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Helping Patients Plug In: Lessons in the Adoption of Online Consumer Tools

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Acknowledgment

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About the Foundation

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I. Executive Summary

HEALTH INFORMATION TECHNOLOGY (HIT) HAS THE potential to improve clinical excellence, the care experience, and the continuity and affordability of care. Information technologies focused specifically on patients offer an opportunity to engage patients by giving them more control over their care and making them key partners in health-related decisions. An increasing number of innovative providers are using electronic tools such as electronic health records (EHRs) and personal health records (PHRs) to achieve this goal.

To better understand the evolving role of patient-centered health information technology (PCHIT) in clinical care, the authors examined five different types of medical practice settings in California, Massachusetts, New York, Maryland, and the District of Columbia; interviewed physicians, patients, and others; and reviewed the relevant literature. They also looked at PCHIT from a regional perspective to learn about recent developments.

The authors found that PCHIT is gaining a greater foothold in health care settings and that most clinicians are enthusiastic about delivering patient-centered care. The research also found that:

- Some clinicians practice in an environment where the commitment to PCHIT is ambiguous.

- As more providers successfully implement EHRs, some may become concerned about access to the records by both clinicians and patients.

- Health plans are still uncertain about how best to harness data for PHRs and persuade enrollees to use them.

- Some providers roll out PHRs without linking patients' personal data to health information targeted to their particular needs.

- Consumers are clamoring for PHRs that will give them access to clinical data linked to health information targeted to their needs. The PHR adoption curve in organizations that have taken this approach is steep.

- Despite notions to the contrary, safety-net populations are enthusiastic about electronic access to their health care providers and have enough computer savvy to take advantage of patient-centric technologies. However, few community health centers can afford to offer such tools.

II. Overview

P ATIENT-CENTERED HEALTH INFORMATION technology (PCHIT) engages patients in their care by giving them access to electronic tools, including health records at physician offices, personal health records on the Web, online appointment scheduling, and doctor-patient email. However, there is a significant disparity between what patients want to do online and what they are able or allowed to do.

As Table 1 illustrates, about three-quarters of consumers are interested in electronically viewing their medical records and lab results, scheduling appointments, and exchanging email with their physicians. Yet few have such access, even though a sizable number would be willing to pay extra for it.

Table 1: Consumer Access to Electronic Tools

Tool	Would Like to Access	Already Access	Would Pay Extra to Access
Online medical records and test results	78%	6%	26%
Online appointment scheduling	72%	10%	18%
Email to doctor	76%	9%	23%

Source: Deloitte. 2008 Survey of Health Care Consumers.[1]

Some large integrated delivery systems, multispecialty group practices, and community health centers have adopted PCHIT, many electronic health records (EHRs) now include patient portals, and commercial personal health records (PHRs) are proliferating. But PCHIT is far from widespread.[2]

Any technology that facilitates communications and helps consumers organize health information, act upon it, and weigh the implications of their decisions qualifies as PCHIT. Along with EHRs, PHRs, online appointment scheduling, and secure doctor-patient email, the term encompasses electronic access to lab results, decision-support tools, prescription refills, and other applications.

To be truly patient-centered, an application must link a person's health data to content that puts the data in context for that individual and answers the question, "What does it mean in my case?"

PCHIT helps consumers take control of their health and to be key partners in health-related decisions. It also improves the quality and cost-effectiveness of health care. For example, research suggests that patients immediately forget 40 percent to 80 percent of everything a doctor tells them in the exam room.[3] EHRs can generate an electronic summary of a doctor visit to be printed and taken home—a powerful tool because it wraps the clinician's notes around health content targeted to the individual.

The Patient-Centered HIT Initiative

The findings in this report are based on the PCHIT Initiative, which explored the challenges and opportunities related to greater PCHIT adoption. A team from the Center for Information Therapy in Bethesda, Maryland, studied the delivery of health care—particularly patient engagement with HIT—by observing dozens of exam room encounters in models of care that included community health centers, health plans, integrated delivery systems, multispecialty group practices, and solo and small physician practices.[4] To promote transparency, the project maintained an open-access blog regarding its observations.

