Democratic Mis-haps: The Problem of Democratization in a Time of Biopolitics

Jenny Reardon

Department of Sociology, University of California Santa Cruz, 235 College 8, Santa Cruz, CA 95064, USA
E-mail: reardon1@ucsc.edu

Abstract

Following the stringent critiques of organizers of the Human Genome Diversity Project for excluding people from the initiative's early planning, subsequent administrators of high-profile efforts to study human genetic variation, such as the International HapMap Project, have made great efforts to stress the importance of including the people who are to be the objects of study in research design and regulation. Such efforts to 'democratize' genomics would appear to represent a positive development. However, in practice they have satisfied few as they fail to recognize the most basic lesson of the Human Genome Diversity Project debates: genomics raises questions not just about the inclusion of people, but about their very constitution. Positing concrete, stable subjects in society, current efforts to 'democratize' genomics fail to recognize that entangled in the fundamental questions about nature posed by this emergent form of technoscience are fundamental questions about the order and constitution of societies. The creation of sustainable and desirable forms of governance require us to come to terms with challenges posed to liberal democratic practices and values, such as inclusion, in an age defined partially by this mutual dis/ordering of nature and society.

Keywords biopolitics, co-constitution, genomics, democratization, publics, race

In the worlds of science-in-the making in which I think and act, in recent years I have found myself surrounded by a surprising number of allies. These days, many in the arena of human genomic variation research require little convincing that the ideas and practices of this domain of research raise complex and vexed questions about how to order and value human beings in society. Not only do genome scientists and policy-makers acknowledge these connections, they have initiated concrete changes in practice. In particular, some in the highest posts of genomic administration (program officers at the National Human Genome Research Institute in the United States, lawyers who pen ethical protocols to guide

Jenny Reardon is an Assistant Professor of Sociology and a Faculty Affiliate of the Center for Biomolecular Sciences and Engineering at the University of California, Santa Cruz. In her research, Reardon seeks to extend our emerging understanding of how science and the social order are co-produced, and to explore how such understandings might help us to more adequately address questions of social justice in a technoscientific age. She is a primary organizer of a two-year Science and Justice Initiative at the University of California, Santa Cruz. Her book, *Race to the finish: Identity and governance in an age of genomics*, was published by Princeton University Press in 2005.

genomic practices globally, etc.) have in recent years argued passionately, persuasively and persistently that if genomic ideas and practices for knowing the order of nature alter and change the conditions of people's lives around the globe, then these diverse people should have a say in how this research is designed and regulated (Greely, 1997; International HapMap Consortium [IHMC], 2003, 2004).[1] In short, administrators of large public human population genomics projects today call for the democratization of this emergent field of technoscience.[2]

Most notably, in 2003 organizers of the International Haplotype Map Project (HapMap)—a transnational effort to sample the world's human genetic variation—announced that it had instituted 'a process of community engagement, or public consultation' in order to 'give people … input into such issues as how the populations from which the samples were collected would be named' (IHMC, 2003: 792).[3] Many who worried that the HapMap would repeat the problems of the Human Genome Diversity Project—a project that sought to sample the DNA of indigenous people, but failed to include any indigenous people in the initial planning of the project—celebrated this decision.[4] If the problem of genomic governance demonstrated by the Diversity Project had been one of expert-controlled decision-making, and the solution one of narrowing the gap between experts and people, then this move to give people (here figured as 'communities') more of a say over the design and regulation of genomic studies represented a step in the right direction.

Although in many ways innovative and promising, this effort by a major international genomics project to become more inclusive and participatory has left many of 'the people' asked to take up the new participatory roles, and many of the bioethicists and social scientists who originally had been so enthusiastic, disgruntled.[5] In this article, I seek to demonstrate that this disgruntlement follows from HapMap organizers' difficulty acknowledging and addressing a fundamental question provoked by the emergence of the life sciences as an important site of governance—that is, as an important site for the formation of contemporary selves and citizens (Foucault, 1997a; Haraway, 1991; Rose and Novas, 2005). Namely, in a world characterized by practices such as genomics, practices that are knitting people from around the globe together and pulling them apart in novel ways, who are 'the people' who can legitimately play a role in governing genomics? Positing inclusion and participation as the solution to the problems of genomic governance, this crucial question about the constitution of 'people' with whom the HapMap Project could engage largely fell outside of organizers' critical vision. Thus, they missed a central problem of governance they would ultimately face: a problem that emanated in the first instance not from the failure to include people, but from a lack of reflection on how a 'people' could form who could be engaged by the study.

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1 These administrators conveyed their passion and enthusiasm for these new roles for research subjects in their interviews with me (Author's fieldnotes).

2 By 'democratize' I mean efforts to include 'people' in decisions normally made by 'experts'. See, for example, Arditti *et al.* (1980), Clarke *et al.* (2003) and Treichler (1987).

3 For an official description of this project see IHMC (2003) and www.hapmap.org (accessed September 2006).

4 For an account of the Human Genome Diversity Project, and the controversies surrounding it, see Reardon (2005).

5 Some of the bioethicists and social scientists I interviewed even went so far as to state a desire to dissociate themselves from the HapMap (Author's fieldnotes).

