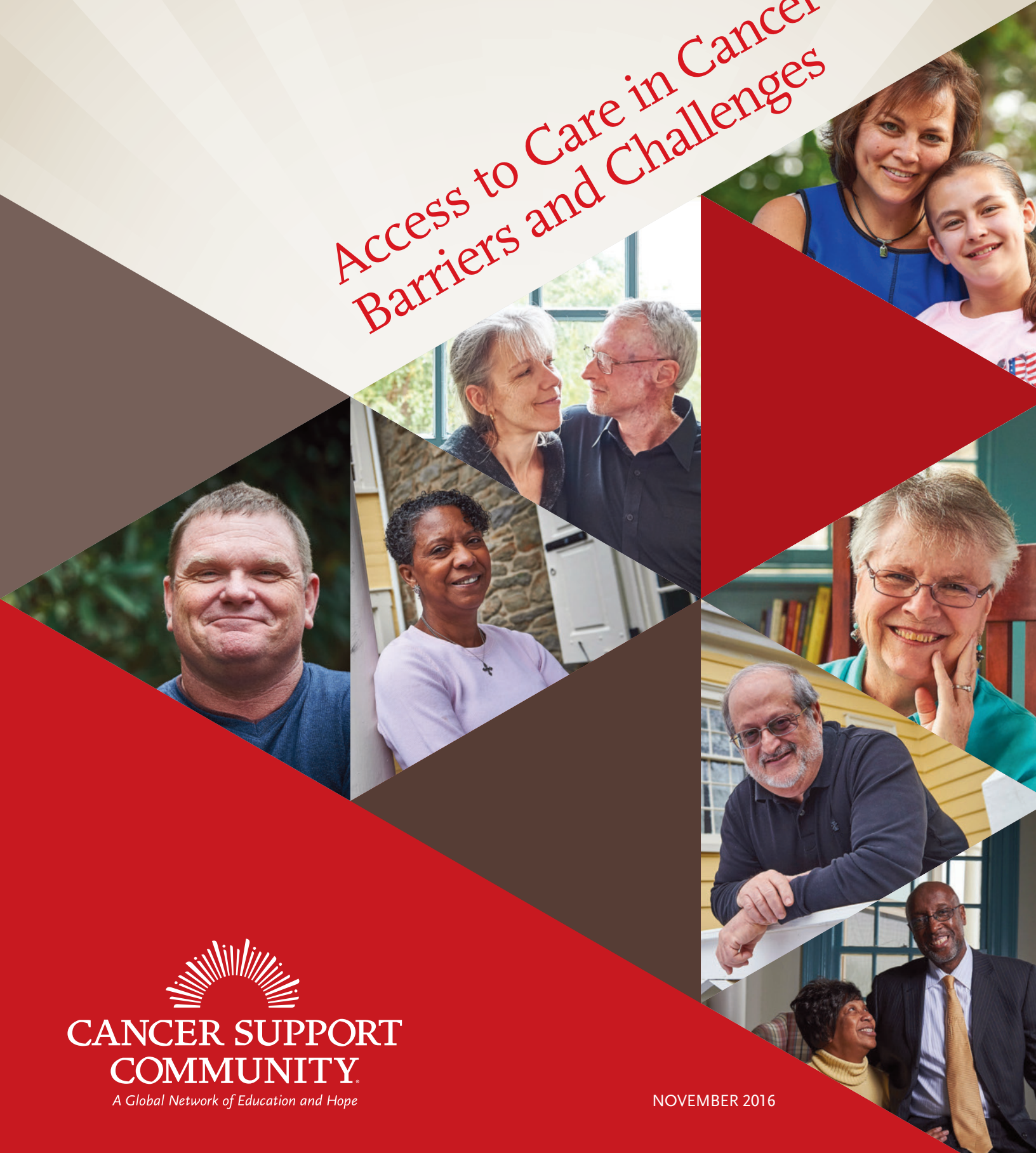


# Access to Care in Cancer 2016: Barriers and Challenges



**CANCER SUPPORT  
COMMUNITY.**

*A Global Network of Education and Hope*

NOVEMBER 2016



## ABOUT THE CANCER SUPPORT COMMUNITY

As the largest professionally led nonprofit network of cancer support worldwide, the Cancer Support Community (CSC), including its Gilda's Club affiliates, 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.

## DEAR FRIENDS,

There are more than 15.5 million cancer survivors in the United States today, and that number is expected to increase to 20 million in less than 10 years (American Cancer Society, Cancer Facts, 2016). Cancer diagnosis and treatment are complex, as are the health coverage needs of people living with and beyond a cancer diagnosis.

In the current climate of health care reimbursement and coverage reform, payer and provider consolidation, and escalating health care costs, navigating cancer care becomes increasingly complex for patients and their caregivers. Since the Affordable Care Act (ACA) was passed six years ago, more than 20 million Americans have gained health insurance coverage through Medicaid expansion, Marketplace coverage, and expansion of age limits on private insurance plans (HHS ASPE Issue Brief, 2016). Despite expanded coverage and access to services as a result of the ACA, including the removal of pre-existing condition and lifetime cap limitations, many challenges remain for patients accessing comprehensive cancer care.

We are at a point in history like no other, and it is imperative that we as a society track against the goals and targets of the ACA and other attempts at reform to assess how the evolving health care system impacts Americans living with cancer. The Cancer Support Community (CSC) is leading this work by exploring the impact of health care reform on cancer survivors, and informing policymakers of our findings in order to guarantee that the U.S. health care system is adequately serving people affected by cancer.



Kim Thiboldeaux, Chief Executive Officer

In 2013, CSC launched its *Cancer Policy Institute* to bring the patient voice to discussions around the value of cancer care, the cost of care, and barriers to accessing care; as well as informing public policy about these issues. The *Cancer Policy Institute* is particularly proud of its partnership with CSC's *Research and Training Institute* — the only entity of its kind focused solely on studying the cancer patient experience. Through its *Cancer Experience Registry*<sup>®</sup>, the *Research and Training Institute* has contributed extensively to the evidence base regarding the cancer patient experience and the psychosocial impact of cancer and cancer survivorship.

In June of this year, CSC's *Cancer Policy Institute* and *Research and Training Institute* launched a research project 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 findings in the report highlight that despite progress being made expanding access to health care, many patients still experience numerous barriers and challenges. A significant number of patients reported experiencing higher than expected out-of-pocket costs associated with insurance premiums, co-pays for diagnostic tests, co-insurance for services, and co-pays for prescription drugs. Some patients completing the survey indicated that these high out-of-pocket costs have resulted in decisions to forego insurance coverage, tests, procedures, and treatments. In some instances, patients also reported delays in diagnostic tests and treatments because of cost containment measures. Finally, the majority of patients report not receiving social and emotional support as a part of their treatment plan, even when they request it.

Our findings indicate that people impacted by cancer need more access to comprehensive information about their overall care — including risks and benefits, price, outcomes, and other patient impact information. Our *Cancer Policy Institute* is working directly with policymakers and advocates to create a system of transparency so that all patients have access to high quality, comprehensive cancer care that includes social and emotional support.

Because of the more than 1,200 patients who took the time to complete our survey, we are able to summarize patient experiences related to key aspects of accessing care in cancer and track the progress that has been made since the implementation of ACA. We asked questions about access to insurance, access to services, access to providers, and the direct and indirect costs of care. We want to know from patients what is working well and what needs refinement, improvement, heightened awareness, or further research.

The Cancer Support Community would like to thank the patients, physicians, researchers, and funders who made this project possible. Also, thank you for your part now and in the future in ensuring that all people diagnosed with cancer have access to the comprehensive, quality cancer care they deserve.

All my best,

A handwritten signature in black ink that reads "K. Thiboldeaux". The signature is fluid and cursive.

Kim Thiboldeaux  
Chief Executive Officer

# Access to Care in Cancer— The Patient Experience

High-quality cancer care depends on the ability to secure, travel to and pay for needed diagnostics, treatments, and support services. Earlier this year, the Cancer Support Community gathered information on individual experiences accessing care in order to understand barriers to care and better advocate for and support patient needs. One thousand two hundred and eighteen people with cancer answered the call to share their experiences with access to insurance, services and providers, and the direct and indirect costs of care.

Lost in the ongoing debate surrounding health care is how Americans with cancer benefit from, and experience challenges with, a new and evolving health care system. This includes the impact on people covered through the Health Insurance Marketplaces, the unintended consequences of reform on those covered by Medicare, the short- and long-term effects of novel delivery of care models, and the impact of subsequent changes to employer-based plans.

This report builds on previous work of the Cancer Support Community to assess gaps in access, shifts in sites of care, changes to coverage, and the impact of these factors on out-of-pocket costs.

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 and their impact on access to care

Through this report, the *Cancer Policy Institute* aims to highlight patient issues, concerns, and barriers to obtaining cancer care and to communicate these findings to the broader cancer community, including health care providers, advocates, and policymakers, so that we can work together to advance the promise of patient-centered cancer care in America.

The Cancer Support Community (CSC) ensures that all people impacted by cancer are empowered by knowledge, strengthened by action and sustained by community. CSC thanks all the patients and families who help inform and shape CSC research and policy discussions.

# Key Findings

This report contains numerous findings regarding patient access to care in cancer.  
Key findings include:

TOPIC AREA

FINDINGS

Access to Health Insurance



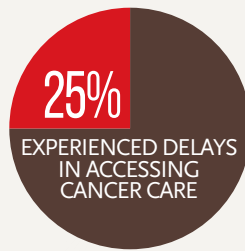
**77.7%** OF PEOPLE SURVEYED HAVE EMPLOYER-BASED COVERAGE OR MEDICARE

**AFFORDABILITY AND MEDICAID INELIGIBILITY** WERE CITED AS REASONS FOR **LACK OF COVERAGE**

PARTICIPANTS WITH **MARKETPLACE COVERAGE** HAD THE **POOREST UNDERSTANDING** OF THEIR INSURANCE **COVERAGE**

Access to Services

**A QUARTER OF RESPONDENTS DID NOT FEEL** CONFIDENT THAT THEY RECEIVED THE CARE THAT THEY NEEDED



**PEOPLE COVERED BY MEDICAID** EXPERIENCED THE **GREATEST CARE DELIVERY DELAYS**

53.3% OF RESPONDENTS REPORTED **NOT RECEIVING SOCIAL OR EMOTIONAL SUPPORT SERVICES**

Treatment Decision Making

**37.6% OF RESPONDENTS** REPORTED **WANTING MORE INVOLVEMENT** IN CARE AND TREATMENT DECISIONS

PEOPLE WITH COVERAGE THROUGH **MEDICAID OR THE MARKETPLACE** MORE FREQUENTLY REPORTED **NOT HAVING ENOUGH TIME** WITH PROVIDERS

**54%** OF RESPONDENTS HAD NEVER HEARD OF **CLINICAL PRACTICE GUIDELINES**

**73%** OF RESPONDENTS HAD NEVER HEARD OF **CLINICAL PATHWAYS**

Cost of Care

**42.6%** OF RESPONDENTS REPORTED THAT THEIR **OUT-OF-POCKET COSTS** HAVE BEEN **LARGER** THAN EXPECTED

**68%**

OF RESPONDENTS **DID NOT DISCUSS HEALTH CARE COSTS** PRIOR TO STARTING TREATMENT

**22% OF RESPONDENTS** REPORTED **SKIPPING RECOMMENDED TREATMENTS** TO MANAGE **OUT-OF-POCKET COSTS**

Cost Containment Strategies

MORE THAN **45%** OF RESPONDENTS WERE REQUIRED TO GET **PRIOR AUTHORIZATION** FOR A TREATMENT THAT WAS PRESCRIBED TO TREAT THEIR CANCER

**14%** OF RESPONDENTS EXPERIENCED **STEP THERAPY REQUIREMENTS**

UP TO **50%** OF RESPONDENTS EXPERIENCED **DELAYS** IN STARTING TREATMENT AND CHANGES TO TREATMENT DECISIONS DUE TO PRIOR AUTHORIZATION AND STEP THERAPY REQUIREMENTS

**28% OF MARKETPLACE ENROLLEES** EXPERIENCED **DIFFICULTIES FINDING AN IN-NETWORK SPECIALIST** IN THEIR AREA

# Overview of Findings

This report is based upon a cross-sectional survey of adults (18 years and older) with a history of a cancer diagnosis. The survey was conducted online between June and August of 2016. Participants were recruited through CSC's network including the *Cancer Experience Registry*®, Affiliate network, advocacy partners, and social and traditional media outlets. Descriptive statistics and statistical analyses were performed using SPSS Version 24; analyses of association used a significance level of .05.

