Conceptualizing a Data Infrastructure for Patient-Generated Health Data

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The Office of the National Coordinator for
Health Information Technology

What are patient-generated health data?

Patient-generated health data (PGHD) are **health-related data** created, recorded, or gathered by or **from patients** (or family members or other caregivers) **to help address a health concern.**

PGHD include, but are not limited to:

Health history

Treatment history

Biometric data

Symptoms

Lifestyle choices

PGHD are distinct from data generated in clinical settings and through encounters with providers in two important ways:

Patients, not providers, are **primarily responsible for capturing** or recording these **data**.

Patients decide how to share or distribute these **data to** health care **providers** and others.

Source: PGHD page on ONC website, www.healthit.gov

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How are patient-generated health data addressed in current policies?

Patient-generated health data are referenced in:

2015 Edition Certification Rule

CMS Quality Payment Program

Federal Health IT Strategic Plan

NIH *All of Us* Research Program

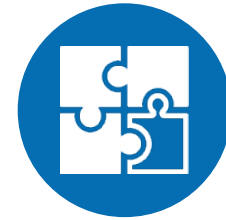ONC Interoperability Roadmap

Overview of the PGHD Project

ONC contracted with Accenture Federal Services to conduct a two-year project to increase knowledge about the capture, use, and sharing of PGHD for care delivery and research through 2024.

Project investigated best practices, opportunities, and gaps and published a draft white paper for public comment

Project coordinated two pilot demonstrations to test implementation of best practices identified in the draft white paper and inform the final white paper

Project is one in a portfolio of projects at ONC that addresses the data infrastructure needed for Patient-Centered Outcomes Research (PCOR)

PGHD Project: Policy Topic Areas

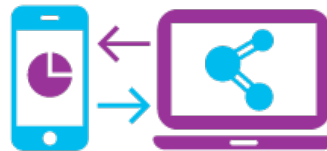**1** Patient Recruitment for Research, Studies, and Trials

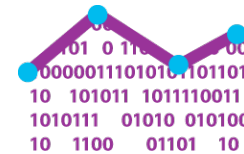**2** Collection and Validation of Data and Tools

3 Data Donation

4 Ability to Combine PGHD with Medical Record Data in Multiple Ways

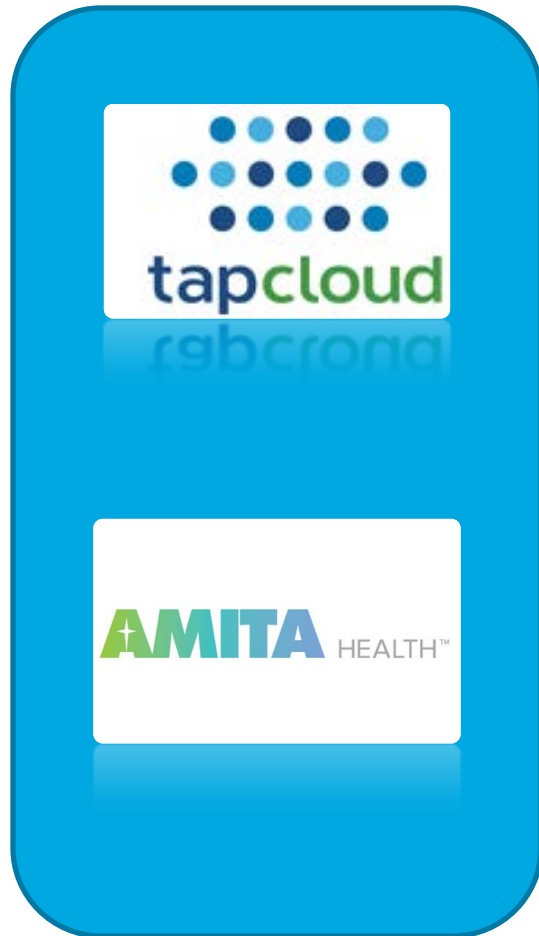**5** Data Interoperability

6 Big Data Analysis

7 Regulatory Overview

PGHD White Paper: Stakeholder Groups

- Discusses current state and emerging trends

- Provides a vision for a future that enables PGHD capture, use, and sharing

- Describes opportunities, challenges, and enabling actions by stakeholders to create a collaborative health IT ecosystem

  » Key Stakeholders Identified:
    – Patients, Clinicians, and Researchers

  » Other Stakeholders Identified:
    – Technology (Developers and Standards Bodies), Payers and Employers, and Policymakers

PATIENTS

OTHER STAKEHOLDERS:

Technology Stakeholders

Collaborative Health IT Ecosystem

Payers and Employers

RESEARCHERS

Policymakers

CLINICIANS

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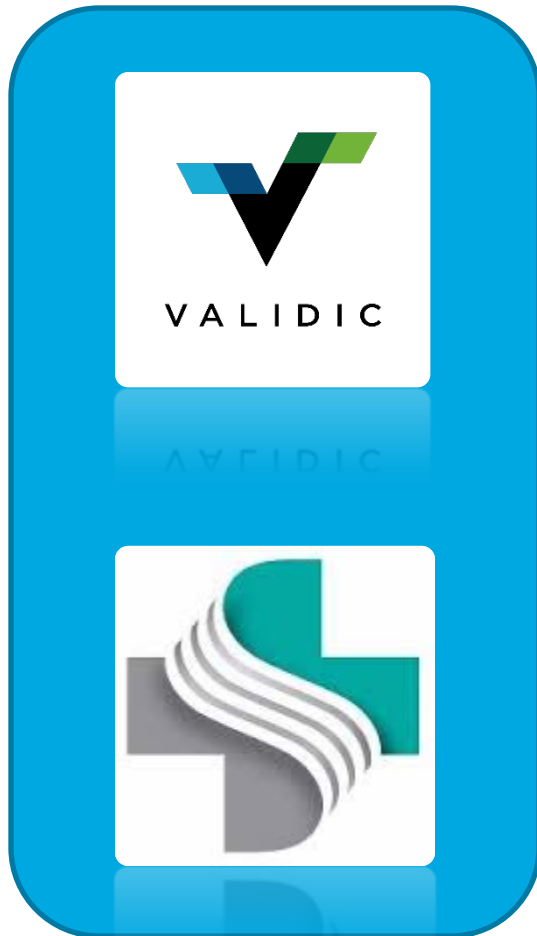Health Information Technology

PGHD Pilot Demonstrations: TapCloud and AMITA Health

- Gathered PGHD and associated clinical results into one application across several medical areas.
  - For example, orthopedic surgery, behavioral health, bariatric surgery, and stroke

- TapCloud connected patients and clinicians outside the clinical setting to identify how patients feel and assessing their health status over time.

PGHD Pilot Demonstrations: Validic and Sutter Health

- Tested personalized care focused on people suffering from Type II diabetes, using remotely collected PGHD from several devices to research the infrastructure and workflows needed to implement and scale PGHD initiatives.

- Employed ethnographic methods to identify areas of improvement to further patient and provider engagement.

Patient-Generated Health Data

For more information, visit:

https://www.healthit.gov/policy-researchers-implementers/patient-generated-health-data

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