

Improving Engagement in Community Level Data Collection

A Research Report

April 2024



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Introduction

Through support from the Robert Wood Johnson Foundation, the CDC Foundation administered a multi-faceted project in partnership with the Centers for Disease Control and Prevention (CDC), us at 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.

For this project, we 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.

We also 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. We 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 Behavioral Risk Factor Surveillance System (BRFSS), Pregnancy Risk Assessment Monitoring System (PRAMS) and Population Level Analysis and Community Estimates (PLACES).

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 can be viewed in our full [Final Collaborative Report](#). Our work herein was funded by the CDC Foundation to conduct the activities outlined herein. This report was developed by our team exclusively and does not necessarily reflect the views of the CDC Foundation, the Robert Wood Johnson Foundation, or our DEC partners.

Behavioral Risk Factor Surveillance System

The BRFSS survey (cdc.gov/brfss) is a random-digit-dialed annual landline and cellular telephone cross-sectional survey of noninstitutionalized U.S. adults aged ≥ 18 years.¹ Specifically, BRFSS is a tool used to collect data on health-risk behaviors, chronic diseases and conditions, access to and use of health care, and use of preventive health services related to the leading causes of death and disability (Wooten KG et al). Over 400,000 BRFSS interviews are conducted annually in all 50 states, D.C., and participating U.S. territories. For this project, we reviewed the BRFSS 2014 and 2017 questionnaires, allowing participants to select the modules of greatest interest to them and their communities. Additionally, we specifically sought insights regarding two notable optional modules, 'Reactions to Race' and 'Social Determinants of Health'.

Pregnancy Risk Assessment Monitoring System

The PRAMS survey (cdc.gov/prams) is an ongoing, state- and population-based surveillance system designed to monitor selected maternal behaviors and experiences that occur before, during, and after pregnancy among women who deliver live-born infants in selected states and jurisdictions in the United States.² PRAMS aims to collect data that support efforts to improve birthing persons' and infant health. The jurisdictions participating in PRAMS represent 8 in 10 live births. This system employs a mixed mode data-collection methodology; up to three self-administered questionnaires are mailed to a sample of mothers, and non-responders are followed up with telephone interviews. An option to complete the questionnaire by web was introduced in 2023. Self-reported survey data are linked to selected birth certificate data and weighted for sample design, nonresponse, and noncoverage to create annual PRAMS analysis data sets that can be used to produce jurisdiction-based estimates of perinatal health behaviors and experiences among women delivering live infants (D'Angelo D et al).³

Population Level Analysis and Community Estimates

The **P**opulation **L**evel **A**nalysis and **C**ommunity **E**stimates (PLACES; www.cdc.gov/places/) is a collaboration between the CDC, Robert Wood Johnson Foundation and CDC Foundation.⁴ PLACES reports county, place, census tract, and ZCTA data and uses small area estimation methods to obtain 36 chronic disease measures for the entire United States.⁴ PLACES allows local health departments and others to better understand the burden and geographic distribution of chronic disease–related outcomes in their areas regardless of population size and urban–rural status and assists them in planning public health interventions. Online resources allow users to visually explore health estimates geographically, compare estimates, and download data for further use and exploration.⁵

County Health Rankings & Roadmaps

The County Health Rankings and Roadmaps abbreviated (CHR&R; www.countyhealthrankings.org) is a program of the University of Wisconsin Population Health Institute.⁶ The CHR&R program provides data, evidence, guidance, and examples to build awareness of the multiple factors that influence health and support leaders in growing community power to improve health equity. The CHR&R are unique in their ability to measure the health of nearly every county in all 50 states, and are complemented by guidance, tools, and resources designed to accelerate community learning and action. CHR&R is known for effectively translating and communicating complex data and evidence-informed policy into accessible models, reports, and products that deepen the understanding of what makes communities healthy and inspires and supports improvement efforts.

City Health Dashboard

The City Health Dashboard (cityhealthdashboard.com) offers more than 40 measures of health and well-being for 900+ cities and towns across the United States.⁷ This data is not only for big cities, as the Dashboard includes all cities and towns with a population greater

than 50,000 and a growing set of towns with smaller populations. As a free health data resource that supports city leaders making these kinds of decisions, the literature provided ideas to help users use data to optimize this opportunity in a way that serves all residents, especially those who need it most (Ofrane, B., 2022).⁸ By providing accessible city-level data on health and its determinants, the City Health Dashboard complements local surveillance efforts and supports urban population health improvement on a national scale (Gourevitch, Marc N, M.D., M.P.H., et al, 2019).⁹

Methods

Project Overview

NADPH sought to apply its unique, human-centered qualitative and community engagement methodology to ascertain community leader, public health professional, and historically marginalized population values and perspectives regarding data democratization, human-centered design across the data life cycle, and equitable data governance for health equity. To accomplish this goal, NADPH worked with key project partners to engage diverse voices from communities across the country in a series of conversations. The project consisted of engagement with each DEC's local community leaders, public health professional collaborators, and historically marginalized population collaborators (three population segments) in a series of (1) one-to-one (1:1) community validation interviews, (2) focus groups, (3) community briefing of preliminary results. Across the five locations, we and our DEC partners engaged over 1,250 public health professionals, community leaders and members of groups who have been historically marginalized. We discuss our role within this entire process below.

Literature Review

A scoping literature search and review was conducted in June 2022 in PubMed and on a specific CDC webpage¹⁰ highlighting publications published at any time regarding equity limitations associated with BRFSS, PRAMS, PLACES, CHR&R, and the City Health Dashboard implementation in practice. Insights sought included but were not limited to survey and

data terminology, inclusivity, definitions, completion incentives, participant selection, question order, sensitivity and data aggregation, availability, and comparability.

1:1 Community Validation Interviews (CVIs) and Focus Groups

CVIs were conducted with community members from each population segment to discuss items within the BRFSS six-question 2014 Reactions to Race (R2R), the seven-question 2017 Social Determinants of Health (SDOH) optional modules (BRFSS 2014 and 2017), and the Phase 8 Core Questionnaire version of PRAMS.¹¹⁻¹² Publicly accessible web links were provided to interviewees in advance which allowed for time to review both the 2014 & 2017 BRFSS and PRAMS questionnaires and an opportunity to choose question sets from the core and other optional modules to be discussed during the one-hour CVI. CVIs importantly provided an opportunity for community members to become familiar with the modules and receive background information and historical context of the question sets therein. The overall purpose of the CVIs were to understand, based on community stakeholder perspectives, limitations to engaging in and completing BRFSS and/or PRAMS surveys. Specifically, the CVIs focused on and collected community stakeholder perspectives regarding survey item relevance and clarity, and overall survey instrument clarity, appropriateness, utility, and inclusivity. For this project, we aimed to engage up to 50 participants in 1:1, ~45-minute interviews, representing three sectors/groups: community leaders, public health departments, and historically marginalized subpopulations to determine feedback alignment and subalignment across groups.

CVI and Focus Group Guide Development

We co-developed, in partnership with the DECs, a single written CVI guide (see Appendix I) and three distinct focus groups guides (see Appendix II) tailored to each community/population segment's focus area and likelihood of experience or interaction with BRFSS, PRAMS, PLACES, CHR&R, and the City Health Dashboard. Specifically, initial CVI and focus group guides were drafted by the NADPH team and shared with the DECs and

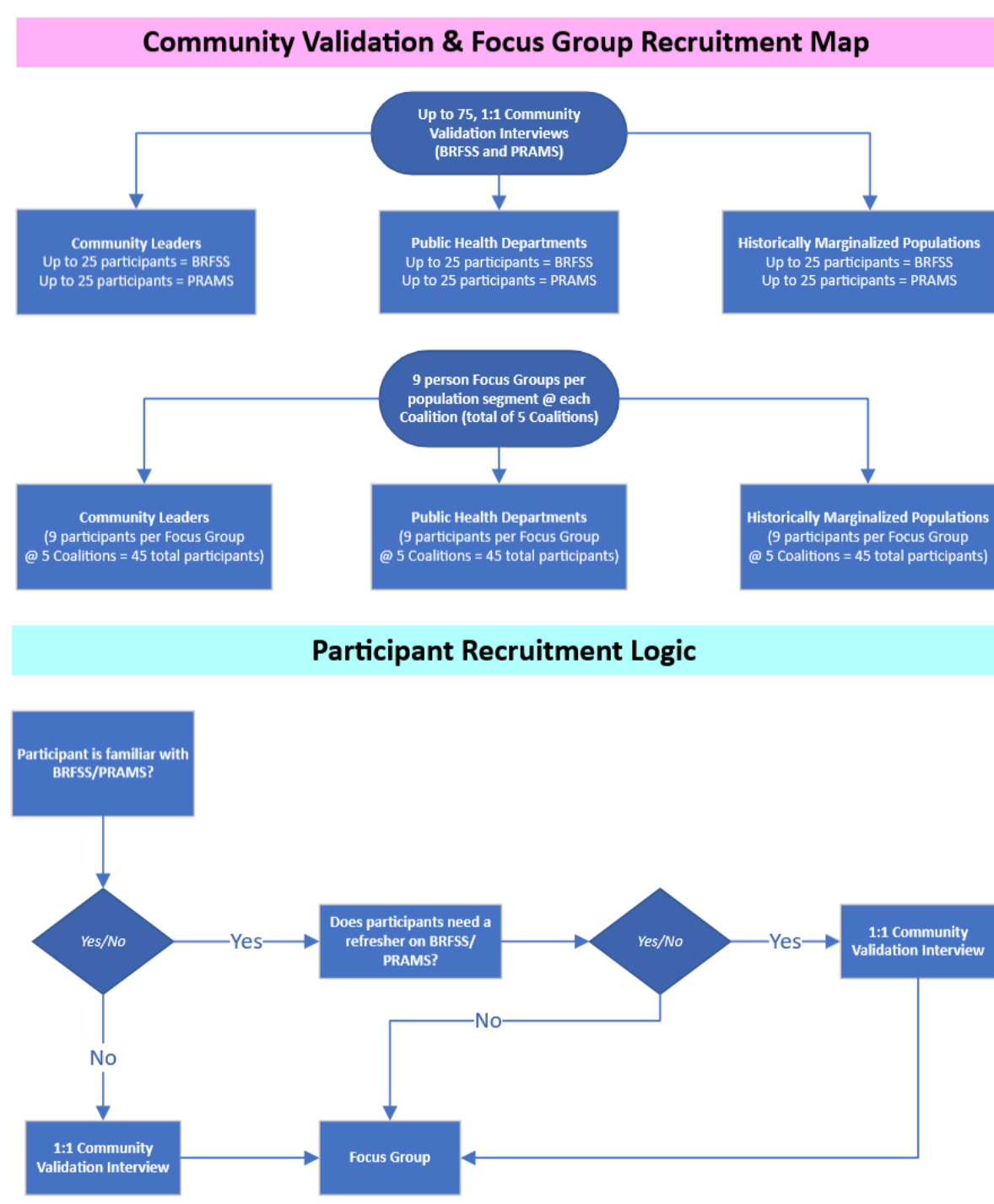
CDC Foundation for feedback and further iteration for refinement and finalization prior to commencing the CVIs and focus groups. CVI and focus group guides were intended to support semi-structured (versus rigid) conversations and engagement with each community/population segment to create a tone grounded in authenticity, trust, compassion, and thoughtfulness.

