

Insight into the Patient Experience

CANCER EXPERIENCE REGISTRY REPORT 2017



A Message



For every person affected by cancer, there's a story. Each story is unique, and each needs to be told. From the financial implications of treatment to the emotional distress of complications, patients across the cancer spectrum struggle every day to manage their disease in their own way.

Developed by our Research and Training Institute, the Cancer Experience Registry Index Report is one solution to that struggle: a diverse collection of individual stories from thousands of patients across the cancer spectrum. Data from the 2017 report reinforces many of the things we're hearing every day from patients, through our Cancer Support Helpline, our Frankly Speaking About Cancer educational programs and radio show, and other wraparound

resources that address patient needs holistically. Patients describe how they're wrestling with the complexity of treatment, the cost of care—especially when, according to the report, only 22% of survey respondents had a discussion about cost with their doctor or care team—clinical trials, and the emotional burden of cancer. All of these cause significant levels of distress, which can impact how care is delivered.

The idea behind the Cancer Experience Registry began with one person—a single patient who wanted to illuminate what it's really like to live with cancer. Despite that humble beginning, our contribution to the cancer community is, I believe, immeasurable. Today, data from the Registry, now 12,000 voices strong, is used across a wide variety of settings by important segments of the health care community: policymakers, lawmakers on Capitol Hill, industry, physicians and researchers. We are the only organization in the world that synthesizes so many different patient voices, bringing to light the experiences of a wide variety of diagnoses, from the rarest to the most common.

In 2016, we expanded our Specialty Registries to 10 to capture the experiences of people affected by various cancer types, as well as caregivers who assist patients. And the Registry will continue to grow, to seek out more diverse points of view from a broader range of cancer types and socio-demographic groups often left out of the larger cancer story. All perspectives must be brought to the table to better understand the full patient experience and address gaps in care.

We could not do all of the work that we do at the Research and Training Institute without dedicated and unwavering support from donors, partners, Advisory Board members, and, most of all, patients and their families. They are the ones who continue to take the time to answer—faithfully and truthfully, while managing a debilitating disease—invaluable questions about some of their deepest fears and greatest hopes related to their cancer experience. For that, you have our deepest gratitude.

A handwritten signature in black ink, reading "K. Thiboldeaux". The signature is fluid and cursive.

KIM THIBOLDEAUX, CHIEF EXECUTIVE OFFICER, CANCER SUPPORT COMMUNITY

What is the Registry?

Clinical advances such as new drug therapies and more sophisticated diagnostic tools have extended lives and improved survival rates of many patients across the cancer spectrum. Yet the complete cancer experience remains less understood by patients and health care providers alike. In particular, the emotional and psychosocial effects of cancer are complex and not simply ancillary to the cancer experience. Instead, they have practical implications for how patients and care teams approach the plan of care.

Since 2013, the Cancer Experience Registry, developed by the Cancer Support Community's Research and Training Institute, has provided a forum for people impacted by cancer to share their voices about issues that matter to them, to connect with each other, and to ensure their experiences are communicated to the broader cancer community—with the goal of making a difference in how people move through their cancer journey. The Registry documents insights from patients across the cancer experience spectrum, illuminates key areas that impact patients' lives, and informs stakeholders looking for data-driven care solutions and broad system change. As of June 2017, more than 12,000 participants—survivors, patients, and caregivers—representing over 45 cancer types have joined the Registry, and the Cancer Support Community is committed to expanding that number in 2017 and beyond.

This report, the second since the Registry's inception, presents analysis of survey responses from a subset of Registry participants in the following areas of focus:

- Demographics and background
- Cancer-related distress
- Quality of life
- Treatment decision-making and planning
- Side effects and symptom management
- Clinical trials
- Financial toxicity
- Work-related experiences

Importantly, Specialty Registries—subsets of the larger Registry—document the experiences of people with specific cancers. These Specialty Registries cover patients with Breast Cancer, Chronic Lymphocytic Leukemia, Chronic Myeloid Leukemia, Lung Cancer, Melanoma, Metastatic Breast Cancer, Multiple Myeloma, Prostate Cancer, and Stomach (Gastric and Gastro-esophageal) Cancer, as well as Caregivers. Findings from these 10 Specialty Registries are also included in the report, and they indicate common themes and shared experiences of people with different cancers—as well as their unique challenges.

The landscape of cancer care and health care continues to evolve, often resulting in difficulties in making treatment and financial decisions. People impacted by cancer face a spectrum of issues related to treatment and the way care is delivered: shifts in insurance coverage and payment mechanisms, new models for clinical trials, and changes in the way doctors and patients make decisions about their care. At the same time, rapid progress is being made in treating different types of cancer. For many, cancer is becoming a chronic disease, and for a growing number the possibility of a cure is now real. The Registry continues to identify new ways to address these issues, including, for example, measures that seek to define and express what ‘value’ means to different people impacted by cancer and how those values can be incorporated into the treatment and care experience.

The Cancer Experience Registry is a unique resource for patients and caregivers across the care continuum. By sharing their experiences, the Cancer Support Community makes sure their collective voice is heard. Through this report, the Research and Training Institute aims to quantify for health care providers, advocates, and policymakers the social and emotional gaps in care and treatment—to better inform and shape policy and improve quality of life for all those impacted by cancer.

METHODOLOGY








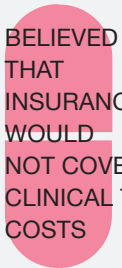

The Cancer Experience Registry is open to anyone diagnosed with any type of cancer at any point along the care continuum, as well as caregivers, including those family members and loved ones who provide or have provided care to someone diagnosed with cancer. They can register online or via a mobile or tablet device at cancerexperienceregistry.org, where they complete questions about their cancer experience. All registrants answer a set of core questions that allow researchers to examine data from people with diverse cancer types and identify commonalities and unique differences across the cancer experience. Those with a diagnosis of a cancer type for which a Specialty Registry exists answer an additional series of questions, including existing validated scales, specific to their kind of cancer in order to address questions for which there is no answer in the current research. These cancer-specific questions have been created by experts in each disease type who specialize in medical oncology, clinical research, advocacy, behavioral research, health care industry and policy, as well as by patient and caregiver representatives. Participation in the Registry is voluntary and the study design has been reviewed by an Internal Review Board (IRB) to protect human subjects. After completing their survey responses, participants can review how others have responded in aggregate.

