



NAVIGATING THE CANCER EXPERIENCE:
REVIEWING THE IMPACT OF LIVESTRONG'S NAVIGATION SERVICES

A LIVESTRONG REPORT
2010

ACKNOWLEDGEMENTS

LIVESTRONG would like to thank the cancer survivors who have shared their experiences with us and helped us to improve the support services we provide to people affected by cancer.

LIVESTRONG also wishes to thank the partner organizations that have made the success of our navigation services possible: EmergingMed, Patient Advocate Foundation and CancerCare.

Additionally, LIVESTRONG would like to thank the navigation team who provide services to cancer survivors daily.

LIVESTRONG Navigation Team

Andy Miller, MHSE, CHES

Claire Neal, MPH, CHES

Chris Dammert, MBA

Melissa Sileo, MSW, LCSW

Teresa Castro

Emily Eargle, MSSW

Sarah Gómez

Ashley Koenings

Jerald Saenz, MA, LPC

Amanda Esparza, MSSW, LMSW

LIVESTRONG Report Committee

Ruth Rechis , PhD

Emily Eargle, MSSW

Melissa Sileo, MSW, LCSW

Emily Smith Goering

Stephanie Nutt, MPA, MA

Yvonne Dutchover, Copywriter

Diana Berno, Art Director



EXECUTIVE SUMMARY

At **LIVESTRONG** we stand with the 28 million cancer survivors around the world. Our mission is to inspire and empower people affected by cancer. We fulfill this mission by empowering people to take action against the world's leading cause of death and by providing direct service through programmatic initiatives and partnerships addressing the needs of cancer survivors.

In 2004, **LIVESTRONG** began providing national, one-on-one navigation services to anyone affected by cancer, regardless of cancer diagnosis, stage or demographic factors. Beginning as an online and telephone service known as **LIVESTRONG SurvivorCare**, **LIVESTRONG's** navigation services were developed to help people affected by cancer learn what to expect during the cancer experience, learn what questions to ask and connect people to appropriate resources.

This report reviews **LIVESTRONG's** commitment to supporting people affected by cancer through our navigation services and highlights the impact this model had in 2010. In summary:

- **LIVESTRONG** supported more than 11,000 individuals affected by cancer by connecting them to educational resources, emotional support, fertility preservation options and financial assistance programs totalling more than \$3 million in savings.
- **LIVESTRONG** met its programmatic goals to help people affected by cancer learn what to expect during the cancer experience, learn what questions to ask and connect these individuals to appropriate resources.

Next steps for **LIVESTRONG's** navigation services include:

- Expanding our navigation services to address our client's most pressing needs
- Conducting a research study to further understand the impact of patient navigation, with an emphasis on the adolescent and young adult population
- Opening a community-based patient navigation center in Austin, Texas

1

BACKGROUND



History

In 2004, Lance Armstrong, internationally known cancer survivor, advocate and champion cyclist, won an unprecedented sixth Tour de France; that win occurred simultaneously with the launch of the now-iconic yellow **LIVESTRONG** wristband. The wristband, Lance Armstrong and the Foundation he created in 1996 resonated with other cancer survivors as symbols of hope and inspiration and encouraged others to address cancer head-on. Phone calls and emails began to pour into the Foundation offices asking for support in living with, through and beyond cancer. Prior to this, the Foundation offered general support and information to anyone affected by cancer, but did not have a focus on providing specialized navigation services.

In the summer of 2004, in response to this new demand, the Lance Armstrong Foundation (now known as **LIVESTRONG**) began a new program, **LIVESTRONG SurvivorCare**. Partially supported by funding from the Centers for Disease Control and Prevention, **LIVESTRONG SurvivorCare** was developed in collaboration with other national organizations with the goal of providing free, comprehensive, one-on-one support to all people affected by cancer, including: individuals who have or have ever had a cancer diagnosis, caregivers, family, friends and health care professionals and providers.

For more than six years **LIVESTRONG SurvivorCare** has provided exemplary navigation services to people affected by cancer, and while the model has evolved in response to client needs over the years, the goals have remained the same — to help people understand what to expect, learn what questions to ask and connect people to appropriate resources. The remainder of this report describes this program in more depth and provides the results of the program's impact in 2010.

LIVESTRONG'S NAVIGATION SERVICES

In 2010, **LIVESTRONG SurvivorCare** was replaced by a more accurate description — **LIVESTRONG's** navigation services — due to internal and client feedback that the name “SurvivorCare” was confusing and did not adequately describe our services. We changed the way we refer to our services to reflect this feedback and to ensure that the cancer community felt these services were applicable to them. This perception was especially important to help us meet our related goal of addressing the growing demand for cancer navigation services.

LIVESTRONG provides services in five main areas: 1) Coping with emotional concerns through counseling and support groups; 2) Addressing insurance, financial and job concerns; 3) Providing education about and matching to clinical trials and new treatments in development; 4) Locating and accessing local resources; and 5) Providing information about fertility risks and access to discounted rates for fertility preservation services.

