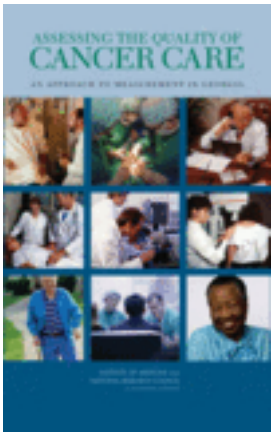

Assessing the Quality of Cancer Care: An Approach to Measurement in Georgia

Jill Eden and Joseph V. Simone, Editors, Committee on Assessing Improvements in Cancer Care in Georgia

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ASSESSING THE QUALITY OF CANCER CARE

AN APPROACH TO MEASUREMENT IN GEORGIA

Committee on Assessing Improvements in Cancer Care in Georgia
National Cancer Policy Board

Jill Eden and Joseph V. Simone, *Editors*

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Joseph V. Simone (*Chair*), President, Simone Consulting, Dunwoody, GA
Lawrence B. Afrin, Associate Professor of Medicine, Medical University of South Carolina, Charleston, SC
Tim Byers, Professor of Epidemiology, Program Leader, Clinical Cancer Prevention and Control, University of Colorado Health Sciences Center, Denver, CO
Vivien W. Chen, Director, Louisiana Tumor Registry, Head of Epidemiology Program, School of Public Health, Louisiana State University Health Sciences Center, New Orleans, LA
Peter D. Eisenberg, Oncologist, California Cancer Care, Greenbrae, CA
Barbara Given, University Distinguished Professor, College of Nursing, Michigan State University, East Lansing, MI
Robert Hiatt, Director, Population Science, Deputy Director, University of California San Francisco Comprehensive Cancer Center, San Francisco, CA
David Lansky, Director, Health Program, Markle Foundation, New York, NY
Benjamin Littenberg, Henry and Carleen Tufo Professor of Medicine and Director of General Internal Medicine, University of Vermont College of Medicine, Burlington, VT
Barbara J. McNeil, Ridley Watts Professor, Head of the Department of Health Care Policy, Harvard Medical School, Boston, MA
Mack Roach III, Professor, Department of Radiation Oncology, Medical Oncology and Urology, University of California San Francisco, San Francisco, CA

Consultant

Joseph Lipscomb, Chief, Outcomes Research Branch, National Cancer Institute, Bethesda, MD (until August 2004)

Staff

Jill Eden, Study Director
Roger C. Herdman, Director, National Cancer Policy Board
Elizabeth J. Brown, Research Assistant

Editor

Kerry B. Kemp

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Penelope Smith, Research Associate
Kathryn Barletta, Research Assistant
Elizabeth J. Brown, Research Assistant
Mary Ann Pryor, Senior Program Assistant
Anike L. Johnson, Administrative Assistant

Reviewers

This report has been reviewed in draft form by individuals chosen for their diverse perspectives and technical expertise, in accordance with procedures approved by the NRC's Report Review Committee. The purpose of this independent review is to provide candid and critical comments that will assist the institution in making its published report as sound as possible and to ensure that the report meets institutional standards for objectivity, evidence, and responsiveness to the study charge. The review comments and draft manuscript remain confidential to protect the integrity of the deliberative process. We wish to thank the following individuals for their review of this report:

Stephen B. Edge, Roswell Park Cancer Institute
Philip Huang, Texas Department of State Health Services
Elizabeth A. McGlynn, The RAND Corporation
Henry W. Riecken, University of Pennsylvania, Professor Emeritus
Barbara K. Rimer, Lineberger Comprehensive Cancer Center and School of Public Health, University of North Carolina at Chapel Hill
Nancy Weiss, Texas Cancer Registry
Rodger Winn, Clinical Consultant, National Quality Forum

Although the reviewers listed above have provided many constructive comments and suggestions, they were not asked to endorse the conclusions or recommendations nor did they see the final draft of the report before its release. The review of this report was overseen by **Harold C. Sox,** *Annals of*

Internal Medicine, American College of Physicians of Internal Medicine, and **Melvin Worth,** Scholar-in-Residence, Institute of Medicine. Appointed by the National Research Council and Institute of Medicine, they were responsible for making certain that an independent examination of this report was carried out in accordance with institutional procedures and that all review comments were carefully considered. Responsibility for the final content of this report rests entirely with the authoring committee and the institution.

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Ed Kelley
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Michael Thun
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Brown University
Joan Teno
Centers for Disease Control and Prevention
Lesley Given
Amy Harris
Nancy Lee
Fred Stallings
DeKalb Surgical Associates
John Kennedy
Emory University Health Sciences Center and Rollins School of Public Health
Otis Brawley
Jim Curran
Michael Johns

Jonathan Liff
Jack Mandel
Jonathan W. Simons
John L. Young

Georgia Cancer Coalition
Kate Canterbury
Maryalice Moses
Nancy Paris
Kathy Russell
Russell Toal
Bill Todd

Georgia Division of Public Health
Rana Bayakly
James Brannon
Dafna Kanny
Linda Martin
Christy McNamara
Kim Redding

Georgia Health Policy Center
Karen Minyard

Georgia Medical Care Foundation
Bill McClellan
Tom W. Williams

Georgia Society of Clinical Oncology
Tom Andrews
Charles Henderson
Frederick M. Schnell

Harvard School of Public Health
Heather Palmer

Institute for Clinical Systems Improvement
Gordon Mosser

Joint Commission on Accreditation of Healthcare Organizations
Elvira Ryan

Marin General Hospital
Lloyd Miyawaki

Miami University of Ohio
John Bailer

Morehouse School of Medicine
Daniel Blumenthal
Nigel Harris
George Rust
Louis Sullivan

