Patient Self-Management Tools: An Overview

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This report was produced under the direction of CHCF's Chronic Disease Care Program, which seeks to improve the health of Californians by working to assure those with chronic diseases receive care based on the best scientific knowledge. Visit **www.chcf.org/programs/** for more information about CHCF and its programs.

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Executive Summary

DEMAND FOR PATIENT SELF-MANAGEMENT TOOLS —technologies used by consumers to manage their health issues outside formal medical institutions—is gaining momentum. This surge of interest springs from a variety of converging influences: new ideas about clinical care, universal concern about costs, political interest in stimulating competition among providers, shifting consumer habits, and an explosion of technological innovation.

Some analyses of this market sort self-management tools into an overwhelming number of micro-segments. Others categorize the market by user group without differentiating much among the technologies themselves. This report attempts to create a typology that distinguishes tools primarily by patient role and secondarily by variations in the complexity of technology.

The various tools may be described as follows:

- Technologies that support *subordinate* patient roles provide modest patient discretion within a strong supervisory context. The approach is similar to the one adopted by the automobile industry, in which the expanding role of devices has reduced the possibility for human error.

- Tools for *structured* roles involve more active but limited patient participation. In these cases, technologists have proceeded cautiously because of physician wariness about sharing control.

- Tools for *collaborative* roles involve patients using their own knowledge and making decisions jointly with clinicians. Such tools engage physicians and patients in the shared decision-making envisioned by disease management advocates and clinical care theorists.

- Tools that facilitate *autonomous* roles help patients take health matters in hand without major participation by clinicians.

While each of these self-management roles has kindled a growing market for new technology, not all have inspired corresponding changes in clinical care delivery. As patients continue to adopt self-management tools, clinicians will need to better understand these tools and how best to apply them in caring for their patients.

I. Introduction

THIS REPORT IS AN OVERVIEW OF AN EMERGING marketplace. Patient self-management tools are instruments of self-care, mobile care, and home care. They help consumers deal with their own medical conditions, or those of loved ones, outside the walls of formal institutions. Interest is mushrooming and businesspeople are betting that future demand will be strong. Knowing about these technologies has become important to doctors, nurses, administrators, policymakers, and businesspeople, not to mention members of the public.

Sometimes patients take up a self-management product on the advice of a clinician. Sometimes they act on their own— exploring a Web site for information about a treatment, for example—but tell their doctors afterward. And sometimes they act on their own and never tell anyone because they don't have a doctor, forget, view their action as irrelevant, or feel that the matter is private.

It follows that self-management tools are patient-focused but not always physician-focused. It follows, too, that not all self-management tools are used in conjunction with disease-management programs, in which doctors and nurses have a central role. A considerable number of these products advance patient-clinician collaboration of the kind that disease-management programs recommend, but just as many exist to help people handle problems more or less on their own.

Because these tools straddle the health care and consumer sectors, their evolution rests not only on concepts of clinical care but also on broader influences, some of them economic and political, some of them involving consumer behavior, and some of them technological. As with other products subject to such complex forces, self-management tools can be improved by law and regulation and disciplined by supply and demand but, ultimately, controlled by no one. What can be said with confidence is that these tools will produce more benefit if health care professionals know about them, discuss them with colleagues and patients, and take part in improving them. This report hopes to advance such knowledge, discussion, and improvement.

II. Self-Management Tools: Definition and Driving Forces

EACH YEAR A WAVE OF NEW PRODUCTS AIMS TO give patients greater control over their illnesses and chronic conditions. External defibrillators deal with sudden cardiac arrest at home, hemoglobin testing kits sell direct to diabetic consumers, and sensor-based systems let the elderly stay in better touch with relatives. The list goes on.

This report covers these technologies and many others. It defines a *patient self-management tool* broadly, to mean "technology used by a patient or informal caregiver to manage health problems outside formal institutions." The term encompasses an extraordinary and expanding array of products sharing a common characteristic: They focus on making non-expert control of health and health conditions easier or better.

The forces influencing the development of these tools fall into four categories: clinical care, economics and politics, consumerism, and technological innovation.

Clinical Care Factors

As the population ages, chronic care becomes increasingly important. The contrast with acute care is significant: A doctor can often address an acute problem with a procedure or prescription, but a patient's chronic problem remains day after day, hour after hour. Because a doctor or nurse can't be present all the time, the consumer must handle the situation on his or her own, with occasional help and advice from clinicians. As one team of experts flatly stated, "Patients with chronic conditions self-manage their illness. This fact is inescapable. Each day, patients decide what they are going to eat, whether they will exercise, and to what extent they will consume prescribed medications."[1]

Clinical care theorists acknowledge the influence of the patient and the concept of shared decision making. A popular, if somewhat wordy, definition of disease management is "a system of coordinated health care interventions and communications for populations with conditions in which patient self-care efforts are significant."[2] These approaches replace the conventional notion of the clinician as expert with a partnership model in which "patients accept responsibility to manage their own conditions and are encouraged to solve their own problems with information, but not orders, from professionals."[3]

Technology vendors, observing these developments and spotting an opportunity, have developed innovative ways to support patient-clinician collaboration. Such collaborative products constitute a major part of the marketplace in patient self-management tools, the four segments of which are discussed later in this report. (See "Segmenting Self-Management Tools by Patient Role.")