OUTREACH AND RECRUITMENT

To attract Cancer Experience Registry participants from a broad spectrum of people impacted by cancer, the Research and Training Institute employs a comprehensive recruitment strategy: leveraging the robust Cancer Support Community Affiliate Network, online community and national helpline; working with key advocacy organizations, members of our advisory councils and professional networks; and utilizing both social and traditional media outlets and the health care industry and hospital networks. Outreach is ongoing with open enrollment.

KEY FINDINGS

THIS REPORT CONTAINS NUMEROUS INSIGHTS INTO THE CANCER PATIENT EXPERIENCE. KEY FINDINGS INCLUDE:

| | | | |
|--|---|---|---|
|  <p>QUALITY OF LIFE</p> | <p>ONLY 39% OF CANCER SURVIVORS RATE THEIR OVERALL HEALTH AS VERY GOOD OR EXCELLENT</p> | <p>53%  ARE WORRIED ABOUT THE FUTURE AND WHAT LIES AHEAD</p> | <p>47% ARE AT RISK FOR CLINICAL DEPRESSION</p> |
|  <p>TREATMENT DECISION-MAKING</p> | <p>93% RATED QUALITY OF LIFE AS A VERY IMPORTANT FACTOR WHEN WEIGHING TREATMENT OPTIONS</p> | <p>24% DID NOT FEEL PREPARED TO DISCUSS TREATMENT OPTIONS WITH THEIR DOCTOR</p> | <p>45%  DECIDE ON TREATMENT TOGETHER WITH THEIR CARE TEAM</p> |
|  <p>SIDE EFFECT & SYMPTOM MANAGEMENT</p> | <p>1 IN 5  REPORTED THAT THE HEALTH CARE TEAM DID NOT EXPLAIN SHORT-TERM SIDE EFFECTS</p> | <p>ONLY 52% SAID THEY RECEIVED GUIDANCE ON LONG-TERM SIDE EFFECTS OF TREATMENT</p> | <p>14% DID NOT TELL THE CARE TEAM ABOUT SIDE EFFECTS AND SYMPTOMS</p> |
|  <p>CLINICAL TRIALS</p> | <p>43% THOUGHT LACK OF TRANSPORTATION WOULD STOP THEM FROM PARTICIPATING IN A CLINICAL TRIAL</p> | <p>77%  BELIEVED THAT INSURANCE WOULD NOT COVER CLINICAL TRIAL COSTS</p> | <p>76% FEAR RECEIVING A PLACEBO IN A CANCER CLINICAL TRIAL</p> |
|  <p>FINANCIAL IMPACT</p> | <p>MORE THAN 1 IN 10 POSTPONED FILLING PRESCRIPTIONS TO REDUCE COST</p> | <p>73% DID NOT TALK ABOUT COSTS OF TREATMENT WITH A MEMBER OF THE CARE TEAM</p> | <p>30% DEPLETED THEIR SAVINGS BECAUSE OF TREATMENT COSTS</p> |

Who is in the Registry?

This report analyzes survey responses from 2,827 patients and survivors—out of the over 12,000 total registrants—living in the United States or United States protectorates who joined the Registry between January 1, 2014 and December 31, 2016 and completed a minimum number of questions. Non-U.S. patients and survivors were excluded from this current report due to significant variations in the delivery of health care. Responses presented in the full Registry analysis are 2,827 unless otherwise noted. The core report findings do not include responses from caregivers; caregiver responses are captured in the

Caregiver Specialty Registry analysis. Note that this report does not present data on all survey questions. Rather, it highlights responses to key questions to provide a broad perspective on important issues affecting patient, survivor, and caregiver communities. Respondents were predominantly non-Hispanic White females with a mean age of 56 (ages ranged from 19 to 89). Many respondents were fairly well-educated—53% had completed a bachelor degree or higher—and 38% were working full-time, 25% were retired, and 17% were not working due to a cancer-related disability or other non-specified reason.



Specialty Registry reports and additional study results are available for download at www.cancersupportcommunity.org/RegistryIndexReport2017

FIGURE 1 GENERAL REGISTRY SURVEY DEMOGRAPHICS

| | NUMBER OF PARTICIPANTS (n) | PERCENT |
|---|----------------------------|-----------------|
| AGE | | |
| | (n = 2,574) | |
| Mean age | 56.1 years, SD = 21.1 | Range: 19 to 89 |
| 18-44 | 552 | 21% |
| 45-64 | 1,453 | 57% |
| >=65 | 569 | 22% |
| GENDER | | |
| | (n = 2,818) | |
| Male | 664 | 24% |
| Female | 2,155 | 76% |
| RACE | | |
| | (n = 2,824) | |
| White | 2,450 | 87% |
| Black or African American | 140 | 5% |
| Asian | 41 | 1% |
| American Indian or Alaskan Native | 27 | 1% |
| Native Hawaiian or other Pacific Islander | 7 | <1% |
| Other | 44 | 2% |
| Multiple races | 51 | 2% |
| HISPANIC ETHNICITY | | |
| | (n = 2,821) | |
| Yes | 121 | 4% |
| No | 2,541 | 90% |
| EDUCATION | | |
| | (n = 2,822) | |
| High school or less | 400 | 14% |
| Associate degree or some college | 886 | 31% |
| Bachelor degree | 769 | 27% |
| Graduate degree or higher | 734 | 26% |
| REGION | | |
| | (n = 2,368) | |
| Urban | 495 | 21% |
| Suburban | 1,272 | 54% |
| Rural | 516 | 22% |
| EMPLOYMENT STATUS | | |
| | (n = 2,630) | |
| Full-time | 1,004 | 38% |
| Part-time | 274 | 11% |
| Retired | 661 | 25% |
| Not employed due to disability | 450 | 17% |
| Not employed (reason not specified) | 241 | 9% |
| ANNUAL INCOME | | |
| | (n = 2,484) | |
| <\$40K | 602 | 24% |
| \$40-59.9K | 300 | 12% |
| \$60-79.9K | 249 | 10% |
| \$80-99.9K | 213 | 9% |
| \$100K+ | 535 | 22% |
| Prefer not to share | 551 | 22% |

More than 45 cancer types were represented in the survey responses, with breast cancer being the most common diagnosis represented in the current report: 24% reported non-metastatic breast cancer and 10% reported metastatic breast cancer diagnoses. The blood cancers chronic myeloid leukemia (12%), multiple myeloma (6%), chronic lymphocytic leukemia (6%), and lymphoma (6%) were also common diagnoses, as were lung, colorectal, and ovarian cancers, each cited by 4% of respondents.

