

Reasons for participating and genetic information needs among racially and ethnically diverse biobank participants: a focus group study

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Abstract In order for DNA biobanks to be a valuable reservoir of genetic information, large numbers of participants from all racial and ethnic backgrounds need to be recruited. This study explored reasons for participating in a new biobank among primarily Hispanic and African American individuals, as well as their general attitudes towards genetic research, and their views on obtaining genetic tests. Focus groups were conducted with Mount Sinai Biobank participants recruited from predominantly lower income, minority communities. The topic guide included questions on The Mount Sinai Biobank, genetic research, and genetic testing. All focus groups were audio recorded, transcribed, and analyzed using thematic analysis. The six focus groups comprised 43 participants: 39 females and four males, aged 27–76 years,

with a median household income category of \$20,000–\$39,999. Twenty-one participants were Hispanic, 20 African American, one Asian, and one White. Participants' reasons for participating in the biobank included altruism, personal and family benefit, and general curiosity. Although there was evidence of conflation between genetic research and genetic testing, most participants held positive views of genetic research and expressed interest in receiving personal genetic test results. Participants wanted to learn more about genetic research and suggested various venues such as health fairs for disseminating information. Participation in biobanks by racial and ethnic minorities is apparently driven by altruism, and desire for personal or collective health benefits. Participants had generally positive attitudes, limited understanding of

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genetics and genetic research, and made useful suggestions regarding information dissemination mechanisms.

Keywords African American · DNA biobank · Focus groups · Hispanics · Motives

Introduction

DNA biobanks are repositories of DNA samples, usually linked with patient medical histories, that are playing a critical role in improving our understanding of the genetics of common complex diseases (Sanner and Frazier 2007). Typically, biobanks are comprised of thousands of participants who voluntarily contribute their samples for research. The first large DNA biobank was established in Iceland in 1998. Since then, large DNA biobanks have been established in the UK, Estonia, Japan, Sweden, and Canada (Kaiser 2002). In the USA, several large-scale biobanks have been established, including those at the Marshfield Clinic in Wisconsin, Vanderbilt University in Tennessee, Northwestern University in Chicago, and The Mount Sinai Medical Center in New York City (McCarty et al. 2008; Roden et al. 2008; Ormond et al. 2009). Research conducted with biobank DNA samples differs in several ways from other methodological approaches. First, participants are consenting to store their DNA for unspecified research purposes over an indeterminate period of time; second, participants are unlikely to receive any results or medical benefits from their participation; and third, the research may uncover gene variants of low penetrance whose clinical utility is unclear (Ormond et al. 2009).

Because of the complexities of DNA biobank research, a number of studies have been conducted to engage and consult community members in advance of biobanks being set up (Godard 2007; Kaufman et al. 2008; Pulley et al. 2008; O'Doherty and Burgess 2009). Generally in these consultations, the public has indicated strong support for biobanks (Godard 2007; Pulley et al. 2008; O'Doherty and Burgess 2009), but limited understanding of what the DNA samples might be used for (Kaufman et al. 2008; Pulley et al. 2008) and concerns about the confidentiality of the genetic data (Kaufman et al. 2008). Now that biobanks have been recruiting for several years and amassed tens of thousands of participants, it is crucial to understand biobank participants' motives for participating in, and to examine their understanding of and perspectives on genetic research. This will help ensure the quantity and diversity of genetic samples needed for future genetic research, and yield the development of clinical applications usable by all. To date, the few studies that have examined the motivations and attitudes of biobank participants have been comprised of mainly White participants (McCarty et al. 2007; Ormond et al. 2009; Lemke et al. 2010). This is reflective of the racial and ethnic composition

of most biobanks worldwide (Haga 2010). It is vital that greater efforts be made to recruit more racially and ethnically diverse populations into biobanks.

In 2007, The Mount Sinai Biobank in New York City was initiated and is distinguished among most biobanks because the participants are recruited from highly diverse communities, with the majority being either Hispanic or African American. The Mount Sinai Biobank currently is comprised of over 10,000 participants, and is projected to recruit 25,000 participants by 2013 (Erwin Bottinger, personal communication).

