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Perspective

A call for social informatics

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ABSTRACT

As evidence of the associations between social factors and health outcomes continues to mount, capturing and acting on social determinants of health (SDOH) in clinical settings has never been more relevant. Many professional medical organizations have endorsed screening for SDOH, and the U.S. Office of the National Coordinator for Health Information Technology has recommended increased capacity of health information technology to integrate and support use of SDOH data in clinical settings. As these efforts begin their translation to practice, a new subfield of health informatics is emerging, focused on the application of information technologies to capture and apply social data in conjunction with health data to advance individual and population health. Developing this dedicated subfield of informatics—which we term *social informatics*—is important to drive research that informs how to approach the unique data, interoperability, execution, and ethical challenges involved in integrating social and medical care.

Key words: health information technology, health informatics, social determinants of health, social needs

INTRODUCTION

As evidence of the associations between social factors and health outcomes continues to mount,^{1–3} capturing and acting on social determinants of health (SDOH) in clinical settings has never been more relevant. A report in 2014 from the Institute of Medicine (now the National Academy of Medicine) noted the value of electronic health records (EHRs) in capturing information on SDOH to inform patient care, and recommended a concise set of social and behavioral domains that should be available in all EHRs.¹ Subsequently, organizations such as the American Academy of Family Physicians,⁴ American College of Physicians,⁵ National Association of Community Health Centers,⁶ and American Academy of Pediatrics⁷ en-

dorsed screening patients to identify social risk factors in clinical settings.

This past year, the National Academies of Sciences, Engineering, and Medicine (NASEM) released a new report that proposed strategies to better integrate social care and healthcare delivery to improve health.⁸ While the earlier report focused on what information should be included, the new report addresses how that information could be used. It also calls for developing a digital infrastructure that can track and organize social care practices (eg, 2-way communication platforms between healthcare systems and community-based organizations to track patient referrals) and is interoperable between health and social care organizations. Related recommendations from the U.S. Office of the National

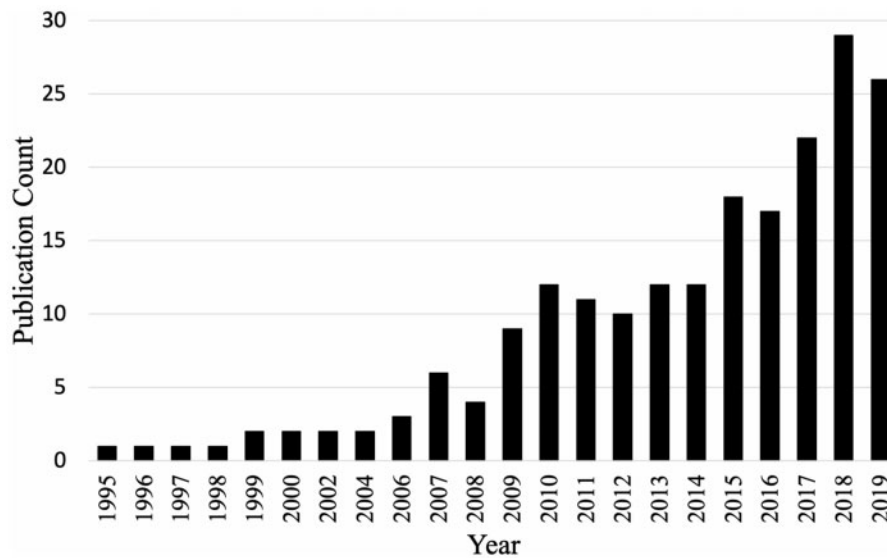


Figure 1. Number of social informatics publications by year, 1995-2019 (source: PubMed search on June 12, 2020). The search used the following terms: ((((((application, medical informatics[MeSH Terms]) OR (applications, medical informatics[MeSH Terms]) OR (bio informatics[MeSH Terms]) OR (clinical informatics[MeSH Terms]) OR (computing, medical informatics[MeSH Terms])) AND (((("social determinants of health"[Title/Abstract]) OR ("social risk factors"[Title/Abstract]) OR ("social needs"[Title/Abstract]) OR ("social risks"[Title/Abstract])))).

Coordinator for Health Information Technology recommend increasing capacity of health information technology to integrate and support use of SDOH data in clinical settings.⁹

THE CASE FOR SOCIAL INFORMATICS

As these efforts begin their translation to practice, a new subfield of health informatics is emerging. This new domain—which we term *social informatics*—studies the application of information technologies to capture and apply social data in conjunction with health data to improve clinical care and advance individual and population health. Social informatics uses SDOH-relevant data from informatics resources, such as EHRs, claims data, and mHealth data, to inform research, enhance patient care, and facilitate rapidly growing activities at the intersection of SDOH and medical care. The increasing attention to this intersection is reflected by a roughly 3-fold increase in health informatics publications in the last decade that include informatics MeSH (Medical Subject Headings) terms and the following terms in the title or abstract: “social determinants of health,” “social risk factors,” “social risks,” or “social needs” (Figure 1).

