Cornell University

Assessing Models of Public Understanding In ELSI Outreach Materials

U.S. Department of Energy Grant DE-FG02-01ER63173

FINAL REPORT

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1 March 2006

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I Introduction

Advances in the science of genetics have implications for individuals and society, and have to be taken into account at the policy level. Studies of ethical, legal and social issues related to genomic research have therefore been integrated in the Human Genome Project (HGP) since the earliest days of the project. Since 1990, three to five percent of the HGP annual budget has been devoted to such studies, under the umbrella of the Ethical, Legal, and Social Implications (ELSI) Programs of the National Human Genome Research Institute of the National Institute of Health, and of the Office of Biological and Environmental Research of the U.S. Department of Energy (DOE). The DOE-ELSI budget has been used to fund a variety of projects that have aimed at "promoting education and help guide the conduct of genetic research and the development of related medical and public policies" (HGP, 2003).

As part of the educational component, a significant portion of DOE-ELSI funds have been dedicated to public outreach projects, with the underlying goal of promoting public awareness and ultimately public discussion of ethical, legal, and social issues surrounding availability of genetic information (Drell, 2002). The essential assumption behind these projects is that greater access to information will lead to more knowledge about ethical, legal and social issues, which in turn will lead to enhanced ability on the part of individuals and communities to deal with these issues when they encounter them. Over the same period of time, new concepts of "public understanding of science" have emerged in the theoretical realm, moving from a "deficit" or linear dissemination of popularization, to models stressing lay-knowledge, public engagement and public participation in science policy-making (Lewenstein, 2003).

The present project uses the base of DOE-funded ELSI educational project to explore the ways that information about a new and emerging area of science that is intertwined with public issues has been used in educational public settings to affect public understanding of science. After a theoretical background discussion, our approach is three-fold. First, we will provide an overview, a "map" of DOE-funded of outreach programs within the overall ELSI context to identify the importance of the educational component, and to present the criteria we used to select relevant and representative case studies. Second, we will document the history of the case studies. Finally, we will explore an intertwined set of research questions: (1) To identify what we can expect such projects to accomplish -in other words to determine the goals that can reasonably be achieved by different types of outreach, (2) To point out how the case study approach could be useful for DOE-ELSI outreach as a whole, and (3) To use the case study approach as a basis to test theoretical models of science outreach in order to assess to what extent those models accord with real world outreach activities. For this last goal, we aim at identifying what practices among ELSI outreach activities contribute most to dissemination, or to participation, in other words in which cases outreach materials spark action in terms of public participation in decisions about scientific issues.

II Theoretical Background

"Public understanding of science," or PUOS, is a relatively new field of scholarly inquiry that has developed since the 1980s. PUOS related projects can roughly be placed in two broad categories:

- projects that aim at *improving* the understanding public(s) have of a specific area of science,
- projects that aim at *exploring* the interaction of the public and science.

Recent efforts have focused on integrating these two by linking research findings with outreach activities. Such efforts have aimed at building conceptual models of public communication of science that would give a comprehensive view of the frameworks that are at play for research in the field and then implementing these models systematically. The following sections discuss these models.

1. The Deficit Model

Not surprisingly, most discussions of public understanding of science emerge from within the scientific community itself. The primary concern there has been, since at least the middle of the nineteenth century, the lack of intellectual public support for scientific ways of thinking and material public support for scientific work – the funds for research (Burnham, 1987; LaFollette, 1990). By the middle 1970s, these concerns led to well-designed surveys fielded for the National Science Board that attempted to measure public knowledge of and attitudes towards science and technology (Miller, 1983a, 1983b). These surveys show that only 10 percent of Americans can define "molecule," and that more than half believe that humans and dinosaurs lived on the Earth at the same time (National Science Board, 2002). Combining these factual questions with ones about the process of science and the institutional place of science has yielded measures of "science literacy" that show, depending on the year and the particular method of interpretation, that only 5 percent of the American public is scientifically literate, and only 20 percent are interested and informed. The rest, by formal definition, are "residual" (National Science Board, 1991, 1993, 1996, 1998, 2000, 2002).

Studies such as these – along with anecdotes common among the scientific community about the public's inability to understand even basic ideas of probability, skepticism, and evidence – have led to cries about the lack of knowledge, and then to new programs for providing information to fill the gap of knowledge (Royal Society, 1985; National Commission on Excellence in Education, 1983). This approach has become known as the "deficit" model, since it describes a deficit of knowledge that must be filled, with a presumption that after fixing the deficit, everything will be "better" (whatever that might mean) (Ziman, 1991, 1992). Vast and important projects to address science literacy have emerged, perhaps most notably the National Science Education Standards in the United States (American Association for the Advancement of Science, 1993; National Research Council, 1996).

However, scholars have identified a series of difficulties with the deficit model. Most notably, many of the questions are asked without providing a context (Wynne, 1995). In what situation with personal relevance, for example, does a nonscientist need to know the definition of DNA? Learning theory has shown that people learn best when facts and theories have meaning in their personal lives (Bransford, National Research Council on Learning Research and Educational Practice, 2000); for example, research has shown that in communities with water quality problems, even people with limited education can quickly come to understand highly complex technical information (Fessenden-Raden, Fitchen, & Heath, 1987). In addition, the interpretation that labels many people "scientifically illiterate" or "residual," while based on good political theory, highlights the power relationships between those with the particular knowledge measured by the surveys and those without. There has been little attention to other forms of knowledge that may be relevant to individuals in their real, everyday lives (Irwin & Wynne, 1996). Another critique is that, after nearly 25 years of gathering on the public understanding of science, and after many more years of active (and often excellent) attempts to affect public knowledge, the numbers seem remarkably stable. Approaching the problem from the perspective of "filling the deficit" doesn't seem to have been a successful approach.

As a result of these concerns, at least three other models have been developed in response to the deficit model: a contextual model, a lay-expertise model, and a public participation model. These models are frameworks for understanding what "the problem" is, how to measure the problem, and how to address the problem.

2. The Contextual Model

The contextual model acknowledges that individuals do not simply respond as empty containers to information, but rather process information according to social and psychological schemas that have been shaped by their previous experiences, cultural context, and personal circumstances. One common area in which the contextual model has been applied is risk perception and risk communication (Krimsky & Plough, 1988; National Research Council (U.S.). Committee on Risk Perception and Communication, 1989; Slovic, 1987). The model acknowledges that individuals receive information in particular contexts, which then shape how they respond to that information. Personal psychological issues may affect the context, such as stage in life or personality type (fearful, aggressive), as may the social context in which information is received (a trusting relationship with an old friend versus a confrontational relationship with a distrusted employer, for example). The contextual model also recognizes the ability of social systems and media representations to either dampen or amplify public concern about specific issues (Kasperson et al., 1988). Newer approaches to the contextual model have attempted to use modern marketing segmentation approaches to identify populations with differing underlying attitudes toward science, without necessarily tying those groups to particular risk contexts or to levels of "science literacy" (Office of Science and Technology & Wellcome Trust, 2000). At the practical level, the contextual model provides guidance for constructing messages about science relevant to individuals in particular contexts, such as using messages about addiction and brain structure as a vehicle for teaching reading to low-literacy adults (who often come from personal or social settings in which drugs and addiction are common) (Baker, 1995).

The contextual model has been criticized for being merely a more sophisticated version of the deficit model: it acknowledges that audiences are not mere empty vessels but nonetheless conceptualizes a "problem" in which individuals respond to information in ways that seem inappropriate to scientific experts (Wynne, 1995). The contextual model recognizes the presence of social forces, but nonetheless focuses on the response of individuals to information; it highlights the psychological component of a complex social psychological setting. The recent use of marketing and demographic approaches has also raised concern that contextual model research is intended as a tool for manipulation of messages to achieve particular aims; the goal might not be "understanding" but "acquiescence."

In response to the deficit and contextual models, researchers expressed concern that perspectives for exploring public communication of science and technology were too tied to the interests of the scientific community, which almost by definition constitutes an elite group in society. The deficit and contextual models often seemed to equate "public understanding of science" with "public appreciation of the benefits provided by science to society" (Lewenstein, 1992). They did not adequately address the social and political context in which the powerful social institutions of science use "science literacy" as a rhetorical tool to influence funding and policy decisions (Hilgartner, 1990), sometimes in political opposition to labor or local interests. Since the mid 1980s, these researchers have stressed the importance of recognizing local knowledge and commitments to political inclusion and participation. From these concerns have emerged two new models: lay expertise and public participation.

3. The Lay Expertise Model

The lay expertise model begins with local knowledge, sometimes called "lay knowledge" or "lay expertise" (Wynne, 1989). This is knowledge based in the lives and histories of real communities, such as detailed local farming or agricultural practices, or historical legacies such as the cultural heritage of African Americans for whom the Tuskegee syphilis experiments are a real antecedent to contemporary opinions about trust in scientific medicine. The lay expertise model argues that scientists are often unreasonably certain – even arrogant – about their level of knowledge, failing to recognize the contingencies or additional information needed to make real-world personal or policy decisions. Basing their analyses largely on case studies (Irwin & Wynne, 1996), proponents of a lay knowledge approach argue that communication activities need to be structured in ways that acknowledge information and knowledge and expertise already held by communities facing scientific and technical issues(Wynne, 1996). While ideas about indigenous knowledge systems in developing countries have not been central to the intellectual development of the lay expertise model, they clearly fit comfortably with that model, as they emphasize the importance of knowledge and expertise that is held and validated by social systems other than modern science (Ellen & Harris, 1996). However, unlike approaches to indigenous knowledge systems that attempt to use modern science methods to verify traditional beliefs, the lay expertise model is explicitly targeted to valuing local knowledge as expertise in their own right (Centre for Study of Environmental Change, 2001; Grove-White, Macnaghten, Mayer, & Wynne, 1997).

Like other models, the lay expertise knowledge is subject to criticism. In particular, it privileges local knowledge over the reliable knowledge about the natural world produced by the modern scientific system. For that reason, it can be called "anti-science," and certainly proponents of local knowledge approaches have been targets of some of the virulent "science wars" disputes of the 1990s (Labinger & Collins, 2001). It is clearly driven by a political commitment to empowerment of local communities. It is also not clear how a model of public understanding based on lay expertise provides guidance for practical activities that can enhance public understanding of particular issues, although it does suggest that activities designed to enhance trust among participants in a policy dispute are more important that specific educational or informational approaches.