As we will see, this problem was not just a problem for the project's creation of a viable system of governance, but also for its ability to create knowledge about human genetic variation. Answering questions about who should be sampled in order to represent human genetic variation (what populations? what individuals within those populations?) entailed answering questions about who can 'stand for', and who can 'speak for', the sampled genomes. In other words, project organizers' ability to discern and name their initiative's objects of study depended upon their capacity to discern and name the subjects who could speak for those objects. Thus, their community engagement entailed more than just communicating 'the science', it proved central to the conceptualization and design of the proposed research. Going around the central question it posed—who are 'the people' that can be engaged?—produced confusion and consternation not only about the definition and status of the subjects in society the project engaged, but also about the populations 'in nature' it sampled.

I suggest that these mis-haps of democratization raise more general questions about governance and democracy in a world where technoscience acts to transform the very concepts upon which Western liberal democratic thinking is founded: *individuals*, *communities*, *people*, *participation* and *inclusion*. In particular, it raises questions about what democratization of human population genomics might mean if this emergent form of technoscience is itself involved in making up the very 'people'—individual and collective—upon which its claim to democratic governance depends. No longer, I argue, is it possible to turn to democratic principles and practices as if they exist in a separate domain, ready to be applied to an undemocratic, expert realm of science. Democracy is not something separate from science, something that can be done to it—as the term *democratize* implies. Rather, in this technoscientific age in which we live, democratic ideas and practices are made along with scientific ideas and practices.

In such an age, I suggest, energies are best spent not on energetic calls for democratization, but on the more subdued task of analyzing how democratization happens—what logics underlie it, what practices make it up. Such efforts might do at least two helpful things. First, they would generate knowledge about the ways in which genomic ideas and practices act to constitute people, publics, voice, representation and participation, and thus the minimum understanding needed to begin to clarify the problems of governance that these consequential acts of constitution pose. Second, they would afford the opportunity to make decisions about how collectivities form and become invested with the power to speak for and govern genomic resources. By their very logic, current efforts to democratize genomics locate agency in a 'we' or a 'people'. Yet, in the case of genomics—a set of practices that are differentiating and aggregating people in novel ways—increasingly there is no self-evident 'people' that exists to take up this task of democratization. Thus, to merely assert a 'we' is to render invisible crucial questions about how and whether 'a people' should form to regulate genomics.

Michel Foucault said in an interview late in his life, '[T]he problem is, precisely, to decide if it is actually suitable to place oneself within a 'we' in order to assert the principles one recognizes and the values one accepts' (1997b: 114). The operative word here is 'decide'. I want to suggest that it is, ironically, only by suspending temporarily offers of inclusion and participation that we might create the conditions for reflective decisions about how and whether we take up the we's, the slots for collective action, offered to us in our technoscientifically mediated worlds.

Documenting democratization-in-action

I base my observations in this article on participant-observation at sites and meetings where the HapMap's 'community engagement' policies and practices formed, as well as on over 30 semi-structured interviews conducted with organizers of the International Haplotype Map Project between 2004 and the present.[6] This study of the HapMap follows from my earlier study of the Human Genome Diversity Project (Reardon, 2005). The Diversity Project figures in most contemporary discussions of it as an exemplar of what can happen if organizers of genomic studies of human groups fail to attend to the ethical and political dimensions of their practice. Despite the attempt by genome researchers to establish human genomics as a new science untainted by politics, the formation of human genomics has been indelibly marked by a history of blatant examples of the ways in which social institutions' labeling of human beings as different can act to render them disposable. Most notably, Nazi uses of biological claims about human difference to justify population extermination left many questioning the very project of drawing distinctions among human beings (Minow, 1990). Population geneticists and their colleagues in anthropology responded to these concerns with intense debates about the meaning and proper role of 'population' and 'race' in ordering studies of human biological diversity—debates that began in the interwar period, and continued through to the decades following World War II (Dobzhansky, 1962; Livingstone, 1962). Convinced that the issue at stake was one of separating out the world of 'science' from that of 'politics', these students of the human sciences focused their efforts on deciding what could constitute a legitimate 'science' of human beings: anthropology or genetics; studies of clines or studies of populations, etc. (Reardon, 2004; Reardon, 2005). The Diversity Project case significantly disrupted this post-World War II faith that keeping science apart from politics could secure the validity of biological studies of human beings.

In the early 1990s, organizers of this initiative proposed to conduct a massive worldwide survey of human genetic variation through sampling indigenous populations before they 'vanished' (Cavalli-Sforza *et al.*, 1991). Yet, despite their interest in studying indigenous populations, two years into the planning of the project, they had informed no indigenous group about their proposed initiative. Thus, not surprisingly, many indigenous rights leaders accused the project of treating them like objects they could study, not subjects with whom they were obliged to consult (Reardon, 2005: 105–108). Organizers defended their decision not to include representatives of indigenous rights groups, saying that there was not yet a Diversity Project. The project, they argued, was still in the planning stage, and at that early

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6 This research is part of a three-year study funded by the US National Science Foundation called 'The paradoxes of participation: The status of "groups" in liberal democracies in an age of genomics'. This study entails a multi-sited ethnographic study of 'democratization-in-action' that compares three different sites where those charged with administering human population genomics seek to include 'populations' as 'participants' in the review and regulation of research: (1) the National Institute of Health's International Haplotype Map (HapMap), which uses 'community engagement' as a participatory form and locates the authority to define groups in the state; (2) partnerships between historically black colleges in the US and the US National Human Genome Research Institute, which uses the concept of a contractual partnership between researchers and researched; and (3) the Native American Research Centers for Health, which use a theory of sovereignty for defining groups and participation. Additionally, the research forms part of a study of global genomic governance called 'Genes without borders? Towards global genomic governance'. For a description of this latter project, see Genes without Borders (2006).

