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

Prepared by:

The Office of the National Coordinator for Health Information Technology

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EXECUTIVE SUMMARY

Over the past twenty years, the nation has witnessed significant progress towards achieving the promise and benefits of health information technology (health IT). Equally, our health information exchange capacity has also increased, leading to improved care coordination, patient access, interoperability, and patient safety, among many other benefits. This proposed approach, invitation for public feedback, and call to action by the Office of the National Coordinator for Health Information Technology (ONC) focus on the steps and results needed to address health inequities and advance the health equity by design of health IT.

Every day, health inequities harm people, communities, and populations across the nation. They range from structural or systemic inequities, such as systemic racism, to personal inequities, such as food and housing insecurity. The individual and collective harms might be immediate, and they might develop and deepen over decades and generations. Structural health inequities might manifest in particular areas, such as health disparities in maternal mortality, and yet reflect systemic health inequities across myriad interconnected systems. We must collaborate and do all we can together to identify and redress health inequities for better health, better care, and better health equity across the nation. Health IT can and must play a key role.

This discussion draft reflects ONC's proposed approach for Health Equity by Design (HEBD). HEBD focuses on the need to include health equity at the outset and as a key feature during the design, build, and implementation of health IT policies, programs, projects, and workflows. With focused HEBD actions in health IT, we can help identify existing gaps and disparities in health equity that could be redressed in the lifecycle of technologies so that the technologies and their uses anticipate, avoid, and reduce, not exacerbate, health disparities. HEBD also designs and builds for the diversity of uses and users and promotes health equity.

HEBD recognizes the interconnections and interdependencies among clinical care and the systemic inequities and myriad social determinants of health outside the clinical settings—where structural and community-level inequities "upstream" lead, for example, to disparities in health care, exacerbated disease states, and costly episodic care "downstream." HEBD uses health IT to move health data into action by identifying and reducing health disparities, and promoting health equity.

For example, by design, health IT can enable providers to use and refer health data collected at the point of care to others across the ecosystem working on services and interventions that mitigate adverse impacts of social drivers of health, such as food banks, housing services, and population-health services. This nationwide ecosystem includes providers, payers, individuals and family caregivers, community-based and social-service organizations, public health agencies, and others. In turn, these partners can leverage health IT to establish patient-specific interventions such as a referral for food or shelter, and share data on structural and individual social drivers of health to improve equity and reduce disparities.

ONC uses HEBD in its own work, as described below in Section III. This integration in ONC's work and policy development, in turn, enables stakeholders, providers, developers, and others across the national health ecosystem to integrate and implement HEBD in their technology and care delivery. For example, ONC added social determinants of health (SDOH) data elements in U.S. Core Data for Interoperability (USCDI) version 2 in July 2021, and released the SDOH Toolkit in February 2023. In this way, stakeholders are not alone in incorporating and implementing HEBD and can access certified health IT used nationwide and a community of resources, tools, and experts upon which to build.

In summary, Section I below describes the proposed approach. Section II provides some examples of HEBD across the national health ecosystem, drawing from the Health Information Technology Advisory Committee's (HITAC) public hearing on the topic in March 2022. Section III describes some of ONC's own efforts thus far to implement this approach and advance health equity by design. ONC solicits public feedback and calls for action to promote HEBD.

Invitation for Public Input: ONC invites stakeholder feedback on the proposed HEBD approach described in this discussion draft and information and examples regarding specific actions and tools that you and others are building and using to support health equity by design locally, regionally, or nationally. We solicit feedback from all stakeholders, including, but not limited to, health care providers, health information networks or exchanges, health information technology users and developers, and individuals and communities, and across the health and human services continuum. This discussion draft identifies questions for feedback at various points and collects and repeats them in a section at the end for your convenience. Feedback is due Monday June 10 at 11:59:59pm ET. The information and feedback you share will help ONC further develop and refine this proposed approach before issuing a final version.

Call to Action: ONC also issues a call to action to catalyze efforts to advance and incorporate HEBD in health IT nationwide. ONC calls upon private- and public-sector health stakeholders and federal partners to apply an HEBD approach and to integrate health equity as a core principle *now* when designing, building, and implementing health IT policies and health IT systems and uses. Lastly, to those who have not yet begun to consider and integrate an HEBD approach, ONC sounds a call to action to consider now how best to integrate HEBD across their efforts.

