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DO NO HARM GUIDE

ADDITIONAL PERSPECTIVES ON DATA EQUITY

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Do No Harm Guide: Additional Perspectives on Data Equity

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In June 2021, we published the *Do No Harm Guide: Applying Equity Awareness in Data Visualization*, a first-of-its-kind resource born of nearly 20 interviews with data experts on how data analysts, researchers, and communicators can apply an equity lens to the way they work with and visualize data.

The guide centered empathy as a key tool for helping data practitioners not perpetuate stereotypes, biases, and other types of harm, and it offered tips for better chart design through language, data ordering, color palettes, and data groups. Further, the guide went beyond data visualization alone, discussing many other equally important aspects for working with and communicating data in equitable ways. These include critically examining data; engaging in lived experiences; building diverse and inclusive data teams; seeking feedback on data products; and acknowledging how "gatekeepers," such as funders, journal editors, and government agencies, affect the data process.

As expansive as the original guide was, we knew there was still more ground to cover. We wanted the guide to serve as a foundation upon which we could continue to explore the topic of equitable data research and communication. Now, we are excited to present this follow-up publication, which presents voices from groups and communities traditionally underrepresented in data research and communication.

In this second volume, *Do No Harm Guide: Additional Perspectives on Data Equity*, we hear directly from members of these communities about their thoughts and experiences on how they take, or how would like others to take, an equitable approach to data work. This volume consists of five essays that cover community-based participatory research, the experiences of Native communities in research and data, building community-academic partnerships in Hawai'i, steps to reduce mental health disparities, and the barriers facing Black women in STEM fields. The authors of these essays, all of whom are members of groups traditionally underrepresented in data fields, are community-engaged researchers and champions for collecting, analyzing, and communicating data equitably.

As we thought about what a second volume of the *Do No Harm Guide* might look like, we were aware of the limitations of our own lived experiences. One author of the first volume is a cisgender white American Jewish man, the other is a cisgender Asian American woman, and our lead substantive editor is a cisgender white American man. As such, we felt that hearing directly from members of other communities would provide insight and depth of experience that we could not.

In January 2022, we began seeking potential contributors, asking our Urban Institute colleagues for their recommendations, and finding people doing interesting work across a variety of fields. After kicking off the project in early February, the authors spent the spring writing their essays. As editors of the volume, we provided each with feedback on content, length, and cohesion with the final volume. We were also fortunate to have a talented team of editors, project managers, and other communications experts to help us guide the authors in their work.

Several themes emerge from this diverse collection of essays. Many of our authors describe the impersonal, almost transactional way that researchers often approach their communities. Whether or not these people and communities have sought the help of researchers, they are often met with harmful results. Throughout history, many studies have inflicted harm on already-marginalized populations—famous examples include medical experiments performed on enslaved women and the nonconsensual use of blood samples taken from a Native community. The legacy of such harm has caused many communities to not trust researchers. Moreover, outreach in the other direction is less common: researchers do not often seek communities' input, advice, and experiences, even though doing so can enrich the research, add a human element to an "ivory tower" approach, and lead to findings that are more likely to be embraced and utilized by the communities the researchers sought to assist.

In response to this imbalance, several of our authors highlight that researchers and data experts must build relationships with communities. Leonore Okwara explores the principles of Community-Based Participatory Research and offers suggestions for how data experts can establish positive, equitable relationships with community members. Jane J. Chung-Do and coauthors place this kind of collaborative research in a specific setting by exploring the experience of the Waimānalo Pono Resarch Hui, a community-academic partnership formed by community leaders and academic partners of the Waimānalo area of the island of Oʻahu. Both essays offer analysts and researchers practical strategies to build trust and forge strong relationships between communities and researchers.

Patrice Kunesh, of Standing Rock Lakota descent, and Kendra Root, a citizen of the Muscogee Nation, document several examples of embarrassment, harassment, and exploitation from researchers among Native American communities and bring those experiences into the modern era by offering recommendations on how data analysts and researchers can fill in the data gaps of Indigenous communities.

Data and data projects can only be made more equitable if work teams are diverse, reflect a variety of experiences, and trained to foreground empathy and equity in their work. In the final essay of this volume, Ashley M. Scott visits the challenges that underrepresented groups, especially Black women, face in the STEM field, both in the educational pipeline and in professional settings. Similarly, Quianta Moore and Marcy Melvin explore how a new generation of mental health practitioners can be trained to conduct their work through an equitable and inclusive lens in order to reduce disparities in mental health and inequities in treatment.

This second volume of the *Do No Harm Guide* is still just the beginning. There are many more voices to hear from, more experiences to understand, and more research techniques to put into practice. As with the original report, the lessons described here are not fixed rules researchers should follow; rather, they are issues to consider when collecting, analyzing, and communicating data. In doing so, not only will data work be more equitable and inclusive, it will also be more useful and more likely to be embraced by the people who are best positioned to use the work in their lives and in their communities.

The Value of Quantitative Researchers in Building Community Trust in Research

LEONORE OKWARA

"Violence, pain, and shame joined as physicians forced the enslaved body into medical service, not to cure, but for profit. Medical experimentation was profitable in terms of recovered health and life for whites, who benefited once the medical process had been perfected."

—HARRIET A. WASHINGTON[1]

Harriet Washington wrote these words in 2006 to describe the history of abuse the Black community has experienced by scientific researchers. J. Marion Sims, often referred to as the father of modern gynecology, provides one infamous example of this abuse. Sims, who ultimately developed a groundbreaking procedure to fix an embarrassing condition for women (the vesicovaginal fistula, an abnormal opening between the bladder and the vagina that causes infections and odor), performed unsafe experiments on enslaved children and adults in the 1840s. Sims could easily acquire slaves to experiment on, so he practiced the procedure on Black enslaved women who could not refuse participation. At the time, white physicians believed "that blacks did not feel pain or anxiety, which excused painful surgical explorations without anesthesia on blacks."[2] Sims performed the procedure without anesthesia, causing excruciating pain, while the other enslaved women watched in horror as they awaited their turns. After much experimentation, Sims developed a successful surgical repair protocol, which he performed for white women under general anesthesia.

Imagine being an enslaved woman, being experimented on without your consent, without anesthesia, and with no way to escape. How would this affect your perception of experiments or research from that day forward? How would conversations about scientific research happen in your family? Would you encourage or discourage your friends and family members from participating in studies? These stories, fears, and words of warning have been passed down through generations.

Generational trauma resulting from historical abuse by researchers has left many communities hesitant to participate in research. Researchers, like Sims, have taken advantage of unsuspecting communities, violated their right to consent, caused physical and emotional harm, performed heinous acts, failed to disclose research activities, and failed to report study findings back to the community.

As a result, these communities often do not trust researchers. Earning community trust requires transparency, accountability, and the establishment of a genuine relationship between the researchers and a community. Today, more researchers are using community-based participatory research (CBPR) to build meaningful and sustainable community partnerships. CBPR principles guide researchers on how to respectfully bring the community to the table as partners in the research, including through shared learning around data collection, analysis, and dissemination. Each member of the research team contributes to this partnership. Although people who work with data sometimes have difficulty understanding the value of building community trust and increasing research transparency, the community's perspective of research can be changed by bringing understanding to a topic through data.[3]

Quantitative researchers can take the following steps to build trust and share findings in a meaningful way:

1. **Humanize** the data, engage in self-reflection, and become immersed in the history of the community.

2. **Identify** ways to garner community input about data-related methods and products.

3. **Establish** the practice of developing summaries of the study findings for the community.

4. **Remain flexible** and patient, because building trust between researchers and the community takes time.

Using Community-Based Participatory Research Methods

CBPR is an approach that creates a bidirectional relationship between the community and researchers.[4]

CBPR principles include the following:

- Promote a collaborative and equitable partnership between the researchers and community throughout the research process.

- Acknowledge that each community has its own identity.

- Focus on an asset-based perspective rather than a deficit-based perspective when identifying community resources.

- Establish a co-learning environment.

- Address issues that are relevant to the community and not just the researcher or research institution.

- Prioritize research and decisions that will benefit all involved.

- Create a summary of findings that is transparent, clear, and dispersible so community members can access and use the information and strategies to make informed personal or collective decisions.

- Extend community-research relationships beyond the current project.[5]

This approach creates a co-learning environment for researchers to acknowledge the limitations of their own expertise and recognize that the community brings expertise to the research process in the form of lived experience that the researchers may not have. CBPR also establishes a collaborative environment for community members to ask questions to researchers directly and share their feedback about research development, management, implementation, and dissemination. People who work with data are vital to the success of this equitable partnership. CBPR acknowledges that every community has an identity, and data are a powerful way to highlight

this identity. Thinking about data from a community-focused perspective reveals that data are more than numbers to be analyzed using mathematical and statistical methods. Data are attached to real people who have history and lived experiences that must be recognized, respected, and advocated for.

1. Learn the Community's History and Humanize the Data

"To gain trust, we must first acknowledge the flagrant abuses of the past and the subtler ones of the present."[6] This is what Harriet A. Washington recommended to physicians and researchers as one of the first steps to building trust. Every research team member should prioritize learning the history of the community by reading texts that describe their historical and modern-day research abuses and experiences. If your study is focused on communities of color, you should consider resources similar to the following:

- *Medical Apartheid: The Dark History of Medical Experimentation on Black Americans from Colonial Times to the Present*[7] provides a historical account of medical and research malpractice conducted on unsuspecting Black Americans.

- *Carte Blanche: The Erosion of Medical Consent*[8] describes how patients' right to informed consent for research participation was violated for decades, especially among people of color.

- *Stamped from the Beginning: The Definitive History of Racist Ideas in America*[9] provides historical insight into racist ideology and how it persists today.

Cultural humility is a lifelong commitment to self-reflection that emphasizes the importance of continuously learning from another community, recognizing that they are experts on their lived experiences, and advocating for communities at a

systemic level.[10] Becoming immersed in the history of a community, whether by hearing from community members or analyzing data from the US Census Bureau, naturally encourages such self-reflection. Self-reflection is also a key component of learning how your internal biases may contribute to how you interpret or present findings.

"Humanizing" the data is also an important part of self-reflection. "Participant 7" is not just a data point; that might be a young Black woman who has been homeless since age 16. "Participant 23" could be an Asian grandfather with a limited income who suddenly became the sole guardian of his three grandchildren and who, despite his mistrust of researchers, reluctantly agreed to participate. Although you may never have the opportunity to meet the participants, you must remember you are working with data from people who may be relying on you to show them how their survey answers have advanced the research. These people will need to interpret this information and use it to make important decisions for themselves, their family, or their community. They are people who have finally decided to give research a chance.

2. Join Community-Facing Research Meetings

"I am giving this research thing one more chance. I did research surveys for the other [research institution] and they never told me what they found out. I'm tired of people coming in and not giving me an update." This is what a community member disclosed to me when I approached her about participating in a research study. Research participants want and need to know what happens with their data.

Moreover, a community's perspective and priorities can drastically differ from those of the researchers. If you are a quantitative researcher serving as the principal investigator (PI) of on a study, one of the most effective ways to engage with the community is by forming a community advisory board, or CAB. A CAB includes community members and relevant providers who represent the study's community

of focus. "Tools and Resources for Project-Based Community Advisory," a toolkit from Urban Institute researchers, provides guidance on forming a CAB and involving it in a project.[11] CAB meetings can be held virtually or in person and should involve key research team members.

