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Biobank Participation and Returning Research Results: Perspectives from a Deliberative Engagement in South Side Chicago

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Abstract

To be respectful of the public, biobank guiding principles and operations should be responsive to and inclusive of the values and beliefs of their participants. In an effort to increase knowledge and inform institutional policies, we conducted a deliberative engagement of individuals from two healthcare facilities in South Side Chicago that serve different socioeconomic communities to consider biobank policies regarding return of research results. We recruited primary caregivers of children receiving care at either a Federally Qualified Health Center or a university-based practice to attend two full-day deliberative engagement sessions, which included four educational presentations followed by focus group discussions. Surveys were administered to assess attitudes before and after the engagement, and an evaluation was conducted to assess the deliberative engagement process. All 45 participants self-identified as African American. Focus group themes included: 1) overall interest in biobank participation, broad consent, and recontact; 2) root causes of distrust and potential biobank strategies to facilitate trust; 3) perceived positive and negative aspects of receiving research results; and 4) strong interest in receiving and managing their children's research results. Survey data indicated the same degree of interest in receiving results about themselves as about their children. Pre- and post-session findings showed mainly non-significant attitudinal changes in level of interest in biobank participation and return of research results, although there was a decrease in level of concern regarding identification from research data. Our findings reveal shared community insights important in facilitating relationships and policy discussions between biobank researchers and research participants.

Keywords

biobank; deliberative engagement; research results; research participant; ethics; policy; trust; return of results

INTRODUCTION

There is increasing public and scientific interest in the value and use of biobank data worldwide. Biobanks are collections of tissue samples, blood samples, genotypic data and/or phenotypic data. They may focus on specific diseases [Hilner et al., 2010], whole populations [McCarty et al., 2008], or exclusively on pediatric or parent-child enrollment [Gurwitz et al., 2009]. The number of samples is growing exponentially both in the U.S. and

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abroad with many large collaborations [McCarty et al., 2011] and international consortia [Riegman et al., 2010]. Biobank-based research is also evolving from a "one-sample research question" to one sample that can be stored indefinitely and used for multiple research questions – including some that are not known at the time of participant recruitment [O'Brien, 2009]. This phenomenon raises many research-ethics questions. For example, how does one adequately discuss the risks and benefits of contributing adult and pediatric samples and/or data to a biobank when the research questions are unknown? More specifically, how should informed consent and reconsent procedures, privacy protections, and return of aggregate and individual research results to research participants be addressed? It is not clear how well the broader public understands these complex issues, or what processes should be in place in order to engage and sustain communication with biobank participants.

These ethical and social issues are of actual and immediate importance, given the large number of biobanks that already exist and that are being developed worldwide. Nonetheless, many research-ethics questions, including whether to return research results, have not been resolved [Greely, 2007; Haga and Beskow, 2008]. There is also no consensus on what role the public should play in the development of biobank policy, although there is a growing movement to include the public as more co-equal partners in translational research [Dresser, 2001; Israel et al., 1998; Minkler and Wallerstein, 2008]. Furthermore, there is a lack of information about what minority and traditionally underrepresented groups think about questions raised by biobank policies, in particular, return of research results.

There are moral and pragmatic justifications to support both returning and not returning research results [Haga and Beskow, 2008; Ossorio, 2006; Ravitsky and Wilfond, 2006; Renegar et al., 2006]. Some argue that disclosure of research results should be avoided until there are enough studies to confirm their clinical utility and validity [Beskow, 2006; Schulte, 1991]; others argue that disclosure may lead to participants' undue anxiety or inappropriate reassurance [Clayton and Ross, 2006]. On the other hand, some maintain that respect for patient autonomy means that participants should be allowed to receive real-time information [Bookman et al., 2006; Knoppers et al., 2006; Ossorio, 2006]. From a pragmatic perspective, some argue that disclosure might keep participants interested and involved in the study and might ensure better and more accurate phenotypic data, while others maintain that the time and expense necessary for counseling would make biobanking too costly [Miller et al., 2008; Ravitsky and Wilfond, 2006].

