From the Field:
Community Perpspectives
on Precision Medicine

CAN PRECISION MEDICINE ACTUALLY HELP PEOPLE LIKE ME? AFRICAN AMERICAN AND HISPANIC PERSPECTIVES ON THE BENEFITS AND BARRIERS OF PRECISION MEDICINE

Vivian M. Yeh, PhD[1]; Erin M. Bergner, MPH, MA[2];
Marino A. Bruce, PhD, MSRC, MDiv [2,5]; Sunil Kripalani, MD, MSc[1,4];
Victoria B. Mitrani, PhD[3]; Titilola A. Ogunsola, BS[2];
Consuelo H. Wilkins, MD, MSCI[6-8]; Derek M. Griffith, PhD[2,5]

Objective: To better understand African American and Hispanic perspectives on the potential benefits of precision medicine, along with the potential barriers that may prevent precision medicine from being equally beneficial to all. We also sought to identify if there were differences between African American and Hispanic perspectives.

Design: Six semi-structured focus groups were conducted between May 2017 and February 2018 to identify benefits and barriers to precision medicine. Three groups occurred in Nashville, TN with African American participants and three groups occurred in Miami, FL with Hispanic participants.

Setting: At community-based and university sites convenient to community partners and participants.

Participants: A total of 55 individuals participated (27 in Nashville, 28 in Miami). The majority of participants were women (76.5%) and the mean age of participants was 56.2 years old.

Results: Both African Americans and Hispanics believed precision medicine has the potential to improve medicine and health outcomes by individualizing care and decreasing medical uncertainty. However, both groups were concerned that inadequacies in health care institutions and socioeconomic barriers would prevent their communities from receiving the full benefits of precision medicine. African Americans were also concerned that the genetic and non-genetic personal information revealed through precision medicine would make African Americans further vulnerable to provider racism and discrimination in and outside of health care.

Conclusions: While these groups believed precision medicine might yield benefits for health outcomes, they are also skeptical about whether African Americans and Hispanics would actually benefit from precision medicine given current structural limitations and disparities in health care access and quality. *Ethn Dis.* 2020;30(Suppl 1):149-158; doi:10.18865/ed.30.S1.149

Keywords: Precision Medicine; Attitudes; Focus Group; African American; Hispanic

INTRODUCTION

Patients, providers, and researchers are increasingly excited about the potential of precision medicine to transform medicine, health care and improve population health[1,2] through translational clinical research and biomedical technologies.[3] We must, however, prevent precision medicine from exacerbating racial and ethnic health and health care disparities since state-of-the-art therapies tend to be unequally distributed across the population.[4] The recruitment of racially and ethnically diverse people into precision medicine research studies and providing all populations equal access to precision medicine interventions are important first steps,[5] but even when health care is accessible, African Americans, Hispanics and other underserved groups routinely receive poorer health care quality than Whites and others,[6,7] even when individuals have similar insurance and economic standing.[8-10]

Understanding how African Americans, Hispanics and other

---

[1] Center for Clinical Quality and Implementation Research, Vanderbilt University Medical Center, Nashville, TN
[2] Center for Research on Men's Health, Vanderbilt University, Nashville, TN
[3] University of Miami, School of Nursing and Health Studies, Coral Gables, FL
[4] Division of General Internal Medicine and Public Health, Department of Medicine, Vanderbilt University Medical Center, Nashville, TN
[5] Center for Medicine, Health, and Society, Vanderbilt University, Nashville, TN
[6] Department of Internal Medicine, Meharry Medical College, Nashville, TN
[7] Meharry-Vanderbilt Alliance, Vanderbilt University Medical Center, Nashville, TN
[8] Division of Geriatrics, Department of Medicine, Vanderbilt University Medical Center, Nashville, TN

Address correspondence to Vivian M. Yeh, PhD; Center for Clinical Quality and Implementation Research; Vanderbilt University Medical Center, 2525 West End Ave, Nashville, TN 37203; Vivian.m.yeh@vumc.org

medically underserved groups perceive precision medicine is critical to understanding how these groups may engage with precision medicine. Recognizing diverse patient perspectives will help build an understanding of how precision medicine may be delivered successfully and not exacerbate health and health care disparities. Consequently, in this study, we sought to explore three research questions: 1) what do African Americans and Hispanics think are potential benefits of precision medicine? 2) what do African Americans and Hispanics think are potential barriers to precision medicine being equally beneficial to all? and 3) are there differences between African Americans and Hispanics in their perceptions of the perceived benefits and barriers to precision medicine?

