© *Journal of Higher Education Outreach and Engagement*, Volume 22, Number 1, p. 107, (2018)

Assessing Community Health Priorities and Perceptions About Health Research: A Foundation for a Community-Engaged Research Program

Pearl A. McElfish, Christopher R. Long, R. Michael Stephens,
Nicola Spencer, Brett Rowland, Horace Spencer, and
M. Kathryn Stewart

Abstract

We performed this study to better understand communities' health priorities and willingness to participate in research in order to reduce health disparities. To include communities whose members often experience health disparities and may lack opportunities to participate in research, student interns from multiple disciplines administered the Sentinel Network's 33-item survey in nontraditional locations. The survey was completed by 3,151 respondents. The five most frequently identified health concerns were diabetes, cancer, hypertension, heart problems, and weight. Concerns varied by race/ethnicity. In general, respondents across all races/ethnicities—especially Pacific Islanders—expressed willingness to participate in research. The study demonstrates the effectiveness of this method for identifying health priorities and willingness to participate in research. The results illustrate minority communities' willingness to participate in research if provided the opportunity. Insights gained from this study are informing current and planned community-engaged research to reduce health disparities among minority communities.

Keywords: Community-based participatory research, community-engaged research, health disparities, minority health, service-learning

Introduction

Although advances in medicine have extended the length and quality of life for many, not all have benefited equally. Minority populations experience health disparities in morbidity and mortality across the life course *(CDC, 2013)*. Minority populations are often underrepresented in health research, and increased participation is cited as one way to help address health disparities *(Aungst, Haas, Ommaya, & Green, 2003; Cottler et al., 2013; Ford et al., 2005; Minkler & Wallerstein, 2008; UyBico, Pavel, & Gross, 2007; Wendler et al., 2006; Yancey, Ortega, & Kumanyika, 2006)*.

As part of an effort to increase minority populations' role in health research, five Clinical Translational Science Award (CTSA) sites formed the Sentinel Network in 2008. Partner universities included Washington University, University of California–Davis, University of Michigan, University of Rochester, and Einstein College of Medicine. Two community organizations, Community–Campus Partnerships for Health and Patient Advocates in Research, are also part of the Sentinel Network. The University of Florida joined the network in 2012. The objective of the Sentinel Network is to collaborate across CTSA sites to develop strategies for addressing health disparities through community-engaged approaches. One of the Sentinel Network's first projects was to establish a sustainable network that encourages ongoing, real-time assessment of top health concerns and willingness to participate in research *(Cottler et al., 2013)*. In 2009, each of the original five universities was awarded funds for one Community Health Worker (CHW) through the American Reinvestment and Recovery Act supplemental grant, and additional resources were leveraged through local CTSA sites' community engagement (CE) programs to conduct the Sentinel Network Survey. In total, 5,979 surveys were conducted across the five sites *(Cottler et al., 2013)*.

Facilitated by the University of Arkansas for Medical Sciences (UAMS) Translational Research Institute, UAMS has focused community-engaged research efforts on reducing health disparities in the African American, Hispanic/Latino, and Pacific Islander communities. These three communities experience significant health disparities nationally and in Arkansas. For example, all three communities have higher rates of Type 2 diabetes, hypertension, and certain types of cancers *(Blackwell, Lucas, & Clarke, 2014; McElfish, Rowland, et al., 2016; Phillips, Quick, & Goodell, 2013; Schiller, Lucas, & Peregoy, 2012)*.

UAMS joined the Sentinel Network in 2012 and administered the Sentinel Network Survey at its Northwest Arkansas Campus in 2013 and at its Central Arkansas campus in 2014. The aim of the dual-site project was to gain an understanding of the communities' health priorities and of their willingness to participate in research, with the goal of using this information to guide community-engaged research to reduce health disparities in these communities. Gathering broad community input is a common first step in engaging the community in community-engaged research *(Hardy, Bohan, & Trotter, 2013)*. The goal of this survey was to gather input from the community to inform subsequent community-engaged research. The survey was paired with other engagement efforts and qualitative interviews that are described elsewhere *(McElfish, Goulden, et al., 2017; McElfish, Kohler, et al., 2015)*.

Methods

Survey

The survey was conducted for 14 months in Northwest Arkansas and 9 months in Central Arkansas. Drawing on initial Sentinel Network methodology, this study used the same core survey from the initial 2009 Sentinel Network project *(Cottler et al., 2013)*. The core survey consisted of 33 items and took approximately 5 minutes to complete. Items included age, zip code, race, level of education, diagnosis of common health problems, insurance, smoking, experience with research, willingness to participate in research, and recommended compensation levels for research participation. No identifying information was collected other than the respondent's zip code. To increase access, the survey was translated into Spanish, Marshallese (the primary language of the Pacific Islander community in Northwest Arkansas), and Hmong (the primary language of the Asian community in Northwest Arkansas). Survey respondents were not compensated for their participation.

Recruitment

Nontraditional locations were targeted for respondent recruitment and survey administration, with the goal of including communities whose members often experience health disparities and may not otherwise have the opportunity to participate in research. These locations included community centers; food banks; federally qualified health centers; local community health clinics for the uninsured; grocery stores in low-income neighborhoods; laundromats; libraries; parks; and Women, Infants, and Children (WIC) clinics. Potential respondents were approached at these locations and asked to participate in a short community health survey. Respondents provided verbal consent prior to participation.

