



Anne Silber. *In Burgundy: Orange Roofs*. Serigraph, © 1989. Sheet size 22" × 28".

Research partnerships furthering the science of quality of cancer care can lead to improved outcomes for patients.

National Cancer Institute Partnerships in Quality-of-Care Research

Steven B. Clauser, PhD

Background: Improving the quality of cancer care delivery is a research priority for the National Cancer Institute (NCI). The NCI addresses this priority in part through a variety of research partnerships with public and private organizations designed to measure, monitor, and improve the quality of cancer care delivery.

Methods: NCI-sponsored quality-of-care initiatives are reviewed in three areas: improving process and outcome measures, building strong data infrastructures to monitor the quality of cancer care, and developing practice-based quality-of-care research partnerships for privately sponsored and government-sponsored delivery programs.

Results: Research partnerships strengthen the overall portfolio of NCI-sponsored research into understanding and improving cancer care delivery. These partnerships have made significant contributions in standardizing metrics of clinical effectiveness and health-related quality of life, in developing monitoring systems to track disparities in cancer care and identify opportunities for improvement, and in understanding ways to intervene in cancer care delivery to improve adherence to evidence-based practice. These partnerships also contribute to the productivity of investigator-initiated quality-of-care studies and often provide leverage for rapid adoption of this science by organizations that participate in these projects.

Conclusions: Research partnerships in measurement, data infrastructure, and service delivery are an essential part of the NCI's research program to advance the science of quality of cancer care. Collectively, these projects inform participating organizations on gaps in quality and opportunities for improving cancer care delivery. They also foster the development of tools for changing care processes that can lead to better outcomes for cancer patients and survivors.

Introduction

In recent years, the quality of health care provided to the American public has become a concern of government, the public, and payers. Cancer care delivery is not immune from these concerns and has become the focus of the

Institute of Medicine's National Cancer Policy Board and several professional organizations and professional medical societies.^{1,2} Studies and reports have documented that some cancer patients are receiving too much treatment, others too little, and still others the wrong treatment.³⁻⁵ Even when recommended clinical treatment is provided, patient and caregiver support for the emotional, physical, and social burdens associated with cancer often is not optimal.⁶ Although existing research offers varying reasons for these conditions, most observers suggest there is much more to learn about why variations in treatment and outcomes exist, not only in terms of the underlying disparities in quality, but also in the mechanisms for stimulating and sustaining improvement.

Several strategic planning documents from the National Cancer Institute (NCI) have identified the im-

From the Outcomes Research Branch, Applied Research Program, Division of Cancer Control and Population Sciences at the National Cancer Institute, Bethesda, Maryland.

Submitted January 25, 2009; accepted May 11, 2009.

Address correspondence to Steven B. Clauser, PhD, Outcomes Research Branch, Applied Research Program, Division of Cancer Control and Population Sciences, National Cancer Institute, EPN 4086, Mail Stop 7344, 6301 Executive Boulevard, Bethesda, MD 20892. E-mail: clausers@mail.nih.gov

The opinions expressed in this article are those of the author and may not reflect the opinions of the National Cancer Institute.

provement of quality of cancer care as an NCI research priority. Drawing from several Institute of Medicine reports, the NCI defines quality of cancer care to mean “the provision of evidence-based, patient-centered services throughout the continuum of care in a timely and technically competent manner, with good communication, shared decision-making and cultural sensitivity, and with the aim of improving critical outcomes (including patient survival and health-related quality of life).”⁷

This multifaceted definition of quality of care requires a comprehensive research agenda that enhances our understanding of how to measure, monitor, and improve the quality of cancer care. Such an agenda also must investigate barriers impeding access to evidence-based therapy and work closely with public and private partners to translate evidence-based interventions into community practice.

Partnerships between research-based organizations and organizations that pay for, provide oversight of, or deliver services to cancer patients are important for advancing research in quality of care. Often, research findings are not implemented in practice and thus fail to improve the quality of health care received by US residents. Effective partnerships can accelerate the adoption of quality-of-care measurement systems by health care organizations,⁸ improve the translation, dissemination, and use of research findings for physicians, other clinicians, patients, consumers, policy makers,

and other decision makers to effect needed health care changes,⁹ enhance sustainability of high performance through research into oversight and/or incentive intervention systems that effectively reward organizations for adherence to evidence-based practice,¹⁰ create greater accountability for partnering organizations to work together to be successful, thereby extending the reach of limited research dollars for these projects, enhance the likelihood that evidence from the research will be used by partners to improve care, and improve the capacity of academic-based researchers to launch studies involving the implications of cancer care delivery quality of care initiatives on the cost, accessibility, and health-related quality of life (HRQOL) of individuals diagnosed with cancer.

This article provides an overview of the NCI’s research partnerships in quality of care. “Partnerships” refers to the specific, formal research collaborations with public and private organizations that pay for, regulate, and deliver cancer services or with agencies that jointly fund research targeted to these organizations. These partnerships take several forms and include many organizations; only a few are discussed in this article. Academic-based researchers and research organizations also are sometimes included in these partnerships, especially when they are working with other public- and private-sector organizations under research programs coordinated by the NCI. The partnerships described here do

