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## NEW RESEARCH SHOWS DISCONNECT BETWEEN PATIENTS AND POLICYMAKERS ON DEFINITION OF 'VALUE' IN CANCER CARE

*Cancer Support Community study shows patient perspectives of 'value' in their care*

WASHINGTON – (Sept. 29, 2016) – New findings presented by the Cancer Support Community suggest that a significant proportion of patients have difficulty conceptualizing value in terms of current cost-benefit models used by policymakers.

Out of the 31 percent of patients who defined value as specifically relating to their health care experience, only 10 percent related cost to value as part of their definition.

The 1,415 patients in the study, recruited from the Cancer Experience Registry, were asked to answer the open-ended question: When considering your cancer experience, how do you define value?

Typical health-specific responses were: “Value is quality of life...” or, “[Value is] the best possible cancer treatment center available that has the best...team of oncologists.”

Furthermore, 40 percent of those surveyed defined value in the context of personal beliefs. For example, one respondent answered, “Value is making the most of each day to serve others.”

Another 29 percent of respondents had difficulty conceptualizing value as a notion related to their health care. For example, they responded that they did not understand or that there was “no value.”

The data was presented today at the Annual Conference of the Association for Value-Based Cancer Care in Washington, D.C.

“Of all the proposed formulas for measuring value in health care, there is not yet one that accurately takes into account the personal preferences and values of the people intended to receive this care. We continue to find in our research that the patient voice is not fully represented in value framework discussions,” said Kim Thiboldeaux, CEO of the Cancer Support Community.

In current discussions on value, organizations such as the National Comprehensive Cancer Network, the American Society of Clinical Oncology, the Institute for Clinical and Economic Review, and others are developing frameworks to measure value using various algorithms of clinical benefit, toxicity and cost. These frameworks do not necessarily reflect individual patient perspectives on value. Researchers from this study recommend incorporating the comprehensive needs of the end-user, the patient, into all framework solutions.

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

For more information on the Cancer Experience Registry, please visit [www.CancerExperienceRegistry.org](http://www.CancerExperienceRegistry.org).

### **About the Cancer Support Community**

As the largest professionally led nonprofit network of cancer support worldwide, the Cancer Support Community (CSC) is dedicated to ensuring that all people impacted by cancer are empowered by knowledge, strengthened by action and sustained by community. CSC achieves its mission through three areas: direct service delivery, research and advocacy. The organization includes an international network of Affiliates that offer the highest quality social and emotional support for people impacted by cancer, as well as a community of support available online and over the phone. The Research and Training Institute conducts cutting-edge psychosocial, behavioral and survivorship research. CSC furthers its focus on patient advocacy through its Cancer Policy Institute, informing public policy in Washington, D.C. and across the nation. For more information, please call the toll-free Cancer Support Helpline at 888-793-9355, or visit [www.CancerSupportCommunity.org](http://www.CancerSupportCommunity.org). *So that no one faces cancer alone*®