Personal Health Record Overview

Personal Health Records (PHRs) in conjunction with electronic health records (EHRs) are tools aimed at promoting client participation in health care decisions through increased access to medical care information via electronically maintained medical records. PHRs were included in the HITECH Act Meaningful Use Incentive Program aimed at increasing adoption and meaningful use of EHR technology. Meaningful Use’s (MU) three stages created a glide path to PHR implementation and patient adoption by introducing PHR in Stage 1, clients be able to view, download, and transmit their data in MU Stage 2\(^1\), and MU Stage 3 has an objective to improve health outcomes through quality, safety, efficiency, and access to PHRs as a health management tool. PHRs can be tethered or untethered electronic portals.

Tethered PHRs (electronic patient portals) are web based accounts given to patients sponsored by health care provider, hospital, or health plan which offer patients the ability to view selected EHR data collected during a health care visit. Patient portals can also provide additional functionality and information, such as:

- Pertinent clinic visits and hospital discharge information
- Secure communication with providers
- Information driving client responsibility through shared decision making
- Patient education
- Secure, communication with care team
- Online prescription refills
- Bill payment

Untethered PHRs are freestanding patient-controlled repositories of data where an individual can collect their health information and collect medical information from numerous health records. In other words, the patient is responsible for collecting and storing his or her health information into the untethered PHR. The intent of the freestanding PHR is engage the patient and empower them in their own health care. Pros/Cons of this—patient must be engaged to have a robust PHR, but the patient will have to determine all the potential data sources and request information from those providers.

\(^1\) CMS EHR Incentive Programs: 2015-2017 (Modified Stage 2 Overview)
Current State
Health care organizations have deployed organization-specific PHRs technology and patient education programs encouraging PHR use by patients, streamlining communication between patients and their care teams and providing electronic access to her medical information. Other efficiencies with PHRs include access to online appointments, facilitated prescription refill requests, and patient education tools. Studies have shown widespread patient communication of PHR tools to a broad population can improve use of PHR tools and engagement in personal health care. Challenges persist as awareness of the need for consumer access to their health data is growing. A list of challenges include:

- **Low Adoption** – Widespread patient adoption of personal health applications and patient portals remains low.
- **Multiple patient portals** – Health care organizations, including ambulatory providers, hospitals, and health plans are offering PHRs and consumer tools.
- **Smaller practice’s ability to deploy PHRs** – Smaller practices may not have the human or financial resources to deploy PHR technical services.
- **Ongoing education and communication** – Need for dedicated and ongoing education and outreach to consumers
- **Health literacy and Usability of tools** – Strategies are needed to enhance the usability of these systems, especially for people with low literacy, low health literacy, or limited technology skills.
- **Competing Priorities** – Many providers have other priorities to address
- **More than IT project** – Implementing PHRs requires technical implementation but also requires clinical workflow modification and operations and culture change
- **Reimbursement** – Patient and care team email communication is largely unreimbursed.
- **Broader information needs** – Current PHRs are sponsored by health care organizations, but chronically ill patients receive care from multiple providers. Thus, patients may have to access multiple PHRs for clinical information. Widespread ecosystem for consumer access, especially patient-to-provider exchange has not yet emerged.

**Value Proposition for Medicaid Community Personal Health Record**
With Medicaid Expansion, Colorado Medicaid’s diverse populations have grown to over 24% of the Colorado population\(^2\). HCPF has identified consumer health tool investment, including PHRs and consumer health apps as strategic objectives for engaging Medicaid clients in their health and care. To date, HCPF’s targeted consumer health tools have focused in the eligibility and enrollment function focusing on benefit and administrative information. An additional Medicaid client initiative funded by a CMS grant is HCPF’s Testing Evaluation Functional Tool (TEFT) grant piloting PHRs to the community-based Long-Term Services & Supports (CB-LTSS) population focusing on the blind, elderly, and disabled (EBD) and the Intellectually and Developmentally disabled (ID/DD) populations. With the implementation of the TEFT grant, both these populations and their care givers will have broader

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access to consumer health tools, such as PHRs. TEFT grant planning and implementation learnings can be used for wider Medicaid client population engagement tools, and potentially extended to broader populations over time.

