Article

Use of a Qualitative Story Deck to Create Scenarios and Uncover Factors Associated with African American Participation in Genomics Research

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Abstract

To explore the willingness to participate in genomics research among African Americans, we developed a technique specifically suited to a relaxed social setting. The "Qualitative Story Deck," (QSD) is a gamified, structured elicitation technique that allows for the spontaneous creation of scenarios with variable attributes. We used the QSD to create research scenarios that varied on four details (race/ethnicity of the researcher, research goal,

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biospecimen requested, and institutional affiliation). Participants created scenarios by randomly choosing cards from these categories and provided: (1) a judgment about their willingness to participate in the research project represented; and (2) their thought process in reaching a decision. The QSD has applicability to topics involving decision making or in cases where it would be beneficial to provide vignettes with alternate attributes. Additional benefits include rapid rapport building, applicability to little known or sensitive topics, and suitability for both qualitative and quantitative analyses.

Diversity in medical research is an imperative to equity in treatment innovations, health care delivery, and health promotion. Yet, we continue to see an underrepresentation of African Americans, a population that experiences profound health disparities, in research studies whatever the disease or condition under study (Duma et al. 2018; Haga 2010; Knepper and McLeod 2018; Landry et al. 2018). This underrepresentation is the result of multiple factors, including a distrust of researchers and health professionals relating to past research abuses as well as continued experiences of discrimination in health care settings (Lee et al. 2019; Scharff et al. 2010). Genomic studies, the foundation for advances in precision medicine, are particularly challenged due to specific issues of distrust around the collection of biospecimens and the use of biobanking (Cohn et al. 2015; Halbert et al. 2016; Haldeman et al. 2014; Lemke et al. 2010). Biospecimens and DNA are uniquely tied to identity. When they are collected with an intent for use in future, yet to be defined studies, a host of fears emerge, including the unauthorized use of samples for paternity testing, criminal justice purposes, and human cloning (Cohn et al. 2015; Lee et al. 2019).

While we have ample evidence of the underrepresentation of African Americans in genomics research and knowledge of a hesitancy their part to participate in research, we do not have equally clear solutions. To date, research on willingness to participate has been dominated by qualitative, often focus group, explorations of "barriers" and "facilitators" (George et al. 2013; Hughes et al. 2015; Martinez et al. 2017; Owens et al. 2013). This has been problematic for several reasons. Focus groups are ill suited to the exploration of sensitive, abstract, or remote topics (Cyr 2016; Wolgemuth et al. 2015). In addition, willingness to participate in genomics is a challenging topic. Many Americans have little understanding of basic genetic concepts and may not be able to conceptualize what genomics research entails or why it is important, leaving participants to struggle for

context (Christensen et al. 2010). Moreover, as noted, research participation brings up sensitive topics of race, discrimination, and research abuse in underrepresented communities (George et al. 2013; Halbert et al. 2016; Passmore et al. 2020). For African Americans, the US Public Health Service Syphilis Study at Tuskegee in particular is a longstanding example of injustice and research abuse as is the more recently publicized story of Henrietta Lacks (Javitt 2010; Lee et al. 2019; Reverby 2010; Scharff et al. 2010). Thus, the study of research participation requires a well-established rapport and the ability to communicate the remote aspects of context while allowing participants some measure of social distance from the discussion (Latkin et al. 2016; Oltmann 2016). Interestingly, although distrust of researchers is a well-known barrier to research participation, those studying willingness to participate in research do not typically report what should be important information that speaks to validity—e.g., the race/ethnicity of data collectors and the procedures to establish rapport (Miller 2017; Professor et al. 2008).

Another challenge to studying willingness to participate in research is related to the nature of the question itself. Without the use of ranking or rating exercises (Bernard 2017), qualitative explorations of barriers and facilitators miss that the decision to participate is a process that involves the weighing of some factors in relation to others (Bruch and Feinberg 2017). For example, we know that people list an altruistic research goal, financial incentives, and trust in the research team as motivations to participate in research (Garza et al. 2017). Yet, we have not been able to explore whether there is a point where a larger financial incentive outweighs an altruistic goal or vice versa. We also do not know how big and complex concepts such as altruism and trust are operationalized in participant consideration of their willingness to participate in research. Methodologies that can get at willingness to participate need to allow for this compensatory nature of decision making and provide a means for participants to envision a real context (Bruch and Feinberg 2017; Evans et al. 2015).