> *Understanding how African Americans, Hispanics and other medically underserved groups perceive precision medicine is critical to understanding how these groups may engage with precision medicine.*

METHODS

Setting

This study was conducted by a team from the Precision Medicine and Health Disparities Collaborative, a cooperative agreement funded by the National Institute on Minority Health and Health Disparities (NIMHD) that focuses on the Southeastern region (HHS Region IV), home to the largest African American population in the United States and a rapidly growing Latino population. The Precision Medicine and Health Disparities Collaborative is a partnership between Vanderbilt University Medical Center, Vanderbilt University, the University of Miami, and Meharry Medical College.

We conducted this study in the metropolitan areas of Nashville, Tennessee and Miami, Florida. Nashville (defined as Nashville – Davidson – Murfreesboro – Franklin) is the second largest metropolitan statistical area (MSA) in Tennessee[11] and Miami (defined as Miami-Fort Lauderdale – West Palm Beach) is the largest metropolitan statistical area in Florida.[11] All of the African American study participants were from Nashville, an MSA that is 28% African American, and all of the Latino participants were from Miami, an MSA that is 70% Latino.

Recruitment

To ensure recruitment of African Americans and Hispanics, we worked with groups within our institutions who have established relationships with community partners. These partners' longstanding work have embedded them into minority communities. We employed convenience sampling strategies with our community partners to reduce recruitment burden and to get an economically and educationally diverse sample of participants.

In Nashville, recruitment occurred with the Meharry-Vanderbilt Community Engaged Research Core (a partnership between Meharry Medical College and the Vanderbilt University Medical Center that provides assistance for all phases of community engaged research) and Nashville Opportunities Industrialization Center (a community-based education, training, counseling and job placement organization). In Miami, focus groups were conducted in partnership with the University of Miami's Behavioral & Community Shared Resource Core and Citrus Health Services, a federally qualified health center. All focus groups occurred in community-based sites that were convenient for the participants.

Participant Inclusion Criteria and Demographics

All participants were required to be aged ≥18 years. In Nashville, eligible participants had to self-identify as African American. In Miami, participants had to self-identify as Hispanic or Latino.

Fifty-five people participated in six focus groups divided evenly across Miami (n=28) and Nashville (n=27). See Table 1 for additional details on the participant characteristics. Demographic questionnaires in English (Nashville) and

Table 1. Participant demographics

Characteristic	Miami, FL, n=28	Nashville, TN, n=27	Full sample, N=55
Age, Mean(SD)	57.0(12.8)	54.8(9.9)	56.2(11.7)
Sex/Gender, n(%)			
Male	4(14.3)	7(25.9)	11(20.0)
Female	24(85.7)	12(44.4)	36(65.5)
Missing	0(0)	8(29.6)	8(14.5)
Race, n(%)			
African American	0(0)	19(70.4)	19(34.5)
White	25(89.3)	0(0)	25(45.5)
Other	3(10.7)	0(0)	3(5.5)
Missing	0(0)	8(29.6)	8(14.5)
Hispanic, n(%)			
Yes	28(100.0)	0(0)	28(50.9)
No	0(0)	19(70.4)	19(34.5)
Missing	0(0)	8(29.6)	8(14.5)
Education, n(%)			
8th grade or less	6(21.4)	0(0)	6(10.9)
Some high school	3(10.7)	7(25.9)	10(18.2)
High school or GED	11(39.3)	2(7.4)	13(23.6)
Some college or 2-year degree	6(21.4)	2(7.4)	8(14.5)
College graduate or more	2(7.1)	2(7.4)	4(7.3)
Missing	0(0)	14(51.9)	14(25.5)

Spanish (Miami) were completed. All but one of the 28 of the Miami participants were born outside of the United States: 26 were born in Cuba, and one was born in Colombia. The one participant born in the US was born in Florida. Due to a data collection error, no data were collected from eight Nashville participants and 14% of the overall sample were missing some data. Of the 47 participants for whom we have complete demographic data, 36 (76.5%) were women.

