



C-Change
Cancer Core Library

Introduction

C-Change is a nonprofit organization that seeks to leverage the combined expertise and resources of its members to eliminate cancer as a major public health problem as quickly as possible. It is comprised of over 130 leaders from public, private, and nonprofit sector organizations. C-Change acts as a forum for the Nation's key cancer leaders to come together and collaborate to affect changes that will help to realize their shared vision: a future where cancer is prevented, detected early, and is either cured or managed successfully as a chronic illness.

To organize and focus the efforts of C-Change, the organization includes seven teams that address issues of critical importance to the achievement of the organization's mission to eliminate cancer as a major public health problem. C-Change teams function as the entities that turn dialogue into action. Each of the teams controls its own budget, sets its own agenda, and develops its own action plans. The seven teams include the following: (1) Access to Quality Cancer Care, (2) Research, (3) Clinical Trials, (4) Primary Prevention and Early Detection, (5) State Cancer Plans, (6) Workforce, and (7) Tobacco Control

This Cancer Core Library is an initiative of the Access to Quality Cancer Care Team. The library is a collection of seminal pieces on issues related to access to quality cancer care to help a wide variety of audiences. Potential audiences include policy makers at various levels of government, state/tribal Nation and territory cancer control coalitions, and community health center staff members. The library includes sources such as Web sites, government and private sector reports, and journal articles.

Criteria for Inclusion in the Cancer Core Library

The C-Change Access to Quality Cancer Care Core Library includes books, government and private sector reports, journal articles, and Web sites that pertain to access to quality cancer care issues. Other cancer issues are equally important; however, this library is a product of the C-Change Access to Quality Cancer Care team and its scope is limited to issues of access and quality. The resources included in the library resulted from suggestions made by the Access to Quality Cancer Care team members. Reports from the Institute of Medicine and the President's Cancer Panel were included in the library because of the wealth of information contained in their content and citations. Other printed materials and Web sites are listed to address as many issues as possible related to access to quality cancer care. Neither the list of printed materials nor the list of Web sites included in the library is a comprehensive collection of resources relevant to access to quality cancer care; however, they are the resources that the team members wanted to offer to their colleagues in the cancer care arena.

If you would like to contribute to the library, please use the submission form provided on the Web site. The library will be updated at least annually and more often if warranted.



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Web Sites

Advocacy Organizations

- The [Association of Community Cancer Centers](#) (ACCC) represents members of the cancer care team and includes physicians, other health professionals, and hospital administrators. ACCC seeks to provide information on topics such as legislative and regulatory changes as well as cancer program management.
- The [National Governors Association](#) (NGA) is a bipartisan policy group that represents the collective voice of the Nation's governors. The [NGA Center for Best Practices](#) offers information about state cancer programs that address education and prevention, surveillance, early detection and screening, intervention and treatment, and research.
- The [Council of State Governments \(CSG\)](#) is a nonpartisan, nonprofit organization that seeks to foster excellence in state government. CSG alerts state elected and appointed officials to emerging social, economic, and political trends; offers innovative state policy responses to rapidly changing conditions; and advocates multi-state problem-solving to maximize resources and competitiveness.
- [Cancer Leadership Council](#) is a national advocacy organization comprised of cancer patient organizations, professional societies, and research organizations addressing public policy issues in cancer.
- [The National Coalition for Cancer Survivorship](#) is a survivor-led cancer advocacy organization that advocates quality cancer care for all Americans and empowering cancer survivors.

Childhood Cancer

- ❖ [CureSearch](#) is the result of a collaboration between the Children's Oncology Group and the National Childhood Cancer Foundation. Among other resources, the Web site offers information specific to a child's age, treatment stage, and type of cancer.
- ❖ [Candelighters Childhood Cancer Foundation](#) is a group committed to the mission of providing support, education, and advocacy for children and adolescents with cancer, survivors of childhood/adolescent cancer, their families, and the professionals who care for them.

Cultural Issues in Health

- [The Center to Reduce Cancer Health Disparities](#) at the National Cancer Institute (NCI) has brought together [references](#) where culturally specific help pertaining to cultural issues in health is available. The Center also supports a research program that will address cancer health disparities across the cancer control continuum from prevention to end-of-life care. To guide this expansion of disparities-focused research, the NCI has developed a [Strategic Plan for Reducing Cancer-Related Health Disparities](#).
- According to [CDC'S Office of Minority Health and Health Disparities](#), cancer is an area where specific population groups experience disproportionate rates of incidence, prevalence, mortality, survival, risks, and treatment. [Settlement.Org at Work](#) is a Web portal devoted to professional development information for

frontline workers and managers of immigrant-serving organizations in Ontario, Canada. Featured on this site is a research paper developed by the Access Alliance Multicultural Community Health Centre (AAMCHC) and its partners titled [*Racialised Groups and Health Status: A Literature Review Exploring Poverty, Housing, Race-Based Discrimination and Access to Health Care as Determinants of Health for Racialised Groups*](#). This paper focuses on the impact of income, housing, race-based discrimination and access to health care on the health status of racialised groups in Toronto, Canada.

Databases/Surveillance

- The [Cancer Surveillance Futures Project](#), an outgrowth of discussions at C-Change, offers forecasts and scenarios for the next decade as well as recommendations for how cancer surveillance can play its optimal role.
- The [National Cancer Data Base](#) (NCDB) is a joint project of the [American Cancer Society](#) (ACS) and the [Commission on Cancer](#) (CoC) of the [American College of Surgeons](#) (ACoS). The NCDB is a comprehensive clinical surveillance resource. Its [benchmark reports](#) offer data tailored to individual requests.
- [SEER*Stat](#) is a tool that can be used to analyze the [Surveillance, Epidemiology, and End Results \(SEER\) Program](#) of the [National Cancer Institute](#) (NCI) and other cancer databases.
- The [SEER-Medicare Database](#) links SEER and Medicare claims data, providing detailed information about elderly persons with cancer.
- The [North American Association of Central Cancer Registries, Inc.](#) (NAACCR, Inc.), is a professional organization that develops and promotes uniform data standards for cancer registration; certifies population-based registries; aggregates and publishes data from central cancer registries; and promotes the use of cancer surveillance data and systems for cancer control and epidemiologic research, public health programs, and patient care to reduce the burden of cancer in North America.