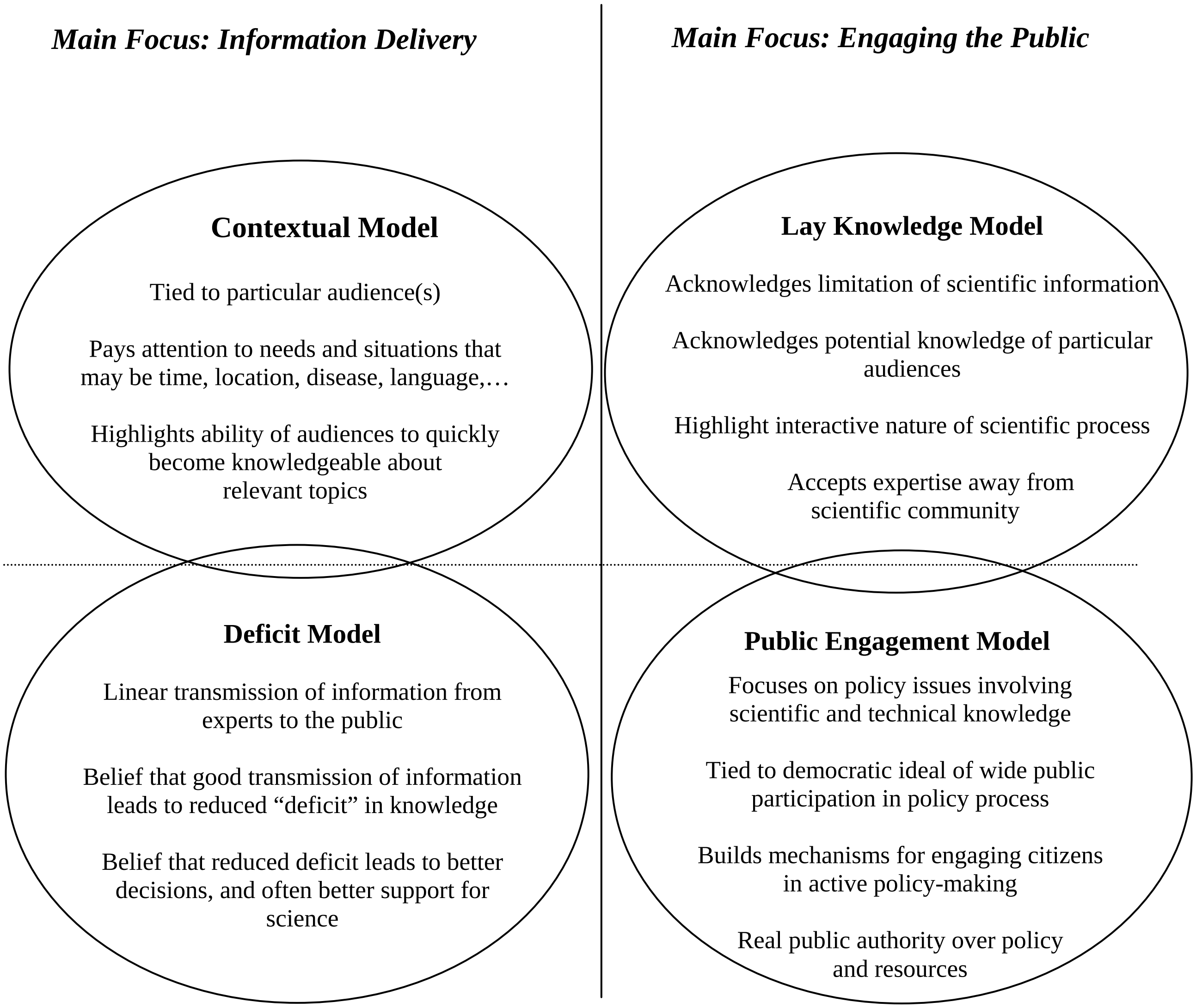
4. The Public Engagement Model

Finally, a "public engagement" model has emerged, focusing on a series of activities intended to enhance public participation in science policy. These activities include consensus conferences, citizen juries, deliberative technology assessments, science shops, deliberative polling, and other techniques (see, for example, Hamlett, 2002), Wachelder, 2003), (International Science Shop Network, 2003). The public participation activities are often driven by a commitment to "democratizing" science – taking control of science from elite scientists and politicians and giving it to public groups through some form of empowerment and political engagement (Sclove, 1995). Not all activities envisioned by supporters of public engagement necessarily require turning over control; in the United Kingdom, the public engagement model is sometimes called the "dialogue" model and is intended to highlight the importance of seeking public input into science issues, without necessarily yielding control (House of Lords, 2000; S. Miller, 2001). Moreover, the public engagement model appears to be similar to more established techniques such as public meetings and public hearings, although formal discussion of these links has not taken place(McComas, 2001).

Because the public engagement model, like the lay expertise model, carries with it a commitment to a particular stance about political relations, it can be criticized for addressing politics, not public understanding. Proponents of public participation, however, counter that the deficit model and contextual models are equally political, for they link the "problem" of public understanding to individuals rather than social relations (Dornan, 1990; Jasanoff, 1997).

Still, the public engagement model can be criticized for focusing on the process of science and not the substantive content (though some public engagement activities, especially consensus conferences, do commit significant resources to education), for serving only small numbers of people, and sometimes for having an "anti-science" bias.

In sum, the driving force behind these four theoretical models is different. While two of the models thrive at delivering information to the general public or to a specific group (deficit and contextual models), the other two are about actively engaging citizens with science (see Figure 1). In the present project, we will test whether actual outreach can be mapped on these models, or if other models need to be defined in order to capture the reality of practice. We will base our discussion on a case study approach, and analyze the objectives and outcomes of selected projects. We will therefore use the case method as a way to rebuild or improve theory, as proposed by Burawoy and his colleagues (1991).



Contextual Model

Tied to particular audience(s)

Pays attention to needs and situations that may be time, location, disease, language,…

Highlights ability of audiences to quickly become knowledgeable about relevant topics

Lay Knowledge Model

Acknowledges limitation of scientific information

Acknowledges potential knowledge of particular audiences

Highlight interactive nature of scientific process

Accepts expertise away from scientific community

Deficit Model

Linear transmission of information from experts to the public

Belief that good transmission of information leads to reduced “deficit” in knowledge

Belief that reduced deficit leads to better decisions, and often better support for science

Public Engagement Model

Focuses on policy issues involving scientific and technical knowledge

Tied to democratic ideal of wide public participation in policy process

Builds mechanisms for engaging citizens in active policy-making

Real public authority over policy and resources

Figure 1: Conceptual Models of Public Communication of Science and Technology

The previous discussion will serve as the theoretical background to explore the research questions outlined in our introduction:

RQ1: Based on our assessment on how real world outreach activities (the case studies) accord to the theoretical models, how can these models be refined?

RQ2: Based on our case study analysis, what we can expect DOE-funded outreach projects to accomplish -in other words what goals can reasonably be achieved by different types of outreach?

RQ3: How can the case study approach be useful for DOE-ELSI outreach as a whole –in other words, what are the lessons that can be retained for the present exercise?

As a preliminary step, we will provide an overview, a “map” of DOE-funded of outreach programs within the overall ELSI context to identify the importance of the educational component, and to present the criteria we used to select relevant and representative case studies. The following section describes the methods used to map DOE-ELSI activities, and to analyze the selected projects.

III Methods

1. Mapping DOE-ELSI Projects

We performed a content analysis of 1994-2000 projects’ abstracts. The 94 abstracts, which were submitted by DOE-ELSI grantees to the Human Genome Program Contractor-Grantee workshops in 1994, 1996, 1997, 1999 and 2000 (workshops IV to VIII), were downloaded from DOE ELSI web page (DOE-ELSI, 2003). Our analysis focused on the 1994-2000 period since abstracts for projects funded prior to that period were not posted online at the time of the analysis.

The coding matrix used for the analysis of the abstracts included 4 sets of variables: (1) the nature of the project; (2) its primary intended audience; (3) the primary public communication of science model in which the project conceptually fits; and (4) the main communication medium used for outreach in the project.

The “nature of the project” variable was a categorical variable that included four program areas as possible categories. We used as program areas the ELSI Research Planning and Evaluation Group categories (ERPEG, 2000). The categories were the following: privacy and fair use; clinical integration; genetic research; education and resources.[1] We also included an “others” category for projects that did not fit specifically in any of the general program areas.

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[1] The program areas are the following (ERPEG, 1999, p. 7)

Privacy and Fair Use. To ensure that genetic information is interpreted correctly and used appropriately, and that public policies developed to protect genetic privacy and to reduce the likelihood of genetic discrimination are informed by ELSI research. Activities in this area examine the meaning of genetic information and how to prevent its misinterpretation or misuse.

The “primary intended audience” categorical variable included youth/high school students, college students, professional groups (excluding teachers) general, teachers, general public, low literacy adults, minorities, and other specific audiences (non professionals), as categories. Since the analysis was exploratory in nature, the categories were defined after reading the sample of abstracts. In other words, no preconceived idea of what these audiences needed to be was applied before hand.

Finally, the “communication medium” variable included workshops, curriculum materials conferences/workshops, radio, web, radio shows, exhibits, CDRoms, printed books, magazines, television series/documentaries, and other types of frameworks, as categories.

2. Case Study Analysis

2.1. Selection of the Case Studies

The goal was to select case studies that would match the following criteria, in support of our research questions: (1) The target audience should be an adult population. Potential audiences were therefore the general public, low literacy adults and minority groups;[2] (2) the case studies should allow us to discuss the 4 theoretical models of public communication of science that were presented earlier; (3) different communication medium should be used for each project; (4) the case studies should include only completed projects, in order to be able to compare objectives and outcomes. The case studies were to be used as a way to improve theory, as proposed by Burawoy and his colleagues (1991).[3]

2.2. Documenting the Case Studies

The goal was to analyze the case studies in relationship to the existing theoretical models for public communication of science. We therefore looked at the goals of each project in relationship to its content and its outcomes. Our assessment of the outcomes of the project is

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Clinical Integration. To ensure that genetic technologies and information are optimally integrated in clinical settings, and that health care policies reflect the knowledge gained from ELSI research. Activities in this area examine the impact of genetic testing on individuals, families, and society with the aim of informing clinical practices and policies related to genetic testing and counseling.

Genetic Research. To ensure that genetic research is conducted in an ethically sound manner, and that research policies are informed by ELSI research and experience. Activities in this area focus on informed consent and other issues related to the design, conduct, participation in, and reporting of genetics research.

Education and Resources. To ensure that the public and health and other professionals are genetically literate and aware of ELSI issues related to genetic technologies and information. Activities in this area include the development of ELSI and genetic-based curricula, web-based educational activities, PBS television series, videos, and CD-ROMs for a wide variety of audiences.

[2] Projects targeting professional groups were excluded since our goal was to discuss issues raised by public understanding of ethical, legal and social issues related to genomics research in everyday life, i.e. outside of a professional context

[3] According to grounded theory, case studies can form the basis for the development of general theories, the researcher approaching the case studies with no preconceived ideas of what they might encounter (Babbie, 2001; Strauss & Corbin, 1990). Burawoy and his colleagues (1991, p. 10) take a whole different approach, using observations to identify “theoretical gaps and silences” in existing theoretical frameworks.

based on a retrospective analysis of the available documentation as well as on interviews with the project leaders. Since summative evaluation was not conducted for some of the projects, our comments regarding the outcomes should not be taken as critiques, but rather as assessments of how the outcomes of the projects mapped onto the theoretical models. The methods used for the analysis are outlined below.

1. In-Depth Qualitative Interviews With Project Leaders[4]

We used a semi-structured interview format, in which the interviewer has a series of specific questions to be raised during a conversation with the interviewee (Leech, 2002). No formalized sampling methodology was applied to determine the sample of case studies, or interviewees. We therefore do not expect to generalize conclusions reached through the interviews to other projects, but will rather use the conclusions as a basis for discussion of theoretical concepts.

2. Historical Review of Documents

Whenever possible, we analyzed the content of the project outreach document drafts in a historical perspective, in order to identify if the project goals had evolved as the project went on. We also tracked and examine evaluation research that might have been performed on the project, and analyzed the final report submitted to DOE-ELSI officers.

3. Analysis of Web-Use

When applicable, we tracked public use of web-documents related to the project.

4. Content Analysis of Documents

We analyzed the final outreach materials used by each project to reach the target population (book chapters; articles; conference proceedings; e-mails, etc) in order to identify what were the themes disseminated through the project, Whenever possible (i.e. if evaluation information was available or if some feedback mechanisms were built in the project) we analyzed the type of response the materials covered elicited from the audience.

IV Results

A. Mapping DOE-ELSI Projects

The goal of the content analysis of the DOE-ESLI abstracts was to identify the proportion of projects in the DOE-ELSI portfolio that could be classified as public communication of science efforts. As explained earlier, we classified the DOE-ELSI projects under consideration in 5 categories: projects related to “privacy and fair use” issues; projects related to “clinical

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[4] And users whenever possible.

integration," projects related to "genetic research," educational projects, and "others). We then analyzed more particularly the educational projects, in order to determine the type of audience they attempted to reach, the type of communication models they followed, an the communication medium they relied on.

In terms of type of projects, 77% of the 1994-2000 DOE-ELSI projects had an educational component (Figure 2), which is in line with DOE-ELSI stated goal of promoting education for genetic information related issues, and demonstrates that DOE-ELSI has indeed a potential to impact public understanding of ethical, social and legal issues related to genomic research.

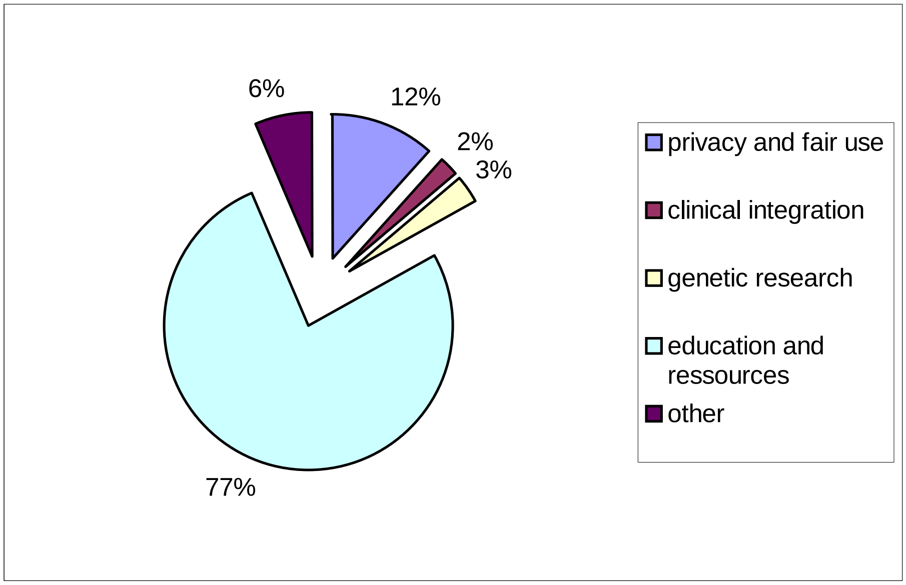

Figure 2: DOE-ELSI funded projects program areas (1994-2000)

Among the educational projects, 23% were attempting to reach youth audience, and/or specifically high school students (Figure 3). The same percentage of projects was geared toward professional groups (excluding teachers). As far as the general public is concerned, 21.6% of the projects were aimed at that audience. Only 2.7% of the projects analyzed targeted low literacy adults.

