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Constructing Participation in Genetic Databases

Citizenship, Governance, and Ambivalence

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This paper discusses the discourse of 'participation' in the context of genetic databases. Focusing on UK Biobank, it suggests that this discourse can be seen as a reflexive institutional response to public ambivalence towards science and expertise. Drawing on empirical evidence from focus groups, I explore how people from various backgrounds constructed and contested two different kinds of participation in UK Biobank. The first relates to people providing research materials to genetic databases and the second to people becoming 'co-decision makers' in these projects. My analysis highlights how focus groups positioned themselves and others in relation to UK Biobank and drew on a variety of 'discursive repertoires', such as altruism, public ignorance, expertise, and lay empowerment. I conclude that discourses of participation reflect the way people position themselves and others – as experts, publics, patients, or research subjects – in relation to the opportunities and uncertainties of new biomedical research.

Keywords: *genetic databases; biobanks; participation; citizenship; ambivalence*

Introduction

There have been a number of initiatives to create nationally based genetic databases or biobanks, which combine genetic, medical, genealogical, lifestyle, and other personal data collected from large numbers of people. The most prominent examples have been in Iceland, Estonia, Britain, Latvia, Singapore, Japan, and, most recently, Canada and the United States (Kaiser 2002; National Institutes of Health 2004). The aims of these initiatives are

manifold, from improving scientific understanding of the etiology of common diseases and developing the prescription of targeted pharmaceuticals, to securing valuable economic resources for countries seeking to compete in a global economy (Mieszkowski 2003). Their development has been characterized by scientific, financial, and ethical uncertainty and controversy, with few to date realizing the original visions of their organizers (Rose 2003). This article focuses on the British initiative, UK Biobank, funded as a public-charitable sector partnership between the UK state Medical Research Council, the Wellcome Trust charity, and the UK government's Department of Health (Barbour 2003; UK Biobank 2005). UK Biobank began its recruitment toward the end of 2006, collecting blood samples and medical and lifestyle data from 500,000 people in the 40-65 age range across the national population of Britain. Once completed, it is likely to constitute the largest cohort database of its kind in the world.¹

Genetic databases have prompted intensive discussion by social scientists and ethicists about the various social and ethical issues that flow from people's provision of tissue samples and forms of personal information to these projects. Numerous commentaries have addressed concerns around consent, benefit sharing, ownership, commercial exploitation, feedback, confidentiality, privacy, misuse of samples and data or research findings, surveillance, and the formation of appropriate ethical and governance frameworks (Beskow et al. 2001; Caulfield, Upshur, and Daar 2003; Chadwick and Berg 2001; Eriksson 2001; Martin 2001; Merz et al. 2002; Snaedal 2002; Wendler and Emanuel 2002; Williams and Schroeder 2004; Wylie and Mineau 2003). There is also a body of empirical research on accounts of people who actually have the experience of providing samples and information to existing genetic research projects (2004; Haimes and Whong-Barr 2004; Hoeyer 2002, 2004; Whong-Barr and Haimes 2003; Williamson et al. 2004).

Institutions that organize genetic databases and academic commentators identify the people who have provided or will provide samples and data to these initiatives in a variety of ways. For example, in legal and other documentation associated with the Estonian Genome Project, the expression

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“gene donors” is used (Estonian Genome Project 2005), and some of the social science and ethics literature refers to people as “donors” (Hoeyer 2002, 2004; Martin 2001; Rendtorff 2001). Other researchers prefer the terms “human subjects” or “research subjects” (Merz, McGee, and Sankar 2004; Potts 2002; Wylie and Mineau 2003), or “sources” (Wendler and Emanuel 2002). It would be fair to say, however, that the most popular language is that of *research participants* or *participants*. This is ubiquitous in the official documentation of UK Biobank—in reports on consultative exercises with the public (People Science and Policy 2002), the development of its scientific protocol (MRC, Wellcome Trust, and Department of Health 2002), and its recent draft Ethics and Governance Framework (MRC, Wellcome Trust, and Department of Health 2003). Many social scientists and ethicists have also adopted it in their discussions of biobanks (Berg 2001; Beskow et al. 2001; Busby 2004; Chadwick and Berg 2001; Caulfield, Upshur, and Daar 2003; Eriksson 2001; Haimes and Whong-Barr 2004; McInnis 1999; Sade 2002; Stegmayr and Asplund 2002; Tutton 2004; Weldon 2004; Williamson et al. 2004).²

It is beyond this article to trace how discourses of participation have developed in different research contexts throughout time (see Corrigan and Tutton 2006).³ But the popularity of this language in relation to genetic databases is reflected in contemporary discourses of active citizenship that emphasize people’s rights (and duties) to participate in decision-making processes (Marinetto 2003; Turner 2001). This interesting congruence between the languages used in the current research context of genetic databases and that of active citizenship is explored further here against a background of changing relations among publics, science, and expertise. I draw on evidence from a series of focus group discussions conducted as part of a project sponsored by the UK Economic and Social Research Council (ESRC). This project, “Transformations in Genetic Subjecthood,” explored the different subject-positions that people constructed for themselves and others in their accounts of the ownership, control, and use of genetic information in the distinct yet intersecting contexts of genetic testing and genetic databases (Tutton, Kerr, and Cunningham-Burley 2005).⁴ This article examines the ways different focus groups discussed participation in relation to UK Biobank, and how individuals in the groups situated themselves and others in various subject-positions during the course of their discussions. By focusing on subject-positions, I show how people’s constructions of participation draw on and inflect wider social and discursive contexts, and are shot through with ambivalence.

