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Engaging Antiracist and Decolonial Praxis to Advance Equity in Oregon Public Health Surveillance Practices.

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COMMENTARY

Engaging Antiracist And Decolonial Praxis To Advance Equity In Oregon Public Health Surveillance Practices

ABSTRACT Public health surveillance and data systems in the US remain an unnamed facet of structural racism. What gets measured, which data get collected and analyzed, and how and by whom are not matters of happenstance. Rather, surveillance and data systems are productions and reproductions of political priority, epistemic privilege, and racialized state power. This has consequences for how communities of color are represented or misrepresented, viewed, and valued and for what is prioritized and viewed as legitimate cause for action. Surveillance and data systems accordingly must be understood as both an instrument of structural racism and an opportunity to dismantle it. Here, we outline a critique of standard surveillance systems and practice, drawing from the social epidemiology, critical theory, and decolonial theory literatures to illuminate matters of power germane to epistemic and procedural justice in the surveillance of communities of color. We then summarize how community partners, academics, and state health department data scientists collaborated to reimagine survey practices in Oregon, engaging public health critical race praxis and decolonial theory to reorient toward antiracist surveillance systems. We close with a brief discussion of implications for practice and areas for continued consideration and reflection.

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There is growing discourse regarding structural racism and public health in the US.[1–3] Dozens of organizations and state and local health departments have declared racism a public health crisis.[4] Yet most of this attention is directed outward toward racism that is “out there” in the world of social, economic, and political systems. Missing from the discourse is attention to the racism “in here”—specifically, embedded within public health knowledge production, surveillance, and data systems.[5–7]

However, what gets measured and how, and which data get collected and analyzed, are not matters of happenstance.[7,8] Rather, as we argue here, public health surveillance systems and data practices are (re)productions of political priority, epistemic privilege (defined here as the centering and valuing of dominant-group perspectives and knowledge), and racialized state power. These systems must be interrogated to determine whether they align with the ethical principles of epistemic (relating to knowledge production), procedural, and data justice and what role these systems play in impeding or supporting antiracist and decolonizing praxis in public health. Unfortunately, scholarship to date discussing the limitations, future potentials, and ethical issues within these surveillance systems and data practices has failed to engage these matters entirely.[9,10] The field thus remains beholden to a "colorblind" and power-blind ethics that makes the racialized power dynamics of these systems and practices invisible.

Here we outline a critique of standard public health surveillance systems and data practices as reflected in the largest public health surveillance system in the US: the Behavioral Risk Factor Surveillance System (BRFSS). We draw from the social epidemiology, critical theory, and decolonial theory literatures to illuminate matters of power germane to epistemic and procedural justice in the surveillance of communities of color. We then summarize how community partners, academics, and state health department data scientists collaborated to reimagine public health surveillance systems and data practices in Oregon, engaging public health critical race praxis[11] and decolonial theory to design antiracist data systems. We close with a discussion of implications for practice and areas for continued consideration and reflection.

Structural Racism, Power, And Population Health Surveillance

A fundamental component of public health practice is population health surveillance and monitoring.[12] Although updates to the Public Health Accreditation Board's 10 Essential Public Health Services explicitly center equity,[13] structural racism is not mentioned. As Sirry Alang and colleagues note,[6] "that our surveillance systems do not routinely collect data on racism is one indication of how White supremacy plays out in public health." Surveillance efforts that have included racism have been limited to individual experiences of racial discrimination and are often optional—for example, the BRFSS Reactions to Race Module.[14] Efforts to better measure structural racism "out there" have increased;[2,3,15,16] however, little attention has been directed to the internal workings of public health surveillance systems and data practices, leaving uninterrogated the impact of White supremacy and settler colonialism in shaping the logics and methods that undergird them.[5,6]

