

Automating data collection methods in electronic health record systems: a Social Determinant of Health (SDOH) viewpoint

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ABSTRACT

Social Determinant of Health (SDOH) data are important targets for research and innovation in Health Information Systems (HIS). The ways we envision SDOH in “smart” information systems will play a considerable role in shaping future population health landscapes. Current methods for data collection can capture wide ranges of SDOH factors, in standardised and non-standardised formats, from both primary and secondary sources. Advances in automating data linkage and text classification show particular promise for enhancing SDOH in HIS. One challenge is that social communication processes embedded in data collection are directly related to the inequalities that HIS attempt to measure and redress. To advance equity, it is imperative that care-providers, researchers, technicians, and administrators attend to power dynamics in HIS standards and practices. We recommend: 1. Investing in interdisciplinary and intersectoral knowledge generation and translation. 2. Developing novel methods for data discovery, linkage and analysis through participatory research. 3. Channelling information into upstream evidence-informed policy.

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1. Introduction

1.1. Social Determinants of Health (SDOH) and Health Information Systems (HIS)

Social determinants of health (SDOH) refer to “the conditions in which people are born, grow, live, work and age” (Marmot et al., 2008). SDOH arise from various forces (social, political, economic) which contribute to individual factors with significant influence over health status, e.g., income, education, culture, and so on. Individual and population-level data reveal predictable, independent, and intersectional associations between SDOH variables and health outcomes (Conway et al., 2019; Gold et al., 2018; Gottlieb et al., 2015; Lofters et al., 2017; Marmot et al., 2008). There are various material, psychosocial, and neo-material pathways (Raphael et al., 2020) leading to intersections of access and privilege contributing to health status (Crenshaw, 2017; Hankivsky & Christoffersen, 2008). Health inequities (variations in health outcomes, which are unjust due to their relationship to social determinants, as per Kawachi et al., 2002), are primarily measured by availability and quality of resources, level and quality of social connectedness, and relative status within a population. Health equity is a core concept of population health promotion, and a primary objective of SDOH paradigms (Lucyk, 2018; Lucyk & McLaren, 2017).

Greater attention to SDOH and health equity has facilitated international and interdisciplinary partnerships to alleviate and advance our understanding of

health disparities through health metrics, e.g., the Institute of Medicine Measures of Social and Behavioural Determinants (Bambas, 2005; Giuse et al., 2017). In a health information system (HIS), SDOH may be codified based on individual attributes, such as annual income, level of education, occupation, domestic status, as well as by the characteristics of a population. These can include median income level, density of services, level and type of education, paid employment, cultural values, migration, etc. (Public Health Agency of Canada [PHAC], 2016; Raphael et al., 2020). Measurements of SDOH are relevant for profiling, prediction, and targeted response; facilitating comprehensive care, treatment, and prevention (Hewner et al., 2017; Monsen et al., 2017; Winden et al., 2018). Combined with effective knowledge dissemination and translation, SDOH data provide potential for novel insights into determinants of health, which can lead to more comprehensive and precise healthcare decision-making, both in clinical and policy-making spheres (Barbosa & Nelson, 2016; Brewer et al., 2020; Chiolero & Buckeride, 2020; Hunter et al., 2015; Zhang et al., 2017).

As HIS digitise, health data are becoming more frequently managed in Electronic Health Records (EHRs) or similar virtual health information storage and management (e.g., Community Health Records, Electronic Medical Records, etc.; Beck et al., 2012; Winden et al., 2018). These tools can facilitate data sharing (Bazemore et al., 2016; Shahmoradi et al., 2017) and generate greater

quantities of standardised data suitable for analysis (Mooney & Pejaver, 2018). Through large data sets, SDOH information in health systems may enhance capacity to identify and predict health risk, and may promote better understanding of relationships between health determinants in complex systems (Kasthurirathne et al., 2020; Kwon et al., 2021; Thapa et al., 2021). With EHRs becoming more prevalent, greater quantities of patient data will be available in digitised and analysis-ready format (Ehrenstein et al., 2019).