We addressed the challenges described above with both setting and method. To aid in rapport, we set our interviews in Black barbershops where the members of the research team had worked previously (Harris-Lacewell 2010; Linnan et al. 2012). We developed a Qualitative Story Deck (QSD), a deliberately social and fun, gamified, structured elicitation technique to allow for the spontaneous creation of stories/scenarios with variable attributes. QSD has roots in several methods. It is a card sort (Bernard 2017; Morse 2016; Ryan and Bernard 2003) used to create experimental vignettes like those used in survey research (Aguinis and Bradley 2014; Atzmüller

and Steiner 2010) for a qualitative adaptation of a choice experiment frequently used in the study of decision making (Bruch and Feinberg 2017; Clark et al. 2014). This approach allowed us to: (1) frame questions so that they would be easy to understand and respond to; (2) get at the interaction of factors affecting willingness to participate in research; and (3) use an engaging methodology that fit in with the setting of the barbershops.

Method

We used the QSD technique to create research scenarios that varied on four dimensions: (1) race/ethnicity of the researcher; (2) research goal; (3) type of biospecimen requested; and (4) institutional affiliation of researcher. Participants created scenarios by randomly choosing cards from these categories and provided a judgment about their willingness to participate in the research project represented. They were also asked to describe their thought process in considering the decision. In the end, we were successful in interviewing 84 participants the majority of whom were men (70%) who all self-identified as African American. All data collection activities were reviewed and approved by the University of Maryland, College Park Institutional Review Board (#1143589).

Setting and Rapport

Our interviewers were experienced, skilled men and women who self-identified as people of color and were familiar with the social context of the barbershops. We chose to work in barbershops due to the specific environment they provide. Black barbershops are cultural spaces marked by light-hearted, jocular, and relaxed discussion about serious, even controversial, topics (Harris-Lacewell 2010; Linnan et al. 2012; Mills 2005). All shop owners and barbers gave consent for data collection activities, which were held only at times convenient for them. We did our best to avoid getting in the way of the business of the shops. Interviewers spent considerable time in the shops socializing and building rapport where they engaged in group conversations. They approached both clients and barbers to let them know about the project and interview.

Interviews were conducted with those who self-selected. As an activity, the QSD was perceived as fun and interesting and although interviews were held away from others whenever possible, they had the added advantage of piquing the interest of others in the shop who later asked to be interviewed.
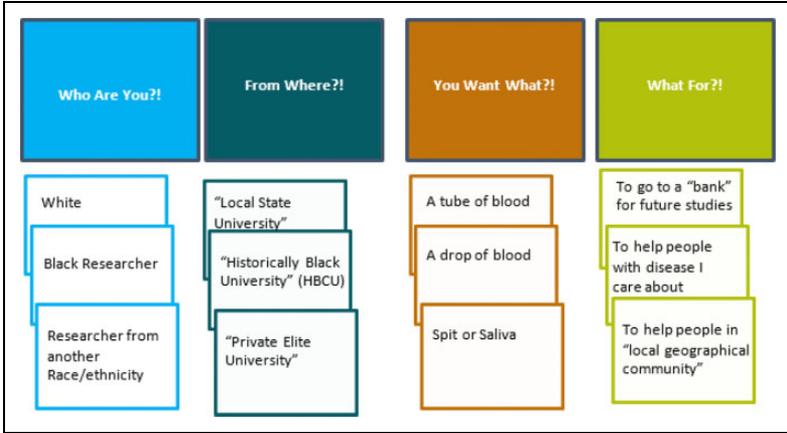
Figure 1. Card pile categories and variants.

Frequently, clients and barbers in the shops also encouraged newcomers to participate.