Data Collection and Data Collector Training

Under the supervision of the principal investigators, university student interns performed all data collection. Twenty-eight student interns (16 in Central Arkansas and 12 in Northwest Arkansas) were recruited from community health promotion, nursing, public health, and sociology degree programs. Students served 8 hours per week for 12 weeks as part of a research internship. Prior to data collection, all students completed training on the Health Insurance Portability and Accountability Act (HIPAA) and an 18-module social/behavioral research course through the Collaborative Institutional Training Initiative (CITI) program. Students also completed a 4-hour training session that addressed cultural awareness and sensitivity, Institutional Review Board (IRB) compliance, proper data entry, and data collection techniques, including building rapport, special situations (e.g., respondents with low literacy level, cognitive impairment, or difficulties with hearing or vision), and general interviewing skills. Students rehearsed and were tested on survey administration procedures prior to administering surveys in the field. A systematic quality assurance and control plan was used to identify data collection problems, and further training was provided as needed. Students from racially and ethnically diverse backgrounds—fluent in English, Spanish, Marshallese, and/or Hmong—were recruited. Bilingual students were strategically assigned to locations with a high number of community members that spoke each particular language. Students conducted the survey in teams of two. Surveys were either read aloud to respondents or self-administered, depending on respondents' preferences. Data were collected using paper and pencil instruments and then entered into an electronic data capture system.

Analytical Methods

Closed-ended items were analyzed by race/ethnicity. Means with standard deviations are presented for continuous variables. Binomial and proportional confidence intervals are presented for categorical variables.

Open-ended items asked respondents to list their "three top health concerns." Across all respondents, a total of 6,848 health concerns were listed. These open-ended responses were coded independently by two coders, who began by categorizing responses into categories based on the five most frequently mentioned concerns in Cottler et al.'s *(2013)* original research: hypertension, diabetes, cancer, weight, and heart problems. The coders then developed 22 emergent categories to capture the other most frequently mentioned concerns (e.g., insurance/cost/access, mental health, asthma/respiratory, bones, dental problems, arthritis, kidney concerns, etc.). Some health concerns directly implicated more than one category and were therefore included in more than one category. For example, the reported concern "arthritis and anxiety disorders" was assigned to the categories for arthritis and mental health. For any concerns to which the two coders assigned different categories, discrepancies were resolved through discussion. Using the 27 categories, the coders were able to categorize 84.7% of all concerns listed by respondents. The remaining 16.3% of codes were not mentioned by enough respondents to be included as separate themes. For example, aging, Ebola, water quality, and vaccinations were each mentioned as top health concerns by fewer than three respondents.

Results

Description of Respondents

The survey was completed by 3,151 respondents. Demographic characteristics of respondents are presented in Table 1. All percentages are based on the number of completed responses to the relevant item. Among respondents, 68.7% were female, 81.7% had received a high school diploma, and only 18.9% had completed a bachelor's degree. The average age was 37.5 years (SD = 14.5). With respect to race and ethnicity, respondents who described themselves as Hispanic/Latino were counted as Hispanic/Latino and not as part of any other race/ethnicity. In this way, 42.7% described themselves as White, 21.2% as Hispanic/Latino, 17.1% as Black/African American, and 9.2% as Pacific Islander. A further 4.6% described themselves as belonging to multiple races/ethnicities. As shown in Table 1, respondents who self-identified as Asian (1.9%), American Indian (1.5%), Middle Eastern (0.3%), or "Other" (1.5%) also took part in the survey. However, because of the relatively low numbers of respondents in these groups, further results are not presented separately for these groups. For the five larger groups, Table 2 presents respondent demographic characteristics by self-reported race/ethnicity.

Table 1. Demographic Characteristics of Survey Respondents

Demographic Characteristics	Number (%; 95% CI)
Race/Ethnicity	
Hispanic/Latino	653/3084 (21.2; 19.7, 22.6)
American Indian	48/3084 (1.5; 1.1, 2)
Asian	60/3084 (1.9; 1.5, 2.4)
Black/African American	527/3084 (17.1; 15.8, 18.4)
Middle Eastern	8/3084 (0.3; 0.1, 0.4)
Pacific Islander	284/3084 (9.2; 8.2, 10.2)
White	1316/3084 (42.7; 40.9, 44.4)
Biracial/Multiracial	141/3084 (4.6; 3.8, 5.3)
Other	47/3084 (1.5; 1.1, 2.0)
Sex	
Female	2014/2928 (68.8; 67.0, 70.4)
Male	914/2928 (31.2; 29.5, 32.9)
Education	
High school diploma	2458/3007 (81.7; 80.4, 83.1)
College degree	567/3007 (18.9; 17.5, 20.3)
Age (M ± SD)	37.5 ± 14.5

Note. CI = confidence interval. Means and percentages are based on the number of valid responses to each item. Respondents who described themselves as Hispanic/Latino were counted as Hispanic/Latino and not as part of any other race/ethnicity.

