

# Preparing for Patient-Generated Documents: Initiatives Call for Incorporating Patient-Generated Data in the EHR

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An engaged patient more effectively communicates with providers, participates in decision-making, manages their own care, and complies with healthcare regimens. "Ensuring that each person and family are engaged as partners in their care" is one of the priorities of the National Quality Strategy, and patient engagement has been cited by the Nursing Alliance for Quality Care as the cornerstone of patient safety and quality.

The promise of patient engagement to improve health outcomes and lower cost of care is strong. Health IT strategist Leonard Kish coined the phrase "patient engagement is the blockbuster drug of the century;" the expression has since been popularized by many in the healthcare industry, including National Coordinator of Health IT Farzad Mostashari.

The Centers for Medicare and Medicaid Services' (CMS) "meaningful use" EHR Incentive Program regulations, along with Office of the National Coordinator for Health IT (ONC) EHR Standards and Certification Criteria regulations, roll out patient engagement in incremental steps. The National eHealth Collaborative has also disseminated a Patient Engagement Framework 2012 initiative that aligns with these incremental steps.<sup>1</sup>

Patient engagement for stage 1 meaningful use is focused on sharing information with patients such as clinical summaries and educational resources through patient portals. With stage 2 meaningful use, the concept of patient-generated health data (PGHD) is introduced and includes:

- Care experience surveys
- Symptom assessments
- Self-management diaries
- Patient-generated data in the EHR
- Questionnaires
- Previsit
- Health history
- Demographics

While stage 3 meaningful use requirements have yet to be defined, there is strong industry support for increased incorporation of PGHD into the EHR to include information via secure messaging and data from remote monitoring devices. For stage 3, the types of PGHD are expanded in the NeHC framework.

Recognizing the transformative power of patient engagement and PGHD when incorporated into the EHR, the ONC's Office of Planning and Policy commissioned a study with the Research Triangle Institute (RTI). The resulting white paper, titled "Patient Generated Health Data," was published in April 2012.<sup>2</sup> Following this publication, the ONC Health IT Policy Committee on PGHD held a public hearing in June 2012. The RTI study and hearing both address the evolving definition of PGHD, the related technical, operational, and policy issues, as well as possible options regarding the role of the government to resolve these issues. Patient-generated data is generally regarded as data created, recorded, gathered, or inferred by or from patients or their designees (including devices). This data is different from data gathered within the provider setting in two fundamental ways:

1. Patients, not providers, are responsible for capturing or recording these data.
2. Patients direct the sharing or distribution of these data to healthcare providers and other stakeholders.

Patient-generated health data is not a new concept to HIM professionals who have supported provider organizations with the development of policies and work processes to incorporate the information patients bring from home into the medical record,

such as blood pressure readings, blood glucose values, headache diaries, spirometry readings, and INR values. The RTI findings confirmed that researchers "did *not* find examples of PGHD flowing directly in the EHR without a review process or review policies in place."<sup>3</sup>

It is clear that as technology marches forward there will be a proliferation of personal health devices and smart applications resulting in a rapidly increasing volume and variety of data. In a televised interview, renowned cardiologist Eric Topol, MD, described how this "future" has already taken effect in his practice. He now prescribes more mobile applications than medications in his practice. The data flowing from smart apps and mobile devices into the EHR will be "structured or unstructured, machine-readable or not, numeric, text, image, waveform, etc." as noted in the RTI paper.

IT standards are required to move this variety and volume of data wirelessly from devices into personal health records and practice EHRs. Many standards development organizations are involved in this process, including Health Level Seven (HL7), Institute of Electrical and Electronics Engineers, American Society for Testing and Materials, Digital Imaging and Communications in Medicine, International Standards Organization Technical Committee 215, European Committee for Standardization Technical Committee 251, and International Electrotechnical Commission Technical Committee 62.

AHIMA is currently participating in the HL7 workgroup developing a Patient-Generated Document Implementation Guide based on the Consolidated Clinical Document Architecture standard specifying the metadata to tag patient-generated health data. This tagging will ensure that as the data is exchanged, it will retain its provenance as patient-generated. The standard includes tagging of data generated by a patient's device or patient's agent acting on behalf of the patient in a nonclinical capacity. Maintaining the author of the data is important in establishing the credibility of the data and ensuring the integrity and trustworthiness of the data for clinical decision making as it flows across the continuum of care.

Standards alone do not achieve interoperability. The global interoperability collaborative Integrating the Healthcare Enterprise (IHE), founded by HIMSS and the Radiological Society of North America, conducts an annual "Connectathon" in early winter, where engineers, companies, and providers gather to implement IHE "profiles" that have been developed through an open consensus process, including patient care device domain profiles. Manufacturers and vendors can identify the level of interoperability achieved amongst their products. Successful implementations then move on for demonstration in the HIMSS Interoperability Showcase and similar regional events.

While technological readiness evolves, HIM professionals must consider the implications of patient-generated documents and data, properly preparing their organization for the changes ahead. HIM professionals should participate and initiate important strategic and business conversations regarding meaningful use, patient engagement, and PGHD.

These conversations should include information governance, policy and procedure-with particular attention to workflow-and technology readiness. HIM professionals should coordinate with IT and data governance teams within the organization to ensure PGHD is an agenda item in the 12-month plan. Encourage the use of vendors active in IHE and specify IHE Patient Care Device Domain compliance in RFPs, requesting printed Integration Statements. HIM professionals must be prepared to contribute their knowledge and experience regarding maintenance of the Master Patient Index, which includes cleaning up of duplicates and overlays. These strategies, algorithms, and technologies to prevent patient and data mismatches in the EHR will be required in any system install that accepts PGHD.

Patient engagement and PGHD will transform the EHR from a transactional support tool to a clinical decision support tool. As medicine evolves to include information science, HIM professionals are well positioned to design, implement, audit, and improve the systems and work processes to include PGHD and manage health information.

## Notes

1. NeHC. "[Patient Engagement Framework](#)."
2. Research Triangle Institute. "Patient-Generated Health Data." April 2012.  
<http://www.rti.org/pubs/patientgeneratedhealthdata.pdf>.
3. Ibid.
4. Ibid.

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