The initiative sought to assess:

- The technological innovations in place to facilitate more patient-centered care;
- How patients and clinicians used HIT at different stages of implementation;
- How they communicated about improving patients' health;
- Opportunities for improving clinician-patient communication and the engagement of patients and families in all aspects of care; and

- Access to PCHIT tools by safety-net populations and opportunities for providers to use such tools to coordinate care for these populations.

The project team focused on clinical settings where HIT is replacing paper-based systems, rather than on those with mature HIT or none at all, and on health care providers with a diverse clientele. This approach revealed hurdles faced by those that are considering, or in the process of implementing, information technologies. The team observed providers in areas of California, Massachusetts, New York, and Maryland—locations served by most of the project's sponsors—and in Washington, D.C.

Clinicians and administrators often raised the issue of disparate access to the Internet among safety-net populations and how that might affect PCHIT use. Although income and other demographic factors do have an impact, data suggest that many people— even those with lower incomes—now have access to the Internet (Table 2).

Table 2. Internet Access among Demographic Groups

Demographic	Percent Who Have Access
Household earns less than $40,000	61%
Household earns more than $40,000	91%
No high school degree	41%
High school graduates	69%
College graduates	93%
Caucasians	78%
African Americans	68%
English-speaking Latinos	75%

Source: Pew Internet & American Life Project.[5]

It is important to think about PCHIT in the larger context, beyond Internet use, because there are new technologies that do not involve a computer on the patient's end. For example, a mobile phone may be the most effective vehicle for certain populations to receive health information, be it in the form of an automated, multilingual phone call, a text message such as a medication reminder, or a more sophisticated combination of audio, graphics, and video.[6]

Language, health literacy, access to computers and the Internet, geographic location, and little if any continuity of care do pose significant barriers to widespread use of PHRs among vulnerable populations. However, it is possible to overcome such obstacles. MiVIA, a PHR designed specifically for seasonal and migrant workers in California's Sonoma Valley, shows how electronic tools can be effective if they are adapted to meet particular needs.[7]

III. PCHIT in Five Practice Settings

To get a better sense of the extent to which PCHIT has penetrated health care, the project team examined five types of clinical settings: safety-net providers, health plans, integrated delivery systems/group model plans, multispecialty group practices, and small physician practices. It observed daily activities; interviewed patients, physicians, and others inside and outside these settings; and consulted print and Web sources regarding PCHIT specifically and HIT generally.

Safety-Net Providers

Community health centers were an important focus of the PCHIT Initiative because of concerns about the barriers that safety-net populations face regarding access to health information technology. The safety-net providers cited in this report were primarily federally qualified community health centers, which serve an estimated one in eight uninsured patients. Seventy-five percent of patients at such centers are uninsured or on Medicaid.[8]

National surveys suggest that the number of community health centers and physician practices with fully or partially implemented EHRs is about equal, although these providers are among the minority of clinics and practices with EHRs.[9] (There are no comparable data regarding PHRs.) While one might expect that extremely limited resources would restrict the ability of community health centers to innovate in terms of HIT, observations of the safety-net providers in this report revealed that many are as technologically savvy as their non-safety-net counterparts. Some even have state-of-the-art EHRs. One way they can finance HIT improvements is through a limited number of grants, depending on the region.[10]

Broad Interest in HIT

Providers and some patients at these locations—including those that offer multilingual care—generally welcomed the idea of patient access to EHRs. Data from a recent survey demonstrate that interest in email access, online appointment scheduling, and electronic access to medical records and test results is equally high among insured and uninsured people.[11] Few of the community

Participating Organizations

California

- La Clínica de la Raza
- Lifelong Medical Care
- Redwood Community Health Coalition
- St. Joseph Health System

New York

- Institute for Family Health
- Queens Health Network
- Unite HERE!
- Urban Health Plan

Massachusetts

- East Boston Neighborhood Health Center
- Cambridge Health Alliance

Maryland

- Baltimore Medical System

District of Columbia

- District of Columbia Primary Care Association

health centers in this report have PHRs, although Cambridge Health Alliance and the Institute for Family Health recently launched them.

At community health centers, patients get information about their care via electronic and other means. They are receptive to the idea of connecting with their physicians online. However, communication among physicians is often disjointed, and patients themselves may end up as the information go-between for doctors. The fact that such patients already are at a striking disadvantage when it comes to health information exacerbates the challenges caused by fragmented care.

