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Commentary

Implementing social and behavioral determinants of health data collection: insights from a pragmatic trial

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Abstract

In response to growing evidence and recognition that social and behavioral determinants of health (SBDOH) differentially affect the health-care experiences and outcomes of patients with cancer, there has been an increased focus on optimizing the routine collection of such data. In spring 2024, we launched a pragmatic clinical trial titled "Effect of Early Point-of-Service Social and Behavioral Determinants of Health (SBDOH) Screening and Enhanced Navigation on Care Delivery for Patients With Breast Cancer" (ClinicalTrials.gov identifier NCT06019988) at our academic health system. Instruments and modalities were selected following a process of collaborative and iterative consensus building that included an in-person discovery workshop with patients, national experts in psychometrics and SBDOH collection, health system leadership, faculty and staff stakeholders, and study sponsors. The final protocol, which used the Consolidated Framework for Implementation Research, follows a stepped-wedge cluster-randomized format and compares 3 SBDOH screening instruments—Accountable Health Communities Health-Related Social Needs Screening Tool, Health Leads Social Screening Tool, and the National Comprehensive Care Network Distress Thermometer and Problem List—and 3 delivery modalities—the Epic electronic health record patient portal; bidirectional text-based conversational agent ("chatbot"), and interactive voice response administered by phone. Despite substantial resources, multidisciplinary collaboration, and advanced planning, we encountered challenges related to patient navigation, stakeholder engagement, and technological integration. We describe our experience as a guide for others aspiring to realize real-world implementation of routine SBDOH data collection.

Introduction

Social and behavioral determinants of health (SBDOH), or the conditions in which people live, work, and age, as well as the dietary and lifestyle habits they pursue, have known implications for patients' access to health care and their ability to achieve favorable health outcomes (Table 1).[1,2] There has been increased focus on collecting SBDOH data over the past 5-10 years, an interest that has been unquestionably heightened as a result of the inequities brought into relief by the COVID-19 pandemic.[3-7] Health-care systems and electronic health record (EHR) vendors have expanded the "Social History" sections of the EHR to enable documentation of various SBDOH domains, such as housing, food, and finances, all of which are associated with worse outcomes in patients with cancer.

Within SBDOH domains, unmet social needs (eg, limited access to transportation, food insecurity, inadequate childcare) and the psychological challenges engendered by these needs present barriers to cancer care that can contribute to treatment delays, decisions to opt out of treatment, and even increased risk of recurrence and mortality.[8-11] Unfortunately, most of these potentially modifiable SBDOH-related barriers to care are identified only after a patient's first oncologic appointment, if at all, which may prevent patients from receiving timely social support and may further complicate their ability to navigate health-care systems effectively.[12] Early identification of these potential barriers in patients with breast cancer may allow care teams to proactively mitigate the social risk factors that contribute to delayed treatment and, given the known adverse impact of treatment delay on survival after breast cancer diagnosis,[13-17] concomitantly worse outcomes.

Many health systems have attempted to standardize methods of collecting and storing SBDOH data in EHR platforms (eg, the

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Table 1. Social and behavioral determinants of health.

Economic stability	Neighborhood and physical environment	Education access and quality	Community and social context	Health-care access and quality	Food	Physical activity	Substance use and exposure
Debt	Housing	Early childhood education	Community engagement	Health coverage	Access to healthy options	Access to exercise equipment and safe spaces	Alcohol
Employment	Parks	Higher education	Discrimination	Quality of care	Dietary patterns	—	Illicit drugs
Expenses	Safety	Language	Social integration	Clinician availability	Hunger	—	Tobacco
Income	Racial residential segregation	Literacy	Stress	Clinician linguistic and cultural competency	—	—	—
Medical bills	Transportation	Vocational training	Support systems	—	—	—	—
Support	Walkability	—	—	—	—	—	—
—	Zip code/geography	—	—	—	—	—	—

Adapted from Healthy People 2030[47]; the Kaiser Family Foundation[48]; and Hatef et al., "Integrating social and behavioral determinants of health into patient care and population health at Veterans Health Administration," AIMS Public Health.[49]

Epic Social Determinants of Health Wheel); however, rates of nonrandom missingness among these data fields remain high[18,19] due to inconsistent documentation of patients' demographic and socioeconomic information; nonroutine approaches to and systematic errors in data collection; and, for oncology patients, an understandable reluctance to raise the socioeconomic challenges they may be facing in the context of a new cancer diagnosis. Without access to reliable information, clinicians are less able to effectively identify and potentially mitigate barriers related to SBDOH.[20]

