wellcome Trust, the way that BioBank fits into its own schemes and initiatives indicates to potential participants that the project does not emerge from ground zero. The institution has some infrastructure, some research, and some common interests in its existing work. If a visitor goes to the MRC's site, the association with existing clinical trials links this new project to established work in standard medical trials of the Council.

[18] In July 2000, *Science* reported that The Wellcome Trust started a $150 million initiative, which followed the publication of the rough draft of the human genome. Celia Caulcott, a Wellcome Trust program manager was reported as stating, "We didn't feel we could wait." Quoted from Elizabeth Pennisi, "Wellcome Trust Backs Genome Computation (grants money for development of computer programs to analyse human DNA)," *Science* 289: 5479 (July 28, 2000): 525.

Fig. 1 BioBank UK 'fact sheets'

Wellcome Trust	Medical Research Council
FAQs	Frequently asked questions about Biobank
Need for the project	Why is the project needed and what benefits will it deliver?
Status and history of the project	Status and history of the project
Possible structure and management	Current approach to the organization of biobank UK
Ethical implications and public consultations	Ethical implications and public consultations
Protocol development	Developing the approaches to sample collection and storage
Other information	Draft Protocol (PDF format)**
Contact*	

Sources: * <<http://www.wellcome.ac.uk/en/1/biovenpop.html>> (accessed May 20, 2002)
**<<http://www.mrc.ac.uk/index/public-interest/public-consultation/public-biobank_consult.htm>> (accessed September 28, 2002).

All of this can be produced through the hypertext link, in a seemingly seamless flow and with the click of a mouse. Focusing on the project's web presence in relation to other forms of representation highlights, not the project's futuristic dimensions, but its present practices. These aspects are downplayed when only the rhetoric and discourses are considered. From these perspectives alone, the project emerges and is driven by revolutionary technology and science. However, in putting representational technologies to work, historical and complex aspects emerge more prominently. In particular, I illustrated how BioBank is linked to the history and the particular interests of the Medical Research Council and the Wellcome Trust. This worked to produce some anxiety as to who definitively (re)presents the project.

Furthermore, if we locate these pages in the timeline of BioBank's history, the link to the two locations of BioBank pages above illustrate an anxiety by the independent/dependent relationship here in representing the endeavor. The two sites were not linked to each other before funding commitments in April of 2002. However, they were accessible through an address link only through a specific news release in the Wellcome Trust's archives. In addition, although they are now mutually linked, the 'fact sheets' about Biobank are still almost mirror images of one another. The text are very similar, but more importantly the legitimacy of the information (and of BioBank) is strengthened through the link and reproduction of the text in these two well-established British organizations.

5.3 > Defining BioBank?

These two venerable British entities provide seemingly straightforward answers, but the information is limited. The visitor might ask, 'What will BioBank UK be?' Will it be a proposed biological collection venture, as (re)presented by the WT, or clinical research trial, as (re)presented by the MRC? This is significant for considering how volunteers – as individuals or populations – should participate or, even, imagine what their participation should be.

By the time funding was committed in principle, the visitor to the BioBank pages was told that through November of 1999 and April 2002, several consultations, workshops, and committees were commissioned by the MRC and Wellcome Trust, Britain's Human Genetics Commission, and the House of Lords. In this section, I want to suggest that BioBank is many things in representational endeavors produced from these meetings. Specifically, I want to examine these in relation to BioBank's virtual presence. I want to especially highlight that in the text of the BioBank pages at the MRC/WT, BioBank is dominantly some thing else. Further, although Biobank is circulated multiply in these other endeavors, it is unproblematically multiple and complex: it is a repository for biomaterial, a place to deposit multiple types of information, a home for ongoing clinical medical research itself, a potential commercial enterprise, a resource for continuing/new medical research, medical practice, and public health services.

5.3.1 > Preliminary faqs and facts

The BioBank presence at both the Wellcome Trust and MRC provide the same response to the question, 'What exactly is BioBank UK?' What is interesting here is the present tense in which the question is asked. These two sponsors' answer can be found in a section on 'Frequently asked questions,' in which a number of anticipated queries are proposed, answered, and reproduced by/through both the sites.[19] The initial response is put thusly for the question,

[19] The questions posed, in order, are: 'What exactly is BioBank UK?', 'Who is behind the study?', 'Who would be involved?', 'Why would only middle-aged members of the population be recruited?', 'Will the samples be anonymous?', 'If I volunteered, could my insurance company find out about the results of research in my sample?', 'Would current or future employers be able to gain access to the information?', 'Would the police have access

> This is a proposed research study aimed at establishing how genes, lifestyle, and environmental factors interact to affect people's health. It is thought that this type of research could lead to important improvements in the ways we treat and prevent ill health.[20]

Neither the collection of data or DNA samples nor a computerized database is specifically mentioned in this general definition. The description, however, hints at a particular type of study with a connection between a *proposed* project – in the form of a *research study* – and *potential* medicine. Furthermore, the problem at hand is genomic biomedical science, rather than collection of data nor the construction of a centralized database, as emphasized in the expert reports and consultations.

Not surprisingly, the sponsors of the project are keen to situate the project within biomedicine. Tom Meade, chairman of the protocol development committee stated,

> We are not doing this for idle curiosity. We are setting up this scheme so we can improve the medical treatment of British people. That is our specific aim.[21]

In particular, the current project is associated with endeavors aimed at eventually preventing and curing common diseases and conditions. Consequently, the current project is situated within both clinical genetic medicine and pharmacogenomics.[22] However, the project is also situated, at least, within areas of medical informatics and public health units.

Following along the series of questions and responses the website poses, the visitor finds factual responses to general queries put forward about the project, such as 'Who is

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to the information?', 'Who would own the information and be able to use it?', 'Would pharmaceutical companies be able to access the information?', 'How would you reassure people that the information was being used properly?', 'How long will the samples be used and monitored for?', and 'When would the project deliver medical benefits?'

[20] The Wellcome Trust website WT > Biomedical Science > UK Biobank > FAQs [<<http://www.wellcome.ac.uk/en/1/biovenpopfaq.html#1>> Archived site (May 5, 2002) PDF P8-9].

[21] Quoted in *Observer* (February 13, 2000) Also quoted in 'Science Lesson Pack' (Levels 3 & 4) of *Learn.co.uk* an educational website from the British newspaper, *The Guardian*, which states as its aim to support the national educational curriculum in the UK. The site can be accessed at the following web address: <<http://www.learn.co.uk>>. The specific lesson that 'Gene bank will show what makes every one of tick' can be found at: <<http://www.learn.co.uk/glearning/secondary/science/lesson01/scgene.htm>>.

[22] See the draft protocoll for BioBank UK.

behind the study?' The answer: the Wellcome Trust and MRC. 'Who will be involved [in the study]?' The answer, for now: a half million volunteers. Further, the visitor is given an explanation of why volunteers will be recruited from a population aged 45-69.[23] It has been decided that it will involve collecting blood samples and lifestyle information from about 1% of the British population. Here, the expectation is morbidity, but at low rates for the next decade or two. This will facilitate the studies that the funders are concerned with. These are focused on common conditions affecting the older population of the UK. The project also entails tracking these against the volunteers' medical records over time. The period discussed has been for at least a decade.

The next eight questions deal with access, security, and social consequence issues, either regarding the samples or information. Implicit in the questions is the assumption that the project has been planned and if not underway, certainly on its way. In other words, the visitor is engaged as a potential human experimental subject for a conventional clinical/epidemiological study. The last question considers individual benefit and, finally, an explanation for the long-term deferment of such medical benefits emerging from this project. Here, at the WT/MRC BioBank site, the database (or at least collections for one) follows the idea that the project is *a* study. During the period I examined these websites, the WT and MRC did not supplement the actual substantive text of these faqs page or much of the other text in the other 'facts sheets.'

However, during the period of 1999-2002, consultations, working groups, and expert reports occurred. Summaries and reproductions of these can be found online through BioBank's sponsors' websites. Rather than integrating these 'findings' into the 'fact sheets,' the MRC/WT continued to maintain the same information, opting to simply attach the documents to their sites. In addition to online availability of the more general reports on human genetic databases developed by the Human Genetics Commission and the House of Lords, between 1999 and 2002, several reports and public consultations were commissioned by the Medical Research Council and the Wellcome Trust.

5.3.2 > Sites of other BioBank(s)

[23] Initially, the age range was 45-64 and later extended to 69.

Unmentioned in the WT/MRC BioBank pages, both the Medical Research Council and the Wellcome Trust have supported the creation of large-scale collections of DNA of plant and animal (including human) material. Both organizations have the infrastructure and long experiences of large scale human population database projects for epidemiological studies and have been building up their genomics infrastructure – part of the UK's Post-Genome Challenge. As of the summer of 2001, the MRC was supporting thirteen human DNA collections. Further, it has promoted the use of these collections to clinical researchers studying 'common diseases' such as cancer, multiple sclerosis, asthma, type 2 diabetes, among others.[24] The connection of the Biobank to existing and new biomaterial and data banks circulates largely in the workshops and expert meetings.

In a memorandum on human genetic databases to the House of Lords, the Medical Research Council made the following arguments for government support of BioBank UK (then the UK Population Biomedical Collection) within the context of the current state of such collections in Britain:

(a) current collections are too small to allow statistically meaningful research
(b) current collections do not have enough high quality health information
(c) the UK has too little DNA left in its collections
(d) current collections are not based on full consent for this type of research

Here, the project is again closely connected to bio-material repositories. However, it is also connected with epidemiological and health informational (data) –banks and –bases.[25] In these regards, the project is supported to incorporate, build upon, and mediate these diverse resources. Although the association hints at the project as a research resource, and argues that it requires data on a large-scale to be 'statistically meaningful,' it does not explain what type of research it would be used for or emphasize. Rather, this aspect is left open, leaving BioBank broadly defined, and open to expansion, extension, and emergence.

The House of Lords Select Committee on Science and Technology eventually produced a report in March 2001, which incorporates these views of Biobank in its general

[24] MRC's Clinical Research News (Autumn 2001) <<http://www.mrc.ac.uk/pdf-clinical_research_news.pdf>> last accessed September 9, 2002.
[25] *Human Genetic Databases: Memorandum*: Sec. 23 p. 7, submitted by the MRC to the H. Lords S&T Select Committee Inquiry (2001) available for download at the MRC's website.

report on human genetic databases. The report can be found at the UK's government site. Further, it provides a link to the 'UK Population Biomedical Collection,' (now BioBank UK webpages), connecting directly to the Medical Research Council's pages devoted to the BioBank project.[26] [27]

The Human Genetics Commission's (HGC), the UK Government's advisory body on human genetics policy also produced a report on human genetics databases, and a visitor to its website can also find, under the topic 'Human Genetic Databases,' a link to the House of Lords report. [28] The HGC's Working Group was formed with the directive to study broad issues about human genomic databases in the UK, for both medical and non-medical purposes and produce a consultation document to the UK Government. The preliminary report was published in November of 2000 and the final findings published within another document in May 2002, two months after the printing of the draft proposal.[29] The

[26] The Science and Technology Select Committee of the House of Lords was yet another expert committee set up to report 'on human genetic databases' by the Government. Their report was published in the spring of 2001. It, too, was made publicly available, and can be found at the UK's official parliament website, in PDF format. Its main recommendation on such databases to the Parliament, including that of BioBank, was that the 'primary means of regulating human genetic databases should be the UK's Data Protection Act 1998 and that [with one exception] no additional protection is required for personal genetic data.' The report addresses the UK Population Biomedical Collection (esp. in Ch. 4 and 5) recommending that the Government earmark funds to the MRC and Department of Health (DoH) for this initiative. Further, it addresses the need for GP (general practitioners') data to be compatible with one another and the necessity to harmonize the National Health Services (NHS) electronic records with whatever system emerges from that of the project (1.16/5.28). In Sec 1.13, the report summarizes Paragraph 5.25: "Recognising that the UK Population Biomedical Collection project will stand or fall on its ability to manage the data, we recommend that the MRC and The Wellcome Trust should give high priority to ensuring that all aspects of the data handling and computing requirements for this important project have been fully addressed, and make appropriate plans to meet its needs." The discussion of the initiative emerges partly from written evidence from the MRC and Wellcome Trust as well as from excursions of the members of the committee to on site locations such as the Wellcome Trust's Human Genome Campus in Hixton, in which researchers briefed them on its data sequencing strategy and the basics of bioinformatics.

[27] However, the BioBank pages at both the MRC and Wellcome Trust do not provide links to the Department of Health. All, except for the Wellcome Trust, are public sites, in the governmental sense, but difficulties in distinguishing between public and private are beginning to surface. By private I mean, here, in the sense that decisions were primarily made behind closed doors.

[28] As of August 31, 2002, this could be reached at: <<http://www.hgc.gov.uk/>>. The Human Genetics Commission is an advisory body set up by the UK Government at the end of 1999.

[29] In the 2000 document, the Working Group defines genetic information as 'any information about the genetic makeup of a person' and focused specifically on genetic information obtained through analysis from a biological sample. ['Whose hands on your genes? : A discussion on the storage protection and use of personal genetic information' (November 2000), a report by the Human Genetics Commission (2.1)] They make some effort to distinguish

preparations for this report coincided with that of the House of Lords' report. The Working Group contrasts the two studies in its consultation document, which the HGC makes available online. In the document, the Group also reports that their consultation is focused on investigating public attitudes towards such databases and on determining their regulatory structures. The Select Committee, on the other hand, in its call for evidence, sought responses primarily from those involved in maintaining, developing, or using human genetic databases or those who are actively planning to do so, and not the broader public.

The Medical Research Council and Wellcome Trust also created a working group. The members were to study the plans for what was presented as a large-scale database six months after publicly announcing the project, in November of 1999.[30] A report was put out to a multidisciplinary workshop held by the working group, prior to the meeting that explicitly compared BioBank to Iceland's project.[31] This acted as a base to draw on issues for discussion. The group was chaired by Tom Meade, the director of the MRC Epidemiology and Medical Care Unit at the Wolfson Institute in London, and its members primarily addressed the following questions:

1. What type of information would be included?

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several ways in which genetic information can be obtained. These include family history, external observable characteristics, and analysis of blood or bodily tissue. [See Box on page 4 of 'Whose hands on your genes?'] They also suggest explanations as to why genetic information may be 'special' and therefore treated differently from other kinds of personal information. The reasons they suggest are that it is uniquely identifying information, obtainable from a very small amount of material and does not require lengthy observation or history-taking, or knowledge/consent, and, lastly, because of its predictive ability.[29] After each section of the report, generally headed by a query, such as 'What is genetic information?' and followed by their answer, a list of questions are provided for readers to respond. These are presumably people with vested interest, or at least enough interest to respond to the questions. These responses can be done either through regular post or online. This was not the only report emerging out of the Human Genetics Commission on human genetic databases in this period. There were several other reports, workshops, meetings, and expert committees pertaining to large scale genomic databases and information. Among this report is a document entitled *Inside Information* that could be found online through the Human Genetics Commissions site in May 2002. In the 2002 document, the HGC revised their discussion of genetic information, in particular personal genetic information, to include any genetic information, which can identify an individual. Therefore, their discussion, here, is inclusive of any of the three means of obtaining genetic information described above.

[30] 'Report on the Workshop on Human Biological Sample Collections,' (held at the Wellcome Institute, London) (November 1999). See MRC's website.

[31] Paul Martin and Jane Kaye 'The Uses of Biological Sample Collections and Personal Medical Information in Human Genetics Research' (1999 November) available online at <<http://www.mrc.ac.uk>>.

2. What diseases would be investigated?
3. What were the roles of GPs (general practitioners)?
4. Who were the volunteers to be?
5. What would be the size of the sample population?

They also discussed:

1. ownership
2. accessibility of data

These latter were seen as distinct from the others, described as 'social and ethical' issues.

In addition, they began to develop ideas for the management structure and design of collecting the required data. The proposal took the following form:

1. A small number of regional centers will recruit volunteers.
2. The overall project will be centrally managed and coordinated. It will be led by a project director responsible to funders.
3. A separate body or committee (independent of both users of the 'information' and scientists developing the project) will ensure samples and data collected are used responsibly and within the terms of consent obtained. This committee will be responsible to the public, research participants, and 'other' stakeholders.

In an interesting move, the workshop members parceled out three different spheres of BioBank: the science, ethics, and management. Further, the discussions were situated within an overall frame of the construction of an informational database, but its prospective nature and its broad-base, which would work to ensure its future utility, were not forgotten.

About a year and a half later, in the spring of 2001, the working group reconvened, holding the 'UK Population Biomedical Collection Protocol Development Workshop,' again chaired by Meade.[32] This expert workshop was held in order to draft the project's protocol.

[32] This workshop was held at the Royal College of Physicians, London, England on April 17, 2001 and the report was published in August 2001.

In the introductory session, Meade, stated that several decisions had already been made about the project, including that

> participants would be volunteers who would 'opt in' and that the data would not be licensed exclusively to private industry as in Iceland.[33]

This is an example in which the sponsors and proponents of the project present BioBank (or the UK Population Biomedical Collection) antithetically to the Iceland project. Recall that the Icelandic state opted to use presumed consent in the collection of non-gene information from its population. BioBank would ensure that participants provide informed consent and that the data/database(s) were publicly owned *and* managed. However, BioBank's proponents also make the case for the importance of such a project to Britain's future.

Furthermore, in the protocol development workshop, Frances Rawle, MRC's project manager for this project, characterized BioBank more fully as an ongoing endeavor. He pointed out that one of the funders' main aims in pursuing this initiative was to develop a long-lasting, leading resource and genome science infrastructure in the United Kingdom.

The *emphases* in these arenas were in identifying BioBank with biomedical and data collection. However, BioBank in these venues was also conceived as multiple and complex: biological material collection, information collection project, epidemiological study, health survey, and infrastructural base for Britain's scientific, public health, and economic future as well as a model and perhaps standard for the international genomics community. One might argue that workshops were venues for negotiating the parameters of BioBank. However, not only did the workshop, summaries, and expert reports, characterize BioBank as unproblematically multiple, so did the draft protocol, which I will illustrate below. However, what I want to highlight here is that the BioBank web 'fact sheets' remained the same.

5.3.3 > The protocol

In March 2002, the MRC/WT, made the draft protocol available for downloading at their sites, <Protocol Development>. In February 2002, this document was presented to

[33] Summary of the UK Population Biomedical Collection Protocol Development Workshop found at the MRC's site.

potential funders and sponsors. In this 47-page document, 'BioBank UK: a study of genes, environment, and health,' the project team provides its scientific rationale, method, strategy, and timeline. Included in this document is a vision of how to begin, structure, manage, and maintain what they describe as a 'prospective cohort study.' The team provides detailed procedures for collecting and storing biological materials and various information and explanations as to how they should be analyzed and how they should be used.[34] This document continues to be the most current, detailed, publicly available description of the BioBank UK study, written to ascertain funding, both governmental and non-governmental, for the project.[35]

The document opens with a brief description of BioBank. A variant of the pages at the MRC/WT websites, the project is described to be,

> the large scale investigation of combined genotype/exposure effects on disease risk.[36]

However, unlike the BioBank pages, it is described, here, as more than a simple epidemiological study. Rather, its ability to expand into multiple studies is revealed. In the protocol, it is identified with other large-scale studies, specifically those with blood samples.[37]

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[34] The document was drafted months earlier – spring/summer 2001. It was discussed at by an expert working group set up by the MRC/WT and discussed at a protocol development workshop in April 2001.

