

Measuring And Addressing Health-Related Social Needs in Cancer:



Working Group Recommendations



Background

It is well established that health outcomes are impacted significantly by factors outside of the health care system. Social Determinants of Health (SDOH) are societal factors that directly or indirectly influence a person's health outcomes in a positive or negative manner. The World Health Organization defines Social Determinants of Health (SDOH) as the "conditions in which people are born, grow, live, and age and the wider set of forces and systems shaping the conditions of daily life, including policies and systems, development agendas, social norms, social policies and political systems." Due to historic and ongoing systemic and interpersonal injustices, there are significant disparities in who experiences adverse SDOH and related adverse health outcomes. These inequities impact cancer incidence and outcomes across race, geography, ethnicity, sexual and gender identity, and socioeconomic status. In recognition of the impact of SDOH on overall health and health outcomes, health systems have begun initiatives to improve health system screening for Health-Related Social Needs (HRSN). HRSN are defined as "an individual's unmet, adverse social conditions (e.g., housing instability, homelessness, nutrition insecurity) that contribute to poor health and are a result of underlying social determinants of health (conditions in which people are born, grow, work, and age)." "

Given the crucial impact of HRSNs on health outcomes, systems are beginning to incentivize healthcare organizations to integrate HRSN screening. The Healthy People 2030 Initiative by the Department of Health and Human Services includes numerous goals related to addressing SDOH. The Center for Medicare and Medicaid Services (CMS) has proposed implementation of the quality measures "Screening for Social Drivers of Health" and "Screen Positive Rate for Social Drivers of Health" throughout a variety of CMS quality programs. Additionally, the Centers for Medicare and Medicaid Innovation (the Innovation Center) has included within the Enhancing Oncology Model a requirement that participating practices screen for HRSNs with several HRSN tools offered as examples including the NCCN Distress Thermometer and Problem List, the PRAPARE Screening Tool®, and the Accountable Health Communities Screening Tool. A number of states have also taken steps to address the needs of Medicaid enrollees through the use of Section 1115 waivers, which allows them to add non-clinical services to benefit packages that could include SDOH-related services.

As government and commercial payer systems pursue policies to advance HRSN screening, it is critical that broader system transformation is also pursued to support this paradigm shift. Healthcare organizations are facing record workforce shortages, the healthcare professional workforce is struggling with high rates of burnout and administrative burden, and patients often face question fatigue after repeatedly completing questionnaires. Stakeholders must come together to acknowledge and support the need for systems transformation to better support HRSNs screening and service connection, while also endorsing streamlined high-impact measures, policies, and practices that can support these activities with the resources and infrastructure warranted and without undue burden on patients, caregivers, and providers.

The National Comprehensive Cancer Network convened a working group on *Measuring and Addressing Health Related Social Needs in Cancer* on April 13, 2023 to explore high-impact measures for endorsement, identify barriers to uptake of HRSN screening and follow up, and to promulgate policy and practice recommendations to address these barriers. The group was co-chaired by Yelak



Biru, MCS, President and Chief Executive Officer of the International Myeloma Foundation and Loretta Erhunmwunsee, MD, Vice-Chair, NCCN DEI Directors Forum; Associate Professor, Division of Thoracic Surgery and Division of Health Equities at the City of Hope National Medical Center. The Working Group consisted of 15 representatives from leaders and experts throughout various fields of oncology. Working group members included representation from physicians, health information technology companies, pharma/biotech companies, payers, patient advocates, researchers, social workers and accreditation organizations. The group used an evidence-based and consensus driven process to identify high impact health-related social needs for measurement and intervention for cancer. The three objectives for the working group meeting were to: (1) Identify high impact measures for Health-Related Social Needs in oncology (2) Identify challenges and opportunities to integrate HRSN measurements into policy and practice (3) Develop recommendations for integration of the highest impact HRSN measures into policy and practice.

Measure Recommendations

The Working Group was asked to identify high-impact measures for HRSN screening. Ultimately, the group proposed four core measures that should be assessed for all patients presenting for cancer care, followed by additional measures for consideration of incorporation depending on community conditions and patient needs. The Working Group's four core measures are:

