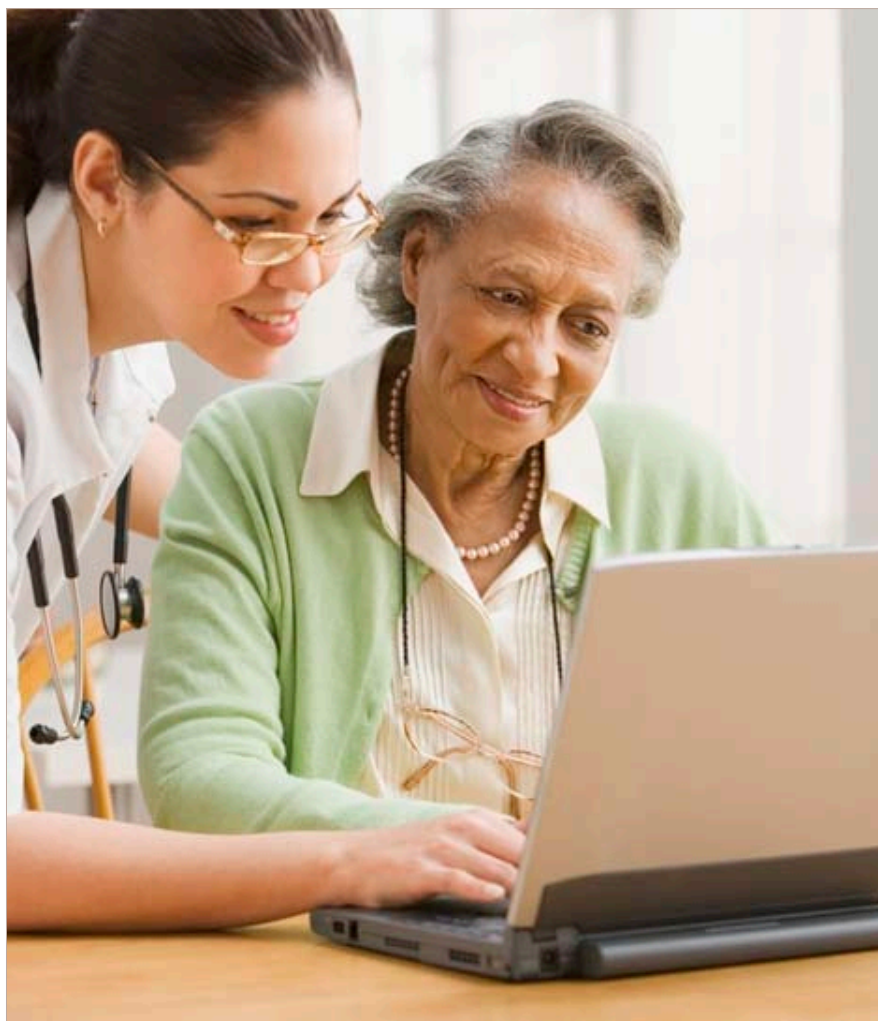




CALIFORNIA  
HEALTHCARE  
FOUNDATION



## **Safety-Net Providers Bring Patients Online: Lessons from Early Adopters**

April 2009

# **Safety-Net Providers Bring Patients Online: Lessons from Early Adopters**

*Prepared for*

CALIFORNIA HEALTHCARE FOUNDATION

*by*

Susan Baird Kanaan, M.S.W.

## About the Author

Susan Baird Kanaan is a consultant and writer with a special interest in the uses of public policy to improve community health.

## About the Foundation

The **California HealthCare Foundation** is an independent philanthropy committed to improving the way health care is delivered and financed in California. By promoting innovations in care and broader access to information, our goal is to ensure that all Californians can get the care they need, when they need it, at a price they can afford. For more information, visit [www.chcf.org](http://www.chcf.org).

# Contents

**2 I. Introduction**

---

**4 II. Four Case Examples**

Cambridge Health Alliance:  
MyChart Patient Portal

Primary Care Information Project, New York City  
Department of Health and Mental Hygiene:  
eClinicalWorks Patient Portal

Institute for Family Health, New York:  
MyChart-MyHealth

UCSF HIV/AIDS Program, San Francisco General Hospital:  
myHERO

---

**12 III. Patients with Multiple Providers**

MiVIA Serves Patients on the Move

Designing a PHR for Information-Sharing in the Seattle  
Area

---

**14 IV. Lessons from Early Adopters**

---

**16 V. Conclusion**

---

**17 Sources**

---

**18 Endnotes**

---

# I. Introduction

*Making online health resources available to safety-net patients offers a number of potential benefits.*

WHILE RESEARCH INTO THE FEASIBILITY AND BENEFITS of providing online resources for underserved Americans continues, a few safety-net clinics around the country are already offering clients such tools as electronic health record (EHR) portals and personal health records (PHRs).

This report provides a look at the experiences of several early adopters, focusing on why and how the initiatives were undertaken; what services are provided and planned for the future; what benefits and challenges have been encountered; and what lessons would be useful for others interested in such programs. Because most of these initiatives are still young — in some cases, only a few months old — the case examples focus on objectives, plans, and start-up experiences.

