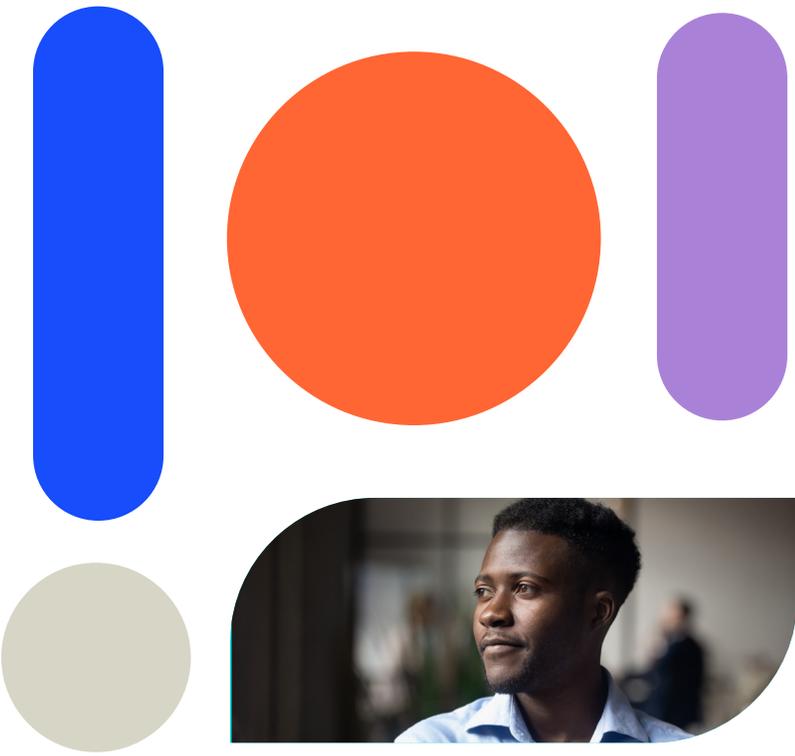


# Electronic Health Information for Health Equity

The AHIMA Foundation in sponsorship with Optum





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# Executive Summary

The prevalence of type 2 diabetes is rapidly rising in the United States and increasing access to Personal Health Records (PHR) may help improve disease management. PHR is defined as an electronic, universally available, lifelong resource of health information needed by individuals to make health decisions. Many studies have found that individuals who frequently use PHR have better glycemic control, medical adherence, and HbA1c levels. Few studies focus on PHR use among underserved patients. Through a combination of interviews and surveys, this study seeks the perspective of providers and health administrators to understand baseline use of PHR among underserved patients, barriers to increasing PHR adoption, benefits and ideal use of PHR, and the impact of the COVID-19 pandemic on PHR use. A total of 31 Health Information Management (HIM) professionals and care providers participated in the study.

Only 5 of the 31 study participants report that over 50% of the underserved patient population has access to PHRs. Participants report the most important social determinants of health for the successful management of type 2 diabetes are socioeconomic condition (66%), access to technology (60%), and education or health literacy (60%). The most significant perceived barriers to PHR access are lack of access to a computer, cell phone, or the internet (21%) and no perceived need for PHR by patients (21%). A preference for in-person communication (50%) is most frequently ranked in the top 3 barriers. The COVID-19 pandemic exposed many patients to virtual care and the benefits of PHR.

Study participants report that implementing PHR, enhancing its features, and working to improve patient adoption and utilization levels has the potential to make a significant impact for the management of type 2 diabetes. Based on interview and survey responses, the study offers multiple recommendations on a global and tiered basis for health systems to increase the usage of PHR. These recommendations include making PHR registration a top-down articulated priority, leveraging SDOH data to match patients' needs with community programs, and leveraging PHR to promote care plan adherence and reduce gaps in care.



