

# Genomics Education for the Public: Perspectives of Genomic Researchers and ELSI Advisors

Lynn G. Dressler,<sup>1</sup> Sondra Smolek Jones,<sup>2</sup> Janell M. Markey,<sup>3</sup>  
Katherine W. Byerly,<sup>4</sup> and Megan C. Roberts<sup>4</sup>

*Aims:* For more than two decades genomic education of the public has been a significant challenge. As genomic information becomes integrated into daily life and routine clinical care, the need for public education is even more critical. We conducted a pilot study to learn how genomic researchers and ethical, legal, and social implications advisors who were affiliated with large-scale genomic variation studies have approached the issue of educating the public about genomics. *Methods/Results:* Semi-structured telephone interviews were conducted with researchers and advisors associated with the SNP/HAPMAP studies and the Cancer Genome Atlas Study. Respondents described approach(es) associated with educating the public about their study. Interviews were audio-recorded, transcribed, coded, and analyzed by team review. Although few respondents described formal educational efforts, most provided recommendations for what should/could be done, emphasizing the need for an overarching entity(s) to take responsibility to lead the effort to educate the public. Opposing views were described related to: who this should be; the overall goal of the educational effort; and the educational approach. Four thematic areas emerged: What is the rationale for educating the public about genomics?; Who is the audience?; Who should be responsible for this effort?; and What should the content be? Policy issues associated with these themes included the need to agree on philosophical framework(s) to guide the rationale, content, and target audiences for education programs; coordinate previous/ongoing educational efforts; and develop a centralized knowledge base. Suggestions for next steps are presented. *Conclusion:* A complex interplay of philosophical, professional, and cultural issues can create impediments to genomic education of the public. Many challenges, however, can be addressed by agreement on a guiding philosophical framework(s) and identification of a responsible entity(s) to provide leadership for developing/overseeing an appropriate infrastructure to support the coordination/integration/sharing and evaluation of educational efforts, benefiting consumers and professionals.

## Introduction

FOR MORE THAN TWO DECADES, educating the public about genetics has been both a major concern and challenge (Brownrigg, 1999; Chen, 2001; McInerney, 2002; Owens and Breithaupt, 2002; Hsieh, 2004; Chen and Goodson, 2009; Dubochet, 2009; SACGHS, 2011; Bonham *et al.*, 2012). When the Human Genome Project (HGP) started in 1990, ~5% of its budget was set aside to support research related to the ethical, legal and social implications (ELSI) of genomic research (Collins and Mansoura, 2001). Four priority ELSI areas were identified, including the need for education and training. However, after a few years, the education focus was discontinued along with several other public education initiatives. Many factors,

including the complexity of the United States educational system, contributed to the decision to end this priority area.

Since the HGP, almost every aspect of genomic research has changed—scope, technology, applications, and societal implications. Most large-scale genomic studies have transitioned from population-based to individual, often disease-based studies collecting coded but linked individual genomic and clinical information. Technological advances now provide scientists the opportunity to sequence the genome at a reasonable cost and there is a growing expectation that genomic information will soon be incorporated into routine clinical practice (Burke and Diekema, 2006; Dressler *et al.*, 2012). Genomic information related to health and disease is currently being discussed in popular media; genomic tests are being

<sup>1</sup>Mission Health, Fullerton Genetics Center, Personalized Medicine, Asheville, North Carolina.

<sup>2</sup>Department of Social Medicine, School of Medicine, University of North Carolina, Chapel Hill, North Carolina.

<sup>3</sup>Division of Hematology/Oncology, School of Medicine, University of North Carolina, Chapel Hill, North Carolina.

<sup>4</sup>Gillings School of Global Public Health, University of North Carolina, Chapel Hill, North Carolina.

directly marketed to consumers; (ACMG, 2008; Sterling, 2008; McBride, *et al.*, 2010) and the translation of genomic findings into clinical care is a major driver of biomedical research (Dressler and Juengst, 2006; Green, *et al.*, 2011). As genomics has entered the public's eye, there has been a resurgence of efforts to educate the public (American Society of Human Genetics (ASHG), 2013; Chen, *et al.*, 2008; Kaphingst *et al.*, 2009; Verhoeff, *et al.*, 2009; Korf, 2011) about the relationship between genomics, health, and disease.