National Cancer Institute
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Molla Donaldson
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Elaine Power
Northwest Crescent
Debbie Davis
Diane Stapleton
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Betty Castellani
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J. Ted Holloway
William Hoskins
Southwest Georgia Alliance
Angela Prince
Rita Salain
University of Southern California
David Quinn
University of Wisconsin
June Dahl
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Executive Summary

Shortly after 1998, leading members of Georgia's government, medical community, and public-spirited citizenry began considering ways in which some of Georgia's almost $5 billion, 25-year settlement from the tobacco industry's Master Settlement Agreement with the 50 states could be used to benefit Georgia residents. Given tobacco's role in causing cancer, they decided to create an entity and program with the mission of making Georgia a national leader in cancer prevention, treatment, and research (GCC, 2001, 2003). This new entity—called the Georgia Cancer Coalition, Inc. (GCC)—and the state of Georgia subsequently began implementing a far-reaching state cancer initiative that includes five strategic goals: (1) preventing cancer and detecting existing cancers earlier; (2) improving access to quality care for all state residents with cancer; (3) saving more lives in the future; (4) training future cancer researchers and caregivers; and (5) turning the eradication of cancer into economic growth for Georgia (GCC, 2001).

In conjunction with this effort, GCC contracted with the Institute of Medicine (IOM) to identify a set of measures that could be used to gauge Georgia's progress in improving the quality of its cancer services and in reducing cancer-related morbidity and mortality (Toal, 2003). The measure set should be pertinent to the mission and goals of GCC, in a form that is reasonable to implement, and drawn from established clinical guidelines or quality measures already in use. The current availability of the data necessary to develop the measures was not a principal concern because GCC intended to invest simultaneously in creating a state-of-the-art information infrastructure.

The IOM Committee on Assessing Improvements in Cancer Care in Georgia was established in the fall of 2003. Its assigned mission was to develop a set of quality-of-cancer-care measures that could be used by states—Georgia in particular—to assess progress in improving cancer-related services and in reducing cancer morbidity and mortality; to address economic, geographic, racial, and ethnic disparities in cancer care; to inform the governor, state legislature, and executive branch of GCC's progress; to contribute to quality improvement initiatives and health education; and to educate the state's health care community and the general public about cancer.

As described below, the committee first developed a conceptual framework for its review of potential quality measures for Georgia's cancer initiative. After deliberating and considering scientific and other evidence, the committee decided to recommend 52 quality-of-cancer-care measures spanning the domains of cancer prevention, early detection, diagnosis, and treatment services. In addition, the committee recommended that Georgia take steps to capture cancer patients' experiences as indicators of quality, as well as to understand and seek to reduce economic, geographic, and racial or ethnic disparities in the cancer burden and quality of cancer care. The committee believes that evaluating patients' experiences will be as critical to assessing the quality of cancer care as deploying the 52 recommended quality indicators. It also believes that cancer outcomes will not meaningfully improve for Georgia unless disparities in the quality of cancer care are remedied.

APPROACH TO THE STUDY: KEY CONCEPTS AND METHODS

The IOM committee began by establishing some basic definitions and concepts, including what constituted good quality health care, how to define quality measures, and what principles and criteria the committee should use to select quality measures for cancer care. The committee decided to recommend a rather slim set of quality-of-cancer-care measures, noting that in the future, as Georgia's quality monitoring system matures, GCC can expand the scope and types of measures it employs.

To define good quality health care, the committee built on the classic work on quality of care of Avedis Donabedian and others (Donabedian, 1980; IOM, 1998, 1999a, 2000a,b, 2001a,b; Asch et al., 2000; McGlynn, 2002, 2003a,b; McGlynn and Malin, 2002; McGlynn et al., 2003). Accordingly, it defined *good quality health care* as patient-centered care that makes desired health outcomes more likely and more consistent with current professional knowledge (IOM, 1990, 2001a). In other words, good quality care means "doing the right thing, at the right time, in the right way, for the right person—and having the best possible results" (AHRQ, 2001). The

committee also agreed that there are three types of quality problems in health care—underuse, overuse, and misuse (IOM, 1998). Because patient-centeredness is fundamental to high-quality health care (IOM, 2001a), the committee also took the view that measuring patients' perspectives, experiences, and preferences regarding the structure, process, and outcomes of cancer care is fundamental to measuring quality.

Using the excellent work of Donabedian and the IOM Roundtable on Health Care Quality as background, the committee devised a scoring evaluation and an informative staff-prepared one-page description for the review of potential quality measures as noted below. The committee limited its review to measures that might be used to track progress in controlling four types of cancer that together account for more than half of the cancer cases and deaths in Georgia—namely, breast, colorectal, prostate, and lung cancers. Because earlier IOM reports (IOM, 1999a) have pointed to a "wide gulf" between what is known about cancer care and what is actually experienced by many Americans, the committee further narrowed its review to focus on clinical indicators of quality, that is, measures useful in assessing the quality of preventive, diagnostic, and therapeutic patient care, rather than potential community-based, public health measures.

