



CANCER STIGMA AND SILENCE AROUND THE WORLD: A LIVESTRONG REPORT
FINAL REPORT

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EXECUTIVE SUMMARY

In 2007, **LIVESTRONG** executed a global cancer research study intended to give people affected by cancer a chance to share their cancer experiences and their perspectives on the cancer problem — a problem that is too often shrouded by stigma and silence.

For the study, **LIVESTRONG** collected multiple sources of data — including an analysis of media coverage, public opinion surveys, and semi-structured interviews — from countries around the world to better understand how cancer is portrayed and perceived. Argentina, Brazil, China, France, India, Italy, Japan, Mexico, Russia, and South Africa were included in the study. The results of the global research are presented across three categories: General Perceptions of Cancer; Stigma and Myths About Cancer; and Evidence of and Opportunities for Progress.

Six “lessons learned” were derived from the global research results:

1. Around the world, cancer continues to carry a significant amount of stigma; however, there are opportunities to capitalize upon shifting perceptions and positive change.
2. Awareness of cancer prevention, early detection, treatment, and survival are on the rise; however, too many people still report that they feel uninformed when it comes to cancer.
3. Communication is critical to decreasing cancer-related stigma, raising cancer awareness, and disseminating cancer education. People with a personal history of cancer — especially well-known or celebrity survivors — and multiple mass media channels are key resources for dissemination.
4. The school system represents a potential venue for cancer education, and increasing cancer awareness among children may be an investment with high returns.

5. When facing cancer, people around the world want information and emotional support for themselves and their families.
6. Tobacco use and poor nutrition are widely acknowledged as cancer risks. Programs and policies that help people translate this awareness into action are needed.

In response to these lessons and the additional insights gained from the research, **LIVESTRONG** offers the following calls to action:

1. Where opportunities exist to raise awareness of existing tools to combat cancer, public education and resource campaigns are needed that directly address the cancer-related stigma noted across the three sources of data presented in this report and the associated lessons learned; and
2. The global cancer community should capitalize upon positive shifts in attitudes about and awareness of cancer and leverage these shifts to develop, test, and disseminate effective media campaigns and behavioral interventions to decrease the incidence of and morbidity and mortality associated with cancer.

LIVESTRONG plans to use the results of this research to strengthen patient advocacy in international settings and to build a global grassroots movement. These activities will help people around the world to have accurate perceptions of cancer; to prevent stigma from inhibiting people in their cancer control efforts; to help people affected by cancer receive the support, services, and information they need; and to support ample access to services that facilitate healthy living — all of which will help in decreasing the global cancer burden.

1

INTRODUCTION



“When I came to know it was cancer, I was scared due to the fatality of the disease. Then when the doctor sent me back (home), I was scared of death.... There is nothing for my wife and kids if something happens to me; even this house is in someone else’s hand ... I was the one who took the lead in doing everything. When I fell, everyone was sad and depressed.... No one comes here now ... not my relatives nor my friends ... no one comes by to ask if I’m feeling better.”

Above, a 38-year-old man from India talks about the devastating impact cancer has had on him and his family. The quotes above and below are taken from interviews LIVESTRONG conducted with cancer survivors.

In this quote, a woman recalls the stigma she encountered while undergoing treatment for non-Hodgkin lymphoma:

“They [friends and associates] said that if they go into my bathroom, maybe I had left some chemical residue and that maybe they will get infected. They stopped talking to me, greeting me, nobody was going to the house.”

These stories offer a firsthand account of the pain endured by cancer survivors and their families because of cancer-related stigma. “Stigma” in this case refers to the perception of the person affected by cancer

as differing from the norm in a negative or undesirable way. This perception often leads to discrimination against the stigmatized person, which in turn results in a loss of status, rejection, or isolation (Ling & Phelan, 2006). As evidenced by the quotes above, the social, emotional, and financial devastation that all too often accompanies a diagnosis of cancer is, in large part, due to the stigma and silence surrounding the disease (Lagnado, 2008).

In 2008, the International Agency for Research on Cancer (IARC) released its World Cancer Report (IARC, 2008), which indicated that cancer accounts for approximately 12% of all-cause mortality worldwide. IARC estimated that globally

7.6 million people died from cancer and that 12.4 million new cases were diagnosed in 2008. The report went on to project that, due to increases in life expectancy, improvements in clinical diagnostics, and shifting trends in health behaviors (e.g., increases in smoking and sedentary lifestyles), in the absence of significant efforts to improve global cancer control, cancer mortality could increase to 12.9 million and cancer incidence to 20 million by the year 2030.

Combating stigma and overcoming silence will play important roles in changing this trajectory. The World Health Organization reports that there is “clear evidence that healthy lifestyles and public health action by governments and health practitioners could ... prevent as many as one third of cancers worldwide” (WHO, 2003). Current research suggests that key global cancer risk factors – tobacco use, obesity, and infection – are a direct function of behavior; therefore, they are potentially malleable given appropriate and effective interventions (Anand et al., 2008; Danaei, Vander Hoorn, Lopez, Murray, & Ezzati, 2005). Additionally, behavioral factors – including participation in recommended cancer screening – are key to improving cure rates for cancer. Advancements in cancer treatment, including

palliative care, can greatly reduce the morbidity of cancer, decrease suffering, and improve function for people diagnosed with the disease (IARC, 2008).

All of these positive developments in the fight against cancer have the potential to be silenced by stigma (Keusch, Wilentz, & Kleinman, 2006). If there is a strong stigma associated with cancer or if people do not know what healthy behaviors to adopt, they may not engage in practices that reduce their cancer risk. Individuals may delay identification of the disease if fear of stigma creates a barrier to getting cancer-related symptoms checked by a doctor. Once diagnosed, stigma can negatively affect medical decision making, and the provision of supportive care can become a significant source of stress and can increase suffering. At a population level, governments and health systems are less likely to devote resources to reduce their cancer burden if individuals affected by the disease are reluctant to express their needs and concerns or to advocate for themselves or others.

The global fight against cancer and efforts to reduce cancer-related stigma can be strengthened through a greater understanding of how cancer is portrayed around the globe and perceived by the public

(Keusch et al., 2006). This level of understanding requires a comprehensive investigation, using methods that collect a variety of population perspectives on cancer, a complex disease with myriad implications. Central questions include: How do people perceive cancer? Where are gaps in awareness and the need for education?

The American public’s perception of cancer provides an interesting case in point. Data from the U.S. National Cancer Institute’s 2007 Health Information National Trends Survey (NCI, 2010) suggest that the American public perceives cancer as a prevalent, but preventable and controllable disease. Consistent with national cancer statistics (ACS, 2010), almost 60% of Americans believe that they have a “moderate” to “very high” chance of being diagnosed with cancer in their lifetimes. Ninety-four percent of Americans think that routine cancer screening helps detect cancer when it’s easy to treat, and more than 70% disagrees with the statement: “There’s not much you can do to lower your chances of getting cancer.”

“There’s no worse disease than ignorance.”

