The Genetic Town Hall

Public Opinion About Research on Genes, Environment, and Health

Genetics & Public Policy CENTER

Johns Hopkins University

Contents

Authors:

Shawna Williams

Joan Scott, M.S., C.G.C.

Juli Murphy, M.S.

David Kaufman, Ph.D.

Rick Borchelt

Kathy Hudson, Ph.D.

Acknowledgments

The town halls were supported by Grant Number U01HG004206 from the National Human Genome Research Institute. The content of this report is solely the responsibility of the authors and does not necessarily represent the views of the National Human Genome Research Institute. We especially are grateful to the NHGRI Program Director Jean McEwen for her guidance and assistance throughout the project.

Jonathan Ortmans, Mark Marich, and Erin Wiley of the Public Forum Institute, and their local collaborators, handled recruitment and logistics, and provided moderating expertise for each town hall. Bill Baker, Daphne Freeman, and Dennis Lowe of Baked Media developed the short video used to explain the proposed study.

The authors thank Sara Brinda and Katherine Groff for their help with the manuscript.

We thank the members of the Public Consultation Project's Citizens Advisory Panel for their invaluable suggestions as we planned the town halls. Acknowledgement goes to The Pew Charitable Trusts for funding our previous work in public consultation, laying the groundwork for this project. Most importantly, the Center thanks the town halls' hundreds of unpaid participants, who took the time to deliberate and share their opinions with us.

Cities and dates

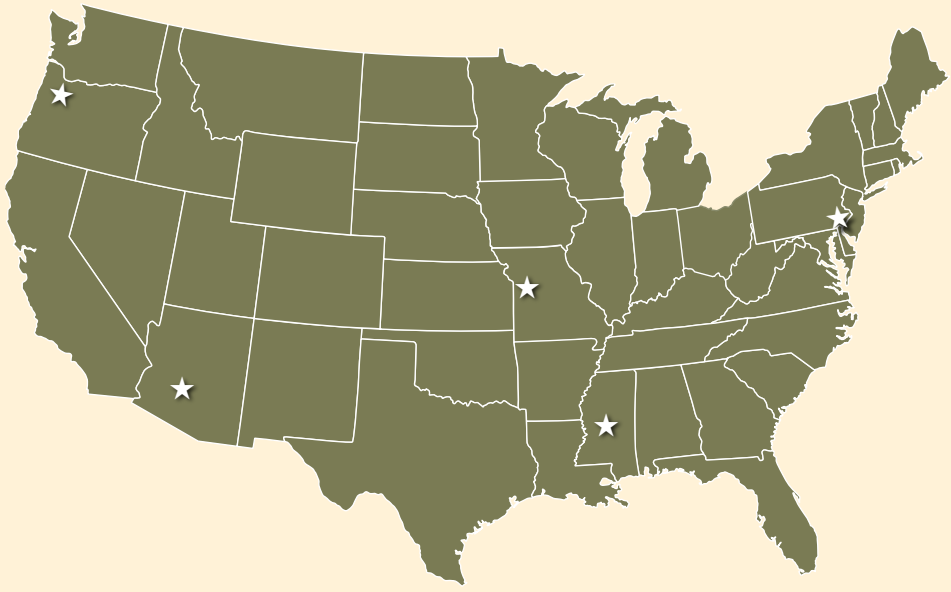
Kansas City, Missouri
Saturday, March 8, 2008

Phoenix, Arizona
Saturday, April 5, 2008

Jackson, Mississippi
Saturday, April 19, 2008

Portland, Oregon
Thursday, April 24, 2008

Philadelphia, Pennsylvania
Tuesday, May 13, 2008



Preface

In September 2006 the Genetics & Public Policy Center was awarded funding from the National Human Genome Research Institute of the National Institutes of Health (NIH) to study the American public's attitudes toward a proposed large-cohort research study of genetic and environmental contributors to health. Specifically, NIH and other federal agencies were interested in the possibility of collecting both genetic and non-genetic information on half a million volunteers who would be followed for a period of 10 years or more in order to study the links between genetic and environmental factors and common diseases. Prior to undertaking such an initiative, the agencies wanted to understand public attitudes about and willingness to participate in such a research project.

