

Geneticists' Views on Science Policy Formation and Public Outreach

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Though much research about the public's views of scientists, genetic research and its moral, ethical, and social implications exists, little has been done to investigate how scientists view their own role(s) in public discussions and policy formation related to genetic research and technologies. We interviewed 20 academic geneticists in the United States about their perceptions of the roles they and others (e.g., professional societies, the public, ethicists, and elected officials) do and should play in the formation of science policy, the communication of science to the public, and the public discussions of moral and ethical issues raised by scientific advances. The participants in our study thought that scientists should be more actively involved in public outreach and science policy formation, but frequently they felt ill-equipped and unsupported by their peers and institutions to pursue these activities. Furthermore, many were skeptical of or did not trust elected officials—who they consider uninformed about the issues and too driven by political agendas—to formulate sound science policy. They do, however, have faith in the ability of scientific societies to influence policy effectively, and some thought that societies should play a larger role, both in science policy and as a liaison between scientists and the public. Finally, participants offered suggestions for increasing the involvement and influence of scientists in science-policy formation and public discourse.

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INTRODUCTION

While there are plenty of stereotypes about scientists—the disheveled hair, the unique fashion sense, the lack of discernable social skills—the fact is that they are no longer denizens solely of the Ivory Tower, nor can they afford to be. Genetic research increasingly touches the lives and imaginations of ordinary people. Genetic technologies are being used to predict disease risk, convict or exonerate those accused of crimes, and

enhance the plot lines of Hollywood movies. There is a growing need for genetics experts to enter the public sphere. How do geneticists view this need? Is stepping out of the lab a *responsibility*, or merely a choice that biomedical scientists are free to make? Are biomedical scientists *obligated* to engage the public and policy makers in critical discussions of science? If so, why? What barriers do scientists face when seeking to share their knowledge and perspective with non-scientists? What are or ought to be the roles of scientists and others (e.g., professional societies, the public, elected officials) in the development of science policy, and in the public discourse about the implications of scientific research?

While many studies have surveyed the public's views of scientists and scientific research [National Science Board, 2002; Research!America, 2004], few have addressed how *scientists*—specifically biomedical scientists—view their own role in the public sphere. Effective science policy must be informed by the science itself and those who conduct that science. Knowing how scientists perceive their relationships with other stakeholders is of great importance in designing and evaluating strategies to facilitate the fruitful participation of all concerned.

While a recent effort by Research!America and Sigma Xi assessed scientists' "attitudes about public outreach, from benefits to barriers,"¹ most of the studies on biomedical scientists' views have been conducted outside the United States [Kerr et al., 1997; Prpic, 1998; Nicholas, 1999; MORI, 2000; Middleton-Price, 2002]. The largest and most comprehensive of these is a study commissioned by the Wellcome Trust. Completed in 2000, "The Role of Scientists in Public Debate" details the results of a nationwide survey of 1,540 scientists in the UK regarding their involvement in discussions of scientific research with members of the general public (public outreach/engagement). This study found that most of the scientists they surveyed believe that "it is their duty to communicate their research and its social and ethical implications to policy makers, and to the non-specialist public" [MORI, 2000]. They also found that scientists in the UK felt poorly equipped to fulfill this obligation. Despite this, just over half of those interviewed had participated in at least one public engagement activity in the previous year. In another survey conducted in the UK, 81% of genetics professionals reported having received no training in communicating science or its implications to the lay public [Middleton-Price, 2002]. This study also found that the most common way in which scientists had engaged the public was through talks at schools and colleges.

A smaller study conducted by the British Society for Human Genetics of their membership covered a similar set of questions to the Wellcome Trust study, and also asked respondents which moral and ethical issues raised by scientific research deserve more thorough public debate.² A study of Croatian scientists

¹http://www.researchamerica.org/outreach/science_outreach.html

²One of the best resources for finding these and similar studies is also based in the UK. The psci-com website (<http://www.psci-com.ac.uk>) was developed by the Wellcome Trust and is a gateway to a wealth of resources on the interplay between society, science and technology.

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found that a major source of a scientist's self-perceived ethical obligations derive from their status as professionals [Prpic, 1998]. A small study of molecular geneticists in New Zealand found that the scientists' sense of responsibility to society was both ethical *and* pragmatic, and included communication with and education of the public [Nicholas, 1999, 2001]. This group of scientists also cited barriers to such engagement, including lack of time or professional recognition.

Within the US, the appropriate role of scientists in society has been explored largely in conferences, commentaries by individual scientists, and thought pieces by non-scientist academics [Camenisch, 1996; Beckwith, 1997; Reiser and Bulger, 1997; Wiggins, 1997; Woolley, 1997; Beeson et al., 2001]. Norman Augustine has exhorted scientists to "become as adept in dealing with societal and political forces as they are with gravitational and electromagnetic forces" [Augustine, 1998]. Bentley Glass, a geneticist and former president of the American Association for the Advancement of Science (AAAS), described the obligation of scientists to communicate science to the public as a duty in the name of democracy, because democracy "rests secure only upon a basis of enlightened citizens who have imbibed the spirit of science and who comprehend its nature as well as its fruits" [Glass, 1993]. More recently, Alan Leshner, in an editorial in *Science* argued for a reciprocal relationship between scientists and the public: "The centrality of science to modern life bestows an obligation on the scientific community to develop different and closer links with the general population" to "help evolve the compact between science and society so that it will better reflect society's current needs and values" [Leshner, 2003]. There have also been a number of science advocates in Congress who have exhorted scientists to become more involved in the political process [Brown, 1995; Lawler, 1995; Rogers, 2003]; one of the most prominent was Representative George E. Brown, who repeatedly urged "...greater involvement in the policy process by the rank and file scientist and scientific organizations" [Brown, 1995].

