

# Community Needs, Concerns, and Perceptions About Health Research: Findings From the Clinical and Translational Science Award Sentinel Network

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Although more than 80 000 clinical trials are conducted each year in the United States, less than 1% of the population participates in these studies.<sup>1</sup> Women, the elderly, members of racial/ethnic minority groups, and rural populations are often underrepresented in research,<sup>2,3</sup> leading to findings that do not account for genetic, cultural, linguistic, racial/ethnic, gender, and age differences. A representative population sample in clinical trials is important both from an ethical perspective and to ensure external validity of findings.<sup>3-5</sup>

The community health worker (CHW) intervention model could help eliminate this discrepancy. CHWs are lay community members who share a common language and culture with the people they serve.<sup>6</sup> CHWs primarily deliver interventions, navigate patients through cancer treatment, educate patients about their diverse conditions, and facilitate connections to hidden populations. The value of the CHW in research is increasingly recognized; some states now certify CHWs to further professionalize their role.<sup>7,8</sup> In fact, the *American Journal of Public Health* devoted its December 2011 issue to work associated with CHWs.<sup>7,9</sup>

Recognizing this potential, the Clinical and Translational Science Award (CTSA) Strategic Goal 4 Committee (Enhancing the Health of Our Communities and the Nation) of the National Institutes of Health (NIH) established the CTSA Community Engagement Resource Development Workgroup. This group subsequently received an American Reinvestment and Recovery Act supplemental grant in 2009 to collaborate across 5 CTSA sites and 2 community-focused national organizations to develop procedures to increase community participation in research, build the capacity of CHWs to expand their role in research by increasing the rigor of health evaluation

**Objectives.** We used results generated from the first study of the National Institutes of Health Sentinel Network to understand health concerns and perceptions of research among underrepresented groups such as women, the elderly, racial/ethnic groups, and rural populations.

**Methods.** Investigators at 5 Sentinel Network sites and 2 community-focused national organizations developed a common assessment tool used by community health workers to assess research perceptions, health concerns, and conditions.

**Results.** Among 5979 individuals assessed, the top 5 health concerns were hypertension, diabetes, cancer, weight, and heart problems; hypertension was the most common self-reported condition. Levels of interest in research participation ranged from 70.1% among those in the "other" racial/ethnic category to 91.0% among African Americans. Overall, African Americans were more likely than members of other racial/ethnic groups to be interested in studies requiring blood samples (82.6%), genetic samples (76.9%), or medical records (77.2%); staying overnight in a hospital (70.5%); and use of medical equipment (75.4%).

**Conclusions.** Top health concerns were consistent across geographic areas. African Americans reported more willingness to participate in research even if it required blood samples or genetic testing. (*Am J Public Health.* 2013;103:1685-1692. doi:10.2105/AJPH.2012.300941)

metrics in the field, and establish a sustainable network, the Sentinel Network, to provide ongoing, real-time assessments of top health and neighborhood needs, concerns, and research perceptions. The data could then be immediately shared with NIH-CTSA sites, and local communities to increase the representativeness and relevance of research by facilitating community participation.

The Sentinel Network is built on an interactive community program called HealthStreet, founded by the lead author (L. B. C.) when she was at Washington University in St. Louis. HealthStreet uses CHWs for 4 aims: to assess the medical problems and health concerns of community residents, to engage in bidirectional sharing of information between the community and research investigators, to link community residents to medical and social services, and to

provide community members with opportunities to participate in research.

HealthStreet builds trust between the research community and the general public<sup>6,10</sup> by directly engaging individual residents (the program's first aim) rather than focusing on agencies, providers, and organizations as partners, as is more typical in community engagement research.<sup>6</sup> This strategy ensures that HealthStreet's efforts do not bypass the input of community members or inadvertently privilege the perceptions of community leaders and service providers.<sup>11-13</sup>

Community members often perceive research as primarily meeting the needs of the researcher.<sup>14,15</sup> Recognition of these and other issues has led to an increasingly robust literature on methods to engage the community in research.<sup>10,14,16,17</sup> In line with HealthStreet's

