

Data Equity Coalition: Community Conversations on Racism & Health

Revised March 2024



Project Background

Through support from the Robert Wood Johnson Foundation, the CDC Foundation administered [a multi-faceted project](#) in partnership with the Centers for Disease Control and Prevention (CDC), the National Alliance Against Disparities in Patient Health (NADPH) and Data Equity Coalitions (DECs) in Atlanta, Detroit, Durham, Pittsburgh and San Antonio—local organizations collaborating with communities to improve access to and use of public health data.

As part of the project, the DECs and NADPH conducted coordinated and tailored research investigating opportunities for surveillance systems to better respond to local data priorities related to the social and structural determinants of health (SDOH), including the experiences and impacts of systemic injustices.

The DEC and NADPH efforts sought to understand community and local public health SDOH data needs and priorities, the strengths and limitations of existing SDOH survey tools and promising approaches for increasing access and use of public health data. The DECs and NADPH gathered community feedback through one-on-one community survey validation interviews, focus groups, testing approaches to increase survey participation, piloting SDOH survey modules and facilitating community discussions. Feedback focused on use of the [Behavioral Risk Factor Surveillance System \(BRFSS\)](#), [Pregnancy Risk Assessment Monitoring System \(PRAMS\)](#) and [PLACES](#). Across the five locations, our DEC and NADPH partners engaged over 1,250 public health professionals, community leaders and members of groups who have been historically marginalized.

View a collaborative recap of the project and a list of promising actions for surveillance systems to consider for enhancing community engagement and developing more relevant SDOH metrics in our [Final Collaborative Report](#).

Our Role

As a local DEC for the project, DataWorks NC was funded by CDC Foundation to conduct the activities outlined herein. This report was developed by our team and does not necessarily reflect the views of the CDC Foundation or the Robert Wood Johnson Foundation.

What this Project Is

DataWorks NC is one of 5 organizations in the United States participating in the Data Equity Coalition Project. The main purpose of this project is to inform the national dialogue on racism and health, centering the concerns of Durham's communities of color, low income, and historical disinvestment. Working closely with community partners, DataWorks aims to identify meaningful questions about racism for consideration in two national, CDC survey efforts:

- [Behavioral Risk Factor Surveillance System \(BRFSS\)](#)
- [Pregnancy Risk Assessment Monitoring System \(PRAMS\)](#)

