E-Disease Management

Prepared for:
CALIFORNIA HEALTHCARE FOUNDATION

Prepared by:
Gregory LeGrow and Jane Metzger
First Consulting Group

ihealthreports

November 2001

Acknowledgments

This report was written by Gregory LeGrow and Jane Metzger of First Consulting Group's applied research department, Emerging Practices. They would like to acknowledge the valuable assistance of Jeffrey Ford of FCG Doghouse Technology Services. A number of industry experts, early adopters, and vendors contributed their time and experiences, and their assistance was also critical to assembling this view of the state of the practice and the possibilities for the future. See Appendix C for a list of these individuals.

The **California HealthCare Foundation**, a private philanthropy based in Oakland, California, focuses on critical issues confronting a changing health care marketplace by supporting innovative research, developing model programs, and initiating meaningful policy recommendations.

The iHealth Reports series focuses on emerging technology trends and developments and related policy and regulatory issues.

Additional copies of this report and other publications in the iHealth series can be obtained by calling the California HealthCare Foundation's publications line at 1-888-430-2423 or visiting us online at **www.chcf.org**.

ISBN 1-929008-76-7
Copyright © 2001 California HealthCare Foundation

Contents

4 **Overview**

6 **Purpose**
What is E-Disease Management?
The potential of E-Disease Management

10 **I. Understanding the Technology**
Four Operational Models
Basic Technology Requirements
Ehealth Tools
Acquiring Technology

24 **II. Organizing E-Disease Management**
Sponsors and Their Objectives
Status of Adoption by Sponsors
Status of Adoption by Consumers

30 **III. How Effective Is E-Disease Management?**

34 **IV. Challenges, Lessons, and Practical Advice**
Defining the Disease and Population Focus
Clinical Appropriateness
User Participation
Privacy and Security
Use of Data by Third Parties
Costs and Return on Investment
Financing and Reimbursement

41 **Appendices**
Appendix A: Top Ten E-Disease Management Web Sites
Appendix B: Vendor Iinformation
Appendix C: Interview List
Appendix D: Glossary

47 **Endnotes**

Overview

Two-thirds of health plans use some form of disease management to proactively coordinate patient care and promote self-management.[1] With the potential to cut direct medical expenditures, improve health status, build patient and physician loyalty, and reduce lost work days, both health care providers and employers also are increasing their use of organized disease management to provide care and support to the chronically ill.

Success with disease management requires delivering the right interventions, at the right time, in the right way, to all the right patients. Accomplishing this necessitates a more continual exchange of data and information than is available through paper-based processes and traditional approaches to patient education and support. Therefore, it should be no surprise that applying Web-based tools to disease management—"e-disease management"—is one of the most active areas for leveraging the Internet in health care.

The vendor community has been offering increasingly robust products focused on both patients' needs and those of physicians and nurse case managers. Some health plans and provider organizations have been the early adopters of e-disease management; most purchase ready-made applications, which, in many cases, are also hosted by e-disease management vendors. Others assemble purchased elements such as disease-related content and interactive tools on a Web site that they develop and maintain.

Chronically ill consumers who must manage their disease each day are interested in a more active and informed role in their health management and can benefit from the personalization and access to tools available from Web-based technology. A growing number are becoming early participants in e-disease management, either through the sponsorships of their health plans or providers who have enrolled them in disease management programs, or by obtaining products on their own.

So far e-disease management is delivered in four operational models:

1. **Patient self-directed** focuses the tools on the patient, without electronic linkage to others involved in their care.
2. Many current products build on nurse case management, a common element in programs focused on high-risk

patients, and provide **patient support with electronic linkage to the case manager** for purposes of communication and information-sharing.

3. Similarly, a third model supports the physician care management relationship through **patient support with electronic linkage to the patient's physician**.
4. A fourth model, which can include patient-focused and clinician-focused tools, provides decision support to disease management in the **clinician practice site**.

Each of these can provide a range of tools accessed through an industry-standard PC or, in the case of some patient-focused products, a specially designed home-monitoring device. A common misconception about e-disease management is that information is necessarily flowing over the Internet. In fact, connectivity among patients and clinicians and between participants and the e-disease management application is often accomplished via a direct dial-up connection and not over the public Internet.

E-disease management is in its infancy and practical experience in how best to implement new tools and measure results is extremely limited. However, surveys of institutional sponsors and conversations with the vendor community suggest an increasing level of interest and activity. The chronically ill are a growing population that consumes a disproportionate share of health care dollars. E-disease management promises to bring more affordable and more personalized tools to the settings where decisions about care are made—in the patient's home and in the clinician's practice site. Although it is not yet clear when, how, and in what form e-disease management will gain a strong foothold, it is clear that such programs will have a place in health care.

Early adopters of these programs stress that e-disease management must be thought of as a tool for enhancing a well-established disease-management program and not a substitute for it. Therefore, an organized approach to disease management is a necessary first step. By selecting the appropriate technology and training, and by supporting users, involving physicians in program design, and providing periodic updates to clinical content and tools, e-disease management promises to reduce both program and health care costs, increase patient satisfaction, and improve quality of care.

Recommended starting points include:

- Focus first on the disease management program—its target patients and their needs as well as its organizational structure—and then on the technology. This is sometimes difficult because the technology itself is attention-getting and exciting.
- Build the program with physicians in the lead and active participants in the design.
- Use e-disease management as a way to support the patient-physician relationship and design and implement it accordingly.
- Treat e-disease management as a serious project that needs assigned accountability and staff resources. It is hard work to fit the technology into various workflows and to ensure active participation of both patients and physicians.
- Be sure to add value for physicians and their patients and require extra tasks of physicians only when there is no alternative.

E-disease management is an important element in the mushrooming arena of electronic communication in the health care field. FCG and CHCF are publishing a series of reports on aspects of electronic communications. In addition to this report, the series includes:

- Wireless and Mobile Computing
- E-Encounters
- E-Prescribing

Purpose

By 2010, 40 percent of Americans will suffer from a chronic disease.[2] Already, caring for the chronically ill consumes a disproportionate share of national spending on health care. Organized efforts to better serve these patients and bring down the costs of their care through disease management programs began about a decade ago. Sponsored by both health plans and provider organizations, early programs had limited information technology to aid physicians and other caregivers in managing patients with complex needs or to support them in managing their own health.

Web technology now offers tools for disease management that are cheaper and more accessible than both paper-based systems and traditional information technology (IT). New opportunities to enable physicians and other caregivers to support patients in the many decisions they need to make are now available. Except for anecdotal stories in the trade literature and a limited amount of research, little is known about these tools and the early experience of integrating them into organized disease management.

This report introduces the forms and functions of e-disease management, reviews the state of the practice, and offers practical advice from early adopters. It is intended to serve as an information resource for potential sponsors and users of this emerging health care Web application. The information was developed from literature searches, conferences focused on patient-interactive support and disease management, a review of the proliferating vendor products and services, and interviews with vendor staff and project managers in implementation sites.

What Is E-Disease Management?

The term "disease management" is used somewhat loosely to describe a coordinated and proactive approach to managing care and support for patients with chronic illnesses such as diabetes, congestive heart failure, asthma, HIV/AIDS, cancer, and others.

In support of disease management, the Web offers many new information tools that provide communication and access to knowledge, and enable patient self-management. In this report, any application of Web-based technology to organized disease

management is considered "e-disease management." (This definition does not require data transmission over the Internet.) E-disease management covers a broad range of applications, some focused exclusively on patients, some aiding primarily clinicians (e.g., physicians and case managers), and others supporting collaboration between patients and clinicians.

This report is organized as follows:

REPORT SECTION	Contents
Purpose	The components of e-disease management and the contributions that participants can potentially expect.
Understanding the Technology	The operational models for e-disease management, the technology that supports them, and the types of ehealth tools currently available.
Organizing E-Disease Management	Sponsors and their objectives and available information about the adoption of e-disease management by sponsors and consumers.
How Effective Is E-Disease Management?	The state of knowledge about effectiveness of e-disease management; mini-case studies.
Challenges, Lessons, and Practical Advice	What potential users must consider: selection of patient populations, clinical appropriateness, encouraging patient and physician participation, usability of technology, privacy and security, and financial issues. Practical advice for those implementing applications.
Appendices	The leading e-disease management Web sites; vendor information; e-disease management vendors and sponsors interviewed; glossary of terms.

The Potential of E-Disease Management

E-disease management is a tool for implementing disease management, not a program in itself. Therefore understanding disease management is an important first step in understanding what e-disease management is and how it can support care. Whether operated by health care providers or health plans, organized disease management programs incorporate one or more of the components in Figure 1 on the following page.

Although disease management approaches vary in complexity, they all include some combination of these elements. Advanced approaches incorporate most, if not all of them, integrated into a new care model for patients.[3-7]

Regardless of the complexity of the specific approach, information technology (IT) is a powerful enabler of organized disease management.[5] The Internet and Web-based tools make some IT support more accessible because they are cheaper and easier to implement and introduce many totally new tools. The various forms and functions of e-disease management can potentially make contributions to several of the elements of disease management.

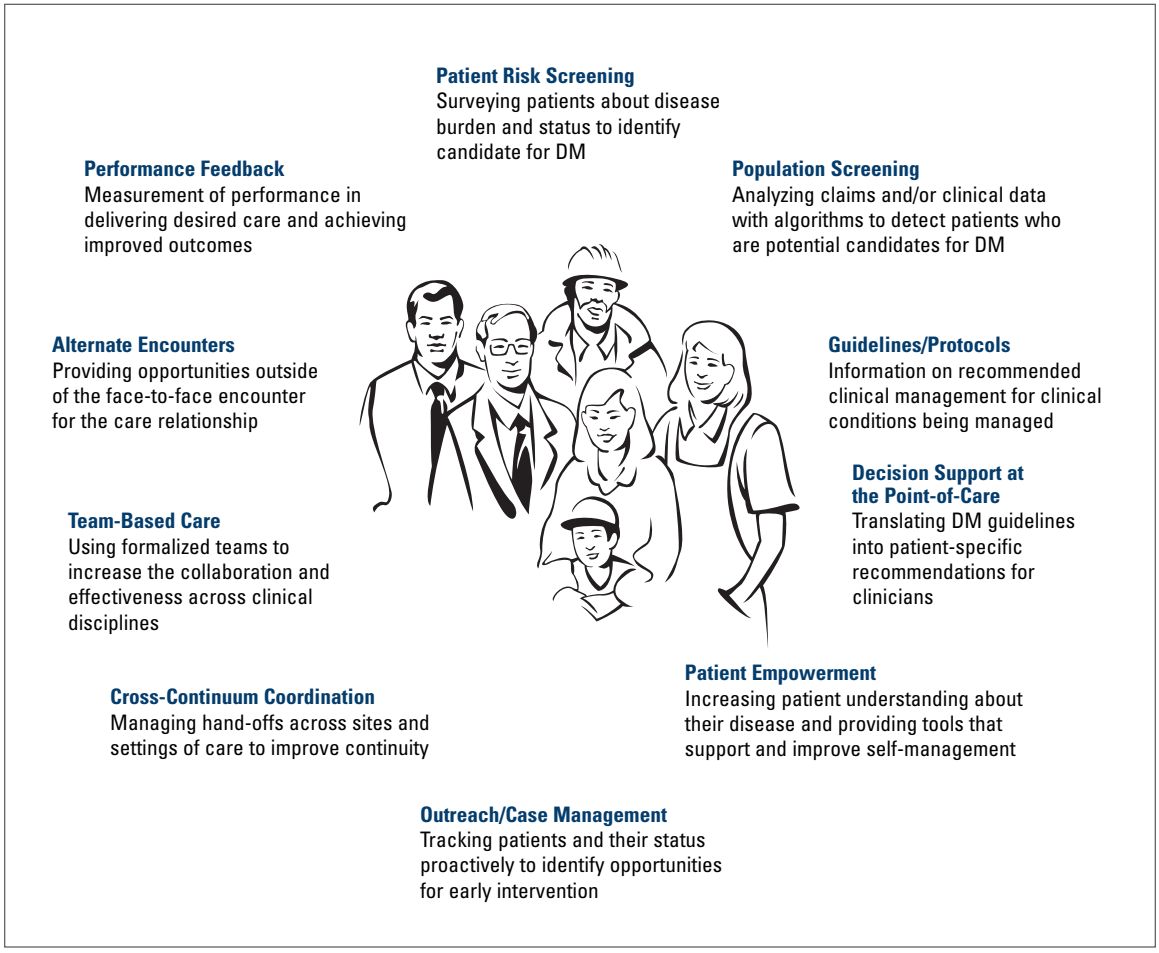
The ability to deliver decision support—both to clinicians and to patients—has been the focus of many disease management tools to date (see Table 1). This results from a widespread recognition that traditional approaches to aiding clinicians in doing the right things for their patients or in guiding patients to do the right things for themselves have not delivered good results. The advent of "e" (electronic) applications

in disease management, has resulted in improvement in several areas:

- Ease and accuracy of data entry to aid in patient monitoring
- Improved patient communication with caregivers
- 24-hour patient access to disease-specific information and interactive advice
- Improved access to patient tracking and decision-support tools in practice sites of physicians and case managers

The added contributions of the Web over traditional IT communication infrastructure are lower cost and easier access, including the locations where both clinicians and patients make the decisions that matter the most—the exam room and at home.

Figure 1. Components of Disease Management



Disease Management Program Guidelines

To fit the definition used by the Disease Management Association of America, a disease management program:[1]

- Supports the physician/patient relationship and plan of care;
- Emphasizes prevention of exacerbations and complications utilizing cost-effective, evidence-based practice guidelines;
- Emphasizes patient empowerment strategies such as self-management education; and
- Continuously evaluates clinical, humanistic, and economic outcomes with the goal of improving overall health.

