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ORIGINAL ARTICLE

Differences in preferences for models of consent for biobanks between Black and White women

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Abstract Biobanks are essential resources, and participation by individuals from diverse groups is needed. Various models of consent have been proposed for secondary research use of biospecimens, differing in level of donor control and information received. Data are needed regarding participant preferences for models of consent, particularly among minorities. We conducted qualitative semi-structured interviews with 60 women to examine their attitudes about different models of consent. Recruitment was stratified by race (Black/White) and prior biobank participation (yes/no). Two coders independently coded interview transcripts. Qualitative thematic analysis was conducted using NVivo 10. The majority of Black and White participants preferred "broad" consent (i.e., blanket permission for secondary research use of biospecimens), and the second most preferred model for both groups was "study-specific" consent (i.e., consent for each future research study). The qualitative analysis showed that participants selected their most preferred model for 3 major reasons: having enough information, having control over their sample, and being asked for permission. Least preferred was notice model (i.e., participants notified that biospecimens may be used in future research). Attitudes toward models of consent differed somewhat by race and prior biobank participation. Participants preferred models of consent for secondary research use of biospecimens that provided them with both specific and general information, control over their biospecimens, and asked them to give permission for use. Our findings suggest that it will be important for researchers to provide information about future uses of biospecimens to the extent possible and have an explicit permission step for secondary research use.

Keywords Biobanks · Informed consent · Race/ethnicity · Participant preferences

Introduction

Research with stored biospecimens can provide substantial societal benefits, including greater understanding of disease mechanisms and discovery of new therapeutic modalities (Davey Smith et al. 2005; Hansson et al. 2006; Khoury et al. 2004; Stjernschantz Forsberg et al. 2011). However, participants who donate biospecimens for research may face some risks (Meslin and Quaid 2004; Trinidad et al. 2011) including unwanted information disclosure, particularly as genetic data generated in biobank research is increasingly linked to clinical data (Greely 2007; Wendler and Emanuel 2002). A critical social and ethical issue in biobank research is secondary research use of biospecimens, or the use of samples for research that was unplanned at the time of biospecimen collection (Chen et al. 2005; Murphy et al. 2009; Salvaterra et al. 2008; Simon et al. 2011; Williams and Wolf 2013).

Various models of consent have been proposed for secondary research use of biospecimens (Hansson et al. 2006; Mello

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and Wolf 2010; Petrini 2010; Stjernschantz Forsberg et al. 2011; Wendler 2012). Many biobanks have used a notice model of consent, in which individuals are notified that their biospecimens may be used for secondary research purposes, often as part of a general consent form used at the time of donation. In an opt-out consent model, individuals are notified that their biospecimens may be used for secondary research purposes at the time of donation, but they are able to opt-out of secondary use. In a broad, or blanket, model of consent, individuals are asked for their permission to allow storage and use of their biospecimens for all secondary research purposes. In a study-specific model of consent, individuals are asked to give consent for each future research study in which their biospecimen would be used (Simon et al. 2011). In 2011, the US Department of Health and Human Services released an Advance Notice of Proposed Rulemaking (ANPRM), seeking public perspective to guide possible changes to policies regarding human subjects' research protection (U.S. Department of Health and Human Services 2011). The current policy is that research using biospecimens previously collected for research or clinical use can be conducted without additional consent if certain conditions are met, including if any personal identifying information is removed or not recorded or if the research meets requirements for waiver of consent (Platt et al. 2013; U.S. Department of Health and Human Services 2009). The National Institutes of Health (2014) recently finalized a revised Genomic Data Sharing policy which details that funding applications submitted on or after January 25, 2015 should, among other things, include informed consent wording detailing that samples will be used for broad biomedical purposes without specific data use limitations.