CVI and Focus Group Recruitment

NADPH coordinated with each DEC to engage each DEC's local community leaders, public health professional collaborators, and historically marginalized populations in CVI and focus group activities. Each DEC identified and assigned a person on their team to work and coordinate with NADPH around local language and translation needs/requirements to schedule and facilitate the CVIs and focus groups. Community members who were initially unfamiliar or familiar with BRFSS and/or PRAMS were invited to participate in CVIs to become either familiar or more familiar with questions asked within the survey(s) at their discretion. Figure 1 below provides a detailed illustration of our recruitment map and logic.

In cases where language translation service was needed for one or more community members engaged, the NADPH team held community validation interview training with each DEC to offer guidance on how to ask probing questions and collect qualitative feedback using NADPH's community validation interview guide and focus group guides. DEC members were welcome to participate in community validation interviews and focus groups in listening/non-participation mode only.

Figure 1. Community Validation & Focus Group Recruitment Map and Participant Recruitment Logic



Data Collection

CVIs were conducted virtually and focus groups were conducted either virtually, in-person, or hybrid (virtual/in-person). CVIs and focus groups were recorded and transcribed verbatim using an automated transcription software tool within Microsoft Teams.

Qualitative coding and analysis were conducted using NVivo Microsoft Excel software using inductive data coding methods. Quotes from transcripts were coded into both categorical and actionable themes and subthemes by a single lead coder using the grounded theory approach¹³, all of which were subsequently reviewed by a second and third analyst for discussion and to resolve any coding discrepancies. Preliminary codes were shared by us with the entire project team and a subset of CVI and focus group participants for community feedback to ensure alignment and understanding of results, followed by final coding and synthesis by the NADPH team. Quantitative information concerning participant demographics and responses to discrete interview questions regarding the utility and inclusivity of BRFSS and PRAMS were assessed using Microsoft Excel. A post-CVI demographic survey was distributed to CVI participants to collect aggregate details about participants' personas (community leader or representative, historically marginalized community member, public health department representative).

Ethics Statement

While our efforts herein were not intended as human subjects research, all participants verbally consented to participate in our interviews and focus groups. Participant responses were collected solely for the purpose of identifying common use cases for and quality improvement opportunities related to the BRFSS and PRAMS survey modules and the PLACES platform metrics and design.

Results

Literature Review

Our literature review revealed several insights and equity limitations associated with the implementation of BRFSS, PRAMS, PLACES, CHR&R and the City Health Dashboard. One study (Slabaugh et al.)¹⁴ identified equity limitations associated with BRFSS and three studies (Dinour et al.¹⁵, Almeida et al.¹⁶, and Christiansen-Lindquist et al.¹⁷) identified equity limitations associated with PRAMS. Two studies (Razzaghi et al.¹⁸ and Holt et al.¹⁹) identified equity limitations associated with the PLACES dataset and three studies (Remington et al.²⁰, Stiefel et al.²¹, and Anderson et al.²²) identified equity limitations associated with CHR&R. Lastly, two studies (Gourevitch et al.⁹ and Spoer et al.²³) identified equity limitations associated with the City Health Dashboard. We discuss these in detail below.

BRFSS

Slabaugh et al. recognized the need for enforcing the standardization of definitions of Health-Related Quality of Life (HRQOL-4, a core module of BRFSS 2014 and 2017), rural health, and community health.¹⁴ Specifically, they discussed how the Healthy Days set of questions assessing general health has not been validated among non-English speakers and thus syntax, diction, wording changes, and question order once translated for non-English speakers could affect responses. Authors recommended enforcing the standardization of the HRQOL-4 s, a 4-item set of questions, as non-English speakers can potentially respond differently to a translated HRQOL-4, especially the first question assessing general health, and wording changes and question order could affect responses.

PRAMS

Dinour et al. discussed how food insecure populations may not participate in national surveys like PRAMS due to high mobility and a possible lack of consistent phone coverage.¹⁵ They also noted that PRAMS does not precisely capture the spectrum of food insecurity; the survey inquires only about reduced food intake and anxiety about food budgeting or

supply. Ultimately, they discuss how PRAMS may neither sufficiently nor precisely capture the level of sensitivity needed to identify all women experiencing food insecurity.¹³

Almeida et al. suggests the inclusion of a robust measure of interpersonal racial discrimination on the PRAMS survey, a question to assess whether this factor accounts for racial/ethnic inequities in adverse birth outcomes which remain unexplained by maternal sociodemographic, behavioral and medical variables.¹⁶ Authors recommend at a minimum, making the current Standard question on discrimination a Core question asked by all participating states. Furthermore, authors recommended PRAMS include a validated scale of interpersonal racial discrimination in the core section of PRAMS.¹⁶ The purpose of including this as a standard question is to assess the frequency, duration, and intensity of exposure across the life span of racial discrimination in specific settings such as health care and employment.¹⁶

Lastly, Christiansen-Lindquist et al. described differential response rates by maternal race and ethnicity among non-Hispanic Black women who were less likely to respond to the PRAMS survey than non-Hispanic White women.¹⁷ This introduces bias if those who do not respond are fundamentally different from those who do. The authors noted a lack additional information about the women who did not respond and further indicate it is unknown whether the distribution of risk factors, such as stillbirth, differ from those who respond versus do not respond.¹⁷ Christiansen-Lindquist et al. also discussed recommendations to improve PRAMS response rates among non-Hispanic Black women who experienced a stillbirth and evaluate whether/how changes in survey incentives impact response rates for racial/ethnic minorities.¹⁷ Future studies on expanding the PRAMS questionnaire are necessary and more work should be done to include stillbirth, appropriate survey incentives, and evaluation as to whether response rates continue to differ by maternal race and ethnicity.¹⁷

PLACES

Razzaghi et al.¹⁸ and Holt et al.¹⁹ discussed limitations around the fact that BRFSS data are collected for civilian persons who are non-institutionalized, thus excluding, for example,

persons living within long-term health care facilities and/or incarcerated populations. For instance, Holt et al.¹⁹ discussed how the estimation for the number of people with chronic obstructive pulmonary disease (COPD) includes only non-institutionalized adults outside of nursing homes who may have urgent health needs related to treatment of their COPD. They recommended that further work be done to include these population segments to better serve both urgent and non-urgent population health needs among communities.

CHR&R

Both Remington et al. and Stiefel et al. discussed how data from the CHR&R data estimates have limitations due to data comparability across states and data aggregation across structures of local government, states, county-level, border counties, neighborhoods, suburbs, non/metropolitan use and other geographic areas. These state and jurisdictional level factors may influence estimates for both CHR&R Health Outcomes and Health Factors. To better understand the accurate use of health factors and measures (i.e. local health, violent crimes, high school graduation rates, chlamydia screening patterns, adult obesity, food environment index and physical activity indicators), it is important to first understand the data collection methods and models within these structures of local government and other sparsely populated areas. Recommendations from this study encourage users of the CHR&R study results to look to local sources of data to understand the health or their community. Furthermore, authors caution users about the use of county-level estimates within states and possible overestimation of differences in border counties.

Anderson et al. noted a well-published disagreement within the literature on what 'rural' means and how the term should be defined and measured.²² This disagreement in terminology for the "rural" creates problems for policymakers and the healthcare providing community. Authors suggest standardizing the definition and measurement of rurality is a difficult task. Moreover, it is likely impossible based on the variety of interests on how the term 'rural' should be used. Additionally, aside from not having a widely used standard definition of rural, authors note a limitation within the CHR&R.²⁰⁻²² It does not consider all possible factors that determine community health. For example, physical environment

includes multiple factors (air pollution, water quality, the built environment). Yet, it does not and possibly may not be inclusive of all the factors for a robust definition of the physical environment. Several limitations have been noted regarding the conceptual framework of health factors and resulting outcomes are open to critique. Caution must be used when making statements about CHR&R study results.

City Health Dashboard

Gourevitch et al. discussed the fact that tools like the City Health Dashboard cities do not address the equally critical needs of rural populations.⁹ They encouraged further work on addressing challenges around data sparsity to equally address the needs of rural populations, which could be especially critical for rural populations living near but outside of large metropolitan areas. Moreover, Spoer et al. discussed how SDOH factors captured within tools like the City Health Dashboard are often reflective of the total population of cities or neighborhoods versus racial subpopulations or minority groups.²³ If not properly weighted, estimates concerning the well-being of minoritized subpopulations within a given city or neighborhood could be overestimated and/or poorly generalized or contextualized.

