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Attitudes of African American parents about biobank participation and return of results for themselves and their children

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Abstract

Introduction—Biobank-based research is growing in importance. A major controversy exists about the return of aggregate and individual research results.

Methods—We used a mixed-method approach in order to study parents' attitudes toward the return of research results regarding themselves and their children. Participants attended four two-hour, deliberative-engagement sessions held on two consecutive Saturdays. Each session consisted of an educational presentation followed by focus-group discussions with structured questions and prompts. This manuscript examines discussions from the second Saturday which focused on the benefits and risks of returning aggregate and individual research results regarding both adults (morning session) and children (afternoon session). Attitudes were assessed in pre- and post-engagement surveys.

Results—We recruited 45 African-American adults whose children received medical care at two health care facilities on the South Side of Chicago that serve different socioeconomic communities. Three dominant themes were identified. First, most participants stated that they would enroll themselves and their children in a biobank, although there was a vocal minority opposed to enrolling children, particularly children unable to participate in the consent process. Second, participants did not distinguish between the results they wanted to receive regarding themselves and their children. Supplemental survey data found no attitudinal changes pre- and post-engagement. Third, participants believed that children should be allowed access to their

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health information, but they wanted to be involved in deciding when and how the information was shared.

Discussion—Participant attitudes are in tension with current biobank policies. An intensive educational effort had no effect on their attitudes.

Keywords

child; parent; biobank; genetic research; return of results; deliberative engagement

Introduction

Biobanks may be disease specific or population based. They may enroll only adults or only children; they may enroll parent-child dyads or family units. Biobanks vary in size from a few dozen participants to over 100,000 participants. The research conducted using biobank-based data ranges from descriptive epidemiology to longitudinal health outcomes to genome-wide association studies.[1-3]

In the United States (US) and internationally, rules governing the participation of minor children in research are different from those governing the participation of adults in three important ways.[4] First, while adults voluntarily consent for themselves to participate in research (unless they lack decision making), the participation of children requires parental permission.[4-5] Second, healthy children can only be enrolled in research that poses at most minimal risk. In general, research ethics review considers enrollment in biobanks to be minimal risk.[4,6] As such, parents have the authority to enroll their children.[4-5,6] Third, while children, particularly young children, lack capacity to enroll in a pediatric biobank, children do mature and reach majority. There is a body of literature about the need to re-consent these minors when they reach adulthood.[5,7-9]

One of the main controversies in biobank-based research is the return of research results.[4,10-14] Historically, the research community did not return any research findings, but broad public disagreement with that policy, supported by advocacy from some scientific and ELSI (ethics, legal and social issues) investigators, has led to reevaluations of this practice.[14,15] While there is broad consensus among healthcare researchers in favor of returning aggregate results for research involving children and adults – “although mechanisms for implementing this process are poorly developed” – the return of individual research results remains quite controversial.[16] There is growing consensus, however, that healthcare researchers have an obligation to return research results that are ‘actionable,’ that is, that would alter clinical management.[16-19] In contrast, the public generally expresses great interest in learning their personal genetic information, regardless of clinical utility.[20]

The controversy about how to handle results persists even as research findings become less immediately relevant. While many studies find that adult participants want the return of most results for themselves and their children,[21] the consensus guidelines (written in 2006 and revised in 2010) recommend against the return of research findings that are ambiguous.[17-18] This is in part because of the resources it would require to explain the findings sufficiently to the participants.[18] Healthcare researchers are even more hesitant to return

ambiguous research findings about children.[9,13] Professional guidelines also recommend against testing children for conditions that only have clinical relevance in adulthood.[22-25] The main arguments in support of non-disclosure of pediatric results are: 1) the right not to know one's genetic predispositions; 2) the child's right to privacy – even from his or her own parents; 3) to avoid labeling and stigmatization; and 4) to reduce the risks of parents seeking non-validated therapies and preventions to counteract the genetic risks identified in their children.

