

Community leaders' perspectives on engaging African Americans in biobanks and other human genetics initiatives

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Abstract There is limited information about what African Americans think about biobanks and the ethical questions surrounding them. Likewise, there is a gap in capacity to successfully enroll African Americans as biobank donors. The purposes of this community-based participatory study were to: (a) explore African Americans' perspectives on genetics/genomic research, (b) understand facilitators and barriers to participation in such studies, and (c) enlist their ideas about how to attract and sustain engagement of African Americans in genetics initiatives. As the first phase in a mixed methods study, we conducted four focus groups with 21 African American community leaders in one US Midwest

city. The sample consisted of executive directors of community organizations and prominent community activists. Data were analyzed thematically. Skepticism about biomedical research and lack of trust characterized discussions about biomedical research and biobanks. The Tuskegee Untreated Syphilis Study and the Henrietta Lacks case influenced their desire to protect their community from harm and exploitation. Connections between genetics and family history made genetics/genomics research personal, pitting intrusion into private affairs against solutions. Participants also expressed concerns about ethical issues involved in genomics research, calling attention to how research had previously been conducted in their community. Participants hoped personalized medicine might bring health benefits to their people and proposed African American communities have a "seat at the table." They called for basic respect, authentic collaboration, bidirectional education, transparency and prerogative, and meaningful benefits and remuneration. Key to building trust and overcoming African Americans' trepidation and resistance to participation in biobanks are early and persistent engagement with the community, partnerships with community stakeholders to map research priorities, ethical conduct of research, and a guarantee of equitable distribution of benefits from genomics discoveries.

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Introduction

Genomics is today's ascendant science, promising revolutionary improvements in the prevention and treatment of illness, and people all over the globe have pinned their hopes on its success. From public research institutions to commercial pharmacogenetics enterprises and gentech startups, from

government funding agencies to corporate investors, from technologists and bench scientists to the individual clinicians staffing health care facilities, excitement about the dream of personalized medicine could hardly be greater. And for members of the public predisposed toward or fighting debilitating diseases thought to be genetically linked, like Alzheimer's, autism, schizophrenia, cancer, and heart disease (Amberger et al. 2009; Green et al. 2011; Miller et al. 2007; Watkins and Farrall 2006), the quest for solutions in genetic screening and therapeutics is of utmost importance. With the momentum the field of human genetics enjoys and the profit potential of its products, what must not be lost sight of are the implications for populations disproportionately burdened by ill health and poverty in the USA and abroad.

African Americans make up one such population disproportionately affected by ill health and poverty (Abrahams 2006; Agency for Healthcare Research and Quality 2012; Kjellstrom et al. 2007; LaVeist et al. 2009), yet they are grossly under-represented in DNA biobanks. Population or disease-based DNA biobanks make the work of genomics possible. These massive-scale repositories contain tissue and blood samples linked to their human donors' health histories, behavioral and environmental information, and medical records. The data are stored indefinitely to be shared for multiple lines of research over time. It is essential that these pools of genetic data be diverse according to geographic ancestry so that future clinical applications of personalized therapies can be available to everyone (Losow 2005; Rugnetta and Desai 2011), thus the importance of developing ethnic-specific genetic arrays for African, Latino, Asian, and European ancestry. The problem is, to date, donations to biobanks have largely come from persons of European descent.

There is a lack of information about what African Americans think about biobanks and the ethical questions surrounding them (Lemke et al. 2012). Likewise, there is a gap in capacity to successfully enroll African Americans as biobank donors. The purposes of this mixed methods community-based participatory study were to: (a) explore African Americans' perspectives on genetics and genomic research, (b) understand their views on what facilitates and what obstructs participation in such studies, and (c) enlist their ideas about how to attract and sustain engagement of African Americans in biobanks and other human genetics initiatives. In this paper, we report findings from the first phase of the study, which involved four focus groups with urban African American community leaders.

Background

Enrollment in biobanks bears resemblance to enrollment in clinical studies generally. Researchers have noted time and again that it is challenging to recruit and retain African Americans in clinical studies (Mills et al. 2006; Sellars et al. 2010). The low

number of African Americans participating in clinical trials is often attributed to issues of distrust and discrimination experienced within the healthcare system (Corbie-Smith et al. 1999; Thomas and Quinn 2008). African Americans also indicate their reticence comes from knowledge of abusive and exploitive research practices in the past (Jones and Harris 2011; Siminoff and Arnold 1999; Washington 2006; White 2005). The Tuskegee Study of Untreated Syphilis remains the most infamous example of unethical medical experimentation on African Americans. In the Tuskegee experiment, Public Health Service researchers compiled data on the effects of the spontaneous evolution of syphilis among African American males in Alabama. From 1932 to 1972, 399 syphilitic men were left untreated to die from the disease, even when penicillin was readily available and in wide use as a curative agent (Jones 1992). Pain and anger as a result of this study continue to be felt by African Americans who react by refusing participation in research (Russell et al. 2012).

