



Technology and Citizenry: A Model for Public Consultation in Science Policy Formation

Gregory Fowler

School of Community Health
Portland State University
(gflower@geneforum.org)

and

Kirk Allison

School of Public Health, University of Minnesota
(alli0001@umn.edu)

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Abstract

Probably the most interesting feature of the 40-year history of biomedical biotechnology is the extent to which it has been open to – and influenced by – concerns over social values and the public’s voice. Good intentions notwithstanding, however, benchmarks and best practices are woefully lacking for informing the policy-making process with public values. This is particularly true in the United States where the call for “public debate” is often heard but seldom heeded by policy-making bodies.

Geneforum, an Oregon-based non-profit, has developed a practical and working model designed to encourage deliberative democratic processes for addressing the ethical and social issues raised by emerging biotechnologies. Ordinary citizens do not need to be scientists to understand the important implications of the new technological advances. When factual information and basic principles are conveyed in linguistically and culturally appropriate ways, the scene is set for a shift from monologue to dialogue, from “I-thinking” to “We-thinking,” to occur.

This paper describes the Geneforum model structured to intensify the democratization of policy decision-making, in general, using genomic science, in particular, as one example of its application.

The calls for public consultation

It was 40 years ago that the label, “genetic engineering” appeared in an essay entitled, “Portents for a Genetic Engineering” (Hotchkiss 1965). Today, “functional genomics” fuels new biomedical efforts of unprecedented scope and complexity ranging from personalized genomic medicine (McGuire et al. 2007) and public health genomics (Burke et al. 2006) to human enhancement. From the beginning of the “new genetics,” biomedical biotechnology has been viewed by scientists as involving social value commitments and thus requiring a more democratic discussion. For example, Hotchkiss set the tone by concluding his essay with the words:

The best preparation will be an informed and forewarned public, and a thoughtful body scientific. The teachers and the science writers can perform their historic duties by helping our public to recognize and evaluate these possibilities and avoid their abuses. For these things surely are on the way. (Hotchkiss 1965, 202.)

With the advent of recombinant DNA techniques in the 1970s, the scientists themselves were at the forefront of those who argued that: “[T]he social consequences of the recombinant DNA technology are too enormous and important to be left to specialists alone” (Nader 1986, 159).

Contemplating the prospect of human applications of that technology in the 1980s, NIH developed for human gene transfer research the most extensive public review process in the history of biomedical experimentation, and in 1990, Nobel laureate James Watson launched the U.S. Human Genome Project with a public commitment to complement the molecular mapping of human chromosomes with research designed to anticipate and address the social value issues raised by the project’s work:

Doing the Genome Project in the real world means thinking about these outcomes from the start, so that science and society can pull together to optimize the benefits of this new knowledge to human welfare and opportunity. (Watson and Juengst 1992, xv-xvi.)

For many scientists today, taking science and technology to the public is fast becoming a recognized and valued activity. A recent full-page editorial in the journal *Nature* (2004) extolled the virtues of “going public.” A year later, Alan Leshner, the Editor and CEO of the American Association for the Advancement of Science, articulated a similar vision in an editorial in *Science* about “where science meets society” (Leshner 2005).

In the view of Mark Cantley, former Advisor Research-Directorate-General of the European Commission on Biotechnology,

Given the profundity of the challenges thus brought into public and policy debates, democratic theory in the era of the knowledge society must take on board the involvement of citizens in the production, use and interpretation of knowledge for public purposes. (Cantley 2005.)

In spite of the many calls, a striking feature of the history of genetic engineering and biomedical biotechnology, especially in the U.S., is the extent to which the genome science policy process has remained largely impervious to the fears, hopes and concerns of the public. As illustrated by the emotional and persistent backlash against genetically modified organisms – and the more recent stem cell debates in the U.S. – strategies to integrate prevailing social values into the science policy-making process remain controversial, at best, and inadequate in the extreme. Unease is further complicated by a regulatory divide between publicly and privately funded research, on the one hand, and a deficit in clear articulation of fundamental concepts to the public, on the other (Allison 2007).