For the Center, the agreement represented a welcome opportunity to continue and expand on our public engagement work. We believe strongly that the public should have a hand in shaping policy, including science policy. Accordingly, we've used focus groups, interviews, town hall meetings, and national surveys to assess public attitudes on topics ranging from embryonic stem cell research to genetic privacy to reproductive genetic technologies.

This project afforded us the perfect opportunity to both share information with the public and reflect citizens' views and ideas back to planners of the research at NIH in a meaningful way.

The Public Consultation Project on Genetics, Environment, and Health began with a series of 16 focus groups in six locations. Participants were shown a video the Center had developed explaining the proposed large-cohort study, and then discussed whether the study should be done and why or why not, and what factors would influence their willingness to participate. Following the focus groups, 27 individual interviews about the proposed study were conducted with community leaders in the same locations. The qualitative data from the focus groups and interviews helped shape the subsequent phases of the project, a national survey and a series of town halls. The town halls took place in the same cities as the focus groups and the interviews.

The five town halls were held from March-May 2008 in Jackson, Mississippi; Kansas City, Missouri; Philadelphia, Pennsylvania; Phoenix, Arizona; and Portland, Oregon. These forums were larger and more diverse than individual focus groups, ranging from 76 to 134 participants each. We conducted the town halls both to gather further feedback about the proposed study and to test the town hall format's effectiveness as a public consultation tool.

The town halls were free, open to all, and publicly advertised. In our recruitment efforts, we attempted to achieve a mix of town hall participants that matched the demographics of each community. In the end, the events attracted groups who tended to be more highly-educated than the general populace: More than half had received a bachelor's degree, while fewer than 20 percent had no education beyond high school (see table on page 6).

The Process

In each community we selected a site that was publicly accessible and a day and time that would maximize attendance. Three of the town halls took place on Saturday mornings beginning at 10:00, while the remaining two were held on weekday evenings at 5:30. Each lasted approximately two and a half hours. Participants were given name tags when they arrived, and chose their own seats at one of the large, round tables in the room (except in Phoenix, where the town hall was held in an auditorium).

A senior member of the Genetics & Public Policy Center staff began each session by welcoming the participants and explaining that the goal of the Public Consultation Project – and of the town halls – was to gather feedback on a proposed large-cohort government study of genes, environment, and health. The staff member also explained that the Center did not have a stake in whether the study went forward, but rather was committed to reflecting public feedback accurately to NIH. She then introduced Jonathan Ortmans of the Public Forum Institute, who served as the moderator for each town hall.

Recruitment

The Public Forum Institute used a network of local coordinators to invite an array of citizens mirroring U.S. Census Bureau demographic statistics for that city. Information about the town halls was posted on community notice boards and event calendars, in libraries, and in other locations. Blast emails and phone calls also were used, and in some locations, stories about the town hall ran in local newspapers prior to the event.

The moderator spoke briefly about what participants could expect during the town hall, and then laid out the three main questions the event would address:

1. Do you think the government should create a national biobank? Why or why not?
2. Would you participate in such a biobank? Why or why not?
3. What conditions need to be in place in order for the biobank to happen?

Participants were shown a nine-minute video (see box, page 5) about the proposed study and given the opportunity to ask questions about it. They also used electronic keypads to indicate whether they thought the study should be done, and if so, whether they would participate. Aggregated responses were projected in real time on a screen behind the moderator to show participants the mood of the room and spur discussion.

The moderator then led participants through a series of questions about the proposed study. In each case he first gave participants time to discuss the question with others sitting at their table (or, in Phoenix, with those sitting nearby), and to jot down answers in individual workbooks. After about five minutes of deliberation, participants were encouraged to share their answers with the rest of the room. The answers again were projected in real time. Participants were then asked to vote on which of the listed factors were, in their view, the most significant. The results of these votes were shared immediately with the group.