Although numerous efforts are currently underway, educating the public about genomics continues to be a challenge (Dubochet, 2009; Lea *et al.*, 2011; SACGHS, 2011; Sorensen and Brand, 2011; Bonham *et al.*, 2012; Leshner, 2012). Many of the same questions from early genome variation studies remain unanswered, (Brownrigg, 1999; Chen, 2001; McInerney, 2002; Hsieh, 2004; Bonham *et al.*, 2012) including fundamental issues related to how the public should be educated; who should be responsible for this education effort; and what should be the goals and objectives of public education programs.

We conducted a pilot study to learn how genomic researchers and ELSI advisors, who were affiliated with past and current large-scale genomic variation studies, have approached this issue. This work is part of a larger study to understand how a variety of ethical, legal, and social issues have been addressed in large-scale genomic studies. This article focuses on one of those issues, educating the public about genomics.

## Methods

### Overview

Two main projects were selected to represent early and current large-scale genomic studies: the SNP/HAPMAP studies and the Cancer Genome Atlas (TCGA) study, respectively. We reviewed the literature and publically available documents and conducted a content analysis of the ELSI issues associated with these studies. Five major issues emerged that continue to be relevant today: (1) educating the public about genetics and genomics; (2) concern about group harm; (3) reciprocity and return of research results; (4) collection and use of human specimens; and (5) access to and sharing of genomic data and related clinical and personal information. These five areas provided the framework for interviews with genomic researchers and ELSI advisors associated with the SNP/HAPMAP and TCGA studies to understand how these issues have been or can be addressed. The results presented here focus on the respondents' perspectives and experiences related to educating the public about genomics.

### Semi-structured interviews

**Population.** Using publically available information, we invited 76 genomic researchers and ELSI advisors associated with the SNP/HAPMAP and TCGA studies to participate in semi-structured one-time interviews. Individuals who had participated in one or more of the studies of interest, especially those who were involved in study development, design, conduct, and ethics oversight, were invited to participate. We contacted individuals by email and then followed up with phone calls to confirm interest in participating and, if interested, to coordinate a time for the interview. Although all interview responses were anonymized, at the request of several individuals to further protect their privacy, responses from researchers and ethics advisors were pooled. Because of

this, all data are represented as one group of respondents and were not stratified into responses from "researchers" and responses from "ethics advisors."

**Approach and analysis.** Informed by the literature review and content analysis (see supplementary material), an interview guide was developed, tested with a group of genomic researchers and ethics advisors unaffiliated with the SNP/HAPMAP or TCGA studies, and revised for subsequent one-on-one semi-structured interviews. Phone interviews lasting 45 to 60 min were conducted by two interviewers (LD and SJ). Both interviewers were trained for consistency, approach, and content. The interview consisted of three main sections (see supplementary data for details): (1) general impressions of ELSI issues related to the respondent's study(s); (2) specific ELSI issues and how they were addressed (five areas, including genomic education of the public); (3) common threads, lessons learned, and remaining challenges. In section 2, for the specific issue of education, each respondent was asked to describe the policy, approach, or activities that were associated with educating the public about their study and/or genomics in general. Respondents were asked to describe the effectiveness of these (or other) programs to improve the public's or community's understanding of genetics, genomics, and health, and how these programs can be improved, including what is required to do this. For analysis, any mention of "education" or "health literacy" throughout the interview was coded.

All interviews were audio-recorded, transcribed, and assigned a study identification code. No personal identifiers were collected and no master list was maintained that linked the code to the respondent. Verbal consent was obtained from all respondents. We followed established qualitative methods criteria to assure the rigor and trustworthiness of data collection, coding, and analysis procedures (Strauss and Corbin, 1990; Patton, 2002; Charmaz, 2006). First, transcripts were checked for accuracy, and the interview text was then analyzed for content related to genomic education and health literacy. After development of a coding schema by the study team, two analysts (J.M. and S.J.) coded the transcripts independently and compared for agreement. Areas of disagreement were resolved through discussion, and when necessary, by a third coder (L.D.). The ATLAS.ti software program was used to aid in indexing (i.e., attaching codes to interview text), searching, and retrieving sections of data related to genomic education. In-depth analysis of the coded data was conducted by team review through a rigorous iterative process of analytic induction using a grounded theory approach (Denzin, 1989; Strauss and Corbin, 1990; Charmaz, 2006). We also collected demographic information from each respondent, including age, sex, education, primary field of expertise, years of experience, study affiliation(s), and role(s) on the study (project planning/study design, ELSI advisor, primary investigator).

