



**Promising Actions:
Creating Responsive
Data Across the
Survey Lifecycle**

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The second chapter of promising actions offers opportunities to create relevant SSDOH data throughout the survey lifecycle.

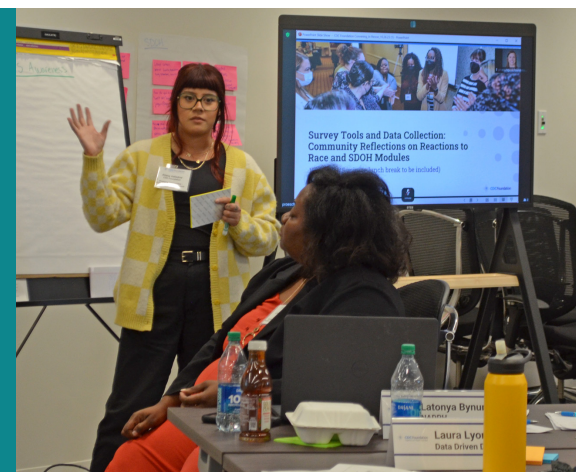
Many of our participants perceived that public health data professionals create questions and deploy surveys tools and strategies that do not center on community priorities or reflect their preferred ways of sharing information about their lives.

This affects survey participation and community buy-in as well as the accuracy, relevance and reliability of the resulting data.

Role of Structures and Institutions for Understanding Systemic Inequities

We use a two-part definition of SSDOH:

- “Conditions in which people are born, grow, work, live and age,” (social determinants) and
- “The wider set of forces and systems shaping the conditions of daily life...[including] economic policies and systems, development agendas, social norms, social policies and political systems” (structural determinants)^{13, 14}



SYSTEMS OF OPPRESSION

This refers to the totality of formal and informal ways societies maintain consistent advantages of power, opportunity and wealth for certain populations at the expense of other populations based on often imposed identity factors such as race, ethnicity, gender identification, class, language, geography, sexual orientation, etc.

Through mutually reinforcing sub-systems (education, housing, health care, criminal justice, etc.), distinct groups are consistently advantaged or marginalized, leading to predictable inequities between groups. (Adapted from: [Hardeman et al., 2022](#); [National Equity Project, 2024](#); and, [Harvard Global Health Institute, 2024](#)).

UNDERSTANDING SSDOH'S CONNECTION TO HEALTH

Several DECs and NADPH assessed the relevance of two [Behavioral Risk Factor Surveillance System](#) (BRFSS) modules: the Social Determinants of Health module (SDOH, [2017](#) and [2022](#) versions) and the Reactions to Race module ([2014](#) version).*

The BRFSS SDOH module focuses on social determinants, seeking to understand how daily conditions contribute to health outcomes.

The Reactions to Race module aims to understand how racially based interpersonal and institutional discrimination—components of structural racism—function to produce inequities in daily conditions, health and wellbeing.

RESOURCE SPOTLIGHT: [Framework for Approaching Power in Systems](#)

There are several resources available on creating equitable data systems, including CDC Foundation's [Principles for Using Public Health Data to Drive Equity](#), the [Toolkit for Centering Racial Equity Throughout Data Integration](#) by Actionable Intelligence for Social Policy (AISP), [Resilient Communities Need Gender Data](#) by Data2X and [Charting a Course for an Equity-centered Data System](#) by the Robert Wood Johnson Foundation—all of which we highly recommend.

Participants underlined the importance of ensuring survey respondents understand how the SDOH and Reactions to Race—and other identity-focused modules—relate to public health. They stressed participatory approaches as a method for designing questions to measure the phenomena they were created to capture.¹

The [NADPH](#) and [DataWorks NC](#) reports dive deeper into the takeaways for the Reactions to Race module. However, feedback on this module is broadly applicable to other survey tools that seek to understand identities or assess discrimination or systems of oppression:

- Provide adequate context about the questions and why they are being asked.
- Design a follow-up approach to offer resources to those triggered by the questions.
- Reframe questions so that they focus on the root causes of inequities (e.g., racism in education and hiring practices) rather than the symptoms (e.g., low income).
- Pay attention to questions' implicit focus. (See Resource Spotlight on the next page).
- Shift focus to assess how advantage creates and supports systems of oppression.
- Provide a frame of reference. Survey participants are aware of racism and other systems of oppression, but they felt ill equipped to answer the questions about interpersonal discrimination when they do not see how others are treated.
- Consider next steps. Both individuals who identify as being part of a minoritized group and as part of the advantaged group were unsure as to what they could do to change the systems.