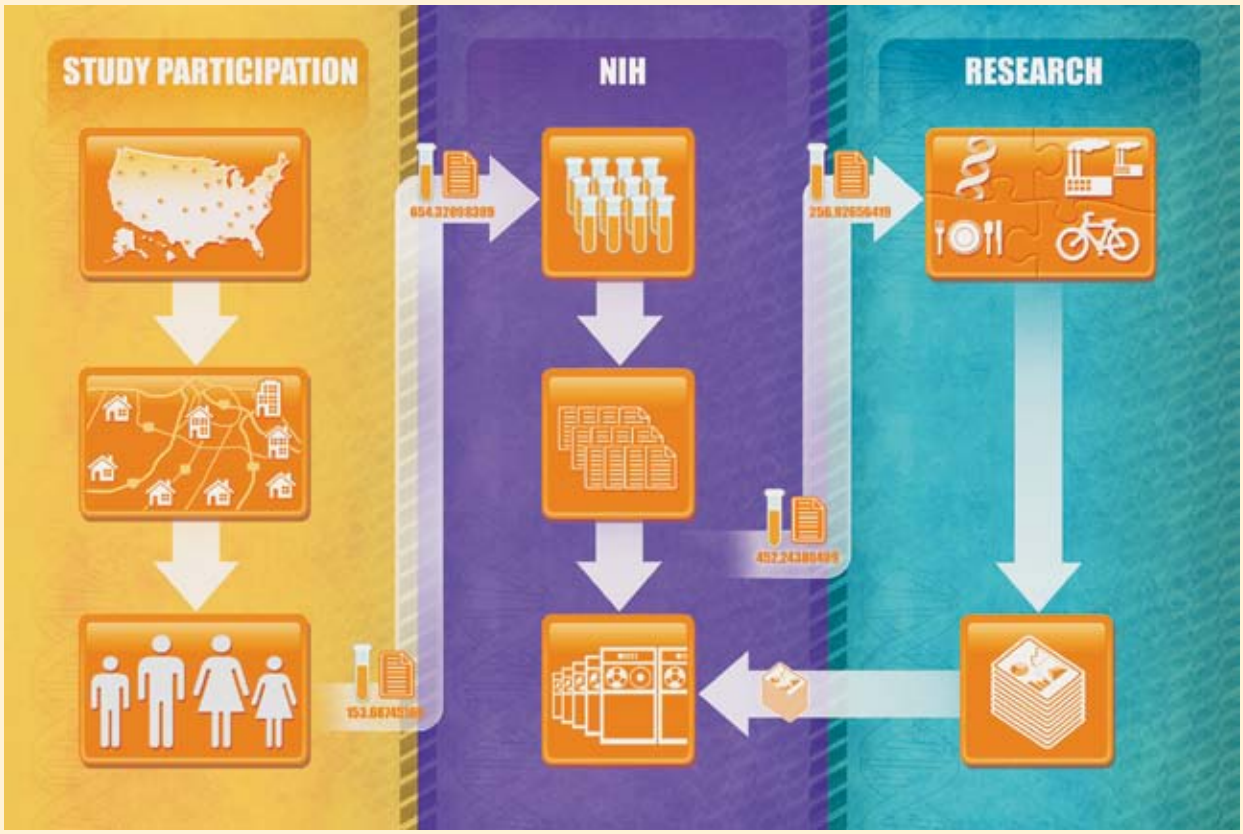
Near the end of the event, participants voted again on whether the study should go forward, and whether they would participate in such a study. They were asked to share any closing thoughts about the study, and finally were thanked for their participation by the Center staff member. Workbooks in which participants had shared their thoughts were collected as particpants exited.