As a case in point, in March 2007 – acting on its mandate – the HHS Secretary’s Advisory Committee on Genetics, Health and Society (SACGHS) solicited public comments on its draft report of the promise, opportunities and challenges of pharmacogenomics (SACGHS 2007). The committee received 58 comments: 53 from subject-matter experts, but only 5 from the public at large. While many factors contribute to the disparity, at least one which deserves serious attention is the suggestion that U.S. policy formation regarding genome-based research and applications remains remote from the public.

Notable exceptions to this conclusion can be found primarily in Europe.

In a landmark popular referendum in June 1998, Switzerland voted by a 2:1 majority not to ban genetic engineering (Ribiero 1998). The popular initiative, called the “Gene Protection Initiative,” was rooted primarily in a substantial degree of citizen unease over what was initially viewed as a scary and mysterious new technology. Its stated goals were the prohibition of transgenic animals, the banning of all field releases of transgenic crops and the prevention of patenting certain inventions of biotechnology. Before the popular vote took place, the Swiss Parliament committed itself to enact a strict regulatory framework, but no bans. In the intervening three years of intense public education by the media, biotechnology industry, and the scientific and medical communities, general opposition to genetic engineering decreased from 62 percent to 33 percent, and acceptance increased from 25 percent to almost 40 percent.

These significant shifts in public values reflect both a proactive interest of the public, and a scientific community willing seriously to listen, use understandable terminology, and actively engage in interviews and forums (van Est and van Dyke 2000). Given time, money and the open sharing of ideas, complex societal issues raised by new technologies can be brought to the public’s attention allowing, at a minimum, for better-informed democratic decisions to be reached.

In Denmark, The Danish Board of Technology, an arm of the Ministry of Science, Technology and Development, recently celebrated two decades of consensus conferences and scenario workshops with Danish citizens. Working in collaboration with the Danish Parliament’s Committee of Science and Technology, the focus of the two methods is to create a framework for dialogue among policy-makers, experts, and ordinary citizens about technology policies (Andersen and Jaeger 1999).

The United Kingdom’s Wellcome Trust is the largest non-governmental source of funds for biomedical research in the world (www.wellcome.ac.uk). Among its other objectives, the Trust uses a broad spectrum of strategies to achieve its commitment to the public engagement of science aimed at raising awareness and understanding of the achievements, applications and implications of biomedical research. The Trust’s “Public Perspectives on Human Cloning” was one of the first publications to appear in the wake of the creation of “Dolly,” the world’s first mammal cloned from an adult cell in 1998. Van Est and van Dyke (2000) view the English and Dutch political responses to this event as making partial use of informed societal debate, Switzerland and the Netherlands more fully so, while political systems in the U.S., South Korea and Italy largely ignored its informative potential.

As further confirmation that Europe is seriously committed to the pursuit of public-interest science, in December 2001, the European Commission agreed to a “Science and Society Action Plan.” The document sets out a new strategy to make science more accessible to European citizens, and 38 objectives to achieve that goal (see http://ec.europa.eu/research/science-society/action-plan/action-plan_en.html).

In stark contrast to the above examples, the results of a research project designed to assess the likelihood of implementing a Canadian model of public consultation on xenotransplantation policy in the U.S. showed that the regulation of American biotechnologies remains in the domain of the scientific elite. In

that study, consulted members of the U.S. xenotransplantation community questioned the meaning of an “informed public” and agreed that gathering public opinion is desirable but not without rigorous public education strategies (Allspaw 2004). These observations are similar to those articulated by the National Bioethics Advisory Committee and numerous other blue ribbon federal commissions calling for “public debate” and “a more educated public” in the policy-making process (see <http://www.bioethics.gov/reports/reproductionandresponsibility/index.html>).

While “education” is clearly an important part of the equation, realizing social responsibility in a democracy requires more than education alone. It requires influence on the direction of policy decisions. It requires clear assertion of community values relevant to policy options. It requires finding a way for ordinary citizens to work in partnership with technical and scientific experts to produce policy that expresses community values and uses the best facts available (Garland 1999).