Our project focuses on whether the attitudes and values of an informed public cohere with these guidelines. More specifically, we focused on whether the guidelines resonated with the attitudes and values of informed African-Americans parents from diverse socioeconomic communities. We focused on African Americans because they are less likely to provide genetic samples for biobanks [26-27], and we wanted to understand the underlying reasons for this hesitancy. To examine this issue, we conducted a deliberative engagement with African-American parents from two health care facilities on the South Side of Chicago that serve different socioeconomic communities. A deliberative engagement involves educational programs followed by focus groups in order to identify the attitudes and values of an *informed* public. It differs from a deliberative democracy, which seeks population representation.[28-29] As part of our deliberative engagement, we surveyed the participants both before and after the engagement intervention to determine whether there were attitudinal changes. Previous population surveys have shown that most participants want research results returned,[15,30-34] but these surveys did not include a didactic component to ensure that participants understood the issues. We hypothesized that additional knowledge about the risks and benefits of biobank research and the return of results would modify participant preferences.

Methods

We used a mixed-method, deliberative-engagement approach to study parents' attitudes toward the return of research results regarding themselves and their children. Adults whose children received medical care from one of two pediatric clinics on Chicago's South Side – from a Federally Qualified Health Center (FQHC) and from a university-based practice (UBP) – were recruited. Participants attended four two-hour, deliberative-engagement sessions held on each of two consecutive Saturdays. Each two-hour session consisted of an educational power-point presentation that allowed for questions and discussion by the participants. The didactics were followed by focus-group discussions with structured questions and prompts. Topic discussion guides are enumerated in Table 1. Topics discussed on the first Saturday included types of biobanks, genetic research, informed consent, privacy protection, data sharing and biobank participation. Both disease-specific and population-based biobanks were described, and it was explained that biobanks were designed either to allow or not to allow re-identification of participants. On the following Saturday, participants were instructed to express their opinions about the development of a large-scale, population-based biobank at the University of Chicago and were asked to consider the pros and cons of designing the biobank to allow or not to allow the return of results. The primary focus of the educational slides was on the benefits and risks of returning, and personally receiving, aggregate and individual research results regarding both adults (morning session)

and children (afternoon session). Six types of possible results generated by biobank-based research were discussed: 1) results about treatable conditions, 2) results about untreatable conditions, 3) information about reproductive risks, 4) incidental results (e.g., misattributed parentage), 5) results with uncertain meaning, and 6) results that would not have clinical impact but might have personal meaning (e.g., predisposition to thrill-seeking). Following each presentation the participants took part in a focus-group discussion and responded to questions and prompts. A 24-question survey using mainly five-point Likert scales addressed participants' attitudes and beliefs regarding biobanks and the return of results. The survey was administered both before and after the entire engagement in order to assess attitudinal changes.

Focus group discussions were transcribed and uploaded to Atlas.ti (version 6), a qualitative data management and analysis software program (http://www.atlasti.com). Approximately 25% of transcripts were double coded, and differences were identified and discussed until consensus was achieved. The full study methodology is provided elsewhere,[35] and PowerPoint slides and focus-group guides are available from the corresponding author. The study was approved by the University of Chicago's and Northwestern University's Institutional Review Boards, which waived the requirement for written informed consent. In this manuscript, participants are identified by site of recruitment (Q=FQHC, and U=UBP), by gender (F=female, and M=male), and by a unique number.

Results

Forty-five participants participated in didactic and deliberative discussions. Thirty-four (76%) participants were female, and the mean age was 41 years. All were parents of at least one child and self-identified as African American. Educational achievement was varied, with ten (22%) having at most a high school degree and nine (20%) having at least a four-year college degree. The rest had some college education (26, or 58%) (see Table 2).

In the approximately 27 hours of tape-recorded discussions, we coded 36 categories. In this manuscript we describe and analyze discussions focused on the topics raised on the second Saturday – participants' willingness to enroll themselves and their children in a biobank, and attitudes toward and interest in the return of individual and aggregate results for oneself and for one's child. Three dominant themes were identified: 1) comparative attitudes toward enrolling oneself and one's child, 2) comparative interest in the return of individual and aggregate research results regarding oneself and regarding one's child, and 3) control over when and how to return results to children. We supplemented our second qualitative theme with quantitative survey data.