**TABLE 1—Demographic Characteristics of Sentinel Network Participants, by Site: 2010–2011**

Characteristic	Washington University in St. Louis (n = 2253)		University of California, Davis (n = 1030)		University of Michigan (n = 1049)		Albert Einstein College of Medicine (n = 714)		University of Rochester (n = 933)		Total (n = 5979)	
	No. (%) or Mean ± SD	Metropolitan % <sup>a</sup>	No. (%) or Mean ± SD	Metropolitan % <sup>a</sup>	No. (%) or Mean ± SD	Metropolitan % <sup>a</sup>	No. (%) or Mean ± SD	Metropolitan % <sup>a</sup>	No. (%) or Mean ± SD	Metropolitan % <sup>a</sup>	No. (%) or Mean ± SD	Metropolitan % <sup>a</sup>
Hispanic/Latino	24 (1.1; 0.6, 1.5)	3.1	476 (46.4; 43.3, 49.5)	19.5	59 (5.7; 4.3, 7.1)	3.9	335 (48.0; 44.3, 51.7)	51.1	107 (11.7; 9.6, 13.8)	5.9	1001 (16.9; 15.9, 17.8)	5.9
Asian	6 (0.2; 0.1, 0.5)	3.1	157 (15.3; 13.1, 17.5)	14.9	145 (13.9; 11.8, 16.0)	3.0	26 (3.7; 2.3, 5.1)	3.6	7 (0.8; 0.2, 1.3)	3.3	341 (5.8; 5.2, 6.3)	3.3
African American	1890 (83.9; 82.4, 85.4)	44.8	175 (17.1; 14.8, 19.4)	8.6	301 (28.9; 26.1, 31.6)	32.0	195 (27.9; 24.6, 31.3)	30.5	497 (64.4; 51.2, 57.7)	12.8	3058 (51.6; 50.3, 52.8)	12.8
White	309 (13.7; 12.3, 15.1)	47.1	161 (15.7; 13.5, 18.1)	53.0	497 (47.7; 44.7, 50.7)	59.1	89 (12.8; 10.4, 15.5)	12.8	269 (29.5; 26.5, 32.4)	76.6	1325 (22.3; 21.3, 23.4)	76.6
Biracial/multiracial	15 (0.7; 0.3, 1.0)	1.8 <sup>c</sup>	22 (2.1; 1.3, 3.0)	4.0 <sup>c</sup>	15 (1.4; 0.7, 2.2)	1.9 <sup>c</sup>	16 (2.3; 1.2, 3.4)	1.9 <sup>c</sup>	14 (1.5; 0.7, 2.3)	1.5 <sup>c</sup>	82 (1.3; 1.1, 1.7)	1.5 <sup>c</sup>
Other <sup>b</sup>	8 (0.4; 0.1, 0.6)		35 (3.4; 2.3, 4.5)		25 (2.4; 1.5, 3.3)		37 (5.3; 3.6, 7.0)		19 (2.1; 1.2, 3.0)		124 (2.1; 1.7, 2.5)	
Female	1204 (53.4; 51.4, 55.5)		545 (53.2; 50.1, 56.3)		706 (67.6; 64.6, 70.4)		499 (71.3; 67.8, 74.6)		570 (62.8; 59.6, 60.7)		3524 (59.4; 58.2, 60.7)	
High school diploma	1611 (72.1; 70.2, 74.0)		718 (72.1; 69.2, 74.9)		974 (93.6; 92.1, 95.1)		493 (72.2; 68.7, 75.5)		793 (87.4; 85.3, 89.6)		4589 (78.3; 77.2, 79.4)	
Age, y	39.2 ± 13.7		42.3 ± 14.6		40.9 ± 19.0		46.1 ± 15.1		46.5 ± 15.3		42.0 ± 15.6	
Body mass index	29.2 ± 7.6		28.5 ± 6.4		27.3 ± 7.2		28.3 ± 6.4		29.5 ± 7.0		28.7 ± 7.1	

Note. CI = confidence interval. Means and percentages were derived according to how many people answered a particular question.

<sup>a</sup>Data on metropolitan populations > 18 years were obtained from the 2010 census. The metropolitan population for Washington University in St. Louis included St. Louis City County, MO. The metropolitan population for the University of California, Davis, included Sacramento and Yolo counties. The metropolitan population for the University of Michigan included Washtenaw, Wayne, and Genesee counties. The metropolitan metro population for the Albert Einstein College of Medicine included Bronx County, NY. The metropolitan metro population for the University of Rochester included Monroe County, NY.

<sup>b</sup>Alaska Native/Eskimo, American Indian, Middle Eastern, and Pacific Islander totals were reported as ≤ 1%. In the 2010 census data, Other included Biracial/Multiracial populations.

<sup>c</sup>Biracial/Multiracial and Other combined percentage.

second aim to engage in bidirectional sharing of information between communities and researchers, this literature stresses the need for community members to provide meaningful input into study content. With the discrepancy between participants enrolled in research studies and the populations to whom findings relate, efforts are needed that effectively link people to desired medical and social services (the third aim) and that use this exchange to inform individuals of opportunities for relevant research (the fourth aim).

Past studies evaluating barriers to research participation indicate that members of under-represented groups have concerns with respect to inconvenience of study times, other logistical burdens, and fears about being a guinea pig.<sup>12,18,19</sup> That mistrust, directed at researchers and health professionals, is decreasing as a result of new community engaged research efforts.<sup>20,21</sup> Programs such as the CTSA Sentinel Network and HealthStreet can help change these perceptions.

Here we report findings generated from the Sentinel Network's first study on the assessment of health needs and concerns at 5 diverse CTSA sites. We describe the Sentinel Network study protocol, assessment, and results from the first phase of the collaboration.

**METHODS**

The Sentinel Network builds the capacity of CHWs to engage individuals in their communities by discussing their health concerns and priorities, conferring with them about their research experiences and expectations, and linking them to research opportunities. The Sentinel Network collaboration in place at the time of this study included 5 Resource Development Workgroup sites: Washington University in St. Louis, Missouri (L. B. C.), the University of Rochester, Rochester, New York (N. M. B.), the University of Michigan, Ann Arbor (M. D.), the Albert Einstein College of Medicine, Bronx, New York (H. S.), and the University of California, Davis (S. A.) Sentinel Network sites are geographically and demographically diverse and were in varying stages of their CTSA funding at the time collaboration was initiated.