As experience with the Geneforum mode of public consultation demonstrates, complex societal issues raised by a spectrum of emerging biotechnologies can be brought to the public’s attention in ways in which informed democratic decisions about their application can be reached. Ordinary citizens do not need to be scientists to understand the important implications of the new technological advances. When factual information and basic principles are conveyed in linguistically and culturally appropriate ways, the scene is set for a shift from monologue to dialogue, from “I-thinking” to “We-thinking,” to occur (Jasanoff 2005).

Part of that transformation hinges on trust. Mistrust of the scientific establishment, fueled in Europe by the infamous 1996 UK mad-cow disease fiasco, tells us that attention must now be paid to the way in which knowledge and expertise is expressed, heard and acted upon in dialogic encounters (Cunningham-Burley 2006) and public engagement (Wynne 2006). Building trust is bidirectional. Scientists often mistrust the public, viewing it as incapable of coming to “right” conclusions regarding ends, prudential judgments regarding means, or regarding limits which are necessarily a function of values intersecting resource constraints and (perceived) risk (Taylor 2007). “Deciding what is important requires value judgments. Deciding how to achieve a higher level objective requires factual knowledge” (Keeney 1992). This raises the issue of spheres of competency. Expert technical knowledge is critical for designing the means to achieve the valued outcome.

So, how do we develop public trust in the practice and application of the newly emerging biotechnologies, and the democratic institutions which support them, in the twenty-first century, and beyond? Can we give new life to the concept of democracy – of government by the people – by weaving ordinary citizens more deeply into our decision-making processes; and through those processes, build community?

Cunningham-Burley (2006) suggests “... a sharing of power and greater public involvement in the early stages of policy formation and scientific and medical agenda setting,” echoed by Joley and Rip (2007) specifically in the case of contentious research and development.

Sheila Jasanoff (1995) reminds us of the need to talk, and sometimes to argue, about the scientific and technological choices that confront us: “In science, as in politics, the need for this process of inquiry, debate and learning – ‘participatory democracy’ – is endless.”

According to Beierle (1999), five social goals are key to evaluating public consultation approaches:

1. Educating and informing the public;
2. Incorporating public values into decision-making;
3. Improving the substantive quality of decisions;
4. Increasing trust in institutions; and

5. Reducing conflict and building community

Communication, listening, and transparency are mutually reinforcing requisites for realizing these goals. While there is obviously no one single formula for success in all of these arenas, one model developed in Oregon to promote dialogue at the intersection of genetics, ethics, and public values – an extension, actually, of the Oregon Health Decisions Model (Garland 1994, 1999) – comes close: Geneforum (<http://www.geneforum.org>).

A rational model for public consultation

Since its birth in 1999, Geneforum has evolved into an on- and off-line information platform for collecting public values and disseminating objective information on genome science to a broad spectrum of stakeholders.

Geneforum endeavors to create, in the words of Hotchkiss, an “informed and forewarned public” by addressing issues that are, for the most part, in the early stages of development and, in many cases, lacking any federalized policy framework (e.g., genetic privacy, gene doping, direct-to-consumer marketing of DNA information).

Geneforum believes that this “ahead-of-the-curve” approach is critical toward directing genome science in socially-responsible directions, a strategy which is significantly different from those generally used in the U.S. that allow the science to proceed until it reaches a critical impasse before engaging in any public discourse.

Driven by its core belief that public policy decisions will result in better outcomes to the extent that they are based on both public values and scientific knowledge, Geneforum uses a three-pronged approach designed to optimize the creation of socially responsible genetic science policy:

