



June 10, 2024

Dr. Micky Tripathi
National Coordinator
Office of the National Coordinator for Health Information Technology
330 C Street NW
Floor 7, Mary E. Switzer Building
Washington, DC 20201

Submitted electronically to inquiry.healthit.gov

RE: Advancing Health Equity by Design and Health Information Technology: Proposed Approach, Invitation for Public Input, and Call to Action

Dear Dr. Tripathi:

The Health IT End-Users Alliance (the Alliance) appreciates the opportunity to provide the Office of the National Coordinator for Health IT (ONC) with feedback on the [Advancing Health Equity by Design and Health Information Technology: Proposed Approach, Invitation for Public Input, and Call to Action](#) white paper, as published on ONC's website on April 5, 2024.

The Alliance brings together health information professionals, physicians, hospitals, and other front-line health care providers and organizations that use health IT in the provision of care to ensure that policy and standards development activities reflect the complex web of clinical and operational challenges facing those who use technology tools for care. By working collaboratively across settings of care, the Alliance is focused on priorities for how technology can best support clinical care and operations.

The Alliance appreciates ONC's commitment to prioritizing health equity as a throughline in the design, build, and implementation of health IT policies, programs, and workflows. We share ONC's vision of Health Equity by Design (HEBD) designing and building for the diversity of uses and end-users, including using health IT to leverage health data into action by identifying and reducing disparities. The Alliance strongly agrees with ONC that HEBD cannot be limited to part of the health care ecosystem – it must be incorporated into every facet of health care for true health equity to be achieved. We see end-users playing a role in all components of HEBD and have identified areas of opportunity for collaboration below.

Priorities for Health Equity by Design

Data Collection and Use to Operationalize Health Equity

Achieving equity in health and health care is a shared priority for health care end-users that includes the collection of needed data to identify disparities and work towards improving care delivery for better patient outcomes. The Alliance strongly encourages ONC to consider how the standardization, collection, and reporting of data, particularly social drivers of health (SDOH) data, can best be leveraged within its HEBD approach. Collecting SDOH data in a way that is culturally appropriate, favors self-reporting, and

aligns with individual preferences requires specific skills, and connecting individuals with appropriate services to address SDOH needs requires significant effort. [We believe](#) federal support will be required to create and test standardized and validated data elements and data collection tools, and we encourage ONC to work with CMS, end-users, and other health care stakeholders in the development of these tools.

The Alliance appreciates ONC's recently published draft [2024-2030 Federal Health IT Strategic Plan](#) (the draft Plan) containing objectives related to advancing the collection and use of standardized SDOH data; ensuring data collection involves appropriate consent for and understanding of secure sharing and use of this information; and encouraging equity, safety, and user-centered design principles in the development and use of health IT. While flexibility in screening tools and processes can allow end-users to best collect these data within existing workflows and environments, the lack of standard approaches can lead to inconsistent data classifications and collection, struggles to track progress over time, and the inability to share this data across organizations and care settings to efficiently coordinate care.

The Alliance acknowledges there can be great uncertainty for end-users in terms of operationalizing health equity throughout health IT systems, including how the technology that powers those systems supports (or hinders) that process. Health IT tools cannot be fully evaluated in isolation; they must be considered in the context of a health care facility's operations and clinical workflow and their ability to deliver in that environment. We believe ONC's vision for HEBD should emphasize the importance of developing the necessary technology supports and operations from the outset, because those health IT tools and operations can then find and collect health equity data, which will help create more understanding of health equity within an end-user's organization.

As ONC identifies areas to expand its work in HEBD, the Alliance encourages the inclusion of the Office of Management and Budget's (OMB) Directive No. 15: Standards for Maintain, Collection, and Presenting Federal Data on Race and Ethnicity¹ in future workplans. Directive No. 15 combines the collection of race and ethnicity information into one question on the census and other federal forms. This change implemented by OMB creates a technical need for end-users as how and where they collect this data will now shift. As we discussed above, we encourage ONC to identify standardized approaches with the inclusion of end-user feedback while developing HEBD compliance materials.

Improved collection and use of relevant demographic and social factor data to identify and guide efforts to address disparities can positively impact health care delivery and operations. Collecting duplicative data or reporting it to government programs without realistic opportunities to connect the data to care improvements only increases burden and may be seen by patients as overly intrusive. The Alliance's [Data to Support Equity Consensus Statement](#) references several principles to guide efforts to ensure the collection of this data prioritizes health equity, is used optimally and appropriately, is actionable, and remains purpose-driven:

- Prioritize continued development of standardized and validated SDOH data elements to be collected in a consistent, comparable fashion for priority domains.
- Align selected domains across federal and state health care programs and reporting requirements, and by commercial health plans.
- Develop consensus on validated instruments to be used for data collection.
- Recognize the shared obligation across providers, public programs, payers, and community-based organizations to collect and appropriately share SDOH data, with appropriate compensation for data collection and management of health-related social needs, as well as ensuring the availability of data for providers to support clinical and social care delivery.

¹Available at: <https://www.govinfo.gov/content/pkg/FR-2024-03-29/pdf/2024-06469.pdf>.

