



CALIFORNIA  
HEALTHCARE  
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## **Participatory Health: Online and Mobile Tools Help Chronically Ill Manage Their Care**

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# **Participatory Health: Online and Mobile Tools Help Chronically Ill Manage Their Care**

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*by*

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## About the Author

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## 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).

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# I. Introduction

*“In our country, patients are the most under-utilized resource, and they have the most at stake. They want to be involved and they can be involved. Their participation will lead to better medical outcomes at lower costs with dramatically higher patient/customer satisfaction.”*

— CHARLES SAFRAN, M.D., PRESIDENT  
AMERICAN MEDICAL INFORMATICS ASSOCIATION  
TESTIMONY BEFORE THE SUBCOMMITTEE  
ON HEALTH OF THE HOUSE COMMITTEE  
ON WAYS AND MEANS, JUNE 17, 2004

OF THE \$2.2 TRILLION IN TOTAL U.S. HEALTH CARE spending in 2007, 75 percent (\$1.7 trillion) went to care for patients with chronic conditions.<sup>1</sup> Yet despite this staggering expenditure, there are pervasive problems with the care received by people with chronic illness or condition. According to the National Council on Aging, a third of all chronically ill people say they leave a doctor’s office or hospital feeling confused about what they should do to continue their care; 44 percent of people (aged 44 and older) with chronic conditions want their doctors to spend more time talking with them; and 57 percent report that their health care providers have not asked whether they have help to manage their conditions at home.<sup>2</sup> These patient perceptions are borne out by their poor record regarding continuing care: The disturbing results of a study published in 2003 indicated that chronically ill patients receive recommended preventive care only 56 percent of the time.<sup>3</sup>

A major contributing factor in this serious chronic care shortfall is the fragmented nature of health care delivery in America. The health care system’s incentives are not well aligned for the management of chronic conditions or of a person’s overall health, instead forcing people to seek care episodically. And within this episodic structure, transitions from one care-giving site to the next tend to be poor. Moreover, patients themselves often contribute to the patchiness of the care continuum, many only inconsistently engaged in managing their own health. A significant manifestation of this problem is patients’ failure to uniformly follow and abide by their doctors’ medical advice and instructions.

Health care delivery in the United States has been further hampered by a limited amount of digital health data and the exchange it facilitates among providers, patients, and caregivers. The lack of data liquidity often hinders people, providers, and payers alike from understanding what works and what does not, and from delivering optimal care at the right time.

In particular, the lack of electronic health records in physician practice has made it difficult for providers to track patients over time, and what is tracked tends to be episodic. Most patients spend only

a few minutes with clinicians throughout the year. But what happens the rest of the time, especially for patients with chronic conditions, who could benefit greatly from frequent, near-continuous monitoring?

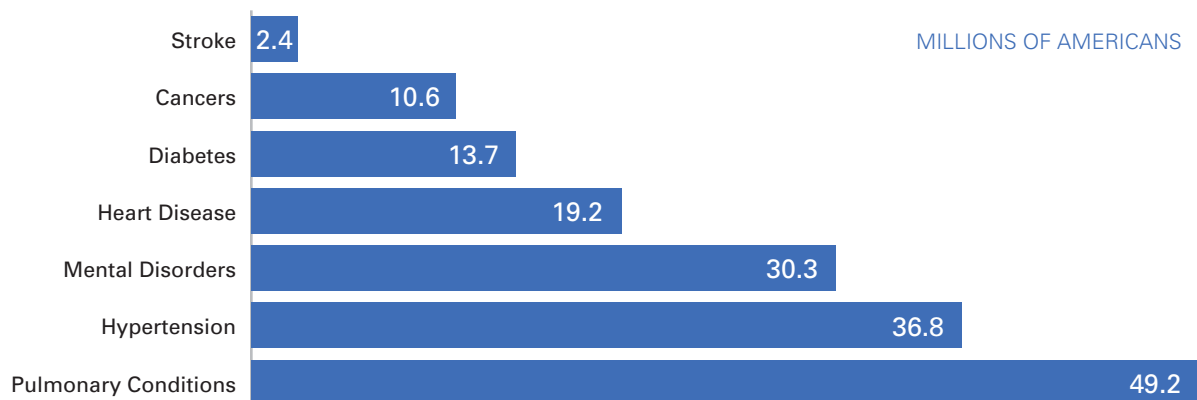
That “rest of the time” is the opportunity gap that new tools—via online and mobile platforms—can bridge. This paper describes some of the platforms and applications that are emerging to support patients in managing their health care not only at

home but also almost anywhere else outside their clinician’s office. Sources include extensive interviews by the author with stakeholders in the field, whose experiences and resulting views are presented throughout the report. The paper focuses particularly on the development of tools that can help individuals manage chronic conditions. A concluding section emphasizes some challenges and barriers to the successful implementation of such tools.

### The Rising Toll of Chronic Illness

The definition of a “chronic condition” is somewhat elastic—the Improving Chronic Illness Care organization describes it as “any condition that requires ongoing adjustments by the affected person and interactions with the health care system”<sup>4</sup>—but it is estimated that 133 million people, or almost half of all Americans, live with a chronic condition.<sup>5</sup> That number is projected to increase by more than one percent per year by 2030, resulting in an estimated chronically ill population of 171 million.<sup>6</sup> The most prevalent chronic conditions in the United States include asthma, depression, diabetes, hypertension, and congestive heart failure, and almost half of all people with chronic illness have multiple conditions.<sup>7</sup> According to the Centers for Disease Control, chronic diseases contribute to 70 percent of all deaths nationally.<sup>8</sup>

**Figure 1. The Prevalence of Chronic Diseases in the United States**



Source: MEPS; *An Unhealthy America: The Economic Burden of Chronic Disease—Charting a New Course to Save Lives and Increase Productivity and Economic Growth*, Milken Institute, October 2007.