stage, only *scientists* could meaningfully contribute.[7] Members of indigenous groups strongly disagreed. In particular, they argued that the project's description of indigenous people as 'vanishing' or 'disappearing' demonstrated the profound political content of the project's purportedly apolitical discussion of so-called matters of science. After decades of effort working for the recognition of the existence of indigenous people, many indigenous rights activists found maddening Diversity Project organizers' claims that indigenous people were about to become extinct. Far from discovering new truths about the world, and humans' place in it, they argued that the project was poised to remake the world in a manner that would render their lives invisible, and thus unlivable. Viewing the project as a threat to their very existence, and a source of new forms of racism and colonialism, numerous indigenous groups issued declarations against the project. In December 1993, for example, the World Council of Indigenous Peoples labeled the Diversity Project the 'Vampire Project'.[8]

  Mired in controversy, the Diversity Project received no further support from the US government.[9] Further, motivated by fear that any association with the initiative would undermine their own efforts to study human genetic variation, US government administrators of human genome research made every effort to distance themselves from it. When National Institutes of Health (NIH) officials did venture to propose their own initiative to study human genetic variation in the late 1990s, by all accounts, the problems of the Diversity Project still weighed heavily on their minds. Seeking to avoid the mistakes of this much maligned initiative, they placed a heavy emphasis on their intention to include the people they hoped to sample in the planning of their own initiative.[10] Far from a racist or oppressive enterprise, they argued that their project would adhere to democratic principles of inclusion and participation. In particular, through a process its organizers named *community engagement*, they would not just consult, but engage communities, giving them the opportunity to 'provide input into the informed consent and sample collection processes—and into such issues as how the populations from which the samples were collected would be named' (IHMC, 2003: 792).[11]

7 Organizers argued that one needed to know what the scientific project was before discussing the ethics of it. They did not recognize that this very effort to form a scientific agenda raised fundamental ethical and political questions. For a discussion of these points, see Reardon (2005).

8 For a more thorough description of the opposition to the project see Reardon (2005: 103–106) and Indigenous Peoples Council on Biocolonialism (n.d.).

9 An initiative that closely resembles the Diversity Project in goals and principal organizers does move forward with support from IBM and National Geographic under the name Genographic (NationalGeographic.com, n.d.). This project has sought to revive the goals of the Diversity Project, drawing upon many of the same ideas and performances of participation as the HapMap. I analyze this initiative in the context of the larger study of 'democratization-in-action', of which this analysis of the HapMap is a part.

10 Community engagement/consultation figured centrally in all official project descriptions (see IHMC, 2003, 2004).

11 Many project documents and organizers of the project flip back and forth between the language of 'engagement' and the language of 'consultation'. Some I interviewed explained that 'engagement' was intended to signal a commitment to integrating 'communities' into the decision-making process of the project in a way that could lead to 'meaningful' changes in the project's policies and practices. Not all agreed with this commitment, which may account for the use of both terms (Author's fieldnotes). Additionally, the project reported a preference for the use of the term 'public consultation' in Japan (IHMC, 2004: 471). The Coriell Cell Repository, where cell lines from the International HapMap are stored, uses the language of 'community consultation' (see Coriell Institute for Medical Research, 2004).

On the face of it, this proposal sounds sensible and straightforward: the Diversity Project demonstrated that organizers of genomic research do not always see the dangers their research poses to people; thus, the people who are subject to these dangers, and thus who are more likely to know what they are, should be involved in decisions about project design and regulation.[12] Yet, despite its clarity in principle, in practice a murkier reality emerged. In this article I attend to this practice, and in so doing seek to reveal some of the deeper ontological and political issues that underlie current efforts to democratize genomics through including 'people' in its design and regulation.

The International Haplotype Map: the challenges of democratization in an age of emergent biopolitics

To begin to understand these issues, let us consider the simple question: what is the International HapMap Project? If one looks at the official webpage of the project, one can read the following answer:

> The International HapMap Project is a multi-country effort to identify and catalog genetic similarities and differences in human beings. Using the information in the HapMap, researchers will be able to find genes that affect health, disease, and individual responses to medications and environmental factors. (IHMP, n.d. a)

This sounds clear enough. However, from its very inception, the project faced the same problematic, fundamental question faced by the Diversity Project: how do you catalog and identify the genetic similarities and differences of the human species? Do you sample individuals or groups? If groups, how do you define these groups?[13] Returning to the official website of the HapMap, a seemingly straightforward answer can be found:

> The International HapMap Project is analyzing DNA from populations with African, Asian, and European ancestry. (IHMP, n.d. b)

Hints of complexity, however, begin to emerge if one considers that 'African, Asian and European' strongly resonate with the racialized categories African, Mongoloid and Caucasoid that date back to the initial racial classifications of Blumenbach in the late eighteenth century. Yet, as multiple interviews with organizers of the HapMap revealed, project organizers resist this suggestion that racial categories played any role in shaping the initiative's sampling strategy. Consider the following exchange with a project organizer (PO):

> *INT*: Let me ask about what these populations in fact represent … . I imagine that if I asked you 'Can the samples be said to be representative of race?', you would say no.
>
> *PO*: Right.
>
> *INT*: And if I said it was representative of Africans or Chinese?
>
> *PO*: The answer would be no. (Interview with the author, 1 Dec. 2004)

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12 For a more detailed explanation of this rationale, see Foster (2006).

