The Pros and Cons of Collecting Patient-Generated Health Data

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Abstract

Providers base their care decisions on information received from the patient, such as vital signs, symptoms, medical allergies, laboratory results, and a variety of other types of data. Traditionally, the information is generated in a clinical setting: during a visit, in a lab, in a diagnostic screening office, etc. Much of these data constitute a one-time snapshot, often gathered infrequently. New technologies, howeve,r can enable patients to generate important data outside of these settings and with greater frequency. The greater depth, breadth, or continuity of data that patients share with their providers may lead to better care and outcomes. Patient-generated health data (PGHD) is health-related data such as health history, symptoms, biometric data, treatment history, lifestyle choices, and other information that are created, recorded, gathered, or inferred by or from patients or their designees to help address a health concern. The incorporation of PGHD can complement current and existing clinical data, potentially fill in the gaps of the clinical information and provide a holistic and comprehensive indication of the patient's health. The use of PGHD offers an opportunity to capture needed information for use during care, with potential cost savings and improvements in quality, care coordination, and patient safety. Some providers may be concerned that incorporating PGHD into clinical processes will increase the burden of reviewing data, subject the providers to unrealistic patient expections, and increase professional liability. Specifically, there are concerns that providers will be held accountable for information they did not receive or reviewe in a timely manner, especially if the information requires an urgent response. Additionally, some providers have expressed concern about the financial impact of PGHD including the use of staff and physician time for reviewing, processing and analyzing the data and potentially integrating it into the EHR. On the other hand, patients may be concerned about their providers failing to use PGHD to meet their health care expectations. Concerns may include whether the information sent was securely received and saved in the patient's chart; whether the information was shared with his or her provider or family members as appropriate; and whether the patient generated data were valued and well-received by their doctor. In a study done by Project Health Design, health care professionals identified three main benefits of PGHD accessibility in clinical settings: 1) deeper insight into a patient's condition; 2) more accurate patient information, particularly when of clinical relevance; and 3) insight into a patient's health between clinic visits, enabling revision of care plans for improved health goal achievement, while avoiding unnecessary clinic visits. Including patient generated clinical data has the ability to impact the care received by the patient. It can be used to improve outcomes and enhance the path of communication between the patient and the provider. Incorporating this potential is not without risk, however; organizations should assess and consider how existing processes, workflows and systems can be impacted by PGHD and how to incorporate these vital data to reap the substantial benefits.