## PARTICIPANTS

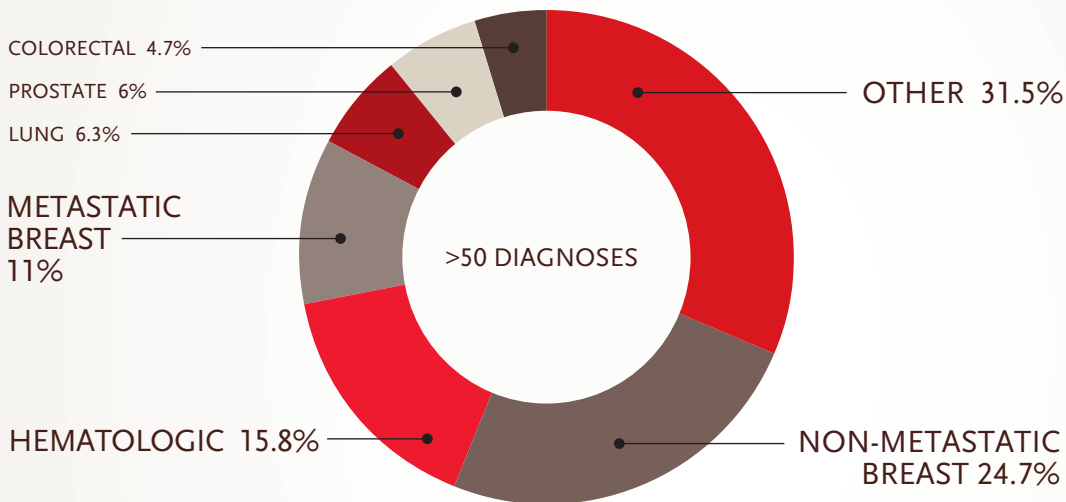
While 1,218 individuals took the survey, this analysis is based on the 1,046 respondents who reported living in the United States and receiving a cancer diagnosis. Sample item responses are 1,046 unless otherwise noted, as not all patients answered every question. Respondents were predominantly non-Hispanic, white, and female. The majority were between the ages of 45 and 64 years old (54.9%) and 38% were working full-time or part-time. While the lack of racial and ethnic diversity is a limitation of the analysis, these findings may, in fact, underrepresent access to care issues, as prior research has shown that African Americans and Hispanics are more likely to experience barriers to obtaining health care (National Healthcare Quality and Disparities Report, 2014).

CHARACTERISTICS	PERCENTAGE
<b>AGE (n=982)</b>	
18-44	8.8%
45-64	54.9%
65 AND OLDER	36.3%
<b>GENDER (n=982)</b>	
FEMALE	78.6%
MALE	21.4%
<b>RACE (n=976)</b>	
WHITE OR CAUCASIAN	86.5%
BLACK OR AFRICAN AMERICAN	6.4%
ASIAN OR PACIFIC ISLANDER	2.3%
MINORITY OR MULTIRACIAL	1.5%
AMERICAN INDIAN OR ALASKAN NATIVE	1%
PREFER NOT TO SHARE	2.3%
<b>ETHNICITY (n=859)</b>	
HISPANIC OR LATINO	6.4%
NOT HISPANIC OR LATINO	84.4%
PREFER NOT TO SHARE	9.2%
<b>EDUCATION (n=980)</b>	
ASSOCIATE DEGREE OR LOWER	36.3%
BACHELOR'S DEGREE OR HIGHER	63.7%
<b>EMPLOYMENT (n=982)</b>	
RETIRED	35.1%
NOT EMPLOYED, DISABILITY OR OTHER	26.9%
EMPLOYED FULL-TIME	26.4%
EMPLOYED PART-TIME	11.6%

The survey delivered responses from people with more than 50 different cancer types. Breast cancer was the most common single cancer diagnosis reported, with 11% reporting a metastatic breast cancer (MBC) diagnosis, and 24.7% reporting a non-metastatic breast cancer (non-MBC) diagnosis. Other frequently reported diagnoses included hematologic cancers (15.8%), lung (6.3%), prostate (6.0%), and colorectal cancers (4.7%). Diagnoses with the greatest prevalence within the “other” category included ovarian cancer (3.4%), skin cancer (3.2%), and brain and central nervous system cancers (2%).\*

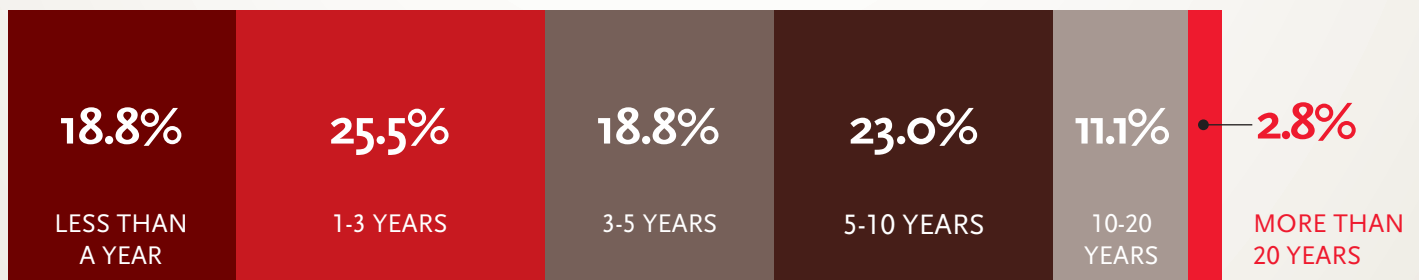
## Participants' Cancer Diagnoses

(n=1,046)



At the time of survey completion, over 70% of respondents were currently in treatment or receiving follow-up care, with 63.1% receiving a diagnosis within the last five years. Of those not currently in treatment (n=262), 67% were in remission, and 17.2% were in active surveillance for their disease. Among those in remission, 85.5% reported attending follow-up visits.

## Time Since Diagnosis



\* Diversity of reported cancer diagnoses is a direct result of CSC's outreach efforts through the *Cancer Experience Registry*® to better understand treatment access issues across cancer diagnoses.



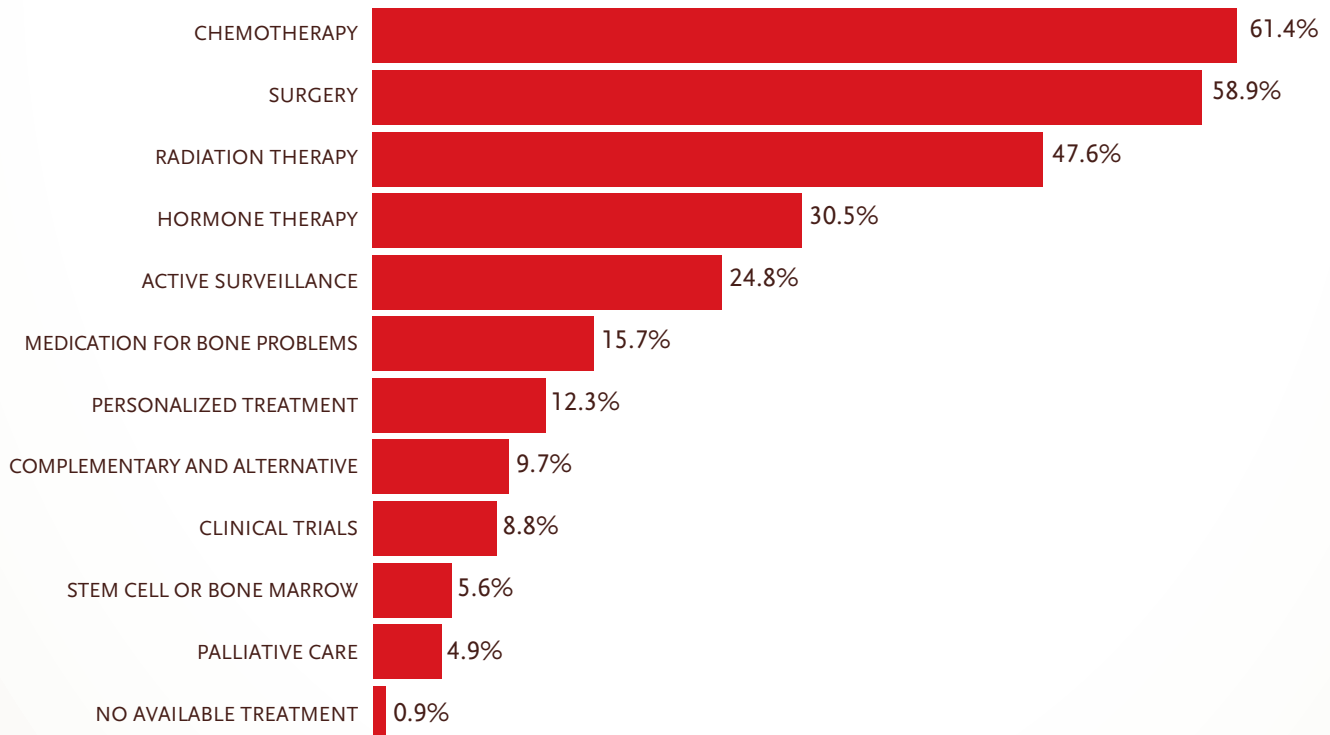


Participants were asked about the type of treatment they had received. Across all participants in the survey, chemotherapy\* (61.4%), surgery (58.9%), and radiation therapy (47.6%) were the most frequently reported treatment types. When looking at treatment by cancer diagnosis:

- Chemotherapy was most commonly reported by respondents diagnosed with:
  - colorectal cancer (83.3%);
  - metastatic breast cancer (71.4%); and,
  - lung cancer (70%).
- Surgery was reported by those diagnosed with:
  - non-metastatic breast cancer (84.8%);
  - colorectal cancer (79.2%); and,
  - metastatic breast cancer (63.5%).
- Radiation therapy was reported by those diagnosed with:
  - metastatic breast cancer (63.5%);
  - non-metastatic breast cancer (61.8%); and,
  - lung cancer (5.3%).
- Hormone therapy was reported by those diagnosed with:
  - metastatic breast cancer (65.1%); and,
  - non-metastatic breast cancer (63.6%).

## Participants' Cancer Treatment Types

(Multiple responses allowed, n=953)



\* For the purpose of this study, “chemotherapy” includes all non-hormone drug therapy, including immunotherapy.