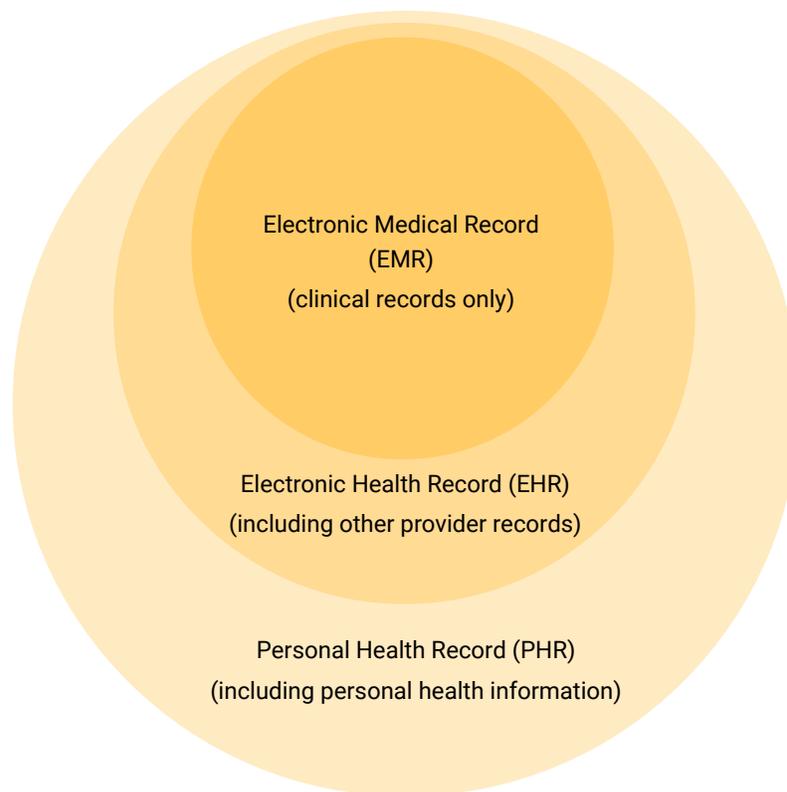
# Background

## Better type 2 diabetes management and the personal health record are linked

Type 2 diabetes is rapidly increasing in prevalence in the Dallas/Fort Worth area. It is estimated that over half a million individuals with type 2 diabetes reside in the area, a number that is projected to double by 2025 (North Texas Community Health Collaborative Diabetes Strategic Plan 2015-2016). The prevalence of type 2 diabetes and the rate of new diagnoses in Texas is far greater than the U.S. national average (Johnson et al. 2019). The rise in type 2 diabetes prevalence in the region is associated with factors such as a high prevalence of obesity, low socioeconomic status, and insufficient environmental resources including food deserts, lower healthcare access, and unavailability of safe recreation areas. Without intervention, the population of people with type 2 diabetes in the Dallas/Fort Worth area will continue to grow at this alarming rate.

Several studies have found that patients who frequently used PHRs had better glycemic control, medical adherence, and HbA1c levels (Kaelber, 2008). A PHR is defined as an electronic, universally available, lifelong resource of health information needed by individuals to make health decisions (Robinson et al. 2020, Cotter et al. 2014, Graetz et al. 2020, Benyamou, 2011). It is an extension of the electronic health record (EHR), which is a record of health information maintained by the provider containing all the information in a patient's medical record in an electronic form (Figure 1). Personal health record systems are not static repositories for patient data; they combine data, knowledge, and software tools, which help patients to become active participants in their own care (Tang, Ash, Bates, Overhage and Sands, 2006).

**Figure 1: Defining EMR, EHR, and PHR**



In type 2 diabetes management, PHRs are used to develop a complete record of health information, enhance patient awareness of their type 2 diabetes management, and stimulate behavioral changes. The PHR is also a way to address a patient's legal right to access and review their patient record in any format they choose, and to proactively and accessibly offer a patient their health information. While health information in the PHR is reflective of EHR information, legally, health information ownership has not yet been universally defined complicating patient access and use. In 21 states, including Texas, the EHR data is owned by the hospital and/or physician. Only in the state of NH is EHR data owned by the patient. The remaining 28 states have yet to define that standard (Who Owns Medical Records: 50 State Comparison, 2012). Regardless of who owns the data, when patients have a copy of their health information in their custody (most often, through the PHR), they can become active participants in their health.

### Vulnerable patients have inequitable access to the PHR

Vulnerable populations have three times less access to their health information than their more affluent counterparts (Patel, Barker W, and Siminerio, 2016). Among underrepresented populations (low-income households, rural and urban households, and aging populations) lack of health information, services, and technology result in lower usage rates of preventive services, less knowledge of chronic disease management, higher rates of hospitalization, and poorer reported health status (Patel, Barker, and Siminerio, 2016).