In this regard, these surveillance systems and data practices reflect what Tukufu Zuberi and Eduardo Bonilla-Silva refer to as "White logic":[17] "a context in which White supremacy has defined the techniques and processes of reasoning about social facts." This logic manifests in colorblind methodological practices that center claims of "neutrality" and "objectivity" (so-called White methods) under the gaze of (mostly) White data scientists. Epidemiological surveillance practices on racial health inequities skirt considerations of data scientists' positionality—that is, their multiple and intersecting social identities, histories, and associated power relations and how they shape the scientists' perspectives and approaches to research. Such practices thereby center Whiteness and normalize the invisibilization of the White scientific gaze, effectively obscuring power relations that shape racial(ized) knowledges and data narratives. In other words, public health has failed to interrogate the manner in which and extent to which structural racism has corrupted the very mechanisms that communities of color rely on to identify, measure, and justify action against it.

As noted by Nancy Krieger,[18] "a theoretical vantage is crucial to seeing and appraising evidence" related to racism and health, and so, too, is it crucial to seeing and appraising how racism shapes the definitions, availability, perceived legitimacy, and uses and misuses of evidence. But seldom does our field engage theory in appraising existing public health surveillance systems and data practices. Indeed, it appears that theories around knowledge and its production, power, and structural forms of exclusion have had no role in shaping the contours and functions of US public health surveillance systems and data practices.[10,19–21] However, these systems and practices are not neutral, apolitical, or value-free exercises.[8] Rather, they are rooted in a series of knowledge-power relations that serve to define what counts as data, which data are collected, who collects and analyzes data, who has access to data, how data can and cannot be used, and which data are viewed as legitimate.[5] Public health data are thus a "social product"[8] and, in the context of structural racism, a reproduction of political priority, epistemic privilege, and racialized state power. So how is it that our field has yet to name and address this?

We believe that this is in part the result of a collective failure of US public health and public health training programs to properly engage theories of power and knowledge production as germane to public health surveillance systems and data practices. Leading surveillance guidelines make no mention of matters of power, structural racism, inclusion, community voice, or community knowledges.[19] Moreover, none of the seventy-three competencies developed by the Council on Education for Public Health for accrediting master of public health degrees mentions power, structural racism, theories of racialization, or epistemology.[22] Similarly, none of the eight competencies specific to epidemiology,

Team members understood that centering the margins in reimagining surveillance systems fundamentally required prioritizing voice.

or the seven specific to biostatistics, speaks to researcher positionality or intended research audience[5,23] as germane to the production and interpretation of epidemiologic knowledges. And to our knowledge, core epidemiology training texts and extant surveillance system literature do not discuss the racialized nature of surveillance systems.

This systemic silence is an expression of colorblind racism and is not random. Rather, it is a predictable consequence of public health institutions functioning as what critical race scholars refer to as "racialized organizations" and artifacts and reproductions of "White space,"[24,25] such that standard public health surveillance systems and data practices are cast as race-neutral despite their perpetual reification of power hierarchies and racist institutionalized logics. This explains how the BRFSS can have zero measures of structural racism in 2024, forty years after the Heckler Report,[26] as such measures would require the state to spend resources specifically to document and take action on the racist social structures and racialized knowledge systems that sustain it.

This context illustrates well Michel Foucault's notions of "objects," "ritual," and "the privileged," as well as dynamics of repressive and productive power within knowledge production.[5] In the "ritual" of public health surveillance systems and data practices, data are gathered and used to frame and name particular issues—creating "objects" of epidemiologic knowledge. The ritual continues after data collection and analysis, into matters of dissemination and policy discussion. Those who are credentialed and paid to carry out the ritual of producing the objects of knowledge are what Foucault called "the privileged." This process is recursive: The ritual requires certain skills, and it values certain epistemic orientations, which then inform what is required to become credentialed as the privileged. So long as the ritual remains in place, the objects produced will remain much the same.