Financial Assistance

- The [Patient Advocate Foundation](#) (PAF) is a nonprofit organization that offers mediation and liaison services to patients, serving as a link between a patient and their insurer, employer, creditors, doctors, and/or attorneys.
- [CancerCare, Inc.](#) is a national nonprofit organization that provides free professional support services to anyone affected by cancer (i.e., people with cancer, caregivers, children, loved ones, and the bereaved). By calling the organization's cancer line, a patient can receive medical information and referrals to various services in the patient's area.
- The [Leukemia and Lymphoma Society](#) provides supplemental financial assistance for people with leukemia, lymphoma, multiple myeloma, and Hodgkin's disease.
- The [Veterans Health Administration Cancer Program](#) facilitates care and financial assistance for eligible veterans and their dependents at VA's throughout the United States.

Foundations

- [The Commonwealth Fund](#) is a private foundation that supports independent research on health care issues with the goal of promoting a health care system that offers superior access, quality, and efficiency. The Fund's Web site allows the user to search for information on specific topics in health care access and quality.
- The [Kaiser Family Foundation](#) (KFF) is a private foundation that aims to be an independent source of facts and analysis for a variety of audiences that include policy makers, the media, and the public. KFF operates a number of Web sites that address issues of access and quality, including [statehealthfacts.org](#), which offers state profiles and state comparisons, and [kaiseredu.org](#), which provides those interested in learning about health policy easy access to data, research, and analysis.
- [The Robert Wood Johnson Foundation](#) is devoted exclusively to improving the health and health care of all Americans. They work with a diverse group of organizations and individuals to identify solutions and achieve comprehensive, meaningful, and timely change.

Government

- The [Centers for Medicare and Medicaid Services](#) (CMS) conducts and sponsors [demonstration projects](#) designed to measure the effect of potential program changes. One of the ongoing demonstrations is the [cancer prevention and treatment demonstration for ethnic and racial minorities](#).
- The [Division of Cancer Prevention and Control](#) (DCPC) at the [Centers for Disease Control and Prevention](#) (CDC) offers a wealth of information likely to interest individuals who are concerned about issues of access and quality, and includes fact sheets, surveillance, and site-specific information.
- The NCI's [Cancer Information Service](#) (CIS) serves as an educational resource for the public about cancer prevention, risk factors, symptoms, diagnosis, treatment, and research. CIS information specialists can be reached by telephone, TTY, and the Internet.
- The [Health Disparities Collaboratives](#) at the [Bureau of Primary Health Care](#) (BPHC) in the [Health Resources and Services Administration](#) (HRSA) were designed to effect change in primary health care practices with the goals of improving health care and eliminating health disparities. Information specific to access to quality cancer care includes [measures of cancer population](#).
- The [National Cancer Institute](#) (NCI) is the federal government's chief agency for cancer research and training. Its Web site offers information about a variety of issues related to cancer care access and quality, including resources about clinical trials, stages of the continuum of cancer care, and site-specific information. The NCI also has a hotline (800-4-CANCER) where practitioners and consumers can receive assistance.
- The [President's Cancer Panel](#) (PCP) is charged with monitoring the development and implementation of the activities of the National Cancer Program. Recent topics addressed by PCP annual reports include cancer among Native Americans, challenges of survivorship, and the translation of research into cancer care.

- [Agency for Healthcare Research and Quality \(AHRQ\)](#) is a public health service agency in the Department of Health and Human Services (HHS). AHRQ sponsors and conducts research that provides evidence-based information on health care outcomes; quality; and cost, use, and access.

Nonprofit Organizations

- The [American Cancer Society](#) is a community-based, nationwide organization whose Web site offers a wealth of resources related to access to quality cancer care such as assistance with finding clinical trials and information about treatment options.
- The [Intercultural Cancer Council](#), housed at the Baylor College of Medicine, promotes initiatives and research to eliminate the unequal burden of cancer among racial and ethnic minorities and medically underserved populations. Individuals interested in cultural issues surrounding access to quality cancer care may find their [cancer fact sheets](#) particularly useful.
- The [National Quality Forum](#) is a nonprofit membership organization that aims to develop and execute a national strategy for health care quality measurement and reporting. Agendas, presentations, and reports from recent cancer-related activities can be found under [current activities](#).
- The [RAND Corporation](#) is a nonprofit institution that aims to inform policy through research and analysis. Their projects include the [First National Report Card on the Quality of Health Care in America](#), which includes cancer pain and palliation in the Quality Assessment Tools System.
- [The Association of State and Territorial Health Officials \(ASTHO\)](#) is the national nonprofit organization representing the state and territorial public health agencies of the United States, U.S. Territories, and District of Columbia.
- [The Association of State and Territorial Chronic Disease Directors](#) (otherwise known as “CDD”) is a national public health association, intended to link the chronic disease program directors of each state and U.S. territory to provide a national forum for chronic disease prevention and control efforts.

Pain Resources

- The [American Alliance of Cancer Pain Initiatives](#) is dedicated to promoting cancer pain relief nationwide by supporting the efforts of State Cancer Pain Initiatives. Cancer Pain Initiatives are voluntary, grassroots organizations composed of nurses, physicians, pharmacists, social workers, psychologists, and representatives of clergy, higher education, and government. Initiatives and their participants provide education and advocacy to health care providers as well as cancer patients and their families.
- The [American Chronic Pain Associations](#)’ mission is to support and educate patients and their families, as well as raise awareness among health care professionals, policy makers, and the public at large about chronic pain and pain management.
- The [American Academy of Pain Management](#) provides credentialing, accreditation of facilities, networking opportunities, continuing education, quality publications, and an annual clinical meeting.