To have a measurable effect on health outcomes, availability of a patient-facing health record is not enough. Only if it is accessible and understood by patients, will it result in improved engagement and disease management. As health systems go beyond simply extending access to a PHR towards meaningful use of the record, it is important to ground this conversation within the larger discussion of health literacy. The presentation of PHR data in an easily understandable, user-friendly format is crucial. A commitment to organizational health literacy, the degree to which organizations equitably enable individuals to find, understand, and use information and services to inform health-related decisions and actions for themselves and others becomes especially important (What is Health Literacy, CDC). Within the framework that health literacy drives better patient engagement, autonomy, and understanding, equitable access to a useable PHR becomes essential.

Very few studies focus on how to increase patient engagement through PHR in underserved communities. Even fewer studies focus on the perspective of healthcare stakeholders, including providers, of how best to utilize PHR to improve type 2 diabetes care in these populations. The objective of this study is to understand baseline use of PHR among underserved patients, barriers to increasing PHR adoption, benefits and ideal use of PHR, and the impact of the COVID-19 pandemic on PHR use.



# Methods & Study Sample

The AHIMA Foundation in sponsorship with Optum conducted a mixed-methods study to investigate challenges and opportunities to expand PHR access to traditionally underserved patients in the greater Dallas/Fort Worth Texas area. The study consisted of an analysis of existing literature, semi-structured interviews with numerous healthcare stakeholders, and an online survey. From December 2020 to March 2021, the team conducted interviews with providers (dietitians, nurses, diabetes educators, and a surgeon) as well as healthcare administrators. Study participants were identified using a snowball sampling method from AHIMA members and either i) completed a brief pre-interview survey and a 30 to 60-minute interview or ii) completed a more extensive survey.

A total of 31 individuals participated in this study representing a range of professions and health systems. Of the study participants, 21 respondents work in health information management (HIM), 3 work in management, and 7 are providers with direct patient contact. Respondents are employed at a variety of organizations including large health systems and hospitals, Federally Qualified Health Centers (FQHCs), physician groups, Skilled Nursing Facilities (SNFs), Accountable Care Organizations (ACOs), and social support organizations (Table 1). Organizations varied significantly in size, with some respondents working in hospitals with less than 10 beds, while others in hospitals with over 600 beds. All but two of the organizations are in major cities or urban areas in Texas.

There is a great degree of variation in the percentage of underserved patients the respondents estimated their organizations treated. Sixteen respondents estimated that less than 50% of the patients they treated are underserved and 10 respondents estimated that 50% or more of the patients they treated are underserved.

In the study sample, the most used EHR systems are Epic (12 organizations) followed by Cerner (6 organizations). The rest of the facilities use a variety of EHRs: Athena, CPSI, Cerner Artiva, eClinical Works, Healthland Centriq, Meditech Magic, Mosaiq, My Unity, NextGen, and Pega.

**Table 1: Organizations where Study Participants are Employed**

Organization Types	N
Health System (unspecified facility)	3 (11%)
Hospital	10 (36%)
Federally Qualified Health Center (FQHCs)	3 (11%)
Physician Groups	4 (14%)
Skilled Nursing Facilities (SNFs)	1 (3%)
Accountable Care Organizations (ACOs)	1 (3%)
Social Support Organization	6 (22%)

N = 28

# Results and Discussion

## Baseline Access to PHR

Only 5 of the 31 study participants report that over 50% of the underserved patient population had access to their PHR. These same 5 systems serve predominantly underserved patients and 3 of them employ Epic for their EHR. Epic is the most widely used EHR vendor for patient engagement in the United States and is considered most usable for patients (Best in KLAS, 2020). These systems have had success leveraging Epic’s portal functionality to extend access to their underserved patients. On the other end of the spectrum, the facilities that have the lowest percentages of use of the PHR by vulnerable patients used Cerner (2), Epic (1), NextGen (1), and Pega (1). While patient portals have become quite common, usability and functionality vary widely. None of our health systems are utilizing a home-grown or independently developed personal health record or portal. The functionality and design of the portal and PHR offered to their patients is limited to that which is offered by the EHR provider.

