

**SOCIETY FOR PARTICIPATORY MEDICINE**  
**COMMENTS ON ONC FEDERAL HEALTH IT STRATEGIC PLAN**  
**May 2, 2011**

posted as a comment on

<http://www.healthit.gov/buzz-blog/from-the-onc-desk/hit-strat-plan/>

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I am writing as Chair of the Public Policy Committee of the Society for Participatory Medicine. The Society represents individual and institutional members nationwide including patients, non-professional caregivers, and clinicians. It was founded to study and promote participatory medicine, which is centered around 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 tenets, we invite you to peruse 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>).

Our comments focus on Goal IV of the Federal HIT Strategic Plan - "Empower Individuals with Health IT to Improve Their Health and the Health Care System." This Goal breaks down into three Objectives, and a number of Strategies to achieve each Objective. The Goal and Objectives are laudable, but we would seek to strengthen the Strategies -- by involving patients in the development of the system -- so as to increase the likelihood of achieving the Goal in a meaningful way, and to do so sooner than five years from now.

One overarching comment on this Goal is that it is not integrated with the concept of care coordination, which is discussed elsewhere in the strategic plan. In order to fully realize the goal of patient centeredness, the patient must be involved in the coordination of his or her care. This omission highlights the perspective of the ONC on health care as something that is provided to patients rather than as a partnership process that involves patients, clinicians and non-professional caregivers. The patient-centeredness criteria promoted as part of the proposed rule on Accountable Care Organizations should be incorporated into the Strategies used to achieve this Goal. While these criteria are not all health IT-specific, the ONC makes the point in the strategic plan that that health IT enables patient empowerment, transparency, and achievement of the Triple Aim. Thus, all process, systems and standards improvements called for in the patient centeredness portion of the ACO rule should be brought to bear on the health IT strategic plan.

Objective IV.A: Engage Individuals with Health IT.

Strategy IV.A.1: Listen to individuals and implement health IT policies and programs to meet their interests.

Comment: We applaud ONC's willingness to participate informally in online public dialogue, but we would like to see greater transparency to this informal communication so that each conversation is not known only to members of a particular group. We would also like to see ONC crowdsourcing suggestions of additional forums in which to participate, and documenting these interactions in a central online public repository. The Society would welcome the opportunity to participate in the more formal mechanisms for public input (i.e., the federal advisory committees, and their subcommittees and workgroups). We believe that the voice of the patient could be better heard, and individuals more effectively engaged, if there were a patient advisory council established to advise the ONC on further development and implementation of the strategic plan, rather than limiting patient input to a seat on a subcommittee or workgroup. The Society would welcome the opportunity to participate in such an advisory council as well.

Strategy IV.A.2: Communicate with individuals openly and spread messages through existing communication networks and dialogues.

Comment: We would encourage ONC to pursue its strategy of communicating through existing networks and social media. We further recommend that ONC work with the Society to initiate annual, national and perhaps regional patient-oriented symposia or conferences on patient-oriented health IT to share developments and seek input on what is working and not working from a patient perspective.

The existing forms of communication with patients, and even inventories of resources for patients, are disappointing. For an eloquent comment on how this is so, please see Regina Holliday's recent blog post entitled "One of Us. One of Us." at <http://reginaholliday.blogspot.com/2011/04/one-of-us-one-of-us.html> (4/22/2011). It is a compelling explication of a recent allegorical painting of hers. A brief excerpt follows:

I went to the [HHS Health IT meaningful use] site and at the top of the page you can click on a large link field with a picture of a stethoscope labeled Information for Providers or you can click on a field with two faceless Caucasian avatars labeled "Information for Consumers". On the provider side you will learn about the importance of accurate patient data, the power of CPOE and CDS and the money saved by implementation. You will see that CMS has incentives tied to implementation. You will see the ONC is available to help you. You will find out about REC's, HIE's and Beacon Communities. There are 22 active links on this page that will lead you to hundreds of other links that will explain the legislation and process more fully.