We propose that efforts to identify unmet social needs should begin (at a minimum) with optimizing and standardizing the collection of SBDOH data at scale. Among women with breast cancer, we hypothesize that this approach will be especially beneficial for Black and Hispanic women, who are substantially less likely to receive guideline-concordant care than are their White counterparts.[21,22] Yet, successful implementation of large-scale SBDOH screening programs remains challenging for several reasons, beginning with the plethora of potential instruments for collection. Despite the creation and validation of multiple social needs screening tools over the past decade, researchers have yet to reach a consensus on the SBDOH elements that constitute an "optimal" instrument.[23,24] Second, there are both practitioner-side (eg, EHR integration) and patient-facing technological considerations, as we have limited knowledge of patients' preferred mode of contact (in person or digital) and interaction modalities (eg, health-care portals, phone-based text messages, real-time phone calls, paper forms, interview).[25] There is evidence that clinicians understand the utility of SBDOH data and tend to endorse SBDOH screening, but there is limited time in the clinical encounter, and few clinicians are comfortable asking patients about social needs and referring them to available resources.[26-28] Finally, it is unclear to what extent and in which contexts rapid and universal social needs *screening* of all individuals should be performed compared with in-depth and personalized social needs assessments.[29]

At the Perelman School of Medicine at the University of Pennsylvania, we designed and launched a pragmatic clinical trial, "Effect of Early Point-of-Service Social and Behavioral Determinants of Health (SBDOH) Screening and Enhanced Navigation on Care Delivery for Patients With Breast Cancer" (ClinicalTrials.gov identifier NCT06019988; hereafter referred to as "Breast SBDOH"), in spring 2024. We hypothesize that early, anticipatory point-of-service screening for SBDOH—made operational through the EHR and linked with interventions to redress modifiable contributors to breast cancer disparities—will improve the equity, effectiveness, and efficiency of care for patients with breast cancer. We are evaluating 3 previously validated data-collection instruments and 3 modalities to identify optimal data-collection approaches across multiple sites within Penn Medicine that bridge academic and community settings.

In March 2023, trial principal investigator Oluwadamilola M. Fayanju, MD, MA, MPHS, led a discovery workshop attended by approximately 50 stakeholders, including patient advocates (4 of whom are coauthors on this article and all of whom are active at the local and national levels with clinical trial cooperative groups and community engagement); clinical and administrative leaders across our institution; study sponsors and featured speakers from across the country, including a psychometrician who has developed widely used patient-reported outcomes for patients with cancer; a cancer epidemiologist who studies the experience of patients at time of diagnosis; and a renowned breast medical oncologist with expertise in survivorship and patient-reported outcomes. Before the workshop, substantial prework and review of the existing literature and candidate SBDOH screening instruments was conducted by Dr Fayanju's research team as well as attendees; during the workshop, there was engaged review and collective selection of the study instruments as well as a plan for development of the trial. Instruments and modalities for SBDOH assessment in the trial were ultimately selected through this process of collaborative and iterative consensus building. Over the next several months, we worked closely and iteratively with our patient advocate colleagues and 1 of our faculty co-investigators—an expert in community engagement and health literacy who is also a licensed clinical social worker—to meticulously review not only how the screening instruments would be transformed for use in the Epic patient portal, the texting chatbot, and the interactive voice response systems but also the scripting for how we would actually introduce the screen to patients and manage the multitude of responses we might encounter.

The final protocol, which used the Consolidated Framework for Implementation Research, follows a stepped-wedge, cluster-randomized format.[30,31] The instruments being compared are the Accountable Health Communities Health-Related Social