[35] Prior to its broader public availability and its online presence, in March 2002, a revised proposal was distributed to international scientific experts for evaluation. Also to be noted, the proposal writer, according to the report from the protocol development workshop, is Dr. Emily Banks, but it is written on behalf of the UK project team. In addition, the downloadable proposal has no authors named or the names of team members including the project managers. In fact, only the logos of the three institutional collaborators appear on the cover page.

[36] 'Draft Protocol for BioBank UK: A study of genes, environment, and health' (Feb 2002):7. << http://www.wellcome.ac.uk/en/images/biobank_protcl_0202_word_5986.doc>>.

[37] The team associates its project with two kinds of research: first, with 'Country-based biological collections,' such as those planned in Iceland, Estonia, and Canada, and second, to 'Cohort and other studies. The authors cite the European Prospective Investigation into Cancer and Nutrition (EPIC) as an example of the latter. The proposal team emphasizes the differences between BioBank and the other country studies and highlights similarities to the latter. EPIC is a large multi-center initiative. It involves 500, 000 individuals from ten European nations, who contribute information, through experimental instruments in the form of detailed questionnaires on diet and lifestyle, physical measurement, and blood samples stored in liquid nitrogen. For more information about EPIC, see the webpage for The Nutrition and Cancer Unit of IARC (International Agency for Research on Cancer), part of the WHO (World Health

In the team members' words, the main difference between BioBank and either of the two types of studies the authors compare it with, is its unique feature of "large scale comprehensive prospective information on genotype, exposure and outcome." [38] [39]

The project then is also described as encompassing the establishment of both data- and biomaterial-banks. Therefore, the initiative as both a biological sample collection and epidemiological data collection is also envisioned. In this capacity, it would serve as a common resource for existing research and new studies on human genetic variation. This is elaborated here by the authors,

> By collecting and storing biological samples and detailed data on exposure on at least 500,000 individuals aged 45-69 *the project will constitute a national research resource available to the scientific community for a large number of studies* (my italics).

Further, at least for the proposal's authors, BioBank UK will also be a national resource. As a research resource, especially for British scientists and research organizations, we can gather from this statement that BioBank UK will also be a national symbol. Forward-looking, as Britain's flagship project, the project will propel the nation into future work in medical genomics and solidify Britain's place in the biosciences and new biomedicine. The proposal's authors continue, noting that

> BioBank UK is *designed to provide a broad and comprehensive framework for future research* into the combined effects of genotype and exposure to various factors (my italics).

Organization) in Lyon, France, which coordinates the study. <<http://www.iarc.fr/pageroot/units/ntr.htm>>

[38] Draft Protocol for BioBank UK, p. 13. The authors contend that BioBank's necessity lies in its wider scope than any of these collections and/or studies. They point to the homogeneity of the populations in the nation-based collections cited above, in contrast to the unique heterogeneous population in BioBank's proposed cohort/database. In the second instance, the authors point out that the EPIC study is limited by the incompleteness of the information that they collect, which focuses on diet.

[39] The team, however, points out the similarities of their cohort to those in other projects, and therefore, the future utility and links of BioBank to other projects. These examples include EPIC, The Million Women Study, The Whitehall Study, ALSPAC, and ProtecT, p. 32.

The project is even more definitively characterized in the proposal as not only nationally and internationally relevant, but globally so. It will contribute to structuring the very future of global genetic research. However, the authors do not discuss the actual construction of a physical database, and provide only a brief discussion of the inclusion and future need to consult information technologists and database development specialists for the endeavor.[40]

5.4 > Mediating/representing technologies and technologies of representation

According to the text of the 'fact sheets,' in May 2002, we cannot physically put our arms around BioBank, even though the sponsors can answer 'What exactly is BioBank?' However, between 1999 and 2002, when I examined its representations, BioBank remained at a conceptual stage. The physical centralized database, its immediate infrastructure and hubs, as well as recruitment are still in its planning stages. The question, therefore, remains open, 'what exactly *will* Biobank be?' In April of 2002, funding had been committed, a draft proposal published, and a number of expert committees set up and reports written based on public and professional consultations and workshops. Does BioBank exist today then?

The sponsors presented these activities as developing many possibilities for this emerging project. However, its repeated identifications with biomaterial collections already in the UK and those being developed were important for certain potential partners. These connections helped to establish that there is some infrastructure in the UK and that the road to BioBank had already in some sense, been paved. Further, linking these databases to the BioBank also strengthened the position for the future of these and new collections as well as the continued expansion of Britain's bioinformatics and genomics infrastructure. None of this, however, is presented in the web 'fact sheets.'

The UK Population Biomedical Collection, as it was originally named, reinforces the association between this project and the biological tissue or sample repositories and their 'collections,' as they have generally been described in the UK. While the choice of the endeavor's name is not of great concern in the expert workshop reports, it is reflected in the broader consultation documents. In one of the early public consultations, the question of naming was put to the participants. Asked for comments about the name 'BioBank UK,'

[40] See Section 3 especially paragraph 2 of the draft protocol.

some individuals felt that it was not representative enough, in that it did not emphasize the medical dimension of the project, while others took exception to the 'bank' aspect in regards to its commercial connotation. The question reflected the need to obtain and keep the British public's backing of the endeavor.[41] According to this report, BioBank UK is specifically a 'national database' project, although only a small portion of the United Kingdom's population will be represented in the proposed database/study. It may be argued that, in fact, the project's new name, BioBank UK, besides being shorter than the former name, has a much broader, more flexible connotation – ready to incorporate the broader UK population.

Instead of asking and expecting a response to 'What exactly is BioBank?' or even 'What will BioBank UK be?,' we might turn to the question into, '*How* is it doing today?' In this way, we may expect to shift the focus onto not only processes but relations, rather than accepting the project as some material and contained/containable object. The issue is no longer merely the construction of a physical database.

The web faq's sheet provides the visitor with a response, that is distinct from those circulated in meetings, the protocol, and other documents. Further, neither the MRC nor the Wellcome Trust updated the faq sheets although the project was 'developing.' In fact, the BioBank (re)presented in the faqs sheet is not necessarily wrong, but it is only one of the Biobanks. The question I posed above aims to shift the attention to relations, but it also aims to engage representations of emerging projects in a more current sense. How do these projects' sponsors begin to establish them?

Here, I considered the question through its web presence. Specifically, I illustrated how the project was (re)represented online and the boundary work they do. I also showed how (re)presentations of the endeavor differed by putting representational technologies to work. The use of web technologies and their associated methods contrast strongly with traditional technologies of representation, meetings, workshops, etc. which have been modified into the 'new' technologies.

In other words, by bringing the web into the analysis, I illustrated a multiple approach to (re)presenting the project in it process. In its webpages, presented to the

[41] See *BioBank UK: a Question of Trust*. [People Science and Policy Ltd, "BioBank UK: a Question of Trust," report commissioned by the Medical Research Council and the Wellcome Trust, People Science and Policy Ltd.: London, March 2002].

broader audience, BioBank emerges as primarily as a clinical study of disease, similar to traditional epidemiological studies, (by the fact of its collection – the construction of a physical database is absent) but contained by a database. In the expert workshops and consultations, prospective database collection emerges dominantly as well as versions of BioBank as a resource for long-term studies and as the basis for a UK genomics infrastructure.

Further, for the sponsors, the web pages for BioBank of the MRC and the Wellcome Trust work as repositories for the occasional updates on the project's development. However, in this 'emerging' area of biomedical technoscientific research/practice, the web presence works as a site in which broader publics must be addressed, but not necessarily engaged. The text in the BioBank's fact sheet-like pages provided in the MRC and WT's sites is limited. Also, as we saw earlier, from a technical perspective, the web pages are mostly static and conservative. There are few hypertext links and their contents are primarily text. The occasional updates are primarily in the form of documents available for downloading. However, the sites that the BioBank pages are embedded in are dynamic in the sense that they use more visual technologies and hypertext. In this staid form, the project is invoked as in development, future-oriented, but not futuristic.

How much effort is placed in actually engaging publics in developing the project is a good question. In the next two sections, by taking into account the anxieties that I located in the web presence/(re)presentations of the project above, I explore the construction and enrollment of volunteer and/or participants for a deferred technological database.

5.5 > Virtually experimental subjects/objects

5.5.1 > Experimental relations: constructing subjects

As noted earlier, BioBank's institutional sponsors' emphasize the importance of public engagement in this biobank endeavor. Such engagement is represented by the following statement taken from a BioBank page housed at the Wellcome Trust's site:

> Since the beginning of the project, the funders of the UK BioBank have been committed to an ethically sound approach to the collection,

> storage and use of samples, and to extensive public consultation to identify public concerns and priorities.[42]

As described above, the BioBank UK sponsors have conducted or had commissioned public and health professional consultations through these 'planning' stages of the project. According to the funding organizations, these results are being used to help them then develop the management structure and detailed design of the project.[43]

According to the sponsors, they are especially concerned that the British public view themselves as consulted in developing the project. In March of 2002, the public consultation report, *BioBank UK: A Question of Trust*, commissioned by the Wellcome Trust and the Medical Research Council and conducted by People Science & Policy Ltd. was published. In this report, People Science reported that the MRC/WT project team wanted to explore issues that would affect recruitment and the propensity of UK individuals to volunteer for such a project. In this public consultation, only members of the proposed population, or cohort, those individuals aged 45-69, were chosen to participate.

In this report Biobank UK is described as:

> a proposed resource that will enable medical researchers to study a number of diseases, including the principal UK killer diseases – cardiovascular diseases and cancer. The major purpose is to enable the study of diseases where genes, or combination of genes, interact with lifestyle and the environment.[44]

Here, BioBank, is described as a large scale database collection project for medical/epidemiological study. The report, then, provides a description of the roles of individuals as, primarily ongoing, blood donors and data objects, subjected to continued tracking and follow-up investigation.[45]

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[42] http://www.wellcome.ac.uk/en/1/biovenpopeth.html

[43] As noted earlier, summaries and documents resulting from the specific consultations and ethics workshops are accessible, in downloadable form, through BioBank's web presence at the Wellcome Trust and the Medical Research Council.

[44] *BioBank UK: A Question of Trust* (March 2002): 8.

[45] [The researchers will] collect blood samples, health and lifestyle information from a sample of 500,000 adults [who are] residents in the UK aged 45-69. These people will be tracked for ten years, primarily through their National Health Service (NHS) records. Ongoing information

The consultation study authors also reported that at the time this consultation was drafted, the Wellcome Trust and the Medical Research Council had already undertaken two consultation exercises:

1. "Public Perception of Human Biological Samples" – The first (September 2000) was structured as a series of focus groups with the general public 'where the researchers fed into the group key features of the BioBank UK'[46] in order to 'elicit reactions and identify concerns.' The document was focused on management and the security of the database. In addition, the authors conducted interviews with representatives of groups thought to have specific concerns about this type of medical research resource. These included individuals from minority ethnic groups, interest groups, and medical personnel.[47]
2. "Consultation with primary care health professionals on the proposed UK Population Biomedical Collection" – The second (October 2000) specifically explored the views of medical personnel, whose commitment are seen as essential by the project team for the successful construction and maintenance of the database.[48]

Its sponsors maintain they have involved various publics and consider their input. Which publics and how? The three consultations organized by the MRC and WT, included one set each of: (a) health professionals and (b) broader publics, and (c) target populations. Further, to 'identify' public concerns and priorities, questions were constructed that concerned anxieties in the procedures of volunteering, rather than critically engaging the public about the project's very basis. The aim of the consultations was to locate anxieties in volunteering and deficiencies in genetic knowledge.

The dilemma for the project's sponsors is to obtain individual volunteers and bring the wider UK public to perceive themselves as, at least, possible volunteers. This is important for the project to succeed long-term expansion.[49] Yet the language of the websites'

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will need to be added to individual records 'as the project progresses.'[45] This includes data, not only from NHS records, but further interviews and questionnaires.

[46] *BioBank UK: A Question of Trust* (March 2002): 8.

[47] *Public Perceptions of Human Biological Samples* commissioned by the MRC and Wellcome Trust and carried out by Cragg Ross Dawson (September 2000).

[48] *Consultation with primary care health professionals on the proposed UK Population Biomedical Collection* commissioned by the MRC and Wellcome Trust (October 2000).

[49] Prior to the consultations, the UK team had already decided that individual consent would be a prerequisite, which they perceived would bypass some of the problems that plague the Iceland endeavor. Still, informed consent was understood by the project's proponents as requiring clarification. Full consent would be obtained from all participants and the breadth of consent would be all-inclusive. Bobrow, also stated, "Participants will have to agree to take

faq sheets positions BioBank as predominantly the biomedical clinical study, that is, *the* project.

While BioBank UK's funders suggest the importance of public participation not only from the proposed targeted population but from the UK population at large,[50] the faqs page addresses the proposed (or presupposed) concerns by a potential volunteer for *this* study: the collection of a UK biobank. Here, I want to address the question as to 'where - or to which project - are participants asked to contribute?' In the multiple, expanding, and future oriented initiative, another question arises 'how are individuals being asked to contribute?'

In the WT/MRC's websites, in emphasizing BioBank itself as a study, the potential volunteer is told that various types of information will be provided by him/her, including diet, lifestyle, medical history, and a DNA sample.[51] The draft protocol gives more detail and the characterization of the necessary information is broader. Here, patients will provide information associated with 'exposure.' They will be given a questionnaire about themselves and if accepted into the study, they will be required to sign a consent form, give information about their medical history, lifestyle, including diet, undergo a physical examination, and provide a blood sample. [See Figs. 2 and 3].

The transfer of the patients' accounts of their experiences will be mediated by a number of study tools, such as the questionnaire, medical tools for physical assessment, and blood sampling paraphernalia. A specially trained nurse will verify, validate, and perform the tasks of physical assessment and blood collection. Subsequently, all the data will be entered into electronic databases. Then the patients' health and lifestyles will be monitored for years, and periodic follow-ups will ensue. After five years, for instance, all volunteers will be expected to give details of changes in their lifestyle through a follow-up questionnaire, and every two years a portion of the participants will be contacted for additional follow-up. [See Figs. 2 and 4].

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part for all diseases. There will be no opt-out clause, for example, if a person is happy to be tracked for ingrown toenails but not for cancer..." <<http://www.biomedcentral.com/news/20010221/05>>.

[50] However, these population categories are made distinct. This is particularly reinforced in the participants called for in the consultations as well as in the websites of its two main sponsors. Specifically, one group is the cohort or potential volunteers; the other is the broader UK population. Still another might be the practical medical/health personnel (practicing professionals).

[51] Frequently asked Questions (faqs) Question # 3 'Who would be involved?') <<http://www.welcome.ac.uk>> [May 20, 2002].

According to the scheme in the protocol, volunteers will be free to withdraw from further participation of the study at any time, but how a volunteer's information is used is out of their hands. In the protocol, the multiple Biobanks as study, resource, and framework for unnamed studies is especially apparent. It is expected that the information collected may be useful in a number of kinds of research studies on specific diseases/conditions well into the future.[52] The emphasis is on establishing the framework/model 'study' rather than on establishing a project based on specific conditions or diseases. It also doubles as a resource for these latter research studies. The project does have some direction in that it aims to look at a wide range of 'common' diseases and conditions that afflict the older British population, such as cancer, heart disease, Alzheimer's, Parkinson's, diabetes and asthma.

Fig. 2 From Collection to relevant information:

(1) Questionnaire (self-administered, validated, and initially collected by trained research nurse)
(2) Interview (conducted by research nurse)
(3) Physical examination (conducted by research nurse)
(4) Blood sample (taken by research nurse)
(5) Diet diary
(6) Informed consent
(7) Follow-up

All information derived from individuals and mediated through these sources are translated, processed, and stored in 'hub' and 'spokes' of BioBank's database(s). However, these efforts are not discussed in detail in the protocol, reports, and/or websites.

While the BioBank faqs page sites suggests to the visitor that it will be many years before any medical benefits are obtained, its proponents present a somewhat varied account of benefits to the broader public. Meade has stated that it could yield its first fruits in around five years. In particular, the expectation of the sponsors and funders of the project is that these initial benefits will be in the industry of medicine-making. As to benefits for specific individuals, Meade is quoted as stating,

> The main results in determining the important interactions between genes and lifestyle will probably take more than 10 years.[53]

[52] Draft Proposal for BioBank UK available for download at the WT'/MRC's website.
[53] 'Britain plans world's biggest gene database' (July 9, 2001) <<http://www.bioexchange.com/news/news_page.cfm?id=6571>>.

Fig. 3. Proposed Sources and Collections from Individuals (according to BioBank UK's draft proposal)

(1) Yield 'exposure'* data:
* refers to factors other than genotype, which may be related to the risk of various outcomes.
- demographic
- socioeconomic status
- lifestyle/habits
- reproductive
- medical history (past health, disability/impairment, psychological factors)
- physiological
- early life factors (e.g. birth weight)

(2) Yield more detailed information about the individual
- NHS (National Health Service) identification number
- Medical/surgical history and current situation
- Current medication

(3) Physical assessment
- Biophysical
  - Blood pressure
  - Pulse rate
  - Forced expiratory volume (FEV1)
- Anthropometric
  - Height
  - Weight
  - Waist/hip ratio

(4) Blood sample (50 ml.)
- Genotyping
- Biochemical
- Proteomic
- Metabonomic studies

(5) 7-day diet diary
- self-reported

(6) Informed consent

This issue is brought up in the BioBank pages as well. In the section entitled, 'Why is the project needed?', the visitor is confronted with the following preformed explanation,

> Genetic components have been implicated in many different conditions - including cancer, diabetes, asthma and Alzheimer's disease - and in our susceptibility to infectious diseases. But finding the genetic factors responsible is complicated by the multiplicity of factors involved, by the small effect of each individual factor, and because environmental factors that alter our propensity to illness - such as smoking, obesity or pollution - may have a profound influence on the genetic contribution [May 5, 2002].

This sounds a lot like a compromise on the nature/nurture debate. The current scientific view is that the influence of genes is modulated in complex ways, in which the environment

plays a major role. This may have been a tough sell for the future of genetics and disease research. However, the explanation continues,

> Picking apart this complexity requires a study to be on a huge scale. In time, it would help us to understand:
>
> - the relationship between diseases and specific genes or genetic variations;
> - the number of people who carry a particular gene or genetic variation and hence are at increased risk of disease;
> - the way in which interactions between genes and environmental factors are involved in the cause of disease.