In deciding which quality-of-cancer-care measures should emerge from the evaluation process, the committee was guided by the principles and selection criteria of the National Quality Forum's Strategic Framework Board, which were reflected in the scoring evaluation (McGlynn, 2002). Each measure should relate directly to one of the first two strategic goals of GCC, either preventing cancer and detecting existing cancers earlier, or improving access to quality care for all Georgians with cancer. Each measure should have a clear and compelling rationale and should avoid imposing an undue burden on those providing data (with the understanding that critical improvements to Georgia's cancer information infrastructure may be necessary). Each measure should be actionable so that Georgia providers and other stakeholders can use it for making decisions or taking steps to improve the state's cancer care, and each measure should help GCC lead the improvement of cancer care in Georgia. Additional criteria the committee used as ideals to guide its decisions about whether to accept or reject specific quality-of-cancer-care measures were each measure's importance, scientific acceptability, and feasibility/utility (NQF, 2003). Finally, the committee weighed the strength of the evidence for each measure, using the hierarchy of evidence developed by the U.S. Preventive Services Task Force—with randomized clinical trials (Grade I evidence) at the top, followed by well-designed, controlled trials without randomization, cohort, or case control studies (Grade II evidence), and expert opinion, descriptive studies, and case reports (Grade III evidence).

RECOMMENDED MEASURES FOR ASSESSING THE QUALITY OF CANCER CARE IN GEORGIA

The 52 quality-of-cancer-care measures recommended for Georgia by the committee are discussed below. The state should regularly revisit the measure set to consider potential new measures, make adjustments to existing measures, and retire measures if they prove to be ineffective or no longer relevant. As can be seen in Table ES-1, the recommended measures are organized in terms of their relationship to specific elements of the cancer control continuum:

- **Measures related to preventing cancer.** The objective of cancer prevention is to avoid the development of cancer (e.g., via the use of interventions that eliminate or reduce exposures to the causes of cancer, including tobacco, environmental carcinogens, and lifestyle factors). Ten of the recommended quality measures pertain to cancer prevention.
- **Measures related to detecting cancer early.** The objective of early detection is to allow the cancer to be treated at a localized stage when prospects for success are greatest (e.g., via the use of screening tests to identify premalignant disease or cancer in persons without signs or symptoms of cancer). In the case of colorectal cancer, colonoscopy screening can also prevent the development of cancer. Five of the recommended quality-of-cancer-care measures pertain to early detection.
- **Measures related to diagnosing cancer.** The objective of cancer diagnosis is to confirm the presence or absence of cancer and to ascertain the stage of disease. Fourteen of the measures recommended for Georgia are related to cancer diagnosis.
- **Measures related to treating cancer.** The objective of cancer treatment is to cure cancer or improve the patient's quality of life through the provision and coordination of the basic treatment modalities—i.e., surgery, chemotherapy and/or hormonal therapy, and radiation—as well as psychosocial support, rehabilitation, and symptom management and palliative care. Twenty-three of the recommended quality measures pertain to cancer treatment.

Quality Measures Related to Preventing Cancer (Ch. 3)

For most cancers, including lung cancer, the search for effective primary treatments continues, and the most effective means of control is prevention (Alberg and Samet, 2003). The committee recommends that Georgia adopt 10 quality measures related to cancer prevention: two measures of smoking rates, two measures of the delivery of smoking cessation interventions, one measure of obesity trends, and five measures of cancer incidence rates.

TABLE ES-1 Recommended Quality Measures for Tracking Georgia's Progress in Cancer Control[a]

Measures Related to Preventing Cancer (Ch. 3)
- **Smoking rates and interventions**
  - 3-1. Adult smoking rate
  - 3-2. Adolescent smoking rate
  - 3-3. Smokers who receive advice to quit
  - 3-4. Smokers who are recommended pharmacotherapy to assist in quitting smoking
- **Trend in obesity**
  - 3-5. Adult obesity rate
- **Cancer incidence rates**
  - 3-6. Cancer incidence rate (all sites)
  - 3-7. Breast cancer incidence rate
  - 3-8. Colorectal cancer incidence rate
  - 3-9. Lung cancer incidence rate
  - 3-10. Prostate cancer incidence rate

Measures Related to Detecting Cancer Early (Ch. 4)
- **Use of cancer screening interventions**
  - 4-1. Breast cancer screening rate
  - 4-2. Colorectal cancer screening rate
- **Cancer stage at diagnosis**
  - 4-3. Early-stage breast cancer diagnosis
  - 4-4. Advanced-stage breast cancer diagnosis
  - 4-5. Advanced-stage colorectal cancer diagnosis

Measures Related to Diagnosing Cancer (Ch. 5)
- **Adequacy of diagnostic and surgical specimens**
  - 5-1. Timely breast cancer biopsy
  - 5-2. Use of needle biopsy in breast cancer diagnosis
  - 5-3. Tumor-free surgical margins in breast-conserving surgery
  - 5-4. Appropriate histological assessment of breast cancer
  - 5-5. Appropriate histological assessment of colorectal cancer
- **Adequacy of pathology reports on surgical specimens**
  - 5-6. Pathology laboratories' compliance with reporting standards for cancer surgical specimens
  - 5-7. Adequacy of pathology reports on breast cancer surgical specimens
  - 5-8. Adequacy of pathology reports on colorectal cancer surgical specimens
  - 5-9. Adequacy of pathology reports on lung cancer surgical specimens
  - 5-10. Adequacy of pathology reports on prostate cancer surgical specimens
- **Documentation of cancer pathologic stage before chemotherapy or radiation treatment begins**
  - 5-11. Breast cancer stage determined before treatment
  - 5-12. Colorectal cancer stage determined before treatment
  - 5-13. Lung cancer stage determined before treatment
  - 5-14. Prostate cancer stage determined before treatment

continues

TABLE ES-1 Continued

Measures Related to Treating Cancer (Ch. 6)

Receipt of appropriate primary therapy for cancer

6-1. Cancer patients' participation in clinical trials
6-2. Inappropriate hormonal therapy before radical prostatectomy
6-3. Appropriate external beam radiation therapy (EBRT) doses for prostate cancer
6-4. Appropriate hormonal therapy with EBRT for prostate cancer