Economic and Political Factors

The rising cost of American health care continues to plague public and private payers, prompting them to examine new ways of reviving an old idea: people caring for themselves and their loved ones at home. On the government side, unless taxes are raised or benefits cut, annual expenditures by Medicare's Hospital Insurance trust fund, its biggest pot of money, are expected to exceed annual revenues by 2012 and exhaust total assets by 2020.[4] In the private sector, General Motors reports that expenditures to insure its American employees, retirees, and dependents came to $4.8 billion in 2003, more than its worldwide net income for the same year.[5] Ford Motor's story is worse: In 2003 it spent $3.2 billion on health care—*six times* the company's worldwide net income.[6]

Numbers like these underline the potential value of patient self-management tools. Consider home monitoring and messaging systems, with which patients connect to peripheral devices, take vital signs, test for other physiological values, and transmit results to remote clinicians. These systems allow routine procedures to be performed by patients or informal caregivers, rather than nurses or doctors, in settings less expensive than the clinic or the office.

In Washington, meanwhile, advocates of reform are shaping an agenda that identifies excessive health care costs as a symptom of an ailing market, but the absence of competition as the underlying disease. They view this competitive problem as stemming not from any shortage of doctors and hospitals, but from the system's overall lack of "transparency." In other words, buyers—consumers included—don't have enough information about the relative performance of health care providers, so they can't make comparisons and negotiate among them. The cure? Support hard measures of relative performance, and then encourage development of self-management tools that translate these measures into easy-to-understand comparisons.

In April 2004 the president established the Office of the National Coordinator for Health Information Technology. Of the four objectives its new director has enumerated for his tenure, he calls the third *personalizing care*, which he defines as "well-informed patients... equipped to actively participate in their own care and decision making."[7] He explains: "Innovations in technology are emerging to give patients electronic access to their health record and the ability to gather specific information tailored to their illnesses, chronic conditions, and health characteristics. ...[Patients' decisions] should include not only what actions to take on their behalf but also whom they select to treat them and where they seek treatment."[8]

Consumer Factors

Public opinion surveys, followed up by market tests and pilot programs, suggest that consumers are price-sensitive about health care services and are likely to change behavior in response to higher charges.[9] These findings have added more impetus to the development of market-oriented self-management tools, such as comparison engines that draw on expanding stores of data to compare health insurers, hospitals, and even individual doctors. *Consumer Reports*, the Medicare program, and the Leapfrog Group, an

organization sponsored by large employers, all offer online engines to help consumers balance quality and financial factors when making health care choices.[10]

But, as motivating as prices are, they are not the only considerations that prompt people to embrace self-management tools. Consumers are also interested in saving time and gaining convenience; they are just too busy to sit around waiting rooms. Home monitoring and messaging systems trade off personal service by professionals in exchange for avoiding trips to the doctor's office. An expert observer of the trend, a doctor who runs the telehealth programs of the Veterans Health Administration, writes, "Patients are showing that, as health care consumers, they want their experiences to mirror their expectations as consumers in other areas of their life. ...[This means] giving people more involvement in deciding what health care they want to receive and how they want it delivered."[11]

Technological Factors

By the standards of mainstream laboratory science, innovation in information technology (IT) moves at lightning speed. The World Wide Web, the publicly accessible face of the Internet, pervades every aspect of modern commercial life, yet it was devised only 16 years ago, a period scarcely longer than the development cycle of a single prescription drug.

IT's progress since has been relentless. Microprocessor chips continue to get smaller, cheaper, more pervasive and, of course, more powerful. The impact of such gains is magnified by parallel innovations in telecommunications, most recently in wireless applications. Together, microprocessors and telecommunications make patient self-management tools possible. Constant refinement is blurring the lines that once separated information technology, medical technology, and assistive technology, regardless

of which label might once have applied; recent medical and assistive technologies incorporate computing and communications features that make them, in the vernacular, "smart."

These days, the technological transition from "dumb" to "smart" happens so routinely that it is hardly noticed. Not long ago, for example, the typical treadmill in the basement did not feature advanced electronics. But now a user can dial in weight, select an exercise duration, choose among routes hilly and flat, and generate a customized workout. During exercise, the treadmill offers digital feedback on distance, time, and calories consumed. It also connects to a chest-strap monitor and displays heart rate. And some of the latest models can upload readings into laptops or PCs for longitudinal record-keeping and cardiac health analysis.[12] For a heart patient who needs to control his or her weight and get moderate exercise, this machine qualifies as a self-management tool.

Today IBM, Intel, Fujitsu and others push research and development aimed at making everything smart, with an early focus on mobile and home health care. Under the banner of ubiquitous or pervasive computing, researchers work on bringing the cost and size of microprocessors and sensors down to where they can attach cheaply to light switches, water faucets, closet doors, drawer handles, kitchen cabinets, oven dials, and pill boxes. One idea is to use sensors to profile the activities of frail elderly patients living independently so that abnormal activity alerts loved ones to possible problems. When will the cost of sensors be low enough for such distributed application? As an upcoming section of this report discusses, one startup company believes the time is now. (See "Tools for Subordinate Roles.")

III. Segmenting Self-Management Tools by Patient Role

THE FIELD OF PATIENT SELF-MANAGEMENT TOOLS is new, and researchers define the market in many different ways. Some scatter products across a confusing array of micro-segments. Others go to the opposite extreme, segmenting by users—elders, baby boomers, and so on—without drawing useful distinctions among the technologies themselves. A better approach is to classify self-management tools in a typology matrix formed along two lines: The primary axis defines the range of roles that patients play when using the tools; the second axis traces the complexity of the technology. (See Figure 1.)