## Social determinants of health & barriers to PHR access

To understand the impact of social determinants of health (SDOH) on baseline management of type 2 diabetes and potential limitation placed on the effectiveness of a well-designed PHR, study participants rated each SDOH as low, neutral, or high. Among all participants, socioeconomic condition is most frequently rated as “high” (66%) followed by access to technology (60%) and education level or health literacy (60%) (Table 2).

A comparison of these general findings to the results of a smaller cohort of respondents, who specifically work in health systems serving 50% or more underserved patients, finds that this cohort more frequently rated each social determinant of health as “high.” Among this subset of study participants, socioeconomic condition remains the most important contributor to successful management of type 2 diabetes followed by access to social support with 90% and 80% rating each SDOH as “high” respectively (Table 2).

**Table 2: Impact of Social Determinants of Health for Successful Management of Type 2 Diabetes**

Social Determinant of Health	All Respondents n = 32			Predominantly Underserved n = 32		
	Low	Neutral	High	Low	Neutral	High
Availability of health care services (clinic hours, transportation to clinic, etc.)	8 (25%)	10 (31%)	14 (44%)	0 (0%)	4 (40%)	6 (60%)
Access to technology (cell phone, computer, internet)	5 (16%)	8 (25%)	18 (56%)	1 (10%)	3 (30%)	6 (60%)
Education level / health literacy	6 (19%)	7 (22%)	18 (56%)	3 (30%)	1 (10%)	6 (60%)
Language barrier	8 (25%)	7 (22%)	16 (50%)	1 (10%)	2 (20%)	7 (70%)
Socioeconomic condition (poverty, stress at home, access to healthy foods, etc.)	5 (16%)	5 (16%)	21 (66%)	0 (0%)	1 (10%)	9 (90%)
Social support (safe housing, family/friends at home, etc.)	6 (19%)	8 (25%)	17 (53%)	0 (0%)	2 (20%)	8 (80%)

\* In some cases, not all numbers will add to n due to missing data

Participants were asked to rank a list of common barriers identified from the literature review to understand their perceived barriers to accessing PHR for underserved patients with type 2 diabetes in Texas (Turner et al. 2020, Tieu et al. 2015). In the overall study sample, lack of access to a computer, a cell phone, or the internet (21%) and no perceived need for a patient portal (21%) are the most frequently cited barriers to accessing PHR. A preference for in-person communication (50%) is most often ranked among the top 3 perceived barriers followed by no perceived need for PHR (46%) and lack of access to a computer, cell phone, or internet (43%) (Table 3).

A comparison of these general findings to the results of the smaller cohort of respondents, who specifically work in health systems serving 50% or more underserved patients, finds that the relative ranking of perceived barriers differed in those serving predominantly underserved patients. In this subsample of the study, insufficient health literacy is most frequently ranked as the number one barrier (27%) and most frequently ranked in the top 3 barriers (64%). Preference for in-person communication (18% ranked number 1, 55% ranked top 3) and language barrier (18% ranked number 1, 45% ranked top 3) are the next most important perceived barriers (Table 3).

**Table 3: Perceived Barriers to Accessing Personal Health Records Ranked by Importance**

Barrier	All Respondents n = 28				Predominantly Underserved n = 11			
	1st	2nd	3rd	Top 3	1st	2nd	3rd	Top 3
Difficult and / or ambiguous process of accessing patient portal	3 (11%)	3 (11%)	5 (18%)	11 (39%)	0 (0%)	1 (9%)	2 (18%)	3 (27%)
Insufficient health literacy	3 (11%)	5 (18%)	3 (11%)	11 (39%)	3 (27%)	3 (27%)	1 (9%)	7 (64%)
Lack of access to a computer, a cell phone, or the internet	6 (21%)	4 (14%)	2 (7%)	12 (43%)	1 (9%)	3 (27%)	0 (0%)	4 (36%)
Lack of comfort or experience with a computer / cell phone	1 (4%)	2 (7%)	4 (14%)	7 (25%)	1 (9%)	1 (9%)	0 (0%)	2 (18%)
Language barrier	2 (7%)	3 (11%)	3 (11%)	8 (29%)	2 (18%)	1 (9%)	2 (18%)	5 (45%)
No perceived need for a patient portal	6 (21%)	6 (21%)	1 (4%)	13 (46%)	1 (9%)	1 (9%)	1 (9%)	3 (27%)
Security concerns	1 (4%)	0 (0%)	1 (4%)	2 (7%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)
Preference for in-person communication	4 (14%)	4 (14%)	6 (21%)	14 (50%)	2 (18%)	1 (9%)	3 (27%)	6 (55%)
Unsure / unaware that they can access PHR	2 (7%)	1 (4%)	3 (11%)	6 (21%)	1 (9%)	0 (0%)	2 (18%)	3 (27%)

