"A modern public health data system must execute a plan for governance, decision-making, and community engagement that centers addressing structural racism and creating equity in its design and operation. This means transparency, accessibility, and interoperability in all aspects of how the public health data system runs, how the system interacts with other systems, and how it takes in new information to respond to emerging and ongoing health issues."—RWJF

### **EQUITABLE USE OF DATA**

Using data that comes in the form of numbers, percentages, averages, and other statistics is one way in which we describe the world we live in. In both the public and private spheres, this kind of information can be immensely powerful in identifying problems, setting priorities, constructing stories, shaping opinions, creating policy agendas, making business decisions, and evaluating programs.

Data, quantitative and qualitative, is a critical component of advancing health equity. But quantitative data does not speak for itself. If numbers, percentages, averages and statistics are not considered within the past and present context from which they arise, people will do their own sense-making at best, and completely dismiss them at worst. Using data in a way that advances an equitable world requires an equitable approach to developing, designing, and using the systems and the information it holds. We must give context alongside data, and describe what numbers alone can't tell us.

Because data, and the conclusions drawn from data, plays a key role in this council's recommendations we find it important to also share some guidance on how we see data being better used to advance equity. A number of organizations have developed principles to guide equitable data use, including the Robert Wood Johnson Foundation (RWJF), the Association of State and Territorial Health Officials (ASTHO), and UW-Madison's Population Health Institute. We borrow heavily on their work in articulating the role we see for data in the pursuit of health equity. We also weave into the emergent themes from this Council's work.

## Capture and track data about the many social determinants of health

Call out box: The social determinants of health are "the conditions in the environments where people are born, live, work, play, worship, and age, that affect a wide range of health, functioning, and quality of life outcomes" (Health People 2030). These determinants go well beyond simply access to health care. They are themselves a product of how power, politics and policy; histories and economies, as well as decisions, governance, and justice, have played out over long periods of time to create the conditions of our lives today. Addressing these underlying conditions is vital to improving health equity in Wisconsin.

This value speaks to the importance of creating and using data that can meaningfully capture the role of factors beyond the scope of visits to doctors' offices and individuals' choices in creating health. Our data systems must be set up to advance health equity. This may require data system owners to incorporate data that exists elsewhere, devise new ways to capture community-relevant and community-level determinants of health, or figure out ways to leverage data systems to nimbly adapt to emerging needs. Our data must allow us to understand and address the ways in which structural poverty and structural racism, as well as other inequities that we continue to face today, prevent us from advancing health equity and harm the health of communities bearing the brunt of these inequities.

# Clearly articulate the purpose for collecting and analyzing data

Data has been used in many harmful ways, including to stigmatize communities facing inequities. Data have also been used to mobilize action for policy and systems changes needed to improve community health. The use of data to advance health equity requires clearly identified needs, gaps and opportunities; and that the questions being pursued are rooted in equity commitment to justice. As a process, these steps creates an opportunity to ensure this pursuit drives the questions that get asked and, in turn, the data can reveal the kinds of answers that can inform positive change through improved decision-making that will further the pursuit of health equity.

### Ensure equity and community engagement in data governance

The data and information organizations use to advance health equity themselves must be generated and governed equitably. The people and communities about which data exists must have voice in the collection and interpretation of that data, and in the case of our tribal communities, data sovereignty must be honored and respected. This will improve the data being collected and the quality of information and interpretation, all the while building shared support for and trust in the creation, analysis, and application of information in the pursuit of health equity.

#### Perform holistic and accessible data and policy analyses

Collecting data on the social determinants of health is only the first step. We know many factors influence our health and so we need analyses that consider the breadth of factors and identify the most important ones in any given context. By using data that reflects the connection between the key determinants of health and specific health outcomes, analyses become more meaningful and effective. This is because the inclusion of the determinants allows for a fuller more holistic picture of the key drivers of health, thus illuminating the variety of ways to create better health. At the same time, data must be presented accessibly and clearly – the people who consume, digest, and use data need to be able to effectively wield this information to better understand, identify and disrupt the factors that affect our health.

## Craft narratives to advance health equity

Data is only one possible input in stories. We need to lift up the stories about community resilience, survival and ability to thrive in spite of adversity, and avoid only highlighting the struggles and challenges that marginalized communities face, this is how we can more effectively represent the full breadth and depth of people's lived experiences and present needs. This requires building relationships rooted in trust and shared understanding with marginalized communities in order to effectively work alongside these communities to create these new narratives. This requires choosing words, both in our public documents and private conversations, that center communities' strengths and assets, reflect a commitment to an equitable society, and exemplify the values and principles guiding health equity work.

## Cultivate and deepen our ability to engage with data critically

Taking a data-informed approach to informing our actions has limitations that we must recognize. We must all become critical thinkers and check our assumptions about the information we consume. This can start by encountering data with the following questions in mind:

- Which questions are being asked to generate the numbers and how, why, and by whom are they are being asked?
- What data are being used to answer these questions and what data do we not have?
- What decisions are being made about which data are included and highlighted and by whom?