## Health IT End-Users Alliance
Consensus Statement on Data to Support Equity

**Summary**

Achieving equity in health and health care is a key priority that requires collection of data to identify disparities and monitor efforts to improve. Current efforts to standardize and increase uniform collection and reporting of relevant data on race, ethnicity, preferred language and social drivers of health are promising but more needs to be done to support physicians, hospitals and other health care providers given the push to require to collect, use and share this data for public and private programs. Outstanding issues include agreed-upon and validated standards and instruments to support interoperability, training in how best to collect sensitive data, and the development of tools and workflows to efficiently collect data and share it in ways that respect individuals' privacy preferences, avoid redundant or inaccurate data collection, and minimize burden on individuals, clinicians and other providers. Collection of data should be actionable, purpose-driven and supported by appropriate and accessible technology and other resources that support connection to social services and other interventions to address identified needs. Ongoing research is needed to support these efforts.

**Issue**

A significant body of evidence indicates that access to and outcomes of health care can vary by factors such as race, ethnicity, disability, sexual orientation, gender identity, socioeconomic status, geography, and preferred language, with disadvantaged groups faring worse than others on a range of health outcomes in the United States.[1] The current Administration has prioritized equity in health and health care as a national goal and identified the need for better data on individuals served as a way to focus care improvements and identify disparities, track progress, and promote accountability. This includes, for example, recommendations to improve standardized data collection as a key element of the report from the Presidential COVID-19 Health Equity Task Force and other statements.[2]

As the health care system works collaboratively to ensure we have the right data to guide and evaluate programs and efforts, we must retain as the primary goal equity in clinical care and health – outcomes that reach far beyond data collection.

Collecting data to identify and address disparities is important and collectively the health care system is making progress in developing standards. Within the Department of Health and Human Services (HHS), the Office of the National Coordinator for Health Information Technology (ONC) has included standards to collect demographic, sexual orientation, gender identity, and social drivers of health (SDOH) data within the United States Core Data for Interoperability (USCDI). ONC

has also funded The Gravity Project, which brings stakeholders together to advance health and social data standardization for health equity.[4] The HL7 Gender Harmony Project focuses on standards to support the meaningful capture of sex and gender identity.[5] Furthermore, the data classifications used within billing systems, and particularly ICD-10, have incorporated a growing number of codes to identify social needs and other influencers of health.[6] Providers should be appropriately compensated for the time and resources needed to address their patient populations. To facilitate payment, Current Procedural Terminology Evaluation and Management (E/M) Office and Other Outpatient Services coding guidelines descriptions have the potential to facilitate how capturing SDOH data impacts the complexity level or length of the office visit. Increased discharge planning efforts to address health-related social needs documented during acute care and emergency department visits should also be factored into reimbursements.

Increasingly, federal health programs are bringing forward policies that encourage or require screening and the collection of demographic and SDOH data.[7] This includes, among others, the inclusion by the Centers for Medicare & Medicaid (CMS) of quality measures in Medicare's inpatient hospital prospective payment system that require attestations regarding hospital commitment to health equity, screening for five social drivers of health (food insecurity, housing instability, transportation needs, utility difficulties, and interpersonal safety), and the screen positive rate for those same social needs.

In many instances, the CMS has given providers, clinicians and payers flexibility to select tools for screening – claims data, electronic clinical data, choice of standardized patient assessments, patient-reported data and surveys. While flexibility allows providers to work within their own environments, the lack of standard approaches could lead to inconsistent classifications and screenings and difficult and/or impossible to track progress over time and score measures, as well as an impediment to sharing social risk data across organizations. CMS acknowledges the lack of standards for gathering SDOH data and suggests that there will be additional emphasis on standardized and validated screening instruments in the future. They agency has also supported development of a screening tool for the Accountable Health Communities model under the Center for Medicare & Medicaid Innovation (CMMI).[8]

Increasingly, state Medicaid programs have undertaken efforts to address equity and social drivers of health, including through Section 1115 waivers, with 23 such waivers either approved or pending in November 2022.[9] These state-based approaches leverage a variety of tactics to encourage screening for and acting on SDOH and addressing health equity. In addition, accrediting organizations like The Joint Commission and the NCQA are also incorporating screening and data collection expectations with the goal to reduce disparities.[10]

**Opportunities and Challenges**

Improved collection and use of data to identify and guide efforts to address disparities can positively impact care delivery and operations. Key opportunities include ensuring that information used to make referrals to vetted community-based organizations (CBOs) and community health workers that help to address SDOH or other needs results in information back to the health care provider (closed referral loops). In addition, healthcare settings need to be able to receive referrals from CBOs that easily generate clinical appointments with clear location information. All stakeholders will need to work together to understand how best

to collect these data, including efforts to ensure data quality and consistency so that information collected in one setting can be shared and understood in another setting, using consistent data standards.

