

The Office of the National Coordinator for Health Information Technology (ONC) Health Information Technology Advisory Committee Virtual Hearing March 10, 2022

Testimony of

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Please allow me to express my gratitude to appear before the members of this distinguished advisory committee and for your dedication and leadership particularly related to the development of Health Information Technology (HIT) polices, standards, implementation specifications, and certification criteria relating to the use of HIT to promote equity. It is my pleasure to join these fellow panelists to provide thoughtful observations and insights into future oppertunities to strengthen the nation's HIT infrastructure to support improved health and wellbeing for all Americans, particularly those most impacted by social and health inequities.

I've had the distinct honor to serve as the Chief Informatics Officer at AllianceChicago, a US Department of Health and Human Services, Health Resources and Services Administration (HRSA) funded Health Center Controlled Network (HCCN). I began my clinical profession as a Pediatric ICU and Trauma Services Nurse and soon thereafter developed a strong interest in Biomedical Informatics. I completed my informatics training in 2001 and have worked in both academic medical centers and community-based healthcare organizations throughout my career. I joined the informatics team at AllianceChicago in 2004 and have been committed to leveraging the power of health information technology solutions to improve individual, community and public health. From my first days working as an ICU nurse, to my current role in informatics, I have seen firsthand the significant impact of social and economic disparities on the health and wellbeing of individuals, families, and communities. For the past 20+ years, I've dedicated my professional life toward developing solutions to promote health equity.

AllianceChicago (AC) is one of the oldest and most respected HRSA funded Health Center Controlled Networks (HCCNs). Founded 25 years ago, the AC has been developing shared infrastructure to support HRSA funded Community Health Centers (CHCs) particularly in the implementation and use of HIT. Building upon groundbreaking work promoting cutting-edge use of Electronic Health Records Systems



(EHRS) and other HIT¹, AC has built expertise and infrastructure in broader information technology including digital health, health IT policy, interoperability, data analytics, practice coaching and quality improvement. In addition, AC operates an innovative, community-based technology enabled research and innovation network focused on expanding the participation of community-based organizations, clinicians and patients in research. AC links more than 72 CHCs across Illinois and 18 other states that reach more than 3.9 million, highly diverse patients. The communities served include urban and rural populations, low-income and uninsured individual, racial and ethnic minorities, LGBTQ community, refugee and homeless populations. The mission of the organization is to improve individual, community and public health through innovative collaboration and has always been focused on health equity and the commitment to reduction and elimination of health disparities.

To support the realization of the mission, AC utilizes the Learning Health System (LHS) model² as the primary framework to inform the design and delivery of services. The LHS model has been a fitting framework to ensure the use of evidenced-based practice standards in care delivery, allow for the examination of outcomes at the population level, and to further inform the development of scientific evidence as well as recommend adjustments to clinical guidelines in order to improve care to the underserved. The LHS model can inform the design, development, and implementation of programs and services aimed at achieving greater health equity. Like the LHS model, our approach to understanding opportunities related to health equity begin with assessing and identifying social, economic, environmental, physical, and behavioral factors that impact health and wellbeing. Upon completing individual and population level assessments, it is necessary to create a comprehensive, prioritized patient-informed plan of care. Based on the plan of care, interventions are organized and implemented according to patient preferences, resource availability, and impact on desired outcomes. Through formal research and evaluation methodologies, we evaluate the impact and outcome of our work and introduce system level changes as necessary to improve health equity.

Identify/Assess

Based on AC's collective experience, I wish to share with you some challenges and opportunities we envision as we seek to optimize our efforts to achieve health equity for all individuals and families served by our community health centers. To organize my commentary, I've reflected on our experiences in each phase of the LHS cycle described above. As mentioned, our work in health equity often begins with the assessment and identification phase of the process. The goal of this phase of the process is to gather as much information as possible to determine oppertunities to improve health equity. AC began our initial work in health equity as an early participant in the HRSA sponsored Health Disparities Collaborative (HDC)³. The HDC initiative started in the late 1990s and was a national effort in

¹ Enhancing Quality in Patient Care (EQUIP) Project | Digital Healthcare Research (ahrq.gov)

² How Learning Health Systems Learn: Lessons from the Field (ahrg.gov)

³ Quality Improvement Implementation and Disparities: The Case of the Health Disparities Collaboratives on JSTOR



which more than 900 CHCs incorporated an approach to rapid-cycle quality improvement, learning collaboratives, and a chronic care management model with a focus on reducing health disparities. One of the key learnings from the HDC initiative was that while practice and organizational improvements could help reduce disparities; social, environmental and community factors have significant impact on health outcomes. A major recommendation from the HDC experience was that CHCs should develop an approach to assess patients for social care needs and implement "enabling services" to mitigate social and economic risk impacting health outcomes⁴.