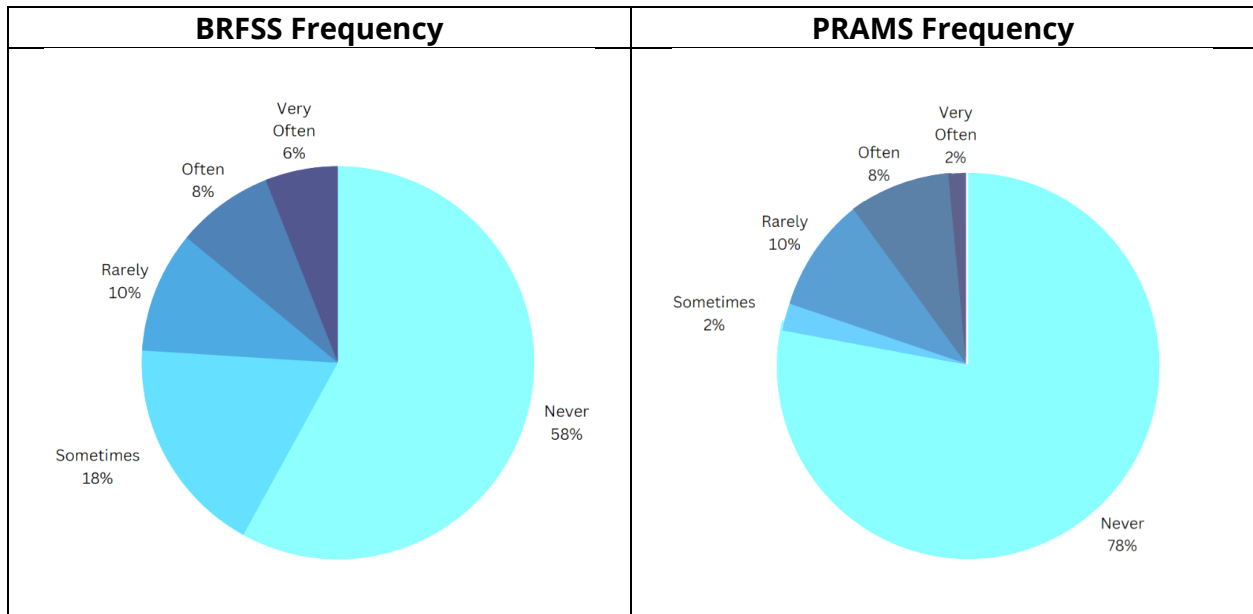
CVIs for BRFSS and PRAMS

A total of 50 individuals participated in CVIs and 48 individuals participated in the post-CVI demographic survey (see Appendix III). Among the 48 respondents, most (77%) self-identified as community leaders or representatives, historically marginalized community members (19%), and public health department representatives (40%). Most participants were over age 31 years (92%) and most had at least a masters level education (52%). Most participants identified as women (79%), were born female (83%), and identified as straight (i.e., not gay or lesbian, etc.; 85%). Most participants identified as Black, African American, African (56.3%), White or Caucasian (33%), or Hispanic, Latino, Spanish (17%), and born in the United States (90%).

CVI participants (n= 50) were asked to rate, on a scale from 1-10 with 10 being the highest rating and 1 being the lowest, their perceptions of BRFSS' and PRAMS' usefulness and

inclusiveness. BRFSS was rated as 8/10 for useful and 8/10 for inclusive, and PRAMS was rated 9/10 for useful and 8/10 for inclusive. CVI participants (n= 50) were also asked to indicate their usage frequencies for both BRFSS and PRAMS. Most CVI participants indicated that they have used neither BRFSS (58%) nor PRAMS (78%).

Figure 2. BRFSS and PRAMS Frequency Among CVI Participants



BRFSS – Reactions to Race and Social Determinants of Health

A total of 172 comments were received for the optional Reactions to Race module and 129 comments were received for the optional Social Determinants of Health Module. Six qualitative themes were identified based on comments received for survey items within Reactions to Race and seven themes were identified for survey items within Social Determinants of Health.

Reactions to Race

Figure 3 below illustrates the six qualitative themes identified based on CVI participant comments on the Reactions to Race optional module. Overall, CVI participants felt the module focused too heavily on race versus culture/ethnicity that bears more influence over how one’s origin/racial identity is perceived by others. For example, individuals within the Middle Eastern/North African community are often labeled as “White” yet their

culture/ethnicity is perceived by others as drastically different from that of the generalizable White population within the United States. Also, participants felt the response options within questions inquiring about the frequency at which one thinks about their race (never, once a year, once a month, etc.) were too granular and thus difficult to recall by memory. Response options that are general descriptors along a Likert scale (i.e., very frequent, frequent, etc.) would be relatable response options that might help avoid confusion or poor memory recall. CVI participants also felt the questions concerning race relations at work were one-dimensional and should better account for race relations with respect to 1) powerful system- (versus interpersonal) level issues that affect race relations in the workplace and 2) the diversity of work arrangements undertaken by members of the community (i.e., contract and/or part-time work versus full-time, benefitted employment) that affect their overall health maintenance and outcomes.

CVI participants also commented on racial dynamics within the health system, noting that race and racism affect broader dynamic processes within the health system that subsequently influence events within microcosmic health system encounters. Upon such encounters and other encounters where there may be racial motivation, there is a much broader range of physical symptoms and feelings that one might experience than what is presently listed or suggested in respective survey items. For instance, the survey suggests that one might experience “headache, an upset stomach, tensing of your muscles, or a pounding heart” as symptoms or “angry, sad, or frustrated” as feelings upon a racial or racism encounter. However, participants noted more precise feelings of confusion, puzzlement, and/or startlement, as well as feelings that could not be specifically placed, described, or categorized (i.e., feeling “some type of way”).

Figure 3. Qualitative Themes Based on CVI Participants Feedback for the Optional 'Reactions to Race' 2014 BRFSS Module

Affirm Culture/Ethnicity Not Race	<ul style="list-style-type: none"> • How do other people usually classify you in this country? Would you say: White, Black or African American, Hispanic or Latino, Asian, Native Hawaiian or Other Pacific Islander, American Indian or Alaska Native, or some other group?
Avoid Granular Response Options That Are Not Easily Recalled By Memory	<ul style="list-style-type: none"> • How often do you think about your race? Would you say never, once a year, once a month, once a week, once a day, once an hour, or constantly?
Race Relations In Work Settings Are Not One Dimensional	<ul style="list-style-type: none"> • Within the past 12 months at work, do you feel you were treated worse than, the same as, or better than people of other races?
Race Affects The Dynamic Process of Healthcare	<ul style="list-style-type: none"> • Within the past 12 months, when seeking health care, do you feel your experiences were worse than, the same as, or better than for people of other races?
Expand The Range of <u>Symptoms</u> One Might Experience Based On Reactions To Their Race	<ul style="list-style-type: none"> • Within the past 30 days, have you experienced any physical symptoms, for example, a headache, an upset stomach, tensing of your muscles, or a pounding heart, as a result of how you were treated based on your race?
Expand The Range of <u>Feelings</u> One Might Experience Based On Reactions To Their Race	<ul style="list-style-type: none"> • Within the past 30 days, have you felt emotionally upset, for example angry, sad, or frustrated, as a result of how you were treated based on your race?

Social Determinants of Health

Figure 4 below illustrates the six qualitative themes identified based on CVI participant comments on the Social Determinants of Health module. CVI participants expressed, in reaction to questions concerning housing stability, that “loaded” questions (i.e. questions that have built in assumptions about communities or their experiences) regarding housing status should be avoided. For example, questions concerning payment for mortgage, rent, or utility bills, and movement from one “home” to another, appear to dismiss the fact that one’s housing circumstances may comprise of: 1) arrangements outside of traditional mortgage, rent, or utility bills (i.e., ability to live with a caretaker), and/or 2) living within a shelter or other setting that one may not consider as a traditional “home.” CVI participants also felt that questions should focus more on matters and access to resources that

contribute to financial stability versus mainly on personal finance management. Additionally, participants felt that jargon should be avoided in both questions and response options (i.e., making “ends meet” and/or how finances “work out”).

Moreover, CVI participants felt that questions concerning environmental versus situational safety should be avoided. For instance, the question inquiring about safety from crime within one’s neighborhood assumes that crime may only occur within one’s neighborhood (versus also in one’s home within a neighborhood that might be considered as generally safe from crime). CVI participants also felt that questions inquiring about how frequently one feels stressed should be rephrased to focus on whether one might encounter determinants of stress or face local factors that generally cause or contribute to stress. CVI participants also felt that survey questions and response options should also focus more on food supply sustainability versus food affordability, as affordability does not equate to sustainability (i.e., instances where free food supply programs are not a sustainable option or opportunity for the community). In addition, CVI participants felt that questions inquiring about one’s ability to afford to eat a “balanced meal” should instead focus on access to an affordable, healthy, and nutritious meal, as the notion of a “balanced” meal can be subjective depending on one’s culture, lifestyle, medical status, etc.

Figure 4. Qualitative Themes Based on CVI Participants Feedback for the Optional 'Social Determinants of Health' 2017 BRFSS Module

<p>Avoid Loaded Questions about Housing Stability</p>	<ul style="list-style-type: none"> • <i>During the last 12 months, was there a time when you were not able to pay your mortgage, rent or utility bills?</i> • <i>In the last 12 months, how many times have you moved from one home to another?</i>
<p>Avoid Loaded and Subjective Questions and Answer Options That Infer Environmental Versus Situational Safety</p>	<ul style="list-style-type: none"> • <i>How safe from crime do you consider your neighborhood to be?</i>
<p>Question Should Be More Specific to Sustainable Food Supply, Regardless of Financial Costs for Food</p>	<ul style="list-style-type: none"> • <i>"The food that I bought just didn't last, and I didn't have money to get more." Was that often, sometimes, or never true for you in the last 12 months?</i>
<p>Change A Balanced Meal to An Affordable, Healthy and Nutritious Meal</p>	<ul style="list-style-type: none"> • <i>I couldn't afford to eat balanced meals." Was that often, sometimes, or never true for you in the last 12 months?</i>
<p>Avoid Jargon (i.e., "Ends Meet") and Focus on Matters and Resources That Contribute to Financial Stability</p>	<ul style="list-style-type: none"> • <i>In general, how do your finances usually work out at the end of the month?</i>
<p>Focus on Determinants or Local Factors Contributing to Stress (i.e., Financial, Environmental, etc.) Versus Frequency of Stress</p>	<ul style="list-style-type: none"> • <i>Stress means a situation in which a person feels tense, restless, nervous, or anxious, or is unable to sleep at night because his/her mind is troubled all the time. Within the last 30 days, how often have you felt this kind of stress?</i>

PRAMS

CVI participants were provided an opportunity to comment on survey items focused on the following descriptive categories: pre-conception care (items 1-8), Medicaid and WIC program participation (item 9), health insurance coverage (item 10-11), content of prenatal care (items 12-18), cigarette smoking and alcohol use (items 19-27), physical abuse (items 28-29), attitudes and feelings about the most recent pregnancy (items 30-33), breastfeeding (items 34-37), infant health care (items 38-42, 48-49), contraceptive use (items 43-47), and demographics (items 50-52). CVI participants either reviewed, provided general comments, or provided explicit feedback on pre-conception care (n= 9), Medicaid and WIC program participation (n= 4), health insurance coverage (n= 5), content of prenatal care (n= 12),

cigarette smoking and alcohol use (n= 4), physical abuse (n= 5), attitudes and feelings about the most recent pregnancy (n= 6), breastfeeding (n= 8), infant health care (n= 9), contraceptive use (n= 7), and demographics (n= 2). Explicit CVI participant feedback is summarized in Table 1 below.

