Promising Actions:

Improving Data about Social and Structural Determinants of Health using Survey Systems

CDC Foundation
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The views expressed here do not necessarily reflect the views of the Robert Wood Johnson Foundation or the Centers for Disease Control and Prevention (CDC).

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The CDC Foundation helps the Centers for Disease Control and Prevention (CDC) save and improve lives by unleashing the power of collaboration between CDC, philanthropies, corporations, organizations and individuals to protect the health, safety and security of America and the world.

The Robert Wood Johnson Foundation (RWJF) is committed to improving health and health equity in the United States. In partnership with others, we are committed to taking bold leaps to transform health in our lifetime and paving the way together to a future where health is no longer a privilege but a right. To achieve that vision, we are deepening our focus on dismantling one of the biggest barriers to health in America, structural racism. For more information, visit *www.rwjf.org*.

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Introduction

To improve health outcomes for all, it is essential diverse communities are at the forefront of public health decisions.

Through support from the Robert Wood Johnson Foundation, the CDC Foundation administered a multi-faceted project to gather communities' perspectives on the use of survey data to improve health.

Project partners included the Centers for Disease Control and Prevention (CDC), the National Alliance against Disparities in Patient Health (NADPH) and Data Equity Coalitions: Neighborhood Nexus, Data Driven Detroit, DataWorks NC, Black Equity Coalition, and Community Information Now.

The Data Equity Coalitions (DECs) are local organizations collaborating with communities to improve access to and use of public health data. The DECs are National Neighborhood Indicators Partnership (NNIP) members or collaborate with their local NNIP member. NNIP helps local communites use data to shape strategies and investments so all neighborhoods are places where people can thrive.

The DECs and NADPH conducted coordinated and tailored research investigating opportunities for public health survey-based surveillance systems (herein referred to as survey systems) to respond to local information needs about the social and structural determinants of health (SSDOH), including the experiences and impacts of systemic injustices.

The report adds to a growing body of data equity tools by providing insights on creating inclusive, accessible and effective largescale public health survey systems that capture relevant and actionable SSDOH data.

Project Background

The DECs and NADPH led community survey validation interviews*, focus groups and community discussions, tested approaches to increase survey participation and fielded social determinants of health survey modules.

Activities focused on the Behavioral Risk Factor Surveillance System (BRFSS), Pregnancy Risk Assessment Monitoring System (PRAMS) and PLACES.

The DECs and NADPH partners engaged more than

1,250

public health professionals, local leaders and community members from groups that have been historically marginalized.

The resulting promising actions are intended for public health survey systems and can be considered across contexts to enhance SSDOH data to accurately reflect lived experiences and inform local action to advance health equity.

A review of project reports and meeting minutes identified

311 promising actions

or tangible steps public health practitioners can take to enhance survey systems to meet local SSDOH data needs and priorities.

The CDC Foundation held monthly check- ins, hosted virtual listening sessions and held an in-person convening to synthesize results across partners.

The *Principles for Using Public Health Data to Drive Equity* provided guidance to thematically code the 311 promising actions. A primary theme was identified for each action.

The themes were reviewed and refined during a series of three interactive workshops with the CDC Foundation, DECs and NADPH.

* A rigorous and structured approach to understand whether communities are aware of surveys and survey questions; if the terminology used in survey questions is understandable and reflects their lived experiences; and how community may use the data in their work.

Findings from Our Partners

This report includes collective insights from across project activities. Readers are encouraged to explore the nuanced findings from the DECs and NADPH.

Black Equity Coalition's (Pittsburgh, PA) report discusses five workshops structured to bring researchers into conversations with community leaders and members to modulate the power dynamics between these groups and start learning together to build inclusive survey practices.

Community Information Now's (San Antonio, TX) report discusses research to assess response rates across four survey sampling strategies to understand opportunities to increase response rates from historically marginalized groups often underrepresented in survey samples.

Data Driven Detroit's (Detroit, MI) report discusses using their Neighborhood Vitality Index community-driven pilot process to administer BRFSS Social Determinants of Health and Reactions to Race modules. The group shares insights on developing locally relevant survey tools and data collection techniques.

DataWorks NC's (Durham, NC) reports discuss results from a series of community conversations around the intersection of racism and health and shares community-driven findings about how health surveys can better show how structural racism impacts health and wellbeing.

