This document is part of a group of supplemental materials for use by the National Commission to Transform Public Health Data Systems, an independent commission convened by the Robert Wood Johnson Foundation (RWJF). These materials were used to inform Commission discussions and recommendations.
Expert Panel Convenings: Introduction
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**Background and Approach.** Significant data gaps exist for populations based on a wide range of demographic characteristics. The COVID-19 pandemic has shined a bright light on a critical health inequity – the inadequacy of our existing data systems for identifying disparate risks and impacts of the virus across populations, inadequacies that also had significant implications for the ability of state and local communities to provide necessary resources in response to the pandemic, such as guidance for prevention and treatment, testing, medical care, and vaccinations. This inequity has much broader implications than just those related to a single virus. As part of the quick strike grants funded to inform the National Commission to Transform Public Health Data Systems, the Robert Wood Johnson Foundation supported a series of virtual convenings with expert panels, each focused on identifying barriers and opportunities for improving data systems in ways that would help to eliminate data gaps for five populations: American Indians/Alaska Natives, Blacks/African Americans, LGBTQ+ communities, people with disabilities, and women.

Each panel consisted exclusively of individuals who brought expertise to the issues based *both* on their work and training with data and on their own personal lived experience as members of the community. As such, these panels enabled the expertise and voices from within populations’ own communities to guide the direction for recommended strategies and approaches to advance data systems and data equity. Each panel convened virtually for a total of eight hours over three days. (In addition to these convenings, the lead for each panel produced a landscape analysis, which can be found as follows: American Indians/Alaska Natives; Blacks/African Americans; LGBTQ+ communities; people with disabilities; women.) This report provides a summary of the key themes that emerged during those convenings. Each population has unique issues and concerns that must be considered in the context of creating transformative change in health data systems, and as such, separate reports that follow have been produced with in-depth findings and recommendations from each panel. Below, we provide a brief overview of the cross-cutting themes, those that emerged consistently across panels and thus across populations. These themes reflect panels’ recommendations about how to achieve long-term systems-level change.

**Summary of Cross-Cutting Themes.** Importantly, many of the themes below are undergirded by the notion of *power* – the belief that whoever holds the data and controls the systems around those data,
also controls the narrative and ultimately has more decision-making power over distribution and use of the resources. And currently, the power in data systems – and institutions that build, support, and sustain them – are rooted in dominant white, heteronormative, ableist, and patriarchal values, which foster existing systems of oppression and continue to “other” all of those who do not fit into these norms. By doing so and glossing over nuances in each subpopulation, individuals and their communities are only understood through a deficit lens, where their behaviors and traits are problematized. Panels, regardless of whether they were based on race/ethnicity, sexual orientation, gender identity, sex, or disability status, all touched on the idea that there needs to be a major shifting and redistribution of power to truly effect transformative change in data systems – from conception, to collection, to analysis, to dissemination. The themes below reflect recommendations for how to achieve this.

- **Narrative change** is critically needed (1) to reframe the purpose of data systems from business, monitoring, and accountability to health, wellness, and equity and (2) to reframe the health and well-being of populations to focus on their strengths, assets, and value to society as opposed to the existing deficits framework.

- **Data and data systems must be decolonized**, such that they are redefined in ways that are no longer rooted in dominant white, heteronormative, ableist, and patriarchal culture, recognizing and valuing diverse cultural histories, values, norms, and perspectives.

- **Authentic community engagement and partnership** with a population, where population members have a seat at the table in decision-making about data and play a role in providing meaningful oversight of data across its life cycle (collection, analysis, reporting, and dissemination), is necessary to ensure data, data systems, methodology, and research questions are relevant and valid.

- **Data ownership** where community members have access to and can lead and/or participate in data systems fosters trust and engagement and transfers power to communities that are the focus of the data.

- **Training and capacity building** for both members within a population as well as those outside of the population must be a priority so that data and data systems reflect population-specific needs, culture, and history and so that systems build the pipeline within and leverage existing assets of a population.

- **Definitions** of terms identifying populations need to be clarified to create greater consistency across data systems.

- Data need to be **disaggregated** within broad categories of populations to reflect populations’ diversity and to acknowledge that they are not a monolith.

- Data systems need to more consistently include the collection of a **broader array of demographic variables** to allow for analysis of intersectional identities and to reflect the wide range of experiences that impact the health and well-being of the nation’s population.
• Technical advances that allow for **systems-level interconnectivity, interoperability, and data integration** are necessary so that data across systems can communicate with each other and data consumers can access data longitudinally across an individual’s life span and link data across a wide range of social determinants of health.
American Indian and Alaska Native Expert Panel Report

“Data is a restorative and healing process across collection, ownership and dissemination.” – AI/AN panel participant

A panel of American Indian and Alaska Native (AI/AN) technical advisors from diverse tribal backgrounds and with public health data systems experience including current and former federal employees, academics, public health practitioners, experts across the age spectrum, and broad disciplines came together in a series of virtual meetings to discuss public health data system issues and improvements and to offer recommendations and insights to guide the development of the Robert Wood Johnson Foundation’s strategy and future investments in transforming public health data systems. The AI/AN panel included an AI/AN panel leader, selected by RWJF, and nine AI/AN members who each brought their diverse perspectives and deep understanding of data, research, and public health data system gaps for AI/AN people. Panel support included a facilitator and a writer to capture insights and recommendations. Panel members were provided drafts of this report for review and comment; however, due to tight timelines, not all panel members were able to participate in the review.

This report is not intended to be a synthesis of the diverse views of the panel, rather a range of expressed highlights. This report is organized around the key questions: why, what, who, how, and what next on the path to achieve data equity for AI/AN.

Notes from the AI/AN panel:

This AI/AN panel of technical advisors does not represent the views of any or all of the 574 federally recognized AI/AN tribal nations in the United States. They provided their insights on the salient issues based on their technical expertise and experience working on AI/AN data issues. The diversity of opinions represented on the panel is included in this report; however, not all points in the report were agreed upon by all panel members.

An AI/AN Landscape Analysis, authored by the panel lead, is available for review and is not meant to represent the views of panel members. It was provided to the panel to give detailed background information prior to the gatherings and can provide some context for the insights and recommendations shared in this report.
WHY: Data and research about AI/ANs must be grounded in an understanding of the history and current context of AI/ANs and tribal nations. AI/AN people have always been data gatherers, data users and data stewards, yet these traditional ways of knowing are often misrepresented, overlooked or misappropriated.

- **Unique political status of AI/AN tribal nations**

  “There is no equity without recognition of sovereignty.” – AI/AN panel participant

  - Tribal nations are sovereign nations, and AI/AN individuals are either citizens or descendants of tribal nations. Defining AI/ANs solely as a racial group does not honor the unique political status of tribal nations.
  - Each tribal nation is sovereign and has the right to govern all data aspects.
  - External data systems must work in consultation with tribal nations on ensuring AI/AN data is collected, analyzed, used, interpreted and reported consistent with tribal laws and code, policies, procedures and preferences.
  - Urban AI/AN data presents challenges for tribal nation governance and is often dependent on ethics, relationships and community gatekeepers, not laws, policies, or practices.
  - Researchers and public health practitioners must understand the history, culture, and data practices of each individual tribal nation to ensure data is interpreted and used in the correct context.
  - Traditional ways/traditional science/Indigenous data is often discredited by western institutions as not real data, or not grounded in western sciences, or not having undergone rigorous western methods of credibility and reliability.
  - Restoration of cultural values of spirituality, prayer, relations and collectivism that are inclusive of community voice including elders and youth is at the core of building equitable AI/AN data systems and data practices.

WHAT: AI/AN data is often collected, analyzed, interpreted and reported in ways that lead to inaccurate and/or irrelevant interpretation.

- **Terminology and data definitions**

  “Things are often decided for us without us, especially with regard to the terms that are used to define us.” – AI/AN panel participant

  - The term AI/AN should be used consistently across federal and state data systems; terms such as Native American or Indigenous are not specific enough for describing AI/ANs in the United States.
  - Determination on the proper use of data as AI/AN in combination with multiple races or Latinx/Hispanic ethnicity vs. AI/AN alone must be made in tribal consultation and may vary by tribal nation.
Investments in strategies and linkage projects to prevent racial misclassification are critical to improve the quality of AI/AN data.

Public health data systems across federal and state governments must use consistent definitions and terminology for AI/ANs.

Creation of a tribally driven AI/AN data definition standard would allow for ease of data linkages and other methods of data sharing across disperse systems.

When considering collection or reporting of self-reported tribal affiliation, tribal nations should be consulted on its use and whether it can be made public.

Interoperable data systems are needed to capture AI/AN individuals who migrate between tribal and urban settings (e.g., for healthcare or when a tribal member goes missing in an urban area).

**Data disaggregation**

"Without accurate stories and the numbers, we cannot design interventions that promote health and well-being of our people." – AI/AN panel participant

- Accurate and meaningful AI/AN data disaggregation is necessary to understand public health needs.
- AI/AN data should not be combined with other distinct racial categories.
- Categories such as "multiracial" or "other" should not be used to ensure full access and review of the data for AI/AN.
- Data suppression policies should be developed in consultation with tribal nations to allow for access to data for tribal governance that might otherwise not be public.
- Data disaggregation is key to improving public health information. Demographic variables of particular note include: race (single race, multiple), ethnicity, tribal affiliation/enrollment, open-ended variables, residency, age, and gender identity that is inclusive of LGBTQ2S+.

