**WORKSHOP - Racism as a public health issue: what is the role of data?**

**Breakout room session notes (6/3/21 & 6/10/21)**

During a recent presentation focusing on the role of data in declaring [racism as a public health issue at the 2021 Best Starts for Kids Summit](https://www.youtube.com/watch?index=24&list=PLU1Hbisgo666qqm4PGktRaDBRrjdpVASI&v=b5_wUqkUt5U), we asked participants to provide feedback and ideas on 4 different questions including:

* + - How we (as agencies and institutions that collect, analyze, and disseminate data) can change the legacy of data being used against communities,
		- How data can address racism,
		- What additional data/tools/resources you wish you had to address impacts of racism, and
		- What does data justice look like?

We summarized attendee ideas by 4 themes (reflected in the boxes below):



At the next two Communities of Opportunity-sponsored workshops, attendees were invited to discuss actionable steps based on these 4 themes that agencies and institutions that collect, analyze, and disseminate data could incorporate into organizations and processes to support data justice. The notes below reflect the suggestions and ideas for each theme as well as some relevant resources.  This document captures questions, dialogue, and suggestions community posed during the breakout sessions. These notes have not been altered or edited and directly reflect the voices of the community partners.

**Community-based participatory research [Breakout room notes]**

*Increase community participation in all parts of the data collection process. This includes community input before data is collected and community input to inform the story the data tells. Below you’ll find questions that participants posed to assist with the increase of community participation in data.*

* How do we determine our user groups? Make sure that more community members are present?
* How do we as institutions collect data that the community really needs?
* How do we build trust with our partners?
* Our organization had a development project and asked community partners on their thoughts on the development and they completely surprised us by saying that they don’t want to develop the land because it belonged to the Duwamish people.
* How do we make sure not to marginalize minority communities within minority communities. Within the African community, many resources are allocated for the larger African immigrant groups and often ignore the smaller African immigrant groups.
* Why do communities have to fill out a form to participate in certain forums and groups? We need to make it easier for community members to participate in community events.

**Approaches to data collection​ [Breakout room notes]**

*Be more inclusive of different data collection approaches and methods. Value community knowledge the same as academic rigor. ​ Below you’ll find suggestions for how systems can more inclusive of different data collections processes.*

Data collection challenges: Some organizations feel like they have an over-surveyed constituency. Members of the community they serve do not like to be surveyed, are asked for data from many different organizations/institutions, are reluctant to provide data, and only really can get data from folks is through financial incentives (which is not sustainable). Asked about what we are other strategies that others have tried to reach survey reluctant communities.

* Some communities are so heavily surveyed, and the asks for input and data are not coordinated by organizations collecting the data. Appears that organizations do not talk to each other and do not coordinate efforts in data collection, which then becomes burdensome for community members to repeatedly respond.
* Often those who are willing to fill out surveys are often those with those that have time (like older adults), not as likely to hear back from POCs, working families, younger people, etc. even though those are often groups whose input is most needed.
* Often the most marginalized groups are the least likely to be counted or detected in data collection efforts, and this leads to them being rendered invisible in many ways.
* A city talked about success in partnering with CBOS  to look at data, and identify data that is most important or helpful.
* Contracted with CBOs to pay and compensate, still are many trusted advisors we may not be aware of, but a comprehensive list of organizations or individuals who are willing to participate/advise could be helpful.
* Someone suggests that the Coalition of Community Health Boards as an organization to consult with that brings together expertise from a variety of communities.
* CBPR is one way to make data more meaningful to those who are part of research. While It feels to us that these data are important, the engagement is ongoing and can take lots of time for individuals and organizations to provide.
* Surveys can get boring, so changing platforms might be one way of keeping people engaged.
* What are platforms that are being used? During the pandemic so much data collection went to digital forms, but that is not always the best way to reach communities. Others suggested panel discussions over zoom, using mobile devices out in the field and many used paper forms before COVID.

A discussion group member shared out recent local policy changes regarding to promote data transparency and equity:

E2SHB 1272 - Concerning health system transparency.Sponsors: Representatives Macri, Cody, Fitzgibbon, Davis, Hackney, Thai, Kloba, Rule, Simmons, Pollet, Dolan, Slatter, Riccelli and Harris-Talley. What this bill does: Requires hospitals and provider-based clinics to disclose detailed financial, operations and patient demographic information (e.g. race, primary language, gender, income, any disability, and zip code) and patient outcomes, requires that public hospitals include additional detailed reporting about their community health improvement services. Why it’s important:  Provides for measurement of quality of care and costs to inform cost-effective purchasing of health care, improves ability to measure and thus reduce health disparities, and will help the state understand the true costs of healthcare in order to establish sustainable pricing levels. Progress: Passed Senate Health & Long Term Care March 26.