Chronic disease is a major contributor to rising health care spending. Of each dollar spent on health care in the United States, over 75 percent (\$1.7 trillion) goes toward treating chronic illness. The greater the number of chronic conditions a person has, the higher the health spending on their care.<sup>9</sup>

## II. Participatory Health: The Role of Self-Management in Chronic Care

*“[There is] a vicious cycle in which uncoordinated care contributes to further patient suffering—both for lack of an integrated approach at the provider level and from patients’ own lack of knowledge and skills to help themselves.”*

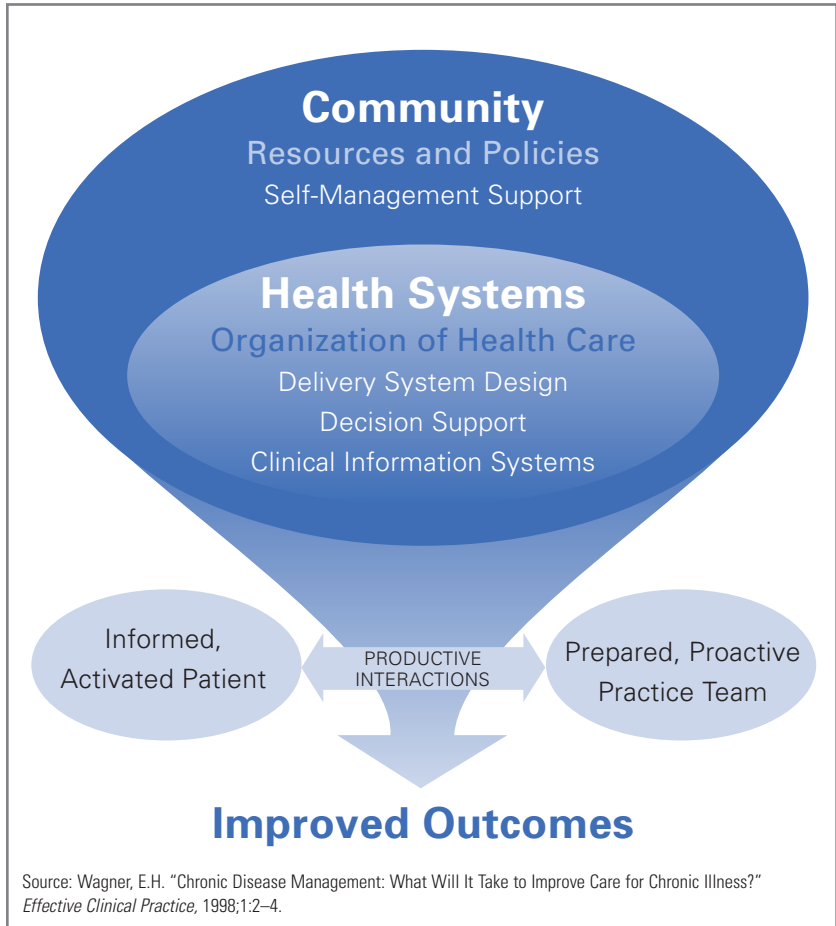
— DR. JAMES SCHIBANOFF, EDITOR-IN-CHIEF  
MILLIMAN CARE GUIDELINES<sup>10</sup>

EFFECTIVELY DEALING WITH CHRONIC CARE REQUIRES A team approach, bringing together clinicians, providers, caregivers, and most notably, patients. This section deals with the significance of patient self-management within the continuum of chronic care.

### The Chronic Care Model

For decades, researchers have studied methods for managing chronic care. A synthesis of much of this research can be found in the Chronic Care Model (see Figure 2), published in 1998 by the MacColl Institute for Healthcare Innovation and the Robert Wood Johnson Foundation.

**Figure 2. The Chronic Care Model**



As shown in Figure 2, self-management support is an essential element in the model, emphasizing the patient's central role in managing personal health in the context of and collaboration with other community resources as well as formal health systems.<sup>11</sup>

### **The Ideal Connection: Continuous, Tailored, Actionable**

Patient-recorded observations of daily living (ODLs) include information on personal activities and experiences such as diet, exercise, mood, sleep, and adherence to medication regimens. A patient who conscientiously records personal ODL data can create a meaningful profile of their own health that can lead to productive exchanges with health care providers. As the Project Health Design initiative on personal health records (PHRs) sums up the potential for these interactions, "collecting ODL data through PHRs gives both clinicians and patients insights that are unattainable in records that capture information only from clinical encounters."<sup>12</sup>

An illustrative example is blood pressure monitoring. When a hypertensive patient's blood pressure is taken in a physician's exam room, the patient might exhibit higher blood pressure than would be the case outside the clinical setting (due to the patient's anxiety during the examination). In contrast, when a patient records blood pressure on a regular basis away from the clinician's office, a more realistic profile of the patient's hypertension status may emerge.

Over the past decade, a growing portfolio of tools has been developed to support people in gaining confidence and competence in self-managing their chronic care. An ideal system for chronic self-care management, making use of such tools, would incorporate the following features:

- Support for the full range of a patient's health activities, including self-defined regimens;
- Regular monitoring of patient status;
- Ongoing adjustment of health regimen by patient and/or providers based on patient status (through connecting with providers and health coaches);
- Interpretation of patient data in relation to individual treatment goals;
- Support for ongoing learning by patient and providers about patient's health;
- Timely communication to the patient of tailored and actionable recommendations and advice; and
- Repetition of this cycle at appropriate intervals.

Applications that provide only some of these features will deliver less effective health outcomes than those that integrate the entire complement. In particular, systems without feedback mechanisms linking the patient back to a clinician or health coach may be effective in improving interim outcomes but are not likely to achieve longer-term benefits. For example, a system that delivers medication reminders alone, while useful for bolstering medication adherence, is unable on its own to adjust medication dosage based on changing patient measurements (e.g., blood pressure).



### Patients Seek Ongoing Conversations with Their Doctors

Beyond merely searching for health information is patient “engagement” with such information and its sources, both online and elsewhere. The Edelman Health Engagement Barometer, launched in October 2008, identified about 22 percent of American adults as “health info-entia” —that is, people who most actively seek health information and discourse. What drives these people toward those parties with whom they seek health engagement is trust, authenticity, and satisfaction. And among all sources of information and contact, health information seekers expect “conversations with my doctor” to be the most important nexus for health engagement (see Figure 3).<sup>13</sup>

**Figure 3. Patients See Conversations with MDs as Becoming Most Important**



Source: Edelman Health Engagement Barometer, October 2008, [www.engageinhealth.com/docs/edel\\_healthbarometer\\_r13c.pdf](http://www.engageinhealth.com/docs/edel_healthbarometer_r13c.pdf).