Participants, Citizens, and Genetic Databases

The way that individuals are constructed as participants in the contexts of biobanks and genetic research can be understood with reference to social theories that elucidate changing notions of personhood. This is the approach taken by Oonagh Corrigan (2004), who used work on governmentality to argue that the "participant" as a particular subject in biomedical research should be considered a recent innovation. In the past, people were the passive and expendable objects of research; after the atrocities of World War II, they became vulnerable subjects requiring protection by ethical bodies, whereas today they are constructed as "empowered citizens who, given sufficient information, are able to make free, informed, rational and thus moral choices with respect to their participation" (Corrigan 2004, 86). For Corrigan, therefore, research participation is exemplary of the way neoliberal governmentality functions, governing individuals through their regulated choices (Rose 1998).

Individual choice is also a key issue in accounts of reflexive modernization, by which participation in research—as an expression of contemporary "life politics" (Giddens 1992)—can be understood in terms of how individuals construct their self-identity. Their choice to participate or not relates to what Anthony Giddens (1992) called the "reflexive project of the self"—in other words, the construction of a coherent narrative of self-identity in relation to multiple choices (cf. Wendler 2002). Such choices are, however, characterized by ambivalence, which is to say by uncertainties and doubts about the value and benefits of technological change and by distrust toward scientific institutions and the role of experts in decision-making processes (Beck 1997). In the UK context, this public ambivalence can be linked with various incidents and controversies around bovine spongiform encephalopathy (BSE) and Creutzfeldt-Jakob disease (CJD), GM food, and vaccines. Some commentators have suggested that these may have contributed to a loss of confidence in science and its institutions, which the organizers of genetic databases need to consider in their governance arrangements (Kaye and Martin 2000).

Against this background, we might see the conception of human subjects as the "participants" as opposed to the "subjects" of research as an institutional response to this ambivalence, especially by UK Biobank given the examples above.⁵ A discourse of participation, with its connotations of partnership, resonates with calls for researchers and their publics to find a common purpose in furthering scientific and medical advances (Fears and Poste 1999), and the observation that medical innovation will increasingly depend on the "active participation" of certain public groups (Webster

2002, 448). Genetic databases are a case in point because their success depends on large numbers of “healthy” individuals being willing to provide samples and personal information about themselves.

Erica Haines and Michael Whong-Barr (2004) have engaged with this discourse of participation in their research into people’s accounts of how they came to agree to be included in the North Cumbria Community Genetics Project (NCCGP).⁶ They explicitly rejected using a discourse of “donation” to conceptualize people’s involvement in the NCCGP because it leads to an unsophisticated account centered on the donation/nondonation dichotomy, and a view of donors as being involved in an uncomplicated one-way act. Instead, they used “participation” because it “implies a more active process of engagement with, and sharing in, the creation of the database” (Haines and Whong-Barr 2004, 60). From analysis of the interviews they conducted, they constructed different kinds of participants: there is the “active participant,” who stresses his or her willingness to help; the “cost/benefit participant,” who talks in terms of weighing up personal risks against greater collective goods; the “passive participant,” who can see no reason not to provide the samples and/or personal data; and the “reluctant participant,” who regrets having done so. Therefore, Haines and Whong-Barr used participation as an analytical framework that permitted them to explore the multiple and complex subject-positions that people occupy in relation to genetic databases. Their work shows that people participate in different ways, and therefore we might see participation as a contingent and varied process.

There is, however, a certain ambiguity to the use of participation in relation to genetic databases. When Giddens argued that the appropriate institutional response to ambivalence is to foster greater public participation, he referred to the public becoming more actively involved in decision making. This implies a different kind of participation from the one discussed by Haines and Whong-Barr, and shifts the focus from the sphere of individual choices to one of collective rights and responsibilities, in other words, to that of citizenship.

