



November 16, 2018

MEMORANDUM

To: ASPE Impact Research Study at ASPEImpactStudy@hhs.gov

FROM: Judi Lund Person, MPH, CHC
Vice President, Regulatory and Compliance
NHPCO

RE: Request for Information – IMPACT ACT Research Study – Provider and health plan approaches to improve care for Medicare beneficiaries with social risk factors

The National Hospice and Palliative Care Organization (NHPCO) is writing to comment on the Request for Information from plans and providers on approaches to improve care for Medicare beneficiaries with social risk factors. NHPCO is the largest membership organization representing the entire spectrum of hospice and palliative care programs and professionals in the United States. We represent over 4,000 hospice locations and more than 57,000 hospice professionals in the United States, caring for the vast majority of the nation's hospice patients. NHPCO is committed to improving end-of-life care and expanding access to hospice and palliative care with the goal of creating an environment in which individuals and families facing serious illness, death, and grief will experience the best that humankind can offer.

We appreciate the work of the National Academies of Sciences, Engineering, and Medicine (NASEM) to identify the six practices that achieve high levels of performance for beneficiaries with social risk factors. The six factors of commitment to health equity, data and measurement, comprehensive needs assessment, collaborative partnership, care continuity, and engaging patients in their care are all tenants of the hospice care model. Hospice is considered to be the model for quality, compassionate care at the end of life. Hospice care involves a team-oriented approach of expert medical care, pain management, and emotional and spiritual support expressly tailored to the patient's wishes.

Emotional and spiritual support also is extended to the family and loved ones. Generally, this care is provided in the patient's home or in a home-like setting operated by a hospice program. Medicare, private health insurance, and Medicaid in almost every state cover hospice care for patients who meet certain criteria. Today, many hospice care programs have added palliative care as a service line to reflect the range of care and services they provide, as hospice care and palliative care share the same core values and philosophies. Defined by the Centers for Medicare and Medicaid Services and the National Quality Forum in 2008, "*palliative care* means patient and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual

needs and to facilitate patient autonomy, access to information, and choice.”¹

Palliative care extends the principles of hospice care to a broader population that could benefit from receiving this type of care earlier in their illness or disease process. To better serve individuals who have advanced illness or are terminally ill and their families, many hospice programs encourage access to care earlier in the illness or disease process. Health care professionals who specialize in hospice and palliative care work closely with staff, community volunteers, and community resources to address all symptoms of illness, with the aim of promoting comfort and dignity. Therefore, hospices are uniquely poised in communities across the country to transform a health care industry from a medical model to a compassionate holistic care that has accounted for social risk factors since the inception of the benefit.

NHPCO is pleased to answer the questions in the RFI below.

How do plans and providers serving Medicare beneficiaries identify beneficiaries with social risk factors?

Hospices identify beneficiaries with social risk factors and continue to assess them through the comprehensive assessment process and the development of the individualized plan of care. As required by regulation, hospices update the plan of care at least every 15 days through interdisciplinary team meetings or more frequently as needed.

Recommendation: Consider applying the requirement of [Title 42 Part 418.54](#) to all providers, which requires hospices to conduct a comprehensive assessment and regular updates to the individualized plan of care by an interdisciplinary team that takes into account psychosocial, emotional, and spiritual care.

Approaches beyond the NASEM principles and health plan taxonomy that work to improve care for Medicare beneficiaries with social risk factors

- 1. Are social risk data being used to target services or provide outreach? If so, how? How are beneficiaries with social risk factors identified?**

Hospices continue to identify ways to reach communities where there are beneficiaries with social risk factors through community meetings, connections with the faith community and a variety of other outreach efforts. The valuable relationships developed with community organizations where services are offered is a key component of the identification process. The development of these relationships over years are critical to the success hospices have had to adapt to the needs of the beneficiary and family. The volunteer network also allows hospices to support those beneficiaries with serious illness and with identified social risk factors to learn about the “wrap around” services and supports available as palliative care and hospice are needed.

¹ [Code of Federal Regulations](#), § 418.3

2. Are there especially promising strategies for improving care for patients with social risk?

NHPCO believes that successful strategies are those that start with the comprehensive assessment and development of an individualized plan of care. This assessment and plan will ensure that providers and plans can access what is needed for the individual beneficiary and their family to address any and all social risk factors with attention to cultural and linguistic appropriateness^{2,3}. The ability to identify specific beneficiary and family needs, provide meals, caregiver respite, or transportation to appointments are all temporary measures to alleviate beneficiary and caregiver strain. Hospices that have developed ties in the community demonstrate their ability to respond to beneficiary needs in the community every day. Although ASPE is focused on service delivery, we also encourage an examination of the broad institutional structures that impact access to health care.⁴

3. How are costs for targeting and providing those services evaluated? What are the additional costs to target services, such as case management, and to provide additional services (e.g., transportation)? What is the return on investment in improved outcomes or reduced healthcare costs?

