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**Final Report
HIEs and Personal Health Records
Community of Practice**

Key Considerations for

HIE-based Personal

Health Records

Submitted to

Office of the National Coordinator for Health IT
In partial fulfillment of
Contract # 14-233-SOL-00533

Submitted by

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Health Information Exchange (HIE) Shared Collaborative Learning Combine
Key Considerations, Venesco and Personal Health Records Community of Practice
Office of the National Coordinator for Health IT (ONC)
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GLOSSARY

CoP	Community of Practice
EHR	Electronic Health Record
HIE	Health Information Exchange
HIT	Health Information Technology
MPI	Master Patient Index or Master Person Index
RTI	RTI International (large non-profit research and technical institute in North Carolina)

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Executive Summary

Background. In recent years, there has been increasing recognition of the importance of Personal Health Records (PHRs) in accomplishing healthcare transformation in the U.S. health system. The catalysts for this growing interest in PHRs include the inclusion of patient engagement measures in the CMS Meaningful Use requirements for providers, studies showing that engaged patients have better health outcomes and lower costs, increasing interest in care coordination, greater interest among patients in having access to their electronic medical records, and increased investment in technologies to support consumer health, including apps and wearable devices. While Electronic Medical Record (EHR) developers have developed patient portals that are "tethered" to a patient's records in a single organization, there has recently been growing interest in implementing the cross-organization PHRs that Health Information Exchange (HIE) organizations can provide.

This Key Considerations document was developed by Venesco, the ONC contractor who facilitated and supported the HIEs and Personal Health Records Community of Practice (CoP) and worked closely with its members in the creation of this report. The PHR CoP was established in March, 2015 by the Office of the National Coordinator for Health Information Technology as part of the extensive federal interest and investment in the promotion of consumer engagement in healthcare. The CoP included 13 HIE member organizations from around the nation who have established HIE-sponsored PHRs or are in the process of doing so and were interested in sharing best practices and lessons learned with each other and other HIEs. This report is intended to provide practical and real-world guidance to HIEs who are interested in adding a cross-organization PHR to their portfolio of services.

Report Overview. This document includes the following sections:
- Overview of the PHR Community of Practice
- PHR Design Goals, Capabilities, and Challenges
    - Requirements: PHR Capabilities and Functionality
    - Major Issues and Barriers
- Strategy for Designing and Implementing an HIE-Sponsored PHR
    - Steps to Complete Before and After the RFP
    - Flow Chart of PHR Procurement and Decision making
- Phased Development of Implementation Plan
    - Adoption and Marketing to Providers and Hospitals
    - Value Proposition and Sustainability Issues
    - Marketing and Outreach to Patients
- Bright Spots in PHR Implementation
    - Kansas Health Information Network (KHIN)
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    - Appendix: List of CoP Member Organizations

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1 Introduction

This document, titled "Key Considerations for HIE-based Personal Health Records", represents the final report for the Personal Health Records Community of Practice created by Venesco, the ONC contractor engaged to facilitate and support the CoP in close collaboration with the members of the PHR CoP, which was sponsored by the Office of the National Coordinator for Health IT (ONC) during fiscal year 2015. Its primary objective is to provide practical and useful guidance to Health Information Exchange (HIE) organizations who are interested in designing and implementing a Personal Health Record (PHR) as part of their portfolio of services. PHRs sponsored by HIEs are still relatively new, so it is our intent to describe the current state of implementation and provide valuable insights to HIEs just embarking on their PHR journey.

1.1 Growing Interest in Personal Health Records

In recent years, there has been increasing recognition of the importance of PHRs in accomplishing health care transformation in the U.S. health system. There are a number of reasons for the growing interest in PHRs, which include the following trends:

- The inclusion of patient engagement measures in the CMS Meaningful Use Requirements

- A number of studies have shown that engaged and activated patients—those who have the skills, ability, and willingness to manage their health and health care--experience better health outcomes at lower costs compared to less activated patients. For example, patients with the lowest activation scores incur 21% higher costs than patients with the highest activation scores[1,2,3].

- The interest in improved care coordination as a means of enhancing care and outcomes and lowering costs, especially for patients with chronic medical conditions.

- The increased availability of electronic health records, and the interest of patients as well as providers in having access to their electronic records

- Increased investment in technologies to support consumer health, including apps and wearable devices.

With the expansion of electronic health records, EHR developers have developed their own Personal Health Records or patient portal systems, which allow patients to have direct access to much of their clinical data, including such items as diagnoses, procedures, allergies, medications, surgeries, lab results, and other data and to manage on-line such activities as scheduling of visits and prescriptions and refills. This type of PHR is referred to as a "tethered" PHR, since it is typically limited to a single health system. While these tethered systems have become popular, many patients get their care from numerous providers, so their tethered PHR record may be incomplete. Thus, there has been growing interest in developing non-tethered, cross-organization PHRs, including those sponsored by Health Information Exchange (HIE) organizations. These untethered systems may have the advantage of providing comprehensive longitudinal information across the numerous providers where the patient has received care.

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1.2 The Value Proposition: What value will an HIE-based Personal Health Record bring to patients, providers, other stakeholders, and the HIE itself?