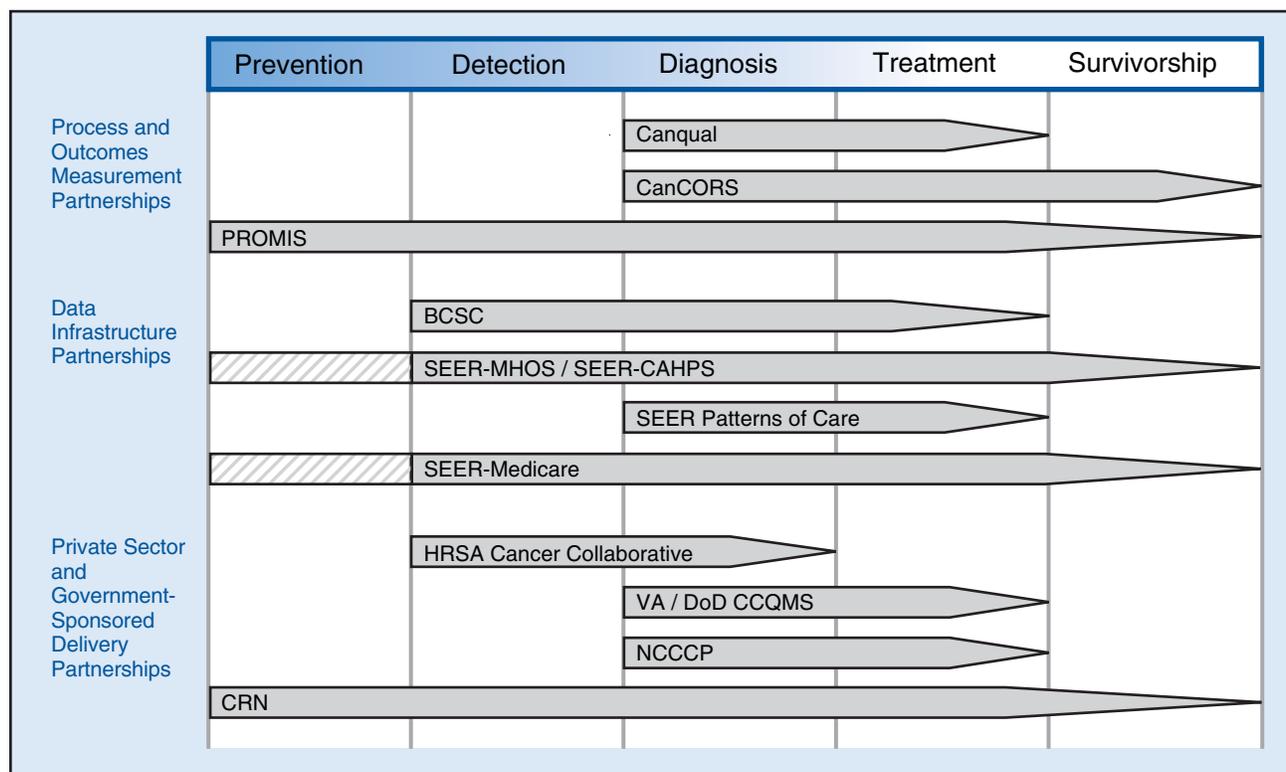


Figure. — The Cancer Control Continuum: NCI partnerships in quality-of-care research. PROMIS = Patient-Reported Outcomes Measurement Information System, BCSC = Breast Cancer Surveillance Consortium, CanCORS = Cancer Consortium for Outcomes Research and Surveillance, Canqual = Cancer Quality Measures Project, NCCCP = NCI Community Cancer Centers Program, SEER-MHOS = Surveillance, Epidemiology and End Results-Medicare Health Outcomes Survey, SEER-CAHPS = Surveillance, Epidemiology and End Results-Consumer Assessment of Healthcare Providers and Systems, HRSA = Health Resources and Services Administration, VA/DoD CCQMS = Department of Veterans Affairs/Department of Defense Colorectal Cancer Quality Monitoring System, CRN = Cancer Research Network.

not include academic investigator-initiated research supported through NCI grants. This research is essential for creating the science base that partnerships depend on for measuring, monitoring, and improving quality of care. The focus here is on recent NCI-sponsored research partnerships that are designed to improve the process and outcome measurements of quality of care in order to allow better comparisons of interventions and performance across plans, providers, and populations and, over time, build stronger data and methods infrastructure for conducting quality-of-care population surveillance and practice-based or systems-based research, and engage directly with practice-based research organizations to develop and test interventions to improve adherence with recommended practice.

The Figure displays the various partnerships described in this article by their contributions to each of these three areas across the cancer care continuum. As discussed in this article, collectively, these research partnerships support a wide array of measurement, surveillance, and intervention research that informs participating organizations on gaps in quality, opportunities for improvement, or tools for changing care processes that can lead to better outcomes.

Process and Outcome Measurement Partnerships

The cancer care delivery system is characterized by major variations and inequities regarding who has access to health care and who receives quality care once access is achieved. Despite these inequities, few standardized quality measures have been developed to evaluate and monitor the delivery of cancer care at either the system level or the provider level in the United States. Most available measures have been limited to cancer screening, such as rates of adherence to evidence-based screening procedures in the early detection of breast cancer, colorectal cancer, and cervical cancer. For example, the National Committee for Quality Assurance has for many years developed and deployed screening measures for breast, colorectal, and cervical cancer as part of its Health Employer Data Information System reporting system.¹¹ However, few measures of other dimensions of cancer care, including diagnosis, treatment, and symptom management, have sufficient evidence of validity and usability behind them for broad acceptance and use.¹²

Research partnerships in cancer care quality measurement serve multiple purposes. The following examples illustrate how they can facilitate the development and enhanced application of process and outcome measures.

Enhancing Quality Improvement and Accountability

The first purpose of partnerships is to serve as delivery sites for “quality improvement” studies, which involves developing evidence about how to best measure and evaluate care processes within a health care organization (eg, a cancer center, specialty office-based practice) to determine whether some standard of practice is achieved and maintained in that setting over time.

The US Department of Veterans Affairs (VA) Quality Enhancement Research Initiative uses organizational research to advance the implementation of evidence-based practice into routine care settings.¹³ This VA initiative has developed applications for several disease sites and has pursued research partnerships with the NCI in 2001–2004 on cancer screening.¹⁴

The second purpose of partnerships is to provide the research environment for “accountability” studies. These studies foster the ability to measure and test the impact of objective judgments regarding the comparative performance of health care providers or organizations on health care performance. The NCI has less experience with these types of studies. However, national measures of the Health Employer Data Information System are an example of where research organizations such as the Agency for Healthcare Research and Quality, accrediting organizations such as the National Committee for Quality Assurance, and health care payer organizations such as the Centers for Medicare and Medicaid Services (CMS) have partnered to create accountability performance measurements in health plans that are reported to the public. These measures enable Medicare beneficiaries to annually select Medicare Advantage health plans based on quality.¹⁵

Facilitating Prospective Tracking of Quality Through Multiple Data Sources

The NCI has included academic research organizations as part of quality-of-care research partnerships. One example involves a large-scale national-level study that deploys quality indicators to prospectively track patterns of care and outcomes for cohorts of newly diagnosed cancer patients. The Cancer Consortium for Outcomes Research and Surveillance (CanCORS) supports a prospective cohort study of 10,000 patients with newly diagnosed lung or colorectal cancers recruited in geographically diverse populations and health delivery systems to better understand the quality of cancer diagnosis and treatment services in community practice.¹⁶ CanCORS involves a group of academic research sites, an HMO-based research site, and the VA to collect data from several VA hospital-based research sites. CanCORS has developed or adopted measures of quality from multiple data sources (ie, medical records, administrative claims, patient and provider surveys) to track large cohorts of newly diagnosed cancer patients for long-term outcomes following well-documented treatments. These data sources also include assessments of patient-centered outcomes, such as HRQOL.