**WHO:** To achieve AI/AN health equity, all entities involved in public health data systems must be involved in efforts to education and improve AI/AN data.

- **Entities to engage in AI/AN data issues with public health data systems include but are not limited to:**
  - Tribal nations.
  - Native-serving institutions, such as Indian Health Boards, Tribal Epidemiology Centers, American Indian non-profits/community-based organizations (including national, regional and local entities and urban and reservation partners).
  - Academia (e.g., researchers, data scientists and epidemiologists).
  - Federal, state, county, and city governments.
Clinics and hospitals, philanthropy, policy-makers, corporations, and professional organizations (national, regional and local).

HOW: Ensuring AI/AN data equity requires engagement with tribal nations and urban Indian organizations.

- Tribal consultation
  Federal Tribal Consultation is defined in Executive Order 13175 and in the recent January 2021 Presidential Memorandum that “charges all executive departments and agencies with engaging in regular, meaningful, and robust consultation with Tribal officials in the development of Federal policies that have Tribal implications.”

  “When Indigenous people [tribes] have control of their data, it can be a threat to those who benefit from oppression – it makes the gaps apparent and holds people accountable.” – AI/AN panel participant

  - Public health data systems at federal, state, and local governments that include AI/AN tribal data require tribal consultation.
  - Recognize that AI/AN capacity exists to support advancing public health systems that include AI/AN data solutions, strengths, and protective factors to close health disparity gaps.
  - Relationship building between all partners is the critical first step to ensure tribal governance over AI/AN data.
  - Greater education of all partners is necessary to understand tribal public health authority and governance over AI/AN data.

- Urban AI/AN data and urban confer
  An Urban Confer is an adaption of the Tribal Consultation for urban Indian organizations (UIOs). UIOs participate in the Urban Confer process to fulfill the fiduciary obligation of all levels of government to provide services to AI/ANs living in urban areas. The Indian Health Service is required to confer with UIOs, and a current effort is underway to extend this across HHS.

  “The majority of AI/ANs live in urban areas, yet the data of AI/ANs in urban areas has all of the same issues of AI/ANs in tribal nations without the protections. Urban confer can mitigate some of the issues.” – AI/AN panel participant

  - Public health data systems at federal, state, and local governments that include urban AI/AN data should consider an urban confer.
  - More states should confer with UIOs especially when using federal funding.
  - UIOs are often engaged in AI/AN data efforts but without the involvement of tribal nations, governance and protections around AI/AN data in public health systems require further clarification.
Investments in urban AI/AN data governance mechanisms, such as ethical principles, are needed to protect and support tribal data governance of urban AI/AN data, as urban AI/AN are often a target of researchers wanting to avoid tribal governance protocols.

- **Public health practice and research**

  “*With an ethical framework, there is a call for accountability and mutual respect. It is important to consider how to think about [accountability] through the cultural practice of maintaining relationships.*” – AI/AN panel participant

  - Researchers involved in data collection for public health systems must ensure they are following all the research governance requirements of tribal nations.
  - Relationship building between all partners is critical to ensure tribal governance of AI/AN data.
  - Tribal research protocols and governance mechanisms vary by tribe and often have a unique sovereignty and community harm/benefit principle above and beyond individual human subjects protections (e.g., tribal resolution, IRB review, consent, data sharing agreements, dissemination policies and guidance) and are often reviewed periodically and can be revoked by the tribe.
  - Research with urban AI/ANs may involve partnership, communication, and conferring with UIOs and community leaders that often include elders and youth.
  - Researchers must be accountable to the tribal nations or AI/AN community in all phases of their research; their work will be strengthened and more meaningful with mutual respect and relationship building.

- **Public health data systems at federal, state and local governments**

  “*Transparency in public health data systems is not always available for AI/AN data.*” – AI/AN panel participant

  - Federal, state and local governments should consult with and consider the needs of AI/AN tribes in their public health data systems development and upgrades; this could include co-production of policies and procedures.
  - Public health data systems must be updated and interoperable to ensure AI/AN data can be adequately and accurately captured.
  - Public health data systems must collaborate with tribal data collection efforts and work toward integration.
  - Public health data system staff must receive education and training on AI/AN data issues, like the complexities of socio-political constructs and big data and technology.
  - Public health data systems should be aware of and work toward applying the international data principles of FAIR (findable, accessible, interoperable, reusable) and CARE (collective benefit, authority to control, responsibility, ethics), which when applied together serve to facilitate tribal data governance.
WHAT NEXT: Again, with an eye to achieving equity, the panel had several short- and long-term recommendations for investment in the infrastructure, interoperable systems and capacity across all levels to ensure accurate, reliable and consistent data across all systems to increase understanding about AI/AN populations.

- **Public health data systems**

  “First the governance mechanisms are put in place, followed by money and resources to do the work of improving data quality through equitable data systems.” – AI/AN panel participant

  - Public health data systems should include data suppression policies that are developed in consultation with tribal nations on their data needs.
  - The federal government and states should help fund efforts to better integrate public health data systems with the needs and concerns of tribal nations.
  - Uphold and enforce OMB data standards and consult with tribal nations on the long-term changes needed for AI/AN data equity.

- **Workforce development**

  “[It] begins in childhood with intergenerational knowledge sharing about how AI/AN people have always been researchers and the cultural values of such.” – AI/AN panel participant

  - There is a need for U.S. educational systems to include accurate information on AI/AN history and current issues for all students at all levels, regardless of race and ethnicity.
  - Public health data systems would benefit with additional AI/AN people in all careers that intersect with public health data systems (e.g., funeral homes, vital statistics, electronic health records, public health, research).
  - Educational partnerships between public health jurisdictions and schools of public health to build educational pathways for equity-focused individuals to access training and careers on AI/AN data needs and solutions broadly and specifically within tribal and urban AI/AN communities.
  - Education and training for public health practitioners on maximizing data capacity in existing systems such as best practices in tabulation, weighting and small area estimates in data analysis.
  - Mechanisms to build and maintain institutional knowledge and ensure transfer of knowledge over time are important for sustaining workforce capacity and ensuring standards of data practice.
● Tribal and urban AI/AN data capacity

“Tribal data infrastructure has never had the same investments as other public health departments in the U.S.” – AI/AN panel participant

- Investment in strengthening tribal data systems, urban and rural, is needed to ensure data is accurate and reflective of AI/AN community needs and centers community voice and intersectional issues.
- Acting on the trust responsibilities to AI/AN tribes, federal and state governments should invest in data efforts conducted by tribal nations to collect, manage and analyze AI/AN data.
- Tribal nations and UIOs need additional resources to develop and strengthen interoperable data systems, encompassing tribal and urban AI/AN data.
- Broadband access across tribal lands will significantly improve data capacity.
- Economic development and creation of tribal data careers in tribal communities, urban and rural, is needed to build equitable AI/AN data capacity.
- Electronic health records system improvements and coordination are needed across tribal, urban and Indian Health Service (IHS) systems.
American Indian and Alaska Native Population Expert Panel
(For additional information, please see panelist bios.)

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Overarching Convening Goal – Identifying opportunities for transforming health data systems to address data gaps, eliminate disparities, and promote health equity

Preamble. What are the guiding principles of what a modern-day, equity-oriented public health data system does?

Equity in action is social justice. An operational definition of equity in health is “the absence of systematic disparities” (Braveman & Gruskin, 2003) in health outcomes or determinants of health and health data systems. An equity-oriented public health system strives for fairness and is rooted in the “principles of distributive justice” (Braveman & Gruskin, 2003), intentionally eliminates inequities in data collection and data misrepresentation, and practices distributive justice by allocating resources to groups to level the playing field.

The perspective of race brings into focus the understanding of power as a resource and the complex, “institutionalized inequities” that are present in current health data systems (Ospina & Foldy, 2009). The Robert Wood Johnson Foundation (RWJF) Black/African American Expert Panel met three times for a total of eight hours to discuss how RWJF can transform health data systems to address data gaps, eliminate disparities, and promote health equity. At the core of these discussions was the emphasis the panel placed on the power of the community, which was the key to truly transforming health data systems. It is critical to center Black voices and to acknowledge the research capacity of the community. Community engagement should be central to all research activities, including those related to data.

This panel calls for RWJF and other key stakeholders to be held accountable for dismantling systemic barriers that impede on opportunities to adequately address data gaps, eliminate disparities, and promote health equity for Black/African American communities. Accountability begins with operating from a lens of decolonization in research, utilizing the term “structural racism” in the framing of issues related to data and health, understanding that equity is a process, and viewing data as a tool for social activism. Accountability also includes understanding how intersectionality and political, economic, and social determinants of health affect outcomes.

Definitions:

To ensure mutual understanding, we define several key terms that were highlighted during the Black/African American Expert Panel sessions.