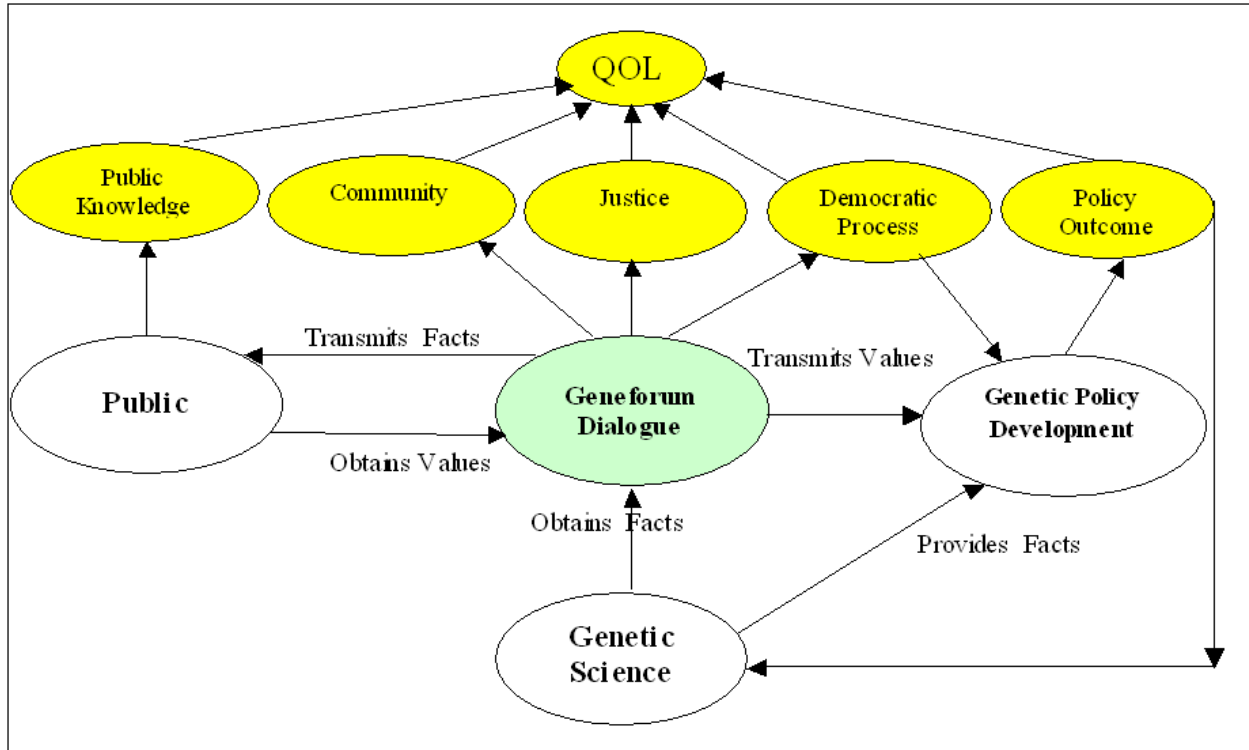
1. Increase the capacity of citizens to understand the impact of genetic science in their lives (Education);
2. Enable citizens to better understand and make informed decisions about the complex social and ethical dimensions of genetic research through dialogue (Engagement); and
3. Informing genetic policy through the measurement and monitoring of public values (Consultation).

Together, these approaches deliver what we label as “democratization,” an effort to inform the public consciousness – without manipulating it – and, in so doing, to build the capacity for bringing an informed public voice into the genetic policy process.

The Geneforum process

As illustrated in the flow schematic in Diagram 1, Geneforum relies upon genetic science for scientific facts and issues and then creates on- and off-line dialogues between the public and experts. The process strengthens important elements of democratic society: community, justice, and democratic processes. The ‘products’ of the process are an increase in public knowledge and, ultimately, policy outcomes. Public knowledge is mediated through public accessibility of content (hence a technical article in a journal does not automatically qualify as public knowledge in this sense, even if produced via public funding in a public institution). Democratic processes, public values and scientific data inform genetic policy development, whose policies feed back into genetic science *as policy*: the social accountability of science to public values. Public knowledge, community, justice, democratic processes and policy outcomes support quality of life in a democracy.

Diagram 1: An Overview of the Geneforum Process



As an outcome of this multi-faceted process, citizens become more capable of discussing and understanding the science of genetic research – and the complex social and ethical issues generated by it – and strengthen democratic deliberation in policy development.

As depicted in Figure 1 below, the Geneforum process also consciously creates an environment of dialogue and community building within the public sphere on- and off-line (e.g., at its Web site and through focus groups and random sample surveys).

