Principles for Using Public Health Data to Drive Equity

A guide to embedding equitable practices throughout the data life cycle

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Acknowledgments

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Setting the Stage

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 ensuring community-level participation and voices are at the center of these discussions. 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 application of the CIE® Data Equity Framework to several national surveillance systems and the review of existing frameworks that define equity principles within specific U.S. centric and global contexts.

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.

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. The resources utilized in our environmental scan and cited throughout this document are not meant to be an exhaustive list of the full array of compelling work happening in the field of data equity. In addition, the data equity principles and application document are not a substitute for the previously developed toolkits and guides providing specific examples and recommendations. Rather, we saw an opportunity to summarize the application of a set of health equity principles, consistent with what is currently being considered in the field, to each stage in the public health data life cycle. We hope this document is complementary and additive to existing resources.

In particular, we want to acknowledge the influential work included in the following resources:
- 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

For more information on sources used throughout this document, please refer to Works Cited on page 26.

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- [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

The reflections in this document help apply equity-centered principles throughout the data life cycle for key public health actors, including at the community, local, state and national levels. We believe when these actors begin to embed the data equity principles into their everyday work, they can support data democratization across communities and data systems.

While this document may be most relevant to public health agencies and researchers, we recognize data developers and practitioners across disciplines, as well as community partners, stand to benefit from strategies that can shape data systems to equitably collect and manage population data for authentic storytelling and dynamic decision-making. We also encourage public health funders to actively consider how grantees approach data throughout the life cycle and emphasize these actions when developing public health research and interventions.

Health Equity in the Context of the Data Equity Principles

The reflections from the environmental scan and discussion of equity are grounded within the definitions provided by the U.S. Centers for Disease Control and Prevention Office of Minority Health and Health Equity (2022):

Health Equity is the state in which everyone has a fair and just opportunity to attain their highest level of health. Achieving this requires focused and ongoing societal efforts to address historical and contemporary injustices; overcome economic, social, and other obstacles to health and healthcare; and eliminate preventable health disparities.

Health Disparities are differences in health outcomes and their determinants between segments of the population, as defined by social, demographic, environmental and geographic attributes.

Health Inequities are health differences or disparities that are systematic, unfair and avoidable.

Acknowledging Intersectionality, Race and Racism

Through the environmental scan, we determined a need to emphasize the consideration of intersectionality as a theoretical framework when applying the data equity principles.

Intersectionality suggests multiple social categories, such as race, ethnicity, gender or socioeconomic status, intersect at the micro level of individual experience to reflect multiple interlocking systems of privilege and oppression at the macro, social-structural level (e.g. racism, sexism, classism) (Bowleg, 2012).

When confronted with inequities in health outcomes along familiar categories, such as race, gender, class or disability status, data users should look deeper at the differing experiences, exposures and opportunities of these populations resulting from systemic and structural biases (Hankivsky, 2017). The reflections throughout this document will encourage public health actors to take thoughtful steps for crafting data systems that can carefully measure not only population health but the nuanced human experiences of everyday people.

While intersectionality can give us the framing to reflect on the overlapping nature of systems and identities, our environmental scan also revealed a need to include a specific focus on race, as it is experienced, and racism's impact on public health data. We found the intersection of race with other demographic categories, such as gender, LGBTQ identity, disability status or rural location demonstrates that even within these groups, populations of color experience the greatest risks and the magnitude of the differences of these risks is larger than for other characteristics because of the additional effect of structural racism.

Several of the works reviewed emphasized the permeation of structural racism as the root cause of the racial disparities in the United States, and the historical tendency to attribute observed differences in outcomes to unsubstantiated genetic factors (Mendez, 2021).

For the reflections across the data life cycle, we have adopted the following definitions of race and racism.

> **Race** is a social construct used to group people. Race was constructed as a hierarchal human-grouping system, generating racial classifications to identify, distinguish and marginalize some groups across nations, regions and the world. Race divides human populations into groups often based on physical appearance, social factors and cultural backgrounds (Race, 2012).

> **Racism** is a system—consisting of structures, policies, practices, and norms—that assigns value and determines opportunity based on the way people look or the color of their skin (Health Equity, Center of Disease Control and Prevention Office of Minority Health and Health Equity, 2022).

Medical, public health and social science researchers have often inappropriately attributed racial disparities in health outcomes to innate, genetic or biological differences related to racial categories—or left the summary open to that conclusion. However, the social categories of race are a poor proxy for genetic differences. It has been well documented by the Human Genome Project that there are no consistent genetic differences between the social groups we identify as races. There is as much difference between individuals in the same racial group as there is between the racial groups themselves. The genes accounting for the visible characteristics used to separate races, like eye and skin color, account for an extremely small proportion of an individual's genes (Genetics vs. Genomics Fact Sheet, 2018). Additionally, researchers rarely considered the input of these racial and ethnic communities to inform and refine their research efforts. The variable race is also an incomplete and potentially misleading proxy for socioeconomic status, culture, behaviors and lived experiences. The result is data systems not only lack the capability to examine meaningful group differences among racial categories but also perpetuate harmful narratives about health disparities, their root causes and their solutions (Kauh, 2021).

To move forward from these historically harmful narratives, it is imperative to emphasize the distinction between race as a social construct and racism as a system. The reflections throughout this document also aim to facilitate thoughtful examination of the social categories of race and the impact of racism in all its forms across the data life cycle.

