

National Cancer Survivorship Resource Center

# Quality of Life: Information Delivery

Expert Panel Summit Workgroup Overview

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### The Changing Face of Information Delivery

Information delivery is rapidly changing and new modes of information delivery continue to emerge. A recent Pew Internet Study reports that 75% of adults and 95% of teenagers in the United States have access to the internet and 85% of American adults have a cell phone (Fox, 2010). Even with this ever increasing access to information, 93% of adults living with a chronic disease still report asking a health care professional for information to deal with medical issues (Fox, 2010). Information from the “Trends in Cancer Information Seeking” HINTS Brief (Health Information National Trends Survey) further solidifies the continuing preference of adults to receive information from health care professionals. The HINTS data indicate that as the availability of information online is increasing; health care consumers’ trust in that information is decreasing while consumer trust in information from a health care professional is increasing (NCI, 2010). However, this decrease in trust does not mean health care consumers are not turning to the internet for information. 55.3% of consumers who reported having sought cancer information went to the internet first (NCI, 2010).

The Pew Internet Project is beginning to dig deeper into the different types of information people are seeking from health care professionals versus from peers. The project found that people are more likely to turn to a health care professional to get an accurate medical diagnosis, information about alternatives and recommendations for specialists, hospitals, or other facilities. When seeking information about how to cope with day-to-day health situations, people were more likely to turn to peers (Fox, 2010).

These findings have interesting implications for cancer survivors transitioning out of treatment. As survivors transition back to the activities of daily living, survivors seeking information may begin to rely more on internet and peer information sources.

Education is needed in both the general population and among health care providers to raise awareness of the different types of information delivery that are available and how to utilize these information tools in disease self-management. Implications from the HINTS study must also be considered. Over 50% of cancer information seekers are turning to the internet, but only 18.9% of respondents reported trusting the information retrieved (NCI, 2010). As cancer survivors and caregivers rely more on the internet as an information resource during the transition out of treatment, it is important to have tools and resources to help them navigate the information and determine its quality and relevance.

The following is the Quality of Life: Information Delivery workgroup’s evaluation of the current survivorship information landscape and recommendations for the future.

### Workgroup Progress: Identifying gaps and resources

The information delivery workgroup meetings had three major themes: the availability of different types of information that cancer survivors need; the need for survivors to have a tool to assist with information seeking, alleviate information overload and recognize issues in information quality; and communication between health care professionals and survivors about the information survivors are finding and using in disease self-management.



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To investigate the availability of different types of survivorship information, the workgroup began by brainstorming known resources for cancer survivors. Workgroup members also ranked the perceived information availability in the following categories: tests and treatments, care planning, health promotion, side effects/symptoms, interpersonal/emotional, insurance, return to work, sexual function and fertility, advanced care planning and caregiving. The workgroup then reviewed web-based information from leading cancer organizations to evaluate the actual availability of information in the above categories (websites surveyed are listed in Table 3).

**Table 1: Perceived vs. Actual Availability of Survivorship Information**

Domain	Perceived availability (range 1-10, 1=lowest 10=highest)	Actual availability (% of sites providing information)
Advanced Care Planning	4	20%
Care Planning	4	60%
Caregiving	3	70%*
Health Promotion	6	70%
Insurance	4	50%
Interpersonal/Emotional	5	80%
Return to Work	4	40%
Sexual Function and Fertility	4	60%
Side effects/Symptoms	7	90%
Tests and Treatments	7	90%

\*2 sites noted information was limited for caregivers

From this investigation, the workgroup found information gaps in advanced care planning, return to work and insurance. There was also limited information on sexual function and fertility and care planning. Interestingly, the group perceived a low availability of information for caregivers and found seven of the ten sites did have caregiver information although two sites noted that this information was limited. Contributions by this workgroup and by the Programs and Navigation Workgroup led to the development of the “Quality of Life: Information Delivery Resource Inventory”. This inventory includes responses from the workgroup members about information available to the general population of cancer survivors. The workgroup was also asked to investigate the presence of culturally tailored materials on these surveyed websites. Only four websites offered information in both Spanish and English and none reported specific information for different patient populations revealing a significant gap.

With the large amount of information available to cancer survivors on the web, by phone, and through health care professionals, the workgroup felt that it was important to look into resources available to the public, or specifically cancer survivors, to help information seekers sort through cancer information to determine reliability and validity. This investigation uncovered three distinct tools: DICSERN (Charnock, 1998), SPAT (LaRue, 2000) and the NCI Fact Sheet: Evaluating Health Information on the Internet (NCI, 2011). Some organizations, including the American Cancer Society, have adapted the NCI fact sheet for use on the organizations’ websites. The workgroup discussed the pros and cons of each tool and came to the conclusion that a cancer specific checklist would be useful to supplement the NCI fact sheet and other more lengthy tools available to evaluate the validity and reliability of information resources. Thus, the workgroup drafted the “Cancer Survivors’ Information Tip Sheet”. The tip sheet



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provides basic information for cancer survivors to help with the transition from treatment by identifying relevant issues that cancer survivors may face, providing key questions that survivors should ask health care professionals, suggesting some reliable web-based information resources and providing tips to help survivors evaluate the information retrieved.

The third theme of discussion in the information delivery workgroup was the importance of communication between the health care professional and survivor about the survivor's needs and information seeking behaviors. The NCI publication outlining six functions of Patient/Family-Clinician communication in the cancer setting was used as a guide for workgroup discussion. The six functions include: fostering healing relationships, exchanging information, responding to emotions, managing uncertainty, making decisions and enabling patient self-management (Epstein and Street, 2007). The workgroup agreed that these elements were important to improve communication patterns between health care professionals and survivors. The workgroup also agreed that health care professionals should be aware of the information seeking behaviors of patients, not be afraid to talk about what patients are finding online and recommend trusted sources of information to patients.