- 1. **Transportation Access:** Studies have found that patients with transportation challenges may forgo needed treatment if these needs are unaddressed. Specifically, transportation barriers are associated with delayed follow-up after abnormal screening test results, decreased access to specialized oncology care, and lower rates of receipt of guideline-concordant treatment. Transportation access also expands beyond the accessibility of a car to get to treatments and appointments. Examples of transportation considerations can include access to transit, availability of parking at a facility, tolls, parking fees, and availability of a family member who is able to drive a patient to and from an appointment. Many areas have low-cost or no-cost transportation options available for non-emergency medical transportation, but patients, providers and caregivers may not be aware of these services. As such, transportation access is identified as a core measure to screen for and to ensure that there are appropriate resources available and accessed for those with an identified need.
- 2. **Housing Security:** Housing has been identified as having a bidirectional relationship with cancer outcomes. Homelessness, temporary housing, unaffordable housing, unsafe housing, and unsafe neighborhoods have an impact on cancer incidence, identification, and treatment access, while a cancer diagnosis and the expense of treatment can also impact housing status. VIII Multiple studies have found that exposure to housing insecurity is associated with worse cancer care and worse cancer outcomes. VIII Healthcare systems should screen patients for housing security issues that may impact their ability to access cancer treatment and connect them to available governmental and community resources.
- 3. **Access to Food:** The interplay between food insecurity and cancer risk is also bidirectional. Food insecurity can increase cancer risk, while the cost of cancer treatment increases the likelihood of food insecurity. Access to adequate nutrition is correlated with better cancer outcomes, and food insecure patients are more likely to delay or forgo cancer treatment. ix.x



Estimates of the percentage of people navigating a cancer diagnosis and food insecurity range between 17% and 55% of the cancer patient population. Healthcare systems should screen for food insecurity and connect to available governmental, community-based, or health-system resources.

4. **Financial Security:** A cancer diagnosis and associated treatment can result in both a significant increase in household out-of-pocket medical expenses, while patients and informal caregivers and family members may also experience lost wages and time at work. Patients beginning the care journey with lower-income and fewer resources are disproportionately impacted by this challenge, though it may also impact higher-income patients. Financial insecurity has been associated with missed or delayed treatment and follow-up screening interventions, decreased reported health self-efficacy and treatment decision-making, decreased health-related quality of life measures, and increased mortality risk. xi,xii,xiiii The working group recommends screening all patients for financial security so that patients with identified needs can be referred and connected to available resources and so that this can be incorporated into a broader cost of care discussion.

In addition to the group prioritizing these four areas for assessment and intervention, they recommended additional HRSNs that could be assessed based on the screening results of the initial measures. The additional screening could be algorithmic, where patients are asked open-ended questions about their specific needs through a personalized, patient centric approach. Recommended secondary topics include:

- 1. Social support and caregiver support
- 2. Utility assistance
- 3. Work support, including employer accommodations and paid sick leave
- 4. Neighborhood and community safety
- 5. Health insurance needs
- 6. Health literacy and health insurance literacy
- 7. Digital connectivity

Frequency and Approach to HRSN Screening

The working group emphasized that HRSN screening should be a routine part of clinical care and recognized as a critical part of the care conversation. It should not be approached as a "check the box" exercise. The Working Group recommends screening for HRSN at least annually and again at any significant care transitions. Examples of care transitions may include when treatment plans are updated, when a patient moves from one treatment modality to another, and during survivorship care planning. Regular screening for HRSN could also be helpful when patients are receiving care at multiple sites within a health system or across health systems. Electronic Health Record (EHR) systems could support care teams in screening for and addressing HRSN and inform them of relevant conversations that patients have had in other parts of their care journey. It is also important to note that it is common for a patient's HRSN to change throughout the care period. Throughout the treatment journey, a person may experience changes in employment, insurance coverage, caregiver support, or living situation which may have a significant impact on the above-listed measures and



their ability to continue to receive care. Routine HRSN screening will support treatment planning and inform needed adjustments, as it may reveal potential challenges associated with different treatments options or surveillance strategies. Adherence to these recommended screening timepoints is vital when it comes to considerations around the patient's treatment outcomes. While being sensitive to question fatigue and administrative burden, the working group recommends that healthcare systems implement infrastructure including specialized staff like navigators and social workers that can support HRSN screening and follow up. Additionally, healthcare professionals should incorporate open-ended questions into care visits like "What has changed since I last saw you that might impact your ability to access treatment?" so that patients can be referred to specialized staff to appropriately address HRSNs.

Identified Barriers

In addition to identifying the recommended measures for screening, the Working Group considered numerous barriers that could impact the ability to screen for HRSNs and the subsequent interventions that may be needed. Barriers included mistrust of providers and health care entities, a dearth of education and training for healthcare professionals, limited bandwidth among healthcare professionals, and a lack of reimbursement for these services.

