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Social Determinants of Health: Data Standardization in Electronic Health Records

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Introduction

Social determinants of health (SDoH) are environmental or contextual factors that influence health. More specifically, SDoH are defined as "conditions in the places where people live, learn, work, and play that affect a wide range of health and quality-of life-risks and outcomes".(Centers for Disease Control and Prevention, 2021) With an ever-growing emphasis on the health of populations and widespread recognition of the importance of SDoH in health outcomes, there is substantial demand for well-structured and clinically useful SDoH data. (Institute of Medicine, 2014) Additionally, there is collective evidence that integrating SDoH data into electronic health records (EHRs) enhances our ability to forecast patient outcomes (Chen, Tan, & Padman, 2020) (K. Craig et al., 2021) (PAN FOUNDATION, 2021) Multiple screening tools exist to support standardized collection and documentation, and there is some available

standard terminology to support documentation. However, current evidence indicates poor documentation of SDOH in EHRs. (Guo et al., 2020) Moreover, we must address the standardization and communication of SDOH data across both traditional health care settings and community-based settings providing critical services that address SDOH. These priorities and needs are clearly reflected in the recent Institute of Medicine report “The Future of Nursing 2020-2030: Charting a Path to Achieve Health Equity” and its recommendation that health care systems “incorporate nursing expertise in designing, generating, analyzing, and applying data to support initiatives focused on social determinants of health and health equity using diverse digital platforms, artificial intelligence, and other innovative technologies.” (Wakefield, Williams, & Le Menestrel, 2021)

SDoH, environmental and contextual factors influencing health, are of vital importance to patient care outcomes. When a patient is underinsured, lacks knowledge, does not have transportation, or has conflicting ethical or religious beliefs, there is a possibility that they may not follow the recommended care plan. This lack of adherence could interfere with effective treatments, discharge planning, or planning for transitions between care settings, resulting in potentially avoidable re-admission and poor health outcomes. Without assessment and documentation of SDOH, there would be no basis for a system of referral to community organizations and other resources that could alleviate barriers to realizing positive health outcomes. Moreover, without systematic documentation of SDOH, we could be greatly hampered in discovering their role in human health through scientific research. Understanding the role of SDOH in human health is particularly important as we work to understand the underlying causes of health disparities, to which SDOH appears to contribute substantially. (Tai, Shah, Doubeni, Sia, & Wieland, 2021)

Improvement of SDOH often requires external interventions by governments, non-governmental organizations (NGOs), philanthropists, businesses, and community volunteers. However, the clinical team of patients, nurses, physicians, and other clinicians can collaborate, employ technology, and access resources to address SDOH in the interest of improving health outcomes. Conceptual models of SDOH developed by the Kaiser Family Foundation and Healthy People 2030 agree that economic stability, neighborhood/built environment, education, community and social context, and the health care system

constitute the five domains of SDoH; KFF includes food as a sixth domain. (USDHHS Office of Disease Prevention and Health Promotion, 2022a) (Heiman & Artiga, 2015) The relationship between these factors and human health has been firmly established by a large body of scientific evidence, from epidemiologic to epigenetic studies. (USDHHS Office of Disease Prevention and Health Promotion, 2022b) (Bollati & Baccarelli, 2010)

Informaticians have worked tirelessly for decades to advance data standardization with the goal of supporting semantic interoperability, a term defined for the international EHR standards body Health Level Seven as “the ability to import utterances from another computer without prior negotiation, and have your decision support, data queries and business rules continue to work reliably against these utterances”. (Dolin & Alschuler, 2010) Substantial progress has been made in numerous areas of health and health care. However, it is vital that we continue to identify and address emerging priority areas for data standardization as health care evolves. The purpose of this paper is to describe and characterize the need for data standardization related to SDoH in electronic health records, describe existing efforts to address this need, and make recommendations for the future in support of advancing human health.

