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Foreword

The U.S. health system is not as safe, effective, or efficient as it needs to be. Furthermore, care is too often not delivered in a timely manner, personalized to patient needs or provided to those in need regardless of race, ethnicity, gender, or socio-economic status. While addressing these challenges will require a comprehensive multi-level approach, most observers agree that there is great need for widespread adoption and implementation of electronic health information technologies (HIT). Yet HIT (like many other technological innovations) is mired in old models of adoption and implementation that are slow at best and very often simply ineffective. Over the past 5 years, the authors of this book have been studying a variety of attempts to adopt proven HIT, aimed at supporting patients and their families as they face serious health problems and have seen the importance of leadership, the value of managing organizational turbulence, the contribution of efficient implementation support, and the essential role of sound technology itself to successful use.

Innovations are not adopted nearly as fast in healthcare as they are in other industries. How long has it taken, for instance, to see real progress in the area of electronic medical records? For well over 20 years, some of the leading healthcare institutions have been operating such systems. Yet until very recently these were considered as isolated examples that could not be replicated elsewhere. Proven innovations and evidence-based practices only rarely become standard practice. Why? What factors prevent the adoption and implementation of innovations, particularly technological innovations? Clearly, multiple issues are involved. The innovation itself certainly plays a central role. Rogers' considerations such as compatibility, observability, relative advantage, trialability, and complexity all play a role. But so do the staff of the organization, its structure and leadership, and the environment within which it functions. The complex interaction of these variables determines the ultimate outcome.

This is particularly true with respect to innovations that are implemented through a healthcare provider organization but primarily benefit the patient rather than the organization itself. Interactive Health Communication Systems (IHCS) or e-Health systems are a prime example. These systems have been shown to improve quality of life of patients, and early data suggests that they can have positive effects on family caregivers as well. Often these technologies are offered

through and promoted by the healthcare provider. In a sense the provider has little to gain from them. They may even reduce utilization, which in some financing arrangements can damage the bottom line of the organization.

When there is such a disconnection between the benefit that these systems offer to patients and their families and the lack of direct benefit to healthcare providers, the implementation process becomes a very complex issue. It is this issue that these authors address. They are well suited to do so. Between them, they have led the development and testing of some of the premier IHCS in existence today. Gustafson and Hawkins led the development of the Comprehensive Health Enhancement Support System (CHESS). Their numerous randomized trials provide evidence of the benefits to quality of life, social support, and participation in healthcare. In a similar vein, Brennan and her colleagues pioneered Heart Care and other technologies aimed at helping patients cope with severe illness such as HIV and heart disease. Together they have made numerous efforts to implement their systems, and they have had mixed successes.

Hence the question returns: How do organizations inhibit or promote the adoption and implementation of innovative practices, especially those that benefit the patients but not the healthcare providers? And is there a tool that organizations can use to enhance the likelihood of successful and appropriate implementation?

This book addresses this question. Based on strong theoretical foundations they have gone beyond assessments to create a practical tool that can be used by organizations wishing to implement an IHCS, and have tested it in a variety of organizations and with a variety of technologies.

Finally, they have illustrated their work through several compelling case studies built around attempts to implement one of their IHCSs, CHESS. Some have been quite successful while others have failed. This book presents an insightful examination of those attempts based on the model they developed.

This is an extremely insightful, practical book that will be of great benefit to everyone interested in spreading e-Health technologies – caregivers, executives, policy-makers, purchasers, payers, and the research community. We cannot afford to wait.

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1 Patient-Focused Technology and the Health Care Delivery System

Patricia Flatley Brennan

The promise of e-health is upon us! Specialized, patient-focused computer systems – such as health-related websites, consumer health informatics tools, patient portals to hospital records and clinical resources, and palm-top reminders for medications and disease management – help lay people and their family caregivers better understand their health challenges, participate in health care choices, cope with the implications of disease and injury, and maintain contact with their clinical care providers. These innovations are acceptable to lay people, young and old, help reduce health disparities and increase knowledge of, and involvement in, their own health care processes, and provide ongoing, point-of-living monitoring of complex health problems. Through use of these easily accessible innovations, patients and their family caregivers have greater sense of control over their own health care, and physicians, nurses, and health educators gain a better understanding of the day-to-day experiences of people facing complex health problems. Yet, most of these innovations emerge as freestanding, single-purpose interventions, reaching only those who stumble on their presence on the Web or those fortunate enough to obtain care from visionary clinicians who direct their patients to these valuable resources. It is the intent of this book to provide a theoretical basis and a series of experiential learning observations in such a way as to foster more rapid, effective implementation of innovative computer systems for patient use.