For hospice providers, targeting and providing these services are a part of the holistic approach to care that hospice offers to patients and their families. Case management is a given, as is a comprehensive assessment and individualized plan of care. The cost for targeting social risk factors is a part of that process. The provision of services, such as transportation, meals, and caregiver support, would often be provided by hospice volunteers at little or no cost to the hospice. The reduction in healthcare costs may include no hospital admissions or emergency department visits as the patient and their family is supported in home settings.

4. What are the best practices to refer beneficiaries to social service organizations that can address social risk factors?

Success in referring beneficiaries to social service organizations will involve building and maintaining community relationships so that needs can be identified and services can be provided seamlessly. For patients with serious illness, the care needs can be complex and multi-faceted, so collaboration with other social service agencies is a must and built on trust and experience.

5. What lessons have been learned about providing care for patients with social risk factors?

Addressing the most basic needs for beneficiaries and their families is essential before any improvement in health can be assumed. If a beneficiary is food insecure, has transportation issues that will impact the ability to get to doctor appointments or if the caregiver is stressed, the ability to focus on health issues is significantly diminished. A comprehensive assessment, which

² O'Brien, A, et.al. Considering Aboriginal palliative care models: the challenges for mainstream services. [Rural and Remote Health 2013; 13: 2339](#)

³ [Culturally and Linguistically Appropriate Services](#)

⁴ Reimer-Kirkham S, et. al. Death is a Social Justice Issue: Perspectives on Equity-Informed Palliative Care. [Advances in Nursing Services. Vol. 39. No. 4 pp 293-307](#)

includes questions that would indicate risk areas, will be essential for developing the plan and securing the resources to meet these needs.

6. What are barriers to tailoring services to patients with social risk factors? How can barriers be overcome? For patients with social risk factors, how does patients' disability, functional status, or frailty affect the provision of services?

The complex needs of the beneficiary with serious illness and their family are specific to each beneficiary, and the social and medical needs and risks are impossible to disentangle. Beneficiaries in need of food, housing, transportation and other social needs are on their own to manage outside the medical system. Although clinicians recognize there is a need to provide social support and stability in order to achieve improved health outcomes, there is no mechanism currently to address non-medical needs. Clinicians often only have time to address the diagnosis, symptoms, and treatment of a serious illness with few resources to address the social risk factors upon discharge from their care. Other members of a beneficiary's care team are needed to provide the necessary wrap-around support for beneficiaries and ensure quality of life for this patient population.

Hospice is a holistic approach to care that could be replicated from the end-of-life setting to the primary care setting and would be effective in addressing social risk factors. As a part of the comprehensive assessment and care planning process, these factors are addressed in dialogue with the patient and family. For beneficiaries whose stay in hospice is less than the median length of stay of 18 days, it is much more difficult to address with the limited time the beneficiary receives the hospice benefit. Community-based palliative care has started to address some of these needs for beneficiaries with serious illness and could continue to address these risks, although we have found that it may still be too late to have a real impact on quality and total cost of care.

Data

1. Which social risk factors are most important to capture?

There are 3 important social risk factors that hospices have found to be the most informative when developing the individualized plan of care. The socioeconomic position, social relationships and the community context. The socioeconomic position is often collected by other providers and payers, but the information is not consistently shared between providers and plans. The information is critical to understanding the beneficiary and family's level of health literacy and financial strain. The socioeconomic information may also inform the provider of whether the beneficiary and family are able to secure consistent housing, food, medication, and transportation that could impact the priorities in the care plan.

Another informative social risk factor is the social relationships because they provide an indication of services that may need to be provided by the hospice to address caregiving and custodial needs. Social relationships are important to ensure there is a meaningful support network in the community such as friends, family, faith community, and extended caregivers. Beyond providing the hands-on help in the home, the social relationships (if present) also reduce beneficiary anxiety and fears when interacting with the clinical team.

Finally, the community context is vital to understanding the social risk factors that impact quality and total cost of care. The cultural diversity – beyond race and ethnicity, language, and nativity – cannot be captured by standardized methods of data collection such as surveys. A successful strategy in some communities is to identify and train “lay health care workers” who are trusted leaders in the community. In order to understand the community context and its complexities, qualitative data collection is necessary to capture the local community’s belief regarding the elderly, disabled, serious illness, end of life care, and the community’s general relationship with local medical institutions and clinicians. Collecting data regarding the community context must use qualitative information gathering modalities (e.g. beneficiary interviews, extended time in local establishments, wind shield observations, and community leader interviews) to obtain meaningful findings. However, we recognize the qualitative data collection methods are costly and time consuming. We recommend holding stakeholder meetings to develop qualitative data collection guides/protocols and identify interoperable IT investment to share the qualitative data across plans and providers.

