National Cancer Institute

NCI Office of Communications and Education:

Connecting the Cancer Community Through Communications

Presented to the National Cancer Advisory Board February 4, 2009

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U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

National Institutes of Health



Presentation Overview

Presentation Overview

- Who We Are and Our Environment
- A History of Growth and Innovation
- How We Got Here
- Our Audiences Are Diverse and Increasingly Global
- Our Programs and Reach are Broad and Deep
- Guiding Principles Moving NCI Communications Forward
- An Update on CIS and Plans for the Future



Who We Are and Our Environment

Our Federal Mandate

In carrying out the National Cancer Program, the Director of the National Cancer Institute shall:

- "...provide public and patient information and education programs, providing information that will help individuals take personal steps to reduce their risk of cancer, to make them aware of early detection techniques and to motivate appropriate utilization of those techniques, to help individuals deal with cancer if it strikes, and to provide information to improve long-term survival..."
- "...provide physicians and the public with state-of-the-art information on the treatment of particular forms of cancers, and to identify those clinical trials that might benefit patients..."
- "...to the extent practical, in disseminating the results of such cancer research and treatment, utilize information systems available to the public"
- ".... maintain and operate a database to collect, catalog, store, and disseminate insofar as feasible the results of cancer research"

OCE Mission Statement

OCE advances the mission of NCI by *disseminating research results* to the public to improve the lives of those affected by cancer.

Working closely with *scientists and partners*, OCE uses effective methods to *reach diverse audiences* and meet their needs for the latest, evidence-based cancer information.

Where We Are Today: Our Communications Environment

Opportunities

- Robust cancer-research initiatives and programs
- Internet and social media
- New administration in place with new plan to combat cancer

Challenges

- Need to coordinate and centralize communication efforts
- Wide array of audiences to serve
- Need to refine and strengthen public-education outreach efforts



A History of Growth and Innovation

How We Have Evolved: Communications and Education Organizations at NCI

2002 - 2006 1970 - 1997 1997 - 1998 1999 - 2000 2001 2007 CIS, Technologies, Journal OC and OESI ICRDB(PDQ), OLA transferred restructured moved to OC to Oxford **OLA and HPB** Outreach and moved out of OC Partnerships and **OC** restructured **OC and OESI** ICIC dissolved **HPB** integrated Communications merged Cancer.gov is **CIS** and Patient with OESI. 5 Coordination are created Media Education branches created (CancerNet & Communication moved out of Relations reorganized into 2, **OESI** becomes part CancerTrials OCC Leadership for NCI and matrix mgmt moved to OD of OCRP merged) Office of Office of Cancer OCC: Press Office. OC: Press Office, CIS. OC: Press Office, CIS. OC: Press Office, CIS. Communications (OCC): Communications and Health Promotion, Graphics & AV, Graphics & AV, Graphics & AV, Graphics & AV. Technologies. Technologies. Technologies, ICRDB(PDQ), **Education (OCE):** CIS, Press Office, Graphics ICRDB(PDQ), ICRDB(PDQ), Outreach and Partnerships Content Management, Paul Van Nevel. & AV, Patient Education, Outreach and Outreach and (OLA & Health Promotion). CIS, Technologies, Health Promotion. **Director** Public Affairs, Planning, Partnerships (OLA & Partnerships (OLA & Nelvis Castro, Acting Director Paul Van Nevel, Director Health Promotion). NCI Cancer Bulletin, Health Promotion). Office of Cancer Operations, OERD Sue Sieber, Director Mary McCabe. Information, **OESI:** Clinical Trials International Cancer (Cancer Education, Acting Director Communications Education, Patient Education. Information Center (ICIC): Professional Education and Education Office of Clinical ICRDB(PDQ), CancerNet, Lenora Johnson, Director & Research Diss. (OCICE): **Research Promotion OESI:** Clinical Trials Journal of the JNCI. **Operations Research** Education, Patient ICRDB(PDQ), (Office of Education Sue Hubbard, Director, ICIC CSD Established: OESI and Office). CancerNet, CIS, and Special Initiatives Education. ORO (former market research Lenora Johnson. Patient Education. within this office): Charmaine Cumminas. from OC) shifted into CSD. Acting Director Clinical Trials Sue Hubbard, Director Ed Maibach, Director Education. Acting Director CancerTrials Website, Patient Education. CSD Absolved: ORO shifted 9 into OESI