Data Democratization for Advancing Health Equity

Through the environmental scan and discussions, we have identified championing data democratization as a powerful approach to advancing equity and addressing past harms from research practices.

Data Democratization is making data accessible to people and assuring they have the tools and resources to understand the data (Mckinlay, 2020).

Historically, public health agencies and researchers have piloted studies to better understand inequities and barriers but without the consistent inclusion of the communities they seek to help. Data democratization calls for us to not only make information available to all community actors but also facilitate community inclusion, ownership and governance (Mckinlay, 2020). The result is communities who have been historically excluded from shaping their own population narratives around race, gender, disability and sexuality can drive community agency in data systems with the most impact on their daily lives.

Advancing equity in public health data requires collaboration and participation across multiple sectors and actors. Throughout this document, we provide reflections for a variety of multi-sector contributors to the public health data landscape, offering insight into where across the data life cycle they can facilitate data democratization.

It is important to acknowledge there can be competing priorities in developing approaches to equitable data design and collection. The involvement of the community allows for the prioritization of community-defined goals at a particular time. This can create tension with the important public health goal of being able to compare health outcomes in the same community over time and between different geographic areas, which requires some level of consistency in data measures and data collection. Recognizing this tension can provide communities, in partnership with public health departments or other entities who are collecting the data, the opportunity to jointly consider the trade-offs and decide on what balance between the potentially competing priorities is best for a given project. Prioritizing community goals could still allow for consistency in how data measures are defined. The analysis and discussion of conclusions and suggestions that stem from the data can be presented in the context of the explicit consideration of the potential trade-offs.

Commitment to Using Data to Achieve Equity

Public health and policy decisions rely on population data to identify health disparities, allocate financial and human resources, enact laws and regulations and establish public services. The need for equitable data systems that account for social factors like where people live, their healthcare access and even the discrimination they face, has become increasingly important to not only facilitate effective decision-making at the local level but also reduce health disparities (DMI and Health Equity, 2022).

Through the lens of the data life cycle, the data equity principles acknowledge the power data has in shaping community landscapes 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.

For the purpose of this document, the phases of the data life cycle include the following cyclical stages:

Planning: Developing a mission or purpose for data integration, understanding the local context and identifying appropriate variables.

Collection: Gathering information to inform research, program or policy. This includes primary and secondary data collection.

Access: The practices associated with who can securely obtain, view or use data and for what purpose.

Analysis: Using data to develop findings, interpretations and conclusions, while understanding the biases in some algorithms' applications and research methodologies.

Dissemination: Sharing findings from the data to appropriate audiences.

Overview of Sections and How to Use this Document

We begin with outlining the five data equity principles as a tool to implement across the public health field, highlighting the specific phases of the data life cycle that closely align with each principle.

To showcase how organizations and individuals could apply the data equity principles through their everyday work, projects, policies and within their communities, we have proposed considerations for equitable actions:

- **Equitable Actions Through the Data Life Cycle:** Applying the data equity principles to each phase of the data life cycle with practical examples of their implementation according to the phase.

- **Equitable Actions Through Organizational Level:** Applying the data equity principles to various levels of organizations—national, state and local, tribal and Indigenous and territorial—with practical application examples.

These considerations are not a comprehensive outline of how the data equity principles can be applied. The considerations within this document are reflections and suggestions to help different audiences apply the data equity principles to their projects, communities and systems.

We imagine different data practitioners will utilize this document in different ways. For example, community-based organizations can find examples of clear equity changes they can make in their deliverables and local health departments and funders can consider how their funding approaches could support equitable data practices.

Moving towards more equitable data practices happens in various spheres of work, such as across industries and sectors, organizational levels, community levels, research and program management. By applying the data equity principles to these different domains, we hope to showcase the diverse way equitable actions can be integrated into different spheres and for different practitioners to see how they can be applied to their work.

A glossary of terms, found within the Appendix on page 26, outlines terms used throughout the document and provides additional background.

Data Equity Principles

The data equity principles are designed to help guide researchers, collaboratives, government entities and public health initiatives in centering equity throughout the data life cycle. To eliminate health inequities, organizations and individuals should incorporate the following five equity principles throughout the entire data life cycle, from project and research conception to data use, dissemination and action.

Recognize and define systemic factors

Use equity-mindedness for language and action

Allow for cultural modification

Create shared data agreement

Facilitate data sovereignty

PRINCIPLE 1

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

Recognizing the historical and existing systemic inequities is a crucial first step in designing and implementing public health programs and research efforts. That history should inform future efforts to appropriately engage with harmed communities and mitigate future harm through data collection and program implementation.

It is critical to ensure differences in health outcomes among people of different racial, ethnic, sexual orientation, gender, disability or other identities are not erroneously attributed to genetic or biological differences and are recognized as consequences of inequitable systems.

Potential Applications:

1. Explicitly acknowledge the systems, policies and practices that have led to historical inequalities and influence the links to health outcomes.

2. Consult with local community members to identify relevant social, political and economic factors that can shape how health outcomes are measured and reported.

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.

Equity-mindedness examines unequal outcomes to identify patterns based on race (as a social category), gender identity, sexual orientation, disability status, immigration status and other forms of self-identity that are subject to systemic and structural bias (Mckinlay, 2020).