Information Gaps

One patient reported that he had left an appointment with a specialist not knowing if he had a medical problem or needed more care. Because his primary care doctor did not have electronic access to the specialist's progress notes, he was unclear about what to do next. This patient commented: "I want my doctors to meet me half way."

Patients grappling with gaps in information about their care may consult others in the community or simply drop the matter. The project team observed that neither physicians nor patients liked these alternatives and that during doctor visits, patients typically did not discuss such predicaments unless the physician asked.

A recent study of oncologists suggests that physicians often do not ask patients about their feelings when opportunities arise: Only 22 percent of participants said they followed up with prompts such as "Tell me more about that" after terminally ill patients expressed a concern.[12] This finding may be relevant in the safety-net setting as well, especially among patients who would like doctors to "meet me half way" through better interaction and by providing more information between visits.

A Missed Opportunity

Several of the community health centers in this survey presumed that patients would not have access to EHRs or other electronic tools. A number of them said this was not feasible because computers or the Internet were not accessible to patients. But the data in Table 2 indicate otherwise. An impact of this presumption, according to one EHR vendor, is that patient access to EHRs has not been included in implementation plans, even though other health care organizations offered patient access when they rolled out identical EHR systems. The consequence is a missed opportunity that could exacerbate disparities in HIT adoption and health care.

Observations and discussions with support staff revealed that the potential for HIT at community health centers is untapped. At a gathering hosted by the District of Columbia Primary Care Association, one clinic administrator, referring to an effort to make computers available in local clinics, said: "Whenever I walk into the waiting room, there is always someone using the computer" and "We'll never know if people will use this if we don't set it up." A primary care physician at Urban Health Plan, a community health center in The Bronx, New York, that serves a largely Latino population, said: "Almost of all of my patients use email. It would be great if my patients would email me. It would be so much more convenient because it is so hard to connect by phone."

At community health centers where there were no plans to deploy EHRs, some staff physicians who had previously used the technology expressed discomfort about this state of affairs and seemed more eager than others to adopt EHRs. A primary care physician working at La Clínica de La Raza in Oakland lamented that all seven health centers in California where she initially interviewed for jobs were strictly paper-based. Her experience suggests that lack of HIT in these settings could have a negative effect on health centers' efforts to recruit young physicians.

Economical Tools Available

Expensive technologies such as EHRs are not a prerequisite for other, more economical patient-centered tools, as some community health centers can attest. At the Whitman-Walker Clinic in Washington, D.C., which has implemented an EHR system, pharmacists use Web tools such as MedactionPlan.com to prepare medication regimens for print-out or electronic transmission to patients. In addition, MedactionPlan.com enables consumers to create medication lists for themselves and family members, and to receive medication reminders.

Patients who receive care at Queens Health Network in New York City can deliver personal health information to other providers by swiping their smart card through an inexpensive card reader. The readers, which plug into any personal computer, are located in emergency rooms in the city. Plans call for readers to be located in libraries as well.

One hurdle that may inhibit PCHIT adoption at community health centers is reimbursement. They receive payments on a per-visit basis, and no reimbursement if a patient accesses services online. Given that clinics are already squeezed financially, it may not be feasible for them to incorporate patient-centered technologies.

Health Plans

No health plans agreed to let the project team visit and assess their PCHIT. (Kaiser Permanente and other integrated delivery systems/group model health plans are discussed in the following section.) However, a few plan representatives and others did speak with the team about their PHR-related experiences as long as their comments remained anonymous.

Theoretically, health plans would benefit substantially from more efficient use of resources for delivering services and from greater participation of patients in their care. Moreover, they sit at a crossroads of data that could populate PHRs. As an executive at one large health plan put it: "Our role in the HIT space is leveraging [the HIT] infrastructure to be the conduit between clinical and administrative data; we can facilitate important data connections."

But conversations revealed many uncertainties about health plans' role in advancing this tool. What is the most productive way to harness data and engage consumers? Who should pay for and own PHRs? Is widespread adoption by patients even possible?

Who Should Pay for PHRs?