In addition, to fit the definition, the program must have all of the following components:

- Population identification process
- Evidence-based practice guidelines
- Collaborative practice model to include physician and support-service providers
- Risk identification and matching of interventions with need
- Patient self-management education (may include primary prevention, behavior modification programs, and compliance/surveillance)
- Process and outcomes measurement, evaluation, and management
- Routine reporting/feedback loop
- Appropriate use of information technology

Table 1. Potential Contributions of E-Disease Management to Disease Management Programs

	POTENTIAL IMPACT OF E-DISEASE MANAGEMENT APPLICATIONS	
DM COMPONENT	**Clinician Participant**	**Patient Participant**
Patient Risk Screening	Ease of analyzing survey	Ease of completing surveys
Population Screening	Prompt notification of patients who can benefit	Personal notification*
Guidelines / Protocols	Ease of accessing best practice information	Increased understanding of and collaboration in decisions regarding management
Decision Support at the Point-of-Care	Increased likelihood of matching patients with needed interventions	Increased likelihood of receiving recommended interventions
Patient Empowerment	Increased patient compliance and effectiveness in self-management	More relevant information and tools to improve self-management
Outreach / Case Management	Increased knowledge of patient status and earlier intervention	Enhanced communication and support
Alternate Encounters	Ease of communication and increased options for meeting patient needs for care and information	Easier and more frequent access to care and information
Performance Feedback	Ease of accessing aggregate and personal performance	Access to practice comparison information*

**Necessary functions included in some product designs but not in common use today.*

I. Understanding the Technology

E-DISEASE MANAGEMENT INITIATIVES CAN VARY significantly in both their technical approach and functional scope. Below are descriptions of the operational models, the basic technology needed, and the many e-disease management tools currently available.

Four Operational Models

Current e-disease management applications connect the participants in four different ways:

- Patient self-directed
- Patient focused with case manager linkage
- Patient focused with physician linkage
- Clinician focused (physician or case manager practice site)

Understanding the significant differences in these models is important both for classifying operating programs and for getting a sense of the vendor marketplace.

Model 1. Patient Self-Directed

This model is focused on the patient; no other participants are *electronically* linked to the application. This does not mean that patients are not made aware of or instructed in the use of self-directed tools. In fact physicians and case managers often recommend such tools to their patients and may even facilitate future exchange of information.

As Figure 2 shows, patients initiate interactions by accessing self-management tools available on a commercial or private Web site. They can access public or personal areas of these sites to use the available tools. Many of the current products give ongoing support to patients by enabling them to create personal Web pages to store personal health records and capture disease-relevant information that can be printed and shared with clinicians or used in self-management.

Figure 2. Patient Self-Directed E-Disease Management

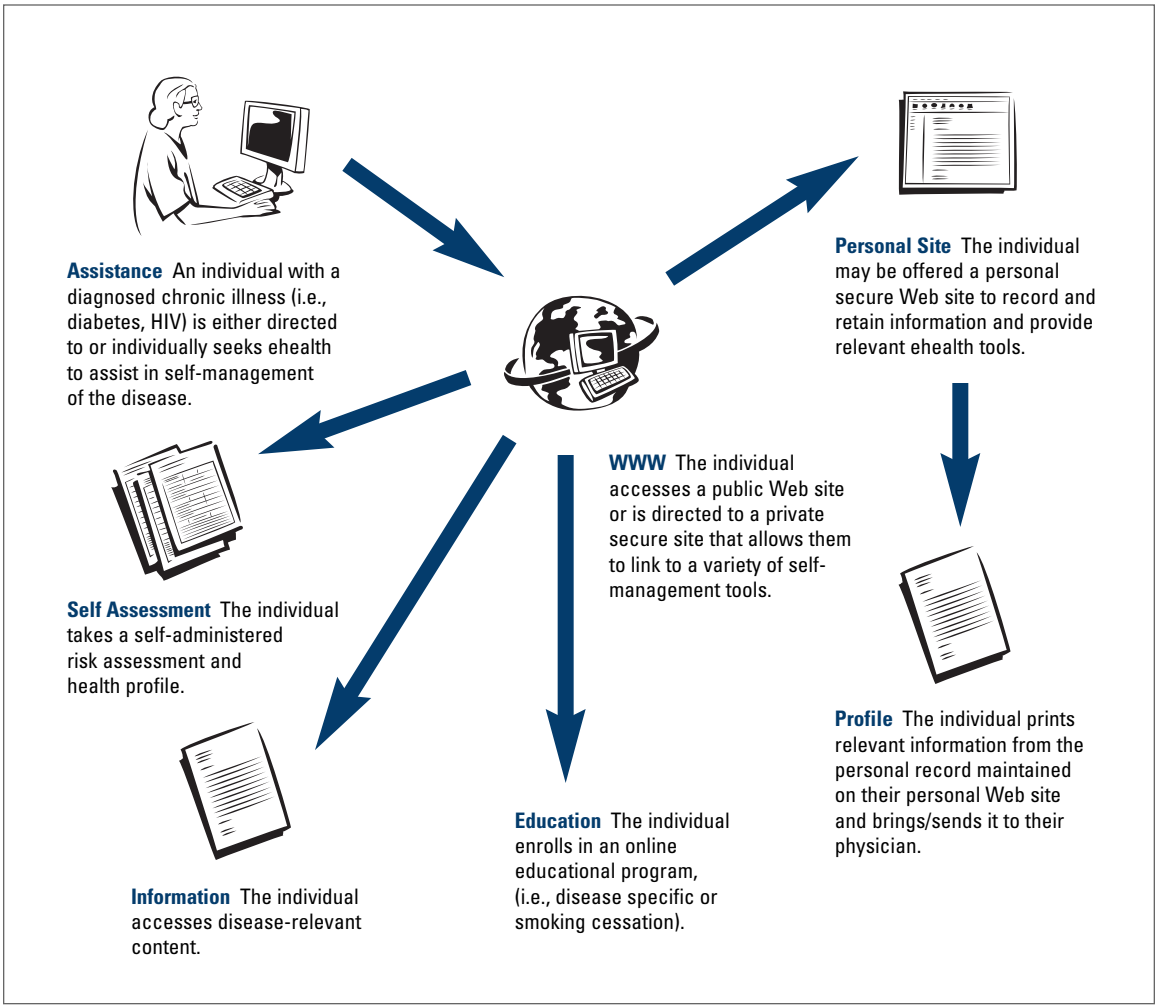
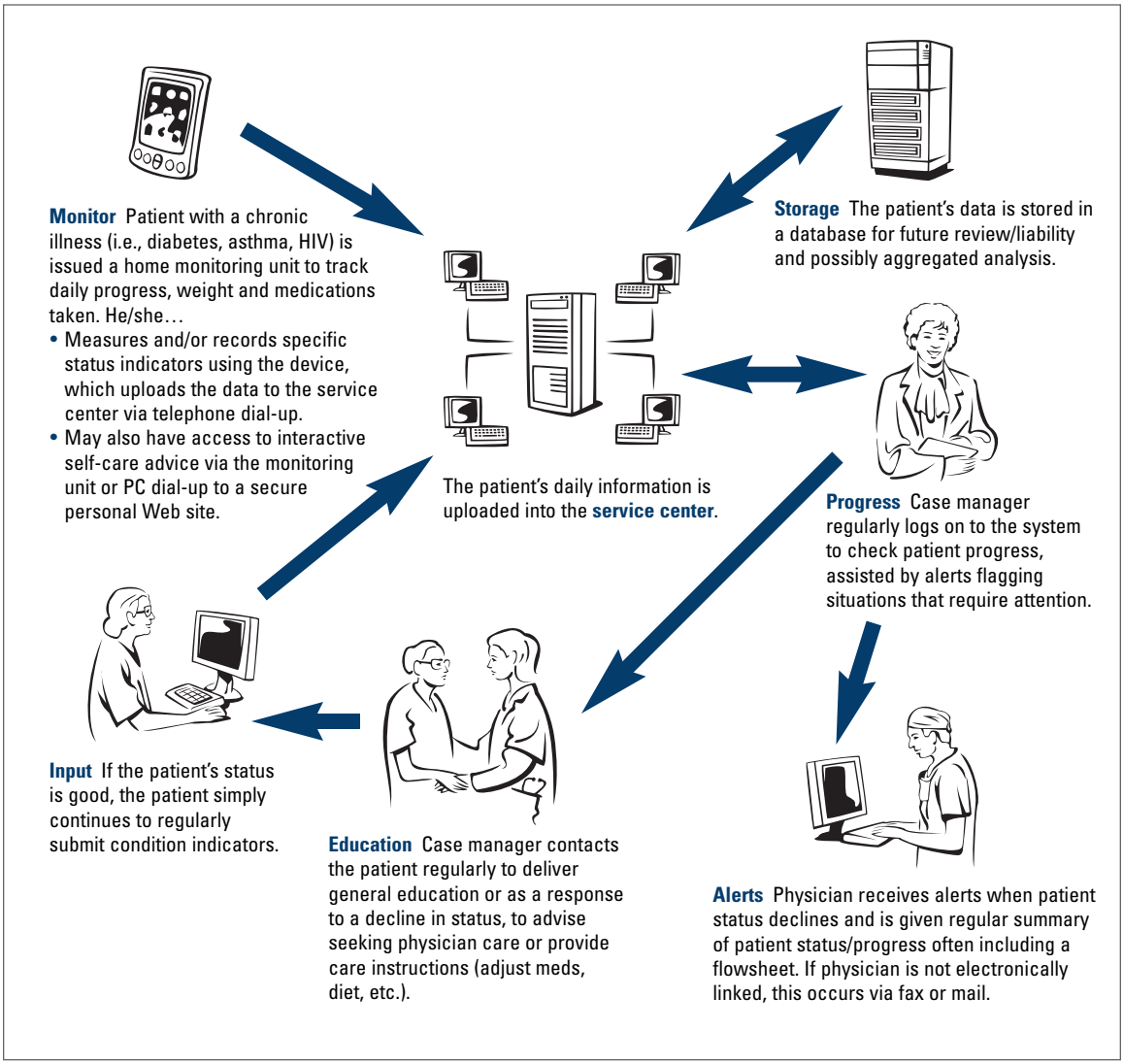


Figure 3. Patient-Focused E-Disease Management with Case Manager Linkage



Model 2. Patient-Focused with Case Manager Linkage

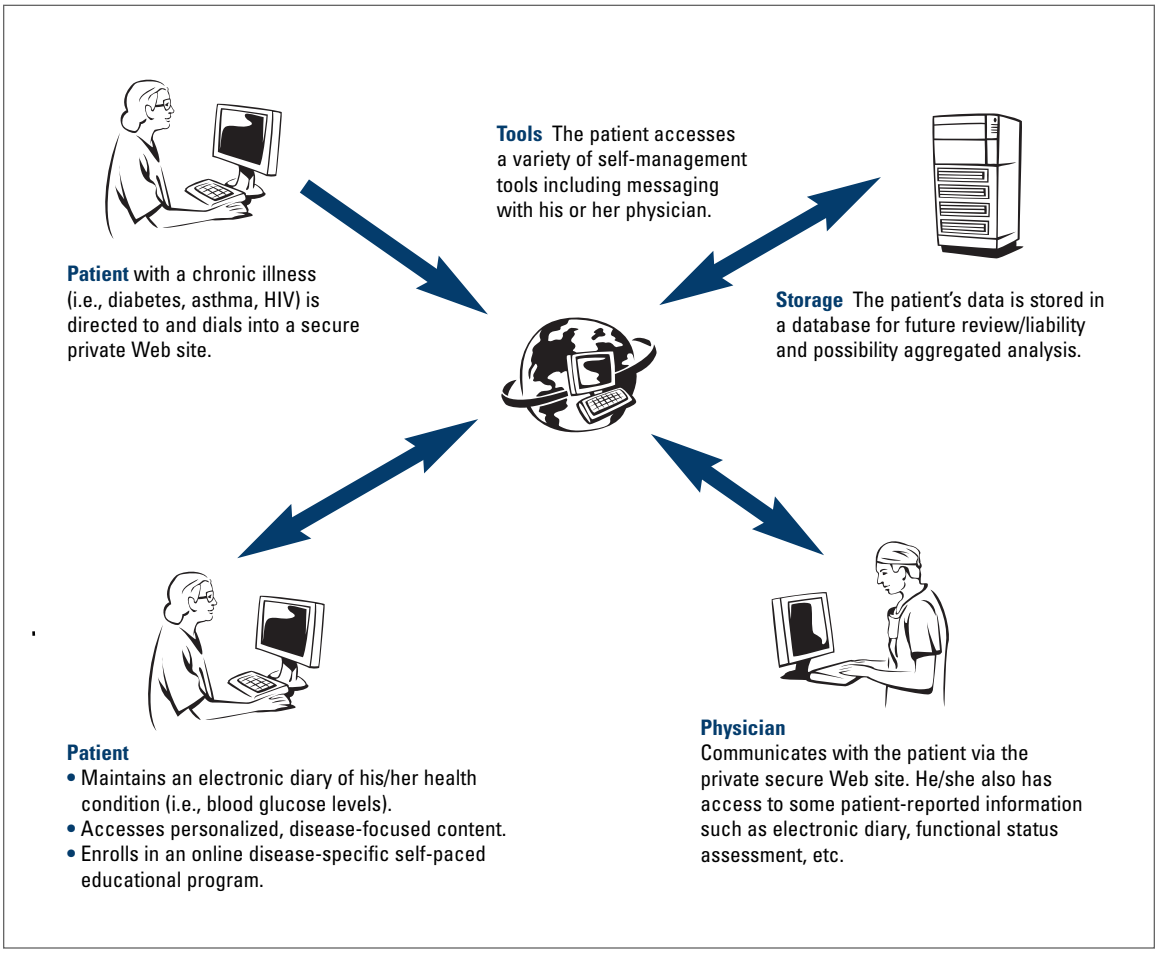
Nurse case management is a common element of disease management programs[8] and many current e-disease management products are designed to enhance communication between the patient and a nurse case manager (either in-house case management or case management that is included in the product offering). This model is apt to target higher-risk individuals who require frequent monitoring and follow-up by a case manager. As with the example in Figure 3, most approaches involve the use of a home monitor and/or PC through which the patient reports daily progress and receives interactive self-management advice and support through a variety of tools.

