

ORIGINAL RESEARCH

Patient and Patient Caregiver Perspectives on Social Screening: A Review of the Literature

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Background: Health care policy and practice-level enthusiasm around social screening has emerged in the absence of a clear appreciation for how patients feel about these activities. Yet patient and caregiver perspectives should be used to establish the rationale and inform the design and implementation of social screening initiatives.

Methods: We conducted a systematic scoping review to better understand patient and patient caregiver perspectives regarding multidomain social screening in US health care settings.

Results: We identified 16 articles. Thirteen studies assessed the perspectives of patients; a partially overlapping 9 studies assessed the perspectives of adult patient caregivers. Most articles assessing the acceptability of social screening reported that patients and patient caregivers generally found it to be acceptable. Notably, there was some variation by screening approach and prior experiences in health care settings, as well as mixed findings by race/ethnicity and gender. Participants from several articles raised concerns regarding data documentation and sharing, highlighting the potential for social data to contribute to provider bias.

Conclusion: The themes emerging in this diverse set of largely descriptive studies warrant deeper and more rigorous exploration as social screening initiatives expand in health care settings across the United States. (J Am Board Fam Med 2023;36:66–78.)

Keywords: Caregivers, Clinical Medicine, Delivery of Health Care, Social Determinants of Health, Social Care, Socioeconomic Factors, Screening, Systematic Review

Introduction

As part of their deepening commitment to health equity, a growing number of professional organizations and health care policies now encourage social screening assessments in the context of health care delivery.^{1–4} For example, multiple public health and medical associations have endorsed screening patients for social adversity, including food insecurity, housing

instability, and transportation barriers.¹ In addition, multiple state Medicaid agencies have increased Medicaid managed care contract requirements related to these assessments.^{2,3,5} Most recently, the Centers for Medicare and Medicaid Services added social screening quality measures to propose federal rules for payment incentive programs.⁶ Reflecting this surge in enthusiasm, some evidence suggests that payers and health care delivery systems are increasingly incorporating social screening into more traditional clinical health risk assessments.⁷

The policy and practice-level interest in social screening, however, has emerged in the absence of a clear understanding of how patients and patient caregivers feel about these activities. Yet patient

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perspectives are critical for designing and implementing equitable and effective social screening initiatives. We conducted a scoping literature review to identify and synthesize existing research as well as outstanding evidence gaps regarding patient and patient caregivers' perspectives on social screening activities.

Methods

In this article, we present findings that correspond to one of several research questions posed in a broader systematic scoping review on social screening in health care settings. The other topics in this review included provider perspectives, screening tool development, and validity testing as well as screening implementation approaches.⁸ The parent scoping review was based on the 5-step Arksey and O'Malley methodological framework,⁹ which involved identifying the research questions, identifying relevant studies, selecting relevant studies, and charting the data. Given the substantial number of articles relevant to each of the parent study's research questions, we separated the final step—collating, summarizing, and reporting results—by topic area.

Identifying Relevant Studies

We adapted a previously published, 2-concept search for the psychometric properties of social screening tools designed to capture articles related to both screening and social factors.¹⁰ The search was refined by 3 study team members (EMB, VL, ED) in consultation with an experienced university librarian and modified for each database. We searched peer-reviewed literature (PubMed and EMBASE) and sought out expert referrals for health care-based studies on social screening published between January 1, 2011 and August 8, 2021. Complete search strings can be found in Appendix 1. Search results were uploaded into Covidence, a web-based software platform used to organize systematic reviews.¹¹

Selecting Relevant Studies

Studies were included if they met the following criteria:

1. Evaluated the perspectives of patients and/or patient caregivers;
2. Focused on social screening tools that covered two or more social domains to reflect the growing interest in and implementation of multidomain tools.^{3,6} These included but were not strictly limited to housing, food, utilities, transportation,

finances, employment, social isolation, and legal issues (we excluded violence/safety concerns and adverse childhood events given the robust existing literature on those domains^{12–14});

3. Took place in or informed initiatives being designed to take place within a US health care setting;
4. Represented original research (ie, not perspective/commentary pieces or reviews);
5. Were written in English.

Initially, two members of the study team (EMB, VL, ED, BA, MM, HA, RF) independently reviewed each title and abstract based on inclusion criteria. Researchers discussed and resolved conflicts during scheduled weekly team meetings. Pairs from this research group reviewed 40% of the articles before achieving consistent consensus, on which the study team determined that remaining titles and abstracts could be screened by one reviewer each. A similar approach was applied to reviewing full texts of the screened-in articles; 43% of these articles were reviewed by two reviewers. Team discussions focused on articles where the two reviewers' comments were discordant until the team's abstractions were consistent. Remaining full texts were reviewed and abstracted by one reviewer per article.