Some experts believe that payers and purchasers should bear the cost because they would be the primary beneficiaries. But they also caution that "the rationale for payers to provide PHRs is not mature" and that "they may be reluctant to do so."[13] Other researchers found that one large health plan's PHR reduced the number of patient visits and phone calls to doctor offices, producing savings that might make this tool more affordable.[14]

Consumers also may be reluctant to pay for PHRs. One study found that diabetics were lukewarm to the idea of paying a user fee for a diabetics-specific portal that would generate health care cost savings.[15]

Health plans realize that PHRs can greatly improve the management and cost-effectiveness of care for their chronically ill members. At one large plan, 30 percent to 40 percent of members who were actively managing their chronic conditions used the plan's PHR, compared to 10 percent to 15 percent of members generally.

Data Challenges

After a health plan creates a PHR infrastructure, there is still the challenge of converting disparate administrative data into meaningful information for patients. The information must be presented in a relevant context, tailored to patients' individual needs, and delivered in a timely fashion. Another big challenge is the lag time in administrative data processing, which can make it difficult to send targeted messages to patients at specific moments.

Some clinicians reported that health plans are unsure about the relative value of investing in PHRs in comparison to other quality and cost-management programs, such as disease management. Clinicians' understanding of the benefits of PHRs may be quite different from plans' strategic vision, which in turn may not be in tune with patients' perspective. Indeed, as Forrester Research concluded, health plan members "have not raced to adopt" PHRs.[16]

Physicians who contract with health plans are not reimbursed for tasks they perform outside of patient visits, such as email or phone communications. Reimbursing clinicians for such tasks could foster PCHIT in this setting. In New York, Group Health Inc. and HIP Health Plan of New York are experimenting with the "medical home" model in which primary care physicians not only care for patients, but also coordinate services with other health care professionals on patients' behalf and are reimbursed accordingly. This reimbursement model could support patient access to a variety of electronic technologies, including email, appointment scheduling, and clinical decision-support tools.[17]

Integrated Delivery Systems/Group Model Plans

Kaiser Permanente, which serves about one-fifth of all Californians, and other integrated delivery systems like it are in many ways a PCHIT benchmark. They have the highest EHR and PHR penetration in health care. About 20 percent of enrollees at Kaiser, or more than 2 million members, use its PHR, relaunched in November 2007 as My Health Manager.[18]

Participating Organizations

California

■ Kaiser Permanente/Oakland Medical Center

Washington, D.C.

■ Kaiser Permanente/West End Medical Center

■ U.S. Department of Veterans Affairs Medical Center

Within the last six years, the number of adult enrollees at Seattle-based Group Health Cooperative who have taken advantage of access to a PHR through the MyGroupHealth Web site has grown to 36 percent.[19]

My HealtheVet

The U.S. Department of Veterans Affairs actively promotes My HealtheVet, a portal for benefits, services, and access to some health records. In the future, veterans will be able to view their appointment schedule, copayment balances, portions of their EHR, and more. Although patient adoption has not reached the levels seen at Kaiser and Group Health Cooperative, the VA system is innovative because of its potentially high transparency. Pilot sites allow patients full access to their entire medical record through My HealtheVet, including physicians' progress notes.

The VA has not integrated patient-centered tools into its health care system as thoroughly as Kaiser and Group Health Cooperative have. Physicians do not interact with My HealtheVet in their clinical work, and, outside the pilot sites, My HealtheVet still offers much less access to EHRs and fewer direct links to health content explaining a patient's personal data. But efforts are under way to enhance connectivity. For example, surveys of My HealtheVet users who participated in pilot testing and of clinicians who provided services to them will yield, along with focus groups and interviews, insight on ways to make the portal more responsive to veterans' needs.

Leadership Role for Big Providers

The HIT innovations and refinements at Kaiser, Group Health Cooperative, and the VA are crucial because, as large integrated delivery systems, their progress may inspire others to follow. A big challenge these three systems face is scaling their technologies down to the level of small medical practices, where the vast majority of health care is delivered. On the

other hand, they may be able to draw upon regional innovations. Kaiser Permanente Colorado Region, for example, has pioneered electronic messaging between physicians and teens, an advance that other Kaiser regions could find useful.[20]

Additional challenges will be transferring—both internally and externally—the knowledge these providers have gained about technology, workflow, and attitudes regarding PCHIT, and the risk that pressures for consistent service to large enrollee populations will inhibit innovation. Other health care providers might benefit if large integrated delivery systems were to assemble and publicly release a PHR implementation "toolkit"—a repository of knowledge about everything from identity authentication procedures to strategies for promoting adoption of PCHIT by patients and staff.