In practice, equity-mindedness includes considering how data cleaning, coding, removal of specific information for data collation and analysis decisions affect the ability to describe the needs of specific populations and population subsets. While we recognize the efforts made around data standardization to ensure the consequences of analytic choices are visible and understood, organizations and data practitioners should include diverse perspectives in data coding and analysis decisions. While challenging, we encourage public health practitioners to consider the potential oversights in prior standardization efforts and necessary ramifications, as well as the rapid transition in language and norms experienced by the field. Ideally, we can actively strive to be reflective of these changes while involving community members in the definition of data standards and metadata.

The advantages and disadvantages of using specific data sources, types and informants and how data from such sources are synthesized, should be examined for equity implications, and the pros and cons openly communicated to all participants, data users and community partners. For instance, considering different sources may not equitably reflect all populations and the selection of key informants can be biased by the selector(s). Describing all components of the data system, including goals and measures, in clear language and user-friendly formats is crucial for individuals who do not routinely work with data to become key contributors to data systems.

Based on the populations being studied, data developers may consider whether additional qualitative data is needed to provide a more comprehensive understanding of what story the data is telling. When utilizing secondary data, consider the original intentions and limitations of the data collection and what data may need to be supplemented with the end-user population in mind.

Potential Applications:

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

2. Engage diverse data practitioners and communities when developing new practices related to data cleaning, coding, analysis, synthesis and dissemination.

3. Provide clear language, goals and measurements in user-friendly formats.

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.

True community engagement involves not only working with the community but also taking action based on their input and having them lead data efforts and projects. By pulling from the diverse perspectives of community members and proactively including them in data development, the data collected can tell a much more holistic story of the community. Data developers should include the lived experience and traditional knowledge of community members in conducting research and developing impactful interventions.

Doing so involves assessing how to incorporate and act on community input across each phase of the data life cycle, including defining the key public health problems and research questions, sampling design, selecting or designing data collection instruments, identifying and recruiting participants and respondents, interacting with participants to collect data and liaising with participating communities to make meaningful interpretations of the data and then to share results. For example, making changes for cultural modifications within the data life cycle ensures the data collection methods are in the appropriate language for the community or sub-languages. Additionally, community involvement assures that important contextual factors are captured in data collection and are included in analyses.

While standardization allows for comparison across communities, provides a level of utility of the data and can support contextualizing some experiences, these benefits should be balanced with the ability to make the data meaningful to specific communities and whether the context for comparison is accurate.

Researchers should involve community members to ensure the meanings of terms and concepts are consistent with those held by the community and determine what forms of data outputs would be most useful for them.

Potential Applications:

1. Engage communities when developing new data collection tools and/or adding modules to programmatic and disease-specific surveillance systems.

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

3. Use data and community engagement to prioritize what issues are addressed/ questions asked in developing the research agenda and plan.

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.

Developing a shared set of questions to be answered with the data allows intentional data collection and use, minimizing the undue burden for the affected populations while not exceeding the community gain. This includes working with community members from the beginning to identify ethical considerations and potential areas of concern.

Historically, data collection practices often exclude input from the focal research population because it prioritizes institutional goals above community needs. This shapes data narratives and also leads to a lack of transparency; over time, this can breed and deepen community distrust. Flip the narrative to begin with the community. The community research collaborations then allow for joint interpretation of what stories the data is telling with affected populations when the data is being collected, analyzed and shared. It is crucial to include adequate time frames in the planning process to allow for inclusive engagement.

Researchers, program implementers and policymakers should take time to communicate the intent of the collection and negotiate with communities to find win-win solutions and be prepared to significantly modify, or even abandon, projects that are unacceptable to communities. Thus, recognizing the need for data sovereignty among communities participating in research (Nelson, Jenkins, Zanti, Katz, Berkowitz, Burnett & Culhane, 2020).

Potential Applications:

1. Seek input from entities who have direct contact with or are led by members of affected populations on the most appropriate issues to consider when collecting, analyzing and sharing community level data.

2. Engage in project development processes that are more inclusive of the subject population.

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

PRINCIPLE 5

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

Data sovereignty occurs when communities control the development of data sources as well as improved collection of official statistics on their community members. Improving data sovereignty is important for all communities, especially those that have been historically marginalized.

While data sovereignty can be applied to all communities, consideration should be taken for how each community views data sovereignty with historical context and background. For example, in the United States, it is important to note the historical context surrounding the sovereignty of tribal nations. Specifically, sovereignty was formalized in nation-to-nation agreements between tribes and the U.S. government; the agreements recognize American Indian tribes as domestic sovereign nations that possess self-government. This also translates to Indigenous data sovereignty which is the right of a nation to govern the collection, ownership, and application of its own data. Data sovereignty for other areas and nations may also have implications for the laws applicable to the data.

For the purpose of the data equity principles, data sovereignty looks to move communities to the forefront of the conversations of all aspects of data management. Communities, including Indigenous and tribal communities, should determine how the data will reflect the interests, values and priorities of their people and nations, ensuring those statistics are useful to their needs and community interests.

Oversight and control of the data at the community level is just one step in redistributing power to traditionally marginalized communities.

Potential Applications:

1. Ensure current data collected across the agency from communities reflect the communities' values and priorities.

2. As new data collection surveillance systems are developed among tribal communities, these communities should be consulted, engaged and asked to guide to scientists throughout the data life cycle.