In the present study, we therefore set out to explore the motivations, attitudes, and understanding of the ethnically and racially diverse participants who have consented to participate in The Mount Sinai Biobank in New York City. The primary aims of the study were to examine these racially and ethnically diverse biobank participants' reasons for participating in biobank research, and to assess their information needs regarding genetics, using a qualitative methodological approach. Our secondary aims were to examine participants' attitudes and understanding of genetics and genetic research, as well as their attitudes towards one application of genetics research, providing individuals with personal genetic test results indicating disease susceptibility (i.e., personal genetic testing). Our overarching aim is to engage local communities in dialogues about biobanks and genetic research so that future educational and awareness programs can be appropriately targeted to the information needs of these diverse communities. This study was conducted as part of Project ENGAGE (Evaluating Information Needs to Generate Community Engagement and Genomics Education) which is supported by the Charles R. Bronfman Institute for Personalized Medicine.

Methods

Study design

This was a qualitative study in which focus groups composed of Mount Sinai Biobank participants were conducted to collect data on reasons for participating in The Mount Sinai Biobank, understanding of and beliefs about genetic research and personal genetic testing, and genetic information needs. The study was reviewed and approved by the Mount Sinai School of Medicine IRB.

Study population

Participants for this study were patients who had consented to participate in and donate blood to the large DNA Biobank study at Mount Sinai Medical Center (MSMC) between March 2008 and March 2010. Potential participants

were eligible for inclusion in the present study if they were a Mount Sinai Biobank participant and spoke English as their primary language. All Mount Sinai Biobank participants are required to be at least 18 years of age; therefore, all participants in the present study were also aged 18 years and over.

Recruitment procedures

Potential focus group participants were initially made aware of Project ENGAGE by research assistants recruiting for The Mount Sinai Biobank at various clinics at MSMC. Biobank recruiters approached patients in MSMC clinics to ask if they were interested in participating in the biobank. If a patient was interested, the biobank recruiter checked to see if the patient was already a biobank participant. If the interested patient was not already enrolled, the recruiter went through the informed consent with them. The informed consent procedure for The Mount Sinai Biobank recruitment included providing potential participants with an eight-page consent document, complemented by a verbal explanation. They were informed they would be required to answer a questionnaire about their family history that would take up to 15 min to complete; that they would have up to two tablespoons of blood drawn; that the purpose of the study was to “collect, store, and study medical information and blood samples”; that the “information may be used to advance the medical community’s understanding of different diseases”; and that “this understanding may lead to better and more effective treatment options and improvement in quality of life.” The following information was also provided: “Your samples will be stored in The Mount Sinai Biobank freezers for an indefinite number of years and will be used for future research including genetic testing. Genetic testing is the study of your genes which are threadlike particles made of deoxyribonucleic acid (DNA). DNA is inherited and contains the structure and function of all the cells that make up your body. For example, genes control the color of each person’s hair and eyes as well as many of the other features that make us different from each other.” Prospective participants were specifically told that they would not receive any information regarding the results of the DNA testing.

Potential participants were then given a flyer describing the Project ENGAGE focus groups and informing them that, if they agreed, a Project ENGAGE staff member would be contacting them by phone. Mount Sinai Biobank participants who expressed interest in learning more about the focus groups provided the study recruiter with their name and phone number, and were subsequently phoned by Project ENGAGE staff. Over 50% of potential participants were approached for recruitment via the Internal Medical Associates (IMA) clinic at MSMC: the majority of IMA patients are African American or Hispanic, only 10% are

White, and the clinic accepts patients with no insurance, Medicaid, and self co-pay as well as those with insurance. When informed about the ENGAGE study by biobank recruiters, 124 individuals initially gave permission for ENGAGE staff to contact them by telephone about participating in the ENGAGE focus groups. Of these 124 individuals, eight were determined not to be biobank participants and so were not eligible for inclusion in the present study. Of the remaining 116 biobank participants, three were deemed ineligible during the phone call with a member of the ENGAGE team because they did not speak English, giving a total of 113 potentially eligible biobank participants.

The 113 biobank participants contacted by ENGAGE staff comprised 97 (85.8%) women and 16 (14.2%) men. Regarding race/ethnicity, 54 (47.8%) were African American, 49 (43.4%) were Hispanic, eight (7.1%) were White, and two (1.8%) were Asian. Of these, 70 individuals either could not be reached ($n=29$), actively declined to participate ($n=13$), or agreed to participate but did not turn up to their scheduled focus group ($n=28$), giving a final sample size of 43 participants in the ENGAGE focus groups (43/113, response rate of 47%). There were no significant differences in gender or ethnicity distribution between the 43 individuals who did and the 70 individuals who did not ultimately participate in the focus groups. Eligibility criteria for participation in the focus groups were being a Mount Sinai Biobank participant, and speaking English as their primary language. Individuals were screened on the eligibility requirements, and if eligible, invited to attend a focus group.