\* In some cases, not all numbers will add to n due to missing data

When we look only at the subset who work with over 50% underserved patients, access to a computer, cell phone, or the internet is not a top-listed barrier in this group. This reflects survey data collected in the census that suggests that 91% of households in Texas have access to a computer and 82% have access to broadband internet (US Census, 2019). The census is an imperfect but larger sample of household access to a computer or cell phone in the state of Texas.

The difference in the perceived barriers between the general sample and smaller subset working with majority underserved patients highlights how perceptions that are not reflective of the lived reality of a health system's most vulnerable members will impact policy and programmatic decisions. Limited and deprioritized PHR interventions and development at health systems could be due to decision makers at health systems that have incorrect perceptions about barriers to access and meaningful use of the record.

While a minority of respondents (16%) reported that barriers to accessibility would be insurmountable, resulting in no tangible benefit for this population, the vast majority (84%) emphasized that a PHR should be a prioritized intervention to see benefits in the management of chronic disease and that current barriers could be addressed to ensure meaningful use of the record.

**The importance of highlighting perceived barriers.**

**The sample of HIM professionals, administration and care providers have an important perspective and unique insight into the logistics and delivery of a PHR. These same professionals shared what they believed to be barriers for the most underserved patients at their health systems to better understand barriers to access and use of PHR systems. However, this is an imperfect perception impacted by respondent biases. These perceived barriers may not represent the true reality of the patients these respondents represent in our study. Our comparative analysis mitigates that risk. Those who work most closely with underserved patients know those realities best.**

**Table 4: Perceived Barriers to Accessing Personal Health Records Ranked by Importance**

Barrier	7th	8th	9th	Bottom 3
Difficult and / or ambiguous process of accessing patient portal	1	5	0	6
Insufficient health literacy	5	1	0	6
Lack of access to a computer, a cell phone, or the internet	3	0	1	4
Lack of comfort or experience with a computer / cell phone	1	1	0	2
Language barrier	1	4	10	15
No perceived need for a patient portal	3	2	4	9
Security concerns	6	7	8	21
Preference for in-person communication	4	1	1	6
Unsure / unaware that they can access PHR	4	7	4	15

N = 28

The lowest ranked perceived barriers to effective PHR use are language barrier and security concerns (Table 4). Respondents highlighted that there are already significant efforts to address language issues and that translation online is a prevalent tool used. Security concerns are no longer as prevalent due to improvements in technology and widespread use of electronic portals for non-health related sensitive information. One respondent from a health system serving predominantly underserved patients described that the emergence of online banking and money exchange had forced general trust in those security systems, so he did not feel that the population at his clinic are deterred by security concerns around their health system.

### Benefits of PHR & ideal use

Survey and interview respondents agreed that ready access to your health information through a PHR is beneficial to the patient. Themes highlighted by respondents included increased transparency and using PHR as a tool for patient understanding. PHR is an important communication link between the patient and provider. Features can vary from scheduling appointments or receiving lab results to receiving educational resources and communicating directly with the doctor if something comes up unexpectedly. Respondents report that the most effective modes of communication linkages through the PHR are (1) in portal secure communication (50%) and (2) text messaging (50%) as ways to share information and reminders about appointments, lab results, and care plans. PHR as a medium for health information, when effectively digested by patients, can have a positive impact on adherence to care plans. This tool can improve chronic disease management, especially in the case of type 2 diabetes where lab results and consistent monitoring of Hba1c levels and the medication involved can be difficult. Respondents also highlighted downstream impacts such as using health information as a tool to improve patient advocacy, and as a result, the care they receive in the clinic. For example, one respondent who works with a system serving over 50% underserved patients, shared that once a PHR was implemented,

“coordination of care would be easier since they could show records to/share records with other providers, and the patients would have copies of results, notes, instructions etc. to refer to later and a way to message the physician without having to schedule, travel to, and pay for an appointment.”