• **Decolonizing Research** – “Decolonization creates a significant opportunity to redefine the meaning of research from and within the community. It critically examines the underlying assumptions that inform the research and challenges the widely-accepted belief that Western methods and ways of knowing are the only objective, true science.” Through decolonization, research becomes a form of empowerment (Datta, 2018).

• **Structural Racism** – “Structural Racism in the U.S. is the normalization and legitimization of an array of dynamics – historical, cultural, institutional and interpersonal – that routinely advantage whites while producing cumulative and chronic adverse outcomes for people of color. It is a system of
hierarchy and inequity, primarily characterized by white supremacy – the preferential treatment, privilege and power for white people at the expense of Black, Latino, Asian, Pacific Islander, Native American, Arab and other racially oppressed people” (Lawrence & Keleher, 2004).

- **Equity as a Process** – “Equity is more than a list of simple practical strategies; it is a lens and an ideological commitment. Equity is a process through which we ensure that policies, practices, institutional cultures, and ideologies are actively equitable” (Equity Literacy Institute).

- **Intersectionality** – A phrase coined by civil rights activist and legal scholar Kimberlé Crenshaw, meaning “the complex, cumulative way in which the effects of multiple forms of discrimination (such as racism, sexism, and classism) combine, overlap, or intersect especially in the experiences of marginalized individuals or groups” (Perlman, 2018).

- **Social Justice Activism** – Activism is “a doctrine or practice that emphasizes direct vigorous action especially in support of or opposition to one side of a controversial issue” (Merriam-Webster).

- **Social and Political Determinants of Health** – “The social determinants of health are the economic and social conditions that influence individual and group differences in health status” (Braveman & Gottlieb, 2014). The political determinants of health, as defined by author Daniel Dawes, explore the political decisions and drivers underlying the social determinants of health (Erdelack, 2020).
**Why?** Philosophy around equity, what equity means in the context of the entire objective of the transformed public health data system. We explore issues of voice, power, use of data, etc. in the context of equity. Equity should be a theme running through all projects and data systems.

**KEY TAKEAWAY:** Access to data = power; power at all levels is critical for collecting, accessing, and interpreting data to address health disparities in Blacks/African Americans.

There is a need to decolonize public health data systems

Discussion around power and data collection focused on data access, data analysis, and data interpretation. Regarding data access, in theory any citizen owns government-sponsored, publicly available data, yet the panel noted that most individuals do not have the specific skill sets needed to access public health datasets on their own. Requests can be made to obtain access to data, but access to data (e.g., to make decisions for oneself or to make decisions based on one’s position within a community [i.e., politicians, legislators]) may be influenced by the position of the person or institution asking for the information. Position and influence within the organization or community can also impact timeliness at which requests for data access are fulfilled.

Access to data may also be impacted by institution type. While there are several public datasets open for use, it is more common for academic, research, and government institutions to have the ability to access data and the knowledge and statistical software to analyze data. Due to the positioning of these institutions, academic, research, and government institutions may also be able to influence the type of data being collected. Institutional size and resources can also impact data access. Academic and community institutions with fewer resources may have more difficulty accessing data or may have more difficulty affording the personal and statistical analysis software needed to analyze the data.

Individuals and organizations with the most access to data also possess the power to determine how data are used. For example, academic and governmental institutions house data and may use the data to further organization-specific needs (e.g., research funding, distribution of resources within communities). Those with access to data have the power to interpret the data to shape the narrative about populations and population subgroups. Organizations can use data to shape narratives (positive or negative) about populations and population subgroups, often without accountability or transparency in data access and analysis. Data can be used to manipulate population subgroups (e.g., by zip code, congressional district) to change how resources are distributed (e.g., political representation, health-related resources).

Distributive justice is the fair distribution of resources. Recognizing that power is a resource, the discussion of power is essential when reviewing data collection systems and research efforts. The ability to access and analyze health data systems is an example of using power as a resource. Data determines funding allocations, services offered to communities and individuals, and ultimately tells the story of the people that it represents. Distributive justice requires those in positions of power related to data access first acknowledge the power in designing data collection tools and conducting research, analyzing data using computing programs, and knowing what data sets are available and how to access. After acknowledgment, institutions must decentralize themselves from the research narrative. Understanding
the power in the collection, use, and interpretation of data, and ultimately creating opportunities for shared power between individuals, communities (including community-based organizations), and institutions (e.g., academic institutions; local, state, and federal government), is a requirement for dismantling the established systems of inequities in health data usage.

The panel discussed the notion of decolonizing public health data systems. A decolonized view of data collection acknowledges the inherent power of institutions, but also recognizes the power of the community. There is the potential for frequent misinterpretation of data without the added context of community perspectives. The lack of specificity in geographic information in data systems and the growing threat of gentrification can mask persistent needs from within a community. Community-rooted organizations are attuned to the needs of the community through empirical evidence by being based in the area in which they serve. These organizations may lack the technical skills necessary to formally interpret data, but given the right tools and partnerships community-based organizations will be instrumental in transforming health data systems.
**What?** Focuses on the content of the data – what are we tracking (objectives, measure areas), what type of data should we be tracking, how should we handle new types of data and new volumes and varieties of data, etc.

**KEY TAKEAWAY:** Leverage existing data sources to add variables that collect data to describe nuances within Black populations.

From the beginning of the three-day conversation, the panelists emphasized the importance of nuances in the Black community. The panelists discussed that the current view of Black people in data sets is monolithic – not considering how different characteristics within the community influence data outputs and interpretations. This panel would like to see data systems acknowledge that the Black community consists of a diverse group of people, and this acknowledgment should be reflected in how data is collected and interpreted.

Panelists mentioned that there are aspects of current data collection tools that are not as applicable to the Black community as they are to others. Many data collections tools that are currently in use were not created considering Black experiences. The panelists suggested that Black community leaders and Black researchers be consulted for additional data variables or rephrasing of questions that solicit improved responses and data interpretation for Black participants. The panelists also encouraged centering other Afrocentric forms of expression as data collection tools (e.g., storytelling, using narrative to add context to quantitative data).

**Missing Variables and Data Sets**

- Heritage/Country of Origin
- Classification of income above $75k
- Gender Identification
- Social Services Data
- Qualitative Data
- Impact of Violence (Police Brutality, Domestic Terrorism)
- Improved Geographic Information (Neighborhood-specific, Rural)
- Adverse Childhood Experiences (ACEs)
- Intersectional Data Sets (Race/Poverty Status, Race/Education Level, Race/Sexual Orientation, Race/Geographic Location)

**Missing Communities**

- Black people living in U.S. Territories
- Black Immigrants
- Black people living in rural communities
- Black people who are incarcerated
- Black people living with disabilities
- Black youth
- Black seniors
**How?** Focuses on the system infrastructure including governance, legal and privacy issues, operability, coordination, data stewardship, ethics, etc.

**KEY TAKEAWAY:** The discussion on system infrastructure centered around four main topics – data connectivity, governance, data access, and data analysis and interpretation.

From the approach that health outcomes do not occur in isolation, it is vital that data systems are connected to gain a more complete understanding of data outputs. Technology to connect several different systems is a reality in today’s world. Amazon Web Services is a program that operates behind many of the platforms used daily. This program connects users’ data to produce predictive advertisement. The development of similar technology can be beneficial in the public health and social data realm. An understanding of the social determinants of health acknowledges that innumerable factors affect health. By connecting systems, scientists and citizens would have a better understanding of data output context and have more information when proposing solutions. If public health data systems work in tandem to standardize variables, it would be feasible to create a connected system that better educates decision makers.

Data literacy and data accessibility are crucial to an equity-oriented health data system. The members of this panel noted that data belongs to the community, but there is often a barrier to access. Barriers can include the lacking technology resources to access the information, a delay in receiving the information from the institutions that the community collected, and knowledge about the types of data sets available. Many public data sets are large and not user-friendly; this can be intimidating. COVID-19 has shown that it is possible to make large sets of data easily digestible for community use. The COVID-19 map by Johns Hopkins University demonstrated how institutions can create data dashboards or other platforms to translate health data that informs health decisions. It is not enough to have data sets available; to operate equitably, institutions must invest tools for accessibility and education on data literacy.

Governance is an important aspect of data system infrastructure. The panel expressed a desire for there to be an oversight committee for health information collection and usage for the Black community. Similar to Tribal Institutional Review Boards (IRBs) that were created due to historical mistrust, the Black community deserves the right to oversee research efforts concerning the community to weigh risks and benefits for the community. The creation of a Black/African American IRB is one way to combat the insidious nature of structural racism in research and give Black/African American communities agency over research.
Who and what next? Focuses the capabilities that need to be turbo charged, like workforce to make this transformed data system happen. What needs to happen now with the chance of sustainability? What might be risks to transformation?

The panelists acknowledge the rare opportunity and importance of participating in this discussion. The goal of this convening is to address data gaps, eliminate disparities, and promote health equity; the members of this group are dedicated to this goal in their everyday work. These challenges are not new and will not be changed in an instant. This group emphasizes the importance of acknowledging the historical context for present-day outcomes, as inequities are a direct result of centuries of deliberate actions against the Black community in America. These individuals are hopeful that this exercise will result in fruitful changes and that the Robert Wood Johnson Foundation will heed the recommendations below. The Black/African American expert panel is dedicated to not only naming problems but identifying solutions; it is our hope that RWJF shares the same perspective.