The case manager receives frequent updates on patient status, including a combination of measurements and answers to questions about functional status, etc. When reported physiologic metrics fall outside of normal ranges, many systems include alerts to the case manager and system-generated alerts to the patient to trigger follow-up contacts as appropriate.

Model 3. Patient-Focused with Physician Linkage

With similarities to both of the prior models, this configuration involves a patient accessing a secure Web site where he/she can use a variety of tools much like the patient self-directed model. However, unlike the self-directed model, the patient's physician is also directly linked to the application, as shown in Figure 4, and can respond to emails and/or access information stored (physiologic status measurements, etc.). Although clinician-patient interactions tend to be less frequent than in the case management model, physicians communicate directly with patients using the secure Web site to drop off and pick up messages and obtain other information.

Figure 4. Patient-Focused E-Disease Management with Physician Linkage



Model 4. Clinician-Focused

E-disease management tools are provided in the physician or nurse case manager practice site, as depicted in Figure 5 below. Although the patient benefits when receiving care, the design does not include electronic linkage with the patient between encounters.

From their offices, physicians and/or case managers use a variety of tools to assist with point-of-care management, accessible over a local area network (LAN) or through a dial-up connection to a Web site. Patients may access applications such as pre-visit self-assessments or engage in self-directed or guided education at kiosks or terminals in the practice site. Although these applications are especially valuable for managing populations with chronic conditions, they tend to be used for a physician's or case manager's entire patient population.

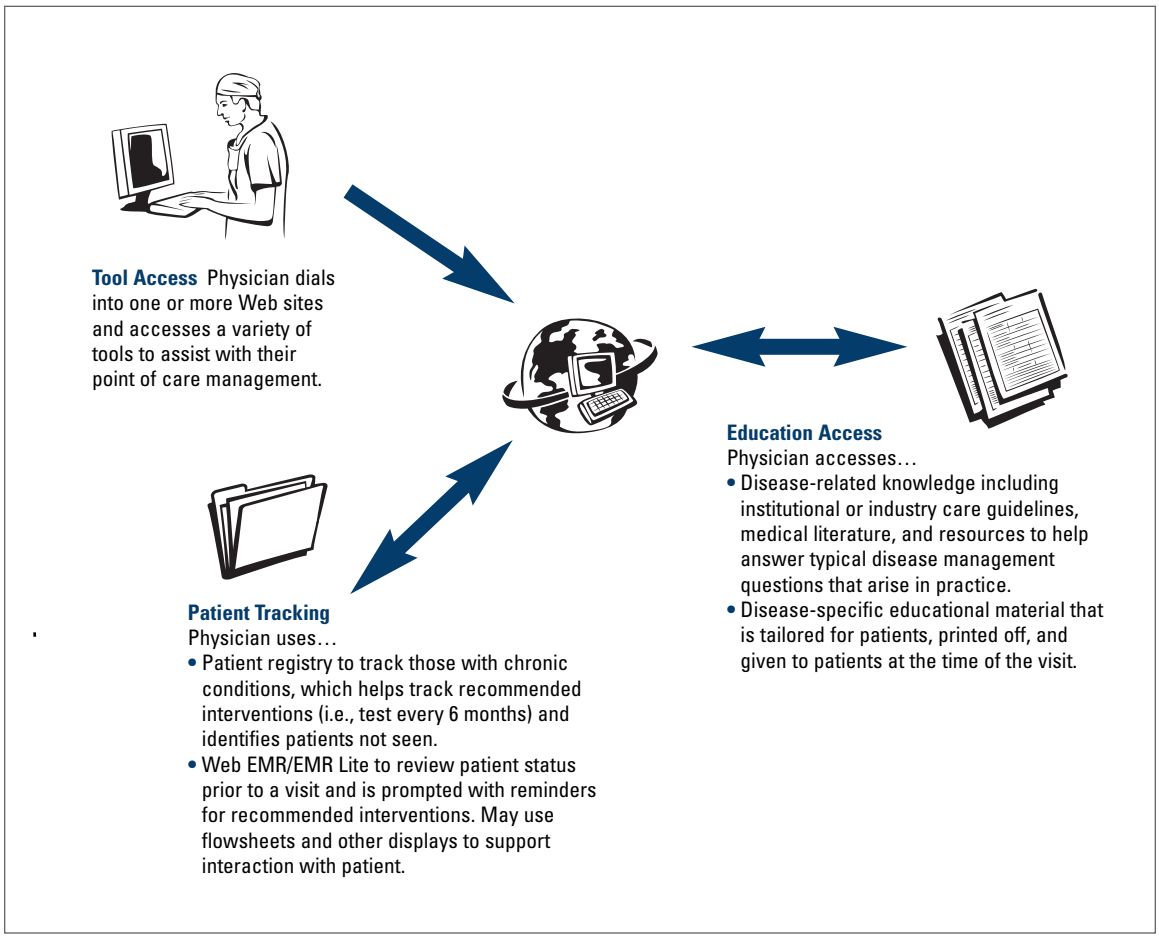
Basic Technology Requirements

One of the advantages of e-disease management is the relative ease of providing the technology for consumers or patients, their caregivers, and the sponsor or host of the program. Following is a discussion of the fundamentals of the technology.

Connectivity: Three Approaches

A common misconception of e-disease management is that information is necessarily flowing over the Internet. In fact, three different approaches are used to connect participants with e-disease management applications.

Figure 5. Clinician-Focused E-Disease Management



Direct data transfer: A direct dial-up connection via an analog phone line is used to transmit data directly to the sponsor's disease management system. Direct data transfer also includes interactive voice response systems (IVR), in which the patient uses a touchtone phone to enter vital signs and answer standard questions.

LAN dial-up: A similar approach is a direct dial-up connection; but instead of just uploading data, patients dial into the sponsor's local area network (LAN) using a PC-based modem, which they use to then interact with the disease management system.

Internet-accessed: Unlike the direct dial-up, the user goes through an Internet service provider to a Web site, accessing either a public or secured, private portion of the site. Mobile computing and wireless web devices can also use the Internet to send and receive information.

Consumer/Patient Requirements

Most products for patient self-directed care (Figure 2) require only a simple personal computer (PC) set-up, as shown in Table 2. For operational models linked with a case manager (Figure 3) or physician (Figure 4), patients use a standard PC, a special interface device designed for the application and requiring no computer skills, and/or a home monitoring device for measuring key status indicators on a regular basis (one or more times a day). PC access requires a Web browser and an Internet connection. None of the products requires the latest browser technology, but early releases may not be adequate to run all of a product's features. Similarly, slow connection speeds have at least temporarily limited data-intense applications such as the transmission of video images.

Self-monitoring is a key component of self-management for patients with chronic illnesses such as asthma (peak flow), diabetes (blood glucose levels), or congestive heart failure (weight). In some cases, a monitoring device, such as a digital scale, airflow meter, or glucometer actually takes and transmits the reading (typically via dial-up access). In others the patient enters the reading manually when connected to a Web site. Either way, there are advantages to both the patient and the caregiver over manual diaries because electronic data can be graphed, providing a better view of the patient's status over time. This method also provides a more complete picture of patient status and at a lower cost than periodic telephone calls from a case manager. Home monitoring systems often include both physiologic monitoring devices and interactive advice to the patient, either through the local device or through a dial-up connection to a personal Web site.

Wireless mobile computing technology—including personal digital assistants (PDAs) and other handheld devices connected via wireless Web—offers even greater mobility to the user. Expanding the interaction to anywhere the

Table 2. Basic Technology Requirements for Patient or Consumer and Clinician Participants in E-Disease Management

	OPERATIONAL MODEL		
PARTICIPANT	**Patient Self-Directed**	**Patient-Focused with Clinical Linkage**	**Clinician Practice Site-Focused**
All models need an industry standard PC with browser and dial-up. Other model-specific options are listed below.			
Patient or Consumer	and/or special access device (possibly home monitoring) with dial-up access	and/or special access device (possibly home monitoring) with dial-up access	✘
Clinician	✘	or LAN access	or LAN access

patient may be is particularly useful for patients on medication regimens that require frequent administration and on a pre-determined schedule (such as patients with HIV/AIDS). According to vendors interviewed, most current efforts using wireless devices are early experiments, usually involving limited data entry and viewing, as an adjunct to using a PC rather than as the sole interface for the patient. (For more information on mobile computing and wireless technology, consult the *Wireless and Mobile Computing Report* in this series.) Another tool possibly available for future adoption in e-disease management is a watch that monitors and reports to others the wearer's vital signs and can even pinpoint a wearer's location using a global positioning system.

Clinician Requirements

The primary technology requirements for clinicians and case managers linked to disease management applications are similar to those of consumers and patients. Most e-disease management applications are run either locally via LAN connection or via access to a remote Internet server using a Web site to display patient data and interact with disease management enrollees. To access the site and use the applications, clinicians need a PC with a Web browser and a LAN or dial-up Internet connection.

In some configurations, physicians are not electronically linked to the disease management application but can receive periodic reports of patient status or alerts of significant or potentially hazardous changes in a patient's condition via a phone call or by fax, pager, or email.

Sponsor/Host Requirements

The sponsor or host of e-disease management applications has greater technology requirements than other program participants. Whether the sponsor runs the application itself or has a vendor run it (an arrangement called hosting), a dedicated computer server is generally necessary to run the application and collect, analyze, and store data, as well as create and deliver personalized information to program participants. To avoid any gaps in availability organizations should run a backup server that can pick up the workload in the event the first computer server stops functioning.

Applications that support disease management are using increasingly complex and highly personalized tools, such as interactive health risk assessments and self-care plans, that can incorporate extensive decision rules and logic to guide interactions. Data mining—an application that analyzes data to understand user behavior profiles, population characteristics, and program effectiveness—is also becoming common. Depending on the application's specific functionality, level of sophistication, and integration with other systems; varying levels of hardware and supporting infrastructure are necessary to support an application.

Ehealth Tools

A large number of ehealth tools relevant to disease management can be used alone or in combination with any one or more of the four operational models described above. The different types of e-disease management tools can be categorized according to their focus or primary user:

- ***Patient-focused tools:*** stand-alone tools used by individuals without direct electronic linkage with clinician.
- ***Tools linking patients and clinicians:*** tools designed to accomplish electronic linkage between patients and their physicians or case managers, in addition to other functions.
- ***Clinician point-of-care tools:*** tools used to improve the ease and consistency of delivering care to patients under a disease management approach—can be focused on a physician or a nurse case manager.

- ***Sponsor-focused tools:*** tools of additional use to program or product sponsors.

Table 3 describes the inventory of tools in each category identified through examining a large number of commercial products and disease management programs.

Table 3. Inventory of E-Disease Management Tools

PATIENT-FOCUSED TOOLS

TOOL	Description	ACTIVE USERS			
		Patient	Physician	Case Mngr	Sponsor
Health Risk Assessment Survey	Online, self-administered risk assessment with feedback on results and recommended behavior changes. Can be used to identify disease management candidates.	✔			
Disease Assessment Survey	Online, self-administered assessment focused on a particular disease. May include feedback and action planning. Can be used to identify disease management candidates.	✔			
Personal Action Plan	A program that helps the user develop and implement self-management actions regarding their disease through specific interventions (e.g., exercise, diet, self-monitoring).	✔			
Medical Knowledge / Research	Disease-related information including educational materials, medical literature, information guides, and links to related Web sites.	✔			
Self-Education Modules About Disease and Self-Management	Self-paced learning modules focusing on disease-specific education and self-care training.	✔			
Patient-Selected Notification of New Disease Information	Electronic notification of patient-selected topics of interest. May also include pushed information.	✔			
Personal Experiences / Stories	Real-life stories and experiences shared by others with the same condition. Can include video, audio, or text.	✔			
Newsletters / Community Bulletin Boards	General health and/or disease information and postings.	✔			
Frequently Asked Questions	General health and/or disease-specific answers to frequently asked questions.	✔			
Online Clinical Trial Information	Online access to information about available clinical trials.	✔			
Online Discussion / Chat Groups	Anonymous online discussion for individuals facing similar crises and concerns. Can be facilitated or a patient-managed group.	✔			
Personal Email with Discussion Group / Chat Members	Two-way messaging that allows individual communication between discussion group members.	✔			
Online Ask-a-Nurse / Expert	Online submission and response to patient questions from a nurse or other expert not directly involved in the patient's care.	✔			

PATIENT-FOCUSED TOOLS, cont.