1. Comparative attitudes toward enrolling oneself and one's child

Some parents expressed differing opinions about enrolling themselves and their child(ren) in a biobank. Most participants said that they themselves would enroll in a biobank. The majority said that they would also enroll their children; however, there was a vocal minority opposed to doing so. One participant said, “I wouldn't do it. I would let him decide, or her decide if she wanna get in that at 18” (QF06). Another individual stated, “I think that should be their choice. That's their body” (UF03). One participant said, “I think I'll allow my kid

[to] be about ten or eleven, and I explain to them why I took part in [the biobank] and get them the choice whether they wanna be a part of it or not" (UM01). Some participants explicitly stated that making such distinctions between self and child was inappropriate. "If it's good enough for you, it should be good enough for your kids," (QM03) said one participant.

2. Comparative interest in the return of individual and aggregate research results regarding oneself and regarding one's child

In the focus-group discussions, participants expressed similar attitudes about the return of results for themselves and that for their children. In the focus groups we specifically differentiated between aggregate and individual results. Participants were slightly less interested in the receipt of aggregate data regarding both themselves and their children than of individual results. A few participants expressed disinterest in receiving aggregate data: "A group research [result], I don't think I would necessarily need to get that information. You know, it's not really benefitting me personally, so no, I wouldn't really need it" (QF07).

During most of the discussions about participation in and governance of biobanks, participants did not have contrasting opinions about biobanks that enrolled adults or children. Similarly, virtually no differences were expressed with regard to the return of pediatric or adult results. Participants even mentioned this explicitly: "It's the same thing as far as with adults as with children" (QM03). Some participants went so far with this analogy that they actually reinterpreted their child's results as their own. When asked whether he would like to receive his child's results, one individual stated, "I need all *my* information" (QM06) [emphasis added]. Another man said, "You need all *yours*." (UM06) [emphasis added].

Very rarely did participants express the view that there was or should be a difference between biobanking with children and with adults. "Doing research on myself is different than how I feel about my kid," (UF01) said one woman without elaborating. Another comment came from a man who noted that it was possible his child could perceive his having her results as "an invasion of [her] privacy" (QM04).

The qualitative data are affirmed and supplemented by our survey data regarding participants' attitudes about the types of results they would and would not want returned from biobank-based genetic research. Overall there was strong interest in having all individual research results returned, with greatest interest expressed in asthma > Alzheimer disease > results about a gene linked to a specific racial/ethnic group > results about a gene with unknown implications (Table 3). On a scale of 1 to 5 – in which 1 represented a strong interest and 5 a strong lack of interest in having results returned – the average scores regarding having one's own results returned on the pre-survey ranged from 1.10 ±0.72 (Alzheimer disease) to 1.58 ±0.99 (gene with unknown implication). On the post-survey, the average scores ranged from 1.24 ±0.83 (asthma) to 2.21 ±1.50 (gene with unknown implication). The changes in interest about receiving one's own results were not significant for any condition pre- and post-survey. Similarly, the average scores for interest in having one's child's results returned on the pre-survey ranged from 1.10 ±0.42 (both asthma and Alzheimer disease) to 1.60 ±1.02 (gene with unknown implications). On the post survey, the

average scores ranged from 1.24 ±0.83 (asthma) to 2.21 ±1.60 (gene with unknown implications). These changes in interest about receiving results about one's child were not significant for any condition pre- and post-survey. Most notable was that virtually all participants (≥97%) rated their interest in receiving results about themselves and their children the same for all conditions in both the pre- and post-surveys.

3. Control over when and how to return results to children

Many participants expressed a desire to maintain control over their children's health information. They believed they had a right to know all of their child's research results: “I don't think there's anything that they [parents] shouldn't know” (UM03). In these people's view, knowing (and even wanting to know) one's child's research results was seen as important to a good parent-child relationship: “If you don't [want to know], there's something about your parenting that you need to get on top of” (QM04).