* While not of focus within this project, BRFSS also includes Sex at Birth and Sexual Orientation and Gender Identity modules, for which the feedback gathered by project partners may be applicable.

FOCUS ON SYSTEMS CHANGE

Participants stated that the SDOH and Reactions to Race modules focused on “proximal” individual experiences that exist within constraints imposed by biased systems. The modules did not examine the larger systems of oppression and biases at work perpetuating health inequities.

The participants—and the DECs and NADPH alike—reiterated public health’s current methods for understanding SDOH focus on *social* determinants, and could do more to understand *structural* determinants.

Partners and some participants acknowledged public health is still learning the best approaches for understanding how systems of oppression function and for triangulating data on structural determinants with health survey data.

They offered suggestions to support survey systems in assessing how governmental and institutional policies and laws and the ways they are enforced perpetuate health inequity.^{9,10,15} Suggestions included: surveying institutions about their policies, assessing institutional policies using existing data, using other cross-sector datasets in partnership with experts to triangulate with health survey data and gathering information on environmental conditions.

RESOURCE SPOTLIGHT: Why is it Problematic to Focus Data Collection on Groups who are Marginalized when Addressing Inequities?

Drs. Link and García’s 2021 article, [Diversions: How the Underrepresentation of Research on Advantaged Groups Leaves Explanations for Health Inequalities Incomplete](#), discusses focusing data on groups who are marginalized as a three-fold problem.

1. This focus emphasizes and pressures communities that are marginalized to help “solve” a problem they did not create and insinuates that persons in the community need to be fixed.
2. It leaves explanations about health inequities incomplete because collected data do not illuminate how advantage works (also referred to as privilege).
3. It shields advantaged groups from scrutiny and effectively contributes to perpetuating health inequities. Advantaged groups may not understand the dynamics of oppression because in many ways their advantages are perceived as invisible within the broader system.

WALK THE WALK

Participants stressed survey systems can interrogate the ways their own policies and practices uphold underlying biases. Doing this well requires survey systems to partner authentically and humbly with communities and local institutions and to partake in often tough conversations about the ways the systems do and do not support community needs.

Planning

- ● Planning includes activities to set the survey system’s mission or purpose, define its scope, understand the historical and ongoing contexts within which it operates and plan for its infrastructure, including identifying variables of interest, developing survey tools, outlining data collection plans and so forth. Planning happens both initially and on a recurrent basis for many survey systems.

Our research underscored the importance of Planning in producing SSDOH data that is prioritized by varied communities and reflective of diverse lived experiences.

The decisions and actions taken in this stage trickle down through the entire system and affect how useful resulting findings are for communities, local public health professionals and other decision makers invested in pursuing wellbeing.

Our project highlighted that a cornerstone to advancing the utility and relevance of SSDOH data is centering the priorities and perspectives of those groups from which the data is gathered. Doing this can reap long-term benefits:

1. Increase community buy-in for the survey system, creating formal and informal data champions and channels for increasing data awareness and use.
2. Ensure that the questions being asked are reflective of lived experiences, approachable and understandable to respondents—and in turn, measuring the phenomenon they intend to measure.
3. Help survey teams proactively plan to increase participation among important groups that are often underrepresented in survey samples.

Throughout the survey lifecycle, public health professionals are encouraged to consider the [Person-Role-System framework](#)¹⁰ and consider actions that can be done at an individual level.

For example, in Planning, public health professionals can take time to assess their own biases and worldviews. In Analysis and Interpretation, they can consider the assumptions embedded in routine analytic decisions and question if other approaches would be more meaningful to understanding SSDOH.

PROMISING ACTIONS

General Planning

INVOLVE THE COMMUNITY UPFRONT

Involve the community upfront when making decisions on survey creation, priority questions, amendments and testing. This can be done by holding focus groups or setting up community advisory boards where community members are compensated for their expertise. This activity could be built into cooperative or similar agreements and include the associated accountability metrics.

BUDGET AHEAD TO COMPENSATE PARTNERS

Budget ahead to compensate community partners, members, organizations and intermediaries that will be engaged throughout the project. Review contractor and subgrantee budgets engaging these actors to ensure they build in adequate compensation.