Table 1. CVI Participant Feedback on PRAMS Phase 8 Core Mail Questionnaire Items

PRAMS Phase 8 Core Mail Questionnaire	
Descriptive Category of Survey Items	CVI Participant Feedback
Pre-conception care (items 1-8)	<ul style="list-style-type: none"> • Use terms that are simple to understand to accommodate individuals with low health literacy. • Describe “healthy weight” and consider adding response choices for health conditions (e.g., diabetes) that are tied to weight. • Consider those that know neither their height nor weight based on no recent medical visit or inability to recall. • Include an option for "Unsure" or "Don't Know" to further understand those with depression. • Add to response options community health worker, doula, midwife and non-traditional support as an option. • Define “regular” for those who are unknowledgeable of screening recommendations. • Include urgent care as a response option.
Medicaid and WIC program participation (item 9)	<ul style="list-style-type: none"> • Consider placing the response item "I don't have any health insurance for my prenatal care" last versus first. • Avoid assumptions that the respondent is a woman; consider using person of child-bearing age, a person or families birthing, birthing people/person. • Remove “husband” and simply list partner. • Consider wanted versus unwanted pregnancy.
Health insurance coverage (item 10-11)	<ul style="list-style-type: none"> • Consider adding response options for persons who lack health insurance in the first

PRAMS Phase 8 Core Mail Questionnaire	
Descriptive Category of Survey Items	CVI Participant Feedback
	trimester but become insured in the second or third trimester.
Content of prenatal care (items 12-18)	<ul style="list-style-type: none"> • Add questions about measles, mumps and rubella as well as COVID-19. • Consider the term 'human milk feeding' versus breastfeeding to avoid stigma for and accommodate persons who are unable to breastfeed. • Add vaping as a response option to smoking. • Reorder the options of the response choices so they start off as positive. • Replace the word "wanted" and reconsider questions that can be triggering for those who intentionally sought to become pregnant. • Where depression is mentioned, consider using words that are or allude to anxiety, such as "underappreciated" or "overwhelmed."
Cigarette smoking and alcohol use (items 19-27)	<ul style="list-style-type: none"> • Add follow up questions on marijuana use, e-cigarettes, hookah, and other forms of substance inhalation. • Consider inquiring about socioeconomic or personal reasons for not or stopping breastfeeding (i.e., returning to a workplace with low access to childcare, clean/safe breastfeeding or milk pumping facilities, cost of breastfeeding, lactation consultant accessibility, etc.).
Physical abuse (items 28-29)	<ul style="list-style-type: none"> • Include questions about emotional and/or financial abuse. • Consider how legal issues concerning physical abuse might affect responses. • Be mindful of asking questions that can be triggering for respondents.
Attitudes and feelings about the most recent pregnancy (items 30-33)	<ul style="list-style-type: none"> • Where applicable, add over a month as an option. • Provide therapy resources to support respondents who answer emotionally triggering questions.

PRAMS Phase 8 Core Mail Questionnaire	
Descriptive Category of Survey Items	CVI Participant Feedback
	<ul style="list-style-type: none"> • Rephrase potentially triggering questions about pregnancy outcomes to be sensitive to a persons who might have experienced pregnancy or child loss. • Consider asking with whom the baby presently lives and offer a subsequent list of response choices for intimate partner, adoption agency, or another person.
Breastfeeding (items 34-37)	<ul style="list-style-type: none"> • Consider adding a question(s) on family planning/contraception. • Inquire about and delineate between breastfeeding, lactation/pumping, and human milk feeding. • Include a response option on mechanism for receiving information about breastfeeding and/or human milk feeding (e.g., social media, etc.).
Infant health care (items 38-42, 48-49)	<ul style="list-style-type: none"> • Consider offering information on safe sleep practices and information. • Ask how often does baby sleep alone and about co-sleeping. • Add a section on feeling respected by provider at prenatal care visits. • Consider revising questions, where applicable, to account for the possibility of twins or about a particular baby/birth. • Inquire about a follow-up question about, and how respondents receive information about safe baby sleep (i.e., sudden infant death, how the baby sleeps, sleep frequency). • When inquiring about how baby sleeps, include "other" as a response option (i.e., dresser, box, container, etc.).
Contraceptive use (items 43-47)	<ul style="list-style-type: none"> • Inquire about where respondents get information on family planning/contraception. • Inquire about whether respondent and/or partner are trying to get pregnant and reasons why. • Replace "husband" with "partner."

PRAMS Phase 8 Core Mail Questionnaire	
Descriptive Category of Survey Items	CVI Participant Feedback
	<ul style="list-style-type: none"> • Add “no contraceptive needed” for non-birthing people . • Ask more questions focused on the intersection of contraception and social determinants of health.
Demographics (items 50-52)	<ul style="list-style-type: none"> • Inquire about concerns about body mass index. • Include "midwife" as a response option, where applicable.

Focus Groups

A total of 15 focus groups were conducted with groups of individuals across the three community/population segments and DEC: six conducted in English (n= 4) and Spanish (n= 2) with members identifying with historically marginalized communities; five with members identifying as community leaders; and four identifying as public health leaders. A total of 27 individuals who participated in a CVI subsequently participated in a focus group.

Table 2. Quantity of Focus Groups and Qualitative Themes per Community/Population Segment

Community/Population Segment	# of Focus Groups
Historically Marginalized Communities (English and Spanish languages)	6
Community Leaders	5
Public Health Leaders	4
<i>Total</i>	15

Qualitative coding analysis of focus group transcripts and detailed notes was conducted until thematic saturation and enrichment were reached in identifying overarching themes, actionable subthemes, and illuminating quotes. Illuminating quotes along each actionable subtheme per community/population segment are provided in Appendix III. We present each overarching theme and quantify and describe their respective actionable subthemes below.

Historically Marginalized Communities

Among key comments received by individuals identifying as historically marginalized community members during focus groups conducted in partnership with all five DEC's (n= 115), overarching themes identified were community data collection through collaboration and dedication to action (53.9%); data translation and relation (14.8%); system versus personal control (9.6%); context and disaggregation (8.7%); and confusion, skepticism, and intent (13.1%). Actionable subthemes within each overarching theme are provided in Table 3.

Table 3. Summary of Overarching Themes and Actionable Subthemes Based on Historically Marginalized Community Member Perspectives

Overarching Theme	Actionable Subtheme	Frequency (%)
Community Data Collection Through Collaboration and Dedication to Action	Data collection must be followed by dedication and action to address expressed, changing, or implied community needs reflected in the data collected.	22 (19.1)
	Data collectors and collaborators should be well-supported and invested, engaging, and trustworthy members of the community with compassionate values, ambition, and expectations.	20 (17.4)
	Consider community as those who protect the well-being and sustainability of a group with a shared identity or situation (versus only themselves or group affiliations).	20 (17.4)
Data Translation and Relation	Information and data collection tools should contain terms that are accessible and understandable to communities and to help communities translate and relate to the data.	17 (14.8)
System versus Personal Control	Data should reflect what SDOH factors are within (versus outside of) historically marginalized communities' immediate control.	11 (9.6)
Context and Disaggregation	Aggregated or pooled data requires context and or disaggregation to avoid generalized assumptions that obscure subpopulation needs, risks, and outcomes.	10 (8.7)

Overarching Theme	Actionable Subtheme	Frequency (%)
Confusion, Skepticism, and Intent	Address any lack of clarity around why community data is collected and how it is used to serve a purpose.	8 (7.0)
	Address skepticism about robust survey data collection efforts that enrich data collectors but not communities.	7 (6.1)
<i>Total</i>		115 (100)

Community Leaders

Among key comments received by individuals identifying as community leaders during focus groups conducted in partnership with all five DECs (n= 104), overarching themes identified were community data collection through collaboration and dedication to action (52.7%); system versus personal control (26.0%); local data accuracy and reflection (5.7%); context and disaggregation (5.7%); confusion, skepticism, and intent (5.7%); and timely data for timely action (3.8%). Actionable subthemes within each overarching theme are provided in Table 4.

Table 4. Summary of Overarching Themes and Actionable Subthemes Based on Community Leader Perspectives

Overarching Theme	Actionable Subtheme	Frequency (%)
System versus Personal Control	Data should reflect lived experiences to better understand what SDOH factors are within (versus outside of) historically marginalized communities' power or immediate control.	27 (26.0)
Community Data Collection Through Collaboration and Dedication to Action	Using and sharing local-level data and data disaggregation are necessary to draw local comparisons, pursue and receive funding, and address service and equity gaps through strategic alignment across geographies.	19 (18.2)
	Build community awareness and training about democratized data resources through regular and frequent updates to support local community understanding, connectedness, and collaboration efforts.	19 (18.2)
	Qualitative and quantitative data and robust methodologies are necessary to measure equity, determine if community efforts are	10 (9.6)

Overarching Theme	Actionable Subtheme	Frequency (%)
	equitable, and measure and monitor community wide impact against funding and SDOH policy.	
	Data collection must be followed by dedication and action to address community needs and describe community resilience reflected in the data collected.	7 (6.7)
Local Data Accuracy and Reflection	Uphold trust that PLACES and other local data sharing platforms are accurate and reflective of local communities.	6 (5.7)
Context and Disaggregation	Aggregated or pooled data requires context and or disaggregation to avoid generalized assumptions that obscure smaller population needs and risks.	6 (5.7)
Confusion, Skepticism, and Intent	Address skepticism about robust survey data collection efforts that enrich data collectors but not communities.	6 (5.7)
Timely Data for Timely Action	Address how untimely data serves as barrier to understanding and addressing community needs in a timely fashion.	4 (3.8)
	<i>Total</i>	104 (100)

Public Health Leaders

Among key comments received by individuals identifying as community leaders during focus groups conducted in partnership with all five DEC's (n= 104), overarching themes identified were community data collection through collaboration and dedication to action (33%); local data accuracy and reflection (26.6%); methods to enhance small area estimates (19.1%); data utility and engagement (10.6%); social and demographic context (10.6%). Actionable subthemes within each overarching theme are provided in Table 5.

