

Piloting BRFSS Survey Modules and Assessing Alternative Distribution Methods Final Report December 2023

Project Background

Through support from the Robert Wood Johnson Foundation, the CDC Foundation administered <u>a multifaceted project</u> in partnership with the Centers for Disease Control and Prevention (CDC), the National Alliance Against Disparities in Patient Health (NADPH) and Data Equity Coalitions (DECs) in Atlanta, Detroit, Durham, Pittsburgh and San Antonio — local organizations collaborating with communities to improve access to and use of public health data.

As part of the project, the DECs and NADPH conducted coordinated and tailored research investigating opportunities for surveillance systems to better respond to local data priorities related to the social and structural determinants of health (SDOH), including the experiences and impacts of systemic injustices.

The DEC and NADPH efforts sought to understand community and local public health SDOH data needs and priorities, the strengths and limitations of existing SDOH survey tools and promising approaches for increasing access and use of public health data. The DECs and NADPH gathered community feedback through one-on-one community survey validation interviews, focus groups, testing approaches to increase survey participation, piloting SDOH survey modules and facilitating community discussions. Feedback focused on use of the <u>Behavioral Risk Factor Surveillance System (BRFSS)</u>, <u>Pregnancy Risk Assessment Monitoring System (PRAMS)</u> and <u>PLACES</u>. Across the five locations, our DEC and NADPH partners engaged over 1,250 public health professionals, community leaders and members of groups who have been historically marginalized.

View a collaborative recap of the project and a list of promising actions for surveillance systems to consider for enhancing community engagement and developing more relevant SDOH metrics in our <u>Final</u> <u>Collaborative Report</u>.

Our Role

For this project our team at Community Information Now (CINow) participated as the local DEC of San Antonio, TX. This report was developed by our team and does not necessarily reflect the views of the CDC Foundation or the Robert Wood Johnson Foundation.

Local Context

Bexar County (San Antonio), Texas is home to nearly 2.1M people, of whom 61% are Hispanic, 26% white, 7% Black or African American, and 3% Asian. Of those 25 years and older, 85% have at least a high school diploma or GED. One in five children lives in poverty, and one in five people under age 65 lacks health insurance. Social/non-medical drivers of health and racial inequity are critical priorities.



Community Information Now (CINow) is a nonprofit local data intermediary based in San Antonio, Texas, with a vision of *improved lives and decreased disparities through democratized data*. CINow sought to understand how alternative approaches to administration of a subset of Behavioral Risk Factor Surveillance System (BRFSS) survey modules compared to each other and to the Texas BRFSS household telephone survey in terms of both response rates and respondent demographic characteristics. The two BRFSS modules fielded, 2022 Social Determinants of Health (SDOH)¹ and 2014 Reactions to Race (RR), were selected because the topics are key to health in Bexar County, but the community lacks local data for many of the issues (e.g., social support, racial bias in health care).

Methods

CINow fielded the two modules and a set of demographic questions in English and Spanish (1) by SMS text to two third-party probability panels, (2) by mail with two reminder postcards a week apart to a stratified random sample of 2,500 Bexar County households (proportional to share of county households in each ZIP code), and (3) by social media and email to a convenience sample of CINow's own contacts and partners, who shared the survey with others. This work required two different sets of survey questions, as probability research panels have standard demographics that cannot be modified, and four different survey collectors (links), to track distribution method for each response received. Responses were collected digitally for all methods using a Qualtrics URL and/or QR code, and a pre-paid postage response option was also offered for mailed surveys.

The questions in the two BRFSS survey modules were unaltered. Additional questions captured demographics and other respondent characteristics (e.g., disability, veteran status). Both probability panels collect panel member demographics when members join and do not allow any of those questions to be asked again. The probability panels incentivized responses; no incentives were offered for the mail or convenience surveys. All surveys and related materials (e.g., mail cover letter) were offered in both English and Spanish.