Fully implemented online resources can support a broad spectrum of patient activities, including: 1) viewing medical records and key medical data; 2) conducting essential transactions with health care providers such as secure messaging, refilling medications, and scheduling appointments; 3) accessing online medical knowledge and health educational materials; 4) managing personal health information (e.g., blood pressure or weight) and sharing relevant information with providers; 5) receiving decision support for health care and health management decisions; and 6) participating in health-related online social networks.

Safety-net providers — which care for low-income, underserved, and vulnerable populations — include public hospitals, community health centers, local health departments, and certain other providers such as AIDS clinics, school-based clinics, and private physicians. Many are certified as Federally Qualified Health Centers (FQHCs) and funded by the Health Resources and Services Administration (HRSA); others rely on local, state, and foundation funding.

Making online health resources available to safety-net patients offers a number of potential benefits:

- **Better health care.** Use of health information technology (IT) can improve efficiency, quality, and continuity of care.

- **Family involvement.** Technology can help patients and their families become active in a patient-centered health care team.
- **Chronic disease care.** Digital tools contribute to managing chronic illness, which is on the rise, especially among low-income populations.
- **Basic equity.** These health-enhancing tools are available to most Americans, and arguably should be available to all.

An argument can also be made that the time is right. Research from the Pew Internet Project and others indicates that almost all Americans are part of the trend toward greater use of the Internet and computer resources, for health and other purposes.<sup>1</sup> Susannah Fox, associate director of digital strategy for the Pew Internet and American Life Project, said, “There are lots of erroneous assumptions about technology adoption. One of them starts with the phrase ‘the digital divide’ . . . .” The research of Pew and others shows that “the safety-net population” is not a monolith, but a composite of many segments on a spectrum. Some individuals have little familiarity with computers; but many others have access to them at home or work and are increasingly comfortable on the Web. The spectrum also includes young people who are adept at text-messaging and able to help older family members with technology.

A number of barriers may inhibit safety-net providers from making online resources available, including lack of funding, heavy workloads, and high staff turnover. In addition, there may be resistance from clinicians due to time constraints, reimbursement policies, and concerns about uncontrolled messaging from patients. Other problems include patients’ lack of access to computers and high-speed Internet, as well as language and literacy issues.

Nevertheless, there is cause for optimism: The Obama Administration has reaffirmed the previous administration’s goal of universal access to electronic medical records by 2014, and Congress is allocating billions of dollars for that purpose.<sup>2</sup> New efforts will build on a health IT foundation constructed over the past decade by government, private, and joint initiatives.<sup>3</sup> HRSA funding has helped stimulate the adoption of EHRs and PHRs by safety-net providers, including one profiled here.

The experiences of these leading-edge providers illustrate the range of approaches that are possible. Now, early in the arc of adoption and before a possible surge in use, is the time to learn from the innovators.

## II. Four Case Examples

### Cambridge Health Alliance:

#### MYCHART PATIENT PORTAL

Cambridge Health Alliance (CHA), a public safety-net provider, serves seven communities outside Boston in more than 20 primary care sites, three acute care hospitals, and other facilities. It has a Medicaid managed care plan. Many residents are low-income immigrants dealing with multiple barriers. A third or more speak a language other than English, and about 15 percent need and receive language assistance. A significant portion of CHA's patients come from outside the service area, attracted by its cultural and linguistic capabilities. At present, there are 80,000 individuals on its primary care panels.

Hilary Worthen, M.D., CHA's senior director of clinical informatics, said the Alliance subscribes to the principle put forward by the Institute of Medicine that high-quality health care is patient-centered, and that patient-centricity involves the free flow of information.<sup>4</sup> CHA's board of directors and CEO regard IT as key to quality and efficiency, and they have supported a sizable investment in it. CHA has used an EHR system, EpicCare, since 2004.

The decision to implement the MyChart patient portal, Dr. Worthen said, "followed naturally," reinforced by clinic medical directors who lobbied to make this resource available to patients. The Alliance launched MyChart in January 2008 in a pilot project at Union Square Family Health Center in Somerville, Massachusetts. CHA is rolling it out, three clinics at a time, to all of its primary care clinics in 2009.

The portal offers standard MyChart functions, including secure messaging; prescription and referral requests; views of medication lists, problem lists,

and immunizations; and appointment cancellation. Test results, which require considerable work and collaboration on the front end, will be rolled out in a future expansion. Patients use MyChart primarily for non-urgent advice requests, process improvement suggestions, and refills. MyChart does not currently give access to Web-based health information resources. The Alliance has libraries of information online that patients can view and print, but these resources are not yet integrated with the portal. The pilot uses an English-only portal. Although CHA is one of many safety-net organizations that believe multilingual capabilities are needed and have lobbied the vendor to this effect, none is available at present.<sup>5</sup>

CHA's organizers expressed surprise about the low rate of MyChart adoption in the pilot year and the gap between expressed interest and usage. For example, as of December 2008, about a third of the 600-patient panel of Union Square's co-medical director, Dr. Rachel Wheeler, had asked for and received an activation code; but only a third of that group (or one-ninth of her patients) have used the portal. The Alliance only collects data on the percentage of patients being activated and on the use of messaging, both of which show accelerated trends.<sup>6</sup>

Although every exam room has a terminal loaded with MyChart, most users access the portal through computers at home or work. Many say their children provide technical assistance. People in the large homeless population served by CHA can have access through public libraries or the clinic-based computers. Providers use office visits to talk with patients about this resource, and the leaders believe they are gradually creating a subset of people who can accomplish medication refills and other activities

online, thus freeing up office staff time. Patients who find it inconvenient to visit the doctor appreciate using MyChart's secure messaging function for brief, non-urgent communications with their providers.