LIVESTRONG takes a comprehensive approach to providing patient support by recognizing that many aspects of an individual's life (e.g., financial status, physical health, emotional well-being, loved ones, employment, etc.) are impacted by a cancer diagnosis. We provide patient-centered support that is responsive to cancer survivors' stated and assessed needs by using a centralized system and working with strong partners who provide exemplary services.

Upon initial contact with **LIVESTRONG**, all phone and email inquiries are answered by navigators who are bilingual (English and Spanish) and located at **LIVESTRONG** headquarters in Austin, Texas. Navigators, utilizing a standardized intake process, ask the client about his or her cancer-related needs and assess which programs, services or partners can best meet these needs. Navigators are then responsible for coordinating referrals as necessary, providing appropriate follow-up and ensuring the client's identified needs are met as well as assessing future needs that may arise. Ongoing, personalized follow-up occurs at multiple points after the initial contact; assessment and referrals to specialized services are also a critical component to **LIVESTRONG's** navigation services model. This personalized follow-up provides an opportunity to address any new barriers that have arisen and helps the client get support for these new needs.

” I have found the **LIVESTRONG** program to be the single biggest source of information and help I have ever seen for any issue. I received info on clinical trials, financial support and emotional support for me and my family. Even though I was a little hard to get a hold of at times because of my treatment, the staff constantly followed up with phone calls and to make sure I got all of the help I needed. I cannot thank everyone at the organization enough. I no longer feel so alone in my journey.

— Anonymous survey respondent

LIVESTRONG GUIDEBOOK

Available for free to **LIVESTRONG** clients, the **LIVESTRONG** Guidebook addresses specific concerns that cancer survivors, loved ones and caregivers may have during each phase of the cancer experience. It helps survivors navigate the health care system to find reliable resources and the best care for their situations. The Guidebook provides the information that is needed from the time of diagnosis, through cancer treatment and post-treatment. The general themes of the Guidebook content include understanding how cancer can affect the physical, emotional and day-to-day lives of survivors. The information is also helpful for loved ones and those assisting as caregivers. The **LIVESTRONG** Guidebook was created with the input of cancer survivors and the health care professionals who serve them.

The Guidebook is a two-book set. Book 1 is the **LIVESTRONG** Guidebook, which provides information that survivors need to deal with cancer and treatment. Book 2 is the **LIVESTRONG** Guidebook Planner and Journal. This book helps survivors plan and keep track of different aspects of the cancer experience, including medical, financial and personal information. The Planner and Journal provide worksheets and calendars to support topics and information described in Book 1.

In order to deliver comprehensive and individualized services, navigators ensure our clients have access to **LIVESTRONG** programs and other educational resources. This may occur by directing clients to resources and organizations, ordering free materials on the clients' behalf as well as connecting clients to partner organizations if needs match the services. The primary organizations providing direct service are CancerCare, Patient Advocate Foundation, EmergingMed and **LIVESTRONG**.

CancerCare

CancerCare is a national nonprofit organization that provides free, professional support services for anyone affected by cancer. This includes people with cancer, caregivers, children, loved ones and the bereaved. **LIVESTRONG**'s partnership with CancerCare began at the inception of the **LIVESTRONG** SurvivorCare program in 2004. Initially through this partnership, CancerCare administered the client intake process and provided emotional support and resources to clients. While **LIVESTRONG** continues to refer to CancerCare as a valuable resource in the cancer community, the formal relationship between **LIVESTRONG** and CancerCare ended in May 2010 when **LIVESTRONG**, as described more thoroughly below, had the capacity to staff navigators to coordinate the referral process and the emotional support navigators to provide direct emotional support to clients.

Patient Advocate Foundation (PAF)

LIVESTRONG partnered with PAF in January 2005. PAF is a national nonprofit that provides case management services to individuals affected by chronic, life-threatening and debilitating illnesses. The partnership

with PAF allows **LIVESTRONG**'s navigation services to provide information about resources for financial assistance, assistance for the uninsured and underinsured, access to medical treatments, assistance handling debt and financial management issues, assistance handling employment discrimination/retention issues and assistance applying for programs such as Medicare, Medicaid, Social Security and Social Security Disability.

EmergingMed

In September 2005, **LIVESTRONG** began a partnership with EmergingMed. EmergingMed is a national organization that provides information and education about clinical trial options and matches people with clinical trials based on the specifics of an individual's cancer diagnosis and experience. With this partnership, **LIVESTRONG** began providing information and education about clinical trial options and began matching people to clinical trials. **LIVESTRONG** clients are able to access these services through the standardized navigation referral process as well as through a direct phone number and web link on LIVESTRONG.org/GetHelp.

LIVESTRONG

LIVESTRONG serves two primary roles within the navigation services program: service coordination and direct support services. First, as described above, **LIVESTRONG** is the primary and ongoing point of contact for people who reach out to our navigation services and is responsible for service coordination. During the intake process, **LIVESTRONG** navigators assess the needs of the client and then

The biggest help to me [as a caregiver/ family member] is that **LIVESTRONG** had all the information in one place (clinical trials, research, financial, medical, social, etc.). This was a huge help in that I didn't have to chase down all those separate 'threads.'