In addition, 2 community-focused national organizations participated in the training of CHWs and the establishment of guidelines for

TABLE 2—Demographic Characteristics of Sentinel Network Participants, by Race/Ethnicity: 2010–2011

Characteristic	White (n = 1325)	African American (n = 3058)	Hispanic/Latino (n = 1001)	Asian (n = 341)	Biracial/Multiracial (n = 82)	Other (n = 124)
	No. (%; 95% CI) or Mean $\pm$ SD	No. (%; 95% CI) or Mean $\pm$ SD	No. (%; 95% CI) or Mean $\pm$ SD	No. (%; 95% CI) or Mean $\pm$ SD	No. (%; 95% CI) or Mean $\pm$ SD	No. (%; 95% CI) or Mean $\pm$ SD
High school diploma	1177 (89.4; 87.7, 91.0) 44.3 $\pm$ 16.8	2315 (76.7; 75.2, 78.2) 41.8 $\pm$ 14.9	587 (61.7; 58.6, 64.8) 41.2 $\pm$ 14.4	311 (94.8; 91.8, 97.0) 35.8 $\pm$ 17.0	70 (86.4; 79.0, 93.0) 38.3 $\pm$ 14.9	93 (77.5; 70.0, 85.0) 46.0 $\pm$ 17.3
Age, y	27.7 $\pm$ 6.9	29.6 $\pm$ 7.6	28.9 $\pm$ 6.2	24.0 $\pm$ 4.1	28.7 $\pm$ 6.4	26.8 $\pm$ 5.7
Body mass index						

Note. CI = confidence interval. Means and percentages were derived according to how many people answered a particular question.

community engagement efforts: Community-Campus Partnerships for Health (S. D. S.) and Patient Advocates in Research (D. E. C.). Although each CTSA site had unique approaches to engaging its communities, each agreed to this CHW model and contributed to and agreed on all of the methods described.

### Recruitment and Training of Community Health Workers

Each site received funds for one full-time-equivalent CHW; additional resources were leveraged from the CTSA, the community engagement program, volunteers, practicum students, and graduate students for additional CHWs. Of the 9 CHWs hired, 8 were female, 5 were African American, 2 were White, 1 was Asian, and 1 was Hispanic. CHWs ranged in age from 22 to 52 years (mean = 35.8), and they had a diversity of experience.

Although there were no set criteria, CHWs were required to be gregarious and outgoing members of their community. Specifically, one CHW managed a student-run free clinic, another had a nursing background, and others were volunteers in their community. CHWs attended a 2-day training session in St. Louis that focused on ethics, privacy, confidentiality, risk management, the intent of each assessment question, protocol methodology, medical terminology, and the methods to be used in recruiting participants and gathering results. Training included vigorous interactive role-playing to solidify each concept.

### Participant Recruitment and Assessment

CHWs recruited adults 18 years or older for the Sentinel Network study between March 2010 and September 2011 at places where people congregate, such as barbershops, beauty shops, parks, shelters, bus stops, community agencies, churches, neighborhood associations, health care facilities, sports venues, grocery stores, laundromats, nail salons, fitness centers, colleges, gas stations, check cashing venues, and health fairs. CHWs spoke with community residents individually, providing each with a brief, standardized explanation of the study. A total of 5979 individuals participated in the study.

Sentinel Network partners developed a common CHW-administered assessment that was vigorously pilot tested by CHWs and principal

investigators with respect to its acceptability, feasibility, and contextual relevance. A Spanish-translation version was developed by the team at the University of California, Davis. Although each site had the option of including additional items, a core set of questions approximately 15 minutes in length formed the basis for the Sentinel Network intake at all sites.

The CHW assessed the location of the contact (with GPS coordinates), the date and time of contact, and the location's zip code and recorded the individual's observed gender and self-reported age, race/ethnicity, height and weight, and last grade completed. The CHW elicited from participants their top 3 health concerns and their top neighborhood concern. Participants were then asked whether they had ever been told by a health professional that they had a problem with high blood pressure, depression, heart disease, diabetes, cancer, or arthritis; a disease of the muscles or bones; asthma; or a kidney problem. CHWs then elicited participants' smoking history and health insurance status. Next, they asked a series of questions about participants' research participation history (beginning with "Have you ever been in a health research study?") and their perceptions regarding research, after which they asked participants to indicate what they believed was "fair market" compensation for a 1.5-hour study that included a blood test. The final question elicited participants' level of interest in taking part in a research study.

### Data Management and Quality Control

Sites sent hard copies of their data to the Washington University team monthly. Data entry and quality control were completed at Washington University; feedback was given to each site on a regular basis to ensure protocol fidelity. General issues were discussed during biweekly conference calls with all team members.