It is certainly the case that participation in biomedical research is increasingly being framed as a matter of citizenship (see, for example, Chadwick and Berg 2001; Human Genetics Commission 2002; Petersen 2004; Salter and Jones 2005). Sue Weldon (2004) examined this further and teased apart the different kinds of participation at stake, arguing that “for the lay public to participate fully in genetic research as citizens [they must] find a role alongside researchers and other professionals, in negotiating science’s ‘licence to practise’” (Weldon, 2004, 178). This can be achieved

by recognizing that people can participate in genetic databases not only as the *sources of blood samples and data* but also as *potential co-decision makers*. Weldon's argument draws on recent sociological accounts of citizenship in the contexts of science and technology that discuss the changing relationships among publics, policy makers, and scientific expertise (Irwin 1995, 2001; Irwin and Michael 2003; Petersen and Bunton 2002; Rose and Novas 2005). These accounts draw on a version of citizenship that is characterized by dynamic and active processes of citizen involvement (Turner 2001). This kind of "active citizenship" has been promoted by various government-led efforts throughout the past two decades to encourage community involvement in local decisions about urban planning, local government, and health (Marinetto 2003; Turner 2001).⁷

A number of sociologists have, however, registered the ambiguities of *active citizenship*, noting that circumscribing the *rights* of citizens to participate is a set of *obligations*. For example, Petersen and Lupton (1996) noted that individuals may be obliged to be educated first before they can become legitimate participants in consultation exercises or other initiatives. Other researchers have highlighted the limitations of institutionalized initiatives to involve publics in debates about developments in science. They have pointed to the influence that professional groups have in defining the agenda and the conclusions of these exercises, so that participants tend to engage with issues not on their own terms but on those set by these groups (Dunkerley and Glasner 1998; Irwin 2001).⁸ Kerr and Cunningham-Burley (2000) suggested that these initiatives, as an institutional response to public ambivalence, have been limited and are unlikely to overcome lay skepticism and doubt about scientific decision making.

In the context of genetic databases, we can see the emergence of the discourse of participation as a reflexive institutional response to public ambivalence toward science and expertise, drawing on the dominant values of individual choice, autonomy, and borrowing the language of active citizenship. Yet, as Weldon recognized, this participation is one by which individuals can be involved more readily in the provision of blood samples and personal and medical information to genetic databases than they can in the governance of these projects. Therefore, a certain ambiguity remains around the different meanings of participation.

In this article, I build on this ambiguity and consider the two different types of participation identified above. I discuss how participation—in terms of people providing research materials to genetic databases *and* acting as "co-decision makers" in the creation and governance of these projects—is actively constructed and contested in different social and discursive contexts.

To do so, I draw on a series of focus group discussions about participation in UK Biobank. Like Haimes and Whong-Barr, I direct attention toward the various subject-positions that participants construct for themselves through the accounts they give of their and others' potential involvement in this project and its governance. I show how these accounts are characterized by ambivalence about the choices that they or others may make, and about the role of institutions and scientific experts associated with UK Biobank.

Constructing Participation in UK Biobank

As described in the introduction to this article, the focus groups discussed here were conducted as part of the project "Transformations in Genetic Subjecthood." The project involved a total of nineteen focus groups, conducted over two phases. In the first phase, focus groups were undertaken with a range of people, some of whom had direct involvement in or experience with human genetics research or services. These people included genetic counselors, staff in a clinical genetics department, government advisors, members of an umbrella organization for people affected by genetic disorders, researchers at a pharmaceutical company, managers of human tissue collections at a university research institute, actuaries with an interest in genetics, campaigners from public interest groups, and university-based researchers. We also conducted groups with people who, at least at the time of recruitment, appeared to be less involved but whose views we considered important given the wider social implications of genetics research and services. These included members of a Friends Meeting House, refugees, school students, and members of a local patients support group.

The project therefore adopted a symmetrical approach with the focus group methodology, which is to say that we recruited both "lay" and "professional" focus groups. Often, focus groups have been seen to be more appropriate for eliciting the views of laypeople or publics as opposed to professionals (Cunningham-Burley, Kerr, and Pavis 1999; Wilkinson 1998). Following Alderson, Farsides, and Williams (2002), however, we set out to create contexts in which both so-called professionals and laypeople could speak in free-ranging and semistructured group environments. This was not without its problems and challenges.⁹

Toward the end of this first phase of focus groups, there were a number of events, organized to mark the fiftieth anniversary of the delineation of the double helix, which encouraged greater public dialogue about genetics. Led by our initial analysis of the focus groups, we developed an interest in interactions

between people who might identify themselves—or be identified—as either “expert” or “lay.” Therefore, these events, which involved professionals in the field of human genetics and governance, representatives of patient and public interest groups, and other people discussing the social implications of genetics, seemed good sites in which to observe some of these interactions (see Kerr, Cunningham-Burley, and Tutton in press). We therefore attended a number of events, and organized two ourselves, as part of the project. Our interest in such interactions led us to convene a further set of groups with bodies that had a range of specialist and lay members, some of which were involved in decision making and governance, such as a strategic health authority board, a local research ethics committee, a charitable research funding panel, and a local patients’ advisory group, as well as groups with experiences of other social settings such as lay magistrates and members of an environmental campaign organization.