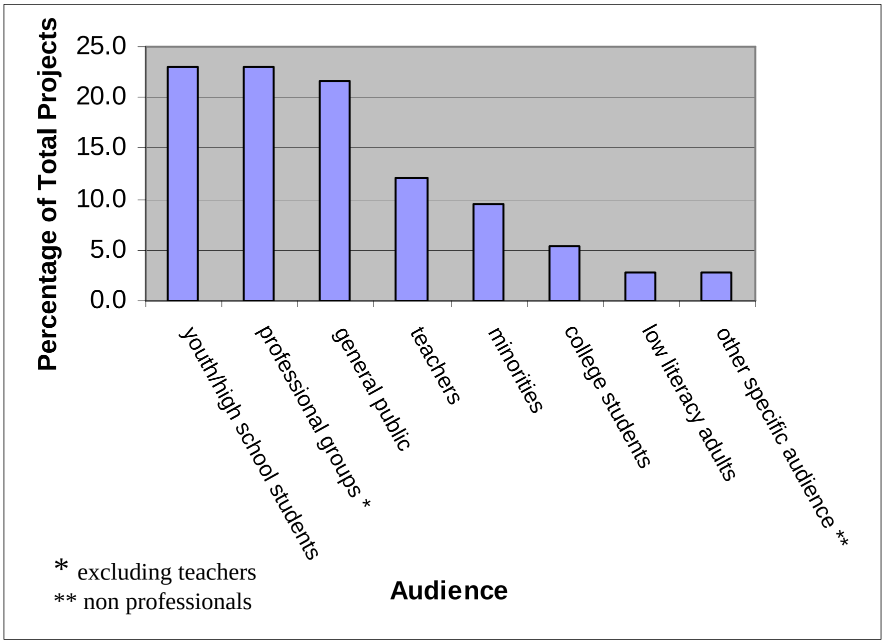

Figure 3: Audiences of DOE-ELSI Funded Projects (1994-2000)

Based on the information provided in the projects' summaries, we identified which model of public communication of science each educational project fit more (Figure 4).

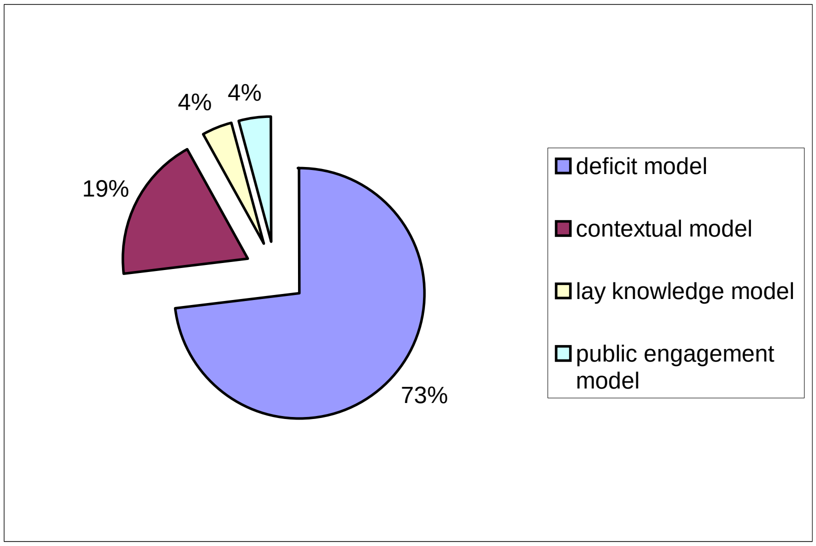

Figure 4: Public Communication of Science Models and DOE-ELSI Educational Projects

As Figure 4 shows, most of the projects analyzed fell in the "deficit" communication model. This result is not surprising, since this model is the most commonly used framework for science outreach projects. It is also in line with one of the stated goals of DOE-ELSI, "to ensure that the public and health and other professionals are genetically literate and aware of ELSI issues related to genetic technologies and information." (ERPEG, 2000). This assumes, of course, that the deficit approach does indeed impact levels of awareness and understanding of the targeted audiences, which only sound summative evaluation of the projects could demonstrate.

We also identified the main communication medium that the DOE-ELSI education projects used (see Figure 5).

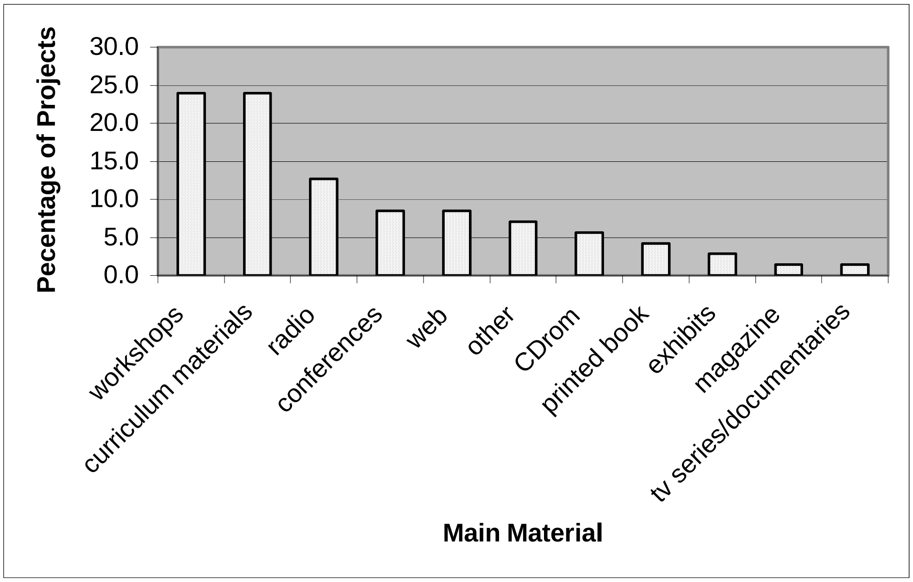

Figure 5: Main Communication Medium Used by the DOE-ELSI Educational Projects

Curriculum materials and workshops were the most frequently used communication medium for the projects analyzed. Since the main audiences for the projects were school-age populations and professional groups, this is not surprising. A wide range of materials/frameworks was, however, also used, the most frequently used being radio programs (12.7%), conferences (8.5%) and web-based projects (8.5%). It should nevertheless be noted that traditional media, such as magazines or television, were the least used communication medium. Such material would however be a good channel for a larger uninformed public, for whom traditional media is often the only source of information for science-related issues (Gerbner et al, 1981; LaFollette, 1990).

B. Case Studies

1. Selection of the Case Studies

In accordance with the results of the “mapping activities” exercise (identification of the main audiences for the educational projects, of the main communication mediums used by the projects, of the main public communication of science model followed by the projects), we selected five case studies (see Table 1).

Table 1: Case Studies Selected

Case Study / **Attributes**	***The Geneletter***	***Challenges of Genome Research for Minority Community***	***Your Genes Your Choices***	***The Hispanic Radio Model and Science Education Outreach Project***	***A Question of Genes***
Target Audience (*)	General public	Minorities, mainly African-American community	Low-literacy adults	Hispanic community	General public
Main Communication Medium	Web newsletter	Conferences	Printed book	Radio programs	Television documentaries
Public Communication of Science Model*	Diffusion model	Contextual model	Diffusion model	Contextual/ public participation models	Lay knowledge model
Project Schedule	1996-1999	2001-2002	Book published in 1999	1996-1999	Aired November 1997

* As defined in the first abstract of the project; the target audience might have evolved over time

** As evident in the first abstract of the project

2. Case Studies Analysis

1. A “Web-based” approach: The *Geneletter*

a. <u>Presentation of the project: objectives and intended outcomes</u>

Supported by DOE-ELSI funds from 1996 through April 1999, *Geneletter* intended to reach a broad public audience by reporting on scientific, ethical, legal and social aspects of genetics through a web-based newsletter. The idea of Phillip Reilly (Director of the Shriver

Center[5] at that time, and co-PI of the project with Dorothy Wertz), was that whoever would use the Internet for public education about genetics and ethics would have power over public education. Indeed, a general search on the World Wide Web shows that newsletters focusing on ethical, legal and social issues specifically related to genomic research are rare.[6]

Geneletter published 10 issues on its site at www.geneletter.org, from July 1996 to February 1999. After that period (and ending of the DOE funding), the *Geneletter* was turned over to GeneSage (a California-based Internet start-up, aimed at genetic professionals) in return to a $20,000 donation to Shriver Center.

b. Outreach Materials

According to Dorothy Weiss, the content of the articles was defined by the editors (also authors of the articles), the main concern being to arise interest in the readership. Conferences on ELSI related issues were the main source of ideas as far as content of the articles was concerned. In other words, potential users' input was not used for content definition.

We performed a content analysis of 196 pieces published between July 1996 and February 1999, in order to identify the main focus of each article, as well as the specific themes it addressed.

Each issue of the *Geneletter* included one or more of the following type of pieces: Update on Scholarly Conferences (5% of total pieces); Update on Community Events/Community education/websites of interest (2.3%); Book Reviews (8%); New Article (79%); and Case Study (5%).

"Ethical issues" were the main focus of the "new articles" for 24% of the sample, "legal issues" for 19%; "social issues" for 28% and "scientific issues" for 25%, indicating that the *Geneletter*'s content was in line with its stated objective. The table below outlines the main themes discussed in the articles, by decreasing level of presence:[7]

Genetic testing, genetic counseling:	**present in 24% of the articles (*)**
Science background on genetics:	**20%**
Legislation and genomics:	**15.3% (*)**
New research on genomics:	**10.7%**
Eugenics:	**10.2**
Cloning:	9.7% (*)
Public opinion/public perceptions:	9.2%
Privacy issues:	7.1% (*)

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[5] The Shriver Center was established by the UMBC (The University of Maryland, Baltimore County) in 1993. According to its website, "The Shriver Center's diverse programs engage the strengths and resources of higher education in finding creative solutions to some of the most troublesome social problems of our times" (see http://www.shrivercenter.org/aboutshriver/welcome.html).

[6] A number of publications do address ethics and genetics, although not through a newsletter format (see http://home.uchicago.edu/~ebetran/ethics.html for a list of sites); the National Information Resource on Ethics and Human Genetics (http://www.georgetown.edu/research/nrcbl/nirehg/) also provides some useful links.

[7] The percentages do not add to 100 since several themes could be addressed in the same article.

Treatment of Human Subjects:	6.1%
Insurance related issues:	5.1%
Market related issues (new products, etc)	4.1%
Behavioral genetics:	2.6% (*)
Patenting:	2.6% (*)
Litigation related to genetics:	2.6%
Stem cell research:	2%
Gene therapy:	2% (*)
Media coverage of genetic issues:	2%

(*) DOE-ELSI research categories, as reported on the DOE-ELSI webpage.

In sum, *Geneletter* addressed a wide range of issues, in line with the DOE-ELSI research agenda.

c. Audience/Readership

Geneletter users were divided among company-bases users(.com-38%), network users (.net-31%), educational institutions-based users (.edu.-26%), with fewer from organizations (.org-4%) and government (.gov-1%).

Geneletter editors kept record of web traffic statistics. According to *Geneletter* final report, the average number of hits on *Geneletter* webpage per day was 1857 between September 18, 1996 and October 26, 1999. The most active day was February 22, 1999 (shortly after the eugenics issue was published), with 6904 hits. The least active day was September 21, 1996, with 19 hits. [8] Starting with the March, 1997 issue which contained articles on the ethics of cloning, readership shot up to an average 5000 site visits per week and remained there until the site was transferred from the Shriver Center in October 1999. The average user session lasted 7 ½ minutes.

The audience was broad, including 6th graders to graduate individuals. According to D. Weiz, “no visible difference in knowledge was apparent between the groups, as shown by the types of questions asked through e-mail or chatbox.”

d. Users’ Feedback/Evaluation data

Users’ feedback was made possible through two channels: a chatbox, and direct e-mails to the editors.

The chatbox did not prove to be an effective tool for discussion; numerous technical problems were encountered, the chatbox being hard to access. All together, 200 items were posted in the chatbox. However, no real interactive discussion took place. In sum, as pointed out in *Geneletter* final report “it appears that although people were eager to seek information from the editors via email, comparatively few were eager to “chat” about issues related to genetics.”