Interactive Health Communication Systems (IHCS) generally employ computers to deliver health information, coaching and communications resources, and clinical information to lay people. Guided by a range of theories from health behavioral change to social marketing, these resources purport to help laypersons better understand, cope with, and manage their health concerns. Some IHCS are condition-specific, bringing specialized knowledge and support to persons who share a common concern. Others are more general purpose, providing access to a range of health-significant information. Most systems are designed to be freestanding and not linked to a patient's clinical record, but recent changes both in technology and in public policy portend greater integration of consumer information and clinical records.

It is timely to bring health care 'online,' not simply through creating clinical records and billing systems but through the selection and systematic

deployment of consumer health innovations that help health care organizations and practitioners achieve their clinical service goals. Gaining full value from consumer health tools requires re-engineering of clinical care services. Integrating electronic health innovations into the portfolio of care services provided by a health care organization demands purposeful, systematic strategies that insure realization of the promise of these innovations for achieving clinical care goals and organizational objectives. Exploring the challenges and barriers, facilitators and enhancers, of implementing clinical computing innovations for patient care provides a guide for others interested in expanding clinical care services through direct-to-consumer computing tools.

This book will be of interest to many readers. It targets clinical care providers (physicians, nurses, health educators, psychologists) and product line managers for complex services such as cardiovascular health or cancer treatment as well as health systems administrators who recognize the limits of meeting patient care needs through traditional service strategies. Additionally, students of innovations of all types will find many new insights among the interesting case studies and informative analyses presented here. Finally, policy-makers and those who finance health care services will find among these chapters a clear illumination of the elements necessary to successfully implement technology extensions of health care services.

This book will be of particular interest to medical informaticists. It offers a view into the ‘people and organizational issues’ that challenge the process of moving from prototype devices to fully implemented systems. It offers an unusual view on the user group – moving beyond the individual sitting at the computer screen to the contextual care team, exploring the perspectives of the visible and invisible members of the clinical care team, including nurses and physicians, registration desk clerks, clinic administrators, and the information systems department. The text highlights, but does not resolve, significant challenges in medical informatics, such as the articulation of psycho-educative information systems with clinical records systems, human computer interface from the perspective of users not only naïve to computing but also naïve to the clinical care process, and the importance of consumer vocabularies in clarifying and communicating clinical concerns of consumers.

1.1. Where Does Patient-Focused Technology Fit in Health Care Delivery?

Contemporary health care is challenged on many fronts. Accomplishing health care outcomes requires that patients and their families be actively engaged in their care. Their critical role as co-creators of health outcomes demands the presence of effective, easy-to-use information technology applications that both extend the reach of clinical care providers and support patients and their families in their self-monitoring and care tasks. Creating parallel but independent information systems is wasteful and may impede timely, effective care delivery.

Information technologies, particularly those developed with the patient and family as the anticipated direct users, complement and extend existing health care services. They provide pathways for communication and information exchange. Information technologies create an environment where patients and their families can explore clinical records or health education programs at a time, and with a level of privacy, that best meets the patient's preferences. Information technologies, properly integrated with clinical information services, provide a platform for creating personal health records that facilitate self-awareness and promote self-monitoring. This level of understanding of the patient's trajectory of health care concerns and human responses enhances the patient's and family's role as informant, co-decision-maker, and partner in care.

Health care services in the United States are characterized by many misalignments, which can add challenges to patients' and families' full participation in their care. Chief among those is the fragmented approach to service delivery and care financing, which necessitates an episodic approach to clinical practice. That is, patients receive care in discrete units of service within which individual problems may be addressed and ameliorated but which lack attention to continuity over time, ongoing care demands, and care monitoring needs. Yet it has long been evident that an episodic approach to care over-responds to emergent symptoms without any incentive or opportunity to put into place the services that support long-term health behavior change, facilitate the clinical investment necessary to remain engaged in a care process, or provide the health education services that supports self-maintenance. Effectively designed information technologies have the potential to 'bridge the gap' between care episodes. Institutional investment in direct-to-consumer health information technologies (HIT) makes sense to the extent that this investment serves to meet organizational goals and is likely to fulfill the success criteria held by the organization.

