Refreshing the Dialogue on Clinical Trials

Research done for the Frankly Speaking about Cancer Clinical Trials program

JUNE 2016





CANCER SUPPORT COMMUNITY

A Global Network of Education and Hope

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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) 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,

Today, there is real hope for the future of cancer treatment. Research is opening the door to new understandings of how cancers arise, grow and spread. These discoveries are rapidly being translated into new therapies that are making a real difference in the lives of many people facing cancer. All of this progress, every step on the journey, has resulted from clinical trials. The success of every trial depends on patients who are willing to participate in these trials.


Kim Thiboldeaux, Chief Executive Officer

In the United States, less than five percent of all adult cancer patients ever enroll in a trial, a figure that has not significantly changed in decades. The rates of participation vary widely depending on where patients receive their treatment. Participation is notably lower for patients treated outside of academic medical centers and for older people, underserved populations and minorities.

While work has been done to increase participation in clinical trials, more is clearly needed. As an organization that focuses on evidence-based psychosocial support of people affected by cancer, the Cancer Support Community researched emotional, personal, family, community and cultural barriers to participation in cancer clinical trials and worked to find solutions to those barriers.

This report summarizes our research findings and recommendations based on a year-long initiative beginning in June 2015. We were able to glean insights into patients' experiences around deciding to participate in cancer clinical trials and the actual language they use to describe clinical trials. These efforts provide the foundation on which we have built our *Frankly Speaking About Cancer Clinical Trials* program.

On behalf of the Cancer Support Community, I would like to thank the patients, caregivers, health care providers, researchers, advocates and funders who made this project possible by participating in interviews, advisory board meetings, surveys and our Cancer Experience Registry®. Our hope is that this project contributes to increasing participation in cancer clinical trials. Finally, we salute the courage, wisdom and determination of every person who faces cancer and makes the commitment to being in a clinical trial.

All my best,

Kim Thiboldeaux
Chief Executive Officer

Research Summary

INTRODUCTION

The landscape of cancer clinical trial recruitment in the United States is crowded, well-traveled territory. Many professional and advocacy groups committed to improving cancer care have endeavored to increase the number of patients participating in clinical trials. As a result, a spectrum of educational and informational resources has been developed in recent years. The results have been, at best, disappointing.

The Cancer Support Community (CSC) initiated the *Frankly Speaking About Cancer Clinical Trials* project in the belief that new ideas and approaches are needed to increase awareness of and participation in clinical trials. By deepening our understanding of the factors that both encourage and deter clinical trial participation, we hope to contribute to a better understanding of the cancer experience leading to more rapid new treatments and cures.

Clinical trials play a critical role in advancing cancer prevention, diagnosis, treatment and, increasingly, quality of life. Every step of progress depends on the ability to recruit for and conduct research studies that establish the safety and effectiveness of new therapies. Nationally, less than five percent of all adult cancer patients ever enroll in a trial, a figure that has not significantly changed in decades. The rates of participation vary widely depending on where patients receive their treatment and are notably lower for patients treated outside of academic medical centers and for older people, underserved populations and minorities.

There are many reasons why clinical trial participation remains low. They include economic and structural barriers that serve as disincentives to both patients and providers for seeking out and enrolling in trials. For some populations, historical and cultural issues create distrust of the medical system and reluctance to be part of a research program. Conversely, biases about the willingness or ability of members of these communities to participate successfully (as well as biases against older patients and women) have meant that in many instances the conversation about clinical trials never takes place.

Patients often express misconceptions, myths and concerns about participating in trials that have prevailed for decades, despite the many educational outreach efforts aimed at addressing these issues. Interested patients frequently encounter serious barriers to finding appropriate trials or may be faced with significant logistical issues in accessing them. Many patients are reluctant to change doctors or treatment facilities in order to access a trial. In addition, while new therapies and new models for designing and implementing clinical trials present promising opportunities for increasing awareness and participation in studies, they also bring with them new challenges.

The ways in which clinical trials are presented can become barriers in and of themselves. Informed consent forms are long and complex and often not written in lay language. In many instances, lay summaries of the protocol, its potential outcomes and side effects are not available. Patients and providers lack tools to help explain not just the trial itself but the issues that confront potential clinical trial participants in making their decisions. As discussed below, the timing of the conversation about clinical trials can influence the extent to which patients are open to participating as well as their perception of potential benefits and risks.

It is worth noting that pediatric cancers are the remarkable exception to this situation. The overwhelming majority of children with cancer are treated in specialized oncology centers where clinical trial participation is the norm, not the exception. According to the Children's Oncology Group, more than 60 percent of children with all cancer types participate in a trial at some point during their treatment. The reasons for this are structural as well philosophical, and to some extent provide a model for rethinking the approach to adult clinical trial enrollment.

Achieving the goal of increasing awareness of and participation in clinical trials requires a multifaceted, collaborative approach that begins with a deep dive

into understanding the barriers that contribute to low levels of patient enrollment. It is equally important to assess clinical trial enrollment in light of emerging therapies, new models for delivering care and new approaches to designing and implementing research studies. For example, rapid progress in developing new therapies is transforming the outcomes of treatment for people facing a variety of cancers, including many with advanced disease. Clinical trials provide patients with access to these developing therapies and increase the potential benefits of clinical trial participation for many patient populations.

The research done for this project confirms that barriers to clinical trial participation are found at every stage of the cancer journey and in every clinical care setting. They range from structural obstacles to deep flaws in the way critical information is made available and communicated. They involve questions of how patients understand their cancer diagnoses, make decisions about their treatment, their personal and financial goals and values, and issues related to disparities and gaps in care.

The factors that impede cancer clinical trial enrollment are so widespread and prevalent that is easy to allow the problems to obscure the view of a future in which every patient understands the importance of clinical trials, discusses the option of a trial with their treatment team and has access to trials that are appropriate to their cancer.

The focus of CSC's Frankly Speaking About Cancer Clinical Trials project is on refreshing the conversation about clinical trials with patients and providers and providing a range of resources that speak to diverse populations of cancer patients and caregivers in a changing environment. This report summarizes the project and highlights its findings, recommendations and resulting initiatives. These efforts are a first step in an ongoing, collaborative and evolving program to address a significant and highly critical area in oncology today.

In beginning this project, CSC acknowledges the remarkable efforts of the many individuals and organizations who have brought their resources, expertise and insight to addressing these issues. We thank the members of our stellar Advisory Board, who have taken a very active role in this project, as well as the many patients, caregiver and providers who helped us. Our goal is to build on best practices rather than duplicate them, to use what is known about what works and what does not, and to work collaboratively with advisors and partner organizations to develop tools to match the needs of today's rapidly changing oncology landscape.

PROJECT STRUCTURE AND METHODOLOGY

CSC's *Frankly Speaking About Cancer Clinical Trials* project was launched in June 2015. The initial effort has included:

Methods

- Formation of an Executive Advisory Board representing patients, oncologists from both the academic and community settings, advocates, communicators and industry partners. See page 35 for a list of Advisory Board members.
- An initial meeting of the Advisory Board to identify key issues, establish priorities and develop an action plan with monthly follow-up calls to obtain feedback and provide updates on progress.
- Assessment of best practices and programs as reported by Advisory Board members, demonstrated by online, print and audiovisual resources, and reported in scientific literature.
- Interviews with 27 key opinion leaders and stakeholders to assess perceived barriers, potential solutions and critical issues.
- Development and dissemination of an online survey to assess patient and caregiver attitudes and behaviors related to clinical trials. This survey produced 587 responses.
- Additional data from the Cancer Experience Registry on the patient experience with clinical trials.
- In-depth analysis of the survey and interview results from outside experts.

