

*Special article*

## Empowering patients using computer based health support systems

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With the increased pressure to contain health-care costs, it is critical to find more effective ways of providing information, emotional support, decision making, and behaviour change assistance for patients. In the United States, a doctor spends approximately 18 minutes in face to face contact with the patient during each clinic appointment.<sup>1</sup> During morning hospital rounds, physicians spend on average just over four minutes in the patient's room.<sup>2</sup> It has been proposed that ideal physician communication with patients with breast cancer should be tailored to patients' needs or coping styles to reduce their distress.<sup>3</sup> However, in an environment of continued pressure to reduce healthcare costs, it is virtually impossible for doctors to give patients adequate information or even direct them to appropriate support resources. If costs are to be reduced while at the same time improving patient support we must find new ways to help patients to cope with their disease, make necessary decisions, and gain emotional support. Computer systems can help to fill this void.

A key problem encountered by people facing a health crisis is that they are often given information when they are least able to take it in, such as at the time of diagnosis. Siminoff and others have concluded that nearly all studies point to serious gaps in patient recall and understanding of the information they are given.<sup>3 4</sup> The problem is exacerbated by the fact that patients often feel pressure (real or imagined) to decide quickly about issues they have never faced before.<sup>5</sup>

Providing information and support under such circumstances can be challenging because individuals vary in the amount, type, and timing of the information and support they want or need to receive.<sup>6</sup> Also, few information and support resources provide a wide variety of options to fit the different problem solving and learning styles that individuals may adopt under stressful conditions. Research shows, for instance, that alternative forms of information such as talking with other patients with similar diagnoses and reading personal descriptions of other people's decisions, treatments, consequences, and coping strategies can be particularly useful to patients.<sup>7</sup> Information and support resources need to be convenient, timely, non-threatening, anonymous, under the user's control, and flexible

enough to adapt to differing coping and learning styles. The use of such positive coping strategies by people in health crises yields better health outcomes, greater efforts to improve functioning, and greater resistance to psychological dysfunction.<sup>3 8-10</sup> CHESS, the Comprehensive Health Enhancement Support System, was designed to meet these goals.<sup>11 12</sup>

*"It [being diagnosed with breast cancer] was overwhelming at first. Because you want to find out everything you can so you make sure you make a good decision, but you're not sure what decision to make because you have never had it before. On CHESS you can read and read. And that was good because when you first find out you have breast cancer, you don't know where to go [for information]. On CHESS all the stuff was here. Also there were other women on the system that were just full of information and so helpful. I came on everyday. I was on there bugging them with all these questions and asking the Expert too. So it was just wonderful for me. I asked questions to the women like what should I ask my doctor..."*

(User of CHESS breast cancer module.)

### Development of CHESS

CHESS is a multiservice computer system containing information, social and behavioural change, decision making, and referral support for people facing health crises. It combines education, behaviour change theory, and risk management technology to improve patients' quality of life and to reduce demands on doctors' time and costs of care. Currently, there are CHESS modules covering breast cancer, HIV/AIDS, heart disease, Alzheimer's disease (for the caregiver), sexual assault, and substance abuse. Other modules currently under development address prostate cancer, menopause, and asthma.

CHESS was developed by a team of health decision, information, education, and communication scientists at the University of Wisconsin-Madison's Center for Health Systems Research and Analysis (CHSRA). CHESS was designed on the premise that a successful information and support programme must: (a) understand the unmet needs of patients and their families; (b) provide superior alternatives to address those needs; (c) promote good decision making and implementation planning; (d) develop patients' skills and

