Abstract
Over the past decade, the world has demonstrated an increased interest in and awareness of the unique needs of cancer survivors. Survivorship care plans are a communication tool intended to provide guidelines for the healthcare of survivors as they complete active cancer care, and for the duration of their lives. The Internet represents a unique way to communicate with cancer survivors, and data from several groups indicate that increasing numbers of survivors both desire information about their care and seek this information on the Internet. A handful of US-based groups have developed Internet-based tools for the creation of survivorship care plans. The first of these, the LIVESTRONG Care Plan (www.livestrongcareplan.org), is available via the OncoLink cancer information website based at the University of Pennsylvania. Data from the first three years since the launch of this tool demonstrate increasing use by survivors from nearly every continent, with international users accounting for 16% of total users. Data from these users also demonstrate wide variability with regard to receipt of previous survivorship information and treatment summaries based on location of residence. This variation emphasises the vital role that Internet-based survivorship care plans may continue to play in the care of survivors worldwide.

Keywords
Survivorship care plan, cancer survivor, Internet, cancer-associated late effects, long-term effects, treatment summary, survivor

Disclosure: The authors have no conflicts of interest to declare.
Acknowledgement: This work is supported in part by the Lance Armstrong Foundation.
Received: 19 March 2010 Accepted: 30 July 2010 Citation: European Oncology, 2010;6(2):10-3 DOI: 10.17925/EOH.2010.06.02.10
Correspondence: Christine Hill-Kayser, 3400 Spruce Street, 2 Donner Building, Philadelphia, PA 19146, US. E: hill@uphs.upenn.edu

International Recognition of the Unique Needs of Cancer Survivors
Over the past five years, the important role of survivorship care plans for all cancer survivors has been formally recognised. In the US, recommendations from the Institute of Medicine in 2005 that all patients completing active cancer care be provided with a survivorship care plan were a major part of this impetus. Particularly since that time, the available literature has expanded dramatically with regard to recognition of unmet needs of cancer survivors. Cancer survivors remain at risk of recognised late effects of treatment related to surgeries, chemotherapies and radiation; in addition, several groups have demonstrated that cancer survivors may not receive appropriate surveillance for recurrent disease and/or age-appropriate screening for other illnesses, and others have found survivors to be at increased risk of infertility, unemployment and anxiety/depression. Cancer survivors in the US report rarely receiving survivorship information and treatment summaries based on location of residence. This variation emphasises the vital role that Internet-based survivorship care plans may continue to play in the care of survivors worldwide.

The Essential Role of Survivorship Care Plans
A survivorship care plan is primarily a tool for improved communication. Ideally, survivors should be provided with care plans at the time of completion of active cancer therapy, or during active therapy if this course is protracted or indefinite. Survivorship care plans should be individualised, and should be based on as many factors as possible that may affect an individual’s future health; these may include, but are not limited to, cancer diagnosis, age, health behaviours, demographic features and cancer treatments received. Survivorship care plans should then address as many long-term risks and healthcare concerns as possible, while also providing guidelines for surveillance for cancer recurrence, screening and care for age-related illness and resources for care for infertility and psychosocial concerns. This information may serve both to facilitate communication and to empower survivors to ensure that they receive complete care. Data accrued and published by
several groups over the past two decades have demonstrated that more and more cancer survivors desire as much information as possible about their disease and treatment, and that many are ready and willing to take an active role in managing their care.21,22 Certain demographic groups of cancer survivors appear to seek information more frequently than others, namely those who are younger (<65 years of age), females, those on higher incomes and those who receive regular healthcare from the same provider(s). Although desire for information and autonomy has been demonstrated to vary with such demographic features as well as with cultural norms, giving survivors worldwide the option to have further information seems universally indicated.

The Internet as a Tool for Cancer and Survivorship Information

Although healthcare providers appear to appreciate the potential benefit of providing survivorship care plans,23 creating them is certainly a resource-intensive activity that may be expensive and time-consuming. In response to this, a small number of co-operative and survivorship-orientated US-based groups have initiated efforts to provide care plans via the Internet. The Internet represents a rapidly growing source for transmission of health information worldwide.