In order to explore African Americans' views on returning research results, we employed a modified form of deliberative democracy, which we refer to as a "deliberative engagement." Deliberative democracy is a method of policy-making that relies on informing and consulting the public [Fishkin, 2009; Gutmann and Thompson, 1996; Gutmann, 2004]. Rather than simply seeking public "votes" or "raw opinions," this method views deliberation as central to ensuring that participants are informed and can discuss the specific policy questions. This process can be adapted to examine scientific policies, about which the public is often poorly informed, so that public participation can become meaningful, and to allow informed citizens to engage critically in discussion and policy [Kim et al., 2009; Schicktanz et al., 2011]. One effort to engage the public in deliberative democracy regarding biobanks was conducted in British Columbia [MacLean and Burgess, 2010]. Broad consensus was reached about the value of biobanks, and the need for oversight and for greater public education. There was disagreement about ownership of samples, the role of the community in governance, blanket consent, and who should decide when to return research results [O'Doherty and Burgess, 2009]. With a similar methodology, a "deliberative public forum" was utilized in Western Australia to inform individuals and to assess biobank participation, oversight, consent, and the type of feedback participants wanted to receive from the biobank

[Molster et al., 2011]. One of the limitations reported in this public deliberation was the lack of representation of ethnic minority communities among the participants. The authors recommended that new strategies be identified to recruit under-represented groups in these engagements.

We conducted four two-day, deliberative engagement programs involving African Americans whose children received clinical care in two urban healthcare facilities that served different socioeconomic communities to consider and debate biobank policies regarding the return of research results. In this article, we report on the four primary themes from our focus groups as well as the survey findings regarding biobank participation and return of research results.

MATERIALS AND METHODS

Design

Our deliberative engagement utilized four twenty-minute educational slide presentations in order to inform participants on key biobank issues. Each of the presentations was followed by four topic-matched focus group sessions to facilitate discussions. The overall process is depicted in Table I. Educational content presented on Day 1 Session A included types of biobanks, genetics, genetic conditions, and genetic research. During Session B informed consent, potential benefits and harms of biobank-based research, privacy and re-identification were presented. During Day 2 Session A, the education session content included potential benefits and risks of returning, and personally receiving, aggregate and individual research results for themselves. The last education session focused on these same issues with respect to their child's results. The educational slides are available upon request. Table II lists an outline of the focus group discussion guide topics. Attitudes and beliefs were assessed by surveys before and after the entire engagement in order to assess any changes in opinions and to measure the range of views held by participants. Copies of supplemental public genetics educational materials were made available on site at the end of Day 1 and Day 2. A brief survey to evaluate the process of deliberative engagement was also administered after each day of deliberation.

Participants and Recruitment

Participants eligible for our study were adult, English-speaking primary caregivers of pediatric patients receiving care from two healthcare facilities serving different socioeconomic communities in South Side Chicago. One facility was a university-based practice (UBP) at a pediatric hospital that has a mainly privately insured clientele. The second facility was a community-based Federally Qualified Health Center (FQHC). FQHCs are U.S. federally supported health centers that provide primary care services to medically underserved and vulnerable populations (U.S. Department of Health and Human Services 2011). We recruited a convenience sample of two groups of participants from each facility rather than a broadly representative "mini public" as reported by others who have utilized traditional deliberative democracy recruitment methodologies [Molster et al., 2011]. Participants were recruited in the healthcare facilities by a trained research assistant, who provided prospective participants with oral and written explanations of the project and also distributed recruitment flyers. The recruiter introduced himself as an employee of the University working with one of the doctors at the clinic. He was instructed to use clear and easily understood language, to take as much time as needed, and to request the caregiver's help in understanding the public's attitudes toward biobanks and genetic research through our study. Participants were offered $50 in compensation for each focus group that they attended and they received an extra $50 if they attended all four sessions.

Data Collection

Focus groups were chosen as a semi-structured method of collecting information in order to allow for open discussion, varying viewpoints and clarification of information. A total of 16 audiotaped focus groups – eight with UBP participants and eight with FQHC participants – were conducted between January and March, 2011. The focus groups consisted of 9-13 participants each and lasted approximately two hours. Participants met on two consecutive Saturdays, with two focus group sessions held on each day. Pre- and post-session attitudinal surveys were administered as well as an evaluation survey. Lunch was provided between focus group sessions. The focus groups were held in a building geared for educating and training clinic staff and was located near both the UBP and FQHC clinics. Oral consent was received from the participants at the start of each session. Trained and experienced moderators utilized four focus group discussion guides of open-ended questions (27 items total) and probes in order to facilitate discussion relating to issues in biobanking. By the conclusion of the focus groups, theoretical saturation was achieved with no new insights emerging. A 24-item survey was developed to assess participants' attitudes and beliefs about biobanking before and after the deliberative-engagement session. The survey on attitudes utilized primarily Likert scales to assess opinions regarding genetic research, research participation, informed consent, return of research results of adults and children, and included a demographic section. In addition, after each day of focus groups, participants were asked to fill out a 10-item evaluation survey to assess the quality of the educational presentation as well as to indicate potential areas for improvement in the deliberative engagement process. We utilized a coding system so that participants remained anonymous and yet allowed us to compare survey findings from Day 1 to Day 2. The surveys were developed using the Tailored Design Method [Dillman 2007] as a general guide.

