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ORIGINAL ARTICLE

Willingness to participate in genomics research and desire for personal results among underrepresented minority patients: a structured interview study

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Abstract Patients from traditionally underrepresented communities need to be involved in discussions around genomics research including attitudes towards participation and receiving personal results. Structured interviews, including open-ended and closed-ended questions, were conducted with 205 patients in an inner-city hospital outpatient clinic: 48 % of participants self-identified as Black or African American, 29 % Hispanic, 10 % White; 49 % had an annual household income of <$20,000. When the potential for personal results to be returned was not mentioned, 82 % of participants were willing to participate in genomics research. Reasons for willingness fell into four themes: altruism; benefit to family members; personal health benefit; personal curiosity and improving understanding. Reasons for being unwilling fell into five themes: negative perception of research; not personally relevant; negative feelings about procedures (e.g., blood draws); practical barriers; and fear of results. Participants were more likely to report that they would participate in genomics research if personal results were offered than if they were not offered (89 vs. 62 % respectively, $p<0.001$). Participants were

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more interested in receiving personal genomic risk results for cancer, heart disease and type 2 diabetes than obesity (89, 89, 91, 80 % respectively, all $p<0.001$). The only characteristic consistently associated with interest in receiving personal results was disease-specific worry. There was considerable willingness to participate in and desire for personal results from genomics research in this sample of predominantly low-income, Hispanic and African American patients. When returning results is not practical, or even when it is, alternatively or additionally providing generic information about genomics and health may also be a valuable commodity to underrepresented minority and other populations considering participating in genomics research.

Keywords Genomics research · Interest · Interviews · Patients · Personal results

Introduction

Minority ethnic groups are underrepresented in genomics research (James et al. 2008). As of June 2009, 92 % of participants in genome wide association studies were of White ethnicity (Haga 2010). Patients from ethnic minorities have been found to be significantly less likely to enroll in cancer genetics epidemiological research than patients of White ethnicity (Ford et al. 2006). This under-representation is important for many social, ethical and pragmatic reasons. For example, some DNA variants that have been found to be associated with type 2 diabetes susceptibility in European White populations have subsequently failed to show associations in people of other ancestry backgrounds (Lewis et al. 2008; Yang et al. 2010). It is important that greater numbers of individuals from underrepresented racial and ethnic groups participate in genomics research into complex diseases such as cancer and type 2 diabetes to ensure that benefits of such research are obtained for all, not primarily for individuals of recent European ancestry.

The reasons for minorities being underrepresented in genomics research are likely to be complex. In addition to practical barriers such as language barriers (Gill et al. 2009), economic circumstances, transportation constraints and social factors related to time (Ejiogu et al. 2011; Farmer et al. 2007; Kagawa-Singer 2000), psychological factors such as lack of understanding of the research (Gill et al. 2013), lack of confidence, as well as fear and cultural beliefs (Ejiogu et al. 2011; Farmer et al. 2007; Kagawa-Singer 2000) are all likely to play a role in non-participation. Mistrust of research institutions and investigators may be a particularly important attitudinal barrier to research participation among African Americans (Braunstein et al. 2008; Byrd et al. 2011).

Some studies have examined willingness to participate specifically in genomics research and biobanks, and reasons for that willingness or lack thereof, among minority populations. Although many altruistic and personal reasons for participating were expressed by primarily African American and Hispanic biobank participants in one focus group study (Streicher et al. 2011), distrust was found to be a major theme expressed by African Americans when discussing biobank participation in another focus group study (Halverson and Ross 2012). Non-Hispanic Whites were more likely than individuals of other racial and ethnic groups to enroll in a clinic-based biobank (Ridgeway et al. 2013). Refusers gave different reasons for non-participation compared to nonresponders: refusers more often cited privacy concerns, while nonresponders more often identified time constraints as the reason for non-participation (Ridgeway et al. 2013). In other research on obesity, lack of time emerged as a main reason for non-participation, including lack of time to dedicate to a topic seen as low priority (Levickis et al. 2013). In a recent review of the reasons participants give for taking part in biobanks, 8 out of the 13 studies showed evidence of participants having an expectation of personal benefit through receiving health-related information, and three of these discussed whether this could be considered a form of "therapeutic misconception" (Nobile et al. 2013).

There is some evidence to suggest that people may be more likely to participate in research that they perceive to be personally relevant to them: this is suggested from empirical research such as the study in which a significant reason for lack of participation was lack of time for a topic viewed as a low personal priority (Levickis et al. 2013), and from the evidence suggesting that people are more likely to participate in biobanks when they believe they will receive personal benefit through health-related information (Nobile et al. 2013). It would therefore be interesting to know whether and how individual factors regarding specific complex diseases, such as having a personal or family history of the condition, worry about the condition, and belief about the causes of the condition, are related to willingness to participate in genomics research in these underrepresented minorities, given the suggestion that the more personally relevant the research appears to be, the more likely people may be to participate.

Genomics research on complex conditions such as cancer, type 2 diabetes, heart disease and obesity has the potential to be translated into significant public health benefit via several pathways, including identifying individuals at high risk so that they and/or their doctor can potentially take action to reduce their disease risk. In order for that benefit to be realized, it will at times be necessary for patients to be willing to have their DNA tested or sequenced and then to personally receive the results of that testing. Previous research in general populations has found that there are high levels of interest in receiving personalized genomic information for a range of conditions (Lerman et al. 2002; Andrykowski et al. 1996; Sanderson et al. 2004), and some evidence suggests that interest levels are as