Table 5. Summary of Overarching Themes and Actionable Subthemes Based on Public Health Leader Perspectives

Overarching Theme	Actionable Subtheme	Frequency (%)
Methods to Enhance Small Area Estimates	Specific methodologies, which can be costly or cumbersome to implement, for quantitative and qualitative data source selection and analysis are or can be used to construct or measure lived experiences with SDOH within smaller area estimates.	18 (19.1)
Community Data Collection Through Collaboration and Dedication to Action	Support present or planned utility and alignment in leveraging PLACES and other local data sharing platforms to support data-informed initiatives with community partners targeting health disparities in specific communities.	17 (18.1)
	PLACES and other local data sharing platforms can be useful to identify and reach populations in need of specific services or education related to SDOH in an unbiased and timely manner to help stabilize their engagement.	14 (14.9)
Local Data Accuracy and Reflection	PLACES and other local data sharing platforms are trusted resources to efficiently obtain small area estimates and census tract level data.	13 (13.8)
	PLACES and other local data sharing platforms can be used as a starting point to further analyses and optimized to address reporting bias, address data limitations, and better compare demographic groups across counties and use case scenarios.	12 (12.8)
Data Utility and Engagement	Support PLACES as an interactive, accessible, and visually engaging dataset for all users.	10 (10.6)
Social and Demographic Context	PLACES should include racial and sex-gender demographics and related discrimination experience data to help contextualize local racism as a SDOH.	10 (10.6)
<i>Total</i>		94 (100)

Discussion

The present work is one of few, if not the first, to recently (post-COVID-19) engage individuals who identify as members of historically marginalized populations, community leaders, and/or public health department leaders in sharing perspectives on national public health surveillance processes. We have scoped equity limitations reported in the literature by researchers to date and garnered related perspectives from persons with personal and/or professional lived experience in inequity concerning further opportunities to embed equity across national public health surveillance processes.

Alignment Among CVIs and the Literature

Our CVI findings show several areas of alignment among researchers and CVI participants with question, or lack thereof, of questions concerning food insecurity being one of them. For example, CVI participants noted that the BRFSS question seeking reactions to the statement “the food that I bought just didn’t last, and I didn’t have money to get more” was either confusing or unclear. Specifically, participants were unsure whether the question indicates that food was of poor quality or highly perishable, there wasn’t enough money to buy a sustainable food supply, or both. This finding should be taken into consideration with that of Dinour et al. recommending more precise and targeted questions about food insecurity in PRAMS.¹⁵

Moreover, CVI participants expressed concern about the BRFSS Reactions to Race module not having distinct categories for race that are more culturally and biologically focused. Specifically, and for example, Middle Eastern North African (MENA) communities hold significant concerns about being seemingly forced to classify themselves as White within the survey when they often do not identify with the dominant White culture in which they live or reside. This aligns with Spoer et al. regarding the challenge of capturing data that is reflective of the total population of cities or neighborhoods versus racial subpopulations or minority groups.²³ Failure to address this concern will result in either inaccurate reporting

and/or populations estimates that misrepresent communities within a single geographic area.

According to the literature, state and jurisdictional level factors may influence estimates for health outcomes and factors.²⁰⁻²² Similarly, participants who identified as public health leaders expressed concern and an interest in understanding the methodologies for data source selection and analysis to construct or measure disparities within smaller area estimates.

Alignment Across Focus Groups

We have described overarching themes and actionable subthemes based on our assessment of the literature and qualitative feedback from CVIs and focus groups with historically marginalized populations, community leaders, public health department leaders who identify as persons with lived experience, either personal or professional, in inequity. Our focus groups identified several areas of alignment across two or more community/population segments (summarized in Table 6) which may serve as starting points to continuously guide policymaking and programming centered on advancing equity by embedding persons with lived experience in inequity throughout largescale public health data systems and dissemination platforms, including but not limited to BRFSS, PRAMS, PLACES, CHR&R and the City Health Dashboard. Importantly, programmatic funding and incentives should be created, sustained, and/or prioritized along these areas of alignment to ensure that institutions receiving support are held accountable to the goals, best interests, and wellbeing of local communities in which those institutions are embedded.

Table 6. Areas of alignment among historically marginalized populations, community leaders, and public health department leaders to advance equity in the data lifecycle

Community Data Collection Through Collaboration and Dedication to Action
Data collection must be followed by dedication and action to address expressed, changing, or implied community needs reflected in the data collected.
Data collectors and collaborators should be well-supported and invested, engaging, and trustworthy members of the community with compassionate values, ambition, and expectations.
Consider community as those who protect the well-being and sustainability of a group with a shared identity or situation (versus only themselves or group affiliations).
Support present or planned utility and alignment in leveraging PLACES and other local data sharing platforms to support data-informed initiatives with community partners targeting health disparities in specific communities.
PLACES and other local data sharing platforms can be useful to identify and reach populations in need of specific services or education related to SDOH in an unbiased and timely manner to help stabilize their engagement.
Qualitative and quantitative data and robust methodologies are necessary to measure equity, determine if community efforts are equitable, and measure and monitor community wide impact against funding and SDOH policy.
Data collection must be followed by dedication and action to address community needs and describe community resilience reflected in the data collected.
Support present or planned utility and alignment in leveraging PLACES and other local data sharing platforms to support data-informed initiatives with community partners targeting health disparities in specific communities.
PLACES and other local data sharing platforms can be useful to identify and reach populations in need of specific services or education related to SDOH in an unbiased and timely manner to help stabilize their engagement.
Context and Disaggregation
Aggregated or pooled data requires context and or disaggregation to avoid generalized assumptions that obscure <u>subpopulation</u> needs, risks, and outcomes.
Aggregated or pooled data requires context and or disaggregation to avoid generalized assumptions that obscure <u>smaller population</u> needs and risks.
System versus Personal Control
Data should reflect what SDOH factors are within (versus outside of) historically marginalized communities' immediate control.
Data should reflect lived experiences to better understand what SDOH factors are within (versus outside of) historically marginalized communities' power or immediate control.
Confusion, Skepticism, and Intent
Address any lack of clarity around why community data is collected and how it is used to serve a purpose.

Community Data Collection Through Collaboration and Dedication to Action

Address skepticism about robust survey data collection efforts that enrich data collectors but not communities.

Conclusion

The Improving Engagement in Community Level Data Collection project held a unique and collaborative mission and goal to understand current uses and limitations to enhance BRFSS, PRAMS, PLACES, CHR&R, and the City Health Dashboard based on community and public health practitioner perspectives. This involved intentional and authentic collaboration with three distinct groups of community members (historically marginalized populations, community leaders, public health department leaders) to understand potentially converging and/or diverging perspectives about and recommendations for these data resources. This project uncovered a need for community validation in addition to cognitive testing efforts that seek to pretest core and optional modules on the BRFSS and other national instruments. Community validation methodologies will contextualize datasets (that should include social determinants of health) and improve the ability to compare demographic groups across counties and zip codes utilizing use case scenarios to depict the cultural differences. According to the CDC²⁴ scientific research dating back to the 1980's clearly showed that personal health behaviors played a major role in premature morbidity and mortality. This deficiency was viewed as a critical obstacle to state health agencies trying to target resources to reduce behavioral risks and their consequent illnesses. To meaningfully continue this work to understand community perspectives on public health data systems and to respond to community feedback, it will be important to have ongoing and sustained opportunities to share our qualitative findings with the hopes of informing national, state, and local public health policy efforts that seek to further embed equity in largescale surveillance systems and data sharing platforms based on perspectives of persons with personal and/or professional lived experiences in inequity. Consultative, trauma-informed methodologies between researchers, data intermediaries and communities that gives more than it extracts is paramount to optimizing the data lifecycle to benefit all communities.

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Appendix I – CVI Guide

Survey Validation Interview Guide

Agenda:

- *Introductions from Project Team*
- *Ask for Permission to Record*
- *Request Introduction from Interviewee*
- *Would you prefer to review the BRFSS and/or PRAMS survey(s) in English or Spanish?*
- *Considering all of the BRFSS and PRAMS modules, which topics do you feel concern you or work the most?*
 - *If any, mention prepared list of topics from participant spreadsheet*
- *Are there any other specific sections or modules that you would like to review with us to provide you perspectives on or reactions to the survey questions?*
- *Would you say there are important questions missing in the survey modules/sections we covered today?*
- *Would you like to share any experiences that relate to the survey questions we have discussed?*
- *Based on those experiences, what are your natural reactions to the survey questions within this module/section?*

Facilitator Note: Unpack survey. Dissatisfied / Satisfied, Survey Shortcoming or Recommendations / Affirmations, Ambiguity in questions as written.

Asking enough questions, Survey Length, survey data, data shortcomings and other concerns...

- *Would you say the response choices to those questions are sufficient?*
- *Given your experience with BRFSS, what feedback do you have concerning the **Reactions to Race module?***
- *Given your experience with BRFSS, what feedback do you have concerning the **Social Determinants of Health module?***
- ***PRAMS** – On a scale of 1 to 10, how would you rate the survey?: useful / inclusive*
- ***PRAMS** – How often do you use? never, rarely, sometimes, often or very often*
- ***BRFSS** - On a scale of 1 to 10, how would you rate the survey?: useful / inclusive*
- ***BRFSS** – How often do you use? never, rarely, sometimes, often or very often*
- ***How would you describe PRAMS / BRFSS in three words?***
- ***ASK TO PUBLIC HEALTH / COMMUNITY LEADER ONLY** - If you had a magic wand and could change anything about (your work), what would that be?*
- *Closeout / Next Steps*

Appendix II – Focus Group Guides

Instrument Title: Discussion Guide: Focus Group I: Community Leaders

Total Participant time required: 1 hour + 10 minutes – 1 hour + 50 minutes

Total focus group time: 1 hour + 10 minutes – 1 hour + 50 minutes

Break: 0 minutes

OVERALL QUESTION TO ANSWER IN FOCUS GROUP DISCUSSIONS:

The purpose of the focus group with community leaders is to accomplish the following:

- a) Understanding community leaders' familiarity and use of BRFS, PRAMS, and PLACES as well as other sources of data like County Health Rankings and City Health Dashboard.
- b) Identifying the most relevant uses of PLACES data to their constituents in decision-making. Focus groups would use human-centered design principles to consider what additional guidance, facilitation efforts, training and technical assistance would need to be developed to increase community level utility of PLACES data.
- c) Identifying community-level data needs related to SDOH, racism and other relevant data sources that would be useful to their constituents in decision-making.
- d) Identifying and documenting effective, real-world examples of BRFS, PRAMS and PLACES data use cases / end user experiences by localities for decision-making, program planning and implementation.
- e) Hearing from the community what enhancements to PLACES would increase the utility of the platform, and what data are necessary for them to address SDOH in their communities that they currently don't have access to.

