Chapter 24

Evaluation of Personal Health Services and Records

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24.1 Introduction

Information and Communication Technology (ICT) has changed information management practices at points of care, but it is also empowering patients and individuals to take a more active role in their health and care. Through consumer-focused health ICT, such as personal health records and personal health services (e.g., health apps), people have the ability to be more engaged in their health. This is a rapidly expanding market, yet the body of evidence showing the benefits of these tools is smaller than it should be given the size of the market. Before we describe some of the evidence, we should define some of the types of consumer-focused health ICT.

24.1.1 Definitions

There are many different terms used to describe aspects of consumer health ICT with, of course, sometimes overlapping and confusing definitions. For this chapter, we will define and use the following:

- Personal Health Service(s)
- Personal Health Record
- Personal Health Information

Personal Health Services (PHS) are more broadly defined than PHRs. These are any consumer-focused health ICT tools that can help people to engage in their own care. We have included PHRs in the broader taxonomy of PHS (see Figure 24.1). PHS do not necessarily have the mandate to provide a longitudinal record and can be focused on a specific aspect of healthcare or wellness. For example, they could provide information about foods or they could be a diet mobile health app that lets you track your diet. A PHS could support home telemedicine or it could be an activity tracker. More streamlined services have the advantage of focusing on a particular health behaviour (e.g., quitting smoking, screening for a diagnosis, or improving health literacy about a condition) and may be used in a targeted way to support a specific health issue, assess for current risk, or help a person with a behaviour change.

A **Personal Health Record** (PHR), also sometimes referred to as Personal Controlled Health Record (PCHR), is an ICT application designed to allow patients (or their designated caregivers) to store and manage their personal health information (PHI). The American Health Information Management Association (AHIMA) defines the PHR as an:

> electronic, universally available, lifelong resource of health information needed by individuals to make health decisions. Individuals own and manage the information in the PHR, which comes from healthcare providers and the individual. The PHR is maintained in a secure and private environment, with the individual determining rights of access. The PHR is medical and health information that is directed and maintained by the patient and is separate from and does not replace the legal record of any provider. (AHIMA, 2005)

The specific data elements stored within a PHR varies between different application providers. Table 24.1 has some examples.

Some PHR systems are highly comprehensive, storing a wide amount of information about patients. In other cases, the PHR application may deliberately be narrow in scope in an effort to maintain a separation between consumer information and that in the custody and control of a healthcare provider, but still maintain the concept of a longitudinal record.

PHRs that are tightly connected to a provider-based Electronic Medical Record (EMR) and represent subsets of the data represented in the corresponding provider record are called *tethered* PHRs. In contrast, *untethered* PHRs are stand-alone and may provide users with the functionality to export/import their personal health data to/from selected provider-based EMR systems, based on defined interoperability interfaces.