Another notorious incident of medical exploitation came to light with the much publicized book "The Immortal Life of Henrietta Lacks" (Skloot 2010), which reignited medical mistrust in African American communities. Mrs. Henrietta Lacks, an African American woman, grew up on a poor Southern tobacco farm, married young, and moved to Baltimore. In 1951, after the birth of her fifth child, she was diagnosed with cervical cancer. A Johns Hopkins Hospital physician harvested a tissue sample from her tumor without her knowledge. Her cells demonstrated an amazing capacity to grow and reproduce indefinitely and became the first viable human cell line, launching the entire biotech industry. Called HeLa cells, they were commercialized and have been in continual use all over the world ever since (Hannah 2000).

For more than 60 years, Henrietta Lacks' cells have been kept alive in the lab and have played pivotal roles in the prevention and diagnosis of cervical cancer, as well as advances in treatment for a number of other diseases including leukemia, influenza, Parkinson's disease, and AIDS (Hannah 2000). Mrs. Lacks died 8 months after her cells were taken. While her cells made medical progress and corporate profits, Mrs. Lacks' children and grandchildren grew up in relative poverty, receiving no benefits; they did not even know about Henrietta's major contribution to humankind. Her family finally found out about her cells when they were contacted in the 1970s to participate in a follow-up study investigating the genetic fates of her descendants. The story of Mrs. Lacks not only highlights the unethical practice of doing research involving human subjects without their informed consent and the intersection of race, poverty, and vulnerability but it also raises important questions relative to biobank storage and data sharing from which profitable products may be derived.

In 2008, a state-funded collaborative research effort called the Wisconsin Genomics Initiative (WGI) brought together the Marshfield Clinic, Medical College of Wisconsin,

University of Wisconsin—Madison School of Medicine and Public Health, and University of Wisconsin—Milwaukee College of Nursing to facilitate biobanking in Wisconsin and data sharing among genomics researchers in the state. The biobank that was developed has few (if any) data from racial/ethnic minorities; no African Americans from the metropolitan areas of Wisconsin have contributed to the genetic database and bio-repository. Enhancing the diversity pool of this biobank, inclusive of African Americans—the largest minority population in the state, is important as the science is advanced. The current study is an outgrowth of WGI scientific activities and is supported by the Initiative.

Methods

This report is about the first phase in a larger, mixed-methods community-based participatory research study about African Americans' perspectives on and involvement in genetics and genomics research. We engaged community leaders in first phase focus groups because of their knowledge of and influence in the African American community. From these findings, we designed the second phase of the study to understand the perspectives of community leaders' constituencies. From the findings of phases 1 and 2 and in conjunction with the community leaders, we constructed a survey that was administered to 212 members of the African American community.

Recognizing that individuals of African descent do not comprise one monolithic population and valuing the diversity among those whose geographic heritage is sub-Saharan Africa, we also engaged African Immigrants in a separate but parallel three-phased study to meet the same specific aims. Results from phase 1 with the African immigrants have been published and are not reported in this manuscript (Buseh et al. 2012).

In the first phase of the study with African Americans, focus groups allowed us to explore and understand key community leaders' perspectives on genetic and genomic studies while probing further into those factors that would facilitate or obstruct participation of urban African Americans in biobanks and other genetics initiatives. In partnership with the Black Health Coalition of Wisconsin, a highly respected nonprofit community-based organization (CBO) that addresses health issues and advocacy needs of African Americans, a purposive sample of 21 African American community leaders (e.g., executive directors of community organizations, prominent community activists, highly regarded educators) were recruited to participate in four focus groups attended by six, five, five, and five participants, respectively. This sample size and group size are adequate for exploratory focus group studies (Krueger and Casey 2009).

Focus groups of approximately 2 h duration were held in the evening hours in a conference room at the university. They were moderated by the study's principal investigator, an African-American, PhD-prepared investigator who has collaborated with the African American and African Immigrant communities on prior participatory projects. Upon receipt of written informed consent, each focus group participant completed a short sociodemographic information sheet. A semi-structured focus group guide, developed in conjunction with community members, was used to elicit discussion about perspectives on genetics and genomics research, facilitators and barriers to participation in such studies, and ideas about how to attract and sustain engagement of African Americans in biobanks and other genetics initiatives. All focus groups were digitally recorded and transcribed verbatim by an African American owned commercial transcription service. All procedures were approved by the University Institutional Review Board.