Trust/Mistrust/Distrust

Working group members acknowledged that screening for HRSNs can make a patient feel shame, embarrassment, or concern that disclosure will impact their treatment options. Working group members noted the need for training health professionals to foster trust so they can be equipped to approach screening with humility and sensitivity. A survey presented by the National Patient Advocate Foundation found that patients were most likely to trust their doctor with this screening, and less likely to trust other care team professionals such as social workers, patient navigators, and nurses. This can present challenges as physicians have limited capacity to complete this assessment This insight into a patient's perspective on trust shows the need for education for the patient, the provider, and their team to normalize HRSN screening and ensure patients feel comfortable disclosing their needs to a variety of members of the care team. Doctors could start the conversation around HRSN, but the full discussion should be team-based so that staff can assist with identifying and addressing the patient's needs throughout their care journey. During these conversations, care teams should be thoughtful about how they document any identified needs in EHR systems to ensure that patients trust that the information being collected will support their care experience and not cause them harm.

Education and Training Needs

Working group members reported that there is currently a dearth of training and education for healthcare students and professionals on both the importance of HRSN and the best practices in screening for and intervening to address HRSN. Without adequate training in why this evaluation and intervention is necessary and how to effectively facilitate these conversations, healthcare professionals may feel ill-equipped or may not understand the importance. When implemented as a check-the-box exercise rather than a critical part of the care conversation, HRSN screening may cause more harm than benefit for the patient. Additionally, there is a lack of education on the part of



the general population on the importance of this screening and the impact HRSN may have on health outcomes. Patients and their caregivers may not understand the impact that health-related social needs could have on treatment and care.

Bandwidth Issues and Administrative Burden

Working group members acknowledged that HRSN screening may cause workflow issues, EHR challenges, administrative burden, and staff burnout as teams are asked to take on additional responsibilities in administering screening and follow up for HRSN. Healthcare professionals are already experiencing unprecedented burnout and fatigue. Implementing additional screening needs without reducing other responsibilities or ensuring adequate additional dedicated staff time may lead to additional burnout and poor implementation of the service.

Reimbursement Challenges

Currently, connecting patients to services to address HRSN is not a reimbursable service. Because these services are not billable, there is little incentive or capacity for providers to comprehensively implement HRSN screening into practice. Reimbursement can be especially important when we consider the implications of this across the health system. If screening for and addressing HRSN were to become a reimbursable service, then it would provide for the support training needed for staff, the infrastructure for providers to take the time to screen for these needs and could help to alleviate bandwidth issues if proper resources can be dedicated to the administration of such services.

Recommendations

In recognition of the critical importance of HRSN screening and the current barriers identified above, the Working Group developed:

A. Practice Recommendations

- 1. Healthcare institutions must not only screen for HRSNs, but also have a plan to address any unmet needs that may be identified. Screening without a plan to address the unmet need may further harm the patient. Prior to implementing HRSN screening, healthcare institutions should identify and develop referral systems and sources for appropriate services. Healthcare institutions should also consider developing mechanisms to put care plans in place to address identified HRSN. Health systems are also encouraged to develop strong and equitable partnerships with community-based organizations to address HRSN.
- 2. HRSN screening is not a "check the box" exercise and should be conducted as a part of the care conversation. HRSN screening should be viewed as a "discussion-based screening". HRSNs should routinely be collected as a part of clinical care but should be more comprehensive than simply asking a patient to fill out a form. The professional completing the screening which may be any member of the care



team such as a patient navigator or social worker, should begin the conversation by making it clear that they are asking the patient for the information with the intent of addressing identified needs while explaining how identifying and addressing these needs is relevant to their care. The professional completing the screening should open by asking permission to have the conversation and acknowledge the potential sensitivity of some of the questions that may be asked during the screening. Given the sensitive nature of some of the information asked, patients may not feel comfortable sharing. Care teams must support and respect a patient's decision to not provide this information if they are not comfortable doing so. If a patient is comfortable with continuing, the professional completing the HRSN screening should also guery patients on barriers that would keep them from accessing their care and then work to connect them to relevant resources. Open-ended questions can be used throughout the conversation so that the professional completing the screening is able to find out more about the patient's experience and needs. The screening should end with an open-ended question that allows the patient to identify any other issues that might be barriers to care that did not arise during the conversation. Healthcare professionals should use the information gathered to inform their care and treatment planning conversations.

