

**U.S. Department of Health and Human Services** Assistant Secretary for Planning and Evaluation Office of Health Policy

# Incorporating Social Determinants of Health in Electronic Health Records: A Qualitative Study of Perspectives on Current Practices among Top Vendors

# FINAL REPORT

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### Office of the Assistant Secretary for Planning and Evaluation

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# Incorporating Social Determinants of Health in Electronic Health Records: A Qualitative Study of Perspectives on Current Practices among Top Vendors

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#### ABSTRACT

**Background:** Social determinants of health (SDH) are increasingly seen as important to understanding patient health and identifying appropriate interventions to improve health outcomes, in what is a complex interplay between health system, community, and individual level factors.

**Objectives:** To investigate the development of software products that allow health care providers to identify and address patients SDH in health care settings, we conducted interviews with six electronic health records (EHRs) vendors with large market shares in both ambulatory and inpatient settings. We conducted thematic analysis of the interviews to a) identify their motivations to develop such software products, b) describe their products and uses, and c) identify facilitators and challenges to collection and use of SDH data—through their products or otherwise—either at the point of care or in population health interventions.

**Findings:** Our findings indicate that vendor systems and their functionalities are influenced by client demand and initiative, federal initiatives, and the vendors' strategic vision about opportunities in the health care system. Among the small sample of vendors with large market shares, SDH is a new area for growth, and the vendors range in the number and sophistication of their SDH-related products. To enable better data analytics, population health management, and interoperability of SDH data, vendors recognized the need for more standardization of SDH performance measures across various federal and state programs, better mapping of SDH measures of interest.

**Conclusion:** Vendors indicate they are actively developing products to facilitate the collection and use of SDH data for their clients, and are seeking solutions to data standardization and interoperability challenges through internal product decisions and collaboration with policymakers. Lacking policy standards around SDH data, product-specific decisions may end up being de-facto policies 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 in order to further promote integration of SDH data into the standard of care for all health systems.

#### **INTRODUCTION**

Given the potential importance of social determinants of health (SDH) in affecting health outcomes, this paper explores the perspectives of key stakeholders at the nexus of health care policy and health care systems, namely those of electronic health record (EHR) vendors. Based on qualitative semi-structured interviews with a purposive sample of top EHR vendors, it describes current vendor activities and products related to SDH. It also examines vendors' views on the demands for SDH-related EHR products, challenges in areas like standardization and interoperability, and the potential for growth in use of SDH data to support better clinical care and patient outcomes.

#### BACKGROUND

There are a growing number of studies that indicate SDH factors– such as income, education, race and ethnicity, employment, community resources, and social support– are associated with health outcomes. In their landmark report, Unequal Treatment: Confronting Racial and Ethnic Disparities, the National Academies of Medicine (NAM) called attention to the significant variation in the rates of medical procedures by race, even when insurance status, income, age, and severity of conditions are comparable. In doing so it paved the way for understanding the need to document and address disparities in health care.<sup>1</sup> Moreover, it called attention to what is now understood to be a highly complex association between system- and patient-level factors, social risk factors, and patient health outcomes.

Health care reform initiatives over the past decade have simultaneously incentivized value-based care payment models and the adoption and development of EHRs under the assumption that greater efficiency and quality of care can be achieved at a lower cost through better coordination of care and sharing of patient information among health care providers.<sup>2,3</sup> Current national commitment to value-based care continues to emphasize health information technology (IT) and interoperability of electronic health records in lowering health care costs.<sup>4,5</sup> At the clinical level, EHRs enable computer-based decision support, reminders, alerts, data sharing between facilities, and may encourage patient engagement. EHRs also support public health surveillance and research. Greater emphasis on the value of health care over volume has further drawn attention to the importance of SDH in potentially affecting health outcomes. As such, quality measures related to SDH have been developed and health systems are increasingly interested in capturing SDH data through EHRs in order to assess their performance against such measures.<sup>6</sup>

Three widely-recognized SDH screening tools in the U.S. are: 1) NAM's set of social and behavioral measures, which includes 11 social and behavioral domains;<sup>3</sup> 2) the National Association of Community Health Center's (NACHCs) Protocol for Responding to and Assessing Patients' Assets, Risks, and Experiences (PRAPARE) tool, which includes 20 domains;<sup>7</sup> and 3) Center for Medicare and Medicaid Innovation's Accountable Health Communities (AHC) tool, which includes five domains.<sup>8</sup> The Appendix provides a comparison of these three common tools, and demonstrates that they not only vary in terms of the overall number of domains or questions, but which domains are emphasized.<sup>9</sup> For example, NAM recommends screening for alcohol and tobacco use, whereas PRAPARE emphasizes gathering information about living conditions and social status. All three include questions around the domain of interpersonal violence and safety.

According to NAM, the integration of SDH into EHRs would enable health providers to address health inequities and support research into how social and environmental factors influence health, and if these factors should be considered during clinical care.<sup>6</sup> While NAM's 11 SDH domains are recommended for SDH screening tools, health care organization may also include additional SDH domains to meet all the needs of their patients. A recent study of six health systems found they all included domains such as housing, food insecurity, and transportation in their tools which are not among NAM's recommended domains.<sup>10</sup> By adapting questions and domains of screening tools, organizations have effectively created many different SDH screening tools.<sup>i</sup> Lack of standardization for incorporating data from various screening tools has limited the usefulness of the data within and across EHR systems.<sup>11</sup>

There are numerous federal, state, and local efforts that contribute to the integration of SDH in EHRs. Within the U.S., the Health Information Technology for Economic and Clinical Health (HITECH) Act (2009) and the Patient Protection and Affordable Care Act (2010) encouraged the widespread adoption of EHRs and required the collection of basic demographic data.<sup>12,13</sup> These laws offered guidelines that at first specified race/ethnicity capture, then broadened the capture of race/ ethnicity and introduced the capture of sexual orientation and gender identity. Later, they came to include standards for capturing information for specific questionnaires or scoring related to social behavioral and psychological history of the patient, and standard terminology (e.g., Logical Observation Identifiers Names and Codes (LOINC) codes) for the transfer of care documents.

