Informatics to support the IOM social and behavioral domains and measures

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ABSTRACT

Consistent collection and use of social and behavioral determinants of health can improve clinical care, prevention and general health, patient satisfaction, research, and public health. A recent Institute of Medicine committee defined a panel of 11 domains and 12 measures to be included in electronic health records. Incorporating the panel into practice creates a number of informatics research opportunities as well as challenges. The informatics issues revolve around standardization, efficient collection and review, decision support, and support for research. The informatics community can aid the effort by simultaneously optimizing the collection of the selected measures while also partnering with social science researchers to develop and validate new sources of information about social and behavioral determinants of health.

Keywords: social determinants of health, EHR

INTRODUCTION

A person’s social and behavioral determinants of health (SBDH) provide clinically useful information for patient care. On the individual level, they permit screening for psychosocial problems and tailoring of treatment plans to improve adherence. On the population level, they allow segmentation according to psychosocial risk to target care management and coordination programs. Other than the social history that is irregularly and idiosyncratically collected as part of clinical practice, information about these determinants remains largely untapped. Moreover, the information that is currently collected lacks the standardization needed for quality improvement, research, and population health applications.

The HITECH program, with its Meaningful Use provisions, serves as an opportunity for advancing the social and behavioral history agenda. The US Department of Health and Human Services’ Office of the National Coordinator for Health Information Technology and Centers for Medicare and Medicaid Services has established criteria under which health professionals can collect incentives and avoid penalties for their use of electronic health records (EHRs), including the certification criteria for the health records that they use. Earlier stages of the program identified several criteria relevant to social and behavioral history, such as smoking history, but the chosen criteria do not constitute a comprehensive and coordinated panel.

Directed by a collection of federal and private sponsors, the Institute of Medicine created a Committee on Recommended Social and Behavior Domains and Measures for EHRs. The committee was asked to identify a concise, complementary, and evidence-based panel of SBDH domains and a set of scientifically valid operational measures for these domains. This paper examines the informatics issues germane to collecting, storing in the EHR, and using the panel of 12 SBDH recommended by the committee.

The committee chose a conceptual framework based on five levels of SBDH: sociodemographic characteristics; psychological factors; behavioral health factors; individual-level relationships and living conditions; and neighborhood and community contextual and compositional factors. Several domains within each of the five dimensions were enumerated and scientifically evaluated for their feasibility, usefulness, and validity.

The committee developed the following terminology to provide a consistent approach to measurement of the domains. A domain, also known as a construct, was defined as a concept that represents a SBDH. A domain may be divided into dimensions called subdomains, where each subdomain has its own operational definition and measurement tools. For example, sexual orientation was considered a domain, and self-identification and choice of partner were considered subdomains.

The operationalization of a domain refers to the use of measures to quantify or to encode the domain. Whereas some domains have indicators that can be observed directly (e.g., body mass index may be calculated from height and weight), most SBDH domains require the use of a self-reported measurement instrument. Measurement instruments include validated sets of questions and answer options. Some domains have an accepted metric, which serves as a reference definition of the measurement of the domain. For example, a common metric of physical activity is metabolic equivalent task minutes. A common metric provides interoperability among related measures, because each can be represented on the same reference scale. For example, both the exercise vital signs (a two-question measure recommended by the committee) and accelerometer output that comes from devices like Fitbit can be converted to metabolic equivalent tasks. Figure 1 depicts the relationships among these terms.
STANDARDIZATION AND INNOVATION

To optimally support shared clinical decision-making, population health management, and research, the SBDH data must be defined, collected, stored and transmitted according to standards. We first emphasize that standards for transporting data are not sufficient to achieve this goal. For example, even if a common code set for race is accepted, data obtained from different sources may not be comparable if one system relies on health worker determination and another system relies on patient self-report. Therefore, agreement on the operational measure of the domain or subdomain is essential for standardization. The committee has recommended a panel of indicators with common questions and answer sets, which should lead to more consistent responses.

There will be an important tension for informatics researchers between standardization and innovation. While there is room for innovation in data collection in the sense of improved graphical user interfaces and workflows, the recommendation of specific measures creates a demarcation between implementation of validated measures as a standard of care and research into better measures. For example, the recommended measure for social connections and isolation includes how many times the person talks on the telephone. Alternative measures incorporating the use of social networks remain to be validated. The latter should be the subject of social science and informatics research and the committee’s recommendations include a process for updating to the recommend panel of standard measures with research advances. Development of common metrics for all SBDH domains is another priority.

ACQUIRING DATA ON SBDH

The collection of SBDH in a manner that affords standardization is a major undertaking. The committee recognized that for this to be feasible, the burden on clinicians, practices, and patients must be minimized. Technologies employed to collect the data provide only part of the solution; provider workflow and patient engagement are critical. Even in collecting the SBDH panel data through patient self-report, clinical workflow will need to be altered by the need to verify the self-report and ensure its availability for clinical care. Ultimately, changes in medical culture will be necessary to align the imperative for better collection of SBDH information with clinicians’ beliefs, values, and attitudes toward its importance to patient care and population health.

The committee recommends that most SBDH data should be self-reported. The report identifies a set of questions to guide development of self-report questionnaires and methods. The questions need to be phrased so that they are comprehensible by all persons, giving special attention to low literacy populations; applicable to all persons across the life course and adapted to account for individuals with functional impairments; and capable of being translated vernacularly without loss of meaning.