# Health Insurance Coverage

## ACCESS TO HEALTH INSURANCE

The passage of the Affordable Care Act (ACA) gave millions of Americans access to health insurance coverage through the opening of the Health Insurance Exchange Marketplace and the expansion of Medicaid eligibility. Especially important to people with cancer, the ACA eliminated annual and lifetime caps and limits on pre-existing conditions. These changes help protect patients living with chronic illnesses, which require long-term treatment and follow-up care.

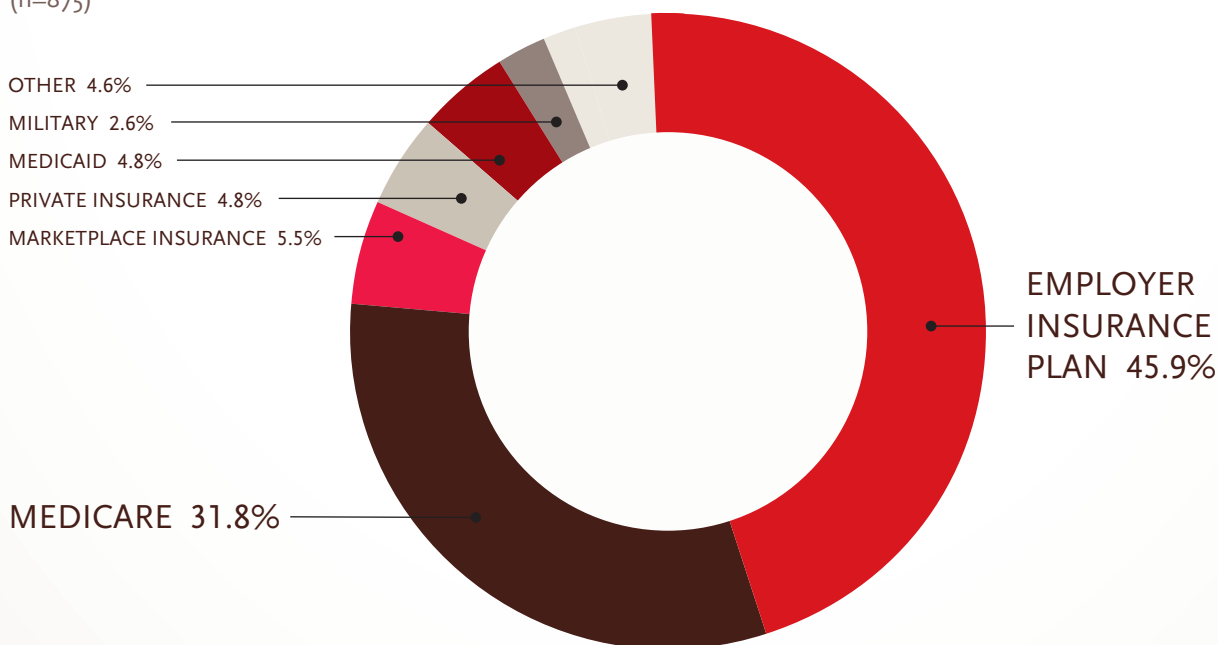
Eliminating coverage decisions based on pre-existing conditions means that anyone can obtain coverage regardless of health status. This is especially important to people with cancer who are no longer limited to their current insurance plan and can change plans without worrying about denial of coverage based on their cancer diagnosis. The benefit also helps people considering career changes or needing spousal coverage.

While Medicaid expansion was intended to provide health coverage to millions more adults nationally, there are 19 states that did not expand their programs, leading to a coverage gap for 3 million low-income Americans (Kaiser Family Foundation, 2016). Outside of the coverage gap, Americans have more health insurance coverage options than ever before, but as insurers consolidate and some begin to leave the Marketplace, access to coverage again becomes a pressing issue.

At the time of the survey, most respondents had employer-sponsored (45.9%) or Medicare (31.8%) coverage. Fifteen people in the sample reported not having health insurance coverage, primarily due to lack of affordability or ineligibility for Medicaid or employer-sponsored coverage.

## Types of Health Insurance Coverage

(n=875)

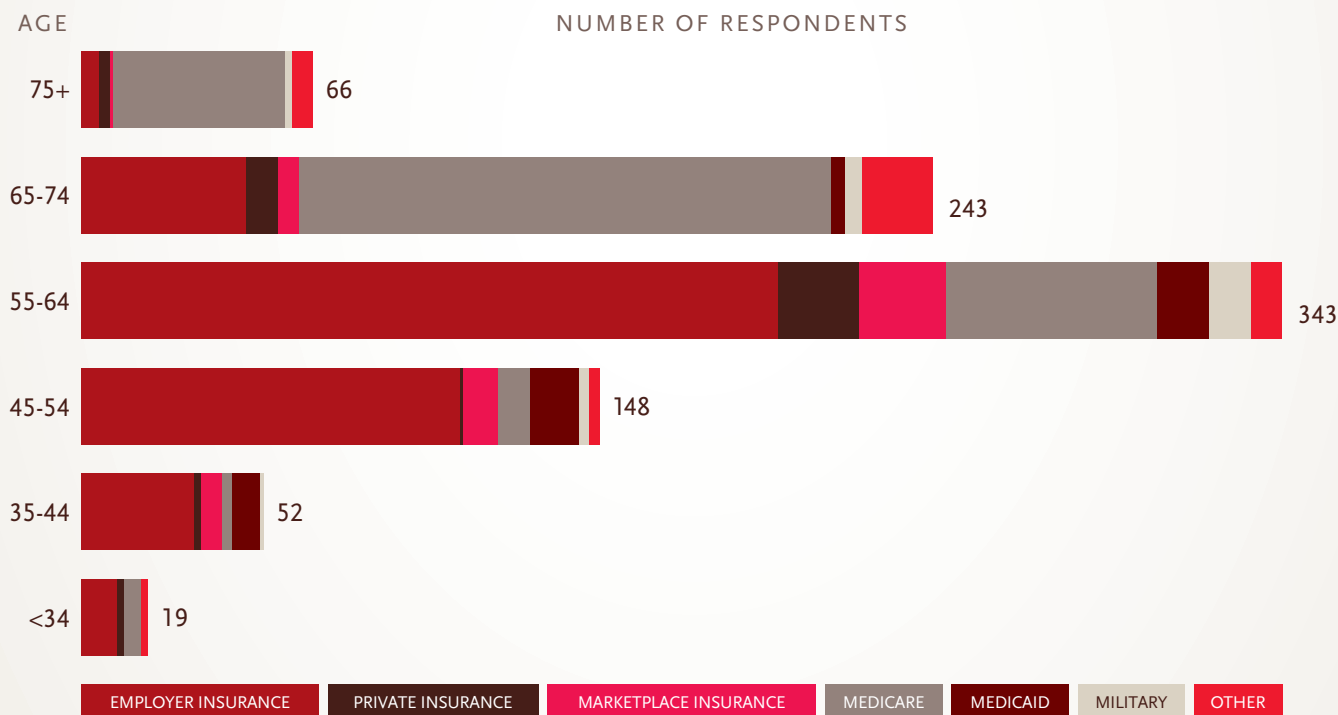


The majority (62%) of participants under age 65 reported having employer-sponsored health insurance. In comparison, 17% of participants 65 years and older indicated that they were covered by employer-based health insurance, while 65% were covered by Medicare. Among respondents ages 35-44, 15.4% had Medicaid coverage, and 11.5% had Marketplace coverage.

Two-thirds of Medicare recipients (67%) reported having traditional Medicare and 27% were covered by Medicare Advantage. Also among Medicare recipients, 87% reported having a Medicare supplement plan to help pay for Medicare deductibles and coinsurance amounts, whereas 13% had Medicaid in addition to Medicare coverage to help pay for high or long-term care expenses. The share of the population with Medicare coverage is expected to increase in the next 14 years as the youngest baby boomers, the largest part of the cohort, age into Medicare.

A quarter (27.7%) of those reporting Medicare as their primary health care coverage were under 65 years old, the traditional Medicare eligibility age. Individuals under age 65 can qualify for Medicare coverage based on disability status. Overall, 42% of survey respondents with Medicare coverage reported inability to work due to disability.

## Primary Source of Health Care Coverage by Age



### THE UNINSURED

In order to improve access to health insurance coverage, and consequently health care, it is important to understand more about the survey respondents who reported not having health insurance coverage at some point in the last 12 months (n=15). They gave four reasons for their lack of health insurance coverage including: cannot afford health insurance (43%); not eligible for Medicaid (31%); not eligible for employer-sponsored insurance (25%); and employer does not pay for insurance (18%).

When asked how they paid for medical care, the largest portion of uninsured respondents (27.7%) indicated they received care through free or government clinics or health care facilities, or that they paid out-of-pocket (27.7%). The remainder reported that they did not receive care because they could not afford it (22.2%), or they did not receive care due to lack of health insurance (11.1%).

More than half (53%) of the uninsured people surveyed faced problems with medical bills. Those who reported difficulty with medical bills indicated putting off or skipping health care in the past year due to cost constraints. For example, 43% said that they skipped doctor-recommended tests or treatments or failed to fill prescriptions because of the high cost.

This parallels findings from the CSC’s *Cancer Experience Registry*® indicating that high levels of financial distress can significantly affect treatment adherence among people with chronic myeloid leukemia (Buzaglo et al., 2014). Lack of treatment adherence might ultimately influence overall health outcomes and cost of care to the health system. These findings suggest that additional resources are needed to ensure that no cancer patient goes without care due to lack of insurance or affordability.

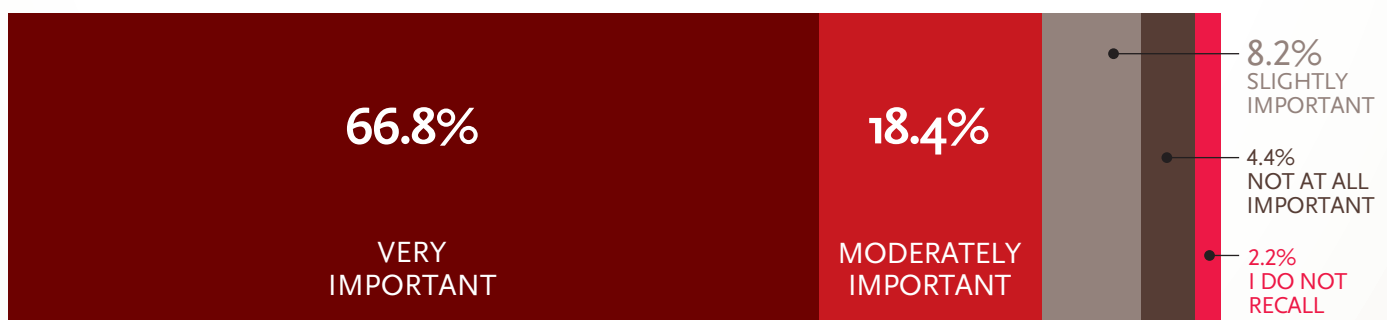
### SELECTION AND UNDERSTANDING OF HEALTH INSURANCE COVERAGE

According to the survey results, overall cost\* remains the single most important factor in choosing a health insurance plan. Approximately 85% of survey participants reported that cost was very or moderately important in their decision. This is consistent with a study completed by the U.S. Department of Health and Human Services, which found that enrollees in Marketplace exchange plans are price sensitive (HHS ASPE Issue Brief, 2016). The majority of survey participants indicated that they tried to anticipate the medical services they would need when choosing a health insurance plan (75.6%). In general, health insurance plans with higher deductibles, which require individuals to assume responsibility for a greater amount of initial health care costs, have lower monthly premiums. Plans with higher deductibles also tend to have higher out-of-pocket costs and narrow networks for specialty care; additional costs may accrue when patients are forced to seek out-of-network care. For people living with cancer, understanding health insurance plan structures and coverage is a critical part of being engaged in their health care decisions.

