

Health Record Bank of Oregon Advisory Committee

Minutes and Response to Issues Raised

Portland State Office Building (PSOB)

800 NE Oregon Street
Conference Room 1D
Portland, OR 97232

October 28, 2008

3:00 p.m. – 5:00 p.m.

Members in attendance were:	Joan Ash, Nancy Clarke, Andy Davidson, Dick Gibson, MD, Tom Holser, Gil Muñoz, Jody Pettit, M.D., and John Sattenspiel, M.D.
The following members were not able to attend:	Rick Benton and Corliss McKeever.
Project team:	Miles Hochstein PhD., Douglas Jones, Barry S. Kast, MSW, Lisa Mallett, Tom Ricciardi, Ph.D. Dave M. Witter Jr.
Guests included:	Tristan Horne, Marcus Malcolm, Wayne Manuel, Ree Sailors, Abby Sears and Greg Wenneson.

Introductions were made and recognition and gratitude expressed to those present who had worked on the Health Record Bank of Oregon (HRBO) in the past: Miles Hochstein, Jodi Pettit, Tom Ricciardi, Greg Wenneson and Dave Witter.

Barry Kast presented the [HRBO conceptual plan](#) with the PowerPoint slides and interaction with Douglas Jones, and consultants, Dave Witter, Tom Ricciardi and Miles Hochstein. The advisory committee fully participated and presented many questions and comments.

The following issues were identified for further development. These issues are not presented in the sequence they were raised but grouped by theme in a logical order consistent with the presentation to the Committee.

■ **What is the definition of success to CMS?**

Success will be defined by a series of milestones in the development and implementation of the HRBO, not a single endpoint. These milestones include an initial beta roll-out and a later large-scale roll-out. Specific measures of success are included in the grant proposal and work plan. The level which each of these measures should achieve remains to be determined.

■ **The definition of PHR is broad.**

We agree that PHRs take many forms and offer a spectrum of patient control levels. The CMS-funded grant to the State of Oregon mandates a particular kind of personal health data store using an HRB model.

■ **Will this be a PHR or an HRB?**

The State of Oregon has been funded by CMS to develop an HRB. Please see project documents for what this means, and for information on how a PHR is similar to and different from the HRB model. Some people refer to an application that presents individual health data for viewing as a “PHR,” and in that sense this HRB includes a PHR.

■ **Will the HRB be specific to Oregon or is it a generic system?**

The HRB idea is currently being implemented in three pilot projects in Washington. Other PHR projects around the country also include varying degrees of patient control. HealthVault and GoogleHealth are national HRBs, and may be incorporated as well as “back-ends” for HRB-like services, as is being done in Washington State.

■ **Who will be the end user?**

Patients and patient designees including physicians and clinical staff will be the end users.

■ **What would the caregiver find valuable?**

A long-term aggregating repository of medical information that is available when seeing a new patient, or a patient who has not been consistently seen within the current service setting, and that enables the physician to view past or current medications, lab tests, diagnoses and other information.

The HRB is predicated on the idea that caregivers sometimes lack important information, and that the consumer can help the caregiver by providing that missing information or, as consumers routinely do in the exam room, providing information that enables physicians to ask better questions.

■ **What would the consumer find valuable?**

A long-term aggregating repository of medical information that remains available over time and that can be used when he/she enters a new care setting to report past or current medications, lab tests, diagnoses and other information.

The HRB is intended to support better and more informed conversations between providers and patients. The HRB is predicated on the proposition that consumers will find it valuable to have copies of their health information, much as they find it valuable to have copies of their financial records. Having a partial but longitudinally uninterrupted view of their records will permit them to take a more active role in their care and responsibility for their health status.

■ **What data will be available to whom and where and when?**

All data types available to the HRB will be available to patients and patient authorized physicians, at any Web enabled location, at any time. See our plan document for authorization pathways.

■ **Will every current Medicaid life be enrolled in the system? There is a lot of churning, etc. What is the scope and target population?**

The goal is to make all Medicaid enrollees eligible to enroll. We do not anticipate that all will elect to participate by opening an account.

■ **Is enrollment voluntary for the patient? Will OHP patients be willing to volunteer?**

All participants in this project will be volunteers, because enrollment is voluntary. Nonetheless, the contracted community partner(s) will be expected to “market” the HRBO to eligible consumers and encourage its use.