Data Abstraction for Parent Study

Two reviewers independently extracted the following data from eligible full-text studies: study population (patients, patient caregivers, or providers), participant characteristics (eg, age, race/ethnicity, language), study setting, study design, and sample size as well as whether they included relevant data regarding each of the parent review topics. Reviewers ranked the quality of each study's evidence using Grading Recommendations Assessment Development and Evaluation (GRADE) criteria.¹⁵

Data Abstraction for Patient and Patient Caregiver Perspectives Study

Three team members (EMB, VL, LMG) reviewed and synthesized findings from articles categorized in the parent review pertaining to patients or patient caregiver perspectives. Two team members (EMB, VL) then abstracted relevant study outcomes: perspectives about the rationale for health care systems to collect social information, acceptability of general screening as well as screening for specific social domains, preferences regarding mode

Table 1. Characteristics of 16 Studies Describing Patient and Patient Caregiver Perspectives Regarding Multidomain Social Screening in US Health Care Settings

First Author, Publication Year	N	Data Source	Population	Study Setting	Race/Ethnicity
Wylie (2012) [†]	50	Qualitative	Adolescent and young adult patients	Primary care	Latinx/Hispanic (28%) NL/H Black (48%) NL/H White (14%) Other (10%)
Hassan (2013)	401	Quantitative	Adolescent and young adult patients	Primary care	Latinx/Hispanic (29%) NL/H Black (54%) NL/H Asian (2%) NL/H White (9%) Other (4%)
Colvin (2016)	143	Quantitative	Adult patient caregivers	Inpatient	Latinx/Hispanic (6%) Black (18%) White (71%) Other (12%)
Careyva (2018)	115	Mixed methods	Adult patients	Primary care	Latinx/Hispanic (68%) NL/H (32%)
Hamity (2018)	68	Qualitative	Adult patients, adult patient caregivers	Primary care; specialty care; ED	N/A
Byhoff (2019) [†]	50	Qualitative	Adult patients, adult patient caregivers	Primary care; ED	Latinx/Hispanic (31%) NL/H Black (37%) NL/H White (29%) Other (4%)
De Marchis (2019)	969	Quantitative	Adult patients, adult patient caregivers	Primary care; ED	Latinx/Hispanic (33%) NL/H Black (22%) NL/H White (36%) Other (9%)
Kocielnik (2019)	30	Mixed methods	Adult patients	Research setting	Latinx/Hispanic (30%) NL/H Black (27%) NL/H White (20%) Other (20%) N/A (1%)
Langerman (2019)	516	Quantitative	Adolescent patients, adult patient caregivers	ED	Adolescents: Latinx/Hispanic (21%) NL/H Black (65%) NL/H White (7%) Other (6%) Caregivers: Latinx/Hispanic (8%) NL/H Black (69%) NL/H White (14%) Other (9%)
Byhoff (2020)	20	Qualitative*	Adult patients	Primary care	Latinx/Hispanic (100%)
Emengo (2020)	7	Qualitative	Adult patient caregivers	Primary care	Latinx/Hispanic (29%) NL/H Black (14%) NL/H Asian (29%) N/A (29%)
Rogers (2020)	1161	Quantitative	Adult patients	Integrated health system clinics (details not specified)	Latinx/Hispanic (50%) NL/H Black (6%) Asian (9%) NL/H White (30%) Other (3%)

Continued

Table 1. Continued

First Author, Publication Year	N	Data Source	Population	Study Setting	Race/Ethnicity
Oldfield (2021)	154	Quantitative	Adolescent patients, adult patient caregivers	Primary care	Adolescents: Latinx/Hispanic (85%) Black (13%) Asian (1%) White (27%) Other (55%) Caregivers: Latinx/Hispanic (85%) Black (11%) White (31%) Other (58%)
Palakshappa (2021)	103	Quantitative	Adult patients	Primary care	N/A
Wallace (2021)	10	Qualitative*	Adult patients	ED	Latinx/Hispanic (20%) NL/H Black (20%) NL/H Asian (10%) NL/H White (40%) N/A (10%)
Spain (2021)	106	Qualitative	Adult patient caregivers	Primary care	Latinx/Hispanic (100%)

*Mixed methods study that solely examined patient perspectives using qualitative methods.