Over the next year, there are many plans for the continuation of this project. There will be additional data collection and analysis, with a focus on obtaining data on clinical trial participation by traditionally underserved groups, and developing targeted materials, tools and resources for patients, caregivers and providers.

FINDINGS

This Research Summary is a summary of the findings of this project through June 1, 2016. Specifically, in this section, we are reporting data from qualitative interviews with 27 key opinion leaders and stakeholders and survey results from 587 respondents. The quotes included in the text are taken from the stakeholder interviews.

IDENTIFYING AND ANALYZING BARRIERS

The quantitative and qualitative research done to date provide rich information about the multiple factors that affect participation in cancer clinical trials. Results suggest that barriers to participation can be generally grouped into the following (yet often overlapping) categories:

Location and Setting of Treatment

Where a patient receives treatment influences access to clinical trials and the likelihood that any individual patient will participate in a study. The major gap is between academic centers which have the resources to offer a wide range of clinical trials and community centers in which trials often increase the work and costs associated with patient care.

- Physicians in smaller centers and private practice have little incentive to offer trials – which are often labor intensive for physicians and staff, require additional monitoring of patients and can add costs to running the practice. Community cancer centers that do participate in clinical trials are often not able to offer a full range of studies for any specific cancer type. Smaller practices often do not have the ability to hire protocol coordinators or data managers and perceive trials as adding to the time requirements for each patient without measurable benefit to either the patient or the practice.

"I believe in clinical trials but we are not in a position to offer them to most of our patients. If they ask, or we think they can benefit from that approach, we refer them to one of the large cancer centers in the area. A lot of our patients would rather get their treatment closer to home."

– Community oncologist with large Northeast suburban practice

"We do have clinical trials in my practice, but we might have a couple of studies in my area and a total of ten or so across the board. That isn't going to serve every patient's need."

– Community oncologist specializing in genitourinary cancers in a Southwest community practice

"I knew my cancer was rare, and that it was advanced. We were thinking clinical trials from the beginning, but the hospital in my town didn't offer any for my cancer. We had to look elsewhere. I would have gone anywhere for the right trial."

– Stage IV thymus cancer patient

- Referring a patient to another treatment center can be an economic disincentive to a physician who stands to lose that patient and potential revenue streams from that individual. This economic issue is more likely to apply to oncologists in community settings than to academic physicians who are often salaried.

"It's not unusual for me to see a newly diagnosed patient who has had one round of standard chemotherapy. They might be a good candidate for a trial but they aren't eligible because they have already started treatment. I have to think that is a way for the community physician to hold onto that patient."

– Comprehensive cancer center oncologist

- Patients are often reluctant to leave their doctors and cancer centers to go to another facility for a trial. Oncology patients frequently have strong bonds with their oncologists. Leaving that doctor or traveling to another center, especially if it is distant, can be a serious obstacle to enrolling in a trial.

"I had a newly diagnosed patient with cancer of the pancreas whom I thought was an excellent candidate for a trial at another center. He heard me out and then declined. He was adjusting to the diagnosis and felt comfortable with our team, and didn't want to leave."

– Community hospital oncologist

"When I refer a patient to a trial at another center, my patients sometimes get upset. They ask if I am abandoning them or giving up. I have to reassure them that I am trying to get the best available option for them – and they can always come back."

– Comprehensive cancer center oncologist

"I recently had a close friend die. She had lung cancer and didn't want to travel to a cancer center away from her home to be on a clinical trial. There was nothing I could say to change her mind."

– Patient, two-time clinical trial participant

- Larger facilities may have more resources to help patients on a trial. These can include protocol coordinators and nurses, financial counseling offices, enhanced ability to provide emotional and psychological support, nutritional counseling and other symptom management as well as logistical support, such as transportation.

"Our whole team is involved in and educated about clinical trials. The patient can talk to me, or the nurse practitioner or the social worker. We also have an entire office that helps people work out the financial issues. No matter who the patient talks to, the nurse aide, the dietician, that person is going to understand the value of clinical trials."

– Comprehensive cancer center oncologist

- Clinical trials may be more embedded in the culture of academic medical centers and thus more likely to be discussed with patients and presented as a treatment option earlier and more often in the treatment process.

"We raise the issue of clinical trials with every patient we see in the first appointment. We want to make sure it is part of the conversation and that we don't leave anyone out, for any reason."

– Comprehensive cancer center oncologist specializing in advanced melanoma

"I have a list of about 50 trials available in my department at any one time. It is part of the normal process to talk about trials with this group of patients."

– Comprehensive cancer center oncologist specializing in lung cancer

Timing: Missed Opportunities at Every Stage of the Journey

There is no single "right" time for doctors to discuss the option of a clinical trial with a patient, but it is clear that there are missed opportunities at every stage of the journey.

- Initial diagnosis: For many people, the time immediately following diagnosis can be the period of highest stress, a time in which both patients and family are absorbing the impact of their altered world and trying to make decisions about their cancer and their lives. It can be difficult for doctors to bring up the option of clinical trials with patients who are experiencing information overload, looking for "answers" and may not fully understand their situations.

  The obstacle may be more formidable when the appropriate clinical trial requires changing doctors or treatment centers. In that case, often already fearful and distressed, patients are faced with having to negotiate a new system. Many also feel pressure to begin treatment as soon as possible and are reluctant to take the time to relocate for their care.

"I literally screamed when I was told I had metastatic lung cancer. I couldn't think of anything and I didn't hear anything the doctor said that day. I eventually did end up on a trial but I could never have considered it in those first few days."

– Patient

"We knew from the beginning the prognosis for my wife's cancer wasn't good, and that trials were an option, but our whole lives were turned upside down. We had questions about what to tell the kids and what would happen to her job. We just wanted answers."

– Caregiver, husband of patient who died of breast cancer

- Early treatment: Once primary treatment has been initiated, it is often difficult to assess patients for potential clinical trial eligibility or to introduce the topic to patients. For patients with high risk or advanced cancers, clinical trials are often a potential first option.

"If your doctor doesn't discuss clinical trials with you, you should raise the topic, and if you don't get a good answer, you should get a second opinion. A lot of patients though don't want to leave their doctors."

– Patient advocate and cancer survivor

- Ongoing Treatment: For patients who relapse, for whom initial therapies fail or for those who require ongoing therapy, the opportunity to discuss clinical trials can occur at numerous points. These conversations can be difficult as they often involve treatment for advanced disease or change in disease status. Patients may not perceive a benefit of being on the trial, which can then be exacerbated by the absence of open, honest discussion about individual values. They may fear being a "guinea pig" or getting a placebo, or believe that being on a trial is only for "last ditch efforts and lost causes." Additionally, this may be another point in which patients need to change doctors and treatment facilities to access appropriate trials.

"Every patient with advanced cancer needs to have that honest, open discussion about the available treatment options and the potential benefits. It has to include conversation about what is important to the patient. Trials are part of that conversation."

– Patient advocate and cancer survivor

"I have changed the language I use when I discuss clinical trials with my patients. I am much more careful about being clear about the potential benefits might be and what kind of expectations patients should have when they enroll on a trial."

– Oncologist specializing in gastric cancers

- Long-term Treatment: Increasingly, people with cancer are living longer with their cancers. For many, this means being on multiple treatments and experiencing a myriad of long-term effects of both their disease and its treatment. Patients report that long-term side effects are a major issue affecting quality of life. This growing population presents new opportunities for discussing patient values and quality of life and implementing studies designed to address these issues.

"We have more patients living longer on therapies that were not available a few years ago. We don't know much about the long term effects of these treatments. We need more trials to look at these issues."