■ **Because of “churn” there will be people who are uninsured that were Medicaid clients at some prior time. We should broaden the definition of eligibility to them as well. This will help reduce costs at hospitals that are not reimbursed for the costs of their care. How about an operational definition that permits persons who have been on Medicaid within the previous year to be Medicaid-eligible for the purposes of the HRBO?**

“Churn” is the tendency of Medicaid enrollees to leave and return to eligibility, or to change plans and providers with relatively high frequency. For the HRBO to offer persistent data about an individual, information from all plans and providers, as well as from periods when the individual is not enrolled in the Medicaid program, must be included. The planning team has been thinking along these lines and raised the possibility with the CMS project officer.

■ **Will this be expanded to other populations?**

That is the goal, but not within the period of this grant.

■ **How easy will it be for someone to enroll, and have data available?**

It will be as easy as can be engineered. An individual will receive credentials as a Medicaid recipient. Using those credentials plus shared secrets to login into the system, the following functions will be available:

- Request that data from one or more sources (for example DMAP) be downloaded into their HRB account.
- Set access permissions, from restrictive to permissive.
- Print a wallet card if they are able and wish to do so.
- Print a copy of records to present to the provider at the point of care.
- Give a username or other credentials to a provider or provider’s staff to login and view and/or print records.

■ **The target population only covers half of the project. What provider groups are being targeted? Who is going to have an opportunity to log on to access the data, given a rich population of patients? The HRBO should focus on providers serving a high concentration of Medicaid patients.**

These are important issues. The use of the system itself is intended to be 100% voluntary for providers and for patients. We recommend that providers NOT use it unless they believe that they will be able to find information that is useful for patient care.

The HRBO's goal is to ensure that the information it contains will justify its use. The role of the community partner is to educate and involve providers so that they are aware of the HRBO and its potential utility in those circumstances in which patient data appears to be less complete than it should be.

■ **The practitioner and the patient are the heart of the health care system. The HRBO should not interfere in the “doctor-patient relationship.”**

This theme has been repeated in numerous discussions with key stakeholders. The HRBO is

being designed to strengthen, not interfere with, the doctor-patient relationship. Washington State has used an apt slogan for its three projects “Starting a Conversation about Health” and we see this as an important goal of the HRBO project: Better communication between providers and patients about current health issues.

■ **Is the HRBO focused on or limited only to primary care?**

The HRBO will initially focus on primary care and emergent care, and particularly focus on new patients or frequent users of diverse services.

■ **Will patient histories be provided at the point of care?**

HRBO will focus on data types in priority order. Patient histories are relatively low priority.

■ **What is the source for allergy and immunization data? How do we know we will get any of this information?**

Allergies would be obtained by consumer-entered self report. Immunization data will eventually be available from the state immunization registry (ALERT). A high priority has not yet been placed on this information. The team invites input on the relative importance of different data types set forth on page 5 of the discussion draft narrative plan.

■ **What consumers value most of all is lab data.**

Labs would be very useful, and our discussions indicate that the absolute number of labs in Oregon needed to capture most lab tests is relatively limited.

■ **The first schematic slide doesn't show patient input.**

Yes, the first slide is not quite right and will be amended.

■ **When does data get loaded? When and how much access does the provider get?**

Data gets loaded when patient establishes an account or authorizes its establishment on his or her behalf. The provider gets as much access as the patient authorizes, up to and including ongoing access.

■ **The timing of data load is key. Will it be there before the patient arrives?**

Population of the data store will probably not occur before first login and sign up. After opening an account it will be continuous, subject to various technical parameters. An alternative under consideration in other states is to populate the database for all Medicaid recipients and only make it available once an account is established. This issue is worthy of further discussion. It is worth noting, however, that with the implementation of the new MMIS, it may be more difficult than anticipated to transfer data easily from DMAP to the HRBO in the immediate future.

■ **Will patients be easily able to authorize that their MDs have access their information quickly?**

HRBO seeks to make it as easy as possible to authorize access. We anticipate that this will include an option for consumers to authorize full access to their providers on sign up, and an option to authorize one time access to a single provider, or other similar limited access options. However, the HRBO does not anticipate at rollout that patients will be able to pick and choose specific data elements to share. Upon sign up the approach will be an all-or-

nothing data authorization.

