

Patient-Generated Health Data

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
- symptoms
- biometric data
- patient-reported outcome measures

PGHD differ from data generated in clinical settings and through encounters with health care providers in two important ways:

1. Patients, not providers, are primarily responsible for capturing or recording these data.
2. Patients decide how to share or distribute these data to providers and others.

Examples of PGHD include blood glucose monitoring or blood pressure readings using home health equipment, exercise and diet tracking using a mobile application, and questionnaires such as screening, medication adherence, risk assessment, and intake.

Why are PGHD important?

PGHD supplement existing clinical data, filling in gaps in information and providing a more comprehensive picture of ongoing patient health. PGHD can:

- Provide information about how patients are doing between medical visits.
- Gather information on an ongoing basis, rather than only at one point in time.



- Provide relevant information for preventive and chronic care management.
- Improve patient safety, for example by gathering information on medications taken and allergies.

Patients already provide relevant medical information to health care providers during intake or when discussing response to treatment. Changes in a patient's condition or symptoms, which typically occur outside of a traditional medical encounter, may prompt a change in the treatment approach.

How does health IT support PGHD?

The increasing availability of patient portals makes it possible for patients to submit health information electronically:

- Patients can complete questionnaires online or send information via secure electronic messaging.
- Practices can send reminders to patients to submit data and follow up with patients as needed based on a review of the PGHD.

For example, clinical information is gathered from patients at Brigham and Women's Hospital and affiliated practices through a previsit electronic journal (eJournal). Patients felt more prepared for visits and health care providers found this helpful, with no adverse impact on workflow.

How do I incorporate PGHD into my medical practice?

To incorporate PGHD into your practice, start small. Your practice is probably already collecting some form of PGHD, but may want to expand on this by introducing electronic methods for patients to submit health data. Here are some steps to take.

1. Develop a strategy and educate staff about the value of PGHD and its potential to improve care and efficiencies:
 - Focus on the goal and value of PGHD and benefits to patients and clinical care.
 - Consider criteria for success.
2. Assess what the practice is already doing to collect PGHD, assess needs for additional PGHD, and develop a roadmap for change:
 - What types of PGHD are already being used?
 - What types of additional PGHD would be most valuable?
 - Is the PGHD an electronic version of what is currently being collected or new information, such as biometrics?
 - How can processes be adjusted to take advantage of health IT?
 - Where will the use of PGHD fit into the care process?
 - Who is responsible for the success of implementing PGHD?
3. Establish clear policies and procedures:
 - What PGHD will be accepted?
 - How and when will the data be received and reviewed and by whom?
 - Are there changes that must be made to the workflow to support the use of PGHD?

“Finding ways to engage the patient in a meaningful way to participate in designing and testing approaches to PGHD can help with early success and promoting a culture of partnership.”

**– Technical Expert Panel
National eHealth Collaborative**

- How will the data be flagged as being patient-generated in the medical record?
4. Educate patients and families about:
 - The ways they can provide health information.
 - The benefits of providing health information.
 - Expectations regarding the use of this information by the practice.
 5. Plan a pilot:
 - Start small, such as medication lists, symptom tracking, or administrative information.
 - Make changes as needed.
 - Build on successes.
 - Tailor to situational and local requirements and context.

Selected Resources

Deering, M.J. (2013). *Issue brief: Patient-generated health data and health IT*. Office of the National Coordinator for Health Information Technology.

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Office of the National Coordinator for Health Information Technology. *Consumer eHealth: Patient-Generated Health Data*. (2014).

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Shapiro, M., Johnston, D., Wald, J., & Mon, D. (2012). *Patient-generated health data. White paper*. Prepared for Office of Policy and Planning, Office of the National Coordinator for Health Information Technology. Research Triangle Park, NC: RTI International.

http://www.healthit.gov/sites/default/files/rti_pghd_whitepaper_april_2012.pdf