†Omitted findings regarding general acceptability because authors presented findings that were redundant with a larger sample of the same study.

Abbreviations: ED, emergency department; NL/H, non-Latinx/Hispanic.

of administration and screening context, and perspectives about data privacy/security specifically related to social screening.

Results

Search Results

The parent study's initial search yielded 10,869 records, including duplicates. Among the 6,778 unique records, 95% (n = 6,414) were removed during title and abstract review. Three hundred sixty-four full-text studies were screened; 82 met parent scoping review inclusion criteria. Sixteen of these described patient and/or patient caregiver perspectives about social screening in health care settings (Figure 1). We synthesize the results of these articles below.

Article Characteristics

The majority of articles took place in primary care settings (n = 11/16) (Table 1). Thirteen studies assessed the perspectives of patients described as adolescents, young adults, or adult patients; a partially overlapping nine studies assessed the perspectives of adult patient caregivers. Seven articles included some assessment of how participant perspectives varied within or between different racial and ethnic groups.

Study methods included qualitative,^{16–22} quantitative,^{23–29} or mixed methodologies;^{30,31} all were cross-sectional. Sample size varied widely; the median was 105 (range: 7 to 1161). Half of the articles^{16,18–20,22,25,27,28} reported findings regarding patient and patient caregivers' experience(s) with social screening in a real-world health care setting; the others were conceptual^{17,21,23,24,26,29,30} (ie, “asking how would you feel if”) or took place within a research setting.³¹ Each article approached our constructs of interest using different measures, and qualitative studies rarely indicated the number of patients endorsing specific findings (which is standard). Together, these differences made it challenging to compare findings across studies.

Using GRADE criteria, we classified evidence from two of 16 studies as low quality and the remaining 14 as very low quality. This was primarily due to sample size and sample selection as well as the authors' use of descriptive methodologies (see Appendix 2).

Patient/Patient Caregiver Perspectives on the Perceived Rationale of Social Screening

Seven articles^{16–20,22,29} provided patient or patient caregiver perspectives on the rationale for health

care delivery systems to incorporate social screening initiatives (Table 2). Most participants from four articles indicated that social needs information can or should be used to improve care.^{16,17,19,29} Rogers et al.²⁹ reported that participants who identified as female, Black, or Hispanic were most likely to agree with this sentiment; participants who identified as male, White, or Asian or Pacific Islander (API) were the least.

Other stated rationales for social screening were that the health care setting is a safe^{16,17,19,20,22} or convenient^{18,20} space for discussing social needs. Participants from four articles^{17,18,20,22} indicated that social screening has the potential to improve patient-provider relationships, in part by making patients or patient caregivers feel more supported and cared for by the health care team.^{17,18}

Patient/Patient Caregiver Perspectives on the General Acceptability of Social Screening in Health Care Settings

Eleven articles^{16,17,19,21–25,27,29,31} assessed whether patients and/or patient caregivers generally found social screening to be acceptable. Two pairs of these articles^{17,24;22,25} published separate but similar qualitative and quantitative findings from the same study populations. In this article, we present findings from

only the larger quantitative sample^{24,25} from each pair (Table 3).

The majority of participants from five^{23,24,27,29,31} of the six quantitative articles^{23–25,27,29,31} agreed or strongly agreed that social screening is appropriate, comfortable, or should be asked by their child’s clinician or health system. Of the three qualitative articles^{16,19,21} reporting on the acceptability of social screening, two^{16,19} indicated that participants generally found it to be acceptable. In parallel, participants from both also conveyed concern regarding the sensitivity of collected information. Participants from the third qualitative article²¹ indicated that they did not believe social screening would be acceptable within their communities.

Differences in Acceptability by Patient/Patient Caregiver Demographic Factors

Five^{23–25,29,31} articles explored whether patient and patient caregivers’ acceptability of social screening varied by demographic characteristics, including race, ethnicity, gender, socioeconomic status, age, and education (Table 3). Two^{24,25} of the three articles^{24,25,29} that present differences in acceptability by participants’ racial and/or ethnic identity found no association; Rogers et al.²⁹ reported that participants of API descent were significantly less likely