- [The American Academy of Pain Medicine](#) (AAPM) is the medical specialty society representing physicians practicing in the field of Pain Medicine.
- The American Pain Foundation, along with HealthMark Multimedia, offers [Cancer Pain: Your Guide to Relief™](#), a CD-ROM to Help Cancer Patients and Caregivers Understand and Manage Pain.
- [City of Hope](#) is a biomedical research, treatment, and educational institution dedicated to the treatment, prevention, and cure of cancer and other life-threatening illnesses. The City of Hope's Web page [Pain/Palliative Care Resource Center](#) is dedicated to patient educational resources devoted to pain management.
- The [Hospice and Palliative Nurses Association's](#) (HPNA) goals are to: exchange information, experiences, and ideas; promote understanding of the specialties of hospice and palliative nursing; and study and promote hospice and palliative nursing research.
- [Hospice College of America](#) (HCA) is the distance learning subsidiary of [Hospice Foundation of America](#). HCA is a public charity that offers a variety of professional education opportunities to those interested in health care issues at the end of life. HFA is an approved provider for HCA and their courses offer CEU's for selected disciplines.
- [International Association for the Study of Pain](#) (IASP) is a nonprofit professional organization dedicated to furthering research on pain and improving the care of patients with pain.
- [Partners Against Pain](#) is an alliance of [patients](#), [caregivers](#), and [health care providers](#) working together to alleviate unnecessary suffering by leading efforts to advance standards of pain care through [education](#) and [advocacy](#).
- The [National Chronic Pain Society](#) (NCPS) is an advocacy group that helps people to deal with chronic pain. NCPS focuses on educating people about treatment options that can help create a better quality of life for those who suffer with chronic pain.
- The [National Pain Foundation](#) is an online education and support community for persons in pain, their families, and physicians. The information provided indicates possible treatment options and pain information that is peer reviewed by leading pain specialists.
- The [Pain and Policy Studies Group \(PPSG\)](#) is located at the University of Wisconsin's Comprehensive Cancer Center. The PPSG sponsors a World Health Organization communications program directed at improving health professionals' access to information about pain management, palliative care, and pain-related policy. This objective is accomplished through publication of the quarterly WHO newsletter and maintenance of a World Wide Web site for [Cancer Pain Release](#).

Palliative Care

- The [National Consensus Project for Quality Palliative Care](#) has the purpose of promoting the implementation of Clinical Practice Guidelines that ensure care of consistent and high quality, and that guide the development and structure of new and existing palliative care services.

- The [Clinical Practice Guidelines for Quality Palliative Care](#) was developed through consensus of care organizations and describes the core precepts and structures of clinical palliative care programs.
- The [National Hospice and Palliative Care Association](#) is a non-for-profit organization committed to improving end-of-life care and expanding access to hospice care with the goal of profoundly enhancing the quality of life for terminally ill patients and their loved ones.

Patient Navigation

- The 109th Congress of the United States of America passed the [Patient Navigator Outreach and Chronic Disease Prevention Act of 2005](#) to amend the Public Health Service Act to authorize a demonstration grant program. This program's goal is to provide patient navigator services to reduce barriers and improve health care outcomes.
- The National Cancer Institute's Center to Reduce Cancer Health Disparities houses the [Patient Navigator Research Program](#) (PNRP): Eliminating Barriers to Timely Delivery of Cancer Diagnosis and Treatment Services. The program is intended to facilitate the development of effective patient navigation systems.
- [The Center for Patient Partnerships](#) is comprised of physicians, researchers, teachers, and health policy and management experts at the University of Wisconsin-Madison. The Center works to empower patients as equal partners with providers to achieve successful health care outcomes. The Center assists people with cancer and other life-threatening and chronic illnesses who are experiencing the red tape, confusion, fear, and doubts, which often arise when diagnosed with a serious medical condition and that impede access to quality health care.

Policy

- The Institute of Medicine (IOM) has established a [National Cancer Policy Forum](#) (the Forum), effective May 1, 2005, to succeed the existing [National Cancer Policy Board](#) (1996-2005, the Board). The Forum identifies emerging policy issues in the Nation's effort to combat cancer and explores them through convening activities that enable all members to be full participants in identifying and debating critical issues and examining potential actions.
- The [American Society of Clinical Oncology](#) (ASCO) maintains a bi-monthly updated Policy Watch link on their Web site that provides current policy information regarding the fight against cancer.
- The Oncology Nursing Society's position on [Patients' Bill of Rights for Quality Cancer Care](#) is available online and in hard copy.
- [Pain and the Law](#) has been developed by the [Center for Health Law Studies at Saint Louis University](#) and the [American Society of Law, Medicine and Ethics](#) under a grant from The Mayday Fund.
- The National Governors Association [Public Health Services Policy](#) regarding our Nation's public health system has the mission to prevent disease and disability, promote healthy lifestyles, and protect against public health threats, including biological, chemical, and nuclear terrorism.

State and Local Level Resources

- [State Cancer Profiles](#) provide views of cancer statistics at the national, state, and county level. The statistics provide information to assist in prioritizing cancer control efforts.
- The [National Governors Association](#) Cancer Control and Prevention Web site is designed to provide a national clearinghouse of best practices in cancer control and prevention, thereby empowering states to share what works in the battle against cancer.
- The [U.S. Conference of Mayors](#) developed [Best Practices on Promoting Cancer Awareness and Healthy Cities](#), which allows Best Practices Center Mayors to share information about their own approaches for solving problems in their cities.

Survivorship

- [The National Coalition of Cancer Survivors](#) is the oldest survivor-led cancer advocacy organization in the country and a highly respected authentic voice at the federal level, advocating for quality cancer care for all Americans and empowering cancer survivors.
- [The CDC's cancer survivorship goals](#) for access to quality care and services include the creation and implementation of, along with partners, successful strategies to help the millions of people who live with, through, and beyond cancer. The prioritized needs and recommended strategies to address access to quality care and services are described.

