Public Health Data Systems Performance during COVID-19, Health Equity

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I am glad to join this panel as we discuss the critical challenges presented by the worldwide SARS COV2 pandemic. As with so many aspects of American society, this pandemic has ripped the covers off a public health infrastructure held together by spit, sweat and string.

Less than one third of local health departments employ an epidemiologist.[1] The status and workforce needs for epidemiologists in state and territories have been well documented. [2] In addition to classically trained epidemiologists a wide range of data experts are needed trained in Geographical Information Systems (GIS), public health informatics, big data analysts, demographers, medical informatics the list grows. People who make up the workforce are the most important need. Interoperability, superhighways of information are useless without human beings to design, monitor and interpret data. Data never speaks for itself, there is always a human being speaking and interpreting all data. That human component not only includes people with special training in public health data, it includes all other professionals and the public because "data" is simply another language to be learned and understood. That workforce must reflect the diversity of our nation by race, class, and gender. Investments must be made in this human infrastructure. Such investments must be done with an intentional goal of addressing racism, classism, gender bias as we recruit and train health professionals. We should support workers central to data collection and analysis as they increase their technical skills. If more community health workers were trained to be GIS experts, data analysts, epidemiologists the type of questions and the communities of concern would change. A failure to have anti-racism and social justice as foundational pillars will guarantee the replication of our present racist, colonial, and inequitable systems.

I wish to add my voice to the dozens of reports, letters, organizations pleading for the federal government to halt the divestment of our public health infrastructure. [3] For over twenty years, Trust for America's Health had advocated for an investment in our public health infrastructure. The latest report details recommendations for federal as well as state and local funding. [4]

A wide range of common-sense changes need to be immediately implemented. We need data systems that talk to each other. We need to stop creating hard siloed data bases by each disease. We need to immediately upgrade the hardware and software needed to do public health surveillance. Of course, we need to link to our medical data systems more effectively, but we also need to link to other systems critical to the health of populations (e.g. economic, housing, employment, criminal "justice"). Funding the data pipeline from the source (e.g. Community Health Workers) to national analysis is foundational to a strong data infrastructure. As CSTE points out in their Data: Elemental to Health Campaign, this must include a) electronic case reporting b) syndromic surveillance systems c) a standardized electronic vital records system d) an electronic laboratory reporting system that includes private and public health laboratories e) a national notifiable disease surveillance system. [5]

Today, I would like to concentrate my remarks on how we can overhaul and construct a public health data infrastructure that will begin to address our needs to improve health equity. The failures of today's data systems during Covid-19 are many and have been catalogued in a range of reports and commentaries. Ancient fax machines are still be used to report cases, lack of standardization on data being collected, difficulty of obtaining real time data so that the epidemic can be actively tracked, and interventions coordinated. Resolve to Save Lives issued a report last year endorsed by Trust for America's Health , the American Public Health Association, the Association of Schools & Programs of Public Health and Johns Hopkins Bloomberg School of Public Health that addressed these failures.

> *"The use of accurate, real-time data to inform decision-making is essential for infectious disease control. In the ongoing COVID-19 pandemic, there is an overwhelming amount of data, including many indicators that can be misleading if not considered correctly. Unlike many other countries such as Germany, Senegal, South Korea, and Uganda, the United States does not have standard, national data on the virus and its control. The US also lacks standards for state-, county-, and city- level public reporting of this life-and-death information."* [6]

Health inequities are systemically created across socially defined groups in a manner that is avoidable, unjust, and unfair. How can we conceptualize, operationalize, and analyze the data of a structurally racist and inequitable system? [7]

With this in mind, it is useful to consider the following questions.

Who is seen and valued? In plain English, who defines what is data, who collects it, and who controls how it is analyzed?

It is a fact, though not a surprise, that data about race and ethnicity of individuals testing positive for, hospitalized with, and dying from Covid-19 remains largely unknown. Few states initially tracked this information, and those that did had high proportions of the data fields left blank.[8] It is a sad commentary that journalistic organizations, not for profit advocates and some academic centers became the most reliable sources of such information.[9,10] We Must Count, a coalition of public policy and advocate organizations, has called for what should be a minimal standard.

