WHAT ARE PGHD?

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

EXAMPLES OF PGHD SOURCES

- Mobile applications
- Wearable devices
- Registered medical devices
- Surveys and questionnaires

EXAMPLES OF PGHD

- Activity level
- Symptoms
- Biometric data
- Medication effects

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?

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
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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