Transcriptions were imported into NVivo 9.0, a qualitative analysis software program that assisted us in data management (© QSR International 2013). Thematic analysis using continuous comparison was employed guided by Braun and Clarke (2006). Four members of the research team did initial independent analyses, then met to discuss and debrief to ensure consensus and consistency in interpretations. Inter-rater reliability was established in this way at several points in the process of analysis, enhancing the validity of findings. Preliminary findings were presented and discussed at a community forum organized by the partnering CBO, and their feedback was incorporated into the results presented here.

Results

Characteristics of focus group participants

A total of 21 African American community leaders participated in the phase 1 study. They ranged in age from 29 to 73 years; the mean was 56.8 years (SD=10.65). Participants in these focus groups were highly educated; 19 % had completed a 4-year college degree, and 38 % had completed a graduate degree. Eighty-one percent were females. The median income category was \$60,000–69,999. In regard to marital status, 35 % were married, 15 % were single, 40 % were divorced, and 10 % were widowed.

Themes emerging from the focus groups

Broad themes emerging from analysis of the focus group transcripts were: (a) pervasive skepticism about biomedical research, (b) troubling nature of genomics research, and (c) conditions for engagement of African American communities in biobanks and other genetics initiatives. In the sections that follow, these broad themes and their sub-themes are

presented with excerpts from focus group discussions as substantiation.

Pervasive skepticism about biomedical research

According to these community leaders, African Americans as a whole are deeply skeptical about participating in biomedical research of any kind. Well-known abuses of African Americans at the hands of researchers' generations ago are still very much alive in the African American consciousness. More recent local history of researchers' less than honorable dealings with the African American community reinforces the distrust. To add to the controversy surrounding participation in studies, African Americans need only look around them to see disparities in the prevalence and burden of disease. They see increased morbidity and mortality in their community even as medical discoveries seem to promise other Americans opportunities for longer and healthier lives. One participant suggested that biomedical research literally brings forth a "visceral response" in African Americans. Another insisted, "The trust has been so damaged."

Legacy of Tuskegee and Henrietta lacks The notorious Tuskegee Study of Untreated Syphilis set the "precedent" justifying African Americans' unwillingness to expose themselves to danger in biomedical research. In every focus group, participants brought up the legacy of this study:

The syphilis study in the 1940's; a lot of people think about that, the whole thing they did with syphilis. And, the men didn't have a clue. That leaves a bad taste in our mouths from way back in history, makes us leery of research. It is difficult to forget.

Fear is what comes to mind when I hear the word research. The first thing I think of is the Tuskegee Experiment. What are you going to do to us again? Most Black people say, 'You are not using my body for no testing because ain't no telling what I'll end up with. I might not live to see the research over.'

The more recent revelations about circumstances surrounding HeLa cells rekindled angst and anger in the African American community in relation to clandestine human subject research. Without permission, recompense, or acknowledgement, the human tissue of one individual was used in medical experimentation over many decades to global effect, spawning countless medical discoveries, and generating untold corporate profits. Meanwhile, neither the donor nor her family knew of the human tissue contribution, or the uses to which it was put:

And, who's the lady they took the cells out of, and she didn't even know it? Henrietta Lacks. They took cells and have been using them for how many years. She

didn't know it, nor did her family. And they are just now finding out, while for decades medicine made a lot of money. I'm not opposed to helping people, but you have got to get my permission to use what I have donated. You can't be sneaking around with it.

What the popular book (Skloot 2010) and news coverage about it made widely known was that the unwitting donor was an African American woman, Henrietta Lacks, whose children have lived in poverty, dealing with chronic illnesses and lacking health insurance, while her cells have generated corporate profits over six decades. Participants indicated that learning about her case redoubled their distrust of medical research:

Henrietta Lacks didn't get a dime. They used this woman for 50 or 60 years for different stuff, making millions of dollars off her cells. And, all along, the family couldn't even afford health insurance.

Suspicion was reinforced, as was resistance:

There is always some mess-up in research. It doesn't turn out right for us. It is against us. You really get angry because of the way they did things to our people.

Local history of being taken advantage of by researchers Against the backdrop of infamous events like the Tuskegee Syphilis Study and the Henrietta Lacks case, participants described a local history of ill feelings about researchers who come into the African American community to recruit study subjects. As community leaders, they were in a position to know about biomedical researchers coming into the community looking to recruit African American subjects. In the focus groups, they referred to a number of studies done over the years in their city, recounting the problems they had observed: (a) African American community leaders were invited into the research process only "after the fact" when decisions about focus, design, and outcomes had already been made; (b) community leaders were used merely as "entry points" to the "bodies" needed to do the research; (c) researchers neglected to come back to participating communities with the products of their investigations; and (d) research institutions failed to offer adequate resources and credit to the communities that make their studies possible.