Challenges in Standardization of SDoH Data

Currently, there is poor documentation of SDoH in EHRs despite the growing recognition of its importance, and calls for the inclusion of SDoH in EHRs have been made by organizations such as the National Academies of Medicine and American Academy of Nursing. A recent study of administrative data collected by Veterans Health Administration hospitals in the U.S. showed little documentation of SDoH, including housing instability and substance use disorders. (Wray et al., 2021) Similarly, a large study of EHRs in a Florida clinical research network indicated very poor utilization of ICD-10-CM "Z codes" (codes Z55-Z65), standard codes that are widely available and can be used to classify non-medical determinants of health. Additionally, comparison with U.S. census data indicated that SDOH were substantially underreported.(Guo et al., 2020)

A recent health affairs article asserted that the two main challenges in advancing the use and interoperability SDoH data include: 1) lack of consensus on standards for capturing or representing SDoH in EHRs, and 2) insufficient evidence that once information on them has been collected, social determinants can be effectively addressed through referrals or other action tools. (Cantor & Thorpe, 2018) To address these challenges and effectively use social determinants in health care settings, researchers suggested creating national standards for representing data related to SDoH in EHRs. They also suggested incentivizing data collection through financial or quality measures and expanding the body of research that measures the impact of acting on the information collected. (Cantor & Thorpe, 2018) Interviews with private EHR vendors revealed the need for more standardization of SDoH performance measures across various federal and state programs, better mapping of SDoH measures to multiple types of codes, and developing more codes for all SDoH measures of interest. (Freij et al., 2019)

Status of SDOH Data in Electronic Health Records

There are two primary sources of SDoH data: 1) Data externally derived from community-level information, and 2) Individual-level data collected directly from a patient or caregiver. It is crucial to consider the accuracy of applying community-level or geographically determined data to an individual. Community-level data, however, may be beneficial at a systems level, may enhance the performance of predictive models, and may be of interest to the researcher who is exploring the associations of community context to health outcomes of populations.

Individual-level data provided by a patient or caregiver may be a more accurate description of SDoH. Individual-level data collection can be accomplished through screening tools, such as checklists, interviews, or surveys. Data collection can be accomplished at the point of care or prior to a care event through a portal, personal health record, kiosk, tablet or smartphone. The Committee on Recommended Social and Behavioral Domains and Measures for EHRs recommended that most SDoH data be self-reported and collected using one of varied possible platforms, including home computers and hand-held devices, with each method ensuring privacy and appropriate validation. (Adler & Stead, 2015) However,

the implementation of data collection processes outside of the care system can present challenges. As a result, most screening is accomplished during a health care encounter using an embedded tool.

For some years, various SDoH screening tools have been created and added to EHRs by vendors and health care systems. There have been three major approaches to representing SDoH in EHR systems. One approach is to examine existing structured and unstructured data in current EHRs to extract SDoH data. (Hatef et al., 2019) A second approach is to collect standardized social determinants health data using the EHR. The third approach is to use the FHIR standard to create profiles and extensions which will allow external data to be used in the EHR. An example is the implementation of the North Carolina Department of Health and Human Services (NCDHHS)'s SDOH Screening Form. The NCDHHS Screening Form is implemented as a live FHIR Questionnaire in an EHR. (McDonald, Tenenbaum, & Amos, 2019) (Watkins et al., 2020)

Not all systems use valid and reliable instruments with standardized data elements. A study of the practices of six EHR vendors with the largest market share revealed that they are responding to client demand, federal initiatives, and their own strategic plans in creating tools. However, they recognize the need for better standardization and mapping of measures to the current multiple types of codes and the development of additional codes to enable analytics, population health management, and interoperability of the data.(Freij et al., 2019) Healthcare organizations must develop a protocol for collecting standardized and interoperable SDoH using valid tools within an EHR if they are to improve health, lower cost, advance healthcare access, assess SDoH needs, link to community-based services, and develop a sustainable business model to fund the needed community resources. Interoperability along with common value sets, and the capability to use this data in analytics processes are key considerations. (Health Catalyst Editors, 2019)