Previous research has indicated that populations including cancer patients (Helft et al. 2007; Huber et al. 2013; Pentz et al. 2006), research participants (Chen et al. 2005; Scott et al. 2010), clinical patients with private insurance (Rahm et al. 2013), and the general public (Secko et al. 2009) generally support biobanking and secondary research use of stored biospecimens. However, previous studies have found that African Americans (Chen et al. 2005; McQuillan et al. 2006; Scott et al. 2010), Hispanics (Scott et al. 2010), and younger adults (Luque et al. 2012; McDonald et al. 2013) are less supportive of biobank research or less willing to donate a biospecimen for secondary research use. More empirical research is needed to address preferences for models of consent for secondary research use of biospecimens among potential donors. Of particular concern is the lack of data from groups underrepresented in research (Luque et al. 2012; Pentz et al. 2006), including racial and ethnic minorities and individuals with limited educational attainment (Beskow et al. 2001; Jeffers 2001; Kaufman et al. 2012; Stephenson 1996). It is critically important to understand the preferences for models of consent for secondary research use of biospecimens of diverse individuals, because participation of all population subgroups in biobanks is essential to reach translational research goals (Meslin and Quaid 2004; Moodley et al. 2014; Pentz et al. 2006). Therefore, in this study, we conducted an in-depth examination of Black and White women's views about different models of informed consent and examined whether these perceptions varied by race or prior biobank participation.

Methods

Design overview

In order to examine participants' preferences for models of consent in depth, we conducted qualitative, semi-structured, individual in-person interviews with 60 women.

Participants

All participants in this study were female. We only recruited women affiliated with a comprehensive cancer center because we sought to examine how model of consent might affect enrollment in a biobank through a breast health services clinic at the center. To investigate whether racial group and prior biobank participation affected preferences for model of consent, we stratified recruitment by race (Black/White) and prior participation in a biobank called the Women's Health Repository (WHR) (yes/no). The WHR is a biobank resource established to support research on cancers affecting women. Participants in the WHR, a cohort of 11,316 women who sought breast health services at a breast health center affiliated with a comprehensive cancer center at a large metropolitan hospital, had previously agreed to be recontacted for research purposes.

For the present study, inclusion criteria were self-reported race as either non-Hispanic Black or non-Hispanic White and having utilized breast health services (e.g., screening or diagnostic mammogram, breast biopsy, or breast cancer care). We focused on women identifying as either Black or White because these two groups comprise over 90 % of individuals in St. Louis city and county (U.S. Census Bureau 2012). We recruited only women who had utilized breast health services so that the participants who had and had not participated in the WHR biobank would be more comparable.

We sent 138 WHR participants, selected at random, letters describing the study and asked them to call and schedule an appointment for an interview. Thirty-four women called to schedule an interview; of these 34, 31 women completed an interview. To recruit the other participants, we distributed flyers at branches of the Alvin J. Siteman Cancer Center, an academic cancer center connected with a large metropolitan hospital, including the main urban branch, two suburban branches, and one exurban branch. We also gave presentations

about the study to a breast cancer advocacy group and patient and family advisory council, and members of these groups distributed information about the study. Interested women were asked to call the study office to schedule an interview. Twenty-nine women recruited through these mechanisms called to schedule an interview, all of which were completed.

Qualitative interview procedures

We developed the qualitative semi-structured interview guide based on existing empirical literature. Interview questions were designed to investigate participants' preferences for and thoughts about four models of consent for secondary research uses of biospecimens (i.e., notice, opt-out, broad, study-specific). We also examined participants' perceived benefits and concerns related to each consent model and other factors affecting consent model preferences.

The interview began by exploring participants' general views on medical research. Following these questions, the interviewer provided each participant with a brief overview of the four consent models, and participants were asked to describe their initial thoughts about their most and least preferred model. Next, participants were presented with a more in-depth description of each consent model and then were asked a series of open-ended questions to explore their reactions to the model and the perceived pros and cons of the model. The interviewer also asked about their reactions to benefits and concerns described in the literature related to each model. After this in-depth discussion of the four models, participants were again asked to choose a most preferred and least preferred model and described their reasons for these preferences. Interviews were conducted by trained masters-level research staff and lasted about 60–90 min. Participants received a $50 gift card to a local grocery chain for their participation. All interviews were digitally recorded and transcribed verbatim. The university institutional review board approved this study, and all participants completed an informed consent process.

