June 3, 2019

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

Re: Medicare and Medicaid Programs; Patient Protection and Affordable Care Act; Interoperability and Patient Access for Medicare Advantage Organization and Medicaid Managed Care Plans, State Medicaid Agencies, CHIP Agencies and CHIP Managed Care Entities, Issuers of Qualified Health Plans in the Federally-facilitated Exchanges and Health Care Providers

Dear Ms. Verma,

On behalf of the Coalition to Transform Advanced Care (C-TAC), we appreciate the opportunity to provide comments on this proposed rule in regard to its effects 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 made up of over 140 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 advanced illness care in the U.S.

C-TAC’s definition of advanced illness is when one or more conditions becomes serious enough that general health and functioning begin to decline, treatment may no longer lead to preferred outcomes, and care oriented toward comfort may take precedence over attempts to cure – a process that extends to the end of life and that for some individuals and their families may lead to transition to hospice.

Overall, we are in support of this proposed rule and agree it provides opportunities to make patient data more useful and transferable through open, secure, standardized, and machine-readable formats while reducing restrictive burdens on healthcare providers. We have comments on the following sections:

Care Coordination Through Trusted Exchange Networks: Trust Exchange Network Requirements for MA Plans, Medicaid Managed Care Plans, CHIP Managed Care Entities,
and QHPs in the FFEs

Care coordination is very important for those with advanced illness, since currently their care is often fragmented and uncoordinated, and so we are in support of any means to improve that, such as promoting trusted exchange networks. We would point out that in addition to sharing key health information, these networks should also focus on capturing and sharing peoples’ goals and preferences and any advance directives and/or POLST documents they may have. The process we refer to is called “advance care planning” but is really comprehensive planning for matching “what matters” to the patient and family to services rendered and is not just about their wishes regarding emergency life-extending treatments. Such conversations/documents are currently difficult to access and not transferred across networks, which undermines people getting the care that they want or that is in line with their goals and values.

In addition, community-based organizations need to be included in such exchange networks so that they are aware and can contribute to information on referral, enrollment, and use of community services like home-delivered meals. As CMS focuses more and more on social determinants of health, such data exchanges with community services are key. We also recommend that CMS explore ways to assist community organizations to develop or upgrade information systems to become interoperable with health care ones to fully share important data.

Improving the Medicare-Medicaid Dually Eligible Experience by Increasing the Frequency of Federal-State Data Exchanges

The dual eligible population has many with advanced illness in it and so we are in favor of increasing the frequency of federal-state data exchanges. However, we know that this will require major changes for some states that may lack the resources to fully participate in such exchanges and this should be addressed in any final rule requirements.

Request for Stakeholder Input

You asked for public comment for consideration in future rulemaking on how CMS can achieve greater interoperability of federal-state data for dually eligible beneficiaries. We would again suggest that capturing and sharing advance care planning conversations and documents is a critical aspect of improving the care for this population. We also suggest that CMS find ways to link community-based organization into information exchanges since they play a vital role in supporting the dual eligible population. However, these organizations often lack information technology systems which are not linked to data systems with health care organizations Therefore, as noted above, we recommend that CMS explore ways to assist community organizations to develop or upgrade information systems to become interoperable with health care ones.

Revisions to the Conditions of Participation for Hospitals and Critical Access Hospitals

We are in support of these revisions as they will help care coordination for those with advanced illness who, unfortunately, have more frequent emergency department visits and hospitalizations. We appreciate that this proposed rule only requires these changes for those hospitals that already have systems to facilitate them. However, while that makes sense for the present, ultimately, all hospitals will need to do this to improve care
coordination.

**Advancing Interoperability in Innovative Models**

We are in support of using innovative CMS/CMMI models to not only test new care delivery and payment systems but also infrastructure ones like information technology. This may require that such models provide upfront investment to let participants secure the appropriate information systems to better track and coordinate care for the model.

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

Sincerely,

*Marian Grant*

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