- 2. Do you routinely and systematically collect data about social risk? Who collects this data? When is it collected? Is it collected only once or multiple times for a beneficiary? Is it collected consistently across populations (i.e. Medicare beneficiaries, Medicaid beneficiaries, patients receiving specific services, etc.)? What are the burdens of this data collection on plans, providers, and beneficiaries?**

As noted above, hospices identify beneficiaries with social risk factors and continue to assess them through the comprehensive assessment process and the development of the individualized plan of care. As required by regulation, hospices update the plan of care at least every 15 days through interdisciplinary team meetings or more frequently as needed. The hospice nurse collects the information for the initial and comprehensive assessment. The interdisciplinary team continue to provide insights and feedback to the individualized plan of care and is not restricted to Medicare beneficiaries. The hospice care delivery model applies to all hospice patients in order to reduce confusion and burden on the care team.

- 3. Would standardized data elements for EHRs help you to collect social risk data? If so, how could these data elements be standardized?**

Hospices need financial support to implement standardized elements if they are not already collected in their EHR systems. The EHR solutions in the field are not customized for the hospice population; however, hospices have worked with vendors to use the existing platform and diligently negotiate with vendors to collect data elements to comply with Medicare regulations. Although this approach meets the need, hospices are often left out of the business requirement discussions and testing to ensure the EHR system can adapt to collecting social risk factors that are meaningful for the end-of-life population. If standardized data elements are considered for EHR, we urge ASPE to ensure the full spectrum of providers, from primary care providers to hospices, are included in the development of the social risk data elements.

- 4. What are barriers to collecting data about social risk? How can these barriers be overcome?**

A primary barrier for being able to collect the data about social risk factors falls squarely in the area of electronic medical records. Many current electronic medical record systems do not collect data about social risk. Adding new elements to the EMR system is challenged by the

financial capital requirements and is exacerbated by limited interoperability across data systems, particularly when considering a variety of community providers. With the rapid pace of new data collection requirements and software vendor hours needed to customize data systems, the financial burden to ensure the compliance with regulatory requirements, financial requirements, and IT security is high. This is often a factor for providers who may be committed to addressing social risk factors but IT infrastructure and interoperability issues make it impossible.

5. What do you see as promising future opportunities for improving data collection? For using existing or future data to tailor services?

The rapid growth in research and development of advanced technology offers promising opportunities to collect social risk data and specialize treatment options for patients. Information technology security, software development, artificial intelligence, machine learning, telemedicine, mobile health applications, and blockchain technology all offer promising opportunities for personalized care plans that consider health behavior, treatment plans, and multiple social risk factors^{5,6,7,8}. However, the abundance of data will not solely address quality and total cost of care nor does it always accurately predict a person's right to choose healthcare options^{9,10}.

We urge ASPE and all stakeholders to not lose focus on the human aspect of providing health care. Health care is more than analyzing data and administering treatment. High quality care with high rates of beneficiary satisfaction are the result of care teams that focus on the person, honoring their wishes, and taking the time to build a relationship. If we fall victim to fancy bells and whistles or assume that the data collected gives us the ability to "tell/predict" what the beneficiary should or shouldn't have for services, we may lose sight of protecting that beneficiary choice for their own goals of care. After 40 years of experience, hospice have proven that the foundation to high quality and high satisfaction is person-centered care honoring care goals defined by the beneficiary and family.¹¹

We strongly urge Medicare to include social risk factors for beneficiaries in the commitment to person-centered care, especially for beneficiaries with serious illness or at the end of life. Much can be learned from the whole-person approach practiced in hospice, which includes discussions with the beneficiary about goals and values, as well as advance care planning, comprehensive assessment and care planning. NHPCO stands ready to discuss any of our comments on this RFI at any time.

Thank you for the opportunity to comment.

⁵ [Will Blockchain Transform Healthcare?](#)

⁶ [Ten Promising AI applications in Healthcare](#)

⁷ [AMIA Calls for Federal Alignment of Health Data Privacy Policies](#)

⁸ [Machine Learning Healthcare Applications - 2018 and Beyond](#)

⁹ [Why so many people chose the wrong health plan.](#)

¹⁰ [3 reasons Why Comparative Analytic, Predictive Analytics, and NLP Won't Solve Healthcare's Problems](#)

¹¹ [Measuring Patient-Centeredness of Care for Seriously Ill Individuals: Challenges and Opportunities for Accountability Initiatives](#)