Qualitative data analysis

We conducted a directed thematic analysis of the qualitative interview data using NVivo 10 (Hsieh and Shannon 2005; Miles and Huberman 1994). An initial qualitative codebook was developed based on prior literature and input from the research team. The codebook was revised throughout the interview process to add inductively derived codes. After the interviews were completed, all data were independently coded with the final codes by two trained coders. Analysis was based on consensus codes. After coding, memos summarizing each code were created and used to identify core themes related to participants' preferences for the consent models and their perceived benefits and concerns for each model. We first examined themes overall and then whether themes differed by participant race and prior participation in the WHR biobank.

Results

Sample

About half (52 %) of the participants had no education beyond high school. The average age was 56 years (standard deviation of 7.5 years). Our recruitment scheme consisted of four strata (Black/White) and (WHR participants/women that did not participate in WHR), resulting in a sample with 16 Black and 15 White WHR participants and 15 Black and 14 White women who had not participated in WHR.

Consent model preferences

Participants were asked for their consent model preferences at two points during the interview, as described above. The majority of participants overall (60 %) selected the broad consent model as their most preferred model, with study-specific as the 2nd most preferred model (32 %). The notice consent model was the least preferred model overall (45 %), with study-specific as the 2nd least preferred model (30 %). Participants' selections for most and least preferred consent models were generally similar by race. The broad consent model was most preferred by both Black and White participants, and the study-specific consent model was the second choice for the most preferred model for both groups. The notice consent model was least preferred by both Black and White participants.

As shown in Table 1, we found three major qualitative themes related to why participants selected a model of consent as most preferred: having enough information, having control over their sample, and being asked for permission. The stratified analysis demonstrated that some of these qualitative themes differed by participant race. For example, being provided with specific information about secondary research uses prior to and after donating was particularly important for Black participants, including information such as where and how their sample would be used and wanting to be told each time their sample was used. Another major theme among Black participants was that people should be asked to give permission before researchers could use their samples in a future study. In contrast, an important theme among White participants was that being asked for permission one time was preferable to being asked for each study, leading them to prefer the broad consent model over the study-specific consent model.

Table 1 Main qualitative themes and representative quotes relating to choosing model of consent as most preferred

	Representative Quotes for Main Qualitative Themes		
	Having enough information	Having control over their biospecimen	Being asked for permission
Study-specific model of consent	"It's informed. It's inclusive. There's a relationship." *P55, White, did not participate in WHR biobank*	"Because I want to give my consent…each time they want to use my sample." *P12, Black, participated in WHR biobank*	"Each study they will ask you your permission. Before." *P29, Black, participated in WHR biobank*
	"I would like to know some information about each study… just keeping me informed as to what's been taking place because there may be something that I'm totally against." *P15, Black, did not participate in WHR biobank*	"It gives you more choice on your donation…I might give a sample today and next week decide I don't wanna do that anymore; if something in my life changes and I feel differently about it, I should have the right to say no, I want you to stop…" *P25, Black, participated in WHR biobank*	"They're asking me for my permission before each study, and that means that they're gonna call me or write me via mail, and ask me to have something back on a certain day or certain time for future study…They're asking me for each." *P36, Black, participated in WHR biobank*
	"I think it keeps me as informed as the researchers are." *P46, White, did not participate in WHR biobank*	"If there was something really, it doesn't sound right to me, then that'd give me the opportunity to say no." *P9, White, participated in WHR biobank*	"I want to be asked each time, for each study, and give my written consent for exactly what would happen." *P56, White, did not participate in WHR biobank*
Broad model of consent	"You're being informed of what's going on and what's going to happen with your blood." *P37, White, participated in WHR biobank*	"It gives the participant, giving the sample some level of control and options" *P14, Black, did not participate in WHR biobank*	"You've asked permission, and you only would need to do it once and you're good for future donations." *P60,White, did not participate in WHR biobank*
	"And hopefully they're gonna give me some general information about the multiple studies in the future." *P26, Black, participated in WHR biobank*	"Because they ask you permission once to use your samples multiple times, so you know upfront what's going on." *P38, Black, did not participate in WHR biobank*	"Because once you give them permission for them to do it in the future …you know okay they do it; … you don't have to constantly…keep on doing it." *P10, Black, participated in WHR biobank*
	"Giving permission one time is really all that's necessary, as long as adequate information is given, like what kinds of studies they would be." *P53, White, participated in WHR biobank*	"It offers the opportunity for the person to… get some ideas about how it might be used and it also gives the person being asked for the sample some control." *P3, White, participated in WHR biobank*	"It's just very clearly spelled out that they're, you know that the researchers are asking you for permission for future, to use your blood and tissues for future purposes." *P31, White, participated in WHR biobank*

