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

*Re: Medicare Program; Hospital Inpatient Prospective Payment Systems for Acute Care Hospitals and the Long Term Care Hospital Prospective Payment System, etc. [CMS-1694-P]*

Dear Administrator Verma:

I am writing on behalf of the Society for Participatory Medicine (SPM) to respond to the above-referenced FY19 IPPS Proposed Rule and Request for Information [CMS-1694-P], a Notice of Proposed Rulemaking ("NPRM").

SPM is a unique, non-profit, membership group, advocating for a mission of shifting networked patients from being mere passengers to being responsible drivers of their health, with providers who encourage and value them as full partners. Our members include patients, patient advocates, clinicians, caregivers and a wide variety of others involved in health care personally and professionally.

Our comments and recommendations focus on the sections of the NPRM dealing with patient access to their health information. In a recent speech to the HIMSS health care technology meeting, White House senior advisor Jared Kushner called for a "technological health care revolution centered on patients." That call echoes SPM's founding principles, and our comments should be seen within the context of our long and deep commitment to this goal.

Our specific comments are as follows:

**Proposed Changes to the Medicare and Medicaid EHR Incentive Programs (now referred to as the Medicare and Medicaid Promoting Interoperability Programs): CMS is proposing that beginning with the EHR reporting period in CY2019, the 2015 Edition of Certified Electronic Health Record Technology (CEHRT) will be required.**

**SPM Comments:** We strongly support requiring the 2015 CEHRT edition for the CY2019 reporting period. We agree, as the rule puts it, that this will "support increased patient access to their health information through email transmission" and, through improved interoperability, provide "patients more

control of their health data to inform the decisions that they make regarding their health.” Providing this type of access, helping patients participate as full partners in their care, has been a central goal of SPM since its formation in support of a new breed of “e-patient;” i.e., individuals “equipped, enabled empowered and engaged in their health care” as informed consumers.

Moreover, it is important to note that no significant labor will be required from providers to implement the new functionalities required, making this change fully compliant with the administration’s commitment to “patients over paperwork.” We also believe CMS should work with the Office of the National Coordinator for Health Information Technology (ONC) to ensure that future editions of CEHRT require portals that allow patients to enter their email address, a secure Direct protocol messaging address and an approved third-party app, both to receive their patient data and automatically receive any additional data whenever the provider EHR receives it. In addition, patients will benefit if CMS and ONC ensure that as soon as possible U.S. Core Data for Interoperability (USCDI) capture more of the patient’s full health care record at any given facility, as required by HIPAA, which can then be linked to Application Programming Interfaces (APIs) such as FHIR, enabling even greater functionality.

### **Renaming the “Provide Patient Access Measure” the “Provide Patients Electronic Access to Their Health Information Measure” and modifying the requirements.**

**SPM Comments:** Under this measure, a patient or his/her representative would be provided timely access to view online, download, and transmit health information. In addition, the eligible hospital or critical access hospital (CAH) would have to ensure that the patient’s health information is available to access using any application configured to meet the technical specifications of the API. We support this change, with its emphasis on electronic access to health information, and also support the increased weighting proposed for this measure in 2019 and 2020.

At the same time, we have a number of concerns. Different federal agencies are encouraging consumers to access and use their electronic health information, but definitions of the information to be made available vary significantly among them. CMS and other federal agencies should use a consistent vocabulary with regard to patient access to health information. We strongly urge use of language that meets the consumer-centered standard put forth in the NPRM: information “to inform the decisions that [people] make regarding their health.” This definition should be comprehensive, including clinician notes and mental health information. CMS has the opportunity to ensure that patients receive a standardized, consumer-centric and comprehensive electronic health care record that also accommodates the needs of clinicians for providing and coordinating care. A medical record that meets that test should supersede the current cherry-picking of data requirements.

The NPRM uses the term “timely access.” We believe that should be defined as “within 24 hours” and a “reasonable fee” for such electronic information should be defined as “free.” A number of our members work at or interface with institutions that have met this test. With electronic health records (EHRs) now common, this definition of timely addresses the important problem of medical ignorance that patients and loved ones face today, as you have eloquently spoken about in regard to your husband’s unexpected hospitalization. This once more puts “patients over paperwork,” not from the federal bureaucracy but from the unnecessary bureaucracy still common in too many hospitals.