— Cancer survivor, Mexico

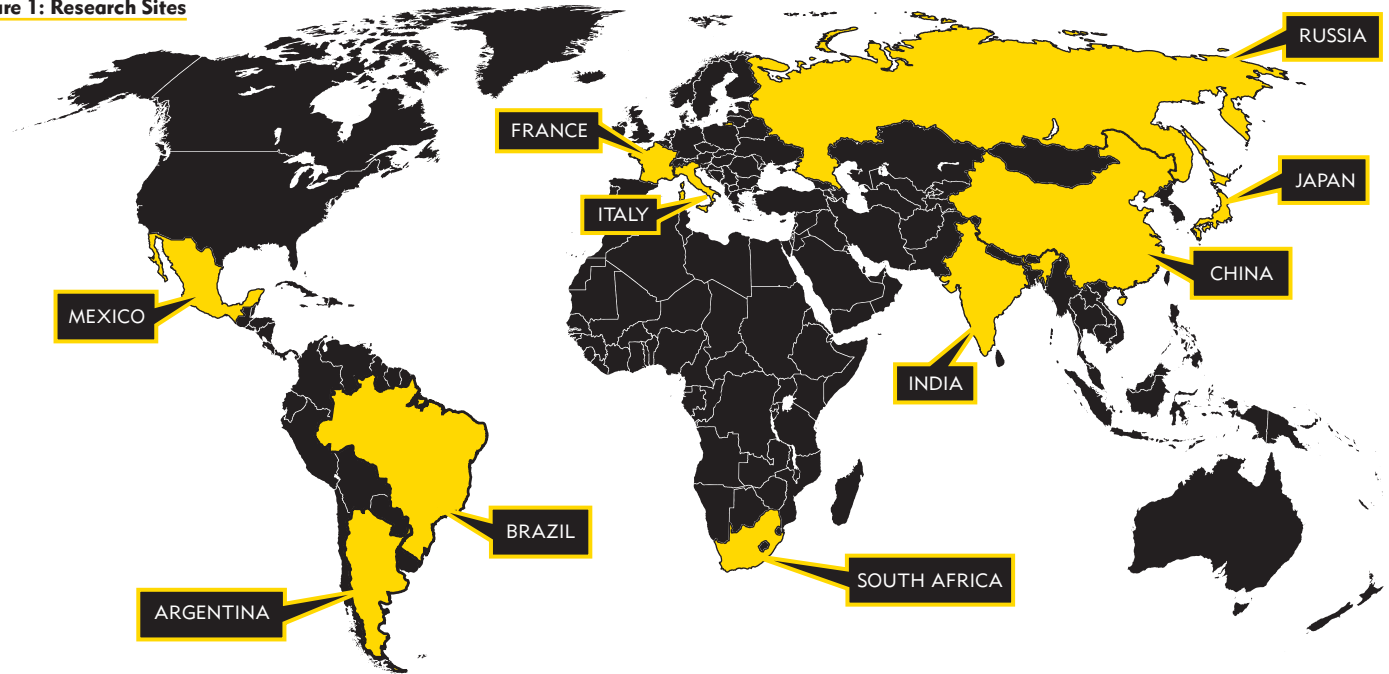
Despite these favorable perceptions, evidence shows that cancer-related stigmas exist and more awareness and education are needed. More than half of American adults (61%) automatically think of death when they hear the word “cancer.” Troubling percentages report that it seems like “everything causes cancer” (55%) and that “there are so many recommendations for preventing cancer, it’s hard to know which ones to follow” (75%).

In anticipation of the sharp increase in the global cancer burden over the coming years (IARC, 2008; WHO, 2003) and in keeping with its mission to empower people affected by cancer, in 2007, **LIVESTRONG** launched a global cancer research study. The study was intended to give people affected by cancer a chance to share their cancer experiences and their perspectives on the global cancer problem—a problem that is too often shrouded by stigma and silence. The ultimate goal of this research is to increase the availability and accessibility of resources for survivors and their families to fight cancer around the world.

LIVESTRONG and Global Cancer Control

LIVESTRONG is a nonprofit organization and a leader in the area of cancer survivorship. The mission of this organization is

Figure 1: Research Sites



to inspire and empower people affected by cancer. To this end, **LIVESTRONG** fights for the 28 million people around the world living with cancer today. **LIVESTRONG** connects individuals to the support they need, leverages funding and resources to spur innovation and engages communities and leaders to drive social change. For more information, visit **LIVESTRONG.org**.

The **LIVESTRONG** global cancer research study was designed to inform a strategic approach to reduce cancer-related stigma and raise awareness of the disease. The results of this

research—which are the contents of this report—are intended to enable **LIVESTRONG** to extend its mission beyond the United States and into the international arena. Furthermore, **LIVESTRONG** will use these results to partner with cancer advocacy organizations worldwide to develop programming and services intended to effect positive change and reduce cancer incidence, morbidity, and mortality.

LIVESTRONG collected multiple sources of data—including an analysis of media coverage, public opinion surveys, and semi-structured interviews—in 10 countries to better understand how cancer is portrayed and perceived around

the world. Argentina, Brazil, China, France, India, Italy, Japan, Mexico, Russia, and South Africa were included in the research (**Figure 1**).

Table 1, on page 5, provides information on risks of cancer incidence and cancer death and the most common and most deadly types of cancer. These statistics were taken from IARC’s GLOBOCAN (Ferlay et al., 2010) and are intended to provide context for the results included in this report.

LIVESTRONG has shared preliminary research results at national conferences and on **LIVESTRONG.org**. It also has used the data internally in

developing programs and services. The intent of this report is to integrate the multiple sources of data gathered from thousands of people and give voice to their perspectives on and experiences with cancer. While people who participated in **LIVESTRONG**’s global cancer research do not represent the entire cancer community among all countries and cultures, they do provide important insight into the ways in which cancer is thought about around the world. The results of this research will help to illuminate the opportunities for changing public perceptions of cancer, combating cancer-related stigma, and elevating awareness of the global cancer burden.

Table 1: Cancer Statistics for the Ten Countries Included in LIVESTRONG's Global Cancer Research

Country	Risk of Getting Cancer Before Age 75	Risk of Dying From Cancer Before Age 75	Top 3 Incident Cancers: Women	Top 3 Incident Cancers: Men	Top 3 Causes of Cancer Mortality: Women	Top 3 Causes of Cancer Mortality: Men
Argentina	21.0%	11.7%	Breast Colorectal Cervix uteri	Prostate Lung Colorectal	Breast Colorectal Lung	Lung Prostate Colorectal
Brazil	17.6%	10.5%	Breast Cervix uteri Colorectal	Prostate Lung Stomach	Breast Cervix uteri Lung	Lung Prostate Stomach
China	18.9%	13.3%	Lung Breast Stomach	Lung Stomach Liver	Lung Stomach Liver	Lung Liver Stomach
France	29.9%	11.1%	Breast Colorectal Lung	Prostate Lung Colorectal	Breast Colorectal Lung	Lung Prostate Colorectal
India	10.4%	7.5%	Cervix uteri Breast Ovary	Lung Lip, oral cavity Other pharynx	Cervix uteri Breast Ovary	Lung Other pharynx Lip, oral cavity
Italy	26.8%	11.2%	Breast Colorectal Lung	Prostate Colorectal Lung	Breast Colorectal Lung	Lung Colorectal Prostate
Japan	20.4%	9.7%	Breast Colorectal Stomach	Stomach Lung Colorectal	Colorectal Lung Stomach	Lung Stomach Colorectal
Mexico	13.4%	8.2%	Breast Cervix uteri Stomach	Prostate Lung Stomach	Breast Cervix uteri Liver	Lung Prostate Stomach
Russia	21.1%	13.9%	Breast Colorectal Corpus uteri	Lung Colorectal Stomach	Breast Colorectal Stomach	Lung Stomach Colorectal
South Africa	20.3%	14.3%	Breast Cervix uteri Oesophagus	Prostate Lung Oesophagus	Breast Cervix uteri Oesophagus	Lung Oesophagus Prostate

“The problem of cancer is a world problem.”