All data collection tools and educational slides were pretested by internal and external experts. Cognitive interviews [Willis, 2005] were conducted with three community volunteers, and all materials were pilot tested in five sessions with 8-10 clinical ethics fellows and faculty (non-geneticists, non-researchers) at the University of Chicago. In addition, the study materials were presented to the University of Chicago Community Advisory Research Council for feedback, and the study was approved by the University of Chicago's and Northwestern University's Institutional Review Boards. The survey tools and discussion guides are available upon request.

Data Analysis

Focus group discussions were transcribed, and independent checks by two investigators confirmed accurate and verbatim transcription. Transcripts were uploaded to Atlas.ti (version 6), a qualitative data management and analysis software program (http://www.atlasti.com). A provisional codebook, with inclusion and exclusion criteria, was developed by the investigators to assist in the identification of key opinions and themes. Two investigators double coded a subset (~25%) of transcripts, and any coding differences were identified. Codes were further refined through an iterative process until agreement was reached. Data reduction and analysis were conducted through summative content analysis [Hsieh and Shannon 2005] with the aim of describing individuals' views about biobanking participation and return of research results. Outputs of codes were used to identify patterns in the data and to examine code context. Key quotes were selected to illuminate the main categories of focus group findings.

Survey data were analyzed using SPSS (version 16.0). Descriptive summary statistics were used to summarize responses to all questions. Chi-square tests were performed to compare participant demographics. Student t-tests were used to assess pre- and post-engagement attitudinal changes In the Likert scale, five categories were collapsed into three, combining

the “strongly” and “somewhat” categories at either end of the scale (e.g., “strongly agree” with “somewhat agree”) in order to facilitate analysis and interpretation. Because respondents were allowed to skip individual items, the sample size varied by question.

RESULTS

Participant Characteristics

Forty-five individuals participated in the deliberative engagements. All participants were primary caregivers of children, two groups receiving primary care at the FQHC (n=22), and two groups at the UBP (n=23). One hundred percent of participants self-identified as African-American and 76% were women. Compared to participants from the UBP, individuals from the FQHC were more likely to have ≤ a high school diploma (~36% vs. 9%, $p < .05$). UBP participants were more likely to have ≥ a bachelor’s degree (~30% vs. 9%, $p < .05$). Table III provides additional demographic information about the participants.

Focus Group Findings

1. Overall interest in biobank participation, broad consent, and recontact—The majority of participants from both facilities indicated interest in their own and their children’s participation in biobank-based research. One UBP participant articulated, “I would enroll my child for the same reason I enroll myself: because I believe in the value of research for future generations.” Others mentioned that they would participate in order to benefit themselves or their children and to advance science. When asked whether their views about biobank participation had changed after each day of focus groups, most reported the same level of overall interest for themselves, and a few indicated increased interest. One FQHC participant explained that the engagement process increased her interest: “Hearing [other participants’] opinions about things, how they feel, and then seeing … visual things [i.e. the slides].” Some participants also expressed the opinion that they represented their community and needed to bring back to it their experience with our biobank engagement. One FQHC participant said, “I feel more like I’m obligated to do it just to represent those of us in this area, of this lifestyle.”

Participants were asked how they would feel about giving broad consent to participate in a study that would store and share their genetic research information. The vast majority of participants from both facilities said they would give broad consent. A few participants, however, expressed some confusion about what broad consent could provide to research participants. For example, one person from the FQHC who advocated broad consent said, “If someone can give their broad consent, I think by that same token they should be able to receive all the information back in a broad way also… You get what you put in.”