### Analyses

Data were analyzed by site and by participant race/ethnicity. At Washington University, 3.1% of individuals who were contacted decided not to participate. Although such records were not kept at other sites, observations indicated that the rate of nonparticipation seemed to be equivalent across the sites. We used means and standard deviations to calculate continuous variables and proportions and binomial

**TABLE 3—Top Health and Neighborhood Concerns of Sentinel Network Participants, by Site: 2010–2011**

	Washington University in St. Louis	University of California, Davis	University of Michigan	Albert Einstein College of Medicine	University of Rochester	Total
<b>Top health concerns<sup>a</sup></b>						
Sample size	n = 1983	n = 945	n = 987	n = 588	n = 816	n = 5319
First	Hypertension	Diabetes	Cancer	Hypertension	Cancer	Hypertension
Second	Diabetes	Cancer	Weight	Diabetes	Diabetes	Diabetes
Third	Cancer	Hypertension	Diabetes	Weight	Hypertension	Cancer
Fourth	Heart problems	Heart problems	Heart problems	Cancer	Weight	Weight
Fifth	Weight	Weight	Hypertension	Heart problems	Heart problems	Heart problems
<b>Top neighborhood concerns<sup>a</sup></b>						
Sample size	n = 1598	n = 759	n = 854	n = 346	n = 661	n = 4186
First	Safety/crime	Safety/crime	Safety/crime	Health	Safety/crime	Safety/crime
Second	Drugs	Health	Health	Safety/crime	Health	Health
Third	Health	Drugs	Environment	Environment	Economy	Drugs
Fourth	Environment	Environment	Economy	Drugs	Drugs	Environment
Fifth	Economy/sexually transmitted diseases	Health care	Peace/respect	Youth programs	Health care	Economy

<sup>a</sup>Among those with a concern.

confidence intervals to calculate categorical variables. SAS version 9.2 (SAS Institute, Cary, NC) was used in conducting the analyses.

## RESULTS

The sample was racially/ethnically diverse (Table 1). The majority of Sentinel Network participants were African American (51.6%; n = 3058). Those who reported being Hispanic or Latino (regardless of other race) were counted as such and removed from any other category; they made up 16.9% (n = 1001) of the sample. In addition, 5.8% reported being Asian (n = 341) and 1.3% reported being biracial or multiracial (n = 82). American Indians, Alaska Natives, Pacific Islanders, and Middle Easterners took part in the study but made up less than 1% of the sample. White participants accounted for 22.3% (n = 1325) of the sample.

Underrepresented populations were specifically targeted and thus were more highly represented than in the 2010 census demographic data for their community (Table 1). Washington University, the University of Michigan, the University of Rochester, and the University of California, Davis, oversampled African Americans, Hispanics/Latinos, or Asians relative to their area population. The Albert Einstein College of Medicine produced

a sample roughly consistent with the local demographic profile of its area ( $\geq 80\%$  of area residents belong to minority groups).

Other demographic characteristics are shown in Table 2. More than half of the respondents at each site were women (59.4% overall). The mean age of participants was 42.0 years, and 78.3% had graduated from high school. The mean body mass index (defined as weight in kilograms divided by the square of height in meters) was 28.7 across all sites, which is considered overweight.<sup>22</sup> Mean ages stratified by race/ethnicity ranged from 35.8 years among Asians to 46.0 years among those classified as “Other.” The percentage of participants with a high school diploma ranged from 61.7% among Hispanics to 94.8% among Asians. Mean body mass index ranged from 24.0 among Asians to 29.6 among African Americans.

### Health and Neighborhood Concerns

The 5 most frequently mentioned health concerns across sites, among those reporting at least 1 concern (n = 5319; 89.0%), were hypertension, diabetes, cancer, weight, and heart problems (Table 3). Although not shown, the top 5 concerns did not vary according to respondents’ age or race/ethnicity.

Table 3 also shows the top neighborhood concerns by site, again among those reporting

at least 1 such concern (n = 4186; 70.0%). Respondents at all of the sites, with the exception of the Albert Einstein College of Medicine, mentioned safety and crime as the most salient concern. Another concern in the top 5 among all sites was health; drugs and environment were mentioned as priorities by respondents from 4 of the 5 sites. When stratified by age, sexually transmitted diseases replaced economy as a top neighborhood concern among respondents younger than 30 years (data not shown). Hispanic respondents reported health care as one of their top 5 neighborhood concerns.

Data on actual health conditions and topics were elicited with yes–no questions; concerns are shown in Table 4. Overall, high blood pressure was most commonly cited, followed by depression and arthritis. With the exception of respondents at the Washington University site, high blood pressure was the most prevalent health condition reported. The least common conditions reported overall were heart disease and cancer, each at 4.8%.

Health conditions were examined according to race/ethnicity as well (Table 4). In the case of all conditions, Asians reported the lowest prevalence of any racial/ethnic group. Whereas high blood pressure was the most prevalent condition reported among African

**TABLE 4—Health Conditions, Insurance Status, and Smoking Behavior Reported by Sentinel Network Participants, by Site and Race/Ethnicity: 2010–2011**