Below is a general guide for leading our focus groups. We may modify this guide as needed as each focus group will inform the subsequent groups.

Before the group begins, conduct the informed consent process, including compensation discussion.

I. Introduction (10 m)

- Welcome participants and introduce yourself.

-
- Explain the general purpose of the discussion and why the participants were chosen.
 - Discuss the purpose and process of focus groups.
 - Explain the presence and purpose of recording equipment and introduce observers.
 - Outline general ground rules and discussion guidelines such as the importance of everyone speaking up, talking one at a time, and being prepared for the moderator to interrupt to assure that all the topics can be covered.
 - Review break schedule and where the restrooms are. (In-person focus groups only.)
 - Address the issue of confidentiality.
 - Inform the group that information discussed is going to be analyzed as a whole and that participants' names will not be used in any analysis of the discussion.
 - Read a protocol summary to the participants.

Discussion Guidelines:

We would like the discussion to be informal, so there's no need to wait for us to call on you to respond. In fact, we encourage you to respond directly to the comments other people make. If you don't understand a question, please let us know. We are here to ask questions, listen, and make sure everyone has a chance to share.

If we seem to be stuck on a topic, we may interrupt you and if you aren't saying much, we may call on you directly. If we do this, please don't feel bad about it; it's just our way of making sure we obtain everyone's perspective and opinion is included.

We do ask that we all keep each other's identities, participation and remarks private. We hope you'll feel free to speak openly and honestly.

As discussed, we will be tape recording the discussion, because we don't want to miss any of your comments. No one outside of this room will have access to these tapes and they will be destroyed after our report is written.

(If assistants present) Helping are my assistants ____ and _____. They will be taking notes (and/or translating my questions) and are here to assist me if I need any help.

Let's begin. Let's find out some more about each other by going around the room one at a time. Tell us your first name, about the work you do in your community, and the communities you serve. I'll start.

II. Topic Generation (50-90 minutes)

The focus group facilitator will explain:

We are interested in identifying use cases and/or end user experiences among localities in using BRFSS, PRAMS, and/or PLACES and other related resources like County Health Rankings and City Health Dashboard for local-level decision-making, program planning and implementation.

This group is convened today with the goal to understand or learn:

- Your familiarity with and use of BRFSS, PRAMS, and/or PLACES as well as other sources of data like County Health Rankings and City Health Dashboard.
- Your most relevant uses of BRFSS, PRAMS, and/or PLACES data to support your or your constituents' decision-making.
- Data and data resource needs you and/or your communities might use or need (e.g., additional guidance, training, technical assistance, etc.) to identify strategies and facilitate decision-making around improving local health equity.
- Your potential experience(s) with using BRFSS, PRAMS, and/or PLACES data and/or other resources (i.e., County Health Rankings and City Health Dashboard) to support communities' or community-level decision-making, program planning and implementation.
- Your ideas or suggestions around enhancements to BRFSS, PRAMS, and/or PLACES as well as other sources of data that could increase their local-level utility to address health equity in your communities.

Let's get started!

- The initial question about familiarity with PLACES data:

Ø Today we are here to talk about PLACES data. We also want to consider as well as other sources of data like County Health Rankings and City Health Dashboard. What comes to mind when you think about these data sources?

- Next question related to experience using PLACES data:

Ø Thank you for sharing your thoughts. How might you have used PLACES data to support your or your constituents' decision-making?

- Next question related to community needs to better understand or use PLACES.

1. Take a topic that was just brought up and prompt the group for more information:

Ø Now, I want to discuss if or how you and your communities' might wish to better understand ways to use PLACES data. This could include but not be limited to additional guidance, training, technical assistance, etc. I will pause there and open this discussion.

· Next question related to community-level data needs related to SDOH, racism and other relevant data sources.

Ø Now, I want to discuss and learn more about your data needs with respect to SDOH, racism and other relevant data. What would be useful in this regard to support you and your communities' and/or community-level decision-making?

· Next question related to real-world examples around PLACES data use. If useful, bring up a subject or examples that members or the focus groups have already shared.

Ø Next, can you share examples/more about your own experience(s) in using or attempting to use PLACES data to support your communities' or community-level decision-making, program planning and implementation?

(NOTE: The goal is for the participants' experience to lead the way, therefore eliciting the most authentic data possible.)

· Next question related participants' ideas or suggestions to enhance current PLACES data to address SDOH.

Ø Thank you for your engagement thus far. We reached the final question/topic, which is to learn your ideas or suggestions to enhance current PLACES data, particularly to address specific SDOH in your communities. In your opinions and based on your experiences, what might you suggest?

The following is a guideline for topic generation. The actual process may vary according to each group's progress and the experience of previous groups. The list below is a menu of items, along with references, that explores data limitations presented and discussed in the literature regarding PLACES, County Health Rankings, and City Health Dashboard.

Remember: We will not address every issue with every group and we may address issues not on this list as they arise.

Issues for focus group exploration:

I. PLACES: Population Outreach and Engagement Limitations

- Observation or perception that data excludes vulnerable populations (e.g., institutionalized or and incarcerated populations) and therefore cannot be generalized to those groups.

- Perception that certain vulnerable populations must be accounted for by other means in planning for urgent public health events.

References

Example #1:

"BRFSS data are collected for noninstitutionalized civilian persons and exclude populations that might be particularly vulnerable to severe COVID-19 illness, including

those living in long-term care facilities and incarcerated populations, and might therefore not be representative for those groups."

Citation: Razzaghi H, Wang Y, Lu H, et al. Estimated County-Level Prevalence of Selected Underlying Medical Conditions Associated with Increased Risk for Severe COVID-19 Illness — United States, 2018. *MMWR Morb Mortal Wkly Rep* 2020;69:945–950. DOI: <http://dx.doi.org/10.15585/mmwr.mm6929a1>

Example #2:

"the estimates of the number of people with COPD here refers to noninstitutionalized adults who may have urgent needs related to treatment of their COPD. These estimates do not include those in nursing homes, for example, who must be accounted for by other means in planning for urgent events."

Citation: Holt JB, Matthews KA, Lu H, Wang Y, LeClercq JM, Greenlund KJ, Thomas CW. Small Area Estimates of Populations With Chronic Conditions for Community Preparedness for Public Health Emergencies. *Am J Public Health*. 2019 Sep;109(S4):S325-S331. doi: 10.2105/AJPH.2019.305241. PMID: 31505141; PMCID: PMC6737821.

II. County Health Rankings: Local Data Collection Norms, Standardization, Localization, Aggregation, and Combination

- Perception that data should be used as a starting point verses end point given local-level effects around data collection practices, patterns, and norms; data interpretation; and data uses that may partially or fully account for observed or measured differences.

- Perception that data comparability or aggregation/combination across states introduce limitations with respect to state- and jurisdiction-level factors that may influence final data estimates.

· Perception or observation that combining data from low-income neighborhoods with wealthier areas within the same metropolitan county masks health disparities.

· Perception that standardizing data definitions and measurements is a difficult task and likely impossible given the variety of interests on how the terms should be used.

References

Example #1:

"... data from the Rankings should be used as a starting point, not an end point, and we encourage users to look to local sources of data to understand more about the health of their community. For example, in New England counties do not necessarily reflect the structure of local government. In large urban counties such as Los Angeles County, county-level statistics may not be especially useful, whereas in sparsely populated areas, counties are too small as units of analysis since many services are delivered by groups of counties. Finally, combining data from low-income urban neighborhoods with wealthier suburbs in the same metropolitan county masks these health disparities."

Citation: Remington, P. L., Catlin, B. B., & Gennuso, K. P. (2015). The County Health Rankings: rationale and methods. *Population health metrics*, 13, 11.
<https://doi.org/10.1186/s12963-015-0044-2>

Example #2:

"The CHR&R also noted limitations regarding data comparability across states due to state- and jurisdiction-level factors that may influence estimates for both Health Outcomes and Health Factors.¹⁷ For example, among Health Outcomes measures, 3 of 5 measures are state-level measures from the Behavioral Risk Factor Surveillance Survey

(BRFSS). As underscored by the CHR&R team, the BRFSS states that "...SAEs are for county-level use within states and should not be aggregated to MSAs or other geographic areas across state lines," (p. 3).¹⁸ Similarly, 6 of 30 measures for Health Factors are based on data collection methods or models with state-level effects. For example, the violent crimes measure is subject to the reporting norms of residents and law enforcement officers in states and jurisdictions. For high school graduation rates, the CHR&R warned that although there have been changes made on a national level to ensure comparable graduation rates across the US, there may still be variation in terms of cohort and graduate definitions among states. The CHR&R also suggested that differences in chlamydia screening patterns that may exist across states and health care systems may partially account for differences in rates of sexually transmitted infections. Further, for the adult obesity, food environment index, and physical inactivity indicators, the models used to derive estimates may overestimate differences in border counties."

Citation: Stiefel, M. C., Straszewski, T., Taylor, J. C., Huang, C., An, J., Wilson-Anumudu, F. J., & Cheadle, A. (2020). Using the County Health Rankings Framework to Create National Percentile Scores for Health Outcomes and Health Factors. *The Permanente journal*, 25, 1. <https://doi.org/10.7812/TPP/20.012>

Example #3:

"On a conceptual level, there is a lack of agreement between invested parties on what 'rural' means and how the term should be defined and measured. This creates problems for policymakers and the health-care providing community [2]. Standardizing the

definition and measurement of rurality is a difficult task and likely impossible given the variety of interests on how the terms should be used. The U.S. federal government has multiple definitions for the term [2]. Scholars should choose definitions in line with their research question and available data and resources.

Another limitation is that the CHR does not take into account all possible factors that determine community health. For example, the physical environment domain encompasses multiple factors (air pollution, water quality, the built environment), but it of course does not and cannot account for all possible components that could make up one's definition of the physical environment. The conceptual framework of the health factors and outcomes are certainly open to critique, and therefore some caution must be used when making statements about study results."