Approximately 85% of respondents reported that cost was a “very” or “moderately” important factor in choosing a health insurance plan.

## Importance of Cost in Selecting Health Insurance Coverage

(n=549)



\* Overall cost includes premiums, deductibles, coinsurance and copayments for covered services plus all costs for services that are not covered.



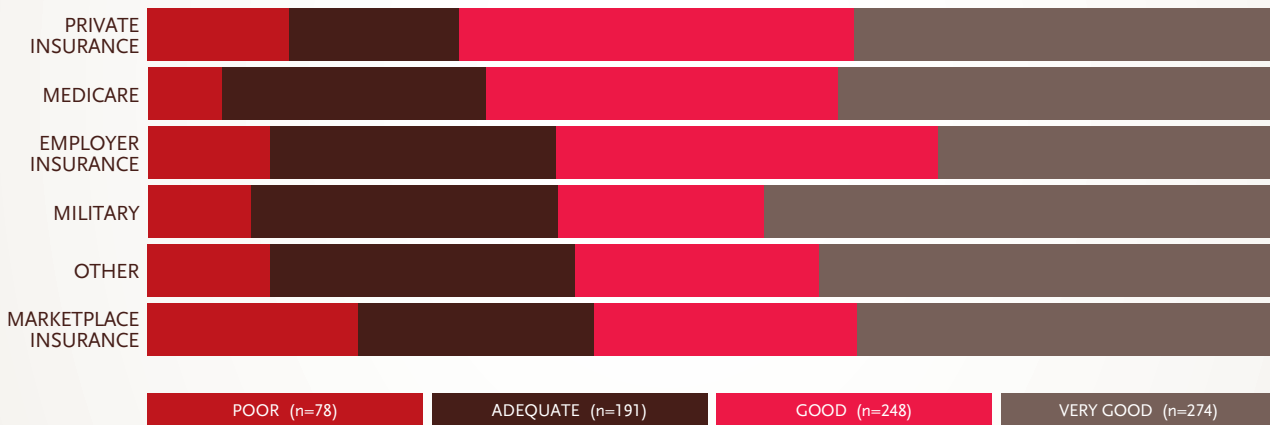
Ten percent of respondents reported poor understanding of their health insurance. People with less understanding of their insurance more frequently reported not being able to receive the care they felt they needed. This finding points to the need to provide more education and support around health insurance to people with cancer so that they can better understand and advocate for their care.

Life with cancer can encompass a myriad of tests, appointments, and medications, both in-hospital and through outpatient care services. As expenses accrue, it can become increasingly difficult for patients and families to understand their financial obligations. Survey respondents covered by Marketplace coverage were more likely to have a poor understanding of their health insurance coverage (17.4%) compared to those covered by Medicare (6.4%) or Military (9.1%) coverage.

In the sample, the level of understanding of health insurance coverage increased with age. Nearly 60% of participants in the “55-64” and “65 or older” age groups reported having “good” or “very good” understanding of their health insurance coverage compared to 27% of those in the “45-54” age group, and 19% of those in the “35-44” age group.

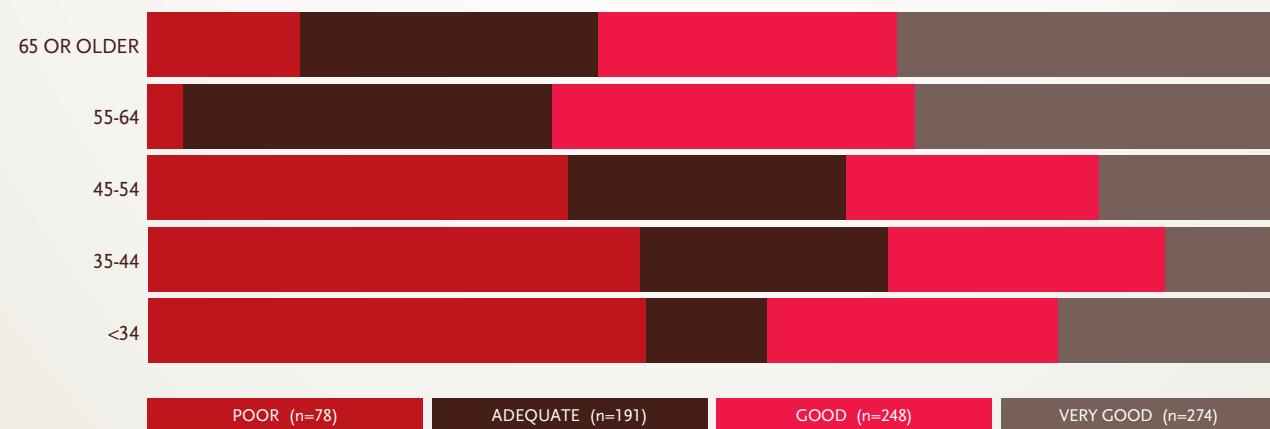
## Understanding of Services Covered by Insurance Coverage Type

(n=791)



## Understanding of Services Covered by Age

(n=791)



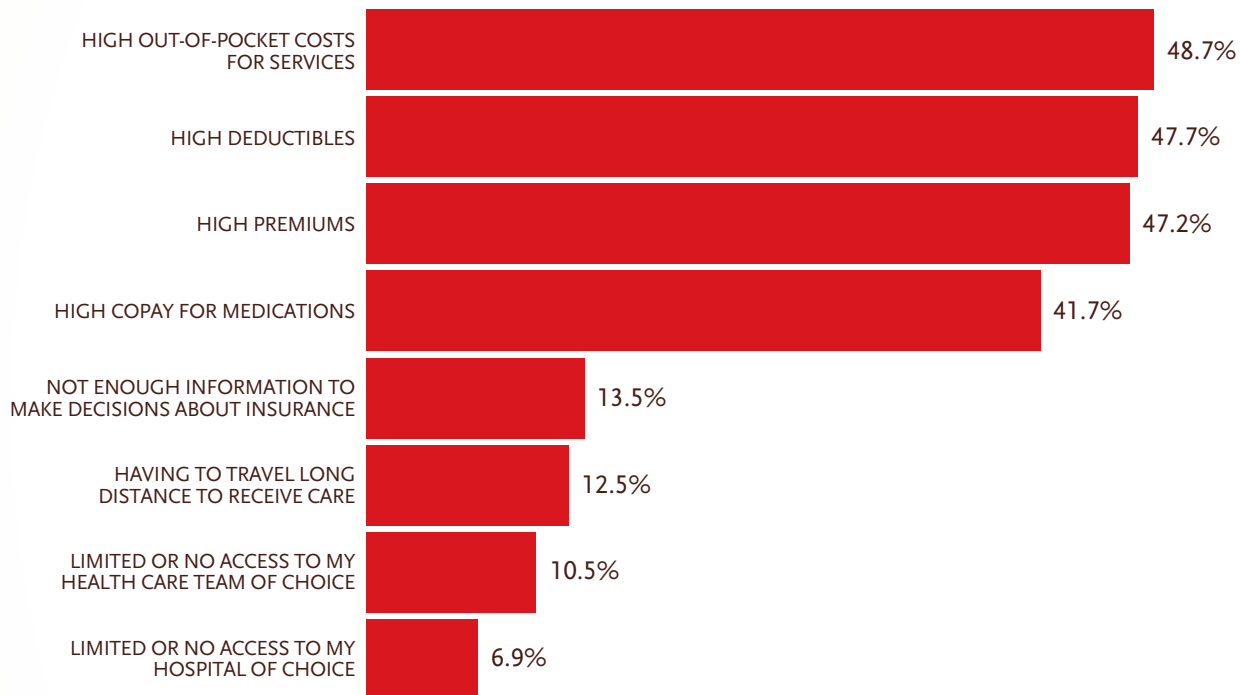
### TOP CONCERNS ABOUT HEALTH INSURANCE

When asked about their top concerns related to health insurance, survey respondents cited factors associated mainly with cost. Most participants experienced concerns with high out-of-pocket costs for services (48.7%), high deductibles (47.7%), high premiums (47.2%), and high copay costs for medications (41.7%). People with Marketplace or employer-sponsored coverage were more concerned with high deductibles and other cost issues than individuals with Medicare or Military coverage.

The top concerns about health insurance for survey respondents involve the costs associated with insurance.

## Top Concerns About Health Insurance

(Multiple responses allowed, n=750)



Other concerns about health insurance identified by survey respondents were directly related to knowledge of and proximity to care, including not having enough information to make a decision about insurance (13.5%), having to travel long distances to receive care (12.5%), and having limited or no access to their health care team (10.5%) or hospital (6.9%) of choice.

Individuals with Marketplace, Medicare or Military coverage identified limited access to hospital of choice and having to travel long distances to receive care more frequently than those with employer-sponsored or private coverage.

## Access to Services

The benefits of cancer care coordination are well documented. People with cancer need comprehensive care, including resources to inform and support decisions related to diagnostics and treatment, managing side effects and physical concerns, navigating financial and insurance questions, and helping with psychosocial issues. Yet, even among people in this sample who report having good access to health care, barriers to true comprehensive care persist.

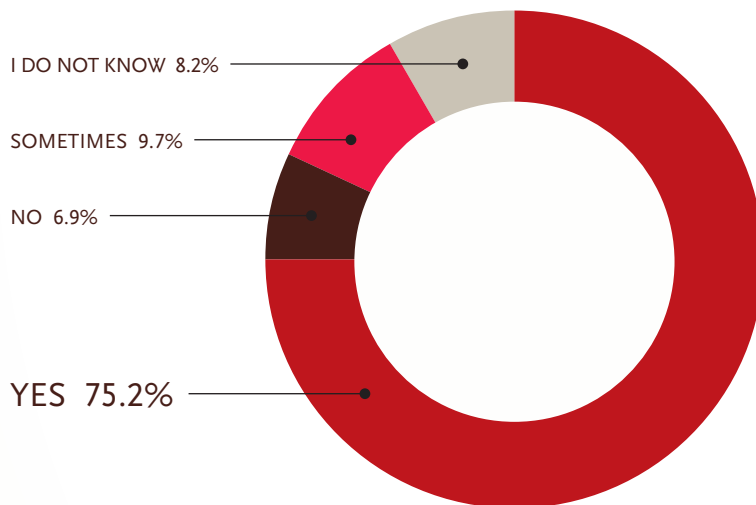
### ACCESS TO CARE (MEDICAL AND PSYCHOSOCIAL)

While most of those surveyed felt that they were able to receive the care that they needed (75.2%), an alarming number felt they did not (6.9%), sometimes felt they did (9.7%), or did not know (8.2%) if they received the care they needed. Altogether, a quarter of those surveyed did not feel confident that they received the care that they needed. These results highlight a growing need for interventions aimed at ensuring that patients are informed and empowered to be more active participants in their health care.

Altogether, a quarter of those surveyed did not feel confident that they received the care that they needed.

### Are you able to get the care that you need?

(n=951)



Among respondents with insurance, those with Marketplace coverage more frequently indicated that they did not get the care they needed (20.8%). Participants with Medicaid coverage were more likely to respond “sometimes” (21.4%) or “I do not know” (21.4%) when asked if they got the care they needed.