The sponsors do not raise the question of the enormity of the problem of complexity here, but instead they claim that *the* solution will be provided by a population study on a *huge scale*.

Furthermore, the collection of enormous amounts of varied information from the general population of the UK becomes an imperative not only for understanding disease etiology but for finding ways to prevent, ameliorate, or cure the diseases. If researchers are to ascertain environmental and genetic factors of complex, multi-factorial, disease and conditions, "a huge scale" study, rather than individual or small scale studies, is necessary to draw out statistical significance in the many variables, which may increase or decrease our chances of succumbing to a particular disease. Therefore, the general population needs to participate – not just individuals. Furthermore,

> This understanding would help in the design of a new generation of drugs to counter most major diseases. It would also help to explain why some patients respond well to particular drugs and others do not. The data could also be used to predict the likelihood that an individual would develop disease, so that medicines could be used to prevent the onset of disease, rather than as a treatment for symptoms once a disease develops.[54]

[54] <<http://www.mrc.ac.uk>> See the Wellcome Trust's pages for the duplicate or mirror description at: [Jan 2002 and May 2002 archives of WT's website. More recently located: <<http://www.wellcome.ac.uk/en/1/biovenpopned.html>> last accessed September 28, 2002. This statement has been retained on the Wellcome Trust's BioBank pages since September 30, 2001, when first accessed. At this time, the project was known as the UK Population Biomedical Collection and this statement appeared on the BioBank's initial page, without the proposed query.

This argument for the initiative creates continuity between the project and industry without invoking the latter. Although, this is not made explicit in the web pages, the role of industry is provided in more detail in the draft proposal to potential funders. Rather, the argument aims to appeal to the general UK public.

Instead of active engagement with potential participants, the BioBank's representation through its web pages suggests that individuals acknowledge and accept their role in this project as information recipients and subjects (at least potentially). Tom Meade of the MRC stated,

> Recent advances in genetics, including mapping the human genome, are almost certainly going to provide exciting opportunities to develop major new advances in medicine.… We know the public wants to benefit from new advances in medicine but we also recognize serious social anxieties have been expressed. These anxieties have to be addressed, so public consultation is essential if this project is to succeed – it is not just window dressing. Developing a database of this kind would simply not be possible unless there is widespread public understanding and acceptance of the objectives and methods.[55]

Widespread UK participation in terms of acceptance and involvement of the BioBanks - long term *genomic vision, infrastructure, and practices* - is needed, but this entails construction of passive subjects.

The 'fact sheets on BioBank UK say little about using a 'UK population.' There is no detailed explanation for using a heterogeneous population in either the MRC or Wellcome Trust's sites. The issues of homogeneous versus heterogeneous populations and complexity of gene-environment interaction are still enormously debated in scientific communities.[56] Further, the issues of using cohort studies and of using a prospective genomic population database (both characteristics of BioBank) in gene identification research for complex, common diseases continues to be raised by a number of researchers in varied scientific

[55] <<http://www.biomedcentral.com/news/20010221/05>>.

[56] Certain aspects of Iceland's population for the IHD were criticized by a number of researchers in various scientific communities. In particular, its homogeneity (which the deCODE representatives now describe as 'relative homogeneity') and the transferal of findings based on a data set characterized as such to the wider world population.

communities.[57] Yet BioBank has been able to avoid these concerns to some large extent in its web (re)presentations. In the scientific discursive regime, the UK/sample population is a heterogeneous one, but in a technology-centered discursive regime the BioBank/UK population is an object/technology for research. [58] The sponsors of BioBank have been able to de-emphasize both descriptors for its BioBank population.

Visitors to these sites are not envisioned as participants or made privy to such contentious issues. Rather, I would suggest, through the low-key web pages, visitors are envisioned to relate to their place in the deferred study/collection/database as primarily potential information volunteers to this large-scale epidemiological study. Here, with Biobank described as 'a research study' on genes, health, and environment, they are subjects in a low-risk epidemiological study and collection. They are also potential future British beneficiaries of its outcomes. However, the visitor is reminded that outcomes might not directly impact individuals, but more likely the UK population as a whole, as the genomics infrastructure is set in place, a great achievement for the whole state, and medical benefits attained by the descendants of the individuals.

Like the initiators of the IHD and GeneTrust™, the sponsors of BioBank UK are concerned with having a role in public education of science, medicine, and health. However, the content, what is communicated, and how this plays out at their sites differ. DeCODE and DNA Sciences are very interested in providing disease information, especially, their genetic components. The latter is especially interested in doing this online, and especially for

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[57] David Clayton and Paul M. McKeigue, "Epidemiological methods for studying genes and environmental factors in complex diseases," *The Lancet* 358 (October 20, 2001): 1358-60.

[58] Even in the expert workshops discussions about the sample population, the age of the sample cohort was more contentious than the choice of a British population or the populations heterogeneity. In its sampling strategy, the cohort is identified as middle-aged British population, aged between 45-69. The population, it is argued, might be particularly important and informative in identifying the genetic etiology of common conditions and diseases that affect the British population. The upper limit was under much discussion and, actually, the current 69 cap was once lower 64/5. The contention over the age cap concerned the ability to follow the cohort for at least ten years (a higher cap may create problems if too many individuals die off and a low cap may mean that the cohort is not useful in studying the conditions that were desired). Further, during the Protocol Development Workshop (April 17, 2001), cohort size was also an important issue. The overall aim of quantifying gene-environment interaction is based on statistical design. Therefore, significance is greatly enhanced if the number of events is increased without affecting data quality and/or relevant generalizability. The members discussed focusing recruitment in socially deprived areas in order to increase the number of events but for the members, this raised concerns about the degeneration of data quality. (See Protocol Development Committee report, April 17, 2001.)

a general audience. Mostly, for the sponsors of BioBank, education of publics about genetics is only alluded to in proponents' quotes and in expert workshop or consultation documents. These statements primarily suggest that the publics must be made aware that in all likelihood results from the project will not have any direct benefit on their own person, or if it should, it would not be for many years (this is also in the faqs section in the BioBank webpages). More direct, though, is the assertion that plans must be made to educate the publics to understand the concept of risk and such statistical thinking rather than in genetics education per se and to integrate this with existing public health services in the country.[59]

Just four months after funds were earmarked for BioBank and seven months after Secretary of Health, Alan Milburn, announced funds for the parks and reiterated the role of the DOH in the BioBank scheme, the Department of Health issued a report on outlining the plans to develop these Genetics Knowledge Parks in the UK over the following five years. These aim to link academic research, industry, education, clinical genetics expertise, and healthcare,

> the overall objective will be to improve healthcare through better public understanding of genetics and to provide opportunities for increasing UK industrial competitiveness in this fast moving area.[60]

The British publics of all ages and ethnic backgrounds will be taught about genes, health and risks. In the Cambridge Park, "the flow of genetic knowledge from research into clinical practice and policy will be an important theme."[61] The sponsors of the endeavor may be slowly and cautiously developing BioBank, but much of the infrastructure seems to be moving somewhat more quickly, and with somewhat less fanfare.

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[59] It is the case, though, that both the MRC and the Wellcome Trust are both heavily involved in public science education, both online and offline. The Wellcome Trust has online exhibitions.

[60] UK Department of Health, "The Genetics Knowledge Parks Network – Overview," (August 2002), UK Department of Health: 7 (1-29).

[61] UK Department of Health, "The Genetics Knowledge Parks Network – Overview," (August 2002), UK Department of Health: 14 (1-29).

5.6 > (In)forming knowledge

5.6.1 > (Re)presenting a (real)listic BioBank

In terms of BioBank UK as a collection, its sponsors have played the public domain or ownership card from its initial public outing in the late spring of 1999. If we re-consider public/private as analytical framework, we may ask how the broader public and individuals fit into the public BioBank UK project? In this chapter, I turned to BioBank's web presence, which I found located the absence of such a physical construction but produced some anxieties in locating, characterizing and representing a project (or is it projects?). As I showed, the ability to represent the project is primarily behind drawn curtains, although eventually resulting in occasional public displays (document summaries/reports). [See Appendix 2 of this chapter for a reading of the multi-faceted and/or negotiated 'beings' of BioBank].

The explicit representational information, in the form of 'fact sheets,' about BioBank at the Wellcome Trust and MRC has been limited. As noted, the protocol team state in the draft proposal that the web may be put to greater use once the database is built/constructed. Specifically, they describe web use as providing updates about the project's development for/to the general public. The reality is, though, that the publics have not been privy to detailed discussions or made active participants through the BioBank web sites that I examined.

However, even without a physical BioBank, the project's virtual realm is already used to draw boundaries in defining, practicing, and participating in the endeavor. In Latour's term, BioBank's web presence does (re)present BioBank – standing in for the absent technoscience. In particular, the virtual (re)presentation of one version of BioBank is expanding, multiple, distributed and dispersed. This version is predominantly described and bantered about for the various expert and potential funding communities. However, the MRC/WT's static informational fact sheets for the distribution of information to the broader audience present a somewhat low key version of BioBank. In this case, its web representation is put to (boundary) work. The virtual representation of this emerging project (as the sponsors intended through the MRC/WT) is clearly more than merely representation.

As noted, BioBank is envisioned as a node in the forward looking long-term genetic research programme of the UK, the Medical Research Council, and the Wellcome Trust, but also of the health system of the UK through the Department of Health and National Health

System. It is a project whose history is embedded within those of its funders' and collaborators' institutions, which are part of the UK's science, technology, and medical establishment. The genetic services of these institutions are closely tied to the UK's future place in global genetic science, pharmaceutical, biotechnology, and computer industries. These are all invoked and at stake in the project, but also already working and collapsed into BioBank's overall web presence, making a *real*stic project. The UK Government does not want to find itself caught on the track of 'third world science.' Genomics is the dominant science and databases a dominant technology.

The visitor to the site is treated as an observer, an outsider, not a potential partner. Up to this point, those who represent the UK project have not used the web as a means of recruitment, but this does not mean it is not a critical node of their project. The endeavor's dominant web presence (re)presents the project, contributing to the definition and characterization of BioBank UK and affecting how it is to be understood, even though the specific BioBank pages are static. Further, it suggests certain relations between (scientific) experiment(ers) and subjects in that it already articulates and locates certain hierarchical relationships, anxieties, and levels of participation, authority, and judgments in regard to the project. Focusing on the virtual aspects helps to highlight the ambiguities and anxieties of such an emerging biomedical technoscience. In particular, the virtual multiple presences and representations of this 'proposed' BioBank help to illustrate the circulation of anxieties and their constitutive roles in helping to establish a technoscientific object not yet physically built or implemented.

5.6.2 > Information and knowledge

For the sponsors and BioBank team, the web simply provides a communication link for transferring information about the database project's progress to the public and perhaps the media. While PDF files of certain reports from expert and focus groups are provided for downloading, the webpages themselves do not include in-depth information or details about the project. Neither is its website specifically meant as a space for public debate or engagement. Rather, certain individuals and publics were invited offline, at specific points of the project's development – for face to face consultation with expert consultants, the guidelines for questions provided by expert groups.

However, information to be ascertained from individuals of the UK population, for recruitment, is important to the sponsors. The publics and volunteers provide the source/raw material, although their knowledge and/or experiences must be verified/validated/interpreted by the proper experts – either the nurses who do the collection of samples and data or the commissioned researchers who do the consultations. See Fig. 4 for a reconstruction on how the sponsors envision how to create data from the experiences of participants for BioBank.

Here, I want to explore briefly the concept of (genomic) information, especially transformations and types thereof, in a project so thoroughly located in this 'information age.' For computational biology, genomics, and its associated technologies, the exchanges of various types of information are especially relevant to database research and 'in silico' laboratories. The move, in this study, is to consider information within the relations between the development of such large-scale genomic databases and populations. How does information move, how is information described, translated in, by, and through these representative sites and technologies? Current analyses of such databases assume that information is exchanged. By doing so, containing information in a secure database, whatever 'IT' may indeed be, remains central in various public and professional discussions.

According to the sponsors of BioBank, the data will not be held by a private company. The data will be held by the Wellcome Trust and the MRC. In the FAQs section of the Wellcome Trust's pages on the project, answers the question, 'Who would own the information and who would be able to use it?' as follows:

> The study would be in 'public ownership' through an independent body set up by the MRC, the Wellcome Trust and the Department of Health. The data would only be available to medical researchers. Management of the databases and access to them would be overseen by a monitoring/oversight body accountable to the public, the participants and to the funding bodies. The resource would be available to scientists in both the public and private sectors, but there would be very strict controls to protect the confidentiality of participants.

In other words, the funding and organizing partners will establish an independent monitoring committee to supervise access to data and samples. They will ensure that rules of anonymity and confidentiality are followed and will also be empowered to veto any action that they judge to be unacceptable.

While the aspects are described in more detail through the draft protocol, the coordination of information from the varied sources, tissue/blood sample, physical examination by volunteers' general practitioners, information from the National Health Services records, and patient/volunteer verbal responses from the self-administered questionnaire(s) and interviews is not accomplished by/at/through the project's web presence.

Fig. 4 Envisioning the path of information to data collection
(a reconstruction of sponsors' vision)

1. Specified recruiting centers are envisioned as responsible for recruitment of participants, liaison with general practices (GPs), and initial processing of biological material. [See draft proposal (DP): 14]
2. However, in a practical sense identification of potential recruits begins with GPs. All those 45-69 and registered at participating general practices will be sent a letter about the study and an invitation to participate. This letter will be signed by their general practitioner, and accompanied by the study questionnaire and consent form. [The emphasis so far is to use those GPs who have a commitment to electronic patient records.]
3. Potential data subjects are identified. Participating GPs will be asked to filter out those they believe unfit or unsuitable for the study (based on guidelines provided by the initiators). [DP:14] The others are asked to participate. The individual will fill out the 10-page lifestyle/health/history questionnaire. [Questions cover the areas of socio-economic status, demography, habits/lifestyle, diet, reproductive history, family history, past history, disability/impairment, psychological status, and early life factors and are aimed to yield exposure data. See DP: 16]
4. The individual then sets up an appointment with a nurse at one of the regional 'spokes' centers:
   a. with his/her information-rich document. The specially trained nurse will then conduct an interview with the individual in order to 'validate' and translate the individual's answers. In addition, more detailed information might be obtained.
   b. The nurse will also conduct a physical assessment on the individual and
   c. take a blood sample. [The proposal authors envision this whole process as taking between 30-45 minutes.]

In other words, the validation of information and collection of baseline data and biological samples is done at these regional sites.
Blood sample to data collection (4 –6):

5. The regional centers process the biological samples (ideally within a 2-hour traveling time from the sampling point).
6. DNA extraction is then done, preferably locally on fresh samples, to avoid degradation and promote quality.
7. Issues of short and long term storage of the samples were still under discussion for fresh, frozen, unprocessed, and processed samples. Storage space, methods, utility, and cost are all issues.

Questionnaire, interview, and physical examination information to data collection (7 & 8):

8. These data are then inputted into the regional centers' computer terminals and sent to a centralized database located at a central 'hub' organization. Its responsibility is overall management and delivery of the project, database and financial management, and quality control. [The data will be coded but not completely anonymous. This will permit updating through follow-up. See #9]
9. The individual/volunteer/patient/data subjects are followed up on periodically for at least ten years. [See draft protocol: 13] They will receive a repeat questionnaire via post. Follow-up also occurs through their regular visits to their GPs. During the protocol development meeting in April of 2001, the approach to obtain follow-up still had not been decided. [Possibilities were suggested: such as questionnaires, occasional downloading of information, more sophisticated and/or automated system, establishing core data items beforehand (See report Sec. 2.3]
10. Analysis and genotyping of the blood samples are envisioned to be limited to centralized facilities, the 'hub.' [See draft protocol: 13] Discussed in the April meeting were advantages such as avoiding loss of samples, duplication, and maintaining a database of information centrally. However, drawbacks were also seen. In particular, industry may want to have direct access to samples. Raised was the possibility of 'hotel' facilities. Also proposed was that of two major centers involved in resource management and that, for security reasons, storage should be at two distinct geographical locations. [See protocol development workshop (PDW) report. Sec. 2.1]
11. Data obtained from the blood samples, stored where? This issue is raised in the PDW Report. [Sec. 2.3 "How should the genotypic data be stored: as a subset of the clinical information database, or in a separate but appropriately linked database (in particular if not all of the 500, 000 volunteers are genotyped?"]
12. Linkage of all the data obtained from information derived from volunteers, not only to each other, but other sources were emphasized. [Sec. 2.3 "Most importantly, linkage to the central NHS death registry and to cancer registries." Also, "Prescription records, embedded in GPs own electronic records…." In addition, "Patient medication records held by pharmacies. These have information on prescriptions actually dispensed….Hospital admission data and other hospital records….Social, environmental and economic data, perhaps upon using postcodes as a link to a variety of sources….Within the cohort, identification of siblings and other family relationships."]

Sources: BioBank's web presence and draft protocol.

In the guidelines for the envisioned path of information collection, personal experience/knowledge from potential volunteers is mediated by professionals (expert nurses), who also collect anthropometric and biological samples. This is the means by which these individuals' experiences and knowledges are grouped/attached/associated with their individual biosample/genetic material and physical characteristics which are amenable to quantitative transformation and therefore all are translated/transformed into data.

These in turn can ultimately be mediated through/by/at the unseen, deferred database and translated/transformed into new knowledge. Thus, the deployment of BioBank's web presence already suggests a structuring and classifying of information and/or knowledge and/or data. It begins to work at creating potential volunteers as conventional research subjects, not as equal participants.

5.6.3 > (Re)presentational matters in representational practices

Iceland's parliament enacted legislation, the Iceland Health Sector Database Act, in December of 1998. This act permitted the creation and maintenance of a medical/health information database, with a provision of presumed consent of the Icelandic population to participate in such a project. In January of 2000, the Icelandic Health Ministry awarded a twelve-year license to deCODE and/or its subsidiary to 'build' and run a 'depersonalized information' health database.[62] After this time, much of the large-scale public debate died down.[63] A perusal of Mannvernd's website in 2002 showed less updating of its site after January of 2000. However, the Iceland project, or rather the controversy, currently stands in as the (anti)-model for those shaping other large-scale biomedical databases.[64]

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[62] The license agreement stipulated several conditions. Those of particular interest to this study are that the database must be exclusively located in Iceland, the licensee must ecru all cost, and that the licensee is granted access to the database only temporarily, and that this should not exceed 12 years. Further, in return, the Ministry of Health and Social Security must receive a regularly updated copy of the database and have access to statistical data from the database for use in health planning, health policy-making, and health reports. [See License Agreement]

[63] For an argument concerning continued private debates in the Iceland case, see Hilary Rose, "Gendered genetics in Iceland" *New Genetics and Society* 20: 2 (August 2001): 119—38.

[64] See, for example, J Kaye & P Martin, "Safeguards for Research Using Large Scale DNA Collections," *British Medical Journal* 321 (2000): 1146-9 and Ruth Chadwick, "The Icelandic database – do modern times need modern sagas," *British Medical Journal* 319 (August 14, 1999): 441-4.