A key challenge will be to ensure adequate consideration for individuals and communities across the continuum of care. It may be that some settings, such as primary care, are more appropriate for data collection across demographic and SDOH categories, although no one setting should bear a disproportionate burden. Settings and locations that are already among the most resource constrained, particularly those serving historically minoritized and marginalized communities with longstanding disinvestment, will require reinvestment, such as supplemental adequate payment for these additional, often time-consuming tasks. In addition, stakeholders need to understand and respect patient preferences for how and when data are collected and shared, and what privacy considerations may come into play. As outlined by HIPAA and other statutes, individuals should have portability and control over their personal information. Systems will need to be transparent and rigorous about how they use and protect data to earn the trust of individuals. Further, CBOs and other organizations not considered as HIPAA-covered entities should be encouraged, including via funding, to adopt, implement, and attest to comprehensive data protection practices.[11] Policymakers may need to develop and fund efforts to educate individuals on the rationale, benefits, and risks of sharing information on health-related social needs with health care providers.

As policy moves in the direction of greater collection of detailed demographic and SDOH information, more should be done to understand the interaction among policies and technology. This includes working to align data standards (including data elements and value sets), technical capabilities, operational processes, and workforce capabilities. In addition, stakeholders need to understand the full range of costs and benefits of data collection – and whether the costs and benefits are equally shared. Investments in innovation, particularly directed towards proximate leaders from historically marginalized communities for relevance of insights, involvement in decision-making, and community wealth creation, will go a long way to providing modern, secure health IT that supports the privacy preferences of individuals and the sharing of information that will allow the nation to make progress toward eliminating inequities in health care.

As policymakers and stakeholders advance these efforts, they should endeavor to strike the right balance between requirements to collect data and realizing positive benefits from the data collection.[12] This is directly in line with the objectives of existing CMS efforts such as the Meaningful Measures program, which seeks to reduce the number of Medicare quality measures and ease the burden on providers. Similarly, some of the data elements required for the original Meaningful Use program were challenging to operationalize and interpret. The goal for health equity efforts must be translating data into greater patient engagement, better care and more equitable outcomes – not just data collection.

## Principles

The following principles should guide efforts to ensure that relevant demographic and social factor data are available to advance equity.

1. Prioritize continued development of standardized and validated demographic and social drivers of health (SDOH) data elements to be collected in a

consistent, comparable fashion for priority domains (e.g., housing stability, food security, access to transportation, utility assistance, and personal safety).

2. Align selected domains across federal and state healthcare program and reporting requirements (HRSA, Ryan-White, Medicare, Medicaid, etc.) and by commercial health plans.

3. Develop consensus on validated instruments to be used for data collection (as appropriate for a given setting, context or domain), with a preference for self-reporting of race, ethnicity and other factors.

   a. Develop and support adoption of validated technical tools to support collection in standardized formats and the ability to share electronically, when appropriate.

   b. Develop and support adoption of technical tools to protect privacy and maintain autonomy over how personal information is used, consistent with individual preferences (Note: Once in a provider record, these data become EHI and will be shared with those that have the right to access medical records).

4. Recognize that there is a shared obligation to collect and appropriately share relevant demographic and SDOH data. As appropriate, public programs, payers and community-based organizations should collaborate in order to optimize the collection of these data elements, with appropriate compensation for data collection and management of health-related social needs. Data must be available to providers in support of clinical and social care and provider-based efforts to address equity.

5. Keep the primary focus for collecting demographic and SDOH data on meeting patient needs versus secondary uses of the data.

6. Individuals' privacy must be retained through the adoption of comprehensive data privacy practices by community-based organizations (CBOs) and other entities.

