

Value of Personal Health Records: A Joint Position Statement for Consumers of Health Care

Save to myBoK

by the American Health Information Management Association and the American Medical Informatics Association

Position

The American Health Information Management Association (AHIMA) and the American Medical Informatics Association (AMIA) advocate empowering individuals to manage their healthcare through the use of a personal health record (PHR). The PHR is a tool for collecting, tracking, and sharing important, up-to-date information about an individual's health or the health of someone in their care. Using a PHR will help people make better health decisions and improves quality of care by allowing them to access and use information needed to communicate effectively with others about their healthcare.

Basic Principles

- Every person is ultimately responsible for making decisions about his or her health.
- Every person should have access to his or her complete health information. Ideally, it should be consolidated in a comprehensive record.
- Information in the PHR should be understandable to the individual.
- Information in the PHR should be accurate, reliable, and complete.
- Integration of PHRs with EHRs of providers allows data and secure communication to be shared between a consumer and his or her healthcare team.
- Every person should have control over how their PHR information is accessed, used, and disclosed. All secondary uses of PHR data must be disclosed to the consumer, with an option to opt-out, except as required by law.
- PHR products should be certified by CCHIT to comply with data standards, include a minimum data set, identify each data's source, and meet security criteria consistent with HIPAA.
- The operator¹ of a PHR must be accountable to the individual for unauthorized use or disclosure of personal health information. The consumers should be notified immediately of breaches in security that could lead to disclosure of personal health information.
- A PHR may be separate from and does not normally replace the legal medical record of any provider.
- Privacy protection of PHR data should follow the data. PHR data must not be used in any discriminatory practices.

Questions and Answers

Why should everyone have a PHR?

We believe that all individuals should be able to readily access, understand, and use their personal health information. A PHR allows individuals to be more active partners in their healthcare, and gives them up-to-date information when and where they need it. A PHR provides a single, detailed, and comprehensive profile of a person's health status and healthcare activity. It facilitates informed decisions about the care of the individual. It may also reduce duplicate procedures or processes—such as repeated lab tests and x-rays—saving time and money. A PHR helps people prepare for appointments, facilitates care in emergency situations, and helps track health changes.

What media should you use for a PHR?

We encourage individuals to begin tracking their health information in whatever format works best for them, even if the choice is paper. We recommend that individuals use an electronic media to facilitate a timely, accurate, and secure exchange of

information across healthcare institutions and providers. PHR information should always be stored in a secure manner just as you would store other confidential personal information such as financial information.

How can an individual choose a PHR supplier?

Individuals can create their own PHR, or may be offered one by a variety of sources, such as a healthcare provider, insurer, employer, or a commercial supplier of PHRs. Each supplier has different policies and practices regarding how they may use data they store for the individual. Study the policies and procedures carefully to make sure you understand how your personal health information will be used and protected. Policies to look for include privacy and security; the ability of the individual, or those they authorize, to access their information; and control over accessibility by others. If the PHR contains the same information that the doctor has seen, it has more usefulness for tracking purposes than information from insurance forms. For example, insurance claims information may list the diagnosis or medication but not the details (for example, actual blood pressure reading or dose of the medication taken).

What should a PHR contain?

Broader than a medical record, the PHR should contain any information relevant to an individual's health. In addition to medical information such as test results and treatments, a PHR may include diet and exercise logs or a list of over-the-counter medications. A PHR should contain the following information:

- Personal identification, including name and birth date
- People to contact in case of emergency
- Names, addresses, and phone numbers of your physicians, dentists, and specialists
- Health insurance information
- Living wills, advance directives, or medical power of attorney
- Organ donor authorization
- A list and dates of significant illnesses and surgical procedures
- Current medications and dosages
- Immunizations and their dates
- Allergies or sensitivities to drugs or materials, such as latex
- Important events, dates, and hereditary conditions in your family history
- Results from a recent physical examination
- Opinions of specialists
- Important tests results; eye and dental records
- Correspondence between an individual and his or her provider(s)
- Current educational materials (or appropriate Web links) relating to one's health

Where individuals should begin:

A good place to begin is with a visit to www.myPHR.com (a site provided as a free public service by AHIMA) for further information on creating and managing a PHR. We suggest that people find out if their healthcare providers, employer, insurers, or another individual or organization offers a PHR. If an individual needs to obtain copies of medical records themselves, they can contact doctors' offices or each facility where they have received treatment.

Each person can create a PHR at his or her own pace, perhaps starting with the next medical visit. The important thing is to get started.

Note: Because the use of personal health records is an issue of importance to both organizations, AHIMA and AMIA collaborated on the development of this joint position statement.

Note

1. An "operator" could be a healthcare provider, health plan, commercial supplier, government agency, employer, union, fraternal order, and so forth.

Article citation:

AHIMA; American Medical Informatics Association (AMIA). "Value of Personal Health Records: A Joint Position Statement for Consumers of Health Care" *Journal of AHIMA* 78, no.4 (April 2007): 22,24.

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