

ORIGINAL RESEARCH

Patient Research Interest Differences by Gender and Race/Ethnicity: A North Texas Primary Care Practice-Based Research Network (NorTex) Study

Tanjina Shabu, MPH, Anna M. Espinoza, MD, Sydney Manning, MS,
Roberto Cardarelli, DO, MPH, and Kimberly G. Fulda, DrPH

Background: Recruiting and increasing participation of women and racial/ethnic groups remains an ongoing struggle despite the National Institutes of Health Revitalization Act mandating the inclusion of these populations. This study examined gender and racial/ethnic differences in research interest in participating in Practice-Based Research Network studies focused on cardiovascular disease (CVD), diabetes, cancer, and mental health research.

Methods: A total of 1348 participants and 18 NorTex clinics from the North Texas Primary Care Registry Project (NRP) database were included in this cross-sectional study. Participants who signed up through the registry to participate in future research projects and self-reported as non-Hispanic White, Hispanic, or non-Hispanic Black were included. Research interest in heart disease, high cholesterol, high blood pressure and heart failure were categorized as CVD; depression and anxiety were categorized as mental health; diabetes and cancer research were coded as single item dependent variables.

Results: Of registry participants, 72% were female, 34.5% were Black, and 24.4% were Hispanic. Of participants, 70% (n = 942) were interested in CVD research, the leading area of interest. Mental health research (56.3%, n = 755) was the second highest area of interest, while cancer had the least interest (38.4%, n = 515). After controlling for age, smoking, and having a diagnosis of the medical condition, gender did not predict interest in CVD, diabetes, cancer, or mental health research. However, race/ethnicity significantly predicted interest in diabetes and cancer research.

Conclusion: Results indicate there are racial/ethnic differences in interest in specific research topics among our registry participants. This information may be helpful to develop successful recruitment strategies. (J Am Board Fam Med 2022;35:225–234.)

Keywords: Cancer, Cardiovascular Diseases, Cross-Sectional Studies, Diabetes Mellitus, Ethnicity, Mental Health, Practice-Based Research, Primary Health Care, Registries, Texas

Introduction

Recruiting research participants representing both male and female and minority populations for

medical research presents a distinct challenge for clinical researchers.^{1,2} Despite the National Institutes of Health (NIH) Revitalization Act mandating the inclusion of women and minorities in all federally funded research studies,³ recruitment of these populations remains an ongoing struggle.^{4,5} The lack of diversity among participants in biomedical research is a limitation for presenting more applicable treatment outcomes

This article was externally peer reviewed.

Submitted 10 August 2021; revised 23 November 2021; accepted 30 November 2021.

Health Services Advisory Group, Phoenix, AZ (TS); North Texas Primary Care Practice-Based Research Network (NorTex), Department of Family Medicine and Osteopathic Manipulative Medicine, Texas College of Osteopathic Medicine, University of North Texas Health Science Center, Fort Worth, TX (AE, KGF); Department of Pharmacotherapy, System College of Pharmacy, University of North Texas Health Science Center, Fort Worth, TX (SM); and Department of Family and Community Medicine, University of Kentucky College of Medicine, Lexington, KY (RC).

Funding: No external funding was received for this project.

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

Corresponding author: Kimberly G. Fulda, DrPH, NorTex, Department of Family Medicine and Osteopathic Manipulative Medicine, University of North Texas Health Science Center, 3500 Camp Bowie Boulevard, Fort Worth, TX 76107 (E-mail: Kimberly.Fulda@unthsc.edu).

for underrepresented groups.^{6,7} Failure to engage diverse participants further exacerbates health disparities and makes minorities more vulnerable to poor health outcomes.⁸ Therefore, increasing participation of women and racial/ethnic groups is critical to reduce the overall burden of health disparities and decrease the pressure on health care.

Gender and Research Participation

Inclusion of women in biomedical research remains low even though they are equally affected by chronic diseases such as cardiovascular disease (CVD; 39% female participants), hepatitis (39%), HIV (35%), and chronic kidney disease (42%).⁹ Including women in research is vital to make decisions on dosage, safety, and efficacy of therapeutic agents.¹⁰ Due to a lack of participation of women and the historic exclusion of women of child bearing age or who are pregnant, agencies such as the Food and Drug Administration and NIH, are interested in ensuring higher enrollment of women in clinical trials.¹⁰ Factors such as age, methods of recruitment, existing health conditions, prior research participation, researcher-participant relationship, and sex inequality may affect participation of women in research.^{7,11,12}