FIGURE 2 CANCER TYPES OF SURVEY PARTICIPANTS

| | NUMBER OF PARTICIPANTS (n) | PERCENT |
|-------------------------------|----------------------------|---------|
| CANCER | (n = 2,827) | |
| Breast Cancer, Non-Metastatic | 673 | 24% |
| Chronic Myeloid Leukemia | 342 | 12% |
| Breast Cancer, Metastatic | 294 | 10% |
| Multiple Myeloma | 172 | 6% |
| Chronic Lymphocytic Leukemia | 168 | 6% |
| Lymphoma | 168 | 6% |
| Lung | 109 | 4% |
| Colorectal | 106 | 4% |
| Ovarian | 100 | 4% |
| Prostate | 90 | 3% |
| Melanoma | 53 | 2% |
| Endometrial | 45 | 2% |
| Head and Neck | 42 | 2% |
| Kidney | 40 | 1% |
| Stomach | 22 | 1% |
| Esophageal | 10 | <1% |

Note: Additional Registry participant diagnoses represent a broad range of cancer types, including bone, brain tumor, cervical, liver, pancreatic, sarcoma, testicular, thyroid, etc.

At the time they completed the survey, 14% of respondents were less than a year from their diagnosis, while 35% had received their diagnosis at least five or more years ago. Of those responding, 22% had a metastatic disease condition and nearly one-fifth (19%) had experienced a recurrence of their cancer.

FIGURE 3 TIME SINCE DIAGNOSIS AND CANCER STATUS OF PARTICIPANTS

| | NUMBER OF PARTICIPANTS (n) | PERCENT |
|-----------------------------|----------------------------|---------|
| TIME SINCE DIAGNOSIS | (n = 2,053) | |
| <1 year | 291 | 14% |
| 1–1.9 years | 451 | 22% |
| 2–4.9 years | 602 | 29% |
| >=5 years | 709 | 35% |
| METASTATIC | (n = 1,894) | |
| | 418 | 22% |
| RECURRENCE | (n = 1,970) | |
| | 383 | 19% |



IDE MILLS

Diagnosed with Stage IV Lung Cancer and Cancer Support Community Advisor

“The Cancer Experience Registry is an invaluable tool for researchers to gain in-depth information about the social and emotional issues impacting people facing cancer. I want to encourage more people to join the Registry and share their stories. For me, working with the Cancer Support Community as an advisor to this important project has given me a chance to tell my story and to help me find purpose and meaning from my cancer experience.”

CSC would like to remember friend and advisor, Ide Mills, as a passionate advocate for support, education and the advancement of patient-centered care.

What are we learning?

PERCEPTIONS ABOUT HEALTH

Despite their cancer diagnosis, 39% described their overall health as very good or excellent, while 25% viewed their health as poor or fair (Figure 4). In fact, 15% of respondents believed their health was much better than others. Twenty-two percent indicated their health was slightly better, 21% believed slightly worse, and 11% much worse (Figure 5).

FIGURE 4 PERCEPTIONS OF OVERALL HEALTH

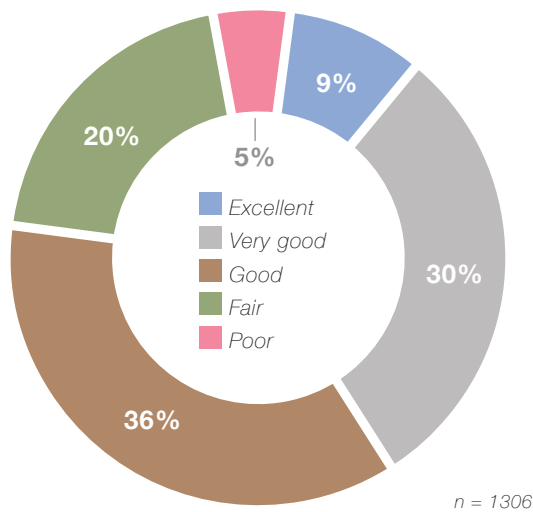
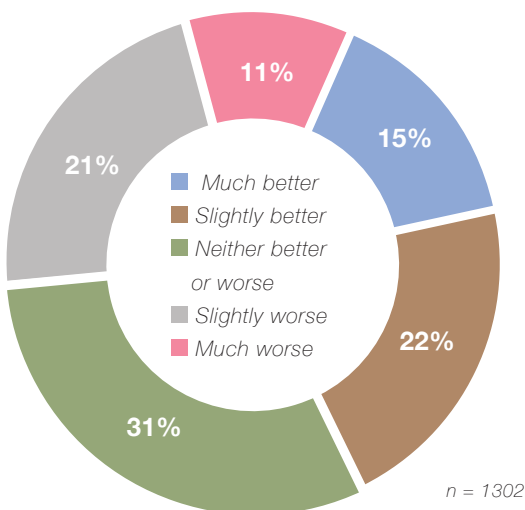