Perceptions of each consent model

Although participants had a clear preference for the broad consent model, they identified several positive and negative aspects of each model. Tables 2 and 3 show these qualitative themes. Qualitative themes identified for positive aspects of the notice consent model were as follows: the model is efficient, makes good use of researcher and participant time, and would provide more samples for research (see Table 2). However, we did identify themes related to negative aspects of the model, including that some participants did not believe they would receive enough information with this model. Other concerns about the notice model included a loss of control, feeling disrespected, and that the model seemed unethical (see Table 3). Some differences in these qualitative themes were noted by participant race and prior WHR biobank participation. Black participants said that they felt a lack of control with the notice consent model and that their ability to make a choice to participate had been taken away. A similar but distinct theme emerged from White participants, who thought they should be asked for permission for secondary research use of samples. WHR participants viewed the notice consent model as disrespectful and did not like the lack of information. In contrast, women who had not participated in the WHR more often identified a lack of control as a concern with this model.

Qualitative themes for the benefits of the opt-out consent model were that researchers would have a greater number of samples compared with broad or study-specific models of consent, and that people would have more control over their samples compared with the notice consent model since they would be able to decline to participate in secondary research. Participants also thought that being given a way to refuse the use of their samples in secondary research made them feel respected. The qualitative themes related to the negative aspects of the opt-out model included concern that samples would be used despite their wishes, if they opted out of secondary research use of their biospecimens. These participants further described that a model of consent that required participants to take action to withdraw if they did not wish for

Table 2 Main qualitative themes and representative quotes related to perceived benefits for each model of consent

