

NCI Community Cancer Centers Program Guide to NCI Resources

The National Cancer Institute is committed to making progress against different cancer types through varied approaches. To this end, it develops, funds, and disseminates a vast array of programs, materials, and resources. Staff from across the Institute compiled this **Guide to NCI Resources**. This descriptive listing of key resources aims to meet the anticipated needs of the NCI Community Cancer Centers Program pilot sites.

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PART I: Resources to Support NCCCP Program Areas

CLINICAL TRIALS

Patients at NCCCP pilot sites have access to the very latest cancer prevention and treatment advances through NCI-sponsored clinical trials. Making these trials available locally will likely draw more patients onto clinical trials and enable researchers to build on these findings to develop and evaluate effective prevention and treatment strategies.

The National Cancer Institute (NCI) has developed and supported a number of resources designed to increase public understanding of and support for clinical trials in hopes of increasing clinical trial accrual rates.

For Professionals

Online Training and Information for Sites to Conduct Clinical Trials

NCI's Clinical Trials Portal

Designed as a “one-stop” for information about cancer clinical trials, this Web-based portal provides direct links to a searchable database of 5,000+ clinical trials, recent trial results, and consumer education materials.

<http://www.cancer.gov/clinicaltrials>

Incorporating Cancer Clinical Trials Into Your Practice

This Web-based course is for healthcare professionals who are new to the clinical trials research process. The course contains practical information for professionals interested in referring patients to clinical trials, or conducting clinical trials, for the first time.

<http://cancer.gov/clinicaltrials/course>

Human Participant Protections Education for Research Teams

This is a Web-based course developed at the National Institutes of Health (NIH) for physicians, nurses, and other members of clinical research teams. This online course satisfies the NIH human subjects training requirement for extramural researchers obtaining Federal funds.

<http://cme.cancer.gov/clinicaltrials/learning/humanparticipant-protections.asp>

Cancer Trials Support Unit (CTSU)

The CTSU is a service provided by the NCI to allow members of the NCI-sponsored Cooperative Groups, members of the Community Clinical Oncology Program (CCOP), and CTSU Independent Clinical Research Sites (CICRS) to access any of the NCI-sponsored clinical trials on the CTSU Web site and activate them at their sites.

<http://www.ctsu.org/>

CTSU e-Course

The e-Course is an online educational program that introduces and explains the CTSU. The e-COURSE was created to provide registered CTSU members and those interested in becoming registered members with a convenient method of learning about participation in NCI-sponsored clinical trials through the CTSU.

<http://ecourse.ctsu.org/>

NCI's Central Institutional Review Board (NCI CIRB)

The NCI CIRB Initiative is designed to help reduce the administrative burden on local IRBs and investigators while continuing a high level of protection for human research participants. A local IRB's use of the CIRB-facilitated review mechanism enables an investigator to enroll patients into adult and pediatric Cooperative Group clinical trials significantly faster than when employing traditional methods of IRB review.

<http://www.ncicirb.org/>

Clinical Trials Data Monitoring and Reporting

Adverse Event Expedited Reporting System (AdeERS): NCI's Web-based system for submitting expedited reports for serious and/or unexpected events forwarded to designated recipients and NCI for all trials using an NCI-sponsored investigational agent.

<http://ctep.cancer.gov/reporting/adeers.html>

Common Toxicity Criteria and Common Terminology Criteria for Adverse Events (CTCAE): Standard terminology used to name and to describe the severity (grade) of adverse events that occur in the treatment of cancer.

<http://ctep.cancer.gov/reporting/ctc.html>

Patient Care Costs and Coverage Issues in Clinical Trials

This Web page consists of multiple links that provide a guide to insurance coverage and clinical trials, a searchable list and map of U.S. states that require health plans to pay for the patient care costs associated with clinical trials, and information about financial assistance organizations to help patients.

<http://www.cancer.gov/clinicaltrials/learning/page5>

NCI's Clinical Trials Infrastructure and Programs

NCI's Community Clinical Oncology Program

The Community Clinical Oncology Program (CCOP) is a network for conducting cancer prevention and treatment clinical trials by community medical practitioners. This network connects academic centers (Research Bases who design and conduct the trials) with community physicians (CCOP, MB-CCOP) who accrue patients to those trials.

<http://dcp.cancer.gov/programs-resources/programs/ccop>

CCOP and MBCCOP Research Base Protocols (Cancer Control and Prevention Trials)

Information on active protocols by Research Base located at this site is updated as protocols are approved.