UNDERSTAND SELF-DEFINED IDENTITIES

Understand the self-defined identities of the communities you seek to survey, such as race, ethnicity, gender identity, sexual orientation, geography, class, ability, language, culture.

Collaborate with communities to understand how historical forces may have shaped their experiences and led to certain health outcomes and possible reasons why community members may be underrepresented in surveys (e.g., individuals in the LGBTQIA+ community may fear being outed without their consent if there is not a clear data protection plan).

UNDERSTAND SELF-DEFINED GEOGRAPHIC BOUNDARIES

When gathering geographically defined data, work with communities to understand their self-defined geographic boundaries, such as those of their neighborhood. Collaborate to understand how historical forces may have shaped that neighborhood or area, leading to certain health outcomes. Consider how data provided at local levels according to analytic decisions or constraints may or may not meet the needs of local contexts. Be transparent about possible limitations.

Example: Using counties, ZIP Code tabulation areas (ZCTAs) or census tracts may still aggregate areas with deep inequities within them. Using estimation or modeling methods reliant on the assumption that proximal areas are similar may overlook the impacts of redlining, gentrification and segregation which situate communities with extreme wealth and extreme poverty side by side. DataWorks NC highlight some of their work in this space in [Claiming History, Space and the Future: This is Bragtown](#).

PROMISING ACTIONS

General Planning

ENSURE TRANSPARENCY

Make plans for ensuring the survey purpose, dissemination plans and the ways data will be protected are reiterated and transparent to participants at every step of the survey—from recruitment to data collection to sharing results.

CONSIDER CHANGING THE NAME

The name surveillance systems generates mistrust in communities due to harmful past experiences with other governmental surveillance systems. Consider changing to something inviting like “observing,” “trending” or “pattern assessment.”

ASSESS IF QUESTIONS CREATE ACTIONABLE DATA

In the planning process, assess whether questions create actionable data to inform changes in policies, practices and programs that contribute to health equity.



PROMISING ACTIONS

Preparing to Understand Structural Determinants

REGULARLY ASSESS QUESTION AND RESPONSE OPTIONS

Regularly assess demographic survey questions and response options (e.g., race/ ethnicity, sexual orientation, gender identity, ability, geography) to ensure the terminology reflect the latest preferences across groups and captures the diversity of lived experiences captured in the survey.

RESOURCE SPOTLIGHT: Disaggregating Data

- The Leadership Conference on Civil and Human Rights Education Fund: [Data Disaggregation Action Network](#) works to advance state and federal policies related to data disaggregation. The site includes blogs and the report [Disaggregation Nation: A Landscape Review of State Race & Ethnicity Data Collection](#).
- Urban Indian Health Institute: [Best Practices for American Indian and Alaska Native Data Collection](#)
- LGBTQIA Resource Center at UC Davis: [LGBTQIA Resource Center Glossary](#)
- National Academies of Sciences, Engineering and Medicine: [Measuring Sex, Gender Identity and Sexual Orientation](#)
- Urban Institute: [Do No Harm Guide: Collecting, Analyzing, and Reporting Gender and Sexual Orientation Data](#)

UNDERSTAND MULTIPLE DIMENSIONS OF RACE AND ETHNICITY

Consider capturing multiple dimensions of race, ethnicity and culture, going beyond self-identified race/ethnicity to also collect street race, defined as how others in U.S. society perceive one's race, which is more predictive of inequitable outcomes.¹⁶

RESOURCE SPOTLIGHT: Socially Assigned/Street Race

- [Using “Socially Assigned Race” to Probe White Advantages in Health Status](#) by Dr. Camara Phyllis Jones and colleagues (2008)
- Urban Institute: [Observing Race and Ethnicity through a New Lens, An Exploratory Analysis of Different Approaches to Measuring “Street Race”](#)
- UCLA Latino Policy and Politics Institute: [Centering Black Latinidad: A Profile of the US Afro-Latinx Population and Complex Inequalities](#)

PROMISING ACTIONS

Preparing to Understand Structural Determinants

EMPLOY A LIFE COURSE PERSPECTIVE

Employ a life course perspective when developing survey questions. Research demonstrates that stress throughout different points in life, including adverse childhood experiences, impact health later in life. The research elevates the cyclical and inter-generational nature of accumulating disadvantage.¹⁷⁻²¹

Data developed using a life course perspective create opportunities to inform policy that addresses “sensitive periods” across people’s lives (e.g., the first year of life, adolescence, pregnancy) and can help identify interventions to promote and lay the groundwork for wellbeing in later life.