Focus group procedures

The six focus groups each comprised four to 12 participants and were conducted in a conference room at MSMC between January 2010 and March 2010. Before the start of each focus group, participants gave written informed consent and answered a brief anonymous questionnaire. The questionnaire included basic socio-demographic measures, one question on past participation in genetic research or genetic testing, and one question on personal and family history of genetic diseases. A circular seating arrangement was used for the focus groups, and refreshments were provided at the side of the room. Each focus group lasted approximately 60 min. Experienced moderators led the focus groups, and a note-taker was present to record important participant expressions and actions not captured on the audio recordings. Participants received a \$40 Visa gift card as compensation for their time. Each focus group was audio recorded and subsequently transcribed for data analysis. The Project Manager reviewed each transcript for accuracy and inserted key participant expressions and actions observed by the note-taker where necessary.

Table 1 Focus group topic guide

Topic	Questions
1. Past participation in Biobank	Do you remember taking part in this? What was the study about? Do you remember what the blood samples will be used for? Why did you choose to be part of it?
2. Genetics and genetic research	When you hear the term “genetics” what do you think about? How do you feel about genetic research? What do you think people in your neighborhood think about genetic research?
3. Genetics and genetic testing	Have you or anyone you know ever had a genetic test? What was the genetic test for? What do you think about genetic testing? If you were in a situation where a genetic test would be offered to you: would you want to take the test? Why or why not? If you had an increased risk for a horrible disease later in life, and there was a test that could tell you if you had this risk. Would you want to know that you would be at increased risk for this disease later in life? What about genetic testing on a child to see if they are at risk for certain conditions later in life? Is that different? Would you want to know about your child’s risks? If you were trying to decide whether to have a genetic test for you or your child: What kind of information would you want before deciding? Who would you ask for information? Whose opinion would be important to you in making a decision?
4. Information needs	Would you like to have more information about genetic research and genetic testing? What sort of information would you like? The hospital is interested in the best way to put this information together. How should we tell your community about genetics? Who do you think would be the best person or organization to give you this information?

Introductory text and additional prompts not included here; the entire guide can be obtained from the corresponding author

Focus group guide

The focus group guide consisted of four sections (see Table 1). Each section had a brief introduction followed by four to six open-ended questions with specific probes to facilitate discussion. A team of researchers and an African American and a Latino community resident developed the guide, which was subsequently piloted with two Mount Sinai Biobank participants. The focus group guide was constructed to address biobank participants’ reasons for participating in, understanding of, opinions about, experience with, and interest in: (1) the Mount Sinai Biobank specifically; (2) genetics research in general; and (3) genetic testing. The fourth and final section addressed participants’ information needs and preferences about each topic.

Data analysis

The focus group data were analyzed using thematic analysis (Braun and Clarke 2006). In brief, transcripts were read, manually coded, and organized according to content into categories by an investigator. New categories were created until a repeating category was apparent, themes were extracted from the coded categories, and a codebook was

developed to record key themes and categories. A second and third investigator double coded a subset of the transcripts and any differences were identified. Coding was discussed and reconciled between the three investigators, and a revised codebook was developed.

Results

Demographics

A total of 43 participants attended six focus groups. Twenty-one participants self-identified themselves as Hispanic, 20 as African American/Black (including two who self-identified as Caribbean/West Indian), one as Asian, and one as White; ages ranged from 27 to 76 years; 39 participants were female; and the median yearly household income category was \$20,000–\$39,000 (see Table 2 for full descriptive characteristics of the participants).