— **LIVESTRONG** client,
June 2010

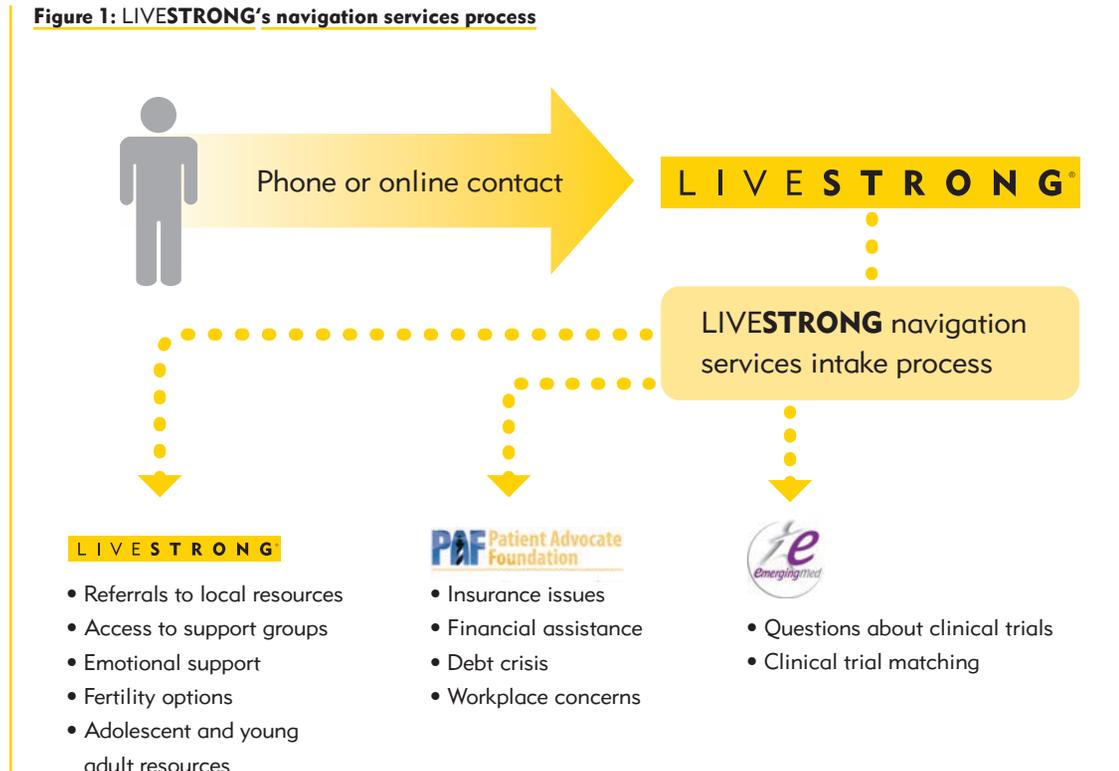
connect that client with the appropriate services, resources and partners. This may include connecting the client with **LIVESTRONG** resources, such as the **LIVESTRONG** at the YMCA program, the **LIVESTRONG** Guidebook or the Living After Cancer Treatment Brochure series. (See sidebar on the **LIVESTRONG** Guidebook, page 4.)

Second, as a direct service provider, **LIVESTRONG**'s emotional support navigators are available to provide direct emotional support to people who contact **LIVESTRONG**. Moreover, clients can receive referrals to local and community resources and programs.

Additionally, in 2009, **LIVESTRONG** acquired the assets of two nonprofit organizations, Fertile Hope and Planet Cancer. Fertile Hope began as a national nonprofit organization dedicated to providing reproductive information, support and hope to cancer patients and survivors whose medical treatments present the risk of infertility. With this acquisition, **LIVESTRONG** incorporated Fertile Hope's hotline for addressing cancer-related fertility concerns and the administration of the fertility preservation assistance program, Sharing Hope, into **LIVESTRONG**'s navigation services. Additionally, Planet Cancer, whose goal is to provide support and increase awareness for young adults diagnosed with cancer, was also acquired and their programs, including an online community platform, were integrated into **LIVESTRONG**.

Figure 1 is a visual representation of **LIVESTRONG**'s navigation services process that was in place at the end of 2010.

Figure 1: LIVESTRONG's navigation services process



” I prayed for a miracle. I got it! When I say my prayers tonight I will thank God for Sarah at **LIVESTRONG**. She is referring me to one of the Foundation's partners. It is a group that helps people like me who need things like mammograms and ultra-sounds and have no health insurance. First things first. Get the tests done. If it shows further care is needed, I will cross that bridge if and when I need to. Thing is I will know I do not need to cross it alone.

— **LIVESTRONG** client, August 2010

2

METHODS



To assess how well **LIVESTRONG** is meeting its goals to help cancer survivors understand what to expect, learn what questions to ask and connect people to appropriate resources, ongoing program evaluation and data analyses are conducted. A variety of evaluation methods are used to gather quantitative and qualitative data. This report focuses on the quantitative data collected and the following chapter provides a review of the methods used to collect this data. Qualitative data, gathered through periodic interviews and focus groups with clients, is also an important component of **LIVESTRONG**'s program evaluation; however, a comprehensive analysis of this data is out of the scope of this report, though illustrative quotes are included throughout.