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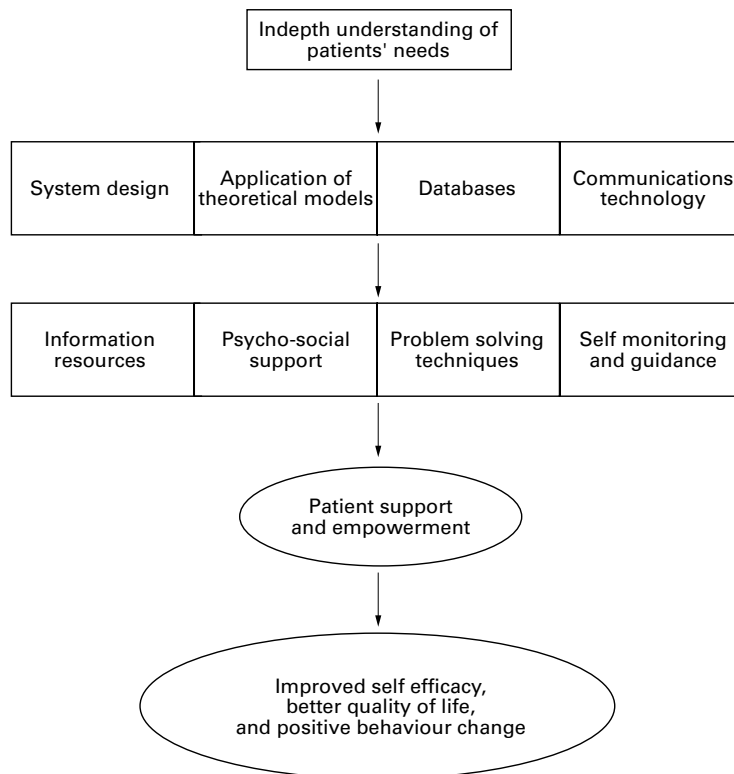


Figure 1 The foundations of CHES.

confidence in one's ability to take responsibility for managing one's health care (self efficacy); (e) provide access to social support to foster self efficacy; and (f) provide feedback so that people can monitor their own efforts.

The content of all CHES modules is built on extensive studies of patients' needs. A thorough understanding of patient and family needs is essential to developing high quality computer based health support systems. Before developing a module, an indepth literature review is completed, numerous nominal groups are conducted, as well as one-on-one interviews. These form the basis for the needs assessment survey. Surveys are then distributed to the targeted population. For example, our breast cancer needs assessment surveys were sent to women with breast cancer, their partners, and their adult daughters from seven hospitals and healthcare management organisations in Wisconsin, New Jersey, Minnesota, Louisiana, and Missouri. The surveys are designed to assess the relative importance of the many issues that patients face, as well as how well those needs are being met.

Once a needs assessment is completed we begin applying the results to the system and content design (fig 1). We begin with the system design, which includes designing charts of content, applying theoretical models, and determining database structures, and the communication technology to be used.

The next level of development revolves around content. This includes developing informational resources, psychosocial support, problem solving techniques, and self monitoring tools and guidance. Throughout the development process our user feedback is crucial.

Once a module is completed, pilot testing begins and further refinements are made. Throughout the entire process the design team focuses on the desired outcomes of the module including patient support, empowerment, and health risk reduction, which in turn results in improved self efficacy, better quality of life, and positive behaviour change.

There are several ways to obtain information and support in CHES. One can access all the material in CHES in three different ways: via a table of contents structure that categorises content by general topics; by keywords or phrases; or by services. CHES provides various comprehensive services that can be broken into four components: (1) information services, (2) social support services, (3) problem solving services, and (4) self monitoring and guidance services. These services are integrated through keywords and other expert systems.

### Information services

#### QUESTIONS AND ANSWERS

Questions and answers is a database of short answers to commonly asked questions about a particular health crisis. The questions are derived from indepth studies of needs among patients, their partners, and healthcare providers. They are answered by teams of experts. Users can either type in a keyword and then select from a list of questions addressing this keyword or they can review the structured list of questions sorted by a hierarchical menu and select the questions they wish to pursue. They can then read the answers (frequently supplemented by pictures and other graphics to highlight key points) and, if they wish, follow links to more indepth material in other CHES services using keyword links provided.

#### INSTANT LIBRARY

The instant library contains full text articles to provide more depth and differing perspectives of issues within the topics. Material includes brochures and pamphlets, patient education material, and scientific articles. Each article contains information about the source of the article (including the author and their affiliation), copyright date, and CHES reviewer comments. As in questions and answers, the user can go through a hierarchical menu structure or choose a keyword to access the various instant library articles.

#### PERSONAL STORIES

CHES includes true accounts of people who have struggled with a particular health crisis. Trained journalists interview patients, partners, and adult children to create personal descriptions of their experiences and how they coped with the health crisis. The stories are designed to address the issues that were found to be of most importance in the needs assessment and to present a balanced picture of what it is like to have a particular health concern. Each core story is approximately 1000 words long, however most stories also

contain expansions, which allow a reader to pursue specific topics in more depth. For example, in the breast cancer module readers of a core story about “Carlene” may read a paragraph about how her husband reacted to the cancer. If they are interested in reading more about how Carlene’s husband coped, they can click on a hyperlink to read five more paragraphs which provide greater details on his reaction, struggles, and support. After reading the expansion they can return to the core story. Stories are indexed by topics as well as by demographic characteristics of the people.