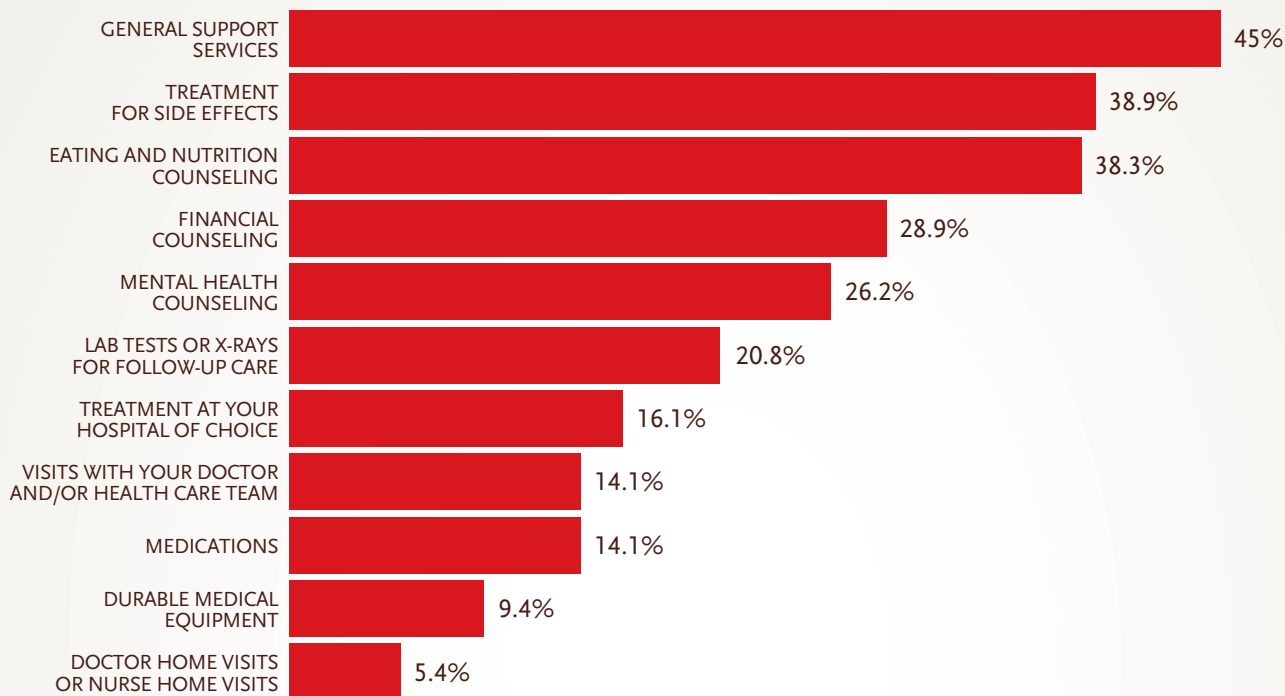
Among those who felt they did not get the care they needed, the top services they did not receive were general support services (45%), treatment for side effects (38.9%), eating and nutrition counseling (38.3%), financial counseling (28.9%), and mental health counseling (26.2%). Respondents with employer-sponsored coverage and Medicare coverage were most likely to report not receiving treatment for side effects (45.3% and 40.6% respectively) and eating and nutrition counseling (39.1% and 37.5% respectively).

While it is evident that increasing the availability of health coverage is an important step towards improving access to care, gaps in services remain. These findings highlight the need for systemic change that includes comprehensive, high-quality care throughout the cancer continuum.



## What are the services you feel you need, but you are not able to receive?

(Multiple responses allowed, n=149)



Based on time since diagnosis, respondents who received a cancer diagnosis within the past year identified treatment for side effects and eating and nutrition counseling (both 40.6%) as services needed and not received. Survey respondents who are a moderate time beyond diagnosis (3-5 years) cited financial support as an unmet need, underscoring the lasting financial impact of a diagnosis of cancer. Those individuals 5-10 years beyond their cancer diagnosis identified general support services and treatment for long-term side effects as unmet needs.

Across all health insurance types, survey respondents identified availability, coverage, and high cost of services as the top reasons services were not received. However, Medicare recipients were more likely to report that services were not offered (53.1%), or they did not know they were available (34.4%), while people with Marketplace coverage indicated they could not receive some services because they were not covered by their health insurance (61.5%) or could not afford the high cost (38.5%). The differences in the reasons that services were not received underscore the manner in which patients navigate the health care system. Medicare-covered patients may need additional education on the services available to them, whereas Marketplace-covered patients would benefit from financial counseling and guidance.

### ACCESS TO ADDITIONAL CARE/SERVICES

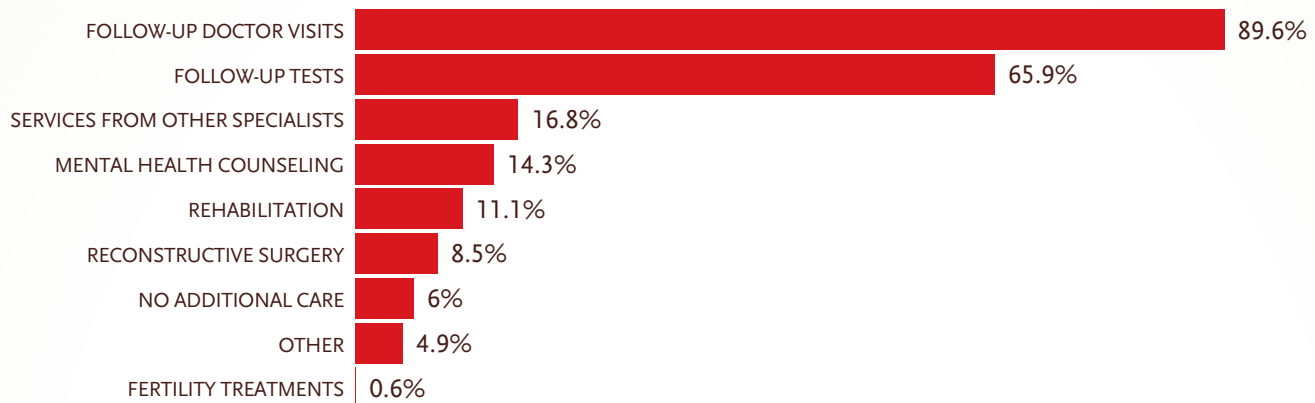
Respondents were asked to identify additional care that they received beyond primary treatment. A high percentage of respondents (89.6%) reported receiving follow-up visits with their doctors; 65.9% reported receiving follow-up tests, while only 14.3% indicated receiving mental health counseling. For those who indicated “other” many reported receiving lymphedema treatment, acupuncture, yoga, nutrition counseling, and palliative care.

Across all health insurance types, availability, coverage, and high cost of services were identified as the top reasons services were not received.



## Additional Care and Services Received

(Multiple responses allowed, n=939)



### ACCESS TO SOCIAL/EMOTIONAL SUPPORT

The Institute of Medicine (IOM), National Comprehensive Cancer Network, and American College of Surgeons all recognize that screening for psychosocial distress is an integral part of providing comprehensive care to people with cancer (IOM Report, 2013). Additionally, research conducted by CSC has found that newly diagnosed patients experience distress across a wide range of concerns, and a third of patients more than a year from diagnosis continue to experience concerns across a range of issues including worrying about the future, feeling lonely/isolated, and financial concerns (Buzaglo et al., 2016).

The need for social and emotional support services, a core function of the Cancer Support Community, is well documented and thus was a priority area for this survey. Participants were asked if they received social or emotional support as a part of their cancer care. More than half (53.3%) indicated that they had not. Only 36.5% of those surveyed received social and emotional support as part of their cancer care.

For the remaining respondents who answered “other,” many noted that they received services but only after a protracted wait time. Others reported taking the initiative to seek out support resources upon not receiving referrals or recommendations from their providers. Still others indicated that they assembled social and emotional support from friends, family, and faith organizations.

These findings indicate that there is more work to be done to ensure that people with cancer have better access to social and emotional support. Notably, providers need the referral resources to offer community-based support, such as the Cancer Support Community, so that they can seamlessly integrate referrals into treatment and survivorship care plans.

More than half of respondents reported not receiving social and/or emotional support as a part of their cancer care. Nearly 70% of those reported that they would have liked to have received such services.

## Receipt of Social and/or Emotional Support Services

(n=940)



When looking at this issue by insurance type, people with Marketplace coverage were more likely to report receiving social and emotional support (50.3%) compared to people with Medicare (44.2%) and those with Medicaid coverage, who were the least likely to have received social and emotional support services (28.6%). This underscores the need to identify those at highest risk, address their social and emotional concerns, and provide access to financial assistance if needed.

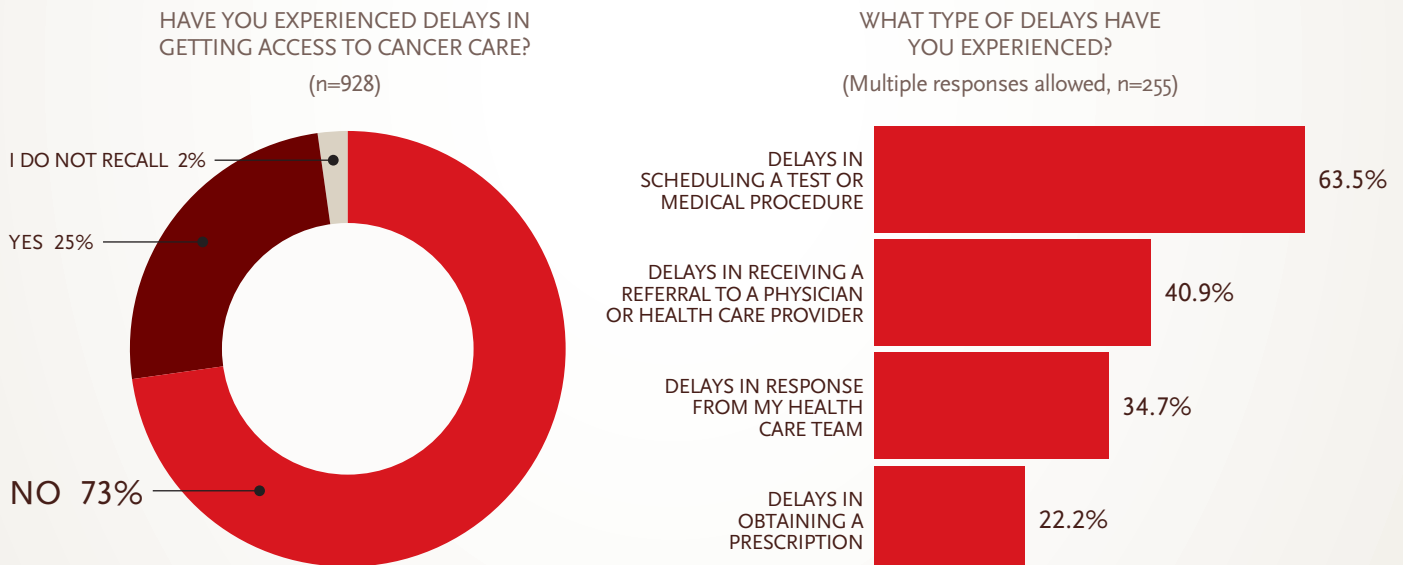
In this survey, receipt of social and emotional support services was inversely related to age, with 25-34 year olds reporting the highest (42.1%), and respondents 65 and older reporting lowest (31.5%) receipt of such services. While age discrepancies exist, fewer than 50% of participants in all age groups reported receiving social and emotional support services. Among those who did not receive social and emotional support services, 67.5% reported they would have liked to receive such services.