Neighborhood Nexus' (Atlanta, GA) report discusses their partnership with local community based organizations (CBOs) to conduct a series of activities around community expectations regarding public health data collection and communication. Findings focus on Latino/a/x/e communities and those who do not speak English as their preferred language.

National Alliance Against Disparities in Patient Health's (NADPH) report discusses findings from 51 one-on-one community validation interviews, 15 focus groups (106 participants) and a community briefing with individuals identifying as local community leaders, local public health professionals and members of historically marginalized groups from the five DEC localities. The report provides cross-cutting analyses about the relevancy of public health surveys to local contexts, common uses of survey data and perspectives on data democratization and equitable data systems.

Despite the breadth of communities and backgrounds represented by project partners and their respective research, rural areas, jurisdictions with smaller public health and/or data infrastructures, localities in the western U.S. and state public health agencies were not well represented in project activities. We hope to fill these gaps in the future.

Who This Report Is for

This report is intended for organizations and individuals that manage largescale (i.e., national, state, citywide or similar) survey-based public health surveillance systems, herein referred to as survey systems, with an emphasis on those administered by U.S. governmental agencies.

Public health surveillance is a tool to monitor health outcomes with the goal of protecting and promoting the health of all people. However, using the term "surveillance" can be problematic because many groups mistrust surveillance systems due to harmful past experiences with governmental programs. Guided by this feedback, the term "survey system" is used throughout the report.

Navigating This Report

It can feel overwhelming to employ all the promising actions at one time. This is particularly true when a system serves diverse and intersecting communities across different geographic and community contexts.

The promising actions are intended as a starting point. As you read the report, consider actions that best align with the needs of the communities you serve and those that seem most feasible. Then, reflect on ways to move toward those actions which require substantial infrastructure change to implement.

Transforming public health systems to sustainably support community needs and priorities is a long-term process. The most important action is to prioritize humility, learning and growth.

The report is organized into four sections:

1. **Introduction:** Including links to in-depth partner reports.

2. **Promising Actions for Strengthening Trust and Partnerships:** Actions on building trust and strengthening partnerships with communities and survey participants.

3. **Promising Actions for the Survey Lifecycle:** Actions to embed equity and inclusivity from survey planning to data collection to analysis and dissemination.

4. **Conclusion:** Reflections for next steps and a call to action.

Definitions and Acronyms

You can find a complete list of definitions for the terms used throughout this report in Appendix A. Some key acronyms to keep in mind include:

- **CBO:** Community-based Organization

- **BRFSS:** Behavioral Risk Factor Surveillance System

- **DEC:** Data Equity Coalitions

- **DRH and DPH:** Division of Reproductive Health and Division of Population Health within the National Center for Chronic Disease Prevention and Health Promotion, Centers for Disease Control and Prevention (CDC)

- **NADPH:** National Alliance Against Disparities in Patient Health

- **PLACES:** Population Level Analysis and Community Estimates

- **PRAMS:** Pregnancy Risk Assessment Monitoring System

- **SSDOH:** Social <u>and</u> structural determinants of health
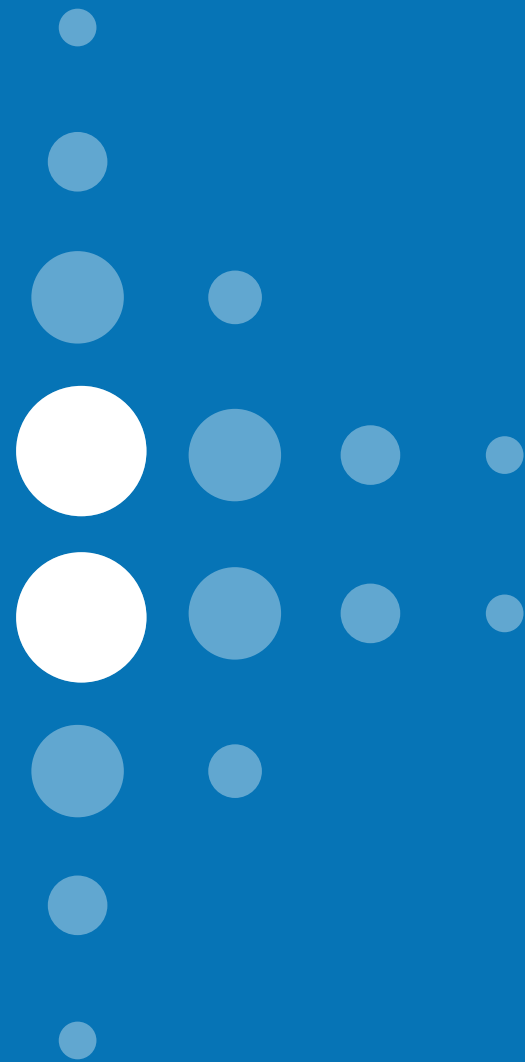
Promising Actions:
Fostering a
Trustworthy System

