Weitzman Institute
2023 VIRTUAL Symposium

Panel Presentation #2
"Data is Only as Good as its Analysis":
Beyond Clinical Practice—
The Role of Big Data and Policy in Promoting
a Pro-Health Built Environment

Tackling Old Problems with New Solutions in Primary Care   **May 2023**

Presentation Summary Points:

1 Panelists emphasize the importance of "trustworthiness" and discuss the limitations and biases in big data, suggesting that not everything can or should be studied. Big data in healthcare should consider the limitations of existing data systems, access issues, and the need for community engagement.

2 The panel discussed how to reimagine big data to prioritize community-led research and focus on specific health equity goals. Reimagining big data involves creating community-led research and involving communities in defining and describing health equity.

3 The speakers highlight the challenges of utilizing data in advocacy efforts and emphasize the importance of considering different perspectives and whose reality is being represented. The misuse of data and biased interpretation can be a concern when advocating for certain decisions or policies.

4 They mention the lack of public access to comprehensive data from health centers, despite the existence of large data repositories. Additionally, the panel mentions the lack of public visibility and understanding of health center performance data as a challenge. Questions were raised as to why there is no common data management tool to analyze and share data, emphasizing the value of making health center data visible and understandable.

PANELISTS:
(Clockwise from top left)

**Monica R. McLemore,
PhD, MPH, RN;
Kyu Rhee, MD, MPP;
Sara Rosenbaum, JD;
Neely Williams, MDiv, EdD**

MODERATOR:

**Ninez A. Ponce,
PhD, MPP**

The Weitzman Institute Virtual Symposium: "Tackling Old Problems with New Solutions" featured a panel discussion on the topic of big data and its impact on health equity. Panel moderator, **Dr. Ninez Ponce**, Director of the Center for Health Policy Research at UCLA, and Professor and Endowed Chair at the UCLA Fielding School of Public Health, Department of Health Policy and Management, started the conversation by highlighting the significance of population health surveys, specifically focusing on the California Health Interview Survey (CHIS), the nation's largest state health survey. The California Health Interview Survey (CHIS), which is led by Dr. Ponce, is recognized as a national model for data collection on race/ethnicity, sexual orientation and gender identity (SOGI) and immigrant health. CHIS collects comprehensive data on various aspects of health, living conditions, education, occupation, income, and trauma history. The goal is to understand the underlying factors contributing to health inequities.

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Dr. Ponce emphasizes the importance of **data equity**, which involves collecting, analyzing, interpreting, and distributing data in a way that marginalized communities can access and utilize. She expresses a commitment to prioritize data quality and engage policymakers and community advocates in the research process. Dr. Ponce then moves on to discuss the **seven "V's" of big data**: *volume* (the large sample size of the survey), *velocity* (delivering data quickly), *variety* (collecting data on diverse subgroups), *variability* (adapting to changing concerns and adding new content), *veracity* (ensuring data quality and transparency), *visualization* (making data easily understandable), and *value* (centering equity in survey objectives). She provided examples of each V, highlighting the extensive data collected over the years, the quick delivery of data during the COVID-19 pandemic, the diverse range of demographic information collected, the inclusion of new content and sampling approaches, the importance of data quality and visualization, and the overall value of centering equity in data collection and research.

Dr. Kyu Rhee, Senior Scholar at Stanford University School of Medicine, describes himself as a product of the Federally Qualified Health Center (FQHC) Movement as a National Health Service Corps scholar working in underserved communities. He discusses the three key concepts related to big data: the **3D's** (*data*, *determinants*, and *decisions*), and emphasizes the importance of considering broader determinants of health and using data to inform better decision-making. He also advocates for augmented intelligence, where technology and humans work together to make better decisions and improve health outcomes. Additionally, he introduces the concept of "techquity," which involves promoting health equity through workforce diversity, data trust, equity dashboards, and equitable, transparent, and ethical artificial intelligence (AI).

Dr. Monica McLemore, Professor at the Child, Family and Population Health Department at the University of Washington School of Nursing, shares her perspective on the limitations of current big data sets. She advocates for retrofitting and reforming existing data collection methods and reimagining new data sets that address the diverse needs of marginalized communities. She proposes the framework of "retrofit, reform, and reimagine" to guide these changes. She suggests updating the language and variables used in surveys to avoid unhelpful proxies and assumptions. McLemore advocates for a reformation that considers diversity, in-group and within-group differences, and challenges white supremacy in data analysis. Finally, she calls for a complete reimagining of big data sets to better serve marginalized communities.

