

June 25, 2018

The Honorable Alex Azar  
Secretary  
U.S. Department of Health and Human Services  
Hubert H. Humphrey Building  
200 Independence Avenue SW  
Washington, D.C. 20201

Ms. Seema Verma  
Administrator, Centers for Medicare & Medicaid Services  
U.S. Department of Health and Human Services  
200 Independence Avenue, SW  
Washington, D.C. 20201

**Re: Fiscal Year (FY) 2019 Medicare Hospital Inpatient Prospective Payment System (IPPS) and Long Term Acute Care Hospital (LTCH) Prospective Payment System Proposed Rule, and Request for Information [CMS-1694-P]**

Dear Secretary Azar and Administrator Verma,

The undersigned organizations are members of the consumer community committed to ensuring that new models of care delivery and payment provide the comprehensive, coordinated, patient- and family-centered care patients<sup>1</sup> want and need while helping to drive down costs.

As consumer advocates, we are heartened by the intent of the proposed policies to create a patient-centered health care system that promotes greater price transparency, interoperability and overall value. We agree that giving people easy, meaningful access to cost, quality and clinical information is critical to achieving a transformed health care system. However, it is not enough to make information available: people want help understanding it, and want to discuss and make decisions about health and wellness in partnership with their care team. Consumers want to work together with providers to assess treatment options, compare providers and evaluate outcomes and experiences that matter to them. Efforts to transform our health care system must also prioritize patient experience and strategies for meaningful engagement, which includes shared decision-making informed by individuals' goals, life circumstances and desired outcomes.

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<sup>1</sup> For brevity, we refer in various places in our comments to "patient" and "care," given that many federal programs and initiatives are rooted in the medical model. Any effort to improve patient and family engagement must include the use of terminology that also resonates with the numerous consumer perspectives not adequately reflected by medical model terminology. For example, people with disabilities frequently refer to themselves as "consumers" or merely "persons" (rather than patients). Similarly, the health care community uses the terminology "caregivers" and "care plans," while the independent living movement may refer to "peer support" and "integrated person-centered planning."

We offer the following comments on CMS’s proposals and requests for information so that relevant policies and practices will be finalized with consumer needs and priorities at the forefront.

- **Meaningful Measures in Hospital Quality Reporting and Value Programs**

The Medicare hospital quality reporting and payment programs are a critical component in advancing our shared goals of value-based payment and improved care delivery. These programs have unique yet complementary objectives to ultimately achieve the goals of the National Quality Strategy through increased transparency and the promotion of payment that rewards quality care rather than volume. We are concerned that proposals to remove measures as a way to reduce duplication and reporting burden will compromise the availability of performance information for public use.

In particular, we believe that all measures related to patient safety must be publicly available in a format that is usable by patients, families, employers and the public at large. We strongly urge CMS to not withhold or curtail public information on deadly infection rates and rates of accidents and injuries in American hospitals by removing these critical measures from the IQR or the QRP. Once a measure is removed from the IQR, there is no guarantee that the information will be reported in an accessible way for public use, or reported with the same level of granularity. Patients and families deserve full transparency of safety and quality measures. We also urge CMS not to remove safety measures from the Value Based Purchasing (VBP) Program. Any assessment of hospital quality must include patient safety and account for adverse events. Furthermore, no hospital should be rewarded for excellence in the VBP Program if they have a high rate of preventable infections.

Finally, as CMS considers the criteria for measure removal in these programs, we are concerned by the lack of guardrails in place to ensure that consumer priorities are reflected in the calculation of a measure’s “value” (the proposed eighth criteria). Focusing on cost alone does not reflect the potential for assessing or improving domains of care quality that are important to patients and families. For example, some aspects of care quality require continuous monitoring because they are essential to high-quality patient care or have serious consequences if done poorly (e.g., patient safety, patient experience).

- **Promoting Interoperability Program (*Formerly Meaningful Use*)**

Overall, we support the focus on health information exchange and patient electronic access in the reconstituted Promoting Interoperability Program (PIP). However, *providing* information access is not enough. A 2014 national survey<sup>2</sup> on health information technology and patient engagement and ongoing technical assistance work has revealed a compelling expectation among women and families for a dialogue with providers — a partnership, rather than one-directional access.

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<sup>2</sup> National Partnership for Women & Families, *Engaging Patients and Families: How Consumers Value and Use Health IT*, p. 29 (Dec. 2014), available at <http://www.nationalpartnership.org/research-library/health-care/HIT/engaging-patients-and-families.pdf>.

We are dismayed, therefore, that CMS is proposing to eliminate complementary patient engagement measures that encourage patients and family caregivers to use online access (*View / Download / Transmit*), communicate electronically with providers (*Secure Messaging*) and contribute information to their medical record that is specific and material to their care (*Patient Generated Health Data*). Not only will these changes limit the impact of the Provide Patients Electronic Access to Their Health Information measure, but they will also limit the program’s effectiveness in promoting meaningful improvements in interoperability.