Receipt of appropriate adjuvant therapy for cancer

6-5. Adjuvant radiation after breast-conserving surgery
6-6. Adjuvant hormonal therapy for invasive breast cancer
6-7. Adjuvant combination chemotherapy for breast cancer
6-8. Adjuvant chemotherapy after colon cancer surgery

Receipt of appropriate follow-up after treatment for cancer

6-9. Follow-up mammography after treatment for breast cancer
6-10. Follow-up colonoscopy after treatment for colorectal cancer

Minimization of cancer patients' suffering

6-11. Cancer pain assessment
6-12. Prevalence of pain among cancer patients
6-13. Cancer deaths in hospice
6-14. Cancer patients' hospice length of stay

Cancer survival and mortality rates

6-15. Breast cancer 5- and 10-year survival rates
6-16. Colorectal cancer 5- and 10-year survival rates
6-17. Lung cancer 5- and 10-year survival rates
6-18. Prostate cancer 5- and 10-year survival rates
6-19. Breast cancer mortality rate
6-20. Colorectal cancer mortality rate
6-21. Lung cancer mortality rate
6-22. Prostate cancer mortality rate
6-23. All cancers mortality rate

[a]NOTE: The IOM committee's recommended quality-of-cancer-care measures for Georgia pertain primarily to the control of four major cancers: breast, colorectal, lung, and prostate cancer. The full report includes detailed one-page summaries of each recommended quality measure with descriptions of (1) the recommended quality measure; (2) the originator or source of the quality measure; (3) the consensus on care (a brief explanation of the evidence underlying the measure); (4) knowledge vs. practice (a description of what is known about the gap between the evidence and current practice); (5) the approach to calculating the recommended measure, including the numerator, denominator, population for whom the measure should be constructed, and comments (if appropriate); (6) potential sources of data and performance benchmarks, including data limitations (if any); and (7) key references for the evidence and information about current practice.

Smoking rates and interventions. Cigarette smoking accounts for at least 30 percent of cancer-related deaths and a staggering 87 percent of lung cancer deaths in Georgia (ACS, 2004). Thus, the application of evidence-based, effective means to discourage individuals from taking up smoking and to help current smokers quit smoking could help prevent a substantial portion of cancer cases (IOM, 2003a).

The first two recommended measures related to cancer prevention are smoking rates among adults and smoking rates among adolescents in high school. Because many of the health risks associated with smoking are reduced after quitting (U.S. DHHS, 1989), two additional quality measures recommended by the committee pertain to the delivery of recommended smoking cessation interventions. One is the percentage of smokers aged 18 and older advised by a health professional to quit smoking in the past year. The other recommended measure is the percentage of adult smokers whose health professional recommended or discussed medication to help them quit smoking in the past year.

Trend in obesity. The fifth quality measure related to cancer prevention is the adult obesity rate. Obesity, defined as a body mass index of 30 or more,[1] is a major risk factor for breast, colorectal, and other types of cancer (Vainio and Bianchini, 2002; Key et al., 2004). One way to help prevent such cancers, therefore, is by reducing obesity (Friedenreich, 2001).

Cancer incidence rates.[2] Cancer incidence rates are the ultimate indicators of success in preventing cancer. With sustained and effective cancer prevention efforts, Georgia should eventually experience declining cancer incidence rates. For that reason, the committee recommends that the state track five measures of cancer incidence: the incidence of all cancers combined (all sites) and the incidence of breast, colorectal, lung, and prostate cancer, respectively.

Quality Measures Related to Detecting Cancer Early (Ch. 4)

Five quality-of-cancer-care measures are recommended by the committee in the realm of early detection: two measures that track the use of cancer screening interventions and three that track the stage at which cancer is diagnosed.

Use of cancer screening interventions. The first recommended measure related to early detection is the proportion of women aged 52 to 69 with

[1]Obesity is commonly defined using a formula based on weight and height known as the body mass index (BMI). Persons with a BMI of 30 or higher are considered obese. BMI is calculated as weight (in pounds) divided by height (in inches squared) multiplied by 703.

[2]Cancer incidence rates are usually expressed as the number of new cancers per year per 100,000 population at risk.

one or more mammograms in the past 2 years. Numerous randomized clinical trials have yielded strong evidence that routine mammography screening reduces the risk of death from breast cancer by as much as 35 percent (USPSTF, 2002a; Fletcher and Elmore, 2003; NCI, 2004). The evidence supporting regular mammography is strongest for women aged 50 to 69 (USPSTF, 2002a). Although monitoring should begin at age 50, the measure starts at age 52 because it will be applied retrospectively and should allow for the full 2 years to receive recommended screening.

The second recommended measure is the proportion of adults aged 52 to 80 who have been screened for colorectal cancer (i.e., received either a fecal occult blood test within the past year, flexible sigmoidoscopy within the past 5 years, colonoscopy within the past 10 years, or double-contrast barium enema within the past 5 years). The United States Prevention Services Task Force (USPSTF) and most other guidelines recommend that starting at age 50, all people should be periodically screened for colorectal cancer using one of the available options (USPSTF, 2002b; Winawer et al., 2003; IOM, 2003a).

Cancer stage at diagnosis. Two of the recommended quality measures related to early detection track breast cancer stage at diagnosis. One is the proportion of new breast cancer cases in Georgia diagnosed at a treatable early stage (in situ or localized), and the other is the incidence of advanced-stage breast cancer (regional or distant stage) among females aged 40 and older. If Georgia significantly increases routine mammography screening, women diagnosed with breast cancer will be more likely to be diagnosed with treatable, early-stage disease (USPSTF, 2002a; IOM, 2003a), and the incidence of advanced-stage breast cancer in the state will decline.

