C-TAC
COALITION TO TRANSFORM ADVANCED CARE

To: PCORTF@ahrq.hhs.gov April 19, 2022

Re: Request for Information: AHRQ's Proposed Patient-Centered Outcomes Research Trust Fund Strategic Framework

On behalf of the Coalition to Transform Advanced Care (C-TAC), we appreciate the opportunity to comments on this strategic framework regarding its effect on those living with serious illness.

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 is made up of over 180 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.

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[i]. This definition has been widely adopted, including by the National Committee for Quality Assurance (NCQA) and the National Quality Forum (NQF). Those from historically disadvantaged communities who also have serious illness experience poorer care[ii] and access making improving their care a health equity opportunity.

Responses to RFI Questions

<u>Question 1: Overall reactions to the strategic framework</u>- We support this framework and feel it does promote the vision of advancing equitable whole-person care across the lifespan.

The only major challenge faced by the U.S. healthcare system not addressed in it is that of payment and how current financial incentives often promote care not in line with the framework's strategic goals. Adding or addressing this challenge in the framework could improve it and guide research to identify better payment and incentive options to deliver better and more equitable care.

<u>Question 2: Input on (non-ranked) high-level priority areas</u>

We support these priority areas with the following suggestions:

- *Area B Prevention and Improved Care of Patients with Chronic Conditions*- We suggest a clarification by what is meant by "chronic illness". Our concern is that, depending on that definition, some people living with aggressive, life-limiting serious illnesses may be excluded. Examples of such nonchronic conditions could be cancer, infections, and neurological conditions such as amyotrophic lateral sclerosis (AML).
- *Area C Patient, Family, and Provider experiences of Care*- We appreciate the inclusion of trust as a key factor in care and look forward to research addressing this important aspect. Given the title of this area, we also suggest that the concept of whole-person care be broadened to include family caregiver and spiritual components, since these have a significant impact on health and quality of life.

Question 4: How to target investments within high-priority areas

- *Specific ages/stages or apply AHRQ's investments equally across the lifespan*- We would advocate for focus on the most vulnerable populations which would likely include the youngest and oldest among us rather than evenly across the lifespan.
- *Transitions in care*- We also agree that transitions in care is an issue for those with chronic or serious illness and so would advocate for targeting investment with that focus.

Question 5: Suggestions for applying the strategic framework

- *Dissemination and integration*- We share your concern about how AHRQ can improve the dissemination of patient-centered outcomes research evidence to decision- makers at the local, state, and federal levels. We believe that by working with these decision-makers, some of these findings could be boosted by required metrics to track their outcomes and payment for those outcomes to ensure they are adopted into clinical practice reimbursed by government payers. We also feel such mandatory outcome measurement and payment is also the most effective way to ensure the sustainability of initiatives that seek to enhance the integration of patient-centered outcomes research findings into practice.
- *Complementary partnerships and collaborations (both public and private) to increase the impact of AHRQ's PCORTF investments*- We feel that going beyond health care providers and health care organizations to include community organizations and faith-based ones would be an effective way to apply learnings from this framework and ensure trust and more equitable care delivery.

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

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[i] Kelly A and Bollens-Lund E. Identifying the Population with Serious Illness: The "Denominator" Challenge. Journal of Palliative Medicine. 2018;21(S2). https://doi.org/10.1089/jpm.2017.0548

[ii] https://www.capc.org/project-equity-improving-health-equity-for-people-with-serious-illness/equitable-access-to-quality-palliative-care-for-black-patients-a-national-scan-of-challenges-and-opportunities/