Promising Actions:
Fostering a Trustworthy System

The research for this report originally focused on the technical aspects of how largescale surveys could respond to local SSDOH data needs.

As the project progressed, community-based findings emphasized that responding to local data needs requires community trust.

Instead of asking "How can we make people trust our system?," we can flip the narrative and ask,

"How can we foster a trustworthy system that meets the public's needs?"

The first chapter of promising actions elevates opportunities for survey systems to build trust with communities and increase community engagement in decision making throughout the survey lifecycle.

Actions demonstrating a long-term commitment to mutually beneficial partnership and the wellbeing of all groups can foster trust and improve the ability of survey systems to accurately capture and report on the lived realities of diverse communities.

Ultimately, the focus on partnership serves as a basis for effective solutions that address longstanding health inequities.

The promising actions for building community trust are intended for survey system team members regardless of their role throughout the survey lifecycle.

Fostering a system that merits the public's trust and meets their needs entails investments not only in the technical data infrastructure but in the ecosystem of people, partnerships and communities that play a role in the system's success.

Our partners' research highlighted that local public health professionals and community leaders who are already aware of national public health surveys and platforms trusted the accuracy and reliability of this data.[1] **This is a solid foundation for building stronger ties with all communities**.

Why Is Engaging Diverse Community-based Organizations Important?

We view diverse community-based organizations (CBOs) as critical actors in the public health ecosystem that can serve as bridges between public health agencies and diverse communities.

We define CBOs as non-profits deeply rooted in specific geographies and focused on enhancing the wellbeing of population groups (e.g., Tribal Nations and Indigenous people, Black/African American groups, immigrants, LGBTQIA+ groups) or issue areas (e.g., workers' rights, environmental justice, food security) by using their community ties and trusted status.

RESOURCE SPOTLIGHT:
Partnership and Trust-building

• CDC Foundation's Recommendations for Strengthening Partnerships between Health Departments and CBOs

• Spitfire Strategies toolkit, Replenishing Trust: Civil Society's Guide to Reversing the Trust Deficit

• Urban Institute's Community Engagement Resource Center offers varied resources on engaging communities in data practices

Creating Equitable Community Partnerships

The below promising actions describe ways of fostering community trust and creating supportive spaces for collaboration and shared decision making with communities.

Building strong, reciprocal community partnerships requires both personal, invested relationships and supportive institutional infrastructures.[2, 3]

As with any partnership, project partners identified mutual accountability, transparency and inclusive communications as cornerstones of success.

Sustainably embedding community voice into the fabric of public health surveys takes substantial time and consistent effort. These promising actions are not intended to be completed all at once.

> **Partner organizations and community members are concerned about perpetuating exploitative data collection practices without providing feedback or benefit to the communities.**
>
> **There needs to be clear communication of expectations and a real intention to support these communities by improving access to opportunities.**
>
> **Dr. Rachele Hendricks-Sturrup, NADPH**

Getting Started: Building Community Partnerships

RECOGNIZE PAST HARMS

Before (re)building trust, public health professionals must recognize and acknowledge harms caused by past and ongoing approaches[4-6] used by other governmental agencies and the public health and medical communities – all of which decrease trustworthiness.

Communities can be reluctant to partner with data professionals and skeptical of datasets because they view public health surveys as an extractive system where potential risks outweigh benefits.

UTILIZE DATA FOR COMMUNITY NEEDS

Only seek data from communities if your primary purpose is to use the results to inform actions and pursue solutions prioritized by those communities. Do not seek data to advance your career or organizational goals or simply define a problem without intending to support the community in addressing the problem in the ways they deem best.

DEMONSTRATE A LONG-TERM COMMITMENT

Before a community will want to partner, it can take significant time and repeated action demonstrating a commitment to long-term partnership and community wellbeing. Find ways to show ongoing support of the community and its initiatives, ground the partnership in shared goals, give individuals and communities space to be angry and collectively agree to concrete actions to prevent future harm.