There are many federal initiatives that have spurred SDH data collection through EHRs. Under the Medicare Access and CHIP Reauthorization Act of 2015 (MACRA) and the Merit-based Incentive System's (MIPS) Promoting Interoperability category (formerly the Advancing Care Information performance category), providers may be rewarded for quality and performance measures such as screening for SDH.<sup>14</sup> There are also incentives for certified health information technology (IT) use through Centers for Medicare & Medicaid (CMS's) 2018 Promoting Interoperability (PI) program; this program will absorb Stage 3 certification criteria developed under the Meaningful Use (MU) program. Federal agencies such as the CMS, the Centers for Disease Control and Prevention, and the Health Resources and Services Administration each have initiatives that promote the integration of SDH into health care delivery systems, through quality, accreditation, and/or payment models. This includes the Comprehensive Primary Care Plus (CPC+) model and AHC. Medicaid's Home and Community Based Services and CMS's 2016 Medicaid Managed Care rule have encouraged states to include more community based, non-clinical services that may address SDH.<sup>15</sup> More broadly, Medicare Accountable Care Organizations (ACOs) promote value over volume, and base shared savings on cost, utilization, and quality measures. States are also engaged in innovations around the collection and use of SDH in population health improvement programs to improve health equity.<sup>16</sup> At the local level, health care providers, health departments, universities, legal aid, and social service organizations are developing health improvement interventions that rely on the collection and use of SDH data. Finally, the Improving Medicare Post-Acute Care Transformation Act of 2014 or the IMPACT

<sup>&</sup>lt;sup>i</sup> The Social Interventions and Evaluation Research Network (SIREN) has created an on-line Social Need Screening Tools Comparison Table with detailed information on nine widely used screening tools, including links to the specific screening tool, and language for questions on each domain of the screening tools. It can be found at: <u>https://sirenetwork.ucsf.edu/node/17826</u>.

Act (P.L. 113-185), mandated the Office of the Assistant Secretary for Planning and Evaluation (ASPE) to conduct research on issues related to socioeconomic status in Medicare's value-based payment programs.

With expanded governmental interest in value-based care and health care quality, EHR vendors have had both indirect and direct roles in working with policymakers and health care systems. Their indirect role in policymaking has occurred through partnerships with the federal government, health care systems, and other technology companies.<sup>17,18</sup> In forging these relationships, policymakers have directly contributed to the evolution of EHR vendors' interest in actively engaging in population health, as opposed to simply medical record-keeping products.<sup>19,20</sup> For example, the most recent partnership, between a multitude of EHR vendors and health technology companies with the American Medical Association, will create a common data model for patient care that intends to lead to an integrated health model.<sup>18</sup> In addition, vendors are increasingly incorporating social determinants of health into their EHRs as a way to collect comprehensive patient information that can inform patient care and help their clients respond to the anticipated quality demands of value-based purchasing.<sup>21</sup> Some have dubbed this as a shift from EHRs to comprehensive health records.<sup>22</sup> Given the large market shares of some EHR vendors, and the role of the market in development of EHR features, some have expressed concern with the emergence of an EHR monoculture in terms of meeting patients' and clinicians' needs, costs, and interoperability.<sup>23</sup>

Recent figures on EHR adoption rates in inpatient and outpatient settings present a clear statement on the relative market share of some vendors over others. Data released by the Office of the National Coordinator for Health Information Technology (ONC) on its Health IT Dashboard in July 2017 indicated that only a few vendors of certified health IT products dominate the EHR market. In 2016, there were 684 health IT developers supplying certified health IT to 352,395 ambulatory primary care physicians, medical and surgical specialist, podiatrist, optometrists, dentists, and chiropractors; Epic supplied the 2014 certified health IT to over 30 percent of these providers, and nearly another 30 percent of the market was covered by Allscripts, eClinical Works, athenahealth, and NextGen Healthcare combined.<sup>24</sup> Fewer health IT developers (186) supplied certified health IT to 4,520 non-federal acute care hospitals, however only 10 companies supply over 98 percent of all hospitals, with Cerner, Epic, and MediTech supplying the largest shares.<sup>25</sup> Across both ambulatory care and hospital settings, three commercial companies dominate the market of EHR vendors; Cerner, Epic, Allscripts.<sup>26</sup>

#### METHODS

We began with a scan of PubMed for peer-reviewed literature and grey literature involving EHRs, Meaningful Use, SDH, and/or health disparities. Results were limited to recent publications written in English between January 2012 and June 2018. Through a preliminary review of over 250 articles, we identified 52 for in-depth review and thematic analysis of current practices for collecting and using SDH data through EHRs, uses of SDH data in EHRs for clinical care, and promising opportunities for improving such data collection.