### **Eliminating four CEHRT measures**

**SPM Comments:** We oppose the proposal to eliminate these four measures: Patient-Specific Education; Secure Messaging; View, Download or Transmit; and Patient-Generated Health Data. Eliminating these measures directly contradicts a CMS goal repeatedly emphasized in the NPRM; i.e.,

striving “to put patients first by ensuring they, along with their clinicians, are empowered to make decisions about their own health care using data-driven insights.” Dropping these requirements does not improve the data-driven insights available to patients; rather, it diminishes them.

The problems cited in the NPPRM with these measures that allegedly show them not aligning with current program goals seem as if they could be readily remedied, and they do not seem, as claimed, to detract from provider innovations in the use of CEHRT. Based on our members’ experiences, we do not believe the evidence supports them being “burdensome to health care providers.”

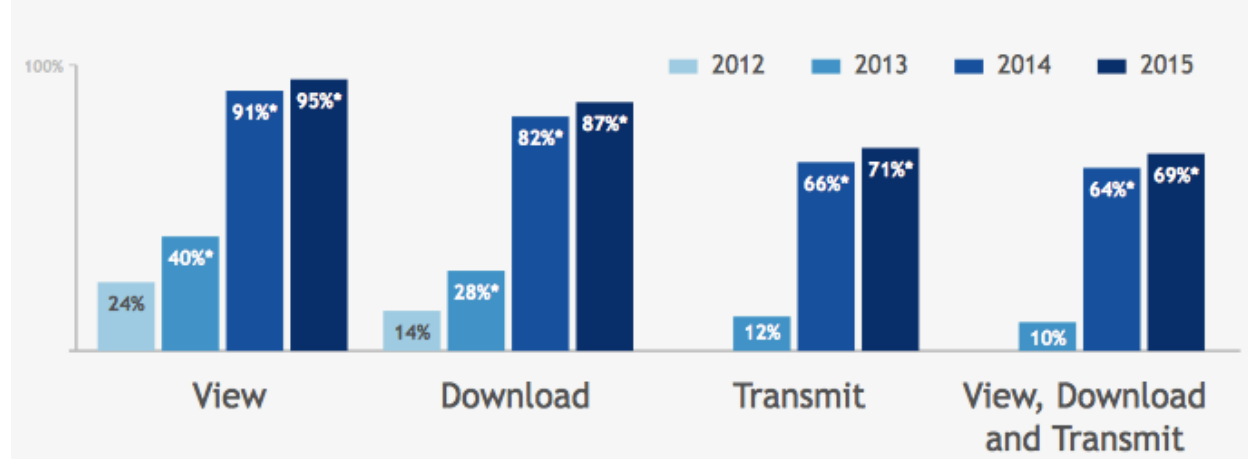
Indeed, we believe the evidence supports not only retaining these measures, but strengthening the requirements. Existing Meaningful Use requirements stipulate that an eligible organization must attest to the use of view, download, or transmit functionalities by just one patient in electronically accessing their health data. We propose that the requirement be increased to 10% of an eligible organization’s patient population, for the following reasons:

- Patient access to both technology and health data has grown dramatically
- Healthcare providers report patient platform usage rates as high as 85%
- Patients follow doctor recommendations related to digital health
- Engaged patients are critical for the success of value-based payment models
- Patient/consumer use of digital health tools boosts the economy overall

While the “one patient” requirement may have provided a comfortable onramp to online patient engagement some few years ago, today’s environment justifies a more robust requirement. Although 10% is a very conservative required threshold, it still signals providers that CMS is serious about its patient access aspirations and the need for tangible results. In support of this comment and proposed change, we would like to point out that patient access to both technology and health data has grown exponentially in recent years.