Race/Ethnicity and Research Participation

Racial/ethnic minorities may be less informed about the importance of research as White people, and this lack of information influences their perception about clinical research.⁴ Historically, a low level of trust impacted racial/ethnic minority groups' willingness to participate in medical research.^{2,13–15} For example, Black respondents may be less willing to participate due to past abuses, such as the Tuskegee Syphilis Study.^{15–17} Prior studies reported that Black people and Hispanic people may have more distrust toward doctors, have more negative attitudes about clinical trials, and are less willing to be a participant in clinical trials than White people.^{5,18}

Factors that may hinder research participation include whether the minority groups are informed of research opportunities, whether they are medically eligible to participate, and whether their personal circumstances allow it.¹⁹ Stigma such as the fear of being associated with a clinical condition can

also be a barrier to racial/ethnic minority groups participating in research.^{2,20}

Practice-Based Research Networks and Research

Practice-Based Research Networks (PBRNs) have been identified as “clinical laboratories for primary care research and dissemination,” and a method by which research findings may be more readily implemented into practice.²¹ Tapp and Dulin²² have suggested that it is necessary to structure PBRN research to more closely match the needs of providers, patients, and local communities; make research protocols amenable to participant needs; and facilitate research participant recruitment. While evidence suggests racial/ethnic differences in willingness to participate in medical research, no studies were identified that assess differences in gender and racial/ethnic interests in primary care and mental health research within a network of primary care providers. This study examined gender and racial/ethnic differences in research interest in PBRN studies focused on CVD, diabetes, cancer, and mental health research.

Methods

The North Texas Primary Care Registry Project

The North Texas Primary Care Practice-Based Research Network (NorTex) was established in 2005 at the University of North Texas Health Science Center at Fort Worth (HSC) to facilitate and conduct research in primary care settings.²³ The North Texas Primary Care Registry Project (NRP) was created through a partnership with NorTex clinics to develop a database of potential participants willing to be contacted and recruited for NorTex research projects. The NRP allows researchers to assess the feasibility of future projects, demonstrate an accessible participant population for research grants, and, most importantly, quickly identify and recruit participants into studies.

Study Population and Data Collection

As of July 17, 2020, a total of 1,348 people from 18 NorTex clinics had signed up to participate in research through the NRP. Data collected from the beginning of registry enrollment, in August 2008, through July 17, 2020, were included in this

analysis. For this analysis, “participants” includes people who signed up for the NRP registry to be contacted and recruited for future research projects. Only registry participants who self-reported as non-Hispanic White, Hispanic, or non-Hispanic Black were included in this analysis. Other racial groups (eg, Native American/Alaskan, Asian/Pacific Islander and other) were excluded due to low participation numbers ($n = 40$). Race (White and Black) was combined with ethnicity (Hispanic and non-Hispanic) to create 1 variable for analysis. Race/ethnicity was also missing for 71 participants. A ballot box was placed in the reception area of participating clinics, with 4×6 index cards, asking permission for patients to be contacted for NorTex studies. Patients and individuals visiting any of the 18 participating NorTex clinics could fill out a card to enroll in the NRP. Flyers were posted to advertise the registry among clinics, physicians, and potential subjects. The index card is 2-sided and is available in both English and Spanish. More participants signed up for the NRP between 2008 and 2012. While the number remained consistent from 2013 to 2016, registry sign up slowed from 2017 to 2020. Only 1 participant signed up in 2020. This was due to the closure of clinics during the COVID-19 pandemic. Since the current data analysis and the introduction of telehealth, we have redesigned the NRP card so that it now includes a QR code. Participants will have the option of completing the registration online.

The front side of the card provides information about the registry, consent information, contact information for the principal investigator, potential risks and benefits of enrolling in the NRP, and other study relevant information. On the reverse side of the card, there are sections for demographic information, medical history, and research interests assessed through a checklist. Demographic characteristics include gender (male, female), race/ethnicity (White, Hispanic/Latino, Black/African American, Native American/Alaskan, Asian/Pacific Islander, and other), and age. Potential participants are also given the option to receive e-mails and updates from NorTex. Individuals 18 years of age and older are eligible to participate in the NRP. Each card contains a numeric clinic code linking it to a specific clinic and records the potential participants’ contact information and date of birth. The cards are collected periodically by staff from NorTex’s research coordinating team. The data are then entered into the database, and cards are kept in a secured cabinet. The NRP

was approved by the University of North Texas Health Science Center, North Texas Regional Institutional Review Board.