Rev./Dr. Neely Williams, Director of Community Engagement at Tennessee Community Engaged Alliance Against COVID-19 (TN CEAL), and a community advocate and engagement strategist, highlights the impact of big data and AI on communities and the need for responsible stewardship of these technologies. She emphasizes that while data and technology can be powerful tools for improving lives, they can also have unintended consequences if not properly managed. Dr. Williams shares personal experiences, such as discovering her house on Google Maps and realizing the extent to which technology can track and monitor individuals. She stresses that her community is often unaware of the implications of data collection and research. Further, she emphasizes the importance of considering the impact of data on policy-making, community profiling, and the well-being of future generations. She urged the audience to think critically and contextually about how data and AI are used and to be mindful of the potential negative consequences for marginalized communities. Dr. Ponce acknowledges Neely Williams as a moral compass and appreciates her insights on data as a public good and the limitations of regulation and policies.

Professor Sarah Rosenbaum, Emerita Professor of Health Law and Policy and Founding Chair, Department of Health Policy, at the George Washington University Milken Institute School of Public Health, is a civil rights lawyer with extensive experience in advancing health equity through evidence-based policymaking. Professor Rosenbaum describes her role as a translator of evidence, using data to persuade lawmakers to adopt more equitable policies. She focuses on healthcare access, financing, and the effects of policy decisions on health equity. She acknowledges her reliance on data creators and analysts, mentioning her collaboration with Dr. Ponce for visualizations. Professor Rosenbaum emphasizes the importance of data in informing policy decisions and discusses the significance of both big quantitative data sets and qualitative data in her work. The introductions set the stage for a discussion on data equity research, highlighting the significance of population health surveys, the importance of centering equity in data collection, and the need for improvements and innovations in big data sets.

Veracity: The Truth and Power in Transparency

The panelists discuss the importance of getting close to the truth in survey research, engaging with communities, and being accountable for data accuracy and potential biases. They note that the misuse of data and biased interpretation can be a concern when advocating for certain decisions or policies. Under the theme of veracity, which involves getting as close to the truth as possible in survey research,

Seven "V's" of Big Data:

- **VOLUME** (the large sample size of the survey)
- **VELOCITY** (delivering data quickly)
- **VARIETY** (collecting data on diverse subgroups)
- **VARIABILITY** (adapting to changing concerns and adding new content)
- **VERACITY** (ensuring data quality and transparency)
- **VISUALIZATION** (making data easily understandable)
- **VALUE** (centering equity in survey objectives)

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methods, community engagement, and accountability. The panelists emphasize the need to present data to the populations being represented and engage with community organizations for feedback and validation and to ensure that the data does not do harm. They also highlight the potential for bias and misuse of data and the importance of accountability and owning up to mistakes. Rev./Dr. Williams highlights how communities need to be included in the process:

> *"Your analysis can only be as good as you are informed by the people that you collect the data from. Because we then become not just people invited to the table, but we are people who are on the table. We are just as much a part of the table but I'm tired of being invited to Thanksgiving dinner, and you're serving turkey when all I really wanted was chicken. I want to be able to help set the menu. I want to be able to be a part of the process, so that when it comes to the end of the end result, it reflects where it came from."*

The panelists then delve into the intersection of big data and policy in FQHCs and communities. They explore the complexities of using big data, such as issues of access, complexity, and the limitations of existing data systems.

Reimagining Big Data and Policy

The panelists advocate for **involving communities as co-researchers, and considering them as the primary stakeholder in the health system**, with the goal being to create community-driven and community-led research that can accurately describe and define health equity. They note the need to consider the limitations of existing data systems, including access issues, generate community-driven data, and create a common data management tool to increase visibility and understanding of health center performance data.

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Dr. McLemore highlights the limitations and biases in big data, suggesting that not everything can or should be studied. She calls for reimagining big data to prioritize community-led research and focus on specific health equity goals. In response to a question about the lack of public visibility and understanding of health center performance data, the panelists discuss the need for a common data management tool that would allow health centers to share and analyze data. They express their frustration with the current state of data repositories, which often lock up data and limit visibility. Professor Rosenbaum highlights the challenges of using data in legal arguments and emphasizes the importance of considering different perspectives and whose reality is being represented. She mentions the lack of public access to comprehensive data from health centers, despite the existence of large data repositories. She questions why there is no common data management tool to analyze and share data, emphasizing the value of making health center data visible and understandable. Additionally, they propose the implementation of community-based institutional review boards where community members are paid to support research efforts and would address the lack of public visibility and understanding of health center performance data.

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In sum, the panelists emphasize the importance of transparency, community engagement, and the need to rethink traditional approaches to data collection and analysis in order to promote accuracy, trustworthiness, and health equity. Their discussion revolved around the concept of veracity in data collection, representation, and usage. The speakers stressed the importance of community engagement, accountability, and avoiding harm in the pursuit of truth. They also discuss the need for reimagining big data to prioritize community-led research, address health equity goals, and make data more accessible and transparent. The conversation specifically touches on the context of FQHCs and the challenges and opportunities in utilizing big data in these settings.

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For More Information

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