This study was reviewed and approved by the University of North Carolina Institutional Review Board (IRB).

## Results

### Demographics of respondents

Twenty-five individuals agreed to participate in the interviews, 16 males and 9 females. Our respondents were highly educated (16 PhDs, 8 MDs, and 1 R.N.), and many had participated in multiple large-scale genomic studies (HGP/

HAPMAP/SNP/1000 genomes/TCGA). Primary fields of expertise included ethics/law/policy (7), genetics/genomics (10), medicine (3) and other (1 each: theology, consumer, public health, and informatics). One respondent did not report primary field of expertise. None of the respondents described their profession as being related to education or communication.

*General perspectives and experiences with genomic education*

Nearly every respondent discussed the need to educate the public. Except for the HGP, however, few of our respondents reported any formal public education programs associated with their study. Instead, most responses focused on what *should* be done rather than providing descriptions of what *has been* or is currently being done. Overall, education approaches were described by some as being “more feasible” when they targeted a specific disease, such as cancer, or a

specific group, such as high school students. Others highlighted the difficulty in determining the “best” approach to educating a diverse group of people, even if, for example, the group is composed of all cancer patients.

Five thematic questions emerged from the analysis describing how our respondents were speaking about educating the public: (1) What is the rationale or purpose for educating the public about genomics? (2) Who is the intended audience for education? (3) Who should be responsible to educate the public? (4) What should these programs look like—what approaches should be used, what should the content be? and (5) Why is educating the public so hard?

*What is the rationale for educating the public about genomics?*

Our respondents described a variety of reasons why it is important to educate the public about genomics, especially as it relates to health (Table 1). Several respondents reported

TABLE 1. WHY THE PUBLIC SHOULD BE EDUCATED ABOUT GENOMICS AND HEALTH

<i>Theme</i>	<i>Corresponding quotation(s)</i>
Inevitability of genomic medicine	“I have seen a real interest [develop] in education about this [genomics] among people. A lot of this stuff was new when we did it [in 1997]. People didn’t think about it much. Now a lot of people think about it [genomics and health]. . . . It’s hard to repress it [genomic information]. So having people themselves saying ‘I know how it’s being used, and I want to address my insurance company because I know about this.’ That’s why I think education is more important [now].” (P8) <sup>a</sup>
Obligation/responsibility to educate	“I think these kinds of studies (SNP, HAPMAP, TCGA) . . . in a major way demand that we communicate what it is we’re looking for, and . . . to the extent that we find something that we do a better job of explaining what those findings mean.” (P24) “Why shouldn’t the American public know that there are a zillion kinds of cancers, [that] there are also different kinds of pieces of them . . . [DNA samples, tissue samples, urine sample] . . . as opposed to lumping it all together and saying ‘We want a biospecimen.’ So I just see it as an obligation to educate as well.” (P15)
Rapidly changing nature of genomic research	“We’re in a situation where the technologies and the information that we’re generating today and even more tomorrow are not known to the general scientific community [nor] the general public. Most of these things were invented after the people that are affected went to school. It’s devilishly complicated in some cases. And so I think that we really do have to work on public education at a level that we haven’t done in the past and that as far as I can tell nobody is currently thinking about doing.” (P22)
Minimize harm	“I think, in general, any effort to increase the public’s knowledge about genetics and genomics is useful, particularly where we’re talking about difference, and our society is so based on difference and not just <i>talking</i> about difference but <i>valuing</i> difference and <i>ranking</i> difference.” (P24) “Making sure people understand what genetic variation means, and that we don’t get misinterpretation and misunderstanding of these things. We already [have] a lot of problems in this society with an over-estimate of the importance of genetics and with genetic determinism . . . if people start thinking about complex behavior or mental processes in the same way they think about Tay-Sachs or Huntington’s disease that is a misunderstanding [that] can be very dangerous.” [P5]
Reduce fear and misunderstandings	“... some people [are] just saying, ‘I don’t want to do it. You know I’m afraid of it [participate in a research DNA databank].’” (P8). “... when people find out they’re at risk for say breast cancer, they sort of disappear from the [health care] system because now they’re scared. . . . there’s dozens of social aspects which you need to take into consideration. So that’s a big problem. (P13)
Trust and transparency in science	“... public support is critical to what we do, and the only way you get public support and trust is to earn it.” (P14) “... you want people to understand where their money’s going and what you’re trying to do with it.” (P12) “... there’s a disconnect between what the public is exposed to and [their] level of genetic literacy and genetic knowledge . . . the disconnect has to do with understanding what is actually possible; what a test or a piece of research can do for you or your community.” (P23)