high among African Americans as among Whites (Satia et al. 2006). However, the same research suggests that African Americans also have concerns about genetic testing due to implications for discrimination (Satia et al. 2006), and one US survey found that individuals of White ethnicity were significantly more likely than individuals from other ethnic groups to express interest in several types of personal pharmacogenomic testing (Haga et al. 2012). There is also some evidence to suggest that Hispanic populations perceive there to be more disadvantages of genetic testing than African Americans and Whites, and that both Hispanics and African Americans are more concerned about the potential for genetic testing abuses than Whites (Thompson et al. 2003). It is important to elucidate levels of willingness to receive personalized genomic information among individuals from different racial and ethnic groups so that existing health disparities are not further exacerbated due to unequal uptake of disease risk information that could potentially be health protective. Relatedly, it is important to consider underrepresented patient perspectives on the currently vigorously debated specific issue of whether personal results from genomics research should be returned to research participants (Beskow and Burke 2010; Wallace and Kent 2011; Kollek and Petersen 2011; Fullerton et al. 2012; Clayton and McGuire 2012; Dressler 2012). On the one hand, offering individual results could lead to stronger communication between participants and researchers which may lead to greater satisfaction (O'Daniel and Haga 2011), more health involvement, and more support of research. On the other hand, offering to return individual results poses significant pragmatic challenges regarding timeliness and resource allocation, and disclosing results could create an unclear line between medical practice and clinical research (Meltzer 2006).

A handful of studies addressing interest in receiving personal results specifically from genomics research in diverse populations using a focus group methodological approach have recently been conducted (Bollinger et al. 2012; O'Daniel and Haga 2011). One of these studies suggested that individuals from diverse backgrounds seem interested in receiving personal results from genomics research (Bollinger et al. 2012). Additionally, a large online survey of US adults suggested that providing individual research results is a strong motivation to individuals to participate in genomics research, and that there were few differences among demographic groups (Kaufman et al. 2008). These studies suggest that there is public support for returning personal results from genomics research to participants, and that individuals may be more likely to participate in genomics research if they receive personal genomic information through their participation; they also provide some data suggesting that there are few differences between racial or ethnic groups.

However, individuals who are prepared to attend focus groups about genomics research may be relatively homogeneous and more likely to respond positively to questions about participating in genomics research than others, while respondents to online surveys by definition have access to the internet, and have literacy levels that enable them to read and interpret an online survey. In addition, only two studies have assessed interest in receiving personal genomic information about obesity among obese adults (Segal et al. 2007a), and among parents of obese children (Segal et al. 2007b), both of which were focus group studies. Research is needed that addresses interest in receiving personal results from genomics research regarding complex conditions such as obesity and related diseases, among racially and ethnically diverse individuals from underprivileged backgrounds, using methodologies (e.g., structured interviews) that do not put literacy demands on the individuals.

Factors associated with desire for personal results from genomics research have been under-explored. Empirical research in the clinical genetics realm has suggested that cognitive factors such as perceived threat of disease are important predictors of uptake of genetic test results for diseases like hereditary breast cancer and colon cancer among high risk populations (Lerman et al. 1994, 1995; Jacobsen et al. 1997; Croyle and Lerman 1993; Bratt et al. 2000; Cameron et al. 2009). Genetic causal beliefs have also been found to be a possible predictor of interest in personal genomic information (Segal et al. 2007a). There is theoretical support from models of health behavior that support both of these cognitions being potentially important predictors of interest in receiving personal results from genomics research (Rogers 1983; Leventhal et al. 1997, 2001). However, to our knowledge, no studies to date have examined whether key emotions and cognitions such as perceived threat of disease and genetic causal beliefs about disease are associated with interest in receiving personal results from genomics research.

In addition to perceptions of threat and causal beliefs, it is important to consider whether understanding of genomics, or genomic literacy, is associated with willingness to receive personalized genomic information, given how central this could be to ensuring that people make informed decisions. One early study found no association between perceived understanding of genetics and interest in learning about personal genetic risk of cancer from genetic testing (Andrykowski et al. 1996). More recently, in a study with 105 women at increased risk of breast cancer, understanding of test results was not associated with interest in genetic testing overall, but there was an association with willingness to pay for genetic testing: willingness to pay was positively associated with cancer worry and inversely associated with understanding of test results (Graves et al. 2011). The association between interest in personalized genomic information and objective or perceived understanding of genomics warrants further investigation.

In summary, research examining willingness to participate in genomics research about complex diseases, as well as

reasons for and against that willingness, and desire for personal results from the research, among underrepresented minorities is needed. Obesity rates are higher among Hispanics and African Americans than Whites (Flegal et al. 2010), and it is therefore particularly important that underrepresented minorities participate in research on obesity and obesity-related diseases such as type 2 diabetes, heart disease, and cancer (Bray 2004). Complex diseases such as obesity, heart disease, type 2 diabetes and cancers are all also conditions that are at least potentially "medically actionable" (e.g., a medical intervention is available), and recent reports from key professional stakeholders such as institutional review board (IRB) professionals favor the return of individual results from genomic research that are medically actionable (Dressler et al. 2012). Having a better understanding of how underserved populations such as low-income Hispanic and African American communities view genomics research into these complex conditions, and their attitudes towards receiving personal genomic results from that research, would therefore be valuable and help to shed light on potential barriers and facilitators regarding their involvement in and desire for personal results from genomics research. This should aid efforts to address the barriers or concerns about participating on the one hand, and possibly misconceptions about the potential benefits on the other.

In the present study, our overarching goal was to examine willingness to participate in genomics research on four complex conditions (obesity, cancer, heart disease and type 2 diabetes) among a sample of underrepresented minority patients, including their reasons for or against that willingness, and their desire for personal results from it. We also took advantage of the fact that this study was conducted in a medical school setting in which many of the patients have previously been approached to participate in a DNA biobank (Streicher et al. 2011): as a secondary aim, we therefore explored whether there were differences in attitudes between DNA biobank participants and non-participants so that we could examine how representative the views of the DNA biobank participants were of the population from which they were drawn. We have previously published the results of our focus groups with participants of this DNA biobank, who were primarily Hispanic and African American, and found that the reasons expressed for participation were similar to those previously reported in primarily White biobank participants, particularly altruism and an expectation of personal health benefit (Streicher et al. 2011). As noted by others, quantitative data on this topic would be useful to complement the previous qualitative studies that have been conducted (Bollinger et al. 2012). Our aims in the present study were therefore as follows:

Aim 1 To explore levels of willingness to participate in genomics research about four complex diseases (obesity, heart disease, type 2 diabetes, cancer) that are medically actionable and prevalent among a primarily low-income, Hispanic, African American, and White outpatient clinic population. We hypothesized that African American and Hispanic patients would be less willing than White patients to participate in the genomics research.

