

June 3, 2019

The Honorable Seema Verma
Administrator
Centers for Medicare & Medicaid Services
Department of Health and Human Services
200 Independence Avenue, SW
Washington, DC 20201

Re: CMS–9115–P; 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 Administrator Verma:

We are writing to comment on the proposed rule from the Centers for Medicare and Medicaid Services (CMS) on interoperability and patient access. As discussed in the proposed rule, we agree that Americans need to make informed health care decisions. We are also pleased that the proposed rule acknowledged the importance of providers and patients being engaged in shared decision-making. Yet, we remain concerned that shared decision-making remains an undefined concept within the agency and will require significant investment in improving providers' communication skills and ensuring that information and data are translated into high quality decision aids. To truly empower patients to "effectively manage their own health, care, and costs"¹ will require the agency to prioritize implementation of the National Quality Partners Playbook: Shared Decision-Making in Healthcare (Playbook).²

The availability of electronic health information to patients is a strong first step but is not sufficient to "support the health and wellness of individuals through informed shared decision-making."³ We are encouraged that the National Quality Forum achieved consensus from patients, providers and others through the development of the Playbook in defining standards for health care stakeholders to reference on how to achieve high quality shared decision-making. Moving forward, we hope that CMS will work with our organizations to advance shared decision-making fundamentals for healthcare organizations, establish a measurement framework for shared decision-making, and then implement the "Drivers of Change" outlined by the Playbook.

Many of our organizations signed a November 13, 2018 letter urging CMS to advance the Playbook's recommendations (see attached). While providing patient access to information is a

¹ 84 Fed. Reg. 42, page 7611

² http://www.qualityforum.org/Guidance_to_Improve_Shared_Decision_Making.aspx

³ 84 Fed. Reg. 42, page 7614

necessary prerequisite to shared decision-making, the partnership between patients and providers to translate information into improved health care decisions will require more than raw data. It requires specialized training to develop providers' person-centered communication capabilities, validation that patient decision aids meet the quality standards outlined in the Playbook and deference in coverage decisions to the outcome of a high quality shared decision-making process.

Therefore, we are writing to emphasize our support for CMS prioritizing the implementation of meaningful high-quality shared decision-making as a necessary next step to achieve an informed healthcare system that empowers patients to choose health care treatments and services that align with their values, preferences and priorities. We highly recommend the following four concrete next steps:

(1) CMS should reinforce importance of person-centered communication skills development among providers. As CMS strives to create a system in which “individuals can further facilitate communication with their care teams,”⁴ a vital missing link is ensuring that providers have particular communication competencies to learn what is most important to patients and make sure the plans they have for treatment are consistent with what people actually want. CMS could ask providers and health systems to report on how many of their staff have completed communications skills training modules and identify doing so as a component of demonstrating effective shared decision-making. A number of evidence-based clinician communication skills training platforms are readily available to support this objective.⁵ As identified by the Agency for Healthcare Resources and Quality (AHRQ), “Even though a clinician explains a diagnosis, test result, or treatment option to a patient, if the person walks away and does not understand the explanation, it has not been an effective communication.”⁶ Learning what is most important to patients and families helps providers know what the patient and family is actually hearing and understanding.⁷

In a series of recent consensus recommendations and reports, the National Academies of Sciences Engineering and Medicine (NASEM) has consistently called for all healthcare systems to prioritize communication skills training among all health care team members^{8 9}, as well as to improve communication among health care providers, individuals with behavioral health and mental health challenges, and family members.¹⁰ NASEM has also emphasized the role of care

⁴ 84 Fed. Reg. 42, page 7627

⁵ <https://communication-skills-pathfinder.org/>

⁶ <https://www.ahrq.gov/cahps/quality-improvement/improvement-guide/6-strategies-for-improving/communication/strategy6gtraining.html>

⁷ <http://nationalacademies.org/hmd/Reports/2017/integrating-the-patient-and-caregiver-voice-into-serious-illness-care-proceedings.aspx>

⁸ <http://nationalacademies.org/hmd/reports/2013/delivering-high-quality-cancer-care-charting-a-new-course-for-a-system-in-crisis.aspx>

⁹ <http://www.nationalacademies.org/hmd/Reports/2014/Dying-In-America-Improving-Quality-and-Honoring-Individual-Preferences-Near-the-End-of-Life.aspx>

¹⁰ <http://nationalacademies.org/hmd/Reports/2019/the-intersection-of-behavioral-health-mental-health-and-health-literacy.aspx>

teams in providing integrated palliative care that use skilled communication to elicit patient and family values, preferences and priorities as the standard of practice for high quality, value-based care delivery.^{11 12}

(2) CMS should work with stakeholders, including patient representatives, to establish appropriate standards for achieving high quality shared decision-making. CMS should identify, through the formal guidance process, the appropriate policy levers and accompanying standards for high-quality shared decision-making. Our organizations stand ready to work with CMS to identify the standards for high-quality shared decision-making in order to ensure that health systems are set up to succeed. First, by the end of 2019, the patient advocacy community will help convene CMS with the National Quality Forum (NQF) and other relevant stakeholders to review the NQF Playbook process and outline priorities for a guidance on shared decision-making. It is important to note that shared decision-making is a process that may or may not be informed by a patient decision aid, depending on the circumstances. Providers whose reimbursement may be impacted by incentives to conduct shared decision-making should have appropriate guidance from CMS, and patients should have assurances that shared decision-making will empower them, not overwhelm them or steer them to a payer-preferred treatment.