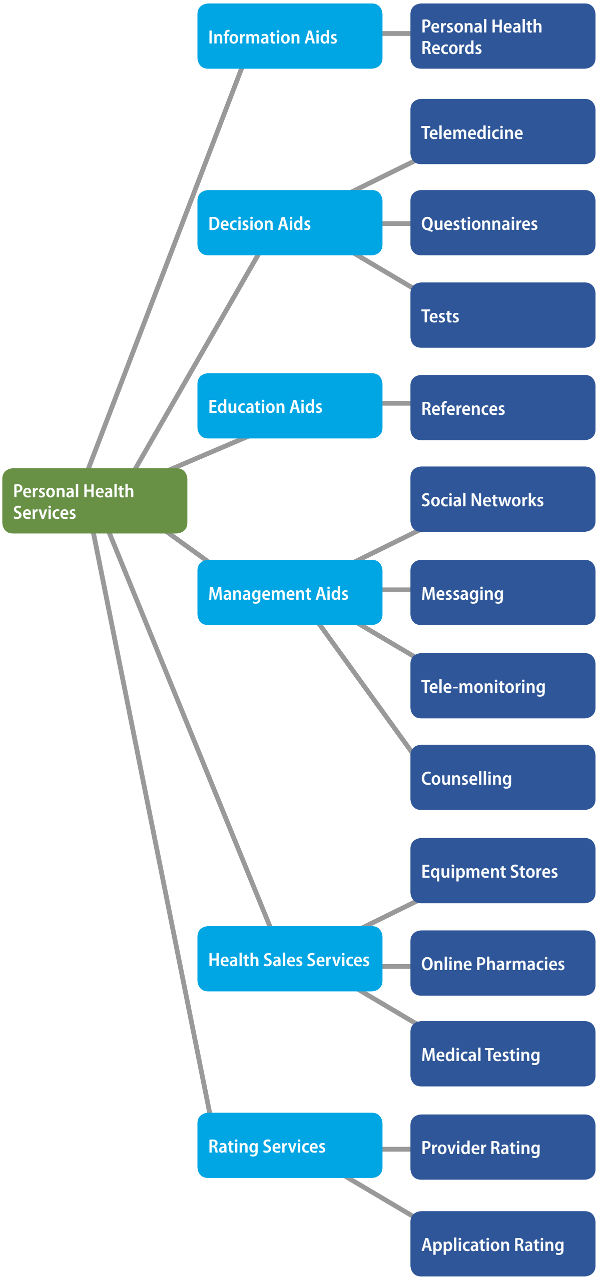

Figure 24.1. A breakdown of the broad range of personal health services.

Table 24.1
Typical Elements in a PHR (based on AHIMA, 2005)

1. Personal identifiers, such as name and date of birth
2. Emergency contact information.
3. Names, addresses, and phone numbers of physician, dentist, and other specialists
4. Health insurance information
5. Living wills and advance directives
6. Organ donor authorization
7. A list and dates of significant illnesses and surgeries
8. Current medications and dosages
9. Immunizations and their dates
10. Allergies
11. Important events, dates, and hereditary conditions in family history
12. A recent physical examination
13. Opinions of specialists
14. Important tests results
15. Eye and dental records
16. Correspondence with providers
17. Permission forms for release of information, operations, and other medical procedures
18. Any other miscellaneous information about patient health such as exercise regimen, herbal medications, and any counselling.

PHRs are a place to store and manage personal health information (defined below). Thus they can be considered an information aid for patients: a place to review, recall or share personal health information when needed to support care. However, PHRs may also integrate patient-centric knowledge bases or decision-support that extends beyond the basic function of storing information. Such advanced functionality may help with wellness activities, the management of chronic diseases or other targeted health problems, such as addictions, obesity, and mental health. Some of these functions are also available in Personal Health Services, so there is admittedly overlap between a focused PHR and robust Personal Health Services.

Personal Health Information (PHI), in contrast to both PHS and PHR, is not an application where the information resides, but is the information about an individual. It is information about an individual and that individual's health, and can include information on diagnoses, medications, encounters with care, lab results, health activities, and functional status. Table 24.1 provides application functions and also types of PHI.

Personal health information can reside in a number of ICT systems from consumer-focused ICT to provider-focused ICT and from health ICT to non-health ICT systems, such as government systems or insurance systems.

24.2 Potential Benefits of PHS

Personal Health Services have many potential benefits to multiple stakeholders. This assumes that the PHS is properly designed, implemented, promoted, adopted, and, more importantly, that it offers services that the users need and find useful. Some of the reported potential benefits include: improving patient engagement in and accountability for their own care; enabling patients to better manage their health information and the information of their family members; providing essential information to patients and other healthcare providers in emergencies or while travelling; improving communication between patient and provider; and reducing administrative costs (Tang, Ash, Bates, Overhage, & Sands, 2006). More specifically, potential benefits can be grouped into three broad categories: (a) benefits to the consumer (i.e., the intended user of the PHS — the patient); (b) benefits to the consumer's circle of care (i.e., caregivers, healthcare providers); and (c) benefits to the overall healthcare system.

24.2.1 Potential Benefits to the Consumer

One often-stated purpose of using a PHS, such as a PHR, is supporting the user to engage in their care through accessing credible health information. This can include both personal health information (their own PHI) and general health information related to their health, such as information on medications, health conditions, or how to exercise. Consumers can use credible and evidence-based information to become better informed about their health, which allows them to improve their own illness and wellness management. Many chronic conditions require a degree of self-management, such as lifestyle changes, adherence to medications, self-monitoring (e.g., blood pressure, blood sugars). PHS can enable users to better manage their own chronic conditions by providing tools, reminders and feedback. The chronic care model (Bodenheimer, Wagner, & Grumbach, 2002) highlights the need for engaged patients, and PHS can be one way of both engaging and empowering patients in their chronic disease management.

