

Perspective

Integrating patient voices into the extraction of social determinants of health from clinical notes: ethical considerations and recommendations

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ABSTRACT

Identifying patients' social needs is a first critical step to address social determinants of health (SDoH)—the conditions in which people live, learn, work, and play that affect health. Addressing SDoH can improve health outcomes, population health, and health equity. Emerging SDoH reporting requirements call for health systems to implement efficient ways to identify and act on patients' social needs. Automatic extraction of SDoH from clinical notes within the electronic health record through natural language processing offers a promising approach. However, such automated SDoH systems could have unintended consequences for patients, related to stigma, privacy, confidentiality, and mistrust. Using Floridi et al's "Al4People" framework, we describe ethical considerations for system design and implementation that call attention to patient autonomy, beneficence, nonmaleficence, justice, and explicability. Based on our engagement of clinical and community champions in health equity work at University of Washington Medicine, we offer recommendations for integrating patient voices and needs into automated SDoH systems.

Key words: social determinants of health, electronic health records, patient acceptance of health care, bioethical issues, natural language processing

INTRODUCTION

Addressing social determinants of health (SDoH)—nonmedical factors that affect health and health outcomes—is critical for improving patient care and achieving health equity.¹ Unmet social needs, such as financial hardship, food insecurity, and housing instability, may account for 40%–90% of health outcomes.² Because screening and referral are associated with improved outcomes,³ the National Academies of Sciences recommends integrating SDoH into healthcare with electronic health records (EHRs) playing a central role.⁴ The Center for Medicare & Medicaid Services set forth guidelines that recommend voluntary reporting of positive screening rates for

© The Author(s) 2023. Published by Oxford University Press on behalf of the American Medical Informatics Association. All rights reserved. For permissions, please email: journals.permissions@oup.com SDoH (including food insecurity, housing instability, transportation needs, utility difficulties, and interpersonal safety) in 2023, mandatory reporting in 2024, and use of these metrics to drive reimbursement by 2026.⁵ To meet these guidelines, health systems need efficient ways to capture and use SDoH data in the EHR without adding administrative burden.^{1,6}

Although much effort has aimed to develop EHR-based screening and referral systems for SDoH,⁷⁻⁹ implementation barriers persist.¹⁰ Some patients express discomfort and confidentiality concerns about SDoH screening.¹⁰ Compared with traditional medical needs, some patients perceive social needs as less relevant to healthcare¹¹ and of lower priority to bring up with busy clinicians.¹² Patients with more social needs express more discomfort documenting this data in the EHR.¹³ Further, patients vary in their perceptions about whether a health system should intervene on identified needs.¹⁴ The high burden of screening perceived by clinical staff also limits adoption.15-17 Although self-administered screening through patient portals can help,^{18,19} racial, ethnic, literacy, and other barriers to use continue to persist^{20–25} despite gains in technology adoption over the past decade.²⁶ Because patients with social needs may face barriers due to limited literacy and digital access,²⁷ additional SDoH strategies are needed. Pressure for health systems to comply with the emerging reporting guidelines⁵ increases the appeal of automated strategies that extract SDoH from clinical notes over traditional SDoH screening strategies, particularly given increased financial strain of COVID-19 pandemic.²⁸

The growing literature on extracting social needs from unstructured clinical notes using natural language processing (NLP) demonstrates potential to improve the utility of SDoH data in the EHR while reducing costs of traditional SDoH screening and documentation by clinical users.²⁹ For example, Lybarger et al³⁰ demonstrate how NLP can augment structured SDoH data in the EHR to provide a more comprehensive picture of patients' social needs. Accurately and reliably extracted social needs could automatically populate structured data elements in the EHR that trigger computerized decision support and closed-loop referrals with community-based organizations.^{18,31} The biomedical informatics field is making extraordinary strides toward these new "automated SDoH systems" through initiatives like the National NLP Clinical Challenge on extracting SDoH.³² Given this progress, the desire to implement these advances in clinical operations will only grow.^{33,34} As social needs screening and referral becomes standard of care, the potential unintended consequences of automated SDoH systems for patients must be taken into serious consideration. Ethical considerations must take precedence.

ETHICAL CONSIDERATIONS

Automated SDoH systems have significant potential to enhance healthcare, but efforts to extract social needs from clinical notes could also exacerbate patient concerns regarding privacy, stigma, and mistrust. Although many patients find SDoH screening and navigation acceptable,^{12–14} unintended consequences are well documented.^{35,36} Patients express concerns about the use of artificial intelligence (AI) in healthcare, such as cost, safety, security, data quality, and lack of personal choice, all of which impact patient acceptability.^{37–40} We wish to bring focus to the importance of incorporating perspectives of patients into the design and implementation of automated SDoH systems as an emerging type of AI. "AI4People" is an ethical framework comprised of 5 principles to guide the development and adoption of AI technologies: *Patient*

autonomy, beneficence, nonmaleficence, justice, and *explicability.*⁴¹ The framework lays a foundation for "a Good AI society," which researchers have used to characterize bias in clinical NLP⁴² Using the AI4People framework, we examine ethical considerations of automated SDoH systems from the perspectives of patients.