<http://prevention.cancer.gov/programs-resources/programs/ccop/resource/protocols>

NCI's Cancer Centers Program

NCI-designated Cancer Centers are a major source of discovery of the nature of cancer and of the development of more effective approaches to cancer prevention, diagnosis, and therapy.

<http://cancercenters.cancer.gov/>

NCI's Clinical Trials Cooperative Group Program

The Clinical Trials Cooperative Group Program is designed to promote and support clinical trials (research studies) of new cancer treatments, explore methods of cancer prevention and early detection, and study quality-of-life and rehabilitation issues.

<http://www.cancer.gov/cancertopics/factsheet/NCI/clinical-trials-cooperative-group>

Clinical Trials at NIH

The clinical trials conducted by the National Cancer Institute (NCI) on the NIH campus represent the core of the clinical program of the NCI's Center for Cancer Research (CCR). At the CCR, basic and clinical science are seamlessly integrated with a mission to reduce the burden of cancer through exploration, discovery, and the translation of novel approaches into compassionate and effective care for all cancer patients. Our clinical studies are aimed at answering critical questions about a particular disease or disease process and at identifying promising new therapeutic interventions that can then be confirmed in larger studies carried out across the country at cancer centers participating in NCI-supported research.

<http://bethesdatrials.cancer.gov/>

Education and Outreach Information

NCI has a variety of resources designed for health professionals regarding clinical trials. Some materials of particular note are described below. All materials can be ordered through NCI's Cancer Information Service at 1-800-4-CANCER or accessed directly through the NCI's *Clinical Trials Education Series (CTES)* Web page.

<http://www.cancer.gov/clinicaltrials/learning/clinical-trials-education-series>

Print

Cancer Clinical Trials: The Basic Workbook

Cancer Clinical Trials: The In-Depth Program

Cancer Clinical Trials: A Resource Guide for Outreach, Education, and Advocacy

These train-the-trainer workbooks were developed for health care professionals to learn basic and in-depth information about clinical trials as well as how to conduct outreach to communities. The workbooks are divided into chapters covering various clinical trial concepts and exercises to supplement the learning.

CD-ROM

Cancer Clinical Trials Education Series CD

All of the Clinical Trials Education Series materials are available on this CD.

Slide Programs

Cancer Clinical Trials: The Way We Make Progress Against Cancer

Covers the basics about clinical trials—what they are, who takes part, different types of trials, protecting patients' safety, risks and benefits, and where to find trials. (13-slide PowerPoint presentation with talking points)

Cancer Clinical Trials: The Basics

Covers the topics included in "Cancer Clinical Trials: The Way We Make Progress Against Cancer," plus phases of clinical trials, randomization, types of trials, protocols, and barriers to participation. (27-slide PowerPoint presentation with talking points)

Cancer Clinical Trials: In-Depth Information

Covers clinical trials in greater detail than "Cancer Clinical Trials: The Way We Make Progress Against Cancer," and "Cancer Clinical Trials: The Basics." Includes topics such as the drug development and improvement process, phases of clinical trials, types of trials, and protocol development. (31-slide PowerPoint presentation)

La historia de José

A fotonovela-style introductory Spanish-language presentation that takes you on the journey of José, a man who is given the option of enrolling in a prevention clinical trial. The second presentation follows the same story with a female subject. For general audiences who are not familiar with clinical trials.

La historia de Ana

A fotonovela-style introductory Spanish-language presentation that takes you on the journey of Ana, a woman who is given the option of enrolling in a treatment clinical trial. The second presentation follows the same story with a male subject. For general audiences who are not familiar with clinical trials.

Conversemos un rato

This Spanish-language slide presentation covers the basics about clinical trials—what they are, who takes part, different types of trials, protecting patients' safety, risks and benefits of trials, where to find trials, and issues of concern to Latino audiences. Appropriate for community leaders and health care providers.

For Patients

NCI provides a number of award-winning publications to increase public understanding of clinical trials and their importance. Some materials of particular note are described below. All materials can be accessed directly via <http://www.cancer.gov> or ordered through NCI's Cancer Information Service at 1-800-4-CANCER.

Booklets

Taking Part in Clinical Trials: What Cancer Patients Need to Know

Defines clinical trials, discusses what patients might expect if they participate in a trial, and discusses things to think about when deciding to participate.