This has been the case in the BioBank endeavor. The development of BioBank UK has not been uncontroversial in several respects.[65] These discussions are generally divided into three broad branches: scientific, technical, and social/ethical. In the first instance, the issues are over the scientific validity and purpose of the BioBank. Critics argue that the interactions between genes and environmental factors are too random and complex to disentangle and quantify, and therefore, to yield significant benefits to the population. Others contend that there needs to be more clarity as to whether the project's goals are for specific and/or for broad use and how these will be defined. Such decisions, they argue, have repercussions for baseline measures as well as for the population cohort. In the second category, the main issues concern information privacy, database security, and linkage of the various informational sources into a comprehensive, centralized one. Lastly, in the third category, the issues are characterized as concerns about ownership and accessibility of data.[66]

These concerns are genuine but these discussions as they are set up do not get to this project in *real* terms. Rather, these public discussions emphasize the emerging nature of the project: genomics is new, individualized medicine, database technology is new. Furthermore, attempts to locate and precisely pinpoint the project in terms of a construction of a physical database lose sight, sites, and signs towards BioBank UK. 'What is/are being represented?' and 'how?' are at least as important questions as the questions asked of 'who is representing the project now?' and 'for whom,' as well as 'how do we regulate the databases and their information tomorrow?'

Of the three projects I look at here, BioBank as a physical comprehensive database is in the earliest planning stages. The sponsors and media have pointed out that caution and careful proceeding in the development of protocol and planning mark their project over others, especially the Iceland endeavor. Further, from its inception, the project's sponsors had agreed in principle on informed consent and non-exclusive access to the data – responding and hoping to avoid the controversies that befell the Iceland project. Proponents of BioBank point out that through these planning stages, expert and public consultations

[65] See, for example, Helen Wallace, "The need for independent scientific peer review of Biobank UK." (Letter to the Editor) *The Lancet* 359: 9325 (June 29, 2002): 2282; Paul McKeigue, David Clayton, Tom Meade, Emily Banks, Lars C Stene, Paul Elliott, Mark McCarthy, Paul Burton, Nathaniel Rothman, Montserrat Garcia-Closas and Sholom Wacholder, "Study of genes and environmental factors in complex diseases." (Letter to the Editor) *The Lancet* 359: 9312 (March 30, 2002):1155.

[66] See the November 1999 protocol development workshop report.

and careful deliberation are preceding any initiation of the database/collection/study/resource base for future research. I do not dispute that there have been efforts to consultation. If populations are the limiting resource, barring force, public approval and voluntary participation are necessary for genomic medicine to be successful. Sponsors of private and public/private ventures agree.[67]

However, as we saw, when examined more closely, these efforts highlight that simply asking questions about who gets to represent the projects and/or database and how the database will be constructed, maintained, and accessed are inadequate to better understand this 'emerging' biomedical technoscience. As I have shown in this chapter, we need to address questions of what is represented and how so. We need to examine how these projects are constructed in a more relational way and in a context of the present in order to ascertain the place of these endeavors in our lives today.

5.6.4 > Updating project sites

This study focuses on the virtual presence of BioBank only up to the spring of 2002 when its three sponsors earmarked funds to the endeavor. According to their BioBank pages of October 2003, project implementation is now fully underway. The current efforts are to select appropriate locations to host the Coordinating Centre ('hub') and the Regional Centres ('spokes'). These are based on applications submitted by interested parties in the United Kingdom. Since December 2002, the project, now 'UK Biobank' has a new image, and its own website: <<http://www.ukbiobank.ac.uk/>>. This revamped (re)presentation is splashier, more public friendly, accompanied by a new layout, with many more graphics and photos of largely adult (British?) individuals – potential participants? In one photo a middle-aged attractive minority woman holding a card (resembling either a credit card or perhaps a biochip card) chats on a cell phone, perhaps, making a deposit to BioBank?

BioBank has become formally associated with its two main sponsors, the Wellcome Trust and MRC. In the BioBank case, I highlight the creating of coherency(ies) in making the project *real*stic. By turning to the virtual (re)presentation/presence of this emerging

[67] However, to the issue of informed consent, the question must be raised as to what this means when the studies, to which an individual's information is to be used are yet unknown. On a more fundamental note, though, has to do with what information can possible mean in terms of these secure databases that the projects' sponsors allude to.

technoscientific social project, I highlight the disturbances of time/space that help create a multiple, but coherent, and real and realistic project(s) to (1) a broader public/potential participants, (2) potential funding agencies and organizations, and (3) the UK government. I look at the (re)presentations and their development through its expanding web to highlight the associations and boundaries made with various means of representation, online and offline, specifically in respect to broader publics, and illustrate the co-construction of bioinformatic and genomic meanings and the relations between individuals and the database project and its sponsors in these (re)presentational endeavors of this emerging project.

The BioBank project emerges from preexisting streams of infrastructure but it also extends and creates new ones.[68] The third collaborator, the Department of Health has ceded the virtual representational endeavor of the project to the Wellcome Trust and MRC. However, on January 16, 2002, its Secretary, Alan Milburn announced the establishment of several UK Genetics Knowledge Parks and two genetics reference centers. These are intended to provide infrastructure, professional education, and public outreach and education (including primary and secondary education) on genetics, disease, and risk.[69]

[68] For genomics/bioinformatics infrastructural initiatives in the UK by the Wellcome Trust and MRC, see for example, Elizabeth Pennisi, "Wellcome Trust Backs Genome Computation.(grants money for development of computer programs to analyse human DNA), *Science* 289: 5479 (July 28, 2000): 525. For the Wellcome Trust Genome Campus "which includes the Sanger Centre – home of the UK's major gene-sequencing operation… The Trust's long-term commitment to the campus currently stands at $265 m," Michael Balter, "Scientists with clout," *Science* 274: 5291 (Nov 22, 1996): 1292-5.

[69] Alan Milburn, "Putting Britain at the Leading Edge of Advances in Technology," given at the International Conference Genetics and Health – A decade of opportunity, (January 16, 2002) speeches, Department of Health online << http://www.doh.gov.uk/speeches>>.

CHAPTER 5 > APPENDIX 1
Chronological Timeline of some of BioBank UK's (re)presentational events

1998	MRC receives increased funding from the government's Comprehensive spending review. The MRC bid for funding included the proposal to support national DNA collections as part of the Post-Genome Challenge. (See "MRC funds large-scale human genetic database" *Nature Medicine* 4:12 (1998): 1346).
1999 May	proposal for UK Population Biomedical Collection first discussed in an expert workshop organized jointly by MRC and WT.
1999 June	Medical Research Council, The Wellcome Trust, and Department of Health announce a funding collaboration to propose the UK Population Biomedical Collection (UK PBC) (See "People Power: population profiles and common disease," *Wellcome News* (1999) Q3:18.)
1999 Nov. 11	Wellcome Trust workshop on 'The Use of Biological Sample Collections and Personal Medical Information in Human Genetics Research' (4.5.2002 – WT website) also titled, 'The Use of Biological Sample Collections for DNA and other Analysis' (5.20.2002 –WT website)
2000 September	Public Perceptions of Human Biological Samples commissioned by the MRC and Wellcome Trust and carried out by Cragg Ross Dawson (report available online http://www.mrc.ac.uk and http://www.wellcome.ac.uk)
2000 October	Consultation with primary care health professionals on the proposed UK Population Biomedical Collection
2000 November	The UK Government's advisory Human Genetics Commission publishes 'Whose hands on your genes? – a discussion document on the storage protection and use of personal genetic information.'
2001 March	House of Lords Report on 'Human Population Databases' printed July 20, 2000 call for evidence Oct 10, 2000 last day for submitting evidence Nov 2000 – Feb 2001 public hearings
2001 April 17	Workshop for UK PBC Protocol Development (held at the Royal College of Physicians, London) – The new Protocol Development Committee was charged with planning the recruitment and baseline data collection in much more detail (up to this point). The aim of this meeting was to identify the information essential for studies of specific

	disease groups. (See notes on introductory remarks by Tom Meade in the report cited below.)
2001 August	Report published on 'The UK Population Biomedical Collection Protocol Development Workshop' (held April 17, 2001)
2001 December	NGO GeneWatch UK Report on BioBank UK 'Who's Hands on your Genes?'
2002 January	Public consultation on UK PBC – 'BioBank UK: A Question of Trust'
2002 February	Draft Protocol for 'BioBank UK: A study of genes, environment and health'
2002 March	Draft Protocol online
2002 April	MRC, WT, and DH announce initial funding commitment of £45 million to the project. (press release April 29, 2002)
2002 May	HGC publishes a report on genetic information, 'Inside Information: balancing interests in the use of personal genetic data'
2002(3)	Pilot studies begin to be set up and implemented
2003 January	UK BioBank has its own website

Recruitment thought to take 5 years, and a full 5-year follow-up on the cohort would not be complete until 2013.

2009	Full-scale recruitment begins and database construction begins
2014	BioBank 'fully' implementable.

CHAPTER 5 > APPENDIX 2
A reconstruction of some of the many BioBanks (drawn from its draft protocol)
[bold – some Biobanks]

- BioBank UK, as **a study, it is focused on genetic epidemiology**. The study will enable prospective studies of genetic and environmental risks in diseases of later life. In particular, the emphasis is on 'common diseases.' These are those in the UK "of major public health importance."[70] The team points out that the initial £45 million will be used to recruit and obtain baseline epidemiological information. Additional funds will be needed to carry out more detailed, varied investigations on cohort subsets.
- Ideally, since the study aims for an ability to analyze genetic and/or environmental factors, the initial study and therefore the **database** set need to be very large at the subject level (500,000 individuals).
- Recruitment of subjects (age 45-69) will take place in regional medical facilities, where **medical records are already electronically formatted**. The project emphasizes the heterogeneity of the population, from a wide socioeconomic background and ethnic origin. Here, the taking of blood samples will occur. In addition, a questionnaire about lifestyle will be distributed. The volunteers will be asked about various vicissitudes of their lives, daily living practices, and family history. Although self-administered in the volunteers' own homes or locales, additional interviews with a health professional will take place after the questionnaire is collected. Here, the volunteers' answers can be re-examined, and validated. In addition, (physical) information will be collected, such as blood pressure, height, weight, etc. This information will then be inputted into an electronic format at these local facilities.[71]
- Therefore, the study/database system needs to encompass a wide physical, or geographic, area. To facilitate this, according to the draft proposal, up to 600 general practitioners (GPs) in the UK, serving patients (in the proposed population, above), but also with computerized record-keeping established, would be enlisted to participate in the study. Therefore, the **coordinating infrastructure of the project**/database will be sprawling.
- Since the **study is prospective**, broadening its use for other research, information ascertained from tissue/biological samples and lifestyle information from questionnaires, will need to be linked to personal medical records.
- Because the project is prospective, it will span many years and require **ongoing collection of information** from experiences from research subjects. These will take the form of occasional questionnaires and on occasions when the volunteers visit their GPs. At the time the draft protocol was written, the team leaned towards the view that the questionnaires would be delivered via regular mail.

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[70] Tom Meade, T Michael Dexter and George Radda, reply "The need for independent scientific peer review of Biobank UK." (Letter to the Editor) *The Lancet* 359: 9325 (June 29, 2002): 2282.

[71] See Table 1 'Potential baseline measures' p. 33 of the draft protocol for BioBank UK.

- Genotyping, from the bio-samples, will be done at a centralized facility and transformed into genetic data. These **bio samples collections** must be stored as well.
- A genetic data base must somehow then by linked with the other data sets: lifestyle data and medical data, that is, made compatible with each other. Therefore, efforts must be made to establish a **UK bioinformatics infrastructure**.
- Although collections of the varied information will take place locally, overall, the team imagines that all the information will be centrally managed and coordinated. Therefore, a **physical infrastructure**, with trained nurses, physicians, and management team are needed or need to be identified.
- The project/database, though, will be publicly held, described as under 'public ownership.' An independent committee will be formed and liaison and be responsible to participants, publics, and other stakeholders. According to the sponsors, investigators will only have access to data, and not DNA, blood, and/or tissue samples. Companies will also have access to data, but only on a non-exclusive basis.
- Investigators will compete for access to information, through submissions of research proposals aimed at attempting to elucidate some genetic and environmental components of disease risk for specific conditions or complex, common diseases. BioBank supporters envision that the population-based cohort, its prospective nature, and large scale will provide a **future resource** and **model to the world's genomics community** for understanding specific gene-environment interactions for a wide range of health-related conditions, from heart conditions to cancer risk to drug response.
- Some researchers have pointed out that the goal in the BioBank initiative is not gene discovery but **the identification of interactions between identified genes and environmental factors of public health significance**.[72] Therefore, it will mainly be helpful in establishing risks to certain conditions. Proponents of the project, therefore, have also pointed out the importance of stepping up **public science education** so that publics understand risk. However, it should be pointed out that there is no attempt to do this in the BioBank pages.

[72] See A.F. Wright, A.D. Carothers, and H. Campbell, "Gene-environment interactions – the BioBank UK study," *The Pharmacogenomics Journal* (2002) 2: 75-82.

6.1 > (Re)presenting representational informatic sites

Genomics, hardly a common term a decade ago, is now expected to revolutionize the medical sciences. However, according to some, 'genomics' is obsolete already, and replaced now by 'post-genomics.' In the area of human medical genetics, the development of networked informational databases/banks provides the dominantly representation of what the future of (biomedical) research has in store. Where once the collections of biomaterial and its manipulation were thought to be the basis of genetic research, 'information,' its collection, storage, and manipulation, is taking center stage. Furthermore, these databases/banks are being planned and implemented on a large scale.

Yet, in a 1999 report, "Human Biological Sample Collections," based on a workshop given by the private British charity, the Wellcome Trust, the head of the Trust's Biomedical Ethics Section, Tom Wilkie and another member, Pat Spallone commented on the status of human genomics,

> Nothing is settled about the science, which is at its earliest stage. [2]

However, these database schemes continue to emerge. Further, the current rhetoric includes transparency and public inclusion in the development of such endeavors. Proponents of human population genomics acknowledge the need for public acceptance and participation. These individuals who would participate also happen to be the sources, or potential sources, for these projects. Here is an interesting dilemma. How, I wanted to ask, do the proponents represent such emerging projects, with their uncertain science and technologies not yet materialized?

In this dissertation, I considered biomedical technoscience, focusing on large-scale database research, to investigate how these projects are made more real (or realistic). I investigated web-based (re)presentational endeavors of human genomic population databases for medical research and therapeutic and diagnostic development. By using several cases, I explored how various genomic projects' websites perform some aspects of the

construction of the database projects, in particular, coherence- and subjectivity- making, of emerging 21st century biomedical sciences.[1]

By emerging, I meant composed of uncertain science/technology. I examined the character of websites in so-called *emerging* biomedical technosciences to understand how and to what extent they contribute to the construction and movement of information between those engaged in science and the public. I argued that the websites are technosocial spaces in which the creators of these biomedical informatic genomic population database endeavors (re)present bodies, life itself, even 'lively bodies,'[2] as they (re)present their projects and themselves within the larger scheme of genomic medicine. Potential participants, human subjects, populations, (genetic) information, and scientific objects are co-produced with the (re)presentations of their absent/deferred genomic databases.

By (re)presentation, I meant that representations work to stand in for the physicality and/or complexity of objects.[3] Further, the term '(re)presentation' indicates the shifting, multiple, and relational aspects of representing. The sponsors of these projects seek to create something – information – that is valuable, easily transformable, securable, and containable. In doing so, they must simplify, fragment, and/or recreate other objects and subjects.

By exploring the roles web representations play in generating reasons for building such technologies and genomic medicine, this study aimed at informing discussions about public participation. The roles of individuals in the publics were multiple. For example, they are to be human experimental subjects and possible recipients of benefits in these biomedical informatics projects. More generally, this study also aimed at informing discussions about public communication of science and technology. I showed that the web presence of the human genetic database enterprises plays a significant role in establishing these specific endeavors by creating a virtual social space, where experimental subjects, objects, and relations among the various actants are made, including the website visitor.

I brought hypertextuality and associated technologies, which better highlight (re)presentational acts, in my analysis. However, this is more than just a methodological

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[1] I borrow the idea of making coherence(s) and singularities from John Law and Annemarie Mol. See *Complexities: social studies of knowledge practices*, eds. John Law and Annemarie Mol, Durham, NC, Duke University Press, 2002 and *Aircraft Stories: decentering the object in technoscience*, Durham, NC: Duke University Press, 2002.

[2] This term is borrowed from Donna Haraway, see *Modest_Witness@Second_Millennium_ FemaleMan©_Meet_Onco Mouse™: Feminism and Technoscience*, New York: Routledge, 1997.

[3] I borrow this term from Latour and will elaborate further below.

move. The turn to the web and hypertextuality is to argue that the web's interactive aspect requires consideration of the role of the visitor in examining the (re)configuration of these (re)presentations. The virtual space is a mode of being. Ontological politics happens in these spaces.

My interest in these databases arises from my interest in issues of representation, heterogeneity, and boundary work. The sociologist of science, Bruno Latour writes,

> Hundreds of scientific disciplines and instruments constantly bring far away places, objects and times to us which are thus represented – that is presented again – for our inspection.[4]

Currently, no work specifically explores the ways in which the web presence contributes to their making. What I have shown is that genomic database endeavors are about (re)presenting *and* transforming bodies by and through digital and means in order to network and manage them.[5] One intention of this dissertation is to characterize the uses to which database schemes and (genetic) information are put by their creators as they attempt to establish this area of research as legitimate. These were shown to be highly specific to their sites.

Further, using three specific cases of such endeavors, I highlighted certain web presences as indicators of tension and of the creators' anxieties in communicating these uncertain projects to the potential participant. I also characterized some of the unexpected effects brought about by the structures of representation embodied by the websites in these representations. There are fragilities and multifarious changes in early practices and, in this dissertation, I explore these issues in the establishing of nascent practices (here, in the form of specific endeavors) of genomic science and medicine. In particular, I drew attention to the assemblages of capitalism, science, and/or the state to establish, or make more certain, specific schemes.

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[4] Bruno Latour, "Visualisation and Social Reproduction," *Picturing Power: Visual Depiction and Social Relations*, eds. Gordon Fyfe and John Law, New York: Routledge, 1988: 15.

[5] Gene/genetic/genomic information is expanded to include such additional information as: familial, genealogical, lifestyle, medical, dietary, and environmental. Many associations are made, but they are left uncharacterized specifically in any of these sites.

Since the report of the completion of a rough draft of the human genome sequence in February 2001, there has been a deluge of calls for continued genomic efforts.[6] The sequencing of the human genome was a huge and significant effort. The HGP serves as a symbol of public science and of international collaboration and cooperation (and, as some have demonstrated of competition). Furthermore, it resulted in enormous amounts of information, a public resource for scientists all over the world, academic, public, and private. However, it is now depicted as analogous to a laundry list, merely providing the raw material (or rather, data). We are told that it marks only the beginning for (post) genomics. The real work – of supplementing, translating, and interpreting – lies ahead.