Reported Health Condition	Site										Race/Ethnicity				
	Washington University in St. Louis (n = 2253), No. (%; 95% CI)	University of California, Davis (n = 1030), No. (%; 95% CI)	University of Michigan (n = 1049), No. (%; 95% CI)	Albert Einstein College of Medicine (n = 714), No. (%; 95% CI)	University of Rochester (n = 933), No. (%; 95% CI)	Total (n = 5979), No. (%; 95% CI)	African American (n = 3058)	Hispanic/Latino (n = 1001)	Asian (n = 341)	Biracial/Multiracial (n = 82)	Other (n = 124)				
Arthritis	427 (19.8; 18.1, 21.5)	190 (20.0; 17.5, 22.7)	213 (20.3; 17.9, 22.9)	155 (22.0; 19.0, 25.2)	195 (25.0; 22.0, 28.2)	1180 (20.9; 19.9, 22.0)	597 (21.0; 19.5, 22.5)	159 (17.0; 14.6, 19.4)	31 (9.4; 6.3, 12.5)	20 (24.4; 15.1, 33.7)	16 (13.7; 7.5, 19.9)				
Asthma	408 (18.0; 16.5, 19.7)	169 (17.9; 15.4, 20.4)	158 (15.1; 13.0, 17.4)	110 (15.6; 13.0, 18.5)	169 (21.6; 18.8, 24.7)	1014 (17.7; 16.7, 18.7)	553 (18.8; 17.4, 20.2)	158 (16.9; 14.5, 19.3)	32 (9.7; 6.5, 12.9)	16 (19.5; 10.9, 28.1)	16 (13.7; 7.5, 19.9)				
Cancer	74 (3.3; 2.6, 4.0)	39 (4.1; 2.9, 5.6)	79 (7.6; 6.1, 9.3)	32 (4.5; 3.1, 6.3)	51 (6.6; 5.0, 8.6)	275 (4.8; 4.3, 5.4)	120 (4.1; 3.4, 4.8)	32 (3.4; 2.3, 4.6)	8 (2.4; 0.8, 4.1)	5 (6.1; 0.9, 11.3)	7 (5.9; 1.7, 10.2)				
Depression	582 (25.8; 24.0, 27.6)	293 (28.8; 26.0, 31.6)	245 (23.4; 20.9, 26.1)	124 (17.5; 14.8, 20.5)	225 (24.9; 22.1, 27.8)	1469 (24.8; 23.7, 25.9)	659 (21.7; 20.3, 23.2)	235 (23.6; 21.0, 26.3)	25 (7.4; 4.6, 10.1)	30 (36.6; 26.2, 47.0)	33 (27.3; 19.3, 35.2)				
Diabetes	194 (8.7; 7.5, 9.9)	161 (15.8; 13.6, 18.2)	132 (12.6; 10.7, 14.8)	105 (14.9; 12.3, 17.7)	148 (16.3; 14.0, 18.9)	740 (12.5; 11.7, 13.4)	367 (12.2; 11.0, 13.3)	166 (16.7; 14.4, 19.1)	28 (8.3; 5.3, 11.2)	13 (15.9; 8.0, 23.8)	24 (19.8; 12.7, 26.9)				
Diseases of the musculos or bones	840 (37.3; 35.3, 39.3)	96 (10.1; 8.3, 12.2)	76 (7.3; 5.8, 9.0)	53 (7.5; 5.7, 9.7)	69 (8.9; 7.0, 11.2)	1134 (19.8; 18.8, 20.8)	751 (25.6; 24.0, 27.2)	102 (10.9; 8.9, 13.0)	20 (6.1; 3.5, 8.6)	16 (19.5; 10.9, 28.1)	5 (4.3; 0.6, 7.9)				
Heart disease	38 (1.7; 1.2, 2.2)	79 (7.8; 6.2, 9.6)	76 (7.3; 5.8, 9.0)	28 (4.0; 2.6, 5.7)	60 (6.7; 5.1, 8.5)	281 (4.8; 4.2, 5.3)	115 (3.8; 3.1, 4.5)	49 (5.0; 3.6, 6.3)	17 (6.0; 2.7, 7.3)	11 (13.4; 6.0, 20.8)	8 (6.6; 2.2, 11.0)				
High blood pressure	600 (26.6; 24.8, 28.5)	355 (34.8; 32.0, 37.9)	292 (27.9; 25.2, 30.7)	240 (34.1; 30.6, 37.7)	351 (38.1; 34.9, 41.3)	1838 (30.9; 29.8, 32.1)	1005 (33.0; 31.4, 34.7)	312 (31.5; 28.6, 34.4)	59 (17.3; 13.3, 21.3)	28 (34.2; 23.9, 44.4)	46 (37.7; 29.1, 46.3)				
Kidney problem	245 (10.9; 9.6, 12.2)	83 (8.8; 7.0, 10.7)	45 (4.3; 3.2, 5.7)	29 (4.1; 2.8, 5.9)	49 (6.4; 4.7, 8.3)	451 (7.9; 7.2, 8.6)	245 (8.4; 7.4, 9.4)	74 (7.9; 6.2, 9.7)	12 (3.6; 1.6, 5.7)	9 (11.1; 4.3, 18.0)	3 (2.6; 0.0, 5.4)				
Other health topics	1095 (48.8; 46.7, 50.8)	507 (49.8; 46.6, 52.9)	873 (83.5; 81.2, 85.7)	594 (83.7; 80.7, 86.3)	776 (84.4; 81.8, 86.6)	3845 (64.7; 63.5, 66.0)	1887 (61.2; 59.4, 62.9)	563 (56.6; 53.5, 59.7)	249 (73.0; 68.3, 77.7)	65 (79.3; 70.5, 88.0)	96 (78.1; 70.7, 85.4)				
Has any type of health insurance	1217 (54.5; 52.4, 56.5)	283 (27.8; 25.0, 30.6)	172 (16.5; 14.3, 18.9)	170 (23.9; 20.9, 27.3)	208 (22.6; 20.0, 25.5)	2050 (34.6; 33.4, 35.8)	1295 (42.8; 41.0, 44.5)	235 (23.7; 21.0, 26.3)	23 (6.7; 4.1, 9.4)	33 (40.2; 29.6, 50.9)	27 (22.0; 14.6, 29.3)				
Has smoked cigarettes in the past 30 d															

Note. CI = confidence interval. Percentages were derived according to how many people answered a particular question.

