Reconsidering Democracy

History of the Human Genome Project

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What options are open for people—citizens, politicians, and other nonscientists—to become actively involved in and anticipate new directions in the life sciences? In addressing this question, this article focuses on the start of the Human Genome Project (1985-1990). By contrasting various models of democracy (liberal, republican, deliberative), I examine the democratic potential the models provide for citizens' involvement in setting priorities and funding patterns related to big science projects. To enhance the democratizing of big science projects and give citizens opportunities to reflect, anticipate, and negotiate on new directions in science and technology at a global level, liberal democracy with its national scope and representative structure does not suffice. Although republican (communicative) and deliberative (associative) democracy models meet the need for greater citizen involvement, the ways to achieve the ideal at a global level still remain to be developed.

Keywords: *citizenship; democracy; big science; Human Genome Project; contextualization*

A year after the Berlin Wall came crumbling down in 1990, the international Human Genome Project (HGP) to map and sequence the entire human genome was launched in the United States. The Human Genome Project is biology's first worldwide big science project. The project started in a period

Author's Note: For their comments and criticisms, thanks to Mark Brown, Steve Fuller, Hans Harbers, Femke Merkx, Nikolas Rose, and Jean Tillie. For editing, thanks to Sheila Gogol. Early drafts of this article were presented at Goldsmith University, London; at the conference titled Normative, Political, and Cultural Aspects of Human Genetics of the Dutch research school of

Science Communication, Vol. 24 No. 4, June 2003 479-502
DOI: 10.1177/1075547003252333

of major political and cultural transformations that enlarged the spread of democracy, challenged the scientific order, especially its legitimacy in the political order of the Cold War, and increasingly globalized economics, culture, politics, and science.

With the HGP, molecular biology became part of the postwar trend in the physical sciences, astronomy, and engineering toward "big science." Yet even though building international DNA databases might be compared to building big instruments or big apparatuses, the landscape of molecular biology significantly diverges from physics or astronomy. The HGP is not pure science that produces knowledge on human DNA, nor is it a formal transnational project that produces DNA information. It is a *contextualized* research enterprise that promises to bring health and wealth. The project has been set up in the context of a society that highly values health and wealth. But what are health and wealth? More precisely, what is human life or a good life? Who is entitled to have a good life?

In modern societies, defining human life is not or is no longer the prerogative of religious, political, medical, or scientific authorities. A plurality of definitions and beliefs of the good life, of identities and ways of living, has merged. Rather than being authorities whose normative and epistemological statements on human life are accepted as true, the life sciences, in particular biology and medicine, have become contested areas in which a multitude of actors are involved, ranging from social movements, women's groups, nongovernmental organizations (NGOs), journalists, government officials, and research councils to private industries. These actors talk, act, and negotiate in any number of public and private spheres. The context in which knowledge is produced speaks back, as Nowotny, Scott, and Gibbons noted (2001). What does this mean for the political negotiation and decision-making processes related to big science projects in biology? From the perspective of democracy rather than science, the challenge is how to conceptualize democratic negotiation and decision-making processes on global science projects. What options are open for people—citizens, politicians, and other nonscientists to become actively involved and anticipate new directions in the life sciences? In addressing this issue, I focus on the start of the HGP. What can we learn about citizenship related to global science projects from the

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Science, Technology, and Modern Culture, Amsterdam; and at the 4S conference titled Fashioning the Future: Science, Technology, and Visions of Progress in Cambridge, MA. Part of the article was written during a fellowship at Harvard Medical School, Division of Medical Ethics, in Boston, MA. I am grateful for financial support by the Netherlands Organization for Scientific Research (NWO). Address correspondence to Marli Huijer, University of Groningen, Faculty of Philosophy, A-weg 30, 9718 CW Groningen, The Netherlands; telephone: 31 50 363 6154; fax: 31 50 363 6160; e-mail: m.huijer@philos.rug.nl.

history of the controversies and negotiations preceding the HGP? What new political and scientific options for the active involvement of people have developed since the end of the 1980s? By contrasting various models of democracy (liberal, republican, deliberative), I examine the democratic potential the models provide for citizens' involvement in setting priorities and funding patterns related to big science projects.

Big Science

The trend toward big science started right after World War II in the United States. The experience of effective military research and development and the large-scale use of science in the war gave rise to a postwar expansion of academic research. The postwar economic growth and material wealth and the Cold War imperatives intensified this process. Analogous to the world of big business and big government at the time, the world of science enlarged its scale. The ideal of investigator-initiated, peer-reviewed "small science" was replaced in part by the model of research organizations consisting of hundreds of people and large institutions primarily funded by the state. Over time, visionary plans like the Apollo Project for a manned Moon landing, the Hubble Space Telescope, and the unsuccessful Superconducting Super Collider grew from the expanding scientific world.

As far as I can ascertain, the term *big science* was coined by the physicist Alvin Weinberg (de Solla Price 1963, 2; Weinberg 1961, 1962, 1967). In 1967, he published *Reflections on Big Science*, seeking justifications for big science in high-energy physics, nuclear energy, the behavioral sciences, manned space exploration, and last but not least, molecular biology. The growth of science occurred at a time when many scientific activities required extremely elaborate equipment and large staffs of professionals, and the scientific enterprise was mushrooming and becoming much more complicated. The term *big* referred to the numerous people, laboratories, and costs involved, as well as the growing complexity of science itself.

When big science came of age, it was clear that it required not only scientific excellence but also political skills. The growing complexity and importance of the scientific enterprise and the increasing demands for research funding forced scientists to sell their science projects (Nelkin 1987). They had to be able to convince the general public, elected representatives, and private investors that their research project was an excellent investment. "It is quite conceivable that our society will tire of devoting so much of its wealth to science, especially if the implied promises held out when big projects are launched do not materialize in anything very useful," Weinberg cautions in

Reflections (1967, 83). Communicating with the public and knowing how to use the political system appeared to be prerequisites for gaining support for big science or "big instrument" projects.