Aim 2 To explore the reasons people gave for their willingness or lack of willingness to participate in genomics research into complex diseases, and whether mistrust emerged as a dominant theme in the reasons given.

Aim 3 To test the hypothesis that people would be more willing to participate in genomics research into complex diseases generally if personal results were offered than if they were not offered, and to examine desire for specific personal results from genomics research regarding four complex diseases, within this patient population.

Aim 4 To explore measured demographic and psychosocial factors associated with (a) willingness to participate in, and (b) desire for personal results from, genomics research into four complex diseases.

Materials and methods

Study design

This was a structured interview study conducted with patients attending an outpatient clinic at a hospital in New York City (NYC). The study was part of the ENGAGE Project (Evaluating information Needs to Generate Community Engagement and Genetics Education) which was supported by The Charles Bronfman Institute of Personalized Medicine. The study was reviewed and approved by the Icahn School of Medicine at Mount Sinai IRB.

Participants and recruitment

Participants for this study were recruited from the Internal Medicine Associates (IMA) at Mount Sinai Medical Center in NYC between June and September, 2010. The majority of patients at the IMA clinic 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. Patients were eligible for this study if they spoke English and were 18 years of age or older. Interviews were conducted in a private room at the clinic. Fifty-three percent of eligible approached patients agreed to participate. We have previously described in detail the study population, including

demographic characteristics and disease causal beliefs, in this sample of patients elsewhere (Sanderson et al. 2013).

Measures

Interview items comprised closed- and open-ended questions which were either adapted from published instruments or developed for this study based on focus groups conducted with patients from the same hospital population (Streicher et al. 2011).

Demographic characteristics

Measures included age, gender, race/ethnicity, household income, education level and number of children. Age was assessed with an open-ended question and subsequently categorized into 18–40 years/41–50 year/51–59 years/60–85 years.

Family and personal history of disease

Family history of disease was assessed with four questions asking participants how many living and deceased close blood relatives had ever been told by a health professional that they had obesity/heart disease/type 2 diabetes/cancer. Personal history of disease was assessed by asking participants whether a health professional had ever told them they had each of the four conditions, and self-reported weight status was assessed by asking participants which of four categories best described their weight (see Sanderson et al. 2013 for more details).

Disease-specific worry (Perceived threat)

Worry about disease was assessed with four questions: "How worried are you about heart disease [type 2 diabetes/cancer/obesity]?" Response options were categorized as: very worried ("extremely"/"a great deal"), "moderately worried", and not very worried ("somewhat"/"not at all").

Genetic causal beliefs

Genetic causal beliefs were assessed by asking participants how much they thought each disease was inherited through a person's genes. Response options were dichotomized into "not at all/a little" vs. "some/a lot."

Subjective understanding of genomics and genetic testing

Understanding of genomics was assessed with: "How much do you feel you know about the relationship between human genes and health?" Response options were categorized into no understanding ("not at all"), some understanding ("not very much"/"a small amount") and a lot of understanding ("quite a lot"/"a great deal"). Understanding of genetic testing was assessed with a single item ("You have a clear picture of what genetic testing is") adapted from previous research (Sanderson et al. 2005; Sanderson and Wardle 2008).

Biobank participation

Participants were asked "Have you previously been asked to participate in The Mount Sinai Biobank or other genetic research projects?" and "Did you participate in The Mount Sinai Biobank?" In addition, names of participants in the present study (which were kept separate to their questionnaire data) were checked against the full list of biobank participants, by names being securely e-mailed to the biobank coordinator. Using this approach, we confirmed biobank participation and date of recruitment into the biobank.

Willingness to participate in genomics research and reasons for or against willingness

Respondents were told the following: "Imagine you have been invited to take part in a genetics research study. The study is looking at genetic risk factors for diseases like heart disease, type 2 diabetes, cancer, and obesity. As part of the study, you are asked to provide one blood sample for laboratory tests and to fill out questionnaires on your health, diet and lifestyle." Initial interest in participating in the genomics research was measured with the following item: "Would you want to participate in this genetic research study?" ("No, definitely not"/"No, probably not"/"Yes, probably"/"Yes, definitely"). Depending on their answer to the previous question, they were then asked: "In your own words, can you tell me why you would not/would want to participate in the genetic research study?"

Next, a genomics research scenario where personal genomic results were not returned to the patients was presented: "Now please imagine that as part of the informed consent process you've been told that you will not get back any personal genetic information from the study". The respondent was then asked "Would you want to participate in this genetics research study?"

The third genomics research scenario was introduced with, "Now please imagine that as part of the informed consent process you've been told that you will get back personal genetic information from the study." Respondents were then asked "Would you want to participate in this genetics research study?" Response options for all three questions were "No, definitely not"/"No, probably not"/"Yes, probably"/"Yes, definitely".

Desire for personal results from genomics research

The desire for personal results questions were preceded by: "Now please imagine that you have taken part in this genetics

research study, and you are told that you can find out your personal genetic results if you want them. These genetic results can give some information about your future risk of developing each disease, but they can't tell you definitely whether you will or will not get the disease." Respondents were then asked, "Would you want to find out your personal genetic risk results for heart disease/type 2 diabetes/cancer/obesity?" Response options were: "No, definitely not"/"No, probably not"/"Yes, probably"/"Yes, definitely".