The drive for collecting more information is enormous, the pace is fast and furious. Technological advances permitted the faster than projected sequencing of the human genome. The continuing rapid increase in creating more computing power in ever-smaller physical space will drive the next steps in putting the human genome sequence to work. The logical next step to the sequence, the story goes, involves the collection of larger amounts of information. These are needed to provide the necessary large numbers to obtain statistical weight and the number of case outcomes supposedly identifying genetic and environmental factors, risks, and predispositions.

In this narrative, science, together with, its handmaiden, technology will once again be our savior, providing genome efforts the speed, impetus, and power, to answer the problems of disease, health, and life. However, these claims are not uncontested among the biological community – in either their central ambition nor in the details of specific projects. Meanwhile, these efforts to collect information storm ahead. Therefore, to approach my main question, 'how do these emerging projects begin to solidify,' this study looked at three cases: Icelandic Health Sector Database (IHD), the GeneTrust™, and BioBank UK (now UK BioBank).

I drew on a number of current approaches in science and technology studies (STS). In particular, I provided a close analysis of the virtual efforts of these projects' initiators in combination with an analysis of the representational, institutional, and political strategies that they employed to establish their emerging technosciences at the local, national, and global levels. The problem of virtual representation has been largely ignored in the current discussions about these databases.

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[6] See, e.g. *Nature* and *Science* (February 2001).

Aspects of human genomics are being transformed at the virtual representational level, through (re)configurations and (re)circulation of concepts, practices, and (communicational) tools at, by, and through these websites.[7] Genomic medicine and its tools – here, in particular, databases – do not simply emerge from the revolution of biomedicine, information technology, and computers. Borrowing from current STS approaches, I maintain that they are locally configured.

Just at the turn of the century, deCODE's IHD became both an international indicator of genomic medical endeavors gone astray *and* of our post-genomic future.[8] I followed the current scholarship on this area of scientific research to the extent that I begin with this project. However, by beginning with the assumption that the primary aim of these endeavors is to construct large-scale human population databases, my analysis diverged from the analyses put forward in other studies. This representational approach allows me to avoid the scenario of solely focusing on the problems of physical database construction. I began with the question, 'what will these databases be?' but shifted the question to 'how are they doing work today?' By focusing on communicational aspects, my aim was to draw exclusive attention away from the database constructions themselves and to draw attention to the constructions of relations and subjectivities in these local spaces.

The focus on database construction has led to a kind of hierarchical structure and to an exclusionary discursive regime in which technoscientific expertise and efficiency dominate. In addition, where database construction dominates discussion, it forecloses other discourses. Much of the rhetoric in the debates was highly technical or inserted claims that the databases have not yet been constructed, producing a wait and see attitude in the larger public. In examining the virtual representations, I found that its creators deferred much discussion of the physical databases.

There are of course aspects of new genetics research as well as advances in computer sciences and technologies that contribute to these projects. However, the sponsors also borrow certain aspects of genetic science, traditional methods of genetic epidemiology, and statistics on which to rest the assurances of their projects. A great deal of rhetoric has been

[7] The construction of physical institutional infrastructures and material objects are important but in this project, they are put in the process rather than taking center stage.

[8] Of further interest in pursuing this area is the fact that a number of researchers cite the deCODE/IHD site as a resource for information and as a resource for their readers to learn more about the project, but did not, themselves, engage it, except for its rhetorical purposes.

deployed, describing these technosciences as revolutionary and as in the process of emerging. However, I showed that even this rhetoric proved incomplete upon closer examination of specific projects. Their representations of their endeavors are specific assemblages that are inclusive of many aspects.

Non-technological and non-scientific aspects contribute to making these assemblages cohere. Of particular importance are factors involved in value-making in this age of informational capitalism as well as the rise of health fetishism and the increasing accessibility of such information. Only the close, multi-case study and relational approaches to examining language/technology offer the possibility of studying the (re)configurations, boundaries and (dis)connections of local, national, and global schemes in (re)presenting genomic technoscience and life itself as well as the anxieties these (re)configurations may produce for a potential participant.

In terms of the science, it is still uncertain whether databases ought to draw on genetically heterogeneous or homogeneous populations, what types of information should be collected, and what number of individuals are required to yield an informationally adequate database for medical research. These projects have a high adaptability to each specific location. There are economic and political reasons for continuing with these endeavors.

Ten years ago, the internet and biotech sectors were barely making a dent economically. Today, both have intensified, even though the bubble burst for both, to some extent, in the late 1990s. The internet and biotech industries are central concerns for the private and public sectors. The interest in genetics, the internet, and computers, is not entirely new, especially at the state level. Setting up and/or further solidifying the infrastructure for them and interweaving them is a strong impetus for these large-scale, multi-discipline, multi-sector operations.

In recent years, there has been an expansion of general database construction, use, *and* invisibility of their use in industrialized societies.[9] The anxieties are real. On the one hand, in the United States concerns over increased surveillance looms large. The current tides shifts somewhat, in this post 9-11 age, but, the issue is not settled. On the other hand, many of us like the convenience of these technologies and what is exchanged – even if it

[9] For the rise and spread of databases, see for example, Simon Garfinkel, *Database Nation: the death of privacy in the 21st century*, New York: O'Reilly, 2001.

comes at the price of increased consumer surveillance. We receive the convenience of e-commerce rather than the hassles of parking, crowds, and time at the mall, the so-called discounts every time an individual uses their club membership cards, and the time-saved at highway toll booths with EZ-PASS. The list could continue with ATM machines, airline databases, DMV (Division of Motor Vehicles) databases, etc. We are increasingly networked to these databases, and whether we are ecstatic about them or not, most of us see them as necessary. Further, as in the examples above, an exchange is made, but the standard political question is 'who decides?' This is not an unimportant question, but in my project, I focused on the questions, 'what are decided?' and 'how are these decisions made?'

Turning back to my case studies, although the sponsors claim to be inclusive of broader publics, I argued that what genetic information means entailed representing not only the database projects, but potential participants, and the larger audiences. Why is this important? These representations of science, medicine, and technology were not completely un-negotiated. They do not emerge solely out of natural scientific claims. Politics happens where relational (re)presentations are at work in the sites.

Besides the increasing use of the internet, networking, and accessibility of information, there is also the issue of rising healthcare cost (for all three of the nations whose projects I look at), and the current concern of a rapidly aging population. In industrialized societies, we are generally living longer, but are we living better, that is, healthier? The sponsors of these projects' promise a step in this direction as well as steps towards lowering healthcare cost through a preventive – or lifestyle change – approach to health/medical management. For example, we saw that BioBank's (re)presentations of the endeavor and of genomic medicine embodied this ideal.

Yet, I also see a public desire for the promises of personalized medicine and healthcare management. Yes, there are concerns about the affront to personal privacy and breaches of security. But the promises are enticing: precision and clarity in the dealing with the vicissitudes of living – of aging, stress, and illness. Further, there is the promise of new ease in dealing with these problems. In our modern culture's climate of fast-paced information overload, it is appealing to gather our information, to hand them over to a database, and to have the answer handed back to us, with precise, targeted results and possible solutions. In these schemes, mediated by technology, the answers do not lie in the messy, complicated, community and state efforts necessary in making changes in our larger

environment. Instead, the answers lay in the 'simplicity' of exacting change in the individual, especially through targeted life-style, physical, and physiological alterations. The Gene Trust site worked hard to embody these aspects of simplicity, clarity, and individual choice into its vision of genomic medicine and its project. However, as I also showed, the site worked hard to help the individual visitor embody these aspects as well.

Here, then, I also want to suggest a re-conception in our relations to technology. In this instance, I attempted to locate an understanding of databases by putting it into a socio-technoscientific process. I did this by focusing on relationality in representational work, attending to communication, rather than the technoscientific artifact's current centrality in our field of vision. Through these cases, I highlighted the need to take seriously the complexity and work involved in creating realistic projects. A human genomic database is an object of sorts but it is also more than this. It is an assemblage of concepts, meanings, practices, individuals, families, populations, sciences, technologies, states, corporations, genes, and data.

Genomic science contributes potently to post-industrial thinking and is infused with the discourses of globalization, capitalism, and development. However, it is not only because of the potential capabilities of current medical biosciences, but because of their current ability to manipulate and alter life that I believe more critical focus on genomic endeavors is needed. Further, I suggest a rethinking and retooling on how matters of emerging technosciences, particularly in the biomedical arenas, are engaged at diverse public levels are needed especially in light of the continued interdisciplinary, crossdisciplinary, and public face of genomic medicine.

There are several defining characteristics, as noted by proponents themselves, of such endeavors. These are the emerging, experimental qualities of such projects, their technoscientific characteristics, and their public interfaces (at very early stages of science and technology).

Each case study examined the web presence of a specific technoscience project as intertwining multiple social spaces. Here, relations and specific experimental subjects are made and/or envisioned as (re)presentational acts of the projects take place. My main goals were to:

A > describe the social formation that these particular web presences create. Here, I argued that each web site is both a representational space (in more traditional terms of

providing representations of medical technoscience) and a technosocial space. To accomplish this, I took into account the relations between technology and language.[10]

B > complicate 'databases.' I put them back into the process, and drew attention to the relational attempts to construct technoscientific objects and subjects in these endeavors. In doing so, I was able to comment on the circulation of information in these virtual sites and to speak to emerging uses language of and about life, bodies, health, and wellness in terms of 'information.'

C > to make theoretical points by use of my work on databases. Besides putting hypertextuality in the analysis of these biomedical informatics projects, these endeavors themselves should inspire a need for exploring alternative methods for locating ways to get at these complexities. I suggest that several tools in science and technology studies can be a starting point. Here, in this dissertation project, I have adopted and adapted the following frameworks:

a > multiplicity/coherences

b > representation/re-presentation

c > boundary/classification work

d > actor network

In particular, I illustrated the usefulness the interdisciplinary perspectives and methods of science and technology studies in highlighting and exploring what is marginal and unstated in the dominant discourses (both public and professional) in regard to these projects. Not unrelated, the frameworks helped me highlight what are unintended side effects arising from the structure and content of these websites.

6.2 > On experiment: information and life

By focusing on the project's virtual presence, I problematized the concept of genomic information, specifically framed within the project initiators' (re)presentations of

[10] I borrow the idea of 'social space' and the examination of the relations between technology and language from J. Macgregor Wise's idea of 'Technology/Language.' He uses this as a framework to analyze what he describes as 'stratification' between the 'technology (content)' the 'language (expression).' [1997: 113]) Wise concentrates on the media technologies as a whole. In this dissertation, I want to take his notion farther or, at least, more locally at the specific level of virtual representations of human bio-genomic medical informatics.

information on the world wide web. Each case has its own specific configuration of gene/genetic/genomic information. The virtual presence of the California company, DNA Sciences' Gene Trust™ dominantly characterizes genetic information within a frame of the internet and consumer privacy. Through DeCODE's IHD web presence, genetic information circulates through networks of Icelandic history, epidemiological research, and database research. In the BioBank UK's case, genetic information is constructed through a series of mediation processes from biomaterial collections to the potential volunteer to future networks of databases.

In examining the three projects closely, I foregrounded the differences and specificities in negotiating their meanings and uses of genetic information and database projects. However, to develop this idea further and more broadly requires examination of other domains of research – perhaps non-human database schemes – and therefore, I can only begin to explore this direction of enquiry here. In this study, I de-limited my discussion of these machinations in order to highlight the construction of subjects and, in particular, the envisioned relations as to their roles in these specific endeavors and to an envisioned 'genomic medicine.'

There are both multiple and broadening uses of genetic information at play in these genomic endeavors. For example, I illustrate a conflation in the described collection processes of an individual's genetic information with personal information about her/his life. This might be thought of as biolife information and living information, perhaps analogous with Donna Haraway's lively bodies, in her discussion of gene fetishism.[11] Further, I show that a seemingly self-contained website provides certain spaces to circulate and associate disparate and sometimes competing ideas of personal and public genetic information so that coherent *information* emerges. The question of whether or not this is a larger trend in conceptions of gene, genetic, and/or genomic information requires further examination.

A number of science studies researchers have dealt with the issue of information and genetics. Scholarly works investigating the life sciences and the evolution of the body have primarily focused on genetic metaphors, including in the metaphor of information. A number have studied the metaphors of text, for example, DNA as the 'book of life.' Others

[11] Donna Haraway, *Modest_Witness@Second_Millennium_FemaleMan©_Meet_Onco Mouse™: Feminism and Technoscience*, New York: Routledge, 1997.

have studied the metaphor of maps and blueprints.[12] A number of other studies have focused on the technologies of genetic engineering. Recently, others have focused on how biomedicine is being shaped by computer technologies as well.[13] I highlight, in particular, a media/ communicating/ representing technology, the internet, especially its web aspects in emerging biomedical science and practices. The web aspects have generally been ignored in science studies. Information technology has generally been viewed in the genetic research realms as simply a medium, a communication or representing technology, for scientific work. In this project, I suggest that a more complex frame around representing technologies is needed in studies in the biomedical life sciences.

In particular Lily E. Kay and Evelyn Fox Keller have demonstrated the use of the metaphor of information in the development of (molecular) biology.[14] Haraway has highlighted the collapse of that metaphor. Now, she argues it is taken in a literal way. In this direction, material technological containers house information, which literally make organisms. She has described the genetic database as "high-order mimesis." Here, she states,

> A biochemical genome is already a second order object, a structure of a structure, or conceptual structure of a chemical entity; and the electronic genome databases represent still another order of structure, another structuring of information.[15]

Further, she continues,

> The genome is a figure of the 'already written' future, where bodies are displaced into proliferating databases for repackaging and marketing in the New World Order.[16]

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[12] See especially, Richard Doyle, *On Beyond Living: Rhetorical Transformations of the Life Sciences*, Stanford: Stanford University Press, 1997, Lily E. Kay, *Who Wrote the Book of Life? A History of the Genetic Code*, Stanford, CA, Stanford University Press, 2000 and Evelyn Fox Keller, *The Century of the Gene*, New York: Oxford University Press, 2000.

[13] Timothy Lenoir, "Shaping Biomedicine as an Information Science," in *Proceedings of the 1998 Conference on the History and Heritage of Science Information Systems*, eds. Mary Ellen Bowden, Trudi Bellardo Hahn, and Robert V. Williams, Medford, NJ: Information Today, Inc., 1999: 27-45. An online version of this paper can be found at Lenoir's homepage: <<http://www.stanford.edu/dept/HPS/TimLenoir/shapingbiomedicine.html>>.

[14] Lily E. Kay, *Who Wrote the Book of Life? A History of the Genetic Code*, Stanford, CA, Stanford University Press, 2000 and Evelyn Fox Keller, *The Century of the Gene*, New York: Oxford University Press, 2000.

[15] Haraway, 1997: 99.

[16] Haraway, 1997: 100.

I engage local machinations for this displacement, in the cases I examine here, but will pursue this area further in subsequent work.

One characterization of the biotech industry and venture start-ups that is widely agreed to be known for certain is, namely, that they are uncertain. Initiators, of course, add disclaimers against the certainty of their projects. Two companies, I looked at here, DeCODE and DNA Sciences, in their SEC filing for public offering, are no exception.[17] Critics have pointed out that it could be the case that none of these databases will yield any practical information. By this I presume they mean that no pharmacogenomic applications may arise. Surprisingly, it is BioBank, the public project that seems the most certain, at its early stage, to claim new medicine/healthcare will come out of such a project.

Experiment and risk are certainly aspects of this industry, as they are for science, and, after all, life itself. Many of us may find these aspects of life, frustrating at times, but no less necessary and desired. A salient question to ask, though, is 'How do we choose experiments and risks?' One way to answer this is to answer the following, 'who gets what, when, and where?' Taking this path is to answer the decidedly political questions. However, in this project – itself an experimental project of sorts – I suggest, we also need to ask, 'Has the experiment begun in any meaningful way?' and then, ask, 'If so, who's risking, who is risked, and what is at stake?'[18]

According to the sponsors, what is risked is not very much – merely information. In human experimentation terms – as pointed out by deCODE's CEO – it is low risk for the subjects. The risk comes later, if the information is misused (for example, by insurance companies or employers). However, this assumes that the sponsors know what genetic information is. In this project, I showed how 'information' is characterized, deployed, and

[17] See also deCODE's Annual Report, 2000.

[18] The science studies critics of these projects, especially the deCODE venture, have aptly addressed the question about risks, specifically as they relate to genetic identification discrimination. Bioethicists, in particular, have focused on the problematic individual versus community rights issues especially as they pertained to the matter of informed, or rather presumed, consent raised in the deCODE project. The nation-state issues that arise in this controversy have been topics of much discussion in this case. Hilary Rose has discussed the gender issues involved. Her work is focused on the female Icelandic population. [If one peruses the top management page, one is struck by the fact that all are men and all quite young.] Less discussed are issues about race and ethnicity in the population resource, which I hope to pursue in future research, particularly in relations to genetic variation and common heritage and resource.

co-produced with the other (re)presentational acts of the database/study and its sources (individuals and populations) by the projects' sponsors. I argued that meanings of genetic information, or rather information from individuals sought by these sponsors, are more and less than gene information, that is, information extracted from a gene). Further, I showed that more is at stake. Haraway writes that "the promise of the genome is its capacity to occupy the future." The stakes here are the contest, or the politics, over the shape and content of such promises. The politics is politics by other means.

6.3 > On site: websites and virtual space

This study demonstrates that the websites of large-scale human genomic databases projects are productive areas for examining complexities of emerging biomedical technosciences today. The websites are not (just) representation of science (of genomics) or technology (of a database).[19] The virtual sites are spaces to envision specific object(s) (e.g. databases, populations, information) and create specific kinds of subject(s) (e.g. volunteers, consumers, data subjects, visitors, publics). However, they may also provide a space for certain practices (e.g. virtually-based relations, defining boundaries between knowledge makers, information providers/recipients, and experiment(er)/subject relations). In other words, these are political spaces in which knowledge, practices, and subjects are legitimized, negotiated, and contested.

By allowing the world wide web to be invisible in the analyses of genomic technosciences, analysts have underestimated the significance of the emerging discursive work generated by and through the sites. They have overlooked the importance of the various modes of representation that converge at specific sites or that are distributed, linked, or relegated to other sites and spaces. In other words, they have missed the unspoken and un/intentional inclusionary or exclusionary practices - boundary work – that is done on, by, and through the websites. They do not take into account the design, links, documents, protocols, journal articles, advertisements, press releases that do work to define and participate in the negotiations of certain practices in the discourses among varied actants.

[19] On the performativity aspect see Annmarie Mol, "Missing Links, Making Links: The Performance of Some Artheroscleroses," in *Differences in Medicine: Unraveling Practices, Technologies, and Bodies*, eds. Annemarie Mol and Marc Berg, Durham, NC: Duke University Press, 1998: 144-65.