Video summary

Participants viewed a video about the proposed study. The video illustrated that:

- People possess different variations of the same genes, and these variations can have different effects depending on an individual's environment, lifestyle, and other genes. In order to be representative of the U.S. population and to detect weak genetic and environmental influences on health, the proposed study would include a large number of people.
- The project would collect genetic samples and data from up to 500,000 U.S. residents. At a local health clinic, the volunteers would give blood samples and information about their medical histories, diets, lifestyles, and environmental exposures.
- Volunteers would be contacted for updates on their health periodically for up to 10 years.
- NIH would analyze the blood samples. Researchers from inside and outside the agency could apply to use volunteers' information to study how genes, environment, and lifestyle contribute to disease. Volunteers' information would be coded to hide their identities from researchers.
- Researchers' findings would become part of the NIH databank, contributing to our understanding of many common diseases.
- Other countries have launched similar projects.

Schematic: The proposed study (from video)



Demographics

What is your gender?	All	Kansas City	Jackson	Phoenix	Portland	Philadelphia
Male	40.1%	33.7%	37.5%	42.6%	45.6%	43.3%
Female	59.9%	66.3%	62.5%	57.4%	54.4%	56.7%
How old are you?						
29 or under	25.9%	13.7%	44.4%	17.7%	25.0%	33.9%
30-44	23.8%	18.6%	16.7%	19.4%	33.3%	32.3%
45-59	30.6%	39.2%	16.7%	38.7%	31.0%	24.2%
60 or over	19.6%	28.4%	22.2%	24.2%	10.7%	9.7%
What is your race/ethnicity?						
White, non-Hispanic	59.6%	67.3%	28.6%	72.6%	81.0%	40.3%
African American, non-Hispanic	31.7%	29.7%	71.4%	9.7%	10.7%	40.3%
Hispanic	3.7%	2.0%	0.0%	14.5%	1.2%	3.2%
Asian or Pacific Islander	2.1%	0.0%	0.0%	0.0%	1.2%	11.3%
Other	2.9%	1.0%	0.0%	3.2%	6.0%	4.8%
What is the highest level of education that you have completed?						
Did not graduate from high school	2.3%	0.0%	2.8%	4.8%	4.6%	0.0%
High school graduate	14.4%	11.8%	18.3%	22.6%	12.6%	8.2%
Some college or technical or vocational school	28.5%	26.5%	40.8%	24.2%	24.1%	27.9%
Bachelors degree or higher	54.8%	61.8%	38.0%	48.4%	58.6%	63.9%

Agenda for Town Hall on Genes, Environment, and Your Health

00:00* **Welcome and Overview**
Genetics & Public Policy Center staff member

00:10 **Overview of the Town Hall Process**
Jonathan Ortmans, The Public Forum Institute (moderator)

00:25 **Initial Impressions**
Participants viewed a video describing the proposed cohort study. Using keypads, they responded to questions on whether the study should go forward, and whether they would participate in it.

00:40 **Benefits and Burdens**
At each table, participants listed benefits and burdens of the proposed study. They then discussed responses as a group. Participants rated how important each response was to them using their keypads.

1:10 **Acceptable and Unacceptable Types of Research**
Participants built lists of what types of research should and should not be permitted to be conducted using the data collected in the proposed study. Subsequently, they used their keypads to rate the items on the lists.

1:20 **Return of Results**
Following a discussion on the challenges of returning individual results, participants used their keypads to vote on whether results should be returned.

1:30 **Policy Needs**
The moderator asked participants what policies would make the proposed study successful. Using keypads, participants rated the proposed policies on their level of importance.**

2:00 **Build your own Contract**
At their tables, participants listed elements that should be included in research agreements between the researchers and study participants for the proposed study. They then shared these ideas with the rest of the room, and participants used their keypads to rate the importance of different elements.

2:20 **Closing Impressions**
Participants answered questions on whether they thought the proposed study should go forward, and if they would participate. The moderator then showed how the results compared with those from the national survey.

2:35 **Evaluation**
Participants evaluated different aspects of the town hall meeting.

2:40 **Concluding Remarks and City Comparison**
Genetics & Public Policy Center staff member
Participant responses to questions on the proposed study were compared to responses from previous town hall meetings (if applicable).

* Town hall meetings began at different times of the day. 00:00 indicates the beginning of the meeting.