– Oncologist practicing in an academic medical center

Patient and Physician Biases Related to Specific Populations

Traditionally, specific populations, including racial minorities, older adults and women have been underrepresented in clinical trials. While there have been significant, ongoing efforts to address these issues, recruiting and enrolling these individuals on trials continues to present challenges. There are a number of barriers that contribute to this problem.

- There are historical and cultural issues that engender mistrust of the medical profession and clinical trials among African Americans and other minorities. The shadow of the Tuskegee experiments still looms and continues to contribute to reluctance on the part of African Americans to participate in clinical trials.

"My African American patients do ask different kinds of questions about clinical trials. They are more likely to express distrust about the medical profession and reservations about being in a research study."

– Oncologist in an academic medical center

- Treatment decision making for some ethnic groups, including African-Americans, Hispanics and Arabs, is often rooted in family, community and culture. The process of educating and informing these individuals can require additional time and cultural sensitivity.

"I find I can't have the conversation about clinical trials with my minority patients during a regular appointment. We need to set up a separate time, and bring the family into the discussion. I also have to give these patients more time to talk to community connections."

– Academic oncologist

- There are persistent biases in recruiting and enrolling patients representing some groups on clinical trials. This includes older people as well as members of minority groups and underserved populations.
- Logistical and financial issues may affect minorities, older people and underserved populations more severely than other groups. While the costs of trials are covered, participating in a trial can involve indirect costs including transportation, child care and lost job time.

"People talk about Tuskegee, but the truth is that isn't what's keeping black people off of trials. The problem is that no one ever has the discussion with them. There's an assumption that they won't want to participate or won't comply."

– African American cancer survivor and advocate

"I was asked to be on an exercise trial after treatment. It meant going to the Center three times a week during the middle of the day. The only people who can do that are people who don't have to worry about being at work or who is going to take care of their kids."

– African American cancer survivor and advocate

Difficulties in Finding Appropriate Trials and Matching Them to Specific Patients

The information infrastructure for clinical trials is fragmented and inadequate. While there are multiple resources available to both physicians and patients, they are difficult to use and to interpret, often not current and scattered. While this problem is more pronounced in community settings, it is an obstacle to patients and physicians in academic medical centers as well.

"I spend hours on the phone and email talking to colleagues in other centers, trying to find trials for my patients. It requires that one on one connection and it is very time consuming, but in my field a lot of patients go on trial. We don't have great options with standard therapy."

– Comprehensive cancer center oncologist specializing in gastric cancer

"My wife was a market researcher. She really knew how to find information. When she was diagnosed, we wanted to find trials, but she couldn't figure it out. It was impossible to know what trial was right for her and whether she would be eligible."

– Husband of triple negative breast cancer patient

"I would say finding trials is the biggest challenge for me,"

– An oncologist who has practiced in both academic and community settings.

"I worked in the field. I knew people to talk to, but there were over a hundred open trials for my cancer, and I needed a trusted broker to guide me through the process. I couldn't do it on my own."

– Patient with advanced cancer

"There are resources that are in almost every clinical office setting that aren't being used and coordinated well with government resources such as clinicaltrials.gov. Requiring the database to have standardized data and content fields would allot electronic patient matching to clinical trials as part of the treatment discussion. It would provide the information to the clinician at the point of treatment. We believe this will significantly reduce missed opportunities."

– Patient advocate

Persistent Myths and Misconceptions

Despite the many, often excellent efforts of multiple organizations, patients still hold to a number of myths and misconceptions about clinical trials. These include:

- Fear of being a lab rat or guinea pig.
- Fear of getting a placebo.
- "End of the road" or last ditch effort concerns.
- Lack of perceived personal benefit.

Data from the CSC's Cancer Experience Registry® supports the prevalence and persistence of these beliefs as well as their impact on clinical trial enrollment.

Poor Public Awareness of the Importance of Clinical Trials

Studies indicate a generally high awareness of the existence of clinical trials, but the majority of patients still do not understand that a trial might be an option for them when they are diagnosed with cancer.

> *"We have to start educating people about trials before they are sitting in a doctor's office making a decision about treatment. We have done this with organ donation. We need the same kind of public information campaign for trials and research."*
>
> – Cancer survivor and advocate

The Challenges of Cancer Clinical Trial Designs

Traditional trial designs often present significant obstacles to potential patients in terms of eligibility requirements and logistical issues. In addition, many patients do not perceive clear potential benefit to an individual patient. Rigid designs that make crossover impossible or disqualify patients who develop side effects or complications can also serve as disincentives to patients and physicians.

New trial designs bring new challenges. While these trials are often more "adaptive" and flexible, they also:

- Are often focused on genetic mutations that occur in small percentages of patients – making recruitment more difficult.
- Are conducted at academic centers requiring many patients to change doctors or travel.
- Require tissue from biopsies, which may either not be available or require additional interventional procedures.
- Rely on oncologists, especially those in community setting, who may be unfamiliar with new trial designs to refer patients.

> *"I think the new trial designs will transform clinical research, but the impact is just beginning to be realized. It really has not made that much of a difference to patients or physicians yet."*
>
> – Oncologist

PROPOSING SOLUTIONS

The goal of *Frankly Speaking About Cancer Clinical Trials* is not just to increase the quantity but also the quality of resources available to patients, caregivers and providers. This requires a targeted and tiered approach that works to demystify clinical trials and incorporates the patient experience and voice into the discussion.

A main focus is on improving communications and creating tools and resources that will open the doors for patients and their treatment teams. This demands not just an increase in awareness of the importance of clinical trials, but an across-the-board improvement in the quality of the communications and outreach.

Broadly speaking, the pathway to achieving these goals includes:

- Identifying specific points at all stages of the cancer treatment process during which clinical trials can and should be discussed, and tailoring interventions to meet the specific needs of patients and caregivers at these times.
- Providing tools, resources and materials to all members of the treatment team to help navigate the discussion and the decision-making process. This needs to include, but also go beyond physicians. Nurses and nurse practitioners play a key role in patient communications, but many patients also trust other members of the team and seek information and advice from them.

- Providing tools, resources and materials to patients to assist with their understanding of clinical trials and aid in their decision making using patient-friendly, patient-generated language. These materials need to be more visual and attuned to the actual decision-making process that patients go through when they consider enrolling in a clinical trial. All tools should include patient testimonials and graphics that enhance the accessibility of the messages.
- Tailoring these resources to reflect differences in health literacy, cultural sensitivities, age and the potential benefits of clinical trials at various points in the treatment project. This requires inclusion of testimonials from patients, caregivers and key opinion leaders in language that is appropriate to their specific situations. A one-size-fits-all approach will not work.
- Refreshing and demystifying the language of clinical trials. A key to this is incorporating the many voices of patients and caregivers in any communication. An additional critical factor is working towards standardized, clear concepts and terminology to talk about clinical research and its benefits.
- Planning for focus groups and community-based research with minority cancer patients to discuss the specific barriers to and opportunities for clinical trial participation among group members.
- Making better use of existing clinical trials resources.
- Creating a better framework for including the patient perception of value in the discussion of clinical trials. This might include role modeling conversations for

both patients and providers as well as work sheets and other materials to help guide this conversation.

- Generating a public awareness campaign utilizing patients, caregivers and providers to raise awareness of clinical trials via traditional media, social media and grassroots efforts.
- Incorporating clinical trial awareness and advocacy in CSC's policy and grassroots initiatives.

Some solutions are beyond the reach of this endeavor. One interviewee, a well-informed caregiver for a young wife who died of triple negative breast cancer, suggested that IBM's Watson be charged with coming up with a new information matrix for matching patients to studies. While a major overhaul of the information infrastructure would be a significant contribution to the field, it can only be suggested by this project. Nor can the issues related to economic disincentives, overall trial design and many of the logistical challenges patients and physicians face be adequately addressed within this framework.

