

# Patient Portals: Challenges and Opportunities for Patient Engagement

September 2016

## Important Content Note:

This technical assistance resource was developed prior to the August 2017 release of the Health Center Compliance Manual by the Health Resources and Services Administration's (HRSA) Bureau of Primary Health Care (BPHC). The BPHC Compliance Manual, issued August 2017, indicates where PINS, PALs and other program guidance are now superseded or subsumed by the BPHC Compliance Manual.

See:

<https://bphc.hrsa.gov/programrequirements/pdf/healthcentercompliancemanual.pdf>



NATIONAL ASSOCIATION OF  
Community Health Centers

7501 Wisconsin Avenue  
Suite 1100W

Bethesda, MD 20814

Phone 301.347.0400

Fax 301.347.0459

[www.nachc.com](http://www.nachc.com)

---

## ACKNOWLEDGEMENT

The National Association of Community Health Centers (NACHC) promotes the provision of high quality, comprehensive health care that is accessible, coordinated, culturally and linguistically competent, and community-directed for all underserved populations.

We wish to acknowledge the following for their contributions to this guide:

**Chris Coughlin**, OCHIN Senior Policy Analyst

**Jenny Probert**, Application Analyst

**Nate Warren**, Patient Engagement Coordinator

OCHIN  
1881 SW Naito Parkway  
Portland, OR 97201  
[www.ochin.org](http://www.ochin.org)

**For further information, please contact:**

National Association of Community Health Centers  
7501 Wisconsin Ave., Suite 1100W  
Bethesda, MD 20814  
(301) 347-0400

## DISCLAIMER

This project was supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) under grant U30CS16089, “Technical Assistance to Community and Migrant Health Centers and Homeless.” (Total grant award is \$6,375,000.00. Zero percent of this project was financed with non-governmental resources.) This information or content and conclusions are those of the author(s) and should not be construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HHS or the U.S. Government.

---

# Table of Contents

---

- Introduction** ..... 2
  - Types of Patient Portals ..... 2
    - Table 1. Common Features of Patient Portals ..... 3
    - Tethered Portals ..... 3
    - Standalone Portals ..... 4
    - Personal Health Record (PHR) ..... 4
    - Using Portals for Patient Engagement ..... 4
    - Meaningful Use ..... 4
  
- Potential Approaches and Best Practices to Address Portal Implementation Challenges** ..... 6
  - Challenges ..... 6
  - Technology ..... 6
  - Patient Access ..... 6
  - Privacy and Security ..... 7
  - Potential Approaches and Best Practices ..... 7
  - Considerations in Providing Portal Access to Adolescents ..... 9
  
- Conclusion** ..... 12
  
- Appendix** ..... 13
  - Glossary ..... 13
  - Resource List ..... 14

# Introduction

---

Actively involving patients in their own health care through patient engagement is a central component of current health reform activities. This strategy can be implemented to help achieve the “triple aim” of improved health outcomes, improved care quality, and lower costs.<sup>1</sup> The ability of health care providers to securely share information with patients through patient portals has been one measurement of patient engagement under the Medicare and Medicaid Electronic Health Record (EHR) Incentive Programs. Although almost all health centers<sup>2</sup> are using an EHR and more than 85% received Meaningful Use incentive payments in 2013, there are concerns that many health centers face multiple challenges to meet Stage 2 and 3 Meaningful Use requirements, including the ability to “meaningfully” engage patients.<sup>3</sup>

The Office of the National Coordinator for Health Information Technology (ONC) recently released a “playbook” to help health care providers use technology to engage patients through patient portals. The patient portal is an important tool that can provide patients with the knowledge, access to information and confidence to manage their own health and health care. The playbook highlights the opportunities that such portals provide for more effective care, efficient workflows, and engaged patients, as well as the challenges inherent in introducing patients, providers, and staff to the portal, getting patients enrolled and questions about privacy and security.<sup>4</sup>

This issue brief provides a high level overview of patient portals with a focus on considerations and possible approaches health centers can take to address the challenges of using patient portals to actively engage patients. When implementing a patient portal, one particular challenge is the issue of providing access to patient information through the portal for adolescent patients. The brief also addresses some of the specific challenges to providing portal access to adolescents, but it is important to note this option and its respective best practices are still emerging.