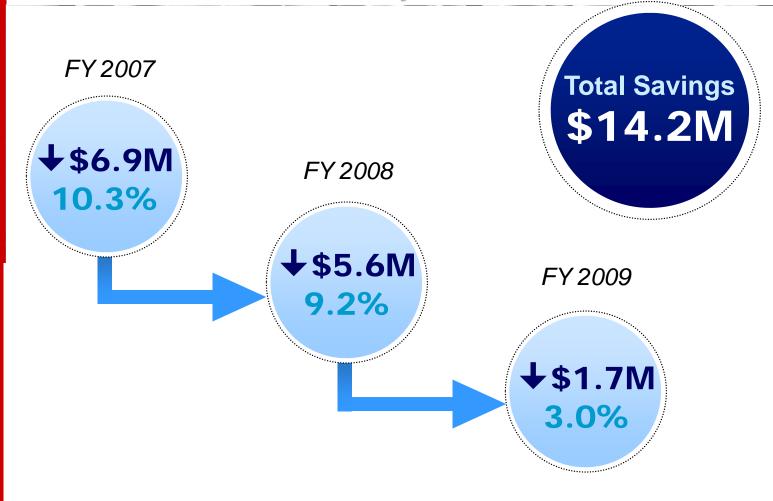
Mary McCabe, Director

How We Have Evolved: *Leadership Committed to Improvements*

"With this reorganization, we have made considerable progress toward streamlining the organizational structure and *building on the Synergies that exist between parts of OD* that already work closely together."

— Dr. John Niederhuber, January 3, 2007 NCI Cancer Bulletin

How We Have Evolved: Increased Efficiencies Saved Money





How We Got Here:

Assessments Enabled Us to Take An Up-close and Personal Look at OCE

How We Got Here: *EC and MITRE Reviews*

EC subcommittee recommendations were addressed:

- OCE budget streamlined
- Cancer.gov Web Council (Jan '09) and Web Operations Team (July '08) launched

External MITRE operations analysis conducted:

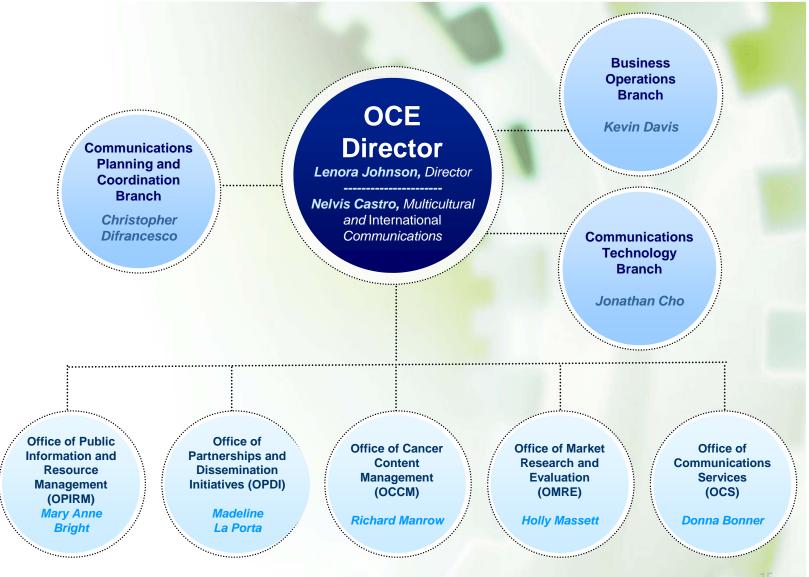
- Comprehensive staff and NCI stakeholder interviews
- National survey of external stakeholders
- Programs, staffing, operations, budgets and contracts assessed
- IT infrastructure analyzed
- IT transition plan developed

How We Got Here: *The Formation of a New Organization*

Emphasis on greater efficiencies and outcomes:

- Merged OC and OESI
- Realigned OCE staff and functions to DOCs
- 23% budget reduction, contract consolidation

The New Office of Communications and Education



Where We Fit:

A Key Organization That Serves the Director and Creates Connections Among the NCI DOCs