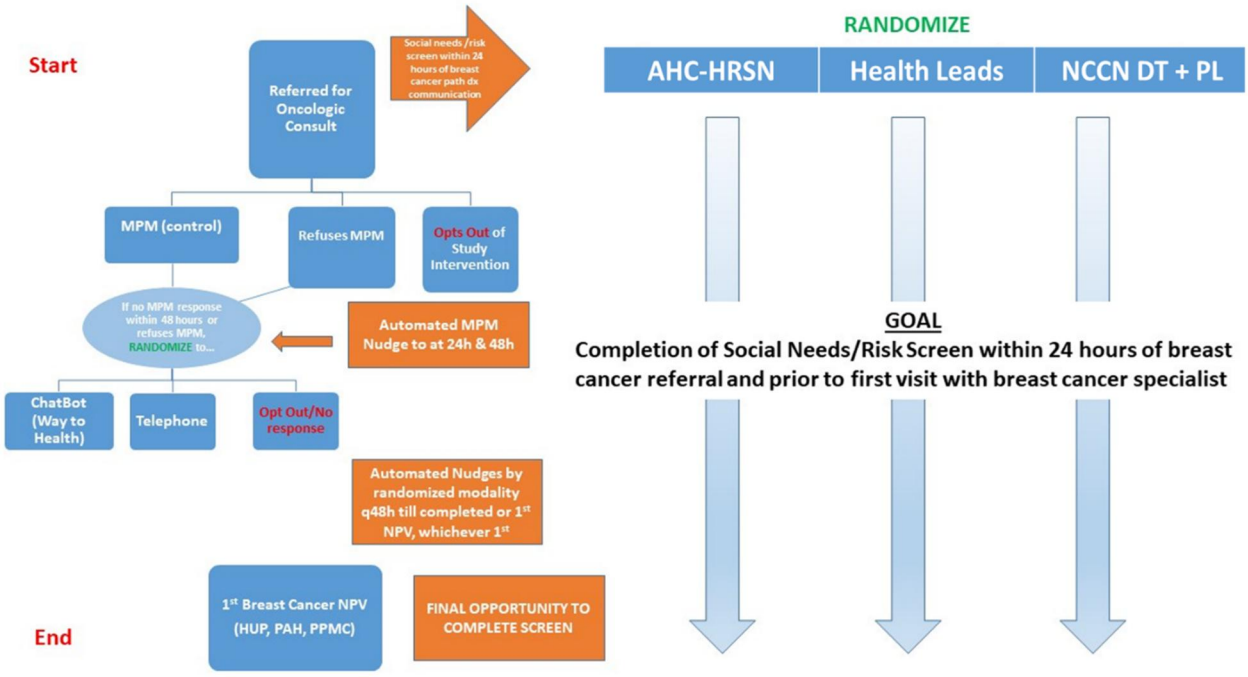

Figure 1. Clinical trial flow diagram. AHC-HRSN = Accountable Health Communities Health-Related Social Needs Screening Tool; Health Leads = Health Leads Social Screening Tool; HUP = Hospital of the University of Pennsylvania; MPM = MyPennMedicine (ie, MyChart patient portal messaging); NCCN = National Comprehensive Cancer Network; NPV = New Patient Visit; PAH = Pennsylvania Hospital; PPMC = Penn Presbyterian Medical Center.

Needs Screening Tool, Health Leads Social Screening Tool, and the National Comprehensive Care Network Distress Thermometer and Problem List. The 3 delivery modalities are the Epic EHR patient portal ("MyPennMedicine"), a bidirectional text-based conversational agent ("chatbot"), and interactive voice response administered by phone (Figure 1).[32-34] Anticipating that we would want additional patient-sourced feedback beyond the perspectives of our advocates, we began with a soft launch of the trial for 1 month with a limited number of patients and radiology clinicians, and we incorporated the findings from this initial soft launch into the conduct of the rest of our trial. After this brief pilot period, the study fully opened to enrollment on May 1, 2024, at 4 Penn Medicine facilities (Perelman Center for Advanced Medicine, Penn Presbyterian Medical Center, Pennsylvania Hospital, and Radnor). Six months after trial launch, we began recruiting participants (30 patients who participated in the trial or opted out at initial contact as well as 15 clinicians or clinical leaders) for semistructured interviews on a rolling basis. These interviews seek to evaluate contextual mechanisms contributing to the effectiveness of data-collection instruments and modalities employed in the trial.

Despite stakeholder engagement, financial support, careful contingency planning, and extensive exploration of potential obstacles, we encountered challenges related to patient navigation, stakeholder engagement, and technological integration as we deployed the trial. We describe these challenges below with an accompanying timeline (Figure 2) as a guide for others aspiring to realize real-world implementation of routine SBDOH data collection at their institutions.