But if you hit that faceless link for Consumers you will see two Paragraphs. The first is a very brief overview of the power of EHR's to improve medicine. It has one active link to a dead end pdf explaining EHR's more in depth. The next Paragraph is about Privacy. If you hit that link it will lead you to a page entitled, "Privacy and Security." This page

contains 20 links to various white papers and pdf's about privacy in relation to the EHR.

Has comparing two links on HHS page ever made you cry? It made me cry. It made me cry to see so little was expected of patients. On those pages it seems as though we are only consumers worried about privacy and security and little else. It seemed our research paths are one way communication only and not open to discourse.

Objective IV.B: Accelerate individual and caregiver access to their electronic health information in a format they can use and reuse.

Strategy IV.B.1: Through Medicare and Medicaid EHR Incentive Programs, encourage providers to give patients access to their health information in an electronic format.

Comment: Mere access is not sufficient. It must be linked with education of patients and providers regarding the value that may be created by active sharing of information, so that information is not simply provided in a printed or electronic visit summary. It is critical to link clinical information to diet, exercise and other lifestyle and behavior choices made by patients between visits to their health care providers, and to resources patients can access in making healthy choices. In addition, clinical summaries should contain references to online information and communities that the provider can recommend to the patient as being most reliable and relevant to his or her condition. Finally, there should be greater standardization across visit summary formats (think: nutrition label on packaged food) so that patients may have reasonable expectations about what information they will receive from providers, and so that they may readily absorb information presented in these records.

Strategy IV.B.2: Through federal agencies that deliver or pay for health care, act as a model for sharing information with individuals and make available tools to do so.

Comment: The Direct Project and Blue Button projects have demonstrated the ease with which information may be transferred, but they are not conduits for secure messaging or structured records. Patients need the ability to access structured data and share it with other providers, regardless of network affiliations, and with family members, friends or other caregivers. Easy access to data in the ways that make the most sense to patients is critical, and input from a patient advisory board would allow ONC to better focus government investment in the right tools.

Strategy IV.B.3: Establish public policies that foster individual and caregiver access to their health information while protecting privacy and security.

Comment: ONC should promote easy sharing of patient health care data (including claims data) with patient-oriented computer and smartphone applications ("apps"). This sharing and aggregating of data will allow for analysis of data in new and potentially useful ways.

Objective IV.C: Integrate patient-generated health information and consumer health IT with clinical applications to support patient-centered care.

Strategy IV.C.1: Support the development of standards and tools that make EHR technology capable of interacting with consumer health IT and build these requirements for the use of standards and tools into EHR certification.

Comment: OCR should shy away from reinventing the wheel when seeking to systematize standards for interoperability and data integration. The perfect is the enemy of the good, and pursuing development of new standards (a la PCAST) rather than building upon existing standards and protocols may unnecessarily delay achievement of the goals of the ONC Health IT Strategic Plan, to the detriment of patient care and patient centeredness in the meantime. (Without endorsing a particular standard, the Society notes that the Continua Alliance has developed one, and seems to have achieved a critical mass of device and communications systems constituents.)

Strategy IV.C.2: Solicit and integrate patient-generated health information into EHRs and quality measurements.

Comment: Every patient encounter already starts with patient-generated insights. ONC should seek to leverage health IT to implement real-time two-way communication between patients and care teams. Patient insights, together with data generated by monitors (the two types of patient-generated information identified in the strategic plan), must be integrated in to the clinical information workflow. I am the leading expert on my own health, and the information that I provide should not be discounted or distrusted merely because I am not a clinician.

Strategy IV.C.3: Encourage the use of consumer health IT to move toward patient-centered care.

Comment: ONC should promote certification of apps based on their utility in managing care as demonstrated through research, so that apps that work to improve quality and reduce cost may be provided to patients by their providers or insurers at no additional out-of-pocket expense. Identifying resources and removing price barriers in this manner is the health IT equivalent to making primary care available without copayments, as promoted by the Affordable Care Act. This is another sort of investment that should be encouraged by ONC which may be expected to yield significant returns in terms of improved care, efficiency and population health outcomes.