Table 2. Rationale(s) Provided for Social Screening

First Author (Year)	Findings
	Key Quantitative Findings
Rogers (2020)	79% of participants agreed that their health system should use social needs information to improve care for patients <ul style="list-style-type: none"> • Females more likely to agree than males (OR, 1.7; 95% CI, 1.5, 2.0) • Black participants (OR, 2.3; 95% CI, 1.7, 3.2) and Hispanic participants (OR, 1.8; 95% CI, 1.1, 3.0) more likely to agree than White participants • Participants who completed some college or vocational school were less likely to agree than participants with less than a high school education (OR, 0.7; 95% CI, 1.4, 3.1); participants who completed college or additional schooling were more likely to agree (OR, 1.7; 95% CI, 1.4, 3.1) • No differences by social needs or age
	Key Qualitative Findings
Wylie (2012)	Some participants expressed that social screening could improve patient-provider relationships Few participants expressed that their health clinic is a safe space where participants could receive confidential help
Hamity (2018)	Most participants believed social screening data can be used to improve patient care Participants believed assessments need to lead to action
Byhoff (2019)	Participants expressed that social screening can be used to improve patient care and make them feel supported Participants expressed that health care settings are safe places to discuss social needs but that health care teams should not be expected to resolve social problems
Byhoff (2020)	Participants believed social screening can enhance whole-person care
Emengo (2020)	Participants expressed that social screening can provide a safe space for expression and make them feel supported
Spain (2021)	Participants believed the clinic is a convenient, nonstigmatizing place to discuss social needs

Abbreviations: OR, odds ratio; CI, confidence interval.

Table 3. General Acceptability of Social Screening

First Author (Year)	Findings
Key Quantitative Findings	
Hassan (2013)	33% of participants would welcome social screening <ul style="list-style-type: none"> No differences by age, gender, or race/ethnicity
Colvin (2016)	71% of participants wanted their child's doctor to ask about social issues <ul style="list-style-type: none"> More common among participants who had been previously screened versus those who had not (86% vs 65%) No differences by socioeconomic status
De Marchis (2019)	79% of participants found social screening appropriate <ul style="list-style-type: none"> Higher odds among participants who had been previously screened versus those who had not (OR, 1.82; 95% CI, 1.16, 2.88) Higher odds among participants who trusted their clinician versus those who did not (OR, 1.55; 95% CI, 1.00, 2.40) Lower odds among participants who had experienced prior discrimination within the health care setting (OR, 0.66; 95% CI, 0.45, 0.95) Higher odds among participants recruited from primary care settings versus EDs (OR, 1.70; 95% CI, 1.23, 2.38) Higher odds among participants recruited from sites with 80%+ publicly insured uninsured participants (OR, 1.71; 95% CI, 1.03, 1.86) No differences by age, sex, race/ethnicity, education, income, preferred language, child's health, number of reported social risks, receipt of prior assistance, discomfort with screening domains, or interest in assistance
Kocielnik (2019)	Most participants found social screening comfortable (data not shown) <ul style="list-style-type: none"> No difference between high- and low-literacy participants
Rogers (2020)	85% of participants agreed that their health system should ask about one or more social needs <ul style="list-style-type: none"> Females more likely to agree than males (OR, 1.7; 95% CI, 1.3, 2.2) Participants of Asian or Pacific Islander descent less likely to agree than White participants (OR, 0.7; 95% CI, 0.6, 0.9) Participants who endorsed social needs more likely to agree than those who did not (OR, 3.7; 95% CI, 2.0, 6.9) No differences by age, gender, or education
Oldfield (2021)	84% of participants found screening "comfortable" or "very comfortable" <ul style="list-style-type: none"> No difference between caregivers and adolescents
Key Qualitative Findings	
Hamity (2018)	Most participants found social screening appropriate
Byhoff (2019)*	Participants' acceptability was influenced by whether they felt respected by their provider(s)
Byhoff (2020)	Many participants found social screening acceptable
Wallace (2021)	Participants did not think communities would find social screening acceptable; expressed positive or neutral responses about being screened themselves
Spain (2021)	Many participants positively experienced being asked about social needs Some participants preferred to focus their clinical time on discussing their own health-related priorities

Abbreviations: ED, emergency department; OR, odds ratio; CI, confidence interval.

*Omitted other findings regarding general acceptability because authors presented information that was redundant with a larger sample of the same study.

than White patients to agree that their health system should ask patients about one or more social needs. Among the three articles that assessed perspectives by gender,^{24,25,29} one found that females were more likely than males to agree that their health system should ask about social needs.²⁹ None of the three articles^{23,24,29} that present acceptability by income or socioeconomic status

indicated that there were significant differences between groups nor did the studies that assessed differences by respondent education level,^{24,29} literacy,³¹ or age.^{24,25,29} Among the two articles^{24,29} that explored differences in acceptability by social need, one²⁹ found that acceptability was greater among participants with self-reported social needs. The other²⁴ found no association.