Challenges of patient navigation within a large, complex health system

When newly diagnosed patients seek treatment at large, complex health systems, they need to not only identify and pursue the correct point of entry but also navigate multiple departments and clinicians, especially when they are initiating multifaceted and multimodal care for complex conditions such as breast cancer.[35,36] Patients face new and overwhelming self-management responsibilities that extend beyond the health-care setting. These new responsibilities are particularly challenging for patients from marginalized populations, who may already have limited access to vital resources and care due to preexisting rurality, poverty, and systemic racism. At Penn, patients newly diagnosed with nonmetastatic breast cancer almost always meet with a breast cancer surgeon for their first postdiagnosis consultation as part of a multidisciplinary care team. Yet, the initial stages of the Breast SBDOH trial uncovered numerous logistical challenges to establishing care with an oncology treatment team:

- **Multiple phone numbers.** It emerged in the period before trial launch that patients can choose from multiple phone numbers when trying to make an appointment. Depending on the number they call, patients could be shunted to different call centers within our institution, where they could encounter drastically diverse call hold times and multiple transfers. Patients could also try to schedule through the MyPennMedicine patient portal, but doing so often involved waiting for a scheduler to return their call, potentially leading to "phone tag" and other types of delays.
- **Site-to-site variation in health system entry.** The Breast SBDOH study spans 4 clinical sites, a mix of academic and community-based clinics within the Penn Medicine system, and these sites vary in scheduling practices, appointment availability, practices for referral to nurse navigation, and more. We recognized that referring patients to the SBDOH study would add an extra step to the established diagnostic notification and resource referral processes. Thus, we created the breast social assessment coordinator role due to the lack of a single, unified pathway for scheduling surgical consults.

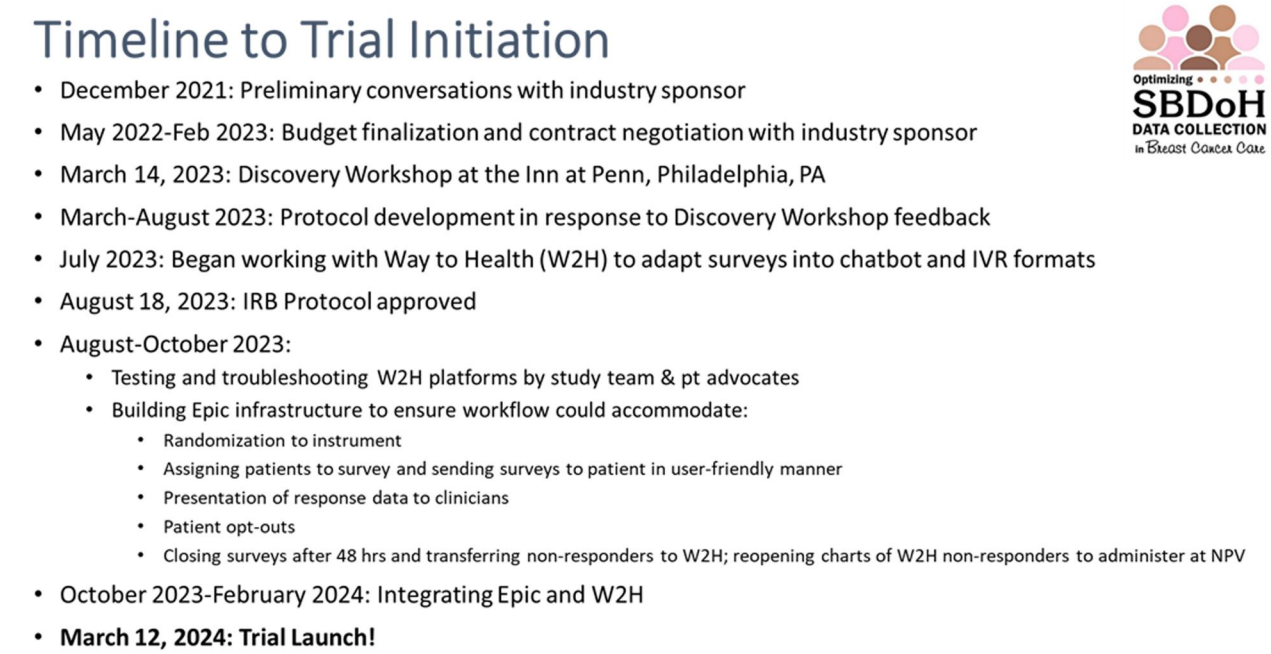

Figure 2. Timeline of trial development and implementation.

Breast social assessment coordinators are dedicated clinical research coordinators who enroll patients referred by radiology and the new patient office into the Breast SBDOH trial, interacting with patients early in the scheduling process to introduce the trial.