“Smart” health systems are capable of continuously enhancing their capacity to incorporate, manage, analyse, and share information. Automating data collection processes are important developments towards unlocking the potential of “Big Data”/AI in the health sector. Improving the technological efficiency of HIS strengthens the flow of health data (Figure 1). As EHRs are increasingly adopted in health systems, there are many anticipated opportunities for innovation in research and design (R&D), including improvements to surveillance and forecasting, better interoperability between data-holders and enhanced communication for data-driven decision-making (Bauer et al., 2020; Chiolero & Buckeride, 2020; Mooney & Pejaver, 2018). From a methodological point of view, however, there is still a considerable need for applied and theoretical research on data collection and incorporating SDOH as meaningful data points into HIS (Theiss & Regenstein, 2017). In this viewpoint article, we aim to explore avenues for SDOH data collection from technical and social perspectives.

2. Perspective

2.1. SDOH data collection practices in EHR systems

EHR data on SDOH can include individual and population-level variables. These vary by site but can include variables such as: income status, education,

occupation, housing status, food security, race, ethnicity, immigration status, sexual orientation, gender identity, intimate partner violence, social connectedness, disability status, family size and status, religion and spirituality, access to services, and neighbourhood socioeconomic conditions, and others (Lindemann et al., 2017; Lofters et al., 2017; Monsen et al., 2016; Pinto et al., 2019, 2016; Winden et al., 2018). EHR systems can prompt data collection within a standard set of variables. These may be based on calls to research and action from stakeholders in the health system at large (professional organisations, research institutes, patient groups, etc.) or specific HIS goals (e.g., effective resource allocation, population surveillance, clinical/epidemiological research agendas; Adler & Stead, 2015; Chen et al., 2014; Chhabra et al., 2019; Gold et al., 2017; Gottlieb et al., 2015; Hripcsak et al., 2015; Lewis et al., 2016).

Currently, research on SDOH data collection in EHR systems focuses on data available through patient–provider interactions in health care settings. HIS SDOH input may come from human transcribers (e.g., in clinical notes or carts), or automated survey instruments (e.g., intake questionnaires). This does not necessarily need to take place in physical health care settings, with the internet playing a greater role in digital transmission of health information. Similarly, although not mainstream, it is a promising avenue for data science, nonetheless, incorporating geocoded census data (Biro et al., 2016) or other records relevant to the patient available through public repositories or archives, is a promising entry point for SDOH into HIS. Additional data sources and data holders for SDOH may include social media, satellite imagery, public archives, and so on and can be merged with data sets for population health analysis (Thapa et al., 2021).

Some of the potential for AI in SDOH data retrieval and analysis in EHR systems comes from the ability to mine relevant SDOH information captured in clinical notes through Machine Learning (ML),

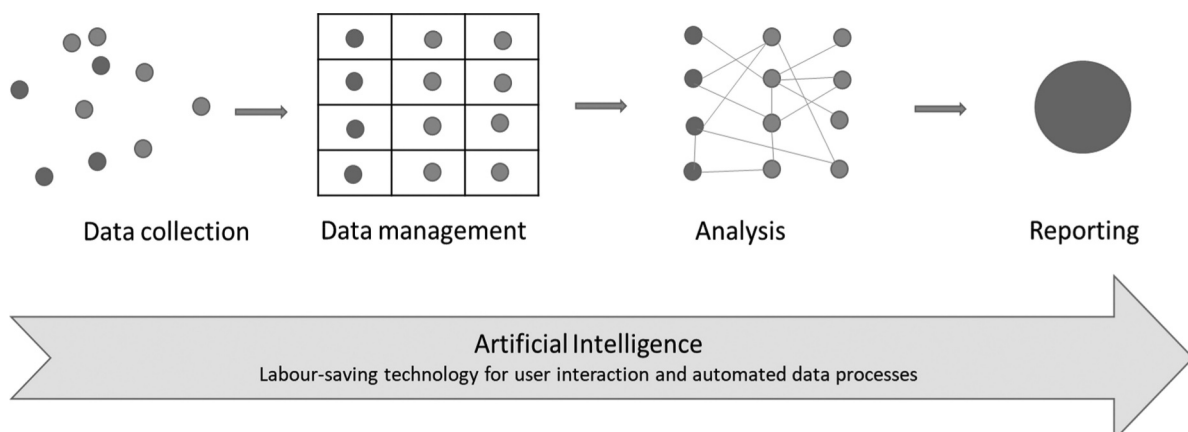


Figure 1. Stages in information flow.