FIGURE 5 PERCEPTIONS OF HEALTH AS COMPARED TO OTHERS

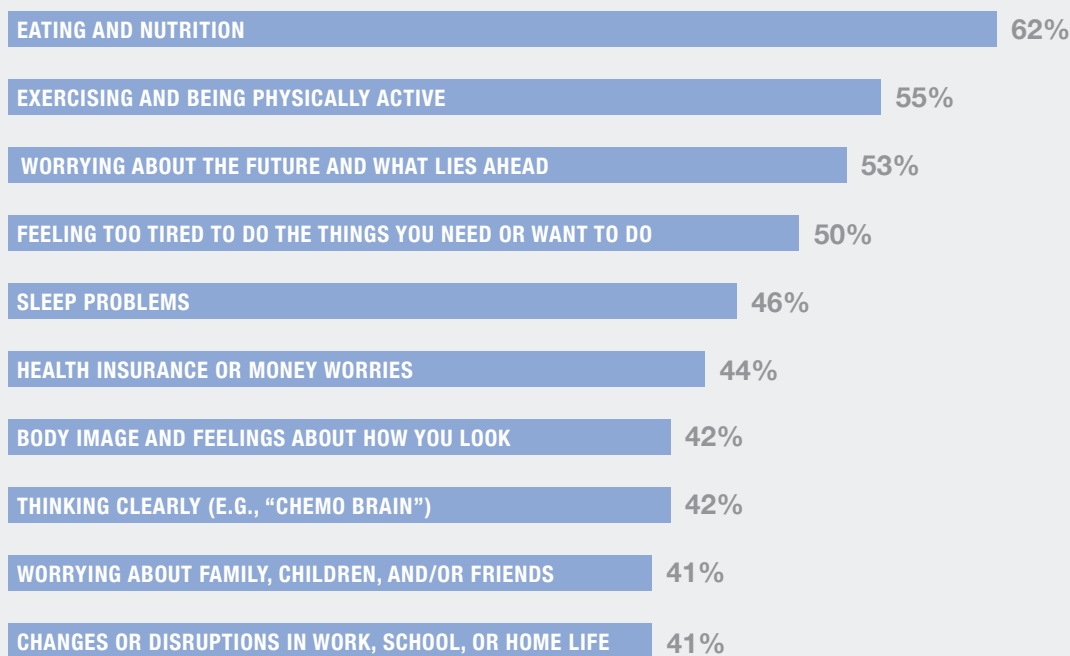


CANCER-RELATED DISTRESS

Many patients—from the newly diagnosed to patients multiple years out from a diagnosis—experience varying levels of distress related to psychological, social, and financial concerns. High levels of distress can negatively impact patient outcomes, and alleviating distress, through screening and support, is an integral component of any cancer care plan.

The Cancer Experience Registry measures cancer-related distress using CancerSupportSource^{®1}, a validated screening instrument that examines 25 concepts related to psychosocial, practical, and physical needs. Using a 0–4 point scale, respondents (n = 2,141) rated whether they were “not at all” (0), “slightly” (1), “moderately” (2), “seriously” (3), or “very seriously” (4) concerned about each of the 25 items. Among respondents, the 10 most common concerns—rated a 2, 3, or 4 by the most respondents—spanned the physical, emotional, and financial realms (Figure 6). At the top, 62% reported being moderately to very seriously concerned about their eating and nutrition. Exercising and being physically active (55%), feeling too tired to do things (50%), sleep problems (46%), thinking clearly (42%), and moving around (41%) were additional top physical concerns. Emotional concerns among the top 10 included worrying about the future (53%), body image and physical appearance (42%), thinking clearly (42%), worrying about family and friends (41%), and disruption to everyday life (41%). Finally, 44% reported moderate to very serious concern about the financial impact of cancer (Figure 6).

FIGURE 6 TOP 10 CONCERNS ACROSS REGISTRY PARTICIPANTS



Percent of Patients Moderately to Very Seriously Concerned

n = 2141

The experience of severe levels of distress can potentially lead to depression, which may worsen quality of life and is associated with increased health care utilization and costs and poorer patient outcomes. Using the CancerSupportSource 4-item depression risk subscale, in the Cancer Experience Registry, it was found that nearly half (47%) of respondents were identified as at risk for clinically significant levels of depression. Psychosocial distress affects different patients in different ways and can manifest throughout the entire cancer experience. Clearly, large percentages of patients express deep concern—even symptoms of depression—across disparate facets of their lives, making it challenging for medical professionals to provide effective care.

QUALITY OF LIFE

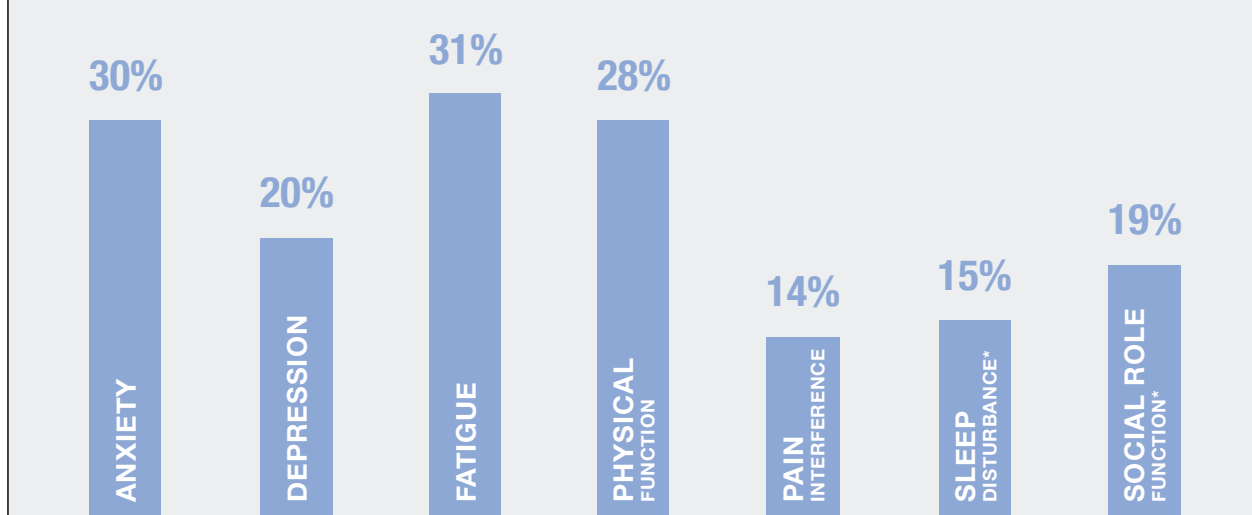
Health care professionals involved in cancer care constantly strive to maintain or improve the quality of life—physical, emotional, or social—for anyone

affected by cancer, and care plans increasingly emphasize quality of life as a primary concern, especially as more and more patients are living longer with their disease. The survey incorporated the PROMIS-29 (Patient Reported Outcome Measurement Information System) scale to gain insight into respondents' views about their quality of life across seven areas of life.² Each of these areas is assessed using four questions, and most responses are required to reflect only the last seven days (Physical Function and Social Role Function questions have no required time scale). Specifically, PROMIS-29 compares how respondents describe their quality of life in each area to other U.S. population groups (see Figure 7).

Across all Registry respondents, nearly one-third (30%) reported substantially worse anxiety symptoms than the national average, and 20% reported worse depression symptoms (Figure 7).

FIGURE 7 **PERCENT OF CANCER SURVIVORS REPORTING WORSE QUALITY OF LIFE**

n = 1305



Note: All comparisons are vs. general U.S. population, except where * denotes comparison to U.S. population group balanced to include more people with chronic illness. Worse quality of life is defined as having a score that is at least 1 standard deviation poorer than the respective comparison group.

Roughly one-third reported worse fatigue symptoms (31%), physical functioning (28%), and pain interference (14%). Compared with reference groups balanced to include chronic illness, 15% reported worse sleep disturbance and 19% reported worse social functioning.