Specific Recommendations:

- Resources for Black research workforce development
- Research on Capacity Building
- Investing in training community health workers and leaders in data literacy
- Fund continued education for community leaders
- Increased engagement with community in all levels of research and include community leadership
- Advance qualitative data collection efforts
- Increase Data Accessibility by providing Data Dashboards and Data Glossary
- Provide Supplemental Data Sets; Invest in Black-centered data sets
- Connect Social Service Data to Health Data
- Connect data from existing large scale data systems/studies with local data to add additional context
- Require grant-funded data collection projects to include community engagement with demonstration of fair compensation for community projects

Landscape Analysis

A landscape analysis was prepared to help panelists prepare for the convening.
Sources


Black/African American Expert Panel
(For additional information, please see panelist bios.)

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Synthesis Report from the LGBTQ+ Communities Expert Panel

BACKGROUND

The LGBTQ+ Communities Expert Panel convened for eight hours over three days in April 2021, with an overarching goal to identify opportunities for transforming health data systems to address data gaps, eliminate disparities, and promote health equity. Expert panelists were jointly identified and recruited by Robert Wood Johnson Foundation (RWJF) staff (Maryam Khojasteh, Program Officer) and the panel leader. Panelists offer a valuable range of lived experiences and intersectional identities as Black, Hispanic and White; cisgender and transgender; gay, lesbian, queer, and same-gender loving people. Further, panelists are professionals with deep subject matter expertise spanning multiple sectors and systems, including education, health care, housing, juvenile justice, public health, and social services, as well as policy, advocacy, research, and practice arenas.

LGBTQ+ Expert Panel Members

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<tr>
<th>Name</th>
<th>Title and Organization</th>
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<tr>
<td>Amy Hillier</td>
<td>Associate Professor, School of Social Policy &amp; Practice, University of Pennsylvania</td>
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<tr>
<td>Aisha Canfield</td>
<td>Director, Ceres Policy Research</td>
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<td>Dustin Duncan</td>
<td>Associate Professor of Epidemiology, Columbia University</td>
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<td>Estevan Garcia</td>
<td>Chief Medical Officer, Cooley Dickinson Health Care; GLMA board member</td>
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<td>Jeremy Goldbach</td>
<td>Associate Professor, Director of the Center for LGBTQ+ Health Equity, University of Southern California</td>
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<tr>
<td>Emily Greytak</td>
<td>Emily Greytak, Director of Research, ACLU</td>
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<td>Angela Irvine-Baker</td>
<td>Founder and Principal Consultant, Ceres Policy Research</td>
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<td>David Johns</td>
<td>Executive Director, National Black Justice Coalition</td>
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<td>Mara Keisling</td>
<td>Executive Director, National Center for Transgender Equality</td>
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<td>Clinical Assistant Professor, UT-Austin School of Nursing</td>
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<td>Johanna Olson-Kennedy</td>
<td>Medical Director, The Center for Transyouth Health and Development, Children’s Hospital of Los Angeles</td>
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<td>Jonathan Rendina</td>
<td>Assistant Professor of Psychology, Hunter College</td>
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<td>Jama Shelton</td>
<td>Assistant Professor, Silberman School of Social Work, Hunter College</td>
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Panel leader Amy Hillier prepared a landscape analysis, which panelists reviewed and commented on prior to the convening. Sam Bradd, Founder and Executive Director of Drawing Change, served as our graphic recorder, creating visuals that helped synthesize and energize panel discussions. Some of his graphics are included in this report. Sarah Strunk, Strategic Advisor with Healthy Places by Design, served as panel coordinator and note taker.

Session agendas were developed with intention and facilitated organically to offer opportunities for structured and emergent thinking. Each focused on a key question and specific goals.
Panel discussions prioritized young people ages 10-26, because of their unique vulnerabilities relating to puberty, their legal dependence upon adults, and transition to economic independence and adulthood.

## RECOMMENDATIONS

### TO PROMOTE HEALTH EQUITY WITHIN MARGINALIZED POPULATIONS

Panel recommendations extend beyond data about LGBTQ+ communities, specifically, and are essential to improving the health and wellbeing of all marginalized communities. We describe these broad ideas first, then address the public health data recommendations specific to LGBTQ+ communities.

### FOCUS ON WELLNESS AND ACCOUNTABILITY OF SYSTEMS.

Efforts to mitigate health disparities focus too much attention on individual-level health outcomes. We must transform how we think about health equity before we can transform data systems intended to promote health equity, including by addressing data gaps. What health equity means and looks like should be defined by marginalized communities, themselves, not only by those with institutionalized power. This means centering the voices of members of the LGBTQ+ community who are most marginalized, including Black, Indigenous, and people of color (BIPOC LGBTQ+), people with disabilities, and people with low income. It does not mean holding stigmatized, marginalized communities responsible for fixing and overcoming the oppression they experience from harmful systems. Social justice is an essential precursor to health equity. This requires transparency in how and why data are collected (or not collected), accountability for harm done (whether directly through systems or indirectly through omission of data and attention), and a commitment to interrogating and redistributing power. Health equity means focusing attention on wellbeing broadly defined (physical, mental, spiritual, and sexual health), with the goal of ensuring all people thrive, not just eliminating health disparities. It means looking upstream and addressing root causes—white supremacy, colonialism, racism, anti-Blackness, sexism, cissexism, heterosexism, ableism—and not exclusively on surveillance of otherwise expected downstream health outcomes. It means collecting data not only from, but about education, social service/child welfare, justice, and healthcare systems to hold them accountable for providing high quality care regardless of the identities, income, ability, or geographic location of those they serve. As part of this shift, professionals must adopt new language and new ways of thinking about seemingly intractable problems.

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<th>Session #1</th>
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<tr>
<td><strong>What do we want for LGBTQ+ communities?</strong></td>
<td><strong>What data do we need?</strong></td>
<td><strong>How do we get there?</strong></td>
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<td>Goals:</td>
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<td>• Develop a sense of community and shared purpose.</td>
<td>• Use breakout sessions to focus on subpopulation needs and data gaps.</td>
<td>• Establish data priorities and implementation plan.</td>
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<td>• Push each other to dream big, think expansively.</td>
<td>• Identify strategies for addressing data gaps.</td>
<td>• Reflect on our process and implications for our own work.</td>
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<td>• Set groundwork for brainstorming and decision-making.</td>
<td>• Lay foundation for final priorities and plan.</td>
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PROMOTE A NEW DATA ETHIC.
Developing, promoting, and institutionalizing a new data ethic is essential for transforming administrative data systems, national surveillance systems, and new data collection through research studies. Federal human subject protections, interpreted and enforced by institutional review boards (IRBs), are necessary but not sufficient for eliminating disparities and promoting health equity. We call for a data ethic based on these principles:

- Promote social justice rather than social control.
- Focus on care with a commitment to not cause harm.
- The people represented in the data should be the ones to define “harm.”
- Uphold the humanity of stigmatized, marginalized communities and not focus on people as problems.
- Reflect the priorities and needs of people most impacted, as communicated by them.
- Be driven by health needs and commitment to reducing suffering and fostering wellbeing, not by mere curiosity. There should be intentionality in what data are collected.
- Incorporate language that is respectful and mirrors language communities use for themselves, recognizing that language and people’s identities/status change over time and context.
- Involve those from whom data is being collected in meaningful (not tokenizing) ways, from developing RFPs and reviewing grant proposals to designing data systems, conducting research, communicating research findings and implications, and conducting peer reviews.

ACKNOWLEDGE PAST AND ONGOING HARM AND COMMIT TO DOING BETTER.
Systems designed to ensure that people thrive, including by providing care, protection, and rehabilitation have (and continue) to harm marginalized communities. Institutions, systems, and governments should work to restore trust by acknowledging these harms. The American Psychological Association’s (APA) Feb. 2021 Resolution and Canadian Prime Minister Justin Trudeau’s 2017 apology to LGBTQ2 Canadians provide examples. Acknowledging harm is an important step, but it cannot end there. Systems must demonstrate an ongoing commitment to doing better and remaining accountable to marginalized communities.

FOCUS ON MULTIPLY MARGINALIZED COMMUNITIES.
Direct resources to data about those who hold multiple marginalized identities such as LGBTQ+/same gender loving (LGBTQ+/SGL)\(^1\) people who are BIPOC or have disabilities. The addition of SGL is important here because much of the shift we propose includes making space for the ways that stigmatized, marginalized communities talk about themselves and what they need to thrive. Minority stress theory and empirical research demonstrate how stigmatization, discrimination, and fear of rejection, among other forms of trauma, compromise physical and mental health. Within LGBTQ+/SGL communities, certain groups are particularly vulnerable, including young people and older adults, transgender, non-binary, and bi-sexual individuals, people from rural communities, and those from politically conservative states. Not only is it critical to acknowledge the increased risk faced by these multiply marginalized populations, but also to acknowledge their experiences may differ not only in degree but also in kind – as the needs, experiences, and perspectives of LGBTQ+ people will differ depending on the other identities they hold.