—Semi-structured interview participant, Italy

2

METHODS



With the aim of capturing a well-rounded representation of perspectives on cancer, **LIVESTRONG** used multiple methods to gather data in Argentina, Brazil, China, France, India, Italy, Japan, Mexico, Russia, and South Africa. These methods led to three complementary, but distinct, types of data – specifically, narrative, quantitative, and qualitative data – which could be triangulated to paint a rich and nuanced picture of global cancer awareness. **Appendix B** shows the final sample sizes for each country and for each type of data collected.

GLOBAL MEDIA AUDIT

A content analysis of media data was included as one way to make inferences regarding general perceptions of cancer in various populations and cultures.

Measures. The media audit included multiple sources of media published between January and December 2007 across all the research sites. The analysis is based solely on coverage available via electronic databases. Additionally, only media sources with substantial circulation (and, therefore, a suggestion of substantial population reach) and with archives available for review were included in the analysis. “Substantial circulation” was determined by a separate audit of circulation figures. The media sources were examined

to determine the most often discussed cancer-related topics and the tone of cancer-related media coverage.

The media audit sought to collect a representative sample of approximately 100 media objects (i.e., articles) from each country. A native language analyst in each country conducted the search for and reviews of media objects. Search strategies were largely consistent across the research sites: In all countries, the word *cancer* had to appear at least three times for an article to be included in the review. There was some variation, however, due to differences in the volume of cancer-related media coverage and linguistic factors. In France, the criterion for inclusion was raised to at least five mentions of cancer in an article, due to the high volume of cancer-related

media coverage in that country. In India and South Africa, where the word “cancer” was often used to refer to something other than the disease, the inclusion criterion stipulated that cancer had to be mentioned in the article’s title and appear at least eight times in the body of the text.

Analytic approach. All coding was done in English. Native language analysts reviewed the final coding and provided additional contextual information based on their cultural experiences in the country. The narrative data from the 929 articles included in the content analysis were coded in relation to several themes, including the major idea of each article; the types of cancer mentioned; the key messages; the “successes” (e.g., coverage of cancer-related activism) versus “opportunities” (e.g., stories about a lack of access to cancer treatment) observed with respect to cancer; and calls to action for cancer prevention and control. Key findings were summarized for each of these themes, both within and across countries.

PUBLIC OPINION RESEARCH (POR)

LIVESTRONG also conducted a POR survey so that a large sample of participants from each

country included in the media audit would have an opportunity to speak directly about cancer awareness; how they obtain cancer-related information; cancer-related stigma; general attitudes and behaviors related to cancer prevention and control; and what they hoped their respective home countries would do regarding the cancer problem.

Measures. The POR survey was completed by 4,506 adults (approximately 500 individuals per country) across each of the countries (except Russia). The survey questions were added to existing national omnibus surveys. As such, the sampling methodologies used were specific to each country’s protocol; however, omnibus surveys are generally intended to result in a respondent sample that is representative of a country’s population. Survey data was collected between April and May 2008. In Argentina, Brazil, China, Mexico, and South Africa, surveys were fielded via computer-assisted telephone interview (CATI). The survey was fielded electronically in France, Italy, and Japan; face-to-face data collection was conducted in India.

Survey respondents reported their age, gender, social grade, and connection to cancer. In determining their connections

to cancer, the choices were personal history of cancer; family history of cancer; cancer caregiver; and no connection. About 17% of the POR respondents had a personal connection to cancer, most often through a family member who had been diagnosed with the disease. The survey instrument included 10 questions that covered a variety of topics, including:

- cancer-related stigma (e.g., “I worry about catching cancer from people who have it”);
- perceptions of cancer (e.g., “People with cancer can survive”);
- cancer-related awareness (e.g., “I know what to do to prevent cancer”);
- preferred sources of cancer information (e.g., doctor, friends and family, Internet);
- reasons why people avoid cancer screenings (e.g., “Screening is too expensive”); and
- the respondents’ hopes for what their home countries will do about cancer (e.g., “I wish my country would provide more funding for research, make treatment more accessible, or provide more services for survivors”).

Analytic approach. Summary statistics (frequencies) were used

to provide descriptive data across all countries and within each research site. Exploratory analyses were used to compare results across key socio-demographic characteristics (e.g., age) of survey respondents.

SEMI-STRUCTURED INTERVIEWS

Finally, semi-structured interviews were conducted with individuals from India, Italy, Japan, Mexico, and South Africa. These sites were chosen in order to collect qualitative data that would represent a geographically and socio-economically diverse set of interviews. **LIVESTRONG** reached out to organizations in each of these countries and worked with points of contact to recruit cancer survivors and cancer care professionals to participate in interviews. “Man on the street” (MOS) interviews were conducted with individuals from the general public who were within the vicinity of interviewers and who were willing to take the time to share their perspectives. Interview participants included cancer survivors (n = 11); leaders in cancer-related nonprofit or governmental organizations and cancer care professionals (n = 11); and MOS interviews (n = 80).

Measures. The semi-structured interview protocol covered a variety of topics and was consistent across countries.

Table 2 shows the topics for each of the participant groups.

Relevant, additional questions were included on a case-by-case basis when additional topics were brought up by the interviewees. Interviews were audio taped and transcribed in the respondents’ native languages and then translated into English by native language analysts. Interviews with cancer survivors and cancer care professionals lasted, on average, 30 minutes; MOS interviews took about five minutes to complete. Interviews were completed between April and May 2008.

Analytic approach. Authors Ellen Burke Beckjord and Jill Schaeffer independently reviewed and coded each country’s transcribed interview data and met to achieve convergence on the themes represented in the text. Their analysis followed recommended techniques for theme identification (Ryan & Bernard, 2003), including examining text for evidence of word or phrase repetition, use of metaphors or analogies, and transitions in discussions (where themes are often revealed).

Exemplary quotes for each theme were entered into a database and color coded based on country and participant category (cancer survivor, cancer care professional, or MOS). The quotes were cut and sorted into thematic categories. Categories

Table 2: Topics Covered in Semi-structured Interviews

Cancer Survivor Questions
Please tell me your story about your diagnosis and your treatment.
What was your reaction when you learned you had cancer?
Could you tell us about your disease from the diagnosis to the treatment to your situation today?
Did you talk about cancer with your family and friends, and if you did, how did they react?
Because of cancer, did some of your relationships with people change?
Cancer Care Professional Questions
What is the perception of cancer in (country)?
In general, do people in (country) talk about cancer?
Are there any stigmas associated with cancer?
What are the most common problems for people with cancer?
When a patient is diagnosed with cancer, what does he or she do?
How has the perception of cancer changed over time?
How can (country) raise awareness about cancer?
“Man on the Street” (MOS) Interview Questions
What words come to your mind when you think of cancer?
What is the perception of cancer in (country)?
How serious do you consider the problem of cancer to be in (country)?
What is being done in (country) to combat cancer?
Do you have any experience with cancer?
Do you talk with your friends and family about cancer?
Do you think there’s something that people can do to avoid getting cancer?

were not mutually exclusive; that is, a quote could be included in more than one theme. Each theme was summarized, and particularly illustrative quotes were selected. Once the qualitative data from the semi-structured interviews was organized into thematic categories, the media audit’s narrative data and the POR survey’s quantitative data were integrated into the overall results.