Matters of repressive and productive power are embedded throughout the ritual.[5] This includes the power to set surveillance agendas and data priorities, power to shape or manufacture public narratives around policy issues, power to generate and perpetuate stigma, and power to "own" or control access to data. Repressive power is also observed in which types of data are not collected, who is not involved in data collection and analysis, and whom data are not collected about and from. Productive power is observed in which data are collected (and by whom), which data narratives are produced, and how communities of color are described within those narratives. For example, notions of being "at risk" and "vulnerable" are quintessential to surveillance work. Use of terms such as "vulnerable" not only obscures structural relations of power that drive health inequities but also can "generate…the 'vagueness' necessary to host common and damaging narratives, undermining the accuracy and therefore the efficacy of public health research."[27] Moreover, these examples illustrate the relevance of Noel Cazenave's notion of linguistic racial accommodation[28] as germane to public health surveillance systems and data practices, in that traditional practices use language and framing that appeal to dominant-group sensibilities for apolitical neutrality—namely, by not identifying structural racism as a system of power that creates and maintains "risk" and "vulnerability."

In this capacity, public health surveillance systems and data practices present as a form of epistemic violence, described as "when empirical data are interpreted as showing the inferiority of or problematizes the Other, even when data allow for equally viable alternative interpretations."[29] The violence occurs not only after data are collected vis-à-vis interpretations that pathologize, problematize, and stigmatize communities of color (for example, calling them "vulnerable" and mapping them red),[30] but also before data are collected vis-à-vis the epistemic privileging of only certain forms of knowledge—namely, survey-based data via predetermined questions. This amounts to an epistemic erasure and silencing of communities of color.

This preemptive erasure and silencing illustrates what Kristie Dotson refers to as a "practice of silencing."[31] A central concern is the manner in which those speaking from the margins can have their knowledge or knowledges dismissed or otherwise be perceived or portrayed as incapable of possessing any relevant or credible knowledge within a given context, also known as "testimonial quieting." Similarly, traditional public health surveillance systems and data practices make clear that the state views communities of color as possessing no knowledge of their own that is worth asking about. The standard BRFSS telephone interview is, effectively, the poster child of testimonial quieting. These surveys have limited ability to produce anything other than narratives of risk and vulnerability because their existence and use is premised on an epistemology of deficits, damage, and needs anchored in logics of White supremacy and settler colonialism. They were not conceived, nor are they designed or implemented, with matters of epistemic justice or antiracism in mind; they are, in effect, the quintessential "master's tool."[32]

Toward Antiracist And Decolonial Public Health Surveillance In Oregon

Against this backdrop and theoretical grounding, community partners, academics, and state health department data scientists are collaborating to reimagine traditional public health surveillance systems and data practices in Oregon. As in most states, the Oregon BRFSS and related surveys are the primary source of population health data. Although these surveys may be useful for generating certain types and forms of data, they are rife with limitations. In this regard, public health can benefit by more thoroughly engaging Black feminist and public health critical race praxis notions of "centering the margins"[11] (or starting and anchoring discourse on a topic with the perspectives of marginalized groups) and decolonial theory. Here, we briefly describe the procedural aspects of the collaboration[33,34] and then summarize how we engaged antiracist and decolonizing principles and praxis to orient ourselves toward public health surveillance systems and data practices that better center communities of color.

The Engaging Communities in the Modernization of a Public Health Survey System project has been described in detail elsewhere.[33,34] Starting in 2019, the Oregon Health Authority collaborated with and funded the nonprofit Coalition of Communities of Color to colead the work. Community-specific data project teams were created for the Latinx, Black/African American, Native American, and Pacific Islander communities in Oregon. The Latinx and Black/African American teams formed a joint workgroup and used a formative participatory assessment approach to address challenges in the Oregon BRFSS and Student Health Survey data system by centering community partnership and leadership in understanding and interpreting data; identifying strengths, gaps, and limitations of data and methodologies; facilitating community-led data collection on community-identified gaps in the data; and developing recommendations. A summary of our process is shown in exhibit 1, with procedural details and core outcomes and lessons learned described elsewhere.[33,34]

Our work illustrates a way to reconcile the disconnect between addressing structural racism both "out there" and "in here."