13 For a description of the troubles Diversity Project organizers faced answering these questions, see Reardon (2005).

When pushed to articulate how this organizer *would* describe the population that was sampled in Africa, the following conversation ensued:

INT: So, who could be considered a member of the population that was sampled when [the geneticist] and others went to Africa?

PO: [T]he criteria—I'm just guessing because I can't remember. The [sampling] criteria may include residents in this local community and self-representation as . . . Yoruba.

INT: Right. And so then that sample would only represent whatever the sampling strategy was? That's how you would define—

PO: That's what all samples represent, is just whatever the sampling strategy was. (Interview with the author, 1 Dec. 2004)

In an effort to distinguish their Project from the Diversity Project, most organizers of the HapMap deny that theirs is a project entangled in the complexities of race,[14] an ordering technology project documents deem 'a largely social construct' (IHMC, 2003: 793).[15] Instead, they emphasize their use of the exact tools of science to name populations: in this case, researchers' sampling criteria.[16]

The word the official website uses to describe the method behind this approach is 'precision'. As it explains:

The way that a population is named in studies of genetic variation, such as the HapMap, has important ramifications scientifically, culturally, and ethically. From a scientific standpoint, *precision* in describing the population from which the samples were collected is an essential component of sound study design . . . . From a cultural standpoint, precision in labeling reflects acknowledgment of and respect for the local norms of the communities that have agreed to participate in the research. From an ethical standpoint, precision is part of the obligation of researchers to participants, and helps to ensure that the research findings are neither under-generalized nor over-generalized inappropriately. (IHMP, n.d. c, italics added)

In interviews with me, and in their own writing, several project organizers stress the importance of this project commitment to precision. Indeed, one project organizer explained that, in the case of the sampling done in Africa, the project is 'not studying Africa'. The object of analysis is not even 'all the Yoruba; it's the 90 DNA samples from the Yoruba that we had' (interview with the author, 5 Sept. 2006).

However, such a position poses a significant problem: to claim the object of analysis is only 'the 90 DNA samples from the Yoruba that we had' is to insist on a degree of precision

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14 However, at least a few organizers did acknowledge that it was disingenuous to maintain that the project's sampling strategy lacked any connection to racial thinking. As one organizer explained this to me:

I think that there is no question that the sampling strategy was based on—somewhat on practical circumstances— but somewhat on sort of scientific . . . rationale, that you know, looking at people with different continental origins, which some people would translate into 'race', would be a way of getting, you know, sort of the maximum genetic diversity, sort of around the globe. (Interview with author, 1 June 2005)

Another just simply stated: 'It is by race: Black, White, Chinese, Japanese' (Interview with author, 7 Sept. 2006).

15 The adjective 'largely' allows these researchers to hold on to a 'scientific' concept of race. For more on the strategies genome scientists use to deny the validity of race while still deploying it, see Reardon (2004).

16 Diversity Project organizers also referred to 'researchers' sampling criteria' to answer complex questions about group identity. For the problems this move presented, see Reardon (2005: 114–122).

that would render the HapMap useless. As another project organizer explained to me (this time with reference to the sampling done in China):

> PO: If you sampled Han in Beijing Normal [University], and you sampled in Shanghai, and you sampled someplace way out west, and they were just terribly different from each other, and the tag SNPs [single nucleotide polymorphisms] from one just had no bearing on the other, then unfortunately we would have done a HapMap that had these four little points that were sort of useless for any other population.

> INT: Right. So in that sense, the samples collected in Beijing weren't just representative of those people, but … they were representative of something bigger than that, or the HapMap wouldn't have worked.

> PO: That's right. (Interview with the author, 30 May 2005)

As this organizer implies, the governments of the United States, Japan, China, Canada and England did not spend tens of millions of dollars to go to Nigeria or to China to learn something about 90 or 45 people (the number of people sampled in each place respectively). These people were picked with the hope that they would represent a larger group of human beings.

However, because the question of representation in human genetics (and now genomics) has been historically dangerous, understandably many organizers of the HapMap sought to avoid the issue altogether by either appealing to precision, or by declaring that 'the Project [did] not aim to define populations' (IHMC, 2004: 469). Yet, the whole point of the project was to *represent* human genetic variation in a manner that would allow researchers to 'determine common patterns of DNA sequence in the human genome' (IHMC, 2003: 789).[17] As the conversation cited above continued:

> INT: But you were trying to represent global diversity.

> PO: So then the question is how can you extrapolate from that [the sampling criteria], what's your rationale for extrapolating from that to other things? Yes. … Well, OK, the argument made there was that … if we had left African populations out altogether, we would have been ignoring not only the greatest diversity, but also the source of human diversity.

