A Field Guide to Online Personal Health Records

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Since the late 1990s when DrKoop.com first encouraged us to put our medical health histories online, web-based personal health records, or PHRs, have been a subject of much interest and debate in the healthcare community. Leading the discussion are issues of privacy, patient ownership of data, accuracy, and availability of data. In 2001, I had the privilege of working with a prominent pediatric hospital to develop a customized PHR for their patients with chronic health problems (with a focus toward treatment tracking for “frequent flier” kids), so the subject remains near and dear to me.

I recently was asked by a large integrated delivery system client in the Midwest to look into the current “state of the state” of PHRs. The organization was considering a PHR primarily to meet the proposed Stage 2 Meaningful Use criteria by offering patients electronic access to their health information. But the organization also saw value for both patients and providers by using a PHR as an aggregation tool for integration of patient data from their three core EMR systems (one inpatient, two ambulatory) into one longitudinal patient record.

It was interesting to discover how the PHR market has evolved over the past 10 years. What I found was that PHRs that are based on patient data fed from healthcare provider systems have stratified into three distinct flavors: tethered, portal, and open platform PHRs.

### Three Types of PHRs Fed by Patient Data from Healthcare Provider Systems

- **Tethered**
  - Provide patients with an electronic copy of health information (including lab results, problem lists, medication list, allergies, discharge summary, procedures) upon request using secure electronic methods.
  - Provide patients with an electronic copy of their discharge instructions and procedures at time of discharge upon request.
  - Provide access to patient-specific education resources.

- **Portal**
  - Provide access for all patients to PHR populated in real time with health data.
  - Provide access to patient-specific educational resources in primary languages.
  - Record patient preferences (e.g. preferred communication media, healthcare proxies, treatment options).
  - Document family medical history, in compliance with GINA, the Genetic Information Nondiscrimination Act of 2008.

- **Open Platform**
  - Provide patients with access to self-management tools.
  - Utilize electronic reporting on experience of care (details still under review).

Tethered PHRs

The fastest route to providing a patient-facing personal health record is to use a tool provided by your EMR vendor. For example, Epic MyChart and GE Centricity Patient Online are read-only “windows” into the EMR. The PHR is usually just one component of a more comprehensive patient portal with tools for physician communication, physician scheduling, and bill inquiry and payment. A number of major health systems have implemented a tethered PHR. For example, Oregon Health and Science University and Dean Clinic are just two of several organizations that have rolled out Epic’s MyChart, including the iPhone application.
In general, tethered PHRs are an excellent option for many healthcare organizations. They are easy to configure and are well supported by your core EMR vendor, but they have some inherent limitations. They are tied to a single product. If your organization has multiple ancillary, ambulatory, and inpatient EMRs, you will likely have multiple tethered PHRs as a result, which will lead to a less than optimal patient experience.

Also, most tethered PHRs limit the amount of data the patient is allowed to enter or maintain themselves. If the encounter didn’t happen in the facility with the tethered PHR, there is no way for the patient to add it to their record. In that, the tethered PHR needs to be seen more as a convenience for patients to access their data from your facility and not be marketed as a complete PHR solution. For that, you need to look to the next two flavors of PHRs.

**Portal PHRs**

Portal PHRs are products from third parties that can be branded to your facility and are fed by your systems but are capable of supporting self-entered information as well as entry from multiple EMR systems (including partner facilities). The PHR itself is offered as part of a more comprehensive “patient portal” product, incorporating physician communication and schedule request functionality. Examples include Medem iHealth (now MedFusion), MedSeek, and RelayHealth. Cerner’s PHR also fits in this category, being based on their Cerner Connect (HIE) platform, rather than directly tied to their Millennium EMR platform.

Some of these names will be more familiar as HIE enabling data aggregators. The core technology behind a PHR related to medical information import and display can be “turned” to be provider facing as well.

As such, the portal PHR tends to be a product you purchase in addition to the rest of your physician connectivity suite for HIN/HIE enablement. If you are a geographically diverse system with multiple hospitals on multiple EMRs and also wish to integrate ambulatory data from affiliated physicians, a portal PHR solution is a great way to go not only for your patients but for your physicians as well. For example, Saint Luke’s Health System in Kansas City has implemented RelayHealth’s portal product (internally branded at Saint Luke’s as “Carelink”) for provider connectivity and rolled out the PHR as well although PHR wasn’t their primary driver for the project.

