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October 3, 2022

Denice Ross
U.S. Chief Data Scientist
Office of Science and Technology Policy
1650 Pennsylvania Ave. NW
Washington, DC 20504

Dear Ms. Ross:

The Infectious Diseases Society of America (IDSAs) appreciates the opportunity to provide comments to the White House Office of Science and Technology Policy in response to its Request for Information regarding equitable data engagement and accountability. IDSAs represents a community of more than 12,000 physicians, scientists, public health experts and other health professionals who specialize in infectious diseases and HIV medicine. Our members work across a variety of health care settings and are on the front lines in responding to COVID-19, monkeypox virus (MPV), antimicrobial resistance and other infectious diseases challenges. Comments and recommendations on selected questions from the RFI are found below.

Among examples of existing Federal collaborations with (a) Tribal, territorial, local, and State governments or (b) local communities involving equitable data, *what lessons or best practices have been learned from such collaborations?*

In the interest of protecting the public's health, standardized definitions are needed, especially for demographic data. Health care institutions need to collect the same information in the same categories. We also need expanded definitions, e.g., "Asian" and "Latino/a/x" are extraordinarily broad and mask inequities between and among different groups. Gender identity also needs to be collected for comparison purposes. Reporting these elements should be required so that data are complete nationally and can be used for health care and public health decision making.

COVID-19 and Monkeypox Virus

Both the COVID-19 pandemic and the current MPV outbreak demonstrate the need for equitable data and utility of collaborations across levels of government. Inequitable impacts of disease, and in the case of COVID, hospitalizations and deaths, have been documented through access to equitable data. During the COVID pandemic, access to health care data by local, state and federal governments increased due to required reporting of COVID cases. Timely access to data provides health care facilities, local communities and governments with the ability to plan and respond to public health emergencies with greater effectiveness and speed. Hospitals need data to conduct surge planning and adjust staffing and other resources based on expected patient volume. Local and state public health departments need access to timely data to identify outbreak trends and determine appropriate prevention and mitigation measures to keep communities safe. More granular data is

important to illustrate how an outbreak impacts subgroups, including disproportionate impacts based upon race, ethnicity, age, geography, gender, sexual orientation and socioeconomic status. It is crucial to uncover disparities early and track them closely in order to inform equitable responses and target resources (such as limited quantities of therapeutics) to communities with the greatest need and highest risk. Access to equitable health data is facilitated by the continuation of the requirement for hospitals to maintain COVID-19 and seasonal influenza reporting and electronic reporting of information on acute respiratory illness in any future public health emergency by reporting to the Centers for Disease Control and Prevention (CDC) National Health Safety Network (NHSN), or other appropriate CDC-supported surveillance system, as determined by the Health and Human Services Secretary.

Antibiotic Resistance

IDSA has long been a leader in combating the worldwide spread of antibiotic resistance (AR) and supports clinicians treating patients with resistant infections, leading antibiotic stewardship and infection prevention and control programs and conducting research into new treatments and methods of preventing AR. Each year, more than 35,000 people die because of antibiotic-resistant infections, with more than 2.8 million infections occurring in the United States, according to CDC's [Antibiotic Resistance Threats Report](#). Last year, CDC and experts at the University of Utah School of Medicine [released estimates](#) that treating six of the top AR threats identified by CDC contribute to more than \$4.6 billion in health care costs annually. [Initial data](#) indicate the existence of health disparities related to AR. For example, community-associated ESBL-Enterobacterales have higher incidence rates in certain geographic areas with lower median incomes and limited English proficiency; community-associated MRSA rates are higher among Black communities; and candidemia rates are nearly twice as high among Black individuals. AR complicates care and worsens outcomes for a wide range of health care conditions in which disparities exist, further exacerbating health inequities.

CDC is addressing AR health equity through the following goals:

- More systematically expanding the collection of disparities- and equity-focused data across multiple surveillance and data collection efforts to improve antibiotic use (AU) and reduce AR in disproportionately affected populations.
- Continuing to characterize health inequities related to key bacterial pathogens across incidence, infection outcome and antibiotic resistance at a geospatial level, linking inequities to social determinants of health indicators.
- Supporting infection control and patient safety efforts, including support to states to address health disparities related to AR pathogens and antibiotic use.
- Addressing educational needs that impact diverse frontline health care workers' ability to protect themselves and their patients from infections.
- Focusing on strategies to address disparities in quality of care in long-term care.

IDSA applauds these goals and calls on the federal government to continue pursuing additional research and data on AR in order to understand differences in risk and strategies to combat AR in different communities. It is critical to provide CDC with additional funding to support this work and to build the infrastructure in health care facilities necessary to support the collection and reporting of data.

What resources, programs, training, or other tools can facilitate increased data sharing between different levels of government (Tribal, territorial, local, State, or Federal) related to equitable data?

Public health emergencies such as COVID-19 and MPV have shone a spotlight on the lack of equitable health data. The [New York Times](#) recently published an article that addressed the lack of transparency of health data and lack of information on COVID-19 broken down by demographic groups. The article reported that race/ethnicity data were missing in about a third of COVID case reports collected by the federal government because of a lack of infrastructure and workforce in health departments to collect demographic data and fill in gaps after surges of COVID cases. Additionally, public health departments still have very little data on inequities surrounding uptake of therapeutics, particularly oral antivirals, despite the fact that the federal government has been directly managing their allocation and distribution. Sustainable public health infrastructure would allow the collection and interoperable exchange of equitable data by public health professionals and health care providers. This would help inform decisions about where to focus scarce resources and how to implement community outreach and health care services to slow the spread of disease and associated human and economic impacts. This has real world consequences as the United States still experiences 400-500 deaths a day from COVID-19, and more than 24,000 people have been infected in the current MPV outbreak in the U.S., with MPV disproportionately impacting minorities, notably African American and Hispanic/Latino communities.

