The Public Health Institute at Denver Health Data Equity Principles

The Public Health Institute Commitment to Equity in Data

The Public Health Institute at Denver Health (PHIDH) aspires to present data humbly, recognizing numbers never tell the whole story. We strive to work with individuals and communities to learn and share their stories to improve collective understanding. Knowing that people, from various communities, across life circumstances have inequitable opportunities to achieve optimal health, we commit to pair numbers and stories to inform policy and systems change to improve health for all.

Purpose: The intent of this document is to demonstrate ways in which we at PHIDH can make the methods in which we analyze data more equitable. The principles below are meant to prompt conversations with colleagues and community members about how we are analyzing our data to ensure that we aren't making any of these decisions alone. Given that maintaining confidentiality is a priority for PHIDH staff; at times, maintaining confidentiality will supersede the consideration and implementation of some of these principles. Continued learning and conversations will allow us to continually improve our equitable data practices even when confidentiality must be protected. This document is meant to be a living document and as we learn more, it will be updated over time.

The Data Equity Principles

1. We recognize that systemic, social, and economic factors – racism being the largest – impact health outcomes.

2. We understand that health inequities are worse for communities who experience injustice.

3. When we talk about people, we use a strengths-based approach; when we talk about inequities, we use a systems level approach. We do this to avoid judgment, blame, or marginalization of individuals or communities.

4. We strive to include the lived experience and traditional knowledge of community members into population health analysis, because the community health experience is complex.

5. We proactively engage communities to identify inequities and disparities, interpret findings, shape our work, and act toward improving health.

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1. **We recognize that systemic, social, and economic factors – racism being the largest – impact health outcomes.**
   a. Identify ways in which systemic racism and discrimination affect health outcomes.
   b. Understand that race is a social construct not an inherent biological determinant of health.
   c. Learn more about populations and health issues with which we are not currently familiar.
   d. Recognize and challenge how personal biases affect analysis and reporting of data through thoughtful discussion with those we work with and self-reflection. This can be done by writing about the research or evaluation team including what biases they may have, how that may have impacted the work, and what the team might do differently next time.
   e. Share choices we make when collecting and analyzing data. Be transparent about the limitations of our analyses and data sources.
   f. Encourage our funders to understand and align with our internal efforts around equitable data reporting.

   Examples:
   - When you want to talk about the differences in health experiences or health outcomes the variable of 'race' should only be used to highlight that certain communities have poorer outcomes because of the experience of racism or greater exposure to structural drivers of poor health. To avoid stereotyping, recognize that singular elements of demographic data are not the sole explanation for an outcome or effect. Dig deeper into other variables that may be influencing the associations between one community and disease risk factors. The American Medical Association's new policy on the importance of recognizing race as a social construct when thinking about community health can provide more context: https://www.ama-assn.org/press-center/press-releases/new-ama-policies-recognize-race-social-not-biological-construct
   - It is important to contextualize your data. When you only have 'race' and can't dig into what it might be a proxy for, don't use it or be transparent that race is probably standing in for something else, but you don't have the data to find out what.
   - Include an explanation of who identified participant race and ethnicity and the source of the classifications used (i.e. self-report or selection, investigator observed, database, electronic health record, survey instrument, market data, etc.).
   - Funders of our work often ask for a limited set of demographics factors (Black, White, Hispanic, Asian, Native Hawaiian/ Pacific Islander etc.). Internally we often collect this information in a more expansive manner that relates better to the community. Sometimes this may require us to collapse our categories for grant reporting causing it to not align with our internal equity goals. This is acceptable; however, we should continue discussions with funders so they can better align without commitment to equity in data.

2. **We understand that health inequities are worse for communities who experience injustice.**

   a. Disaggregate data by race, ethnicity, gender, nativity, ancestry, income, location, and other factors to the extent possible while cognizant of intersectionality. Very few individuals experience life through a single lens. Most experience more than one at the same time and at times disaggregation may hide this intersectionality.

   b. Support the collection and use of new data to fill gaps in knowledge about populations underrepresented by current methods through means that do not introduce bias into the data or alienate individuals.

   c. Avoid analyses that privilege a population as being "normal" or "desirable" compared to others denying the experience of those in smaller groups.

   d. Understand how p-values can lead us to call a problem experienced by a large group "real" while we dismiss the very same problem experienced by smaller groups as "chance". P Values are highly dependent on sample size.