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Be aware that as with a tethered PHR, patients are limited to viewing data from your facilities, and this may not be seen as a truly cross provider “personal” health record. An ED visit to a competitor’s hospital would not show up in the patient’s PHR (unless, of course, your competitor is participating in a HIN).

That said, a portal PHR is still a wise investment and would help your organization deliver on Stage 2 Meaningful Use criteria and could provide a framework for HIE connectivity as well. The client I was performing the recent assessment for selected a portal PHR (NoMoreClipboard.com) for their PHR and physician connectivity solution.

**Open Platform PHRs**

In 2008, two major players entered the PHR market: Google Health and Microsoft HealthVault. These tools offer a true provider-neutral PHR platform that patients can add their own data to as well as “hooks” for importing data directly from pharmacies, lab providers, and health networks.

The fundamental difference is that your health system does not own this record. You feed patients’ records, and the records are then the patients’ to keep and maintain. There are tools to import pharmacy data from major retail networks and direct interfaces from networked glucometers and home health monitors. They can even import data from competitors’ networks as well. In terms of the promise of a truly “personal” health record, these tools lead the way.

A number of major health systems have rolled out direct support for the open platform PHR.
The Cleveland Clinic is an early supporter of data export to Google Health while continuing to provide a tethered PHR for their Epic Clinical EMR. The Mayo Clinic partnered with Microsoft to populate data into HealthVault, and a new PHR based on HealthVault was recently rolled out by Virtua, a multi-hospital system in Marlton, New Jersey, as a part of its Virtua Woman health and lifestyle portal.

A major challenge is that because you do not host or own this data, the onus is on the patient to go to Google or Microsoft and create an account that you can then link to. Whereas in a portal or tethered solution, you can simply hand the patient an ID card at discharge and have your support team create the account.

So where does the health system fit into this? If the goal of a PHR is to provide value to the patient that will help retain them as a future customer, how does this open solution help?

First, simply by supporting an open platform PHR, you present your organization as a forward-thinking health system, and you are compliant with Stage 2 Meaningful Use criteria. And because more of the patient’s longitudinal health history across health systems is in the tool, there is stronger incentive for maintenance and daily use.

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To preserve brand identity, there are multiple products that provide a customizable shell that lays across the top of an open platform PHR, offering your health system a branded “entry point” into the PHR as well as adding custom data elements and health maintenance tools. For example, the Mayo Clinic Health Manager tool is built on top of the HealthVault platform. One can create a Health Manager account without being a Mayo patient. The security and access is controlled by Microsoft, not by Mayo. Mayo is only providing a window into Microsoft’s functionality.

However, since this PHR is entirely patient-owned, this data cannot be easily repurposed into a provider-facing view for HIE enabling. This is a true personal health record solution.

All or Nothing?

In the end, the ultimate solution for your organization may be some blend of the three aforementioned flavors of solutions. A number of portal PHR vendors support import and export with the open platform PHRs, so you can support both the open platform and your HIE enabled portal PHR. Likewise, your tethered PHR may be your preferred offering to patients, while you also support open platform export for those savvy enough to have established them.

Your PHR strategy must take into consideration several general caveats:

1. **Providers are skeptical of patient-entered data.** While giving patients the ability to customize their records is a key to them taking ownership and retention, be aware that providers continue to be skeptical about the validity of patient-entered data, especially documentation of any previous encounters, treatments, or diagnoses. I’ve heard from several physicians that “Google is the hypochondriac’s best friend”, and there is a great fear of trusting a “medical record” that may have been altered to suit an ulterior motive. To ameliorate this, most PHRs that allow data for import have non-editable indicators of where the data was sourced. Be sure that in any solution you pursue, that the user editable areas are clearly segregated and identified.

2. **Also be aware that right now, user adoption of PHRs is very low.** One healthcare system I recently worked with indicated that use of their tethered PHR (for which every patient was given a login at discharge) was less than 10 percent on an ongoing basis (though initial signup rates were higher). Studies by Forrester and The Advisory Group put use of portal PHRs at a much lower rate. And Microsoft recently announced that due to low user volumes (leading to lower search traffic through their Bing tools in HealthVault), they were not anticipating HealthVault to be profitable in any foreseeable timeframe.