In 2016 the National Association of Community Health Centers (NACHC) and its partners developed a Social Determinants of Health (SDOH) Risk Assessment tool called the Protocol for Responding to & Assessing Patients' Assets, Risks and Experiences (PRAPARE)⁵. AC was a pioneering partner in the PRAPARE effort and deployed the initial tool at 3 participating health centers. Among the many lessons learned in this effort, a few are worth highlighting; 1) it is difficult, in the context of providing healthcare to individuals with complex needs, to efficiently collect SDOH data on every patient that presents for care, 2) colleting data only one-time is a "snapshot" of the patient's (and in some cases, the family's) social care needs, 3) collecting SDOH data only from patients that present for care doesn't allow for the collection data across the entire patient population and 4) patients often present with more than one social care need, making prioritization of social care needs challenging and complex⁶. We also recognize that the PRAPARE protocol emphasis individual social, emotional, and financial needs, therefore, other methods are necessary to assess physical (place based), environmental, and behavioral factors as well as policy and structural determents of health. Using a single method to collect SDOH data often leads to a "more blurry" picture in terms of our understanding of need as we have yet to optimize the availability of multisector data to inform our social care interventions. We are currently experimenting with using a combination of data collection methods including collecting information from the individual as well as curating data from public and community-based data sources. Using a mixed-method data collection approach allows for a more comprehensive understanding of the social, economic, behavioral and structural factors that impact health, health disparities and equity.

Recently, AllianceChicago completed the development and implementation of a predictive model for the proactive prevention of lead risk poisoning⁷. In this project, AC and its partners were able to develop an innovative predictive model that alerts pediatric care providers of a patient's risk for lead poisoning. The predictive model includes data inputs from more than 11 data sources spanning clinical data from the EHRS and data from the Women, Infants and Children's (WIC) program as well as various municipal

⁴ ReportFinal.edits.indd(aapcho.org)

⁵ Homepage - PRAPARE

⁶ Collecting SDOH in the Clinical Setting - Findings from the National PRAPARE Pilot 2019.pdf

⁷ <u>Predictive Analytics for Proactive Lead Poisoning Prevention | Pediatrics | American Academy of Pediatrics (aap.org)</u>



databases containing information on building blueprints, household tax assessments, and city violations records. The Lead Prevention project demonstrates the power of utilizing already existing data assets to create a more "clear picture" of a patient's risk profile. Ultimately, the expansion of HIT policy and standards to increase the availability and use of heterogenous, multisectoral data is necessary to support improved health equity.

Once SDOH data is gathered at a local level, the information should be shared with other organizations that care for patients including social care and community-based providers. The Gravity Project has developed an initial Implementation Guide (IG) which defines the exchange of SDOH content using the Fast Healthcare Interoperability Resources (FHIR) standards⁸. The FHIR IG defines how to represent and share content used to support the screening, clinical assessment/diagnosis, goal setting, and the planning as well as performing of interventions. This FHIR IG facilitates the sharing of information between key stakeholders including healthcare providers, community-based organizations, and social care programs. AC has agreed to partner with HL7 to test this FHIR IG and looks forward to sharing the results from our pilot implementation.

Plan

In healthcare, the term "Care plan" or "Plan of Care" has significantly evolved. The earliest known Nursing Care plan is attributed to Ellen L. Buell, a public health nursing instructor at Syracuse University, NY and dates back to the 1930s. Its relevance to health equity cannot be overlooked as the core concept of this proposed care plan included a listing of all family members and their current health status, socioeconomic metrics, housing conditions, nationality, as well as social and emotional health status. This early version of the NCP has also evolved over time, however today's NCP plan is still grounded by a comprehensive biopsychosocial assessment and thus includes domains covered in the initial version. The contemporary NCP includes five required components 1) assessment, 2) expected outcomes, 3) interventions, 4) rationale for interventions and 5) evaluation of the impact/outcomes of the plan¹⁰. There is an abundance of research already published about the need for a longitudinal plan of care versus the usefulness of an episodic care plan. However, there is confusion how to operationalize a plan of care particularly because of unaligned definitions from various disciplines and disagreement about the best approach to create a harmonized care plan¹¹. The most recent version of

⁸ HL7.FHIR.US.SDOH-CLINICALCARE\Home Page - FHIR v4.0.1

⁹ The American Journal of Nursing Vol. 30, No. 4 (Apr., 1930), pp. 399-407 (9 pages)

¹⁰ The Nursing Process | American Nurses Association | ANA (nursingworld.org)