As a recipient of a multiyear Robert Wood Johnson Foundation Pursuing Perfection grant, CHA developed an extensive planned care program for patients with chronic conditions, supported by several IT tools. Conceptually, Dr. Worthen said, MyChart fits right in. Dr. Wheeler added, "Continuous information is what starts to change when people use MyChart, because it enables lots of back-and-forth conversation. This process is about forming a team between patients and physicians. And I really like the simple 'thank you' messages that I get when I email patients with results. With a letter, we are never sure it arrived or was understood." To date, patients with chronic diseases have not used MyChart as intensively as others—possibly, she speculated, because "they tend to be older."

In general, CHA's clinicians have not resisted automation, which has been under way for several years. They have some concerns, however, about the time it takes them to recruit patient users to MyChart and to explain the application. Dr. Wheeler said she uses her discussions of diagnostic codes with patients as a teaching opportunity and a way to explain the medical records and the information she tracks. Privacy has not been an important issue. "The only patients I've encountered with privacy concerns are software engineers!," she quipped. However, she noted that home computers typically have multiple users, and that when patients' children provide technical assistance, they may see sensitive information. With these patients, Dr. Wheeler asks whether there are medications or problems they would prefer others not to know about.

Different segments of CHA's patient population have quite different experiences with technology

use, Dr. Worthen has noticed. For example, many patients from Brazil are comfortable with computers because they do videoconferencing with relatives there, while members of some other nationalities have no such experience. And "the younger generation," he noted, "has skipped the PC altogether, and is adept with text-messaging and cell phones." It is important to bring text-messaging into e-health tools, he added; that and meeting diverse language needs are the long-term directions he hopes the vendor will take.

Dr. Worthen voiced concerns about the sustainability of online health resources in many settings. CHA evolved a business plan (based on Massachusetts' former uncompensated care pool) that was solid enough to enable EHR adoption. But the Alliance, like other safety-net organizations in the state, is hard hit as a result of the state's health care reform and its low levels of reimbursement. Secure messaging is part of this concern: While email communication is proving beneficial to patients, it is not reimbursed, and may eliminate a revenue-generating office visit. This is a common issue for health care organizations that offer patients online resources because they believe it is the right thing to do, but worry about paying a financial price for doing so.

---

*"This process is about forming a team between patients and physicians. And I really like the simple 'thank you' messages that I get when I email patients with results. With a letter, we are never sure it arrived or was understood."*

---



## Primary Care Information Project, New York City Department of Health and Mental Hygiene:

### ECLINICALWORKS PATIENT PORTAL

New York City's Primary Care Information Project (PCIP) is a two-year initiative in which the city is subsidizing licensing and support to enable 2,500 primary care providers to implement the eClinicalWorks (eCW) EHR and portal by the end of 2009.<sup>7</sup> The goal of this ambitious initiative is to enhance the health of New Yorkers by improving their health care and increasing consumer participation using electronic records.

The project began with providers who serve the Medicaid population (primarily young families) and in areas, such as the South Bronx, with high proportions of low-income residents. Many speak one of the city's 40 non-English languages. Serving more than 500,000 people, these priority providers fall in roughly equal proportions into three categories: hospital outpatient departments, community health centers, and private practices. When implementation began in early 2008, only 25 percent of the city's primary care providers had EHRs; by early 2009, more than 1,500 had signed up for the program.

PCIP's coordinator of consumer informatics, Melinda Jenkins, Ph.D., F.N.P., describes herself as the "hands-on patient engagement queen" in the project. The consumer informatics component aims to take full advantage of the patient-oriented functions available through eCW and to encourage patients to expand their self-care using online tools. Dr. Jenkins has two major areas of responsibility: encouraging and helping overstretched primary care providers to use the patient portal with their patients; and working with the vendor, programmers, and others to optimize the EHR and patient portal for patient education and self-management.

She gets feedback from providers and patients on how they would like the portal modified and meets twice weekly with the vendor's project manager to discuss changes. In addition, PCIP uses a readiness assessment process to help practices understand how to prepare for using eClinicalWorks. Once practices are about to begin implementation, Kathryn LaSorsa, PCIP's city research scientist, conducts an assessment with practice leaders. The detailed questions cover clinical, administrative, billing, and quality improvement areas. She creates a readiness report for each practice, outlining strengths and gaps and suggesting next steps.