Procedures

Focus groups were conducted between May 2017 and February 2018. Three groups were conducted in each city, ranging in size from six to 10 participants per group. Institutional review boards at both Vanderbilt University Medical Center and the University of Miami School of Nursing and Health Studies approved the study. Verbal informed consent was obtained at the beginning of each focus group.

Focus groups followed a semi-structured format and were conducted by trained moderators. There was ethnic concordance between the moderators and the participants. The Nashville focus groups were conducted in English and the Miami focus groups were conducted in Spanish.

Moderators began by reading the definition of precision medicine aloud to ensure participants began the group with a baseline understanding of the concept: *"According to the National Institutes of Health, precision medicine is an approach to disease treatment and prevention that seeks to maximize effectiveness of therapies by taking into account an individual's genes, environment, and lifestyle*." Moderators then guided the discussion with a series of questions probing the participants' familiarity with precision medicine, their thoughts on precision medicine, the ways precision medicine

Table 2. Precision medicine moderator guide and focus group questions

We are interested in finding out the best way to share information about precision medicine with different communities and we want to hear your thoughts and ideas.
1. What types of things have you heard about precision medicine?
a. Where have you heard these things?
b. From who?
According to the National Institutes of Health, precision medicine is an approach to disease treatment and prevention that seeks to maximize effectiveness of therapies by taking into account an individual's genes, environment, and lifestyle.
2. What do you think about precision medicine(PM)?
3. How do you think precision medicine will affect the health care you receive? How do you think PM will affect health care overall?
4. How do you think precision medicine will affect your daily life?
5. How accessible do you think precision medicine is now? How accessible will it be in the future?
6. Who do you think will benefit the most from precision medicine?
7. Do you have any concerns about precision medicine? What types of information would be helpful to address these concerns?
8. Do you think that using precision medicine more would require doing less of something else in medical care? If so, what would you be willing to give up in order to get more use of precision medicine?
9. Who do you think would be the best person or organization to provide information about precision medicine to you and your community? How would you like to learn about precision medicine?

may/may not affect the health care they receive, beliefs about whether they would have access to precision medicine, and their concerns about precision medicine (Table 2). Each focus group lasted approximately 60 minutes and individuals were given $25 for their participation.

Data Analysis

The six focus groups were digitally audio-recorded, transcribed verbatim, and imported into the qualitative data software package NVivo 11 (NVivo qualitative data analysis Software; QSR International Pty Ltd. Version 10, 2012). Spanish audio to English transcription was completed by GMR Transcription, a privately held company that uses bilingual human translators who are American Translator Association certified. Two bilingual research staff also verified the English transcript by back-translating the documents into written Spanish, and then validating the written Spanish against the Spanish recording.

Each transcript was 'chunked' into segments of text that represented distinct issues or concepts. Significant passages were highlighted and margin notes were made to: a) summarize themes with a combination of restatements of the data and direct quotes, and b) document potential questions, connections, underlying themes, and possible implications of the text for further analysis. Two trained research analysts reviewed two focus group transcripts to begin coding, enhance the reliability of the coding process, and develop an initial codebook. Both analysts reviewed the transcripts independently to identify codes and met to develop, refine, and establish definitions and rules for codes and their assignment. Using the refined codebook, they then reviewed and independently coded a third focus group, achieving an inter-rater reliability of 79%. With inter-rater reliability established, the remaining transcripts were divided between the two analysts for in-depth textual analysis and coding to identify themes and subthemes.

We used a phenomenological approach to understand both "what" the phenomenon is and "how" people experience or understand it.[12] In addition, we used a thematic analytic strategy to analyze participant responses within coded text segments for similarities and differences that clustered to classify emerging themes.[12,13] Thematic analysis is considered appropriate when researchers are seeking to discover, organize and describe interpretations of the data.[14]

Saturation was reached in both the data collection and thematic analysis. Selected, concise quotes that captured the overall meaning of the theme, and that could be accurately understood outside of the context of the focus group transcript, are presented in this article.