Analyses

For the main statistical analyses, willingness and interest were dichotomized into *yes* ("yes probably"/"yes definitely") vs. *no* ("no definitely not"/"no probably not"). Chi-squared (χ^2) tests were used to examine associations between participant characteristics and willingness and interest. p values of less than 0.05 were considered significant. All statistical analyses were performed using IBM SPSS Statistics v.19. To assess the open-ended questions on reasons for being willing or not willing to participate in a genomics research study, we used thematic analysis. In brief, the answers to the open-ended questions were all read, manually coded, and organized according to content into categories and themes independently by two of the study investigators (SCS and MZ). The two codebooks were then compared to each other and any differences were identified. Coding was discussed and reconciled between the investigators, and a revised codebook was developed.

Results

Background characteristics

Nearly half of the participants were Non-Hispanic Black, and over a quarter were Hispanic. Ages ranged from 22 to 85 years; 69 % were female; nearly half had an annual household income of less than $20,000; 18 % had a Bachelors or advanced degree. A third of participants reported that they had been diagnosed with type 2 diabetes, 29 % obesity, 19 % heart disease, and 6 % cancer. When these responses were summed, 62 (30 %) participants reported having none of the four diseases, 53 (26 %) reported having one of the diseases, 31 (15 %) reported having two of the diseases, and 6 (3 %) reported having three of these diseases. None of the participants reported having all four of the diseases. Nearly two thirds self-identified as being overweight or obese. Fifty-eight percent of respondents reported having at least one family member who had been diagnosed with cancer, 62 % with heart disease, 66 % with type 2 diabetes, and 42 % with obesity. When these responses were summed, 20 (10 %) individuals reported that they did not have any family members with any of the four diseases, 30 (15 %) reported that one of these diseases occurred in one or more of their family members, 55 (28 %) that two of these diseases occurred in one or more of their family members, 62 (31 %) that three of these diseases occurred in one or more of their family members, and 31 (16 %) that all four diseases occurred in one or more of their family members. One hundred and fifty one (74 %) participants reported having at least one child. As Table 1 shows, over half (56 %) of the participants in the present survey were confirmed as having participated, although only 32 % self-reported that they had participated, in The Mount Sinai Biobank. Of the individuals who self-reported being biobank participants, the majority (91 %) were also confirmed as being in the biobank. However, of those who said they had not participated in the biobank, over a third (39 %) were subsequently identified as actually having participated in the biobank.

Willingness to participate in genomics research

As Fig. 1 shows, when asked about participating in a hypothetical genomics research study with no mention of personal results being or not being returned, 82 % initially responded yes definitely/probably (mean=3.10, SD=0.78). When it was specifically indicated that personal results would *not* be offered, 62 % responded yes definitely/probably (mean=2.66, SD=1.03); when it was indicated that personal results *would* be offered, 89 % responded yes definitely/probably (mean=3.38, SD=0.77). See Table 2 for detailed breakdown of responses.

Non-parametric Wilcoxon Signed Ranks Tests were used to compare the mean scores for willingness to participate in genomics research under the three different scenarios. Participants were less willing to participate in genomics research when it was specified that personal results would not be returned than when there was no mention of personal results (2.66 vs. 3.10, respectively: $Z=-6.20$, $p<0.001$). They were more willing to participate in genomics research when it was specified that personal results would be returned than when there was no mention of personal results (3.38 vs. 3.10: $Z=-5.16$, $p<0.001$). And they were more willing to participate in genomics research when it was specified that they would receive personal results than when it was specified that they would not receive personal results (3.38 vs. 2.66: $Z=-8.12$, $p<0.001$).

We examined associations between the characteristics assessed (age, gender, race/ethnicity, children, annual household income, educational attainment, overall family history of disease, personal diagnosis of disease, disease-specific worry, genetic causal beliefs, understanding of genomics, understanding of genetic testing, self-reported and confirmed biobank participation) and interest in participating in genomics research (a) in general, (b) if personal results were not offered, and (c) if personal results were offered.

Table 1 Self-reported and confirmed participation in The Charles Bronfman Institute of Personalized Medicine Biobank, Icahn School of Medicine at Mount Sinai, among 205 outpatients at Mount Sinai Hospital in New York City, June to Sept 2010

	Confirmed biobank participant					
	No		Yes		Total	
	N	%	*N*	%	*N*	%
Self-reported biobank participant						
No	83	60.6	54	39.4	137	67.2
Unsure/no answer	0	0.0	2	1.0	2	0.5
Yes	6	9.1	60	90.9	66	32.4
Total	89	43.8	114	56.2	205	100.0

There were no associations with age, gender, race/ethnicity, children, annual household income, educational attainment, personal diagnosis of disease, or understanding. *Interest in participating in genomics research in general* was positively associated with overall family history of disease (p=0.045); worry about obesity (p=0.022); genetic causal beliefs about heart disease (p=0.001); and genetic causal beliefs about obesity (p=0.036) (see Supplemental Table 1). *Interest in participating in genomics research if personal results were not offered* was associated only with confirmed participation in the biobank: 69 % of participants who had previously participated in the biobank were interested compared with only 54 % of participants who had not participated in the biobank (p=0.035) (see Supplemental Table 2). *Interest in participating in genomics research if personal results were offered* was positively associated only with worry about obesity (p=0.015), and genetic causal beliefs about heart disease (p=0.004) (see Supplemental Table 3).

Reasons for being willing to participate in genomics research

When the 167 participants who had said that they would be willing to participate in genomics research were asked an open-ended question about why they were interested, four broad overarching themes emerged: (1) to help others outside of the family (altruism); (2) to help family members; (3) for personal health benefit; and (4) for personal curiosity and improved understanding (see Table 3).

