C+TAC
COALITION TO TRANSFORM
ADVANCED CARE

July 10, 2024

Re: Addressing the Needs of Patients with Complex Chronic Conditions or Serious Illnesses in Population-Based Total Cost of Care (PB-TCOC) Models (RFI)

Submitted electronically to PTAC@HHS.gov

On behalf of the Coalition to Transform Advanced Care (C-TAC), we appreciate the opportunity to respond to this RFI regarding addressing the needs of patients with complex chronic conditions or serious illnesses in PB-TCOC models.

C-TAC is a national non-partisan, not-for-profit coalition dedicated to ensuring that all those living with serious illness, especially the sickest and most vulnerable, receive comprehensive, high-quality, person- and family-centered care that is consistent with their goals and values and honors their dignity. C-TAC comprises more than 200 national and regional organizations including patient and consumer advocacy groups, practitioners, health plans, faith-based and community organizations, and others who share a common vision of improving care for serious illness in the U.S.

Responses to select RFI Questions

What are the characteristics of patients with complex chronic conditions or serious illnesses? What are the characteristics of the highest cost patients with complex chronic conditions or serious illnesses?

- C-TAC defines serious illness as a health condition that carries a high risk of mortality and either negatively impacts a person's daily function or quality of life, or excessively strains their family caregivers. This definition has been widely adopted, including by the National Committee for Quality Assurance (NCQA) and the National Quality Forum (NQF).
- Currently, persons with serious illness often receive services contrary to their individual care preferences due to lack of informed care planning, while underutilizing community services, palliative care, and hospice. This leads to high unmet needs and poor quality of life.
- Persons with serious illness receive their care in multiple settings, and often without coordination or access to comprehensive palliative care services delivered by an

interdisciplinary group, leading to fragmented, uncoordinated care, and challenges accessing additional services that may be available in their community.

- Persons with serious illness that do not have access to care coordination earlier in their course of a serious illness can face burdensome healthcare costs due to frequent inpatient admissions, emergency department visits, facility stays, and low value treatments that impact quality of life for people and their family caregivers.

How are high-cost patients with complex chronic conditions or serious illnesses prospectively identified by payers, ACOs, and providers?

The current prevalence of persons with serious illness can be determined using the definition listed in the first answer or by a comprehensive analysis for those enrolled by a payer. Using administrative claims data, a state payor, such as Medicaid, or a private payer can identify members with serious illness using one of three different approaches:

1. Population-Based Approach. People identified through claims with specified diagnosis and functional criteria demonstrating ongoing decline, including proxies for level of function and risk of future hospitalizations.
2. Past hospice utilization. Members who have received hospice care. This approach will identify individuals with terminal illness closer to the end of life.
3. Decedents. Members who died during the specified period. This approach will identify individuals who may or may not have accessed hospice services prior to death. Sudden death and death from causes other than a serious illness should be removed from this analysis.

What are the major challenges that affect patients with complex chronic conditions or serious illnesses? What are the major challenges that affect providers' ability to care for these patients?

- As noted, persons with serious illness often receive services contrary to their individual care preferences, while underutilizing advance care planning, palliative care, home and community-based services, or hospice. These services help people make treatment decisions better aligned with their goals and values, address their important social needs, and provide education and support to them and those who matter most to them. This in turn reduces unwanted utilization.
- Providing access to specialty palliative care services throughout the continuum of care and across care settings, can reduce potentially preventable events and mitigate these challenges. Specialty palliative care includes a range of coordinated, specialized palliative care services delivered by an interdisciplinary team skilled in delivering person-centered care outside of the hospital and hospice settings and can be made available to people with serious illness across geographies and cultural settings. This can also include:
    - Ensuring each person's physical, social, psychological, and spiritual needs are assessed on an ongoing and standardized basis.
    - The development of care plans, using shared decision making, based on those needs and the person's individual goals and preferences.

    - Accessible care 24/7 (using technology as appropriate) and available throughout the continuum of a serious illness (including in the home when appropriate).
    - Comprehensive and coordinated care, with seamless transitions, and with integration of clinical and community-based services and supports for the person and family caregiver(s).

