

Penn's online survivorship care plans empower cancer survivors, caregivers

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An online tool that provides cancer survivors and their family members with an easy-to-follow roadmap for managing their health as they finish treatment and transition to life as a survivor got high marks from users, according to new University of Pennsylvania School of Medicine research which will be presented this weekend at the American Association for Cancer Research (AACR) 100th Annual Meeting 2009 in Denver. Ninety-seven percent of people who used OncoLife, the first online cancer survivorship care plan tool - developed by physicians and nurses from Penn's Abramson Cancer Center - rated their experience with the tool as "good" to "excellent," and 84 percent said they planned to share their plan with their health care team.

The findings reveal that OncoLife can serve as one way to fulfill the Institute of Medicine's recommendation that the 12 million cancer survivors across the United States use plans like these to become knowledgeable about the potential late effects and learn about the specialized follow-up care they'll need following their disease.

"This tool empowers patients to open important dialogue with their healthcare providers to better understand the effects of their cancer treatment," says James Metz, MD, an associate professor of [Radiation Oncology](#) who serves as editor-in-chief of OncoLink and the department's Chief of Clinical Operations. "Because this tool is Internet based, cancer survivors and healthcare providers now have an easy and reliable way to obtain information regarding survivorship care issues instantaneously."

Penn researchers surveyed 3,343 individuals who created OncoLife care plans during an 18-month period in 2007 and 2008. In addition to cancer survivors, who made up 62 percent of the OncoLife users, health care providers and family or friends of survivors also created care plans on the site. In a survey of the survivors who made OncoLife plans -- whose diagnoses included more than 34 different cancers - 97 percent reported finding the information on the site to be helpful.

The researchers say the high number of users who said they planned to share their care plans with their [health care](#) providers is encouraging. Since many patients rely on their primary care physicians to deliver this multidisciplinary "survivorship care" after they're released from treatment with oncologists, communication is essential to helping patients get the care they need. Previous Penn research has shown that breast cancer survivors - the nation's largest group of [cancer survivors](#) - give low marks to their primary care doctors' knowledge of late effects of cancer therapies and ways to manage symptoms related to their disease or its treatment. In the new Penn study of OncoLife users, just 13 percent said they had received survivorship information in the past.

OncoLife care plans are available in both English and Spanish through OncoLink (www.oncolink.org), the Internet's first multimedia cancer information resource, which receives 385,000 unique visitors each month. By inputting information about the type of chemotherapy agents patients received, location of radiation therapies and/or types of surgical procedures they had, patients, family members and their doctors or nurses can create an easy-to-understand, personalized survivorship plan. Among topics addressed in the plans are potential late effects of treatments, ways to reduce risk of and monitor for these effects, and recommendations for future [cancer](#) screening. The plans also offer guidance on issues like sexuality, fertility, and genetic risk.

"Putting survivorship care plans in the hands of patients allows them to

become educated about their risk, have well-informed discussions with their healthcare teams and be advocates for their own care," says OncoLink nurse educator Carolyn Vachani, RN, MSN, AOCN, a member of the research team.

Source: University of Pennsylvania School of Medicine ([news](#) : [web](#))

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