

**Health Record Bank of Oregon**  
**Reference materials reviewed in HRBO deliberations.**  
**Last updated January 15, 2009**

The materials listed herein may be of use to parties interested in personal health records (PHRs), health record banks (HRBs) and the Health Record Bank of Oregon (HRBO).

**Disclaimer:** The list is not intended to be the full universe of available information. No conclusions should be drawn from the inclusion of any listings or the lack of inclusion of other possible information or links. Website links included were active at the time entries were added to the list.

**Certification Commission for Health Information Technology (CCHIT)**

CCHIT website: <http://cchit.org/>

Personal Health Records (PHR) Work Group: <http://cchit.org/phr/>.

PHR Decisions: <http://phrdecisions.com/>.

[Consumer's Guide to Certification of Personal Health Records~](#)

9/29/2008      [Personal Health Record \(PHR\) 09 Introduction](#)

9/29/2008      [Personal Health Record \(PHR\) 09 Criteria \(Draft 01\)](#)

12/22/2008     [CCHIT Certified 09 Personal Health Records \(PHR\) Criteria DRAFT 2](#)

12/22/2008     [CCHIT Certified 09 Personal Health Records \(PHR\) Test Script DRAFT 1](#)

Health Information Exchange (HIE) Certification: <http://cchit.org/certify/hie/index.asp>

Interoperability Work Group: <http://cchit.org/interoperability/>

**Center for Information Technology Leadership (CITL)**

Middleton, Blackford presentation: "The Value of PHR in the Clinical Setting at the Kay Center for E-Health Research at Claremont Graduate University (Kay-CGU Symposium 2008: A Course in Consumer Health Informatics) on April 12, 2008, available at [http://www.citl.org/research/KaySymposium\\_2008\\_Middleton.pdf](http://www.citl.org/research/KaySymposium_2008_Middleton.pdf).

Kaelber DC, Shah S, Vincent A, Pan E, Hook JM, Johnston D, Bates DW, Middleton B. The Value of Personal Health Records, CITL, 2008. Available at [http://citl.org/\\_pdf/CITL\\_PHR\\_Report.pdf](http://citl.org/_pdf/CITL_PHR_Report.pdf).

**Department of Health & Human Services (U.S.)**

Federal HIT initiatives website: <http://www.hhs.gov/healthit/>

Office of the National Coordinator (ONCHIT): <http://www.hhs.gov/healthit/onc/mission/>

12/15/2008 Secretary Leavitt Announces New Principles & Tools to Protect Privacy:

<http://www.hhs.gov/news/press/2008pres/12/20081215a.html>

Supporting documents:

- [The Nationwide Privacy and Security Framework for Electronic Exchange of Individually Identifiable Health Information](#)
- [Privacy and Security Framework: Introduction](#)
- [Privacy and Security Framework: Correction Principle and FAQs](#)
- [Privacy and Security Framework: Openness and Transparency Principle and FAQs](#)
- [Privacy and Security Framework: Individual Choice Principle and FAQs](#)
- [Privacy and Security Framework: Collection, Use, and Disclosure Limitation Principle and FAQs](#)
- [Privacy and Security Framework: Safeguards Principle and FAQs](#)
- [Privacy and Security Framework: Accountability Principle and FAQs](#)
- [The HIPAA Privacy Rule's Right of Access and Health Information Technology](#)
- [Personal Health Records \(PHRs\) and the HIPAA Privacy Rule](#)
- [Draft Model Personal Health Record \(PHR\) Privacy Notice & Facts-At-A-Glance \(the "Leavitt Label"\)](#)
  - Blank model template:  
[http://www.hhs.gov/healthit/documents/PHR\\_NoticeBlankTemplate.pdf](http://www.hhs.gov/healthit/documents/PHR_NoticeBlankTemplate.pdf)
  - Example model template for Birch Health:  
[http://www.hhs.gov/healthit/documents/PHR\\_NoticeBirchHealthExample.pdf](http://www.hhs.gov/healthit/documents/PHR_NoticeBirchHealthExample.pdf)
- [Reassessing Your Security Practices in a Health IT Environment: A Guide for Small Health Care Practices](#)

**Dossia Project**      <http://www.dossia.org/>.

**Health Record Bank Alliance**      <http://www.healthbanking.org/>

2008 Fact Sheet and Principles:

<http://www.healthbanking.org/docs/HRBA%20Principles%20&%20Fact%20Sheet%202008%20FINAL.pdf>.