The last measure related to early detection is the incidence of advanced-stage colorectal cancer. If Georgia improves the rate of routine colorectal cancer screening, the incidence of advanced-stage colorectal cancer will decline (USPSTF, 2002b; IOM, 2003a).

Quality Measures Related to Diagnosing Cancer (Ch. 5)

Fourteen quality measures recommended by the committee are related to diagnosing cancer: five measures of the adequacy of diagnostic and surgical specimens; five of the adequacy of pathology reports on surgical specimens; and four of the staging of patients' cancers prior to chemotherapy or radiation treatment.

Adequacy of diagnostic and surgical specimens. The first of the five recommended quality measures pertaining to the adequacy of diagnostic and surgical specimens is the proportion of women who receive a biopsy within 14 days of the first documentation of a category 4 or 5 abnormal mammogram. The National Comprehensive Cancer Network recommends a

follow-up biopsy of suspicious or highly suggestive abnormal mammograms (NCCN, 2004c). The IOM committee believes strongly that, under such circumstances, women should not have to wait longer than 14 days for a biopsy of the mammogram abnormality.

The second recommended quality measure is the proportion of women who have a needle biopsy of the breast at least 1 day before breast cancer surgery. Needle biopsy is preferred to alternative diagnostic approaches because it is quick, accurate, and less invasive and also yields a better cosmetic outcome (Liberman, 2000; Collins et al., 2004; Baxter et al., 2004; NCCN, 2004c).

The third recommended quality measure is the proportion of breast cancer surgery patients whose surgical margins are free of tumor after the last surgery. The goal of breast cancer surgery is to completely remove the tumor and to obtain clear surgical margins. There is extensive evidence that surgical margins that are not clear are associated with higher rates of breast cancer recurrence (Silverstein et al., 1999; Fredriksson et al., 2003; NCCN, 2004b).

The final two measures related to the adequacy of diagnostic and surgical specimens track the adequacy of histological assessment of lymph nodes for patients who undergo surgery for cancer: first, the proportion of Stage I and Stage II breast cancer cases with sentinel node biopsy or histological assessment of 10 or more axillary lymph nodes; and second, the proportion of colorectal cancer surgery patients with documented histological assessment of 12 or more lymph nodes. There is extensive literature showing that survival of colorectal cancer increases with the number of *recovered* lymph nodes, regardless of how many nodes are positive (Stocchi et al., 2001; Le Voyer et al., 2003; Compton, 2003).

Adequacy of pathology reports on surgical specimens. Pathologists' findings are critical to proper cancer staging, treatment decisions, and the evaluation of a patient's prognosis. Thus, five of the recommended quality measures related to cancer diagnosis pertain to the adequacy of pathology reports on surgical specimens from patients with breast, colorectal, lung, or prostate cancer. One measure is the proportion of pathology laboratories that report College of American Pathologists (CAP) data elements as required by the American College of Surgeons' Commission on Cancer. Pathology reports on cancer specimens examined in Commission on Cancer-certified laboratories must contain the scientifically validated elements from reporting checklists developed by CAP (Commission on Cancer, 2003; Gal et al., 2004; Srigley et al., 2004; Compton, 2004; Fitzgibbons et al., 2004). The four other measures are the proportion of pathology reports on surgical specimens from patients with the four major types of cancer—breast, colorectal, lung, and prostate cancer—that include the CAP data elements required by the Commission on Cancer.

Documentation of cancer pathologic stage before chemotherapy or

radiation treatment begins. Chemotherapy and radiation treatment of most cancers should not be initiated until the pathologic stage of the cancer has been determined and documented in the medical record. Documenting the stage of cancer is essential to the provision of good quality cancer care (Compton, 2003). Thus, four of the quality-of-cancer-care measures recommended by the committee for Georgia pertain to the documentation of cancer stage. The measures are the proportion of breast, colorectal, lung, and prostate cancer cases, respectively, with medical chart documentation of pathologic tumor stage before chemotherapy or radiation is initiated.

Quality Measures Related to Treating Cancer (Ch. 6)

If Georgia is to significantly improve cancer outcomes for its residents, it must aim for the delivery of evidence-based cancer treatment statewide. As shown in Table ES-1, the committee recommends that Georgia adopt 23 quality measures to gauge the state's progress in improving cancer treatment. Four of these measures pertain to the receipt of appropriate primary therapy for cancer; four to appropriate adjuvant therapy for cancer; two to appropriate follow-up care for cancer; four to the minimization of cancer patients' suffering; and nine to cancer survival and mortality rates.

Receipt of appropriate primary therapy. One of the recommended measures related to primary therapy for cancer is the proportion of cancer patients in treatment in Georgia who participate in clinical trials. National Cancer Comprehensive Network guidelines strongly encourage cancer patients to participate in clinical trials (NCCN, 2004a). Furthermore, expanding participation in cancer clinical trials is a principal, strategic goal of GCC (GCC, 2003).

The other three recommended quality measures related to primary therapy for cancer track whether prostate cancer patients receive evidence-based care. Although evidence on the comparative efficacy of the alternative treatments for prostate cancer is scarce (Potosky et al., 2000), evidence supporting the optimal delivery of recommended treatments is well established. The committee selected the three recommended quality measures related to therapy for prostate cancer taking that evidence into account.

