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## Missed Opportunity? Twenty Percent of Breast Cancer Patients Don't Know Their Recurrence Risk Status

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**SUMMARY:** According to the recent study *Empowering Choices in Breast Cancer Treatment*, one of every five women with early-stage breast cancer does not know

whether she is at high or low risk for cancer recurrence, pointing to the need for better communication between doctors and patients about genomic test results.

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One in eight women will be diagnosed with breast cancer over her lifetime. Together with their doctors, women with early stage breast cancer that is estrogen receptor positive and lymph node negative must make the important decision of whether to include chemotherapy in their treatment plan. Determining the benefits of chemotherapy in an individual case can be informed by gene expression profiling (GEP). This fact sheet reports findings from a new patient survey on how women's decisions about their breast cancer treatment are influenced by GEP technology.

GEP can help determine a patient's risk of the recurrence of breast cancer. Assessing the recurrence risk can then help guide the decision of whether to include chemotherapy in the treatment plan—i.e., a low recurrence risk suggests that chemotherapy may add no value, whereas chemotherapy should be part of the treatment plan for a high-risk patient.

The *Empowering Choices in Breast Cancer Treatment* study was led by the UCLA Center for Health Policy Research in collaboration with Harvard University's Brigham and Women's Hospital and Aetna. Voluntary participants in the survey were Aetna health plan members, female, and less than 65 years of age. All had received the GEP test during breast cancer treatment between 2009 and 2012.

### *Among the findings:*

#### **Doctors are the main source of GEP information.**

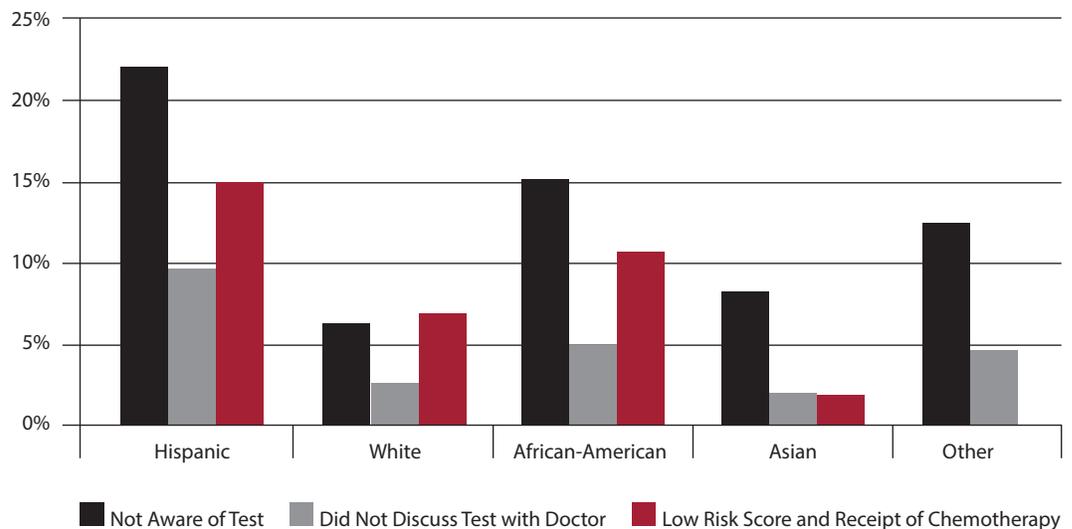
The majority (60 percent) of patients first learned about the GEP test from their doctors.

#### **Doctors who order the test recommend it widely.**

Eighty percent of the participants reported that their doctors recommended the test; only 14 percent of patients had actively asked their doctors to be tested.

Exhibit 1

## GEP Test Awareness and Receipt of Chemotherapy, by Racial/Ethnic Group



### Communication about test results is lagging.

Ninety percent of the women surveyed were aware that they had been tested, but approximately 20 percent of the women did not know whether they were considered to be at high or low risk for recurrence.

### Some patients at low risk still receive chemotherapy.

The majority of patients surveyed received chemotherapy as recommended by the clinical guidelines. Still, 7 percent of the women at low risk for recurrence received chemotherapy.

### Disparities exist in communication and care.

Overall, 10 percent of the participants were unaware of having been tested (i.e., they did not recall their doctor's telling them about it), but the proportions were higher among Hispanics (22 percent) and African-Americans (15 percent) than among whites (6 percent).

Reports that the doctor did not discuss the test were more frequent among Hispanics (9 percent) and African-Americans (5 percent) than among whites (3 percent).

The numbers of low-risk patients receiving chemotherapy were higher among Hispanic and African-American patients (15 percent and 11 percent, respectively) than among white and Asian patients (7 percent and 2 percent, respectively).

The survey shows that the vast majority of doctors of the patients surveyed used the test results according to guidelines. However, more efforts are required to empower all patients with this information, which can improve both quality of care and quality of life. In particular, patients should be educated on the test's importance with regard to choosing between treatment options. Improving patient knowledge is critical to engaging patients in deciding what care they will receive, and it may also spare women the stress and discomfort of potentially unnecessary chemotherapy.

## Methods

The survey was launched in August 2013 and closed December 2013, with a high response rate of 63 percent. Survey participants completed the survey by mail or online. The objective of the survey was to understand patients' perspectives on how GEP results affected their choices in treatment. Information was collected from 890 racially/ethnically diverse women: white (62 percent), African-American (13 percent), Hispanic (12 percent), and Asian (11 percent).\* The mean age of the women at the time of testing was 52 years. Fifty-eight percent of all respondents were fully employed, and 73 percent were married or with a long-term partner.

Twelve percent of all participants in the survey reported an annual household income of less than \$40,000. The remaining women fell into the following income brackets: \$40,000-\$74,999 (21 percent), \$75,000-\$99,999 (14 percent), \$100,000-\$124,999 (11 percent), \$125,000-\$149,999 (9 percent), >\$150,000 (26 percent), and unknown (7 percent). Hispanics (20 percent) and African-Americans (22 percent) were more likely to report an annual household income of less than \$40,000.

Thirteen percent of the women surveyed reported an education level of high school graduate or lower, 62 percent reported having a college education, and 24 percent reported having a graduate degree. Respondents resided in 45 states, with the following distribution in the U.S. Census regions: North Central (11 percent), Northeast (23 percent), South (48 percent), and West (18 percent).

\* White, African-American and Asian are non-Hispanics who identify as belonging to these racial groups. Two percent of the sample did not identify as white, African-American, Asian, or Hispanic, including multiracial individuals who did not primarily identify with one race.

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