Variables

Independent Variables

Gender (male, female) and self-reported race/ethnicity (non-Hispanic White, non-Hispanic Black, and Hispanic) were the primary predictors in this study. Whereas we realize that gender is not binary, gender was collected as male/female on the NRP card. This limits inferences about nonbinary gender groups. Potential confounders included age, smoking status (smoker or nonsmoker), and having a diagnosis of a cardiovascular health condition, diabetes, mental health disease, or cancer. Age was calculated by subtracting the participant’s date of birth from the date the card was recorded and was analyzed as a continuous variable. A cardiovascular health condition was considered present if the participant selected a diagnosis of heart disease, high blood pressure, high cholesterol, or heart failure. Diagnoses of depression and anxiety were coded under the variable “mental health condition.” Prior diagnosis of cancer was considered present if the participant indicated breast cancer, colon cancer, prostate cancer, or cervical cancer.

Dependent Variables

On the recruitment card, registry participants were asked, “What health topics do you find important and want to see more research be done on?” to assess interest in specific research topics. Participant responses were categorized as “yes” and “no.” Research interest in heart disease, high cholesterol, high blood pressure, and heart failure were categorized as research interest in cardiovascular health. Interest in depression and anxiety were categorized as research interests in mental health conditions. Research interests in diabetes and cancer research were coded as single item dependent variables.

Statistical Analysis

Analyses were conducted using SPSS version 25.²⁴ Descriptive statistics are presented for demographic characteristics, counts, and frequencies are listed for categorical variables, and means and standard deviations are provided for continuous variables. Descriptive measures were used to examine the distribution of interest in health research topics by gender and race/ethnicity. Differences in research interest by gender and race/ethnicity were analyzed using Pearson’s χ^2 .

Simple logistic regressions were performed to determine the associations between gender and race/ethnicity with interest in research related to cardiovascular disease, diabetes, cancer, and mental health. Four multiple logistic regression models were composed to assess the same association while controlling for smoking status, age, and the diagnosis associated with the research interest. For example, the model assessing the association between race/ethnicity, gender, and research interest in cardiovascular health controlled for prior diagnosis of a cardiovascular health condition. Odds ratios (OR), adjusted odds ratios (AOR), and 95% confidence intervals (CI) were computed. Results were considered statistically significant at $\alpha = 0.05$.

Results

The NRP included 1348 eligible participants. Descriptive measures are presented in Table 1. Seventy-two percent ($n = 950$) of individuals enrolled in the NRP were female. Forty-one percent were White, 34.5% were Black, and 24.4% were Hispanic. Seventy percent ($n = 942$) of participants indicated that they were interested in CVD research, which was the leading area of interest. Mental health research (56.3%, $n = 755$) was the second highest area of interest among participants, while cancer had the least amount of research interest (38.4%, $n = 515$).

There were significant differences by gender for CVD diagnosis ($P < .001$), interest in CVD research ($P = .001$), diabetes diagnosis ($P = .005$),

interest in diabetes research ($P = .004$), mental health disorder diagnosis ($P < .001$), and interest in mental health research ($P = .02$). No gender differences were identified for cancer diagnosis or interest in cancer research. There were significant differences by race/ethnicity for CVD diagnosis ($P < .001$), interest in diabetes research ($P < .001$), interest in cancer research ($P < .001$), mental health disorder diagnosis ($P < .001$), and interest in mental health research ($P < .001$). There were no differences by race/ethnicity for interest in CVD research, diabetes diagnosis, or cancer diagnosis (Table 2).

Females were less likely than males to report an interest in CVD research (OR, 0.63; 95% CI, 0.48–0.83) in unadjusted analyses; however, this association did not remain after controlling for potential confounders. Race/ethnicity did not predict interest in CVD research in either unadjusted or adjusted analyses. Other predictors of interest in CVD research in the adjusted model included age and having a prior diagnosis of CVD (Table 3).

In unadjusted analyses, females (OR, 0.70; 95% CI, 0.55–0.89) were less likely to be interested in diabetes research than males, and Hispanics were more likely to be interested than Whites (OR, 1.85; 95% CI, 1.38–2.47). The association between gender and interest in diabetes research did not remain significant in the adjusted model; however, the association with race/ethnicity did. In the adjusted analysis, Hispanics had 1.82 times increased odds of being interested in diabetes research compared with Whites (AOR, 1.82; 95% CI, 1.30–2.54). Having a prior diagnosis of diabetes also significantly predicted interest in diabetes research in the adjusted model.

Gender was not associated with interest in cancer research in either the unadjusted or adjusted analyses; however, differences were observed for race/ethnicity. Black people were less likely than White people to be interested in cancer research in both the unadjusted (OR, 0.61; 95% CI, 0.46–0.80) and adjusted (AOR, 0.61; 95% CI, 0.46–0.80) analyses. Having a prior diagnosis of cancer was also associated with interest in cancer research in the adjusted model.

