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Patients, Consumers, and Caregivers: The Original Data Stewards

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Abstract

Introduction: For patients and families, the issue of data quality is personal. When treatment decisions or research conclusions are based on incomplete or inaccurate information—a misdiagnosis, an incomplete medication list, the wrong demographic data— care safety, quality, and outcomes suffer—and patients and families suffer.

Opportunity for Change: Thanks in part to the power of health information technology, individuals have new opportunities to be part of the solution when it comes to assessing and improving data quality. Building on a framework for data quality, there are numerous opportunities for patients to be part of ‘feedback loops’ to understand and improve data quality are presented.

Foundation for the Future: As the source of patient-centered data, consumers have important roles to play in reviewing and confirming their own health information and should be engaged partners in efforts to understand and improve the quality of electronic health data.

This commentary is written in response to "Transparent Reporting of Data Quality in Distributed Data Networks" (Kahn et al.) and builds on recommendations outlined in the framework.

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Keywords

Health Information Technology, Quality, Patients, Consumers

Disciplines

Health Information Technology

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Patients, Consumers, and Caregivers: The Original Data Stewards

Erin A. Mackay, MPH¹

Abstract

Introduction: For patients and families, the issue of data quality is personal. When treatment decisions or research conclusions are based on incomplete or inaccurate information—a misdiagnosis, an incomplete medication list, the wrong demographic data—care safety, quality, and outcomes suffer—and patients and families suffer.

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Introduction

For patients and families, the issue of data quality is personal. When treatment decisions or research conclusions are based on incomplete or inaccurate information—a misdiagnosis, an incomplete medication list, the wrong demographic data—care safety, quality, and outcomes suffer. Patients and families suffer. *Thanks in part to the power of health information technology, individuals have new opportunities to be part of the solution when it comes to assessing and improving data quality.* Consumers are not only the foundation of the Data Quality Framework Kahn et al., but have important roles to play in reviewing and confirming their own health information along the chain of data stewardship.

Recognizing patients and families as sources of valuable information and powerful forces for change in identifying and preventing errors will also help to foster a culture of safety and build a sense of partnership between providers and patients in the mutual pursuit of better health and care. Building on Kahn et al.’s figure following the chain of data stewardship, I have overlaid opportunities for patient engagement at each step of the process, underscoring the critical role of individuals as the original data stewards (see Figure 1).

The Role of Online Access

The number of people with online access to their electronic health information is growing by leaps and bounds. Before the Health Information Technology for Economic and Clinical Health (HITECH) Act, patients had a right to receive a copy of their health records within 30–90 days under the HIPAA Privacy Rule. Now,

thanks to Meaningful Use, patients have the ability to view online, download, and transmit their own records within 36 hours after a hospital discharge, or within four business days after a doctor receives the health data.¹ Health information is increasingly available at the click of a button with Blue Button. Blue Button is an easy, secure method for individuals to download their medical records in digital form from a secure website offered by doctors, insurers, pharmacies or other health-related services.² Implementation of these policy changes is underway, and there are undoubtedly individuals who still struggle to access their own health information (electronically or otherwise), and work is necessary to improve the experience and utility of online access for patients. Nonetheless, online access to clinical information is an opportunity to partner with patients and families to assess and enhance the quality of health care data.

Patient Generated Health Data (PGHD)

As patients and families get easier access to their medical records and health data, possibly for the first time, it is inevitable that they will have feedback—corrections, additions, and observations to share. In fact, the *absence* of health information produced, shared, and reviewed by patients themselves contributes to poor data quality. Patients and their caregivers can provide information critical to high-quality research and care delivery, including family health history, treatment side effects, changes in health status or functional status, and even treatment outcomes.³ Too often, records are missing key data about health outcomes—did the patient get better after the recommended course of treatment?

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Corrections and amendments are another important type of PGHD. Patients are often the first to identify errors in their own records. Increased access by individuals to their own health information will likely increase the number of errors identified by patients. These could include updated medication lists, nontolerated medications, other allergies, and more. These and other *patient* generated health data complement clinical information generated by care teams to provide a comprehensive view of an individual's health, thus enhancing data quality, as well as enabling more meaningful conclusions to be drawn from secondary uses of this data.

With greater online access to their health information and new tools to electronically communicate and share information with providers, patients and families can help improve the accuracy and reliability of data stored in medical records. I recently heard a speaker at the Office of the National Coordinator (ONC)'s Consumer Summit affectionately refer to the benefits of this new capability as an "army of free fact checkers."