Biology's Promotion into the Big Science League

Weinberg (1967) anticipated that biology would move into the realm of big science by the end of the 1970s. Then, he wrote, the large government physical science and engineering laboratories would be called upon to help in "the massive attack on human disease" (138-39). Specific technological changes made his prediction come true a decade later. The invention between 1983 and 1986 of the polymerase chain reaction, a technique whereby the enzyme polymerase excises a discrete DNA segment from the genome, which can then be amplified a millionfold, was "a fundamental tool that made feasible such megaprojects as the Human Genome Initiative" (Rabinow 1996, 136). The subsequent development of automated sequencing machines supported the idea that sequencing the entire human genome would be a promising project. Another influential technological development was the rise of global communication and information systems such as fax and the Internet. BIONET, the first electronic network for molecular biologists, started in 1984. In addition, the development of electronic databases such as GenBank—funded in 1982—made it feasible to store and handle the huge quantity of data the sequence project would produce (Kelly 1989).

It is not only technical and scientific achievements that brought biology into the realm of big science. Political, social, and economic *conditions de possibilité*, to borrow a phrase from Foucault (1969), are also of importance. They include the political and economic transformations at the end of the 1980s. The fall of the Iron Curtain and the subsequent triumph of free-market capitalism and liberal democracy imposed on science the task of securing economic competitiveness rather than military goals and objectives. In addition, opportunities for scientific cooperation with the USSR, which had been off limits for decades, opened up. A second change that prompted the project is the pursuit of unity in Western Europe, paving the way for a concerted genome project in Europe. A third factor is the U.S. recession in the 1980s and the threat of simultaneous Japanese economic expansion. In the early 1980s, as a result of the economic potential of recombinant DNA technology, it was still quite easy to start and run American biotechnology ventures. In 1983, however, the decline of the U.S. economy led to a stock fall of American biotechnology. Japanese and European pharmaceutical and chemical giants could acquire a stake in American companies at low prices. The United

States feared Japan or Europe would become the dominant players in biotechnology. "The HGP will prime the American economic pump. It is a critical time to develop new biological technologies. If we decline to do so, we can all rest assured that our competitors will fill the vacuum," Leroy Hood noted (1990, 13).

These combined conditions shaped the foundation for biology to start the big scientific enterprise called the Human Genome Project.[1] In the United States, the first serious proposal to sequence all three billion base pairs of the human genome originated from the Department of Energy (DOE), which was experienced at successfully implementing projects of this magnitude.[2] The initial proposal met with a great deal of criticism from the scientific community. Discussions on the design of the project went on from 1985 to 1990. As a result, the project grew larger and more complex. Its first goal became the completion of a 2- to 5-centimorgan linkage map within five years.[3] Sequencing was only to be initiated on a large scale once the technological development had reduced its costs (in 1987, the estimated sequencing costs were $1 to $2 per base). The parallel study of other genomes such as bacteria, yeast, the nematode, and the fruit fly was brought in to alleviate the early criticism that the project was not worthwhile and would divert funds from other biology research. Moreover, comparisons with these organisms could enable researchers to better understand the DNA of humans.

One observation relevant to the issue of democratic deliberations on global science projects is that the HGP "could materialize only through a coalition between science, industry and government agencies" (van Dijck 1998, 119). The project itself was not generated by a committee of scientists or physicians convinced of the need for the information. Shortly after the U.S. Department of Energy in New Mexico advanced the megaproject, David Botstein of the Massachusetts Institute of Technology stated:

> I do not believe that there is any strong scientific justification for knowing the sequence of the entire human genome. The motivation for doing it is, frankly, political, or science political, more than it is that science is being held up by our lack of knowledge of every nucleotide (base pair) in the genome (quoted in Joyce 1987, 35).[4]

The DOE's interest in a sequencing project was widely suspected to be feathering a nest that had been rather empty of late due to sizeable cuts in government spending on energy. The political support of powerful New Mexico senator Domenici was a big help in getting the project started. His staff drafted legislation resulting in a Senate bill approved by Congress in 1987. A special section of the bill was devoted to the genome project, giving DOE a mandate to initiate this type of project (Cook-Deegan 1991, 120, 137; Davis et al. 1990, 342; Rechsteiner 1991, 455). In Watson's (2000) retrospective of this mandate, it is again evident that political rather than scientific incentives were the engine behind the HGP:

> The American public, as represented by their congressional members, proved initially to be much more enthusiastic about the objectives of the Human Genome Project than most supposedly knowledgeable biologists, with their parochial concerns for how federal monies for biology would be divided up. The first congressionally mandated monies for the Human Genome Project became available late in 1987, when many intelligent molecular geneticists still were sitting on the fence as to whether it made sense. In contrast Congress, being told that big medical advances would virtually automatically flow out of genome knowledge, saw no reason not to move fast. (P. 201)

In the following years, the political skills of subsequent proponents such as James Wyngaarden, Ruth Kirchstein, James Watson, Walter Gilbert, and Leroy Hood, who knew how to convince Congress and the public to invest in their plans, helped the HGP become a reality.

Big Science and Democracy

Why argue in favor of citizens taking part in the planning phase of big science projects like the Human Genome Project? Why not leave the developing of a research agenda, the setting of priorities, and the funding of big science projects to scientists?

The first and rather obvious reason as regards launching the HGP is that big science projects cannot be born or survive without public support. The serious demands on public resources mean big science projects create a need for scientific choice. It is impossible, even for a rich country like the United States, to fund all the big science projects scientists have in mind. The choices between various big science projects, between science and other fields relevant to society, or between various routes to be taken within a specific project, are made in the political and public arena. It is evident that citizens should have a direct or indirect say in or agree with the *allocation of public resources*.