I. HEALTH EQUITY BY DESIGN FOR HEALTH INFORMATION TECHNOLOGY

ONC's proposed approach for HEBD focuses on the need to include health equity at the outset as a key feature during the design, build, and implementation of health IT policies, programs, projects, and workflows. This approach identifies existing gaps and disparities in health equity that could be redressed in the lifecycle of technologies so that the technology and its use reduce, not exacerbate, health disparities.[1] It designs and builds for the diversity of uses and users. In practice, HEBD identifies and incorporates health equity considerations from the beginning and throughout the technology design, build, and implementation processes.[2]

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[1] Office of the National Coordinator for Health Information Technology, 2022 Report to Congress: Update on the Access, Exchange, and Use of Electronic Health Information, p. 40 (Feb. 28, 2023).
[2] Office of the National Coordinator for Health Information Technology, Health Data, Technology, and Interoperability: Certification Program Updates, Algorithm Transparency, and Information Sharing, 89 Federal Register 1192, 1194 (Jan. 9, 2024).

A. Background

Health equity means the attainment of the highest level of health for all people, where everyone has a fair and just opportunity to attain their optimal health regardless of race, ethnicity, disability, sexual orientation, gender identity, socioeconomic status, geography, preferred language, and other factors that affect access to care and health outcomes.[3] In its 2003 monograph *Unequal Treatment*, the National Academies of Sciences, Engineering, and Medicine (formerly Institute of Medicine of the National Academies) documented widespread inequities in health care access, quality, experience, and outcomes attributable not only to socioeconomic status, but also to race, education level, literacy, geography, and other factors.[4] Since then, the studies and documentation have broadened and deepened.[5]

Over the past two decades, the public and private sectors have invested extensively in health IT adoption and infrastructure. Health IT has become an enabling tool to support national health goals, including promoting health and wellness, enhancing the delivery and experience of care, accelerating research and innovation, and connecting healthcare with health data.[6] Despite health IT's pivotal role in enabling national health goals, ONC recognizes that health IT can act, in certain instances, as a driver of disparities by unintentionally exacerbating them. Health IT can also be a useful tool to help identify and eliminate disparities. This has been underscored in numerous settings and studies and, as examples, can pertain to implementations involving artificial intelligence (AI) as well as clinical decision support (CDS) systems. AI and CDS are increasingly used by health care providers and can inadvertently codify and embed bias within technology by employing models that are broadly inaccurate or not rigorously evaluated, implementing models calibrated with unrepresentative data, or allowing models to be misapplied by practitioners. Similarly, adulterated patient data can be replicated and promulgated across health systems, potentially injuring patients.

We also better understand the interconnections and interdependencies among clinical care and the systemic inequities and myriad social determinants of health outside the clinical settings. We need only look to the COVID-19 pandemic for stark and compelling reminders and evidence. The underserved communities historically subject to personal and systemic discrimination and inequity have had substantially higher rates of infection, hospitalization, and death from COVID-19.[7] Research shows that socioeconomic factors, environmental factors, and health behaviors account for approximately 80 percent of a person's and population's health status; while traditional clinical care accounts for approximately 20 percent of one's health status. The COVID-19 pandemic has highlighted this reality repeatedly, at both individual and community or population health levels.

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[3] Centers for Medicare & Medicaid Services, CMS Strategic Plan: Health Equity, p. 1 (May 22, 2023). See generally U.S. Department of Health and Human Services, Health Equity and Health Disparities Environmental Scan (Mar. 2022).
[4] Institute of Medicine of the National Academies, Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care (2003).
[5] For example, Health Affairs has recently devoted entire issues collecting studies on Racism & Health (Feb. 2022), and Tackling Structural Racism in Health (Oct. 2023).
[6] Office of the National Coordinator of Health Information Technology, 2020-2025 Federal Health IT Strategic Plan, p. 5 (Oct. 30, 2020).
[7] Leo Lopez III, Louis H. Hart III & Mitchell H. Katz, Racial and Ethnic Health Disparities Related to COVID-19, 325 Journal of the American Medical Association 719 (Jan. 22, 2021) (summarizing studies).

A future state, where health disparities are eliminated and health equity is promoted by design, would make the U.S. health system more just, would enable individuals to attain their best possible health outcomes, and would enable communities to have access to and distribution of health resources in a more equitable manner. Health IT can serve as an enabling tool to help identify and to address health inequities. Health equity by design can do so strategically and systematically to meet this national imperative for health equity as soon as possible.

B. ONC's Health Equity by Design (HEBD) Approach

ONC recognizes and embraces health IT's potential to mitigate, and ideally eliminate, widespread health disparities borne from systematic inequities that remain pervasive within the U.S. health and healthcare systems. ONC further recognizes that health IT cannot address all of the societal and institutional factors that drive health inequities in the United States today. However, it is vital to mobilize health IT to identify and mitigate health disparities where applicable, and even more important, that we not allow health IT to perpetuate or even magnify health equity gaps endemic in our systems today.

