Willingness of women to participate in obstetrical and pediatric research involving biobanks

Renate D. Savich¹ · Beth B Tigges² · Lisbeth Iglesias Rios³ · Joanne McCloskey⁴ · Kristine Tollestrup⁵ · Robert D. Annett¹

Received: 14 November 2018 / Accepted: 12 November 2019 / Published online: 28 November 2019
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Abstract

Use of biobanks for future genetic/genomic testing has increased. Biospecimens are increasingly being collected from infants/children; however, little is known about attitudes towards collection of biospecimens from postpartum women and their child. Using a hypothetical consent, this study investigated willingness to participate and attitudes, beliefs, and concerns related to consent materials requesting the biobanking genetic samples. A cross-sectional mixed methods design included women who reviewed a hypothetical consent related to biobanking genetic samples. Women were asked about their willingness to participate, followed by a focus group about biobanks and genetic/genomic testing. Post-focus group questionnaires assessed willingness to participate, the influence of study characteristics, and attitudes about genetic testing. Women ($N = 37$) were 29.0 ± 7.3 years of age (range 19–44); 51% had children and 28% were currently pregnant. A total of 46% were Hispanic (H), 38% were White non-Hispanic (WNH), and 16% were Native American (NA). Seventy-six percent (28/37) initially indicated that they would participate in the hypothetical study. Race and ethnicity impacted whether women would participate. Fewer NA women indicated that they would participate compared with H women and with WNH women ($p < 0.02$). Age, pregnancy status, having children, education level, insurance status, and income had no impact on participation decision and willingness to biobank specimens. NA and H women indicated that they were less likely than WNH women to agree to participate in a long-term biobank study. Given the importance of determining the genetic influence of health and disease, it is critical to attend to the questions and concerns of minority women regarding genetic studies.

Keywords Biobank · Informed consent · Genetic testing · Children

Introduction

Pediatric biobanking appears to be rapidly expanding, and there is no doubt that research in this area will have a major

impact on the health of children (Boyer et al. 2012; Henderson et al. 2013). The potential for diagnosis, prevention, and treatment of childhood illness is enormous as evident in the federal mandate for the Precision Medicine Institute (Collins 2015; Collins and Varmus 2015). However, a challenge to obtaining biological samples is acquiring informed consent to collect and bank samples for genetic/genomic testing (Joseph et al. 2008; Kang et al. 2013; Neidich et al. 2008; Ormond et al. 2009; Samuel et al. 2012). It is critical that pediatric research include populations at high risk of adverse outcomes, such as those from Native American, Hispanic, or African American communities (Li et al. 2018). Unfortunately, little research has investigated the concerns of families from these groups related to biobanking and future genetic testing (Kong et al. 2016; Hens et al. 2011a; Salvaterra et al. 2014).

Pediatric research and the use of genetic material from women and children requires a careful and thoughtful consent process (Samuel et al. 2012). Obtaining valid informed

✉ Robert D. Annett
rannett@umc.edu

¹ Pediatrics, University of Mississippi Medical Center, 2500 N State St, Jackson, MS 39216-4505, USA

² College of Nursing, University of New Mexico, Albuquerque, NM, USA

³ School of Public Health, University of Michigan, Ann Arbor, MI, USA

⁴ Department of Family and Community Medicine, University of New Mexico Health Sciences Center, Albuquerque, NM, USA

⁵ College of Population Health, University of New Mexico Health Sciences Center, Albuquerque, NM, USA

consent for the research is already complex, yet when research includes sensitive issues such as the impact of genetics upon child health, this can further complicate the process by raising parent worry about the genetic contribution to a child's health condition. Even more sensitive may be when minority families are included in sampling. Not only the use of genetic samples, but also the use of experimental medications and completion of questionnaires can create different perceptions among the participants (Annett et al. 2004).