All standard eCW portal functionalities are available to PCIP participants, including secure messaging, viewing lab results, medication refill requests, referral requests, and updating personal information and health history. However, Dr. Jenkins pointed out that data entry by patients is limited and they have no access to a continuity-of-care document—a portable summary of their record. She wants patients to be able to use the portal for self-management, and this, she said, is how the tool should evolve. She and her colleagues are working with the vendor to develop more options for patients, including: tools for medication reconciliation and management; automated links from diagnoses and treatments to patient education materials; and a family-style portal where a parent or caregiver could have proxy access to information collected on all family members. She said, "All of today's EHR applications are complex, clunky, and have a high learning curve—and that's the state of the art!" For now, she advises practices to follow the Kaiser Permanente example and create their own Web pages where they can post links to health education materials and community resources.

The PCIP project—believed to be the largest implementation of primary care EHRs in the

country—is in the early stages of promotion and implementation. There are barriers to swift adoption. As of December 2008, although hundreds of New York City providers had implemented the EHR, only five practices were using its patient portal. Dr. Jenkins noted that though current research shows that patients want and use online communication, providers lack an incentive to change their practice routines. Some providers add an unnecessary barrier with incorrect assumptions about their low-income patients' lack of interest in online resources.

Dr. Jenkins said there are tremendous pressures on primary care providers (especially small practices) that severely limit time and money for introducing patients to online resources. Further, reimbursement policies discourage online messaging in lieu of office visits. She wondered how well practices will be able to sustain their use of electronic resources once the city's underwriting and coaching support end. PCIP is collecting data on usage, return on investment, quality, and other factors, and expects to have publishable data sometime in 2009. The patient portal and the use of all forms of patient education by providers will be evaluated.

---

*“This is a wonderful time to be involved in communication and working with patients. The potential is mind-boggling.”*

---

At a population level, Dr. Jenkins anticipates that the EHR initiative will reduce government spending on acute care but that the return on investment is not likely to flow to individual primary care practices. Overall, however, she is optimistic: “This is

a wonderful time to be involved in communication and working with patients. The potential is mind-boggling. The tools available now are evolving, and we just have to keep working to evolve this as much as we can so patients can be in control of their own health care.”

### **Institute for Family Health, New York:** MYCHART-MYHEALTH

The Institute for Family Health operates a network of 16 community health centers that provide care based on the family practice model to diverse, underserved communities in New York City (Manhattan and the Bronx) and the Mid-Hudson Valley. The Institute also provides health care at eight sites that serve the homeless, and it sponsors two family medicine residency programs.

In New York City, the Institute serves numerous minority populations, including African Americans, Caribbean Americans, Latinos, and new African immigrants. More than half of the residents of each of the Bronx communities served live in poverty. Educational attainment is low; in most communities served, only about half of adults have high school diplomas. The Institute's health centers in the Mid-Hudson Valley serve a disproportionate number of patients from underserved communities, relative to the area's population. Half of the Institute's Ulster County patients have incomes below the federal poverty level. Across all Institute practice sites in Mid-Hudson, more than a third of patients receive Medicaid and about 15 percent are uninsured.

In 2002, the Institute implemented an EHR, EpicCare, and in 2007 it received a three-year HRSA grant to mount the patient portal, which it named MyChart-MyHealth. The HRSA grant covers start-up costs; research on patients' health information, health literacy, and computer literacy needs; customization of the portal to meet these

needs; and some marketing and training for patients to use the portal. Involving patients in their own care is standard practice for President and CEO Dr. Neil Calman, and he has always shared people's charts with them; so the program fits well with the Institute's core philosophy.

Implementation of MyChart-MyHealth began in early 2008 with a pilot project in the Urban Horizons Family Health Center in the Bronx, where Medical Director Adam Szerencsy, D.O., is coordinating implementation for all of the Institute's health centers. The transition from pilot to rollout at six New York City sites took place over the second half of 2008. By February 2009, about 1,100 patients had signed up. According to Dr. Szerencsy, the Institute's strategy is to get as many participants as possible, and then to track the impact on services and clinical outcomes.

With funding from its HRSA grant, the Institute is collaborating with a team from Columbia University's Department of Biomedical Informatics, headed by Dr. Maxine L. Rockoff, to carry out a research program on the MyChart-MyHealth implementation. Focus groups, usability analyses, phone interviews, and paper-based surveys are being used to analyze patients' views and experiences. Based on these inputs, the Institute plans to develop educational materials, further develop the site, and engage in marketing efforts tailored to patients' needs and preferences.

Using MyChart-MyHealth, patients can review their health information, learn about their health conditions, see test results, send secure messages to their health center, request prescription refills, and schedule appointments. The Institute has focused its early data collection on the number of people signing up for MyChart-MyHealth every month, by clinic site and provider. The Epic software also tracks and reports on what functionalities patients are using. So

far, the most commonly used module is test result viewing, followed by messaging, prescription refills, and problem and medication list viewing.

Dr. Szerencsy said the Institute has not yet found a satisfactory way to build educational resources and links into MyChart-MyHealth, since the Institute relies on third parties to provide health information resources, and they are expensive or do not integrate well. He reported that the implementation team, working with PCIP and the University of California, San Francisco, is exploring with the National Library of Medicine a way to link patient portals directly to MedlinePlus.

