

**SOCIAL RISK
INFORMATION
IS SENSITIVE
INFORMATION**

- Privacy
- Policy and Practice
- Considerations for Social Risk Factor
- Screening in Health Care Settings

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Social Risk Information is Sensitive Information: Privacy Policy and Practice Considerations for Social Risk Factor Screening in Health Care Settings was written by the following staff and students at the Center for Health Law and Policy Innovation of Harvard Law School: Rachel Landauer, Adithi Iyer, Katie Garfield, and Carmel Shachar. Additionally, this resource would not have been possible without the insight and expertise shared by many individuals including: Victoria Dexter and Therese Kempf, Safe Horizon; Alison LeBlanc; Arvin Garg, Child Health Equity Center; Zoe Bouchelle, Denver Health Center for Health System Research and Children’s Hospital of Philadelphia PolicyLab; Katherine Marçal, Rutgers School of Social Work; Stuart Lewis, Geisel School of Medicine at Dartmouth; Richard Sheward, Children’s HealthWatch at Boston Medical Center; Elizabeth Egan, Kristin Woods, and Ariana Witkin, Boston Medical Center; and Erin Salvo, Public Consulting Group.

ABOUT THIS RESOURCE

Health-related social needs (HRSN) screening is increasingly integrated into health care delivery, including as a result of evolving federal and state regulations. By and large this is a positive development—screening is associated with benefits such as increased linkages to responsive services and supports. However, social risk information is sensitive and warrants attention to privacy. This resource reviews ways in which HRSN information collected in a health care setting may be accessed and used by third parties in ways that potentially harm patients and their families. To illustrate various risks, this resource describes example scenarios and offers potential starting points in identifying and navigating similar concerns. However, this resource should not be construed as providing legal advice; organizations should conduct their own analyses based on the facts and particularities of their unique situations. For tailored consultation on specific legal issues, please consult an attorney.

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Background

Mounting evidence suggests that health outcomes vary extensively based on nonmedical factors that impact health.¹ These factors include the conditions in which a person grows, lives, and works—often referred to as social determinants of health (SDOH).² Examples of SDOH include community access to safe housing, transportation, nutritious foods, and clean drinking water.

In recognition of the impact of SDOH on health outcomes, health care systems are increasingly looking to identify and address patients’ individual-level, unmet health-related social needs (HRSN). Many such initiatives involve HRSN or “social risk factor” screening: the use of validated or other tools to inquire about access to safe housing, sufficient nutritious food, difficulty maintaining utilities, interpersonal violence, and other domains. Some of these initiatives, though not all, then extend beyond screening, with the identification of a need triggering the offer of services and supports, referral to community-based social services, etc.

Evolving federal and state regulation is helping to drive HRSN screening in more clinics, hospitals, and other health care settings. For example, the Centers for Medicare and Medicaid Services (CMS) recently instituted the first HRSN screening requirements for hospitals—as of 2024, Medicare’s Inpatient Quality Reporting program requires screening for all admitted adult patients.³ CMS has also encouraged HRSN screening through the promotion of tools such as SDOH Z codes, which support standardization in medical records,⁴ and reimbursement for SDOH risk assessment in Medicare Part B.⁵ At the state level, Medicaid 1115 demonstration waivers providing targeted HRSN benefits and other policy flexibilities are underway and having similar impacts.⁶

Figure 1 National Policies for HRSN Screening in Health Care Settings

POLICYMAKER	MANDATE	INCENTIVE
CMS Medicare Parts A/B	Hospital Inpatient Quality Reporting ⁷	Reimbursement for SDOH Risk Assessment ⁸
CMS Medicare Part C	Health Risk Assessment by Special Needs Plans ⁹	No Policy ¹⁰
The Joint Commission	Ambulatory Health Care, Behavioral Health Care, Critical Access Hospital, and Hospital Accreditation ¹¹	No Policy ¹⁰
NCQA	Health Equity Accreditation and Health Equity Accreditation Plus Programs ¹²	HEDIS Social Need Screening and Intervention (SNS-E) Measure ¹³

Identifying a Patient’s Social Risk Factors is Important. Understanding and Minimizing Downstream Harm is too.

