

Principles for Using Public Health Data to Drive Equity

A guide to embedding equitable practices
throughout the data life cycle

Executive Summary Developed by

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Acknowledgments



Robert Wood Johnson Foundation

Principles for Using Data to Drive Equity was made possible with support from the Robert Wood Johnson Foundation. The views expressed here do not necessarily reflect the views of the Robert Wood Johnson Foundation.

The report was compiled by the CDC Foundation. The CDC Foundation is an independent, nonprofit organization that helps the Centers for Disease Control and Prevention (CDC) and public health communities do more, faster by forging effective partnerships between CDC and individuals, foundations and corporations to fight threats to health and safety.

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Center for State, Tribal, Local, and Territorial Support

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In addition, a special thank you to Renee Canady, Michigan Public Health Institute (MPHI); Hilary Heishman, Robert Wood Johnson Foundation; and CDC Foundation team members Sandra Bonzo and Pierce Nelson for their valuable input.

Executive Summary

With the emergence of COVID-19 and its devastating and disparate impacts on communities, researchers and public health practitioners are recognizing their power to shift conversations about health inequities by centering these conversations on community-level participation and voices. Acknowledging this power, the Principles for Using Public Health Data to Drive Equity aim to ensure the integration of equity principles across the data life cycle.

[The Principles for Using Public Health Data to Drive Equity](#) (also known as data equity principles) bring an equity lens to each stage of the data life cycle. Their development is the result of an environmental scan conducted by the CDC Foundation of current national data surveillance systems to identify best practices to build equity-oriented data. The data equity principles incorporate and build on existing guidelines, frameworks, action plans and thought leadership of many who are pushing the field of data equity forward. They are not a substitute for the previously developed toolkits and guides providing specific examples and recommendations.

What we explore with the data equity principles—and what we believe contributes to the public health field—is a broader framework that views research beyond the project level to consider how our methods throughout the data life cycle can make more impactful and equitable contributions to public health data systems. The data equity principles provide a framework for a shift in thinking about how equity-mindedness throughout the entire data life cycle can shape and create more equitable data systems.

Data Equity Principles

The data equity principles acknowledge the power data has in shaping community health and wellbeing by encouraging a shift in practice by multiple data contributors to help eliminate health inequities, minimize bias in data and further repair trust with communities who have experienced prior harms. There should be a focus on applying equitable practices, such as the data equity principles, throughout the data life cycle, integrating them at each step of the process.



PRINCIPLE 1

Recognize and define systemic, social and economic factors which affect individual health outcomes and communities' ability to thrive.

Potential Application: Explicitly acknowledge the systems, policies and practices that have led to historical and current inequities and influence factors linked to health.

Example Reflection Questions: What factors do members of our focal community want measured regarding this health issue?

How can our data capture the current and historical policies, biases, customs and structures that cause some groups to have worse health outcomes than others?

Do we use strengths-based language and inclusive visuals to describe the communities or groups reflected in the data?

Do we explicitly acknowledge the unjust systems and structures which lead to the measured health inequities?

How will we discern program acceptability and effectiveness across different groups?





PRINCIPLE 2

Use equity-mindedness as the guide for language and action in a continual process of learning, disaggregating data and questioning assumptions about relevance and effectiveness.

Potential Application: Discontinue exclusionary practices such as utilizing racially or culturally standardized reference categories across all programmatic and disease-specific data analyses.

Example Reflection Questions: How can we gather more complete data around race, ethnicity and language to understand the differential impact of system-level factors?

How can we use this work to understand and leverage community assets and strengths?

How does the way we aggregate racial and ethnic groups obscure unique experiences?

How can we expand our epidemiologic methods to increase availability of data regarding small populations—such as indigenous peoples—so as not to render these groups invisible in reporting?

What steps will we take to communicate how collected data is used to address the concerns of the communities and/or groups represented in the data?

In what ways does our report elevate and contextualize the lived experiences of communities and/or groups represented in quantitative data?

Have we explicitly acknowledged and described how data collection and methodological decisions may affect the ability of our data to inform equitable action?



PRINCIPLE 3

Proactively include participants from the communities of interest in research and program design to allow for cultural modifications to standard data collection tools, analysis and sharing.

Potential Application: Assess currently implemented programmatic and disease-specific surveillance systems for opportunities to proactively engage community members.

Example Reflection Questions: How can the same data be organized and shared in different ways to meet the unique needs of many communities?

In disseminating results, what audiences are most important to reach and what stories are the most important to tell, as defined by community members?

Even though scientifically validated, are survey questions meaningful and relevant to the focal community?

What approaches are we using to analyze and interpret our data in collaboration with community members?

In what ways will we build capacity among community organizations and leaders to effectively access and use the data to pursue their self-defined needs and actions?

How are we fostering growth mindsets to listen to community feedback and use it to improve our data processes in iterative and ongoing ways?



PRINCIPLE 4

Collaborate with agencies and the community to generate a shared data development agenda ensuring a plan for data completeness, access and prioritized use to answer high-interest questions.