Final survey samples were merged and iterative proportional fitting algorithm (raking) was used to design weights and analyze the combined sample. Population estimates used to weight demographic variables and achieve known population margins were collected from the 2021 1-year American Community Survey. Demographic weighted variables include: sex, age group, education, race/ethnicity, and employment. Categories for two variables, education and race/ethnicity, had to be collapsed since categories with <5% of the sample cases can create very unequal weights in raking. For the education variable, "less than high school" had a small count and was combined with "high school degree." For the race/ethnicity variable, "2+ races" and "other" categories had to be combined. Cases with missing data were removed for variables that were weighted since weighting procedures require complete cases. However, cases with missing data were kept for all other variables. Population totals vary by question since all available data was used.

¹ A draft version of the final 2022 SDOH Module accessed in May 2022 was used. This included all of the same questions as the final 2022 SDOH module, as well as three additional questions that were removed in the final module.

Results

The mail survey response rate was only 1.0% (n=24 valid responses), much lower than the 4%-5% anticipated. The two panels together yielded 315 valid responses, higher than expected, with a response rate around 60%. The snowball convenience sample, for which a response rate cannot be calculated, yielded another 237 responses. While the digital convenience sample survey yielded the most responses of all four samples, the panel surveys produced the most complete responses. The response rate, response totals, and external cost per response for each method are summarized in Table 1. External costs are any expenses other than staff time, such as the contracted probability panel fees, printing and mailing services, and postage.

Table 1. Survey Distribution Methods, Response Totals, and External Cost per Response

	Panel A	Panel B	Mail	Convenience
Weeks open	2	2	5	7
Response rate	58%	61%	1%	-
Valid responses	120	195	24	237
External cost per response	\$112	\$110	\$161	\$0

As shown in Table 2 on the following page, none of the four samples closely matched Bexar County adult population in terms of race/ethnicity, sex, and age. The age and race/ethnicity breakdown for the mail and convenience samples are estimates, as the response options did not mirror those of the probability panels. The two probability panels combined were more representative of the county population in terms of race and ethnicity than the unweighted BRFSS response set and other methods, but respondents were disproportionately female for all methods tested.

Initial survey data processing, weighting, and analysis are complete, with all four samples combined using hybrid weights to yield a robust dataset (n=576) representative of Bexar County's adult population. Table 3 compares key demographic characteristics for the Bexar County population, the unweighted combined sample, and the final weighted combined sample.

Table 2. Bexar County Adult Population (18 years and older) and Respondent Characteristics

	Bexar County Percent	BRFSS Percent*	Panel A&B Percent	Mail Percent**	Convenience Percent**
Age					
18-29	16.6	16.4	13.1	14.3	7.8
30-44	22.3	22.4	26.1	42.9	32.6
45-64	22.2	30.1	39.2	28.6	43.1
65+	12.8	31.1	21.7	14.3	16.5
Race/Ethnicity					
Black, non-Hispanic	6.8	8.7	6.5	13.6	11.2
Hispanic	61.3	39.5	61.8	50.0	46.7
Other/multiracial, non-Hispanic	6.3	6.6	2.3	4.5	5.6
White, non-Hispanic	25.6	45.2	29.4	31.8	36.4
Sex					
Female	50.7	54.0	59.7	60.0	78.4
Male	49.3	46.0	40.3	40.0	21.6

^{*} Unweighted ** Percentages estimated for age and race/ethnicity due to varying response options across methods

Table 3. Comparison of County, Unweighted Sample, and Weighted Sample Demographic Characteristics