- **The paper workflow (“print and carry”) is a serious mistake. This population can’t be expected to go to a library and print the information. Look for the “sweet spot,” a place that can help patients sign up and use the record and has a lot of target patients and providers that are committed to using the HRB.**

The HRBO will offer Web browser access to patients and authorized providers. A natural component of such access is the opportunity to print. We are developing approaches that might be used by community partners to integrate HRBO data from a browser into the work flow, including reading directly from a browser and printing. Whether direct downloads will be added as a function of the HRBO at a future date is yet to be determined.

- **What about the whole Emergency Department (ED) scenario? The paper scenario is a problem there.**

A wallet card might be a good option in the ED, particularly for those unable to offer consent onsite due to cognitive impairment. Alternatively a Web address and login ID on a wallet card might also be a good solution. We are open to provider-preferred solutions within the context of the simple technology made necessary by the constrained budget, and within the context of patient consent principles.

- **What latitude does the project have to get data sources to provide data? The politics around this will also be huge.**

We should be thinking both about what the technology partner and community partner offer in terms of data sources as part of their proposals, but also in terms of how the state can bring its leverage to bear. For example, the technology vendor might propose a data source with which the state has limited ability to help. In what areas can the state help, and do we make that public in advance and in the RFP?

- **Is it easier to pull information from an interface, or is it more difficult to get from the ambulatory EMR? It apparently is easier to get from the hospital interface using the CCD or CCR. It could come from the hospitals with less difficulty than from the doctors’ offices.**

A hospital or hospital system is certainly a potential community partner. Individual doctors’ offices or even small group practices are almost surely not potential community partners.

- **People using OHP are a lot more Internet savvy than had been thought. OHP found that 30% of OHP have access at home.**

And a further 20 or 30 percent had access to the Internet in the library or elsewhere. The community partner(s) will be asked to propose how Internet access would be extended to those without access, or who have language or cultural barriers, or disabling conditions that obstruct their use.

- **Do we have a user interface (UI) for the provider or not? It would be helpful if this were clarified through labels on the technology architecture slide, as well as understanding of sequence.**

Simplicity and transparency dictate that their will likely be a common user interface for account holders and providers. Providers may have additional functionality available. Provider authorization keys may, for example, lead to a multi-patient search function that

would not be available to individual patients. However the basic browser interface would be common to account holders and authorized provider users.

- **The second technology slide shows the patient and the provider as equal circles, rather than the information flowing through the patient.**

The information does not flow exclusively through the patient because authorized providers may access patient information through a browser.

- **There is no legal requirement to put information into an electronic repository.**

This question appears to come from a feeling of “You can't make me do this!” Not only can the state not make providers supply data in electronic format, this is not a goal of the grant. However, if an organization is selected as a community partner then, having made that choice as part of the grant, it will be expected to work with the technology partner to facilitate data transfer. The planning team discussions do not center on requiring provider data in order to get payment. Rather the team is seeking access to readily available data sources.

- **Is use of the HRB voluntary for providers? Will Medicaid providers be mandated to provide data? Providers are concerned about what may be required of them. For example, will they be asked or required to give the HRBO a CCR or CCD? The data acquisition issue is huge. The data requirements vary depending on whether the practice is hospital- or office-based.**

Exporting data to and using the services of the HRBO are voluntary for providers. We do not anticipate that Medicaid providers will need to transfer any additional data beyond that which they currently provide to Medicaid. It is undetermined whether participating Medicaid providers, in order to contribute to or use the system, will need to register with the HRBO via a simple online sign up. While HIPAA requires that patient health information be accessible to the patient, nothing requires providers to transmit electronic or paper documents to the HRBO.

There seems to have been a widespread misunderstanding that providers will be required to modify their EMRs or be compelled to provide data into the HRB. Only contracted community partners will be asked to foster data transfer from EMR systems to the HRB, and they will do that as a grant funded activity. Other data sources may include:

- (1) patient self-entered data;
- (2) reports from various Oregon laboratories;
- (3) RxHubSureScripts;
- (4) pharmacies (for example, Walgreens, CVS).

The selected technology vendor will offer the best potential capture rate for data from these and other data types, for the largest percent of the Medicaid population. Data from a community partner EMR will probably be less important than data from labs and pharmacies. The HRBO aspires to grow the number of data sources that feed the HRB over time.

- **The consumer control principle is only half of the implementation process. If Medicaid expects to improve care, providers need an easy way to access and provide data, confidence in the information available, ability to amend, and so on.**

Ease of authorized access is a goal. Confidence in stored information is relative. All reports

from the HRBO will be tagged by source. To the extent that the provider may have questions about the accuracy or thoroughness of a report, the HRBO information may initiate a conversation between doctor and patient about, for example, current medications, recent tests or diagnoses or where and when tests were taken, and facilitate obtaining additional information about a patient.