**TEFT Overview** – CMS awarded the TEFT Grant to Colorado for planning and implementation of consumer tools for certain LTSS waiver populations—specifically the EBD and SLS-ID/DD populations. Colorado currently serves 22,384 EBD and 4,007 Supported Living Services (SLS-ID/DD) enrollees. Through rich stakeholder engagement the TEFT project team leveraged state partnerships with Community Centered Boards, Single Entry Points, Regional Care Collaborative Organizations, Accountable Care Organizations (ACOs), Home and Community Based Service (HCBS) providers, along with technical support from the HIEs—CORHIO & QHN. Internal HCPF programs, the person-centered initiative and No Wrong Door project teams also contributed feedback for the Assessment Tool redesign. TEFT’s four main consumer tools demonstrate and adopt PHR Systems with LTSS clients are as follows:

- **Experience of Care Survey** - Field test a beneficiary experience survey within multiple community-based long-term services and supports (CB-LTSS) programs for validity and reliability
- **Functional Assessment and Standardized Items** (FASI) - Field test a modified set of functional assessment measures for use with beneficiaries of CB-LTSS programs
- **Personal Health Record** - Demonstrate use of PHR systems with beneficiaries of CB-LTSS.
- **eLTSS Plan** - Identify, evaluate, and harmonize an electronic Long-Term Services and Supports (eLTSS) plan in conjunction with the Office of the National Coordinator’s Standards and Interoperability Framework.

The Planning Phase criteria were developed based on feedback from Stakeholder meetings held in 2014. Stakeholders recommended including both clinical and non-clinical data fields. PHR users will include clients, caregivers/family members and care coordinators and will focus on a Person-Centered approach and consent solutions developed. CMS provided a selection of technical vendors for evaluation and selection, and CORHIO, Orchestrate Health, and HCPF collectively selected the vendor. The TEFT grant plans to evaluate the following data points:

- Frequency of Use
- Who is using it and how often
- How clients access the data
- Efficient coordination of services, tracking scheduled appointments and units
- Coordinating health information
- Increase in quality of care

**Leveraging the HIE** - There is an opportunity to build out a wider ecosystem for consumer health information access by leveraging HIEs. HIEs integrate data sources and can offer a PHR with robust information from multiple data sources. Currently, tethered systems through individual health care
organizations or health plans require patients and care givers to deal with and manage multiple PHRs. Leveraging existing HIE platforms, a centralized and comprehensive medical record could be available by the HIE. Additionally, the TEFT pilot will help us understand what level of infrastructure is needed to integrate clinical and administrative data and steps needed to implement a patient facing portal. The growing elderly population with its multiple chronic conditions managed by different specialists make cross-organization PHR access even more important.

Architecture diagrams
Figure 1. eLTSS Plan Sharing Context Diagram
Operational Considerations

Finance – Client/Patient and care givers awareness of PHRs and other health information tools is increasing. HCPF has made investments and secured funding to build from the TEFT grant planning and implementation work to plan for a common Medicaid client Personal Health Record (PHR) leveraging HIE connections and Medicaid enterprise systems. Funding for Medicaid’s client PHR was secured from Colorado General Fund and approved HIE Advanced Planning Document (APD) funding. Future enhancements to broader non-Medicaid population must be cost allocated.

Sustainability

- Policy Levers can be leveraged to recommend or require usage of a Personal Health Record for high-risk, high-cost populations. Identifying patient populations who could benefit from a PHR and incorporating required usage of PHR in demonstrations and waivers is just one available policy lever to support adoption, use, and sustainability. Possible policy levers should be listed, discussed as part of implementation planning.