Commonly, representations of SDoH for individuals are inferred using community-level data, assigned to the individuals based upon their geocoded locations. This approach makes a sweeping assumption that the patient's social and environmental characteristics are the same as those of the larger community

surrounding an address of record, while many others— including those cited above—rely on patient self-report. (K. J. T. Craig et al., 2021) While selfreport can be an effective tool, nurses collecting patients' SDoH information in this way meet resistance. The reasons include patients' lack of understanding of the relationship between their care and what they perceive as non-health-related data, as well as privacy questions and concerns related to stigma and shame (Berkowitz et al., 2021; PAN FOUNDATION, 2021) Individual sensor measurements such as air quality measurements from wearable devices have tremendous potential as direct, individual measurements of SDoH. Sensor measurements and other patient-generated health data (PGHD) could be integrated into electronic health records to support both clinical decision making and subsequent research efforts. (V.L. Tiase et al., 2020; V. L. Tiase, Sward, et al., 2021; V. L. Tiase, Wawrzynski, et al., 2021) Currently, there are numerous policy and technical barriers, including a need for standardization, to the integration of PGHD into electronic health records. (V.L. Tiase et al., 2020) Platforms and tools for better integrating sensor data into research efforts are emerging. (Gouripeddi et al., 2020) An innovative alternative to measurement is the individual assignment of SDoH using computational models, which can be used to simulate SDoH data in situations where it can not be directly measured. (Lund, Gouripeddi, & Facelli, 2020a, 2020b) As we realize innovation in measuring or inferring SDoH, the need for standardization persists.

Large-scale secondary analysis of SDoH data that has not been standardized is challenging, and relies upon the harmonization of site-specific SDoH data to common data elements. The Observational Medical Outcomes Partnership (OMOP) Common Data Model and the Patient Centered Outcomes Research network (PCORnet) Common Data Model are two examples of common data models to which EHR data including SDoH data can be harmonized. For example, OMOP is used to harmonize data for the National Covid Cohort Collaborative (N3C) and its associated research studies. (Haendel et al., 2021) The PCORnet Common Data Model supports PCORnet, a nationwide research network, as well as PCORnet RECOVER, a largescale initiative aimed at better understanding post-acute sequelae of SARS-CoV-2 (PASC). (PCORnet: The National Patient-Centered Research Network, 2022) (Fleurence et al., 2014) However, given variation in the structure of the data from the source EHRs, there

is substantial information loss in the process of harmonization. Moreover, these projects suffer from a lack of SDoH data, given widespread lack SDoH data inclusion in source EHRs.

Standards and Terminologies for Representing SDoH in EHRs

International Classification of Diseases

Given the importance of SDoH data in improving health outcomes and lowering costs, the International Classification of Diseases, Tenth Revision Clinical Modification (ICD-10-CM) developed a set of standardized data elements within a category of codes known as "Z codes". Z codes are a subset of ICD-10-CM codes used to capture reasons for encounters, as well as those factors known to influence health status and contact with health services. (Mathew, Hodge, & Khau, 2020) There are nine categories of Z codes related to SDoH and multiple subcodes within each category. In total, the ICD-10-CM provides 97 granular codes that can be used to describe SDoH, including education and literacy, employment and unemployment, occupational exposure to risk factors, problems related to housing, problems related to social environment, problems related to upbringing, problems related to a primary support group, and problems related to psychosocial circumstances. (ICD10Data.com, 2022)

LOINC/ SNOMED

Logical Observation Identifiers Names and Codes (LOINC) and Systemized Nomenclature of Medicine - Clinical Terms (SNOMED CT) are comprehensive and commonly used standardized terminologies. LOINC and SNOMED are separate clinical terminologies, but the standards organizations that govern the two systems are working together to build closer links and reduce duplication. The approach is for LOINC to provide codes representing the "questions" and SNOMED CT to provide codes of nominal and ordinal items representing the "answers" of information items. A 2019 analysis by the Gravity Project found that codes exist to represent SDoH in both SNOMED-CT and LOINC. Still, they are often not comprehensive, may or may not match the commonly used screening tools, and do not consistently match practice needs. (Arons, DeSilvey, Fichtenberg, & Gottlieb, 2019)