TOOL	Description	ACTIVE USERS			
		Patient	Physician	Case Mngr	Sponsor
Referral Directories	A database of disease-relevant services and care providers.	✔			
Personalized Health Calendar	Electronic calendaring with reminders for suggested care steps (i.e., monthly check-up).	✔			
Personal Health Profile / Record	Capture of patient-specific medical information for subsequent access by the patient. Can include self-reported or electronically fed information, or a combination. Can be disease-focused or a general health record.	✔	✔	✔	
Personal Decision Support	Program that helps patients think through difficult treatment decisions.	✔			
Electronic Diaries (manual and direct feed)	Allows patients to electronically record journal entries either using direct upload of data or manual entry. Diaries may include online feedback and can be printed and brought/sent to physicians or case managers.	✔	✔	✔	
Home Monitoring with Interactive Real-time Feedback	Home monitoring devices that measure a disease-specific status indicator and provide immediate feedback to the patient regarding their status and possibly appropriate self-management response.	✔			
Online Retail Store	Online store of disease-related medical supplies, books, and videos.	✔	✔	✔	

TOOLS INCLUDING PATIENT-CLINICIAN LINKAGE AS A DESIGN ELEMENT

TOOL	Description	ACTIVE USERS			
		Patient	Physician	Case Mngr	Sponsor
Patient and Physician / Case Manager Messaging	Two-way clinical messaging between patients and physicians/case managers.	✔	✔	✔	
Push Messaging	Electronic notification from service providers that can include both patient-specific reminders (medication reminders) and population-based ones (influenza vaccination).	✔	✔	✔	
Push Surveys	Collects patient self-reported information regarding functional status, satisfaction, etc.	✔	✔	✔	
Daily Health Questions	Collects disease-related health questions used to assess the status of patient's health and identify need for further follow-up.	✔	✔	✔	
Live Chat with Ask-a-Nurse / Expert	Online discussion with a nurse or other expert regularly involved in the patient's care.	✔	✔	✔	
Physician / Case Manager Posted Educational Materials	Health-related information focused on the specific needs of an individual posted for patients to review.		✔	✔	
Tailored or Customized Educational Material Pushed to Patients	Health-related information focused on the specific needs of an individual delivered to patients via an electronic push.		✔	✔	

TOOLS INCLUDING PATIENT-CLINICIAN LINKAGE AS A DESIGN ELEMENT, cont.

TOOL	Description	ACTIVE USERS			
		Patient	Physician	Case Mngr	Sponsor
Pre-visit Assessment	A structured approach to collecting information from a patient before a specific health encounter. Can be done online from home or at a kiosk or terminal in the practice/clinic.	✔	✔	✔	
Home Monitoring Data Flows	Electronic charting/graphing of home monitoring data (patient self-reported or downloaded from monitoring device).	✔	✔	✔	
Home Monitoring with Automatic Transmission for Case Manager Review	Electronic charting/graphing or home monitoring data with alerts when values are outside of normal or patient-specific limits.	✔	✔	✔	
Patient Personal Health Record with Clinician Access	Electronic access to patient personal health record (typically only with patient consent).	✔	✔		

CLINICIAN POINT-OF-CARE-FOCUSED TOOLS

TOOL	Description	ACTIVE USERS			
		Patient	Physician	Case Mngr	Sponsor
Registry for Tracking Patients	Tracks encounter dates and disease-specific information for patients enrolled in ongoing disease management.		✔		
Visit Plans with Status and Intervention Update	A printout or display that summarizes disease history and management status of patient, highlighting gaps in care against disease management guidelines.		✔		
Online Access to Medical Knowledge	Access to medical literature, reference works, external Web sites.		✔		
Online Clinical Care Guidelines (internal or external)	Recommended clinical management for disease conditions being managed (may be internally developed or from an external source).		✔	✔	
Frequently Asked Practice Questions	Answers to frequently asked patient ment questions, i.e., the latest thinking about treating hypertension in a patient with diabetes.		✔		
Flowsheet with Physician Observations	Electronic or manual input flowsheets that include physician observations and can be included as part of a medical record.	✔	✔		
Tailored and Customizable Educational Material	Health-related information focused on the specific needs of a patient that can be customized and given to the patient at the time of the visit and/or used during patient interaction.		✔		

SPONSOR-FOCUSED TOOLS

TOOL	Description	ACTIVE USERS			
		Patient	Physician	Case Mngr	Sponsor
Population Screening	Analysis of claims and/or clinical data using algorithms to identify potential disease management candidates and recommended interventions including patient access to information.	✔			✔
Online Risk Screening	Online survey used to identify potential disease management candidates.	✔			✔
Database Mining Tool	Tool used to analyze disease patterns of population and determine program's effectiveness based on information captured through patient- and/or physician-focused e-tools.		✔	✔	✔
Online Clinical Trial Recruitment	Online recruitment through information posting and pushes to recruit potential clinical trials candidates.				✔
Push Info About New Programs and Products	Electronic notification from sponsors regarding new programs and/or products.				✔

Bundling of Tools

Almost all e-disease management products now offer more than one of the tools shown in Table 3, but even within categories, none employs all of them. However, there is a trend in the marketplace toward the bundling of tools to create a comprehensive application.

Success of any interactive Web portal requires regular customer use. This is especially true of patient-focused applications, which seek to become the user's trusted source of information and daily self-management support. Commercial vendors selling to individual consumers and institutional sponsors, such as health plans and provider organizations, share this interest in being the preferred source on which the customer relies. Providing value to users, by meeting their multiple needs for information and assistance, is important to gaining a high level of use. This is sometimes termed "stickiness."

Bundling of tools for e-disease management is also a result of the maturation of products from initial informational offerings to more interactive and personalized ones. Vendors' limited success in building a viable business on information access alone has also contributed to packaging tools together. In its fairly short life, the vendor community has already undergone much consolidation, as companies work to gain market presence in the consumer or physician market. The trend toward broader product offerings is sure to continue.

Bundling of tools also offers a way to ensure that individual patients find the mix—in terms of content and presentation—most effective for them and suited to the particular stages of their illness. Some tools, such as those offering knowledge access on treatment options, risk assessment for complications, and individualized care planning, are more suited to the patient with a newly diagnosed illness. Tools supporting daily management come into play later.

Depending on the individual's learning style, he/she may choose to gain information and support through reading health material, participating in discussion groups, using ask-an-expert features, or reading personal stories. Research results from early sites, such as the one created as part of the CHESS project (Comprehensive Health Enhancement Support

System) by the University of Wisconsin-Madison Center for Health Systems Research, has shown that patients with the same illness use very different tools, depending on their preferred style of interaction.[9] Some product designs allow patients to select features such as health topics and tools and to sign up for reminders and other outreach features, thus permitting further customization of interactions.

Patterns of Bundled Tools

The current marketplace includes almost every possible combination of ehealth tools focused on disease management. However, there are a few discernible combinations that are becoming common:

- Home monitoring systems tend to come with interactive advice provided either through automated program logic or direct caregiver feedback. In addition to uploading data (from physiologic monitors or self-reported), these products often allow the patient to review flowcharts and educational content.
- Personal Web sites tend to offer ehealth tools providing disease-focused content and a range of other aids to self-management. Most common are diaries and personalized care planning support. Least common today are e-retail and information on relevant clinical trials.
- The personal health record is almost never the only ehealth tool offered. Increasingly, this feature is bundled with disease-related content, health diaries, and flow sheets. Disease-focused personal health records often include additional bundled features, such as disease-related chat groups.

Acquiring Technology

As with any software application, sponsors of e-disease management tools must decide on the most appropriate means of obtaining and assembling applications for their customers. Factors to consider include local IT resources and capabilities, the organization's approach to its Web initiatives overall, the complexity of the application, cost, and the desired time frame for rollout. Sponsors need to decide both how they will obtain the application and whether they will host and maintain it. Here are some details about the build, buy, and outsource options.

Build

Few sponsor organizations are opting to build an entire e-disease management offering internally. Instead, those who adopt a build approach often develop a site that acts as a shell tying together a variety of ehealth tools. Although some tools may be built in-house, others—such as content for health libraries, self-assessment and self-management tools, newsletters, and other information sources—are often obtained in the marketplace. Even vendor-developed applications typically include elements acquired from other vendors, especially in the areas of medical content and medical news. (Appendix A includes a listing of award-winning disease management Web sites, all of which include a number of elements and provide a good introduction to the state of the practice.)

Buy

Sponsors who choose not to build can obtain assembled applications from e-disease management vendors. The vendor marketplace now includes a large number of applications that can set up personal Web sites for patients and/or physicians and include many features and information resources. Although there are still single-disease-focused products, typical application suites cover several disease states and allow the sponsor to serve a number of disease management programs through a single source. Some combine general wellness with disease-oriented modules, permitting the sponsor to serve an even broader population of patients.

There are several financing mechanisms available to sponsors that do not wish to buy an e-disease management product outright. Most vendors offer their products via an application service provider (ASP) in which applications are leased on a subscription basis and priced on a per-patient- or per-physician-basis. Regardless of the procurement method chosen, most vendors brand the offering to identify the sponsor organization and provide some ability to customize products to include or omit functions and modify content or presentation.

Current vendor products support the four operational models described previously. Figure 6, compiled in March 2001, depicts the e-disease management marketplace, including representative products in each category. (Note that this includes products for in-house disease management and outsourced case management.) The organization of the marketplace corresponds to the operational models: patient self-directed (Model 1), patient-focused with case manager or physician linkage (Models 2 and 3), and tools focused on the practice site of the case manager or physician (Model 4). (Appendix B provides vendor and contact information for every product listed.)

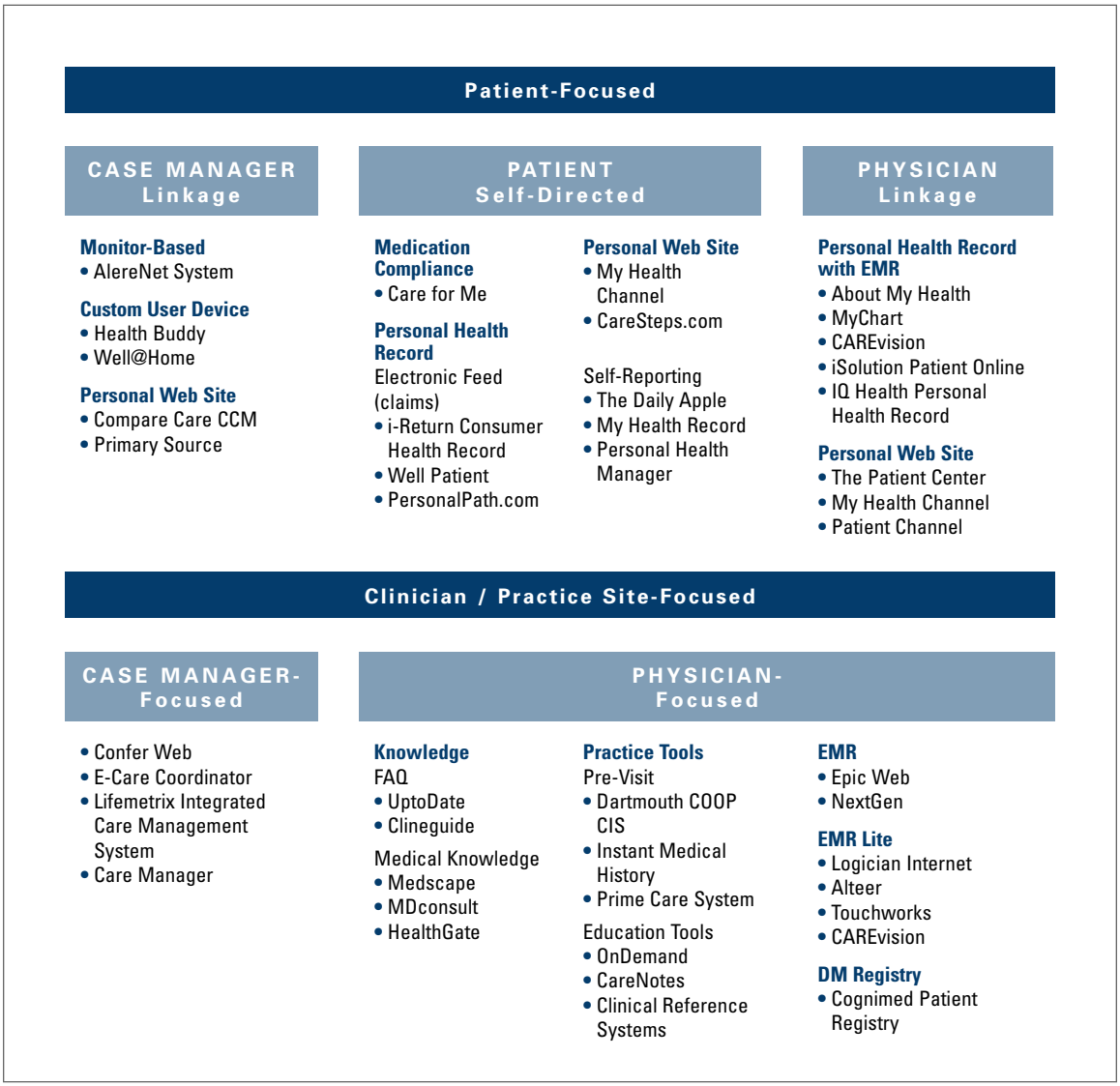
Outsource

Organizations that do not wish to run their own disease management programs completely in-house can:

- Outsource case management, or
- Outsource care responsibility for the group of patients entirely.

Vendors of both types tend to rely heavily on e-disease management tools. Representative examples of the first type are included in Figure 6.

Figure 6. Overview of the E-Disease Management Vendor Market



II. Organizing E-Disease Management

E-DISEASE MANAGEMENT IS AVAILABLE IN MANY forms and is adopted in different ways by consumers and institutions. This section describes current models for sponsorship and available information about the adoption of e-disease management.

Sponsors and Their Objectives

Potential institutional sponsors that decide to assume the cost of consumer use (and sometimes also physician use) of e-disease management products and services may be influenced by one or more business interests. Table 4 summarizes the major business objectives of sponsors.