With regard to potential reconsent, participants from the FQHC expressed more interest than those from the UBP in being recontacted and reconsented if there was an opportunity for a researcher to use their genetic research information in a study other than the one for which it was originally intended. One participant from the FQHC said, “I think you should be notified. If you say you gon’ do A, B, C, D, another study with E, I think you should be notified what E is about. That’s like what [the lecturer] was talking about [with] the Native Americans [i.e., the Havasupai] up there: They fill out for one study, and they did something else… I think they should call you or make sure you understand this is what we’re gonna test for.” A few individuals, however, stated they didn’t need, or want, to be recontacted. One person from the UBP said, “If the review board says somebody can be helped by [another researcher’s using the data], I am fine with it.” Someone else from the UBP commented on the logistical challenges of reconsent: “To my mind, the cost of calling 10,000 or thousands of people, would make the research prohibitive.”

2. Root causes of distrust and biobank strategies to facilitate trust—Although participants expressed strong interest in biobank participation, all groups discussed causes of fear and distrust of research and the way in which to facilitate trust during the process of educating and recruiting research participants. Some discussion focused on historical events, cultural issues, and lack of education as root causes of fear and distrust. Tuskegee was mentioned twice in UBP groups. One FQHC participant remarked that "some people, especially certain races, worry they gonna be used as guinea pigs. It's a trust issue. We been bamboozled for so long, it's always going in your memory banks. We afraid of some things we don't know." One UBP participant noted that the older generation might be skeptical of how research data would be used and that "people like my granny … think [researchers] will take this information and run with it." One participant said that she felt her 15-year-old son did not have enough education to understand biobank research fully and said he was concerned about her participation in our deliberative engagement project. She said he told her, "Don't give 'em nothing" because, she explained, "he don't want you all to clone me… He just really went off like, 'Why you wanna support the mad scientists?'" In responses from both facilities, individuals discussed how some of the fear of research was related to a lack of understanding and education about biobanks. This, they said, could lead to a failure to trust researchers and a disinclination to participate in research.

A number of participants described their thoughts about how research recruitment and biobank strategies could be used in establishing trust within communities. One FQHC participant discussed how he was approached for our deliberative engagement study. He described his view of appropriate research recruitment: "It has to do with being comfortable [with the recruiter]." Having time to build a relationship with the biobank or institution was mentioned as important, and one FQHC participant talked about the recruiter's explanation that this project was a University of Chicago study: "That's why I'm here: I have seen a trust. I can trust the services that I get here." Likewise, an UBP participant said, "Inasmuch as the hospital continues to try to build positive relationships with those in the community, I think you'll see a higher increase in participation based on the positive relationships that you get in the community." Another UBP participant said that "having good people … [who are] respectful and careful" was important. Deliberants mentioned that the physical appearance and the manner in which a biobank participant recruiter presents him/herself matters, and that the recruiter needs to "relate to that group in terms of dressing." For instance, one person talked about *not* wearing a suit to recruit in some South Side communities. Regarding the racial background of the recruiter, one UBP participant mentioned, "Some Black men would not receive well with [the recruiter] being White… They would want to hear it from somebody else, unfortunately."

3. Perceived positive and negative aspects of receiving research results—One of the main reasons participants gave for participating in biobank research was to receive individual research results about themselves, or their children, in order to improve their well-being. One FQHC participant stated, "If I feel something is extremely wrong with this child, we can get a return [of research results] … and then hopefully one day I can come up with an answer." On the value of receiving research results, one UBP participant stated, "Having more [research] information positions me to plan for my treatment, plan for my quality of life, plan for what would happen if I can't make decisions." One UBP participant felt that by enrolling in a biobank, research results would be available to some who could not afford tests in routine care. She said, "I'm totally for the biobanks, because it gives opportunities to those who don't have any insurance… 'cause a lot of times you can't get all the necessary tests. [Doctors] will overlook a lot of things because they're too expensive."

Although the majority of participants were interested in participating in biobank research and receiving research results, participants discussed a few negative consequences that could

result from disclosure. A number of participants in both groups mentioned fear of what they might find out, stress in hearing the results, the potential for error, and having the "wrong people," such as the police, get the results due to lack of confidentiality. One UBP participant stated, "[If] it's a possibility that you're telling me I have HIV from this sample, I'm not going to give, 'cause I'd rather not know about it." With respect to hearing a difficult diagnosis from research results, one FQHC participant said, "I could go into depression, major depression … so [receiving research results] in itself may cause other problems." Another FQHC participant commented on the lack of privacy: "Confidentiality is a big part of it… it [research results] may be passed around where people may be able to get access to it… I don't want everyone to know my information." A number of participants from both clinics discussed the recent WikiLeaks scandal and explained how a lack of privacy is simply a fact of life. Another concern was that uninsured people might not be able to pay for necessary care following results disclosure or have access to the benefits that may become available because of research findings. One UBP participant stated, "You've got [the result] and you don't have the money to pay what it is to get that fixed."