Beneficence

Automated SDoH systems should benefit and empower people by promoting well-being and preserving dignity.⁴¹ SDoH interventions are only clinically useful if they are used by care teams to benefit patients.⁴³ Patients may feel reluctant to share social needs they perceive not relevant or beneficial to their care.11,12,40 Automatic extraction has the potential to alleviate patient discomfort associated with traditional social needs screening methods.¹⁰ By mining clinical notes, automated SDoH systems could increase the availability of contextual patient information to care teams, leading to fewer assumptions and more informed communication with patients.^{44,45} Although automated SDoH systems could mitigate some clinical burdens of traditional social needs screening, clinicians may still lack awareness of EHR-based SDoH documentation⁴⁶ or the time to follow up on identified social risks.¹⁰ Time burdens of automated SDoH systems could be even greater given the potential for false positives that may benefit from a "human in the loop" to review the accuracy of extracted social needs before patient follow-up. The benefits of automated SDoH systems may be limited if the identified social needs are not actionable, calling into question the ethics of screening without the capacity for community referral.³⁵ Unlike mining EHRs for health conditions that are addressed through medical interventions,⁴⁷ the clinical utility of SDoH interventions relies on a fragile network of community organizations.⁴³ Compared with traditional medical needs, health systems may be less equipped to respond to some social needs (eg, utility difficulties) than others (eg, interpersonal safety). While it may be technically feasible to efficiently extract a given social need through NLP,^{29,30} pathways are needed that will equip clinical staff and community-based organizations to effectively respond.

Nonmaleficence

Automated SDoH systems should avoid harm by preserving privacy, confidentiality, and security, and preventing data misuse,⁴¹ including potential harms from inaccurate data generated by AI.48 Repeating answers to questions considered by some patients as sensitive (eg, interpersonal violence) can trigger unpleasant or potentially traumatic memories and engender feelings of being judged.⁴⁹ Clinicians may feel uncomfortable routinely inquiring about adverse social circumstances, particularly if they lack experience or training on eliciting and responding to social needs, which may leave patients frustrated when those needs are left unmet.³⁵ Automated SDoH systems could reduce the potential for subsequent discomfort by surfacing social needs already identified in clinical notes, and help the workforce respectfully listen and collaborate with patients to address SDoH.⁵⁰ However, surfacing and sharing social needs mined from clinical notes that patients believe were discussed privately with their clinician could inhibit trust, communication, and therapeutic relationships. Automated screening could feel intrusive, especially if findings are incorrect. False positives can misguide conversations and lead to unnecessary efforts to link patients with social services, while false negatives fail to identify and meet patients' needs.43 Compared with traditional clinical data, inaccurate SDoH data could lead to even greater potential for stigmatization, such as labeling a patient "homeless" versus "diabetic." Inaccuracies could increase patient distrust, particularly in populations with historic marginalization⁵¹ and at greater risk for social needs. Patients also express security concerns about SDoH data misuse.⁵² Although automated SDoH systems can surface social needs for clinicians that might otherwise be missed, we must weigh potential benefit and harms.

Autonomy

Automated SDoH systems should provide individuals the freedom to make decisions for themselves, including how much agency to delegate to AI.⁴¹ Although many patients find social needs screening and navigation in healthcare acceptable,¹²⁻¹⁴ not all patients desire assistance.53-55 Few screening tools ask patients about their interest in assistance for identified social needs.⁴³ As regulatory requirements place pressure to screen every patient for social needs.⁵ healthcare systems have the opportunity to implement SDoH screening in ways that are sensitive to patient preference and preserve autonomy. Automated SDoH systems should not assume that patients wish to have their social needs mined and acted upon without providing patients the autonomy to decide. These systems should ask patients for permission⁵⁰ and obtain informed consent to use social needs mined from their clinical notes. AI tools that "operate surreptitiously in the background"³⁷ can break public trust, particularly if patients who do not want the technology used in their care discover its use only after deployment. We need best practices for implementing SDoH screening and referral interventions,^{10,56-58} including automated SDoH systems that respect patient autonomy. Informatics techniques can provide patients with greater visibility of how social needs extracted by automated SDoH screening are shared.^{59,60} Patients could be provided the freedom to opt-out of automated SDoH screening, similar to national recommendations that help normalize other potentially stigmatizing services, like HIV screening.^{61,62} Another possible direction is for automated SDoH systems to offer features for patients to opt-in to the use of extracted social needs in their care, similar to EHR-based research permissions.63