If You Want To Find Ways To Prevent Cancer...Learn About Prevention Clinical Trials

Easy-to-read brochure that explains the basics of cancer prevention trials.

Taking Part in Clinical Trials: Cancer Prevention Studies

Provides information about cancer and clinical trials and helps people decide if participating in a chemoprevention trial is right for them.

La participación en los estudios clínicos: Lo que los pacientes de cáncer deben saber

This is the Spanish-language version of *Taking Part in Clinical Trials: What Cancer Patients Need to Know*.

La participación en los estudios clínicos: Estudios para la prevención del cáncer

This Spanish language version of *Taking Part in Clinical Trials: Cancer Prevention Studies* provides information about cancer and clinical trials and helps people decide if participating in a chemoprevention trial is right for them.

Si tiene cáncer...Lo que debería saber sobre estudios clínicos

This is the Spanish-language version of *If You Have Cancer...What You Should Know About Clinical Trials*.

If You Have Cancer and Have Medicare... You Should Know About Clinical Trials

Resource for Medicare recipients who have cancer. It provides general information about cancer clinical trials, Medicare coverage, and questions to ask before joining a clinical trial.

Providing Your Tissue for Research: What You Need to Know

This brochure is meant to complement the face-to-face education between clinicians and potential clinical trial participants. It provides a balanced discussion of questions and answers on how tissue specimens are collected and used in research.

Videos

Cancer Trials...Because Lives Depend On It

Discusses prevention and treatment clinical trials to create general awareness about them. (10 minutes, including discussion guide.)

Cancer Clinical Trials: An Introduction for Patients and Their Families

Discusses treatment clinical trials for patients and their families who may be considering participation. (18 minutes, including discussion guide.)

Handbooks

Handbooks that provide information on clinical trials that take place at the NIH campus in Bethesda, MD are available to order and download at

<http://bethesdatrials.cancer.gov/information-and-resources/printable-materials.asp>.

Clinical Trials Patient Handbook

Provides an overview of cancer clinical trials including information on how to find and join a clinical trial.

A Guide to Cancer Clinical Studies

Provides an overview of cancer clinical trials that has been customized to meet the needs and concerns of the African-American community. This guide explains why clinical trials are important, why someone should participate, and the costs of clinical trials.

HEALTH DISPARITIES

NCI consistently seeks to develop or expand programs to increase outreach to the uninsured, underrepresented, and disadvantaged populations and increase access to cancer prevention, screening, treatment, follow-up care, palliative care, survivorship plans, and end-of-life care.

For Professionals

The Center to Reduce Cancer Health Disparities

The Center to Reduce Cancer Health Disparities (CRCHD) is the keystone of NCI's efforts to reduce the unequal burden of cancer in our society. As the organizational locus for these efforts, the Center directs the implementation of and supports initiatives that advance understanding of health disparities.

The Center maintains a comprehensive Web site at <http://crchd.cancer.gov>. In addition, the Center publishes a monthly e-mail communication providing timely information on cancer health disparities research, training, and awareness efforts. Subscription information is found on this site.

Reports and Publications

These materials have been identified as some of the most influential in the field of cancer health disparities. Many can be downloaded from the CRCHD Web site.

Examining the Health Disparities Research Plan of the National Institutes of Health: Unfinished Business

<http://www.iom.edu/CMS/3740/22356/33275.aspx>

Making Cancer Health Disparities History

<http://www.chdprg.omhrc.gov/pdf/chdprg.pdf>

Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care

<http://www.iom.edu/report.asp?id=4475>

Facing Cancer in Indian Country

<http://deainfo.nci.nih.gov/advisory/pcp/YakamaBook.pdf>

Voices of a Broken System

<http://156.40.135.142:8080/webisodes/pcpvideo/ClickHere.html>

The Unequal Burden of Cancer

<http://www.iom.edu/CMS/3740/5646.aspx>

Enhancing Interactions to Reduce Cancer Health Disparities: An NCI-wide Workshop

http://crchd.cancer.gov/attachments/Final_HD_Proceedings.pdf

National Cancer Institute Special Populations Networks: Achievements and Lessons Learned 2000-2005. (2006). CANCER, 107(S8), 1931-2098.