TREATMENT DECISION-MAKING AND PLANNING

Patients face a range of treatment options throughout their diagnosis. Encouraging them to assert more control in the decision-making process—to become their own best advocate—is a goal of many health care professionals and cancer care teams. The survey asked a variety of questions related to treatment decisions and planning. Responses revealed relatively high degrees of awareness and engagement (Figure 8). For example, nearly half (46%) reported they knew quite a bit or very much about their treatment options before making decisions. However, more than one-third (35%) reported that they were a little bit to somewhat knowledgeable, with 20% reporting they had no knowledge about their options before making decisions.

Two-thirds (66%) felt they were heavily involved in the decision-making process, while less than 10% reported no involvement. Similarly, 38% were fully prepared to discuss their treatment options with their physician, while almost one in four (24%) felt not at all prepared.

Support—whether emotional, instrumental and/or informational—from loved ones, caregivers, and health care professionals can play a significant role in treatment decision-making, yet 60% of respondents reported no support prior to making treatment decisions. Perhaps not surprisingly, 40% of respondents said they would have liked more support. A significant number would have liked more time to think through their choices: 27% reported they did not have enough time, although nearly half said they had sufficient time and nearly a quarter (23%) had more than enough.

Shared decision-making is a powerful tool for people affected by cancer, and 45% of respondents reported that they decide on treatment together with their care team. Thirty-four percent receive input from their team first, while only 8% leave all decisions

to their care team (Figure 9). Involvement of loved ones appears to be equally important. Forty percent reported that they make decisions after hearing from their loved ones, and even more (43%) make treatment decisions together. Under one-fifth (16%) make decisions on their own, and almost no one leaves decisions entirely to their loved ones (Figure 10).

Any cancer treatment plan demands that patients and their care team agree on outcomes that matter most to patients—in the short and long term. Is treatment intended to cure or eliminate any evidence of disease, or is it intended to shrink a tumor or prevent metastases, or both? Does the patient insist on minimal side effects, pain, and discomfort, or is s/he happy with an intensive chemotherapy regimen? The survey revealed that an overwhelming majority of respondents (93%) considered quality of life as very important when weighing treatment options. Slightly smaller proportions believed that length of life (79%) and the impact of their treatment on their family (74%) were quite a bit or very much a factor in selecting a treatment or therapy. Although cost of care figures heavily throughout the data as a source of distress for many patients, just 33% reported that financial implications were a factor in decisions about treatment (Figure 11).

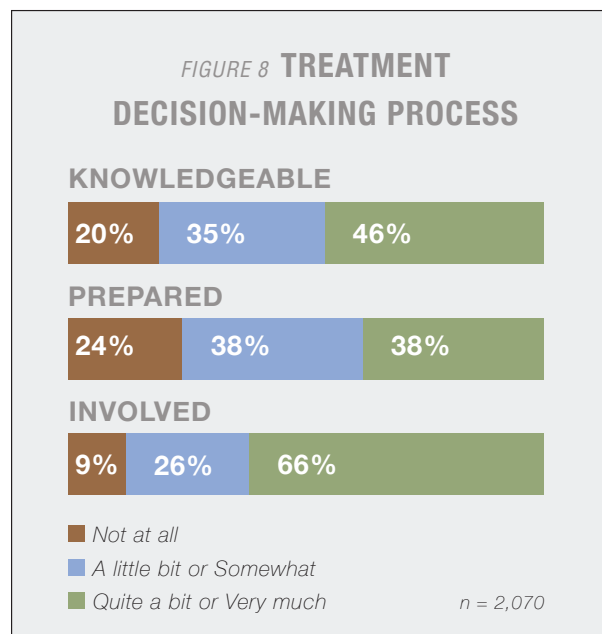


FIGURE 9 HOW PATIENTS MAKE DECISIONS WITH THEIR HEALTH CARE TEAM (HCT)

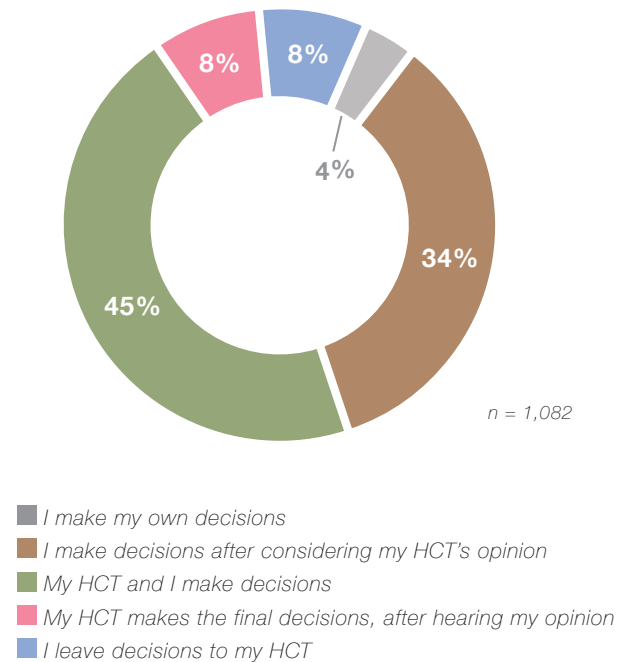


FIGURE 10 HOW PATIENTS MAKE DECISIONS WITH THEIR LOVED ONES

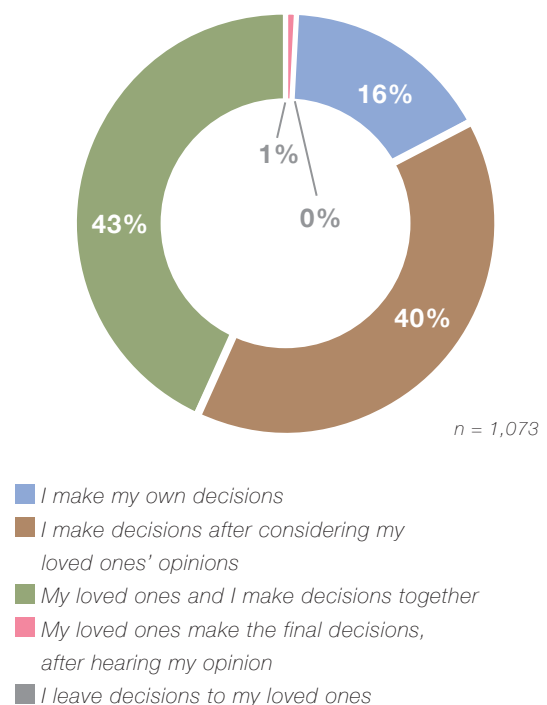
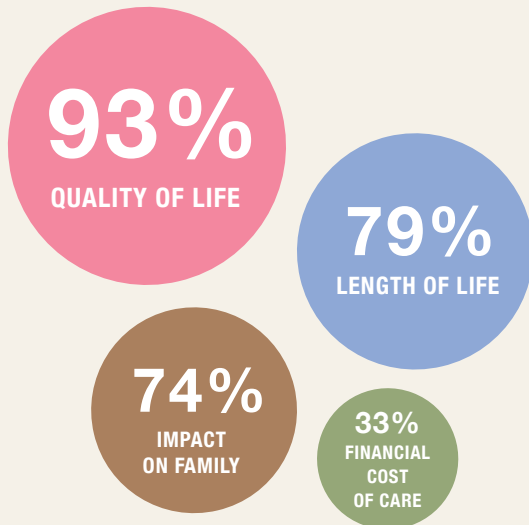