We did include a plan for responding to needs identified through the SBDOH screening instruments. At the end of each instrument, patients had to indicate whether they wanted assistance with the needs they reported. Our study team was notified of any patients who responded as wanting assistance; we would then notify the breast surgical oncologist (all of whom had been notified and educated about the trial before initiation) with whom the patient had been scheduled. The surgeons were then prompted to contact our patient navigation and social work teams and have them connect with the patient before or at their upcoming scheduled visit. Of note, we are tracking the proportion of patients who requested assistance, the proportion of these individuals who received assistance, and whether and how this assistance was documented in the EHR. In addition, we will analyze in parallel how many patients had scores or responses that in other circumstances and at other institutions are deemed to reflect unmet needs (eg, a score ≥4 on one of the SDOH instruments, the National Comprehensive Care Network Distress Thermometer and Problem List, has been used to trigger social services referrals at other institutions).

Although the breast social assessment coordinator role helped address some of the logistical challenges noted above, its creation also uncovered more challenges that can affect the SBDOH trial. For example, an attempt to streamline the points of entry into the health system led to new clinical workflows and lack of consensus on the duration and frequency of patient navigators' involvement in patient care pathways, reflecting the difficulty of securing buy-in from stakeholders that has been observed in other attempts to implement patient navigation.[37] Thus, although there are well-documented benefits of patient navigation in the breast cancer population (eg, promoting access to timely screening, diagnosis, and treatment), uptake of navigation services is challenged by substantial logistical barriers to implementation[38-40] that were reflected in our own experience.

Coordination across stakeholders

Early lessons after implementation: changing from the "warm handoff" to the "callback" method

To implement a large-scale SBDOH screening program, communication and collaboration with stakeholders across various service lines contributed to modifications in study design, processes, outcome measures, and delivery methods.[41] Launching the Breast SBDOH study involved collaboration among research staff (eg, breast social assessment coordinators), breast surgical oncologists, breast radiologists, the patient scheduling office, social workers, and patient advocates. Engagement with all these stakeholders was key to developing the breast social assessment coordinator–facilitated patient enrollment process that the study currently uses.

For example, we initially tested an enrollment process in which the breast social assessment coordinator provided a "warm handoff" for the patient, engaging directly with the diagnosing radiologist and patient when the diagnosis was communicated and connecting the patient to the scheduling office by phone. During the pilot phase, however, we came to realize that the process was unwieldy for everyone involved, even on a small scale, and that the benefits of the warm handoff (immediately establishing patient care) were quickly outweighed by the obstacles. Factors impeding the process included individual radiologists' schedules, the time of day they made phone calls about diagnoses, and patient and breast social assessment coordinator availability. If the radiologist left a voicemail for the patient, getting the breast social assessment coordinator on the phone when the patient called back added steps. We also had to consider the effect of the breast social assessment coordinator's presence on the call during which diagnoses were communicated: There was sometimes perceived encroachment on the communication style

of the radiologist by the breast social assessment coordinator's presence as well as upset on the part of some patients, who felt emotionally unable to engage with SBDOH collection in the wake of a new cancer diagnosis. The warm handoff was also suboptimal from the perspective of the scheduling office, given the high volume of calls they receive and the concomitant difficulty of incorporating breast social assessment coordinators into their workflow.

Feedback from stakeholders prompted our decision to move to a callback method. In the callback method, patients were briefly introduced to the study by the radiologist or (if diagnosed outside our health system) the patient scheduler setting them up for appointments before being contacted by the breast social assessment coordinators, who were contacted by radiologists and patient schedulers by secure chat with the names of patients to be contacted and potentially enrolled in the trial. Breast social assessment coordinators subsequently contacted the patients to tell them more about the trial and conduct the consent and enrollment processes. We appreciate the fact that a trusted clinician can potentially be more effective at raising the study with the patient and increasing patient willingness to consider enrollment. However, the callback method was adopted after receiving considerable feedback from stakeholders (including breast radiologists, who deliver the initial diagnosis to patients) that the joint phone calls between clinicians, patients, and breast social assessment coordinators were not logistically feasible. Moreover, the callback method streamlines the enrollment process, facilitates handoff between breast social assessment coordinators (who can notify each other about outstanding tasks, leading to more continuity and better data collection), and affords patients more time to process their diagnoses between the initial call with a radiologist or scheduler and the subsequent call with the breast social assessment coordinator. The process is, however, "high touch," and ways to implement the SBDOH tools we are trialing into real-world settings will require prospective sites to assess baseline and required personnel to facilitate implementation.