# III. Platforms for Health Care Connecting: The Internet, Broadband, and Wireless

*“Mobile could be a game-changer.  
But only for those who  
get in the game.”*

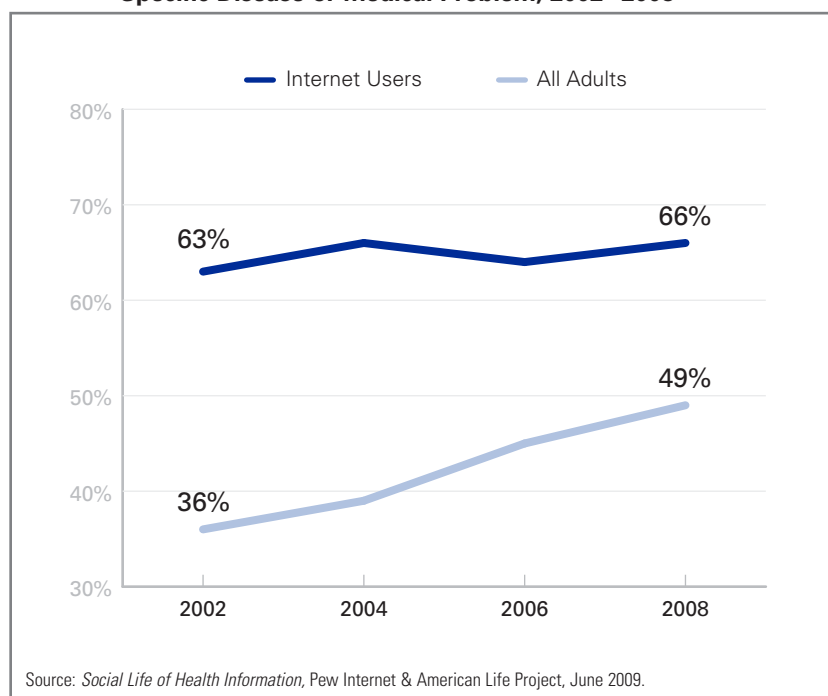
— SUSANNAH FOX  
PEW INTERNET & AMERICAN LIFE PROJECT

AS DISCUSSED ABOVE, A CRITICAL SUCCESS factor for self-care management in chronic care is frequent, regular monitoring. Consumers’ Internet connectivity in general, and their use of online health information in particular, significantly support such monitoring. Both of these phenomena have now become more commonplace among the general public in the United States.

## The Internet in Health

The number of eHealth consumers—people who search for health information on the Internet—has more than doubled since 2002, reaching 146 million American adults in 2008.<sup>14</sup> Further confirming that eHealth behavior has gone mainstream, data from the Pew Internet & American Life Project found that 66 percent of Internet users (49 percent of all adults) seek information online regarding specific diseases and conditions.<sup>15</sup>

**Figure 4. Those Who Have Looked Online for Information About a Specific Disease or Medical Problem, 2002–2008**



Furthermore, the Pew Internet project found that people with chronic health conditions tend to use online health information more often than other adults. For example, 51 percent of people with a chronic condition seek information online regarding prescription and over-the-counter drugs, compared with 35 percent of people who have no chronic conditions. Similarly, 42 percent of people with a chronic condition look for information online regarding alternative treatments, versus 25 percent of people with no chronic illness.

### Broadband and Mobile: Growing Importance for Health Information

The increasing use of broadband and wireless telecommunications both improves and expands online information seeking. Wide bandwidth, which has reached 63 percent of Internet connectivity in 2009, is faster and keeps people online longer.<sup>16</sup>

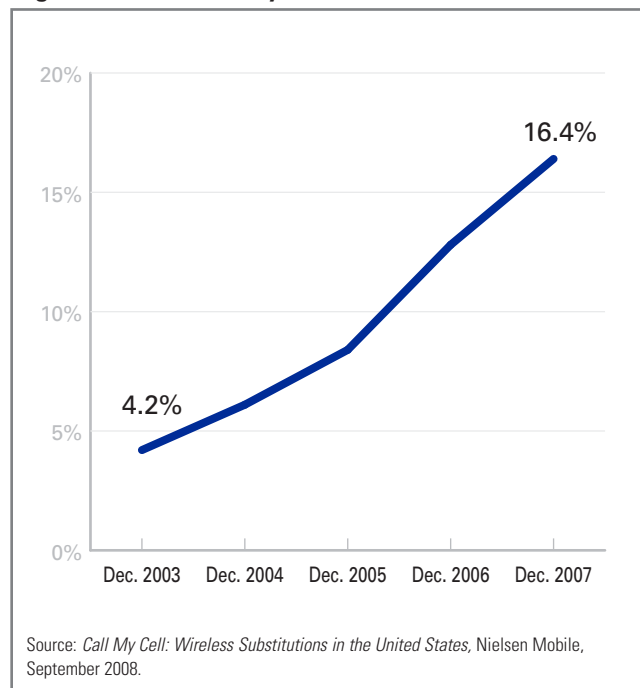
This strong uptake in broadband bodes well for online health information because such information tends to be relatively complex, requiring significant user time and attention, which broadband makes far easier. Not surprisingly, then, the Pew project found that people with broadband are more likely (88 percent) to search online for health information than are people who have slower Internet connections (72 percent).<sup>17</sup>

The Pew project found an even stronger correlation between mobile platforms and the use of the Internet to seek health information: 89 percent of people with wireless Internet connections seek health information online, compared to only 40 percent of consumers who use only a wired Internet connection. A difference may also be found in the quality of the interactions: According to Susannah Fox in *The Social Life of Health Information*, “E-patients with mobile access to the Internet are more likely than those who have tethered access to contribute their

comments and reviews to the online conversation.” This behavior was also identified in *The Mobile Difference*, where the Pew project reported that wireless access is associated with deeper engagement and participation in online communications.<sup>18</sup>

The significance of mobile communications platforms for health information increases with the growing number of Americans who only have wireless phone connections, with no landlines. By June 2008, 17 percent of American households (about 20 million) had no landline phones, relying entirely on wireless telephone connections.<sup>19</sup>

**Figure 5. Wireless-Only Households in U.S., 2003–07**



Most likely not to have a landline are people with lower incomes (46 percent of wireless-only households have annual earnings of \$50,000 or less), younger people (64 percent between 18 and 34 years old), and those with smaller households (one or two people). For all these wireless-only

people, mHealth—the term for seeking and exchanging health information online via a mobile platform—“levels the access to health care and health information,” according to Claudia Tessier, president of the mHealth Initiative, a Massachusetts-based, nonprofit that supports the integration of health care applications with cell phones and other mobile devices. “Not everybody has a PC, but the adoption of mobile phones is off the map. Potentially, anyone can ‘do’ mHealth from their wireless phone.”<sup>20</sup>

Another example is the Pill Phone application, introduced by Verizon Wireless and other carriers in 2008, which allows people to look up drug interactions over their phone, as well as schedule pill reminders.