such as Natural Language Processing (NLP), or other text classification methods (Feller et al., 2018; Kino et al., 2021; Stemerman, 2020; Teng & Wilcox, 2022). Advanced computational analysis of SDOH variables collected through EHRs has contributed to great accuracy in assessing risk factors for various health outcomes (Comer et al., 2011; Feller et al., 2018; Jamei et al., 2017; Navathe et al., 2018; Oreskovic et al., 2017; Roth et al., 2014; Ye et al., 2018). These may be applied to assessing psychosocial conditions, infectious disease transmission, and risk of hospital (re)admissions. The use of free-text data may increase as NLP algorithms and other ML coding advances and is incorporated into HIS (Lindemann et al., 2017). Enhancing the volume and quality of data, for example, by linking multiple sources of information, can lead to considerable analytical advantages through ML (Jamei et al., 2017; Roth et al., 2014; Teng & Wilcox, 2022; Ye et al., 2018). Linking data from multiple sources, through fair and transparent relationships between partners and stakeholders, is a vital step in encoding comprehensive SDOH data in HIS (Jain et al., 2017). The availability and usability of SDOH data depends on how HIS uses technology to maintain and strengthen relationships with end users (Zulman et al., 2016).

2.2. Avoiding inequities in health and social communication processes

The widespread adoption of standardised collection tools in EHRs is an important direction for applied research (Adler & Stead, 2015; Gold et al., 2017). Currently, clinical notes and screening questions are key sources of SDOH data. One challenge is that although SDOH are highly relevant for health, screening or dialogue on SDOH is not often part of standard clinical exchanges (Gottlieb et al., 2015; Winden et al., 2018). The nature of SDOH and the information they represent, which are subjective, intersectional, and socially constructed (Lucyk & McLaren, 2017), may also complicate the development of data collection methods and tools. There may also be deficits in the ability to conceptualise or use SDOH data in the health care setting (Hatef et al., 2019), especially the ability to translate SDOH information into meaningfully enhanced care plans or population health efforts (Breen et al., 2019). These, and other challenges pertaining to translating such complex constructs into valid measurements (e.g., social desirability bias (Krumpal, 2013)), often result in missing or unreliable information of interest when it comes to SDOH (Pinto et al., 2016).

In addition to the way in which individuals interact socially in care settings, health information collection also faces the issue of who may be systematically excluded from certain care or data collection settings

(Pinto et al., 2016). SDOH data currently collected through EHR systems may represent only a subset of the population (e.g., primary care users and/or those routinely participating in census surveys). EHR-derived data for population-level analyses of social risk would therefore be limited due to limitations in who is represented in the sample. EHR systems can conceivably incorporate various details on socio-economic conditions to patient records from multiple sources. Geocoded data or other types of linked data, including from GPS or personal smartphone apps, are also realistic possibilities for capturing and representing SDOH in EHR systems. However, global HIS are still in the early stages of developing robust legal and ethical frameworks to protect privacy and user-rights (World Health Organization [WHO], 2021).

Finally, as technology permits further automation in analytics and communication processes, existing biases in communication processes can have detrimental and multifaceted implications for health (Ntoutsis et al., 2020). For example, implicit biases increase the risk of inappropriate diagnosis and/or treatment recommendations (Syed, 2021). Furthermore, when biases manifest in social interactions, this can distort communication channels required for SDOH data collection, as well as trusting and caring connections at the centre of healing relationships (Allan & Smylie, 2015; Armstrong et al., 2001; Browne et al., 2018). The convergence of data streams, the manner in which information is determined to be relevant or irrelevant, and the complexities of coding and encoding in communication systems (Hall, 2009) affect embodied experiences within systems. There is therefore a risk that automating SDOH data collection processes, within systems currently characterised by many forms of social biases, could exacerbate health inequity.