Equitable Actions Through the Data Life Cycle

The five data equity principles form the mutually reinforcing background in which all of the stages of the data lifecycle take place. As you work through the continuous stages of the data life cycle, keep in mind that each of the principles applies to each stage. Incorporating the principles in each stage will help achieve the goal of equitable data.

Recognize and define systematic factors

Facilitate data sovereignty

Use equity mindedness for language and action

Dissemination

Planning

Analysis

Collection

Access

Create a shared data agreement

Allow for cultural modifications
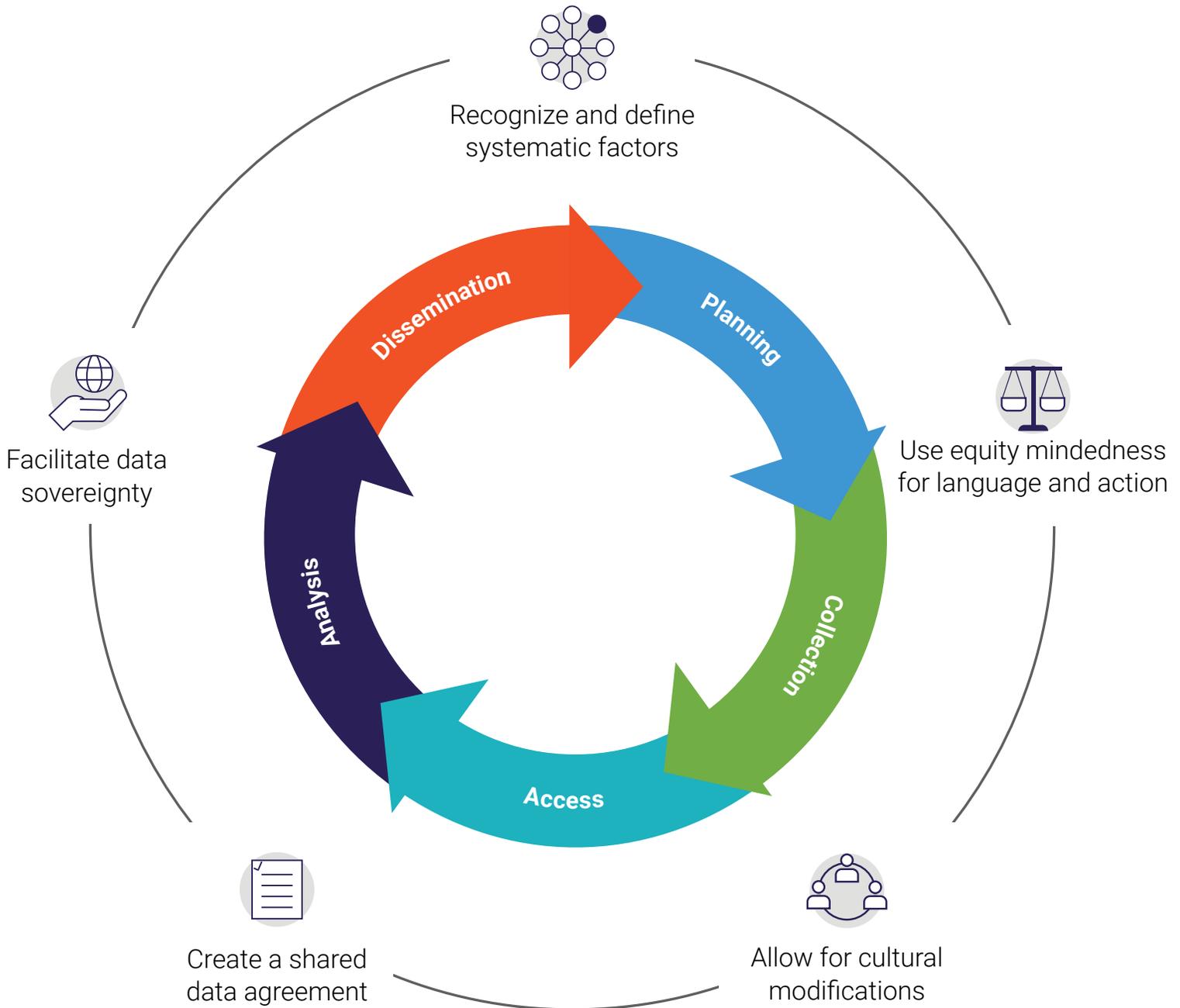
The following section provides opportunities for equity considerations throughout each stage of the data life cycle. The preliminary list for each life cycle stage is an overview of actions.

Data Planning

Developing a mission or purpose for data integration, understanding the local context and identifying appropriate variables.

Use data and community engagement to prioritize what issues are addressed and questions asked in developing the research agenda and plan.

Apply a human rights lens, such as identity, privacy and individual autonomy, to data governance, and employ a governing body that represents the community served (Boyd, Grounds, Johnson, Suarez, Harrell, Rogers & Morrison, 2021) (Health Data Governance Principles, 2022).

Ensure investment program awardees have foundational understanding of health equity, the social determinants of health and the resources to collect and analyze data to advance health equity (Health Equity Framework, 2020).

Work with multiple levels of government to align and coordinate health equity efforts.

Build data literacy among organizations and community members (Nelson et al, 2020).