The term 'civic scientist' has been coined to describe those researchers who are active not just in the scientific community, but also in the human community [Lane, 1999]. Engagement with the public—or with science policy formation—entails not just educating or informing, but listening and learning. A civic scientist recognizes herself as one part of a whole that is far more complex and rich than a single scientific discipline, and with much more to offer or consider than solely a scientific perspective.

If we accept that a strong relationship between the scientific community and society is a worthy and even necessary goal, how can it best be achieved? While several groups have taken steps toward this goal [The Center for the Health Professions-UCSF; Woolley, 1992; Jasanoff et al., 1997; Dresselhaus, 1998; Jackson, 2003; Brown et al., 2004], the design of efforts to forge and maintain this relationship must take into account the views of US scientists regarding their roles and responsibilities in public and science policy engagement. Studies done abroad are insufficient, as the conduct and understanding of science are influenced by national culture and politics [van Heyningen and Cox, 2002; Leshner, 2003]. Furthermore, knowing how scientists perceive the roles of others can inform the development of effective strategies to increase scientists' involvement.

Geneticists are of particular interest given the dramatic way in which genetic science has permeated society over the last decade, and the promise that genetic medicine will play a role in everyday medicine in years to come. The Human Genome Project thrusts genetic science into the public eye, garnering considerable news coverage and generating discussion, hope, and fear among the public and policy makers. Consequently, geneticists may have an interesting and unique perspective on

the relationships between scientists and the world outside of the laboratory.

Here we present data from a set of in-depth interviews with 20 US academic geneticists about their perceptions of the roles they and others play in public discussions and policy formation related to genetic research and technologies. These data may provide a basis for refining the engagement efforts currently underway, and importantly, for encouraging and assisting scientists, scientific organizations and institutions, and academic departments in the design of effective, targeted approaches to improve the relationships between the scientific community, the general public, and the governments that represent them.

MATERIALS AND METHODS

Recruitment

Laboratory scientists from academic or government research centers were recruited for in-depth, semi-structured interviews. The membership database of the American Society of Human Genetics (ASHG) was queried (by ASHG staff) for individuals who met the following criteria, as defined by the 2003 Membership Application:

- Primary affiliation—Genetics, Pediatrics, Pathology, Psychiatry/Psychology Medicine, Ob/Gyn, Reproductive Medicine, Neurology, Family Medicine, or Internal Medicine Department in a medical school, or in a public health or graduate school, college or university, hospital or clinic, institute or foundation, or government;
- Academic rank code—Professor, Associate Professor, Assistant Professor, or Instructor;
- Major type of work—Research;
- Laboratory setting—University or government affiliated research lab;
- Research designation(s)—Basic clinical or lab research;
- Special interest areas—Differentiation, development and morphogenesis, molecular genetics, genomics, or neurogenetics/behavioral genetics.

A total of 275 recruitment e-mails were sent, explaining the study and requesting participation. Interested individuals replied by e-mail. Study staff then responded to any questions and scheduled the interview. Recruitment was stopped once we achieved our goal of 20 participants. Prior to the interview, each participant received an Interview Disclosure Statement describing the study. The study protocol and Interview Disclosure Statement were reviewed and approved by the Johns Hopkins Medicine institutional review board.

Participants

Of the 20 participants included in the study, five are researchers of differentiation, development, and morphogenesis; eight are molecular geneticists; three are genomicists (scientists who study genetic variation at the level of the genome, rather than, e.g., at the DNA level); and four are neuro/behavioral geneticists; all conduct basic research. The participants included 5 women and 15 men, a distill representative of the distribution in the recruitment pool (approximately 30% female). The participants work in 14 different cities within 10 states and are employed by the federal government or a university medical school. Participants range in age from 34–56, with an average age of 43.8 (median of 44). Eight participants have a country of origin other than the United States. Nineteen participants are self-described as White. All participants are currently married or have been married, and all but three have children. Half of the parti-

cipants identified themselves as Catholic, Jewish, or Protestant, while the other half self-identified as agnostic, atheist, or having no religious preference.

Data Collection

Participants were asked about their scientific background, attitudes about the professional responsibilities of scientists, personal experience with public engagement and science policy formation, perceptions about barriers to participation in such activities, suggestions for improving scientists' participation in public engagement and science policy formation, as well as their views on the process of setting science policy, communicating science to the public, and engaging the public in discussions of the implications of genetic research.

One interview was conducted in person, with remaining interviews conducted over the telephone. The duration of the interviews ranged from ~50 to 120 min, with an average of ~70 min. A brief demographic survey was administered following the interview. The interviews were audiotaped. Audiotapes were labeled with a code, transcribed, and destroyed at the end of the study to protect participants' privacy. Transcripts were stripped of identifying information. Participants were not compensated for taking part in this project.

Analysis

The narrative data were managed using the qualitative data analysis program NVivo 2.0. Data collection and analysis were an iterative process. Analysis began with the first interview. Themes were identified and used to inform the coding process. Codes were refined as more data were analyzed.

RESULTS

Setting Science Policy

The majority of the scientists in the study thought that professional scientific societies should play a prominent role in setting national research priorities and influencing the allocation of federal research dollars. In addition, when asked whom they trusted most to contribute to the formation of science policy, participants overwhelmingly cited scientists and/or professional societies.