FIGURE 11 IMPORTANT FACTORS FOR TREATMENT DECISION-MAKING



Percent responding Quite a bit to Very much
n = 1,013

In addition, respondents indicated there was a great deal of communication between themselves and their providers on treatment goals. A large majority (82%), for example, reported that goals set forth by their health care team were adequately explained to them, while 74% indicated that they informed their care team about their own goals. Intriguingly, a significant proportion (22%) did not share their goals—despite the fact that 81% of respondents overall felt comfortable discussing treatment goals with their health care team. A good doctor-patient relationship builds trust and can lead to more accurate selection of treatment and more effective care.

SIDE EFFECTS AND SYMPTOM MANAGEMENT

Managing physical and emotional side effects of treatment can be one of the biggest sources of anxiety among cancer patients, and health care teams work hard to implement a treatment plan that promotes efficacy while maximizing quality of life. The success of the plan depends, however, on transparent and sustained patient-provider communication. Of those who answered questions pertaining to side effects, 76% reported that they were informed of possible side effects

of their treatment, 55% were guided on ways to cope with and manage side effects, and half (51%) reported that health care professionals highlighted specific side effects that needed immediate medical attention. Fewer than half (40%) were told about which side effects were not as urgent (Figure 12).

At the same time, 60% of respondents felt more than adequately prepared to manage side effects. Still, a sizable proportion (16%) reported being ill-prepared to tackle side effects, suggesting the need for improvement in providing comprehensive guidance on what to expect from various treatments. Indeed, 14% of respondents noted that they actually refrain from alerting their provider of the existence or severity of side effects and disease symptoms.

Many cancer treatments have short-term or long-term side effects, or both. Respondents indicated more familiarity and understanding of short-term effects: 79% reported someone on the care team explaining short-term effects, although this also means that one in five respondents (21%) reported that the health care team did not explain short-term side effects. Of even greater concern, only half (52%) indicated they received guidance on their treatment's long-term effects. This can have implications for overall quality of life as treatment advances and people live significantly longer lives after a cancer diagnosis.

CLINICAL TRIALS

Clinical trials prior to a drug's availability on the open market are not only an important method for accumulating valuable information on a drug's efficacy and potency: they also offer cancer patients an important treatment option. Nationally, the overall percentage of cancer patients participating in clinical trials remains low at approximately 3% (NIH, 2010). As Registry findings indicate, there continue to be misconceptions among patients about clinical trials, which can lead to insufficient participation. Reasons for choosing not to participate in a clinical trial were varied and reflected a range of concerns—from financial worries to fear of the unknown (Figure 13). More than three quarters

of respondents (77%) strongly believed that their insurance would not cover a trial, despite rules requiring many insurance providers to consider a trial as they would any other form of treatment. A slightly higher proportion (80%) reported they were uncomfortable with taking part in a clinical trial because they were concerned about random selection (similar to a coin toss) to a treatment. Similar proportions expressed strong anxiety about side effects (76%) and the chance they would receive a potentially ineffective placebo (76%). Nearly half (46%) were afraid of being used as a “guinea pig”—indicating, perhaps, an aversion to losing some

semblance of control over their treatment or lack of trust in the medical community’s concern for their welfare. Finally, many respondents cited logistical concerns against joining a trial: 65% believed there were no trials conducted in their local community and 43% believed barriers such as transportation would prevent them from participating. Effective clinical trials can lead to advances in cancer therapies and treatments. Yet they require active patient participation. As this survey reveals, increased patient awareness, accessibility, and engagement about clinical trials as a treatment option are critical for improving care and advancing the future of cancer treatment.