Figure 1. Patient Self-Management Tools: Typology and Illustrative Product Groups
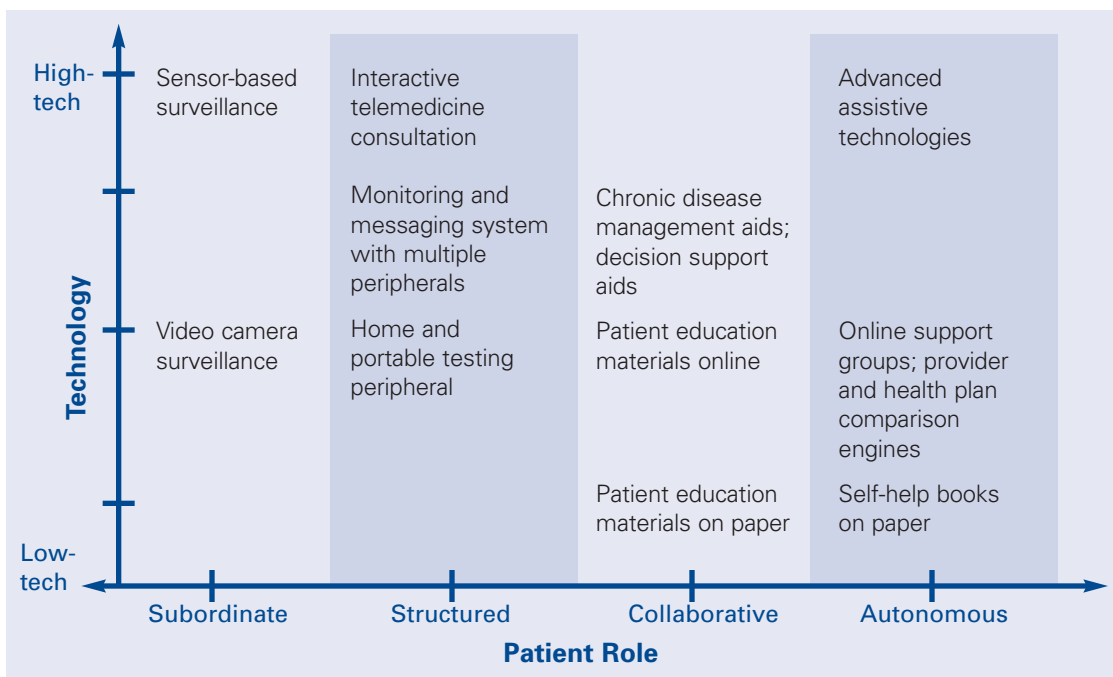
The product groups cited in Figure 1 are illustrative, not definitive. Altogether different ones could have appeared in their stead and, judging from research underway in such companies as Johnson & Johnson, Motorola, and Samsung, still others will come along. The central point of the matrix is that technology development relates directly to the roles that consumers play as they cope with health problems. These

roles are dynamic and can change under the influence of the technology itself. This said, they vary from subordinate to structured to collaborative to autonomous, each explained here:

Subordinate. Tools that facilitate subordinate roles provide modest patient discretion amid controlling and supervisory technology. An example is a video camera system used for safety in a home or residential institution. Home surveillance based on ubiquitous sensors represents an advanced form of the same idea. At first glance, such technologies might not appear to warrant inclusion in this typology. But, on further reflection, living with automated rather than hands-on solutions is an option like any other. The adopter's motivating instinct might be dependence, but it might also be a liking for cost savings, convenience, precision, consistency, and avoidance of human error. Typically the resident—or a family member—remains aware of these devices and learns how to retain a measure of privacy and control in their presence. On the other hand, sometimes a patient gives informed consent and the rest of the matter passes completely out of his hands (as with implanted stents, for example). In these cases, the technologies are simply too controlling—and the corresponding element of patient participation too minimal— to warrant inclusion in a typology of self-management tools.

Structured. Tools for structured roles involve more active, though still limited, patient participation. Because self-management is an unfamiliar variable to much of organized medicine, technology vendors proceed cautiously on the issue of patient latitude. Many of them erect boundaries to placate physicians, whom they see as wary about losing control of their schedules or medical decisions. In scripting the back-and-forth elements of its online consultations tool, vendor RelayHealth limits the patient end of the conversation strictly to the clinical subject at hand,

assuring doctors of the kind of control over virtual visits that they have, presumably, over face-to-face encounters.

Vendors may also constrain the patient role to accommodate a rather different clinician expectation: that the patient will be frail, unsure about new technology, and uncomfortable using it except in simple situations. And sometimes, unambiguously, the most important consideration is prudent medicine rather than physician perception. If the tool is new or at least new to many patients, and the readings, doses, or other features must be carefully calibrated, good reason exists for a careful structuring of patient discretion.

Collaborative. Tools for collaborative roles involve patients drawing on their own knowledge and making decisions jointly with clinicians. Such tools support the progressive models of physician-patient interaction envisioned by disease-management advocates and clinical-care theorists. Some would say these technologies serve the true ideal of patient self-management, in which professional and layperson work cooperatively on a medical problem and in so doing employ tools: for diabetics, perhaps a blood glucose meter that downloads readings into a PC; for cancer patients, perhaps a Web site providing decision support.

Autonomous. Tools supporting autonomous roles stand at the opposite end of the spectrum from subordinate patient tools and help patients take matters in hand without much participation from clinicians. Reasons for acting alone vary. Sometimes health insurance does not reimburse clinicians to provide the pertinent care; weight management is a common example. Sometimes people lack insurance altogether. Sometimes they are habitual self-helpers and are unimpressed with experts. And sometimes they have doctors, trust them, and still use an independent tool on the side to address a vexing problem.

Technology, the vertical and secondary axis in Figure 1, ranges from low-tech to high-tech. These terms lack exact definitions and are offered as approximate descriptions, but they define a spectrum of complexity that helps with analysis. As Figure 1 indicates, two self-management tools that qualify as low-tech are educational materials on paper, often dispensed by clinicians to patients expected to assume collaborative roles; and self-help books, typically purchased by patients bent on assuming autonomous roles. Paper materials like these have a place in this typology, first, because they play important parts in the real world of patient self-management and, second, because print, lest we forget, is a powerful innovation, albeit a simple or low-tech one by today's standards.