2.3. Advancing health equity through SDOH perspectives

The SDOH perspective relies on interdisciplinary explanations for mechanisms and causal relationships within the data (Bryant, 2009; Raphael & Bryant, 2015). For example, from an SDOH perspective, poverty is not necessarily a phenomenon resulting from behaviour or lifestyle choices, but is equally related to features intrinsic to the social environment (languages, roles, abilities, and relationships available to an individual), and the circumstances one is born into (Marmot et al., 2008). Disadvantages experienced by patients contribute to each other, and compound across multiple dimensions of health, in ways directly related to their access to communication and information systems. The overall complexity of SDOH variables therefore presents complex system-level methodological and ethical challenges.

Higher quality and quantity of information increases accuracy of prediction, and ostensibly improves our knowledge of needs and promising care and prevention practices (Hassan et al., 2015; Rabovsky et al., 2017; Tan-McGrory et al., 2018; Vest et al., 2017). Yet, capturing medical information is not an objective process (Mykhalovskiy, 2001). As with all social data, findings only form a representation of social reality, the interpretation and representation of which forms its own material reality, constructed through social exchange of information and constrained by pre-existing social and cultural structures (Alvesson & Sköldbberg, 2017; Schutz, 2012). Standardised data collection determines how individual patients are represented through health data and “live” in the health system.

Essentially, when considering EHRs and the collected data they hold, we can anticipate that implicit biases present at data entry serve to perpetuate the bias at reporting and end use stages (Leslie et al., 2021) and that HIS are responsible for measuring and disrupting health inequities from multiple perspectives. Although there is considerable perceived potential for automating SDOH data collection, health researchers and practitioners must recognise that long-term population health improvements through health analytics rely on the assumption that clarity of information will disrupt systematic reproduction of inequality. Siloed and/or uncritical development of technology in HIS can exacerbate existing systemic inequities through reproducing barriers to care and service access. Further understanding the effects and processes of stakeholder engagement in EHR/HIS development and decision-making may provide insight into the health equity potential of partnerships.

As local, global, and interconnected health systems prepare to develop AI for health purposes, a focus on just and equitable application of technology is a guiding principle (World Health Organization (WHO), 2021). Researchers have observed that automated decision algorithms have perpetuated marginalising biases in the public sector (Carter et al., 2019; Ntoutsis et al., 2020). Systemic and ideological political economic drivers in local contexts are the essence of SDOH. Critical equity perspectives may permit greater awareness for the role of actors within health institutions in creating or maintaining inequalities (Liebel, 2020). Researchers in the field should provide space for contemplating how processes for acquisition, management, and use of information can variously maintain or subvert value systems (Harding, 2006). For example, gender perspectives, which are crucial to the SDOH approach, can provide evidence of “institutional erasure” of non-gender conforming individuals in the health system (Bauer et al., 2009; Vermeir et al., 2018). At a population-level, we must also attend to the historical use of routine collection of demographic

data (Legg, 2005) in structuring inequalities, especially racialised identities entangled in national mentalities (Anderson, 1991).

3. Conclusion

Health care surveillance and decision-making in health care provision can benefit from technological automation. However, there is a significant risk that advancement in this area could inadvertently exacerbate health existing disparities. Data collection in newly emerging digital spaces can offer opportunities to generate meaningful analyses of personal or community-level data, as well as moderately large quantities of data to support precision population health. Bringing SDOH perspectives into HIS R&D can facilitate an integrated schema of risk factor data for the context (i.e., the patient or population under surveillance), thereby providing opportunities to adequately address health equity by bringing attention to power dynamics inherent in cultural contexts of the HIS. As health systems incorporate AI technologies into HIS for risk factor surveillance, precision medicine, and population health equity, we will need to address systemic biases from many fronts. This should incorporate local, relational, critical, and trans-disciplinary forms of research.