Themes

Themes emerging from the focus groups were organized into five main categories: (1) reasons for participating in

Table 2 Socio-demographic characteristics of participants

Total (n=43)	Participants n (%)
Age, mean (SD)	43 (12), range 27 to 76 years
Sex	
Female	39 (90.7)
Male	4 (9.3)
Race/ethnicity	
Hispanic	21 (48.8)
African American	20 (46.6)
Asian	1 (2.3)
White	1 (2.3)
Household income	
<\$20,000	13 (30.2)
\$20,000–\$39,999	8 (18.6)
\$40,000–\$59,999	6 (14.0)
\$60,000–\$79,999	3 (7.0)
\$80,000–\$149,999	5 (11.6)
≥\$150,000	2 (4.7)
Don't know/unsure	3 (7.0)
No answer	3 (7.0)

The Mount Sinai Biobank; (2) understanding of The Mount Sinai Biobank; (3) understanding of genetics, genetic research, and genetic testing; (4) attitudes toward genetic research and genetic testing; and (5) information needs and preferences. Each theme is described in more detail below.

Reasons for participating in the Mount Sinai Biobank

As Table 3 shows, the primary reasons for participating in The Mount Sinai Biobank were: (1) altruism (e.g., “*If it helps one, one other person, one little ... finding, then it was totally worth it*”); (2) personal and family benefit (e.g., “*I wanted to be a part of it because I wanted to learn more about, causes of, and more about, you see heart disease and stuff like that because I know ... my grandmother, she was a diabetic, my great grandmother was a diabetic, my mom passed, and she was a diabetic. And I have a brother who is a diabetic. So I am concerned*”); (3) the recurring and cross-cutting theme of helping the next generation (e.g., “*I believe that it's gonna be helpful to the next generation, not so much for this generation, but the next generation*”); and (4) general curiosity (e.g., “*I was curious about the diseases and how it works...*”). Also as shown in Table 3, there was also evidence of some participants incorrectly believing they would receive personal genetic test results through their participation in the Biobank (e.g., “*I thought they would give me in terms of who I was related to. Like Bush, or ...?*”),

although others were aware that this was not the case (e.g., “*She told us that we wouldn't find out anything*”).

Understanding of the biobank

Understanding of the purpose of The Mount Sinai Biobank was limited. When participants were asked what they remembered and understood about The Mount Sinai Biobank, most participants were able to give only very simple responses: (1) heredity (e.g., “*They're checking heredity*”); (2) completing a questionnaire (e.g., “*The survey of diseases in the family*”); (3) having blood drawn (e.g., “*They drew blood to check out certain things from our blood, that's what I was told*”); (4) receiving \$20 (e.g., “*I remember that, I know that it was twenty dollars because I work in the primary and they're always there.*”); or (5) stated that they did not know what the purpose of the research was (e.g., “*I know they took my blood... we went through the whole discussion... but I can't remember why they drew the blood.*”). A handful of participants' responses indicated that they understood that the biobank was a research study that will hopefully help shed light on certain diseases (e.g., “*I was told they use the DNA to see if they further help people with diabetes and certain disease, you know?*”), but there was no indication of any more in-depth understanding of what the biobank was about. When asked whether they remembered having participated in The Mount Sinai Biobank, one of the 43 participants said they did not recall having participated.

Understanding of genetics, genetic research, and genetic testing

Understanding of genetics

Many people clearly understood genetics primarily in terms of heredity and the inheritance of traits: for example, when asked what the word “genetics” meant to them, responses included “*Traits we carry from our parents*”, “*Kinds of things that we may inherit... passed on down to our children, our grandchildren*”, and “*Our make-up. What we're made of. Hereditary.*” One woman had previously thought about genetics primarily in this way (inheritance of traits such as hair color), but since having breast cancer had expanded her view of genetics to include disease, stating, “*I think of it as also the good and the negatives, since last year I had breast cancer, so always think, ok might give me brown hair, but now I think of it as illnesses as well.*” Many people also gave single word answers, particularly “*DNA*”. Very few people had heard of the terms “genomics” or “genome,” and there was little understanding of what the Human Genome Project was: for example, when asked specifically about the Human Genome Project, responses

