

Personal Health Records Policy Statements Adopted by the American College of Physicians

General Comments on Personal Health Records (PHRs):

1. ACP supports the use of personal health records as one mechanism of creating patient-centric repositories of clinical information.
2. PHRs should be secure and adhere to all current privacy and security standards.
3. Clinical information and guidance provided by the host or creator of the PHR program should comply with the relevant URAC standards for web-based clinical content (http://www.urac.org/consumer_standards.asp).

Features of Personal Health Records for Consumers and Patients:

4. Individuals should be able to access their health and medical data conveniently and affordably.*
5. Individuals should have the option of selecting what data they wish to import to or export from untethered PHRs;** however the usefulness of PHRs to medical professionals will be dependent on the availability of accurate and complete data.
6. Individuals should be able to decide (i.e., authorize) when their health data is exported from their untethered PHR, and to whom. Individuals should be able to refuse to make their health data (contained in an untethered PHR) available for sharing (i.e., opt out).*
7. Individuals should have the option of providing different levels of access to untethered PHRs for specific users of their PHR.
8. Individuals should be able to designate someone else, such as a loved one, to have access to and exercise control over how their untethered PHRs are shared.*
9. Individuals should receive easily understood information about all the ways that their health data may be used or shared.*
10. Individuals should be able to review which entities have had access to their personal health data.*
11. Individuals should have complete control over all un-tethered PHRs. However, functionality of PHRs connected to a physician's electronic medical records (i.e., tethered PHRs) will be controlled by the physician, consistent with existing patient consents and the physician's medico-legal obligations (e.g., types of information exported/exported to/from PHR to EHR).
12. Adolescents, minors and emancipated minors should have a right to confidential PHRs for the management and treatment of conditions for which the adolescent, minor or emancipated minor has the right to consent according to individual state regulations.

Personal Health Records Features:

13. PHR data should be collected in a structured format that uses standardized medical terminology described in laymen's terms. Collection in this manner will facilitate authorized export of data to EHRs and EMRs.
14. PHRs should permit voluntary, export of selected data (with authorization by the patient) to EHRs and untethered EMRs.

15. PHRs should permit voluntary, (with authorization by the patient) import of selected data from EHRs and untethered EMRs.
16. PHRs should accept, organize and display patient-specific claims-based data from payers including diagnoses, medications, procedures, tests, and other data aggregated by payers based on claims information.
17. PHRs should create robust audit trails regarding access to, or modification of, data in the PHRs.
18. Terminology used in PHRs should be appropriate to a typical patients' comprehension.

Physician-related Issues for Personal Health Records:

19. The existence of a PHR should not obligate a treating physician to review, correct, edit, contribute to, or manage in any way such a PHR.
20. Physicians should be responsible for reviewing data selectively imported by the physician from a PHR electronically to an EMR or printed/incorporated into a paper-based medical record.
21. Physicians should be responsible for the quality, accuracy and presentation of data exported to and incorporated in a tethered Personal Health Record from the physician's electronic medical record.
22. Physicians should be compensated for time spent creating, updating or reviewing a PHR.

* Consumer and patient-focused principles with an asterisk are based on principles endorsed by the Markle Foundation Personal Health Technology Council and the following organizations:

AARP

ACOR – Association of Cancer Online Resources

AFL-CIO

American Hospice Foundation

Center for Medical Consumers

Consumers Union

Families USA

Health Privacy Project

International Association of Machinists and Aerospace Workers

Maternity Center Association

National Coalition for Cancer Survivorship

National Consumers League

National Partnership for Women and Families

SEIU – Service Employees International Union

** An untethered personal health record is defined as the patient's compilation of his medical records from his providers whereas the tethered PHR is the patient's view of a subset of the physician's electronic medical record. Wolter, Julie, and Beth Friedman. "Health Records for the People: Touring the Benefits of the Consumer-based Personal Health Record." *Journal of AHIMA* 76, no.10 (November/December 2005): 28-32.