> *"I suggest having a modern infrastructure that at least provides the information to the patient and clinician in a key step forward. This would require standardized information regarding inclusion and exclusion criteria to be adopted by all clinical trials and including this information in EHRs, perhaps by requiring it in the Medicare/Medicaid Meaningful Use program."*
>
> – Patient Advocate

Specific solutions launched in this first year of *Frankly Speaking About Cancer Clinical Trials* include:

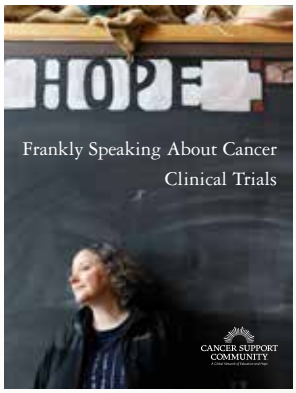
- Developing a photo novella (an eight-chapter book narrated by photos of cancer patients and captions that illustrate the conversations patients are and should be having about clinical trials with family, friends and their health care team).
- Developing English and Spanish fact sheets to help dispel myths and misconceptions about clinical trials.
- Videotaping cancer patients telling their own stories of participating in clinical trials.
- Enhancing and continuing to develop CSC's online clinical trial resources.
- Recruiting a Cancer Support Helpline® Clinical Trials Navigator to provide patients with additional one-one-one support and guidance through the clinical trials process.
- Making better use of existing resources, including the CSC's Open to Options® program and other organizations' well-developed clinical trial materials and services.

- Launching a public awareness campaign utilizing patients, caregivers and providers to raise awareness of clinical trials via traditional media, social media, online and grassroots efforts.
- Presenting a series of 15 Clinical Trial Workshops in CSC Affiliates across the country.
- Presenting a series of clinical trial webinars, tweet chats and other online and social media events and promotions.
- Hosting a three-part series on CSC's internet radio show, *Frankly Speaking About Cancer.*
- Incorporating clinical trial awareness and advocacy in CSC's policy and grassroots initiatives.

Next Steps

This is an ambitious and optimistic agenda, one that can only be accomplished in collaboration with CSC's partners and advisors. Over the next year, our specific objectives include expanding efforts to assure that we address the needs of underserved populations and continue developing and disseminating the materials and programs that have been developed to date and are planned. These include:

- Conducting focus groups or other community-based research in diverse geographic locations with African Americans, Latinos and Asian Americans to deepen and broaden our knowledge and understanding of the culturally-based issues that currently impact these populations in their decision-making processes related to clinical trials.
- Developing targeted materials for specific populations. Special emphasis will be given to assuring that these materials are culturally appropriate, accessible and in the language of the user populations.
- Developing partnerships with organizations and providers to optimize the distribution of these materials.
- Disseminating and evaluating the *Frankly Speaking about Cancer Clinical Trials* photo novella. Early discussions indicate a strong interest from cancer centers and other organizations in partnering to provide this unique resource as a tool to use with their patient and caregiver populations. A key to these partnerships will be translating the photo novella into Spanish.
- Utilizing CSC Workshops and Advisory Boards to further explore the issue of refreshing the language about clinical trials and making it more congruent with the patient voice and experience.
- Developing patient activation, discussion and shared-decision-making tools to assist patients in starting discussions about clinical trials with their health care team, assessing their values and beliefs around clinical trials, and understanding the personal benefits of participating in clinical trials.
- Expanding our national media, social media and grassroots campaigns to raise awareness of clinical trials and the importance of clinical research as well as to raise awareness among patients and health care providers of the supportive services offered by CSC and other organizations to help understand and navigate clinical trial search, barriers, and decision making.



Detailed Results of Patient and Caregiver Survey

BACKGROUND

This chapter summarizes the key findings from the Cancer Support Community's survey of 506 patients and 81 caregivers conducted in late 2015 through early 2016. The survey focused on patient and caregiver beliefs, attitudes, decision making, information preferences, information-seeking efforts, patient-provider communication and experiences related to clinical trial participation.

The Cancer Support Community (CSC) conducted this survey to inform the development of the Frankly Speaking about Cancer Clinical Trials program initiated in June 2015. The survey was first conducted in November, 2015 and received a total of 532 responses. In an effort to increase participation from underserved populations who were not well represented in the original effort, CSC worked with several partner organizations to re-release the survey in March 2015, an effort that resulted in 55 additional responses.

The survey consisted of between 39-50 questions, depending on the respondent's cancer experience with clinical trials. In both releases, respondents were recruited through CSC mailings, social media and with the cooperation and assistance of partner organizations.

DISTINGUISHING FEATURES OF THE SURVEY

The CSC patient survey is unique, because of its sampling strategy, and the depth of questions and additional topics explored.

- Few, if any, surveys assess attitudes and awareness of clinical trials among cancer caregivers. The inclusion of caregiver responses in this survey provides an in-depth perspective. Given the influence that cancer caregivers can have in both the treatment decision making and the care of cancer patients, the data provided by this survey address a significant informational need.
- The design of this survey was unique in both breadth and depth in terms of how it assesses many topics, including clinical trial communications, information-seeking, values, preferences, attitudes, and beliefs. The survey consisted of up to 50 questions (depending on whether or not a respondent had considered participating in a clinical trial) written and reviewed by experts in the field. The survey also allowed respondents to explain their understanding and experience of clinical trials in open-ended questions.

PARTICIPANT DEMOGRAPHICS

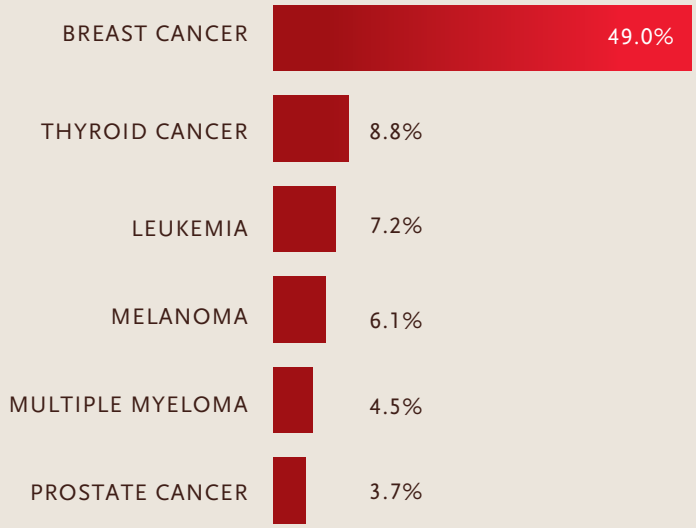
- **85.5%** of patients and **82%** of caregivers were **female.**
- The average age of **patients** was **59 years** and the average age of **caregivers** was **52 years.**
- **85%** of patients and **70%** of caregivers identified as **Caucasian.**

DEMOGRAPHIC CATEGORY	CANCER PATIENTS	CANCER CAREGIVERS
AGE	58.7 years old (s.d. =11.3 years)	52.2 years old (s.d. =13.2 years)
GENDER	14.1% Male 85.5% Female	15.7% Male 81.9% Female
RACE & ETHNICITY	84.8% Caucasian 1.6% American Indian 6.5% African-American 1.8% Asian 7.5% Hispanic or Latino	69.8% Caucasian 6.0% American Indian 18.0% African-American 3.6% Asian 13.3% Hispanic or Latino
HIGHEST LEVEL OF EDUCATION	0% Less than high school 6.4% High school, trade school, or GED 28.1% Some college 30.9% Bachelor degree 34.6% Graduate degree or higher	2.4% Less than high school 12.2% High school, trade school, or GED 19.5% Some college 35.4% Bachelor degree 30.5% Graduate degree or higher