Table 2. Demographic Characteristics of Survey Respondents, by Race/Ethnicity

	Hispanic/Latino (*n* = 653)	**Black/African American (*n* = 527)**	**Pacific Islander (*n* = 284)**	**White (*n* = 1316)**	**Biracial/Multiracial (*n* = 141)**
Demographic Characteristic	**Number (%; 95% CI)**	**Number (%; 95% CI)**	**Number (%; 95% CI)**	**Number (%; 95% CI)**	**Number (%; 95% CI)**
Sex					
Female	458/590 (77.6; 74.3, 80.1)	318/469 (67.8; 63.6, 72.0)	154/263 (58.6; 52.6, 64.5)	880/1268 (69.4; 66.8, 71.9)	85/136 (62.5; 54.0, 70.2)
Male	132/590 (22.4; 19.0, 25.7)	151/469 (32.2; 28.0, 36.4)	109/263 (41.4; 35.5, 47.4)	388/1268 (30.6; 28.0, 33.1)	51/136 (37.5; 29.1, 45.3)
Education					
High School Diploma	342/608 (56.3; 52.3, 60.2)	474/505 (93.9; 92.0, 96.1)	178/264 (67.4; 61.8, 73.1)	1178/1301 (90.5; 89.0, 92.1)	114/131 (87.0; 81.3, 92.8)
College Degree	51/608 (8.4; 6.2, 10.6)	106/505 (21.0; 17.4, 24.5)	7/264 (2.7; 0.7, 4.6)	329/1301 (25.3; 22.9, 27.7)	20/131 (15.3; 9.1, 21.4)
Age (M ± SD)	34.0 ± 11.1	35.7 ± 13.8	37.2 ± 12.2	40.3 ± 16.1	33.4 ± 13.7

Note. CI = confidence interval. Means and percentages are based on the number of valid responses to each item. Respondents who described themselves as Hispanic/Latino were counted as Hispanic/Latino and not as part of any other race/ethnicity.

Most Frequently Mentioned Health Concerns

The five most frequently mentioned concerns—diabetes, cancer, hypertension, heart problems, and weight—accounted for over half (52.0%) of all concerns mentioned, alone or in combination. These five concerns were also the five most frequently mentioned concerns of the original Sentinel Network Survey *(Cottler et al., 2013)*, where they did not vary according to age or race/ethnicity. However, as Table 3 indicates, the five most frequently mentioned concerns in the present study do vary as a function of race/ethnicity, with Pacific Islander and biracial/multiracial respondents noting concerns related to insurance/cost/access (26.8% of concerns mentioned by Pacific Islander respondents; 16.4% of concerns mentioned by biracial/multiracial respondents). Furthermore, Pacific Islanders were the only group to list kidney problems as a top health concern (11.2% of concerns mentioned by Pacific Islander respondents).

Table 3. Top Five Health Concerns of Survey Respondents, by Race/Ethnicity

	Total (n = 3151)		**Hispanic/Latino (n = 653)**		**Black/African American (n = 527)**		**Pacific Islander (n = 284)**		**White (n = 1316)**		**Biracial/ Multiracial (n = 141)**	
Number of Concerns	6848		1331		430		295		854		128	
First	Diabetes	939	Diabetes	254	Hypertension	217	Diabetes	135	Cancer	377	Diabetes	42
Second	Cancer	865	Cancer	206	Diabetes	174	Insurance/ Cost/Access	79	Heart Disease	343	Hypertension	42
Third	Hypertension	688	Hypertension	110	Cancer	150	Hypertension	79	Diabetes	279	Cancer	28
Fourth	Heart Disease	618	Heart Disease	95	Heart Disease	106	Cancer	48	Weight	246	Heart Disease	23
Fifth	Weight	462	Weight	85	Weight	83	Kidney	33	Hypertension	205	Insurance/ Cost/Access	21

Note. *Each respondent could list up to three of their "top health concerns." Some health concerns were coded as belonging to multiple categories. Respondents who described themselves as Hispanic/Latino were counted as Hispanic/Latino and not as part of any other race/ethnicity.*

Survey Results

The survey also asked respondents to indicate whether they have ever been told by a health professional that they have arthritis, asthma, cancer, diabetes, depression, heart disease, high blood pressure, a kidney problem, or a disease of the muscles or bones. Table 4 presents responses to these items by race/ethnicity, along with responses to items assessing whether or not respondents have health insurance or have smoked in the past 30 days. For these items, the most prevalent health conditions differed as a function of race/ethnicity. From among the listed conditions, White respondents' and Hispanic/Latino respondents' most reported condition was depression (39.9% of White respondents and 16.5% of Hispanic/Latino respondents), Black/African American respondents' most reported condition was high blood pressure (36.3%), and Pacific Islander respondents' most reported condition was diabetes (28.2%).

The survey evaluated whether or not respondents had previously participated in health research, and it assessed respondents' willingness to participate in several types of health research studies, as well as their likelihood to take part in health research in general. For example, the survey asks respondents if they would participate in health research studies in which researchers only ask questions, in which researchers want to review respondents' health records, in which respondents have to take medicine, and so on. Table 5 presents responses to these items by race/ethnicity. Overall, 21.3% indicated that they would "definitely" take part in a health research study if they had the opportunity and 62% said they "may" participate if given the opportunity. However, only 10.8% reported having had the opportunity to participate, and only 8.5% of respondents reported having ever been in a health research study.

Compared to other race/ethnicity respondents, a relatively large proportion of Pacific Islander respondents reported having ever been in a health research study (19.4% vs. 8.5% of all respondents). In addition, 39.1% of Pacific Islander respondents indicated that they would "definitely" take part in a research study if they had the opportunity (compared to 21.3% of all respondents). Pacific Islander respondents were particularly likely to express willingness to participate in studies in which they might have to "take medicine" or "stay overnight in a hospital or clinic" (48.4% and 43.9% of Pacific Islander respondents vs. 28.2% and 32.3% of all respondents, respectively).