ONC envisions HEBD as a systematic approach in which health equity is considered at each phase of health IT system design and at every stage of policy and implementation to help mitigate widespread inequities in health and care systems. The use of an HEBD approach with health IT ensures that equity considerations are identified and incorporated as a core principle in the *design*, *build,* and *implementation* of health IT systems, and the resulting health IT products and capabilities are foundationally equity-enforcing. Even if one cannot yet build and meet all needs now, through HEBD one <u>can</u> anticipate and consider the diversity of uses and users and not inadvertently build in inequities and significant barriers to future uses and iterations.

ONC weaves equity considerations throughout our work. ONC is particularly focused on leveraging an HEBD approach when delivering on its mission, especially as it relates to health IT *data* standards, health IT *certification*, electronic health data *exchange, coordination* of health IT-related activities, and *measurement* and monitoring of health inequities in health-IT related activities. To illustrate, the figure below organizes some of ONC's core activities that enable an HEBD approach to help address health inequity systematically and comprehensively. This draft discusses the activities in detail in Section III.

Figure 1: ONC's Current HEBD Approach and Activities

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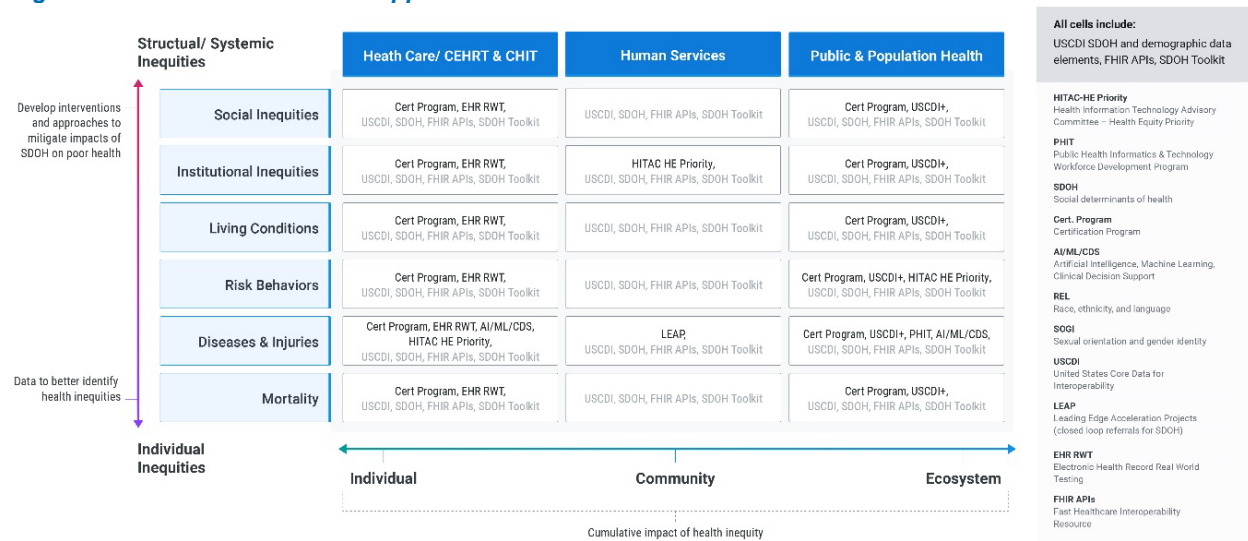
The figure also illustrates how leveraging data to target "upstream" structural or system inequities can help prevent avoidable "downstream" individual inequities in health care. ONC's health IT policy development and coordination activities help turn data into actions that advance health equity nationwide. More equitable data standards (such as the SDOH, race and ethnicity, SOGI, and disability data elements in USCDI) enable more consistent data collection and greater interoperability, which can help better identify, measure, and address health inequities in traditional health and human services settings. In turn, these efforts can also help to identify structural and systemic inequities "upstream" and inform what kinds of interventions could be developed "upstream" to mitigate the impacts of social determinants on poor health—the factors outside the clinical settings that explain 80 percent of our health status. Health IT used in this way enables providers to collect and use health data collected at the point of care to create interventions and referrals to mitigate adverse impacts of social drivers of health, such as food banks, housing services, and population-health services. In addition, these partners can also leverage health IT to establish population-level interventions and can share data on structural and individual social drivers of health to improve equity and reduce disparities.

As ONC looks through this lens and applies an HEBD approach, ONC strives to achieve these aims:

- That health IT, its workflows, and accompanying policies are focused on helping eliminate disparities in health and care access and contribute to equitable health outcomes;
- That health IT systems are designed to identify and quantify disparities and can be utilized to target "upstream" causes to prevent avoidable "downstream" healthcare conditions such as an advanced disease state or episodic health crisis; and
- That federal authorities related to interoperability, health care data standards, certification requirements for health IT, and health IT coordination improve health equity consistent with this approach.