CANCER HISTORY

The following describes the patient sample in terms of their experiences with cancer:

TYPE OF CANCER (N=506):



TIME SINCE DIAGNOSIS:

44.5% diagnosed 2011 or later

16.4% diagnosed 2014 or later

CANCER STAGE:

27.9% diagnosed with metastatic cancer

26.4% experienced recurrence of cancer

62.4% in remission

CANCER TREATMENT

JUST UNDER HALF OF PATIENTS (48.3%) ARE CURRENTLY IN TREATMENT

- 44.1% traveled beyond hometown for treatment
- 52.4% received 2nd opinion for treatment

TREATMENT SETTING (INITIAL):

- 31.2% Academic or comprehensive cancer center
- 33.3% Community hospital/ community cancer center
- 24.2% Private oncology practice
- 0.6% Veterans Affairs (VA) hospital/ medical center
- 3.2% Family practice/primary care physician
- 0.6% I don't know

32.5% OF PATIENTS CHANGED TREATMENT CENTERS THROUGHOUT THEIR TREATMENT

For those who changed treatment facilities, 55% are now at an academic or comprehensive cancer center. For those who have changed, they are now at:

- 55.2% Academic or comprehensive cancer center
- 15.2% Community hospital or community cancer center
- 16.6% Private oncology practice
- 2.1% Veterans Affairs (VA) hospital or medical center
- 2.1% Family practice/primary care physician

AWARENESS OF AND BELIEFS ABOUT CLINICAL TRIALS

- **81.4%** had heard of a clinical trial before their diagnosis.

Participants reported their beliefs about the reasons for clinical trials and results are presented in the chart below:

WHY ARE CLINICAL TRIALS CONDUCTED?	% ENDORSING
Find out if a new treatment (not yet approved by Food and Drug Administration) works	83.0%
Test whether a new treatment is safe	75.5%
Find better ways to treat symptoms from cancer and cancer-treatment	69.4%
Compare a new treatment to a treatment that is already FDA approved	69.2%
Track people over time	62.1%
Improve quality of life	58.3%
Find out if a new treatment will help a specific patient	56.5%
Compare two FDA approved treatments	51.2%
Find better ways to detect cancer early	47.2%
Find better ways to prevent cancer	44.1%
Provide new treatments for cancer to patients who cannot afford them otherwise	38.7%

BELIEFS ABOUT CLINICAL TRIALS

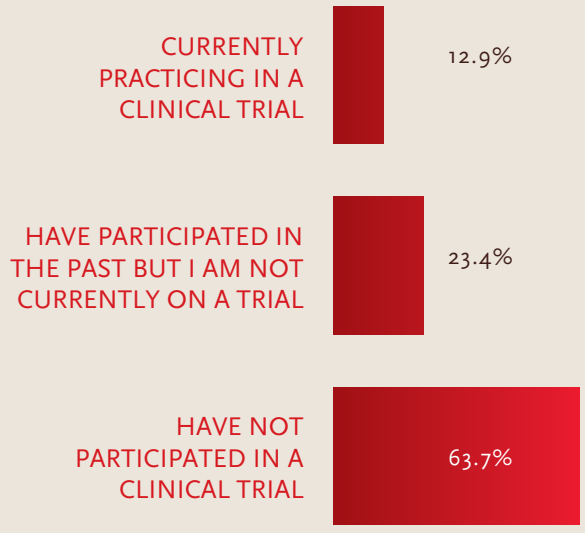
	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE OR DISAGREE	AGREE	STRONGLY AGREE
I would have access to new, innovative treatments	0.9%	2.0%	20.8%	50.5%	25.8%
I trust that the health care team running the clinical trial has my best interest at heart	4.3%	9.5%	28.2%	40.1%	18.0%
I am uncomfortable with being randomly assigned (like tossing a coin) to determine which treatment I receive	6.3%	17.6%	21.9%	37.9%	16.3%
Cancer clinical trials are the only way to find new treatments for patients	3.2%	23.0%	24.8%	34.5%	14.6%
I do not have concerns that I will be used as a "guinea pig" for research	12.6%	17.1%	26.6%	30.4%	13.3%
A clinical trial would have more appointments and procedures	3.4%	13.6%	25.9%	44.0%	13.2%
I have financial concerns about participating in a clinical trial (for example insurance deductibles or other out-of-pocket costs)	19.0%	22.4%	25.6%	22.0%	10.9%
I have logistical concerns about participating in a clinical trial (for example time off work, childcare)	16.1%	25.3%	21.9%	26%	10.6%
I fear the treatment wouldn't work	8.1%	13.8%	40.4%	28.0%	9.7%
I have unanswered questions about clinical trials	15.8%	21.8%	30.0%	25.9%	6.4%
I would receive a placebo/"sugar pill"	10.3%	16.4%	49.3%	18.7%	5.3%
I have transportation concerns about participating in a clinical trial	23.3%	27.6%	20.6%	20.6%	7.9%

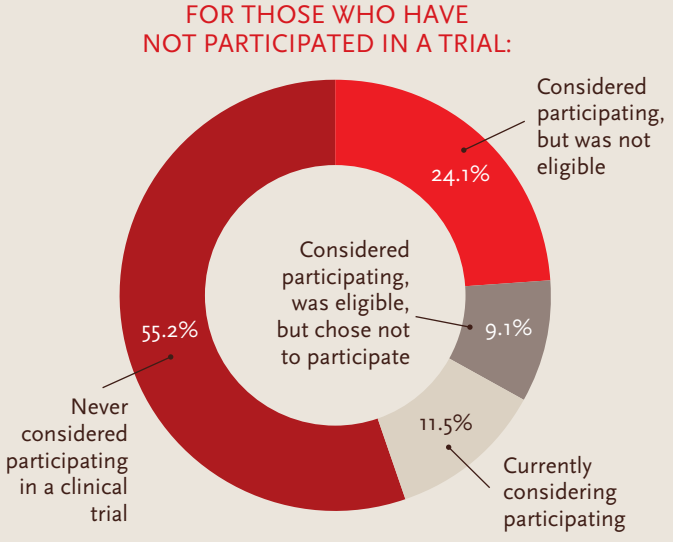
BELIEFS ABOUT CLINICAL TRIALS (CONT.)

	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE OR DISAGREE	AGREE	STRONGLY AGREE
I would have a better quality of life if I participated in a clinical trial	8.2%	22.3%	55.6%	9.6%	4.3%
There are no clinical trials available in my community	28.9%	19.9%	34.5%	11.3%`	5.4%
A clinical trial is the last resort once you've run out of other treatment options	25.3%	31.2%	17.8%	17.8%	7.9%
I have privacy concerns about participating in a trial	28.1%	35.4%	25.6%	7.3%	3.6%
I do not have concerns about potential side effects	28.4%	46.1%	13.9%	9.5%	2.0%

CLINICAL TRIAL PARTICIPATION

- Just over a third of patients (**36.3%**) have participated in a clinical trial.
- **52%** of patients had never considered participation in a clinical trial.





CLINICAL DECISION MAKING

- One important factor in the decision to participate is whether it would mean a change in the treatment facility or health care team.
    - 31% of patients reported a change in facility or provider would be necessary to participate in the trial, and
    - 49% reported that this would influence their decision about participating.
- For the majority of patients (71%), the most important reason to participate in a clinical trial was for the hope for a better chance of survival.
- Furthermore, nearly two-thirds reported improved quality of life also influenced their decision.

