NATIONAL COALITION FOR CANCER SURVIVORSHIP

December 13, 2019

The Honorable Seema Verma
Administrator
Centers for Medicare & Medicaid Services
Department of Health and Human Services
200 Independence Avenue, SW
Washington, DC 20201

Re: Oncology Care First Model: Informal Request for Information

Dear Administrator Verma:

The National Coalition for Cancer Survivorship (NCCS) is a national organization representing survivors of all types of cancer in efforts to ensure access to high quality care for all people with cancer. We focus on the entire cancer journey, from diagnosis through treatment and survivorship, aiming to help patients sustain a high quality of life throughout.

We appreciate the opportunity to comment on the Oncology Care First model, as described in the Informal Request for Information released on November 1, 2019. We have joined the Cancer Leadership Council in comments that focus substantially on the challenges raised by the calculation of the monthly population payment and the identification of the benchmark for performance-based payments. One shared concern, as articulated in the coalition letter, is that there be adequate resources in the model, through monthly population payments that include enhanced services payments, to support high quality care. Additional concerns are that that the performance-based payment structure could influence treatment choices and limit care and so severely penalize practices that they are unable to remain in the model. Those potential shortcomings of the model must be addressed to ensure that the model meets its promise of fostering patient-centered care.

Additional Care Transformation Activities

NCCS has carefully monitored the progress of the Oncology Care Model (OCM), through stakeholder meetings on the model, frequent feedback shared by participating practices, and careful consideration of the OCM evaluations. We are aware of the challenges that some participating practices have encountered from OCM participation, and we are also aware of the concerns about the OCM risk model.

At the same time, we have been pleased by the impact of the practice transformation activities required of OCM practices. The evaluations of OCM detail some of the positive benefits of the practice transformation activities, and both oncologists and patients inform us that the practice of care planning is yielding significant benefits. Many oncologists have signaled that undertaking the 13-element care planning process is not simple, yet those same oncologists typically assert that the benefits outweigh the burdens.

During the course of the OCM, NCCS has been engaged in a multi-faceted effort to obtain feedback from cancer patients regarding their cancer care experience and how to improve it. Part of this effort has been to develop a set of quality measure concepts related to the cancer care experience, which we will discuss later in this letter.

The clear advice from cancer patients and survivors is that there should be regular assessment and monitoring of their functional status during treatment and during post-treatment survivorship. The Informal Request for Information identifies a seventh practice redesign activity that will be required in the Oncology Care First model. This activity is the "gradual implementation of ePROs." This activity is intended to enhance care coordination. The RFI also states that "Information from ePRO systems can be used for monitoring patient symptoms in clinical care and identifying high-risk patients for complications or utilization of emergency services."

We support the use of ePRO instruments or systems. However, we believe that ePROs are tools for practice transformation, but not a practice transformation activity itself. Thus, we think that the additional care transformation activity for the Oncology Care First model is more accurately described as monitoring of functional status during treatment and beyond. We think the concept of monitoring of functional status—as urged by our patient advisors – more accurately describes the care transformation effort that would advance the overall movement to patient-centered care. In a care transformation activity that focused on monitoring of functional status, the ePRO system would be an important tool to support the care transformation effort.

Survivorship Care in the Oncology Care First Model

We have advocated the establishment of a cancer survivorship care model, as a parallel model to the OCM. In making the case for a survivorship care model, we suggested that an episode of care model would foster care planning and coordination in a way that is currently not typically available to cancer survivors. At the same time, we have conceded that establishing a reasonable rate of reimbursement for a survivorship bundle might be difficult to do, on the basis of historical charges. We fear that historical charges will understate the cost of quality survivorship care. We urge the Innovation Center to consider additional means – beyond historical charges – to establish prospective payments for survivorship care.

We understand enhanced services payments will be included in the monthly population payments for all patients (those receiving drug treatment, those receiving hormonal therapy, and those receiving post-treatment survivorship care), but we suggest that certain care transformation activities – 24/7 access to a clinician, patient navigation, care planning, and monitoring of functional status with an ePRO instrument – be given additional weighting in calculation of reimbursement for survivorship care. We believe these care activities are especially critical to quality survivorship care, and monthly population payment rates should be adjusted to reflect that.