Recent work has shown that over 50% of a US sample of cancer patients used the Internet to seek cancer-related information, with many citing the reason for Internet use being to help them make informed decisions regarding treatment and side effect management.24 Although cancer survivors appear to continue to prefer interpersonal communication with healthcare providers over all other sources of information, many appear to augment information provided with that from other sources, often the Internet,21 and a recently surveyed group of US survivors reported that they would turn to the Internet for cancer-related information second only to their healthcare provider.25

Although data regarding Internet use by non-US survivors are more limited, use of the Internet for cancer-related information appears to be increasing worldwide. Carlsson recently documented a rise in Swedish Internet use in the past decade, with 6% of cancer patients seeking Internet-based information in 1998 versus 59% in 2008.26 A recent survey of Australian women demonstrated that 62% of women presenting to a breast screening programme accessed the Internet for health-related information, and 70% related that they would access the Internet for breast cancer information if incurring such a diagnosis.27 Similarly, Newnham and colleagues demonstrated that 77% of ambulatory Australian oncology patients report seeking cancer information on the Internet.28 Certainly, in many parts of the world the availability of non-English-language information may be an obstacle to those seeking cancer information on the Internet, as has been documented by Chinese29 and French groups;30,31 however, the Internet appears to be a tool whose role in providing information is increasing worldwide at a rapid pace.

International Use of Internet-based Survivorship Care Plans, Including the LIVESTRONG Care Plan

Currently, a handful of Internet-based tools for creation of survivorship care plans are available. The first of these, the LIVESTRONG Care Plan, was first made available via OncoLife, a cancer information website based at the University of Pennsylvania, in May 2007. OncoLink (www.oncolink.org) is a website dedicated to the general needs of cancer patients and survivors, as well as their family members and caregivers, and serves over 3.9 million pages monthly to 385,000 unique internet protocol (IP) addresses. The care plan tool, first launched with the name OncoLife, was developed by a small team of oncology nurses and physicians. After being piloted to test groups of survivors, the tool was made publicly available via the OncoLink website. Detailed design and implementation procedures have been described previously.32 The care plan tool is designed to allow users to enter information regarding demographics, diagnosis and treatments received. Once this information has been entered, users receive customised, individualised survivorship care plans that may be printed or stored electronically in portable document format (PDF). Over the nearly three years since the tool was made available, it has evolved over six iterations. With each iteration, further information has been added and user queries have become more detailed to allow improved customisation of information provided. From the time of launch, the care plan has been available in both English and Spanish.

With the second care plan iteration, queries regarding location of residence were added. As of March 2010, 10,405 care plans had been created, with data regarding location of residence available for 8,969 users. After the first 18 months of availability, with a total of 1,872 users with residency data available, 91% of users reported being from the US,
Supportive Oncology

6% from Canada and only 3% from other countries. Further data have been presented in abstract form, and are updated here. Use by non-US individuals has continued to increase, with 14% of users now reporting living outside the US. In addition, the group of non-US survivors using this tool has become increasingly diverse, with 34% being from Canada, 31% Europe (most commonly Great Britain) and 26% Australia/New Zealand (see Figure 1). Small percentages of users now represent Asia (4%), South/Central America (2%), Africa (2%) and the Middle East (1%).

Both US and non-US users were equally likely to have utilised the Spanish version of the care plan tool (2% in both groups). Breast cancer was the most common diagnosis in both groups (46% and 36%, respectively), and the groups remain similar demographically: median diagnosis and current age are 49 and 53 years, respectively, in the US group, versus 47 and 50, respectively, in the non-US group.

Users completing care plans appear to be somewhat more likely to be survivors themselves (62%) than family members/friends (10%) or healthcare providers (27%) among US users compared with non-US users, 54% of whom identified themselves as survivors (13% family members/friends and 31% healthcare providers). Healthcare providers who created plans for survivors identified themselves as physicians more often in non-US (15%) than US (9%) countries.

Interestingly, non-US users were more likely to report having received previous survivorship information (18%) than were US users (12%) (p<0.001). Non-US users were also much more likely to report having received a written treatment summary (37%) than were US survivors (14%) (see Figure 2). These trends varied significantly across regions of the world: Australian users reported receiving a treatment summary in 70% of cases and survivorship information in 40%. This compares with only 21% of European survivors receiving treatment summaries and 10% receiving survivorship information, and Canadian survivors receiving treatment summaries in 25% of cases and survivorship information in 18%. These data are very interesting in that they demonstrate that potentially more attention is paid to survivorship issues in countries other than the US. Physicians in other parts of the world appear more likely to use a tool such as the LIVESTRONG Care Plan for their patients, and survivors appear more likely to have received treatment summaries and survivorship information from other sources. This appears to vary considerably, as would be expected, based on region, with Australian survivors having a much higher likelihood of receiving this information than US and European survivors, and Canadian survivors having an intermediate likelihood.