- Keep the primary focus on collecting demographic and SDOH data to meet patient needs.
- Support patient privacy through the adoption of comprehensive data privacy practices for all health care stakeholders.
- Federal, state, and local governments and health plans should actively provide funding, technical resources, and infrastructure to support training, implementation, and care coordination.
- Continue and expand research to improve SDOH data collection to optimize improved equity, including appropriate use of demographic and SDOH data in artificial intelligence tools to ensure disparities are identified and addressed alongside mitigating bias and harm.

Artificial Intelligence

When examining the many opportunities for incorporating HEBD into the health care ecosystem, the Alliance recommends **ONC specifically consider the role of artificial intelligence (AI) tools within health IT**. Research has shown that using AI can increase the accuracy of imaging studies, improve the safety of some medical devices, support clinical diagnosis, and optimize the scheduling of operating rooms. However, those who design these tools are generally not the people using them to provide care, which can lead to serious gaps in the design and intent of these tools compared to their implementation and impact. These design gaps can unintentionally exacerbate disparities and perpetuate inequities within health care. We [support](#) federal standards and guidelines that incorporate both risk management approaches and transparency measures to support safe, equitable, and appropriate use of AI tools in health care.

Real-World Testing

Over the past decade, end-users have found that new technical approaches to gathering and sharing health information—that are then included in regulatory requirements—are not sufficiently grounded in real-world experiences and do not adequately consider the implementation pathway for health care. This includes issues such as how new approaches work within existing infrastructure, engaging with and educating patients on their role in utilizing the technology, and how new tools and requirements will fit into the array of regulatory requirements that health IT end-users face. The Alliance’s [Real-world Testing Consensus Statement](#) references several principles that support **ONC’s HEBD goals**, as **real-world testing of standards prior to mandated adoption** would allow for more comprehensive, equitable standards to be designed, built, and implemented:

- Real-world testing should inform and investigate whether the standard (or health IT policy) will encompass a complete solution to achieve the desired goal, respect and accommodate the privacy needs of patients, or disparately impact clinicians who care for underserved or marginalized communities.
- Health IT end-user engagement should be supported to maximize the end-user's ability to provide effective input, including prioritizing clinicians who care for the underserved and providing those clinicians resources in order to facilitate their participation.
- The health IT community should work together to identify expectations for rigorous real-world testing, including needed metrics, methods of accountability, external expert review, impact on health equity, and public reporting of the outcome.
- Standards and health IT policies must ensure equity and embrace diversity by including end-user involvement, conducting real-world testing, and creating resources for standards development.

A Diverse Workforce

The Alliance strongly believes that a diverse health care workforce reflective of the U.S. population is needed to address health disparities and increase health equity. This is especially true for patients of color,

who tend to be less healthy than the U.S. majority, experience less access to care, and receive a lower quality of care due to systemic racism and accompanying systems of oppression. Achieving a more diverse workforce is essential to improving patient outcomes and society's overall health.² A workforce reflective of the population supports all end-users to provide more accessible, inclusive, comprehensive, responsive, and culturally effective care to reduce or eliminate health disparities. We encourage ONC to work with other HHS partners, including the Office of Minority Health (OMH) and the Health Resources and Services Administration (HRSA), to develop strategies to continue increasing the diversity of the clinician workforce as an important aspect of HEBD.

Patient Privacy and Trust

The Alliance agrees with ONC on the importance of protecting patients' data privacy and that it is an important aspect of HEBD. Patients often don't understand when their electronic health information (EHI) flows out of Health Insurance Portability and Accountability Act (HIPAA)-covered entities and beyond the protection of HIPAA, and therefore are unlikely to be fully aware or understand how non-covered entities can use and share their EHI. The Alliance recommends ONC provide further education for individuals and work with other federal government partners to ensure appropriate statutes and regulations are in place to protect individuals' EHI when not covered under HIPAA protections. Providing patients with a baseline understanding of who is responsible for protecting their EHI in various situations would support health equity and reduce disparities in patient health education levels.

Expanding ONC-Stakeholder Engagement on Health Equity

The Alliance appreciates ONC's desire to hear from the health care community on how best to advance health equity and joins ONC in viewing HEBD as a collaborative partnership that will require all parts of the health care ecosystem to work together in order to achieve its goals. We believe practicing clinicians and health care facility staff are key stakeholders in these discussions and would welcome the opportunity to convene or engage in a meeting between ONC and a diverse group of end-users to build cooperation and understanding for what would make ONC's vision of HEBD most successful. The Alliance looks forward to connecting further to discuss how we might best facilitate or participate in a meeting that would provide ONC with the most helpful feedback.

Conclusion

The Alliance applauds ONC for taking steps to further its HEBD goals by prioritizing health equity as a key feature during the design, build, and implementation of health IT policies, programs, projects, and workflows. We stand ready to work with ONC to ensure that the end-user perspective is taken into account as public and private sector stakeholders collaborate to make further progress in designing systems centered around health equity. For further questions related to the contents of this letter, or the Alliance and our policy positions, please contact American Health Information Management Association (AHIMA) Senior Director of Regulatory and International Affairs Andrew Tomlinson at Andrew.Tomlinson@ahima.org or by phone at 443-676-7106.

Health IT End-Users Alliance Members

American Academy of Family Physicians
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American Health Information Management Association
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² Joni Strom Williams, Rebekah J. Walker, Leonard E. Egede, Achieving Equity in an Evolving Healthcare System: Opportunities and Challenges, The American Journal of the Medical Sciences, Volume 351, Issue 1, 2016, <https://doi.org/10.1016/j.amjms.2015.10.012>.