<sup>a</sup>P, participant code.

that it is timely to provide this education because both the science and its ethical implications have “become real” and have entered the public consciousness, especially with direct to consumer marketing of tests and popular media coverage. Some respondents described that education is needed because of the inevitability of genomic medicine being part of routine health care. Many described how the rapid pace of research, especially new knowledge generation and its implication for gene–disease relationships, is not well understood by most scientists, much less the “general public.” A sentiment described by several respondents was that education was a responsibility or obligation that should be taken seriously. For some physician respondents, education was a natural extension of “what we always do in clinical care” (i.e., educating about genomics is similar to educating the patient about the procedure they will be having). Other respondents described how education was more about good communication and that scientists “need to do a better job of explaining what [genomic] findings mean.”

Minimizing harm to groups or individuals was another rationale described for educating the public. This was based on the belief that through education the public would gain an understanding of human diversity and genetic variations, and consequently the tendency to “rank differences” as good and bad should shift to understanding differences as “something more neutral.” Many respondents described that, with education, the public would be in a position to “better balance” the anticipated benefits, limitations, and potential harms of genomic information, thereby minimizing current fears or misperceptions about genomics and also lead to empowering individuals to be more informed and involved in their health care decisions.

For some respondents, education was also considered a critical component of the research enterprise, and that “public support is critical to what we [researchers] do.” Through “education and transparent communication,” including clearly explaining “what is actually possible, without hype,” the public can develop trust and support for genomic science and increase participation in research studies.

*Who is the audience?*

Our respondents discussed a wide spectrum of public audiences for whom genomic education should be provided (Table 2). Five groups of “publics” were most commonly identified: (1) students, especially those in high school; (2) potential research subjects being recruited for genomic research; (3) patients who were under the care of a physician; and (4) the “general” public (not otherwise specified). In discussing the HGP, one respondent indicated that the public was considered by NHGRI to include “broad audiences [from] PBS series to high schools to town meetings for the public.” High school students were considered one of the important audiences, “starting about 10th grade.” Some described a ripple effect “because they [the students] go home and educate their parents.” Respondents also recognized that high school education programs would require having “instructors who were competent to deal with these [genetic] complexities.”

*Who should be responsible for education?*

Although we observed strong support for educating the public, positions varied widely regarding who should be re-

TABLE 2. WHO IS THE AUDIENCE?  
WHO IS RESPONSIBLE?

<i>Audience for Genomics Education</i>	<i>Responsible to lead effort</i>
Main groups	
Students (High school especially)	Teachers Educational Curriculum Educational experts NIH, NSF
Patients	Health care providers Public Health Educators
Potential research subjects	Researchers; Funders
General public (not otherwise specified)	NIH; NCI, NHGRI, NSF Each genomic study Federal Government Educational organizations IOM ELSI community Not the private sector
Other “publics”	
Scientists	NS
Media (reporters, journal editors)	NS
Policy makers	NS
Teachers (especially high school)	NS
New or expectant parents	NS
Disease-oriented societies	NS

NS, not specified.

sponsible for this effort (Table 2). The sentiment that education was “someone else’s responsibility” was commonly articulated: “Eventually [we] decided maybe public education was somebody else’s job [not the NHGRI or HGP].” The different perspectives on whose job it should be included teachers, health care providers, researchers, government, NIH and professional educators. Responsible entities to lead and fund the educational effort were similarly diverse (e.g., secondary school system, the scientific community, the medical community, the specific genome variation study, the NIH, NSF, and the government). Some positions were also contradictory, where the same entity (scientific community, NIH, government) was held responsible by some respondents, but not by others. However, respondents did agree that someone or some entity needs to be in charge and responsible for educating the public.

