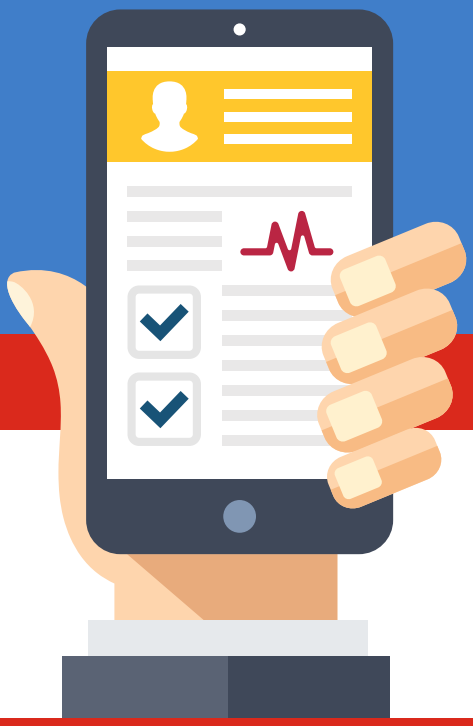
The Office of the National Coordinator for Health Information Technology

WHAT ARE PGHD?



PATIENT-GENERATED HEALTH DATA

Health-related data created and recorded by or from patients outside of the clinical setting to help address a health concern

EXAMPLES OF PGHD

- ACTIVITY LEVEL
- SYMPTOMS
- BIOMETRIC DATA
- MEDICATION EFFECTS

EXAMPLES OF PGHD SOURCES

- MOBILE APPLICATIONS
- WEARABLE DEVICES
- REGISTERED MEDICAL DEVICES
- SURVEYS AND QUESTIONNAIRES

WHAT ARE THE BENEFITS OF PGHD USE?

FOR PATIENTS & CAREGIVERS

Empowers patients to better manage their health and actively participate in their health care

FOR CLINICIANS

Provides a holistic view of patients' health over time and enables shared decision-making about care plans

FOR RESEARCHERS

Provides access to more expansive and diverse datasets to aid in clinical research

WHAT ARE THE **DRIVERS** OF PGHD USE?

Desire to gain a more holistic and longitudinal view of patients' health

Increased care coordination for chronic conditions

Regulations that incent the capture and use of data from non-clinical settings

CURRENT STATE

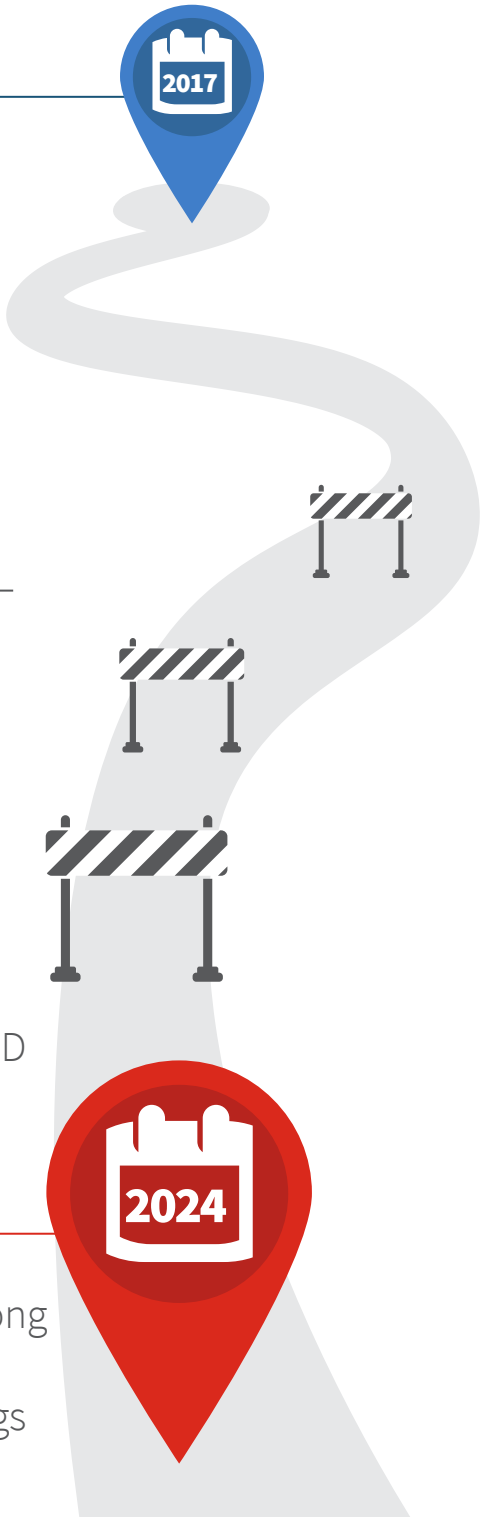
- Clinicians make decisions based on data they collect in clinical care settings, reflecting intermittent, discrete points in time
- Researchers and clinicians often don't have real-time access to information about patients' lives outside of clinical setting

