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Implementation of a New Web-Based Health Monitor Initiative: Identification of Positive as well as Restricting Factors in a Small Community

A Thesis

In

The Department of Education

Presented in Partial Fulfillment of the Requirements For The Degree of Master of Arts at Concordia University Montreal, Quebec, Canada

June 1999

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ABSTRACT

Implementation of a New Web-Based Health Monitor Initiative: Identification of Positive as well as Restricting Factors in a Small Community

Zahra Punja

This project involved the development of a unique web-based environment to help patients understand and manage their disease. The project's main objectives were to help patients gain easy and direct access to the database of disease information (disease synopsis, a list of books and medical literature, and direct links to other credible websites) and the disease's respective health self-monitoring form. This website was unique because it was first of its kind to have an on-line individualizable and printable health management form for physicians to give to their patients. Furthermore, this website also served as a supplementary tool for patients to get general information and resources for their diagnosis.

In this study, there were three main phases. The first phase was the needs analysis, which surveyed patients and physicians from a rural Connecticut community. The second phase involved the pedagogical and technical development of the on-line Health Monitor Initiative (HMI). The last phase involved the evaluation of the HMI system. During the evaluation portion of this study, patients were given a package containing a diagnosis summary sheet, a self-monitoring form and an example of a self-monitoring form already filled out, directly after the consultation. This was an attempt to "reinforce" the information given by their physician during consultation. This information sheet was not intended to substitute traditional oral information, but to complement and reinforce it. Because this website served as a prototype of a system in which the entire database of summary information could potentially be built, the short-term aim of this project was to research, design, produce and evaluate the prototype system. The long-term aim of this project was to improve quality of patient education, enhance patient satisfaction and increase compliance to treatment. The unique experiences and empirical data gained from outpatients in this small community provided invaluable insights on the need, implementation problems and potential for improved health care. The actual design and implementation of the prototype web-based health monitor initiative provided (a) new information, (b) positive patient-doctor responses and (c) a critical view of the realities and potentials of patient education.

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Table of Contents

Chapter One: Introduction	**1**
The Health Monitoring Initiative (HMI)	3
Research Questions	5
The Hypothesized Model	6
Figure 1: The Hypothesized Triad	7
Figure 2: Conceptual Representations of the Conventional versus the Proposed Models for Doctor-Patient Communication	8
Proposed Plan for Thesis	11
Rationale for the Use of Information Technology in Medicine	12
Chapter Two: Stage One: The Needs Analysis	**14**
Review of the Literature	14
Doctor-Patient Communication	15
Doctor versus Patient Perspectives	17
Patient-Centered Model (1996)	19
Health Belief Model (1974)	22
Health Decision Model (1984)	22
History of Health Informatics Communities	23
Medical Education Developments using Information Technology	24
Recommendations on Future Research from the Literature	25
The Needs Analysis	26
Context	27
Sample	28
Administration	28
Community	28
Physician	28
Instrumentation	29
Administration	29
Community	29
Physician	29
Methodology	30
Administration	30
Community	31
Physician	31
Results	32
The Administration Interview	32
The Community Surveys	33
Table 1: Age Distribution of People Surveyed in Needs Analysis	34
The Physician Surveys	35
Discussion	37

Limitations of the Sampling	37
Limitations of the Methodology	39
Conclusion	40
Strategies to Improve the Needs Analysis	40
Implications for Design and Development of the Web-Based HMI Product	42
Chapter Three: Stage Two: Research, Design and Development of HMI	**43**
Design Principles for Design and Development of HMI	43
Phase I: The Research and Design Phase	46
Phase II: The Storyboarding Phase	49
Phase III: The Website Development Phase	51
Phase IV: Formative Evaluation: Subject Matter Expert Review	51
Sample	51
Instrumentation	51
Methodology	52
Results	52
Discussion	54
Chapter Four: Stage Three: Summative Evaluation of the Prototype	**55**
Patient Evaluations of the Prototype	56
Sample	56
Instrumentation	56
Methodology	57
Results	59
Discussion	60
Physician Evaluations on the Implementation of the Prototype	61
Sample	61
Instruments	62
Methodology	63
Results	63
Discussion	65
Limitations of the Methodology and Sampling of Needs Analysis	65
Recommendations: New Additions to the Health Informatics Field	70
Conclusions	74
References	**76**
Appendix Table of Contents	**81**

List of Figures and Tables

Figure 1: The Hypothesized Triad	7
Figure 2: Conceptual Representations of the Conventional versus the Proposed Models for Doctor-Patient Communication	8
Table 1: Age Distribution of People Surveyed in Needs Analysis	34

Chapter One

Introduction

This century will be remembered for many technological achievements including the advances made in the medical and health informatic fields. Specific to life style and well-being of the population, the next century will also see a significant change in people's attitude towards preserving their health. People will become more conscious about self-preventative measures to resist the diseases that plague humankind, how to take care of the diseases they have, learn more about the diseases afflicting their loved ones and how to live with them in the most productive way. In the new millennium, computer and information technology will play a key role, offering these necessities via such channels as the web-based health monitor initiatives (personal communication, Tazdin Esmail, January 1999).

Over the past two decades, with the growing use of computer-based technologies, numerous health and medical informatics communities and associations have emerged. Although some use the terms "medical informatics" and "health informatics" interchangeably, over the past decade more refined definitions of each have developed. By definition, health informatics is the application of information technology to the management of health information or the systematic use of data to manage and provide health services (MacDougal *et al.*, 1996). Medical informatics, on the other hand, is now become a branch of health informatics, in that it involves the use of information technology and computing science specifically for medical science research and for the diagnosis and treatment of disease. As Altman (1997) summarizes, "the primary goals of

medical informatics are to improve the overall health of patients by combining basic scientific and engineering insights with the useful application of these insights to important problems."

As computers are increasingly becoming the norm in the health care system, computer-based technologies are being used in all aspects of the health care system. Of particular interest, recent developments include managing and maintaining (i) database information flow for patient management, (ii) medical records information systems, (iii) hospital discharge summaries, (iv) cost accounting and (v) treatment plans. The Medical Informatics field has made significant progress in the area of biotechnology, in designing 3-D automated programs to simulate surgery, in designing computer-aided goal-based scenario diagnosis programs and trauma management programs and lastly, in developing drug design programs. The Health Informatics field now has automated laboratory testing, and is currently investing a great deal of time, energy and money in the education and training of health professionals.

Thus, the long-term goal of medical informatics has shifted to improving quality of care delivered to patients and to creating technologies that improve the cost-effectiveness of providing this care by concentrating on health outcomes and on evidence-based medicine. There is now, more then ever, a need to understand how we can improve our performance in achieving prevention goals and problem management goals by ensuring that patients take responsibility for their own care (Purves, 1996).

The Health Monitoring Initiative (HMI)

The Health Monitoring Initiative (HMI) project described in this thesis involves the development and evaluation of a dual version (patient and physician) on-line patient education system based on a review and analysis of the literature. The HMI system subsumes both versions.

The physician version of the on-line HMI system allowed physicians to access, individualize and print the information and the self-tracking forms. The information sheets on this system had specific website addresses for patients to follow-up (see Appendix page A28). With this version of the system, physicians can provide tangible individualized personal information to the patient directly after the consultation.

The patient version of the on-line HMI system allowed both patients and their families access to a general version of the same system. This version allowed patients to (i) access the information webpages, (ii) follow direct links to the affiliated organizations specializing in each of the six diseases, and (iii) access and print the self-monitoring forms to fill out and take to their doctor upon their next visit. The objective of this version of the HMI system was to (a) provide follow-up information on a disease after the consultation and/or (b) encourage patients to be more informed and therefore more assertive with their doctor upon their next visit.

The design of this product and the empirical research that was conducted in the form of a needs analysis and a formative evaluation were informed by a review of the literature in the area of information technology and community medical education.

Following the logic outlined above, this thesis reports on a research and development project in medical informatics focused on addressing some of the needs voiced by the patients and the physicians in the literature. To individualize the patient education system, the goal of the project was to provide an on-line environment where information and self-management forms could be accessed, customized, printed and then given to patients by their physician directly after the consultation. This project was carried out in a three-stage process.

The first stage consisted of a needs analysis. This included a thorough review of the literature in the area of computer uses in patient-doctor communication. The needs analysis was used to gather information to gain insights concerning the needs of the local community of physicians and patients. The needs analysis was also designed to involve the local community in designing and developing a patient education system. It was hoped that by customizing the system for the local community, the system would be more effective and useful.

The second stage included the design, development and formative evaluation of the prototype system. The design and development of the HMI patient education system, and

the formal process undertaken to conduct the formative evaluation were informed by the review of the research literature.

The final stage included the "summative" evaluation of the HMI system -- summative in that it marked the end of this research, but formative, still, in the sense that the evaluation involved a prototype, a partial implementation of the idea.

All three stages stemmed from the main research question, underlying the project, which concerned the effectiveness of the individualizable information given to the patient directly after the consultation. In order to investigate this question, it was necessary to examine several dimensions, as discussed further in this thesis.

Research Questions

The questions which motivated this project were:

- If more individualized diagnosis and management information was given directly after the consultation by the doctor, did this increase patients' understanding and compliance to the management of their disease?
- Did providing all patients an equal amount of diagnosis and management information promote fairness and equal treatment by the medical profession?
- Did this system increase the likelihood of the patients following-up in finding the resources additional information, thereby increasing their satisfaction and health outcomes?

- Did placing the individualized diagnosis and health management forms within a web-based application increase patient and doctor access to information technology, thereby helping the health care team take active and informed participation in health education?
- Did this innovation increase patients' interest or motivation for active participation, independent learning and self-management regarding their disease?
- Lastly, did this result in better management of the patients' illness with improved outcomes?

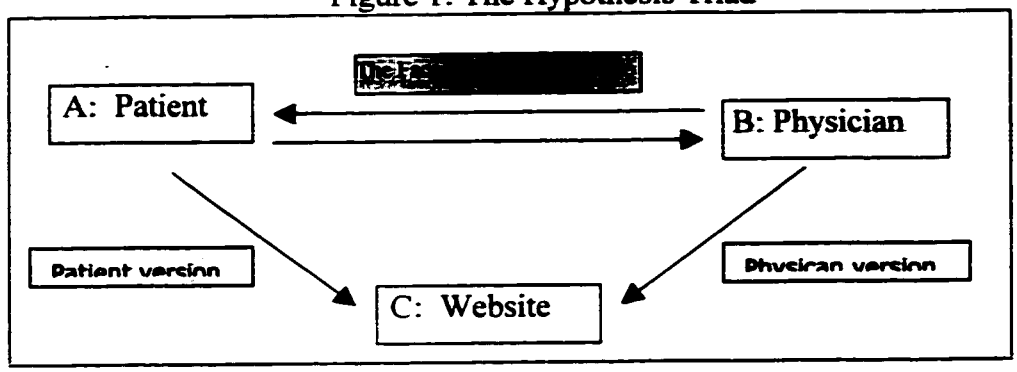
The Hypothesized Model

The literature describes many innovative techniques for effectively tackling the problems associated with doctor-patient communication. Nevertheless, it has been shown that the information-giving process is very time consuming for most doctors. Literature has suggested that physicians should implement the "four Rs approach" in patient education, namely (i) reach agreement on goals, (ii) rehearse the goals, (iii) repeat the goals, and (iv) reinforce the goals (Purves, 1996). These steps are undoubtedly highly beneficial to the patient, but very time consuming for the physician, especially when done properly and with multiple disease states or with multi-system disorders (personal communication, Dr. K. Bandali, March 1999).

The HMI system reported in this thesis was intended to ameliorate the patient-doctor communication problems. Figure 1 summarizes in brief the hypothesized triad encounter between the three interacting components of this HMI system, namely (i) patient-physician

(a-b), (ii) patient-website (a-c), and (iii) physician-website (b-c). Figure 1 also shows how the website can facilitate a face-to-face encounter (a-c → a-b), and how the website can facilitate patients in following-up with on-line information (b-c → b-a → a-c) after seeing their physican.

Figure 1: The Hypothesis Triad



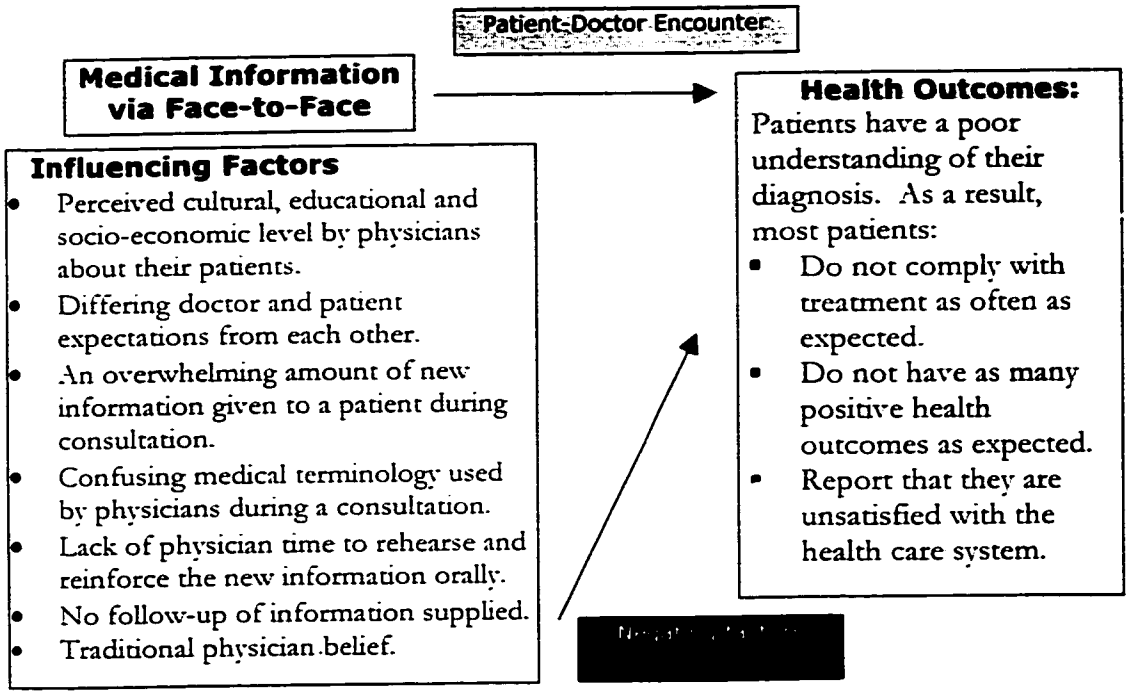
From figure 1 we get figure 2. Figure 2 is a conceptual representation of the conventional model of doctor-patient communication and the proposed HMI model for doctor-patient communication.

Model I in figure 2 lists the influencing factors when medical information is given during the conventional patient-doctor consultation. The influencing factors affecting effective doctor-patient communication in the conventional model are the cultural, educational and socio-economic level assumptions made by the physicians about their patients, the differing doctor and patient expectations from each other, the overwhelming amount of new oral information given during the face-to-face consultation, the confusing medical terminology used by physicians to explain a diagnosis or disease process, the lack of time for the physician to reinforce the information supplied and lastly, the traditional belief system of the physician. This model illustrates how the influencing factors undoubtedly

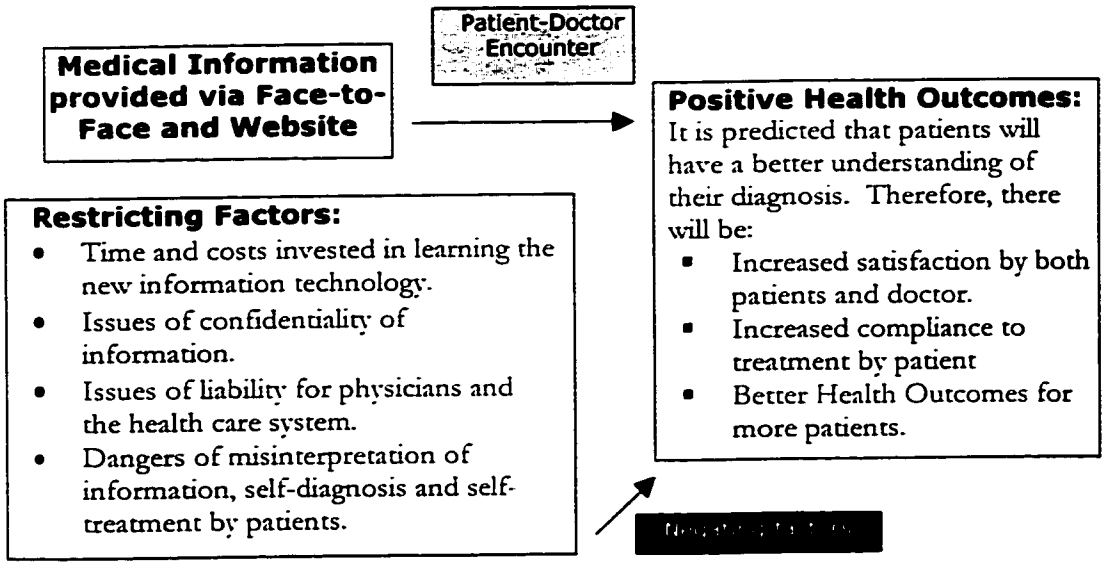
affect the conventional doctor-patient communication process in a negative manner. In turn, as reported in the literature. health outcomes are affected.

Figure 2: Conceptual Representation of the Conventional versus the Proposed Models for Doctor - Patient Communication

a) Model I – The Conventional Concept



b) Model II – The Proposed HMI Concept



Model II in figure 2 lists the potentials of the proposed HMI system. Despite its present restricting factors, the proposed system appears to offer significant benefits to the health care industry in the long-term. Because the focus becomes the patient, and treating all patients as equals when providing information, many of the barriers to effective doctor-patient communication (i.e., perceived cultural, educational, socio-economic background of the patient) presented in Model I are removed. The predicted positive health outcomes of the proposed HMI system include increased understanding, greater patient satisfaction, and compliance to the recommended treatment leading to more positive health outcomes.

Presented in Model II are some new issues that confront the success of this system, including issues of costs, liability and confidentiality. Nevertheless, with the health care system currently spending increasing amounts of money on information technology, issues of costs of training, maintaining and implementing on-line environments should be less problematic. Costs ultimately will have to be evaluated in terms of cost-benefit, given the hypothesis that increased spending on information technology may yield efficiencies and cost reductions in other areas of the health care system. As security improves with on-line technology, issues of confidentiality and liability will also be removed. The more on-line patient education environments that are designed, used and monitored, the less likelihood of misinterpretation, self-diagnosis and self-treatment by patients.

With the implementation of the proposed web-based Health Monitor Initiative (HMI) system, it was hypothesized that doctors, too, will be more satisfied with the positive patient outcomes, therefore more satisfied with the health care system. Since the on-line HMI system emphasizes and encourages independent learning by providing the patient with on-line information, resources and self-monitor sheets, patients can participate and engage in managing their medical problems by accessing the appropriate, relevant and current information at their own convenience. As a result, this system was hypothesized to save the physician a great deal of time in educating the patient.

It was also hypothesized that this "information-giving" medium would lead to less frustration by the physicians because of their patients' apparent lack of adequate conceptual understanding of their disease process, its implications and its management. As a result of the implementation of the HMI information sheet, doctors will be able to give uniform information to each patient without bias with regard to gender, age, nationality, ethnicity, socio-economic status or educational background. An informed patient, regardless of their personality, can, as a result of this patient-physician-website encounter, be more confident and assertive with the physician in obtaining the information they seek (personal communication, Dr. K. Bandali, March 1999).

One of the initiatives to design the proposed HMI system was to conduct a "needs analysis" of the local community that would be directly affected by this new patient education initiative. This will be discussed in the proceeding chapter.

Proposed Plan for Thesis

This thesis is divided into four chapters. As the reader will recall, this chapter introduced the area of medical informatics, outlined the HMI product, presented the conceptual models and outlined the research questions. This chapter will conclude by presenting the rationale for the use of information technology in patient education. The next chapter, Chapter Two, provides a brief description of the needs analysis, presents a thorough literature review, the context of the research, the instrumentation used, the methods used, and presents the results, discussion and conclusions obtained from it. It also discusses the implications and principles for the proposed evaluation and the development plan of the HMI system. The third chapter reports the research, design and development stages for the on-line prototype system. This includes the theoretical and pedagogical rationale for the HMI, as well as the technical stages undertaken to design and develop the HMI system. This chapter discusses the results and suggestions obtained from the formative evaluation by the different subject matter experts, which lead to the final product. The final chapter describes the summative evaluation portion of the project, - summative in that it marks the end of the presented research, but formative still, in the sense that the evaluation involved a prototype, a partial implementation of the idea, for the further development and deployment of the concept. In this section, both the intended evaluation and the actual methodology implemented are presented and discussed. Also presented are the sample, the instrumentation, the results, the discussion and the conclusions, as well as the reflections on the limitations of the project and recommendations for future research. Lastly, the appendix contains (i) all the materials needed to conduct the needs analysis, (ii) all the printed information and self-monitor sheets from both the patient and the

physician on-line databases and (iii) all the evaluation materials used to evaluate the implementation of the prototype.

Rationale for the Use of Information Technology in Medicine

Based on the numerous influencing factors affecting the present patient-doctor communication process, the present project, the HMI, pertains to an area of development that is very much needed and potentially very useful to the patient community at large.

The HMI system focuses on relieving the current patient-doctor communication problems correlated with poor compliance, less positive health outcomes and lack of satisfaction. The HMI system allows practitioners to provide an equal amount of information to all their patients, printed information for follow-up, reinforcement and self-learning, interactive on-line monitor forms, and individualizable forms to encourage physicians to engage in more patient teaching. It focuses on educating the patient and encouraging the patient to take active and informed participation in the management of their disease, thereby potentially resulting in more compliance, increased satisfaction and better health outcomes. The internet-based nature of the modules that were developed allowed for easy access and usability by both patients and doctors. This innovation was focused on providing patient education using technology as both a medium of instructional delivery and a resource for patient education. The findings in the literature review that follows, concerning studies of patient-doctor communication, reinforce the projects' strong theoretical and pedagogical basis.

Due to the proposed nature of the on-line production, the physician version of the learning environment would be individualizable, allowing the doctor to specify personal details about individual patients. The patient version of the on-line environment was designed to be completely non-threatening as patients could access the information and resources at their own time and as frequently as needed, allowing adequate time for review and transfer. It would also provide consumers with specific health information, relevant medical literature and website addresses of recognized health organizations for each of the six diseases.

Chapter Two

Stage One: Needs Analysis

The aims of this needs analysis were (i) to provide the researcher more insight into this project via a review of the literature and (ii) to give patients and physicians an opportunity to voice their opinions and experiences at the commencement of the design and development of the HMI initiative. Hard (1992) stresses the importance of conducting a needs analysis exercise before any commitment to a new systems is made.

The review of the literature highlights important findings in the area of doctor-patient communication, the two points of view concerning this information-giving process, various models proposed by researchers, a history of health informatics communities, innovative health education developments via information technology, and lastly, suggestions and recommendations for further research based on the literature. After the review, the steps that were implemented in the needs analysis as a result of the findings from the literature will be elaborated in detail.

Review of the Literature

The paragraphs to follow will highlight the important findings in the area of patient education using information technology according to published literature on the subject. In particular, the literature review will highlight the findings on the "information-giving" process, the two points of view, namely, the doctor's and the patient's perspectives, and will proceed by presenting the different models that were developed to help solve the

problems in the doctor-patient communication process, namely the Patient-Centered Model (Purves, 1996), the Health Belief Model (Becker, 1974) and finally the Health Decision Model (Eraker *et al.*, 1984). The review will conclude by summarizing the recent history of the Health Informatics communities that have developed, the innovative medical educational developments they and others have developed with the help of information technology, and recommendations that have been made for further research in this area.

Doctor-Patient Communication. Information-giving has long been recognized as beneficial in health care in terms of physiological as well as psychological outcomes (Bysshe, 1988; Hayward 1975). Patients who are well informed are more likely to experience less painful, difficult or anxiety provoking situations and are more compliant to their treatments (Cortis *et al.*, 1996). Information appears to have an empowering effect, enabling patients to take more control over their health care, and to comply with medical treatment (Latter *et al.*, 1992).