** At the Kansas City town hall, the order of the Build your own Contract session and the Policy Needs session was reversed.

Results

Benefits and burdens

The moderator asked participants first to consider the potential benefits and drawbacks of the study. Improved prevention of and treatments for disease came up frequently, as did identifying environmental or lifestyle factors that could lead to longer, healthier lives. Some participants surmised that the study would lead to a reduction in health care costs. Disease prevention and/or treatment was voted the most important benefit in all of the town halls.

Either loss of privacy, or the possibility that insurance companies might obtain individuals' genetic information and use it against them, ranked as the most significant concern about the study in every town hall except for Jackson's. Topping the list in Jackson was the potential that the study's findings could be used for genetic manipulation in the future. Participants cited the cost of the study as a burden; a few also mentioned the cost to companies should their products (e.g., plastic) be found to be harmful to human health. During the benefits and burdens discussion and at other points during the town halls, participants frequently expressed concern that pharmaceutical or other companies might profit off of the taxpayer-funded proposed study. "They may produce drugs that are so expensive that most people couldn't afford them," said one participant.

A less-frequently-voiced – but still fairly common – concern was that the results would be used by law enforcement or for various nefarious purposes: "Even though you're a number, you're still putting yourself at potential risk for this knowledge to be out among the folks to use for not curing diseases, but for perhaps engineering different diseases to wipe out populations."

Top benefits and burdens

Kansas City

Benefits

- Cure and prevention of disease
- Increased knowledge

Burdens

- Abuse of information by insurance companies
- Lack of laws to protect participants' privacy

Jackson

Benefits

- Disease prevention (e.g., change diets, exercise)
- Eliminate hereditary diseases and birth defects

Burdens

- Possibility of future genetic manipulation
- Insurance companies would discriminate

Phoenix

Benefits

- More precise treatment of specific illnesses
- Improve chances for prevention (docs have more info)

Burdens

- Claims or coverage denied by insurance companies based on information
- Personal privacy

Portland

Benefits

- Better prevention will decrease health care costs
- Educating the public about environmental causes of disease*
- Good data for scientists to consider*

Burdens

- Security of information
- No real way to ensure privacy

*tie

Philadelphia

Benefits

- Eradicating disease
- Identifying contributing factors to disease

Burdens

- Possible discrimination based on genetic information
- Who benefits?

Acceptable and unacceptable types of research

Participants were asked to consider what types of research should and should not be done with the information collected by the proposed study. Research aimed at curing disease was commonly cited as acceptable, and some participants named conditions such as cancer, birth defects, and diabetes. Some suggested that diseases affecting large numbers of people should be the highest priority. Identifying environmental factors that cause disease came up several times.

Human cloning was cited in every town hall as an unacceptable use of the proposed biobank, although in one case participants differentiated between reproductive cloning (unacceptable) and cloning aimed at regenerating organs or otherwise curing disease (acceptable). Participants frequently named research aimed at altering humans or creating "designer babies" as unacceptable. Another area of concern was "things that point out differences between gender, or race, or anything like that that people use to discriminate." Other areas mentioned included weapons development, intelligence, alcoholism, and sexual orientation.

Returning individual results

During the focus groups many participants voiced a strong desire for research results, even if they indicated a heightened risk of an untreatable disease such as Alzheimer. Similarly, 91 percent of survey respondents indicated they would want information about their individual health risks "even if there was nothing [they] could do about them."

Participants used electronic keypads to vote and workbooks to note their thoughts down throughout the town halls.

As a prelude to the discussion on return of individual research results, the moderator gave participants an example: The study might pinpoint a genetic variant that increases the risk of developing diabetes from 10 percent to 15 percent. He asked participants whether they would want to know if they had the higher-risk variant. A strong majority in all town halls voted yes. The moderator then asked participants why they would want the information, or why not.

Many of those who wanted the information said that it would induce them to take steps to avoid getting the disease. Others wondered what the point would be: "What difference does it make? That's infinitesimal." Some thought the results would simply cause them unnecessary stress and worry.

