Beth Israel Deaconess Medical Center   ***Policy Manual***
Title: Patient Generated Health Data Guideline **DRAFT**   ***Guideline***   ***Purpose:*** **To define and provide a process to incorporate Patient Generated Health Data into clinical practice.**

Purpose*:* Beth Israel Deaconess supports the inclusion of patient generated health data (PGHD) as part of the medical record to enable patients and clinicians to better diagnose, assess, and manage health conditions. This document provides guidance to clinicians and patients using patient-generated health data in clinical practice.

Patient Generated Health Data defined: Health related data, including health history, symptoms, biometric data, treatment history, lifestyle choices, and other information that is created, recorded, or gathered by or from patients or their designees. PGHD includes data obtained from patient controlled electronic devices, PatientSite questionnaires, and paper-based surveys.

> **Types of PGHD:** Currently providers receive a variety of documents generated by the patient or outside of clinical areas. They may include but are not limited to the following.
> 1. **Prescribed testing for defined periods of time** such as automatic blood pressure cuff or holter monitors. These tests, which are ordered as diagnostic testing and are professionally reviewed, will continue to appear in test results tracking through webOMR.
> 2. Patient-Reported **Health History** such as entries of family and social history, symptom-diaries, patient reported outcomes, and immunization updates.
> 3. Patient-Collected **Physiologic Data** such as home blood pressure recordings, weight measurements, or glucometer logs.

Data Governance: Patients providing data to BIDMC consent to the data being stored, managed, and used accordingly as part of their patient medical record.

Privacy: PGHD data are subject to the same privacy policies as clinical data stored in the patient medical record (see Policy # PV-04 Confidentiality, Policy # ADM-04 Information Systems Department Data Security Policy).

Using Data For Clinical Decisions: Clinicians may use PGHD to guide treatment decisions, similarly to how they would use data collected and recorded in traditional clinical settings. Judgment should be exercised when electronic data from consumer health technologies are discordant with other data.

Process for Obtaining and Using PGHD

The collection and use of PGHD should adhere to the following process elements

1. Request
2. Collection
3. Transfer
4. Storage
5. Notification
6. Review and Reconciliation
7. Action

1. **Request (Decision to Collect):** The decision to collect and upload PGHD is a joint decision between patient and provider, discussing indications, length or frequency of data collection, and expectations around review.

2. **Collection:** Data may be collected and recorded on paper or electronically, depending on the needs and preferences of patients and clinicians.

3. **Transfer:** Data collected for the purposes of clinical care through this process should be transferred to the medical center for incorporation into the patient medical record in line with existing policies (see Policy # PV-13 Defining the Designated Record Set and the Patient Medical Record).

   a. For paper-based data collection, data should be incorporated into the medical record through scanning, or summarized or transcribed into a sheet or note.

   b. For electronic data, data should be transferred securely to BIDMC. Where possible, PatientSite and related applications should be the standard mechanism for patients to transmit data to BIDMC.

4. **Storage:** Data shall be securely stored in compliance with existing BIDMC policies for storage of electronic patient data. Metadata should be appended to all electronically captured PGHD specifying where, how, and when it was collected and transferred. (see Policy # PV-07 Safeguarding Protected Health Information and Personal Information, and Policy # ADM-04 Information Systems Department Data Security Policy)

5. **Notification:** Notification to the clinician can be either active or passive depending on the use case. The process should be specified prior to data collection.

6. **Review and Reconciliation of Data:** Data collected from patients should be reviewed and/or reconciled as specified by the requesting clinician.

Vice President Sponsor:

Approved By:

☐ **Operations Council** _____
Chief Operating Officer

Health Information Management Committee

☐ **Medical Executive Committee** _____
Chair, MEC

☐ **Academic Council** _____
Chair, Academic Council

Requestor Name:

Date Approved:

Next Review Date:

Revised:

Eliminated: (Date)

References:

Draft Change Log

Date	Changes
2/2015 v6	Incorporated Feedback from team Pared down scope/details.
3/2015 v7	Reconciling changes from 2/23/2015 Meeting • Confirmed this is a guideline not a policy • Add back process for obtaining and using PGHD in clinical practice • Removed "ideally" from "PPGD is ideally a joint decision" • Changed "order" to "request"
8/4/15 v8	Preparation for sharing outside group • Inclusion of existing PPGD References • Standardized terminology (patient medical record) • Removed details about storage ("behind BIDMC firewall") and replaced with "Data shall be securely stored in compliance with existing BIDMC policies for storage of electronic patient data"