## Types of Patient Portals

ONC defines a patient portal as “a secure website where patients can access their medical history and often certain information from their electronic health record. Using patient portals, patients can typically complete forms online, communicate with providers, request prescription refills, pay bills, review lab results, and schedule appointments.”<sup>5</sup> Portals can also be used to send alerts to patients when it is time for them to schedule preventative or chronic care appointments. See Table 1 for common features of patient portals.

---

1 “Health Policy Brief: Patient Engagement,” *Health Affairs*, February 14, 2013.

2 Health centers are organizations that receive grants under the Health Center Program as authorized under section 330 of the Public Health Service Act, as amended.

3 Lee A. Green et al., “Sustaining “Meaningful Use” of Health Information Technology in Low-Resource Practices,” *Annals of Family Medicine* 13, no. 1 (January/February 2015): 17-22.

4 ONC Patient Engagement Playbook. <https://www.healthit.gov/playbook/pe/introduction/>

5 ONC Patient Engagement Playbook. <https://www.healthit.gov/playbook/pe/introduction/>

**Table 1. Common Features of Patient Portals<sup>6</sup>**

Feature	Most Portals	Some Portals
Discharge Summaries	x	
List of Medications	x	
Immunizations	x	
Allergies	x	
Lab Results	x	
Notes from office visits		x
Ability to exchange secure email with health care team		x
Request prescription refills		x
Schedule non-urgent appointments		x
Update contact information		x
Make payments		x
Fill out forms		x
Access educational materials		x

### **Tethered Portals**

A tethered portal is a secure website that is directly tied to one health care organization's EHR. Therefore a patient that has a primary care provider at a health center, sees one or more specialty providers at a separate specialty clinic, and who has been admitted to a hospital could easily have three separate portal logins – one to see his or her primary care record, another for the records from the specialists, and a third for the hospital portal – even if all three organizations use the same EHR product. For each provider practice/organization patients are enrolled and given a username and password to use to log in via an Internet connection and access their patient record through the portal. Most major EHR vendors offer a portal, and these tethered portals are what most providers are offering to their patients. Some health centers are electing to join the OpenNotes® movement, an initiative to share provider clinical notes directly with patients and their proxies. This has been implemented in some health centers through a patient portal tethered to the EHR.<sup>7,8</sup> Tethered portals are offered and managed by health care organizations such as health centers, clinics, and hospitals.

6 ONC Patient Engagement Playbook. <https://www.healthit.gov/playbook/pe/introduction/>

7 National Association of Community Health Centers. *Health Information Exchange: Opportunities and Challenges for Health Centers*. June 2016.

8 <http://www.opennotes.org/>

## **Standalone Portals**

Standalone patient portals are not directly tied to one EHR product. These portals are product agnostic and can be linked to EHR information either from a single clinic or multiple providers. Many commercial health plans offer patient portals that provide educational materials, benefit information, and access to bills and claims. Standalone portals can be offered and managed by health care facilities, health insurance companies, or employers.

## **Personal Health Record (PHR)**

There is another type of portal that is managed by consumers/patients. PHR service providers such as Microsoft HealthVault or WebMD give patients the ability to access, aggregate, and manage their own health information. Patients can transfer information among providers, correct inaccurate demographic, medical, or billing information, and track and monitor their own health. Patients can compile data from a variety of sources, as well as add information they report themselves, such as blood sugar levels. Some PHRs also allow data feeds from EHRs and other data sources.