Figure 1: Geneforum Strategies for Promoting Dialogue and Building Community

<u>Geneforum Offline Activities</u>	<u>Geneforum Online Activities</u>
Community talks	Online surveys and polls
Public forums	Online forums
Focus groups	Consumer resource guides
Public opinion surveys	“Genetizen” blog authored by experts
Programs with schools and educational institutions	Interviews with thought leaders
Media outreach	User participation tools (e.g., posting of comments and questions)
	Knowledge warehouse for offline activities (e.g., past public forums, survey summaries and analyses)

Through its consultative process, Geneforum obtains values from the public (hopes, fears, priorities and uncertainties about the issue or issues being explored) which it transmits to the genetic policy development process wherever it is being debated, from corporate boardroom to legislative chambers. As a result, public participation in a deliberative (discursive) democracy is encouraged, and socially just policy outcomes are made more likely.

Geneforum acts on the belief that public policies are ethically justified and legitimate to the extent that they emerge from the reasonable deliberation of free and equal citizens who will be significantly affected by them (i.e., a good process is the best route to good policy outcomes). Of note, deliberative processes support three important goals: fulfilling the normative rationale of democracy in policy formation, augmenting the legitimacy of policy formation and implementation, and finally contributing to professional enquiry, including in the area of genomics enhancing population participation upon which that knowledge base depends (Fischer 2007).

While Geneforum advocates passionately on behalf of good process, it never lobbies, or intentionally introduces bias on behalf of particular policy alternatives. Impartiality is a guiding principle of the Geneforum model.

Linking the public voice with the policy process

In order to develop a genetic policy which reflects informed public values, Geneforum uses several unique strategies:

1. Identification of a policy receptor site;
2. Translation of public values into policy-relevant input;
3. Partnership with experts; and
4. Separation of fact (technical content) and value.

Receptor site

Policy receptor sites are vehicles of policy which, in order to focus their activities, connect the public to the actions of the state through identifiable social structures such as committees, commissions, legislatures, boards of directors, and negotiation teams (Garland 1999).

In the Oregon State Legislature, the “Advisory Committee on Genetic Privacy and Research” is one such entity. Working on behalf of the members of that committee, GeneForum continues to use its tools of consultative strategies to “... educate the public and obtain public input on the scientific, legal, and ethical development in the fields of genetic privacy and research” (Fowler 2002).

The focus of generating public input is to tap into values by way of value-laden questions that can be effectively and wisely discussed among a broad cross section of the public. For example, who owns genetic information? Is it the individual? The family? Humanity? Who should have access to genetic information? Private individuals or families? Businesses? The State? These are not factual matters to be decided by experts, but rather a matter of the values of the community (Fowler and Garland 1999; Garland 1999).

Partnership with the experts

Going to the community for its values won't work if there is no partnership with experts. The collaboration makes most sense when it is seen as half of a joint effort between the general public and technical experts, both helping to shape the political decisions of policy makers. The expertise GeneForum seeks comes from a broad spectrum of sources – whatever areas necessary in order to move the policy process forward.

The values that guide public policy decision-making should be rooted in the values of the public, and the beliefs that guide public policy decision-making should be based on scientific findings. This requires that the public, as stakeholders, evaluate relative desirability while experts evaluate relative likelihood (Anderson et. al. 1998).

A model of public consultation structured to partner citizens, experts, and policy makers in a coordinated process can “broadly formulate the decision problem, guide analysis to improve participants’ understanding of decisions, seek the meaning of analytic findings and uncertainties, and improve the ability of interested and affected parties to participate effectively in the risk decision process” (Stern and Fineberg, 1996: 3).

Fact-value separation

Normatively, decision-making consists of two phases: problem structuring and evaluation (Von Winterfeldt and Edwards 1986; Clemen 1991). Problem structuring involves the identification of alternatives, values that distinguish the alternatives from one another, and uncertain events that could affect the values associated with a particular alternative.

Evaluation is a matter of weighing the relative desirability of various outcomes and the likely impacts of various uncertain events in deciding which alternative is, on balance, preferable.

The GeneForum methodology of fact-value separation, that is distinguishing technical from value judgments, is predicated on the belief that a clear understanding of this distinction can enhance the quality of public input to public policy decision-making and counter the objections that are so frequently raised when public input is offered to inform public policy decision-making.

