



Amplify: Letting Community Engagement Drive ‘Evidence to Action’ Planning

Populations that are not captured in existing data structures are unlikely to have their nuanced needs adequately expressed or prioritized by decision-makers, contributing to COVID-19 health inequities. This session facilitated a conversation about humanizing data management by maximizing community engagement, surveys, interviews, and focus groups, while uplifting traditional and local stories. Panelists discussed best practices for collecting data in ways that honor the participants and for conveying data in ways that result in more comprehensive support (policy change, wrap-around services, capacity building, etc.).

What is humanizing data collection?

- Humanizing data collection refers to the process of collecting data in a way that honors participants and does not exploit their traumas.
- Organizations must be intentional about centering community needs and amplifying community voices, in decisions around data collection.

Why is amplifying community voice in data collection important?

- Many populations, notably people of color and LGBTQ+ people, have either been systematically excluded from data/research or have been exploited and treated poorly by researchers.
- These communities may be more likely to mistrust governmental organizations and other institutions that are conducting research or collecting data.
- These communities also may be more likely to experience worse health outcomes due to the legacy of systemic oppression.
- This makes it particularly important to engage with those communities and collect data in a way that does not widen those disparities.
- Additionally, data collection that centers on community voice often correlates to data conveyed in a way that closely aligns with community needs, which is important because data can have a tangible impact on policies and on people’s quality of life.
- Data collection that amplifies community voice and conveys community needs is more likely to result in decision-makers centering the community in their work and in their allocation of resources.

How can organizations best amplify community voice in data collection?

- Organizations need to consider who may have been historically excluded from data collection and the reason why. Common reasons communities may be excluded from data collection include data not being collected in their languages or in locations they frequent.
- In data collection efforts, organizations should make a thoughtful and intentional effort to diversify where and how they collect data.
- Organizations should also collect data in a way that honors participants. This means that communities should benefit from this data collection, and researchers should not collect data in a way that exploits — or seems to exploit — participants’ trauma and life stories.

- At the same time, organizations need to explicitly acknowledge that many communities have previously been exploited and mistreated by researchers, and they need to build trust with communities prior to collecting more data.
- When possible, communities should lead in both data collection and in turning data into decisions about policies and resource allocation. Community members are experts in their own lives and needs, and external groups can improve their data collection by having the humility to recognize their limitations.



Resources to learn from:

The below resources may be helpful starting points for health departments, but it is important to note that every community is different, so these resources may need to be adapted.

[Charting a Course for an Equity-Centered Data System](#)

Recommendations that discuss how entities can improve their data systems and identify needed investments to improve health equity related to data infrastructure. These recommendations feature a series of white papers relevant to a broad range of stakeholders.

[Empowering Equitable Data Use Partnerships and Indigenous Data Sovereignties Amid Pandemic Genomics](#)

An article that provides a framework for partnering with Indigenous communities in research and data collection. A major guideline for data collection focuses on creating equitable data use agreements. Other guidelines focus on building trust and sustainable relationships.

[Engaging Immigrant and Racialized Communities in Community-Based Participatory Research During the COVID-19 Pandemic: Challenges and Opportunities](#)

A peer-reviewed study that considers the importance and challenges of community-based participatory research during COVID-19. The article concludes that community-based participatory research requires flexibility to pivot and equity in research participation.

[Leveraging Community Information Exchanges for Equitable and Inclusive Data: The CIE Data Equity Framework](#)

A toolkit that advises entities on building a Community Information Exchange data system from an anti-racist lens. Key recommendations include naming and dismantling existing systems of oppression in data collection; reimagining ways to address people's needs; and building practices for restorative justice.

[A Toolkit for Centering Racial Equity Throughout Data Integration](#)

A toolkit that helps organizations center racial equity across six stages of the data collection process: planning; data collection; data access; algorithms/use of statistical tools; data analysis; and reporting and dissemination.

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