Participation by the VA in CanCORS has led to rapid testing of the CanCORS medical records abstraction tool as part of a multicenter pilot project to measure and improve the quality of care for veterans diagnosed with colorectal cancer.¹⁷ The NCI also has initiated a partnership with VA investigators to develop and test an ongoing survey strategy to include self-report data from cancer patients and caregivers on the burden of colorectal cancer associated with treatment in VA facilities as

part of this quality improvement effort. These items are expected to draw heavily from CanCORS surveys.

Improving Clinical Effectiveness Measurement

National studies have been instrumental in building the evidence base of what constitutes quality of care in community settings and in identifying the gaps in quality that need attention. However, they have not built an infrastructure of standardized, quality-of-care measures that have been widely adopted by cancer care delivery systems for quality reporting and improvement. To address this need, the NCI partnered with the Centers for Disease Control and Prevention (CDC), the CMS, and the Agency for Healthcare Research and Quality in 2004 in a new initiative. These four agencies contracted with the National Quality Forum (NQF) to create the Cancer Care Quality Measures Project, an effort to seek broad national voluntary consensus on a set of national performance measures, or NQF consensus standards, that could be used to assess the quality of cancer care in the United States and create a framework for reporting and updating these measures.¹⁸ The NQF project developed a set of measurement priorities for cancer care quality, and it conducted a review of existing measures in the areas of breast cancer diagnosis and treatment, colorectal cancer diagnosis and treatment, and symptom management and end-of-life treatment. It then endorsed a set of core measures in each of these areas for use in one or more of the following areas: provider accountability for quality, quality improvement, population-based surveillance, and research.

The breast and colorectal cancer measures endorsed by the NQF in 2006 have been incorporated into the accreditation program of the Commission on Cancer (CoC) for community cancer centers. These measures include semiannual reporting by these centers on quality-of-care indicators established by the CoC. Rapid implementation was facilitated by a research partnership between the NCI and the CoC in 2006 to develop and test reporting templates for hospital-based cancer registries to report these measures to the CoC and receive feedback from the Commission on their adherence with the measures. By 2008, 1,460 accredited CoC-approved community cancer centers were reporting on their adherence to these quality measures twice annually and working on projects to improve data completeness and performance.¹⁹ The research partnerships established between the NCI, other federal agencies, the NQF, and the CoC were essential for the rapid development, refinement, and dissemination of these measures in community cancer centers across the United States.

Improving the Understanding of HRQOL

The NCI has partnered with six NIH institutes to sponsor studies to assess and improve quality of care through patient-reported outcome measures. The Patient-Reported Outcomes Measurement Information System (PROMIS), an initiative funded by the NIH Roadmap,²⁰ was awarded in August 2004 to six academic-based research sites and a statistical coordinating center.²¹ The broad objec-

tives of the PROMIS are (1) to develop and test a large bank of items measuring patient-reported outcomes related to physical and emotional HRQOL, (2) to create a computerized adaptive testing (CAT) system that would allow for efficient, psychometrically robust assessment of patient-reported outcomes in clinical research and practice involving a wide range of chronic diseases (including cancer), and (3) to create a publicly available system that could be added to and modified periodically and that would allow clinical researchers and practitioners to access a common repository of patient-reported outcome items suitable for CAT system applications.

The NCI awarded a cancer-specific component to the PROMIS that includes the development of additional cancer-relevant patient-reported outcome domains (eg, illness impact, sexual function, sleep/wake function, perceived cognitive functions).²² The NIH research partnership has been useful in developing these cancer domains in a manner that will allow application in other disease domains as appropriate. Although the initial phases of PROMIS are focusing on measurement to support clinical trials, the investigators have developed a Web-access PROMIS assessment center that contains research tools for applying these items to a wide variety of research applications, including clinical practice improvement.²³ In 2008, the NIH approved a second round of applications for the PROMIS initiative, and these may include the deployment of items banks and CAT in clinical practice.²⁴ The PROMIS has great potential to support standardized quality-of-care outcome indicators in a quality improvement framework.

Fostering the Development of Patient-Centered Measurement

A key challenge for cancer care delivery systems is to improve the patient experience of cancer care. The Institute of Medicine recently noted the gaps in care for cancer patients needing psychosocial services and support, including a need for improved communication between health care providers and their cancer patients and survivors.^{6,25} The NCI has launched a patient-centered communication initiative to address these gaps in care. One of the first products of this effort was the 2007 monograph titled *Patient-Centered Communication in Cancer Care: Promoting Healing and Reducing Suffering*, which outlined six core functions of patient-clinician communication that are central to patient-centered cancer care.²⁶ These core functions are managing uncertainty, responding to emotions, exchanging information, enabling patient self-management, fostering healing relationships, and making decisions. The NCI is currently partnering with the Agency for Healthcare Research and Quality and its integrated delivery system research network to identify specific domains and subdomains that characterize each of the six functions of patient-centered communication and to identify candidate measures and data collection methods. The goal is to test their feasibility for data collection, reporting, and improvement in cancer programs.²⁷ The NCI hopes this

effort will stimulate research initiatives to place increased attention on developing the types of measures and interventions for cancer programs that can effectively address the emotional, physical, and social sequelae that patients experience with cancer treatment.

Data Infrastructure Partnerships

Another area of research activity in the NCI is the development of robust population-based data initiatives that employ indicators of quality to inform the nation on the quality of cancer care delivery. Cancer research benefits from the deployment of a strong cancer registry system that provides information on cancer incidence and mortality, as well as the use and costs of certain cancer therapies. Health care researchers and policy makers have expressed a growing desire to extend the ability of these surveillance systems to not only inform research on the cost, access, and quality of cancer services, but also measure other patient-reported outcomes of care, including HRQOL and patient experience with care. This section highlights some benefits of the partnerships that the NCI has created or is developing to extend the ability of cancer registries to support these interests.