As described in Table 1, the process involves three-steps:

Table 1: The Geneforum Fact-Value Separation Process

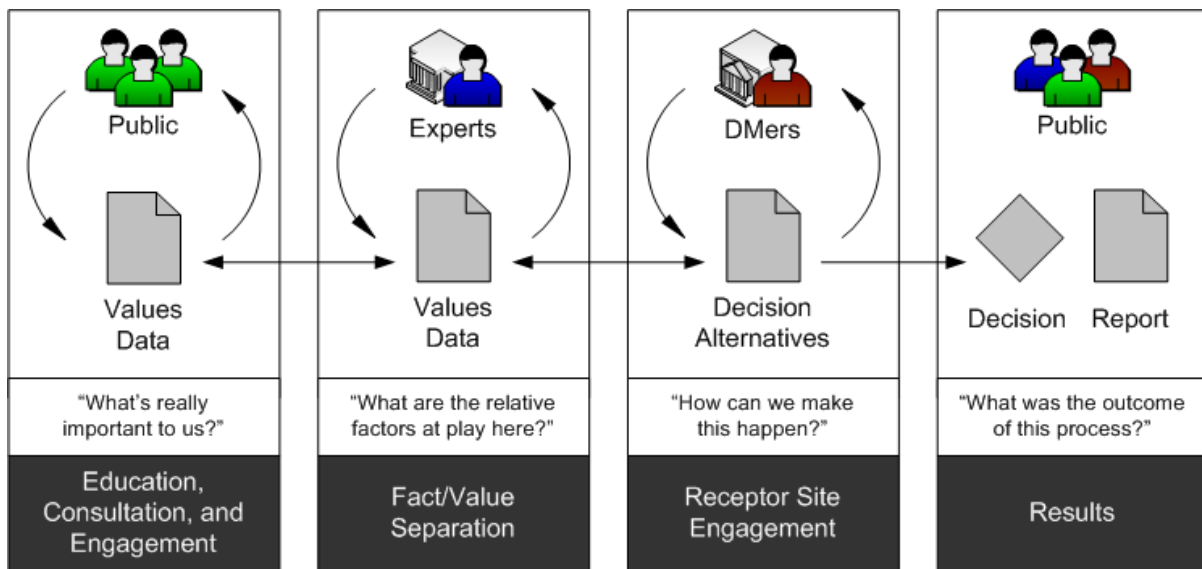
Values: Relative importance	Get from the public
Facts: Relative likelihood	Get from experts
Alternatives: Relative preference	Get from decision makers

The final step of trading off information about facts and values to determine the relative desirability of various public policy alternatives is left to the policy decision makers.

As depicted in Figure 2, the Geneforum consultation process can be summarized into three steps:

1. Experts review the initial compilation of public values to look for factual assumptions that may be questionable (i.e., the probability of policy X resulting in consequence Y) and, when possible, provide their best judgments as to the correct assumption(s);
2. Policy makers then review the draft to see how it can be made more useful for guiding choices among the alternatives with which they will be faced;
3. The public participants (with facilitation) create a final report to be sent to the policy making receptor site.

Figure 2: Technology and Citizenry Model v.1.0



The outcome of this process will be, at the very least, a structured list of shared values and a list of important value differences. It may also be possible to provide a list of differing beliefs regarding matters of technical judgment that account for differences in preferences among alternatives and also a list of possible modifications to current plans that can be expected to enhance public support.

The Geneforum proof-of-concept

The 1999 Oregon Legislature created the Genetics Research Advisory Committee (GRAC), a gubernatorially mandated group of Oregon healthcare professionals and policymakers, to explore the issues of genetic privacy and research in Oregon. Throughout its deliberations, the GRAC had the benefit of input from Oregonians around the state generated from a series of focus groups, statewide surveys, interviews with opinion leaders, town hall meetings, public forums, and responses to internet interactive scenarios, all developed and conducted by Geneforum. As a result of the data contributed by these consultative public strategies, the GRAC included in its final report to the state legislature a unanimous recommendation to create a new, and ongoing, advisory committee to monitor genetic research and privacy throughout the state. The following language in that Bill reflected both the experienced – and proposed – role of the public in that process:

As part of its regular activities, the Advisory Committee on Genetic Privacy and Research shall create opportunities for public education on the scientific, legal, and ethical development within the fields of genetic privacy and research. The committee shall also elicit public input on these matters. The committee's recommendations shall take into consideration public concerns and values related to these matters. The committee should make reasonable efforts to insure that this public input is representative of the diversity of opinion in the Oregon population. (ORS 192.549(8); Fowler 2002.)