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[8] For comparison purposes “Your Genes, Your Choices” had 2, 624 average hits per day, and “Challenges and Impact of Human Genome Research for Minority” 398 per day.

Readers asked a wide variety of questions through the “Letter to the Editor” feature, i.e. emails. The editors received over 800 inquiries through this medium. We performed a content analysis of 177 e-mails sent to the editors.[9] Out of those, 21% expressed support for the Geneletter webpage; 12.4% addressed a theme not related to Geneletter content; 24% were related to education (i.e. school project; course content; graduate work).The e-mails analyzed addressed the following themes:

Genetic testing	16.4%
Scientific background on genetics	13%
Cloning	13%
Legislation	10.2%
Insurance	3.4%
Gene therapy	2.3%

Themes present in less than 2% of e-mails: Privacy issues, Treatment of Human Subjects, Eugenics, Market related issues (new products, etc), Behavioral genetics, Litigation related to genetics, Stem cell research, Media coverage of genetic issues, Public opinion/public perceptions, Patenting.

Issues raised by readers were therefore in general in line with *Geneletter* content. However, and as noted by D. Weiss, “readers’ queries focused on popular science issues (cloning, Jurassic Park) rather than on ethical concerns.” Whenever possible, the editors made a point of answering readers’ queries. Many of the e-mails, however asked very broad questions (therefore hard to answer, according to the editors) such as “Tell me everything you know about the Human Genome Project.” One may therefore wonder to what extent the content of the Geneletter’s articles was appropriate for the knowledge level of a fraction of the readership.

e. Follow-up (changes after initial project ends)

The initial project ended with DOE-ELSI funding in October 1999. *Geneletter* resumed its publication in February 2000, with a new editor, Paul Billing, and with financial support from GeneSage. *Geneletter* had lost a lot of readership by then, but eventually got back in track. Geneletter targeted audience shifted to primary care physicians. Articles were written by staff and freelance writers, and format of the letter changed. According to D. Weiss, the quality of articles varied. Sixteen issues were published between February 2000 and May 2001 (one a month). The project went out of funds in January 2001, and the last 4 issues re-used previously used material.

D. Weitz did want to insure the continuation of the project as it was initially set up (i.e. geared toward a broad audience, but was unsuccessful at getting *Geneletter* back to the Shriver Center, Since she believes that there is a real need for this type of publication, she started a new collaboration with the University of Montreal. Although the readership of the new publication

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[9] We used a convenient (i.e. not random) sample of e-mails that were kept by the project P.I. The goal was to get a general sense of the type of issues addressed by the readership, in relationship to the content of the outreach documents.

might be smaller than the Geneletter one (emphasis will be more on legal issues) the site will provide information on ethical and legal issues.

f. Outcomes of the Project

According to our analysis, the project's content was in line with its objectives, and the *Geneletter* was reaching the intended audience. Engagement of the readers was however limited, the chatbox not generating discussions. However, the project objectives evolved when it was turned over to private investors, therefore jeopardizing to some extent its potential impact on public understanding of ethical and legal issues related to genomics.

g. Case Study in Relationship With the Theoretical Models

Geneletter essentially followed the Deficit model. As we explained earlier on, this model focuses on increasing public understanding of scientific issues, and on increasing levels of scientific literacy among the general public. Projects that follow this model aim principally at filling the gap of scientific knowledge of a broad public by providing accurate information a-priori defined by experts. *Geneletter*'s general objective and organization were in line with this theoretical framework. *Geneletter* aimed at increasing public understanding of ethical, legal, and social issues related to genomics, the editors defining the themes to be covered and addressing a broad range of ethical, legal and social issues related to genomics research. No specific audience was targeted, the editors aiming at reaching all interested individuals.

This approach seemed to be successful: (1) readership of the newsletter was broad, and included 6th graders to graduate individuals; (2) the site had 5000 site visits per week (after March 1997), the average user session lasting 7 ½ minutes, a reasonably high number for a specialized newsletter [ADD REF]; (3) the themes raised by the readership in the "Letters to The Editor" were in line with the content of the articles posted on line, which shows that indeed, the audience was eager to learn more about the issues covered. It is difficult to assess, however, what was the impact of the newsletter on the rest of the readership (i.e. that did not communicate through e-mails with the editors) since no evaluation data addressing that question was available. Also, the question of what level of information should be provided to a targeted audience, i.e. what readers actually need to know, is apparent from the analysis of the project. As the PI of the project pointed out, the e-mails often raised very broad questions that were hard to answer. Some of the readers may therefore have found the content of the newsletter too sophisticated for their level of knowledge.

Although *Geneletter* fits in the Deficit Model of public communication of science, it cannot be criticized for providing information out of context, which has been one of the main criticisms of the deficit model. Most of the articles (and particularly the "case study" format used to address some in the ethical issues) used a framework that made the information provided clear and easy to understand, and that made it as relevant as possible to readers' lives. In other words, *Geneletter* had some characteristics that are usually not found in Deficit approaches and that are more in line with the Contextual Model of public communication of science.

Another feature of the project shows that the Deficit Model cannot fully fit the *Geneletter*. Some interaction between project leaders and readership did take place through e-mails, which demonstrate that the project did, to some extent, engage citizens with science. Although we do not know to what extent this did spark public participation in decisions related to scientific issues, it does demonstrate that there might be an overlap between the Deficit model and the Public Engagement model. It also points out the necessity to define more precisely what academics mean by "engagement with science" which can range from sparking interest among the public, to engaging citizens in decision-making procedures related to science. Such definitions are clearly needed if project leaders want to include sound evaluation plans (linking objectives to outcomes) in their projects.

In sum, the analysis of the *Geneletter* shows that the Deficit Model does not fully capture the reality of this type of outreach. A project that, at first glance, might have appeared as a traditional deficit approach had characteristics that made it fit in several theoretical models.

2. A "Workshop Based Approach:" the Human Genome Project Information Conference, The Challenges and Impact of Human Genome Research for Minority Communities"

a. Presentation of the Project: Objectives and Intended Outcomes

The National Educational Foundation of Zeta Phi Beta Sorority, Inc. received support from DOE-ELSI to sponsor information conferences on the Human Genome Project for minority communities (the sorority has adopted the Human Genome Project as a national project, and has put an emphasis on providing related information to its chapters' communities members). Five major conferences took place in the following locations: New Orleans (in 1999), two conferences in Philadelphia and one in Atlanta (in 2000) and Washington D.C. (in 2001). DOE funding has been the backbone for the project and has helped set up the conference concept. The Foundation got support from DOE-ELSI for the New Orleans, the Atlanta and the Philadelphia conferences. The conferences broadly aimed at involving minorities members with science and genetics. The goals were to provide minority community members with information about the Human Genome Project and to find out what were minorities' concerns related to current genomic research, in order to provide feedback to the funding agency. They also aimed at getting minority college students interested in the areas of genetics, biotechnology and related science. In sum, as specified in the final report of the July 7-8 Philadelphia Conference, the conference goal was:

> " to raise the level of awareness, in minority communities, of the rapid strides being made in human genome research and the background of the HGP, its potential and value to minorities, particularly in the area of health care; to identify issues that are important to the minority community and avenues for more involvement of this community; to explore post-conference ways of continuing input from and update of minorities."

b. Outreach Materials

We will focus our analysis on the Philadelphia (July 7-8, 2000) conference, which was funded by DOE-ELSI. Leaders of the conference were Issie L. Jenkins, Esq, Zeta Foundation chair and Dr. Malvern, Conference Project Director. A planning committee composed of Issie Jenkins, Kathryn Malvern, Audrey Thorton (Community Coordinator), and Barbara Henderson (Advisory Council member) developed the program for the conference. An Advisory Council (always the first entity to be set up) provided advice on program development and was in charge of disseminating the information to the communities. The Advisory Council (also called the committee advisory group) was composed of around 25 representatives from minority organizations, from governmental agencies, health organizations, churches and educational institutions, in other words of "people that knew the community" (Jenkins, 2002). According to Issie Jenkins "the committee advisory groups have been very instrumental in identifying people in that community who could be a part of the program … and in raising questions that may be of interest to them so that [they] may be included in the program." According to Dr Malvern, the Advisory Council was also instrumental in getting community members to attend the conference. Dr. Malvern pointed out that community leaders, such as ministers, can encourage the attendance of individuals that might otherwise be left out of the process.

The conference combined experts' presentations and panel discussions, workshops and public discussions. In addition, copies of the book "Your Genes Your Choices" and handouts (both provided by DOE), were made available to the conference participants. Organizers thrived at creating a very mixed group of presenters (researchers, DEO representatives, private researchers, sociologists, anthropologists, educators). The goal of the presentations was to first provide a general scientific background (on genes, proteins, …) to the conference attendees, in order to make the presentation of the Human Genome project, of its potential benefits and of its ethical, legal and social implications, easier to understand for the audience. The main presenters (and the topics they covered) were the following:

- Dr. Ari Patrinos, Associate Director, Health and Environmental Research at DOE (History and accomplishments of the HGP);
- Dr. John Quackenbush, The Institute for Genomic Research (Genes and genomes: Decoding the book of life);
- Dr. Karen Nelson, The Institute for Genomic Research (The benefits of genetic research in improving health and health care).
- Panel discussion on implications of HGP for minority health issues: Dr. Georgia Dunston and Dr. Robert Murray (Howard University Medical School);
- Dr. Mary Kay Pelias, Louisiana State University Medical School (Genetic problems in clinical practice and biomedical research);
- Dr. Fatimah Jackson, Anthropologist, University of Maryland (Scientific and folk ideas about heredity);
- Dr. Chris Adams, Mosiac Technologies (Private industry and its role in the biological revolution)
- Panel discussion on ELSI of HGP for minorities: Phyllis Epps, Esq, Health, Law and Policy Center, University of Law Center; Dr. Jennifer Smith, FBI Laboratory, DNA analysis unit; Dr. Jeroo S. Kotval, School of Public Health, New York State University; Dr. Pamela Sankar, Center of Bioethics, University of Pennsylvania; Moderator: Issie Jenkins, Esq., The Shelton Group.

In addition, workshops covered the following topics, and aimed at producing a list of concerns and associated recommendations, related to minorities and genetics:

- Genetic screening, testing and counseling: Issues of importance to the minority communities;
- Expanding the pool of minority scientists; Genomics and its challenge in the education of minorities;
- Minorities in the scientific workforce; Career development;

The Reverend Dr. Deborah Wolfe, a conference panelist, produced 14 questions for which she requested answers at the conference. As she put it : "since, as you know, I did not participate in bringing about this great discovery [the genetic code] and since I really know so little about the details of the study, all I can do as a teacher, as a preacher, as an interested citizen is to raise questions to you who are specialists." The conference was therefore not only a setting for experts to disseminate their knowledge, but also for lay individuals to formally participate.

In sum, the experts' presentations and discussions were balanced as far as scientific versus ethical, legal and social issues are concerned, and raised questions that were of interest to the audience, as the evaluation data demonstrated (see next section).

The conference proceedings were posted online on the DOE ELSI webpage (at http://www.ornl.gov/hgmis/publicat/zetaphibeta).

c. Audience/Readership

Since there was hardly any newspaper, television or radio coverage prior to the conference, advertisement for the conference was restricted to the organizers' flyers and mailings. The organizers directly reached out to the members of the community by speaking to organizations to let them know about the conference, and by providing them with materials and registration forms to give to their members.

As we mentioned earlier, the conference organizers made a point of encouraging attendance by minority communities through the Advisory Council. Dr. Melvern, for example, reported the following story:

> "So I was telling you the story about the judge in PA, she said, "Dr. Melvern, you are not going to get the Chinese community this time, because they are all focused on Chinatown." [The judge] said, "I will be the conduit," and she was for what was happening, and she would be part of whatever happened later. She was there at the conference, she had all the material…. So I am saying, you must have a true leader, she has kept that community involved."

Each day, the conference was attended by 250 individuals representing among others, minority organizations, civic groups, religious groups, leaders in health communication, local government officials and students. Roughly 3/4 of the audience was composed of African Americans.

d. Users' Feedback/Evaluation Data

Users' feedback from previous conferences was used by the organizers to define the framework of the 2000 conference. More specifically, as suggested by 1999 conference attendees, more time was reserved for public discussion during the 2000 conference.

The participants to the Philadelphia 2000 conference were asked to fill out surveys at the end of the conference and workshops. Descriptive statistics related to the survey data was included in the conference final report for DOE. We report the most relevant findings in this section:

- 55 attendees requested to serve as future Community Liaison Coordinators, and signed up to be trained as such.