"Individual scientists and scientific societies [have the most to contribute], just because they have the greatest knowledge of the fields, and what is possible, and what needs to be done, and what direction things need to go."

Among those who thought professional societies should play a role, half believed that societies are not playing as large a role as they should.

"I think they should play a very strong role, and I think it's underplayed . . . I don't know if professional societies, for instance, lobby Congress, but if they don't, that should be done . . . I think they should [have] a very, very strong role there."

In fact, when a specific role was mentioned, lobbying and/or advocacy was the most common: advocacy both to Congress and to the general public. Others thought professional societies should build on what they already do.

"...the things I've seen come out of [professional society] consensus conferences and work groups . . . have been well thought out, rational, reasonable approaches: very heavily placing realistic values on the knowledge that's there. So, perhaps we should do

more of that, but give them more credence, and make sure that those perceptions and knowledge [are] passed on to policy makers . . ."

However, some pessimism was voiced about the ultimate effectiveness of professional societies.

"You go to the American Society of Human Genetics, and we all write letters to our Congressmen, and we urge this that and the other: It makes no difference because ultimately the decision is political."

According to our sample, professional societies should take the lead in facilitating the participation of individual scientists in setting national research priorities. Most thought that scientists' participation in science policy formation should be in the context of a larger group, such as a professional society, advocacy group, or ad hoc advisory board. Some participants cited concerns about conflicts of interest and inappropriate influence of personal agendas as the reason for group (vs. individual) participation. The greater power of professional societies as large, established entities was also mentioned as enhancing their capacity to influence decision-making in Congress. While half of our participants thought that scientists are currently fulfilling their role by participating on relevant policy or advisory boards within their societies, several said that scientists should participate more.

While all of the scientists we spoke to thought that the public should have input into determining national research priorities, many were concerned that the public is not adequately informed about scientific issues, making their input a potential hindrance to science.

"[The] public [are] the people . . . spending their tax money, so they certainly have a role. The problem is that the [public doesn't] understand a lot of the research. They don't have the knowledge to . . . say what's important and what's not; where the dollars should go or shouldn't go."

Two scientists thought that the public currently has too much sway in determining scientific priorities, though the majority thought that since most academic research is publicly funded, taxpayers should have a voice in allocation decisions. Only three scientists thought that the public is doing a good job of fulfilling their role in setting research priorities.

The majority of participants thought that ethicists have a role to play in priority setting, and half of those thought ethicists' primary role was to frame the issues, enabling a thorough and informed discussion.

Participants believed the role of elected officials is to allocate resources to scientific research at the broadest level, not to set scientific priorities. For example, elected officials should allocate funds to the National Institutes of Health (NIH) and the National Science Foundation (NSF), but not direct how that money is spent. Participants thought that bureaucrats (e.g., at the NIH) and/or elected officials currently have the most influence on the formation of science policy, broadly; however, no participants identified elected officials when asked who they trusted to contribute to detailed science policy. Participants thought that elected officials, like the public, lack the necessary information to think critically about science or its implications, and are skeptical of their motives.

"I worry about the government being manipulated . . . by politicians who—almost in the absence of adequate knowledge—are willing to just promote their own political views, rather than really . . . getting some adequate scientific information."

About a third of those who responded said that elected officials have a responsibility to make sure they have access to—and avail themselves of—quality scientific input. An equal number (i.e., 1/3) of participants thought that elected officials adequately fulfill their current role; however, only two participants thought that this participation is helpful—rather than harmful or neutral—to science. A number of participants expressed frustration with what they believed to be often understandable, but onerous involvement of policy makers, citing instances such as the HIPAA privacy regulations and CLIA as burdensome regulations that create unnecessary red-tape. Others thought many—though not all—elected officials' performance inadequate, citing the “current political environment,” the August 2001 stem cell decision, the recent attempts by Congress to discontinue funding for approved research, and their perception that the present administration is unwelcoming to science.

Participants' views of government bureaucrats were more favorable, as they often saw them as fellow scientists (e.g., at the NIH). These scientists thought that because bureaucrats are not elected or appointed and not beholden to a constituency and the election cycle, they are sufficiently immune to or protected from politics. In addition, they were more likely to ascribe to bureaucrats responsibilities including regulating and stewarding scientific research into medical or commercial use.

Communicating Science to the Public

Scientists and the popular press were most commonly cited as being responsible for communicating research results and their implications to the public, but few of the scientists we talked to thought that this process consistently works well.

“We're very bad at explaining things simply without insulting people... so we need help.”

“... sometimes it's much harder to refute a sound bite with a well-reasoned argument... if you want to make the 7 o'clock news... you're only going to do it if you can say what you want to say in 15 sec.”

When the media was mentioned, most participants voiced mixed reviews, praising some news outlets and expressing disappointment in others. Terminology and jargon were cited as examples of difficulties in the media's communication of science to the public.

“... to a certain extent, one has to be very careful about one's wording and how one presents things; but even then, there's a lot of misconception... for example: cloning. The word “cloning” means different things to different people.”

Despite the challenges, the scientists we talked to were adamant about the need to communicate scientific findings to the public in an effort to achieve increased public awareness and understanding of science. They thought this was particularly important with regard to the public's support of science and their ability to participate in science-policy formation and the national dialogue about the implications of scientific research. In addition, many participants thought that scientists should do more to inform or educate the public than they are doing currently.