The Internet affords an institution the ability to extend services beyond its own walls, and thus provides a particularly advantageous environment for institutions that want to use technology to achieve complex patient care goals. The Internet has had one of the fastest rates of adoption of any innovation in history. It took 20 years since its inception as ARPANET, to have enough home computers, applications, and ease of use to allow the Internet to reach critical mass (enough people using it, for it to be self-sustaining). But it took only 11 additional years for it to be adopted by nearly half of the US population [1]. At the time of writing, 72 percent of Americans report using the Internet. Of those users, 91 percent use e-mail and 67 percent have made purchases online [2]. According to the Pew Internet and American Life Project, the growing ranks of experienced Internet users, as well as the deepening reach of the Internet into all aspects of American culture, have raised all Americans' expectations about what is available online. A large share of Internet users now say that they will turn first to the Internet when they next need information about health care or government services. Sixty-six percent of users look for health or medical information online and 58 percent regularly visit a website that provides information or support for a specific medical condition or personal situation [2]. The Web has become

the 'new normal' in the American way of life and those who do not go online constitute an ever-shrinking minority [3].

One of the key reasons for the growth in the Internet is the increasing availability, usability, and acceptance of computers. Today it is possible to purchase a fast, Internet-ready, desktop computer for about \$400 with laptops costing as little as \$600. Internet appliances are even less expensive (\$100–\$500) and may soon actually surpass desktop computers on some dimensions of functionality. For example, several vendors have recently begun to offer Internet appliances that eliminate the need for a mouse by having users touch a large, wireless, hand-held screen with a pen. Whatever the configuration, computer technology offers great promise in helping institutions meet their patient care goals.

Thus, the time is right for institutions to explore how to best use the Internet as a pathway to providing care for patients. Experimentation is necessary, even desirable, as learning institutions and the technologies they evaluate continue to grow and evolve. Exploration of the experiences of several organizations experimenting with a proven, innovative IHCS offers many lessons to the reader.

1.2. Achieving Success with Interactive Health Communications Systems

Determined investment in IHCS must arise from the goals of the organization itself. Organizations are motivated to participate for many reasons – the technology's fit with their institutional mission, the cachet of research participation or being technically innovative, the desire to try new ways to achieve sustainability of other organizational operations, such as patient education or appointment scheduling. It is critical that the decision to implement such a technology be made recognizing that this means more than an investment in a piece of software; it is an investment in a process of design, a philosophy of patient-and-family engagement, and a vision that rests care strategies on dissemination of health knowledge and facilitation of peer support. It is also important for decision-makers and implementers to understand that the decision to adopt such an innovation is only the first small step in realizing its potential benefits to the organization and to consumers. Adoption of a computer innovation is just the starting point of a long, and often challenging, process of implementation.

Implementation of innovative approaches to achieving operational goals necessitates defining success in many ways. In situations where an organization seeks specific interventions for care of patients with a particular disease process, demonstrating that the innovation is effective within that patient population and their family system is essential. Sometimes an institution seeks experience with a particular technological approach; demonstrating the ability to integrate the technological approach into the institution's repertoire of resources constitutes success. A third definition of success occurs when the innovation's impact on significant organizational mission components is determined. Finally, as is common with experimental strategies, an innovation may be considered

successful with the implementation of the general concept of the innovation, whether or not a specific instance of that innovation remains viable.

It is the central thesis of this book that successful implementation of IHCS is a function of characteristics of the organization itself, the nature of the technology, and the manner in which the innovation is introduced into the organization. We frame these considerations as a Readiness for Implementation Scale (RIS).

1.3. Readiness for Implementation Scale

Through a process integrating expert judgments, extensive field testing, and intensive case studies, our team developed a framework for assessment that can aid organizations, clinicians, and treatment managers in planning, adopting, and implementing consumer-focused technology interventions. Our panel of experts identified seven key factors that contribute to successful implementation:

- Organizational Environment
- Organizational Motivation
- Technology Usefulness
- Promotional Strategy
- Implementation Process
- Department–Technology Fit
- Key Personnel Awareness and Support.