#### CONSUMER GUIDE

This service provides a practical overview of hundreds of services and resources, including specific medical specialists, financial services, and community support services. The consumer guide was developed based on assessments of consumer perceived barriers to seeking and receiving satisfactory service, as well as providers’ frustrations with service delivery to people facing health related crises. It includes an overview of each service, what to expect, how to prepare for an appointment, how to assess the quality of the service, and how to get the most out of the service. Because our research indicates that often people do not know what to say when they contact providers, sample questions to ask are given where appropriate.

#### REFERRAL DIRECTORY

This is a database of several hundred national public and non-profit agencies that offer information, support, and referrals external to CHESS. It contains most, if not all, of the following information: agency name, hours of operation, phone and fax numbers, availability of a telecommunication device for the deaf phone service, email and web site addresses, and a brief description of the services provided. Local referral directories can also be created for specific geographical areas.

#### DICTIONARY

CHESS is written for the most part at an eighth grade (13 years of age) reading level. The dictionary defines medical and technical terms in common English to enhance users’ understanding of the information provided. The dictionary is accessible any time from anywhere within a CHESS module. CHESS research studies have shown that many users will go through the dictionary systematically, one word at a time.

#### WEBLINKS

This service (which is only on the internet version of CHESS) describes and provides a direct link to quality web sites which have information related to the specific module.

#### Social support services

##### DISCUSSION GROUP

The discussion group acts as an online support group that is available 24 hours a day, seven

days a week. The goal is to provide users with a “safe” place where people facing similar health crises can receive and give support. Participants choose their own code name and password thus protecting their anonymity. They exchange information and experiences, ask questions, and offer insights to the group. Each group, normally comprising no more than 50 people, is monitored by a trained facilitator whose primary role is to ensure that discussions are supportive. There are some open discussion groups that any CHESS user can access and several limited access discussion groups for specific groups (for example, women with metastatic breast cancer, partners of women with breast cancer, etc).

#### ASK AN EXPERT

Users can anonymously type in questions about their illness and receive a private response from a health information specialist within two working days. Experts respond by providing clear, concise information, coaching, and emotional support, but never give medical advice. They draw on the expertise of a panel of consultants comprising doctors, nurses, pharmacists, health educators, dietitians, lawyers, and other professionals.

Although ask an expert is primarily a vehicle for private communication between the user and expert, it also provides an open expert service where questions and answers with universal relevance to the users are listed. If someone asks a question that the expert believes is of value to more than just the individual user, he will first respond privately to the person who asked the question, and then later remove all personal information in the question and answer and put the information in the open expert section.

The ask an expert service also provides a great resource for keeping modules current and identifying information that patients are either not receiving from their healthcare providers or that needs further clarification. It is an excellent source for new questions and answers.

#### Problem solving services

##### DECISIONS AND CONFLICTS

This component uses multiattribute utility theory to help people think through difficult decisions<sup>13 14</sup>—learning about options, selecting and weighing decision criteria, and applying criteria to options. It provides access to experts’ insights into specific decisions (that is, what treatment to have, whether to join a clinical trial, etc). Users can see descriptions of each option or read a brief personal story of a person who chose that option, or both. They can read about criteria that other people considered in making the choice, why each criterion may be an important consideration for them, research findings, or how each type of intervention affects each criterion. Instead of recommending a particular action, CHESS asks what choice the user is leaning towards and lets them see what the computer predicted they would say based on their input. The

intention is to provide a structured way to think through a difficult decision.

#### ACTION PLAN

One of the highest priorities identified by patients, partners, and adult children who use CHESS is the need to know how to play a more central part in their treatment. It is one thing to decide to adopt a particular behavioural change, and yet another to implement that decision in the face of ingrained habits or family pressures. The action plan helps users to set up a plan of action. It combines statistical decision theory and behaviour change theory with various skill building components to help users to identify goals, resources, and social supports as well as obstacles they may face. It helps the users to identify what rewards they will give themselves along the way and what actions they need to take to implement this plan. Once the user has set up a plan, they can see how likely they are to succeed. A Bayesian statistical model predicts the chances of successful implementation. The program asks users several questions about their plan. Using the answers to these questions, a prediction of the likelihood of success and ways that they can strengthen their prospects for successful implementation are displayed. CHESS has both generic action plans that can be used on any decision and tailored action plans (for example, changing one's diet in the heart disease module).