Americans (33.0%), Hispanics (31.5%), and Asians (17.3%), the most prevalent condition reported among Whites was depression (36.2%). Enrollment in health insurance ranged from 56.6% among Hispanics/Latinos to 79.3% among biracial or multiracial participants. Current smoking rates ranged from 6.7% among Asians to 42.8% among African Americans.

**Research Experiences and Perceptions**

Overall, 87.3% of the respondents (ranging from 71.5% at the University of Rochester site to 99.7% at the Washington University site) were interested in participating in research (Table 5). With the exception of Washington University, respondents at all sites reported that they were least willing to participate in a study in which they would have to take medication (mean = 49.3%; overall range: 27.8%–68.1%). Participants stated that they would be most willing to take part in a study wherein they were asked about only their health (mean = 85.2%; range: 76.1%–93%). At the Washington University site, participants overwhelmingly reported being willing to provide a blood sample (95.2%), relinquish their medical records (92.4%), and provide a sample for genetic purposes (91.8%). With respect to fair compensation for a study that involved a 1.5-hour interview and a blood draw, responses (means) ranged from \$63.41 among participants at the University of Rochester site to \$79.72 among participants at the Albert Einstein College of Medicine site (overall mean = \$73.54).

We also assessed research interest according to race/ethnicity. Rates of past study participation were low in all groups, ranging from 11.4% among Hispanics/Latinos to 21.2% among Whites (Table 5). Interest in study participation was higher among respondents in the “other” racial/ethnic category (70.1%) and among African American respondents (91.0%).

More African Americans than respondents in any other racial/ethnic group were interested in participating in a study (91%), providing a blood sample (82.6%), providing a sample for a genetic study (76.9%), providing access to medical records (77.2%), staying overnight in a hospital (70.5%), and using medical equipment (Table 5). Asian respondents were least willing to report interest along each of these categories.

TABLE 5—Research Experience and Perceptions Reported by Sentinel Network Participants, by Site and Race/Ethnicity: 2010–2011