RESULTS

Both African American and Hispanic participants believed that precision medicine had similar benefits and barriers with a few notable exceptions: African Americans expressed concerns that racism might affect the benefits they receive and that non-genetic personal information could be misused. We explore this in more detail below.

Perceived Benefits

Overall, African American and Hispanic participants had a positive perception of precision medicine and they generally viewed precision medicine as an innovative tool that is "a way to get to the bottom of things" and "a full way of treating." More specifically, participants perceived three potential and interrelated benefits of precision medicine: treating biological root causes, individualized care, and decreasing medical uncertainty. First, precision medicine could identify the root cause of a health care problem, particularly at the level of genetics.

> "[Individuals] want to find out the real solution, the real route to fix that problem to move [for] ward as well, so the next generation or other people that are in your environment won't have to go through that," said an African American participant.

Identifying the root cause of disease offered the potential to find a cure, rather than simply addressing the symptoms of the illness. As another African American participant noted,

> "We tend to treat a lot of symptoms, to me, as opposed to getting to root cause and finding a cure that addresses root causes so this thing goes away."

The second benefit was the potential that precision medicine might improve the personalization of treatment. Participants acknowledged that treatment outcomes vary. Since precision medicine is an approach that is based on patients' unique needs, genetic make-up and "individual chemistry" as one African American participant put it, taking a more personalized approach might enhance treatment outcomes for patients. Beyond the broad factors that may put someone at risk for disease, identifying individual genetic factors was seen as an important step forward. In addition, as one African American participant suggested, precision medicine involves the providers considering "different points of view regarding the patient: the personal aspect, the physical aspect, the environment, everything." This comprehensive assessment then informs the provider about what treatment should be recommended, and as one Hispanic participant suggested, "based on that then they give the medication for the patient." In sum, there was a consistent perception that precision medicine would be similar to caring for the whole person.

Lastly, participants believed precision medicine could reduce uncertainty for patients and providers about treatment; it was an important innovation that could "improve" health care - as one Hispanic participant put it - but it was not regarded as a separate cure-all. As one African American participant noted,

> "The doctor should know exactly what it is he's dealing with. And there is a tailored or custom or a precise as possible treatment plan that has been formulated to address that thing, that [is] need[ed]. So, taking the guesswork out."

African Americans expressed concerns that racism might affect the benefits they receive and that non-genetic personal information could be misused.

Participants believed that the highly specific information provided by precision medicine might promote the selection of treatments that work. Another Hispanic participant described the benefits from the patient perspective:

> "They would have more knowledge about the person, about the genes, and the best conditions they can provide for the person to have better health or for the illness the person might have. And it would be good for the patient in the psychological and emotional aspect making them feel safer and more protected."

For patients receiving precision medicine, knowing the in-depth nature of this approach may assure them they are receiving quality care and increase patient satisfaction.

Perceived Barriers

Despite generally favorable views on the potential of precision medicine, African American and Hispanic participants were uniformly concerned about how precision medicine would actually be provided given the limitations of the existing health care delivery system and the economic barriers that prevent equal access to precision medicine treatments. In addition to these concerns, African Americans noted concerns about racism and discrimination within the system but Hispanic participants did not.

Limitations of the Health Care System

Both African Americans and Hispanics expressed skepticism about whether health care institutions were positioned to deliver precision medicine to all patients, and if all patients could equally benefit. As one Hispanic participant said:

> "The idea is perfect… [but] they have to put it into practice [laughs]."

Explicit expressions of doubt were also common. When asked about how accessible precision medicine may be, a Hispanic participant answered: "not very accessible." Overall, this skepticism was rooted in the participants' experiences receiving health care.

Participants had reservations about the delivery of precision medicine in the current health care system: Hispanic participants noted "there is no time" and "everything is just too expensive. That's what is going to get in the way." Another Hispanic participant voiced specific concerns about how institutional entities interact.