“I can see us as the people who are not just writing up papers for publication, but also doing outreach, and talking to high school students, or primary school students, and the lay public in town hall meetings... to disseminate information in a way people can understand.”

Societal Discussions of the Implications of Genetic Research

Participants held a variety of views about who should lead societal discussions of the moral, ethical, and policy issues raised by biological and biomedical research, though two leadership structures were most frequently suggested. A third of participants thought that ethicists should take the lead in these discussions.

“I'm going to nominate ethicists first, mostly because I see them as people who can hopefully articulate the key issues, identify the people who are going to be most mindful of each issue and... frame a debate without necessarily taking sides.”

In contrast, a third of participants thought that many people should contribute equally to the discussions.

“... what we need is a concerted effort across a number of different aspects of society to ensure that we have enough participation on the part of people in government, that we have enough input on the part of scientists, and... maybe there's a role for a few grassroots firebrands driving the debate, and insisting that the questions be addressed.”

Once again, a major concern voiced by participants surrounding discussions of the implications of scientific research was the low level of education and scientific understanding among the public. This theme came up throughout the interviews, in a variety of contexts. Many participants admitted that some of the responsibility for the lack of the understanding on the part of the public “reflects [scientists'] poor education of the public at large about what constitutes 99% of our day to day work.”

A lesser, but conspicuous concern of some of the scientists was the role they thought that religion sometimes plays in discussions of the ethical implications of science and subsequent policy decisions. The main concern among this group was that in discussions of science, religious views are often relied upon in the absence of—or despite—scientific fact. They are concerned that a small group of vocal citizens with strong religious convictions will have a disproportionate influence on science policy.

Professional Responsibilities

Almost all of the scientists in our study believed that scientists' participation in public engagement and policy formation is a responsibility. About half thought the responsibility derives from their role as professionals, and the same number cited receipt of federal funding as creating obligations. Slightly fewer thought their responsibilities derived from a personal responsibility as a member of the human community.

“However much scientists whine about it, [the life of a scientist is] enormously privileged because of the freedom involved. And for that freedom, you've got to have a certain amount of giveback. And the giveback has to be some moral and ethical responsibilities to the community at large, especially if they're funding your work.”

When asked to whom these responsibilities are owed, the majority said the society at large, or humanity. Research subjects, the scientific profession, the scientific record, and one's self were also each mentioned more than once.

“You have so many responsibilities. You have responsibilities to your family and yourself. You have responsibilities to the public, paying your wage for the most part. . . . And I think you have a responsibility to humanity, in general. . . .”

Personal Experience with Public Engagement and Science Policy Formation

For many of the participants, part of the responsibility of being a scientist is informing the public and engaging them in discussions about science; however, when asked to describe the most effective means of influencing the public and the policy-making process, participants were often at a loss. In lieu of a definitive answer, many cited public engagement activities designed to inform and educate the public.

“I think open forums [are] the best format, where we invite the public to attend, and the interested ones come in. I also think there should be more television and radio exposure of discussions or issues. . . .”

Others thought that working through their professional societies was a more effective strategy.

Many—but not all—of the scientists we interviewed had participated in some sort of public engagement activity. Most participants had taken part in two or more different types of activities; most commonly, presentations to school classes, community groups, or disease advocacy groups. The participants had also talked with patients, elected officials, journalists, and had brought high school students into their labs to learn about genetics.

Barriers to Participation

Scientists face significant barriers to achieving the level of involvement in public outreach and science policy formation that many would like (see Table I). The most frequently mentioned barriers were time and the absence of credit toward tenure.

“...especially in large, private university medical schools, it’s not seen as anything that’ll get you promoted. Or, it takes time away from doing things that you have to do to get promoted, or that you’re told you have to do to get promoted. So, unless you’re already very famous for your science, getting famous for talking to school groups, and so forth, isn’t going to help you.”

Another disincentive is the threat of being stigmatized by one’s peers for being actively involved in public education and public policy debates.

“[The] Carl Sagan Syndrome. . . that if you become a little bit too well known, you sort of forfeit your seriousness as a scientist.”

Thus, the scientific community itself may discourage some scientists from talking with the media or being “too” publicly visible.

Additionally, participants frequently said that they did not know how to find forums in which to engage the public in discussions about science, and they lacked the necessary communication skills.

“It’s kind of hard to know where to start, in terms of—like if you did want to talk to a school group or something, I wouldn’t quite know how to go about it.”

“...but for the average scientist and the very serious scientist, it’s a matter of poor access, and no reward, and poor training. It would help if we actually knew how to address a room of non-scientists. We’re kind of poor communicators.”

Several participants mentioned unsuccessful attempts to get involved in public education activities. For example, some had signed up for ASHG Mentor Network [American Society of Human Genetics], but had not, to their disappointment, been tapped to participate.

Contrary to the experience of most, several participants cited support they had encountered from their institutions, peers, professional societies, or enthusiastic audiences.

“All the people that I’ve worked for have been very positive about. . . what we broadly call community outreach. I have to say, I have not had any problem in going out to do this with groups of people, when I have had the inclination to do so.”

We were not able to identify any common characteristic among those who perceived supports rather than barriers to participating in science outside the lab.

Suggestions for Improvement

Participants offered a number of suggestions for improving scientists’ participation in public and science policy engagement (see Table I). Their thoughts fell into three broad categories: government-based changes, changes others should make, and changes scientists themselves should make. Two government-instituted changes suggested by participants that could improve the climate for science nationally are to have more scientists in government and to maintain a non-partisan, fully representative national science advisory board, completely divorced from politics (implying that they did not believe such a body currently exists).