Data Collection

At the onset of the interview, interviewers presented participants with four piles of cards representing four details about a hypothetical genomics research project. These details were: (1) Who are you? (researcher race/ethnicity); (2) Where are you from? (institutional affiliation of the researcher); (3) What do you want? (type of biospecimen requested); and (4) For What? (goal of the research). Each category included three variants. Under "Who are you," researchers could be White, African American, or another unspecified race/ethnicity. Institutional affiliations included an elite private university with a well-known history of research abuse, a state university, and a local Historically Black University (HBCU). Each of these institutions were specifically named on the cards (although institution names are omitted here). Biospecimen requests included a tube of blood, a drop of blood and spit/saliva. Finally, research goals could be "to help people with a disease I care about"; "to specifically help people in [local community]; or "to go to a 'bank' for future studies" (see Figure 1).

STEP 1: Piles were placed face down (showing only pile categories) in front of the participant and we asked them to create a hypothetical research
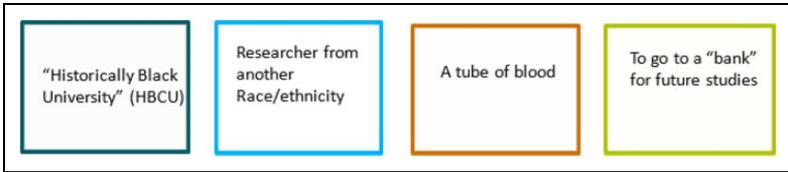
Figure 2. Research scenario 1 example.

scenario by choosing one card from each pile and turning them over (see Figure 2).

Participants were then asked if they would agree to participate in the project represented. Interviewers probed on participant answers and the influence of each card on their decision (e.g., Ok, so you wouldn't want to do this study. Why? Was it because the researcher came from "HBCU"? Was it because of the use of a data bank? etc.). Once the participant addressed the role each card played, interviewers moved onto Steps 2–3.

STEPS 2 and 3: The process in step 1 was repeated with two more sets of cards. Participants were asked to explain their responses.

STEP 4: All cards were laid face up and participants were asked to choose a card from each pile that, when put together, would create what they would consider to be an ideal project—the one in which they would be most likely to participate. Participants were asked to thoroughly explain their choices. Interviewers used probes as necessary.

STEP 5: The interviewer replaced the institutional affiliation chosen by the participant in the ideal scenario (step 4) with a wild card representing the government as an institutional affiliation. Participants were then asked how the change impacted their willingness to participate in the final hypothetical scenario. Participants were asked to thoroughly explain their choices. Interviewers used probes as necessary (see Figure 3).

Choice of Scenario Characteristics

Our choice of the four dimensions used in research scenarios was informed by previous research. The researcher's race was included to explore the relative weight of racial/ethnic concordance, which is a known facilitator of trust in research and health care (Frierson et al. 2019; Fryer et al. 2015; Shen et al. 2018). The research goal was included to explore the power of altruism in willingness to participate in research (Chin et al. 2016; Hughes et al. 2015; Ojukwu et al. 2018). It also afforded an opportunity to explore the role of biobanking, a known barrier. Institutional affiliation is less well
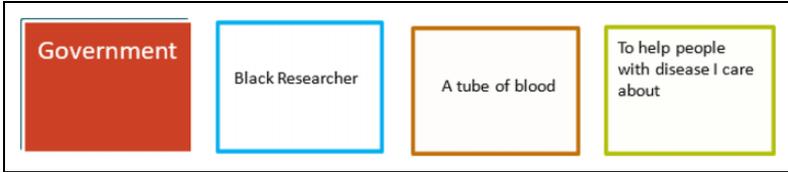
Figure 3. "WILD CARD" research scenario example.

studied but also described as a barrier to participation, especially regarding institutions associated with research abuse (Davison et al. 2017; Smirnoff et al. 2018). The choice of biospecimen was intended to flesh out the differential effects of type of biospecimen (saliva and drop/tube of blood), invasiveness of data collection, and the use of DNA more generally. Finally, the choice to add the "WILD CARD" of government was the result of previously described mistrust inspired by the U.S. Public Health Syphilis Study at Tuskegee among other incidents and conspiracy theories that involve the victimization of African Americans (Cohn et al. 2015; Mattocks et al. 2017; Quinn et al. 2019).