Building on this information, we conducted key informant interviews with research and product development staff at six EHR vendor companies to learn more about their current activities related to the integration of SDH in EHRs. We discussed several key themes with the vendors including:

- Why EHR vendors are developing SDH products
- What kinds of products they are developing and for what uses
- How standardized SDH data are used, and how easily can they be shared among and across different types of providers
- Lessons learned from developing and implementing SDH products
- Policy-related requests to further the development and use of SDH products

The study, its research questions, and its interview protocol were reviewed and approved by NORC's Institutional Review Board to ensure compliance with requirements for the conduct of human subjects research.

#### VENDOR SAMPLE AND RECRUITMENT

To select participants, we first identified the top 10 vendors by market share in both inpatient and ambulatory settings. We prioritized the top three vendors with market penetration in both settings, followed by the six additional vendors ranked 4-6 in inpatient and ambulatory settings, respectively, for a total purposive sample of nine vendors.

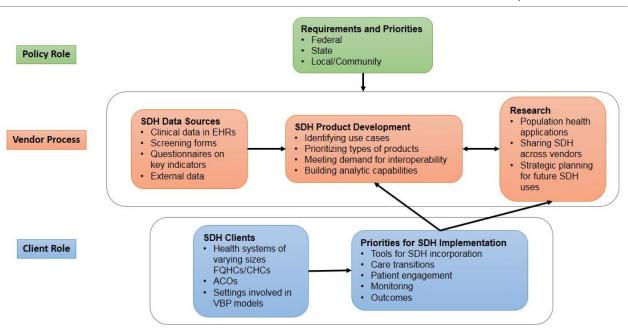
Vendors were contacted for recruitment via e-mail solicitation that introduced the project and purpose of the interview. We sought out staff members of the product development teams and were able to schedule interviews with representatives from six vendors, with 1-3 people from each vendor choosing to attend each call. In order to facilitate open discussions of issues in the field, vendor approaches to SDH, and strategic thinking, we have kept the vendor and participants' names confidential in this report. Participants primarily spoke on behalf of their company, and few identified information that was shared as their own personal view.

#### **INTERVIEW PROCESS**

To guide the discussions, we developed semi-structured interview guides probing the main research questions identified above. The interviews were 60-minutes long and were audio-recorded and transcribed for the purposes of analysis. Following analysis and reporting, all recordings and transcripts will be destroyed.

#### ANALYSIS

Using the transcribed notes, we conducted a thematic analysis of pre-existing and emergent themes using N-vivo software. This first involved the development of a conceptual model to facilitate coding based on preliminary interviews, which continued to be refined via iteration throughout the interview process (Exhibit 1). The conceptual model, the research questions, and the interview guides were used in combination to develop an appropriate coding structure to capture salient concepts and themes.





The conceptual model illustrates the drivers and process of SDH product development among EHR vendors. The green bands show demands for SDH collection from federal, state, and local policies. The orange bands illustrate the internal vendor process, including their work with SDH data sources, product development, and research. The blue bands represent the health system clients of the vendors, including federally qualified health centers (FQHCs), ACOs, and those participating in other value-based payment models. These clients or customers have their own interests and preferences in relation to the policy environment, the needs of their patients, the resources in their community, and their own models of health care. They are the sites for implementation and testing of SDH tools, and are often part of the development among top EHR vendors, we explored the successes/facilitators, challenges/barriers, and lessons learned from their processes of product development, and solicited feedback for policymakers to consider that would improve the collection and use of SDH data for patient care.

#### FINDINGS

Below we present findings based on key themes that were explored and that emerged from the vendor interviews. These findings highlight a range in development of SDH products among this sample of top EHR vendors, and offer insights into plans and requirements for further development of SDH products for use at the point of care and for population health initiatives.

#### MOTIVATORS OF SDH PRODUCT DEVELOPMENT

All vendors in our sample stressed the importance of meeting their clients' needs and demands, and that the one of the main drivers of their clients' interests in collecting and using SDH in the course of health care delivery was the expansion of value-based care programs. Vendors cited value-based care programs such as Patient Centered Medical Homes Models, CPC+ and ACOs as driving their clients to ask for SDH products within their EHRs. Two vendors noticed most demand came from clients that were Federally Qualified Health Centers (FQHCs) or community health centers, whereas another observed more widespread interest from academic medical centers, integrated delivery systems, and pediatric and/or specialty groups, stating, "there is interest, not only in utilizing [SDH] from a workflow standpoint, but also making sure that [SDH] becomes an integral part of the patient's story over different settings, so that it's becoming more norm as part of the handoff between care settings."

Additionally, four vendors also identified the PI incentives for EHR use and ONC health IT certification requirements as main drivers for the integration of SDH in EHRs. From the general increase in EHR use in health care to specific requirements around demographics and psychosocial issues, vendors' EHR platforms were intrinsically structured to collect SDH data. One vendor explained this trajectory as follows:

ONC has minimum guidelines for EHRs, for workflows and information that should be captured. Originally there were guidelines, 5-6 years ago, that further elaborated on race/ ethnicity capture. Within the past 4-5 years, race/ethnicity was broadened, sexual orientation and gender identification was introduced. Then a standard way of capturing information for specific questionnaires or scoring related to social behavioral and psychological history of the patient.