If you are a quantitative researcher but are not the PI, ask the PI to join the community partner-facing meetings. If these meetings are not currently taking place, suggest that the PI consider hosting regular meetings with community partners. These touchpoints are crucial to building researcher-community trust and gaining insight on community priorities. When research team members who work with the data do not engage the community in the data discussions and dissemination, negative experiences are more likely to occur.

Quantitative researchers need to have several meetings with the community and use their skill in explaining data so all attendees can understand the information and make decisions about next steps.[12] At the initial community meeting, introduce yourself to the community leaders, describe your role in the project, emphasize your enthusiasm for collaborating and seeking their guidance at every step of the research process, and provide an opportunity for questions. During subsequent meetings, continue sharing updates about the data progress; ask for questions and feedback; clarify and refine decisions around meaningful outcomes by asking for guidance; prioritize findings; ask for recommendations on how to structure and format these findings; and discuss the best format, channel, and frequency through which to share outcomes with the community. Regular participation in these community-facing meetings will provide community partners with a clear understanding of the research process and provide you with insight on how to meaningfully interpret and report findings.

If joining community-facing meetings is not an option, focus on understanding the community's history and humanizing the data.

3. Develop Community Summaries and Communication Methods

Complex scientific data needs to be translated so communities can use the information and develop strategies to make informed personal or collective decisions. People who work with data usually tailor their findings to a scientific audience, but with CBPR, that content should also be tailored to the community. No matter the data source, you should prioritize the development and dissemination of community summaries, which are concise overviews of research findings developed for those who may directly benefit from the information.

Dr. Stephen B. Thomas at the University of Maryland's Center for Health Equity[13] relies on Black barbershops and hair salons, which are trusted community partners within the Black community, to communicate information about the importance of getting cancer screenings and the COVID-19 vaccine. In a recent article,[14] one of Dr. Thomas's colleagues explained, "It's important at this critical juncture to make sure we are using a full-court press to get good information to every community." But how does "good information" get to every community?

One way to create meaningful summaries and determine the community's communication preferences is to ask them directly during the community-facing meetings. To disseminate findings from a stroke study, Sarah Barnfield and her colleagues collaborated with two groups of community members to understand their perspective on the most effective way to develop summary reports.[15] With community input, the researchers learned that it was important that the reports avoided scientific jargon, included a glossary at the end of the report, and presented text in small sections rather

than paragraphs (among other recommendations). The community also shared the importance of adding a concise summary to the beginning of the report and using questions as headings rather than statements.

Design, Content, and Communication Best Practices

If you cannot garner insight directly from the community, other researchers and organizations have shared best practices that provide guidance on design, content, and communication channels. Some of these practices are as follows:

- **Use an active voice, focus on main outcomes of the studies, and use concise explanations.**[16] The goal of these summaries is not for the community to replicate the methodology but rather for them to understand the key findings and how to use that information. For the scientific community, reports typically describe the background, methods, results, and discussion. In a community summary, present the main message in one to three sentences and provide a recommendation for what the community should do with this information (as you would in the conclusion section of a publication). For example, this simple call to action might appear in a summary for the community:

  If you have questions about how to qualify for financial support to cover food and clothing costs, call 1-800-555-1234. Find out more about getting help.

- **Use visual cues, bullet points, color, and graphics where possible to draw the audience to the main message.**[17] Increasing the font size, bolding, underlining, or inserting shapes around the message are all ways to draw attention. For example, you could replace "How does homelessness affect my community?" with **"How does homelessness affect my community?"**

- **Know your audience, and refrain from using jargon or scientific terms** they may not understand.[18] For example, the title "Advancing a Conceptual Model of Evidence-Based Practice Implementation in Public Service Sectors" could be changed to "New and Improved: Changing the way We Provide Public Services."[19] The CDC Everyday Words[20] website can help you translate jargon into plain language. Searching "evidence-based," for example, will provide several phrases that can be used to describe this concept to the community. For a scientific audience, you might write, "The organization works with multiple clinical and program sites to increase agencies' capacity to provide evidence-based interventions and connect youth to clinic services." While writing for the community, on the other hand, you could use "The organization helps clinics and community groups provide programs shown to work to prevent teen pregnancies and connect youth to clinic services."

- **Refer to other examples for inspiration.**[21] For example, the CDC Clear Communication Index provides sample materials that have been redesigned using the index.

- **Reference graphic design sites**, such as Canva, that provide guidance on developing user-friendly summaries.[22]

- **Explore ways to disseminate findings to the community.**[23] Some options could include a physical mailer with a study of summary of findings, an email newsletter, a thank-you email with a link to a summary report, an electronic one-page summary, social media posts, infographics, a standard report, toolkits, caregiver groups, newspapers, health fairs, flyers, guides, radio segments, pamphlets, presentations to local community groups, press releases, videos, or a virtual or in-person town hall meeting.

4. Acknowledge That Changing How Quantitative Researchers View Data Will Take Time

"To effectively engage in a participatory process to data analysis, the statisticians must understand the priorities, language, and experiences of community members and organizational representatives."[24]

Scott Rhodes and his colleagues described how quantitative researchers must have skills that extend beyond what is typically required and expected of them. Effectively viewing the data from a community lens relies on several factors, including the data practitioner's comfort level with community engagement, the community's history with research and the institution, and time.[25] Becoming well versed in cultural knowledge and effective communication strategies, mastering the skill of communicating meaningful outcomes to two different audiences, and incorporating ways to build community trust into your daily workflow while working against project deadlines will take time. As you become more comfortable thinking about data from a community perspective, you will also identify other ways to build trust and increase research transparency that have not been outlined here. It may take time to see a shift in how the community views research, but it can be done.

Rosa Gonzalez-Guarda and her colleagues at the Duke University School of Nursing reviewed key components of the CBPR framework for community engagement and provided examples of how it was implemented through community advisory boards at various institutions.[26] For example, the Center for Urban Youth and Families at Rutgers University School of Nursing focuses on improving the health of families and children living in urban areas and used a CAB model for researchers to gain insight from the community about research projects. A research fellow from the center sought support from university statisticians about the study design for an asthma-related project of interest to the community. One of the recommendations the statistician made was to randomize participants at the individual level. The CAB vocally disapproved of randomizing participants this way. To address their concerns and improve transparency, the fellow invited the statistician to a CAB meeting, giving him the opportunity to hear directly from the community, answer their questions, and come to an agreement on an alternative randomization approach. The community's concerns were respected and adequately addressed, and the statistician was a key player in facilitating this successful discussion.

Conclusion

These recommendations are meant to serve as a starting point; they are not a one-size-fits-all approach. Thinking about data from a community perspective can be difficult, but starting with just one of these recommendations can make the shift easier. For example, although you may not currently have the capacity to participate in community-facing meetings, you can instead develop a one-page summary that the PI can review with community partners on your behalf. Even when working on a study that is at an aggregate or national level, you can still engage with the community by (1) acknowledging the sacrifice that the community has made to contributing to this data and (2) practicing cultural humility by making a lifelong commitment to learn from other communities whenever possible.

Taking an equitable and inclusive approach to communicating data by engaging in self-reflection, collaborating with community partners, and sharing back data that is meaningful and clear to the community will build trust between the research institution and community, increase access and transparency to study findings, create a space for shared learning and understanding, and shift how quantitative researchers approach data.

Chapter Two Notes

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We Are Still Here: Decolonizing Native Data in Service of Socially Just Relations

PATRICE H. KUNESH

KENDRA ROOT

For decades, Native American people and communities in the United States have been overlooked, undercounted, and simply forgotten by data practitioners.

As the worst effects of the COVID-19 pandemic ravaged the US, Native American health clinics did not have access to the health data that federal agencies are required to collect and share.[1] Throughout the pandemic, the Bureau of Labor Statistics issued monthly reports about the devastating loss of jobs for every demographic group except Native Americans.[2] On election night in 2020, a major network used a category label of "something else" to refer to Native voters.[3] And in recent years, advocacy groups have highlighted heightened violence against Native women and girls,[4] yet still no authoritative data accounts for these offenses.[5]
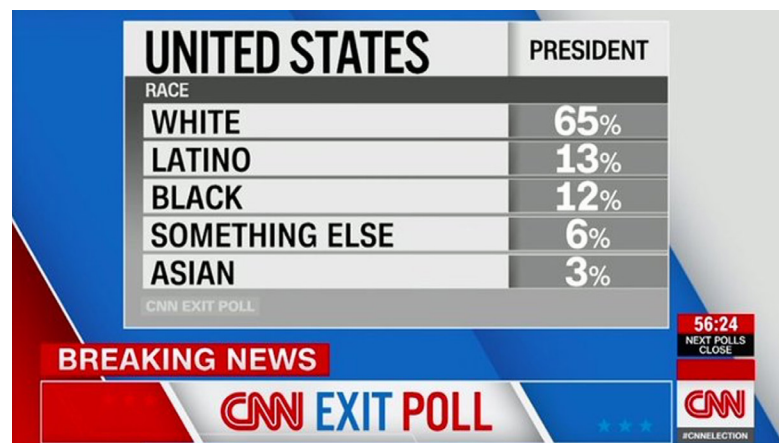
Screenshot of CNN 2019 election night results making Native voters invisible.

These transgressions are not just bureaucratic neglect and media misapprehension. Shrouding Native people in a blanket of invisibility and relegating them to obscurity perpetuates the settler colonial paradigm of supremacy and privilege where they—we— are erased and made inconsequential. Countering this harmful narrative is a responsibility of data agents who seek to "do no harm" in their pursuit of data collection and analysis. It also is a broader imperative to correct the historical record about Native Americans' lived experiences and their contributions to our society and economy. When Native people are left out of the data, they are excluded from discussions and decisions in which lifesaving resources are allocated and justice is served.

For data practitioners to create more inclusive data collection and analysis processes, they must both do no harm and do justice. But to do either, data agents must first understand the unique political relationship to the federal government that Native tribes and peoples have and their steadfast pursuit of self-governance. Previous research has failed to respect cultural and professional relationships and thus caused serious harm to the Native community. Currently, Indian Country faces two data exigencies—its disparate health care system and unfathomable violence against Native women. The lessons embedded here are for data agents to recognize the importance of discerning the lived experiences hidden from the calculus of raw data. By adopting a suite of essential Native values into research that touches and concerns Native people and their communities, data practitioners can avoid reifying the harmful "vanishing Native" or pathologizing cultural differences and disparities to address these critical data needs. These Indigenous principles—respect, reverence, reciprocity, relationship, and responsibility—are the taproot of honor and justice for our first Americans.

Indian Country Is Politically Self-Determined, Distinctively Diverse, and Culturally Driven

For centuries before the formal organization of the United States of America, hundreds of native tribes inhabited and stewarded these lands from coast to coast. Native American tribes were governed by cultural systems of leadership, and these tribes nurtured their health and well-being through balanced relationships with lands, animals, and plants. Colonization caused radical upheavals in these traditional systems of government and their relationship to the land.

Through an early course of treaty making, the US recognized tribes as distinct—albeit domestic—sovereign entities, acknowledged their status in the Constitution (US Const. art. I, § 8), and assumed

legally binding obligations known as the federal trust responsibility. The young government used the tenets of Manifest Destiny to justify removing Native peoples from their homelands and subjugating them to the dominant power of the US. Today, 574 federally recognized tribes govern almost 60 million acres throughout the country. Through self-determination, their economies have grown and their populations have rebounded.