Moving to the callback method allowed us to balance the logistical challenges caused by attempted integration with existing radiology workflows, provided patients with sufficient time to grapple with receiving their new cancer diagnosis before being introduced to the trial, and removed the practical constraints on breast social assessment coordinators to facilitate patient conversations with the scheduling office while also gaining consent from the patient for the study. Nonetheless, based on feedback from our patient advocate co-investigators and from participants themselves, we felt that it was important to continue to pursue preconsultation SBDOH screening where possible to inform care planning, identify barriers early in the care trajectory, and enhance patient-clinician trust and communication by showing that the clinical team cares about them as people and not just patients.

To facilitate communication with the various groups involved, including our radiologists and the scheduling office, our study team found success in identifying a trial "champion" (ie, a direct point of contact to act as a liaison between the core study team and the contact's department) for each of these groups who would work with the study team and the breast radiology team to facilitate dialogue, collaboration, and feedback. More broadly, other pragmatic trials have remedied communication issues through a partnership approach, where stakeholders collectively reviewed protocols and actively contributed feedback both upfront and throughout the trial enrollment period.[41] We have accomplished this through regular meetings as well as monthly email reminders to our contacts in the radiology and scheduling offices, which provide opportunities for exchange of mutual feedback. Patient advocates (M.B., R.E., J.G., S.R.S.), who have been integral to protocol development and ensuring feasibility and acceptability of the screening instruments following their adaptation to the 3 modalities, also meet with us routinely and are providing guidance as we prepare for qualitative analysis of the trial experience.

Unexpected overlap with other SBDOH programs and research interventions

Although the rarity of structured SBDOH data collection drove the development and implementation of our trial, we found that parallel interventions were occurring in our health system with regard to SBDOH data collection as well as patient scheduling that interfered with our ability to enroll some patients. Penn is a busy academic health system with a robust research program, which sometimes makes avoiding these conflicts impossible.

Specifically, a separate pilot program to facilitate faster intake of patients with newly diagnosed breast cancer affected eligibility of patients for our study as the throughput of patients being scheduled by the scheduling office increased, and new patient visits were scheduled on a much faster timeline than expected and was compatible with our instrument assignment and randomization protocol (Figure 1). Communication with the scheduling office on patient referral processes for our study (eg, clarification of inclusion criteria, timeline for the schedulers to refer patients to the study team) was essential to mitigate confusion that arose when different studies also enrolling newly diagnosed patients were also requiring the attention of the scheduling office. Finally, our pilot was occurring within the context of simultaneous efforts by primary care at Penn to increase SBDOH data collection. Accordingly, patients in our pilot who already had established primary care clinicians at Penn had varying degrees of prepopulated data and were also at potential risk of survey fatigue. As part of her clinical leadership role, Dr Fayanju was actually an active participant in the "competing" quality improvement project for faster intake of new patients describe above, although our trial was conceived long before this quality improvement initiative was launched. Her involvement in both initiatives and her connectedness to the larger research community at our institution meant that we were ultimately able to adapt our trial to the real-world parallel initiatives being undertaken to achieve our shared goal of improving patient care for all.

Technological challenges with implementation of digital screening tools

The Breast SBDOH study aims to identify the optimal combination of survey instrument and modality for collection of SBDOH data. To evaluate 3 different modalities—patient portal, chatbot, and interactive voice response—in combination with 3 survey instruments, we needed to adapt each instrument to ensure compatibility with the 3 delivery modalities. Further, we needed to reliably transfer data collected by Way to Health, the external platform that administers chatbot and interactive voice response surveys, into Epic, our EHR system. We used a multidisciplinary team of analysts, developers, and clinical informaticians to create a system spanning 2 distinct digital platforms that automated the process of administering social needs screeners to patients, recording data, and presenting data in an easily visible and accessible fashion to clinicians within the EHR. In building this system, we encountered various technological challenges, such

as time delays in capturing real-time data in chatbot conversations and issues mapping survey responses collected in the Way to Health chatbot and interactive voice response platforms to the flowsheets attached to patient encounters in the EHR. We also identified several tasks that could not be automated, such as some forms of patient-level data entry by breast social assessment coordinators, alerts to clinicians and social workers for patients requesting assistance for the unmet needs they reported, and a manual review of data transfer between platforms. Standardized protocols (eg, procedures for breast social assessment coordinators to send secure messages to providers alerting them of patients requesting assistance; steps for breast social assessment coordinators to enter and review patient data in Research Electronic Data Capture; and processes for routine quality control of data, along with a rotating data audit schedule across breast social assessment coordinators and project managers) were developed, along with robust documentation resources (eg, a handbook given to each breast social assessment coordinator at the time of training) to facilitate these aspects of the trial that could not be automated.