IDENTIFY OPPORTUNITIES TO FOCUS ON SYSTEMS

Identify opportunities to shift the focus of survey systems seeking to address inequities from individual-focused questions to ways of addressing other system layers (e.g., interpersonal, institutional and structural).²²

Moving beyond questions about individual experiences of racial discrimination, surveys could survey institutions themselves (e.g., health care, education) or use publicly available resources to understand the ways institutional policies promote and detract from equitable health outcomes.

This type of data may help communities demonstrate the ways systems work locally to support or inhibit health equity and point to tangible policy and program interventions. One DEC partner assessed the wage structure of a large institution, which is the major employer in the area, to describe how the institution’s wage structure created economic inequities in local communities.

PLAN FOR ENVIRONMENTAL CONDITIONS DATA

Plan to collect, aggregate and disseminate data about infrastructure and environmental conditions that influence health and the policies that produce those conditions in ways that uplift opportunities for action and policy change.

USE EXISTING DATA SOURCES

To avoid overburdening participants, use existing administrative data sources in partnership with local and topical experts to contextualize survey results about systems of oppression, including racism (examples: legal datasets, availability of providers, building permits). Compensate local data intermediaries and topical data experts for their support in integrating different datasets.

PROMISING ACTIONS

Survey Tool Design

EMPLOY INCLUSIVE, STRENGTHS-BASED LANGUAGE

When developing questions, use plain, inclusive, non-judgmental and strengths-based language relatable to broad audiences—particularly for questions related to the SSDOH and systems of oppression. Failure to take this step will undermine all other steps taken to build trust and engage communities.

Some Key Ideas:

- Avoid questions with broad assumptions (e.g., asking about housing using “home” when individuals may move between shelters or other situations).
- Avoid jargon (e.g., “making ends meet”).
- Strive to ensure demographic questions enable all survey takers to feel represented (e.g., questions around gender identity should not be strictly limited to male/female dichotomies).
- Ensure response options reflect or give space for all possibilities, notably when asking about feelings.
- Ensure response options do not reinforce dominant hierarchies (e.g., “white” is listed first in a question about race).
- Add questions considering multiple dimensions of one topic (e.g., food insecurity is related to healthiness, access, affordability and sustainability).
- Design questions to be clear and easily recalled (e.g., ask if people encountered specific actions from others in the healthcare system).
- Avoid phrases like “sedentary lifestyle” and “burden,” which may feel judgmental.

Reports from [National Alliance Against Disparities in Patient Health](#), [Community Information Now](#), [DataWorks NC](#) and [Neighborhood Nexus](#) have added details.

CONDUCT COMMUNITY VALIDATION

In addition to conducting cognitive testing of survey questions, conduct community validation to ensure survey questions make sense in real-world contexts and to capture the emotional response around potentially triggering topics, such as experiences of systemic oppression.

PROMISING ACTIONS

Survey Tool Design

COLLABORATE WITH SPECIALISTS

Collaborate with vendors and survey administrators to understand how the questions are received by respondents. Ensure specialists in trauma-informed approaches are included in the process to craft questions that mitigate triggering topics, such as those regarding racism or sexual and gender-based violence and have a plan to provide additional support if questions are triggering to respondents.

EXPLAIN QUESTIONS

Add explanatory introductions to modules to explain why questions are being asked and how they relate to health. This is particularly important for questions related to systems of oppression. Ensure explanations go beyond traditional trigger warnings to provide deeper context, prepare respondents for the questions to come and offer information about resources for respondents.

FOCUS ON QUALITATIVE DATA

Identify and pursue opportunities for gathering qualitative data, particularly when seeking to understand differential access to the SSDOH and the experiences and impacts of racism and other systems of oppression.

Examples: Consider a methodology like the [BRFSS Asthma Call-back Survey](#) to shorten initial survey length and create space for understanding experiences at greater depth through call-back conversations. Consider creating opportunities – such as a messaging platform where participants can leave comments about module questions or share open-ended responses on topics.