Aims in the current study were to (1) assess women's attitudes, beliefs, and concerns related to the use of biobanking for genetic material and (2) identify factors that contribute to women's willingness to participate in long-term pediatric studies. This project tested the hypothesis that ethnic/racial minority women would be less willing than White non-Hispanic women to participate in research that included genetic/genomic testing and biobanking. Our secondary hypothesis was that research components, including genetic testing, would influence the participant's decision.

Methods

Study design and sample

A cross-sectional mixed methods design involving focus groups and questionnaires included women recruited from clinics at an academic health sciences center. Eligible participants were: a) female, 18–44 years of age; b) capable of providing informed consent; and c) able to read and speak English. Women were recruited from 3 strata: (a) never been pregnant, (b) currently pregnant, and (c) women who have children but are not currently pregnant. Study procedures were approved by the Institutional Review Board and written informed consent was provided by all participants.

Procedure

Participants were recruited 4 weeks before focus group sessions. Confirmation letters were mailed to each participant 1 week beforehand. Each of the 4 focus group meetings began with consenting women and followed by moderator providing a scripted overview of the hypothetical consent as participants read along. After reading the hypothetical consent, participants completed a 3-item questionnaire (willingness to participate).

Focus groups were moderated by an experienced facilitator and were audiotaped. The example hypothetical consent form was from the National Children's Study (NCS), a birth cohort study asking participants to provide biospecimens for future genetic testing. Participants were provided with the entire NCS consent form.

After the 3-item questionnaires were completed, the focus group discussion began and lasted for 45–60 min. Open-ended questions asked about the biobanking of genetic information for future testing as described in the NCS consent. Questions were continually explained, modified, and redirected to encourage discussion and ensure that all aspects of women's attitudes, beliefs, and concerns about the biobanking of genetic information were discussed. After the focus groups, participants again completed the 3-item questionnaire and this was followed by the 7 brief questionnaires presented below. Participants received a gift card as appreciation for their time.

Measures

Willingness to participate

Items were adapted from the earlier work by Annett and colleagues (Annett et al. 2004; Brody et al. 2006; Brody et al. 2005). Women were asked, "If you had to choose now, how likely would you agree to enroll yourself and your child in this study?" Response choices ranged from "definitely not" (Boyer et al. 2012) to "definitely yes" (Neidich et al. 2008). Women were then asked, "If you had to say for sure, would it be "yes" or "no"?" Women were also able to indicate reasons for their decision.

Influence questions

Participants were asked how study components would influence their decision to "not participate" or "participate." Response options ranged from "strongly influences me to not participate" (Boyer et al. 2012) to "strongly influences me to participate" (Neidich et al. 2008).

Perceptions of the hypothetical consent

Women were asked about their perceptions of participation for both themselves and their child. These items have been previously empirically evaluated (Annett et al. 2004; Brody et al. 2003). Response choices ranged from "not at all" (1) to "a lot" (7).

Attitudes towards genetic testing

This 11-item measure was adapted from the factor structure of the Genetic Attitudes Assessment Tool (GAAT), which measures parental attitudes towards genetic testing for childhood hearing loss (Li et al. 2007). For this study, the words "hearing loss" were replaced with "health problems." An example of an item is "I would not want to have genetic testing for my child because the information could be misused." Response options ranged from "strongly disagree" (1) to "strongly agree" (5).

Item responses were added to create a total score; a higher score indicated a more positive attitude about genetic testing (Cronbach's $\alpha = 0.784$).

Trust of medical researchers

Trust was measured using 6 items that have been associated with willingness to participate in a hypothetical pediatric biobank and research (Neidich et al. 2008; Hall et al. 2006). Participants responded to items such as “I trust medical researchers to keep my samples and medical information confidential and private” using a scale ranging from “strongly disagree” (1) to “strongly agree” (5). Item responses were added to create a total score; a higher score indicated a more positive attitude about trust in medical researchers (Cronbach's $\alpha = 0.902$).