- 83 attendees filled the survey and provided self-reports in the following areas:
    - Usefulness of the conference: 88% felt the conference was very successful in imparting useful information to members of their groups (8.4% somewhat useful; 2.4% don't know)
    - Knowledge gain:
        - 67.5% learned a great deal about the science being done on the HGP (25% a little)
        - 56.3% learned a great deal about the ethical implications of the HGP (35% a little);
        - 55.8% learned a great deal about the potential harmful effects of the HGP for minority groups (34% a little);
        - 55.1% learned a great deal about the social implications of the HGP (29% a little);
        - 53.8% learned a great deal about the potential benefits of the HGP for minority groups (35% a little);
        - 43% learned a great deal about the legal aspects of the HGP (30% a little)
    - Attitudes toward the potential effects of the HGP:
        - 48.7% felt that the benefits would be greater than the harmful effects;
        - 15.4% felt the harmful effects would be greater than the benefits;
        - 35.9% did not know.
    - Concerns for racial/ethnic community:
        - 80.8% concerned about the availability of genetic information to employers;
        - 79.7% concerned about the availability of genetic information to insurers;
        - 78.9% concerned that HGP benefits would be available only to privileged groups;
        - 78.9% concerned by potential program development using genetic information to alleviate crime, alcoholism and poverty.

The conference seemed therefore to have achieved the goal of informing its audience and raising awareness of the potential benefits and harmful effects of the HGP for minority communities. However, the percentages reported above should be interpreted with caution, since only 33% of the attendees (assuming that the same 250 people attended the conference every day) filled in the evaluation survey.

Using the web as a resource for potential dissemination of the conference proceedings had a limited success. As of 4/30/2002 (i.e. almost 2 years after the conference), the site had had only 2,021 visitor sessions (of these, 932 individuals visited the site once). The average visitor session length was, however, somewhat long (23 minutes).

e. Follow-up

Initiatives for 2000-2001 were developed at the end of the conference. They included the future selection and training of Community liaison coordinators, informational and training sessions for Zeta Phi Beta Sorority Regional Directors, State Directors and Chapters. As mentioned earlier, 55 attendees were interested in being future Community Liaison Coordinators, and signed up to be trained as such in the Philadelphia area. Training classes were to be organized by the Foundation, training materials including stated objectives, written lesson plans and training videos. Conference follow-up plans included grant writing to support the training program.

Plans were also made to organize additional conferences, particularly in Chicago (2-day conference) and in the West. Several mini conferences were also coming up at the time of our interviews, a mini conference was going to take place in Norfolk Virginia (part of the last DOE grant had funding for 10 mini conferences).[10] Finally, a conference was to be organized in DC in 2001 (the funding coming from other sources than DOE).[11]

f. Outcomes of the Project

The project did succeed in initiating the propagation of HGP related information to minority communities, way beyond the conference itself. The fact that 55 of the conference attendees signed up to become community liaison coordinators demonstrates that the conference motivated some individuals to reach out to their communities, which was ultimately the goal of the conference. As Dr. Malvern puts it, “we need to give [the conference participants] enough knowledge and enough training so that they can go out and give the same information to their own constituencies.” The conference was therefore only one component of a more complex outreach process. The conference was the location where different possible community liaisons were identified. After training, the community liaisons were supposed to be able to disseminate the information in their community. Through the chapters of the sororities, smaller conferences were to be organized, in order to reach as many individuals as possible. We do not have data, however, on the success of the informational process that was initiated by the conference.

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[10] The mini-conferences are organized in towns the Foundation would have more difficulty to reach, such as the ones situated in rural areas (for example, a mini-conference was organized in Arkansas for farmers).

[11] http://www.tech-res-intl.com/hgp/.

g. Case study in Relationship With the Theoretical Models

The project broadly followed the “contextual model” of public communication of science. As we have explained in an earlier section, according to this model, researchers identify populations that might have different underlying attitudes and concerns related to genomics research without necessarily tying those groups to particular risk contexts or to levels of "science literacy." Outreach projects are then built in a way that is relevant to these audiences. The conference focused on minority needs and concerns. What is particularly interesting is that the conference was used as a setting not only for the dissemination of relevant information, but also to find out the characteristics of the particular context at play. For instance, the reverend Dr. Deborah Wolfe, a conference panelist, produced 14 questions for which she requested answers at the conference. As she put it : “since, as you know, I did not participate in bringing about this great discovery [the genetic code] and since I really know so little about the details of the study, all I can do as a teacher, as a preacher, as an interested citizen is to raise questions to you who are specialists. The meetings with the community liaisons were also a place where specific minority concerns could be identified. Dr. Malvern synthesized this point in the following way:

> “You see, we don’t necessarily know all minority issues. Take for instance the Hispanics, their morals and culture can be different and when we think in terms of something that happens in the community, we could think that it is negative when for them it is a positive thing. Therefore it is important to get their leaders involved, so that we can more easily understand [the context] and get into those communities.”

Philadelphia Conference organizers and community liaisons did share the goal of providing useful information to their community through outreach. But as one of the community liaisons put it “the challenge was that people [had] a different interpretation of outreach. Everybody was going towards a goal, but using different ways to get there.” (Lieu, State of the Arts, Health communication). In other words, coordinating these different conceptualizations of outreach might be a challenge, even within the conceptual model of public communication of science.

Finally, the project also somewhat followed the deficit model, by providing background knowledge a-priori defined by experts. The goal was to help the audience grasp the basic scientific content needed to be able to constructively discuss ethical, legal, and social issues related to genomic research and its applications. This raises the following question: Can the contextual model stand out without a “deficit” type of approach as a backbone? It seems difficult to conceive that that could be the case. Even if an outreach project is designed in order to answer the needs of a specific audience, as it was clearly the case here, providing background information will be a mandatory first step, if the communicators want to bring the audience to a shared level of basic knowledge.

3. A “Printed Book” Approach: Your Genes Your Choices (YGYC)

a. Presentation of the Project: Objectives and Intended Outcomes

In 1995, the American Association for the Advancement of Science (AAAS) Directorate for Education and Human Resources received funding from DOE-ELSI to conduct an outreach effort on the Human Genome Project. The project was part of the “Science + Literacy for Health” initiative. The project objectives were the following (AAAS, 2003)

“- to develop new adult literacy materials on the Human Genome Project--a book, teacher's guide, and a resource database on the Internet;

- to help low-literate adults acquire the factual content base they need to understand the ethical, legal, and social implications of the Human Genome Project; and
- to develop and conduct an outreach campaign to disseminate project materials to U.S. libraries and community organizations.”

According to a mid-1995 AAAS progress report, recent literacy surveys had found that a large number of adults lacked skills to bring meaning to much of what was written about science, which denied them access to vital information about their health and well-being. AAAS therefore wanted to use its existing network of adult education providers and volunteer science and health professionals to develop a high-interest reading book and accompanying curriculum. In other words YGYC was originally conceived as an “adult literacy tool”, for a GED market. The initial objective of the project was therefore to educate the general public by conceiving materials at lower reading and conceptual levels, which would make them more accessible to everyone. Introducing the science as a relevant element to help understand the nature of the issue would also provide a means of elevating science, for it to become an essential part of the way people form an opinion about the ELS issues.

b. Outreach Materials

“Your Genes, Your Choices,” an illustrated book, was to describe the HGP, the science behind it, and the ethical, legal and social issues involved. Its initial intended audience was to be adults with 6th to 8th grade reading skills. The book was to provide “contexts and definitions for most science information and concrete language, examples, and illustrations to support abstract concepts.” It was also supposed to provide real-life situations the readers would be able to relate to. The goal was to give just the amount of science that was necessary for readers to be able to understand the ELS issues related to genomics. Although lower-level education had previously been done at the community level, this was to be a national initiative. The goal of having the least amount of science necessary for understanding ELS issues, and of keeping scientific information provided at a very basic level was to be a challenge, since scientific issues surrounding HGP were many and complex. Keeping simplicity as a goal was however important for several reasons:

- the objective of the book was to address the ethical, and not the scientific issues related to HGP;

- the limited length of the book would not allow for excessive information given that most basic concepts will have to be explained;

- "Less is more" when teaching science. Too much science would overwhelm the reader;

- Emphasizing <u>relevance</u> of science over science itself might lead readers to interest in science;

Project managers could also safely assume that all adults have had some direct or indirect experience with ELS issues – which would provide a context with which to explore issues related to HGP. Catherine Baker, the author of the book and a "plain-language" writer, said that she defined the "complexity level" of the book simply by writing it as easily as she could, though she admitted using words or terms that she once would have considered too complicated. She also pointed out that although people did not need to know much science to understand the issue one of the major goals of the book was, however, also to give that science background, in order to make sure the audience understood the ELSI points.

Early evaluation work was performed to determine the content of the book. In particular, a focus group was conducted in May 1995 amongst low-literacy adults. The participants were asked what they would like to know about genes. The responses were the following:

- Where genes were located;
- Know more about how genes work; what they do;
- Know how genes can be damaged;
- Know how many genes there are in human body; their size;
- If every person has the same number of genes;

Participants were asked to read the list of proposed book chapter topics and to indicate if these were topics they would like to know more about. Participants were also asked to read the first two pages of the introductory chapter of the first draft – they felt material was not too difficult. Some participants suggested pronunciation guidance in the text for difficult words as well as a glossary**.** Overall, the participants liked the tone and felt that this was a book they would like to read**.** Participants, after being given a 2-page "future story" that was taken from the first chapter, indicated interest in learning more. They suggested to "keep up the good work" and agreed that the material was interesting. They also suggested "having a lot of examples" and "more details." In sum, most of the comments of the initial focus group participants were taken into account for later drafts of the book.

A focus group performed in 1996 aimed at understanding the interests of the audience, and asked questions such as: "What would you like to know more about in terms of genetics?" and "Who should make decisions (about how genetic information should be used)?"Additionally, 4 workshops were held in 4 sites, with the help of genetic counselors as facilitators.

The initial draft of the book was reviewed by members of the advisory panel who were experts in the fields of genetics and genetic counseling, plus other experts selected by the AAAS project director. Comments and concerns of reviewers were compiled in writing by evaluation consultants and communicated to the author. In other words, at least 10 people reviewed the first draft. Later on, two reviewers (Dan Drell and Robert Cook-Deegan, a published author of academic science) worked with the author one-on-one.

The final draft of the book (93-pages) uses an interesting format: each chapter starts with a personified anecdote, presenting an individual in a "real-life" situation, and ends by asking the reader to take a stand on the issue at play, or how (s)he would react in the same situation. The "real life" situation is then used as a backbone to present basic scientific facts about genetics. However, the level of scientific information might be more complex than what was initially intended. The author pointed out that as she learned more about the science, she included more advanced ideas than she normally would have, and that genetic professionals tended to emphasize the need to include more science

Professionals involved in the drafting of the book included:

- Catherine Baker – Author, YGYC, Plain Language Writer
- Maria Sosa – Science Literacy Trainer and Editor-in-Chief of Science Books and Films, Directorate for Education and HR programs, AAAS
- Shirley Malcom – Head, Directorate for Education and HR Programs, AAAS
- Jim Miller – Senior Program Assoc, Program of Dialogue on Science, Ethics and Religion, AAAS
- Dan Drell – Program officer at DOE
- Olivia Masih White – A geneticist at U of Northern TX
- Marcia Harrington – DC public library
- Carol Osgood – The Learning Bank
- Tracy Gath – Literacy tutor

As far as content is concerned, the book broadly covers ELSI issues related to genomics, and more particularly the following topics:

- genetic testing and its implications;
- genetic counseling;
- discrimination based on genes;
- prenatal testing and its implications;
- reproductive technology and its implications;
- DNA and privacy issues;
- biotechnology farming and its implications;
- germ-line therapy, genetic engineered medicine;
- eugenics;
- cloning.

c. Audience/Readership

As of June 2000, 8,000 copies of the book had been printed. Books had been handed out to judges, conferees, congressional staff, and others. A Google search for "Your Genes, Your Choices performed at the same time retrieved more than 200 links (w/o errors). Additional data shows that 6000 people had visited the website where the book was posted, 5000 returning to the site.

In 2002, Jim Miller (Senior Program Associate, AAAS Dialogue on Science) pointed out that he had distributed the book to a significant number of religious education leaders. Dr. Olivia White (Geneticist at the University of Northern Texas) used hundreds of copies as background resources for workshops with clergy. Clergy members have remarked on its potential to stimulate discussion within congregations.

A new Web search conducted on 10/23/02 for "Your Genes, Your Choices" produced 53,000 different links. Some were repetitive and others unrelated, but current use varied from a resource for educators (K12 to the university level) to resources for genetic counselors.

- 568 Links for "Your Genes, Your Choices and K12"
- 6,100 Links for "Your Genes, Your Choices and genetic screening"
- 5,150 Links for "Your Genes, Your Choices and Teacher Resources

Additionally, the book is also often used as a resource in undergraduate courses in bioethics, as show links to a large number of syllabi.

