



# CONSIDERATIONS FOR DOCUMENTING AND SHARING HEALTH-RELATED SOCIAL NEEDS INFORMATION IN PEDIATRIC CARE SETTINGS

Many pediatric health systems *have recently implemented* social needs screening and support programs in response to growing recognition of the impact of social factors on child health and mandates and incentives from organizations like The Joint Commission and the Centers for Medicare & Medicaid Services (CMS). As health systems begin systematically collecting health-related social needs data from patients and families, health system leaders, payers, and policymakers will have to develop standards and best practices for documenting and sharing this potentially sensitive information.

This brief builds on a *previous PolicyLab issue brief* focused on health-related social needs screening in pediatrics and is grounded in recent qualitative research, including several studies from Children's Hospital of Philadelphia (CHOP) which span different health care settings. In this brief, we will review current policies and clinical trends around health-related social needs screening and summarize benefits and risks related to documentation and sharing of health-related social needs information in pediatrics. While questions including which social needs should be screened for in health care settings and which screening instrument to use are outside the scope of this brief, they are the focus of active work and remain of critical importance for future conversation.

Seeking to center caregiver perspectives and aligned with the concept of user-centered design, we will highlight emerging evidence related to documenting and sharing health-related social needs and recommend evidence-based approaches to data management. We will also consider the intersection of caregiver preferences and mandates for expanded health information sharing.



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## THE STATE OF SOCIAL NEEDS SCREENING IN PEDIATRICS

*Several studies* have demonstrated that health-related social needs are associated with an increased risk of adverse health outcomes in both adult and pediatric populations. With greater recognition of the link between social needs and health outcomes, there is growing interest in incorporating social needs screening and referral processes in health care settings. This movement has also been driven by mandates and incentives from *regulatory bodies, professional society engagement* and *new payment opportunities*. The following table highlights four of particular relevance:

<p><b>The Joint Commission</b></p>	<p>In 2023, <i>The Joint Commission</i> incorporated a requirement for social needs screening in the inpatient setting as part of their accreditation processes in an effort to reduce health disparities.</p>
<p><b>Centers for Medicare &amp; Medicaid Services (CMS)</b></p>	<p>In early 2024, CMS began requiring hospitals to <i>screen</i> inpatients for five domains of social need: food insecurity, interpersonal safety, housing insecurity, transportation insecurity and utility needs. This screening is intended to be recorded in the electronic health record (EHR) and <i>ICD-10 codes</i> corresponding to individual social needs have been provided to facilitate documentation and reimbursement.</p>
<p><b>HEDIS Social Need Screening and Intervention (SNS-E) measure</b></p>	<p>In 2023, <i>HEDIS implemented the Social Need Screening and Intervention (SNS-E) measure</i> to evaluate, using electronic clinical data, the percentage of health plan members who have been screened for food, housing, and transportation needs, and provided corresponding interventions for any positive screens.</p>
<p><b>American Academy of Pediatrics (AAP)</b></p>	<p>The AAP <i>recommends routinely screening</i> for health-related social needs. However, standards for collection, documentation and sharing of social needs information do not currently exist.</p>

## RISKS AND BENEFITS OF DOCUMENTING AND SHARING HEALTH-RELATED SOCIAL NEEDS IN PEDIATRICS

There are several potential benefits to documenting caregiver-reported social needs in children’s electronic health records (EHR), including:

- Supporting provision of resources that address these needs.
- Supporting dedicated social care team members, such as social workers and community health workers, in working with families through resource navigation.
- Facilitating care coordination enhancement and adjustment of medical care to accommodate social needs. For example, families with identified barriers to transportation could have multiple follow-up appointments scheduled on the same day to minimize the need for repeated travel.
- Minimizing redundancy in screening by ensuring families are not screened repeatedly, thereby reducing the risk of re-traumatizing families or engendering mistrust by repeatedly asking sensitive social needs questions.
- Collecting and measuring population and individual level data over time to move toward better data-driven provision of community-level services and resources.

However, documenting caregiver-reported social needs in the child’s EHR presents risks, including:

- Challenges related to patient privacy.
- Potential for discord among multiple caregivers who have proxy access to a child’s medical record.
- Potential sharing of data with third parties.
- Potential for explicit or implicit biases among members of the care team.
- Potential for anchoring bias, with information about a child’s social needs inappropriately biasing a provider’s diagnosis or treatment plan.