## **Using Portals for Patient Engagement**

Patient portals can be powerful tools to not only share information with patients, but to provide patients with the information they need to engage in shared decision-making. Portals can engage patients as active participants in their health care, which can be especially useful within a Patient Centered Medical Home (PCMH) model of care. A literature review of the impact of patient portals shows that engagement through patient portals can help patients with chronic diseases manage their treatment, but also contribute to other practice improvements such as reduced call volume, more effective care, lower utilization of health services, and improved responsiveness to patients' needs.<sup>9</sup> There is also emerging evidence that portals can improve preventative care, including findings that patients with portal access are more likely to follow through on screening recommendations that they can access through the portal.<sup>10</sup>

## **Meaningful Use**

The Medicare and Medicaid EHR Incentive Programs have encouraged patient involvement in their health care. One of the objectives in Meaningful Use Stage 2 is Patient Electronic Access. The goal is to efficiently provide patients with access to their health information. To meet the objective, providers must give patients the ability to view online, download, and transmit their health information within 4 business days of the information being available to the eligible provider (EP). This access can be implemented with a patient portal and can help patients make informed decisions regarding their care and allows them to share information with other health care providers and caregivers. In order for a provider to meet this objective, the patient must be able to access this information on demand, such as through a patient portal or PHR.<sup>11</sup> This requirement will continue as part of the Medicaid EHR Incentive

---

9 Emont, S. (2011, May). Measuring the impact of patient portals: what the literature tells us.

10 Patient access to online health action plans enhances rate of preventive care. (2016, February 9). Retrieved from <http://share.kaiserpermanente.org/article/patient-access-to-online-health-action-plans-enhances-rate-of-preventive-care/> (accessed 7/1/16).

11 [https://www.cms.gov/Regulations-and-Guidance/Legislation/EHRIncentivePrograms/Downloads/2016\\_PatientElectronicAccess.pdf](https://www.cms.gov/Regulations-and-Guidance/Legislation/EHRIncentivePrograms/Downloads/2016_PatientElectronicAccess.pdf) accessed 6/7/16.

tive Program, and is anticipated to be a component of the Advancing Care Information performance category under the Merit-Based Incentive Payment System (MIPS) currently being implemented under the Medicare Access and CHIP Reauthorization Act of 2015 (MACRA). Another objective of Stage 2 is for providers to use secure electronic messaging to communicate with patients. Patient portals can help providers meet this objective.

# Potential Approaches and Best Practices to Address Portal Implementation Challenges

---

## Challenges

Implementing a patient portal and sending patients an invitation to sign up for the portal is not enough to get most patients to enroll. Some portals entail a cumbersome enrollment process, and others may have outdated interfaces that do not necessarily work well with mobile devices. In addition to technological issues, there are potential attitudinal barriers on the part of patients, providers, and staff. Health centers also may be concerned that their patient population does not have access to computers or smart phones, and therefore will not have the ability to log in regularly and use the patient portal. Finally there are issues and concerns surrounding privacy and security.

## Technology

Patient portals will continue to evolve, and hopefully some of the technological issues will get resolved over time. There is currently emphasis on the development of provider and patient applications that can connect to EHRs. FHIR (Fast Health Interoperability Resources) is the next generation standards framework with a goal to enable standardized interfaces for data submission, query, and retrieval. This new technology should provide opportunities for updating existing portal technology.