Published Literature

Access to Clinical Trials

Journal Article

National Cancer Clinical Trials: Children Have Equal Access; Adolescents Do Not (Bleyer, W. A., Tejada, H., Murphy, S. B., Robison, L. L., Ross, J. A., Pollock, B. H., et al. *Journal of Adolescent Health* 1997;21(6):366-375.)

Adolescents have higher cancer incidence and those with cancer have lower mortality reduction than children. This authors of this article found that the disparities extend to access to national cancer clinical trials: irrespective of their race or ethnicity, older adolescents have less access to trials.

Other Source

Knowledge and Access to Information on Recruitment of Underrepresented Populations to Cancer Clinical Trials

(Ford, J. G., Howerton, M. W., Bolen, S., Gary, T. L., Lai, G. Y., Tilburt, J., et al. Evidence Report/Technology Assessment No. 122 (No. 05-E019-2). Rockville, MD: Agency for Healthcare Research and Quality, 2005.)

Completed by the Johns Hopkins University Evidence-based Practice Center (EPC) and commissioned by the Agency for Healthcare Research and Quality (AHRQ), this report

was requested and financially supported by the National Cancer Institute (NCI). The document is the result of a systematic review of the existing evidence regarding the recruitment of underrepresented populations into cancer clinical trials. The content focuses on questions in six areas: (1) methods used to study recruitment strategies; (2) measures of recruitment success; (3) comparison of two or more recruitment interventions for cancer treatment trials; (4) comparison of two or more recruitment interventions for cancer prevention trials; (5) barriers and promoters of recruitment; and (6) physician attitudes and perceptions about recruitment.

Disparities/Systemic Barriers

Institute of Medicine

Unequal Treatment: What Healthcare Providers Need To Know About Racial and Ethnic Disparities in HealthCare

(Institute of Medicine. Washington, DC: National Academy Press, 2002.)

In this report, the IOM assesses the extent of racial/ethnic differences in health care that are not due to access-related factors. The document analyzes potential sources of these disparities, including bias, discrimination, and stereotyping. The report includes recommendations at the individual, institutional, and health system levels.

Institute of Medicine (National Cancer Policy Board)

Equitable Access to Cancer Services: A Review of Barriers to Quality Care

(Mandelblatt, J. S., Yabroff, K. R., and Kerner, J. F. *Cancer* 1999;86(11):2378-2390.)

Following a wide-ranging review of literature on cancer care, the authors of this article developed a conceptual framework that they use to describe patient, provider, and system barriers to cancer services. The most common patient barriers are related to age, race, and socioeconomic status. At the provider level, one barrier of particular concern is poor communication between medical professionals and diverse patient populations. The authors note that constraints of the medical care system can impede the delivery of care, though they acknowledge that further research is needed to assess the impact of the rise of managed care organizations on cancer care.

Editorial

Health Disparities-Less Talk, More Action

(Lurie, N. *New England Journal of Medicine* 2005;353(7):727-729.)

In a recent editorial, RAND author Nicole Lurie discusses the large amount of research documenting the existence of racial and ethnic disparities in health care. Efforts should be made to take action and make changes, but documentation is still needed.

Journal Articles

The Impact of Medical Interpreter Services on the Quality of Health Care: A Systematic Review

(Flores, G. *Medical Care Research and Review* 2005;62(3):255-299.)

Noting that 21 million Americans have limited English proficiency (LEP), the author conducts a literature review to analyze the impact of interpreter services on quality of care. Reviewed as a whole, the literature reveals that LEP patients as a group receive inferior quality of care. When LEP patients have the services of an

interpreter, often the person filling that role is untrained. This leads to negative outcomes for all LEP patients, particularly those with mental disorders. Quality indicators including patient satisfaction and patient outcomes are highest when LEP patients have access to trained professional interpreters.

Racial and Ethnic Disparities in Cancer Screening: The Importance of Foreign Birth as a Barrier to Care

(Goel, M. S., Wee, C. C., McCarthy, E. P., Davis, R. B., Ngo-Metzger, Q., and Phillips, R. S. *Journal of General Internal Medicine* 2003;18(12):1028-1035.)

This paper addresses the issue of racial/ethnic disparities in cancer screenings by analyzing whether the disparities are due to one's race/ethnicity or whether or not one was born in the United States. Across racial and ethnic categories, foreign-born respondents were less likely to indicate that they received cervical, breast, or colorectal cancer screenings than were U.S-born respondents. The researchers found that adjusting for access to care somewhat minimized the disparities in screening between native and non-native respondents.

The Quality of Cancer Care: Models of Excellence

(Smith, T. J., Desch, C. E., and Hillner, B. E. National Cancer Policy Board commissioned paper, 1998.)

In contrast to the majority of the related literature that discusses the ability to improve small sections of cancer care, this paper addresses the question of how to improve an entire system of care. The authors describe what a useable model of excellence would look like and how it would be applied and evaluated, as well as major barriers to implementing such a model. In addition, analyses of some specific model programs are included.

Social Disparities in Cancer: Lessons From a Multidisciplinary Workshop

(Weissman, J. S., and Schneider, E. C. *Cancer Causes and Control* 2005;16(1):71-74.)

This article provides an overview of issues relating to cancer disparities based on a 2004 workshop. Included among the topics addressed are the impact of race, socioeconomic status, insurance, and access to care.

Voices of a Broken System: Real People, Real Problems

(President's Cancer Panel. U.S. Department of Health and Human Services, 2002.)

The 2001 Annual Report offers four major issue categories regarding cancer care: system barriers that undervalue cancer prevention, education, and screening efforts; financial barriers faced by people who are under- or uninsured; physical barriers that people confront when they live in distant, rural, or frontier areas with no transportation system and a lack of specialists; and information and education barriers for providers, patients, and the public.

Facing Cancer in Indian Country: The Yakama Nation and Pacific Northwest Tribes

(President's Cancer Panel. U.S. Department of Health and Human Services, 2003.)

