

Cancer research pioneer works with Apple on mobile app to track breast cancer survivors' experiences

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Dr. Patricia Ganz

UCLA cancer research pioneer Dr. Patricia Ganz and collaborators Apple and Sage Bionetworks today announced the launch of Share the Journey: Mind, Body and Wellness after Breast Cancer, a patientcentered mobile app that empowers women to be partners in the research process by tracking their symptoms and successes.

Available for download today at the iTunes App Store, Share the Journey was developed by UCLA's Jonsson Comprehensive Cancer Center, Penn Medicine, Dana-Farber Cancer Institute and Sage Bionetworks. The app is an interactive research study that aims to



understand why some <u>breast cancer</u> survivors recover faster than others, why their symptoms vary over time and what can be done to improve symptoms.

Ganz, who is director of cancer prevention and control research at the Jonsson Cancer Center, was a key collaborator with Apple and Sage in developing Share the Journey, which marries science and technology by using surveys and sensor data on the iPhone to collect and track fatigue, mood and cognitive changes, sleep disturbances and reductions in exercise.

Share the Journey is one of five new apps being launched in conjunction with Apple's ResearchKit, an open-source tool that serves as a streamlined hub for iOS apps that can help speed scientific progress toward cures by amplifying the patient voice in shaping research directions and outcomes.

Share the Journey shifts the center of care, healing and intervention into the hands of women who have survived breast cancer. Its creators say that collecting women's experiences after <u>breast cancer treatment</u> will create a trove of data based on well-validated surveys and measurements that will be continuously improved upon based on the participants' feedback.

Women who have undergone surgery, radiation or drug therapy to treat breast cancer often experience symptoms that affect their quality of life and impede recovery.

"We're excited to use these new ResearchKit tools to expand participant recruitment and quickly gather even more data through the simple use of an app. The data it will provide takes us one step closer to developing more personalized care," said Ganz, who also is a professor at the UCLA Fielding School of Public Health. "Access to more diverse patient-



reported health data will help us learn more about long-term aftereffects of cancer treatments and provide us with a better understanding of breast cancer patients' experience."

Share the Journey is open to women between the ages of 18 and 80 who live in the United States, whether or not they have had breast cancer. Those who have not had breast cancer will contribute important data to the app that will help researchers understand which symptoms may be related to cancer treatment and which may be part of the normal aging process. The developers also are creating a Spanish-language version of the app and planning to expand the study to other countries.

"One reason to build these apps and run these studies is to see whether we can turn anecdotes into signals, and by generating signals find windows for intervention," said Dr. Stephen Friend, president of Sage Bionetworks and a principal investigator for Share the Journey. "We're most interested in disease variations and the hourly, daily or weekly ebb and flow of symptoms that are not being tracked and completely missed by biannual visits to the doctor."

The platform is based on the concept that if individuals' experiences were at the center of the <u>research process</u>, researchers working in virtual teams might be able to get efficient, inexpensive and ubiquitous ways of gathering information using websites, tablets or an app. This technology will allow Sage and other teams to include patients and other study participants as owners of their own data and equal partners.

"We need to better understand some of the long-term negative treatment effects, such as fatigue, that can be associated with the disease control benefits of cancer therapies. What are the biological mechanisms that underpin those effects and why some survivors are more vulnerable to those effects than others," Ganz said.



"With Share the Journey, women can tell us when something's wrong, and the app has the potential to capture valuable information on the patient experience. Our current cancer care system lacks the ability to predict or treat these chronic and enduring symptoms, but Share the Journey can set us on a path toward understanding why some people recover and some do not."

Provided by University of California, Los Angeles

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