#### Self monitoring and guidance services

##### PERSONAL PROFILE

This service allows users to record their demographic information, physical and emotional health, treatment history, thoughts, and activities towards behaviour change and actual behaviour over time. Users are automatically prompted to complete their profile at installation and to update it at least every two weeks. CHESS collects the data entered and translates them into user friendly charts that help users to (a) receive tailored feedback about their health and emotional status and health behaviours which they chose to track; (b) identify and prioritise key concerns and possible actions or behaviours to improve health status; (c) track changes in their health and wellbeing over time; (d) share their charts with their healthcare providers, with other CHESS users, or with the CHESS expert (in the ask an expert service) if they so choose; and (e) link to other relevant CHESS material.

##### ASSESSMENT

This service assesses a person's lifestyle on a single risk behaviour or condition, and gives suggestions on how to reduce that risk or condition. For example, an assessment in the HIV/AIDS module determines a person's likelihood of transmitting the infection to others and gives advice on how to reduce the risk. In the heart disease module there is an assessment for depression that informs the user about depression and tells them whether they are likely to be suffering from it and therefore should see a physician for a professional assessment.

CHESS was originally designed as a DOS based system to allow the widest possible dissemination on almost any IBM compatible personal computer. Minimum hardware requirements were a 386 microprocessor, 2 megabytes of RAM, 40 megabytes of hard disk, a color VGA monitor, and a modem. Rapid advances in computer technology and hardware cost reductions resulted in converting CHESS to a Windows based system. A 486 microprocessor is needed to run this version of CHESS. With the recent explosion in access to the internet, CHESS is now available on the internet.

Regardless of the underlying operating system, CHESS has always been designed with the non-computer user in mind. As a result, CHESS has been used by thousands of individuals of varying ages and socioeconomic status, including those with no previous computer experience. With the users' permission, CHESS collects use data (such as keystroke use, amount of time in a particular service, etc). Although there have been differences in how CHESS has been used, all types of participants, regardless of their age, education and socioeconomic level, have used CHESS heavily and have benefited from it:

*"At first I read everything I could read in the instant library. And the questions and answers, I used. I read everything that was pertinent to my situation. And then the ask an expert. I used that because you could tap into previous questions that were asked. You could go through the questions like results of chemotherapy and after-effects. Once I started radiation, I started to read everything about radiation. At first I didn't read about radiation because I wasn't doing it. CHESS is very timely because you can read about what you are getting yourself into before the fact or during the fact. That's how I did it."*

(User of CHESS breast cancer module.)

#### Summaries of some of the research findings from CHESS

##### PILOT WITH IMPOVERISHED MINORITY WOMEN

This study involved eight African-American women in an impoverished inner city area.<sup>15</sup> Most had no computer experience, some no typing experience. CHESS was well received, heavily used (nearly 900 times in 15 weeks), and produced feelings of acceptance, motivation, understanding, and relief. Some study participants become a source of information for their community.

##### USE BY OLDER WOMEN

A federally funded project examined the ability to reach a full population of older (> 65 years) women with breast cancer in a five county region surrounding Madison, Wisconsin. Virtually all providers (93%) agreed to participate, 78% of eligible patients have been referred, and 73% of those have accepted CHESS. User rates were equivalent to other studies of breast cancer. The only factor that predicted use was "live alone". Neither age, education, nor computer familiarity had an effect. Quality of life increased more for the 67% of patients who used CHESS most. Findings were consistent with quality of life

improvements found with younger patients with breast cancer, except that in the older population cognitive functioning also improved.

#### RANDOMISED CLINICAL TRIAL FOR YOUNGER WOMEN

CHESSE's impact on the quality of life of younger women with breast cancer in Madison, Indianapolis, and Chicago (funded by the National Cancer Institute) is currently being evaluated. 356 patients were recruited into the study. Early analyses of 110 patients found that using CHESSE leads to quality of life improvements exceeding 0.33 SD (compared with the control group) in 13 of 28 measures compared with one measure for the control group. Areas of improvement include closeness to friends and family, feeling sad, worry about death and deterioration, enjoying life in the moment, accepting illness, effects of stress, having someone who cares, loneliness, tiredness, and activity level. The data also suggest reductions in number of physician office visits for women with CHESSE. The study will be completed at the end of 1998.