HRSN screening is foundational to identifying and addressing patient HRSN. As explained by CMS, social risk factor data are “a valuable tool.”¹⁴ Improved data collection “supports the health care system in driving improvements where they can have the greatest impact on health equity and reducing disparities.”¹⁵ Moreover, use of SDOH Z codes or other notations in a medical record supports the integration of HRSN into patient-level treatment plans, care coordination, and monitoring.¹⁶

At the same time, the collection of this new type of data carries some concern. For example, existing research highlights potential negative impacts on patients and the patient-provider relationship of asking sensitive questions about HRSN without meaningful follow-up (e.g., providing support for identified needs or otherwise helping patients connect with resources).¹⁷ Research also suggests that some patients who are comfortable with being screened are uncomfortable with results being documented in their medical record.¹⁸ Reasons include stigma and the fear that HRSN information will be shared outside the person’s health care team.

This resource focuses on concerns about unsafe or otherwise unwanted disclosures of HRSN information—especially when documented in medical records. The following three scenarios illustrate what this may look like, and why federal patient information privacy law does not always protect patients from harm. The section that follows then provides a starting point for navigating these and similar scenarios.



Scenario 1

A parent is concerned that sharing social risk information will put their family at higher risk for investigation or other intervention by Child Protective Services.

Can it happen? Yes. The HIPAA Privacy Rule permits covered entities (e.g., most hospitals and other health care providers) to disclose protected health information to “[a] public health authority or other appropriate government authority authorized by law to receive reports of child abuse or neglect.”¹⁹

Neglect in particular is a nebulous concept and susceptible to conflation with poverty. Health care providers may feel obligated, morally or under state law, to report a patient to child protective services based on social risk factors such as inadequate housing;²⁰ a report may be made with the hope or expectation that a patient and their family will be connected to necessary resources.

Notably, identification of social risk factors may also have the opposite effect. Consider the following example: A pediatrician suspects neglect when their patient misses three appointments in a row and is not getting insulin as prescribed. HRSN screening reveals that the root causes of the issues are a lack of transportation options and a fridge—not neglect.

The Harms of Unwarranted Reports to CPS

CPS reporting of abuse or neglect based on social risk factors raises several concerns about unwarranted reporting including:

- CPS investigations alone (i.e., without substantiation of maltreatment) can still be a traumatic and disruptive experience for patients and their families.²¹
- Reporting—even the fear thereof—can undermine a person’s willingness to speak about HRSN or seek assistance, and negatively impact the patient–provider relationship.²²
- Worsening disparities; nationally, Black children are disproportionately reported to CPS compared to white children.²³



Scenario 2

A clinic that works with survivors of domestic violence is concerned that housing instability and other social risk information will be weaponized against a patient in a custody dispute.

Can it happen? Yes. The HIPAA Privacy Rule permits covered entities to share protected health information identified in a court order.²⁴ This means that, depending on what a judge decides about its relevance to the case, social risk information documented in a patient’s medical record may make its way into the custody battle.



Scenario 3

A physician is concerned about documenting disclosures of interpersonal violence, and whether others—especially the perpetrator of violence—will have access to that record.

Can it happen? Yes. Parents generally have access to a minor child’s record,²⁵ which may create risks for parents experiencing or who have experienced intimate partner violence and their children.²⁶ The HIPAA Privacy Rule also allows covered entities to share a person’s health record with (1) their personal representative and (2) a family member involved in the individual’s care or payment for care as long as the individual does not object.²⁷ It is also possible that a perpetrator will have access to a patient’s health record from a source other than the health care organization, e.g., from the patient themselves.