The 2002 Annual Report offers a discussion of the state of cancer care for patients who are members of the Yakama Nation and Pacific Northwest Tribes. The report

includes the scope of existing problems for these patients and describes how the characteristics unique to Native Americans affect cancer care.

NASW Standards for Cultural Competence in Social Work Practice

(National Association of Social Workers. NASW Press, 2001.)

The report provides definitions of and supports social work practice that encourages cultural competence. The report also serves as a guide for social workers in responding effectively to the diversity inherent in the agencies and systems in which they work and with the clients and communities they serve.

National Cancer Institute Special Project: Barriers of Translating Oncology Research to Social Work Practice

(National Association of Social Workers, 2003.)

In 2002, the National Cancer Institute (NCI) awarded the National Association of Social Workers (NASW) a grant to investigate how oncology social workers incorporate new research findings into their daily practice. The purpose of the project was to explore barriers to translating oncology research to social work practice, and to develop innovative dissemination strategies. The report includes a discussion of findings as well as recommended action steps.

Defining Access to Quality Cancer Care

Institute of Medicine

Ensuring the Quality of Health Care

(Institute of Medicine. Washington, DC: National Academy Press, 1999a.)

This report resulted from a comprehensive review of the evidence of barriers that limit access to cancer care, the adequacy of quality assessments, and the effectiveness of treatment and delivery mechanisms. The document addresses five questions: (1) What is the state of the cancer care "system"? (2) What is quality cancer care and how is it measured? (3) What cancer care quality problems are evident and what steps can be taken to improve care? (4) How can we improve what we know about the quality of cancer care? (5) What steps can be taken to overcome barriers to access to quality cancer care? The report summarizes the state of knowledge about quality cancer care and offers recommendations intended to address inadequacies.

Institute of Medicine (National Cancer Policy Board)

Access to Quality Cancer Care: Evaluating and Ensuring Equitable Services, Quality of Life, and Survival

(Mandelblatt, J. S., Yabroff, K. R., and Kerner, J. F. National Cancer Policy Board commissioned paper, 1998.)

A variety of issues related to barriers to access quality cancer care from prevention to end-of-life care are addressed in this paper. Included among the topics are: a framework for evaluating barriers; a review of which barriers are most relevant to each stage in the spectrum of care; and research, education, and policy recommendations intended to produce equitable access to quality care for all Americans.

Journal Article

Access to Quality Cancer Care: Consensus Statement

(American Federation of Clinical Oncologic Societies. *Journal of Clinical Oncology* 1998;16(4):1628-1630.)

The American Federation of Clinical Oncologic Societies (AFCOS) is a coalition of all professional clinical oncology societies. AFCOS addresses concerns about changes in the U.S. health care delivery system and the impact that they may have on quality patient care. The AFCOS consensus statement emerged from collaboration among the nine member societies as well as input from the Cancer Leadership Council.

Measuring Quality of Care

Institute of Medicine

Measuring the Quality of Health Care

(Institute of Medicine. Washington, DC: National Academy Press, 1999b.)

This report examines a variety of issues related to quality of health care, addressing questions such as: Can quality of care be defined? Where do quality-of-care concerns lie? What are the major approaches to quality measurement? Also, advances in and challenges to quality measurement are discussed. The report's conclusion is that the quality of health care can and should be measured and improved.

Institute of Medicine (National Cancer Policy Board)

The Quality of Cancer Care: Does the Literature Support the Rhetoric?

(Hillner, B. E., and Smith, T. J. National Cancer Policy Board commissioned paper, 1998.)

In this paper, the authors examine evidence of inadequate cancer care, including overutilization of ineffective treatments and underutilization of effective treatments. The authors also address the question of whether findings reported in the literature suggest that there are characteristics of providers, facilities, or delivery systems that affect the quality of care. The third major topic discussed is the degree to which measures of quality cancer care are valid and meaningful.

Assessment of the Quality of Cancer Care: A Review for the National Cancer Policy Board of the Institute of Medicine

(Schuster, M. A., Reifel, J. L., and McGuigan, K. National Cancer Policy Board commissioned paper, 1998.)

This paper is conceptually split into two sections. The first half of the paper explains the methodologies and uses of quality assessment, including how information is collected, what forms it takes, and specific methods for evaluating its quality. The second half of the paper reports what efforts have been made to measure quality for three specific types of cancer: breast, childhood, and prostate cancer. The authors conclude that current attempts to assess the quality of cancer care in the United States are in an early phase. Most efforts have focused on measuring prevention and screening; efforts to measure the quality of diagnosis and management are less well-developed.

Journal Articles

See the May/June 1997 Issue of *Health Affairs* (Volume 16, Issue 3), which discusses Quality in a Changing System: Challenges in Measuring Quality.

Quality Improvement Efforts in Oncology: Are We Ready To Begin?

(Bennett, C. L., and Crane, J. M. *Cancer Investigation* 2001;19(1):86-95.)

The existence of large variations in the quality of cancer care in the United States is well-documented. Continuous quality improvement (CQI), also known as total quality management (TQM), has been discussed as one alternative to traditional report cards. This paper focuses on the potential advantages and disadvantages of CQI, includes reviews of four instances of the use of CQI in cancer programs, and offers recommendations for future CQI efforts.

Developing a Reliable, Valid, and Feasible Plan for Quality-of-Care Measurement for Cancer: How Should We Measure?

(Kahn, K. L., Malin, J. L., Adams, J., and Ganz, P. A. *Medical Care* 2002;40(6[Suppl III]):73-85.)

In this paper, the authors examine how to manipulate the design of a quality-of-care measurement system so that the system generates feasible and reliable data relevant to cancer patients. The four areas of design discussed in the article are case identification, data source, data collection strategies, and the quality-of-care measurement model. The authors conclude that when designing a quality-of-care measurement system, one has to consider tradeoffs between burden and validity.