	Site										Race/Ethnicity				
	Washington University, St. Louis (n = 225), No. (%; 95% CI)	University of California, Davis (n = 104), No. (%; 95% CI)	University of Michigan (n = 104), No. (%; 95% CI)	Albert Einstein College of Medicine (n = 714), No. (%; 95% CI)	University of Rochester (n = 93), No. (%; 95% CI)	Total (n = 927), No. (%; 95% CI)	White (n = 132), No. (%; 95% CI)	African American (n = 30), No. (%; 95% CI)	Hispanic/Latino (n = 100), No. (%; 95% CI)	Asian (n = 31), No. (%; 95% CI)	Black/Multiracial (n = 82), No. (%; 95% CI)	Other (n = 124), No. (%; 95% CI)			
Has ever been in a health research study	394 (17.8; 16.2, 19.4)	102 (10.1; 8.3, 12.0)	394 (17.8; 16.2, 19.4)	80 (11.3; 9.1, 13.9)	158 (17.3; 14.9, 20.0)	1065 (17.1; 16.1, 18.0)	275 (21.2; 19.0, 23.4)	52 (17.4; 16.0, 18.7)	113 (11.4; 9.4, 13.4)	49 (4.4; 10.7, 8.1)	17 (21.0; 12.1, 29.9)	19 (35.5; 9.1, 21.8)			
Interested in participating in research studies	1857 (93.7; 90.3, 99.9)	785 (83.8; 81.3, 86.1)	1857 (93.7; 90.3, 99.9)	558 (78.5; 75.3, 81.5)	553 (71.5; 68.2, 74.7)	4654 (87.3; 86.4, 88.2)	1067 (85.5; 83.5, 87.5)	2357 (91.0; 89.9, 92.1)	782 (84.5; 82.2, 86.9)	263 (79.7; 75.4, 84.0)	69 (86.3; 78.7, 93.8)	82 (70.1; 61.8, 78.4)			
Would participate in a study if asked only about health	2080 (93.0; 92.0, 94.1)	847 (83.5; 81.0, 85.7)	2080 (93.0; 92.0, 94.1)	541 (76.1; 72.8, 79.2)	701 (77.3; 74.4, 80.0)	5059 (85.2; 84.3, 86.1)	1143 (87.3; 85.5, 89.1)	2655 (87.5; 86.3, 88.7)	816 (82.2; 79.8, 84.6)	252 (73.9; 69.2, 78.6)	66 (80.5; 71.9, 89.1)	83 (68.0; 58.8, 76.3)			
If researchers wanted to see your medical records	2075 (92.4; 91.3, 93.3)	726 (71.7; 68.8, 74.4)	2075 (92.4; 91.3, 93.3)	439 (61.8; 58.1, 65.4)	423 (46.6; 43.4, 50.0)	4291 (72.5; 71.3, 73.6)	946 (72.1; 69.6, 74.5)	2339 (77.2; 75.7, 78.7)	689 (69.5; 66.7, 72.4)	173 (50.9; 45.6, 56.2)	51 (63.0; 52.5, 73.5)	70 (56.9; 48.2, 65.7)			
If you had to give a blood sample	2140 (95.2; 94.4, 96.1)	770 (75.9; 73.2, 78.5)	2140 (95.2; 94.4, 96.1)	464 (65.4; 61.7, 69.9)	565 (62.2; 59.0, 65.4)	4629 (78.1; 77.1, 79.2)	1021 (77.7; 75.5, 80.0)	2595 (82.8; 81.3, 84.0)	747 (75.5; 72.8, 78.1)	195 (57.2; 51.9, 62.4)	61 (74.4; 64.9, 83.8)	73 (59.4; 50.7, 68.0)			
If asked to give a genetic sample	2082 (91.8; 90.1, 92.9)	718 (70.9; 68.0, 73.7)	2082 (91.8; 90.1, 92.9)	412 (58.0; 54.3, 61.7)	4251 (71.9; 70.8, 73.1)	4251 (71.9; 70.8, 73.1)	940 (71.8; 69.4, 74.3)	2328 (76.9; 75.4, 78.4)	657 (66.4; 63.4, 69.3)	176 (51.6; 46.3, 56.9)	61 (74.4; 64.9, 83.8)	67 (54.9; 46.1, 63.8)			
If you had to take medicine	1527 (68.1; 66.2, 70.1)	520 (51.7; 48.6, 54.8)	1527 (68.1; 66.2, 70.1)	292 (41.3; 37.6, 45.0)	250 (27.8; 24.8, 30.8)	2906 (49.3; 48.0, 50.6)	638 (48.7; 46.0, 51.5)	1599 (53.0; 51.2, 54.8)	478 (48.4; 45.3, 51.6)	94 (27.7; 22.9, 32.4)	40 (48.8; 38.0, 59.6)	47 (38.8; 30.2, 47.5)			
If asked to stay overnight in a hospital or clinic	1886 (84.6; 83.1, 86.1)	584 (57.7; 54.6, 60.8)	1886 (84.6; 83.1, 86.1)	329 (46.4; 42.7, 50.2)	399 (43.8; 40.5, 47.0)	3723 (62.9; 61.7, 64.1)	796 (60.6; 57.9, 63.2)	2133 (70.5; 68.9, 72.1)	588 (66.4; 63.3, 69.5)	112 (32.8; 27.9, 37.8)	48 (58.5; 47.9, 69.2)	55 (45.1; 36.3, 53.9)			
If you might have to use medical equipment	2023 (90.2; 88.0, 91.5)	697 (68.9; 65.9, 71.7)	2023 (90.2; 88.0, 91.5)	390 (54.9; 51.2, 58.6)	426 (47.2; 43.9, 50.6)	4118 (69.6; 68.5, 70.8)	897 (68.4; 65.9, 70.9)	2278 (75.4; 73.8, 76.9)	631 (63.7; 60.7, 66.7)	169 (49.6; 44.3, 54.9)	56 (68.3; 58.2, 78.4)	67 (54.9; 46.1, 63.8)			
Fair compensation for a study with a 1.5-h interview and a blood test, \$	1198 (64.3; 62.2, 66.5)	639 (63.5; 60.8, 66.5)	1198 (64.3; 62.2, 66.5)	400 (56.7; 53.0, 60.4)	419 (45.1; 42.6, 47.6)	3209 (60.0; 58.7, 61.4)	751 (60.1; 57.4, 62.8)	1572 (51.2; 49.2, 53.2)	604 (65.9; 62.8, 68.9)	158 (46.5; 43.0, 53.9)	49 (60.5; 49.9, 71.1)	58 (50.4; 41.3, 59.6)			
	78.25	67.52	78.25	79.72	63.41	73.54	58.34	81.00	75.15	68.71	61.68	65.52			

Note. CI = confidence interval. Percentages were derived according to how many people answered a particular question.

Regarding fair compensation for a study 1.5 hours in duration that involved a blood draw, African Americans were highest in their expectations (mean = \$81.60), followed by Hispanics (mean = \$75.15). The lowest end of the range was \$61.68, the average reported by Whites.

Sharing Findings With Communities

Efforts were made to share Sentinel Network findings with the communities in which the data were collected as well as among other researchers. A community brochure was produced in which summarized study findings were presented. To ensure bidirectional sharing of information, we shared the data with our community advisory boards and asked for their input into the development of study materials.

DISCUSSION

The goals of the Resource Development Workgroup—to collaborate across CTSA sites, to build the capacity of CHWs, to increase the rigor of health evaluation metrics in the field, and to establish a network for ongoing, real-time assessment of health and neighborhood needs and concerns—are being met. With the data obtained, CTSA sites are working with their local communities to increase the representativeness and relevance of research by facilitating community participation.