There is considerable literature concerning the impact of PHRs on improving the patient experience of health care, outcomes, and cost. This literature includes compelling consumer survey results and anecdotal evidence indicating that consumers are very interested in using PHRs and are doing so increasingly, and are interested in having their cross-organizational medical record data in an easily accessible and centralized place.   A 2014 national survey by the National Partnership for Women and Families showed that the number of patients with on-line access to the information in their providers' EHRs is now 50%, which is nearly double the rate in 2011. Those with on-line access use it frequently, with 55% using on-line access three or more times a year. The more often consumers access their health information online, the more they report that it motivates them to do something to improve their health.   In addition, there are clear advantages of the "one-stop shopping" approach that HIE-sponsored PHRs represent for patients, providers, payers, and other stakeholders.

The CoP membership identified the advantages and value propositions listed below.

- Having an HIE base for the PHR provides greater interoperability, depth of information, and ability to integrate data sources, which in turn provides better service to the consumer and to other stakeholders.

- Brings additional value to existing HIE users to keep them as customers and helps attract new organizations as HIE customers

- Simplifies Meaningful Use compliance for the patient engagement measure (attractive to overburdened providers)

- Current tethered systems (e.g., one healthcare organization) require the patient who is seen by multiple providers to deal with and manage multiple PHRs, in contrast with the centralized and comprehensive patient record provided by the HIE.

- Increasing patient interest in having access to their comprehensive longitudinal patient record across organizations

- Increasing engagement of patients in their care. An engaged patient is more adherent, less costly, and has better outcomes[1].

- An increasingly elderly population with multiple chronic diseases managed by different specialists makes such cross-organization PHR access even more important.

- Relevance to the emergence of person-centered shared care planning, in which providers and patients collaborate on a dynamic electronic care plan as part of new models of care delivery designed to improve the achievement of the "Triple Aim" (better patient care and experience, better health/outcomes, and lower costs)

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1.3 Overview of ONC, CMS, HHS, and Other Efforts to Promote Consumer Engagement in their Healthcare

The work of the ONC Personal Health Records CoP has taken place within the context of a number of other important national policies and programs designed to promote the engagement of consumers in their health care. Brief sketches of a number of these initiatives are provided below for the reader's reference.

Meaningful Use Stage 2. One objective of the Meaningful Use Stage 2 regulations is to provide patients with the ability to view online, download, and transmit (VDT) their health information. Providing patients with an electronic copy of their health information helps them and their caregivers have the information they need to engage more in their care and enables them to identify potential errors or omissions in their records. They have the ability to share their health information to make sure that everyone is on the same page to support care coordination and self-management.

Blue Button. Through the public-private Blue Button initiative, ONC and its supporters are increasing individuals' access to their clinical and claims-related health information from diverse sources. The voluntary Blue Button program includes over 500 organizations, including federal agencies, healthcare provider systems, health insurance plans, labs, retail pharmacies and others who have committed to enable consumer access to their online health data or to getting the word out to fuel more consumer awareness and demand for access to their digital health data.

Consumer eHealth Program. ONC's Office of Consumer eHealth (OCeH) catalyzes, coordinates, and inspires others to support consumer engagement via eHealth by influencing policy and standards development, convening diverse stakeholders, building public-private partnerships, and providing thought leadership through writing and public speaking. The program emphasizes the "Three A's" strategy for consumer engagement via eHealth: increase people's *access* to their own digital health information; ensure that information is *actionable* via apps and tools, and promote a change in *attitudes* regarding traditional consumer and provider roles.

Federal Advisory Committee Workgroups. Two federal workgroups comprised of volunteer subject matter experts issued joint recommendations in 2014 to the HIT Policy Committee and the HIT Standards Committee concerning how to support the use of patient-generated data in the next stage of Meaningful Use for EHRs. A third workgroup of the HIT Policy Committee plans to consider how to increase patient activation as a member of a defined care team, engage patients in assessments of their health, and use technology to deliver care to patients outside of traditional care settings.

Investing in Innovation (i2) Program. ONC created the Investing in Innovation (i2) program to award prizes competitively to stimulate innovation. These competitions, referred to as health IT developer challenges, focus on innovations related to: (1) the goals of HITECH and clearing hurdles related to the achievement of widespread health IT adoption and meaningful use; (2) ONC's and HHS's programs and programmatic goals, and (3) the achievement of a nationwide learning health system that improves quality, safety, and/or efficiency of health care.

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VA's Innovation Program. The US Department of Veterans' Affairs manages the VA Center for Innovation that includes an industry Innovation Competition that has been in existence since 2010.

Care Planning. As the capabilities of health IT tools increase and a national infrastructure for electronically sharing health information becomes widespread, individuals and stakeholders throughout the care continuum are converging around a vision where a single care plan can be captured, dynamically updated, and utilized in a secure and appropriate fashion by individuals, caregivers, and any member of the individual's virtual, interdisciplinary care team.

Patient-Generated Health Data. Patient-generated care data are health-related data that are created, recorded, gathered or inferred by or from patients or their designees. These data are distinct from data generated in clinical settings and through encounters with providers in that (1) patients are primarily responsible for capturing and recording these data, and (2) patients direct the sharing or distributing of these data to the recipients of the individual's choosing. There are no widely established policies to define the optimal use of patient generated health data, much less how to support it.