> "There is a lack of coordination between the insurance and the doctor, and the patient….so until that's done, [precision medicine] isn't going to be established."

Since the current system is not providing health care with the same quality and accessibility across patients, participants doubted the system could rise to the challenge of providing precision medicine equally to all.

Socioeconomic Barriers to Precision Medicine

Both African Americans and Hispanics expressed concerns that economic forces would prevent people of their ethnic group from receiving precision medicine. As one Hispanic participant explained, "…in this country, medicine is a business." Therefore, as another Hispanic participant noted, access to precision medicine would be "depending on the insurance you have….and depending on the money you can pay."

Many participants believed that their personal access to precision medicine may be limited not because of their group identity but because of their socioeconomic status.

> "Precision medicine... I may not get the full benefit because I'm not at the right hospital or I'm not at the right elite status to receive that," stated an African American participant.

Some expressed concerns about being judged primarily by their socioeconomic status. As another African American participant expressed, "Money is power, so that's what they see. The consequences of the economically motivated health care system means you will be denied the best care if you have lower social economic status." As one Hispanic participant put it:

> "If the insurance companies aren't even authorizing a medication….[then] this precision medicine….[will be]… almost a luxury to have."

Participants did not necessarily believe providers were at fault or that provider biases might limit their receipt of precision medicine. Rather, they saw socioeconomic barriers as a symptom of larger systemic limitations. In relation to physicians, one African American participant explained,

> "You may be getting as

> much as they can provide."

Participants' discontent instead focused on insurance companies, which were universally panned. Another African American participant explicitly stated that providers also were powerless to act within the systemic limitations.

> "You can have the best doctors, but if your insurance doesn't cover it, they only can do so much."

Racism at Multiple Levels May Affect Who Benefits from Precision Medicine

While Hispanic participants were not concerned about ethnic discrimination, African Americans were concerned about racism. In addition to socioeconomic barriers to care, African American participants believed that racism could prevent them from accessing precision medicine benefits.

> "Because the color of our skin… because of our environment. Not having insurance, not having good jobs, just not having all the things we need. We're not gonna get the best of anything."

Many African Americans were alert to racism because of historical examples in health research and medical care. Multiple participants were aware of injustices:

> "In past history there were times when studies were done where people were often compromised in some way."

Specific instances of medical wrongdoing were listed: "When they did the syphilis study on the Black men," and "when they did the hysterectomy and the tubal ligations on the Black women."

In current health care examples, an African American participant described being targeted by providers to receive unnecessary treatment:

> "Those slum doctors out there… treating [sic] something that don't even need to be treated."

Another participant explained that this might occur when providers are motivated to receive the greatest compensation possible from each patient:

> "They get you to come back, so they can get that insurance money."

African Americans also raised concerns regarding privacy and were cautious about sharing too much personal information, implying that engaging with precision medicine may lead to negative unintended consequences. Sharing genetic information was viewed as potentially revealing too much:

> "When we start dealing with the DNA… [you are] giving the government a whole lot of access to you."

Beyond genetic data, African Americans were also worried about sharing the information necessary for other aspects of precision medicine. Divulging information about their lifestyle, living situation, and family history was considered a risky proposition – after all, this highly personal information could provide ammunition for a provider to judge you. As one African American participant suggested,

> "When they go that deep and they have all that information, it's almost like you're going to be judged."

The negative consequences of provider judgement could also mean that ultimately precision medicine would be denied.

> "If I'm Black….they may take all this information and judge you….you may fit in a category….too many liabilities or something, so she may not quality for this certain type of medicine."

In this situation, trying to engage with precision medicine may result in exposure to racism and judgement without reaping any personal benefit.