*What should education programs look like: approach and content?*

Except for the early phase of the HGP, few described previous or existing formal education programs associated with their study. Instead, most respondents provided suggestions for the types of educational approaches that should be considered and the content of a public education program. Suggestions varied widely and addressed both general educational approaches and specific content areas (Table 3). Several respondents underscored the need for educational approaches to be culturally sensitive, including respecting personal identity when scientific findings are in conflict with origin stories.

TABLE 3. CONTENT AND APPROACH OF A PUBLIC EDUCATION PROGRAM

Approach
<ul style="list-style-type: none"> <li>• Culturally sensitive and innovative approaches</li> <li>• Genomics in context, situational</li> <li>• Avoid hype, be neutral about importance</li> <li>• Be honest about where taxpayer money is going</li> <li>• Ask public what they want to know and understand</li> </ul>
Content
<ul style="list-style-type: none"> <li>• Common sense understanding of genomics</li> <li>• Understand how genomics improves health, not what alleles do</li> <li>• General genomic education, not study specific</li> <li>• Study-specific education (e.g., related to TCGA, HAPMAP, etc)</li> <li>• Concepts and definitions (genetic determinism, genetic variation, DNA, genetics, risks, benefits)</li> <li>• Clear communication about the meaning of study results</li> <li>• Importance and limitations of science; scientific research process</li> <li>• Implications of genomics for individuals, family, and society (ethical, legal, social)</li> <li>• Understand sharing information among investigators, clinicians, patients, research subjects</li> <li>• Economic and political aspects of genome science (DTC, pharma, healthcare)</li> <li>• Details about DNA banking and data banking</li> <li>• Informed consent process/forms with consistent language, definitions, descriptions relevant to genomics research and testing</li> <li>• Risk and benefit of participation in clinical trial and nonclinical studies</li> </ul>

For both high school students and the general public, most respondents highlighted the need for innovative educational approaches including opportunities associated with the “digital age” and “social media.” Several described the need for a concerted effort to develop public internet information sites. One respondent suggested a “continuing patient education site,” analogous to continuing education for clinicians. Another suggested the development of a “national online clearinghouse of [genomic] information for the public”; a site that would be vetted and updated by experts and communicated in plain language. Respondents also underscored the need to have end-user (i.e., the public) feedback regarding what and how they want to learn. Relevant to this theme was the importance of community engagement, including employing different approaches to accomplish this, “from Community-Based-Participatory Research (CBPR)” to community lectures. Another common theme focused on “avoiding hype,” utilizing an “unbiased, transparent,” and honest approach about the opportunities and limitations of genomics research.

Although the suggested content of these programs was variable and sometimes conflicted from one respondent to the next (Table 3), some common themes emerged. One theme was a philosophy that education should provide a common sense understanding of genomics; with a “solid curriculum that is broadly disseminatable.” Respondents did not expound on what this means, nor how to do it. An-

other theme focused on the need to define and explain terms consistently (e.g., genetic variation; genetic research), whether during an informed consent process or in the development of a public education program. In addition, many respondents described their concern about the harm of “genetic determinism” and how education should address (and minimize) this concern.

Often respondents recommended that education should include the ethical and social implications of genomic research. The discussion of ELSI issues was also supported in the context of the informed consent process, although some respondents cautioned against making this part too detailed. Although ELSI was considered important, others wanted more emphasis placed on “understanding the scientific process,” citing how the informed consent process is an opportunity for educating potential research subjects about how science is conducted, including the need to validate findings. A few respondents emphasized how the informed consent process should make clear certain details and nomenclature, such as what it means to “take a DNA sample” and “what it might mean in terms of creating cell lines.”

Although some respondents suggested that education of the public be “study-specific” (e.g., related to SNP/HAPMAP or TCGA), others suggested that the public health benefits are more important to focus on, “the benefits to the community will accrue from improvements in public health not from understanding the purpose of the project.”

*Why is this so hard?*

Our respondents described many challenging, often interwoven issues associated with educating the public. Five main themes emerged from their discussion (Table 4).