As far as web-use, HGMIS provided the following data: as for April 30, 2002, the online version of the book had had 11,652 visitor sessions, 6,198 being unique visitors. The average visitor session length was 7 minutes and 39 seconds.

d. Users' Feedback/Evaluation Data

No summative evaluation was performed for the final draft of the book, although the book's author admitted it would have been useful. However, Catherine Baker did give anecdotal accounts of people who had read the book and had liked it, although some pointing out that they didn't necessarily learn more about "genes." Dr Malvern, Director of the Philadelphia Conference that we presented earlier on, used the book as an additional resource for the conference participants and commented: "Your Genes, Your Choices? People will kill for those little books!"

e. Follow-up

An additional chapter on Human Cloning was added to the 2nd addition (chapter 8). This was made possible through supplemental funding. Additionally, Dan Drell (DOE) suggested putting the book on CD-ROM format. He also pointed out that the book could be used as a model for a behavioral genetics publication (this new project was in process at the time of the interviews).

f. Outcomes of the Project

As far as readership is concerned and as assessed by the large number of web-sites referring to the book, the project was a success. The book will also have an international reach. A Spanish translation of the book had just been approved at the time of our interviews (the translation been very loyal to the original text) and an Icelandic translation was under discussion.

Although widely distributed, the book did not reach the originally intended audience, which was a low-literacy adult group. A generational gap in the interest in the book was also pointed out, younger people seeming more likely to take an interest in the book than the elderly population. However, the book did generate wide interest and was used by a wide variety of audience in different setting (congregations; college classes, etc…).

g. Case Study in Relationship With the Theoretical Models

The project associated to the development and distribution of the book "Your Genes Your Genes" followed the traditional "Deficit Model" approach to public communication of science. As we have pointed out earlier, this model is the most widely used in the context of science-related outreach. Interestingly, however, the book aims at encouraging readers to seek additional information. In other words, the book is supposed to be the starting point of a self-administered educational program on genetics. Notably, in the last chapter of the book, the author writes that "[readers] have made a choice to gain some control of genetic issues by reading this book. Now [they] have the choice to remain informed."[12] Encouraging self-education is clearly going beyond a purely "deficit model" approach since it actively promotes the engagement of the readers with the issue at hand. We have also discussed how the book was widely used as basis of discussion in settings such as religious congregations or college classrooms. The book was therefore actively promoting public engagement with science, and a critical approach to ELSI related to genomics. In other words, in the context of YGYC, the "deficit" approach shows some overlap with the "engagement" model, if engagement is conceptualized as "empowerment" of the readers.

A number of additional observations can be made. First, although the book's creators emphasized that the focus of the book would be on ELSI and not on science, it is unclear, upon reading the book, what the real focus is. Even some of the individuals affiliated with the project (i.e. Jim Miller) felt that the main goal of the book was to educate readers about science. This again brings up several points that we have discussed earlier on. What does the public need to know as far as science is concerned in order to be able to understand ethical, legal and social issues related to scientific advancements? Is it possible to define a common bottom line that would be applicable to a broad population, and if yes, by which means should that be defined?

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[12] This would have been an excellent opportunity to provide readers with resources that would continue to further their knowledge, maybe through a list of useful web links. The "taking control of the issue" terms, which are a powerful rhetorical tool, could also have been stressed out at the beginning of the book.

Second, we mentioned that no summative evaluation of the project had been performed, although the project leaders stressed the importance of such an evaluation. One of the reasons for such a lack of evaluation might the fact that it wasn't included in the initial grant proposal, and therefore no funds were available later on for that purpose. Evaluation data could have helped us assess with more detail how the book promoted readers' empowerment.

4. A "Multiple" Approach: A Question of Genes -- If Your Could Read Your Life Story . . . Would You Want to Know How it Ends?

a. Presentation of the Project: Objectives and Intended Outcomes

On September 16, 1997, a special program titled "A Question of Genes: Inherited Risks" was aired on public television nationally. The program had been developed with funds from DOE-ELSI. Through case studies, the documentary aimed at exploring the drama, social and ethical dilemma raised by genetic testing, and at appealing to a broad audience. The general philosophy of the documentary was "to tell what the technology means, not what it does." (Schwerin).

The project was developed at the initiative of the filmmaker, Noel Schwerin, who had worked previously on science-related documentaries (for programs such as NOVA in particular). The filmmaker performed all the background research necessary for the program. The filmmaker then brought the project to an executive producer, Angier Production, to work on a proposal to be submitted to DOE.

b. Outreach Materials

Two types of outreach materials were developed in the context of the project: First, the documentary that was aired on national television, and second, a website that was developed concurrently provided additional information and links relevant to the topic at hand.

The documentary provided a series of 7 profiles, or case studies, of people "like you and me" that had had to deal with issued related to genetic testing in the course of their life. The people were the ones directing telling the stories– there was no narrator. In some cases, the individual recounted his/her experience and provides necessary scientific information. In others, a doctor or expert was providing relevant background. As a general rule, the filmmaker wanted people to directly share their personal experiences. As Noel Schwerin put it: "I believe that they are the experts… They had the real data". This was also a way to engage the audience as they were to sympathize with the "real-life" narrators. The 7 profiles presented in the documentary were given equal weight, although they did not all present the same point of view. The goal was to get the audience to think about the issue, and to realize the dilemma that such situations might pose as far as ethical considerations are concerned, while presenting only the science that was needed to understand the case study. Noel Schwerin pointed out that it was often "tricky to give just enough information as not to get confused." In some instances, additional information was provided at the end of the case study, through a scroll-down text.

The 7 case studies were also presented (and still are) on the website related to the project (www.pbs.org/gene/), which was an important component of the outreach project since it gave the opportunity for interested viewers to find out more about the issues at hand. Video clips with audio were posted for each case study – users could also read transcripts of the scripts. Each case study was also accompanied by a link to an Educator's Guide specific to that topic, as well as links to a discussion forum (users could post comments and questions to the discussion forum from September 16th to October 13th, 1997. During this time users were able to interact with a panel of participants from the TV program which included physicians, patients and researchers).

c. Audience/Readership

It is, of course, hard to assess the size of the audience that did see the program when it was aired on national television, although it did have the potential to reach millions of individuals. It seems reasonable to assume, however, that the audience that was reached was the typical audience for such TV shows broadcasted on PBS, i.e. an educated, interested in science, public.

As far as the educator's guides are concerned (provided through the website), they were distributed to 66,000 professionals in the fields of genetics, ethics, biology, public health and related fields. Results from a bounced back-survey card (223 responses) provided with the educator guide indicated that 63% of the respondents were professors or teachers. Additionally, the website had 40,000 hits in its first 3 months, a very high traffic for such a show.[13]

d. Users' Feedback/Evaluation Data

Users had the opportunity to participate in an on-line survey evaluating the web-site. It also asked whether or not visitors to the web-site had seen the program – or were reaching the web-site independently, and how users found out about the web-site. Questions were both multiple-choice and had spaces for open-ended comment. However, only 22 people filled in that survey.

Some evaluation of the TV program was provided through the bounce-back survey cards and through phone interviews with a sample of the people that had been provided with the education guide (94 interviews). Respondents, overall, gave very positive feedback on "A Question of Genes," 92% of the respondents indicating that the program was excellent. More than 85% of the respondents indicated that they had or would use "A Question of Genes" as an educational resource; 92% videotaped the program for future use, 80% saying that they would recommend it as viewing to their students.[14]

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[13] This data is presented in the executive summary prepared by Media Management Services, Inc. (January 9, 1998) for Oregon Public Broadcasting.

[14] See footnote 12.

e. Outcomes of the Project

The timing for the project was perfect for the format used for the program. Since media coverage about these issues was still minimal, people were more genuine and more eager to share their experiences. According to Noel Schwerin, “it was an amazing opportunity to find out how people felt about these issues.” However, Noel pointed out that this would be more difficult nowadays, since people have more the feeling that this type of information is powerful and would be less eager to expose their private feelings.

As shown by the evaluation data and the press coverage, “A Question of Genes” was a highly successful documentary that obtained several awards. Not only was the documentary used as a TV program and discussed through the website. Anecdotal evidence shows that it is also used in high school settings and other educational settings. The use of the film is sustained, the video being on back order at the Oregon Broadcasting. Noel Schwerin was invited to talk about the film at Berkley and Stanford, and a screening of pieces of the film shown at a meeting of the American Association of the Advancement of Science, for an audience of bioethicists

Six years after the documentary was aired, the website still has hits, the main reason being, perhaps, that it is maintained through the web site of PBS, and featured as a teacher resource.

f. Case Study in Relationship With the Theoretical Models

“A Question of Genes” exemplifies how the “lay knowledge model” for public communication of science can be used in an outreach setting. As we discussed in Chapter II proponents of a lay knowledge approach argue that communication activities need to be structured in ways that acknowledge information, knowledge and expertise already held by communities, or individuals, facing scientific and technical issues. Although this model has often encountered critiques within the scholarly communities dealing for public communication of science, this case study demonstrates that it might be a good way to approach issues that do have high relevance for people’s life, and that might provoke strong feelings. In other words, as Noel Schwerin argued, having “real people” explain how they dealt with genetic counseling will explain “what the technology means, not what it does.” If this is the goal of the outreach, a “lay knowledge” approach might be the way to go.

The case study also reveals some overlaps between the theoretical models we presented in Chapter II, by fostering engagement of the participants with science. The TV program led the viewers to go to the website, and to get the educators guide in order to use it in other type of settings. In other words, the “lay knowledge” model did show some overlap with the “public engagement” model. The project also provides the scientific information necessary for the audience to be able to understand the case studies. In that sense it does share some of the characteristics usually attributed to the “deficit model” of public communication of science.

Finally, the project displayed some characteristics of the contextual model, in that it did pay attention to the needs of particular audiences, the people for whom genetic counseling might particularly relevant. By emphasizing what the technology meant and what it did, i.e. by focusing on attitudes rather than on knowledge, the project clearly did not stay at the “deficit model” level.

In sum, this case study demonstrates again that theoretical views of public communication of science do not capture the reality of the field work.

5. A “Radio-Program” approach: The Hispanic Episodes

a. Presentation of the Project: Objectives and Intended Outcomes

In 1998, the Self Reliance Foundation (SRF)[15] got 3-years funding from DOE-ELSI to develop a series of radio shows focusing on the HGP and its scientific, medical and ELSI implications, as well as complementary outreach projects. The shows were to be broadcasted on the Hispanic Radio Network (a Spanish-speaking radio network), the purpose being to “help inform the Spanish-speaking population in the US about the HGP and its ELSI implications, and motivate them to access the resources available for further education and information on these issues.”

b. Outreach Materials

1. Radio Programs

From February 1998 to February 2000, the project developed more than 75 brief (1-2 minutes) radio programs, that were broadcasted on 3 radio shows of the Hispanic Radio Network:

- 30 programs through “Fuente de Salud” (carried by 36 station affiliates),
- 10 programs though “ Planeta Azul” (carried by 96 station affiliates),
- 10 programs through “Saber is Poder” (carried by 31 station affiliates).

These programs covered the following themes:

- Utilizing Hispanic individuals involved in aspects of Genome Research and its implications,
- Economic implications of Genome Science,
- Bio industry involvement in the genetic revolution,
- Encouraging Hispanic students to pursue science and biotechnology as a career.

The project also developed 3 hour-long shows for the radio talk show “Mundo 2000” (carried by 17 affiliates), in which Spanish-speaking experts in genetics discussed a number of issues, and answered audience questions.

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[15] The SRF is a non-profit organization, which mission is to linking Hispanics in the US with informational resources.

2. Newspaper Column

The project used the syndicated newspaper column “la Columna Vertebral” to provide information about genomics and its implications. “La Columna Vertebral” is syndicated in 82 Spanish language newspapers.