The total Native population has increased more than 87 percent since 2010,[6] from 5.2 million to 9.7 million people. Even with that growth, the US Census Bureau estimates that reservation residents

were undercounted by almost 6 percent, the largest undercount of all population groups.[7] Although the Census Bureau does not consider this "statistically significant," for Indian Country, the numbers matter. Each undercounted household and individual means a loss of funding and resources to address social and economic disparities in historically underserved communities. Population trends also influence the contours of voting districts at all levels of government. When Native people are counted and have access to the ballot, they have the opportunity to be represented and to be the representative.[8]

For the past two years, the COVID-19 pandemic has upended nearly every aspect of Native health and well-being. Collectively, Native Americans have suffered the most severe health and economic consequences of the pandemic. COVID-19 infections hit reservation communities the hardest, with the highest infection rates of major population groups[9] and a mortality rate 2.5 times that of non-Hispanic white people.[10] The public health emergency soon exposed another crisis: acute overcrowding and inferior housing conditions across Indian Country,[11] which exacerbated the spread of COVID-19 and created an imminent health threat. Moreover, Native youth have suffered the highest rate of caregiver loss from the pandemic, more than 4.5 times higher than the rate for non-Hispanic white children.[12]

The pandemic also shut down tribal economies. When tribal governments closed business enterprises, tribal revenue streams vanished overnight, forcing layoffs and drastic cuts in health and human services. The pandemic now threatens decades of modest improvements in social and economic conditions across Indian Country. Over the past 30 years, per capita income on reservation lands has increased from $9,650 to $14,355, but it still hovers at poverty levels. Even modest income supports from tribal governments of an additional $4,000 a year for the poorest households have made significant and lasting differences, according to analysis of data from the

Great Smoky Mountains Study of Youth: high school graduation rates increased almost 40 percent, the chances of 16- and 17-year-olds committing a minor crime were reduced 22 percent, and the likelihood of voting in adulthood demonstrably increased.[13]

As tribal nations seek to understand the collective consequences of the pandemic in their communities, one aspect is clear: data are essential to addressing the current, more obvious problems as well as less-visible structural inequities. Without access to reliable data, tribes remain an "asterisk" nation,[14] relegated to a footnote at the bottom of a report or the "something else" category. Being ignored in the data or marginalized in reports further perpetuates the harmful settler colonial narrative of erasure, marginalization, and exclusion.

How Data Practices Have Harmed Native Lives

As part of their nation-building mandate, tribal governments have an inherent interest in the collection and use of data concerning their people and communities. General data practices with Native populations often obscure patterns of inequality because of small sample sizes or fail to explore the context behind the data points, which would reveal the lived experiences of Native people. Better-attuned data practices are informed by traditional Native values of respect, reverence, reciprocity, relationship, and responsibility. These principles seek to safeguard Native people from research practices that might be biased, stigmatizing, or harmful. They are also instructive rules of engagement when working with data concerning Native communities. Two academic research projects in particular illustrate the repercussions data collection can have when Native values and cultural norms are not respected.

1. Barrow Alcohol Study of 1979

Leaders of the Inupiat community in Barrow, Alaska, worried about the impact of alcohol use and associated accidental deaths in their community.

They invited a group of sociology researchers to assess the problem and work with them to devise solutions. At the conclusion of the study, researchers wrote a report entitled "The Inupiat, Economics and Alcohol on the Alaskan North Slope" and released it simultaneously through a public press release and to the Inupiat community.[15] The press release was picked up by the *New York Times*, which ran a front page story entitled "Alcohol Plagues Eskimos" on January 22, 1980. The story read,

> *The Inupiat Eskimos of Alaska's North Slope, whose culture has been overwhelmed by energy development activities, are 'practically committing suicide' by mass alcoholism... researchers said here yesterday. The alcoholism rate is 72 percent among the 2,000 Eskimo men and women in the village of Barrow, where violence is becoming the most frequent cause of death as a result of 'the explosive and self- destructive abuse of alcohol,' the researchers said.*

> *'Offshore oil development is expected to peak in 2010 or 2015,' ... one of the researchers, said at a news conference. 'We don't see the Eskimos surviving till then. This is not a collection of individual alcoholics, but a society which is alcoholic, and therefore facing extinction.'[16]*

This depiction of the Barrow community implied to the Inupiat people that they were the problem. They felt targeted and stigmatized, which led to harmful stereotypes and inflicted more trauma upon the community, including increased depression and suicide for those who felt trapped in a hopeless situation and general social disharmony among families.[17] Many of the Inupiat in Barrow and other Alaska Native communities felt the researchers had violated their trust by failing to share the study with them before taking it to the media, because doing so precluded the community from collectively reviewing the report's findings and considering its implications. Thereafter, many Alaska Native people and communities doubted that further research would

be conducted in a respectful manner, which strained relationships with researchers and curtailed mutually beneficial study opportunities.

2. Havasupai Tribe in the Grand Canyon in Arizona

The Havasupai Tribe is a small community located deep in the Grand Canyon in Arizona. In 1989, Havasupai tribal leaders sought to learn why diabetes was so prevalent within their community and, like the Inupiat community, wanted to find ways to improve their health and well-being. They allowed university researchers to take blood samples from community members to determine whether community members had genetic links to diabetes. Without the tribe's knowledge or express consent, other researchers used the Havasupai blood samples in unrelated genetic research and published articles about the tribe's cultural origins.[18] The Havasupai community was stunned by this unwarranted examination of their biological data and the researchers' distorted theories about their core beliefs. Although the tribe eventually prevailed in their lawsuit against the researchers to regain control of their data, the tribe received no monetary compensation for their damages, so Havasupai leaders exercised traditional justice and banished the researchers from the reservation.[19]

These case studies illustrate starkly different world views between researchers and the Native communities they were entrusted to observe. Native communities had invited the researchers into their homes and relied on them to provide constructive insight into their colonialized, compromised condition. Instead of honoring that trust, the academic researchers, who stood to benefit from their work, employed paternalistic practices that erased identities, devalued authentic voices, and perpetuated harmful stereotypes of Native culture and ways of life.

A significant oversight in the research revealed a crucial crossroads with data: In taking the bold step to document their challenging conditions (the effects of alcohol use and diabetes), these Native communities

were also celebrating their survival and resilience despite incredibly harsh conditions and brutal policies of assimilation. Their stories are not simply data points: they are oral testimonies and evidence of injustice, of struggle, and of perseverance to achieve self-determination and to take back control of their destinies so badly damaged by colonial oppression. By exposing the consequences of colonization through their own frailties and vulnerability, they sought to connect the past to the future and create hope for new generations.

The implications of these studies are clear: although we must do no harm, we also must do justice. We can accomplish both by approaching research through the lens of cultural understanding, which includes respect for diverse views of history, reverence for traditions and ceremonies, reciprocal relationships that honor traditional knowledge and lived experiences, and responsible handling of such precious information. When researchers incorporate these cultural understandings into their methods, they derive much richer information, produce deeper insights into lived experiences, and honor the subjects of their inquiry.[20]

The housing needs study of the Cheyenne River Sioux Reservation, one of the first self-studies in Indian Country,[21] provides a good example of this approach. The study collected and analyzed tribal members' interests on an array of housing issues, their awareness of financial products and the lending process, and their desire for neighborhood amenities. At first, tribal members were hesitant to respond to the survey and did not know how to answer the questions; no one had ever asked them about their needs or wants. They had never been asked to be the architect of their own vision or to design their own community. Although the information collected was critical to the tribe's future housing development, equally important to the success of the project was the tribal government's respectful relationship with the community. That relationship engendered

the invaluable trust and respect of the planners, which was later reciprocated in other challenging circumstances.

Understanding Indian Country's Complicated Relationship with Data

Native nations and their citizens occupy a different space than other communities of color in the US because of their political relationship with the federal government. Over time, this relatively small population has experienced some of the greatest socioeconomic disparities and the most remarkable gains in our society. Appreciating the origins of these inequalities and contours of such progress requires accurate and timely data.

Native people often feel invisible or ignored in studies and reports, and when they are included, they can feel stigmatized and demeaned.[22] Access to good data is limited, and sometimes data are not collected in useful ways or are collected incorrectly by misclassifying Native people. Data on Native people can be challenging to work with because of small population size, irregular geographical sectors, and confidentiality concerns, so deriving meaning from a set of data points requires context and thoughtful consideration of the circumstances behind the information.

Two areas in particular, health care and violence against women, illustrate these data challenges, and solving these problems is impossible without better access to good data.

1. Health Care

Even before the pandemic, Native Americans experienced worse health outcomes and shorter life spans than other population groups in the US.[23] Throughout the COVID-19 pandemic, this already vulnerable population faced tremendous challenges in accessing health care and suffered the highest rates of infection and mortality. Despite these known disparities, Native communities continue

to be overlooked or marginalized by public health institutions and unable to access the data required to address their health care needs.

Misclassification of race is a common way that Native people are overlooked and undercounted. A 2012 study of hospitals and clinics in the Pacific Northwest by the Indian Health Service examined patient deaths by racial classification data and linked tribal registry death certificates.[24] The authors found that 17 percent of American Indian and Alaska Native deaths were misclassified, with many of the deceased classified as "white." This led to a significant undercount of Native deaths and associated causes, all of which are vital public health and safety information.

Such errors and misclassification are harmful. When Native people are diminished in the data, they are excluded from discussions and decisions about health care funding and services, research projects, and community interventions. This absence from the data only deepens long-standing disparities.

Even when good data exist, tribal health providers across the country often cannot access them. A recent report from the US Government Accountability Office (GAO) investigated concerns raised by tribal epidemiology centers (TECs) that they could not access epidemiological data, including basic information on COVID-19 test results or patient diagnosis codes.[25] Although federal law authorizes TECs to access data from the US Department of Health and Human Services for a variety of public health purposes, bureaucratic approval procedures made doing so nearly impossible. Like other health centers, TECs use this data to monitor the spread of COVID-19 and to conduct other analyses that support public health decisions in Native communities. Having limited or no access to data significantly impaired tribal governments' ability to analyze the severity of the pandemic and to provide appropriate services to their communities.

The GAO study highlights several common problems concerning interactions between federal agencies, tribal governments, and Native communities, primarily that tribal governments often are overlooked as entities entitled to access data under federal law. In this case, officials did not recognize that they were required to provide critical data to TECs. To rectify this problem, the GAO recommended clarifying this express authority and delineating lines of communication to ensure TECs have access to this critical data. This is a much-needed solution, but it is perhaps too late—it came more than two years after the pandemic began.

2. Violence against Women

Another epidemic is raging in Indian Country: the silent crisis of missing, murdered, and trafficked Indigenous women and girls. This crisis and the prevalence of violence against Native women has devastated Native families and communities across the US. In 2021, the National Information Crime Center documented more than 5,000 cases of missing Native women.[26] Despite constituting the smallest share of the US population, Native people represent the second highest number of reported missing persons.[27] In Wyoming, for example, Native women constituted 57 percent of missing persons reports.[28] Law enforcement experts say the real numbers are likely higher because of underreporting, racial misclassification, and jurisdictional gaps.[29]

Equally disturbing is the disproportionate rate of violence against Native American and Alaska Native women:[30] more than 80 percent of Native women have experienced some form of violence in their lifetime,[31] by far the highest rate among all women. Tragically, murder is the third-leading cause of death for Native women in the US.[32]

As hard as it is to fathom such dangerous circumstances, not much is known about the background and context to this violence. What we do know is that gender-based violence is not

Source: "Our Bodies, Our Stories," Urban Indian Health Institute, accessed August 17, 2022, https://www.uihi.org/projects/our-bodies-our-stories/. Artwork by Matt Echohawk-Hayashi for Urban Indian Health Institute.
Note: MMIWG = missing and murdered Indigenous women and girls.

traditional to Native American culture. A few studies have attempted to investigate further, such as the National Intimate Partner and Sexual Violence Survey,[33] a survey by Amnesty International,[34] and the US Department of Justice's National Violence against Women Survey.[35] Despite these research efforts, gaps in the data remain. Empirical data are lacking on the relationship between different forms of violence against women, such as victimization in childhood and subsequent victimization, and on the consequences of violence against women, including injury rates and use of medical services.