SUPPORT DIFFERENT PERSPECTIVES

Once relationships are established, be prepared for community partners to disagree, ask tough questions and push back on what public health professionals may view as standard practice or most efficient. In these times, do not turn away. Grapple with their different perspectives and resultant tensions through respectful dialog and resolution– perhaps engaging an outside facilitator.

Cornerstones of Strong Partnerships

HOLD THE DATA SYSTEM ACCOUNTABLE

In collaboration with communities, develop qualitative and quantitative metrics to assess the ways the data system has or has not benefited communities and populations of focus, notably through changes in outcomes important to communities.

Example: Institute mechanisms, such as community governance committees or external assessments, to hold data professionals and survey systems accountable to the communities they serve and monitor if the data is being used fairly. Make findings publicly accessible using non-technical language.

BE TRANSPARENT FOR ACCOUNTABILITY

Create transparent, accessible and public mechanisms to show where governmental funds are invested and dispersed to respond to self-defined community health priorities.

FOSTER INCLUSIVE AND ACCESSIBLE COMMUNICATION

Foster inclusive and accessible communication about the data system by creating and disseminating plain-language, transparent multi-mode communications.

Example: Use varied platforms (online, print, trusted messengers, etc.) to share program information, from its goals to funding sources to how the data will be used.

BUILD FEEDBACK LOOPS

Create standard processes to embed community feedback loops into survey systems. When data professionals seek community insights, document the ways that input is reflected in the work and if changes could not be made, explain why not.

Example: Feedback loops may look different depending on the ways partners and communities engage. State agencies may receive funds as part of a federal cooperative agreement. In this case, what is the process for states and federal agencies to receive and incorporate feedback from communities?

Strengthening Community Partnerships

SHOW UP FOR COMMUNITY OUTSIDE OF RESEARCH

Engage with communities routinely and reciprocally before you "need" something. Join existing community events and initiatives and get to know community members. Aim to understand past research projects and how they interact with your own.

Examples: Ask if you can attend and regularly participate in community events when appropriate, instead of always asking the community to come to your events. Include engagement in community events in data system job descriptions.

[Report Detroit](#) digitized the boundaries of research efforts to show where communities are over- or under-researched, providing a springboard for partnership, minimizing duplication and maximizing resources and data.

ACKNOWLEDGE COMMUNITIES ARE NOT MONOLITHS

Seek to understand the context and history of the places encompassed in your data system, talk with diverse groups about community assets and understand what it means to be respectful when engaging each community.

Example: Engage local historians. See [Data Research Center's Systemic Inequity Collection](#) and [Communities Count blog post](#). Spark conversations about assets through workshops or frameworks like [Asset Based Community Development](#).

RECOGNIZE THE EXPERTISE OF COMMUNITY MEMBERS

Engage community members throughout the survey lifecycle. As part of this, identify opportunities to include community leaders and local/grassroots CBOs addressing the survey's issues of focus.

Example: As a team, level set about the different ways people bring expertise; establish collaboration and meeting norms that engage various actors on equal footing without traditional qualification or educational barriers.

NOTE: Your approach to recognizing expertise may differ by level of operation.

- Local or city level: create local community data advisory boards

- Statewide: create data boards including CBO, local health department and healthcare representatives

- National: tap into existing knowledge-exchange networks (e.g., [National Neighborhood Indicators Partnership](#), [Actionable Intelligence for Social Policy](#)) or mandate (and fund) inclusive state boards in cooperative agreements.

Strengthening Community Partnerships

IDENTIFY FORMAL AND INFORMAL TRUSTED COMMUNITY LEADERS

Seek diverse community collaborations to understand community diversity, priorities and challenges and build bridges between public health and communities.

Example: Your approach may differ by level of operation.

- Local or city health departments may prioritize staff routinely attending different coalition meetings across their jurisdiction.

- State or federal agencies can partner with local data intermediaries or CBO collaborations.

Whenever working with a community, map the local ecosystem of CBOs and leaders as well as assets important to communities (e.g., libraries, religious facilities, businesses, parks). Use a variety of formal and informal information networks to find authentic community leaders that are held accountable by the community. This will require engagement of leaders with viewpoints different than your own, which may not always feel "comfortable."