Justice

Although automated SDoH systems should be fair and equitable by promoting prosperity and preserving solidarity,⁴¹ these systems have the potential to disempower patients when imperfect mining leads to the unintentional creation of biased SDoH data that can reinforce inequities.^{37,64} Use of stigmatizing language that is disapproving, discrediting, and stereotyping to describe patients⁶⁵ can negatively impact clinicians' attitudes toward patients and their clinical decision-making.⁶⁶ Although researchers, who have described the prevalence of racially stigmatizing language in the EHR, call for changes in documentation practices,67,68 historical language in clinical notes could be extracted by automated SDoH systems and label patients in ways that stigmatize care and transmit bias. For example, systems could surface clinical text describing a patient as a "drug seeker"69 when extracting social needs related to the SDoH domain of substance use. Mislabeling patients with inaccurate social needs is a further concern. How patients are asked about social needs can impact the quality of responses received. Similarly, NLP performance relies on reducing the dimensionality of input data, affecting the quality of social needs extracted. For example, some social needs like polysubstance use may be expressed in complex and nuanced ways in clinical notes (eg, current use, past use, and multiple types of drugs),

which impacts the fidelity of NLP.³⁰ Although no automated SDoH system is infallible, inherent biases in data, algorithms, and system use can unintentionally exacerbate inequities.^{53,64} Unequal treatment based on extracted social needs may be particularly consequential for patients from groups that have experienced historical marginalization evidenced in the EHR, including Black individuals^{67,68} and transgender people.⁷⁰ In addition to improving NLP performance,³⁰ informatics efforts can guide the just implementation of automated SDoH systems. For example, rather than "auto-populating" SDoH data in the EHR, systems could "auto-suggest" social needs identified by NLP for human review first. Such implementation choices could help guard against false positive or otherwise inaccurate SDoH data.

Explicability

Automated SDoH should exhibit transparency and accountability while supporting the 4 other traditional bioethics principles.⁴¹ To be beneficent and nonmaleficent, automated SDoH systems must enable patients to understand the potential for good as well as potential for harm. For example, systems should inform patients about how these tools intend to help and potential risks to privacy, data security, data quality, or system misuse. To support autonomy, automated SDoH systems must enable patients to decide whether and how their SDoH data are used. For example, systems should allow patients the choice to participate, whether assistance is desired, and from whom. To be just, the implications of using automated SDoH systems should be readily understandable to all patients regardless of their experience with AI. Limited digital and health literacy in some populations with high social needs makes it critical to find clear and effective means to explain the potential implications of using automated SDoH systems for informed consent. Just systems should not create or perpetuate bias-we should strive for antibias systems. Organizations deploying this technology should take accountability for unintended consequences to patients. All of these assurances require that patients have a voice in the design and implementation of automated SDoH systems.

RECOMMENDATIONS

Patient acceptability of automated SDoH systems is contingent on mitigating patient concerns,^{37–40} particularity for individuals with social needs for who automated SDoH systems might impact most. Ethical principles can help drive mitigation efforts, but patients must have a voice in these systems. At the University of Washington Medicine, we are leading an effort to accentuate patient voices concerning the clinical extraction of SDoH. Based on our partnership with clinical champions and an advisory board of community advocates (Table 1), we offer recommendations for improving and diversifying patient engagement to ensure that efforts to implement automated SDoH systems are informed by patient input and reflect ethical principles.

Engage patients inclusively

Efforts driving the use of SDoH data extracted from EHRs should include patients from traditionally marginalized or underrepresented communities. Patients from these groups express concerns and opinions that are critical to the implementation of automated SDoH systems. Patients from marginalized groups may be more likely to experience social needs, putting these groups at greater risk should automated SDoH systems make mistakes. Engagement should



Kase Cragg is a transmasculine-nonbinary person with lived experience as a recipient and provider of mental healthcare, both of which informs their work. He earned dual master's degrees from the University of Washington in public health and social work, where they focused on the SDoH that impact transgender and nonbinary peoples' engagement with the healthcare system. They are a member of the "Birth Includes Us" research team, a study that examines queer and transgender experiences in pregnancy and birthing. He currently works in Seattle as an intensive outpatient therapist for youth and families.