4. Strong interest in receiving and managing children's research results—The majority of participants indicated interest in being notified about aggregate and individual research results about both themselves and their children. Most of the participants were also interested in receiving similar types of individual research findings about themselves and their children: treatable conditions, untreatable conditions, gene findings with uncertain meaning, and gene changes more common in a certain ethnic group. In both FQHC and UBP groups, some participants talked about wanting any and all research findings researchers had about themselves as well as their children. One UBP participant said, "If *you* know [all of my results], why can't I?" Likewise, an FQHC participant stated, "I brought this child into the world. I need to know everything that is going on."

Participants were asked whether children who participate in biobanks should be told that their parents had received their research results. While the majority felt that children should be told, there were a few participants who said it would depend on the condition and/or the child's age. One FQHC participant said, "I'm not telling my kid that they crazy. If they tell me that my child be probably mentally retarded, then I'm not gon' tell them that." One FQHC participant talked about how the child's level of maturity would dictate her decision: "I might feel it at 11, and I might not feel it till she 18… [It will be] when I figure she can take it." A participant from the UBP commented on a parent's decision whether to disclose research information: "Yes, I think the child has a right to know, [but] the parent is the one that ultimately makes the decision on to tell this child." Most participants felt that the parent should have access to the child's research results and should be the person to disclose the information to the child. One FQHC participant said, "If the parent is the one signed them up, then that's the one that need to receive the information and do the explaining."

Survey Findings

Our pre- and post-engagement assessment of attitudes revealed few statistically significant changes in views toward biobank participation and return of research results. Pre-assessment results that were not significantly different from post-assessment results are listed in Table IV. The majority of participants were very or somewhat interested in participating in a biobank, and this interest increased slightly from 78% to 81% over the two days. Most indicated interest in receiving individual research results that would indicate a risk for asthma (89%) and for Alzheimer's disease (93%); and 80% were interested in receiving findings indicating a gene change more common in a racial group. Eighty-two percent of participants were interested in disclosure of research findings with uncertain significance (Table IV). Over 97% of participants rated their interest in receiving research results about

themselves and their children the same for all conditions in both the pre- and post-engagement, and level of concern regarding the protection of privacy of genetic research information (Table IV) remained the same (85% concerned) across sessions. However, from the first to last session, there was a decrease in perceived likelihood of identification from genetic research data ("very" or "somewhat likely" 55% to 30%, $p<.05$), and in perceived harm from being identified ("very" or "somewhat likely" 46% to 29%, $p<.05$).

The evaluation surveys from both days revealed that the majority (95% pre- and 100% post-sessions) of participants agreed that the slides were easy to understand, the amount of information on the slides was about right, that they felt comfortable giving their opinions, and that "meetings like ours" were a good way to find out about people's opinions regarding the design of a University-sponsored biobank. Most (95% pre- and 97% post-sessions) also agreed that the amount of time for the educational and discussion parts was about right. All participants on Day 1 agreed that they knew more about biobanking after attending the session, and 97% of Day 2 participants agreed that they knew more about issues in returning research results. There were no statistically significant changes in the evaluations from pre- to post-engagement.

DISCUSSION

Several studies document high research participant support for participating in biobanks [Chen et al., 2005; Pentz et al., 2006; Lemke et al., 2010], although data on the attitudes of members of racial and ethnic minority populations are scant. Our participants, who represented Aftican-Americans from a broad spectrum of socioeconomic and educational backgrounds in South Side Chicago, likewise supported participation. Similar to findings reported in other studies, our participants were proponents of broad consent, recontact, and data sharing [Ludman et al., 2010; Lemke et al., 2010; Brown Trinidad et al., 2010]. A finding not reported elsewhere is that many participants did not distinguish between reasons for their own and for their children's participation in biobank research. Documenting these findings is important, as our sample, while small, was from a diverse group of African Americans whose opinions on issues in biobank participation are not well documented in the literature.