Table 3 Reasons for participating in the Mount Sinai Biobank

Categories	Participant quotes
1. Altruism	
Good cause	“...if I donate blood, I just figured why not? It's for a cause.”
To help others	“If it helps one, one other person, one little finding, then it was totally worth it.” “Because it might help somebody else.”
To advance research	“Yeah. I was just trying to say that right now, my participation was really because I feel it's in its infancy. 'Cause I do feel like there are dangers associated with this kind of testing, with the knowledge base, but it's worth the risk, and it is in its infancy. They don't know whether certain genes strain is the contributing factor. That's the process, you know that'll take 200,000 people if you don't have it or something.”
2. Personal and family benefit	
Learn more information	“Well, I would like to know more about what the blood-drawing brings up.”
Learn more about family	“I find it interesting, 'cause when I was young I did a genealogy chart, so I found out a lot of things already about my family, so I am kind of more curious to find out some more information.”
Learn more about diseases that run in family	“I wanted to be a part of it because I wanted to learn more about, causes of, and more about, you see heart disease and stuff like that because I know ... my grandmother, she was a diabetic, my great grandmother was a diabetic, my mom passed, and she was a diabetic. And I have a brother who is a diabetic. So I am concerned”
Learn more about self	“I wants to know more information about knowing who I am, what's inside of me, and one time I never want to know ... and it's important that I know so I could pass it on to my kids, and this is embarrassing, when you don't know.”
To receive personal results	“I thought they would give me, like, in terms of who I was related to. Like Bush. Or ...?”
3. To help the next generation	
Help next generation	“I believe that it's gonna be helpful to the next generation, not so much for this generation, but the next generation.”
Help children and grandchildren	“The generation ... my children is coming up and my grandchildren. We gotta be prepared for, for their health, their well being, because there are gonna be a lot of people sick.”
4. General Curiosity	
Curious	“I was curious about the disease and how it works.”
Because it's cool	“I thought it was cool ... I thought it was great ... I think one day I could, call up and say, hey, what goes on with those genes. I'm care free when it comes to that, all of that stuff. I feel like ... we are here, time is limited, let's live, what happens along the way, its ... its, you don't have control over that.”

included “It's like the cloning?” and “Does that ask questions about your family or something? Like a diagram?”.

Conflating genetic research and genetic testing

Considerable confusion between genetic research and personal genetic testing emerged throughout the focus groups, with participants often conflating the two. This particularly became apparent when people were asked about genetic testing (i.e., having personal genetic testing to receive information about personal genetic susceptibility to disease), and their responses suggested that they interpreted the question as being about genetic research (e.g., general research into disease genetics). One example of this occurred when a facilitator asked the group, “If you were in a situation that somebody would offer you a genetic test, would you take it?” and a participant responded, “Only if I get the results back.” In another instance, the facilitator

asked, “...would you want to take a test to find out whether you would come down with some disease later in life...?” and the participant responded: “Yes ... as long as it helped somebody or something, if it was helpful or something like that.”

Attitudes towards genetic research and genetic testing

Positive attitudes towards genetic research

When the facilitator and participants were clearly discussing genetic research, the majority of participants primarily held positive attitudes towards genetic research. This was often due to the belief that it would lead to positive outcomes regarding diseases (e.g., “I feel when it comes to genetic research, it's very important because, like for a lot of things like autism and different things like that, you're trying to find out where it comes from and, that's a big deal

right now, because it's popping up so much now, that it, and it didn't before and they're trying to figure out why. So these things are good.") Several participants also emphasized that genetic research was a positive thing as long as the community benefited from it (e.g., *"It's a good thing if it benefits the community."*).

Positive attitudes towards genetic testing

Despite the confusion at times between genetic research and genetic testing for personal use, the majority of participants appeared to hold positive attitudes towards personal genetic testing, to the extent to which they understood it, and stated that they would be interested in receiving personal genetic test results for themselves. For example, when asked, "If you were in a situation where a genetic test would be offered to you, would you want to take the test?" all participants in one focus group responded "Yes". Reasons for interest in genetic testing included: (1) the belief that it could help them prevent or prepare for disease (e.g., *"If you knew about it with plenty of time in advance, modify your lifestyle,"* and *"to see if you could take steps to do certain things, whether there's medication or change in diet, or whatever, and also, even if you can't, just to kind of prepare yourself."*) and (2) to provide children with information (e.g., *"I would want to know because I have children and my children have children, and would want to know what's in my body, what are in my genes that could affect them and can affect their children"* and, *"If it's genetic, it is gonna go down the lineage, I would want to know and they should know."*).