Table 4. Health Conditions, Insurance Status, and Smoking Behavior Reported by Survey Respondents, by Race/Ethnicity

	Total (n = 3151)	Hispanic/Latino (n = 653)	Black/African American (n = 527)	Pacific Islander (n = 284)	White (n = 1316	Biracial/ Multiracial (n = 141)
Reported Characteristic	**Number (%; 95% CI)**	**Number (%; 95% CI)**	**Number (%; 95% CI)**	**Number (%; 95% CI)**	**Number (%; 95% CI)**	**Number (%; 95% CI)**
High blood pressure	850/3092 (27.5; 25.9, 29.1)	93/638 (14.6; 11.9, 17.6)	186/512 (36.3; 32.2, 40.7)	69/279 (24.7; 19.8, 30.2)	416/1298 (32; 29.5, 34.7)	23/138 (16.7; 10.9, 24)
Depression	860/3047 (28.2; 26.6, 29.9)	103/624 (16.5; 13.7, 19.7)	116/503 (23.1; 19.4, 27)	36/274 (13.1; 9.4, 17.7)	512/1284 (39.9; 37.2, 42.6)	31/136 (22.8; 16, 30.8)
Heart disease	196/3018 (6.5; 5.6, 7.4)	10/617 (1.6; 0.8, 3)	30/503 (6; 4.1, 8.4)	23/273 (8.4; 5.4, 12.4)	104/1268 (8.2; 6.8, 9.9)	7/136 (5.1; 2.1, 10.3)
Diabetes	427/3047 (14; 12.8, 15.3)	64/631 (10.1; 7.9, 12.8)	68/502 (13.5; 10.7, 16.9)	78/277 (28.2; 22.9, 33.9)	167/1276 (13.1; 11.3, 15.1)	15/137 (10.9; 6.3, 17.4)
Cancer	199/3033 (6.6; 5.7, 7.5)	10/620 (1.6; 0.8, 2.9)	23/500 (4.6; 2.9, 6.8)	23/276 (8.3; 5.4, 12.2)	115/1279 (9.0; 7.5, 10.7)	6/137 (4.4; 1.6, 9.3)
Arthritis	526/3057 (17.2; 15.9, 18.6)	44/628 (7.0; 5.1, 9.3)	80/506 (15.8; 12.7, 19.3)	32/274 (11.7; 8.1, 16.1)	308/1288 (23.9; 21.6, 26.3)	19/137 (13.9; 8.6, 20.8)

Note. Table 4 continued on next page.

Table 4. Health Conditions, Insurance Status, and Smoking Behavior Reported by Survey Respondents, by Race/Ethnicity

	Total (n = 3151)	Hispanic/ Latino (n = 653)	Black/African American (n = 527)	Pacific Islander (n = 284)	White (n = 1316	Biracial/ Multiracial (n = 141)
Reported Characteristic	**Number (%; 95% CI)**	**Number (%; 95% CI)**	**Number (%; 95% CI)**	**Number (%; 95% CI)**	**Number (%; 95% CI)**	**Number (%; 95% CI)**
Muscle/bone diseases	208/3025 (6.9; 6.0, 7.8)	33/627 (5.3; 3.7, 7.3)	26/499 (5.2; 3.4, 7.5)	32/274 (11.7; 8.1, 16.1)	92/1270 (7.2; 5.9, 8.8)	7/134 (5.2; 2.1, 10.5)
Asthma	450/3028 (14.9; 13.6, 16.2)	47/625 (7.5; 5.6, 9.9)	108/501 (21.6; 18, 25.4)	25/272 (9.2; 6.0, 13.3)	211/1272 (16.6; 14.6, 18.7)	21/136 (15.4; 9.8, 22.6)
Kidney Problem	187/3009 (6.2; 5.4, 7.1)	22/615 (3.6; 2.3, 5.4)	19/497 (3.8; 2.3, 5.9)	33/271 (12.2; 8.5, 16.7)	91/1271 (7.2; 5.8, 8.7)	6/135 (4.4; 1.6, 9.4)
Has smoked cigarettes in past 30 days	795/3105 (25.6; 24.1, 27.2)	54/641 (8.4; 6.4, 10.8)	147/521 (28.2; 24.4, 32.3)	48/281 (17.1; 12.9, 22)	449/1299 (34.6; 32, 37.2)	41/141 (29.1; 21.7, 37.3)
Has any type of health insurance	1936/3086 (62.7; 61.0, 64.4)	254/637 (39.9; 36, 43.8)	381/516 (73.8; 69.8, 77.6)	94/275 (34.2; 28.6, 40.1)	944/1295 (72.9; 70.4, 75.3)	102/141 (72.3; 64.2, 79.5)

Note. CI = confidence interval. Means and percentages are based on the number of valid responses to each item. Respondents who described themselves as Hispanic/Latino were counted as Hispanic/Latino and not as part of any other race/ethnicity.