24.2.2 Potential Benefits to the Circle of Care

PHS can improve communication between users and healthcare providers, such as enabling users to provide information on function between visits, ask more informed questions, as well as manage prescriptions, refills, and appointments (Tang et al., 2006). Further, when patients share their PHI with healthcare providers, the providers can gain valuable information on daily function, adherence, behaviours and symptoms that might not be easily captured during visits for care. This can help with decision-making, lead to improved communication, and result in better overall understanding of the issues around the progress of a disease or wellness management, both by the provider and by the patient (Tang et al., 2006). Informal caregivers, too, can benefit from access to a patient's PHR as a tool for communicating across the team, and to better understand the needs and treatments and rationale for treatments.

PHS can also provide another treatment option for providers to offer to patients. As evidence develops, providers will be able to increasingly suggest PHS options to help people with a range of health conditions such as asthma, diabetes, fertility, glaucoma, HIV, hyperlipidemia, and hypertension (Price et al., 2015) and, in all likelihood, other conditions in the future.

24.2.3 Potential Benefits to the Healthcare System

Potential PHS benefits to the healthcare system include reduced healthcare costs due to the potential improved management of various chronic conditions. This, however, is very much dependent on the actual capabilities of the PHS and how well it is adopted by its users. In addition, PHS have the potential to improve management of overall wellness; they emphasize prevention, which, in turn, may help reduce overall healthcare system costs in time (Tang et al., 2006). Although there is a potential, this is far from proven and there is much evaluation to do to better understand the impact of PHS. Also to be considered is the effort that consumers will put into managing their PHI through these various services (Ancker et al., 2015). Despite the potential benefits, the evidence for PHSs and PHRs is limited and there are challenges to adopting these tools.

24.3 Challenges for PHS

Personal Health Services, especially digital PHS, are relatively new and rapidly evolving. We do not yet know all of the positive impacts or the unintended consequences of these tools.

24.3.1 Accuracy & Safety

One challenge that has been considered is the fact that the accuracy of PHI recorded online by patients (and their informal caregivers) is dependent on the way it is collected, not to mention other factors such as computer literacy and age of the person recording the information (Kim & Kim, 2010). The provenance[1] of the PHI entered into PHR applications is important for judging its accuracy. For example, PHI data such as prescriptions and diagnoses that are entered by patients based on recalling their memories of prior visits with care providers may have lower accuracy than data directly downloaded from provider-facing (clinical) information systems or entered based on written reports. Conversely, data is that is recorded by people prospectively about their behaviours (e.g., diet, exercise, medication adherence) may be more accurate than what is recalled or described in a physician visit. PHRs have been found effective in increasing the data quality of provider medication lists (Wright et al., 2008). Provenance of PHI is increasingly important as PHS and other systems are interconnected. Unfortunately, provenance information is rarely kept in PHS and PHRs, which may compromise the objective of ensuring accuracy of PHI.

While PHRs are not considered medical devices in the classical sense, their implementation may introduce hazards that require careful consideration. Patient safety with PHS is a voiced concern from a provider perspective, both in terms of considering data of unclear accuracy and origin in clinical decision-

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[1] Provenance is lineage of data, such as who entered the data, who may have approved it, reviewed it, and modified it over time.

making, as well as in terms of the potential safety ramifications of allowing patients to access clinical data that they may not properly understand (Wynia, Torres, & Lemieux, 2011).

Patient controlled PHRs have been a safety concern in cases where patients are free to withhold certain information from providers and in emergency situations (Chen & Zhong, 2012) or when access or sharing is not clear. Conversely, patients may assume, incorrectly, that data is immediately shared and a message or comment that is urgent and written in a PHS or PHR is viewed by a healthcare provider, for example, when it might not be. The reverse is also true, as it has been argued that intelligent "assistant" services based on PHRs can help improve the safety of certain consumers, for example by providing self-management support to patients with heart failure (Ferguson et al., 2010).