In the first phase of focus groups, we presented groups with an information leaflet that had been produced by the UK Biobank partners. This, we reasoned, would allow them to engage with the way that this project was represented by the institutions behind it. The leaflet outlined the case for UK Biobank and sought to respond to anticipated questions about its governance, the use of samples and data, and the implications for people who might consider becoming participants. On this basis, we asked the focus groups to discuss issues concerning the value and implications of this kind of research project, whether people would be willing to take part, and the kinds of considerations that might influence their decisions. We also raised questions about arrangements concerning the ownership and commercial exploitation of tissue samples, although I do not have space to discuss these here. In the second phase, given that some of the groups selected comprised “expert” and “lay” members involved in governance, the development of the UK Biobank Ethics and Governance Framework offered a good opportunity to explore questions about which kinds of people should be involved in the governance of this project.

On a reflexive note, I should point out that, as the moderator in all of these groups, I adopted the language of participation used in the UK Biobank material when framing questions to the focus groups. Therefore, the discussions in the focus groups were conducted within this framework. Also, in analyzing the discussions that took place in the groups for this article, I have adopted the “active interview” approach outlined by James Holstein and Jaber Gubrium (1995). I too conceive of the individuals in the focus groups as participants, because, in conjunction with the research team that formulated the questions and created the context of the focus groups,

they shared in actively constructing meanings, their own subject-positions, and those of others, including that of the moderator. Throughout my analysis, I use the expression *participant* to underscore the point that the people speaking are participants in one form of research often talking about others, or themselves, as potential participants in other kinds of research.

I present the focus group accounts in two sections, although there are overlapping themes between them: the first is concerned with exploring some of the discourses groups drew on to frame their discussions of people's participation in UK Biobank as the providers of tissue samples and personal information; the second focuses on the issues raised by possible public participation in the governance of UK Biobank.

Participation in UK Biobank by Providing Samples and Data

After giving the focus groups opportunity to read through the UK Biobank information leaflet, one of the first issues put to them was whether they thought people would be willing to participate in this project by providing blood samples and medical and personal information about themselves. There was a range of responses to this both within and across groups. As I show, these were often characterized by ambivalence, associated in part with different subject-positions that people adopted in the discussions.

Some groups, especially with participants who positioned themselves as knowledgeable of, or as actors in, current policy discussions, drew on dominant discourses around participation and community involvement that have been highlighted in this article already. For instance, one participant in the group convened with university-based natural scientists said,

- 1: But there's a move, isn't there, to involve people more in new medicines and trials and things. So they become more a part of it rather than just treating them like a number, you know, in a study, and perhaps we're going to see a bit of that, that you are . . . you become not just the subject, but in a way the active recruit or the patient even. And you, you're actually quite interested in it over the years.¹⁰

This participant's notion of the "active recruit" was someone who took an interest in the project beyond his or her immediate dealings with it as the provider of research materials. As such, it resonates with the earlier discussion

in this article that UK Biobank might be part of a wider set of changes in the way that people recruited for research are conceived.

The same participant suggested that the interest people might take in the research derived from the trait of curiosity, which, he considered, defined the human species. Another participant in this group, however, when he spoke from a personal position on this issue, was much more ambivalent about this “curiosity”:

- 2: Yeah; it's interesting. I mean . . . it's a difficult one for me in some ways, because I can see some circumstances in which, in actual fact, I'd rather do the ostrich and bury my head. . . . The thing . . . is . . . curiosity driven is fine at the third person level when it comes down to you personally, it's, it's; I think one . . .

The second participant therefore expressed some ambivalence about the drive to discover knowledge, especially when reflecting on its potential personal implications. His position is a reflexive one, suggesting a distinction between abstract scientific knowledge and knowledge with a personal impact. This distinction may have been reinforced by the group's earlier discussion about the personal and familial implications of genetic testing.

A discourse of community involvement was mobilized by the group of government advisors on human genetics. Their discussion of the question about whether people would be interested in participating in UK Biobank was shaped on the whole by a policy concern about whether it would successfully achieve its sample of 500,000 people. Interestingly, one member of the group immediately positioned himself as a potential participant in UK Biobank when he said, “I'd certainly like to take part.” There was little ambivalence about participation in UK Biobank. Indeed, this participant and some others in the group had quite a positive view of this issue, and drew on their knowledge of birth cohort studies undertaken in Britain. They suggested that the way these had recruited and retained participants might be relevant for UK Biobank:

- 1: Well, it is true again that I mean the . . . birth cohort studies were remarkable in that they got virtually 100 percent.
- 2: The loyalty in ALSPAC [the Avon Longitudinal Study of Parents and Children] is amazing. I mean, people who've moved away from Bristol area still regularly come back from all over the country. They feel so enthusiastic; they feel they're part of something which is revealing something, you know.

The idea that people might feel involved in “revealing something” echoes the comment made in the first group. It alludes to a notion of a partnership

between researchers and participants, and, by referencing ALSPAC—a longitudinal birth cohort project in the Avon area of England (Avon Longitudinal Study of Parents and Children 2005)—the idea that people’s sense of community belonging, or citizenship, is expressed by their participation in this project.