## Patient Access

It is understandable that health center staff would be concerned that their patients might not have access to computers or smart phones, and therefore would not have the ability to sign up for and use a patient portal. However, a 2015 Pew internet study found that a significant number of people with low income have smartphones and computer access. Half of those polled in households with income of \$30,000 or less owned smartphones, and 63% of these individuals use their smartphone to find health information.<sup>12</sup>

Early studies of patient portals found low rates of enrollment and significant disparities in enrollment by race and ethnicity.<sup>13</sup> Several studies have attempted to identify patient reported barriers to enrollment including the finding that a lack of patient awareness of the portal is often the main barrier of enrollment.<sup>14</sup> Other barriers to enrollment include negative attitudes about the portal or computer related issues. In one study, most respondents felt positive about portal features, but black respondents were less likely than white respondents to rank features such as getting lab results as important. These findings indicate that strategies to include enrollment should not only focus on

---

12 Case Management Insider. *Low-income Patients Tuning into Digital Solutions*. June 2015.

13 Goel MS, Brown TL, Williams A, Cooper AJ, Hasnain-Wynia R, Baker DW. Patient reported barriers to enrolling in a patient portal. *Journal of the American Medical Informatics Association : JAMIA*. 2011;18(Suppl 1):i8-i12. doi:10.1136/amiajnl-2011-000473.

14 Ronda MC, Dijkhorst-Oei L-T, Rutten GE. Reasons and Barriers for Using a Patient Portal: Survey Among Patients With Diabetes Mellitus. Eysenbach G, ed. *Journal of Medical Internet Research*. 2014;16(11):e263. doi:10.2196/jmir.3457.



sharing information about features and providing multiple follow-up notifications, but when looking to reduce racial disparities in enrollment, access is not the only barrier to be addressed.<sup>15</sup>

## Privacy and Security

As an extension of the EHR, patient portals need to adhere to the Health Insurance Portability Act of 1996 (HIPAA). Health centers need to ensure that appropriate policies, processes and staff training are in place to ensure that patients' privacy is protected as required. One important access is proxy access to information. There are times when someone may need access to someone else's patient information. Examples include a parent of a child, an adult child of an elderly parent, a caregiver, a health care power of attorney, or someone else the patient wants to involve, i.e., a spouse.<sup>16</sup> If the portal is able to support proxy access, then the organization is able to give each authorized representative a unique, secure login to access the portal. Sometimes patients share their own login credentials with family members or caregivers, and that makes it difficult to have an audit log of points of access to the patient record.

## Potential Approaches and Best Practices

As noted above, there are many barriers to patient enrollment,<sup>17</sup> but there are best practices about how to approach patient engagement to maximize enrollment. While each portal product will have differences, some basic steps have been identified to help make portal enrollment easier for patients, including:

- Provide simple, secure portal signup
- Develop an automatic enrollment policy
- Register patients in the office
- Market and educate effectively<sup>18</sup>

OCHIN, a Health Center Controlled Network (HCCN), provides a hosted Epic ambulatory care EHR with access to the MyChart patient portal to almost 100 health centers in 18 states across the country. OCHIN recently compiled best practices from across the network and shared these with members. Some examples of best practices around portal enrollment and usage are included below, and many of these could be adapted for other EHR and portal implementations.

---

15 Goel MS, Brown TL, Williams A, Cooper AJ, Hasnain-Wynia R, Baker DW. Patient reported barriers to enrolling in a patient portal. *Journal of the American Medical Informatics Association* : JAMIA. 2011;18(Suppl 1):i8-i12. doi:10.1136/amiajnl-2011-000473.

16 HIM Body of Knowledge™. Retrieved from <http://bok.ahima.org/>

17 Goel MS, Brown TL, Williams A, Cooper AJ, Hasnain-Wynia R, Baker DW. Patient reported barriers to enrolling in a patient portal. *Journal of the American Medical Informatics Association* : JAMIA. 2011;18(Suppl 1):i8-i12. doi:10.1136/amiajnl-2011-000473.