Two additional qualitative articles^{16,20} explored perceptions of acceptability within a sample of Latinx participants. Byhoff et al.¹⁶ reported that most of their sample found screening to be acceptable. Spain et al.²⁰ did not directly explore this question but uncovered relevant themes. While many participants from this study reported positive experiences related to social screening, others preferred to focus their clinical time discussing their own health-related priorities.

Differences in Acceptability by Patient/Patient Caregivers' Prior Health Care Experiences

Seven articles^{16,17,19–21,23,24} indicated that prior health care experiences, including provider relationships, influenced participants' perspectives regarding social screening acceptability (Table 3). Two^{23,24} identified a positive association between prior exposure to social screening and perceived appropriateness. One of those articles²⁴ additionally

found that participants who trusted their clinicians were more likely to find social screening to be appropriate, and those who had experienced discrimination in a health care setting were less likely to find it appropriate.

Four articles^{16,17,20,21} also discussed how trust influenced perceptions of screening, noting participants' comfort disclosing information to providers with whom they had a respectful relationship or who demonstrated genuine care for their well-being. Two^{16,20} described the perspectives of Latinx participants, who attributed some level of trust to cultural and linguistic congruence with their providers. In contrast, participants from three articles^{17,19,21} expressed concerns that disclosing sensitive social information might bias providers against them. Three partially overlapping articles^{17,19,20} spoke to the importance of provider follow-up, noting that participants did not need to be screened for the sake of screening, although participants from one¹⁷ also expressed that they did

Table 4. Preferences for Mode or Administration of Social Screening

First Author (Year)	Findings
Key Quantitative Findings	
Kocielnik (2019)	72% of low-literacy patients favored chatbot-based screening over a self-administered survey (compared to 11% of high-literacy participants)
Palakshappa (2021)	82% of participants found tablet-based system easy to use 85% of participants thought most people would learn to use the tablet-based system quickly 87% of participants felt very confident using the tablet-based system
Key Qualitative Findings	
Wylie (2012)	Most participants found a self-administered, computer-based questionnaire easy to use
Careyva (2018)	Many participants expressed that tablet-based, self-administered social screening was acceptable <ul style="list-style-type: none"> • Younger participants expressed concerns regarding older participants' technological literacy • Some older participants expressed a preference for speaking with a person over using a tablet
Hamity (2018)	Previously screened participants wanted screening done in more preventive contexts than the ED
Byhoff (2019)	Participants believed social screening must be conducted with compassion and empathy Participants had no strong preference for in-person or electronic screening or when social screening should be conducted during the medical visit
Byhoff (2020)	Many participants believed that having a strong relationship with providers made participants more comfortable sharing information regarding their social needs Participants believed that transparency/trust demonstrated throughout the screening process was important
Emengo (2020)	Participants preferred patient navigators to conduct screens over physicians Participants were satisfied with being screened in waiting room
Wallace (2021)	Participants would feel comfortable disclosing information to providers who demonstrated that they genuinely cared for participants' well-being; most examples provided were of nurses and community health workers
Spain (2021)	Participants preferred to be screened by nurses and community health workers over clinicians Many participants appreciated empathetic and respectful approach that centered listening, relationship-building, and follow-up Participants did not want to disclose social circumstances without a subsequent conversation or follow-up

Abbreviation: ED, emergency department.

not expect health care providers to resolve their social issues.

Patient/Patient Caregiver Perspectives Regarding Setting and Mode of Administration

Eleven articles^{16–22,24,28,30,31} explored participants’ perspectives regarding at least one element of the screening process (Table 4). Three^{18,20,21} described participants’ preferences regarding which health care team members should conduct social screening and found (or suggested) that participants favored patient navigators, social workers, nurses, and/or community health workers over clinicians. In a partially overlapping three articles,^{17,20,21} participants emphasized that screening should be conducted with compassion and empathy.

Five articles^{19,22,28,30,31} explored the use of self-administered screeners. Together, they found that participants across the age spectrum (adolescents to 65+) thought self-administration was comfortable, acceptable, and/or easy to use. Two other articles^{17,19} explored multiple modes of assessment and identified no clear preferences for in-person, electronic, clinician-administered, or telephone-based screening.