3. Toll-Free number

An 800-telephone number was listed at the end of the radio programs. A bilingual operator would answer the call, and use a database of over 15,000 local organizations, ranging from health clinics to science museums, to provide additional referral information. The goal of the 800 number was to link people up with information or systems related to what was needed.

c. Audience/Readership

Although no data is available as far as the specific shows in which DOE-funded programs were broadcasted are concerned, general information about the syndicated programs is available: “Fuente de Salud” reaches an estimated 48.9% of the Hispanic population of the US, “Planeta Azul” 86.4%, “Saber es Poder” 46.2% and “Mundo 2000” 20.9%. In addition, the combined circulation of “La Columna Vertebral” is 2.5 million readers.

d. Users’ Feedback/Evaluation Data

As explained earlier, a toll-free “Hispanic Community Resource Hotline” telephone number is set up at the Self-Reliance Foundation. Interesting data should be available through that channel, since the number of calls, as well as the caller’s demographic profile (gender, age, ethnic heritage, level of education) are recorded. Unfortunately, it has been difficult for us to obtain data related to the DOE programs.

e. Follow-up

In 2001, Self Reliance started to move in the direction of a broader outreach that would involve a greater mix of components. The philosophy is the following: the radio program can get someone interested in the topic, but the goal is also to help people follow-up on their interests. One of the most recent projects that SRF have come up with is “celebre la ciencia” which is funded by the National Science Foundation. For that project, SRF tries to combine media and high profile events, like community festivals. Information on why science is important and how families can get involved is presented in the media, with examples of science museums and zoos where families can get involved in science (a radio project for the “pigeon project” at Cornell is currently in preparation). Recently, SRF had 6 science-related organizations represented at the Mount Pleasant festival in Mount Pleasant (MD), as well as a hands-on area. Notices were posted on the radio and a couple of local TV news programs announced the event.

f. Case Study in Relationship With the Theoretical Models

The project clearly fits into the Contextual Model of public communication about science, since it was specifically geared toward the Hispanic population and tailored to their needs and attitudes. Since Hispanics make 11 to 15 percent of the US population, and data has shown that a significant fraction of this minority feel discriminated against by the US health care system, the project intended specifically to reach and inform that audience. Radio seemed like a good medium since it appears that most of the Latino population have a good access to that medium -- a greater access than the lower-income African-American families.

The project also had a public engagement component. The toll-free number was to promote a self-informational process for the audience of the radio shows. The SRF clearly intends to go beyond informational engagement, as the follow-up projects demonstrated, by promoting active participation of Hispanic families in science activities, such as the ones displayed in science museums, and therefore increase general interest for scientific issues.

C. Test of Theoretical Models: Conclusions

In the absence of methodologically sound summative evaluation data (comparing project objectives to its outcomes), it was nearly impossible to assess the actual impact of some of the funded educational projects. Our assessment of projects' outcomes is based on our analysis of the available data and on interviews, and not on data specifically gathered for evaluation purposes. In other words, our comments shouldn't be taken as critique of the projects, but rather as a means to discuss the theoretical models.

Before discussing the models per say, it seems useful to present some concepts that are used in some models, and more particularly the idea of "public engagement." What is "public engagement" in the context of science-related outreach, and what type of engagement can these projects reasonably aim at increasing? Although educators would define "to engage with science" as "to increase an individual's interest and involvement with science," policy-makers would tend to give the term a "political" dimension. This might explain why "engagement" is limited to "public participation in science policy" in the "public engagement" model for public communication of science. However, as the case studies demonstrate, we could argue that citizens can clearly be engaged in science (and ultimately in science policy) at different levels. We propose the following levels of engagement with science:

1. Individuals can engage in a simple interaction with experts to discuss scientific issues and their ethical implications (ex: *Geneletter* e-mails);
2. Individuals can be empowered through different public participation processes (ex: A Question of Genes project; the minority conferences);
3. Citizens can be given authority as far as decision-making over science policy is concerned. In this case, scientific experts are to some extent disempowered. This form of engagement is the one traditionally put forward through the Public Engagement in science model. However, although it is encountered in some public communication of science instances (ex: consensus conferences) we did not identify it within the DOE-ELSI educational portfolio.

This categorization could be used as a basis to define the goals of the educational projects, if indeed engagement is one of their objectives. In the following discussion, we will use a broad conceptualization of “engagement” that includes all the dimensions presented above.

What is the connection between the theoretical approach to public understanding of science that we have discussed in Chapter II, and the reality of outreach? Different conclusions can be reached from our analysis of the case studies. As we have seen, the projects that were analyzed in this report have objectives and outcomes that clearly seem to fit into one of the theoretical models for public communication of science. However, a more detailed analysis shows that they might also fit into one, or more, of the other models.

All case studies share the goal of communicating accurate scientific information to an audience, whether this audience is the general public or a specific group. In other words, the Deficit Model of public communication of science seems to be, whatever the context, an overarching framework for outreach. A problem seems however to arise: the level of knowledge that needs to be fostered is not clear (as shown by *Geneletter* e-mails content or “Your Genes Your Choices” change over time as far as the book content and detail level). This is not surprising since there is a lack of consensus regarding the basic question of what constitutes an adequate knowledge of genetics, a point that has been brought up in 2000 by the EREPG. The EREPG report noted that “a major gap in DOE-ELSI education and resources portfolio is the absence of studies that examine basic issues such as what each audience (students, teachers, nurses, judges, lay public) actually needs to know about genetics and ELSI.” In other words, basic research regarding what constitutes genetic literacy is needed for the Deficit Model to successfully be used as framework for outreach.

Projects that seem to fall in the “deficit” model had also some “engagement” component. We discussed how the YGYC book was widely used as basis of discussion in settings such as religious congregations or college classrooms. The book was therefore actively promoting public engagement with science, and a critical approach to ELSI related to genomics. In other words, in the context of YGYC, the “deficit” approach showed some overlap with the “engagement” model, if engagement is conceptualized as “empowerment” of the readers.

Projects that followed the Contextual Model of public communication of science were also emphasizing public engagement, one of the goals being to promote public involvement in science. Here again, an overlap between models traditionally presented as incommensurable in theoretical discussions is apparent. As we said before, a “contextual” model pays attention to specific audience needs in specific situations. We found that that this type of project, although attempting to provide information and promoting understanding of a scientific issue, aimed more particularly at shifting attitudes toward using scientific knowledge, rather than at specifically increasing knowledge. In sum, such projects’ underlying goal was to change the relationship between a specific community and scientific knowledge. It might be useful to include in the summative evaluation of such projects measures of attitude change.

Finally, the project that fitted the “lay knowledge” approach did display characteristics compatible with the “public engagement” model, by actively encouraging participants to seek more information about genetic counseling, and by making the film available to a wide variety of audiences, for particularly in educational settings.

In sum, the analysis of outreach projects clearly demonstrates that theoretical approaches to public communication of science do not capture the complexity of the reality of informal science education projects. The theoretical models discussed in the scholarly literature seem to be far too static and tend to be presented as incommensurable, when in reality they should be taken into account simultaneously. Individual models should also be refined by integrating insights provided by the case studies analysis:

- Outreach projects have all a “Deficit Model” approach as a backbone, even if they seem to follow other theoretical approaches.
- “Contextual Model” projects aim not only at increasing knowledge, but also at changing the audience’s attitude toward science and scientists.
- “Public Engagement” can take place at three different levels:
    . through a simple interaction between citizens and scientific experts,
    . by empowering citizens,
    . by providing real public authority over policy.

Figure 6 (next page) proposes a revised version of the theoretical models of public communication of science that takes into account the conclusions reached through the case studies analysis:

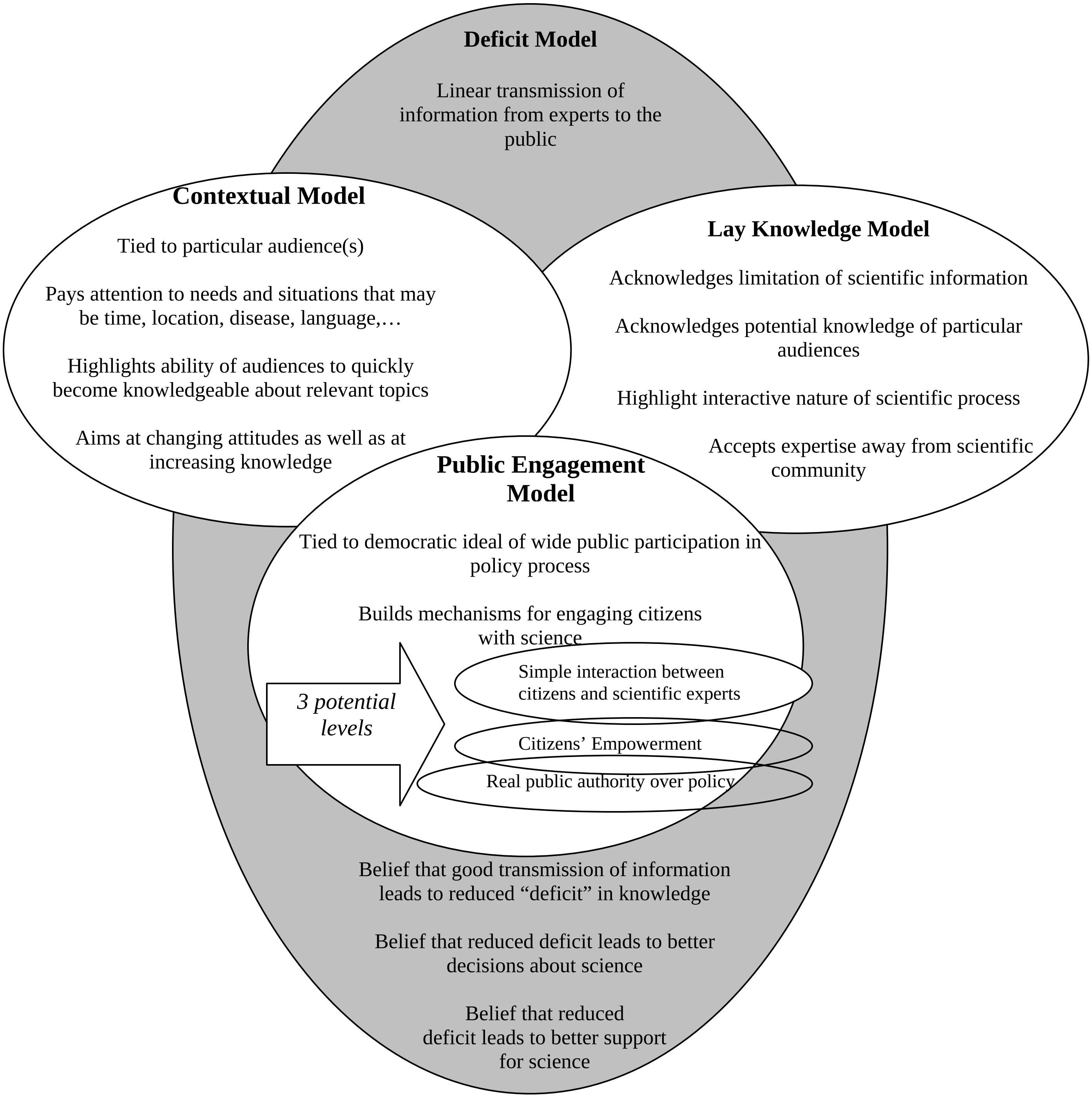

Figure 6: Revised Conceptual Models of Public Communication of Science

V Lessons to Be Retained

A number of conclusions discussed through this report can have operational usefulness for the DOE-ELSI funding program.

As a general underlying framework, projects that are funded through the DOE-ELSI projects should be conscious of which of the revised theoretical models presented on page 40 they plan to fit in. This, then, could translate into formalized program evaluation plans that should be included in the DOE funding (a number of project managers pointed out that they wished to perform such evaluations, but that often the lack of resources (funding) had prevented them to do so in a methodologically sound manner). Setting project goals (as far as intended audiences and outcomes) and comparing them to the project actual outcome through a summative evaluation would clearly be facilitated if a framework such as the one proposed on page 40 was used as a backbone.

Projects fitting into the Contextual-Engagement model, such as the "Human Genome Project Information Conferences" did illustrate how important it was to build connections within minority communities, and more importantly, to get the opinion leaders of such communities involved in the project. However, promoting such an involvement requires strong interpersonal communication skills, and a time commitment that often DOE-funded project leaders cannot spare. Building on these comments, it could be suggested for DOE to devote funding to a Public Relations type of program that would use the existing materials developed through other projects to promote discussion through a network of connections among carefully and strategically chosen communities. In other words, as our project has demonstrated, quality materials have been developed in a number of settings. The goal would be to continue their distribution instead of continuously remodeling the materials. In sum, DOE-ELSI might consider funding a project whose purpose is networking-building instead of new material development. Rather, this project would use existing material as the core of outreach. The networking could start by building collaborations with organizations such as the Kiwanis Club, the Boy Scouts, or the Speakers Bureau

Projects using the Deficit-Engagement Model could benefit for the following observations: the projects analyzed seem to demonstrate that although they reached, to some extent, the audience that were intended to reach, this might not have been as successful as possible. Traditional media are the main source of science-related information for the majority of the American population. If indeed the goal is to reach large numbers of individuals, traditional media are the way to go, and the SRF project is a good example of this. In other words, DOE-ELSI might consider a call for proposals for projects aiming at using traditional (as opposed to science) media. This could include, of course, regular network radios, but also other informal education media, such as mall displays. At a second level, as recently developed by the SRF, DOE-ELSI could implement projects within community venues themselves, by taking advantage of existing events such as fairs.