In the literature, there is a new trend towards including the patient as the focal point of the health care team. As one of Yale's faculty member stated, "an educated, involved patient is a doctor's best tool in treatment" (personal communication, Dr. M. Sadigh, October 1998). Yet despite the remarkable effects of information-giving proven in many studies in the past two to three decades, patients still complain about the lack of information given *during* or *following* a consultation with a physician or health care provider (Purves, 1996).

Communication and patient education is part of the health provider's role. It is an essential component of the role, which can not be delegated, and which has lasting health and social outcomes over time (Simpson *et al.*, 1991). Better communication between patient and doctor improves (a) diagnostic accuracy (Beckman & Frankel, 1984), (b) adherence to the prescribed treatment (DiMatteo *et al.*, 1993), (c) health outcomes, (d) patient satisfaction (Bayer Survey, 1995) and (e) clinician satisfaction.

Patient education is highly correlated with patient satisfaction. Most problems with preventative care as well as medical treatment reside in the patients' poor understanding of their illness either due to poor information delivery or due to the complex nature of medical terminology (Beckman *et al.*, 1984). Medical jargon is often misunderstood by the patient (Becker, 1985). A recent study concluded that patients do not follow-up with treatment due to (a) the patient's concern about side effects, (b) the patient's perceptions that a medication is not helping, (c) the patient's perceptions that their condition is not improving, (d) the patient's preconceived belief and perception of the efficacy of the treatment, (e) the complexity of the regime and (f) the patient's relationship with the clinician (Michenbaum &Turk, 1987). The principle underlying problem in all these factors is the lack of understanding and inadequate education of the patient regarding the seriousness and prognosis of their disease (personal communication, Dr. K. Bandali, March 1999). The end result is dissatisfaction with the health care system and reduced effectiveness of treatments and interventions.

Doctor versus Patient Perspectives. In reviewing the literature, two main perspectives concerning patient education, satisfaction and compliance emerge, namely, patients' and doctors'. Both these perspectives, which are markedly diverse, explain the dissatisfaction generally expressed by both parties.

From the patient perspective, lack of information and problems in communicating with health care professionals usually come at the top of patients' concerns (Audit Commission, 1993; Cortis *et al.*, 1996). In a survey conducted by Daniels (1989), patients rated poor communication as the number one cause of dissatisfaction with hospital care. Extensive medical jargon and the doctors' non-verbal communication are two powerful forces leading to patients' lack of understanding of their diagnosis.

From the physician's perspective, poor medical outcomes result from non-compliance, and this in turn, accounts for much of the general dissatisfaction currently expressed toward the delivery of health care (Becker, 1985). When health care professionals think about patient compliance in relation to health outcomes, they feel that the preventative or treatment goal is simply dependant upon whether or not the individual follows advice sufficiently (Becker, 1985). Practitioners also feel that giving too much information can lead to worrying behaviors that can lead to negative health outcomes (personal communication, Dr. Daniels, 1998).

In a study conducted by Waitzkin (1984), it was found that doctors' non-verbal communication was related with outcomes of medical care such as compliance,

satisfaction and physiological responses to treatment. Patients almost always want as much information as possible, and doctors do not realize this (Waitzkin, 1984). Waitzkin's study found that barriers to effective transmission of information were related to characteristics of patients such as sex, education, social class and background and characteristics of doctors such as social-class, background, income and perception of patients' desire for information. He felt that doctors tend to underestimate patients' desire for information and have misconceptions about the process of giving information. In Waitzkin's study, patients wanted to know almost everything and thought that the information would be helpful. In 65% of the patient-doctor encounters, doctors underestimated their patient's desire for information. Waitzkin also found that there were no major class differences in the desire for full information to be communicated in comprehensible terms.

Despite the amount of information patients seek about their diagnosis, several studies have shown that patients fail to remember much of what was told to them during consultation (Ley, 1988). Researchers have found that as many as half of the physician's statements are forgotten by the patient almost immediately after the consultation (Becker, 1985).

Thus far, the literature has shown that patients want as much information as possible on their diagnosis, but practitioners don't realize this. When patients are given detailed information about their disease state, either the medical terminology confuses patients or they forget the information as soon as the consultation is over. As a result, there have

been many approaches to help patients remember the information given to them by their physician. Ley *et al.* (1973) suggested that written instructions should be provided whenever possible to reinforce the oral communication. Waitzkin (1984) suggested that an effective type of communication tool might involve having a "multi-level" explanation whereby the doctor gives the technical explanation and then translates it into simpler terms. Waitzkin also suggested that practitioners should increase the information that they provide to their patients. Becker (1985), too, recommended that information intended specifically to inform patients about their treatment regimen would increase adherence, if specific instructions are given with some form of reinforcement. Kahn (1993) introduced the concept of 'personalized leaflets' which directed the patient on follow-up treatment and self-care procedures. Purves (1996) proposed the Patient-Centered Model, which will be discussed further below.

The Patient-Centered Model (Purves, 1996). Purves (1996) proposed a "triad encounter model" comprising three interacting relationships. These three interacting relationships occur between (i) the clinician-patient, (ii) the clinician-computer, and (iii) the patient-computer. In this model, he emphasizes that the patient be an active participant in the management of his/her disease, and calls this the "Patient-Centered Approach". In his approach, he introduced the "4 Rs Approach" to Patient Education, which are (i) reaching an agreement on goals, (ii) rehearsal of these goals, (iii) repetition of these goals and (iv) reinforcement of the goals (Purves, 1996).

The patient-centered model encompasses six interacting variables namely (i) exploring both the disease and the illness experience. (ii) understanding the whole person, (iii) finding common ground regarding management. (iv) incorporating prevention and health promotion. (v) enhancing the patient-doctor relationship. and (vi) being realistic (Purves. 1996). In this model. the patient focuses on communicating their medical history, their problems. their ideas, their expectations, their feelings, their decision making and their care planning. The clinician responds to the patients needs and guides this decision making. care planning and care intervention. The computer facilitates this doctor-patient communication by monitoring the care plans, prompting for care interventions and by providing both a health record and knowledge support system for the doctors (Purves. 1996).

The role of the computer is vital for the success of the model Purves introduces. In his model. the computer serves as an electronic health record and monitor system, which integrates clinical knowledge (decision support as well as patient-focused computer education). quality assurance and networking. The clinician can have pre-consultation assessments and histories taken by the computer while ensuring that necessary data sets are extracted (e.g. functional status, self-care assessments) without having an impact on the time and process for the consultation (Purves. 1996). Purves emphasizes that a compatible electronic health record should support the clinical method in which the doctor can consciously seek decision support from the computer. The decision support needs to supply clinical knowledge to aid the doctor in assessing the patient's problem

and *sharing information* with the patient in making a decision on management planning and goal setting.

In this model, the patient-centered approach emphasizes that the patient assume an active role in the management of their disease. In recent studies, patient-centered clinical methods have shown improvement in patient satisfaction and outcome of care (Purves, 1996). However, Purves does mention barriers physicians face in maintaining the patient-centered approach. Within any consultation, both the doctor and patient have a learning agenda. This agenda is disturbed by the anxiety general practitioners feel when trying to cover all four time-consuming interactive components of the patient-centered method (Purves, 1996).

It is a fact that as many as half of the physician's statements are forgotten by the patient almost immediately (Becker, 1985). Therefore Ley *et al.* (1973) suggest that written instructions should be provided whenever possible to reinforce the oral communication and Becker (1985) proposes that providing information intended specifically to inform patients about their regimen will increase adherence. Purves (1996) suggests that by making use of the "4 Rs of Patient Education" (Reach agreement on goals, Rehearsal, Repetition, and Reinforcement), the patient receives the necessary encouragement to achieve their learning outcomes. Purves feels that the health service should be tailored to the individual's experience, understanding, and ability to communicate. Following this rationale, Kahn (1993) introduced the concept of 'personalized leaflets' which direct the patient on follow-up treatment and self-care procedures.

Health Belief Model (Becker, 1974). Becker's Health Belief Model suggests that whether or not an individual will follow professional advice depends on the patient's (i) health motivation, (ii) perception of susceptibility, (iii) perception of severity, and (iv) evaluation of costs and benefits of recommended health-promoting behavior (Becker, 1985). In his research, Becker found that patients possess powerful, well-defined health beliefs that sometimes conflict with the physician's assessment of the problem. Becker also found that some patients sometimes reject an unanticipated diagnosis too painful to accept (Becker, 1985). Nevertheless, patients' attributions of illness etiology are of crucial importance, and can affect their emotional state, behavior, self-treatment, and presentation of symptoms (Stoeckle *et al.*, 1980). How patients understand their disease is an indicator of the success of the patient-doctor communication. The more they understand, the more likely they are to comply with their treatment and the more satisfied they are in the health care system (Mathews, 1983; King, 1983).

Health Decision Model (Eraker *et al.* 1984). The Health Decision Model is based on Becker's Health Belief Model. Research has shown that the Health Belief Model influences health actions (Eraker *et al.*, 1984). Some "health belief factors" are uncontrollable, thereby making patient compliance unpredictable and treatment outcomes not always positive (personal communication, Dr. K. Bandali, March 1999). Nevertheless, research has found that reassurance and patient teaching from the doctor, both "controllable factors", depend for their success on an acknowledgement of the patient's specific understanding of his or her condition (Sapira, 1972). Information and

patient teaching in the clinical context removes or reduces anxiety, resulting in better outcomes (Waitzkin *et al.*, 1976).

Several studies have proven patient education results in better health outcomes. In a study where the physicians were tutored to spend more time on patient teaching, patients exhibited high levels of knowledge, with appropriate beliefs about the diagnosis and its treatment, and were more compliant with the treatment regimen than were patients of the non-tutored physicians (Inui *et al.*, 1976). In another study, where newly diagnosed diabetics were informed about their condition and those aspects of the disease that the patient was capable of controlling, patients in the "informed group" had less difficulty managing their disease than did the controls (Lowery *et al.*, 1976).

Detmer (1997) predicted that informed citizens who assume greater responsibility for the management of their health will increasingly challenge health care professionals to provide evidence for their clinical recommendations. As a result, in the last decade, there has been an increased emphasis and commitment by health educators to include the patient as part of the health care team and in providing quality information to the community at large.

History of the Health Informatics Communities. In a recent survey (Harris, 1996) conducted in the United States, 90% of the surveyed sample thought that information technology will improve and that better health information would be available to the public in the not too distant future. In the UK, Community Health Councils were set up

in the mid 1970's. One of their functions was to serve as a 'watch dog' monitoring the quality of health care and the quality of "information-giving" (Cortis *et al.*, 1996).

In Canada, Shopper's Drug Mart, one of the largest pharmaceutical companies, has recently established the Health Watch system to monitor both the quantity and quality of prescriptions given to the patients, the side effects and the compliance rate by providing medication information to its consumers. In Canada, veterinary clinics, too, have long established summary printouts providing pet owners with personalized information and follow-up care for the management of their pets' diseases.

At the present time, Information Medical Systems Inc., Creative Multimedia, IVI Publishing, HealthSoft and InfoTech have all reproduced general health and disease state information through computer-based technologies, yet because of its location (i.e., CD-ROM by request), the information is inaccessible to most of its intended audience. It appears that, in the past decade or so, there has been a huge trend toward community health education, yet most patients still complain of the lack of information given to them by their doctor.

Medical Educational Developments using Information Technology. In the health care field, general information pamphlets and discharge summary sheets have been created about common diagnoses. With respect to diagnosis, computer-based technology has been applied to designing computer-aided diagnosis programs, which help doctors target the diagnosis including the appropriate investigations and treatment. As noted above,

Kahn (1997) introduced personalized leaflets to be given to the patient following the completion of the consultation. However, these leaflets did not include a list of follow-up resources or personalized self-management forms and, therefore, patients did not fully benefit from them. Summary sheets have also been created in the medical division of prescribed treatments.

Recommendations on Future Research from the Literature. Research has found that the relationship between communication and clinical outcomes is both under-researched as well as poorly researched (Ley, 1988). Lack of research in this area is primarily due to the proportionately small sum of money allocated by the health care system towards "health informatics" to date. Within the United States, the health care sector spends only 3% or less of its budget on information technology, compared with other information-intensive industries that spend 8% or more (Detmer, 1997). Given the information-intensive nature of health care industry, a greater amount in the range of investment from 6%-10% is not unreasonable (Detmer, 1997).

Future computer-based applications in the field of health care should offer users a means of interacting with their health care providers, accessing reliable medical literature, and tracking key data needed to monitor and maintain their own health (Detmer, 1997). As suggested by Detmer, "This innovative educational strategy will seek to educate all citizens about health and its maintenance. It should enable interested citizens to monitor their own health status and participate via electronic means for specific education at minimal cost."

Future developments should try to ensure that patients will receive quality health care and health care education regardless of their geographic setting, perceived social status or educational background. These developments should promote self-care/learning through a patient-centered approach (versus a disease-centered method) and should provide multi-level explanations (Purves, 1996).

Hopefully, the emerging information technology era, combined with a patient-centered approach as opposed to a disease centered approach, will encourage the general practitioners to concentrate more on the patient's agenda, giving patients increased responsibility for their own care and greater ownership of their own problems (Purves, 1996). As Purves suggests, the computer will furnish the physician, on demand, with information that be patient-focused, promote self-learning, be asynchronous and accessible (e.g., using hypertext), have credible knowledge and have an intelligent presentation (e.g., presenting clinical information in a graphically appealing way). Such support systems will provide substantial benefit to the patient in understanding and managing their disease (personal communication, Dr. K. Bandali, March 1999).

The Needs Analysis

As the reader will recall, the literature reports that there are severe consequences to health outcomes when patients have difficulty understanding their disease. There also appears to be miscommunication and varying expectations from the health care team. Patients have reported to want as much information as possible, and this finding is stable across

different educational, cultural, geographic and socio-economic backgrounds. The needs analysis was designed to validate and refine the findings reported in the literature as well as to involve the local community in a project that would eventually call for their participation. The paragraphs to follow describe the procedures, instrumentation, sample, context, and results from the needs analysis that was carried out at the commencement of this project.

Context

The context of the project was a small town (approximate population 3500), 45 minutes South of New Haven Connecticut, called Waterbury. The local residents there speak either English or Spanish or both.

St. Mary's Hospital is a medical community known for its teaching facilities for Yale University's Department of Internal Medicine. It is the central teaching hospital for Internal Medicine residents and interns and is the health care provider for this region. The department emphasizes teaching at the faculty level, at the peer level and at the patient level to improve the welfare of both the clinician staff and the community at large.

The Department of Health Informatics at this hospital encourages innovative methods for improving quality education to the community, as it is their mandate to improve communication between the hospital and the community as well as to improve computer literacy skills amongst the resident staff.

Sample

The participants were a random sample of recipients of health care from the local community as well as volunteer physicians enrolled in the Internal Medicine Department at Yale University who were affiliated with St. Mary's Hospital.

Administration. One administration and faculty member of Yale University's Department of Internal Medicine was also interviewed. This attending physician was responsible for the attending rounds and for resident reports. He was 28 years of age and this was his first year teaching at the post-graduate level of medicine.

Community. There were also twenty volunteer community members who participated in the study. They were between the ages of 18 and 65 years. Although, they were from various ethnic backgrounds, they all spoke English.

Physicians. There were five volunteer physicians who participated in the needs analysis. They included specialists and residents who had completed at least seven years of university including four years of medical school. They all had had various undergraduate degrees ranging from the social sciences to the health sciences as well as post-graduate qualifications. The physicians were between the ages of 21 and 55 years of age. They were all English speaking, although their nationalities varied. Approximately sixty-percent of the participants were male, and forty percent were female. They all were full-time practitioners.

Instrumentation

In conducting this "needs analysis", a survey to obtain the opinions of the local community of doctors and patients, the following instrumentation was employed.

Administration. One Attending Physician, who was also part of the administration, was interviewed about the hospital's efforts and mandate in patient education. The interview questions inquired about the hospital's current initiatives in community health education, the disadvantages and advantages of them, the changes they would make in the future, and any suggestions to contribute to this HMI system. See page A6 in the Appendix section to see the interview questions asked to the Attending Physician.

Community. Twenty outpatients were surveyed at a local mall. The survey administered to them focused on acquiring information about their impressions of the doctor-patient communication that they had experienced and inquired about their awareness and satisfaction with St. Mary's Hospitals' current initiatives in community health education. The questionnaire inquired about their level of reading, speaking and comfort level in English, their access to computers, their level of comfort of using computers as a means to gather information, and their level of comfort of using the internet. They were also asked for input and suggestions on the prototype system to be developed. See pages A2 – A3 in the Appendix to view the survey questionnaire.

Physicians. Interns and Residents were administered a consent form followed by a two-page survey inquiring about their participation and opinions about patient education. The

survey mostly employed an open-ended question format asking clinicians about their computer skills, their level and comfort of computer use, their satisfaction with the current organization of patient education, as well as their views about patient education. Some of the questions asked of the clinicians included estimations of time invested in patient education during a consultation at the continuity clinics as well as the percentage of patients who complied with the recommended treatment plan. Clinicians were also asked how they gave medical information to their patients, their present frustrations with the information-giving process, the likelihood of them researching follow-up resources to give to their patients and their views on information technology. They were also asked if they would like to see an information website created for patients and physicians to access and lastly, they were asked what suggestions they had on the proposed HMI system. The survey questions required the clinicians to reflect about their knowledge, experience and motivation to use information technology to educate their patients. See page A4-A5 in the Appendix section to review the survey questionnaire.

Methodology

Adminstration. It was intended to interview the various administrative departments of St. Mary's Hospital. Due to the variant schedules of the administration departments, not all departments or department representatives were available. Furthermore, since this study was a non-hospital project, non-Internal Medicine departments were hesitant to participate. As a result, it was possible to interview only one person at the administration and faculty level. The administration was also asked about institutional priorities in community and patient education.

Community. It was intended to interview or survey inpatients who have recently been diagnosed with an illness, but due to patient confidentiality and legal issues, this method of recruiting patients was not possible. As a result, for the purposes of this stage of the project, twenty surveys were distributed randomly to twenty community members from the local mall. These local residents who were surveyed were asked general questions about the "information-giving" process between the doctor and the patient. In particular, the public was asked about their satisfaction from doctors in terms of patient education as well as technology integration in enhancing patient education. Specific questions are as outlined in the survey questionnaire (see Appendix pages A2 to A3) and included questions about their illness, the adequacy of medical information obtained, including the symptoms of the present problem, symptoms to follow and the expected symptoms to be aware of.

Physicians. It was intended also to survey physicians in both inpatient as well as outpatient care, as well as interns and residents, but due to time constraints with the physicians' schedules, arranging this ideal method of data collection was not feasible. As a result, surveys were given to a variety of physicians including in-house faculty as well as Internal Medicine residents. Doctors were asked what difficulties they had encountered in their patient-physician relationship and what information they thought was important for a patient.

Results

The following sections will discuss in detail the results found from the community surveys, the administration surveys and the physician surveys.

The Administration Interview. The interview with the administration was conducted with an open ended question format (questions can be found in the appendix pages A3 -A4). The interview revealed that the fundamental mandate of the health informatic communities is to make patient education more accessible for the general public. The administration at St. Mary's Hospital has taken many steps to assist in patient and community education by setting up outpatient seminars conducted by nurse practitioners. The hospital also distributes a seasonal health magazine called "Insights" which discusses medical prospects in medicine, highlights recent stories of successful patient treatments, addresses issues affecting the local community and provides a community calendar and a list of support groups. This magazine is an effective means to communicate with the public about health issues affecting the local population. St. Mary's Hospital also has a kiosk at the local mall that gives patients information about their specific needs and also has the ability to print out any particular general information the patient needs by accessing the database of information sources using their computer.

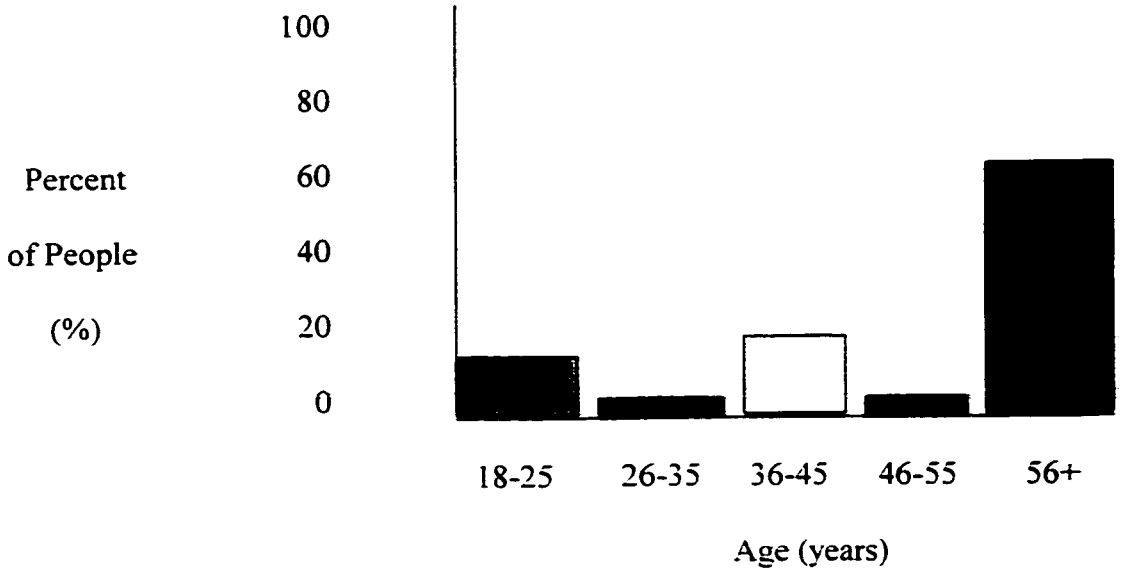
The administrator interviewed felt that there is a great need for patient education in the area of secondary management and disease prevention. He also mentioned that despite the need for health education regarding birth control and (premarital) safe-sex practices, St.

Mary's Hospital, being a Catholic Church affiliated health institution, does not offer these types of services.

In terms of medical terminology, he noted that the extensive medical language that is commonly used by doctors and that is instilled in everyday patient education programs should be simplified and kept to a minimum. In his experience, patients who come forward with interest and enthusiasm leave discouraged and afraid to ask "stupid" questions when doctors use too much medical lingo. He feels that medical terminology can be a "conversation-stopper" if used extensively and unnecessarily.

The Community Surveys. Of the twenty community surveys returned, the first language of 75% of the respondents were English. The remaining twenty-five percent was made up of Spanish and Indian. Seventy-five percent of the people surveyed felt that their level of English was very good to excellent. Table 1 shows the age distribution of people surveyed. The majority of the people (60%) surveyed were 56 and over.

Table 1: Age Distribution of People Surveyed in Needs Analysis



More than half of the sample (55%) did not have a computer at home, and of those who didn't have a computer at home, seventy-seven percent did not have access to a computer. Of the forty-five percent who had a computer at home, only half had access to the internet. Surprisingly, of all the people fifty-six and older surveyed, not even one had a computer at home. As a result, sixty percent of the survey sample did not use the internet and sixty-five percent of the surveyed sample did not know how to access websites. Of the seven people who knew how to access websites, only two people used it as a means to gather medical information.

Of the people interviewed, fifty-five percent were diagnosed with something in the past six months and eighty percent stated that they received verbal information from their doctors. Only forty percent of those that received information remembered, understood or knew how to spell their diagnosis properly (e.g. "Shogrines" Syndrome). Only fifty-five

percent of the people surveyed admitted adhering to the treatment. Fifty percent of the people surveyed felt that the information-giving process could use improvement. The vast majority (seventy-five percent) of the people surveyed felt that, at times, the medical terminology confused them and caused further misunderstandings. Furthermore, only thirty-five percent of the people surveyed were given pamphlets about their diagnosis and only ten percent of the people surveyed felt that they were adequately directed to more information. These findings clearly echo the findings reported in the review of literature.

The Physician Surveys. Of the five physicians surveyed, the first language of eighty percent was English. Depending on the roles of the physicians, the number of patients seen per day varies considerably. As a result, time spent with the patient also varied from ten to ninety minutes, with the majority of patients seen anywhere from fifteen to twenty minutes.

Sixty percent of the physicians surveyed did not have a computer in their office, but all of them had access to a computer with internet access in their department. Eighty percent of the physicians surveyed felt comfortable using the internet. All of the physicians surveyed knew how to access websites and generally used the internet for email (80%), information (100%), business (40%) and entertainment (40%).