It bears mentioning that technology appears to describe a steady evolutionary course from low to high. But trends in the role of patients are more complex. Demographics—a better-educated populace, for instance—argue for a diminution over time in patient subordination and a corresponding increase in autonomy. But it's also the case that the same patient might behave collaboratively with one doctor and autonomously with another, or subordinately at one stage of an illness and collaboratively at another, and so on. For that matter, innovations such as interactive telemedicine can involve patients in either structured or collaborative roles. Personal health records can encompass an even wider range of participatory styles, from structured to collaborative to autonomous, depending on how much data access the layperson has. In general, the lay role depends on the choices of patient, doctor, and institution, and on the nature of the condition. What's most telling is that market trends do not point to the emerging dominance of any one style or the pending eclipse of any others. Instead, innovation is flourishing with regard to all four.
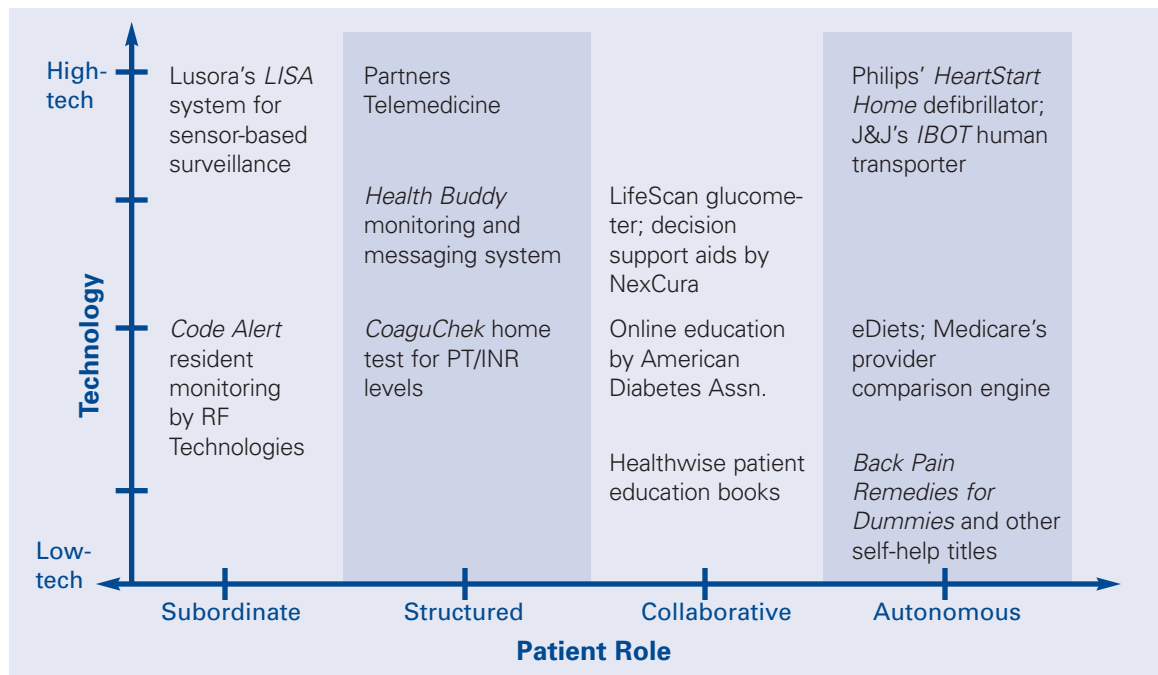
Tools for Subordinate Roles

As previously mentioned, using a video camera to observe a stroke patient or distributed sensors to track the movement of frail elders are instances of self-management tools that entail subordinate patient roles. Optimism about demand for such tools rests on demographic developments such as the number of people living into their 80s and beyond, some proportion of whom will want or need the extra measure of assurance that controlling and supervisory technologies provide.

Because of staff shortages in hospitals, nursing homes, and assisted living facilities; video camera surveillance is already common. But Intel, Eastman Kodak, Hewlett-Packard, and others see bigger opportunities in coupling microprocessors with transmitters and sensors that detect sound, motion, pressure, temperature, and the presence of other objects. The goal is to devise small devices that can not only detect subtle signals but identify them—as heartbeats, for example—and communicate the information to other devices. These sensors might someday be embedded in everyday objects throughout the home, allowing the elderly and their loved ones to use them in subordinate self-management.

A commercial form of this technology could be on the market as soon as the end of 2005. To describe market trends more fully, Figure 2 goes beyond the general product groups named in Figure 1 and cites particular tools that represent each group. One of them is the Lusora Intelligent Sensory Architecture (LISA). For a wholesale cost that it insists will be around $1,000 per residential unit, LISA's originator, a company called Lusora, proposes to provide home security vendors and property management firms with its installation kits. The kits include motion and temperature sensors the size of cigarette lighters; they are designed to attach to doors, windows, medicine cabinets, and refrigerators. Residents can also opt for tiny LISA

Figure 2. Patient Self-Management Tools: Typology and Specific Examples

Technology	Subordinate	Structured	Collaborative	Autonomous
High-tech	Lusora's *LISA* system for sensor-based surveillance	Partners Telemedicine		Philips' *HeartStart Home* defibrillator; J&J's *IBOT* human transporter
		Health Buddy monitoring and messaging system	LifeScan glucometer; decision support aids by NexCura	
	Code Alert resident monitoring by RF Technologies	*CoaguChek* home test for PT/INR levels	Online education by American Diabetes Assn.	eDiets; Medicare's provider comparison engine
			Healthwise patient education books	*Back Pain Remedies for Dummies* and other self-help titles
Low-tech				