Information in the HRB account is not intended to function as a medical record. The HRBO anticipates allowing annotation, and possibly amendment, of the record by either patient or provider. This further highlights the fact that the information in an HRB is not a medical record and will not be represented as such. It offers a good starting point when significant clinical information is lacking at the point of care.

- **Many PCPs are reluctant to see OHP patients currently, and a system that is cumbersome to use will not succeed. It can't be expensive for the provider to use or a significant disruption to the practice workflow.**

The system will be available at no cost to PCPs, and they will not be obliged to expend practice resources or engage in activities that would intrude on practice workflow. However, the HRBO may offer the PCP the opportunity to read a paper record provided by a patient, or to view the person's information via a Web browser, with minimal effort.

The PCP is under no obligation to examine the information contained in the HRB unless he or she feels that additional information relevant to quality care might be found there. A desire for minimal disruption was in part the basis for Washington State's "print and carry" strategy for providing health information to the provider.

- **Ease of workflow remains a significant issue. The provider must be willing to do "something" to get the information.**

The ease of use has been assumed but we need it to be explicit. The HRBO will offer Web browser access to patients and authorized providers. A natural component of such access is the opportunity to print. Additional approaches might be developed for use by community partners to integrate HRBO data from a browser into the work flow, including reading directly from a browser and printing.

- **How about financial incentives to use data?**

To some extent the community partner is receiving an incentive to facilitate the provision of EMR data. More broadly, obtaining data sources would be a contractual responsibility of the technology partner and may be posed in the RFP as follows: "Given requirements for these data elements, with whom do you propose to establish relationships and what technical means will you use to acquire their data?"

- **The hospitals want to see this succeed. MDs also need to be able to input data. To achieve this, the project will have to offer incentives.**

The team has not contemplated MD data input. Though this has not been precluded, the project probably should not depend on them given the already burdensome challenges they face. The state most surely could not pay them enough.

- **The permanency or persistence of data in an HRB assumes everything is sustainable, correct?**

Permanency has multiple meanings. The availability of HealthVault and GoogleHealth means

that no-cost persistence is available for future storage of a patient's data, even if the grant funded HRBO infrastructure (which might include data transfer networks and the user interface component) is canceled for lack of funding. So data permanency is different from institutional permanency. Institutional permanency through sustainable funding is the goal, but absent institutional permanency, at least two viable paths to data permanency and limited accessibility are known to exist.

■ **When a patient wants to transfer data between institutions, remember that many different IT systems are in place already.**

This reflects a misunderstanding of proposed functionality. Initially, transfer of information between groups will occur via browser or paper only. No higher level exchange is proposed under the grant at this time.

■ **What might we be able to expect in terms of interoperability. A matrix of ease of acquisition vs. desired data would be a useful planning tool.**

The matrix of ease versus value is important to deciding what data should be pursued. We look forward to receiving that input from the Advisory Board

■ **Portability is missing. Consumers may choose to use a free health bank elsewhere. Will a Medicaid PHR be able to compete with HealthVault or GoogleHealth? To avoid this, the HRBO will need an easy way to get data into HealthVault. How much will Medicaid be willing to invest in interfaces?**

One potential solution for building the Oregon HRB is to follow the Washington State model and use HealthVault or Google Health as the data storage and interoperability platforms for HRBO. In that model:

- Medicaid funds will be used to build data transfer systems, and a user front end for managing authorizations and security.
- Should Medicaid funding no longer be available in the future, consumers, would retain access to their data stored in one of these large and highly secure national Health Record Banks.

■ **Kaiser is exporting to HealthVault.**

The planning team is aware of this. Kaiser is engaged in a limited experiment with employees. Currently Kaiser is beta testing it with KP Employees. Once that is done, they plan to turn on the functionality for all KP Patients. The Kaiser effort points to the potential viability of GoogleHealth and HealthVault as potential solutions for the HRBO.

■ **It does seem that progress is being made. What are the RFP criteria? Can we see this? Glad to see that there is a process there. But we are still wrestling with critical issues, especially data entry into the system and the impact of the HRBO on practice workflow.**

These issues have been partly addressed earlier. With regard to workflow, the team understands the challenge. One approach would be to convene a group of physicians and clinical managers to ask them directly how they would like this system to function to maximize its utility. Another possibility would be to call on an OHSU researcher like Paul Gorman to do some rapid empirical work using pseudo-HRB records to find out what works locally.