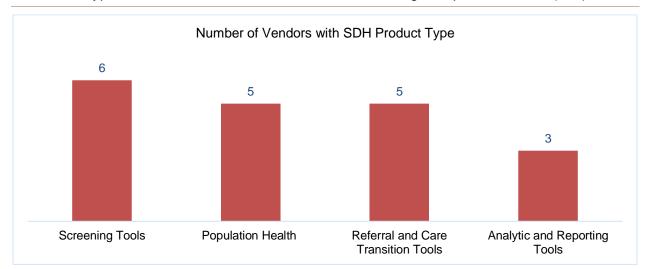
As a result, all health systems using certified EHRs are collecting some SDH data, though they may not necessarily view it or act upon it as such. One vendor explained, "with Meaningful Use, every practice has access to EHRs and there is an immense amount of data that is available [that] has not widely been used for outcomes data research," such as research or interventions on SDH.

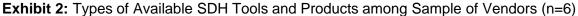
Even among the small sample of vendors, they varied in the extent to which their work to develop SDH products had been formalized and become central to their business model, or was just beginning. The most advanced vendor had integrated SDH measures into its main platform and lines of business, and the least was seeking intellectual property rights to integrate the copyrighted PRAPARE screening instrument into its EHR platform.

#### TYPES OF SDH PRODUCTS AND THEIR USE CASES

While there are many potential uses of SDH data in EHRs, there is neither a universal mechanism for collecting SDH variables, nor a definitive set of SDH measures to collect. The

types of SDH products created and used by vendors varies greatly based on their client needs and input, and their own strategic planning. In general, vendors have or are in the process of incorporating SDH data in screening tools, population health management tools, tools to improve referral management, and analytic tools (Exhibit 2).





Screening tools are the most common type of SDH product. All vendors mentioned the use of

#### **PRAPARE Core Measures:**

- 1. Race
- 2. Ethnicity
- Migrant and/or Seasonal Farm Work
- 4. Veteran Status
- 5. Language
- 6. Housing Status
- 7. Housing Stability
- 8. Address/Neighborhood
- 9. Education
- 10. Employment
- 11. Insurance
- 12. Income
- 13. Material Security
- 14. Transportation
- 15. Social Integration and Support
- 16. Stress

#### **PRAPARE Optional Measures:**

- 1. Incarceration History
- 2. Refugee Status
- 3. Safety
- 4. Domestic Violence

screening tools as a part of their platform to collect SDH data. Among the types of screening tools, most vendors described using a configuration of the NACHC's PRAPARE tool due to their clients' current demands and its use of structured data and distinct outcomes. The PRAPARE tool is part of a national multi-organizational effort to help primarily community health centers (i.e., FOHCs) and other providers collect data on and address their patients' social determinants of health needs.<sup>7</sup> It consists of 16 core measures and four optional measures; users are encouraged to collect standardized data on "ALL" core measures, not just some. PRAPARE EHR templates exist for most top vendor platforms, and it is also free as part of a publicly available toolkit. Two vendors mentioned working with NACHC on the development of the PRAPARE tool. In addition, two vendors mentioned developing their proprietary value sets; one developed a fully integrated screening product that includes eight NAM recommended measures, and two from PRAPARE. Most vendors also described the use of standardized tools to

capture behavioral health data, including the Columbia-Suicide Severity Rating Scale (C-SSR),<sup>27</sup> and Patient Health Questionnaire-09 (PHQ-09).<sup>28</sup>

All vendors described offering clients multiple or customizable the screening tools, to focus on fewer or additional measures as needed. As one vendor explained: "our overarching strategy is to collect SDH data at the individual level in a structured way that is flexible for clients." Another vendor described the multiplicity of screening tools its clients use, and the back-and-forth dynamic with clients that ultimately leads to the development and tailoring of tools:

A number of organizations that were using [our social history] form that has been there for a long time. They were creating their own forms to be able to collect this data in a variety of different ways. In some cases they were using other tools, such as the PRAPARE tool, that a number in our group liked and adopted, and it made sense... And so, in some cases it really is...customers being innovative and using different tools and giving us feedback that is determining the best way for us to standardize this on a go forward basis. We certainly never want to restrict customers from doing what they think they need to be successful or to be innovative.

Further, variation in the applicability of SDH indicators can be associated with the populations served by clients. As an example, one vendor described working with a pediatric clinic that was interested in collecting SDH, but needed to have tools that were appropriate for strategically impacting pediatric care, such as ways to evaluate food security and assess maternal depression. In order to address the multiple needs of clients, one vendor mentioned meeting with multiple clients at once to discuss what domains were the most appropriate. However, even with a consensus on commonly applicable SDH, the vendor still allowed flexibility for customers to add or remove indicators as necessary.

Finally, variation in screening tools reflects the lack of common screening requirements across different federal or state programs. One vendor explained the challenges of developing screening tools that account for federal and state requirements and clients' preferences, and their efforts to develop tools that capture all required measures without compromising providers' workflow:

The biggest challenge I've come across is getting the [EHR] system preconfigured with standard information. Mostly what I've seen is each state has a different set of requirements in terms of content, questionnaires, screening tools.... there is variation in requirements from state to state or even in a state depending on the practice size or if they are an FQHC... [Also] some things [may be] a standard [measure] when it comes to a federal requirement but [how] some [measures] are [collected may be] more specific to [a client's] workflow. In which case we have to make [the measures] go into different sections [of the EHR rather than be in one form that matches the federal requirements]. [The requirements] break the flow sometimes. The customers just want ease of documentation so the challenge is how we can bring everything together into one place. Some being structured data that is standard and some being non-standard customer specific data.