Potential Application: Embed communities in data governance structure to elevate community voices and create balanced power structures.

Example Reflection Questions: How will community expertise and perspectives be centered throughout the project or initiative?

How will we engage community members to prioritize what issues are addressed and questions asked in developing the research agenda and plan?

How will community members be involved in identifying solutions to challenges that arise throughout the data lifecycle (e.g., poor recruitment, small sample sizes)?

What actions do community members want to promote in response to the data findings?

How are we collaborating with communities to identify relevant actions that address the health inequities identified in our data collection?

How will we hold ourselves accountable to impacted communities in our response to the health inequities identified?



PRINCIPLE 5

Facilitate data sovereignty by paving the way for communities to govern the collection, ownership, dissemination and application of their own data.

Potential Application: Ensure current data collected across the agency from communities reflect the communities' values and priorities.

Example Reflection Questions: Who has ultimate decision-making power for the project?

If the community raises concerns, will the idea or plan be revised, reconceived or even suspended?

How is data sharing governed and do community members have control over who can access the data?

Have we created transparent processes and accountability that ensures tribal nations in our jurisdiction have access to their national data?

The Data Lifecycle

The phases of the data life cycle include the following:

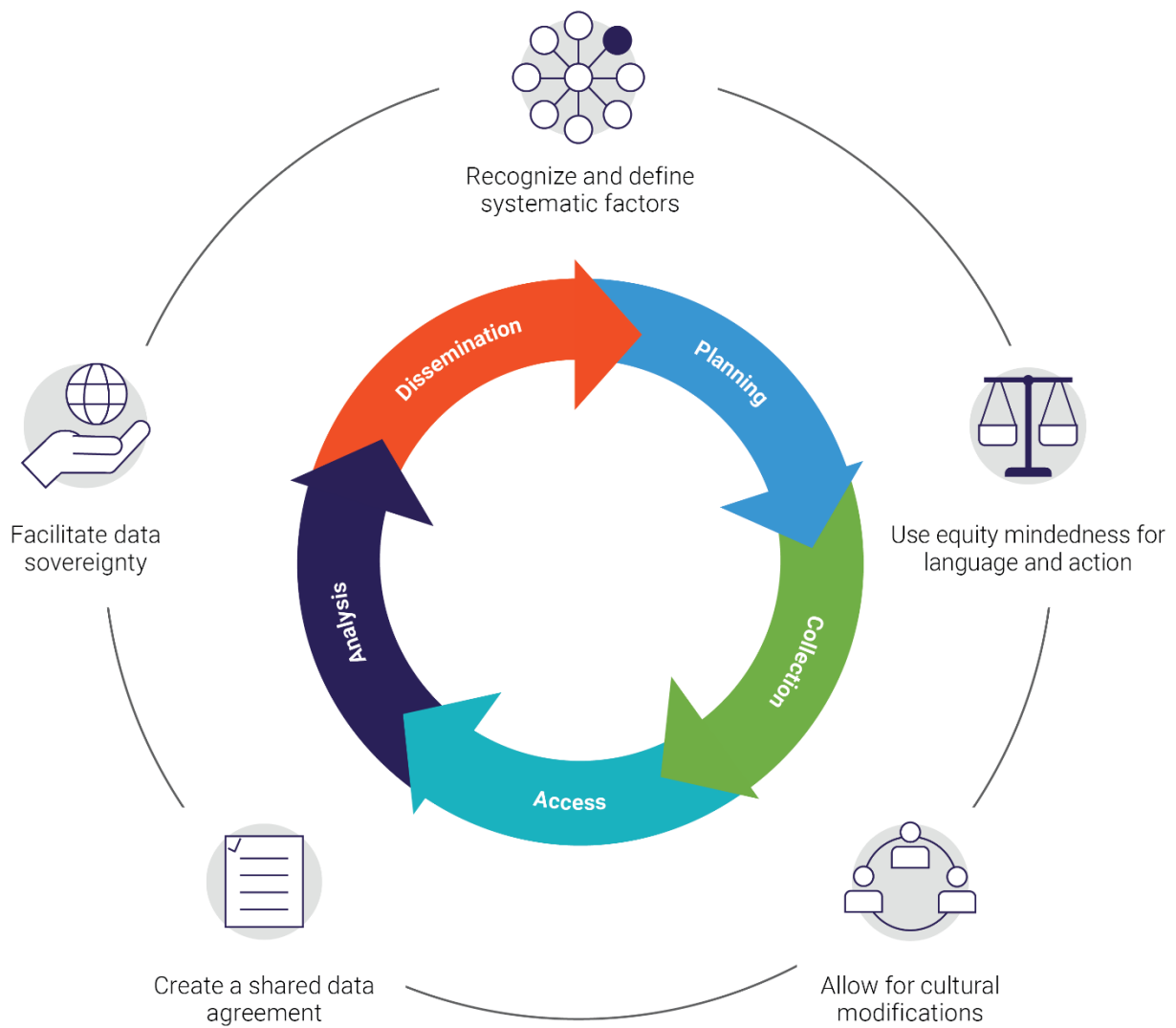
- **Planning:** Developing a mission or purpose for data, defining issues to be addressed through data, understanding the current and historical local context and assets and identifying inclusive methodologies and appropriate variables.
- **Collection:** Gathering information to inform research, program or policy. This includes primary and secondary data collection as well as quantitative and qualitative data collection.
- **Access:** The practices associated with determining who can securely obtain, view or use data and for what purpose.