Social informatics complements existing subfields of health informatics, including translational bioinformatics, clinical research informatics, clinical informatics, consumer health informatics, and public health informatics.¹⁰ While each of these subfields intersects with social informatics, these intersections alone inadequately address questions and associated research approaches most relevant to advancing social and medical care integration. Specifically, we argue that the subfield of social informatics would tackle the following unique issues regarding data sources, interoperability, methods, and ethics:

Social informatics data sources and interoperability

While data on social conditions, such as lack of access to adequate food, housing, and transportation, may be obtained during clinical

encounters, they can also be derived from nonclinical sources such as local and national government datasets. Once these data are incorporated into the healthcare system, they facilitate the NASEM report’s recommendation of increasing the health sector’s awareness of social risks of patients and populations (Table 1).⁸ Yet, regardless of their source, social data are neither uniformly collected nor commonly captured in EHRs in a structured format. As the availability of social data rapidly increases in response to new policy and payment models that incentivize these different awareness strategies, there will be new opportunities to integrate these data into EHRs and implement social care interventions that address identified risks.

While the EHR is always expanding to include new types of data, several unique challenges must be overcome to capture and leverage social data sources. For example, social information relevant to medical care is not limited to that reported by patients. Home addresses may be linked to a wide range of measures of neighborhood conditions such as neighborhood deprivation and violence, walkability, and access to grocery stores. However, social data are not stagnant. If a food pantry closes or a patient moves, data on access to local food pantries for an individual patient will change rapidly, making address-based linking challenging to keep up to date as patients move and social resources change. Linking only to home address may also omit relevant information in the case that a patient lives and works in different neighborhoods. Thus, there is a need for new approaches to representing geography-based measures in EHRs beyond interoperability solutions that have primarily been designed to connect patient-level data that exist in 2 places. Additionally, best practices must be established for how to best collect and merge rapidly changing social information.

Robust capture and use of social data also involves information exchange with organizations outside of health systems, such as community-based organizations and government agencies that collect area-level data. These types of data exchange can support the NASEM report’s recommendations to improve alignment (synergies between the medical and social care sectors) and advocacy (activities to support policy and systemic change at the population level) (Ta-

Table 1. Social informatics activities related to the 2019 National Academies of Sciences, Engineering, and Medicine's Report on Improving Social and Health Care Integration⁸

Activity	Definition	Examples of How Social Informatics Can Support the Clinical Application of These Activities
Awareness	Activities that identify the social risks and assets of defined patients and populations.	Optimizing the collection, linkage, storage, and retrieval of SDOH information—whether collected in clinical settings or imported from community sources—so that it is accessible to inform healthcare practices. Automating notification of social risk factors to team members within healthcare settings.
Adjustment	Activities that focus on altering clinical care to accommodate identified social barriers.	Enhancing clinical and population health tools within EHRs to incorporate SDOH information into care activities. Improving EHR functionalities to prompt care actions based on social risks.
Assistance	Activities that reduce social risk by providing assistance in connecting patients with relevant social care resources.	Designing workflows to address SDOH within EHRs. Increasing the efficiency of documenting assistance given to patients. Automating assistance referrals to both healthcare setting-based (eg, case manager) and community-based (eg, housing placement organization) organizations that address social needs.
Alignment	Activities undertaken by healthcare systems to understand existing social care assets in the community, organize them to facilitate synergies, and invest in and deploy them to positively affect health outcomes.	Facilitating electronic linkages between health systems and community-based organizations.
Advocacy	Activities in which healthcare organizations work with partner social care organizations to promote policies that facilitate the creation and redeployment of assets or resources to address health and social needs.	Retrieving population SDOH data and associated care activities to inform policy decisions.

EHR: electronic health record; SDOH: social determinants of health.

ble 1).⁸ The heterogeneity of the digital platforms from which these data are derived requires new interoperability solutions. For example, in order for healthcare systems to communicate information via digital platforms to community-based organizations, there will need to be solutions that meet the highly regulated security standards of health systems, yet are accessible across sectors, as information collected about individuals from nonclinical sources does not consistently adhere to the same policies—like the Health Insurance Portability and Accountability Act (HIPAA)—that govern healthcare system data. As an example, data about a patient's food insecurity would be covered by HIPAA when captured in an EHR but not covered by HIPAA if generated by a noncovered entity such as a food bank. While HIPAA has helped to standardize data exchange between healthcare systems, new clear and consistent standards (particularly across states) are needed to facilitate data exchange between health and nonhealthcare entities.