Patient Role

cameras; they go into the housing behind conventional light switches, where they can operate off the existing wiring and monitor a room without the need for an independent power source. Consumers may also buy a wearable LISA pendant that is part tracking device, part emergency alarm, and part automatic fall detector. The concept: If a frail relative doesn't activate a room sensor by getting up in the morning, or doesn't activate a door sensor by moving about for an extended time, or if the pendant detects a sudden gravitational shift of the sort associated with a fall, LISA will alert caregivers using a conventional phone, a cell phone, email, or a Web interface.[13]

Additional research into subordinate self-management tools is taking place at Oregon Health Sciences University (home to an "intelligent bed" for tracking sleep patterns), the University of Virginia (site of a "smart chair" for monitoring breathing and heart rate), Georgia Tech (development of a "digital family portrait" for displaying data from home monitoring to distant family members) and the University of Rochester (setting for gait analysis and memory-assistance projects).[14]

Such undertakings—as well as many discussed in the next section, "Tools for Structured Roles"—embody a general technology trend found inside and outside medicine: the shift from human-in-charge to device-in-charge. Representative tools accomplish feats not only of mechanical and electrical engineering but of social engineering. In some cases, they prod humans to do things that humans would otherwise not do, but in others they do things better than humans do and steer users away from the center of the action.

Automotive innovation illustrates the general point. For decades, drivers have been responsible for slowing down their cars, with mixed results. Then carmakers introduced the antilock brake system (ABS), which harnesses sensors and computerized electronics to detect, and compensate for, driver error. If the driver brakes too hard, the ABS pulses the brake mechanism on and off to prevent wheel lockup and skidding. The conse-

quence is that drivers do less braking on their own and the number of accidents comes down.

In health care, as well, patients are assuming more dependent roles as technology becomes more active. The so-called artificial pancreas, now under development by Medtronic and others, embodies device-in-charge principles within the field of implanted prosthetics.[15] Today, insulin-dependent diabetics monitor blood sugar levels with the aid of glucose meters and inject insulin as results indicate. By combining aspects of a glucose meter and an insulin pump, the artificial pancreas aims to take both tasks out of human hands. Attached to a diabetic's abdomen either internally or externally, the ensemble will continuously check glucose levels, inject proper amounts of insulin, and then check again. In other words, it will collect physiological information, "learn" from it, and modify future action accordingly.

The prosthetic pancreas is not yet ready to stand in for the natural one, but developers are making steady progress, whittling away at the need for human intervention in both the monitoring and injection processes.[16] When the device is perfected, a diabetic will give his or her consent and have the appropriate components implanted. The patient will remain ultimately responsible for self-managing the diabetes but will surrender important day-to-day decisions to the tool.

Tools for Structured Roles

The home monitoring and messaging systems alluded to earlier, in which patients test for vital signs and other physiological values, entail active self-management but in conditioned and bounded ways. Prodded by sound and text reminders originating from a table-top appliance or perhaps a personal digital assistant (PDA) or cell phone, the patient takes his medications, steps on a weight scale, dons a blood pressure cuff, uses a blood glucose meter, or performs other basic chores. These peripherals respond via cable or

wireless transmission back to the messaging devices, which process, display, and store data before transporting it beyond the home over telephone lines or other means to a nurse or doctor. Many devices also engage the patient in simple yes-no dialogues regarding compliance with a doctor's orders and experiences of recent symptoms.

Because of the growing population of chronically ill and the escalating costs of home health nursing, interest in these systems is strong. Estimates for the size of specific markets vary but can provide order-of-magnitude guidance. One research firm pegs 2005 U.S. revenues at $2.65 billion and projects annual sales growth of 8.5 percent for home and portable peripherals, the product family consisting of the aforementioned blood pressure/pulse cuffs, blood glucose meters, and weight scales plus electronic thermometers, electronic stethoscopes, peak flow/respiration meters, coagulation monitors, pulse oximeters, apnea monitors, cardiac monitors, cholesterol monitors, fetal/pediatric monitors, neurological monitors, and other tools.[17]

Big business has seen the growth potential of these tools and moved in: Honeywell through a 2004 acquisition, Matsushita/Panasonic in a 2003 joint venture with Bayer, and Philips through a 2002 acquisition. (See Table 1.) Today, these large-company offerings, like those of the smaller companies against which they compete, are improving but still lack many helpful features. Products present users with reminder messages, immediate test results, and perhaps some basic questions. But patients do not see trending information, do not receive on-the-spot education about the implications of any specific result, and are not presented with context-specific decisions to make and actions to take. Occasionally, systems instruct users in simple matters of technique—how to operate a blood pressure cuff, for example—but not in the higher-order problem-solving skills called for by chronic care advocates.[18]