Building a Consortium of Research Sites to Improve Breast Cancer Screening

The most longstanding of the NCI's data infrastructure projects is the Breast Cancer Surveillance Consortium (BCSC). Initiated in 1994, the BCSC is the foremost research resource dedicated to understanding the determinants of high-quality mammography in community practice in the United States.²⁸ The Consortium currently consists of a statistical coordinating center and five data collection and research sites working under NCI sponsorship. BCSC sites are academic-based researchers who are working with cancer registries and/or community radiology facilities to study the combined and individual effects of breast density, age, and hormone replacement therapy on the accuracy of screening mammography. They also are conducting screening accuracy audits with feedback to mammography facilities, monitoring improvements in existing technology, and tracking changes in the use of technology. BCSC investigators have published more than 290 papers examining factors associated with high-quality screening mammography in more than 2 million women, including 86,700 women with cancer.²⁹

Broadening the Ability to Assess Quality of Care

The NCI has improved the utility of cancer registry programs by partnering with the Surveillance, Epidemiology and End Results (SEER) Program registries and the CMS to link cancer registry databases to insurer data, including those from the Medicare and Medicaid programs. SEER-Medicare data include cases for the years each registry has been part of the SEER Program and include more than 2.4 million persons with cancer. The SEER-Medicare-linked database, identified by the Institute of Medicine as one of the few national resources

for examining the quality of care,¹ has enabled the assessment of cancer histology, treatment utilization, variation, and cost, resulting in more than 250 peer-reviewed SEER-Medicare publications in the past 10 years on the quality or cost of cancer care for Medicare beneficiaries.³⁰ Examples of the types of studies regarding quality of care supported by SEER-Medicare that are unavailable through SEER data alone include investigating patterns of care for persons with cancer before a cancer diagnosis and during long-term follow-up. Registry-based surveillance systems have greatly expanded our knowledge about the dissemination and diffusion of recommended therapies and gaps in care throughout the cancer care continuum, and these systems are especially useful for investigating the quality of care of vulnerable populations based on age, race, and the availability of insurance.

Research findings from studies sponsored through SEER-Medicare research partnerships have been used to develop educational and training opportunities to increase adherence to state-of-the-art cancer therapy in community practice. For example, Schrag et al³¹ used SEER-Medicare data to identify an expanded use of adjuvant chemotherapy for Medicare beneficiaries with stage II colon cancer despite uncertain evidence. These findings influenced clinical guideline development and updates for practicing oncologists.³²

Enhancing Dissemination Studies of Evidence-Based Therapies

In cancer especially, research and practice have benefited from highly developed cancer registries at state, regional, and national levels that measure and monitor cancer incidence, stage at presentation, initial treatment, survival, and mortality. For example, the NCI's Pattern of Care/Quality of Care studies enhance the NCI's SEER hospital-based registry with detailed data on cancer therapy from physicians' offices, thereby allowing researchers to investigate the adoption of recommended therapies for initial treatment for the most common cancers.³³ The NCI's patterns of care studies cover a 20-year period between 1987 and 2007 and address more than 20 cancer sites. These data provide important information on the receipt of cancer therapies not well documented in hospital records. These include, for example, data on hormonal therapy or chemotherapy. The NCI has used these data to develop educational and training opportunities that improve the use of state-of-the-art cancer therapy in community practice. In particular, patterns of care/quality of care research findings on the dissemination of cancer therapies into community practice have been examined and linked to the NIH Consensus Development Conference Statements and the NIH Clinical Alerts and Advisories.³⁴⁻³⁶ Approximately 25 articles have been published from these data, providing national population-based information on whether treatment dissemination into community practice adheres to consensus guidelines, possible determinants of dissemination, and variations in therapy.³⁷

Tracking HRQOL for Cancer Patients Enrolled in Managed Care

The NCI also has enhanced existing population-based outcomes research to focus on the HRQOL of cancer patients and survivors. Building on the success of the SEER and SEER-Medicare data sets described above, the NCI has partnered with the CMS to successfully link SEER to the Medicare Health Outcomes Survey (MHOS) as a means to better understand how health plans address the HRQOL of cancer patients and survivors in comparison to other plan enrollees.³⁸ The MHOS is an annual self-report survey of the physical and emotional status of a random sample of 1,000 enrollees in all Medicare-Advantage health plans. Respondents are resurveyed 2 years later if they are still enrolled in the same plan. The CMS uses the MHOS to monitor whether the HRQOL of Medicare beneficiaries enrolled in managed care is improving, staying the same, or declining. The MHOS collects a variety of data on demographics, comorbidities, and symptoms, but its primary strength for cancer outcomes research is the inclusion of the SF-36 Medical Outcomes Study form, a well-validated tool for measuring and comparing HRQOL across diseases.³⁹ Early research suggests that disparities exist in HRQOL across different races, ethnicities, and cancer diagnoses.⁴⁰ The NCI and the CMS have linked SEER and MHOS respondents from 1998 to 2001 and are currently working to expand the linked data set through 2006. Once completed, the data set will provide HRQOL data on more than 50,000 cancer patients and survivors and more than 250,000 individuals without cancer. Efforts are underway in 2009 to develop a public research resource similar to the NCI SEER-Medicare data resource so that external investigators can access these data for studies on the quality of life of Medicare managed care enrollees with a diagnosis of cancer.

Increasing the Understanding of Patient-Centered Care for Cancer Patients and Survivors

The NCI is working with the CMS to link SEER data to the Consumer Assessment of Health Providers and Systems Survey (CAHPS). The CAHPS survey is the preeminent public domain resource for measuring and reporting on the patient experience of care in health plans, hospitals, other health facilities, and physician groups.^{41,42} Medicare enrollees use CAHPS to compare and select health plans and hospitals.⁴³ Among the patient experience domains contained in CAHPS are access to care and doctor-patient communication, which are areas of particular importance to cancer patients and survivors.^{44,45} More than 500,000 individuals respond to CAHPS each year. Linking SEER data to the CAHPS will provide the first population-based assessment of patient experience in the Medicare program for cancer patients and survivors compared with Medicare beneficiaries never diagnosed with cancer. This data set, expected to become available in 2010, will greatly facilitate population-based cancer research and surveillance on how well the Medicare program achieves patient-centered care for cancer patients and survivors.