### COVID-19 pandemic impact

The COVID-19 pandemic is considered an inflection point with regards to PHR use by many study participants. While the pandemic exacerbated barriers to accessing care and accentuated the importance of social determinants of health, it necessitated that many patients become more familiar with technology. Unable to see their physicians in person, the pandemic increased telemedicine use and exposed many patients to PHR for the first time. A respondent shared “patients are readily accessing records due to Telehealth visits”. This pandemic will drive shifts in the perceived preference for in-person communication (50% ranked as a top 3 barrier) and lack of comfort using a computer, cell phone, or the internet (25% ranked as a top 3 barrier) since it has exposed many to virtual healthcare access. An unintended benefit of this pandemic is that more health systems are poised to integrate PHR use into their regular care. Virtual medicine and PHR were integral to care delivery over the past several months and are likely here to stay.



## Recommendations

Recommendations for increasing PHR access and use have been developed by aggregating interview and survey results. The recommendations are divided by level of health system readiness. Tier 1 recommendations are geared towards health systems that currently have no PHR, Tier 2 are for those with a PHR, but no current initiatives, and Tier 3 are for those systems trying to strengthen their PHR initiatives and patient adoption (Figure 2). Recommendations reflect this study’s sample and should not be considered exhaustive. For meaningful change, PHR use and the implementation of these recommendations must be prioritized by the leadership of a health system with provider buy-in and patient co-creation. All recommendations should be adopted to each health system’s specific context, needs, and resource capabilities.

**Figure 2: Spectrum of PHR Capabilities**

LOW CAPACITY		HIGH CAPACITY	
Tier 1	Tier 2	Tier 3	
<ul style="list-style-type: none"> <li>• No PHR</li> <li>• No Intervention</li> </ul>	<ul style="list-style-type: none"> <li>• Basic PHR features (appointments, lab results, etc)</li> <li>• Limited PHR use</li> <li>• No initiatives to promote adoption</li> </ul>	<ul style="list-style-type: none"> <li>• Advance PHR features (data visualization, bilingual, etc.)</li> <li>• Extensive PHR use</li> <li>• Initiatives to promote adoption</li> </ul>	

## GLOBAL RECOMMENDATIONS

### **Recommendation 1: PHR registration and use should be a top-down articulated priority, even if it is unfunded.**

Respondents share that PHR availability is not enough to drive registration and use. One respondent believes that the reason their clinic did not have many patients registered to use their PHR is that it had never been articulated as a priority to ensure follow-up. Organizational alignment and physician buy-in can be created by showing the value of patient PHR engagement by highlighting improved outcomes as well as time and cost savings for providers. This organizational alignment about the importance of PHR can create an environment conducive to enrollment and meaningful use.

### **Recommendation 2: Leverage PHR to promote care adherence and reduce gaps in care through reminders.**

To promote patient engagement with preventive and follow-up care, study participants recommend leveraging features such as medication, exercise goals, and healthy eating reminders. Ideally, these follow-ups and reminders would be through an automated text as most patients have a cell phone and are familiar with text messaging. During the COVID-19 pandemic, text message reminders have been used for appointment reminders, virtual check-ins, and vaccination schedule requests among many other things. As health literacy remains an important barrier, text messaging may also be used to send relevant health education videos to patients. The use of behavioral economic interventions such as financial incentives may further help increase engagement and promote healthy lifestyle changes.

### **Recommendation 3: Design PHR as a one-stop-shop solution to promote patient engagement while creating partnerships between health systems and technology vendors.**

To avoid disparate technologies that might overwhelm patients and inhibit effective engagement, study participants recommend a one-stop-shop patient engagement platform that is interoperable across health systems. The platform's features might include, but are not limited to, self-scheduling/rescheduling, pre-visit communications, telemedicine and remote monitoring, patient education, provider messaging, and post-visit communications. In interviews, providers recommend integrating summary views of patient information and novel methods for tracking lifestyle data due to the repetitive and ongoing nature of type 2 diabetes care management. Stronger partnerships between technology companies and health systems may help promote more patient-centric technology capabilities.