7. Federal, state and local governments and health plans should actively provide funding, technical resources and infrastructure to support training, hardware and software implementation and maintenance, evaluation and quality improvement, and coordination between health care organizations and CBOs to connect individuals to resources so that identified needs can be met, with a specific commitment to invest in innovators and implementers in and from historically marginalized communities.

8. The health care community needs appropriate tools and processes to close social service and CBO referral loops, including standardized approaches to data elements and screening tools (as appropriate to the setting and population) and technology to limit the need for one-off interfaces.

9. Given the primary focus on clinical care and health, policymakers must set reasonable expectations on extent of collection (when, how often, in what settings) to collect sensitive data, including focus on cultural humility and trauma-informed care. Different settings of care may require different approaches. The federal government should provide financial and technical support on how best to collect sensitive information.

10. Policymakers, standards developers, public/private coalitions, and others with influence on industry-wide rules, regulations, and norms related to topics such as coverage and payment, data privacy, and technological infrastructure, should proactively learn from health innovators, investors, patients, and caregivers from historically underinvested communities to inform and guide their priorities and foster accountability for impact.

11. Continue and expand research to improve SDOH data collection to optimize improved equity. This includes research on:

    a. How best to leverage SDOH data in ways that are clinically relevant and linked to care plans;

    b. How best to collect SDOH data and the workforce skills needed;

    c. Patient attitudes toward collection of SDOH data and preferences for how and how often data should be collected;

    d. The clinical validity and reliability of data collected and instruments used;

    e. The link between screen positive and connection made and between connection made and needs met; and

    f. Appropriate use of demographic and SDOH data in artificial intelligence tools to ensure that disparities are identified/addressed and bias or harm is avoided or mitigated.[13]

[1]Racial and Ethnic Health Inequities and Medicare (kff.org); Krahn GL, Walker DK, Correa-De-Araujo R. Persons with disabilities as an unrecognized health disparity population. Am J Public Health. 2015;105 Suppl 2(Suppl 2):S198-S206. doi:10.2105/AJPH.2014.302182; COVID-19 Racial and Ethnic Health Disparities. Centers for Disease Control and Prevention. Published February 11, 2020. https://www.cdc.gov/coronavirus/2019-ncov/community/health-equity/racial-ethnic-disparities/index.html ; Using sexual orientation and gender identity data in electronic health records to assess for disparities in preventive health screening services - PubMed (nih.gov).

[2]HETF_Report_508_102821_9am_508Team WIP11-compressed.pdf (hhs.gov); *Federal Evidence Agenda on Lesbian, Gay, Bisexual, Transgender, Queer, and Intersex (LGBTQI+) Equity*.

[3]United States Core Data for Interoperability (USCDI) | Interoperability Standards Advisory (ISA) (healthit.gov)

[4]Gravity Project (thegravityproject.net)

[5]Gender harmony: improved standards to support affirmative care of gender-marginalized people through inclusive gender and sex representation | Journal of the American Medical Informatics Association | Oxford Academic (oup.com)

[6]ZCodes Infographic - 2022 (cms.gov)

[7]CMS Office of Minority Health. The Path Forward: Improving Data to Advance Health Equity Solutions. Baltimore, MD: Centers for Medicare & Medicaid Services; November 2022.

[8]The AHC Health-Related Social Needs Screening Tool (cms.gov)

[9]Section 1115 Waiver Watch: Approvals to Address Health-Related Social Needs | KFF

[10]New and Revised Requirements to Reduce Health Care Disparities | The Joint Commission. A New Effort To Address Racial And Ethnic Disparities In Care Through Quality Measurement | Health Affairs

[11]Examples of privacy principles include the American Medical Associations Privacy Principles (https://www.ama-assn.org/system/files/2020-05/privacy-principles.pdf) or the AHIMA Policy Statement on Health Information Held by HIPAA Non-Covered Entities (hipaa-nce-policy-statement-final.pdf (ahima.org)).

[12]DOI: 10.1056/NEJMp2211648

[13]See, for example, the state of California request of hospitals to ascertain how healthcare facilities and other providers are addressing racial and ethnic disparities in commercial decision-making tools and algorithms.) 8-31-22 HRA Letter.pdf (ca.gov)