FIGURE 12 DISCUSSIONS OF TREATMENT SIDE EFFECTS WITH HEALTH CARE TEAM

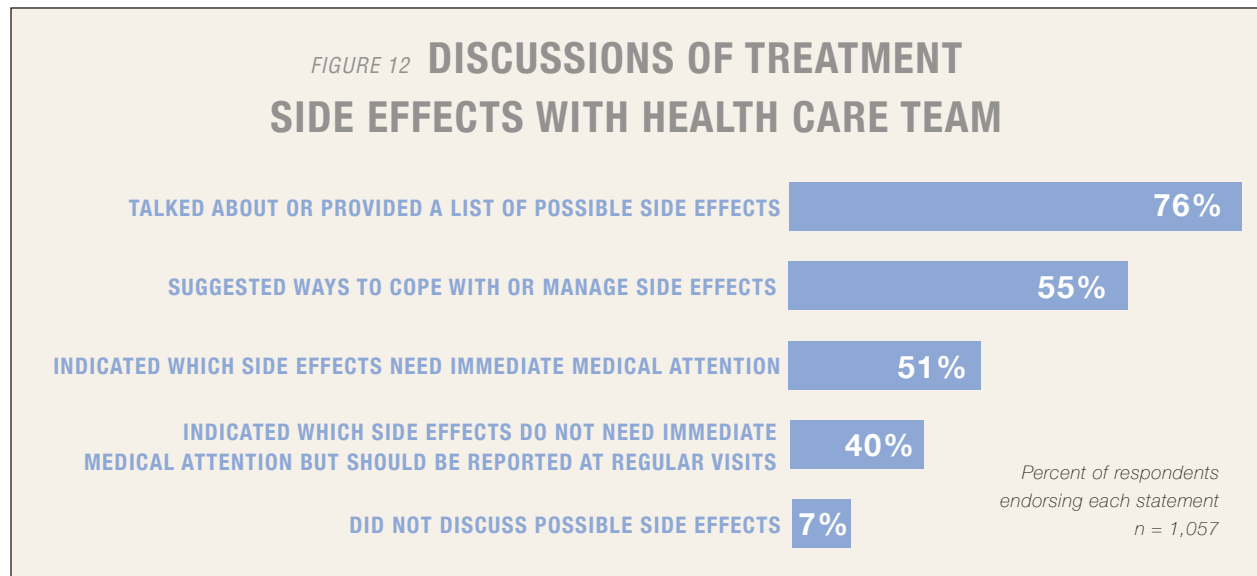
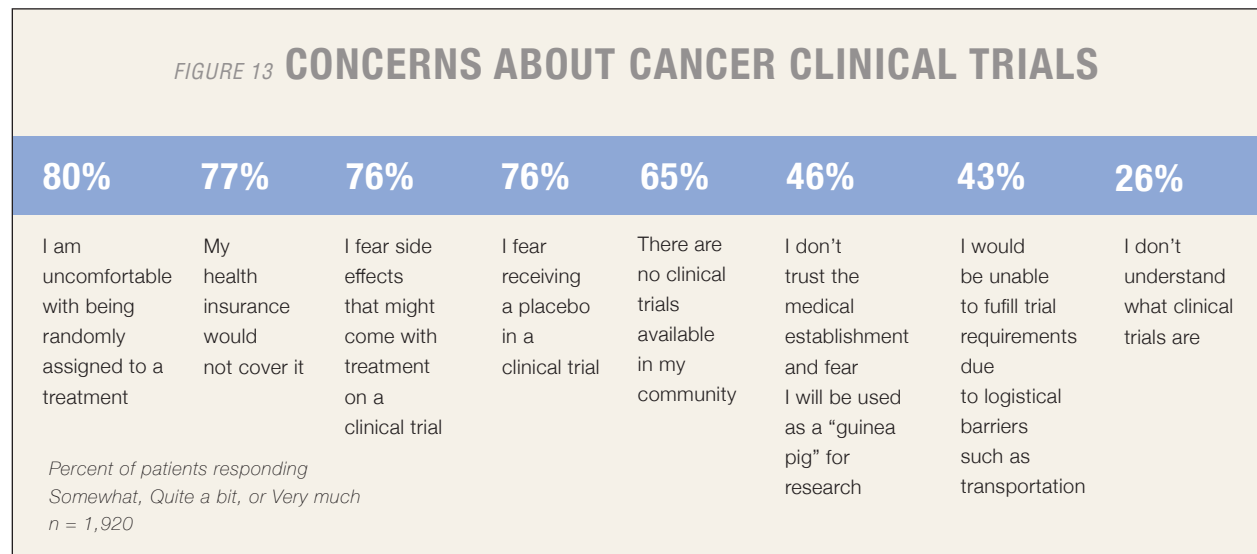


FIGURE 13 CONCERNS ABOUT CANCER CLINICAL TRIALS



FINANCIAL TOXICITY

The term “financial toxicity” refers to the detrimental effects high cost of care can have on patients—encompassing not only actual spending, but money owed as well as distress due to lack of funding or insurance coverage. As noted above, Registry respondents listed monetary worries or lack of health insurance coverage as one of the leading sources of cancer-related distress. In fact, 58% of survey respondents reported that cancer had significantly impacted them financially. To assess more specifically how the financial cost of cancer impacts patients’ emotional well-being, respondents were asked the extent to which thoughts about managing the cost of care intruded into their thinking. Using the Impact of Events Scale, which measures emotional responses to potentially stressful events³, the survey found that up to 37% of respondents were experiencing clinically significant levels of anxiety about managing the cost of care (IES intrusive thoughts subscale ≥ 13). Experiences included, “having trouble falling asleep,” “thinking about it when I didn’t mean to,” and “other things keep making me think about it.”

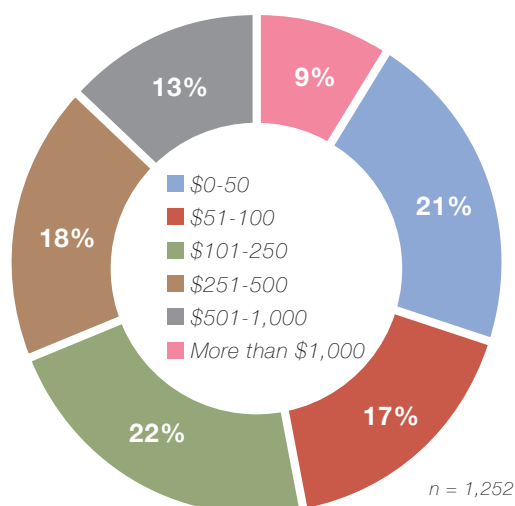
Understanding of financial matters is crucial to navigating the cancer experience. Yet findings from the survey indicate that 73% of respondents did not have a discussion about costs with a member of their care team. Of the 214 respondents who did have those conversations, most (32%) spoke with a financial counselor, while 27% spoke to a nurse navigator or physician. Choosing the right time to have a financial discussion is a delicate matter for many people affected by cancer. According to the survey, 64% of respondents who had a conversation with their health care team about finances began speaking about cost before beginning treatment, while 17% started when they received their diagnosis. Fifteen percent started discussing finances once treatment commenced.

Insurance coverage can mask the monetary impact that patients experience on a regular basis. Many respondents were able to quantify monthly out-of-pocket costs related to their cancer. Responses were

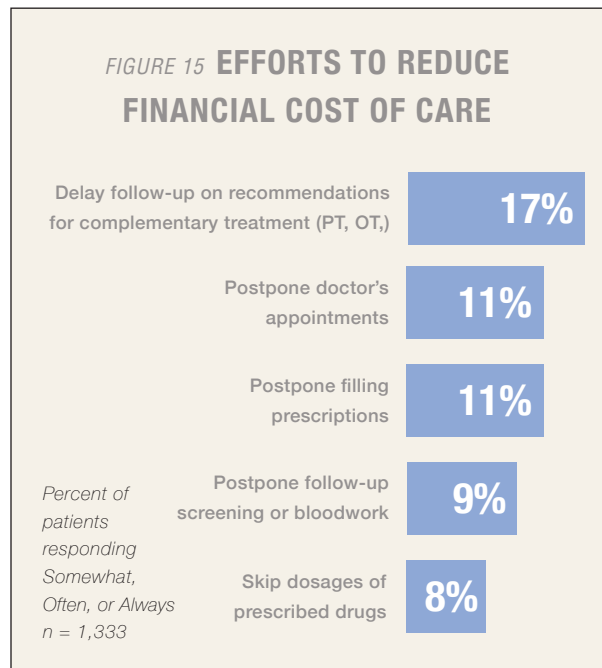
spread fairly evenly across a spectrum of cost ranges: 21% spend less than \$50; 17% between \$51-\$100; 22% between \$101-\$250; 18% between \$251-\$500; 13% between \$501-\$1,000; and 9% spend over \$1,000 (Figure 14). While the smallest proportions reported the highest spending, \$50-\$100 per month adds up for many families, especially as many people are on limited budgets, and increasing numbers of people are on maintenance therapies where treatment can last for months and years. These monthly out-of-pocket costs are particularly significant to the growing number of older adults in the U.S., who tend to have less disposable income available to them.