Table 5. Research Experience and Beliefs Reported by Survey Participants, by Race/Ethnicity

	Total (*n* = 3151)	**Hispanic/ Latino (*n* = 653)**	**Black/African American (*n* = 527)**	**Pacific Islander (*n* = 284)**	**White (*n* = 1316)**	**Biracial/ Multiracial (*n* = 141)**
Reported Characteristic	**Number (%; 95% CI)**	**Number (%; 95% CI)**	**Number (%; 95% CI)**	**Number (%; 95% CI)**	**Number (%; 95% CI)**	**Number (%; 95% CI)**
Has ever been in a health research study	262/3084 (8.5; 7.5, 9.5)	27/634 (4.3; 2.8, 6.1)	59/520 (11.3; 8.8, 14.4)	54/279 (19.4; 14.9, 24.5)	82/1289 (6.4; 5.1, 7.8)	12/139 (8.6; 4.5, 14.6)
Has ever had opportunity to participate in health research	332/3060 (10.8; 9.8, 12)	31/625 (5.0; 3.4, 7)	85/513 (16.6; 13.5, 20.1)	43/274 (15.7; 11.6, 20.6)	129/1289 (10.0; 8.4, 11.8)	16/138 (11.6; 6.8, 18.1)
Has signed up for a research registry	56/3051 (1.8; 1.4, 2.4)	5/622 (0.8; 0.3, 1.9)	14/514 (2.7; 1.5, 4.5)	12/274 (4.4; 2.3, 7.5)	8/1284 (0.6; 0.3, 1.2)	5/139 (3.6; 1.2, 8.2)
Would participate in a study:						
If only asked questions	1805/3008 (60.0; 58.2, 61.8)	327/604 (54.1; 50.1, 58.2)	286/509 (56.2; 51.8, 60.6)	139/272 (51.1; 45, 57.2)	848/1274 (66.6; 63.9, 69.2)	83/134 (61.9; 53.2, 70.2)
If researchers wanted to see medical records	1355/3019 (44.9; 43.1, 46.7)	299/609 (49.1; 45.1, 53.1)	181/511 (35.4; 31.3, 39.7)	117/275 (42.5; 36.6, 48.6)	599/1278 (46.9; 44.1, 49.6)	70/136 (51.5; 42.8, 60.1)

Note. Table 5 continued on next page

Table 5. Research Experience and Beliefs Reported by Survey Participants, by Race/Ethnicity

	Total (*n* = 3151)	**Hispanic/Latino (*n* = 653)**	**Black/African American (*n* = 527)**	**Pacific Islander (*n* = 284)**	**White (*n* = 1316)**	**Biracial/ Multiracial (*n* = 141)**
Reported Characteristic	**Number (%; 95% CI)**	**Number (%; 95% CI)**	**Number (%; 95% CI)**	**Number (%; 95% CI)**	**Number (%; 95% CI)**	**Number (%; 95% CI)**
If had to give a blood sample	1602/3028 (52.9; 51.1, 54.7)	365/610 (59.8; 55.8, 63.8)	246/513 (48.0; 43.6, 52.4)	131/277 (47.3; 41.3, 53.4)	693/1278 (54.2; 51.4, 57)	66/137 (48.2; 39.6, 56.9)
If asked to give a genetic sample	1342/3015 (44.5; 42.7, 46.3)	301/608 (49.5; 45.5, 53.6)	177/512 (34.6; 30.5, 38.9)	117/275 (42.5; 36.6, 48.6)	606/1271 (47.7; 44.9, 50.5)	57/137 (41.6; 33.3, 50.3)
If might have to take medicine	852/3022 (28.2; 26.6, 29.8)	206/610 (33.8; 30, 37.7)	115/513 (22.4; 18.9, 26.3)	134/277 (48.4; 42.4, 54.4)	306/1272 (24.1; 21.7, 26.5)	30/138 (21.7; 15.2, 29.6)
If asked to stay overnight in hospital or clinic	978/3031 (32.3; 30.6, 34)	187/612 (30.6; 26.9, 34.4)	158/515 (30.7; 26.7, 34.9)	122/278 (43.9; 38, 49.9)	413/1274 (32.4; 29.9, 35.1)	35/138 (25.4; 18.3, 33.5)
If might have to use medical equipment	1067/3018 (35.4; 33.6, 37.1)	216/606 (35.6; 31.8, 39.6)	161/516 (31.2; 27.2, 35.4)	125/276 (45.3; 39.3, 51.4)	447/1270 (35.2; 32.6, 37.9)	40/138 (29.0; 21.6, 37.3)
If didn't get paid	1096/3010 (36.4; 34.7, 38.2)	233/606 (38.4; 34.6, 42.5)	156/508 (30.7; 26.7, 34.9)	99/277 (35.7; 30.1, 41.7)	494/1272 (38.8; 36.1, 41.6)	44/138 (31.9; 24.2, 40.4)

Note. Table 5 continued on next page

Table 5. Research Experience and Beliefs Reported by Survey Participants, by Race/Ethnicity

	Total (*n* = 3151)	**Hispanic/Latino (*n* = 653)**	**Black/African American (*n* = 527)**	**Pacific Islander (*n* = 284)**	**White (*n* = 1316)**	**Biracial/ Multiracial (*n* = 141)**
Reported Characteristic	**Number (%; 95% CI)**	**Number (%; 95% CI)**	**Number (%; 95% CI)**	**Number (%; 95% CI)**	**Number (%; 95% CI)**	**Number (%; 95% CI)**
Likelihood to take part in a research study:						
Definitely take part	629/2960 (21.3; 19.8, 22.8)	104/593 (17.5; 14.6, 20.8)	105/493 (21.3; 17.8, 25.2)	104/266 (39.1; 33.2, 45.2)	257/1268 (20.3; 18.1, 22.5)	19/137 (13.9; 8.6, 20.8)
May take part	1835/2960 (62.0; 60.2, 63.7)	393/593 (66.3; 62.3, 70.1)	303/493 (61.5; 57.0, 65.8)	121/266 (45.5; 39.4, 51.7)	809/1268 (63.8; 61.5, 66.7)	90/137 (65.7; 57.1, 73.6)