SCIENCE SERVING

Center for Biomedical Informatics and Information Technology

Center for Cancer Research

Center to Reduce Cancer Health Disparities

Center for Strategic and Scientific Initiatives

Div. Cancer Biology

Div. Cancer Control and Population Sciences

Div. Cancer Epidemiology and Genetics

Div. Cancer Prevention

Div. Cancer Treatment and Diagnosis

Div. Extramural Activities

NCI-Frederick Office of Scientific Operations

Office of HIV and AIDS Malignancy

SBIR Development Center

SERVING SCIENCE

Office of Advocacy Relations
Center for Cancer Training

Coordinating Center for Clinical Trials

Office of Communications and Education

Office of Government and Congressional Relations

Office of Management

Office of Media Relations

Office of Science Planning &

Assessment



Our Audiences Are Diverse and Increasingly Global

The National Cancer Institute Has Diverse Audiences



Consumers, including patients, friends and families; the underserved, prevention seekers, etc.



Researchers



Health-care providers



Advocates and partners

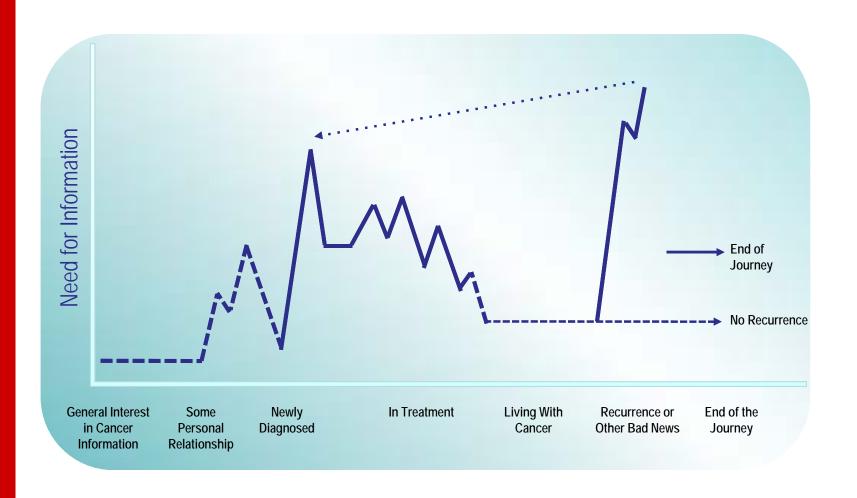


Media



Policymakers and program planners

Consumers' Cancer Journey Peaks and Valleys of Information Needs (and Stress Levels)



Consumers' Health Literacy

Seen by Level of Medical Knowledge and Type of Need as They Move Through the Cancer Journey

Fluent Generally high medical literacy

Designated Searcher Translating search skills into finding medical information

Looking for the "best of a few good items"



Surrogate for Patient
Deeply engaged;
looking for focused,
comprehensive, complete
information

Conversant
Especially if relevant to own situation



Searching for Questions Struggling to frame the questions and understand what the doctor is telling them



Persistence
Pays Off
Answers to specific
questions with growing
knowledge

Determination and persistence can trump skill



Looking Forward Worried about recurrence or their family

Low Medical Literacy Both words and concepts are new



Medical

Interested
Looking for a few
good items with
no strong need or
goal



Co-Browsers Looking for answers, but need help with Web and medical info

General Interest Personal Interest Interested

Making Decisions Handling Side Effects End of Life New Diagnosis Patients, Friends & Family

Location on the Cancer Journey

Coming to Grips With a New Diagnosis



Cancer information needs at this time:

What do I need to know?
Where do I find
what that term means?

What are the details about this cancer?
What are my chances?
How did I get cancer?

- 62% of U.S. adult cancer patients call their doctors when they first become aware of health or medical issues; 15% consult family or friends; and 12% go online
- 39% of online cancer patients have visited Cancer.gov
- 42% of cancer patients are completely satisfied with the Cancer.gov Web site
- 56% of cancer patients indicated they had heard of the National Cancer Institute's Cancer Information Service

