Reviewer's report

Title: Integrated Personal Health Records: Transformative Tools for Consumer-Centric Care

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Reviewer: William Yasnoff

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Summary

This is a well-written and generally thoughtful manuscript reporting on the timely and important topic of integrated personal health records (PHRs). It is especially noteworthy since it includes the summarized results of the September, 2006, conference entitled, "Personal Health Records and Electronic Health Records: Navigating the Intersection." After a few needed corrections and omissions are addressed, and balance is improved on several issues that could be misleading (as described below), it will be a significant and helpful contribution to this domain.

Major Compulsory Revisions

1. Add some discussion and references about Health Record Banks

One increasing popular implementation approach to integrated PHRs is the Health Record Bank, defined as "an independent organization that provides a secure electronic repository for storing and maintaining an individual's lifetime health and medical records from multiple sources and assuring that the individual always has complete control over who accesses their information." (http://www.healthbanking.org ). Although the authors briefly discuss this at the top of page 14, references should be made to the existing literature (e.g. (1) Ramsaroop P, Ball MJ. The Bank of Health: A Model for More Useful Patient Records. MD Comput 2000; 17 (4): 45-8; (2) Gold JD & Ball MJ. The Health Record Banking Imperative: A Conceptual Model. IBM Systems J 2007; 46/1:43-55; and (3) Shabo A. A Global socio-economic-medico-legal Model for the Sustainability of Longitudinal Electronic Health Records. Part 1 & 2. Methods Inf Med 2006; 45: 240-5 & 498–505) to alert readers this option and thinking behind it, which represents a key part of what the authors describe as "Recent Progress Toward Integrated PHRs."

2. Reference the recent (and very relevant) NEJM articles on this topic

Two articles that are directly relevant to this topic appeared recently in the New England J of Medicine (probably after this manuscript was submitted): (1) Mandl KD and Kohane IS. Tectonic Shifts in the Health Information Economy. NEJM 2008; 358;16:1732-7; (2) Steinbrook R. Personally Controlled Online Health Data -- The Next Big Thing in Medical Care? NEJM 2008; 358;16:1653-6. These articles should be referenced.
3. Remove editorial comment about the need for a personal health identifier
On page 9, under the bullet "Identification Process," the authors state, "This issue is problematic in the U.S. which remains virtually alone among developed economies in the inability to implement a national unique personal health identifier." This purely editorial comment should not be included without a detailed and balanced discussion justifying the need for such identifiers (especially since there is considerable evidence that they are not necessary as well as substantial political opposition to their creation and use). Since such a discussion is well beyond the scope of this paper, the above sentence (which is not really relevant to this manuscript) should be deleted. Removing it does not compromise the key message that a reliable process is needed to positively identify patient information.

4. Add reference to Westin's recent work on privacy for the IOM
On page 10, in the first paragraph, the authors briefly review some of the recent survey findings on consumer attitudes about health information privacy. A reference to the recent report prepared for the Institute of Medicine by Alan F. Westin, a well-known and highly regarded privacy expert, should be included (Westin AF: How the Public Views Privacy and Health Research. Institute of Medicine, 11/07, available at http://www.iom.edu/CMS/3740/43729/48528.aspx )

Among other findings, the report indicated that only 1% of respondents to this national survey would be comfortable having their health and medical information freely used by researchers without their consent.

5. Avoid overstating the potential of the current RHIO model
On page 10, in the section on "No Mediating Structure," the authors state that "Collaborative initiatives known as Regional Health Information Organizations (RHIOs) involving hospitals, physician practices, laboratories, pharmacies, and other organizations are now emerging as a tenable model for health information exchange at a regional level." The phrase "... emerging as a tenable model ..." is not justified based on the current evidence, with most RHIOs either stalled or failing outright (See Fried BM: Gauging the Progress of the National Health Information Technology Initiative. California Health Care Foundation, 1/08, available at http://www.chcf.org/topics/view.cfm?itemID=133553 )

A phrase such as "... being explored as a possible model ..." is more consistent with available evidence today.

6. Clarify existing data about consumers' willingness to pay for integrated PHRs
On page 11, first bullet under "Value Realization/ROI," the authors state "Although many of the perceived PHR benefits accrue to consumers, it is not clear that they are willing to pay or subsidize the cost ..." This statement could be misleading, since all available evidence (albeit meager) indicates that a substantial number of consumers will in fact pay for such services (52%

7. Avoid implying widespread use or success of distributed PHR model as described in the Markle Common Framework

The section on "Common Framework" on page 12 could be misleading without an accompanying explanation that there are no current implementation examples of a federated PHR model (as described in the Common Framework), and that in fact all (or nearly all) existing PHR implementations are centralized. Otherwise, the reader might incorrectly conclude that this is a feasible and/or widely used architectural approach.

Minor Essential Revisions

1. page 1, Introduction, line 1, change "... that strengthen ..." to "... that can strengthen ..."
2. page 2, Background, paragraph 1, line 9, change "Med-alert" to "Medic-Alert (tm)"
3. page 2, Background, paragraph 2, line 2, change "... word, processing ..." to "... word processing ..."
4. page 3, first line, change "... adapted ..." to "... utilized ...
5. page 3, first paragraph, last sentence, change "... price we pay by not investing in ..." to "... opportunity cost from the absence of ..."
6. page 3, PHR MODELS AND FUNCTIONS, second paragraph, line 5, change "... is allowed ..." to "... is typically allowed ..."
7. page 4, line 2, change "... consumers, can add to and modify portions ..." to "... consumers can add to or annotate portions ..." ("modify" evokes extreme concern among providers who are justifiably worried about the integrity of data obtained from an integrated PHR that originated with external sources other than the patient)
8. page 4, last line, change "... functions as described below." to "... functions:"
9. page 5, TRANSFORMATIVE POTENTIAL OF INTEGRATED PHRS, consider mentioning the provision of a more complete record here. Although it is mentioned later, seems that it deserves more prominent placement as it is a key benefit.
10. page 8, Scope of Work/Responsibilities, line 10, change "... many if not most ..." to "... many, if not most, ..."
Level of interest: An article of importance in its field

Quality of written English: Acceptable

Statistical review: No, the manuscript does not need to be seen by a statistician.

Declaration of competing interests:

I am Founder and President of the Health Record Banking Alliance (HRBA), a non-profit organization that promotes patient-controlled repositories of health information (no compensation).