The evaluation methods used to collect the data highlighted in this report include:

- **Review of intake forms to understand clients' requested needs and the services provided**

During the phone and online intake process, **LIVESTRONG** gathers basic demographic information and specifics related to the client's cancer experience. If someone contacts **LIVESTRONG** by phone, a navigator asks the client the intake questions verbally and then enters those responses into a standardized database. In the online intake process, the client enters this information through an online form available at LIVESTRONG.org/GetHelp. Intake forms are reviewed on an ongoing basis to inform program delivery and compliance with internally set standards.

- **Reports among LIVESTRONG partners**

Monthly, each **LIVESTRONG** partner, including **LIVESTRONG**, reports on their interactions with referred clients via an online survey and participates in teleconferences to foster collaborative discussions about client care and programmatic goals.

- **Analysis of six-week follow-up surveys to assess the long-term impact of the program**

Since 2007, **LIVESTRONG** has conducted an anonymous follow-up survey with clients to assess how well **LIVESTRONG** meets the needs of people affected by cancer and the quality of the navigation experience. Six weeks after initial contact with **LIVESTRONG**, clients are sent a follow-up survey either via email or mail. Surveys are available in English and Spanish.

The following sections of this report present the results from the quantitative data collected in 2010 in each of the three areas highlighted above.

3

RESULTS



Results presented here are intended to provide an overview of LIVESTRONG clients served in 2010 and the impact that navigation services had on our clients' cancer experiences. The results do not include all of the information collected, but rather provide an overview of the primary characteristics and findings from data sources used to evaluate LIVESTRONG's navigation services, including intake documentation, partner reporting and the six-week follow-up survey.

INTAKE PROCESS

In 2010, LIVESTRONG provided support to 11,194 clients. Through the phone and online intake process, LIVESTRONG collected demographic information about the person diagnosed with cancer and client characteristics about the person requesting services, whether they were a person diagnosed with cancer, a loved one or a health care professional.

DEMOGRAPHICS FROM THE INTAKE PROCESS

Age

As indicated in Figure 2, the majority of clients served through LIVESTRONG's navigation services were between the ages of 26 and 64—almost half (44%) were between the ages of 40 and 64.

Race/Ethnicity

As indicated in Figure 3, the majority of clients served through LIVESTRONG's navigation services identified as Caucasian/white. However, due to LIVESTRONG's efforts to improve outreach to the Hispanic/Latino population, 19% of individuals identified as Hispanic/Latino. See sidebar on LIVESTRONG's Hispanic/Latino outreach campaign, page 11.

Fig. 2: Age

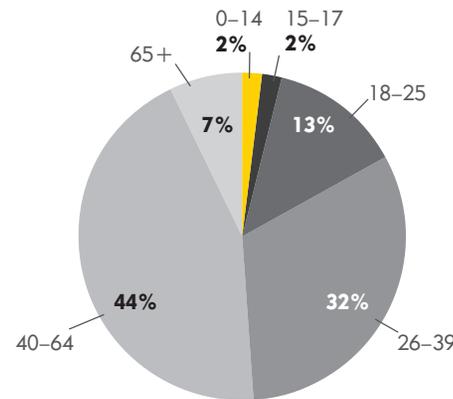
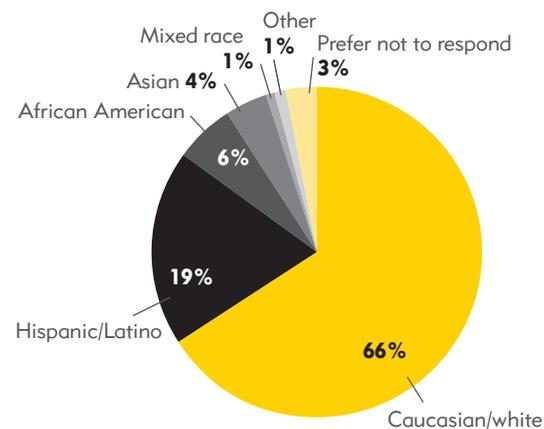


Fig. 3: Race/ethnicity



With all the stress that surrounds a diagnosis, it was a relief to have help with such a time-sensitive, financially difficult and potentially life-altering issue. Now that treatment has passed and recovery is in progress, it's possible to look back at the decisions that had to be made in that short window between diagnosis and treatment and appreciate the impact on life post-treatment. I could not have done it without the Sharing Hope program.

—LIVESTRONG client,
September 2010

Gender

More than half of LIVESTRONG clients identified as female. See Figure 4.

Survivorship Stage

LIVESTRONG provides support to clients across the cancer continuum. As indicated in Figure 5, the majority of clients sought support from LIVESTRONG when they were newly diagnosed (33%) or on treatment (37%). However, it is interesting to note that 14% of clients were finished with treatment, yet still needed support.