One hundred percent of the physicians interviewed were not satisfied with the way in which patient education and patient information is organized for doctors. Present frustrations with information-giving to a patient include: (i) poor clinical organization, (ii)

lack of consistency of information given to patient by different physicians, (iii) the large amounts of unimportant information clinicians have to shift through to get the important information from the charts. (iv) difficulties obtaining information about previous hospitals the patient has visited. (v) problems accessing ambulatory reports. and (vi) knowing that some patients may be non-compliant.

When physicians were asked how they gave information to the patient, all of them stated that they provided information through "direct conversation". On average, physicians reported that approximately fifty-to-sixty percent of their patients adhere to their recommended treatment. When giving a diagnosis, sixty percent of the physicians felt that they were likely to research information to give to their patients. The other forty percent said that they didn't have the time and they didn't know where to find information quickly (i.e., in less than one minute). Interestingly, the sixty percent who felt they were likely to research the information were residents who are learning and gaining experience. The other forty percent who did not have time to research information to give to their patients were experienced physicians who had been in practice for a while. However, a remarkable eighty-percent felt that they make time to direct their patients as to where they might get more information about the diagnosis.

One hundred percent of the physicians felt that the internet would help doctors educate their patients about their diagnosis, but only if the information was from credible institutions. Many physicians noted, with concern, that websites without regulation may misinform the patients. These physicians felt that the websites should be screened in

advance before being given to a patient. Lastly, when asked to give their opinion on what would be relevant information to give to patients if a one-page diagnosis summary sheet were to be developed, physicians recommended that information be given about (a) the diagnosis and its explanation, (b) the nature of disease process, (c) the treatment options and side effects of treatment, (d) the lifestyle changes required (e.g. change diet, discontinue smoking and drinking), (e) what the current research says, (f) website addresses and other resources, (g) when to call a doctor and who to call during an emergency, (h) the benefits of medical compliance, and (i) preventative measures.

Discussion

The results from the needs analysis provided some constructive insights concerning the realities of the doctor-patient communication process as well as the potential benefits to be derived from the implementation of a HMI system. However, due to the small sample sizes and restrictions on conducting the needs analysis, there were some severe limitations to the inferences that can be made from the results. In the paragraphs to follow, the limitations in both the sampling and methodology will be discussed.

Limitations of the Sampling. It should be noted that because the majority of the people (60%) surveyed in the community were over 55, a sampling range limitation was in effect limiting the generalizability of the results presented. It would be incorrect to conclude that the local population had poor computer literacy skills and poor access to the internet as a result of the findings from this needs analysis. However, given that we are confronted

with an aging population, and that older people typically experience many health problems, the results are informative.

As the reader will recall, the purpose of the needs analysis was to involve a local population that have been diagnosed and treated with a disease in the past six months. They did not have to be diagnosed and treated at St. Mary's Hospital, even though it was preferred that they had been. Secondly, it was intended to interview or survey in-patients who have recently been diagnosed with an illness, but due to patient confidentiality and legal issues, this methodology of recruiting patients was impossible. As a result of interviewing people randomly from the mall, who may not have had the direct experience of being treated at St. Mary's Hospital, the results generated from the needs analysis may not directly apply to the population served at the hospital. Some of the people surveyed had been to a doctor before, but had not been diagnosed with anything recently. As a result, they could not relate to the questions asked. They could only predict what they would like to hear from doctors rather than speak from actual experience.

It would have been better to survey physicians in inpatient as well as outpatient settings, as well as interns and residents. Due to time constraints of the physicians' schedules, arranging this ideal method of data collection was not possible. Of the ten surveys distributed, only five were returned. The five received were obtained from a variety of physicians including faculty as well as residents. The limitations in this methodology and sampling are reflected in the variability in opinions which may be attributable to the differences in the amount and type of experience exhibited by the surveyed physicians.

Because the sample size was so small, slight differences may be magnified to yield non-representative results. Grouping all the physicians' statements and ratings together without giving background information about each obscures important differences.

Ideally, it would have been better to interview as many physicians as possible from different faculties, departments and the administration, including the ones who specialize in patient education at St. Mary's Hospital. However, due to the schedules, not all departments or department representatives were available. Furthermore, because a non-St. Mary's Hospital researcher conducted this project, other departments were hesitant to participate. As a result, only one faculty member from the Department of Medicine was interviewed at the administrative level. Because of the faculty member's limited experience in the patient education field and because he was a fresh graduate from the Internal Medicine program, the assumptions and conclusions drawn from this interview may not fully represent the realities which exist in the health care system.

Limitation of the Methodology. Observation of actual consultations between the patient and the doctor in the clinic also would have been ideal, but due to the legalities involving patients in research and in-patient confidentiality, this method of data collection could not be conducted. In the mall, people did not recognize the researcher and thought that the researcher was an external auditor or an evaluator evaluating the performance of the hospital. On occasion, people became very defensive and protective over St. Mary's Hospital, and as a result, perhaps didn't give honest answers because of their misperception of the researcher's role. Furthermore, some of the interns and residents

appeared to feel under investigation and suspected the intention of the survey questions and were therefore perhaps hesitant to give honest responses.

The above mentioned limitations of the methodology and sampling restricts the generalizability of the findings from the needs analysis. A technical limitation to the needs analysis was that, because most of the people surveyed were above 50 years of age, they, sometimes found it difficult to read the small print on the survey sheets. The researcher read the items to the respondent when required.

Conclusion

Although there was variability among results, perhaps based on the small sample size, they were nevertheless generally in agreement with the conclusions reported in the literature. In this section, the strategies suggested to improve future needs analyses as well as the implications this stage had for the design and development of the Web-Based HMI product will be discussed.

Strategies to Improve the Needs Analysis. For research to be productive, it has to be supported by the host institution. It can not be independent of the local environment. Future researchers should spend at least one to two months to settle into the new environment and identify individuals who would be able to contribute their time, resources and skill to the research of interest.

A more effective approach to the design of the needs analysis could have been to recruit two to three physicians from continuity clinics, and have them distribute anonymous surveys to their long-term care patients. As the reader will recall, literature in the area of effective patient education states that communication and patient education is the health provider's role. This role can not be delegated, if lasting health and social outcomes are the goal (Simpson *et al.*, 1991). Michenbaum and Turk (1987) also state that the patient's relationship with the clinician affect the degree to which patient's will follow-up with the prescribed care. As a result, with the consent, support and initiative of the respective doctors, patients are more likely to comply, and more long-term studies can be carried out.

An alternative strategy to designing this needs analysis could have been to randomly select patients from the hospital from agreed upon departments (i.e., inpatients on their road to recovery, inpatients being transferred to outpatient clinics versus inpatients being transferred to ICU). By following patients from selected populations, the results might be more reliable.

Future needs analysis should also have well-defined inclusion and exclusion criteria. For example, sensible inclusion criteria for selected surveyed patients might include a regular outpatient status, a defined range of ages (e.g. 18 to 45 years), non-psychiatric status, English-speaking, as well as having a minimum of two to three doctor visits in the past year. Designing a needs analysis on this basis would obviously require more planning and

organization, but would nevertheless yield results that are more representative and applicable to the population at large.

Implications for Design and Development of the HMI System. The needs analysis reinforced what was stated in the literature. Together, the results of the literature review and the needs analysis informed the design and development of the prototype HMI system. Following the recommendations obtained in the needs analysis, the content of the prototype system was to be medically audited by a group of physicians from each sub-specialization. Both the physician and the patient version of the on-line diagnosis summary sheets were to include as much information as possible and were to include multilevel explanations, thereby minimizing the medical terminology used. The physician version of the on-line environment for physicians was to have a print option, so that the physicians could personalize the information and forms to give to their patients directly after their consultation.

Chapter Three

Stage Two: The Research, Design and Development of the Web-Based HMI System

The six diseases chosen by the Department of Health Informatics for inclusion in the prototype were Asthma, Diabetes Mellitus, Hypertension, Coronary Heart Diseases (CAD), Chronic Obstructive Pulmonary Disease (COPD) and Congestive Heart Failure (CHF). For each disease, a one-page diagnosis summary and self-management sheet was researched, designed and developed. The diagnosis summary sheet included a multi-level explanation, MEDLINE articles, references from medical texts and literature and direct links to medically audited instructional websites.

Design Principles for the Design of the HMI System from Literature

The following design principles were derived from the literature review.

- As the reader will recall, medical terminology was reported to confuse the patient (Daniels, 1989). As a result, Waitzkin suggested that the health information site should be communicated in comprehensible terms and through multi-level explanations (Waitzkin, 1984).

- Secondly, research in the area of doctor-patient communication states that doctors' non-verbal communication leads to a "conversation-stopper" (personal communication, Dr. Dizon, October 1998). In the studies Waitzkin conducted, he found that there were no class differences in the desire for full information (Waitzkin,

1984). As result, simplified, thorough and equal amounts of information should be given in a standardized way to all patients.

- Thirdly, it has also been found that as many as half of physician's statements are forgotten by patients almost immediately after the consultation (Becker, 1985). As a result, Ley *et al.* (1973) suggested that written instructions should be provided and used to reinforce oral information when possible. Kahn suggested that this written instruction should be specific and personalized (Kahn, 1993).

- Fourthly, research has reported that patients who participate in their treatment have better health outcomes. Therefore, Purves (1996) suggested that the patients should take an active role in the management of their disease process and that the computer should serve as a means to enhance this role.

- Fifthly, Becker's Health Belief Model (1974) posits that the more patients understand their disease, the more likely they are to comply to their treatment (Mathews, 1983; King, 1983). As a result, every initiative should be taken so that the patient can understand and participate in the management of their disease process.

- Sixthly, research has found that physicians who spend time in patient education (i) have patients who exhibit higher levels of knowledge about their disease process, (ii) comply more to the prescribed treatment and (iii) have improved health outcomes.

Inui *et al.* (1976) suggested that physicians should spend more time in patient teaching to increase these levels of knowledge exhibited by the patient.

- Seventhly, research has found that despite the availability of health information via information technology in the past decade, patients still need guidance about the knowledge from their health care providers. Detmer (1977) suggested that patients and the community at large should be provided with quality information via communication technologies. Detmer also suggested that patients should also be provided with a computer-based means of interacting with health care providers, accessing reliable medical literature, and tracking key data to monitor and maintain their own health.

- Lastly, Purves reported that a lot of information in the past has been delivered through the disease-centered method. Purves suggested that health information of the future should be available from a computer and should be patient-centered, promote self-learning, be asynchronous, accessible by hypertext, have credible knowledge and an intelligent presentation (Purves, 1996).

Based on this summary of the literature, the various design and development principles were derived. In the proceeding paragraphs of this chapter, specificities of each phase of the development of the HMI product will be outlined in detail.

Phase I: The Research and Design Phase

The research and design phase of this process was the most important stage of web-page design and development. Planning out the theoretical frame as well as the design of the website by taking into account the rationale for the theoretical framework, the target audience, the learning environment, and the advantages of the layout gave the website purpose and meaning.

In planning the purpose of this website, there were two main goals established. The first was to provide a patient-specific on-line environment for physicians (physician version) so that they could personalize and print the diagnosis summary sheets and self-management forms to give to their patients. The second purpose was to provide a patient-centered website for patients (the patient version) to get general information and aids to manage their own disease. An important component of these environments was that they should be self-directed, flexible enough to meet individual needs, self-paced, accessible from any place, and specialized in application for this target group.

Everything stemmed from these major objectives. Because the website served as a resource base, external links were researched and an average of three external links was found for each and every topic. Then, each disease was researched, and the information found was summarized and simplified, so that medical terminology could be minimized for the benefit of the patient. Several internal medicine residents helped locate and summarize information for each disease, following a review of the medical textbooks and medical articles, with simplification of complex medical terminology. Much of the

information gathered and summarized from different credible websites was incomplete, sometimes giving only partial information, and had therefore to be updated, compiled, consolidated and perfected. Literature in the area of web-page design and development was also located and read to assist in the design and development of each component of the website. Lastly, different web-page development software was reviewed to identify the most appropriate tool to build the HMI prototype. As a result, Claris HomePage 3.0 was used and Paint Shop Pro was used to create the graphics.

The website was also designed to have a consistent theme throughout. Research has found that inconsistent themes within the website confuse users and permit them to escape the immediate frame of reference while engaging in nonlinear, multidimensional learning (Spiro *et al.*, 1990). As a result, with an inconsistent theme, it would be very easy to escape the website without knowing it. Therefore,

- Each page of the website included a clean table of contents located on the left-hand side of each page.

- On the main information pages, thoroughly researched and edited information was summarized. Each webpage was designed to have a multilevel explanation of the disease.

- A means to give feedback about the presentation, content, ease of navigation, structure, amount of information and level of information to the authors or the editors of the website was also designed.

- Each webpage was designed to have a list of resources where more information could be obtained. The resource types varied in depth. The website itself provides general information without employing a lot of medical terminology, but the books and articles provided contain more extensive use of medical terminology and require that the patients research the resource themselves. The health organization websites that are linked with the HMI system are designed specifically for patients and are therefore user-friendly and easy-to-read.

- For the physician version of the HMI system, each webpage has an option for physicians to write in their patient's name and health identification number before printing out the form and giving it to the patient.

In summary, the rational for the design was that every page was designed to have a consistent layout so that the user would identify that this webpage was part of an entire website. By placing the content in a table, the users can scroll up and down to view the table of contents, the content and the external links. Furthermore, all pages have anchors so that the user can go directly to the spot on the page where they need certain information.

Phase II: The Storyboarding Phase

Before programming the content and layout in hypertext markup language (html), a very important step was taken to see how all the webpages would be integrated together. First a non-linear concept map, or a flowchart was made to identify the major topics from the subtopics. Furthermore, the user is never trapped in the website and is consistently given the same options in every screen. Each page is also linked with outside sources for (i) reinforcement of the summary information, (ii) further information about that particular disease, or (iii) information on other diseases. Each page has a table of contents. There is also a title at the top of each page with the Health Monitoring Initiative's logo, a list of anchors for that page on top of the subtitle and a crest of the affiliate school of reference, Yale's Department of Internal Medicine.

Phase III: The Website Development Phase

The foundation of this website was based on researched recommendations from the literature in the area of webpage design for instruction (Lynch, P. *et al*, 1997).

To create the diagnosis-support sheets and the on-line interactive forms there was a three-phase process that occurred. First, the six diseases had to be studied and understood by the researcher. Then a group of physicians were recruited and asked what practical and useful information the patient could collect on a day-to-day basis. A difficult decision was deciphering what information would be considered useful in managing the disease process. Based on the insights and recommendations of the physicians, the diagnosis summary sheets and self-tracking forms were written, designed and developed for each of

the six diseases. Also, summaries on each of the eighteen external links for each of the six diseases were researched, evaluated and written.

The self-monitoring forms were developed for each of the six diseases based on the practicality in monitoring and the value of regularly monitoring one's health and disease process. This self-monitoring initiative was designed to provide useful and user-friendly "plug-in values" forms to be printed by the doctor, filled out by the patient and returned to the patient's doctor upon the next visit. The limitation in designing this system was that equipment that is needed to measure the dimensional units (i.e. weight, blood pressure, peak flow and glucose level) is quite expensive for an average person, but is nevertheless obtainable from local pharmacies.

Based on this information, two versions of the same system were developed. The patient-version had general information sheets and the self-monitor forms on each of the six diseases that the patient could access at any time or location, they print, fill out and give to their doctors upon their next visit. The physician-version of the same system required the physician to execute a login procedure with a password. After entering the system, the physician had the ability to individualize the disease summary sheets and health monitoring forms with the patient's name and health ID number before printing and giving it to their patients. This option was available for physicians so that they could individually educate their patients on how to fill out the forms, thereby making the visit more personal.

Lastly, all images were created with PhotoShop 3.0 on the basis of their graphic appeal, appropriateness and consistency with the overall theme.

Phase IV: Formative Evaluation: Subject Matter Expert Review

This was the most important part of the research, as the forms derived from this database would be given to patients during the trial period. If there was any incorrect information, it could place patients in danger and therefore impose liabilities on the hospital. As a result, medically auditing the content was vital for the success of this program.

Sample. Six physicians were asked to evaluate the content, the presentation and the usefulness of the media of the HMI database. Of the six physicians, one was a Yale Internal Medicine Associate professor, working at St. Mary's Hospital in the Ambulatory Care Department. He was also the Medical Informatics Director in that he designed multi-media modules on infectious diseases. The second physician was St. Mary's Hospital's Chief Informatics Officer, who edited the content and presentation of the database. Three of the physicians were specialists in the area of Internal Medicine - an Endocrinologist, a Cardiologist and a Respiratory Specialist, who were asked to edit the content by the Chief Health Informatics Officer of the hospital. The sixth and last editing physician was a Cardiologist from the University of Toronto.

Instrumentation. The main instruments that were used for the content evaluation were the products themselves, that is, the print-based and a computer-based copy of the draft of the on-line database of information (see pages A9 to A60 in the Appendix). The drafts were

also uploaded to the researcher's school account. (Presently, the Health Monitoring Initiative website can be viewed at http://alcor.concordia.ca/~z_punja/valehome). The main instrument that was used for the media and presentation of the product was an on-line feedback sheet (see pages A61 to A63 in the Appendix).

Methodology. Out of the six physicians who formatively evaluated the website, the researcher requested three of the six participants and the remaining three were asked by the Chief Informatics Officer of St. Mary's Hospital to evaluate and edit the content and presentation of the HMI website before the implementation. The request was given at least six weeks prior to the summative evaluation, thereby giving the expert evaluators time to correct the inaccuracies of the information.

Results. No significant changes were indicated by the experts. The three St. Mary's Hospital Internal Medicine specialists (i.e. Respiratory Specialist for COPD and Asthma, a Endocrinologist for Diabetes, and a Cardiologist for Hypertension, CAD and CHF) as well as the Chief Health Informatics Officer from St. Mary's Hospital, asked to evaluate the content of the diagnosis summary sheets had no changes to make to the drafts submitted.

As a result, after the six-week period, a formal consent was obtained to proceed with the testing of the prototype. No changes were suggested and no technical, content or presentation changes were made to the system before the summative evaluation of the trial of the system.

However, after the summative evaluation was conducted, one of the specialists in Cardiology at the University of Toronto responded with a more critical appraisal of the content and presentation. Overall, the evaluator commented positively on the overall structure, ease of navigation, amount of information, level of information, follow-up references, the quality of the resources, personalized self-monitoring forms and the overall concept. As he stated in his own words, "Putting references for reading and other websites is a great idea for those who want to know more. Personalized self-monitoring forms can help a patient take 'charge' of his/her own care." He felt that the HMI was an excellent concept and this patient education initiative is highly needed in a culture like ours.

However, it is important to make note of the content suggestions he made to the medical evaluators of the website. He felt that the overgeneralization of a disease state could be dangerous for the general practitioner who may not know, for example, that Congestive Heart Failure (CHF) is an important cause of atrial and ventricular arrhythmia and sudden cardiac death. He also noted, with concern, that some of the information was too comprehensive. For example, "It might not be important to suggest that the first manifestation of CHF can be arrhythmia (or palpitations) or symptoms of low output such as forward failure (fatigue and 'dizziness') or backward failure (orthopnea/ paroxysmal nocturnal dyspnea)." He also noted that in the Coronary Artery Disease (CAD) webpages, there was no mention of smoking as a major risk factor, and the importance of modifying this behavior. He suggested that, in addition to including smoking as a risk

factor, the summary should include other risk factors such as exercise, diabetes, glucose intolerance, abdominal obesity and family history. As he explains himself, "myocardial infraction occurs because a fatty plaque suddenly ruptures and a clot forms on it, acutely obstructing the vessel (as opposed to slowly occluding the vessel with atherosclerotic plaque)." Lastly, he mentioned that in some cases, "blood pressure monitoring may be unnecessary and cause undue anxiety for readings that are out of the normal range."

Discussion. As seen, the accuracy of the information, as well as the quantity and quality of information presented, depended on the quality and thoroughness of this content evaluation. Clearly, some form of official sign-off procedure must be used in conjunction with the expert review of content to ensure thoroughness.

The next chapter will provide an in-depth analysis of the samples and instrumentation used, the methodology taken, the results found and the discussion of both the patient and physician evaluations of the prototype. Chapter Four will also discuss the limitation of the methodology and sampling of the summative evaluation and will make recommendations to future research in the area of health informatics.

Chapter Four

Stage Three: Summative Evaluation of the Prototype

It was the aim of this summative evaluation to provide more insight into the realities of implementing a system such as the HMI. The evaluation was intended to provide an opportunity, to physicians and patients alike, to voice their opinions and experiences concerning this product's usability and practicality. To reiterate, the Health Decision Model (Eraker *et al*, 1984) asserted that there is greater compliance if the patient has a greater perceived control over his/her care and better understanding of the care. The reader will also recall that in Purves' (1996) Patient-Centered Model, the emphasis was placed on involving the patient as much as possible in the medical team to improve health outcomes. In this third and final stage of the project, both patients and physicians evaluated the system.

The paragraphs to follow will summarize the sample, instrumentation and results from both the physicians as well as the patients surveyed from a rural Connecticut community. The last section will address the limitations of the methodology and sampling of both the patient and the physician evaluations as well as highlight recommendations for future research in the area of information technology and medicine.

Patient Evaluations of the Prototype

Sample. Out of the twenty surveys administered, fourteen patient surveys were returned. This reduced return was probably a result of bad weather and the time of the evaluation, which was during the Christmas holidays. All fourteen respondents were outpatients from the St. Mary's Hospital Family Health Clinic, the unit used in the evaluation portion of the study. The surveyed patients were between 18 to 50 years of age. A little more than fifty percent of the sample patients spoke Spanish as their first language. All fourteen outpatients were female. Seven patients surveyed were given information sheets about Asthma, one patient was given information about Hypertension, one patient was given information about COPD, and the remaining five were given information about diabetes. No patient was given information sheets about CHF or CAD.

Instrumentation. A one-page survey was given to each of the participating patients. The survey had ten direct questions asking about the usefulness of the diagnosis summary sheet, the self-monitoring form, the example form and the resources listed (i.e. websites, books, and the articles). Patients were also surveyed about the likelihood of them accessing the resources and their satisfaction with the information given See page A66 in the Appendix to view the survey.

Quality of patient care was based on a Likert-type scale. The higher the score that was reported, the better the quality of care. Hence this measure of quality inevitably reflected the doctors' and patients' learning objectives based on their learning agenda from the

consultation, as well as reflected perceptions of the treatment and the care the patients received.

The patients were asked general questions about the information-giving process between doctor and patient. In particular, the patients were asked about the usefulness of the diagnosis summary sheets, health monitor form, the example form and the resources listed on it. Also, the patients were asked about the accessibility of the resources, the likelihood of them complying to the recommended treatment, their perceived ability to take better care of themselves, their expected health outcomes and their overall satisfaction with the health care system.

Methodology. It was initially intended for the physicians to be randomly assigned into one of two groups: experimental or control. In the experimental group, it was intended to give the physicians a formal workshop presenting a summary of the literature, and explaining the purpose of the evaluation and their role. It was intended to give them instructions to verbally give their patients information about their diagnosis, to explain it in both a technical and simplified format, and then give each patient a printout of the diagnosis and self-monitor forms. It was intended for the doctor to explain the purpose of the diagnosis sheets, the self-monitor forms and how to access the resources listed on the sheets to the patient. The doctor would then give an evaluation survey to the patient to be handed back to the doctor in the sealed envelop provided upon completion of the survey. It was intended for the control group to be given the same format of information, within the time period prescribed. The only difference would have been that the doctors in the

control group would not have administered the self-management and diagnosis summary sheets, but rather only a survey on satisfaction, expected compliance and expected health outcomes to be handed back to the doctor in a sealed envelop.

The procedure which was actually implemented was a s follows. Each patient, who visited the clinic on the days the summative evaluation took place, was briefed individually by the researcher on the purpose of the HMI system, the requirements for their involvement and their participation. On a voluntary basis, each patient was requested to orally accept to participate. Once the patient had agreed to participate, the researcher, in a consultation office, explained to the patient the purpose of the evaluation, gave the patient the requested educational forms and summary sheets, and then administered the one-page ten-question patient survey. This evaluation process between the researcher and the patient took no more than 5 minutes. The researcher explained to the patient that only a medical doctor was in a position to give advice about any particular questions or any potential concerns that they may have after reading through the sheets. The researcher advised the patient to consult their physician upon their next visit for follow-up.