Females were more likely than males (OR, 1.33; 95% CI, 1.04–1.69) and Hispanic people (OR, 0.58; 95% CI, 0.43–0.77) and Black people (OR, 0.70; 95% CI, 0.54–0.91) were less likely than White people to be interested in mental health research. Neither gender nor race/ethnicity significantly predicted interest in mental health research

Table 1. Descriptive Characteristics of Study Sample ($n = 1348$)

Variable	Mean (SD)
Age	50.2 (13.46)
	n (%)
Gender	368 (27.9)
Male	950 (72.1)
Female	
Race/ethnicity	
White	508 (41.1)
Hispanic	302 (24.4)
African American	427 (34.5)
Smoking status	
Smoker	274 (20.4)
Nonsmoker	1068 (79.6)

Abbreviations: SD, standard deviation.

Participants are defined as people who signed up for the NRP registry to be contacted and recruited for future research projects.

Table 2. Descriptive and Unadjusted Analysis of Gender and Race/Ethnicity Within Each Category

Variable	n	%	P
Cardiovascular health condition diagnosis			
Yes	794	59.3	
No	545	40.7	
Gender			<.001
Male	246	67.2	
Female	533	56.5	
Race/ethnicity			<.001
White	12	61.7	
Hispanic	136	45.0	
African American	282	66.4	
Interested in cardiovascular health research			
Yes	942	70.2	
No	399	29.8	
Gender			.001
Male	283	77.3	
Female	645	68.2	
Race/ethnicity			.848
White	355	69.9	
Hispanic	213	70.8	
African American	305	71.6	
Diabetes diagnosis			
Yes	348	25.9	
No	994	74.1	
Gender			.005
Male	115	31.4	
Female	226	23.0	
Race/ethnicity			.755
White	126	24.9	
Hispanic	82	27.2	
African American	112	26.2	
Interested in diabetes research			
Yes	659	49.1	
No	682	50.9	
Gender			.004
Male	204	55.7	
Female	443	46.8	
Race/ethnicity			<.001
White	230	45.3	
Hispanic	182	60.5	
African American	197	46.2	
Cancer diagnosis			
Yes	89	6.6	
No	1253	93.4	
Gender			.156
Male	30	8.2	
Female	57	6.0	

*Continued***Table 2. Continued**

Variable	n	%	P
Race/ethnicity			.146
White	41	8.1	
Hispanic	22	7.3	
African American	21	4.9	
Interested in cancer research			
Yes	515	38.4	
No	826	61.6	
Gender			.968
Male	140	38.3	
Female	363	38.4	
Race/ethnicity			<.001
White	216	42.5	
Hispanic	133	44.2	
African American	132	31.0	
Mental health disorder diagnosis			
Yes	594	44.3	
No	747	55.7	
Gender			<.001
Male	135	36.9	
Female	450	47.6	
Race/ethnicity			<.001
White	283	55.8	
Hispanic	87	28.8	
African American	179	42.0	
Interested in mental health research			
Yes	755	56.3	
No	586	43.7	
Gender			.021
Male	189	51.6	
Female	555	58.7	
Race/ethnicity			<.001
White	320	63.0	
Hispanic	149	49.5	
African American	232	54.5	

Participants are defined as people who signed up for the NRP registry to be contacted and recruited for future research projects.

in the adjusted model. Having a prior diagnosis of a mental health illness and age did predict interest in the adjusted model.

Discussion

Cardiovascular Disease

We found no significant difference in research interest in cardiovascular health between Black and Hispanic participants compared with White participants. Statistically, however, Black people are 20% more likely to die from heart disease than White people²⁵ and share the greatest