LIMITATIONS

Though the inclusion of narrative, quantitative, and qualitative data enabled a comprehensive examination of international perspectives on cancer prevention and control, the results presented here should not be over-generalized. The media audit data may not fully represent each country’s routine coverage of cancer, as the audit was based solely on coverage available via electronic

databases. The POR survey and semi-structured interview participants may not be representative of each site’s sociodemographic makeup or culture, nor of each country’s population of cancer survivors or cancer care professionals. For these reasons, **LIVESTRONG** offered relatively few examples of country-specific results, favoring a more general presentation of the research findings in this report.



RESULTS

3

Here, we present the results from the global media audit, the Public Opinion Research (POR) survey, and the semi-structured interviews. The results are organized into three categories: General Perceptions of Cancer; Stigma and Myths About Cancer; and Evidence of and Opportunities for Progress.

GENERAL PERCEPTIONS OF CANCER

Figure 2 shows a series of quotes gathered from the semi-structured interviews, with flags denoting the source country for each quote. These quotes are most often a response to the question: "What words come to your mind when you think of cancer?" The quotes are sequenced from the top to the bottom to display a continuum of negative to positive perspectives on cancer. At the top is the quote, "Cancer is a death sentence," a sentiment expressed by interview participants from each country. However, moving down the continuum, the quotes begin to shift from mortality to morbidity, recognizing cancer as a preventable and treatable illness.

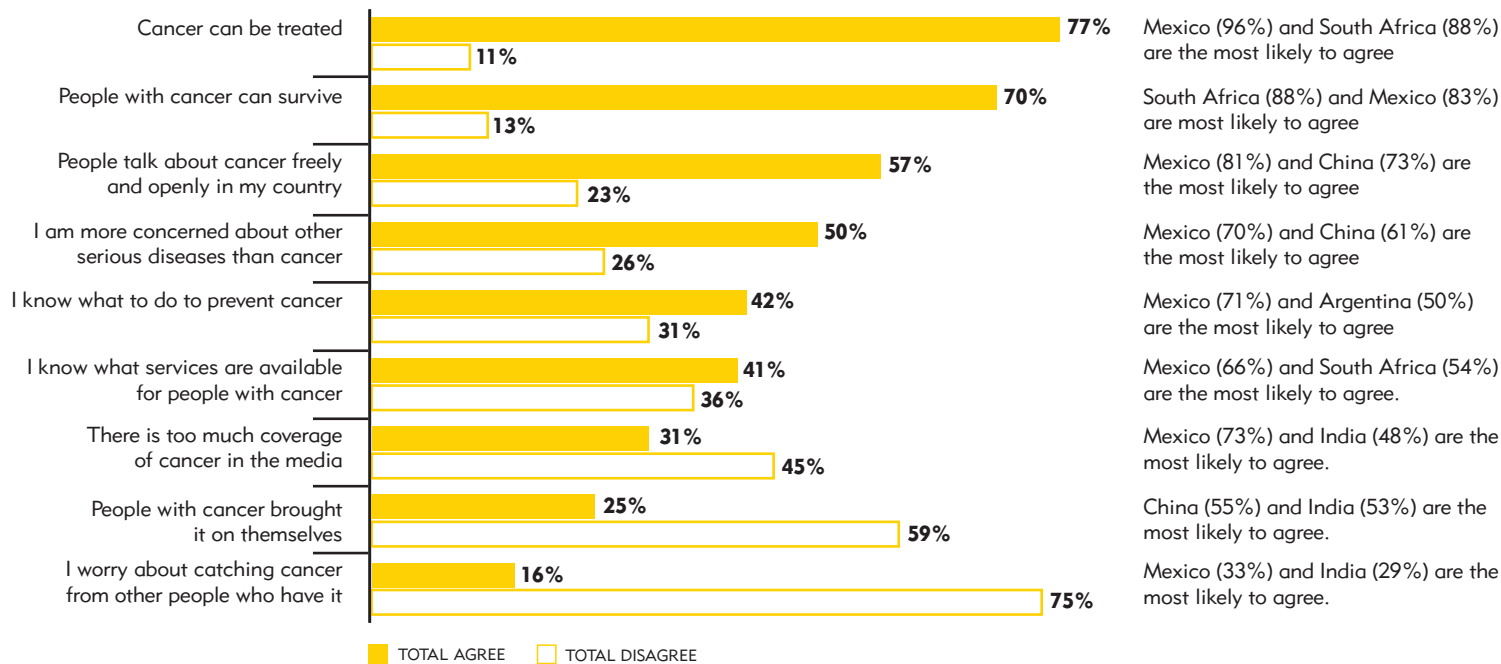
Finally, the continuum displays quotes that dismiss fear of cancer completely, ending with a quote at the bottom from a South African participant: "We can beat cancer."

One particularly noteworthy feature of **Figure 2** is that it shows that perspectives on cancer are far from uniform, both within countries and around the globe. The variety of perspectives gathered from the semi-structured interviews is consistent with the results of the POR survey. Most respondents (more than 70%) believed that cancer is a treatable disease and that individuals diagnosed with cancer can survive. However, only 40% reported feeling well-informed about cancer.

Figure 2: A Global Continuum of Perspectives on Cancer



Figure 3: Global Perspectives on Cancer From the POR Survey With Highlights by Country.



Mexico (96%) and South Africa (88%) are the most likely to agree

South Africa (88%) and Mexico (83%) are most likely to agree

Mexico (81%) and China (73%) are the most likely to agree

Mexico (70%) and China (61%) are the most likely to agree

Mexico (71%) and Argentina (50%) are the most likely to agree

Mexico (66%) and South Africa (54%) are the most likely to agree.

Mexico (73%) and India (48%) are the most likely to agree.

China (55%) and India (53%) are the most likely to agree.

Mexico (33%) and India (29%) are the most likely to agree.

Figure 3 shows the positive and negative perspectives on cancer gathered from the POR survey, including noteworthy findings by country. Responses of “neither agree nor disagree” are excluded from the figure.

In addition to echoing several sentiments from the semi-structured interview data shown in **Figure 2**, **Figure 3** offers additional insight into perceptions of cancer around the globe. Just over half of respondents felt that cancer is talked about “freely and openly” in their country; however, more than 40% were either neutral or disagreed with this statement. Encouragingly,

relatively few respondents “worry about catching cancer.” But it is concerning that less than half of respondents reported that they “know what to do to prevent cancer,” and only 41% reported to know about services for cancer survivors. Together with the semi-structured interview data, these results suggest that there is much work to be done to combat cancer stigma and to improve cancer awareness on a global scale.

STIGMA AND MYTHS ABOUT CANCER

Looking deeper into the data, it becomes clear that

cancer-related stigma and myths about cancer are important problems that must be addressed. Stigmas about cancer present significant challenges to cancer control: stigma can have a silencing effect, whereby efforts to increase cancer awareness are negatively affected (“Cancer is associated with a ‘hush-hush’ attitude” (cancer care professional, Japan). Stigma can affect individuals’ behaviors, such that they are less likely to adopt cancer-risk-reducing behaviors or seek out the support and services they need when they are diagnosed with the disease. As one interview participant in Italy said, “It’s [cancer] something that people are very scared about. I

don’t think people talk about it. I think people don’t get informed, and nobody really knows ... where you can get help.”