DISCUSSION

We explored what African Americans and Hispanics think are the benefits of precision medicine and what barriers may prevent their ethnic groups from receiving equal precision medicine benefits. We also sought to explore ethnic differences in the perceptions of these benefits and barriers. In sum, we found more similarities than differences in both the perceived benefits and barriers, but we did find some noteworthy differences. These findings are important to inform strategies to recruit participants into research programs and initiatives like *All of Us:* a federal research program to collect data from one million people living in the United States to accelerate our ability to detect and address individual differences in biology, lifestyle, and environment that can be modified to improve health.[15]

Both African Americans and Hispanics were generally optimistic about the potential of precision medicine to lead to innovations in health care that may improve diagnosis and treatment, and yet many also expressed a number of concerns. These concerns were not about precision medicine, per se, but the context in and through which precision medicine would need to function so that broad communities can benefit from these translational innovations in clinical and biomedical care. Specifically, participants from both ethnic groups were concerned that differential access to health care, time and resource limits on medical visits, and the cost of medical care would limit access to the full benefits of precision medicine. This skepticism was grounded not only in their knowledge about past research and health care abuses, but also in their personal health care experiences and those of others. Participants saw this as a systemic problem, not one of individual providers intentionally providing differential care by social class, economic status or insurance type.

The most significant ethnic difference noted in our study was in the discussion of racism as a barrier to receiving precision medicine benefits. African Americans expressed concerns that racism could affect their ability to reap benefits but Hispanic participants did not. The direction, while perhaps not the magnitude of this difference, is consistent with prior research. For example, Hispanics from Denver, CO expressed less concern about potential discrimination from direct-to-consumer genetic testing than African Americans.[16]

African Americans noted the history of medical research that was only done on African Americans[17] and the concern that these research practices may make their way into the clinical care of African Americans.[18,19] Interestingly, while researchers have speculated that these medically underserved groups may be especially sensitive to the risks of sharing genetic information,[20] African Americans in our focus groups were just as concerned with sharing personal lifestyle and environmental information, based on previous negative interactions with providers that decreased patient trust.[21] Earlier studies have found that even African Americans with distrust will participate in biobank research;[22] however, it remains unclear if these privacy concerns would lead African Americans to avoid precision medicine. Hispanics also participate in biobanking research[23,24] and have higher awareness of direct-to-consumer genetic testing than African Americans.[25] Nonetheless, biobank participation does not necessarily translate into precision medicine use. A recent systematic review has found that both Hispanics and African Americans have less access and are less likely to use genetic testing[26] than non-Hispanic Whites despite being equally interested.[27]

Limitations

This study had several limitations. Because African Americans and Hispanics were recruited from different cities, it is unclear if differences are a function of cultural beliefs, the historical and socioeconomic context of city, or some combination of the two. Since only two individuals in our Miami focus groups were not Cuban, it is unclear if our findings apply to other Hispanics. Because of the limitations of our data on socioeconomic status and educational attainment, it is unclear how these factors may shape our findings.

CONCLUSIONS

Despite these limitations, our study is important because it is one of the first to describe the perspectives of African Americans or Hispanics on the potential benefits and barriers to precision medicine. Precision medicine is likely to identify genetic and genomic "variants of unknown consequences" rather than wholly conclusive results[28,29] that may actually serve to increase medical uncertainty for patients and providers not reduce them.[30,31] Additional studies with larger samples are needed to understand African American and Hispanic perspectives across contextual and demographic factors.

ACKNOWLEDGEMENTS AND COMPLIANCE WITH ETHICAL STANDARDS

We would like to thank the Nashville Opportunities Industrialization Center, the Meharry-Vanderbilt Community Engaged Research Core, the University of Miami's Behavioral and Community Shared Resource Core, and Citrus Health Services for helping us recruit participants and the

Precision Medicine and Health Disparities Collaborative External Advisory Board. We would also like to thank Dalia Lorenzo, the program manager at the University of Miami, for her help in conducting focus groups.

Institutional review boards at both Vanderbilt University Medical Center and the University of Miami School of Nursing and Health Studies approved the study. This research was conducted in adherence to the ethical standards of the IRB and the Helsinki Declaration of 1975, as revised in 2000. Informed consent was obtained from all participants in this study. This research has been supported in part by NIH/NIMHD (5U54MD010722-02) and The Center for Research on Men's Health at Vanderbilt University.

Conflict of Interest

No conflicts of interest to report.