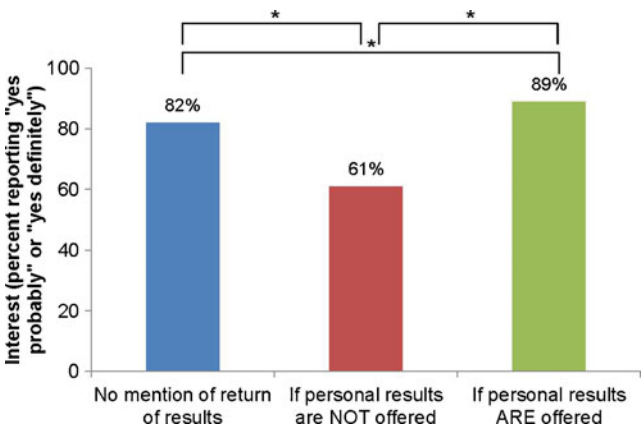

Fig. 1 Willingness to participate in genomics research in which personalized genomic information (PGI) is not mentioned, is not offered, or is offered (*p<0.001)

To help others outside of the family (altruism) Many participants stated that they would be willing to participate in genomics research "to help" others, whether to help science and research (e.g., "To help science," "The idea is you're doing research… Though it's one dimensional if you can get something to work with that would be great"); to help society (e.g., "To learn more about it and get a better understanding for society and improve health"), to help the public understand disease and risk (e.g., "Really help public to understand diseases," "Because genetics can help people be aware of risks"), to help future generations (e.g., "Future research for next generations," "So that I can find out about these diseases and hopefully it can help society, and future generations, so that they don't go through what I'm going through"), to help others in general (e.g., "To help somebody else," "Help others," "So that it can be helpful to others and to me"), or specifically to help their own community, country or race (e.g., "Want to know about own health or Puerto Rican peoples," "It would be helpful to mass population, helpful to my race," "To help the community with better health outlook," "To get a better understanding how to prevent major diseases in America," and "…Anything that would help the community in whatever I can participate in that would better my life and other patients.")

To help family members Several individuals stated that they would be willing to participate in genomics research because it might help their family, and to a lesser extent their friends. For example, one individual stated, "To help my nieces and nephews and maybe it could help them so they don't have to go through what I'm going through," while another stated, "Because I want to know what I can pass on to my children and grandchildren," and another said, "Because you never know what you could be doing for people. It could help me and it could help others, my family, my kids."

Table 2 Willingness to participate in genomics research under three different conditions among 205 outpatients at Mount Sinai Hospital in New York City, June to Sept 2010

	Participant response options							
	No definitely not		No probably not		Yes probably		Yes definitely	
	N	%	*N*	%	*N*	%	*N*	%
Condition								
No mention of return of results[a]	8	3.9	28	13.7	102	49.8	65	31.7
No personal genomic information provided	38	18.5	37	18.0	81	39.5	44	21.5
Personal genomic information provided[b]	7	3.4	15	7.3	75	36.6	106	51.7

[a] Two individuals responded "don't know" or chose not to answer

[b] Five individuals responded "don't know" or chose to answer

For personal health benefit Many participants gave reasons that indicated that they felt that participating in genomics research would lead to personal health benefit. There were several subthemes here. Some individuals stated that they would be willing to participate because they had a family history of disease (e.g., "Because I have a lot of illnesses in my family"), and some because they had a specific disease themselves (e.g., "I want to get rid of diabetes; my mother and I, out of eight children, have diabetes"). Several individuals felt that participating would help them learn about their own health (e.g., "To better my health," "To gain more knowledge about own health," and "To learn more about one's health"), several felt that it would help them learn about their body (e.g., "It would help me learn more about my body," "I would like to know what's going on with my body"), and several felt that it would help them find out "what's wrong" with them (e.g., "To find out what's wrong," "I would like to find out if anything is genetically wrong with me especially since half my illnesses I don't understand why I have them"). A number of individuals were willing to participate because they believed that it would help them find out what they were at risk of (e.g., "To see if I'm at high risk for any of those diseases"), and for personal prevention of disease (e.g., "To find out if I'm at a high risk of certain diseases and if they can prevent it before something happens"). One person focused primarily on learning about their genes, stating, "To find out what is in your genes. I would like to find out about my genetics. I like to find out anything that I have."

Several individuals were primarily concerned about their health in terms of their weight. For example, one individual said, "I want to know why I am clinically obese when I do everything right (eat and exercise) and I am not diabetic. I want to know why I am unable to lose weight." Another said, "Concerned about weight," while another said, "The diseases that are mentioned runs in my family. I'm obese and want to know how serious my case is since I do believe it's genetic. I just want to be safe." There was also a general, more non-specific sense that it could be personally beneficial expressed, e.g., "If I'm going to benefit from it I don't mind," and "Because it can only help me, no downside." One individual said that keeping them busy would be a reason

Table 3 Reasons for willingness and lack of willingness to participate in genomics research among 205 outpatients at Mount Sinai Hospital in New York City, June to Sept 2010

	Theme	Example quote
Reasons for being willing to take part in genomics research (*N*=167)	1. To help others outside the family (altruism)	"It would be helpful to mass population, helpful to my race"
	2. To help family members	"To help my nieces and nephews and maybe it could help them so they don't have to go through what I'm going through"
	3. For personal health benefit	"To find out if I'm at a high risk of certain diseases and if they can prevent it before something happens"
	4. For personal curiosity and improved understanding	"I've always been interested in genetics and would want to be part of the study to learn more"
Reasons for being unwilling to take part in genomics research (*N*=36)	1. Negative perception of research	"I'm not a lab rat"
	2. Not personally relevant	"I'm just not interested. I feel like it doesn't pertain to me"
	3. Negative feelings about research procedures	"Because I am scared of getting my blood drawn"
	4. Practical barriers	"Because I have two kids at home and I can't… because they are, have to be back and forth, don't have time to participate"
	5. Fear of personal results	"Scared to know"

for participating, "Because my health problem is so bad now, I want to know as much information as I can get. I also want to do it to keep busy."