A lot of times the ones doing the research are disrespectful to the community. Decisions are already made before they bring the community to the table. They leave the community out of everything until it is time to implement.

The problem is that so much research gets started in the African American community, and then it stops and we never see them again. And, there we are, left with nothing.

This happened for real—researchers come knocking on my door and they say, ‘You’re African American. You know other African Americans. We need them for our research.’ They tell me they have gotten 2 million dollars to do a project, and they haven’t offered my organization 50 cents for a cup of coffee. We are just supposed to be volunteers.

Moreover, participants believed researchers too callously regarded African Americans as advantageous targets for experimentation:

We are guinea pigs. Folks are always experimenting with something, and then they prescribe it to us.

They were aware of the National Institutes of Health Revitalization Act of 1993 mandating the inclusion of women and minorities as subjects in clinical research, yet suspected it was the letter of the law that brought most researchers to their community, rather than genuine concern for the health and well-being of African Americans:

The NIH is saying now to researchers, ‘We are not going to give you money unless you get more people of color involved in your study.’ That is what is going on, not a real caring about things that impact our lives.

Unabated health disparities Persistent health disparities in the African American population further engendered doubt and distrust of biomedical research. Participants perceived limited efforts by leaders in scientific and clinical arenas to understand the reasons behind disproportionate ill health among African Americans. They believed there is no health problem that does not adversely affect African Americans, yet the social determinants of health are being ignored.

Things that are associated with disease among the African American population are taken for granted. Yeah, they have high incidences of HIV. They have high incidences of diabetes and high blood pressure. And, no real effort to understand why that is and how it can be changed. What about where they live? What about people’s health care being tied to jobs and they are unemployed? I know how it is to be without health insurance.

Participants testified to a complex, poorly integrated, and sometimes discriminatory US health care system; and insufficient efforts to make it possible for members of their communities to access timely, high quality treatment:

Look at the disparity in health care in our community. There need to be policy efforts to do something, not just for today but longstanding, that has a future and will truly do good for the community.

Such experiences, they pointed out, make people less inclined to react favorably to the medical profession overall:

I don’t trust those doctors just because they are doctors. They are supposed to be nurturing, but they make you feel like you don’t know anything. They cut you off. They dismiss what you say is going on in your body. They see somebody for 5 minutes and see no need for a conversation.

They made the link between unabated health disparities and lack of research participation by African Americans:

There is total turmoil in the central city—homelessness, unemployment, AIDS. Our central city is ranked worst in the country for jobs. We’re suffering from too many things. Health is not the only issue, besides we don’t have health care anyway. Are we going to get tested genetically? We don’t even think about it. I don’t need another issue on my plate. I got to try to feed my kids.

Troubling nature of genomics research

When asked to consider genomics research in particular, these African American community leaders were torn between their fears and their hopes. Invasion of privacy was one of their concerns. They also worried that genetic information could be used with injurious intent. At the same time, they imagined discoveries that could improve the health of their community.

Intrusion into private affairs The necessity of divulging personal and family health histories in genomics studies felt intrusive. Participants believed the documentation of private affairs, like whether there was mental illness in the family, could be an obstacle for African Americans, perhaps more so than for other populations. They pointed out that keeping private sensitive details about oneself and one’s family had always served a protective function against oppression:

That old adage continues generation after generation—Don’t hang your dirty laundry in public. You just don’t go out there and tell people that someone in your family is mentally ill or has some other disease. You don’t talk about if someone is sick.

Whatever happens in the house stays in the house. To give out your family history is like prying open a can that has been sealed for a hundred years.

Using data for harm Participants argued that genomic data could be manipulated for evil or for good. As one said, “Because other studies have been done against us, our fear is—will the data be in the right hands?” Ever mindful of the

deplorable history of racism in the USA, these community leaders expressed serious misgivings about uses to which genetic materials from African Americans might be put. They literally discussed among themselves whether genomic science would be employed to annihilate their community:

Genetics—you can improve something or you can destroy something. If there is a genetic code and you wanted to alter it, all you've got to do is study genetics and you can eliminate a whole race.

The government entity that is in charge of the research does what they want to do with the data. That's what I'd be afraid of. Who's in government and what are their attitudes toward ethnic minorities? Results could be used in a negative way for racism and discrimination against our people. I fear that this kind of genetics work could be used to try to annihilate us.