O’Reilly Media notes that medical applications are the third-fastest-growing category of applications available at Apple’s iTunes Store, after games and travel. Starting with PHR-related applications, such as health diaries for recording ODLs such as weight, daily calorie intake, and sleep habits, measures have begun to wirelessly move automated clinical readings and observations into electronic health records. iPhones, too, have seen an explosion in health applications developed expressly for it. Since the first health application was sold in 2008, the iPhone AppStore has become a clearinghouse for mobile health applications. As of June 2009, there were over 500 medical applications available at the iTunes store, thus far focused more on health professionals than consumers, though that is changing.

While there is promise for the role of mHealth, Susannah Fox of the Pew Internet & American Life Project cautions that “there are still pockets of people who lack access to the basic technology, lack the skills required to participate, lack interest in trying something new, or who may lack the sense that they are welcome.” Thus, she warns, while 61 percent of American adults are part of what the Pew project terms the “stationary media majority,” with broadband and a cell phone, there is not yet “full patient participation” in eHealth. Her key observation is that, “Mobile could be a game-changer. But only for those who get in the game.”<sup>21</sup>

## IV. Connecting Chronic Care Patients: eHealth Self-Management Applications

*“Doing remote monitoring is a great idea, but in and of itself it’s not enough. Feeding back to the patient immediately is also necessary. Tools that just absorb data and present it to a back-end, like home monitoring, don’t close the loop.”*

— MARK BLATT, M.D.  
DEVELOPER OF INTEL’S HEALTH GUIDE

THIS SECTION OF THIS REPORT PROVIDES DETAILS OF selected self-management applications and pilots of particular relevance to patients with chronic conditions. It is not an exhaustive directory of such applications but is intended instead to provide a sense of the breadth of self-care applications emerging in the chronic care market. The applications discussed are grouped as follows:

- Health video games;
- Medication management;
- The “other” medical home;
- Diabetes care;
- Weight management; and
- Wellness.

### Health Video Games

Adults are a fast-growing segment of the video game market, with more than half of U.S. adults playing these games, and about one in five playing every day or almost every day. More than four out of five U.S. adults ages 18 to 29 are video gamers, although only one in four people ages 65 and older uses video games at all.<sup>22</sup>

There is growing evidence of the clinical effectiveness of health e-games. Clinical trials funded by the Robert Wood Johnson Foundation, the National Institutes of Health, and others are gathering data on the efficacy of health e-games for managing health conditions including cancer, asthma, diabetes, and cystic fibrosis, among others. The Robert Wood Johnson Pioneer Portfolio’s Health Games Research project tracks these developments ([www.healthgamesresearch.org](http://www.healthgamesresearch.org)).

One of the first clinical trials testing the effectiveness of health video games involved Packy & Marlon, an interactive adventure video game that uses experiential learning to improve self-management of diabetic children and adolescents. Keeping their game character’s blood glucose within the normal range, through appropriate insulin

and food, helps players win the game. This six-month study indicated that a well-designed action-adventure video game can significantly improve health learning, skill development, and behavior change.<sup>23</sup>

Another clinical trial focused on HopeLab's video game, Re-Mission, which was developed to enhance adherence to self-administered medication regimens among adolescents and young adults with malignancies, including acute leukemia, lymphoma, and soft-tissue sarcoma. In this trial, the video game intervention significantly improved treatment adherence and indicators of cancer-related self-efficacy and knowledge in young patients undergoing cancer therapy.<sup>24</sup>

As of June 2009, there were over 600 health e-games (online and PC-based), according to Douglas Goldstein, founder of iConecto, a digital media company, and of Gaming4Health, a health e-games portal. These health e-games cover a wide range of subjects, from wellness to at-risk acute chronic conditions and even catastrophic care. The games were a \$6.7 billion market in 2007 according to *Health eGames Market Report—How Video Games, Social Media and Virtual Worlds Will Revolutionize Health*, co-authored by Goldstein.<sup>25</sup> The report describes four consumer categories: exercise; brain fitness; healthy behaviors (e.g., nutrition); and condition management. The largest segments are exercise games (sometimes called “exer-games”) and brain fitness. The condition management segment, which focuses on managing chronic disease, is smaller but shows significant activity.

A growing number of exer-games and brain fitness games are being produced by major video game publishers such as Nintendo (Wii Sports and WiiFit), Namco (Active Life Outdoor Life), and Electronic Arts (Active Sports). Other health e-games are sponsored by government agencies and non-profits, such as Nanoswarm and Escape from Diab,

video games targeted to children and young adults with diabetes, that were funded with a \$7 million grant from the National Institute of Diabetes and Digestive and Kidney Diseases of the National Institutes of Health. With regard to determining the efficacy of these games, the Robert Wood Johnson Foundation's Pioneer Portfolio awards grants focused on expanding the current evidence base regarding ehealth video games, through the Foundation's \$8.25 million Health Games Research program. (See “Health e-Games: A View of the Future,” on the following page.)

It should be noted that health e-games have generally not been adopted for use in the context of the health care relationship—with doctors, hospitals,

#### **Health e-Games: A View of the Future**

Douglas Goldstein, of iConnecto and Games4Health, has given extensive consideration to the future of e-gaming. Goldstein expects that changes in consumer video game modes, especially multi-player online and casual gaming, can create engaging environments for supporting and managing fitness, health, and medical care. He also notes that there are opportunities to “change health behaviors in areas such as COPD in women, breast cancer awareness, and heart disease and many other conditions, through the power of entertainment and play in the form of health e-games.”

“The power of health e-gaming isn't just about the game itself, but about engaging people with media that they love and have spent billions of dollars of their own money to purchase. Consumers are already spending millions on health e-gaming: Why not follow the customer?” Goldstein asks.