Table 3. Simple and Multiple Logistic Regression for Research Interest

Variable	Simple logistic regression		Multiple logistic regression	
	OR	95% CI	AOR	95% CI
Interested in cardiovascular disease research				
Gender (male)				
Female	0.63	0.48–0.83	0.79	0.58–1.08
Race/ethnicity (White)				
Hispanic	1.04	0.76–0.43	1.39	0.98–1.98
African American	1.09	0.82–1.44	1.06	0.78–1.44
Diagnosed with CVD	4.26	3.32–0.46	4.21	3.16–5.62
Smoking	1.08	0.81–1.45	1.16	0.82–1.64
Age	1.03	1.02–1.04	1.01	1.00–1.02
Interested in diabetes research				
Gender (male)				
Female	0.70	0.55–0.89	0.76	0.57–1.02
Race/ethnicity (White)				
Hispanic	1.85	1.38–2.47	1.82	1.30–2.54
African American	1.04	0.80–1.35	1.00	0.74–1.35
Diagnosed with diabetes	11.73	8.38–16.42	12.73	8.83–18.35
Smoking	0.77	0.59–1.00	0.85	0.61–1.17
Age	1.01	1.00–1.02	1.00	0.99–1.01
Interested in cancer research				
Gender (male)				
Female	0.97	0.78–1.29	1.02	0.78–1.33
Race/ethnicity (White)				
Hispanic	1.07	0.80–1.43	1.03	0.76–1.40
African American	0.61	0.46–0.80	0.61	0.46–0.80
Diagnosed with cancer	2.29	1.48–3.54	2.27	1.43–3.60
Smoking	0.94	0.72–1.24	1.01	0.75–1.36
Age	1.00	0.99–1.01	0.99	0.98–1.00
Interested in mental health research				
Gender (male)				
Female	1.33	1.04–1.69	1.04	0.78–1.40
Race/ethnicity (White)				
Hispanic	0.58	0.43–0.77	0.84	0.59–1.18
African American	0.70	0.54–0.91	0.83	0.61–1.13
Diagnosed with mental health illness	8.44	6.51–10.93	7.97	5.98–10.62
Smoking	2.06	1.55–2.73	1.11	0.78–1.59
Age	0.98	0.97–0.99	0.97	0.96–0.98

Abbreviations: OR, odds ratio; AOR, adjusted odds ratio; CI, confidence interval; CVD, cardiovascular disease.

Participants are defined as people who signed up for the NRP registry to be contacted and recruited for future research projects.

burden of cardiovascular disease in the United States.²⁶ One possible reason for Black and Hispanic participants not showing interest can be lack of awareness about research as studies found that Black participants are interested in learning about CVD prevention programs, and both Blacks and Hispanics are more likely to participate in health research if given the opportunity.^{19,27}

There was no gender difference observed in CVD research interest after adjusting for all confounding variables. While we found females were less likely than males to be interested in CVD research in the unadjusted analysis, this did not remain true after controlling for race/ethnicity, prior diagnoses of CVD, smoking, or age. Males were significantly more likely to report a diagnosis of CVD; therefore, the lack of gender difference in

the adjusted model may be a result of controlling for prior diagnosis. Other research has identified that potential reasons why women may be less interested in CVD research include lack of awareness, and lack of knowledge due to low education.^{28–30}

Diabetes

Our study found that Hispanics have a higher interest in diabetes research compared with Whites, and this coincides with higher incidence rates reported for this ethnic group nationally.³¹ We did not, however, find a difference in interest in diabetes research between Black and White respondents. This is a point of interest because Blacks are 60% more likely to have been diagnosed with diabetes and twice as likely to die from diabetes as compared with Whites nationally.³² One reason for our finding may be that we did not find a significant difference in self-reported diagnosis of diabetes by race/ethnicity among our respondents. Furthermore, members of high-risk groups often do not perceive the severity of diabetes and underestimate their chances of being diagnosed with diabetes,³³ which can be associated with the lack of interest in participating in related research. Diabetes fatalism has also been attributed to lack of self-care and may be important for recruiting patients in this area.³⁴

Though females were less likely than males to be interested in diabetes research before controlling for potential confounders, we did not find gender differences in our adjusted model. The higher prevalence of diabetes among males in our study (31.4%, $n = 283$) supports national data that 13.3% of all men aged 18 years or older have diabetes compared with 10.8% of all women aged 18 years or older.³⁰ In addition, our study saw a higher percentage of males (55.7%, $n = 204$) being interested in diabetes research compared with females. Some of the key factors such as prioritization of health and positive outlook that affect diabetes self-management behaviors in men can be attributable to their interest in research as well.³⁵

Cancer

Our study found that Black participants are less likely to be interested in cancer research studies than White participants. This is concerning, because Blacks have the highest mortality rate of any racial/ethnic group for all cancers combined

and for most major cancers.^{36–37} Nationally, the overall cancer incidence rate is higher among Black males than White males but higher among White females than Black females.³⁸ Low socioeconomic status, communication gaps with providers, mistrust of research and the medical system, fear, embarrassment, and lack of knowledge about the origin of cancer have been found to have a negative impact on clinical cancer research participation rates.^{39–41}

In our study, gender did not predict interest in cancer research. The overall prevalence of cancer was low among participants. Only 6.6% of participants reported being diagnosed with cancer, and the number of female participants diagnosed with cancer ($n = 57$) was higher than male participants ($n = 30$). The National Cancer Institute Surveillance Epidemiology and End Results and Centers for Disease Control and Prevention report that men have higher incidence and mortality rates from cancer than women, whereas, our study showed low prevalence of cancer diagnosis among men.^{37,42} Lack of trust in the health care system, socioeconomic factors, and recruitment barriers may affect cancer research participation rates among women.³⁹ A sociological view of the barriers experienced by all demographics, and especially women from traditional cultures, is important to understand patterns of cancer diagnosis, and to design successful cancer research interventions.^{39,43}