Negative attitudes towards genetic research

Few negative attitudes towards genetic research were expressed, although one participant asked, *"I mean, they're doing genetic research on babies where you can say that you want a girl instead of a boy, you want to have blue eyes instead of green eyes, I mean, they're testing, they're doing, or whatever, that case may be, I mean, how far are we gonna go with this?"*. The vast majority of negative attitudes were expressed in the context of discussions about how other people in their community felt about genetic research. The majority of participants said that even though they themselves were comfortable with genetic research, members of their communities would not feel the same, and that this was primarily because of (1) a lack of understanding regarding benefits (e.g., *"You know, if they're against it [genetic research] it's because they're ignorant of how it could benefit things"*), (2) a lack of awareness (e.g., *"People are afraid of what they don't know ... the fear is there ... they don't understand it, they are not aware of it"*), and (3) concerns about confidentiality (e.g., *"Their names, they are*

gonna know everything because it's on paper ...and they're, you know, and they are just afraid to sign to anything or participate because you may want to know too much about them.").

Negative attitudes towards genetic testing

Only a few participants expressed negative attitudes and lack of interest in genetic testing and receiving personal genetic information. One participant who was hesitant about getting genetic testing expressed that it would worry her too much and she would rather *"just live life"*, while another woman stated that she would not want to do *"something preemptive ... when there is no necessary need for me to do something about it."*

Although most participants were in favor of genetic testing for personal use, views on genetic testing of children were much more mixed. One participant stated, *"it's their right to know that they have ... there is a chance that they are inheriting something from someone else,"* while another participant stated, *"I would not want to sit there and put that fear into them ... because like you said because there is no guarantee,"* and another said, *"I'm split there. Because I have young children in my family who have had sarcoma, and if genetic testing can help find out, when they are born, that they're going to get something like that, fine. But then I have other things, you know, you're thinking the child is going to get this, the child is going to get this, you're never gonna live."*

Information needs and preferences

Table 4 shows participants' information needs regarding genetic research, genetic testing, and genetics in general. Many participants wanted to know the types of research that could be done with blood samples and which genetic tests were available. One woman epitomized the questions asked about genetic research and genetic testing by saying, *"What would people have questions about? I think people would ask well, why should we do this? How is it going to help us? You know, down the line, what's it gonna do for us?"*

The participants also suggested a variety of places to disseminate genetic information (Table 5). Suggestions heard multiple times were health fairs, community centers, and churches. The participants also said that they would like to learn about genetic information through print materials and wanted genetic information materials made available in multiple languages. Many participants did not like the idea of learning about genetic information through text messages and phone calls. Some participants liked the idea of a trusted website with genetic information, while others thought that a website alone would not suffice since it would exclude some portions of society, e.g., older

Table 4 Information needs: type of information about genetics desired

Information needs category	Type of information desired
Genetic research	What type of research can be done with a blood sample? How will confidentiality be protected? What are the benefits?
Genetic testing	Roles of health and life insurance in genetic testing The pros and cons of genetic testing The procedure/process of genetic testing Why should we do genetic testing? What will the genetic test results tell me? How will confidentiality be protected? Is counseling available before and after test result? Who could get genetic testing? What genetic tests are available? Am I susceptible? Long-term effects How much longer do I have to live Help with dealing with the anxiety of genetic testing Can testing harm the person being tested?
Genetics	How genetic diseases are passed down How genetics affect different races How genetics affect genders

people. Participants wanted to hear about genetic information from health care providers and people who had been affected with a disease. One participant suggested that genetic information pamphlets should be disseminated and that this would prompt people to then go to their doctor to discuss the information in the pamphlet. One participant

summed up how they felt genetic information could be disseminated by stating, “*I think you should do, like a combination type of things. You have the church, doctors, some researchers, and you hold a big street fair or something. So if anybody has questions they have different people to talk to.*”

Table 5 Information needs: preferred sources of information about genetics

Category	Preferred source of information
People	
Health care providers	Doctors (medical staff), specialists, social workers
Lay people	Friends, family, a person who had the disease
Leaders	Community leader, district leaders (specific to the Black and Hispanic communities)
Other	Actors, God
Places	
Institutions	Workplace, health department, welfare office, church, children’s school, hospitals
Street fairs	Health fairs, mobile trucks, Block meetings, community centers
Businesses	Library, nail salon, Laundromat
Internet	Trusted website or email
Delivery formats	
Print	Newsletters, newspapers, magazines, billboards, posters, pamphlets, information tables, visuals
Media	Commercials, TV, movies, radio announcement
Community outreach	Support groups, workshops
Other	Word of mouth, have a person from each culture at street fair explaining genetics, have genetic information presented in different languages, ensure that the program happens every year