Multispecialty Group Practices

Although the multispecialty groups cited in this report are structurally different, the key PCHIT issue for all of them is PHRs.

The PHR portal at Harvard Vanguard Medical Associates, a private group based in Boston, is MyHealth Online, a feature of the commercial EHR system that Harvard Vanguard implemented several years ago. Partners HealthCare—a large, academic, integrated delivery system with many outpatient practices in the Boston area—developed its own portal, Patient Gateway.

Participating Organizations

California
- John Muir Health
- Sharp HealthCare

Boston, MA
- Harvard Vanguard Medical Associates/Atrius Health
- Partners HealthCare

Mixed Results

At the multispecialty group practices where patients can access their personal clinical information, results have been mixed. Many clinicians expressed enthusiasm for such access, and some practices actively encourage patients to take advantage of it—for example, by distributing brochures at nursing stations. At Partners HealthCare, clinic managers work with medical staff to encourage the use of Patient Gateway—a secure electronic link that patients can use to communicate with their doctor about appointments, medications, and more—by posting announcements in prominent places about new services and by promoting access opportunities.

However, some Partners physicians communicate with patients by email outside of Patient Gateway, and clinicians there and at Harvard Vanguard did not consistently explain to patients the benefits of using MyHealth Online and Patient Gateway. In addition, accountability for patient engagement varies: Partners assigns responsibility for the success of its PHR to a "physician leader," while there is no such accountability at Harvard Vanguard.

At other health care providers in the Boston area, most notably Beth Israel Deaconess Medical Center, the PHR adoption curve among patients has been relatively flat, data suggest, even though patients do not have to pay any additional fees for PHR-related services.[21]

Interviews revealed that at both Harvard Vanguard and Partners HealthCare, HIT competes with multiple clinical initiatives for priority status. This may hinder a coordinated approach to fostering PHR adoption. Moreover, their payers apparently do not make a significant effort to promote the tools, and the two practices expressed uncertainty about the best way to do that in the absence of a "toolkit." Clinicians and administrators said their organizations might benefit from strategies such as contests, advertising, and integrating PHRs into clinical operations.

Small Physician Practices

Ninety-three percent of physician practices have fewer than six doctors, and 96 percent have fewer than ten. Less than 10 percent of practices in this population have fully implemented EHRs, although up to 25 percent have partially implemented them.[22] In California, 14 percent of physician practices have fully implemented EHRs, according to a recent survey.[23]

Participating Organizations

California

- Blackhawk Medical Center

Washington, D.C.

- Center for Practice Innovation/American College of Physicians

Blackhawk Medical Center, a three-physician practice in Danville, California, illustrates the challenges small practices face. As part of the John Muir Physician Network, an independent practice association that promotes HIT adoption among its affiliates, Blackhawk is in the process of fully converting to an EHR system, which the practice will tie into the network's patient portal. Despite Blackhawk's highly committed physicians and office staff, the conversion has proved to be time-consuming.

EHR Pressures

Small practices cope with several pressures when they implement EHRs. One is showing a return on investment over the long term. A second is justifying the upheaval caused by transitioning from paper to electronic records. Indeed, on the project team's first visit to Blackhawk, its lead physician apologized for the medical charts on his desk that he was reviewing in preparation for scanning. The transition was still under way when the team visited again three months later. Converting to digital format involves an intensity of effort that can delay HIT initiatives to give patients access to health information.

A third pressure is the competition from local group-model practices, where HIT adoption tends to be higher and there is more financial, technical, and legal support. A recently published survey found that the biggest barrier to EHR use among California physicians is the cost of purchase, followed by the difficulty and expense of implementation.[24]

The Center for Practice Innovation (CPI), an amalgam of more than 100 small practices under the aegis of the American College of Physicians, is fostering PCHIT adoption. CPI's work demonstrates that small practices have the ability to experiment with HIT because, unlike other practices that are part of health care systems, they retain control of workflow and other factors, which makes them more nimble. For example, several use subscription-based messaging—a relatively low-cost option—and enable patients to enter personal data into the practice's information system.[25]

Ideal Medical Home (www.idealmedicalhome. org), a confederation of health care organizations and individuals, promotes patient-centered, financially viable information technologies in physician practices. At IdealMedicalPractices. org, members share new technologies—including patient-assessment and feedback tools—and best practices. The goal is to improve clinical operations at minimal cost.