Engage with communities in data collection instrument design.

Partner with other national agencies and stakeholders to develop standardized data collection requirements and practices promoting data to address health inequities.

Manage data as a strategic asset for the public good to allow multiple levels of government to be effective and efficient (Nelson et al, 2020).

Explicitly include health equity elements, such as demographic information of race by gender, sexual orientation, disability status, nationality, income, as key competitive factors in selection criteria and review and selection committee processes when reviewing proposals.

Define the social categories of race during the experimental design as a sociopolitical framework, not a biological one, specify the reason for its use in the study and include measures to address racism as a driver of disparate outcomes (Boyd, 2020).

Embed community stakeholders in data governance structure to elevate community voices and create balanced power structures.

Engage community members in the data network development process to ensure usability (Boyd et al, 2021).

Data Collection

The process of gathering information to inform research, program or policy. Includes primary and secondary data collection.

Elevate programs aimed at community-driven research needs.

Create public forums to demonstrate how data helps advance public health data collection for administrative purposes, like clinical data.

Fully disclose possible future uses of any data, especially for public use.

Prioritize collecting qualitative data to contextualize quantitative findings and highlight inequities in various communities.

Regularly review existing data sources to determine what additional data is needed to identify inequities (e.g., more robust demographic information) (Health Equity Framework, 2020).

Expand the data collection categories beyond current organizational and governmental standards and incorporate social determinants of health data in the collection process.

Improve local, regional and national data interoperability to more efficiently connect data collection to distribution of social resources and proactively detect inequities in subpopulations.

Data Access

The practices associated with who can securely obtain, view or use data and for what purpose.

Share data with jurisdictions, communities and other partners for legitimate public health purposes and to potentially establish data use agreements for timely data sharing (Lee, 2009).

Provide resources, processes and avenues to facilitate dispositioning of data in accordance with participants' wishes (Nelson et al, 2020).

Publicize clear data release schedules and information on where to go and how to access data once released (Nelson et al, 2020).

Adhere to data management best practices for data access, including clear data destruction parameters following use (Nelson et al, 2020).

Carefully deidentify and anonymize data prior to release.

Use role-based permissions for data access to ensure security and confidentiality (Nelson et al, 2020).

Develop an accessible data request process with clear policies and procedures for evaluating requests.

Clearly document why data is unavailable such as legislation, data quality, preparation, etc. (Nelson et al, 2020).

Include community stakeholders in defining which data should be reused.

Data Analysis

Using data to develop findings, interpretations and conclusions, while also understanding the potential for biases in this stage.

Use multiple levels of analysis to determine the complex intersection of impact on a population. For instance:
- Utilize human-led algorithm use (i.e., humans can override an algorithm at any point in the process) (Nelson et al, 2020).
- Disaggregate data and analyze intersectional experiences such as looking at race by gender, sexual orientation, disability status, nationality, income, etc.
- Use participatory research to print multiple perspectives on data interpretation (Nelson et al, 2020).

Involve diverse stakeholders in the early conversations on the purpose of the algorithms/ statistical methods prior to development and implementation.

Create opportunities to identify issues early on to provide meaningful services and support to populations or communities rather than for "threat" amplification (Nelson et al, 2020).

Engage domain experts (staff) and methods experts (scientists) to ensure the data model used is locally appropriate to examine the research questions (Nelson et al, 2020).

Report on subpopulations across applicable analyses to inform how health care trends may disproportionately impact populations by income, geography or the social categories of race and ethnicity.

Support developing research into new types of analyses that better document the longitudinal impact and weight of structural influences on health outcomes.

To correctly assign racism, and not the social categories of race, as a risk factor, name racism and its forms—interpersonal, institutional or internalized—that may create compounding effects (Boyd, 2020) (Hardeman, 2022).

Avoid including genetic interpretations of race; if race and genetics are being expressed jointly, delineate the intended implication (Boyd, 2020).

Avoid analyses that privilege a population as being normal or desirable compared to others (Data Commitment and Principles, 2019).

Data Reporting and Dissemination

Sharing findings from the data, framed in an accessible and relevant way, to appropriate audiences.

Use a strengths-based approach when discussing populations; use a systems-level approach when discussing inequities as a means to avoid judging, blaming and marginalizing individuals/communities.

Develop differentiated messaging for different audiences that considers the appropriate level of details, technical jargon, language, length and format (Nelson et al 2020).

Report results in an actionable form to improve the lives of those represented in the data (Nelson et al, 2020).

Acknowledge specific ways structural racism and other harms to communities are likely to be reflected in the data when reporting differential results by the social categories of race and ethnicity.

Clearly document the data analysis process along with analytic files so others can reproduce the results.

Consult with the respective and/or local tribal or Indigenous leaders on analyzing and interpreting the data when reporting on or about tribal and Indigenous peoples.

Build in qualitative narratives to contextualize quantitative data.

Acknowledge missing data and data biases and limitations.

Cite the experts, particularly scholars of color, whose work forms the basis of the field's knowledge on racism and its effects (Boyd, 2020).

Insist that articles on race, gender, class and other health inequities rigorously examine structural and systemic biases by using theoretical frameworks that address the weight of each level of racism on a particular population (Boyd, 2020).

