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HITAC Health Equity by Design Hearing Content & Exchange of Data

Epic Written Testimony

Good afternoon. My name is Janet Campbell, software developer and Vice President of R&D Relations for Epic. I'm thankful for the opportunity to provide Epic's perspective on opportunities to better leverage information technology to identify, monitor, and ultimately treat the very real disparities that currently exist within our nation's healthcare system.

Our testimony today is informed by over 40 years of EHR development experience. Our software is deployed in every state in the country, including at numerous federally qualified health centers, and throughout healthcare settings representing both more traditional fee-for-service based reimbursement models to full at-risk arrangements and everything in between. Our organizations provide everything from street medicine to concierge care. Moreover, our software is used internationally, in countries such as Finland, where the social care system is administered using the same EHR as the healthcare system.

Based on our experiences in these varied settings, we propose the following priorities for identifying and treating the disparities of care and outcomes in medicine and healthcare today.

Accurately and Completely Capture Race, Ethnicity, and Language (REaL) to Identify Disparities in Care

Understanding disparities in outcomes relies on having accurate and complete data to identify patients. While collection of race, ethnicity, and language information is supported in most certified EHRs today, we still face many challenges:

- Data collection rates remain low. Perhaps due to patient resistance or lack of organizational commitment, many organizations lack accurate data about their patients, which makes identifying disparities difficult, if not impossible. I'd like to recognize one organization who uses Epic – UC San Diego Health – who increased their collection of REaL data from less than a third of their patients to 94% of patients, through a combination of staff training, patient communication and outreach, and workflow redesign. UCSD proves that increasing collection rates is possible, but it may take more than just technology to achieve it. HHS and professional societies should collect best practices from organizations like UCSD and model and encourage them more broadly so that others can replicate their success.
- Standards for representing REaL are variable, which can introduce confusion to organizations attempting to capture and summarize this data for given programs. Race and ethnicity are represented at different levels of granularity, and through different codesets, and there exists little guidance or standardization on how to "roll up" extremely granular representations for the purposes of reporting. I'd like to recognize ONC's initial work to survey the landscape of codesets and capture strategies across EHRs. We encourage additional efforts to reduce codeset variation across programs and to provide best practices for balancing granularities in this data with appropriate rollup strategies.
- When REaL data is consistently collected and represented in EHRs, we then have the opportunity to identify disparities. Existing electronic clinical quality measures, already widely in use to measure the extent to which providers adhere to clinical best practices of care, are today stratified by race and ethnicity. We recommend establishing and publishing benchmarks that consider these stratifications and others (such as preferred language or sexual orientation) and including them in more public reporting about overall program success. Such transparency will allow CMS, Congress, and other policymakers to track the extent to which current programs are truly benefiting all individuals and more precisely identify opportunities for improvement.

These three interventions, while seemingly small, can begin implementation today and represent the most immediate opportunity for identifying disparities in care.

Advance the Standards for Collecting and Exchanging Social Determinants of Health

Beyond REaL data, which can describe patient demographics in broad strokes, more important to a holistic understanding of patients' health is information about their social determinants. While many organizations regularly assess patients for concerns such as lack of access to transportation, exposure to environmental dangers, or risk of past or current trauma, representing this data in a standard and uniform way is not yet mature.

While we are encouraged by the inclusion of SDOH data in USCDiv2 and the proposed representation for this data in CDA documents and FHIR resources, the industry will need much more experience implementing standards in small pilots before moving to widespread adoption. Exchanging this information in a meaningful way will require much more alignment among stakeholders about which social domains should be assessed and what screeners are appropriate for assessing each domain. For



example, is a housing insecurity risk score of 7 worrisome? If the community cannot align on standardized screening assessments made freely available without licensing restraint, each organization will need to map their customized assessments to some sort of standard risk determination, an onerous exercise that could introduce needless complexity and delay implementation.

These technical challenges are solvable, but progress may feel slow. We encourage HHS to support and work with existing efforts such as HL7's Gravity Project, which was designed to align data concepts so that standardization and exchange of data will be possible.

Encourage Adoption of Interoperable Technology by All Stakeholders

Assessing social needs in patients is only the beginning. To address these needs, organizations are dependent on a patchwork of social programs and agencies. Some programs are well-funded and technologically sophisticated, such as Trinity Health, who administers a diabetes prevention program through their EHR that includes health coaching at the local YMCA and healthy food through Trinity's farm share. Using both patient-facing technology and portals for community partners, Trinity has made more than 450 healthy food deliveries to 50 households per week. However, the majority of work to address the social needs of Americans still relies heavily on community-based organizations with little to no interoperable technology and in some cases, even limited connectivity.

In many ways, the social care landscape of today resembles the healthcare landscape of 15 years ago. We have an opportunity to learn from both the successes and the challenges that stemmed from the HITECH Act and to apply those learnings to modernizing the fabric of our social support network:

- Incentivize the adoption of interoperable technology by community-based organizations.
- Develop and establish curricula to help community-based organizations hire staff with the core competencies needed for a more connected environment.
- Establish regional entities that can help agencies understand and choose among technological options and aid in their implementation.
- Finalize the HIPAA Coordinated Care NPRM issued in 2021, to enable increased interoperability among all stakeholders, including more sensitive social care entities. Reduce individual state-by-state variation in privacy laws that might impede interoperable exchange.
- Embrace the existing work already done through TECCA to prioritize future adoption of social care uses cases, as standards mature and trading partners come online.

Certified EHRs and the healthcare organizations who use them will play a crucial role in strengthening how our country cares for all who call it home. All of us have spent time, money, and energy building the existing healthcare technology ecosystem into what it is today – now, it is time to fold social care into that technological infrastructure, not as a separate or standalone entity, but as one that can interoperate freely and with ease.

We look forward to continuing to work with you on this most important issue. Thank you.