Personalized Health Care. While the concept of personalized health care is not new, genomic, proteomic, and other discoveries are accelerating the tailoring of patient treatments, risk assessment, and diagnostic reasoning. Personalized medicine has been defined as "the tailoring of medical treatment to the specific characteristics of each patient . . . [involving]… the ability to classify individuals into subpopulations that are uniquely or disproportionately susceptible to a particular disease or responsive to a specific treatment." (*Priorities for Personalized Medicine*, Report to President's Council of Advisors on Science and Technology (PCAST), 2008). Another relevant link is the one below describing the new NIH Precision Medicine program:
http://www.nih.gov/precisionmedicine/workshop-20150701.htm

2   Overview of the HIE Personal Health Records Community of Practice

2.1   Impetus for ONC to create a PHR Community of Practice

In 2014, ONC had decided to initiate a number of Communities of Practice (CoP) workgroups in key areas of interest to ONC and its key stakeholders that are of significant relevance to the ONC Interoperability Roadmap. One topic of ONC interest was HIE-based Personal Health Records. ONC has supported Health Information Exchanges implementing Personal Health Records through its State HIE Cooperative Agreement Program. In addition, ONC's State Health Policy Consortium launched the PHR Ignite project to support the use of a variety of PHRs through pilot programs that provided patients access to their health information. These patients used a non-tethered PHR, which is not connected to a provider's electronic health record (EHR) system. The project also provided formative research to support work in consumer engagement through use of PHRs.

There has also been increasing interest in PHRs among HIEs. CMS issued an FAQ stating that HIE-based PHRs can be used to achieve Meaningful Use Stage 2 Patient Engagement measures. A key advantage of an HIE-based PHR for patients is that it allows patients to access health

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information from any provider connected to the HIE, instead of only information limited to a single hospital or provider.

As more HIEs adopt PHRs or consider doing so, ONC continues to receive questions related to implementing this technology. Accordingly, it seemed that there was a clear need to convene HIEs to share knowledge about their experiences with implementation since little guidance existed elsewhere. Thus, ONC selected HIE-based PHRs as one of its three CoP topics for Venesco in FY 2015.

2.2   Leadership and Membership

Leadership for the CoP was provided by the ONC Champion and by the Venesco contractors, which have facilitated and provided support for the CoP and its membership. The workgroup consisted of 13 geographically distributed Health Information Exchange Organizations who are either managing an operational HIE-based patient portal or shared PHR or are in the process of implementing such a portal/PHR. These member organizations are listed in the Appendix.

2.3   Goals

The CoP workgroup had three major goals:

1. To establish a community of Health Information Exchange Organizations with shared PHRs.

2. To identify and discuss key issues and lessons learned for HIEs adopting shared PHRs.

3. To develop and disseminate a Key Considerations final report for HIEs adopting shared PHRs.

3   PHR Design Goals, Capabilities, and Challenges

As an HIE begins to pursue its interest in establishing a PHR as an addition to its repertory of services, there are a number of issues HIE leaders must consider prior to moving forward with developing an RFP to select a PHR developer. These include the following:

3.1   The Need and Environment: What is the impetus for implementing a PHR in your region/state and what are the characteristics of the healthcare environment that must be taken into account?

Although there are general principles that apply to planning for and establishing an HIE, it is important to recognize that an approach that works well in one HIE region may not be as effective in another due to environmental and other differences Environment in this context relates to assessing the interest of providers, consumers/patients, hospitals, health plans, legislative and governmental bodies, and other stakeholders, as well as identifying relevant regulations, changing patterns of payment, and existing and new incentives. If possible, the HIE should conduct focus groups and/or surveys with consumers, providers, and other stakeholders to determine their interest in using the PHR and which features would be of most interest. A budget should be prepared including the additional resources that will be necessary to develop, market, and implement the PHR. Barriers and other impediments should also be identified and examined for their impact on rolling out the PHR, and the HIE should address these barriers as much as possible as part of the planning process.

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3.2   Requirements: Examples of PHR Capabilities/Functionality

HIEs who have implemented PHRs emphasize how important it is to be clear on what functionality the HIE and its stakeholders want in the PHR. It is important to start with a basic set of functions that have been demonstrated to be useful and appealing to patients, caregivers, and providers, with the capability to expand to more advanced functions in response to evolving stakeholder interest and need.

The capabilities and functionality to be considered include:

- Display of information in a consumer-friendly format
- Ability of patients to view such basic information as diagnoses, procedures, medications, allergies, lab results, etc.
- Ability to connect to an HIE
- Access by any web-enabled device, including mobile phones
- Tracking/graphing of health measures
- Patient educational information
- Ability to assess degree of consumer and provider use of specific functions, through such services as Google Analytics
- Support for client branding to appeal to providers
- Well-designed state-of-the-art security system and consent infrastructure
- Provision for integration of consumer-entered data or patient-generated health data
- Languages offered by the PHR

3.3   Major Issues and Barriers

- Patient Authentication
  - ➢ **In-person authentication is a significant problem.** It is clearly important to assure that the person who is requesting access to a patient's medical record is in fact the patient whose care is documented there (or is the patient's legally authorized caregiver or representative). HIEs have found, however, that accomplishing this through in-person authentication at each facility where the patient has received care is a cumbersome and onerous process for both providers and patients. It is a significant impediment for patients to have to visit each of a number of facilities in order to obtain access to all of their medical records (i.e., to have access to their comprehensive medical records.)
  - ➢ **On-line self-authentication process could be developed as an alternative**. HIEs with PHRs are finding that it is helpful to have an on-line self-authentication process to replace the burdensome in-person authentication at each facility. Therefore, some are creating a process whereby patients can authenticate themselves remotely by answering key questions much like the types of questions individuals are accustomed to answering

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to obtain access to financial information where security is important. It is a costly process to develop, however, so this should be a consideration.

- Workflow Issues

There are a number of potential workflow issues associated with implementing an HIE-based PHR. A key workflow issue concerns where in the patient workflow it is appropriate to discuss PHR participation with patients. This issue is discussed below.