Public health critical race praxis was core to early formative discussions among project team members regarding existing BRFSS and Student Health Survey surveillance efforts. Many team members were already engaging core public health critical race praxis principles within their respective work before joining the project and viewed it as a generative foundation to guide the collaboration. Three of these principles were particularly salient throughout the project: voice, social construction of knowledge, and disciplinary self-critique.[11] The principle of voice, or "prioritizing the perspectives of marginalized persons,"[11] was foundational to the project, from team formation throughout dissemination of the work. Team members understood that centering the margins in reimagining surveillance systems fundamentally required prioritizing voice. Members also appreciated the connection between voice and social construction of knowledge, or the idea that because knowledge is a social product,[8] any "established knowledge within a discipline can be reevaluated, using antiracism modes of analysis."[11] Team members viewed their engagement as necessary to the production of new, alternative, or counter knowledges about health in communities of color. As such, team members leaned openly into disciplinary self-critique, or the "systematic examination by members of a discipline of its conventions and impacts on the broader society."[11] Together, these three principles grounded the teams' epistemic orientation in antiracist praxis.

The project teams also engaged decolonial

EXHIBIT 1

An equity-centered approach to reimagining public health surveillance systems in Oregon

Data equity processes	Community-government partnerships	Collaboration-based outcomes
Relationship building	CCC is invited to colead the work with OHA staff Researchers and organizations from Latinx and Black/African American communities are invited to join the participatory analysis workgroup	OHA and CCC convene Latinx and Black/African American participatory analysis workgroup
Community survey review	Collaboration between Latinx and Black/African American workgroups, CCC, and OHA staff	Review and critique of survey systems, including question wording and missing contextual questions
Community-led data collection	CCC leads with support from OHA and university and community partners	Researchers engage high school students to inform improvements to survey questions
Data analysis and community vetting	CCC and workgroups request survey data analysis, and OHA staff provide it for team review CCC staff analyze data and present to workgroups and OHA staff Groups discuss interpretation of analysis and reacts to findings iteratively	Iterative process among workgroups, CCC, and OHA staff, providing data, analyzing, requesting further data, and providing feedback
Communication	CCC and workgroups collaborate to develop recommendations to be included in the final report and disseminated across OHA	Recommendations for improving survey systems are developed
Impact	CCC and workgroups present final report and recommendations to OHA's public health partners across the state	Recommendations are informing the modernization of OHA survey systems activities (for example, creation of a Youth Data Council)
Sharing back to community and practitioners	CCC and workgroups share findings and lessons learned with community and practitioner groups	Community briefs and academic articles are written and shared across networks Ongoing dissemination within OHA programs and leadership

SOURCE Authors' analysis of the Oregon partnership. **NOTES** CCC is Coalition of Communities of Color. OHA is Oregon Health Authority.

theory within project planning, engagement, and reporting and dissemination processes, with four interrelated considerations proving particularly formative. First, team members were attentive to what Linda Tuhiwai Smith described as the commodification of knowledge—in general, the ways in which community members are dispossessed of their knowledges through extractive engagements with outsiders, who then become the sole arbiters and beneficiaries.[35] Second, and relatedly, members reflected on Aileen Moreton-Robinson's notion of "the White possessive,"[36] or a "mode of rationalization…that is underpinned by an excessive desire to invest in reproducing and reaffirming the nation-state's ownership, control, and domination." For example, discussions that arose early in the planning process raised concerns around the availability of, access to, and ownership of existing data. BRFSS and Student Health Survey data generally are not accessible to the public beyond static PDF reports that quickly become outdated. This raised questions about whom the data are actually for (research gaze) and whether the community tangibly benefits from their collection (matters of distributive justice). In considering Smith's and Moreton-Robinson's work,[35,36] team members were mindful not only of the extractive and dispossessing history and present proclivities of public health surveillance systems and data practices but also of the myriad reasons for community distrust of government organizations when it comes to "state" data. Members were accordingly attentive to concerns about how surveillance practices feel like a one-way "taking" of information for the taker's benefit, how the taking itself can be a form of harm, and how what is taken might be used in a way that causes harm.