The procedure described above was different from the intended methodology. The departure from the planned approach was necessitated by several major restricting factors (e.g., lack of required funding and availability of computer-resources to effectively evaluate the system). As a result, the personalized on-line diagnosis summary sheets and self-management forms were pre-printed and handed to the patients after the consultation

by the researcher. Each doctor and nurse at the clinic was given a prescription-like pad of sheets (see A65 in the Appendix chapter to view the request forms). The clinic staff were directed to educate their patients about their specific diagnosis orally during the consultation with the physician. After each consultation with the patient, if their patient had any one or more of the six diseases (i.e. Chronic Obstructive Pulmonary Disease, Congestive Heart Failure, Coronary Artery Disease, Asthma, Diabetes, or Hypertension), they directed their patient to the researcher. The researcher then gave the patients the appropriate sheets requested by the doctor, explained to them how they should fill the self-monitoring sheets out, and then informed them about the evaluation. This information sheet was not intended as a substitute for traditional oral information, but rather to complement and reinforce it. The researcher explained the purposes of the diagnosis and self-monitor diagnosis sheets and gave the patients an evaluation sheet asking questions with relation to understanding, satisfaction, compliance, and expected health-outcomes.

Results. Out of the twenty surveys administered, fourteen patient surveys were received. Based on the completed surveys, ninety-one percent of the patients felt that the information on the diagnosis, the health monitor forms and the example forms were very useful.

Of the patients surveyed eighty-nine percent viewed the resources given (websites, books and articles) as likely very useful and seventy-four percent of the patients felt that they would follow-up on the resources. A limitation that should be highlighted is the actual

effectiveness of the resources. Even though eighty-nine percent of the patients viewed the resources as being useful, it should be noted that the patients had not accessed the suggested resources prior to making that assessment. This figure merely represents their perceived value of the resources provided and their intentions of expected follow-up behaviors. It is not hard data about actual behavior. Nevertheless. intentions and perceived value may lead to related behaviors.

In line with the literature findings. the surveyed patients felt that by understanding their illness they were more likely to follow the treatment their doctor gave (ninety-five percent), that they would take better care of themselves (ninety-four percent) and that their health outcomes would improve (eighty-eight percent). When asked, "As a result of this education sheet. did you feel that you were more satisfied with the health care system?", ninety-seven percent of the patients surveyed stated that they were more satisfied with the health care system as a result of this education initiative.

Discussion. Of the patients the doctors had sent to the researcher, seventy-four percent stated that they would access the resources provided. However, it should be noted that this is their perception of their future behavior, not the result of an actual follow-up study. Nevertheless, following Bandura's (1977) self-efficacy theory, we might infer the strength of a persons belief in his or her ability to undertake or maintain treatment is related to behavior.

In the literature reviewed, there were no long-term studies conducted to demonstrate that once patients were given as much information as they wanted they did access and use it. As a result of not evaluating the actual usage of the resources, a limitation of this study is that it doesn't provide hard evidence that patients will access and use the additional information even if it is made accessible.

Physician Evaluations on the Implementation of the Prototype

Sample. For this phase of the project, the physician participants were Yale University's Department of Internal Medicine Department post-graduate medical residents who were working at St. Mary's Hospital. At this teaching hospital, there are about eight Yale faculty members working and teaching in the Department of Medical Education supervising the medical residents enrolled in the Internal Medicine program.

Participants in this study included the doctors who were stationed at the Department of Internal Medicine at St. Mary's Hospital during the evaluation months. The evaluation was conducted at the affiliated outpatient family health clinic, during the afternoon clinic days. The participants were between the ages of 24 and 35 years. They all spoke English as their first language, although their nationalities varied. Three were male and seven were female. They were all full-time post-graduates in Internal Medicine.

Out of the twenty physician surveys administered, ten physician surveys were received. In total, only ten doctors participated in this study due to busy, variant and rotating

schedules of the doctors. Of the ten doctors, six were medical residents and the remaining four were medical interns.

Instruments. Two surveys inquiring about different aspects of the project were given to the doctors. The first survey inquired about their impressions and reflections concerning the self-monitor track form and the second survey inquired about the diagnosis summary sheet (see A67 and A68 in the Appendix).

Survey questions on the health monitor sheet (see A68) inquired about comprehensiveness of the health self-monitor form, its presentation and usefulness. Physicians were asked about the potential effectiveness of a program like the HMI, the benefits for the patients' health, belief systems and decisions. Lastly, physicians were also asked about the usefulness for themselves as practitioners and as patient educators.

Survey questions on the diagnosis summary sheet (see A67) inquired about the comprehensiveness of the information, the depth and quality of information as well as their impressions of the multilevel explanation. Physicians were asked about the usefulness of the information sheet to the patients health, usefulness of the resources, the accessibility via web for physicians and patients, the value of giving the sheets to the patient directly after the consultation, and lastly the potential of initiatives similar to the HMI.

Doctors were also asked about the accuracy of the content, the layout and perceived usefulness of the information. Finally, doctors were also asked their opinions on the relationship between patient education and compliance, health outcomes and satisfaction.

Methodology. The doctors were given the same printouts as the patients from the on-line physician version and asked to fill out an evaluation sheet. They were also given an introductory sheet (see A64 in the Appendix) explaining the project, implementation, and the evaluation as part of St. Mary's Hospital patient education initiatives, and lastly they were given a prescription-like pad of HMI "Request Forms" (see A65 in the Appendix).

Each doctor, who was at the clinic on the days the summative evaluation took place, was briefed individually by the researcher on the purpose of the HMI system, the requirements for their involvement and their participation, on a voluntary basis, was solicited. Once the doctor had agreed to participate, the researcher explained his/her role and responsibilities. The main and sole responsibility of the physician who participated in this evaluation was to send their eligible patients (i.e., those who had one of the six diseases - asthma, COPD, CAD, CHF, hypertension or diabetes) to the researcher upon the end of their consultation with a HMI request form. This procedure for conducting the summative evaluation was implemented in an attempt not to disturb the present clinical routines of the doctors.

Results. Out of the twenty physician surveys administered, ten physician surveys were received. Based on the eight people who responded to question number one (see page A67 in the Appendix), twenty-five percent of the doctors felt that the disease information

was inaccurate even though the editing physicians had reviewed it in the preceding part of this stage. All of the doctors surveyed felt that the information was presented in a logical way and all of them also felt that the information was useful to a patient. Out of the eight doctors who responded to the questions regarding the degree of usefulness of the forms, eighty-seven percent of the doctors surveyed felt they were very useful.

All the doctors surveyed found the resources very useful, yet only fifty percent of the doctors predicted that their patients would access them. One physician stated that, "Knowing the education level and their difficulty in understanding English, I think that these explanations are too sophisticated for my typical patient. Ninety-nine percent of my patients would not attempt or even know where to start to research an article or website". Another doctor stated that "A simplification of the language would help particularly as many of the patients have English as their second language", implying that further simplification would be needed for her patients.

One hundred percent of the doctors also felt that the health monitor initiative would increase the compliance to treatment and improve the health outcomes for the patient. As one doctor stated, "This education initiative would be helpful and improve compliance." All of the doctors felt that the information and self-management sheets should be further developed by providing printed and on-line health monitoring sheets of all types of diseases for all future patients. Some suggested additions on the information sheet that the doctors recommended were more information about the treatment, the importance of

compliance. drug interactions and adverse affects. Overall. ninety percent rated this patient education effort above average.

The discussion and conclusions drawn from both the patient and the physician evaluations of the prototype will be covered in the paragraphs to follow.

Discussion. Interestingly. the varying perceptions of the doctors and patients seem to fit in with the literature in this area. From the patient perspective. literature seems to suggest that doctors underestimate the amount of information their patients want.

This study found similar results in that doctors felt the information on the "information sheets" was too difficult to understand. thereby decreasing its usefulness. Doctors surveyed also felt that most of their patients would not access the resources.

Limitations of the Methodology and Sampling

The actual design and implementation of the prototype web-based health monitor initiative provided new information. positive patient and doctor responses and a critical view of the realities and potentials of patient education (personal communication, Dr. Daniels, January 1999). It contributed to the increased awareness of the prevalent problem of poor doctor-patient communication. While this is a recognized problem for medical education for all levels, it is particularly a problem in the clinical context due to the nature of the medical profession. It also improved awareness of the dangers of misinterpretation and independent decisions by patients (for example, stopping

medication prematurely). It also forwards awareness on issues of doctor-patient confidentiality and physician liability. An unmonitored on-line system could have serious legal implications for doctors and insurance companies. The potential value of this system may be limited by the reservation of doctors and legalities imposed by medical insurance.

This HMI innovation attempted to create a product that is very much needed and potentially very useful to the patient community at large. The physician version facilitated quicker patient teaching to occur during the consultation, resources for the physician to use, and an option to tailor the information given before printing the forms. Through a patient-centered approach, the patient version reinforced the oral information from the consultation by providing all patients an environment to learn equal amounts of information about the pathophysiology of their disease, its treatments and its management. These features were complemented by the on-line medium of delivery, which facilitated easy access, asynchronous flexibility, follow-up resources, and self-management forms for self-care and active involvement. The on-line nature of the product is completely non-threatening and it can be used as frequently as needed by both patients and doctors who have basic training in computer skills.

Nevertheless, there were some major limitations to this study. In summary, limitations that prevented the intended methodology to be implemented were (i) the undue delays of the website to be placed on the hospitals server by the scheduled summative evaluation date, the (ii) lack of availability of the computer equipment in the individual consultation

offices, (iii) the lack of funds to buy the equipment necessary to conduct the research, and finally (iv) the inappropriate context, setting and sample of patients and doctors to test the effectiveness of the HMI patient education system.

One of the biggest limitations to this study is the fact that there were inaccuracies in the content presented to the patients after the editing physicians had reviewed it. During the survey period with the Internal Medicine physicians, one of the doctors noticed an inaccuracy in information on the hypertension diagnosis summary sheets. The diagnosis summary sheet had stated that the target blood pressure range was 140/90; however, if the person is a diabetic then the target blood pressure should be lower. The research was terminated as soon as this was revealed, as this misinformation could have negatively affected the patients' lives if they had diabetes along with hypertension. On the health monitor forms for hypertension, it was made clear to the researcher by a physician, during the summative evaluation period, that the times of blood pressure measurements were just as important as the actual readings. The research had to be terminated when these omissions and inaccuracies were discovered.

The second major limitation was the undue delays at all stages and the general lack of cooperation and communication from the supervising physicians involved to see that this project proceeded and would be brought to conclusion. As a result of the delays, the content was not edited and the HMI system was not mounted on the hospital's website by the planned date.

The third significant limitation to this study resulted from the lack of funds for this research. Certain equipment such as the much-needed computers, laser printers and funds that were needed to conduct this research were lacking. The lack of funds resulted in other problems in testing the HMI project. At the family health clinic, there are no computers in the clinic designed for patient use. The in-use clinical computers at the clinic were networked with the hospital's main server but did not have internet access. The inkjet printers that were available were also inefficient, lacking speed, the most important feature needed for this setting, as the patient education material would be needed promptly. As a result, there was no opportunity to teach patients or the physicians how to use the computers to access the HMI website, and no computers available in the clinical setting to access the website.

As a result, all the sheets had to be preprinted (from the patient version of the HMI system) and prepackaged and given to the patients by an intermediary. The intermediary was the researcher for this project, who was not qualified to handle the extensive questions (both in quantity and quality) the patients, were asking. Unfortunately, because the physicians were under a great deal of time duress. Many doctors were reluctant to administer the package themselves to their patients after consultation. The researcher, therefore, had to redesign how to give the patients the information. Given all the constraints of the situation, the researcher administered the appropriate educational materials, depending on the doctor's request, as well as the patient surveys. This was a major limitation to the study as the failure to answer the patient's questions can impair their ability to assimilate new information in the context of their present consultation.

In some cases, patients only spoke Spanish. There were Spanish translators at the clinic helping doctors and nurses, but they were very busy. As a result, assisting the researcher or the patient in translating the survey at regular intervals was not feasible given the (i) shortage of translators, (ii) the time constraints to give the survey and (iii) the fact that most patients had waited over an hour to see the doctor.

During the evaluation time, the prototype database was not on the St. Mary's website server. This served as a limitation to the study because the potential users (i.e., the physicians and patients) could not evaluate its on-line interactive properties. Furthermore, if the patients wanted to access the resources, external links and the on-line self-monitoring forms, they would not have been able to as they were not permitted to use the clinic's computer.

Another limitation was that the database was not on the hospital's server as there were no security measures to manage the site. When reviewing the literature in this area, it was found that health professionals have chosen not to monitor their patient's progress on-line due to the numerous variables that come into play. First, there is an issue of confidentiality. On-line, people who know how to decode barriers can view personal information. For reason of confidentiality, plug-in forms were not programmed to databases. The second issue is legality. There are many factors which affect change, especially in the medical world. A patient may communicate seemingly normal experiences, but in reality may experience abnormal symptoms. If this is not diagnosed

early, it could lead to a significant disorder leading to a broader exposure to liability on the part of the physicians. Thirdly, to implement a database would require doctors to manage it. Technically speaking, a database might require relatively little effort to implement, but administratively speaking, it requires a team of management officers to monitor it on a on-going basis. Lastly, literature states that physicians are afraid of being bombarded with requests by patients, if email was an option to communicate to one's physician. For this reason, the medical practice has maintained its traditional stance regarding communication.

Another limitation to the study concerned the lack of testing of the approach in the long-term. Choosing a sample at a continuity clinic might have paved the way for further inquiry.

Recommendations: New Additions to the Health Informatics Field

There were issues here that were beyond the scope of this research (e.g., how to make computers more accessible to the general and local public). Nevertheless, there were also manageable problems presented here that could be solved. The following are recommendations for conducting research in the area of information technology in Medicine.

- Future research projects can incorporate creating on-line environments that are focused on providing patient education using technology as both a medium of instructional delivery and a resource for patient education.

- As the reader will recall, the survey revealed that people 50 and over who did not have children living with them at home generally did not have a computer or computer access from home. Of course, with an aging population and given that we get sicker as we age, this is an important issue. As a result, each hospital should have a Patient Education Center that is equipped with a computer room somewhere in the hospital (e.g. the library). The library should have facilities that encourage and allow patients to access the internet, to download information and to print information that they need.

- It appears that despite the difficult medical language, patients are very interested in their own health. For this reason, in areas where a significant proportion of the population is different than the national language, the diagnosis summary sheets should also be provided in the language necessary to accommodate the other ethnic groups. Language should not serve as a barrier to communication.

- For future researchers conducting clinical research, it is very important to make sure that the information is correct. Medical editors should take extra caution in attending to the fine details. Furthermore, several editors from the specialized field should edit the same document before it is tested. The researcher should also have a form that each editor should sign to formalize the process. Someone's life can be drastically altered as a result of inaccurate published information.

- Researchers should also to try to find financial resources to cover the cost of the research. The design can be very well laid out, but if there are no funds to implement it, then problems will arise in research. Research money can be allocated by networking with a pharmaceutical company and/or by applying to a research grant (i.e. FCAR or the National Library of Medicine).

  If this project had a research grant to (i) buy the equipment (e.g. the computers, the software, the printers), (ii) program the equipment to meet the needs of the evaluation, and (iii) provide monetary rewards to participants for each survey they completed, this would have increased the likelihood of obtaining reliable results. Furthermore, providing monetary rewards can serve as incentives for patients who had waited over an hour to see the doctor to participate in a study. However, it should be noted that if financial incentives are used, they could bias the sample and the results. Nevertheless, having financial resources for this study would have also enabled the researcher to hire temporary computer assistants and translators to translate the survey into Spanish.

- It is also very important to know the staff where you conduct the research. Conducting clinical research effectively needs cooperation and accommodation by all the staff. Testing research in an area familiar to the researcher and with participants who are already familiar to the researcher makes the administration of the research a lot easier. Ideally, it would be best for a doctor to test this on his or her patients, as they have complete control over the environment. If this is not possible, then it is important to

have a team of doctors who participate in the administration of the research as they have the power to make changes.

- A better evaluation design would have been to give each participating doctor a computer with an internet connection and a laser printer in their consultation room. This way, after each consultation the doctor can explain the concept, as well as how to fill in the self-monitor sheets and then, subsequently, individualize and print the necessary forms and summary sheets for the patients. This would be most effective because if the patient has specific questions about his/her illness, then they could ask their doctor directly. By doctors administering the health monitor forms and education sheets, it would make the visit personal and make the patient feel part of the health care team, thereby increasing the likelihood of the patient complying to the treatment. The doctor can also conduct long-term studies by asking their patient to bring back the health monitor form with them during their subsequent visits.

- Another good approach is to conduct the summative evaluation of the prototype while the patients are waiting to see the doctors. Upon the patient registering with the secretaries, the secretaries can give a little letter of introduction to the patients while they wait. Voluntarily or by means of a remuneration, the patients can fill out the survey while they wait to see a doctor. This would be a good design because the patient can read over the sheets before the consultation and ask any questions that occur to the doctors during their visit. The disadvantage to this design is that it would

require preparatory work with the medical secretaries. This perhaps could be overcome with a monetary gift.

- Another way to test the effectiveness of this study would be to ask several doctors to administer the health diagnosis summary and self-management forms to their patients over a period of a week. Before giving them the package of materials and instructions, set out a training program for them to understand what the research is about, what the literature says, what is the rationale and what are the hypotheses.

Conclusions

As proven, this HMI concept encourages physicians to concentrate more on the patient's agenda and give the patient the responsibility for his/her own care as well as greater ownership of his/her own problems. As discussed in this thesis, this computer-based "information-giving" medium can potentially offer patients a means of (i) interacting with their health care providers, (ii) accessing reliable medical literature, and (iii) tracking key data needed to monitor and manage their health. Nevertheless, due to the methodological, sampling, financial and context limitations imposed on the study, the key research questions reflected perceptions and self-perceptions rather than hard data. As a result of the self-reported measures, the effectiveness of the HMI system on increasing understanding and therefore health outcomes could not be tested. In this study, we were not able to investigate whether or not (i) patient compliance increased, (ii) resources were accessed, and finally (iii) patients took interested, active and informed participation in the management of their disease. However, due to the enthusiastic responses received from

the patients and physicians during the summative of the prototype, there is good reason to conclude that the HMI system should be pursued through further stages of development and implementation to anticipate worthwhile benefits.

The potential benefits of the HMI system include (i) saving the physician a considerable amount of time, (ii) making the patient feel involved in the health care team, (iii) making the visit more personal, (iv) encouraging the patient to take a more active role in the management of their disease and in maintaining a healthy lifestyle, and (v) encouraging the patient to take more initiative in their treatment by providing a tangible follow-up measure. The further development of this initiative will also send a positive message to the community about the health care system. As Purves (1996) emphasized, future patient education systems should be accessible on-line, be patient-focused, self-learning, asynchronous, have credible knowledge and have an intelligent presentation. The hypothesized HMI concept would readily fulfil this, and be a very valuable tool in doctor-patient communication resulting in positive outcomes for the patient, which would be very gratifying for both the patient and physician (personal communication, Dr. K. Bandali, March 1999).

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Appendix

Table of Contents

Contents	Page
Needs Assessment: Community Interview Questions...	A2
Needs Assessment: Physicians Interview Questions...	A4
Needs Assessment: Faculty/Administration Interview Questions...	A6
Health Monitor Initiative Welcome Page...	A7
On-Line Password and Login Page for Physicians...	A8
On-Line HMI System for Physicians: Asthma Diagnosis Summary Sheet...	A9
On-Line HMI System for Physicians: Asthma Self-Monitor Track Record Sheet...	A11
On-Line HMI System for Physicians: Asthma Self-Monitor Track Record Sheet – Example...	A12
On-Line HMI System for Physicians: Diabetes Diagnosis Summary Sheet...	A13
On-Line HMI System for Physicians: Diabetes Self-Monitor Track Record Sheet...	A16
On-Line HMI System for Physicians: Diabetes Self-Monitor Track Record Sheet – Example...	A17
On-Line HMI System for Physicians: COPD Diagnosis Summary Sheet...	A18
On-Line HMI System for Physicians: COPD Self-Monitor Track Record Sheet...	A20
On-Line HMI System for Physicians: COPD Self-Monitor Track Record Sheet – Example...	A21

Contents	Page
On-Line HMI System for Physicians: CHF Diagnosis Summary Sheet...	A22
On-Line HMI System for Physicians: CHF Self-Monitor Track Record Sheet...	A25
On-Line HMI System for Physicians: CHF Self-Monitor Track Record Sheet – Example...	A26
On-Line HMI System for Physicians: CAD Diagnosis Summary Sheet...	A27
On-Line HMI System for Physicians: CAD Self-Monitor Track Record Sheet...	A30
On-Line HMI System for Physicians: CAD Self-Monitor Track Record Sheet – Example...	A31
On-Line HMI System for Physicians: Hypertension Diagnosis Summary Sheet...	A32
On-Line HMI System for Physicians: Hypertension Self-Monitor Track Record Sheet...	A34
On-Line HMI System for Physicians: Hypertension Self-Monitor Track Record Sheet – Example...	A35
On-Line HMI System for Patients: Asthma Diagnosis Summary Sheet...	A36
On-Line HMI System for Patients: Asthma Self-Monitor Track Record Sheet...	A38
On-Line HMI System for Patients: Asthma Self-Monitor Track Record Sheet – Example...	A39
On-Line HMI System for Patients: Diabetes Diagnosis Summary Sheet...	A40
On-Line HMI System for Patients: Diabetes Self-Monitor Track Record Sheet...	A43

Contents	Page
On-Line HMI System for Patients: Diabetes Self-Monitor Track Record Sheet – Example...	A44
On-Line HMI System for Patients: COPD Diagnosis Summary Sheet...	A45
On-Line HMI System for Patients: COPD Self-Monitor Track Record Sheet...	A47
On-Line HMI System for Patients: COPD Self-Monitor Track Record Sheet – Example...	A48
On-Line HMI System for Patients: CHF Diagnosis Summary Sheet...	A49
On-Line HMI System for Patients: CHF Self-Monitor Track Record Sheet...	A51
On-Line HMI System for Patients: CHF Self-Monitor Track Record Sheet – Example...	A52
On-Line HMI System for Patients: CAD Diagnosis Summary Sheet...	A53
On-Line HMI System for Patients: CAD Self-Monitor Track Record Sheet...	A55
On-Line HMI System for Patients: CAD Self-Monitor Track Record Sheet – Example...	A56
On-Line HMI System for Patients: Hypertension Diagnosis Summary Sheet...	A57
On-Line HMI System for Patients: Hypertension Self-Monitor Track Record Sheet...	A59
On-Line HMI System for Patients: Hypertension Self-Monitor Track Record Sheet – Example...	A60
On-Line Feedback Sheets...	A61
Letter of Introduction of the HMI Evaluation to Patients...	A64

Contents	Page
HMI Request Forms from Physicians...	A65
Evaluation of the HMI System by Patients...	A66
Evaluation of the HMI Diagnosis Summary Sheets by Doctors...	A67
Evaluation of the Health Monitor Sheets by Doctors...	A68

Appendix

Needs Assessment: Community Interview Questions

1. What is your age? _____ years

2. What is your first language? _____

3. Rate the following on the following scale.

(5=excellent, 4=very good, 3=basic, 2=poor, 1=don't know)

a) Your level of reading in English? 1 2 3 4 5

b) Your level of speaking in English? 1 2 3 4 5

4. Do you have a computer at home? Yes No

a) If NOT, do you have access to a computer? Yes No

b) If yes, does this computer have Internet access? Yes No

5. Rate your level of comfort with the Internet? 1 2 3 4

(4= very comfortable, 3=comfortable, 2=not comfortable, 1=don't use Internet)

6. Do you know how to access websites using a computer? Yes No

7. What purposes do you use the Internet for? (check all the ones that apply to you.)

- ☐ entertainment
- ☐ email
- ☐ chats
- ☐ information
- ☐ business
- ☐ other:_____

8. Have you been diagnosed with any disease or illness in the past 6 months? Yes No

9. During your consultation, did your doctor give you any information about your diagnosis?

Yes No

If so, what kind of information?

10. Did you understand the information that was told to you during the consultation?

Yes No

11. During the consultation, did you feel involved in the process of your treatment, like you were a part of your health care team?