Note. *CI = confidence interval. Means and percentages are based upon the number of valid responses to each item. Participants who described themselves as Hispanic/Latino were counted as Hispanic/Latino and not as part of any other race/ethnicity.*

Discussion

The current Sentinel Network study adds to the initial Sentinel Network study in several ways. First, lacking funding for CHWs, UAMS recruited university student interns as data collectors. This provided university students hands-on research experience and demonstrated their ability to rapidly collect the data in multiple languages from diverse respondents. The five sites of the original Sentinel Network collected 5,979 surveys over 18 months, with per site participation ranging from 588 to 1,983, for an average of 1,064 per site *(Cottler et al., 2013)*. UAMS students collected 3,151 surveys over 14 months. Although we are strong proponents of employing CHWs throughout health care systems, including research, this study documents an additional means of broad community assessment when funds are not available to hire CHWs.

In addition, the current study recruited significantly more Hispanic/Latino and Pacific Islander respondents than did sites in the initial study. The initial study did not report Pacific Islanders as a separate racial/ethnic category; however, the current study included 284 Pacific Islander respondents. Pacific Islanders are severely underrepresented in research and are often aggregated with Asian Americans in health assessments *(Applied Research Center & National Council of Asian Pacific Americans, 2013; Ro & Yee, 2010; Roehr, 2010; Srinivasan & Guillermo, 2000)*. The present study provides one of the first direct assessments of Pacific Islanders' willingness to participate in research. It is notable that Pacific Islander and biracial/multiracial respondents listed insurance/cost/access as a primary concern, with more than one quarter of Pacific Islanders listing this as a primary concern. Although many populations in Arkansas and throughout the United States have experienced increased health care access through the Affordable Care Act and Medicaid Expansion, not all populations receive these benefits. Many Pacific Islanders in Arkansas are Compact of Free Association Migrants and are not eligible for Medicaid Expansion, and many cannot afford insurance premiums and copays *(McElfish, Hallgren, & Yamada, 2015; McElfish, Purvis, et al., 2016)*.

It is imperative to increase minority participation in health research in order to reduce health disparities. This study and the prior Sentinel Network study provide evidence that minority populations are willing to participate in research if afforded the opportunity, even when the respondents are not being paid. If "hard-to-reach populations" are willing to participate in research if provided the opportunity, the research enterprise must look at ways to increase such opportunities.

Community Engagement and Use of the Results

Local stakeholders reviewed the questions from the Sentinel Network Survey and selected the best locations for recruitment. Similarly, we have sought, and will continue to seek, input from community advisory boards who represent the community. In this context, the Sentinel Network Survey has provided a broad assessment of community needs and an increased number of respondents providing input into our research agenda. UAMS has used the Sentinel Network Survey data to inform our community engagement efforts targeted at reducing health disparities among minority communities in Arkansas. Furthermore, documentation of diverse respondents' willingness to participate in research if provided the opportunity highlights the need to create such opportunities for these communities. The insights gained from this study were shared with stakeholders and have served as the basis to inform ongoing community-engaged research efforts in the communities. The priorities and information from the Sentinel Network Survey have led to the initiation of 11 collaborative research projects, and others are being planned *(Hallgren, McElfish, & Rubon-Chutaro, 2015; McElfish, Bridges, et al., 2015; McElfish, Goulden, et al., 2017; McElfish, Hallgren, et al., 2016; McElfish, Kohler, et al., 2015; McElfish, Moore, et al., 2016; McElfish, Post, & Rowland, 2016; McElfish, Rowland, et al., 2016; Scott, Shreve, Ayers, & McElfish, 2016)*.

Limitations and Strengths of the Research

The primary limitation of the research is that it was conducted with a convenience sample, limiting generalizability. In addition, the survey was brief and completed by respondents engaged in other daily activities (e.g., laundry, health care, shopping). Student interns reported that recruiting respondents anonymously enhanced participation; however, this approach makes it impossible for the researchers to follow up with respondents to share the survey results or information about research opportunities in which they might have an interest. Furthermore, because the study team agreed to use the same survey that was implemented in other Sentinel Network sites, local stakeholders' input in selecting questions was limited. Although local stakeholders reviewed the survey questions and selected the best locations for recruitment, the level of engagement was broad rather than deep. This broad approach differs from other community-engaged research practices where a smaller number of stakeholders provide in-depth input throughout the entire research process. It is important to note that the authors used this Sentinel Network Survey as a first step in the engagement process, informing more traditional engagement efforts that are described elsewhere *(McElfish, Goulden, et al., 2017; McElfish, Kohler, et al., 2015)*. Despite these limitations, the study documents the ability to engage a large number of underrepresented, minority community members in survey research. The study builds on and expands the findings of the initial Sentinel Network study and serves to inform research priorities of the UAMS Translational Research Institute.

