

## Background

In the current climate of health care reimbursement, coverage reform and escalating health care costs, navigating cancer care becomes increasingly complex for patients and caregivers.

Given the truly fluid marketplace and many payment and care models being established without critical engagement or information from the patient, it is imperative to assess the ongoing reality of patient access to comprehensive, quality cancer care; care that includes biomedical as well as psychosocial care.

## Purpose

The intent of this initiative is to better understand the challenges people face when accessing care and examine them within the context of the goals and targets of health care reform. The current report addresses the following topics:

- Access to and understanding of health insurance
- Access to services
- Treatment decision making
- Cost of care
- Cost containment strategies

## Survey Methods

In Spring 2016, CSC along with a team of experts developed a survey to further explore the cancer patient experience as it relates to accessing health care and living within a new and evolving system of health care. The survey was conducted online between June and August of 2016.

Participants were recruited through CSC's network which includes the Cancer Experience Registry®, Affiliate network, advocacy partners, social, and traditional media outlets. 1,218 cancer survivors completed survey questions regarding access to insurance, services, and providers as well as direct and indirect costs of care.

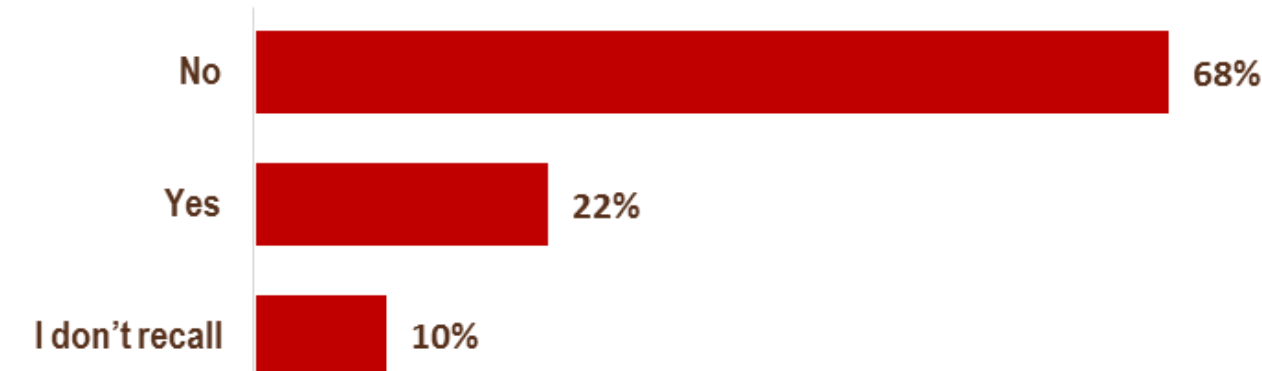
## Participants

<b>Age (n=982)</b>	
45 to 64	54.9%
65 or older	36.3%
<b>Gender (n=982)</b>	
Female	78.6%
<b>Race (n=976)</b>	
White / Caucasian	86.5%
<b>Education (n=980)</b>	
College Degree or Higher	63.7%
<b>Employment (n=982)</b>	
Retired	35.1%
Not employed, disability or other	26.9%
Full-Time	26.4%
<b>Insurance Coverage (n=875)</b>	
Employer Sponsored	45.9%
Medicare	31.8%
Marketplace	5.5%

## Results

### Discussion of Health Care Costs

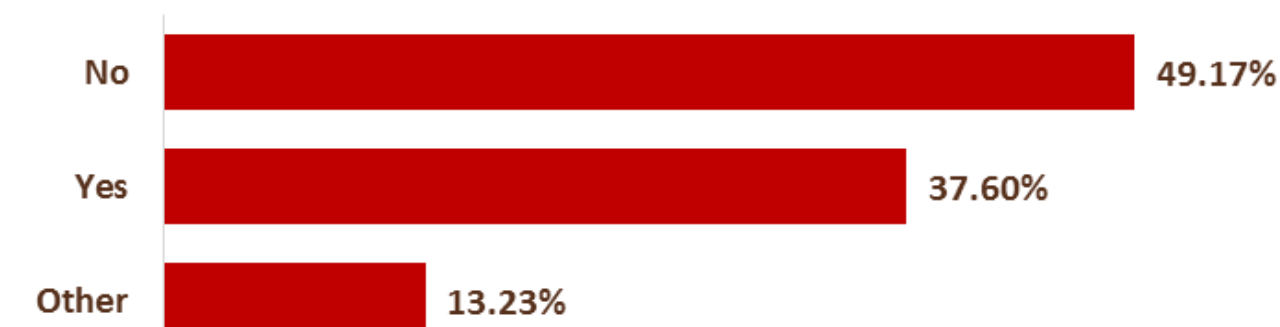
Did you ever discuss with your doctor how much you would have to pay for your health care services before you received them? (n=922)



- 78% of patients with cancer either have not or do not recall discussing costs with their health care team prior to treatment.
- The main reasons respondents gave for not discussing the cost of treatment with their doctors were:
  - Clinician did not bring it up (51.2%);
  - Embarrassment in discussing personal finances (9.8%); and
  - Lack of understanding of insurance coverage (8.3%).
- Almost 43% of participants reported that, within the last 12 months, their out-of-pocket costs were larger than expected.
- Almost 22% of patients chose not to get some of the healthcare services they need due to high OOP costs. In particular, 18% (n=891) of patients said costs inhibited them from filling prescription drugs to treat their cancer.