The absence of active support for PCHIT applications in small practices may conflict with patients' enthusiasm for them. An informal poll of patients by a physician at Blackhawk Medical Center showed that many were interested in doctor-patient messaging. This mirrors the findings of physicians at a small practice in Tennessee who discovered that among their patients who had Internet access, 78 percent were interested in electronically contacting, or receiving health information from, their doctor's office.[26]

IV. Market Variations in PCHIT

REGIONAL QUALITY-IMPROVEMENT AND HIT initiatives, interventions by local or state government, and the competitive dynamics of, and history of health care delivery in, a particular market affect efforts to advance PCHIT. This chapter presents a summary of key factors—many of them related to the broader HIT landscape—that have shaped patient-centered technologies in California, Massachusetts, and New York.

California

Multispecialty group practices and integrated delivery systems are among the leading EHR and PHR innovators in California. The Palo Alto Medical Foundation, for example, was one of the first medical groups nationwide to give patients access to a PHR offering a wide range of personal clinical information and links to targeted health content on the Web. Other large medical groups also have implemented PHRs or other PCHIT tools, but they remain a minority.[27]

Some health plans have actively advanced PCHIT, among them Kaiser Permanente. Its members can access their clinical health records and all lab results, securely communicate with clinicians, review and renew prescriptions, request appointments, and link to educational content and self-management tools from their personal health information.

However, there are still big HIT gaps in California. Among federally qualified community health centers and other safety-net providers, fewer than 5 percent of more than 500 clinics use electronic systems to manage clinical information.[28] Efforts by state and local government to drive HIT adoption among safety-net providers have been limited.

Grant Funding for HIT

To fill this gap, The California Endowment launched the Community Clinics Initiative (CCI) in 1999. CCI has provided $41 million to boost the information management capacity at 163 clinics and 15 regional associations.[29]

Several CCI grants in the last several years have targeted HIT investment, although little of that effort has focused on patient-centered applications. The CCI (now in partnership with the Tides Center, a nonprofit fiscal sponsor), the California HealthCare Foundation, and the Blue Shield of California Foundation are sponsoring a project called California Network Electronic Health Record Adoption to foster EHRs at safety-net providers in the state. This venture will build EHR support hubs offering technology, technical support, vendor management, and other services that community clinics often cannot afford.

As of 2003, there were EHRs at 5 percent of medical clinics and 3 percent of dental clinics. About 23 percent and 9 percent of these providers, respectively, had established committees to plan EHR implementation.[30]

Massachusetts

Surveys suggest that the largest health plans in the Boston area—Harvard Pilgrim Health Care, Tufts Health Plan, and Blue Cross and Blue Shield of Massachusetts—are the highest-quality plans in the country. New England's decade-long focus on comparative performance measurement through a variety of regional quality initiatives has created a competitive market for quality rankings. Of the top 20 health plans nationwide, 15 are in New England.[31]

This quality focus and the major impact of Boston's large teaching institutions have spurred considerable HIT adoption in large physician practices. Small practices are increasingly getting wired due to pressure from larger providers. For example, the physician network Partners Community Health Care Inc. in the Boston area recently mandated that all of its small and medium-size practices connect to the network's EHR by January 1, 2009, or they will be dropped from the network.[32]

According to one estimate, 29 percent of physician practices in Massachusetts have adopted EHRs. Among these practices, 84 percent can document patient visits via their EHR system, but only 47 percent can order laboratory tests by computer and only 45 percent can prescribe medications electronically.[33]

Patient Usage Falls Short

Based on the PCHIT Initiative's observations and anecdotal information, many consumers in Massachusetts have electronic access to their personal health data, but few appear to be taking advantage of it. Many of Boston's large providers have launched PHRs tied to their EHRs, yet at practices the project team visited, less than 10 percent of the eligible patient population uses them.