**Population health management is common use case for SDH data.** Three vendors described the development of proprietary population health management tools capable of using population health data algorithms, extracting population health data, and/or researching community level needs for patients. One describes more disease-specific use related to the analysis of opioid use, pain tolerance, and pain medication abuse mapped to SDH in areas of opioid addiction. Though

there is still not widespread use of SDH data in population health initiatives, one vendor expected that they could be used for diabetes management and food security, or medication adherence and utilities. One also described a common request from clients to use secondary survey data to identify "hot spots" or areas of high social need in the communities they serve. It uses data from the CDC Social Vulnerability Index to improve providers' understanding of community-level social health needs.<sup>ii</sup> All vendors recognized growing demand from clients to, as one put it, "move the needle in population health".

For most vendors, the use of referral products is still in early development or newly integrated into their platform. For the five vendors with products capable of making referrals for community services, the common methods are 1) through the use of a third-party tool, like Aunt Bertha,<sup>29</sup> 2) using an EHR-integrated tool, like order forms and workflows, or 3) using a proprietary tool that allows information exchange among health care systems and outside service providers. These tools are capable of improving exchange between providers for care transitions, finding community resources available within a specified radius of a patient's home address, providing a list of requests or interventions that have been recommended for a patient or assigning a patient to a certain referral program, and providing direct messaging between providers and/or community resources for a warm handoff and coordination of complex cases. One vendor describes options that clients have in creating and using referral tools, and offers examples of their use:

One tool that [we] developed is a search tool that finds community resources given the SDH factors that are at the highest risk. For example using the patient's home address, we can look within say a 5 mile radius and show all of the transportation services or all of the food pantries. There are different services that are available to the patients. In order to do so our customers can build a list [themselves] or use a third-party vendor that can compile a list that helps them manage the rapidly changing community landscape. Relying on a [third party] vendor in this space, is a strategy that makes sense.

Further, the vendor has created a portal so that the health system and the community service provider that patients' are referred to can communicate. One interviewee explained:

The portal was really to close that loop from a community referral perspective so that they could be on the same care team, they could share parts of the record as appropriate, and they could even contribute feedback by way of notes or simple assessments to really round out the whole picture of someone's care and to who may be above and beyond the traditional team such as the PCP of a specialist.

The vendor views such tools as a way of connecting to community-based service providers that historically have not used EHR products, but that are integral to addressing the whole health of a patient.

Other vendors also want to close the feedback loop with information on whether or not patients followed through or benefited from the referral, and to have that information reflected in the EHR. Typically, this is done by someone on the clinical care team documenting that the referral

<sup>&</sup>lt;sup>ii</sup> The CDC Social Vulnerability Index "uses U.S. census variables at tract level to help local officials identify communities that may need support in preparing for hazards, or recovering from disaster." (<u>https://svi.cdc.gov/</u>)

has been fulfilled. Among community health clinics, one vendor observed that referrals are often made within a clinic or facility. One interviewee explained:

They may have WIC services available within their facility. They may have other social services, a Medicaid office, you could go into and register for Medicaid, a lot of different services like that do reside in these community health centers. They'll initiate their own internal process for referring to those folks who are in there locally. If they're not local then it's more of picking up the phone, referring outside of the facility, and having different communication mechanisms there. In a lot of times in those scenarios, it's printed out documentation, fax documentation, phone calls, not much electronic interaction with those from within the EHR anyway.

Vendors recognized that there is a lack of consistency in how referrals are documented or managed across EHR systems due to variations in proprietary designs.

Vendors varied in their ability to provide data analytics and reporting. Similar to the use of referral products and capabilities, vendors are still in the early stages of developing mechanisms for analytics and reporting related to SDH. Three vendors interviewed reported using SDH data from the EHRs for risk stratification and outcome assessment. One mentioned the specific use of SDH for reporting to Medicaid for value-based care incentives. Another described the use of analytics and reports for following a patient's progression, but was unsure if there is a specific mechanism for reporting SDH. Specifically, the vendor noted concerns with maintaining flexibility in screening tools available to clients and mapping those tools to the same field for analysis. One vendor described strategic development efforts to allow SDH to be included in existing report functions and hopes for being able to take that data to the next level for gaps identification and population management.

In terms of assessing health outcomes, vendors report that measuring both short term outcomes, such as the completion of the referral, and long-term outcomes, such as changes in costs, utilization, and health outcomes, are difficult both technically and due to challenges addressing SDHs. One vendor has observed clients defining impacts in terms of quality metrics such as reducing readmission rates or reducing emergency department utilization; it reported that one client assessed outcomes from the person's perspective of their wellness.

To develop better analytic tools, one vendor has developed a proprietary value set which it is analyzing for the development of risk algorithm that incorporate SDH. It has found that SDH indicators are highly concentrated among a third of the clients, or that 30 percent of clients have collected 90 percent of the SDH that have been found in the data set. Further, it reports that 90% of what is being collected is only for 13 types of SDH measures, namely separation or divorce, death in the family, unemployment, problems living alone, addiction in family, and caregiver roles; less common are issues like homelessness or child abuse. These measures are represented as International Statistical Classification of Diseases and Related Health Problems version 10 (ICD-10) and Z codes.

#### LESSON LEARNED IN CAPTURING SDH DATA IN CLINICAL CARE

While screening tools are a common way of capturing SDH data, they are also dispersed throughout the EHR. Currently, vendors enable the collection of SDH at different parts of the clinical encounter and by different people. This is done to accommodate the needs of the clients and their existing workflows. Data can be collected in many ways throughout the clinical workflow and encounter, and all of the vendors described the need to be flexible, as there is not a one-size-fits-all method for appropriately capturing SDH data.

