

Roundtable Discussion

The Healthcare IT Puzzle: Something Is Missing ...“Oh yes, *the patient!*”

Putting the patient at the center of health care is a desirable yet “radical” goal that remains elusive, even in the wake of the transformative power of electronic tools and the Internet.

Health care is stalled in a culture based on treating disease rather than promoting health of the *whole* patient; reim-

bursement paradigms limit how providers can expand their relationship with patients beyond prescriptions and procedures and make it difficult for holistic care to be delivered.

To probe ways in which patients might become the nucleus of health care, with their concerns and require-

ments adequately captured in their personal health records, the nonprofit Institute of Federal Health Care convened a roundtable discussion that included participants from federal agencies, congressional staff, patient-advocacy organizations, provider groups and technology firms and organizations.

Roundtable participants agreed that the personal health record is the main tool for bringing about cultural transformation — and it should truly be a tool, not just a data repository. It should tell the patient’s health story across time, and should be structured to encompass all factors that patients see as affecting their health status, not just the physical ones.

It would be a lost opportunity to use new technology to shore up the current disease centered system of care. A “whole shift” in workflow design is needed, roundtable participants agreed. Medical schools need to incorporate patient centered care into their curricula.

A Cultural Challenge

Effecting a cultural transformation that puts the patient at the center of health care will not be easy, roundtable participants agreed. The current system is based on the convenience of the clinician, not of the patient. And, patients themselves may be reluctant to engage in crafting a personalized health plan unless they see an immediate need to do so.

“We must create living, working models that show how things can be

Recommendations from the discussion ...

- **“We need to shift from a problem-based disease care system to putting the patient at the center, with optimal health as the outcome.”** Such a seismic cultural transformation last occurred with the 1910 Flexner Report that changed medical education — and is long overdue. **“We need a complete redesign of the system,”** in which the “empowered patient” meets the “receptive health care team.”
- **Transparency is essential.** There should be “symmetry” of information, with the patient knowing everything that his/her medical team does. **“You knew that and didn’t tell me”** — these are words the patient never should have to utter.
- **Financial barriers are daunting and must be addressed.** Providers must be able to engage patients in care of the *whole* person and receive compensation for doing so. Patients need transparency in financial information, so they know how much they are paying for their care. **“Patients should have a way to track medical costs. This is a major issue of choice.”**
- **Standardization and interoperability are essential.** **“We are surrounded by things that capture information, and it’s a tragedy that we can’t bring it all together.”**
- **The “empowered” patient care community should be tapped to provide advice and support about living with disease.**
- **Patients should be accountable as well as empowered.** **“The challenge is to incentivize people to focus on health care even when they are feeling well.”** Unless patients are willing to use their personal health data, **“it is not much good.”**
- **Patient-centered care should be anchored in mobile devices such as smart phones that patients can take to their physicians’ offices.** **“We need to keep things simple. Everything that succeeded on the Internet did so because it was simple.”**
- **Patient centered care involves a team of coaches — not all of them physicians — in sync with one another on behalf of the patient.**

done differently,” one participant urged. The data and tools needed to craft personalized health plans exist, but they need to be standardized and coordinated. The starting point for creating such a plan should be the patient’s own health goals and wishes.

Laying A Foundation

While there is much to be accomplished, incremental improvements are taking place. Examples:

- ◆ Efforts within the Department of Health and Human Services aimed at achieving “meaningful use” of electronic records should help in addressing the *whole* patient through such requirements as giving patients access to their health information, connecting that information to education resources to help put it into context, providing a followup summary of each patient visit (50% to 80% of what a patient hears during a visit is forgotten shortly afterward), and sending reminders for followup care.

- ◆ The Veterans Affairs Department has established an Office of Patient Centered Care and Cultural Transformation with the daunting task of shifting the culture of the entire VA health care system — from problem-based disease care to patient-centered care, with optimal health as the outcome.

Four centers of innovation are being established to develop ways to improve outcomes and to increase the cost-efficiency of the system, and to determine how new tools and practices can be incorporated throughout the VA. These centers could be models for the entire nation, it was noted.

- ◆ Kaiser-Permanente makes use of the electronic record to allow its physicians to spend 30 minutes per patient and is engaged in record-sharing

with VA medical centers in several locations.

- ◆ In New Zealand, the Lifetime Health Diary provides relevant information on Maori patients in a one-page format that can show trends over time. Information is “pre-loaded” by allied personnel in partnership with the patient, so the physician can gain an immediate picture of the patient’s health. The information is owned by the patient.

- ◆ The Agency for Healthcare Research and Quality (AHRQ) is developing a registry of patient registries to support research that can benefit multiple stakeholders and reduce duplication of effort.

- ◆ Authorized in the Patient Protection and Affordable Health Care Act, a Patient-Centered Outcomes Research Institute (PCORI) is being established as a nonprofit corporation that can help physicians, patients, purchasers and policymakers in making informed decisions about health care by providing evidence on the effectiveness of various treatments and services in subpopulation groups. Such groups would encompass racial and ethnic minorities, age groups, women, and individuals with various comorbidities and genetic and molecular subtypes.

Other Pilot Programs

- ◆ *The Daily Plan.* Initially pilot tested at five facilities, this VA program is designed to enhance patient safety by involving them in their care. Patients are given a single document that describes what can be expected on a specific day of hospitalization. It currently is being implemented throughout the VA system.

- ◆ *Accountable Care Organizations.* Authorized under the Patient Protec-

tion and Affordable Health Care Act, ACOs are networks of clinicians and hospitals that share responsibility for providing care to patients. Such networks just are being formed, with the program scheduled for launch in January 2012.

“We should squeeze HHS for regulations that mandate care coordination,” one participant urged.

- ◆ *The Direct Project.* Under the policy aegis of the Office of the National Coordinator at HHS, this project specifies a secure, standards-based way to send authenticated, encrypted health information directly to trusted recipients over the Internet.

Patients and physicians need to work as partners, the group said, and must wield the persistent passion to bring about massive cultural change.

Participants in this roundtable: Dan Blum of TATRC; Basit Chaudhry of IBM Research; E-Patient Dave deBronkart; Alexandra Drane of Eliza Corporation; Dolores Dunn of the House Committee on Veterans Affairs; Rick Erdtmann of the Institute of Medicine; Ted Eytan of Kaiser-Permanente; J. Michael Fitzmaurice of AHRQ; Tracy Gaudet of the Veterans Affairs Department; Eric Hilleman of the Senate Committee on Veterans Affairs; Regina Holiday; Hamish MacDonald of the Lifetime Health Diary; Saralyn Mark of NASA; Kim Nazi of the Veterans Affairs Department; Lygeia Ricciardi of the Office of the National Coordinator at HHS; Mark Scrimshire of HealthCamp Foundation; Joshua Seidman of the Office of the National Coordinator at HHS; Ted Smith of the Office of the National Coordinator at HHS; Mary Anne Sterling of HIMSS; Amy Tenderich of DiabetesMine; Daniel Tietz of the New York State Department of Health AIDS Institute; Kate Tipping of the Office of Policy and Planning at HHS; Tom Velez of Computer Technology Associates, Inc.

The roundtable was moderated by Stanley Pappelbaum of Professional Health Technologies. IFHC Managing Director is Nancy Tomich (www.fedhealthinst.org).