#### RANDOMISED CLINICAL TRIAL EVALUATING CHESSE FOR HIV POSITIVE PATIENTS

A three year study, funded by the Agency for Health Care Policy and Research (AHCPR), to evaluate a CHESSE module for men and women who were HIV positive was completed in 1994. A total of 200 people infected with HIV (100 receiving CHESSE and 100 not) were involved.<sup>16</sup> Subjects were randomly assigned to receive either no intervention (control) or CHESSE in

their homes for six months (first cohort) or three months (second and third cohorts). All subjects were surveyed at pre-test and with two and five month post-tests.

#### Use

On average, CHESSE was used daily by the 116 subjects during a 20 week period.<sup>12</sup> Demographic characteristics, HIV illness stage, and health situation had little effect on how much CHESSE was used. Women, minorities, and those with less education were more frequent users of information, decision analysis, and planning.<sup>17</sup>

#### Health status

Compared with the control group, five of eight quality of life measures (activity, reduced negative emotions, social support, cognition, participation in health care) significantly improved in the people who had access to CHESSE.<sup>16</sup>

#### Health service utilisation

Average time spent with clinicians when a visit occurred dropped significantly (17%) in the CHESSE group compared with the control group. CHESSE significantly reduced average length of stay compared with the control group. Cost of care decreased by an estimated \$400/person/month or approximately 30% of the total cost.<sup>16</sup>

#### PILOT STUDY EVALUATING TREATMENT COMPLIANCE IN ADULT CHILDREN OF ALCOHOLICS

A total of 21 adult children of alcoholics were randomly assigned to receive (1) CHESSE, (2)

### Case study 1: Jeremy

Jeremy is an African-American man who was diagnosed with HIV infection in November 1992, when he was 36 years old. He began having HIV related health problems in 1993, and he was introduced to CHESSE in July 1995. At that time, his CD4 count was 248: quite low, but not quite at the AIDS defining threshold of 200. He was unemployed due to poor health, was not receiving federal disability income assistance or any other income assistance, was uninsured except for the local county health service, and was living with his mother and sister, dependent on them totally for financial support.

Jeremy used CHESSE extensively throughout the 47 weeks he had access to the system. He logged a total of 1003 episodes of use, involving 1644 distinct uses of CHESSE services. His total time of use was over 409 hours, or approximately 8.7 hours each week. Although his use was heavier in the early weeks, in his final weeks of access Jeremy still averaged about six episodes of use each week for approximately 100 minutes/week.

Jeremy used all CHESSE services, although the discussion group accounted for approximately 90% of all his services uses. He used the decision aid program to think through whom to tell about his HIV status. He used the action plan program several times to help him to stop smoking. He read extensively in questions and answers, instant library, getting help/support, and personal stories. He asked eight questions of the expert, all medically related and ranging from the effectiveness of nicotine patches and alternative treatments to medication side effects and symptoms of dementia and depression. He was active with the discussion groups, frequently writing messages in the open discussion group, as well as the private groups for people of colour and heterosexuals. He asked many questions of other users, and he was always upbeat and supportive of others. He made many close friendships, crossing boundaries of race, sex, sexual orientation, and socio-economic status. He was instrumental in organising several in-person gatherings of study participants.

During the course of the study, Jeremy did succeed in giving up smoking. He also reported significantly reduced use of marijuana (down by 50%) and cocaine (down by 70%) by the end of the study. He successfully applied for federal income assistance and obtained federal health coverage. He was able to find his own apartment and return to living independently.

Based on survey data, Jeremy reported higher scores after four and eight months of CHESSE access (compared with his pre-test scores) on each of the following scales: self report Karnofsky score, emotional wellbeing, social/family wellbeing, relationship with doctor, functional wellbeing, participation in health care, fatigue, and coping.

Jeremy said that what he liked most about CHESSE was the information on different health issues and meeting and talking with others who were also dealing with HIV. He said he learnt from CHESSE, "how to live with HIV and how to handle, look for, and deal with situations that come from having HIV". He also said, "CHESSE has made it possible for me to deal with HIV in more positive ways—that is, it gave me the courage to deal with my ailment and to fight to live longer. It gave me hope". His major concern about CHESSE was that, "when this study is over, I'll be giving up something that has become what I call a part of me. I'll have to part with the computer and friends".

