



CANCERCARE®

The 2016 CancerCare Patient Access and Engagement Report Methodology

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In 2015, CancerCare initiated a research project to define engagement according to people diagnosed with cancer, identify barriers to their engagement with care providers and characterize the financial, emotional, social and quality-of-life costs of cancer to patients and families. The 2016 CancerCare Patient Access and Engagement Report is a summary and analysis of the data collected through this project.

Survey Development

Surveys were developed to focus on six separate components of the patient experience:

1. Understanding the diagnosis of cancer
2. Participation in treatment decisions and planning
3. Communication with the care team
4. Financial and insurance issues
5. Symptoms, side effects, and quality of life
6. Survivorship

The multitude of diverse patient experiences shared with CancerCare social workers guided the development of our survey questions. We asked our advisory board, a group that includes renowned experts in survey development, patient engagement, and care of cancer patients to review and comment on the questionnaires. We then piloted the surveys with CancerCare clients to ensure the questions were clear and the surveys could be completed in a reasonable amount of time.

The six surveys averaged 41 questions and took 20 minutes to complete. At the beginning of each, respondents were asked to complete the 11-question Patient Activation Measure® (PAM®), a validated survey tool developed in 2004 by Judith H. Hibbard at the University of Oregon. Patient activation refers to an individual's knowledge, skills, and confidence for managing one's own health and health care¹.

Although not discussed in this report, the PAM results combined with the cancer-specific findings are being studied in order to inform recommendations on how proven strategies promoting activation may be applied to help cancer patients more effectively engage with their health care.

Patient Recruitment and Survey Deployment

We sought to create respondent samples that represented the national population of cancer patients by gender, age, ethnicity, income, education and cancer type. Because the surveys were to be administered online, we were able to recruit participants through consumer panels. All survey respondents were at least 25-years-old and had received a definitive diagnosis of cancer from a physician or other health care practitioner.

Through filters, the research vendors used specific criteria so that each survey sample had approximately 25% coverage in the Northeast, Midwest, Southeast and Southwest/West. In order to reflect the experiences of people with many kinds of cancer, we defined a 50/50 mix of the four most common cancers (breast, colorectal, lung, prostate) and those less common types, excluding non-melanoma skin cancer. The target number of valid responses for each survey was 500 or more; the research vendors sent approximately 3,000 e-mails per survey

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to reach this goal. Respondents who accepted the invitation to participate were randomly assigned one of the six surveys to complete.

CancerCare made a deliberate decision not to ask patients in its own client database to complete these surveys. Our intent was to gather data on the experiences of a broad and diverse group of people with cancer, and not bias the results by enlisting those who have used our services and therefore are at least somewhat engaged in their own care. For that same reason, we did not solicit participation through on-line communities or chat rooms.

The six surveys were administered from July through November 2015.

Data Analysis and Reporting

Data was collected, sorted, validated, and aggregated to produce cross-tab reports of the results. CancerCare and Harborside Press then analyzed the data and examined the cross-tab reports for any significant differences among the profile characteristics. Differences between responses across groups of respondents were tested statistically at a confidence level of 0.90, meaning that there is a 90% probability the differences between any two groups of patients are meaningful, rather than random. Harborside Press created the final report, with stages of review and approval from CancerCare. The advisory board of the 2016 CancerCare Patient Access and Engagement Report reviewed the survey methodology, the data analyses, and the final report before publication.

This report represents a first examination of the survey data. Plans for further work with this data include deep analyses of the responses within each profile characteristic.

Study Limitations

This study was conceived to better understand the unmet needs of cancer patients across the entire U.S. population. Although the findings of this study may in fact be representative of cancer patients overall, we are only claiming with confidence that the results reflect the populations as defined within each survey.

To be truly representative:

- Every member of the population should be eligible to participate in the study
- Every member of the population should be equally likely to participate in the study
- Participants should be randomly selected
- A sufficient number of participants would need to participate in the study

The chief constraints to capturing truly representative samples for each survey were availability of appropriate respondents and funding. To the best of our knowledge, no one sample exists that includes every cancer patient in the U.S. Our approach to be as representative as possible and to reduce bias was to recruit participants for this study from reputable national panels of consumers. These panels include millions of U.S. consumers who are profiled on a broad range of characteristics.

Since the studies were conducted via online surveys, our samples skew toward more educated, affluent, and engaged respondents. This was especially evident in the profile characteristics of non-white respondents.

The funding available for this project limited us to obtaining 500 respondents per survey. Considering our interest in identifying differences based on profile characteristics, we applied recruitment quotas on education, age, income, and type of cancer, while also prioritizing diverse respondents.

In summary, although we do not claim our report findings to be precisely representative of the U.S. population, we have a high degree of confidence that the results reflect the experiences, perceptions and opinions of a significant proportion of the people across the U.S. who have been diagnosed with cancer and that it is a valuable addition to existing knowledge.

¹ Hibbard JH, Mahoney ER, Stockard J, Tusler M. Development and testing of a short form of the patient activation measure. *Health Serv Res.* 2005;40(6 Pt 1):1918-1930. doi:10.1111/j.1475-6773.2005.00438.x.