**Health Record Bank of Greater Louisville – Louisville Health Information Exchange (LouHIE)**      <http://www.louhie.org/>.

[LouHIE Executive Overview \(vision, mission, organizational structure, etc.\)](#)

[LouHIE By-laws](#)

[LouHIE Ethics Policy 20071026 \(PDF\)](#)

[LouHIE Business Plan v. 5-20-08](#)

[LouHIE Research Reports](#)

**Markle Foundation – Connecting for Health**      <http://www.connectingforhealth.org/phti/>  
[The Common Framework for Networked Personal Health Information: Overview and Principles](#)

The separate component documents can be accessed for downloading at

<http://www.connectingforhealth.org/phti/> or the entire Common Framework can be [downloaded](#) in PDF (8.11 MB).

### **Medicare PHR Pilot Program: Arizona and Utah**

Vendor Solicitation information <https://www.noridianmedicare.com/phr/forvendors.htm>.

Solicitation for Participation:

[https://www.noridianmedicare.com/phr/docs/phr\\_vendor\\_solicitation.pdf](https://www.noridianmedicare.com/phr/docs/phr_vendor_solicitation.pdf).

PHR Pilot Solicitation, Attachment A – PHR Tool and Vendor Requirements

[https://www.noridianmedicare.com/phr/docs/attachment\\_a.pdf](https://www.noridianmedicare.com/phr/docs/attachment_a.pdf).

HealthcareITNews story <http://www.healthcareitnews.com/story.cms?id=10407>.

### **Medicare PHR Pilot Program: South Carolina**

GovernmentIT story <http://www.govhealthit.com/online/news/350341-1.html>.

South Carolina PHR portal <https://www.myphrsc.com/>.

### **Oregon Health Information Security and Privacy Collaborative (HISPC) – Consumer Engagement Project**

Final Report, October 2007 [http://www.q-corp.org/q-](http://www.q-corp.org/q-corp/images/public/pdfs/OR%20HISPC%20consumer%20project%20rpt%202007.pdf)

[corp/images/public/pdfs/OR%20HISPC%20consumer%20project%20rpt%202007.pdf](http://www.q-corp.org/q-corp/images/public/pdfs/OR%20HISPC%20consumer%20project%20rpt%202007.pdf).

### **South Carolina Medicaid Health Data Exchange**

Story: [http://charleston.net/news/2008/jul/21/s\\_c\\_medicaid\\_patients\\_records\\_go\\_online48185/](http://charleston.net/news/2008/jul/21/s_c_medicaid_patients_records_go_online48185/).

South Carolina Health Data Exchange <http://www.schiex.org/>.

### **Washington State Health Care Authority: Health Record Banking**

WA State HCA website: <http://www.hca.wa.gov/hit>.

[Final Report to the Legislature](#) (1.8 MB), submitted December 1, 2006

2008 [Grant Solicitation for Consumer-Controlled Health Record Bank](#)

[Three Pilot Projects to Receive State Grants](#) Totaling \$1.7 Million to Test Consumer Managed Health Record Banks.

About the Grant Awards: [http://www.hca.wa.gov/hit/grant\\_awards.html](http://www.hca.wa.gov/hit/grant_awards.html).

Grant Applications (proposal submissions):

- [Community Choice, Physician, Hospital, Community Healthcare Network \(PHCO\)](#) (931.3 KB)
- [Inland Northwest Health Services \(INHS\)](#) (1.2 MB)
- [Inland Northwest Health Services \(INHS\), Addendum](#) (43.7 KB)
- [St. Joseph Hospital Foundation and The Critical Junctures Institute](#) (1.4 MB)

Pilot Project Presentations, August 27, 2008

- [St. Joseph's Hospital Foundation/Critical Junctures Institute](#) (1.2 MB)
- [Community Choice – PHCO \(Physician · Hospital · Community · Healthcare Network\)](#) (996 KB)
- [Inland Northwest Health Services \(INHS\)](#) (876 KB)

[Health Record Bank Evaluation Plan](#) (21.4 KB)

## **Washington State Health Care Authority: AccessMyHealth**

The AccessMyHealth.org partnership, convened by the Washington State Health Care Authority, is supporting the concept of online personalized health records: [http://www.accessmyhealth.org/AccessMyHealth.org Fact Sheet](http://www.accessmyhealth.org/AccessMyHealth.org%20Fact%20Sheet)

Consumer survey results <http://www.accessmyhealth.org/survey-results.php>.