In order to foster shared learning and encourage public feedback, this discussion draft:

- Provides a brief overview of health inequity and disparities in the United States and the importance of health equity, including opportunities for health IT to enable health equity;
- Describes ONC's view of an HEBD approach;
- Highlights activities and projects within ONC, as well as examples from the health care stakeholder community, to illustrate an HEBD approach in action; and,
- Includes a call to action to federal partners and private- and public-sector health organizations to apply an HEBD approach and to integrate equity as a core principle now, when designing, building, and implementing health IT systems and related policies.

By sharing this discussion draft, ONC recognizes the iterative learning and development inherent in this approach and practice. That is why we invite the experience, feedback, and collaboration of all stakeholders on the HEBD approach we describe and ONC's associated aims, across the diversity of users, communities, and health care settings. Do you think this draft identifies the core issues and heads in the right direction? Are there changes you recommend based upon your own experiences with health inequities and health equity by design? We further invite feedback on current practices and exemplars to inform real-world considerations when implementing an HEBD approach, as well as feedback on areas of near-term and long-term opportunity for entities to advance health equity in developing and using health IT. ONC will update this working document as part of ONC's commitment to a sustained, intentional effort to reduce health care inequities and their negative impacts on individuals and communities, and to integrate HEBD in health IT and electronic health information exchange nationwide.

This discussion draft outlining an HEBD approach, invitation for public feedback, and call to action are also part of ONC's response to the Biden-Harris Administration's priority to advance equity. *Executive Order 13985, Advancing Racial Equity and Support for Underserved Communities Through the Federal Government*, directs federal agencies to advance equity[8] for all, including communities that have long been underserved, and address systemic racism in our Nation's policies and programs and in their implementations. This invitation for feedback and call to action also respond in part to one of the six recommendations in ONC's 2022 Report to Congress, *Update on the Access, Exchange, and Use of Health Information*: support HEBD to include equitable access to information and communications technology and improve health outcomes by building equity into the design of health IT.

II. HEALTH EQUITY BY DESIGN ACROSS THE NATION'S HEALTH ECOSYSTEM

Like interoperability, health equity by design is a critical cornerstone of the nation's health ecosystem, requiring coordination and collaboration. Many stakeholders have already begun working to build and implement health equity by design in their respective areas of focus. At the same time, the nation and our national health ecosystem need a comprehensive approach to health equity by design across all individuals and communities, stakeholders, and core use cases. Health and health care implicate a diverse ecosystem of stakeholders and use cases nationwide. Common use cases such as value-based care delivery and pandemic care illustrate how health inequity in one system can impact health equity or exacerbate health inequity in another interconnected system. Health equity by design is not limited to just one system or some systems, but must permeate all to achieve real health equity for individuals, communities, and the nation. Health equity by design across the nation's health ecosystem applies to all stakeholders and use cases, although particular needs, factors, barriers, and design might be adjusted or tailored for different stakeholders or use cases.

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[8] Executive Orders 13985 and 14091 define "equity" as "the consistent and systematic treatment of all individuals in a fair, just, and impartial manner, including individuals who belong to communities that often have been denied such treatment, such as Black, Latino, Indigenous and Native American, Asian American, Native Hawaiian, and Pacific Islander persons and other persons of color; members of religious minorities; women and girls; LGBTQI+ persons; persons with disabilities; persons who live in rural areas; persons who live in United States Territories; persons otherwise adversely affected by persistent poverty or inequality; and individuals who belong to multiple such communities."

Health Care Stakeholder Groups (not exhaustive)	National Use Cases (not exhaustive)
• Providers (clinical, behavioral, etc.) • Hospitals & health systems, Skilled nursing facilities, Tribal clinics, Community clinics • Individuals/patients/family caregivers, communities • Laboratories, pharmacies • Payers (including CMS) • Health IT/EHR developers, App developers/innovators, Devices • HIEs, Registries • Community-based organizations, Social-service organizations, Faith-based organizations, Referral platforms • Data standards organizations • Public Health • Research • Government (national, state, tribal, territorial, local)	• Value-based & fee-based care delivery • Health equity and disparities • Social determinants of health • Interoperability • Shared care planning and coordination • Remote care, PGHD, device data • Patient access • COVID-19 • Patient safety • Public and population health • Precision medicine and genomics • Research • API/app innovation • Digital quality measures • Artificial intelligence & Machine learning