They were also concerned about ramifications for individuals whose DNA would be “captured in a database somewhere.” Would this identifying information be used to deny rights and privileges? Would a new level of surreptitious surveillance be made possible?

Our DNA is like our Social Security number. If they have our DNA, they can know everything about us. And they can use that however they want, including tracking you. The criminal justice system gets your DNA and all of a sudden they got a match to you. I distrust that system because genetics could be misused unless there is a protected process to make sure they don't get information from my research specimen.

Possible solutions for succeeding generations Despite their trepidations, participants were open to learning about genomics science and how it could facilitate personalized medicine and more targeted prevention and treatment of disease. They could envisage genomic solutions to health problems for future generations of African Americans and realized the importance of research participation now to make that happen for their community:

An omission like not getting Blacks involved in genetics research; that could cause harm to future generations in our families.

There would be advantages to genetics research in the African American community if we could find out information about family history and genetics for individuals and they could be advised in areas where they are vulnerable.

They were hopeful:

Genetics studies should be welcomed if there is a way to find a cure for diabetes, high blood pressure, sickle cell

anemia, asthma, breast cancer, Alzheimer's—things that affect African Americans.

Conditions for engagement of African American communities in biobanks and other genetics initiatives

These community leaders stressed that in order for scientists and academic institutions to get African Americans to participate in genomic studies, certain conditions for engaging the community must be fulfilled. In their discussions with each other, they stipulated the minimum requirements: respect for the community, authentic collaboration, bidirectional education, transparency and prerogative, and meaningful benefits and remuneration.

Respect for the African American community In all the focus groups, participants kept returning to the issue of having to struggle in a system that still does not respect them—does not know and value their history, wisdom, skills, or credentials. They stressed that redress was essential if researchers ever hoped to make inroads in the African American community:

It is going to take a long-term process to engage the African American community in genetics research. We have been used and not given information for so long; you can't just tell people to get over it.

You have to be respectful of the African American community. Be patient with the African American community. Recognize we have concerns based upon historical evidence of research abuse of African Americans.

We have to be treated with decency and respect. As a race of people we have been demeaned for hundreds of years. We need to be acknowledged for what we give to the world by being in research. In Henrietta Lacks we see somebody who gave something to the world and was never acknowledged.

When you go into our neighborhoods you have to be respectful. If the research project gains public visibility; then there should be visibility for the community as well, not just the university. Any project should be a joint effort with equal respect. Don't make the community invisible after you get your data.

Authentic community collaboration Tying respect to collaboration, one participant said, “When universities do research in the community, they take all the credit. It should be a joint effort with equal respect.” Because so much negativity had accrued in African Americans' dealings with the health care system and with academia, participants contended that

relationship mending was in order before trying to engage members of their community in genomics research:

As African Americans, our attitude toward the health-care system and medical research in general, is still sullied by the reverberations of racism and the discrimination that continues today. Unless there are fundamental relationships built, there will be no successful genetic projects.

Time, investment, and sustained presence in the community were prerequisite to engaging African Americans in research partnerships. Community leaders and their constituencies had to be able to trust those who would probe into their genetic makeup and family background:

Anybody who wants to do research on us needs to be in the community before you come talking about doing research. We have to see you regularly to believe that we can trust you to advocate for our issues. We have to know you, know that you are good people. We have to know that you will not misrepresent us.

In any kind of partnership, they had to be able to see themselves reflected in the makeup of the research team. But they were not talking about token positions filled by African American community members. Rather, they were suggesting the need for African Americans in research leadership roles that bring with them legitimate funding and decision-making powers:

It is important that you have some of us from the community doing the research, asking the questions, participating in all of it. We need to be more than the subjects of your research.

Who is better to understand us than us? I would love to see people of color study people of color. It is always put in other people's hands to study us, and then they become experts on what is good for us.

As opposed to the lack of collaboration they sensed in past dealings with researchers who approached them as community leaders only after research projects were already mapped out and data collection was underway, participants wanted authentic collaboration from the start. They wished to have meaningful influence in setting research foci and goals, planning methods, and carrying out “checks and balances” on the conduct of studies. And they wanted research to come full circle bringing new information and solutions back to the community:

The follow-through is important. The findings have to be translated into what we can do in our daily lives to improve our health.

Bidirectional education African American community leaders said that education in preparation for involvement in

genomics research needed to be bidirectional. While they were clear that researchers are the biomedical experts with the knowledge about genetics, genomics, and personalized medicine, they also insisted that African Americans have much to teach would-be researchers about how to engage with community members and how to recognize the full measure of their intellectual grasp, abilities, and resilience:

Academia has its knowledge base. So does the community. Before you deal with involving any subjects in your study, let's dialogue about how we are going to communicate with each other—academia and community.