3. **However, this user community is growing, especially among younger, more technically literate patient populations.** Many parents are creating PHRs for their babies and using printouts from that record to help fill out school forms. Many PHRs are also being pitched to adult

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children caring for elderly parents as a way of having their parents’ health information easily accessible during a crisis. And coming back to the population that got me engaged with PHRs in the first place, patients with complex chronic health issues continue to be strong adopters of PHRs since tracking of their complex conditions can be difficult in a paper-based system and, unfortunately, their health issues will likely continue throughout their lives. Further, use of tethered PHRs is also on the rise, with one site reporting a 35 percent signup rate, and almost half of those who signed up actually used the system to review lab results in their PHR.

Recommendations & Next Steps

Despite the challenges, a PHR holds great potential for patient health. Having access to one’s own medical record is a recognized right, and these tools can help patients take ownership of their own records and their own health.

If you are a facility predominantly with a single EMR, the tethered PHR is an easy choice. If you maintain multiple EMR systems across your organization, the portal PHR solution may be right for you, and even more so, if you intend to roll it out as a component of a larger HIE strategy.

Clearly, I believe that the open platform PHR is going to be an important component moving forward, but it may take some time to mature. At this stage, you will be well served by supporting export to Google Health or HealthVault, but you may not want to build your organization’s PHR offering around this platform. This may change in the years to come as more tools for creating “custom entry points” enter the market. Here are some pragmatic next steps you can take when evaluating the right type of personal health record for your organization:

1. Learn more about PHRs:
   - The American Health Information Management Association (AHIMA) maintains an excellent web resource on personal health records at http://myphr.com. At this site, there are patient testimonials and industry resources to help you make the case to your organization for PHRs.

2. Define the vision for and objectives to be achieved by a PHR:
   - Meaningful Use can be supported by a tethered strategy alone even in a multi-EMR setting.
   - Going to a portal and/or open platform PHR should be justified by increased benefit to your organization AND your patients. The Virtua Woman PHR mentioned above was rolled out as a value-add to a larger women’s health product offering. The Cleveland Clinic and the Mayo Clinic both got considerable publicity for their open platform partnerships. How will the additional benefits of a portal or open platform PHR be presented to YOUR patient population and marketed?

3. Assess your own PHR options:
   - For single EMR organizations, does your EMR vendor offer a tethered PHR?
   - Are you currently using HIE or physician connectivity portal toolsets that might already include PHR functionality?
   - What are your local competitors doing? What do you need to do to leapfrog their functionality?

4. Decide if you will support open platform PHRs:
   - Even if you have a portal or tethered solution, offering an export to support Google Health and HealthVault is a great way to expand your services and increase patient satisfaction.

Other PHRs

This article is concerned with three flavors of provider-centric PHRs. There are two other types of PHRs to be aware of:

1. **The Self-Maintained Record** – This is a fully patient maintained personal health record with no data feeds from healthcare providers. This is the old Dr Koop.com model. These can be desktop applications or web-based solutions, but they are entirely self-maintained.

2. **The Claims-Fed PHR** – offered by insurance providers, it shows you your health history by way of your submitted claims. These PHRs usually include health management tools as well.

Both PHRs have direct benefit to consumers, but neither is directly fed by or maintained by healthcare providers.
• DrKoop.com is a Registered Trademark of Vitacost Holdings, Inc.
• MyChart is a Registered Trademark of Epic Systems, Inc.
• Centricity is a Registered Trademark of General Electric Company.
• iHealth is a Registered Trademark of Medem, Inc.
• MedSeek is a Registered Trademark of MedSeek, Inc.
• RelayHealth is a Registered Trademark of McKesson Technologies, Inc.
• Cerner Connect and Cerner Millennium are Registered Trademarks of Cerner Corporation.
• Google Health is a Registered Trademark of Google, Inc.
• HealthVault is a Registered Trademark of Microsoft Corporation.

About the Author

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Jim Balabuszko-Reay has over 18 years of experience as an accomplished program manager and advisor to healthcare and IT executives. His deep understanding of healthcare operations, breadth of technical experience, and strong interpersonal skills enable Mr. B-Reay to demonstrate equal comfort assessing technical details, managing a diverse project team, or facilitating decisions among a group of executive and clinical sponsors. With a background in application design and data warehousing, Mr. B-Reay has also assisted healthcare clients in reaping the benefits from operational systems by creating innovative solutions to convert transaction-based clinical and financial data into strategic information to support management decision-making.

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