    Yes No

    If so, what did your doctor do to give you that sense of feeling involved?

    If not, why not?

12. Did you comply with the treatment recommended by your doctor?

13. Are you presently satisfied with the way in which your doctor gives information to you?

    Yes No

14. Did your doctor give you any pamphlets about your diagnosis?

    Yes No

15. Did your doctor direct you to where you could get more information about your diagnosis?

    Yes No

16. What do you consider to be the ideal way of having information about your diagnosis being relayed to you?

17. Give an example of your:

(i) worst consultation experience:

(ii) best consultation experience:

11. If a summary diagnosis sheet were to be developed and given too you directly after the consultation, list the type of information that would be relevant to you (i.e. indicative symptoms, symptoms to follow, etc.)

12. Any other comments to add?

Needs Assessment: Physician Interview Questions

1. What is your first language? _____

2. Do you have a computer in your consultation office? Yes No

a) If NOT, do you have access to a computer in your department? Yes No

b) If YES, does this computer have Internet access? Yes No

5. Rate your level of comfort with the Internet? 1 2 3 4

(4= very comfortable, 3=comfortable, 2=not comfortable, 1=don't use Internet)

6. Do you know how to access websites using a computer? Yes No

7. What purposes do you use the Internet for? (check all the ones that apply to you.)

- ☐ entertainment
- ☐ email
- ☐ chats
- ☐ information
- ☐ business
- ☐ other:_____

8. In your opinion, what is "patient education"?

9. Are you presently satisfied with the way in which patient information is organized for doctors?

Yes No

10. Approximately, how many patients do you see a day? _____

11. Approximately, how much time do you spend during a consultation? _____

12. What are your present frustrations in dealing with information-giving during a consultation?

13. During any given consultation, how do you present patients with information about their diagnosis?

14. After you have diagnosed a patient, how much % of your patient population, generally comply with the recommended treatment?

15. When giving a diagnosis, what is the likelihood of you researching information *to give* to your patients?

(4= very likely, 3=likely, 2=unlikely, 1=very unlikely, 0=never)

0 1 2 3 4

Why or why not?

16. Do you have time to direct your patients as to where they can get more information about their diagnosis?

Yes No

17. Do you think technology (i.e. the Internet) would help doctors educate their patients about their diagnosis?

Yes No

Why or why not?

18. If a one-page diagnosis summary sheet were developed to assist doctors in the information-giving process, what information would you think would be relevant to place on it?

19. Do you have any further comments to add?

Needs Assessment Surveys

Needs Assessment: Faculty/Administration Interview Questions

1. What is the mandate of the administration in terms of technology integration in patient education?

2. What steps has the administration taken to assist in patient and community education programs?

a) Have you found them to be effective?

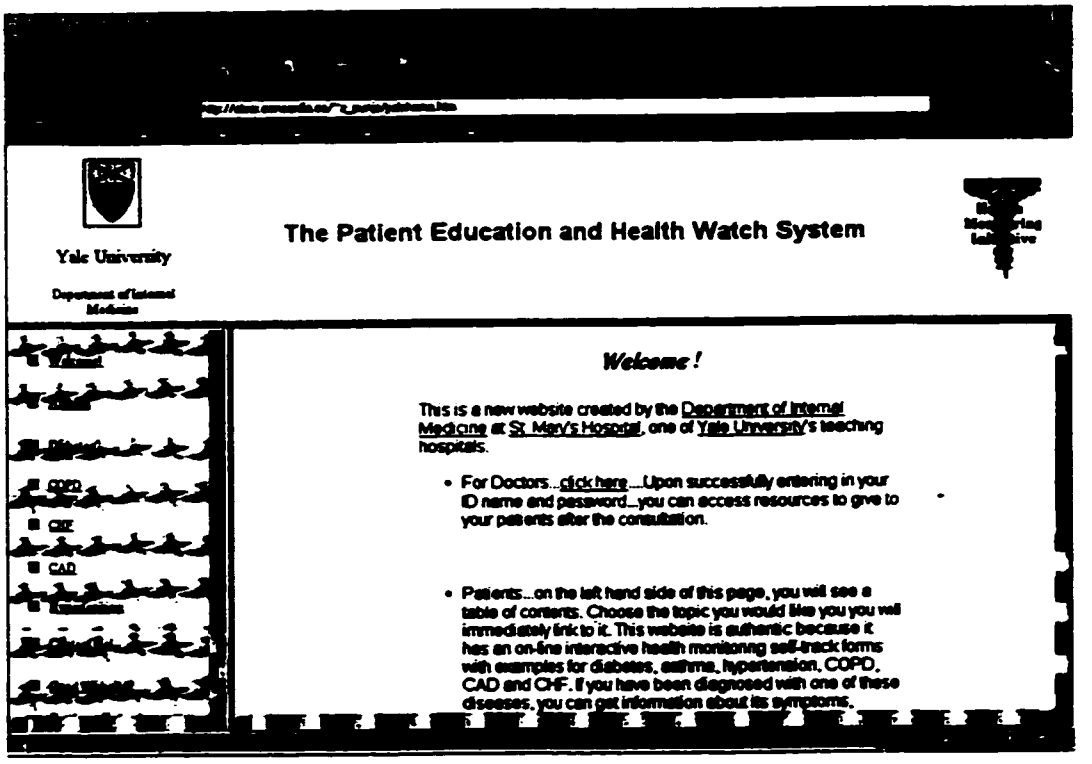
b) What were some of the unexpected pitfalls of the patient educational programs?

c) What would you do different in the future?

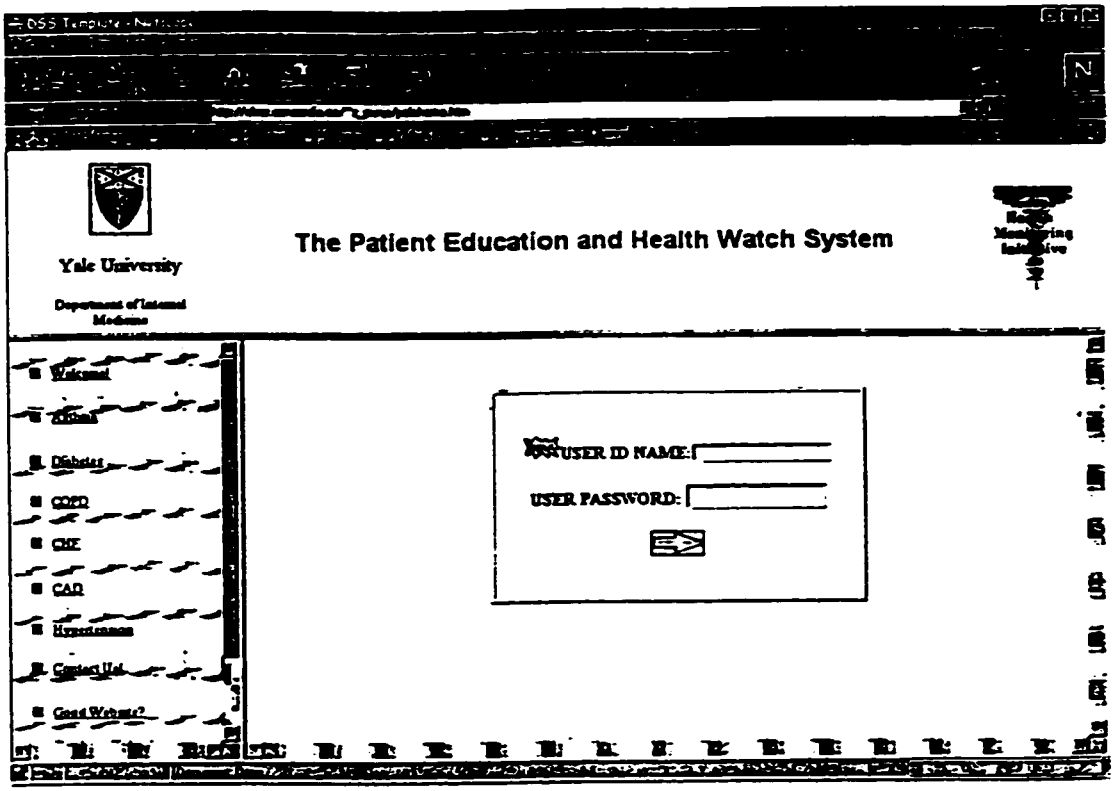
3. If a one-page patient diagnosis summary sheet, including a list of resources for patients to get more information about their diagnosis, were to be developed, what important elements should be included in it?

4. Do you have any comments or suggestions to make?

Health Monitor Initiative Welcome Page



On-Line Password and Login Page for Physicians



On-Line HMI System for Physicians

ASTHMA

| What is Asthma? | How do we diagnose it? | How do we treat it? | How do we manage it? |
| Websites | Books | Medline Journal Articles | Blank Self-Monitor Form | Example Form

Patients Name (Last, First) **Health Identification Number**

What is Asthma?

Asthma is a chronic lung disease characterized by inflammation of the airways because of increased sensitivity to a variety of environmental triggers. Triggers such as pollutants, viral URIs, allergens, irritants, emotions, medications, food additives and cold air, irate the airways causing narrowing of the airways and breathing difficulty. An asthma attack can be identified by a sudden onset of wheezing, coughing, shortness of breath and tightness in the chest.

How do we diagnose it?

Early warning signs used to diagnose asthma including feeling fatigued, itchy throat, runny nose, a constricted feeling in the chest, headache and a change in color and amount or thickness of sputum (mucus).

How do we treat it?

In terms of treatment, a balanced approach, consisting of drug and alternative therapy, is usually what doctor's plan out for their asthma patients. For drug therapy, the two main types of medications commonly used to treat asthma are (I) *Anti-inflammatory agents* such as corticosteroids, cromolyn sodium and nedocromil and (ii) *Bronchodilators* such as beta-agonists, methylxanthines, anticholinergics and leukotriene inhibitors). Likewise, alternative therapy is just as important in your treatment as it treats the asthma triggers and its associated conditions. Forms of alternative therapy include reducing your exposure to allergens and irritants such as cigarette smoke and discontinuing exercise when you can feel the onset of an asthma attack. Treating the cause of asthma is just as important as treating the symptoms.

To control the onset of your persistent asthma attacks, it is important to adhere to the prescribed treatment your doctor gives, as well as to educate yourself of the nature of the disease and the signs and symptoms you should watch out for. It is very important for you to understand your diagnosis, take an active role in its treatment and for you to adhere to the recommended therapy your physician suggests.

How do we manage it?

As part of the new heath initiative, it is important for you to monitor your peak flows by keeping a daily record of your peak flow. It is highly recommended that you monitor your peak flow at home by buying a *peak flow meter* from your local pharmacy. Ask your doctor to help you understand how to record the readings properly and to read your *peak flow measurements*. You should bring this record with you on your next visit, as it will assist your doctor in personalizing your asthma management program. Also as part of improving patient education efforts, below is a list of resources to assist you in further readings of your diagnosis. Should you experience symptoms such as wheezing, persistent colds, sputum production, shortness of breath, your peak flow dropping to the red zone, contact your doctor immediately.

- **Websites on Asthma...**

  The Lung Association - The Asthma Resource Center

  http://www.lung.ca/asthma/

  The Canadian Lung Association's "Asthma Resource Center" contains resources for asthma sufferers, educators, and health professionals. Including details of medications, management, nutrition, exercise, pregnancy, and asthma at school.

  JAMA - The Asthma Information Center

  http://www.ama-assn.org/special/asthma/

  This is an excellent website covering top stories, news, special reports, conferences, medical research articles, support and information groups and patient education material.

  Asthma and Allergy Information and Research

  http://www.users.globalnet.co.uk/~aair/asthma.htm

  An excellent website giving a definition, a medical description, characteristics of asthma, facts about it, information about the drugs used for asthma, information about the peak flow, asthma triggers and causes and general information about how asthma interacts with your body.

- **Books** (all books below are located in St. Mary's Hospital Library)
  - Gershwin, Eric M. *Bronchial Asthma.* 2nd Edition, Grune and Stratton Publishing, c1986.
  - Weinber, Miles. *Managing Asthma* Williams and Wilkins Publishing, c1990.
  - Weiss, Myron Stein. *Bronchial Asthma: Mechanisms and Therapeutics* 3rd Edition, Little Brown Publishing. c1993.

- **Medline Journal Articles** (all journals below are located in St. Mary's Hospital Library)
  - Harrison, B.D. (1998). Psychosocial Aspects of the Asthma in Adults. *Thorax, June; 53(6): 519-25.*
  - Pirie, J., Cox, P., Johnson, D, and Schuh, S. (1998). Changes in Treatment and Outcomes of Children Receiving Care in the Intensive Care Unit for Sever Acute Asthma. *Pediatric Emergency Care, April; 14(2): 104-8.*
  - Woolcock, A.J., Dusser, D. and Fajac, I. (1998). Severity of Chronic Asthma (Editorial). *Thorax, June; 53(6): 442-444.*

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Health Self-Monitor Track Record Sheet

Asthma - Peak Flow Measurements

Instructions

This sheet is provided for you to monitor your peak flow measurements. Make you read the accompanying diagnosis summary sheet on asthma and ask your doctor how to fill in this monitoring sheet. The purpose of this health monitoring sheet is so that both you and your doctor can monitor your health and the management of your disease regularly. Make sure that you remember to take your peak flows in the morning and in the evening. Create a simple legend system, whereby, your morning (am) peak flows are represented by an "x" and your evening (pm) peak flows are represented by a "o". Then in the chart below, place an "x" or an "o" in the box that best fits your range of measurement and continue to record your measurements throughout the week. Your doctor will tell you what your personal best is. If your peak flow measurements are very high or too low, please contact your doctor immediately. Otherwise, make sure to bring this monitoring sheet with you upon your next visit to the doctor. If you have any questions, please make sure you ask your doctor.

Patients Name (Last, First) _____

Health Identification Number _____

My Personal Best _____

	MON	TUES	WED	THURS	FRI	SAT	SUN
600 + l/min							
550 - 599 l/min							
500 - 549 l/min							
450 - 499 l/min							
400 - 449 l/min							
350 - 399 l/min							
300 - 349 l/min							
250 - 299 l/min							
200 - 249 l/min							
150 - 199 l/min							
100 - 149 l/min							
50 - 99 l/min							
0 - 49 l/min							

LEGEND:	TIME:
	AM
	PM

On-Line HMI System for Physicians

Health Self-Monitor Track Record Sheet - Example

Asthma - Peak Flow Measurements

Patients Name (Last, First) Smith, John

Health Identification Number 123-456-789

My Personal Best 400 liters per minute

	MON	TUES	WED	THURS	FRI	SAT	SUN
600 + l/min							
550 - 599 l/min							
500 - 549 l/min							
450 - 499 l/min							
400 - 449 l/min		o				o	
350 - 399 l/min	o	x	o		o	x	o
300 - 349 l/min	x		x	o	x		x
250 - 299 l/min				x			
200 - 249 l/min							
150 - 199 l/min							
100 - 149 l/min							
50 - 99 l/min							
0 - 49 l/min							

LEGEND:	TIME:
x	AM
o	PM

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DIABETES MELLITUS

| What is Diabetes? How do we diagnose it? | How do we treat it? | How do we manage it? |
| Websites Books Medline Journal Articles | Blank Self-Monitor Form | Example Form

Patients Name (Last, First) **Health Identification Number**

What is Diabetes?

Diabetes Mellitus is a group of conditions in which glucose (sugar) levels are abnormally high. These group of conditions are *Insulin-Dependant Diabetes Mellitus (IDDM)* also called Type I Diabetes, *Non-Insulin Dependant Diabetes Mellitus (NIDDM)* also called Type II, and gestational diabetes, which occurs during pregnancy. IDDM most often develop in children and young adults and for this reason, IDDM is commonly referred to as "*Juvenile Diabetes*".

Normally when we eat, foods containing proteins, fats and carbohydrates are broken down to simpler, easily absorbed chemicals. One of these is a form of a simple sugar called glucose. Glucose circulates in the blood stream where it is available for body cells to use. The body relies on glucose as a source of fuel for important organs such as the brain. Normally, the pancreas makes the correct amount of insulin needed to allow glucose to enter body cells. The pancreas is a large gland located behind the stomach, which produces a hormone called insulin. Diabetes occurs when the pancreas stops making enough insulin, which is necessary for the proper metabolism of digested foods. As a result, in people with diabetes, not enough insulin is produced and therefore glucose builds up in the blood, overflows into the urine and passes out of the body unused.

How do we diagnose it?

Early detection leading to a diabetes diagnosis include frequent urination (particularly at night), increased thirst, increased hunger despite the increased appetite, unexplained weight loss, and extreme tiredness. The loss of this extra sugar and water in the urine results in dehydration, which causes increased thirst.

How do we treat it?

It is important to adhere to the prescribed treatment your doctor gives, as well as to educate yourself of the nature of the disease and the signs and symptoms you should watch out for. It is very important for you to understand your diagnosis and take an active role in its treatment. Treatment of diabetes either NIDDM or IDDM requires both drug therapy and non-drug therapy. No matter which type of diabetes you have, it is important to understand that diet and exercise will now play a big part in controlling your diabetes. It is important to eat three meals a day at regular times without frequent snacking between those meals. You can schedule one snack per day at a time agreed upon by your doctor. When first diagnosed with diabetes, it is important to understand that your blood sugar levels are not normal and therefore, you must not eat any sugar products (i.e. sugar, cookies, cakes, candy, ice-cream, etc.) until your blood sugar levels have stabilized to a normal level. Your doctor will help you learn more about eating healthy. Make sure you ask your doctor how you can adjust your lifestyle to increase the amount of your daily exercise.

How do we manage it?

The type of drug therapy you use depends on the severity of your diabetes. If you have Type II Diabetes, you will most likely be given pills. These pills are only administered to diabetics whose bodies make some insulin. These pills are not insulin substitutes but help your insulin to work better. If you have Type I Diabetes, it is important for you to monitor your blood glucose levels by keeping a daily record of your *blood-glucose levels*. It is highly recommended that you monitor your blood-glucose at home by buying a *glucometer, blood-glucose monitoring strips* and a *blood-glucose-monitoring lancet* from your local pharmacy. Ask your doctor to help you understand how to record the readings properly and to read your *finger-stick glucose measurements*. You should bring this record with you on your next visit, as it will assist your doctor in personalizing your diabetes management program. Also as part of improving patient education efforts, below is a list of resources to assist you in further readings of your diagnosis.

Insulin or pills used to treat diabetes may sometimes cause your blood sugar level to drop to low. The signs of low blood sugar are headache, weakness, sweating, palpitations or feeling of anxiety. If you experience such signs, eat or drink something sweet (i.e. sugar water, orange juice or honey) right away and call your doctor immediately. If you notice a persistent feeling of thirst, frequent urination and loss of weight over a couple of days, your blood sugar has probably escalated. In any case; call your doctor immediately.

- **Websites on Diabetes Mellitus....**

  The Insulin-Free World Foundation

  http://www.insulin-free.org/

  Insulin-Free World On-Line covers the latest news, information, programs, pharmaceuticals, research and awareness campaigns. This site was created by diabetics, for diabetics.

  The American Diabetes Association

  http://www.diabetes.org/default.htm

  This website includes a calendar of events, news, research findings and information for both diabetic patients and health care professionals. It tells you how to donate money to this cause and how to access the local magazine.

  The Juvenile Diabetes Foundation International

  http://www.jdcure.org/index.html

  This site informs users about the Juvenile Diabetes Foundation, information of diabetes, most recent publications, how to join and be a member of JDF, how to donate to JDF, news, support groups and stories written by diabetes patients.

- **Books** (all books below are located in St. Mary's Hospital Library)

- Davidson, Mayer, B. *Diabetes Mellitus: Diagnosis and Treatment.* Churchill Livingston Publications. c1991.
- Haire-Joshu, Debra. *Management of Diabetes Mellitus: Perspectives of Care Across the Life Span.* 2nd Edition. St. Louis Mosby Publications. c1996.
- Kerstein, Morris D. *Diabetes and Vascular Disease.* Lippincott Publication. c1990.

Medline Journal Articles (all journals below are located in St. Mary's Hospital Library)

- Henry, R.R. (1998). Type 2 Diabetes care: The Role of Insulin Sensitizing Agents and Practical Implications for Cardiovascular Disease Prevention. *American Journal of Medicine, July 6; 105(1A): 20S-26S.*
- Hsueh, W.A. and law, R.E. (1998). Cardiovascular Risk Continuum: Implications of Insulin Resistance and Diabetes. *American Journal of Medicine, July 6; 105(1A): 4S-14S.*
- Peters, A.L. and Schriger, D.L. (1998). The New Diagnostic Criteria for Diabetes: The Impact on Management of Diabetes and Macrovascular Risk Factors. *American Journal of Medicine, July 6; 105(1A): 15S-19S.*

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Health Self-Monitor Track Record Sheet

Diabetes - Finger-Stick Glucose Measurements

Instructions

This sheet is provided for you to monitor your finger-stick glucose measurements. Make you read the accompanying diagnosis summary sheet on diabetes and ask your doctor how to fill in this monitoring sheet. The purpose of this health monitoring sheet is so that both you and your doctor can monitor your health and the management of your disease regularly. Make sure that you remember to take your glucose measurements in the morning and in the evening. Create a simple legend system, whereby, your blood-glucose levels for the morning (A), afternoon (B), evening (C) and bedtime (D) blood-glucose measurements are represented. Then in the chart below, place an "A", "B", "C", or "D" in the box that best fits your range of measurement and continue to record your measurements throughout the week. If your blood-glucose measurements are very high or too low, please contact your doctor immediately. Otherwise, make sure to bring this monitoring sheet with you upon your next visit to the doctor. If you have any questions, please make sure you ask your doctor.

Patients Name (Last, First) _____

Health Identification Number _____

	MON	TUES	WED	THURS	FRI	SAT	SUN
> 600 g/dl							
550 - 599 g/dl							
500 - 549 g/dl							
450 - 499 g/dl							
400 - 449 g/dl							
350 - 399 g/dl							
300 - 349 g/dl							
250 - 299 g/dl							
200 - 249 g/dl							
150 - 199 g/dl							
100 - 149 g/dl							
50 - 99 g/dl							
0 - 49 g/dl							

LEGEND:	TIME:
A	Before Breakfast
B	Before Lunch
C	Before Diner
D	Bed Time

On-Line HMI System for Physicians

Health Self-Monitor Track Record Sheet - Example

Diabetes - Finger-Stick Glucose Measurements

Patients Name (Last, First)
Smith, John

Health Identification Number
123-456-789

	MON	TUES	WED	THURS	FRI	SAT	SUN
> 600 g/dl							
550 - 599 g/dl							
500 - 549 g/dl							
450 - 499 g/dl			D				
400 - 449 g/dl			B	D			
350 - 399 g/dl		D	A	C	D		
300 - 349 g/dl	D	B	C	A	C		B
250 - 299 g/dl	C	A		B	B	C D	A
200 - 249 g/dl	B	C			A	B	C D
150 - 199 g/dl	A					A	
100 - 149 g/dl							
50 - 99 g/dl							
0 - 49 g/dl							

LEGEND:	TIME:
A	Before Breakfast
B	Before Lunch
C	Before Diner
D	Bed Time

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CHRONIC OBSTRUCTIVE PULMONARY DISEASE (COPD)

What is COPD? | How do we diagnose and treat it? | How do we manage it? | Websites | Books | Medline Journal Articles | Blank Self-Monitor Form | Example Form

Patients Name (Last, First) **Health Identification Number**

What is COPD?

Chronic Obstructive Pulmonary Disease (COPD) is an infectious disease affecting the lungs. COPD is a disease of the air passage way. It is an expiratory airflow limitation with components of asthma, emphysema and chronic bronchitis. COPD is caused by the hyperproduction of mucus from various infections, which causes obstruction to nasal drainage and a progressive loss to lung function. Infection usually results from an exacerbation from pollutants, viruses, allergic reaction and bacteria such as *Haemophilus influenzae, Moraxella catarrhalis and Streptococcus pneumoniae.*

How do we diagnose and treat it?

