Promising Actions:
Fostering a Trustworthy System

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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**

PROMISING ACTIONS

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.

PROMISING ACTIONS
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?

PROMISING ACTIONS
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.