### DELAYS GETTING ACCESS TO CANCER CARE

When survey participants were asked about delays experienced accessing cancer care, 25% reported experiencing delays. 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%).

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.

## Delays in Care



People with Medicaid coverage were more likely to experience delays in gaining access to cancer care (38.1%), compared to Medicare-covered respondents (19.1%). Younger respondents were more likely to experience delays in getting access to cancer care with 39% experiencing delays compared to older patients of whom only 16.6% experienced delays in gaining access to cancer care. Among individuals reporting delays in receiving care, those with employer-sponsored coverage reported the greatest delays in scheduling a test or medical procedure (65.7%), and receiving a referral (42.9%). Medicare enrollees experienced delays in scheduling tests and procedures at a high frequency as well (56.9%).



# Treatment Decision Making

Following the full rollout of the ACA, providers, payers, and patients have had to learn to manage the changes that accompany health care reform. Expansion of health care services to millions more Americans has forced payers to find ways to manage their budgets differently. While cost containment strategies, such as pre-existing conditions and annual and lifetime caps on reimbursement are a thing of the past, alternative cost containment strategies have arisen or have been expanded, sometimes delaying or limiting treatment options for people with cancer.

As many people now live longer after treatment and some cancers are considered chronic conditions, short- and long-term quality of life and treatment side effects must garner greater attention in treatment decision making. Shared decision making between patients and providers is necessary to improve outcomes and better manage cancer as a chronic illness. Empowering people with cancer to participate more fully in treatment decisions is a critical step in helping manage the cost and access issues identified in this survey.

In the study, 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. Research indicates that active participation in health care decisions may lead to greater treatment adherence and better health outcomes in people with cancer (Sandman et al., 2012). One-third of respondents reported not having any choice in the type of treatment they were given. This underscores the need for continued efforts to promote shared decision making models within the cancer provider community.

Based on time since diagnosis, people who were most recently given a diagnosis of cancer reported the least amount of choice in cancer treatment options (39.3%), with almost a quarter (23.4%) indicating that they would have liked a choice. In contrast, people 5-10 years and 10+ years from diagnosis reported that they were given a choice of treatments at the time of diagnosis at 58.6% and 54.1% respectively.

A number of those surveyed (15.7%) indicated that they were not as involved in their treatment decision as they would have expected. A small yet significant number indicated that they were involved as much as they would have expected but were overwhelmed by the number of choices, which led to difficulty making a decision (4.8%). This underscores the importance of presenting information about treatment options in a way that is easily understandable to patients.

People recently diagnosed (<1 year; n=169) were more likely to report that they were not as involved in treatment decisions as they would have expected (21.8%). Those diagnosed within the last five years were less likely to report involvement but with greater associated difficulty in making a decision than people diagnosed more than five years ago. In short, individuals diagnosed more recently felt as though they were less involved in decision making than they expected yet also felt overwhelmed by the number of decisions.

More than a third (37.6%) of respondents indicated that they would have liked to have been more involved in decisions about their care and treatment options. This speaks to a clear need for enhanced engagement between patient and provider so that patients feel more involved in treatment decisions.

Notably, 16.3% of respondents felt like they did not have enough time with their doctor during their appointments. People with Medicaid (23.8%) or Marketplace (20.8%) coverage were more likely to feel like they did not have enough time with their doctors than those

More than a third of respondents indicated that they would have liked to have been more involved in decisions about their care and treatment options.

with Medicare (4.3%) or employer-sponsored (16.7%) coverage. There is an inverse relationship between time from diagnosis and patients feeling they did not have enough time with doctors during appointments. People who were within three years of diagnosis indicated that they did not have enough time with their doctors (19.2%). While those who were more than three years from diagnosis were less likely to report feeling they did not have enough time with their doctors at appointments (13.9%).

### CLINICAL GUIDELINES AND CLINICAL PATHWAYS

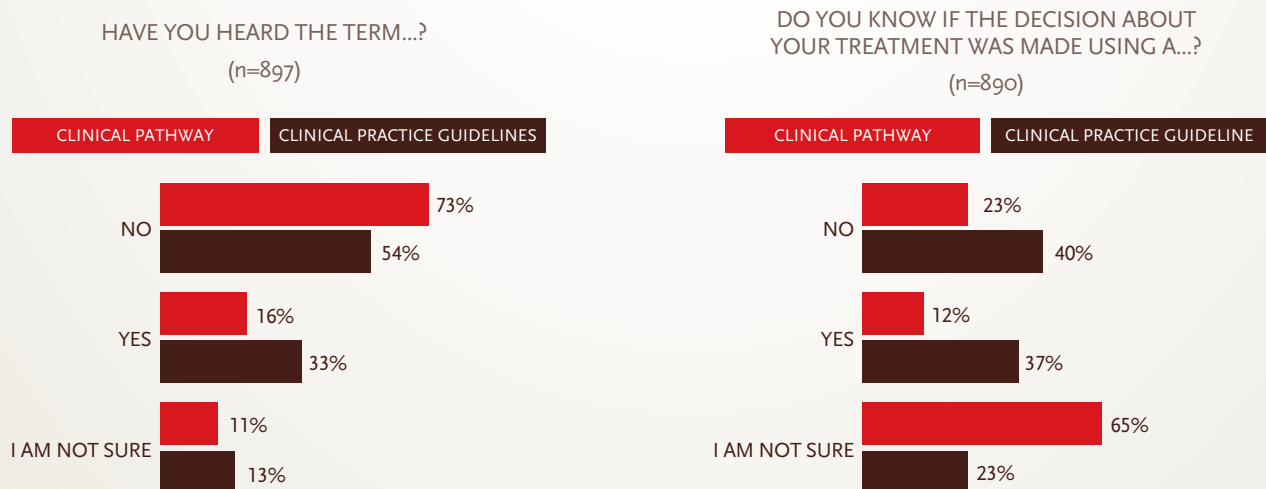
Oncology clinical practice guidelines are tools developed through the integration of clinical trials data and real-world evidence, as well as physician expertise. Clinicians use guidelines to help chart the treatment course. In oncology, two of the leading organizations that develop clinical guidelines are the National Comprehensive Cancer Network (NCCN) and the American Society of Clinical Oncology (ASCO). Other organizations such as the U.S. Preventive Services Task Force (USPSTF) develop screening and prevention guidelines for activities such as screening mammograms for breast cancer and PSA testing for prostate cancer.

Approximately 900 people answered survey questions related to clinical practice guidelines and clinical pathways. Over half (54%) of survey respondents reported not knowing the meaning of the term “clinical practice guidelines.” At the same time, respondents had little (23%) to no awareness (40%) of whether their treatment decision was based on a clinical practice guideline.

Similarly, the majority of respondents (73%) had never heard of clinical pathways, with 88% reporting uncertainty about whether the decision regarding their treatment was based on a clinical pathway. Those with private insurance (14.6%) were more likely to know if their treatment decision was made as a part of a clinical pathway compared to those covered by Medicare (10.5%) or Marketplace insurance (10.4%).

Clinical pathways are standardized treatment protocols developed by payers. They seek to reduce variance in care, and in turn reduce the cost of care. As value-based reimbursement models become more common, clinical pathways have found favor among payers as a way to reduce care variation and eliminate waste. While value is an important consideration, it should not be prioritized at the expense of evidence-based and/or personalized cancer care. Transparency in the development of clinical pathways, in concert with the use of clinical practice guidelines, is recommended to ensure that evidence-based treatment is available to the millions of individuals whose treatment follows a clinical pathway.

## Awareness of Clinical Guidelines and Clinical Pathways



# Cost of Care

The impact of financial difficulties on patients with cancer are becoming well recognized. Patients report financial distress as more severe than other sources of distress associated with physical, social, and emotional functioning (Delgado-Guay et al., 2015). Findings from a research study on the impact of health care costs on well-being and treatment among cancer patients, suggest that insured patients undergoing cancer treatment experience substantial financial burden, and that health insurance coverage does not eliminate financial distress among cancer patients (Zafar et al., 2013).

Results of this study indicate that cost of care is a major concern for people facing cancer with a wide range of impact on treatment and lives.

## OUT-OF-POCKET COSTS

People surveyed reported that, within the last 12 months, their out-of-pocket (OOP) costs were larger than expected (42.6%). Respondents with employer-sponsored coverage were the most likely of all insurance types to report larger than expected OOP costs (49.9%), whereas Medicare-covered individuals were the least likely to report larger than expected OOP costs (32.5%) but most likely to report that their OOP costs were about what they expected (43.9%). When asked about the source of OOP expenses, respondents most frequently named oral medications (44.3%) and injections or shots (49.4%).

## DISCUSSION ABOUT COST OF TREATMENT

The increasing cost of cancer care in the U.S., coupled with added financial responsibility shifting to patients, demands patients and providers consider cost as a part of the treatment discussion. Yet, a startling 78% of survey participants either have not had a discussion or do not recall discussing health care costs with their doctors prior to receiving treatment.

This is not altogether surprising given research showing that doctors are not prepared to discuss or comfortable discussing cost of care with their patients (Schrag et al., 2007). Doctors are being tasked with controlling costs through bundled reimbursement and cost containment strategies. In addition to clinical expertise, doctors are now expected to be knowledgeable in the wide variety of health care coverage plans and copays across the health care insurance market. Additional resources are needed to help prepare physicians and patients to have productive conversations about the cost of care.

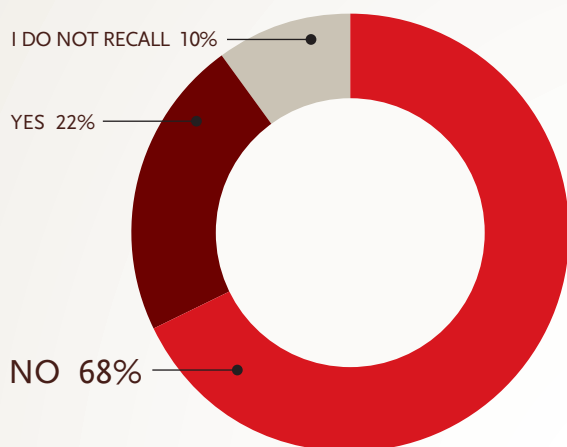
78% of survey participants either have not had a discussion or don't recall discussing health care costs with their doctors prior to receiving treatment.



## Discussion of Health Care Costs

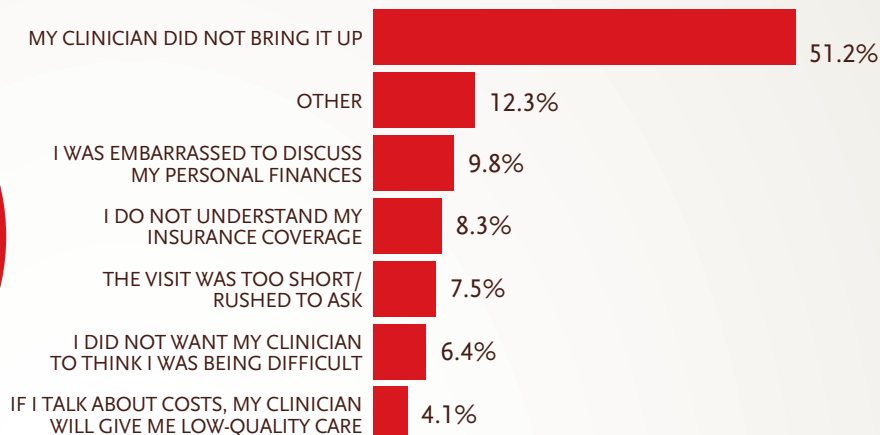
DID YOU EVER DISCUSS WITH YOUR DOCTOR HOW MUCH YOU WOULD HAVE TO PAY FOR YOUR HEALTH CARE SERVICES BEFORE YOU RECEIVED THEM?