Provide continuing education for existing editorial staff and efforts to hire and promote new editors who are well versed in the history of how structural biases, including systemic racism are inherent in social, economic, political, medical and other institutions and how to apply that understanding

Revisit editorial and publication guidelines regularly to ensure they capture the evolving racial definitions and sociopolitical structures (Boyd, 2020).

Use experienced reviewers who have demonstrated familiarity with racism and its pathophysiologic mechanisms, the physical effects that potentially accompany it, such as increased blood pressure and stress hormone levels, through their own scholarship and work.

Equitable Actions Through Organizational Levels

To build on the work developed by peers in this area, the CDC Foundation further refined the equitable actions across the different organizational levels with which we work. The following tables break these actions down in the context of national, state and local, tribal and Indigenous and territorial organizations, focusing on considerations most relevant to each organizational level while not being overly prescriptive.

It is important to point out that implementation methods around data principles vary across all levels within an organization as well as across levels of governmental work.

Considerations at each organizational level can also be applicable at other organizational levels. There is overlap in the actions different organizational levels can, and should, take to be more intentional and equitable in their data management. Each level plays a unique role, though, and only some actions can take place at certain levels. The considerations we outline apply most specifically to each organizational level's work, functions, priorities and data systems.

Though the following section is broken into considerations of how the data equity principles could be applied in various organizational levels, it is also imperative that the equitable data principles are applied across levels and the data system is viewed as a whole, integrated structure.

These actions are provided as considerations to launch practitioners at each level into the necessary discovery process for their work.

National

National public-sector bodies, such as any branch, department office, division, etc., with a national public service mission. Examples include the U.S. Centers for Disease Control and Prevention, National Institutes of Health and the Centers for Medicare and Medicaid Services. The considerations below are most applicable to organizations at the national level, but they are not a complete list of how national organizations can apply the data equity principles.

Planning

1. Identify and define factors that shape the socio-political framework of commonly used variables, such as the social categories of race and socioeconomic status.
2. Include health equity elements in notice of funding opportunities, selection criteria and review processes.
3. Partner with other national agencies and collaborators to develop standardized data collection requirements and practices to promote using data to address health inequities.
4. Establish a common language and agreed upon sources and methods on reporting on community-based indicators.
5. Establish a research and governance plan in coordination with continental representative groups such as the National Congress of American Indians, National Asian American Pacific Islander Mental Health Association or the National Alliance for Hispanic Health.

Collection

1. Fully disclose all potential data use to research and national surveillance system participants, and archive on websites for national data.
2. Expand data categories beyond the World Health Organization (WHO) and the Office of Management and Budget (OMB) standards.
3. Oversample traditionally marginalized/overlooked populations to ensure representation in data national surveillance systems.
4. Develop data portals with easily accessible data from multiple sources, such as PLACES. The PLACES Project provides model-based population-level analysis and community estimates to all counties, places, census tracts and ZIP Code Tabulation Areas (ZCTAs) across the United States.

Access

1. Publicize clear, accessible data release schedules and policies on websites for national data. This includes resources, processes and avenues for re-dispositioning data in accordance with participant wishes.
2. Develop data sharing agreements with other national and subnational agencies to create a centralized hub for multiple data sets.
3. Create, use and share high-quality metadata to inform requesters what data is available.
4. Encourage free or low-cost data request processes; coordinate with subnational or subpopulation representatives to define appropriate data reuse.

National Cont.

Analysis

1. Use multiple levels of analysis and ensemble modeling and provide support to subnational health systems and community-based organizations to conduct such analyses.
2. Report on subpopulations across applicable analysis to inform how health care trends may disproportionately impact populations by income, geography, disability or race and ethnicity.
3. Use a non-proprietary algorithm that allows for transparency and replication.
4. Disaggregate data and analyze intersectional experiences. This is especially important at the national level since these organizations are typically working with the largest datasets and may limit the unintentional disclosure of personal information and privacy protection.
5. Avoid analyses that privilege a population as being normal or desirable compared to others.
6. Avoid offering genetic interpretations of the social categories of race; if race and genetics are being expressed jointly, delineate the intended implication. To correctly assign racism, and not race, as a risk factor, name racism and its forms—interpersonal, institutional or internalized—that may create compounding effects (Boyd et all, 2021).
7. Connect methods experts with more localized domain experts to ensure appropriate data is used in the correct analytic way to examine the research questions in national context.

Dissemination

1. Use a systems-level approach when discussing inequities as a means to avoid judgment, blame and marginalization of individuals and communities. For instance, when reviewing national smoking rates by educational attainment, acknowledge the multiple levels of personal, social, and political influences that lead to an increased rate of smoking for those with only a GED compared to those with a graduate degree.
2. Consider require articles focused on racial health inequities to rigorously examine racism. Consider require articles on other subpopulations to rigorously examine potential impact from longstanding structural systems.
3. Use experienced reviewers who have demonstrated, through their own scholarship and work, facility with racism and its pathophysiologic mechanisms (the physical effects that potentially accompany it, such as increased blood pressure and stress hormone levels). Provide continuing education for existing editorial staff and efforts to hire and promote new editors who are well-versed in racism and its application on the history of structural biases, including systemic racism is inherent in social, economic, political, medical and other institutions.
4. Provide clear documentation of the data analysis process along with analytic files so that others can reproduce result.