The way these two groups focused on active participation and community involvement can be contrasted with how other groups drew on discourses of helpfulness and altruism, and reflected on the individual costs and collective benefits entailed by participation. The group of genetic counselors expressed some ambivalence about the universal appeal of participating in UK Biobank but said that many people would agree to do so because they wished to assist research:

- 1: I can’t imagine there’d be streams of people volunteering, but I’d imagine a lot of people would agree. And I do think; I do think people do, you know, many people feel some [] obligation to be involved in research or if they—or that kind of sort of doing something they’re not going to personally benefit from but that may benefit other people.
- 2: Right.
- 1: And do feel; and if it’s just—
- 3: Altruistic.
- 1: Yeah, altruistic; if it’s just a blood sample, then sort of no big deal really.

The obligation that people have to assist research is identified by the other participant in this exchange as “altruistic” in character. This altruism would seem to be minimized, however, by the suggestion that people are only giving up something of little consequence to them personally. Klaus Hoeyer (2002) has identified a similar “discourse of minimisation” in his interviews with people who provided blood samples to the Umea Medical Biobank in Sweden. This discourse negotiates between the idea that individuals are making a contribution to research that is not insignificant in terms of potential collective benefits, but which it is insignificant on a personal level because it involves only a small amount of blood. This discussion of people’s likely altruism was, however, bracketed by concerns about police access to UK Biobank, which raised some uncertainty in the group about the confidentiality of the information stored in its database. This provision made the group more ambivalent about the project, because they were unsure of the conditions under which this could happen. They concluded that this might also affect the public’s willingness to take part, because the possibility of police access could “stick in people’s minds.”

One participant, who had been very positive about the benefits that could flow from this project when the group had briefly discussed its merits at the

outset, became ambivalent later in the discussion when she imagined herself as someone who had received an invitation from her family doctor to participate in UK Biobank:

- 4: [R]ight, I've got the letter through my letterbox—it's me. I'm thinking, "I don't want it to be," actually. I don't want . . . to be put in the . . . making that decision. I've suddenly gone off the idea. And I hope it's not going to be me.

When positioning herself as a potential participant of UK Biobank, this participant became far more ambivalent seeing that she would be faced with the responsibility of making a personal decision as to whether she would be a participant. This may have been made more problematic in light of the issues and concerns that the group had just discussed about the project.

Other groups associated people's knowledge about science or genetics with their likely participation in UK Biobank. There was a concern, for example, about people's understandings of biomedical research such as UK Biobank. These discussions were characterized by an interesting ambiguity. On one hand, this issue was constructed in some groups as one of people having a fully informed individual choice about the implications of what they were being asked to do. This was seen in a group held with staff at a clinical genetics department, who suggested that people's participation in UK Biobank must also be an educational process through which they became informed, specifically about what they are asked to consent to, but also more broadly about genetics. They positioned themselves as professionals with experience in recruiting patients for research and drew on this to express some reservations about the success of such a process. One participant related an anecdote that was revealing on this point:

- 1: Some of mine have real difficulty getting somebody to sit down and go through with them what they're actually signing and I don't know if you've seen the MRC [Medical Research Council] consent form for DNA sample, it's A4 with like twelve tick boxes and we've got to go through it and they go, I'll just sign that, I'll do anything that'll help anybody else, they don't want . . . they'll do it.

Through this anecdote, it is implied that the process of informing participants could be potentially more complicated because, in this individual's experience (supported by others in the group), patients could sometimes be uninterested in performing the role of the "informed individual" and were just willing to do what they saw as "helping others" (cf. Hoeyer 2002). Although this group stated it was important that patients were aware of what they were

asked to do by researchers, they also recognized that people's desire to help could mean they were less interested in receiving information. A similar finding has emerged from Helen Busby's (2004) research with blood donors, which she related to a process by which people "entrust" their blood to the National Health Service. Therefore, we might see altruism as challenging the discourses of participation and active citizenship, which stress the value of people actively informing themselves. It also raises a philosophical question of whether the participation of people who choose not to inform themselves but "to help others" is any less ethically or morally valid.

On the other hand, although many of the above group's concerns were shared by the members of the umbrella organization for people affected by genetic disorders, they conceived of potential participants in UK Biobank not only as individuals requiring information to make choices for themselves but also as members of a public deficient in their knowledge about genetics. They suggested that one barrier to the project recruiting its participants might precisely be this lack of knowledge among the public:

- 1: Do you think on balance that people . . . will want to participate in this?
- 2: Well, I think it depends of their knowledge of genetics. I mean . . . would they know what a DNA blood sample was, or what it could be used for?
- 1: Right.
- 3: No, I think that the uptake of this might be quite low actually. I don't think they . . .
- 1: Why's that, do you think?
- 3: Well, I mean apathy or ignorance or fear, I suppose. Fear, there'll be an element of fear.

