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The screenshot shows the Us TOO Prostate Cancer Support Community website. At the top, there's a navigation bar with 'Home', 'New', 'Recommended', 'Discussions', 'Journals', 'Members', 'About', and 'Join'. A 'Join today' button is prominently displayed. Below this, there's a section for 'All new and active discussions & journals' with two entries: 'Surgery vs. Radiation ?!?' and 'California Medical Cannabis'. To the right, there's a 'Sign in to see more' section with a login form (E-mail, Password), a 'Forgot password?' link, and a 'Sign in' button. Below the login form is a 'Group leaders' section with profile pictures and names: Beth, Heather1, Jackie\_UsTOO, pccogirl, and terravoo.

*Us TOO International Web site*

*Information and support found in online forums can help cancer patients learn to deal with their illness, according to a new study.*

## The Internet and cancer: how online social networking is revolutionizing cancer health care

by [HANS VILLARICA](#) and [NATALIE BAILEY](#)

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Online communities may help patients survive cancer.

A new study examined online health forums and monitored how well they lead to learning. Researchers found that the potential for these communities is vast, but only under the right conditions.

“Consumer participation is a great force,” said Jagdip Singh, one of the head researchers of the study in which patients are referred to as consumers. “When consumers are connected they can be very effective in managing their conditions by learning from each other.”

The findings are slated to appear in the June 2010 edition of the Journal of Consumer Research, a University of Chicago Press publication.

Charles Maack, 77, an advocate for Us TOO International, a non-profit prostate cancer organization based in Downers Grove, said online communities have been playing a key role in his and others’ ongoing fight with prostate cancer.

“Empowering the patient, that’s what we’re trying to do,” said Maack, who has mentored over a thousand people for 13 years. “We’re trying to give them enough information so that they can then go to their doctor with a better understanding [of their situation].”

Just as doctors or professionals can benefit from social networking, so too can patients, said Dr. Robert Hsiung, a clinical associate psychiatrist at the University of Chicago Medical Center.

“It wasn’t happening before when patients were going to doctors in isolation,” he said. “Now they are joining forces and gaining a sense of empowerment.”

Dr. Roy Beveridge, the medical director of US Oncology, a national health care service based in The Woodlands, Texas, said medicine has been slow to join other industries in using the latest technology.

US Oncology, which serves roughly 16 percent of cancer patients in the United States, plans to unveil an online patient resource in the first quarter of 2010. The portal will be available to anyone and will provide reliable sites and virtual rooms for patient discussions.

According to the 2009 Annual Internet Survey by the University of Southern California, 52 percent of respondents said the Internet was important in helping them maintain their social relationships—up from 45 percent in 2007. Fifteen percent reported they are members of an online community.

While these figures are not exclusive to online cancer communities, patients are increasingly looking to such groups at the beginning stages of their illness, in effect asking crowds of people what to do next.

Singh, a marketing professor at Case Western Reserve University in Cleveland, found his inspiration for the study from John Dewey, a psychology pioneer. Dewey theorized that pragmatic learning happens when individuals reflect on their problem and then use a community to refine and explore solutions.

“[The theory] captures the complexity of how real consumers learn and make decisions in the [online] marketplace and is a considerable advancement over existing consumer decision-making models,” said Julie Ozanne, a professor of marketing at Virginia Tech University.

The use of online health resources has sparked controversy, particularly among members of the medical community. Some physicians are worried people are acting on misinformation, an occurrence that could have dangerous side-effects.

Online forums are important, Beveridge said, but the most important part of the process is making sure patients are talking to others as similar to themselves as possible and not simply focusing on success stories.

“That personal interaction becomes important, but patients who are doing very well tend to dominate a lot of the chat rooms,” he said.

Marketers are just as concerned about consumers receiving the wrong information.

“The problem is that it may be difficult or impossible for patients themselves to tell in advance which discussions will turn out to be helpful,” said Alan Malter, associate professor of marketing at the University of Illinois, Chicago. “Learning the wrong stuff could be potentially risky in the case of medical decision making.”

Hsiung operates a free online message board for people coping with mental illness. He said, while the Internet can be a convenient and cheap resource, consumers need to be wary.

“Caveat emptor,” he said. “You get what you pay for and, as someone who offers a free site, I believe there can be good sites and there can be bad ones.”

The potential benefit of these forums, if they function correctly, is unmatched. Online patients can tap a global network much larger than their local community. More importantly, users can potentially find hundreds or even thousands of people in their same situation.

“The wisdom of the crowds in the community is hard to replicate by an individual’s networks alone,” Singh said, adding that since online forums are here to stay it is critical to know how they work.

Mary Gilly, professor of marketing at University of California, Irvine, agreed and said it would benefit doctors to consider this development.

“It is important that health care professionals understand these online support communities and work with their patients who participate in them rather than outright resisting consumer efforts to learn more about their affliction,” she said.

Beveridge described a problematic exchange arises when patients present information that is not using evidence-based medicine.

“There’s an immense amount of material on the Internet that is purely hokum and made up,” he said. “Negativity comes when patients bring in expectations based on false hope just because someone said on a blog that something is going to cure their cancer.”