Excessive Cervical Cancer Mortality: A Marker for Low Access to Health Care in Poor Communities

<http://crchd.cancer.gov/attachments/excess-cervcanmort.pdf>

Assessing Cancer Health Disparities

A number of NCI-funded statistical tools and programs can measure and track cancer incidence and mortality. By utilizing these resources, NCCCP pilot sites can gain a greater appreciation of the cancer burden in their communities and population groups.

NCI Cancer Statistics

<http://www.cancer.gov/statistics/>

SEER Methods for Measuring Disparities

This report reviews different methodological approaches germane to measuring progress toward the goal of eliminating cancer-related health disparities.

<http://seer.cancer.gov/publications/disparities/>

State Cancer Profiles

The State Cancer Profiles site characterizes the cancer burden in a standardized manner in order to motivate action, integrate surveillance into cancer control planning, identify areas and demographic groups, and expose health disparities.

<http://statecancerprofiles.cancer.gov/help/about/>

Cancer Mortality Maps & Graphs

The interactive maps, graphs, text, tables, and figures featured on this Web site depict geographic patterns and time trends of cancer death rates for more than 40 cancers.

<http://www3.cancer.gov/atlasplus/index.html>

Programs in Cancer Health Disparities Research

Cancer Disparities Research Partnership Program (CDRP)

The program supports the planning, development, and conduct of radiation oncology clinical trials in institutions that care for a disproportionate number of medically underserved, low-income, ethnic, and minority populations but have not been traditionally involved in NCI-sponsored research. In addition, CDRP supports the planning, development, and implementation of nurturing partnerships between applicant institutions and committed and experienced institutions actively involved in NCI-sponsored cancer research.

<http://www3.cancer.gov/rrp/CDRP/index.html>

Centers for Population Health and Health Disparities (CPHHD)

This initiative supports transdisciplinary, multi-level, integrated research to elucidate the complex interactions of the social and physical environment, mediating behavioral factors, and biologic pathways that determine health and disease in populations, leading to an understanding and reduction of health disparities.

<http://www.dccps.cancer.gov/populationhealthcenters/index.html>

Community Networks Program (CNP)

The Community Networks Program (CNP) aims to reduce cancer health disparities through community-based participatory education, training, and research among racial/ethnic minorities and underserved populations.

<http://crchd.cancer.gov/cnp/cnp-project-listing.html>

Minority-Based Community Clinical Oncology Program (MBCCOP)

The Minority-Based CCOP supports expanding clinical research in minority community settings; brings the advantages of state-of-the-art treatment and research to minority individuals in their own communities; involves primary health care providers and other specialists in cancer prevention and control studies; establishes a base for extending cancer prevention and control and reducing cancer incidence, morbidity, and mortality in minority populations; and examines issues in Minority-Based CCOP performance.

<http://www.cancer.gov/prevention/ccop/>

Minority Institution/Cancer Center Partnership (MI/CCP)

The Minority Institution/Cancer Center Partnership program increases Minority-Serving Institutions' participation in cancer research and research training; increases the involvement and effectiveness of the Cancer Centers in research, research training and career development; and develops more effective research, education, and outreach programs that will have an impact on minority populations.

<http://minorityopportunities.nci.nih.gov/institutions/miccp.html>

NCI CURE Program

The CURE (Continuing Umbrella of Research Experiences) philosophy of research training and career development builds on the success of The Research Supplement for Underrepresented Minorities and strategically addresses each level of the biomedical research and educational pipeline to increase the pool of underrepresented minority candidates. It emphasizes scientific areas of greatest need and expands and extends the period of training and career development.

<http://minorityopportunities.nci.nih.gov/mTraining/index.html>

Patient Navigation Research Program (PNRP)

The Patient Navigation Research Program (PNRP) aims to develop innovative patient navigation interventions to reduce or eliminate cancer health disparities and test their efficacy and cost-effectiveness. These interventions are designed to decrease the time between a cancer-related abnormal finding, definitive diagnosis, and delivery of quality standard cancer care services.

<http://crchd.cancer.gov/pnp/pnrp-research-sites.html>

Patient Navigation Research Program Resource Manual

The Patient Navigation Research Program Resource Manual clusters patient education materials (treatment-specific and general cancer support materials) across the cancer continuum to facilitate ease of use by navigators when working with patients facing a breast, cervical, prostate, or colorectal cancer diagnosis. The material is used as part of NCI's Center to Reduce Cancer Health Disparities Patient Navigation Research Program and is also available to clinicians and health educators for use beyond the scope of this research program.

