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## Part II: A Qualitative Study of Social Risk Screening Acceptability in Patients and Caregivers

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## Abstract

**Introduction**—This study aimed to better understand patient and caregiver perspectives on social risk screening across different healthcare settings.

**Methods**—As part of a mixed-methods multisite study, the authors conducted semi-structured interviews with a subset of adult patients and adult caregivers of pediatric patients who had completed the Center for Medicare and Medicaid Innovation Accountable Health Communities social risk screening tool between July 2018 and February 2019. Interviews, conducted in English or Spanish, asked about reactions to screening, screening acceptability, preferences for administration, prior screening experiences that informed perspectives, and expectations for social assistance. Basic thematic analysis and constant comparative methods were used to code and develop themes.

**Results**—Fifty interviews were conducted across ten study sites in nine states, including six primary care clinics and four emergency departments. There was broad consensus among interviewees across all sites that social risk screening was acceptable. Four main themes emerged: (1) participants believed screening for social risks is important, (2) participants expressed insight into the connections between social risks and overall health, (3) participants emphasized the importance of patient-centered implementation of social risk screening, and (4) participants recognized limits to the healthcare sector's capacity to address or resolve social risks.

**Conclusions**—Despite gaps in the availability of social risk-related interventions in healthcare settings, patient-centered social risk screening, including empathy and attention to privacy, may strengthen relationships between patients and healthcare teams.

## INTRODUCTION

As the evidence grows on how social risks such as housing insecurity, food insecurity, and material hardship impact health, both social risk screening and social care interventions are becoming more common in U.S. healthcare practices. This growth can be attributed to recent recommendations from medical professional associations, and importantly, new financial incentives from payers and government programs, such as Medicare's Accountable Health Communities.<sup>1–5</sup> Research on these programs to date has demonstrated that they are feasible to implement<sup>6,7</sup> and may help to reduce specific social risk factors and improve health.<sup>8–15</sup> However, relatively little research has explored patient perspectives on these initiatives, which is critical for patient-centered implementation.<sup>16–21</sup> Much of the existing literature has instead either described clinician perspectives on social risk screening,<sup>22–26</sup> or has been limited to a specific social domain like food insecurity or intimate partner violence.<sup>18,27</sup>

The authors conducted interviews with patients and caregivers of pediatric patients across different healthcare settings and geographic regions to better understand the experience and expectations associated with healthcare-based social risk screening.

## METHODS

As part of a larger mixed-methods multisite study, the authors conducted semi-structured interviews with patients and caregivers who completed a survey that included the Center for Medicare and Medicaid Innovation 10-item social risk screening tool, which was developed for the Accountable Health Communities demonstration project.<sup>28</sup> Following completion of the screening questions, respondents answered 22 additional survey items regarding screening acceptability and experiences. Methods and details of the recruitment and survey are described elsewhere.<sup>29</sup>

### Sampling and Interviews

Study sites included academic and community primary care practices and both general and pediatric emergency departments across nine U.S. states. English- and Spanish-speaking patients and caregivers of pediatric patients were recruited into the study by trained research assistants if they or their child had presented for a non-emergent evaluation at one of ten participating study sites. Recruitment occurred from July 2018 to February 2019. After completing the screening and study survey, respondents were asked if they would like to participate in a semi-structured interview expected to last 30 minutes. A mean of 45% of survey respondents at each site were willing to participate in an interview. Of those respondents who indicated they would be willing to participate in an interview at each site, five were randomly selected for the interview. One-on-one interviews were performed to respect participant privacy. All sites attempted to conduct interviews in person and directly after participants' clinical encounters; three sites offered phone interviews within 7 days of survey completion. Interview training was done across all sites for quality assurance.

The interview guide was developed by the study team and included questions exploring participants' reactions to social risk screening, screening acceptability, preferences for screening administration, prior social risk screening experiences, and expectations for social assistance (Appendix Text 1). Interviews were piloted at the main study site ( $n=3$ ). After finalizing the interview guide, all study site interviews were conducted in English or Spanish by trained bilingual research staff, audio recorded, professionally transcribed, and translated. The study was approved by the University of California, San Francisco IRB (17-23110); seven of the study sites additionally obtained site-specific IRB approval.