Discussion

In this focus group study conducted with predominantly lower income, minority biobank participants, we found that participants' reasons for taking part in The Mount Sinai Biobank were often altruistic, e.g., to help future generations, advance research, and because it was for a good cause. There was also considerable discussion regarding whether and how the participants would benefit themselves from the research; in some instances, there seemed to be evidence of the “therapeutic misconception,” that is, the belief that by participating their own health would be directly improved through receiving personal genetic test results. In other instances, the perception of potential benefit seemed more to be derived from the belief that by participating they might learn more about a disease or diseases that they were particularly concerned about, often because they themselves or a family member were affected by that disease. These findings suggest that future efforts to engage diverse communities with biobank research may benefit from including information about causes of disease and disease prevention for these communities; to some extent, this may provide both a “teachable moment” about disease prevention as well as a way in which biobank researchers can give back to the communities with whom and for whom they are working.

This is the first study, to our knowledge, that has examined reasons for participating in a biobank among participants recruited from racially and ethnically diverse communities. We found that motives for participating in the Mount Sinai Biobank among this primarily Hispanic and African American population were quite similar to those motives previously reported by others among primarily White populations, e.g., altruism, to learn about personally relevant disease, and for family gain (McCarty et al. 2007; Ormond et al. 2009; Lemke et al. 2010). Two studies have been conducted with biobank participants in the Northwestern University Biobank (The NUGene Project). Ormond et al. (2009) conducted an interview study using both quantitative and qualitative methods to examine NUGene participants' motives for participating and understanding of biobank and genetic research, while Lemke et al. (2010) conducted focus groups to explore NUGene participants' views on research participation and genetic data sharing; however, in both studies the participants were mainly White (86.0% and 76.0%, respectively). Both NUGene participants and Mount Sinai Biobank participants expressed general altruistic reasons for participating and many anticipated personal and family gain. Ormond et al. (2009) also reported that several NUGene participants wanted to “give back” to medical research because they had personally benefited from a medical discovery; this was not a sentiment expressed by Mount Sinai Biobank participants in our focus groups. McCarty et al. (2007) examined 924 self-administered surveys sent to

participants in the Marshfield Clinic Biobank. More than one third of participants indicated that the \$20 compensation greatly influenced their decision to participate in the Biobank. Although none of The Mount Sinai Biobank participants stated the compensation as a reason they participated, some participants only remembered this part of the biobank enrollment procedure.

While most NUGene and Marshfield Clinic Biobank participants understood that the purpose of the biobank was to benefit future patients, we found that Mount Sinai Biobank participants did not seem to understand the purpose of the biobank. However, when NUGene and Marshfield Clinic Biobank participants were further pressed to explain biobank research, their understanding was more limited (McCarty et al. 2007; Ormond et al. 2009; Lemke et al. 2010).

Lemke et al. (2010) also asked NUGene participants about their understanding of and views on genetics and genetic research more generally. Similar to Mount Sinai Biobank participants' understanding of and views on genetics and genetic research, Lemke et al. (2010) found limited understanding of genetics and genetic research, but strong support for genetic research. Thus, our findings support previous findings from US studies in which there have been low levels of public understanding of genetics (Lanie et al. 2004; Kessler et al. 2007; Christensen et al. 2010), yet positive attitudes toward genetics research, among both biobank participants and among the general population (Lemke et al. 2010). The findings reinforce the need for educational efforts to ensure that communities understand the research they are being asked to participate in. Where there was understanding, it was primarily linked to ideas about heredity and inheritance of traits.

None of the previously published biobank participant studies have assessed participants' attitudes toward personal genetic testing; however, in previous focus group research with underserved, culturally diverse populations who were not enrolled in biobanks, participants indicated that they either felt that genetic testing was “good” since it could lead to disease prevention and preparation, or “a double-edged sword” since it could lead to prevention but could also be used unethically, cause anxiety, or provide false reassurance (Catz et al. 2005). In contrast to these findings, the majority of biobank participants in our study felt that genetic testing was “a good thing” and expressed interest in receiving personal genetic test results. Only a minority felt that genetic testing would worry them too much: none of the biobank participants expressed the idea that genetic testing was a “double-edged sword”. However, when biobank participants in our study discussed genetic testing of children, they then expressed three distinct views: proponents of childhood genetic testing, dissenters of childhood genetic testing, and childhood genetic testing as a “double-edged sword.”