Prostate cancer survivor David Sauls, 64, used online message boards throughout his cancer battle. Equipped with more information, he approached his treatment as a dialogue between himself and his doctor, a trend he believes will grow.

“The doctors are coming around,” he said. “They understand that change is here. It’s never going to go away. It’s only going to get bigger.”

The study monitored six threads, or conversations, in an undisclosed, but well-reputed health Web site. The threads included 80 people and over 300 postings in almost 11 months.

Singh and co-author Rama Jayanti of Cleveland State University observed successful learning in two of these threads. They found that patients from these forums reflected on their situation using other people’s experiences and then approached their doctor to discuss treatment options.

In pragmatic learning, the focus is placed on the cycle of thinking about a problem, turning the problem inside-out by using different perspectives, and then creating new experiences through experimentation. In some of the threads, Singh said this cycle was blocked by the patient’s inability to alter his behavior. Another thread didn’t work because the patient lacked sufficient confidence to approach the doctor with new information.

To make existing communities work, Singh said people need to come to them willing to interact with others and learn from their experiences. “It’s not simply to read and hear stories,” he said. “It is to make yourself more effective.”

Sauls said it is the combination of this learning and camaraderie in an online community that helps patients come out of this crisis stronger.

“It empowers you to make the decision that’s right for you,” he said. “[It lets you know that] you’re not alone, you’re not in it by yourself. You get a feeling of, ‘Well, they’re helping me, and maybe I’m helping them too.’”



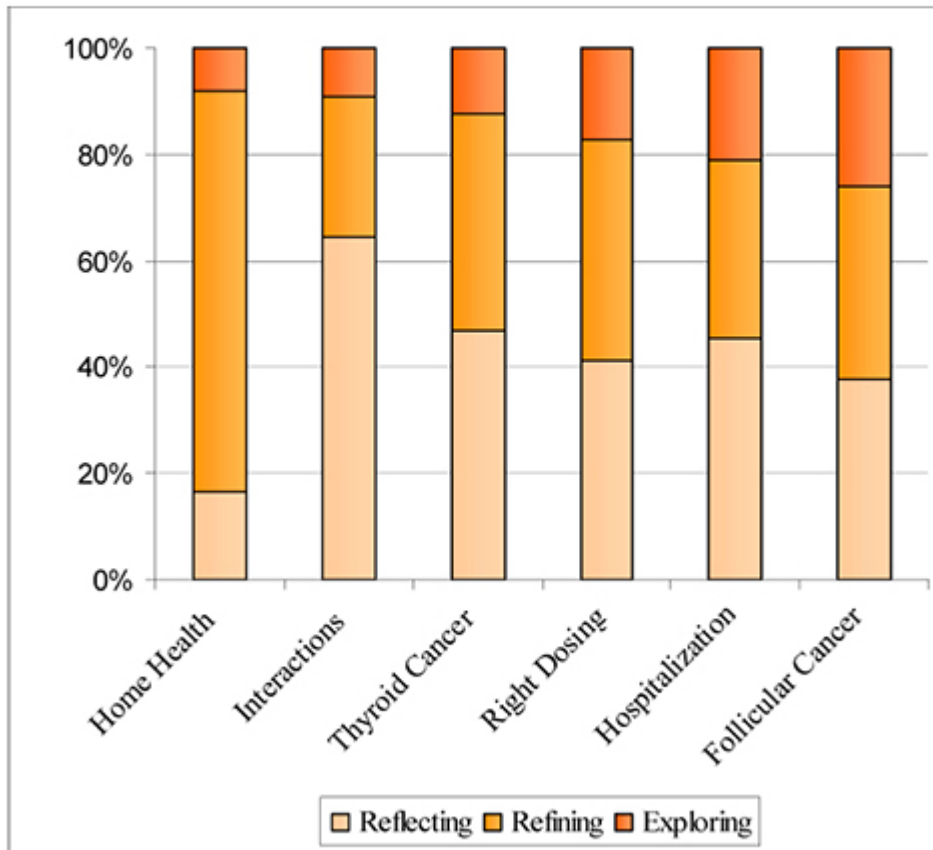
*Jagdip Singh and Rama Jayanti*  
 Researchers Jagdip Singh and Rama Jayanti monitored online cancer forums to assess their potential for learning.

### 3 types of learning processes in online communities

	REFLECTING	REFINING	EXPLORING
Mechanisms	Introspection and interpretation	Interaction and integration	Experimentation
Key players	Self only	Self and others in community	Self and others in community
New experiences?	No	No	Yes
Focus	Interpreting and making sense of one’s own experiences	Integrating others’ experiences to gain an understanding of one’s condition	Positing cause-effect connections and testing them to facilitate problem solving

*Jagdip Singh*  
 Singh and Jayanti’s research uses this framework to determine the effectiveness of online message boards.

## Relative incidence of types of learning processes across threads



Jagdip Singh

Researchers Singh and Jayanti plotted the relative incidence of the three learning processes and found successful learning in two of the six threads.

Natalie Bailey and Hans Villarica/MEDILL

People share their views on using Internet resources for their health concerns

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