**Case study 2: Michelle**

Michelle was 44 years old when she was diagnosed with breast cancer in May 1995. She is white, has a high school education, and lives alone in rural Wisconsin. Shortly after her diagnosis, she was given CHESS. Two weeks later she had a mastectomy. She did not have any adjuvant therapy.

Michelle used CHESS extensively throughout the 26 weeks that she had access to it. She logged 699 distinct uses of CHESS services. Her total time of use was over 234 hours, or approximately 9.0 hours each week.

Michelle used all of the CHESS services, although the discussion group accounted for approximately 86% of all her services uses. The second most accessed service by Michelle was ask an expert, followed by questions and answers and the instant library.

In her first week of use, Michelle read over 70 questions and answers, read two personal stories of women who had a mastectomy, wrote five messages in the open discussion group, and used the surgery decision aid briefly. She also asked numerous questions in the ask an expert service. Her questions covered the following areas (in the order they appear): ability to donate blood or be a bone marrow donor, mastectomy as an outpatient surgery, loss of arm movement as a result of surgery, hormone therapy, when to see an oncologist, what questions to ask and what tests are done at the pre-operation examination, prophylactic mastectomy, mammograms, side effects from surgery, tamoxifen, and Cytosin side effects.

Based on survey data, Michelle reported higher scores after five months of CHESS access (compared with her pre-test scores) on each of the following scales: emotional wellbeing, social/family wellbeing, social support, cognitive functioning, active involvement in life, self efficacy, participation in health care, and mood.

Michelle said the following about CHESS:

*"CHESS gave me the mental and emotional strength to overcome breast cancer and to realise how very precious life is. I think a program like CHESS saves lives. I wish all people with prolonged illness could get the kind of emotional support that we breast cancer ladies get from CHESS. They would never feel alone or helpless. CHESS is Hope!"*

professional group psychotherapy, or (3) a combination of the two. Attendance at the psychotherapy only sessions was 50% whereas attendance at the group sessions by people who also had CHESS averaged 93%. CHESS was used 928 times by the CHESS only group and 1279 times by the CHESS plus psychotherapy group. Quality of life in the psychotherapy only group deteriorated on four of six dimensions while the CHESS groups improved on all six dimensions and CHESS plus psychotherapy group improved on five of six dimensions. This study offers preliminary evidence that CHESS might improve treatment compliance and effectiveness of treatment as evidenced by the improved attendance and quality of life scores.

Some of the most compelling evidence for effectiveness of CHESS comes from the actual experiences of CHESS users, which we illustrate with two case studies.

**Discussion**

CHESS is a computer support system with demonstrated efficacy. It has been used in many healthcare organisations in the United States and in Canada and Sweden. In part, we attribute the impact of CHESS to its careful needs assessment and design. But the implementation of these systems is just as important as the content and presentation. CHESS enters an organisation only after there is strong support for it among administrative and clinical staff and when there is a commitment to providing computers to patients who don't have them and training to all.

CHESS is now available on the internet, as are many other interactive health communication applications. Although many have good content, they lack the comprehensiveness and

ease of use of CHESS. Our concern about healthcare web sites is that it is not enough to simply create an appealing or even content rich web site. The field is becoming littered with organisations that have had substantial capital investment to create such systems but have failed to thrive. One reason is that although comprehensiveness of content and services is important, ease of use is equally important. People need to be able to easily find the information they are seeking.

Another reason for the failure of many systems is that there is no adequate planning on how to integrate the system into an organisation. The literature on change<sup>18</sup> suggests that there are several factors that influence the successful adoption of a new technology. Some of these relate to creating (or building upon existing) tension for change: getting key people to deeply believe that existing ways of providing information and support are terribly inadequate and that continuing in the current way is unacceptable. This can involve creating an organisational mandate for change, ensuring that the current tension for change is high, making every effort to clearly identify and understand the needs of the customer, and gaining the involvement and support of senior leaders for the project. Moreover, one needs to ensure that the clinical staff as well as the users of the system see the new system as having clear advantages over the existing processes. Strong evidence of the system's effectiveness helps to calm fears.

Social support must exist for those who implement and use the change. This requires understanding the needs of all those involved in the implementation, including clinical and administrative staff and the patients and their

families. Unless these key actors see the system as meeting their personal and organisational goals they will be not be supportive. Social support coming from an influential and committed champion is important. The leadership of the roll out also needs to be from someone with authority and influence and have the support of a senior leader.