Results

Quality of Data and Data Collection

The result of the application of the QSD was relaxed, informative interviews that produced rich data about the interaction of research scenario attributes. By using the QSD, we captured participant perspectives more quickly than if we had used a more typical question format. The visual and game-like aspects allowed participants to immediately understand and respond (Glegg 2019). As a result, both our interviews and the transcripts they produced were quite short. Each interview lasted approximately 20–30 minutes, which reduced participant burden and also afforded rich data. Our transcripts were short but were composed of a clear majority of participant words rather than those of our interviewers as a result of the incorporation of visual cues (Glegg 2019). Due to of all these factors as well as the structuring of the interview, coding and analysis was also particularly quick and efficient.

We found that participants enjoyed the game-like approach. We did not ask for feedback on the method, but several participants commented on it. For example, "It's cool. I like this stuff . . . because I feel like if you would have, like, did it any other way . . . it would have just been like boring or lose the person's interest."

In all, the combination of the social setting with the data collection method created an environment where we were able to quickly build rapport and access candid responses. For example, the following quotes illustrate a freedom of expression commonly found in our transcripts.

Participant: Yeah. I think going to the university is robbing people, period, because you can get all this good sweet information you can get out of school right off YouTube. YouTube University, that's what I call it.

Interviewer: You think they're taking advantage of people.

Participant: Hell yeah. You've got to take out all these student loans and then you've got to pay it back, you've got to fucking pay. Fuck that, excuse my French.

Interviewer: No, you're fine. You're good.

Participant: I'm just saying. I ain't with the shit at all. Like I said, I don't care about who is researching or what school it is.

Interviewer: What about the reason that they're researching, does that matter?

Participant: Well let's go, let's dig into the diseases, where they come from. We can go down the line and find out where they come from. Most of them, shit, they're created for big pharma. They create a sickness, then they create a solution.

Accessing the Unexpected and Understanding the Interaction of Attributes

The use of the QSD helped uncover feelings that emerged for participants that may not have emerged in response to more abstract questions. For example, the combination of unexpected attributes in a hypothetical study sometimes led participants to unpack perceptions that they may not have otherwise. The following quote comes from a participant who was surprised by the hypothetical research scenario involving a Black/African American researcher from a private elite university.

Interviewer: Yeah, he works for [private elite university]. He didn't go there for school.

Participant: I don't know, because I mean, you've got Black people that try to act White, too, so I don't know. It depends on how he approaches it.

Interviewer: Okay. So, you would need to feel him out...

Previously, this participant interpreted the Black/African American researcher as trustworthy and the private, predominantly White university as not. In combination, however, he expresses a more nuanced assessment providing us with richer data. In a similar scenario, the research project scenario chosen involved a White researcher representing an HBCU.

Interviewer: Yeah, this is a White person working at [HBCU], so—
Participant: Yeah, he may do care about them . . . .
Interviewer: So does [HBCU] save the situation? I'm trying to understand.
Participant: Well, a little bit. This is a little—because he works around Black people . . .

Previous studies have found racial concordance (between researcher and participant) to be a predictor of willingness to participate (Frierson et al. 2019). Our findings add that both the institutional affiliation and the racial identity of the researcher can act as heuristics or shortcuts in the decision-making process, representing trustworthiness. Thus, there are circumstances in which White researchers might be found trustworthy.

Another example of the value of exploring the interaction of variables comes from the final scenario presented to participants. As noted, in step 5, a wild card was pulled from the deck and replaced the institution card in the ideal scenario with the government. The introduction of government as the institutional affiliation was often a deal breaker. Almost all (96.3%) participants agreed to participate in their chosen ideal situation. However, once that ideal institution was changed to government, willingness to participate dramatically dropped to 22.8%. The following are a few examples of participant responses from three separate interviews.

Participant: Nope. I ain't doing nothing for the government. Nope.
And,
Participant: Brakes, emergency brakes! Something is going on.
And,
Participant: No! I'm ready to back out the deal.
Interviewer: Okay, you're backing out the deal. Okay. Is there any reason now that you? . . .
Participant: Oh the government, they're shady. They're up to something . . . .