**LISTEN TO AND COMPENSATE THOSE IMPACTED FOR MEANINGFUL ROLES IN RESEARCH.**
Centering the voices and experiences of those impacted at all stages of data collection, analysis, dissemination, and use is essential to the transformation of data systems to promote health equity. This requires prioritizing the hiring and promotion of LGBTQ+ professionals of color. When hiring youth, time should be compensated rather than offering tokenizing opportunities to merely advise. Lived experience must be valued in the same way that we privilege educational degrees and professional credentialing when seeking to address health inequalities. This may require modifying or eliminating educational requirements and not linking salaries to educational degrees. Relevant examples include the [Whole Youth Model](#) involving LGBTQ+ youth participation in collection of data about sexual orientation and gender identity and expression (SOGIE)\(^2\), and the hiring of youth with lived experience of homelessness by the Department of Housing and Urban Development (HUD) to review proposals for Homelessness Demonstration Program. Hiring people with lived experience should not be limited to front-line positions; it must also include leadership positions. This requires investing in staff with lived experience to develop research skills, through formal education, certificate and training programs, and fellowships. Exposing more undergraduates, including those at historically Black and Latinx institutions, to research through coursework and internships will also increase the pipeline to research careers. The William T. Grant [Scholars Program](#) provides an example of investing in early-career researchers.

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\(^1\) Same gender loving is a term used by African American/Black people who are equally proud of their African heritage as they are their membership within the LGBTQ+ community. For more, see the [National Black Justice Coalition Terminology Workbook](#).

\(^2\) Our panel did not have sufficient time to carefully discuss the difference between SOGI and SOGIE (including gender expression) and whether SOGI or SOGIE data should be the focus.
COLLECT DATA ON SYSTEMS.
Government data surveillance systems generally focus “downstream” on individual health behaviors like substance use, eating, and sexual behavior, implying that poor health outcomes result from individual behavior choices rather than the failure of institutions and systems further “upstream.” This reflects the dominance of the Western and United States-based medical model of health and lack of investment in preventive public health measures in this country. Data systems should expose discrimination, not pathologize individuals. This requires data about the impact institutions, neighborhoods, communities, environments, cities, and states have on individuals. It also requires a centering of systems and system actors as the loci of analysis, in addition to – and to a greater degree – impacted individuals. This should include not only what causes harm and why, but also an assessment of what system changes are, and are not, effective in reducing harm and promoting health.

FOCUS ON WELLNESS AND THRIVING.
The focus on health disparities and negative health outcomes for marginalized communities too often means people at the mercy of systems that function as they are designed to are understood primarily through the lens of risk. Health equity must be understood from an asset based perspective, not just the absence of negative health outcomes. Data measures might focus on thriving, healing, resilience, positive change/movement, and connection to supportive adults and peers. CERES Policy Research EBP+ Collaborative provides an example of this positive reframing, focusing on concepts such as leadership, resourcefulness, healing, and connectedness. Like research on harm, this should extend beyond the impacted individual to systems to better understand the nature of systems promoting health and effectively fostering these positive aspects.

BROADEN THE CONCEPT OF WHAT COUNTS AS DATA.
Transforming data systems requires broadening ideas about what counts as valid, reliable, “good” data. Investments in data collected by NGOs/CBOs and through qualitative and participatory methods are essential. Quantitative statistical data is important but, like all data, is not without limitations. Qualitative research is also important and not without limitations; it needs to be considered as legitimate and useful as quantitative data. Better training in recognizing, using, and respecting qualitative data is needed in public health fields. Across all systems, there needs to be a greater understanding of the differences between anecdotal information and qualitative data/research.
INVEST IN NGO RESEARCH CAPACITY.
Important data collection and analysis takes place outside of academic research institutions. Investment in the research capacity of nonprofit service and advocacy organizations as well as grassroots collectives is essential to addressing data gaps and promoting health equity. Quite often those working in community-based organizations and other advocacy or organizing groups are closer to the communities than academic institutions and scholarly researchers. As such, they have a better understanding of the needs and perspectives of the communities and may be better qualified to conduct research. Foundations and government agencies should and, in many cases, do invest in these organizations and their staff through technical assistance, training, fellowships, and scholarships for college/graduate coursework. Beyond financial support, foundations, universities, and government agencies need to consider research by NGOs and community organizations (“grey literature”) as equally valid as research from academic institutions, assessing it on its merits, not its outlet. This includes citing it and considering it in policy and practice decisions. People with marginalized identities and lived experience of discrimination should have leadership roles in developing and implementing research, programs, and policy.

PROMOTE CROSS-SYSTEM DATA INTEGRATION.
Administrative data systems must support integration across agencies so we can understand the impact of involvement with/exposure to educational, social service, child welfare, justice, health, and healthcare systems. This requires reconceptualizing care across systems, not just technical interoperability. Such efforts should consider whether/how marginalized young people are experiencing hyper surveillance. Examples include the CERES Multi-System Data Analysis project, to track youth from school through the child welfare system, behavioral health agencies, and into the justice system, and efforts of Actionable Intelligence for Social Policy (AISP). This work must also be mindful of the legitimate privacy and safety concerns related to unified big data systems, including the disparate potential harm on marginalized communities.

RECOMMENDATIONS TO PROMOTE HEALTH EQUITY WITHIN LGBTQ+ COMMUNITIES
In many regards, the needs of LGBTQ+ communities will be served by attending to the needs of other stigmatized, marginalized communities including BIPOC LGBTQ+ and people with disabilities. Some of those commonalities are addressed in the first section of this report. This section focuses on the unique vulnerabilities of LGBTQ+ communities related largely to longstanding partisan political and ideological battles around LGBTQ+ rights and preclude systematic collection of SOGIE data. Our panel meetings took place the week the Arkansas General Assembly overturned the Governor’s veto and approved the nation’s first ban on gender-affirming medical treatment for transgender children under age 18. Heteronormativity, cisnormativity, homophobia, and transphobia permeate government and private data systems, limiting the collection of data essential to LGBTQ+ health equity and threatening the erasure of certain
marginalized identities. Reversing these longstanding types of oppression requires recognizing the political nature of SOGIE data and a willingness to allow LGBTQ+ people to be simultaneously seen/counted and protected.

INCLUDE SOGIE QUESTIONS WHEN OTHER IDENTITY-BASED DEMOGRAPHICS ARE INCLUDED.
Resources must be directed to integrate SOGIE data into federal surveys in ways that will yield accurate results and not impose harm. The proposed Census Equality Bill would mandate SOGIE questions, including in the U.S. Census and American Community Survey by 2030. The Youth Risk Behavior Survey (YRBS) includes questions related to sexual orientation, but the question about transgender status is not mandated for states and localities, nor has it been added to the federal YRBS; the Behavior Risk Factor Surveillance System (BRFSS) mandates questions about neither. Including SOGIE questions on federal surveys is essential to documenting the increasing number of people who identify as LGBTQ+ which, in turn, is essential to securing federal resources to serve these communities. However, survey designers, administrators and data analysts need to have the knowledge, training, and capacity to add and use SOGIE items with care and intention.

TRAIN SYSTEMS TO UNDERSTAND DATA.
Before education, justice, child welfare, social service, health and healthcare agencies collect SOGIE data, staff should receive training about and distinctions between sexual orientation, gender identity, and gender expression. Such training should underscore that ALL youth and adults have a sexual orientation, gender identity, and gender expression; SOGIE data are not relevant exclusively for LGBTQ+ communities. Staff should be encouraged to have open-ended conversations with clients about their SOGIE as often as possible to incorporate the complexity of identities, including across race and ethnicity. Staff must also understand the fluid nature of SOGIE and be prepared to revisit these conversations with clients. Examples include training materials developed by the U.S. Department of Housing and Urban Development (HUD) to implement the Equal Access Rule and publications by the Human Rights Campaign and Fenway Institute about SOGIE data collection. In addition to training, those developing and implementing administrative data systems—including private software vendors—need incentives to adopt SOGIE data standards and integrate SOGIE data with care and intention. SOGIE data integration is beginning across justice, youth care, child welfare, and public health systems.

DEVELOP AND TEST NEW SCALES AND MEASURES.
Existing scales and measures often reflect a white, cisgender, heterosexual norm and treat everyone else as “other.” Resources should be directed to develop and test new and refined measures with LGBTQ+ populations. Specifically, testing should focus on real world settings and cognitive interviewing. This should include creating and testing measures of LGBTQ+ young people’s perception of clinical measures such as anxiety and depression. In addition, language used to collect data about sexual activity needs to be “queered” to make room for asexual identities and non-penetrative sex.
PROTECT PRIVACY AND SAFETY. While in the 2020 *Bostock v. Clayton* case the Supreme Court ruled that federal employment protections on the basis of sex extend to sexual orientation and gender, it is still legal and common practice to fire people on the basis of their LGBTQ+ identities in much of the United States. Passage of the national Equality Bill and promotion of local policies that prohibit discrimination on the basis of SOGIE are essential before SOGIE data collection in administrative data systems can be mandated. Agencies must develop policies that prioritize data confidentiality and intentionality. The Ceres Whole Youth Model report (page 18) includes a model policy to ensure safe and beneficial use of SOGIE data.