A second argument is found in considerations pertaining to the *new relations between science and society.* The acknowledgement of the interwovenness of society and science, the coproduction or coconstruction of science and society (Bijker and Law 1992), stresses the need for citizens to anticipate and reflect on the potential new worlds that big science projects produce in conjunction with globalizing and localizing economies, cultures, and politics. Big science projects in biology and medicine do bring about new knowledge, information, and technologies, but they also generate new identities and new types of social, political, and economic order. In an era of highly educated people, citizens are ready to discuss the social as well as scientific and technological products of science projects.

A third argument is related to the need for *robust knowledge*. Trust in science is no longer guaranteed by scientific publications, the elite status of scientists, or a call upon experts. Sciences, especially the life sciences, have become contested areas. Skepticism about the promises and possibilities of medicine and biology has grown as a result of people's enhanced knowledge of science and the greater transparency about failures of all sizes in medical practice, experimental settings, and public health care. The media attention for medical successes and failures augments the uncertainty people feel about what to accept as true, just, or correct, and who to accept as an expert. To maintain or re-create trust, social knowledge should be brought in from the start. Negotiations on what knowledge should be produced and how it should be produced are part of the democratic decision-making processes.

Arguments for the involvement of people in the negotiations on big science projects can also be found in *considerations pertaining to democracy itself*. In democratic theory, it is generally taken for granted that political decisions affecting all the members of society should be made democratically. Big science projects like the Human Genome Project have implications far beyond the borders of the countries participating in them. Most of the people affected have no chance to take part in the political negotiations and contestations on the projects, nor do the governments prioritizing and funding the projects represent them. Big science projects increasingly assume the air of global enterprises, but democracy is still a national practice. Nation states, however, are gradually more undermined by the re-emergence of local and regional allegiances and the development of supranational organizations. To guarantee the elementary democratic principle of political equality, the equal right to participate for all members of society, ideally citizens all over the world should be equally entitled to participate in the negotiations on big science projects. As a defining feature of democracy, the "rule by many" can only come within reach if the many are treated as equally qualified to participate in the negotiations on the issues profoundly affecting them. The ways to achieve this ideal at a more global level partly still remain to be developed.

Another defining quality of democracy is the recognition and acceptance of *pluralism, that is, various conceptions of the good*. In dealing with difference, it is crucial that citizens be able to enter into discourses on alternative technological and scientific routes and to add alternative proposals to the scientific agenda. Openness to a variety of norms, values, knowledge traditions, and practices enhances the value of pluralism and creates a greater diversity of sciences and scientific disciplines.

The answers to the question of how democratic societies can deal with big science and how people's involvement in setting priorities and funding these projects can be put into effect depends on how we conceptualize democracy. In the history of democratic theory, the meaning of democracy ranges from representative forms of democracy, where governing collective affairs is conferred on those periodically elected to direct, to participatory forms of democracy, where citizens engage in self-government and self-representation. In distinguishing liberal, republican, and deliberative views of democracy and connecting them to different views on science-society relations, I explore the possibilities there were at the time for public and political involvement in the HGP, and address what they mean to present relations between big science and democracy.

Liberal (Interest-Based) Views of Democracy

In a liberal view of democracy, the role of people in big science projects is fashioned as the citizens' approval of the decisions on science budgets made by their government representatives, quantified as votes for individuals and programs. Prior to the official decision, a democratic political process occurs in which the preferences and interests of each citizen are transmitted to political representatives. As Habermas (1996b) argues:

> According to the liberal view, the democratic process takes place in the form of compromises between competing interests. Fairness is supposed to be granted by the general and equal right to vote, the representative composition of parliamentary bodies, by decision rules, and so on. Such rules are ultimately justified in terms of liberal basic rights. (P. 26)

In a liberal model, processes of formulating political opinions in the public sphere and in parliament obey the structures of market processes. People who most successfully appeal to the public and expand their circle of political friends achieve the greatest political and public support. In his reflections on big science, Weinberg (1967) notes that the successful mobilization of large scientific organizations requires a great man with a great idea and great mission (Mr. Somebody, as Latour would say) or a small group of men who really care (Latour 1987, 31-33; Weinberg 1967, 134). In the case of the HGP, this is demonstrated by the appointment of James Watson as director of the U.S. HGP. Watson is not only a widely respected scientist, he is also an experienced lobbyist. In the "recombinant DNA wars" of the 1970s, Watson played a decisive role in the lobby to safeguard DNA research from state regulation. In the case of the HGP, Watson's authority was called on to muster a majority in the scientific as well as the public world. His status as codiscoverer of the double helix and author of the best-seller *The Double Helix* guaranteed the publicity so sorely needed to gain public support.[5] In addition, his connections in the community of biologists guaranteed higher and more numerous allies than the dissenters could ever come up with.

Surrounded by a small circle of enthusiasts such as Berg, Cantor, DeLisi, Dulbecco, Gilbert, Hood, Olson, Sinsheimer, and Zinder[6] and supported by a wide range of organizations such as the National Research Council, the National Academy of Sciences, the Howard Hughes Medical Institute, the Department of Energy, the National Institutes of Health, the international Human Genome Organization, private corporations, universities, and members of Congress, Watson led a successful lobby to gain public and political support. Although the strategy did not turn out well for the House of Representatives Appropriations Committee, which voted in July 1990 against giving the project the full amount requested by then-president Bush (Anderson 1990), Watson and his allies achieved their goal when Congress decided two months later to give the Human Genome Project the go-ahead.