As these quotes suggest, the government was a powerful and meaningful indication of a lack of trustworthiness that predictably trumped previously acceptable research scenarios.

Analysis

Quantitatively, we were able to use a classification and regression tree (CART) analysis to determine primary drivers in participant decisions (Breiman 2017; Lemon et al. 2003; Passmore et al. 2020), although other approaches might have been possible. CART analysis (Breiman 2017; Lemon et al. 2003) was applied to all data using the SPSS 25 software (IBM, Chicago, IL). CART recursively partitions the entire sample (parent node) into smaller subgroups (child nodes) based on the binary outcome variable (acceptance or rejection of research scenario). At each partition, this method identifies the factor that best separates data into subgroups related to the outcome, repeating the process until the sample is divided into homogeneous groups and resulting in a classification tree. The benefit of this strategy, relative to other analytical techniques, is that it automatically yields combinations of factors that statistically significantly separates the data based on the outcome variable (willingness to participate in the research).

Qualitatively, we took a team based iterative–inductive thematic approach (Cascio et al. 2019) using NVivo 12 software to facilitate qualitative data management and analysis. The primary goal of our analysis was to reveal on the ground experiences and knowledge of participants that contributed to willingness to participate in research. The stages of the coding process included initial open coding followed by axial coding to express connections between themes and concepts (Sbaraini et al. 2011; Strauss and Corbin 1997). Emergent themes were discussed with the research team for interpretation. We found a high level of consensus across coders, in large part, because the data were so contextualized within research scenarios. Participants expressed their views on individual scenario characteristics both clearly and directly. In our case, themes were unusually consistent across participants, indicating that we were able to tap into well-developed shared knowledge and perspectives on research participation.

Methodological Strengths and Limitations

As noted, the QSD was a fun, quick elicitation method that successfully produced interesting and new knowledge about the willingness to participate in research. For those interested in the adaptation of the method to incorporate other categories or topics, the QSD is ultimately customizable. The number of cards or categories may be adjusted to need, although we

would warn that asking about too many scenarios or too many variable attributes may become tiresome for participants. The use of wild cards can be eliminated or expanded. We found that it was a fun way to gain a bit more data without adding an entirely new scenario possibility. Finally, because the QSD so closely resembles a choice experiment, it can be used purely qualitatively and adapted as a mixed method. Our CART analysis approach is an option as is conjoint analysis with the use of a Likert type scale of likeliness to participate (Hauber et al. 2016).

We also recognize that there are limitations to the technique. For example, the use of the QSD limited the number of factors that could be explored to those included on the cards. We discovered insights regarding race/ethnicity of the researcher, research goal, institutional affiliation, and use of biospecimens. There are, of course, other factors that might contribute to willingness to participate in research such as the use of financial incentives. We limited our story deck to include four factors because we felt that adding more might add so much complexity as to limit the benefit of the technique. Ultimately, this a limitation in any use of a card sort or vignette.

Relatedly, the use of the QSD requires a solid knowledge of the topic to facilitate the development of appropriate attributes. Our team relied on previous research and a well-developed literature of barriers and facilitators to willingness to participate in research. For other less well-explored topics, the development of a story deck may require preliminary research such as a more traditional pile sort or free listing methodology (Bernard 2017). Finally, while the QSD and other types of vignettes are powerful tools to understand attitudes and knowledge, it is important to note that they may not accurately predict behavior. There is, of course, a fundamental difference between the verbalization of reaction to a hypothetical situation and a real-life behavioral response.

A final limitation of this research is in the use of barbershops. The shops were, in some ways, an ideal setting. However, we recognize that conducting the research in a single type of social space introduced a potential selection bias. We cannot say whether conducting interviews in another setting, such as a church or fraternal organization, might have produced different views on the topic.