The first and most active PHR—PatientSite, at CareGroup Healthcare System in Boston—has about 35,000 active consumer users, a recent study reported.[34] Penetration is difficult to gauge in this case because the study did not cite how many consumers were eligible to use PatientSite.

In December 2007, Gov. Deval Patrick announced a new "compact" on health, with the goal of devising a comprehensive approach to tackling the state's entrenched health care problems.[35] It is still unclear if patient-centered technologies will be a significant part of this initiative.

New York

The state and city of New York have assumed leadership roles in HIT adoption—perhaps a bigger role than in any other state. But few policymakers have specifically called for patient access to and engagement in health information technologies.

In 2004, state legislators approved the Health Care Efficiency and Affordability Law for New Yorkers Capital Grant Program—often referred to as HEAL

NY—that involves investing up to $1 billion over four years. Among the program's primary objectives is investing in HIT and health information exchange.

A main component in phase five of the program, regarding a future HIT infrastructure, is designing a system in which medical information "follows the consumer" so consumers "are at the center of their care."[36] This effort is aligned with the consumer-centric approach promoted by the American Health Information Community, a federal advisory body that makes HIT recommendations to the U.S. Department of Health & Human Services.

The Rise of RHIOs

With state and federal funding as a stimulus, many regional health information organizations (RHIOs) have formed in the New York City area and in communities statewide. RHIOs typically provide one or both of two core services: the governance body and policies for facilitating information exchange among participating entities, and the technical infrastructure for automated exchange.

The New York City Department of Health has launched the Primary Care Information Project, a particular emphasis of which is to help wire the city's federally qualified health centers and other safety-net providers. A main goal of the project is to improve chronic care self-management, so it tries to advance the patient-centered applications in HIT.

HIT at Community Health Centers

Some federally qualified community health centers—such as those that are part of the Institute for Family Health, whose mission is to improve access to primary care, especially for the medically underserved—already have fully functional EHRs. But most are still in the preliminary stages of EHR and PHR development. In early 2008, the institute was to begin planning for integrating PHRs into fully functional EHR systems at community health centers.

To spur HIT adoption by private medical groups, the state has deployed a private, non-profit corporation called IPRO to provide free assistance through the national Doctor Office Quality Information Technology Project. IPRO, which assesses and tries to improve health care services through innovative technologies and methods, helps 350 adult primary care practices select, implement, and optimize HIT systems. Although consumer access to personal health information is not an explicit objective of the project, its efforts may ultimately improve such access.

The various HIT endeavors in New York state prompted public and private partners to form the New York eHealth Collaborative, which builds consensus on the state's HIT-related policy priorities and collaborates on implementing technologies. The collaborative aims to identify and overcome barriers to widespread adoption of HIT and thereby enhance consumer engagement in maintaining and managing their health.

Conclusion

An increasing number of health care providers are adopting health information technologies that place patients at the center of care. However, a number of technical, strategic, and financial hurdles are stifling further progress. Until these hurdles can be overcome, the full potential of these technologies to engage patients in their care will remain elusive.

Endnotes

1. "Many consumers want major changes in health care design, delivery." Deloitte: 2008 (www.deloitte.com/dtt/article/0,1002,cid%253D192717,00.html).

2. According to the National Alliance for Health Information Technology, PHRs are "an electronic record of health-related information on an individual that conforms to nationally recognized interoperability standards and that can be drawn from multiple sources while being managed, shared, and controlled by the individual."

3. Kessels, R.P.C. "Patients' memory for medical information." *Journal of the Royal Society of Medicine* 2003;96(5): 219–222.

4. The nonprofit Center for Information Therapy (www.ixcenter.org) advances the science and practice of "information therapy"—that is, making evidence-based health information available in a timely fashion to help meet the specific needs of individuals and to support sound decision-making.

5. Estabrook, L., Witt, E., and Rainie, L. *Information Searches That Solve Problems.* Pew Internet & American Life Project: December 30, 2007 (www.pewinternet.org/pdfs/Pew_UI_LibrariesReport.pdf).

6. A variety of information delivery strategies are profiled in Seidman, J., and Barish, D. *Health Information Technology: Innovative Applications for Medicaid.* Center on Children and Families, Georgetown University Health Policy Institute: December 2007.

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