If I'm part of your research, and I start to ask you questions just like you are asking me questions, it shouldn't be one-way. You will be surprised how much the community knows. We are not stupid. Don't take us for granted.

It is a matter of building capacity on both sides. The community lets academia know how to act when you are in our community, not like you are above us.

Participants offered recommendations about educational content and delivery to ensure that African Americans would be informed participants and consumers in the genomics enterprise. First of all, they called for general consciousness raising and basic education about the field of genetics and genomics:

What is needed is Genetics 101 for everyone in the community at places where people are—in barbershops, churches, community centers, block club meetings.

Second, they suggested it was important to consider who would be best suited to teach:

Have African Americans doing the educating. If the people delivering the message don't look like me, I wonder how they really can know my needs.

Third, they encouraged use of a full range of educational modalities:

Use billboards, radio stations, local papers, rap groups. Put it out there through music. Go to churches and schools. Make it visual. Put your picture up in the buses. We are a visual people. You need a catch phrase like, 'Get to Know Your Genes.' And, there is going to have to be some face-to-face conversation.

They emphasized the multiplicative nature of community-based education:

Once each of us learns something, we will inform others, and that's how you get the message out.

Further, participants advised that not only must the African American community be taught to understand the

potential of genomic science; it must be taught to appreciate the risks. Specific to risks, they voiced a number of questions about genetic repositories, research protocols, and protection of human subjects:

Let us know exactly what biobanks are, and what they will do with our DNA. Who will take our deposits out? What will they use them for? Will they get our permission? How much money will they make?
 Maybe I agree to let you keep my sample right now, but what if I have a different mindset 10 or 20 years down the line? Do those people still have my DNA? What if I don't agree with what they are doing?

Transparency and prerogative The details about biobanking these African American community leaders wanted to learn about as part of bidirectional education between academia and community illustrate the transparency they were seeking. Participants stressed that in order for them to participate in genomic research and endorse such studies to other African Americans, there would have to be openness, communication, and accountability in all procedures:

My participation would be based on who is doing the study and what prompted that person to look into this genetic topic.
 What is the purpose of the study? Who is going to get the results?
 I want to know what organization would be funding it; who would have privileges to the information; and how you are going to disseminate results.

In addition to transparency, they wanted prerogative about uses of their genetic materials:

I want to know when my genetic materials are being used. I want to know what you are using them for each time you dip into that biobank.
 If they decide to use my DNA for something other than what I signed for, then they have to tell me. I want to be able to read the information and make the decision whether I would like to participate in that new phase of study or not.
 If it is an insurance company doing the research, then I would not give permission for my DNA to be used. Take the insurance industry totally out of it if you want to do genetic research in our communities.
 If I don't trust, or I don't agree with what somebody intends to study, I need to be able to say, 'No, don't use my specimen.' We have to have some veto power. There is no guarantee that all scientists are good of heart.

These terms stipulated by the African Americans in this study go to the heart of current ethical dilemmas in the field.

Meaningful benefits and remuneration The final condition for engagement in genomics research discussed by participants was meaningful benefits and remuneration. There had to be foreseeable benefits for the African American population and a protocol for sharing profits and discoveries generated from use of individuals' genetic donations. Again, participants' concerns are in line with questions being raised in the literature about how this sea change in medical science is to be ethically transited. About benefits, they said things like:

I want to know how any particular study relates to Black people. That would be extremely important to me. Is it geared toward curing diseases that impact us the most?
 The research has to be for the better good of our families, as well as the community. I want to know how are my children, and grandchildren, and children after that going to benefit from the research. In Black American culture, seven generations down is how we look at it.
 If it is a matter of saving African American lives, now or in the next generation, that would be something worth depositing my DNA for.

About remuneration, they broached the topic of proprietary control:

Do my deposits to the biobank pay dividends? Researchers get the information they want and they get our body specimens, but we get nothing in return? That's not fair. You got to give something to folks taking part in these studies.
 You read about these research companies making millions of dollars. The educated donor of genetic material will want to know what monetary incentive there is. There should be a monetary benefit in the long-term if something evolves from that genetic material.
 If out of something genetic I have donated they find a cure for a disease—at that point, my family members should have direct financial benefit from that, which is probably what should have happened with the Lacks family.

Furthermore, they talked about fair distribution of research outputs. They wanted assurance that any prevention or treatment innovations developed from genomic research to which African American communities contributed would be made accessible and affordable to those same communities.

Individual donors, too, they believed should be apprised of personal genetic information, informed about any actionable findings, and assured return of results that might help them reduce risk factors and/or obtain early diagnosis and treatment for an identified heritable condition:

If you find something in my genetics that needs to be addressed, will the services be made available to me?