The moderator then explained that individual research results are usually not returned to study participants because of logistical burdens (such as the need to replicate results in a certified clinical laboratory) and because the findings are preliminary and may be contradicted by future research. Given these factors, he asked participants how important access to individual results would be to them if they were asked to join the study.

Some participants still felt strongly that results should be returned. "I am giving you a piece of my person, my physical being. If I want information back about me, that should be available to me," one said. A few said that subjects should recognize that the study's purpose is to generate knowledge for the common good, and should participate out of altruism rather than a desire to obtain results. Some said the study should not return results because study data could not be anonymized fully if results were to be returned, and thus privacy could be compromised. A few said that taxpayers should not bear the extra cost of returning results to individuals. Nevertheless, at the end of the discussion on return of results, more than 70 percent of town hall participants responded "yes" to the question, "Balancing your desire for this information with all of these concerns, do you think the study should try and give this information back?"

Return of results

	All	Kansas City	Jackson	Phoenix	Portland	Philadelphia
Let's say there is a 10 percent risk that anyone may develop diabetes, and a 15 percent chance that anyone with a particular genetic variant may develop the disease. This finding would be published in the medical literature. But if you were a participant, would you want to know if you happened to be one of people who carried this variant?						
■ Yes	82.9%	91.6%	81.9%	82.8%	75.3%	79.4%
■ No	17.1%	8.4%	18.1%	17.2%	24.7%	20.6%
Balancing your desire for this information with all of these concerns, do you think the study should try and give this information back?						
■ Yes	70.7%	70.5%	84.7%	53.2%	69.6%	73.7%
■ No	29.3%	29.5%	15.3%	46.8%	30.4%	26.3%

Policy needs

The moderator asked, "If I were to make you king or queen for the day, what policies would you put in place for this type of study to be successful?" He asked participants to look again at the lists they had made of potential benefits and harms of the study, and to think of ways to maximize the benefits and lessen the harms.

The idea that companies should not profit from the taxpayer-funded study came up again during this portion of the discussion. However, some participants favored schemes whereby pharmaceutical companies could use data from the study provided they fed some of their profits back into the study or other government programs, or compensated study participants. Other participants suggested limiting the price charged for drugs developed using study results, enabling more people to benefit from them.

Both implementing universal health care and prohibiting health insurance companies from using individuals' genetic information to discriminate against them came up in several town halls. Participants wanted to ensure that study subjects would be treated fairly and that all demographic groups would be represented. Some said that access to the study data and its uses should be closely monitored; health insurers and law enforcement agencies were specifically mentioned as entities that should not have access.

Many participants offered suggestions specific to the study itself, such as convening a committee to oversee it. One man said that Congress should oversee the study's budget, but other participants said that politicians' influence on the study should be limited. A woman said that consent should be required from the family members of study subjects, "because if there's a return of information, and you find out you have a disease risk, then your family members have that disease risk." Several participants felt that any knowledge gleaned from the data should be made freely available to the public.

Top policy needs

Kansas City

- Guarantee you cannot be denied healthcare
- Guarantee process of collection and storing (ensure safety)

Jackson

- Limit/restrict access to the data
- Funding to follow up on results of research (e.g., treatment options for participants)

Phoenix

- Provide everyone with access to research benefits
- Feed profit from research results into government programs for citizens (e.g., Social Security)

Portland

- Require research findings be public
- Provide insurance to research participants

Philadelphia

- Protect privacy
- Report lethal or harmful findings to subject

Building a research agreement

In many of the focus groups that preceded the town hall phase of the Public Consultation Project, the idea arose that there should be an agreement between researchers and study subjects that would not only protect the subjects' interests but obligate researchers as well. Focus group participants suggested that this agreement should go beyond the informed consent that is routine in human subjects research, spelling out the researcher's obligations to participants (such as protecting privacy) as well as the subject's obligations to the study. We decided to explore this theme further in the town halls.

