Giving Voice to Cancer Progress

Results from the PACE Cancer Perception Index:
A Six-Nation, Public Opinion Survey of Cancer Knowledge and Attitudes
The war on cancer is far from over. But we are making steady progress. Progress that depends on continuous innovation - small steps that we hope will one day lead to cures for the more than 200 types of cancer we now know exist. Progress that has to be protected, in light of spiraling healthcare costs and global economic trends that pose a threat to continuous innovation and, in turn, our fight against cancer.

That’s why Lilly Oncology has launched a global network to help improve the way in which decisions are made on cancer-related policy, the development of new treatments, and patient access to care. Called PACE (Patient Access to Cancer care Excellence), the initiative aims to speed up the progress of research and development in cancer treatment and encourage policies that give more patients access to high-quality, personalized cancer care.

We’re putting the interests of patients at the center of our efforts and are working in a collaborative way with many stakeholder groups. To achieve our goals, we’re implementing public initiatives, policy research, training programs, events, and a variety of communications efforts.

As a first step, we surveyed the general public, cancer patients, and caregivers in several countries (France, Germany, Italy, Japan, the United Kingdom, and the United States) to understand their perspectives – a total of more than 4,300 people. This is what we learned.

Sue Mahony, Ph.D.
President, Lilly Oncology

The artwork and narratives featured on the cover and throughout this brochure were selected from the Lilly Oncology On Canvas: Expressions of a Cancer Journey Art Competition and Exhibition presented by Lilly Oncology in partnership with the National Coalition for Cancer Survivorship (NCCS). To view additional submissions, visit www.LillyOncologyOnCanvas.com.
Patients’ voices should play a more central role in decisions affecting how cancer research is focused and funded and which treatments reach those who need them most. Achieving a stronger patient voice is one of four key goals of the PACE Action Plan. With this in mind, PACE surveyed the general public, in addition to people with cancer and their caregivers, to learn what they know and how they feel about the current state of cancer treatment and care and the role of the healthcare system and patient involvement in improving that care. We also wanted to get a clear picture of what they expect – not only from us, but from all who have joined in the fight against cancer.

Here’s what we asked, and what people told us…

Is cancer a death sentence?

Today, a near majority (48 percent) in the countries surveyed say “no.” In the U.S., 65 percent of the public agrees that cancer is not a death sentence. And it’s true: cancer deaths in the U.S. have fallen 20 percent in the last 20 years.1 Deaths from cancer have also declined in the five other countries included in the PACE survey.

And while cancer remains a global health crisis – with more than a 70 percent increase in worldwide incidence and mortality expected from 2008 to 20302 – many cancers have now shifted from an acute to a more chronic disease, and some cancers are now curable.3

“The Path”

When I first embarked on my cancer journey, the path ahead was daunting. There was so much to learn about my cancer, decisions to make about my treatment, and a wide range of emotions to navigate. The terrain felt unknown, overgrown and overwhelming.

With every tentative step, the path began to reveal itself to me. As I slowly walked, the way became clear, and, over time, I realized that if I just looked up, my path was dotted with signs of hope to guide me along the way. This short poem from my cancer journal inspired the painting:

Even when you cannot see the path that you must walk once you step out on faith you’ll find your way by heart.

The voices of cancer patients should be louder

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21% did not know / neither agree nor disagree

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“Jumping Out of the Darkness”

Acrylic by a Person Diagnosed with Cancer

Some say that when you are on the brink of life and death, your life flashes before your eyes. When I learned I had cancer, I saw my future and everything I needed to live for. If I left now, I would miss out on so much – my kids, my husband. I knew I needed to be strong and come out fighting. So, whenever I needed to find my “happy place,” I would close my eyes and picture myself horseback riding. Cancer simply became a hurdle for me to jump over – as did chemo, hair loss, surgery, and double mastectomy. Each time, I dug in my heels, grabbed onto the reins, closed my eyes, and jumped like my life depended on it.

How satisfied are you with the progress against cancer?

Nearly 60 percent surveyed are satisfied with the progress made in the fight against cancer over the past 20 years. And more than half of overall respondents (56 percent) realize that continuous innovation – small steps – are responsible for treatment progress, rather than major breakthroughs. Still, concerns remain:

- In every country but France, a majority or near majority thinks its country invests too little in fighting cancer.
- Strong majorities say it takes too long for new cancer medicines to reach patients.
- And in all countries surveyed, except Japan, most state that progress in cancer research will be slowed as a result of the poor economy.