NOTE: When engaging community leaders, sometimes referred to as gatekeepers, it is important to recognize some "official" gatekeepers are in positions of power over community members in a way that does not facilitate trust and may hurt your relationship with community members. When working with communities, it is important to build a network of partnerships across power differentials and not rely on one individual.

REGULARLY ASSESS WHO IS NOT REPRESENTED

Regularly assess which groups are not represented in engagement activities, understand why that may be and create intentional and thoughtful plans to address those gaps.

Example: Conduct regular partner assessments, such as that found in NACCHO's MAPP toolkit, to understand the types of individuals or organizations who are routinely partners, then also identify potential gaps. For example, are you engaging any grassroots community power-building organizations?

Strengthening Community Partnerships

STRIVE TO CREATE REPRESENTATIVE TEAMS

Strive to create representative data teams, expanding connections and innovations to recruit individuals from across the communities served by the survey system and building internal infrastructure to support career development and promotion.

TAKE A GROWTH MINDSET

Continually reflect on methods for engaging with communities and question old approaches to understand what can be learned. There is usually more than one good way to engage with communities and best practices can change over time.

> **Example:** The Community Tool Box includes guidance on community-centered approaches. Prioritize regular training for staff to be able to authentically engage those with different lived experiences such as that offered by the Groundwater Institute.

CASE STUDY: DATA DRIVEN DETROIT'S NEIGHBORHOOD VITALITY INDEX

Data Driven Detroit (D3) employed many of these promising actions in the development of their Neighborhood Vitality Index (NVI). The history of NVI outlines the community-based impetus for the index and the ways D3 engaged community development organizations (CDOs) throughout decision making processes. The resulting NVI indicator list was developed over the years by invested local partners representing varied sectors, with input from hundreds of people along the way. This approach resulted in buy-in from community organizations and foundations that see themselves reflected in the indicators.

As part of this work, D3 developed an invested party map that shows which organizations and funders are connected to indicators in the index. The map supports network building and connect partners for potential projects. To embed feedback loops, the team regularly updates a webpage dedicated to lessons learned where they share how they have integrated community feedback. The group developed the NVI alignment matrix to communicate the value-add of the NVI and offer clarity on how other local efforts interact to avoid duplication and over-surveying communities. To support community partners in leveraging the NVI, D3 also developed a Potential Products, Audiences and Uses guide.

Recalibrating Power Dynamics

> "Power manifests in how decisions are made, the people and networks involved in making decisions, how problems and solutions are framed, what ideas are considered in the process, and how to measure success.
>
> **Lili Farhang and Xavier Morales**[7]

To reflect diverse lived experiences and produce actionable data, survey systems can assess the ways communities have—or have not— had the power to decide what data is collected, how it is collected and how it is used.[8]

Project partners highlighted the importance of examining survey system structures, practices and policies to **assess if those whom the data is about and those most impacted by health inequities are woven into decision making networks and governance structures**. Who decides on the survey's final topic areas and questions? Who decides who can request and gain access to data? Who decides how findings will be disseminated?

Openly acknowledging power imbalances between communities and governmental public health agencies can help public health professionals identify actions that promote shared decision making and shift power to communities. Data professionals can also consider ways of using their own power as data experts to support communities in making the case for their priorities.

> "We have always said that the richest databases are people's memories and that is something that is always discounted in places of power.
>
> **John Killeen, DataWorks NC**

Recalibrating Power Dynamics

UNDERSTAND AND ACKNOWLEDGE POWER

To address power imbalances, public health data professionals must first understand what power is and how it operates throughout public health systems and organizations. [9-11] While individuals can use existing resources to deepen this understanding, creating inclusive data systems also requires that survey and organizational leadership create a supportive culture that itself acknowledges power dynamics and encourages critical and open reflection among team members and with community on the ways power operates across the survey system.

Example: Human Impact Partners has partnered with health departments and communities across the U.S. to center equity and build collective power with social justice movements. Reflecting on their learnings, the team has created various resources on power, including:

• Resources for Collaboration and Power Sharing between Government

• Activities to Deepen your Power-building Analysis (including guidance on power mapping).

The Greater Boston Anti-Displacement Toolkit also includes a power mapping facilitation guide.

MAP POWER

Build in opportunities throughout the survey lifecycle to assess the administrative agencies' own power. Conduct a power mapping to identify opportunities to share power with communities throughout the data process.