Without these measures, providers have little incentive to do anything but “turn on” data access, rather than actively inform patients and caregivers about what information is available and how it could be beneficial. Data from the 2017 Health Information National Trends Survey indicate that individuals who were offered *and encouraged* by their health care provider to use their online medical record were nearly twice as likely to access it as those who were offered but not encouraged.<sup>3</sup> We urge CMS to reinstate these measures of active patient engagement to encourage hospitals to establish workflows to electronically share information with patients and integrate critical patient-generated data into their medical records, thereby promoting interoperability and patient-centered care.

We strongly support the requirement to transition to the 2015 Edition of CEHRT, which enables critical functionalities that are foundational to a patient- and family-centered health care system, including application programming interfaces (APIs) for consumer access, more robust demographic data collection and information on social determinants of health. Collecting and using this information not only has clinical relevance, but also is vital for improving health outcomes and enhancing health equity. We encourage CMS to develop corresponding measures encouraging providers to use these and other person-centered functionalities enabled in the 2015 CEHRT, such as care plans and links to community resources and supports, in future performance years of the PIP.

- **Request for Information: Supporting Greater Price Transparency**

We believe greater access to information helps consumers engage in their care in meaningful ways and we are encouraged by CMS’s focus on greater transparency. However, a truly empowering approach to price transparency does not leave people to make high-stakes health care decisions on their own, but equips them with the information they need to make shared decisions about their care together with their care team.

We support requiring hospitals to disclose standard charges in a more useful manner to patients, and believe this information will help consumers understand the magnitude of costs for different services and compare hospitals accordingly. Since these charges are not reflective of what consumers ultimately pay, however, patients and families also deserve individualized estimates of out-of-pocket costs in advance of services, including information on deductibles, co-insurance and copayments. In addition, cost information

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<sup>3</sup> Patel, V., & Johnson, C. (2018, April). Individuals’ use of online medical records and technology for health needs. Office of the National Coordinator for Health Information Technology. ONC Data Brief 40. Retrieved June 2018, from <https://www.healthit.gov/sites/default/files/page/2018-03/HINTS-2017-Consumer-Data-Brief-3.21.18.pdf>

should be supplemented with data on provider quality and health outcomes to prevent their conflation, as consumers may be led to believe that higher prices are indicative of better quality care. We agree that CMS should assess hospital compliance and publicize those hospitals that fail to publicly post and annually update standard charges in a user-friendly format online.

Lastly, we encourage CMS to be mindful of unintended consequences in future efforts to promote price transparency. The Federal Trade Commission has expressed concern that there is significant risk that competing providers could use price transparency in an anticompetitive manner, to the detriment of consumers.<sup>4</sup> In addition, without the integration of quality information alongside costs, price transparency initiatives could exacerbate longstanding health disparities, particularly if low-income groups sacrifice higher quality for lower prices. The need for thoughtful design of price transparency tools is vital.

- **Request for Information: Positive Solutions to Achieve Better Interoperability:** We support the goal of achieving widespread electronic exchange of health information across the health care spectrum. We believe that data is a shared resource, rather than a competitive asset, and that information needed to optimally care for the patient needs to be available to those who care for the patient - including the patient herself. We appreciate that this Administration is committed to bold action to advance interoperability and support efforts to keep pushing to enable patients and their providers to seamlessly access and share their digital health information.

## **Conclusion**

Thank you for the opportunity to comment on the proposed changes to the Inpatient Prospective Payment System and provide input on various efforts to improve interoperability and price transparency. We look forward to working with HHS to enhance the quality of care, bolster meaningful engagement and improve health outcomes. If you have any thoughts or questions about these comments, please contact Erin Mackay at (202) 986-2600 or [emackay@nationalpartnership.org](mailto:emackay@nationalpartnership.org).

Sincerely,

American Association on Health and Disability  
Asian & Pacific Islander American Health Forum  
Caregiver Action Network  
Caring From a Distance  
Consumers' Checkbook/Center for the Study of Services  
Engaging Policy  
Healthwise

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<sup>4</sup> Leo, M., Feinstein, D., & LaFontaine, F. (2015, June). Letter to The Honorable Joe Hoppe and The Honorable Melissa Hortman, Minnesota House of Representatives, Re: Amendments to the Minnesota Government Data Practices Act Regarding Health Care Contract Data. Retrieved June 2018, from [https://www.ftc.gov/system/files/documents/advocacy\\_documents/ftc-staff-comment-regarding-amendments-minnesota-government-data-practices-act-regarding-health-care/150702minnhealthcare.pdf](https://www.ftc.gov/system/files/documents/advocacy_documents/ftc-staff-comment-regarding-amendments-minnesota-government-data-practices-act-regarding-health-care/150702minnhealthcare.pdf)

Institute for Patient- and Family-Centered Care  
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National Partnership for Women & Families  
The Empowered Patient Coalition/[EngagedPatients.org](http://EngagedPatients.org)