# Empowering the Patient: Tailored Health Information for Decision Making

Holly B. Jimison, Ph.D.[1], Alex Chaffee, B.S.[1], and David Lansky, Ph.D.[2]

[1]Informed Patient Decisions Group, Oregon Health Sciences University, Portland, Oregon
[2]Center for Outcomes Research, St. Vincent Medical Center, Portland, Oregon

Recent studies of patients with chronic disease have shown that patient satisfaction and health outcomes are improved when patients and their families learn to better understand their disease and when they actively participate in treatment decisions and in the management of their care at home. There are several advantages to using computers to assist in providing such health and decision-making information to patients. Consumer health information systems have been useful in providing patients with access to information on health, disease, diagnosis, and treatment. However, to make systems for patients more useful, substantial progress needs to be made in providing a properly focused, patient-tailored and summarized view of the relevant information. Patients need to have medical information presented in a way that facilitates informed and active participation in decisions regarding their health care.

In our work on the *Patient Health Information System* we have concentrated on developing innovative methods for communicating tailored information on medical risks, medical outcomes, and patient outcome preferences. The system consists of two main components: 1) a module that offers patients intelligent access to commercially-available databases of health information, and 2) a prototype research module that synthesizes tailored risk and preference information to aid patients' decision making.

The databases for the first module are stored on CD ROM and contain a wide variety of health information from newsletters, patient brochures, magazines, and medical journals. Patients also have access to standard medical triage information that is available in electronic form.

The research module of the *Patient Health Information System* was designed to assist patients' interpretation of information from the many new outcomes databases for chronic diseases. The prototype application area for the research module is chronic back pain. We use information from a back pain decision model and outcomes database to direct the assessment of patient preferences and to tailor the display of decision making information. To facilitate the assessment process of patient preferences we developed a novel hierarchical outcomes model. For the back pain model we used questionnaire items from the back pain outcomes instrument from St. Vincent Hospital in Portland, Oregon. We use this database of outcomes information pre- and post-treatment to determine sensitivity of preference weights during assessment. This allows the interaction with the patient to be focused, so that time is spent on the most important aspects of the treatment decision.

A further design goal of the *Patient Health Information System* was to enhance a patient's understanding the relative magnitudes of risks and benefits of medical procedures without relying on purely quantitative information. We chose to augment currently available health risk appraisal programs, that provide information on lifestyle risks, with risk and benefit information on single event risks. To this end we created a method of displaying medical treatment risks in the context of familiar single-event daily life risks of similar magnitude. This information is also tailored to an individual patient and presented in a context of associated benefits.

With the growing interest and involvement of patients in their health care decisions and management, it will become increasingly important to give patients access to useful and focused information to assist in their informed participation.

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