

Unregulated web marketing of genetic tests for personalized cancer care raises concerns

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Websites that market personalized cancer care services often overemphasize their purported benefits and downplay their limitations, and many sites offer genetic tests whose value for guiding cancer treatment has not been shown to be clinically useful, according to a new study from Dana-Farber Cancer Institute.

Internet marketing of cancer-related gene tests is unregulated. Therefore, there is wide variation in how these services are presented - posing a challenge for consumers and their physicians, the researchers reported in the March 5, 2015 issue of the *Journal of the National Cancer Institute*.

"We wanted to see if consumers are getting a balanced picture of benefits and limitations of these services," said Stacy Gray, MD, AM, first author of the report analyzing 55 websites marketing the services.

"We found a lot of variation. Some of the information is good, but all of it needs to be looked at critically by consumers and [health care providers](#)."

The study found that "in general, the benefits of these personalized cancer products are reported much more frequently than are the limitations," said Gray. In addition, 88 percent of the websites offered one or more "nonstandard" tests that lacked evidence of clear clinical utility in routine oncology practice.

Gray is a medical oncologist and investigator at the Dana-Farber Center for Outcome and Policy Research. The senior author is Katherine

Janeway, MD, a pediatric oncologist at Dana-Farber/Boston Children's Cancer and Blood Disorders Center.

In their report, the researchers noted that "Internet marketing may be detrimental if it endorses products of unproven benefit."

The investigators analyzed personalized or precision cancer medicine (PCM) products and services marketed by private companies, [academic medical centers](#), physicians, research institutes and other organizations.

PCM was defined by the authors as "...products or services that could be used to tailor, personalize, or individualize care based on genomic or tumor-derived data." PCM often refers to testing DNA from samples of a patient's tumor to detect mutations or other genetic abnormalities that may help physicians predict how the disease will behave, and - in a limited but growing number of cases - select a drug or drugs "targeted" to the particular mutations found in the cancer. Such targeted agents may be more effective and cause fewer adverse side effects than standard chemotherapy.

These tests are termed "somatic" because they look at the genetic characteristic of the tumor itself. Another type of PCM testing, called "germline," analyzes the patient's personal genome - a panel or set of inherited genes and other DNA - and may turn up altered genes in a healthy person that raise his or her risk of developing cancer.

A majority of the Internet sites (58 percent) offered somatic testing, and 20 percent marketed germline testing, the study found. In addition, 44 percent of sites offered some form of personalized cancer care.

The report cited examples of marketing claims such as:

- "Reduce trial and error at the prescription pad. Genetic testing is

a tool for better patient care, greater accuracy, lower costs, enhanced care - that is our promise."

- Using the marketer's "enhanced treatment options, our patients experienced a greater life expectancy, often with less side effects than standard treatment." A late-stage pancreatic cancer patient's life "was extended five years by (our product)-guided treatment."
- "Our laboratory analyzes your tumor's response to 8-16 drugs and combinations to identify which treatments will work best to kill your cancer."

Claims and other information posted on Internet sites are not subject to regulation by agencies such as the Food and Drug Administration (FDA) or the Federal Trade Commission (FTC). More recently, the FDA has said it intends to begin regulating genomic testing more broadly.

Even if regulation of the websites becomes a reality, the researchers said, "Oncology providers will need to guide patients as they navigate decisions about personalized [cancer](#) medicine."

Provided by Dana-Farber Cancer Institute

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