A complex maze of jurisdictional rules impedes data sharing among law enforcement authorities and prevents a coordinated criminal justice response. Domestic violence cases or missing persons reports often involve several law enforcement agencies, including county sheriff offices, state police, federal law enforcement, tribal public-safety departments, and even international criminal authorities. Processes and terminology differ widely among

these many agencies, such that a person identified as Native in one jurisdiction could be classified as non-Native in another.[36]

Gaping holes in law enforcement in Indian Country also frustrate data collection and agency coordination among tribal, state, and federal agencies. Despite new awareness about violence against and trafficking of Native women, few studies exist from which to build intervention and prevention efforts. Sadly, Native women remain at a higher risk of exploitation and violence in their own communities while we wait for more data.[37]

Recommendations: Data Challenges Offer Innovative Research Opportunities

Incorporating Native principles of respect, reverence, reciprocity, relationship, and responsibility into data collection offers a useful way to approach the data with a decolonizing perspective, beginning with the recognition of the sovereign status of Native American tribes. These principles can help data practitioners appreciate the reality of Native resilience and its myriad individual, social, political, and cultural dimensions. Working in this space requires deeper and more empirical data exploration around the lived experiences of people who have long been left out of research narratives.

To be sure, there are many challenges in collecting and analyzing data concerning Native people and communities. Some of these challenges include

- wholesale data gaps, such as inadequate statistics on unemployment from the US Bureau of Labor Statistics, the chronic census undercount, and missing information on Native-owned farms;

- a lack of centralized data systems and uniform processes to collect and analyze data, misclassifications of race/ethnicity, and jurisdictional gaps, especially in the criminal justice system;

- limited sample sizes concerning Native communities, which can produce unreliable data across diverse geographic regions; and

- mistrust of data collection and government agencies because of the lasting impact of previous inappropriate and questionable data collection practices, which in turn can impede the creation of trusting relationships with tribes and Native people.

Every challenge offers an opportunity, and several tribes and organizations are using this social and political history and applying Native data principles to help promote more equitable Native participation and representation in data collection and research. Some of these data improvement initiatives include the following:

- The Navajo Nation and White Mountain Apache Tribe built a robust COVID-19 contact tracing team and a public health workforce in partnership with the John Hopkins University Center for American Indian Health,[38] state universities, and the Indian Health Service.

- The National Institute of Health is creating a Tribal Collaboration Working Group[39] to assist with All of Us, a broad study of diseases based on cataloguing and researching genetic samples.

- The Urban Indian Health Institute is developing a *Best Practices for American Indian and Alaskan Native Data Collection* guide so federal, state, and county public health departments recognize tribal governments as an equal partner in health care and to encourage building more trusting, reciprocal relationships with Native communities.[40]

- IllumiNatives, a nonprofit initiative designed to increase the visibility of and challenge the negative narrative about Native nations and peoples in American society, has released a comprehensive report on Native American

K–12 curricula, *Becoming Visible: A Landscape Analysis of State Efforts to Provide Native American Education for All*.[41]

- The US Bureau of Labor Statistics will start reporting and tracking the economic health of Native Americans more frequently.[42]

- Congress has recently reauthorized the Violence Against Women Act and included provisions to increase safety and justice for victims who have seen little of either. These include reaffirming tribes' jurisdiction to prosecute non-Native perpetrators of sexual violence, sex trafficking, stalking, child violence, and obstruction of justice, authorizing tribes to prosecute non-Native people who assault tribal law enforcement officers.[43]

- Efforts are under way in the federal and state government to bring awareness to the epidemic of missing, murdered, and trafficked Indigenous women and girls. A few such efforts are the National Indigenous Women's Resource Center, Minnesota's newly created Office for Missing and Murdered Indigenous Relatives, and the US Department of the Interior's new unit to pursue justice for missing or murdered American Indians and Alaska Natives.[44]

In many ways, Indian Country is indeed "something else"—tribal economies are making tremendous contributions to state and local communities and are a distinct and important component of our nation's economy. No matter how difficult it is to measure, Indian Country remains important to our social fabric and economy.[45] We deserve to be seen and acknowledged for who we are: people and communities with the highest potential and much to offer.

Chapter Three Notes

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Decolonizing Research and Data in the Hawaiian Community: A Waimānalo Model

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From the beginning, Native Hawaiians, or Kānaka Maoli, the first people to arrive and settle on the Hawaiian Islands, have been data scientists. To build their self-sufficient society, Native Hawaiians collected data about their natural surroundings to meticulously create sophisticated and sustainable resource management and food systems, which for centuries fed up to a million people on the islands.

However, the spread of Western imperialism across the Pacific in the early 19th century led to forced assimilation and the illegal occupation of the Hawaiian Kingdom in 1893.[1] American businessmen took advantage of Hawai'i's tropical climate to grow sugar, pineapples, and other crops, and they began building mass agricultural plantations for extraction and export. These plantations diverted natural resources, depleted nutrients in soil, and displaced Native Hawaiians from their homes. This pattern of exploitation and displacement continues today through extractive tourism, real estate industries, and militarization. As a result, Native Hawaiians face pervasive health and social disparities in their own ancestral lands as well as higher levels of chronic diseases and poverty and lower levels of educational attainment and access to health care compared with other major ethnic groups in Hawai'i.[2]

Shedding light on these disparities is critical, but data scientists must be mindful to not focus only on these deficit-based statistics, which can reinforce damaging stereotypes of brown and Black communities as being lazy, unhealthy, and poor. Researchers and institutions that report data on communities of color must also consider collecting data on racism, systemic violence, and historical and intergenerational trauma. To do no harm, we must ensure that we ground statistics in a social justice lens by contextualizing them in historical and contemporary structures of oppression.

We must also disaggregate data when possible. Native Hawaiians are often lumped into the racial category *Asian American* and

Waimānalo Pono Research Hui members regularly hold Mālama ʻĀina Day, where community and family members come together to take care of the land.

Pacific Islander, which ignores the diversity of 23 million people with heritages from roughly 50 ethnic groups and more than 40 countries.[3] Although in 2000, the US Census Bureau created a separate category for Native Hawaiians and Pacific Islanders, this new designation still aggregates Native Hawaiians in data analysis and reporting, rendering their disparities, strengths, and unique factors invisible.

Recognizing the strengths of a community when reporting disparities can provide a balanced narrative that is often missing in mainstream conversations.[4] Despite systemic challenges, Native Hawaiians have survived and thrived. Since the 1970s, the Native Hawaiian Renaissance Movement has made tremendous strides in revitalizing Native Hawaiian cultural practices, such as the Hawaiian language, oceanic voyaging, food cultivation, and land and ocean restoration.[5] Many Native Hawaiian immersion schools have been established, dramatically increasing the number of Native Hawaiian speakers. And Native Hawaiian communities across the islands have come together to restore land devastated by invasive species, overpopulation, and overdevelopment and

to create innovative spaces and structures to reclaim, decolonize, and indigenize research about themselves.

These efforts show that to do no harm when collecting and disseminating data about Native Hawaiian communities, the paradigm of how we do research must be transformed to decolonize data and research by putting communities and their values at the center.

Waimanalo Pono Research Hui: An Example of Decolonizing Data and Research

Like other Indigenous communities and communities of color, Native Hawaiians have a long history of being the subject of unethical and exploitative research. From 1866 to 1969, for example, Native Hawaiians with Hansen's disease were forcibly exiled to a remote northern peninsula on the island of Molokaʻi and subjected to unethical medical studies conducted by government physicians.[6]

Today, community members continue to express their frustration with researchers "taking from the community without giving back to it," being disrespectful of cultural protocols, and holding

damaging stereotypical notions of their community.[7] To shift the power imbalances and colonial paradigm of research, many Native scholars, community leaders, and their allies advocate for decolonizing methodologies that revitalize and integrate cultural practices into the research. These approaches can transform the deeply entrenched distrust that communities hold toward researchers, institutions, and the research enterprise to create equitable partnerships. Collecting and reporting data requires us to go beyond the goal of doing no harm. We must ensure that these efforts lead to real, tangible, meaningful, and sustainable benefits for the community.

One example of decolonizing research is the Waimānalo Pono Research Hui, a community-academic group formed to promote community-driven and culturally centered research.[8] The Waimānalo Pono Research Hui was formed in 2017 by community leaders of Waimānalo and their academic partners. Waimānalo is a rural, predominately Native Hawaiian community located on the eastern side of Oʻahu.[9] "Pono" means "just," "balance," and "righteous," and "Hui" means "group." Before 2017, many research projects took place in Waimānalo, with varying degrees of community involvement. The Waimānalo Pono Research Hui sought to build on these previous grassroots efforts by inviting Waimānalo community members and researchers who had worked with the community for years to a series of monthly informal gatherings to share a meal and "talk story." Initially, these gatherings had no agenda other than two main goals: (1) to identify community preferences and priorities to inform future research and programming initiatives and (2) to build and strengthen relationships within the Waimānalo community and between the community and researchers. Long-term goals were kept open to allow for participatory and organic processes to unfold.

After meeting for several months, the discussions yielded a clear mission with a set of priorities. Under the guidance of the community elders, the group collectively agreed that its mission was "to collaborate and work toward a healthier Waimānalo through education, aloha ʻāina [love of the land], and honoring and transferring ʻike [knowledge] and values of our kūpuna [elders] to our keiki [children] through pono research principles."[10]

The Waimānalo Pono Research Hui embraces participatory and Indigenous approaches to actively and meaningfully help communities decolonize the research process, such as the Indigenous Research Agenda and the ʻĀina Aloha research framework. The Indigenous Research Agenda recenters the goal of the research process in self-determination of Indigenous peoples.[11] The ʻĀina Aloha research framework is centered in Native Hawaiian values and community. It promotes interdependent relationships between people and the ʻāina (land) through the values of mālama ʻāina (to care for, protect, and maintain land), puʻuhonua (a safe place, a sanctuary), and laulima (many hands working together toward a specific goal).[12] ʻĀina Aloha focuses on research that is action oriented, collective, and protective of ʻāina and intellectual rights that are accountable and relevant.