  ➢ **When is the best time to offer a patient portal to a patient or consumer? Before a clinic/hospital visit, at registration, during a visit with a nurse?** While there is not a single correct answer, it is critical that suggesting a patient portal never be done when it interferes with patient care in any way. Good possibilities include: **at the time of discharge from a hospital or clinic, or whenever a provider is speaking with a patient concerning follow up care, such as medication use.** Admission to a hospital or clinic can sometimes also be a well-timed opportunity, but only if the patient is not in pain and the conversation does not impede patient care. It should be noted that providers are very important in promoting patient use of the PHR, since they are in a particularly strong position to discuss the advantages of PHR participation and may have an ongoing healthcare relationship with the patient.

- Privacy and Security

It is important to research both federal and state privacy laws since privacy laws vary significantly from state to state, and some are more restrictive than the federal HIPAA regulations. These state variations include considerations related to behavioral health data exchange and restricted access to pediatric data. Privacy and security laws and regulations are important to both providers and patients, so it essential that these be understood and taken into account in designing and implementing the PHR. ONC's eConsent Toolkit focuses on educating patients about the sharing of their electronic health information through a HIE.

- Technical Issues

Technical issues will tend to vary by HIE, developer, and other factors. One issue that has arisen for some HIE-based PHRs is the lack of interoperability between EHRs that has impeded the HIE provision of PHR scheduling of appointments. This capability is important to patients and is typically offered as part of the services offered by tethered portals in individual systems, so HIEs are working on the interoperability needed for their cross-organization PHRs to meet the visit scheduling needs of patients. Another issue is to ensure that there is sufficient time allowed for testing the new technology prior to full implementation.

- Willingness of providers to invest time in marketing to patients and other tasks associated with establishing PHRs

Although HIE PHRs typically work to assure that providers are not burdened with such activities as establishing patient accounts (which is usually done by HIE clerical staff), provider buy-in is very important since providers are important in talking up the PHR to their patients as a helpful tool. Provider buy-in is enhanced by the value of the PHR in helping

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them meet the Meaningful Use Stage 2 patient engagement requirements and its value in engaging patients in their care.

- Integration of Patient-Generated Health Data

  The best methods for incorporating or integrating consumer-generated data into the PHR are still in development, although ONC and other funders, such as the Robert Wood Johnson Foundation, have supported research on specific approaches to capturing and using data directly from patients. For example, Geisinger conducted an ONC-funded Beacon Community project in which patients accessed their medication lists and provided feedback to their providers online through the patient portal prior to an upcoming visit. The findings were that patients were eager to provide feedback on their medication data and felt it enabled them to track their medications in a more effective manner. Geisinger found that the information provided by the patients was useful and accurate. Pharmacists made patient-suggested changes in 80% of the cases, and providers found that medication reconciliation was more efficient, with significant time savings[5]. HIEs can access this resource on examples of patient-generated initiatives as well as discuss this issue with their developer.

- Proxy Access

  Policy issues which arise include the need to disconnect minors from parent accounts at 18 and other issues relating to federal and state regulations concerning minors and their access to their healthcare records. HIEs should be aware of the relevant regulations in their states and also work closely with their developers to develop resolutions to these policy issues that are appropriate for their specific situation and state.

- Concerns of providers with tethered PHRs

  Some providers who already have access to tethered PHRs for their patients are pleased about the associated patient loyalty and retention advantages, so may be reluctant to participate in cross-organization HIE-based PHRs, especially since they have already purchased a tethered product so would have the additional cost of adding a second PHR product. Some HIEs have found that providing organization-specific "branding" and additional functionality makes their PHRs more attractive to these providers.

4   Strategy for Designing and Implementing an HIE-Sponsored PHR

There are a number of key components and steps that must be addressed by the HIE as it designs and implements its PHR system prior to issuing an RFP to developers. This document will not provide an RFP per se as a product, but it does seek to identify the key steps, the high level requirements, and the selection criteria. Once these top level requirements have been identified, the HIE can refine and further refine them over time. These high-level requirements and issues include the following:

- What is the regulatory and healthcare landscape? This is important to know since states are so different in their regulations as well as in their healthcare systems, and these differences can represent both facilitators and barriers to implementation.