Examples:

- Small sample sizes are going to happen. To address small sample sizes we suggest determining how to deal with small sample sizes before data collection and analysis. Report your results in more than one way and be transparent about the dilemmas, compromises, and choices made in collection and analysis. When possible, engage with communities whose representation in your data is small about how they would want data about their identities combined with the identities of other groups.

- New theories are emerging on how to best approach data through an intersectional lens. For more ideas see: bit.ly/IDC-primer

- It is very easy to use white individuals as the baseline comparison group, largely because they are often the largest subgroup, which automatically often makes them the "normal" standard. There are times where this can be beneficial and makes the most sense statistically, but it is important to be explicit about that choice and have conversations about how you are making comparisons.

- P-Values are most important for peer reviewed literature and represent statistical significance. For most of the work we do in public health, clinical or programmatic significance should also be considered when determining what are meaningful data or outcomes. Here is a link to a great explanation of why. https://weallcount.com/2022/07/29/dont-let-the-p-in-p-value-stand-for-privilege/

3. **When we talk about people, we use a strengths-based approach; when we talk about inequities, we use a systems level approach. We do this to avoid judgment, blame, or marginalization of individuals or communities.**
    a. Use person first language in written descriptions to acknowledge a person's identity beyond their condition, ability, situation, or experiences.

Examples:

- Think about who you are putting the onus on for change, what your definition of success is, and if your question is in alignment with your equity goals.
    o "Is our project making LGBTQ+ students more comfortable in our school environment?" This puts the onus for change on the LGBTQ+ students when it should be on the school environment. "Is the school environment changing to allow LGBTQ+ students to feel more comfortable and engaged?"
- The CDC has a guide for preferred terms for select populations, groups and communities: https://www.cdc.gov/healthcommunication/Preferred_Terms.html

Use This… (Based on consensus, research or subject matter expert)	Instead of this…
People/ Person with disabilities/ a disability	Disabled
Persons who use drugs/ people who inject drugs or Persons with substance use disorder	Drug users/addicts/drug abusers
People/Persons who are underserved by [specific service/resource]	Underserved people/communities
People/Persons experiencing homelessness	Homeless people/the homeless
People/Persons with lower incomes, People with incomes below the federal poverty level	Poverty-stricken or Poor People
People/Persons with a mental illness, People with a pre-existing mental/behavioral health disorder	Mentally Ill, Crazy, Insane
People/Persons with undocumented status	Illegal Immigrant
Older Adults, Persons Aged [numeric group], Elders when referring to older adults in a cultural context	Elderly/ Senior
People/Persons who are at an increased risk for [condition]	Vulnerable or high-risk population
[Racial or Ethnic Group] persons	Referring to people by their race/ethnicity
LGBTQ or Lesbian, gay, bisexual (when referring to self-identified sexual orientation)	Homosexual
Transgender, assigned male/female at birth, gender non-conforming, two spirit	Transgenders/ transgendered/ transsexual

4. **We strive to include the lived experience and traditional knowledge of community members into population health analysis, because the community health experience is complex.**
   a. Work to tell a story through data so that we, in partnership with community, can act with the data.
   b. Recognize that data can have a powerful effect on people. Commit to create the time and space to process and receive feedback anytime data is being presented.
   c. Pair data visualizations and graphics with a simple written summary to increase clarity and accessibility of your work to audiences with varying data literacy.

   Examples:
   - Mixed Methods Research- The combination of both quantitative and qualitative data to draw of the strengths of each to facilitate a more comprehensive understanding of a topic and potential solutions
   - A Visual Abstract is a summary of the key findings of an article, presented in a graphical format for easy uptake by readers. It gives the reader a quick overview of the main study findings at-a-glance and helps them decide whether the paper is relevant to their interests. Such a representation of the study also allows for better dissemination of the article to a broad audience. https://support.jmir.org/hc/en-us/articles/4403710296091-Visual-Abstract-Gallery
   - Photovoice- Photovoice is a process in which people use photo images to capture aspects of their environment and experiences and share them with others. The pictures can be paired with captions created by the photographers, to bring the realities of the people's lives to light to inspire change. Photovoice may be used to encourage critical consciousness. Through choosing, discussing, and reflecting on the submitted photos, people can come to a clearer understanding of the economic, social, psychological, and political forces that impact themselves and their communities. It is often used to uplift the voices of individuals and communities that are often not given a voice to bring about change, improve conditions, and enhance lives by reaching and influencing decision makers. A great example of work within PHIDH can be found here: EYE_PhotoVoiceReport_030223 (strongerwithout.com)