The Waimānalo Pono Research Hui is also centered on participatory approaches, such as community-based participatory research (also discussed in Chapters 2 and 5), which aims to build authentic relationships and establish trust between academics and communities by promoting equitable partnerships.[13] All of these approaches are rooted in social justice; prioritize the community; apply a critical lens to individuals and communities; and seek to increase community capacity by building on community strengths, knowledge, and perspectives. They also focus on producing benefits and findings

TABLE 1

WPRH Protocols and Rules of Engagement

PROTOCOL TOPIC AREA	DESCRIPTION OF PROTOCOLS
PROJECT IDENTIFICATION	All research must be relevant to the Waimānalo community and undergo a formal review and approval process by WPRH members. Approval can only be granted by Waimanalo community members.
PROPOSAL DEVELOPMENT	Proposal preparation requires a representative of WPRH from the Waimānalo community and must demonstrate equitable partnerships and relevant benefits to the community and researcher.
FUNDING	Time and funds must be allotted for Waimānalo community participation.
PROJECT IMPLEMENTATION	Regular updates should be provided in person to WPRH members at the beginning of a project and every three months after. WPRH members are allowed to provide support and input on the project.
DATA OWNERSHIP	All attempts will be made to ensure the Waimānalo community owns any data collected from the research project. If nonnegotiable, the data will be accessible to WPRH members and participants must reconsent for any data to be used in future studies.
DISSEMINATION	Findings must be reported back to WPRH members for feedback and approval before dissemination with the wider public. Dissemination activities require approval, and Waimānalo residents directly affected by the findings must be invited and involved in these activities.
STUDENT INVOLVEMENT	Students must obtain permission from WPRH members to collaborate and are expected to follow all protocols.

Source: Samantha Keaulana, Jane J. Chung-Do, Illima Ho-Lastimosa, Phoebe W. Hwang, Kenneth Ho, Theodore Radovich, Michael Spencer, et al., "Waimānalo Pono Research Hui: Establishing Protocols and Rules of Engagement to Promote Community-Driven and Culturally-Grounded Research with a Native Hawaiian Community." British Journal of Social Work 49 (2019): 1023–40.

Note: WPRH = Waimānalo Pono Research Hui.

that are meaningful and important to the community. To put these values into practice, the Waimānalo Pono Research Hui created protocols and rules of engagement that promote community consent and culturally centered approaches, equitable resources and benefits, and data sovereignty and dissemination, shown in table 1.[14] By adhering to these rules of engagement when approaching their own work, data practitioners can highlight communities' strengths and engage in research that benefits the communities rather than extracting from and exploiting communities.

"Pilina" is at the heart of all successful and effective research partnerships. Pilina can be loosely translated as "relationships, connections, fitting, adhering to one another." Without cultivated relationships and an in-depth connection with the community, researchers cannot understand what is relevant to the community. Before researchers pitch an idea, they must show up and take the time to get to know the community and build pilina. This process allows everyone to get to know each as complex human beings rather than by their labels alone. As one study participant in Hawaiʻi said, "understand that your acceptance in the community varies on how well the community knows you or feels that they have gotten to know you.[15] Therefore, the Waimānalo Pono Research Hui requires that all participants join at least three meetings or community activities before pitching an idea to the Hui. When an idea is pitched to the community, only those who live in Waimānalo are allowed to vote on the proposal, which keeps power within the community.

Community consent is expected to be interwoven in every step of the research process, from conceptualization of the research idea to data dissemination. The default should always be to ask and never assume. The process of consent includes discussing and gathering input from the community, even if it is harsh or negative. Researchers must have the humility and openness to take criticism,

learn from it, and do better. Moreover, it is the responsibility of researchers to ensure the community fully understands what they are consenting to. This process is necessary to ensure the approach is truly centered in the values, practices, priorities, and strengths of the community.

Equitable resources mean that the community is properly compensated for their time, knowledge, and role in the project. It cannot be assumed that the community is willing to be unpaid volunteers while researchers and their students are paid. If possible, community members should have paid roles in the project and be an active part of the research team, such as a co–principal investigator. Ideally, for a project to be truly community-driven, the principal investigator should be from the community, and the funding should run through the community. Researchers can lend their expertise to the project, but the ultimate decisionmaking power should stay within the community. To build this capacity in Waimānalo, Ke Kula Nui O Waimānalo, a nonprofit organization, was started by seven members of the Waimānalo Pono Research Hui in 2017. This nonprofit houses and owns the research and programs that have been developed by the community, for the community.[16] Another important component that grant proposals must include is food. In the past, some funders have not allowed project funds to be used to purchase food. Recognizing the importance of sharing a meal in Hawaiian culture, the Waimānalo Pono Research Hui requires that every proposal includes food in its budget, and the person pitching the idea must make this possible.

Data sovereignty is a critical aspect of decolonizing research and data. The Waimānalo Pono Research Hui protocols and rules of engagement state that the data produced by the project must be owned by the Waimānalo Pono Research Hui. That means other researchers who wish to access the data and conduct a secondary data analysis must first ask the Waimānalo Pono Research Hui for permission

and cultivate a relationship with the community. Participants must be reconsented to ensure they understand and approve of the study purpose. Even though the data may be deidentified, every study must be approved by the Waimānalo Pono Research Hui because of the risk of group harm.

The community should be the first to know the results of the study, and the data should be shared with them first. The community should be continuously updated at every step, especially when the data are being interpreted, to ensure the results are accurately grounded in the community's lived experiences. In the data dissemination stage, community members should be lead authors or coauthors so they can tell their own story. For far too long, the stories of disenfranchised communities have been told by outsiders—often white men with more institutional privileges. This consolidation of dissemination has not only led to errors in the stories being told, it has also led to sacred stories being shared without permission and to stories that perpetuate racist and sexist stereotypes, portraying these communities as "lesser than." Therefore, it is important to the Waimānalo Pono Research Hui that they tell their own stories.

Recognize that data can be disseminated in many ways. Although peer-reviewed publications are traditionally thought of as the primary avenues for research dissemination, they are often inaccessible to nonacademic communities. Journals charge exorbitant fees for people not affiliated with academia to access articles, and even when those articles can be accessed, they are not written in an approachable way for a general audience. The Waimānalo Pono Research Hui prioritizes different modes of dissemination to ensure the results first get back to the community in meaningful ways. For example, the Waimānalo Pono Research Hui has held a series of community gatherings where the results of its projects are reported through a combination of dissemination strategies, such as verbally sharing the results and creating handouts, banners, and presentation slides with community-friendly infographics. The event is family friendly and interactive, with cultural arts and crafts, activities, and food. These in-person gatherings are culturally appropriate and facilitate peer-to-peer information transfer that is highly effective. Because community gatherings are limited in reach, the Waimānalo Pono Research Hui reaches broader audiences through social and broadcast media. In 2021, Ke Kula Nui O Waimānalo hosted monthly Facebook Live events to feature programs that serve Native Hawaiians. The video recordings are archived on the group's Facebook page and have been viewed 7,244 times.[17] Also in 2021, the programs and research of the Waimānalo Pono Research Hui have been featured on the *Science Zone* podcast, which was broadcast live to an estimated audience of 6,000 per episode on the University of Hawai'i radio station KTUH 90.1 FM and archived online.[18] One episode highlighted the impact of accepting Indigenous science as an important paradigm for knowledge gathering and dissemination.[19]

Practical Recommendations

Based on our lessons learned and experiences in decolonizing data and research in the Native Hawaiian community of Waimānalo, we have curated these practical recommendations for others who are striving to be ethical and pono data scientists:

1. **Frame all data** in a social justice context by providing the historical context of how the disparities came to be.

2. **Recognize the strengths of the community** to promote a balanced and strength-based narrative.

3. **Disaggregate data** for communities of color.

4. **Collect and report data on the social determinants of health** to provide a comprehensive picture of the issue.

5. **Put relationships at the heart** of all successful and effective research partnerships.

6. Weave consent into every step of the research process, from conceptualization of the research idea to data dissemination.

7. Include community representatives in data interpretation; they can decipher findings with an expert, lived-experienced lens.

8. Properly compensate community members for their time, knowledge, and role in the project.

9. Recognize that data sovereignty is a critical aspect of decolonizing research and data. The community should also be the first to know the results of the study.

10. Build capacity for communities to tell their own stories where community members are lead authors or coauthors.

11. Create structures where Indigenous communities lead decisionmaking processes; doing so is critical to successful decolonization efforts.

Conclusion

The data we collect and report on Native Hawaiian communities should not only do no harm—it should also truly benefit these communities by creating spaces and structures that promote co-learning, reciprocal and equitable relationships, and meaningful involvement. Moreover, data should be collected to illustrate the historical and perpetual violence committed against Native Hawaiian communities. Such a task decenters individual social and health behaviors, refocuses efforts on addressing structural gaps, and highlights the external environmental factors beyond community control. Despite Native Hawaiians' long history of oppression and current US occupation, the community has survived and thrived, demonstrating their resilience and power. These stories should be told through the data that are collected and told by the people of this community.

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Achieving Mental Health Equity through a Community-Informed Research Approach

QUIANTA MOORE

MARCY MELVIN

The United States is experiencing a mental health crisis. Although this crisis is not new, the COVID-19 pandemic has dramatically increased mental health care needs and made it more difficult for people to access mental health services. The pandemic has also worsened underlying inequities that drive health disparities.

Despite overall rates of suicide decreasing in 2019 and 2020, suicide rates in communities of color increased during that period. Among youth and young adults, deaths by suicide increased more than 45 percent for Black Americans and about 40 percent for Asian Americans from 2012 to 2019 (figure 1).[1]

FIGURE 1

**Deaths by Suicide in the US by Race among 12- to 17-Year-Olds, 2001–19**

Deaths per 100,000 12- to 17-year-olds
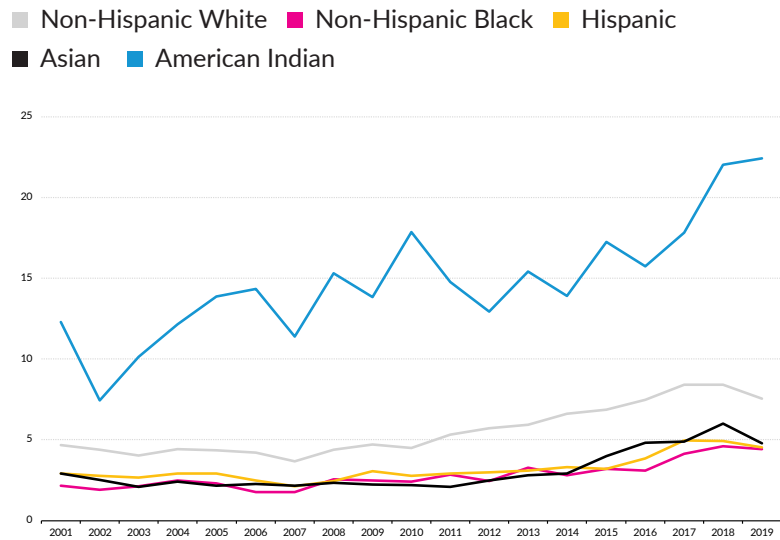
Source: Authors' analysis of data from the Centers for Disease Control and Prevention, National Center for Health Statistics. See "About Underlying Cause of Death, 1999-2020," CDC WONDER, accessed August 17, 2022, https://wonder.cdc.gov/ucd-icd10.html. Data are from the "multiple cause of death" files, 1999–2020, as compiled from data provided by the 57 vital statistics jurisdictions through the Vital Statistics Cooperative Program.