The political process in which the HGP gained public support is in accordance with a liberal, interest-based view of democracy. Liberal democrats like Ackerman, Fukuyama, and Rawls pursue possibilities for democracy within the confines of the state and its organizations. What matters are credibility, rhetorical skill, publicity, and persuasive arguments. In this model, public debate is limited to constitutional affairs and legislation insofar as it affects people's negative rights, the interests of citizens as private persons who are or could be harmed. Interest groups are strong partners in putting issues on the public and political agenda. An example of these debates are the public discussions in the United States and Europe on whether information related to individuals should be disclosed to outside parties, such as employers, insurance companies, or family members.[7] As protectors of the citizens' interests, governments guarantee the right to privacy by formulating privacy acts and other regulations.

In liberal views of democracy, the public is not engaged in negotiations on the priorities and funding of science projects. Following Weinberg's distinction between "internal criteria" (the field's ripeness for exploitation and the competence of the field's scientists) and "external criteria" (technological merit, scientific merit, and social merit) (Weinberg 1963), a strict sequence of decision making is followed. Only when scientific panels have decided that the internal criteria are fulfilled do external criteria come into view. The next "external" choice between scientific projects is made by scientific panels and governmental bodies based on shared social values and socioeconomic utilities.[8] Addressing the problem of human disease, for example, is considered a generally supported goal, and scientists and governmental institutions should translate this social goal into the right choice of scientific projects. Assuming that biomedical science is supported on a "real large scale because out of it have come means of eliminating man's infirmities," Weinberg (1967) states:

> When the end to be achieved is important enough, and when the state of the science suggests that more support will lead to more results (and both these circumstances apply to biomedical science), then we are justified in going all out in our plea for public support. (Pp. 113-4)

To make people understand the advantages science projects bring, they need to be educated.

As regards the Human Genome Project, the wish to find public support for the project, to show or teach people the relevance to human welfare and the values of man, and to protect citizens' interests by preventing them from harm, was expressed by the founding of the human genome advisory committee's ethics working group in 1989 (later called the ELSI Working Group). One of its first recommendations was to organize town meetings throughout the United States beginning in 1991 to inform the general public about the human genome initiative and solicit opinions on the ethical, social, and legal issues it raised. These town meetings, however, never really came off the ground.[9] In addition, a total of 3 and, later on, 5 percent of the genome budget was made available for activities addressing the project's ethical, legal, and social implications (Watson 1992; Watson and Jordan 1989, 654).[10] The main purpose, however, was apparently more to protect the HGP from social criticism than to involve nonscientists in the negotiations on the project itself (Andrews 1999, 206). As Watson (1992) wrote:

> We need to explore the social implications of human genome research and figure out some protection for people's privacy so that these fears do not sabotage the entire project. Deep down, I think that the only thing that could stop our program is fear; if people are afraid of the information we will find, they will keep us from finding it. We have to convince our fellow citizens somehow that there will be more advantages to knowing the human genome than to not knowing it. (P. 173)

Because the United States does not have a cabinet-level department of science and technology, and because of the unanimous opinion that the HGP is something "we should go on with," there have not been any public or parliamentary debates in the United States on *why* such a project should be supported, in other words, on the wisdom of the HGP as a scientific project.[11] Debates on starting national human genome projects did take place, though, in the European Parliament and in Germany.[12] Political groups in Europe support the concerns about the possible implications of the project, as expressed in the European Parliament by the German Green representative Benedikt Härlin. Yet, the decision of France, Italy, the United Kingdom, and after some delay, the entire European Commission to join the U.S. initiative was not based on public or political interaction and dialogue on the possible routes to be taken in molecular biology. It was based instead on the feeling that once the United States got the project off the ground, genomics would become a more global development and they could not lag behind (Philipson 1991, 92).[13] In Japan as well, scientists and government officials felt they were forced to cooperate "simply because the U.S. government has decided to initiate it and allocate a budget for it" (Swinbanks 1989).

In a liberal representative democracy like the United States, it is obvious to politicians and scientists alike that investing large sums of public money in scientific projects should be democratically legitimized. In itself though, this is not a reason to argue in favor of the involvement of citizens in the negotiations in the planning phase of big science projects. The decisions on what knowledge should be produced and how and by whom are left to scientists and scientific panels. Once elected representatives are confident that investments in new projects are to the nation's benefit, do not harm the citizens' interests, and do not go against public opinion (the public's aggregated preferences), there is little need for public involvement in the planning phase of scientific projects. The educational move, as part of a liberal science policy, does not open opportunities for citizens to participate in the planning phase of science projects. People are not invited to join in the process of exploring alternative scientific routes and patterns of funding. The involvement of people in big science projects is constrained to governmental decisions on external criteria, their scientific and social merit, and to interest groups putting negative implications on the political agenda. In terms of the coevolution of science and society, we can speak of "weak contextualization" characterized by communication patterns that are determined largely by institutions or representatives of institutions (Nowotny, Scott, and Gibbons 2001, 143). In a liberal democracy, science does speak to society, but society only speaks back via members of legislative bodies, governmental panels, and interest groups, and the topic of discussion is restricted to how to cut the scientific pie and prevent the negative implications of big science projects.

Republican (Communicative) Views of Democracy

According to republican views of democracy, public support for big science projects is generated by a process that gives the public an opportunity to weigh their scientific costs and benefits against their value to society or humanity. The public is conceived as an ethical community that tries to reach a consensus on the res publica, the matters of public concern.[14] Politics embraces the articulation of the common good and is a way for people to become aware of their interdependence. In this model, the state's raison d'être lies in enabling all people to feel free to speak their mind. It guarantees "an inclusive opinion and will-formation in which free and equal citizens reach an understanding on which goals and norms lie in the equal interest of all" (Habermas 1996a, 269-70).