Conclusion

The QSD is an engaging, interactive method to engage African Americans (and potentially other groups), to explore their willingness to participate in various types of health research. It can be customized to incorporate a range

of factors that may influence the decision to participate. Importantly, it can also elicit data on the relative weight of these factors. The QSD technique may also be informative in explorations of decision making on other topics, such as vaccine use or other health behaviors or in cases where it would be beneficial to provide vignettes with variable attributes.

Authors' Note

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Declaration of Conflicting Interests

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References

Aguinis, H., and K. J. Bradley. 2014. Best practice recommendations for designing and implementing experimental vignette methodology studies. *Organizational Research Methods* 17:351–71.

Atzmüller, C., and P. M. Steiner. 2010. Experimental vignette studies in survey research. *Methodology* 6:128–38.

Bernard, H. R. 2017. *Research methods in anthropology: Qualitative and quantitative approaches*. Lanham, MD: Rowman & Littlefield.

Breiman, L. 2017. *Classification and regression trees*. New York: Routledge.

Bruch, E., and F. Feinberg. 2017. Decision-making processes in social contexts. *Annual Review of Sociology* 43:207–27.

Cascio, M. A., E. Lee, N. Vaudrin, and D. A. Freedman. 2019. A team-based approach to open coding: Considerations for creating intercoder consensus. *Field Methods* 31:116–30.

Chin, L. J., J. A. Berenson, and R. L. Klitzman. 2016. Typologies of altruistic and financial motivations for research participation: A qualitative study of MSM in HIV vaccine trials. *Journal of Empirical Research on Human Research Ethics* 11:299–310.

Christensen, K. D., T. E. Jayaratne, J. S. Roberts, S. L. R. Kardia, and E. M. Petty. 2010. Understandings of basic genetics in the United States: Results from a national survey of Black and White men and women. *Public Health Genomics* 13:467–76.

Clark, M. D., D. Determann, S. Petrou, D. Moro, and E. W. de Bekker-Grob. 2014. Discrete choice experiments in health economics: A review of the literature. *PharmacoEconomics* 32:883–902.

Cohn, E. G., M. Husamudeen, E. L. Larson, and J. K. Williams. 2015. Increasing participation in genomic research and biobanking through community-based capacity building. *Journal of Genetic Counseling* 24:491–502.

Cyr, J. 2016. The pitfalls and promise of focus groups as a data collection method. *Sociological Methods & Research* 45:231–59.

Davison, K. K., J. N. Charles, N. Khandpur, and T. J. Nelson. 2017. Fathers' perceived reasons for their underrepresentation in child health research and strategies to increase their involvement. *Maternal and Child Health Journal* 21:267–74.

Duma, N.J. V. Aguilera, J. Paludo, C. L. Haddox, M. Gonzalez Velez, Y. Wang, K. Leventakos, et al. 2018. Representation of minorities and women in oncology clinical trials: Review of the past 14 years. *Journal of Oncology Practice* 14: e1–10.

Evans, S. C., M. C. Roberts, J. W. Keeley, J. B. Blossom, C. M. Amaro, A. M. Garcia, C. Odar Stough, K. S. Canter, R. Robles, and G. M. Reed. 2015. Vignette methodologies for studying clinicians' decision-making: Validity, utility, and application in ICD-11 field studies. *International Journal of Clinical and Health Psychology* 15:160–70.

Frierson, G. M., B. M. Pinto, D. C. Denman, P. A. Leon, and A. D. Jaffe. 2019. Bridging the gap: Racial concordance as a strategy to increase African American participation in breast cancer research. *Journal of Health Psychology* 24: 1548–61.

Fryer, C. S., S. R. Passmore, R. C. Maietta, J. Petruzzelli, E. Casper, N. A. Brown, J. Butler, M. A. Garza, S. B. Thomas, and S. C. Quinn. 2015. The symbolic value and limitations of racial concordance in minority research engagement. *Qualitative Health Research* 26:830–41.

Garza, M. A., S. C. Quinn, Y. Li, L. Assini-Meytin, E. T. Casper, C. S. Fryer, J. Butler, N. A. Brown, K. H. Kim, and S. B. Thomas. 2017. The influence of race and ethnicity on becoming a human subject: Factors associated with participation in research. *Contemporary Clinical Trials Communications* 7:57–63.