Discussion

In genomics, there is the promise of prevention and tailored treatment of chronic illness; paradoxically, African Americans, who bear a disproportionate burden of chronic illness, participate at low rates. To better understand the lack of participation, we went to leaders in the African American community in one US Midwest city to get their views. According to our findings, historical injustices in the conduct of biomedical research lie at the root of enduring suspicions among members of the African American community. While there was an appreciation for the knowledge to be gained through genetics and genomics research, attitudes about research involving human subjects were sullied by reverberations of racism and exploitation. Lack of control over genetic samples once donated raised fears about how DNA research might be used to stigmatize and even annihilate. Further, connections between genomics and family history made research in this area immediately personal, pitting intrusion into private affairs against possible solutions for succeeding generations.

Pervasive skepticism about biomedical research, lack of trust in the health care system, and distress about worsening health disparities characterized discussions about genetics among African American community leaders in this study. Like Corbie-Smith et al. (1999) 15 years before, we found that African Americans were worried that geneticists are motivated by money, status, and prestige, rather than by wanting to positively affect the health of African Americans.

The Tuskegee Untreated Syphilis Study and the Henrietta Lacks case were particularly influential in the responsibility participants felt to protect their community from harm and disadvantage. Evidence that the tragedy of Tuskegee lives on generation to generation to dissuade research participation by African Americans (Corbie-Smith et al. 1999; Freimuth et al. 2001; Shavers et al. 2000) reinforces what Jones (1992) in the book “Bad Blood: The Tuskegee Syphilis Experiment” claimed in his unparalleled history, “No scientific experiment inflicted more damage on the collective psyche of black Americans than the Tuskegee Study” (p. 38).

In addition, ethical implications of the Henrietta Lacks case were emphasized by participants in this study. In March, 2013, new headlines about scientific behavior in the Lacks case seemed to verify participants’ suspicions. The successful sequencing of the HeLa genome started a veritable firestorm when genetic information about Mrs. Lacks and her descendants was released to the public, again without their consent;

calling into question whether privacy and anonymity can ever be promised in genomics research (Skloot 2013).

African American community leaders in this study also attributed their caution about genetics research to prior victimization by “helicopter research” (Hiratsuka et al. 2012), wherein academic researchers figuratively drop into minority communities, hover there to collect data, and then leave—not to be heard from again. Despite their trepidations, however, participants held out hope for personalized medicine and the health benefits it might bring to their people; they wanted African Americans to have a “seat at the table.” What they envisioned was a way forward for a participatory genomics science that stipulated basic respect for the African American community, authentic collaboration, bidirectional education, transparency and prerogative, and meaningful benefits and remuneration.

The story of African Americans’ mistrust of health care institutions and biomedical research has been told in many studies (e.g., Hall et al. 2001; Musa et al. 2009; Shoff and Yang 2012; White 2005). Their specific mistrust of human genetics research is only more recently becoming apparent (Bonham et al. 2009; Bussey-Jones et al. 2010; McDonald et al. 2012; Skinner et al. 2008). What researchers have found is that African Americans tend to view genetic screening as eugenic in motivation and harmful to society (Beeson and Duster 2002), and compared to European Americans, they are less optimistic about genetic testing (Achter et al. 2005). They are generally opposed to commercial entities like insurance and pharmaceutical companies having a hand in genetics research (Halverson and Ross 2012). Countering this line of research, results of a genetic study of nicotine dependence employing a large, population-based sample suggested that eligible African Americans are as willing to participate in genetic studies as their European American counterparts—if they can be reached (Hartz et al. 2011). According to these researchers, African American under-representation in genetics/genomics research is explained in population-based studies by difficulty locating and contacting them in the community and in clinical trials by their lesser access to health care.

Notwithstanding the importance of pursuing adequate recruitment strategies to reach African Americans, we agree with those researchers who argue that there are complex, historically based reasons for lower rates of genetics research participation by African Americans. Findings of this study provide context and insight into how African Americans have formed their attitudes about genetics/genomics research and what actions it might take by researchers and research institutions to fully engage them in genetics initiatives. Similar to findings from Lemke et al. (2012), these findings emphasize the priority that African Americans place on respect for their community and their wish for equitable access to any new treatments accrued from research using stored tissue samples and health information they have contributed.