In developing processes for documenting and sharing social needs information, health systems need to balance family and caregiver perspectives, ensuring compliance with federal and state regulatory requirements, and developing documentation workflows that support an appropriate social care response.

## CAREGIVER PERSPECTIVES ON DOCUMENTING AND SHARING HEALTH-RELATED SOCIAL NEEDS DATA

As a growing number of health systems have implemented social needs screening and support programs, research on the feasibility, acceptability and impact of these programs is expanding. Many studies to date, including *multiple studies* led by CHOP investigators, have found that screening is feasible to implement and is generally acceptable to families across

care settings, particularly when it is accompanied by resource provision and support.

There is a growing body of research that explores caregiver perspectives on next steps following a positive social needs screen, including how social needs data should ideally be documented and shared. A *recent systematic scoping review* examined the literature on patient and caregiver perspectives regarding multidomain social needs screening in U.S. health care settings. This review found only seven studies that specifically examined perspectives on documentation and data sharing, and just five of these studies included parent perspectives on social needs documentation in pediatric health care settings. Here we summarize key findings from several of these studies, and two more recent studies conducted at CHOP.

In a *2019 cross-sectional survey*, which included 231 pediatric caregivers across nine states, 61% of respondents reported being somewhat or very comfortable with social risk information being included in the EHR. However, *in a companion qualitative study*, parents and caregivers highlighted privacy concerns around documentation of social needs information. Several caregivers highlighted past experiences of perceived bias and discrimination in health care settings and stressed the need for confidentiality around screening results to ensure they did not contribute to biases in care delivery.

Some respondents worried that their responses might be shared with individuals outside their health care teams, and they expressed concerns about other patients or caregivers potentially hearing or seeing their social risk screening responses. Respondents acknowledged the tension between desiring privacy and the logistics of providing social care, understanding that collecting and documenting social need and social risk information might be a necessary step towards receiving assistance.

In a *2021 qualitative study*, researchers conducted 17 focus groups across eight pediatric primary care clinics, including a total of 134 parents and other primary caregivers who all identified as Hispanic/Latinx, and examined their perspectives on social needs documentation and data sharing. Caregivers in this study expressed concerns about how the information might impact their immigration status or eligibility for government benefit programs, and many noted that they looked to alternative sources of support, such as community-based organizations. Concerns about Child Protective Services involvement were also prevalent, with parents balancing trust in their providers with fears of over-surveillance.

In a *2023 study* involving 20 parents from pediatric primary care clinics, participants identified several concerns about social needs screening and documentation. While parents recognized

potential benefits of social needs screening, they expressed privacy concerns, fear of negative outcomes and concerns that social needs might remain documented in the EHR even after they had resolved. Parents emphasized the need for transparency about the purpose of social needs screening and the planned uses of social needs data.

Recent studies at CHOP, including *one conducted in the inpatient setting* and another conducted in the *primary care and emergency department setting*, revealed that most parents were comfortable with documentation of social needs in the EHR, particularly when providers were transparent about why this information was being collected and how it was going to be documented and shared. Some caregivers felt more comfortable with documentation of concrete resource needs, such as food insecurity, but expressed hesitancy around parental mental health needs and intimate partner violence being documented in their child's chart.

Caregivers in these studies shared several **potential concerns about social needs documentation**, including concern that documentation of these needs could lead to bias, discrimination, and judgement from clinicians or increase the likelihood of Child Protective Services involvement. To mitigate these concerns, caregivers felt that members of their care team should clearly explain that the purpose of social needs screening was to provide families with resources and support and should outline where this information would be documented and how it would be shared.

The studies also gathered **caregiver perspectives on sharing social needs information**. Caregivers in all three care settings expressed that they wanted control over how and with whom their social needs data would be shared. Most parents felt comfortable sharing social needs data with social workers and members of their medical team to facilitate resource provision and inform any needed adjustments to their plan of care. However, fewer parents were comfortable with insurance companies receiving social needs data. Caregivers worried that health insurers could use social needs information to increase their out-of-pocket costs for clinical care or raise their insurance premiums and did not feel this information was relevant to insurers unless they were equipped to provide families with resources targeted to their needs.

Some caregivers identified potential impacts of social needs data sharing on family safety, particularly if proxies, including other caregivers or family members with access to their child's medical record, were able to view social needs information that they disclosed. Caregivers felt that having control over how and with whom their social needs data would be shared would increase their comfort in completing social needs screenings.