Navigating the Federal “Open Notes” Mandate

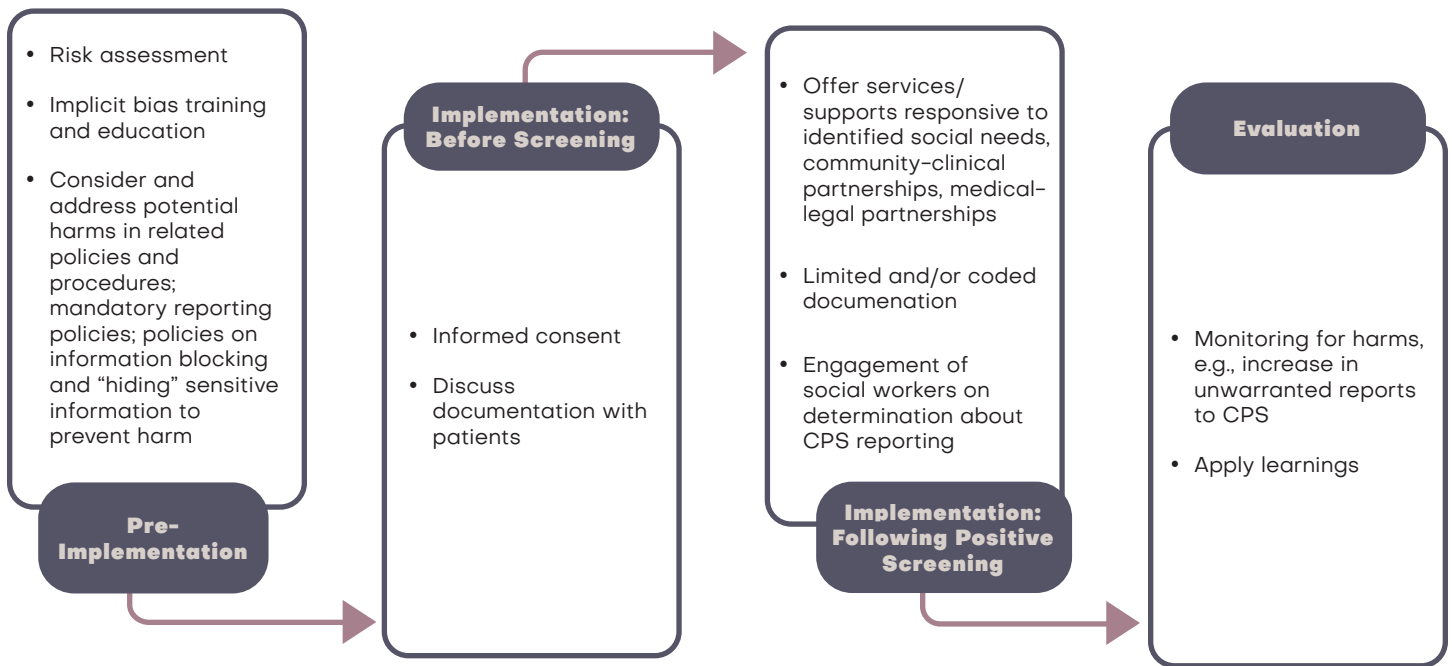
Federal rules on interoperability and information blocking require health care organizations to give patients secure online access to their electronic health information.²⁸ This is sometimes called the “open notes” mandate. Clinicians are permitted to “hide” notes in a record for reasons including to prevent harm;²⁹ however, advocates have nonetheless raised strong concern about the risk of disclosure documentation and increased accessibility by a perpetrator.³⁰

Addressing Privacy Concerns in Practice

By building an HRSN screening program that considers disclosure risks and aims to minimize harm, health care organizations can better position their program to support high-quality, whole person care. Strategies for risk mitigation exist at all phases of a screening intervention: pre-implementation, implementation, and evaluation. Core strategies, with helpful resources and tips from experts in the field are laid out in Figure 2, below.

An examination of risk in the **pre-implementation phase** creates an opportunity to integrate mitigation measures in program design, training, and workflow/process development. In **implementation**, risk mitigation may look like informed consent, meaningful patient engagement around identified social needs, and limited and/or coded documentation, among other activities. Finally, disclosure-related harm (e.g., an increase in unwarranted reports to CPS) is something that can be monitored among other outcomes (e.g., follow-up) in **evaluation**.

Figure 2 Minimizing Risk of Harm Across the Intervention



PRE-IMPLEMENTATION

STRATEGY

Implicit bias training and education

Appropriate policies and procedures

HELPFUL RESOURCES

[Mandated Implicit Bias Training for Health Care Professionals—A Step Toward Equity in Health Care](#)

[Trauma-Informed Care Tips Sheet for Healthcare Providers](#)

TIPS FROM EXPERTS IN THE FIELD

“Organizations should implement training to ensure providers are aware of the potential for bias related to the documentation of HRSN.”

“Most screening are now rolling out via MyChart. People fill them out before they even go to the doctor. It is important that the health system update their consent to screening and put that **ahead** of the questions. Right now, there are these very uninformed intros that almost always just say ‘your results might be shared with your healthcare team’—which is different than ‘your results might be used against you in a court case.’”

“Review screening tools to ensure that they are comprehensive, since HRSN risks are interlocking and interact.”

“Limit access to HRSN for patient proxies to reduce the potential for unwanted or unsafe disclosures.”