24.3.2 Health and Technology Literacy

PHS and PHRs can provide many potential benefits but may also create new barriers, in particular for populations with low technological or health literacy. The adoption of various PHSs may create a health "digital divide". Evidence for the significant impact of technology literacy has been shown in several studies (Hilton et al., 2012; Wagner et al., 2012). Age has been validated as a predictor for technology literacy. In a randomized trial, Wagner et al. (2012) found that likelihood of PHR use decreased with age. Technology literacy in elderly populations has shown to be a significant barrier. Kim and colleagues have shown that low-income, elderly populations have a significant disadvantage of accessing online PHR services (Kim et al., 2007, 2009). These results agree with studies by Lober et al. (2006), who also researched the impact of cognitive impairment and disability in elderly populations.

Consumers do not commonly understand the medical terminology used by providers or in provider-centric records. Translating that terminology to plain language that is accessible to consumers requires significant effort if done manually. Automated solutions have been developed based on ontological engineering methods (Bonacina, Marceglia, Bertoldi, & Pinciroli, 2010) and data extraction from social health networks (Doing-Harris & Zeng-Treitler, 2011). Aside from the terminology, there is the question of how much support consumers need in documenting and interpreting important medical information, in particular their online test results. One study of consumer support needs indicated that educational and psychosocial support services were less frequently used than technical support (Wiljer et al., 2010).

24.3.3 Privacy and Security

PHI may be highly sensitive and thus needs to be carefully protected. There is significant interest in PHI from a variety of legitimate parties, including various sectors of industry (e.g., pharmaceuticals and marketers), employers, insurers, but also for fraudulent use (e.g., identity theft, credit crime). Besides patient privacy, provider privacy must also be considered, as the PHR may open up information to consumers and other parties that has traditionally been kept in private EHRS or EMRS, accessible only to physicians.

Privacy concerns are among the most important barriers perceived by both patients (Chhanabhai & Holt, 2007; Hoerbst, Kohl, Knaup, & Ammenwerth, 2010; Wen, Kreps, Zhu, & Miller, 2010) and providers (Wynia et al., 2011). Although the PHI maintained in PHS is equally sensitive to that information maintained in provider-facing systems, PHR systems are not generally subject to the same privacy regulations and legal protections.

Granular privacy controls that let consumers choose what data to share with which healthcare provider are easier to interpret by users. However, such an ability to withhold PHI raises significant care and liability issues (Cushman, Froomkin, Cava, Abril, & Goodman, 2010). Social networking features, while popular, are also challenging as consumers have difficulty correctly interpreting their privacy controls (Hartzler et al., 2011).

Cohort effects may be observed based on particular groups of consumer populations; younger consumers tend to be more willing to share their PHI (Cushman et al., 2010). Particularly vulnerable populations, such as consumers with conditions that are associated with social stigma, may require dedicated considerations, for example, people with mental health conditions (Ennis, Rose, Callard, Denis, & Wykes, 2011) and people living with HIV/AIDS (Kahn et al., 2010). Research on the latter population has indicated a high willingness to share PHI with providers and a lower willingness to share with other non-professionals (Teixeira, Gordon, Camhi, & Bakken, 2011).

Because of the patient-centric nature of PHSs and PHRS, traditional privacy consent directives such as identity-based access ("share PHI only with my doctor, Dr. X") and role-based access ("share my PHI with all doctors") are limited and fall short. The first alternative is considered too restrictive to support a continuum of collaborative care around the patient where the patient may have wished a new emergency room physician to have access to PHI in an emergency. The second alternative is considered too broad (i.e., providing little protection). Specific process-based privacy models have been developed in response to this problem (Mytilinaiou, Koufi, Malamateniou, & Vassilacopoulos, 2010). A related issue is emergency access to PHI in cases where the consumer is not able to provide consent (Chen & Zhong, 2012).

24.4 Current State of Evidence

While, there have been several reviews completed examining the expected and actual benefits of PHS, there is still a relative lack of evidence on the benefits of PHS. This is due, in part, to the rapidly changing nature of PHS and its various platforms. Smartphones and wearable technologies, for example, are radically altering platforms where various PHS apps are being developed.

Genitsaridi, Kondylakis, Koumakis, Marias, and Tsiknakis (2015) reviewed and evaluated 25 PHR systems based on four main requirements: free and open source software requirement, Web-based system requirement, specific functionality requirements, and architectural / technical requirements. Only four (MyOscar, Indivo-X, Tolven, and OpenMRS) out of the 25 PHR systems reviewed met the free and open source software and Web-based requirements, which were considered as basic requirements for a PHR system regardless of its functionality level. These four PHR systems, in addition to six other highly popular PHR systems, were then evaluated based on specific functionality requirements (i.e., recording of a problem, diagnosis, and treatment, self-health monitoring, communication management, security and access control, and intelligence factors) as well as architectural requirements (i.e., stand-alone, tethered, or interconnected). This study determined that there is a need for better design of PHRs in order to improve self-management and integration into care processes (Genitsaridi et al., 2015).