 Manhattan Research, e-Health Landsc



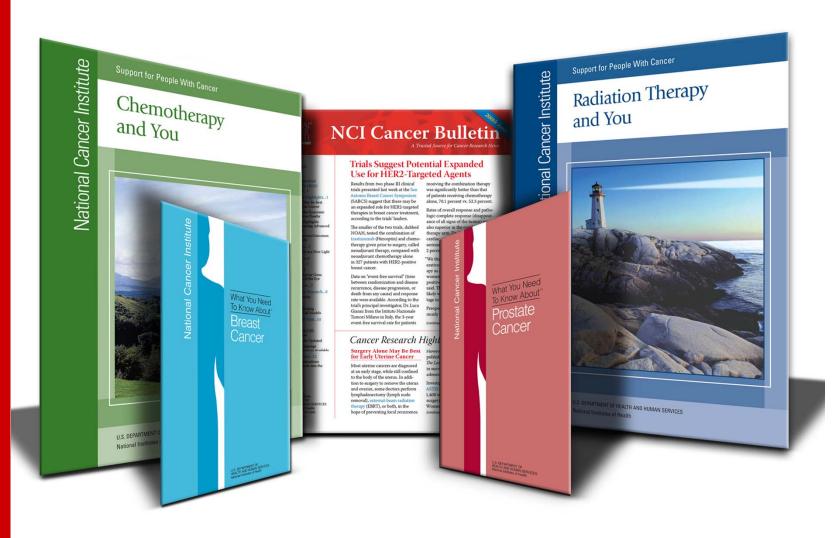
Our Programs and Reach Are Broad and Deep

What We Offer: OCE Functions and Programs



What We Offer: *OCE Functions and Programs*

Communication Leadership for NCI	 Communications Strategy Roundtable Documentation and Publication Clearance Web Standards and Guidelines Assuring NCI's Brand & Identity Aligning NCI Priorities & Public's Info Needs
Providing Expertise & Support to NCI DOCs	 Communications Support to DOCs Comprehensive Communication Planning Coordination of Communication Services Across OCE
Partnerships & Research Dissemination	 Building Awareness for Participation in Clinical Trials Training and Education Supporting Dissemination Priorities Cancer Care Professional Outreach Engaging Partners in Shifting Research to Practice Multicultural Media Outreach
Market Research, Evaluations & User- centered Analysis	 Market research to Inform Communication Strategies Online Analytics for Cancer.gov Continuous Quality Assurance & Results Management
Multicultural & International Cancer Communications	 Leadership on Cancer.gov/espanol Assuring Culturally and Linguistically Appropriateness Supporting Minority Outreach and Partnerships Coordinating Communications for NCI's Global Efforts
Management of NCI's Public-facing Channels	Contact Centers Cancer.gov & Cancer.gov/espanol • NCI Bulletin ent of NCI's Public-Facing Channels
Management of NCI-facing Channels	NCI Intranet – myNCI Event Calendar/NCI Calendar at a Glance NCI Library Services OCE Intranet
Communications Technologies	 Management of OCE's Communications Platforms Support to Cancer.gov CISnet Identifying, Adapting, and Engaging Innovative Technologies
Communications Operations and Infrastructure	 Publications Ordering, & Distribution Printing & Audiovisual Services & Standards Gift Fund Response System NCI Graphics & Biomedical Images
Content & Materials Development & Management	 PDQ Cancer Information Database Management of Clearance Process NCI Content Management Cancer Care Support materials Dictionaries & Drug Information











National Cancer Institute



Guiding Principles Moving NCI Communications Forward

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Our Commitment

 NCI fulfills the parameters of the National Cancer Act in ways befitting a new era of communication