What was important regarding clinical trial decision making:
Patients who participated/considered

	NOT AT ALL IMPORTANT	LOW IMPORTANCE	NEUTRAL	MODERATELY IMPORTANT	VERY IMPORTANT
Hope for greatest chance of survival	3.2%	.8%	10.4%	14.8%	70.8%
Overall better quality of life	1.2%	1.6%	13.9%	19.0%	64.3%
Helping future patients	1.6%	2.0%	10.4%	29.4%	58.7%
Having access to new, innovative treatments	1.6%	1.6%	12.4%	26.7%	57.4%
The possibility of fewer side effects from treatment	2.4%	4.0%	19.8%	23.4%	50.4%
Getting access to extra levels of care and support	1.6%	4.0%	13.6%	31.6%	49.2%
The trial had little to no additional cost to me	4.9%	4.5%	19.4%	25.9%	45.3%
My doctor recommended it	6.3%	4.4%	25.4%	26.2%	37.7%
I asked for or found additional information about clinical trials	7.5%	3.8%	32.5%	34.2%	22.1%
My family/ significant others have strong positive feelings about me participating	11.6%	7.2%	35.7%	24.1%	21.3%
Hearing the experiences of other patients	9.0%	10.2%	29.4%	32.2%	19.2%
Another health care provider encouraged it (e.g. nurse, social worker)	10.9%	8.1%	40.3%	26.6%	14.1%

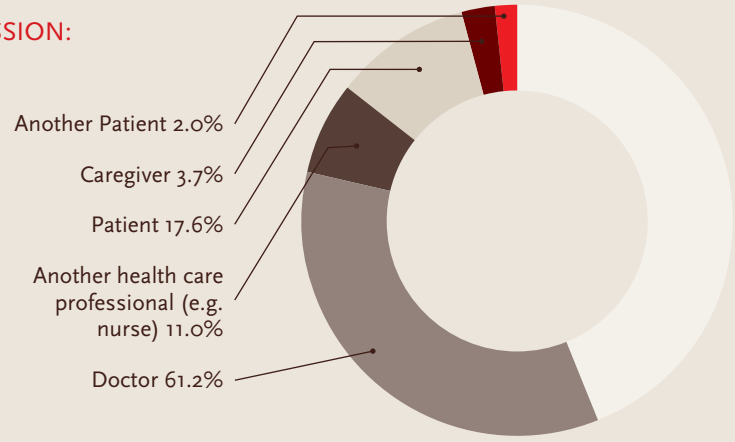
What was important regarding clinical trial decision making:
Patients who never considered clinical trials

	NOT AT ALL IMPORTANT	LOW IMPORTANCE	NEUTRAL	MODERATELY IMPORTANT	VERY IMPORTANT
Hope for greatest chance of survival	1.5%	1.5%	7.4%	14.8%	74.8%
Overall better quality of life	0.7%	2.0%	12.2%	20.8%	65.1%
Helping future patients	0.0%	3.4%	7.4%	26.4%	62.8%
Having access to new, innovative treatments	0.7%	1.4%	9.5%	29.3%	59.2%
Getting access to extra levels of care and support	0.0%	0.7%	9.4%	34.2%	55.7%
The possibility of fewer side effects from treatment	0.7%	1.4%	12.2%	33.1%	52.7%
The trial had little to no additional cost to me	2.0%	4.1%	24.3%	34.5%	35.1%
My doctor recommended it	2.0%	4.7%	11.4%	30.2%	33.6%
Hearing the experiences of other patients	1.3%	8.1%	22.8%	36.9%	30.9%
I asked for or found additional information about clinical trials	6.7%	7.4%	30.2%	26.8%	28.9%
My family/significant others have strong positive feelings about me participating	2.0%	7.4%	40.5%	30.4%	19.6%
Another health care provider encouraged it (such as a nurse or social worker)	4.1%	7.4%	36.5%	39.2%	12.8%

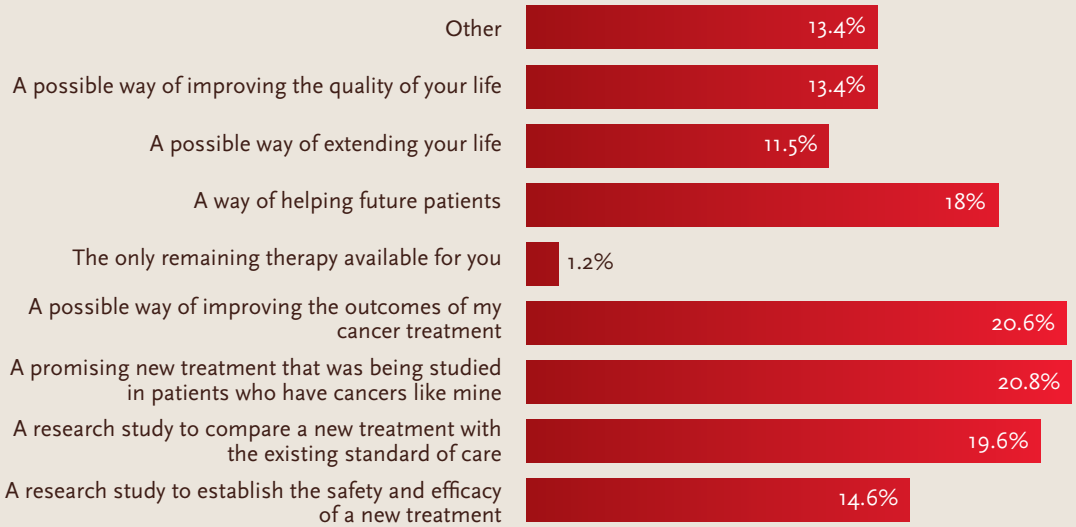
COMMUNICATION ABOUT CLINICAL TRIALS

PERSON FIRST INITIATING THIS DISCUSSION:

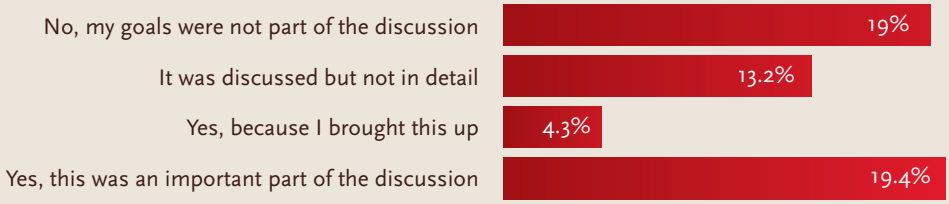
Just over half of patients (56.7%) reported that they had discussed a clinical trial with their health care team. For over half of these patients, that discussion was initiated by their physician.



HOW WAS CLINICAL TRIAL PRESENTED TO YOU?



Only 19% felt that their goals and values related to participating in a clinical trial were meaningfully addressed in the discussion with their healthcare team.



SEEKING INFORMATION ABOUT CLINICAL TRIALS: EXPERIENCES AND PREFERENCES

- 93% percent reported more time with their doctors to discuss the trial would be "somewhat" or "very" helpful in aiding in decision making. While 57% reported having had this, notably one quarter reported not having this at all.
- 61% reported that a website which included clinical trial information would be "very helpful" in identifying clinical trials or aiding in decision-making, yet only 22% were provided with a website that explained clinical trials. One third located a website on their own.
- 66% reported that speaking directly with another patient who had participated in a clinical trial would be helpful, yet only 6% of patients reported that this was an option offered to them.
- Nearly 80% reported that receiving images (e.g. photos, illustrations, or animations) that helped explain clinical trials would be "somewhat" or "very" helpful, yet only 11% received this information.