In parallel, thanks to the HITECH Act and Meaningful Use requirements, the ability of providers to give patients access to data has grown significantly and achieved near universal levels, particularly in hospitals. According to ONC (as illustrated below), the percent of hospitals enabling patients to electronically view, download and transmit their health information grew almost 7-fold between 2013 and 2015.<sup>1</sup>

Figure 1: Percent of non-federal acute care hospitals that provide patients with the capability to electronically view, download, and transmit their health information, 2012-2015



Moreover, there is a demand for this information. Almost 30% of Americans were offered access to their online medical record and viewed it at least once within the past year<sup>1</sup>. Kaiser Permanente, a pioneer in patient portal use, reports that more than half of its 9 million members are active users of its My Health Manager service, and more than 70% of eligible members have registered to use it.<sup>2</sup>

Surpassing those levels, Healthvana, a platform company that links patients and clinicians at numerous healthcare clinics and systems, reports that 85% of patients log in to take action, for example by checking test results.<sup>3</sup> With examples of usage rates as high as these, a 10% patient usage requirement should be fairly easily achievable.

In addition, if we want to evolve health behaviors to encourage people to take advantage of digital health, we will get there faster if trusted healthcare providers such as doctors and nurses play an explicit role. Building a measurable threshold into “meaningful use” requirements essentially forces healthcare organizations to recognize that they play a role in shaping health behaviors, and harnesses their power to influence public behaviors. According to ONC, among patients who accessed their records online in 2017, 63% were specifically encouraged by their healthcare provider to do so.<sup>4</sup> That represents significant progress, but we are not yet ready to effectively retire this standard.

Finally, engaged patients are critical to the success of the value-based payment models central to the effort to curb costs and improve outcomes. Given that factors outside of the traditional health care system account for 90% of health outcomes, consumers should be encouraged to act as partners in their health and health care. Digital tools, often enabled by online portals, are an important component.

Researchers at the University of California-San Francisco, University of Washington and Kaiser Permanente followed nearly 18,000 patients with diabetes for five years and found those who requested statin refills exclusively via the patient portal decreased medication non-adherence by 6%. In addition, patients who used the Internet-based portals decreased their risk of high cholesterol levels by 6%.<sup>5</sup>

Finally, patient access to digital health data also provides direct and indirect benefits, some of which are economic. The “transmit” capability, especially as enabled by the integration of APIs, unleashes new opportunities for economic investment and growth. In the last seven or eight years, corresponding with growing access by patients to their health data, digital health investments by both VCs and members of the Fortune 50 have grown. According to Rock Health, in the digital health category, total venture capital funding, size of deals and number of deals have increased dramatically.

In addition, consumer-facing companies such as Apple, Google and Amazon that had not previously invested in the healthcare space are now doing so—a trend that will only accelerate if the government continues to support the flow of health data to and through consumers through programs such as MyHealthEData. Our proposed revision of “meaningful use” patient data access requirements to a 10% participation threshold is a natural extension of this ambitious work already underway.

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<sup>1</sup> <https://www.healthit.gov/sites/default/files/page/2018-04/HINTS-2017-Consumer-Data-Brief-april-2018.pdf>

<sup>2</sup> <http://www.healthcareitnews.com/news/patient-portals-prove-prowess-kaiser> and <https://www.healthaffairs.org/doi/10.1377/hblog20160407.054362/full/>

<sup>3</sup> <https://healthvana.com>

<sup>4</sup> <https://www.healthit.gov/sites/default/files/page/2018-04/HINTS-2017-Consumer-Data-Brief-april-2018.pdf>

<sup>5</sup> <http://www.healthcareitnews.com/news/patient-portals-prove-prowess-kaiser>

**Stakeholder feedback regarding new or revised CoPs/CfCs/RfPs for interoperability and electronic exchange of health information.**

**SPM Comments:** We strongly support the targeted use of Conditions of Participation, Conditions for Coverage and Requests for Proposals as indispensable tools to ensure a patient's or resident's (or his or her caregiver's or representative's) right and ability to electronically access his or her health information without undue burden and "routinely receive relevant electronic health information." Although we realize this RFI focuses on hospitals, we support plans to spread this initiative across the continuum. Importantly, the history of health information technology adoption by providers, hospitals did not adopt electronic health records in a widespread manner until the financial incentives of the HITECH Act came into play. That history makes it clear that the influence CMS exerts through CoPs/CfCs and RfPs will play a crucial role in ensuring implementation of that vision that timely and affordable patient access to a complete electronic medical record, across the continuum of care becomes a reality. In response to CMS's specific questions about how to operationalize the desired goals in CoPs, we would suggest using our comments in this document as guidance in strengthening the requirements of 42 CFR 482.24 in regard to medical records services and 42 CFR 483.13 in regard to patients' rights

