

June 21, 2021

Shalanda Young
Acting Director
Office of Management and Budget
725 17th Street, NW
Washington, DC 20503

RE: Methods and Leading Practices for Advancing Equity and Support for Underserved Communities Through Government [OMB-2021-0005]

Dear Acting Director Young:

Thank you for the opportunity to respond to the Office of Management and Budget's (OMB) request for information (RFI) entitled "[Methods and Leading Practices for Advancing Equity and Support for Underserved Communities Through Government.](#)"

AHIMA is a global nonprofit association of health information (HI) professionals. AHIMA represents professionals who work with the health data from more than one billion patient visits each year. AHIMA's mission of empowering people to impact health drives our members and credentialed HI professionals to ensure that health information is accurate, complete, and available to patients and providers. Our leaders work at the intersection of healthcare, technology, and business, and are found in data integrity and information privacy job functions worldwide.

AHIMA appreciates OMB's attention to the urgent need to ensure that agency policies and actions equitably serve all eligible individuals and communities, particularly those that are currently and historically underserved by our healthcare system. AHIMA supports the use of public policy to reduce and eliminate health disparities and inequities, both in the face of the ongoing pandemic and in healthcare more generally. The underlying causes of health disparities are complex and involve social determinants of health (SDoH), racism and discrimination, economic and educational disadvantages, differential access to high-quality care, individual behavior, and biology.¹

Today, communities including racial and ethnic minorities, sexual and gender minorities, individuals with disabilities and those living in rural areas experience a share of acute or chronic diseases and adverse health outcomes disproportionate to their non-minority counterparts. This disproportionality is reflective of the health inequities that exist in our healthcare system today.

Equity Assessments and Strategies

How might agencies collect data and build evidence in appropriate and protected ways to reflect underserved individuals and communities and support greater attention to equity in future policymaking?

¹ Hooper, Monica Webb. "COVID-19 and Racial/Ethnic Disparities." JAMA, JAMA Network, 23 June 2020, jamanetwork.com/journals/jama/fullarticle/2766098.

Health information professionals have the knowledge and expertise to inform ongoing public policy discussions to promote health equity. To meet the needs of diverse populations and reduce and eliminate health disparities and inequities, AHIMA believes that public policy must encourage the standardized and consistent collection of accurate and complete patient demographic and SDOH data. Data collection must be done in ways that are culturally appropriate and community competent to better understand the community being served and related needs. This includes supplementing demographic information with more granular collection of data regarding race, ethnicity, sexual orientation, gender identity, and intersex status using standardized categories to enable individuals to self-identify and increase the utility of the data for the entities collecting them.

To understand the status of historically underserved communities, AHIMA believes that policymakers need accurate and representative population-level data that describe populations in all their complexity. There are currently numerous issues impacting federal healthcare programs related to incomplete and inaccurate data. These issues are compounded by many factors including a lack of standardized processes for collection of patient demographic data and social determinants, technologic limitations including the inability of certain platforms to accurately capture demographic information, lack of understanding by staff as to why patient demographic data are collected, and lack of trust due to history of mistreatment of disenfranchised minority populations.

AHIMA members have noted specific problems pertaining to data relating to sexual orientation and gender identity, for which data are often not collected consistently or completely. It is also noteworthy that population-level data for certain groups, such as people with intersex traits, do not exist.² AHIMA notes that recommendations to address problems associated with the collection of sexual orientation and gender identity data have been recently issued by the National Academy of Sciences (NAS). In a consensus study report, the NAS recommended that “entities throughout the federal statistical system; other federal agencies; state, local, and tribal departments and agencies; private entities; and other relevant stakeholders should consider adding measures of sexual orientation, gender identity, and intersex status to all data collection efforts and instruments, such as population-based surveys, administrative records, clinical records, and forms used to collect demographic data.”³

When implementing this recommendation, the NAS recommended that OMB should reconvene the Federal Interagency Working Group on Improving Measurement of Sexual Orientation and Gender Identity in Federal Surveys and charge it with developing government-wide standards for the collection of data on sexual orientation, gender identity, and intersex status. AHIMA concurs with this recommendation and agrees that the establishment of measurement standards for sexual orientation, gender identity, and intersex status could bolster consistent and standardized data collection activities in government and nongovernment health entities. These data can be used to identify disparities and evaluate efforts to address them at both the population and individual level.

How can agencies best balance collecting demographic information about program applicants and participants with the potential effect on program participation that these questions may cause?

As noted above, lack of trust due to history of mistreatment of disenfranchised minority populations is a substantial barrier to accurate and complete data collection. AHIMA believes that data collectors, and in

² "13 Recommendations." National Academies of Sciences, Engineering, and Medicine. 2020. Understanding the Well-Being of LGBTQI+ Populations. Washington, DC: The National Academies Press. doi: 10.17226/25877.x

³ Id.

particular healthcare providers, must work to build trust among historically marginalized communities. Policy must encourage providers to be transparent and communicate clearly about the purposes for which data is being collected and used, while raising awareness of how different populations may participate in this process. Additionally, trust can be built by identifying and supporting efforts to overcome historical mistrust in healthcare institutions. This includes encouraging strong patient-provider relationships, creating opportunities for community leaders to be consulted in decision-making processes, identifying and dismantling policies that support structural racism and discrimination, and fostering a commitment to improving the experiences of marginalized communities.

To ensure that collection of data does not detrimentally impact program participation, AHIMA also believes that federal agencies must promote the ethical collection and use of SDoH and demographic data. It is possible that data used within the context of biased algorithms and programs may lead to discrimination, stigmatization, and implicit bias. Policy must safeguard against the perpetuation or aggravation of such occurrences. AHIMA supports efforts to ensure “equity by design” in federal programs.

Thank you for the opportunity to provide comments in response to this RFI. Should you or your staff have any additional questions or comments, please contact Lauren Riplinger, Vice President, Policy & Government Affairs, at lauren.riplinger@ahima.org and (202) 839-1218 or Matt Kerschner, Director of Regulatory Affairs at matthew.kerschner@ahima.org and (312)-233-1122.

Sincerely,

A handwritten signature in cursive script that reads "Wylecia Wiggs Harris".

Wylecia Wiggs Harris, PhD, CAE
Chief Executive Officer