TABLE I. Participants’ Views on Participation in Public Outreach and Science Policy Formation

Barriers to participation	Lack of time to engage in activities outside of those required to earn tenure Absence of credit toward tenure for public engagement activities Professional stigmatization (the “Carl Sagan Syndrome”) Unaware of venues or opportunities for public engagement and participation in policy formation Lack of necessary skills (e.g., ability to communicate science to non-scientists)
Suggestions for improvement	Encourage more scientists to enter government service Include in the education of science trainees, instruction on the social and policy implications of science, and on communicating science to non-scientist audiences Improve science education in public high schools Increase interaction of scientists with Congress and the media

To reduce the barriers to scientists' involvement, participants suggested that instruction on the social and policy implications of science, and on the communication of science to non-scientist audiences should be a formal part of a scientist's training. Additionally, NIH grants could provide some percentage of a scientist's salary to fund public outreach and education.

The most frequently suggested change for others to implement was improved science education in public high schools, starting with better scientific training of high school educators. Two participants suggested better science education in public health and law schools to improve the science literacy of those likely to become government bureaucrats and elected officials. There was also a suggestion that it is not only science literacy that must be improved, but also the public's understanding of and ability to evaluate risk.

Several participants suggested that perhaps the best way for others to approach the problem of scientific literacy is through the media.

"[Science] makes great storytelling, and it makes for great TV.... But it has seldom been used that way...there have been some really good quality scientific media on TV.... I think of things like Sir Richard Attenborough's series... 'Here we are in the jungle of Peru, waiting for the...'—these are fabulous. They convey some of that infectious enthusiasm."

The last set of suggestions had to do with changes that scientists themselves should make in their own behavior. There were several calls for increased interaction with Congress and the media. Participants suggested that professional societies and individual scientists should participate in letter writing campaigns to Congress, and take advantage of the Opinion sections of local and national newspapers. There was also a suggestion that working through established, trusted advocacy groups may allow individual scientists to more effectively influence policy makers and the policy-making process.

DISCUSSION

Science is embedded within a larger cultural and political environment. In order for science to thrive, the scientific community must embrace the reality that multiple constituencies play key roles in determining science policy. To be maximally effective, the scientific community must partner with policy makers, ethicists, members of the media, and the public who funds the research and must ultimately live with its results.

In order to further understand the current set of relationships among biomedical scientists, the public and policy makers, and to facilitate the broadening and strengthening of these relationships, we sought the views of the scientists themselves. These data are a starting point for informing strategies to enable the biomedical science community to participate more fully in the democratic process in a way that fosters mutual respect among scientists, the public, and the policy makers.

Defining Roles and Responsibilities

Many study participants expect their professional societies to play a central role in many aspects of the research process—from influencing national research priorities to facilitating and mediating scientists' interactions with the general public and the world of science policy. These scientists trust professional societies to be their representatives to government, and their emissary to the public. They believe their societies can represent them faithfully, while muting the influence of

the biases of individual scientists, who may have personal scientific agendas that are not representative of an entire field. Professional societies, participants claim, have the necessary depth and breadth of knowledge about their field to make judgments about current research and projections of scientific directions on the horizon. In addition, professional societies are large, established entities with a presence on Capitol Hill and access to elected officials. These two characteristics of professional organizations make them not only well placed to fulfill these roles, but also duty-bound to do so.

The scientists' view that professional societies ought to play a larger role than they have to date may derive from their faith in the capacity of scientific societies to influence policy and liaise with the public, along with some sense of intimidation at the prospect of facing such tasks on their own. A number of professional societies, such as the AAAS, currently do take up some of these roles. Several presidents and members of AAAS have made public statements about the importance of scientists' participation in science beyond the bench [Jasanoff et al., 1997; Dresselhaus, 1998; Nye, 1999; Jackson, 2003; Leshner, 2003]. However, these statements usually call for increased education of the public by scientists [Bak, 2001; Priest, 2001; Sturgis and Allum, 2004] and only rarely advocate for a two-way conversation with the public [Jasanoff et al., 1997; Leshner, 2003]. Despite the efforts of some professional societies and participants' faith in the abilities and potential of professional societies generally, study participants remain skeptical about the ability of such organizations to truly impact policy for reasons that largely relate to a mistrust of elected officials.

Contrary to some of the rhetoric one hears about the divisive relationship between scientists and ethicists, the participants in our study largely had a positive view of ethicists, who bring a broad knowledge base and a variety of different viewpoints to the table. Their broad view enables ethicists to frame the moral and ethical implications of research. This ability to contextualize science in the larger cultural and political sphere is where the scientists thought the ethicist's input was most valuable. Participants did not want ethicists to make pronouncements about or be able to dictate what research can and cannot be conducted.

Perhaps surprisingly, study participants welcome the public's involvement in the formation of science policy and discussions of the implications of science. Indeed, it should be noted that the inclusion of lay advisors in the design and review of research protocols has been tried and has met with some success in the area of breast cancer research [Andejeski et al., 2002; Young-McCaughan et al., 2002]. However, study participants did stipulate an adequate awareness and/or understanding of the science as necessary. As has been shown by many studies and surveys over the years, the level of scientific knowledge and understanding among the American public is woefully inadequate [National Center for Education Statistics, 2000; National Science Board, 2002; International Association for the Evaluation of Educational Achievement, 2003]. Scientists in our study do not place the full burden of responsibility for this deficit on the public, yet they do feel it limits the public's ability to participate fully in the dialog. The passion that our participants felt about the importance of science literacy may spring from a belief that with improved understanding will come increased acceptance and support for science (the deficit model) [Bak, 2001; Priest, 2001; Sturgis and Allum, 2004]; however, this proposition is untested. It must be noted that reasonable, informed, educated people can disagree on the value of a scientific research program, agenda, or policy.