CONCLUSION

LGBTQ+ communities experience a wide range of health disparities. LGBTQ+/SGL people with intersectional stigmatized and minoritized identities experience health disparities disproportionately. The most common health disparities include HIV, hepatitis, mental health challenges (including anxiety, depression, suicidality, and disordered eating), kidney and urinary tract problems, certain cancers, and heart disease. COVID-19 revealed and exacerbated existing health disparities. Many LGBTQ+ youth who quarantined with unsupportive family have suffered from isolation, threatening their mental health and social development. Depression, anxiety, and suicidality all increase, and general wellbeing decreases, in the absence of affirming social connections. Unemployment, economic precarity, and housing instability already have a disproportionate negative impact on LGBTQ+ communities that is being intensified by COVID-19. LGBTQ+ communities are more likely to be living in poverty and lack access to medical care and paid leave, further contributing to their economic and health vulnerability during the pandemic. LGBTQ+ populations may be less likely to seek medical care, testing, and vaccination because of previous negative healthcare experiences.

It is difficult to fully quantify these potential disparities, as accurate counts of the LGBTQ+ population simply do not exist. Membership in these communities is largely based on individual, invisible identities, so only people who feel comfortable and safe identifying with them can be counted. Ideologically and politically motivated efforts to deny and stigmatize LGBTQ+ identities create hostile environments for LGBTQ+ communities and suppress self-identification. Furthermore, sexual and gender identities can be fluid, and people engaging in same gender-loving sexual or gender non-conforming behaviors do not necessarily identify with current LGBTQ+ labels. Population counts are further jeopardized by the political nature of government-led surveys like the U.S. Census and American Community Survey, making it difficult to incorporate and standardize questions about sexual orientation and gender identity. As a result, counts of LGBTQ+ communities are significantly underestimated. This must change if we are to address health disparities and inequities.
People with Disabilities Expert Panel Report

This report presents distilled recommendations based on a convening of panelists with expertise in public health and people with disabilities. This convening adds insight into the ways people with disabilities are represented in public health data systems and the gaps in those data systems. In addition to being experts in this field, the panel leader, panel co-facilitator, and eleven panelists each have lived experience with disability. This report is organized around five key questions: why, what, who, how, and what next.

WHY: In order to transform disability data systems using a health equity lens, the public health sector should promote a paradigm shift and narrative change in the ways disability populations are currently perceived, understood, and analyzed.

The public health sector predominantly frames people with disabilities as a source for medical intervention, treatment, and prevention rather than as part of their own minority population that experiences health disparities. Disability is commonly perceived as a diagnostic functional limitation and is categorically understood as a deficit across many disability data systems. This framing within public health has contributed to a pattern of disability data collection and analysis that lacks a health equity lens for disability populations. If the field promotes a paradigm shift and corresponding narrative change to the ways disability is experienced (including across the life span), people with disabilities can be seen as being a minority population and also as possessing a cultural identity. With this recognition, the public health sector can shift the framing of disability from one that is medicalized to one that engages with people with disabilities as a demographic and with disability data as demographic markers. Crucially, this paradigm shift and narrative change should occur within the traditional “gatekeepers” and cornerstone public health entities, which have traditionally stewarded disability data and the ways in which disability is framed in the public health sector. Such changes are crucial because the dominant paradigm and narrative can carry implications in the ways disability is framed in policies. In this way, disability data collection and analysis through a health equity lens can be more broadly informed by areas including: social determinants of health, institutional/societal inequities and barriers to health, and evaluation/monitoring of long-term health disparities within disability populations.

Panelist comments/observations included:

- Public health must recognize that people with disabilities are a medically underserved population in addition to being a bona fide health disparities population, and this needs to be taken into consideration during public health crises to address individual-level and specific needs.
- There needs to be a paradigm shift where it is unacceptable not to consider disability along with other demographic characteristics like gender, etc.
- There needs to be a total paradigm shift because even if we have the data and there isn’t a paradigm shift, then the way the information is going to be interpreted and how it will be used
could cause further harm and further control of these populations; we need to reinform the paradigm about how people (public health professionals) even think about disability.

WHAT: Disability data collection should occur across existing national, state, and local levels of data collection sites. This would require expanding interoperability of existing surveillance systems to include disability identifier questions across all levels of data collection so that the field can better connect disability status with health as well as with social determinants of health.

Disability data are often siloed from existing surveillance systems and/or are inconsistently collected across data systems. The American Community Survey utilizes six disability questions (ACS 6), which provide a starting place to collect disability information from populations. Although these six disability questions are included in many national surveillance tools, they are not consistently present across all required surveys at national, state, and local levels, and while the six questions are adequate, they do not completely identify disability populations, for instance people with mental health disabilities. Embedding standard disability questions such as these six disability questions across other existing and federally mandated surveillance tools would improve and minimize gaps in disability data. Other examples for which data are needed to inform broader public health strategies and to better understand health disparities of disability populations include: 1) data on homeless, incarcerated, and immigrant populations and 2) the ways in which disability populations are impacted by climate crises. States also have varying consistencies in the existence of demographic information on disability populations, including types of settings people with disabilities live in (e.g., group homes, long-term care, and nursing homes), race/ethnicity, and type of disability. State-level data on disability populations are inconsistently provided and are needed to allow comparisons across state models of service delivery and state policy implementation and to support allocation of funds for disability services and programs within states.

Panelist comments/observations included:

- [We need to] work more closely to improve disability data collection within existing required national surveys by implementing the ACS 6 questions as part of regular data collection.
- There is a need for more data collections from within underserved people in the disability community, such as people of color, immigrants, people with mental health conditions, and incarcerated populations.
- State-level disability data need to be more consistent, improved, and mandated.
- When disability is not included in national existing surveillance tools, it’s impossible to leverage the same tools and instruments that look at racial inequities.

WHO: There is a need for a more universal use of disability definition across public health data systems that incorporates the understanding of disability across the life span and that includes subgroups that are historically excluded from disability framing. For example, one panel member shared that state lawmakers use different definitions of disability when developing legislation; this can have the effect of inadvertently excluding certain populations from access to services. Since
Definitions of disability influence the ways in which disability populations are categorized, reflected, and counted within public health data systems, a universal framing of a disability definition would improve the presence and consistency of disability data across public health data systems.

Disability definitions are wide ranging, and these definitions have implications in two key areas. First, the definitions determine what accommodations, services, programs, and entitlements people with disabilities can access. Likewise, some subgroups within disability populations (e.g., some immigrants or some homeless individuals) may not have consistent or high-quality access to public health systems and thus will not be counted as part of a broader disability demographic. Disability definitions are also used to provide civil rights protections to certain categories of people with disabilities in a given context and/or setting. Second, because many disability definitions are developed with embedded ableist biases, entities that inequitably apply disability definitions to collect and use data can inadvertently perpetuate stigma, and the resulting data themselves can be significantly limited in scope. In other words, if the public health sector cannot fully identify whom to count, the information in our public health data systems will be inaccurate.

Panelist comments/observations included:
- The public health sector should realize that entities apply disability definitions to facilitate service access among disability populations, and these [definitions] are premised upon certain privileges. As a result, there’s likely a large group [of people with disabilities] that do not have access or are not being counted/represented (e.g., people with mental health concerns, chronically homeless, institutionalized and carceral populations, populations that are nonverbal such as nonverbal autistic people, people with substance use disorders, and DeafBlind people).
- Stigma is an embedded bias within disability definitions. It does not recognize the fact that everyone will experience disability at some point in their lifetime or the need to represent people with disabilities at various points in their lifetime.
- A standard definition of disability would be useful and helpful. The narrowed application of disability definitions is embedded with societal biases and when implemented in policies can be limiting (in access to services, accommodations, and/or entitlement programs).
- Disability definitions are driven by the institutions that use them and the entities that are asking the questions but are not based on the terms of disability communities themselves.

HOW: Infrastructure and mechanisms need to be created to enable the accountability, enforcement, and regulatory measures to ensure consistent disability data collection across the federal and state levels.

Data on disability populations are predominantly collected and analyzed through a medicalized frame (e.g., through health insurance enrollment information, diagnostic codes, and other forms of health care interactions). However, the COVID-19 pandemic illustrated the ways in which disability public health data are inconsistent in or completely absent from data on testing, access to vaccine rollouts, access to PPE, COVID-19-related deaths, and other data that would have better informed a public health strategy.
Infrastructure to support disability data collection is absent and leaves vulnerable populations out of broader public health strategies during times of crisis. To enforce disability data collection, regulatory policies at the federal level should be established so that data collection entities and data stewardship efforts are held accountable for inclusion of disability data within existing surveillance tools at multiple levels. Data and policymaking are inextricably linked, and thus it is necessary to create disability-informed congressional committees, state-level committees, disability advisory committees within departments of public health, and other advisory boards to guide policymakers in the inclusion of disability populations in policy and regulatory development.