Quality Measurement

We are pleased that the Innovation Center, during the course of the Oncology Care Model, has been open to input from cancer stakeholders regarding the quality measures that are utilized in the model. However, as we have all acknowledged, available measures (both outcome and process) have limitations. Current outcomes measures focus on reduced utilization of unnecessary emergency department visits and hospitalizations . These are important outcomes for cancer patients, but there are other outcomes that are as important to patients. Patients care about how well they live with and beyond cancer and the degree to which their health care team helps them address the effects of cancer that go beyond the immediate symptoms of treatment.

To address this concern of patients, NCCS undertook a patient-driven measure development effort, which we called Redefining Functional Status: a Patient-Let Measure Development Effort. We convened a group of patients and used a structured RAND Delphi process to identify the domains of functional status that were important to measure. Throughout the project, we let the patient committee, comprised of cancer survivors representing a variety of types of cancer and backgrounds, guide the work and the decisions made about outcomes to prioritize and how to measure them, resulting in a truly patient-centered product. The result of the project is a set of prioritized patient-reported outcome measurement domains and a recommendation that cancer providers conduct routine functional status assessment (including, at minimum, the prioritized domains) to help those with cancer to redefine functional status during treatment and survivorship. Finally, we created quality measure concepts for a set of measures, including both process measures related to the routine assessment of the prioritized domains via a validated survey instrument, as well as outcome measures for performance related to improvement in functional status.

We have included as an appendix to this letter a description of the NCCS Redefining Functional Status project. While the quality measures defined in our project will not be developed and ready for use when the Oncology Care First model begins, we believe that the project can inform the practice transformation requirements of the model. We welcome further discussions, and we urge the Innovation Center to continue its open dialogue with stakeholders regarding the best quality measures for use in alternative payment models, including the Oncology Care First model.

We appreciate the opportunity to comment on the Oncology Care First model, and we look forward to additional discussions with the Innovation Center on this important issue. Please feel free to contact me at sfuldnasso@canceradvocacy.org with any questions.

Sincerely,

Shelley Fuld Nasso, MPP
Chief Executive Officer

Redefining Functional Status:
A Patient-Led Quality Measurement Effort

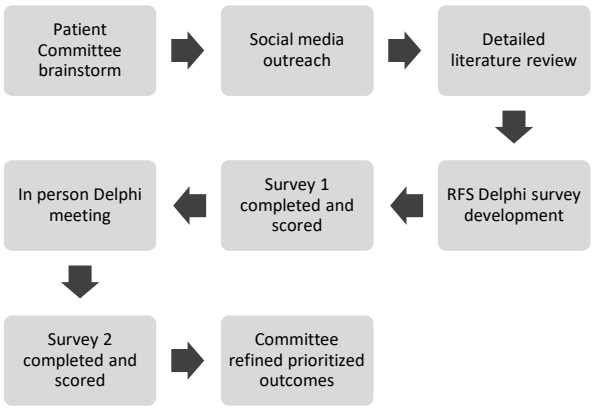
Background

In 2018 the National Coalition for Cancer Survivorship (NCCS) was awarded a grant from the American Institutes for Research (AIR), with support from the Robert Wood Johnson Foundation, to lead a group of cancer survivors in defining a new quality measure concept to represent cancer survivors' ability to return to functional status following cancer treatment. NCCS assembled a stellar committee of experienced patient advocates, survivors who represent diverse cancer experiences and types of cancer, to define quality measures that are meaningful to survivors. NCCS used a novel project design to develop a conceptual definition of functional status, during and after cancer treatment. NCCS was the only patient advocacy organization selected in a highly competitive selection process.

Methods

The NCCS project team convened a diverse group of cancer patients and survivors to serve as the committee (RFS Committee) guiding the project. NCCS also convened a technical expert panel (TEP) comprised of oncology clinicians and quality experts to provide guidance and support to the RFS Committee and project team.