The first phase of the Sentinel Network study focused on assessing community needs and bidirectional communication through a new network of 5 sites and 2 national organizations. Findings about health concerns were consistent according to site, race/ethnicity, and age, with hypertension, diabetes, and cancer among the top concerns. These self-reported health concerns are among the top 25 priority research topics listed in a recent Institute of Medicine report.<sup>23</sup> Similarly, the conditions that were most likely to be reported by Sentinel Network respondents, hypertension (30.9%) and depression (24.8%), are consistent with national prevalence rates of these conditions.<sup>24,25</sup>

In addition, neighborhood concerns were consistent across site, race/ethnicity, and age groups, with safety and crime ranked as the top concern (an issue also raised by participants in a series of Federal Interagency Working

Group sessions held around the country). Such concerns call attention to the need to understand and evaluate the social determinants of health: “the conditions in which people live, learn, work, play, and pray.”<sup>26(pS15)</sup>

A majority of Sentinel Network respondents reported interest in taking part in health research and had clear opinions about the kinds of research in which they would be willing to participate; they also identified fair levels of compensation. Across all sites, participants were most likely to report willingness to take part in a study that is noninvasive and does not require a hospital stay, medical equipment, or taking medication. Their reported rate of previous participation in health studies was well above the national average of less than 1%.<sup>1</sup>

One of our salient findings is that African Americans reported more willingness to participate in research than respondents from other racial/ethnic groups. Interestingly, this included more willingness to be involved in studies in which blood and genetic samples were drawn from participants, which may suggest that the reluctance of African Americans to participate in medical research as a result of the US Public Health Service study of syphilis in Tuskegee, Alabama,<sup>27–29</sup> is waning. This finding confirms other recent study results suggesting that African Americans may not be less willing than members of other racial/ethnic groups to participate in clinical studies<sup>30,31</sup> and may even be overrepresented in certain areas of research, such as phase I trials.<sup>32</sup> One genetic study showed that when greater efforts were made to contact African Americans, their rate of participation was higher than that of Whites.<sup>33</sup>

Thus, our results contradict previous studies indicating that African Americans are less willing to participate in medical research.<sup>12,34–36</sup> The willingness of our respondents to participate in clinical/health research bodes well for the new NIH National Center for Advancing Translational Sciences, which aims to facilitate the implementation of diagnostics, therapeutics, and devices pertinent to improving health<sup>37</sup> and speed the translation of basic discoveries into therapies.<sup>38</sup>

### Limitations and Strengths

Although the Sentinel Network study has many strengths, its limitations include the use

of a convenience sample, the brevity of the assessment, and the cross-sectional nature of the data. These limitations are overshadowed by the network’s strengths, which include its ability to scale up efforts to collect real-time data from underrepresented populations commonly missed by most clinical research trials and community health endeavors. This maximizes the generalizability of the findings. Given that non-White racial/ethnic groups now constitute more than one third of the population in the United States,<sup>39</sup> their inclusion in clinical trials is increasingly important.<sup>3</sup>

A better understanding of racial/ethnic variations in clinical trial participation and health research outcomes is critical in helping meet the health care needs of an increasingly diverse US population. Thus, the CTSA mission to enhance the health of local communities requires innovative methods that reach out to underrepresented populations. With the Sentinel Network model, this aim was achieved through ongoing multidirectional feedback loops that included community members, agency staff and leaders, researchers, and NIH.

Another strength is the large, geographically and ethnically diverse sample of 5979 community members. The diversity of this sample would not have been possible without CHWs, who, as a result of their experience and training, are respectful and culturally sensitive. These qualities are more important than homophily for successful community engagement.<sup>40</sup>

### Conclusions

The reliance on CHWs in the Sentinel Network assessment model was found to be successful and feasible, and it led to a further expansion of the model. Specifically, a second phase of the Sentinel Network is currently being implemented. In this phase, along with a sixth site (University of Florida) being added, participants are actively being recruited into a study that links them to medical and social services as well as opportunities to participate in research. CHWs then track the success and satisfaction of participants at 1-month intervals; this pilot is intended as a first step toward meeting the HealthStreet program’s aims and planning future collaborative comparative effectiveness research across these and other CTSA sites.

The results of this study show that CHWs are crucial to the success of community-engaged research. With its focus on expanding the role of CHWs to include research and an emphasis on reducing health disparities by facilitating broader research participation, the Sentinel Network is an innovative approach that challenges the status quo and works toward person-centered research to promote better health outcomes for all. ■

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### Contributors

L. B. Cottler led the writing and editing of the article and contributed to the design of the assessment. D. J. McCloskey provided advice in the formulation of the Sentinel Network and participated in the editing of the article. S. Aguilar-Gaxiola, N. M. Bennett, H. Strelnick, and M. Dwyer-White participated in the design of the assessment and the editing of the article. D. E. Collyar and S. D. Seifer assisted in the study design and the editing of the article. S. Ajinkya performed statistical analyses, reviewed data, and coordinated editorial comments on the article. C. C. O’Leary and C. W. Striley participated in training of community health workers and the editing of the article. B. Evanoff helped design the Sentinel Network project and provided feedback on the data analysis.

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### Human Participant Protection

The Sentinel Network protocol was approved by each site's institutional review board (IRB), with Washington University serving as the coordinating center. Community health workers completed standard IRB training at their respective institutions. Interested participants provided verbal informed consent at some sites if identifiable data were not collected (University of Rochester, University of Michigan, University of California, Davis) and signed consent forms at the other sites (Washington University, Albert Einstein College of Medicine).

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