Within the EHR, vendors described a number of places where SDH data could be collected or found. These include EHRspecific data sets or forms, problem tables, free-text fields located in various places (e.g., social history section, clinical notes and assessments section, details section of structured screening tools), the demographic section of the patient's health record, and the patient portal. For example, one vendor explained that a clinician can pull race and ethnicity information from previous EHR-based entry, or the kioskbased registration information, and can simply ask patients to verify for an SDH screening. Another example is if a "Instead of focusing on the physicians putting information in, it might be helpful to take a look at it from the view of how to get the information out, in an easier fashion that would make analytics ... more doable and set up cases of value, demonstrating case studies, and showing providers the benefit." – Vendor Perspective

depression screening such as the PHQ-09 was completed on a prior visit, the comprehensive SDH assessment form would automatically bring in that depression score.

In a clinical encounter, the person collecting and entering SDH data into the EHR varies based on the available resources of the office, time allocated for the visit, availability of kiosks at check-in, and the sensitivity of the data to be captured. Even with these differences, vendors noted that typically the nurse or medical assistant inputs SDH data during the patient triaging process.

Vendors shared lessons on the most appropriate manner to collect specific types of SDH data. They include:

- For behavioral health questions and assessments, it may be better for behavioral health workers or providers to facilitate those screening tools;
- In community health centers with limited resources, clinical health workers are appropriate persons for entering SDH data.
- For sensitive domains or questions such as intimate partner violence, homelessness, and child abuse, one vendor observed that patients may feel more comfortable and are more truthful answering through a kiosk or patient portal.

General trends in implementation of SDH data collection tools indicate that clients start small, focusing on particular dimensions of interest. One vendor advises clients to begin by picking a cohort (e.g., asthmatics or a chronic disease) among their patient population because an SDH implementation fully rolled out among 40,000 patients in a health system would be a huge undertaking. Instead, vendors tend to recommend defining a set of priority patients to screen first, so issues like technical difficulties and workflow can be worked out.

#### CODING STANDARDS AND INTEROPERABILITY

Data standards are codes for the capture and exchange of electronic health data that govern and ease their integration with other data sets for analysis and use. Specifically, vendors report the use of ICD-10, LOINC and Systematized Nomenclature of Medicine (SNOMED) codes, which

are necessary for the standardized coding of multiple aspects of the patient record.<sup>30,31</sup> The ICD-10 codes cover diagnosis, with accompanying Z-codes that allow the provider to code additional justifications/rationale for a given code;<sup>32</sup> LOINC provides laboratory and clinical observational codes; and SNOMED-CT provides documentation of problem lists and clinical information, and is required terminology to allow interoperable data exchange.

"We're required to map to the ICDs and SNOMED. The issues that we are seeing is that SNOMEDs are limited, and there can be a lot of information that is collected where there is no SNOMED available." – Vendor

Due to a lack of standardization, vendors described challenges with the multiplicity and ambiguity of coding SDH measures. One vendor summarized the multiplicity of codes for the same condition as follows:

When looking at the ICD-9 and 10 codes there are eight domains that have been defined and about 96 codes that are under those eight domains. When looking at the ICD-9 codes there are about 45 codes that can be used for SDH and when you look at cross-walking those there are about 127 codes in SNOMED that link back to a SDH. Looking at the free-text, there are about 710 ways to characterize SDH. For example looking at unemployment there are at least 20-30 ways to describe that information.

Conversely, in the absence of SDH coding standards, some practices use mock current procedural terminology (CPT) or procedure codes to track the services that they might be assigning. For example, since LOINC and SNOMED do not provide codes for transportation assistance, practices may wish to have a dummy CPT code to track it.

Using the example of bereavement, the vendor described a scenario in which a multiplicity of similar codes requires a judgment call from the vendor:

'Death in the family' is a highly concentrated code. Within its Z-codes, bereavement or grief, are listed as synonyms...but bereavement can also be used for other ICD-10 codes and could be coded outside of the ICD-10 domains. It is hard for [vendors] to standardize because even the codes and regulations are inconsistent; there has to be standardization to be able to analyze the data; and you have to make judgment calls that may be too liberal or too conservative depending on the side of the coin you sit on.

Even with well-known tools like PRAPARE, vendors must sometimes make idiosyncratic coding decisions. In general, the PRAPARE tool has very specific questions and answers; for example, a click list of options for level of education. PRAPARE can link to LOINC terms for each of the responses, so that data is stored in a very structured way that can be accessed on the backend that is preferable to these vendors. Where the ambiguity arises in mappings is in questions like: "What is the highest level of school you've finished?" Although the LOINC/SNOMED answer might be the same, the vendor would not feel comfortable making the decision to code to one or

the other. From the vendor perspective, ideally PRAPARE would be hard coded to a single standard to ensure consistency and interoperability.

Further, not all SDH information can be coded and free text fields are frequently used. In spite of the tens of thousands of codes among ICD, LOINC, and SNOMED, some vendors commented that a lot of information that is collected cannot be characterized by a given code and falls into free text. One vendor reports that:

[In] order to capture all of the data, it is necessary to understand the codes that are being used like ICD-9, ICD-10, and SNOMED. Additionally, it is necessary to have a free text collection method in order to fully capture everything that is being ascertained in the EHR system. Eighty percent of the information needed for the holistic view of the patient is captured outside of the EHR system free-text response or outside of the normal physician-patient encounters and relationship.