Receipt of appropriate adjuvant therapy. Noting that adjuvant therapies that are critical to the survival of breast and colorectal cancer patients are frequently underused, the committee recommends that Georgia adopt four quality indicators to monitor cancer patients' receipt of appropriate adjuvant therapy (Du et al., 1999; Nattinger et al., 2000; Gilligan et al., 2002; Hahn et al., 2003). The available data on the benefit of adjuvant therapy for lung and prostate cancer are too limited or inconclusive to support recommending measures in these areas.

The first three recommended quality measures pertain to adjuvant

therapy for breast cancer. One measure is the proportion of selected women who receive adjuvant radiation within 8 weeks of breast-conserving surgery for invasive breast cancer. An established, high-level evidence base shows that adjuvant radiation after breast-conserving surgery markedly reduces the risk of recurrence in the same breast compared with surgery alone (Early Breast Cancer Trialists' Collaborative Group, 2000).

The second recommended quality measure is the proportion of selected women who receive adjuvant hormonal therapy for invasive breast cancer. Considerable evidence shows that adjuvant hormonal therapy—tamoxifen in particular—reduces the risk of tumor recurrence and significantly improves survival for women with early-stage hormone receptor positive breast cancer (Early Breast Cancer Trialists' Collaborative Group, 1998; Adjuvant therapy, 2000; Baum et al., 2002; Winer et al., 2002; Goldhirsch et al., 2003).

The third recommended measure is the proportion of selected breast cancer patients who receive adjuvant combination chemotherapy. An extensive body of research based on randomized trials shows that combination chemotherapy substantially increases relapse-free survival and survival overall for women under age 71 with operable breast cancer (Adjuvant therapy, 2000; Cole et al., 2001). There are insufficient data to either support or discourage adjuvant chemotherapy for women over age 70.

The fourth recommended quality measure related to adjuvant therapy is the proportion of selected colon cancer patients who receive adjuvant chemotherapy after surgery. Numerous randomized trials have shown that adjuvant chemotherapy substantially increases disease-free and overall survival of patients with Stage III colon cancer (Moertel et al., 1995; IMPACT Investigators, 1995; Wolmark et al., 1999; Potosky et al., 2002).

Receipt of appropriate follow-up care. The committee recommends that Georgia adopt two quality indicators to monitor appropriate follow-up of individuals treated for cancer. The first recommended measure is the proportion of women with breast cancer who receive a follow-up mammogram by 19 months after their diagnosis. The measure focuses on the 19 months after a breast cancer diagnosis to allow for a 12-month follow-up period after a 7-month therapeutic period. The second recommended measure is the proportion of patients treated for Stage I to Stage III colorectal cancer who receive a follow-up colonoscopy within a year of their surgery. Insufficient evidence or consensus exists to support recommendations for measures of follow-up after treatment for lung or prostate cancer.

Minimization of suffering. The committee recommends that Georgia use four quality indicators related to the minimization of cancer patients' suffering. One measure is the proportion of cancer patients with documented pain assessment. Severe pain is often characteristic of cancer patients' experience during the course of treatment and afterwards, as well as in the later

stages of terminal disease (Goudas et al., 2001; Allard et al., 2001; IOM, 2003b). Several studies indicate that the most important predictor of inadequate pain relief is a discrepancy between the patient's and the physician's assessment of the severity of pain (Jacox et al., 1994; Reifel, 2000). Consequently, numerous clinical guidelines advise that patients be directly queried regarding their level of pain (Jacox et al., 1994; WHO, 1996; ONS, 2002; National Consensus Project for Quality Palliative Care, 2004; JCAHO, 2004; NCCN, 2004d). The second recommended measure is the prevalence of pain among cancer patients. Although there are no definitive estimates of the prevalence of pain among cancer patients, a measure of prevalence across varied care settings and in different subgroups should provide information about the adequacy of pain management (Symptom management, 2002).

In addition, the committee recommends that Georgia use two measures to monitor the use of hospice services at the end of life. Hospice is a home-based or inpatient program of palliative and supportive care services that provides physical, psychological, social, and spiritual care—and it is the gold standard of care for dying persons, their families, and other loved ones (ASCO, 1998; NCCN, 2004e). One of the recommended quality measures, therefore, is the incidence of cancer deaths in hospice. Most patients are referred to hospice too late to fully benefit from hospice care, and some dying cancer patients are not referred at all (MedPAC, 2002; NCCN, 2004e). The other recommended measure is the proportion of cancer patients who have a hospice length of stay of at least 7 days. The median length of hospice stay for adult cancer patients was 15.4 days in 2000, but a substantial proportion of cancer patients receive hospice care just days before death (AHRQ, 2003).

Cancer survival[3] and mortality rates.[4] If Georgia succeeds in narrowing the gap between what is known about effective cancer treatment and what is practiced in health care settings, the state will eventually see improved cancer survival rates and reduced cancer mortality rates. For that reason, the committee recommends that Georgia track 5- and 10-year relative cancer survival rates for each of the state's four most common cancers: breast, colorectal, lung, and prostate cancer. The committee also recommends that Georgia track mortality rates caused by each of these four cancers, along with the mortality rate for all types of cancer.

[3]Cancer survival rates may be measured in terms of either (1) *observed survival rates* (which measure the actual percentage of cancer patients still alive at some specified time after diagnosis, including deaths from cancer and all other causes), or (2) *relative survival rates* (which adjust observed rates to account for death due to causes other than cancer).

[4]Cancer mortality rates are measured by the number of people who die of cancer within a year, expressed in terms of number of deaths per 100,000 people.