Share of Adults Reporting Symptoms of Anxiety and/or Depressive Disorder during the COVID-19 Pandemic, by Race and Ethnicity
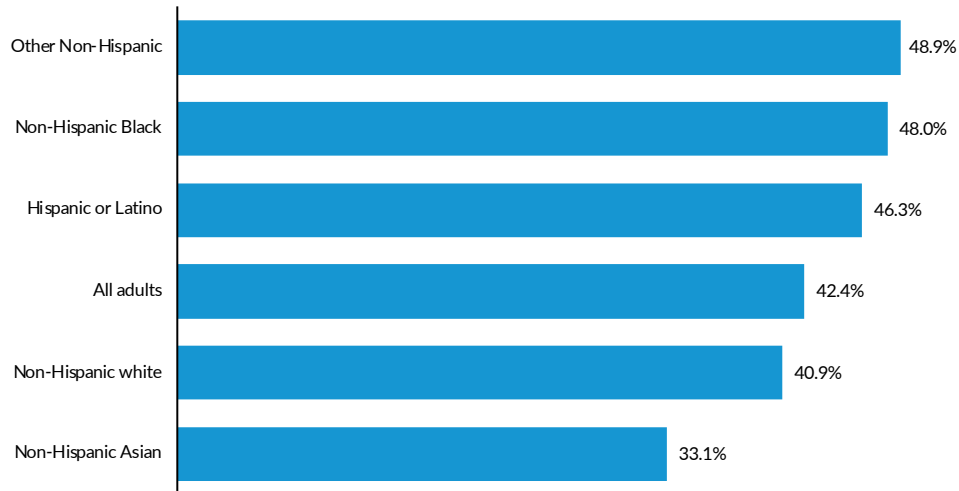
Source: Nirmita Panchai, Rabah Kamal, Cynthia Cox, and Rachel Garfield, "The Implications of COVID-19 for Mental Health and Substance Use" (San Francisco, CA: Kaiser Family Foundation, 2021).

Throughout the pandemic, Black adults and Hispanic or Latino[2] adults were more likely than white adults to report symptoms of anxiety and depression (48 percent and 46 percent versus 41 percent; see figure 2).[3]

Access to care for mental health disorders is highly inequitable: around 50 percent of white people have access mental health services compared with 33 percent of Black and 34 percent of Hispanic/Latino people.

These disparities in mental health and access to care are related to the history of racism and bias in the fields of psychology and psychiatry. These biases continue to affect the current mental health system, particularly for young adults, communities of color, essential workers, and unpaid adult caregivers (most of them women), all of whom have been especially hard hit by mental distress and increased substance use as a result of the pandemic.[4] Over the past 50 years, the field of psychology has failed to fully represent people of color and to address ongoing concerns about white normativity in psychology and the use of instruments and practices that discriminate against people of color.

Several guidelines and recommendations have been issued to address these concerns, but they do not have the force of professional ethics codes, and compliance remains voluntary.[5] So what steps can researchers and mental health professionals take to create more inclusive mental health practices?

A History of Inequitable Access to Mental Health Care and Ineffective Treatment

Many assessment tools and therapeutic interventions currently considered best practices, such as the Stanford-Binet Intelligence Test and cognitive behavioral therapy, were initially created for middle-class white communities, wholly excluding communities of color. For decades, intelligence tests and other standardized tests were used to promote eugenics and the belief of a white racial hierarchy.[6] The bias of the Sandford-Binet Intelligence

Test, which measures intellectual functioning and is often used to identify emotional disturbance, contributes to Black students being overrepresented in the categories of intellectual disability and emotional disturbance relative to students of other races or ethnicities.

Moreover, studies have neglected to consider the efficacy of cognitive behavioral therapy on historically marginalized populations.[7] When therapeutic interventions (such as cognitive behavioral therapy, which was created and normed on middle-class white people) are ineffective within diverse communities of color, the recipients of the therapeutic intervention are often blamed rather than the intervention itself.[9] Those individuals are frequently considered noncompliant. Moreover, data on intervention results, particularly concerning race and ethnicity, are not collected consistently. This makes it impossible to disaggregate information and precludes the ability to see outcomes in specific communities.

Overall, US health care records contain limited data on race and ethnicity, hampering efforts to ensure improved quality for all.[9] As the nation becomes increasingly diverse in terms of race and ethnicity, advancing health equity requires an understanding of how health and health disparities are experienced by people of color, Indigenous or Native people, and other marginalized groups. And when looking to existing data for answers, the information is rarely available:[10] either health equity data are not collected, or the existing information on race and ethnicity is lumped into broad categories that do not allow distinct groups to be seen. These flaws in data collection and reporting render populations invisible, mask unique needs, and hide strengths and assets, meaning that decisions are made affecting people's lives and well-being without complete information.[11]

These issues have led to a lack of statistically significant representation of communities of color in the development and creation of assessment tools and therapeutic interventions, leading to methodological flaws in clinical trials and ultimately inaccurate diagnoses and inadequate care.[12]

Three Steps to Address Disparities in Mental Health and Inequities in Access to Treatment

To ensure that assessment tools and interventions are relevant to all races and cultures, researchers, academics, and clinical practitioners across the country must reevaluate current practices. One example of an intervention that was reevaluated to be more effective in different communities is Culturally Modified Trauma-Focused Treatment, which is a modified version of trauma-focused cognitive behavioral therapy that is used with Hispanic or Latino children.[13] The adaptation of the treatment more fully integrates culturally specific topics into its approach, such as spirituality, gender roles, family, personalism, and respect.

Without culturally competent, linguistically accessible tools and interventions, outcomes will continue to be suboptimal. In recognizing these challenges, researchers must craft an intentional, systematic path forward that allows them to engage authentically with the communities they are working with at all steps of the process, from needs assessment to implementation and dissemination of results. To do so, researchers should take three important steps.

1. Train new generations of researchers with a culturally sensitive lens

Systemic change in research practices must begin in higher education. Institutions of higher learning can train future generations of researchers to engage with communities from the beginning and center the voices of people with lived experience at all stages of the research process.

Equipping researchers and mental health professionals in graduate school with the knowledge and skills

to engage with diverse communities is essential. Professors can consistently incorporate diversity, equity, and inclusion in research design classes so future researchers and mental health professionals are prepared to meet the growing needs of communities and work alongside them as new practices are developed. A professional discipline that embraces community engagement and data equity will lead to better data, knowledge, and evidence-based interventions. Moreover, community involvement in research will ensure that findings resonate with the community and create more buy-in for clinical interventions.

2. Apply community-engaged research methods in all research processes

Community engagement in the research process makes research more relevant, translatable, and sustainable, which in turn improves the possibility of reducing health disparities.[14] Community engagement can entail including a representative sample of the community in the research process, presenting research findings in an accessible way to community members and engaging in other actions that place community stakeholders on equal footing with the research team.[15]

A common approach to research that involves community members is community-based participatory research, or CBPR (also discussed in Chapter 2). Research projects using CBPR are designed in a way that shares power, resources, credit, results, and knowledge between communities and researchers.[16] CBPR can include sharing research dollars with communities by hiring people with lived experience, building the capacity of local organizations and community members, and supporting local businesses.

CBPR necessitates an authentic research community partnership founded on mutual trust. Before a community or one of its leaders can be expected to help the researchers, provide resources, or show

support, the researchers must demonstrate a true commitment to sharing power and decisionmaking with the community. Contributing to and being involved with the community fosters trust, which will allow for more authentic engagement and more accurate results.

Open, honest communication between researchers and communities (which requires active listening) is also critical to fostering trust.[17] Further, when working with communities, researchers should be transparent and share resources. That transparency must also be followed with accountability, which begins when communities have a clear understanding of the research process, are informed of findings, and are involved in plans or next steps following the research. Authentic partnership requires transparency in intention and action. Researchers should be clear about their intentions and understand that initial rejection or pushback from communities on research questions, interventions, or the presence of researchers may be a response to prior experiences.

3. Ensure funders support culturally sensitive research

Entities that fund research can help foster and set expectations that grantee research design teams are diverse and that the research conducted must include community engagement and person-centered outcomes. Incorporating diverse perspectives in the research process can make studies more inclusive, patient-centered, relevant, and useful for informed decisions.[18] Because researchers should earn trust before moving forward with a research agenda,[19] funders should also allow flexibility during the planning period of research projects and in the project timeline overall.

Funders can also support the use of CBPR and data equity by requiring that a portion of grant dollars is used to support community involvement in the research. Researchers are often compensated for their time spent conducting research, but community

members typically are not. Specific grant guidance on the allocation of research dollars to support community involvement could help ensure more researchers include communities in research design, data collection, and data analysis and interpretation.

Conclusion

Research shows that children and families across the US have experienced enormous adversity and disruption throughout the COVID-19 pandemic and that the worsening child and adolescent mental health crisis is inextricably tied to stress brought on by the pandemic and the ongoing struggle for racial justice.[20] In fact, the American Academy of Pediatrics, the American Academy of Child and Adolescent Psychiatry, and the Children's Hospital Association declared a national emergency in child and adolescent mental health in 2021, citing the COVID-19 pandemic as an accelerator of trends observed before 2020.[21]

To effectively intervene during this crisis and reduce mental health disparities in access and treatment, we need evidence and data that adequately represent affected communities. Adequate representation of communities of color is particularly important in mental health, because the field of psychology has contributed to systemic inequities, racism, racial discrimination, and denigration of people of color.[22] In 2021, the American Psychological Association issued an apology to people of color for their role in promoting, perpetuating, and failing to challenge racism, racial discrimination, and human hierarchy in the US.

Although enacting the aforementioned three steps is a start, making significant changes to how data are collected and developing less biased, more informed approaches are also crucial to addressing the child and adolescent mental health crisis.[23] Recognizing contributions of inequity by the mental health field and proactively sharing power and resources with communities are only the first steps for achieving racial health equity in mental health.

Chapter Five Notes

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Exploring the Obstacles in Science, Technology, Engineering, and Mathematics and Their Impact on Black Women

ASHLEY M. SCOTT

For more than a decade, government agencies have emphasized both diversifying the talent pipeline for science, technology, engineering, and math (STEM) fields and increasing the number of individuals available to fulfill STEM workplace demands.[1]