Patient Satisfaction and Quality of Life in Cancer Outpatients: Results of the PASOOC Study

(Kleeberg, U. R., Tews, J. T., Ruprecht, T., Hoing, M., Kuhlmann, A., and Runge, C. *Supportive Care in Cancer* 2005;13(5):303-310.)

This paper focuses on the premise that a cancer patient's satisfaction with care and quality of life are indicative of the quality of care that the patient is receiving. The overall satisfaction rate among respondents was high. Still, there were several specific areas that need improvement, including shared decision making and physician-patient communication.

Evaluating the Quality of Cancer Care: Development of Cancer Quality Indicators for a Global Assessment Tool

(Malin, J. L., Asch, S. M., Kerr, E. A., and McGlynn, E. A. *Cancer* 2000;88(3):701-707.)

This paper documents the authors' efforts to develop quality of care indicators using a novel case-based approach intended to compare various managed care organizations. Quality indicators were developed for 6 types of cancer, human immunodeficiency virus (HIV), and 39 general adult conditions (GAC). The results indicate that the development of quality indicators that address the entire spectrum of care is feasible; future research is needed to assess the reliability and validity of the indicators.

Quality Breast Cancer Care: What Do We Know?

(Malin, J. L., Schuster, M. A., Kahn, K. A., and Brook, R. H. *Journal of Clinical Oncology* 2002;20(21):4381-4393.)

The authors of this study reviewed literature that discusses patterns of care for breast cancer patients, including examination of data sources. The results of the study indicate that the available data have many limitations, even considering the fact that more patterns of care research has taken place in breast cancer than in any other cancer. The authors advocate for the expansion of reliable data on the quality of cancer care so that changes in quality can be studied.

Monitoring and Improving Quality of Cancer Care: Easy To Recommend, Difficult To Accomplish

(Markman, M. *Cancer Investigation* 2001;19(1):96-97.)

This editorial provides a brief introduction to issues relevant to the topic of health care quality. The author discusses concerns that arise in the movement from a consensus that "quality must be addressed" to the creation and implementation of "quality assurance" programs.

The Case Identification Challenge in Measuring Quality Cancer Care

(Pearson, M. L., Ganz, P. A., McGuigan, K., Malin, J. R., Adams, J., and Kahn, K. L. *Journal of Clinical Oncology* 2002;20(21):4353-4360.)

This article considers the challenges inherent in case identification in measurement of quality cancer care. The authors discuss possible options for rapidly identifying newly diagnosed patients, including using claims or other administrative data, cancer registries, cancer registry rapid case ascertainment, pathology laboratories, and physicians' offices. Even though most of the approaches have limitations, room for improvement of case identification still exists.

How Good Is the Quality of Cancer Care in the United States?

(Schuster, M. A., McGlynn, E. A., and Brook, R. H. *Milbank Quarterly* 1998;76(4):517-563.)

Although the quality of health care in the United States varies significantly by location and provider, the authors conclude that overall, care in the United States often fails to meet professional standards. The major components of poor care are insufficient care, excessive care, and incorrect care. The authors suggest that a quality measurement system be established to provide the multitude of parties in the health care system with the information needed to ensure that only high-quality care is delivered.

Ensuring Quality Cancer Care: Clinical Practice Guidelines, Critical Pathways, and Care Maps

(Smith, T. J., and Hillner, B. E. National Cancer Policy Board commissioned paper, 1998.)

This paper describes the formulation and use of clinical practice guidelines for cancer care. Issues addressed include what guidelines exist, how the guidelines have been

developed, what evidence suggests that the guidelines are being used, and whether the guidelines being used are having a visible effect on cancer care quality.

Palliative Care

Institute of Medicine

Improving Palliative Care for Cancer

(Institute of Medicine. Washington, DC: National Academy Press, 2001.)

In its 1999 report *Ensuring Quality Cancer Care*, the Institute of Medicine recommended that more resources be directed toward ensuring quality of care at the end of life. In this report, the Institute finds that medical advances that allow cancer patients to live longer have outpaced improvements in the development and delivery of palliative care. This report describes the major barriers that prevent people from receiving excellent palliative care and offers a series of recommendations designed to alleviate the problem.

Journal Articles

Palliative Care Needs of Cancer Patients in U.S. Nursing Homes

(Johnson, V. M., Teno, J. M., Bourbonniere, M., and Mor, V. *Journal of Palliative Medicine* 2005;8(2):273-279.)

This paper reports on a tremendous need to pay more attention to nursing home cancer patients' palliative care. On average, more than 50 percent of the patients who survived to respond to a second assessment reported that they had experienced severe pain. This issue is particularly important because as the elderly population increases, palliative care in nursing homes will become even more important.

Model Policy for the Use of Controlled Substances for the Treatment of Pain

(Federation of State Medical Boards of the United States, I. *Journal of Pain and Palliative Care Pharmacotherapy* 2005;19(2):73-78.)

This article is an expansion of the Model Guideline for the Use of Controlled Substances in the Management of Pain written by the Federation of State Medical Boards in 1998. The Model Policy informs licensees that the state medical board considers pain management to be central to the practice of medicine. The Model Policy discusses physicians' dual responsibilities to minimize the potential for abuse of controlled substances and to prescribe opioid analgesics when necessary for the relief of pain.

Other Sources

Guideline for the Management of Cancer Pain in Adults and Children

(Miaskowski, C., Clearly, J., Burney, R., Coyne, P., Finley, R., Foster, R., et al. Glenview, IL: American Pain Society, 2005.)

Authored by the Cancer Pain Management Guideline Panel of the American Pain Society, this book describes changes that have occurred in the understanding of the causes, measurement, and management of cancer pain since the Agency for Health Care Policy and Research (AHCPR, now the Agency for Healthcare Research and Quality, AHRQ) established Cancer Pain Guidelines in 1994. In addition to an overview of cancer pain, topics covered include methods for guideline development,

assessment of cancer pain, cancer pain management, management of procedure-related pain in children and adults, and quality improvement in cancer pain management.