In contrast to the stipulated welcome of public participation in the scientific enterprise, these scientists harbor marked skepticism about the abilities of elected officials to adequately and appropriately discharge their duties with respect to

science policy. Here too, these scientists assume some of the responsibility for the ignorance they perceive among policy makers, but they also hold elected officials responsible for seeking out quality scientific information and counsel. It seems that this responsibility can be discharged in many ways, from fostering relationships with individual researchers to enlisting the services of the National Academy of Sciences; however, access to high-quality scientific information does not resolve the concerns study participants had about what they thought to be the inappropriate entrance of politics into science. While some of these concerns may be due to a general distrust of elected officials, the scientists did mention specific instances of what some felt to be government intrusion into science (e.g., President Bush's August 2001 embryonic stem cell decision; the effects on research of the new privacy regulations) and which have contributed to their negative disposition toward elected officials.

However, participants may underestimate the realities of the US political process. These scientists have set a high standard for the level of science literacy required by the public and policy makers to participate in the formation of science policy. This standard may be difficult or impossible to achieve, and inconsistent with the level of expertise expected of the public and policy makers in other technically complex areas of policy. William Wells Jr, a former chief of staff at the White House Office of Science and Technology Policy, has reported, "[Congressional] (m)embers and staff say that one of the most difficult things to get scientists and engineers to understand is the tough reality faced by members in balancing competing interests, building working alliances, and achieving acceptable compromises" [Wells, 1996]. This expectation of scientists may derive from their devotion to and enthusiasm for science, though such high standards of knowledge may be difficult for scientists themselves to meet with respect to federal-policy formation.

The Civic Scientist

Individually, participants identified many professional responsibilities that are characteristic of a civic scientist and that have been identified by others [Woolley, 1992; Beckwith, 1997; Wiggins, 1997; Ziman, 1998; Berg, 2001; Green, 2001; Miller, 2001; Editorial, 2004; Young, 2004]. Collectively, our data confirm many of the themes identified in interview and survey research done abroad, suggesting a degree of universality in the views of biomedical scientists on these issues, and the barriers they face in living up to their perceived responsibilities. They talked about the need to inform the public and policy makers about their science (be it individually, or through participation in their professional societies) [Heden, 1980; Reiser and Bulger, 1997]. These participants believe scientists ought to engage the public in discussions of the moral and ethical implications of their research but they were not sure how or which approaches might be most effective [Beckwith, 1997]. This uncertainty is reflected in the findings of an Institute of Medicine report on public engagement that, "There are many, many ways to engage the public, but there has not been enough scientific study on the most effective ways to interact with the public" [Institute of Medicine, 2000].

How Things Should Change

The scientists we interviewed made a number of suggestions about how the role of scientists as a whole ought to change, and how to nurture and support what we and others have referred to as the 'civic scientist.' Many of the structural changes suggested seem achievable, though the amount of work required to accomplish such goals may be daunting. Success may be measured in increased participation of

scientists in public engagement and science policy formation, individually, through their professional organization, or through some other venue.

Study participants believe the training necessary for these interactions needs to begin in the first stages of a scientist's career. As Representative George E. Brown once said, "I hope that you don't take this personally, but the science and engineering community is poorly prepared," to engage the science policy process [Brown, 1995]. A small part of that is already in place, through a stipulation in NIH training grants for annual ethics education of trainees; however, there are several problems with how this requirement is implemented. For example, the programs or courses designed to satisfy the requirement are often solely focused on ethical issues internal to science, such as data falsification, conflicts of interest, and treatment of human and non-human animal research subjects. These courses often do not address (or mention only briefly) the moral, ethical, and policy issues that arise at the intersection of scientific research and society. Another problem is that only trainees are required to attend. Those scientists who are mentors—and have significant influence on trainees—are not obligated to participate. In spite of its limitations, the current training grant requirement can be used as a starting point for a broader research ethics curriculum.

The NIH requirement could also be used as a template for developing trainees' communication skills. The inability to communicate science effectively is a barrier for potential civic scientists on several levels. Not only can it prevent a scientist from even making the attempt to engage the public or policy makers in discussions of science, but also, if she *does* attempt communication, in the absence of said skills, she may do more harm than good. Outside academia, programs like Research!-America's science and media forums have been developed to address this very issue [Brown et al., 2004].

Nonetheless, even if these skills are present, there is still the problem of the barriers presented by the tenure system. The dedication of some percentage of salary support in NIH grants to outreach/engagement activities would solve the problem that many scientists have of unfunded time and lack of recognition for the work. It would also be a significant incentive to those who are not currently motivated to participate in civic activities, or science outside of the lab. Ultimately, though, tenure committees must place value on participation in outreach activities if nurturing civic science is the goal.

One of the main aims of civic activity for the scientists we interviewed was to improve science literacy among the public; however, most of the ideas they put forward to address this issue required changes in others, not themselves. The most common recommendation was a need for improvement of high school science education. Additionally, they called for increased use of television as a tool for science education and information dissemination. This recommendation should be taken seriously, as studies have shown that most people get their information about scientific research through this medium [National Science Board, 2002].