This type of relationship was not believed to end when the child reached majority. Several participants mentioned that they would still like results about their child even after the child turned 18 or started college. Several of our participants stated that they would expect their children to continue to share these findings with them. In two discussions, participants were probed about whether they would still share their health information with their own parents. Several participants responded that they would and do, despite the fact that they are competent adults. “Even the age I'm at right now, my parents should still know what's going on in my life” (QM06).

Some participants also believed that guardians should act as gatekeepers between the researchers and their children. “Parents may choose what information to give a child,” says one participant (UF11). Another woman said of the decision whether to inform the child of his or her research results, “I think the child has a right to know, [but] the parent is the one that ultimately makes the decision to tell this child” (UF07). Another participant said that the child would be told “when I decide I wanna talk” (QF01).

Discussion

Population biobanks are important resources for facilitating large-scale research in the study of the roles of both genetic and genetic-environmental factors in health.[2-3] Not surprising, individuals who agreed to spend two Saturdays discussing biobanking were hypothetically willing to enroll themselves in a biobank. Most were also willing to enroll their children. However, a minority expressed reluctance about enrolling their children, particularly young children, because they wanted to engage their child in the decision-making process. This finding is consistent with discussion in the literature that children should be asked to assent or at least to have the right to dissent to biobank enrollment, and that in studies that collect data longitudinally, the child's participation should be reviewed over time to give greater authority to the maturing adolescent. [5,7-9]

While healthcare policy makers distinguish between the return of research results regarding adults and children in biobank-based research, our participants did not. In our quantitative data, over 97% of our participants expressed the same level of interest in receiving their

child's research results as their own. In the discussions some even conflated the return of their child's research findings with the receipt of their own health information. Several participants also rejected the idea that the child had a right to keep health information private from the parents and claimed that, even as adults, their own parents had a right to know the participants' health information.

In general, our participants believed that children should be allowed access to their health information, but they wanted to be involved in deciding when and how the information was shared. A positive interpretation of this gatekeeping function is that parents would share the information at ‘teachable moments’ and would provide more information as their child developed the capacity to understand and engage with the information.[36] The concern, however, is that parents might wait for a ‘right moment’ that never arrives and the information may be lost.[36]

Our findings are consistent with other research that finds that many adults believe that they have the right to know everything about themselves. They also want to know everything about their children. Parents believe that they have their child's best interest at heart, that they know their child best, and that they have the authority to decide whether their child should participate in research.[37] Whether their children would agree with their decisions is unknown. One study from Belgium found that adolescents generally were accepting of empowering parents on their behalf.[38] However, there was some sensitive information that the adolescents thought should be kept private from their parents (e.g., drinking habits).[38] Likewise, U.S. children do not always agree with their parents on enrollment in research or about who should be informed about some research findings.[10,39]

Providing aggregate results may not fully satisfy participants, but it is consistent with the concept of respect for research participants as persons without providing a false sense of clinical significance. Consistent with other studies, however, we found our participants less interested in receiving aggregate results.[30,32] The main reason to return individual research findings is to incentivize participation and to show respect for the wishes of the participants.[7,21] Major reasons to restrict access to individual research findings include 1) avoidance of promoting the therapeutic misconception, 2) avoidance of the increased research costs that the return of results would require in terms of genetic counseling; 3) avoidance of the costs of doing or repeating the research in a CLIA-approved laboratory, and 4) protection of children's right to health information privacy, even from their own parents.

Despite the major investment of time and resources, our participants' views remained virtually unchanged in the pre- and post-surveys. Possible explanations for this have been given elsewhere and include: 1) the neutrality of the educational material presented; 2) individuals who agreed to participate already were aware of the risks and benefits; or 3) community attitudes are independent of knowledge.[40] More significant, however, was the lack of distinction made about benefits and risks of benefits/risks of returning results for self and for child despite educational material that described how the participation of children in biobanks was unique and the reasons it might need different guidelines. Either the reasons we provided were not persuasive, the participants did not agree with them, or the

participants did not understand them. In our own defense, there appeared greater nuance in the qualitative data than shown in the quantitative survey data.