These factors will be addressed more extensively in chapter 5, Implementation Model Development and Testing. Clinicians and administrators can use these factors to appraise their organization's readiness to adopt and innovate, determine the extent to which the current state of the innovation will tax or capitalize on existing resources and directions in the organization, and get a fair appraisal of both the investment needed to make the innovation a success as well as the likely pay-offs to arise from these investments. Using this framework can help institutional planners determine whether the institution is ready to make the commitment to adopt and innovate in this manner.

We stress that there is no 'ideal' configuration of responses to these factors – rather careful study of each factor illuminates to the organization and to innovators' dimensions of success. Clinicians and administrators can appraise their organization's readiness to adopt and innovate, determine the extent to which the current state of the innovation will tax or capitalize on existing resources and directions in the organization, and get a fair appraisal of both the investment needed to make the innovation a success and the likely pay-offs to arise from these investments. Using this framework can help institutional planners determine whether the institution is ready to make the commitment to adopt and innovate in this manner.

This text provides a principled approach to support health care managers, clinicians, and educators who wish to complement clinical services with interactive health technologies. We first present a detailed description of one of

the best-known, and most extensively tested, interactive health technologies – the CHES system. CHES, the Comprehensive Health Enhancement Support System, was developed at the University of Wisconsin–Madison over the past 15 years. CHES provides lay people with Internet access, an integrated suite of resources including educational instructions about disease processes, self-care advice, professional consultation communication with others who share similar care concerns, and tools to help them make and implement key decisions about their health and health care. Using short video interviews and texts of personal stories, CHES introduces lay people to others who have faced and managed similar health problems. CHES helps in care and care management decision-making by providing lay people with specialized tools that help them clarify values, weigh alternatives, and explore their own experiences. CHES is an ‘industry standard’ for consumer health informatics innovations that includes four key components believed essential to promoting individual self-management: information, peer support, professional counseling, and self-monitoring. It serves as a prototype for hundreds of clinical and health-focused consumer informatics innovations. This book provides an extensive exploration of how CHES, as an exemplar of technology-based direct-to-consumer interventions, has been implemented through a series of research projects. The lessons learned provide insight for any type of IHCS implantation. In fact, other IHCS were included in the validation of the implementation model.

Next we provide an overview of the relevant literature on innovation and organizational issues in the implementation of innovations followed by considerations for successful technology implementations. Then we present a model that will allow organizations to assess their readiness to adopt interactive health care technologies. Drawn from the literature and the wisdom of experts in innovation, technology, and health care, this model allows an institution not only to benchmark its progress toward implementation, but also to determine where to invest resources to increase the chance of successful implementation. Six case studies describing a range of health care institutions’ experiences with adopting and implementing CHES illustrate both the critical success elements from the model and highlighting factors, which facilitate or impede implementation. Finally, we summarize the major lessons from the case studies and explain how organizations can use this same model to integrate interactive health technologies into their suite of services.

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2

CHESS: Translating Research into Practice

Robert P. Hawkins and Susan Dinauer

To provide context for the case studies that comprise the core of this book, this chapter will present both a description and some history of the IHCS that was the subject of these adoptions and implementations. CHESS aimed to provide an interactive, user-driven system on a computer via a number of specific disease-focused modules combining information, social support, and decision and planning tools to patients facing a health crisis. Typically, such a health crisis produces enormous stresses on the patient and the family, which require substantial coping responses [1] as they respond to the threat posed by the diagnosis, learn about the disease and its treatments, make treatment and other decisions, seek sources of emotional and practical support, and so on. The premise of CHESS was to assemble in one place and in an integrated form the resources needed for effective coping, to be a continuing presence in the lives of its users, and thus improve quality of life. CHESS would be available at any time of the day when most convenient or most needed by the patient and family.

One contrast with many other IHCS is particularly important. IHCS that focus on primary prevention or lifestyle behavior changes have the challenging task of creating or maintaining a “tension for change,” or even a challenge of attracting users and maintaining their attention in the first place. In contrast, CHESS began with life-threatening diseases, such as a recent diagnosis of cancer, HIV, and coronary artery disease, where people are typically highly motivated to obtain information and support. Hence it focuses on providing deep content instead of mechanisms to attract users or create tension for change. Later additions serve people managing chronic conditions such as heart disease, asthma, smoking cessation, and dementia care, but these also have assumed user motivation.

The other key issue considered here is the dissemination of CHESS. Since CHESS was developed in a research environment, initial usage of CHESS modules was confined to individuals participating in research studies. However, the developers also recognized the need to further understand how to implement CHESS in a clinical environment. A research consortium comprised of health care providers was formed in part to better understand how CHESS could be integrated into clinical practice.