An influx of funding is needed to sustain the public health infrastructure needed to seamlessly share equitable health data in the 21st century. Congress has already provided nearly \$1 billion to date for the CDC's Data Modernization Initiative (DMI). The DMI – which began before the COVID-19 pandemic – is a commitment to build the world-class data infrastructure and workforce that are ready for the next public health emergency. Robust, sustained, annual funding would ensure we can build and maintain modern public health systems and infrastructure, including at state, territorial, local and tribal health departments. The need for investment in modern public health data systems that keep pace with evolving technology is far greater than existing resources will support and will require a sustained federal investment, including more than \$7.84 billion over the next five years. The DMI is creating a standards-based interoperable public health infrastructure, ensuring all systems can communicate and share data seamlessly with one another; advancing standards so that information can be stored and shared across systems; and facilitating complete and timely reporting so that our public health system has essential data on race, ethnicity, treatments and comorbidities that are critical for achieving equity in public health response.

Similarly, funding is needed to support the health care infrastructure and workforce necessary to collect and report data and to partner with public health. The CDC NHSN supports health care facilities (including hospitals and long-term care facilities) in the collection and reporting of data on health care associated infections, antibiotic resistance and antibiotic use. During the COVID-19 pandemic, NHSN has expanded to more than 37,000 health care facilities providing data and strengthening surveillance efforts. Additional resources are needed for NHSN to sustain these efforts and expand to additional facilities.

What resources, programs, training, or other tools can expand opportunities for historically underrepresented scholars and research institutions to access and use equitable data across levels of government?

In order to expand opportunities to access and use equitable data, research institutions need to hold diversity, equity, inclusion and access (DEIA) as central tenets, especially when working with underrepresented populations and communities. Mistrust of research in underrepresented populations stems from failures in transparent communication by researchers and investigators as well as historical examples of experimentation on marginalized groups. When communities engaged in research such as clinical trials are not engaged as partners, it creates mistrust and limits the impact of these studies. Mistrust can also dissuade students in underrepresented communities from pursuing careers in research. In order to develop a base of trust, non-interrupted education and partnership with communities is needed to be built over time, not only when they are engaged in research activities.

The federal government should fund research that fills patient- and stakeholder-prioritized evidence gaps and is representative of diverse patient populations and settings. Additional recommendations for research are found below.

- In funding clinical trials, incentivize research that prioritizes including diverse participants from a variety of ethnic, racial, gender identity and age backgrounds to improve representation in clinical research. African American/Black, Latinx and Indigenous populations and adults aged 75 and older often have incredibly low participation in clinical trials, which contributes to health inequities. Additionally, increase inclusion of vulnerable groups, such as pregnant and immunocompromised patients, in clinical research trials when possible.
- Study the effectiveness of recruitment strategies for clinical trial volunteers, and factors that may prevent these strategies from reaching underrepresented populations.
- Support clinical trial research that actively fosters community engagement in underrepresented populations in clinical research trials. Further support should be directed to studies evaluating the impact of community-based and nontraditional clinical trial sites compared to traditional urban academic health centers on community and participant engagement.
- Evaluate the impact of engaging community clinicians and frontline physicians in clinical trial research and development, particularly clinicians and researchers who are a part of the community being studied or who have lived experience of the health issue. Frontline physicians and other community clinicians can offer insight to trial planning and should be reimbursed for their time and expertise. As active members and trusted figures in trial site communities, these individuals help build transparency and public trust. Additionally, they help expand potential trial participant pools, which can improve trial diversity. Further, studies have shown that involving clinical researchers can ease the translation of research results into clinical care.
- Include international sites where feasible in funded research trials to increase generalizability of findings globally.
- Proactively fund and develop infrastructure that supports research on emerging infectious disease threats.

What resources, programs, training, or tools can make equitable data more accessible and useable for members of the public?

Agencies within the Department of Health and Human Services conduct a tremendous amount of research. Communications tailored toward the public to explain this research and equitable data generated by research are essential to help people without a health care or public health background understand how equitable data can inform decisions about their health and health care. Communication strategies should study different communication methods and modalities and consider approaches that

have been shown to be best suited to different population groups, especially groups that have historically experienced discrimination and stigma and who have been heavily impacted by health inequities, including people of color, sexual and gender minorities and people with HIV.

The federal government should research the effectiveness of novel strategies to engage the public and target audiences beyond academia in the dissemination of scientific findings and public health recommendations, including digital and social media strategies, live participatory “short talk” events and community outreach initiatives. Research is also needed to study the impact of misinformation on trust in scientific research, specifically focusing on key populations most likely to fall prey to misinformation, the effect of misinformation on willingness to cooperate with scientists and clinicians and the effect of novel strategies in combating misinformation surrounding scientific research.

Thank you for the opportunity to provide comments on equitable data engagement and accountability. If you have questions about these comments, please contact Amanda Jezek, IDSA senior vice president, public policy and government relations, at ajezek@idsociety.org.

Sincerely,

A handwritten signature in black ink, appearing to read 'D. McQuillen', with a stylized flourish at the end.

Daniel P. McQuillen, MD, FIDSA
President