Conclusion

As communities and health researchers seek to address health disparities, it is imperative to increase minority participation in health research. Participation in research among minority communities is shown to increase when engaged research methods are used *(Minkler & Wallerstein, 2008; Yancey et al., 2006)*. Although community-engaged research often uses input from community advisory boards, broad assessments of community needs are rarely conducted. The current and prior Sentinel Network studies demonstrate a method for obtaining broad community input on health priorities and willingness to participate in research. Of greatest value, both the current and prior Sentinel Network studies document that minority communities profess willingness to participate in research if provided the opportunity. The studies challenge researchers to consider that the relative lack of research participation among minorities may not be caused by a lack of willingness to participate, but instead by other constraints, including lack of opportunity.

Acknowledgments

The Translational Research Institute supported the project described, grant UL1TR000039, through the United States National Institutes of Health (NIH) National Center for Research Resources and National Center for Advancing Translational Sciences. The content is solely the responsibility of the authors and does not necessarily represent the official views of the NIH. The authors would also like to acknowledge the efforts of the student data collectors.

Compliance with Ethical Standards

This project was determined to be exempt from human protections oversight by the IRB at the University of Arkansas for Medical Sciences. Informed consent was obtained from all individual respondents. The authors have no conflicts of interest to report.

References

Applied Research Center & National Council of Asian Pacific Americans. (2013). *Best practices: Researching Asian Americans, Native Hawaiians and Pacific Islanders*. New York, NY: Authors. Retrieved from https://d3n8a8pro7vhmx.cloudfront.net/ncapa/pages/33/attachments/original/1430842908/Best-Practices-AANHPI.pdf?1430842908

Aungst, J., Haas, A., Ommaya, A., & Green, L. (2003). *Exploring challenges, progress, and new models for engaging the public in the clinical research enterprise: Clinical Research Roundtable Workshop summary.* Washington, DC: National Academies Press.

Blackwell, D., Lucas, H., & Clarke, T. (2014). *Summary health statistics for US adults: National Health Interview Survey, 2012*. Washington, DC: Centers for Disease Control and Prevention. Retrieved from http://www.cdc.gov/nchs/data/series/sr_10/sr10_260.pdf

Centers for Disease Control and Prevention. (2013). CDC health disparities and inequalities report—United States, 2013. *Morbidity and Mortality Weekly Report, 62*(Suppl. 3), 1–187.

Cottler, L., McCloskey, D., Aguilar-Gaxiola, S., Bennett, N., Strelnick, H., Dwyer-White, M., . . . Evanoff, B. (2013). Community needs, concerns, and perceptions about health research: Findings from the clinical and translational science award sentinel network. *American Journal of Public Health, 103*(9), 1685–1692. doi:10.2105/ajph.2012.300941

Ford, J., Howerton, M., Bolen, S., Gary, T., Lai, G., Tilburt, J., . . . Bass, E. (2005). Knowledge and access to information on recruitment of underrepresented populations to cancer clinical trials. *Evidence Report/Technology Assessment (Summary)*, No. 122, pp. 1–11.

Hallgren, E., McElfish, P. A., & Rubon-Chutaro, J. (2015). Barriers and opportunities: A community-based participatory research study of health beliefs related to diabetes in a US Marshallese community. *Diabetes Educator, 41*(1), 86–94. doi:10.1177/0145721714559131

Hardy, L. J., Bohan, K. D., & Trotter, R. T., II. (2013). Synthesizing evidence-based strategies and community-engaged research: A model to address social determinants of health. *Public Health Reports, 128*(6, Suppl. 3), 68–76. doi:10.1177/00333549131286S311

McElfish, P. A., Bridges, M., Hudson, J., Purvis, R. S., Bursac, Z., Kohler, P., & Goulden, P. (2015). Family model of diabetes education with a Pacific Islander community. *Diabetes Educator, 41*(6), 706–715. doi:10.1177/0145721715606806

McElfish, P. A., Goulden, P. A., Bursac, Z., Hudson, J., Purvis, R. S., Yeary, K. H. K., . . . Kohler, P. O. (2017). Engagement practices that join scientific methods with community wisdom: Designing a patient-centered, randomized control trial with a Pacific Islander community. *Nursing Inquiry, 24*(2). doi:10.1111/nin.12141

McElfish, P. A., Hallgren, E., Henry, L., Ritok, M., Rubon-Chutaro, J., & Kohler, P. (2016). Health beliefs of Marshallese regarding Type 2 diabetes. *American Journal of Health Behavior, 40*(1), 248–257.

McElfish, P. A., Hallgren, E., & Yamada, S. (2015). Effect of US health policies on health care access for Marshallese migrants. *American Journal of Public Health, 105*(4), 637–643. doi:10.2105/AJPH.2014.302452

McElfish, P. A., Kohler, P. O., Smith, C., Warmack, T. S., Buron, B., Hudson, J., . . . Rubon-Chutaro, J. (2015). Community-driven research agenda to reduce health disparities. *Clinical and Translational Science, 8*(6), 690–695. doi:10.1111/cts.12350

McElfish, P. A., Moore, R., Woodring, D., Purvis, R. S., Maskarinec, G., Bing, W., . . . Goulden, P. A. (2016). Social ecology and diabetes self-management among Pacific Islanders in Arkansas. *Journal of Family Medicine and Disease Prevention, 2*(1), 026.