In Western democracies, the involvement of citizens in debates on the ethical and social implications of science and technology has become quite common in the past decade. There is growing government awareness that citizens should be informed about scientific developments and be able to develop an opinion on their acceptability and desirability. A common method for reaching this goal is via the public debate method, town meeting, citizens' conference, or consensus conference model of scientific deliberation, involving face-to-face meetings where a cross-section of a country's general public hears the testimony of various experts and interested parties and drafts the framework within which their political representatives can then make policy. A second way is by setting up independent national forums consisting of representatives of various groups that have a stake in tomorrow's research agenda, as described by Fuller (2000), an advocate of the republican approach to science:

> In short, to realize the republican ideal of the open society in an era of Big Science, forums must be provided so that *all* professional knowledge producers can participate in determining the direction their fields take and the general public can influence the process in a manner that is commensurate to their interest in such matters. (P. 97)

In republican views of democracy, people are conceived as the sovereign bearers of a public good or civic ideal that cannot be delegated to political representatives, government agencies, or scientists. In accordance with the dichotomy Hannah Arendt formulated between science and "the human condition" (Arendt [1958] 1998, 323-24; Drucker 1998, 315), the call for people's involvement in science and technology is aimed at reintroducing "human values," "human existence," or "lived experience" into the cognitive scientific activity. Sclove, active in the U.S. Loka Institute, speaks of science passing a “reality test” in consensus conferences, “a groundedness in the daily experience and concerns of everyday people—that expert conclusions routinely fail” (Sclove 2000, 44). Science as the realm of knowledge production is demarcated from society, the public sphere where thoughtful and lived-through intentions and agreements are reached on the distribution, application, and integration of science and technology.

In relation to the U.S. Human Genome Project, there was barely any evidence of this governed involvement of citizens. There were no citizens’ conferences in the United States on the HGP. The only country where a conference on human genome mapping was organized prior to the start of the HGP (1989) was Denmark, the country where consensus conferences originated. Nor were there any national forums, a rather recent phenomenon in the worldwide process of increased democratization. Most countries did not initiate national forums until the beginning of the 1990s, in other words, after the HGP had started. Consensus conferences and national forums in themselves, however, are not a guarantee that people are involved in the planning phase of big science projects. Consensus conferences are usually held if and when scientists disagree on the implications of new knowledge and technologies. If science is undisputed or can prove its own merits, the political domain claims no sovereignty, as Barber notes (Barber 1988, 14-15). Although advocates of consensus conferences, such as Sclove (1995) and Fuller (2000) would like to broaden the issues for citizen participation in science and technology and include the design and planning phase, consensus conferences often come too late, after a project has already been launched. The demarcation between the internal cognitive activity of science and an external public sphere of moral reasoning related to humanity and lived experiences—even if conceptualized as an artificial boundary—limits public options for deliberation to questions of how to implement and govern the facts, knowledge, methods, theories, and technologies created by the sciences.

Republican views meet the need for greater citizen involvement. Consensus conferences and national forums provide opportunities to hear the voices of people whose opinion traditionally goes unheard. The procedure, where scientists are questioned by nonscientists, can make science and technology more responsive to democratically stipulated societal arrangements. Although consensus conferences and national forums are limited to face-to-face meetings where local or national scientists interact with people from their own country or region, the use of the Internet as a source of information and communication gives citizen panels of different countries an opportunity to exchange information and opinions. A shortcoming of these methods is that many citizens and voices are excluded from the process. Instead of being open to all citizens and voices, the participants are a selected group of citizens who are interested in science and dedicated to the common good (Marris and Joly 1999, 26). The possibility is overlooked that one individual who is not at all representative of the general public might voice an opinion that could unexpectedly get broad public support. Another limitation is that the topics of deliberation are stipulated by the organizing agencies (like the Dutch Rathenau Institute, the U.S. Loka Institute, or the Danish Board of Technology).

Much like the liberal view, the republican view presents a top-down model in which state authorities and scientists decide which topics need public support or deliberation. In terms of the coproduction of science and technology, we could speak of a middle-range contextualization. Scientists enter the "agora," as Nowotny, Scott, and Gibbons (2001) call the public arena where transactions, communications, and dialogues between scientists and agents from a variety of other sectors take place. They are prepared to discuss all kinds of issues and agendas with people as long as people do not touch on the cognitive core of science itself or on forms of science that are not in dispute. Society is allowed to speak back, but not to stipulate the topics of debate.

Deliberative (Associative) Views of Democracy

According to deliberative or associative views of democracy, public agreement or disagreement with big science projects is the result of a multitude of communication processes regulating deliberations of culturally mobilized publics. Whereas liberal and republican views center society in the state, deliberative views proceed from the idea of a decentered civil society—a decentered public sphere.

Inspired by Habermas' (1996a) reflections on the public sphere as an informal network where more or less rational opinion- and will-formation can take place, theorists of deliberative democracy emphasize the importance of a contemporary oppositional and decentered public sphere. Critical voices and insurgencies that start in oppositional civil society are viewed as important pressures for greater democracy. Authors like Benhabib (1996), Dryzek (2000), Mouffe (2000), and Young (1996) revive the ideal of a decentered public sphere or civil society by introducing difference as a crucial constituent of democratic politics. The public sphere is conceptualized as heterogeneous spaces where a plurality of opinions, beliefs, values, and concerns are expressed and heard. In these spaces, open political discussions take place, opinions are formed, and political wills are articulated. The process of deliberation consists of reasoning but also of laughing, story telling, expressing emotions, greeting, rhetoric, testifying, and gossiping, which can bring about agreement and compromise as well as disagreement.