Three vendors reported that some depression surveys are challenging to analyze because they combine free text with dichotomous yes/no responses. For example, one mentioned yes/no questions that are accompanied by free-text fields intended to add content that patients may be willing to describe in more detail. Clients appreciate being able to capture these explanations from patients via the free text, in spite of the challenges with codifying free text.

Altogether vendors explained that such issues result in difficulties aggregating, sharing, and analyzing SDH information. In terms of aggregation, one vendor explained:

In an ideal world all of this [SDH] information would be collected in a codified way and there would be a table where they can see all of this information. However, in the world today all of the information can be variable in terms of where and how it is collected. It sometimes comes up in the problem table, but we have not begun to even look at the freetext physician notes section, where they anticipate even more information may be collected. In general it is supposed to come in the problem table, and is supposed to be codified, but we know that given the current state we will have to develop a more comprehensive code set.

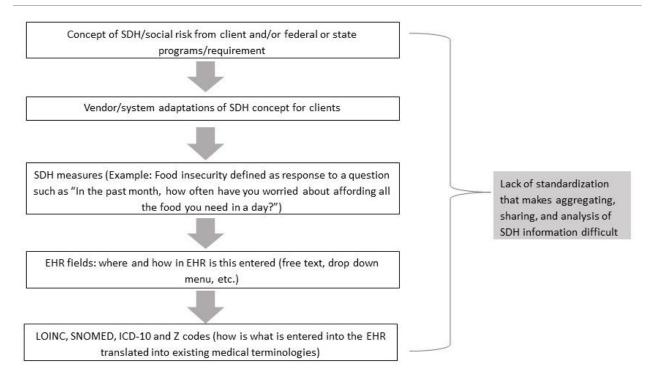
In terms of interoperability, lack of standards in both what SDH data is collected and how it is coded also makes its exchange among health care providers difficult. While vendors can use the Consolidated Clinical Document Architecture (C-CDA) to make electronic referrals to community service providers and support system-to-system exchange, one vendor explained that the C-CDA document does not codify the specific SDH data elements but generally allows for the electronic exchange of referrals from within the EHR.

Another vendor reports working on a project with some of the Regional Health Information Exchange Organizations interested in receiving SDH data. They are starting with race and ethnicity with the intent of sending additional information as the project develops, and anticipate other states will express similar interest. Finally, vendors described challenges with analysis of SDH data due to lack of standardization. One vendor spoke of the need to standardize or structure SDH data while preserving client flexibility in its collection. An interviewee explained:

If the data is more structured, the analysis is easier. If we have to scale to many clients, with many different screening tools, our job is not to force into one screening tool, but is to normalize the results of the screening tools, so we can map food insecurity tools A and B to the same field that can then be used for analysis. As an IT vendor that kind of data structure is very important.

Though clearly the benefit of standardization was viewed from the perspective of the potential benefit to the vendor itself, it is understood that generally better standardization would allow health systems to better analyze and interpret SDH data in clinical decision-making. Exhibit 3 depicts the chain reaction of variability that leads to the lack of standardization and limits on the use of SDH data in patient care and population health planning.

Exhibit 3: Systemic Variability Leading to Lack of Standardization and Usability of SDH data



#### DISCUSSION

Vendors in this sample indicated that in the absence of national standards, customers are getting "pretty creative" in the collection and use of SDH data. They showed support for discussions among vendors, standards bodies, and government organizations to reduce ambiguity in the code sets, as well as to ensure all voices are heard. Ultimately, several emphasized that vendors must follow the recommendations that public agencies outline, and sought direction on standardized SDH tools, codes, and incentives.

**Standardized tools to collect SDH data.** Given the lack of standardization of the tools used to collect SDH, and variability in what is being collected, vendors would appreciate some direction on what to collect. Vendors commented that because SDH has become a buzzword that encompasses numerous concepts, having standardized definitions across all governing organizations defining these constructs would improve the field from a research and analytics perspective. It would also help vendors build better tools that are interoperable. In addition, vendors note that if different federal programs can agree on a set of measures this will facilitate more consistent use of a specified set of SDH data collection tools. For example, one individual commented that, "the PRAPARE tool is great, but the private sector doesn't seem to be open to it, and it is not an exact match to some of the other national programs already, so there is some disconnect there" that leads to the implementation of differing tools and solutions.

**Standards for SDH data coding and interoperability.** Based on their comments and described activities, vendors appear to be oriented towards use of standard terminology that would better enable interoperable exchange of SDH-related data. In some cases more than one standard is

assigned to a particular data element. Vendors would appreciate guidance on the preferred standard to be used for a subset of data elements. However, they also caution that not all elements can be codified and how a specific tool that is implemented in the EHR should be left up to the client or health system. In particular, this relates to making determinations about the tools that are most useful to their practices, with the recognition that the data they capture must roll up to meet federal reporting standards.

Vendors are involved in the discussions and work groups related to SDH standards that promote data capture and interoperability. In some cases, vendors are participating as part of national standards development organization activities; for example, serving in the Health Level-7 International (HL7) C-CDA standards workgroup. In other cases, vendors are pursuing a more targeted

## Two Vendors' Views on their Role in Creating Coding Standards

"Yes, we have a role to play [in developing standards for coding SDH data], but we also want to be cognizant of the optics, and want other vendors to participate. We don't want to be perceived as commandeering the narrative."