State and Local

Any department or agency of a state or locality with statewide jurisdiction and responsibility, or any department or agency of a local jurisdiction. Examples include the Georgia Department of Public Health (state), the Fulton County Board of Health (local) and the New York City Department of Health and Mental Hygiene (local, city). The considerations below are most applicable to organizations at the state and local level, but they are not a complete list of ways these organizations can apply the data equity principles.

Planning

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.

Collection

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.

Access

1. Establish data-use agreements to facilitate timely data sharing between local, 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.

Analysis

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 (Nelson et al, 2020).
3. Use appropriate comparison groups to contextualize findings (i.e., do not assume White as normative) (Boyd 2020).
4. 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.

Dissemination

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.

Tribal and Indigenous

Distinct health service agencies, often within a greater federal health agency, responsible for providing health services to specific tribal and Indigenous populations. Examples include the Indian Health Service, National Indian Health Board and the Urban Indian Health Institute. The considerations below are most applicable to tribal and Indigenous organizations, but they are not a complete list of ways these organizations can apply the data equity principles.

Planning

1. Coordinate health equity efforts within the state/region-based community organizations to elevate the research needs of Indigenous population, especially when populations may be across geographical boundaries.
2. Actively build data literacy among organizations and community members to amplify their involvement across the data life cycle.
3. Establish a common language and agreed upon sources and methods for reporting on tribal and Indigenous community-based indicators.
4. Elevate the research needs of Indigenous groups to funders to help shape the funding strategy.

Collection

1. Prioritize collecting qualitative data to contextualize quantitative findings and reveal inequities in communities.
2. Regularly review existing data sources to determine what additional data is needed to identify inequities (e.g., more robust demographic information).
3. Include tribal and Indigenous members in defining which data should be collected and reused.
4. Create public forums that enable those who are interested to see how use of their data helps advance public health for data collection linked to administrative purposes, such as clinical data.

Access

1. Carefully deidentify and anonymize data prior to release.
2. Ensure base data is housed within the community it serves or with trusted community-based institutions that have the community's best interests for use at heart.
3. Adhere to data management best practices to secure data as they are collected—specifically with carefully considered, role-based access.
4. Include tribal and Indigenous members in defining which data should be reused and processes for outside access.

Analysis

1. Partner with community-based organizations and Indigenous members to provide detailed local context in analysis.
2. Ensure a human can override the sampling/analytic algorithm at any point in the process (Nelson et al, 2020).
3. Connect Indigenous domain experts and methods experts to ensure the data model used is appropriate and statistically valid to examine the research questions in an Indigenous community context.
4. Disaggregate data and analyze intersectional experiences.

Dissemination

1. Develop differentiated messaging to consider appropriate level of details, technical jargon, language, length and format to communicate to diverse populations.
2. Require articles on tribal health inequities to rigorously examine structural systems and historical and ongoing political harms.
3. Consult with the respective and/or local tribal leaders on data analysis and interpretation when reporting.
4. Acknowledge missing data, biases and limitations of the data.

Territory

A geographic area belonging to or under the jurisdiction of a governmental authority that operates with some level of autonomy but that is not yet admitted to the full rights of a state. Examples within the United States include American Samoa, Guam, the Northern Mariana Islands, Puerto Rico and the U.S. Virgin Islands. The considerations below are most applicable to territorial organizations, but they are not a complete list of ways these organizations can apply the data equity principles.

Planning

1. Identify and define variables that shape the socio-political framework between individual territories and overarching governmental authority.
2. Research, understand and disseminate the history of local policies, systems and structures involved, including past harms and future opportunities.
3. Coordinate health equity efforts with local community-based organizations to elevate the research needs to local funders.
4. Embed communities in data governance structure to elevate community voices and rebalance power structures.

Collection

1. Provide full disclosure of possible future use of any data collected.
2. Prioritize the collection of qualitative data to contextualize quantitative findings and inform how inequities manifest in various communities.
3. Regularly review existing data sources to determine what additional data is needed to identify inequities (e.g., more robust demographic information).
4. Adhere to data management best practices to secure data as they are collected, specifically with carefully considered, role-based access.
5. Update data collection practices based on community feedback and real-life limitations.

Access

1. Establish clear processes for submitting a request to agency for making data open, including how requests will be evaluated.
2. Adhere to data management best practices for data access.
3. Provide free or low-cost data.
4. Create, use and share high-quality metadata to inform requesters what data are available.

Analysis

1. Connect local content experts with methods experts to ensure the data model used is appropriate to examine the research questions in local context.
2. Use multiple measures of validity and fairness.
3. Use appropriate comparison groups to contextualize findings.
4. Avoid analyses that privilege a population as being normal or desirable compared to others.

Dissemination

1. Acknowledge specific ways structural racism, colonialism and other harms are embedded in the data when reporting differential results by the social categories of race and ethnicity.
2. Develop differentiated messaging to consider appropriate levels of details, technical jargon, native language, length and format to communicate to distinct territorial populations.
3. Cite the experts, particularly scholars of the complex economic, political and cultural relationship between the U.S. government and American territories, whose work forms the basis of the field's knowledge on racism, exploitation and its effects.
4. Acknowledge missing data and data biases and limitations.

Next Steps

In this document, we have explored the application of data equity principles across the data life cycle. The data life cycle presents a continuous opportunity for improvement. As you reach the stage where you will disseminate the data, you should start planning for how to utilize and share the data as well as how you will continue to develop and reflect upon new data.