The Gravity Project

In 2017, a multistakeholder meeting was convened by the Social Interventions Research and Evaluation Network (SIREN) under the auspices of the University of California San Francisco. In 2019, with funding from the Robert Wood Johnson Foundation and EMI Advisors, LLC, SIREN launched The Gravity Project. The goal of The Gravity Project was to serve as a national collaborative to develop consensus-based data standards that aim to improve the process by which SDOH data is gathered, coded, and shared. The Gravity Project develops Use Cases, identifies common data elements and their associated value sets, develops consensus-based sets of code recommendations, and develops related HL7 Fast Health Interoperability Resources (FHIR) guides to facilitate the exchange of SDoH across settings (Lousberg, 2022)

Drivers of Improved Standardization

In addition to the development of standards and terminologies to support the collection, re-use, and exchange of SDoH data, other organizations and efforts are currently influencing the standardization of SDoH data. These influences range from the large-scale implementation of specific screening tools to policy and funding initiatives, to large-scale data harmonization efforts. These drivers actively shape the way SDoH data is collected and used. We detail several examples below.

Federal Health IT Strategic Plan (2020-2025). The standardization and interoperability of SDoH data recently became a federal priority. In 2020, the Office of the National Coordinator for Health Information Technology released its new Federal Health IT Strategic Plan, with a specific objective of integrating health and human services data for "addressing SDoH at the individual and population levels." It specifically seeks to "advance standardization and interoperability of SDoH and social service data across federal programs through the use of standard health IT terminologies, definitions, and methods for data collection and exchange." (*The Office of the National Coordinator for Health Information Technology, 2020*)

Vendor-driven standardization. Vendors are actively developing products to facilitate the collection and use of SDoH data for their clients and seek solutions to data standardization and interoperability challenges through internal product decisions and collaboration with policymakers. Due to a lack of policy standards around SDoH data, product-specific decisions may result in de facto standardization, given the market shares of particular vendors. However, commercial vendors appear ready to collaboratively discuss policy solutions such as standards or guidelines with each other, health care systems, and government agencies to further promote the integration of SDoH data into the standard of care for all health systems. (Freij et al., 2019) *Accountable Health Communities* (AHC). In the AHC model, the U.S. Centers for Medicare & Medicaid Services is partnering with communities in 21 states to implement a systematic program for assessment and referral related to SDoH. This program uses a 10-item screening tool called the Accountable Health Communities (AHC) Health-Related Social Needs (HRSN) Screening Tool. (Centers for Medicare & Medicaid Services, n.d.)

Clinical Research Data. Large, multi-center clinical research data networks such as the N3C Collaborative seek to harmonize non-standardized data describing SDoH. (Bennett et al., 2021) While harmonization poses several challenges, including loss of information during sequential code transformations, it offers a means to study the role of SDOH in human health in the absence of standardization.

Global Efforts to Advance Standardization

LOINC and SNOMED, previously described, are international standards organizations.

However, there are other international efforts in progress. The United Nations Sustainable Development Goals (SDG) are a collection of 17 interrelated global goals that seek to provide a "blueprint to achieve a better and more sustainable future for all." (World Health Organization, 2019) Of these, Goal 3 Good Health and Wellbeing, aims to "ensure healthy lives and promote well-being for all at all ages." However, there is a recognition that the SGDs are interlinked, and SDoH-related health indicators pervade the factors influencing these goals. These Core Health Indicators have provided the

basis for mapping work within the WHO Family of International Classifications Network Family Development Committee. (World Health Organization-Family of International Classifications (WHO-FIC) Network, n.d.)The ultimate goal of the work has been to standardize potential value sets for the Core Health Indicators, which may then be used to collect data, for example, at an individual level via the EHR. Individual-level data might then be aggregated in order to track progress against the SDG Goal 3 targets. While Core Health Indicators cover aspects such as health status, service coverage, health systems, and certain risk factors, the potential influence of wider determinants is less well formed, and SDoH are therefore less likely to appear in future EHRs. For example, there are currently no Core Health Indicators relating specifically to poverty, education, and inequality (SDGs 1, 4, and 10, respectively). Further foundational work is needed to recognize and represent the impact of these and other wider determinants. (World Health Organization, 2018)