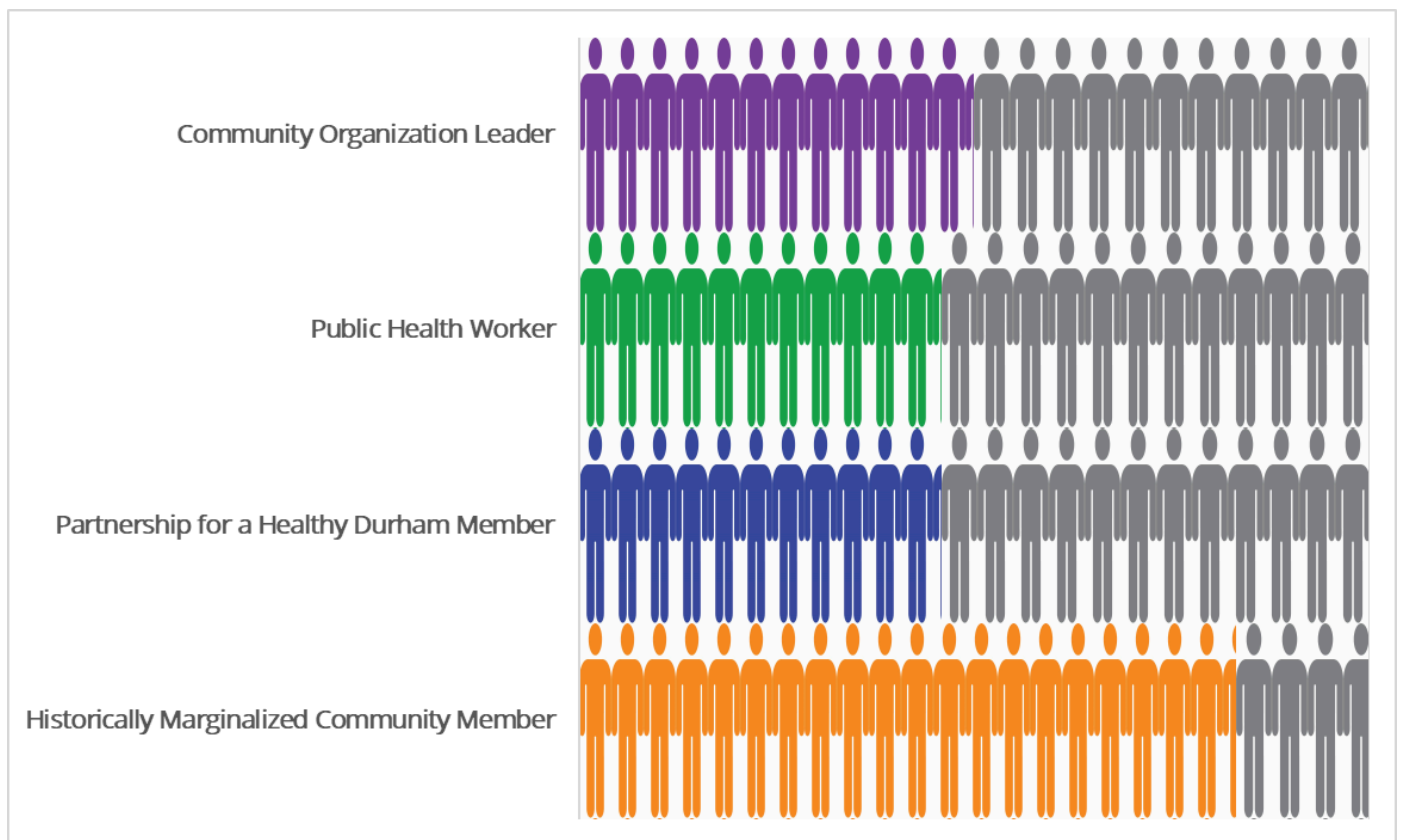
The [Durham Community Health Assessment](#), administered by the Durham County Health Department, has repeatedly shown racism to be a primary issue of concern for Durham community members. Durham's long standing coalition of health-focused community organizations and members, [the Partnership for a Healthy Durham](#), established a [Racial Equity Task Force](#) and adopted racial equity principles in response to the 2017 Community Health Assessment results as well as frequently voiced community concerns.

DataWorks hosted three community conversations to discuss the intersection of racism and health, and we recruited participants largely from the Partnership for a Healthy Durham.

Who Participated

24 Durham community members participated in our conversations, including 4 men and 20 women.

- 12 participants are leaders of community organizations
- 11 work in public health
- 11 are members of the Partnership for a Healthy Durham
- 20 are from historically marginalized communities of Durham



What They Said

We started by discussing how folks envision health equity. Here's what folks said:

What image, word, or phrase comes to mind when you think of 'health equity?'



Then we talked about how public health agencies in North Carolina use CDC survey data, and how it can be improved from an antiracist perspective. The North Carolina Department of Health and Human Services listed these points in response to how they use CDC survey data:

North Carolina

- Highlight the prevalence of sedentary lifestyle among North Carolina adults and promote the development of a statewide physical fitness campaign.
- Provide data for the North Carolina Prevention Report Card and Women's Health Report Card.
- Determine the prevalence of disability and activity limitations among North Carolina adults.
- Describe demographic, behavioral, and quality of life characteristics of North Carolina adults with disabilities.
- Determine diabetes preventive care knowledge and practices among North Carolina adults with diabetes, and describe the impact of diabetes on cardiovascular disease burden in North Carolina.