- 3. Health organizations and systems must invest in and support both technology and staff capacity for this type of work. Staff must have dedicated time to both screen for and address HRSN. Recognizing the time constraints of staff, health systems should dedicate portions of paid staff time to HRSN screening and follow up. Health Information Technology may also be used as a tool for continuous check-in, automate referral processes, and provide opportunities to follow up on any of the patient's needs.
- 4. Health organizations and systems must provide training and education on both why screening for and addressing HRSN is an integral part of quality care and how to do this well. Healthcare systems should provide training for healthcare professional students and staff on how HRSN impact care outcomes and why it is the role of the healthcare system to ensure these are addressed. It should be included in medical, nursing, and allied health professional school curricula, professional training, and a requirement for continuing medical education. Training on how to identify available resources in their area to address the identified needs of a patient should also be provided. Additionally, healthcare systems should provide training on unconscious bias, and how to have these conversations including empathic inquiry, cultural humility, and cultural sensitivity.
- 5. HRSN screening and follow-up to connect patients with relevant services must be integrated into comprehensive care plans. Health systems should integrate HRSN screening and follow-up into comprehensive care plans in an effort to normalize this type of screening for patients. As recommended by this Working Group, screening for HRSNs annually and at any point of the care transition will help to normalize this as part of the patient experience. Health systems should utilize Health Information



Technology as a tool for this integration. HIT systems can provide reminders and documentation opportunities, while also automating referrals for identified needs during the initial and subsequent care planning periods.

B. Policy Recommendations

- 1. CMS and other payers should reimburse for Health-Related Social Needs screening visits and discussions. Comprehensive screening and addressing of HRSNs requires adequate time and resources on the part of healthcare systems. As healthcare professionals are already overburdened, sufficient reimbursement will be required to integrate these services into the health system in a comprehensive manner. Additionally, multiple provider types including physicians, nurses, social workers, advanced practice providers, and patient navigators should be able to bill for this service to ensure sufficient capacity. In addition to creating a billing mechanism for the service¹, CMS and other payers should consider the incorporation of this quality measure into value-based payment models with an associated financial incentive.
- 2. CMS and other payers should incorporate a risk adjustment payment for providers with a high-screen positive rate for HRSN among their patient population. CMS has begun to explore ways to reward providers providing high-quality care to historically disenfranchised/underserved populations including the use of the area deprivation index and people with dual eligibility for Medicare/Medicaid. However, these measures are imperfect and may not holistically identify patients with significant HRSNs. As such, the working group recommends using the screen positive rate and connection to additional services as a mechanism to more accurately capture patient needs and provider interventions. This will incentivize provider action on HRSNs while also providing proper reimbursement for serving higher need populations.
- 3. Congress should allocate funds to support education and training programs for all health professionals, patients, and caregivers that incorporates the importance of addressing HRSN as well as best practices in addressing HRSN. Understanding the role that SDOH and HRSN play in care outcomes, as well as how to effectively address these issues within care systems, is critical to effective healthcare practice. This education and training is not currently routinely offered. Congress should establish funding to support these education and training efforts focused on multiple populations within the care setting and at multiple levels of healthcare training.
- 4. NCI should incorporate HRSN screening and interventions to address into the accreditation process for NCI designated cancer centers. In addition to considering these factors for NCI designated cancer centers, NCI should provide adequate funding within the grant structure to reimburse for these activities and conduct evaluations to identify best practices. The National Cancer Institute should recognize

¹ Note: Since the convening of this working group, CMS has recently proposed mechanisms to address this gap in the Proposed 2024 Physician Fee Schedule rule



5. the critical role that HRSN screening and interventions play in high-quality cancer care. This can be incorporated into the accreditation process but should also be supplemented with additional funding to ensure that healthcare institutions and cancer centers have the capacity to meet this need. Other accreditation entities such as the American College of Surgeons Commission on Cancer should also include HRSN screening as part of its accreditation for cancer programs, to also incentivize health systems to incorporate such screening.

C. Professional Society Guidelines

- Clinical practice guideline and pathway developers should consider incorporating HRSN screening and referral throughout guidelines and pathways. Screening for HRSN should be incorporated into the assessment of patients at the time of diagnosis as part of the diagnostic work-up and at regular intervals during treatment and/or surveillance after the completion of treatment.
- 2. Consideration should be given to the development of a clinical practice guideline or pathway specific to the utilization of best practices in HRSN screening, discussion, and referral. As the evidence regarding the impact of HRSNs on health outcomes evolve and best practices are established for assessing HRSNs, developing an evidence-based approach to screening and addressing HRSNs as part of routine care delivery will be important. Development of guidelines or pathways with scalable recommendations for how to optimally deliver HRSN-related care can increase awareness and access to equitable assessments and referrals.

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