Together and apart, distributed and confined, in their shifting configurations, these work to create and construct specific technoscientific subjects/objects. They contribute to creating and constructing specific meanings, practice, and hierarchies for this (emerging) genomic science.

To ignore the sites is to ignore that these sites themselves work to bring together varied interests, but that they also exclude various groups at various moments. The initiators of the three endeavors, investigated in this study, acknowledge the importance of public acceptance of their projects, not only from specific volunteers, but at the broad level. Furthermore, they claim that they encourage broad public participation in the development of genomic medicine. DNA Sciences claims that a thoroughly private endeavor is the way to maximize transparency as well as personal choice, individual privacy, and control over one's own information. BioBank invokes its public status as a means of maximizing public engagement and transparency. The public/private framework used in recent discussions is insufficient to discuss the production and distribution of 'information' (genomic) here, where my concern is with the issue of effectivity.

In this project, I develop an alternative discursive scheme that speaks to the endeavors of a technoscience in the making, affecting and constructing virtually real subjects and objects today, rather than deferring inclusiveness of the potentially volunteered for tomorrow – that is, when (or if) the databases are built, sciences are certain, and the genomic vision defined. Here, in these spaces, I explored what *is* done in order to explore how subjectivities are also made. I have illustrated in three cases how genetics, medicine, technology, culture, and nature are constructed as configurations of value and meaning, converging in these websites. Specifically, I have suggested how web cultures and practices influence genomic medicine today in particular locales.

In a state of high anxiety today over possible epidemics, such as SARS (severe acute respiratory syndrome), obesity, age-related and/or lifestyle conditions due to the rising age of certain industrialized populations as well as rising health care costs, genomics may sound like an appealing avenue to travel. Further, in times when the dominant frameworks are neo-liberal-, market-, consumer- orientations, genomic medicine in the form of personalized health care seems an easy sell.

However, the cultures of hyper-individualism and personal freedom contribute to the overwhelming fears of government surveillance and intervention. Further, the dot-com

and tech-stock bursts in the late 1990s also contribute to publics' skepticisms of private firms. These anxieties and contradictions may have furthered the hyper-information culture developing today. Anxieties exist over information overload. However, the influx of information coupled with the possibilities of personal assembly and appropriation of this information in this age of individual choice makes the internet an appealing resource for today's 'global' individual.

As I suggested in the introduction, these websites are centers where visitors can go to participate, be educated, and disciplined in 'genomic medicine.' The question though is which version? Through my multiple case studies approach, I showed that public, private, and public/private institutions are all involved in the partaking in these endeavors of contestation in this virtual space. Human population databases and genetic information are being assembled together from specific discourses and practices that are not always from the natural sciences. This was especially illustrated in the Gene Trust project in which online consumer privacy discourse converged with genetic privacy discourse. However, objects and subjects (re)presented in these sites can be taken out of their specific social contexts as well as re-assembled, or (re)presented in a new context. For instance, this we saw in the deCODE website in which the Icelandic population, it history, biology, and culture reconstituted into the company's context.

Site visitors are 'invited' to participate in the re-assembly of meanings but to a limited extent. Further, I have suggested that these online site visitors can be kept back from the messy, social and scientific sites of these projects origins. Instead, they are treated to hyper-technologized, shifting, simplified, and/or purified (re)presentations in and by these virtual spaces. In, at, and through these sponsors' virtual sites, politics of (re)presentation are at work in which valuable information and legitimate knowledge are identified, rules and practices forged, and subjectivities envisioned and enacted. Reality is being made in these virtual spaces. In the next section, I explore further the trouble with virtual/real boundaries for potential participants and everyday living bodies.

6.4 > Informatic bodies and everyday life

A number of authors have considered how modern communication and life sciences are produced through a common move. Donna Haraway, the feminist cultural historian and

critic, describes this move as "the translation of the world into a problem of coding."[20] She and other authors explore how these translations affect and/or alter relations of the body with the world. The result is a number of highly engaging and important body studies and studies on technological innovations on the body.[21] In my project, I continue the examination of informatics, information, and cybernetics in order to explore how relations between human bodies and the world are altered. However, rather than focus primarily on the body or on the technologies as such, I seek to examine the *making* of the networks that produce informatic bodies.

Haraway theorizes the cyborg. Her work in this area is much cited and helped produce a whole literature on the cyborg.[22] Katherine Hayles, a cultural historian of information, also theorizes the posthuman. Instead of focusing on the body, she focuses on the tools and techniques that work towards its production. Hayles, in her history of informatic bodies, characterizes posthuman thinking as (a) privileging informational pattern over instances of material embodiment, (b) perceiving consciousness as a sort of secondary symptom, that is, an epiphenomenon, (c) perceiving the body as the 'original prosthesis that we all learn to manipulate,' and (d) configuring the human being so that it can be 'seamlessly articulated with intelligent machines.'[23] Essentially, while we think of the cyborg as the literal coupling of man and machine, the posthuman does not necessarily entail the melding of the biological with the digital. In the latter case, the incorporation is further interiorized and not necessarily superficially seen.

My move to investigate relationality and web representations aims to problematize the modernist dualist framework of nature and artifice and the more current virtual and real. Catherine Waldby, a media and cultural studies scholar, in a study on current iconographies of the body explores how the body is altered in cybernetic or informatic translations. She

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[20] Donna Haraway, *Simians, Cyborgs, and Women: The Reinvention of Nature*, New York: Routledge, 1991: 164,

[21] See for example the works of Donna Haraway, *Modest Witness*, Catherine Waldby, *The Visible Human Project*, Paul Rabinow, and Margaret Lock. For more general studies on how medicine, science, and technologies work to transform the body see the authors in the volume *Deviant Bodies: Critical Perspectives on Difference in Science and Popular Culture*, eds. Jennifer Terry and Jacqueline Urla, Bloomington, IN: Indiana University Press, 1995.

[22] A good place to look at all the rhizomatic literature that her work has spawned is online. See, for example, the Popular Cultures website <<http://www.popcultures.com/theorists/haraway.html>>.

[23] Katherine N. Hayles, *How we became posthuman: virtual bodies in cybernetics, literature, and informatics*, Chicago, IL: University of Chicago Press, 1999.

follows Bruno Latour in his observation that recent years have produced a crisis in 'purification' work. By purification Latour and Waldby mean the work of maintaining distinct boundaries between humans and non-humans. Biomedicine and biotechnology offer numerous illustrations of the rapid work of hybridization. Here Latour gives us several examples,

> frozen embryos, expert systems, digital machines, sensor-equipped robots, hybrid corn, data banks, psychotropic drugs….[24]

This sense of crisis resulted in further works theorizing the 'cyborg' and 'posthuman,' which Waldby critiques.[25] She contends that, in the end, these studies maintain the familiar modernist frames of linearity and duality. Here the 'cyborg' (or posthuman) merely replaces the 'human.' In these cyborg schemes, we simply move from being human to cyborg to posthuman. The 'cyborg' creates a hybrid identity, but still, we simply become less organic and the human is reconfigured as an informational system. Thus, the human/machine or nature/artifice divide is maintained.

Instead she states that,

> [T]he posthuman can best be understood as a point of view or insight made available by the contingency of technics. The possibility of the posthuman is not to do with the transcendence of the human, its replacement, but rather with the recognition and exposure of the networks of production which constitute human techno-genesis.[26]

In addition to bracketing this problem in cyborg/posthuman theorizing, it is this 'recognition and exposure of the networks of production' that I want to highlight in my own project. Here, I begin to explore how the 'translations of the world to the problem of coding' and informatics alter the bodies' relations to the world, not by directly examining the

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[24] Bruno Latour, *We have never been modern*, translated by Catherine Porter, Cambridge, MA: Harvard University Press, 1993.
[25] See especially the volume edited by Chris Hables Gray, *The Cyborg Handbook*, New York: Routledge, 1995, the earlier work of Donna Haraway, and Katherine N. Hayles, *How we became posthuman: virtual bodies in literature, cybernetics, and informatics*, Chicago, IL: University of Chicago Press, 1999.
[26] Catherine Waldby, *The Visible Human Project: Informatic Bodies and Posthuman Medicine*, New York: Routledge, 2000: 48-9.

iconography of the body as Waldby does, but by 'exposing' and examining the possible relations produced in the networks of production of biomedicine today.[27] In making this move, I aim to show the ambiguity and tensions created in such networks. Waldby takes up these ambiguities herself.

In her study on the Visible Human Project (VHP), she illustrates the paradox of the new biomedicine.[28] On the one hand, the Visible Human presents a distinctive and pure human body. In fact, it presents the project as a complete archive of the human anatomy. On the other hand, the project aims to enable the work of hybridization. She states,

> for its part claims to present a coherent and exhaustive human anatomy, the sum of organic parts, yet it disaggregates that anatomy not according to the any logic of organic integrity but rather according to the logics of tomographic visuality and display…. Living flesh and digital data are brought into workable and assignable relations to one another, so that data space and anatomical space are placed in a kind of enabling confusion.[29]

These 'workable relations' and 'enabling confusion' are what I highlighted in my own project. However, rather than focus on 'living flesh,' human anatomy, and figurations of the body as Waldby does in her study, I begin to draw attention to practicing bodies, identities, and lifestyles in my exploration of how subjectivities are be produced in and through these virtual bio-informatic sites.

The use of web communication also helps me to turn to an aspect not presented in the majority of these informatic body studies. This is the living everyday body, which is, to be fair, largely absent in these emerging endeavors. These web representations may present simply and unproblematically – through interactive, rapid, and efficient means – the conveyance of new biomedical science and practices to the broader audiences. Through this new mode of communication, it may appear that the creators produce more direct and clearer representations of these biomedical projects. The proponents of the human biomedical informatic projects present to the broader publics and potential participants the

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[27] This project sets up future work for examining how the informatic biomedical practices and perception produced in these virtual sites continue in non-virtual dimensions.

[28] The public project created three-dimensional recordings of actual human bodies – first of a male (1993) then a female (1995). These were dissected, photographed, and then converted these into visual data files to produce, presumably, exhaustive archives of the human anatomy.

[29] Catherine Waldby, *The Visible Human Project: Informatic Bodies and Posthuman Medicine*, New York: Routledge, 2000: 44-5.

promise of individualized medicine and preventive healthcare. Further, they present not only the promise of, but supposed steps towards, active participation in the making of a 'revolutionary' and new global medicine and lifestyle that will also make these subjects' lives simpler through technologies.

The web sites stand in for the absent physical spaces in which genomic medical research may be practiced. The circulation of 'information to be collected' from participants through the websites together with the browsing visitor provide a sense of active participation on the latter's part. Embodied knowledge and information from site visitors and measurable information are assembled and (re)presented together in these virtual spaces. The potential participant is taken up into the virtual medium and networks that have already taken hold of the anatomical human body.

However, the necessity to 'log-off' and perform some duties for the sake of the projects' endeavors is an indicator of the resistance of the body to these informational schemes. Blood samples and some kinds of outside contact and collection are required. At the same time, though, the relative ease of simply 'logging-on' and 'logging-off' at will and resuming life outside the screen also indicate the insidiousness of virtual perception and its interpenetration of the embodied visitor.[30]

Through the Visible Human Project (VHP), Waldby shows the collapse in the problematic humanist distinctions between actual and virtual, subject and object, and machinic and organic. However, she also shows us the trouble created in the collapse of those distinctions with the concomitant aims to maintain them. In the following example, she explains what happens when a user employs some version of the visible human software. She asserts,

> If the anatomy theatre takes place in virtual space, the interface inserts itself as a distinction between the subject and object of knowledge, safely located on either side of the terminal screen. The user can manipulate the image with a one-way touch, the masterful touch of the cursor or virtual scalpel, while the image-object is deprived of agency or the power to return the touch. The interface acts as prophylactic barrier which allows only unidirectional action

[30] Here, I borrow Katherine Hayle's notion of virtuality as the "cultural perception of that material objects are interpenetrated by information patters" [Hayles: 1999: 13-4]. This is not meant only as a 'psychological phenomenon.' Rather it is "instantiated in an array of powerful technologies. The perception of virtuality facilitates the development of virtual technologies, and the technologies reinforce the perception." [Hayles: 1999: 14]

> from subject to object, while protecting against any other kind of encounter.[31]

The focus for Waldby, in this study, is on 'figures' created by the VHP, that is, the iconographies of the human body. She acknowledges the trouble produced through the interface. In particular, she points out its inability to absolutely stabilize the divide between the actual and virtual. She recognizes that it is a space of representation, of projection, and of implication for the user. Further, she acknowledges the user's, or visitor's, investment and location (with)in these virtual spaces that may in fact be non-voluntary. However, since her aims are other, Waldby does not expose the locations of anxieties and tensions for the virtual visitor who must somehow contain herself, her identity, her person, safely in *and* beyond the virtual realm.

She shows, instead, with the Visible Human that "all interior spaces are superficial, that all depth is only latent surface." In the VHP, layers upon layers of the donors' body are sliced, imaged, and digitally translated. Waldby asserts,

> [I]f the VHP and its cognate technologies can produce the body interior as infinitely available surface then there is no depth of embodiment which is free of technological contamination. Like all those other biotechnologies which can work the body from the molecular level upwards, the VHP and related imaging technologies can order the endosoma according to the complex technosocial economies and assemblages. It is no longer only the body's surface which is socially marked and produced. The entire organ-ism is open to 'superficial' modes of inscription.[32]

However, where Waldby and others have demonstrated that the new biomedical technologies, especially imaging devices, efface the distinction between surface and depth, in my project, I aimed to capture the surfacing of (an)other aspect of human interiority.[33]

In the biomedical informatic projects' websites, potential participants are enrolled to view and participate in the surfacing of their own interiorities. These latter include how

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[31] Catherine Waldby, *The Visible Human Project: Informatic Bodies and Posthuman Medicine*, New York: Routledge, 2000: 158.
[32] Catherine Waldby, *The Visible Human Project: Informatic Bodies and Posthuman Medicine*, New York: Routledge, 2000: 159.
[33] For other work in this area of imaging bodies, see the volume *The Visible Woman: Imaging Technologies, Gender, and Science* edited by Paula Treichler, Lisa Cartwright, and Constance Penley, 1998.

potential participants understand and articulate health, disease, and relations to their own bodies (and bodies' states) as well as to their families. It is not only the physical body that is made external. However, the increasing externality of these once private and interior spaces also requires re-articulation and validation through digital technology and high tech spaces. These are forms of mediation and instruments brought even closer to home for ever larger numbers of individuals. The 'figure' becomes each one of us rather than the kind of model figures as in the Visible Human or the human genome project. Further, what is new is not the externality of the psychic along with the soma but the continued and real-time tracking, re-articulation, re-configuration, and transformation of the living/lively body into and through these digital networks.

As I have argued, though, throughout this dissertation, the qualities of 'liveliness' and 'realness' are unstable in these sites. The degree depends upon the assemblage or configuration of technoscientific efforts to life and information and constraints therein. As we saw, for instance, the human (material) cannot be completely written out of these informational projects. In the relentless drive today to create new forms of bio-value throughout life, there is an increasing demand for subjective life and practices to conform to informational logics. The computer and the internet's roles in these networks work for the creators of these biomedical informatics projects to conceal the power of these forces in practical life, but I have aimed to capture instead that they do in fact reveal the trouble for potential subjects and/or objects.

In the world wide web today, the biomedical 'techno-genesis' of the lively body is furthered through this mode of communication. In particular, I drew attention to the aspects of 'on demand' (or real-time) and 'dependence on technical environments.' These might be further illustrated by considering a different body of work, in particular, David Levy's discussion on the nature of the document today. He argues that how we understand and interact with documents influences the way we read, organize our thoughts, and create order and structure in our intellectual worlds. He wants us to recognize that books, journals, and printed matter are more than containers from which content can now be 'liberated' in the digital age. In fact, in the same vein, digital materials, whether a receipt generated from an electronic system or a website, also influence the way we think and live.[34]

[34] David M. Levy, *Scrolling Forward: Making Sense of Documents in the Digital Age*, New York: Arcade Publishing, 2001.

According to Levy, what is so powerful, confusing, and uncertain about a digital document as compared to a print document is its schizophrenic existence. There is the digital representation – the collection of bits stored in a hard drive or floppy disk – but this representation is insufficient as a good characterization of digital documents because the stated bits cannot be understood through the human senses. The other side of digital document is that digital representation is a 'generator' or a kind of 'master' that permits (re)production. Levy describes this latter in the following,

> [Y]ou can make copies of the representation itself, the bits…. But you could also be said to make copies from the digital representation: when you create perceptible forms, say, by printing your Microsoft Word file or displaying it on your computer screen.[35]

It is this latter sense of copying that Levy is concerned with because for him these reproductions are what we can read, see, and/or hear. Here, Levy provides us with a brief history of the eventual privileging of text in computer systems, which he places in the mid-1960s. Prior to this period, electronic systems, he contends, privileged the practice and display of computation. Text, at that point, had been merely an input. "Text," he writes,

> [I]n these new cases became the primary object of the user's attention, with the computations inside the computer (the operations needed to edit and display the text, for example) taking a back seat.[36]

Eventually, we came to WYSIWYG – the well-known acronym for 'what you see is what you get.' However, Levy describes this characterization of digital documents as a kind of masterful illusion, concealing messiness and repeated manipulation. From here, he describes the rise of hypertext.[37] For Levy the idea of hypertext (a notion of non-linear webs of text) is not new but what made computer-based hypertext a possibility was the separation of digital representation and perceptible form.

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[35] David M. Levy, *Scrolling Forward: Making Sense of Documents in the Digital Age*, New York: Arcade Publishing, 2001: 139.
[36] David M. Levy, *Scrolling Forward: Making Sense of Documents in the Digital Age*, New York: Arcade Publishing, 2001: 143.
[37] Today, sometimes described as hypermedia to encompass other forms of media types.

What the world wide web did – first with the Mosaic browser and later, commercially with Netscape and Microsoft Explorer – was to make possible a translation of digital representation into perceptible forms across the globe. In other words, it made possible the (re)display of formatted documents and hypertext. Further, it made it possible to (re)display these documents on demand – what Levy calls a 'just-in-time scheme.'[38] Levy acknowledges that these – audio, film, video, text – various medium or techniques have been around for a long time, but with digitization, we now have a single medium in which to represent all kinds of documentary forms. In addition, with the internet – as it stands today – we begin to have a global infrastructure in which these can be represented and actualized. He sums it up as 'more, faster, farther, easier, cheaper.'[39]

Unlike print, digital representations are lighter, more compact, and easily modified without leaving a trace. Further, what differentiates these digital representations are the speed and flexibility in transforming them into perceptible forms only when needed. However, all of this raises a number of problems. Chief among them, according to Levy, is that unlike in the actualization of a paper document, digital representation does not lose its dependence on the technologies that are used to produce it. This is not a new problem as other forms of representation, such as video and audio, have this problem. However, Levy points out that for digital representation there is a higher level of sensitivity to technical environments. Further, there is rapid change in the technological artifacts in terms of both hardware and software. This latter situation has not been the case either with video or audio.