Social informatics methodologies and applications

Beyond unique data sources and interoperability challenges, social informatics also requires the development of unique methodologies. Social data can inform real-time clinical decision making, supporting the NASEM report's recommendations around adjustment (altering medical care to take social barriers into account) and assistance (activities that more directly address patients' social needs) (Table 1).⁸ As one example, structured data elements that capture patients' transportation needs can facilitate patient-level interventions related to providing transportation assistance. These clinical decision-related applications distinguish social informatics from public health informatics, which is less focused on clinical care delivery at the individual level.

Current EHRs are not designed to assist providers in using social risk information to improve clinical choices that can mitigate the impacts of social risk factors on health outcomes. While clinical deci-

sion support (CDS) tools that facilitate medication safety and adherence to evidence-based guidelines are commonly embedded in EHRs, social care CDS tools (eg, prompts for tuberculosis screening for patients living in homeless shelters or alerts to prevent prescribing refrigerated medications for patients experiencing homelessness) have not been well developed, impeding their ability to facilitate adjustment-related social care activities. Effective development and implementation of social CDS is hampered by a lack of evidence on the "five rights" for effective CDS:¹¹ the right information (what is the "right" social care information?), to the right person (who needs to see the social information to facilitate social care?), in the right format (should social care data be displayed as an alert?), through the right channel, at the right time in the workflow.¹¹ Currently, there are no best practices, let alone an evidence base, for social care CDS.

Social informatics ethics

Social informatics also will need to assure the ethical acquisition, use, and exchange of social data, and guard against unintended consequences of creating, storing, and applying social data.^{12,13} These challenges present unique questions to the broader field of informatics. For instance, how might we prevent health insurers from excluding patients for "pre-existing social conditions" documented in their EHR? And how do we assure that risk-prevention tools are free of racial bias and do not exacerbate racial inequalities in care and outcomes?¹⁴ These concerns become more acute when considering how informatics tools may be applied to influence clinicians' decisions about allocating scarce resources and making referrals.

Additional ethics questions relate to where—and for how long—social information "lives" in healthcare data systems. For certain populations and content, extra safeguards are incorporated in EHRs to prevent access to sensitive information (eg, adolescent sexual history). How should social data be generated, updated, and protected, and from whom? What social information should a healthcare pro-

vider be able to see that is collected by a social care sector worker and vice versa? New approaches to patient consent need to be developed and tested in relation to these issues.

DISCUSSION

A dedicated subfield of social informatics can catalyze the implementation of recommendations made in the 2 National Academies reports and advance the integration of medical and social care. This new field will demand new data infrastructure and exchange capacity, new policies, new practice tools, new regulations, and a deep commitment to ethical data use. In turn, these require a dedicated research agenda to assess the best approaches.

We hope that communities of practice and research will help to both establish and nurture this rapidly evolving field. Relevant expert groups could be built into the American Medical Informatics Association, the American College of Physicians, or other professional organizations. In parallel, the Office of the National Coordinator for Health Information Technology could articulate a social informatics research and policy agenda as one novel Scientific Initiative.¹⁵

Finally, in its current 10-year Strategic Plan (2017-2027), the National Library of Medicine (NLM) acknowledges the importance of social factors to research addressing health disparities.¹⁶ Associated strategic objectives focus on the critically important task of developing SDOH data standards and processes. To more comprehensively support social informatics, the NLM could expand their SDOH approach to other objectives—particularly those related to informatics applications and knowledge delivery infrastructure—in order to explicitly surface and address the unique needs of social and medical care integration activities. The NLM as well as the Agency for Healthcare Research and Quality should support research on these and other questions relevant to social informatics. Additionally, the NLM could consider expanding its objective of enhancing research training on informatics and data science to incorporate training on social informatics topics, including ethical issues involved in social data integration.

Creating this new subfield of informatics is necessary to drive research that informs how to approach the unique interoperability, execution, and ethical challenges involved in incorporating social information into health care. Social informatics will be a new tool in the toolbox for better integrating social and medical care in ways that can improve individual and population health and health equity.

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AUTHOR CONTRIBUTIONS

All authors contributed to the conception, design, drafting, editing, and revising the manuscript. All authors approved the final version for submission and agree to be accountable for all aspects of the work.

CONFLICT OF INTEREST STATEMENT

None declared.

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