Medical researchers' justice

Perceptions of justice in clinical research were measured using a previously validated 4-item instrument (Neidich et al. 2008). Item responses were added to create a total score; a higher score indicated a more positive attitude about medical research (Cronbach's $\alpha = 0.771$).

Understanding of biobanks

Understanding of the confidentiality of biobanks was measured using a 7-item questionnaire that has been previously validated (Neidich et al. 2008). Content is related to accessibility of medical information (2 items), privacy (4 items), and perceptions of minimal risk (1 item). Respondents indicated whether they thought the item was “true,” “false,” or “not sure.”

Demographic items

Items assessed women's age, race and ethnicity, pregnancy status, and number and ages of children, level of education, health insurance, and family income.

Data analysis

Participant's willingness to participate was examined across demographic variables and questionnaire data with paired chi squares for categorical variables and *t* tests for continuous variables. Univariate linear modeling was utilized for subsequent examination of groups on questionnaire scores. Internal reliability of questionnaires was assessed. All data was analyzed in SPSS (IBM Corp. Released 2013. IBM SPSS, Version 22.0).

Results

Demographics and willingness to participate

Participant characteristics

Focus groups involved a total of 37 participants (range 9–12 women/group, age range 19–44 years; Table 1). Women were predominantly Hispanic, on public health insurance or had no insurance, were likely to have experienced pregnancy, and were from households with incomes of \$40,000 or less, reflecting the racial/ethnic composition of the location.

Women were asked about both their willingness (yes/no) and the degree of their willingness to participate in a study which included biobanking (willingness to participate questionnaire, 1 = definitely not participate, 7 = definitely participate). Prior to the focus group, 26 (70%) of the women were willing to participate. After the focus group discussion, 27 (73%) were willing to participate. Attitudes towards participation did not change as a result of the focus group (4.70 vs 4.86; $p = .38$). Ten (27%) of women were consistent in not willing to participate at any time, and these opinions were significantly stronger after the group (1.8 95% CI 1.06–2.54) than they were before (2.7 95% CI 1.93–3.53, $p = .0001$). In contrast, the women who were willing to participate before and after the focus group became even more positive after the discussion (5.5 95% CI 5.01–6.06 vs 6.0 95% CI 5.53–6.47; $p = .0001$).

We observed race/ethnicity to be significantly associated with willingness to participate. Before the group, 13/14 (93%) of White non-Hispanic (WNH) women, but only 11/17 (65%) of Hispanic (H), and 2/6 (33%) of Native American (NA) women were willing to participate ($X^2 (2) = 7.59$; $p = .022$). After the group, differences remained ($X^2 (2) = 7.64$; $p = .022$) with NA ($OR = 0.04$; 95% CI = 0.003–0.54; $p = .02$) and H women ($OR = 0.19$; 95% CI = 0.02–1.82, $p = NS$) less likely to be willing to participate than WNH women (Fig. 1). Age, pregnancy status, currently having children, education level, and family income were not associated with willingness to participate (Table 1). Women who were currently pregnant, had more education, and at least have some private insurance expressed more willingness to participate.

Concerns and perceptions about long-term birth cohort studies and genetic testing

Study components and willingness to participate

Our analyses included the extent to which distinctions were made between 11 study components in the final participation decision. Five of the components distinguished between those who would and would not participate (Table 2). Interestingly, these were among the lowest ranked features by both groups, but women who indicated that they would not participate rated

Table 1 Sample characteristics and post-focus group willingness to participate (yes/no)

