



# Development and utilization of complementary communication channels for treatment decision making and survivorship issues among cancer patients: The CIS Research Consortium Experience



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## ABSTRACT

**Objective:** Cancer patients and survivors are assuming active roles in decision-making and digital patient support tools are widely used to facilitate patient engagement. As part of Cancer Information Service Research Consortium's randomized controlled trials focused on the efficacy of eHealth interventions to promote informed treatment decision-making for newly diagnosed prostate and breast cancer patients, and post-treatment breast cancer, we conducted a rigorous process evaluation to examine the actual use of and perceived benefits of two complementary communication channels – print and eHealth interventions.

**Methods:** The three Virtual Cancer Information Service (V-CIS) interventions were developed through a rigorous developmental process, guided by self-regulatory theory, informed decision-making frameworks, and health communications best practices. Control arm participants received NCI print materials; experimental arm participants received the additional V-CIS patient support tool. Actual usage data from the web-based V-CIS was also obtained and reported.

**Results:** Print materials were highly used by all groups. About 60% of the experimental group reported using the V-CIS. Those who did use the V-CIS rated it highly on improvements in knowledge, patient-provider communication and decision-making.

**Conclusion:** The findings show that how patients actually use eHealth interventions either singularly or within the context of other communication channels is complex.

**Practice implications:** Integrating rigorous best practices and theoretical foundations is essential and multiple communication approaches should be considered to support patient preferences.

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## 1. Introduction

### 1.1. Background on cancer patient decision making and information channels

Advances in breast and prostate cancer treatment and supportive care have led to a growing number of care options for patients and survivors (Tiwari and Roy, 2011). Patients with these early stage cancers typically often are presented with a choice of treatment options with

similar outcomes. These “preference-sensitive” decisions require knowledge about the treatment alternatives and an understanding of one's own values to ensure a quality decision (O'Connor et al., 2007, Sepucha et al., 2010). Cancer patients also need to manage long-term disease and treatment effects, cope with the psychological challenges of survivorship, and find support for health promoting behaviors during the “re-entry” phase of their cancer experience (Stanton, 2012). As a result, cancer patients and survivors are increasingly assuming an active role in treatment decisions (Cayton, 2006) and would benefit from well-designed and effective support tools. Access to evidence-based and understandable medical information to increase self-efficacy is foundational to informed decision making and the delivery of this information can be provided in various communication channels and

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approaches. Although traditional communication approaches, such as printed materials are still widely used, the advances in technology and rising Internet usage (Zickuhr and Smith, 2012) have made eHealth approaches in patient support tools commonplace. These eHealth tools have been shown to facilitate the patient's role in treatment decision making, communication and survivorship management (Dorfman et al., 2010, Hawn, 2009). With the emerging evidence supporting the positive impact of well-designed and theory-driven eHealth tools and the broad availability of multiple information sources, this paper focuses on the systematic development of eHealth cancer decision tools for the Cancer Information Service Research Consortium's (CISRC) randomized trials and the utilization of complementary interventions (print and eHealth). Our findings provide insights into the exploration of how patients use complementary information sources (Rains, 2007, Ruppel and Rains, 2012, Dutta-Bergman, 2004, Johnson and Meischke, 1993) in their decision making.

### 1.2. Overview of the cancer information research consortium study and interventions

The NCI-funded Cancer Information Service Research Consortium's (CISRC) multi-site randomized trial tested three theory-based interactive, multi-media interventions to help newly diagnosed prostate and breast cancer patients make informed treatment decisions (Projects 1 and 2, respectively) and breast cancer patients prepare for life after treatment (Project 3). The study design and implementation are described in detail elsewhere. (Marcus et al., 2013).

Using a theory-guided (Miller and Diefenbach, 1998, Miller et al., 1999) evidence-based approach (Fleisher et al., 2008, Fleisher et al., 2014, Holmes-Rovner, 2007), three separate VCIS eHealth interventions (one per research project) were designed and evaluated to determine impact on informed decision making and quality of life outcomes. The V-CIS for each project was available in two formats – CD or on the Internet. The 2 versions were identical, just delivered on two formats so participants could choose based on their own preference and access to high-speed Internet (since this was a rich multi-media based site). The interventions were also informed by emerging best practices and standards for development, including: health literacy and cultural relevance, utilization of vetted evidence-based content, and rigorously solicited stakeholder and user input throughout the iterative development process. In addition to the impact evaluation, we conducted an extensive process evaluation to determine participants' perceptions of the value of the intervention as well as their subjective and objective utilization of the intervention which is the focus of this paper.

