October 3, 2022

NSTC Subcommittee on Equitable Data
Office of Science and Technology Policy
Eisenhower Executive Office Building
1650 Pennsylvania Ave. NW
Washington, DC 20504

RE: OSTP Engagement and Accountability RFI

Dear Ms. Ross,

The American Psychological Association (APA) appreciates the opportunity to comment on the Office of Science and Technology Policy (OSTP), Subcommittee on Equitable Data of the National Science and Technology Council request for information. This request represents a step in the right direction towards ensuring that stakeholders across disciplines are represented in future efforts to collect, use, and distribute equitable data.

APA is the largest scientific and professional organization representing psychology in the U.S., numbering over 133,000 researchers, educators, clinicians, consultants, and students. For decades, psychologists have played a vital role in the development and use of equitable data. These contributions have been essential to the current standards of data collection. We offer the following comments in response to the RFI to ensure future policy changes to data collection, storage, and use is equitable and representative of underserved communities.

**Data Collection Practices**

Data is foundational to achieving any population-based behavioral health or health equity goal imaginable, as well as ensuring civil rights compliance by covered entities. Better national standards and uniform data collection practices could have an outsized impact on efforts to narrow health disparities. Yet complete data collection remains largely unavailable for many populations at greater risk of discrimination in healthcare settings and insurance coverage. Cross-agency data-sharing, analysis and reporting is essential to ensure adequate representation of underserved communities. Information sharing can aid efforts to better understand the nexus between social determinants of health, civil rights compliance, and health equity.

We recognize the important role demographic data plays in addressing discrimination and health disparities. At minimum, future policies rule should require disaggregated race, ethnicity, and disability data collection and reporting. The collecting agency or entity should consult with these groups on effective strategies for ensuring the availability and dissemination of data that is crucially needed to protect civil rights and achieve health equity. One important example is the gaps in data that exist for Asian American and Pacific Islander and Native American communities, partially due to historical aggregation of unique groups into larger umbrella terms that fail to properly represent their diversity. Similarly, people of Middle Eastern and North African descent are largely left out from federal data sets.
Improve Data Availability

Barriers to data exist across society, including within government. The ability for researchers, policymakers, and the public to access relevant and useful information is often hindered by a lack of transparency or availability. Communities are often unaware of what data government collects and possesses. This hinders research and informed policymaking, including by individuals seeking to highlight data inequities or disparities across underserved populations. Transparency around data collection, increasing availability and uniformity would help to ease the burden on researchers and allow for more information to be gleaned from data currently collected.

In addition, data, especially that collected by government, should be made available to the extent possible to enable its use by outside entities. Increased availability of disaggregated, anonymized data is essential to enabling more research into underserved communities. The government should work to centralize and publicize current data resources.

APA has joined other likeminded organizations in signing onto the Transparency and Openness Promotion (TOP) Guidelines, a set of standards aimed at making research data and processes more open by default. The TOP guidelines offer several recommendations on open research data and availability that would assist government in improving data access.

Improve Planning and Cross-Agency Collaboration.

Agencies should continue to strengthen coordination with state and local public authorities to collect, disaggregate and report data as it relates to the hardest-hit populations, to address current disparities more effectively. This includes authorizing grants to state, local and territorial governments to support the modernization of data collection methods and infrastructure and disseminating that data to all relevant stakeholders. Information will guide the actions federal agencies can implement to address social determinants of health leading to poorer health outcomes among certain populations. To promote synergies within federal agencies as it relates to the health of our population, APA recommends the following steps: 1) integrate more behavioral analysis into national response efforts, including consideration of findings from the Behavioral Risk Factor Surveillance Survey, the Youth Risk Behavior Survey and other population-based survey findings, and 2) foster collaboration with health equity offices across government, along with federal agencies responsible for safety net programs, to mitigate underlying social determinants of health responsible health inequities and improve population health.

The Role of Technology

Address the unique role of technology and barriers to using technology. Many populations have unique issues. For example, older adults can use and benefit from technology. Some older adults may be unfamiliar with the technology and/or have functional or physical impairments that may require more training and support in the use of technology. The variation in tech platforms and uses across institutions is a barrier because consumers have to learn different systems and processes. Standardizing platforms as much as possible will reduce this barrier. ¹, ²

Increase Outreach to Underserved Populations

For the government to truly collect more comprehensive and impactful data on underserved populations, it must seek to meet these communities where they are. Data collection methods should be created with the input of members of target populations to ensure effectiveness of language and collection methods. More effort must be made during the development stage to avoid harm. Research efforts designed at the federal level must translate easily and clearly to data collection efforts at the local level. This will help to increase the likelihood that data collection efforts are successful and equitable goals designed at the federal level are achieved when collecting data at the local level. Also, members of target communities should be employed to aid in the data collection process. Underserved populations may harbor resistance to data collection attempts from outsiders. Seeking to collect this data using members of the target community not only helps to increase effectiveness of collection, but also serves to provide the community with employment and engagement opportunities.

Data and Social Determinants of Health

Improved data collection and research on social determinants of health (SDOH) are two ways of improving alignment across federal agencies to address SDOH in policy and programs. The collection of data relating to SDOH should be consistent across all systems so that all providers, payers, and other stakeholders are collecting and reporting the same types of SDOH data. Another example is improving alignment among federal programs such as Medicaid, CHIP, SNAP, WIC, etc. to effectively address SDOH in a holistic way is measurement and documentation. Measuring SDOH has numerous barriers, including philosophical beliefs on the part of providers that it is not their place to be asking such questions, training barriers in not knowing how or what to ask patients, and practical barriers with challenges in identifying community-based interventions to address SDOH and ensuring patients receive these services once identified. If all third-party payers (Medicare, Medicaid, private insurers, etc.) required the same data to be collected, it would greatly increase provider participation and ease documentation burdens that currently exist. However, without actively addressing the aforementioned barriers to implementation, any efforts are unlikely to be fully successful. These steps, along with greater interoperability across electronic health data systems, would contribute greatly toward helping to align health services with community-based services addressing patients' health and social needs.

APA again thanks you for the opportunity to comment on this policy. If APA can be of any further assistance, please contact Corbin Evans, Senior Director of Congressional and Federal Relations, at CEvans@APA.org.

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