Private Sector and Government-Sponsored Delivery Partnerships

Improving the ability to measure and monitor the quality of care in cancer delivery settings is important because it helps identify gaps in quality and opportunities to improve community practice. Research partnerships in this arena facilitate the development of the data infrastructure as well as knowledge about how to deploy these measures in observational and clinical studies and in quality improvement projects. Measurement research partnerships are necessary, but they are not a sufficient condition for improved practice. Practice-based research partnerships with publicly and privately sponsored delivery systems also are required in order to apply research-based interventions in organizations to change patient care systems, provider behavior, and patient engagement in ways that support evidence-based practice once opportunities for improvement are discovered. This has been referred to in the literature as an important element of translational research, or getting from “the bench to the bedside.”⁴⁶ Failure to do this effectively has been identified as an important reason for the long lag time from research to practice.⁴⁷

The NCI has invested in research partnerships with private-sector delivery systems to link research and practice. The following examples illustrate the strengths of these partnerships.

Examining the Quality of Care Delivered by Community Health Plans

The Cancer Research Network, a consortium of 14 major not-for-profit integrated delivery systems, is providing a mechanism for NCI to use multiple perspectives to more rapidly examine the quality of care delivered by health care organizations.⁴⁸ This consortium has sponsored quality-of-care research across the cancer care continuum, including studies of methods for improving tobacco cessation programs (prevention), the impact of the lack of cancer screening and early detection on the incidence of breast and cervical cancers diagnosed at late stages (screening), breast cancer treatment effectiveness in older women (treatment), and clinical and pathologic predictors of recurrence after ductal carcinoma in situ (survivorship).^{49,50} The contributions of data from each member organization to a common data warehouse have enabled the Cancer Research Network to create large standardized data sets across multiple plans to support a variety of quality-of-care studies. This research platform has been especially important in explicating how race and ethnicity contribute to gaps in quality of cancer care.⁵¹

Extending Evidence-Based Practice to Community Cancer Centers

The NCI Community Cancer Centers Program (NCCCP) was created in 2007. This pilot program extends research and evidence-based practice beyond NCI-sponsored comprehensive cancer centers to the communities where cancer patients live.⁵² The NCCCP is composed of

10 geographically distributed non-profit community-based cancer centers. The 10 sites include two multihospital systems, one of which has three and the other five affiliated hospital cancer centers. Sixteen cancer centers are included in the pilot.

All NCCCP pilot sites are required to pursue improvement activities in the following six core program components: reducing health disparities, improving quality of care, enhancing survivorship programs, implementing biospecimen collection protocols, developing plans for integrated health information technology, and increasing clinical trial accrual. NCCCP projects regarding quality of care involve expanding multidisciplinary center cancer care, improving adherence to evidence-based practice, and implementing genetic testing programs. Pilot sites are encouraged to coordinate project activities and work with external research partners where appropriate. NCCCP projects include forming a quality improvement collaborative among the sites and with the American College of Surgeons/Commission on Cancer. The collaborative is working to improve the capacity of the sites to collect the NQF-endorsed breast cancer diagnosis and treatment and colorectal cancer clinical effectiveness measures described earlier. The goal will be to share performance data and best practices among the sites so that all sites improve their performance in collecting and reporting these data and engage in systems change where necessary to improve adherence to evidence-based care.

Developing a Working Model for Quality-of-Care Research Across Federal Agencies

The NCI also has engaged with government-sponsored service delivery programs. The following highlights unique aspects of this kind of initiative.

A final area of practice-based research includes NCI partnerships with government-sponsored delivery programs as part of the Quality of Cancer Care Committee (QCCC). The QCCC was established as part of the wider NCI Quality of Cancer Care Initiative launched in 1999 and is designed to focus on cancer as a working model for quality-of-care research and application across federal agencies.⁵³ The aim of the QCCC is to promote collaborative research to improve the state of the science for defining, monitoring, and improving the quality of cancer care in federally sponsored health care programs. Part of its mission is to promote research to ensure that the best evidence is used for decision-making in coverage and delivery of services and that research efforts address evolving questions in care delivery, benefit coverage, regulation, and standard setting.

In 2002, the NCI embarked on a QCCC collaboration with the CDC and the Health Resources and Services Administration (HRSA) to launch the Health Disparities Cancer Collaborative (HDCC). This project was part of a broader HRSA Disparities Collaborative initiative called the Breakthrough Series, which was implemented for several disease areas by the Institute for Healthcare Improvement, a nonprofit organization that works with

health care organizations to improve health care processes and results.⁵⁴ The Cancer Collaborative adapted elements from the chronic care model developed by Wagner et al⁵⁵ to improve the quality of breast, colorectal, and cervical cancer screening and follow-up. Twenty-three community health centers participated in the Cancer Collaborative from 2003 to 2005. The collaborative learning model involved three in-person sessions and the expectation that local teams would be organized at HRSA-sponsored community health centers to pursue the Plan/Do/Study/Act cycles that identify deficiencies in quality, implement quality improvement interventions, and measure the resulting change. Participating health centers reported and shared quality improvement experiences during three annual learning sessions and talked by teleconference monthly. The HDCC developed and tested an Internet-accessible package of information, software, and written materials to support planned cancer screening programs throughout HRSA's Bureau of Primary Health Care. At baseline in 2003, HDCC cancer screening rates were 58% for breast cancer, 69% for cervical cancer, and 20% for colorectal cancer. By 2005, the majority of participating centers had experienced improvement in screening rates, ranging from a low of 56% of centers for colorectal cancer to a high of 75% of centers for cervical cancer.⁵⁶ The HRSA has decided that improvements for the HDCC were sufficient to implement features of the program in HRSA/BPHC-supported health centers nationally in order to obtain similar cancer screening improvements elsewhere.