Links & Documents about PHRs, EMRs & HRBs <http://www.accessmyhealth.org/links.php>.

## **Published Materials**

Bernstein WS, Murchison JV, Dutton MJ, Keville JD, Belfort RD. Whose data is it anyway? Expanding consumer control over personal health information, California Healthcare Foundation, February 2008 Issue Brief. Available at <http://www.chcf.org/documents/chronicdisease/WhoseDataIsItAnywayIB.pdf>.

Bourgeois FC, Taylor PL, Evans SJ, Nigrin DJ, Mandl KD. Whose personal control? Creating private, personally controlled health records for pediatric and adolescent patients. JAMIA 15(6) 737-743, Nov/Dec 2008. Available at <http://www.jamia.org/cgi/content/abstract/15/6/737>.

California Department of Insurance. Personal Health Records: A Helpful Tool for a Healthier You, May 2008. Available at <http://www.insurance.ca.gov/0500-about-us/upload/PHRreport051908.pdf>

Geardon, CJ, Barrett M, Brennan PF, Kibbe D, Lansky D, Nobel J, Sands D. Perspective on the future of personal health records, California Healthcare Foundation, June 2007. Available at <http://www.chcf.org/documents/chronicdisease/PHRPerspectives.pdf>.

Goldman J. Personal health records: employers proceed with caution. California Healthcare Foundation, Issue Brief January 2007. Available at <http://www.chcf.org/documents/healthit/PersonalHealthRecordsIB.pdf>.

Halamka JD, Mandl KD, Tang PC. Early experiences with personal health records. JAMIA 15(1) 1-7, Jan/Feb 2008. Available at <http://www.jamia.org/cgi/content/abstract/15/1/1>.

Kaelber DC, Jha AK, Johnston D, Middleton M, Bates DW. A research agenda for personal health records (PHRs). JAMIA 15(6) 729-736, Nov/Dec 2008. Available at <http://www.jamia.org/cgi/content/abstract/15/6/729>.

Mandl KD, Simons WW, Crawford WCR, Abbett JM. September 12, 2007 BMC Medical Informatics and Decision Making 2007, 7:25: Indivo: a personally controlled health record for health information exchange and communication. Available at <http://www.biomedcentral.com/content/pdf/1472-6947-7-25.pdf>.

Miller H, Vandenbosch B, Ivanov D, Balck, P., Summer 2007 JHIM: Determinants of Personal Health Record Use: A Large Population Study at the Cleveland Clinic. Available at [http://www.epicsystems.com/docs/mychart\\_study.pdf](http://www.epicsystems.com/docs/mychart_study.pdf).

Ralston JD, Carrell D, Reid R, Anderson M, Moran M, Hereford J, Patient Web Services Integration with a Shared Medical Record: Patient Use and Satisfaction. JAMIA 14(6) 798-806, Nov/Dec 2007. This describes Group Health's experience in Seattle. Available at <http://www.jamia.org/cgi/content/abstract/14/6/798>.

Tang PC, Ash JS, Bates DW, Overhage JM, Sands, DZ. Personal Health Records: Definitions, Benefits, and Strategies for Overcoming Barriers to Adoption JAMIA 13(2) 121-126, Mar/Apr 2006. Available at <http://www.jamia.org/cgi/content/abstract/13/2/121>.

### **Other Presentations and Web Conferences**

Holt, Matthew presentation: "The History & Future of the PHR OR Are a bunch of fleas arguing over who owns the dog?" at Northern California HIMSS on December 15, 2006, available at [http://www.nocalhimss.org/events/presentations/20061207\\_Holt.pdf](http://www.nocalhimss.org/events/presentations/20061207_Holt.pdf).

