Obtaining Quality Healthcare through Patient and Caregiver Engagement

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By Vera Rulon, MS, RHIT, FAHIMA

At AHIMA's National Convention Angela Kennedy, EdD, MBA, RHIA, shared a story about her adopted daughter's diagnosis of cystic fibrosis, and the difficulty Kennedy faced in getting her daughter's medical history. Kennedy's story made it clear: Without this essential health information, patient empowerment is nearly impossible. It's like asking someone to build a house without the benefit of blueprints.

Public Good: It's Personal

The concept of health records as the foundation for patient empowerment was made even more personal by Dave deBronkhart, author and co-founder of the Society for Participatory Medicine who is also known as "ePatient Dave." In an article in *iHealthBeat*, deBronkhart provided examples of how a lack of access or access to incorrect information in medical records could have dire consequences.

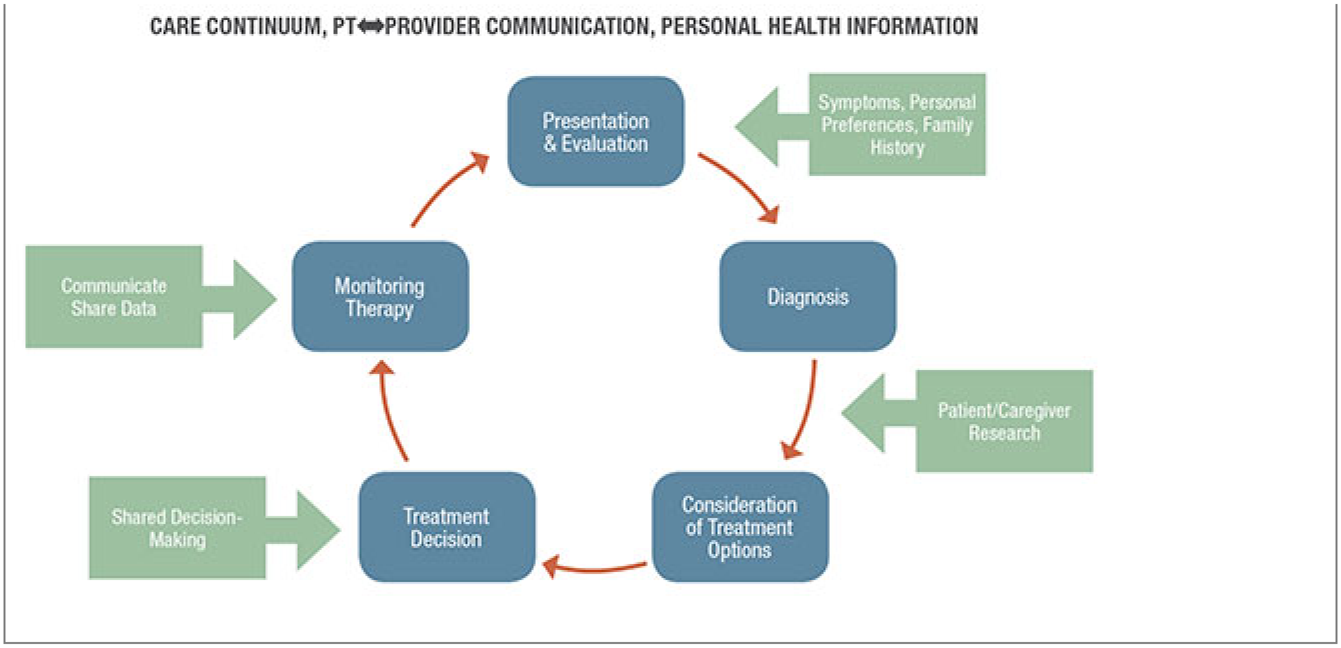
In the *iHealthBeat* article "Patient Participation: Let Patients Help with Medical Record Quality, Completeness," deBronkhart wrote:[1]

- "When my mother was discharged to rehab two years ago, her hypothyroid came across to the new system as hyper. The best clinician in the world, reading that information, would have correctly caused a disaster."
- "I talked earlier this year with a nurse who was involved in the death of a patient because of a fact missing from the chart, and just last week I heard about a case where 'rule out' was omitted when a chart was transcribed—'rule out afib' came across as 'afib.'"

These stories are personal, but not rare. Health information management (HIM) professionals can help solve these issues starting with an understanding of how access to information can empower patients.

The Patient Journey

This table demonstrates patient input along their healthcare journey.



Patient Journey: Engagement and Shared Decision-Making

Information is power, and good communication is a prerequisite to truly sharing the power of decision-making. Shared decision-making is an integrative process between a patient and clinician that:[2]

- Engages the patient throughout the process of decisionmaking
- Provides the patient with balanced information about treatment options
- Incorporates patient preferences and values into the medical/treatment plan

The following examines each step in the patient journey through the lens of the patient’s contribution to health information.

Family and medical history: Knowledge of family medical history by patients and caregivers can help patients and their medical teams assess the risks of various diseases. Digital technologies can help keep personal and family health information up-to-date and track it quickly and seamlessly.

Diagnosis: When patients do their own research online, they come prepared to ask questions of their physicians. The power of questions is most prominent in the diagnosis process and in helping both the doctor and patient assess options.

Decisions on treatment: Providers can share options in real time through digital technologies. More importantly, by understanding patient preferences, shared decision-making is improved by providing access to medical information in real time.

Monitoring and maintenance: Deploying mobile technologies may help patients and caregivers monitor health status, maintain adherence to medical treatments, and share their data with their healthcare team. This part of the journey lends itself to the support of patient communities.