Citation: Anderson, T. J., Saman, D. M., Lipsky, M. S., & Lutfiyya, M. N. (2015). A cross-sectional study on health differences between rural and non-rural U.S. counties using the County Health Rankings. *BMC Health Services Research*, 15, 441. <https://doi.org/10.1186/s12913-015-1053-3>

III. City Health Dashboard:

- Perception that the survey is focused on cities and thus does not address rural population needs around data sparsity.
- Perception and observation that the SDOH and health outcomes often examined in the survey are from the total population of cities or neighborhoods versus important racial/ethnic subpopulations within them, which could bias data interpretations depending on the type and size of those subpopulations.

References

Example #1:

"focus on cities does not address the equally critical needs of rural populations; future efforts must address challenging issues of data sparsity to meet this important priority."

Citation: Gourevitch, M. N., Athens, J. K., Levine, S. E., Kleiman, N., & Thorpe, L. E. (2019). City-Level Measures of Health, Health Determinants, and Equity to Foster Population Health Improvement: The City Health Dashboard. *American journal of public health*, 109(4), 585–592. <https://doi.org/10.2105/AJPH.2018.304903>

Example #2:

"the SDH and health outcomes examined here are from the total population of cities or neighborhoods, not the AA/AA subgroup population within them. This could bias outcomes depending on the type and size of other population groups co-residing in the places in question. To that point, cities and neighborhoods that had significant AA/AA subgroup populations also had larger Hispanic and non-Hispanic Black populations than did cities and neighborhoods with significant NHW populations. This fits with our finding that cities and neighborhoods high in AAs were more racially diverse than cities and neighborhoods with significant NHW populations."

Citation: Spoer, B. R., Juul, F., Hsieh, P. Y., Thorpe, L. E., Gourevitch, M. N., & Yi, S. (2021). Neighborhood-level Asian American Populations, Social Determinants of Health, and Health Outcomes in 500 US Cities. *Ethnicity & disease*, 31(3), 433–444. <https://doi.org/10.18865/ed.31.3.433>

IV. Closing (10 m)

- Closing remarks.
- Thank the participants.
- Issue their compensation if available or explain the payment process if not.

Instrument Title: Discussion Guide: Focus Group I: Public Health Departments

Total Participant time required: 1 hour + 10 minutes – 1 hour + 50 minutes

Total focus group time: 1 hour + 10 minutes – 1 hour + 50 minutes

Break: 0 minutes

OVERALL QUESTION TO ANSWER IN FOCUS GROUP DISCUSSIONS:

The purpose of the focus group with community leaders is to accomplish the following:

a) Understanding public health departments' familiarity and utility of BRFSS, PRAMS and PLACES, as well as other sources of data like County Health Rankings and City Health Dashboard.

b) Identifying health department needs related to SDOH, racism and other relevant data sources that would be useful to their decision-making and programmatic, policy and procedure planning.

c) Hearing from health departments what enhancements to BRFSS, PRAMS and PLACES would increase the utility of the platform.

d) Focus groups would use human-centered design principles to consider what barriers exist to involvement at any point of the data lifecycle.

Below is a general guide for leading our focus groups. We may modify this guide as needed as each focus group will inform the subsequent groups.

Before the group begins, conduct the informed consent process, including compensation discussion.

I. Introduction (10 m)

- Welcome participants and introduce yourself.
- Explain the general purpose of the discussion and why the participants were chosen.
- Discuss the purpose and process of focus groups.
- Explain the presence and purpose of recording equipment and introduce observers.

-
- Outline general ground rules and discussion guidelines such as the importance of everyone speaking up, talking one at a time, and being prepared for the moderator to interrupt to assure that all the topics can be covered.
 - Review break schedule and where the restrooms are. (In-person focus groups only.)
 - Address the issue of confidentiality.
 - Inform the group that information discussed is going to be analyzed as a whole and that participants' names will not be used in any analysis of the discussion.
 - Read a protocol summary to the participants.

Discussion Guidelines:

We would like the discussion to be informal, so there's no need to wait for us to call on you to respond. In fact, we encourage you to respond directly to the comments other people make. If you don't understand a question, please let us know. We are here to ask questions, listen, and make sure everyone has a chance to share.

If we seem to be stuck on a topic, we may interrupt you and if you aren't saying much, we may call on you directly. If we do this, please don't feel bad about it; it's just our way of making sure we obtain everyone's perspective and opinion is included.

We do ask that we all keep each other's identities, participation and remarks private. We hope you'll feel free to speak openly and honestly.

As discussed, we will be tape recording the discussion, because we don't want to miss any of your comments. No one outside of this room will have access to these tapes and they will be destroyed after our report is written.

(If assistants present) Helping are my assistants _____ and _____. They will be taking notes (and/or translating my questions) and are here to assist me if I need any help.

Let's begin. Let's find out some more about each other by going around the room one at a time. Tell us your first name, about the work you do in your community, and the communities you serve. I'll start.

II. Topic Generation (50-90 minutes)

The focus group facilitator will explain:

We would like to learn about your familiarity with and perceived utility of BRFSS, PRAMS and PLACES, as well as other sources of data like County Health Rankings and

City Health Dashboard.

This group is convened with the goal to understand or learn:

- Your familiarity with BRFSS, PRAMS, and PLACES data and other sources of data like County Health Rankings and City Health Dashboard.
- Your perspectives on the utility of BRFSS, PRAMS and PLACES data and other sources of data like County Health Rankings and City Health Dashboard.
- Your needs regarding SDOH, racism and other relevant data sources that would be useful to support your decision-making and programmatic, policy and procedure planning.
- Your ideas and perspectives around what enhancements to BRFSS, PRAMS, PLACES data would increase the utility of these resources.
- Your perspectives and experiences around barriers that might exist to better engaging or involving public health department stakeholders in the BRFSS, PRAMS and PLACES data lifecycle.

Let's get started!

· The initial question about familiarity with PLACES data:

Ø Today we are here to talk about PLACES data. We also want to consider as well as other sources of data like County Health Rankings and City Health Dashboard. What comes to mind when you think about these data sources?

· Next question related to experience using PLACES data:

Ø Thank you for sharing your thoughts. How might you have used PLACES, County Health Rankings, and City Health Dashboard data to support your decision-making?

· Next question related regarding SDOH, racism and other relevant data sources.

Ø Now, I want to discuss and learn more about your data needs with respect to SDOH, racism and other relevant data. What would be useful in this regard to support your decision-making?

· Next question related to real-world examples around PLACES data use. If useful, bring up a subject or examples that members or the focus groups have already shared.

Ø Next, can you share examples/more about your own experience(s) in using or attempting to use PLACES, County Health Rankings, and City Health Dashboard data to support your decision-making, program planning and implementation?

(NOTE: The goal is for the participants' experience to lead the way, therefore eliciting the most authentic data possible.)

· Next question related participants' ideas or suggestions to enhance current PLACES data to address SDOH.

Ø Thank you for your engagement thus far. We reached the final question/topic, which is to learn your ideas or suggestions to enhance the utility of the PLACES, County Health Rankings, and City Health Dashboard data platforms?

The following is a guideline for topic generation. The actual process may vary according to each group's progress and the experience of previous groups. The list below is a menu of items, along with references, that explores data limitations presented and discussed in the literature regarding PLACES, County Health Rankings, and City Health Dashboard.

Remember: We will not address every issue with every group and we may address issues not on this list as they arise.

Issues for focus group exploration:

I. PLACES: Population Outreach and Engagement Limitations

- Observation or perception that data excludes vulnerable populations (e.g., institutionalized or and incarcerated populations) and therefore cannot be generalized to those groups.
- Perception that certain vulnerable populations must be accounted for by other means in planning for urgent public health events.

References

Example #1:

"BRFSS data are collected for noninstitutionalized civilian persons and exclude populations that might be particularly vulnerable to severe COVID-19 illness, including those living in long-term care facilities and incarcerated populations, and might therefore not be representative for those groups."

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- Perception that data comparability or aggregation/combination across states introduce limitations with respect to state- and jurisdiction-level factors that may influence final data estimates.
- Perception or observation that combining data from low-income neighborhoods with wealthier areas within the same metropolitan county masks health disparities.
- Perception that standardizing data definitions and measurements is a difficult task and likely impossible given the variety of interests on how the terms should be used.

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IV. Closing (10 m)

- Closing remarks.
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Appendix III – Illuminating Quotes

Table 6. Illuminating Quotes within Overarching Themes and Actionable Subthemes Based on Historically Marginalized Community Member Perspectives

Overarching Theme	Actionable Subtheme	Illuminating Quotes
Community Data Collection Through Collaboration and Dedication to Action	Data collection must be followed by dedication and action to address expressed, changing, or implied community needs reflected in the data collected.	<p><i>"...data helps us to prioritize almost of like which house is on fire. And while we want to go out and serv and help everyone, we know that that's just simply not possible.</i></p> <p><i>And that's why we need more leaders all plugged in doing this work so we can all take a different angle of it."</i></p>
	Data collectors and collaborators should be well-supported and invested, engaging, and trustworthy members of the community with compassionate values, ambition, and expectations.	<p><i>"I think we need to start paying for this. I think we need to put that in our budgets that, you know, we've got different communities coming up to the table all the time, sharing lived experience and transportation is not covered. I mean, that's a barrier in itself. So, I'm just thinking we need to be really putting that in our budgets when we are developing surveys and wanting feedback from the community. We need to start paying for it. Indeed, transportation is an issue even for people who have access to it."</i></p>
	Consider community as those who protect the well-being and sustainability of a group with a shared identity or situation (versus only themselves or group affiliations).	<p><i>"Maybe the responsibility in the survey world is to study, that is to study how we take care of each other. Coming to people from a place of humility and being like look like there's a lot we don't know. There's a lot that we need to understand and just being able to work on empowering people to feel like they can buy into that process. Again, coming back to community and what makes a community, people need to feel like they believe in something, first and foremost in themselves."</i></p>

