

Nothing About Me Without Me - Participatory Medicine, Meaningful Use, and the American Hospital Association

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Meaningful Use Stage 2 regulations were released in March by CMS and ONC. Over the past month or so, I've been working with other members of the Society for Participatory Medicine (thank you, all) to prepare comments on these regulations from the patient perspective. Last Friday, we filed two comment letters on the proposed regulations. One [letter to the ONC on Meaningful Use Stage 2](#), and one [letter to CMS on Meaningful Use Stage 2](#). Each letter opens like this:

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 in the attached letter, 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.”

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.

Comments are being accepted through Monday May 7, 2012.

I invite you to read the Society for Participatory Medicine press release, **Participatory Medicine Society Urges Quick Patient Access to Medical Information**, outlining the Society's stance on the issue, and the recent posts on the Society's blog, e-patients.net, explicating the **SPM Meaningful Use Stage 2 comment letters** a little further, and putting them in context -- in particular, juxtaposing them against the **American Hospital Association comments** calling for a 30-day delay in patient access to information once it's in their EHRs. (The proposed rule calls for up to 36-hour and 4-business-day delays, depending on context, and the SPM comments call for immediate access.) Technologically literate commentators, including **Fred Trotter**, take issue with the AHA's view that 30 days are needed to respond to a request for an EHR. (Fred's post says a lot more -- check it out.)

Finally, take a few moments to consider Regina Holliday's comments on the proposed rules, filed in the form of a slideshow featuring her paintings:

Long Stories: The Story Of Meaningful Use and Why the patient voice matters..

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