The committee envisioned SBDH self-reported data to be collected in multiple ways and through various platforms: on home computers or handheld devices shortly before or after an office visit, particularly primary care encounters; in the reception area of clinics on computers or paper-and-pencil questionnaires; and, in some cases, with assistance from clinical support staff. SBDH data are sensitive, so whichever workflow is used, patient privacy needs to be assured while the questionnaires are completed.

Generating appropriate questions for the panel of SBDH data is challenged by the nature of the underlying phenomena that is at once permanent and variable. For example, gender and race hold relative permanence (other than errors, changes in definitions, and rare gender reassignment) but other SBDH, such as exposure to intimate partner violence, may change many times. Additionally, clinical judgments sometimes rest on the current state of SBDH for an individual and...
other times rely on life-time exposure. Thus, acquiring a relevant panel of SBDH for an individual requires knowing both current and past experiences.

Efficient collection of these data represents a major opportunity for informatics research because of the need for principled innovation. This includes the design of user interfaces, use of audio and video assistance, design of optimal workflows within clinics, and methods for home-based administration of instruments. Metadata strategies are needed to annotate the measures with mode of administration information, the time and context of data collection, and the measurement tool. Alternative approaches to collecting data must be evaluated for comparability. Despite the variation in user interface, the measures must remain standardized. An interesting possible line of research would be to study social media – for example, using text mining – to better understand how patients express and understand social and behavioral issues.

STORAGE THAT SUPPORTS USE OF SBDH INFORMATION

Full realization of the potential of collecting social and behavioral data requires that they be stored according to common standards, facilitating shared decision support, data exchange, and research uses. One of the advancements of the report is that by putting forward common conceptual domains, common measures, and common metrics, the standardization of the storage of data elements then becomes straightforward.

An unanswered question regarding SBDH is where the physical storage of the data should be. Incorporating SBDH data into a single EHR makes that data difficult to access by other providers; additionally, maintaining currency and version control becomes nearly impossible if SBDH data are stored in multiple EHRs. An effective solution may emerge through health information exchange and other models of distributed health data management.

To serve clinical care, the data should be accessible at the point of the clinical encounter and be easily integrated with other data from the EHR. The data should be accessible to the patient for download and via portals and personal health records. It should be readily transferable to other clinicians; it should be incorporated into research data network initiatives, it should be incorporated into population health and quality improvement initiatives, and it should be available for public health uses focused on surveillance and detection of health disparities.

INTERPRETATION AND REUSE

While SBDH are inherently valuable, use of the data requires rethinking the care encounter. There must be an efficient mechanism for clinicians to review and act on the entered data. New techniques to support efficient review, either through prioritizing which data need to be reviewed or by improving visualization techniques, are needed.

Even with only 12 determinants included in the recommended panel, generating patient-specific recommendations based on the answers will likely benefit from various forms of decision support. Best practices can be represented as guidelines, reminders, and alerts, ideally linked to care processes designed to act upon the data (e.g., follow up on depression screening). Order sets can be driven by the SBDH. Further research is needed on how to generate the decision support, how to present it to the user, and how to update the decision logic.

Patients will need an effective means to review the SBDH panel, correct the information, manage the information, and act on the information. While the report focuses on the incorporation of the data into the EHR, direct patient use of the information may become the most important outcome of the initiative. Patient-targeted decision support could include referrals to community agencies, self-help programs, dietary modifications, exercise regimens, etc. One can envision a plethora of apps and other self-management tools that leverage SBDH data outside of the clinical care environment. The committee envisioned employer-based or health plan wellness programs among the early adopters of the recommended panel.

SBDH data will provide important and currently unavailable perspectives for many kinds of research and quality improvement. The research agenda includes identifying new SBDH-disease associations, effectiveness of interventions conditional on SBDH variables, and how best to act on them. The latter must be fed back to improve decision support. The data should support both primary research in social and behavioral determinants and applied research in their use in improving health.

There must be linkages with SBDH indicators in other parts of the national health system, such as the public health system. This includes a link from the EHR to public health, such as for community interventions like housing and from public health to the health record, analogous to what is currently done for immunizations.

Privacy issues related to SBDH raise novel challenges, especially for the more sensitive domains like intimate partner violence. Current informatics approaches such as the printed after-visit summary may need to be modified to avoid inadvertent disclosure that could place the patient at increased risk. Some population-level uses can be served with de-identified data. Implementers must be mindful of possible unintended consequences such as disruption of valuable clinical assessment strategies. For example, faced with time pressures and alternative sources of information, clinicians may stop asking more probing questions about alcohol use, relying solely on the social history collected in the waiting room.

CONCLUSION

The use of SBDH in clinical practice promises to improve clinical care, prevention and general health, patient satisfaction, research, and public health. Incorporating a panel of SBDH into practice creates a number of informatics research opportunities as well as challenges. The informatics issues revolve around standardization, efficient collection and review, decision support, and support for research. The informatics community can aid the effort by simultaneously optimizing the collection of the selected measures while also partnering with social science researchers to develop and validate new sources of information about SBDH.

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COMPETING INTERESTS

None.

CONTRIBUTORS

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