NASW Standards for Palliative and End of Life Care

(National Association of Social Workers. (2004). NASW Press.)

The NASW Standards for Palliative and End of Life Care are designed to enhance social workers' awareness of the skills, knowledge, values, methods, and sensitivities needed to work effectively in end-of-life situations.

Patient Navigation

Journal Article

Using Navigators To Improve Care of Underserved Patients

(Dohan, D., Schrag, D. *Cancer* 2005;104(4):848-855.)

In this report, the authors define patient navigation, distinguishing it from other cancer support services; describe how programs are organized; and discuss the need for research on program effectiveness. The conclusions demonstrate that patient navigation is understudied, and literature documenting its effects and effectiveness is limited. The authors believe that studies will establish feasibility across a range of health care settings and performance relative to alternative approaches for addressing barriers to care among the underserved.

Cancer Patient Navigation: Published Information

(http://c-changetogether.org/about_ndc/newsroom/default.asp)

This paper provides background information, from published and other sources, on programs and services available to assist cancer patients, families, and caregivers in overcoming barriers to access and navigate the system. The report identifies research and program descriptions published in the medical and social sciences literature documenting the need for and role of patient navigation in cancer care. It explores the history of cancer patient navigation in the United States, examines existing models that address the access and navigation needs of cancer patients, and reviews issues in U.S. health care that affect cancer patients. It concludes that patient navigation services and programs hold the promise of improving timely access to diagnosis and treatment, assisting patients and caregivers in managing and coordinating cancer care, and helping them achieve an acceptable quality of life.

Expanding Access to Cancer Screening and Clinical Follow-up Among the Medically Underserved

(Freeman, H.P., Muth, B.J., and Kerner, J.F. *Cancer Practice* 1995;3(1):19-30.)

This paper describes a patient navigator intervention in an inner-city public hospital that was implemented with the goal of addressing the higher cancer incidence and mortality that affects the black community relative to levels seen in other racial/ethnic groups. The initiative found that patients who had access to a navigator were over 30 percent more likely to complete recommended breast biopsies. Those who completed a biopsy did so in significantly less time than those who were not assisted by a navigator.

Poverty, Culture, and Social Injustice: Determinants of Cancer Disparities

(Freeman, H.P. *CA: A Cancer Journal for Clinicians* 2004;54:72-77.)

In this editorial, Dr. Harold Freeman gives the reader a brief yet valuable introduction to the topic of cancer disparities, including current knowledge and background information. He offers conclusions and recommendations, including the Patient Navigator Program, which by working on an individual level aims to eliminate barriers that patients face in obtaining satisfactory diagnosis and treatment in a timely fashion.

Screening

Effectiveness/Quality

Institute of Medicine

Fulfilling the Potential for Cancer Prevention and Early Detection

(Institute of Medicine. Washington, DC: National Academy Press, 2003b.)

This report analyzes evidence that suggests the burden of cancer can be reduced through cancer prevention and early detection. The effectiveness of screening methods and interventions is considered, as are ways to expand screening and improve the potential benefits of interventions. The report includes lung cancer as a case study, which shows the problems that arise when the science surrounding new screening technology is uncertain. Also included is a discussion of professional education and training needs, government programs that support cancer prevention and early detection, and future directions for research.

Financial Issues

Journal Article

Type of Health Care Coverage and the Likelihood of Being Screened for Cancer

(Gordon, N. P., Rundall, T. G., and Parket, L. *Medical Care* 1998;36(5):636-644.)

In exploring whether the type of outpatient health insurance impacted the likelihood of individuals aged 20 to 64 years receiving recommended cancer screening procedures, the authors found that differences in screening procedures exist with regard to various types of coverage. Adults with private outpatient insurance were more likely to receive such procedures. Specifically, those who were members of a health maintenance organization were most likely to receive preventive screening tests. Further, the authors found that individuals who received care primarily from one physician had an increased chance of having screening procedures, regardless of the type of health plan.

Surveillance

Book

The Prevention and Control of Cancer in the Information Age. Horizons 2013: Longer, better life without cancer

(McDonald, M.D. Edited by H.G. Brown and J.R. Seffrin. American Cancer Society, 1996)

This book describes the discussions from a futures symposium sponsored by the American Cancer Society. Its contents chronicle the insights, strategies, and forecasts offered during the symposium by the attendees.

Journal Articles

A Vision for Cancer Incidence Surveillance in the United States

(Howe, H.L., et al. *Cancer Causes and Control* 2003;14(7):663-672.)

In this paper, the authors call for a comprehensive framework for cancer surveillance. Ideally, the framework would integrate data about cancer incidence with other cancer surveillance networks to provide information about stages across the continuum. The importance of the framework lies in the fact that the cancer registry is an essential component of the infrastructure that seeks to decrease the burden of cancer.

A National Framework for Cancer Surveillance in the United States

(Wingo, P.A., et al. *Cancer Causes and Control* 2005;16(2):151-170.)

The National Coordinating Council for Cancer Surveillance consists of representatives from the American Cancer Society, Centers for Disease Control and Prevention, National Cancer Institute, National Cancer Registrars Association, and North American Association of Central Cancer Registries. The Council has worked to build a national framework for cancer surveillance. Issues related to each stage of the continuum of disease progression are addressed, as are crosscutting information needs.

Survivorship

Institute of Medicine

Childhood Cancer Survivorship: Improving Care and Quality of Life

(Institute of Medicine. Washington, DC: National Academy Press, 2003a.)

The intent of this report is to provide a seminal analysis of childhood cancer survivorship. Its contents offer a comprehensive policy agenda that links advances in health care delivery, education and training, and research to improve the long-term outlook for survivors of childhood cancer. Issues range from the epidemiology of childhood cancer to those relevant to adult survivors, such as employment and health insurance coverage.

Journal Article

Providing Quality Care in Childhood Cancer Survivorship: Learning From the Past, Looking to the Future

(Harvey, J., Hobbie, W. L., Shaw, S., and Bottomley, S. *Journal of Pediatric Oncology Nursing* 1999;16(3):117-125.)