Recalibrating Power Dynamics

REBALANCE POWER

Reframe how business is done to recalibrate power dynamics. Pursue participatory practices where community members hold meaningful decision-making power in data systems and provide community members with what's needed to participate, including financial support, translation services, etc.

> **Examples:** Power can be shared with communities through participatory data governance approaches, inclusive and accessible funding, community approval processes for data access and community capacity building to support making the case for their own priorities.

AMPLIFY COMMUNITY POWER

Find approaches to amplify community members' power in the data and research process.

> **Example:** The Black Equity Coalition highlights their approach to workshops that not only brought community members and researchers together, but provided information to community members about the ways they can exercise their power to influence research and data locally.

RESOURCE SPOTLIGHT:
Framework for Approaching Power in Systems

Recalibrating power dynamics in governmental systems is a monumental task. The Person-Role-System framework[12] can help individuals and departments understand how to use formal and informal power and roles within a system to accelerate change. The framework discusses the ways individual mindsets and narratives interact with professional and personal roles within a system.

Multi-Layered Partnerships and Equitable Funding

The third set of promising actions focus on building multi-layered organizational community partnerships and funding the system for success.

The project activities highlighted a key conundrum for largescale survey systems: what is the approach to engage communities when your system serves diverse and intersecting communities across different geographic and community contexts?

Our research and project approach elevated the value of:

1. Investing in interdependent layers of community and organizational partnerships that lend and borrow trust to relay insights and develop feedback loops—from communities to local CBOs to state and national organizations and government agencies.

2. Considering various types of diversity in partnerships, such as racial and ethnic diversity, geographic diversity, diversity in lived experiences, gender and sexual diversity and beyond.

Facilitating a strong ecosystem around public health survey systems can create networks where communities are central in decision making and partnerships withstand transition, tensions and funding fluctuations.

> **When engaging community partners, don't only ask if help is needed but also ask 'What does help look like?'**
>
> **Black Equity Coalition Workshop Participant, Pittsburgh, PA**

Build Multi-Layered Organizational Partnerships

STRENGTHEN EXISTING NETWORKS

Strengthen existing networks of local data intermediaries (local organizations collaborating with communities to improve access to and use of public health data), CBOs and local health departments and elevate collective practices.

Examples: Meet entities in spaces where they already gather by partnering with individual organizations or engaging collaborative bodies such as the National Neighborhood Indicators Partnership or the National Association of Community Health Workers. Use these spaces to understand community data needs and priorities and to gather insights around pressing data system questions.

Support communities of practice and offer resources to both local networks and community members to participate in them.

EXPAND NETWORKS

Expand networks by pursuing partnerships with organizations not often considered in health-related initiatives, such as local libraries, park and recreation departments and agriculture networks. These organizations can support community members in accessing and using survey data.

Example: Civic Switchboard encourages partnerships between libraries and data intermediaries.

Approaches to Equitable and Trust-based Funding

INVEST IN PEOPLE-CENTERED DIMENSIONS

Beyond the data infrastructure, invest in the people-centered aspects of data collection and dissemination. Thus, increasing the trustworthiness of the entire data ecosystem.

Example: Areas of focus for additional funding:

- Bi-directional capacity building for communities to access and use data and for public health to improve partnerships

- Relationship building across data networks

- Community-led survey advisory boards, participatory governance and analysis

- Data intermediaries who can help expand data use and translation to action

- Funding to increase sample size, pursue data for disaggregation and localize results

FUND RELATIONSHIPS

Beyond project-based funding, consider different funding models to provide long-term support for building and managing relationships. Consider continued funding to sustain relationships after projects complete.

Example: Trust-based Philanthropy Project's approach elevates values and grantmaking practices when developing funding strategies.

The Community Justice Collaborative in Durham, Chapel Hill and Raleigh have started writing in "reverse-consultancy" funding in grants which offers consulting rates for neighborhood participants in tax equity work.

CONSIDER PARTICIPATION BARRIERS

Consider the barriers to participation and try alternative approaches to make funding accessible to grassroots community organizations with local trust.

Example: Assess barriers created by cumbersome governmental application processes and revisit reporting processes that may create added work for CBOs without substantial administrative infrastructures.