Beyond what we have covered here, throughout the data life cycle, there are additional places to further refine how to apply data equity principles, such as how datasets are shared and created. While the discussion in this document does not fully cover every facet of the data life cycle and data maintenance, we hope the discussion here helps users analyze methods and strengthen data practices to drive equity.

Suggestions for next steps in the application of the data equity principles are:

Expanding traditional data systems contributors

When exploring data systems, the data equity principles can aid in expanding conversations outside one discipline and outside of traditional public health—such as the community perspective and expanding data conversations within other disciplines.

Having communities lead the data development and storytelling ensures community understanding, support for and participation in the solutions that come from the data. All community actors can have the expertise to contribute to the productive use of meaningful public health data. The data equity principles help empower those outside of traditional data management roles to elevate their roles in data systems.

Cross-agency and organizational level collaboration

While we have provided considerations for applying the data equity principles within various levels of organizations, data systems should also be explored across organizational levels and disciplines.

Biases within our communities, within our organizations and within each of us, can unknowingly affect our data systems. By adapting the data equity principles and applying them throughout the process, we hope to strengthen each step with the goal of achieving health equity.

Appendix: Glossary of Terms

We have gathered definitions for key terms used throughout this document and have included hyperlinks as to where you can learn more about the provided definitions.

Community inclusion: Community inclusion is the opportunity to live and exist as a contributing member of the community while being valued for one's abilities and uniqueness, regardless of disability.

Cultural modification: The modification of a society through innovation, invention, discovery or contact with other societies.

Data life cycle: Comprised of planning, collection, access, analysis and dissemination.

Data planning: Developing a mission or purpose for data integration, understanding the local context and identifying appropriate variables.

Data collection: Gathering information to inform research, program or policy. This includes primary and secondary data collection.

Data access: The practices associated with who can securely obtain, view or use data and for what purpose.

Data analysis: Using data to develop findings, interpretations and conclusions, while understanding the biases in some algorithms' applications.

Data democratization: Involves making data accessible to people regardless of whether they have analytics, IT or software background, to be able to make sense of data.

Data dissemination: Sharing findings from the data to appropriate audiences.

Data literacy: The ability to read, analyze, use and communicate the findings within the data.

Data sovereignty: Refers to a group or individual's right to control and maintain their own data however they see fit, which includes the planning, collection, storage, interpretation and dissemination of the data. It also refers to following the applicable data laws based on geographically where the data is stored.

Data use agreement: A data use agreement sets the parameters of the permitted uses and disclosure of the data.

Equity mindedness: Examining unequal outcomes to identify patterns based on race/ethnicity, gender identity, sexual orientation, disability status, citizenship status and other facets of self-identity.

Health disparities: Differences in health outcomes and their determinants between segments of the population, as defined by social, demographic, environmental and geographic attributes.

Health equity: The state in which everyone has a fair and just opportunity to attain their highest level of health. Achieving this requires focused and ongoing societal efforts to address historical and contemporary injustices; overcome economic, social, and other obstacles to health and healthcare; and eliminate preventable health disparities.

Health inequities: Health differences or disparities that are systematic, unfair and avoidable.

Indigenous: Relating to the earliest known inhabitants of a place and especially of a place that was colonized by a now-dominant group.

Interoperability: Interoperability is the ability of two or more systems to exchange health information and use the information once it is received.

Intersectional and Intersectionality: The complex, cumulative way in which the effects of multiple forms of discrimination based on different aspects of an individual's or group's identity (such as racism, sexism and classism) combine, overlap or intersect especially in the experiences of marginalized individuals or groups.

Pathophysiologic: The functional changes in the body's biologic processes that accompany a particular syndrome or disease

Race: Social construct used to group people. Race was constructed as a hierarchal human-grouping system, generating racial classifications to identify, distinguish and marginalize some groups across nations, regions and the world. Race divides human populations into groups often based on physical appearance, social factors and cultural backgrounds.

Racism: Racism is a system—consisting of structures, policies, practices and norms—that assigns value and determines opportunity based on the way people look or the color of their skin. This results in conditions that unfairly advantage some and disadvantage others throughout society.

Interpersonal Racism: Pre-judgment, bias or discrimination by individuals. When one individual acts in an adversely discriminatory way towards another and when their personal racial beliefs affect their public interaction.

Institutional Racism: The unfair policies and discriminatory practices of particular institutions (schools, workplaces, etc.) that routinely produce racially inequitable outcomes for people of color and advantages for white people.

Internalized Racism: Developing ideas, beliefs, actions and behaviors that align with racism. Internalizing the stereotypes and ideology.

Social determinants of health: The conditions in the environments where people are born, live, learn, work, play, worship and age that affect a wide range of health, functioning and quality-of-life outcomes and risks.

Principles for Using Public Health Data to Drive Equity

Refer to the five data equity principles to help guide you as you embark on new data projects, analyze current methods and work towards more equitable public health data systems.

PRINCIPLE 1

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

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.

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.

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.

PRINCIPLE 5

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

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There are many thought leaders and experts across fields working on creating more equitable public health and other data systems. Their current and continued work is essential to changing conversations and data life cycle management. This list does not represent an exhaustive compilation of all of those contributing to this field. Rather it includes sources directly used throughout this framework.

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