2.1. The CHESS System

CHESS is an information and support service delivered to individuals over the Internet. CHESS is freestanding; that is, it does not need to be embedded in an institution's electronic patient record system and can be accessed through computers linked to the Internet. Users view CHESS resources through browsers with a unique code name and password.

CHESS was developed by researchers at the University of Wisconsin starting around 1990, although its roots are obvious in at least one precursor system. CHESS modules dealing with a specific health crisis or disease are built around both a topic structure and a set of services. The particular topics (typically 20–30 subsuming several hundred more-specific keywords) are of course different for each disease, but in each case that structure is developed through a combination of reviewing literature, clinical knowledge, focus groups and interviews with patients and family members, and a quantitative needs assessment process typically involving hundreds of respondents [2, 3]. Since the resulting topic structure varies by disease, it is much more useful to describe CHESS overall through its services – the particular ways of responding to patient and family needs. Since its inception, CHESS has provided three different kinds of services: Information, Communication/Support, and Planning or Analysis Tools. Describing them will give a sense both of what CHESS is and how it facilitates improvement in quality of life.

Information Services provide information on an extensive list of topics in a variety of formats. *Questions and Answers* include brief answers (most displayable as a single screen) to many (typically more than 400) frequently asked questions about the disease by displaying only the much smaller sets associated with a topic or particular keyword. As an alternative to this single-focus mode of dealing with information, the *Instant Library* provides hundreds of complete articles drawn from the scientific and/or popular press. These were initially copied whole into the system (with copyright permission when not from the public domain), but later evolved to be links to their sources on other websites. The *Resource Guide* typically provides descriptions to help users visualize what it will be like to receive a service, such as disability assistance or hospice, or what it will be like to have breast-conserving surgery or chemotherapy. It then helps them learn to identify a good provider and be an effective consumer. *Personal Stories* are first-person accounts of how individuals coped with their health crisis. Professional writers interview patients and their families and then attempt to maintain that person's "voice" in telling their stories, both in an overview version and in expansions on topics the needs assessments indicate are likely to be of greater interest to some readers than to others (e.g., what it was like during chemotherapy, dealing with an insensitive doctor, fighting a health insurance company, etc.). Later CHESS versions also provided *Video Gallery* versions that allow users to see patients (and in some cases their spouses as well) talk about how they coped with the disease and its treatment. *Resource Directory* provides descriptions of local and/or national services and ways to contact them. And after CHESS itself became Web-based, *WebLinks* provided direct connections to other high-quality websites specific to the disease.

Communication Services offer both information and emotional support to users. Patients and their families use bulletin board style *Discussion Groups* to share information and support. There are separate groups for patients, partners, and a group open to any CHES user, and some CHES modules have employed topical groups as well (e.g., faith, end-of-life). Groups are limited to 50 members and monitored by a professional facilitator. *Ask an Expert* allows users to ask very specific questions, often about situations too specific to be covered by *Questions and Answers*, and then to receive a confidential response from knowledgeable specialists. To illustrate the kind of expertise involved, CHES cancer modules have subcontracted with National Cancer Institute's (NCI's) regional Cancer Information Service (a telephone-based information service) to have questions answered by Cancer Information Specialists. As an additional feature in later CHES versions, question-response pairs thought to be more generally useful were depersonalized and made available for all users within *Open Expert*. Also in later versions, *Journaling (My Diary)* provides a private (content saved only on the user's computer) place where users write their deepest thoughts and feelings about the disease and treatment in a timed, controlled environment. The system provides guidance about what sorts of journal entries are likely to stimulate useful self-reflection or analysis.