At a public hearing held on March 10, 2022, ONC's Health Information Technology Advisory Committee explored equity considerations in health IT with experts from the fields of health equity, health IT, and health data exchange. We learned about a large pediatric practice that provides care across three counties in rural Georgia. During each patient visit, the intake staff conducts a family assessment to identify the social needs of patients receiving care. The social worker triages patients and coordinates support services by initiating referrals. The practice is connected to the Georgia Health Information Exchange Network (GaHIN), the state-designated health information exchange (HIE). GaHIN leverages its technology and connectivity to collect SDOH data to assist providers in using interoperability to expedite and improve **care coordination and deploy social and community-based services**. GaHIN has established networks with healthcare providers and health systems, including the Morehouse School of Medicine. Morehouse uses a strategic approach applying health IT to collect data from underserved populations to mitigate and address health inequities. Its collaborative approach includes digital health literacy awareness, provider education, and training through state, local, territorial, and tribal partnerships. As a result of this collaboration and coordination, HIE services contribute to the promotion of equitable access to healthcare, community services, and disparities reduction across the counties, through:

- Data collection and SDOH screening assessments identify potential needs unrelated to patient care (i.e., housing, financial, clothing, food, or transportation), allowing for data exchange with community and social care organizations.
- Addressing the digital divide by ensuring broadband access is available in rural communities to increase access to virtual care.
- Providing data from patient monitoring tools and digital health literacy training enabling providers to use technology in practice and transmit health care data to other practitioners.
- Data collection and care coordination to identify and mitigate health inequities aimed at improving the health outcomes of individuals with chronic conditions.

Another example from the hearing comes from one state but has parallels nationwide. An event notification system allows providers throughout the state to receive "admission/discharge/transfer" (ADT) encounter messages from hospitals as their patients move between sites of care. As initially designed, the system performed **patient matching** using home addresses—which would not work for patients with no address or unstable and often-changing addresses. Had health equity issues been given forethought during initial system design, then the potential harms to already-underserved housing-insecure patients might have been avoided at the onset.

Artificial intelligence and machine learning present another instructive example. A presentation by one expert from IBM Watson identified the many kinds of bias that can cause health inequity or bias in such algorithms and technologies. There might be data invisibility or incomplete health data, e.g. missing data or incomplete data in EHRs and other data sets favoring groups that have access and robust health data profiles; data bias in sample selection; bias in modeling structure and selection of metrics for prediction; lack of cohort diversity; and unrepresentative training data. There might also be research bias; provider bias; missing data on environmental, occupational, and life-course exposures; and missing data or understanding about the people, places, and factors that make up the data.

These are just three of myriad examples illustrating how critical it is to integrate health equity by design frameworks from the outset of health IT development and use in order to identify and reduce health inequities and promote health equity across the national health ecosystem. We hope that you will share important examples from your work. Details about the effort; its purpose; how it was designed, built, and implemented; barriers faced; improvements still needed; etc., would be very helpful.

Invitation for Public Input:

1. What ways do you design and integrate health equity in health information technology, exchange, and use, across your work in health care and delivery?
2. What are the exemplars and lessons you would share with ONC in your feedback?
3. What are your immediate priorities for health equity by design, and your long-term priorities?
4. What are the leading barriers to health equity and health equity by design that you experience in your efforts? How do you think ONC can help?

III. HEALTH EQUITY BY DESIGN THROUGHOUT ONC'S POLICIES AND PROGRAMS

ONC is charged with coordination of nationwide efforts to implement and use the most advanced health information technology and the electronic exchange of health information. ONC does this through regulations, grants, and cooperative agreements, as well as standards activities, the health IT certification program, electronic health information exchange and interoperability, coordination initiatives, and monitoring and measurement.

ONC's policies, programs, and initiatives, influence the design, build, and implementation of health IT and thus can enable national health equity imperatives throughout. ONC performed an extensive landscape analysis, conducted a literature review, and engaged federal partners and non-governmental entities through listening sessions, webinars, direct interviews, and other vehicles to inform this HEBD approach and current practices. ONC identified a portfolio of activities aimed at establishing health equity as a cornerstone in development and deployment of health IT.

A. Data Terminology Standards

ONC curates the U.S. Core Data for Interoperability (USCDI) to enable greater nationwide interoperable exchange of health information through standardized data classes and elements, including standardized electronic exchange of equity, social determinants of health, and public health data.[9]

ONC updates the USCDI annually. USCDI Version 1 was adopted as a standard in the ONC Cures Act Final Rule, published May 1, 2020, and included race and ethnicity data elements. USCDI Version 2, released in 2021, introduced critical data elements to identify and help address health disparities, including four SDOH data elements (SDOH Assessment, Problems/Health Concerns, Goals, and Interventions), and Sexual Orientation and Gender Identity (SOGI) data elements. USCDI Version 3, released in July 2022, added additional health equity-supporting data elements such as disability status, mental function, tribal affiliation, and insurance information. USCDI Version 4 added 20 new data elements that advance the Biden-Harris Administration's priorities of advancing equity, diversity, and access across all healthcare settings. Draft USCDI v5 now proposes to add additional data elements that focus on improving patient care and facilitating patient access, while promoting equity, reducing disparities, supporting underserved communities, and enabling public health data exchange. As these data are captured and exchanged with uniform standards, health providers and systems, federal, state, and local governments, and community-based organizations can use the data to help identify disparities, provide care, and develop solutions and interventions to address them.

