Conceptualizing a Data Infrastructure for the Capture and Use of Patient-Generated Health Data

The Office of the National Coordinator for Health Information Technology (ONC) defines patient-generated health data (PGHD) as health-related data created and recorded by or from patients outside of the clinical setting to help address a health concern.[1] To date, patient health information, such as activity level, biometric data, symptoms, medication effects, and patient preferences, has been predominantly collected by members of the care team in a clinical setting or through clinical in-home devices for remote monitoring.

The rise of innovative digital health technologies has increased the ease of capturing, using, and sharing PGHD. Such technologies enable patients to share their health data in real-world settings and in real time with clinicians and researchers. Although patients are creating an abundance of PGHD, several technical and cultural barriers have slowed the adoption of PGHD in care delivery and research. Capitalizing on these technologies and mitigating the barriers to using the data captured require the development of guidance and best practices for integrating PGHD into clinical and research settings.

ONC developed a white paper that envisions a health IT ecosystem that optimizes PGHD use for care delivery and research settings through 2024. It identifies many, but not all, opportunities and challenges related to widespread capture, use, and sharing of PGHD. It offers suggestions for stakeholder action to address the challenges identified. The paper focuses on the perspectives of patients, clinicians, and researchers as the key stakeholder groups in the use of PGHD. It also calls on policymakers, technology developers and standards bodies, and payers and employers to support the capture, use, and sharing of PGHD for use in care delivery and research. The white paper also includes an overview of the pilot demonstrations' findings, which provided real-world insights.

Use the hyperlinks to read the project's White Paper and accompanying infographic, as well as a pilot demonstrations infographic.

The project also developed a Practical Guide that offers suggested practices and questions to consider for the implementation of the capture, use, and sharing of PGHD in clinical and research settings. The intended audience of this document includes patients and caregivers, clinicians, researchers, health information technology (IT) professionals, and health care administrators. Depending on the size of the clinical or research organization (e.g., large health system, solo practitioner), considerations or requirements that influence how the guide is applied at that organization may differ.

Use the hyperlink to read the project's Practical Guide.

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[1] "Patient-Generated Health Data," March 21, 2018,
https://www.healthit.gov/topic/scientific-initiatives/patient-generated-health-data.