George, S., N. Duran, and K. Norris. 2013. A systematic review of barriers and facilitators to minority research participation among African Americans, Latinos, Asian Americans, and Pacific Islanders. *American Journal of Public Health* 104:e16–31.

Glegg, S. M. N. 2019. Facilitating interviews in qualitative research with visual tools: A typology. *Qualitative Health Research* 29:301–10.

Haga, S. B. 2010. Impact of limited population diversity of genome-wide association studies. *Genetics in Medicine* 12:81–84.

Halbert, C. Hughes, J. McDonald, S. Vadaparampil, L. Rice, and M. Jefferson. 2016. Conducting precision medicine research with African Americans. *PLoS ONE* 11: e0154850.

Haldeman, K. M., R. J. Cadigan, A. Davis, A. Goldenberg, G. E. Henderson, D. Lassiter, and E. Reavely. 2014. Community engagement in US biobanking: Multiplicity of meaning and method. *Public Health Genomics* 17:84–94.

Harris-Lacewell, M. V. 2010. *Barbershops, Bibles, and BET: Everyday talk and Black political thought*. Princeton, NJ: Princeton University Press.

Hauber, A. B., J. M. González, C. G. M. Groothuis-Oudshoorn, T. Prior, D. A. Marshall, C. Cunningham, M. J. IJzerman, and J. F. P. Bridges. 2016. Statistical methods for the analysis of discrete choice experiments: A report of the ISPOR conjoint analysis good research practices task force. *Value in Health* 19:300–15.

Hughes, T. B., V. R. Varma, C. Pettigrew, and M. S. Albert. 2015. African Americans and clinical research: Evidence concerning barriers and facilitators to participation and recruitment recommendations. *The Gerontologist* 57: 348–58.

Javitt, G. 2010. Why not take all of me: Reflections on the immortal life of Henrietta Lacks and the status of participants in research using human specimens. *Minnesota Journal of Law, Science and Technology* 11:713.

Knepper, T. C., and H. L. McLeod. 2018. When will clinical trials finally reflect diversity? *Nature* 557:157–59.

Landry, L. G., N. Ali, D. R. Williams, H. L. Rehm, and V. L. Bonham. 2018. Lack of diversity in genomic databases is a barrier to translating precision medicine research into practice. *Health Affairs* 37:780–85.

Latkin, C. A., N. Vu Tuyet Mai, T. Viet Ha, T. Sripaipan, C. Zelaya, N. Le Minh, G. Morales, and V. F. Go. 2016. Social desirability response bias and other factors that may influence self-reports of substance use and HIV risk behaviors:

A qualitative study of drug users in Vietnam. *AIDS Education and Prevention* 28:417–25.

Lee, S. S. J., M. K. Cho, S. A. Kraft, N. Varsava, K. Gillespie, K. E. Ormond, B. S. Wilfond, and D. Magnus. 2019. "I don't want to be Henrietta Lacks": Diverse patient perspectives on donating biospecimens for precision medicine research. *Genetics in Medicine: Official Journal of the American College of Medical Genetics* 21:107–13.

Lemke, A. A., W. A. Wolf, J. Hebert-Beirne, and M. E. Smith. 2010. Public and biobank participant attitudes toward genetic research participation and data sharing. *Public Health Genomics* 13:368–77.

Lemon, S. C., J. Roy, M. A. Clark, P. D. Friedmann, and W. Rakowski. 2003. Classification and regression tree analysis in public health: Methodological review and comparison with logistic regression. *Annals of Behavioral Medicine* 26:172–81.

Linnan, L. A., S. Thomas, H. D'Angelo, and Y. Owens Ferguson. 2012. *African American barbershops and beauty salons*. New Brunswick, NJ: Rutgers University Press.

Martinez, P., C. Cummings, K. J. Karriker-Jaffe, and K. G. Chartier. 2017. Learning from Latino voices: Focus groups' insights on participation in genetic research. *The American Journal on Addictions* 26:477–85.

