



The Office of the National Coordinator for Health Information Technology

A PRACTICAL APPROACH TO THE USE OF PATIENT-GENERATED HEALTH DATA (PGHD)



The Office of the National Coordinator for Health IT (ONC) contracted with Accenture Federal Services (AFS) to research and provide analysis on the capture, use, and sharing of patient-generated health data (PGHD) in care delivery and research settings through 2024. The project consisted of a white paper informed by two pilot demonstrations.

PILOT DEMONSTRATIONS



PURPOSE

Develop processes to test the implementation of concepts outlined in the PGHD white paper in real world settings.



GOAL

Document the successes and barriers for implementation of PGHD use by key stakeholders, and inform revisions to the white paper.

VALIDIC AND SUTTER HEALTH

- Validic worked with Sutter Health to test personalized care focused on people living with Type II Diabetes. Remotely collected PGHD from a multitude of devices were used in the research of the infrastructure and workflows needed to implement and scale PGHD initiatives.
- Ethnography was included to identify areas of improvement with the program to further patient and provider engagement in the pilot demonstration.



TAPCLOUD AND AMITA HEALTH

- TapCloud worked with AMITA Health to gather PGHD and associated clinical results into one application across several medical areas such as orthopedic surgery, behavioral health, bariatric surgery, and stroke.
- The TapCloud application connects patients and clinicians outside the clinical setting by identifying how patients feel and assessing how they are progressing with their care plans.



WHAT INSIGHTS CAN BE DRAWN FROM THE PGHD PILOT DEMONSTRATIONS?

Insights from the pilot demonstrations revealed key findings in four areas related to the implementation of the capture, use, and sharing of PGHD.

STRATEGIC PLANNING

DEFINING REQUIREMENTS

IMPLEMENTING

MONITORING AND ADOPTING





STRATEGIC PLANNING

First, an organization should consider the potential value of implementing the use of PGHD.

DEFINING OBJECTIVES

The potential value of PGHD use includes:



Improving patient health outcomes



Enhancing the patient experience



Alerting care teams for early intervention



Taking advantage of new reimbursement models

ASSESSING THE BUSINESS CASE

Organizations should define the metrics for measuring success as well as determining the scope and scale for using PGHD. The business case should articulate how using PGHD adds value to the organization (including impacting existing revenue models). Potential costs should be evaluated, including:



- Devices provided to patients
- Software services
- Data analysis platforms and services
- Technical support
- Training for clinicians, care team members, patients, and caregivers



RECRUITING SUPPORT AT ALL LEVELS

- **Identify executive sponsor:** Organizations should identify a leader who will champion the concept and business case within the organization's leadership team and among staff members.
- **Enlist key staff members:** Organizations should enlist key staff members across relevant departments to represent their workflow perspectives and to contribute to technical requirements.



DEFINING REQUIREMENTS

The use of PGHD will likely involve new technologies or modification to existing systems. Organizations should define requirements for building effective processes.

GATHERING REQUIREMENTS



Providing technical solutions and options for sharing PGHD



Determining how using PGHD will impact existing health IT systems and identify if additional supporting systems are required

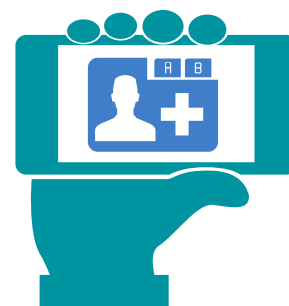


Designing a storage strategy for the PGHD

IDENTIFYING PATIENT-FACING TECHNOLOGIES

Patients' needs and preferences should be at the forefront of decisions about selecting technologies for PGHD capture. Types of patient-facing technologies include:

- **Registered medical devices:** medical instruments intended for diagnosis and treatment, regulated by the FDA
- **General wellness products:** devices or apps intended for using maintaining or encouraging health and activity





IMPLEMENTING

There are several activities organizations should consider when implementing the use of PGHD.

SUPPORTING USERS

Create processes for addressing potential user issues, including support for patients and caregivers as well as care team members.

REVIEWING AND ACTING ON PGHD

Provide tools to interpret and analyze PGHD. Develop methods to identify trends in the data and utilize clinician-facing dashboards.

SUSTAINING ENGAGEMENT

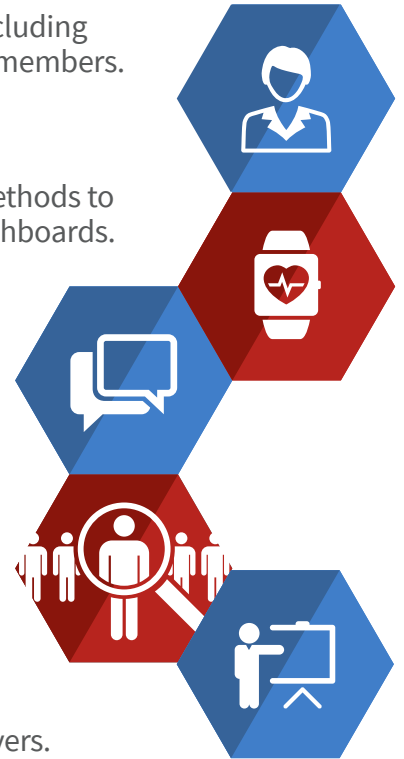
Establish positive feedback loops with patients and encourage them to continue donating PGHD.

RECRUITING AND ENROLLING PATIENTS

Create mechanisms to recruit and enroll patients in-person, online, and through the use of registries.

TRAINING STAFF

Train care teams and research staff to use the selected technology and provide guidance to patients and caregivers.



MONITORING AND ADAPTING

Monitoring data-related concerns and adapting the use of PGHD as needed will help support the evolving needs of the organization.

ADDRESSING CLINICIANS' AND RESEARCHERS' POTENTIAL DATA-RELATED CONCERNS



Accuracy of PGHD



Increased clinician workload due to large volume of PGHD



Integration of PGHD with the medical record and relevance to clinical management



Responsibilities for acting based on PGHD



Privacy and security of PGHD

UNDERSTANDING THE PRIVACY AND SECURITY REGULATORY CONTEXT

Before implementing the use of PGHD, conduct a scan of relevant federal and state laws, regulations, and guidelines that impact the project, as well as of relevant organizational policies.

