

People with Lived Experiences of Inequity in Data Sharing Projects

Findings from the 2021 All In National Inventory

Higher involvement of PWLEI in data sharing collaborations is correlated with data practices that advance health equity.

There is growing evidence about the benefits of including people with lived experiences of inequity (PWLEI) in public health decision-making and affording PWLEI positions of authority to shape expectations, decisions, and outcomes.

PWLEI often know best what needs to happen in the community to improve health and wellbeing. Indeed, higher involvement of PWLEI in data sharing collaborations is correlated with data practices that better contribute to the advancement of health equity.

It is essential that data projects include PWLEI in meaningful ways in the data sharing cycle.

On average, only a quarter of data sharing collaborations include PWLEI at a high level

Levels of PWLEI Involvement in the Data Sharing Cycle



Positive effects of PWLEI inclusion on data practices

COLLABORATIONS WITH HIGH LEVELS OF PWLEI INCLUSION

Assess Risks of Sharing

Sample size: 60 projects

74%

assessed how the risk of data sharing could vary by identity group

Include Community Level Data

Sample size: 65 projects

68%

incorporated community level data into their analyses

Address Data Biases

Sample size: 61 projects

74%

addressed potential biases within the data collected

COMPARED TO COLLABORATIONS WITH LITTLE TO NO PWLEI INCLUSION

35%

48%

34%

Potential benefits of PWLEI engagement



Equity

Draw focus on historically underfunded areas

Identify and address biases and harms of existing data systems and processes

Identify gaps that prevent addressing structural racism and inequities



Sustainability

Provide feedback to help minimize harm in future data collection

Promote further PWLEI inclusion and minimal barriers to participation

Address power relations and create environment that fosters trust



Analysis

Discover new ways to interpret data

Provide qualitative stories to contextualize quantitative data

Improve the understanding of community beliefs and practices among partners



Systems Change

Identify needs unique to each community

Facilitate and expedite the development of locally relevant initiatives

Report data in actionable form to improve lives of those represented in data

Suggested Resources

Click or scan for resources



Charting a Course for an Equity-Centered Data System by RWJF



A Toolkit for Centering Racial Equity Throughout Data Integration by AISP



Rising Equitable Community Data Ecosystems (RECoDE) by data.org

About This Survey

Data Across Sector for Health (DASH), working with its partners at All In, data.org, NADPH, and others, carried out the National Inventory 2.0 survey in 2021.

Overall, DASH surveyed 143 participants of data sharing collaborations across the United States about how PWLEI are involved in their work.