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Society of Pain & Palliative  
Care Pharmacists  
(SPPCP)

Supportive Care Coalition  
(SCC)

March 8, 2021

Wilfred Agbenyikey, Sc.D., MPH  
P/PM Senior Level | COR III  
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Centers for Medicare & Medicaid Services  
Center for Clinical Standards & Quality  
QMVIG - Division of Quality Measurement  
7500 Security Boulevard. Woodlawn, MD 21244-1850  
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Project Officer's Email: wilfred.agbenyikey@cms.hhs.gov

Dear Dr. Agbenyikey:

The National Pediatric Palliative Care Task Force and our state coalition partners commend the Centers for Medicare and Medicaid Services (CMS) for funding the development of two patient-reported quality measures for palliative care services for patients age 18 years and older. As these two measures speak to the priorities of adults living with serious illness, they are relevant beyond palliative care to all clinicians who care for adults with serious illness. These measures were developed in a thorough, inclusive process led by the American Academy of Hospice and Palliative Medicine, the National Coalition for Hospice and Palliative Care, and RAND. We commit to disseminating these measures among our field.

We also encourage CMS to fund the conduct of a similar project for children, to develop pediatric patient-reported measures and caregiver proxy tools which assess how well pediatric palliative care clinicians deliver palliative care to children with serious illness and their families.

To ensure that these quality measures are meaningful to children and their families, we would recommend that the project:

- Engage children and adolescents with serious illness in developmentally appropriate ways, and their families, in the measure development process.
- Recognize the importance of family-centered care and define the family as the "unit of care."
- Create patient-reported proxy measures for children with serious illness, based on the age and developmental stage of the child.
- Create parent-reported proxy measures specific to the care of children with significant neurologic impairment.



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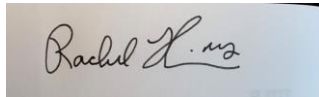
Supportive Care Coalition (SCC)

- Develop guidelines to assess and align parent-reported proxy and patient responses to the quality measure

As a multi-disciplinary Task Force composed of pediatric palliative care physicians, advanced care clinicians, social workers, chaplains, and family advocates, we along with our state coalition partners are committed to improving access to high-quality pediatric palliative care and are actively engaged in developing real-world solutions to address barriers to care. We would welcome the opportunity to advise or partner with CMS on opportunities to develop patient-reported measures and caregiver proxy tools for children and their families.

Thank you for your consideration of our comments. If you would like to discuss this issue in more detail with us and other experts within the Task Force, please contact Devon Dabbs, Project Director, National Pediatric Palliative Care Task Force at [devond@nationalcoalitionhpc.org](mailto:devond@nationalcoalitionhpc.org).

Sincerely,



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