### Data Analysis

Two researchers (EB and EHD) used basic thematic analysis and constant comparative methods to code transcripts.<sup>30</sup> These two team members independently analyzed 14 transcripts line by line, generating common codes from the data to summarize key ideas. The transcripts were then re-evaluated to group codes in conceptual categories. A third member of the research team (LMG) reviewed the codes to adjudicate discrepancies and refine and harmonize codes into a cohesive coding scheme. The coders then independently analyzed

and applied this coding scheme to the remaining transcripts, followed by regular meetings to discuss discrepancies and add new codes and categories until thematic saturation was reached. Once the final codebook was agreed upon, the coders reviewed and systematically applied the final codes to all transcripts. As a final step, the study team identified emergent concepts, themes, and representative quotes. Preliminary codes were presented to representatives from each study site for feedback. Coding and analysis was performed using Dedoose coding software, version 8.2.14.

## RESULTS

The final sample included 50 patients or caregivers from six primary care clinics and four emergency departments. Demographic characteristics of interviewed participants did not significantly differ from participants in the larger survey study (Table 1).

Interviews provided insights about when, how, and why social risk screening is acceptable. Four key themes emerged: (1) participants believed screening for social risks is important, (2) participants expressed insight into connections between social risks and overall health, (3) participants emphasized the importance of patient-centered implementation<sup>31</sup> of social risk screening, and (4) participants recognized limits to the healthcare sector's capacity to address or resolve social adversity.

### Social Screening Importance

Across all study sites, respondents reported that screening for social risks was acceptable, important, and necessary. Common themes related to acceptability emerged, including that screening increased the sense of whole-person care,<sup>32</sup> social risks were prevalent and therefore asking about them was important, and healthcare settings are considered safe spaces to discuss social risks. Taken together, these themes suggest that participants believed social screening was valuable in healthcare settings.

When encouraged to share specific reactions to clinic-based social risk screening, many interviewees noted that they felt “cared for” and “listened to” when clinicians or staff asked about social risks and their home environment. Social risk questions were seen as important areas of inquiry, signaling interest in respondents as people, rather than “just” patients. One respondent stated, “It was a great survey to take. Actually, I’m glad I took it to see that somebody out there actually cares, you know?” Instead of discomfort with the personal nature of the screening questions, many stated that asking about social risks strengthened the patient-provider relationship and could enable clinical providers to get a whole-person view of their patients.

Many interviewees described “relief” or “gratitude” after completing the social risk assessments, noting that the social questions were “important to ask.” Interviewees specifically and frequently referred to the high cost of housing and food insecurity across study sites. In cases where the respondents did not endorse experiencing socioeconomic adversity themselves, many discussed someone they knew who was struggling. Participants’ lived experiences or direct knowledge of others experiencing social adversity highlighted

how social screening was not only acceptable, but important and necessary in clinical settings.

Respondents discussed the importance of social risk screening in relationship to their view of healthcare settings as safe spaces where they can turn if they did not know where else to go for help. They hoped that healthcare settings could be alternative access sites for a range of social services, in particular government benefit programs such as the Special Supplemental Nutrition Program for Women, Infants and Children, the Supplemental Nutrition Assistance Program, or Section 8 housing assistance. In referring to social risk screening in healthcare settings, interviewees invoked concepts related to a no wrong door approach.<sup>32</sup> Referring to her own experience in an emergency department, one respondent stated, “[People] come here and want help. I would basically feel comfortable with somebody coming to me [to screen for social risks] because I need help in an emergency room. Like I said, this is the place where people help people. So, I think it’s the one of the best places to do it.” By including social risk screening in an environment where people already seek care for both medical and social needs, the respondents reinforced the importance of including social risk assessments.