What are the major barriers associated with participation and engagement in APMs from providers serving patients with complex chronic conditions or serious illnesses?

Payment for models with serious illness populations should be value-based, available to qualified organizations of any size, and includes risk adjustment, upfront investment, accountability, standardized metrics, and quality improvement, and covers both clinical and social services.

While palliative care can lead to coordinated, high-value care that aligns with person preferences, the current reimbursement structures does not enable individuals to access interdisciplinary supportive services unless they are hospitalized or have elected hospice care. While outpatient palliative care consultations, assessments, and advanced care planning are reimbursable through fee-for-service for billable members of the interdisciplinary team, and are available to beneficiaries in a clinic or telemedicine setting today, these services do not typically extend into the home or allow for a team-based, longitudinal approach to care for the duration of a person's illness. This creates gaps in care which result in crises and emergency department visits or hospitalizations.

Introducing a bundled payment rate, or a pre- determined amount of money paid to a provider organization to cover the average costs of all services needed to achieve a successful outcome for a pre-defined episode of care, can allow for financial incentives to provide coordinated care that accounts for the higher risk associated with people who are seriously ill.

What are examples of effective care models for patients with complex chronic conditions and/or serious illnesses? What specific issues have these models focused on (e.g., patient- centered care, preventable events, management of care transitions, equity/health related social needs, specific conditions)?

- Care models that provide access to specialty palliative care services throughout the continuum of care and across care settings can reduce potentially preventable events and mitigate the challenges of fragmentation, underutilization, and unwanted care. Specialty palliative care includes a range of coordinated, specialized palliative care services delivered by an interdisciplinary team skilled in delivering person-centered care can be made available to persons with serious illness across settings. This can also include:
    - A comprehensive assessment to identify each person's physical, social, psychological, and spiritual needs on an ongoing and standardized basis.

- The development of person-informed care plans via a shared decision-making process that incorporates the needs and the person's individual goals and preferences.
- 24/7 access to care, using technology as needed, and available throughout the continuum of a serious illness and across settings.
- Comprehensive and coordinated care, with seamless transitions, and with integration of clinical and community-based services and supports for the person and family caregiver(s).

What are best practices in performance measurement for patients with complex chronic conditions or serious illnesses?

The main goals of performance measures for PB-TCOC models for persons with serious illness should be to confirm the quality of the person's experience. That would encompass the key aspects of care: access, affordability, timeliness, and clinical components addressing the person's quality of life, their ability to be a partner in the plan of care and treatment plan, and their satisfaction with communication and information being provided. Ideally they would be patient-reported measures such as the Ambulatory Palliative Care Patients' Experience of Receiving Desired Help for Pain and also the 2024 MIPS Measure #495: Ambulatory Palliative Care Patients' Experience of Feeling Heard and Understood. Both were developed for community-based palliative care programs but are available for other models providing care to those with serious illness. We also advocate for assessment and support of the family caregiver since they are a key partner in ensuring people with serious illness get the care they need.

We do not see the need for PB-TCOC models measurement to differ from those of other APMs.

Furthermore, we recommend that PB-TCOC models should consider a range of performance characteristics including:

- Demographics of those accessing and utilizing services, including race/ethnicity, socioeconomic status, gender, and geography and allowing for self-identification.
- Completion and timeliness of assessments including those for cognitive and physical function, caregiver status and burden, pain, goals for care, and health related social needs.
- Beneficiary and caregiver experience of care and quality of life.
- Provider and care team experience of care.
- Health services utilization and costs, including primary care provider visits, inpatient admissions, readmissions, timeliness of care delivery/delays in care, pharmacy benefit utilization, access to home-based services, and hospice length of stay.
- Quality, including transitions of care and advance care planning

Thank you for the opportunity to respond to this RFI. If you have any questions, please contact Marian Grant, Senior Regulatory Advisor, C-TAC, at mgrant@thectac.org.

Sincerely,

Marian Grant and Torrie Fields

Advisors
Coalition to Transform Advanced Care (C-TAC)