"It's hard as an IT company to push a standard, because others may perceive it as bias. When an open standard for social determinants is pushed from a national group it is better and that's something we support."

approach, for example getting involved with non-governmental initiatives, such as one lead by SIREN (Social Interventions Research & Evaluation Network), to improve interoperability of SDH data in EHRs.<sup>33</sup> Finally, vendors continue to engage in industry efforts focused on health information exchange. One reported participation in an industry-wide interoperability initiative called Carequality that grew out of the Sequoia Project.<sup>34</sup>

**Incentives for SDH data collection and use.** From the demand side, clients drive demand, investment, and more development, as do policies, including incentives and value-based care. However, vendors wonder whether the incentives will be fair and whether SDH collection is a fad versus a priority with longevity. One vendor poses the question of whether SDH will come to be as large a movement as Quality Improvement was for health care.

#### CONCLUSION

Vendor systems and their functionalities are the result of the multiple, inter-related forces of federal policy and regulation, client demand, and the vendors' own strategic vision for opportunities in the health care system. Because of their unique position in the market, and the significant impact their organizational decisions have on EHR-based data capture, and therefore, on clinical practice we have conducted a set of key informant interviews focused on SDH. These interviews explored the vendors' strategies and interests, including the roles of client demand and federal policies related to SDH capture and use. We explored issues related to use of standards and interoperable information sharing, use cases for SDH to improve clinical care and processes, and potential avenues for growth in use of SDH data.

Interviews indicated that even among vendors with the largest market shares in both ambulatory and inpatient settings that SDH is a new area for investment, and there is still room for growth in terms of product development and analytic capacity. While all vendors' interviewed use or have enabled some SDH data collection screening instrument in their EHR platform, they vary in terms of capacity to track referrals and analyze data. The vendor with the most advanced functionality has fully integrated SDH screening instruments into its main population health platform that will be available to all of its clients, and the vendor with the least advanced capabilities is still working through copyright issues to use the validated PRAPARE instrument. They also ranged in those simply seeking to help clients meet regulatory obligations to those engaged in research to develop products that will help clients better target and address needs of their patients, including those related to SDH. Vendors have identified a number of challenges primarily with analyzing SDH data and sharing them among health systems and their partners. This includes challenges with multiple overlapping but distinct performance metrics and indicators across various federal and state programs, lack of agreement on mapping SDH measures to codes, and lack of codes for all measures. Finally, as with much of health care, there is a general problem with interoperability that makes sharing and using SDH data difficult. Vendors appear to have taken a role in resolving these challenges through participation in policy development, standardizing bodies, and vendor specific solutions and decisions. With the lack of policy regulations around SDH data, product-specific decisions may end up being de-facto policies given the market shares of particular vendors. However, vendors appear ready for formal policymaking discussions to seek solutions that may further promote the integration of SDH data into mainstream health care delivery.

This study has shown that in the absence of standardization of SDH screening instruments, measurements, and codification that EHR vendors will provide their health system clients multiple options and flexible tools to meet their varying needs and interests. Though limited to a small number of vendors that we could reach in a short timeframe, the vendors have a large market share and were consistent in the need to remain adaptable and responsive to client needs and federal and state requirements. However they, along with their clients, appreciate the

potential for standardized SDH data to identify patients with high social need, to improve care coordination between health care providers and community service providers, and to build further evidence on the connections between SDH and health outcomes through better data analytics and population health management. Vendors and providers seek approaches that balance the use of existing data with the need to collect standardized new data in order to streamline the integration of SDH data in providers' workflow, and to create a holistic picture of patients within the health care setting that may ultimately reduce health disparities.

In order to advance the collection and use of SDH data in health care settings through EHRs, the findings from this study suggest at least three next steps. They are to:

- 1. Identify core SDH elements where standard development is still needed;
- 2. Provide guidance on preferred terminology standards for some SDH measures; and
- 3. Identify if there are a subset of SDH measures that all EHRs can collect.

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### APPENDIX. EXAMPLES OF SOCIAL AND ECONOMIC RISK SCREENING TOOLS<sup>9</sup>

Social & Economic Risk	Recommended	PRAPARE: Protocol	Accountable
Screening Tool	Social and	for Responding to	Health
C	Behavioral Domains	and Assessing	Communities
	and Measures for	Patient Assets,	Screening
	Electronic Health	Risks, and	Tool <sup>8</sup>
	Records <sup>3</sup>	Experiences <sup>7</sup>	
Total # of questions	24	21	10
Residential address	Х	Х	
Race/ethnicity	Х	Х	
Alcohol use	Х		
Tobacco use & exposure	Х		
Depression	Х		
Education	Х	Х	
Financial resource strain –	Х		
overall			
Household income		Х	
Household size		Х	
Housing		Х	Х
Food		Х	Х
Clothing		Х	
Utilities (phone, gas, electric)		Х	Х
Medicine / health care		Х	
Child care		Х	
Transportation		Х	Х
Neighborhood safety		X*	
Interpersonal violence / safety	Х	X*	Х
Physical Activity	Х		
Social connections / isolation	Х	Х	
Stress	Х	Х	
Migrant / seasonal farmworker		Х	
Veteran status		Х	
Primary language		Х	
Incarceration history		X*	
Refugee status		X*	
Insurance status		Х	

\*Optional questions in Protocol for Responding to and Assessing Patient Assets, Risks, and Experiences (PRAPARE)

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This table is formatted according to the U.S. Department of Health & Human Services Section 508 Accessibility guidelines. In order to make it compliant, we adapted the original table to use X's instead of dots to represent inclusion of a question about a domain on the screening tool.