Potential sponsors with the greatest direct *financial* interest in improving the management and status of patients with chronic disease are payers, providers with capitated reimbursement (including outsourced disease management companies), and employers; this is because any reduction in utilization of health care services represents a dollar savings in costs of care and, for employers, more productive work time.

Given that taking care of patients is their core business, many provider organizations and health plans also see the excellence of care and service they deliver as a strategic priority. This impetus is reflected in a number of broad industry initiatives such as the National Chronic Care Consortium and the IHI Chronic Care Collaborative, which involve many health systems and physician practices with limited, if any, capitated reimbursement.[3, 10] The increasing focus on population-based performance measurement from JCAHO, NCQA, and CMS (formerly HCFA), as well as growing interest among employers, will continue to reinforce this priority.

The three main sponsors of organized disease management—health plans, providers and employers—also have an interest in supporting their patients, members, and employees in more effective health management because many of these people are already online and wish to become more actively involved.

There are a number of reasons why many physicians welcome e-disease management. First, they are aware that patients with chronic illness are not very well served by traditional encounter-based health care, and physicians are often frustrated in their attempts to meet these patients' needs for care, information,

Table 4. Business Objectives of E-Disease Management Sponsors

	POTENTIAL E-DISEASE MANAGEMENT SPONSORS				
BUSINESS OBJECTIVES	Providers	Health Plans	Employers	Pharmaceutical Companies	Vendors
Improved Patient Status / Reduced Service Utilization	✔	✔	✔		
Excellence of Service and Care	✔	✔			
Consumer Satisfaction / Retention	✔	✔	✔		
Physician Satisfaction	✔				
Opportunity to Market Other Products and Services	✔			✔	✔
Opportunity for E-Retail				✔	✔
Opportunity to Bundle with Other Routine Business Transactions	✔	✔	✔		
Third-party Use of Data				✔	✔

and support. When the physician practice or umbrella organization, such as a hospital or health system, provides tools that many patients desire, the result can be increased patient recruitment and retention. In addition, physicians generally welcome IT that helps them in their work and benefits their patients, as can be accomplished with both patient- and practice-focused e-disease management.

Sponsors benefit from the referral directories facilitating access to providers, specialty services, and educational offerings that are common elements of many bundled e-disease management offerings. For the sponsor, this can represent an additional way to market products and services. Some applications also allow consumers to sign up for "push" messaging on selected topics. This channel to consumers is a major motivator for pharmaceutical companies and other sponsors who are investing heavily in direct-to-consumer marketing and for vendors who offer additional e-products or services. Recruitment of patients for clinical trials is part of the business model for a number of commercially available e-disease management products. Another revenue generator for some commercial ventures is e-retail of disease-relevant products, such as medical supplies, books, medical equipment, etc.

Although not directly related to disease management, institutional sponsors can also be motivated by the opportunity to have patients/members perform other business interactions online. The most common examples are patient requests for prescription renewals and appointments transmitted to a physician's practice via electronic messages rather than by telephone. Examples for health plans include customer ability to view insurance coverage information, switch primary care physician, or request an insurance card. Many online patients welcome this mode of conducting their routine business. For the sponsor, transferring telephone, fax, and paper communications with customers to the Web offers better customer service and lower administrative costs.

The rich database of information that is built when large numbers of patients use e-disease management tools to document their status, health management behaviors, preferences,

medications, and other treatments is of commercial interest beyond providing insight into populations to the organizations responsible for their care. Because of the early diffusion of the technology, this is more of a potential than a reality today, but selling access to aggregated information is part of the business model for some vendors and potential sponsors of e-disease management alike.

Status of Adoption by Sponsors

Except for static displays of information accessible over the Internet, e-disease management is in an early stage of adoption, particularly as part of an organized disease management program. This section reviews the current state of adoption, based on limited published information and conversations with early adopters and vendors.

Provider Organizations

Provider organizations (or their physicians) have the advantage of being the preferred source for online information about health care. The chronically ill online consumer shows an even stronger preference than the online consumer for receiving health care information from their own physician, with 87 percent reporting that as their top-rated source.[2]

Interest of General Online Population in Sources of Health Care

	Percent
Own doctor	62
National experts	61
Hospitals	58
Insurance company	45
Drug company	42
Internet company	42
Media company	33

Source: CyberDialogue 2000

Despite this advantage, health systems, hospitals, and physician practices are still in the initial stages of offering tools to their patients. Figure 7 shows the current status of disease-related and general patient support tools offered by 70 hospitals and health systems in late 2000 and early 2001.[12] Health care content—the most widely available ehealth tool—is fully implemented in only about one-third of this sample. Both personalized health content and home-based monitoring linked to records are rare; but these numbers could look somewhat different in a year or two, since 20 percent of the organizations indicated that adding this functionality was a high priority for the next year.

In this sample of provider organizations, efforts to offer e-disease management tools to physicians are also in the early stages, as shown in Figure 8.[12] Again medical content is more widely available than either patient-physician email or decision-support tools, such as patient disease management registries, medical records, or care management guidelines integrated with electronic ordering. Progress may be faster in making these tools available—with 19 percent assigning a high priority to adding a patient registry and 22 percent to having orders integrated with guidelines in the next year.

Increasingly, individual physicians offer information and tools to patients on personal and practice Web sites. According to one recent survey, 37 percent of physicians have a Web site for their practice and another 16 percent are interested in having one in the future.[11]

Figure 7. Implementation Status of Ehealth Functions by Hospitals and Health Systems

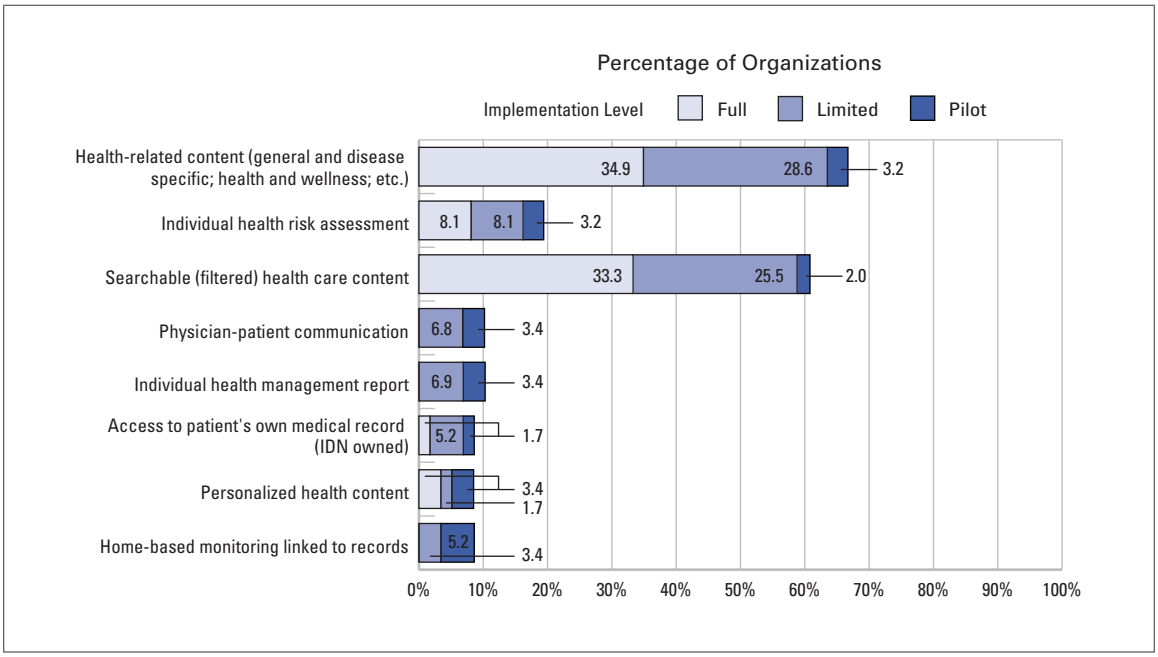
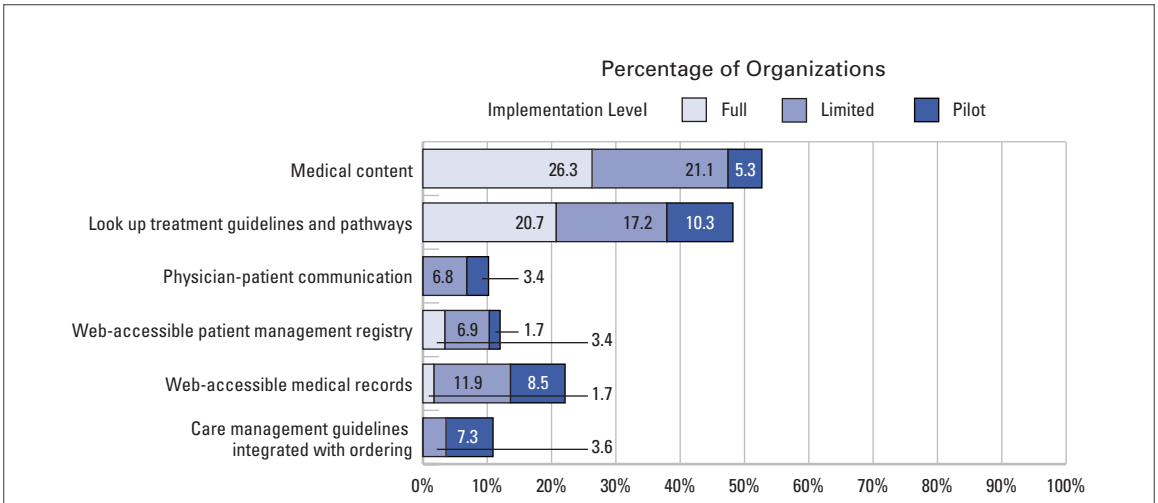


Figure 8. Current Implementation Status of Ehealth Functions for Physicians, Hospitals, and Health Systems



Source[12]

Health Plans

Most health plans are engaged in one or more organized disease-management programs for their members, and larger plans often have a full portfolio of programs. According to the Disease Management Purchasing Consortium, these include in-house and outsourced programs focused on case management and personal support. Roughly 25 percent of programs involve a pharmacy benefits management company, 20 percent are in-house programs, 40 percent involve a disease management company, and the remainder offer a combination of approaches.[13]

Health plans can participate in e-disease management in two ways. For in-house programs, many offer ehealth tools (in-house developed, purchased, or a combination) to members and physicians on their own Web site. One survey completed in late 1999 showed implementation of relevant tools as summarized in Figure 9.

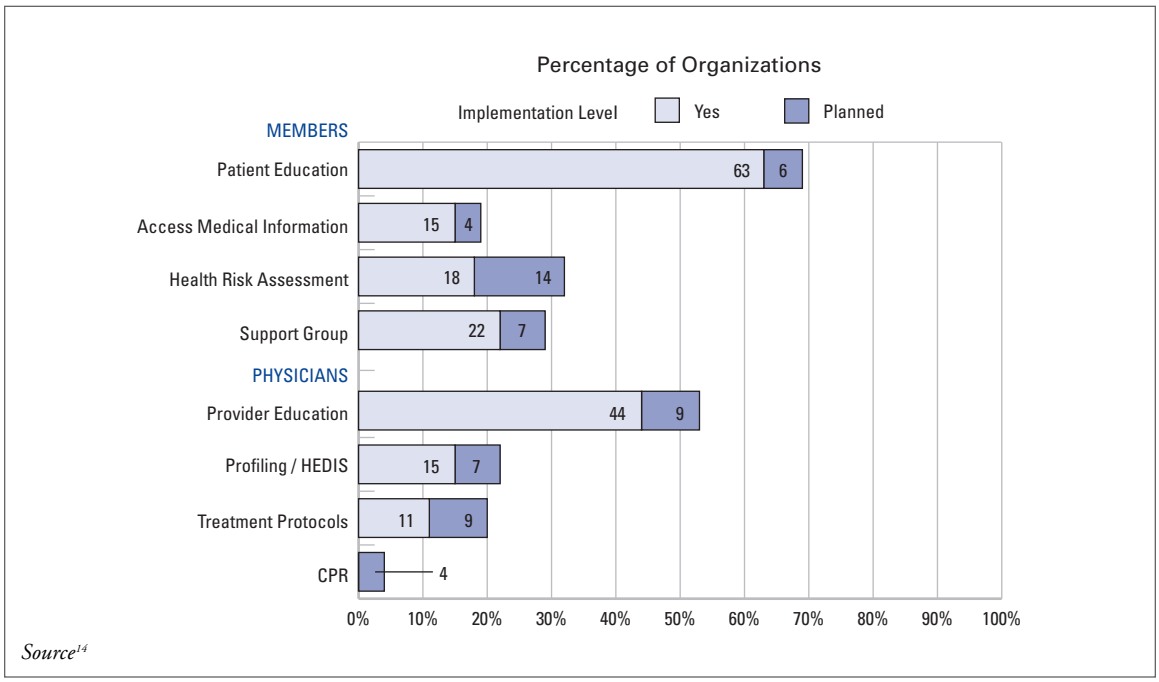
Although passive functions such as access to information (medical content, treatment protocols) were more common than interactive tools such as health risk assessments and support groups for members, many of the health plans not already offering more complex tools were planning to do so.[14]

Many health plans outsource disease-management-related support for certain groups of patients to companies such as LifeMasters, Alere Medical, and CorSolutions, which provide monitoring and outreach to designated patients through a combination of nurse case management and e-disease management tools. Frequently, those that started out with telephone-based monitoring and communication are migrating to the Web-based approaches.

Other Sponsors

Adoption of e-disease management by other sponsors such as employers, pharmaceutical companies, and pharmacy benefits management companies is not well documented. According to vendors, however, employers are increasingly interested in chronic disease management and making e-disease management tools available to their employees who can benefit.