<http://www.ncipoet.org/Patientnavigator/>

For Patients

Fact Sheets

The Center to Reduce Cancer Health Disparities produces a variety of materials that describe the Center's activities. Visit <http://crchd.cancer.gov/news/press-kit.html> for a complete listing.

Human biospecimens play a critical role in our emerging understanding of cancer. However, the manner in which biospecimens are collected from patients and subsequently handled, the quality of the biospecimen-associated information, and ethical, legal, and policy parameters, can affect biospecimen quality and usefulness in cancer research. Scientific advances depend on the availability of biospecimens that have been collected according to the highest scientific and ethical standards.

The NCCCP pilot program aims to increase knowledge of infrastructure requirements, policies and procedures, costs, and other issues (e.g., collaborations or contracts necessary for biospecimen collection, annotation, and storage) required for implementation of the *NCI Best Practices for Biospecimen Resources*, thus enabling community hospitals to participate in biospecimen initiatives that will advance the NCI's research mission.

For Professionals

The Office of Biorepositories and Biospecimen Research

NCI Best Practices for Biospecimen Resources

Currently, there are no standardized procedures for collecting, processing, storing, and distributing biospecimens. The National Cancer Institute has created a plan to address this roadblock to progress in cancer research. In 2005, the NCI established the Office of Biorepositories and Biospecimen Research (OBBR) to guide, coordinate, and develop the Institute's biospecimen resources and capabilities. The OBBR's mission is to ensure that human specimens available for cancer research are of the highest quality.

Using input from researchers, physicians, ethics and legal experts, and patient advocates, the OBBR and the Biorepository Coordinating Committee of the NCI developed the *NCI Best Practices for Biospecimen Resources*, a document that outlines technical and operational best practices for the use of biospecimens in research. This document also outlines best practices for biospecimen-related ethical, legal, and policy issues.

The *NCI Best Practices for Biospecimen Resources* will be updated as new technology and clinical practices emerge and as policy and legal standards evolve. The document can be accessed directly at <http://biospecimens.cancer.gov>

For Patients

The use of biospecimens for research ultimately depends on the willingness of patients to donate tissue while they are undergoing surgery or biopsy procedures.

Providing Your Tissue for Research: What You Need To Know is meant to complement the face-to-face education between clinicians and potential clinical trial participants. It provides a balanced discussion of questions and answers on how tissue specimens are collected and used in research. This booklet can be ordered through NCI's Cancer Information Service at 1-800-4-CANCER or accessed directly through the NCI Web site, <http://www.cancer.gov>.

The cancer Biomedical Informatics Grid™ (caBIG™) leverages the combined strengths and expertise of researchers, cancer centers, others in the cancer community and relevant stakeholder organizations—including industry—to provide a unifying information infrastructure for connecting data, research tools, scientists, physicians and patients. Indeed, the National Cancer Institute believes that caBIG™ will help redefine how cancer research is conducted and, eventually, how cancer care is provided.

One focus of the NCCCP pilot program is to increase knowledge of infrastructure requirements, necessary interfaces, and applicability of specific components of caBIG™ for community hospital settings and increase implementation of electronic medical records and exploration of the application of electronic medical records in the provision of cancer care.

For Professionals

caBIG™ is designed to benefit not only the current caBIG™ community but also those in the broader biomedical field, for whom the shared environment offers an advantage as well. The caBIG™ infrastructure and tools are widely applicable beyond the cancer community, fostering advances in the care of patients with other diseases. caBIG™ software is open-source, meaning anyone can use it or modify it without a licensing fee. Moreover, all caBIG™ tools and data are freely available.

Tools Fact Sheet and an Online Inventory of Tools

Provides descriptions of current and planned caBIG™ products. These are available at: https://cabig.nci.nih.gov/overview/caBIG_Tool_Sheet.pdf and <https://cabig.nci.nih.gov/inventory>

Notable Developments in caBIG™

Noted in periodic updates and posted online. Documents, including white papers and other policies, have also been developed and can be viewed online. http://caBIG.nci.nih.gov/Program_Updates

Online Training Portal

Provides information on opportunities for training with caBIG™ tools and other training resources. <https://caBIG.nci.nih.gov/training>

Interoperability

The ability to exchange information between systems in a meaningful way is a primary strategic goal of caBIG™. The development of interoperable software and systems is ensured in several ways. The most effective solutions are those that are constructed not as single, monolithic, all-purpose systems, but rather as a number of well-defined modules that can be adopted as needed and integrated using open standards. Guidelines related to caBIG™ interoperability are available. https://cabig.nci.nih.gov/guidelines_documentation

caBIG™ Web Site

This site includes a wealth of resources. Weekly news is posted on the home page in “What’s BIG This Week,” which lists all meetings and teleconferences, key outcomes of those meetings and other important activities.

