

Section 6.6 Optimize

Personal Health Record

This tool provides information about personal health records (PHR) for both care coordinators (CCs) who may wish to recommend their patients adopt a PHR, and for community-based care coordination (CCC) programs considering options for offering their patients PHRs.

Time required: 3 hours

Suggested other tools: Approaches to Patient Communications; CCC Patient Plan (and template); Patient Action Plan (and template); Patient Health Diary

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How to Use

1. **Review** the content of this tool to become familiar with personal health records (PHRs).
2. **Determine** what type of PHR offering the CCC program will be making, if any. Encourage patients to sign up for the PHR offered by the CCC program. Use it to monitor patients' health diaries and to track results of lab tests, referrals, etc.
3. If the CCC program does not plan to offer a PHR at this time, **use this tool** as a reference for any questions patients may have about PHRs, and if they show strong interest, use the tool as a resource to guide them in making an informed choice about what PHR to use and how to use it.

Introduction to PHRs

Increasingly, individuals are interested in keeping personal health records (PHRs) to better communicate with their health care providers, enhance their understanding of their health and treatment options, make sure health information is as accurate and complete as possible, and improve family health management. PHRs have been found to improve patient engagement in their health and wellness, which research has shown leads to better health care quality and reduced patient safety issues. (See *A Leadership Resource for Patient and Family Engagement Strategies, 2013* for an extensive list of such research.¹).

PHRs also serve as a health information exchange (HIE) option for individuals to coordinate and combine information from multiple providers. So while many individuals still do not have a PHR, the federal meaningful use (MU) of electronic health records (EHR) incentive program encourages support for providing patients access to electronic data that can be incorporated into a PHR.

Benefits and Challenges in PHR Utilization

- Statistical data show disconnects between what Americans want and what they actually do with respect to access to health information in general, and maintenance of a PHR specifically. For example, data from the Harris Interactive 2012 survey² show:
 - As many as 65% of the American population think it is important to have online access to doctor visits, prescriptions, test results and their health history.
 - Only 17% of Americans reported currently having that access.
- HIPAA rules requires providers to supply individuals with access to their health records (in any format and with certain limited exceptions) and the federal incentive program for meaningful use of EHR (M.U.) requires provision of clinical summaries generated from EHRs. Yet, according to a recent article in American Medical News:³
 - As many as 65% of physicians have indicated access should be limited.
 - 70% of physicians who received incentive M.U. payments for stage 1 said they did not have any patient requests for records.
- Access to health information, however, is not the same as maintaining a PHR. Just the same, according to the California Health care Foundation:⁴
 - Only 7% of individuals actually have a PHR
 - As many as 77% of individuals say they would be likely to use one if recommended by a physician.

The health care agencies of the federal government believe strongly that PHRs can improve health care quality. Not only does the M.U. incentive program require enhanced provision of electronic data to individuals upon their request, but Medicare, the Veterans Health Affairs, and the Department of Defense offer electronic access to health information and support for maintaining a PHR via their Blue Button® initiatives.⁵ Medicare also strongly promotes signing up for Medicare and managing Medicare claims through its MyMedicare.gov web site.

- PHRs are believed to improve health care quality, especially for those with chronic illness, because they:
 - Improve patient engagement by helping patients track their health over time
 - Coordinate and combine information from multiple providers, improving care coordination
 - Ensure patient information is available in emergencies, when traveling, or when patients have moved or changed providers as a result of a change in health insurance or other reason.
 - Reduce administrative costs through less time spent searching for records and for information within a record, and through patient self-access to prescription refill requests, appointment scheduling, test results, and other health information
 - Enhance provider-patient communications; PHRs can serve as a resource for patients to ask questions, remind themselves about conditions they want to report, and supply vital data on their health status (e.g., blood glucose levels, weight changes, depression scores)
 - Encourage family health management by tracking and updating preventive services, providing appointment reminders, reminding persons to take medication and providing other information needed by parents caring for their children, children caring for their parents, spouses caring for one another, and by other (authorized) caregivers

Some caveats must be observed regarding PHRs:

- **Cost:** Offering a PHR generally implies that the provider bears the cost of acquiring and implementing PHR software. In addition, if PHR software is acquired from a third-party vendor and not the EHR vendor, there is a cost to enable sharing of data across the two platforms. Few providers want to pass the cost on to their patients. Cost may be a factor for individuals if they seek their own PHR. Some PHR offerings are no cost (usually with advertisements supporting the PHR) and others charge a nominal fee to individuals.
- **Too Many PHRs:** If individuals are seen by multiple providers in different organizations it is possible for them to have multiple PHRs. The result can be both a cost factor to retrieve data from multiple disparate sources as well as a quality concern if unique information is not readily available. Patients should be encouraged to adopt only one PHR into which they themselves move their data if necessary. (An HIE organization could also support such a service.)
- **Health Literacy:** PHR development requires consideration of patients' health literacy. Some PHRs are just as technical as EHRs; other PHRs are designed using lay terminology and/or provide access to additional information about the contents.
- **Persons with Disabilities:** Obstacles may exist for persons with disabilities in using PHRs; however, such persons often find the ability to increase font size, translate text to sound, and use other computer features to enhance access to health information.
- **Small and Rural Providers:** EHR vendor offerings for small and rural providers may be more limited in PHR options. Lack of high-speed Internet access and service "dead spots" may also be an issue when using any form of electronic records. However, geographic isolation and shortages of providers find that remote connectivity with patients is crucial and may be aided by PHRs.

- **Behavioral Health Use of PHR:** In a study funded by the Agency for Health care Research and Quality (AHRQ), it was noted that the complexity of health care needs and fragmentation of care often experienced by those with mental health disorders may be overcome by the use of electronic personal health records.⁶ However, this study also found that currently available PHRs typically lack mental health-related modules and require some computer competency. While there is strong belief that a PHR and access to one’s EHR (via a portal) can make important contributions for all persons, several researchers are finding that excessive use of cellphones and computers can lead to depression, sleep disorders, low self-esteem, and high level of stress.⁷

PHR Options

The federal government defines PHR as “an electronic record of individually identifiable health information on an individual [patient] that can be drawn from multiple sources and that is managed, shared, and controlled by or for the individual.” There are several dimensions that help describe PHRs:

Sponsor Dimension

Sponsor refers to who supports the PHR for an individual. In the majority of cases, either a provider or the individual him or herself is the sponsor, although payers, employers, affinity groups to which a person may belong, an HIE organization (HIO) or an accountable care organization (ACO) may be a sponsor. Many providers believe that the provider-sponsored PHR is essential to ensure that the information contained in the PHR is accurate. If an individual has multiple providers, however, the provider sponsorship defeats the purpose of a PHR that can integrate data across multiple providers.

Integration Dimension

Integration refers to whether a PHR is integrated with an original source of health information.

- When a PHR is linked directly to a provider’s EHR or a payer’s claims database, it is referred to as a **tethered** PHR.
- A **stand-alone** PHR is one that is not linked directly to any such source. This includes both file folders (paper and/or electronic) that a patient may personally maintain or use of a commercial PHR, such as Microsoft HealthVault and others.
- There may be a **hybrid** situation where an HIO is the sponsor of the PHR and links to multiple sources – although such a PHR is not commonly available today. Individuals may also have a hybrid set of PHRs that include one or more tethered to providers as well as one that is self-maintained.

Platform Dimension

Platform refers to the medium on which the PHR is maintained.

- The definition adopted by the federal government assumes the PHR is **electronic**, but even in that case the platform could be web-based, reside on a personal computer, or be housed on a CD, flash drive, or smart phone.
- While **social media** would be considered web-based, it is worth noting that social media implies processes that are more than a simple hosting of data. Facebook and other social

media sites are supporting PHR creation. MyPHR (www.myPHR.com) is a public service initiative developed by the American Health Information Management Association (AHIMA) to help individuals become better managers of their health information. It describes the story of a woman whose Facebook PHR that chronicled her health history was the quickest and most complete source of information for emergency department providers to save her life.