In the case of large science projects such as the HGP, possible publics include citizens interested in genetics or science in general, patient organizations worldwide, women's groups, genetic counselors, physicians, geneticists, molecular biologists, the relatives of people with hereditary disorders, science journalists, governments of developed and developing countries, international organizations such as the World Health Organization and the United Nations Educational, Scientific and Cultural Organization, NGOs such as Greenpeace, political parties, religious groups, philosophers, jurists, ethicists, and so on. The multiple foci of deliberation and diversity of argumentation guarantee a broad spectrum of opinions. In addition, decisions are not made once and for all; they are permanently subject to deliberation, interaction, and communication. Dissent with a direction that has been chosen is valued as important and can be brought into the discussion again. There are thus ongoing, iterative deliberations that can influence the development and implementation of the project. Other than constitutional guarantees for free speech, limitations on the content and scope of public dialogue are not considered necessary (Benhabib 1992, 99).

Views of deliberative democracy are in keeping with a conception of science that assumes that science, technology, and society are coproduced simultaneously. The highlighting of civil society parallels the recent call for strong contextualization in the social studies of science. Science is called upon to enter the agora, the space or democratic environment where science meets and interacts with people. The agora is viewed as a public space that invites exchanges between a diversity of actors and creates a context where their wishes, desires, fears, preferences, and needs can be articulated, as well as their demands. In the agora, exchanges between civil society and scientists or more formal institutionalized bodies that govern societies are reached by way of transmission mechanisms, trading zones, transactions, and coalitions.

Deliberative views are also in line with critical theories of technology that emphasize the interwovenness of knowledge and power relations (Foucault 1980). Social, economic, and cultural norms and strategies are assumed to be incorporated into the design of science projects from the start, although they disappear from sight in the black box of scientific knowledge and techniques (Latour 1987, 2-15). Human agency, in turn, is not independent of scientific and technological developments; it is constructed itself in a game of truths and power relations (Huijer 1999, 67). Instead of allowing normative delegations and cultural assumptions designed into big science projects to pass unexamined, they are problematized. The involvement of various publics in the contents of big science projects is a way to open scientific development to the influence of a wider range of values. As Feenberg (1995) proposed:

> Delegation can be problematized, although with difficulty, as we have seen in a variety of struggles over work organization, media policy, and the environment in recent years. Debate in the new *technical public sphere* brings the normative content of technical decisions to the surface far more frequently and systematically than in the past. Although the expanding technocracy is a real threat, it is not an irresistible force. An account of it needs to be incorporated into a contemporary "critique of power." (P. 95)

Civil society did not, however, play a key role in planning the HGP. Neither the interaction between citizens or citizen's groups nor the transactions between scientists and people where opinions and criticism were openly voiced were all that easy. The project initially met with a great deal of opposition in the world of molecular biology, but the reservations and criticism that were voiced were not echoed in the broader public and political spheres.[15] In as far as the media covered the project, they reproduced the enthusiasm of HGP supporters. Sporadically, the controversies raised by the proposal were included. U.S. scientists with less-enthusiastic opinions on the project or proposals for alternatives were rarely invited to hearings of the House or Senate committees.[16] A handful of ethicists, lawyers, and philosophers raised questions in bioethical, legal, and science journals (Annas 1989, 1990; Lappé 1987). Although not directly related to the HGP, books on genetic diagnostics and eugenics started to appear (e.g., Duster 1990, Nelkin and Tancredi 1989). The Council for Responsible Genetics, a national organization of scientists, public health advocates, trade unionists, women's health activists, and others, issued a critical position paper on the Human Genome Initiative (Council for Responsible Genetics 1989). Prior to the start of the project, there were some international bioethical meetings. Most of the concerns and deliberations on the Human Genome Project, however, started after the project was set in motion. Ever since, a stream of biocriticism has accompanied the Human Genome Project (van Dijck 1998, 149 ff.).

In theory, deliberative democracy gives people ample opportunities to actively participate in the planning phase of big science projects. However, there were barely any deliberations in civil society during the planning phase of the HGP. Most people outside the biosciences did not know what was going on and felt no need for action. As in the case of consensus conferences and national forums, oppositional civil society only claims sovereignty if science is disputed or introduces ungovernable risks and uncertainties. Because action stems from resistance and opposition, most associational public spheres are reactive rather than proactive. Only after critical reviews appeared on the part of intermediary agents, individuals, or groups who put their know-how at the disposal of nonscientific organizations or the general public were there informal flows of communication and deliberation.

One might say that in the case of the HGP, the need for intermediary agents was caused by the limited access to scientific publications at the time. The introduction of the Internet (1991), the free access to scientific databases with PubMed as a prominent one, people's improved education, and the growing number of consensus conferences have changed this situation and greatly enhanced the publicity of new directions in science. The Internet not only augmented the publicity of new directions in science, but it also enhanced the amount and radius of transnational networks of critical citizens, scholars in science and technology studies included. Hundreds of citizens organizations interested in genetics have emerged in Western and non-Western countries. These organizations have become strong participants in or opponents of the webs of interaction between scientists, political parties, industrial companies, journalists, ethicists, scholars in science and technology studies, NGOs, and so on.

Nevertheless, although the force of civil society appears to have increased, a reactive way of dealing with new processes in science and technology is still more common than a proactive one. Now, new directions in genomics, such as the current advances in proteomics and nanobiotechnology, are still rarely topics of deliberation in civil society. Once again, we are waiting for the critical perspectives of intermediary agents prepared to present their knowledge and views to associations in civil society or the general public. The postulation by Nowotny, Scott, and Gibbons (2001, 206) that science is now a force internal to society, pervasively present in the agora, is not confirmed by the story of the Human Genome Project. As to the planning of science projects, public spheres, agoras, and associations in civil society usually emerge in reaction or opposition to scientific forces. Intermediary agents and critical reviews by journalists or scholars of science and technology can be strong incentives in this process. Despite the bottom-up approach of deliberative democracy, it is science that speaks and society that speaks *back*, and not the other way around.