Overarching Theme	Actionable Subtheme	Illuminating Quotes
Data Translation and Relation	Information and data collection tools should contain terms that are accessible and understandable to communities and to help communities translate and relate to the data.	<i>"One thing that we've decided to do is to add the GAD 7 generalized anxiety disorder, the perceived social support scale... the pH Q9 which screens for depression. Instead of asking people like do you feel depressed, we're asking them these validated skills... our job going forward is if we're running that sort of health assessment, we would need to be able to look and see like, OK, is our measure for depression in the city, in our health department going to be able to be reflective of what's being listed in places?"</i>
System versus Personal Control	Data should reflect what SDOH factors are within (versus outside of) historically marginalized communities' immediate control.	<i>"... if you're going to look for people (with) the most need, don't go into clinical offices expecting people to be there because they may not have the insurance or the money to see the doctor. So, you may have to go somewhere else to find these people."</i>
Context and Disaggregation	Aggregated or pooled data requires context and or disaggregation to avoid generalized assumptions that obscure subpopulation needs, risks, and outcomes.	<i>"I think black people just... get this like blanket thing put over our neighborhood instead of like really digging deep into like what's actually happening... it's like, oh yeah, well, they're fine... because we just get like the, OK, 80% this, 75% this, 10% that. One, That's not really what's actually happening at everybody's house... That's the thing to know when we just have a rich a pool. There is no way in between I can share. So, I'm pooled."</i>
Confusion, Skepticism, and Intent	Address any lack of clarity around why community data is collected and how it is used to serve a purpose.	<i>"There was a lack of understanding and so I feel like there should be some way to put that into a screening because that's actually a big part of it. Because some of the questions, like I said, I always have to start with, this is a generic questionnaire. I have to ask everybody. This has nothing to do with you being black, has nothing to do with you being older or whatever. It has nothing to do with that. This is something that we just have to ask..."</i>

Overarching Theme	Actionable Subtheme	Illuminating Quotes
	Address skepticism about robust survey data collection efforts that enrich data collectors but not communities.	<i>"So, it's like they use data that's already stigmatized and try to put it on a platform and serve it up as this is the proof that we have... it's like, no, that's inaccurate. And then they don't understand, you know, the needs... they'll stigmatize people based off of not understanding their exact situations."</i>

Table 7. Illuminating Quotes within Overarching Themes and Actionable Subthemes Based on Community Leader Perspectives

Overarching Theme	Actionable Subtheme	Illuminating Quotes
System versus Personal Control	Data should reflect lived experiences to better understand what SDOH factors are within (versus outside of) historically marginalized communities' power or immediate control.	<i>"when I think about data, I think about multiple points of information... not just, 'oh, do we have this quantitative whatever'... people's narratives, their stories, their lived experience, those are points of data. Those are points of insight. So, a lot of times we might have quantitative data that tells the story, but people's lived experience can be a counter narrative to them... So, I think we also need to acknowledge that sometimes that is the case, especially when we're talking about communities that have been historically and contemporarily excluded and oppressed. That counter-narrative and other forms of inquiry and knowledge are important and critical."</i>
Community Data Collection Through Collaboration and Dedication to Action	Using and sharing local-level data and data disaggregation are necessary to draw local comparisons, pursue and receive funding, and address service and equity gaps through strategic alignment across geographies.	<i>"My thought was around connecting the population level data to the program level data... any assistance that could be provided to organizations who, you know, realized that they are wanting to be part of a collective that moves this the needle on these outcomes at the population level, but don't have really the expertise to measure it within their own programs and organization. So that could look like, you know, providing</i>

Overarching Theme	Actionable Subtheme	Illuminating Quotes
		<p><i>resources like questionnaires that could help them collect comparable data or even kind of contract type projects where we could provide data that's disaggregated specifically for their program. So, I'm just thinking about oftentimes that access to data we needed at different levels so that all the players that are trying to influence that outcome can see themselves in the population level result."</i></p>
	<p>Build community awareness and training about democratized data resources through regular and frequent updates to support local community understanding, connectedness, and collaboration efforts.</p>	<p><i>"Are you all familiar with community benefit that hospitals to maintain their nonprofit status? They have to provide millions of dollars in community benefit dollars that literally go for community improvement. Well, in this case the year that I had one of my administrative fellows pull the data off the IRS schedule H, which designates all the community benefit resources, it was like \$500 million a year... for community benefit and when you overlay the county health ranking data it says we are missing the boat. That we are more focused on sick care than we are on wellness care or a healthier population. I then invited all the CEOs and their divisions that were responsible for creating their community health needs assessment data set."</i></p>
	<p>Qualitative and quantitative data and robust methodologies are necessary to measure equity, determine if community efforts are equitable, and measure and monitor community wide impact against funding and SDOH policy.</p>	<p><i>"Yet they did a qualitative and quantitative deep dive... by zip code. They identified where the lowest birth weight babies were coming from. They identified the resources that were here in the city and then they showed this presentation of the millions of dollars spent on low birth weight babies and all. There must have been 50 silos. Well, the dollars are coming in and we have the same result today that we did 30 years ago. And some of the recommendations coming out of this really bright group..."</i></p>

Overarching Theme	Actionable Subtheme	Illuminating Quotes
	<p>Data collection must be followed by dedication and action to address community needs and describe community resilience reflected in the data collected.</p>	<p><i>they came up with some recommendations that I thought were outstanding."</i></p> <p><i>"... closing that loop and ensuring that those barriers are removed, it's really a process, it's a long time... and it's takes a bit longer to achieve that. But all of us aren't talking... in terms of whether we're actually closing that loop. I never know are we are we making any headway towards ensuring that that family is now food secure or has transport access to transportation or their housing is secure. We're not the expert of all. We're an expert in our mission and what we're doing. But how do we ensure that we can enlist others to help in closing those loops for our members?"</i></p>
Local Data Accuracy and Reflection	Uphold trust that PLACES and other local data sharing platforms are accurate and reflective of local communities.	<p><i>"... a lot of these sites I might go to when I'm trying to help someone understand data... like 'oh, here's a trusted source' or 'oh, you're writing this grant - have you seen this link?' You can break this down by counties and you can say 'here's what's going on in my county' and 'this is why we need funding for XYZ.'</i></p>
Context and Disaggregation	Aggregated or pooled data requires context and or disaggregation to avoid generalized assumptions that obscure smaller population needs and risks.	<p><i>"we have actually made very limited use of the PLACES data, partially because a lot of things don't get disaggregated a whole lot and it tends to be very snapshot based. So, it gets cut. It gets hard to really dig into a topic. I like it, to get an initial idea about high level conditions comparatively. But... when you try to try to look at trends... try to look at disaggregation... then I move off of it."</i></p>
Confusion, Skepticism, and Intent	Address skepticism about robust survey data collection efforts that enrich data collectors but not communities.	<p><i>"It plays a big part in it because our communities are so leery of, you know, any outside sources, especially collecting data institutions, they get a little bit leery. So it depends on the</i></p>

Overarching Theme	Actionable Subtheme	Illuminating Quotes
		<i>project and I decide how to roll it into the community to help them better understand how it's beneficial to them or not. Everything about data collection is not culturally sensitive."</i>
Timely Data for Timely Action	Address how untimely data serves as barrier to understanding and addressing community needs in a timely fashion.	<i>"I think having the data is one thing and having it as close as possible to represent the time frame that we need to consider is better. And that's not something that we may be able to solve overnight. But like at some point you know 5-year-old or 2-year-old data becomes a barrier to being able to address and to really size what's going on in our communities at the moment."</i>

Table 8. Illuminating Quotes within Overarching Themes and Actionable Subthemes Based on Public Health Leader Perspectives

Overarching Theme	Actionable Subtheme	Illuminating Quotes
Methods to Enhance Small Area Estimates	Specific methodologies, which can be costly or cumbersome to implement, for quantitative and qualitative data source selection and analysis are or can be used to construct or measure lived experiences with SDOH within smaller area estimates.	<i>"When I've done some of the research, what I end up doing is compiling a whole bunch of different data sets. So just not from one source. But then, of course, it's not like an easy coalescence of data. So, you have to end up making surrogates and somewhat like milestones of what big events. And then the contextual context of the data itself changes. So not only is it changing of who reports it, but the contextual context of where that data is gathered is also changing."</i>
Community Data Collection Through Collaboration and Dedication to Action	Support present or planned utility and alignment in leveraging PLACES and other local data sharing platforms to support data-informed initiatives with community partners	<i>"Because if we're all striving to end a certain thing, in our case homelessness, you know we should all be working against the same measures like reducing length of time in homelessness, increasing housing placements and we should all be measuring ourselves against the same thing towards that end. I think as</i>

Overarching Theme	Actionable Subtheme	Illuminating Quotes
	targeting health disparities in specific communities.	<i>we're looking at various social ills or social determinants like housing - in our case if we're all striving for different outcomes then we're not all working towards the same outcome and goal. I'm delivering this but not having to produce you know five different outcomes for 10 different grants right. If funders could align behind this too, which is something we've been working towards, we're saying in homelessness specifically, we're all going to look at length of time, housing placements, reduction in the overall numbers of people, for example."</i>
	PLACES and other local data sharing platforms can be useful to identify and reach populations in need of specific services or education related to SDOH in an unbiased and timely manner to help stabilize their engagement.	<i>"I think that the structure... the model... the framework that they're using basically equates individual behaviors with broader structural, you know, things that need to be addressed. And it conflates those two making it really confusing. I've seen that in my own organization. I've seen that across a lot of other organizations. And I think that's a real challenge. If we're going to get at truly social determinants of health... we have to use frameworks that push us in the unit toward a better understanding of, 'okay, what's the data that really reveals that?' And otherwise we slip into blaming individuals for things that really need to be addressed at a structural level."</i>
Local Data Accuracy and Reflection	PLACES and other local data sharing platforms are trusted resources to efficiently obtain small area estimates and census tract level data.	<i>"... the ability to go up to the website and you know kind of pull off state level data and the county level data and download that... it's nice to be able to like look at our actual data and the trends and the strengths and kind of be able to pull that up quickly."</i>
	PLACES and other local data sharing platforms can be used as a starting point to further analyses and optimized to address reporting	<i>"... there's a bias... as to what they report if they report anything. So... I always would proceed with a lot of caution and do a lot more research... see, especially people in that</i>

Overarching Theme	Actionable Subtheme	Illuminating Quotes
	bias, address data limitations, and better compare demographic groups across counties and use case scenarios.	<i>community, what they have to say about it because the ones who can speak the best... those that are there... (who) deal with it day in and day out."</i>
Data Utility and Engagement	Support PLACES as an interactive, accessible, and visually engaging dataset for all users.	<i>"... the data sets are not easily retrieved by persons that are not hugely technical, technically savvy. So, having that information available at the local level I think would be great."</i>
Social and Demographic Context	PLACES should include racial and sex-gender demographics and related discrimination experience data to help contextualize local racism as a SDOH.	<i>"... something that would be interesting to me... identifying, like, racism through these surveys. I would be curious to see... specific racist behaviors that are asked through the questionnaire instead of just like a broad question about racism. So that's something that I'm specifically curious about."</i>