Analysis Services are intended to help users think through key issues they are facing. These interactive services collect data from the user, process it, and provide feedback. CHES *Assessments* do not offer general Health Risk Appraisals. Rather they focus on specific issues of importance to people managing complex illnesses. In *Health Tracking*, people enter data on their health status every 2 weeks and see graphs illustrating how their health status is changing. In both *Assessments* and *Health Tracking*, CHES uses that information to guide people to other material relevant to their situation. *Decisions* uses two formats to help patients and their families examine important treatment decisions. Video clips show patients talking about how they made their decision. Alternatively, they can use a structured decision analysis to learn about options, clarify values, and learn consequences of choices. *Action Plan* employs a statistical decision theory model (employing concepts of Self-Efficacy and Theory of Reasoned Action) to help users plan behavior changes by identifying goals, resources, and ways to overcome obstacles. CHES development and testing in 2005 added several other analysis services. *Clinician Report* uses a version of *Health Tracking* to allow the patient and caregiver to make a report to the clinical team either just before a scheduled visit or when a status indicator exceeds a threshold indicating a problem. *Easing Distress*, a cognitive behavior therapy program, provides tools to help patients identify emotional distress and avoid being caught up in it, and *Healthy Relating* provides training in effective communication. CHES for pediatric asthma integrates a nurse case manager into the system, and one version of CHES for breast cancer now provides a human cancer information mentor to supplement and enhance the system.

It is illuminating to contrast CHES use with typical Internet access. First, the Internet is a vast repository of information about health (and many, many other things as well), but that repository is unfocused and of varying quality. CHES is a non-commercial system, owned by the University of Wisconsin, whose content and presentation is developed and updated by CHES staff with

input from clinicians and patients. Second, the Internet provides support through chat groups involving large numbers of people, some of whom can be pretenders. CHES (by design) limits discussion and chat group access to a comparatively small number of registered people in a facilitated environment. Third, Internet interfaces vary substantially between websites and can be cumbersome. CHES provides one easy-to-use interface that takes users to important materials within its own boundaries and to specific pages within other websites without having to learn to navigate each site. And fourth, the most important strength of CHES may be that it provides a closed, guided universe of information and support options in an integrated package where everything points efficiently to everything else, instead of requiring search and discovery.

Patients typically get access to CHES through their health care provider. Many organizations that offer CHES also lend computers to patients who do not have their own, something that has become progressively less necessary. Some organizations also offer CHES in their patient education libraries.

When users log on to CHES they enter a code name and password to insure that they are registered users. They see a main menu from which they can choose a general topic, pick a particular keyword, or enter into a service of interest (Figure 2.1). The “interactivity” of the CHES modules employed in the case studies in this book comes from the complete control over choice of content given to the user and the system’s responsiveness in returning requested information, support, or analysis. CHES is not designed to force people to use particular

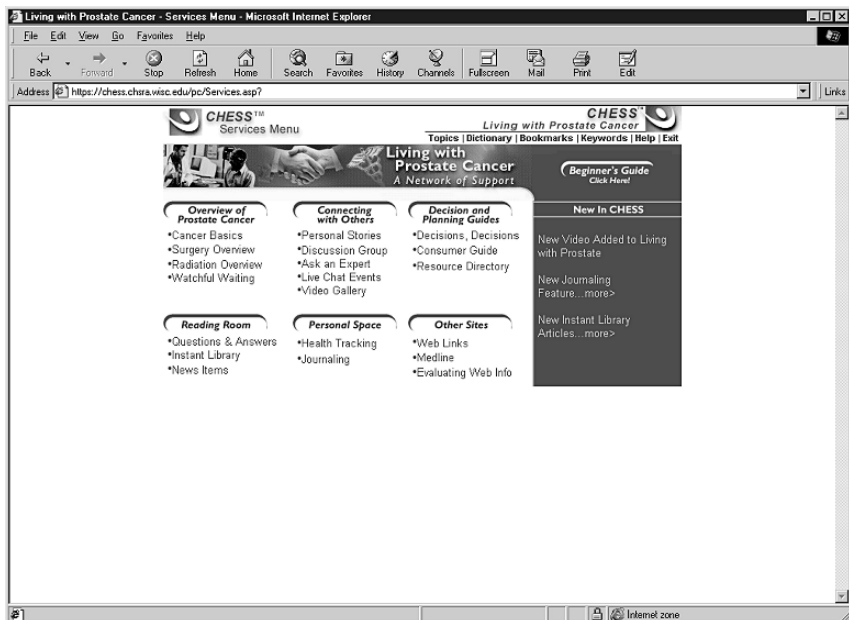


FIGURE 2.1. CHES Internet version – home page.

parts of the system, relying instead on providing information and support in several formats that allow the user to pick the presentation that best fits their learning style. However, versions developed in 2005 track user characteristics such as disease and treatment details or immediate concerns to provide more “tailored” or “personalized” content to the individual. And the next step will be to track what CHES content the user has explored to further tailor suggestions.