High costs of care can lead to patients neglecting treatment in an effort to lessen their financial burden. Of the people who responded to questions about forgoing care for financial reasons, 17% delayed seeking follow-up appointments for complementary (physical or occupational therapy, nutrition counseling) treatment; 11% reported postponing doctor’s appointments, 11% postponed filling prescriptions; 9% postponed follow-up screenings or bloodwork; and 8% actually skipped taking their prescribed medication (Figure 15).

FIGURE 14 MONTHLY OUT-OF-POCKET COSTS



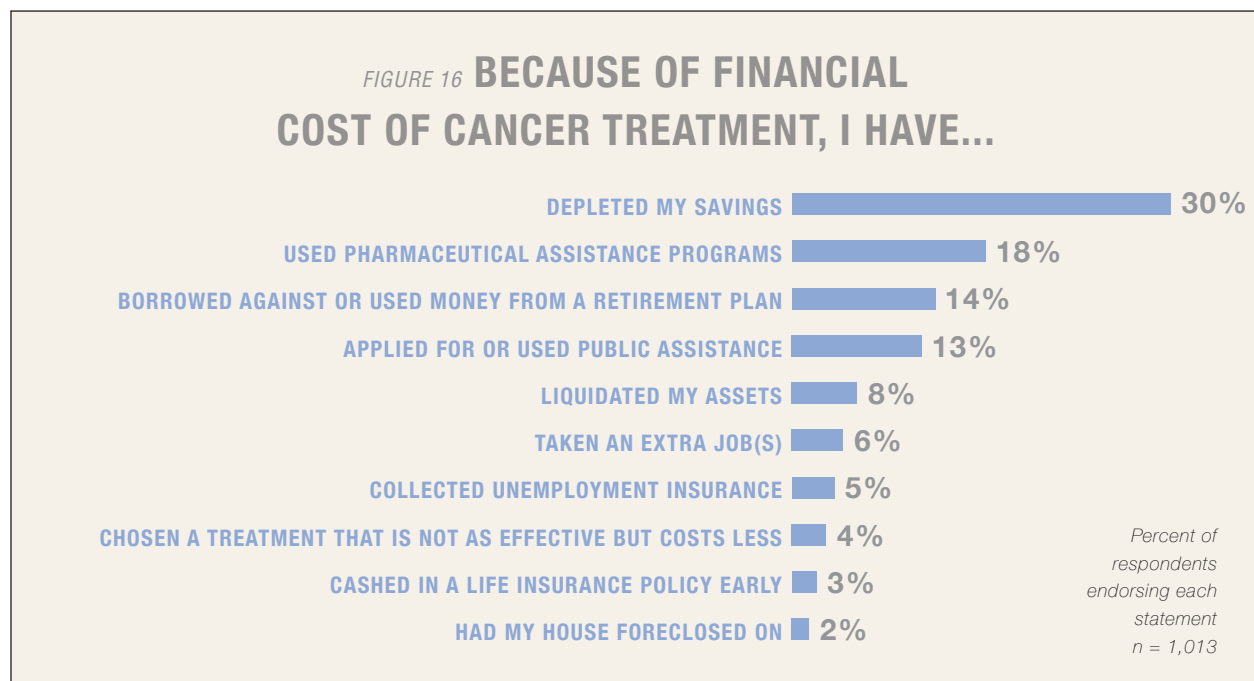
The proportion of patients actually skipping treatment may be small, but the evidence here shows that most patients do experience real stress related to high treatment costs (Figure 16). It is imperative, then, that patients are made aware of the details of their insurance coverage and the financial assistance mechanisms available to them.



WORK-RELATED EXPERIENCES

Managing cancer while going about their daily lives challenges all patients, and one aspect where many have considerable difficulty is work. Faced with the prospect of debilitating and costly treatment, can they afford to reduce their hours or not work altogether? Can they maintain an adequate performance level despite the physical and emotional toll of their treatment? Can they count on colleagues to understand their condition?

In the survey, 38% of respondents were employed full-time at the time of their diagnosis, with 11% working part-time and 25% already retired. When asked if they told people at work of their diagnosis, 92% reported they had. Sixty-one percent of respondents who said the question was applicable to them reported that colleagues provided a lot of support, whereas 13% received little to no support in the workplace. Further, 14% of those in the workplace experienced job discrimination due to their diagnosis or treatment. It is no surprise, then, that two-thirds (66%) of the respondents were somewhat to very stressed about the ramifications—their performance, their career, their relationships—of their diagnosis.



CONCLUSION AND IMPLICATIONS

In order to provide patients and their families with a comprehensive approach to effective treatment and care, the cancer community needs to understand the broader implications of how issues of distress, quality of life, anxiety, and other psychosocial factors can affect different people in different ways. This report summarizes the findings from a range of cancer experiences across these issues in an attempt to uncover common themes. With this report, we are for the first time presenting data from enrollees in our 10 Specialty Registries, targeted to specific cancer types (see separate reports for each of the 10 Specialty Registries, available for download at www.cancersupportcommunity.org/RegistryIndexReport2017). Yet we acknowledge that many information gaps remain. For example, issues specific to underserved patient populations—racial and ethnic minorities, rural and urban populations, sexual and gender minorities—are lacking. For that reason, finely tuned and targeted participant outreach continues to be one of our ongoing goals. In the coming months, we will continue to disseminate data, in different formats, at various conferences and specialist meetings throughout the United States where we hope to continue to raise awareness and understanding of emotional and social issues to the wider health care community.

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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. For more information, please call the toll-free Cancer Support Helpline at 888-793-9355, or visit www.CancerSupportCommunity.org. So that no one faces cancer alone®.

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