<https://caBIG.nci.nih.gov>.

For Patients

A comprehensive Web site to inform the public about the importance and role of caBIG™ can be found at <http://cabig.cancer.gov>.

The caBIG™ Primer, which provides a high-level overview of caBIG™, can be accessed at <https://cabig.nci.nih.gov/overview/cabig-primer>.

Patient Advocates have been associated with the caBIG™ initiative since its launch. Read their “Statement of Expectations, Purpose, and Goals” at <https://caBIG.nci.nih.gov/patientadvocatestatement.pdf>.

QUALITY OF CARE AND SURVIVORSHIP ISSUES

Two of the most pressing cancer-related issues to be addressed through the NCCCP are the quality of cancer care and addressing the needs of cancer survivors.

Quality of Care Resources

For Professionals

Physician Data Query

NCI developed the Physician Data Query (PDQ) to make the most current, credible, and accurate cancer information available to health professionals and the public. PDQ contains peer-reviewed summaries on cancer treatment, screening, prevention, genetics, complementary and alternative medicine, and supportive care; a registry of cancer clinical trials from around the world; and directories of physicians, professionals who provide genetics services, and organizations that provide cancer care.

<http://www.cancer.gov/pdq>

Public/Private Partnership Efforts

NCI has been working in partnership with initiatives sponsored by the American College of Surgeons (ACoS) and participating in American Society of Clinical Oncology (ASCO) to enhance quality of cancer care at both the hospital-based and oncology practice levels. NCI is considering building on these collaborations with both ACoS and ASCO to assess quality-of-care through review of pilot site enhanced infrastructure for quality improvement, the increased utilization of evidence-based guidelines, and review of selected quality indicators as reported to the American College of Surgeons' Commission on Cancer (CoC), the capability and results of multidisciplinary coordination of care, patient satisfaction results compared over the pilot, and consideration of an optional study involving pilot site physician participation in the ASCO Quality Oncology Practice Initiative (QOPI).

American Society of Clinical Oncology (ASCO)

The American Society of Clinical Oncology's Quality Oncology Practice Initiative (QOPI) is an oncologist-led, practice-based quality improvement initiative. Its goal is to promote excellence in cancer care by helping practices create a culture of self-examination and improvement. QOPI includes a set of quality measures, a specified chart selection strategy, a secure system for data entry, automated data analysis and reporting, and a network of resources for improvement. Currently, more than 250 oncology practices are registered for QOPI.

www.asco.org/qopi

American College of Surgeons (ACoS)

Electronic Quality Improvement Packets (e-QulP) for Breast and Colorectal Cancer:

The Cancer Program Practice Profile Reports (*CP³R*) Stage III colon cancer project has demonstrated that improvements in data quality and patient care are possible when the entire multidisciplinary cancer committee supports system level enhancements to ensure complete and precise documentation. To continue on this success, the Commission on Cancer (CoC) is moving forward with providing additional levels of data feedback to our programs to:

- Improve the quality of data across several disease sites
- Foster preemptive awareness to the importance of charting and coding accuracy
- Improve clinical management and coordination of patient care in the multidisciplinary setting.

The Commission on Cancer (CoC) has released an *electronic Quality Improvement Packet (e-QUIP)* for breast and colorectal cancer to each approved program. These Web-based applications provide individual-level case summary reports for breast and colorectal cancers diagnosed in 2003 and 2004, as transmitted to the NCDB by each CoC-Approved program cancer registry. These packets are designed to allow facilities to review and address data completeness in preparation for the release of future *CP³R* initiatives that measure concordance with standard of care guidelines.

In addition, this and future *e-QUIPs*, are designed to specifically promote quality improvement activities that can assist facilities in the fulfillment of the CoC Approvals Standards requirements:

- 2.11, analysis of diagnostic and treatment modalities
- 8.1, complete and document studies that measure quality and outcomes
- 8.2, documented implementation of two improvements that directly affect cancer patient care.

e-QUIP Measures

The *e-QUIPs* are directed toward assessing data completeness for breast and colorectal cancer patients recorded in each cancer program's registry. The *e-QUIP* provides a case-by-case review of cases reported to the NCDB and identifies cases that lend themselves to the future evaluation of concordance for various breast and colorectal cancer measures.