### Recommendations for the Future

The workgroup developed a recommendations matrix that included recommendations, performance indicators and identified gaps. The matrix is structured using the socio-ecologic framework, focusing on individual/survivor, organization/health care system and society/policy levels of intervention in the four essential areas of survivorship care: healthy habits, early detection/disease surveillance, psychosocial and physical post-treatment side effects and provider communication. These recommendations are described in the following section.

### Survivors

Recommendations from the workgroup that directly impact cancer survivors are consistent with the three main themes described previously. The workgroup highlights the existence of prevention, early detection and surveillance information and programs and recommends these programs be adapted to address the issues faced by cancer survivors. Information resources that do not exist or have significant gaps, such as advanced care planning and return to work information, listed above, should be developed. Efforts should also be made to increase survivor awareness of the different channels of information delivery (phone, in person, internet, etc).

The next set of recommendations focus on the need for survivors to have a tool to both rate the quality of information and to sort the quantity of information received. The workgroup agrees that information should be dispersed to survivors throughout the cancer continuum, capitalizing on specific periods of decision-making and transition. Structuring information delivery along the cancer continuum can assist in management of resources.

Lastly, survivors need information resources to improve communication with health care professionals. This communication, especially about survivors' needs and information seeking behaviors is critical to improving the survivorship experience.

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### Health Care System

Recommendations for the health care system are centered on health care professional education, resources and provision of survivorship services. The workgroup recommends continued education for health care professionals with clear and realistic strategies to assist survivors with navigation through cancer survivorship. Health care professionals should also be educated on where to direct survivors to find more information (nurse, social worker, quality websites/cancer organizations, call centers). The workgroup recommends that health care professionals should proactively address common survivorship needs with survivors and complete a survivorship needs assessment or survivorship care plan.

### Society/Policy

This workgroup primarily focused on addressing the needs of survivors directly and through the health care system. However, some policy recommendations resulted from the discussion. The workgroup recommends advocacy to ensure the coverage of costs associated with prevention programs, time spent by health care professionals to create a needs assessment or survivor care plan and communication of the care plan. The workgroup also recommends funding for research to determine the effectiveness of using mobile and smart phone technology to reach different populations of survivors.

### Indicators to Help Measure Progress

In order to evaluate and monitor progress towards improved survivorship outcomes, the following performance indicators were developed based on the workgroup discussions and strategic matrix. Additional work is needed to determine the specific measures, establish baseline value and set specific outcome goals for each of the performance indicators. An assessment of the current capacity of nationwide surveillance systems to support the measurement of these indicators is underway; once capacity is determined, recommendations for measures or proxy measures corresponding to each performance indicator will be developed.

**Table 2: Information Delivery Performance Indicators**

Outcome Domain	Outcome Goal
Healthy Habits	Increase the capacity of current surveillance systems to measure nutrition, physical activity and tobacco use behaviors among survivors
	Create policies to ensure coverage of costs of Health Promotion programs
	Increase in funding for resources
Early Detection / Disease Surveillance	Increase in number of survivors who are aware that fear of recurrence is a common issue
	Increase the number of survivors with adequate coping strategies
	Increase survivor engagement in peer to peer communication
	Increase survivor knowledge about risk of recurrence
Post-Treatment Side Effects (Psychosocial and Physical)	Increase in the early detection/surveillance rates among survivors
	Increase in survivor knowledge of management of late effects
	Increase in survivor awareness of different types of information available.

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Outcome Domain	Outcome Goal
	Increase in the utilization of resources
	Create patient centered materials in priority survivorship areas
	Development and adoption of criteria for assessing the quality of online information
Health Care Professional Communication	Increase in provider awareness of survivorship issues and the importance of supportive survivorship care.
	Adoption of guidelines and policies to promote survivorship as a priority within the healthcare system
	Availability of reimbursement for health care providers focusing on survivorship activities.

**Table 3: Surveyed Cancer Websites:** The following are the organizations and websites that were reviewed by the workgroup and assessed for the information provided for the domains listed in Table 1. Please note that this is not a complete list of trusted cancer information websites, but is representative of the leading cancer organizations workgroup members identified or professionally represent.

Organization	Website
American Cancer Society	cancer.org
Cancer Support Community	thewellnesscommunity.org
APOS	apos-society.org
NCCN	nccn.org
Hopkins Breast Center	hopkinsbreastcenter.org
Kimmel Cancer Center	hopkinsmedicine.org/kimmel_cancer_center
Cancer Legal Resource Center	disabilityrightslegalcenter.org/about/cancerlegalresource.cfm
The Journey Forward	journeyforward.org
WebMD Cancer	webmd.com/cancer/default.htm
ONS	ons.org
LIVESTRONG	livestrong.org
Cancer Care	cancercare.org

**References**

Charnock, D (1998). The DISCERN handbook: Quality criteria for consumer health information on treatment choices. <http://www.discern.org.uk/index.php>

Epstein RM & Street RL Jr (2007). Patient-centered communication in cancer care: Promoting healing and reducing suffering. National Cancer Institute, NIH Publication No. 07-6225. Bethesda, MD.

Fox, S. (2010). Pew Internet and American life project: Cancer 2.0: A summary of recent research. <http://pewrsr.ch/Cancer20>

LaRue, E. (2000) SPAT. <http://www.spat.pitt.edu/index.php>

National Cancer Institute (2010). HINTS Brief 16: Trends in cancer information seeking.

National Cancer Institute (2011) FACT SHEET: Evaluating health information on the internet. <http://www.cancer.gov/cancertopics/factsheet/Information/internet>