(n=922)



WHY DID YOU NOT DISCUSS HOW MUCH YOU WOULD HAVE TO PAY FOR YOUR HEALTH CARE SERVICES WITH YOUR CLINICIAN?

(Multiple responses allowed, n=622)



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%).

Of the 22% of respondents who discussed the cost of treatment, 68.1% of them reported having a family member or caregiver as a part of the discussion. Caregivers not only provide physical and emotional support; they play an important role in the treatment decision making process, especially for newly diagnosed patients, who are asked to make decisions while still processing the news of their diagnosis. Caregivers participate in conversations with health care providers, keep track of paperwork, fill out insurance forms, and help ask and record the answers to questions.

The overwhelming majority of respondents who discussed cost with their doctor reported not using a guide or a decision tool during discussions (77.5%). Those who used a decision tool cited a conversation guide (4.5%), decision aid (2%), or an online tool designed to help calculate OOP costs (2%). Decision tools can provide doctors with the opportunity to structure a conversation with patients around cost issues in a way that is less embarrassing or uncomfortable for patients. Decision tools can also help physicians better understand the cost issues faced by patients.

### IMPACT OF COSTS ON TREATMENT DECISIONS

Health care reform has changed the way treatment decisions are made and how treatment for cancer is paid for. As the cost of medical care increases, and more of the expense is borne by patients, many people with cancer struggle to figure out how to pay for their care, sometimes foregoing recommended care altogether.

Survey respondents reported a number of reasons for not receiving recommended medical care. The primary reasons were\*:

- Insurance company would not pay for it (90.3%);
- Doctor did not accept my insurance (72.2%); and,
- Could not afford the care (71.7%).

Commonly reported secondary reasons for not getting recommended medical care included:

- Could not get time off work (71.4%);
- Could not get child/adult care (50%); and,
- Have scheduled, but the appointment is still months away (47.3%).

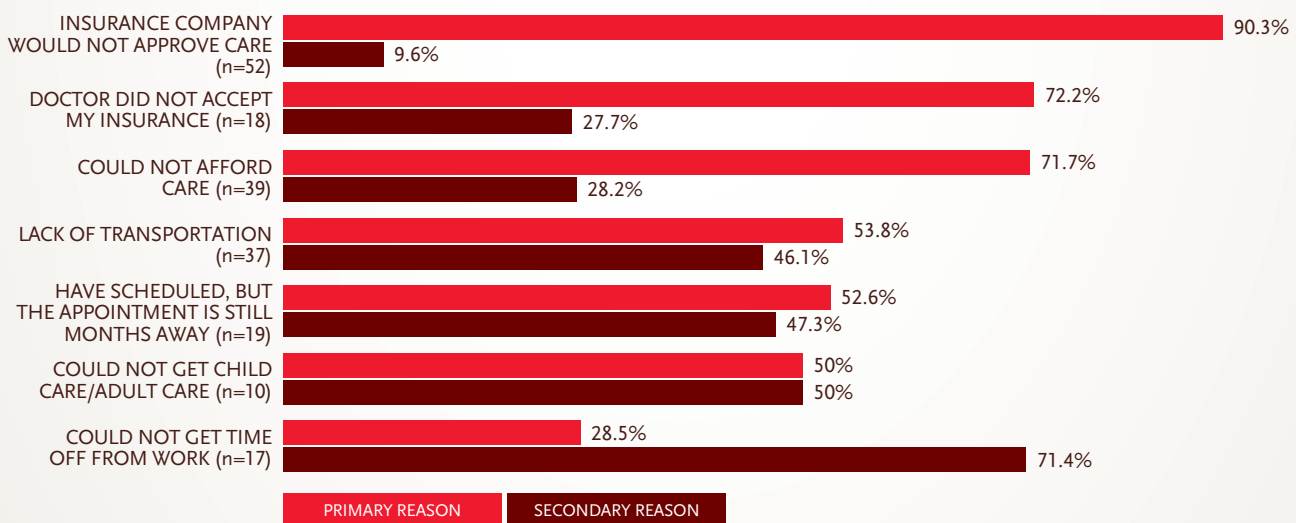
A number of those surveyed said that they were forced to manage costs and services based on steep OOP costs. Almost 22% of respondents chose not to get a recommended health service because of high OOP costs. Services skipped due to high OOP costs included genetic testing, fertility treatments, lymphedema garments, and physical therapy.

Almost 22% of respondents chose not to get recommended health care services because of high OOP costs.

## Reasons for Not Getting Recommended Care

WHICH OF THESE ARE REASONS THAT YOU DID NOT GET ALL OF THE MEDICAL CARE, TESTS, OR TREATMENTS YOU OR A DOCTOR BELIEVED YOU NEEDED?

(Multiple responses allowed, n=62)



Alarming, almost one-fifth (17.8%) of respondents reported not filling prescribed medications due to cost. Almost a quarter of those with private insurance, Marketplace or Medicaid coverage indicated that cost was a factor in the decision to fill prescriptions, whereas respondents with employer-sponsored, Medicare or military coverage were less likely to report cost factoring into these decisions (8.7 - 16.5%).

\* Multiple responses allowed.

## ACCESS TO FINANCIAL ASSISTANCE AND FINANCIAL TOXICITY

The high cost of cancer care has resulted in what is now described as “financial toxicity.” Financial toxicity takes into account the amount of money spent and owed, as well as the stress of lifestyle changes resulting from having more limited resources. It can be as distressing as the physical side effects of cancer treatment, and as long term, even for people with good health insurance coverage. Financial assistance to manage the cost of cancer care can include pharmaceutical assistance programs, assistance with insurance premiums, housing and transportation assistance, and other services provided by organizations that help patients access the care they need.

Findings from this survey revealed that nearly half (49.4%) of patients who indicated that they did not fill prescriptions due to cost sought financial assistance from a third party to help pay for medications. Over 58% of these patients received financial help when they sought out assistance. However, half of those who reported not filling prescriptions due to cost did not seek financial assistance for medications, and 44% of this group were not aware that financial assistance might be an option.

It is also critical that people with cancer understand the services covered by their health insurance so that they can take full advantage of services offered, and anticipate and budget for OOP expenses. Respondents who had a good understanding of their health coverage were more likely to get recommended health care services than those with a poor understanding.

Financial problems caused by cancer have an impact on quality of life (Fenn et al., 2014). To address some of the financial toxicity associated with cancer care, it is important to educate and empower people with cancer to understand their health coverage, seek financial assistance programs, and advocate for themselves if recommended care is denied. Taking control and understanding the nuances of insurance coverage can help alleviate some of the distress caused by financial toxicity.

More than half of respondents who indicated that they did not fill prescriptions due to cost did not seek out financial assistance from a third party for help with the cost of medications.

# Cost Containment Strategies

The pace of innovation in cancer care is accelerating as new diagnostics and treatments lead to improvements in quality of life and better health outcomes. While new technology and services provide excitement, access to them is not equal. Cost containment strategies by insurers, such as prior authorization, step therapy, and narrow networks present challenges for patients in their efforts to access quality cancer care.

## PRIOR AUTHORIZATION

Prior authorization is a process used by some health insurance companies to determine if they will cover a prescribed procedure, service, or medication. It can result in, at best, delays, and, at worst, rejection of recommended services. This survey examined the role of prior authorization in access to treatment and diagnostic tests. Approximately 800 people answered survey questions related to prior authorization.

### Treatment

Almost one half of respondents (45%), reported that, in the last 12 months, they were told that the treatment prescribed for them would require approval from their insurance company.

Prior authorization was needed for oral medications (35.4%) and IV infusion treatments (35.9%). When examined by insurance type, results indicate that prior authorization was most frequently reported by patients with Marketplace coverage (53.3%), followed by patients with Medicare coverage (51.2%). Respondents with employer-sponsored health insurance were least likely to report prior authorization for treatment (50.7%).

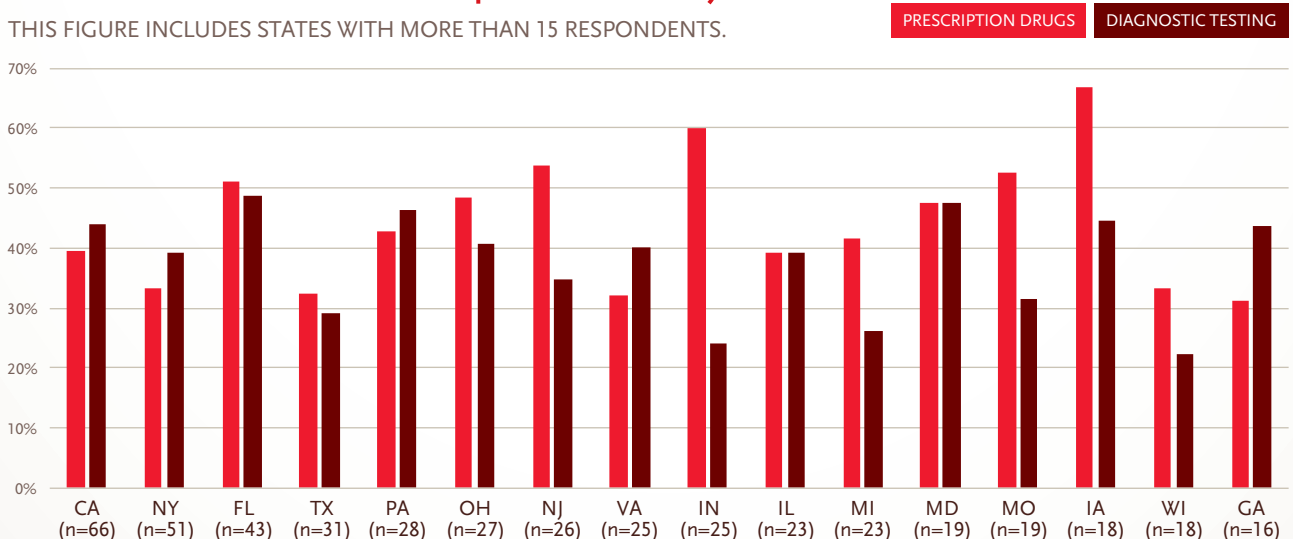
Significant differences in prior authorization requirements exist at the state level. More than half of respondents in Iowa (66.3%, n=18), Indiana (60%, n=25), and New Jersey (53.8%, n=26) reported having to obtain prior authorization before beginning a provider-recommended treatment. In contrast, approximately one-third of respondents in Virginia (32%, n=25), Texas (32.3%, n=31), and Georgia (33.3%, n=16) needed prior authorization before treatment began.

### Diagnostic Tests

More than one-third (37.4%) of respondents reported that, in the last 12 months, they were told that a medical test to help determine their diagnosis would require prior approval from their insurance company.

## Prior Authorization Requirement by State

THIS FIGURE INCLUDES STATES WITH MORE THAN 15 RESPONDENTS.



Prior authorization for diagnostic testing was reported most often for CT scan (51%), MRI (38%), and genetic testing (22%). When looked at by insurance type, results indicate that prior authorization for diagnostic testing was more frequently reported by survey respondents with Marketplace coverage (50%) or private insurance (48.7%) compared to respondents with Medicare coverage (28%).