There are several reasons that cancer is stigmatized. Many people who participated in this research perceived cancer to be a fatal disease (see **Figure 2**). Fears about treatment can also fuel stigma. Take, for example, this quote from a cancer care professional in South Africa: “[People think that] chemotherapy makes you vomit until you want to die. Radiation therapy ... is called ‘ironing’ or ‘burning.’ Cancer symptoms or body parts affected by the disease can cultivate stigma. For

example, another cancer care professional in South Africa is highly stigmatized because the cervix is “part of the body you don’t speak about.” Gynecological or breast cancers may present symptoms that women are reluctant to disclose to their doctors, and they may be even less willing to undergo the necessary physical exams to investigate the cause of such symptoms.

Stigma also may stem from inaccurate perceptions of or myths about cancer. In each of the five countries where semi-structured interviews took place, there was evidence of myths associated with cancer, such as the belief that cancer is contagious, which was reflected in the interview and POR data: “[People] think that with just physical contact, that with just a greeting, I’m going to get your cancer” (cancer survivor, Mexico). According to a cancer care professional in Mexico, cancer may be seen as a punishment: “Lots of times people see cancer as something where they’re paying for something they did before.” Myths about cancer treatment were also

“Do people talk openly about cancer? No, I don’t think they do ... it’s all in hushed tones.”
—Cancer care professional, South Africa

common: “[Patients are] often reluctant to undergo surgery because they believe if you cut into the cancer, it will spread immediately all over the body” (cancer care professional, South Africa). Some of the individuals interviewed perceived cancer treatment to be as bad as, or worse than, the disease itself. “For a lot of patients, there is a fear that this anti-cancer treatment itself is going to kill them,” said a cancer care professional from South Africa.

The notions that nothing can be done to prevent cancer and that cancer is always fatal were other common myths that emerged. “No point in talking about it; once it strikes, it strikes” (MOS, Italy). There were also myths that young people are impervious to cancer: “I don’t think about [cancer]. I’m a young person” (MOS, Japan). Finally, some believed only poverty-stricken populations get cancer: “[People who] have a lot of money say, ‘Well, it’s not going to happen to me’” (cancer survivor, Mexico).

There are many ways that individuals personally affected by cancer experience stigma. Interview participants often

“Every time we get people ... to speak of their experiences [with cancer], this will manage to break down the stigma”

—Cancer care professional, Mexico

described cancer patients as feeling “isolated.” Silence surrounding the disease was a recurring theme. A cancer care professional from Japan talked about an extreme version of silence that was common practice among care providers in the past: “The doctor would tell the family about cancer, but because cancer was seen as miserable, they thought it best not to tell the patient and to hide it from her.” Survivors sometimes cited denial and/or avoidance in reaction to cancer. One cancer survivor in Japan recommended that survivors “make every effort to forget the cancer”; another in Italy said, “I didn’t talk about the disease to anyone. I kept on working.” This kind of denial and avoidance can perpetuate a person’s sense of isolation. As one cancer care professional in Japan put it, “[People diagnosed with cancer] talk about feeling isolated and solitary and that they’re the only ones who will disappear from this world.”

Family members were identified as additional recipients of cancer-related stigma, or alternatively, as a source of stigma. A cancer survivor from Mexico talked about the negative effects of stigma on her family: “It’s not just that they isolated me ... they also isolated my children.” Indeed, several interview participants noted that the cancer experience is extremely difficult for both patients and their families, and that supportive care must be available for the

whole family. Other times, cancer patients withdraw from or are rejected by their families. When this happens, cancer care professionals play a critical role in supporting the patient. “One of the ladies was weeping about how she was rejected by her family. But then she said, ‘But God gave me these [cancer care professionals], and they are my family now’” (cancer care professional, India).

Several interview participants identified the stigma associated with cancer and its treatment as a function of the financial devastation cancer can cause patients and their families. A cancer care professional in India reported that: “[A cancer diagnosis] means very often destruction of the family at large ... by the time the cancer is cured, their family is destroyed and they sometimes wished they were dead.” Relatedly, interview participants also talked about cancer-related stigma in the workplace. Stigma can present barriers when cancer survivors return to work after an illness-related absence, or when individuals with a cancer history try to secure new employment: “It’s like if you have cancer, you stink, there’s no work for you, there are no opportunities for you” (cancer survivor, Mexico). There is often the perception that a person who has been diagnosed with cancer is too ill to be employed. In the workplace, “[cancer] is often kept a secret” (cancer care professional, Italy). For a broad look at the silence

surrounding cancer, the POR data showed that while most respondents would tell their families if they were diagnosed with cancer (78%), far fewer said they would tell their friends (34%). Only 14% of the respondents said they would tell “everyone,” and about 1 in 10 (12%) said they would tell their employers.

Stigma associated with cancer was not directly addressed—or challenged—in many countries, according to the media audit data. France stood out as the country in which media was being used most aggressively to combat cancer stigma. For example, much of the French media analyzed in the audit reflected L’Institut National du Cancer’s survivorship campaign, which promoted the message that people diagnosed with cancer continue to be productive members of society and do not warrant discrimination. **Figure 4**, on page 13, shows examples of cancer stigma in media coverage, as well as some positive perceptions of cancer that refute stigma.

Overall, there was ample evidence across the three sources of data that cancer-related stigma is a significant problem. As one MOS in Italy summarized, “[Cancer] is not a subject that people like to talk about.” Given the threat that stigma and silence pose to progress in global cancer control, it will be imperative to continue

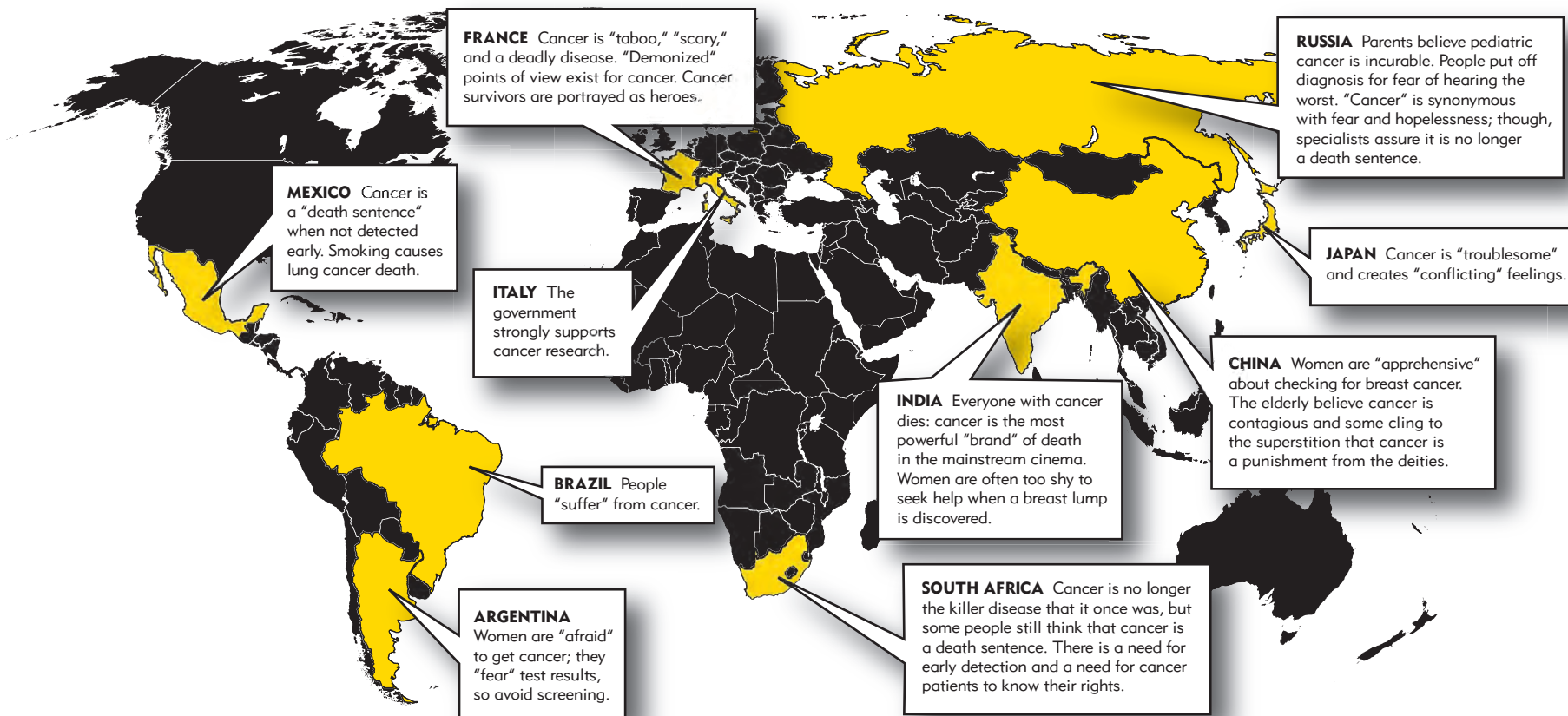
efforts to combat stigma, and to capitalize upon shifts in people’s perceptions of the disease. Fortunately, **LIVESTRONG’s** research also uncovered evidence of these shifts, and identified several opportunities to advance progress and promote positive change.

