

November 13, 2018

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

Kate Goodrich, M.D.
Director, Center for Clinical Standards & Quality
Centers for Medicare & Medicaid Services
Department of Health and Human Services
7500 Security Boulevard
Baltimore, MD 21244

Dear Administrator Verma and Dr. Goodrich:

The undersigned organizations are writing to urge the Centers for Medicare and Medicaid Services (CMS) to establish clear guidance implementing the program to facilitate shared decision-making that is called for in statute.¹ We are encouraged that the National Quality Partners Playbook: Shared Decision-Making in Healthcare (Playbook) has published defining standards for health care stakeholders to reference on how to achieve high quality shared decision-making. Yet, we are concerned that Medicare policies are increasingly referencing shared decision-making without regulations indicating that it meets the standards referenced by the National Quality Forum's (NQF) work on shared decision-making and patient decision aids. 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.

We strongly support high quality shared decision making and the use of patient decision aids that meet national standards. We acknowledge great strides in the development and use of shared decision making between patients and providers. However, we are concerned that in many circumstances, the process of shared decision making has not yet evolved to a level of what would be considered "high quality." Unfortunately, the systemic lack of capacity for high quality shared decision making can pose a barrier to care or it could be simply a "check the box" activity. We share the goals presented in the statute calling for CMS to establish standards for shared decision making that provides patients and providers with information about trade-offs among treatment options and facilitates the incorporation of patient preferences and values into the medical plan. It is imperative that standards be accompanied by meaningful investments in building the capacity for high quality shared decision-making, such as eliminating barriers to use of telehealth, so that it is not a perceived burden on the health system.

Consistent with the statute, the NQF developed multi-stakeholder guidance on national standards and proposed a sustainable process for the certification of patient decision aids.² In addition, NQF initiated the development and use of performance measures that can assess the quality of shared decision making. For example, NQF has endorsed a process measure for shared decision-making (NQF #2962), which we view as a step in the right direction, though it has limitations and we look forward to advancing more robust measures.³ Additionally, development of the Playbook was a

¹ Patient Protection and Affordable Care Act. Section 936 [42 u. S. C. 299b-36] and titled- program to facilitate shared decisionmaking. 2010. Available from: <http://www.gpo.gov/fdsys/pkg/PLAW-111publ148/pdf/PLAW-111publ148.pdf>. 2010.

² National Quality Forum, National Standards for the Certification of Patient Decision Aids, Final Report, Dec. 15, 2016 at http://www.qualityforum.org/Projects/c-d/Decision_Aids/Final_Report.aspx

³ National Quality Partners Action Brief, Shared Decision Making: A Standard of Care for All Patients, October, 2017 at https://www.qualityforum.org/NQP/Shared_Decision_Making_Action_Brief.aspx

consensus-based process of convening of patients, providers, health systems, industry and researchers to identify best practices, as well as barriers and solutions, for the following fundamentals to guide shared decision-making in healthcare organizations:

- Promote leadership and culture;
- Enhance patient education and engagement;
- Provide healthcare team knowledge and training;
- Take concrete actions for implementation;
- Track, monitor, and report;
- Establish accountability for organizations, clinicians and patients.

We know from the Playbook and from experience that shared decision making is not always embraced by health system leaders, it is not well understood by patients (especially those with low health literacy), providers and clinicians are not necessarily trained for it, workflows are not designed to accommodate it, and it is often perceived as burden on providers. We strongly support the “Drivers of Change” as recommended in the Playbook for federal entities, accreditation agencies, patient advocacy organizations, payers and partners in quality improvement to create an environment in which healthcare organizations can implement innovative shared decision-making strategies and maximize the impact for all patients, families, caregivers and clinicians. We agree with the Playbook’s recommendation that CMS and private payers should consider payment models to reimburse for shared decision-making, beginning with preference sensitive conditions and expanding into other areas. It is important to recognize that the Playbook does not recommend shared decision making as a condition of coverage, which has the strong potential to steer patients away from improved health decisions in circumstances where the barriers to high quality shared decision have not been resolved, especially for populations already experiencing disparities in care.

We appreciate the efforts of policymakers to advance shared decision making by making it an indication of clinical practice improvement and referencing it as a goal of alternative payment models. We support the development and implementation of quality measures, patient-reported outcome measures and performance measures that could indicate where shared decision making is successful achieving the NQF’s recommendations for a process of communication in which clinicians and patients work together to make optimal healthcare decisions that align with what matters most to patients. As an example, the statute authorizing the Medicare Health Care Quality Demonstration⁴ encouraged shared decision making between providers and patients, yet their evaluations do not review the extent to which shared decision-making occurred,⁵ likely because it remains an undefined concept by CMS. Similarly, it is not clear what standards providers must meet for shared decision making to be a “clinical practice improvement” under MIPS so that the description of risks and benefits are not subject to bias.

Therefore, we urge CMS to actively collaborate with the National Quality Forum, engaged stakeholders in the development of the Playbook, and other stakeholders representing patients with preference-sensitive conditions to advance shared decision-making fundamentals for healthcare organizations, establish a measurement framework for shared decision-making, and implement the “Drivers of Change” outlined by the Playbook. We stand ready to be your partners on the steps outlined by the Playbook — developing policies that incentivize shared decision making by paying for it, advancing high quality decision aids in clinical practice, supporting policy approaches to make

⁴ [42 U.S.C. 1395cc-3](#)

⁵ [CMS Medicare Health Quality Demonstration](#) at <https://innovation.cms.gov/initiatives/Medicare-Health-Care-Quality/>

shared decision making the standard for informed consent, and accelerating accreditation and certification opportunities.

If you have any questions regarding this letter, please contact Sue Peschin, President and CEO, Alliance for Aging Research, at 202-688-1246 or speschin@agingresearch.org. Thank you for your consideration.

Sincerely,

Allergy & Asthma Network
Alliance for Aging Research
American Association on Health and Disability
American Cancer Society Cancer Action Network
American Medical Women's Association
American Urological Association
Arthritis Foundation
Association of University Centers on Disabilities
Better Medicare Alliance
Brain Injury Association of America
Cancer Support Community
CancerCare
Compassus
Cutaneous Lymphoma Foundation
Depression and Bipolar Support Alliance
Health Hats
HealthyWomen
Heart Valve Voice U.S.
Hydrocephalus Association
International Foundation for Autoimmune & Autoinflammatory Arthritis
Lakeshore Foundation
Lupus and Allied Diseases Association
LymeDisease.org
Mended Hearts
Mental Health America
Multiple Sclerosis Association of America
National Alliance for Caregiving
National Hispanic Medical Association.
National Kidney Foundation
National Minority Quality Forum
National Partnership for Women & Families
National Patient Advocate Foundation
National Transitions of Care Coalition
Partners Healthcare
Partnership to Improve Patient Care
Preventive Cardiovascular Nurses Association
Rehabilitation & Technology Consultants, LLC

The diaTribe Foundation
The National Multiple Sclerosis Society
United Spinal Association
University of Texas MD Anderson Cancer Center
Yale School of Medicine