Author Contributions

Research concept and design: Yeh, Bruce, Kripalani, Mitrani, Wilkins; Acquisition of data: Yeh; Data analysis and interpretation: Yeh, Bergner, Bruce, Kripalani, Mitrani, Ogunsola, Wilkins, Griffith; Manuscript draft: Yeh, Bergner, Bruce, Ogunsola, Griffith; Statistical expertise: Yeh; Acquisition of funding: Kripalani, Wilkins; Administrative: Yeh, Bergner, Bruce, Ogunsola, Wilkins, Griffith; Supervision: Bergner, Mitrani

References

1. Bayer R, Galea S. Public health in the precision-medicine era. *N Engl J Med*. 2015;373(6):499-501. https://doi.org/10.1056/NEJMp1506241 PMID:26244305
2. Collins FS, Varmus H. A new initiative on precision medicine. *N Engl J Med*. 2015;372(9):793-795. https://doi.org/10.1056/NEJMp1500523 PMID:25635347
3. Ma J, Rosas LG, Lv N. Precision lifestyle medicine: a new frontier in the science of behavior change and population health. *Am J Prev Med*. 2016;50(3):395-397. https://doi.org/10.1016/j.amepre.2015.09.035 PMID:26651423
4. Frohlich KL, Potvin L. Transcending the known in public health practice: the inequality paradox: the population approach and vulnerable populations. *Am J Public Health*. 2008;98(2):216-221. https://doi.org/10.2105/AJPH.2007.114777 PMID:18172133
5. Bentley AR, Callier S, Rotimi CN. Diversity and inclusion in genomic research: why the uneven progress? *J Community Genet*. 2017;8(4):255-266. https://doi.org/10.1007/s12687-017-0316-6 PMID:28770442
6. Smedley BD, Stith AY, Nelson AR. *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*. Washington, D.C.: National Academies Press; 2003.
7. Sohler N, Walmsley PJ, Lubetkin E, Geiger HJ. *Equal Treatment: An Annotated Bibliography of Studies on Race and Ethnic Disparities in Health care, Their Cause, and Related Issues*. New York: Physicians for Human Rights; 2003.
8. Zogg CK, Jiang W, Chaudhary MA, et al. Racial disparities in emergency general surgery: do differences in outcomes persist among universally insured military patients? *J Trauma Acute Care Surg*. 2016;80(5):764-775. https://doi.org/10.1097/TA.0000000000001004 PMID:26958790
9. Trivedi AN, Grebla RC, Wright SM, Washington DL. Despite improved quality of care in the Veterans Affairs health system, racial disparity persists for important clinical outcomes. *Health Aff (Millwood)*. 2011;30(4):707-715. https://doi.org/10.1377/hlthaff.2011.0074 PMID:21471492
10. Williams DR, Priest N, Anderson NB. Understanding associations among race, socioeconomic status, and health: patterns and prospects. *Health Psychol*. 2016;35(4):407-411. https://doi.org/10.1037/hea0000242 PMID:27018733
11. Bureau USC. Metropolitan and Micropolitan Statistical Area Tables. 2013. Last accessed Sept 30, 2019 from https://www.census.gov/programs-surveys/metro-micro/data/tables.2013.html.
12. Creswell JW. *Qualitative Inquiry and Research Design: Choosing Among Five Approaches*. Thousand Oaks, CA: Sage Publications. 2012.
13. Fereday J, Muir-Cochrane E. Demonstrating rigor using thematic analysis: A hybrid approach of inductive and deductive coding and theme development. *Int J Qual Methods*. 2006;5(1):80-92. https://doi.org/10.1177/160940690600500107
14. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol*. 2006;3(2):77-101. https://doi.org/10.1191/1478088706qp063oa
15. Sankar PL, Parker LS. The Precision Medicine Initiative's All of Us Research Program: an agenda for research on its ethical, legal, and social issues. *Genet Med*. 2017;19(7):743-750. https://doi.org/10.1038/gim.2016.183 PMID:27929525
16. Rahm AK, Feigelson HS, Wagner N, et al. Perception of direct-to-consumer genetic testing and direct-to-consumer advertising of genetic tests among members of a large managed care organization. *J Genet Couns*. 2012;21(3):448-461. https://doi.org/10.1007/s10897-011-9477-3 PMID:22278218
17. Brawley OW. The study of untreated syphilis in the Negro male. *Int J Radiat Oncol Biol Phys*. 1998;40(1):5-8. PMID: 9422551
18. Corbie-Smith G, Thomas SB, St George DM. Distrust, race, and research. *Arch Intern Med*. 2002;162(21):2458-2463. https://doi.org/10.1001/archinte.162.21.2458 PMID:12437405
19. Boulware LE, Cooper LA, Ratner LE, LaVeist TA, Powe NR. Race and trust in the health care system. *Public Health Rep*. 2003;118(4):358-365. https://doi.org/10.1016/S0033-3549(04)50262-5 PMID:12815085
20. Suther S, Kiros G-E. Barriers to the use of genetic testing: a study of racial and ethnic disparities. *Genet Med*. 2009;11(9):655-662. https://doi.org/10.1097/GIM.0b013e3181ab22aa PMID:19752639
21. Jacobs EA, Mendenhall E, Mcalearney AS, et al. An exploratory study of how trust in health care institutions varies across African American, Hispanic and white populations. *Commun Med*. 2011;8(1):89-98. https://doi.org/10.1558/cam.v8i1.89 PMID:22616359
22. Halverson CM, Ross LF. Engaging African Americans about biobanks and the return of research results. *J Community Genet*. 2012;3(4):275-283. https://doi.org/10.1007/s12687-012-0091-3 PMID:22454259
23. Heredia NI, Krasny S, Strong LL, et al. Community perceptions of biobanking participation: a qualitative study among Mexican Americans in three Texas cities. *Public Health Genomics*. 2017;20(1):46-57. https://doi.org/10.1159/000452093 PMID:27926908
24. Hohl SD, Gonzalez C, Carosso E, Ibarra G, Thompson B. "I did it for us and I would do it again": perspectives of rural latinos on providing biospecimens for research. *Am J Public Health*. 2014;104(5):911-916. https://doi.org/10.2105/AJPH.2013.301726 PMID:24625153
25. Langford AT, Resnicow K, Roberts JS, Zikmund-Fisher BJ. Racial and ethnic differences in direct-to-consumer genetic tests awareness in HINTS 2007: sociodemographic and numeracy correlates. *J Genet Couns*. 2012;21(3):440-447. https://doi.org/10.1007/s10897-011-9478-2 PMID:22271378
26. Canedo JR, Miller ST, Myers HF, Sanderson M. Racial and ethnic differences in knowledge and attitudes about genetic