Table 1. Representative Vendors of Home and Portable Monitors

Company	Year Founded	Clinical Conditions Emphasized	Home and Portable Devices	Peripherals Accommodated by Devices
Alere Medical	1996	Congestive heart failure (CHF); disease-management program for CHF is accredited by National Committee for Quality Assurance (NCQA)	DayLink home unit	Weight scale
AMD Telemedicine	1991	Firm's major business is conventional telemedicine; home monitoring added recently	CareCompanion home unit, AMD videophone	Blood pressure/pulse cuff, electronic stethoscope, glucometer, pulse oximeter, weight scale
American TeleCare	1993	Multiple disease states	Monitoring Station (non-video) home unit, Video Patient Station (two-way live video) home unit, digital camera	Blood pressure/pulse cuff, glucometer, prothrombin time/International Normalized Ratio (PT/INR) device, pulse oximeter, telephonic stethoscope, thermometer, weight scale
Cardiocom	1997	CHF; recent additions include asthma, coronary artery disease, chronic obstructive pulmonary disease (COPD), hypertension, and obesity	CareStar home unit, TeleScale weight scale	Blood pressure/pulse cuff, glucometer, oxygen saturation meter, peak flow/respiration meter, thermometer
Cybernet Medical	1988	CHF, COPD, diabetes, hypertension, wound care	MedStar home unit, PALStar home communications unit, digital camera, video phone	Blood pressure/pulse cuff, electrocardiogram (ECG), glucometer, thermometer, peak flow/respiration meter, pulse oximeter, spirometer, thermometer, weight scale
Health Hero Network	1988	Multiple disease states. Disease-management programs for CHF, COPD, diabetes, and hypertension are NCQA-accredited	Health Buddy home unit	Blood pressure/ pulse cuff, glucometer, peak flow/respiration meter, weight scale
Honeywell HomMed	1999 (Honeywell acquisition in late 2004)	Multiple disease states	Sentry and Genesis home units, digital camera, pager, videophone	Blood pressure/pulse cuff, ECG device, glucometer, peak flow/respiration meter, PT/INR device, pulse oximeter, spirometer, thermometer, weight scale

Table 1. Representative Vendors of Home and Portable Monitors (cont.)

Company	Year Founded	Clinical Conditions Emphasized	Home and Portable Devices	Peripherals Accommodated by Devices
iMetrikus	1999	Asthma, diabetes	AirWatch airway function meter, MediCompass online health record and care management site, MetrikLink modem device for downloading glucometer readings	Glucometer, insulin pump uploads
Philips Medical Systems TeleMonitoring Services	2002 (Philips acquisition)	CHF	TeleStation home unit	Blood pressure/pulse cuff, ECG device, weight scale
Viterion TeleHealthcare (Bayer-Panasonic)	2003	CHF, diabetes	Viterion 100 and Viterion 500 TeleHealth Monitor home units, digital camera, video-conferencing unit, videophone	Blood pressure/pulse cuff, ECG device, electronic stethoscope, glucometer, peak flow/respiration meter, pulse oximeter, thermometer, weight scale

These limitations spell missed opportunities for the telehealth programs of which they are part. The task of engaging the patient more actively—if it is performed at all—falls upon a nurse or doctor working in a conventional non-electronic encounter. Although personal attention from providers is essential, better devices would reinforce the lessons of the professionals and provide some of their own.

In this respect, the Health Buddy products marketed by the Health Hero Network take a step forward. Thanks to well-developed content and sophisticated branching logic, the Health Buddy is clinically smart. It offers voice and text reminders ("Hello. It's time to take your blood pressure.") and asks questions ("Are you more short of breath today than you were yesterday?"). But it also offers education ("Do you understand what to do if you have shortness of breath?"). It even provides triage assistance ("Increased shortness of breath can be a sign of worsening heart failure, or other medical problems. Please call [provider's name and contact information] to report your symptoms.").[19]

Features like these nudge users beyond a structured role and in the general direction of collaboration. When a patient pushes a button to answer a question or enter information, the appliance follows up with another question, which impels the patient to generate another response, and so on. Because the Health Buddy holds up its end of the conversation with substantive content, the patient can associate particular vital sign measurements with recent dietary choices, medication consumption, and exercise in an exchange similar to one that he or she might have with a clinician.

That's not to say that the Health Buddy is fully evolved. The high cost of any proprietary appliance renders it most suitable as a transitional tutoring device, not a permanent addition to the household. Only the vendor benefits if the

patient never graduates to tracking physiological activity in a less complicated, less expensive way. A really useful product would reinforce independent behavior and help avoid long-term dependency. Providers should insist that product content prepare the abler patient for the day when he or she will strap on an ordinary blood pressure cuff or other peripheral, record readings without the aid of a special storage and transmission tool, and consult a doctor, a nurse, a book, or the Web on appropriate next steps. Whatever telehealth organization is paying the bill or caring for patients can then reclaim the device for another user. The Visiting Nurse Association of Boston, a Medicare-certified home health agency, is exploring ways of helping patients transition away from appliances and towards greater self-sufficiency.[20]

Philips Medical Services, meanwhile, is pilot-testing a system that would conduct home monitoring and messaging through broadband television, a platform that could support much more effective teaching about self-sufficiency and other topics.[21] If Philips and Comcast, its broadband partner, can market this product, called Motiva, at an attractive price, weaning patients off expensive proprietary equipment could become a moot concern because the equipment itself might become less expensive.

Self-management tools that structure patient roles are appearing in a growing number of situations. Patients with mechanical heart valves require lifelong treatment with anticoagulants, usually warfarin, to ensure that blood clots do not adhere to the devices. To ensure they're taking the proper doses of the drug, users need to test their blood regularly for International Normalized Ratio (INR) levels, which are indicators of anticoagulation characteristics. Until recently, patients had to travel to a clinic to have this done. Now they can use testing kits to draw blood samples and test INR levels at home, but they must call in results promptly to clinicians or interactive voice response systems.[22] Warfarin

dosing is time-sensitive and safety-critical, so although the kits provide self-management where none existed before, they're programmed to keep the patient's role structured.