> "*to begin tracking and reporting on novel coronavirus testing, COVID-19 cases, and COVID-19 health outcomes using data disaggregated by race, ethnicity, primary language, genders, disability status, and socioeconomic status. Additionally, there are other critical data needs, such as capturing variations in testing and care in rural areas as compared to more densely populated areas…. Racial and ethnic health disparities and inequities can only be eliminated if there is high-quality information by which to track immediate problems and underlying social determinants, as well as to guide the design and application of culturally specific medical and public health approaches. The most useful data on health outcomes is disaggregated by genders as well as broad racial categories such as Black, Latino, Asian, White, or Native American. Ideally, such data is further disaggregated within broad racial groups such as the Asian population, to understand divergent experiences by ancestry. "[11]*

It does not take a genius to think that the structural factors that support white supremacy and classism would be operating during Covid 19. If people of color are not seen, if workers and the dangers they face are not valued then those who define and collect the "data" will not consider the examination of such disproportionate impact important.

The Urban Indian Health Institute with a mission to decolonize data for Indigenous people, by Indigenous people has issued a report card on Covid-19 data Native peoples with the United States receiving an overall grade of D+. [12] The lack of data on people of color, the continued refusal to collect information from some populations and disaggregate data from others is part of structural decisions that amount to data genocide.

Disaggregating data is important if your goal is to improve health. Simply lumping all Black people together is absurd and hides important details. Is the community an immigrant community, is the primary language Spanish or Portuguese? Which Latinx immigrant communities have Indigenous languages as their mother tongue? The Asian communities encompass a third of the globe what arrogance is needed to lump them all together and often not report the data at all? Does national level data tell a county health department what it needs to know to keep its people healthy? The present status of data collection for people of color reflect the original purpose of this racialized data, to support white supremacy. When the goal becomes to prevent disease and protect the health of people, different types of data are needed. We need surveillance systems and methodologies that are useful at city, village, and community levels.

We must track data by class and gender also. This means looking at the data by education level, gender identification, disability status, incarceration status and other factors. How else can we monitor the impact of jobs and job exposure. It was predictable and therefore preventable that congregate living quarters, (dorms, jails and prisons, nursing homes, military barracks) present a challenge with a communicable disease outbreak. Our failure to have surveillance systems by occupation and place of work means that subway staff, transportation, factory, warehouse, grocery store and other essential workers needlessly died. We need the data available in a timely fashion so that we can examine the different risks created by occupational and other social conditions. [13] An outbreak in a local jail threatens the lives of those incarcerated. Most are in jail because they cannot afford bail. Outbreaks threaten the staff that work in the jails and the disproportionately the poor black and brown communities from which those who are incarcerated come.

The first step then is to see and value all people equally. This means that in addition to transforming the face of "data" experts, we must change who is at the table. We must involve other stakeholders than governmental public health staff. We must include the communities who have been historically marginalized. We must establish structures and processes to constantly evaluate not only Covid-19 specific data, but all data impacting the health of the public. Disaggregating data is a first step in seeing all people. Let HITAC include community leaders, historians, faith leaders, social scientists, and a wide range of disciplines on its "data" committees.

In addition to changing the face of persons who are educated to be "data" experts, we must increase the education of everyone else. The public needs to be directly and continually addressed. The responsibility for communicating what we in public health mean by our rates, risks, and other peculiar measures rest squarely on our shoulders. The general public can follow the measurements and statistics involved with monitoring tennis, soccer, football, and many other sports with ease; they can become competent to evaluate public health data and information. That means that those of us who are experts have to decide that such technical expertise must include the communications skills to make clear what our debates are about.

We need to include a range of data sets beyond biomedical measures of health status. We need to measure health and well-being. We need surveillance systems focused on levels of racism, anxiety, stress. We need to monitor economic indicators that impact health. Unemployment, economic inequity, educational gaps. We need to consider and analyze a range of information not traditionally included in public health data. This does not mean simply searching for some summary "index" measure. The evaluation of social structures is complex and cannot be rolled up into a quantitative measure alone. Looking at food insecurity is an important task, but we also need to monitor where health food is available. Structural determinant create health as well as disease. We need to question the underlying assumptions of our data. It is not sufficient to count those who are unhoused. We must ask why in our nation a human being is required to pay rent to simply occupy space. We cannot simply catalogue the social determinants of health ; we must study, understand and challenge how structural determinants created our world and what changes are needed to create a new world.