*Panelist comments/observations included:*

- Some states weren’t even collecting that data on disability in nursing homes and long-term care institutions, but it would be helpful for lawmakers and politicians to know how costly these programs [institutional settings] are compared to someone living in the community.
- If the infrastructure already existed for the disability community to pivot to tracking [COVID-19] outbreaks, understanding transmission, and understanding where we need to allocate and focus, then [the public health response to] disability community efforts would have happened at a rapid response rate.
- [We should advocate for] legislative levers such as regulatory mechanisms to push for disability population to be recognized as a population demographic within the public health community.
- [We should establish] task forces that could inform and advise congressional committees and at the state level among state-level policymakers or state-level advocates.

**WHAT NEXT:** Building a pipeline of public health leaders who are disability-informed and who are themselves people with disabilities is necessary for meaningful, sustainable, and lasting transformational change to disability within public health data systems.

Developing a pipeline of public health leaders who are disability-informed and who are themselves people with disabilities will foster a workforce that maintains and contributes to disability data through a health equity lens. This pipeline will strategically support the current needs and the future of disability data in the field across the sector. For instance, training data analysts who themselves are people with disabilities can expand the capacity of disabled people to be equipped with the tools necessary to use information that empowers disability community needs across advocacy and legislative priorities. Likewise, mandating required curriculum and/or accreditation that infuses disability-informed health equity content across professional health care education can prepare future health care workers to avoid perpetuating damaging stigma, including ableism within health care fields. Funders in the public health field should be intentional with their efforts to include people with disabilities at all levels of the broader public health work; this includes developing a landscape analysis of the field and reviewing requests for proposals. People with disabilities are themselves valued experts at all levels of disability data collection, stewardship, and analysis, and the public health sector should include people with disabilities at every step in the data-gathering process, including identifying priorities for research,
holding key positions within peer-reviewed journals, and advising on procedures to disseminate findings and relevant information for the community.

Panelist comments/observations included:

- Mechanism for leadership needs to be built into the highest levels of the public health sector, including NIH [National Institutes of Health], CDC [Centers for Disease Control and Prevention], NIDILRR [National Institute on Disability, Independent Living, and Rehabilitation Research], etc.
- Bring in and recruit people who have this lived experience and nuanced understanding to analyze and interpret data.
- Educate people with disabilities, and implement best practices for increasing representation in specific fields.
- Pipeline can broaden and/or improve existing mentoring programs (e.g., the American Public Health Association’s disability section).
- We need to develop a repository of experts in between medicine and disability to help bridge the gap in the education realm.
- Education in public health and training is a pressing point. We need to change the way we’re training and talking about educating people with disabilities who will become public health professionals. It does require more people with disabilities in higher ed positions and a reframing within educational settings and higher ed settings about disability, not as an outcome but through a lens of diversity, equity, and inclusion.

Landscape Analysis: Sandy Ho (panel leader) and Lisa I. Iezzoni (technical expert) prepared a landscape analysis, which panelists read prior to the convening.
People with Disabilities Expert Panel

(For additional information, please see panelist bios.)

Panel Leader

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Lurie Institute for Disability Policy

Technical Expert

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Harvard Medical School and Massachusetts General Hospital

Panel Members

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Introduction

Inequities in healthcare access, treatment, and research are widely accepted as a key factor impacting disparities in health outcomes for women (see Landscape Analysis for this panel). Social determinants of health (SDOH) such as the social constructs around race and gender, income levels, educational attainment, transportation and housing access, exposure to violence, geographic location, environmental and other factors play an important role in determining a woman’s risk for negative outcomes and disease-related morbidity and mortality. Women take on many different roles and identities that may influence their health and well-being. This panel of experts (see list of panel members on page 8) spent time examining these intersectional identities and discussing how they are connected with health and social status throughout the lifespan.

Fragmented and siloed data collection and reporting systems can make it challenging if not often impossible to identify root causes of disparities and determine the most influential ways to address them. Gaps in data also have the potential to exacerbate existing disparities. One important takeaway identified by the panelists was an overarching need across public and private systems to do a better job of collecting variables that include both biological sex and gender identity as well as race/ethnicity, so that distinct health and social issues and their intersectional impacts for women and female-identified persons (FIPs) can be identified and addressed appropriately. The panel was unanimous in the conviction that putting accurate, timely, relevant data in the hands of individuals, practitioners, policymakers and institutional leaders has enormous potential to empower women, transform care, enhance health equity and improve outcomes for all women and FIPs at both the personal and population levels. Of note, the panel discussed the differences in health inequities and disparities for women versus FIPs, leading to the recommendation that this expert panel should focus on women’s health, with associated risk factors and health journeys for those who are assigned female at birth. The panel recommends further discussion on the topic of gender identity and needs for gender nonbinary, female identified and male identified for the future in determining best practices for health data systems and outcomes. There is concern that including FIPs with women further exacerbates inequities, and further creates invisibility for the transgender population. Some health inequities related to the societal construct of women as a gender may be relevant and include FIPs, which ties back to the recommendation of appropriately and adequately collecting data with purpose. Some health inequities are tied to health risks based on biological sex (sex assigned at birth), regardless of gender identity.

While great opportunities exist, the panel also urged that special care and attention needs to be paid in these discussions to mitigating unintended consequences related to data collection and connectivity that could be counterproductive to the goal of reducing disparities. These include privacy concerns and the potential that linking social determinants of health (SDOH) data could exacerbate existing biases.
*WHAT are the major needs concerning data gaps as they relate to health equity for women and WHY are they important?*

**Major Panel Discussion Themes that Emerged**

1. *Healthcare systems that are designed to routinely collect and report a standardized and comprehensive set of essential data points, structured to allow for intersectional analysis between variables (reflecting both health and social determinants of health) will be better positioned to focus on ensuring positive outcomes for women.*

   Systems of healthcare delivery and payment are generally designed for business purposes and to ensure legitimacy of claims and not necessarily focused on health care quality or outcomes, particularly for women. For example, health records and billing data typically do not link family members with one another or provide information about social determinants of health. This approach was designed to protect privacy largely because health information such as existing conditions could impact an individual’s employability. The data may also not be linked to race and ethnicity or other key variables so that it can be routinely and easily analyzed. This current framework has a direct negative impact on care access and quality, and working within the parameters of the data and systems that exist also creates challenges and barriers to identifying causes of disparities and addressing health inequities. A new framework for data collection is needed that values women as individuals as well as for their important contributions to society.

   Improving the quality and completeness of data collected from individuals in health and social settings can transform care outcomes by equipping individuals, practitioners and institutions with necessary information to make informed screening, diagnosis and treatment decisions. For example, collecting information about a woman’s housing status has the potential to shed light on risk factors for health that may otherwise go uninvestigated, such as exposure to environmental toxins or infectious diseases that are more likely to occur in overcrowded living situations. Additionally, it is essential to collect data on gender identity, sexual orientation and race/ethnicity as these aspects of identity affect health and well-being for female and female-identified persons.

   Framing and reframing systems to focus on collecting comprehensive and standardized data upfront will also allow integration and interoperability that can provide better research and broader and deeper perspectives into women’s health issues and concerns. Standardizing not just data points, but also the methods of data collection and analysis is critical. With better data and analysis, we can enhance the quality and applicability of research, data collection, quality and data improvement and program evaluation that will guide real-world decision making at all levels ranging from individuals (such as patients and practitioners) to institutions (such as government, health insurers, and nonprofits).
2. **Datasets and systems (including government, public, and private platforms) with the capability to be linked, integrated, and interoperable will allow for a holistic view of women, and a better understanding of their overall health and social needs.**

Stand-alone data sets that do not link constructively with other sources limits needed examination of health issues and the intersections with important social determinants of health across a wide variety of groups and sub-groups. Achieving interoperability is a complicated undertaking because of the diverse array of systems that exist to accomplish varying purposes; issues of privacy as well as other statutory and regulatory barriers to data sharing introduce even more obstacles that will need to be addressed. However, the returns on time and monetary investments made in these efforts would include both better outcomes and long-term cost-savings potential.

For example, public health agencies and researchers routinely work to integrate Medicaid claims and enrollment data with birth certificate data to link pregnancy and birth outcomes to shed light on risk factors related to infant mortality, preterm birth and other negative birth outcomes. With this data linkage, maternal and infant data are paired, and mutual effects can be measured and observed. Similarly, the challenging task of integrating all-payer claims databases and birth certificates would allow for a more intersectional understanding of the role of stressors and allow for analyses across income and payer levels. Across the lifespan, other data linkages can provide important information for the health of female adolescents and reproductive-age women. For example, when data are linked across systems (health care, education, social services, housing, criminal justice, employment, etc.), a broader picture of health comes into focus and can include risks as well as supports from a range of social determinants of health. When we begin to understand these connections, we can understand individuals’ lived experiences related to the question at hand, and co-create or co-identify the most effective preventive actions and interventions for them.