ONC is undertaking similar efforts for health IT programs and health data sets used across federal agencies. In 2022, Secretary Becerra issued the HHS Health IT Alignment Policy directing ONC to engage with HHS agencies to align and coordinate health IT-related activities in support of HHS's health IT and interoperability goals. Specifically, Secretary Becerra directed ONC to establish and oversee a consistent HHS-wide approach for (1) incorporating standard health IT requirements in all applicable HHS funding programs, contracts, and policies, and (2) helping HHS agencies maximize the use of HHS-approved standards and authorities, including certified health IT. Federal partners in this work include the Centers for Medicare & Medicaid Services (CMS), Office for Minority Health (OMH), National Institutes of Health (NIH), Health Resources and Services Administration (HRSA), Centers for Disease Control and Prevention (CDC), Agency for Healthcare Research and Quality (AHRQ), and many others.

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[9] Office of the National Coordinator for Health Information Technology, 2022 Report to Congress: Update on the Access, Exchange, and Use of Electronic Health Information, pp. 20, 30-32 (Feb. 28, 2023).

One example of increased federal coordination is USCDI+, a service that ONC provides to federal partners which seek to establish, harmonize, and advance the use of interoperable datasets that extend beyond the core data elements currently in the USCDI in order to meet agency-specific programmatic requirements.[10] The data elements that comprise the USCDI and USCDI+ can also be used to support many activities including to inform the creation of quality measures, conduct research, and inform alignment and harmonization efforts so that data are interoperable, reusable, and accessible even in instances where health IT may not be in use. Like USCDI, USCDI+ supports data capture, exchange, and use that are critical for supporting data exchange upstream and downstream and for identifying disparities and informing effective interventions to promote health equity. ONC also applies an HEBD approach as part of its involvement in consensus-based processes to develop, pilot, and ballot standards for consideration as part of HHS programs including the ONC Health IT Certification Program. In short, ONC works to design and help inform the build of standards with an HEBD approach, and federal agencies across HHS work to incorporate and integrate them.

B. Health IT Certification

Nearly all non-federal acute care hospitals and over three-quarters of office-based physicians use health IT certified under the ONC Health IT Certification Program. ONC continues to advance the development and use of health IT capabilities and improve the experience of users through this program.[11] Current certification criteria support person-centered health across the health and care continuum and include equity-relevant criteria, some of which are also part of USCDI, the nation's core data set for interoperability.

In addition to improving the capture of equity-supporting data, ONC aims to ensure that data are utilized in ways that enhance health equity. To that end, ONC has adopted through rulemaking policies for the ONC Health IT Certification Program that promote the safe development and use of artificial intelligence (AI), machine learning (ML) and predictive clinical decision support. These policies apply HEBD to bring transparency to the quality and performance of AI/ML-based decision support tools in healthcare.[12] Of special interest is understanding, as part of the capabilities these policies would support, whether the data elements capturing race, ethnicity, SDOH, and SOGI are included in predictive algorithms and whether inclusion or omission of these elements impacts health equity. ONC's Health data, Technology and Interoperability (HTI-1) final rule, released in December 2023, provides users of certified health IT with transparency to better determine if a predictive algorithm exhibits biased performance, prejudice, or favoritism toward an individual or group based on inherent or acquired characteristics, such as age, race, ethnicity, sexual orientation, gender identity, disability status, skin type, and diagnosis.

[10] Office of the National Coordinator for Health Information Technology, 2022 Report to Congress: Update on the Access, Exchange, and Use of Electronic Health Information, p. 40 (Feb. 28, 2023).

[11] Office of the National Coordinator for Health Information Technology, 2022 Report to Congress: Update on the Access, Exchange, and Use of Electronic Health Information, pp. 28-29 (Feb. 28, 2023).

[12] Office of the National Coordinator for Health Information Technology, Health Data, Technology, and Interoperability: Certification Program Updates, Algorithm Transparency, and Information Sharing, 89 Federal Register 1192, 1194-1195, 1231-1282 (Jan. 9, 2024). See also Executive Order 14110, Safe, Secure, and Trustworthy Development and Use of Artificial Intelligence, 88 Federal Register 75191 (Oct. 20, 2023).