Patient/Patient Caregiver Perspectives on Specific Social Screening Domains

Six articles^{16,18,19,22,26,30} explored patient/caregiver perceptions regarding specific social domains (Table 5). These included food security,^{19,22} housing stability or quality,^{19,22,26} social isolation,^{18,19} transportation,¹⁹ financial constraints or resources,^{18,19,22,30} employment and/or education status,^{18,30} immigration status,¹⁶ sex trafficking,²⁶ family responsibilities,³⁰ and legal services.³⁰ The majority of participants indicated that screening for these social issues was acceptable. However, Careyva et al.³⁰ found that two health/health care domains (access to care and health-promoting behaviors) were considered greater screening priorities than any of the social domains they examined. While the authors presented quantitative findings stratified by ethnicity, preferred language, and age, the statistical significance of their differences was not assessed.

Patient/Patient Caregiver Perspectives on Data Documentation and Sharing

Seven articles^{17–22,24} assessed participants’ perspectives regarding social data documentation and sharing;

Table 5. Acceptability of Social Screening Domains

First Author (Year)	Findings
Key Quantitative Findings	
Careyva (2018)	A greater percentage of participants ranked health/health care domains as screening priorities rather than social domains: <ul style="list-style-type: none"> • 26% ranked access to health care as a priority domain • 24% ranked health-promoting behaviors as a priority domain • 15% ranked family responsibilities as a priority domain • 14% ranked financial resources as a priority domain • 6% ranked education and employment as a priority domain • 6% ranked transportation as a priority domain • 1% ranked legal services as a priority domain
Langerman (2019)	59% of participants found sex trafficking and 65% found housing to be acceptable screening domains <ul style="list-style-type: none"> • Adolescents less likely than patient caregivers to find sex trafficking to be an acceptable screening domain (OR, 0.58; 95% CI, 0.39, 0.86) • No differences by gender
Key Qualitative Findings	
Wylie (2012)	Few participants found income sensitive/embarrassing to discuss Few participants found food security status sensitive/embarrassing to discuss No participants verbalized finding housing sensitive/embarrassing to discuss Some participants were confused regarding social domains traditionally handled by parents, such as the use of food stamps, housing, and income security
Hamity (2018)	The majority of participants thought their health system should ask about food affordability and basic living expenses, housing and homelessness, social isolation, and transportation
Byhoff (2020)	All participants found immigration to be an acceptable screening domain
Emengo (2020)	Participants found housing, employment, and social isolation to be acceptable screening domains

Abbreviations: OR, odds ratio; CI, confidence interval.

Table 6. Acceptability of Social Screening Data Documentation and Sharing

First Author (Year)	Findings
Key Quantitative Findings	
De Marchis (2019)	65% of participants were comfortable with integrating social screening data into their EHR <ul style="list-style-type: none"> • Higher odds among participants who had received prior assistance (OR, 1.47; 95% CI, 1.04, 2.07) • No differences by age, sex, race/ethnicity, education, income, preferred language, child's health, number of reported social risks, prior screening experience, discomfort with screening domains, interest in assistance, trust in clinician, prior discrimination within the health care setting, health care setting, or percentage of the patient population publicly insured or uninsured
Key Qualitative Findings	
Wylie (2012)	Some participants spoke in detail about privacy (concerns)
Hamity (2018)	Some participants were concerned about how information would be used and with whom it would be shared Some participants were concerned about how to update their status once it had changed
Byhoff (2019)	Several participants worried about discrimination, bias, and privacy concerns, including EHR documentation Some participants worried about responses being shared outside of the health care setting
Emengo (2020)	Few participants were concerned about physicians receiving results
Wallace (2021)	Some participants were concerned that disclosing sensitive information might bias providers against them None of the participants wanted their social needs documented in medical record Participants were concerned about information following them after their circumstances had changed
Spain (2021)	Some participants were concerned about oversurveillance of communities of color and privacy

Abbreviations: EHR, electronic health record; OR, odds ratio; CI, confidence interval.

findings were mixed (Table 6). Three articles^{17,21,24} explored electronic health record (EHR) documentation. While De Marchis et al.²⁴ found that 65% of participants expressed that they were somewhat or very comfortable with EHR documentation, two qualitative articles^{17,21} indicated that participants did not want social needs documented, noting that they feared being treated differently by providers.

Six qualitative articles¹⁷⁻²² reflected mixed findings about patients' perspectives on sharing results from social screening. A majority of participants in three^{17,18,22} indicated that they had few privacy concerns about the social screening data sharing; however, participants from an overlapping five articles^{17,19-22} indicated that their acceptability of data sharing would be influenced by with whom data would be shared as well as how the data would be stored and updated. Latinx/Hispanic patient caregivers from one study²⁰ expressed concerns about oversurveillance of communities of color as well as potential legal ramifications of sharing sensitive social information. In another article,¹⁷ patients who had previously experienced discrimination within the health care setting expressed the importance of ensuring that screening results remained confidential.