Promising Actions:
Creating Responsive Data Across the Survey Lifecycle

Promising Actions:

Creating Responsive Data Across the Survey Lifecycle

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]
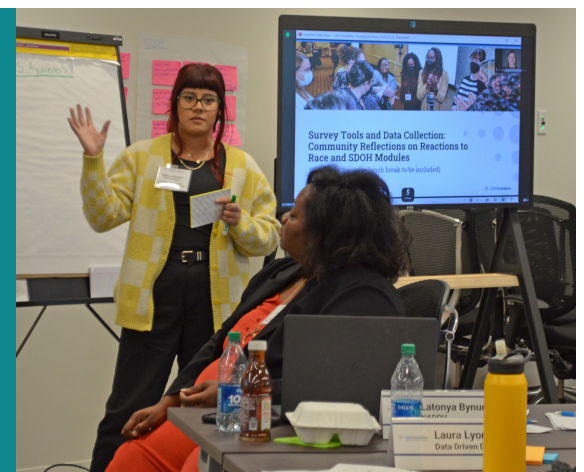
SYSTEMS OF OPPRESSION

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 SSDOH 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.

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.

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.

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

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.

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.

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.

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.

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.

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.

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.

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.

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.

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.

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.

Next Steps

Transforming public heath data systems is a long-term process.

By focusing on community engagement, recognizing community involvement at every stage of the survey lifecycle and building multi-layered partnerships, data practitioners and survey systems can continue to learn and grow with the community.

This report outlines an extensive assortment of promising actions for consideration. Centering each community's unique needs, history and perspective at the forefront of the change is the pivotal first step.

Data practitioners are encouraged to consider feasible actions that best align with the needs of the communities served by the data system.

One recommendation is to determine the impact of the promising actions on your local system and communities. An Impact Effort Analysis Tool maps the impact and effort of the promising actions. Figure C shows an example using an alphanumeric system to indicate different actions from chapters of this report. Engaging community partners is highly encouraged when conducting this assessment.
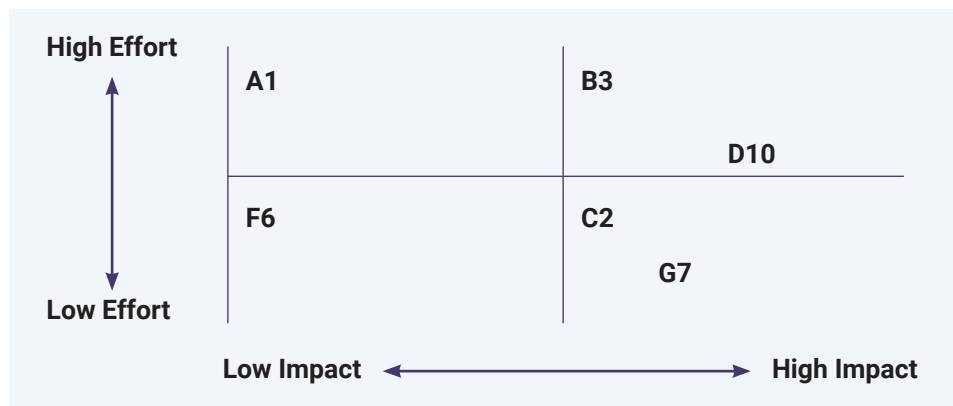
CONTINUE THE CONVERSATION

We encourage you to share this report with your networks to expand and continue the conversation about embedding communities in survey system processes. Through conversation and dialog, we can continue to learn from neighboring communities and practices.

We also encourage you to connect with the CDC Foundation to share how these promising practices may be implemented in your own survey systems, including current and future plans, successes and learnings and additional promising actions that would support this work. The CDC Foundation views sharing learnings as an important mechanism for strengthening the U.S. public health system's ability to equitably respond to emerging public health threats and persistent health challenges.

We look forward to continuing the conversation and strengthening public health data together.

Appendix A: Report Definitions and Acronyms

Community: "a group of people with diverse characteristics who are linked by social ties, share common perspectives and engage in joint action" either based on geographic location (e.g., block, neighborhood, city, state), issue area (e.g., workers' rights, environmental justice, heart disease) or self-defined and/or imposed identities (e.g., youth, Black/African American, workers, athletes, Muslim). Individuals are usually members of multiple communities. Using this definition, "communities" include what may be framed as "those with lived experience" within a particular geography, issue area and/or self-defined or imposed identity. (Adapted from: MacQueen et al., 2011 and Goodman et al., 2014).