**To fully understand all of these health IT interoperability issues, initiatives, and innovations through the lens of its regulatory authority, CMS invites members of the public to submit their ideas on how best to accomplish the goal of fully interoperable health IT and EHR systems for Medicare- and Medicaid-participating providers and suppliers, as well as how best to further contribute to and advance the MyHealthEData initiative for patients.**

**SPM Comments:** As a membership organization built upon patients, clinicians and other stakeholders dedicated to listening to each other as partners pursuing a common goal, we respectfully suggest that CMS cannot engage the public as a partner in the MyHealthEData initiative through a Federal Register invitation. Instead, we believe the agency needs a two-pronged approach. First, it should maximize the power of existing programs. Second, it should practice targeted outreach.

We suggest that CMS adopt a consumer-centered definition of timely access to a comprehensive electronic health information, per our comments earlier. The goal should be that the information crucial to allowing an individual to partner with their clinician to maintain and improve health and well-being is as easily available electronically to the scared 80-year-old widow or widower with a high-school education in rural Indiana, along with her family or caregivers, as it is to the married informatics professor at the Regenstrief Institute in Indianapolis who just turned 65. While some hospitals will always express concerns, the overwhelming "real-world evidence" (to use a phrase from the 21<sup>st</sup> Century Cures Act) is that the potential of the MyHealthEData initiative, with its benefits for every member of the public, can be accomplished without any burden on hospitals.

Maximizing the power of existing programs starts with explicitly endorsing the conclusion that reliable and easy access to the full electronic medical record across the continuum of care is central to patients expressing their values and preferences in the 21<sup>st</sup> century. This should be central to all federal value-based care programs. So, for example, this access would be part of the accountable care organization regulations, Medicare Advantage and select bundled payment programs, such as the oncology care model. Meanwhile, CMS should practice outreach to consumers through roundtables and a "listening tour" with various consumer partner groups. That outreach, however, could start within current programs, such as the patient and family advisory groups that are part of the Partnership for Patients. The key is to infuse that access through, for instance, opening up the clinical notes in the ambulatory and hospital setting, as a valuable part of all "value-based" programs.

Research to date shows that the Open Notes project has improved doctor-patient communication and the confidence of patients in managing their care, whether in tests in the Department of Veterans Affairs (VA), with patients mostly age 60 and older who did not graduate from college,<sup>6</sup> or more broadly.<sup>7</sup> This type of result, to re-emphasize, is precisely what CMS has said in this NPRM that it wants to accomplish with “data-driven insights.”

The proposed consumer-friendly communication of charges (which we support) can only achieve its potential impact with full and consumer-friendly communication including full transparency about the clinical context about the medical service to which those charges apply.

SPM would be happy to expand upon our comments, based on our members’ experiences and research in this area.

If you or your staff wish to discuss any of these comments further, please do not hesitate to contact me.

Sincerely,

A handwritten signature in black ink, appearing to read 'DZS', is positioned below the text 'Sincerely,'.

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<sup>6</sup> Nazi KM, Turvey CL, Klein DM et al. VA Open Notes: exploring the experiences of early patient adopters with access to clinical notes. *J Am Med Inform Assoc.* 2015;22:380-89. [doi:10.1136/amiainl-2014-003144](https://doi.org/10.1136/amiainl-2014-003144)

<sup>7</sup> Wolf JL, Darer JD, Berger A et al. Inviting patients and care partners to read doctors’ notes: OpenNotes and shared access to electronic medical records. *J Am Med Inform Assoc.* 2017;24: e166-72. [doi.org/10.1093/jamia/ocw108](https://doi.org/10.1093/jamia/ocw108)