Early decisions about configuring the system focused on the sign-up process, routing of patients' messages (in the Institute's case, to the physician rather than a nurse), and whether any information in the health record should be restricted from the portal. In making these decisions, planners looked at the experiences of other providers and organizations. They also conducted focus groups, and expect that this input will be useful in marketing the services. For example, a focus group revealed that some patients have the misconception that using messaging could result in having less access to their physicians.

Patients can use various routes to adopting the portal. For many, the most effective is encouragement by their physicians; however, this can be time-consuming for the physician. Patients also can express interest to a nurse or at the front desk, where they can sign a consent form and receive an activation code. There are terminals in the office for patients without computers or who need help with start-up; however, as with other clinics, there has been less use of the office terminal than expected. Technical assistance is available from the Institute help desk. Using HRSA funding, the Institute also plans to develop classes for patients on how to use MyChart-MyHealth.

Clinic leaders cite language and literacy issues as obstacles to patient portal use, along with computer literacy and health literacy. MyChart is only available in English at this point; Dr. Szerencsy speculated that this may account for the lower adoption rates at the Bronx sites. The team is exploring options to translate the site into Spanish. Using its HRSA grant, the Institute plans to develop print and online training materials and to hold classes in a variety of locations, including community technology centers located in housing projects.

The Institute's patients have not expressed particular concern about privacy. Indeed, focus group participants talked about the common fear of any new technology, such as ATM machines, and the way it diminishes over time. Much like Cambridge Health Alliance patients, the Institute's patients are already accustomed to having their health information computerized and knowing it is accessible to multiple providers, and this may have created an atmosphere of trust.

The Institute is also assessing provider readiness and pushback, such as concerns about added workloads due to messaging and patient education requirements. Some providers are hesitant to practice a more transparent form of medicine since it brings into the open some health issues—such as a mental health diagnosis—that may be easier to avoid.

The Institute for Family Health operates in a region rich with health information exchanges such as Regional Health Information Organizations (RHIOs). Dr. Szerencsy said that while “it should all be one big system,” today's reality is that these networks are highly fragmented and at a very early stage of development. For example, data in the three RHIOs in which the Institute participates are incomplete, he noted. In some cases, he can view information but not export it to his system or upload information on his patients. None of this

information interfaces with MyChart-MyHealth, so input from other providers such as local hospitals is not yet available to patients.

### **UCSF HIV/AIDS Program, San Francisco General Hospital: MYHERO**

The multifaceted HIV/AIDS Program at San Francisco General Hospital provides outpatient primary and specialty HIV care, routine and urgent care, and psychosocial support. It integrates patient care with clinical research, and provides ongoing education for patients, providers, and the local community. The program's Ward 86 clinic is a collaborative effort of the University of California, San Francisco (UCSF) Department of Medicine and the San Francisco Department of Public Health. It is one of the oldest and largest HIV/AIDS clinics in the United States, serving about 3,000 patients. Eighty percent of its patients are male, and half are members of racial and ethnic minority groups. About 25 percent have an AIDS-defining condition, and the rest have HIV. Many have co-existing conditions such as hepatitis C.

UCSF Professor of Medicine James Kahn, M.D., led the team that developed Healthcare Evaluation Record Organizer (HERO), a Web-based EHR system that has been used as the clinic record at Ward 86 since 2000 and that also serves as a research database. HERO is integrated with myHERO, a publicly accessible PHR that patients can use to review medications and request renewals; view and learn about lab results; view their medical conditions; record personal health information and concerns; obtain useful health information such as links and clinic information (from MedLine Plus and other sources); and learn about other resources. The PHR, which in the near future will also send reminders, is housed behind a secure firewall on the San Francisco Department of Public Health Web site.

MyHERO was developed with funding from the National Institutes of Health, the Blue Shield of California Foundation, the Agency on Healthcare Research and Quality, the Commonwealth Fund, and CHCF. The creators conducted usability testing and patient focus groups in the initial design process. (Among other requests, participants asked that the “My Problems” section be renamed “My Conditions,” and patients chose the ten lab test results they wanted to be able to view.) The PHR, which was introduced in March 2007, includes a survey tool that enables program managers periodically to find out what the users want.

Dr. Kahn said self-management support is the guiding principle for myHERO, which is designed to “give patients more responsibility by giving them information.” The HIV/AIDS program “curates” the information it makes available to patients—for example, lab test results include not just “the number” but what it means and where to find more information. Dr. Kahn noted that with myHERO, patients can also engage in a number of health management activities. He cited the observation of his San Francisco General colleague, Dr. Tom Bodenheimer, that chronically ill patients need constant support and input for their daily health decisions; what they get in their few minutes with a clinician every few months is not sufficient to motivate and inform them as they manage their complex conditions.

In the myHERO launch, all providers practicing on Ward 86 were invited to participate. Dr. Kahn observed that clinicians first need to be convinced that the innovation is not just “newness for its own sake,” but can deliver real benefits to patients. The hardest thing to accomplish, he added, “is the change in the physician-patient relationship, because by giving patients access to information we’re taking away the physician’s role as gatekeeper of the

information. This places the physician in the role of educator rather than sole information source.” At present, about 30 physicians, nurses, pharmacists, and nurse practitioners participate in myHERO. The clinicians recruit their patients during primary care visits. The first patients targeted were younger individuals deemed more likely to be “early innovators,” who were comfortable with technology despite their limited resources.