### **Connections Between Social and Health Risks**

Participants justified their support for clinic-based screening because of the impact of social risks on both mental and physical health. Many made clear connections between food insecurity and diet-related illnesses, and poor housing conditions and asthma. Most commonly, respondents described stress and its ill-health effects as a consequence of unmet social needs. Per one interviewee: “Stress impacts health like crazy. Poverty and living at a survival level—whether it’s your safety, or finances, or whatever—is massively stressful. I’m sure it just makes everything ten times worse.” Some acknowledged that discussing social risks with their care team could facilitate diagnoses that clinicians might otherwise miss without understanding environmental circumstances. Per one parent, “The doctor has to know, okay, what make[s] the child sick? Especially the child ha[s] asthma and [the doctor] has to know, okay, if there is someone at home smok[ing]... or if someone for the [child’s] safety has to know that, yes, if your patient is okay at home, if that person is safe because... the way the person lives or eats....that might be the cause...”

### **Patient-Centered Screening Practices: Compassion and Privacy**

Many participants who expressed concern regarding healthcare-based social risk screening pointed to specific ways they felt social screening could be improved. Interviewees emphasized the importance of conducting social risk screening with empathy and compassion. They relayed experiences with the healthcare system where they felt they were not treated with respect and expressed concern that if social screening was implemented without consideration for how the questions were asked, or how the information was used by providers, it could dissuade patients and caregivers from disclosing risks.

“I don’t mind, because if I feel like somebody is concerned—really concerned—about me? I will answer the question. But if I feel like there’s somebody just asking me the question, just to be asking me because that’s part of [their] job? I might not answer.”

Participants also highlighted privacy concerns. Several mentioned experiences in the healthcare system related to perceived bias and discrimination, and explicitly mentioned the need for confidentiality around screening results. One respondent suggested social risk screening initiatives be presented in patient-facing literature from the clinic to diminish potential perception of bias in screening practices: “Let them know that it is okay. ‘We understand what you’re going through and we’re here for you and [the clinic] care[s], and while we got Dr. [X] asking you all these personal questions about your life,’ then it’ll be a little more easier. The patient won’t have an attitude with the doctor and the doctor won’t have an attitude back in response to that, because, I read the pamphlet and you all say you all care.”

Some worried about their responses being shared with people outside of their healthcare teams. When asked about including screening as part of the medical record, one respondent stated: “Why? Why should I have it in my medical chart? It’s not helping me in what I’m coming in here for. Some people, when they look at your chart and see that, you know, they become judgmental.” Privacy concerns were expressed as worry that other patients or caregivers might hear or see social risk screening responses. Respondents acknowledged the tension between the desire for privacy and logistics of providing social care, understanding that collecting social information was often a step towards assistance.

“It’s good in a way and it’s not good in a way because some people see that the information going to pass around to different people. But, that’s the only way you could get help, if the information passed around to different people... I do need help... with me and my kids in many different way[s]... I would like someone... [to] share my information to someone to get the help, to get... to help me and my kids.”

Interviewees also were asked to share preferences around screening modality. No strong preference for in-person or electronic screening emerged from the analysis. Similarly, there was no clear consensus related to when during the medical visit social risk screening should be conducted.

### Intervention Expectations

Despite overall agreement that social risk screening is appropriate in healthcare settings and that social and healthcare risks are inter-related, respondents did not consistently expect nor want their healthcare teams to address or resolve all identified social risks. Some considered social risk screening alone sufficient; some mentioned that resource sheets and referrals to social work or community organizations would be helpful. In both cases, people wanted their healthcare teams to be aware of social situations but did not expect them to resolve social problems. In fact, many reported feeling that intervening on social risks was outside the scope of medicine, and that providers and staff were not adequately trained or equipped to solve social issues.

Interviewer: “How do you see the staff here in the emergency department giving you these resources?”

Respondent: “I don’t see it, because they’re here for other purposes.”



Healthcare professionals were described as too busy and overworked to address social adversity. Although asking screening questions was in the purview of the healthcare team, the solution to identified social barriers was not. One respondent stated: “I don’t know in the way medicine is practiced right now, it could be—whether it would be, you know, send doctors over the top. I mean, I just don’t see there’s time for it.” Respondents implicitly understood mounting clinician time pressures and workloads and felt that addressing social risks was infeasible.