The NCI also has a QCCC research partnership with the VA to launch a Colorectal Cancer Quality Monitoring System (CCQMS). The purpose of this research project is to improve care based on a surveillance and reporting system from VA electronic medical records, which can identify and track VA patients with a confirmed diagnosis of colorectal cancer during the calendar years 2005 to 2007.⁵⁷ The CCQMS project was an outgrowth of the VA's participation in the CanCORS project described earlier. The CCQMS includes detailed data indicators of National Comprehensive Cancer Network (NCCN) treatment guidelines that enable VA facilities to evaluate the concordance of cancer treatments given to veterans diagnosed with colorectal cancer with established standards of quality of care for colorectal cancer care.⁵⁸ Quality-of-care indicators were developed that identify receipt of essential therapies (eg, adjuvant chemotherapy for stage III colorectal cancer patients) as well as critical time intervals for receipt of care (eg, time between diagnosis and treatment). Twenty-eight VA medical centers participated in the pilot study and in the development of the data collection and reporting tool. Facilities received ongoing reports about their center's concordance with NCCN guidelines. In addition, several of these centers participated in an Institute for Health Improvement quality improvement initiative to learn how to effectively intervene with these data to improve performance. The VA CCQMS project has collected data on approximately

1,400 colorectal cancer patients. The results of the pilot are still under review.⁵⁹

In 2008, the NCI and the VA enhanced the CCQMS pilot by adding an additional, and complementary, component to measure patient-reported outcomes focused on experiences with colorectal cancer care and HRQOL. The VA medical centers in Durham, North Carolina, and Minneapolis, Minnesota, are developing a patient survey to collect these data.⁶⁰ The project will test the feasibility of collecting and reporting data on a broader spectrum of quality than that already found in the CCQMS clinical effectiveness indicators. The domains under development include doctor-patient communication, coordination of care, and shared decision-making. In addition, logistical issues such as timely patient identification, survey administration, analysis, and reporting will be investigated to align the survey data with the clinical effectiveness data in the CCQMS. The goal is to create a more comprehensive data set for quality intervention and improvement.

The Value of NCI Partnerships on Quality-of-Care Research

The partnerships reviewed in this paper have provided important benefits and “spill-over” effects that demonstrate the leverage potential of these mechanisms to advance quality-of-care research. Linking academic researchers with population-based quality-of-care data partnerships improves the productivity of investigator-initiated researchers, as witnessed by the growing publication record of researchers using the BCSC and SEER-Medicare data resources. These partnerships also have altered care in the United States, as witnessed by the results of the HRSA Cancer Collaborative pilot that were eventually adopted nationwide by health centers sponsored by the agency. These partnerships also enable NCI-sponsored research to learn from and contribute to research activities in other disease areas. For example, the NCI has benefited from the NIH research partnership in PROMIS in developing cancer-specific item banks for HRQOL measures. In addition, the VA is adapting the CCQMS to quality-of-care research applications in stroke and muscular dystrophy (D. Provenzale, MD, oral communication, November 2008).

These partnerships also spawn new research initiatives unanticipated when the partnership started. For example, future plans are underway to adapt the CCQMS tool to the Department of Defense electronic medical record to support a pilot program among treatment facilities that serve active duty military and retirees and their dependents who are diagnosed with colorectal cancer.⁶¹ The Department of Defense also is interested in collecting data on HRQOL and patient experience as part of the pilot research program. If successful, this model will increase the ability to effectively target quality-of-care interventions by enabling the VA and the Department of Defense to work cooperatively within a common measurement framework that supports initiatives to improve patient-centered

care for colorectal cancer patients served within their respective health systems. Similarly, the NQF cancer measures project identified an important characteristic of current cancer registry systems that limits the utility of cancer-registry data to support routine quality-of-care measurement and surveillance monitoring — namely, the long lag time often associated with the collection and release of these data by registries to health care organizations and researchers. The NCI is currently partnering with the Commission on Cancer and NCCCP pilot sites in a test of a rapid quality reporting system that will enable close to real-time reporting of quality indicator data based on the NQF-approved breast and colorectal cancer clinical effectiveness measures.⁶² The rapid quality reporting system pilot will test whether active surveillance of breast cancer and colorectal cancer patients and reductions in the lag time in reporting quality indicators from a period of up to 2 years to a period of a few months or weeks accelerates the adherence of community cancer centers to recommended therapy as defined by these measures.

Conclusions

This overview summarizes how the NCI strategic partnerships are using research to inform and improve quality of cancer care delivery. This is a relatively new approach to research sponsorship, and the importance of many of these partnerships has yet to be determined as we await their impact on outcomes. Yet, we have learned some preliminary lessons. Academic-based, investigator-initiated research is essential for developing the measurement and interventional tools that help us understand why quality of care is a problem in cancer care delivery and the implications for outcomes that matter — survival, patient experience, and HRQOL. However, robust surveillance systems, dissemination research, and interventional research also are needed to put this evidence into practice to improve the quality of cancer care. These research programs often benefit from sound partnerships between research organizations and organizations that pay for, regulate, and deliver cancer care services. More work is needed to explore methods to more effectively incorporate academic researchers as part of these partnerships, given their potential to enhance research productivity and innovation and facilitate rapid dissemination of findings into practice.

The NCI's research priority in quality of care has benefited from a diverse array of these partnerships, both in the value they add to research studies of quality of care and in their contribution to understanding how evidence is translated into practice. However, more knowledge is needed concerning the mechanisms by which translation is both successful and sustained through these partnerships. Strategic partnerships with these organizations are therefore critical to achieving the NCI's research objectives in improving the quality of care. The NCI will continue to explore ways to create better synergy between investigator-initiated research and these strategic partnerships to assure that the incorporation of scientific evi-

dence on the quality of cancer care (once developed and validated) into practice can be accelerated.

Appreciation is expressed to Anne Rodgers for her editorial assistance through several versions of this manuscript.