Consent Model	Qualitative Theme	Representative Quote
Notice	Provides many samples	"The more samples you have, the more possibilities you'll have. You need different ethnic samples anyway. You know I think that's totally fine." *P19,Black, did not participate in WHR biobank*
	Better use of researcher time and funds	"Instead of going and looking for someone, they already have a sample there." *P1, Black, participated in WHR biobank*
	Notified that sample will be used in future	"At least they're informing you rather than not informing you at all which I'm sure in the past there were situations where people weren't informed." *P31, White, participated in WHR biobank*
Opt-out	Researchers have a large number of samples	"I could see where it would … probably gain researchers a lot more samples and be a lot quicker—to gain a big bank of—of samples." *P55, White, did not participate in WHR biobank*
	Having control over whether or not sample is used	"It gives me the option. And the choice of how much further I want to go into participating." *P14, Black, did not participate in WHR biobank*
	Feeling respected	"It's a little bit more respectful… rather than just saying, too bad, so sad, we're doing it… it's saying you know we appreciate the fact that you may not want this. And we're going to let you say no." *P6, White, participated in WHR biobank*
Broad	Having control over whether or not their samples are used	"I like that you have a choice at the time of them taking the sample, to say yes or no." *P49, White, participated in WHR biobank*
	Only giving permission once	"Anytime you give a person permission to do something as a one time and everything, you shouldn't have to be contacted by this person over and over again about the same thing so. You know once it's done, it's done." *P23, Black, did not participate in WHR biobank*
	Being asked for permission	"That would be the one thing, I guess that would be a plus to it, at least they…are asking." *P56, White, did not participate in WHR biobank*
Study-specific	Controlling sample or making an active choice to participate	You have the—the choice. You're not robbed of a choice. You're given that choice. Some people, that means a lot." *P47,Black, participated in WHR biobank*
	Being informed	"[Study-specific]'s the one I'm most comfortable with because you're given more information. You know the time in between when you initially gave consent and the next time they wanna use it…a lot of time could've lapsed or no time; you could have changed your mind and so I just think you oughta have the option. And that you oughta be informed about what they're using it for." *P25, Black, participated in WHR biobank*
	Being asked for permission	"It is good because you don't want nobody to just take your sample and do what they want to do; it's more appropriate for you to ask." *P31, White, participated in WHR biobank*

samples to be used felt deceptive or underhanded (see Table 3). Participants also mentioned wanting to receive more information about secondary research in which their samples might be used. For this model of consent, we observed no differences in themes by participant race or prior biobank participation.

For the broad model of consent, qualitative themes related to the benefits of the model included being asked for their permission and being able to decide whether any donated samples were used in secondary research. Participants generally felt that being asked permission one time (in comparison to being asked multiple times) was sufficient or adequate. Qualitative themes for participants' concerns related to this consent model were that studies might not have enough samples if people did not agree to donate samples for secondary research use, that participants would not have enough details or information about future research studies, and that this model of consent might affect the speed of research. We did not observe differences in themes by participant race or prior biobank participation for this model of consent.

For the study-specific consent model, qualitative themes for the benefits of the model included being able to decide whether samples would be used in secondary research, being asked for their permission for any donated samples to be used in secondary research, and being more informed about each individual future research study in which their sample might be used. Qualitative themes related to participants' concerns for this consent model were that it would be time consuming and wasteful for participants and researchers, due to the amount of time, effort, and paperwork required in contacting individuals. We did observe some differences in qualitative themes by participant race and prior biobank participation.

Table 3 Main qualitative themes and representative quotes related to perceived concerns for each model of consent

Consent Model	Qualitative Theme	Representative Quote
Notice	No active permission	"I think people, um, really need to know that they're making the choice. Not someone's making the choice for them whether to donate samples or not." *P46,White, did not participate in WHR biobank*
	Lack of control over samples	"It should be my decision whether or not I want them to use it in the future." *P22, Black, did not participate in WHR biobank*
	Not enough information	"It seems a little vague like I said before. And I'm a person who wants to know a few more specifics." *P13, White, participated in WHR biobank*
Opt-Out	Not giving active permission	"Yeah, they need to say, do you mind if we do this or that; I think so. Instead of just assuming, saying yes." *P10, Black, participated in WHR biobank*
	Not enough information	"Well, I would like to know when my research is being used." *P39, Black, did not participate in WHR biobank*
	Lack of trust	"Because they're tellin' me that my samples may be used…they weren't asking me my permission….So I don't know what's really built in there, really, that would, safeguard me from them not using 'em." *P45, Black, did not participate in WHR biobank*
Broad	Slowing down research if not enough people agree to participate	"I think if you have too many who, um, don't give permission, then you lessen your research opportunity, which could impact them in the future." *P60, White, did not participate in WHR biobank*
	Wouldn't know details of every future study before giving one-time permission	"I would wanna know each time you wanna sample or whatever, I would like you to give—like, don't just tell me anything. Go into details 'bout it and how it's gonna work." *P41, Black, did not participate in WHR biobank*
	Would not receive updates about research or be able to talk to researchers involved	"After the year is over with. A letter coming from the researcher saying, you know, I want to thank you for, thank you for your donation…your samples allowed us to help further advance you know our studies and our research on cancer…Because then that gives people, it's a good feeling." *P20, White, participated in WHR biobank*
Study-specific	Being bothered by future contact	"A lot of people may not want to be called each particular time. Because…it'd depend on how long that the research is going; that could be anywhere from days to years." *P17, Black, did not participate in WHR biobank*
	Time consuming for participants and researchers	"From the researcher's perspective, I could see where that would be a lot more cumbersome, a lot more work and, um, maybe slow the research down. 'Cuz it would be a lot more work to, where you just have a bank of everybody's stuff, and you can just go get what you need, when you need it, as opposed to waiting to get permission from everybody to study." *P56, White, did not participate in WHR biobank*
	Wasting time, effort, research money, etc. on recontacting participants	"To me, it wastes time and energy of the researchers…. I think the biggest part is the time away from the actual research itself." *P4, White, participated in WHR biobank*