Discussion

Understanding patient and patient caregivers' perspectives about social screening is critical as interest

emerges in an expanding number of new health care sector initiatives and policy decisions. Though our review findings indicate that patients and patient caregivers generally found social screening acceptable, this result should be considered alongside the substantial limitations of existing studies as well as the specific concerns participants raised about social screening data practices and approaches. These together should help to inform health care stakeholders investing in patient-centered and family-centered screening initiatives.

Most studies in this review reported only descriptive findings from small samples, suffered from selection bias, and used nonstandard outcome measures to explore patient and caregiver perspectives on social screening. Notably, they also provided limited consensus about the potential adverse effects of social screening, though several opinion pieces have highlighted the importance of protecting against unintended negative consequences when designing screening initiatives.³²⁻³⁴ Only half of the studies in this review solicited feedback from patients or patient caregivers after they had experienced social screening in a real-world health care setting; hypothetical concerns may not accurately reflect the reality of social screening experiences. Just one article touched on potential trade-offs of social screening; that is, whether screening would lead to less time for other health-relevant

discussions. Future work should explore whether social screening is an efficient, effective, and patient-preferred gateway for social care interventions—particularly in light of concerns that patients and patient caregivers raised about how data might be documented, used, and shared.

In addition, only four articles meaningfully examined differences in outcomes by sociodemographic factors, and just two highlighted the perspectives of a single, marginalized group. While they reported modest differences in social screening acceptability, several qualitative studies in this review indicated that screening initiatives might exacerbate stigmatization and discrimination. Future research is needed to more closely examine strategies for conducting screening among racialized and other historically marginalized populations, whose exposure to discrimination and trauma within and outside the health care setting may influence their experience. A better understanding of what different patient populations find acceptable (or detrimental) will help to maximize the likelihood that screening programs are developed in ways that do not cause harm.

Our findings should be interpreted in the context of several limitations. First, we only screened English-language, peer-reviewed studies from select databases through August 2021. Given that this is a rapidly evolving area of health services research, we may not have captured all relevant studies by the time of publication. Moreover, in restricting our search to academic studies, we may have omitted more practice-relevant information in the gray literature. In addition, while our focus on multidomain tools reflects the national policy interest in multidomain screening initiatives, excluding single-domain tools may have nevertheless resulted in the omission of relevant perspectives. Finally, in this review, we excluded studies that did not distinguish patient/patient caregiver perspectives on social screening from their perspectives on social interventions (eg, referrals to community-based organizations or provision of in-house resources like food boxes or clothing). However, this distinction may be artificial since real-world screening is typically done in concert with interventions designed to connect patients with relevant social services.

Conclusion

The themes emerging in this diverse set of descriptive studies warrant deeper and more rigorous

exploration as social screening initiatives expand in diverse settings across the United States. The existing body of research does not adequately answer all of the questions necessary to ensure that screening initiatives are alleviating, rather than exacerbating, health and social inequities.

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To see this article online, please go to: <http://jabfm.org/content/36/1/66.full>.

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Appendix.

Appendix 1. Search Strings Used to Identify Studies Within the Academic Literature That Pertain to Multidomain Social Screening in US Health Care Settings

(survey[tw] OR questionnaire[tw] OR measure[tw] OR instrument[tw] OR screen*[tw] OR tool[tw]) AND (“Social Determinants of Health”[Mesh] OR “Social Conditions”[Mesh] OR “Health Equity”[Mesh])

OR (“social risk”[tw] OR “social risks”[tw] OR SDOH[tw] OR SBD[tw] OR “determinants of health”[tw] OR “determinant of health”[tw] OR “structural determinant”[tw] OR “structural determinants”[tw] OR “social factor”[tw] OR “social factors”[tw] OR “social inequity”[tw] OR “social equity”[tw] OR “social inequality”[tw] OR “social disparities”[tw] OR “social disparity”[tw] OR “behavioral determinant”[tw] OR “behavioral determinants”[tw] OR “social determinant”[tw] OR “social determinants”[tw] OR “social need”[tw] OR “social needs”[tw] OR “basic needs”[tw] OR “basic need”[tw])) AND (“English”[Language] AND 2000[PDAT]: 3000 [PDAT])