Dr. Kahn says patients can be introduced to myHERO rapidly, but they will benefit from more training. “We find it takes about two to five minutes to train someone who’s completely unfamiliar with the Internet, and to get them an account and email address and log into the system. After that, they learn from trial and error—though we work to see that they mostly experience success.” As for additional training on how to use the PHR to manage their health, he added, “Most patients will benefit from thoughtful education about this, just as they do from education on medication adherence and what labs mean. Patients shouldn’t be left to figure out this tool on their own.” Starting in summer 2009, UCSF will offer user training for groups of patients in a new computer lab in the hospital library, which has multiple monitors that are “protected from prying eyes.”

---

*“By giving patients access to information we’re taking away the physician’s role as gatekeeper of the information. This places the physician in the role of educator rather than sole information source.”*

---

By late 2008, about 200 patients in the HIV/AIDS program were using myHERO. Patients without home computers have access in the clinic waiting room and at other free locations such as libraries. According to Dr. Kahn, “the waiting room computer is used more frequently than the TV, and it’s as attractive as the free food.” Project leaders have analyzed data on how often patients visit the site, what pages they use, how long they stay, and satisfaction rates for a forthcoming article.<sup>8</sup>

Although many patients in the HIV/AIDS program are homeless, virtually all have cell phones, so the leaders plan to apply myHERO to a mobile platform for patients without consistent Internet access. Soon, myHERO will be linked to GoogleHealth. While Dr. Kahn acknowledged some concerns about how large companies like Google will protect personal health information, he said he believes the concerns are outweighed by the potential benefits of linking patients to the powerful new tools. The major benefit from UCSF’s perspective, he said, comes from Google’s links to other providers such as Kaiser Permanente or Cleveland Clinic: “We see GoogleHealth as a RHIO in disguise. We don’t have the mechanisms and agreements for this kind of record portability, but our patients can make their records available to other providers by uploading them onto Google.”

In supporting the myHERO initiative, Dr. Kahn underlined the financial concerns that surround the work of all safety-net programs: “We continue to struggle with insufficient funding, and are trying to find continued support for this novel and important new program.”

## III. Patients with Multiple Providers

*Migrant workers and homeless people have special problems benefiting from online health care resources.*

MIGRANT WORKERS AND HOMELESS PEOPLE HAVE SPECIAL problems benefiting from online health care resources, not only because they lack permanent addresses, but because they use multiple providers. The two programs described below illustrate ways to help these patients maintain their health information.

### **MiVIA Serves Patients on the Move**

MiVIA is designed for mobile, largely Spanish-speaking users who have multiple health care providers. The target population is migrant and seasonal service and agricultural workers, many of whom have limited English and no fixed address. The application is designed to give users (called “members”) the information they need to participate actively in the health care system, including all of their providers.

MiVIA provides members with a portable, free-standing, password-protected PHR, with mechanisms for access and input by any provider with the member’s permission. The program was developed by FollowMe, a pioneer in Web-based PHRs, in collaboration with Vineyard Workers Services and St. Joseph’s Healthcare Services Mobile Medical Unit in Sonoma County, CA, with funding from The California Endowment and the Rural Community Assistance Corporation. Focus groups were used in the initial design work, and upgrades are based on consumer feedback and advisory committees organized by community partners. Members acquire MiVIA free from licensed organizations—health care providers and community organizations.

FollowMe Vice President Heidi Stovall noted that many safety-net clinics are implementing EHR systems, which are not directly interoperable with MiVIA. Despite the potential benefits for patients, providers may lack the time and resources to make dual entries. MiVIA developers have discovered that partner organizations and providers need to be educated about the principles of consumer empowerment and health advocacy. Five health care organizations offer MiVIA in California (including the original Sonoma Valley program), Oregon, and upstate New York.

FollowMe President Cynthia Solomon said challenges in caring for a non-English-speaking and low-literacy clientele continue even after six years' experience. "We're still working out how to handle language issues most effectively," she said. A new Spanish version now under development will be a full mirror image of the English version. However, the provider's language is still an important factor: "We don't always advise the use of the Spanish version," Solomon said. Recent focus groups highlighted the need to add audio and video features to assist non-readers.

### **Designing a PHR for Information-Sharing in the Seattle Area**

Representatives of Washington State's Whatcom County Health Information Network (HInet), which hosts and supports the Shared Care Plan PHR, have been part of a community organizing endeavor in nearby King County aimed at overcoming the fragmentation of health care and information in their area.

A coalition of safety-net providers in the county has been meeting since mid-2007 around a common desire to share health information on their patients, many of whom are homeless. These providers serve the same people, but have no way of knowing what other providers their patients are seeing. They know that some of their data are redundant. Since they believe interoperability among clinical information systems will not happen soon enough, they are looking to a PHR that crosses organizational lines to meet their immediate need for health information exchange. The City of Seattle, the county, and the University of Washington Hospital tertiary care center are among those represented at the table.

The Shared Care Plan was developed primarily to meet the needs of chronically ill patients by a collaborative of HInet, PeaceHealth, and other

regional providers, as well as patients, under the auspices of a Robert Wood Johnson Foundation Pursuing Perfection grant to Whatcom County. Launched in 2002, it gives users control of their health history, including all providers, and supports personal health management activities.