E2SSB 5052 - Concerning the creation of health equity zones. Sponsors: Senators Keiser, Randall, Cleveland, Conway, Das, Frockt, Hasegawa, Kuderer, Lovelett, Nguyen, Nobles, Robinson, Saldaña, Salomon, Wilson, C. What this bill does: Requires the Department of Health, subject to funding, to designate health equity zones statewide and develop projects to reduce health disparities that meet the needs of each zone, allows communities to self-identify as health equity zones and develop projects to track and improve health outcomes. Why it’s important: Community-driven, place-based efforts to reduce health disparities in the most vulnerable populations have been shown to be effective when they have the resources to implement projects sensitive and tailored to the needs of a community. Universal health coverage is necessary, but not sufficient, to achieve health equity. Progress: Passed Health Care and Wellness March 17, referred to Appropriations,

**Increase transparency [Breakout room notes]**

*Institutions should be more transparent about the data collection process and the biases that underlie the data. Below you’ll find best practices that partners shared to be more transparent about the data collection process.*

* I would love us to have a state or regional conference on this. I'm trying to spearhead a lot of data culture change. I'm a program analyst, that's data collection, analysis, reporting and sharing/dissemination. Change our culture around the white-supremacist-centered data experts who are not to be questioned. From epidemiologists to researchers. Sort of the white dominating culture and the data collector analyst culture. In both cases we undermine community voices and any other perspective of where we should get data, how we should use it. It's about decolonizing and being transparent but we have to do it first within our agency. Setting some goals or objectives around that. I know there's others, but I've had trouble finding people who are also working on this. I would love to see examples of goals/objectives around this.
* What we're measuring, how we're showing disparities, it's almost a blame the victim thing. Like high school disparities, we don't measure the systems themselves. We report what's routinely collected and perpetuate the same ways of talking about communities.
* We do one application for different cities. We are about to embark on editing the application for the 2023-2024 funding cycle. We're trying to only ask for information on what we need to make funding recommendations. It's always a challenge, if we're asking to tell us how many people by race that we are serving, are we really serving BIPOC communities in the funds that we are providing to agencies? It's a struggle to get data that our electeds and others are asking us to provide. We can't get it if we don't ask for it. One thing we're going to take off of the demographic section is about how many refugees/immigrants you are serving because some of our cities feel that's pretty invasive. Yet we're asked, we don't know how else to ensure we're serving well these populations. It's important in program planning.
* Cardea provides technical assistance to community orgs that have received BSK funding. Providing 1:1 support, we need this measure but how does it align/resonate with your work? Helping them identify measures that work for them. May not always be perfectly aligned but something needs to be reported back.
* How do we change data culture? We didn't get to solutions - looking at tools, setting objectives, as institutions it starts there. TPCHD interested in starting a group of exploration around assessing our teams, setting objectives, sharing tools and supporting each other as champions in this specific work.

**Research agenda [Breakout room notes]**

*Support the use of data for anti-racist change in policy, process, and practices in institutions and support communities in creating policies.*

* When collecting data, how deep can or should an organization go with their data? Typically the data used is publicly available, or cheap, or not as cleaned as it should be. To answer an immediate problem - it doesn't really address the need aside from the question I'm trying to answer. For example I'd look at census data about how many African Americans are in a certain neighborhood. But not what resources are already being spent.
* We have initial data, I was hoping that the presentation would get to what is public health doing about it. What are some of the outcomes, what is the workplan, what is the County committing to doing for 2022? Working with data we have in various sectors, how can we improve some of those outcomes? As much as I'm a proponent of cocreation it feels off to me that the health department has declared data as a public health crisis and doesn't have a plan.
* We use KC's indicator library, with all of the health indicators, to help us inform all of the funding processes. We ask organizations that are applying for funding how they are going to assist and how they are incorporating different disparities data that you see. Where I would like to get feedback is pushback we hear around why is it that we're only focused on race.
* Often researchers develop the questions, not community.
* For natives, it's the opposite of the one drop rule, a lot of times people are not considered indigenous if they're not part of a federally recognized tribe. Often times people show up as statistically insignificant due to genocide and it's difficult to be found in the data.
* What are your next steps to act on this?