(survey[tiab] OR questionnaire[tiab] OR measure[tiab] OR instrument[tiab] OR screen*[tiab] OR tool[tiab]) AND (“Social Determinants of Health”[Mesh] OR “Social Conditions”[Mesh] OR “Health Equity”[Mesh]) OR (“social risk”[tiab] OR “social risks”[tiab] OR SDOH[tiab] OR SBD[tiab] OR “determinants of health”[tiab] OR “determinant of health”[tiab] OR “structural determinant”[tiab] OR “structural determinants”[tiab] OR “social factor”[tiab] OR “social factors”[tiab] OR “social inequity”[tiab] OR “social equity”[tiab] OR “social inequality”[tiab] OR “social disparities”[tiab] OR “social disparity”[tiab] OR “behavioral determinant”[tiab] OR “behavioral determinants”[tiab] OR “social determinant”[tiab] OR “social determinants”[tiab] OR “social need”[tiab] OR “social needs”[tiab] OR “basic needs”[tiab] OR “basic need”[tiab])) AND (“English”[Language] AND 2000 [PDAT]: 3000[PDAT])

Appendix 2. Evidence Quality of 16 Studies Describing Patient and Patient Caregiver Perspectives Regarding Multidomain Social Screening in US Health Care Settings

First Author (Year)	GRADE Score	Rationale for GRADE Score
Wylie (2012)	Very low	<ul style="list-style-type: none"> • Small, nonrepresentative convenience sample based in a single health care setting • Exploratory and cross-sectional study design • Responses self-reported
Hassan (2013)	Very low	<ul style="list-style-type: none"> • Small, nonrepresentative convenience sample based in a single health care setting • Exploratory and cross-sectional study design • Responses self-reported
Colvin (2016)	Very low	<ul style="list-style-type: none"> • Small, nonrepresentative convenience sample based in in multiple health care settings within the same system • Exploratory and cross-sectional study design • Responses self-reported
Careyva (2018)	Very low	<ul style="list-style-type: none"> • Small, nonrepresentative convenience sample based in multiple clinics • Exploratory and cross-sectional study design • Responses self-reported
Hamity (2018)	Very low	<ul style="list-style-type: none"> • Small convenience sample (no sociodemographic information provided) based in multiple health care settings within the same system • Exploratory and cross-sectional study design • Responses self-reported
Byhoff (2019)	Very low	<ul style="list-style-type: none"> • Small, nonrepresentative convenience sample based in multiple health care settings across several regions • Exploratory and cross-sectional study design • Responses self-reported
De Marchis (2019)	Low	<ul style="list-style-type: none"> • Large, nonrepresentative convenience sample based in multiple health care settings across several regions • Exploratory and cross-sectional study design • Responses self-reported • Accounted for some sources of confounding using multivariable statistical models
Kocielnik (2019)	Very low	<ul style="list-style-type: none"> • Small, nonrepresentative convenience sample based in a single research setting • Exploratory and cross-sectional study design • Responses self-reported
Langerman (2019)	Very low	<ul style="list-style-type: none"> • Small, nonrepresentative convenience sample based in a single health care setting • Exploratory and cross-sectional study design • Responses self-reported • Accounted for some sources of confounding using multivariable statistical models
Byhoff (2020)	Very low	<ul style="list-style-type: none"> • Small, nonrepresentative convenience sample based in a single health care setting • Exploratory and cross-sectional study design • Responses self-reported
Emengo (2020)	Very low	<ul style="list-style-type: none"> • Extremely small, nonrepresentative convenience sample based in a single health care setting • Exploratory and cross-sectional study design • Responses self-reported
Rogers (2020)	Low	<ul style="list-style-type: none"> • Large, nonrepresentative convenience sample based in in multiple health care settings within the same system • Exploratory and cross-sectional study design • Responses self-reported • Accounted for some sources of confounding using multivariable statistical models
Oldfield (2021)	Very low	<ul style="list-style-type: none"> • Small, nonrepresentative convenience sample based in a single health care setting • Exploratory and cross-sectional study design • Responses self-reported
Palakshappa (2021)	Very low	<ul style="list-style-type: none"> • Small, nonrepresentative convenience sample based in a single health care setting • Exploratory and cross-sectional study design • Responses self-reported
Wallace (2021)	Very low	<ul style="list-style-type: none"> • Extremely small, nonrepresentative convenience sample based in a single health care setting • Exploratory and cross-sectional study design • Responses self-reported
Spain (2021)	Very low	<ul style="list-style-type: none"> • Small, nonrepresentative convenience sample • Exploratory and cross-sectional study design • Responses self-reported

Abbreviation: GRADE, Grading Recommendations Assessment Development and Evaluation.