Mental Health

Both Black and Hispanic participants were less interested in mental health research than were the White participants in our study. More White participants (55.8%) reported being diagnosed with mental health disorders than did Black participants (42.0%,) or Hispanic participants (28.8%). In addition, minority communities are less likely to participate in mental health research due to the negative stigma associated with discussing psychological problems.⁴⁴

In contrast with race/ethnicity, there was no significant difference for mental health research between women and men. The number of female participants diagnosed with mental health illness was higher compared with male participants, and this aligns with existing findings by Kuehner, suggesting that women are more likely to be diagnosed with mental health disorders, such as depression, compared with men.⁴⁵ Stigma continues to impact

attitude about mental health among both men and women and affects research participation interest.⁴⁴

NRP in Use

We have used the NRP registry to recruit for multiple research studies. The registry not only allowed us to recruit from a group of people willing to participate in research projects, but it allowed us to target our recruitment efforts for specific study criteria. One example includes recruiting for the Tachygraphic Color Organized Medication System Study. The purpose of this study was to evaluate and refine a system of color-specific symbols to be placed on medication bottles and to assess whether the proposed symbols allowed accurate identification of the meds and their purpose among 65 year old or older patients who were on 5 or more prescribed meds. Study recruitment for the focus groups was completed in 3 days using the NRP.⁴⁶

Limitations

Among the limitations of this study is that causality cannot be inferred from the observed associations because it is cross-sectional. Interpretation of findings in the context of generalization is also limited because this study is only based on participants who voluntarily registered themselves. As such, there is a self-selection bias, which limits the generalizability to the general patient population of the clinics. In addition, the demographic composition of this study does not reflect the population of Texas as the data collected are from primary care clinics located within North Texas. Participants may also be more likely to be interested in the research area with which they have been diagnosed, though this was expected and was controlled for in the analysis. Previous research shows that education level provides a better picture of the knowledge and health research interest rather than race/ethnicity or gender alone.⁴⁷ Because there was no category within the index card asking about education level. Finally, we had a small number of participants respond from other race categories. This limits our ability to include other or multiple racial/ethnic groups in the analysis.

Conclusions

While quality and access to care may lessen disparities, the magnitude of disease distribution differs between genders and various racial/ethnic populations. Without carefully evaluating gender and

race/ethnicity specific interest and disease burden, there is a risk of executing ineffective intervention strategies and missing opportunities to closing the gap of minorities and women participation in health research.¹⁴ On a positive note, PBRNs such as NorTex can facilitate research more efficiently as existing research shows that researchers participating in PBRNs report higher levels of engagement in research implementation and translation activities. Our PBRN was able to successfully survey different populations to identify their research interests, and this has impacted our ability to target our recruitment efforts. This also allows us the opportunity to build trust with our research participants and allows us to incorporate projects that may be of interest to our network patients.

Findings like these may affect the priorities of research agendas of primary care research networks and help refine targeted recruitment efforts to improve knowledge about health care studies among women and minority racial/ethnic groups. This may help increase their recruitment into studies to acquire representative data and provide prevention strategies that target groups with increased disease prevalence. These data also reiterate the need for medical researchers to build trusting relationships with minority communities to understand their needs and inform them about possible research opportunities. Researchers can begin by acknowledging the previous medical abuse of minority research participants, discussing their specific plans to assure their protection, and explaining the need to bridge the disproportionate gap of women and racial/ethnic minority groups.

Further investigations should seek to determine specific factors between the gap of research interest and how the research findings can affect the community of interest. One of the goals of this study was to address the importance of designing research based on the need of a particular gender and race/ethnicity rather than generalizing an intervention to the whole population. The results indicate that primary care researchers should direct their studies toward specific gender and races/ethnicities based on both health disparity and research interest; not just 1 factor alone.

To see this article online, please go to: <http://jabfm.org/content/35/2/225.full>.