Our experience navigating these technological challenges are emblematic of broader barriers to use of digital technologies in clinical trials and concomitant translation of these technologies into clinical practice. First, there are considerable challenges regarding interoperability across EHR systems as well as interoperability between EHR and non-EHR external software and digital platforms such as Way to Health. Often, interoperability is precluded by the differences in data architecture underlying different platforms (eg, the same data points can be stored in different formats and locations across platforms), complicating reliable data exchange.[42] Further, there is no standardized model of SBDOH data representation in the EHR system, although there are nascent federal measures to encourage collection,[43] such as the deployment of Z codes for documenting SBDOH-related clinical interactions and the development of managed care organization contract requirements related to social determinants of health.[44] Existing frameworks lack translational algorithms to integrate results of SBDOH screening tools into the EHR as a universally agreed-upon clinical measure.[45] Moreover, data collected through SBDOH screening tools can be stored in multiple places within the EHR system, some of which can be easily accessible to physicians while others are more obscure. These intra-EHR tools (eg, Epic Social Determinants of Health Wheel, flowsheets) also differ in their data visualization, interpretability, and interactivity, making some tools easier for clinicians to use than others. Finally, even within the same health system, different clinicians may have different degrees and types of interaction with SBDOH data, depending on their particular roles within the health system (eg, dietician vs physician) or the clinical context from which they are accessing the EHR (eg, the outpatient clinic vs the perioperative area). At Penn, for example, the EHR system was updated in 2019 to include a "Social Determinants of Health" module that includes validated questions based on the 2014 *Capturing Social and Behavioral Domains and Measures in Electronic Health Records* Institute of Medicine report. These questions feed into the aforementioned Epic Social Determinants of Health Wheel (which has since been replaced by the Epic Social Determinants of Health Navigator in September 2023). Because this module draws from patients' responses to these prespecified questions, we needed system-level approval to have the responses for our 3 trial instruments feed into this module.

Finally, from a moral perspective, we needed to be able to respond to urgent patient-reported needs quickly and effectively when they were shared as part of the trial. Furthermore, there is substantial evidence that patients are more willing to share sensitive SBDOH-related information about themselves if there is an opportunity for them to directly receive assistance or improve understanding of populations who resemble them.[46] Although the primary purpose of our trial was to optimize collection of SBDOH data rather than to develop interventions for unmet social needs, our trial brought to light an acute need for improved institutional social support that addresses patients' individual contexts, their cancer diagnoses, and other chronic conditions and behavioral factors to help them get the best possible outcomes. We have worked closely with both our information technology and social work teams to develop a workflow that allows for rapid transmission of actionable patient-reported needs to clinicians for preconsultation intervention. In summary, we acknowledge that our trial is ambitious, perhaps excessively so, and that some of the challenges we experienced in part resulted from trying to implement several new logistical processes simultaneously at multiple institutions within our health system.

Conclusions

Across the medical community, attempts have been made to collect data on SBDOH and screen for unmet social needs, but these data are still unlikely to be collected for many patients. Furthermore, when attempts to collect these data are made, they may not be made routine and operational to ensure high levels of quality, uniformity, and equitable uptake. Our trial has the potential to provide a blueprint for others to implement routine SBDOH data collection en route to a broader approach to personalized, patient-centered care that extends beyond breast cancer and even oncology. In concert with our diverse patients and collaborators, we look forward to translating our findings into wide-scale implementation within our health system and beyond.

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Author contributions

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Conflicts of interest

Co-authors T.L.B. and V.L., who are employees of Gilead Sciences, Inc, a sponsor of the study, were involved in the design of the study, the writing of the manuscript, and the decision to submit the manuscript for publication; no new data were reported, but neither of them is involved in the collection, analysis, or interpretation of the data being generated in the ongoing trial described in this commentary. No other authors have conflicts to declare.

Data availability

No new data were generated or analyzed in this commentary.

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Commentary