Many of the computer systems that have been created in the United States are designed specifically to pursue demand management with the goal of reducing costs. CHESS is designed with the patient and their family (not the clinician or administrator) as the key customer. We have not tried to reduce cost, although for some types of disease CHESS has that effect. With our customer being the patient and family, administrative and clinical staff need to believe that meeting the needs that CHESS meets (those of the patient and family) is consistent with their personal and organisational goals. We firmly believe this strategy is right, but it does limit our appeal in some settings.

Skills and self efficacy are crucial to the adoption of any new technology. Those who will need to change their behaviour to implement an interactive health communication application must have the necessary skills. But they must also believe that they are able in the work setting to use those skills effectively. It is not enough to simply set up a system like CHESS (or any other innovation for that matter) into an existing organisation. One must carefully review and revise the incentives, workloads, job descriptions, facilities, and organisational structure to ensure the change will take place.

The adoption strategy is also important for these systems to be successful. Any implementation process that requires extensive effort and complexity will be much less likely to succeed than one whose implementation is simple. This means that adoption of systems like CHESS must be carefully planned with clearly laid out and scheduled tasks together with high quality written support materials offered to staff, and adequate funding to ensure that adoption can in fact succeed.

Finally, these systems are unlikely to become a permanent part of an organisation if they are not carefully monitored and evaluated. As with almost every organisational "improvement" or innovation, there is a high risk that change will not continue over the long run. It is much easier to return to old ways than to make a new change permanent. Senior leaders who want these systems to become permanent must be willing to make it difficult to return to the old way. They need to find that critical element of the old way that can be taken away just as one takes away the keys to a car to ensure that it is not driven. In addition, however, continued monitoring of system performance is essential. Clinicians greatly appreciate hearing about their patient's reaction to a system like CHESS. They also need to know the number of patients using the system and the benefits they have received from it. Moreover, the staff who implement systems like CHESS must feel

comfortable sharing with system implementers the frustrations they encounter with providing the new innovation. If there are breakdowns in such communication one will not be able to identify and fix their weaknesses.

It should also be noted that it is not enough to provide the system only to patients who already have access to the internet. In the United States many publications laud the ubiquity of the internet. But even the most optimistic appraisals say that 21% of adults in the US are regular users of the internet. Moreover, those adults tend to be young. Most of the people who will use CHESS are much older: patients with breast cancer, heart disease, etc. Few of them have access to the internet. Few will take the steps needed to gain internet access unless they are: (1) identified at the time they most need help, (2) recruited to use the system, (3) provided with the equipment and trained to use it, and (4) given ongoing support to correct any problems they have in using the system.

There are two problems with interactive health communication applications that are endemic to its character. Firstly, they are a radical departure from existing ways of providing patient information and support (although the internet has reduced this problem somewhat). Because change is a difficult process we suggest minimising additional burden on the clinic staff. We do not advocate (as some systems do) that the patient's doctor or nurse answers the expert mail questions. This would place an additional burden onto the clinical staff and would lessen the likelihood of successful implementation. Moreover, we have found that patients value being able to ask questions of an independent expert. Surprisingly, this has had a positive effect on patient confidence in their doctor, possibly because CHESS is used as a form of getting a second opinion.

A second problem with most computer based support systems is the relative inflexibility of its accessibility. For example, many systems are designed to be used at community sites such as clinics or libraries. This automatically limits the hours of use and creates barriers to use (such as geographic proximity). Our research has found that people benefit from CHESS when it is left in the home for several months. Nearly half its use occurs between 9 pm and 7 am. The service that keeps people coming back to other parts of CHESS is the discussion group, and frequent use is essential for CHESS' effects. We are convinced that frequent use and accessibility is a must for all computer based health support systems, and that use must be in the home.

As the saying goes, "there is no such thing as a free lunch". It is not good enough to simply create pretty or content rich web sites. These systems cannot simply be located in libraries or community centers to be effective. Unless we want to widen the gap between the haves and the have nots, we must find ways to provide universal access, in the home, to all people in need. Furthermore, these systems cannot simply be dropped into an existing organisation.

No one would expect any organisational innovation to be permanent unless the issues outlined above are addressed. There is no reason to expect otherwise with the advent of interactive health communication applications. The effectiveness of these systems will come with an organisational commitment to adapt systems and procedures in ways needed to bring about a meaningful and timely adoption and use.

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