Early in the project, the RFS Committee members redirected the planned scope in several critical ways. First, the committee objected to the proposed measurement population, which was limited to cancer survivors completing treatment. Instead, the committee concluded that measures must also include people with chronic or metastatic cancer diagnoses who receive extended cancer treatment, and that the committee membership should be expanded accordingly. Second, committee members concluded that the term "return to functional status" is inadequate, and could be detrimental to efforts to improve patient-centered care. They noted that the term implies the expectation of regaining a functional status equivalent to pre-diagnosis. Finally, the committee recommended that a stronger consensus would come from input from more cancer patients, survivors, and advocates. For this reason, the project team added social media outreach to the project methodology, leveraging the connections (e.g., Facebook groups, Twitter chats) of NCCS and committee members.



The figure to the left demonstrates the overall consensus methodology for the project. The RFS Committee members served as the Delphi Panel. Themes from committee brainstorming and the social media outreach, coupled with a detailed literature search, informed the Delphi survey development. Standard RAND Delphi survey methodology was followed, and panelists first completed Survey 1. Areas of disagreement and uncertainty were the focus of discussion during a two-day meeting, followed by Survey 2 completion/scoring.

Following the in-person meeting, the committee met via conference call twice per month for focused measure development and specification. Discussion was facilitated and technical, but the committee's defined role of guiding the project was maintained. During these specification sessions, the committee determined the refinement of the priority patient reported outcomes, the timeframe for outcome assessment and quality measurement, and definitions. Perhaps most notably, the committee continued to direct the project scope, and determined that patient-reported outcome measures alone were insufficient. The committee prioritized several process and experience outcomes for a measure set. The project team selected PROMIS instruments to measure each domain because it is available for free, has widespread domain inclusion, and has undergone significant testing, including in cancer populations.

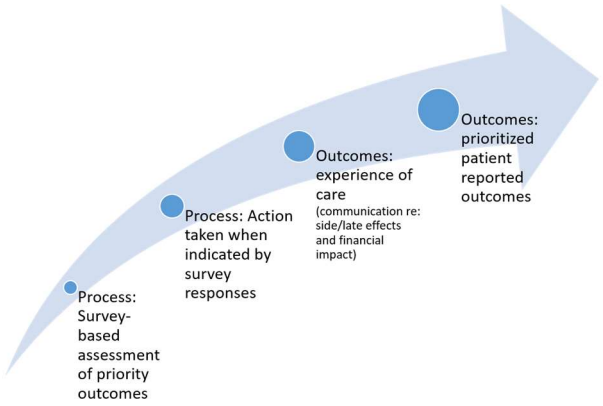
Key Findings

Patient leadership resulted in challenges to common jargon, because the words we use matter in defining quality. As previously noted, early in the project, committee members concluded that "return to functional status," our initial label for the project, did not resonate with them. The project team spent considerable time over multiple meetings discussing the name. Ultimately, the group felt that "functional status" was important and conveyed something different and more specific than a general term like "quality of life." They did not like the idea of "returning" to something because the reality of cancer is that life is never the same after a cancer diagnosis. The committee decided on "redefining," because it acknowledges that patients and the health care team have an active role in determining functional status after a cancer diagnosis. This small but important change indicates active engagement during the cancer trajectory to prepare patients for changes and in managing functional status impacts.

Throughout the project, the committee's discussion illustrated myriad gaps in the existing cancer care system in assessing/addressing functional status, and by extension in supporting those with cancer in redefining functional status during treatment and into survivorship. The team collectively concluded that measurement alone will not address these gaps, and that a broader set of system/practice reforms are required. That said, NCCS continues to support quality measurement regarding redefining functional status as critical to better define gaps and to provide a roadmap for improvement efforts.