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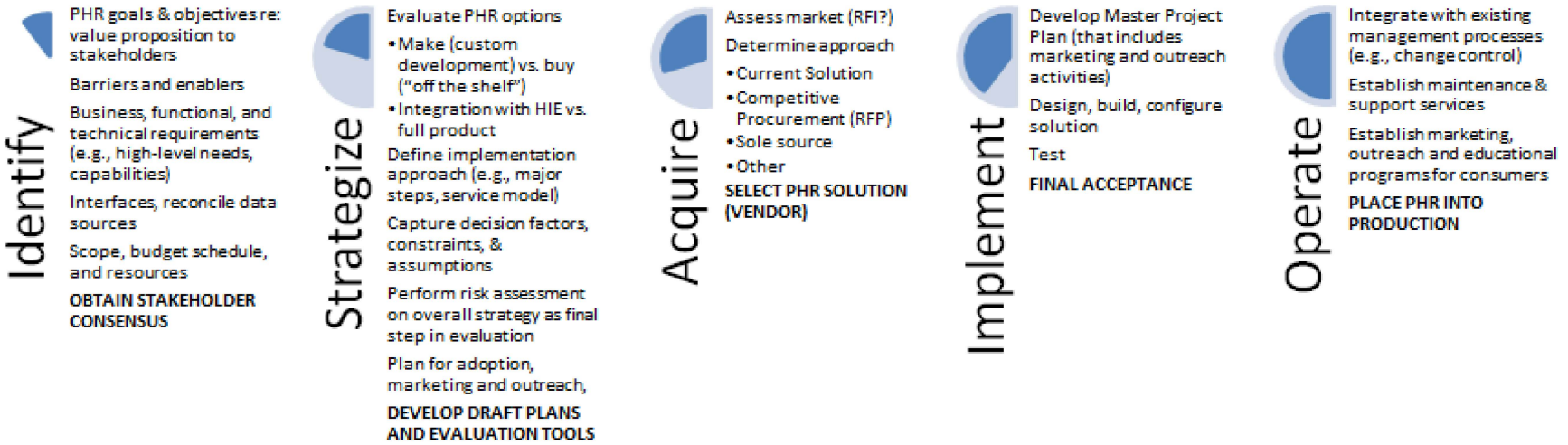
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- Decide on the functionality you want for the PHR. The functionality must include the ability to provide cross-community exchange of information. The PHR must also be able to query the HIE on a frequent basis for specific patients' information in much the same way that a provider can query the HIE for information on their patients. Another big issue is the ability of the PHR to reconcile the different data sources it accesses across the community. That is, the different data sources must themselves be interoperable in the sense that the PHR is able to transform the data from various data sources so that it can be understood. Data can have different meanings across sources, and it is important that the data be meaningful to both patients and providers.

- Strategy and alternatives for PHR procurement. Prior to the RFP, there are a number of questions that must be resolved. Chief among them are: "make vs. buy"—will the product be "off the shelf" or open source–and whether one will use existing products as the foundation when the HIE builds its PHR.

- Functional vs. technical requirements. In the viewpoint of those on the CoP, it is important to first focus on the type of functionality desired in the patient portal, since this will largely drive the technical requirements needed to provide the functionality. The desired functionality should largely drive the technical requirements, although a HIE also needs to outline some technical requirements, just not a detailed set of technical requirements. It was agreed by the CoP that it is important to include specific standards and specifications in the RFP, including IHE functionality.   IHE stands for Integrating the Health Enterprise (www.ihe.net).

- Sample Personal Health Record RFP: "Patient Portal for New Yorkers Design Challenge". New York eHealth Collaborative. January, 2013.   We recognize that it is helpful for HIEs to have access to sample RFPs, so we are providing a link below to access the requirements outlined in a competitive challenge issued in early 2013 by the New York eHealth Collaborative (NYeC) to invite responses to a "Patient Portal for New Yorkers Design Challenge".   http://www.health2con.com/devchallenge/new-york-state-patient-portal-challenge/

4.1   PHR Procurement and Decision making

1. Strategy and Alternatives for PHR Procurement
    a. Make vs. buy, integration vs. full product, capabilities
2. Major Implementation Steps
    a. Identify these prior to the RFP; then adjust and refine as needed later
3. Implementation Risks and Remediation
    a. How best to collaborate and work with your PHR developer
4. Adoption, Marketing, and Outreach (following the RFP)

The flow chart (**Figure 1**) on the following page depicts this process of PHR Procurement and Decision Making in graphic form.

Figure 1. Flow Chart of PHR Procurement and Decision Making

Identify
PHR goals & objectives re: value proposition to stakeholders
Barriers and enablers
Business, functional, and technical requirements (e.g., high-level needs, capabilities)
Interfaces, reconcile data sources
Scope, budget schedule, and resources
OBTAIN STAKEHOLDER CONSENSUS

Strategize
Evaluate PHR options
• Make (custom development) vs. buy ("off the shelf")
• Integration with HIE vs. full product
Define implementation approach (e.g., major steps, service model)
Capture decision factors, constraints, & assumptions
Perform risk assessment on overall strategy as final step in evaluation
Plan for adoption, marketing and outreach,
DEVELOP DRAFT PLANS AND EVALUATION TOOLS

Acquire
Assess market (RFI?)
Determine approach
• Current Solution
• Competitive Procurement (RFP)
• Sole source
• Other
SELECT PHR SOLUTION (VENDOR)

Implement
Develop Master Project Plan (that includes marketing and outreach activities)
Design, build, configure solution
Test
FINAL ACCEPTANCE

Operate
Integrate with existing management processes (e.g., change control)
Establish maintenance & support services
Establish marketing, outreach and educational programs for consumers
PLACE PHR INTO PRODUCTION

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This five-step process is also described below.

- The flow chart begins with the initial step, *Identify*, which focuses on the goals and objectives, scope, budget, resources, business and functional requirements as well as obtaining stakeholder consensus.

- The second step, *Strategize,* focuses on the evaluation of PHR options, including key decisions (make vs. buy, integration with the HIE vs. the full product); defining the implementation approach; capturing decision factors, constraints, and assumptons; risk assessment as the final step in evaluation; the plan for adoption, marketing and outreach, with the end result being the development of draft plans and evaluation tools.

- The third step*, Acquire*, focuses on assessing the market, possibly through an RFI, and determining the appropriate approach, which will entail evaluating such options as the current solution, competitive procurement through an RFP, sole source, or another approach, ending with selection of the PHR solution (developer).

- The fourth step, *Implement,* incorporates developing the master project plan, including the steps of design, build, configure, and test, which will culminate in final acceptance.