> INT: Right. So in what sense would it be wrong to say that the Yoruba population is supposed to be representing the African populations? The issue was 'We don't want to leave out African populations', like you said, 'so the way we're going to deal with that problem is we're going to sample Yoruba'. You didn't say 'Yoruba have the greatest diversity of human populations, so we're sampling Yoruba', you said—

> PO: So you could say it's not *the* strategy, I guess, but *a* strategy to get at that diversity— that greater diversity. Yes, you could say that. (Interview with the author, 30 May 2005)

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17 HapMap organizers' oscillation between claiming their samples were representative so as to establish the scientific value of their project, and denying that the samples were representative to avoid problems faced by the Diversity Project resembles the oscillation Hannah Landecker (1999) describes between cell biologists' claiming that HeLa cells could represent humanity, and then discrediting the link due to anxieties about race.

What did researchers come home with when they went to Africa and collected blood from 90 people in Ibadan, Nigeria? The DNA of the human species? Of a race? Of Africans? Of Yoruba? Of 90 people who lived in Ibadan, Nigeria? These questions about what the DNA sampled for the HapMap will come to stand for, and what categories of human beings it will help legitimate and materialize, have no clear answers at the moment. This in itself is not a problem. The problem is with HapMap practices, which intend to democratize (through inclusion and participation of 'people' sampled), but instead enable organizers to avoid accountability for the role their initiative plays in answering these questions.

These questions are important. They matter for many reasons—for the people sampled, perhaps foremost because they are entangled (as they were in the Diversity Project case) with consequential decisions about what kind of collective subjects exist in society, and thus who has rights of representation. Consider the following exchange between me and a HapMap organizer about how the samples collected in Japan would be labeled:

PO: In the Japanese case, there was an effort to make those criteria [for naming the samples] more specific. ... [T]hrough the engagement, through discussion with the Japanese ... [it became clear that] the community didn't want it more specific.

INT: Really? Why not, do you know?

PO: They thought—which is reasonable—that they didn't all come from this place in Tokyo, that they came from all these other different places, and so they shouldn't be labeled as coming from that place. (Interview with the author, 1 Dec. 2004)

Not all, it turned out, agreed on what it would mean to precisely define populations. In this case, for HapMap administrators, it meant identifying the population sampled in Japan with the city of Tokyo; those who gave samples disagreed. Given this, the question arises: what method can be used to adjudicate between different notions of accurate names of human groups? HapMap organizers, learning from the Diversity Project case, acknowledged that these names have implications for the people sampled, and thus concluded that those people should have a say in the naming process. This, however, only raised a new question: Who are 'the people', and who represents them? As the exchange continued:

INT: So ... I'm wondering in what sense these folks who were in the community engagement have the power to speak for 'the Japanese' on how the label 'Japanese' would be used.

PO: Well, let me rephrase that—you're asking the people who were the prospective donors to speak about how they wanted *their* samples labeled. So you're not asking them to speak for all Japanese ... but rather as the people who are being asked to make the sample donations.

INT: Right. But ... [there] is going to be a label 'Japanese' associated with genetic information.... And just like with Native American tribes, there's an issue of social identity here.

PO: I think we're going to try very hard not to make that claim that they are representative biologically of genetic frequencies among all Japanese—*rather they're representative of genetic frequencies among those Japanese sampled for the HapMap*.

INT: Is that all you can say?

PO: Well, no. Then you have to ask the question—

INT: 'Cause that's not representative, that's just describing what was sampled.

PO: That's describing the sample … (Interview with the author, 1 Dec. 2004)

Similar to this organizer's response to questions about the definition of populations (i. e. defining who the samples collected represented), when presented with questions about the definition of the people who in practice spoke for those populations (i.e. who the people at the community engagements represented), this organizer (who played a central role in crafting the community engagement policy) once again employed a rhetoric and performance of precision (in this case, detailing who gave samples).

As this project organizer ultimately acknowledged, however, this mode of defining communities goes around the question of representation:

PO: I don't think we would hold up the findings of the individual engagements as being representative of larger populations, but they are representative of some people who were asked to think about this and take part in the study.

INT: Yeah, and again we get back to the problem of, you know, is it any more than just those people, in which case it's not—

PO: Oh, it's got to be more than just those people, but how much more is the question.

INT: That's right.

PO: I mean they weren't—they weren't all outliers, they all are, you know, part of something.

INT: Right. And actually, that's part of the question, what were they part of. And part of this comes down to [the questions of]: In what cases is this going to matter? What are the effects of this?

PO: Well, I mean, I would say the reason that this process happened is that this is a high-profile big science project, and that it followed on the unfortunate history of the Diversity Project, and had those two factors not been there, then I don't think this elaborate process would have happened. (Interview with the author, 1 Dec. 2004)

In addition to acknowledging that 'precise' definitions of voice do not resolve questions about who those voices represent, here this project organizer also acknowledges the context that gave rise to this new problem of representation: the Diversity Project debates. In the wake of the Diversity Project controversies, there had been a desire 'to do things the right way' by not excluding, and indeed including 'people' in the process of naming themselves (interview with author, 1 June 2005). But, as one organizer of the HapMap noted when discussing the consultation done in Japan, 'this notion of "let the community decide for themselves what to call themselves" is not quite so simple' (interview with the author, 1 Dec. 2004). One reason, I suggest, is that no clear 'people' with 'concerns' to include existed.

