

Chapter LIII

Designing Medical Research Web Sites

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ABSTRACT

This chapter discusses the design of Web sites to be used as the basis of medical research. It is broken down into three sections: Part 1 discusses the various issues that have to be addressed in the design of a Web site that will be used to assess some intervention based on the Web site. Part 2 discusses the design of such a Web site and the development of a tool to facilitate this process. Part 3 presents the results of preliminary usability analysis for the tool to assist medical researchers in constructing Web sites that can meet the needs and requirements of medical intervention studies. The results of the preliminary interviews, prototype walkthroughs, and preliminary usability studies are presented laying the groundwork for future development and more formal usability studies.

INTRODUCTION

The Internet, specifically the World Wide Web, is being tested by the medical community as a potentially more efficient and effective mechanism to serve the needs of patients and caregivers. The Web can be used to quickly and cost-effectively

disseminate information, collect data and target communications to specific people or groups of people. May et al., (2005) describe a range of efforts in the United Kingdom to provide services via telemedicine. In the United States, researchers have begun to study the efficacy of web-based medical interventions. Studies have

been performed in recent years examining the effectiveness of internet-based interventions with patients suffering from a variety of medical conditions, including heart transplants (Dew et al., 2004), smoking cessation (Lenert et al., 2003), osteoarthritis (McAlindon, Formica, Kabbara, LaValley, & Lehmer, 2003), clinical depression (Christensen, Griffiths, & Jorm, 2004), *traumatic brain injury* (Rotondi, Sinkule, & Spring, 2005), and schizophrenia (Rotondi et al., 2007). While these studies had different degrees of success achieving their goals, they generally concluded that 1) the Internet is a potentially useful tool for medical interventions, and 2) the success of an Internet-delivered treatment depends largely on the design of the website and other electronic communications used in conjunction with the treatment.

The cost to design, implement and maintain a website to be used as the basis for medical intervention research can be high. Projects at the University of Pittsburgh by Rotondi and Spring budgeted equipment, staff and maintenance costs for a medical research website well in excess of \$100,000. Marshall and Haley (2000) report the cost of setting up the site infrastructure alone at \$35,000. Mounting a website for medical research takes from three months to a year, depending on the amount of usability testing that needs to be done. At the same time, an under-budgeted or poorly designed website can result in sub-optimal usability for subjects, data that cannot be used to answer research questions, exposure of sensitive patient data, etc. Poorly designed research websites are created because:

- The medical researcher does not understand the nature of website design. (A researcher may not anticipate the need to translate their professional model of the subject matter into a model manageable by the consumer.)
- The individual or team hired to design the website may not have knowledge about the nature of the subjects or the treatment.

(The designer may not be aware of physical or cognitive impairments that will require simplified navigational systems or reduced page complexity.)

- Medical researchers may not understand the capabilities or the limitations of data gathering related to the website and designers may not be aware of the data analysis needs of the intervention. For example, how will session information be maintained, how will IDs be assigned, and how will treatment groups be identified?
- The designers may not have sufficient knowledge of the Health Insurance Portability and Accountability Act of 1996 (HIPAA) which sets rigorous standards for protecting patients' personal information (Neale & Schwartz, 2004); data collection, storage, and sharing mechanisms must be carefully designed to adhere to these standards.

Websites used in a variety of interventions reported in the literature had many common elements. This suggested that it might be possible to develop tools to aid the development of reliable and functional medical intervention websites at lower cost. With this in mind, we set out to develop a system that would:

1. Eliminate common pitfalls in design
2. Enhance data collection to better meet research objectives.
3. Reduce cost.
4. Ensure that the website is maximally usable by the target population.
5. Ensures that the website is as secure as possible.

The effectiveness of a system can be assessed based on:

1. Time required to build a website.
2. Monetary cost of building a website.

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