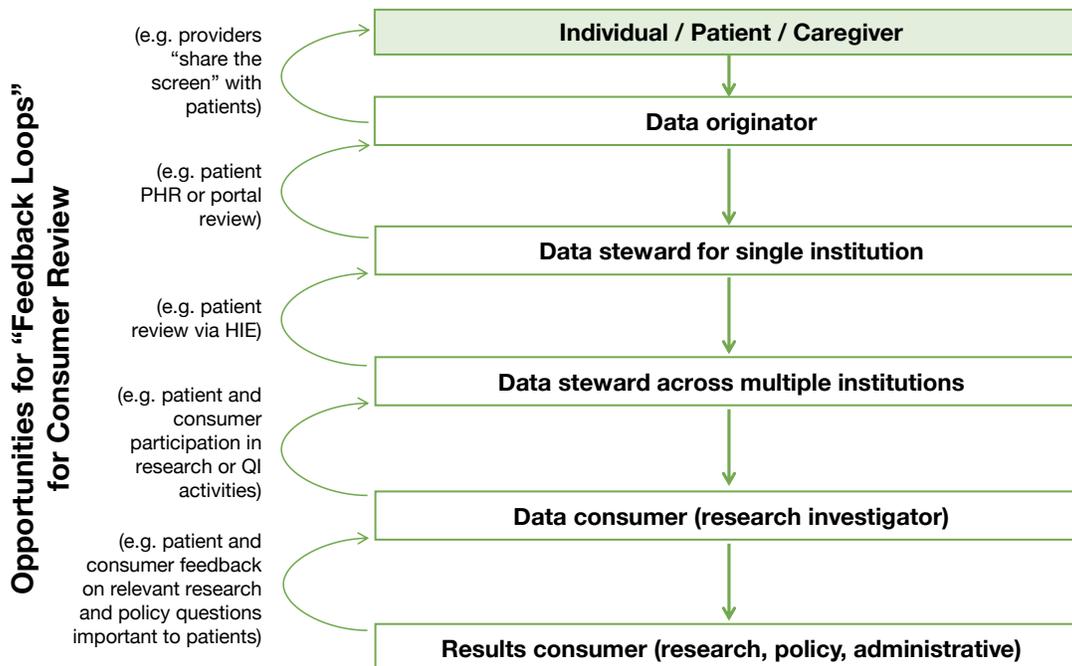
A 2014 nationwide survey found that patients with online access to their health information overwhelmingly use this capability: 86 percent log on at least once a year, and more than half (55 percent) log on three or more times per year. Survey data show that online access has a positive impact on patients' knowledge of their health, ability to communicate with doctors, *and* ability to correct information (for 63 percent of patients). More frequent online access has an even greater impact on ability to correct information (71 percent for frequent users, compared with 48 percent for less frequent users).⁴

Data Quality Framework

As the original generators and stewards of their own health data, individual patients and consumers are the foundation in the data stewardship chain outlined in Kahn et al.'s *Data Quality Framework*. Consumers also want to continue to be involved, considered, and consulted in all aspects of data capture, assessment, and use. Figure 1 takes Kahn's figure and illustrates the potential data contributions of individual patients and consumers, as well as opportunities to support critical data management activities at multiple points along the chain of data stewardship.

In particular, there are opportunities for consumer and patient involvement in improving the quality and integrity of data stored in electronic health records (EHRs) for clinical use (*Data Originator* box). For example, providers could share their computer screen with patients during clinical encounters, allowing patients to see their medication lists or medical records. This gesture not only engages patients in the data entry, but also offers an opportunity for patients to contribute corrections or new information to their record in person. The growing ability for patients to view, download, and transmit their health information electronically extends these opportunities *beyond* the clinical setting. Patients and their families can view their health records and supply missing data or correct inaccurate data via patient portals or secure messaging with their providers. Individuals can review and verify data further down the stewardship chain via a portal offered by a health information exchange (HIE). HIEs collect data from multiple institutions, and some portals allow the patient to see the collective longitudinal record and to offer corrections or amendments to the whole. Finally, at the end of the data stewardship chain,

Figure 1. Augmented Chain of Data Stewardship with the Role and Contributions of Individual Patients and Consumers Highlighted



consumers could review and offer feedback on the relevance or usefulness of the analysis and visualizations being created by clinical researchers and other investigators.

Of course, questions remain about how best to collect and ingest information from patients into the electronic medical record. Questions, for example, such as how to authenticate data coming from patients prior to use (how to confirm when the data were created, whether they were modified in some way, what instrument was used to collect them, etc.). Policies and procedures are still necessary to ensure that providers can receive, review, record, and respond to PGHD shared by patients and families.⁵ *A comprehensive data quality reporting framework for assessing and describing data quality may help to validate PGHD and incorporate them into the medical record, and use them to inform clinical care or health care policy.*

We must also more effectively engage patients and families in an online health environment and educate them about the impact of data quality on their health and health care. Underlying changes to clinical culture are also necessary: moving toward viewing patients as active partners in their care, rather than as passive recipients.⁶ Great strides are being made in patient-centered outcomes research, as exemplified by the Patient Centered Outcomes Research Institute (PCORI), which funds research and supports patients and other stakeholders to meaningfully partner with researchers throughout the research continuum.

Looking forward, we must also broaden our focus beyond current data types and quality issues to consider relevant health data outside traditional clinical settings, such as social determinants of health (building on the Institute of Medicine's recommendations),⁷ and their place and impact in the data quality framework.

Consumers have much to gain from, and contribute to, activities to assess and improve data quality.⁸ Efforts to adopt and implement a comprehensive data quality framework should preserve and reinforce the role of individuals as the original data stewards, generating and sharing critical information to inform better research, safer clinical care, and—ultimately—improved health outcomes.

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