Democracy and Self-Government

Most big science projects are initiated in the United States. Although they have negative as well as positive implications far beyond the U.S. borders, people or governments elsewhere do not have many opportunities to be involved in the negotiation and decision-making processes related to planning big science projects. Even Americans do not have much of a chance to become involved, as is demonstrated by the history of the Human Genome Project. The decision-making processes related to the start of the HGP are mainly in keeping with liberal views of democracy. So, people were only involved indirectly and after the planning phase via their elected representatives who dealt with the external criteria for scientific choice and who saw to their interests. Republican and deliberative approaches of democracy barely played a role in the process.

The prevalence of liberal democracy in the planning phase of the HGP should not keep us from wondering what might happen if democracy's roots in self-government were taken as seriously as its roots in liberalism or if the tension between these two logics was viewed as being vital to democracy (Mouffe 2000, 5). In this respect, it is important to explore the opportunities provided by republican (communicative) and deliberative (associative) views of democracy. What conditions enhance people's involvement in and anticipation of new directions in the life sciences?

Following republican democratic views, it is relevant to appeal to governments and state institutions for a more expansive inclusion of citizens in science policy. Including women and ethnic minorities in agenda-setting forums and consensus conferences, as well as science educators, environmental activists, or other groups traditionally hostile to science, and the people needed to get the job done—secretaries, technicians, and post docs—is an important strategy in reaching a democratic science policy (Fuller 2000).

Whereas republican democrats are state-oriented, the bottom-up organization presented by deliberative democrats contradicts an appeal to administrations for active inclusion. "Beyond laws protecting basic citizenship rights of expression and association, one should not expect much in the way of positive state action to promote the well-being of civil society," Dryzek dryly remarks (2000, 110). Citizens are expected to organize themselves and not be directed by governments or state institutions. Nevertheless, governments do have a role in protecting citizens' initiatives and seeing to it that their voices are not marginalized or excluded. The position of members of civil society in public spheres should be safeguarded, particularly if the mass media and the economic and political powers controlling them dominate the public spheres. The authorities are also in a position to encourage transmission mechanisms between informal and more formal public spheres and between informal spheres and scientists, for example, by inviting science journalists or scholars in science and technology to critically review new directions in the life sciences, by enlarging and maintaining public access to scientific publications, and by stimulating iterative transactions between scientists and people not primarily aimed at reaching consensus or decisions. However, calling scientists to the agora is not the privilege of the authorities, as is often assumed in republican approaches where governmental institutions ask scientists or "experts" to participate in consensus conferences and agenda-setting forums.[17] In deliberative democratic views, a multitude of actors call upon scientists to enter the modern and postmodern agoras, comprehended as agonistic public arenas or transaction spheres where multiple publics and plural institutions participate in various power and knowledge games.

Today, quite a few biologists are willing to level with the public or a variety of people. In medicine and biology, it is hard not to take note of the role of people. Patients, their relatives, and many other actors are engaged in the life sciences and have a say on various subjects. Better education of people in general, combined with the diminished authority of physicians and scientists and the enlarged transparency of scientific controversies, have all contributed to this transformation. Coalitions resulting from the interaction between scientists and various people or groups are part of a hybrid negotiation process where "participation is not a single event, a one-off affair or a preliminary ground-clearing exercise. Instead it is iterative—views are solicited, advice sought, designs modified and then the whole cycle is repeated" (Nowotny, Scott, and Gibbons 2001, 142). The responsibility for this strong contextualization of science and technology should not be entirely passed on to states or governmental institutions, nor to individual scientists or scientific communities. Civil society itself is just as responsible for the negotiation processes in which big science projects come into being and transform democracy, and democratic views, in turn, transform big science projects.

Conclusion

The twentieth century witnessed an unprecedented shift toward democracy: dozens of hitherto nondemocratic countries experienced a transition to democracy, and older democracies were deepened (Dahl 1998). Democracy, however, is not a given or unchallenged practice or idea. Preserving and advancing democracy depends on what people do about it. To enhance the democratizing of big science projects and give people opportunities to reflect, anticipate, and negotiate on new directions in science and technology at a global level, liberal democracy, with its national scope and representative structure, does not suffice. Republican democratic views provide opportunities to include people in agenda-setting forums and consensus conferences. But in this model as well, only the nation's citizens are included and people from other countries are not invited to participate. Although the republican model is effective if governments are prepared to include a plurality of people in science policies, its institutional organization does not meet more global democratic requirements. The republic arena corresponds with the democratic practice of the town meeting rather than with global networks of communication. Conversely, deliberative democratic theorists mainly focus on oppositional civil society in a globalizing world. In view of the fact that global science projects are becoming increasingly common and have profound implications for individual and social life, deliberative democracy could theoretically provide good opportunities for a plural citizens' involvement in big science projects. However, there are no empirical examples of civil society actually providing opportunities to participate in and anticipate big science projects. New global and local arenas, interaction spheres, modes of communication, and institutions still need to be developed to reach this science democratic ideal. To preserve and advance democracy, in this case democratic involvement in negotiation processes on big science projects, "we"—a plurality of citizens, scientists, industries, institutions, and governments—have to be prepared to strive for democratic ideals and try out different democratic practices.

Notes

1. The assertion that the Human Genome Project (HGP) did not belong to the category of large-scale projects such as the Manhattan Project or the Superconducting Super Collider, as is noted, for example, by the Office of Technology Assessment (U.S. Congress 1988, 10), is refuted by the similarities between these projects and the HGP. Like the other big science projects, the HGP was a visionary project. Proponents did not hesitate to use metaphors such as the search for the Holy Grail or the writing of the Book of Life to find public and political support. Likewise, the planning of scientific activities was linked to time scales, often divided in periods of five years, and a bureaucratic organization of the activities and an international coordination of the various contributions to the projects were required. Furthermore, the HGP, like the other projects, was more expensive than the established forms of science. Its performance depended on large amounts of state and private funding. Following Weinberg (1967, 39), the HGP is big science because its start required "extremely elaborate equipment and staffs of large teams of professionals" and because the "scientific enterprise grew explosively and became very much more complicated."