Figure 9. Implementation Status of Ehealth Functions for Member and Physicians: Health Plans



Source[14]

In one recent survey of companies from different sectors of the life sciences industry, every company was focusing early Web efforts equally on consumers and physicians, and including disease-related information and tools in the mix of functions.[15] Some vendors of e-disease management products have also announced partnerships with pharmaceutical companies and pharmacy benefits management companies, so more activity in this sector is likely.

Status of Adoption by Consumers

During the second half of 2000, the number of adults in the U.S. with Internet access grew from about 88 million to more than 104 million.[16] Individual consumers have shown a great deal of interest in disease-related information since the early days of the Web. Accessing health and disease-related information continues to be one of the primary online activities, with somewhere between 60 million[16] and 100 million[17] people having done so at least once.

Not surprisingly, the 35 percent of online health consumers who are chronically ill, and family members and others who are caring for them, value the information and ehealth tools now available. In fact, this is a highly motivated population, living with and managing chronic illness on a daily basis.[2] Providing personalized information and support at the times most useful to the chronically ill is one of the unique contributions of e-disease management.

Online Chronically Ill Seek Information on:

	Percent
Newest treatments/medications	76
Drugs and pharmaceuticals	52
Diet and nutrition	39
Alternative medicine	30

Source: Institute of the Future 2000[2]

However, data are scarce on consumer usage of e-disease management tools beyond basic information sources, and little is known about how those currently online obtain e-disease management tools. One approach for consumers is to seek out and purchase services on their own. Typically, this is by subscription, with many vendors charging monthly fees in the same range as what consumers pay for cable television. Products are advertised and identified through search engines, hot links, etc. Consumers can also be informed through recommendations from their physician, even if the physician is not in a position to cover the cost. Some vendors offering ehealth tools and services to the general public report a growing number of customers, but still accounting for only a tiny fraction of the Internet savvy population. The lack of business success of ventures based on selling information and other ehealth tools suggests that many prefer free sources.

For free access to e-disease management tools, consumers can go to a host of sources, including: commercial vendors whose business model relies on other sources of revenue; their provider organization or physician practice; their health plan; their employer (possibly); or other organizations such as pharmaceutical companies, pharmacy benefits management companies, etc. These sponsors may find it worthwhile to offer e-disease management at no cost to the consumer because of other objectives or business models. In fact, all of these potential sponsors of e-disease management are beginning to compete actively for the attention of this market.

III. How Effective Is E-Disease Management?

THE EFFECTIVENESS OF E-DISEASE MANAGEMENT is of great interest to developers fine-tuning their approaches, to vendors approaching the marketplace with products, and to potential institutional sponsors trying to decide whether and how to become involved. The use of computer technology to provide interactive education and support to patients is new, and employing the Internet or Web-based tools to deliver it even newer. Consequently, the theory and practice of evaluating effectiveness of these new tools is still evolving, and the body of research results small.

One of the earliest researchers in this field, Patricia Brennan, has developed a framework for characterizing the use of interactive health services delivered via computer networks, which is applicable to e-disease management.[18] This includes "metrics of use" and "metrics of effects" as summarized in Table 5.

Table 5. Framework of Measures of Effectiveness for Patient Interactive Technologies

METRICS OF USE*	Description
System-Level Evaluation	Accesses, duration of accesses, percent of target population
Service-Level Evaluation	Number and duration of accesses to available functions
Session-Level Evaluation	Timing and sequence of activities within a session
Subject-Level Evaluation	Access timing and duration, nature and reasons (age, gender, language, education)
METRICS OF EFFECTS*	**Description**
Patient Knowledge	Comprehension of key information about disease and self-management
Health Management Behavior	Follow-through on regular activities of health management and behavior modification
Health Service Utilization	Usage of regular, acute, compliance, and emergency care
Health Outcomes	Population health status (disease-specific indicators) or achievement of personal goals
Patient-Clinician Relationship	Substitution for face-to-face and telephone care; continuity of care and communication

**Source*[18]

Metrics of use are of most interest to developers of e-disease management applications as they assess application design in terms of usability, value of various features, user willingness to enter information, etc. Many of these measures are within the reach of institutional sponsors of e-disease management as well. A number of the vendors offer standard reporting on system- and service-level usage and encourage organizations to monitor this as part of managing the overall program. One vendor offers physician-level reporting (patients enrolled, usage of application for messaging, and other functions) as a window into physician participation in referring patients and supporting use.

Metrics of effects are of interest to sponsors seeking to validate pilot efforts or support decisions about expanding e-disease management to additional patient populations. They are also important to all of the potential sponsors waiting on the sidelines and seeking to understand the business case.

The *promise* of e-disease management is based on theory and research evidence that the personalization and access available from interactive patient decision support can produce better outcomes than traditional approaches based on education and paper.[19] The following examples involving insulin-dependent diabetes—one of the most studied disease states—are illustrative:

- In one comparison of computer-aided logging of glucometer readings with a manual log book approach, graphical and statistical presentation of data for patients resulted in improved self-management (reduction in glucose levels, increase in levels within the patient's target range, and decline in hypoglycemic events).[20]
- In another study of transmission of home glucometer results via modem to the patient's physician versus standard diary results, blood glucose levels in the computer-aided monitoring group were significantly improved.[21]

Interactive support via *telephone and interactive voice response* has also been shown to improve self-management when applied to diseases such as hypertension and diabetes.[22–26]

What few data have emerged about the effectiveness of e-disease management comes primarily from the research community, notably Case Western Reserve and the University of Wisconsin. From each of these academic centers came some of the earliest experimental applications of computer-based (and then Web-based) interactive disease management tools—ComputerLink and the Comprehensive Health Enhancement Support System (CHESS)—and the only formal research.

ComputerLink

ComputerLink, a specialized computer network for caregivers of persons with Alzheimer's disease, is delivered over a free, public-access community network in Cleveland. It provides peer support, professional advice, education, and counseling. Research has demonstrated high levels of participation, user satisfaction, and a reduction in the use of traditional community-based care costs.[27, 28, 29, 30]

CHESS

CHESS is a computer-based support system focused on specific populations (initially AIDS/HIV and breast cancer, now expanded to other diseases). It provides information, support, and problem-solving tools including an instant library, frequently asked questions, decision aids, personal assessment tools, Web links, ask an expert, discussion groups, and personal stories. Research has shown heavy use and higher quality of life in several dimensions (social support, cognitive functioning, more active life), and user-reported reductions in some types of health care costs. CHESS is now being implemented by a consortium of organizations around the country.[31, 32, 33]

The vendor community has also contributed to the slowly growing body of research on the effectiveness of e-disease management; such research is focused primarily on the reduction in costs for patients using their e-disease management application over patients enrolled in a disease management approach without interactive technology or a different one.

Health Hero

In July of 1999, the CHW (California Healthcare West) Congestive Heart Active Management Program, or "CHAMP," run by the Mercy Heart Institute, began using Health Hero with 200 of the program's 400 participants. CHAMP, which had previously used telephone-based case manager support, provided half their patients with a Health Buddy home monitoring device. Case managers used Health Hero's Web page to review patients' data and submitted daily questions and educational information directly to their Heath Buddy device. Patients used the Health Buddy to respond to a case manager's questions using a simple dial-up connection.

Consistent with other research, CHAMP, using case managers and telephone-based outreach, had a significant impact on outcomes. It reduced hospitalizations and ER visits by 66 percent, total bed days by 61 percent, and direct-variable costs by $7,885 per patient per year (PPPY) when compared with standard care.[34] The group using the Health Buddy device, when compared to the same standard care group, recognized even greater savings. The total number of hospitalizations and ER visits decreased by 73 percent, total bed days by 80 percent, and total direct variable costs by $9,151 PPPY. Additionally, 90 percent of the patients using the Health Buddy felt that ongoing communication with their physicians was as good, if not better, when using the Health Buddy.[34]

LifeMasters

LifeMasters, a vendor that also provides e-disease management for congestive heart failure, measured differences between a group of patients using personal computers with Web access and a group of patients using a telephone-based interactive voice response (IVR) system. Results showed that the Web group had fewer hospitalizations and a lower total length of stay. Additionally, the Web group had a higher compliance rate for vital sign entry even though the time to do so took slightly longer than through the IVR process. The difference in cost savings between the two groups was not significant.[35]

The research revealed encouraging information about the ability of non-technology-savvy users to participate in e-disease management. The study group consisted primarily of elderly patients, 92 percent of whom had never used a computer. With more than 80 percent compliance in vital sign entry, the Web group not only adapted to the technology but also began to use it for other activities, such as email, games, and exploring other areas of interest.[36]

Some research evidence suggests that Web-based tools focused on the physician practice can also assist with care management of patients with chronic disease.

Diabetes Care Program Supports Physicians

To support routine monitoring and screening, the Center for Health Services Research, Henry Ford Health System, provided Web-based tools to primary care physicians responsible for HMO patients with diabetes.Tools such as clinical practice guidelines, patient registries, and performance feedback reports were accessed through the corporate intranet used by physicians to access an existing electronic medical record.

A nonrandomized, longitudinal study was performed to examine the effect of usage frequency on the likelihood of patients receiving recommended testing interventions and examinations. Some modest improvements did occur:[37]

- The patients of frequent physician users (12 or more system sessions) were 19 percent more likely to receive lipid profile testing.
- An association between system usage and retinal examination was observed.

In the initial implementation, over one-fourth of the physicians provided with the Web tools actually accessed the system. As the project moves forward, the team is evaluating other methods for engaging physicians and practice staff through additions—such as automated tracking and reminders—geared to integrating the support into routine care.

IV. Challenges, Lessons, and Practical Advice

"A device is not a disease management program. However, when integrated into a well-designed DM program that includes appropriate physician incentives and organizational infrastructure, ehealth technology can contribute to program effectiveness by augmenting communication with patients and increasing the efficiency of data collection and nurse case management."

— Dr. Gordon K. Norman
VP of Health Care Quality
PacifiCare Health System

Successful adoption of e-disease management presents a number of challenges. The following describes some of these, incorporating advice from early adopters and vendors based on their experience to date.

Defining the Disease and Population Focus

E-disease management is being deployed in two different ways: broadly to large groups of patients, and integrated into existing formal disease-management programs targeting particular groups of patients. Either approach involves a strategy and plan, but the latter approach also builds on the foundation of an existing program.

Adding new technology to an existing program is much easier than starting from scratch, and the sponsor is more likely to end up with a sustainable and effective effort. The disease and population focus have already been defined, and many of the other program elements necessary to manage the technology are already in place: clinical governance and care management guidelines; process elements to identify and enroll patients as well as to provide coaching and education; and other organizational infrastructure such as physician champions, nurse educators, and nurse case managers.

Clinical Appropriateness

Virtually all e-disease management applications include clinical content and other interactive advice for patients. Any sponsor needs to ensure the validity of information and tools, as well as the consistency with clinical goals of the disease management program. For applications including nurse case management, the same extends to the boundaries and clinical protocols that guide interactions between case managers and patients.

Whether clinical content and advice protocols are developed in-house or purchased, sponsoring organizations should institute a clinical review by a designated physician responsible for the disease management program and/or a clinical steering committee. A clinical steering committee is advised when there are multiple programs and a need to ensure consistency across them.

There are as yet no accreditation guidelines for disease management programs, although the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) is developing some. There are accreditation guidelines for telephone triage,[38] some of which seem relevant to e-disease management:

- Have a medical director providing clinical oversight of the program.
- Utilize clinical decision support tools that are developed [adopted] with involvement from actively practicing physicians and other providers with relevant current knowledge; are based on scientifically valid and documented clinical principles and processes; and are appropriate to the functions [of the program].
- Review and update clinical decision support tools involving actively practicing physicians and other providers with current relevant knowledge

E-disease management tools also need to be consistent with patient educational content delivered via other means such as education classes, telephone-based counseling, and paper tools and publications. Many sponsoring organizations have a designated patient education service, which is actively involved in this aspect of e-disease management as well.

User Participation

Getting Patients to Participate

Although 100 percent acceptance is far from the norm, early adopters report that many patients are willing to try ehealth tools to help manage their care, especially if their participation is actively enlisted. This requires organized efforts to recruit, train, and motivate patients. As with any marketing campaign, patients are recruited and educated about the benefits of e-disease management. Direct mail and email pushes that target high-risk individuals are used. Many vendors of e-disease management applications provide institutional sponsors with models and materials such as posters, pamphlets, and information sheets.

> Some patients "have unusual fears, such as that the computer will listen in on what is happening in their home, but we can often assuage these fears by explaining what it does and does not do. Many of our older patients already have another family member involved with their care and in communication with the case manager. We sometimes get them involved in persuading the reluctant family member that this is a good idea."
>
> — project manager in a group medical practice

Although traditional techniques for recruiting patients are necessary, they are not sufficient. According to several vendors and implementers, the most significant factor influencing patient participation is physician referral. Patients are more likely to adopt and use the tool if their physician takes a personal role in recommending it. One vendor recommends a two-step process for signing up patients. First the receptionist asks if the patient is interested. If so, an enrollment form is attached to the medical record so that enrollment can be discussed with the patient's physician during the visit.

Once enrolled and trained, patients need to stay motivated, especially when the goal is frequent or daily interaction. Although improved health and a feeling of better communication with caregivers is often enough to motivate patients, additional incentives can also be used. Several vendors can now offer "e" points for self-monitoring or other desired interaction, which patients can redeem for other items.

Promoting Physician Participation

Even if an e-disease management program doesn't involve direct physician involvement from an operational standpoint, it still requires physician support in order to be successful. Fortunately, most physicians are willing to try a program that may help their patients, so long as they perceive a net gain for their patients and no loss of revenue or practice productivity—the same considerations they would likely apply to decisions about any tools for use in the practice site.