18 ONC Patient Engagement Playbook. <https://www.healthit.gov/playbook/pe/introduction/>

There are a number of sign-up methods available, and any member of the clinic team with access to EpicCare, Registration, or Appointments can sign patients up with a portal account. Options include:

- Sign up patients while they are in the clinic or exam room (Epic customers nationwide, including those with OCHIN, recommends this option as the most effective method)
- Provide an Activation Code in Patient Instructions of the After Visit Summary (AVS) to sign up and log in from home
- Provide an Activation Code in a letter with instructions for signing up and logging in from home; the letter can be mailed to patients when an appointment is scheduled or given to patients during a visit (at check-in, at check-out, or at any other point of care in the clinic)
- Email patients a code and sign-up instructions during the patient check-in process

OCHIN suggests that health centers customize their workflows to meet the needs of their clinic staff and patients, and can use any or all of the options listed above.<sup>19</sup>

While computer access does not seem to be a major barrier to portal enrollment, it can be very helpful if the portal has a mobile app that can be used on a smart phone, since smart phones may be more accessible to many patients. Language can also be a barrier for some patients, and there are language options for some portals. For example, there is a Spanish option in the Epic MyChart portal.

While all clinic staff can support portal enrollment, it is especially important for providers to engage patients and help them understand how the information available through the portal, i.e., questionnaires, patient-entered health information, lab results, can help strengthen the communication between the patient and his or her health care team. Using the portal, patients and providers can exchange secure messages, clarify issues and advice, correct misunderstandings, record referral details and/or follow-up care instructions, and link to educational materials.<sup>20</sup> Having providers communicate these features and others can help patients see the positive role that a portal can play in managing their health.

In the OCHIN network, questionnaires can be made available to patients in MyChart, sent with a secure patient message, or attached to an upcoming appointment. For example, the Screening, Brief Intervention, and Referral (SBIRT)/Depression combined questionnaire can be sent to patients in MyChart. With the SBIRT, the patient completes a four-question initial prescreen. Depending on the answers, the questionnaire may branch to the appropriate corresponding full screen questionnaire, including the Alcohol Use Disorders Identification Test (AUDIT), Drug Abuse Screening Test (DAST), and the Patient Health Questionnaire (PHQ-9). This can all be done prior to a visit, through the patient portal.

With the Track My Health feature in MyChart, a patient's health can be monitored between visits. For example, patients can record blood pressure or blood glucose in MyChart daily, and the health care team can review the entries in EpicCare. If a patient enters an unusually high or low entry (the range is customizable for each patient),

---

19 OCHIN. *MyChart Improvement Guide: Tools to Support MyChart Adoption across OCHIN Service Areas*. May 2016

20 Kane, B., Sands, D.Z. (1998, January 1). Guidelines for the clinical use of electronic mail with patients. Retrieved from <http://jamia.oxfordjournals.org/content/5/1/104>.

MyChart immediately sends an InBasket alert message that can be retrieved by clinic staff and shared with the patient's provider.

Helping patients understand the benefits of the portal, and making it as easy as possible for patients to enroll, are important steps to maximize the use of patient portal to support patient engagement.

## Considerations in Providing Portal Access to Adolescents

As discussed earlier, the implementation and use of patient portals need to comply with all appropriate state and federal laws including the Health Insurance Portability and Accountability Act of 1996 (HIPAA). Issues regarding adequate usernames and passwords, how to handle enrollment, policies around proxy access, etc., all need to be addressed as part of the implementation and rollout of a patient portal. Adolescents, often defined as individuals aged 12 through 17, present specific challenges when looking at on-line access to patient information through patient portals.

Most patient portals do not have separate settings to align for privacy laws in different states or for specific populations. When considering adolescent minor patients, there are questions about whether the patient, the parent(s) or all parties should have access to health information through a patient portal.<sup>21</sup> Many states have laws that allow minors to receive specific kinds of health care, like mental or sexual health services, without their parents knowing or consenting. Other state laws stipulate that minors can make decisions on their own if they have an "adult status," like being married or in the military. The actual age when a person is considered an adult and able to make their own health care decisions varies from state to state.<sup>22</sup> And finally, adolescents may want to keep their health care decisions and medical information private, particularly from their parents. These differences in state law and patient preferences and the resulting lack of comprehensive standards have made it difficult for national EHR vendors to provide products that cover all possible configurations.