### **Recommendation 4: Create a targeted, homegrown PHR.**

If a healthcare facility has the resources to dedicate to patient engagement through the patient health record in the early stages of development, more targeted homegrown solutions may be an option. With limits on the usability and functionality of EHR based solutions, providers can consider a solution to meet the innovative requirements highlighted by the study interviewees in an ideal PHR solution. This includes data visualizations of lab results, reliable resources about chronic disease management, and the gamification of interacting with health information for points or other incentives.

In the context of chronic disease management for type 2 diabetes, the most prominent requests for information within the PHR are an ability to track lab results including HbA1c and BGL, access to educational materials, and the ability to book/review appointments. Streamlined options for delivering that information could include texting or calling with patient HbA1c or lab information. This harkens to the importance of not just sharing information beyond the clinic with PHR but integrating components of the tool into the visit. The clinic encounter plays a critical role in supporting underserved and vulnerable patients to understand their health information. Basic utilization can plant seeds for more intensive patient engagement. Patients that are used to patient phone calls or texts in a Tier 1 setting will be less resistant to more intensive projects such as two-way messaging portals, phone apps, programmed lists of frequently asked questions with trustworthy information etc. It is less about the EHR system the health practice builds from, but rather the positive uptick in patient engagement with their health.

## TIER 1 RECOMMENDATIONS

Tier 1 health systems are characterized by the recent adoption of an EHR, with no PHR development yet.

### **Recommendation 1: When developing a PHR, features can be inclusive to the most vulnerable patients in the system.**

Early-stage EHR and PHR development offer an opportunity to include inclusive elements that address barriers to use, such as health literacy, specifically understanding health information in the PHR. Multiple health care workers emphasized that while sharing data like lab results are important, it can also be broken down into digestible nuggets so that raw numbers could be put into context. Reference tables and visualizations can be presented to patients to better understand the implications of their health information. An interview with a diabetes educator highlights the importance of offering education classes and online registration for appointments. Reminders through the portal may work to reduce absenteeism at appointments.

### **Recommendation 2: Registration for the system can begin early, involve reprioritization of workload and should be presented as an opt-out option.**

Resources could be allocated early to create a comprehensive registration strategy for a new system. While hiring staff is a resource-intensive option, there are ways to reallocate responsibilities as they currently exist to include the responsibility to encourage and support patient registration for PHR. The COVID-19 pandemic has presented an unexpected opportunity for entities going through PHR adoption. Health systems have dedicated greater resources to the development and use of digital health options like the PHR. Study participants shared that PHR has presented an important scaffolding for vaccine registration, telehealth visits, and in one case, building out the COVID-19 digital journey for patients to understand what to expect as they come into and leave the hospital. However, there has been no increase in staffing, people have been redeployed and their priorities redistributed. In a transition phase from no PHR to a PHR, it will be important to redistribute responsibilities so that registration efforts are well supported, without the addition of available staff members to support patients learning to sign on and use a new platform. It will be important to define the new norm and interviewees suggested that an opt-out modality will allow for greater registration rates, tackling the inertia that prevents patients from adopting something new.

## TIER 2 RECOMMENDATIONS

Tier 2 health systems are characterized by the availability of PHR but low adoption rates, particularly among underserved patients. Most organizations in this study's sample fall into this category.

### **Recommendation 1: Staff members promote patient registration through fliers, posters, and PHR demonstrations especially during wait times.**

To increase awareness of the availability and benefits of PHR and consequently promote the adoption, all staff members (receptionists, nurses, doctors, etc.) could promote registration. Recognizing physicians have limited time and capacity during clinic visits, study participants recommend taking advantage of waiting times to engage patients using fliers, posters, and PHR demonstrations. Respondents share that "time is the most precious resource needed to be able to share resources." If there is not one person with a defined role as a patient portal representative with time to do it, then a team approach is needed to share information. It is not effective for only "one person to be sharing it. If only the front desk representative or physician says it, the information can get lost. It needs to be reinforced."

### **Recommendation 2: Offer group courses at the clinic or community centers to promote patient registration and encourage them to engage with their health information.**

Study participants recommend adding a segment on registration and use of a patient health record to group courses at the clinic (examples include nutrition or diabetes management courses) or other high-touch community centers such as nursing homes. While patient privacy, security and HIPPA compliance may restrict review of the patient information stored, incorporating registration and use of PHR into existing health education and chronic disease courses is an important approach to address the low rates of initial enrollment in a PHR, and ongoing use. Study participants recommend conducting focused outreach and classes at senior facilities for any patients less comfortable with technology. Group learning is emphasized to promote camaraderie and shared accountability.