The discussion about lack of knowledge becomes linked in this exchange with other concerns about fear or apathy. The researchers at a pharmaceutical company were also ambivalent about people's likelihood of agreeing to participate in UK Biobank for related reasons to those expressed in the previous group:

- 1: I think there would be a fair amount of people wanting to, not the majority, I think, because there is so much skepticism around genetic testing, and you read this, in the tabloids, often this is, um, about insurance issues and so on. So there will be a lot of skepticism, I think, in the general public, but there'll be I guess a fair amount of [].
- 2: I think it will be a significant minority, won't it?
- 1: Absolutely, I think that's right.
- 2: That will want to do this because of the concerns that they've heard in the, when they've read the *Sun* or the *Daily Express*, and you see most of the press you read is negative press, isn't it?

In this second exchange, it is suggested that there is public skepticism about genetics that is partly linked with misrepresentation or misinformation in certain sections of the media. In some groups' discussions, it is possible to see language reminiscent of the way that deficit models of public knowledge and public trust have been articulated in other contexts to do with science (Irwin and Michael 2003). The obverse of this public skepticism was, however, a certain skepticism among a number of groups about the position of the "public" itself, who were seen as largely apathetic or ill-informed. This was evident, for example, in the group with members of the umbrella organization for people affected by genetic disorders. They positioned themselves as actively involved in the debate about issues that were of importance to the public but about which they were ignorant.

Participation in UK Biobank as "Potential Co-Decision Makers"

I now turn to the way that the groups we conducted in the second phase of the project talked about the possibility of public participation in the governance of UK Biobank. In September 2003, the draft Ethics and Governance Framework for UK Biobank was published, following further consultations with publics and professionals (People Science and Policy 2003). The draft framework proposed the creation of an Ethics and Governance Council (EGC) to provide oversight of the project and to represent the interests of participants and the wider publics. The framework did not, however, envisage that participants should be represented on that body and saw little opportunity for participants to have further formal involvement in UK Biobank, beyond being the sources of tissue and data for researchers (Tutton, Kaye, and Hoeyer 2004). In May 2004, after the focus groups I discuss here were completed, the UK Biobank partners advertised for people to join the EGC, and their qualification to do so was largely defined in terms of possessing particular expertise or professional experiences of governance.

We used the development of the draft Ethics and Governance Framework to explore the kinds of people the focus groups thought should form the membership of the EGC. Discussions centered a great deal on the range of expertises that should be marshaled such as in data systems or security, ethics, genetic science, or the law. Often, but not always, prompted by the moderator, groups also considered that laypeople, consumers, research participants, or the public could participate in the EGC. There was, however, quite a degree of ambivalence expressed about the participation of these groups.

There were concerns among some focus groups with how individuals would be recruited, and these stressed the importance of ensuring their independence and having no conflicting interests. There was also the question of how knowledgeable people needed to be, who were not professionally involved in the area, to be effective members of the EGC:

- 1: You know, somebody who's monitoring, really, what the scientific researchers are doing, to my mind . . . it would be pointless to have scientific researchers monitoring them. It ought to be an entirely different group of people . . . who haven't got the vested interests.
- 2: But the problem is if you haven't got the scientific knowledge, you'd be bamboozled, you will be. They will do it, that's a fact of life, isn't it?

In this group, held with members of an environmental campaign organization, there was much ambivalence about the involvement of people with expertise in the EGC because they were seen to have vested interests. There were also doubts, however, about how people who do not have expertise would find a voice in a committee in which others did. It was implied that people with expertise would, indeed, not permit them to find that voice. Given this, there was quite a degree of uncertainty about whether partnerships could be established between experts and laypeople in this context. By contrast, in a group convened with members of a research ethics committee, it was discussed that people did not necessarily have to be knowledgeable before they could effectively participate in a body such as the EGC. This group emphasized the importance of "informed lay representation" and discussed how this could be achieved by drawing on their own experiences of how their committee recruited its members:

- 1: I think it's important to have lay representation . . . a well-informed lay representation.
- 2: Yeah . . . which is difficult to know where to go to get that . . .
- 1: Well, someone with a willingness to absorb it, because our lay members don't always join us fully informed, do they? But—
- 2: Well, it's very difficult really.
- 1: Well, [name], you're a lay member, so you can speak from the lay member point of view. You actually gained quite a lot—
- 3: Yes; yes.
- 1: From coming along—
- 3: Yes.
- 1: And, and become—
- 3: Being trained, yeah.
- 1: More expert in the field.

As this exchange indicates, the second participant was by far the most ambivalent, not only about the merits of lay participants but also about the process by which they could be recruited onto the EGC. The third participant is positioned by the first as a "lay" member of the committee. Although inviting her to speak from that perspective, but actually speaking for her, the first participant challenges the ambivalence expressed about public involvement in the EGC by referring to the experience of the third participant, who has undergone a process of change from being uninformed to becoming informed. Her comment usefully highlights the way that subject-positions such as *lay*, *informed*, or *expert* are not fixed and can change throughout time.