- **What are the budget line items for “everything else” besides managing the project? What is the ratio of spending on community partner and technology partner? This seems like a real problem and may be an argument for inviting joint proposals to describe how to balance the whole package.**

Collaborative proposals, or a proposal that addresses both sets of requirements, may be permitted. The exact ratio of technology to community partner expenditures has not been determined though there are placeholders in the budget line items. Not-to-exceed amounts may be specified in the RFP, or determined based on costs brought forward in proposals.

- **Will proposal responses will be only for community partners and/or technology and/or both?**

HRBO will seek one technology partner and one or more community partners. Joint applications will be considered, but HRBO will treat each component separately.

- **What are we looking at for an HRBO platform? We should be following the lead of the IHE and CCHIT in terms of the requirements. Document repository vendors are limited to IBM, InterSystems, and a couple of German companies. The CCR is a key format. Who can export this?**

The state should identify adopted standards in contracting. Whoever is selected as the technology vendor will need to address what options will be available in the event state funds are no longer available to ensure that account holders still have a usable account and a persistent record?”

- **What is meant by “go-live?” Is this a pilot or is it bigger?**

Insofar as this project is a demonstration of the use of information technology to transform the delivery of effective care, the project may be considered a pilot. Experience gained in the beta testing process for the HRBO will be fed back to the technology and community partners who will be expected to make modifications necessary to cope with any problems noted. The HRBO will be rolled out incrementally and then broadly once the grant period has ended provided sustainable funding is available and the project has demonstrated value.

- **The selected vendor must be able to engineer a Web site that is consumer friendly. The portal must be outside the structure of government in which it is easy to get lost.**

In the long run it will be good to have the HRBO not only seem but actually be genuinely independent of state government, but licensed and regulated in the public interest. Initially, however, the project is federally funded and accountable to the state Medicaid authority under the conditions of the grant.

- **Recommend another bullet related to the technology partner: humility. The selected vendor should stay engaged and help facilitate continuing involvement of Medicaid in this emerging technology-driven world.**

Agreed.

- **In terms of governance, do we need to have a public governance committee? We had too many stakeholders previously. Will we get cooperation in the community if we don't involve the community? Recommend that we keep this in DHS and schedule monthly meetings for the next 15 months. Two meetings are not going to be enough.**

The team is contemplating governance options, some of which may affect future financing of

the HRBO by CMS. While there is no restriction to stakeholder involvement, a small Advisory Committee was appointed to affirm state accountability for the project and avoid the chaotic experience of the Steering Committee. If some or all Committee members are willing, additional meetings on a regular basis can be scheduled. For those who cannot continue, other community representatives can be appointed.

■ **Please define acronyms MMIS and FFP.**

MMIS - Medicaid Management Information System, focused primarily on generating management information and adjudicating claims.

FFP - Federal Funds Participation, the matching arrangement in which state and federal resources are combined to support the Medicaid program.

■ **Keeping in mind the KISS principle (Keep It Simple, Stupid) will our elected officials get a brief once-over about what this is and how it is important?**

Good idea. Consumer-centric health care is the future and the HRBO or something much like it will probably be incorporated into the Health Fund Board recommendations. A legislative briefing is anticipated.

Consumer-centric health care has the potential to be good politics on multiple levels – consumer protection, consumer rights, consumer empowerment, and fitting in with the bipartisan national consensus on the importance of “Health Information Technology” to improving quality and controlling costs.

■ **Evaluation should be on an ongoing basis rather than just at the end. There needs to be involvement of OHPR at the beginning.**

Agreed. Discussions with OHPR have begun and a Memorandum of Understanding is in place to assure ongoing evaluation.

■ **What else is the team looking for from the Advisory team? Do we want feedback? Are we providing value? What questions should be asked to know if the project is moving in the right direction?**

The issues raised at the meeting have been enormously valuable and will assist the team in adjusting the plan to address them. The team will benefit from further recommendations at the next meeting, and any additional input individuals wish to have as the process goes forward.

Next Advisory Committee Meeting: November 18, 2008, 2:00 to 3:30 in the PSOB Room 1D.

An Agenda for the next meeting was not discussed. Members of the Committee reaffirmed their willingness to participate in additional meetings.