	Bexar County	Combined Unweighted		Combined Weighted	
	Adult Population Percent*	Number	Percent	Number	Percent
Age					
18-29	22.5%	58	10.8%	129.2	24.1%
30-39	20.8%	102	19.0%	109.3	20.4%
40-49	17.5%	111	20.7%	91.7	17.1%
50-59	14.5%	115	21.5%	76.6	14.3%
60-69	13.1%	88	16.4%	68.6	12.8%
70+	11.6%	62	11.6%	60.6	11.3%
Race/Ethnicity					
Black, non-Hispanic	6.8%	47	8.8%	38.6	7.2%
Hispanic	61.3%	297	55.4%	316.8	59.1%
Other/multiracial, non-Hispanic	6.3%	23	4.3%	33.8	6.3%
White, non-Hispanic	25.6%	169	31.5%	146.9	27.4%
Sex					
Female	50.7%	360	67.2%	271.8	50.7%
Male	49.3%	176	32.8%	264.2	49.3%
Other					
Military veteran	9.9%	62	11.7%	58.0	10.9%
Has one or more disabilities	15.1%	101	19.1%	109.0	20.6%
High school diploma or less	38.5%	97	18.1%	206.4	38.5%
Graduate or professional degree	10.8%	167	31.2%	57.9	10.8%

^{*} Source: U.S. Census Bureau American Community Survey 2022 1-Year Estimates (multiple tables)



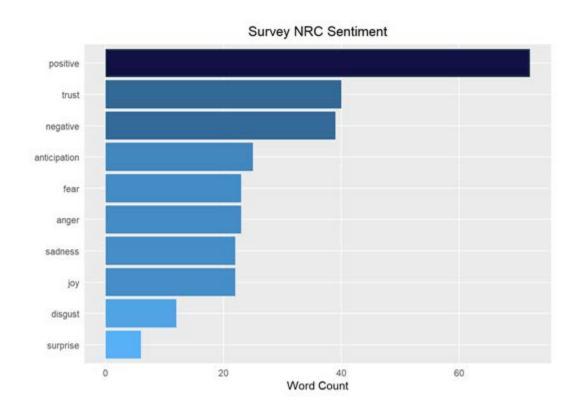
Figure 1. Word Cloud of Free-Text Responses (n=39) to General Open-Ended Question

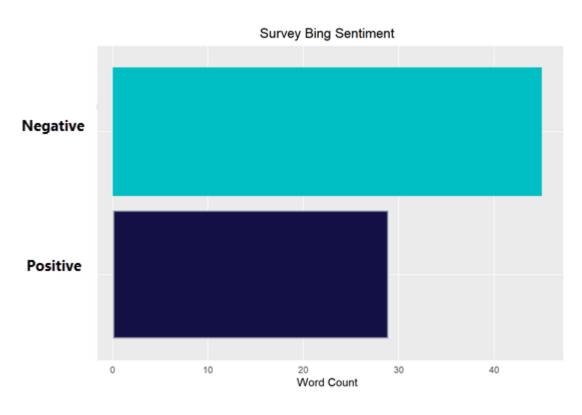
A number of responses to open-ended questions appeared to indicate strong emotions and opinions among respondents, so CINow used R statistical software to conduct a sentiment analysis of the response text. The word cloud in Figure 1 visualizes the frequency with which various words appeared in the text entered by the 39 respondents who answered the question "Are there any other comments you would like to share?" The larger the font, the more times that word appeared in the combined text.

The R package includes the Bing (Liu) and NRC lexicons, which each categorize words by sentiment. NRC maps words to a number of different categories, while the Bing lexicon is binary – each word is categorized as either positive or negative. Figure 2 shows the results of those two analyses. While the analysis using the NRC lexicon identified more words as positive than negative, the reverse was true using the Bing lexicon.

Deeper analyses are continuing outside of this project budget. If funding can be obtained, CINow will develop a web interface to allow public query of the data. Separate analyses will investigate how respondents self-report race/ethnicity when given detailed and write-in responses options, and identify key themes emerging from narrative responses, particularly age- and sex-based bias in health care. CINow plans to present results and findings through a community report and an online website where participants and partners can view key findings.

