Direct patient engagement through social media speeds recruitment to cancer research study

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A crowd-sourcing strategy aimed at accelerating research into metastatic breast cancer has connected advocacy groups, social media, and a dedicated web site to register more than 2,000 patients from all 50 states in its first seven months, say researchers from Dana-Farber Cancer Institute and the Broad Institute of MIT and Harvard.

The Metastatic Breast Cancer Project (MBC Project) was designed to collect health records, tumor specimens, and saliva samples in an effort to understand, at a genomic level, how tumors metastasize and why some patients react differently to treatment than others. By engaging patients directly, the MBC Project has lowered the barrier to participation for patients thereby accelerating progress in our understanding of genetic basis of disease

"It's really fast," said Nikhil Wagle, MD, who is presenting the study at the annual meeting of the American Society of Clinical Oncology (ASCO) in Chicago. "The patients have already done much of the work, and they are excited to say 'count me in' and become partners with whom we can continuously provide feedback about our progress."

Wagle is a medical oncologist at Dana-Farber and is an associate member of the Broad Institute of MIT and Harvard, where the project is based and funded.

One goal of the study is to analyze both tumor and germline genomes of patients with metastatic breast cancer to understand why some individuals have extraordinarily good responses to drugs that haven't benefited most other patients with the same disease. Such "exceptional responders" may turn out to have previously-undiscovered mutations or other genetic changes that render their cancers vulnerable to certain drugs. Uncovering the genomic basis of these responses could someday help identify other cancer patients who could benefit from similar treatments.

About 10 percent of breast cancer patients have metastatic disease when first diagnosed, and as many as one-third of all patients will develop metastatic cancer at some point.

It's estimated that 150,000 women and men are living with metastatic breast cancer in the United States, said Wagle, but only a small fraction are treated at centers that carry out research on tumor samples, making it difficult to recruit the larger number of patients needed for meaningful studies. That's why the project's web site (www.mbcproject.org) prominently displays a "Count Me In" button to begin the enrollment process.

"With this approach, we hope to empower patients to directly participate in research, regardless of where they live, and contribute to the effort to improve outcomes for all people with advanced breast cancer," Wagle said.

Casting a wide net, the study engages patients through social media channels, newsletters, blogs, and advocacy groups. When they enroll through the web site, patients are asked questions about their cancer and treatments and can give consent to have researchers obtain their medical records and collect specimens of stored tumor samples. Patients use a mailed collection kit to provide saliva samples, which researchers at the

Broad Institute analyze for comparison with the tumor's DNA.

To date, 95 percent of the 2,000-plus patients who have provided detailed information about their treatments and experiences. More than 1,100 have given consent to have their medical records accessed, and have consented to have next-generation sequencing performed on the tumor and saliva samples.

Project organizers plan to share the clinical and genomic data generated with researchers beyond the Broad Institute and Dana Farber, using a data-sharing platform that is currently under development. This will offer researchers around the world the ability to conduct studies that may lead to additional breakthroughs.

Inspiration for the direct-to-patient strategy came in part by models in community and political organizing that used social media, said Wagle and Corrie Painter, PhD, associate director for the project. "We have leveraged what already exists in online communities as breast cancer support groups," said Painter.

In addition to tissue specimens and saliva samples, the researchers are planning to collect tumor DNA that is shed by the cancer into the bloodstream, where it can be easily accessed using a "liquid biopsy" blood test. Through serial blood biopsies, tumor DNA can be analyzed over time as the cancer evolves and develops resistance.

Elpida Argenziano, a metastatic breast cancer patient from New York, learned about the project from Painter and Wagle when they spoke at a conference last October. She immediately signed up. "I was so excited," she said. "Here was something involving and engaging patients. It was an incredible thing – it finally feels like people are listening to us."

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