



November 17, 2015

To Whom it may Concern:

I recently had the opportunity to review the survey, “Breast Cancer in Young Women,” which was developed by The Centers for Disease Control and Prevention. This timely project will address gaps in our knowledge about young women with breast cancer and their level of access to comprehensive and high quality cancer care. The rich battery of questions about insurance coverage, financial burden, employment, access to care, and healthcare quality will generate valuable data for the research and practice communities. Additionally, the aims of the survey align with the mission of the Healthcare Delivery Research Program at The National Cancer Institute (NCI) and complement ongoing projects at NCI.

Insurance coverage is a consistent predictor of healthcare access. However, even among the insured, the high cost of cancer treatment coupled with spending caps and cost sharing contribute to enormous out-of-pocket costs and financial burden for patients. The Affordable Care (ACA) may address some of the economic barriers to care; however, we currently have little information about post-ACA healthcare access and quality. The majority of data about access to cancer care comes from SEER-Medicare and is generalizable to adults age 65 and older. Although other surveys, such as the National Health Interview Survey and the Medical Expenditure Panel Survey, can be used to study access to care among young adults, these surveys are not specific to cancer. The survey, “Breast Cancer in Young Women,” captures data about access to specific cancer therapies as well as care coordination and indicators of healthcare quality, making it a valuable data resource. The survey will also yield data about the consequences of financial toxicity for patient’s ability to access necessary cancer treatment and the relationship among the cost of care, adherence to prescribed therapy, and overall quality of life. Work disability is an important contributor to financial toxicity. A growing body of research has begun to characterize the impact of cancer on employment. However, there are many unanswered questions, in particular about extent to which employers offer accommodations to their employees with cancer. The survey, “Breast Cancer in Young Women,” includes a well-curated battery of questions about employment that will enhance the literature in this area.

The aims of the survey, “Breast Cancer in Young Women,” are consistent with the mission of the National Cancer Institute’s Healthcare Delivery Research Program and ongoing activities related to the economics of cancer and the delivery of quality care. The survey complements the

Experiences with Cancer survey, which was administered to a heterogeneous sample of cancer survivors participating in the Medical Expenditure Panel Survey to better understand the burden of cancer on access to healthcare, employment, insurance, and quality of care. Additionally, the survey, “Breast Cancer in Young Women,” complements other surveys that have been conducted by NCI including the Adolescent & Young Adult Health Outcomes and Patient Experiences Study (AYA HOPE) as well as internal work around the impact of cancer on employment and the economic burden of cancer.

In summary, the survey, “Breast Cancer in Young Women,” promises to be an important data resource that will inform efforts to optimize the health and quality of life of young women with breast cancer. I encourage you to review it favorably.

Sincerely,

A handwritten signature in black ink that reads "Janet de Moor". The signature is written in a cursive style with a large, flowing initial 'J'.

Janet S. de Moor, PhD, MPH

Program Director

Healthcare Assessment Research Branch, Healthcare Delivery Research Program

National Cancer Institute, National Institutes of Health