Making people

The lack of a clear 'people' with concerns distinguishes the HapMap from the case of the Human Genome Diversity Project. In the Diversity Project case, the populations targeted formed clear people in society—namely, specific indigenous groups—with clear concerns. HapMap organizers explicitly decided not to sample indigenous groups, arguing that the

Project would place such well-defined minority groups at too high a risk for genetic discrimination.[18]

Sampling more diffuse and less well-defined majority populations, however, presents its own set of problems.[19] Namely, it raises questions about how to define 'the populations' sampled and 'the communities'—or 'the people'—who could speak for them. In such a situation, where a scientific project seeks to sample a group of human beings that do not map onto a clearly defined social or political group, the problem of democratic governance of research becomes more complex than including more 'people' in research design and regulation, as much of the democracy and science literature recommends (Kitcher, 2001; Sclove, 1995). In these situations, the first question becomes not 'How do we include people?', but rather 'How are people being made up in order that they might be included?' What role do scientific and technical practices play in 'making up' these people (Hacking, 1999)? Answering these questions requires that scholars of science and technology pay the same scrupulous attention to the processes by which 'people', 'publics' and the other constituents of democratic governance form as they pay to the processes by which the constituents of technoscience form.[20]

This is a mode of attention that John Dewey advocated for over 80 years ago in his book, *The public and its problems*.[21] Here, Dewey questioned whether there was anything natural or constant about democracy. In particular, he concerned himself with the nature of 'the public', a key constituent of democratic governance. As he observed:

> The days are past when government can be carried out without any pretense of ascertaining the wishes of the governed. (1927: 181)

But, he continued, did contemporary American citizens (he is writing in 1927) have clear wishes? In other words, did they exist as an organized 'public' whose wishes a government could serve? Democracy was supposed to be of the people and by the people, but in America in the 1920s, an era marked by contested and unprecedented levels of immigration, did such an organized and coherent people exist? The idea of a 'public', of a 'people', Dewey argued, certainly made sense for the small agrarian societies that constituted America at its birth. But, he lamented, the Industrial Revolution ended these face-to-face interactions. People, he cynically observed, had become cogs in a machine, their ideas mass-produced and circulated by newspapers (Dewey, 1927: 114). We need not share Dewey's cynicism in this passage (in other passages he is more optimistic) about the role of technology in the construction—or rather destruction of the public—in order to appreciate his larger

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18 Organizers contend that indigenous leaders told them that they did not want to participate. Some questioned the power of these leaders to represent indigenous views (interview with author, 7 Sept. 2006).

19 The language of 'minority' and 'majority' is that of some project organizers.

20 All too often, scholars of science, technology and medicine end nuanced accounts that demonstrate the interweaving of scientific and social practices with a simple call for democratization. These works provide little insight into what counts as 'democracy', a practice as politically important as 'science'. See, for example, Clarke *et al.* (2003), Eglash *et al.* (2004) and Treichler (1987). For a call to work to discern the meaning of democracy and social justice, see Herzig (2006). For an example of the kind of work I think needs to be done, see Epstein (forthcoming) and Wynne (2006).

21 Bruno Latour has recently brought Dewey's writings to the forefront of concern for some scholars of science and technology in his recent art exhibit and volume, *Making things public: Atmospheres of democracy* (2005). This work represents a promising turn in science studies towards attending to the specific forms democracy might take in an age of emergent technoscience.

point: the conditions in which core democratic concepts form—such as *the public* and *community*—change; as this happens, we need to rethink their meaning and place.

Genomics, with its inextricable links to globalization, presents us with one such set of changed conditions. Reconsider the discomfort that the organizer of the HapMap, expressed when I suggested that the collectivity engaged in the community consultation that took place in Tokyo, Japan might in effect speak for 'the Japanese'.[22] His discomfort refracts Dewey's concern 80 years ago:

> [W]here is the public which . . . officials are supposed to represent? How much more is it than geographical names and official titles? . . . Is the public much more than what a cynical diplomat once called Italy: a geographical expression? (Dewey, 1927: 117)

It is, I believe, correct to ask whether a geographical expression or official title (such as Japan) can name a collectivity of human beings who share common concerns and cares. In current debates over how to name groups in genomics, geography is often invoked as an apolitical answer (Rosenberg *et al.*, 2002). It is right to question whether geography acts, as it is implied, as a neutral arbiter of complex and consequential questions about identity.

But if geography is not the answer to how to define 'the people' (or publics) of genomics, the answer also cannot be found by retreating to a narrow construction of 'the people who are being asked to make the sample donations'. In our search for a collectivity around which we can legitimately organize practices of governance, these performances of precision might not only obfuscate the fundamental issues at stake, they also might produce dangerous effects.

The dangers of democracy without understanding

To see these possible dangerous effects, consider one more time the HapMap's sampling efforts in Japan. Organizers are understandably concerned about defining the group sampled and the group engaged as 'the Japanese'. After all, in what sense do the people at a university in Tokyo speak for a group called 'the Japanese'? Does a group, 'the Japanese', even exist? Further, because the Project's community consultation process was founded upon the idea that the population whose genes were sampled could map onto communities whose views would be consulted, to say that the project consulted with 'the Japanese' was tantamount to saying that there were 'Japanese genes'.[23] This raised the concern that, despite claims to the contrary, the project would lead to a reinvigoration of genetic constructions of nation and race. Ironically, this time the biologization of race would not be the result of a science unreflective of its social dimensions, but rather the result of a scientific initiative that was explicitly trying to address those social dimensions by democratizing its practice.