CLIENT CHARACTERISTICS FROM THE INTAKE PROCESS

Connection to Cancer

As indicated in Figure 6, almost half of the clients who contacted LIVESTRONG were diagnosed with cancer themselves. However, a significant percentage of clients who contacted LIVESTRONG were family members (36%) or health care professionals (10%) seeking services on behalf of a person diagnosed with cancer.

Fig. 4: Gender

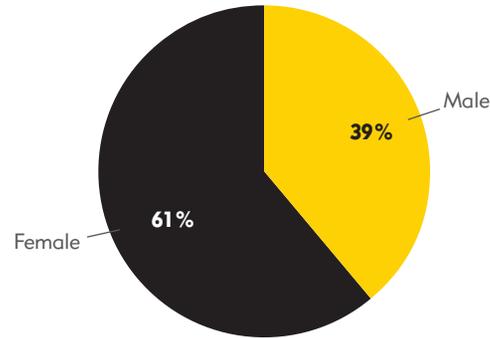


Fig. 5: Survivorship stage

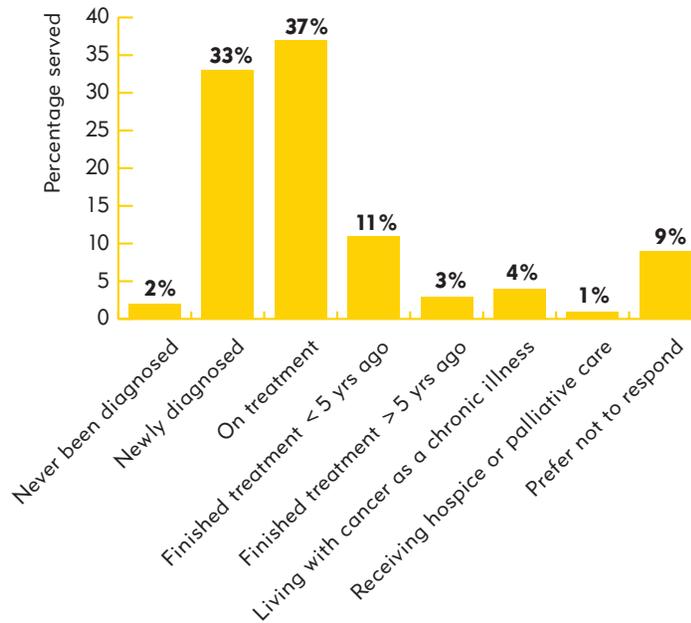


Fig. 6: Clients contacted LIVESTRONG on behalf of...

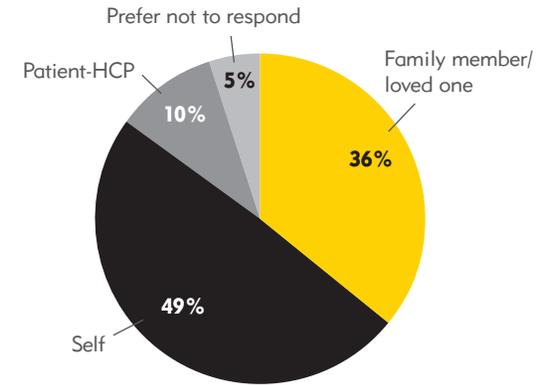
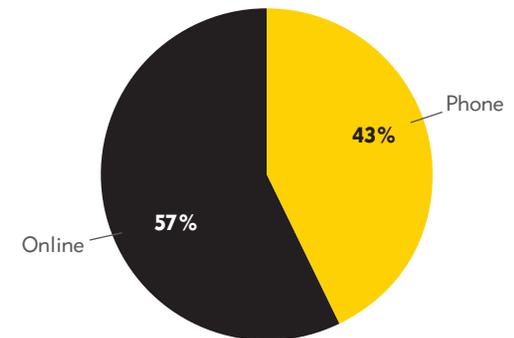


Fig. 7: How clients contacted LIVESTRONG



Modality

As indicated in Figure 7, just over half of clients served by LIVESTRONG's navigation services contacted the program through online mechanisms.

LIVESTRONG HISPANIC/LATINO OUTREACH AND PROMOTORES PROGRAM

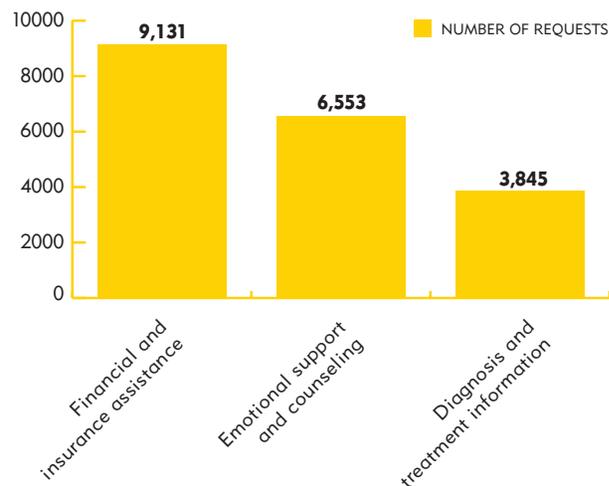
Cancer is the second leading cause of death in the Hispanic/Latino population. Cancer rates for this population are projected to increase 142% by 2030, compared to 45% of overall U.S. cancer incidence. With this growing need in mind, LIVESTRONG launched an awareness campaign in 2008 and continues to develop and implement activities aimed to increase Hispanic/Latino awareness and access to culturally and linguistically appropriate resources. Using tested outreach strategies, LIVESTRONG implemented a national campaign using Spanish radio, newspapers and websites encouraging individuals to contact LIVESTRONG for cancer support. In 2010, more than 25,000 Hispanic/Latino individuals were served through LIVESTRONG's direct support, print or online resources at LIVESTRONG.org/espanol.