(See: <http://www.myphr.com/Stories/SuccessStory.aspx?Id=382>).

- **Paper**, however, is not an uncommon form of PHR, especially for those family members or other caregivers who are essentially the “sponsor” of an individual’s PHR.

Data Source Dimension

Who supplies data to the PHR is the data source. In a tethered PHR, the data source is primarily – and sometimes only – the provider. However, providers who do not accommodate patient entry of information to the PHR might be considered as defeating one of the primary purposes of the PHR, which is to empower the patient to perform self-management. In addition to the provider and patient (or family/ caregiver), medical devices (such as a blood pressure monitor, insulin pump and glucose monitor, pacemaker, and so on) are increasingly sources of data for the PHR.

Business Model Dimension

A sponsor generally acquires a PHR through a licensing arrangement with an EHR or other third-party vendor. However, there is often a wider array of business models with respect to whether the individual pays to use the PHR. These include fee-per-usage, advertisements, or other form of value proposition, such as where the sponsor uses the PHR to create process efficiency, loyalty building, or messaging to attempt to change behaviors and outcomes. For example, an employer may offer employees a free PHR with the hope that enhanced use leads to better health literacy and ultimately better health, which also reduces the employer’s health insurance premiums. Affinity groups may enable free-to-member use of PHRs by agreeing to display advertisements from pharmaceutical manufacturers.

Privacy Protection Dimension

Laws to provide privacy protections of PHRs also vary in the degree to which protection is afforded.

- When a PHR is tethered to a provider or payer sponsor, the PHR is generally governed under the **Health Insurance Portability and Accountability Act (HIPAA)** Privacy and Security Rules. The vendor of the PHR must be a business associate of the HIPAA-covered entity.
- When a PHR is supplied directly to the individual through a commercial vendor (e.g., Microsoft HealthVault), privacy protection is afforded under the **Federal Trade Commission’s** Health Breach Notification Rule (see: <http://www.business.ftc.gov/privacy-and-security/health-privacy>). This regulation is complementary to the Health and Human Services’ Breach Notification Rule. However, it only addresses the vendor’s obligation to report a breach and not spell out what standards to adopt for privacy and security protections as do HIPAA Privacy and Security Rules. Some states also have breach notification statutes that may afford somewhat more oversight.

In evaluating commercial vendor offerings, the public and sponsor should take steps to evaluate the authenticity of a vendor's statements. For example, some vendors will place symbols on their website selling the product that they are accredited by the Better Business Bureau (BBB), sponsored by an affinity group and/or certain providers, indicate the product is HIPAA Certified, and/or use a symbol to indicate a transaction is secure because it uses the Secure Sockets Layer (SSL) standard. If these symbols do not link directly to the BBB, affinity group, provider, or other source that can validate a relationship to the vendor, they are *not valid*. In addition, there is no HIPAA certification of PHRs (or EHRs) sanctioned by the federal government.

- Finally, if an individual establishes his or her own PHR on a personal computer without any commercial product maintaining the data for the individual and the personal computer gets hacked, lost, or stolen – there is **no privacy protection** afforded under any laws or regulations.

Policies, Procedures and Practices to Support PHR Use

Providers who want to support a PHR for their patients should be encouraged to do so. There is strong evidence to support the value of PHR, and individuals appear to be more interested and motivated in using a PHR when encouraged to do so by their providers. However, steps should be taken to ensure both providers and individuals understand what a PHR is and how it should be used.

Provider Roles and Responsibilities

Providers who support PHRs for their patients should ensure that policies, procedures and practices are in place that describe how the support will be provide and what role and responsibilities each professional plays with respect to the PHR. These would include:

- Understanding the differences between a PHR and an EHR. Whether the provider sponsors a PHR or not, it should be understood that the two are separate and distinct. Even as you may research information about PHRs, the line between the two sometimes seems very blurred. The EHR, just exactly the same as the provider's paper records, are the business records of the provider. There is a duality of ownership in these records in that the record itself is owned by the provider, while the individual has the right to access and authorize use and disclosure of the record's content. When offering a PHR, the provider:
 - Is not providing access to the EHR so that the individual can alter it.
 - Must provide access to the EHR so that the individual can view and/or obtain a copy of it (with certain limited exceptions specified in HIPAA or other applicable regulations)
- Assuming responsibility for administratively, physically and technically safeguarding any tethered PHR.
- Developing policies surrounding:
 - What data are routinely supplied to the PHR
 - Who may access the individual's PHR and under what circumstances (e.g., authorization, consent, court order or other requirement)

- How to access PHR data, especially when provided via a patient-supplied source (e.g., CD, flash drive)
- How to validate the authenticity and accuracy of PHR data
- Providing computer literacy training to individuals who are interested in using a PHR.
- Changing the mindset of providers to embrace patient engagement by supporting a PHR.
- Watching for signs that the PHR is being misused and guiding the individual on appropriate precautions (e.g., excessive use of a computer by an individual, others inappropriately gaining access, potential medical identity theft, and others).

Individual Roles and Responsibilities Regarding PHR

It may be helpful for providers to provide information to individuals about PHRs – whether or not the provider supplies a PHR or encourages use.

The following is a set of questions that individuals should consider:

1. Will this PHR enable me to record all the health information I want?
2. Will information automatically be added to my PHR from other sources?
 - What information will be added? How will it be added? Is transfer auditable?
 - Is there opportunity to delete, correct, or add information? How? Is there an audit log?
3. Does the PHR host or sponsor have any ownership rights to the information in the PHR?
4. Can the PHR host or sponsor sell the information to anyone for any reason?
 - If so, how can I ensure my privacy is protected?
 - Can I specify that my information not be sold? How?
5. Will my information be used for employment or insurance coverage decisions?
6. Who has access to information in my PHR?
 - Can I control who (provider, insurer, employer, caregiver, family member) has access to what information (e.g., demographics/insurance, medical, behavioral) and under what circumstances (e.g., specific health care encounter, emergency only, other)?
 - Is there an audit log of who has accessed my PHR?
7. If I no longer am employed, insured, or a patient of the host/sponsor, can I still continue to use the PHR?
8. How do I get my data if host/sponsor goes out of business? How can I transfer my PHR information to another PHR sponsor?
9. Will there be any cost for me associated with use of this PHR? Upfront, ongoing, per access, other?
10. Do you apply targeted advertisement to my PHR? If so, is there a way to use my PHR without this advertisement? How am I assured that advertisers do not get access to my health information?

In introducing individuals to PHRs, encourage them to visit the myPHR website at:

http://www.myphr.com/startaphr/what_is_a_phr.aspx.

References

¹ Available at: http://www.hpoe.org/Reports-HPOE/Patient_Family_Engagement_2013.pdf

² Harris Interactive 2012 survey². Available at: <http://www.harrisinteractive.com/NewsRoom/%20HarrisPolls/tabid/447/ctl/ReadCustom%20Default/mid/1508/ArticleId/1074/Default.aspx>

³ Doctors willing to go only so far on patient EHR access (2013) *American Medical News*. Available at: <http://www.amednews.com/article/20130318/business/130319955/7/>

⁴ New National Survey Finds Personal Health Records Motivate Consumers to Improve Their Health (2010) California Health care Foundation. Available at: <http://www.chcf.org/media/press-releases/2010/new-national-survey-finds-personal-health-records-motivate-consumers-to-improve-their-health#ixzz2xfk0ikYz>

⁵ Your Health Records: About Blue Button. Available at: <http://www.healthit.gov/patients-families/blue-button/about-blue-button>

⁶ An Electronic Personal Health Record for Mental Health Consumers (Georgia) (2012) Agency for Health care Quality and Research. Available at: <http://healthit.ahrq.gov/ahrq-funded-projects/electronic-personal-health-record-mental-health-consumers>

⁷ As an example, see Mental Health Negatively Affected By Excessive Cellphone And Computer Use: Study (2012) International Business Times. Available at: <http://www.ibtimes.com/mental-health-negatively-affected-excessive-cellphone-and-computer-use-study-730100>

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