The standard of care measures for breast and colon disease are now posted on the ACoS Web site at: <http://www.facs.org/cancer/qualitymeasures.html>.

The measures are also on the Web sites of the American Society of Clinical Oncology (ASCO) (<http://www.asco.org/qualitymeasures>) and National Comprehensive Cancer Network (NCCN) (<http://www.nccn.org/>).

Survivorship Resources

NCI's Office of Cancer Survivorship (OCS) seeks to enhance the quality and length of survival of all persons diagnosed with cancer and to minimize or stabilize adverse effects experienced during cancer survivorship. The Office maintains a comprehensive Web site of resources and funding opportunities. OCS promotes the dissemination of information to professionals who treat cancer patients, and the public concerning the problems and needs of cancer survivors and their families. The OCS Web site can be found at <http://survivorship.cancer.gov>.

For Professionals

From Cancer Patient to Cancer Survivor: Lost in Transition

This important Institute of Medicine report details what we know about the challenges faced by survivors as they finish active treatment and live long-term following a cancer history, the nature of the care they receive and the directions we need to take to improve both the quality of life and length of survival of this growing population.

<http://www.iom.edu/?ID=30869>

Journal of Clinical Oncology (Special Issue on Survivorship)

This special issue of the *Journal of Clinical Oncology on Cancer Survivorship* (volume 24, number 32, pages 5101-5169, November 10, 2006) contains 12 articles that review the challenges faced in providing optimal care for cancer survivors who are post-treatment for cancer.

Living Beyond Cancer: Finding a New Balance

This President's Cancer Panel's 2003/2004 annual report provides a national perspective on survivorship issues experienced across different age groups and from patients' as well as their caregivers' and healthcare providers' testimony.

<http://deainfo.nci.nih.gov/ADVISORY/pcp/pcp03-04rpt/Survivorship.pdf>

Information on Follow-up Care After Cancer Treatment

This Web-based Q & A fact sheet for patients/providers is available at

<http://www.cancer.gov/cancertopics/factsheet/Therapy/followup>.

PDQ Cancer Information Summaries

PDQ Cancer information summaries on palliative care issues patients may face during and after their cancer treatment may be found at

<http://www.cancer.gov/cancertopics/pdq/supportivecare>.

Education in Palliative and End-of-life Care for Oncology (EPEC™-O)

This CD-ROM contains a comprehensive curriculum in palliative and end-of-life care developed specifically for clinicians caring for persons with cancer.

<http://www.cancer.gov/aboutnci/epeco>

For Patients

NCI has developed a variety of educational materials for cancer survivors, their families, and caregivers. Some materials of particular note are described below. All materials can be accessed directly through the NCI Web site, <http://www.cancer.gov>, or ordered through NCI's Cancer Information Service at 1-800-4-CANCER.

Moving Beyond Breast Cancer DVD and VHS (with closed captioning)

Facing Forward: Life After Cancer Treatment (English and Spanish)

Ways You Can Make a Difference in Cancer

Taking Time

When Someone You Love Has Completed Cancer Treatment

When Cancer Returns

Coping with Advanced Cancer

When Someone You Love Has Advanced Cancer

PART II: Additional Resources from the National Cancer Institute

CANCER CONTINUUM

NCI develops, implements, and evaluates programs across the cancer continuum. To complement these programs, NCI has developed a large variety of educational materials, many of them designed for patients. These resources are developed based on literature reviews, expert research, and extensive audience testing through interviews and/or focus groups with health professionals and the target audience. Some materials of particular note are described below. All materials can be accessed directly through the NCI Web site, <http://www.cancer.gov>, or ordered through NCI's Cancer Information Service at 1-800-4-CANCER.