Hispanic/Latino individuals often consult trusted community leaders, or promotores (community health workers), for health-related information. Promotores provide in-person support within their communities. In 2010, LIVESTRONG trained 338 promotores with the LIVESTRONG Cancer Survivorship Training Curriculum. Of those trained, 100% reported an increased knowledge of cancer survivorship and an increased confidence in their ability to help cancer survivors in their communities.

Services Provided

Based on their identified needs, clients who contacted LIVESTRONG in 2010 received approximately 38,169 services, an average of slightly more than three services per client. The top three service areas requested in 2010 are listed in Figure 8.

Fig. 8: Top three types of services requested



PARTNER REPORTING

Monthly, LIVESTRONG's navigation partners, including LIVESTRONG, report on their interactions with clients who were referred for services. In addition, through partner reporting we track the financial impact of LIVESTRONG's navigation services through the total number of funds awarded to and saved for clients.

PAF awards funds directly to clients and saves clients' funds through negotiating discounts, maximizing available medication programs and overturning denials from insurance companies. Similarly, CancerCare awards funds through co-pay assistance and other financial support programs. In 2010, through these programs, clients were saved \$867,128 and were awarded \$199,652.

The LIVESTRONG Sharing Hope program contributed to the total funds saved by connecting clients diagnosed with cancer during their reproductive years to discounted fertility preservation options and, for women, donated pre-cycle medications. In 2010, the Sharing Hope program saved \$2,135,675 for more than 500 clients.

In total, LIVESTRONG saved clients \$3,002,803 in 2010.

“The people I spoke with via phone and email were polite, informative and courteous. The services available to cancer patients, survivors and their family (or friends) exceeded my expectations. Thank you all.

—LIVESTRONG client,
August 2010

SURVEY FINDINGS

Follow-up surveys were sent to all clients in 2010 who provided an email or mailing address. Results included here are from 273 completed surveys (9 Spanish and 264 English), representing slightly more than 5% of survey recipients. While the survey responses offer input on a small number of the total client population, they provide important insight into the client experience.

Program Goals

As previously referenced, **LIVESTRONG**'s goals are to help people affected by cancer to learn what to expect, know what questions to ask and connect people to appropriate resources.

As indicated in Figure 9, based on the survey responses, these three goals set forth are being achieved. The majority of respondents agreed that **LIVESTRONG** helped them understand what to expect during the cancer experience (86%), learn what questions to ask (89%) and connect to other resources (86%). In addition, the majority of respondents (92%) reported that **LIVESTRONG** helped them learn something new.

The results reflected in Figure 9 represent the individuals who agreed with each statement.

Refer to Others

An important finding to note is the willingness of clients to refer others to the program. As indicated in Figure 10, the majority of survey respondents would recommend **LIVESTRONG**'s navigation services to others affected by cancer (93%).

SUMMARY

In 2010, **LIVESTRONG** provided support to 11,194 individuals, connecting them with 38,169 services. Reviewing historical data on the program, **LIVESTRONG** served 26% more individuals affected by cancer in 2010 than in 2009, connecting them to 44% more services. **LIVESTRONG** clients were mostly between the ages of 26 and 64, female, Caucasian and newly diagnosed with cancer or on treatment. Most of them contacted **LIVESTRONG** online.

The most requested services by clients fell in the areas of financial and insurance assistance, emotional support and counseling and diagnosis and treatment information. The financial impact of **LIVESTRONG**'s navigation services was significant in 2010, saving clients more than \$3 million dollars.

The results reflected in this report have been used to inform programmatic changes to help enhance the services provided to clients, in particular those seeking peer-to-peer emotional support or individualized information about specific diagnoses to help inform treatment decisions. In addition, these results are used throughout **LIVESTRONG** to inform decisions related to outreach, the creation of educational materials and patient-centered advocacy efforts.

Fig. 9: LIVESTRONG helped me...