The Delphi methodology resulted in the following prioritized patient reported outcome measurement domains: global quality of life (including overall physical and mental health), physical function, pain, fatigue, cognitive function, and psychosocial illness impact (including emotional problems, depression, independence, sense of control, and resilience). Further, one of the project's main consensus recommendations was a core requirement that cancer providers conduct routine functional status assessment (including, at minimum, the prioritized domains) to help those with cancer to redefine functional status during treatment and survivorship. Unfortunately, the RFS Committee consensus and published literature indicate that standard assessment of these domains is the exception, rather than the norm, in cancer care today. As such, we added a group of process measures regarding routine assessment of these domains via validated survey instruments into the RFS measure set. The process measures will help enumerate the current performance gap and highlight initial opportunities for improvement.

The committee also concluded that an RFS measure set must evaluate providers' reaction to any poor or concerning patient responses to any administered survey. Thus, the final measure set also includes a group of process measures regarding provider action taken, as needed.



Finally, the committee prioritized inclusion of measures regarding side effects and late effects of cancer treatment, as well as the financial impacts of cancer. Group evaluation of these domains revealed that measurement is best focused on the quality of provider communications and information sharing. Thus, the RFS set includes indicator statements regarding patient experience outcomes in these domains. Survey development and testing may be required in these areas to allow for full performance measure development.

Lessons for Patient-Led Measure Development

Overall, this project illustrates the value in patient advocacy organizations taking a leading role in quality measure development. As an organization that represents and advocates for patients, NCCS focuses first on the needs of patients, while remaining highly attuned to the broader context of the health care system and sound public policy. NCCS has a broad network of experienced patient advocates from which to draw to form the RFS committee. NCCS identified patients and survivors who had been active in advocacy programs and initiatives with NCCS and other organizations, with an eye toward diversity of cancer experience (site and stage), age, gender, race, ethnicity, and life experience. RFS Committee members did not have experience with quality measurement prior to the project. All are active advocates in their own disease community (e.g., metastatic breast cancer, colon cancer), but their advocacy has focused on research, clinical trials, patient support, and legislative advocacy. Several committee members said they now understand the value of quality measurement broadly and have an interest in continuing their involvement in quality measurement efforts.

Throughout the project, the team and committee took a holistic view of patients as whole people, not just their disease. The committee prioritized outcomes that reflect the psychosocial needs of cancer patients and survivors – needs that are less likely to be considered or met than the physical symptoms and side effects of cancer treatment.

Committee members expressed optimism that the measures specified in the project will help improve care and improve the patient experience. One said, “Patients aren’t always comfortable letting their provider know what they are experiencing, and having a quality measure that allows a patient to share their concerns, issues or changes can overcome the fear or intimidating nature of speaking up.” Another said, “Patient-centered quality measurement is likely one of the few effective ways to influence provider behavior when it comes to how they treat, interact, make assumptions, etc. with patients. We are long overdue to move past patients’ anecdotal stories and feedback about their experience and firmly entrench it in measurement and comparable data.” Another said, “Providers tend to ignore the functionality question if they’ve got the cancer under control. They often say the short and long-term impacts aren’t an issue (from the provider’s point of view) if the cancer is stable. But that’s not right and quality of life is ignored. We need to overcome this. Providers (and patients) need to consider this as a component of decision making.”

NCCS let the committee's input and decision-making guide us and, at times, that led to results that were not exactly what was envisioned at the beginning of the project, resulting in changes in the project scope and definitions, based on the committee's direction. The project ream realized what it truly means for a project to be patient-driven: if you ask patients what they want, you need to be prepared to listen and change course when the answers you received are not what you anticipated.

Acknowledgements

The NCCS project was led by Shelley Fuld Nasso (NCCS) and Kristin McNiff (KM Healthcare Consulting), with support from Elizabeth Goss and Kelsey Nepote. NCCS gratefully acknowledges the members of the RFS Committee – Rebecca Esparza, Betsy Glosik, Matt Goldman, Candace Henley, Allen Hirsch, Kirby Lewis, Allison Rosen, Susan Strong, Desiree Walker, and Dan Weber – for their guidance, patience, time, commitment, and passion.