As the scientists themselves expressed, though, if one wants to improve science literacy among the public, one must be willing to make changes in oneself to affect that literacy. It may be the case that structural changes including those put forth by our participants must be made before scientists have the freedom to change their behavior in major ways. We can also look outside of the US for models, such as the European Commission's Science and Society Action Plan [European Commission, 2002] and the Coastal CRC Citizen Science project in Australia [The Coastal CRC]. There are also several studies in public engagement currently underway in the US and abroad [Genetics and Public Policy Center, 2004; Wellcome Trust, 2004].

There are myriad ways in which individual scientists can lay the groundwork today for positive change. Scientists can begin to let their institutions, professional societies, and elected representatives know their views on how scientists ought to be involved in public engagement and science policy. They can work to change the ethics curriculum for trainees in their own departments to include social responsibility and develop an institutional civic scientist ethos. They can also make sure that their own students are trained to communicate their science to non-scientist audiences. For example, trainees could be required to write a lay-person's summary of her/his scientific research. Scientists can extend this to their department by adding similar requirements to courses they teach. Scientists can also cultivate relationships with members of their university's public relations department or with members of the media—letting them know not only when they get it wrong, but also when they get it right.

It is worth bearing in mind though, that improved science literacy among the public will not necessarily lead to increased support for science [Bak, 2001; Priest, 2001; Sturgis and Allum, 2004]; indeed, it may lead to quite the opposite outcome. The value of improved science literacy and increased reciprocity between the scientific community and the general public is not found in improved support for science, but in the proper functioning of a democratic government. To achieve this goal, scientific organizations and agencies must examine the ways in which they do and can facilitate the participation of scientists in public engagement and science policy. They must develop clear aims (e.g., improved modes of communication between scientists and the public) and success-measures to assess whether such strategies are effective in enhancing science policy and improving relationships among scientists, the public, and policy makers. Successful models can then be used to design and implement programs that integrate science more fully into the society it is meant to serve.

When thinking critically about relationships between the scientific community and the broader society, one requires input not only from the public, but also from the scientists themselves. The findings presented here call for further action by scientists, not only in efforts to improve science literacy among the public and elected officials, but also to achieve a broader goal: these findings suggest a need to foster and sustain a scientific enterprise in the US that is aware of and responsive to society's values.

The vast majority of the scientists we interviewed felt a clear duty and desire to engage both the public and the policy process yet saw these desires frustrated by the barriers of the tenure system and ignorance about how to get involved. Envisioning solutions to these problems, they saw professional societies as best placed to facilitate scientists' interactions with the public and the process of science policy formation. They further look to professional societies to be strong advocates for science, both to the public and their representatives in government.

However, scientists may hold flawed views about the other stakeholders and their roles. The connection the participants see between a right to participate in science-policy decisions and a sophisticated understanding of the science among the public and policy makers discounts the importance of non-scientific perspectives and values. Furthermore, scientists may have an unrealistic and incomplete understanding of the US political process, in a sense, not meeting their own standards for informed participation.

The barriers facing scientists are not insignificant, and will require coordination among professional societies, scientific institutions, funding agencies, and others to mitigate. As science accelerates its integration into the lives of the public, we must accelerate our efforts to forge strong relationships with those who our research impacts in such intimate and profound ways.

Limitations

We recognize that our study may have the problem of selection bias since scientists who were motivated to volunteer may be more likely to view scientists as having responsibilities to the broader community than non-responders. Nevertheless, these participants had a range of previous experience with public engagement. This study's most significant limitation is its size, a common limitation of qualitative research. While these data are not generalizable to all genetic scientists, they do represent a broad range of views and issues that can serve as a foundation for further study, and inform efforts to improve the relationships among scientists and other stakeholders in science education and policy.

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REFERENCES

- American Society of Human Genetics. <http://www.ashg.org/genetics/ashg/educ/003.shtml>.
- Andejeski Y, Bisceglia IT, Dickersin K, Johnson JE, Robinson SI, Smith HS, Visco FM, Rich IM. 2002. Quantitative impact of including consumers in the scientific review of breast cancer research proposals. *J Womens Health Gend Based Med* 11(4):379–388.
- Augustine N. 1998. What we don't know does hurt us. How scientific illiteracy hobbles society. *Science* 279(5357):1640–1641.
- Bak H-J. 2001. Education and public attitudes toward science: Implications for the "Deficit Model" of education and support for science and technology. *Soc Sci Q* 82(4):779–795.
- Beckwith J. 1997. The responsibility of scientists in the genetics and race controversy. In: Smith E, editor. Plain talk about the human genome project: A Tuskegee University conference on its promise and perils and matters of race. Tuskegee, Alabama: Tuskegee Univ. Publications Office. p 83–94.
- Beeson D, Billings P, Darnovsky M, Weiner C. 2001. Proceedings of a Townsend Center Panel. Berkeley, CA.
- Berg B. 2001. Researchers find benefits, barriers in trying to excite the public about science. Seattle, WA: Fred Hutchinson Cancer Research Center.
- Brown GE. 1995. Managing while science and education evolve; 1995 October 20, 1995; Arlington, VA.
- Brown CP, Propst SM, Woolley M. 2004. Report: Helping researchers make the case for science. *Sci Commun* 25(3):294–303.
- Camenisch PF. 1996. The moral foundations of scientific ethics and responsibility. *J Dent Res* 75(2):825–831.
- Dresselhaus MS. 1998. What scientists can do to fight the Frankenstein myth. *The Scientist* 12(5):7.
- Editorial. 2004. Going public. *Nature* 431(7011):883.
- European Commission. 2002. Science and society action plan. Belgium: Office for Official Publications of the European Communities.
- Genetics and Public Policy Center. 2004. The genetic town hall: Making every voice count. Washington, DC: Genetics And Public Policy Center.
- Glass B. 1993. The ethical basis of science. In: Bulger RE, Heitman E, Reiser SJ, editors. The ethical dimensions of the biological sciences. New York, New York: Cambridge University Press. p 43–55.
- Green K. 2001. May 9, 2001. Should scientists advocate public policy? Stephen Schneider ponders the ethics. Stanford Report.
- Heden CG. 1980. The obligations of the microbiologist—some views concerning future possibilities—and future hazards. *NIPH Annals* 3(1):15–26.