Summary & Recommendations

The importance of SDoH in influencing a broad range of health outcomes and healthcare access issues is undisputed. The availability of widely and routinely collected SDoH data in EHR systems could substantially advance our capacity to understand and intervene upon those relationships. We support mandatory adoption and advancement of national and international data standards for representing SDoH, with defined terminologies and profiles that enable compliance. In the U.S., mandatory use and adoption would be entirely consistent with current federal health IT priorities. We believe that the work of the Gravity Project and standards organizations such as LOINC and SNOMED is critical to developing appropriate terminologies and profiles and that nurses must engage in those efforts.

Nurses are the primary collectors of SDoH data in many healthcare settings. Nurses often coordinate care upon transitions such as transfer or discharge and they are well-positioned to intervene or refer based upon the data. Given these key roles related to assessing and intervening upon SDoH, it is crucial that nursing remain engaged in national standardization efforts such as the Gravity Project and that nursing advances and supports future efforts to establish data standards for SDoH at the national and

international level. A lack of engagement by nursing could lead to unactionable SDoH data and suboptimal care resulting from poor documentation or data quality, despite increased burden to nurses and systems.

Additionally, we must acknowledge a) that current documentation of SDoH in EHR systems likely falls to nursing in most settings, and b) SDoH are poorly documented in EHRs.

Contributing factors may include:

- documentation burden,
- workflow challenges,
- clinician engagement in the process,
- the need for interpreters,
- training needs,
- operational challenges,
- lack of a closed-loop between data collection, risk calculation, and referral to a community-based resource,
- patient refusal to answer due to fears of data security, stigma, and inability to connect data collection to their care
- standards might not address the SDoH of interest.

The contributions of these and other factors are minimally understood. In addition to good patient education, nursing needs to invest more time and energy into informatics research and creative innovation to elucidate and address underlying causes of poor SDoH documentation by nurses and other health care providers. The onus is on nurse educators and researchers, as well as skilled and experienced nurses, to conduct this research, disseminate the findings, and promote patient education to enhance the reliability and veracity of patient SDoH self reports.

Research and innovation to advance the collection and use of standard SDoH data to improve patient outcomes are clearly needed. Priority areas for research include documentation barriers, secondary

analyses of SDoH data, community interoperability of existing SDoH data (the systems and processes for closed-loop information sharing to assess and address SDoH), and clinical decision support systems that facilitate appropriate actions based upon standard SDoH data. While we've focused our discussion on a discrete set of commonly recognized SDoH and their standard representation within EHR systems, we must acknowledge that there are other SDoH, such as culture, that clearly influence health outcomes, but cannot be adequately characterized and represented by coded EHR data. Although the limited set of SDoH captured in the EHR is meaningful and important for studying health outcomes, it is a limited representation of the myriad social and other exposomic factors that influence human health. We strongly advocate for a complex systems approach in studying SDoH and their role in human health; an approach that considers other exposomic determinants of health such as the environment, culture, public health measures, and economic conditions, along with clinical and biological variables.

Summary of Recommendations

- Mandatory adoption and advancement of national and international data standards for representing SDoH
- Defined terminologies and profiles that enable compliance
- Increased nursing engagement in ongoing national and international standards efforts
- Research related to root causes of poor SDoH documentation in electronic health records
- Increased education, communication and awareness of the importance of SDoH data
- Research and innovation to advance the collection and use of standard SDoH data with priority areas that include: documentation barriers, secondary analyses, interoperability, and clinical decision support
- Complex systems approaches to studying SDoH and their role in human health

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