The low shares of people of color in these fields and low STEM enrollments in higher education affect the upward mobility of the STEM talent pipeline and, in turn, the pay gap between different groups.[2] Although many initiatives have attempted to increase the representation of people of color in STEM fields, they remain underrepresented, with Black women especially so.
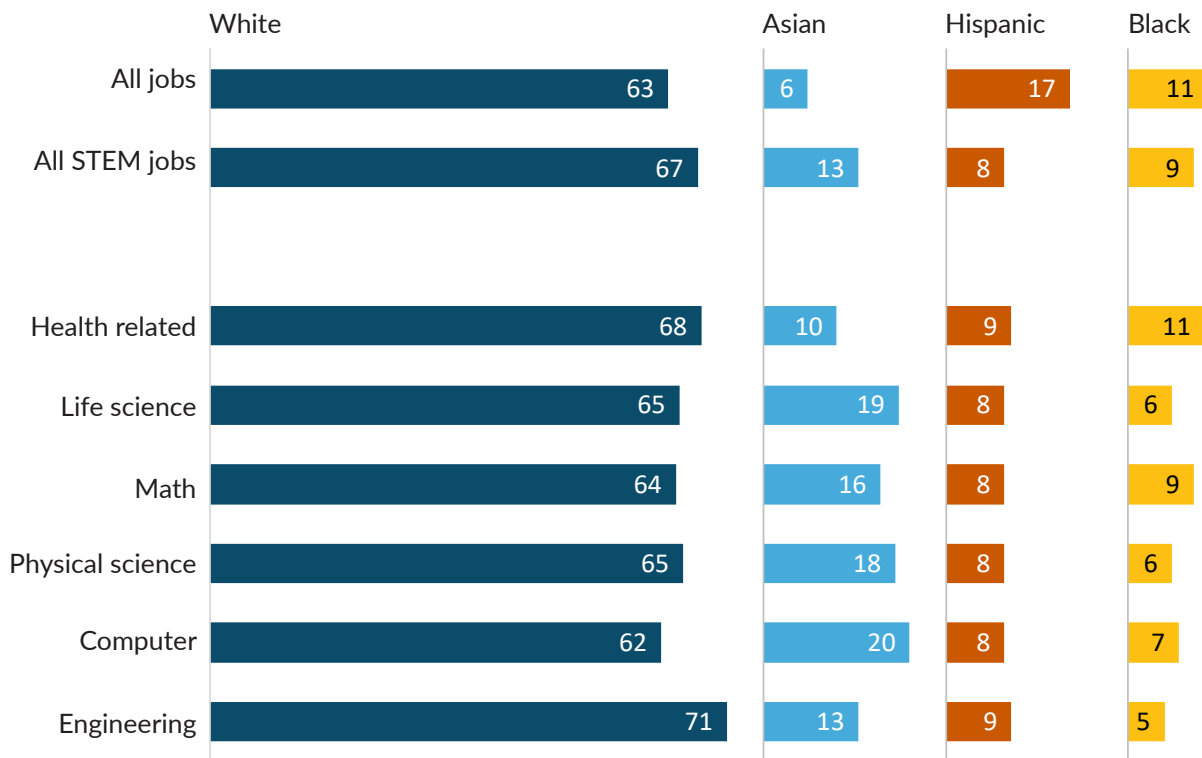
Historically, research shows that women and people of color have been excluded or denied opportunities in STEM compared with their white male counterparts, creating a perception that STEM jobs are reserved for men.[3] Although Black employees make up 11 percent of the total US workforce, they constitute only 9 percent of STEM workers.[4] For women, representation varies significantly across STEM job clusters, with women overrepresented in health-related jobs but vastly underrepresented in computing and engineering jobs.

Men are more likely than women to earn a STEM degree and enter the field, and these disparities are worse for Black women, who report a lack of encouragement to enter the STEM workforce. To decrease and eventually eliminate this gender gap in STEM, we must evaluate and acknowledge the oppression and discrimination faced by people of color, specifically Black women. Groups who are overrepresented in STEM may be unaware of how gender and race contribute to their success. In contrast, Black women tend to experience obstacles to similar success at every step of the STEM pipeline, including in school, in their coursework, and in their careers. The presence of such obstacles has been reported to lead to cultural biases, discrimination, and differences in participation rates.[5] The gender pay gap is wider at higher levels in STEM workplaces, which can further deter Black women from pursuing STEM employment. If employers and educators are interested in addressing these concerns and obstacles, they can ease access to STEM fields for underrepresented groups and create solutions to support and uplift diverse perspectives.

FIGURE 3

Black and Hispanic Workers Remain Underrepresented in the STEM Workforce

Percent of people in each category

	White	Asian	Hispanic	Black
All jobs	63	6	17	11
All STEM jobs	67	13	8	9
Health related	68	10	9	11
Life science	65	19	8	6
Math	64	16	8	9
Physical science	65	18	8	6
Computer	62	20	8	7
Engineering	71	13	9	5

Source: Richard Fry, Brian Kennedy, and Cary Funk, "STEM Jobs See Uneven Progress in Increasing Gender, Racial and Ethnic Diversity" (Washington, DC: Pew Research Center, 2021). www.pewresearch.org/science/2021/04/01/stem-jobs-see-uneven-progress-in-increasing-gender-racial-and-ethnic-diversity/.
Note: Percentages do not sum to 100 because shares for other races and ethnicities are not shown.

Cultural Biases Can Discourage Black Women from STEM Fields

The lack of representation and negative stereotypes many people of color experience in the workplace have made it challenging for Black students to complete their STEM degrees. Part of this disparity stems from challenges that can force Black students to either switch to a non-STEM major or leave their academic institutions altogether.[6] Women with doctorates are more likely than similar men to leave STEM jobs (19 percent versus 16 percent), and Black doctorate holders are more likely than doctorate holders of other races and ethnicities to leave STEM jobs (21 percent versus 17 percent for white people, 14 percent for Asian people, and 14 percent for Hispanic people).[7]

Black women also experience discriminatory stereotyping when pursuing STEM fields of study at historically Black colleges and universities, or HBCUs. One report found that a Black woman studying STEM received insulting questions from white peers at a STEM conference, such as whether there are "smart people at HBCUs."[8] Recalling the story, the student, who attends a Southern HBCU, explained that Black students at HBCUs tend to face misconceptions and cultural biases from their white counterparts.

Cultural biases can affect Black students and leave them with feelings of exclusion, of pressure to work harder, and of otherness—being "made to feel like the minority."[9] Another participant in the study explained she was the only Black woman in her undergraduate engineering program, which was

a partnership between her HBCU and a nearby primarily white institution. The student noted that funding for the program, which was more than $10 million, was later removed and allocated entirely to the primarily white institution. Not only did this shift cause disappointment and frustration in the HBCU community, it also contributed to the perception that whiter institutions are viewed more positively and provide a more desirable environment for STEM, leaving students who attend HBCUs needing to prove themselves by exceeding expectations.

STEM Coursework and Career Paths Often Include Obstacles That Disproportionately Affect Black Women

For many young Black girls interested in STEM, the path from curiosity to reality includes obstacles their peers often do not encounter. Black girls are encouraged by educators to pursue coursework in "softer sciences," such as social work and sociology, rather than in science and mathematics, in turn limiting their ability to explore careers in STEM while in college.[10] And even girls and women who dedicate themselves to STEM fields experience racist and unpleasant educational settings as well as triggering feelings of anxiety and self-doubt.[11]

Relative to white students, Black students are more likely to attend a school in a high-poverty area (defined as a school where at least three-quarters of students receive free or reduced-price lunch), which can disproportionately limit their exposure to STEM fields.[12] Most schools in low-income areas do not have state-of-the-art equipment to support scientific exploration or the infrastructure to support STEM coursework, which limits STEM course options for students.[13] Eighth graders who attend high-poverty schools show a 90-point difference in math and science scores compared with their peers from low-poverty schools, providing evidence that STEM access decreases with higher poverty rates.[14]

Moreover, socioeconomic status can affect a student's awareness of STEM preparation (such as advanced placement courses, high-quality tutors, and educators) and STEM enrichment programs (like summer camps, museums, and learning assistance programs). In one study, a Black woman who majored in biology mentioned that she "didn't really know anything about science also maybe ... because [her parents] didn't have those types of jobs." Her parents were a truck driver and a social worker, compared with her "richer friends' [parents], who were doctors and lawyers."[15]

A study by William H. Robinson and others sheds light on the "female engineering experience," finding that Black doctoral and postdoctoral women students reported a deficiency of female engineer faculty in academic settings and an abundance of gendered, insensitive comments, such as inquiries about becoming pregnant, encouragement of students not to take classes with female professors, jokes about a woman's lack of assertiveness because of her perceived passiveness, and explicit commentary about Black women.[16] Although Black women have maintained a level of resiliency in achieving success in STEM, experiences rooted in structural racism and stereotypes contribute to anxiety, emotional triggers, and unsafe environments that affect the well-being of faculty and students of color, especially in challenging STEM settings. The constant struggle to cope with such racial fatigue generates feelings of "frustration, shock, anger, disappointment, resentment, anxiety, helplessness, hopelessness, and fear," which can be exhausting when coupled with everyday discrimination.

This negative feedback throughout STEM education is an example of how mental health concerns, specifically a lack of feeling accepted, can have a lasting effect on Black women's sense of worth.

There was at least one person in my cohort who jokingly said, essentially, that I only got into the program because I was a Black woman. Adding to that, that I had failed Q1 and somehow still stuck around, it was just like another stab at that confidence, like you don't actually belong here. You're only here to fill the quota.

—TIARA, A BLACK WOMAN WHO COMPLETED A MATHEMATICS PHD[17]

Strategies to Support and Encourage More Black Women in STEM Fields

In 2021, the National Committee on Pay Equity identified August 3, 2021, as Black Women's Equal Pay Day. The date was chosen because August 3, the 214th day of the year, represented the number of additional days in the year that Black women who work full-time must work to earn what white men earned in 2020. Society's inability to diversify STEM jobs has left Black women at a disadvantage in finances and employment, with Black women reporting higher unemployment rates than any other major racial or ethnic group. To begin addressing these continued structural inequalities and barriers, policymakers, educators, and business leaders should consider the following strategies.

1. Diversify Hiring and Expand Leadership Opportunities

Historically, Black women have experienced lower pay and retention rates in the workplace, hindering their ability to advance their career. Employers can promote diverse talent in the workplace by partnering with diverse job boards to create leadership opportunities. Expanding the applicant pool and having the support of more women and people of color in a workplace may reduce implicit bias during Black women's interview processes.

Employers that are not actively hiring can still amplify the presence of Black women by establishing training or rotational programs that allow employees to train in another department or sector in the organization, enhance their skill set, and provide them with additional leadership opportunities. Given that Black women are underrepresented in senior positions, expanding opportunities to train with other colleagues in leadership occupations can equip them with new skills or allow them to expand and grow within the company.

2. Establish Mentorship Pipeline Programs

Although working in STEM can provide more opportunities to improve society and advance technology, doing so in an oppressive environment can be overbearing. Black women in STEM have reported racial microaggressions, mental health concerns, and a lack of confidence. Further, research shows that Black women often have to defend their value in STEM environments. Employers and educators can support Black women by considering and prioritizing their mental health through support groups and mentorship programs. Many Black women cite their mentorship connections as helpful in coping with racism, discrimination, and feelings of isolation. Black women have identified other women in their support group, such as family members, friends, and colleagues who share similar values, as meaningful mentors.[18]

Given that Black women face obstacles relating to their counterparts, some practices offer more holistic, harmonized development, such as investing in standardized mentorship programs that include

informal and formal training opportunities, offering pathways to acquire new skills, and providing space to self-reflect with the support of fellow employees of the same gender.[20] Each of these strategies can help increase the number of Black women in STEM and subsequently increase the likelihood of Black women advancing to senior positions.

Noticing that you're the only African person, African American, or [person] of African descent is very stressful because that adds on an extra—I don't know how to put [it], you have to show yourself that you're worthy or prove it. We [Black women] are the burden bearers, is it because of what people expect, or the position we have allowed them to place us in? It's a lonely feeling.[19]

3. Sponsor or Outsource Child Care Benefits

Before the COVID-19 pandemic, the median Black family spent more than half of their annual income on child care.[21] Black mothers are paid 52 cents on the dollar compare with white fathers, meaning that finding affordable, reliable, and flexible child care can be difficult.[22] And two-thirds of Black mothers are equal, primary, or sole earners in their households, making child care a necessity.[23] Black mothers are also overrepresented in the workforce compared with mothers of other races and ethnicities, demonstrating the pressure Black women face to contribute more financially.[24]

The COVID-19 pandemic only further exacerbated Black women's "normal" child care duties as they began facing homeschooling responsibilities,

increased costs, and reduced child care availability. Although the Biden administration expanded the child tax credit to provide additional financial assistance to families, the law has since expired.[25] This means parents, specifically Black mothers, have faced even greater challenges in providing adequate support for their family and maintaining a healthy work-life balance.