Media seminars could also be organized to inform and educate journalists about HGP related outreach information, specifically for minorities. Programs with Associations such as the

Asian Journalists Associations, of the Black Journalists Association could, for example, be developed.

Projects using the lay knowledge-engagement model are certainly, as the “Question of Genes” project demonstrated, an interesting way to communicate and promote discussion around controversial scientific topics, and have been under-used. However, such approaches would benefit from more theoretical-grounded research. More specifically, funding for anthropological research that would explore where genomics come as relevant in individuals’ lives would be an important step toward using this model adequately. In other words, this research would explore questions such as: what connection do people see with genomics? And what type of connection do they feel they need to have? Only with clear answers to those questions can a lay knowledge approach be used with its full potential (we refer the readers to the growing scholarly literature on the public and genetics currently being published in journals such as *Public Understanding of Science*).

In sum, our project has shown the potential of the outreach funded by DOE-ELSI, while also showing that current theoretical models do not fully capture the real world of outreach.

References

American Association for the Advancement of Science. (1993). *Benchmarks for Science Literacy*. New York: Oxford University Press.

AAAS. (2003). *Featured projects: Science + Literacy for Health: The Human Genome Project.* [Online]. Retrieved on April 10, 2003, from http://ehrweb.aaas.org/ehr/3_1_0.html

Babbie, E. (2001). *The practice of social research*. Belmont, CA: Wadsworth.

Baker, C. (1995). *The Brain Book: Your Brain and Your Health*. Washington, DC: American Association for the Advancement of Science.

Bransford, J., NetLibrary Inc., National Research Council (U.S.). Committee on Developments in the Science of Learning & National Research Council (U.S.). Committee on Learning Research and Educational Practice. (2000). *How people learn: brain, mind, experience, and school* (Expanded ed.). Washington, D.C.: National Academy Press.

Burnham, J. (1987). *How Superstition Won and Science Lost: Popularizing Science and Health in the United States*. New Brunswick, NJ: Rutgers University Press.

Burawoy, M., Burton, A., Ferguson, A., Fox, K. J., Gamson, J., Gartrell, N., Hurst, L., Kurzman, C., Salzinger, L., Schiffman, J., & Ui, S. (Eds.) (1991). Ethnography unbound: Power and resistance in the modern metropolis. Berkeley: University of California Press.

Centre for Study of Environmental Change. (2001). *Public attitudes to agricultural biotechnologies in Europe: final report of PABE project*. Lancaster: Centre for Study of Environmental Change, Lancaster University.

DOE-ELSI (2003). Ethical, Legal, and Social Issues Research: ELSI Research Funded by the U.S. Department of Energy - Abstracts from DOE Human Genome Program Contractor-Grantee Workshops [Online]. Available: http://www.ornl.gov/TechResources/Human_Genome/research/elsi.html`

Dornan, C. (1990). Some Problems in Conceptualizing the Issue of 'Science and the Media'. *Critical Studies in Mass Communication*, *7*(1), 48-71.

Ellen, R. F., & Harris, H. J. (1996). *Concepts of indigenous environmental knowledge in scientific and development studies literature: A critical assessment*. Retrieved 27 March, 2003, from http://lucy.ukc.ac.uk/Rainforest/SML_files/Occpap/indigknow.occpap_TOC.html

ERPEG (2000). The ELSI Research Planning and Evaluation Group (ERPEG) Report.

Fessenden-Raden, J., Fitchen, J., & Heath, J. (1987). Providing Risk Information in Communities: Factors Influencing What is Heard and Accepted. *Science, Technology & Human Values*, *12*(3/4), 94-101.

Gerbner et al. (1981) Scientists on the TV screen*. Culture and Society, 42,* 51-54.

Grove-White, R., Macnaghten, P., Mayer, S., & Wynne, B. (1997). *Uncertain World: Genetically Modified Organisms, Food and Public Attitudes in Britain (in association with Unilever)*. Lancaster: IEPPP, Lancaster University.

Hamlett, P. W. (2002). Technology Theory and Deliberative Democracy. *Science, Technology & Human Values, 28*(1), 112-140.

Hilgartner, S. (1990). The Dominant View of Popularization: Conceptual Problems, Political Uses. *Social Studies of Science, 20*(3), 519-539.

House of Lords. (2000). *Science and Society*. London: UK House of Lords.

Human Genome Project (2003). Human Genome Project Information, Ethical, Legal and Social Issues [online]. Available: http://www.ornl.gov/TechResources/Human_Genome/research/elsi.html. [Accessed March 2003]

International Science Shop Network. (2003). *Living Knowledge: Building Partnerships for Public Access to Research (website)*. Retrieved 27 March, 2003, from http://www.scienceshops.org/

Irwin, A., & Wynne, B. (Eds.). (1996). *Misunderstanding Science? The Public Reconstruction of Science and Technology*. Cambridge: Cambridge University Press.

Jasanoff, S. (1997). Civilization and Madness: The Great BSE Scare of 1996. *Public Understanding of Science, 6*(3), 221-232.

Kasperson, R. E., Renn, O., Slovic, P., Brown, H. S., Emel, J., Goble, R., et al. (1988). The social amplification of risk: A conceptual framework. *Risk Analysis, 8*, 177-187.

Krimsky, S., & Plough, A. (1988). *Environmental hazards: communicating as a social process.* Dover, MA: Auburn House.

Labinger, J. A., & Collins, H. M. (2001). *The one culture? : a conversation about science*. Chicago: University of Chicago Press.

LaFollette, M. C. (1990). *Making Science Our Own: Public Images of Science, 1910-1955*. Chicago: University of Chicago Press.

Leech, B. L. (2002). Asking questions: Techniques for semi-structured interviews. Political Science and Politics, 35 (4), 665-668.

Lewenstein, B. V. (1992). The Meaning of 'Public Understanding of Science' in the United States After World War II. *Public Understanding of Science, 1*(1), 45-68.

Lewenstein, B. V. (2001). Science and Media. In N. J. Smelser & P. B. Baltes (Eds.), *International Encyclopedia of the Social and Behavioral Sciences* (pp. 13654-13657). Oxford: Pergamon.

Lewenstein, B. V. (2003). Popularization. In *Oxford Companion to History of Modern Science*. Oxford/New York: Oxford University Press.

McComas, K. (2001). Theory and Practice of Public Meetings. *Communication Theory, 11*, 36-55.

Miller, J. D. (1983a). *The American People and Science Policy: The Role of Public Attitudes in the Policy Process*. New York: Pergamon Press.

Miller, J. D. (1983b). Scientific Literacy: A Conceptual and Empirical Review. *Daedalus, 112*(2), 29-48.

Miller, S. (2001). Public understanding of science at the crossroads. *Public Understanding of Science, 10*(1), 115-120.

National Research Council. (1996). *National Science Education Standards*. Washington: National Academy Press.

National Research Council (U.S.). Committee on Risk Perception and Communication. (1989). *Improving risk communication*. Washington, D.C.: National Academy Press.

National Science Board. (1991). Public Science Literacy and Attitudes Towards Science and Technology. In National Science Board (Ed.), *Science & Engineering Indicators--1991* (pp. 165-191). Washington: U.S. Government Printing Office.

National Science Board. (1993). Science and Technology: Public Attitudes and Public Understanding. In National Science Board (Ed.), *Science & Engineering Indicators--1993* (pp. 193-215). Washington, D.C.: U. S. Government Printing Office.

National Science Board. (1996). Science and Technology: Public Attitudes and Public Understanding. In *Science & Engineering Indicators--1996* (pp. Chapter 7). Washington, D.C.: U.S. Government Printing Office.

National Science Board. (1998). Science and Technology: Public Attitudes and Public Understanding. In *Science & Engineering Indicators--1998* (pp. Chapter 7). Washington, D.C.: U.S. Government Printing Office.

National Science Board. (2000). Science and Technology: Public Attitudes and Public Understanding. In *Science & Engineering Indicators--2000* (pp. Chapter 8). Washington, D.C.: U.S. Government Printing Office.

National Science Board. (2002). Science and Technology: Public Attitudes and Public Understanding. In *Science & Engineering Indicators--2002* (pp. Chapter 7). Washington, D.C.: U.S. Government Printing Office.

Office of Science and Technology, & Wellcome Trust. (2000). *Science and the Public: A Review of Science Communication and Public Attitudes to Science in Britain* (Vol. 2001). London: Wellcome Trust.

Porter, G. (Ed.). (2002). *Communicating the Future: Best Practices for Communication of Science and Technology to the Public*. Gaithersburg, MD: National Institute of Standards and Technology.

Royal Society. (1985). *The Public Understanding of Science*. London: Royal Society.

Schiele, B. (Ed.). (1994). *When Science Becomes Culture: World Survey of Scientific Culture (Proceedings I)*. Boucherville, Quebec: University of Ottawa Press.

Sclove, R. (1995). *Democracy and Technology*. New York: Guilford.

Slovic, P. (1987). Perception of Risk. *Science, 236*(17 April), 280-285.

Strauss, A., & Corbin, J. (1990). *Basics of qualitative research: Grounded Theory procedures and techniques*. Newbury Park, CA: Sage.

United States. National Commission on Excellence in Education. (1983). *A nation at risk : the imperative for educational reform : a report to the nation and the Secretary of Education, United States Department of Education*. Washington, D.C.: The Commission.

Wachelder, J. (2003). Democratizing Science: Various Routes and Visions of Dutch Science Shops. *Science, Technology & Human Values, 28*(2), 244-273.

Watson, J. D., & Crick, F. H. C. (1953). Molecular Structure of Nucleic Acids. *Nature, 171*(25 April), 737-738.

Wynne, B. (1989). Sheep Farming After Chernobyl: A Case Study in Communicating Scientific Information. *Environment Magazine, 31*(2), 10-15, 33-39.

Wynne, B. (1995). Public Understanding of Science. In S. Jasanoff, G. E. Markle, J. C. Petersen & T. Pinch (Eds.), *Handbook of Science and Technology Studies* (pp. 361-388). Thousand Oaks, Ca.: Sage.

Wynne, B. (1996). May the sheep safely graze? A reflexive view of the expert-lay knowledge divide. In S. Lash, B. Szerszynski & B. Wynne (Eds.), *Risk, Environment and Modernity: Towards a New Ecology* (pp. 44-83). London: Sage.

Ziman, J. (1991). Public Understanding of Science. *Science, Technology & Human Values, 16*(1) (Winter), 99-105.

Ziman, J. (1992). Not Knowing, Needing to Know, and Wanting to Know. In B. V. Lewenstein (Ed.), *When Science Meets the Public* (pp. 13-20). Washington: American Association for the Advancement of Science.

Appendix: Interviews/Contacts Performed

1) *Zeta Phi Beta Sorority Project: Information Conferences on the Human Genome Project*

- Paula Doyle, participant to the Workshop, as a representative of a local community organization– Junior American Medical Association (JAMA)
- Dr. Jenkins, Board Member Emerita, Zeta Phi Beta National Education Foundation
- David Leui, participant to the Workshop, as a representative of a local community organization, State of the Art Inc.
- Kathryn Malvern– Chairman and Conference Project Director, National Educational Foundation, Zeta Phi Beta Sorority, Inc
- Sheryl Martin, DOE-HGMIS, for information on web use

2) Book: "Your Genes, Your Choices"

- Maria Sosa - Science Literacy Trainer and Editor-in-Chief of *Science Books & Films*, Directorate for Education and Human Resources Programs, American Association for the Advancement of Science.
- Shirley Malcom - Head, Directorate for Education and Human Resources Programs, American Association for the Advancement of Science
- Catherine Baker – Plain Language Writer
- Jim Miller - Senior Program Associate, Program of Dialogue on Science, Ethics, and Religion, American Association for the Advancement of Science
- Sheryl Martin, DOE-HGMIS, for information on web use

3) EINSHAC "Genetics in the Courtroom Conferences"

- Judge Michael Getty, Chairman of Chicago Conference
- Judge Jose Lopez, Originator of Science Academy Division
- Judge Pauline Newman, Chair of Advisory Committee
- Franklin Zweig, Coordinator for EINSHAC
- Judge Joan Zeldon, Co-Chair, Australia Working Conversation

4) The Geneletter

- Paul Billings, Vice President for Life Sciences and Clinical Affairs Wipro HealthSciences (and former Editor of the *Geneletter*)
- Dorothy Weiss, CERC-UAP, Shriver Center, UMass (co-PI of the project)

5) Hispanic Radio Episodes

- Robert Purcell, Self Reliance Foundation
- Antonio Vasquez, Director of the Hispanic Radio Network

6) A Question of Genes

- Noel Schwerin, Director, Backbone Media