

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

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4 **General Comments on Personal Health Records (PHRs):**

- 5 1. ACP supports the use of personal health records as one mechanism of creating  
6 patient-centric repositories of clinical information.  
7 2. PHRs should be secure and adhere to all current privacy and security standards.  
8 3. Clinical information and guidance provided by the host or creator of the PHR  
9 program should comply with the relevant URAC standards for web-based clinical  
10 content ([http://www.urac.org/consumer\\_standards.asp](http://www.urac.org/consumer_standards.asp)).  
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12 **Features of Personal Health Records for Consumers and Patients:**

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

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

- 46 15. PHRs should permit voluntary, (with authorization by the patient) import of  
 47 selected data from EHRs and untethered EMRs.  
 48 16. PHRs should accept, organize and display patient-specific claims-based data from  
 49 payers including diagnoses, medications, procedures, tests, and other data  
 50 aggregated by payers based on claims information.  
 51 17. PHRs should create robust audit trails regarding access to, or modification of, data  
 52 in the PHRs.  
 53 18. Terminology used in PHRs should be appropriate to a typical patients'  
 54 comprehension.  
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56 **Physician-related Issues for Personal Health Records:**

- 57 19. The existence of a PHR should not obligate a treating physician to review,  
 58 correct, edit, contribute to, or manage in any way such a PHR.  
 59 20. Physicians should be responsible for reviewing data selectively imported by the  
 60 physician from a PHR electronically to an EMR or printed/incorporated into a  
 61 paper-based medical record.  
 62 21. Physicians should be responsible for the quality, accuracy and presentation of data  
 63 exported to and incorporated in a tethered Personal Health Record from the  
 64 physician's electronic medical record.  
 65 22. Physicians should be compensated for time spent creating, updating or reviewing  
 66 a PHR.  
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68 \* Consumer and patient-focused principles with an asterisk are based on principles endorsed by the Markle  
 69 Foundation Personal Health Technology Council and the following organizations:

- 70 AARP  
 71 ACOR – Association of Cancer Online Resources  
 72 AFL-CIO  
 73 American Hospice Foundation  
 74 Center for Medical Consumers  
 75 Consumers Union  
 76 Families USA  
 77 Health Privacy Project  
 78 International Association of Machinists and Aerospace Workers  
 79 Maternity Center Association  
 80 National Coalition for Cancer Survivorship  
 81 National Consumers League  
 82 National Partnership for Women and Families  
 83 SEIU – Service Employees International Union  
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85 \*\* An untethered personal health record is defined as the patient's compilation of his medical records from  
 86 his providers whereas the tethered PHR is the patient's view of a subset of the physician's electronic  
 87 medical record. Wolter, Julie, and Beth Friedman. "Health Records for the People: Touring the Benefits of  
 88 the Consumer-based Personal Health Record." *Journal of AHIMA* 76, no.10 (November/December 2005):  
 89 28-32.  
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