There is early evidence to support the use of PHRs in some chronic conditions. Based on a systematic review, there is evidence that PHRs can be used to benefit the following: asthma, diabetes, fertility, glaucoma, HIV, hyperlipidemia, and hypertension (Price et al., 2015). There is a small body of empirical evidence demonstrating benefit; however, many of these are short-term studies looking only at changes in behaviour or early clinical outcomes.

There are many factors that can impact the realization of benefits of PHS and PHR, beyond just the features and qualities (such as usability) of the tools themselves. Thus, it is important to consider a wide range of factors in evaluation including, among others: the PHS tool itself; the people who use it directly; the people who use it indirectly (e.g., care providers who see summary information); the context of use; the integration with care; the incentives (e.g., incentives from health insurance). One key issue to consider when evaluating PHS is the interest and capacity of people to manage their health through electronic means. As discussed previously, a health digital divide is possible if services are available through PHS. Consider predictors of use of your users that include education, technical knowledge, and health knowledge (Kim & Abner, 2016). Thus, evaluation (and implementation training) should carefully consider the level of health and technological literacy of the users.

24.5 Selected Case Study Examples

24.5.1 Case study 1 – Kaiser Permanente's *My Health Manager*

Kaiser Permanente, one of the largest health delivery organizations in the United States, began implementing PHR solutions for their members in 2004. The PHR platform, *My Health Manager*, was tethered to their electronic health record (EHR) and included not only information services, but also provided means for secure communication between patients and providers. The system was well received and had been adopted by 2.4 million patients by 2008 (Silvestre, Sue, & Allen, 2009). By 2013, 65% of all eligible Kaiser Permanente members were registered in *My Health Manager*. Early studies showed a significant decrease in office visits (26.2%) within a period of three years, while at the same time there was a ninefold increase in online consultations (phone visits) and a dramatic increase in patient-generated secure messages (Chen, Garrido, Chock, Okawa, & Liang, 2009). Member satisfaction and health outcomes remained largely unchanged over the three-year study, with a few exceptions, particularly with respect to certain chronic disease conditions such as HbA1c control, antidepressant medication management, and osteoporosis management in female populations, which developed negatively. Further studies have also shown that the PHR use has been correlated with significant health benefits in subpopulations such as people with diverse languages and ethnicity (Garrido et al., 2015). However, language and ethnicity both influenced the likelihood of members signing up to the PHR system.

A recent study on Kaiser Permanente's patient outcome improvements focused on virtual doctor-patient communication (Reed, Graetz, Gordon, & Fung, 2015). *My Health Manager* provides the ability for patients and providers to communicate over e-mail as well as schedule appointments and maintain many other health management aspects online. Over 50% of study participants had used the e-mail feature at least once, and almost 50% of participants prefer e-mail as the first method of contact when it comes to their medical concerns. This resulted in 42% of respondents reporting a reduction in phone contact and 36% of respondents reporting a reduction in in-person visits. Overall, the use of the *My Health Manager* system resulted in 32% of users with chronic conditions improving their overall health (Reed et al., 2015). In addition, the results of another study suggest that using tools for health care management (i.e., online medication refills) can result in improving medication adherence (Lyles et al., 2016).

Kaiser Permanente's portal also provides users with access to information about prevention, health promotion, and care gaps. In addition to improved communication and reduction in office visits and phone calls, users of *My Health Manager* are more likely to participate in certain preventive measures, such as cancer screening, hemoglobin A1c testing, and pneumonia vaccination (Henry, Shen, Ahuja, Gould, & Kanter, 2016).