Sample characteristics (<i>N</i> = 37)	Post-focus group willingness to participate	
	Yes (<i>N</i> = 27)	No (<i>N</i> = 10)
Age M (SD)	28.6 (7.0)	29.4 (9.0)
Race/ethnicity		
Hispanic (H)	12	5
White/non-Hispanic (WNH)	13	1
Native American (NA)	2	4
Pregnancy/child status		
Ever pregnant (<i>N</i> = 37)		
Yes	17	6
No	10	4
Currently pregnant (<i>N</i> = 37)		
Yes	9	1
No	18	9
Have children (<i>N</i> = 36*)		
Yes	13	5
No	13	5
Education/insurance/income status		
Education level (<i>N</i> = 37)		
≤ High school	7	5
AA/vocational	5	3
AA/Vocational ≥ College	15	2
Insurance (<i>N</i> = 37)		
No insurance	4	2
Medicaid	9	6
Any private	14	2
Income (<i>N</i> = 37)		
< \$20,000	12	3
\$20–40,000	8	6
> \$40,000	7	1

*Missing data

these components significantly lower than those who would participate. The proposed 21-year length was the most negative factor, but less so for those who would participate. Several components of biobanking were rated positively by both groups but did not distinguish who would or would not participate. The potential impact of helping their own children or other children were the most positive influential factor, but more positive for those who would participate. Therefore, we found that only perceived negative aspects would significantly influence participation.

We investigated whether perceptions of factors related to risk, stress, and inconvenience had an impact on participation (Table 2). Those who would not participate perceived the study to be riskier ($t = 3.32$; $p = .002$; $t = 3.18$; $p = .003$), more physically unpleasant ($t = 3.10$; $p = .004$), and more stressful for children ($t = 2.37$; $p = .023$) and themselves ($t = 2.15$; $p = .038$).

Attitudes towards genetic testing and medical research and willingness to participate

Reliability of the attitudes towards genetic testing (ATGT), medical researchers (MRS)-trust, and MRS-justice was assessed (Cronbach's alphas 0.78, 0.90, and 0.77, respectively). Composite scores of each of the measures were highly correlated with the likelihood of participation (ATGT $r = 0.535$, $p < 0.01$; MRS-trust $r = 0.506$, $p < 0.01$; MRS-justice $r = 0.344$, $p < 0.05$). The ATGT composite score significantly differentiated between participation decision ($p = .01$), as did the MRS-trust sum ($p = .001$; Table 3).

Composite scores on ATGT, MRS-trust, and MRS-justice were examined by race/ethnicity, child/pregnancy status, and education or income (Table 4). ATGT scores were significantly different between the race/ethnicity groups with NA women having a lower score compared with WNH women. No

Note. 1=Definitely not participate, 4=Neutral, 7=Definitely participate

^a $p=0.003$, White/Non-Hispanic vs Hispanic/Native American

^b $p=.002$, Native American vs White/Non-Hispanic

^c $p=.03$, Native American vs Hispanic

Fig. 1 Degree of willingness to participate by race and ethnicity ($N=37$)

significant differences were observed in race or ethnicity for MRS-trust or MRS-justice composite scores. Those who attended college or had any private insurance also scored significantly higher in the survey about ATGT with no differences seen for the other socio-demographic features.

Understanding of the confidentiality of biobanks

Finally, we determined if women had an understanding of who would have access to the information. While most women understood correctly that researchers would have access to the child's medical information (73.8%), there were significant misperceptions and uncertainties about who else, such as other family members, law enforcement, insurance companies, and employers, would be able to access information (Table 5). Thus, for example, 54.7% of the women were incorrect or uncertain about biobanked genetic information would be available to other family members.