There were several limitations to our project. The first was the small sample size, particularly for the quantitative data about interest in receiving results about various health conditions. Second was the lack of generalizability of the qualitative data. Our participants represent a convenience sample of African Americans who live on the South Side of Chicago. While our sample did represent a broad range of educational attainment and received care at two healthcare facilities serving different socioeconomic communities, we cannot extrapolate from this sample about the attitudes of other adult parents from other ethnic or geographic communities.

A third limitation was the use of non-validated educational material. Although we conducted extensive pretesting and piloting of all our materials, it is not clear whether the lack of attitudinal changes was due to lack of participant understanding of the material or a persistence of view despite an intensive educational intervention. Yet even if we had found a major shift in attitudes or differentiation between the return of pediatric and adult results, the intervention lasted approximately eight hours and such an extensive use of resources would not be feasible at the population level. Alternative virtual means of educating the public will need to be developed.

A fourth limitation is that we did not have a question or measurement that specifically asked participants to consider how and whether a pediatric biobank should differ from an adult biobank. Rather, we had two distinct sessions devoted to the return of results – one focused on results about themselves and the other about their children. Likewise our survey asked the participants to rate their interest in receiving results about themselves and about their child in two side-by-side columns, but did not ask them to consider why they should or should not be different. Thus, the fact that the participants did not differentiate between pediatric and adult biobanks regarding the governance, structure, or return of results policies might be due in part to our methods and should be explored more systematically in future studies.

Conclusions

Participants' attitudes are in tension with current biobank policies. Although current policies distinguish between the return of research findings involving adult and pediatric participants, participants in our deliberative engagements did not. Further empirical and analytical research are needed to determine whether 1) the policies need to be changed, or 2) the policies should be upheld despite their unpopularity in the lay community. If one opts for the latter, then additional research is needed to determine whether and how the public can be educated in order to support policies that distinguish biobank research with children from that with adult participants.

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Abbreviations

ELSI Ethics, legal and social issues

FQHC	Federally Qualified Health Center
UBP	university-based practice

Table 1

Discussion Guide Topics

FIRST SATURDAY	SECOND SATURDAY
MORNING Overview of biobanking Genetics	**MORNING** 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
AFTERNOON Biobank-based genetic research	**AFTERNOON** 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

This table is modified from BLOCKED.

Table 2

Demographics (N=45)

Participant Characteristics	N
Age (mean ± s.d.)	41 ±13
Gender	
Male	11
Female	34
Clinic	
FQHC	22
University Based Practice	23
Education	
≤ High School	10
> High School, < College Graduate	26
≥ College Graduate	9
Race	
Only Black/African American	42
Black and other races	3
Number of children	
1-3	36
≥ 4	9
Participated in genetic research	
Yes	1
No	44

Table 3

Pre- and Post-Survey Responses Regarding the Return of Individual Research Results about Specific Genetic Findings

	PRE-SURVEY			POST-SURVEY		
I would want research results returned that identify a change in a gene	**Average parent score ± s.d.***	**Average child score ± s.d.***	**Identical responses for parent and child n/d^ (%)**	**Average parent score ± s.d.***	**Average child score ± s.d.***	**Identical responses for parent and child n/d^ (%)**
Asthma (treatable condition).	1.12 ± 0.44	1.10 ±0.42	40/41 (98)	1.24 ±0.83	1.24 ±0.83	33/33 (100)
Alzheimer disease (largely untreatable condition).	1.10 ±0.72	1.10 ±0.72	41/41 (100)	1.41 ±0.95	1.50 ±1.05	31/32 (97)
Gene linked to specific racial/ethnic group	1.56 ±1.06	1.53 ±1.03	42/43 (98)	1.36 ±0.97	1.48 ±1.00	32/33 (97)
Gene with unknown implications	1.58 ±0.99	1.60 ±1.02	42/43 (98)	2.21 ±1.60	2.21 ±1.60	33/33 (100)

*Average Likert scale ± standard deviation (s.d.) where 1 = strongly agree, 3 = neither agree nor disagree, and 5 = strongly disagree.

^n/d= numerator/denominator. The denominator varies due to non-responders