While Black participants thought that they would feel informed with the study-specific consent model, White participants thought that they would be contacted too much with this model. Similarly, while those participants who were not part of WHR biobank felt informed with a study-specific model of consent, WHR participants more often commented on being contacted too much or being bothered by being asked permission every time a new research project wanted to use their samples with this model.

Discussion

In this study, we examined the preferences for models of consent among a diverse sample of women. Previous studies found that participants are overall supportive of secondary use of donated biospecimens (Chen et al. 2005; Pentz et al. 2006). Murphy et al. (2009) found that the majority of White participants favored broad consent and also found differences in preference by race. In our study, both Black and White participants most preferred the broad consent model and least preferred the notice consent model. Our study also adds an in-depth exploration of women's reasons for these preferences. Prior studies have identified the importance of participants' feelings of control over their sample (Platt et al. 2013; Simon et al. 2011) and the importance of being asked permission (Murphy et al. 2009; Simon et al. 2011); our study adds that feeling informed as a result of the consent process is an essential characteristic of participants' most preferred consent model.

Prior empirical studies that have examined preferences for different models of consent for secondary research use of

biospecimens among the general public have reported mixed results. Thiel et al. (2014) found that participants preferred a study-specific consent model while other studies have found a preference for a broad model of consent (Platt et al. 2013; Platt et al. 2014; Simon et al. 2011; Vermeulen et al. 2009). In one such study, believing that a particular research study might lead to improved treatments or cures was associated with preference for a broad model of consent (Platt et al. 2013), although we did not observe this reason for participants' preferences in our study. We did find, however, that participants were concerned that a broad model of consent might slow down research progress compared with models using an opt-out process. Participants who value research may be concerned about the effect of a consent model on the speed of scientific innovation. Simon et al. (2011) showed that individuals value types of consent that allow them to provide input and be re-consented in the future, and other researchers have found that this makes participants feel respected (Hoeyer et al. 2004; Master et al. 2013). Brothers et al. (2011) found that participants most preferred an opt-out consent model as opposed to a notice model of consent. In the present study, participants noted that broad consent was the most feasible and less time consuming for both themselves and researchers. Our study participants most preferred a broad model of consent as both providing them with control over their sample and giving them more information about secondary research use of donated biospecimens.

In this study, the study-specific model was the second most preferred, with some participants noting that they felt in control with this model and that it provided the most amount of information about secondary research uses. However, some participants also viewed the study-specific model as time-consuming, wasteful, and burdensome, as also observed in prior studies (Hoeyer et al. 2004; Master et al. 2013; Murphy et al. 2009; Platt et al. 2013). We found some differences in qualitative themes about the study-specific model by race, with White participants in particular believing that this model would lead to too much contact, while having specific information about secondary research uses and being asked permission for each study were particularly important among Black participants. In a focus group study examining differences by race, Murphy et al. (2009) found that more White participants preferred the broad consent model and that Black participants preferred to be asked for consent prior to each future research study. In contrast, we found that both Black and White participants primarily preferred the broad consent model, with the study-specific model of consent as second most preferred for both groups.