The most important symptoms of COPD are a chronic and persistent cough, production of sputum, wheezing and labored breathing. Diagnosis is made by how hard you can puff your breath in one second. This is called the *forced expiratory volume or FEV1.* The three main ways to treat COPD are antibiotic therapy, oxygen therapy and pulmonary rehabilitation. Often what is required is a multidisciplinary approach to the disease management, involving exercise and education as well as prescription treatment. Your doctor will chose the therapy that's best suited for your needs, by the severity of your disease diagnosis (FEV1) and your medical and personal history (age, frequency of exacerbation's, comorbid illness). Nevertheless, the three main goals of COPD management must be satisfied. These are: (I) to reduce airflow obstruction, (ii) prevent and manage secondary complication, and (iii) focus on adjunct therapies to improve life quality and symptoms.

How do we manage it?

To achieve the goals of COPD management, it is important to adhere to the prescribed treatment your doctor gives, as well as to educate yourself of the nature of the disease and the signs and symptoms you should watch out for. It is very important for you to understand your diagnosis, take an active role in its treatment and for you to adhere to the recommended therapy your physician suggests.

As part of the new heath initiative, it is important for you to monitor your peak flows by keeping a daily record of your *peak flow*. It is highly recommended that you monitor your peak flow at home by buying a *peak flow meter* from your local pharmacy. Ask your doctor to help you understand how to record the readings properly and to read your *peak flow measurements*. You should bring this record with you on your next visit, as it will assist your doctor in personalizing your COPD management program. Also as part of improving patient education efforts, below is a list of resources to assist you in further readings of your diagnosis. Should you experience symptoms such as wheezing, shortness of breath, fever, and/or change of cough color, contact your doctor immediately.

- **Websites on COPD...**

  The Lung Association - Breath Easy Program

  http://www.lung.ca/copd2/index.html

  This site includes information about the diagnosis, impact, symptoms, causes, processes, self-care management programs and drug treatment types of COPD. It gives an overview of normal and abnormal lung anatomy, lung functions and defense mechanisms of the lungs. Lastly, it gives an overview of how your lifestyle can be impacted with COPD.

  Chest Medicine On-Line

  http://u-net.com/priory/cmol/diagnosi.htm

  This site gives a concrete overview of COPD. It provides a definition, causal factors and treatment guidelines.

  The National Jewish Medical and Research Center

  http://www.njc.org/MFhtml/COP_MF.html

  This sites gives an over view of COPD. Specific topic include: What is COPD? What are the Goals of Treatment? How is COPD Managed? Exercise and Healthy Lifestyle, Avoid Infection, Medication Therapy, Bronchial Hygiene, Breathing Retraining, Oxygen Therapy and Pulmonary Rehabilitation.

- **Books (all books below are located in St. Mary's Hospital Library)**
  - Cherniack, Neil S. ***Chronic Obstructive Pulmonary Disease.*** 1st Edition, Sanders Publishing. c1991.
  - Hodgin, John E. ***Chronic Obstructive Pulmonary Disease.*** W.B. Sanders Publishing. c1987.

- **Medline Journal Articles (all journals below are located in St. Mary's Hospital Library)**
  - Lacasse, Y. and Goldstein, R.S. (1998). Scoring Evidence of Pulmonary Rehabilitation Effectiveness in COPD. ***Chest, July; 114(1): 343-5.***
  - Madison, J.M., and Irwin, R.S. (1998). Chronic Obstructive Pulmonary Disease. ***Lancet, Aug 8, 352: 467-473.***
  - Penrod, J.D., Kane, R.L., Finch, M.D. and Kane, R.A. (1998). Effects of Post-Hospital Medicare Home Health and Informal Care on Patient Functional Status. ***Health Services Research, Aug 1; 33(3 Pt 1): 513-529.***

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On-Line HMI System for Physicians

Health Self-Monitor Track Record Sheet

Chronic Obstructive Pulmonary Disease (COPD) - Peak Flow Measurements

Instructions

This sheet is provided for you to monitor your peak flow measurements. Make you read the accompanying diagnosis summary sheet on COPD and ask your doctor how to fill in this monitoring sheet. The purpose of this health monitoring sheet is so that both you and your doctor can monitor your health and the management of your disease regularly. Make sure that you remember to take your peak flows in the morning and in the evening. Create a simple legend system, whereby, your morning (am) peak flows are represented by an "x" and your evening (pm) peak flows are represented by a "o". Then in the chart below, place an "x" or an "o" in the box that best fits your range of measurement and continue to record your measurements throughout the week. Your doctor will tell you what your personal best is. If your peak flow measurements are very high or too low, please contact your doctor immediately. Otherwise, make sure to bring this monitoring sheet with you upon your next visit to the doctor. If you have any questions, please make sure you ask your doctor.

Patients Name (Last, First) _____

Health Identification Number _____

My Personal Best _____

	MON	TUES	WED	THURS	FRI	SAT	SUN
600 + l/min							
550 - 599 l/min							
500 - 549 l/min							
450 - 499 l/min							
400 - 449 l/min							
350 - 399 l/min							
300 - 349 l/min							
250 - 299 l/min							
200 - 249 l/min							
150 - 199 l/min							
100 - 149 l/min							
50 - 99 l/min							
0 - 49 l/min							

LEGEND:	TIME:
	AM
	PM

On-Line HMI System for Physicians

Health Self-Monitor Track Record Sheet - Example

Chronic Obstructive Pulmonary Disease (COPD) - Peak Flow Measurements

Patients Name (Last, First) Smith, John

Health Identification Number 123-456-789

My Personal Best 400 liters per minute

	MON	TUES	WED	THURS	FRI	SAT	SUN
600 + l/min							
550 - 599 l/min							
500 - 549 l/min							
450 - 499 l/min							
400 - 449 l/min		o				o	
350 - 399 l/min	o	x	o		o	x	o
300 - 349 l/min	x		x	o	x		x
250 - 299 l/min				x			
200 - 249 l/min							
150 - 199 l/min							
100 - 149 l/min							
50 - 99 l/min							
0 - 49 l/min							

LEGEND:	TIME:
x	AM
o	PM

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On-Line HMI System for Physicians

CONGESTIVE HEART FAILURE (CHF)

What is CHF? | How do we diagnose it? | How do we treat it? | How do we manage it? | Websites | Books | Medline Journal Articles | Blank Self-Monitor Form | Example Form |

Patients Name (Last, First)

Health Identification Number

What is CHF?

Congestive Heart Failure (CHF) is a condition in which the heart can not pump enough blood to your body's vital organs. The heart normally circulates blood to and from your body at a certain rate. As blood flow out of the hearts slows, blood returning to the heart through the connecting veins gets built-up causing congestion in the circulatory tissues. The congestion of blood in the veins can result from various sources. It can result from narrowed arteries that supply blood to the heart commonly called Coronary Heart Disease. It can result from scar tissue build-up from a past heart attack that interferes with the hearts normal function commonly known as Myocardial Infarction. Also, it can either result from an infection of the heart valve or heart muscle, commonly referred to as Endocarditis or Myocarditis or from primary heart disease of the heart muscle itself called Cardiomyopathy. In some people, CHF results from birth defects in the heart commonly referred to as Congenital Heart Disease.

How do we diagnose it?

As a result, if CHF occurs in the left side of the heart, fluid collects in the lungs and interferes with breathing causing shortness of breath. People with this kind of heart failure can't exert themselves because they become short of breath and tired. CHF also affects the ability of the kidneys to dispose of sodium and water. If CHF occurs in the right side of the heart, the body retains water, thereby causing swelling normally in the legs, ankles or stomach.

How do we treat it?

CHF usually requires a multidisciplinary treatment program consisting of rest, proper diet, modified daily activities, reduction of fatty and salty foods, proper management of stress and medication. Based on the severity of your disease and your medical history, your doctor will prescribe the drug and treatment program best suited for your needs. Common medications for CHF are diuretics, ACE inhibitors, vasodilators, digoxin, dobutamine, calcium-channel blockers, beta-blockers and/or antithrombotic therapy.

Because of the high risk involved in CHF, it is important to adhere to the prescribed treatment your doctor gives, as well as to educate yourself of the nature of the disease and the signs and symptoms you should watch out for. It is very important for you to understand your diagnosis and take an active role in the management of your disease.

How do we manage it?

As part of the new heath initiative, it is important for you to monitor your *weight* by keeping a daily record of your weight. It is highly recommended that you monitor your weight at home by buying a *scale* from your local pharmacy. Ask your doctor to help you understand how to record the readings properly and to read your scale measurements. You should bring this record with you on your next visit, as it will

assist your doctor in personalizing your CHF management program. Also as part of improving patient education efforts, below is a list of resources to assist you in further readings of your diagnosis. Should you experience continued symptoms of increased swelling in the legs or breathing difficulties, contact your doctor immediately.

- Websites on CHF...

  The Success with CFH Website

  http://www.successwithchf.com/Images/patients.html

  This site includes information for patients like: What is heart failure? How to become a partner in managing my own heart failure? How will nutrition, exercise, smoking and medication affect CHF?

  The Medical College of Virginia Hospitals

  http://views.vcu.edu/chf/congesti.htm

  This site gives information about the background of CHF, findings from clinical trials, non-medical therapies, medical therapies, the therapeutic rationale for different drugs (i.e. Carvedilol, Coreg, Bucindolol and Bosentan), pulmonary edema and about transplants and bypasses.

  Medical Sciences Bulletin

  http://www.heartinfo.com/CHF.html

  This site provides information on CHF. In particular, this site covers: (I) Managing CHF, (ii) Pharmacotherapy of Heart Failure and (iii) Preventing Heart Failure Following Acute Myocardial Infarction.

  Texas Heart Institute - Heart Information Service

  http://www.tmc.edu/thi/chf.html

  This site includes specific information about CHF, thereby including a definition of CHF, basic risk factors, clinical results, symptoms, diagnosis and treatment.

- Books (all books below are located in St. Mary's Hospital Library)
  - Braunwald, Eugene. *Congestive Heart Failure.* Grune and Stratton Publishing: USA. c1982.
  - Hosenpud, J.D. and Greensberg, B.H. *Congestive Heart Failure: Pathophysiology, Diagnosis and Comprehensive Approach to Management.* c1994.

- Medline Journal Articles (all journals below are located in St. Mary's Hospital Library)
  - Bernardi, L. Spadacini, G, Bellwon, J., Hajric, R., Roskam, H., Frey, A.W. (1998) Effect of

Breathing Rate on Oxygen Saturation and Exercise Performance in Chronic Heart Failure. *Lancet. May 2; 351(9112): 1308-11.*

- Harrison, M.B., Toman, C., Logan. J.L. (1998). Hospital to Home Evidence-Based Education for Congestive Heart Failure. *Canadian Nurse. Feb; 94(2): 36-42.*
- Jaagosild, P., Dawson, N.V. and Thomas. C. (1998). Outcomes of Acute Exacerbation of Severe CHF: Quality of Life, Resource Use and Survival. *Archives of Internal Medicine. May 25. 158(10): 1081-9.*

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Health Self-Monitor Track Record Sheet

Congestive Heart Failure (CHF) - Weight Measurements

Instructions

This sheet is provided for you to monitor your wieght. Make you read the accompanying diagnosis summary sheet on congestive heart failure and ask your doctor how to fill in this monitoring sheet. The purpose of this health monitoring sheet is so that both you and your doctor can monitor your health and the management of your disease regularly. Make sure that you remember to take your weight in the morning and in the evening. Create a simple legend system, whereby, the changes in your morning (am) weight is represented by an "x" and the changes in your evening weight is represented by a "o". Then in the chart below, place an "x" or an "o" in the box that best fits your increments of weight gain or weight loss and continue to record your measurements throughout the week. Your doctor will inform you what the normal range of weight increments will be. If there are drastic changes of wieght you experience, please contact your doctor immediately. Otherwise, make sure to bring this monitoring sheet with you upon your next visit to the doctor. If you have any questions, please make sure you ask your doctor.

Patients Name (Last, First) _____

Health Identification Number _____

My Weight _____

	MON	TUES	WED	THURS	FRI	SAT	SUN
+ 10 lbs							
+ 8 lbs							
+ 6 lbs							
+ 4 lbs							
+ 2 lbs							
+ 1 lbs							
no change							
- 1 lbs							
- 2 lbs							
- 4 lbs							
- 6 lbs							
- 8 lbs							
- 10 lbs							

LEGEND:	TIME:
	AM
	PM

Health Self-Monitor Track Record Sheet - Example

Congestive Heart Failure (CHF) - Weight Measurements

Patients Name (Last, First) Smith, John

Health Identification Number 123-456-789

My Weight 110 pounds (lbs)

	MON	TUES	WED	THURS	FRI	SAT	SUN
+ 10 lbs							
+ 8 lbs							
+ 6 lbs							
+ 4 lbs							
+ 2 lbs							
+ 1 lbs		x	o			x	o
no change	x	o	x	o	x	o	x
- 1 lbs	o			x	o		
- 2 lbs							
- 4 lbs							
- 6 lbs							
- 8 lbs							
- 10 lbs							

LEGEND:	TIME:
o	AM
x	PM

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CORONARY ARTERY DISEASE (CAD)

| What is CAD? | How do we treat it? | How do we manage it? |
| Websites Books Medline Journal Articles , Blank Self-Monitor Form Example Form

Patients Name (Last, First) **Health Identification Number**

What is CAD?

Coronary Heart Disease (CAD), is a disease of the heart, which prevents nutrients and oxygen from reaching the heart muscle. In CAD, the coronary arteries narrow and sometimes close. The causes of CAD are build-up from high fat deposits coating the interior wall of the arteries. Over time, this fat makes the arterial walls hard and thick, thereby narrowing the space for blood to travel. Blood not only travels at a slower rate into the heart, but continuous build-up of fat deposits on the arterial wall can block the blood coming into the heart. The more the arteries build-up of fat deposits, the more the body is deprived of oxygen and the essential nutrients. If this situation continues, the heart muscle can be permanently damaged. The amount of damage depends on the location of and the degree of blockage. The two most common consequences of CAD are Angina Pectoris and Myocardial Infarction.

As part of the new heath initiative, it is important for you to monitor your blood pressure by keeping a daily record of your blood pressure reading. Blood Pressure (BP) is the result of two interacting forces by the heart and the arteries. The heart creates a force by pushing blood into the arteries and through the circulatory system, and the arteries create a opposing force by resisting this blood flow. If given a BP reading of 140/90, the 140 is the systolic pressure representing the pressure while the heart is beating and 90 is the diastolic pressure representing the pressure while the heart is resting between beats. A blood pressure of 140/90 ("140 over 90") is considered to be the normal blood pressure for adults.

How do we treat it?

To manage the state of your disease, it is highly recommended to reduce your cholesterol, fat and sodium (salt) intake, to exercise regularly, and to cut down your consumption of alcohol. Many medications are also now available relax constricted blood vessels or prevent blood vessels from constricting or narrowing. Depending on the severity of your disease, your doctor will prescribe the treatment that best suited for your needs. Because there is no cure for coronary artery disease, treatment should not be stopped when you think you are feeling better. If coronary artery disease is not treated properly, the heart will work harder than normal causing unnecessary strain. The blood pressure may rise, thereby increasing the risk blood clotting in an artery narrowed by atherosclerosis (hardening of the arteries). This would deprive the body of blood, carrying oxygen and nutrients, thereby causing permanent kidney, heart and/or brain damage.

Because the risk is so high, it is important to adhere to the prescribed treatment your doctor gives, as well as to educate yourself of the nature of the disease and the signs and symptoms you should watch out for. It is very important for you to understand your diagnosis, take an active role in its treatment and for you to adhere to the recommended therapy your physician suggests.

How do we manage it?

It is highly recommended that you monitor your *blood pressure* at home by buying a *sphygmomanometer*

and a *stethoscope* from your local pharmacy. Ask your doctor to help you understand how to record the readings properly and to read your blood pressure readings. You should bring this record with you on your next visit, as it will assist your doctor in personalizing your CAD management program. Also as part of improving patient education efforts, below is a list of resources to assist you in further readings of your diagnosis. Should you experience symptoms such as chest pain, a feeling of heaviness on your chest, nausea, seating, jaw pain, pain on arm (usually on left arm) and/or shortness of breath, contact your doctor immediately.

Websites on CAD...

The Atlanta Cardiology - Understanding CAD and Your Stent

http://www.atlcard.com/cadstent.html

This site provides information, descriptions, diagrams and a glossary on Coronary Artery Disease (CAD). It answers questions like: What Causes the Disease? Where and How is Angioplasty Performed? and What is a Coronary Stent? How is CAD Diagnosed? Can CAD Be Treated? It also includes information on Symptoms of Coronary Artery Disease and Risk Factors for CAD.

The National Heart, Lung and Blood Institute

http://www.nhlbi.nih.gov/nhlbi/cardio/other/gp/chdfacts.htm

Topic on this site include: Who is at risk for coronary artery disease (CAD)? What is CAD? What causes CAD? What are the symptoms of CAD? Are there tests for CAD? How is CAD treated? What kind of lifestyle changes can help a person with CAD? What medications are used to treat CAD? What types of surgery are used to treat CAD?

The American Heart Association

http://americanheart.org/Heart_and_Stroke_A_Z_Guide/ha.html

This website gives information about heart attacks and the different types of heart disease (CAD) being one of them. The types of questions answered include: What is a heart attack? What causes a heart attack? What are the symptoms and warning signs of heart attacks? What are the treatments for heart attacks? When does a person need a heart transplant? What types of surgery exist for heart attacks? What are the preventative measures I can take?

Books (all books below are located in St. Mary's Hospital Library)

- Boucek, Robert J. *Coronary Artery Disease.* Williams and Wilkins Publishing: USA. c1984.
- Topol, Eric. J. *Atherosclerosis and Coronary Artery Disease.* Lippincott-Raven Publishing: New York. c1996.

Medline Journal Articles (all journals below are located in St. Mary's Hospital Library)

- Gould, K.L. (1998). New Concepts and Paradigms in Cardiovascular Medicine: The Noninvasive Management of CAD. *American Journal of Medicine, June 22; 104(6A): 2S-17S.*
- Smith, S.C. (1998). Lessons from Cholesterol Lowering Trials. *American Journal of*

- Smith, S.C. (1998). Lessons from Cholesterol Lowering Trials. *American Journal of Medicine, June 22; 104(6A): 28S-32S.*
- Smith, S.C. (1998). Risk Reduction Therapies for Patients with CAD: A Call for Increased Implementation. *American Journal of Medicine, Feb 23; 104(2A): 23S-26S.*

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Health Self-Monitor Track Record Sheet

Coronary Artery Disease (CAD) - Blood Pressure Readings

Instructions

This sheet is provided for you to monitor your blood pressure measurements. Make you read the accompanying diagnosis summary sheet on coronary artery disease and ask your doctor how to fill in this monitoring sheet. The purpose of this health monitoring sheet is so that both you and your doctor can monitor your health and the management of your disease regularly. Make sure that you remember to take your blood pressure in the morning and in the evening. Create a simple legend system, whereby, your systolic blood pressure is represented by an "x" and your diastolic blood pressure is represented by a "o". Then in the chart below, place an "x" or an "o" in the box that best fits your range of measurement and continue to record your measurements throughout the week. Your doctor will inform you what the normal range is. If your blood pressure measurements are very high or too low, please contact your doctor immediately. Otherwise, make sure to bring this monitoring sheet with you upon your next visit to the doctor. If you have any questions, please make sure you ask your doctor.

Patients Name (Last, First) _____

Health Identification Number _____

My Blood Pressure (at Doctor's Office) _____

	MON	TUES	WED	THURS	FRI	SAT	SUN
>160 mm/Hg							
150 - 159 mm/Hg							
140 - 149 mm/Hg							
130 - 139 mm/Hg							
120 - 129 mm/Hg							
110 - 119 mm/Hg							
100 - 109 mm/Hg							
90 - 99 mm/Hg							
80 - 89 mm/Hg							
70 - 79 mm/Hg							
60 - 69 mm/Hg							
50 - 59 mm/Hg							
< 49 mm/Hg							

LEGEND:	TIME:
x	Systolic
o	Diastolic

Health Self-Monitor Track Record Sheet - Example

Coronary Artery Disease (CAD) - Blood Pressure Readings

Patients Name (Last, First) Smith, John

Health Identification Number 123-456-789

My Blood Pressure (at Doctor's Office) 140/100 mm per Hg

	MON	TUES	WED	THURS	FRI	SAT	SUN
>160 mm/Hg							
150 - 159 mm/Hg							
140 - 149 mm/Hg						x	
130 - 139 mm/Hg					x		
120 - 129 mm/Hg							x
110 - 119 mm/Hg			x				
100 - 109 mm/Hg		x		x		o	
90 - 99 mm/Hg	x		o		o		
80 - 89 mm/Hg				o			o
70 - 79 mm/Hg		o					
60 - 69 mm/Hg	o						
50 - 59 mm/Hg							
< 49 mm/Hg							

LEGEND:	TIME:
x	Systolic
o	Diastolic

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HYPERTENSION

What is Hypertension? | How do we treat it? | How do we manage it? |
Websites Books Medline Journal Articles | Blank Self-Monitor Form Example Form

Patients Name (Last, First) **Health Identification Number**

What is Hypertension?

Hypertension is the medical term meaning High Blood Pressure. Blood Pressure (BP) is the result of two interacting forces by the heart and the arteries. The heart creates a force by pushing blood into the arteries and through the circulatory system, and the arteries create a opposing force by resisting this blood flow. If given a BP reading of 140/90, the 140 is the systolic pressure representing the pressure while the heart is beating and 90 is the diastolic pressure representing the pressure while the heart is resting between beats. A blood pressure of 140/90 ("140 over 90") is considered to be the normal blood pressure for adults. In 90 to 95 percent of the cases, the cause of high blood pressure is unknown. As a result, this is called essential hypertension. In the remaining cases, high blood pressure is a symptom of a recognizable underlying problem such as a kidney abnormality, tumor of the adrenal gland or congenital defect of the aorta. This type of high blood pressure is called secondary hypertension.

How do we treat it?

To lower your blood pressure, it is highly recommended to reduce your cholesterol, fat and sodium (salt) intake, to exercise regularly, and to cut down your consumption of alcohol. Many medications are also now available to reduce high blood pressure. Medication functions also vary as some eliminate access fluid and sodium, relax constricted blood vessels or prevent blood vessels from constricting or narrowing. Depending on the severity of your disease, your doctor will prescribe the treatment that best suited for your needs. Because there is no cure for hypertension, treatment should not be stopped when you think you are feeling better. If high blood pressure is not treated properly the heart will work harder than normal causing unnecessary strain. The blood pressure may even arise again, thereby increasing the risk blood clotting in a artery narrowed by atherosclerosis (hardening of the arteries). This would deprive the body of blood, carrying oxygen and nutrients, thereby causing permanent kidney, heart and/or brain damage.

How do we manage it?

Because the risk is so high, it is important to adhere to the prescribed treatment your doctor gives, as well as to educate yourself of the nature of the disease and the signs and symptoms you should watch out for. It is very important for you to understand your diagnosis, take an active role in its treatment and for you to adhere to the recommended therapy your physician suggests.

As part of the new heath initiative, it is important for you to monitor your *blood pressure* by keeping a daily record of your blood pressure reading. It is highly recommended that you monitor your blood pressure at home by buying a *sphygmomanometer* and a *stethoscope* from your local pharmacy. Ask your doctor to help you understand how to record the readings properly and to read your blood pressure readings. You should bring this record with you on your next visit, as it will assist your doctor in personalizing your hypertension management program. Also as part of improving patient education efforts, below is a list of resources to assist you in further readings of your diagnosis. Should you

experience symptoms such as chest pain, headaches, visual changes and/or difficulty breathing, contact your doctor immediately.

- **Websites on Hypertension...**

  The American Heart Association

  http://www.hypertensionaha.org/

  This site gives electronic version of the most recent articles on hypertension. it allows you to search and browse for issues and gives you hypothesis and scientific contributions from the collected papers.

  The Pulmonary Hypertension Association

  http://www.phassociation.org/

  The purpose of the Pulmonary Hypertension Association (PHA) is to provide fellowship and educational support on pulmonary hypertension to physicians, patients and their families. The Association provides information on issues such as current research and findings, early detection, resource organizations, organ transplantation, and support networks.

  The Hypertension Network

  http://www.bloodpressure.com/

  This site gives you basic facts about high blood pressure, cholesterol, cardiovascular disease, life style factors (i.e. diet, exercise, stress, smoking, and vitamins), prescription drugs (i.e. doses and side effects), on home/self-monitoring of blood pressure and other factors related to your risk of cardiovascular disease.