The design process is still at an early stage. HInet's Lori Nichols explained that the PHR would be the "front end" for the patient (or a designee), who would control it and carry it from provider to provider. The PHR would communicate with a database populated and shared among the safety-net providers and governed by HIPAA rules.



## IV. Lessons from Early Adopters

*Early adopters express no reservations about the decision to extend online resources to their patients, and report that they are starting to see the benefits.*

THE EARLY-ADOPTER INITIATIVES SHOW THAT IT IS feasible for safety-net clinics with adequate leadership, organizational commitment, and start-up funding to offer their patients online resources, and that these patients will use them. Pioneers stress that roll-out takes longer than expected, due to slow patient or clinician adoption rates, resource limitations, and/or technical hurdles. However, they express no reservations about the decision to extend online resources to their patients, and report that they are starting to see the benefits.

As more providers debate creating online resources for patients, early adopters recommend giving particular attention to several areas:

- **Understanding safety-net patients' needs and capacities.**

Clinicians' misconceptions about their patients' interests and capabilities can be significant barriers to adoption. On the other hand, providers must accommodate patients with limited resources and education, language issues, and lack of computer access. Solutions can include additional language options, video and audio aids that reduce dependence on reading, and text-messaging to engage young patients.

- **Encouraging adoption.** Typically, many more people express interest in online tools, or even sign up for them, than actually use them. To encourage use, entry points need to help the clinics provide better care *and* be perceived by patients as beneficial and simple. Kim Nazi, a Veterans Health Administration staffer who does research on MyHealthVet (the VA portal) usage, said adoption can be encouraged by offering services that “make something easier” and by greater integration of the PHR within routine health care. Research shows that patients are most interested in tools for appointments, medication management, test results, and messaging.

- **Social marketing, training, and technical assistance.** It is not enough to offer PHRs to patients. “A huge PR effort has to happen before any of this takes off in a big way,” said Manhattan

Research's Meredith Abreu-Ressi.<sup>9</sup> Physicians and office staff may find their hands full just recruiting patients and introducing them to the technology. But outreach, technical assistance, and training are important in making PHRs fully functional for both providers and patients.

- **Recognizing privacy concerns.** While safety-net patients typically express far less concern about privacy protections than do Americans as a whole, they still need to be educated about their rights and about potential misuse of sensitive information. This is especially an issue when portals give patients access to online tools that place their health information outside the provider's HIPAA-covered umbrella. This gray privacy area, combined with clinicians' concerns about possible liability related to patient-entered data, may help explain why some clinicians hesitate to encourage their patients to use all the functionalities available to them.
- **Overcoming organizational barriers to adoption and sustainability.** Giving patients access to their medical information and offering them new ways to communicate can be a major paradigm shift for clinicians. It may require a change in the way some practice medicine. Most express concerns about the extra workload, especially at the beginning. Even if patients require little training and technical assistance, it takes time and organizational resources to get them started with portals and PHRs. Many clinicians are concerned that messaging (despite evidence to the contrary) will invite long and frequent messages from their patients. Others worry about reimbursement policies that do not compensate for online activity, some of which may substitute for reimbursable office visits.
- **Assessing and demonstrating impact.** The safety-net programs are watching for administrative benefits in addition to other advantages of online resources. Some report efficiencies such as fewer telephone calls to the office for refills and appointment changes. But hard evidence of results is also necessary, said Dr. Kahn of UCSF, to counter common skepticism about such innovations.
- **Facilitating collaboration.** As more safety-net organizations introduce their patients to online resources, it will be beneficial for them to collaborate. Thomas Horan, Ph.D., a scholar specializing in personal health information systems for underserved Americans, imagines a consortium of safety-net clinics finding economies of scale by purchasing and tailoring a single application—much like New York City's PCIP initiative. In a recent CHCF report, authors Ted Eytan, M.D., and Josh Seidman, Ph.D., proposed another form of support: that large health care organizations with well-established EHRs and PHRs might help safety-net clinics in their regions with health IT challenges they have already addressed.<sup>10</sup>

## V. Conclusion

*Leading-edge safety-net clinics choose entry points that both enhance patients' health management and improve clinical utility and workflow.*

THESE ARE THE KEY MESSAGES FROM THE EXPERIENCES OF pioneering safety-net clinics offering online resources to their patients:

1. "Safety-net populations" are not a monolith but an aggregate of many segments with different capacities, interests, and needs, all of them part of a societal trend toward greater use of digital tools and the Internet.
2. Despite limited resources, education, and computer access, safety-net patients do use the Internet and online health resources.
3. Leading-edge safety-net clinics have successfully implemented EHRs and launched patient portals despite financial, staffing, reimbursement, and other challenges. They choose entry points that both enhance patients' health management and improve clinical utility and workflow.
4. The early adopters typically have an impetus to begin the work, usually in the form of start-up funding. They also have in common the support of their wider organizations and strong leadership from champions of patient empowerment and health IT.
5. Online tools are evolving, partly through interventions by the early adopters to improve program usefulness for patients. On the horizon are mobile/cell platforms, multimedia, and text messaging.