Tools for Collaborative Roles

Traditional ideas of the physician-patient relationship involve the doctor acting as the sole source of expertise and decision-making authority.[23] Recent alternatives to this conception go by different names—shared decision making,[24] collaborative management,[25] the chronic care model,[26] the partnership model,[27] patient empowerment[28]— but concern the same idea: Patient, physician, and family members should pool information and make choices together, whether what's at issue is an acute disease or long-term condition. When experts on chronic care urge clinicians to incorporate "self-management education" and "self-management support" into their repertoires, collaboration is what they have in mind.[29]

One conviction underlying this embrace of collaboration is that patients have the right to take part in crucial decisions affecting their health.[30] Another is that they are capable, with the right support, of making valuable contributions to these decisions.[31] A third is that assertiveness is inevitable in this day and age, and relationships will be less strained if doctors acknowledge as much. For social and generational reasons, today's consumers—not all but many—are predisposed toward taking an active part in decisions that were once relegated to experts—personal health included.[32] According to a poll commissioned by the Pew Internet and American Life Project, 93 million American adults so far have gone onto the Web for health or medical purposes.[33] These 93 million people constitute 46 percent of all adults in the country, an amazing figure.

Given the realities of such patient preparedness in the Information Age, the question for many clinicians is not whether to share information

and decision making but how. In the case of conditions that are serious, chronic, or both, technologies stand ready to help. Tools that support collaborative role playing fall into four subcategories: decision support aids, online interventions, chronic disease management aids, and online health education materials.

■ *Decision support aids* are interactive tutorials and assessments focused, as the term implies, on discrete decisions and major turning points in care. They are "designed to help people make specific and deliberative choices among options by providing, at the minimum, information on the options and outcomes relevant to the person's health status."[34] The better aids link to clinical trial findings and other professional discussions and involve users in decision-tree analysis and relative risk calculations.

A recent evaluation of decision aids by the Cochrane Collaboration reflects the inroads made by the Internet. Of 131 products that appear to be complete and up-to-date, 14 are paper-based, 20 are video-based, two are on CD-ROM—and the other 95 are posted on the Web.[35] A meta-analysis by Cochrane of randomized clinical trials involving the aids called for stepped-up research but found generally positive results. The aids "had positive effects on the decision-making process... enhanced participation in decision making, lowered decisional conflict... and improved agreement between values and choice."[36]

■ *Online interventions* focus on long-term behavior change. They provide ongoing assistance and encouragement for dealing with problems ranging from depression to headaches to eating disorders to HIV/AIDS.[37]

Like decision support aids, online interventions are patient-focused even though their initial adoption often depends on profes-

sional initiative and their design facilitates collaborative problem solving. With their content depth and ease of presentation, they're intended for repeated use by the same patient. A meta-analysis of 22 studies found that these interventions produced generally positive outcomes, such as increased exercise time, enhanced knowledge of nutritional status, increased knowledge of asthma treatment options, increased participation in care, slower physical decline, improved body shape perceptions, and 18-month weight-loss maintenance.[38]

■ *Chronic disease management aids* help patients shoulder the responsibility of living with long-term conditions. As these individuals negotiate the terrain of chronic disease with the episodic help of clinicians, a myriad of self-management tools are available to help.

For example, since 1993, with the publication of results from a large clinical trial, self-monitoring of blood glucose has been a recommended step in diabetes control.[39] Today, diabetics can get the job done with the help of 25 or so commercially available blood glucose meters, which, with every new model, incorporate more computational power and become more useful. LifeScan, one leading vendor, markets what it calls an "ultra-smart" device that has the look and feel of a PDA. In addition to drawing blood, the unit stores readings and charts the results. Users can also upload data directly into their PCs and, with the help of 11 pre-formatted charts and graphs, analyze it in detail.[40]

Thanks to higher survival rates and lengthening life expectancies, many types of cancer have become chronic diseases, as well. The nonprofit Association of Cancer Online Resources (ACOR) maintains about 140 publicly accessible email lists dealing with

various forms of the disease. Participants provide emotional support and answer each other's questions about treatment, side effects, and hospital care. Volunteer "owners"—patients with special expertise— comb postings to ferret out bad information and unwelcome marketers.[41] ACOR reports delivering more than 1 million cancer-related email messages every week.[42]

■ *Online health education materials* are "broader in perspective, helping people to understand their diagnosis, treatment, and management in general terms."[43] They are less rigorous than decision support aids and Web-based interventions and less functionally oriented than chronic disease management aids. They contain the general information for which the Web is famous and occasionally infamous.

Regardless of one's assessment of Web-based health information, it's safe to say that improvements to online health education materials are on the way. Nonprofit organizations like Consumers Union, publisher of *Consumer Reports*, and the American Association of Retired Persons (AARP) are stepping up their production of content about health care. And the federal Agency for Healthcare Research and Quality (AHRQ) recently announced a plan to develop state-of-the-art discussions of the effectiveness of treatments for 10 top conditions affecting Medicare members. The information, in different versions for consumers and health professionals, is slated to become part of the U.S. government's National Guidelines Clearinghouse.[44]

There appears to be little, if any, data on the degree to which doctors actually create collaborative relationships with their patients, much less use Web-based tools to support the process. On the other hand, consumer surveys provide occasional insight into situations that patients view as

collaborative. For advocates of collaboration, these numbers, while sparse, are encouraging. According to Pew, 48 percent of patients who talked to a doctor about something they found online recalled that the doctor was "somewhat interested," and 31 percent said he was "very interested."[45] Another survey, this time by the National Cancer Institute and involving people newly diagnosed with cancer, found that those who went online to educate themselves about a health issue were more likely to describe their relationships with doctors as a "partnership" than were those who did not go online (74 percent vs. 54 percent). Ninety-one percent of the newly diagnosed who went online thought that the information they retrieved helped them talk to their doctors.[46]

Tools for Autonomous Roles

Various reasons impel people to tackle a condition alone, or largely so, without consulting professionals. At some point, even with someone who has collaborated previously with clinicians, the steepest part of the educational slope will have been scaled, the need for support will persist but at less intensity, and the patient, perhaps aided by a family caregiver, will begin to manage largely on his own. As a matter of medicine, economics, and personal psychology, such a transition to autonomy will often be considered a good outcome.