- **Books** (all books below are located in St. Mary's Hospital Library)
  - Goodfriend, Theodore L. *Hypertension Essentials.* Grune and Stratton Publishing. c1983.
  - Kaplan, Norman M. *Clinical Hypertension.* Williams and Wilkins Publishing. c1986.
  - McMahan, Gilbert F. *Management of Essential Hypertension.* Future Publishing. c1984.

- **Medline Journal Articles** (all journals below are located in St. Mary's Hospital Library)
  - Iso, H., Shimamoto, T., Naito, Y., Sato, S., Kitamura, A., Ilda, M., Konishi, M., Jacobs., D.R. and Komachi, Y. (1998). The Effects of Long-term Hypertension Control Program on Stroke Incidence and Prevalence in a Rural Community in Northeastern Japan. *Stroke, Aug; 29(8): 1510-8.*
  - Jay, S.J. (1998). Cigarette Smoking and Sense Uncontrolled Hypertension in inner-city African Americans. *American Journal of Medicine, July, 105(1): 83-4.*
  - Scheinman, J.I., Crevi, D.L., Narla, L.D. and Chan J.C. (1998). Asymptomatic Childhood Hypertension. *Nephron, 79(2): 131-6.*

Health Self-Monitor Track Record Sheet

Hypertension - Blood Pressure Readings

Instructions

This sheet is provided for you to monitor your blood pressure measurements. Make you read the accompanying diagnosis summary sheet on hypertension and ask your doctor how to fill in this monitoring sheet. The purpose of this health monitoring sheet is so that both you and your doctor can monitor your health and the management of your disease regularly. Make sure that you remember to take your blood pressure in the morning and in the evening. Create a simple legend system, whereby, your systolic blood pressure is represented by an "x" and your diastolic blood pressure is represented by a "o". Then in the chart below, place an "x" or an "o" in the box that best fits your range of measurement and continue to record your measurements throughout the week. Your doctor will inform you what the normal range is. If your blood pressure measurements are very high or too low, please contact your doctor immediately. Otherwise, make sure to bring this monitoring sheet with you upon your next visit to the doctor. If you have any questions, please make sure you ask your doctor.

Patients Name (Last, First) _____

Health Identification Number _____

My Blood Pressure (at Doctor's Office) _____

	MON	TUES	WED	THURS	FRI	SAT	SUN
>160 mm/Hg							
150 - 159 mm/Hg							
140 - 149 mm/Hg							
130 - 139 mm/Hg							
120 - 129 mm/Hg							
110 - 119 mm/Hg							
100 - 109 mm/Hg							
90 - 99 mm/Hg							
80 - 89 mm/Hg							
70 - 79 mm/Hg							
60 - 69 mm/Hg							
50 - 59 mm/Hg							
< 49 mm/Hg							

LEGEND:	TIME:
x	Systolic
o	Diastolic

Health Self-Monitor Track Record Sheet - Example

Hypertension - Blood Pressure Readings

Patients Name (Last, First) Smith, John

Health Identification Number 123-456-789

My Blood Pressure (at Doctor's Office) 140/100 mm per Hg

	MON	TUES	WED	THURS	FRI	SAT	SUN
>160 mm/Hg							
150 - 159 mm/Hg							
140 - 149 mm/Hg						x	
130 - 139 mm/Hg					x		
120 - 129 mm/Hg							x
110 - 119 mm/Hg			x				
100 - 109 mm/Hg		x		x		o	
90 - 99 mm/Hg	x		o		o		
80 - 89 mm/Hg				o			o
70 - 79 mm/Hg		o					
60 - 69 mm/Hg	o						
50 - 59 mm/Hg							
< 49 mm/Hg							

LEGEND:	TIME:
x	Systolic
o	Diastolic

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ASTHMA

| What is Asthma? · How do we diagnose it? · How do we treat it? | How do we manage it?
| Websites Books Medline Journal Articles : Blank Self-Monitor Form Example Form

What is Asthma?

Asthma is a chronic lung disease characterized by inflammation of the airways because of increased sensitivity to a variety of environmental triggers. Triggers such as pollutants, viral URIs, allergens, irritants, emotions, medications, food additives and cold air, irate the airways causing narrowing of the airways and breathing difficulty. An asthma attack can be identified by a sudden onset of wheezing, coughing, shortness of breath and tightness in the chest.

How do we diagnose it?

Early warning signs used to diagnose asthma including feeling fatigued, itchy throat, runny nose, a constricted feeling in the chest, headache and a change in color and amount or thickness of sputum (mucus).

How do we treat it?

In terms of treatment, a balanced approach, consisting of drug and alternative therapy, is usually what doctor's plan out for their asthma patients. For drug therapy, the two main types of medications commonly used to treat asthma are (I) *Anti-inflammatory agents* such as corticosteroids, cromolyn sodium and nedocromil and (ii) *Bronchodilators* such as beta-agonists, methylxanthines, anticholinergics and leukotriene inhibitors). Likewise, alternative therapy is just as important in your treatment as it treats the asthma triggers and its associated conditions. Forms of alternative therapy include reducing your exposure to allergens and irritants such as cigarette smoke and discontinuing exercise when you can feel the onset of an asthma attack. Treating the cause of asthma is just as important as treating the symptoms.

To control the onset of your persistent asthma attacks, it is important to adhere to the prescribed treatment your doctor gives, as well as to educate yourself of the nature of the disease and the signs and symptoms you should watch out for. It is very important for you to understand your diagnosis, take an active role in its treatment and for you to adhere to the recommended therapy your physician suggests.

How do we manage it?

As part of the new heath initiative, it is important for you to monitor your peak flows by keeping a daily record of your peak flow. It is highly recommended that you monitor your peak flow at home by buying a *peak flow meter* from your local pharmacy. Ask your doctor to help you understand how to record the readings properly and to read your *peak flow measurements*. You should bring this record with you on your next visit, as it will assist your doctor in personalizing your asthma management program. Also as part of improving patient education efforts, below is a list of resources to assist you in further readings of your diagnosis. Should you experience symptoms such as wheezing, persistent colds, sputum production, shortness of breath, your peak flow dropping to the red zone, contact your doctor immediately.

- **Websites on Asthma...**

The Lung Association - The Asthma Resource Center

The Canadian Lung Association's "Asthma Resource Center" contains resources for asthma sufferers, educators, and health professionals. Including details of medications, management, nutrition, exercise, pregnancy, and asthma at school.

JAMA - The Asthma Information Center

This is an excellent website covering top stories, news, special reports, conferences, medical research articles, support and information groups and patient education material.

Asthma and Allergy Information and Research

An excellent website giving a definition, a medical description, characteristics of asthma, facts about it, information about the drugs used for asthma, information about the peak flow, asthma triggers and causes and general information about how asthma interacts with your body.

- **Books**

- Gershwin, Eric M. *Bronchial Asthma.* 2nd Edition, Grune and Stratton Publishing, c1986.
- Weinber, Miles. *Managing Asthma* Williams and Wilkins Publishing, c1990.
- Weiss, Myron Stein. *Bronchial Asthma: Mechanisms and Therapeutics* 3rd Edition, Little Brown Publishing. c1993.

- **Medline Journal Articles**

- Harrison, B.D. (1998). Psychosocial Aspects of the Asthma in Adults. *Thorax, June; 53(6): 519-25.*
- Pirie, J., Cox, P., Johnson, D, and Schuh, S. (1998). Changes in Treatment and Outcomes of Children Receiving Care in the Intensive Care Unit for Sever Acute Asthma. *Pediatric Emergency Care, April; 14(2): 104-8.*
- Woolcock, A.J., Dusser, D. and Fajac, I. (1998). Severity of Chronic Asthma (Editorial). *Thorax, June; 53(6): 442-444.*

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On-Line HMI System for Patients

Health Self-Monitor Track Record Sheet

Asthma - Peak Flow Measurements

My Personal Best _____

	MON	TUES	WED	THURS	FRI	SAT	SUN
600 + l/min							
550 - 599 l/min							
500 - 549 l/min							
450 - 499 l/min							
400 - 449 l/min							
350 - 399 l/min							
300 - 349 l/min							
250 - 299 l/min							
200 - 249 l/min							
150 - 199 l/min							
100 - 149 l/min							
50 - 99 l/min							
0 - 49 l/min							

LEGEND:	TIME:
	AM
	PM

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Health Self-Monitor Track Record Sheet - Example

Asthma - Peak Flow Measurements

My Personal Best: 400 liters per minute

	MON	TUES	WED	THURS	FRI	SAT	SUN
600 + l/min							
550 - 599 l/min							
500 - 549 l/min							
450 - 499 l/min							
400 - 449 l/min		o				o	
350 - 399 l/min	o	x	o		o	x	o
300 - 349 l/min	x		x	o	x		x
250 - 299 l/min				x			
200 - 249 l/min							
150 - 199 l/min							
100 - 149 l/min							
50 - 99 l/min							
0 - 49 l/min							

LEGEND:	TIME:
x	AM
o	PM

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DIABETES MELLITUS

What is Diabetes? How do we diagnose it? How do we treat it? How do we manage it?
Websites Books Medline Journal Articles Blank Self-Monitor Form Example Form

What is Diabetes?

Diabetes Mellitus is a group of conditions in which glucose (sugar) levels are abnormally high. These group of conditions are *Insulin-Dependant Diabetes Mellitus (IDDM)* also called Type I Diabetes, *Non-Insulin Dependant Diabetes Mellitus (NIDDM)* also called Type II, and gestational diabetes, which occurs during pregnancy. IDDM most often develop in children and young adults and for this reason. IDDM is commonly referred to as "*Juvenile Diabetes*".

Normally when we eat, foods containing proteins, fats and carbohydrates are broken down to simpler, easily absorbed chemicals. One of these is a form of a simple sugar called glucose. Glucose circulates in the blood stream where it is available for body cells to use. The body relies on glucose as a source of fuel for important organs such as the brain. Normally, the pancreas makes the correct amount of insulin needed to allow glucose to enter body cells. The pancreas is a large gland located behind the stomach, which produces a hormone called insulin. Diabetes occurs when the pancreas stops making enough insulin, which is necessary for the proper metabolism of digested foods. As a result, in people with diabetes, not enough insulin is produced and therefore glucose builds up in the blood, overflows into the urine and passes out of the body unused.

How do we diagnose it?

Early detection leading to a diabetes diagnosis include frequent urination (particularly at night), increased thirst, increased hunger despite the increased appetite, unexplained weight loss, and extreme tiredness. The loss of this extra sugar and water in the urine results in dehydration, which causes increased thirst.

How do we treat it?

It is important to adhere to the prescribed treatment your doctor gives, as well as to educate yourself of the nature of the disease and the signs and symptoms you should watch out for. It is very important for you to understand your diagnosis and take an active role in its treatment. Treatment of diabetes either NIDDM or IDDM requires both drug therapy and non-drug therapy. No matter which type of diabetes you have, it is important to understand that diet and exercise will now play a big part in controlling your diabetes. It is important to eat three meals a day at regular times without frequent snacking between those meals. You can schedule one snack per day at a time agreed upon by your doctor. When first diagnosed with diabetes, it is important to understand that your blood sugar levels are not normal and therefore, you must not eat any sugar products (i.e. sugar, cookies, cakes, candy, ice-cream, etc.) until your blood sugar levels have stabilized to a normal level. Your doctor will help you learn more about eating healthy. Make sure you ask your doctor how you can adjust your lifestyle to increase the amount of your daily exercise.

How do we manage it?

The type of drug therapy you use depends on the severity of your diabetes. If you have Type II Diabetes,

you will most likely be given pills. These pills are only administered to diabetics whose bodies make some insulin. These pills are not insulin substitutes but help your insulin to work better. If you have Type I Diabetes, it is important for you to monitor your blood glucose levels by keeping a daily record of your *blood-glucose levels*. It is highly recommended that you monitor your blood-glucose at home by buying a *glucometer, blood-glucose monitoring strips* and a *blood-glucose-monitoring lancet* from your local pharmacy. Ask your doctor to help you understand how to record the readings properly and to read your *finger-stick glucose measurements*. You should bring this record with you on your next visit, as it will assist your doctor in personalizing your diabetes management program. Also as part of improving patient education efforts, below is a list of resources to assist you in further readings of your diagnosis.

Insulin or pills used to treat diabetes may sometimes cause your blood sugar level to drop to low. The signs of low blood sugar are headache, weakness, sweating, palpitations or feeling of anxiety. If you experience such signs, eat or drink something sweet (i.e. sugar water, orange juice or honey) right away and call your doctor immediately. If you notice a persistent feeling of thirst, frequent urination and loss of weight over a couple of days, your blood sugar has probably escalated. In any case, call your doctor immediately.

- Websites on Diabetes Mellitus....

  The Insulin-Free World Foundation

  Insulin-Free World On-Line covers the latest news, information, programs, pharmaceuticals, research and awareness campaigns. This site was created by diabetics, for diabetics.

  The American Diabetes Association

  This website includes a calendar of events, news, research findings and information for both diabetic patients and health care professionals. It tells you how to donate money to this cause and how to access the local magazine.

  The Juvenile Diabetes Foundation International

  This site informs users about the Juvenile Diabetes Foundation, information of diabetes, most recent publications, how to join and be a member of JDF, how to donate to JDF, news, support groups and stories written by diabetes patients.

- Books

  - Davidson, Mayer, B. *Diabetes Mellitus: Diagnosis and Treatment.* Churchill Livingston Publications. c1991.
  - Haire-Joshu, Debra. *Management of Diabetes Mellitus: Perspectives of Care Across the Life Span.* 2nd Edition. St. Louis Mosby Publications. c1996.
  - Kerstein, Morris D. *Diabetes and Vascular Disease.* Lippincott Publication. c1990.

- Medline Journal Articles

Medline Journal Articles

- Henry, R.R. (1998). Type 2 Diabetes care: The Role of Insulin Sensitizing Agents and Practical Implications for Cardiovascular Disease Prevention. *American Journal of Medicine, July 6; 105(1A): 20S-26S.*
- Hsueh, W.A. and law, R.E. (1998). Cardiovascular Risk Continuum: Implications of Insulin Resistance and Diabetes. *American Journal of Medicine, July 6; 105(1A): 4S-14S.*
- Peters, A.L. and Schriger, D.L. (1998). The New Diagnostic Criteria for Diabetes: The Impact on Management of Diabetes and Macrovascular Risk Factors. *American Journal of Medicine, July 6; 105(1A): 15S-19S.*

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Health Self-Monitor Track Record Sheet

Diabetes - Finger-Stick Glucose Measurements

	MON	TUES	WED	THURS	FRI	SAT	SUN
> 600 g/dl							
550 - 599 g/dl							
500 - 549 g/dl							
450 - 499 g/dl							
400 - 449 g/dl							
350 - 399 g/dl							
300 - 349 g/dl							
250 - 299 g/dl							
200 - 249 g/dl							
150 - 199 g/dl							
100 - 149 g/dl							
50 - 99 g/dl							
0 - 49 g/dl							

LEGEND:	TIME:
A	Before Breakfast
B	Before Lunch
C	Before Diner
D	Bed Time

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Health Self-Monitor Track Record Sheet - Example

Diabetes - Finger-Stick Glucose Measurements

	MON	TUES	WED	THURS	FRI	SAT	SUN
> 600 g/dl							
550 - 599 g/dl							
500 - 549 g/dl							
450 - 499 g/dl			D				
400 - 449 g/dl			B	D			
350 - 399 g/dl		D	A	C	D		
300 - 349 g/dl	D	B	C	A	C		B
250 - 299 g/dl	C	A		B	B	C D	A
200 - 249 g/dl	B	C			A	B	C D
150 - 199 g/dl	A					A	
100 - 149 g/dl							
50 - 99 g/dl							
0 - 49 g/dl							

LEGEND:	TIME:
A	Before Breakfast
B	Before Lunch
C	Before Diner
D	Bed Time

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CHRONIC OBSTRUCTIVE PULMONARY DISEASE (COPD)

What is COPD? How do we diagnose and treat it? How do we manage it?
| Websites Books Medline Journal Articles | Blank Self-Monitor Form Example Form

What is COPD?

Chronic Obstructive Pulmonary Disease (COPD) is an infectious disease affecting the lungs. COPD is a disease of the air passage way. It is an expiratory airflow limitation with components of asthma, emphysema and chronic bronchitis. COPD is caused by the hyperproduction of mucus from various infections, which causes obstruction to nasal drainage and a progressive loss to lung function. Infection usually results from an exacerbation from pollutants, viruses, allergic reaction and bacteria such as *Haemophilus influenzae, Moraxella catarrhalis and Streptococcus pneumoniae.*

How do we diagnose and treat it?

The most important symptoms of COPD are a chronic and persistent cough, production of sputum, wheezing and labored breathing. Diagnosis is made by how hard you can puff your breath in one second. This is called the *forced expiratory volume or FEV1*. The three main ways to treat COPD are antibiotic therapy, oxygen therapy and pulmonary rehabilitation. Often what is required is a multidisciplinary approach to the disease management, involving exercise and education as well as prescription treatment. Your doctor will chose the therapy that's best suited for your needs, by the severity of your disease diagnosis (FEV1) and your medical and personal history (age, frequency of exacerbation's, comorbid illness). Nevertheless, the three main goals of COPD management must be satisfied. These are: (I) to reduce airflow obstruction, (ii) prevent and manage secondary complication, and (iii) focus on adjunct therapies to improve life quality and symptoms.

How do we manage it?

To achieve the goals of COPD management, it is important to adhere to the prescribed treatment your doctor gives, as well as to educate yourself of the nature of the disease and the signs and symptoms you should watch out for. It is very important for you to understand your diagnosis, take an active role in its treatment and for you to adhere to the recommended therapy your physician suggests.

As part of the new heath initiative, it is important for you to monitor your peak flows by keeping a daily record of your *peak flow*. It is highly recommended that you monitor your peak flow at home by buying a *peak flow meter* from your local pharmacy. Ask your doctor to help you understand how to record the readings properly and to read your *peak flow measurements*. You should bring this record with you on your next visit, as it will assist your doctor in personalizing your COPD management program. Also as part of improving patient education efforts, below is a list of resources to assist you in further readings of your diagnosis. Should you experience symptoms such as wheezing, shortness of breath, fever, and/or change of cough color, contact your doctor immediately.

- Websites on COPD...

The Lung Association - Breath Easy Program

This site includes information about the diagnosis, impact, symptoms, causes, processes, self-care management programs and drug treatment types of COPD. It gives an overview of normal and abnormal lung anatomy, lung functions and defense mechanisms of the lungs. Lastly, it gives an overview of how your lifestyle can be impacted with COPD.

Chest Medicine On-Line

This site gives a concrete overview of COPD. It provides a definition, causal factors and treatment guidelines.

The National Jewish Medical and Research Center

This sites gives an over view of COPD. Specific topic include: What is COPD? What are the Goals of Treatment? How is COPD Managed? Exercise and Healthy Lifestyle, Avoid Infection, Medication Therapy, Bronchial Hygiene, Breathing Retraining, Oxygen Therapy and Pulmonary Rehabilitation.

- Books

- Cherniack, Neil S. *Chronic Obstructive Pulmonary Disease.* 1st Edition, Sanders Publishing. c1991.
- Hodgin, John E. *Chronic Obstructive Pulmonary Disease.* W.B. Sanders Publishing. c1987.

- Medline Journal Articles

- Lacasse, Y. and Goldstein, R.S. (1998). Scoring Evidence of Pulmonary Rehabilitation Effectiveness in COPD. *Chest, July; 114(1): 343-5.*
- Madison, J.M., and Irwin, R.S. (1998). Chronic Obstructive Pulmonary Disease. *Lancet, Aug 8, 352: 467-473.*
- Penrod, J.D., Kane, R.L., Finch, M.D. and Kane, R.A. (1998). Effects of Post-Hospital Medicare Home Health and Informal Care on Patient Functional Status. *Health Services Research, Aug 1; 33(3 Pt 1): 513-529.*

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Health Self-Monitor Track Record Sheet

Chronic Obstructive Pulmonary Disease (COPD) - Peak Flow Measurements

My Personal Best _____

	MON	TUES	WED	THURS	FRI	SAT	SUN
600 + l/min							
550 - 599 l/min							
500 - 549 l/min							
450 - 499 l/min							
400 - 449 l/min							
350 - 399 l/min							
300 - 349 l/min							
250 - 299 l/min							
200 - 249 l/min							
150 - 199 l/min							
100 - 149 l/min							
50 - 99 l/min							
0 - 49 l/min							

LEGEND:	TIME:
	AM
	PM

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Health Self-Monitor Track Record Sheet - Example

Chronic Obstructive Pulmonary Disease (COPD) - Peak Flow Measurements

My Personal Best 400 liters per minute

	MON	TUES	WED	THURS	FRI	SAT	SUN
600 + l/min							
550 - 599 l/min							
500 - 549 l/min							
450 - 499 l/min							
400 - 449 l/min		o				o	
350 - 399 l/min	o	x	o		o	x	o
300 - 349 l/min	x		x	o	x		x
250 - 299 l/min				x			
200 - 249 l/min							
150 - 199 l/min							
100 - 149 l/min							
50 - 99 l/min							
0 - 49 l/min							

LEGEND:	TIME:
x	AM
o	PM

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CONGESTIVE HEART FAILURE (CHF)

What is CHF? | How do we diagnose it? How do we treat it? · How do we manage it? · Websites Books Medline Journal Articles | Blank Self-Monitor Form Example Form

What is CHF?

Congestive Heart Failure (CHF) is a condition in which the heart can not pump enough blood to your body's vital organs. The heart normally circulates blood to and from your body at a certain rate. As blood flow out of the hearts slows, blood returning to the heart through the connecting veins gets built-up causing congestion in the circulatory tissues. The congestion of blood in the veins can result from various sources. It can result from narrowed arteries that supply blood to the heart commonly called Coronary Heart Disease. It can result from scar tissue build-up from a past heart attack that interferes with the hearts normal function commonly known as Myocardial Infarction. Also, it can either result from an infection of the heart valve or heart muscle, commonly referred to as Endocarditis or Myocarditis or from primary heart disease of the heart muscle itself called Cardiomyopathy. In some people, CHF results from birth defects in the heart commonly referred to as Congenital Heart Disease.

How do we diagnose it?

As a result, if CHF occurs in the left side of the heart, fluid collects in the lungs and interferes with breathing causing shortness of breath. People with this kind of heart failure can't exert themselves because they become short of breath and tired. CHF also affects the ability of the kidneys to dispose of sodium and water. If CHF occurs in the right side of the heart, the body retains water, thereby causing swelling normally in the legs, ankles or stomach.

How do we treat it?

CHF usually requires a multidisciplinary treatment program consisting of rest, proper diet, modified daily activities, reduction of fatty and salty foods, proper management of stress and medication. Based on the severity of your disease and your medical history, your doctor will prescribe the drug and treatment program best suited for your needs. Common medications for CHF are diuretics, ACE inhibitors, vasodilators, digoxin, dobutamine, calcium-channel blockers, beta-blockers and/or antithrombotic therapy.

Because of the high risk involved in CHF, it is important to adhere to the prescribed treatment your doctor gives, as well as to educate yourself of the nature of the disease and the signs and symptoms you should watch out for. It is very important for you to understand your diagnosis and take an active role in the management of your disease.

How do we manage it?

As part of the new heath initiative, it is important for you to monitor your *weight* by keeping a daily record of your weight. It is highly recommended that you monitor your weight at home by buying a *scale* from your local pharmacy. Ask your doctor to help you understand how to record the readings properly and to read your scale measurements. You should bring this record with you on your next visit, as it will assist your doctor in personalizing your CHF management program. Also as part of improving patient education efforts, below is a list of resources to assist you in further readings of your diagnosis. Should

you experience continued symptoms of increased swelling in the legs or breathing difficulties, contact your doctor immediately.

- Websites on CHF...

  The Success with CFH Website

  This site includes information for patients like: What is heart failure? How to become a partner in managing my own heart failure? How will nutrition, exercise, smoking and medication affect CHF?

  The Medical College of Virginia Hospitals

  This site gives information about the background of CHF, findings from clinical trials, non-medical therapies, medical therapies, the therapeutic rationale for different drugs (i.e. Carvedilol, Coreg, Bucindolol and Bosentan), pulmonary edema and about transplants and bypasses.