“The fact that the health e-gaming market, which is funded by consumers themselves, is bigger than the total disease management market should give us some pause to reflect on the potential for consumer engagement in games to enhance health,” Goldstein notes.

and health plans. Nonetheless, a rapidly growing citizen base is engaging with health e-games, most notably the phenomenon of the Nintendo Wii Fit.

## Medication Management

Medication noncompliance has been called the Achilles heel of modern health care. As former Surgeon General Everett Koop is often quoted as saying, “Drugs don’t work in people who don’t take them.”

As much as 60 percent of patients do not adhere to their prescribed medication regimens. According to George Van Antwerp of Silverlink, more than half of people become non-adherent with their maintenance medications within the first 12 months of therapy. Numerous factors drive noncompliance, including forgetfulness, complex instructions, and medication changes, as well as patients’ perceptions of immediate health benefits and side effects.<sup>26</sup> In addition, as health consumers’ out-of-pocket costs increase, many people abandon prescriptions they cannot afford. Finally, difficulty integrating a drug regimen into daily life, particularly with a complex regimen, can compromise adherence.

Developers of applications to address medication noncompliance have gone well beyond the plastic pill box with dosing compartments. Several stand-alone applications, PC- and phone-based, are already on the market. Among the more sophisticated offerings is EMMA, developed by INRange Systems. EMMA links the health consumer’s home with the pharmacy and prescribing physician. The participating pharmacist packages the prescribed medication in a blister pack that is delivered to the patient or caregiver. Instructions for dosing are transmitted via wireless broadband connection to the EMMA Medication Delivery Unit (MDU) in the patient’s home. The MDU is enabled through wireless, two-way, Web-based communications and

software that allows a physician, pharmacist, or other licensed clinician to remotely manage prescriptions stored and released by the patient-operated MDU. The patient’s blister pack is loaded into the MDU, which automatically identifies the medication. When it is time for the patient to take the medication, the MDU alerts the patient audibly and visually.

Wireless communications are also used in a “smart phone” application, eMedMobile, the development of which was funded by the National Institute on Aging and the National Cancer Institute. The phone works with “smart labels” on prescription medication bottles that contain data about the drug. The phone sends alerts to caregivers when a medication is skipped.

HealthHonors is a tool that attempts to motivate patients to continue their drug or wellness regimens using a points-reward system. Patients participate through one of three modes: a Web interface; an interactive phone voice-recognition system; or, a mobile application. Points are accumulated in accounts and can be used on health-related rewards such as copayment discounts, fitness equipment, and gift certificates.

TheCarrot.com, which works with the iPhone or through a Web portal, was developed with pharmacists to help patients manage medication compliance. It has now been expanded to provide tools for tracking a wide range of topics, including medications, nutrition, exercise, energy levels, meditation, moods, sexual activity, ovulation, menstrual cycle, smoking, and television use, among others, all using a calendar format.



## The Other Medical Home

“One could argue that the type of care a patient gets in the doctor’s office or clinic setting far exceeds the need of a common problem. Physicians are distracted by acute issues so we manage on an acute, not chronic, basis. We more often treat the most urgent complaint using the greatest mindshare... and we overlook chronic health management,” observed Dr. Mark Blatt, a family doctor by training whose work with Intel on home health research has resulted in development of the Health Guide.

The premise of Intel’s Health Guide application, and of other tools that focus on remote monitoring, is that the health citizen’s home can be a hub of virtual health care that includes the physician, working remotely. In this regard, Dr. Blatt believes that “the simplest virtual care instrument has been the telephone.” Research has shown that using remote monitoring devices in a patient’s home, coupled with follow-up phone contact, can lower the cost of care delivery while maintaining quality. For example, a recent report, sponsored by the California HealthCare Foundation, reviewed research findings on the clinical effectiveness of telephone care programs, finding some evidence that telephone-based patient education can improve chronic disease outcomes and help patients become more effective advocates for their own care.<sup>27</sup> The Department of Veterans Affairs, which has been a pioneer in piloting home telehealth, has also demonstrated cost-effectiveness in managing chronic care patients at home.<sup>28</sup>

Such devices are especially suited for following and caring for patients with chronic conditions. However, a major problem with the development of such remote monitoring tools is that generally they are not reimbursed through current health care payment systems in the United States. Dr. Blatt argues that, at least technically, it would not be difficult for

the system to adjust: “We’ve reached a level where the uncovered costs in health care such as copays and coinsurance are at a level where, if you charge

### Mobile Management of Crohn’s Disease

Brett Shamosh was first diagnosed with Crohn’s disease at age 16. Inflammatory bowel disease, which includes Crohn’s disease and ulcerative colitis, affects 1.5 million Americans, and Shamosh wanted to help his fellow patients. Doctors advise patients with Crohn’s to keep diaries that detail when symptoms flare up and what is happening when they do. Patients report this information to their physicians during their visit. “If I was more accurate reporting the flare-ups to my doctor,” Shamosh realized, “I might have better worked out my management” of Crohn’s.

In his professional life, Shamosh works in the world of Web 2.0, creating and distributing content online. When he set out to develop a tool for managing Crohn’s, he did what came naturally: He used his professional Web skills. His company, WellApps, was the result, “born out of a problem I was trying to solve.”

Shamosh is working on WellApps with his physician, a GI specialist. Together, they developed an algorithm based on a patient’s diary-recording tasks: flare-ups; stool pain urgency (based on a simple index of 1 to 10); blood in stool (on a scale of light-medium-heavy); and other symptoms and ODLs. As users log symptoms into their diaries over time, they can track whether they are doing better or worse, and can develop a comprehensive record to share with their physicians. For now, the tool is sold retail and through licensing to sponsoring organizations.

A key objective of WellApps is for it to be as useable and as natural a part of the chronic patient’s lifestyle as possible. “I’ve built mobile applications for companies and I’ve built Facebook applications. I know about user experience, which is what was important to me,” Shamosh notes. “The application doesn’t replace a doctor’s diagnosis, but it can help to improve care. Doctors can make better decisions based on patients’ data and adjust medication and advice.”



that amount for, say, a video conferencing phone call coupled with physiologic data from remote sensors, you can pay a provider's salary; \$25 over the wire with minimal overhead might pay a salary for a physician. What's wrong with practicing certain types of medicine this way?" he asks.