Discussion

Increasing understanding of the impact of genetics on health/disease has led to an expansion in researchers seeking specimens for biobanking for the purpose of future genetic/genomic testing. Worldwide research has investigated factors that would influence adults in participation of studies that involve collection of specimens for biobanking, genetic testing, and future research (Beskow et al. 2010; Critchley et al. 2012; Rose et al. 2005; Pulley et al. 2008). These studies revealed critical misperceptions about biobanking and genetic testing, as well as racial and ethnic differences in participation and understanding (Nechuta et al. 2012; Singer et al. 2004;

Zimmerman et al. 2006). Our results are consistent with previous research and extend previous findings specifically for pediatric research. Importantly, clear differences were observed in willingness of women to consent themselves and their child to a hypothetical study where biospecimens would be collected and genetic testing completed. These findings extend previous work by identifying the extent to which research components such as study duration and collection of genetic material likely contribute to the consent of decision-making process (Annett et al. 2004; Brody et al. 2006; Brody et al. 2005). Moreover, we observed that demographic characteristics contribute to the decision-making process. Our findings suggest that remaining issues regarding the confidentiality of biobanks need to be considered in the process of obtaining valid informed consent.

Obtaining biospecimens from infants and children for genetic/genomic testing involves additional ethical issues in the consent process, especially when participants are followed for a long time. Some researchers have emphasized the importance of biobanking in improving child health and strategies to optimize this resource (Brisson et al. 2012; Brothers 2011). Others have shown success in obtaining consent and prenatal biospecimens from pregnant women and fathers (Abdul-Rahman et al. 2016). However, little is known about the influences of women's participation decision related to research involving obtaining of biospecimens from their children and themselves. Our findings suggest that racial/ethnic health care disparities contribute to the participation decision and will be important to appreciate in consenting for research among families participating in biomedical research.

Research investigating the impact of genetics on child health and disease will need to exercise sensitivity to the concerns of minority families. When pediatric research entails biospecimens

Table 2 Characteristics, perceptions of risk, and willingness to participate

	Willingness to Participate		<i>t</i> value <i>df</i> = 37	<i>p</i>
	Yes M (SD)	No		
Influences upon participation	<i>N</i> = 27	<i>N</i> = 12		
Length of the study (21 years)	3.9 (1.5)	2.2 (1.4)	− 3.46	.001
The collection of genetic material from me and my child	5.1 (1.5)	3.1 (2.2)	− 3.40	.002
Fitting the study into my schedule	4.9 (1.4)	3.6 (1.8)	− 2.50	.017
My expectation on whether my child's other parent would want to participate	4.7 (1.5)	3.4 (1.8)	− 2.26	.030
Time it would take to have the medical tests done	3.5 (2.2)	4.7 (1.1)		.03
Positively perceived study components ^b				
Potential to help my child's health	6.5 (0.8)	6.6 (0.8)	NS	
Possibility of helping others when genetically based illness	6.3 (0.9)	6.4 (0.9)	NS	
Regular monitoring of my child's health	5.8 (1.4)	6.4 (1.1)	NS	
The scientific value of the study	5.8 (1.2)	6.1 (1.4)	NS	
Perceptions of the hypothetical consent	<i>n</i> = 30	<i>n</i> = 12	<i>df</i> = 40	
How risky do you think this study is overall for your child?	3.3 (1.6)	5.3 (2.3)	3.32	.002
How risky do you think this study is overall for you?	3.1 (1.7)	5.2 (2.4)	3.18	.003
How physically unpleasant do you feel this study is overall for your child?	3.5 (1.4)	4.9 (2.0)	3.10	.004
How physically unpleasant do you feel this study is overall for you?	2.6 (1.5)	3.9 (1.8)	2.89	.006
How stressful do you think this study is overall for your child?	3.1 (1.6)	4.9 (1.8)	2.37	.023
How stressful do you think this study is overall for you?	3.7 (1.4)	4.3 (1.9)	2.15	.038

^a Questions from (A) influences questions (1 = strongly not participate, 7 = strongly yes participate); (B) perceptions of the hypothetical consent (1 = not at all, 7 = a lot)