C. Electronic Health Information Exchange and Interoperability

ONC adopts through regulation and often establishes the infrastructure standards for consistent and secure access, exchange, and use of electronic health information. ONC's focus on electronic health information exchange likewise promotes health equity and health equity by design.[13]

The Digital Divide

The digital divide – the gap between demographic communities and geographic regions that can access and use modern health information and communications technology and those that cannot – exemplifies and exacerbates healthcare disparities.[14] Although ONC is not funded to finance the widespread expansion of the nation's technology infrastructure, it helps to address challenges with closing the digital divide by supporting standards for health data exchange using existing infrastructure to support underserved settings and populations. Our federal partners at the Federal Communications Commission, for example, have programs that directly work to redress the digital divide in health care.

ONC has adopted a uniform standard for exchange to help address challenges created by the digital divide: the Health Level 7® Fast Healthcare Interoperability Resources® Release 4 (FHIR R4). ONC has adopted certification requirements for health IT that include FHIR-based application programming interfaces (APIs), the same type of technology used every day by smartphones. APIs allow one software application to securely access the services provided by another in real-time. Expanded use of APIs in health care has the potential to provide seamless electronic transmission of information between incumbent health IT systems and third-party applications. Health IT developers can leverage APIs to build apps and other innovative products, benefiting both patients and clinicians. As a result, providers and community-based organizations that do not have the resources to procure and implement a conventional EHR can instead develop more "lightweight" applications that use FHIR-based APIs to access patient data contained in certified EHRs. Similarly, FHIR-based APIs can allow patients to access certified EHR data with apps running on their smartphones. Mobile phones, unlike computers and broadband, are possessed by roughly 85 percent of the U.S. population, across racial and regional groups. Data access provided by FHIR-based APIs allows developers to produce apps implementing any number of functions, such as language support for the 22 percent of the U.S. population who does not speak English at home.

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[13] Office of the National Coordinator for Health Information Technology, 2022 Report to Congress: Update on the Access, Exchange, and Use of Electronic Health Information, pp. 9-10, 23-24 (Feb. 28, 2023).
[14] Federal Communications Commission, Connecting Americans to Healthcare (accessed April 5, 2024).

Social Determinants of Health Data Exchange and Social Care Referrals

Social Determinants of Health (SDOH) are the conditions where people are born, live, learn, work, play, worship, and age that affect a wide range of health, functioning, and quality-of-life outcomes.[15] SDOH can be positive or negative. They can reinforce or promote health equity rather than health inequities. There can be food security as well as food insecurity, adequate housing as well as inadequate housing, social cohesion as well as interpersonal violence. The positive aspects of health and well-being— sometimes called "protective factors"[16]—are likewise important parts of health equity and should be monitored and promoted. Health equity by design considers and promotes the positive factors as well as redresses and avoids health disparities and health inequities.

With the integration of SDOH data through ONC's data elements in USCDI version 2, and nationwide exchange using the FHIR standard for EHRs and APIs, social care referrals become much more possible. When a provider or health system identifies an individual's health related social need as part of screening practices, a care referral can be made, directing an individual to a community-based organization(s) to receive service(s) to help address gaps in social needs such as inadequate food. The services and information can then be shared back to the referring health entity that conducted the screening enabling a closed-loop referral, and to all members of the individual's care teams. ONC continues to develop practical resources and to inform HHS programs and policies to advance the successful implementation of social determinant of health data information exchange including health IT-enabled closed-loop referrals.

ONC has also invested in projects to inform scalable approaches using non-proprietary heath IT data standards to advance social care referrals. As part of the Leading Edge Acceleration Projects (LEAP) in Health IT program, ONC funded the University of Texas at Austin to implement closed-loop referrals between Austin-area hospitals and social service agencies. This project developed a non-proprietary technical platform using a FHIR-based API exchange of SDOH data and referral information between traditional healthcare providers and community-based organizations. The platform addresses barriers that can prevent widespread construction of social referral networks, including workflows that do not include social needs referrals; inconsistent mappings of SDOH taxonomies across organizations; a lack of established contracts and trust arrangements between medical and social service organizations; and a lack of established privacy and consent frameworks operating between clinical establishments and community-based organizations, public health agencies, or other social service entities.

ONC has also developed a *Social Determinants of Health Information Toolkit* which identifies approaches to advance SDOH information exchange through the consideration of foundational elements further explored via the ONC Social Determinant of Health Information Exchange Learning Forum.

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[15] Healthy People 2030, U.S. Department of Health and Human Services, Office of Disease Prevention and Health Promotion, Health People 2030, Social Determinants of Health (accessed April 5, 2024).
[16] E.g., Hugh Alderwick & Laura Gottlieb, Meanings and Misunderstandings: A Social Determinants of Health Lexicon for Health Care Systems, 97 Milbank Quarterly 407, 408-412 (2019).