## RECOMMENDATIONS FOR HEALTH-RELATED SOCIAL NEEDS DOCUMENTATION AND DATA SHARING

Health care providers and health systems can approach social needs data management in a way that centers the perspectives of caregivers and considers the intersection of caregiver preferences and requirements for expanded health information-sharing. The following recommendations align with the available evidence and are applicable across health care settings.

### → Maximize Transparency in Documentation

The literature describes caregiver concerns about the privacy of their social needs information and desire for assurance that documentation will not contribute to biases in care, stigmatization, or other negative outcomes such as referral to Child Protective Services. Health care providers can facilitate transparency about documentation by:

#### *Explaining Why Social Needs are Documented*

Explaining to caregivers how their data will be used can facilitate trust. For example, if documentation will facilitate connection to resources, alert appropriate members of the care team who can help, or assist providers in adjusting the patient's care to better align with their social circumstances. Informing caregivers of these potential benefits could address concerns about disclosure of social need and clarify the intentions of social care efforts. Furthermore, this transparency aligns with evidence that for many caregivers, comfort with social needs documentation is conditioned on the use of that data to provide meaningful support.

#### *Explaining Where Social Needs are Documented*

Research suggests that uncertainty about how social needs information will be recorded is a source of discomfort for caregivers. For this reason, health care providers should disclose to caregivers where social needs information will be documented, whether in the EHR or in a separate database.

### → Maximize Transparency Regarding Data Sharing

Given caregivers' concerns about the confidentiality of their social needs information, transparency about the visibility of their data to other legal guardians or proxies, providers outside the patient's care team, or insurers could promote caregiver comfort. Health care providers and systems can improve transparency about data sharing by:

#### *Explaining How Social Needs Data Will be Shared*

Providing caregivers with information about documentation procedures, including where, why, and with whom social needs will be shared, before administering a social risk or social needs assessment ensures that caregivers have sufficient information to make an informed decision about their participation. There is precedence to label certain documentation as confidential (e.g., adolescent patient notes, results of imaging/lab tests) that require manual release to mitigate potential harms and also comply with the 21st Century Cures Act. Characterizing social needs information as sensitive in order to trigger similar privacy protections and informing caregivers of this distinction seems warranted.

### → Center Caregiver Autonomy and Shared Decision-Making

Health system social care protocols can be developed to center caregiver autonomy and share decision-making between providers and caregivers by:

#### *Highlighting the Ability to Opt Out of Screening and Prioritizing Options*

Offering caregivers the opportunity to opt out of answering individual questions or opt out of screening altogether allows them to engage in social care in a way that aligns with their preferences.

Caregivers who consent to screening should be given autonomy over how their social needs data are documented and shared, through collaborative decision-making. This could include eliciting caregiver preferences related to what information is documented and made accessible, or enabling caregivers to opt out of specific types of data sharing, such as with payers or with providers outside of the patient's care team.

While this would satisfy the principle of EHR user-centered design, this may not always be feasible, and smaller shifts that center caregiver autonomy, such as asking caregivers to consent to and allowing them to opt out of social needs documentation and data-sharing, are a step toward addressing concerns about the protection and meaningful use of social needs information.

Similarly, caregivers with multiple children could be presented with social needs screening multiple times during their care journey. Allowing families to opt out of screening could help reduce redundancy and prioritize caregiver autonomy.

### ***Providing Opportunities to Update Documented Needs***

In response to caregivers' concern that short-term experiences of social need will be recorded permanently in the EHR, health systems can establish procedures for updating documented social needs at frequent intervals in partnership with families. Confirming the accuracy of documented needs, even if a full social assessment is not re-administered, aligns with the evidence regarding caregiver preferences and encourages ongoing dialogue with the care team about families' well-being, priorities and desired support.

Caregivers should have the option to request updates to documented social needs as desired, akin to the approach used to update a patient's medication list; this strategy shifts control of social needs data back to families.

### **→ Carefully Consider How Social Needs Data Are Shared**

Health systems' social care protocols need to consider how social needs data are shared both within and outside of the health system. Health systems can improve data-sharing protocols by:

### ***Limiting Visibility to Relevant Care Team Members***

In collaboration with EHR providers and clinical informaticists, health systems should consider configuring the EHR so that social needs information is accessible only to members of a patient's care team who are delivering social care or tailoring their medical care in response to the patient's social needs. This approach addresses caregiver concerns regarding broad visibility of their highly sensitive and potentially stigmatizing social needs information, while continuing to leverage the EHR as a tool to facilitate connection with health system-based and community-based social resources. Alternatively, social needs could be documented in an area of the EHR that is not immediately visible to minimize access by those who are not members of a patients' care team.

