NCI Office of Communications and Education:

Connecting the Cancer Community Through Communications

Presented to the National Cancer Advisory Board
February 4, 2009

Lenora Johnson
Director
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
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**

<table>
<thead>
<tr>
<th>Year Range</th>
<th>Key Events</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>International Cancer Information Center (ICIC): ICRDB(PDQ), CancerNet, Journal of the JNCI.</td>
</tr>
<tr>
<td></td>
<td>Sue Hubbard, Director, ICIC</td>
</tr>
<tr>
<td>1997 - 1998</td>
<td>Journal transferred to Oxford</td>
</tr>
<tr>
<td></td>
<td>ICIC dissolved</td>
</tr>
<tr>
<td></td>
<td>CIS and Patient Education moved out of OCC</td>
</tr>
<tr>
<td>1999 - 2000</td>
<td>CIS, Technologies, ICRDB(PDQ), OLA moved to OC</td>
</tr>
<tr>
<td></td>
<td>Outreach and Partnerships and Communications Coordination are created</td>
</tr>
<tr>
<td></td>
<td>OESI becomes part of OCRP</td>
</tr>
<tr>
<td>2001</td>
<td>OC restructured</td>
</tr>
<tr>
<td></td>
<td>Cancer.gov is created (CancerNet &amp; CancerTrials merged)</td>
</tr>
<tr>
<td>2002 - 2006</td>
<td>OC and OESI restructured</td>
</tr>
<tr>
<td></td>
<td>OLA and HPB moved out of OC</td>
</tr>
<tr>
<td></td>
<td>HPB integrated</td>
</tr>
<tr>
<td></td>
<td>5 branches reorganized into 2, and matrix mgmt</td>
</tr>
<tr>
<td>2007</td>
<td>OC and OESI merged</td>
</tr>
<tr>
<td></td>
<td>Media Relations moved to OD</td>
</tr>
</tbody>
</table>

**Office of Communications and Education (OCE):**
- Lenora Johnson, Acting Director

**OCS Established:** OESI and ORO (former market research from OC) shifted into CSD.
- Ed Malbach, Director

**CSD Absolved:** ORO shifted into OESI
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*

**FY 2007**

$6.9M

10.3%

**FY 2008**

$5.6M

9.2%

**FY 2009**

$1.7M

3.0%

**Total Savings**

$14.2M
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

OCE Director

Lenora Johnson, Director

Nelvis Castro, Multicultural and International Communications

Communications Planning and Coordination Branch
Christopher Difrancesco

Business Operations Branch
Kevin Davis

Communications Technology Branch
Jonathan Cho

Office of Public Information and Resource Management (OPIRM)
Mary Anne Bright

Office of Partnerships and Dissemination Initiatives (OPDI)
Madeline La Porta

Office of Cancer Content Management (OCCM)
Richard Manrow

Office of Market Research and Evaluation (OMRE)
Holly Massett

Office of Communications Services (OCS)
Donna Bonner
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.

Health-care providers

Media

Researchers

Advocates and partners

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

- Conversant
  - Especially if relevant to own situation

- Low Medical Literacy
  - Both words and concepts are new

- 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

- Designated Searcher
  - Translating search skills into finding medical information
  - Looking for the “best of a few good items”

- 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

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

- Looking Forward
  - Worried about recurrence or their family

- Location on the Cancer Journey
  - Patients, Friends & Family
  - New Diagnosis
  - Making Decisions
  - Treatment
  - Handling Side Effects
  - End of Life
  - Survivors

- Fluent
  - Generally high medical literacy

- Conversant
  - Especially if relevant to own situation

- Low Medical Literacy
  - Both words and concepts are new

- 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

- Designated Searcher
  - Translating search skills into finding medical information
  - Looking for the “best of a few good items”

- 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

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

- Looking Forward
  - Worried about recurrence or their family

- Location on the Cancer Journey
  - Patients, Friends & Family
  - New Diagnosis
  - Making Decisions
  - Treatment
  - Handling Side Effects
  - End of Life
  - Survivors
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 Landscape for Cancer Patients and Caregivers, 2008
Our Programs and Reach Are Broad and Deep
What We Offer:
OCE Functions and Programs

- Communication Leadership for NCI
- Market Research, Evaluations & User-centered Analysis
- Multicultural & International Cancer Communications
- Management of NCI-facing Channels
- Communications Operations and Infrastructure
- Content & Materials Development & Management
- Providing Expertise & Support to NCI DOCs
- Management of NCI’s Public-facing Channels
- Communications Technologies

NCI Functions and Programs
### What We Offer:

**OCE Functions and Programs**

<table>
<thead>
<tr>
<th>Communication Leadership for NCI</th>
<th>Providing Expertise &amp; Support to NCI DOCs</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Communications Strategy Roundtable</td>
<td>• Market research to Inform Communication Strategies</td>
</tr>
<tr>
<td>• Documentation and Publication Clearance</td>
<td>• Leadership on Cancer.gov/espanol</td>
</tr>
<tr>
<td>• Communications Support to DOCs</td>
<td>• Assuring Culturally and Linguistically Appropriateness</td>
</tr>
<tr>
<td>• Comprehensive Communication Planning</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Partnerships &amp; Research Dissemination</th>
<th>Market Research, Evaluations &amp; User-centered Analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Building Awareness for Participation in Clinical Trials</td>
<td>• NCI Intranet – myNCI</td>
</tr>
<tr>
<td>• Training and Education Supporting Dissemination Priorities</td>
<td>• NCI Library Services</td>
</tr>
<tr>
<td></td>
<td>• Event Calendar/NCI Calendar at a Glance</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Multicultural &amp; International Cancer Communications</th>
<th>Management of NCI’s Public-facing Channels</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Leadership on Cancer.gov/espanol</td>
<td>• Contact Centers</td>
</tr>
<tr>
<td>• Assuring Culturally and Linguistically Appropriateness</td>
<td>• Cancer.gov &amp; Cancer.gov/espanol</td>
</tr>
<tr>
<td></td>
<td>• NCI Bulletin</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Management of NCI-facing Channels</th>
<th>Communications Technologies</th>
</tr>
</thead>
<tbody>
<tr>
<td>• NCI Intranet – myNCI</td>
<td>• Management of OCE’s Communications Platforms</td>
</tr>
<tr>
<td>• Event Calendar/NCI Calendar at a Glance</td>
<td>• Support to Cancer.gov</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Communications Operations and Infrastructure</th>
<th>Content &amp; Materials Development &amp; Management</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Publications Ordering, &amp; Distribution</td>
<td>• PDQ Cancer Information Database</td>
</tr>
<tr>
<td>• Printing &amp; Audiovisual Services &amp; Standards</td>
<td>• Management of Clearance Process</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

| | - Web Standards and Guidelines |
| | - Assuring NCI’s Brand & Identity |
| | - Aligning NCI Priorities & Public’s Info Needs |
| | - Coordination of Communication Services Across OCE |
| | - Cancer Care Professional Outreach |
| | - Engaging Partners in Shifting Research to Practice |
| | - Multicultural Media Outreach |
| | - Supporting Minority Outreach and Partnerships |
| | - Coordinating Communications for NCI’s Global Efforts |
| | - NCI Bulletin |
| | - NCI Library Services |
| | - OCE Intranet |
| | - CISnet |
| | - Identifying, Adapting, and Engaging Innovative Technologies |
| | - Gift Fund Response System |
| | - NCI Graphics & Biomedical Images |
| | - NCI Content Management |
| | - Cancer Care Support materials |
| | - Dictionaries & Drug Information |
How We Reach Key Audiences: 
Multichannel Approach
How We Reach Key Audiences:

Multichannel Approach
How We Reach Key Audiences: Multichannel Approach
How We Reach Key Audiences:
Multichannel Approach
How We Reach Key Audiences:
*Multichannel Approach*
Guiding Principles Moving NCI Communications Forward
Guiding Principles Moving NCI Communications Forward

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

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

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 identify the most effective activities for reaching various audiences with the valuable evidence that our research yields
  
  – 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 care-delivery settings that are central to our ability to expeditiously shift research discoveries to clinical practice
NCI’s Cancer Information Service (CIS): Partnership Program

Rationale for Decision (continued)

• Program considered successful, however need existed to:
  
  – Examine the composite of NCI programs serving medically underserved and minority communities and better coordinate those efforts to maximize impact in areas of greatest need
  
  – Examine the evidence NCI’s research generates, the audiences for 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
NCI’s Cancer Information Service (CIS): Partnership Program

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/overtturn decision; reaction focused on:
  - Need to understand decision-making process
  - Consideration of communities most in need
NCI’s Cancer Information Service (CIS):  
*Partnership Program*

*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

<table>
<thead>
<tr>
<th>Time Frame</th>
<th>Activity Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>February-March 2009</td>
<td>Examine the Evidence</td>
</tr>
<tr>
<td>March-April 2009</td>
<td>Integration of Evidence</td>
</tr>
<tr>
<td>April 2009</td>
<td>Examine the Most Effective Approaches for Change</td>
</tr>
<tr>
<td>May-June 2009</td>
<td>Identify Custodial Stakeholders for Integration &amp; Coordination of Change/Impact Initiative</td>
</tr>
<tr>
<td>June 2009-February 2010</td>
<td>Design New Concept</td>
</tr>
<tr>
<td>March 2010-February 2015</td>
<td>Evaluate Impact</td>
</tr>
</tbody>
</table>

- **Greatest areas of concern and vulnerabilities**
- **Greatest opportunities for impact**
- **Potential for national partnership composition**
- **Goals & objectives with supportive metrics**
- **Concept approval**
- **Drafts of new requirements for initiative**
- **Solicitations, reviews, etc.**

---

**Sidebar: Data Gathering**

- **Implement**
- **Evaluate**
- **Process + Progress Toward Impact**
- **Refine**

**Note:**

- = Opportunity to Engage Public
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
CIS Partnership Program

- 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
CIS Partnership Program

• 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
CIS Partnership Program

• 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
CIS Partnership Program

- 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

- 78% of cancer patients use cell phones
- 77% of 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

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