*1. Need for supportive infrastructure, approach, and leadership:* In addition to the need for financial resources, a main issue described by many respondents was that there was no clear entity responsible for taking ownership of this issue. Respondents also recognized the challenges of working with a public education system, which has rigid curricular requirements. One respondent suggested that an issue plaguing the development of education programs is the need to be absolutely correct, “we are too serious about making a mistake.” Other respondents spoke about the need to integrate the “silos of research,” because the “fragmentation [of the research process]” delays the translation of information to clinical care. One respondent emphasized the need for a coordinated effort from NIH to provide consistency across all NIH institutions in nomenclature and language used to explain genome studies, especially in informed consent documents.

*2. Diversity of individuals and groups:* One of the most complex challenges, mentioned earlier, is the large variation among individuals and groups related to their education, literacy, language, and views of how genetics influences health.

*3. Political, Economic, and Philosophical Factors:* Respondents also raised the concern that “special interest” groups, such as direct-to-consumer marketing firms, may be providing biased genomic education to a segment of the population. One respondent suggested the need for a culture that considers participating in science as “the right thing to do [as a society].”

TABLE 4. WHY IS GENOMICS EDUCATION OF THE PUBLIC SO HARD?

<i>Issue/challenge</i>	<i>Respondent position</i>
Supportive infrastructure	
Resource needs	
Time/money/regulations	There is no clear entity to own this effort (P18)
Leadership/education experts	Need professional educators (P12)
Innovative approaches	Need to consider alternative, innovative education approaches (P11)
Institutional factors	
Public education system	Rigid curricular requirements (P1)
Disconnect/fragmentation/silos	Need to integrate research silos (P15)
Prioritizing resource allocation	Fragmentation of research process
Variable informed consent process	Need for uniform consent process
Diversity of individuals/groups	
Variable social, economic, cultural factors	
SES/Education/literacy	Many barriers/complications to public education, including variable literacy, education, language, and views of health care; (P13, P23)
Views of health care and genetics	Personal identity/creation stories in conflict with science; need a more respectful approach to interpret the science (P8)
Identity issues	
Variable health/lifestyle behaviors	
Information seeking/sources	Individuals and groups have different information-seeking behaviors, needs, and sources of information (generational, situational) (P17, P19)
Health beliefs	
Political and economic factors	
Commercial industry	Prevent misinformation or desensitization to risks from DTC, pharma, commercial organizations with incentive to communicate biased information (P7);
Special interest groups	
Public trust and support of science	
Few incentives to educate public	Lack of incentive for noncommercial entity to educate public (P11, P22)
Complex nature of genomic science	
Addressing rapid pace	The science is very complicated and it advances, changes, or evolves every 18 months, how to disseminate information? (P22, P18)
Project-driven science	
Complex implications	Key stakeholders and experts differ on what's important to know (P20)
Concerns about genetic determinism	

SES, socioeconomic status.

4. *Complexity of genome science:* Aside from the rapid pace and volumes of information generated from genomic studies, some of our respondents described the challenge of disseminating evolving findings and that key stakeholders and experts either differ or are not sure what is important for the public to know: “Genetics is pretty complicated even for those of us who do nothing but that...[I’m] not sure what is important for the public to know.”

5. *Conflicting views on fundamental issues:* Adding to this complexity are conflicting views on some fundamental questions (Table 5) This included who should be responsible to lead this effort, for example, whether educating the public should be the role of government, NIH, or researchers; what the goals of a public education program should be, whether this should be “to shape [a] new world view” about the role of genetics in human behavior [and] in human activity” or to improve communication between researchers, clinicians, and research subjects. Since the goal often shapes the content, it was not surprising that different conceptual views also existed for what should be included in a public educational program (e.g., scientific details specific to the project or a general concept of the science).

## Discussion

Although the data presented reflect the perspectives and experiences of our respondents and may not be generalizable to all genomic researchers and ELSI advisors, they offer important insights.