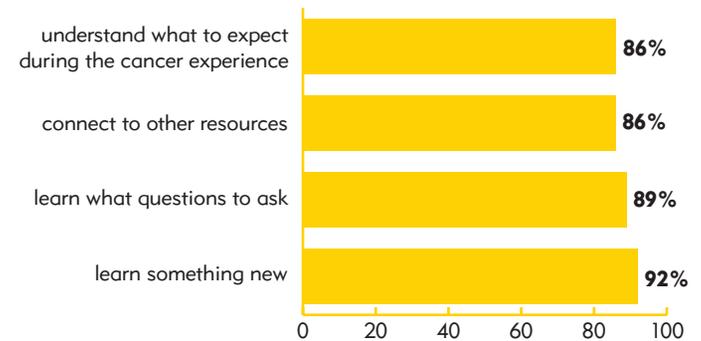
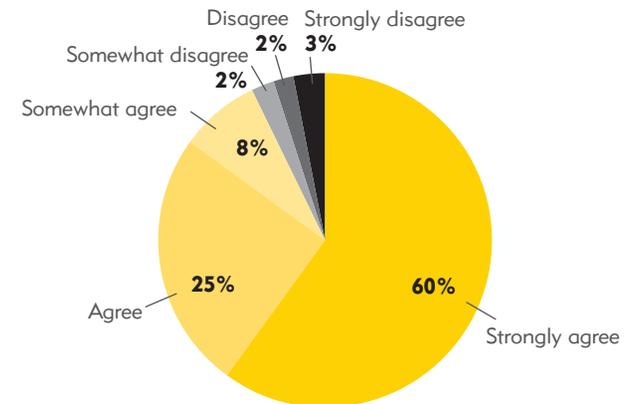


Fig. 10: I would recommend LIVESTRONG



I think the genuine concern and care demonstrated by direct contact with people was most beneficial. There was a true interest of what I'm going through and very practical suggestions on all levels of information.

— **LIVESTRONG** client,
June 2010



4

NEXT STEPS

Based on the results presented in this report and an extensive review of existing patient navigation programs and literature, **LIVESTRONG** will take steps to further improve upon and expand the service offerings and reach of **LIVESTRONG's** navigation services model. Specifically, in 2011, **LIVESTRONG** will:

1) Expand **LIVESTRONG's navigation services to address the most pressing needs experienced by cancer survivors**

As reflected in the results section, the top three service areas requested by **LIVESTRONG** clients were: 1) financial and insurance assistance, 2) emotional support and counseling and 3) diagnosis and treatment information. To better address these needs, **LIVESTRONG** has committed to expanding our partnership network and scope of services in 2011. The following describes this commitment.

Financial and Insurance Assistance

The financial and insurance concerns of cancer survivors are diverse and abundant, ranging from insurance claim denials to paying for transportation and childcare in addition to medical bills. Moreover, addressing these concerns with insurance companies, hospitals and community agencies can be a resource-depleting process in itself. Since assistance with addressing financial and insurance concerns is the most frequently requested service by **LIVESTRONG** clients, **LIVESTRONG** and PAF have expanded their partnership to include the presence of a PAF case manager at the **LIVESTRONG** headquarters in Austin, Texas. Though remaining a PAF employee, this case manager will be a resource for **LIVESTRONG** navigation staff and will provide dedicated and more immediate support to **LIVESTRONG** clients.

Emotional Support and Counseling

While **LIVESTRONG** provides exemplary resources to address emotional needs, it became increasingly apparent through the initial intake process, past research conducted by **LIVESTRONG** and client feedback to navigators that our clients are very interested in connecting with other survivors. Some individuals would prefer to connect with others who are the same age, were diagnosed with

the same cancer and/or live in the same geographic area. No matter the specific areas of interest, connecting with a peer is important to many cancer survivors but can be hard to coordinate.

To address this need, in 2011 **LIVESTRONG** entered into a formal partnership with Imerman Angels, a nonprofit organization whose mission is to provide personalized connections that enable one-on-one support among cancer fighters, survivors and caregivers. **LIVESTRONG** has referred to Imerman Angels for many years, but with this formal partnership referrals will be integrated into **LIVESTRONG's** navigation services process, including individualized follow-up to ensure needs are met and inclusion in the formal programmatic evaluation process.

Diagnosis and Treatment Information

Assistance with identifying and, most frequently, interpreting diagnosis and treatment information was the third most requested service in 2010. With no trained medical professionals on staff, this is an area in which neither **LIVESTRONG** nor its navigation partners could provide expertise. To address this need, in 2011, **LIVESTRONG** entered into a formal partnership with NavigateCancer Foundation (NCF), whose certified oncology nurses provide free, one-on-one medical information and advocacy services to assist patients and family members overcome barriers to the prompt diagnosis and treatment of health problems related to cancer from pre-diagnosis to survivorship. While NCF does not provide medical advice, they do have the expertise to assist clients in understanding their medical documents and to help them develop a decision-making framework that works best for their personal and medical circumstances.

2) Conduct a research study to further understand the impact of patient navigation, with an emphasis on the adolescent and young adult population

A review of the available literature on patient navigation reveals gaps in the research stemming from a lack of agreement and awareness on what patient navigation is. Patient navigation is a growing concept and while some studies suggest positive outcomes from patient navigation, the growing presence of programs in a variety of settings and populations precludes definitive conclusions as to their efficacy (Dohan & Schrag, 2005; Ell et al., 2008; Wells et al, 2008). Aggressive work must be done to redefine the concept, publish findings and grow the services to truly address barriers and needed services for patients along the entire cancer care continuum, including survivorship.