In the intervening six years, Geneforum has remained a member – and continues to work on behalf – of the ACGPR. Many of the findings generated by Geneforum's ongoing work have enriched, and extended, the committee's deliberations, and several have been responsible for keeping Oregon's genetic privacy legislation one of the most comprehensive and forward-looking documents in the U.S.

Conclusion

The Geneforum model presented here provokes some points to consider for the future of emerging technologies, in general, and the science of emerging technologies like genetic enhancement, in particular.

American scientists and science policy makers need to recognize that the public is a key part of the thinking society, with particular interests, concerns and questions about science and technological innovations and how these will shape the future of life on this planet. The public at large is also somewhat less subject to the effects of intramural disciplinary competition. Increasingly, science and technology intersect with people's beliefs and values, in large part because science and technology are becoming involved in issues with ethical and value dimensions regarding the substantive nature of human being on the one hand and the limits of instrumentalization on the other.

To address the newly invested public of science, the idea of a one-directional flow of information needs to be replaced by dialogue, engagement and participation. That means questioning some of the bland and often pejorative stereotypes of the public, finding out more about the public and developing ways of talking with and to them more effectively.

That must have been in Ian Wilmut's mind when he introduced "Dolly," the world's first mammal created from adult cells, to an august audience of scientists, philosophers, religious leaders and the media at a 1997 AAAS Symposium, with the words,

I believe that it is important that society decides how we want to use this technology and makes sure it prohibits what it wants to prohibit. (Wilmut 1997.)

For that to happen, however, effective community engagement will be required and that can occur only if governance 1) ensures that the engagement is reflective of the community – that the aspirations of the special interest groups are calibrated against a broad cross-section of the community; 2) is open with the process of engagement and with sharing information, and with broadly-based steering or reference groups to guarantee transparency; 3) and all stakeholders listen genuinely and empathetically to all voices, and be genuinely committed to embracing the outcomes.

Only in these ways can better decisions, more trust, stronger communities, and embodied democracy be attained.

Scientists, policy-makers and industry also need to collaborate closely and acknowledge the obligation they have individually to engage in dialogue with different groups of the public in accessible but accurate language. This engagement needs to be in clear, non-technical terms, including benefits and costs, and addressed to discrete citizen concerns. While public perceptions and beliefs that run counter to *de facto* expert knowledge are not acceptable justifications for public policies (Brunk 2006), the public is capable of differentiating issues, even if they do not understand all technical details:

People may not possess “expert knowledge,” but this does not mean they have nothing to contribute to decisions about science and technology. (Jasanoff 2005)

The lack of scientific knowledge among the general public often leads policy makers to rely solely upon expert input and omit or trivialize the ordinary citizen’s role in policy development (Brunk 2006; Dean 2005). On the other hand, such an approach can exacerbate public policy conflicts (Sarewitz 2004).

We live with the benefits and the curses of technology, often working to remedy past mistakes through further advances. This ongoing process of inflicting damage and then playing “catch up” increasingly threatens the biogeochemical web upon which all of humanity depends. Until now our technology has been focused on shaping our world. But even through all of that, as a biological organism, the essence of our humanity has not been altered significantly.

For the first time, the biological determinants of humanity are becoming subject to technological manipulation. What does the concept of progress, or enhancement, mean when applied to the human genome? Do we have the necessary expertise on values consensus to proceed? Are we prepared to live with the unintended consequences?

The genomics revolution rolls on, promising tremendous improvements in our ability to secure a new level of physical well being while simultaneously making us very uneasy about the future. So, the question then becomes: If we can’t stop the process, how do we guide it?

Too often the pluralism of our society is seen as an obstacle to creating a viable ethical and political consensus on science and technology. Taken as a whole, the basic objective of the Geneforum model – and others which seek to address similar challenges in different ways – is to make that pluralism a source of enlightenment rather than confusion, an enabling rather than a disabling feature of our democratic way of life.

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