2. The idea to sequence the entire human genome had several origins, for example, a scientific meeting in Utah in 1984 organized by the Department of Energy (DOE), a meeting organized by Sinsheimer in 1985 at Santa Cruz, and an article by Dulbecco in 1986. The DOE was the first to express serious interest in taking on the project (Cantor 1990, 50).

3. A map of the relative positions of genetic loci on a chromosome, determined on the basis of how often the loci are inherited together. The distance is measured in centimorgans (in honor of the American geneticist Thomas Hunt Morgan).

4. Botstein changed his opinion on the HGP while serving on a special National Research Council (NRC) committee chaired by Bruce Alberts in 1987 and 1988 (personal communication).

5. Watson's role in implementing the HGP should not be underestimated. He has been described alternately as "a scientific superstar" (Highfield 1991, 11), "the genome project's most prominent cheerleader" (Annas 1989, 19), and "standing like a colossus over the whole program" (Norton Zinder, quoted in Cook-Deegan 1994, 161).

6. Paul Berg of Stanford University, Charles Cantor of Lawrence Berkeley Laboratory, Charles DeLisi of the Office of Health and Environmental Research at the Department of Energy, Renato Dulbecco of the Salk Institute, Walter Gilbert of Harvard University, Leroy Hood of Caltech, Maynard Olson of Washington University, Robert Sinsheimer of the University of California, and Norton Zinder of Rockefeller University.

7. In the United States, Jeremy Rifkin, president of the Washington-based Foundation of Economic Trends, organized a national coalition of about seventy consumer representatives in April 1988 to call for a permanent congressional board to address the issues of genetic discrimination, privacy, and eugenics evoked by the HGP (Thompson 1989).

8. As regards the Human Genome Project, there was deliberation on internal criteria in the early planning phase (1986-1988), when skeptics like David Botstein and Shirley Tilghman were invited to join the NRC in the scientific discussions on the project (Cook-Deegan 1991, 129), and a skeptic like David Baltimore was invited to chair an advisory committee for the NIH’s first funding of genome research (Cook-Deegan 1991, 141). Now and then, individual ethicists were invited to join the debate. In a later phase (1988-1990), deliberations on internal criteria were closed to scientists and laymen alike. External criteria were introduced after the scientific program had been articulated by the NRC and others, when the social, economic, political, and bureaucratic implications came into view. In the United States, the Office of Technology Assessment performed a technology assessment, mainly aimed at resource allocation (U.S. Congress 1988; see also Cook-Deegan 1994, 150).

9. Instead, the emphasis was on the production of information material for television, the Internet, and other media and on the education of health professionals. See Review of the Ethical, Legal, and Social Implications Research Program and Related Activities 1990-1995 (NHGRI/HGP Reports 1996), and Review & Analysis of the ELSI Research Programs at NIH and DOE (ELSI Research Planning and Evaluation Group 2000).

10. It also prevailed in the European Parliament which, due to concerns about the danger of repeating history, allocated seven percent of its budget to ethical, legal, and social aspects. The Parliament thus guaranteed that the analysis of the implications of the program would be simultaneous with the genome research (Stemerding 1990).

11. The term *parliamentary debate* is understood as a substantial debate between the Cabinet and the opposition about a plan presented by the Cabinet. The art of the parliamentary debate is derived from the British House of Commons. It is common practice in European countries such as the U.K., the Netherlands, and Belgium.

12. In 1989, a Western German national parliamentary committee opposed the entire predictive medicine program. The Bundestag approved this opposition (Dickson 1989).

13. See Balmer 1996 for a description of the political cartography of the UK Human Genome Mapping Project, and Stemerding 1990 in the European Parliament. The United States led the way and spent $5.5 million in 1987, $29 million in 1988, $46 million in 1989, $85 million in 1990, and no less than $166 million in 1991 (Watson and Cook-Deegan 1991, 10). In Italy, a Human Genome Project has been funded since 1987 by an annual budget of $1.3 million (Dulbecco 1990). The UK Human Genome Mapping Project was launched in 1988 with a special annual allocation from the state of about $20 million. The USSR began a program in 1988. In the European community, the total budget for 1990 and 1991 was $17 million (Ferguson-Smith 1991). Japan started a genome research program in 1991 with a budget of more than $5 million over 5 years (Zilinskas 1997). A French program was launched in 1990. Third World countries play a very limited role in the project.

14. The words *democracy* and *republic* each designate types of popular government, the first referring to Ancient Greece, the second to Rome (Dahl 1998, 17).

15. "Aside from scattered press reports, the public remained largely ignorant of the project even after it had been under way for three years," Cook-Deegan concludes in his thorough description of the history of the start of the HGP (Cook-Deegan 1991, 152).

16. Mike Syvaenen of the University of California–Davis, who started a letter writing campaign in April 1990, was invited to testify before Congress in July 1990. Because traveling expenses were not paid, he suggested that Bernie Davis of Harvard University and Martin Rechsteiner of the University of Utah, who both voiced reservations about the HGP, should go and testify instead. Davis was browbeaten by Domenici during the hearing. Rechsteiner arrived too late because he had not been informed that the time of the hearing was changed (personal communication by Mike Syvaenen; see also Mervis 1990 and Hickox 1990).

17. The agora is comprehended in a premodern sense: as in the Ancient Greek polis, a selected group of citizens gather in a closed space and exchange knowledge and views on a particular subject.

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