For personal curiosity and improved understanding Finally, a dominant theme that emerged was that people would be willing to participate in genomics research out of general curiosity and to help them learn more about genomics. Specifically, participants were willing to participate because they felt that it would help them to learn how diseases are inherited (e.g., "I want to know more about how diseases are passed down from parents to children"), to learn about genomics (e.g., "I've always been interested in genetics and would want to be part of the study to learn more," "I want to know a little bit about genetics because I don't understand it exactly"), to learn about specific diseases (e.g., "To learn more about type 2 diabetes"), and for general education (e.g., "For general information," "I just want to know what's going on"). A general curiosity was also expressed (e.g., "I feel that I'm curious to know more"), as was a general interest (e.g., "It will be interesting"), and "To learn more about the study."

Reasons for not being willing to participate in genomics research

When the 36 participants who had said that they would not be willing to participate in genomics research were asked in an open-ended question to state their reasons, five overarching themes emerged: (1) negative perception of research; (2) not personally relevant; (3) negative feelings about research procedures; (4) practical barriers; and (5) fear of personal results (see Table 3).

Negative perception of research Almost a third of the 36 participants' responses indicated that they had negative perceptions of research, the majority of whom indicated that they had a fear of being studied, e.g., "I don't want to be a guinea pig," "I'm not a lab rat," "Don't want to be part of experiments, after effects," "Not too for being the test object in a study," and "Don't want to be studied." One individual stated, "I just prefer not to for personal reasons. I don't want to have my blood involved." One individual believed that the research wouldn't help, stating, "Just don't want to… Know they won't find anything." One participant's response suggested that they did have a concern about lack of privacy, stating, "Don't care too much about research. Once information out, it goes all over." One individual said, "I don't know, maybe it's boring."

Not personally relevant Several participants' responses indicated that they would not want to take part in genomics research because they did not see it as being personally relevant to them, e.g., one individual stated, "I'm just not interested. I feel like it doesn't pertain to me." Here, two individuals stated that they didn't have the "problems" being studied ("Don't think I have those problems" and "Problems don't refer to those tests"), while two other individuals referred to their family history as a reason for not being interested ("Don't have family history" and "Know a lot about family history"). There was also a belief stated by two individuals that they were not at risk because they had good existing health behaviors ("I don't think I'm at risk, I think I eat pretty good" and "I have and do enough to see if I'm healthy or not").

Negative feelings about research procedures A number of individuals specifically referred to having negative feelings about a blood draw as their reason for not wanting to participate, e.g., "Scared of needles," "I am not a good candidate for my blood to be drawn, I'm a hard stick, doctors take blood from my thumb or toes," "Because I am scared of getting my blood drawn," and "Afraid of needles." One individual had negative feelings about being physically examined, stating, "Because I don't like nobody poking on me," and one individual had negative feelings about reading and writing, as well as the blood draw: "Don't like drawing blood, reading, writing questionnaires."

Practical barriers Practical barriers were also mentioned. Part of this was lack of time, and family responsibilities: "Sometimes it's that time. I work and am busy, things to do at home and take care of my mother," "Because I have two kids at home and I can't… because they are, have to be back and forth, don't have time to participate," Inconvenient," "Time factor…" and "Don't know. I might be busy." One individual cited physical difficulties, "Other problems, tough to get around," and one individual cited a pre-existing burden of healthcare or research as a reason for not getting involved in more research, "Take blood every two weeks, don't want more."

Fear of personal results One participant stated their reason for not wanting to participate in the genomics research as "Scared to know."

Interest in receiving personal results from genomics research

When asked whether they would be interested in receiving personal genomic risk results for four complex diseases, 68 % of participants responded "yes, definitely" for heart disease (mean=3.53, SD=0.81), 67 % for type 2 diabetes (mean=3.54, SD=0.79), 70 % for cancer (mean=3.53, SD=0.86), and 61 % for obesity (mean=3.31, SD=1.03) (see Table 4).

In Wilcoxon Signed Ranks tests, participants were significantly less interested in receiving personal results about obesity than about any of the other three diseases: interest was significantly lower for personal genomic information for

Table 4 Interest in receiving personal genomic information about risk of four complex diseases among 205 outpatients at Mount Sinai Hospital in New York City, June to Sept 2010

	Participant response options							
	No definitely not		No probably not		Yes probably		Yes definitely	
	N	%	*N*	%	*N*	%	*N*	%
Heart disease[a]	10	4.9	11	5.4	44	21.5	139	67.8
Type 2 diabetes[a]	10	4.9	8	3.9	48	23.4	138	67.3
Cancer[a]	14	6.8	7	3.4	40	19.5	143	69.8
Obesity[a]	23	11.2	16	7.8	40	19.5	124	60.5

[a] One individual responded "don't know" or chose not to answer

obesity than for heart disease (2.78 vs. 2.85, respectively: $Z=-3.92$, $p<0.001$), cancer (2.78 vs. 3.10: $Z=-3.99$, $p<0.001$) and type 2 diabetes (2.78 vs. 3.01: $Z=-4.09$, $p<0.001$). None of the differences between interest in genomic information about cancer, heart disease and type 2 diabetes were significant (all $p>0.80$). See Fig. 2.

There were very few associations between the characteristics assessed and interest in receiving personal results regarding any of the four diseases. The only factor that emerged as consistently associated with interest in receiving personal genomic risk results was disease-specific worry: for all four diseases, disease-specific worry was significantly higher among those who were interested in receiving personal results than those who were not interested (all $p<0.05$). There were only two other significant associations: participants who had a personal diagnosis of obesity were more likely to be interested in receiving personal obesity genomic risk results from genomics research than those who had not been told they were obese by a healthcare professional ($p=0.004$), and individuals over 60 years of age were less interested in receiving personal type 2 diabetes results from genomics research than younger adults ($p=0.006$). See Supplemental Tables 4–7.