AHRQ 2008 Web Conferences on PHRs

March 05, 2008 [National Web Conference on Personal Health Records: An Overview](#)

April 03, 2008 [Personal Health Records: Personal Control of Health Data and Patient-Provider Communications](#)

May 08, 2008 [Practical Solutions for Engaging Consumers in the Design and Use of PHRs: Beyond User Centered Design](#)

### **PHR Vendor Websites (referenced in other cited materials)**

GoogleHealth	<a href="http://www.google.com/health">http://www.google.com/health</a>
HealthTrio	<a href="http://www.healthtrio.com">http://www.healthtrio.com</a>
Indivo	<a href="http://www.indivohealth.org/">http://www.indivohealth.org/</a>
Microsoft HealthVault	<a href="http://www.healthvault.com">http://www.healthvault.com</a>
NoMoreClipboard	<a href="http://www.nomoreclipboard.com">http://www.nomoreclipboard.com</a>
PassportMD	<a href="http://www.passportmd.com">http://www.passportmd.com</a>
Tolven ePHR	<a href="http://www.tolven.org/ephr.html">http://www.tolven.org/ephr.html</a>

### **Reference Related to Churning and Continuity of Care**

Bayley B, Denfield D, Edlund C, Paradis A, Wright B. Continuity and turbulence in an expanded Medicaid managed care program. Providence Health System - Center for Outcomes Research and Education, April 2001.

Boozang P, Braslow L, Fiori A. Enrollment churning in Medicaid: coverage gaps undermine the managed care system and continuity of care for the chronically ill. Manatt Health Solution, December 2006. Available at:

[http://manathealthsolutions.com/publications/articles/Enrollment\\_Churning.pdf](http://manathealthsolutions.com/publications/articles/Enrollment_Churning.pdf).

DeVoe JE, Krois L, Edlund T, Smith J, Carlson NE. Uninsurance among children whose parents are losing Medicaid coverage: results from a statewide survey of Oregon families. Health Services Research, 43:1, Part II February 2008, 401-418. Available at

<http://www.hsr.org/hsr/abstract.jsp?aid=124>.

DeVoe J, Krois L. Children's Access to Health Care: Results from the Oregon Survey. Office of Oregon Health Policy and Research, January 2006. Available at

[http://www.oregon.gov/OHPPR/OHREC/Docs/CAHS\\_FullReport\\_Final06.pdf](http://www.oregon.gov/OHPPR/OHREC/Docs/CAHS_FullReport_Final06.pdf).

Fairbrother G, Jain A, Park HL, Massoudi MS, Haidery A, Gray BH. Churning in Medicaid managed care and its affect on accountability. Journal of Health Care for the Poor and Uninsured, 15(1) 30-41, February 2004.

Grant VC, Heller L. Slowing Medic-Cal churn: counties collaborate to improve efficiency, California Healthcare Foundation, November 2008. Available at

<http://www.chcf.org/documents/policy/MediCalChurnMEPIC.pdf>.

Hadley J, Holahan J, Coughlin T, Miller D. Covering the uninsured in 2008: current costs, sources of payment, and incremental costs. Health Affairs web exclusive, August 25, 2008, w399-415. Available at <http://content.healthaffairs.org/cgi/content/abstract/hlthaff.27.5.w399>.

Hadley J, Holahan J. Covering the uninsured: how much would it cost? Health Affairs web exclusive, June 4, 2003, w3-250-265. Available at

<http://content.healthaffairs.org/cgi/content/abstract/hlthaff.w3.250v1>.

Hadley J, Holahan J. How much medical care do the uninsured use, and who pays for it? Health Affairs web exclusive, February 12, 2003, w3-66-81. Available at

<http://content.healthaffairs.org/cgi/content/abstract/hlthaff.w3.66v1>.

Sommers AS, Dubay L, Blumberg LJ, Blavin FE, Czajka JL. Dynamics in Medicaid and SCHIP eligibility among children in SCHIP's early years: implications for reauthorization. Health Affairs web exclusive August 7, 2007, w598-607. Available at

<http://content.healthaffairs.org/cgi/content/abstract/26/5/w598>.