The problem then is not the material versus the immaterial. In fact, Levy argues, I think rightly, that the digital documents – although their bits are intangible – are not immaterial. Levy is speaking strictly in terms of digital documents, such as a Word or WordPerfect file. However, this does have implications to the informatic body. Here we can return to Hayles. She makes a similar point to Levy's about information.

In the following quotation, she comments on a speech in which Marvin Minsky suggests – not unlike many other pundits today – that soon we will be able to extract human memories directly from the brain and import them onto floppy disks. She comments,

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[38] David M. Levy, *Scrolling Forward: Making Sense of Documents in the Digital Age*, New York: Arcade Publishing, 2001: 151.
[39] David M. Levy, *Scrolling Forward: Making Sense of Documents in the Digital Age*, New York: Arcade Publishing, 2001: 151.

> The clear implication is that if we can become the information we have constructed, we can achieve effective immortality. In the face of such a powerful dream, it becomes a shock to remember that for information to exist, it must always be instantiated in a medium.[40]

The medium could be a page from a journal, computer generated maps used by the Human Genome Project or the Visible Human Project, or sequences categorized in a database. The point that Hayles wants to drive home is that abstracting information from its material base is a prior imaginary act rather than an act that captures some supposed essential quality of the material. Thus, we see the move to conflate human embodiment with a kind of digital embodiment as information begins to lose its body. Similarly, I highlight genetic information's ambiguity and multiple meanings. However, unlike Hayles, I aim to move beyond the 'imaginary act' in order to show instances in which it is constructed.

Here, Levy's work gives us further insight into the current work in the translating of bodies into code, work with which I am concerned in these particular biomedical informatic cases. In his discussion, the problem is not whether digital documents are material. Rather the problem is that of stabilizing digital documents, but what makes the problem of stabilization new is the 'just-in-time' character of these documents. This 'just-in-time' or 'on-demand' characteristic of digital documentation on the web is related to Levy's concern with the meaning of documents in relation to digital representation today. He queries whether the file is the document or the file plus the technical environment is the document.[41] In light of this problem, we are unsure what digital documents mean. Their ambiguity emerges largely from this character of being produced 'on demand,' to (re)produce or (re)present the document to us. Thus, in Hayles' example above, the medium could be any of the three stated above, journal, maps, or database – but it might be all of them as well, even though each provides different (re)presentations.

For my purposes, Levy's meditation on the nature of documents points to an importance convergence of these biomedical informatic projects with their virtual (re)presentations or presence on the world wide web that has not been taken up in the body studies that deal with biomedical technosciences today. This communicational device helps

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[40] Katherine Hayles, *How we became posthuman*, 1999: 13.

[41] By technical environment, Levy is speaking about both the hardware and software that represent the file in a perceptible form for us.

to make this bioinformatics endeavor a part of everyday life. Web presence plays increasingly larger roles in these emerging biomedical projects. At the same time, the presence of potential participants – and efforts to enroll them – is increasing as well. The move by DNA Sciences to actively recruit and work with participants online is one example of this.

I show instances in which the web presence of these endeavors actually reveal the continuation of the human (body/bodies) as invention rather than inventor, for example situations in which (potential) participants, site visitors, and populations are constructed even while the (web)site visitor 'interacts' with the site. My strategy was to take into account not only the local virtual spaces, but to highlight the spaces in which these virtual and non-virtual ones are entwined. The projects' initiators are situated in different historical and cultural milieus. The projects were initiated in different nations. Within the websites, the sponsors aim to appeal to specific potential participants identified to some extent through different markings at a national level – Icelandic, North American, British. However, as we saw, there were, of course, further markings added to these, such as dutiful citizens, patients, consumers, and/or cyber visitor, especially when sponsors appealed to visitors as individuals rather than part of a population.

The differences, or rather constructed choices, in individuals are especially important in an endeavor that promises individualized prescriptions to health and wellness through a computational, probabilistic scheme. Through hypertext and repeated visits, the visitor is even 'invited' or 'enabled' to participate in assembling the montage of his own person, at both the individual and collective levels. However, I show how there are constraints on such an endeavor. Nevertheless, while the virtual (re)presentations of potential participants incorporated these identifications, the predominant representation of the body in bioinformatics remains largely undifferentiated. The emphasis throughout the three projects' web presence is one of a universal highly regulated and validated informatic/genomic/networked body, hiding particularities of the living body in specific cultural and historical contexts. Further, the (re)presentations reveal the – already decided – biogenetic informational individual as the dominant aim of this invention. This is further hidden by the discourses of the future (or rather, deferred and absent) promises of health and predictive medicine for each individual. In other words, although the potential participant, or each individual body, becomes the 'figure,' each is mirrored, or 'refracted' and displaced, by a universal figure of the future or deferred 'genomic body.'

Importantly, Levy wants us to seriously reflect on what documents mean, and Waldy wants us to reflect on what the body means, in this digital age. I add the need to consider what representation and practices of life mean in the digital era. Specifically, I want us to consider what the living body/subject means in this digital and networked age in which there are the increasing drives to vivify information and produce multiple forms of bio-value at all stages of (everyday) life.[42]

In a work written in the mid 1990s – just prior to the major growth of the internet – Dorothy Nelkin and Susan Lindee considered the spread of 'genetic essentialism' in American (U.S.) popular culture. However, their study leans towards the popular misconception and misrepresentation of the gene in the public (non-scientific) realms.[43] Here, I want to point to two aspects of (web) representations that follow Haraway's work on gene representations.[44] The first is that not only can genes – and genomes – be misrepresented. People can be misrepresented as well. Second, popular culture includes scientific activities whether inside laboratories, physical infrastructures, journal pages, and websites. In addition, the enrollment of broader publics to work at their own bioinformatic body/life continues to grow in speed and efficiency. The new communicational networks facilitate the increase and spread. Further, the displacements are rapidly effaced, replaced by the inevitability and necessity of these projects.

In (re)presenting these bioinformatics endeavors to the broader audience, upon arriving at a website, the visitor is presented with stable and static representations of these emerging projects. Over the course of time, the project's objects are absent to varying degrees as the project develops, but these shifting states can occur even during the course of one visit as the site visitor maneuvers through the site/s. Further, these complex assemblages of (re)presentations of databases, populations, individual participants, and

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[42] Unlike some media theorists today, most notably Friedrich Kittler, I do not want to make the sweeping claim that media determine our situation. See, e.g. Kittler's *Gramaphone, Film, Typewriter*. However, I would agree with Kittler's position on the materialities of communication. Further, as I have argued throughout this dissertation, media technologies, specifically, internet technologies, deserve more serious consideration in exploring how we perceive (in terms of understanding and practice) these biomedical informatic projects today. By treating the websites as social spaces and the projects as complex assemblages, I avoid the technological determinist interpretations of theorists like Kittler who write about the materialities of communication.

[43] Dorothy Nelkin and Susan Lindee, *The DNA Mystique: The Gene as a Cultural Icon*, New York: W.H. Freeman, 1995.

[44] In particular, see Haraway's discussion of gene fetishism and her analysis of advertisements from scientific journals in *Modest Witness*.

genomic medicine can be simplified. The manipulations and indirections are erased in and through the sites' (re)presentations over time. Or, the ambiguity and complexity created through links offsite can be shuttled into a disclaimer or shifted, becoming the responsibility of another site. However, the site visitor is also 'given' or called upon to assemble the meaning(s) of the projects for themselves in order to ascertain and (re)produce their role(s) in them. *Real*istic endeavors are achieved with the enrollment of the site visitor. These sites are political structures and public performances of socio-technoscience today in which knowledge, practices, and subjectivities are made.

In the bioinformatic turn, the perceptible forms of the body, health, and life are translated into the bits and bytes of digital representation. These translations of the human body into code raise the problem of what the organism is or what can be understood, that is, made perceptible, from these digital representations. However, we may be moving from thinking of the 'digital file' in the database that aggregates the data as the *real* body or the organism to a networked notion in which the 'digital file' plus the technical environment as living bodies. However, we need to go beyond Levy's reflections, insights, and queries about the meaning of document to consider how in the increasing vivification of information, what place is there not only for the material substrate – the body (the problem that Waldby takes) up, but consciousness and embodiment.

6.5 > Avenues of exploration

6.5.1 > Information insights

Ronald E. Day, in his *The Modern Invention of Information*, provides an attempt at a critical survey history of information in the modern age.[45] Day considers four case studies – early 20th century European documentation, mid-20th century US and UK cybernetics and information theory, more recent virtual and collective knowledge writings of today, and critical perspectives. He examines how proponents of the social importance of 'information' wrote and spoke about 'it.' He argues that the use of "information" as a synonym for "fact"

[45] Ronald E. Day, *The Modern Invention of Information: Discourse, History, and Power*, Carbondale, IL: Southern Illinois University Press, 2001.

or "knowledge" is a relatively recent phenomenon and describes how that evaluation came to construct a historical, or determined, future until today.

Day takes up the issue of virtuality in the works of Pierre Levy and the trope of utopianism in his works as well as those of Warren Weaver, Norbert Wiener and the European documentalists Paul Otlet and Suzanne Brier. He illustrates how these authors and 'proponents' of information marshal this and other such tropes to further their professional ends. I concur with his account of the current fetishism of information. However, my dissertation contributes to the growing literature on information today by providing more detailed and empirical illustrations of how (bio)-information is created in areas forming in the life and medical sciences today – in our 'information age.'

The question of how information is made and construed to be understood and practiced through relations-building between (database) experiment/er and subjects and (re)-presentations of the database (projects) through the web is important. This is because the question highlights how those with different social powers are permitted, can, and/or do negotiate contemporary restructurings of time/space to marshal authority or warrant to represent (some thing/way/place/time). In the matters of medicine and health, I suggest that this may be a new regime of representation for life sciences and it maybe shifting experience in these sites.

I showed some of the results of these bioinformatics technosciences in the making. What emerges are the (re)presentations or constructions of technoscientific objects and subjects: database endeavors, (genetic) information, populations, and (potential) participants. However, here I want to draw attention to 'genetic information.' A central problem with current frameworks used for addressing these databases is the uncritical use of 'information.' In the biomedical context, this results in the seamless flow from tangible 'lively' bodies to static information about them. I employed the concept of relationality between subject, information, and experiment in the databases in order to highlight the work involved in (re)configuring a seemingly seamless flow.

An expansion of gene information occurs. In all three sites, gene information is circulated with non-gene information, intertwined with considerable amounts of personal, private, and public information about individuals, families, and populations. This expansion of information also occurs in regulatory and legislative efforts in some regions. Although I could not pursue the point in this dissertation, I note that in legislative and regulatory

settings, 'information' circulates together with the issues of commodification, property rights, and privacy. In the websites, information circulates with the issues of genetics, individual bodies, families, databases, disease, media, and the setting of boundaries between public and private. These areas are not mutually exclusive, particularly today. Therefore, this engaging with the web material, which (re)presents 'information' quite differently than it is presented, helps to demonstrate multiple constructions and locate specific constructions of information. Having drawn attention to these practices, I confine most of my discussion to my focal concern, which is the construction and structuring of relations between experiment, objects, and potential subjects.

I see the work here as facilitating further research in this area. As the case studies illustrate, there are overlaps between issues that have been of particular concern in regulatory arenas and those circulating in the websites. I would like to explore these concerns in later work.

The questions for further exploration in these regards are:

- How does tangible, personal DNA become intangible, alienated information as it circulates in virtual realms?
- How does information become defined/characterized as fact, knowledge, thing, and value?
- How does virtuality fit into the scenarios set into motion by proponents of this project? Virtual (objects/subjects)? Public/private information/spheres?
- How do possibilities become conflated with potentialities?
- And, how are human bodies increasingly being defined by information?

These websites and their representations will not directly influence science and/or public policy. However, this dissertation highlights the importance of certain issues, especially those concerned with politics and policy of emerging biosciences. The importance of politics and policy is particularly clear in dealing with issues concerning representations, power, and meaning(s) of (genomic) science and information. However, as I have shown, the representation of information is currently negotiated (and contested). I showed that these representations are multiple and uncertain and deployed as such – especially when multiple audiences are involved. Furthermore, taken out of the database and into the process, where relational aspects are sought, I attempted to indicate that database

information is something –else- other than 'information' embodied. This is no small matter, and one that requires more research and fuller treatment than I can adequately provide in this project. To continue to ignore this area of research would be a tragic flaw in attempts to understand biomedicine, communication, and the place of information in our cultures today. These sites work to legitimize and produce knowledge and expertise. They are expressions of power.

6.5.2 > Limitations and future work

This dissertation project, limited financially, temporally, and geographically, would have benefited if the websites were studied individually at the actual project sites. Ideally, they would still be comparatively examined. In addition, I would have included projects from other nations, especially some outside of Europe and North America. Further, this work is limited by the lack of academic studies on the areas of bioinformatics, website analyses, or database studies. Therefore, there is little pre-existing research for background analysis. In addition, there are few theoretical or empirical sources to draw on in the area of emerging practices and hypertextual analyses. I do hope that this project will be contributing to a growing number of studies in all of these areas, which I believe need more critical engagement. While emerging, I hoped to demonstrate that these practices are here but still shaping rather than shaped.

The three database projects whose web presence are the objects of this study are all currently in different developmental stages. These projects are also based in different nations, and are creating different spaces in which their projects take place. However, while each would make a good case study on its own, by examining all three I have addressed issues that are better understood qualitatively (that these are matters of kind rather than degree), but also better illustrated by using more than one case.

This approach was partly strategic as well as practical. Several cases permit a comparative perspective. Further, the larger issues that I sought to understand (e.g. the specificities of virtual realms, varied representations, global/standardized and personalized/individualized medicine, expertise and public/private relations and contests in emerging technosciences) are better suited to a qualitative multiple case studies approach.

DNA Sciences, a private endeavor that uses its website to recruit subjects, provides a useful example to investigate issues of the web in clinical research and experiment. The DeCODE case provides a better platform for which to explore issues of representation in a project that is more developed and known than the others. Lastly, the (public) BioBank UK case provides a chance to explore representational acts of a project in its conceptual phase. Deploying the sites comparatively permitted me to explore not only how different objects but also different subjects are created, and to emphasize the specificities of each site in relation its projects.

The facts, above, alone should make us wonder about how typical and generalizable these endeavors and their sites are. Such examples and the analyses of these projects highlight:

(a) That any universal claim made for generalizability from the specific situations of any of these emerging large-scale database projects to other such projects requires investigation;

(b) That the manner in which we should extend our thinking about supposed globalizing of technosciences, especially biomedical sciences and clinical practices, require further investigation; and

(c) That the role of the web and internet in medical practices and clinical research requires further investigation. In terms of cyberspace, this means at least, the specific 'real,' local, national, and social context, and the interactions of the spatial and temporal dimensions should be more critically examined.

These problems require some rethinking and retooling of methods – from theoretical/conceptual frameworks to practices – to explore how such initiatives do work. In this dissertation, I provided and worked through one approach to this task.

The fact that these projects are in some ways similar, and yet have some very different meanings and practices illustrates the importance of local culture – even in virtual realms!

Sources constrain all research. My analyses of these databases and their virtual (re)presentations were especially limited by

1. Their emergent stages. All these projects, sciences, and technologies are in their infancy. As such they all were and continue to be, constantly shifting and in flux.

2. Proprietary knowledge. I was limited to public records, which currently, are especially limited (related to #1). The very issues that this project addresses – intellectual and material property rights, access, ownership, privacy and security – to some extent limit my sources.

Still, many interesting, important, and varied accounts of these projects, put forward by those who are invested in their processes and development, exist and may be told. This is especially the case in the virtual realms. Since virtuality was central in my case, it stands to reason that my sources lay primarily on the web. Web-based studies are in any case need to examine the increasing integration of various web and internet aspects into the life and medical sciences as well as clinical medicine. Furthermore, I should note that many of these sources may be lost if they are not archived. As pages are altered/updated, materials are lost/deleted. This is just one aspect that is, at the very least, uncommon in other forms of media representation. In addition, the web's mostly public and popular face is, I would argue, a unique interface, today, to explore emerging technosciences, in which varied and various actants participate in argument, negotiation, and practices to define, characterize, and seek to stabilize certain aspects and kinds.

It was beyond the scope of this project to explore in detail representations of race, class, and gender. I would note here that the issue of gender is conspicuously absent in the representations of these projects. Race, ethnicity, and socioeconomic status are only incidentally discussed in the BioBank and DNA Sciences' projects websites. Further, these tend to be represented – unproblematically – in more technical portions of their sites or in separate documents. In these sites, where disembodied information predominates, gender, however, appears to have become an obsolete category. Rather, in many of the (re)presentations, genetics seems to only affect women through the implementation of genetic practices. In deCODE's website we have the image of the grandmother and grandson. In DNA Sciences' website we have three women – in the FamilyGenetics space – representing potential participants and recruiters. In the deCODE website, we do have photographs of women techno/scientists. However, there are no women on the management team.

On a broader note, web-based research is an important and fruitful arena for researchers studying policy and politics of science or those interested in decision making in the area of emerging biomedical technosciences. Too many discussions are deferred for

tomorrow, when supposedly science is (more) certain and technologies built. These websites do work today. Furthermore, the combined fragility of the webs representations with its increasing networks to many aspects of our lives makes the issues of studying and archiving its sites crucial concerns. Much more needs to be done in exploring how to interpret what is going on in the web and how they relate to the 'real' world and specific situations. In this project, I highlighted anxieties created here, at the cusp/borders/boundaries of material/informational/realities in a biomedical informatic context.