Employers can encourage Black mothers to enter STEM fields by sponsoring child care or providing employees with financial assistance for child care expenses. The National Women's Law Center found that universally available high-quality, affordable child care would lead to a lifetime income increase of more than $100,000 for the average Black mother.[26] Employers could also help by covering children's educational expenses. Ultimately, expanding internal employer options to support working Black mothers benefits both the organization and Black women.

Looking Forward

Needless to say, a one-size-fits-all approach is not realistic for creating supportive environments for Black women in STEM education and careers. By allowing more Black women to enter STEM careers, we can create a STEM workforce that encourages a diversity of perspectives and backgrounds and provides equal paths for career advancement. But doing so will require employers and academic institutions to leverage their resources and eliminate current obstacles, such as gender stereotypes, cultural biases, inadequate STEM resources, and wage gaps. By focusing on actionable steps and understanding the unique experiences Black women have in academia and the workplace, institutions can create inclusive environments that invest in specific interventions to address the needs of Black women and provide measures that increase Black women's visibility and success in STEM spaces.

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Jane J. Chung-Do is an associate professor and the associate chair in the Office of Public Health Studies at the University of Hawaiʻi at Mānoa, where she advises graduate students and teaches courses centered on experiential learning and community research partnerships. She has had the privilege of collaborating with rural and Native Hawaiian communities for over 15 years. Her research focuses on supporting healthy eating habits in rural Native Hawaiian communities through a family-based, backyard aquaponics program called MALAMA, short for Mini Ahupuaʻa for Lifestyle and Mea ʻai through Aquaponics. She also cofounded the Waimānalo Pono Research Hui, a grassroots group aiming to enhance community-driven and culturally grounded research and programming. Chung-Do holds an MPH in social and behavioral health sciences and a DrPH in community-based translational research from the University of Hawaiʻi at Mānoa.

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Alice Feng is a senior data scientist at Natera and a data visualization developer based in the Washington, DC, area. She is passionate about using design to make data and information more accessible to broader audiences and recently has explored ways to bring more diversity, equity, and inclusion into how we visualize data. Her work has appeared in the *Parametric Press* and the *Pudding*. Previously, Alice worked as a data visualization developer at the Urban Institute, where she built interactive and static data features and tools communicating public policy research.

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Kenneth Ho Jr. was born and raised in Waimānalo, resides there still, and is a father to two elementary-school-age daughters. Retired from careers as a firefighter and military officer, Ho now spends his time as a board member for several nonprofits and for public charter in his community. Ho's doctoral work focused on a community-academic partnership, Waimānalo Pono Research Hui, that seeks to utilize Indigenous pedagogy and methods as well as community-based participatory research principles to engage Native Hawaiian community members in shaping educational programming and research. In his free time, Kenneth can be found enjoying the surf, usually at Queen's in Waikīkī. Ho graduated from the Kamehameha Schools and holds a BS in occupational education from Wayland Baptist University, an MS in operations management from the University of Arkansas, and an EdD from the University of Southern California.

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Wesley Jenkins is a writer and editor on the Urban Institute's communications team. He works across policy centers to assist research teams with translating their data and analysis into clear, actionable takeaways. Through his work at Urban, Jenkins helps to ensure that data visualizations are accessible and accurate, acknowledging where data practices may not provide a fully inclusive snapshot of the communities presented.

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Samantha Keaulana-Scott is a public health PhD candidate at the University of Hawai'i at Mānoa. Her research focuses on examining determinants of Native Hawaiian health to demonstrate the relationships between structures of power and individual health. Currently, she is using Indigenous research methods to document the experiences of historical and intergenerational trauma among Wāhine (Native Hawaiian women), and she intends for her work to reveal concrete data to communicate the urgency of health and social needs unique to wāhine. Keaulana-Scott is a member of the Waimānalo Pono Research Hui, a group that adheres to Indigenous community research ethics, and she is a strong proponent of pono (just) research. Her long-term goal is to prevent inequitable opportunities of optimal health by demanding aloha, healing, and reparations for Hawaiians. Keaulana-Scott received her MSW from the University of Hawai'i at Mānoa.

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Of Standing Rock Lakota descent, Patrice H. Kunesh began her legal career at the Native American Rights Fund and has dedicated her career to public service, including through several positions and presidential appointments at the tribal, state, and federal levels. Kunesh is also the founder and director of Peȟíŋ Haha Consulting, a social enterprise committed to building more engaged and powerful Native communities through targeted and culturally centered economic development. Kunesh was recently appointed to the US Treasury Community Development Advisory Board of the Community Development Financial Institutions Fund as the representative for Native communities. She has a JD from the University of Colorado School of Law and an MPA from the Harvard Kennedy School.

MARCY MELVIN

Marcy Melvin is the deputy director of the Hackett Center, a regional center of the Meadows Mental Health Policy Institute. She has more than 25 years of experience in behavioral health policy, training, and clinical practice. As a licensed professional counselor in Texas, she provides direct clinical and supervisory services in various clinical settings to children, young adults, and parents. Marcy is passionate about advancing health equity and reducing disparities, which has been her life's work in various clinical, organizational, and systems settings. Marcy Melvin has a BS in psychology from Xavier University of Louisiana and a MA in clinical psychology from Fisk University.

QUIANTA MOORE

Quianta Moore is the executive director of the Hackett Center for Mental Health, where she focuses on creating transformative change by advancing and scaling evidence-based, community-informed policies, programs, and practices. Recently, Moore served as the Huffington Fellow in Child Health Policy at Rice University's Baker Institute for Public Policy, where her research focused on developing empirically informed policies to advance children's health. Moore uses mixed research methods, including community-based participatory research and surveys, to gain insight into the health needs of communities; develop data-driven, tailored health policy recommendations; and support an equitable future for children and their communities. She has an MD from Baylor College of Medicine, a JD from the University of Houston Law Center, and a BA in sociology from Cornell University.

PATRICE H. KUNESH

MARCY MELVIN

QUIANTA MOORE

LEONORE OKWARA

Leonore Okwara is a program manager with extensive experience performing community-engaged research, including cultivating partnerships with multidisciplinary groups to identify priorities and achieve research goals and serving as a liaison between communities, investigators, and funders. For the past 16 years, she has managed national community-engaged research initiatives within the nonprofit, academic, corporate, and government sectors. Okwara also founded and runs Public Health Research Consulting, a company that creates space for researchers to connect virtually and share best practices to meet the needs of funders and communities, to manage research studies, and to build genuine relationships with communities. She also formed the Association of Black Researchers, a nonprofit that serves as a central resource and support community for a multidisciplinary group of Black researchers.

LEONORE OKWARA

THEODORE RADOVICH

Theodore Radovich is an extension specialist and professor in the College of Tropical Agriculture and Human Resources at the University of Hawaiʻi at Mānoa. Born and raised in Waimānalo, Radovich's research, teaching, and extension activities focus on enhancing food security and self-sufficiency in Hawaiʻi and other tropical areas by optimizing crop yield and quality with regenerative agricultural practices. He cofounded and leads two initiatives at the University of Hawaiʻi at Mānoa: the Sustainable and Organic Agriculture Program and the Waimānalo Learning Center, a project to transform state agricultural experiment stations into centers of learning that empower self-sufficiency in communities. Radovich received his BSc and MSc from the University of Hawaiʻi at Mānoa and his PhD from the Ohio State University.

THEODORE RADOVICH

ILIMA HO-LASTIMOSA

Ilima Ho-Lastimosa is a community coordinator at the Waimānalo Learning Center in the College of Tropical Agriculture and Human Resources at the University of Hawaiʻi at Mānoa, where she is a strong proponent of food sovereignty and sustainability. She is passionate about giving Pacific Island communities the tools, knowledge, and skills to grow food in their backyards. Her favorite method of sustainability is using aquaponics technology to emphasize the genius of ancient Hawaiians, who utilized the ahupua`a system to live and thrive for thousands of years. Ho-Lastimosa is the founder of God's Country Waimānalo, which offers sustainability programs to the Waimānalo and Native Hawaiian communities. She received her BA in Hawaiian Studies and her MSW from the University of Hawaiʻi at Mānoa, and she holds a master's degree in acupuncture from the World Medicine Institute.

ILIMA HO-LASTIMOSA

KENDRA M. ROOT

Kendra M. Root is the research associate for the National Indigenous Women's Resource Center. Raised in the heart of Creek Country—Bristow, Oklahoma—Root is a citizen of the Muscogee Nation whose mother taught her to be a strong Native woman who empowers other women and whose father encourages her to walk in two worlds with one spirit. Root actively participates in tribal ceremonials and cultural activities and has worked in Indian Country for a number of years in many capacities. She currently serves Indian Country by honoring culturally appropriate research and advocating for tribal sovereignty and the health, safety, and wellness of Native American families. Root holds a BS in health and exercise science and an MA in Native American studies from the University of Oklahoma, and she is currently pursuing a PhD from Oklahoma State University, with a focus on the effects of colonial violence on Native Americans.

KENDRA M. ROOT

JONATHAN SCHWABISH

JONATHAN SCHWABISH

Jonathan Schwabish is a senior fellow in the Income and Benefits Policy Center at the Urban Institute, where he studies disability insurance, retirement security, and nutrition policy. He is also a member of Urban's communications team, where he specializes in data visualization and presentation design. Schwabish is a leading voice for clarity and accessibility in research and has written on how to best visualize data, including topics such as technical aspects of creation, design best practices, and how to communicate social science research in more accessible ways. Through his work, Schwabish helps nonprofits, research institutions, and governments at all levels improve how they communicate their research and findings to partners, constituents, and citizens. He teaches data visualization and presentation skills at Georgetown University and American University and founded PolicyViz, a consulting firm that helps clients improve how they communicate data and analysis.

ASHLEY M. SCOTT

Ashley M. Scott is an award-winning data professional, entrepreneur, and consultant who uses her experience in data analytics and business to encourage and champion diversity in the data practitioner pipeline. Scott previously co-led the project management of an American medical tourism facility in Tanzania, and she created the #DataGirl social media campaign, which received international recognition and supports the Data Girl Scholarship. With her online platform, Data Girl Ash, Scott demonstrates tactical approaches to making data-driven decisions while empowering others to pursue their own successful careers. Scott holds an MBA from Mercy College, a BS in public health from the University at Albany, and a Women's Entrepreneurship certificate from Cornell University.

KAHAULAHILAHI VEGAS

Kahaulahilahi Vegas is working on her PhD in public health at the University of Hawaiʻi at Mānoa. She comes from the moku ʻo ʻEwa on Oʻahu, and her ʻohana is from Molokaʻi and Oʻahu. Hawaiian communities have always had an impact on her life, and she strives to give back to those communities. She has been a part of a hula hālau (hula school) where she has been an alakaʻi (leader), and in her spare time, she frequently attends cultural events to support the next generation. She has an MPH from the University of Hawaiʻi at Mānoa, with a focus on Native Hawaiian and Indigenous health.

ASHLEY M. SCOTT

KAHAULAHILAHI VEGAS

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The nonprofit Urban Institute is a leading research organization dedicated to developing evidence-based insights that improve people's lives and strengthen communities. For 50 years, Urban has been the trusted source for rigorous analysis of complex social and economic issues; strategic advice to policymakers, philanthropists, and practitioners; and new, promising ideas that expand opportunities for all. Our work inspires effective decisions that advance fairness and enhance the well-being of people and places.