2.2. Research and Development Process

The roots of CHES lie in an earlier system developed in 1981 by the same research group to address key adolescent health issues. The Body Awareness Resource Network (BARN), funded by the W.K. Kellogg Foundation, initially used Apple II computers placed in middle- and high-school instructional media centers to help teens prevent or reduce smoking, drug abuse, and unsafe sexual activity. On those early personal computers, the system used minimal, simple graphics and resided entirely on floppy disks. Despite adolescents’ supposed lack of interest in health (though perhaps in part because of their interest in computers, then quite novel), BARN attracted substantial use and demonstrated the effects it was designed to achieve [4–6]. The system used games, direct address, and a breezy, irreverent personality (“BARNEY”) to attract and hold adolescents’ interest. It helped them sort out myths from reality, consider consequences of choices, and make better decisions.

When BARN’s developers turned to adult health issues in the early 1990s, computers were more powerful and widely available, so novelty alone was unlikely to be as attractive, particularly for adults. Instead, CHES aimed at people facing health crisis – those whose motivation to deal with the health problem could be assumed, and who were likely to recognize that they needed a mix of information, support, and tools to deal with the crisis. A 5-year grant from the W.K. Kellogg Foundation supported the original development of the overall CHES structure, and grants from several federal agencies supported research to evaluate specific versions of CHES.

Initial CHES modules, covering topics such as AIDS/HIV, Breast Cancer, Adult Children of Alcoholics, Making It in School, and Surviving Sexual Assault, were all stand-alone, DOS-based systems residing on the computer’s hard drive, although from the start there was also a modem-based connection to the Discussion Group with other users and with experts through the Ask-an-Expert service. The DOS base meant that graphics were very simple, and that users navigated by using arrow keys to move across menu options. Nonetheless, even in this simple form, patients randomly assigned to have a CHES computer in their home typically used it frequently for long periods of time, expressed great satisfaction with it, and had better quality of life than those receiving usual care [7, 8]. Patients with HIV/AIDS also report significantly less use of medical services and thus indicated that CHES reduced medical costs.

With the encouragement of the initial randomized control trials, the mid-1990s saw significant changes in CHES. First, the clunky DOS-based system was replaced by a true graphical interface, at first still resident on a local computer but quickly migrating fully to the Internet.

As will be obvious to most readers, the shift to health information and resources residing on the Internet has tremendous advantages, by allowing continuous updating and linkages to other resources far beyond those that could be placed on a single computer's hard disk (for both space and copyright reasons). On the other hand, accessing locally stored materials involved only negligible delays, whereas Internet access, especially through phone lines, can involve delays that are a significant burden on the user. CHES programmers have worked since then on a variety of ways both to reduce the number of downloads and to make each as efficient as possible.

As the use of the Internet grew, researchers and policymakers often expressed concerns about two key Digital Divide issues: (1) that a disadvantaged group (or such groups in general) will have less access to computer-based systems and (2) that even when access is provided, members of disadvantaged groups will make less, or less effective, use of such systems. CHES trials have provided computers to patients, making the first issue moot as a research question (it remains an issue, though a decreasing one, as computers and Internet access become less unusual among disadvantaged households although high-speed access is not yet widespread). In contrast, a variety of CHES research presents a very different picture. Among breast cancer patients, less educated, uninsured, or minority women used CHES just as much as advantaged women, and in fact often benefited more [8]. The trial with AIDS patients came at a time when women could be considered disadvantaged in computer experience and efficacy compared to men (not to mention being a small minority among AIDS patients). Nonetheless, the trial found that women, along with minorities and the less educated, again used CHES as much and with similar effects as advantaged patients [7, 9]. Non-experimental trials provided additional evidence that elderly women [10] and very poor women [11] use CHES in similar amounts as advantaged women and show comparable or greater pre-test to post-test improvements in quality of life.

A second ongoing change has been the addition of CHES modules in a number of new clinical areas, such as Adult Caregivers of Dementia Patients, Prostate Cancer, Heart Disease, Lung Cancer, Smoking Cessation (adult and teen versions), Menopause, Pediatric Asthma Management, and Caregiving for Advanced Cancer Patients and Bereavement Support. The decision to develop a new module came about in a couple of different ways. Sometimes the organizations currently using one of the early CHES modules saw a need among one of their other patient groups for a system like CHES. Many times, clinicians initiated this request and could provide the clinical expertise needed to develop new content. Other times, new organizations or research centers approached the CHES developers about collaborating on a module to enhance current services or research goals.