D. Coordination and Public Hearings

ONC, through coordination activities works closely with partners in the public and private sectors that identify health inequities and facilitate interventions that reduce health inequities and disparities. As the principal federal entity charged with coordination of nationwide efforts to implement and use the most advanced health information technology and the electronic exchange of health information, ONC is at the forefront of the Biden Administration's health IT efforts and is a resource to the entire health ecosystem. ONC's coordinating functions and responsibilities are vast; examples of select approaches to advancing health equity include:

- Promoting diversity across the activities of the Health Information Technology Advisory Committee (HITAC). ONC seeks diverse appointments to the HITAC for those positions nominated by HHS and engages the HITAC to consider and hold hearings on health equity.
- Coordinating federal agency activities regarding health IT to advance the HEBD approach and identify best practices.
- Engaging health IT developers and users in pilots to ensure that ONC's activities and standards promote health equity and serve diverse communities without creating or exacerbating digital divides.
- Engaging provider and patient communities to collaborate on, develop, and disseminate best practices for the efficient use of health IT that advances health equity and patient well-being.

E. Measurement and Monitoring

ONC has long worked to measure and report on the impacts of health IT. For example, ONC conducts and leverages national surveys of healthcare providers and individuals to identify ongoing disparities in health IT use and interoperability and to quantify the impact on historically underserved patient populations. Findings are published in data briefs, peer-reviewed publications, and ONC's health IT dashboard, allowing widespread dissemination. Additionally, these analyses and publications help identify factors associated with health disparities that ONC and stakeholders can target when developing and evaluating potential solutions.

By using HEBD in its own work, as described above, ONC's work and policy development in turn enable stakeholders, providers, developers, and others across the national health ecosystem to integrate and implement HEBD in their technology and care delivery.

Invitation for Public Input:

1. What additional activities, if any, do you think ONC should undertake to implement Health Equity by Design fully and effectively?
2. Are there any activities described above that you think are having unintended, adverse effects on health equity by design?

IV. CONCLUSION

Health Equity by Design focuses on the need to include health equity at the outset and as a key feature throughout the design, build, and implementation of health IT policies, programs, projects, and workflows. An HEBD approach helps identify existing gaps and disparities in health equity that could be redressed in the lifecycle of technologies so that the technology and its use anticipate, avoid, and reduce, not exacerbate, health disparities. It designs and builds for the diversity of uses and users and promotes health equity. It turns data into action, both identifying and addressing health inequities in traditional healthcare settings, and helping to identify structural and systemic inequities "upstream" and develop interventions "upstream" that mitigate the impacts of social determinants on poor health—the factors outside the clinical settings that explain 80 percent of our health status.

ONC has described some of our own efforts to use this lens and approach to improve our policies and practices across our authorities for health IT data standards, health IT certification, electronic health data exchange, coordination of health IT-related activities, and measurement and monitoring of health inequities in health-IT related activities. We have provided some examples of HEBD across the national health ecosystem, drawing from HITAC's hearing on the topic in March 2022. With this discussion draft, ONC is now issuing an invitation for public feedback and call to action.

We invite public input on this proposed HEBD approach and questions across the diversity of stakeholders, including, but not limited to, health care providers, health information networks or exchanges, health information technology users and developers, and individuals and communities across the health and human services continuum. We welcome your feedback grounded in your diverse experiences, expertise, and perspectives on health equity by design. The information and feedback you share will help ONC further develop and refine this proposed approach before issuing a final version.

ONC also calls upon private- and public-sector health stakeholders and federal partners to apply an HEBD approach and to integrate health equity as a core principle *now* when designing, building, and implementing health IT policies and health IT systems and uses. Stakeholders need not wait for ONC to finalize this approach before considering and applying HEBD principles and practices, as many stakeholders already do. To those who have not yet begun to consider and integrate an HEBD approach, we sound a call to action to consider now how best to integrate health equity by design across your efforts, for the sake of health equity and everyone in the health IT ecosystem.

RECAP: QUESTIONS FOR INPUT AND FEEDBACK

For convenience, ONC's questions above soliciting public feedback and information are listed below. Please visit HealthIT.gov/feedback to provide your comments.

1. Do you think this draft identifies the core issues and heads in the right direction? Are there changes you recommend based upon your own experiences with health inequities and health equity by design?
2. What ways do you design and integrate health equity in health information technology, exchange, and use, across your work in health care and delivery? What are the exemplars and lessons you would share with ONC in your comments?
3. What are your immediate priorities for health equity by design, and your long-term priorities?
4. What are the leading barriers to health equity and health equity by design that you experience in your efforts? How do you think ONC can help?
5. What additional activities, if any, do you think ONC should undertake to implement Health Equity by Design fully and effectively?
6. Are there any activities described above that you think are having unintended, adverse effects on health equity by design?
7. How will you heed this call to action? What practical steps will you take, both near term and long term, to use and design technology for health equity improvement purposes?