## Sources

### Case Studies

#### Cambridge Health Alliance

[www.cha.harvard.edu](http://www.cha.harvard.edu)

Hilary Worthen, M.D.  
Senior Director, Clinical Informatics

Rachel Wheeler, M.D.  
Co-Medical Director, Union Square Family Health  
Assistant Chair, Department of Family Medicine

#### Institute for Family Health

[www.institute2000.org](http://www.institute2000.org)

Adam Szerencsy, D.O.  
Medical Director, Urban Horizons Family Health Center  
The Institute for Family Health

Maxine Rockoff, Ph.D.  
Research Scientist, Department of Biomedical Informatics  
Columbia University

#### MiVIA

[www.mivia.org](http://www.mivia.org)

Cynthia Solomon  
President, FollowMe, Inc.

Heidi Stovall  
FollowMe, Inc.

#### New York City Primary Care Information Project

[www.nyc.gov/pcip](http://www.nyc.gov/pcip)

video: [youtube.com/watch?v=Oqf2vWCQhHQ](https://www.youtube.com/watch?v=Oqf2vWCQhHQ)

Melinda Jenkins, Ph.D., F.N.P.  
Coordinator of Consumer Informatics, Primary Care Information Project, NY City  
Department of Health and Mental Hygiene

#### PeaceHealth

[www.peacehealth.org/](http://www.peacehealth.org/)

Kathleen Furtado  
Program Manager, Planned Care, Medical Group Division

#### Shared Care Plan PHR

[www.sharedcareplan.org](http://www.sharedcareplan.org)

Lori Nichols  
Director, Whatcom Health Information Network, LLC (HInet) & Shared Care Plan PHR

#### UCSF HIV-AIDS Program

<http://myhero.sfdph.org>

James Kahn, M.D.  
Professor of Medicine

### Other Informants

Cynthia Baur, Ph.D.  
Director, Division of Health Communication and Marketing, Centers for Disease Control and Prevention

Cheryl Austein Casnoff, Ph.D.  
Associate Administrator, Office of Health Information Technology, Health Resources and Services Administration

Ted Eytan, M.D.  
Consultant

Sue Feldman  
Assistant Director, Kay Center for eHealth Research, Claremont Graduate University

Susannah Fox  
Associate Director, Digital Strategy, Pew Internet and American Life Project

Thomas Horan, Ph.D.  
Director, Kay Center for eHealth Research, Claremont Graduate University

Kim M. Nazi, FACHE  
Management Analyst, Veterans and Consumers Health Informatics Office, Veterans Health Administration Office of Information

Paul Tang, M.D.  
Vice President and Chief Medical Information Officer, Palo Alto Medical Foundation

Christina Wildlake  
Project Manager III, Safety Net, Northern California Community Benefit Program, Kaiser Permanente

## Endnotes

1. The Pew Internet Project frequently releases new research reports and analyses. Search by topic at [www.pewinternet.org/reports.asp](http://www.pewinternet.org/reports.asp).
2. California Executive Order S-12-06, calling for creation of a California eHealth Action Forum to promote “the rapid implementation of health information technology,” is also relevant.
3. Baur, C., and Kanaan, S., *Expanding the Reach and Impact of Consumer e-Health Tools*, DHHS Office of Disease Prevention and Health Promotion, 2006.
4. Institute of Medicine, *Crossing the Quality Chasm: The IOM Health Care Quality Initiative* ([www.iom.edu/CMS/8089.aspx](http://www.iom.edu/CMS/8089.aspx)).
5. CHA does have a large multilingual interpreting service that provides face-to-face and telephone interpreting anywhere in the system as well as document translation services, and its Community Affairs Department does significant work on cultural competence. Because all the initial portal users are English speakers, language was not an issue at the outset; however, Dr. Worthen said, “It will be, and we will need to address it.”
6. On average, 42 percent of CHA’s activated patients, who are about a third of its total number of patients, are using MyChart.
7. The director of the PCIP initiative is Farzad Mostashari, M.D., M.Sc. ([www.nyc.gov/pcip](http://www.nyc.gov/pcip)).
8. The article has been submitted for publication. The UCSF program is also featured in “What It Takes: Characteristics of the Ideal Personal Health Record,” co-authored by Dr. Kahn and Veenu Aulakh of the California HealthCare Foundation, in the March/April 2009 issue of *Health Affairs*.
9. Quoted in Sarasohn-Kahn J, “Industry predictions: What are the drivers shaping health care IT in 2009?” *iHealthBeat*, December 22, 2008.
10. Seidman, J., and Eytan, T., *Helping Patients Plug In: Lessons in the Adoption of Online Consumer Tools*, California HealthCare Foundation, June 2008. ([www.chcf.org/documents/chronicdisease/HelpingPatientsPlugIn.pdf](http://www.chcf.org/documents/chronicdisease/HelpingPatientsPlugIn.pdf)).



**CALIFORNIA  
HEALTHCARE  
FOUNDATION**

1438 Webster Street, Suite 400  
Oakland, CA 94612  
tel: 510.238.1040  
fax: 510.238.1388  
[www.chcf.org](http://www.chcf.org)