
Patient to Partner: App Tracks Breast Cancer Journey For Research



A new patient-centred app now available for download in the iTunes Apple Store will empower women affected by breast cancer to participate in the research process by recording their symptoms and progress using sensors and surveys via their iPhones. The “Share the Journey: Mind, Body and Wellness After Breast Cancer” app is itself an interactive study that will help researchers to understand patterns of breast cancer recovery: why symptoms vary over time, why some survivors recover more quickly than others, and what might be done to improve symptoms.

Many breast cancer survivors who have undergone chemotherapy, radiation and/or surgery experience side effects and symptoms that impact their quality of life and recovery. The app allows patients to collect their own data about cognitive changes, fatigue, mood and sleep disturbances, as well as reductions in exercise. The Share the Journey app places women at the centre of the research process, in line with the concept that information gathered using apps, tablets and websites represents an efficient and inexpensive way to generate important data for virtual research teams.

"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 principal investigator Dr. Stephen Friend, President of Sage Bionetworks. "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."

Share the Journey is currently open to women between the ages of 18 and 80 who live in the US, although the developers plan to expand the study with a Spanish language version and open it to other countries. A breast cancer diagnosis is not a requirement, since data contributed by healthy women can help researchers to understand which symptoms might be related to normal ageing rather than cancer.

The app was developed by the Jonsson Comprehensive Cancer Center at UCLA, Penn Medicine, the Dana Farber Cancer Institute and Sage Bionetworks. It is one of five new apps that are being launched in conjunction with ResearchKit, Apple's open-source tool that streamlines iOS apps for promoting scientific progress by incorporating patients' voices in the direction and outcomes of research.

"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 personalised care," said Dr. Patricia Ganz, director of cancer prevention and control research at the Jonsson Cancer Center and 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."

During the development of the Share the Journey app, Apple and Sage Bionetworks were also advised by Dr. Ann Partridge and Dr. Judy Garber of the Dana-Farber Cancer Institute, Dr. Kathryn Schmitz of the University of Pennsylvania Perelman School of Medicine and Dr. Susan Love of UCLA and the Dr. Susan Love Research Foundation.

Source: [UCLA Jonsson Comprehensive Cancer Center](#)

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