EVIDENCE OF AND OPPORTUNITIES FOR PROGRESS

Despite the existence of cancer-related stigma, there were several instances in which the data provided evidence of positive change. It was noted that improvements in cancer control have reduced many of the fears that trigger stigmatic thinking. A cancer care professional in Italy noted that “cancer is a disease that is accepted in some way.” Also, some cancer survivors talked about feeling completely comfortable discussing their diagnoses. “I told everyone about [my cancer diagnosis], no problem. I had nothing to hide” (cancer survivor, Italy). Advancements in treatment may lead entire cultures toward open discussions about cancer, according to one MOS participant from India, who said, “Now that [cancer] can be cured, people are ready to discuss it openly.”

In nearly all countries, there was media coverage of a national celebrity who was a cancer survivor, a strategy

Figure 4: Examples of Stigma and Anti-Stigma in Global Media Coverage.



that semi-structured interview participants felt was effective in reducing cancer-related stigma. One of the most poignant quotes in the interview data on communicating openly about cancer came from an Italian cancer survivor, who said, "Why not tell others that we went through [cancer], that it was something in the end ... that we came out of? Isn't that important for them to know?"

Indeed, though interview participants talked about

the significant challenges associated with cancer, they also conveyed messages of resilience, strength, and hope. For many cancer survivors, in particular, faith was a vital means of coping and remaining positive. In some cases, the disease itself was seen as a positive life event: "Getting cancer was a chance to reflect on my life, to look deeply" (cancer survivor, Japan). Several interviewees expressed a strong will to fight the disease: "When you find out you have cancer, fight, always fight" (MOS, South

Africa). "I'm not going to be crying in a corner because I have cancer ... I'm fighting for my life" (cancer survivor, Mexico). Moreover, some interview participants relayed powerful messages of hope about surviving cancer and thriving. One cancer care professional from Italy who also happened to be a cancer survivor said, "I can say that, despite cancer, all my dreams have come true. I kept living my life to the fullest – actually, even more fully than if I had never had [cancer]."

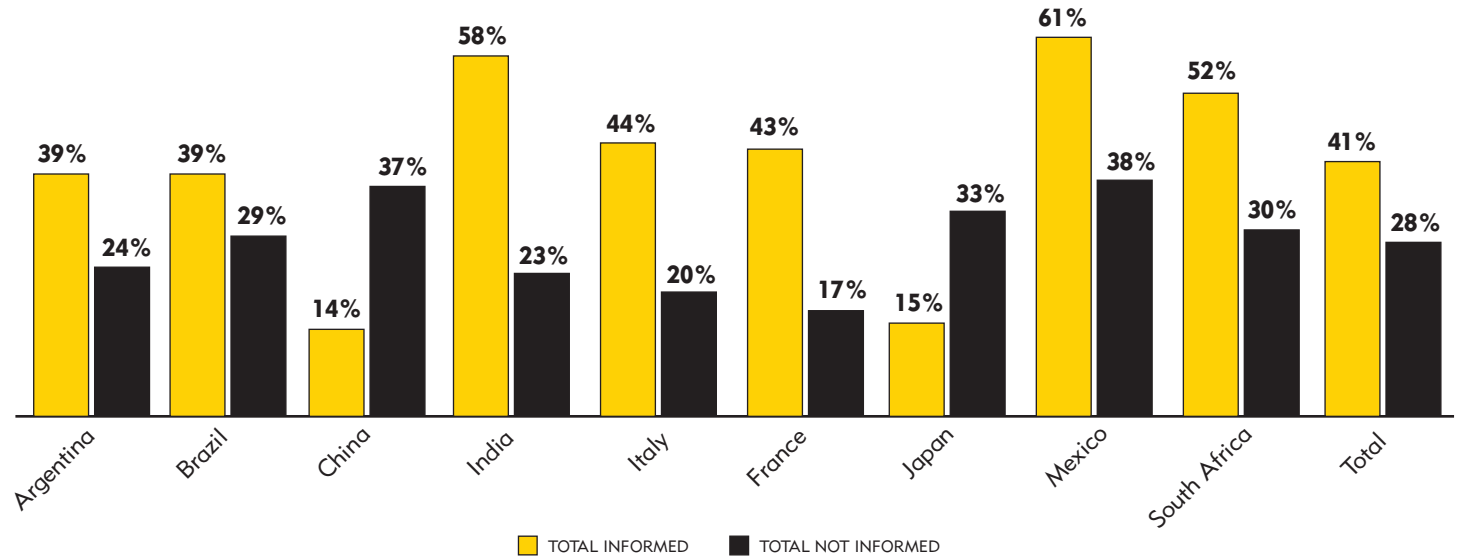
Information was a recurring theme across the sources of data with respect to reducing stigma and raising awareness of cancer. In many cases, gaining knowledge about cancer gave individuals a sense of empowerment. As one MOS in Japan described during an account of his family member's diagnosis: "We all looked [cancer] up on the Internet and studied up on it. With that information, we supported each other." In the POR research, respondents

indicated that the most popular source of cancer information was health care providers (72%), followed by the Internet (45%). Cancer survivors (41%) were also fairly popular sources of cancer information. "Cancer patients very often help others by sharing their experiences" (cancer care professional, India).

Several interview participants regarded awareness as critical to health promotion, early detection, and successful treatment of cancer. One cancer care

professional in India reported that the vast majority of cancers are diagnosed in India when it is too late for a cure. In South Africa, a cancer care professional said awareness was the “number one” strategy to improve cancer prevention and control, and a care professional in Japan noted that “if everyone had the right information ... then people might not have such a frightening perception of [cancer].” The POR results suggest that there is a significant amount of work to be done to improve the degree to which people feel informed about cancer. Respondents were asked, “How well-informed would you say you are about cancer (e.g., types of cancer, causes, preventions, treatments, research, etc.)?” In **Figure 5**, “informed” indicates a response of feeling “very” or “quite well-informed.” Moreover, “not informed” indicates a response of “neither well-informed/not well-informed,” “not very well-informed,” or “not at all well-informed.”