Third, team members visited early and often Smith's reflection on matters of community (mis)representation within settler-colonial state-led knowledge production processes. As she states, "representation is important as a concept because it gives the impression of 'the truth'. …There are problems, too, when we do see ourselves but can barely recognize ourselves through the representation."[35] This concern resonated deeply with team members, all of whom had ample experience in both encountering and countering issues of misrepresentation within their varying areas of professional and cultural practice. Last, and relatedly, members were keen to put Eve Tuck's notion of "suspending damage" into practice.[37] Tuck called for a "moratorium" on "research that intends to document peoples' pain and brokenness to hold those in power accountable for their oppression…yet simultaneously reinforces and reinscribes a one-dimensional notion of these people as depleted, ruined, and hopeless." Team members discussed throughout the project the importance of reimagining public health surveillance systems and data practices to move analytic priorities away from individualist, pathologizing, and deficits-oriented logics that obscure power while centering harm, thereby perpetuating it.

Our initial work to reshape data priorities and collection through the BRFSS and Student Health Survey reflects these considerations,[33,34] and continuing Student Health Survey work illustrates alternative approaches to public health surveillance systems and data practices focused on youth. Specifically, the Coalition of Communities of Color is working with the Oregon Health Authority to build qualitative data capacity, including developing processes for "coding for meaning" and securing collaborative analysis software for Oregon Health Authority analysts and youth to coanalyze data. In addition, the Youth Data Council, formed on recommendations from our collective work, is working to develop and implement their own high school surveys. Moreover, we have outlined a process for the development of community-led "decolonizing data hubs" that generate community-specific data in sustained collaboration with or with technical support from traditional state-led systems.[34] The Oregon Health Authority has already secured federal funding to begin building the foundation for this work. We believe that resources typically allocated strictly to BRFSS implementation (for example, oversampling costs) could be better invested in developing such community-led hubs, and such investments could be incentivized and required as part of funding eligibility guidelines.

Discussion

Public health surveillance systems and data practices must be viewed as both an instrument of structural racism and an opportunity to dismantle it.

Recent scholarship has rightly called for greater focus on centering equity within public health surveillance systems and data practices.[38–40] This has included an emphasis on restructuring public health surveillance systems and data practices to collect data on a broader array of structural factors to address social determinants and advance antiracism.[6,16,38,40] Other scholarship on how to measure structural racism,[2,3] for example, shows promise for informing such efforts. However, work that speaks to the need to pursue authentic efforts to center the voices of communities of color in all stages of the data cycle is limited.[16] That is, even within articulated visions of "equity" within public health surveillance systems and data practices, the credentialed outsider ("the privileged") is still in control of setting data agendas and controlling data narratives about communities of color. Our work seeks to intentionally counter this norm to advance antiracism within survey modernization efforts. Although still in its early stages, it illustrates a way to reconcile the disconnect between addressing structural racism both "out there" and "in here," such that addressing it "in here" might position health jurisdictions to better identify and include additional, new, or alternative data that can better address structural racism "out there."