  Medical Sciences Bulletin

  This site provides information on CHF. In particular, this site covers: (I) Managing CHF, (ii) Pharmacotherapy of Heart Failure and (iii) Preventing Heart Failure Following Acute Myocardial Infarction.

  Texas Heart Institute - Heart Information Service

  This site includes specific information about CHF, thereby including a definition of CHF, basic risk factors, clinical results, symptoms, diagnosis and treatment.

- Books

  - Braunwald, Eugene. *Congestive Heart Failure*. Grune and Stratton Publishing: USA. c1982.
  - Hosenpud, J.D. and Greensberg, B.H. *Congestive Heart Failure: Pathophysiology, Diagnosis and Comprehensive Approach to Management*. c1994.

- Medline Journal Articles

  - Bernardi, L. Spadacini, G, Bellwon, J., Hajric, R., Roskam, H., Frey, A.W. (1998) Effect of Breathing Rate on Oxygen Saturation and Exercise Performance in Chronic Heart Failure. *Lancet, May 2; 351(9112): 1308-11.*
  - Harrison, M.B., Toman, C., Logan. J.L. (1998). Hospital to Home Evidence-Based Education for Congestive Heart Failure. *Canadian Nurse, Feb; 94(2): 36-42.*
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On-Line HMI System for Patients

Health Self-Monitor Track Record Sheet

Congestive Heart Failure (CHF) - Weight Measurements

My Weight _____

	MON	TUES	WED	THURS	FRI	SAT	SUN
+ 10 lbs							
+ 8 lbs							
+ 6 lbs							
+ 4 lbs							
+ 2 lbs							
+ 1 lbs							
no change							
- 1 lbs							
- 2 lbs							
- 4 lbs							
- 6 lbs							
- 8 lbs							
- 10 lbs							

LEGEND:	TIME:
	AM
	PM

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Health Self-Monitor Track Record Sheet - Example

Congestive Heart Failure (CHF) - Weight Measurements

My Weight 110 pounds (lbs)

	MON	TUES	WED	THURS	FRI	SAT	SUN
+ 10 lbs							
+ 8 lbs							
+ 6 lbs							
+ 4 lbs							
+ 2 lbs							
+ 1 lbs		x	o			x	o
no change	x	o	x	o	x	o	x
- 1 lbs	o			x	o		
- 2 lbs							
- 4 lbs							
- 6 lbs							
- 8 lbs							
- 10 lbs							

LEGEND:	TIME:
o	AM
x	PM

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CORONARY ARTERY DISEASE (CAD)

What is CAD? | How do we treat it? | How do we manage it? |
Websites Books Medline Journal Articles | Blank Self-Monitor Form Example Form

What is CAD?

Coronary Heart Disease (CAD), is a disease of the heart, which prevents nutrients and oxygen from reaching the heart muscle. In CAD, the coronary arteries narrow and sometimes close. The causes of CAD are build-up from high fat deposits coating the interior wall of the arteries. Over time, this fat makes the arterial walls hard and thick, thereby narrowing the space for blood to travel. Blood not only travels at a slower rate into the heart, but continuous build-up of fat deposits on the arterial wall can block the blood coming into the heart. The more the arteries build-up of fat deposits, the more the body is deprived of oxygen and the essential nutrients. If this situation continues, the heart muscle can be permanently damaged. The amount of damage depends on the location of and the degree of blockage. The two most common consequences of CAD are Angina Pectoris and Myocardial Infarction.

As part of the new heath initiative, it is important for you to monitor your blood pressure by keeping a daily record of your blood pressure reading. Blood Pressure (BP) is the result of two interacting forces by the heart and the arteries. The heart creates a force by pushing blood into the arteries and through the circulatory system, and the arteries create a opposing force by resisting this blood flow. If given a BP reading of 140/90, the 140 is the systolic pressure representing the pressure while the heart is beating and 90 is the diastolic pressure representing the pressure while the heart is resting between beats. A blood pressure of 140/90 ("140 over 90") is considered to be the normal blood pressure for adults.

How do we treat it?

To manage the state of your disease, it is highly recommended to reduce your cholesterol, fat and sodium (salt) intake, to exercise regularly, and to cut down your consumption of alcohol. Many medications are also now available relax constricted blood vessels or prevent blood vessels from constricting or narrowing. Depending on the severity of your disease, your doctor will prescribe the treatment that best suited for your needs. Because there is no cure for coronary artery disease, treatment should not be stopped when you think you are feeling better. If coronary artery disease is not treated properly, the heart will work harder than normal causing unnecessary strain. The blood pressure may rise, thereby increasing the risk blood clotting in an artery narrowed by atherosclerosis (hardening of the arteries). This would deprive the body of blood, carrying oxygen and nutrients, thereby causing permanent kidney, heart and/or brain damage.

Because the risk is so high, it is important to adhere to the prescribed treatment your doctor gives, as well as to educate yourself of the nature of the disease and the signs and symptoms you should watch out for. It is very important for you to understand your diagnosis, take an active role in its treatment and for you to adhere to the recommended therapy your physician suggests.

How do we manage it?

It is highly recommended that you monitor your *blood pressure* at home by buying a *sphygmomanometer* and a *stethoscope* from your local pharmacy. Ask your doctor to help you understand how to record the readings properly and to read your blood pressure readings. You should bring this record with you on

your next visit, as it will assist your doctor in personalizing your CAD management program. Also as part of improving patient education efforts, below is a list of resources to assist you in further readings of your diagnosis. Should you experience symptoms such as chest pain, a feeling of heaviness on your chest, nausea, seating, jaw pain, pain on arm (usually on left arm) and/or shortness of breath, contact your doctor immediately.

- Websites on CAD...

  The Atlanta Cardiology - Understanding CAD and Your Stent

  This site provides information, descriptions, diagrams and a glossary on Coronary Artery Disease (CAD). It answers questions like: What Causes the Disease? Where and How is Angioplasty Performed? and What is a Coronary Stent? How is CAD Diagnosed? Can CAD Be Treated? It also includes information on Symptoms of Coronary Artery Disease and Risk Factors for CAD.

  The National Heart, Lung and Blood Institute

  Topic on this site include: Who is at risk for coronary artery disease (CAD)? What is CAD? What causes CAD? What are the symptoms of CAD? Are there tests for CAD? How is CAD treated? What kind of lifestyle changes can help a person with CAD? What medications are used to treat CAD? What types of surgery are used to treat CAD?

  The American Heart Association

  This website gives information about heart attacks and the different types of heart disease (CAD) being one of them. The types of questions answered include: What is a heart attack? What causes a heart attack? What are the symptoms and warning signs of heart attacks? What are the treatments for heart attacks? When does a person need a heart transplant? What types of surgery exist for heart attacks? What are the preventative measures I can take?

- Books
  - Boucek, Robert J. *Coronary Artery Disease.* Williams and Wilkins Publishing: USA. c1984.
  - Topol, Eric. J. *Atherosclerosis and Coronary Artery Disease.* Lippincott-Raven Publishing: New York. c1996.

- Medline Journal Articles
  - Gould, K.L. (1998). New Concepts and Paradigms in Cardiovascular Medicine: The Noninvasive Management of CAD. *American Journal of Medicine, June 22; 104(6A): 2S-17S.*
  - Smith, S.C. (1998). Lessons from Cholesterol Lowering Trials. *American Journal of Medicine, June 22; 104(6A): 28S-32S.*
  - Smith, S.C. (1998). Risk Reduction Therapies for Patients with CAD: A Call for Increased Implementation. *American Journal of Medicine, Feb 23; 104(2A): 23S-26S.*

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Health Self-Monitor Track Record Sheet

Coronary Artery Disease (CAD) - Blood Pressure Readings

My Blood Pressure (at Doctor's Office) _____

	MON	TUES	WED	THURS	FRI	SAT	SUN
>160 mm/Hg							
150 - 159 mm/Hg							
140 - 149 mm/Hg							
130 - 139 mm/Hg							
120 - 129 mm/Hg							
110 - 119 mm/Hg							
100 - 109 mm/Hg							
90 - 99 mm/Hg							
80 - 89 mm/Hg							
70 - 79 mm/Hg							
60 - 69 mm/Hg							
50 - 59 mm/Hg							
< 49 mm/Hg							

LEGEND:	TIME:
x	Systolic
o	Diastolic

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Health Self-Monitor Track Record Sheet - Example

Coronary Artery Disease (CAD) - Blood Pressure Readings

My Blood Pressure (at Doctor's Office) 140/100 mm per Hg

	MON	TUES	WED	THURS	FRI	SAT	SUN
>160 mm/Hg							
150 - 159 mm/Hg							
140 - 149 mm/Hg						x	
130 - 139 mm/Hg					x		
120 - 129 mm/Hg							x
110 - 119 mm/Hg			x				
100 - 109 mm/Hg		x		x		o	
90 - 99 mm/Hg	x		o		o		
80 - 89 mm/Hg				o			o
70 - 79 mm/Hg		o					
60 - 69 mm/Hg	o						
50 - 59 mm/Hg							
< 49 mm/Hg							

LEGEND:	TIME:
x	Systolic
o	Diastolic

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On-Line HMI System for Patients

HYPERTENSION

What is Hypertension? | How do we treat it? | How do we manage it? :
Websites Books Medline Journal Articles | Blank Self-Monitor Form Example Form

What is Hypertension?

Hypertension is the medical term meaning High Blood Pressure. Blood Pressure (BP) is the result of two interacting forces by the heart and the arteries. The heart creates a force by pushing blood into the arteries and through the circulatory system, and the arteries create a opposing force by resisting this blood flow. If given a BP reading of 140/90, the 140 is the systolic pressure representing the pressure while the heart is beating and 90 is the diastolic pressure representing the pressure while the heart is resting between beats. A blood pressure of 140/90 ("140 over 90") is considered to be the normal blood pressure for adults. In 90 to 95 percent of the cases, the cause of high blood pressure is unknown. As a result, this is called essential hypertension. In the remaining cases, high blood pressure is a symptom of a recognizable underlying problem such as a kidney abnormality, tumor of the adrenal gland or congenital defect of the aorta. This type of high blood pressure is called secondary hypertension.

How do we treat it?

To lower your blood pressure, it is highly recommended to reduce your cholesterol, fat and sodium (salt) intake, to exercise regularly, and to cut down your consumption of alcohol. Many medications are also now available to reduce high blood pressure. Medication functions also vary as some eliminate access fluid and sodium, relax constricted blood vessels or prevent blood vessels from constricting or narrowing. Depending on the severity of your disease, your doctor will prescribe the treatment that best suited for your needs. Because there is no cure for hypertension, treatment should not be stopped when you think you are feeling better. If high blood pressure is not treated properly the heart will work harder than normal causing unnecessary strain. The blood pressure may even arise again, thereby increasing the risk blood clotting in a artery narrowed by atherosclerosis (hardening of the arteries). This would deprive the body of blood, carrying oxygen and nutrients, thereby causing permanent kidney, heart and/or brain damage.

How do we manage it?

Because the risk is so high, it is important to adhere to the prescribed treatment your doctor gives, as well as to educate yourself of the nature of the disease and the signs and symptoms you should watch out for. It is very important for you to understand your diagnosis, take an active role in its treatment and for you to adhere to the recommended therapy your physician suggests.

As part of the new heath initiative, it is important for you to monitor your *blood pressure* by keeping a daily record of your blood pressure reading. It is highly recommended that you monitor your blood pressure at home by buying a *sphygmomanometer* and a *stethoscope* from your local pharmacy. Ask your doctor to help you understand how to record the readings properly and to read your blood pressure readings. You should bring this record with you on your next visit, as it will assist your doctor in personalizing your hypertension management program. Also as part of improving patient education efforts, below is a list of resources to assist you in further readings of your diagnosis. Should you experience symptoms such as chest pain, headaches, visual changes and/or difficulty breathing, contact your doctor immediately.

- Websites on Hypertension...

The American Heart Association

This site gives electronic version of the most recent articles on hypertension. it allows you to search and browse for issues and gives you hypothesis and scientific contributions from the collected papers.

The Pulmonary Hypertension Association

The purpose of the Pulmonary Hypertension Association (PHA) is to provide fellowship and educational support on pulmonary hypertension to physicians, patients and their families. The Association provides information on issues such as current research and findings, early detection, resource organizations, organ transplantation, and support networks.

The Hypertension Network

This site gives you basic facts about high blood pressure, cholesterol, cardiovascular disease, life style factors (i.e. diet, exercise, stress, smoking, and vitamins), prescription drugs (i.e. doses and side effects), on home/self-monitoring of blood pressure and other factors related to your risk of cardiovascular disease.

- Books

- Goodfriend, Theodore L. *Hypertension Essentials.* Grune and Stratton Publishing. c1983.
- Kaplan, Norman M. *Clinical Hypertension.* Williams and Wilkins Publishing. c1986.
- McMahan, Gilbert F. *Management of Essential Hypertension.* Future Publishing. c1984.

- Medline Journal Articles

- Iso, H., Shimamoto, T., Naito, Y., Sato, S., Kitamura, A., Ilda, M., Konishi, M., Jacobs., D.R. and Komachi, Y. (1998). The Effects of Long-term Hypertension Control Program on Stroke Incidence and Prevalence in a Rural Community in Northeastern Japan. *Stroke, Aug; 29(8): 1510-8.*
- Jay, S.J. (1998). Cigarette Smoking and Sense Uncontrolled Hypertension in inner-city African Americans. *American Journal of Medicine, July; 105(1): 83-4.*
- Scheinman, J.I., Crevi, D.L., Narla, L.D. and Chan J.C. (1998). Asymptomatic Childhood Hypertension. *Nephron, 79(2): 131-6.*

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Health Self-Monitor Track Record Sheet

Hypertension - Blood Pressure Readings

My Blood Pressure (at Doctor's Office) _____

	MON	TUES	WED	THURS	FRI	SAT	SUN
>160 mm/Hg							
150 - 159 mm/Hg							
140 - 149 mm/Hg							
130 - 139 mm/Hg							
120 - 129 mm/Hg							
110 - 119 mm/Hg							
100 - 109 mm/Hg							
90 - 99 mm/Hg							
80 - 89 mm/Hg							
70 - 79 mm/Hg							
60 - 69 mm/Hg							
50 - 59 mm/Hg							
<49 mm/Hg							

LEGEND:	TIME:
x	Systolic
o	Diastolic

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On-Line HMI System for Patients

Health Self-Monitor Track Record Sheet - Example

Hypertension - Blood Pressure Readings

My Blood Pressure (at Doctor's Office) 140/100 mm per Hg

	MON	TUES	WED	THURS	FRI	SAT	SUN
>160 mm/Hg							
150 - 159 mm/Hg							
140 - 149 mm/Hg						x	
130 - 139 mm/Hg					x		
120 - 129 mm/Hg							x
110 - 119 mm/Hg			x				
100 - 109 mm/Hg		x		x		o	
90 - 99 mm/Hg	x		o		o		
80 - 89 mm/Hg				o			o
70 - 79 mm/Hg		o					
60 - 69 mm/Hg	o						
50 - 59 mm/Hg							
< 49 mm/Hg							

LEGEND:	TIME:
x	Systolic
o	Diastolic

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TELL US WHAT YOU THINK ABOUT THE WEBSITE?

Are you satisfied with this website? Answer the questions below and do a little onsite-diagnosis. It'll help us know what's wrong and what's right with our site. To make it easier, we've broken the questions up into five important categories:

- **Accessibility** -- Is it easy to find our site on the web?
- **Navigation** -- How easy is it to move around on our site?
- **Functionality** -- Are we making the most of the web's power?
- **Aesthetics** -- Does our site look inviting?
- **Competitive Edge** -- Does our site compare with other medical education sites?

When you've finished, print this sheet out by clicking the print button on your browser and bring it along with you on your next visit to St. Mary's Hospital -- or click "Start Over" if you've messed up and want to clear the form.

ACCESSIBILITY

Can you find our site on the major net search engines just by entering the website name?

Yes
No

Can you find our site just by entering St. Mary's Hospital?

Yes
No

Can you find our site if you search through other medical education sites?

Yes
No

NAVIGATION

Does the navigation structure of our site allow a first-time visitor to move around logically?

Yes

No

FUNCTIONALITY

Was there any sought-after information that you suggest we provide to visitors to our website?

Yes
No

AESTHETICS

Do you think our website is appealing to view?

Yes
No

Are the graphics on our site appropriate?

Yes
No

Are the animated GIFs and/or pictures relevant?

Yes
No

THE COMPETITIVE EDGE

Do you think this site is better than other medical education sites you've visited?

Yes
No

Does this website do as much as other medical education websites (i.e. provide links, information, self-monitoring interactive forms?)

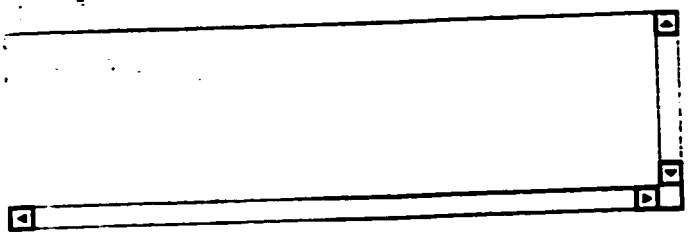
Yes
No

Does our site provide email access to key people you would contact, so

visitors to our site can get answers to non-standard questions?

Yes
No

Do you have any other comments, suggestions or feedback to offer on how we can improve this website?



Start Over

Once you complete this exercise, you can print out this page by using the print button on your browser. If you have any question, please contact the Health Informatics Department at St. Mary's Hospital for further information.

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Letter of Introduction of *The HMI Evaluation* to Patients

Saint Mary's
HOSPITAL
Your Regional Health Care Center

December 28th, 1998

Dear Patient,

Thank you for participating in this Patient Education Initiative. As part of St. Mary's Hospital to improve communication between the hospital and the public, this on-line and print-based health watch system was developed to help patients, like yourself, obtain information and resources on your illnesses. This system has also been designed to provide a self-tracking health monitor system to allow you to monitor and manage your disease.

We would appreciate if you could review the sheets given to you and answer a quick 5 minute survey. All your responses will be kept completely confidential. They will not affect your health status at St. Mary's Hospital nor will your personal records be accessed. Finally, there is no cost to participate.

We would like to continue to improve the communication process between the health system and the public and therefore, we would appreciate your co-operation and your feedback in this process. We want to ultimately, tailor this program for your benefit, so all your comments are highly appreciated.

We thank you for participating in this survey and we hope you have a Happy New Year!

56 Franklin Stree
Waterbury, Connecticut 0670
(203) 574-600

An Affiliated Hospital of Yale University School of Medicin

HMI Request Forms from Physicians

Diagnosis Summary and Health Management Request Forms

Please give my patient the following sheets:

- ☐ Asthma
- ☐ Diabetes
- ☐ Hypertension
- ☐ CAD
- ☐ CHF
- ☐ COPD

Thanks.

Initials: _____

HMI Evaluation Sheet Given to Patients

Evaluation of the Health Monitor System

Thank you for participating in this study. As part of St. Mary's Hospital Patient Education Initiatives, this On- line and print-based health watch system was developed to help patients, like yourself, obtain information and resources on your illnesses. We would like your input as we would like to tailor this program for your benefit. All responses will be kept confidential and will only be used for research purposes. Thank you for taking the time out to fill in this short survey. Have a nice day!

1	2	3	4	5
strongly disagree	disagree	no opinion	agree	strongly agree

1. I find the information on my diagnose(s) useful.	1 2 3 4 5
2. I find the resources given (websites, books, articles) useful.	1 2 3 4 5
3. Because I can access the resources from St. Mary's Hospital Library, I am likely to follow-up on them.	1 2 3 4 5
4. I find the health monitor sheets useful.	1 2 3 4 5
5. I find the example form useful.	1 2 3 4 5
6. By understanding my illness, I am more likely to follow the treatment my doctor recommends.	1 2 3 4 5
7. By understanding my illness, I feel that I am more able to take better care of myself.	1 2 3 4 5
8. By understanding my illness, I feel that my health condition will improve.	1 2 3 4 5
9. As a result of this education sheet, I feel that I am more satisfied with the health care system.	1 2 3 4 5
10. Do you have any comments to add on how this education sheet can be improved?	

Diagnosis Summary Sheet - Doctor Evaluations

Thank you for participating in this study. As part of St. Mary's Hospital Patient Education Initiatives, this On-Line Health Monitoring Initiative was developed to help patients obtain further information and resources on their diagnosis. This system was also developed to help doctors have a means to provide all their patients with more information about their diagnosis. As a result of this new innovative means to give follow-up information directly after the consultation with your patient, we would like your input to further tailorize this program for your benefit. All responses will be kept confidential and will only be used for research purposes. Thank you for taking the time out to fill in this short survey. Have a nice day!

On a scale of 1 to 5, with 5 being the highest score (best) and 1 the lowest score (needs improvement) , please indicate what you feel about the following.

1. Do you find the information on the given disease accurate?	Yes No
2. Do you find the information presented in a logical way?	Yes No
3. Do you think that this information will be useful to the patient?	Yes No
4. On a scale of 1 to 5, how would you rate the usefulness of the information on these diseases?	1 2 3 4
5. Do you find the resources (website addresses, books, and articles) useful?	Yes No
6. On a scale of 1 to 5, how would you rate the usefulness of the resources given?	1 2 3 4
7. Do you find that because of the accessibility of the resources (i.e. all available at St. Mary's Hospital Library) your patients will more likely follow up on it?	Yes No
8. On a scale of 1 to 5, how would you rate the accessibility of the resources given?	1 2 3 4
9. Do you think that educating a patient will increase their compliance to treatment?	Yes No
10. Do you think this initiative will increase the health outcomes for the patient?	Yes No
11. Do you think that this print-based summary sheet given directly after the consultation with your patient expands on and reinforces what you say?	Yes No
12. Do you think that this patient education initiative should be further developed by providing printed and on-line diagnosis summary sheets of all diseases diagnosed to patients?	Yes No
13. On a scale of 1 to 5, retrospectively speaking, how helpful would it be if patients were given a diagnosis summary sheet on their diagnosis directly after consultation in the future?	1 2 3 4
14. Overall, do you think this patient education initiative (i.e. being given a diagnosis summary sheet) will increase satisfaction of health care here?	Yes No
15. On a scale of 1 to 5, how would you rate your impression of this patient education initiative?	1 2 3 4

16. Do you have any comments to add on how this initiative could be improved?

Health Monitor Sheet - Doctor Evaluations

Thank you for participating in this study. As part of St. Mary's Hospital Patient Education Initiatives, this On-Line Health Monitoring Initiative was developed to help patients track and record their own health on a day to day basis. This system was also developed to help doctors have a means to provide all their patients with a regulated health watch system. As a result of this new innovative means to give follow-up information directly after the consultation with your patient, we would like your input to further tailorize this program for your benefit. All responses will be kept confidential and will only be used for research purposes. Thank you for taking the time out to fill in this short survey. Have a nice day!

On a scale of 1 to 5, with 5 being the highest score (best) and 1 the lowest score (needs improvement), please indicate what you feel about the following.

1. Do you find the monitor sheet on the given disease accurate?	Yes No
2. Do you find the monitor sheet presented in a logical way?	Yes No
3. Do you think that this monitor sheet will be useful to the patient?	Yes No
4. On a scale of 1 to 5, how would you rate the usefulness of the monitor sheets of these diseases?	1 2 3 4 5
5. Do you find the example form useful?	Yes No
6. On a scale of 1 to 5, how would you rate the usefulness of the example form given?	1 2 3 4 5
7. Do you think that by having the patient monitor their health will increase their compliance to treatment?	Yes No
8. Do you think this monitoring initiative will increase the health outcomes for the patient?	Yes No
9. Do you think that this print-based monitor sheet given directly after the consultation with your patient expands on and reinforces what you say?	Yes No
10. Do you think that this patient education initiative should be further developed by providing printed and on-line health monitoring sheets of all diseases diagnosed to patients?	Yes No
11. On a scale of 1 to 5, retrospectively speaking, how helpful would it be if patients were given a health monitoring sheet on their diagnosis directly after consultation in the future?	1 2 3 4 5
12. Overall, do you think this patient education initiative (i.e. being given a health monitor sheet) will increase satisfaction of health care here?	Yes No
13. On a scale of 1 to 5, how would you rate your impression of this patient education initiative?	1 2 3 4 5

14. Do you have any comments to add on how this initiative could be improved?