Adopting Data Equity Principles in Public Health Research and Analysis

There is power in data. It drives decisions, influences funding, and can change lives…for better or worse. Implicit biases influence the decisions we make, including data decisions. Biases infiltrate data, potentially skewing or discrediting findings.

Common Ground Health is on a journey to embed data equity principles into our research and analytic processes to ensure that our work is inclusive, equitable, and minimizes potential biases.

Potential for bias exists at every stage of research and analytic processes. To mitigate biases in our work, staff participate in data equity training utilizing an approach developed by Heather Krause at We All Count. We actively integrate and adapt these principles to fit the work we do.

What do we mean by data equity?

Data equity is an approach to critically examining the ways in which data are collected, analyzed, interpreted, and shared. We operate on the principles that:

- Data are not objective;
- Data can create and perpetuate power dynamics;
- Equity needs to be considered throughout each phase of the data life cycle.

Data are collected, analyzed, interpreted, and shared by people who carry with them subjective experiences and potential biases, whether we realize it or not. We integrate an equity lens into our work to ensure that those who the data represent are not misrepresented and/or harmed by our analyses.

How do we integrate data equity principles into our work?

We use the “We All Count” framework, which identifies seven different areas to integrate equity into a data project. These phases are:

1. Funding
2. Motivation
3. Project design
4. Data collection and sourcing
5. Analysis
6. Interpretation
7. Communication and distribution

Here are examples of ways in which we have embedded and adapted these phases, as necessary, to integrate equity into our data work.

Funding: Funding dynamics have the potential to influence the ways in which a project is conducted. At the beginning of a project, we identify the interplay between money, raw data, data reports, and influence within a project. We differentiate raw data from reports as we feel different power dynamics exist between those with the ability to create narratives from raw data and those who have a narrative delivered to them through aggregated data found in a report.

Motivation: Each member of the team brings with them a different reason for participating in a project and different perspectives as to why they feel the organization is working on a particular project. We dedicate time at the onset of each initiative to identify intrinsic and extrinsic reasons for completing a project. Team members individually draft a motivation statement and come to consensus to create a single motivation statement for the organization.

Project Design: Biases can infiltrate all elements of project design if we do not critically assess the ways in which data are collected. Data collection instruments including survey tools, assessment forms, and interview and focus group guides can quickly derail well-intentioned projects if not examined through an equity lens. We find that intentional partner engagement is critical to equitable work. Partner organizations and community residents have provided us with feedback on our data collection tools. They let us know when they may not have felt included in our response options on a survey or when they felt that one of our questions has a "judgy tone." They also let us know what data is important for them so that we can integrate it into our work. For example, members of the Indigenous community in our area wanted to know what specific tribes were located in our region. We were able to build simple skip logic into our tool so that if someone indicated that they identified as American Indian / Alaska Native, they would be prompted to share their tribal membership. In a different example, based on the suggestion of a partner organization, we added a section for fathers and non-birthing parents to a survey we were developing after they noted that maternal and child health section was not as inclusive as it should be.

We also examine the roles of partner organizations and community residents beyond providing feedback and input on tools. Intentional engagement of partners is critical, whether through a Community Advisory Group or Memorandums of

Understanding. Community-based organizations and community residents have helped us to frame questions and responses, think through recruitment strategies and how best to reach the audience that we want to hear from, and determine what incentives may work best for different groups of people.

Data Collection: The ways in which data are collected matter. Who has the opportunity to be heard in data collection efforts? Whose voices are likely to be missing? At Common Ground Health, we try to model a multi-modal approach to primary data collection whenever possible. Our strong preference is for electronic data collection, but we realize that there are still large segments of the population unlikely to complete an electronic survey due to comfort level with technology or access to broadband and the devices it supports. With secondary data, we aren't always able to influence the content or parameters in which data are collected. We do, however, have an ethical obligation to be transparent about who is included and who is excluded from our data through the use of a data biography. A data biography should describe information about the data set including:

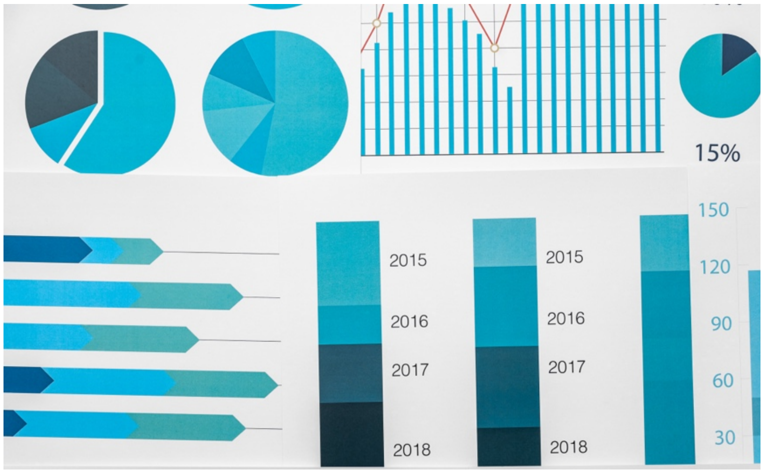
- The source of the dataset
- Who is included in this dataset
- Who is excluded from this dataset
- When the data was collected
- Times when data was intentionally not collected
- Where data were collected
- Why data were collected
- Any limitations with how data were collected

Analysis and Interpretation: Equity does not exist without transparency. Detailed documentation for how data are cleaned, transformed, aggregated, and analyzed is essential for advancing equity. Iterative processes are warranted for interpreting results as well. When making meaning from data, partners with diverse perspectives should review data interpretations to flag for potential biases.

An example of how Common Ground Health incorporates data equity principles is how we have redefined geographic classifications throughout our region. Previously, our work relied on three defined geo-classifications: urban, suburban, and rural. In this over simplistic definition, rural was primarily defined as "not urban." This definition did not consider the nuances of rurality, nor did it include residents' self-perceptions of their geographic area. After conversations with rural partners, we developed a new methodology resulting in six different geographic areas: urban, suburban, rural – transitional, rural – population center, rural, or correctional facilities. These definitions include more nuances and better describe the geography of our region.

Communication and Distribution: Like interpretation, narratives form through specific lenses and perspectives. At the communication and distribution phase, we need to consider key points, including:

- Who creates the narrative?
    - What perspectives or lenses might they be utilizing?
    - Is a group being described who have not had the opportunity to provide insights and context to analyses?
- Who reviews and has editing rights?
- Who has access to the data and at what level?
- Who is centered (or not) in data visualizations?



If analyses focus on a specific group of people, then members of that specified group must have the opportunity to offer context, alternate interpretations, and insights into the ways in which this information is documented and communicated.

Additionally, we modified our approach for depicting race and ethnicity in data visualizations. Our previous model included three main groups: Hispanic, Non-Hispanic Black, and Non-Hispanic White. All other races were omitted from charts and graphs due to small sample sizes within our region. We now include an "All" line in visualizations so that people identifying as Asian, American Indian/Alaska Native, Pacific Islander, Middle Eastern, and those who prefer not to say are still included and represented in the data. While still not a perfect solution, this shift allows for more residents to be visually depicted in our analyses.

How do we continue to advance data equity?

We continue to integrate data equity principles into our research and analytic work. We also continue to promote data collection efforts among community-based organizations and non-academic researchers. Diverse perspectives are vital to advancing data equity. If CBOs do not have the capacity to collect their own data, we are committed to sharing as much data with them as possible while maintaining the terms of each data set. We have yet to integrate the entirety of these principles into one project but will continue to strive to do so.

> *“If we do not address power dynamics in the creation of research, at best, we are driving decision-making from partial truths. At worst, we are generating inaccurate information that ultimately does more harm than good in our communities. This is why we must care about how research is created.”*
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> – Chicago Beyond
> (national philanthropic organization)