"Doing remote monitoring is a great idea, but in and of itself it's not enough. Feeding back to the patient immediately is also necessary. Tools that just absorb data and present it to a back-end, like home monitoring, don't close the loop," according to

Dr. Blatt. He suggests that remote interviews offer an opportunity to inform patients through teachable moments that might use video, avatars, and other entertaining media, resulting in personalized health management. "In the real world I'm trying to figure out what motivates a patient: living forever, having a good time, watching your kids grow up. Once I find a hook, I want to play into it and influence a change in patient behavior." The interaction and personalization offered by these tools provide their behavior-changing potential.

### **Managing Hypertension on the Road**

The Cleveland Clinic works with Microsoft on patient-centric chronic care management through the HealthVault platform. The clinic's chronic care partnership with the technology company focuses on diabetes, heart failure, and hypertension. Once the clinic identifies an appropriate patient for the program, it provides the appropriate monitoring device(s) for the patient to take home; these can include glucometers, blood pressure monitors, peak-flow meters, pedometers, and weight scales.

All devices are connected through the HealthVault platform, which automatically moves data off the monitor into a database (with the consumer's consent). The devices permit continuous reading, enabling the health provider to adjust medications and therapeutic regimens on an ongoing, personalized basis. The clinic believes that early intervention through this monitoring can prevent hospital admissions, lead to robust health outcomes, and lower costs. Also, when patients are armed with information through this program, the clinic finds, they are more engaged with their care: The patient feels empowered by knowing the numbers.

As David Cerino of Microsoft explains, "Nobody can make good decisions in health without decent data, not the individual with the condition, or the caregiver, the care team, or the provider. We are a big believer in data liquidity." Health data liquidity is the ability for data to move freely, liberated from the many data silos—such as electronic medical records, prescription drug claims, hospital records, laboratory, and imaging systems—in which a patient's individual information is now isolated. The premise of health data liquidity is that when health information flows among and between patients and providers, health care can improve: "Growing evidence indicates that liquid health information can facilitate improvements in healthcare access, quality, safety, efficiency, convenience, and outcomes," cited a recent report by Booz Allen Hamilton.<sup>31</sup>

The case of David Jesse, a long-distance truck driver who had hypertension, is illustrative of the program's potential. He participated in the Clinic's pilot and monitored himself on a mobile basis from "the road."

Jesse entered the hypertension management program with a blood pressure of 154/104. Traveling cross-country with a laptop computer, Jesse took daily readings of his blood pressure through a digital monitor and uploaded the readings to his HealthVault PHR. This reading then automatically populated the record for clinicians to review, which helped them manage Jesse's blood pressure on a weekly basis. Traditionally, his physician would not have known of Jesse's blood pressure for the six to twelve weeks between visits. By recording his blood pressure on a daily basis, Jesse and his doctor found a pattern that could be managed with modification of the hypertension medications Jesse was originally prescribed, and after several months, Jesse's blood pressure moderated at 120/82.

Many chronic conditions are amenable to patient self-care tools, according to Dr. Joseph Kvedar of the Center for Connected Health (CCH), a division of Partners HealthCare in Boston, which develops technology-enabled health care programs that deliver care to patients outside of traditional medical settings.

CCH has studied hypertension extensively, among a wide range of chronic diseases. Sixty-five million Americans have hypertension, with 90 percent of middle-aged Americans developing hypertension in their lifetime. Only about one-third of people with hypertension have managed their blood pressure to target goals. Despite effective treatments, only an estimated 23 percent of people with hypertension have their blood pressure adequately controlled, according to CCH.<sup>29</sup>

CCH conducted focus groups with patients diagnosed with hypertension in order to compare two management concepts: online physician visits versus an online feedback Web portal. The online portal included a visual representation of their blood pressure data; targeted automated messaging around blood pressure data; medications and other self-reported information; the ability to email or download data; and educational content. Significantly, however, there was no link between this portal and the user's physician.

Consumers in the CCH focus groups liked the idea of an online-based tracking system as a way to gain insight into their actions. A male patient 47 years of age who participated in the program found that, "It's a valuable tool to measure blood pressure there's no doubt about it. You can actually do research on your own positive behavior, like exercise and your diet."<sup>30</sup> While valuing the personalized, actionable feedback, however, patients believed that coordination with their health care provider would greatly enhance the appeal of this program.

## Dealing with Diabetes

Diabetes, a condition of epidemic dimensions, is among the most challenging chronic diseases to manage, with self-management requiring a great deal of patient engagement. There are currently over 23 million diabetics in the United States, about 8 percent of the total population, with approximately two million new diabetes diagnoses each year. Also, one in four American adults suffers from pre-diabetes. The American Diabetes Association estimated that, in 2007, the direct and indirect costs of diagnosed diabetes nationally totaled \$174 billion.<sup>32</sup>

People with diabetes face a complex matrix of daily challenges. Rajiv Mehta founded ZumeLife to help people deal with these self-management complexities. ZumeLife is a health management tool that helps people deal with chronic conditions via both an iPhone application and Web site. "There are dozens of activities someone dealing with diabetes must do throughout the day: take medications and supplements, test blood glucose, massage feet, exercise, and other tasks that together help manage chronic illness. Then there are things to keep track of: food intake, moods, pain, sleeping habits. It is quite literally an overwhelming set of tasks, a logistical nightmare," Mehta describes.

Mobile/tracking applications can be designed to lighten the chronic patient's burden of keeping track of medications and recording ODLs, and to streamline other tasks for managing complex chronic conditions. With regard to diabetes, the most important self-management task to be addressed by mobile/tracking technology is the patient's charting and graphing of glucose results and the sharing of that information with his or her doctor and health team.

The telephone is an obvious choice as a platform for such applications. In Amy Tenderich's

DiabetesMine Design Challenge, the 2009 winner was a system that evolved the iPhone into a combined glucose meter and insulin pump, with a storage container for strips, doing away with the need for diabetics to carry several devices. (For more on this application, see [www.diabetesmine.com/designcontest](http://www.diabetesmine.com/designcontest).)

The growing list of diabetes applications for mobile platforms reveals the opportunity for an ultimate “mash-up” that combines all of the many functions that patients need to manage, thereby reducing the complexity of doing so on a daily basis. Until that ultimate tool can be developed through application integration and the establishment of standards, patients will be offered a variety of choices for managing diabetes.