## TIER 3 RECOMMENDATIONS

Tier 3 health systems are characterized as having mature PHR systems with existing incentives to increase adoption of PHR.

### **Recommendation 1: Appoint a dedicated person on staff to support patient PHR registration support and walkthrough.**

For tier 3 health systems that can invest additionally into their PHR systems, it is recommended that a dedicated person on staff support patient PHR registration and assistance by walking patients through the portal. Having a dedicated point person on staff will ensure patients are registered and educated on how to effectively use their PHR. This gets patients accustomed to the PHR, thereby increasing the probability of greater levels of patient utilization, an increased understanding of the tool's benefits, and better self-management of the patients' type 2 diabetes. Respondents shared that the "patient portal representative visits the patient while they are onsite" and that it is often more effective than just sharing fliers and documents at admission.

### **Recommendation 2: Invest in additional PHR features, such as data visualization.**

Investing in additional PHR features that would benefit patients, such as having a place to monitor and record symptoms as well as data visualizations of test results to help patients chart their progress regularly is recommended. Investing in PHR features such as this will allow patients to gain a deeper understanding of how best to manage their type 2 diabetes and may encourage stricter adherence to care plans. PHR integration with insulin monitoring devices can give providers a sense of real data points when it comes to type 2 diabetes management day-to-day. This recommendation is shared by all interviewees. Expanding beyond the limited functionalities of "visit history, lab information, and discharge information" will allow the PHR to function as more of a living document in which the patient can edit and share information.

### **Recommendation 3: Gamification of PHR**

Another way to increase patient adoption and active engagement with their PHR is to implement gamification elements for users. A simple way to start this is by incorporating graphs on the main screen that indicate what percentage of the patient's PHR has been filled out. Including user-friendly buttons for patients to click on to complete the remaining sections would increase user engagement. Providers can allow patients with chronic conditions to sync their health data from health trackers or manually enter their data into the PHR. Patients will be able to track their progress and symptoms such as heart rate or blood glucose levels. This could be further incentivized by incorporating a point system with rewards for when patients achieve certain health goals decided upon by the patient and their provider, such as maintaining a blood glucose level within a certain range. Gamification is a user-friendly and captivating way to incentivize patients to monitor their health.

# Study Strengths and Limitations

This study was conducted with limited resources and conducted amidst a pandemic as well as unprecedented storms in Texas not seen for a hundred years. Professionals were interviewed from 28 different health systems. Very few studies focus on how to increase patient engagement in underserved communities through PHR and even fewer studies focus on the perspective of providers and other health professionals. The individuals who participated in this qualitative study are intimately familiar with the benefits of PHR and the challenges underserved patients face when trying to access and utilize their health information.

The study has some limitations that must be kept in mind when interpreting the results. Although the study population involved 28 facilities, participants are primarily AHIMA members solicited to participate rather than a random selection of health professionals. Furthermore, due to the COVID-19 pandemic and the Texas power crisis after three major winter storms in February 2021, it was difficult to recruit many providers and health stakeholders as health systems were overwhelmed. Despite this, the study sample provides a valuable perspective. Future studies would benefit from a larger and more geographically diverse sample to generalize the results of the study to the state of Texas as a whole. Additionally, this study did not include the patient perspective, which will be addressed in a later phase of research by the AHIMA Foundation. While creating any PHR-related intervention, it is vital to engage patients as the key health stakeholders in the development of the program.

## Conclusion

Health systems should prioritize PHR access and understanding as a tool for patient engagement. As chronic disease management becomes a critical priority for patients, consistent and current health information becomes essential to maintain health away from the site of service. The patient portal is a baseline for access and integration with the EHR and should become standard practice across Texas and the U.S. Focusing on patient populations most vulnerable to poor chronic disease management to thoughtfully design and implement PHR programs should be a priority for all health systems. This research hopes to serve as a starting point to inform future interventions at health systems as pilot solutions are designed and implemented. PHR initiatives are not limited to the creation and use of a patient portal. As EHR systems have become ubiquitous in 2021, the next stage of innovation in health information and patient empowerment will be the design and implementation of inclusive PHR solutions to tackle chronic disease management.



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