The group held with members of the medical charity research funding panel was also reflexive about how their positions had changed throughout time. This group had undergone a formal training process to become members of this panel, which assessed applications from researchers to do work on a particular disease. Although it would seem an empowering position to say that for people to be considered legitimate participants they need not be already informed, because through the process of participation they can become so, it is also a deeply ambivalent one. As referred to earlier, Petersen and Lupton (1996) have addressed this ambivalence in the context of public health initiatives in Australia. With reference to the focus groups, it is also ambivalent because the group of members of the research panel used their experience to position themselves as distinct from a homogeneous uninformed "public," who were then subsequently marginalized in their discussions because they saw them as uninterested in the issues at stake.

Their experience of being members of this panel very much informed their discussion of public participation in the governance of UK Biobank. They saw themselves as laypeople or as "consumers," in a partnership with experts, taking decisions about the research that the charity should fund. This partnership was based on the sharing of knowledge in a form that was accessible to all parties. It was suggested that a similar approach could be appropriate for the UK Biobank EGC:

- 1: If you had that sort of committee, the experts, I would feel, would need to be experts in a field that was relevant to it, and in a way to oversee the broad picture coming from the laypeople.
- 2: Yes, and be able to explain things to them.
- 1: Yes, it's like nowadays we'll get people sitting on a committee talking about road works and they don't even drive motor cars you know, and with that; it's being a bit over the top, I know, but it would be important that the committee, the laypeople would be able to talk to an expert and say well that can't be done because of, and give very good reasons.

In this model, suitably informed and motivated lay members of the EGC could play a central role in decision making, if informed by the advice and knowledge of certain experts. For the group, this would be an empowering situation in which experts and their expertise were put into the service of laypeople. There was little uncertainty about the potential success of this arrangement.

Conclusion

I have argued in this article that a discourse of participation is used by the institutions behind UK Biobank because of its associations with notions of partnership, community involvement, and active citizenship, which have been highly valued in current public policy discourse. This conjures up an image of people as actively making informed and involved choices in relation to themselves and UK Biobank. In practice, this participation is likely to be largely confined to providing samples and data to the project, with the likelihood of receiving some general feedback about the progress and key findings of the research in the future. Sociologists, such as Weldon (2004), have argued for a broader conception of participation that would include the ability of people to be involved in the governance of research as well. In this article, I have explored focus group discussions about the issues raised by these different kinds of participation.

The use of the focus groups created contexts in which people with different backgrounds, experiences, and knowledges discussed participation in UK Biobank, in both of the senses outlined above, from a variety of subject-positions. In the groups, participants sometimes positioned themselves and others as potential participants in UK Biobank, and drew on a variety of “discursive repertoires” (see Kerr, Cunningham-Burley, and Amos 1997) that related to altruism, ignorant publics, expertise, lay empowerment, vested interests, and community involvement, to list but a few. As such, discussions of participation were open to much variability. On one hand, in relation to the first kind of participation in UK Biobank, for instance, altruism was cited as a powerful motivator, so that people might decide to take part without wishing to inform themselves so completely. On the other hand, it was said that a lack of knowledge about genetics could adversely affect people’s decision to take part at all. People’s ability to participate in the governance of UK Biobank was considered possible, but there were concerns about appropriate levels of knowledge and expertise, as well as the avoidance of vested interests. Differing perspectives emerged on whether laypeople/lay publics and experts/professionals could form partnerships in the governance of biomedical research.

Much of the ambivalence evident in the discussions arose from when participants, especially those with professional backgrounds in genetic research or services, positioned themselves as potential participants in UK Biobank. Some expressed greater uncertainty and doubt when they dealt with the dilemmas participation posed in personal terms. There was also ambivalence about the attitudes of others, with some groups doubtful about whether publics really were altruistic or informed enough to participate in UK Biobank—and this related to participation in both of the senses used in the article. Equally, some ambivalence seemed to stem from the groups' engagement with the information about UK Biobank produced by its funders, and related to issues such as access and security.

My analysis shows that institutional discourses of participation, drawing on the language of active citizenship and community involvement, are but one of various discursive repertoires on which different groups of people may draw. The focus groups do not suggest that there is a singular "UK Biobank research participant," but a variety of ambivalent and changing participant-positions that are open to contestation. The findings from these groups indicate a complexity and contingency about the way that people discuss involvement in biomedical research that is rarely acknowledged in institutional discourses.