MEASURE SOCIAL NETWORKS

Include questions about community assets and support systems to identify and measure the value of social networks and community safety nets in mitigating adverse health outcomes (e.g., measure social connectedness, local support networks, community safety nets). The University of Pittsburgh Center for Social and Urban Research highlight some examples in their [Quality of Life Survey](#).

REEVALUATE PRIORITY TOPICS

Identify routine processes to evaluate survey topics and determine if questionnaires should be modified or replaced. Employ democratic mechanisms (e.g., multi-stage voting techniques) across communities to make decisions.

Data Collection

- ● Data Collection includes actions taken to gather survey responses, including online, in person, on the phone or in other ways. While much of this stage is defined in Planning, Data Collection entails recruiting diverse participants, collecting surveys using methods informed by the sampling approach, identifying and training data collectors and administering the survey to respondents in ways that foster trust and elicit complete and accurate responses.

Our partners stressed the necessity of community and respondent trust in the survey system overall and the individual data collectors specifically for gathering accurate, highly personal information about SSDOH.

The promising actions elevate the importance of fostering trust throughout Data Collection. From understandable information about the survey to context setting for individual modules to creating inclusive engagements through language access, the following promising actions create avenues for survey systems to foster mutual learning between public health data professionals, respondents and communities.

CASE STUDY:



Our partners at Neighborhood Nexus in partnership with Atlanta Civic Circle developed a new initiative, [Atlanta POV](#), which captures community insights to improve data-informed decision-making within the city.

The project offers a model for systematically capturing community voice, both quantitatively and qualitatively, in an actionable way.



PROMISING ACTIONS

Data Collection

EVALUATE VARIED AND MULTI-LAYERED DATA

Test, implement and evaluate varied and multi-layered recruitment and data collection methods to reach a diverse and representative group of potential respondents and increase response rates among groups often underrepresented in public health surveys. Seek to understand the benefits and drawbacks of different incentive structures, sampling techniques (e.g., panels, oversampling, convenience) and data collection modes (e.g., online, phone, in-person, etc.) that reflect different community preferences. Refer to [Community Information Now](#) and [Data Driven Detroit's](#) reports for insights on different recruitment and collection approaches that seek to improve the participation of underrepresented groups.

USE PLAIN LANGUAGE

When administering consent processes, include text and scripts that transparently communicate the risks and benefits in plain language and in the primary language spoken by the respondent. Explain what types of questions are in the survey, why it is collected, how it will be used, how it is connected to outcomes and demonstrate why it is worth the respondents' time to thoughtfully respond. See Actionable Intelligence for Social Policy's [Yes, No, Maybe? Legal and Ethical Considerations for Informed Consent in Data Sharing and Integration](#).

LEVERAGE LOCAL SURVEYS

For large surveys (e.g., national or statewide), consider administering localized surveys (e.g., by city, county or other locally relevant geographic area) around topics of interest on a rotating community cycle. For example, work with a cohort of communities one year, then another the subsequent year and so forth to create locally relevant data while acknowledging diversity across the entire system.

FOCUS ON UNDERREPRESENTED GROUPS

When gathering response rate information, disaggregate response rates and assess what groups are underrepresented in the final dataset compared to the overall population (e.g., by race/ethnicity, ability, gender, etc. and by intersections between groups). Designate a plan for reporting on and addressing these shortcomings in the next round of data collection.

PROMISING ACTIONS

Data Collection

PARTNER WITH ESTABLISHED DATA COLLECTION PROGRAMS

Through cooperative and other funding agreements, collaborate with existing agencies in communities of interest and express a special interest in supporting data collection efforts being conducted by trusted community members, such as community health workers.

Examples: Many rural areas in Texas have a Texas A&M AgriLife Extension Office with community health workers already working in community; this group is often a bridge between researchers and communities. The Black Equity Coalition also engaged community health workers in a survey about vaccine hesitancy.

CONSIDER ENGAGING TRUSTED SURVEYORS

Consider who is collecting the data from participants and how that may or may not engender trust. The people gathering data have an impact on the respondent's trust and their willingness to answer questions accurately or at all. Engage surveyors who can relate with participants and train them to create trustworthy spaces where participants feel comfortable sharing their experiences.