Both vendors and early adopters recommend implementing e-disease management as an extension and enhancement to the patient-physician relationship, rather than as a barrier. In fact, tools are focused on empowering patients in self-management, not in changing the care management strategies of their physicians; many interactive tools recommend seeing the physician or alerting the responsible physician when intervention is required.

Two strategies used to court physician participation are successful internal pilots and contact with physicians in other organizations using the same or similar technology. In addition, an organized approach to managing clinical content that includes input of respected peers and periodic outreach to physician participants (through surveys, focus groups, interviews) assures physicians that the program is clinically appropriate and responsive to their input. Finally, most operational models seek physician recommendations or referrals (or at least review patient candidates with their designated physician), allowing physicians to have ultimate control of which patients are suited to, and can benefit from, e-disease management.

Technology Must Be Usable

For ehealth tools applied to disease management, the target user, the disease state, and the intervention goal(s) all contribute to selecting a technology that is most suitable and likely to produce the best outcomes. But ultimately, the most important measure of a technology's appropriateness is *whether or not patients are able and willing to use it.* Thus a major design criterion for vendors and selection criterion for sponsors is ease of use.

For some patients certain tools are prohibitive due to physical constraints such as poor eyesight. To overcome this problem, Alere, an e-disease management vendor focusing on congestive heart failure, provides a scale with both audible voice and visual displays. Patients use this "talking scale" to answer questions and to transmit their weight to care providers. Other patient products such as Well@Home and Health Buddy provide specially designed user devices that do not require keyboard entry and feature simple displays that are easy to read.

Regardless of the primary user interface, all "e" programs need to offer some level of training and support, especially for patients who are not computer savvy. Although vendors strive for their products to be simple enough for patients to set up and use with only a limited amount of telephone support, certain individuals will need in-home personalized training. Common support materials such as videos, user guides, and online tutorials are also useful.

Providing 24-hour access to a help desk and a reasonable response time is another essential component to user adoption. Any technology that is not available when a patient needs to access it will quickly be abandoned. This also applies to technical assistance. A help desk staffed to address patient problems or questions needs to be available and made known to users. Many vendors provide online Help and/or Frequently Asked Questions as an adjunct to the help desk,

and for some products and programs, patients turn to the nurse case manager for assistance.

A related barrier to many of today's e-disease management offerings is patient access to, and knowledge of, computers. The so-called "digital divide" excludes some potential beneficiaries —such as seniors and the disadvantaged— at a greater rate than the population at large. Although the gap is closing, this is still a barrier for potential sponsors of e-disease management.

More Medicare Recipients Online

Internet access among Medicare recipients rose to 21.3 percent in 1999, up from just 6.8 percent in 1997.

Source: CMS-sponsored Medicare Current Beneficiary Survey[39]

Some vendors and sponsors, not wanting to wait, avoid the need for PCs and Internet access and instead use a stand-alone home monitoring device or telephone-based IVR system as the primary user interface. Others have begun to experiment with providing computers to patients. In the CHESS program, for example, PCs salvaged from offices upgrading computers have been installed in patient homes, extending the patient population able to participate in e-disease management. This requires home visits to set up the PC and to train the patient or family member—not only in using the application, but also in basic computer skills. With this type of assistance provided, CHESS has achieved good participation from patients.

For sponsors of e-disease management, there is another practical implication of the digital divide. For the foreseeable future, there will still be patients unable or unwilling to use new technology. Therefore two parallel programs for patient communication, coaching, and outreach will be required—one that is e-enabled and one that is not.

Privacy and Security

Like any technology that captures and transmits patient-specific information, e-disease management technology and the policies and procedures governing its use must ensure patient privacy and security, including compliance with HIPAA, the Health Insurance Portability and Accountability Act. Institutional sponsors such as health care providers and health plans need to adopt the same protective measures for patient-identifiable information that will meet these new regulatory requirements.

Whether e-disease management programs use dial-up connections or the Internet, the following security elements represent the minimum required protections:

- Electronic communication between the patient and his or her caregivers occurs *behind* the firewall of the application. In other words, patients must log onto a secure server to access the application before they can gain access to their personal information or can transmit messages to their case manager or physician.
- Patients are required to access the application using a unique username and password. The best models assign a default password but require patients to select their own confidential password upon first logging onto the application.
- Point-to-point security of patient information, most typically using network encryption methods, ensures that information is not lost or intercepted during transmission.
- At a minimum the application tracks all edits of patient information and more ideally all *look-ups and uses* of that information so that an audit trail can be produced that displays who has seen or changed any patient information.

Some applications send notifications to patients via Internet email. One approach avoids passing patient-specific information over the Internet by sending a message that instructs patients to check the secure Web site for new information.

Some vendors can support digital certificates as a means of increasing user authentication. Though vendors report little request for this level of security at present, such an approach may become increasingly common as a way to reduce the operational challenges of confirming the identity of remote patient users and issuing them passwords.

Finally, under the not-yet-finalized HIPAA privacy requirements, disease management vendors working in conjunction with a health plan or provider organization will likely need to sign a contract with that entity establishing themselves as a business associate and obligating the vendor to protect the privacy of patient-identifiable information they handle.

Use of Data by Third Parties

E-disease management applications—those focused on patients as well as those centered on the physician practice—collect detailed information about patients and physicians that is of commercial interest to third parties. The use or sale of information to other organizations is part of the business model of some potential sponsors.

Privacy concerns around the sale and use of Internet customer data continue to fuel a debate both in health care and in society at large. To date, most attention in health care has been focused on electronic prescribing. Although adoption of e-demand management technology is still in the early stages, the same questions about using data for purposes other than the original one—and to the possible detriment of privacy—should be anticipated in the future.

A number of vendor applications include features that give patients control over release and use of the personal information they provide:

- Physician access controlled by patients through: signing a consent form at enrollment; identifying physicians to be granted access; providing a password to others; or printing and providing copies to other parties.
- Use of patient-reported information in aggregated reporting desired by the sponsor and authorized by the patient through a consent form at enrollment.

Costs and Return on Investment

E-disease management programs can be costly: as much as $100,000 to $500,000 for a moderately complex application.[40] Although subscription models for acquiring applications spread the expense out, the combined costs of technology, implementation, and organizational infrastructure represent a major investment for institutional sponsors such as physician group practices, health systems, and health plans.

Most of the implementations to date are fairly new; many are in a pilot or early rollout phase. The current sponsors, which should be considered early adopters, appear to frame the decision as an investment in supporting current patients and reaching many more patients in a cost-effective way, rather than relying on classical return-on-investment thinking alone. For other potential adopters, the research evidence on effectiveness is promising, but limited.

One way of viewing payback is to compare e-disease management with other approaches to patient follow-up and outreach. For example, a traditional disease management program using a call center as the primary patient contact mechanism can cost anywhere from $300 to $1,000 per patient per year; but it can be as low as $50 per patient per year when a Web-based program is used.[13]

A consistent recommendation of early adopters is that sponsors integrate monitoring and performance measurement as a core element in their e-disease management efforts.

Recommended Performance Reporting for E-Disease Management:

- Participant enrollment
- Participant utilization (system and features)
- Participant satisfaction
- Patient functional status
- Disease-specific parameters (health management behavior and status)
- Patient quality of life
- Health service utilization of patients

Knowing how the program is working and what it is accomplishing is critical to fine-tuning current efforts and making decisions about adding additional patient populations or disease states. Regular management reporting should include both metrics of use and metrics of effects.

Financing and Reimbursement

Misalignment of financial incentives is a barrier to more widespread adoption of organized disease management, as well as e-disease management. Here are two examples of misalignment:

- The ideal sponsor is the patient's own physician because the technology can support the patient-physician relationship and decision support can be synchronized with the physician's care management strategy and advice. But, only physicians who care for patients under a pre-paid reimbursement arrangement have financial incentives to engage in organized disease management and decision-support technology. Others are not financially rewarded for better outcomes or reimbursed for the use of technology to achieve better outcomes.
- Health plans do have financial incentives, at least for their HMO patients, but have difficulty linking physicians into their disease management programs. The reality is that most physicians deal with many HMOs; systematic management of some patients using tools and others without is not practical in a busy physician practice.

Reducing this barrier to more widespread adoption requires: more studies demonstrating efficacy and good practices in implementing e-disease management; financial incentives for performance (be they clinical or cost); and partnerships between providers and health plans.

- Once an organization has determined that it will deliver organized disease management, the situation is different. Using patient-focused e-disease management to facilitate communication and contribute to coaching in self-management is far cheaper than traditional models involving nurse case managers and clinical specialists, such as nurse diabetes educators. In fact, these clinicians can manage much larger caseloads when they do not have to rely on periodic telephone contact to see how patients are doing, and they receive much more frequent updates on patient status. Early adopters interviewed for this study also pointed out that e-disease management tools make it possible to include far more patients than traditional approaches covering only the highest risk patients. More documented experience is needed on how to best deploy e-disease management to spur adoption, as well as more research documenting efficacy.

Practical Advice for Getting Started

Be certain of executive leadership.
Accountability, resources, and perseverance are all required for a successful e-disease management project. Commitment and support must come from the top.

Build from the disease management program out, not from the technology in.
The objectives of the program, the needs of its patients, and the organizational set-up for the program and its participants should guide decisions about technology—not the reverse. This is sometimes difficult because the technology itself is attention-getting.

Build the program with, not for, the physicians.
Physician leadership and active involvement are key to success. Building a physician-led team needs to be one of the first steps.

Build a management structure.
Treat e-disease management as a serious project that needs accountability and staff resources to get things done. Assign a physician leader to guide and champion the effort and a project manager to make things happen and build the necessary bridges throughout the organization.

Pilots don't make perfection, but they help.
Pilot testing helps to demonstrate that the concept works and provides local success. Pilots are less essential when the sponsor has a history of successful disease management and/or has prior experience with patient-interactive technology.

Anticipate operational changes and redesign them in advance.
This is especially true of operational models centered in the physician practice. New tasks to consider include enrolling, training, and interacting with patients. Depending on the application, new policies and procedures are also needed for medical records (what to file) and how to ensure prompt response to alerts and patient emails.

Be sure to add value for physicians.
Communications directly with physicians should be the ones they view as important. This may require, for instance, triaging emails from patients according to agreed-upon criteria. Require extra tasks of physicians only when there is no alternative.

Use vendor-supplied clinical content as your starting point.
Vendors have, and continue to make, major investments in content and tools. Early adopters advise using this as a starting point and making necessary revisions, rather than starting from scratch.

Appendices

Appendix A: Award-Winning E-Disease Management Web Sites
Appendix B: Vendor Information
Appendix C: Interview List
Appendix D: Glossary

Appendix A: Top Ten E-Disease Management Web Sites

The following Web sites were ranked as the top ten sites by The Health Industries Research Co. in Santa Cruz, California. Criteria included: Patient can enter health and other information in stages rather than all at once; program stratifies patients into various risk bands with providers notified of high-risk patients; medical devices enable automated data entry; exception reporting; patients can reach a provider real-time; reminder email capability; support groups; e-commerce functions for needed medical supplies and other items.

VENDOR	Location	Web Address
Accordant.com	Greensboro, NC	www.accordant.com
Agilent Technologies, Inc.	Andover, MA	www.agilent.com/healthcare/ihs
Cancerpage.com	McLean, VA	www.cancerpage.com
DiabetesManager, Inc.	Colorado Springs, CO	www.diabetesmanager.com
FitLinxx, Inc.	Stamford, CT	www.fitlinxx.com
LifeChart.com	Mountain View, CA	www.lifechart.com
LifeMasters Supported Selfcare	Newport Beach, CA	www.lifemasters.net
Predictive Sciences, Inc.	Boston, MA	www.predsci.com
ProMedex, Inc.	Raleigh, NC	www.promedex.net
Protocol Driven Healthcare, Inc.	Bernardsville, NJ	www.pdhi.com

Appendix B: Vendor Information

Vendor and contact information is provided below for the vendor e-disease management products listed previously in Figure 6. This is not a comprehensive list although an attempt was made to identify vendors who have been active in this space long enough to have solutions actually implemented. This is a very volatile market, with new partnerships, mergers, and entrants continually being announced, as well as some companies withdrawing from the marketplace. The information was compiled in early 2001.

Patient Self-Management

AboutMyHealth.com, Medscape
www.aboutmyhealth.com

AlereNet System, Alere Medical
www.alere.com

Care for Me, Care for Me, Inc.
www.careforme.com

CareSteps.com, CareSteps, Inc.
www.caresteps.com

CAREvision, HEALTHvision
www.healthvision.com

Compare Care CCM, Advance Med
www.advancemed.com

Health Buddy, Health Hero Network
www.healthhero.com

IQ Health Personal Health Record, Cerner Corp.
www.cerner.com

I-Return Consumer Health Record, I-Beacon, Inc.
www.i-beacon.com

iSolution Patient Online, IDX, www.idx.com

MyChart, Epic Systems, Inc.
www.epicsys.com

MyHealthChannel, iMetrikus, www.imetrikus.com

Personal Health Manager, Well Med
www.wellmed.com

PersonalPath.com, Personal Path Systems, Inc.
www.personalpath.com

The Daily Apple, Caresoft, www.thedailyapple.com

The Patient Center, Salu, www.salu.com

Well@Home, Patient Care Technologies
www.ptct.com

Well Patient
www.wellpatient.com

Physician Practice

Alteer, Alteer Corp.
www.alteer.com

CareNotes, MicroMedex
www.micromedex.com

CAREvision, HEALTHvision
www.healthvision.com

Clineguide, Clineanswers
www.clineanswers.com

Clinical Reference Systems, Clinical Reference Systems, www.patienteducation.com

Cognimed Patient Registry, Cognimed
www.cognimed.com

Dartmouth COOP Clinical Improvement System, FNX Corp., www.fnxnet.com

EpicWeb, Epic Systems, Corp.
www.epicsystems.com

HealthGate, HealthGate Data Corp.
www.healthgate.com

Instant Medical History, Primetime Medical Software
www.medicalhistory.com

LogicianInternet, Medscape
www.medscape.com

MDconsult
www.mdconsult.com

NextGen EMR, MicroMed Healthcare Information Systems, www.nextgen.com

On Demand, StayWell Company
www.staywell.com

PrimeCare System, Prime Care Systems, Inc.
www.pcare.com

TouchWorks, Allscripts
www.allscripts.com

UpToDate, UpToDate, Inc.
www.uptodate.com

Case Management

Care Manager, McKesson
www.mckesson.com

ConferWeb, Confer
www.confer.com

e-Care Coordinator, I-Trax
www.i-trax.com

LifeMetrix Integrated Care Management System, LifeMetrix
www.lifemetrix.com

Appendix C: Interview List

Vendor Interviews

Brad Bowman, M.D., Founder and Chief Medical Officer, WellMed, Inc.