^b Components positively perceived by yes and no groups post-focus groups, but not different by participation decision

for banking, it is critical to understand attitudes about genetic testing and whether racial/ethnic differences exist (Lemke et al. 2012; Campbell and Ross 2005). Findings in this study suggest that minority communities have some distrust in collecting specimens for biobanking. Ethnicity may exert influence upon decision-making in pediatric research that includes biobanking. Little research has focused on Hispanic women and Native American women, and their thoughts about participating in biobanking studies. We found that Native and Hispanic women had significant reservations about research participation that included biobanking. Our findings are congruent with previous

studies that found Hispanic women less likely to participate in the collection of biospecimens at the time of pregnancy (Nechuta et al. 2012). Among postpartum women (58% Hispanic) asked about residual and future biospecimen collection related to their child, race did not have an impact (Kozinetz et al. 2016). Given the increase in the US Hispanic population, it is critical to improve methods for researchers to appreciate the beliefs that might impact enrollment in biobanking studies.

Our study suggests that Native American women are less likely to enroll in research that includes biobanking for future genetic/genomic testing. We observed that Native

Table 3 Attitudes about genetic testing and medical research related to participation decision

	Would participate in study? “Yes”	Would participate in study? “No”	<i>p</i> value
Attitudes towards genetic testing ^a	43.1 (6.2)	34.3 (5.5)	0.001
MRS-trust ^b	22.6 (5.6)	15.6 (5.0)	0.001
MRS-justice ^c	15.1 (3.3)	13.0 (3.9)	NS

^a ATGT total score from 11 items (max score = 55); higher score indicates more positive attitudes about genetic testing

^b MRS-trust total score from 6 items (max score = 30); higher score indicates more positive attitudes towards medical researchers

^c MRS-justice total score from 4 items (max score = 20); higher score indicates more positive attitudes towards justice in clinical research

Table 4 Key demographics and attitudes towards genetic testing (ATGT) total, MRS-trust, and MRS-justice

Demographics	ATGT total ^a M(SD)	MRS-trust ^b	MRS-justice ^c
Race/ethnicity			
Non-Hispanic White (<i>n</i> = 13)	43.8 (6.5)*	20.7 (6.2)	15.3 (3.7)
Hispanic (<i>n</i> = 16)	40.6 (6.0)	22.7 (6.2)	14.8 (2.8)
Native American (<i>n</i> = 6)	35.2 (8.6)*	16.0 (6.0)	12.7 (5.4)
Education level			
< College (<i>n</i> = 19)	38.4 (7.4)**	21.3 (6.6)	13.8 (3.6)
≥ College (<i>n</i> = 16)	43.8 (5.7)**	20.3 (6.2)	15.5 (3.7)
Insurance			
Medicaid/no insurance (<i>n</i> = 20)	38.7 (7.0)***	20.2 (6.8)	14.3 (3.7)
Any private (<i>n</i> = 15)	43.7 (6.3)***	21.7 (5.8)	15.1 (3.8)

*NA vs NHW; *p* = .04***p* = .025****p* = .036^a ATGT, attitudes towards genetic testing (max score = 55)^b MRS-trust, trust of medical researchers (max score = 30)^c MRS-justice, justice in medical research (max score = 20)

American women have less trust in medical research (MRS-trust = 16.0) and differentially value the benefits of clinical research (ATGT = 35.2). These findings instruct researchers to be sensitive to the concerns that accompany efforts to recruit Native American women. Others have voiced this need, including the importance of cultural sensitivity and privacy issues in this population (Dang et al. 2014; Haring et al. 2018).

Components of the research study influenced whether or not the women chose to enroll. Perceptions of risks within the study, physical unpleasantness, as well as the stress of the

study differentiated whether or not women would participate. Altruistic elements of research participation have been reported in studies involving children and may be an aspect that researchers will want to discuss during consent (Klima et al. 2014). Parents appear to want to help others and desired results returned, but concerns for pain related to study procedures may preclude consent for their child (Hens et al. 2011b; Salvaterra et al. 2012). Our findings emphasize that research risks and benefits need to be discussed in order to ensure complete understanding of the study elements and that benefits will not be overstated.