Will progress in cancer research be slowed because of the poor economy?

- France: 63%
- Germany: 62%
- Italy: 64%
- Japan: 46%
- UK: 70%
- U.S.: 66%

“We’re seeing progress in cancer medicine and care through countless innovations that add up to sizeable victories for patients. Still, current economic pressures threaten this progress and place our society’s larger developments against cancer at risk.”

– Newton F. Crenshaw, Vice President, Lilly Oncology

Is the public satisfied with progress made in the fight against cancer?

- France: 59%
- Germany: 61%
- Italy: 59%
- Japan: 30%
- UK: 73%
- U.S.: 61%
The patients come – some alone, others with friends and family. Sick, weak and scared, they sit for hours receiving their treatment. Body in pain, stomach in knots, hands clenched tight. Their future is unknown, yet they sit and wait. I, your nurse, am here to say, “You’re not alone,” for each one of you has an angel with you. The angel gives me the strength to face my day with you. For I see your pain, I hear your worries and I touch your hands. Again, I, your nurse, am here to say, “We are not alone.” I’m a nurse who works in the inpatient cancer unit. My job is hard, but my patient’s fight is harder. The angels help us both to fight a good fight.

Is cancer one disease, or many?
More than four out of 10 people worldwide believe that cancer is a single disease, when in fact it is more than 200 different diseases with many different biological, genetic, and environmental origins. However, a clear majority (62 percent) believes that the same cancer treatment can produce very different results in patients with similar diagnoses.

How much does it cost for a new cancer medicine to be developed?
Large numbers of the public surveyed underestimate the cost and time involved in making a new medicine available to be prescribed to patients. For example, nearly three-quarters of U.S. respondents believe that cancer medicine development costs $100 million or less. In fact, the average cost of developing and delivering one medicine from the laboratory to patients is estimated at $1.2 billion.

How long does it take to develop a new treatment?
U.S. respondents come closest to estimating the number of years it takes to develop a new treatment, with 55 percent indicating 10 or more years. But between 69 and 84 percent in the five other countries believe it takes 10 years or less. In actuality, it takes an average of 10-15 years for a potentially safe and effective medicine to go from laboratory to patients. Ultimately, only five in 5,000 compounds that enter preclinical testing progress to human testing, and only one of these five receives approval for therapeutic use.
The Forest

Watercolor by a Person Diagnosed with Cancer

When I was diagnosed with ovarian cancer, I was overwhelmed by the journey I faced. I had many questions and decisions to make to start my journey. At first, I was paralyzed by the forest of information and the fear of having cancer. With the help of my medical team, family and friends, I have been able to work through the information and make decisions that allow me to find my way through the forest. My journey continues to challenge me with new twists and turns. During this journey, I discovered that I can have a fulfilling life with cancer that is serene and full of happiness.

What concerns you most about a cancer diagnosis?

When it comes to a cancer diagnosis, the inability to pay for treatment is nearly as big a fear for many people (65 percent) as the effect on family and friends (67 percent) and the fear of death (66 percent).

Among patients across the six countries, information about the financial impact of cancer tops the list of unmet needs (55 percent), although help navigating treatment options and information about what to expect emotionally are not far behind.

What do you know about personalized medicine?

Awareness of personalized medicine (the tailoring of medical treatment to the individual characteristics of each patient) is not high. Only one-third of overall respondents and slightly less than half of U.S. respondents are familiar with the term. But support was strong after the concept was explained.

Eighty-five percent think doctors need to discuss personalized medicine with their patients, and 70 percent say they are willing to be tested for it even if it may not work for them. More than 50 percent agree that personalized medicine is most likely to save the healthcare system money by reducing costly side effects and limiting expensive treatments to patients who are likely to respond. Seventy-two percent of the public agree that there is not enough information available to the general public about new treatment options like personalized medicine.

Patients need more information about new treatments and the cost of cancer care

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Greatest concerns if diagnosed?

- Effect on family and friends: 67%
- Death as a result of cancer: 66%
- Paying for treatment: 65%

Awareness of personalized medicine?

