Society for Participatory Medicine

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Marilyn Tavenner, Administrator
Centers for Medicare & Medicaid Services
Department of Health and Human Services
Room 445–G
Hubert H. Humphrey Building
200 Independence Avenue SW
Washington, DC 20201

Re: Medicare and Medicaid Programs; Electronic Health Record Incentive Program—Stage 2
(Docket ID CMS-2012-0222)

Dear Ms. Tavenner:

The Society for Participatory Medicine applauds the work done to date in focusing on patient engagement in the proposed Stage 2 Meaningful Use regulations and the proposed Health IT Standards regulations. It is our hope that the final requirements will be even stronger and more focused in this regard than the current drafts.

As set forth in greater detail below, we have a number of comments that we believe will improve the regulations and their use as a lever to improve patient experience, patient engagement, patient care and, ultimately, patient outcomes.

We would like to highlight two in particular:

> We favor improving the likelihood that patients will access their data by allowing for some **automation of the process of accessing and downloading patient data**, using existing technologies that protect patient privacy and security.
>
> We also favor **immediate patient access to information** in the patient's electronic health record - unless the patient has elected otherwise.

The overarching principle with respect to patient access to electronic health record data running through the entire meaningful use regulation and the health IT standards regulation should be:

"Nothing about me without me."[1]

The Society for Participatory Medicine has individual and institutional members nationwide and has a governing board comprised of both clinicians and patients. It was founded to study and promote participatory medicine, which we define as being centered on networked patients shifting from being mere passengers to responsible drivers of their health, and providers who encourage and value them as full partners. For further background on the Society and its activities, we invite you to see the Society's website (http://participatorymedicine.org), its online journal, The Journal of Participatory Medicine (http://jopm.org) and its blog, e-patients.net (http://e-patients.net).

On behalf of its patient, provider and advocate members, the Society proposes adjusting the draft regulations in a number of specific ways, in order to bring clinicians and patients closer together, to promote greater patient engagement and to achieve greater patient-centeredness, which are keystones of the federal government's health care policies.

42 CFR § 495.6(d)(12)(i) and (ii); 495.6(j)(10)(i) and (ii) – "Provide patients the ability to view online, download, and transmit their health information within four business days of the information being available to EPs."

The four-day delay for patients' access to their own information is arbitrary and limits the ability of patients' advocates and consultants to support the patient. Information should be available to the patient and patents' designees as soon as it is available to any clinical user of the CEHRT other than the author of the information itself. A patient should have the ability to waive the right of access; a provider should not have the right to limit it.

42 CFR § 495.6(f)(12)(ii)(B)"More than 50 percent of all patients who are discharged from the inpatient or emergency department (POS 21 or 23) of an eligible hospital or CAH have their information online within 36 hours of discharge."

Patients who visit the emergency department and are discharged are often told to follow up with their primary care physician within 24-48 hours. As per our comment on the four business day rule, information should be accessible online to the patient and the patient's agent as soon as it is available online to any provider with access to the Certified Electronic Health Record Technology (CEHRT).

With respect to both the four-day and 36-hour proposed rules: In order to assure continuity of care and reduce the incidence of readmissions, the delays allowed under the proposed rules must be eliminated. Earlier access is technologically feasible, and there are other forces at work in the health care economy motivating providers to finalize these records accurately and completely as soon as possible. Once the records exist and are available to other clinicians via the CEHRT, there is no reason why an engaged patient should not have the ability to access them as well.

42 CFR § 495.6(j)(10)(ii)(B) – "More than 10 percent of all unique patients seen by the EP … (or their authorized representatives) view, download or transmit to a third party their health information."

Based on current use rates of PHRs, it seems that the proposed 10% threshold for patient engagement via PHR portals will not be easily attainable. The government is in a position to mandate or recommend pathways to

[1] Valerie Billingham, Through the Patient's Eyes, Salzburg Seminar, Session 356, 1998

improve the usability of patient portals, thereby easing the ability of eligible providers to meet a higher threshold of patient engagement under this measure. For example, the CEHRT can improve the usability of patient portals and messaging systems by improving the quality and timeliness of the information. In particular, it is counterproductive to expect patients to monitor patient portals or secure email inboxes as a manual intermediary between the CEHRT and online services able to act as the patient's agent. CEHRT portals can incorporate systems such as OAuth standard technology for patient-initiated, secure, limited and automated access to the CEHRT portal. With convenient secure access for patient advocates and on-line services, usability would improve, and meeting the 10% threshold will be made easier. It will also be more likely that a higher threshold would be readily achievable under Stage 3 rules.

42 CFR § 495.6(j)(17) – Objective: Use secure messaging to communicate with patients on relevant health information. Measure: A secure message was sent using the electronic messaging function of Certified EHR Technology by more than 10 percent of unique patients seen during the EHR reporting period.

We suggest that this include explicitly both provider to patient messaging and patient to provider messaging. Secure messaging may engage the healthcare provider with feedback that will improve the care plan for an individual patient and the healthcare system as a whole.

* * *

In closing, we would like to stress the importance of making the data available to patients in a way that would also enable the patient's automated agents to access the data on their behalf, therefore making it much more likely that more patients would access EHR data online. The manual steps required in many PHR environments are in part responsible for the limited adoption of these potentially valuable tools. It is also worth noting that security and privacy are significantly enhanced using a separate access path (such as OAuth) for the patient's automated agents so that the patient is not forced to share his or her password with the agent.

Most important, however, is making sure that those patients who want their data as soon as it is available in the EHR (i.e., with no delay) have that option. In order for that to happen, the regulation should be revised to provide that the only permissible delay is that requested by the patient. This is technically feasible, and we believe it is the only way that engaged patients can participate in finding errors in their records and seek timely help from advocates and second opinions in situations where we all need it most.

Thank you for the opportunity to share our perspective. Should you or your staff require any additional information, please do not hesitate to contact us.

Sincerely,

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