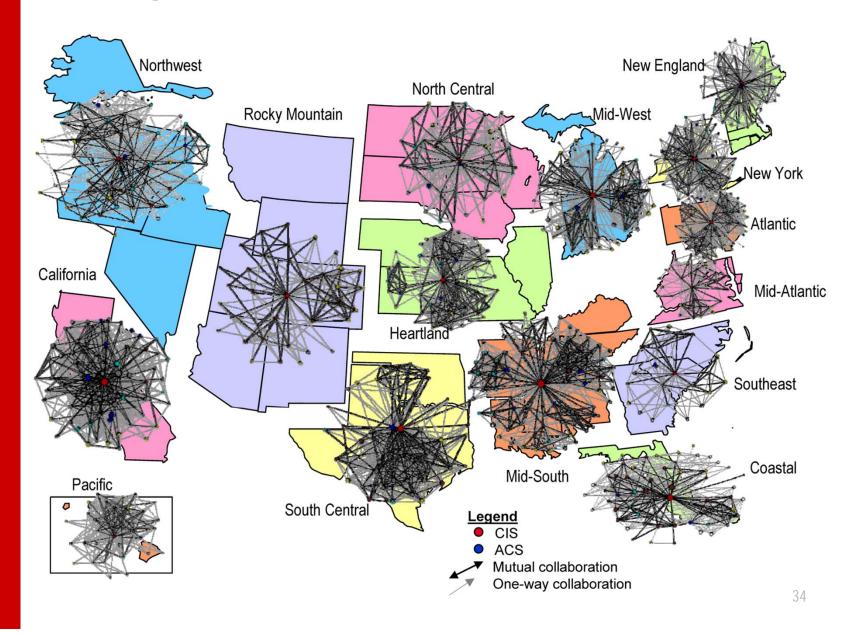
Guiding Principles

- OCE will continue to engage with key stakeholders on NCI's behalf to support the critical work of NCI's leadership and DOCs
- Our goal is to assure that NCI speaks with one voice, and is transparent, effective and inclusive in its outreach
- OCE will accomplish this by utilizing the latest and most effective methods to share NCI's evidence-based cancer information with key stakeholders



An Update on CIS and Plans for the Future

CIS Program Networks



NCI's Cancer Information Service (CIS): Partnership Program

- A bridge between NCI and the community for 30 years
- Portfolio of 750 partners engaged in 300 cancer-control, education and dissemination projects that span states, tribes and territories
- Trusted communication pipeline to community
- Rich history of evaluation
 - CIS brings NCI's credibility, expertise and resources to the community CIS staff are competent and well-connected to their regional areas (Network Analysis, 2008)
 - As a federal agency, no organization providing cancer information has the unbiased promise of government behind it than NCI (MITRE, 2008)
 - 98% of partners stated positive impact on populations served (Westat, 2003)

NCI's Cancer Information Service (CIS): Partnership Program

Accomplishments

- Established Provision of Training and Technical Assistance
- Conducted 200 clinical trial trainings with 400 organizations
- Provided over 112 trainings on evidence-based program planning
- Increased capacity to obtain sustainable health programming at the community level
- Served in leadership capacities on state and tribal Comp Cancer Control Coalitions
- Facilitated the completion of cancer control plans in Puerto Rico and U.S. Territories

Contract Status

- Current Contract Period: 2005-2010
- NCI Executive Committee made decision in August, 2008 to:
 - Procure one contact center contract
 - Not procure partnership program contracts at end of current cycle
- Office of Acquisitions published special notice to announce decision (October 2008)

Rationale for Decision

- Program considered successful, however need existed to:
 - Re-evaluate the context of the environments and approaches through which specific audiences garner cancer related information, and <u>identify the most</u> <u>effective activities for reaching various audiences with the valuable evidence</u> <u>that our research yields</u>
 - Re-evaluate how we move forward within the current information and outreach contexts and position ourselves to better engage in research dissemination efforts that quickly transfer specific areas of our evidence to those for whom it is of greatest value
 - Expand partnerships and associations with clinicians and those in caredelivery settings that are central to our ability to expeditiously shift research discoveries to clinical practice

Rationale for Decision (continued)

- Program considered successful, however need existed to:
 - Examine the <u>composite of NCI programs serving medically underserved</u> <u>and minority communities</u> and <u>better coordinate</u> those efforts to <u>maximize impact in areas of greatest need</u>
 - Examine the evidence NCI's research generates, the <u>audiences for</u>
 which adoption of the evidence has the greatest impact for reducing the
 burden of cancer, and the most effective approaches for disseminating
 that evidence
 - Re-examine how our programs and supportive services are distinguishable from similar organizations

Public Reaction

- To date, more than 100 letters received from stakeholders (e.g., partners, researchers, public, advocates, congressional representatives)
- Media coverage (Oncology Times, Cancer Letter)
- Record participation on Office of Advocacy Relations teleconferences (380+) (12/2/08)
- Public inquiries and pleas to reconsider/overturn decision; reaction focused on:
 - Need to understand decision-making process
 - Consideration of communities most in need

Public Recommendations

- Reconsider the decision
- Extend current contracts until a new concept is in place
- Employ an open and transparent process for developing the new concept with stakeholder input
- Focus efforts on populations and areas with cancer rates higher than the national average