CREATE A SUPPORTIVE PROCESS

Create a supportive beginning-to-end approach for participants, particularly for questions or surveys pertaining to subjects that can be re-traumatizing like racism or sexual and gender-based violence.

- Adequately prepare respondents for what is to come by explaining the purpose of the module as it relates to health.
- Offer definitions and create space for discussions around these definitions.
- Reiterate that participants do not have to answer and can stop at any time.
- Support data collectors in acknowledging their own biases and train them in evidence-based, trauma-informed approaches to gain respondent trust and avoid harm.
- Ensure adequate follow-up by offering resources and information about nearby providers and professional services (possibly using [211 resources](#)).
- For surveys addressing topics with groups that may be put at risk for participating (e.g., sexual and gender-based violence surveys), develop approaches to collecting data and referring to services that ensures participant safety.

PROMISING ACTIONS

Data Collection

THINK ABOUT LANGUAGE

Language access is important throughout the survey lifecycle; however, given the underrepresentation of groups who primarily speak a language other than English in survey samples, attention can be given to language justice at various points throughout data collection.²³

[Neighborhood Nexus](#) and [Community Information Now](#) reports dive into language access. Our collaborative work highlighted several ways to consider language access:

- Engage with community partners who regularly work with groups who speak a language other than English to identify approaches that resonate and to act as compensated interpreters.
- Translated questions can be reviewed for common pitfalls (e.g., lost meaning in translation, becoming out of date, culturally off-putting).
- Some terms and phrases may need to be “localized” so that they can be understood in specific groups.
- Consider adding definitions for medical terms when translating questions to ensure people from different backgrounds understand what is being asked.
- Engage with community-based interviewers who speak languages other than English to build trust and increase respondent comfort in asking questions.

Analysis and Interpretation

- ● Analysis includes systematic data cleaning and sorting, using statistical methodologies and models to generate point estimates, measures of variance and testing hypotheses, identifying interpretive frameworks (e.g., causal diagrams) and understanding the potential impacts of bias throughout the process on the findings' ability to inform action. Interpretation is proximal to Analysis but not the same. Interpretation entails using analytic outputs to draw conclusions and meaning.²⁴

Promising actions for Analysis and Interpretation offer collaborative and participatory approaches that engage communities and respondents.

Our partners emphasized that quantitative data is a marker of lived experiences and reiterated the importance of mixed methods and qualitative data to contextualize the data.

More deeply, the promising actions encourage data teams to acknowledge how all individuals bring their own life experiences, worldviews, logic and training into their work.^{9,10,24} The decisions made about how to categorize data, what statistical tests to run and what conclusions to reach are situated within theoretical and statistical frameworks about causality and interpretation that often go unnamed.

[The Health Equity Tracker's Methodology](#) is an example of data sharing in ways that seek to enhance transparency and understanding around analytic decisions, biases and missing data.

PROMISING ACTIONS

Analysis and Interpretation

COLLABORATE ON PRIORITIES

Collaborate with community members to use analytic approaches that answer communities, public health practitioners and invested parties' priority questions.

INTERPRET IN PARTICIPATORY WAYS

Develop practices of analyzing, contextualizing and interpreting data in collaboration with community members, striving for processes that give communities ownership over final interpretations. Create safe and trustworthy data interpretation spaces where community members can offer open feedback, question data findings, support interpretation and gain understanding of data processes. Throughout the process, question what might be overlooked with quantitative data and consider integrating qualitative data (stories, interviews, etc.) to share a fuller story. Package the data in ways that meet the community's or group's needs and priorities.

Examples: DataWorks NC hosts gallery evenings where data are presented in an art gallery format with interpretation cards. Community members enjoy food and refreshments while discussing the data pieces.

RAISE AWARENESS OF THE SURVEY LIFECYCLE

Survey system leaders can engage the entire data team to ensure everyone understands the complete survey lifecycle, even if it is not fully in the team's domain. This will help those analyzing data understand how it was collected and how it will be used. It also helps them assess the impacts of their analytic decisions on the data's ability to inform action and ultimately, equity.

PROMISING ACTIONS

Analysis and Interpretation

DISAGGREGATE DATA

To the extent possible while still protecting individuals' privacy, disaggregate pooled data (by geographic levels, race, ethnicity, gender, age, etc.) to avoid generalized assumptions that obscure the needs, outcomes and assets of different groups and localities. Collaborate with groups represented in the data to ensure disaggregated data is not used to harm or re-stereotype groups.