This article offers a discussion of the evolution of survivor clinics that cater to survivors of childhood cancer. The authors also address strategies for developing a quality survivorship program.

President's Cancer Panel

Living Beyond Cancer: Finding a New Balance

(President's Cancer Panel. U.S. Department of Health and Human Services, 2004.)

The 2003 Annual Report focuses on issues of survivorship from those affecting children to those affecting older adults. The report offers a variety of recommendations intended to improve follow-up care and quality of life for cancer survivors of all ages.

Treatment

Effectiveness/Quality

Journal Articles

Understanding Cancer Treatment and Outcomes: The Cancer Care Outcomes Research and Surveillance Consortium

(Ayanian, J. Z., Chrischilles, E. A., Wallace, R. B., Fletcher, R. H., Fouad, M. N., Kiefe, C. I., et al. *Journal of Clinical Oncology* 2004;22(15):2992-2996.)

The National Cancer Institute (NCI) has established and funded the Cancer Care Outcomes Research and Surveillance (CanCORS) Consortium to understand the reasons why cancer treatments and outcomes vary and are less than optimal for many patients in the United States. In this article, the authors introduce the goals and methods of the CanCORS Consortium to an intended audience of cancer researchers and clinicians.

Do Specialists Do It Better? The Impact of Specialization on the Process and Outcomes of Care for Cancer Patients

(Grilli, R., Minozzi, S., Tinazzi, A., Labianca, R., Sheldon, T. A., and Liberati, A. *Annals of Oncology* 1998;9(4):365-374.)

The aim of this project was to measure the impact of specialization on processes and cancer patients' outcomes. An analysis of 46 empirical studies addressing the relationship between quality of care indicators and degree of specialization found that processes varied significantly without a clear connection to degree of specialization. In contrast, outcomes as measured by mortality were consistently better when care was provided by specialists. The authors note that the presence of fundamental methodological flaws in the studies translates to measurements that are far from certain. Consequently, the authors conclude that the current evidence provides insufficient guidelines for improving the health care system.

The Relationship of Membership in Research Networks to Compliance With Treatment Guidelines for Early-Stage Breast Cancer

(Laliberte, L., Fennell, M. L., and Papadopoulos, G. *Medical Care* 2005;43(5):471-479.)

The authors sought to examine the relationship between the number of memberships in cancer research networks by a treatment facility and the facility's compliance with guidelines for primary treatment of early-stage breast cancer. Results indicate that patients who receive care from facilities that were members of two or more cancer research networks were more likely to receive treatment in accordance with guidelines than those treated at non-member facilities. Based on this information, the authors conclude that organizational factors involved with membership in cancer research networks might impact the degree to which a facility complies with treatment guidelines and might be useful in improving the quality of care.

Quality of Cancer Care: The NICCO Report

(Schneider, E. C., Epstein, A. M., Malin, J. L., and Kahn, K. A. Paper presented at the American Society of Clinical Oncology 41st Annual Meeting, Orlando, FL, 2005.)

This presentation at the 41st Annual Meeting of the American Society of Clinical Oncology (ASCO) is the first set of results from ASCO's National Initiative on Cancer Care Quality (NICCO). Researchers from Harvard University and the RAND Corporation commissioned by ASCO found that patients with breast and colorectal cancers receive higher quality care than previous research suggested. Researchers concluded that there are opportunities to improve the quality of patient care in some areas, including dose of chemotherapy, treatment side effects, and communication between health care providers and patients.

Developing a System To Access the Quality of Cancer Care: ASCO's National Initiative on Cancer Care Quality

(Schneider, E. C., Epstein, A. M., Malin, J. L., Kahn, K. A., and Emanuel, E. J. *Journal of Clinical Oncology* 2004;22(15):2985-2991.)

This article focuses on the American Society of Clinical Oncology's (ASCO) National Initiative on Cancer Care Quality (NICCO). NICCO was commissioned after an Institute of Medicine report in 1999 found that some cancer patients failed to receive the most effective care available. The initiative is intended to be a prototype for a national system capable of monitoring the quality of cancer care. In this paper, the authors discuss the goals and features of NICCO, as well as challenges that it faces and decisions that will arise if the initiative is expanded.

Financial Issues

Journal Articles

Cost Considerations as Potential Barriers to Cancer Treatment

(Guidry, J. J., Aday, L. A., Zhang, D., and Winn, R. J. *Cancer Practice* 1998;6(3):182-187.)

This paper provides an assessment of perceived barriers to cancer treatment, including racial/ethnic differences in obtaining insurance and direct and indirect costs of treatment. The results indicate that the cancer treatment facilities' staff need to be aware of the non-clinical, financial factors that can have a large, negative impact on patients' treatment and outcomes. These factors include barriers to obtaining and maintaining insurance coverage and costs associated with treatments and tests not covered by insurance.

The Effect of Medicare Health Systems on Women With Breast and Cervical Cancer

(Kirsner, R. S., Ma, F., Fleming, L., Trapido, E., Duncan, R., Federman, D. G., et al. *Obstetrics and Gynecology* 2005;105(6):1381-1388.)

The authors examined the stage at diagnosis among women with either breast or cervical cancer in two Medicare health care delivery services. Controlling for other factors, women enrolled in Medicare HMOs were more likely to be diagnosed with either type of cancer earlier than those enrolled in a Medicare fee-for-service program. The authors contribute this finding partially to the use of, or access to, health care.

Health Insurance and Spending Among Cancer Patients

(Thorpe, K. E., and Howard, D. *Health Affairs, Web Exclusive* 2003;W3-189, W183-198.)

This paper describes data suggesting that 10 percent of all cancer patients under age 65 do not have insurance and within the Hispanic population, 20 percent of patients do not have insurance. The authors found substantial differences in cancer spending by insurance status and determined that the differences in spending are at least partially due to differences in use. This finding suggests that cancer treatment will improve if more patients have insurance.