Building a New Outreach and Dissemination Arm

Examine the In Evidence						
	Integration of Evidence	Examine the Most Effective Approaches for Change	Identify Custodial Stakeholders for Integration & Coordination of Change/ Impact Initiative	Design New Concept		Evaluate Impact
	2			<u> </u>		-○→
sources of corevidence vul	eas of greatest neern and Inerabilities reatest portunities for pact	= Opportunity	Potential for national partnership composition Aim toward behavior change (personal lifestyle, professional practice, clinical operations/systems and community awareness) Public/private interactions	Goals & objectives with supportive metrics Concept approval Drafts of new requirements for initiative Solicitations, reviews, etc.	Evaluate Process + Progress Toward Impact Refine	

How We Can Work Together

- Agree on the most effective role for NCI, given the wide-range of organizations in the cancer field with similar missions.
 - Determine key focus areas that NCI should consider a priority
- Identify organizations that may serve as appropriate national partners so that resources across organizations can be combined for maximum impact.
- Determine areas where NCI's federal resources can best be leveraged at the community level.
- Help carry forth NCI's desire to continue to engage the public in new and innovative ways.

We Value Your Input

ADDITIONAL SLIDES

- Operations
 - 15 competitive cost-reimbursement contracts
 - Located at cancer centers and universities (3 HBCUs)
 - Leveraged by 32 subcontracts and 10 other agreements (\$1.5 mil over 5 years)
 - 78 MPH staff in 41 states, D.C., Puerto Rico, and Guam

- Management:
 - National Training Program based on Public Health Core Competencies
 - National Partner Assessment Criteria
 - Partnership Development Guidelines
 - Web-based Partnership Portfolio Database
 - Comprehensive Evaluation Plan

- Budget
 - Program Cost:

2008 \$9.1 mil

2009 \$8.5 mil

– 55% of total \$15.5 mil CIS budget:

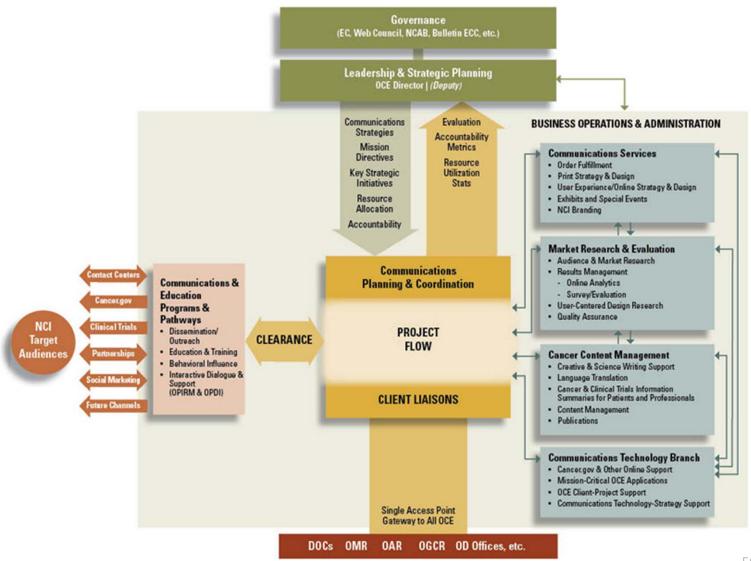
73% labor

16% training and administration

11% travel

- Most common partners
 - NCI grantees (CNP, NCCCP, CECCR)
 - NCI Cancer Centers, CCOP, and M-CCOPs
 - CDC (Comprehensive Cancer Control, Breast and Cervical Early Detection, Cancer Prevention and Control Research Network)
 - ACS and other non-profits (Intercultural Cancer Council, Lance Armstrong, Komen, etc.)
 - State Departments of Health
 - State Coalitions
 - Tribes and Tribal Entities
 - Health Systems: HRSA Federally Qualified Health Clinics

How We Operate: Improved Gateways and Processes



Cancer Patients and Their Use of Technology





Manhattan Research, e-Health Landscape for Cancer Patients and Caregivers, 2008

- 78% of cancer patients use cell phones
- 77% cancer patients watched video clips online
- 56% played or downloaded an online game
- 47% read an online blog
- 17% downloaded a television show or movie from the Internet
- 9% subscribed to a podcast
- 41% of cancer patients visited a social networking site
- Cancer patients and caregivers are twice as likely as average e-health consumers to participate in condition-specific online communities