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Participatory Medicine Society Urges Quick Patient Access to Medical Information:

"Nothing About Me Without Me" is Key Principle, Group Says

BOSTON – The [Society for Participatory Medicine](#), a group representing both clinicians and patients, urged key federal agencies to revise their proposed rules on electronic health records, saying that patients should have immediate access to medical information as soon as it is put into those electronic records.

The Society also expressed support for efforts by Society member Regina Holliday to [protest](#) an American Hospital Association proposal for a 30-day waiting period before patients can access that information.

"Patient engagement is the cornerstone of a successful, cost effective, and high-quality health care system," said Daniel Z. Sands, MD, the Society's president and a practicing internist. "Those goals cannot be achieved unless we give patients access to their own health information and encourage them to use it."

The Office of the National Coordinator for Health Information Technology (ONC) and the Centers for Medicare & Medicaid Services (CMS) are seeking comment on regulations defining what actions hospitals must take in order to qualify for federal payments to encourage adoption of electronic health records. Those criteria, known as "meaningful use," are meant to ensure that subsidies for health information technology help promote higher quality and more affordable care.

The first stage of Meaningful Use goals went into effect in April, 2011. Public feedback is now being sought on Stage 2 goals, including a set of measures related to patient engagement, that are expected to be implemented in 2013.

Sands praised the ONC and CMS for their commitment to engaging patients. The Society, meanwhile, emphasized in its comments that "the overarching principle with respect to patient access to electronic health record data...should be: 'Nothing about me, without me.'"

"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," the Society wrote in formal comments to the government. "We also favor immediate patient access to information in the patient's electronic health record - unless the patient has elected otherwise."

Strengthening the proposed regulations can “improve patient experience, patient engagement, patient care and, ultimately, patient outcomes,” the Society added. (Full comments are [available through this link](#) to the Society’s website.)

The American Hospital Association, in its comments, asked that hospitals be given 30 days after a patient is discharged to make available electronic medical record information to patients. In response, Society member Regina Holliday, an artist and patient advocate, has organized a demonstration to be held Sunday afternoon, May 6, in Washington, D.C., to coincide with the AHA’s annual meeting.

Although Society members who work in hospitals appreciate the concerns that led to the AHA’s stance, the Society supports this effort to persuade them to change it.

The Society for Participatory Medicine has individual and institutional members nationwide and a governing board comprised of both clinicians and patients. It studies and promotes participatory medicine, which it defines as networked patients shifting from being mere passengers to being responsible drivers of their health, along with providers who encourage and value them as full partners.

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