Certainly, these data do not provide enough information to draw conclusions regarding the reasons behind such discrepancies, which are in all likelihood multifactorial and may include differences in healthcare systems, physician–patient ratios and expenditure of resources. Interestingly, however, US and European survivors appear to be among the least likely to receive this information. Hopefully, this trend will begin to change over time, as attention to survivorship issues outside of a few specialised centres within the US is a relatively modern concept. Certainly, these issues have come to the forefront over the past decade, and the few groups who have implemented Internet-based, accessible tools for survivorship care plans are testament to this. Aside from the LIVESTRONG Care Plan, other US-based tools are available through the American Society of Clinical Oncology (www.asco.org) and the Journey Forward Program (www.JourneyForward.org). Other individual US institutions also report developing and implementing Internet-based tools for creation of survivorship care plans, including the Fred Hutchinson Cancer Research Center, the Dana Farber Cancer Institute and the University of Colorado Cancer Center. The fact that most such Internet-based tools, to this author’s knowledge, are US-based, may signify that US providers are aware of a true deficit in survivorship care in this country, which may be worse than exists in some other parts of the world.

Current and Future Roles of Internet-based Survivorship Care Plans in the International Setting

Just as provision of survivorship information is in its early phases of development in many parts of the world, research regarding the best way to provide this information is as well. Several groups have studied the ways in which survivorship care plans may be best provided, and have found that, overall, the healthcare community appears receptive to the care plan concept. Survivors appear willing to use Internet-based tools for creation of care plans, with over 90% of users of the LIVESTRONG Care Plan report ‘good’ to ‘excellent’ levels of satisfaction with it, and over 80% report that they will share the generated plans with the healthcare team. Recent data from other groups demonstrate that a balance between providing high-quantity, high-quality information and avoiding being overly technical and requiring excessive time is important in the design of Internet-based care plan tools.

The huge field of cancer survivorship research and understanding remains quite young at this point. Early data demonstrate that Internet-based tools for the creation of survivorship care plans may be useful, and may result in wide use and high levels of satisfaction worldwide. Based on data from use of one such tool, discrepancies in attention to survivorship issues appear to exist across the globe. Publicly available Internet-based survivorship care plans are one tool to reduce these discrepancies and to provide essential information to all cancer survivors worldwide.

Christine Hill-Kayser is an Assistant Professor of Radiation Oncology at the University of Pennsylvania School of Medicine. Her clinical interests include paediatric oncology, breast cancer and survivorship care. She has dedicated a large amount of time to research associated with the LIVESTRONG Care Plan, and has presented her findings at numerous US and international meetings. In addition, she serves as a Section Editor for the Cancer Survivorship section of Oncolink.

Carolyne Vachani is an Oncology Advanced Practice Nurse at the University of Pennsylvania’s Abramson Cancer Center. She has worked in the areas of medical haematology and oncology, bone marrow transplant, clinical research, radiation therapy and staff development. In her role she serves as the nurse educator for Oncolink, the Penn Cancer Center’s award-winning cancer information website. She serves as the project leader in the development and maintenance of the LIVESTRONG Care Plan and has a strong interest in oncology survivorship care.

Margaret K Hampshire is the Managing Editor of Oncolink. Her entire career has been dedicated to oncology nursing. Her clinical experience spans both medical and radiation oncology. She leads all aspects of the management, planning and development services covering strategic planning, public relations and communications, editorial oversight, research and commercial support services and development, fundraising and grant-making. She is also responsible for the innovation and engagement of services from the private sector, non-profits and non-governmental organisations (NGOs) and the development of Oncolink’s Global Health Initiatives.

James M Metz is an Associate Professor and Vice Chair of the Clinical Division of Radiation Oncology at the University of Pennsylvania School of Medicine, and Associate Director for Clinical Services and Programs at the Abramson Comprehensive Cancer Center. He specializes in treatment of gastrointestinal malignancies. His research interests include clinical application of photodynamic therapy as well as use of the Internet to provide cancer-related information. He serves as Editor in Chief of Oncolink.
Worldwide Use of Internet-based Survivorship Care Plans