- France: 32%
- Germany: 34%
- Italy: 37%
- Japan: 26%
- UK: 29%
- US: 48%
It was only two weeks til our only son’s wedding, but the unthinkable happened: My husband was diagnosed with colorectal cancer, metastasized to his liver and lung. Two weeks of blood work, scans and more tests. We kept our secret at the wedding, but really, we were somewhere else. Cancer had entered our lives.

Two days after the ceremony, we were at “Chemo 101.” Like deer in the headlights, we had wandered through the maze of fighting this horrific disease. We still find ourselves lightheaded and frightened, but hope is what we have now. The colon is gone, the chemo and more surgeries are our future, and we are navigating now. We all join hands for the end to this awful disease.

People want better collaboration on developing new treatments, including their own involvement in clinical trials

PACE survey respondents express a high level of consensus about the ways that all stakeholders—including cancer patients, themselves—can contribute to continuous advances in medical research.

Is cancer R&D well enough coordinated across borders and all stakeholders? The vast majority of survey respondents (98 percent) agree that cancer research and development efforts should be coordinated across national borders. A similarly strong majority (83 percent) agree that greater collaboration between government, academic institutions, non-profit organizations, and pharmaceutical companies is required to accelerate progress in cancer research.

Would you be willing to participate in a clinical trial? The public expresses a willingness to be part of an improved clinical trial and drug development system. For example, more than 70 percent of the general public agree that patients need more opportunities to participate in clinical trials. Today, in the U.S., overall clinical trial participation typically does not exceed five percent of cancer patients.13

In addition, close to nine in 10 respondents would agree to share medical records for the improvement of cancer research and treatment. Still, sizeable minorities report concerns about potential misuse of data.
“To My Children”

Photography by a Person Diagnosed with Cancer

Through surgery and many months of chemo treatments, I have learned so much about love. This season of my life has brought me and my children so close. We have shared times of sadness and many times of joy since this journey began.

I am learning that my days are a gift...
...and I am carefully trying to use each day building good memories with my children.

I choose each day to not fret about yesterday,
I choose each day to not worry about tomorrow,
I choose each day to learn to live the moment at hand to the fullest.

My days are numbered and to embrace each moment as a gift...
It is this gift that I want to give to my children.

Decisions about life-prolonging treatment belong with patients, families, and their physicians

What is treatment to extend life for one year worth?
There is no consensus on how much money should be spent on treatment in exchange for an extra year of life. A sizable minority in European Union nations (40 percent) place a high value on this extra year (up to €200,000 or more). In the U.S., 24 percent believe an extra year of life is worth as much as $200,000 or more.

Who should decide on life-extending treatment?
There is consensus on who should pay for life-prolonging treatments – 72 percent say insurers. Furthermore, strong majorities of respondents want patients and families (78 percent), along with physicians (41 percent), to decide on these treatment options.

Who should decide on life-extending treatment?

- 41% say physicians
- 78% say patients & families

Lara, an oncology nurse, was diagnosed with cancer on March 22, 2006 – a day her husband calls "our D-Day." He says, "You need to embrace your helplessness. You can’t fix this problem. You can’t magically make it go away. So don’t beat yourself up about it. What you can do is talk with your loved ones and the doctor and figure out the best course of action. Support her help her be positive."
“Enduring Strength”  
Mixed Media by a Family Member, Friend, or Caregiver

H-O-P-E, four ordinary letters that, when placed in a certain order, are not ordinary at all. Hope is what nations build on, what people build on, especially those with a cancer diagnosis.

Hope, the magic carpet for cancer patients, is the dream catcher at night when the side effects prevent much needed sleep. It is the soul builder when the only news received is negative. It is the butterfly of happiness when the last treatment is completed, or the first sprigs of hair appear. Hope is the rainbow for the future when the test results show no cancer.

Hope, when fed with positive influences from family, friends and healthcare providers, is solid and everlasting, giving promise for survival – a gift we all can give to another living being.

“A Survivor’s Prayer”  
Photography by a Person Diagnosed with Cancer

Who keeps their hospital bands? Each time I came home from a procedure, I’d take off my band and place it on my desk. I soon had a pile of bands that represented my physical journey with cancer. This portrait symbolizes my spiritual journey.

My spiritual journey took me to a place where I knew if I left this life, I would be in a better place. Today, cancer free, I still find myself in this prayerful position. Not only am I praying, but thanking God for a chance to share with others and inspire.
In January 2011, I had surgery to remove cancer on my right kidney. In May 2011, during an annual OBGYN examination, my doctor found a lump in my left breast. He sent me for a mammogram and ultrasound. After a biopsy revealed cancer. On June 28, 2011, I underwent a double mastectomy followed by chemotherapy and radiation. Through it all, my spirits have been good and my outlook confident due to the excellent care and concern of all the doctors, nurses and technicians involved in my treatment.