- **Analysis:** Interpreting data to develop findings, conclusions and recommendations, while understanding the impact of potential biases stemming from data collection approaches, the use of algorithms and selected research methodologies.
- **Dissemination:** Sharing findings in varied ways and with appropriate audiences to influence program planning, policy making and resource allocation.

To eliminate health inequities, organizations and individuals can incorporate the equity principles throughout the entire data life cycle.

We recognize that organizations may not have domain over all steps of the data lifecycle for all projects; however, the data equity principles are designed so that individuals, teams and organizations could use them to reflect on ways to improve in the areas where they have influence.



Equitable Actions Through State and Local Agencies

The following table provides considerations on ways that organizations at the state and local levels can apply the data equity principles throughout the data lifecycle.

<h3>Planning</h3> <ol style="list-style-type: none">1. Cultivate and leverage partnerships to support health equity efforts across subnational regions.2. Encourage developing a research and governance plan in coordination with community-based organizations.3. Use community engagement to prioritize what issues are addressed/questions asked in developing the research agenda.4. Promote the integration of data, potentially through a health information exchange, to improve accessibility of community services.	<h3>Collection</h3> <ol style="list-style-type: none">1. Create public forums to offer transparency into how data helps advance public health.2. Regularly review existing data sources to determine what additional data is needed to identify inequities (e.g., more robust demographic information).3. Find out why people opt out of providing data for surveys and other data collection efforts and use their feedback to minimize harm in future data collection processes.4. Improve local, regional and national data interoperability to more efficiently connect data collection to social resource distribution and pro-actively have inequity detection in subpopulations. This is explicitly linked to ensuring integration of data for accessibility of community services.
<h3>Access</h3> <ol style="list-style-type: none">1. Establish data-use agreements to facilitate timely data sharing between local, tribal, state and national agencies.2. Provide resources, processes and avenues to facilitate data re-dispositioning in accordance with participants' requests.3. Inform community members on applied standards of interoperability and allow access to the data infrastructure through a human-centered app.4. Clearly and publicly document why some data is unavailable.5. Facilitate data sovereignty by ensuring tribal nations in your jurisdiction have access to their national data.	<h3>Analysis</h3> <ol style="list-style-type: none">1. Partner with community-based organizations to provide detailed local context in analysis.2. Use "early warning" indicators to provide meaningful services and support to populations or communities rather than for "threat" amplification. For instance, using an increase in fentanyl related deaths specific neighborhood statistical areas to rapidly increase NARCAN® distribution rather than expand anti-drug use campaigns.3. Use appropriate comparison groups to contextualize findings (i.e., do not assume white as normative).²4. Empower professionals and community members to use data to improve their work and their communities.5. Correlate place to outcomes.6. Disaggregate data and analyze intersectional experiences.
<h3>Dissemination</h3> <ol style="list-style-type: none">1. Require a strength-based approach to reporting for staff and sub-awardees and encourage a strength-based reporting approach by researchers using local datasets.2. Develop differentiated messaging to communicate to diverse populations. Require articles on other subpopulations to rigorously examine potential impact from longstanding structural biases.3. Require articles on racial health inequities to rigorously examine racism.4. Report data in an actionable form to improve the lives of those represented in the data. State and local legislation often has more day-to-day impact on the communities they serve. By reporting in a means that allows explicit change by those in power, their data dissemination has real-time effects.	



Resources on Equitable Data Systems

The [data equity principles](#) are meant to complement existing resources, thought leadership and guidance in the field of data equity. We would like to acknowledge the following influential resources that you can refer to for more information on building equity across the data life cycle.

- [A Toolkit for Centering Racial Equity Throughout Data Integration](#) developed by Actionable Intelligence for Social Policy
- [A Health Equity Framework](#) developed by the Massachusetts Health Policy Commission
- [Charting a Course for an Equity-Centered Data System](#) developed by the Robert Wood Johnson Foundation
- [Data Commitment and Principles](#) developed by the Denver Public Health Department
- [Data Democratization: The Unsung Hero of Health Equity](#) developed by Health Leads
- [Health Data Governance Principles](#) developed by Transform Health
- [Do No Harm Guide: Applying Equity Awareness in Data Visualization](#) developed by Urban Institute
- [Equitable Evaluation Framework™](#) developed by the Equitable Evaluation Initiative
- [On Racism: A New Standard for Publishing on Racial Health Inequities](#) authored by Rhea Boyd
- [Powering Health Equity Action with Online Data Tools: 10 Design Principles](#) developed by PolicyLink and Ecotrust