TECHNICAL & WORKFLOW CHALLENGES

- Insufficient data storage and technical architecture
- Uncertainty about the accuracy of PGHD devices
- Problematic data curation when merging data from disparate sources
- Continually-evolving security threats and inconsistent or insufficient privacy solutions
- Developing PGHD interoperability standards
- Differing views about rights to access, use, and sharing of PGHD

FUTURE STATE

- Seamlessly and electronically capture and share PGHD among patients, clinicians, and researchers, as well as support interoperability across communities and non-clinical settings



PGHD
ADOPTION CURVE

2012-2015
EXPLORATION & INVESTMENT

- Explosion in the availability and popularity of consumer health devices
- Government exploration of PGHD opportunities
- Patients collect PGHD, but typically do not share it

2016-2017
EARLY ADOPTION

- Cutting-edge organizations see the value of PGHD and begin pilot testing and researching the use of PGHD for specific chronic diseases
- Interest in precision medicine and telehealth increase the focus on PGHD

2018-2023
GROWTH

- Increasing number of patients willing and able to capture and share PGHD with clinicians and researchers
- Interoperability standards that support the capture, use, and sharing of PGHD are adopted
- Clinicians and researchers are easily able to store, retain, and analyze large volumes of PGHD with minimal concern for liability

2024
MATURITY

- PGHD seamlessly and securely flow from the patient to clinicians and researchers as part of routine care and research
- Patient-clinician relationship is balanced and collaborative
- Patients actively engaged in monitoring their health and make fewer trips to the clinician
- More successful research studies due to increased access to patients and the ability for patients to participate remotely

COLLABORATION AMONG STAKEHOLDERS IS NECESSARY TO INCREASE PGHD ADOPTION

PGHD DRAFT WHITE PAPER

ENABLING ACTIONS BY STAKEHOLDER

A PGHD policy framework could consider the following enabling actions:

PATIENTS & CAREGIVERS

- Encourage patients and caregivers to collaborate with clinicians and researchers to determine how capturing, using, and sharing PGHD can be valuable for managing their health.
- Support active patient participation in testing the functionality and usability of devices and apps and in reporting feedback directly to manufacturers and app developers.

CLINICIANS

- Support clinicians who work within and across organizations to incorporate prioritized PGHD use cases into their workflows.
- Foster collaboration between clinicians and developers to advance technologies supporting PGHD interpretation and use.
- Identify and communicate benefits, challenges, and best practices of PGHD use to help strengthen the evidence for its clinical and economic value.
- Encourage clinicians to use PGHD to support patient data donation in research.
- Support clinicians in providing patient education to encourage PGHD capture and use in ways that maximize data quality.

RESEARCHERS

- Call for increased funding for studies that investigate the benefits, challenges, and best practices for using PGHD in care delivery and research.
- Motivate researchers to design and develop studies that incorporate PGHD.
- Expand methods for data donation to research studies.
- Strengthen patients' understanding of consent and data use.

POLICYMAKERS

- Prompt collaboration with industry to strengthen model practices, consumer education, and outreach that support the private and secure capture, use, and sharing of PGHD.
- Call for increased funding for programs that aim to understand the outcomes of PGHD use as part of advanced health care models.
- Encourage review of medical malpractice and liability laws at the state level and how they intersect with legal issues related to the use of PGHD.

DEVELOPERS & STANDARDS BODIES

- Improve usability and accessibility of and implement user-centered design principles into products that capture PGHD.
- Consistently adopt strong privacy and security practices for PGHD capture, use, and sharing and support transparency with consumers about these policies.
- Challenge standards bodies to address the needs of the health care ecosystem for PGHD use and increase the pace of standards development for capturing and integrating PGHD.

PAYERS & EMPLOYERS

- Continue to motivate clinicians to use PGHD as part of clinical care through supportive policies in reimbursement programs.
- Continue to incorporate incentives to use PGHD into insurance plans and wellness programs.

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