### Treatment Decisions

Would you have liked to be more involved in decisions about your cancer care and treatment options? (n=904)



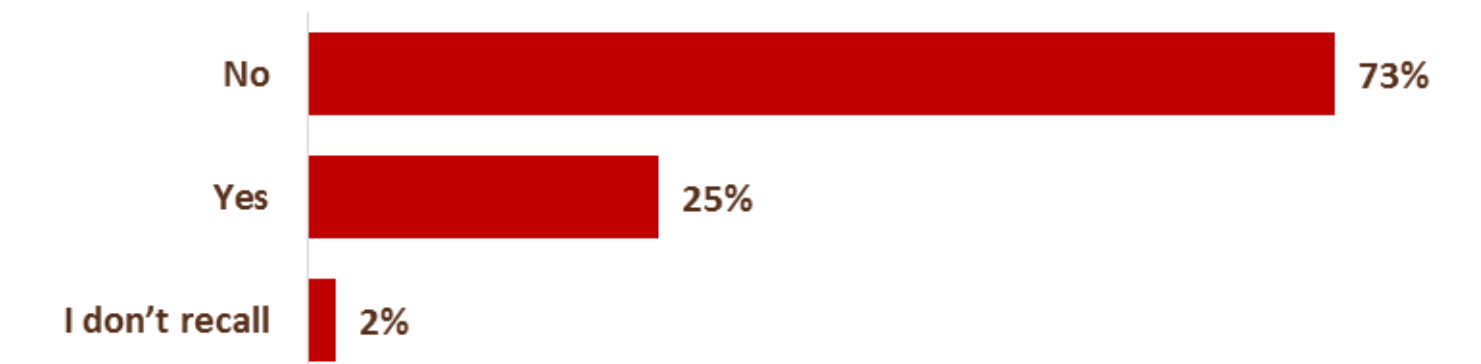
- 53.1% of respondents reported being given a choice of treatment options. Of those who indicated that they did not have a choice, 22.7% reported that they would have liked the opportunity to have a choice.
- 15.7% indicated that they were not as involved in their treatment decision as they would have expected.
- A small yet significant number (4.8%) indicated that they were involved as much as they would have expected but were overwhelmed by the number of choices, which led to difficulty in making a decision.
- 16.3% of respondents felt like they did not have enough time with their doctor during their appointments.

## Implications and Conclusions

These findings demonstrate that despite progress being made in expanding access to health care, many patients still experience significant barriers and challenges to accessing care. We also find there is a gap in patient knowledge about practice guidelines and payment policies. To create a system where all patients have access to high-quality and comprehensive cancer care, educational efforts are needed to enhance patient understanding of information about practice guidelines and payment policies, including information regarding health risk and benefits, costs, patient health, and quality of life outcomes.

### Delays in Care

Have you experienced delays in getting access to cancer care? (n=928)



- 25% of participants reported experiencing delays accessing cancer care.
- The type of delays experienced included:
  - Delays in scheduling a test or medical procedure (63.5%);
  - Receiving a referral (40.9%);
  - Getting responses from their health care team (34.7%); and
  - Obtaining a prescription (22.2%).
- Because of step therapy, over half (52.6%) of those who were prescribed treatment by their doctor had to wait 7-30 days to receive the originally prescribed treatment.
- More than 20% of respondents experienced delays in receiving a cancer diagnosis and 22% faced unexpected OOP cost due to the prior authorization requirement for diagnostic testing or physician-recommended treatment.

### Access to Social and Emotional Support

As part of your cancer care, did you receive social and emotional support services? (n=940)



- More than half (53.3%) of those surveyed indicated that they had not received social and emotional support as part of their cancer care.
- Among those who did not receive social and emotional support services, 67.5% reported they would have liked to receive such services.
- In this survey, receipt of social and emotional support services was inversely related to age, with 25-34 year olds reporting the highest (42.1%), and respondents 65 and older reporting lowest (31.5%) receipt of such services.
- Among those who did not receive social and emotional support services, 45% reported not filling a prescription or skipping appointments due to inability to pay copays.

## Acknowledgements:

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