Participants in our study discussed ethical issues that go to the heart of current debates about biobanks: transparency, confidentiality, ownership and control of human specimens, participant autonomy and right to withdraw, remuneration for commercial successes, and availability of affordable personalized medicine for African Americans. These same concerns are being voiced by the broader public when the question of DNA biobanking is raised and by biobank participants in other ethnic/racial minority groups such as Alaskan Natives (Hiratsuka et al. 2012). While searching for pragmatic solutions to these dilemmas that will improve outcomes for everyone, society must not forget the science that was developed at the expense of marginalized populations (Lederer 2003, 2005) as this has major implications for the advancement of genetics/genomics.

What many biobanks are currently doing is broad consent. What is “transparent” about broad consent is the lack of specificity and participants’ lack of choice over the future use of their biologic contributions (Scott et al. 2012)—not the kind of transparency participants in this study were looking for. Beyond this sample, members of the public, in general, have been requesting a more “informed” consent process for genomics research and are expressing opposition to the patenting and commercialization of genetic discoveries that may decrease access to genetic services (Caulfield et al. 2003; Haddow et al. 2007).

To address ethical questions, some biobanks have established community advisory boards to serve as conduits between scientists and the community (Terry et al. 2012); others have installed an additional layer of ethics oversight beyond Institutional Review Boards to protect participants in human genetic research (Haddow et al. 2007). Still other ideas being discussed are public ownership of biobanks, profit payoffs to communities, and mechanisms to bring clinically significant outcomes back to biobank donors (Scott et al. 2012). Common practices are developing as biobanks grow, but there is little consensus to date about standardized guidelines (Caulfield 2011), which leaves stakeholders like the African American community at a loss in making decisions about participation.

The challenges and poor outcomes from public health interventions among ethnic minorities have in part been attributed to the lack of meaningful community engagement in the planning, implementation, and evaluation of such programs (Guta et al. 2013). A more sustained engagement with why Tuskegee and HeLa have taken on such symbolic power, despite the widespread existence of other racialized injustices, remains a possibility for future analysis. Likewise, it would be worth pursuing an examination of what African American skepticism may have to offer the more general critique of both personalized medicine and community engagement in health services research.

Limitations of the current study must be acknowledged. The research was sited in one city, leaving unanswered questions

about how African American leaders from communities across the USA would respond to inquiries about participation in biobanks and other genetics initiatives. However, involving community leaders in dialogue about genomics science as a first step in engaging African Americans may be a good model for human genetics initiatives in other places. The small purposive sample limits generalizability, and the focus group design does not lend itself to measurement of attitudes or behaviors in the population. The fact that the principal investigator is an African American may have increased the candor with which participants expressed their sentiments (Center for Assessment and Policy Development 2005). The use of an African American owned transcription service hopefully decreased error in committing spoken word to written text and demonstrated our intention to create a more meaningful and lasting relationship with the community. This type of decision we believe may be an important point to consider in the design of future research involving African Americans and other minorities. Although the findings cannot be taken to represent all African Americans, the nuanced descriptions participants offered may be transferable to other similarly situated communities (Stevens 1996).

Conclusion

From insights gained in this study, we offer four recommendations. First, a comprehensive genomics research agenda must not detract from efforts to eliminate structural determinants of health disparities (Khoury et al. 2012). The science of discovery and the science of translation in the field must be accomplished in concert with the examination of structural disadvantages that drive disparities in health, nutrition, education, employment and income, housing, and exposure to environmental toxins and occupational hazards (Angel 2011; Bliss 2011; Martinez et al. 2011; Thomas and Quinn 2008). Second, it is both essential and urgent that scientists forge partnerships with African American communities to map genomics research priorities, design policies for the ethical conduct of this emerging science, and guarantee equitable distribution of its discoveries. Reaching the full potential of a human genome revolution to advance knowledge about gene–environment interactions is dependent on ongoing cooperation between biomedical scientists, clinicians, and the public whom scientists are trying to reach (O’Daniel et al. 2012; Royal and Dunston 2004). Third, the key to building trust and overcoming African Americans’ trepidation and resistance to participation in biobanks and other genetics initiatives is to engage early and persistently with the community (O’Daniel et al. 2012; Terry et al. 2012). Grassroots community partnerships based on transparency and mutual respect must be operative before the design stage of any research project through implementation and utilization of results. Fourth, local African American community

leaders are gatekeepers and guardians who should not be bypassed in capacity building for genetics research in the African American population; they can be the very fulcrum on which bi-directional education between researchers and community members rests.

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Declaration and statement of human rights and ethical standard

Because this study involved human subjects, it was necessary to seek and obtain Institutional Review Board (IRB) approval. Therefore, IRB approval was sought from the appropriate institution before data were collected and all persons give their signed informed consent prior to inclusion and participating in the study. All study protocols were reviewed and approved by the University of Wisconsin—Milwaukee Institutional Review Board, protocol no. 11.089.

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