References

1. Freedman HP. In: Reuben SH, ed. *President's Cancer Panel, Report of the Chairman, 2000-2001. Voices of a Broken System: Real People, Real Problems*. Bethesda, MD: National Cancer Institute, US National Institutes of Health; September 2001.
2. Hewitt M, Simone JV, eds. *Ensuring Quality Cancer Care*. Institute of Medicine and Commission on Life Sciences, National Research Council. Washington, DC: The National Academies Press; 1999.
3. McGlynn EA, Asch SM, Adams J, et al. The quality of health care delivered to adults in the United States. *N Engl J Med*. 2003;348(26):2635-2645.
4. Bloom BS, de Pouvourville N, Chhatre S, et al. Breast cancer treatment in clinical practice compared to best evidence and practice guidelines. *Br J Cancer*. 2004;90:26-30.
5. Baldwin LM, Dobie SA, Billingsley K, et al. Explaining black-white differences in receipt of recommended colon cancer treatment. *J Natl Cancer Inst*. 2005;97(16):1211-1220.
6. Adler NE, Page AEK, eds. *Cancer Care for the Whole Patient: Meeting Psycho-Social Health Needs*. Committee on Psychosocial Services to Cancer Patients/Families in a Community Setting, Board on Health Care Services, Institute of Medicine of the National Academies. Washington, DC: The National Academies Press; 2008.
7. *Plans and Priorities for Cancer Research: The Nation's Investment in Cancer Research: A Plan and Budget Proposal for Fiscal Year 2004*. Bethesda, MD: US Dept of Health and Human Services, National Cancer Institute, US National Institutes of Health. NIH Publication No: 03-4373; October 2002.
8. Fleming BB, Greenfield S, Engelgau MM, et al. The Diabetes Quality Improvement Project: moving science into health policy to gain an edge on the diabetes epidemic. *Diabetes Care*. 2001;24(10):1815-1820.
9. Stetler CB, Mittman BS, Francis J. Overview of the VA Quality Enhancement Research Initiative (QUERI) and QUERI theme articles: QUERI Series. *Implement Sci*. 2008;3:8.
10. Rosenthal MB, Fernandopulle R, Song HR, et al. Paying for quality: providers' incentives for quality improvement. *Health Aff (Millwood)*. 2004;23(2):127-141.
11. National Committee for Quality Assurance. *HEDIS 2009 Technical Specification for Physician Measurement*. Washington, DC: National Committee on Quality Assurance; 2009.
12. Clauser SB. Use of cancer performance measures in population health: a macro-level perspective. *J Natl Cancer Inst Monogr*. 2004;(33):142-154.
13. Yano EM. The role of organizational research in implementing evidence-based practice: QUERI Series. *Implement Sci*. 2008;3:29.
14. Hagedorn H, Hogan M, Smith JL, et al. Lessons learned about implementing research evidence into clinical practice: experiences from VA QUERI. *J Gen Intern Med*. 2006;21(suppl 2):S21-S24.
15. Lied TR, Sheingold S. HEDIS performance trends in Medicare managed care. *Health Care Financ Rev*. 2001;23(1):149-160.
16. Ayanian JZ, Chrischilles EA, Fletcher RH, et al. Understanding cancer treatment and outcomes: the Cancer Care Outcomes Research and Surveillance Consortium. *J Clin Oncol*. 2004; 22(15):2992-2996.
17. Provenzale D. Colorectal Cancer Care – A Quality Measurement Partnership. US Dept of Veterans Affairs, Health Services Research and Development. Project Update. June 18, 2006. http://www.hsrd.research.va.gov/research/abstracts.cfm?Project_ID=2141696559&UnderReview=no. Accessed June 18, 2009.
18. National Quality Forum. National Voluntary Consensus Standards for Quality of Cancer Care. Agency for Health Research and Quality Contract 290-01-002, Development of Standard Measures, Cancer Quality of Care Project. June 10, 2009. United States Department of Health & Human Services.
19. Commission on Cancer Multi-Disciplinary Program. The Electronic Quality Improvement Packets (eQUIP): What's It All About? Chicago, IL: American College of Surgeons. <http://www.facs.org/cancer/coc/equip.pdf>. Accessed May 13, 2009.
20. Zerhouni E. Medicine. The NIH Roadmap. *Science*. 2003;302(5642): 63-72.
21. US Dept of Health and Human Services, National Institutes of Health. Patient-Reported Outcomes Measurement Information System™ (PROMIS) Research Sites (U01). Request For Applications (RFA) Number: RFA-RM-08-023. Released September 26, 2008. <http://grants.nih.gov/grants/guide/rfa-files/RFA-RM-08-023.html>. Accessed May 13, 2009.
22. Cella D, Yount S, Rothrock N, et al. The Patient-Reported Outcomes Measurement Information System (PROMIS): progress of an NIH Roadmap cooperative group during its first two years. *Med Care*. 2007;45(5 suppl 1):S3-S11.
23. Garcia SF, Cella D, Clauser SB, et al. Standardizing patient-reported outcomes assessment in cancer clinical trials: a patient-reported outcomes measurement information system initiative. *J Clin Oncol*. 2007;25(32):5106-5112.
24. Patient-Reported Outcomes Measurement Information System Assessment Center. Bethesda, MD: National Institutes of Health. <http://www.nihpromis.org/Web%20Pages/Assessment%20Center.aspx>. Accessed May 13, 2009.
25. *Crossing the Quality Chasm: A New Health System for the 21st Century*. Committee on Quality of Health Care in America, Institute of Medicine of the National Academies. Washington, DC: The National Academies Press; 2001.
26. Epstein RM, Street RL Jr. *Patient-Centered Communication in Cancer Care: Promoting Healing and Reducing Suffering*. Bethesda, MD: National Cancer Institute, US National Institutes of Health. NIH Publication No. 07-6225; 2007. <http://outcomes.cancer.gov/areas/pcc/communication/monograph.html>. Accessed May 13, 2009.
27. Advancing Research Methodology for Measuring & Monitoring Patient-Centered Communication in Cancer Care. Bethesda, MD: NCI Outcomes Research Branch, National Cancer Institute, US National Institutes of Health. http://outcomes.cancer.gov/areas/pcc/communication/meas_monitor.html. Accessed May 13, 2009.
28. *Breast Cancer Surveillance Consortium: Evaluating Screening Performance in Practice*. NIH Publication No. 04-5490. Bethesda, MD: National Cancer Institute, National Institutes of Health, US Dept of Health and Human Services, April 2004. <http://breastscreening.cancer.gov/essp.pdf>. Accessed May 13, 2009.
29. National Cancer Institute. *Applied Research Program. Breast Cancer Surveillance Consortium: Fact Sheet*. September 2008. http://breastscreening.cancer.gov/about/bcsc_fact_sheet.pdf. Accessed May 13, 2009.
30. Warren JL, Klabunde CN, Schrag D, et al. Overview of the SEER-Medicare data: content, research applications, and generalizability to the United States elderly population. *Med Care*. 2002;40(8 suppl):3-18.
31. Schrag D, Rifas-Shiman S, Saltz L, et al. Adjuvant chemotherapy use for Medicare beneficiaries with stage II colon cancer. *J Clin Oncol*. 2002;20(19):3999-4005.
32. Lyman GH. ASCO clinical practice guidelines: past, present and future. *J Oncol Pract*. 2008;4(5):236-237.
33. Edwards BK, Brown ML, Wingo PA, et al. Annual report to the nation on the status of cancer, 1975-2002, featuring population-based trends in cancer treatment. *J Natl Cancer Inst*. 2005;97(19):1407-1427.
34. NIH Consensus Development Program. Bethesda, MD: US Dept of Health and Human Services, National Institutes of Health. <http://www.consensus.nih.gov/>. Accessed May 15, 2009.
35. NIH Clinical Alerts and Advisories. Bethesda, MD: United States National Library of Medicine. National Institutes of Health. http://www.nlm.nih.gov/databases/alerts/clinical_alerts.html. Accessed May 15, 2009.
36. Kunos C, Gibbons H, Simpkins F, et al. Chemotherapy administration during pelvic radiation for cervical cancer patients aged > 55 years in the SEER-Medicare population. *J Oncol*. 2008;2008:931532.
37. SEER Patterns of Care/Quality of Care Studies. Bethesda, MD: National Cancer Institute, US National Institutes of Health. <http://healthservices.cancer.gov/surveys/poc/>. Accessed May 14, 2009.
38. Clauser SB, Haffer SC. SEER-MHOS: a new federal collaboration on cancer outcomes research. *Health Care Financ Rev*. 2008;29(4):1-4.
39. Ware JE Jr. *SF-36 Physical and Mental Health Summary Scales: A Manual for Users of Version 1*. 2nd ed. Lincoln, RI: QualityMetric, Inc; 2001.
40. Clauser SB, Arora, NK, Bellizzi K, et al. Disparities in health-related quality of life of cancer survivors and non-cancer managed care enrollees. *Health Care Financ Rev*. 2008;29(4):23-40.
41. Jha AK, Orav EJ, Zheng J, et al. Patients' perception of hospital care in the United States. *N Engl J Med*. 2008;359(18):1921-1931.
42. Landon BE, Zaslavsky AM, Bernard SL, et al. Comparison of performance of traditional Medicare vs Medicare managed care. *JAMA*. 2004;291(14):1744-1752.
43. Landon BE, Zaslavsky AM, Beaulieu ND, et al. Health plan characteristics and consumers' assessments of quality. *Health Aff (Millwood)*. 2001;20(2):274-286.
44. Hack TF, Degner LF, Parker PA. The communication goals and needs of cancer patients: a review. *Psychooncology*. 2005;14(10):831-845; discussion 846-847.
45. Baile WF, Aaron J. Patient-physician communication in oncology: past, present, and future. *Curr Opin Oncol*. 2005;17(4):331-335.
46. Sung NS, Crowley WF Jr, Genel M, et al. Central challenges facing the national clinical research enterprise. *JAMA*. 2003;289(10):1278-1287.
47. Shojania KG, Grimshaw JM. Evidence-based quality improvement: the state of the science. *Health Aff (Millwood)*. 2005;24(1):138-150.
48. Cancer Research Network. Bethesda, MD: National Cancer Institute, US National Institutes of Health. <http://crn.cancer.gov/>. Accessed May 14, 2009.
49. Geiger AM, Buist DS, Greene SM, et al. Survivorship research based in integrated healthcare delivery systems: the Cancer Research Network. *Cancer*. 2008;112(11 suppl):2617-2626.
50. Wagner EH, Greene SM, Hart G, et al. Building a research consortium of large health systems: the Cancer Research Network. *J Natl Cancer Inst Monogr*. 2005;(35):3-11.
51. Johnson MR, Clauser SB, Beveridge JM, et al. Translating scientific advances into the community setting. *Oncology Issues*. 2009;24(3):24-28.
52. NCI Community Cancer Centers Program. Bethesda, MD: National Cancer Institute, US National Institutes of Health. <http://ncccp.cancer.gov/>.