One of these new choices comes from Johnson & Johnson’s LifeScan unit. LifeScan is developing an application that interfaces the company’s glucometer, which tracks blood-sugar levels, with the iPhone, which will automatically chart the results, calculate sugar intake during meals, and enable the user to adjust behavior via diabetic medication and food intake.

Mobile management of diabetes could not only improve health outcomes for people with diabetes, but could result in lower costs to individuals and health systems. Vodafone, the European communications company, has invested in t+ Medical, a provider of health services accessed across mobile phones in the United Kingdom. t+ Medical, a spin-off from Oxford University, transfers patient data using standard mobile phones, into which a patient enters data or to which vital signs data are automatically relayed using technology such as Bluetooth, from a range of personal monitoring devices. Diabetic patients record their blood sugar in a text and answer a few simple questions that they then send to a medical call center. t+ Medical has

estimated that providing services to 2 million diabetic patients could save Britain’s National Health Service £1 billion a year (about \$1.6 billion) by significantly reducing in-person patient visits to providers.<sup>33</sup> Such potential savings highlight the greater value to be achieved in a synergy among patient, provider, and health system than in patient self-care without a loop back to the provider and health system.

## Wellness

While this paper focuses on chronic care, it may also be useful to examine another aspect of the continuum: how people who do not have chronic conditions could use these tools to help keep themselves well. Well-being encompasses many dimensions beyond physical health. The Edelman Health Engagement Barometer found that people define well-being not only based on physical health but also on mental health, personal appearance, financial health, and social connectedness.<sup>34</sup>

Polka is a mobile phone application targeted to wellness management. It is an iPhone application integrated with a Web portal ([www.polka.com](http://www.polka.com)) that aggregates personal health data and allows the consumer to share real-time information with emergency, “expert” (such as clinicians), and insurance contacts based on whom the user allows into the network (consistent with HIPAA requirements).

This stream of data can serve not only chronically ill individuals but also people who are well. A well user can log various types of ODLs: sleep, exercise, diet, weight, and well-being measures. Polka can aggregate these data points, giving the consumer a visual picture of their health trends. Charts can be generated based on what the user chooses to track.

## **Sensei for Weight Management**

Dr. Robert Schwarzberg is a cardiologist whose work in telehealth and remote arrhythmia monitoring showed him the promise of providing patients health support outside of the office exam room. Thinking through the critical elements of how to manage population health, he wanted to develop an approach that would be more personal, more targeted, and more actionable, to encourage good health choices. The result was his founding of the company Sensei.

Dr. Schwarzberg knew that mobile phones could be an asset for integrating care into people's daily lives, and Sensei's first product, launched in November 2007, was a mobile-phone-based program for weight management. Sensei for Weight Loss makes a mobile phone into a "personal digital coach" that delivers customized meal recommendations, fitness information, and motivational messages, in real time, throughout the day.

*Consumer Reports* notes that nationally, 80 million people are dieting at any given time, with 60 percent of people trying to diet on their own. Working with dietitians and other experts in weight management, the Sensei team found that people need to set reasonable goals to keep them on-track. The Sensei system operates like a dietitian, Dr. Schwarzberg says. "It captures a personal profile of things you don't enjoy eating, how you prepare your meals, and how you eat, and uses this information to help introduce you to great healthy meals that you'll like." Grocery shopping lists are generated, aggregating food groups and volumes. The system also generates a meal plan using the individual's profile data. The day's calories are calculated in terms of BMI and the personal weight goal, which is organized into successive weight targets for achieving reasonable goals.

Sensei takes advantage of individuals' mobile lifestyles by using their phone to help them better manage their diet. Users set up a personal profile based on various consumer preferences, such as restaurant chains, clothing brands, and retail stores. The program remotely activates the application and sends alerts to the user, based both on the preferences, as well as what is most healthful for them based on that preference. For example, a user with a taste for Mexican food might receive an alert that a taco at a local Mexican food chain would be a healthy lunch choice. After lunch, the phone might remind the user to take a walk. (The system has a pedometer integrated into the overall application through the iPhone's accelerometer feature.)

Sensei also provides incentives for people to stay on track with their diets. For instance, the phone might provide a dollar-off coupon for lunch at the Mexican food chain. Or, after a ten pound weight loss, a \$10 coupon might be awarded for a new pair of jeans at a favorite clothing store. "The more personal we make the incentives, the more valuable it is for the consumer," says Dr. Schwartzberg.

Dr. Schwarzberg also emphasizes that the Sensei platform is applicable beyond weight management; that is, from a technology standpoint, it is not "hard-wired" for weight loss. Rather, Sensei is a content management system that is intended to support a range of self-management applications, including for asthma, diabetes, and other chronic conditions.

## V. The Road to Connecting Patients

*“Clinical settings can contribute to both environmental change and individual behavior change. They are an important part of the solution, but people do not live in clinical settings. They live in supermarkets, convenience stores, schools, playgrounds, restaurants, offices and factories. They also live in a media society—in front of televisions, video games, movies, computer screens, and cell phones... and especially on couches.”*

— WILLIAM NOVELLI, AUTHOR OF  
“HEALTH CARE REFORM HINGES ON  
PRIVATE-SECTOR COLLABORATION”<sup>35</sup>

THE ROAD TO CONNECTING PATIENTS TO eHEALTH WILL be bumpy and dislocating for all health care stakeholders. Both the health care system and the environment in which health care consumers live shape health behaviors, so many factors must change and converge in order to get patients connected. These factors include:

- Aligning incentives;
- Engaging clinicians;
- Clarifying regulations; and
- Inspiring greater health engagement through incentives and personalization.

### Aligning Incentives

The most formidable barrier to connecting patients is financial. Health care is fragmented because of how care is reimbursed. Instead of paying providers to manage a patient’s overall condition, third party payers reimburse based on visits, tests, and prescriptions. The result is that most Americans receive discontinuous care, with services only at acute intervals, which is a particularly serious problem for people with chronic conditions. (There are a few exceptions to this approach: The Kaiser Permanente Health Plan and the Geisinger Health System are two of a handful of health providers with models of more continuous care.)