3.1. Future research directions

Bringing together insights from existing frameworks, theories, and applied research, we propose three general guidelines to support equity-driven advances in automation and SDOH data collection:

- (1) Investing in and planning for interdisciplinary, intersectoral, and participatory knowledge information translation

Fostering interdisciplinary research, especially across social sciences, medicine, and computer science/engineering is an important aspect of future equity-oriented research. Interdisciplinary perspectives on health information systems may offer a realistic and sustainable balance of R&D goals (e.g., precision, comprehensiveness, equity, efficiency, security, user rights, etc.). The lived experiences of practitioners and patients, particularly patients considered to be “at-risk” for poor health based on SDOH, should also be values in all stages of R&D in HIS. This may better capture a broad range of perspectives and potential concerns in experiential participation in HIS (Brewer et al., 2020; Palacio et al., 2017). Continuing to evaluate and consult with providers and patients on promising tools and practices may lead to continually improving processes for capturing and applying SDOH information. In addition to promoting long-term goals of interoperability, this type of participatory and cross-sectoral research partnerships

in HIS may help to address the digital divide through cognisance of frequently intersecting inequities in both access to health care and IT services. Overall, equity-driven methodological decisions for capturing SDOH data require critical engagement with power structures embedded in collection locations.

- (2) Incorporating new SDOH data sources and novel collection methods with existing data sets through data linkage

Discovering novel data sources and building sustainable pathways to data from the SDOH perspective is also important for future research. This includes space to question boundaries around data currently held and maintained by information-holders, as exemplified by practitioners calling for access to data on population mental health trends currently held by social media conglomerates (e.g., Meta Platforms Inc. (Oxford Institute of Information, 2021)). There are also opportunities to collect SDOH data through technological devices and systems outside of traditional care settings. Possibilities include crowdsourcing data for public use or public access to data mined from social media programs or smartphone applications. Existing datasets from ministries of population statistics, economic and other environmental conditions may be available for use in academic and applied research. Researchers have been able to automate parts of these processes by using search algorithms to extract postal codes from patient EHRs to facilitate linkage to population data sets (Biro et al., 2016). Self-monitoring is also extremely relevant in producing health knowledge. Various personal devices and software applications could conceivably be points of access for SDOH information into HIS. Details on the social institutions in which patients and population members navigate are continuously collecting information. There are myriad sources of SDOH data, which can all contribute to robust patient and population health profiles. Building sustainable and equitable information gathering and sharing processes are crucial directions in HIS research.

- (3) Channelling health system generated information into upstream evidence-informed health policy

A paramount concern with SDOH data collection is the capacity for health care providers, and health systems in general, to address the social inequalities that SDOH variables represent. Given the upstream nature of SDOH, to effectively reduce or eliminate the inequitable conditions that contribute to health disparities, policy interventions are a necessary complement to patient-focused interventions (Bambas, 2005; Bambra et al., 2005). More precise data and generally greater quality and quantity of information could lead to

a greater capacity to measure determinants, effects, and mitigating factors in social inequality, especially with regard to macro-level interventions. Better SDOH data in the health care system could therefore potentially lead to policy interventions that are more comprehensive, amenable to evaluation, and likely to reduce social risk factors for morbidity and mortality at individual and population levels. Policies to ensure transparency in data collection, surveillance, and public benefit from AI and automation in the HIS are also integral features of population health. The balance of evidence-informed system-level changes, as well as individually focused health promotion strategies, are important goals for SDOH data collection methodologies in systems to which we aim to support equitable health promotion.

3.2. Closing remarks

Health systems are developing research methods and technologies for improving SDOH data collection, and maintaining information infrastructure and data repositories. Streamlining and enhancing SDOH information in health system dataflow may improve the efficiency of healthcare administration and systemic capacity to address health inequalities. Our research emphasises the need for collaborative, interdisciplinary, and intersectoral research partnerships when it comes to standardising and automating data collection methods. Maintaining an awareness of the holistic and interconnected nature of health and the political, economic, and cultural drivers of SDOH should be guiding principles in HIS design for advancing health equity.

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