Each of these new modules has involved another substantial needs assessment research process, followed by the involvement of clinical experts with CHES

staff to develop the particulars of the new module (even though all so far have still been recognizably CHESS within the initial model outlined above). Importantly, the varied experiences with the initial broad range of CHESS modules led to an insight that has strongly shaped subsequent development directions. It appears that it is not enough to develop a tool that will be useful to those facing a health crisis. A key additional issue is how to identify those people and connect them with CHESS. And it appears that the most effective way so far is to focus on crises where people have close connections with an identifiable group of clinicians, who could identify and recruit potential users of CHESS.

And the third change, more subtle and ongoing, has been the gradual addition of new services or the enhancement of older services that were described in the initial presentation of CHESS structure. Although this was in fact gradual, the process received an important boost from a technology transfer grant (STTR) that focused on developing tools (such as Health Tracking and Bookmarks) that then spread through the CHESS modules and have evolved into various ways of making the system more responsive and individual.

2.3. Dissemination and Implementation of CHESS

The other main event in CHESS history of the mid-1990s was the creation and growth of the CHESS research consortium. The founder and developers of CHESS recognized that its eventual integration into clinical care would be facilitated by constant and persistent engagement with the health care providers who would be the most likely to connect CHESS with potential users. These providers would share developmental responsibilities with the CHESS team providing content that met local standards as well as serving as a site for research and development. This group of leading health care institutions was intended to be a mechanism to test disseminating CHESS beyond research settings and a source of clinical expertise and financial support for developing additional CHESS modules.

A Closer Look: Dissemination of an IHCS

Offering an IHCS through a consortium effort was a non-commercial approach to disseminating this type of technology. Consortium members not only were offered technical support from the developers, but also had the opportunity to participate in research studies and network with other organizations also implementing this same technology. The collaborative nature of the consortium was an important benefit to the members.

Members would share implementation strategies and learn from each other about successful (and non-successful) efforts to deliver CHESS to patients. As their experience grew, the consortium members along with the developers gained a better understanding of the types of people who needed to be involved in an implementation. A key role at the organization was to designate someone as the overall CHESS coordinator, a critical contact person for patients, clinicians, and administrators. Depending on the size of the organization, the

coordinator may also be responsible for recruiting or training new CHES users, but those roles could also be handled either at the clinic level or by additional CHES staff.

The members' firsthand experience at disseminating CHES also guided development and highlighted activities most valuable to an implementation. For some organizations this knowledge would be translated into developing an IHCS of their own.

Before 1993, CHES staff invested a lot of time to develop the consortium idea and recruit the first members. A key member came on board in 1993, but membership grew slowly and the developers were uncertain if the whole idea of the consortium was going to work. However, beginning in 1995, members joined regularly for the next few years. Although membership levels fluctuated over the 10 years the consortium was active, the membership at its peak in the late 1990s included nine organizations ranging from university research-based health care groups to managed care organizations (Figure 2.2).

Each member organization paid an annual consortium fee, and in return were the first invited to partner with CHES in research grants and activities; influenced decisions about new module topic development and enhancements; and received permission to offer CHES modules to any of its patients as long as CHES staff could analyze use data from that organization. (Table 2.1 provides information on modules used by each case study organization.) Members also received implementation and technical support from CHES staff including on-site visits to promote CHES within the organization and work with staff on recruitment and training procedures; regular facilitated calls and other communication among consortium members; monthly use reports; toll-free technical support for users; and internal marketing materials. Members developed implementation procedures that fit best for their organizational setting, as will be illustrated by the case studies later in this book. Members participated in research projects with CHES, ranging from controlled studies to demonstration projects evaluating a variety of implementation best practices.

A Closer Look: Costs

In addition to the \$40,000 annual membership fee to join the consortium, organizations needed to provide other financial support to assure CHES would be successfully implemented. A staff member was needed to act as overall CHES Coordinator at the organization with responsibilities that ranged from promotion of the system to a diverse audience (administrators, clinicians, technical staff, and the end-user (patients and their families)) to recruitment of patients to training and other support for CHES users. In most organizations, laptops were purchased to loan to people who did not have access to a computer to assure that there would be no costs for the patient who wanted to use CHES.