Health information technology (HIT) can enable the healthcare journey and informs patients. The article “Informing and Involving Patients to Improve the Quality of Medical Decisions” published in *Health Affairs* describes how HIT can help patients access the right information at the right time and assist them in making medical decisions. An example in the article from Massachusetts General Hospital is when providers enter a new problem list item for a patient an icon is generated indicating that a decision aid is available. The decision aids, which include educational booklets, DVDs, or interactive tools, help make treatment choices and can be prescribed by the physician and sent directly to the patient.

According to the article, HIT also enables the collection and storage of information regarding patient priorities and preferences. In context of the starkest example of a medical error—operating on the wrong patient—the authors argue that it is equally bad to operate on an informed individual who was given a voice in the decision to have surgery and would have chosen not to have the surgery. The authors state that “the ‘right’ patients for surgery are the ones who are clinically appropriate and who made an informed choice that surgery is the best way to treat their condition.” Healthcare professionals must ensure that every patient is fully informed and involved in making every important decision about their healthcare.

The Evidence: Patient Engagement Improves Quality of Care

Evidence demonstrates that patients can improve the quality of their health records. An example is the Open Notes project launched in 2010. Patients at several hospitals were given access to physician notes through secure patient portals. While physicians were initially concerned about misinterpretation and the potential time expenditure of explaining health record entries, at the “end of the experimental period, 99 percent of patients wanted Open Notes to continue and no doctor elected to stop.”[3]

Another pilot at Geisinger Health System gauged patients’ ability to improve the accuracy of their health records. Patients were given access to their medication lists and were asked to provide feedback. Pharmacists accepted 68 of 121 updates that were submitted by patients—a 56 percent acceptance rate. Also, access allowed patients to add information, such as their use of over-the-counter medication and supplements. In some instances this revealed potential adverse events or errors. For example, one patient had started taking B-12 vitamins post-surgery and had reported this on the form during the study. A provider noted that the patient was already receiving B-12 injections, preventing an overdose.

Taking Action: Implications on Information Governance and Research

Patient and caregiver engagement also means that there is more data being collected, including data gained through novel, intensely personal channels such as “wearable” electronic monitoring devices and sensors. This poses both challenges and opportunities for HIM leadership in the areas of information governance (IG) and research.

Personal information should be incorporated into the patient’s medical record for a complete picture. Standards on how information is collected and classified will be critical to ensure interoperability, access, and usability of health information by providers, patients, and researchers.

The security of personal information is paramount. The Food and Drug Administration (FDA) recently issued the formal guidance for the management of cybersecurity in medical devices. This guidance recommends that manufacturers consider security risks in the development of their devices and include these measures in their FDA submissions.

Research is a very important aspect of information governance and AHIMA’s “public good” strategic efforts. Clinical trials are moving towards more mobile solutions to collecting data and including the patient voice in the design of protocols. The Patient Centered Outcomes Research Institute (PCORI), established as an element of the Affordable Care Act, has set its mission to help inform healthcare decisions and improve healthcare delivery and outcomes. PCORI’s position comes from research guided by patients, caregivers, and the broader healthcare community.[4]

PCORI’s three goals impacting IG are:

- Substantially increase the quantity, quality, and timeliness of useful, trustworthy information in support of health decisions
- Speed the use of patient-centered outcomes research evidence
- Influence clinical and healthcare research to be more patient-centered

Patient-centered systems must be built on trust, especially in this new age of information sharing. As AHIMA’s Information Governance Principles for Healthcare state, organizations “regardless of their roles in healthcare must earn the confidence of patients and society through a firm commitment to ethical and responsible handling of personal health information.”[5] HIM professionals must ensure that trust is both earned and sustained with patients and caregivers.

Making a Difference: The HIM Connection

The aim of AHIMA’s public good strategic pillar is to empower “consumers to optimize their health through management of their personal health information.” One patient who has taken charge of her health is Tracy Okubo, who wrote about her experience with personal health records in a *Health IT Buzz* blog post. Diagnosed with lupus at an early age, Okubo’s family discovered that her medical records had been lost up until age 15. Given the difficulty managing a complex condition like lupus, she took charge of her health via a personal health record and is managing her condition through her personal health information.[6] Tracy leverages her iPhone to track her personal health record which allows her to record details from her doctors visits. She also uses her health plan's patient portal where she accesses personal health information such as lab results, medication lists, and connects with her doctors.

HIM professionals must remember to put patients and caregivers first. After all, HIM professionals also walk in these shoes as parents, friends, individuals, and community members. Remembering this can help keep the patient voice as an HIM professional's North Star, even as the world of information management and communication undergoes its most profound revolution in history.

Notes

[1] Bronkart, Dave. "Patient Participation: Let Patients Help with Medical Record Quality, Completeness" *iHealthBeat*. September 26, 2013. www.ihealthbeat.org/perspectives/2013/patient-participation-in-the-medical-record-let-patients-help-with-quality-completeness.

[2] Charles, C., A. Gafni, and E. Whelan. "Shared Decision-Making in the Medical Encounter: What Does It Mean? (Or, It Takes at Least Two to Tango)." *Social Science and Medicine* 44, no. 5 (March 1997): 681-692.

[3] Delbanco, Tom et al. "Inviting Patients to Read Their Doctors' Notes." *Annals of Internal Medicine* 157, no. 7 (2012): 461-470. http://annals.org/article.aspx?articleid=1363511.

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[5] AHIMA. "Information Governance Principles for Healthcare (IGPHC)." 2014. www.ahima.org/~/media/AHIMA/Files/HIM-Trends/IG_Principles.ashx.

[6] Okubo, Tracy. "Managing My Personal Health Record: My Story of Living with Lupus." *Health IT Buzz*. September 26, 2013. www.healthit.gov/buzz-blog/electronic-health-and-medical-records/managing-personal-health-record-story-living-lupus/.

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