In other cases, cost considerations motivate patients to pursue independent courses. Not only do people with health insurance confront rising copayments and deductibles; oftentimes, coverage for mental health and other problems is subject to ceilings, while issues such as weight management and wellness get no coverage at all. Then, too, those with insurance can lose it, and others won't have it to begin with. Take some combination of these factors and mix in the independent instincts of American consumers, and a lot of autonomous activity is going to manifest itself.

Technology vendors cater to the autonomous. The most-heavily trafficked Web site in the health and fitness category is eDiets, a for-profit enterprise whose 200,000 dues-paying members select meal and fitness plans and interact with online support groups.[47] Recently, in response to mounting public interest in weight as a health issue, eDiets shifted emphasis "from vanity to vitality." Its new online magazine rearranges the order of articles according to the preferences indicated by individual readers. A subscriber with an interest in "Living with Diabetes" or "Healthy Heart" sees a relevant topic on the cover, followed by related content inside.

One thing eDiets does not do is assume that members also consult health care providers, who can seldom bill insurers for weight counseling. An eDiets representative says there's no specific data but guesses that "90 percent of our members are self-motivated," meaning, she says, that "they take part without checking with their doctors or being under a doctor's care."[48] Her estimate adds anecdotal support to the more scientific findings of a 1997 household survey, which found that 61.5 percent of alternative and complementary therapies (including diets) were used without their being discussed with a medical doctor.[49]

Off the Internet, assistive technology helps people with disabilities perform day-to-day activities and remain independent. Some assistive tools—walkers, tub seats, grab bars, and the like—are low-tech. Others are quite the opposite. At the 2004 International Conference of the Rehabilitation Engineering & Assistive Technology Society of North America (RESNA), attention focused on mobile wireless technologies and their potential to serve as "universal remotes" for accessing and controlling other devices. Other priorities included sophisticated navigational and wayfinding tools for people with visual impairments.

The market in wheelchairs offers other examples of assistive technology and self-management tools in the service of autonomy. Some new models require the user to employ some manual effort, which is important for fitness, but also draw upon battery power and motors plus sensors and microprocessors. On steep or difficult surfaces, the sensors and processors calculate the difference between the effort the user applies to the hand rim and the total force needed to propel the wheelchair forward. Then the motor weighs in with just the necessary power to get the wheels going.[50]

Independence Technology, a division of Johnson & Johnson, markets the most recent innovation, the IBOT, a wheelchair originated by Dean Kamen, who also invented the Segway personal transporter. Like the Segway, the IBOT incorporates gyroscopes into the process of locomotion in order to maintain balance while traversing grass, gravel, mud, and curbs. Users can also elevate themselves until they're eye-to-eye with those with whom they're talking. They can climb and descend stairs without help.[51]

Another product, the home heart defibriliator, serves the autonomy of informal caregivers rather than patients. It is for use in the event of sudden cardiac arrest, which occurs more often in the home than in other places and requires a quick response beyond the capacity of most emergency teams. In a somewhat controversial action, the FDA has deemed the defibrillator, made by Philips Medical Systems, safe and effective enough to be sold without a doctor's prescription. Novice users learn to apply the electronic paddles to a victim's chest by reading the manufacturer's written instructions and consulting a tutorial conducted by a machine-generated voice.[52]

Clinical investigators do not spend a great deal of time studying autonomous behavior and its associated tools, which represent a world apart from doctors and nurses. Good data is rare, especially on clinical outcomes—a situation that invites remedial action by professionals. When several investigators set out recently to do a meta-analysis of research involving online communities and electronic support groups, they had to settle for studies of multiple interventions in which the effects they sought could not be isolated; they could not find a single randomized trial evaluating Internet communities alone.[53]

Lack of professional interest aside, the incidence of autonomous behavior on the Internet alone is staggering. As of April 2004 there were almost 25,000 electronic communities listed in the health and wellness section of Yahoo! Groups.[54] The Pew Internet Project reports that about 28 million adult Americans—about 14 percent of all the grown-ups in the country—have gone online to take part in a "support group for a medical condition or personal problem."[55] Undoubtedly, people do some of this in cooperation with their doctors, as instances of collaborative role playing. But it's likely that much, and probably most, of the activity is autonomous.

Reasons for the upward march in adoption are as various as people's personal circumstances. "Online groups," noted researchers in a study of self-help communities for depression, "make it possible for anyone with a computer to overcome many of the logistical barriers to mutual-help participation, such as geographical isolation, lack of transportation, lack of groups for rare conditions ... [and] physical disabilities that make attendance difficult."[56]

Add to the multitude of Internet users the numbers of people employing assistive technologies and the numbers purchasing products, such as the home defibrillator, that promote active self-sufficiency, and the market for autonomous self-management tools is substantial.

IV. Conclusion

ROBUST MARKET GROWTH IS LIKELY FOR TOOLS enabling all four self-management roles: subordinate, structured, collaborative, and autonomous. Tools supporting subordinate roles offer added convenience, greater precision, fewer errors, and less stress. Tools for structured roles encourage adoption by clinicians and serve sensitive situations. Collaborative tools suit better-educated and more confident patients, as well as the aspirations of some doctors. Tools supporting autonomous roles accommodate a host of personal preferences and circumstances.

Disease-management experts have done a good job examining collaborative patient behavior. But less attention has been paid to the other roles that patients play and to the tools they employ; on these fronts, commercial innovation may be outpacing professional know-how. Yet it's the matching of three factors—patient role, technology, and professional response—that makes for high-quality medicine. Self-management markets will keeping growing, as will the need for clinicians to play a contributing role in identifying, developing, and applying effective techniques.

Appendix: Contributors

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