Improving the ability to connect data points and track individuals across various health and social systems also has the potential to improve the physical and mental burden on women applying for and accessing health and social services by streamlining points of access to various systems. Additionally, improving system connectivity could connect women to needed services by allowing comprehensive eligibility determinations to be made more swiftly and easily, improving access to services for women who may not be aware of the full array of available benefits, thus potentially improving health outcomes as well.

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*It is noted that data should be collected in a meaningful, useful and sensitive way so as to improve outcomes and equity for persons assigned female at birth but who do not identify as women, and for female-identified persons as well.*
3. **Health data captured and linked over time and across an individual’s lifespan will improve health outcomes.**

Many factors lead to fragmented data and data gaps across a lifespan. Health insurance coverage may change over time, practitioners and the types of practitioners are different at different life stages, and interactions with different health and social systems may be intermittent. Hundreds of different types of electronic medical record (EMR) and electronic health record (EHR) systems exist, and currently, none of these systems interact in any meaningful way. Tying systems together and creating a full record and history of a woman’s health, including social and clinical conditions as well as diagnoses/procedures/services/treatments, across life stages has the potential to identify early risk factors, improve care and individualize treatment plans. Such data will also allow more valuable assessments of whether and to what extent women and men are getting the care they need versus getting equal care. A growing body of research demonstrates that women in general do not need the same care as men, so catching up with the standard of care for men may be insufficient to optimize women’s care. Similarly, health care needs vary across demographic subgroups of women, such as by age and race/ethnicity. Long-term, longitudinal data gathering and analysis of health and social status throughout a person’s life will ensure quality, comprehensive care.

For example, currently, a woman’s pregnancy record is not typically integrated into her primary care health record. This creates problems because certain conditions during pregnancy such as gestational diabetes and preeclampsia create known risks for women’s cardiovascular health after pregnancy, even in the absence of other risk factors. Knowledge of a woman’s pregnancy record and incorporating it into her history would allow for necessary surveillance and prevention efforts addressing cardiovascular and other risks in the years after pregnancy and of the rest of the life course.

4. **Individuals and organizations from health care delivery, financing (both public and private), patient and consumer advocacy, research and regulatory sectors should be involved in developing and implementing a comprehensive approach to improving data integrity and interconnectedness across the healthcare landscape.**

Making the cultural and structural changes necessary to improve health data collection and interoperability will require considerable effort, time and resources. The initiative will necessitate buy-in, agreement, and alignment among and across sectors and groups with diverse and frequently divergent priorities and viewpoints. A framework for inclusion of this broad and diverse array of stakeholder groups in the earliest stages of system design needs to be planned and implemented in order to establish common goals, maximize resources, avoid duplication of effort, and effectively mitigate barriers and pitfalls. Inclusion and representation should follow the tenets of “centering at the margins” by ensuring that those closest to the health inequities/problems are centered in discussions of how to define, measure, and solve those problems. This should include those whose identities place them at greater risk of poor health, including gender/sexual minority populations, Black, Indigenous, and people of color, people with disabilities, rural residents, and low-income people.
**How do we get there?**

*Proposed Action Items and Recommendations*

The obstacles and costs associated with construction of new systems and modification of existing systems to improve overall data quality, accessibility and connectivity are considerable. Determining how and where to begin is an important yet challenging task. This panel of experts explored the landscape of data challenges to consider top priorities as well as propose short-, medium- and long-term goals that provide a place to begin improving the data landscape to address disparities and health equity for women. The panel recognizes that more work needs to be done to promote health equity for persons who are assigned female at birth but who do not identify as women, and for female-identified persons, which is work that could be taken up separately or parallel to this work. Following are their recommendations.

**Step 1. Short Term:** There was consensus among panelists that a wide-ranging set of stakeholders, centered on those experiencing the worst health outcomes as a result of structural inequities with diverse needs and roles from various sectors will need to be integrated into the process of identifying specific data needs and then linking them to expenditure-based actions. A top priority of the panel at this beginning stage is to initiate a partnership with key stakeholder participants through the development of a National Council or advisory group, potentially at the level of the White House or integrated with the Gender Equity Council, that can provide strategic direction, authority, funding sources and organizational support for a comprehensive data infrastructure to support the health of women/FIP. A major responsibility of the National Council should include establishing and agreeing to a set of guidelines, goals, objectives, measurable outcomes, and benchmarks for success. One panelist suggested this program could be structured similarly to the Healthy People 2020 initiative.

In addition to convening the National Council, another first step and short-term effort is to develop a new framework for addressing the data gaps that affect women’s health equity. This new framework would stress and normalize the concept that women have great value both as individuals and for their role in society, but the way that health and social institutions have been structured has produced systematic discrimination that often results in inadequate care and poor outcomes. Establishment and promotion of this new framework could include a media or storytelling campaign to shed light and awareness on health disparities experienced by women and the important role of data in correcting these disparities. A campaign such as this could provide momentum, interest, and support needed to accomplish the goals and objectives established by the Council.

**Step 2. Medium Term:** With the successful initiation of the organizational structure noted in Step 1, the next step is to gather, evaluate, review, and catalog the data and data connection options surfaced by the National Council, including their identification of possible stumbling blocks and best practices.

The expert panel widely agreed that the first step as a part of this medium-term effort should include the creation and adoption of universal data elements and data standards, and an overarching data governance structure applied across disparate data systems will be instrumental to support the health
of women. An important part of this effort will be to gain input and buy-in from state agencies as well as private sector entities implementing these systems. Setting such standards is the first step in achieving data system integration and interoperability. Other medium-term efforts may include:

- Prioritization of high value data sets and data systems for conformance to the adopted standards.
- Proposed data collection structures and methods that provide the capability for intersectional and over-time analysis as well as advanced analytics.
- Identification of specific gender-based disparities and how gender discrimination interacts with other oppressions and targeted data connectivity initiatives to address them.
- Recommended tools to increase utilization such as incentives, subsidies or penalties for noncompliance.
- Assessment of funding needs and opportunities, and development of cost-benefit analyses to support funding requests.
- Development of a roadmap and timelines with milestones for implementation that includes procurement of resources and establishing authority to support system conformance.

**Step 3. Long Term:** With the formation of the needs analysis and available roadmaps for success identified through Steps 1 and 2, Step 3 can now focus on **creating and executing directed public relations and information campaigns and establishing and sustainably funding the Public-Private-Nonprofit working groups** that will operationalize the approach to women’s health data creation, storage and integration that maximizes diversity and protects privacy rights. Leveraging these partnerships, other long-term actions include:

- Addressing barriers to data sharing and interoperability through targeted legal and regulatory change.
- Application of universal data standards to targeted existing data sets as well as to new and emerging data systems.
- Implementing data sharing agreements and integration of high value data sets.
- Establishing necessary connections between data sets that support longitudinal, over-time analysis.
- Ensuring adequate, sustainable funding for data collection, management, integration, collaboration, reporting, and evaluation.
- Making integrated data accessible for a wide range of stakeholders to examine and assess women’s health care. A current example of an integrated, accessible data system, though somewhat outdated, is the CDC’s WONDER system (wonder.cdc.gov).

*WHO should be involved and what is their role?*

**Key Roles and Responsibilities**

Improving data systems to address health equity for women will require involvement across sectors and stakeholder groups, each with unique roles and responsibilities. This effort should be led and mobilized by **community-based and advocacy organizations** *(including public health and social welfare)* to ensure robust and representative perspectives and agenda-setting that is driven by the experiences of the
groups and individuals most impacted. This effort begins with a sense of community ownership that will be a foundation for development, support, and compliance initiatives.

The expert panel envisions this group will also require the expertise, input and participation from each of the following domains:

- **Federal Government and relevant agencies and offices (NIH, FDA, CDC, CMS, ONC, OMB, OWH, etc.):** Establish a national government focus and central organization point. This may also include creation of a new Administration position specific to data and women’s health equity.
- **Standards developing organizations** (for example, ONCHIT or others): Engage in an advisory process for the creation of women’s health data interchange standards. (Comparable efforts have been undertaken by ONCHIT for both pediatrics and SDOH.)
- **U.S. Congress (individual Members and staff):** Introduce and shepherd legislation and funding initiatives.
- **State and Local Health Agencies; Tribal Organizations; and Public Health Officials:** Gather data, provide regulatory oversight, implementation of funded initiatives.
- **Public Policy Organizations (i.e., NCSL, NGA, etc.):** Pilot test programs, generate ideas and identify emerging best practices that can be shared with their membership.
- **Research Community:** Design and implement models for mining and integrating large data bases. Help identify important data gaps and opportunities.
- **Public and Private Payers:** Participate in adoption of new systems, recognizing that improving data availability and access can have a net positive impact on healthcare costs by improving overall wellness and enabling early access to screening, prevention, and treatment.
- **Providers and Provider Organizations (clinician, clinic, hospital, laboratory, pharmacy, etc.):** Help identify appropriate data and link to health treatment and outcomes.
- **Private Sector Health and IT Industry (EMR, EHR, informational technology vendors, other tech companies, platform developers, etc.):** Develop and design new and emerging technologies, determining what is possible and how it can be done.
Women Expert Panel
(For additional information, please see panelist bios.)

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