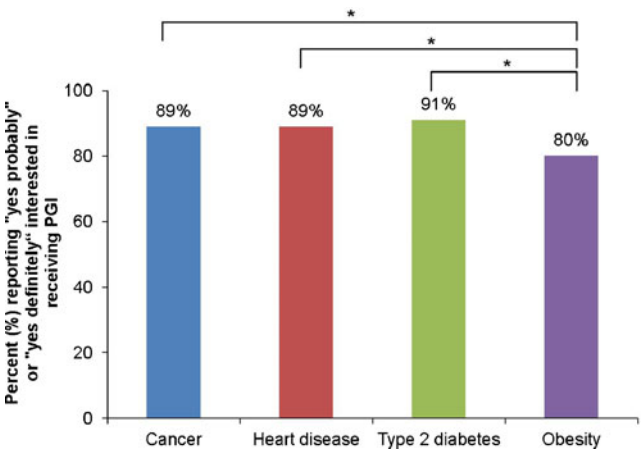

Fig. 2 Interest in receiving personalized genomic information about four complex diseases (*$p<0.001$)

Discussion

In this study, we examined willingness to participate in genomics research on complex diseases (obesity, heart disease, cancer, and type 2 diabetes) among an underrepresented patient population of predominately low-income Hispanic and African American as well as non-Hispanic White clinic outpatients. We also assessed patients' reasons for or against being willing to participate in the genomics research, their desire for personal results from the research, and what demographic and psychosocial characteristics were associated with willingness to participate and desire for personal results.

We found that the majority (82 %) of participants stated that they would be willing to participate in genomics research on the four complex diseases when there was no mention of whether or not personal results would be returned, that this willingness to participate in the genomics research did not differ between Hispanic, African American and White patients, and that distrust did not emerge as a dominant theme among these patients. This differs from the findings of previous research in which non-Hispanic Whites were significantly more likely than ethnic minorities to enroll in a biobank (Ridgeway et al. 2013), and African Americans have expressed significant distrust when discussing biobank participation (Halverson and Ross 2012). This could perhaps be due to the setting of the present study: participants for the present interviews were recruited from a hospital outpatient clinic which accepts patients with no insurance, Medicaid and self co-pay as well as those with insurance. It is possible that patients here regardless of their race or ethnic background have greater trust in their medical institution, the doctors and the research affiliated with the institution because of the healthcare service being provided to them. Some support for this suggestion can be found in the reasons people gave for their being willing or unwilling to participate in the hypothetical genomics research study presented to them. Although the main reason stated for lack of willingness to participate was having a negative perception of research, including not wanting to be a "lab rat" or "guinea pig", this was mentioned by only a small proportion of the participants in absolute terms, and there was little evidence

of distrust beyond this. Additional reasons people gave for not wanting to participate in genomics research echo concerns raised in previous research, including lack of time (Levickis et al. 2013), the research not appearing to be personally relevant to them (Levickis et al. 2013), negative feelings about research procedures such as blood draws (Misiewicz and Winawer 2012) and practical barriers (Ejiogu et al. 2011; Farmer et al. 2007; Kagawa-Singer 2000). Interestingly, there was little evidence of fear of results or implications for insurance, employment or privacy being a potential barrier to participation in genomics research: only one person stated that their reason for being unwilling to participate in genomics research was that they would be "scared to know," and only one person's reason for being unwilling appeared to be linked to concern about the potential for loss of privacy, saying "once information is out, it goes out all over." We speculate that this may perhaps be due to low awareness of the possible implications for insurance and employment (Dorsey et al. 2012), low relevance of these issues given the low income of many of these patients, or low awareness of the current evidence indicating the inherent impossibility of guaranteeing privacy of personal genomic information once donated to genomics research (McEwen et al. 2013; Gymrek et al. 2013). Alternatively, it could reflect a genuine lack of fear or concern regarding these issues.

The majority of people in this study were enthusiastic about participating in genomics research, and the reasons people gave for being willing to participate in genomics research fell into four main overarching themes: to help others outside the family (altruism); to help family members; for personal health benefit; and for personal curiosity and improved understanding. The altruistic motivation has been previously reported (e.g., Lemke et al. 2010), as has the expectation of personal benefit (Nobile et al. 2013). To some extent, our findings provide some evidence of the "therapeutic misconception" (Nobile et al. 2013) in that some of the reasons people provided for participating in genomics reason suggested that they assumed that they would receive specific personal results through their participation, e.g., "To see if I'm at high risk for any of those diseases". However, our findings also suggest that people anticipated that they could personally benefit in a different way: by gaining knowledge more generally. People reported that participating could help them learn more about genomics, inheritance and "how diseases are passed down from parents to children," as well as gain more information about specific diseases such as type 2 diabetes, and that they could gain "general information" and "learn more about the study." This is important because the results highlight that people's perceptions of personal gain through research participation do not always hinge on a misconception about receiving personal results. Rather, they also support the value of other ways in which researchers can "give back" to research participants, such as through providing participants with regular, generic newsletters about the research study, its progress and other relevant aspects such as information about disease, disease prevention and genomics more generally.

Our finding that 89 % of participants were willing to participate in the genomics research study if some personal results were offered, compared to 61 % when personal results were not offered, could perhaps suggest that genomics research involving traditionally underrepresented communities may benefit from offering personal results to potential participants. One possible explanation for this difference though is that it was "created" by the research design: the three hypothetical scenarios were presented in the same order to all participants (no mention of results first, specified that results would not be returned second, and specified that results would be returned third), and to be truly convincing the order would need to be randomly varied between participants to ensure that the results are not the outcome of an "order effect." On the other hand, our findings are consistent with two recent surveys utilizing hypothetical scenarios in other populations which have similarly shown that people are more willing to participate in genomics studies when individual test results have been offered than when results have not been offered, providing some support for the assertion that our findings are not a mere artifact of the study design (O'Daniel and Haga 2011; Kaufman et al. 2008).