Mattocks, K. M., C. Gibert, D. Fiellin, L. E. Fiellin, A. Jamison, A. Brown, and A. C. Justice. 2017. Mistrust and endorsement of human immunodeficiency virus conspiracy theories among human immunodeficiency virus–infected African American veterans. *Military Medicine* 182:e2073–79.

Miller, T. 2017. Telling the difficult things: Creating spaces for disclosure, rapport and "collusion" in qualitative interviews. *Women's Studies International Forum* 61:81–86.

Mills, Q. T. 2005. "I've got something to say": The public square, public discourse, and the barbershop. *Radical History Review* >2005:192–99.

Morse, J. M. 2016. *Analyzing and conceptualizing the theoretical foundations of nursing*. New York: Springer Publishing Company.

Ojukwu, E., L. R. Powell, S. D. Person, Milagros C. Rosal, Stephenie C. Lemon, and J. Allison. 2018. Spirituality and willingness to participate in health-related research among African Americans. *Journal of Health Care for the Poor and Underserved* 29:400–14.

Oltmann, S. 2016. Qualitative interviews: A methodological discussion of the interviewer and respondent contexts. *Forum Qualitative Sozialforschung/Forum: Qualitative Social Research* 17:1–16.

Owens, O. L., D. D. Jackson, T. L. Thomas, D. B. Friedman, and J. R. Hébert. 2013. African American men's and women's perceptions of clinical trials research:

Focusing on prostate cancer among a high-risk population in the South. *Journal of Health Care for the Poor and Underserved* 24:1784–800.

Passmore, S. R., A. M. Jamison, G. R. Hancock, M. Abdelwadoud, C. D. Mullins, T. B. Rogers, and S. B. Thomas. 2020. "I'm a little more trusting": Components of trustworthiness in the decision to participate in genomics research for African Americans. *Public Health Genomics* 22:1–12.

Professor, T. Z., PBS's history detectives, and Eduardo Bonilla-Silva. 2008. *White logic, White methods: Racism and methodology*. Lanham, MD: Rowman & Littlefield.

Quinn, S. Crouse, A. M. Jamison, J. An, G. R. Hancock, and V. S. Freimuth. 2019. Measuring vaccine hesitancy, confidence, trust and flu vaccine uptake: Results of a national survey of White and African American adults. *Vaccine* 37:1168–73.

Reverby, S. M. 2010. Invoking "Tuskegee": Problems in health disparities, genetic assumptions, and history. *Journal of Health Care for the Poor and Underserved* 1:26–34.

Ryan, G. W., and H. R. Bernard. 2003. Techniques to identify themes. *Field Methods* 15:85–109.

Sbaraini, A., S. M. Carter, R. W. Evans, and A. Blinkhorn. 2011. How to do a grounded theory study: A worked example of a study of dental practices. *BMC Medical Research Methodology* 11:128.

Scharff, D. P., K. J. Mathews, P. Jackson, J. Hoffsuemmer, E. Martin, and D. Edwards. 2010. More than Tuskegee: Understanding mistrust about research participation. *Journal of Health Care for the Poor and Underserved* 21:879–97.

Shen, M. J., E. B. Peterson, R. Costas-Muñiz, M. Hunter Hernandez, S. T. Jewell, K. Matsoukas, and C. L. Bylund. 2018. The effects of race and racial concordance on patient–physician communication: A systematic review of the literature. *Journal of Racial and Ethnic Health Disparities* 5:117–40.

Smirnoff, M., I. Wilets, D. F. Ragin, R. Adams, J. Holohan, R. Rhodes, G. Winkel, E. M. Ricci, C. Clesca, and L. D. Richardson. 2018. A paradigm for understanding trust and mistrust in medical research: The community VOICES study. *AJOB Empirical Bioethics* 9:39–47.

Strauss, A., and J. M. Corbin. 1997. *Grounded theory in practice*. Newbury Park, CA: Sage.

Wolgemuth, J. R., Z. Erdil-Moody, T. Opsal, J. E. Cross, T. Kaanta, E. M. Dickmann, and S. Colomer. 2015. Participants' experiences of the qualitative interview: Considering the importance of research paradigms. *Qualitative Research* 15:351–72.