Key Takeaways from our Community Conversations

Structural Racism

Summary statement: Structural determinants of health should be centered instead of individual behaviors & risk factors. Our systems of funding & healthcare are rooted in racist histories. Public health research and communication is focused on individual biology, behaviors, and risk factors – this perpetuates a narrative of personal responsibility, which is visible in the existing uses of data in North Carolina.

Key supporting quote: *“These reports don’t address root causes and completely miss the mark. These are all important things to address, but we need to tackle the foundation in order to resolve the issues. People put bandaids or low-hanging objectives that can be checked off, but needs to be levels deeper.”*

Government Accountability

Summary statement: Where do government funds dedicated toward health equity go? Resources should be dedicated to community, specifically organizers who are already doing the work.

Key supporting quotes: *“When you’ve got a finger pointing at someone, you have to remember you’ve got [many more] fingers pointing at you – [the government] needs to recognize that when they’re pointing a finger at individuals they need to take responsibility.”*

“Do we have data on the amount of government funds that is allocated to address health disparities and what percentage actually reaches this cause?”

“We have people working everyday and we know what we want to see changed – give those people organizing already the resources they need to implement the solutions we’ve already come up with. Solutions that are not designed with us are not designed for us and won’t work for us. Stop having listening sessions and using our ideas to

make money. Folks who are already out here filling gaps we didn't create need to be recognized and compensated. I want firm commitments about what investments CDC and our government systems plan to make into the community. Where's the proof from them that they're going to use the money responsibly, I want to see receipts."

Chronic Stress

Summary statement: Racism results in chronic, consistent stress which contributes to racial health disparities

Key supporting quote: *"Engage our awareness around the day to day stressors: fear of being stopped by the police, actually being stopped by the police, being unable to go outside at certain times of day. The body being under that stress over time leads to actual cellular aging. What is the nature of our food, our daily exposures. There is a difference by race."*

Access to Care

Summary statement: One way that structural racism manifests is through access to health care. This means differences in physical access (e.g. transportation), quality of care, and insurance coverage.

Key supporting quote: *"People who are less connected to systems don't receive resources from public services. People who are homeless or transient are not connected and not represented in survey efforts like this."*

Representation

Summary statement: People from marginalized communities are under-represented in research and public health data. CDC survey data are usually from small groups of people and are interpreted to represent everyone. More diverse representation will improve the usefulness of survey data. More diversity in participants is needed across many identities and circumstances:

- Race
- Ethnicity
- Income & wealth
- Gender identity
- Sexual orientation
- Language spoken
- Age
- Ability
- Rurality
- Nativity

Key supporting quote: *"Mental health is not included in the CDC examples. A lot of health issues stem from not having a healthy mind. People who are not prone to participate in care may have been driven to fear and anxiety about health care by racist experiences."*

Words Matter

Summary statement: Most public health data and documentation is framed to focus on deficits instead of assets. Public health data does not focus enough on prevention. Deficit-focused metrics and language are alienating, community input on language will make national surveys and tools more inclusive. Phrases like "sedentary lifestyle" and "burden" feel judgemental.

Key supporting quotes: *"These [behavioral metrics that North Carolina uses] come from a deficit-based perspective. It's ignoring the structural factors that lead to poor health/risk behaviors."*

"The word 'burden' is very stigmatizing – they are saying people with diabetes are a 'burden' to the state. They didn't choose to have this disease; to classify them as a burden is very stigmatizing."

Opportunities to Improve Survey

Health issues of interest	Data takeaways
<ul style="list-style-type: none">- Access to healthy food- Aging- COVID-19 & vaccine access- Dementia- Drug addiction- Housing- Maternal health, infant health- Racial disparities- Safety- Water quality	<ul style="list-style-type: none">- Disaggregate reported numbers by race, ethnicity, and gender- Make data available at smaller geographic units- Make detailed data available and accessible on how federal funds are distributed and who receives them