Here, we suggest three areas with practice and policy implications for which our collaborative process might guide future efforts. First, although we collectively continue to engage antiracist and decolonial praxis, there is an ongoing learning curve among team members. We represent multiple disciplines and fields of practice, not all of which have afforded opportunities to engage these matters meaningfully in either training or practice settings. In this regard, our work speaks to the need for more systematic inclusion of these matters within training, accreditation, and certification guidelines and requirements to better prepare future practitioners for public health surveillance systems and data practices work. For example, existing accreditation guidelines for epidemiology (and biostatistics) should be reimagined to include "foundational competencies" related to structural racism, White supremacy, settler colonialism,

Public health must engage with considerations of power and epistemic justice as germane to advancing racial equity through and within surveillance practices.

and contingent knowledge-power relations germane to public health surveillance systems and data practices. And epidemiology and biostatistics programs and professors would do well to review their curricula for these matters and revise as needed to minimize the credentialing of colorblind, epistemically violent practitioners and scholars. For those already in practice settings, required training modules or certifications on similar topics could prove beneficial—for example, via updating operational, essential service, and accreditation guidelines for health agencies.[12,13,41] Relatedly, as discussed above, public health data are a social product[8]—produced by people of varying intersecting social locations. This must be acknowledged candidly within public health surveillance systems and data practices, and requirements for positionality statements for those working on surveillance data or applying for related jobs warrant serious consideration.

Second, discussion of modern public health data systems has emphasized the actionability of data, part of which requires greater geographic granularity.[38,42] Existing systems fail in this regard, as standard sampling procedures and analytic goals prioritize, for example, standardized comparison between counties or states over depth and specificity for any one particular community. They also often use politically meaningless geographic bounds such as ZIP codes. Moreover, they generally fail to engage those who live in the communities being surveyed and monitored in data planning, collection, analysis, and dissemination processes. This is not only a missed opportunity to center equity vis-à-vis principles of procedural and epistemic justice but also an epistemic erasure that enables White settler-colonial logics and methods to persist. In this regard, data scientists and practitioners would do well to more thoroughly engage not only with principles of antiracism, decolonization, and data justice[43] but also with literature related to community-based participatory research, citizen science, and small data.[44–46]

Third, extending from our engagement with the work of Tuck and Smith,[35,37] our field needs to reimagine public health surveillance systems and data practices to tell fuller, more humanized, and less pathologizing or stigmatizing data stories of health in communities of color. It is not just that our field needs better BRFSS items, or better surveillance systems in the sense that they are more granular or grounded in community-led data processes. Rather, our field must reimagine systems to deliberately counter the harms, erasures, and occlusions that existing systems enable and perpetuate. Community knowledges must be centered in ways that allow not only for alternative methods and data types but also for alternative logics, such that “risk” and “vulnerability” and “deficits” are not the default epistemic lens. Reimagined survey practice should, for example, leave room for understanding the roles of joy, love, belonging, healing spaces, and modes of community care and resistance in shaping community health. And we—collectively—should allow ourselves and our communities to imagine a future of community health surveillance without surveys. Here, we believe that data scientists and practitioners could find much inspiration not only in the work of Tuck and Smith[35,37] but also in scholarship that engages creative resistance and counternarratives,[47,48] calls for “generative refusal” of default White and settler-colonial logics as means to understand communities of color,[49] and encourages centering “healthful narratives.”[50] In this regard, our work models a process through which stakeholders can hold space to name and respond to these concerns. Here, we believe that establishing “narrative balance” policies—that is, ensuring checks and balances on epistemic orientations and narratives—related to funding eligibility, data reporting, and data access and use warrants deep consideration.

Conclusion

Public health must engage with considerations of power and epistemic justice as germane to advancing racial equity through and within surveillance practices. Our work in Oregon represents a process to better align such practices with principles of antiracism and decolonization and thereby better hear, measure, represent, and respond to health concerns within communities of color. Addressing the consequences of structural racism necessitates addressing the structurally racist, settler-colonial logics that have guided public health surveillance systems and data practices to date. These are not matters of a separate discourse; they are fundamental to any serious conversation in which racism has been declared a public health crisis. There is no future in which public health becomes antiracist without dismantling the racism and settler colonialism latent within its public health surveillance systems and data practices. Our work in Oregon is an earnest effort to begin that process. ■

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