5. **We proactively engage communities to identify inequities and disparities, interpret findings, shape our work, and act toward improving health.**
   a. Collaborate to reveal, evaluate, and alter the power structures that are involved in a data project to get the equity all involved desire. The ways in which we can do this are:
      i. Collaborate with community members to determine data collection methods, design data collection tools, identify key findings from data collected, determine how data should be presented, and guide decision making about future data collection efforts.
      ii. Ensure that those we are collecting data from understand how their data will be utilized and own the data that they are providing (i.e., if an individual decides they no longer want you to have their data, they can tell you to delete it). Permission must be obtained for any additional use of the data outside of the original intent.

Examples:

- PHIDH has several examples of how to engage with community members throughout the research process. A few of note:
  - Public Health for Public Safety Community Leadership Team- PHIDH recruited a diverse team of individuals with lived experience related to violence, victimization and healing. The team committed itself to the goal of prevention violence and victimization and to the promotion of trauma-informed, culturally responsive interventions, systemic transformations and individuals and community healing. The leadership team was empowered to design a community survey and conduct focus groups to further understand the experiences of those that have interacted with the criminal legal system. The team designed the surveys and focus groups, facilitated the focus groups, reviewed and identified key findings from the data, and wrote reports on the data collected.
  - Engaging Youth Expertise (EYE) for Prevention: EYE for prevention is a youth leadership team made up of about 10 youth with lived experience of substance misuse and mental health struggles. The youth have been engaged in the collection and interpretation of both qualitative and quantitative data. Most notably a photovoice project in which the youth leaders engaged youth throughout the Denver Metro area to collect pictures of things in their communities that depicted things that contribute to youth using substances and things that prevent youth from using substances. The youth also hosted discussion groups with youth the gather additional thoughts on photos submitted. The youth were guided through how to analyze the data collected and summarize the information in a format of their choosing. Recommendations and next steps were developed by the youth leaders and the information was used to create trainings to assist adults that work with youth.

Resources List

- **Recommended Reading**
  - [Doing Evaluation in Service of Racial Equity: Debunk Myths](#)
  - [Doing Evaluation in Service of Racial Equity: Diagnose Biases and Systems](#)
  - [Doing Evaluation in Service of Racial Equity: Deepen Community Engagement](#)
  - [Health Equity Style Guide for the COVID-19 Response: Principles and Preferred Terms for Non-Stigmatizing, Bias-Free Language](#)
  - [Equitable Evaluation Framing Paper](#)
  - [Do no Harm Guide: Applying Equity Awareness in Data Visualization](#)
  - Book: [Algorithms of Oppression: How Search Engines Reinforce Racism](#)
  - Book: [Weapons of Math Destruction: How Big Data Increases Inequality and Threatens Democracy](#)
- **Existing Tools**
  - [Dabbling in the Data: A Hands-on Guide to Participatory Data Analysis](#)
  - [Power Mapping and Analysis](#)
  - [Creative Ways to Solicit Stakeholder Feedback](#)
- **Trainings**
  - [Decolonizing Data: Restoring Culture, Building Beauty- Abigail Echo-Hawk](#)
- **Additional Resources**
  - [We All Count](#): It's a project to increase equity in data science. This project has a place for you in it if you want to work towards a world where data science is good, and good for everyone.
  - [Equitable Evaluation Collaboratory:](#) The Colorado Collaboratory is a co-created space where all evaluators can move their practice forward, no matter where they are starting. This community of practice provides evaluators with opportunities to build a shared understanding of what it means to do equitable evaluation, to challenge our own assumptions about how evaluation is currently done and explore approaches to doing evaluation in more equitable ways. This will require you sign up.
  - [Center for Anti-Racism Research for Health Equity-](#) Structural racism is a public health crisis, but it is also a fixable problem. The Center for Antiracism Research for Health Equity (CARHE, pronounced "care") was founded to explore, understand, and ultimately dismantle structural racism.