Understandably, fears of being linked to biological constructions of race and nation have led organizers to resist any association with acts of defining and representing human differences. However, despite this resistance, the question remains: might the HapMap's sampling and democratizing practices end up constituting groups defined by race and nation—such as Japanese, Chinese and African—despite stated intentions to the contrary?

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22 I use 'consultation' instead of 'engagement' here to conform to the HapMap initiative's use of this term to refer to the work in Japan.

23 For this mapping of 'communities' onto 'populations' see Coriell Institute for Medical Research (2004).

Consider the organization of the HapMap. In its first phase, organizers sought to sample what some called 'majority populations'.[24] Given limited funds, organizers reasoned, it made the most sense to first sample populations that represented the greatest amount of human genetic variation. Additionally, they contended that these 'majorities' faced less risk of discrimination than non-majorities.[25] As a result, in China they decided to sample only the Han Chinese, i.e. what they deemed 'the majority population'.[26] In a subsequent phase of the project (named 'Phase III'—'Phase II' was a 'technology upgrade'), they intended to sample additional populations to test this hypothesis: that the 'majority populations' picked in Phase I could adequately represent the world's human genetic variation. One organizer referred to this phase of the project as the 'proof of principle' phase: 'Phase III is supposed to be proof of principle: How well is it working? How well does the HapMap generalize onto different population groups?' (Interview with the author 10 Nov. 2005).

It is not clear how the Phase III data will turn out, but all the organizers I interviewed believed that principle will be (or has been) proved. If this is the case, it will make sense to talk about the samples collected in Tokyo as 'the Japanese' samples and the ones collected in Beijing as 'the Chinese' samples.[27] Under these circumstances, despite the stated intentions of individual HapMap organizers, the HapMap might act to re-biologize identity along racial and national lines. The entry of biological notions of race and nation through the backdoor, where no one is looking, has been well-described and documented by the sociologist and historian of science, Troy Duster (1990). What is less well understood, and what the HapMap illustrates, are more allusive, but linked, problems of governance.

To see these problems, recall that the policy that the HapMap adheres to positions the 'communities' engaged as representatives of 'the population' sampled. These communities have the power to oversee use of those samples through the oversight of a collective body named the Community Advisory Group (CAG).[28] In Phase I of the Project, organizers were uneasy with suggesting that these 'populations' were anything more than the people sampled. Indeed, organizers insisted on adding specific geographical markers ('Tokyo, Japan', 'Beijing Normal University') so as to prevent people from generalizing to all Japanese or to all Chinese. As one organizer explained:

> [T]he label has changed [from Chinese to Han Chinese from Beijing Normal University], and part of it I think is the fear that people are going to over-generalize the population into everybody. And so having a geographical location, somehow it's

24 Although several organizers central to project administration used this language of 'majority' and 'minority', one organizer I interviewed balked at its usage, asking 'majority of what?' (Interview with author, 12 June 2006). I argue that this kind of question about grouping and ordering was exactly the kind of question raised by the HapMap, but also the kind that organizers resisted recognizing.

25 For an example of this logic, see Foster (2006).

26 At least one project organizer critiqued this strategy, arguing that it was tantamount to only sampling 'whites' in the United States (Interview with author, 10 Nov. 2005).

27 Several organizers also argued that the Chinese and Japanese samples were so similar that they could be lumped together for purposes of analysis (Interview with author, 16 Oct. 2006). The article reporting on the results of the HapMap does indeed combine the samples from Japan and China onto the same 'analysis panel' (IHMC, 2005).

28 Although the legal status of the CAGs was still in question at the time of my interviews, they were formed on the principle that 'communities' had the right to regulate the uses of their samples, and could decide to withdraw their samples if they did not approve of proposed studies ('Policy for the Responsible Collection'). For a description of these CAGs, along with their powers, see IHMP (n.d. d).

going to limit people's ability to over generalize to all Han Chinese people. (Interview with the author, 30 May 2005)

However, if in Phase III it is determined that the human beings sampled at the Normal University in Beijing can represent all the people from China, then, by the logic of the project's community engagement policy, the Beijing Normal University Community Advisory Group represents 'the Chinese population'.

There is great unease about this possibility among at least some of those who conducted the community engagements. As one project organizer told me:

> I think there is a chasm between the genomicists saying it's generalizable to all these other groups [and what social scientists think]. Social behavioral people say you can't ever do that because you may say genetically there's no difference, but if you look at the social and political implications, you can't make that generalization, and you shouldn't. ... It goes completely against the whole notion of why we engaged the communities to begin with. (Interview with author, 30 May 2005)

The HapMap's framework of democratization poorly prepares its administrators for these kinds of possibilities. Such a framework presumes that 'people' with interests and desires pre-exist, and democratic genomic practice follows from including them in the process of designing and regulating research. It does not anticipate, or provide any way of addressing, the situation that those in charge of HapMap community engagements find themselves in: one in which 'the communities' in effect form and reform in tandem with sociotechnical systems.