¹¹ patient-centered longitudinal care plan: vision versus reality | Journal of the American Medical Informatics Association | Oxford Academic (oup.com)



the FHIR^R resource CarePlan defines an initial approach to organizing a multidisciplinary plan of care including information about "who is involved" and "what actions" are intended¹². While the current version of the FHIR CarePlan is a step in the right direction, additional context, definitions, and discrete data should be included in future iterations. In the context of health equity, it is imperative that the plan of care be intersectoral. As was true in the 1930s version of NCP, the plan of care should include domains for assessment, interventions and outcomes which can be shared across the ecosystem of organizations that serve the needs of patients, particularly those with complex health, mental health and social care needs. Therefore the care plan must include the social, behavioral, environmental, financial as well as clinical aspects of the patient's status and needs. In order for multisector data sharing to occur, infrastructure investments are necessary particularly in the social care and community-based service arena. In addition, more efforts are needed to build trust for multisector data sharing ¹³. Ultimately a data informed, patient-centered, longitudinal, intersectoral (public/environmental health, education, social services, and community based) plan of care will be needed to achieve a full vision of equity in health and wellbeing.

Intervene

The US social care, environmental health, and financial/housing assistance and other community-based service providers are unlikely to have the depth and level of services necessary to respond to the scale of needs identified through widespread assessment of social care issues. In order to scale social care services, the delivery of interventions will increasingly rely on technology enabled services. In addition, there is growing evidence that consumers are increasingly seeking digital technologies to access services. Take for example, the wearable medical device market which is expected to reach more than \$27 million in sales by 2023 (a jump from only \$8 million in 2017)¹⁴. Beyond the wearable market, the COVID-19 pandemic created a rapid transition to telehealth services and while the future of virtual care is somewhat unknown, several studies project that many aspects of virtual care services will continue¹⁵. With the growth of digital health, virtual care and remote patient monitoring programs, the risk of creating a digital divide is increasingly concerning. The investments in broadband services and infrastructure are necessary, however The Infrastructure Investment and Jobs Act will not be effective if people can't use online applications. Digital Literacy is rapidly becoming a major concern across various sectors, notability during the COVID-19 pandemic within educational institutions¹⁶. Likewise, the healthcare sector has recognized the importance of digital literacy and access to on-line healthcare

¹² CarePlan - FHIR v4.0.1 (hl7.org)

^{13 &}lt;u>Cross-sector collaboration for data sharing – National Center (national complex.care)</u>

¹⁴ Digital Transformation in Healthcare in 2022: 7 Key Trends | DAP (digital authority.me)

¹⁵ Project MUSE - COVID-19: Exploring the Repercussions on Federally Qualified Health Center Service Delivery and Quality (jhu.edu)

¹⁶ <u>SciELO - Brazil - Rethinking Digital Literacy Practices and Educational Agendas in Times of Covid-19 Uncertainty</u> Rethinking Digital Literacy Practices and Educational Agendas in Times of Covid-19 Uncertainty



services ¹². Prior to the COVID-19 pandemic, vulnerable populations were already experiencing the digital divide. It is critical that policymakers, program/service creators, and the workforce responsible for the delivery of services have access to digital health tools which address the needs of diverse populations (age, races, ethnicity, gender, sexual orientation, primary language, and socioeconomic). Furthermore, it is important to create a mechanism to track digital health access and usage across sociodemographic populations to inform future investments and minimize the digital divide.

Evaluation

Big data and advanced analytics including machine learning (ML) and artificial intelligence (AI) are increasingly prevalent in healthcare. These tools offer tremendous promise to optimize diagnosis, treatment, and interventions ¹⁷. Prior to the expansion of ML/AI in healthcare, it was well documented that research programs in the United States significantly underrepresent racial and ethnic minorities ¹⁸. Other studies have examined representation of sociodemographic groups and have documented similar conclusions (e.g., LGBTQ, Older Adults). In addition to developing policies and programs to increase the participation of underrepresented groups in research, specific attention should be focused on developing approaches to protect against bias in ML/AI that can perpetuate health disparities. To achieve the goal of an "equitable learning health system", we must intensify efforts to increase the diversity of individuals involved in community engaged research and evaluation.

In Summary there are four main recommendations that could have a positive impact on the development of a more Equitable Learning Health System:

- Expand IT policy and standards to increase availability and use of heterogenous, multisectoral data
- Support the development of information technology to encourage the coordination of intersectoral care planning and intervention
- Promote the development of community-based training programs to optimize the use of digital health tools which account for varied digital literacy levels
- Intensify efforts to increase the diversity of individuals involved in community engaged research and evaluation

Again, I wish to thank you for the invitation to provide my perspective and experience and I consider it a great honor to have had this time with my fellow panelists and the HIT Advisory Committee. I would also like to extend my gratitude to the more than 260,000 individuals working at the 1,300+ CHCs to

¹⁷ The role of artificial intelligence in healthcare: a structured literature review - PubMed (nih.gov)

¹⁸ https://www.sciencedirect.com/science/article/pii/S0146280618301889



provide care to this countries vulnerable and underserved populations. I have faith that our government and private sector leaders, working together can achieve a more fair, just and equitable community for all.

Sincerely,

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