Respondents referenced prior experiences with social risk screening and referrals that had made them skeptical not only about their clinicians, but about their overall healthcare team’s ability to offer meaningful solutions. Others were simply uninterested in asking for assistance because they felt their care team could not provide anything helpful.

Interviewer: “And, did you want help with any of the issues on the survey? Housing, food, utilities, transportation, any of those things?”

Respondent: “No. I would say transportation but [no].”

Interviewer: “Okay, and why not?”

Respondent: “Because what are you all offering? Nothing.”

Respondents with prior experience navigating social services discussed how important personalized, well-coordinated services would be to help them, but they often expressed that they did not believe this would be feasible for providers. Several interviewees discussed prior referrals to social workers or case managers and noted the importance of warm handoffs to improve the likelihood of meaningful referrals. Multiple participants noted that social workers had specialized knowledge of resources and were often, although not always, helpful in resolving social challenges, most reliably challenges related to utilities and transportation.

## DISCUSSION

Through interviews with 50 patients and caregivers of pediatric patients who had completed a social risk screening questionnaire in either primary or emergency care settings, participants reported healthcare-based social risk screening was important, acceptable, and relevant to health. Respondents also articulated important considerations around strategies to implement screening programs that maximized patient-centeredness. This study complements and expands on the overall study’s survey analysis that focused on patient perceptions of social risk screening acceptability.<sup>29</sup> To the authors’ knowledge, this is one of the most comprehensive studies exploring both patient and caregiver perspectives on and reactions to multidomain social risk screening in both primary care and emergency department settings.<sup>16–24</sup>

Attitudes among providers and healthcare administrators present one key barrier to social risk screening. Prior survey work highlighted clinician skepticism about the value of screening activities.<sup>22,23</sup> Some surveyed clinicians reported that it was not their responsibility to screen for and address social adversity and expressed concern that asking personal questions about patients’ social circumstances could undermine trust between

patients and clinicians.<sup>22,23,34</sup> Participants in our study suggested the opposite is true. They perceived that their healthcare teams were well positioned to perform social risk screening and it was important to do so. Including social information in a healthcare setting improved providers' ability to care for their patients. Importantly, few expressed concerns about the negative consequences of social risk screening. Those that were expressed were related to ensuring that screening was done empathetically, without negative judgment, and with attention to privacy protections. Systems that implement social risk screening initiatives should include privacy protocols and staff training to avoid these potential pitfalls.

Though respondents supported social risk screening, they did not believe that the healthcare system needed to comprehensively address identified social risk factors. Participants suggested that resource sheets and referrals were adequate and seemed to value that their providers were aware of their social context. This contrasts with clinicians' arguments against social risk screening that relate to perceived futility to meaningfully address social adversity.<sup>35</sup>

### Limitations

This study has several limitations. First, it is subject to selection and response bias. Only the opinions of those who agreed to participate are reflected—and respondents who viewed the screening survey favorably may be more likely to have agreed to participate in these interviews. The study is strengthened by the fact that it included respondents across ten healthcare settings and interview analyses suggest that thematic saturation was reached. Second, though the study included patients from ten different clinical sites to ensure broad representation of respondents, the findings may not be generalizable to all healthcare settings. In particular, urban regions in the west and northeast were over-represented compared with rural settings. Third, this study was not designed to compare differences in perspectives between healthcare delivery sites or between individuals reporting specific social risks. Rather, it is hypothesis-generating and should inform future evaluations of social risk screening in different healthcare settings. Finally, the authors did not include participants while reviewing or analyzing transcripts to ensure coding matching lived experience.

### CONCLUSIONS

Interviewed adult patients and caregivers of pediatric patients supported implementation of social risk screening across diverse healthcare settings. Adoption of clinical social risk screening may have both immediate and long-term impacts. Interviewees believe that an awareness of social risks could strengthen patient-provider relationships. They also noted that patient-centered implementation of social screening must include staff trained to show empathy and compassion and establish and maintain data privacy protections. Though some providers may be hesitant to screen patients for social risks, these findings provide evidence that even in health systems with limited capacity to address social risks, patients and caregivers value this screening.



## Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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The study was approved by the UCSF IRB (17-23110); per their own institutional requirements, seven of the study sites also obtained site-specific IRB approvals (University of Arkansas, 217767; Boston Medical Center, H-37489; University of Chicago, 18-0139; University of Colorado, 17-2434; Dartmouth College, STUDY00031049; Hennepin Health, 18-4482; New York University, i18-00004).

EWF is a consultant for Veta Health, which is a company that develops software for chronic disease management. Veta Health also supports HelpSteps, a system for connecting families to social services developed by EWF. In the future, it is possible that this technology will be sold commercially. If this were to occur, EWF and Boston Children's Hospital might receive financial benefits in the form of compensation. As in all research studies, the Boston Children's Hospital has taken steps designed to ensure that this potential for financial gain does not endanger research subjects or undercut the validity and integrity of the information learned by this research. The research published in this paper is not related to any of the above consulting work and was conducted prior to EWF working with Veta Health. STL directed a Center for Medicare and Medicaid Innovation Health Care Innovation Award (1C1CMS330997-03) called CommunityRx. This award required development of a sustainable business model to support the model test after award funding ended. To this end, STL is founder and co-owner of "NowPow, LLC". Neither the University of Chicago nor the University of Chicago Medicine is endorsing or promoting any "NowPow, LLC." entity or its business, products, or services. No other financial disclosures were reported by the authors of this paper.

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**Table 1.**

## Participant Demographics

Variable	Survey and interview participants (n=50 <sup>a</sup> ) %	Survey participants only (n=955 <sup>a</sup> ) %	Fisher's exact p-value
Age, years			0.842
18–44	59	55	
45–64	29	30	
75	12	15	
Sex			0.588
Female	77	70	
Male	23	29	
Participant type			0.732
Patient	80	76	
Caregiver of pediatric patient	20	24	
Approximate %FPL			<b>0.007</b>
<200%	68	55	
200%	33	45	
Race/ethnicity			0.070
Non-Hispanic white	29	37	
Non-Hispanic black	37	21	
Hispanic	31	34	
Other	4	9	
Preferred language			1.000
English	82	82	
Spanish	18	18	
Education			0.600
High school or less	52	43	
Some college and above	48	57	
Self-rated health			0.731
Excellent/Very good/Good	76	76	
Fair/Poor	24	25	
Healthcare setting			1.000
Family medicine	40	40	
Internal medicine	20	20	
General ED	20	20	
Pediatric ED	20	20	
Census region location of healthcare site			1.000
Northeast	30	30	
South	10	10	
Midwest	20	20	
West	40	40	
Participant response to CMMI social risk screening tool			

Variable	Survey and interview participants (n=50 <sup>a</sup> ) %	Survey participants only (n=955 <sup>a</sup> ) %	Fisher's exact p-value
Yes, housing problem	40	41	1.000
Yes, food insecurity	52	41	0.144
Yes, transportation problems	16	21	0.588
Yes, utilities problems	10	13	0.825
Yes, safety concern	0	2	1.000
Overall number of positive social risk screening domains			0.558
No unmet risks	34	39	
1–2 unmet risk(s)	54	46	
3–5 unmet risks	12	16	
Appropriateness of screening at healthcare setting			0.214
Very appropriate	40	55	
Somewhat appropriate	38	25	
Neither	14	14	
Somewhat inappropriate	20	4	
Very inappropriate	6	3	
Comfort with EHR integration of social risk screening results			0.622
Very comfortable	43	44	
Somewhat comfortable	16	20	
Neither	20	16	
Somewhat uncomfortable	6	9	
Very uncomfortable	14	9	

Note: Boldface indicates statistical significance ( $p < 0.05$ ).

<sup>a</sup>Not all participants completed the survey. Respondents who completed >50% of the survey questions were eligible to participate in interviews.

FPL, federal poverty limit; ED, emergency department; CMMI, Center for Medicare and Medicaid Innovation; EHR, electronic health record.