The role of trust is an important issue in the enrollment and retention of minorities in biobank-based genetic research. A significant body of research has been developed in recent years documenting a general mistrust of biomedical research in African-American communities [Adams-Campbell et al., 2004; Bonham et al., 2009; Bussey-Jones et al., 2010; Freimuth et al., 2001; Skinner et al., 2008]. The recent publicity surrounding publication of the Henrietta Lacks story [Skloot 2010] may serve to further decrease the already low levels of trust of clinical research and the collecting and storing of tissue samples found in some African-American communities. In our deliberative engagement, despite some discussion about lack of trust in research, participants described how the benefits of biobank participation outweighed the potential risks. From our engagement experience, two findings about trust offer valuable lessons for those involved in genetic research. First, participants described in detail the recruitment process for our project and how they valued the respect shown to them. Participants cited the respectful demeanor of the recruiter as a key reason for their attendance. They stated the importance of this respect for their future enrollment into actual biobanks. Second, participants wanted to be sure that if discoveries from biobank-based research yielded new treatments, they would have equal access to those benefits. Although international research now has policies in place to ensure benefit-sharing with the groups who participate in research [Hayden, 2007], few, if any, such policies exist for domestic research.

Participants in our engagement indicated both positive and negative aspects of receiving research results but overall expressed strong interest in receiving all types of their individual research results. This finding is similar to what has been reported in other studies [Murphy et al., 2008; Fernandez et al., 2005], and provides support that this interest is found in a broad array of ethnic and socioeconomic groups. One of the findings that has not been previously reported is that when asked hypothetically what types of research results they would be interested in receiving, participants expressed no differences between types of findings they wanted for themselves and for their children. Further research is warranted as this position is different from current policy guidelines, which argue for a more restrictive return of pediatric results [Hens et al., 2011]. The majority of participants also wanted to decide whether, when, and how to disclose research findings to their children. This perspective is somewhat inconsistent with current policy guidelines, which affirm the child's right to health information as the child matures [Hens et al., 2011]. These issues will be discussed in a future publication.

Our pre- and post-engagement survey assessment revealed only minor and not statistically significant attitudinal changes. Participants' interest in enrolling in biobank-based research remained the same across days, and there was no change in concern about privacy protection in biobanking. These findings concur with our focus group results and might indicate, like participants' WikiLeaks references, that participants felt biobank-based research was not exempt from these types of possible breaches, but that the potential benefits of research participation outweigh this potential risk. It is interesting that the percentage of our participants, post engagement, who thought identification and potential harm likely from biobank research participation (approximately one-third) is very similar to that reported by IRB professionals [Lemke et al., 2010].

One challenge encountered in our deliberative engagement was the development of the educational slides. There are no validated teaching modules regarding the ethics and policy issues of biobanks. We conducted extensive pretesting and piloting of all our materials and data collection tools, but our slide presentations and explanations may have been biased. Some participants indicated that this was the first time they had heard the term "biobank." This means that for some, opinions about biobank participation and policy issues were being formulated for the first time. Although we clarified in our education presentation and focus groups that clinical care was not the same as research participation, a number of participants expressed the expectation that biobank participation would provide interpretable findings helpful for personal clinical treatment, which is consistent with findings of possible therapeutic misconception described in other studies [Ormond et al., 2009; Miller and Joffe, 2006]. Some participants also grappled with the concept of broad consent, which was defined and explained in the education sessions. Conducting more extensive pretesting with community members may have revealed some of the more challenging concepts.

Our deliberative engagement utilized educational presentations and focus groups, which allowed for clarification of information, open discussion, varying viewpoints, and rich descriptive data. Our mixed-methods approach also included quantitative surveys to measure specific constructs. Because of the small numbers, we did not see many statistically significant changes although there was a decrease in concern about privacy from Day 1 to Day 2. We report exclusively on views of individuals who were self-described African Americans from two South Side Chicago healthcare facilities serving different socioeconomic communities. The majority of our participants were women, which is consistent with evidence that women are more likely to participate in research studies [Dunn et al., 2004; Eagan et al., 2002]. For this reason, our findings may be more representative of women's views than men's on biobanking issues. While our study findings cannot be generalized more broadly to other African-American communities or to the larger

Chicagoland population which is approximately one third African American, one third Latino and one third non-Hispanic white [CLRsearch.com, 2010], we do believe that our findings' many similarities with other empirical studies on public opinions regarding biobank issues support several themes: interest in biobank participation, interest in return of research results, and importance in establishing trust in key biobank personnel and home institution. We recruited our participants from a population underrepresented in health research studies. This is important in obtaining data from a broad range of locales as well as racial and ethnic groups to inform decisions about institutional, regional, and national policies [Jonassaint et al., 2010]. A wide range of potential research participant views will be necessary to assist in the development of biobank policies and procedures.