testing in the US: systematic review. *J Genet Couns*. 2019;28(3):587-601. https://doi.org/10.1002/jgc4.1078 PMID:30663831

27. Singer E, Antonucci T, Van Hoewyk J. Racial and ethnic variations in knowledge and attitudes about genetic testing. *Genet Test*. 2004;8(1):31-43. https://doi.org/10.1089/109065704323016012 PMID:15140372
28. Ghouse J, Skov MW, Bigseth RS, Ahlberg G, Kanters JK, Olesen MS. Distinguishing pathogenic mutations from background genetic noise in cardiology: the use of large genome databases for genetic interpretation. *Clin Genet*. 2018;93(3):459-466. https://doi.org/10.1111/cge.13066 PMID:28589536
29. Ackerman MJ. Genetic purgatory and the cardiac channelopathies: exposing the variants of uncertain/unknown significance issue. *Heart Rhythm*. 2015;12(11):2325-2331. https://doi.org/10.1016/j.hrthm.2015.07.002 PMID:26144349
30. Reiff M, Bernhardt BA, Mulchandani S, et al. "What does it mean?": uncertainties in understanding results of chromosomal microarray testing. *Genet Med*. 2012;14(2):250-258. https://doi.org/10.1038/gim.2011.52 PMID:22241091
31. Simpkin AL, Schwartzstein RM. Tolerating uncertainty—the next medical revolution? *N Engl J Med*. 2016;375(18):1713-1715. https://doi.org/10.1056/NEJMp1606402 PMID:27806221