The moderator first explained what the standard components of informed consent are, then asked town hall participants what else should be in a research agreement for the proposed study. Although they had been informed that confidentiality is standard in human subjects research, participants in all town halls emphasized the importance of keeping results private, particularly from health insurers. Some wanted to maintain a measure of control over their data: "It would be important that the information was used for specifically what you signed for it to be used for. If they wanted to use it for other uses, they would need further permission." Similarly, some participants said that they should be able to withdraw from the study at any time with the assurance that their information and biological samples would be destroyed – another standard guarantee of research studies.

Another standard part of research agreements that participants emphasized was ensuring subjects' awareness of various aspects of the study, e.g., "disclosure of conflicts of interest such as who is funding the research that is utilizing the data." Participants felt that subjects should know exactly what their information might be used for, whether they would receive individual results, and what obligations and "little inconveniences" participating in the study would entail.

The idea that the study should have a dedicated oversight body or "ombudsman" also came up again during discussion of the research agreement. Some participants said that researchers should be obligated to tell subjects if research revealed they "had something lethal or harmful in their environment, or their diet, or their regimen was harming them."

When asked what subjects' obligations ought to be, many participants said that they "should be truthful." Many participants also felt that, once they had committed to the study, subjects should not drop out early or fail to show up for appointments.

Should it be done and would you participate?

At the start and end of the town halls, participants were asked to vote on whether the study should be done, and whether they would participate in it. In all of the sessions except Phoenix, fewer participants said it should "definitely" or "probably" go forward at the end of the town hall meeting than at the beginning. Similarly, at the end of all of the town halls except Phoenix, fewer said they would "definitely" or "probably" participate in the study. Overall, however, a large majority in all of the town halls supported the study, and most would likely participate in it if asked.

Genetics & Public Policy Center staff member Joan Scott provides an overview of the proposed federal study.

Comparison of initial and closing impressions

	All		Kansas City		Jackson		Phoenix		Portland		Philadelphia	
	Pre	Post	Pre	Post	Pre	Post	Pre	Post	Pre	Post	Pre	Post
Based on what you just learned, do you think this study should be done?												
Yes	87%	79%	87%	74%	92%	86%	85%	85%	85%	77%	82%	74%
No	13%	21%	13%	26%	8%	14%	15%	15%	15%	23%	18%	26%
Would you participate?												
Yes	66%	61%	69%	57%	67%	62%	70%	79%	67%	63%	55%	45%
No	34%	39%	31%	43%	33%	38%	30%	21%	33%	37%	45%	55%

Discussion

How the results compared to the focus groups and survey

The support for the study and likelihood of participation that participants voiced during the town halls was consistent with what we heard in the focus groups and in the national survey we conducted. In the survey, 84 percent of respondents said the study should definitely or probably be done, and 60 percent would definitely or probably participate. Like the focus groups and survey, the town halls demonstrated the importance the public places on access to individual research results. Focus group participants, like those in the town halls, largely felt that study subjects should be able to choose whether to receive individual research results, and what kind.

In both the focus groups and the town halls, participants voiced concerns about privacy, and not allowing health insurance companies access to individuals' data. They also said that the database should not be exploited by pharmaceutical companies or accessed by law enforcement agencies, and that the results should not be used to discriminate against demographic groups. Both groups of participants showed interest in the details of the proposed study's methodology, and many made suggestions aimed at ensuring the findings are robust.

Effect of the Genetic Information Nondiscrimination Act

Town hall participants consistently placed privacy and possible misuse of information among their top concerns about the proposed study. The Genetic Information Nondiscrimination Act of 2008 passed the U.S. Senate on April 24, 2008 (the day of the fourth town hall, in Portland), and cleared the House the following week. It was signed into law by the President on May 21. The bill bars employers and health insurance companies from discriminating against individuals based on their genetic makeup. Despite media coverage of the bill's passage, we saw no change in level of concern about privacy and discrimination between the first three town halls and the final two. Whether and how the new policy affects public attitudes about genetic privacy and discrimination will require follow-up study.

Did the process change participants' opinions?