The application of theory (Miller and Diefenbach, 1998) and intervention development best practices (Fleisher et al., 2014) as well as evaluation of their impact and use, are vital to understanding the value of these tools for addressing the complex issues cancer patients face. Consensus-based standards, such as the International Patient Decision Aid Standards (IPDAS), designed to enhance the quality and effectiveness of patient decision aids using a set of criteria to improve the content, development, implementation, evaluation and systematic development recommendations (Elwyn et al., 2011), have emerged to guide the quality and effectiveness of these tools. However, even when these standards are applied, the picture remains complex as to how patients actually use these support tools, either singularly or within the context of other communication channels (Dorfman et al., 2010, Fleisher et al., 2012, Ryhänen et al., 2010).

This paper describes the iterative, evidence-based and stakeholder driven process used to develop the three eHealth interventions (V-CIS) used in the experimental arm of the studies and a comprehensive process evaluation exploring patients self-reported use and value of both the eHealth and standard print interventions; predictors of V-CIS self-reported use; as well as the actual usage of the web-based version based on data gathered from tracking software. Although not an a priori hypotheses, a stepwise logistic regression was used to identify

predictors of V-CIS self-reported use (e.g. age, education, household income, how much control group materials were read, and recruitment source) conducted separately for each project. With the emergence of eHealth tools, often at the replacement of more traditional patient support tools, it is critical that we understand patient preferences and the potential complementary nature of both traditional and new eHealth approaches. Participant's web usage data also offer rich sources of information that can be used to understand their mechanisms of action and to optimize their effectiveness.

## 2. Methods & materials

### 2.1. Development and description of the virtual CIS (V-CIS) interventions

Although the content of each of the three V-CIS software programs varied given their focus on a specific cancer and time in the trajectory of treatment, a common structure and approach was used. This approach included theoretical underpinnings and health communications best practices. As shown in Fig. 1, four domains were addressed in the development process, including: 1) health communications and multi-media best practices; 2) integration of conceptual and theoretical frameworks; 3) stakeholder engagement; and 4) use of a multi-disciplinary team.

The structure of the intervention was similar across the projects and consisted of four modules: Library – Text-based information on a variety of relevant topics, (e.g., “what is prostate cancer”, treatment options, side effects, clinical trials, emotions after breast cancer treatment). Patient Stories – Multi-media testimonials with actual patients were used and presented either with video or still photographs with voice-overs (a piece of narration in the video, not accompanied by an image of the speaker) focusing on relevant issues including treatment choices, potential side-effects, emotional reactions, and survivorship. Doctor's Office – Video-based and text-based information on cancer-specific topics and frequently asked questions as well as video demonstrations of how to communicate with providers using an evidence-based communication approach (Wen et al., 2012). Notebook – Interactive values clarification or action plan. For Projects 1 & 2, the notebook served as the values clarification tool where patients could list the pros and cons of each treatment approach and rank them in terms of their personal values. For Project 3, the notebook served as an action plan for the issues that were personally relevant to each woman. Additional details about each of the three interventions are described in previous published articles (Marcus et al. 2013).

The theoretical constructs of self-regulatory theory (Miller and Diefenbach, 1998) were operationalized in all three V-CIS interventions by normalizing the experience, using familiar settings as a metaphor, modeling self-management through the patient testimonials and communication role play, and the notebook which facilitated users' identification of their own values and needs. We also addressed the IPDAS standards of providing balanced information and information on all options, including values clarification, and providing navigation in the interactive software through a gender-specific Virtual Guide.

Guided by health communications best practices, the content for each of the three V-CIS programs was based on the literature, adapted from evidence-based resources and was reviewed through a rigorous process with the National Cancer Institute's (NCI) Cancer Information Service (CIS). It was reviewed and re-written by health literacy experts using plain language (with many sections at 5th–8th grade reading level) and both content and visuals were carefully developed and tested for a multi-cultural population. Stakeholders, such as the NCI's CIS national and regional staff and cancer patients were involved throughout the process and many changes were made based on this feedback. The CISRC's multi-disciplinary Intervention Development & Measurement Core (S. Miller PI) oversaw the development and production of the V-CIS interventions, working closely with each of the research teams and the software production company with considerable contribution from each of the Principal Investigators. The development and production of the three eHealth tools required 16 months.

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