A series of charts illustrating these findings are presented below and on the next pages. Some questions were asked to only those who had participated in or considered a trial.

Never considered participating in a trial: What would be helpful to have when making decisions about clinical trials?

	NOT AT ALL HELPFUL	SOMEWHAT HELPFUL	VERY HELPFUL
More time with my doctor to discuss the trial	0.0%	18.1%	81.9%
Printed, easy to understand materials to take home and read	0.7%	25.5%	73.8%
More time with a nurse or research coordinator to discuss the trial	2.7%	29.5%	66.2%
A one-on-one conversation with a nurse, social worker or counselor who could help me develop questions so I could to talk to my doctor about my options	8.2%	34.0%	57.8%
A website that explained clinical trials and included patient stories	2.0%	40.5%	57.4%
A one-on-one conversation with another patient who has participated in a trial	4.1%	44.6%	51.4%
A website or other tool that helps me locate clinical trial options in my area	6.1%	44.9%	49.0%
Videos from health care providers and patients explaining clinical trials	6.8%	51.4%	41.9%
Images (photos, illustrations, animation) that help explain clinical trials	10.1%	48.3%	41.6%
An internet forum where I could get my specific questions answered about clinical trials and could interact and learn from other patients who have been on clinical trials	11.5%	51.4%	37.2%

Participated or considered participating in a trial: What was helpful to have when making decisions about clinical trials?

	NOT AT ALL HELPFUL	SOMEWHAT HELPFUL	VERY HELPFUL
A one-on-one conversation with another patient who has participated in a trial	5.6%	28.2%	66.1%
More time with my doctor to discuss the trial	6.5%	31.5%	62.1%
A website or other tool that helps me locate clinical trial options in my area	11.3%	27.6%	61.1%
A website that explained clinical trials and included patient stories	6.0%	33.9%	60.2%
A one-on-one conversation with a nurse, social worker or counselor who could help me develop questions so I could to talk to my doctor about my options	14.2%	28.5%	57.3%
A website that explained clinical trials	7.7%	41.9%	50.4%
Printed, easy to understand materials to take home and read	8.2	42.5%	49.4%
An internet forum where I could get my specific questions answered about clinical trials and could interact and learn from other patients who have been on clinical trials	18.3%	36.3%	45.4%
More time with a nurse or research coordinator to discuss the trial	20.3%	41.5%	38.2%
Images (photos, illustrations, animation) that help explain clinical trials	20.3%	45.8%	33.9%
Videos from health care providers and patients explaining clinical trials	22.0%	44.5%	33.5%

What clinical trial information had you been offered or located (for those who had participated or considered participating)?

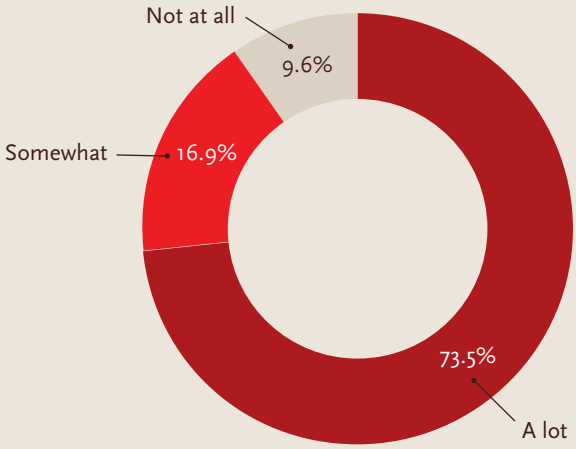
	OFFERED TO ME BY MY HEALTH CARE TEAM	I FOUND	OFFERED TO ME BY MY HEALTH CARE TEAM AND I ALSO FOUND	WASN'T OFFERED AND/OR COULD NOT FIND
Time with my doctor to discuss the trial	57.4%	9.4%	9.8%	23.4%
Time with a nurse or research coordinator to discuss the trial	54.5%	4.3%	8.9%	32.2%
Printed, easy to understand materials to take home and read	52.3%	8.2%	8.6%	30.9%
A one-on-one conversation with a nurse, social worker or counselor who could help me develop questions so I could to talk to my doctor about my options	33.7%	4.0%	4.8%	57.5%
A website that explained clinical trials	22.3%	32.3%	11.5%	33.8%
Images (photos, illustrations and/or animation) that helped explain clinical trials	11.2%	10.8%	3.6%	74.3%
Videos from health care providers and patients explaining clinical trials	6.4%	8.4%	4.8%	80.3%
A one-on-one conversation with another patient who has participated in a trial	6.0%	9.2%	4.4%	80.5%

CANCER CAREGIVERS AND CLINICAL TRIALS

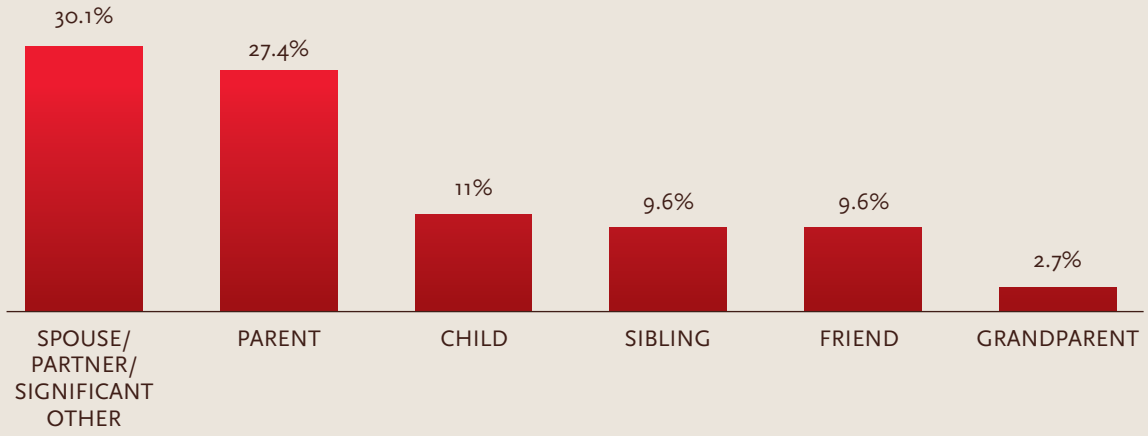
74% of caregivers "strongly identified" with being a cancer caregiver; nearly one third were providing care to their spouses or partners.

- 71.0% of caregivers had heard of clinical trials before diagnosis.
- 49.3% reported that clinical trials were discussed in regards to the patient.
- Who initiated conversation:
  Doctor 65.6%
  Caregiver 21.9%
  Patient 12.5%
- 54.4% of caregivers sought information about clinical trials on their own.

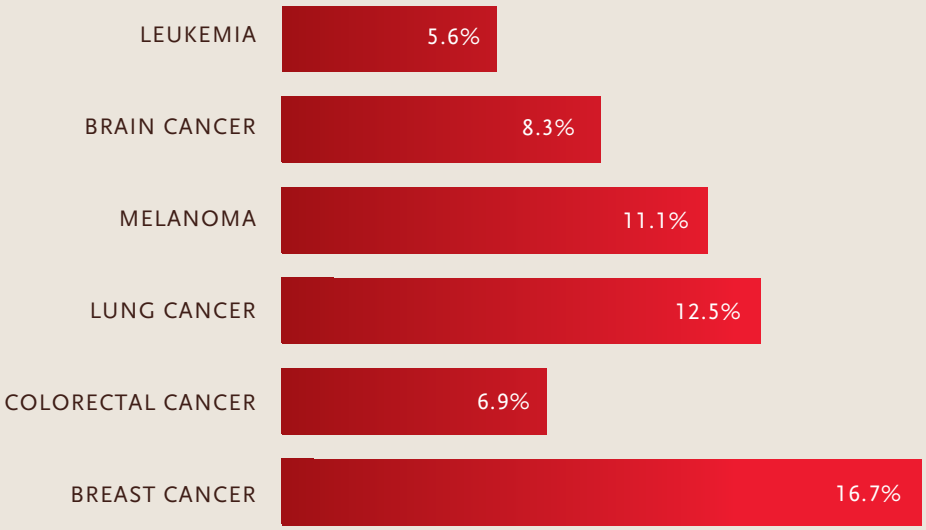
HOW STRONGLY DO YOU IDENTIFY AS A CANCER CAREGIVER?