SUPPORT LOCAL DATA

Provide support (financial, technical assistance) to local intermediary organizations to collect and disaggregate local data. Invest in communities of practice to support the spread of positive practices.

RECOGNIZE ASSUMPTIONS UNDERPINNING DECISIONS

Recognize assumptions underpinning analytic decisions, identify framework(s) used to reach interpretive conclusions and acknowledge how your own worldviews may frame data analysis and interpretation. Communicate this—such as in a [positionality statement](#)—alongside data findings. Conveying this information helps acknowledge the self in interpreting and sharing data and can increase user trust.²⁵

UNDERSTAND INTERSECTIONALITY

Employ an intersectional lens analytically and theoretically to understand how race, class, gender, ability, age and other intersectional identities mutually influence health outcomes.²⁵⁻²⁹ Intersectional analysis is an emerging public health approach, so consult with experts who have experience analytically applying this paradigm.

PROMISING ACTIONS

Analysis and Interpretation

INTERPRET DATA FOR DIFFERENT USERS

Interpret the data for users in different contexts or roles (e.g., individual, community, system) and interpret what the data may mean for each of these groups (e.g., How should a mother use data which tells her that childhood asthma is high in her community? What might this mean for the community leaders? For city officials?).

UNDERSTAND HISTORICAL CONTEXTS

Strive to understand and convey the historical contexts of places and society within which the data is interpreted. Draw linkages between these histories and findings.

Example: In Durham, high concentrations of lead in public parks are the result of historical practices of incinerator sites being converted to parks without adequate remediation in Black communities during the Jim Crow era.

BUILD SOLUTION-ORIENTED GOALS

Generate data that helps communities develop actionable goals by moving from problem-focused to solution-focused data analysis and interpretation. This requires guidance and protocols for understanding and using race and ethnicity as variables in health research and supporting research that measures the health effects of racism.

ANALYZE DATA OVER TIME

Analyze disaggregated data trends over time.

Data Sharing and Dissemination

- ● Data Sharing relates to the practices associated with who can securely obtain, view or use data and for what purpose. Dissemination focuses on the myriad ways data findings and interpretations are shared across varied audiences with different intents and purposes.

Data Sharing and Dissemination promising actions build upon and benefit from the community-centered and equity-focused practices used throughout the earlier stages of the survey life cycle.

The promising actions highlight how to pursue multi-faceted campaigns to build capacity for data use, promote learnings in relevant and accessible ways, change narratives about the root causes of health inequities and support data users in advancing transformative change.

RESOURCE SPOTLIGHT: Data Sharing and Dissemination

- Urban Institute's [Do No Harm Guide on Applying Equity Awareness in Data Visualization](#)
- PolicyLink's [Powering Health Equity Action with Online Data Tools: 10 Design Principles](#)
- American Medical Association's [Advancing Health Equity: A Guide to Language, Narrative and Concepts](#)
- Dr. Rhea W. Boyd et al. (2020) on [Standards for Publishing on Racial Health Inequities](#)

CASE STUDY:



Community Information Now used inclusive approaches to develop [Bexar Data Dive](#), including a variety of SSDOH and health indicators for the county in English and Spanish.

DataWorks NC designed the [Durham Community Health Indicators Project](#) dashboard based on [insights](#) from a year of focus groups, community workshops, user testing and input from the project partner agencies.

PROMISING ACTIONS

Data Sharing and Dissemination

DO NOT STOP UPON PUBLISHING DATA

Aspire to share data in ways that drive public health action. Findings may not be new to communities; the data may reflect phenomena that communities have experienced for some time. Instead of publishing findings and moving on to the next project, consider being a partner who shows up in spaces and supports historically marginalized groups in using data for action.

Give staff the capacity to do this work and celebrate actions which amplify and bring (wanted) attention to the actions communities are already taking to address challenges.

GATHER INPUT TO CONTEXTUALIZE AND SHARE DATA

Ensure communities have input in the ways data is interpreted, contextualized and shared, as well as the target audiences for dissemination. Always share findings with participants and the community writ large.

