



Promising Actions:

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



Introduction

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 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.

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.

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 DEC 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.

Promising Actions

The themes for each section are listed below along with a couple of promising actions for each.

FOSTERING A TRUSTWORTHY SYSTEM

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Creating Equitable Community Partnerships

EXAMPLE PROMISING ACTION: 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 PROMISING ACTION: 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.

Recalibrating Power Dynamics

EXAMPLE PROMISING ACTION: 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.

EXAMPLE PROMISING ACTION: AMPLIFY COMMUNITY POWER

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

Multi-Layered Partnerships and Equitable Funding

EXAMPLE PROMISING ACTION: 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.

CREATING RESPONSIVE DATA ACROSS THE SURVEY LIFECYCLE

Planning

EXAMPLE PROMISING ACTION: 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.

Data Collection

EXAMPLE PROMISING ACTION: 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.

Analysis and Interpretation

EXAMPLE PROMISING ACTION: 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 PROMISING ACTION: 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.

Data Sharing and Dissemination

EXAMPLE PROMISING ACTION: 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.