In addition, research has shown that adolescents may avoid care if they think that their information may be shared with their parents, particularly when dealing with reproductive health, mental health and substance abuse issues. These concerns on the part of adolescents around confidentiality have the potential to contribute to poor outcomes and health disparities, particularly for more vulnerable adolescents.<sup>23</sup> On the other hand, there is also emerging data that electronic access to information, such as is available through a portal, may improve outcomes. One recent finding is that prescription fulfillment data accessed electronically may improve care for adolescent depression.<sup>24</sup>

---

21 Gray, Susan Hayden Pasternak, Ryan H. Gooding, Holly C. Woodward, Kathy Hawkins, Kirsten Sawyer, Susan Anoshiravani, Arash et al. Recommendations for Electronic Health Record Use for Delivery of Adolescent Health Care. *Journal of Adolescent Health*, Volume 54, Issue 4, 487 – 490.

22 Bourgeois, F.C.; Taylor, P.L.; Emans, J.; Nigrin, D.J.; Mandl, K.D. (2008, December). Whose personal control? Creating private, personally controlled health records for pediatric and adolescent patients. *Journal of the American Medical Informatics Association*, 15(6), 737–743. doi 10:1197/jamia.M2865. Retrieved from [http://www.hl7.org/documentcenter/public\\_temp\\_7CA39230-1C23-BA17-0CBCDEB8D0B8876C/wg/pedsdata/Fabienne%20JAMIA%20paper%20\(2\).pdf](http://www.hl7.org/documentcenter/public_temp_7CA39230-1C23-BA17-0CBCDEB8D0B8876C/wg/pedsdata/Fabienne%20JAMIA%20paper%20(2).pdf) [PDF – 78KB].

23 Gray, Susan Hayden Pasternak, Ryan H. Gooding, Holly C. Woodward, Kathy Hawkins, Kirsten Sawyer, Susan Anoshiravani, Arash et al. Recommendations for Electronic Health Record Use for Delivery of Adolescent Health Care. *Journal of Adolescent Health*, Volume 54, Issue 4, 487 – 490.

24 Bourgeois, F.C.; Taylor, P.L.; Emans, J.; Nigrin, D.J.; Mandl, K.D. (2008, December). Whose personal control? Creating private, personally controlled health records for pediatric and adolescent patients. *Journal of the American Medical Informatics Association*, 15(6), 737–743. doi 10:1197/jamia.M2865. Retrieved from [http://www.hl7.org/documentcenter/public\\_temp\\_7CA39230-1C23-BA17-0CBCDEB8D0B8876C/wg/pedsdata/Fabienne%20JAMIA%20paper%20\(2\).pdf](http://www.hl7.org/documentcenter/public_temp_7CA39230-1C23-BA17-0CBCDEB8D0B8876C/wg/pedsdata/Fabienne%20JAMIA%20paper%20(2).pdf) [PDF – 78KB].

Given the many challenges around adolescent access to patient portals as discussed above, some health centers have chosen not to provide any portal access for adolescent health information. However, there are other options that health centers could explore. One recommendation from the Society of Adolescent Health and Medicine is to include providers with experience in adolescent health care as part of any system-wide information technology initiative to ensure that the needs of adolescents are considered as decisions are being made.<sup>25</sup> Determining policies that will allow adolescents access to the patient portal, and will avoid disclosure of protected information to parents or other caregivers is an essential element of any successful patient portal implementation for this population.

As health centers consider possible policies, it is critical that they have full knowledge of state laws pertaining to adolescent confidentiality. Health centers should work with their Primary Care Associations to identify relevant state laws. Determining policies that will allow adolescents access to the patient portal and will avoid disclosure of protected information to parents or other caregivers is essential to the implementation of a successful patient portal for this population.