The least preferred model among all groups of study participants was the notice consent model. Even the participants in our sample who had previously donated a biospecimen to a biobank least preferred this model. Use of this common model of consent could be a barrier for some to participating in a biobank. Despite the fact that many biobanks have used this model of consent, data are lacking regarding participants' feelings about this consent model, particularly data comparing participants' preferences by race. In the present study, participants felt that not being asked permission was unethical and disrespectful; one possible reason may be due to a sense of ownership. In a study by Moodley et al. (2014), participants' preference to be recontacted for secondary research use of samples was related to their belief that they maintained ownership of their samples.

Among participants in this study, the opt-out consent model was neither particularly liked nor disliked. Other ethical analysis has raised the issue that opt-out consent will yield more biospecimens than broad consent. Participants felt that the opt-out model of consent gave them some control, knowledge, and choice over their biospecimen and increased the number of collected samples relative to the use of a broad or study-specific model of consent, themes consistent with prior research (Simon et al. 2011). However, some participants in our study worried that their biospecimens would be used even though they had opted out of secondary research use, potentially affecting their willingness to enroll in a biobank. Participant trust of researchers is an issue that should be examined in future biobank research. Participants in other studies have found opt-out approaches to be passive (Simon et al. 2011) and potentially confusing (Kerath et al. 2013), although we did not find these views in our study.

Limitations

Because this study was powered for qualitative analysis, we were unable to determine whether observed differences in consent model preferences were statistically significant. We included only women in this study because of our focus on a biobank related to women's health research. Research is certainly needed to examine preferences for models of consent among men. Because of the racial and ethnic composition of the St. Louis region, we were unable to examine preferences among other racial and ethnic groups or other language groups, and these are important areas for future study. We selected a purposive sample of women who utilized breast health services to order to explore in-depth preferences among women who would most likely be approached to participate in a biobank with samples that would be used in women's health research. As most of our recruitment methods were connected with a comprehensive cancer center, participant trust in this system may have affected consent model preferences. Future quantitative research may examine how preferences differ among community-based populations not associated with a medical system. It is also critical to note that we were unable to examine the contributions of other factors that may have varied by race, such as

educational attainment or trust in research, to participants' preferences, attitudes, and beliefs. Future multivariable quantitative analyses are needed to examine the separate contributions of race, education, and important other variables to preferences for models of consent.

Conclusions

We found that participants preferred models of consent for secondary research use of biospecimens that provided them with both specific and general information. Overall, participants said that they desired information, some control over their biospecimens, and to be asked permission for use of their biospecimens in the future. Our findings therefore suggest that it will be important for researchers to provide information about future uses of biospecimens to the extent possible. To keep biobank participants informed over time, a Web site could be established and periodically updated with ongoing research, publications, and discoveries that were associated with a particular biobank. To improve the process of consent at the time of biospecimen donation, supplemental brochures or educational materials that focus on the biobank could be a source of information for participants. For example, as part of an opt-out consent process, Pulley et al. (2010) utilized a brief brochure to answer additional questions. Development of informed consent processes that are informed by potential biobank participants is critical to encourage participation across population subgroups.

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Conflict of interest Katherine M. Brown, Bettina F. Drake, Sarah Gehlert, Leslie E. Wolf, James DuBois, Joann Seo, Krista Woodward, Hannah Perkins, Melody S. Goodman, and Kimberly A. Kaphingst declare they have no conflicts of interest.

Compliance with ethics guidelines

Human subject research All procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation and with the Helsinki Declaration of 1975, as revised in 2000. Informed consent was obtained from all patients for being included in the study.

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