Crosscutting Issues in Assessing the Quality of Cancer Care (Ch. 7)

The IOM committee believes that evaluating patients' experiences is critical to assessing the quality of cancer care. Responsiveness to patient-centered needs, preferences, and outcomes is a fundamental attribute of quality of care (IOM, 2001a; AHRQ, 2003). The committee also believes that cancer outcomes will not meaningfully improve for Georgians unless an effort is made to reduce the gross disparities in the behaviors and environmental conditions that lead to cancer, as well as in the incidence, diagnosis, treatment, and outcomes of cancer (IOM, 1999b, 2003c; Landis et al., 2004; Jemal et al., 2004).

For these reasons, the committee recommends that Georgia expand and enhance its cancer information systems to include (1) a patient survey program to collect data pertaining to cancer patients' experiences that can be used to assess the quality of cancer care, and (2) a system for the collection and analysis of high-quality data that yield insights into how best to address racial, ethnic, and socioeconomic disparities in the cancer burden and quality of cancer care. Georgia's use of patient surveys to capture cancer patients' experiences is likely to be groundbreaking. GCC will face numerous and complex survey design decisions and should obtain expert advice. Guidance on sampling design and potential topics for patient surveys are provided in Chapter 7, along with advice about improving the collection of cancer-related data that can be used to understand and reduce disparities. Socioeconomic data will be essential to better understanding racial and ethnic disparities. Georgia should consider using currently available software to geocode its cancer registry records as each new cancer case is entered into the state's surveillance database.

Looking Ahead to the Implementation of Quality-of-Cancer-Care Measures in Georgia (Ch. 8)

GCC now faces the challenge of implementing the quality-of-cancer-care measures. Precisely how this should best be done is well beyond the scope of this report, but implementation is a very important undertaking. In the final chapter of the IOM report, the committee offers advice on important principles of implementation for this first-of-a-kind state cancer care quality program. The IOM committee urges GCC to remember that the purpose of monitoring the quality of cancer care is not only to evaluate progress but also to motivate change. Implementation should begin with a blueprint for a cancer surveillance, monitoring, and evaluation organizational unit. The unit must be managed by the highest level of GCC with the assurance of long-term, sustainable funding. The monitoring system itself should be transparent and public, and it should build on Georgia's existing measurement and reporting systems.

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1

Introduction

Shortly after the tobacco industry's Master Settlement Agreement with the 50 states in 1998, leading members of Georgia's government, medical community, and public-spirited citizenry began considering ways in which some of Georgia's almost $5 billion, 25-year-settlement could be used to benefit the people of the state. Their decision, most fitting given the role of tobacco in cancer, was to create an entity and program whose mission is to make Georgia a national leader in cancer prevention, treatment, and research (GCC, 2001, 2003). This new entity—called the Georgia Cancer Coalition, Inc. (GCC)—and the state of Georgia subsequently began implementing a far-reaching state cancer initiative that includes five strategic goals: (1) preventing cancer and detecting existing cancers earlier; (2) improving access to quality care for all state residents with cancer; (3) saving more lives in the future; (4) training future cancer researchers and caregivers; and (5) turning the eradication of cancer into economic growth for Georgia (GCC, 2001).

GCC contracted with the Institute of Medicine (IOM) for advice on a key component of the cancer initiative's developing information infrastructure and reporting system—a set of measures that could be used to gauge the state's progress in improving the quality of its cancer-related services and in reducing cancer-related morbidity and mortality (Toal, 2003). The measure set would be pertinent to the mission and goals of GCC (as they related to the continuum of cancer care), in a form that is reasonable to implement, and drawn from established clinical guidelines or quality measures already in use. Further, current availability of the data necessary to develop the measures was not a principal concern as GCC intended to

simultaneously invest in creating a state-of-the-art information infrastructure. IOM was asked, however, to recommend likely sources of data and performance benchmarks.

IOM's Committee on Assessing Improvements in Cancer Care in Georgia was established in the fall of 2003 and was specifically charged with developing a set of quality-of-cancer care measures that, if implemented, could do the following:

- measure GCC's impact on cancer prevention, early detection, diagnosis, treatment, and palliative and end-of-life care as well as trends in cancer morbidity and mortality;
- provide insight into and help resolve economic, geographic, racial, and ethnic disparities in cancer care;
- inform Georgia's governor, state legislature, and executive branch of GCC's progress;
- contribute to quality improvement initiatives and health education related to cancer; and
- educate the health care community and the general public about cancer and cancer care.

IOM staff and the committee chair conducted a 2-day site visit to Georgia in advance of committee deliberations. The staff and committee chair interviewed a wide array of individuals representing key cancer-related organizations from around the state, including the GCC, Robert W. Woodruff Foundation, GCC regional planning grantees, Georgia Medical Care Foundation, Georgia chapter of the American College of Surgeons, Georgia Society of Clinical Oncology, state Division of Public Health, Emory University Health Sciences Center, Rollins School of Public Health, Morehouse School of Medicine, and the American Cancer Society.[1]

CONTEXT FOR THIS REPORT

In developing a set of quality-of-cancer-care measures for Georgia, IOM's Committee on Assessing Improvements in Cancer Care in Georgia assumed that GCC will continue to build a comprehensive statewide program with the potential to bring high-quality cancer care to every citizen in the state. GCC's initiative will feature prevention, early detection, prompt diagnosis, effective treatment according to the state of the art, and appropriate follow-up care. Moreover, GCC will build a statewide data system that can support ongoing monitoring and assessment of its progress, the

[1]See the Acknowledgements for a list of individuals.

state of cancer care for all cancer patients in Georgia, and continuous quality improvement statewide.