Community-based Organization (CBO): non-profits deeply rooted in specific geographies and focused on enhancing the wellbeing of population groups (e.g., Tribal and Indigenous groups, Black/African American groups, immigrants, LGBTQIA+ groups) or issue areas (e.g., workers' rights, environmental justice, food security) by using their community ties and trusted status.

BRFSS: The Behavioral Risk Factor Surveillance System (BRFSS) is a system of health-related telephone surveys that collect health data about U.S. residents. BRFSS collects data from more than 400,000 adult interviews annually in 50 states, Washington, D.C. and three U.S. territories.

Data Equity Coalitions (DECs): local organizations collaborating with communities to improve access to and use of public health data. We partnered with DECs in Atlanta, GA, Detroit, MI, Durham, NC, Pittsburgh, PA and San Antonio, TX. All DECs are partner organizations in the National Neighborhood Indicators Partnership.

Ecosystem: we use this term to refer to the complex network of interconnected actors surrounding public health survey systems. This includes the public health data professionals employed in the survey system's technological infrastructure as well as the assortment of people, organizations, partnerships and communities that fund the system, administer the system, input information into the system and use the system's outputs.

Health equity: "Health equity is assurance of the conditions for optimal health for all people. Achieving health equity requires valuing all individuals and populations equally, recognizing and rectifying historical injustices, and providing resources according to need. Health disparities will be eliminated when health equity is achieved." (Accessed from Jones, 2014).

Health inequities: systemic, unfair and avoidable differences or disparities in health outcomes and their determinants between segments of the population defined by shared or imposed social, demographic, environmental and/or geographic identities.

LGBTQIA+: Lesbian, Gay, Bisexual, Transgender, Queer, Intersex, Asexual

National Alliance Against Disparities in Patient Health (NADPH): a national qualitative research partner who supported several activities within this project.

Participants: refers to individuals who participated in any of the research activities conducted as part of this project, including interviews, focus groups and community gatherings.

PLACES: The Population Level Analysis and Community Estimates (PLACES) website provides user-friendly health measure estimates for all U.S. counties, census tracts and ZIP Codes.

PRAMS: [The Pregnancy Risk Assessment Monitoring System](#) (PRAMS) collects data on attitudes and experiences before, during and shortly after pregnancy. PRAMS covers eight of 10 U.S. births and aims to improve birthing persons' and infant health.

Public health surveillance: the ongoing, systematic collection, analysis and interpretation of health-related data essential to planning, implementation, and evaluation of public health practice. (Accessed from [Thacker and Birkhead, 2008](#)).

Public health surveillance system: largescale (i.e., national, state, citywide or similar) systems that collect health outcome and oftentimes determinant information from individuals living in the U.S. with the intent of conducting public health surveillance.

Survey-based public health surveillance system (referred to as survey system throughout the report): Surveillance systems that use surveys as the primary or sole data collection tool. We focus on survey systems operating in the U.S. and those led by governmental agencies.

Public health data professionals: refers to the group of people who represent and work within the technical aspects of public health survey systems and the varied functions executed by these individuals. This term is being used for consistency when referring to the broad spectrum of individuals employed in paid roles as part of public health survey systems (e.g., data analysts, survey methodologists, data collectors, program managers, leadership, etc.).

Social and structural determinants of health (SSDOH): Social and structural determinants of health are the non-medical factors that influence health outcomes. Social determinants are the conditions in which people are born, grow, work, live and age, and structural determinants are the wider set of forces and systems shaping the conditions of daily life. We use SSDOH to emphasize our focus on both aspects of this concept. For additional information on current conversations around defining structural determinants of health, see [this resource](#). Note: when referring to the BRFSS Social Determinants of Health module, we use the acronym SDOH to accurately reflect the name of the module.

Survey lifecycle: all steps of the data process, from planning and designing the data program and its tools and approaches, to collecting data, to determining data access, to analyzing and interpreting data, to disseminating findings to broad and varied audiences.

Systems of oppression: 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, gender identification, class, language, geography (e.g., differences across neighborhoods or across rural vs. urban areas), der, etc. Through mutually reinforcing sub-systems (education, housing, health care, criminal justice, etc.), systemic and intentional advantaging and disadvantaging of distinct groups leads to consistent and predictable inequities between groups. Systems of oppression are forms of structural determinants of health. (Adapted from: [Hardeman et al., 2022](#); [National Equity Project, 2024](#); and, [Harvard Global Health Institute, 2024](#)).

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