

November 18, 2020

Ms. Seema Verma
Administrator, Centers for Medicare and Medicaid Services
Hubert H. Humphrey Building
200 Independence Avenue, SW
Washington, DC 20201

Re: Request for Information: Recommended Measure Set for Medicaid-Funded Home and Community-Based Services

HCBSMeasuresRFI@cms.hhs.gov

Dear Administrator Verma,

On behalf of the Coalition to Transform Advanced Care (C-TAC), we appreciate the opportunity to provide comments on this request for information (RFI) in regard to its impact on those living with advanced illness.

C-TAC is a national non-partisan, not-for-profit organization dedicated to ensuring that all those living with advanced 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 composed of over 170+ 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 advanced illness in the U.S.

Below are our comments not to the specific RFI questions posed, but to categories where we have the most expertise and which will have the most impact for the advanced illness population.

Measure Set Purpose

First, we are in strong support of promoting the accessibility of home and community-based services (HCBS). They are important and needed for those living with advanced illness. Services at home or at community agencies, as opposed to health systems or hospitals, are what people living with advanced illness want and need to haveⁱ. These services also address the non-medical aspects of advanced illness that many struggle with, such as functional disabilities, transportation issues, social isolation, and food insecurity. By increasing access to these home or community-based services, many of the needs of those with advanced illness will be better met, and such services can keep them out of the emergency department (ED) or the hospital if consistently delivered and well-coordinated.

We also support ensuring the quality of these services. Those with advanced illness are a vulnerable population. We therefore support the effort to have a standard set of recommended quality measures for voluntary use by states, managed care organizations, and other entities engaged in the administration and/or delivery of HCBS. While we appreciate that such measures would initially be voluntary, we also recommend making them mandatory at the earliest opportunity so all participating in these programs can be assured of receiving quality care. Releasing the measures to the public, with the appropriate accompanying information for perspective, could also help clients and their families find the best quality services in their area. It should also promote competition among service providers to achieve the highest quality ratings.

Measure Set Organization

We do not have a strong point of view on the benefit of a base vs. extended set of measures although we recognize that the breadth of HCBS likely necessitates different measures for different situations. We would only suggest that the measure sets not be too complicated from an administrative standpoint. Health care providers already struggle with measure overload, and we would not want the same to burden home and community-based agencies who have even fewer resources to deal with administration. Of course, determining the sweet spot of the right measures for clients vs. the few for service providers is always challenging and we would recommend erring on the side of the client.

Measure Set Selection, Criteria, and Type

We support the inclusion of tested and validated measures since, especially if they become mandatory, that will be necessary for providers to use them with confidence. In terms of priority, we would focus on any measure that are patient, or client-reported, and measure outcomes rather than just processes. We recognize that such measures can be challenging for the advanced illness population as many are unable to self report due to cognitive and functional issues. Outcomes for them are ideally an improved current health state or quality of life as opposed to a future one given their limited prognosis. We would be happy to be a resource to work you CMS on identifying potential new measures that meet these criteria.

In addition to the measures already listed for the base and extended set, we would ask you to consider the inclusion of the following additional measures:

- Advance Care Plan -NQF #0326; CMS Quality ID #047- Advance care planning is a key activity for those with advanced illness, as identifying their goals and values should result in more personalized care plans. (For that reason, this measure should be included in *all* Medicare programs). Although this planning process is typically thought of as for future medical treatment, it is also appropriate for planning future living and quality of life options. Thus, it might better be termed “comprehensive care planning.” Therefore, we recommend it be included on the HCBS base measure set to encourage service providers to include the client in any service planning discussions and decisions.

- Timely and appropriate referral to hospice- HCBS working with those with advanced illness will have knowledge of their function, quality of life, and other key factors. As such, there may come a time when the transition to hospice should be considered. Ideally that would be well in advance of the end of life and transition to such care would be smooth. Adding a required measure about timely and appropriate referral to hospice could help ensure that hospice is considered and that the client's eligibility for hospice is evaluated and offered as early as would be appropriate. The existing NQF measure #457 (NQF 0216): Proportion Admitted to Hospice for less than 3 days- National Quality Strategy Domain: Effective Clinical Care, could be possibly used for this purpose.
- ED visits, hospitalization and hospital readmissions- The experience C-TAC and its members have had with more integrated medical and social models in the community is that such models can reduce unwanted or unnecessary medical utilization. Examples include home modifications to allow someone to age in place and reduce the risk of falling. Or ones that help care coordination with community-based medical and social services that can reduce readmissions. Including such measures in the HCBS could signal that unwanted/unnecessary hospital visits are unfortunate for clients and families who generally want to stay well enough to be at home.
- Healthy days in the communityⁱⁱ/days at home- Related to the above, an important factor in quality of life to the individual is how much time they spend at home and how healthy or less burdensome is their time there. Of course, we recognize that developing such a measure is challenging as many people with advanced illness actually do not use a facility in every year, some want to be in a facility as opposed to home, and there is the pressing need for housing and informal caregivers to provide care in that setting. We are aware that CMS is working on such a measure and we suggest it be considered for use here since it sums up the whole goal of HCBS: to keep people safely at home, and would be happy to work with CMS to figure the population and other aspects of this measure to make it helpful and viable.
- Family caregiver stress or burden- Since the focus of HCBS is to keep clients in the community, a measure that monitors how the family caregiver or caregivers, who usually provide the hands-on care to facilitate that, should also be considered. At present, they are only surveyed as part of the hospice CAHPS but that should be extended to non end-of-life care encounters. The VA also surveys family caregivers of those veterans with serious illness and this could be a model for a future Medicare caregiver survey instrument.ⁱⁱⁱ Additional related aspects to measure include the rate of spend-down, the loss of caregiver employment, and the reduction of retirement security for family caregivers as all are major impacts of caregiving.
- Experience of care and care transitions- Medicare program measures typically are tied to the performance of each provider. However, the measures that matter to patients and families are their experience across time, often across multiple providers. Therefore, transitions and care coordination matter, as does comprehensive care planning. In addition, we need built-in feedback loops to fuel improvement and a way to monitor overall system performance. For example, we

ask whether data relevant to patient status, preferences, and plans moves readily across providers, both into the HCBS entity and out of it to any next provider, and into and from simultaneous providers, for that matter. Again, C-TAC and its members would be happy to assist in identifying possible measures for these important aspects of care.

Population

While many of the measures shown in the possible standard and extended measure sets are appropriate for those living with advanced illness, there are functional measures where this population should be excluded. Improvement in function is usually not possible once someone develops an advanced illness and so any measures that penalize a service provider for not being able to improve function are not appropriate for this population. Instead, those measures should be modified to promote alternate goals such as slowing loss of function or optimizing whatever function the client still has.

Thank you for the opportunity to comment on this RFI. If you have any questions, please contact Dr. Marian Grant, Senior Regulatory Advisor, C-TAC, at 443-742-8872 or mgrant@thectac.org.

Sincerely,

Marian Grant

Marian Grant, DNP, CRNP, ACHPN, FPCN
Senior Regulatory Advisor
The Coalition to Transform Advanced Care (C-TAC)
900 16th Street, NW, Suite 400
Washington, DC, 20006

ⁱ Cite?

ⁱⁱ <https://www.cdc.gov/hrqol/pdfs/mhd.pdf>

ⁱⁱⁱ <https://www.healthaffairs.org/doi/full/10.1377/hlthaff.2019.00012>