Figure 5: Global Variability in the Degree to Which POR Respondents Feel Informed About Cancer.



There is a need to increase awareness on a variety of topics. People need guidance in understanding that cancer is a complex disease. “There really is a lot of confusion with respect to the disease ... cancer is spoken of as one single disease, when we know that [cancer is] a lot of diseases lumped together under one name” (cancer care professional, Mexico). Participants in MOS interviews also talked about having heard only of breast and gynecological cancers. “If I don’t have it in my breasts and I don’t have it in my groin either, then I don’t have it. For me, it’s new to know that different types of cancer exist” (MOS, Mexico).

Interview participants in South Africa and Japan noted that providing information that

cancer can be controlled—if not cured—is an important strategy to reduce fear and stigma. “The more knowledge people have, the more likely they are to seek care” (cancer care professional, South Africa). Interviewees also discussed the need to raise awareness about specific types of care, such as palliative care, and about cancer advocacy organizations devoted to helping people affected by cancer. “A lot of people don’t know about cancer associations. There [are] places you can be helped with cancer” (MOS, South Africa).

The data indicated that in the absence of personal experience with the disease, individuals usually need to start from scratch to raise their cancer awareness. Here again, communication was identified

as a key strategy: “The more we talk about [cancer], the better. The more concerned we are toward problems, the more aware we become” (MOS, Italy). Interviewees from Mexico and South Africa repeatedly and specifically mentioned that cancer education should start at a very young age, in grade school. It was noted that this might enable children to educate their parents about the disease, thereby decreasing cancer-related stigma among future generations while also directly combating stigma among adults. In India, a cancer care professional talked about the need for professional education so that health care providers and volunteers in the medical field can be better equipped to provide supportive care to people

diagnosed with cancer.

Interviewees identified mass media as the communication channel with the most promise for raising population-level awareness of cancer control. The media audit data revealed portrayals of cancer in mass media to be balanced between articles that represent “successes” and those that represent “opportunities.” “Successes” were defined as media coverage that promoted a reduction of cancer-related stigma by providing information on topics such as declines in cancer incidence (where applicable); improvements in screening and early detection; treatment options; palliative care; cancer survivorship; government efforts in cancer prevention and control; new research or

“Sometimes I hear it’s a virus; other times I hear it’s in the DNA.... It develops in so many ways.... It’s not easy to understand, but I’d like to know more.”

—Man on the street interview, Italy

funding devoted to cancer; and cancer-related activism.

Articles showing “opportunities” indicated that more work needed to be done. These articles reported on issues such as rising cancer rates (where applicable); treatments that were not successful or that were significantly limited by barriers to widespread access; and a lack of cancer awareness or opportunities for early detection.

Overall, 54% of the articles reviewed represented “successes,” while 46% represented “opportunities.” **Figure 6** shows how the balance of these two types of coverage varied by country; the most “opportunities” in media coverage were noted in Italy and Japan, as highlighted by the red circles.

Considering the interview participants’ expressed interest in mass media and the POR survey’s indication of mass media being a source for cancer information, **Figure 6** suggests that the public is exposed to nearly equal amounts of positive and negative information about cancer. This is consistent, then, with the variety of positive and negative perspectives on cancer observed in the data.

These findings speak to the larger issue of changing the global cancer landscape through reporting more often about successes and capitalizing on opportunities by noting advances in cancer prevention

and control. Many interview participants identified policy as a tool to promote positive change. Policy interventions, such as smoking bans or laws to protect the rights of cancer survivors, were highlighted as ways to translate awareness into action (cancer care professionals, Italy and Mexico).

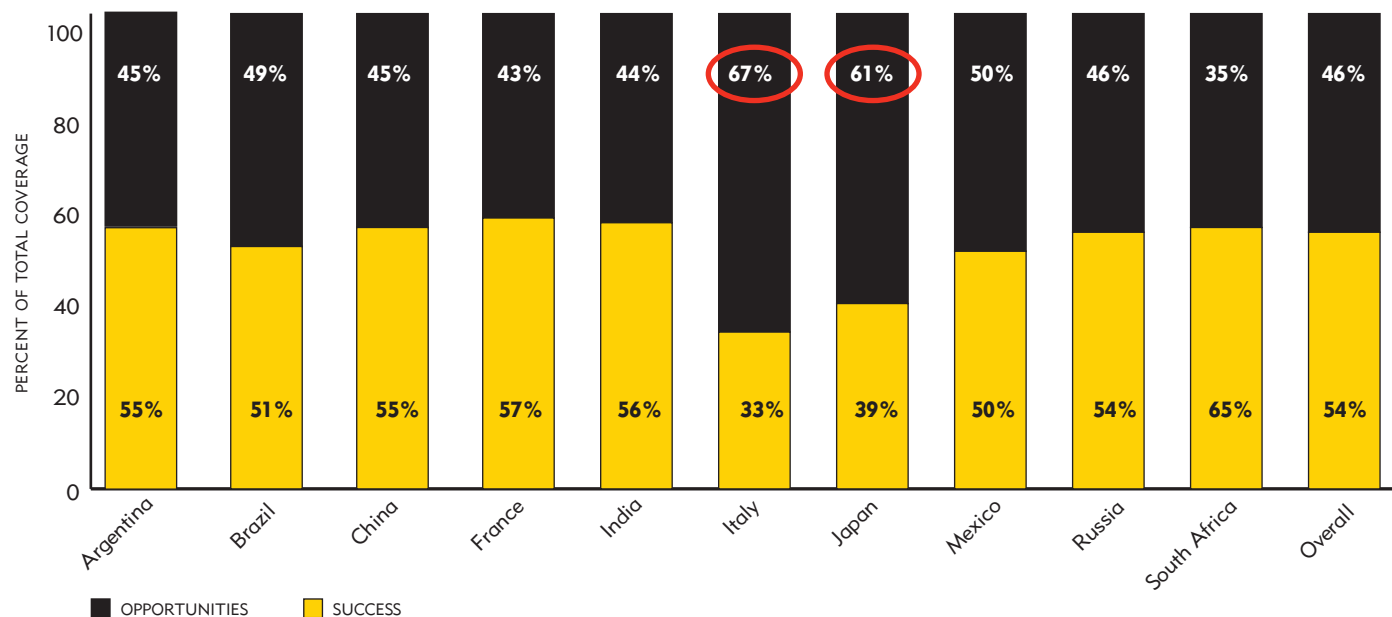
Interview participants recognized the importance of translating awareness into action by making healthy choices and positive lifestyle modifications. Individuals specifically expressed the importance of avoiding tobacco, atmospheric pollution, and foods that are excessively high in fat. They also perceived exercising, drinking plenty of water, and eating healthy or organic foods

as positively associated with reducing risk for cancer. These results were consistent with data from the media audit, which highlighted good nutrition and reducing tobacco and alcohol use to prevent cancer; many articles cited physical activity as an important preventative step.

Participants also emphasized the importance of early detection. “Going to the doctor [for regular checkups] is very important, in my opinion, to prevent cancer” (MOS, Italy). The media audit data also highlighted the role cancer screening plays in prevention and control. Raising awareness—particularly among “at risk” individuals—about cancer screening programs proved a central theme in the

articles reviewed. Data further suggested that the “at risk” group is growing in numbers, given the global prevalence of obesity, smoking, and alcohol use. Barriers to prevention included limited access to care, lack of early detection, and fears about screening results. A significant percentage of POR respondents (41%) indicated that fear of a negative result is their main barrier to getting screened for cancer. Expense (18%) was the second most often cited reason for not getting screened.