First is the need for an entity to take ownership and responsibility for leading the effort to educate the public; who that should be, however, represents one of the most controversial and challenging issues described by our respondents. Many of our respondents did not feel that scientists or the research community could or should do this. Instead, similar to the literature, respondents identified health care providers (ACMG, 2008; Christianson *et al.*, 2010; Sorensen and Brand, 2011; Syurina *et al.*, 2011) and public school teachers (Wefer and Sheppard, 2008; Verhoeff, *et al.*, 2009; Dougherty *et al.*, 2011) as the main vehicles for genomics education for the public. Other respondents echoed suggestions by SACGHS (2011) and others (Byk, 1998) that the government (e.g., Department of Health and Human Services, Department of Education) should take a leading role in this effort. Indeed, important steps are currently being taken at the

TABLE 5. DIFFERING PERSPECTIVES RELATED TO GENOMIC EDUCATION FOR THE PUBLIC

<i>Issue</i>	<i>Perspective</i>	<i>Quote</i>
<i>Who is responsible</i>	Pro-NIH/NSF:	“NIH and NSF ought to pay ...” (P20) “... you need to have an educational limb to the NIH.”(P7) “consistency across these [NIH]institutes ... (P7) about how we’re educating our public whether it’s the cancer public or the NIDA public...”(P15)
	Pro-individual project	“... to the extent that it’s possible, these projects should have (and maybe not each one have its own) public education effort. ... (P24)
	Anti-NIH/Individual project	“I don’t think we’re doing quite enough, but [specific NIH project] should not be the educational vehicle to educate the public about the value and the dangers of genomics. There needs to be another organization ... maybe a spinoff child.” (P7)
	Pro-scientific community	“Probably the scientific community is going to have to do this [public education] ... they’re the people that are on the front end of the ... ‘generation’ business.” (P22) NIH [needs] to be saying that the scientific community ... needs to be engaged in this, and this means you.”(P14)
	Anti-scientific community	“you can’t expect them [scientists] to be a public communications firm. They’re not trained in it. They don’t know how to write in ordinary understandable language ...”(P12)
<i>Content of public education</i>	General understanding of research and future benefits, not science details or details of the project	“Probably more important ... to include opportunities for people to understand about the research process, what it involves, what different kinds of research do, and what’s the path from any particular type of research activity to potential benefit ... that is far more central than whether people understand what an allele is.” (P20) “It [the project]is for the community, and the benefits to the community will accrue from improvements in public health not from [an] understanding of the purpose of the project.” (P9)
	Specific understanding of science and study	“Making sure people understand what genetic variation means, and that we don’t get misinterpretation and misunderstanding of these things ... if people start thinking about complex behavior or mental processes in the same way they think about Tay-Sachs or Huntington’s disease that is a misunderstanding, but misunderstandings can be very dangerous.”(P5)
<i>Goal of education programs</i>	Improved communication about genomic research and results Shape a new world view	“I think these kinds of studies (SNP, HAPMAP, TCGA) ... in a major way demand that we communicate what it is we’re looking for, and ... to the extent that we find something that we do a better job of explaining what those findings mean.” (P24) “It has to be done in K-12 education ... where people’s thoughts and attitudes are formed because in some ways this is an ... educational process about the role of genetics in human behavior, in human activity. That’s not just a scientific issue. It’s really a kind of a world view, and I think we need to shape that world view. (P5)”

federal level (NSF, 2012; CDC, 2013; STEM, 2013) and throughout the National Institutes of Health (NCI, 2013; NHGRI, 2013; NIGMS, 2013). Professional groups (ACMG, 2011; ASHG, 2013) also play a significant role in the development of genomic education programs for the public. *Although these efforts collectively represent enormous gains, they have largely been independent activities.*

Second, is the need for these leaders to be expert not only in content knowledge of genomics, but also in different educational approaches for individuals and populations of diverse demographics (e.g., education, literacy, cultural, social, and religious) and different attitudes, beliefs, and behaviors about their health. These concerns are similar to those expressed in the NHGRI strategic plan white papers (NHGRI, 2011) and SACGHS (2011). Many federal (e.g., NIH, CDC,

NSF), national consumer groups (Genetic Alliance, 2013), and professional groups [ASHG, ACMG, NCHPEG (2007)] offer a spectrum of traditional and innovative approaches, expert-developed content, and multiple resources for educating K-12 and college students, trainees, and health care professionals. Similar to some of our respondents, SACGHS emphasizes the need to develop strategies that improve genetic literacy among diverse populations, with the expectation that education in under-represented and low-literacy populations could prevent further increases in health disparities, highlighting the importance of community participation (SACHGS, 2011) (Christianson *et al.*, 2010). *Consolidating and sharing these different approaches would help inform best practices for more widespread and efficient public benefit.*