24.5.2 Case study 2 – English National Health Service's *HealthSpace*

The National Health Service (NHS) in England attempted an implementation of a public nationwide PHR called *HealthSpace* in 2007. A three-year evaluation was completed by the Healthcare Innovation and Policy Unit at the London School of Medicine and Dentistry (Greenhalgh, Hinder, Stramer, Bratan, & Russell, 2010). It was initially inspired by the Kaiser Permanente model outlined above. The NHS' goals for this PHR were personalizing care, empowering patients, reducing NHS costs, and improving data quality and health literacy. *HealthSpace* included a basic account that would allow a person to record their own data (e.g., blood pressures) and an advanced account where they could gain access to their summary care record (a subset of PHI shared from the patient's

GP) and interact with their GP (to book appointments, message with questions). Additional features were planned over time.

The evaluation of *HealthSpace* was a mixed method, multilevel case study. It covered the policy development, implementation, and patient experience using both qualitative and quantitative methods to develop a rich picture of *HealthSpace*.

The policy and project documentation that was evaluated in this case study highlighted a focus on the technical and managerial aspects of implementing a PHR, with less focus on understanding the user requirements (e.g., through observation and detailed analysis and testing). The evaluation highlighted a design gap in user expectations and needs with respect to how the system was implemented. The deployment of this particular PHR, unfortunately, resulted in poor initial uptake mostly due to a lack of interest, perceived usefulness and ease of use, and a cumbersome account creation process. During the PHR evaluation, *HealthSpace* users expressed disappointment in specific data being unavailable, the need for data self-entry, and an inability to share their information with their healthcare providers seamlessly. The study highlighted that *HealthSpace* was not aligned with the "attitudes, self-management practices, [and] identified information needs" of its potential users (Greenhalgh et al., 2010). The expected benefits of *HealthSpace* were not realized, in large part, due to this gap.

24.6 Issues, Guidance and Implications

PHS and PHRs have the potential for wide ranging impact on care — both directly for the patient and indirectly for the care providers, care organizations, and the overall healthcare system. Thus, we suggest considering evaluation using a broad framework such as the Clinical Adoption Framework (see chapter 3), which includes concepts from micro-level evaluation (system, use, and patient level outcomes) to meso-level and macro-level influencing factors. Also, we encourage the use of multiple methods when evaluating PHS, and a plan that incorporates various assessments to occur over time to see how the PHSs are incorporated into health and wellness behaviours and into healthcare systems. With multi-method studies, one can also develop feedback loops into the PHS programs, using evaluation in an action research framework to improve the chance of success and positive impact of using these tools. Large, single trials, at this stage, may not be able to provide the richness of answers needed to understand how PHSs are being used and why they are achieving (or not achieving) their outcomes. Also, it is important to consider how to incorporate the rate of change of PHS features and functions into the evaluation, as these are rapidly evolving tools.

For example, evaluation can begin prior to system implementation by modelling out the goals of the PHS implementation and related activities and mapping these into the meso- and macro-level contexts. This may, for example, quickly highlight disconnects between the goals of the PHS and macro-level aspects such as legislation or funding limitations for providers (e.g., no mechanism for remuneration for e-communication). Usability evaluations (both usability inspections with experts and usability testing with potential users) can be completed with early prototypes. Once implemented, pilot studies can explore user experience as well as the indirect experience of providers when patients have access to PHS. Future studies can then begin to look at changes in behaviour and changes in outcomes, both clinical and health system (e.g., numbers of visits, numbers of e-visits, and capacity to see patients).

24.7 Summary

PHSs and PHRs are being increasingly implemented as part of health care systems. Despite the efforts in implementation and adoption, the advertising of apps and wearables, et cetera, there is still a gap in sufficient evaluation of PHS. We need a better understanding of how these tools are used and what the impact these tools have on long-term outcomes, both health outcomes and such health system outcomes as capacity and cost.

When planning an evaluation for PHS it is important to consider the goals and plan an evaluation based on those goals and the potential direct and indirect impacts over time. Unintended consequences should be considered. Depending on the scope of the PHS, the evaluation should be broad, assessing impact across the continuum of care (i.e., across the patient's circle of care). To do this, we advocate for multi-method studies that will evaluate the design and adoption of the PHS tools early and throughout its life cycle. A deeper understanding of user needs early (e.g., during concept design, the establishment of projects, the development of policy) will better ensure that the final product meets the actual needs of users. Finally, consider evaluation across the range of dimensions in the Clinical Adoption Framework (see chapter 3) to provide a breadth that is needed to understand the impact of PHS across the micro, meso and macro levels of the healthcare system.

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