A health center controlled network (HCCN), with a hosted EHR across multiple states with different privacy laws impacting adolescent health information, has established a policy whereby only teen patients who are 12 to 18 years old have access to their records through the patient portal. Parents and/or guardians of children ages birth to 11 years old can have proxy access as a patient representative, but there is no proxy access to the information of teen patients. Parents receive notification that their proxy access will be terminated on their child's 12<sup>th</sup> birthday. On the child's 12<sup>th</sup> birthday, the patient can complete the teen access agreement to enroll for an individual patient portal account.

One health center, an early adopter of both an EHR and patient portal, has established a policy restricting information available to parents or guardians with proxy access, starting when the child turns 10 years old. In cases where minor patients have complex medical issues, patients can choose whether or not their parent or guardian(s) can have access to their entire health record. Providers review this decision with adolescent patients annually.

A third example is Children's Hospital Boston, which uses a custom standalone PHR with a patient portal that can accept data feeds from multiple sources. Many of their patients have complex medical histories, and they have gone through an extensive process to generate access policies and rules governing data downloads that build on the hospital's principles and policies while respecting the privacy needs of both patients and parents. They have the ability to tag certain data within the EHR such as labs related to pregnancy, sexually transmitted illnesses, and potentially sensitive problems and medications. When the portal was first launched, that information was not available to either parents or patients.<sup>26, 27</sup> Unfortunately, many EHRs are not able to identify specific potentially sensitive labs, medications and other information, so most portals are not able to manage data in as granular a way as is done at Boston Children's Hospital. However, that might be possible in the future.

---

25 Gray, Susan Hayden Pasternak, Ryan H. Gooding, Holly C. Woodward, Kathy Hawkins, Kirsten Sawyer, Susan Anoshiravani, Arash et al. Recommendations for Electronic Health Record Use for Delivery of Adolescent Health Care. *Journal of Adolescent Health*, Volume 54, Issue 4, 487 – 490.

26 <http://geekdoctor.blogspot.com/2013/05/personal-health-record-use-by.html>

27 Bourgeois, F.C.; Taylor, P.L.; Emans, J.; Nigrin, D.J.; Mandl, K.D. (2008, December). Whose personal control? Creating private, personally controlled health records for pediatric and adolescent patients. *Journal of the American Medical Informatics Association*, 15(6), 737–743. doi 10:1197/jamia.M2865. Retrieved from [http://www.hl7.org/documentcenter/public\\_temp\\_7CA39230-1C23-BA17-0CBCDEB8D0B8876C/wg/pedsdata/Fabienne%20JAMIA%20paper%20\(2\).pdf](http://www.hl7.org/documentcenter/public_temp_7CA39230-1C23-BA17-0CBCDEB8D0B8876C/wg/pedsdata/Fabienne%20JAMIA%20paper%20(2).pdf) [PDF – 78KB].

Providing patient portal access to adolescent patients can be challenging. However, as mission driven organizations serving some of our nation's most vulnerable patients, it is critical that health centers explore the options available to provide patient portal access to adolescent patients. Best practices around adolescent access to patient portals are still emerging. Health centers need to understand the requirements of state laws to protect the privacy of adolescent health information, particularly in the areas of mental health, reproductive health and substance use. Policies need to be developed and communicated to address parental and guardian proxy access. Additional policies to support adolescent enrollment for a portal account are also needed as well as training for frontline staff and providers to ensure that adolescent health information is available when appropriate, and access is restricted when required by state law.

## Conclusion

---

The implementation of patient portals is an important first step in the development of effective patient engagement programs motivating and enabling patients to be active participants in their own health care. In bringing together the multiple components of a patient engagement program, health centers need to give focus to eliminating racial and ethnic disparities in patient enrollment, strengthening communication between providers and patients, and assuring the protection of privacy rights. As health centers move into value-based payment models, patient engagement will be increasingly important and patient portals will be a critical tool that can lead to improved patient outcomes.