- The fifth and final step, *Operate*, includes the process of integration with existing management processes, establishing maintenance and support services, and establishing marketing, outreach, and education programs for consumers, all of which will accomplish the overall goal of placing the PHR into production.

5   Phased Development of Implementation Plan

The key principles for the phased implementation include:

- Implement the PHR one step at a time. This is important to assure savings and cost benefits associated with avoiding wasted functionality that is not of clear perceived benefit to stakeholders. It is very important to know which functionality is of interest to one's stakeholders before proceeding to include it in the first phase of the RFP.

- Start with basic functions and core information presented in a consumer-friendly format. The core information could include such items as current/past diagnoses, procedures, allergies, medications, lab results, etc.

- Provide data in a standards-based format that is feasible for providers and useful for patients.

- Thereafter, add more advanced functionality, such as view, download, and transmit capability, secure messaging, desired timing of clinical updates, integrating patient-generated health data, on-line scheduling of appointments, other reminders and alerts, on-line refills, etc.

5.1   Adoption: Marketing and Outreach to Providers and Hospitals

A number of marketing and outreach steps are needed to maximize and facilitate the adoption of the new PHR services by providers and hospitals.

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- Important to educate providers/hospitals about the potential value propositions for them and their patients. As noted elsewhere in this report, there are numerous reasons why it is attractive for providers and hospitals to participate in an HIE-sponsored PHR. These include: it assists busy providers in meeting the MU 2 and MU 3 patient engagement criteria,; the one-stop shopping it provides is attractive to their patients, especially those who visit multiple providers; it has the potential to enhance the provider's partnership with the patient and the engagement of the patient in their care; and enhanced patient engagement is associated with better outcomes and lower costs, which are increasingly the basis for provider financial rewards in the emerging new payment structures.

- Additional charges for premium services? One HIE with an active and evolving PHR noted that its PHR user group of members have agreed that the cost of the PHR functionality should be shared by all subscribers, even when not all subscribers may use it. This includes such new PHR services as on-line medical refill service. However, it was noted that the subscription fees charged to the participating organizations change annually according to the various services that the HIE is providing, which provides an opportunity for the HIE to recoup at least some of the cost of adding new PHR services. HIEs are also considering whether to charge for custom functionality requested by specific customers, such as establishing links into the system for scheduling appointments.

5.2   Value Proposition and Sustainability Issues

There were a number of questions that arose during CoP discussions concerning the value proposition and sustainability, including whether HIEs should charge providers and/or patients for PHR services. It was agreed that an important PHR value proposition for HIEs is that it adds value to HIE member participation so helps retain existing subscription customers and attracts new customers. For this reason, the prevailing pattern appears to be that there is usually no charge unless specialized functionality is requested by specific providers.

Evolution of future charge patterns and drivers for adoption. Members of the CoP noted that there may eventually be a tipping point for patients as they become accustomed to PHR availability and will ask or even pressure their providers to participate in the HIE/PHR. The tipping point seems very close, given the results of the National Partnership for Women and Families surveys in 2011 and 2014 which showed the increasing value consumers are placing on health IT and the doubling of PHR access to 50% in just three years, with patient use of that access increasing from 80% to 86%[4]. If this pattern of increasing consumer use continues, patients/consumers will soon be the major driver of PHR adoption.

Another possibility as PHRs evolve is that, in the future, new premium functionality may be paid for much like in an app store—basic apps are free, while more sophisticated "premium" apps include a charge. The same may soon be true of HIEs, who will charge for premium services requested by a specific organization, while including all basic services in the general subscription price. Another HIE PHR provider commented that the patient "stickiness" that is appealing to tethered systems may apply to HIEs and their customers as well—the PHR helps retain patients.

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5.3 Marketing and Outreach to Patients

The key questions here include:

- who is marketing to patients

- what are the best approaches to engage them

- how is this impacted by the new value-based payment models

The experienced PHR providers in the CoP agreed that provider support in marketing to patients is critical. A compelling example was provided by a CoP member who described a group of providers in their region who write prescriptions for their patients to participate in the PHR. Another factor is the change in payment models, including those at CMS, to rewarding care coordination, which is strongly related to PHRs. There are also websites and on-line materials describing the advantages of PHRs that can be used in marketing to patients, such as the Arkansas SHARE (State Health Alliance for Records Exchange) website[6]. One PHR provider on the CoP shared the example of Bucknell University in Pennsylvania, which uses the PHR to schedule appointments for students, but also finds the PHR helpful in uploading records for out-of-town students in order to have all of the student's medical records in one place.

6 Bright Spots in PHR Implementation

We are providing in this report two examples of Bright Spots in PHR implementation to provide a real-world picture of how promising PHRs are evolving in actual healthcare settings. These examples are: the Kansas Health Information Network (KHIN) and the Keystone Health Information Exchange (KeyHIE) in Pennsylvania. Both have been active members of the PHR CoP. We appreciate their input and review and thank them for allowing us to share briefly their stories of accomplishment, barriers, and lessons learned.

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7 Kansas Health Information Network, Inc.