Third, conflicting perspectives among our respondents on fundamental issues of education further illustrate how challenging it is to conceptualize an education program. Although overall support for public education exists, respondents were at odds regarding the purpose of such a program; who the public consisted of; who was responsible for this education; and what the content should be. We interpret this observation as being another example of why educating the public is so hard. *Without agreement on fundamental issues of purpose and goals, development and implementation of public education programs will likely be inefficient and ineffective.*

Finally, the complex interplay of these issues creates a major barrier to genomic education. Even after fundamental issues are agreed upon, it is still necessary to navigate through a complicated web of political, cultural, and structural pressures, within and across medical, scientific, and educational disciplines. Considering all these issues, it is not surprising that 13 years after the HGP was completed, the issue of public education is still a major concern.

#### Next steps

The need for genomic education will only grow as genomic information becomes more integrated into daily life and routine clinical care. The original intent of this pilot was to identify and consolidate successful approaches and lessons learned related to educating the public. Instead, our respondents helped to identify continuing challenges and key educational policy issues that need to be addressed. With the numerous educational initiatives currently ongoing or planned, there is great opportunity to revisit this original intent to inform best practices. Informed by the comments from our respondents, the authors suggest that the following next steps be considered.

**Consolidate experiences.** An overarching group, such as the Institute of Medicine, the NIH, or DHHS, should champion the process of identifying, tracking, and coordinating these initiatives and consolidating the growing body of approaches, methods, and experiences to identify lessons learned, best practices, gaps, and challenges remaining.

**Develop programmatic goals derived from a shared philosophy.** Roundtable discussions, think tanks, and/or symposia are needed to bring together key inter-disciplinary stakeholders in academia, government, for-profit, and not-for-profit organizations, not only to share findings, but also to develop consensus on the goals of a consolidated program. Best practices will be different for a program whose goal is to reaffirm the existing American philosophy of public education (i.e., to create an informed citizenry capable of governing itself—including the science it endorses and supports) compared to one that supports another framework, such as advancing public health by getting more Americans involved in genomic research and increasing uptake of genomic medicine.

**Identify knowledge gaps and need for additional research.** The process of reviewing what is being done and what has already been learned offers the opportunity to identify what additional research should be done and develop

consensus around prioritizing which research questions should be addressed. For example, should K12 education competencies set the standard for education of the general public? Should the general public be more involved in what and when they want to learn about genomics? And how does what the public wants to know compare with what health educators, teachers, and health providers feel the public should know?

**Centralized knowledge base.** There is a need to develop and maintain a database to collect and consolidate the different initiatives, approaches, methods, instruments, evaluations, and best practices for public education, a “dbGAP” for education. There is also a need to develop a coordinated, scientifically vetted, and user-friendly public database of educational modules, Websites, interactive learning programs, and/or downloadable smart phone applications that are available to the general public and for health care providers, teachers, and others to refer their patients, students, or constituents. This evidence base should inform educational programs aimed to increase genomics knowledge in a feedback loop of continual learning and improvement.

**Incorporate evaluation as a component of any public education program.** There is a need to incorporate an evaluation component for each public education program, relevant to the program’s goals and objectives. This will require the development of a shared set of metrics to assess a program’s strengths, weaknesses, and effectiveness. A consistent set of benchmarks for program evaluation would allow collection and comparison of similar data across studies (e.g., a comparative effectiveness approach to efficiently inform best practices). For example, metrics could help address when and how to assess whether a program is “working”—whether it is meeting its goals; whether program recipients are satisfied; and what approaches work best for measuring changes in an individual’s understanding of genomics information and/or the impact on their health-care decisions. Incentives from funding organizations could promote the sharing of this information.

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Address correspondence to:

*Lynn G. Dressler, DrPH*

*Mission Health*

*Fullerton Genetics Center*

*Personalized Medicine Program*

*11 Vanderbilt Park Drive, Suite 1500*

*Asheville, NC 28803*

*E-mail: [lynn.dressler@msj.org](mailto:lynn.dressler@msj.org)*