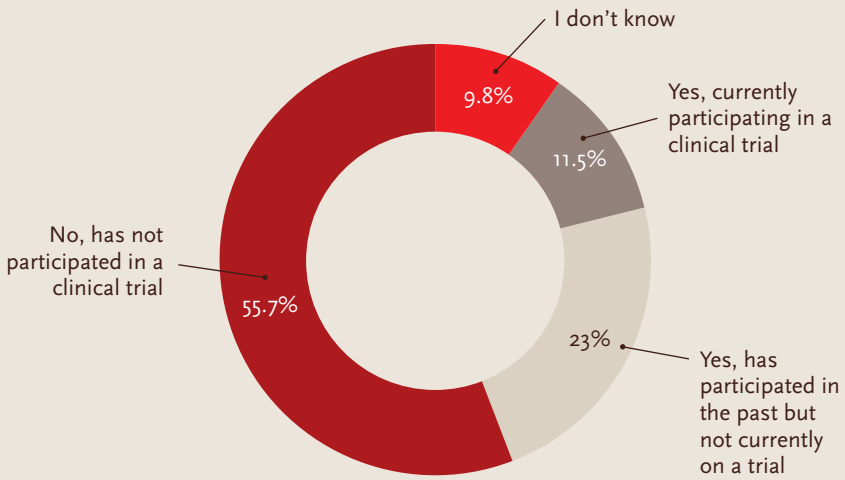
CARE RECIPIENT IS:

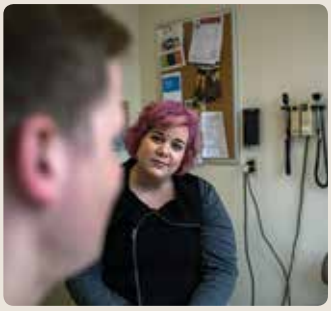


PRIMARY TYPE OF CANCER



HAS THE PATIENT PARTICIPATED IN A CLINICAL TRIAL?





Caregivers play an important role in the discussion about clinical trials, with 74% reporting that they would strongly encourage the patient to participate in the trial.

Caregiver beliefs about cancer clinical trials (n=58 respondents)

	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE OR DISAGREE	AGREE	STRONGLY AGREE
Cancer clinical trials are the only way to find new treatments for patients	5.1%	18.6%	23.7%	33.9%	18.6%
The patient would have a better quality of life if participated in a clinical trial	0%	15.8%	63.2%	14.0%	7.0%
I do not have concerns about potential side effects	23.7%	50.8%	16.9%	6.8%	1.7%
I am uncomfortable with the patient being randomly assigned (like tossing a coin) to determine which treatment is received	7.0%	12.3%	31.6%	40.1%	8.8%
I trust that the health care team running the clinical trial has the patient's best interest at heart	1.7%	6.8%	33.9%	44.1%	13.6%
I fear the treatment wouldn't work for the patient	3.4%	12.1%	37.9%	39.7%	6.9%
I do not have concerns that the patient will be used as a "guinea pig" for research	6.9%	24.1%	29.3%	29.3%	10.3%
The patient would have access to new, innovative treatments	1.7%	3.4%	15.5%	50.0%	29.3%
The patient would receive a placebo/"sugar pill"	14.0%	22.8%	47.4%	15.8%	0%
I have financial concerns about the patient participating in a clinical trial (for example insurance deductibles or other out-of-pocket costs)	16.9%	16.9%	30.5%	33.9%	1.7%
I have logistical concerns about the patient participating in a clinical trial (for example time off work, childcare)	6.9%	20.7%	27.6%	41.4%	3.4%

	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE OR DISAGREE	AGREE	STRONGLY AGREE
A clinical trial would have more appointments and procedures	5.2%	6.9%	29.3%	50.0%	8.6%
I have transportation concerns about the patient participating in a clinical trial	8.9%	16.1%	26.8%	42.9%	5.4%
I have privacy concerns about the patient participating in a trial	19.6%	32.1%	30.4%	16.1%	1.8%
I have unanswered questions about clinical trials	6.9%	10.3%	37.9%	41.4%	3.4%
A clinical trial is the last resort once the patient has run out of other treatment options	15.5%	32.8%	25.9%	24.1%	1.7%
There are no clinical trials available in the patient's community	5.2%	19.0%	44.8%	20.7%	10.3%

Conclusion

Our qualitative research points out barriers to clinical trial participation and some potential solutions to those barriers, especially refreshing and demystifying the language of clinical trials and using patients' own voices in communications. Working towards standardized, clear concepts and terminology to talk about clinical research and its benefits will be critical.

Our quantitative research points out factors that patients and caregivers find important when making clinical trial decisions and concerns that patients and caregivers have about clinical trials. This research also starts to document language that patients use to describe the clinical trials in which they have participated.

Since many respondents may be connected to the CSC community and were responsive to an online survey, we expected our survey sample to include a particularly proactive and engaged subset of individuals. This is evidenced by the fact that over a third of respondents reported participation in a clinical trial, a cancer clinical trial participation rate almost ten times the average. However, even this proactive, engaged set of patients and caregivers had concerns that were not addressed or communicated in a way to completely dispel decades-old myths and misconceptions.

Concerns that both patients and caregivers shared included:

- Possible side effects.
- Discomfort with randomization.
- Financial concerns.
- The patient will be used as a "guinea pig" for research.
- A clinical trial is the last resort once the patient has run out of other treatment options.

More caregivers than patients had concerns about:

- Transportation.
- Fears the treatment won't work.
- Logistical concerns.
- Unanswered questions.

Whether the patient had participated in a trial or not, the most important factors when making clinical trial decisions were:

- Hope for greatest chance of survival.
- Overall better quality of life.
- Helping future patients.
- Having access to new, innovative treatments.
- The possibility of fewer side effects from treatment.
- Getting access to extra levels of care and support.

Factors respondents reported would be helpful in aiding decision making that they tend not to get are:

- More time with their doctors to discuss the trial.
- Websites with clinical trial information.
- Being able to speak directly to another patient who had participated in a clinical trial.
- Receiving images (photos, illustrations, animations) that helped explain clinical trials would be helpful.

Taken together, these findings suggest a clear need to better construct messaging around clinical trials and to more carefully design efforts to reach potential clinical trial participants and their caregivers. For maximum impact, these messages would be communicated with patient-friendly, patient-centric language gathered from and tested by patients themselves. CSC looks forward to partnering in the future with other individuals, organizations and institutions to make progress on achieving the next steps outlined on page 17 and the broad goals outlined on page 15.

CSC is grateful for the patients, caregivers, advocates, health care providers and researchers who freely shared their time and voices. Our goal is to hear their voices, as well as continue to listen so that CSC, other organizations and institutions can increase participation in cancer clinical trials, ultimately leading to advancements in cancer prevention, diagnosis, treatment and quality of life.

We wish to thank the *Frankly Speaking About Cancer Clinical Trials* National Advisory Board for their thoughtful input.

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