Our study is particularly important because diverse study populations in DNA biobanks are needed in order not to further widen the already gaping schism regarding available genomic data between majority versus minority groups. As of June 2009, 92% of participants in genome wide association studies (GWAS) were White (Haga 2010). This matters for many reasons, not least because some diseases are linked to different polymorphisms in different populations. For example, although African Americans and Latino populations experience a disproportionate burden of type 2 diabetes (Florez et al. 2009), most of the participants in DNA biobanks are of European ancestry (i.e., White) and the majority of type 2 diabetes GWAS have similarly been conducted in European populations (Haga 2010). Recent studies have shown that multiple type 2 diabetes susceptibility genes reported in European populations have either failed to show association in people of African ancestry (Lewis et al. 2008) or showed modest contribution to variation in glucose homeostasis (Yang et al. 2010). By comparison, single nucleotide polymorphisms at type 2 diabetes susceptibility loci identified through GWAS in populations of European ancestry have been shown to have similar effects in Asian (Tan et al. 2010) and Mexican American (Yang et al. 2010) populations suggesting that the genetic risk factors may not be identical in different ethnic and racial groups.

Our finding that participants conflated genetic research and genetic testing is in line with findings in previous research (Ormond et al. 2009). This suggests that this is an important confusion in lay audience's minds, and emphasizes that future genomics education should include particular effort to make the distinction between genetic testing for research versus genetic testing for clinical and personal uses explicit and clear. It should also be noted however that there were more questions on genetic testing in our topic guide than on any other topic. Thus, it is possible that these findings in our study were influenced by our own emphasis on genetic testing. The confusion may also have been influenced by the fact that the original Mount Sinai Biobank informed consent procedure referred to genetic testing within the context of genetics research. This is not an unusual occurrence; future educational materials may benefit from always making clear when "genetic testing" refers to testing done in the context of research only, and when "genetic testing" refers to testing done specifically with the intention of returning personalized genetic or genomic results back to individuals.

One limitation of our study was that only 9% of our study sample were male and so our findings are not necessarily generalizable to men. Furthermore, because the focus groups were heterogeneous in terms of race/ethnicity, and because the numbers of Whites and Asians were so small, we were unable to attribute or compare any particular views or beliefs between

racial/ethnic groups. Although we did not find any major differences in our minority sample compared to previously reported majority groups, a study using homogeneous focus groups (e.g., stratified by race/ethnicity) would be needed to assert this more conclusively. Other limitations of our study include that those that agreed to participate in the focus groups may be more positively disposed to research. Additionally, three participants were recruited from the breast cancer treatment center at MSMC, which may have increased the emphasis on breast cancer in some of the focus group discussions.

However, these limitations must be weighed against the strengths, which include that this study is the first to address reasons for biobank participation in an ethnically and racially diverse community of biobank participants. Individuals from traditionally under-represented racial and ethnic groups comprised the majority of our focus group participants: 49% were Hispanic and 47% were African American. These numbers are broadly reflective of the Mount Sinai Biobank participants overall: as of June 2010, there were 9,542 individuals in the Mount Sinai Biobank, of whom 38% self-identified as Hispanic, 28% as African American, 20% as White, 2% as Asian, and 13% as "Other." Mount Sinai Hospital is located on the edge of East Harlem in New York City and these numbers are indicative of the racial and ethnic makeup of the population in this geographic location.

In conclusion, this study provides valuable information on the motives, attitudes, and understanding of ethnically and racially diverse biobank participants. Our results are important since previous research has shown that educational programs to improve understanding of genetics are most effective if they build on existing and correct ideas about genetic inheritance and disease risk (Christensen et al. 2010); thus, the findings will be valuable to the future development of targeted educational materials addressing the information needs and preferences regarding genetics research for diverse communities. It is essential that efforts are made to engage and recruit more racially and ethnically diverse populations into DNA biobanks in the future. Our findings suggest that such efforts might benefit from highlighting relevant potential benefits of the research, and from incorporating information about disease causation and prevention, for these communities.

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