Examples: Data Driven Detroit's community partners had concerns that local, place-based data could be used by private investors and others that did not have the communities' interests in mind if it was made publicly available. There were concerns about development, displacement and targeting of communities. With these partners, Data Driven Detroit identified a process where sensitive data could only be shown to community partners via a password-protected webpage.³⁰

RECRUIT A COHORT OF COMMUNITY AMBASSADORS

Recruit a cohort of diverse, compensated trusted ambassadors and local data intermediaries to support dissemination and translation of the results in community-relevant ways. Support partners in reiterating the survey system's purpose, findings and intended actions to be taken using the data.

PROMISING ACTIONS

Data Sharing and Dissemination

BUILD CAPACITY TO MAXIMIZE DATA'S UTILITY

Build capacity across actors in the public health data system to use public health data and infuse equity into data processes. Help community organizations and leaders access and use public health data to pursue their self-defined priorities. Support efforts to increase health and data literacy.

Examples: Providing 1:1 technical assistance with a community group; hosting community events to create a safe space for individuals to learn and ask questions; designing videos, webinars or podcast episodes that explain the data; engaging art, such as [the work of Liz Monk](#); or hosting community/researcher workshops like those conducted by the [Black Equity Coalition](#).

ACKNOWLEDGE CHALLENGES AND STRENGTHS

Share data acknowledging the challenges faced by communities as well as their strengths and assets. Use asset- and strengths-based language in reporting. One idea is to build out community asset resource maps to use in conjunction with the data.

ARTICULATE RESULTS IN DIGESTIBLE WAYS

Articulate data-driven results in digestible ways for lay audiences by using illustrative reports, graphs, pictures, etc. Package data in ways that will stick in readers' minds, such as comparing the magnitude of a disparity to the number of people attending a concert or sporting event or by developing a mascot for the data sharing platform. Use storytelling techniques to convey personal narratives and humanize the data.

SHARE DISAGGREGATED DATA

To the extent possible, share disaggregated data (by geographic levels, race, ethnicity, gender, age, etc.). Use care that disaggregated data are analyzed and shared in ways that align with best practices to protect confidentiality. If data cannot be disaggregated, provide context that can support readers in understanding the nuances of pooled data.

PROMISING ACTIONS

Data Sharing and Dissemination

ASSESS TRENDS

Share data trends over time and offer plain language information to support readers in understanding what the trends mean (e.g., “When reading the graph from left to right, a downward sloping line means that the rate went down over time, whereas an upward sloping line means that the rate went up”).

CONNECT DATA USERS WITH RESOURCES

Connect people with the appropriate resources, tools, education and other support so they remain empowered to act on the data.

BUILD COMMUNITY FEEDBACK LOOPS

When data sharing, create a continuous feedback loop that encourages open and honest feedback and accountability.

ANALYZE SYSTEMS OF ADVANTAGE

Reframe the approach of assessing systems of *oppression* to examining systems of *advantage* and how they operate to create inequities, placing the emphasis on those benefiting from the system rather than those oppressed by the system.

Our partners discussed how this promising action aligns with moving away from approaches that repeatedly ask individuals to describe painful experiences. Shifting the focus to show how power accumulates can highlight structural causes and underscore the unfair accumulation of advantage. An example is referencing Home Owners’ Loan Corporation (HOLC) maps as green-lining instead of red-lining to invite the conversation of where the money went that did not go to predominantly Black neighborhoods.

PROMISING ACTIONS

Data Sharing and Dissemination

BE MINDFUL OF POLITICAL CONTEXTS

When sharing findings, be mindful of the political contexts in which the data will be situated while still conveying the structural and social determinants of inequities. Collaborate with community members and refer to emerging research to communicate about health equity in approachable ways that convey findings even to groups with negative perceptions about equity-based terminology.

RESOURCE SPOTLIGHT: Communicating About Equity

- Big Cities Health Coalition's [Public Health Changing the Narrative](#)
- The Robert Wood Johnson Foundation's [Structural Racism and Messaging Guide](#)
- The Center for Disease Control and Prevention's Office of Health Equity's work on [health equity messaging](#)

USE LOCAL-LEVEL DATA TO SUPPORT DECISION MAKERS

Use and share local-level data to support decision makers and leaders in making local comparisons, pursuing and receiving funding and addressing service and equity gaps. Customize approaches to community contexts. There is more than one way to package data for community use—this is why intermediaries play an important role in addressing the needs of their specific communities and the organizations they serve.