While there is a growing array of eHealth tools that can help address chronic care self-management, there are poor incentives for adopting these tools, whether for patients to use them, for clinicians to recommend or use them, or for payers to pay for them. Present incentives lead to a pattern of treating patients when it is more expensive to do so. If the reimbursement system could structure payment based on outcomes, this would encourage the treatment of patients earlier and more continuously throughout their disease processes. That, in turn, may make both patients and clinicians

more amenable to the kinds of eHealth connectivity discussed in this report.

As third-party payers work to align incentives, a significant number of health consumers may already be willing to pay out-of-pocket for self-care tools to manage chronic conditions. The AARP's Healthy@Home survey demonstrated that there was interest and willingness to use health and wellness products among both seniors and caregivers, but that cost tolerance among these groups capped at \$50 per month for a product that could help seniors remain well longer. For software-based offerings such as iPhone applications that consumers can use to manage their own chronic conditions, the cost maximum for patients 50 and over was found to be \$35 per month, according to the survey.<sup>36</sup>

## Engaging Clinicians

The ideal model for patient self-care of chronic illness includes loops back to clinicians and health coaches for ongoing monitoring and therapy adjustment. Aligning payment with performance for good chronic care patient outcomes will be a key to engaging clinicians. Beyond payment, however, physicians will also need to adjust their workflow and to develop a sense of teamwork with patients.

As Dr. Joseph Kvedar points out, “the challenge is that doctors haven’t been challenged enough to be participatory. In the old fashioned view of health care, the physician is the shaman or knowledge resource. But if all that separates me from a patient is a textbook, that’s a sad statement.”<sup>37</sup> Dr. Kvedar’s experience in the Connected for Health projects across a range of chronic diseases is that when physicians invest in partnerships with patients, their level of engagement increases and ultimately, “they are probably going to have a higher quality of care and improved outcomes.” If the doctor’s goal is

## The Role of the FDA

When does a smartphone cross the line from a communications device to a medical one? Whenever that point is reached in the eyes of the federal Food and Drug Administration (FDA), the device could fall under FDA regulation. There is not yet a clear line of demarcation. But as more patient-facing sensors transmit data from a personal glucometer or blood pressure cuff to an electronic health record via Bluetooth, and generate a personalized message to the patient recommending a changed medication dose or other health action, the FDA becomes more likely to assert jurisdiction.

Apple, the iPhone company, has anticipated the FDA’s eventual involvement. The company’s iPhone developer legal agreement includes a section titled “Regulatory Compliance for Health, Medical and Related Apps” that puts the regulatory onus for FDA compliance squarely on the application developers themselves. Noteworthy on this subject is that AirStrip Technologies received FDA approval in April 2009 to market the OB mobile medical software application that gives doctors the ability to track expectant mothers and unborn children via iPhones working in conjunction with AirStrip’s hospital patient-monitoring system.<sup>38</sup>

population health improvement, the engaged patient is the one who is more likely to help achieve it.

## Inspiring Greater Health Engagement

What inspires people to get and stay healthy? Self-management of chronic conditions requires personal commitment on the part of the patient. But motivating people to do the right thing for health improvement will often require a “nudge.” This is an element in the concept of “libertarian paternalism” as defined by Cass Sunstein and Richard Thaler in their book *Nudge: Improving Decisions About Health, Wealth, and Happiness*.<sup>39</sup> As health providers need incentives to shift them toward the preventive

end of the care continuum, from treating acute conditions toward prevention and chronic care, so health consumers need similar incentives. One of the ways to do this may be through paying patients for performance. Kevin Volpp of the Wharton School of Business has researched “P4P4P” — pay for performance for patients — and has found that paying people even small amounts can change health behaviors, including smoking cessation, losing weight, and medication compliance.<sup>40</sup>

Regardless of external incentives, for patient self-management tools to be effective they must be personalized to the patient. Marilyn Shreve, former president of the California State Board of Pharmacy, found that “Effective behavioral change interventions using technology must be based on what’s important to ‘me’ and focused on a patient’s unique values, beliefs, culture, lifestyle, and health barriers.”<sup>41</sup>

Dr. Kvedar, of the Connected for Health project, has found that for guidance to a patient to be motivating, it must be shared in a way that is meaningful to the individual. Self-care tools that are customizable to the user will achieve greater engagement and can ultimately lead to better health outcomes.



## VI. Conclusion:

### The Future of Participatory Health

“PARTICIPATORY HEALTH IS THE NEW Woodstock,” quipped David Lester of Theranos, a startup that integrates biological system data with information technology to manage health, referring to the famed 1969 music festival that came to symbolize a younger generation rebelling against the establishment and insisting on being able to “do your own thing.”<sup>42</sup> In a similar fashion, Dr. Lester sees participatory health as breaking the traditional mold of the doctor-patient relationship, which relies upon patient passivity. In this traditional relationship, patients “have been deliberately kept out of their own care,” declares Lester. In participatory health, by contrast, patients actively engage in their own health care in a genuine partnership with providers and trusted experts. Participation is enabled and enhanced by technology such as the Internet and mobile health platforms and, ultimately, promises to have social reverberations more enduring than even a legendary rock concert. “Real health reform,” says Adam Bosworth of Keas, a startup that is developing a highly customizable personal health management tool, “will be a model that’s continuous, cooperative, and coordinated.”<sup>43</sup> At the center of this is a person—a patient, or a caregiver—who can monitor and track behavior, and modify it based on information, vetted by the clinician or the health coach. The resulting model is personally meaningful, motivating, and actionable.

Will the current stakeholders in health adapt to this scenario? In assessing the current portfolio of health care decision tools aimed at consumers, the Center for Advancing Health found that “Tools created within the health care industry will have less

resonance with consumers than those created by independent groups.”<sup>44</sup>

Will that also be the case for self-care chronic condition management tools? Many of the entrants into this market are from outside traditional health organizations. Health providers, institutions, and suppliers to the industry will need to adapt to the world of participatory health, in order to be perceived as relevant and useful to those pioneering patients who are embracing self-care. To the extent that innovations are coming from outside of the health industry, legacy health stakeholders—including providers, plans, and life science companies—will need to partner with innovators in channeling patients to these helpful tools.

The best potential health outcomes can be achieved by linking the patient back to the willing clinician. If incentives align to make that happen, the result stands to mutually benefit patients, providers, and the health system at large.



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