“Organizations should train providers in sensitively communicating with families regarding HRSN.”

“My organization creates talking points and other resources for staff who collect screening responses.”

IMPLEMENTATION: BEFORE SCREENING

STRATEGY

Informed consent/discussing documentation with patients

HELPFUL RESOURCES

[Skills for Engaging in Sensitive Conversations](#)
[Strategic Considerations for Social Needs Screening](#)

TIPS FROM EXPERTS IN THE FIELD

“Information is power. If parents know more about how these screenings are used that would be best. I think the key is making sure the patient understands the potential risks of disclosure as well as the potential benefits.”

“Maximize transparency in why and where HRSN are documented and with whom HRSN are shared. Patients and families should be presented with the opportunity to opt out of screening.”

Sample Script

“We ask all families questions about their needs at home because we may be able to provide resources to help. These questions should take less than [number] minutes to answer and are optional. You can skip any questions you don’t care to answer. Your answers will not be shared with anyone outside of your care team without your permission. If its okay with you, we will record your answers in the chart in [location] so that we can provide you with resources. To protect your privacy, your answers won’t be visible to you or other family members through the patient portal. After you complete the questions, you can also meet 1-on-1 with a staff person to help access additional resources.”

IMPLEMENTATION: FOLLOWING POSITIVE SCREENING

STRATEGY

HELPFUL RESOURCES

TIPS FROM EXPERTS IN THE FIELD

Limiting/coding documentation

[Should Immigration Status Be Included in a Patient's Health Record?](#)

“Do not document HRSN in the EHR if a patient or parent requests that HRSN not be documented.”

Engaging social workers before CPS

Sample Intervention: [Boston Medical Center's Child Protection Team](#)

“Engage social workers, community health workers, and other resource navigators to address financial stressors and other material hardships.”

EVALUATION

STRATEGY

HELPFUL RESOURCES

TIPS FROM EXPERTS IN THE FIELD

Monitoring for harms

[Accountable Health Communities Third Evaluation Report](#)

“Create dashboards to prospectively track balancing measures (including referrals to CPS) to ensure that HRSN screening programs do not create or exacerbate disparities in CPS reporting and that emerging biases can be addressed.”

Addressing Privacy Concerns in Policy

Lawmakers and regulators also have a role to play in safeguarding social risk information.

First, when advancing requirements or incentives to drive social risk factor screening in health care settings, policymakers should consider whether the design of the policy introduces the potential for harm. If so, is it possible to introduce more flexibility or would that defeat the goal of the initiative? Rigid mandates for standardized, detailed documentation of identified social needs may be more reasonable as part of new Medicare billing codes for SDOH risk assessment and may be less so for a quality improvement initiative.

Additionally, policymakers have a growing array of tools at their disposal to ensure that identification of HRSN consistently results in meaningful connection to responsive services and supports. Engagement at this end of the spectrum not only better meets the needs of patients, but also reduces the likelihood that screening results can be used against the patient because the identified risk can be documented as addressed. Supported by the CMS framework on health-related social needs services and supports allowable under Medicaid and CHIP authorities, states can leverage different legal authorities to address HRSN among Medicaid beneficiaries.³¹ Opportunities to cover nonmedical services and supports as a supplemental benefit have also expanded in Medicare Advantage, including through the Value-Based Insurance Design Model and the emergence of Special Supplemental Benefits for the Chronically Ill.³²

Finally, policymakers shape mandatory reporting obligations and can advance the critical distinction between poverty and neglect. In Massachusetts, for example, the Department of Children and Families has an explicit policy that “poverty or homelessness are not per se indicative of child abuse or neglect; and that children should never be removed from their parents and placed into substitute care on the sole basis of homelessness of a family.”³³ By making these distinctions in policy—and engaging in education and outreach to ensure these distinctions are well understood by health care providers—states can limit the potential for unwarranted reporting and intervention.

Conclusion

Permitted disclosures under patient privacy law are such that safety and privacy concerns relating to third party disclosures are real. Disclosures in pediatric settings and in the context of interpersonal violence may be especially sensitive. This assessment does not mean that HRSN screening is, overall, a less valuable pursuit, nor does it necessarily negate potential benefits of HRSN screening; rather, amid the positive developments in the integration of HRSN screening, services, and supports into health care, it is important to acknowledge the potential for unintended consequences and adapt interventions to minimize risk of harm.

Endnotes

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