Living with democratization

These transformations have not been easy for organizers of the community engagements, or for those human beings who have at various points fallen into the precarious category of 'the community' engaged. For organizers, many of whom name social justice as their motivation, it has been wrenching to build relationships with human beings in one place, and then, because of changes to the technical-social system, be forced to tell those people that they are no longer a HapMap 'population', and thus, a HapMap 'community'. For example, in the case of the effort to sample 'the Han Chinese', samples collection originally began in the United States in Denver, Colorado. Tremendous effort was put into drawing together individuals and groups to constitute what became known as the 'Han Chinese in the Denver Metropolitan Colorado community'. These individuals and groups found themselves brought together with other human beings in new ways, and made honest efforts to make those ties meaningful so that they might become a 'community'—a people, that could voice their views and concerns. However, when a subsequent decision was made that people in Beijing, China would represent the 'Han Chinese', organizers of the HapMap effectively de-constituted the 'Han Chinese in the Denver Metropolitan Colorado community'.[29] Their blood, their voices, suddenly had little value.

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29 The reason for this decision is a matter of debate. Many involved with the project administration explained to me that this decision was made because the Han Chinese in China were considered 'purer'. Others adamantly

According to those involved in the community engagement and sample collection done in Denver, the newly constituted 'community' demanded to know why their blood was not used for the creation of the HapMap (whose completion was much celebrated in October 2005) (IHMC, 2005). As one organizer reported:

> People gave a very precious part of themselves. Not only did they give their blood, they gave their opinions and their thoughts about things that were very intimate. (Interview with author, 30 May 2005)

They gave these intimate things with the understanding that their community would be included in an internationally recognized and celebrated science initiative. However, they would later learn that control over the meaning and value of their community and its DNA lay largely in a rapidly changing technical-social system—a system that could constitute them as a 'community' and 'population' just as fast as it could de-constitute them.

Rethinking democratization in an age of biopolitics

Cases like the community engagement and sample collection in Denver, Colorado make clear that, rather than a repository of answers to the complicated questions of governance that genomics raises, at this moment, uncritical recruitment of key liberal democratic concepts, such as *public*, *people*, *inclusion* and *objectivity* (of which *precision* is a part), only raise new questions and present new problems. The meaning, uses and effects of these concepts need to be re-*thought* in the novel context of genomics.

I emphasize thought to highlight that, too often, passionate calls for democratization take the place of substantive analysis of what democratization might mean and how it happens. In much literature on science and ethics, biology and society, democratization figures as an unquestioned good—that which we (critical scholars of science and technology) do not examine. As the HapMap case demonstrates, this lack of critical reflection can lead to knowledges and governing structures never intended: ones that skirt precariously close to the very racialized ideas and governing systems proponents hoped genomics would dismantle; ones that make and remake people, with little attention to the affective ties people form to their new technoscientific identities.

Critical reflection and thought, I argue, are particularly important in a post-Diversity Project world where genome scientists go out of their way to avoid studying groups with clear social identities who might have the infrastructures necessary to critique their research. In the HapMap case, for example, there is no equivalent to the indigenous rights groups who, in the Diversity Project case, acted to slow down planning of the initiative, and to provide critical thought about its broader social and political effects. Some HapMap organizers argued that community engagements would provide this opportunity to slow down and to think critically about the HapMap—and, indeed, the community engagements did slow down the HapMap's completion (IHMC, 2004). However, as organizers of the community

deny this, arguing that it was a matter of politics and social justice: including people in China would enable the inclusion of a nation that had not previously had a chance to participate in genomics (Japan, but not China, participated in the Human Genome Project). Others explained that the ethics and politics of this decision to include China were not clear. A past and continuing history of human rights violations troubled these organizers (Author's fieldnotes).

engagements reported to me on several occasions, the possibility for critique was limited by the overarching assumption that the project would move forward in a form that matched the interests of the genome scientists who proposed it (Author's fieldnotes). Absent the inclusion of well-established social groups (groups with the resources to think and pose questions in a space outside of the one created by the HapMap), little possibility existed for substantive critique of, and reflection about, the Project's role in constituting 'people' and 'populations.'[30]

Systems of governance capable of discerning the problems and potential solutions of a world made and remade in the idioms of emergent forms of technoscience require more thought. In particular, they require thinking through what it might mean to live democratically in worlds increasingly characterized by the co-constitution of knowledge and subjects. To engage in this critical reflection, I argue, the constructivist critiques of scholars of science and technology must not stop at the door of democracy. If we seek to build a science that better serves human ends, then it is not enough to understand how human concerns and interests shape scientific ideas and practices. We must also understand how scientific ideas and practices help form a people with common concerns and interests. Democracy, as much as science, is made up, and the possibility for meaningful and reflective decisions in contemporary biopolitical worlds require that we consider and take responsibility for these intertwined, fundamental acts of world-making. Attempting to substitute democracy for science as the stable solid ground on which we build only precariously moves to the side the most fundamental questions that face us.

Dewey, writing in 1929, in an essay aptly named 'The construction of good', observed:

> There is . . . a prevalent notion that values are already well known and that all which is lacking is the will to cultivate them in the order of their worth. In fact the most profound lack is not the will to act upon goods already known but the will to know what they are. (Dewey, 1960: 212)

If genomics is to make good on its promise to produce 'enormous leaps' in our understanding of who we are, then we must know not only what governs the action and organization of our genes, but also how we want to govern ourselves in a world made anew by genomics ideas and practices. It is only by building practices and institutions that can hold us accountable for these conjoined tasks that we will begin to learn what a government of the people and by the people might look like in a genomic age.

Acknowledgements

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30 Indeed, the HapMap has generated no public controversies.

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