7.1 Introduction/Background

The Kansas Health Information Network (KHIN) formally launched its Health Information Exchange (HIE) on July 1, 2012. KHIN is one of two HIOs that serve the state of Kansas (the other is the Missouri-based HIE known as LACIE). Both HIEs are private networks that were initially sanctioned and regulated by KHIE, the Kansas Health Information Exchange, which is the quasi-regulatory body that then provided oversight. In 2013, KHIE agreed to assign its HIE oversight role to the Kansas Department of Health and Environment (KDHE). Under the leadership of CEO Dr. Laura McCrary, KHIN has grown rapidly since its inception in 2012. By April, 2015, there were more than 2,000,000 unique patients in the KHIN exchange, with access to more than five million patients across exchange connections. More than 1,200 member organizations participate in KHIN, 125 of which are in production (475 facilities), with 320 organizations in the testing phase. The provider portal enables full health information exchange including query functionality and web-based access, with the number of queries per month averaging about 100,000. The HIE also provides state-level interfaces to allow public health transmissions, including syndromic surveillance, immunizations, electronic lab reporting for reportable diseases, the cancer registry, and the infectious disease registry. KHIN services also include secure clinical messaging/Direct, image exchange, alerts, and data extracts.

The KHIN initiatives which have been most in the limelight are: Establishing a patient portal, sharing VA records between VA facilities and non-VA providers in Kansas, exchanging data with the Kansas Infectious Disease Registry, and partnering with county mental health centers now making possible behavioral health referrals using the KHIN exchange. The focus of this Bright Spot summary is KHIN's success in establishing a cross-organization personal health record system for patients based in the HIE.

7.2 Creating and Implementing the KHIN Personal Health Record

Impetus. The reasons for KHIN to implement a personal health record system included:

- Until 2015 it was a KDHE requirement to implement a PHR in order to do HIE business in Kansas.

- Many Kansas patients need medical records from multiple specialists or providers in one location.

- To provide assistance to providers in meeting their MU1 and MU2 patient engagement requirements (less cost for providers, shared reporting for 5% View, Download, and Transmit requirement, improved health of patients through patient education capability, and increased patient engagement in their health)

- KHIN strategic positioning for the future.

RFP Development Phase. CEO Laura McCrary and her KHIN leadership team spent considerable time working with various PHR developers and stakeholders to understand and identify the necessary technical and functional requirements that should be included in the RFP in order to select the PHR developer best suited to KHIN's needs. Once the RFP was issued,

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several finalists were selected from the proposals submitted, and the NoMoreClipboard personal health record system was the eventual developer selected.

KHIN PHR Deployment Strategy. KHIN implemented the deployment strategy for its PHR, MyKSHealth eRecord, in two phases, which are described below along with their characteristics and challenges.

Phase 1: October 2013: Manual push of CCD/C-CDA from provider to patient using Direct

- In-person identification, authentication, and matching at the provider site
- Provider willingness to invest time in provisional account creation
- Provider sends CCD/C-CDA to patient via Direct
- Patient receives email notification of new health information

Phase 2: January 2015: Connection to KHIN HIE for automated push of the CCD/C-CDA to the PHR

- Technology solution – CCD/C-CDA vs. HL7 data
- In-person identification, authentication, matching at the provider site
- Once matched, PHR developer regularly queries KHIN every 6 hours for new documents and auto-routes to patient PHR
- Policy issues for parent accounts: disconnecting minors at age 18 from parent accounts

7.3   Key Features and Capabilities

- Information provided includes: contact information, employment information, emergency contacts, insurance information, medical contacts, medications, illnesses, surgeries and procedures, immunizations, allergies, family medical history, and social history.
- Ability to track and graph: height, weight, and BMI, A1C, steps (pedometer), blood pressure, calories, carbohydrates, blood glucose, triglycerides, bun/creatinine, cholesterol.
- Patient ability to print the information, edit the format of the information, and decide who will have access to it
- Availability of information in either English or Spanish, according to patient preference
- Access to various documents (financial, insurance, legal, medical, and personal)
- Patient education information concerning medications, genetic screening, and other medical issues in English and Spanish
- Direct messaging between patients and medical professionals

7.3.1   KHIN Successes

KHIN PHR accomplishments in its first 1.5 years of PHR implementation included:

- Extensive patient and provider participation: 39 organizations participating
- MU attestation (assistance to providers)
- Addition of patient education software

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- Avoidance of provider costs

- Increased HIE value (no additional charge for PHR services to HIE subscribers)

- Foundation for additional innovation

- Positive feedback from providers and patients.

7.3.2   KHIN Facilitators and Challenges

Facilitators:

- Effective leadership oriented to growth and sustainability

- Kansas requirement that all HIEs must provide a PHR

Challenges/Barriers:

- Kansas has a heavily regulated environment for HIEs

- Providers and patients found the in-person authentication process required at each provider site burdensome

Phase 1

- Manual effort required to extract the summary record information

- Additional provider time and effort to send records to patients via Direct and to push data to patients after each encounter

Phase 2

- New technology solutions needed for the automated push of HL7 data to patients

- Continuing issues of patient identification/authentication at provider sites

- Assuring that query frequency is sufficient to meet MU2 reporting requirements

- Timing of delivery of patient summary documents to patients after the visit

- Issues surrounding MU2 reporting formats

Phase 3 – Next Steps:

- HL7 results delivery with additional lab data and expanded provider participation

- Integration with state immunization registry (results delivery and guidance)

- Remote on-line authentication/identification of patients to facilitate process

Contacts for more information on KHIN and its PHR:

KHIN website: www.khinonline.org

KHIN Leadership:

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8 Keystone Health Information Exchange (KeyHIE®)

8.1 Introduction/Background

The Keystone Health Information Exchange (KeyHIE®), founded and incubated by the Pennsylvania-based Geisinger Health System in 2005, is recognized as one of the nation's oldest and largest electronic health information exchange networks.