We found inconsistent associations between willingness to participate in genomics research and the variables assessed. Interestingly, the only factor significantly associated with willingness to participate in genomics research without personal results being returned was confirmed participation in the biobank: we found that individuals who were confirmed as being biobank participants were significantly more likely to say that they would participate in genomics research without personal results being offered than individuals confirmed as not being in the biobank, which tentatively lends some face validity to our findings. As an aside, over a third of participants who were identified as having participated in the biobank stated that they had not participated in the biobank. This discrepancy suggests that a significant proportion of people who have donated samples to biobanks may not realize or recall that they have done so, which may be relevant to future discussions around the informed consent and the privacy or lack thereof of participants in biobanks and other genomics research.

Our study builds on previous research by examining participants' interest in personalized genomic information by disease type: our study is the first to address interest in personal results for several common complex conditions, specifically obesity, heart disease, type 2 diabetes, and cancer, simultaneously. Our finding that at least 80 % of participants were interested in genomic information regardless of disease type suggests that people will be interested in genomic susceptibility information regardless of exactly what type of disease the genomic information pertains to, at least in the domain of personal susceptibility to common, chronic conditions. Critically, although two

focus group studies have previously assessed interest in genetic testing for obesity among obese adults (Segal et al. 2007a), and among parents of obese children (Segal et al. 2007b), ours is the first to assess public interest in receiving personal results about genomic susceptibility to obesity and to compare that interest to other, related diseases using quantitative methods in a larger, more representative, patient population. Our finding that participants were significantly less interested in receiving personal genomic information about obesity than about cancer, heart disease or type 2 diabetes was novel. It is not immediately obvious what influenced this difference. One possibility is that participants are less interested in genomic risk information about visible traits than non-visible diseases: at least at the extremes, it is usually possible to tell whether a person is obese simply by looking at them and one does not need a genomic or any other kind of test to shed light on this; in contrast, people arguably have less information about their susceptibility to diseases such as heart disease, although they do of course have other personal risk information available to them such as family history, blood pressure, and cholesterol levels. The lack of apparent differences between cancer and heart disease in the present study differs from the results of a large survey in the UK in which participants were found to be significantly more interested in receiving personal genomic results about heart disease than cancer (Sanderson et al. 2004). It is possible that this discrepancy is due to differences in the study populations, or to differences in question framing, but the issue warrants further investigation.

We found that disease-specific worry was the only variable that was consistently related to whether or not participants wanted to receive disease-specific personal genomic results in our sample. This was despite the finding that there were no associations with personal or family history of disease. Previous research has suggested that perceived risk and family history are important determinants of interest in genetic testing for cancer (Croyle and Lerman 1993), which is consistent with data indicating that perceived vulnerability is a key motivator in cancer prevention behaviors more broadly (Lerman et al. 1989; Lerman et al. 1990). Our results suggest that worry about disease is more salient to people when considering receiving personal genomic results than the more "concrete" measures of personal or family history.

Associations between genetic causal beliefs and reactions to personal genetic test results have previously been explored (Cameron et al. 2009; Decruyenaere et al. 2000; Marteau and Weinman 2006), but with the exception of one focus group study examining interest in genetic testing for obesity among obese adults (Segal et al. 2007a), the present study is the first that we are aware of to examine the association between genetic causal beliefs and interest in personal genomic information upstream in the genomic feedback process in an unselected patient population. We previously reported that the majority of participants in this study believed that genetics influences all four diseases "some" to "a lot" (Sanderson et al. 2013). In the present analyses, we found that genetic causal beliefs did not affect interest in receiving personal results. This is in contrast to our expectation that participants who attribute complex diseases to genetic factors would report finding more value in receiving personal genomic results, and are also in contrast to the findings of Segal et al. (2007a). The relationship between genetic causal beliefs and interest in personal genomic information warrant further investigation.

There were some limitations to this study. Most notably, the recruitment of only English-speaking participants limited the enrollment of otherwise eligible Hispanic patients and so the views of the included participants may not accurately reflect others' views in the Hispanic population. Additionally, because of the structure of the survey, we did not provide extensive information about genomics. It will be interesting to explore patients' interest in receiving personal results from genomics research before vs. after they have been provided with more complete information about genomics (e.g., the current limitations of personal genomics). However, the limitations should be weighed against the strengths, which include that the sample comprised primarily underrepresented minorities, and that desire for personal genomic information regarding obesity which is prevalent in the population generally and in underrepresented minorities specifically, as well as desire for personal genomic information regarding three obesity-related diseases, were assessed simultaneously.

In conclusion, willingness to participate in genomics research on complex diseases was high in this underrepresented patient population of primarily low-income African American, Hispanic, and White patients. Distrust did not emerge as a dominant theme; rather, patients saw many advantages to participating in genomics research, both altruistic and personal. Personal motivators for participation included but were not limited to a "therapeutic misconception," and people expressed many other ways in which they and their communities might benefit through their research participation including learning about genomics and about diseases relevant to them personally. Receiving personal results from genomics research was appealing to this underrepresented minority population, as to other populations. Where time and resources allow, the return of results may be valuable both as a service to research participants and perhaps also to allow additional research exploring the downstream cognitive, emotional, behavioral and health impact of those results on the research participants. When returning results is not practical, or even when it is, alternatively or additionally providing generic information about genomics and health in the form of a regular newsletter or website as part of the standard research protocol may also be a valuable commodity to underrepresented minority and other populations considering participating in genomics research into complex diseases.

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Compliance with Ethics Guidelines Saskia C. Sanderson, Michael A. Diefenbach, Randi Zinberg, Carol R. Horowitz, Margaret Smirnoff, Micol Zweig, Samantha Streicher, Ethylin Wang Jabs, and Lynne D. Richardson declare that they have no conflict of interest. All procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2000 (5). Informed consent was obtained from all patients for being included in the study.

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