Shoma Goomansingh advocates for all spectrums of under spoken groups. She is a first-generation Caribbean American from Trinidad and Tobago with a background in computer science. She is a chef, small business consultant, and a certified peer counselor in Washington State. She has experience assisting people who live with serious mental health issues with social resources ranging from housing and employment to drug rehab, sex protection, and free small business consulting. She initiated *Tech Chef Productions*, a start-up company for entrepreneurs and artists. She is passionate about combining her love of research and technology to help make the system a better place for people experiencing mental health complications.



Searetha Simons is passionate about helping people who don't have a voice to speak up, including people experiencing homelessness, mental health issues, and victims of sex trafficking. She has lived and professional experience providing outreach and group facilitation at a Seattle-based organization for prostitution survivors. She served as a resident member of the board for a Seattle-based Housing Group that provides permanent homes and comprehensive services for people experiencing chronic homelessness. A Seattle native, She loves music and was named a "Community Star" by the Starbucks Community Star program, a partnership between Starbucks and Kraken Ice Hockey Team that recognizes anchors in the Seattle Metropolitan community who drive positive change.



J. J. Wong lived with a birth disease, in 5 countries, through various varietal intersectional socioeconomic strata in the healthcare systems to successfully advocate for self and for those who are disenfranchised, marginalized, stigmatized, discriminated, in particular, directly related to basic living: healthcare, housing, nutrition across culturo-lingo-technological-socioeconomic strata. He is intersectionally represented and advocated for the underprivileged/underserved, to bring peace, justice, and wellness (ie, transcendence) to LGBTQQIP2SAA* locally, nationally, and internationally, in body, mind, and spirit.

*LGBTQQIP2SAA: Lesbian, gay, bisexual, transgender, queer, questioning, intersex, pansexual, 2-spirit, asexual, and ally. "P" stands for pansexual: A term that describes a person who may have a physical, emotional, or romantic attraction to people of any gender.



Angeilea' Yancey-Watson has a background in community advocacy and SDoH in her role as a lead program coordinator at a nonprofit organization that addresses health disparities and inequities in healthcare services for people of African descent. She is also a mental health first aid instructor. She earned dual degrees in community psychology and health administration, where she studied SDoH best practices. In her free time, she loves to travel and hike.

include individuals from diverse racial, ethnic and cultural groups, and genders, including individuals with limited English proficiency and those with limited literacy. As a critical part of our work, we have engaged a community advisory board of individuals with lived experience who advocate for communities which are most affected by SDoH (Table 1). This advisory board reflects inclusive advocacy for diverse patient communities to inform automated SDoH systems.

Engage patients with transparency

Automated SDoH systems can be complex and difficult to describe to patients. Although many people experience AI in their everyday lives, individuals with social needs often face literacy and access barriers to technology, leading to disparities in the use of digital health innovations.²⁷ To facilitate informed use of automated SDoH systems that promote digital health equity, patient engagement should focus on ways to describe these systems as transparently and clearly as possible. In our work, we have partnered with clinical and community champions to explore techniques for helping patients with limited digital literacy to understand the use and implications of automated SDoH systems work in everyday terms. Examples include the use of storyboards, scenarios, vignettes, and analogies. We have worked diligently with this community champion advisory board to generate ideas for disseminating research findings about automated SDoH systems to communities of interest. Examples of community-generated ideas include dissemination through posters, video commercials, community pop-ups, webinars, and listening sessions.

Engage patients cooperatively

Patients should be engaged as partners with clinical stakeholders and system designers in guiding the design and implementation of automated SDoH systems. It is important for health systems to understand what patients want and do not want, and to offer them ways to express their needs, preferences, and autonomy. Through coproduction of healthcare services,⁷¹ patients lend tremendous insight into system features and workflows that promote patient experience, such as vulnerable and underrepresented groups who have long shaped care innovations at Kaiser Permanente's Care Management Institute.⁷² Similar codesign methods could integrate patient perspectives into features and workflows for implementing automated SDoH systems, such as considering whether to "autosuggest" rather than "auto-populate" social needs in the EHR. Including patient representatives as advisors in research and practice can elevate the perspectives of marginalized individuals and leverage their expert advice for health equity initiatives,⁷³ requires consideration of compensation, inclusion, and democratic participation.

CONCLUSIONS

Automated SDoH systems offer health systems an efficient method to identify and act on social needs. However, to improve health outcomes, population health, and health equity, it is critical to consider unintended consequences for patients and to give patients a voice. The lens of AI4People provides ethical guidance for system design and implementation that is patient centric.

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AUTHOR CONTRIBUTIONS

Each author made substantial intellectual contributions to elements of the conception or recommendations in this work.

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CONFLICT OF INTEREST STATEMENT

None declared.

DATA AVAILABILITY

No new data were generated or analyzed in support of this research.

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