Figure 2. Sentiment Analysis of Free-Text Responses (n=39) using NRC and Bing Lexicons





Lessons Learned and Issues to Consider

 Begin with a clear understanding of both the logistics of various survey administration methods and any implications for how data can be collected, particularly when integrating with third-party probability panels

BRFSS survey deployment required logistics and technical work we did not have prior experience with, including mail setting up US Postal Service nonprofit postage rates and Business Reply Mail and integrating our Qualtrics survey with the two separate probability panels. Fortunately, we were able to get support from Qualtrics and panel partners to help with panel integration setup but it was a tedious process that requires more programming skills than may be expected.

While using methods like probability panels may prove successful in surveying underrepresented groups in healthcare, much attention needs to be given to the processes used to carry out these activities. Beyond logistics, synthesizing data across several distribution methods proved problematic in ways we did not anticipate. For example, many national survey panels have set demographic questions that are answered once when participants join the panel so any other methods used to collect data will need to use similar demographic breakdowns. In addition, panel companies operate differently and do not all collect the same demographic variables or offer the same response options. Some companies may have two response options to demographic questions, such as "yes" or "no" while others ask for specific details (e.g., housing type, # of rooms). Overall, researching demographic breakdowns and using the same ones across methods is necessary to merge data appropriately.

 National survey demographic categories need to be disaggregated to respond to changes in how people self-identify

The United States is continuously becoming a melting pot and collapsed four to six race categories are not working well. Further, conceptualizing and capturing ethnicity and race separately proves problematic in Bexar County. In testing various survey methods, we found that many demographic categories including race/ethnicity were not diverse enough to capture all the groups or major groups that exist, and third-party probability panels allow no questions or response options for demographic characteristics like race/ethnicity that exist in their own respondent profile. One local organization requested that we include MENA (Middle Eastern and North African) as a race/ethnicity category, as the Census Bureau has traditionally classified MENA people as white, neither white nor African American group feel like an accurate representation. We also heard more in this regard from convenience sample participants who were allowed to give comments. Our qualitative analysis, while preliminary and ongoing, shows that many people do not relate to or identify with traditional race categories. We had multiple responses from Hispanic and other participants who said "I will never identify as white," "I'm not white, I'm Latina" or who said the group they belong to was not listed or captured in the responses. Seeing the variety of responses and open-ended comments participants left about the race/ethnicity they identify with has led us to rethink the way these response options were created to begin with. Clearly, some groups still lack representation in health surveys and we need to consider how these groups will be identified in the future.

Assess survey module questions for culturally relevant language and clarification

BRFSS SDOH and RR module questions were clearly designed to elicit feedback about important health measures to decrease health disparities and inequities. However, individuals and cultures evolve and questions asked should assess opportunities to change along with them to capture valuable responses. We found that while questions were framed in a standard way to get a straightforward response, they lacked cultural relevancy and clarity in what is being measured. For example, asking a question about nutrition, such as fruit and vegetable intake would yield better results if you framed it around the people you are asking. In San Antonio, this might look like providing examples of foods like salsa and guacamole that people may not realize count towards their vegetable consumption.

Questions either need to have real-world examples or need to be made culturally relevant so the audience can understand them. On the two RR questions to the effect of, "...do you feel you were treated worse than, the same as, or better than people of other races?" 21% and 28% (unweighted) of respondents selected "I don't know/Not sure." Twelve percent responded "I don't know/Not sure" to the question asking how often they think about their race. In comparison, no more than 3% of respondents answered "I don't know/Not sure" to any of the other questions in the survey, including a question about sexual orientation. That difference might reflect respondent reluctance to think about and answer questions about race, but it could also mean that respondents did not feel confident that they know how people of other races are treated.