References

1. Pardasani M, Bandyopadhyay S. Ethnicity matters: the experiences of minority groups in public health

- programs. *J Cult Divers* 2014;21:90–8. PubMed PMID: 25306839.
2. George S, Duran N, Norris K. A systematic review of barriers and facilitators to minority research participation among African Americans, Latinos, Asian Americans, and Pacific Islanders. *Am J Public Health* 2014;104:e16–e3.
 3. NIH policy and guidelines on the inclusion of women and minorities as subjects in clinical research [Internet]. National Institute of Health; 2017 [cited 2021 May 20]. Available at: <https://grants.nih.gov/policy/inclusion/women-and-minorities/guidelines.htm>.
 4. Brown M, Moyer A. Predictors of awareness of clinical trials and feelings about the use of medical information for research in a nationally representative US sample. *Ethn Health* 2010;15:223–36.
 5. Erves JC, Mayo-Gamble TL, Malin-Fair A, et al. Needs, priorities, and recommendations for engaging underrepresented populations in clinical research: a community perspective. *J Community Health* 2017;42:472–80.
 6. Hurtado-de-Mendoza A, Serrano A, Zhu Q, et al. Engaging Latina breast cancer survivors in research: building a social network research registry. *Transl Behav Med* 2018;8:565–74.
 7. Green MA, Kim MM, Barber S, et al. Connecting communities to health research: development of the Project CONNECT minority research registry. *Contemp Clin Trials* 2013;35:1–7.
 8. Strutz KL, Herring AH, Halpern CT. Health disparities among young adult sexual minorities in the U.S. *Am J Prev Med* 2015;48:76–88.
 9. Feldman S, Ammar W, Lo K, Trepman E, van Zuylen M, Etzioni O. Quantifying sex bias in clinical studies at scale with automated data extraction. *JAMA Netw Open* 2019;2:e196700.
 10. Liu KA, Mager NA. Women's involvement in clinical trials: historical perspective and future implications. *Pharm Pract (Granada)* 2016;14:708.
 11. Curno MJ, Rossi S, Hodges-Mameletzis I, Johnston R, Price MA, Heidari S. A systematic review of the inclusion (or exclusion) of women in HIV research: from clinical studies of antiretrovirals and vaccines to cure strategies. *J Acquir Immune Defic Syndr* 2016;71:181–8.
 12. Hearld KR, Hearld LR, Hall AG. Engaging patients as partners in research: Factors associated with awareness, interest, and engagement as research partners. *SAGE Open Med* 2017;5:2050312116686709.
 13. Scharff DP, Mathews KJ, Jackson P, Hoffsuemmer J, Martin E, Edwards D. More than Tuskegee: understanding mistrust about research participation. *J Health Care Poor Underserved* 2010;21:879–97.
 14. Svensson K, Ramírez OF, Peres F, Barnett M, Claudio L. Socioeconomic determinants associated with willingness to participate in medical research among a diverse population. *Contemp Clin Trials* 2012;33:1197–205.
 15. Webb FJ, Khubchandani J, Striley CW, Cottler LB. Black–White differences in willingness to participate and perceptions about health research: Results from the population-based HealthStreet Study. *J Immigr Minor Health* 2019;21:299–305.
 16. Mays VM, Coles CN, Cochran SD. Is there a legacy of the U.S. Public Health Syphilis Study at Tuskegee in HIV/AIDS-related beliefs among heterosexual African-Americans and Latinos? *Ethics Behav* 2012;22:461–71.
 17. Davis JL, Green LB, Katz RP. Influence of scary beliefs about the Tuskegee Syphilis Study on willingness to participate in research. *ABNF J* 2012;23:59–62.
 18. Pariera K, Murphy S, Meng J, et al. Exploring willingness to participate in clinical trials by ethnicity. *J Racial Ethn Health Disparities* 2017;4:763–9.
 19. McElfish PA, Long CR, Selig JP, et al. Health research participation, opportunity, and willingness among minority and rural communities of Arkansas. *Clin Transl Sci* 2018;11:487–97.
 20. Rooney LK, Bhopal R, Halani L, et al. Promoting recruitment of minority ethnic groups into research: qualitative study exploring the views of South Asian people with asthma. *J Public Health (Oxf)* 2011;33:604–15.
 21. Westfall JM, Mold J, Fagnan L. Practice-based research—“blue highways” on the NIH roadmap. *JAMA* 2007;297:403–6.
 22. Tapp H, Dulin M. The science of primary health-care improvement: potential and use of community-based participatory research by practice-based research networks for translation of research into practice. *Exp Biol Med (Maywood)* 2010;235:290–9.
 23. NorTex [Internet]. North Texas Primary Care Research-Based Network; 2020 [cited 2021 May 20]. Available at: <https://www.unthsc.edu/research/nortex/>.
 24. IBM Corp. Released 2017. IBM SPSS Statistics for Windows, Version 25.0.. Armonk, NY: IBM Corp.
 25. Heart disease and African Americans [Internet]. Office of Minority Health; 2020 [cited 2021 May 20]. Available at: <https://minorityhealth.hhs.gov/omh/browse.aspx?lvl=4&lvlid=19>.
 26. Virani SS, Alonso A, Benjamin EJ, American Heart Association Council on Epidemiology and Prevention Statistics Committee and Stroke Statistics Subcommittee, et al Heart disease and stroke statistics—2020 update: a report from the American Heart Association. *Circulation*. 2020;141:e139–e596.
 27. Der Ananian C, Winham DM, Thompson SV, Tisue ME. Perceptions of heart-healthy behaviors among African American adults: a mixed methods study. *IJERPH* 2018;15:2433.
 28. Giardina EV, Paul TK, Hayes D, Sciacca RR. Cardiovascular disease risk among young urban women. *J Womens Health* 2016;25:1139–46.

