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Media Contact:

Emily Martin

202-650-5371

emily@cancersupportcommunity.org

STUDY FINDS DISCREPANCY IN 'VALUE' DEFINITION IN CANCER CARE

Study suggests people with cancer do not define value in same way as health care policymakers

WASHINGTON – (May 4, 2015) – Data released today by the Cancer Support Community at the 5th Annual Conference of the Association for Value-Based Cancer Care explored the question: When considering your cancer experience, how do you define value?

Value, as described by the Institute of Medicine, is the “best care at lower cost.” Yet value may be interpreted differently among health care stakeholders.

In looking at a sample of 769 patients with metastatic breast cancer who were asked the open-ended question, nearly half responded to the question in one of two ways. 38.4 percent defined value in terms of a “personal value.” For instance, one patient defined the term as, “Information and appropriate communication of that information at the right time and right place.” Another patient defined it as, “Whatever is going to give me integrity.”

On the other hand, 7.41 percent of patients defined value in terms of an “exchange value.” For example, one patient said, “Value in cancer treatment is getting the best options at the lowest cost, presented to you in a manner that is easily comprehended.”

Of those with a health-specific, exchange value response, 76 percent described treatment benefit as being engaged by or feeling close to their health care provider. Financial cost relative to benefit, or treatment efficacy was mentioned rarely.

In current discussions on the concept of value in cancer care, professional organizations and trade associations, such as the Institute of Medicine, the American Society of Clinical Oncology and others, are measuring value using an algorithm of clinical benefit, toxicity and cost. This study underscores the importance of elevating the patient voice in these discussions.

“Decisions are currently being made regarding how cancer care will be delivered and reimbursed in the future. These decisions must be based on real patient needs and expectations. These study results reveal a disconnect in how patients define value and how it is being measured now by health care policymakers,” said Linda House, President of the Cancer Support Community.

Additional findings revealed that value may not be as clear of a concept with nearly 11 percent of the patients indicating they did not fully understand the question and 3 percent reporting “no value.” Forty-six percent did not answer the question and no assumptions were applied to this group of respondents.

The study specifically looked at people with metastatic breast cancer who were members of the Cancer Experience Registry, an online initiative to capture and understand the experiences of those impacted by cancer.

The goal of the project was to better understand how patients define value so that the cancer community can identify strategies to bridge gaps between health care policy and practice to meet patient needs.

The [full poster is available online here](#)

For more information on the Cancer Experience Registry, please visit www.CancerExperienceRegistry.org.

About the Cancer Support Community

The mission of the Cancer Support Community (CSC) is to ensure that all people impacted by cancer are empowered by knowledge, strengthened by action and sustained by community. In 2009, The Wellness Community and Gilda's Club joined forces to become the Cancer Support Community. The combined organization, with more than 50 years of collective experience, provides the highest quality social and emotional support for people impacted by cancer through a network of more than 50 licensed Affiliates, more than 120 satellite locations and vibrant online and telephone communities, touching more than one million people each year.

Backed by evidence that the best cancer care includes social and emotional support, the Cancer Support Community offers these services free of charge to men, women and children with any type or stage of cancer, and to their loved ones. As the largest professionally led nonprofit network of cancer support worldwide, the Cancer Support Community delivers a comprehensive menu of personalized and essential services including support groups, educational workshops, exercise, art and nutrition classes and social activities for the entire family. Through cutting-edge psychosocial, behavioral and survivorship research, the Cancer Support Community's *Research and Training Institute* is helping CSC change the future of cancer care through education and training. The Cancer Support Community's *Cancer Policy Institute* ensures that the voices of 13.7 million cancer survivors and their families are heard in the nation's capital and state and local legislatures across the country. In 2014, the CSC network delivered nearly \$48 million in free services to patients and families. The Cancer Support Community is advancing the innovations that are becoming the standard in complete cancer care. So that no one faces cancer alone®.

For more information, please visit www.CancerSupportCommunity.org