IMMEDIATE STEPS

1. Invest in a robust public health infrastructure as recommended for decades by public health organizations
2. Specify goals that change the face of "data" experts by investing in our educational structures and creating career ladders for health care workers from Community Health Workers to those with terminal degrees.
3. Commit to a set of competencies that are anti-racist and anti-colonial. This must include an understanding of the role played by "scientists" of all disciplines but especially statistics in supporting the false notion of racial and biological superiority of "whites".
4. See everyone. Collect and disaggregate the data. Embrace communities of color as (at least) equal partners in designing questions to be explored and data to be collected, analyzed, and interpreted.

5. Build the resources necessary for local communities to monitor public health data.

6. Include non-traditional public health information (e.g. outside of bio-medical data) such as economic, environmental, social structures, parks etc. in health and well-being surveillance systems.

We need to dedicate public health to understanding and monitoring the structural conditions of human society which produce health and disease. To paraphrase Abagail Echo-Hawk, health equity and social justice will not be achieved in the United States until public health surveillance systems properly collect and report race/ethnicity, class, and gender. The proper collection of public health data is a necessary but not a sufficient condition. What is required is a movement of people dedicated to organizing the power necessary to implement structural solutions.[14] [15]The solutions that are necessary to create a planet that is healthy, a world at peace, and where social justice is the reality for all people.

[1] National Association of County & City Health Officials. 2016 National Profile of Local Health Departments. 2016

[2] Council of State and Territorial Epidemiologists. 2017 Epidemiology Capacity Assessment Report. 2017

[3] Hagan, C. N., E. J. Holubowich, and T. Criss. "Driving public health in the fast lane: the urgent need for a 21st century data superhighway. 2019." (2020).

[4] The Impact of Chronic Underfunding on America's Public Health System: Trends, Risks, and Recommendations, 2021. Trust for America's Health. https://www.tfah.org/wp-content/uploads/2021/05/2021_PHFunding_Fnl.pdf Accessed May 10, 2021.

[5] Data: Elemental to Health Campaign CSTE https://www.cste.org/page/DM-2021 Accessed May 10, 2021

[6] Epidemics, Prevent. "Tracking COVID-19 in the United States: From information catastrophe to empowered communities (https://preventepidemics. org/wp-content/uploads/2020/07/RTSL_Tracking-COVID-19-in-the-United-States_-7-23-2020. pdf)." *Published July* 21 (2020).

[7] Krieger, Nancy. "Structural racism, health inequities, and the two-edged sword of data: structural problems require structural solutions." *Frontiers in Public Health* 9 (2021).

[8] Pearce N, Vandenbroucke JP, VanderWeele TJ, Greenland S. Accurate statistics on COVID-19 are essential for policy guidance and decisions. Am J Public Health. 2020;110(7):949–951.

[9] The COVID Tracking Project, at *The Atlantic*. The COVID Racial Data Tracker. Available at: https://covidtracking.com/race

[10] APM Research Lab Staff. The color of coronavirus: COVID-19 deaths by race and ethnicity in the U.S. July 8, 2020. Available at: https://www.apmresearchlab.org/covid/deaths-by-race

[11] https://www.wemustcount.org/the-letter Accessed May 10, 2021

[12] Data Genocide of American Indians and Alaska Natives in COVID-19 Data A report card grading U.S. States' quality of COVID-19 racial data and their effectiveness in collecting and reporting data on American Indian and Alaska Native populations. Urban Indian Health Institute. 2021. https://www.uihi.org/projects/data-genocide-of-american-indians-and-alaska-natives-in-covid-19-data/#covid-19-data-report-card Accessed May 10, 2021,

[13] Bassett MT, Chen JT, Krieger N. The unequal toll of COVID-19 mortality by age in the United States: quantifying racial/ethnic disparities. Harvard Center for Population and Development Studies Working Paper Series, Volume 19, Number 3. June 15, 2020.

[14] M4BL. Vision for Black Lives: 2020 policy platform. Available at: https://m4bl.org/policy-platforms.

[15] Poor People's Campaign. A Moral Policy Agenda to Heal America: The Poor People's Jubilee Platform. June 20, 2020. Available at: https://www.poorpeoplescampaign.org/about/jubilee-platform.