Several respondents used an open-ended question at the end of the survey to share that they were unclear why we were asking about race, or expressed positive or negative feelings about it. Some seemed skeptical and distrustful or our reasons for asking the questions, entering comments such as "I'm confused about all the race questions," and "How are you going to use this data about race now?" Race and racism are doubtless polarizing issues for many respondents, but the reaction may also be driven by the sheer proportion of questions focused on race in a survey titled simply "Bexar County Well-Being Survey" with no mention in the brief survey introduction of race as an explicit focus.

The best audience for reviewing national survey modules and questions may be those close to home

While piloting national survey modules and questions with local groups and community individuals may be helpful, there is one important group that needs to be considered—those who administer the phone surveys. Focus groups with surveyors could prove useful and rich in context as these individuals often deal with those in the community who choose to respond or not respond to the national surveys. They have firsthand experience hearing why people would like to participate or not and may be able to shed some light on how respondents are feeling about specific questions, whether they understand certain questions or the purpose of these questions, or whether they dislike or disagree with certain questions or categories. Surveyors may also have the power to influence change by answering questions participants have related to these issues appropriately.

Consideration should be given to having surveys available in several languages and having language localized

By far the two most common languages spoken in Bexar County are Spanish and English, but the number of community members speaking some other language – particularly but not only Arabic, Vietnamese, and Pashto – is growing. Also, we found that the language of validated Spanish-language questions is often outdated and may be poorly understood or off-putting in this community. Some terms and phrases may need to be "localized" so that they are better understood by that particular community.

Building trust and gathering community support

Local data intermediaries need to ask themselves how they can use this data to help their community. Trust with the community must be built by consistently acting with integrity and following through on commitments. Relationships with community organizations and residents, but through one-on-one interactions and mutual accountability, are imperative to high quality and efficient data collection. Figuring out how to best collect, package and disseminate data and information will help in making a lasting impact in surrounding communities. Leveraging networks and doing the appropriate research can be helpful in building lasting relationships with community members.

Even work partnerships have to be handled with care and can have unplanned impacts. We had an unfortunate incident occur with one partner where we found out they were communicating directly with and surveying our focus group participants without our knowledge or agreement. We are certain it was not at all intentional, but it felt like we were cut out of the decision-making and communication loop the minute we had "delivered" the participants they needed, even though our relationships with those participants were still (always) on the line. We feel like we got a taste of being on the receiving end of "extractive" research practices, and although it was not pleasant, it was an incredibly valuable experience for us to have. We already work at it, but we will be even more thoughtful when we ask others to help us with recruitment.

Government and system transparency

For the greatest impact, be clear about the goals of any funded project and what is asked of grantees and community participants. Be open and listen to people in the community. Be aware of the power dynamic here and use it to lift up community voices and experiences, be more inclusive, more respectful and more just.

Key Takeaways and Insights

For other local data intermediaries:

Using datasets like BRFSS and PLACES in data platforms and reports, while also explaining its limitations, will raise awareness of the data and help people use it responsibly. Increasing local awareness of both the value of the data *and* its limitations can also build local support to, for example, fund a larger sample size that would make greater demographic disaggregation possible and make estimates less uncertain. If using a local geography constructed of census tracts or ZCTAs, aggregate PLACES data to that geography to increase its utility.

For public health professionals working within large scale surveillance systems:

- Consider translating the surveys into common languages beyond English and Spanish. Consider whether a panel model would be a better fit for BRFSS or PRAMS, and whether PRAMS participation could be increased by partnering with hospital systems to give mothers information about it at the time of delivery. For BRFSS, the best people to hold a focus group with are those who do phone interviews, as they are most likely to know whether questions are confusing, the response options are inadequate, and so forth.
- Consider opportunities to expand the PLACES modeling approach in ways that enable trending
 over time and demographic disaggregation, and consider partnering with local data
 intermediaries, universities, and larger health departments to demonstrate that the modeling
 approach and Small Area Estimate code can be built upon. For example, explore if census tractlevel data could be aggregated into "super-neighborhood" geographies used in many cities.

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