Meg Hartwell, Product Implementation Manager, McKessonHBOC (formerly iMcKesson)

John Haughton, Medical Director, Active Health Management

Shawn Hopwood, Marketing Director, Health Hero Network, Inc.

Philip Marshall, M.D., Director of Clinical Applications, WellMed, Inc.

Holy Ong, R.Ph. Vice President Product Development, LifeChart

Dan Pettus, Senior Vice President of Client Services, iMetrikus

Sandeep Wadhwa, M.D., Vice President of Disease Management, McKesson HBOC

Sponsor Interviews

Yael Lutzker, Executive Assistant to the Medical Director and Heritage/Health Hero Project Coordinator, Heritage Provider Network (Using Health Hero Network, Inc.)

Fiona McTavish, University of Wisconsin Center for Health Systems Research and Analysis, CHESS

Gordon Norman, M.D., Vice President of Health Care Quality, PacifiCare (Using Alere Medical)

Betta Owens, M.S., Director, CHESS Health Education Consortium, University of Wisconsin Center for Health Systems Research and Analysis

Tom Rancilio, Vice President of Utilization Management, Heritage Provider Network (Using Health Hero Network, Inc.)

Appendix D: Glossary

Application Service Provider (ASP)—A vendor that deploys, hosts, and manages access to a packaged application for multiple parties from a centrally managed facility on a subscription basis. The applications are delivered over networks or via the Internet.

Browser—A software program that interprets documents written in HTML, the main programming language of the World Wide Web. A browser such as Netscape or Microsoft Explorer is required to experience the photos, video, and sound elements on a Web page and assists in quick, easy travel around the Web.

Case Management—Assignment of a nurse or other professional to assist identified patients through an episode of care. In the context of disease management, the case manager provides education, support, and outreach to patients, in some cases including home visits and assistance with arranging for needed medical and community services. This form of case management has a different focus from a more reactive role in determining medical necessity and arranging prior authorization for necessary services.

Data Entry—The transcription of information from the original source into a machine-readable form. Although keyboard entry is the most familiar, other fast-growing methods include scanners, speech recognition, and automatic device-to-system technology.

Database—An aggregation of records or other data that is updateable. Databases are used to manage and archive large amounts of information. Also see relational database.

Data Mining—Analyzing information in a database using tools that look for trends or anomalies without knowledge of the data's meaning.

Disease Management—A coordinated and proactive approach to managing care and support for patients with chronic illnesses such as diabetes, congestive heart failure, asthma, HIV/AIDS, and cancer.

Digital Certificate—An electronic "credit card" that establishes a user's credentials when doing business or other transactions on the Web.

E-Disease Management—The use of Web-based technology in support of disease management to support communication, access to knowledge, and patient self-management. This definition requires use of Web technology but not necessarily transmission over the Internet.

Ehealth Tools—Features and functions packaged as elements of e-disease management applications. Examples include interactive health risk assessments, personalized care management plans, personal diaries for recording self-assessment and self-management, disease-relevant information resources, Frequently Asked Questions.

Encryption—Coding attached to data with the intent to keep the information secure from anyone but the addressee. Encryption can include a password, public and private keys, or a complex combination of all.

Firewall—A security device situated between a private network and outside networks. The firewall screens user names and all information that attempts to enter or leave the private network, allowing or denying access or exchange based on pre-set access rules. Also see encryption.

Home Page—The first or "main" page of a Web site. This usually acts as a table of contents for the layers of pages and additional hypertext links available within the site.

Host—A computer that acts as a source of information or capabilities for multiple terminals, peripherals, and/or users.

HTML—Hypertext Markup Language. The basic programming language for sites on the World Wide Web. This "skeleton" of codes surrounds blocks of text and/or images and contains all the display and commands. A

browser program is needed to interpret HTML and turn it into a graphical display on a computer screen.

Internet Service Provider (ISP)—A company that provides modem or network users with access to the Internet and the World Wide Web. Although some ISPs charge by the hour, most offer monthly or yearly flat rates. Recently, telephone companies have begun to address the notion of combining Internet access rates with local telephone service.

Internet—An international network of computers that operates on a backbone system without a true central host computer, linking thousands of universities, government institutions, and companies. Technically, the Internet and the World Wide Web are not interchangeable terms; the Web is an integral child of the Internet whose ease of use has made it much more popular than its less graphical parent.

Intranet—A member-only network that looks and acts like the World Wide Web. Intranets allow companies to take advantage of Web-based technology and create a private means of exchanging images and text among their networked users.

Local Area Network (LAN)—A network of computer and peripherals in close proximity, usually in the same building. A LAN can facilitate high-speed exchange of text, audio, and video data among hundreds of terminals.

Network—A general term for terminals, processors, and devices linked either by cable or wireless technology. Peripherals, programs, and applications can be shared by the network users.

Outsourcing—The transfer of an organization's IT shop, or large segments of an organization's internal IT infrastructure, staff, processes, or applications to an external company (outsourcer), which then runs those segments on behalf of the organization for a fee.

Software Application—A non-customized computer program developed for sale to multiple customers as is. While some tailoring of the program may be possible, it is not intended to be designed for each user or organization.

Performance—A term used to describe how well a computer system is functioning and relates to the overall productivity of a system, and its availability and response time.

Push Technology—The automatic delivery of Web news and other information without a request from the user. Unlike Web pages and most email where a user downloads or "pulls" information each time in order to view it, push technology requires a user to recognize only once and sends the news as it becomes available, without further prompting.

Remote Access—The connection of two or more computers, via a network, for the purpose of accessing applications and information located in another, remote location.

Server—A computer on a network that manages a specific set of network resources. A server may manage network traffic, printer use, store files, or run remote applications.

Web Site—A group of related files, including text, graphics, and hypertext links, on the World Wide Web. Accessed by typing its unique address, a site usually includes layers of supporting pages as well as a home page.

World Wide Web—An international group of databases within the Internet that uses hypertext technology to access text, pictures, and other multimedia with a click of a mouse. Sites on the Web usually are created in HTML, Java, or both. A browser program is needed to access multimedia aspects.

Endnotes

1. Rojas-Burke, J., "Enhancing health care," *The Oregonian,* March 20, 2001
2. Cain, M., J. Sarasohn-Kahn, and J. Wayne, *Health e-People: The Online Consumer Experience,* California HealthCare Foundation, August 2000
3. National Chronic Care Consortium: www.nccconline.org
4. Boult, C., et al. "Innovative healthcare for chronically ill older persons: results of a national survey," *The American Journal of Managed Care,* 5(9):1162–1171, 1999.
5. Drazen, E. and J. Metzger, *Strategies for Integrated Health Care. Emerging Practices in Information Management and Cross-Continuum Care.* Chapters 6, 7, and 8, Jossey-Bass 1999.
6. Wagner, E., et al. "A survey of leading chronic disease management programs: are they consistent with the literature?," *Managed Care Quarterly,* 7(3):56–55, 1999.
7. Wagner, E. H., R. E. Glasgow, C. Davis, et al. "Quality improvement in chronic illness care: a collaborative approach," *Journal on Quality Improvement,* Vol. 27, No. 2, 63–80, 2001.
8. Restructuring Chronic Illness Management: Best Practices and Innovations in Team-Based Treatment. Christianson, Institute for Research and Education, J. B., R. A. Taylor, and D. J. Knutson, eds, Jossey-Bass, 1998
9. Gustafson, D. H., K. Bosworth, R. P. Hawkins, et al. "CHESS: A Computer-Based System for Providing Information, Referrals, Decision Support, and Social Support to People Facing Medical and Other Health-Related Crises," Proceedings of the Sixteenth Annual Symposium on Computer Applications in Medical Care, 161–165, 1992.
10. www.improviningchroniccare.org
11. FCG unpublished data
12. "Physicians and the Internet," Special Section, Deloitte & Touche Consulting, *Hospitals & Health Networks,* Vol. 75, No. 2, February 2001.
13. Lewis, A. Disease Management Purchasing Consortium, March 2001.
14. First Consulting Group, "Health Plans on the Road to Ehealth," An Emerging Practices Research Review, January 2000.
15. First Consulting Group, "Life Sciences Business to Consumer: on the Road to Ehealth, Overview of the Survey Findings," January 2001.
16. Rainie, L., and D. Packel, "More Online, Doing More: 16 Million Newcomers Gain Internet Access in the Last Half of 2000 as Women, Minorities, and Families with Modest Incomes Continue to Surge Online," The Pew Internet & American Life Project, Washington, D.C., February 2001.
17. "The Coming Battle for the Hearts and Minds of Cyberchondriacs," Taylor, H. and R. Leitman, eds, Harris Interactive, Vol. 1, Issue 7, February 19, 2001.
18. Brennan, P. F., "Characterizing the use of health care services delivered via computer networks," *Journal of the American Medical Informatics Association,* Vol. 2, No. 3, 160–8, May/June 1995.
19. Revere, D. and P. J. Dunbar, "Review of computer-generated outpatient health nehavior interventions: cinical encounters in absentia," *Journal of the American Medical Informatics Association (JAMIA),* Vol. 8, No. 1, 62–79.
20. Ryff-deLeche, A., H. Engler, et al. "Clinical application of two computerized diabetes management systems: comparison with the log-book method," *Diabetes Research,* 19, 97–105, 1992.
21. Shultz, E. K., A. Bauman, et al., "Improved care of patients with diabetes through telecommunications," *Ann NY Acad. Sci.,* 1992:670:141–5.
22. Friedman, R. H., "Automated telephone conversations to assess health behavior and deliver behavior interventions," *J. Med System.* 1998; 22:95–102.
23. Jarvis, K. L., R. H. Friedman, et al., "Older women and physical activity: using the telephone to walk," *Women's Health Issues,* 1997; 7:24–9.
24. Ahring, K. K., J. P. Ahring, et al. "Telephone modem access improves diabetes control in those with insulin-requiring diabetes," *Diabetes Care,* 1992;15:971–5.
25. Meneghini, L. F., A. M. Albisser, et al. "An electronic case manager for diabetes control," *Diabetes Care,* 19998;21:591–6.

26. Piette, J. D. and C. A. Mah. "The feasibility of automated voice messaging as an adjunct to diabetes outpatient care," *Diabetes Care,* 1997; 20:15–21.

27. Payton, F. C., Brennan, P. F., et al. "Cost justification of a community health information network: the computerLink for AD caregivers," *AMIA,* 1995, 566–570.

28. Brennan, P. F., "Computer networks promote caregiving collaboration: the ComputerLink project," *AMIA,* 1993, 156–160

29. Brennan, P. F. and K. Smyth, "Elders attitudes and behavior regarding ComputerLink," *AMIA,* 1994, 1011.

30. Brennan, P. F., "The ComputerLink Projects: a decade of experience," *Nursing Informatics,* 1997, 521–526.

31. Shaw, B. R., F. McTavish, and et al, "Experiences of women with breast cancer: exchanging social support over the CHESS Network," *Journal of Health Communication,* Vol. 5, 135–159, 2000.

32. Pinigree, S., R. P. Hawkins, et al, "Will HIV-positive people use an Interactive computer system for information and support? A study of CHESS in two communities," *AMIA,* 1994, 22–6.

33. Gustafson, D. H., e. W. Boberg, et al, "A computer-based system for empowering persons living with AIDS/HIV infection through education and support," *AMIA,* 1993, 940.

34. "Catholic Healthcare West CHF Program Shows Cost Savings and High Patient Satisfaction with Health Buddy and Health Hero iCare Desktop," Case Study, wwwhealthhero.com.

35. Ruggerio, C. M., E. Barr, et al. "Session 92, Disease Management and Ehealth Can Be Successfully Merged," *2001 HIMSS Proceedings,* Vol. 2, 1–9.

36. "First company to bring management to the Web now has proof of improved clinical compliance, outcomes, costs," *ePharmaceuticals,* January 30, 2001.

37. Baker, A. M., J. E. Lafata, et al, "A Web-based diabetes care management support system," *Journal on Quality Improvement,* Vol. 27, No. 4, 179–190.

38. "Accreditation Manual, 24-hour Telephone Triage and Health Information Standards," American Accreditation HealthCare Commission/URAC, Version 1, 1997.

39. "One in Five Medicare Recipients Online, HCFA Finds," *AHA News,* May 15, 2000.

40. Joch, A., "Can the Web SAVE disease management?" *Healthcare Informatics,* March 2000.

CALIFORNIA
HEALTHCARE
FOUNDATION

476 Ninth Street
Oakland, California 94607
Tel: 510.238.1040
Fax: 510.238.1388
www.chcf.org