The town halls may provide some indication of whether public opinion would change after citizens discussed the study with friends, family, and other members of their communities. Participants' reactions to the study were measured immediately after they viewed the explanatory video, and again at the conclusion of the session. At both times, participants were asked whether they supported the idea of the study and whether they would participate in it. These questions were asked primarily to stimulate conversation, and were not designed as a rigorous quantitative assessment of changes in opinion that occurred during the town hall process. However, it is interesting to note that in every city except Phoenix, support for the study and willingness to participate declined modestly between the beginning and end of the town hall meetings (see page 13).

These differences may stem from the fact that the reasons for (and expected benefits of) the study were laid out in the video just before the initial vote, while the potential drawbacks of the study were highlighted in the ensuing discussions.

Interestingly, the only town hall in which support for the study rose in the final vote – Phoenix – had a different seating arrangement from the other town halls. The Phoenix town hall took place in an auditorium, which was less conducive to small-group interaction than the table seating arrangement in the other sessions. The Phoenix town hall seemed to solidify participants' positions on whether the study should go forward: Though the numbers of participants who answered "definitely no" or "probably no" to this question were unchanged, more participants voted "definitely yes" at the end of the study. However, we did not follow up with participants later to find out whether their opinions had further changed over time. More research would be needed before any conclusions could be drawn about the effect, if any, of the different format.

Some participants complained that they were asked to vote on a study for which many details – such as whether individual results would be returned – were still undecided. It is likely that support and participation would be somewhat different if participants were asked about a specific genome-wide association study for which details were available.

Were the town halls effective?

The town halls confirmed that many of the issues raised in the focus groups and survey also came up in diverse public forums. While uncovering many of the same suggestions and concerns as other phases of the Public Consultation Project, the town halls presented some unique challenges, notably in recruitment. We used multiple methods, ranging from media outreach to contacting individual community leaders, in an effort to attract 150-200 people to each town hall session, but most town halls drew fewer than 100 participants. Town hall participants were better-educated, on average, than the surrounding communities (more than half had at least a bachelor's degree). In addition, their comments indicated that some had a particular interest in genetics, either because they worked in the field or because they or a family member had a genetic condition.

Part of the difficulty in recruiting might stem from the hypothetical nature of the questions participants discussed. Town halls focusing on an actual research project being undertaken in the community might draw a larger and more representative group of participants. As previously noted, many town hall participants wanted to know more details about the proposed study before determining whether they would be willing to participate in it. A planned, funded study would reduce this uncertainty while giving citizens an immediate interest in participating in a town hall – i.e., they might be considering joining the study and want to learn more about it and provide input on some details of its design. However, having an already-planned study necessarily would reduce the range of study design details on which town hall participants could weigh in.

Most participants viewed the town hall experience favorably. When asked evaluation questions at the end of their session, the large majority said they had been able to express their opinion "to a large extent" (65 percent), or "to some extent" (25 percent). Eighty percent felt the video had been "a great deal" or "somewhat" useful, while more than 90 percent felt that the town hall format was "definitely" or "probably" an effective way for the public to share its opinions.

Conclusions

Overall, we saw strong support for the proposed study and its goals both at the beginning and at the end of each town hall. Not everyone who supports the study would be willing to participate in it, but more than half of participants indicated they were likely to participate if asked.

This pilot project demonstrates how a community discussion might be conducted for the proposed study – should it be funded – or for other studies that require public input, acceptance, and participation. One limitation of the town halls, however, is that those who attend are not necessarily representative of their communities; many come because they are stakeholders or are otherwise particularly interested in the topic. Attendees also were better educated than the general populace, with most holding at least a bachelor's degree. A variety of engagement tools would be needed to inform and engage all segments of a community.

Johns Hopkins University

1717 Massachusetts Ave., NW #530
Washington, DC 20036
www.DNApolicy.org

The Genetics & Public Policy Center is a source of accurate and trusted information about public policy related to human genetic technologies, and is supported at The Johns Hopkins University by The Pew Charitable Trusts and with research funding from the National Human Genome Research Institute, the U.S. Department of Veterans Affairs, and Eli Lilly and Company.