KeyHIE partners with hundreds of participating providers, offering patient-consented access to more than 3.6 million electronic health records through a single login. It now serves a network of 19 hospitals, 174 physician practices, 28 home health locations, and 61 long-term care facilities in more than 53 Pennsylvania counties. In August 2015, alone, 2,341 active KeyHIE users accessed 261,000 patient records.

As one of 17 ONC-funded Beacon Communities (2010-2013), KeyHIE's team demonstrated a decrease in unnecessary hospitalizations and an increase in patient satisfaction. These outcomes were directly attributable to care coordinators' ability to leverage health IT to better manage the health of individuals with chronic conditions.

8.2 Creating and Implementing the KeyHIE Personal Health Record (PHR)

Impetus. Launched in 2012, KeyHIE's PHR, known as MyKeyCare, creates a secure patient-friendly online tool to gather, store, and manage health information. Today, MyKeyCare has more than 16,000 enrollees.

Selection of PHR Developer. KeyHIE leadership opted to utilize the PHR that was part of their HIE developer's software portfolio.

KeyHIE PHR deployment strategy. Utilize the PHR system provided by the KeyHIE developer.

- Phase in through promotion of basic features of interest to stakeholders, including demographic data, diagnoses, procedures, medications, surgeries, lab results, allergies, etc.

- Provide an easy to navigate and user-friendly patient website (ongoing patient feedback through surveys and focus groups has been key to improving the site's navigation and documented increases in overall use).

- Evaluate MyKeyCare usage patterns to identify and overcome obstacles.

- Offer basic PHR services at no additional cost to providers who are already HIE subscribers (the addition of the PHR functionality attracts new HIE subscribers and helps retain existing ones).

- Assess patient and provider interest in specific advanced functionality options prior to implementation (ensures that the expense of adding new features is worth it).

- Promote the PHR's value to providers and patients (providers are in an excellent position to market the PHR to their patients; some have used a prescription pad approach to prescribe PHR participation).

- Create a PHR user group which regularly meets to discuss usage trend metrics, possible new services and charges, and related issues.

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8.3   Key Features and Capabilities

- Basic medical information of interest to patients (as mentioned above)

- Patient notification of a new document or a provider message

- Online prescription renewal capability

- Use of Google Analytics to provide daily KeyHIE metrics to assess patterns of patient use and improve the patient website. For example, the change to Quick Links made a major difference in the level of patient use. The Google Analytics measures include the following:

  - Metrics of access, session length, average pages viewed, bounce rate

  - Site traffic volume metrics to examine monthly trends (spikes are noted with the major release of new services)

  - Daily tracking of sessions, level of engagement

  - Usage by type of device, including specific mobile devices

  - Visitors by source, most visited pages

8.3.1   KeyHIE Successes/Accomplishments

- Rapid expansion of the PHR program among HIE subscribers and their patients

- Improvement of ability of patient website navigation, as shown by the short average session duration

- Launch of Quick Link icons on the Home page for high traffic areas, such as View My Files, Request an Appointment, Manage My Record, and Message with provider

- Use of the PHR to help providers meet their MU2 patient engagement requirements

8.3.2   KeyHIE Facilitators and Challenges

Facilitators:

- KeyHIE is based in the Geisinger Health System, which has a large "footprint" in rural Pennsylvania, which facilitates interoperability, given the use of the same EHR system across many of the hospitals and clinics in the region.

- MyKeyCare was adopted by a large health system participant as their Meaningful Use patient portal, which has become a model for other KeyHIE participants.

- Google Analytics is a valuable measurement tool in understanding patterns of usage and how to better tailor the website to meet consumer needs.

- Well-developed community engagement through KeyHIE's longevity, the Director's long tenure, and Geisinger's visibility and impact in the region and state.

Challenges/Barriers:

- Determining the best approach to marketing the PHR to patients (at a wellness visit, at discharge, at a health fair, etc.) but never interfere with patient care.

- Interoperability issues, such as scheduling appointments in provider practices that use a different EHR (this is one potential disadvantage of HIE-sponsored PHRs which KeyHIE

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and other HIEs are working to address, since appointment scheduling is of key interest to patients).

- Referrals from hospitals in the large multi-county region which use a different EHR are another interoperability issue.

- Identifying how best to spread PHR cost, as new services are added; for example, provide basic services at no additional charge, but charge an additional fee for advanced or unique services tailored to specific stakeholders.

Next Steps

- Add services, such as moving to a mobile app, and use Google Analytics data to support the need for enhancements.

- Continue work on the website's *Monitor Health Readings* section to include vital signs and specific measures for cardiovascular, diabetes, and asthma conditions as well as lab results and an exercise log.

- Examine the feasibility of charging additional fees to users who want specific or unique services tailored to their needs, such as health plans.

Contacts for more information on KeyHIE and its PHR

KeyHIE website: www.keyhie.org

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Appendix:

Member Organizations, PHR Community of Practice

Organization
California Association of Health Information Exchanges (CA-HIE)
HealthBridge (Cincinnati)
HealtHIE Nevada/HealthInsight Nevada
Inland Empire HIE (IEHIE-California)
Kansas Health Information Network (KHIN)
Keystone Health Information Exchange (Pennsylvania)
Michiana Health Information Network (MiHIN)
North Dakota Department of Health
Physicians Medical Group of Santa Cruz
RAIN Health Information Exchange and Telemedicine Network (California)
Redwood MedNet (California)
Rhode Island Quality Institute (RIQI)
St. Joseph Health System (California)