Accessed May 14, 2009.

53. What is the Quality of Cancer Care Committee? Bethesda, MD: Outcomes Research Branch, National Cancer Institute, US National Institutes of Health. <http://outcomes.cancer.gov/networks/qccc/>. Accessed May 14, 2009.

54. Taplin SH, Haggstrom D, Jacobs T, et al. Implementing colorectal cancer screening in community health centers: addressing cancer health disparities through a regional cancer collaborative. *Med Care*. 2008;46(9 suppl 1):S74-S83.

55. Wagner EH, Austin BT, Davis C, et al. Improving chronic illness care: translating evidence into action. *Health Affairs (Millwood)*. 2001;20(6):64-78.

56. Knowledge Gateway: Cancer. Bethesda, MD: US Dept of Health and Human Services Health Services Resources Administration. <http://www.healthdisparities.net/hdc/html/collaboratives.topics.cancer.aspx>. Accessed May 14, 2009.

57. Provenzale D. Colorectal Cancer Care - A Quality Measurement Partnership. Durham, NC: US Dept of Veterans Affairs. Health Services Research and Development; June 18, 2006. http://www.hsrd.research.va.gov/research/abstracts.cfm?Project_ID=2141696559&UnderReview=no. Accessed May 14, 2009.

58. National Comprehensive Cancer Network. Welcome to the NCCN: clinical practice guidelines in oncology. <http://www.nccn.org>. Accessed May 14, 2009.

59. Chao HH, Schwartz AR, Hersh J, et al. Improving colorectal cancer screening and care in the Veterans Affairs Healthcare system. *Clin Colorectal Cancer*. 2009;8(1):22-28.

60. Quality Enhancement Research Initiative Fact Sheet: Colorectal Cancer. Minneapolis, MN: VA Office of Research and Development, Health Services Research and Development Service; June 2006. http://www.hsrd.research.va.gov/publications/internal/crc_factsheet.pdf. Accessed May 14, 2009.

61. American College of Surgeons Commission on Cancer. National Cancer Data Base: Quality Tools for Cancer. <http://www.facs.org/cancer/ncdb/qualitytools.html>. Accessed June 18, 2009.

62. Edge SB. New member orientation to the American College of Surgeons Commission on Cancer. <http://www.facs.org/cancer/coc/pdf/sc-cocinfo.pdf>. Accessed May 14, 2009.