Moreover, by discussing participation in two different ways in this article, I have drawn attention to the ambiguity surrounding this discourse of participation. Its associations with notions of partnership, activity, and sharing, and its use in various other contexts by patient groups, government, and organizations, opens up a space in which debate about the extent of people's involvement in the conduct of biomedical research can be addressed in a way perhaps not permitted by a paradigm that emphasizes informed consent above all else. For example, in a submission to the Academy of Medical Science's study on the use of patient data in research, the Genetic Interest Group (GIG) has engaged with this debate. They questioned the kind of participation that many "research participants" would desire, claiming that "passively, many would support research, but if asked to 'participate' beyond giving consent and enrolling, they would probably be quite perplexed as to what this could mean" (Genetics Interest Group 2004, 2). Specifically, they doubted whether many would wish to participate, in Weldon's (2004) terms, as "co-decision makers."

On this kind of participation, the focus groups reported on in this article present quite a complex picture. In the context of laypeople working in organized groups, such as patient groups or charities, the merits of lay involvement were discussed positively. It was envisaged that working in partnership with experts, laypeople could actively exert an influence over what research

was conducted. In other contexts, there was ambivalence toward the possibility of such partnerships and concern expressed about the ability of laypeople to find a “voice.” To an extent, then, these findings support social scientists who have been skeptical about initiatives to involve the public in policy discussions as a way of overcoming their ambivalence toward scientific change or distrust in institutional decision making. The focus groups indicated that there were doubts about how such involvement would work in practice.

Further research needs to be carried out to ascertain the various ways in which the meanings of “participation” in biomedical research are understood and evoked by different actors. Social scientists and bioethicists should become more sensitive to the languages that are used and that they then often adopt in their own commentaries on developments such as in the field of genetic databases. As noted elsewhere, there is no “neutral language” in this context, because *donor*, *participant*, or *subject* each has its own historical trajectories and traditional uses (Tutton and Corrigan 2004). Therefore, it is important to both chart and analyze the shift in discourses that has occurred, and to consider the extent to which such a shift is a reflection of a different understanding of patients or “volunteers” who take part in such research, and whether this can be seen against the backdrop of wider social changes described above around active citizenship and public trust in science and governance. The current research shows how we might begin to see discourses of participation as constructed within different social and discursive contexts, and as reflective of the way people position themselves and others—as experts, publics, patients, or research subjects—in relation to the opportunities and uncertainties of new biomedical research.

Notes

1. What today we know as UK Biobank was first developed in 1998 under the name of the UK Population Biomedical Collection (Barbour 2003). The aim of this project is to support research into the etiology of common diseases in which it is understood there is a complex interplay of genetic and environmental factors. It is a project that has attracted some controversy with respect to both its ethical and governance arrangements (Tutton, Kaye, and Hoeyer 2004), and its scientific merits (Ho and Papadimitriou 2002).

2. Some researchers even use all of these terms interchangeably, such as Williams and Schroeder (2004).

3. To trace the genealogy of the term *participant* in different research contexts across time, comparing it with other expressions such as *volunteer* or *donor* would be an insightful project. Preliminary investigation for this article indicated that discourses of participation can be found in psychological research from at least the 1970s onwards (Devins 1978) and in the clinical trials literature (Ellis 2001). See Corrigan and Tutton (2006) for further discussion.

4. "Transformations in Genetic Subjecthood" was funded by the UK Economic and Social Research Council (ESRC) under its Innovative Health Technologies Programme between April 2002 and March 2004. The principal investigators were Anne Kerr and Sarah Cunningham-Burley, and I worked as the project research fellow.

5. This point came from useful exchanges on the writing of this article with Sarah Cunningham-Burley.

6. The North Cumbria Community Genetics Project (NCCGP) is a genetic database that collects samples and health- and lifestyle-related information from mothers and their children born within the West Cumbria region of the United Kingdom (Chase et al. 1998).

7. In the area of health and health care, the formation of patient and public involvement forums in 2003 in the National Health Service (NHS) is one prominent example of government creating opportunities for greater public involvement (see <http://www.tvha.nhus.uk/maketime4health.html>; National Health Service n.d.). Marinetto (2003) cautioned that such initiatives do not mark a radical redistribution of power but the adoption of a strategy to enable a more effective form of government, reflecting a neoliberal political rationality and its values of self-reliance and self-responsibility.

8. Take for example Alan Irwin's (2001) reflections on the British government-led initiative Public Consultation on Developments in Biosciences (PCDB), conducted in the late 1990s. He argued that this initiative positioned its participants as *reactive* as opposed to active citizens. Irwin's claim is supported by the House of Lords Science and Technology Committee, which took the view that the PCDB was more market research than a genuine public consultation, and was more professionally led rather than "citizen-led" (Irwin 2001, 13). This is despite the organizers' original promise that "[t]his consultation is giving citizens some potential influence on what the future of science will look like" ("Sainsbury Seeks Public View" 1998: 18).

9. In the main, most of the problems faced were practical and related to arranging a convenient time and place for the focus groups to be held. Undoubtedly, many professional people (with experience of social science research previously) had the expectation of an individual interview and so found participating in a focus group a novel experience. These and further issues may be addressed in a future paper.

10. Individual participants in the focus groups are identified by numbers to preserve their anonymity.

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