# Appendix

---

## Glossary

**Affordable Care Act** – The Patient Protection and Affordable Care Act is major health care reform legislation that passed in 2010 to expand and improve access to care and control costs.

**Consumer Mediated Exchange** - gives patients the ability to access, aggregate and manage their health information, including sharing information with providers.

**Electronic Health Record** – a digital version of a patient’s medical record. EHR is also used to refer to the system that stores and manages not only medical and treatment history, but other patient information.

**Health Information Technology** – is a broad concept that includes a wide array of technologies to store, share, and analyze health information. Often shortened to Health IT or HIT.

**HIMSS** - The Healthcare Information and Management Systems Society is a nonprofit organization focusing on the use of information technology and management systems in the health care industry.

**HITECH Act** - The Health Information Technology for Economic and Clinical Health was part of the American Recovery and Reinvestment Act of 2009 and passed to promote the adoption and meaningful use of health information technology.

**MACRA** – Medicare Access and CHIP Reauthorization Act of 2015 provided a two year solution to the health center “fiscal cliff.” It was a major piece of federal legislation that changes how Medicare payments are structured by ending the Sustainable Growth Rate formula, moving towards value-based payments, and consolidating quality reporting programs.

**Meaningful Use** – is often used as shorthand for the requirements to receive payments from the Medicare and Medicaid Electronic Health Record Incentive Programs. As defined by ONC, it is using certified electronic health record (EHR) technology to:

- Improve quality, safety, efficiency, and reduce health disparities
- Engage patients and family
- Improve care coordination and population and public health
- Maintain privacy and security of patient health information

**Merit-Based Incentive Payment System (MIPS)** – The MIPS is a new program that combines parts of the Physician Quality Reporting System (PQRS), the Value Modifier (VM or Value-based Payment Modifier), and the Medicare Electronic Health Record (EHR) incentive program into one single program in which Eligible Professionals (EPs) will be measured on:

- Quality
- Resource use
- Clinical practice improvement
- Meaningful use of certified EHR technology

**ONC** – Office of the National Coordinator for Health Information Technology is part of the US Department of Health and Human Services (HHS). It was created by Executive Order in 2004 and continued through the 2009 HITECH Act. ONC is charged with promoting and overseeing the development of a national Health IT infrastructure.

**Patient-Centered Medical Home** – a primary care model that provides patient-centered, team-based, integrated, accessible care with a focus on quality outcomes.

**Patient Portal** - a secure website where patients can access their medical history and often certain information from their EHR. Using patient portals, patients can typically complete forms online, communicate with providers, request prescription refills, pay bills, review lab results, and schedule appointments.

**Personal Health Record (PHR)** - an electronic application used by patients to maintain and manage their health information in a private, secure, and confidential environment.

## Resource List

**The American Health Information Management Association (AHIMA)** has a number of resources on patient portals. <http://bok.ahima.org/searchresults?q=patient%20portal>. Some resources are only available to AHIMA members.

**Office of the National Coordinator of Health Information Technology (ONC)** has many resources on its website. The ONC Patient Engagement Playbook is a good place to start. <https://www.healthit.gov/playbook/pe/>.

**Health Information Technology, Evaluation, and Quality Center (HITEQ)** is funded through a national cooperative agreement (NCA) by Health Resources and Services Administration (HRSA), and managed by John Snow, Inc. (JSI). HITEQ services provide training and targeted technology assistance to support health centers in full optimization of their EHR/HIT systems for continuous, data driven quality improvement including electronic patient engagement. Visit <http://www.hiteqcenter.org/> for more information.

**The Healthcare Information and Management Systems Society (HIMSS)** provides a number of resources for IT professionals to improve health care through the use of IT. HiMSS provides numerous resources on patient engagement including <http://www.himss.org/library/patient-engagement-toolkit>. One resource looked at PHRs and the Underserved Population in 2011 <http://www.himss.org/phr-and-underserved-population>.