

Data Justice Now

Good Afternoon, my name is Dr. Tyler TerMeer and I have the honor and privilege of serving as the Chief Executive Officer of Cascade AIDS Project and Prism Health. However, that is just one small piece of my story. I stand before you at the intersection of many identities, each of which influences my perspective and provides a framework for how I approach equity, justice, policy, strategy, and visioning. I am also a Black, Cis, Queer man who has been living with HIV for seventeen years.

I'm providing testimony today in support of HB3159, known as the Data Justice Act.

I've opened my testimony today by naming my identity to highlight why context matters. It helps us humanize complex and politically charged topics and better grounds us in the realities of the communities around us, especially those that have traditionally experienced oppression and been positioned furthest from access and opportunity.

While I could write an Op-Ed on the oppressive history of Black folx in this country or even right here in our own backyard (e.g., systemic racism, generational poverty, the pipelines of school-to-prison and/or sex trade work, and overall disproportionality in, well almost everything), the focus of my testimony today is on the causal relationship between lacking data and non-accountability. Specifically, how a lack of data has upheld inequitable relief response in the impact of COVID-19 on BIPOC and LGBTQ+ communities everywhere but specifically here in Oregon – and how this is just one current example of how existing systems have continuously failed BIPOC folx, LGBTQ+ people, and other communities that have traditionally faced inequities.

Oregon does not have the information it needs to tackle the many severe health issues disproportionately impacting BIPOC, LGBTQ+ people, people with disabilities, and other underserved populations.

In fact, **Oregon Health Authority collects little to no data on the identities affecting patients' health.** It wasn't until more than six months into the COVID-19 pandemic, for example, that OHA began receiving information from healthcare providers on the race and ethnicity of COVID-19 patients, despite the disparate impact of the disease on communities of color. Similarly, it took my leading an orchestrated community advocacy effort for Sexual Orientation and Gender Identity data to be acknowledged by OHA and for this collection to begin during a global pandemic.

These inaccurate and incomplete data sets are not nearly as innocuous as they may seem. Data impacts policies on health, education, zoning, and other resources during times of crisis, but also serves as an accountability measure. Identity-specific measures to achieve equity require accurate and robust data to pass legal and legislative hurdles. This has proved to be true time and time again when initiatives in our state have been specific to BIPOC and/or LGBTQ+ communities, and have found themselves vulnerable to litigation (e.g. The Oregon Cares Fund for Black Relief and Resiliency).

Absent explicit data collection and accurate analysis of race, ethnicity, language, disability, sexual orientation, and gender identity; a community-centered and led process; and a new approach to data equity, LGBTQ+ and BIPOC folx valid concerns surrounding accuracy, accountability, and transparency in decision-making for our communities will persist.

Data progress requires commitment at all levels of government and an acknowledgment that it can, and should, be an active tool for racial justice. This information is needed to identify the nature and extent of disparities, to target quality improvement efforts, to make equitable investments, and to monitor progress. America was built on the backs of Black, Indigenous and other People of Color. BIPOC and LGBTQ+ communities hold incredibly valid reasons for mistrust and we have been and will continue to be less likely to gain access to COVID-19 relief resources, testing, and now a vaccine.

Racism, discrimination and oppression are not dormant; to the contrary, they are as conscious as the lives they infringe. As we continue to rebuild after the dueling pandemics of COVID-19 and racial reckoning as well their economic and social impacts, we must remain vigilant. Making progress toward the goal of eliminating disparities will require widespread, reliable, accurate, and consistent data about the patient identity characteristics of the U.S. population.

How can Oregon “manage” institutional racism and discrimination in healthcare or social determinants of LGBTQ+ health when we don’t measure even the most basic characteristics of these populations? We cannot achieve health equity without achieving data justice.

Before I close out my testimony I should be clear about two things:

1. As the leader of an Oregon social service nonprofit, I’m not only advocating for HB 3159 to be approved and implemented as soon as possible, but also as the CEO of one of Oregon’s Federally Qualified Health Center Look-Alike’s, I’ll note that we will also have to navigate the investment of capacity, resources, and time it will require of us to collect and report out on this data. At the intersection of both of those things, I still strongly believe that we must have Data Justice NOW!
2. I’m aware of the letter that was submitted by healthcare providers, facilities and insurers that claims to be “committed to being collaborative partners in the collection of REALD and SOGI data,” and I truly wish that their message would have been framed as wanting to be champions of this work rather than presenting as a “letter of concern.” Let’s call a spade a spade. This is a letter of opposition. The recommendations it makes—which include recommendations unrelated to data standards—would have the effect of delaying or dismantling the policy. It’s shameful and might I add coming from predominately white led organizations.

CAP supports modernizing data collection nationally, but we’re not going to wait for federal action as these groups might suggest. National standards for collecting data erase and traumatize LGBTQ+ people and people of color. We believe collecting data in an inclusive, trauma-informed manner is more important than “reducing administrative burden and avoiding federal and state duplication”.

We can undo racism in America. We can prevent further systemic erasure and violence, but we cannot do so without the critical data that will not only tell the story of BIPOC and LGBTQ+ folx in this pandemic, but continue to build on the legacy laid by our ancestors as we pave a pathway towards liberation, healing sovereignty, and decolonization.