CONCLUSION

Biobanks will continue to grow as an important resource for researchers, and there appears to be broad public interest in the return of research results. Greater public understanding about research using biobank resources is needed to establish trust and to promote an informed and effective public role in the development of guiding principles and operations. A deliberative engagement approach is one way in which to educate and involve a community; however, it requires a large investment by participants and researchers alike. This paper describes one of the first deliberative engagements conducted to assess the views of an ethnically diverse population regarding returning research results. Future research will be needed to assess how best to establish trust and improve participant understanding about biobank research on a wider scale.

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TABLE I

Overview of Deliberative Engagement Process

Day 1	Day 2
Pre-session survey on attitudes	Education session C
Education session A	Focus group C
Focus group A	Lunch
Lunch	Education session D
Education session B	Focus group D
Focus group B	Post-session survey on attitudes
Evaluation survey	Evaluation survey

TABLE II

Discussion Guide Topics

Focus Group A: Overview of Biobanking	**Focus Group C: Return of Your Research Results**
Genetics - what comes to mind	Interest in group results
Genetic research - what comes to mind	Interest in individual results
Reasons people participate in a biobank	Interest and disinterest in certain results
Reasons people do not participate in a biobank	Who should, or should not, decide whether to return results
How you feel about participating in a biobank	How you feel about participating in a biobank
Focus Group B: Biobank-based Genetic Research	**Focus Group D: Return of Your Child's Research Results**
Informed consent – information needed	Interest in group results
Giving broad consent	Interest in individual results
Who is trusted, and not trusted, to protect privacy	Interest and disinterest in certain results
Data sharing with other researchers	Who should, or should not, decide whether to return results
How you feel about participating in a biobank	Whether child should be told parents have results
	How you feel about your child participating in a biobank

TABLE III

Participant Characteristics

	Federally Qualified Health Center (n=22) n (%)	University-Based Practice (n=23) n (%)
Gender		
Female	16 (73%)	18 (78%)
Age		
Years, mean	40	42
Range	20-63	22-62
Education		
≤High school	8 (36%)	2 (9%)
>HS, <BA	12 (55%)	14 (61%)
≥BA	2 (9%)	7 (30%)
Race		
African American only	22 (100%)	20 (87%)
African American plus other races	0	3 (13%)
Number of Children		
1-3	14 (64%)	22 (96%)
4 or more	8 (36%)	1 (4%)
Participated in genetic research		
Yes	0	1 (4%)
No	22 (100%)	22 (96%)

TABLE IV

Attitudes toward Biobank Participation and Return of Research Results (n=45)

Question	**Very Interested**	**Somewhat Interested**	**Neutral**	**A little Interested**	**Not very Interested**	**Don't Know**
How interested are you in participating in a study that would collect genetic samples and health information for future studies?	47%	31%	13%	0%	3%	5%
Question*	Strongly Agree	Somewhat Agree	Neither Agree Nor Disagree	Somewhat Disagree	Strongly Disagree	Don't Know
I would want research results returned that identify a change in a gene:						
That increases risk for asthma (treatable condition).	82%	7%	2%	0%	0%	2%
That increases risk for Alzheimer disease (largely untreatable condition).	91%	2%	0%	0%	2%	2%
That is more common in a specific racial or ethnic group.	64%	16%	11%	2%	2%	2%
Even if medical researchers are not sure what it means for my, or my child's, health.	64%	18%	7%	2%	4%	2%
Question	Very Concerned	Somewhat Concerned	Neutral	A little Concerned	Not very Concerned	Don't Know
In general, how concerned are you about the protection of privacy of genetic information that is collected in research?	67%	18%	9%	0%	4%	0%

* This question was adapted, with permission, from the survey utilized in Murphy et al (2008).

** Missing data ranged from 2-7%, for each question listed.

*** Table IV data reflects the pre-assessment results. There were no statistically significant differences in the post-assessment of these items, nor differences between the two groups.