(3) CMS should work with stakeholders with expertise on shared decision-making and the patient advocacy community to identify a path forward for the certification of patient decision aids. The Playbook recognizes the value of advancing accreditation and certification opportunities. Patient decision aids are often useful tools to support a high quality shared decision-making process that involves effective patient-provider communication to identify and honor what is important to them. It is vital for patient decision aids referenced in shared decision-making to meet standards that will ensure that they improve health care decisions based on unbiased information related to a treatment's clinical effectiveness and implications for outcomes that are priorities for patients. There are several entities that could play a role in certification, including the NQF; the National Committee for Quality Assurance (NCQA) certification programs, which evaluate systems and processes that support data collection, surveys and quality improvement¹³; and the Patient-Centered Outcomes Research Institute (PCORI), which has currently funded 6 projects related to implementing shared decision-making¹⁴ as well palliative care communication¹⁵ skills development studies.^{15 16}

We are also aware that the Washington State Health Care authority has developed a patient decision aid certification process, informed by the International Patient Decision Aid Standards

¹¹ <http://nationalacademies.org/hmd/Reports/2016/Health-Literacy-and-Palliative-Care-Workshop-Summary.aspx>

¹² <http://nationalacademies.org/hmd/Activities/HealthServices/QualityCareforSeriousIllnessRoundtable.aspx>

¹³ <https://www.ncqa.org>

¹⁴ <https://www.pcori.org/research-results/topics/shared-decision-making>

¹⁵ <https://www.pcori.org/research-results/2014/improving-communication-between-patients-and-cancer-doctors-using-patient>

¹⁶ <https://www.pcori.org/news-release/pcori-board-approves-nearly-74-million-research-palliative-care>

Collaboration (IPDASC). The Playbook references the role of organizations that certify continuing education for clinicians as well as the inclusion of shared decision-making in the Hospice and Palliative Credentialing Center's (HPCC) test content for two of its certifications. With these existing efforts in mind, the Playbook calls for the basic step of making "available high-quality decision aids that meet the National Standards for the Certification of Patient Decision Aids" and intermediate step of engaging "patient and advisory family councils (PFACs) in planning at an organizational and program level, which could inform the selection of patient decision aids." We look forward to participating in a process to capture this existing expertise and develop consensus on a pathway for certification of patient decision aids.

(4) CMS should consider many common preference sensitive conditions as priorities for building communication skills among relevant providers and certification of decision aids for those conditions. There are common preference sensitive conditions where the patient's preference, after they are fully informed, should be the guiding principle for treatment choice. Preference sensitive conditions are those where the patient has more than one option for treatment choice and include several common conditions. By emphasizing communication skills development and certification of decision aids that promote a high-quality shared decision-making process for common conditions, CMS would be advancing shared decision making as a function of everyday clinical practice.

We stand ready to be your partners on the steps outlined by the Playbook, and look forward to working with you to achieve an informed and person-centered healthcare system. Please reach out to Sue Peschin (speschin@agingresearch.org) for additional information.

Sincerely,

Allergy & Asthma Network
Alliance for Aging Research
American Association on Health and Disability
Arthritis Foundation
Association of Black Cardiologists
Association of University Centers on Disabilities
Better Medicare Alliance
Brain Injury Association of America
Bridge the Gap - SYNGAP Education and Research Foundation
Cancer Support Community
Compassus
Cutaneous Lymphoma Foundation
David M. White
Depression and Bipolar Support Alliance
Dorney-Koppel Foundation
EBSCO Health
Genetic Alliance
Global Liver Institute

Headache and Migraine Policy Forum
HealthyWomen
Human Services Research Institute
Lakeshore Foundation
Lupus and Allied Diseases Association, Inc.
Mended Hearts
Mental Health America
Multiple Sclerosis Association of America
National Diabetes Volunteer Leadership Council
National Partnership for Women & Families
National Patient Advocate Foundation
National Transitions of Care Coalition
Partners for Better Care
Partners Healthcare
Partnership to Improve Patient Care
Prevent Cancer Foundation
Preventive Cardiovascular Nurses Association
PXE International
RetireSafe
The American Urological Association
The Davis Phinney Foundation
The Medicare Rights Center
Us TOO International Prostate Cancer Education & Support