McElfish, P. A., Post, J., & Rowland, B. (2016). A social ecological and community-engaged perspective for addressing health disparities among Marshallese in Arkansas. *International Journal of Nursing & Clinical Practice, 3*, 1–6.

McElfish, P. A., Purvis, R. S., Maskarinec, G., Bing, W., Jacob, C., Ritok, M., . . . Riklon, S. (2016). Interpretive policy analysis: Marshallese COFA migrants and the Affordable Care Act. *International Journal for Equity in Health, 15*, 91. doi:10.1186/s12939-016-0381-1

McElfish, P. A., Rowland, B., Long, C. R., Hudson, J., Piel, M., Buron, B., . . . Warmack, T. S. (2016). Diabetes and hypertension in Marshallese adults: Results from faith-based health screenings. *Journal of Racial and Ethnic Health Disparities, 4*(6), 1042–1050. doi: 10.1007/s40615-016-0308-y

Minkler, M., & Wallerstein, N. (Eds.). (2008). *Community-based participatory research for health: From process to outcomes*. San Francisco, CA: Jossey-Bass.

Phillips, M. M., Quick, S., & Goodell, M. (2013). *Trends in health disparities: A report for Arkansas.* Little Rock, AR: University of Arkansas for Medical Sciences, Arkansas Center for Health Disparities. Retrieved from http://publichealth.uams.edu/wp-content/uploads/sites/3/2012/06/Trends-in-Health-Disparities_report-Feb-2013.pdf

Ro, M., & Yee, A. (2010). Out of the shadows: Asian Americans, Native Hawaiians, and Pacific Islanders. *American Journal of Public Health, 100*(5), 776–778. doi:10.2105/AJPH.2010.192229

Roehr, B. (2010). Asians and Pacific islanders in US need greater prominence in research. *BMJ, 340*. doi:10.1136/bmj.c2495

Schiller, J., Lucas, J., & Peregoy, J. (2012). *Summary health statistics for U.S. Adults: National Health Interview Survey, 2011*. Washington, DC: Centers for Disease Control and Prevention. Retrieved from http://www.cdc.gov/nchs/data/series/sr_10/sr10_256.pdf

Scott, A., Shreve, M., Ayers, B., & McElfish, P. A. (2016). Breast-feeding perceptions, beliefs and experiences of Marshallese migrants: An exploratory study. *Public Health Nutrition, 19*(16), 3007–3016. doi:10.1017/s1368980016001221

Srinivasan, S., & Guillermo, T. (2000). Toward improved health: Disaggregating Asian American and Native Hawaiian Pacific Islander data. *American Journal of Public Health, 90*(11), 1731–1734.

UyBico, S., Pavel, S., & Gross, C. (2007). Recruiting vulnerable populations into research: A systematic review of recruitment interventions. *Journal of General Internal Medicine, 22*(6), 852–863.

Wendler, D., Kington, R., Madans, J., Van Wye, G., Christ-Schmidt, H., Pratt, L. A., . . . Emanuel, E. (2006). Are racial and ethnic minorities less willing to participate in health research? *PLoS Medicine, 3*(2), e19. doi:10.1371/journal.pmed.0030019

Yancey, A., Ortega, A., & Kumanyika, S. (2006). Effective recruitment and retention of minority research participants. *Annual Review of Public Health, 27*, 1–28. doi:10.1146/annurev.publhealth.27.021405.102113

About the Authors

Pearl A. McElfish is the associate vice chancellor of the University of Arkansas for Medical Sciences Northwest Regional Campus. Her research interests include Pacific Islander health, community-based participatory research, health behaviors research, and qualitative research methods. She received her Ph.D. in public policy with a focus on health policy from the University of Arkansas.

Christopher R. Long is an assistant professor in the College of Medicine at the University of Arkansas for Medical Science and director of research and evaluation at the UAMS Office of Community Health and Research. His research interests include food insecurity, chronic disease prevention, and dissemination of health research results. He earned his Ph.D. in social psychology from the University of Massachusetts.

R. Michael Stephens is the community health program director for the Office of Community Health and Research at the University of Arkansas for Medical Sciences Northwest. He is interested in addressing health disparities among underserved populations and veterans via community-based participatory approaches. He received his MS in community health promotion from the University of Arkansas.

Nicola Spencer is a program manager with the Translational Research Institute of the University of Arkansas for Medical Sciences. She enjoys working with and advocating for communities traditionally underrepresented in research. She received her MHA from Webster University.

Brett Rowland is a research associate in the Office of Community Health and Research at the University of Arkansas for Medical Sciences Northwest. His research interests include health disparities, food insecurity, and homelessness. He received his MA in sociology from the University of Arkansas.

Horace Spencer is a statistician in the Department of Biostatistics at the University of Arkansas for Medical Sciences College of Medicine. His research interests include developing strategies to improve the design, analysis, and interpretation of observational studies, particularly as it applies to community-based research. He received his MS from Stephen F. Austin State University in Nacogdoches, TX.

M. Kathryn Stewart is a professor in the Department of Health Policy and Management at the Fay W. Boozman College of Public Health at the University of Arkansas for Medical Sciences and directs community engagement for the UAMS Translational Research Institute. Her research interests include access to care, health disparities, community health workers, and community-based participatory approaches to research. She earned her M.D. from the University of Arkansas for Medical Sciences College of Medicine.