Figure 6: Global Variability in “Successes” and “Opportunities” Represented in Cancer Media Coverage.



4

CONCLUSIONS



The results of **LIVESTRONG**'s global cancer research speak to progress in combating cancer-related stigma and finding opportunities for increased cancer awareness. The data also support the urgency of addressing the cancer problem at national and international levels. Based on the results presented in this report, **LIVESTRONG** offers the following six "lessons learned":

1. Cancer continues to carry a significant amount of stigma; however, there are opportunities to capitalize upon shifting perceptions and positive change.
2. Awareness of cancer prevention, early detection, treatment, and survival are on the rise; however, too many people still report that they feel uninformed when it comes to cancer.
3. Communication is critical to decreasing cancer-related stigma, raising cancer awareness, and disseminating cancer education. People with a personal history of cancer — especially well-known or celebrity survivors — and multiple mass media channels are key resources for dissemination.
4. The school system represents a potential venue for cancer education, and increasing cancer awareness among children may be an investment with high returns.
5. When facing cancer, people around the world want information and emotional support for themselves and their families.
6. Tobacco use and poor nutrition are widely acknowledged as cancer risks. Programs and policies that help people translate this awareness into action are needed.

“For the person with cancer especially, information is the first medication.”

— Cancer care professional, Italy

“I’m quite sure that ... cancer patients very often help others by sharing their experiences.”

— Cancer care professional, India

“Do I think that survivors talking would remove some of the stigma? Absolutely.”

— Cancer care professional, South Africa

“It is very important that the patient, and also the family, always have hope.”

— Cancer care professional, Mexico

“Rarely do people admit that they have cancer..”

— Man on the street interview, India

“Rarely do people admit that they have cancer.”

— Cancer care professional, South Africa

“I am grateful that I am alive, and my gratitude becomes my strength.”

— Cancer survivor, Japan

“We need to face things directly, learn about them. Because when you learn more about something, you can fight more effectively.”

— Man on the street interview, Italy

NEXT STEPS

Given that cancer is not one disease, but many, with each type presenting a distinct set of risk factors, treatments, and disease trajectories, the variability observed during the campaign regarding how people perceive cancer is wholly appropriate. From LIVESTRONG's viewpoint, this variability elicits two critical calls to action:

1. Where opportunities exist to raise awareness of existing tools to combat cancer, public education and resource campaigns are needed that directly address the cancer-related stigma noted across the three sources of data presented in this report and the associated lessons learned; and
2. The global cancer community should capitalize upon positive shifts in attitudes about and awareness of cancer and leverage these shifts to develop, test, and disseminate effective media campaigns and behavioral interventions to decrease the incidence of and morbidity and mortality associated with cancer.

LIVESTRONG will work to catalyze the media, policy makers, and other leaders to raise public awareness of the global cancer burden and reduce the stigma associated with cancer. Data from the global media audit and POR survey suggest that

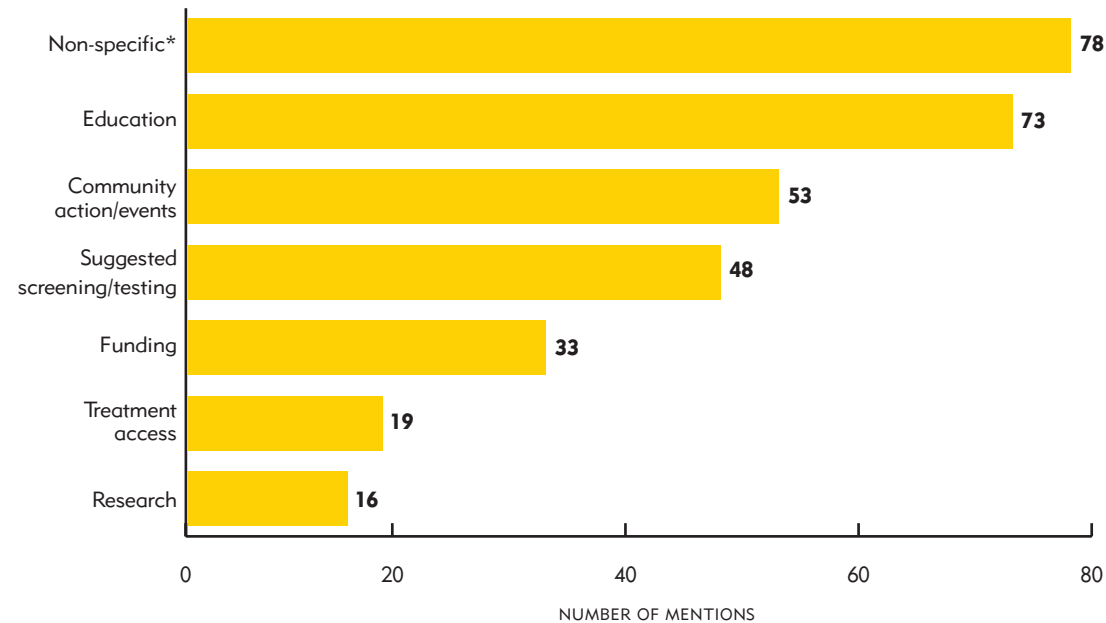
LIVESTRONG will have willing partners in these efforts; enthusiasm exists around the globe to address the cancer problem. The POR results indicated that more than 60% of respondents want their countries to put more government funding toward cancer research and to make cancer treatment more accessible. Regarding cancer survivorship, a little more than half (51%) of POR respondents specifically indicated that more resources should be devoted to those who have been diagnosed with cancer. **Figure 7** shows that many articles were identified through the media audit that called upon citizens, advocacy

organizations, or governments to take specific actions across a variety of areas (e.g., increase education or funding; improve access to screening or treatment) to improve cancer control. Each of these calls to action represents a potential platform from which to launch international efforts to reduce the cancer burden.

LIVESTRONG will build on its efforts in the United States by using these results to strengthen patient advocacy in international settings and to build a global grassroots movement. LIVESTRONG will work with partners around the world to help people have accurate perceptions of cancer; to

prevent stigma from inhibiting people in their cancer control efforts; to help people affected by cancer receive the support, services, and information they need; and to support ample access to services that facilitate healthy living—all of which will help in decreasing the global cancer burden.

Figure 7: Calls to Action in Media Audit Coverage.



*Non-specific = simple statements that "more needs to be done" for cancer research, cancer screenings, cancer detection programs



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Sample Sizes

for Each Data Source
by Country

Country	Number of Articles in Media Audit	Number of Respondents in Public Opinion Research Survey	Number and Type of Semi-Structured Interview Participants
Argentina	73	501	N/A
Brazil	83	501	N/A
China	175	500	N/A
France	110	500	N/A
India	135	504	2 cancer survivors, 2 cancer care professionals, 4 MOS*
Italy	89	500	2 cancer survivors, 3 cancer care professionals, 21 MOS*
Japan	131	500	2 cancer survivors, 1 cancer care professional, 25 MOS*
Mexico	108	500	4 cancer survivors, 11 cancer care professionals, 12 MOS*
Russia	88	N/A	N/A
S. Africa	93	500	1 cancer survivor, 3 cancer care professionals, 18 MOS*

*MOS = "Man on the street" Interviews