- Institute of Medicine. 2000. Exploring challenges, progress and new models for engaging the public in the clinical research enterprise. In: Aungst J, Haas A, Ommaya A, Green LW, editors. Washington, DC: The National Academies Press.
- International Association for the Evaluation of Educational Achievement. 2003. Trends in International Mathematics and Science Study. Washington, DC: National Center for Education Statistics.
- Jackson SA. 2003. Standing on the knife-edge: The leadership imperative; Troy, NY: Rensselaer Polytechnic Institute.
- Jasanoff S, Colwell R, Dresselhaus MS, Golden WT, Goldman RD, Greenwood MRnC, Huang AS, Lester W, Levin SA, Linn MC, Lubchenco J, Novacek MJ, Roosevelt AC, Taylor JE, Wexler N. 1997. Conversations with the community: AAAS at the millennium. *Science* 278(5346): 2066–2067.
- Kerr A, Amos A, Cunningham-Burley S. 1997. The new genetics: Professionals' discursive boundaries. *Sociol Rev* 45(2):279–303.
- Lane N. 1999. The civic scientist and science policy. Washington, DC: AAAS.
- Lawler A. 1995. Robert Walker: The speaker's right hand on science. *Science* 269:749–751.
- Leshner AI. 2003. Public engagement with science. *Science* 299(5609): 977.
- Middleton-Price H. 2002. The role of genetics professionals in public debate—Summary of survey results. Cambridge, England: British Society for Human Genetics. pp 25.
- Miller KS. 2001. Wanted: 'Civic scientists' to educate the public, press and policy makers. Stanford Report.
- MORI. 2000. The role of scientists in public debate. London, England: The Wellcome Trust. pp 50.
- National Center for Education Statistics. 2000. 2000 National Assessment of Educational Progress. Washington, DC: National Center for Education Statistics.
- National Science Board. 2002. Science and Engineering Indicators—2002. Arlington, VA: National Science Foundation.
- Nicholas B. 1999. Molecular geneticists and moral responsibility: "maybe if we were working on the atom bomb I would have a different argument". *Sci Eng Ethics* 5(4):515–530.
- Nicholas B. 2001. Exploring a moral landscape: Genetic science and ethics. *Hypatia* 16(1):45–63.
- Nye MJ. 1999. January 27, 1999. Should scientists become players in the public policy debate? *Science Daily*.
- Priest SH. 2001. Misplaced faith: Communication variables as predictors of encouragement for biotechnology development. *Sci Commun* 23(2):97–110.
- Prpic K. 1998. Science ethics: A study of eminent scientists' professional values. *Scientometrics* 43(2):269–298.
- Reiser SJ, Bulger RE. 1997. The social responsibilities of biological scientists. *Sci Eng Ethics* 3(2):137–143.
- Research!America. 2004. America speaks, Vol. 5. Alexandria, VA: Research!America United Health Foundation.
- Rogers PG. 2003. July 28, 2003. Scientists, it's time to speak up. *The Scientist* 17(15):8.
- Sturgis P, Allum N. 2004. Science in society: Re-evaluating the deficit model of public attitudes. *Pub Understanding of Science* 13:55–74.
- The Center for the Health Professions-UCSF. <http://futurehealth.ucsf.edu/biomed/society.html>.
- The Coastal CRC. http://www.coastal.crc.org.au/citizen_science/. Indooroopilly, Queensland, Australia.
- van Heyningen V, Cox DR. 2002. Advice to governments: Scientific give and take. *Nat Rev Genet* 3(8):631–636.
- Wellcome Trust. 2004. Snap decisions: Novel approaches to public consultation. London, England: Wellcome Trust.
- Wells WG. 1996. Working with Congress: a practical guide for scientists and engineers, Vol. xi. Washington, DC: American Association for Advancement of Science. pp 160.
- Wiggins RC. 1997. Clarification. *The Scientist* 11(3):10.
- Woolley M. 1992. Scientists must communicate to the public in terms that the public understands. *The Scientist* 6(9):12.
- Woolley M. 1997. The comfort zone. *Science* 275(5304):1243.
- Young J. 2004. October 29, 2004. NIH public trust recommendations urge community involvement, communication. Washington Fax.
- Young-McCaughan S, Rich IM, Lindsay GC, Bertram KA. 2002. The Department of Defense Congressionally Directed Medical Research Program: Innovations in the federal funding of biomedical research. *Clin Cancer Res* 8(4):957–962.
- Ziman JM. 1998. Why must scientists become more ethically sensitive than they used to be? *Science* 282(5395):1813–1814.