To date, the evaluation of **LIVESTRONG**'s navigation services has been done primarily through anonymous surveys and informal, but informative, focus groups and interviews. In 2011, we aim to develop a more comprehensive understanding of the extent to which **LIVESTRONG** is achieving its programmatic goals through a formalized research study that will use standardized scales in an effort to:

- Understand the impact of **LIVESTRONG**'s navigation services model in helping people navigate the cancer experience, including outcomes such as understanding what to expect, learning what questions to ask as well as connecting people to appropriate resources.
- Understand the mechanisms for removing barriers to care, improving **LIVESTRONG** client outcomes and addressing service and access gaps throughout the cancer experience.
- Examine the relationships between patient preparedness and empowerment and getting one's needs met throughout the cancer experience.

LIVESTRONG has the opportunity to make a significant contribution to patient navigation research through this study as it does not exclude participants based on diagnosis, treatment stage or ethnicity. In addition, due to the large number of young adults who contact **LIVESTRONG** for support, we have an opportunity to demonstrate the impact of navigation on this specific population throughout the continuum of the cancer experience, from diagnosis to post-treatment survivorship.

3) Open a community-based patient navigation program in Austin, Texas
LIVESTRONG's navigation services model has successfully provided support to people affected by cancer by coordinating a comprehensive referral network that reduces the barriers cancer survivors face as they navigate through a fragmented health care and support system. This idea of supporting patients through navigation is not new.

In 1990 in Harlem, Dr. Harold P. Freeman pioneered an idea to address the many issues experienced by cancer survivors. Dr. Freeman created patient navigation as a program to assist underserved cancer patients in his clinics. In this program, patient navigators assist patients from the point of an abnormal finding until completion of cancer treatment (Freeman, 2006; Freeman, Muth, & Kerner, 1995). Navigators help patients overcome all types of barriers including, but not limited to, linguistic, financial, cultural and transportation.

With Dr. Freeman's example in mind, **LIVESTRONG** is expanding upon the existing navigation program model by adding a new mechanism to serve clients—in-person, face-to-face service. This in-person service will be provided at the **LIVESTRONG** Cancer Navigation Center (Center) located in Austin, Texas, at the **LIVESTRONG** headquarters. Currently, there is no comprehensive cancer care center in Austin or the surrounding communities; thus, individuals are served through a number of clinical care and social service agencies and often face logistical and situational barriers, such as time identifying and contacting numerous support services individually as they try to get support for their emotional, financial and practical needs.

The goal of the Center is to provide community-based navigation services, which ease the burden of coordinating access to care for people affected by cancer in Austin and the five surrounding counties. The Center will act as a pilot project to help inform how community-based navigation services can improve cancer care coordination for clients and other stakeholders, including health care professionals and community organizations. In addition, the Center will provide the opportunity to test diverse outreach strategies to reach underserved populations, including Hispanics/Latinos and adolescents and young adults (those diagnosed between the ages of 15 and 39).

In 2010, extensive research was conducted to identify how **LIVESTRONG** could best meet the needs of people affected by cancer in Austin and surrounding communities. Additionally, the in-person services were pilot tested in late 2010, which informed the formal grand opening of the Center in early 2011. The program evaluation methods highlighted in this report and the research study described above will be used to measure the impact of the new components of **LIVESTRONG**'s navigation services and the data collected will continue to inform how **LIVESTRONG** improves its programs to best meet clients' ongoing needs.

” I am the grandmother of a grandson experiencing testicular cancer. Having raised him from a toddler, he is more like my own child. **LIVESTRONG** has helped me realize this is not a death sentence for him. I am so happy I have someone to talk to about my concerns regarding what is going on day-to-day, and I can relay this information to him. Thank God for **LIVESTRONG**.

— **LIVESTRONG** client,
December 2010

REFERENCES

- Dohan, D., & Schrag, D. (2005). Using navigators to improve care of underserved patients. *Cancer, 104*, 848-854.
- Ell, K., Yourlekis, B., Xie, B., Nedjat-Haiem, F., Lee, P., Muderspach, L., et al. (2009). Cancer treatment adherence among low-income women with breast cancer or gynecologic cancer. *Cancer, 4606-4615*.
- Freeman, H. (2006). Patient Navigation: A community based strategy to reduce cancer disparities. *Journal of Urban Health, 83*, 139.
- Freeman, H., Muth, B., & Kerner, J. (1995). Expanding access to cancer screening and clinical follow-up among the medically underserved. *Cancer Practice, 3*, 19-30.
- Reis, L., A. G., Melbert, D., Krapcho, M., Mariotto, A., Miller, B. A., Feuer, E.J., et al. (eds) (2007). *SEER Cancer Statistics Review, 1975-2004*, National Cancer Institute. Bethesda, MD, http://seer.cancer.gov/csr/1975_2004/, based on November 2006 SEER data submission, posted to the SEER website.
- Wells, K., Battaglia, T., Dudley, D., Garcia, R., Greene, A., Calhoun, E., et al. (2008). Patient Navigation: State of the art or is it science? *Cancer, 113*, 1999-2010.

LANCE ARMSTRONG FOUNDATION
2201 E. SIXTH STREET
AUSTIN, TEXAS 78702
LIVESTRONG.ORG

LIVESTRONG®