- Managed care contracts are additional avenues for articulating requirements for shared HIT resources to support care coordination, transitions of care, and quality measurement. CMS
Managed Care Rule released on April 27, 2016 outlines advance HIE services and shared HIT infrastructure needed to support Medicaid Managed Care.

Accountability

- **Objectives** – Accountability among data sources and users is essential for shared technical services. Agreement upon common objectives with measureable outcomes is important for measuring quality of data, maintenance and support of shared PHR.

- **Metrics** – Aligned and articulated measures are important to temper expectations on implementation milestones and extensibility planning.

- **Progress reporting** – All participating data sources and data users should produce regular progress reports on the agreed upon, aligned metrics advancing the objectives and overall master data management strategy.

Evaluation

- Assess which patient groups are using PHRs, understand how patients are using them, and add functions and data sources to meet the patient needs.

- Identify ideal populations for advanced communication and outreach for PHR use and assess the usage and any correlations to improved engagement and/or health outcomes. Learn from patient populations and create phased approach to additional patient populations.

**Next steps and future necessary considerations for the eHealth Commission including:**
A Consumer engagement and health information tools strategy requires wide stakeholder engagement and strategic planning to identify priorities, risks, and scope for Medicaid client Personal Health Record. Recommended tactics include but are not limited to:

- **Convene a statewide client PHR Planning Committee.**

- **Expanded communication to targeted patient populations** – Patients with chronic conditions or those who frequently visits hospitals or emergency rooms may benefit from targeted outreach on the PHR benefits and use for easy communication with their care team or health information education.

- **Policy analysis** – Analyze policies for sharing/acquiring patient level data across organizations, including proxy access and specific populations LTSS/DD/Caregivers, CHP+/Child approved for MAGI-Medicaid.

- **Priority Use Cases and Functions** – Identify priority use cases and interested community partners’ value proposition.

- **Data systems** – Identify Colorado data systems with client/patient/individual information to be included in a phased approach.

- **Common data set** – Promote collaboration across provider groups, beneficiaries, payers and
accountable entities by identifying an agreed upon core set of data elements for the capture and sharing of eLTSS plan information.

- **Communication and outreach planning** – Establish communication, outreach, and adoption plan.
- **Challenges to address** – Provider workflows, technical challenges, authentication, security, accessibility
- **PHR procurement and decision making** – Build versus buy a full product or certain capabilities

**Conclusion**

**Other state and national examples tethered Personal Health Records:**

- **New York** – New York state patient portal available to all New Yorkers through RHIOs leveraging the SHIN-NY.

- **Kansas** – Memorial Health Center uses KHIN’s sponsored My Health eRecords PHR (NoMoreClipboard) and Department of Veterans Affairs’ My HealtheVet PHR
  - Veteran downloads a CCD from My HealtheVet (VA) and uploads it to My Health eRecords (KHIN), where they send it to Hutchinson Regional Medical Center using Direct.

- **Pennsylvania** – Keystone Health Information Exchange (KeyHIE), in partnership with VNA Health Systems uses KeyHIE’s sponsored PHR MyKeyCare (Get Real Health Instant PHR)
  - Home health care teams from VNA Health Systems conduct an in-home Outcome and Assessment Information Set (OASIS) of the health, environmental and functional status of adult patients.
  - OASIS document is converted to a CCD and sent by home health care teams to caregivers of adult patients using the MyKeyCare patient portal.
  - Caregivers use MyKeyCare to send the CCD to other members of the patient’s care team using Direct.

- **The Blue Button Connector** – Open data source delivered through an open API that makes transparent the health data that is increasingly available to the public, which we believe will help to fuel the creation of new products and services.

**References:** Information on Personal Health Records was collected from CO HCPF TEFT documentation, previous CedarBridge Group contract work, CMS eLTSS Standards and Interoperability workgroup, Medicaid’s HIE Implementation-Advanced Planning Document Update, and industry standard organizations.