The survey also showed significant differences by state for prior authorization for diagnostic tests. Residents of the following states were most likely to need prior authorization: Florida (48.8%, n=43), Maryland (47.7%, n=19), and Pennsylvania (46.4%, n=28). In comparison, only a quarter of respondents in Michigan (25%, n=23), Indiana (23%, n=25), and Wisconsin (21%, n=18) reported prior authorization for diagnostic testing.

### Impact on Access to Care

The impact of prior authorization on access to care is shown in the delays respondents experienced obtaining diagnostic tests and physician-recommended treatments. One-fifth of respondents experienced significant delays in receiving a cancer diagnosis and 22% faced unexpected OOP cost due to the prior authorization requirement for diagnostic testing. Similarly, more than a quarter (26.2%) of people surveyed experienced significant delays in starting physician-recommended treatment, and 17.3% changed their treatment decision due to the prior authorization requirement. Approximately a quarter (23.9%) of respondents reported unexpected OOP costs due to the prior authorization requirement for physician-recommended diagnostic tests or treatments.

### STEP THERAPY

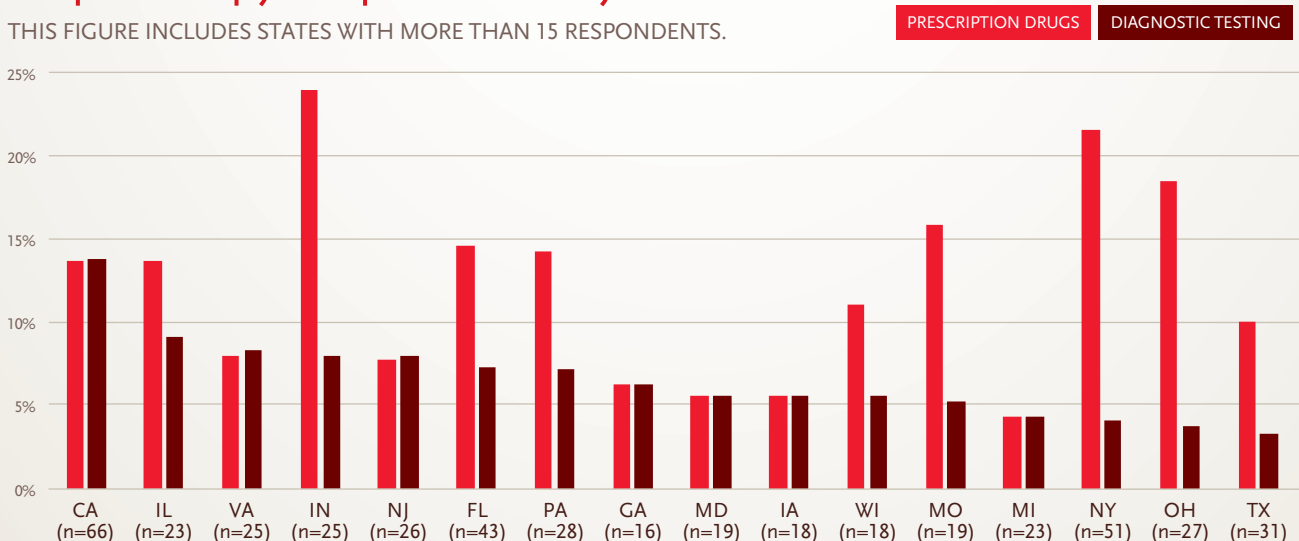
In managed medical care, step therapy is used to control costs and risks posed by diagnostic testing and/or prescription drugs. Step therapy requires that patients try a lower cost medication or test before a more costly one, even when the more costly one was recommended by their physician. Approximately 800 people answered survey questions related to step therapy.

#### Treatment

Our findings indicate that in the last 12 months 14% of respondents were required by their insurance company to take another medication first before they could receive the medication originally prescribed by their doctor. Step therapy was used most often for oral medicines (75%) and least often for IV infusion treatment (8.7%). Step therapy was most frequently reported

## Step Therapy Requirement by State

THIS FIGURE INCLUDES STATES WITH MORE THAN 15 RESPONDENTS.



by people with private insurance coverage (25.6%), followed by those with Medicare coverage (15.2%). Patients with Marketplace coverage were least likely to encounter step therapy for cancer treatment (11.4%).

Among those who encountered step therapy requirements for medications, the analysis revealed significant differences by state. Almost a quarter of respondents in Indiana (24%, n=25), New York (21.6%, n=51), and Ohio (18.5%, n=27) reported having to take another medication first before beginning a provider-recommended treatment. In contrast, less than a tenth of patients in Iowa (5.6%, n=18), Maryland (5.6%, n=19), and Michigan (4.3%, n=23) were required to undergo step therapy.

### Diagnostic Tests

While step therapy for diagnostic tests was less frequently reported overall (7.8%), people with private insurance (16.7%) were more often required to get a different test than the one prescribed by their doctor than people with Marketplace (7%) or Medicare coverage (3.8%). The survey revealed significant differences by state in step therapy requirements for diagnostic tests. Residents of California (13.8%, n=66) were more likely to face step therapy requirements, compared to respondents from Illinois (9.1%, n=23) and Virginia (8.3%, n=25), who were less likely to be required by their insurance company to undergo a different diagnostic test than the one prescribed by their health care team.

### Impact on Access to Care

Step therapy can delay care and, at times, lead to people with cancer having to forego treatment altogether. Among those who experienced the step therapy mandate:

- Almost one-third (32.1%) reported starting the medication required by the insurance company instead of taking the medication that was originally prescribed for them.
- 18.9% started the medication required by their insurance company while simultaneously requesting an exception.
- 16% delayed treatment by deciding not to take the medication and waiting until an exception was granted.
- 8.5% decided not to start any medication.

Overall, almost half (49.1%) of respondents who experienced step therapy requirements for a medication, decided to work with the doctor's office to request an exemption from the insurance company. Half of those (48.6%) reported not receiving the treatment originally prescribed by their doctor. This group elected to accept the treatment mandated by the insurance company. 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. One person reported waiting 30 to 60 days to receive the recommended care. Over half (52.4%) of respondents felt that the step therapy mandate delayed their treatment. At the same time, more than 10% of those who were required to get a different diagnostic test than the one prescribed by their doctor, experienced significant delays in receiving a diagnosis by deciding not to get the test mandated by their insurance company or waiting for an exception to the insurance company's policy.

Step therapy mandates also can have an impact on cost. Over half (52.9%) of respondents experienced unexpected OOP costs due to the insurance company mandated treatment for prescription drugs, and 44% of those who experienced the step therapy mandate for diagnostic testing reported unexpected OOP costs due to this requirement by their insurance company.

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.

Overall, almost three-quarters (71.2%) of them did not seek financial assistance for those unexpected costs, half indicating they did not know that financial assistance was an option.

### **NETWORK ADEQUACY**

Narrow networks limit the number of providers within network, leading some enrollees to pay high out-of-network costs for cancer care. The survey showed the greatest impact on residents of rural and underserved areas where people have relatively few options for comprehensive cancer care.

Over 10% of respondents reported experiencing difficulties in the last 12 months finding an in-network specialist in their area. People with private insurance plans reported the most difficulty (27.5%), while those with employer-sponsored (9.2%) or Medicare (8.8%) coverage reported the least difficulty finding in-network specialists. Overall, when asked about their top concerns related to health insurance, nearly 30% of respondents reported concerns about issues related to narrow networks. This finding highlights yet another way in which people with cancer experience difficulty accessing care.



# Real World Impact and Conclusions

The National Cancer Institute estimates that medical costs for cancer were \$157 billion in 2010, and that costs are projected to increase to \$174 billion in 2020 (Mariotto et al., 2011). At the same time, the focus of the U.S. health care system is shifting towards the value of care patients receive. Both of these trends have implications for the cancer community as we strive to improve the quality of cancer care while also reining in the cost of care. Health care reform includes many important consumer protections, yet the ambiguity of the current economic environment and the uncertain future of health care policy could make the financial impact of a cancer diagnosis even more challenging for many patients. We consider all of these issues as we work to ensure that people with cancer have access to high-quality, comprehensive cancer care. The following findings can guide this work.

In order to play an active role in health care decisions, patients need to understand health insurance plan structures and coverage. Yet, the information surrounding health insurance plan options is complex, and coverage and benefits vary tremendously, both in terms of what they cover and how costs are shared. Notably, one-third of respondents in our sample reported an “adequate” or “poor” understanding of their health insurance coverage. People with a lower understanding of their insurance were more likely to feel that they did not receive the care they needed. These findings affirm the need for patient guidance in understanding coverage options relative to their current as well as future health state.

At the same time, approximately 43% of survey participants reported higher than expected out-of-pocket costs, and 78% of participants reported that cost of care conversations with their health care team did not take place, or they did not recall whether cost of care was discussed prior to starting treatment. Leading areas of concerns include the cost of insurance coverage, with approximately 48% reporting significant concerns about high deductibles, premiums, and out-of-pocket costs for services. In this context, education is a critical piece of improving access to care. People with cancer need help considering their treatment options and the associated costs so that they have a clear understanding of what to expect. Likewise, providers need better resources to enable them to communicate with patients about cost.

As discussions weigh quality versus quantity of care, new strategies are changing the way cancer care is delivered and reimbursed by public and private payers. Yet, these efforts may have unintended consequences that negatively impact quality of life and health outcomes for patients.

Our results indicate a low rate of patient participation in treatment decisions. More than a third (35%) of those surveyed indicated that they did not have a choice of treatment plans. At the same time, the findings highlight a gap in patient knowledge of access barriers, especially of payment policies that are changing the way cancer care is delivered and paid for. For example, many payers attempt to standardize treatment and cut costs by encouraging providers to follow clinical



pathways; however, 73% of patients in this sample had never heard of a clinical pathway. These policies may be well intentioned, but patients should be informed of all available treatment options and the risks and benefits associated with each. Discussions must incorporate medical, psychosocial, and financial factors. Patients also deserve to know of financial or other incentives provided to the health care team for following clinical pathways.

Importantly, as care for chronic conditions, including cancer, becomes more advanced, decisions faced by payers, patients, and families become more complex and often have significant trade-off considerations including adherence, tolerability, cost, and impact on overall quality of life. This change is reflected in the issues faced by participants in our sample, who report experiencing delays in accessing care, skipping recommended care to manage OOP costs, and having difficulty finding in-network specialists.

Although the people in this sample reported good access to medical care, over 53% did not receive social and emotional support services including screening for distress. This suggests a disparity between access to medical care and access to psychosocial care. Psychosocial distress screening and support is a fundamental element of comprehensive cancer care. Evidence that it improves patient outcomes and decreases overall cost supports the integration of these services into the cancer care continuum as required and reimbursable.

The Affordable Care Act has given us the promise of increased access to comprehensive cancer care. As policymakers continue to find ways to deliver care at lower cost, we must work to ensure that the patient voice is represented in every step of the decision making process and that patients are fully engaged. Simultaneously, affordability and other access limitations must be minimized in support of patient adherence. Treatment decisions should be based on the individual patient's clinical and biological profile, input from the patient regarding his or her goals of therapy, and full disclosure of and agreement on the cost implications.

CSC is grateful to the survey participants who freely shared their time and voices so that others might learn. Our work would not be possible without their involvement and support. Their input enables CSC, other advocacy organizations, and health care stakeholders to inform and shape meaningful policy, increasing access to comprehensive care for all people with cancer.

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