Table 5 Women's understanding of biobanks^a

Items	Response options ^b		
	True %	False	Not sure
The research team would have access to your child's medical information	73.8	7.1	19.0
The research team would have access to your child's medical information that is obtained at any medical institution	28.6	28.6	42.9
Your child's participation in a biobank would increase the likelihood that your child's genetic information would be available to other family members	33.3	45.2	21.4
Your child's participation in a biobank would increase the likelihood that your child's genetic information would be available to law enforcement officials.	21.4	40.5	38.1
Your child's participation in a biobank would increase the likelihood that your child's genetic information would be available to your employer	7.1	64.3	28.6
Your child's participation in a biobank would increase the likelihood that your child's genetic information would be available to your insurance company	16.7	50.0	33.3
The risks and discomforts of this research are minimal	71.4	11.9	16.7

^a Percent of women answering questions about the hypothetical consent as "True" "False" or "Not sure"^b Correct responses are in italic numbers

Part of a valid informed consent is the investigator obligation to provide an understanding about genetic testing and to assess appreciation of benefits and risks, thus creating a relationship between researchers and participants. Not surprisingly, our findings reveal that women who felt more positive about genetic testing and trusted medical research acknowledged greater willingness to participate. Attitude towards genetic testing was influenced by race and ethnicity, and those with a higher educational level and private insurance were more likely to have a positive view. Thus, additional researcher sensitivity may need to be developed to enroll women and children at greatest risk for adverse health outcomes, such as those living in rural and medically underserved communities.

Finally, women had several misunderstandings about participating in biobanking. Misunderstandings in pediatric research have been reported by others where it has been unclear to women who would have access to the information obtained from the genetic samples (Hall et al. 2006). Researchers seeking to obtain biosamples are cautioned to be aware of local laws governing protection of participants and to carefully explain to women and families that results are not distributed beyond the research setting, nor can they be used in the future by employers, law enforcement, or insurance companies. Within pediatric studies involving biobanking, a certificate of confidentiality may help to provide this level of reassurance to families (Coffey and Ross 2004; Williams and Wolf 2013; Wolf et al. 2015).

Our study has several strengths in investigating the likelihood of women participating in biobanks for future genetic/genomic testing. We were successful in recruiting Native American and Hispanic women. We evaluated whether there were racial and ethnic differences that might influence research participation that included biobanking. We investigated women's attitudes towards genetic testing and research, and how race and ethnicity impacted these attitudes. Few studies to date have sought to assess the attitudes of minority women towards biobanking for future genetic testing. Our findings begin to inform this gap in our understanding of these attitudes.

Limitations

While the percent of Native American women in the study reflected the percentage of these women in our state, our findings are limited to Native communities in the Southwestern USA. Women under 18 years of age who have a child would be candidates for pediatric research involving biobanking; however, we did not include women under 18 with children in our study. The research participation decision can involve both women and their significant others, yet significant others were not included. Finally, participants were asked to consider a hypothetical pediatric study that included biobanking of

genetic samples, and thus we urge caution in generalizing these findings to actual pediatric clinical trial research.

In summary, our findings inform researchers seeking to enroll women and children in studies that include biobanking for genetic testing. Features of the research can impact participation in long-term research of women and their children when biobanking and genetic/genomic testing are included. Thus, it is imperative upon investigators to carefully consider how biobanking and genetic testing may be perceived by the individuals recruited. Racial/ethnic perceptions of the informed consent participation decision are important to evaluate. Using community advisory committees to highlight and develop solutions for community concerns is strongly encouraged. Understanding of genetic testing and trust in medical research are critical for valid research participation decision-making.

Funding information This work was funded from a grant from the Department of Pediatrics at the University of New Mexico Health Sciences Center for the first author.

Compliance with ethical standards

Conflict of interest The authors declare that they have no conflicts of interest.

Ethical approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed consent Informed consent was obtained from all individual participants included in the study.

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