APPENDIX > Screen shots

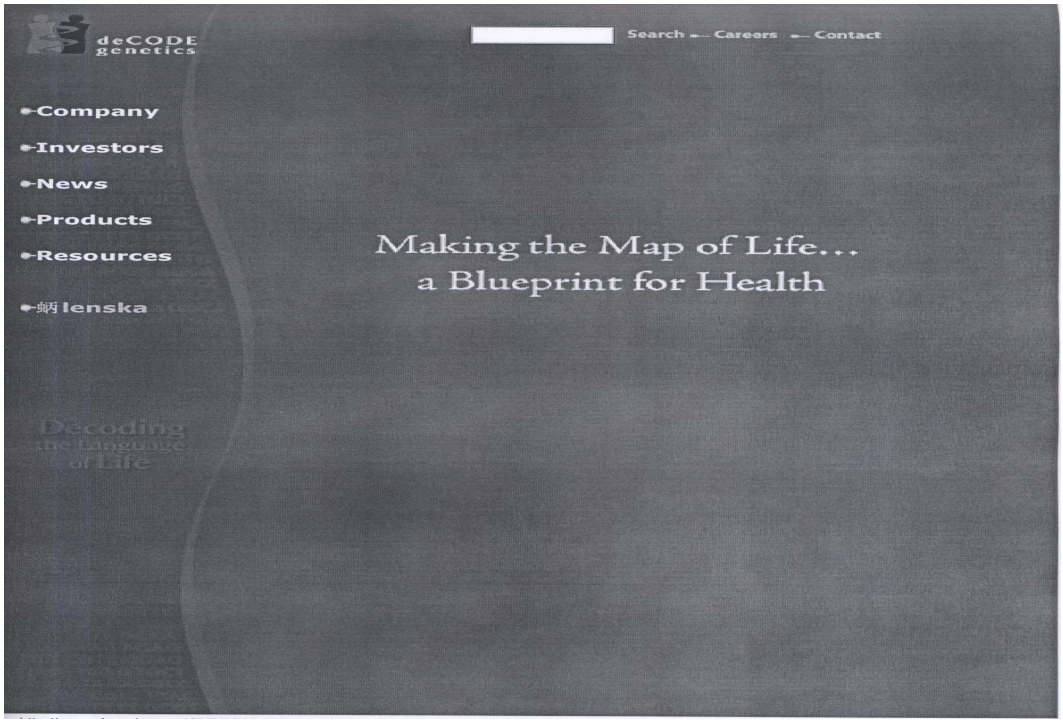

Diagram 1 an early version DeCODE, genetics homepage (dated May 7, 2002)

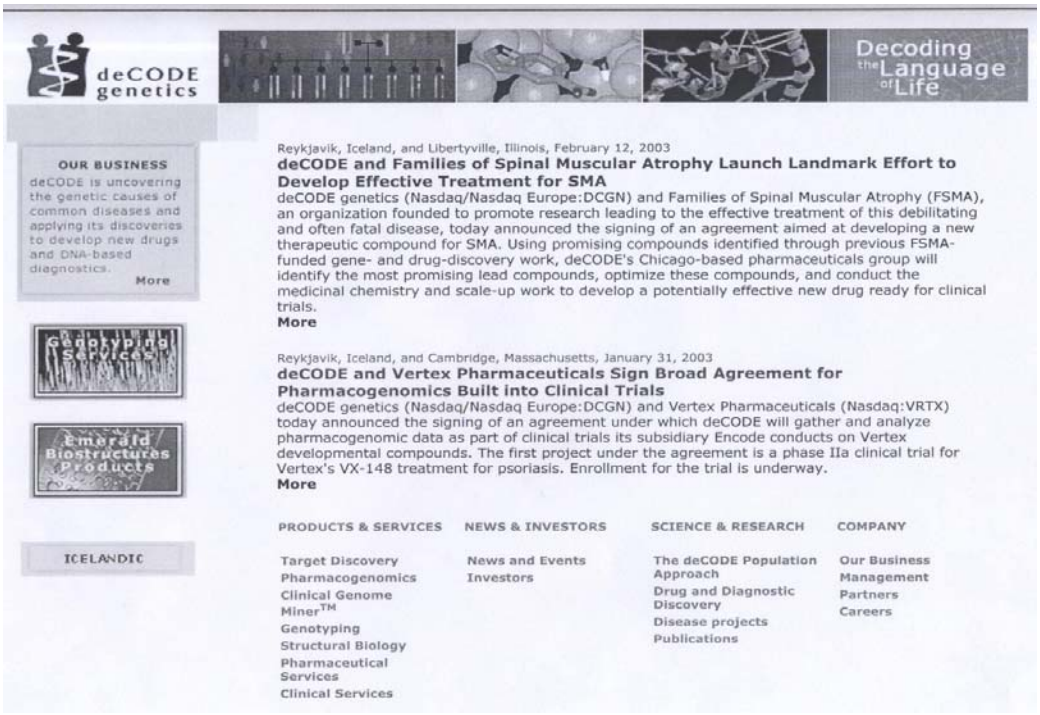

Diagram 2 a later version of DeCODE, genetics homepage (dated February 15, 2003)

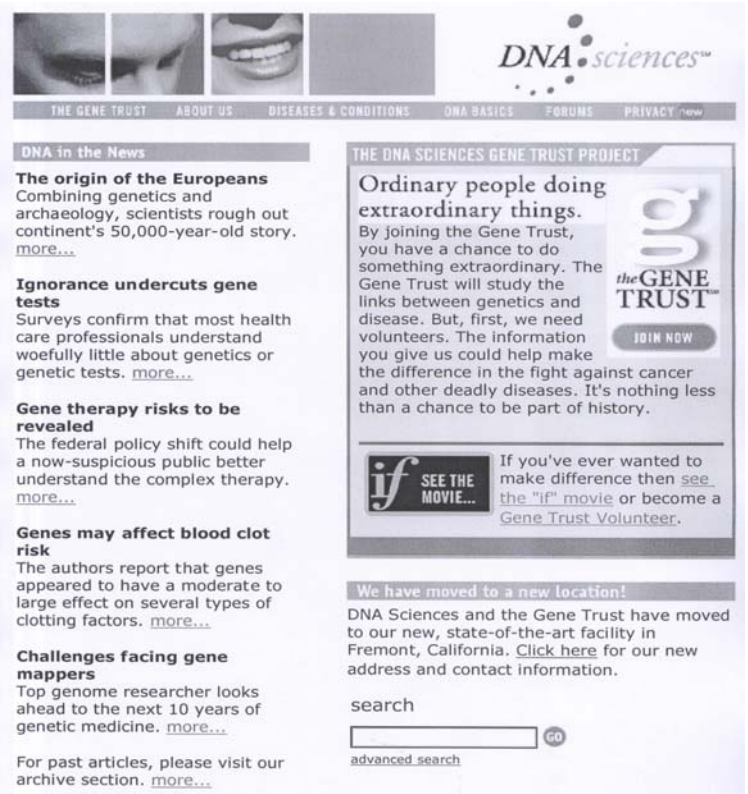

Diagram 3 an early version of DNA Sciences homepage (dated January 18, 2001)

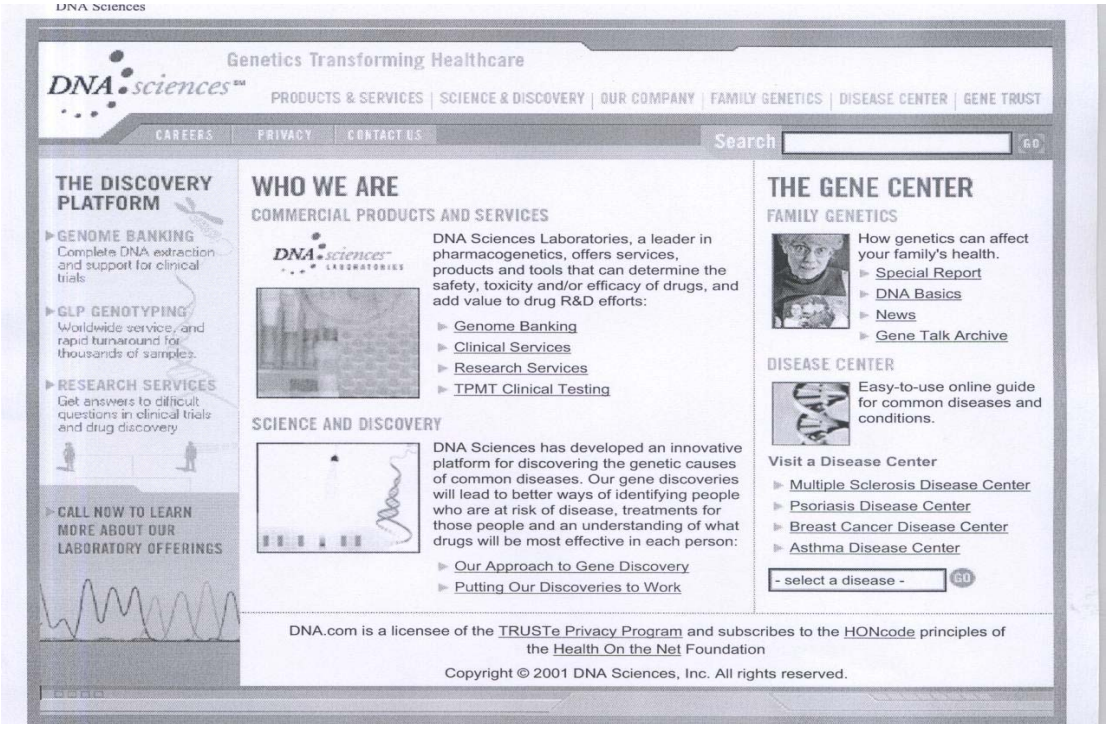

Diagram 4 a later version of DNA Sciences homepage (dated January 26, 2002)

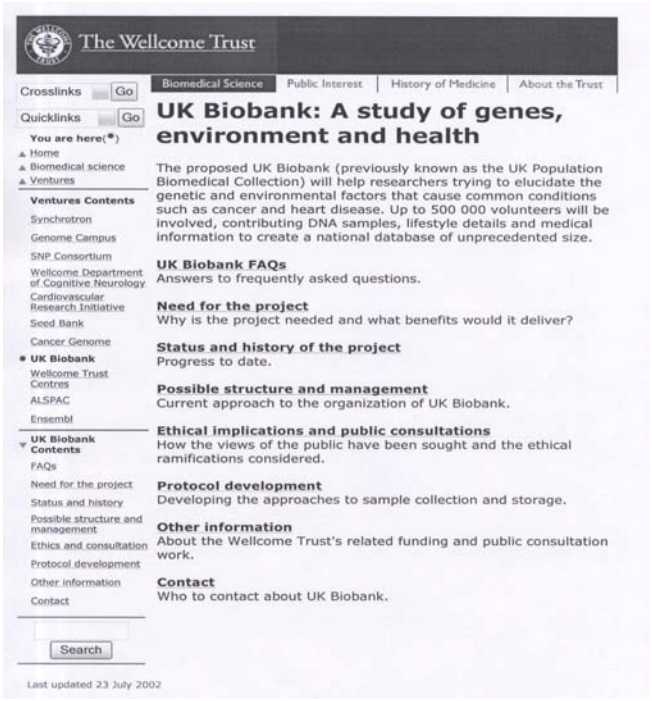

Diagram 5 The Wellcome Trust's Biobank homepage

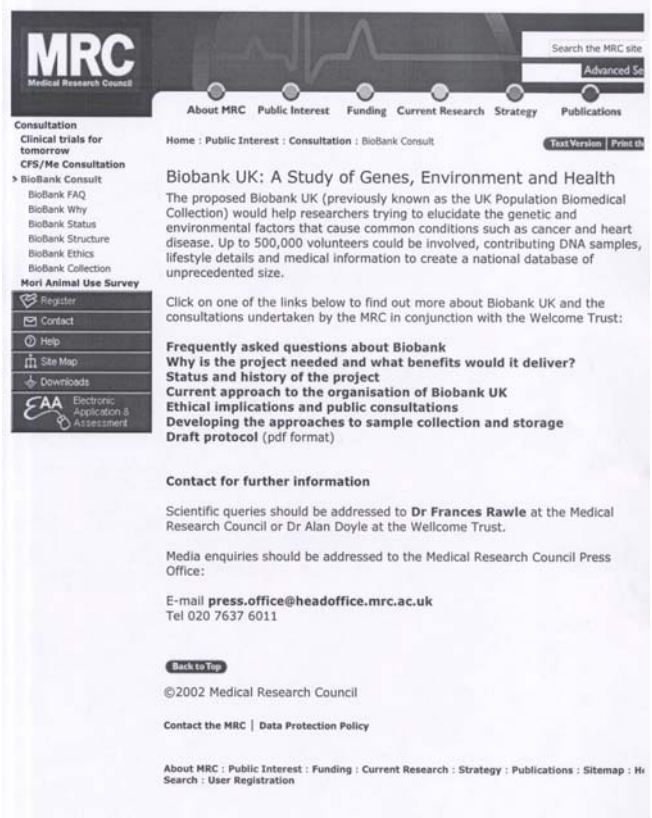

Diagram 6 Medical Research Council's Biobank homepage

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National Institutes of Health's National Human Genome Research Institute (NHGRI) website <<http://www.genome.gov>>

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The Medical Research Council website <<http://www.mrc.ac.uk/ >>.

Nutrition and Cancer Unit of the IARC <<http://www.iarc.fr/>>.

UK BioBank website << http://www.ukbiobank.ac.uk/>>.

PEI P. KOAY
pkoay@vt.edu

EDUCATION

- Ph.D., Science & Technology Studies (STS), Center for Interdisciplinary Studies (CIS), *Virginia Polytechnic Institute and State University*, Blacksburg, VA (1999 – 2003).

  Dissertation title: '(Re)presenting Human Population Database Projects: virtually designing and siting biomedical ventures.'

  Advisor: Richard M. Burian, Professor of Philosophy and Science Studies
  Committee Members:
  Timothy W. Luke, University Distinguished Professor of Political Science
  Ann F. La Berge, Associate Professor of Science and Technology Studies
  Saul E. Halfon, Assistant Professor of Science and Technology Studies
  Megan M. Boler, Associate Professor of Teaching and Learning

- M.A., History and Philosophy of Science and Technology, Institute for the History and Philosophy of Science and Technology (IHPST), *University of Toronto*, Toronto, ON – Concentration in history of biomedicine (1993-95).

  Master's thesis: a history of law and politics of early organ transplantation in the United States.
  Advisor: Pauline M.H. Mazumdar, Professor of History of Medicine

- International Studies Certificate, Summer Certificate Program in International Studies and Affairs, *New York University*, New York, NY (Summer 1996).

- B.A., Liberal Arts concentration in Science, Technology, & Power, *Eugene Lang College - The New School for Social Research*, New York, NY (1989-93).

  Senior thesis: a history of the interactions of physics and biology in nineteenth century debates over the age of the earth.
  Advisor: Jean Le Corbeiller, Professor

RECENT WORK EXPERIENCE

- Teaching assistant: Political Science and Science and Technology Studies departments, *Virginia Polytechnic Institute and State University*, Blacksburg, VA 24061 (1999- currently).

- Digital bibliographer: Feminist Theory Website Project, Center for Digital Discourse and Culture, *Virginia Polytechnic Institute and State University*, Blacksburg, VA 24061 (Summer 2002).

- Freelance print editor and researcher: *Biography Magazine*, A & E Television Networks, New York, NY (Spring 1998- Summer 1999).

- International science and technology video news researcher and producer: 'High-Tech Shower International,' *Science Technology Network* (STN), New York, NY 10019 (Spring 1997 – Summer 1998).

- Adjunct faculty member: Liberal Studies Department, *Parsons School of Design - The New School for Social Research*, New York, NY 10011 (Fall 1996 • Fall 1997 • Spring 1998).

- Undergraduate academic adviser: Liberal Studies Department, *Parsons School of Design - The New School for Social Research*, New York, NY 10011 (Summer 1996 – Spring 1997).

- Assistant email administrator: Information Technologies Department, *John Wiley & Sons, Inc.*, New York, NY 10158 (1996).

TEACHING EXPERIENCE

- Course Instructor: Biomedical Technologies, the Self, and Societies, Liberal Arts Department, *Parsons School of Design, New School for Social Research* (Fall 1996 •Fall 1997 • Spring 1998).

- Teaching assistant: U.S. Government & Politics, Political Science Department, *Virginia Polytechnic Institute and State University*, Blacksburg, VA 24061. (Fall 2000 • Fall 2002 • Spring 2003).

- Teaching assistant: Comparative Politics, Political Science Department, *Virginia Polytechnic Institute and State University*, Blacksburg, VA 24061 (Spring 2001 • Spring 2002).

- Teaching assistant: Humanities and the Life Sciences, Science & Technology Studies, *Virginia Polytechnic Institute and* University, Blacksburg, VA 24061 (Fall 1999 • Spring 2000).

RESEARCH EXPERIENCE

- Science and technology video news archiving, *Science and Technology Network*.
- Interviewing background information for science and technology news stories, *Science and Technology Network*.
- Internet and website archiving.

COURSE DESIGN EXPERIENCE

- Global Environmental Issues, Political Science Department, *Virginia Polytechnic Institute and State University*, Blacksburg, VA, 24061 (Fall 2001).

- Comparative Politics, Political Science Department, *Virginia Polytechnic Institute and State University*, Blacksburg, VA, 24061 (Fall 2001).

- Biomedical Technologies, the Self, and Societies, Liberal Arts Department, *Parsons School of Design, New School for Social Research*, NY, NY 10011 (Fall 1996 • Fall 1997 • Spring 1998).

CONFERENCE AND PRESENTATION EXPERIENCE

- 'Space, Ethnicity, and Velocity,' moderator, Southeastern Women's Studies Association Meeting, SEWSA 2003, *Gender and Technology: Research, Revisions, Policies, and Consequences*, Blacksburg, VA (March 20-22, 2003).

- 'Genomic States,' Conference on the History of Human Experimentation during the 20th Century, *Institut für Medizin- und Wissenchaftsgeschichte*, Lüebeck, Germany (May 18-20, 2001).

PUBLICATIONS

- 'Icelandic (Ad)'ventures: new research? new subjects? new ethics?,' *Advances in Bioethics* 8 (forthcoming).

WORKSHOP/SEMINAR ORGANIZATION EXPERIENCE

- Volunteer assistant, *Choices and Challenges* forum (Spring 2003), 'Big Brother Technologies,' Science and Technology Studies, *Virginia Polytechnic Institute and State University*, Blacksburg, VA.

- Organizing committee member, *Technologies/Moralities: On the Ethical Grammar of Technological Systems*, workshop (March 2003), Science and Technology Studies, *Virginia Polytechnic Institute and State University*, Blacksburg, VA.

- Volunteer assistant, *Choices and Challenges* forum (Fall 2000), 'Public forum on Reinventing the Human," Science and Technology Studies, *Virginia Polytechnic Institute and State University*, Blacksburg, VA.

- Co-coordinator, *Science, Technology, & Gender Seminar Series*, Institute for the History and Philosophy of Science and Technology, *University of Toronto*, Toronto, ON (Fall 1994- Spring 1995).

AWARDS/GRANTS

- Travel Grant, *Institut für Medizin- und Wissenchaftsgeschichte*, Medizinsche Universität, Lüebeck, Germany (May 18-20, 2001).

- Foreign Student Scholarship, Graduate School, *University of Toronto* 1994-5.

- *Eugene Lang College* Grant Award, *The New School for Social Research*; recurring 1989-93.

INTERNSHIP EXPERIENCE

- Research and writing intern, *Environmental Protection Encouragement Agency*, New York, NY (Summer 1991).

LANGUAGES

- Spanish
- French (reading ability)
- Mandarin (comprehension)

CURRENT RESEARCH INTERESTS

- interdisciplinary approaches to politics and policy studies of science & technology
- emerging biomedical technologies and sciences
- history and cultural studies of the body
- public education, participation, and understanding of science and technology
- representations/metaphors/discourses/politics of information, identity, and life (especially genetics)
- technologies of representation (especially internet and web-based)