### ***Training Care Team Members to Respond to Documented Needs***

Social needs can often be a product of structural racism and other systems of oppression. As such, it is critical that those with access to social needs data receive training in *trauma-informed care* to promote understanding of the traumatic experiences that are often associated with social need and ensure that staff are equipped to promote caregiver safety.

Trauma-informed care training, paired with education on best practices for providing social care and tailoring medical care to social needs after they are disclosed, minimizes the risk

that caregivers will be subjected to a double loss: vulnerability to the potential unintended consequences of social needs documentation without receipt of meaningful support.

### ***Restricting Pediatric Patient and Proxy Access***

In light of the *21st Century Cures Act*, which mandates patient access to most sections of the EHR, caregiver concerns about health care proxies and pediatric patients themselves viewing social needs documentation have become even more salient. To counter fear regarding proxy access to social needs data, health systems can restrict release of social risk screening responses in any situation where release of this information could lead to harm for a parent or caregiver.

Health systems can also ensure that pediatric patients cannot view family-level social needs information disclosed by their caregiver, as *research indicates* some caregivers are concerned about social needs documentation negatively impacting their child's perception of their own family and home life. This has particular relevance for adolescent patients who are developing their health literacy skills and may find this information difficult to process. Relatedly, health care systems should carefully weigh the risks and benefits of screening families of adolescent patients, as lines could be blurred in terms of who is answering screening questionnaires.

Careful consideration of data accessibility issues is of particular import in the context of EHR platforms that include information-sharing outside the confines of a health system's EHR. Health systems should determine whether their EHR platforms have the functionality to control inbound (external health system data accessible by internal users) or outbound (internal health system data accessible by external users) data sharing. It may be beneficial for health systems to consider social needs documentation to be protected information under the 21st Century Cures Act and to adopt policies and procedures similar to those currently used to ensure confidential health information disclosed by adolescents is not visible to their parents and caregivers.

### ***Sharing Only What is Required With Insurers***

While social needs data sharing with payers is mandated in some health care settings, many caregivers are wary of insurers' use of their social needs information. For this reason, health systems should share only the minimum social needs data required to meet regulatory standards.

Furthermore, it is important for health systems to communicate transparently with caregivers about the potential positive and negative implications of social needs data sharing with payers, to the extent that those outcomes are presently known. Negative outcomes are understudied but could include changes in the cost of care, a concern caregivers describe in the qualitative literature. Conversely, families

should also be notified if disclosing social needs during a clinical encounter would allow them to access additional payer benefits, such as free or subsidized transportation to medical appointments or medically tailored meals.

With the attention CMS has now placed on health-related social needs assessment and response, and potential financial implications, ICD-10 Z-codes and Healthcare Common Procedure Coding System (HCPCS) coding strategies need to be nuanced to support the regulatory requirements while respecting caregiver preferences.

## CONCLUSION

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While this brief focuses on action by health systems and providers, payers who are incentivizing or mandating social needs screening should also consider caregiver perspectives and preferences when developing these policies. For example, payers could consider not mandating ICD-10 code documentation in pediatric medical records given caregivers' concerns about this information being in their child's medical record permanently and being shared with insurers.

In addition, payers could consider requiring reporting of aggregated, population-level social needs data, rather than individual patient-level data, as this could allow them to track needs over time and inform population-level interventions

without exacerbating caregivers' privacy concerns. Payers who implement screening mandates and incentives can consider also implementing incentives that support social needs response, including sustainable funding for community health workers and other members of the social care workforce.

The documentation and sharing of health-related social needs information in pediatric care settings presents opportunities and challenges. As health systems increasingly integrate social care into clinical workflows, careful consideration must be given to the perspectives of caregivers, particularly around privacy concerns and potential unintended negative outcomes.

As social care integration in pediatrics evolves, it will be important to continue to explore and address the tensions between regulatory requirements, caregiver preferences and the practicalities of health information sharing. By centering family voices and fostering shared decision-making, pediatric health systems can develop protocols that protect families while leveraging social needs data to improve health outcomes.

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