29. Flink LE, Sciacca RR, Bier ML, Rodriguez J, Giardina EGV. Women at risk for cardiovascular disease lack knowledge of heart attack symptoms. *Clin Cardiol* 2013;36:133–8.
30. Bairey Merz CN, Andersen H, Sprague E, et al. Knowledge, attitudes, and beliefs regarding cardiovascular disease in women: The Women's Heart Alliance. *J Am Coll Cardiol* 2017;70:123–32.
31. National diabetes statistics report [Internet]. Centers for Disease Control and Prevention; 2020 [cited 2021 May 20]. Available at: <https://www.cdc.gov/diabetes/pdfs/data/statistics/national-diabetes-statistics-report.pdf>.
32. Summary Health Statistics: National Health Interview Survey: 2018. Table A-4a [Internet]. Centers for Disease Control and Prevention; 2018 [cited 2021 May 20]. https://ftp.cdc.gov/pub/Health_Statistics/NCHS/NHIS/SHS/2018_SHS_Table_A-4.pdf.
33. Ledford CJW, Seehusen DA, Crawford PF. Geographic and race/ethnicity differences in patient perceptions of diabetes. *J Prim Care Community Health* 2019;10:215013271984581.
34. Walker RJ, Smalls BL, Hernandez-Tejada MA, Campbell JA, Davis KS, Egede LE. Effect of diabetes fatalism on medication adherence and self-care behaviors in adults with diabetes. *Gen Hosp Psychiatry* 2012;34:598–603.
35. Chlebowski DO, Hood S, LaJoie AS. Gender differences in diabetes self-management among African American adults. *West J Nurs Res* 2013;35:703–21.
36. Cancer and African Americans [Internet]. Office of Minority Health; 2020 [cited 2021 May 20]. Available at: <https://minorityhealth.hhs.gov/omh/browse.aspx?lvl=4&lvlid=16>.
37. SEER Cancer Statistics Review (CSR) 1975–2016 [Internet]. National Cancer Institute; 2020 [cited 2021 May 20]. Available at: https://seer.cancer.gov/archive/csr/1975_2016/index.html#contents.
38. Henley SJ, Ward EM, Scott S, et al. Annual report to the nation on the status of cancer, part I: National cancer statistics. *Cancer* 2020;126:2225–49.
39. Duma N, Vera Aguilera J, Paludo J, et al. Representation of minorities and women in oncology clinical trials: review of the past 14 years. *JOP* 2018;14:e1–e10.
40. Harvey VM, Enos CW, Chen JT, Galadima H, Eschbach K. The role of neighborhood characteristics in late-stage melanoma diagnosis among Hispanic men in California, Texas, and Florida, 1996–2012. *J Cancer Epidemiol* 2017;2017:8418904.
41. Nonzee NJ, Ragas DM, Ha Luu T, et al. Delays in cancer care among low-income minorities despite access. *J Womens Health (Larchmt)* 2015;24:506–14.
42. Cancer and men [Internet]. Centers for Disease Control and Prevention; 2020 [cited 2021 April 30]. Available at: <https://www.cdc.gov/cancer/dpcp/resources/features/cancerandmen/index.htm>.
43. Nardi C, Sandhu P, Selix N. Cervical cancer screening among minorities in the United States. *JNP* 2016;12:675–82.
44. Ward EC, Wiltshire JC, Detry MA, Brown RL. African American men and women's attitude toward mental illness, perceptions of stigma, and preferred coping behaviors. *Nurs Res* 2013;62:185–94.
45. Kuehner C. Why is depression more common among women than among men? *Lancet Psychiatry* 2017;4:146–58.
46. Cardarelli R, Mann C, Fulda KG, Balyakina E, Espinoza A, Lurie S. Improving accuracy of medication identification in an older population using a medication bottle color symbol label system. *BMC Fam Pract* 2011;12:142.
47. Winham D, Jones K. Knowledge of young African American adults about heart disease: a cross-sectional survey. *BMC Public Health* 2011;11:248.