Cancer Risk and Early Detection

Cervical Cancer: What You Can Do To Protect Yourself (English and Spanish)

Cervical Cancer: What Vietnamese Women Should Know (English and Vietnamese)

Every Woman Should Know About These 2 Tests (English, Vietnamese, and Spanish)

Get a Mammogram: Do It For Yourself, Do It For Your Family (English, Chinese, Vietnamese and Tagalog)

Mammograms: Not Just Once, But For A Lifetime

Genetic Testing for Breast and Ovarian Cancer Risk

Understanding Cancer Risk Web site:

<http://understandingrisk.cancer.gov>

Diagnosis

Common Breast Changes (English and Spanish)

Understanding Breast Changes

Understanding Cervical Changes

Understanding Prostate Changes

What You Need To Know About™ Cancer series

Provides information on many types of cancer. Each publication includes information about symptoms, diagnosis, treatment, emotional issues, and questions to ask your doctor.

<http://www.cancer.gov/cancertopics/wyntk>

Treatment

Surgery Choices for Women With Early-Stage Breast Cancer (English and Spanish)

Treatment Choices for Men With Early-Stage Prostate Cancer

Biological Therapy

Chemotherapy and You (English and Spanish)

Radiation Therapy and You (English and Spanish)

Thinking About Complementary and Alternative Medicine

When Someone You Love Is Being Treated For Cancer

Pain Control Series—Pain Control: A Guide for People With Cancer, Understanding Cancer Pain*, Get Relief From Cancer Pain (*English and Spanish)*

Eating Hints (English and Spanish)

Survivorship

Moving Beyond Breast Cancer DVD and VHS (with closed captioning)

Facing Forward: Life After Cancer Treatment (English and Spanish)

Ways You Can Make a Difference in Cancer

Taking Time

When Someone You Love Has Completed Cancer Treatment

Palliative Care and End of Life

When Cancer Returns

Coping with Advanced Cancer

When Someone You Love Has Advanced Cancer

Education in Palliative and End-of-life Care for Oncology (EPEC™-O)

COMPREHENSIVE NCI RESOURCES

NCI's Cancer Information Service

The National Cancer Institute's Cancer Information Service (CIS) can serve as a first-line resource to help you find the information you need. CIS gives up-to-date information on cancer to patients and their families, health professionals, and the general public. The CIS also provides personalized, confidential responses to specific questions about cancer.

Information specialists explain scientific information in plain language and respond in English or Spanish. Through its network of regional offices, CIS serves the United States, Puerto Rico, the U.S. Virgin Islands, and the U.S. Pacific Territories.

CIS information specialists answer telephone calls Monday through Friday from 9:00 a.m. to 4:30 p.m., local time.

Toll-free: 1-800-4-CANCER (1-800-422-6237)

TTY: 1-800-332-8615

Chat online: www.cancer.gov/help

Smoking Quitline

CIS operates NCI's Smoking Quitline. Smoking cessation counselors are available from 9:00 a.m. to 4:30 p.m. local time, Monday through Friday. They offer help in English or Spanish.

Toll-free: 1-877-44U-QUIT (1-877-448-7848)

For those with Internet access, the LiveHelp instant-messaging service also offers help with quitting smoking. Smoking cessation counselors are available from 9:00 a.m. to 11:00 p.m., Eastern time.

<http://www.smokefree.gov>

cancer.gov

NCI's multiple award-winning Web site contains information about cancer causes and prevention, screening and diagnosis, treatment, symptom management, and survivorship; clinical trials; statistics, funding, and training; and the NCI's programs and research activities. <http://www.cancer.gov>

Within NCI's Web site, there are many resources to be aware of:

Physician Data Query (PDQ®)

Includes peer-reviewed cancer information summaries.

PDQ® International Cancer Clinical Trials Registry

Includes the maintenance of directories of persons and organizations involved in cancer care across the United States and overseas.

NCI Publications Locator

This site can be used to view or order NCI publications.

NCI Cancer Bulletin

This biweekly online newsletter is designed to provide useful, timely information about cancer research to the cancer research community.

Dictionary of Cancer Terms

Contains more than 4,000 terms related to cancer and medicine.

Drug Dictionary

Contains technical definitions and synonyms for drugs/agents used to treat patients with cancer or conditions related to cancer. Each drug entry includes links to check for clinical trials listed in NCI's PDQ® Cancer Clinical Trials Registry.

Spanish-Language Web Pages

NCI's new Web site complements existing Spanish-language resources from NCI, such as the Cancer Information Service (1-800-4-CANCER). Cancer.gov en español currently contains 23 Web pages on different types of cancer, more than 100 peer-reviewed cancer treatment summaries for health professionals and patients, and a dictionary that includes 5,000 terms and definitions in both Spanish and English.

www.cancer.gov/espanol