The love and concern of family and friends empower me. With a large garden to tend and share, writing, painting and community involvement, life is good! My odyssey continues.

Cancer is the sudden storm that shatters the summer day. The traveler, caught unaware, must set aside all her plans. The pelting rain stings her skin like hundreds of tiny needles. The downpour drenches her clothes, which drape heavily over her frame and chill her to the bone. Surrounded by grayness and misery, she grows weary and cries out, “Will this storm never end? Will the sun ever shine again?”

Then, softly, from deep within, comes a whisper. She smiles as she recognizes her old friend. It is Hope, which takes the form of a child who giggles, then grabs her hand and gleefully teaches her how to dance in the rain.
Where do we go from here?

We are at a pivotal point in the fight against cancer. New treatments brought about by continuous, scientific innovation have transformed the lives of millions of cancer patients and can continue to do so. However, the majority of those surveyed by the PACE Cancer Perception Index worry current economic pressures are jeopardizing this progress and placing our society’s larger advances against cancer at risk.

In response, it’s important to improve our understanding of how innovation proceeds against cancer, along with the many forms that innovation can take. For example, improvements in the treatment of cancer tend to be step-wise, building towards larger progress over time. Very often, the full benefits of new treatments are not known until doctors have experience with large numbers of patients in actual practice. Patients respond differently to new medicines—so we do not always know why—with some patients living markedly longer than others on the same treatment. At the same time, innovation in the eyes of patients and caregivers also includes treatments that have fewer side effects and are less complicated or painful to receive. All of these factors merit consideration when establishing the value of new treatments, especially in a difficult economic environment.

To continue to benefit from the knowledge and progress we have made in cancer R&D, we must ensure that cancer continues to be a public health priority, with the patient at the center of it all. Patient advocates, government regulators and policymakers, public and private insurers, scientists, doctors, and industry should work together to:

• Help shape payment reforms and policies on patient access to cancer care that recognize the full value of new treatments to individual patients
• Reform and revolutionize clinical research to make it more flexible, cost-effective, and, above all, faster
• Raise awareness of clinical trials and encourage patients to participate in them
• Educate widely on the nature of cancer, progress in fighting it, the R&D process, and how to assess the full value of cancer treatments

Progress against cancer will continue to be step-wise and continuous—but the steps can become faster, the treatments can be better, and the outcomes for society can be more clearly valuable and enduring.

PACE Cancer Perception Index research methodology*

The PACE Cancer Perception Index™ was fielded between August and September 2012 in France, Germany, Italy, Japan, the UK, and the U.S. National representative samples of the general population ages 18 and over were used for the survey, deploying a random digit dial (RDD) telephone method. The sample comprises approximately 70 percent landline respondents and 30 percent cell phone respondents in each country in order to account for the fact that some households only have cell phones. A total of 3,099 respondents were interviewed, with approximately 500 respondents per country in each of the six participating countries.

For the purpose of comparison, cancer patients and cancer patient caregivers were also interviewed. A total of 663 cancer patients and 669 cancer caregivers were interviewed, with approximately 100 from each group per country in France, Germany, Italy, Japan, the UK, and the US, and 150 from each group in the U.S. Qualified respondents were selected from online panels and interviewed online. The sample source for these two groups was primarily USamp for all countries; in Germany, Survey Sampling Inc. (SSI) was also used; and in Japan, three other sample sources—AIP, Toluna, and SSI—were also used. The sample frame represents a broad mix of age, cancer type, and stage, but may not represent the universe of cancer patients or their caregivers.

*Percentages do not total 100 percent. For tabulation purposes, percentage points are rounded off to the nearest whole number. As a result, percentages may total slightly higher or lower than 100 percent.
References


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Created by Lilly Oncology as a global network spanning diverse sectors, PACE - Patient Access to Cancer care Excellence – aims to encourage public policies and healthcare decisions that speed the development of new medicines, assure cancer treatments respond to the needs and qualities of individual patients, and improve patient access to the most effective cancer medicines.

To learn more about PACE and the PACE Cancer Perception Index, connect with us online at:
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