IOM's Work on Quality of Health Care

IOM has had a long interest in quality of health care (IOM, 1990a,b). Notably, in 1994, the IOM Council issued a white paper, *America's Health in Transition: Protecting and Improving Quality* (IOM, 1994). This was the start of a special initiative on quality of health care, the formation of IOM's National Roundtable on Health Care Quality. The National Roundtable on Health Care Quality began a focused effort on quality in 1995-1996 that was encouraged by a subsequent statement from the National Academies (National Academy of Sciences, National Academy of Engineering, and Institute of Medicine) *Preparing for the 21st Century: Focusing on Quality in a Changing Health Care System* (NAS, NAE, IOM, 1997) and resulted in the release of *Statement on Quality of Care* (IOM, 1998) and *Measuring the Quality of Health Care* (IOM, 1999b).

A series of IOM committee reports related to health care quality followed—on medical errors and safety (*To Err Is Human: Building a Safer Health System*) (IOM, 2000b); on designing a health system to improve quality (*Crossing the Quality Chasm: A New Health System for the 21st Century*) (IOM, 2001a); on health quality reporting (*Envisioning the National Health Care Quality Report*) (IOM, 2001b); on government roles (*Leadership by Example: Coordinating Government Roles in Improving Health Care Quality*) (IOM, 2002); on identifying priorities (*Priority Areas for National Action: Transforming Health Care Quality*) (IOM, 2003c); and on describing some of the priorities (*Health Literacy: A Prescription to End Confusion*) (IOM, 2004), among others. These IOM reports contributed to the development of principles and a conceptual framework for assessing health care quality that will be reviewed in detail in Chapter 2, *Concepts, Methods, and Data Sources*.

Coincident with IOM's thorough exploration of quality of health care in general, IOM's National Cancer Policy Board embarked on an examination of quality of care in the United States specific to cancer. The resulting 1999 report, *Ensuring Quality Cancer Care* (IOM, 1999a), concluded "that for many Americans with cancer, there is a wide gulf between what could be construed as the ideal and the reality of their experience with cancer care." The report also identified quality problems in specific services for cancer patients, such as palliative care, cancer prevention and early detection, and survivorship and led to subsequent follow-up reports on these subjects—*Improving Palliative Care for Cancer*; *Childhood Cancer Survivorship: Improving Care and Quality of Life; Fulfilling the Potential of*

Cancer Prevention and Early Detection (IOM, 2001c, 2003a,b), among others.

IOM's National Cancer Policy Board also looked into what data were collected to track cancer and identify problems at the state and national levels, and what data and data systems would be useful to improve the understanding of cancer at the population level. This report, *Enhancing Data Systems to Improve the Quality of Cancer Care* (IOM, 2000a), identified the need for the development of measures of quality cancer care that could be collected and made a part of existing or future cancer data systems to monitor cancer care and identify problems.

This body of work at IOM and its boards and committees of national experts, and in particular, the specific investigations of quality-of-cancer-care evaluation, data systems, and relationships to stages of care, have provided IOM—and in particular, the National Cancer Policy Board and its Committee on Assessing Improvements in Cancer Care in Georgia—with the requisite experience and expertise to evaluate the plans and programs of GCC and the state of cancer care and reporting in Georgia. Relying on this background, IOM is in a position to suggest improvements in data, quality measures to be employed, and implementation of monitoring within the context of general principles of quality of care analysis and a conceptual framework for assessing quality.

Principles and Framework for Assessing Quality

IOM's efforts to comprehensively define, measure, and design ways to improve quality of care have been built on important early work by others (Donabedian, 1980)—and, in turn, have influenced other more recent efforts that build on IOM's contributions. In its 1997 final report, the President's Commission on Consumer Protection and Quality in the Health Care Industry made recommendations that ultimately resulted in the federal Agency for Healthcare Research and Quality's annual National Health Care Quality Report. The commission's recommendations also led to the establishment of the National Quality Forum (NQF), a not-for-profit membership organization created to develop and implement a national strategy for health care quality measurement and reporting.

Following the 1997 recommendations of the President's Commission on Consumer Protection and Quality, a planning committee was formed to design the NQF. That committee recommended a Strategic Framework Board to set the strategy and the principles and priorities for national quality measurement and reporting. Many members of that board were members of IOM's National Roundtable on Health Care Quality (which also included the first president of the NQF) or had been involved in one or another of the IOM series of quality reports (including prominently IOM's

Crossing the Quality Chasm report) and were therefore intimately familiar with IOM's work. The purpose statement recommended to the NQF, which was adopted with some modifications in November 2001 by the NQF, therefore drew on IOM work and, in particular, linked two of the purpose statement's elements to the six aims from IOM's *Crossing the Quality Chasm* report (IOM, 2001a).

As these events were unfolding, IOM's National Cancer Policy Board was publishing its reports on the quality of cancer care (IOM, 1999a) and on the data systems needed to inform and support quality cancer care (IOM, 2000a) and delivering these reports to the National Cancer Institute. These IOM reports encouraged the National Cancer Institute to take a leadership role in a newly formed U.S. Department of Health and Human Services Quality of Cancer Care Committee, which coordinated the activities of multiple agencies within the department toward the purpose of monitoring and promoting improvements in cancer care quality. The report on data systems also recommended that the Department of Health and Human Services designate a committee to "identify a single set of core quality measures that span the full spectrum of an individual's care and are based on the best available evidence."

Shortly thereafter, the National Cancer Institute opened discussions with the NQF with the objective of funding the development of this core set. A steering committee to advise the NQF on how to proceed was formed, and this committee included two members of the National Cancer Policy Board and two members of the committee for this report. On the basis of the steering committee's deliberations, some initial decisions were made, and a contract to fund development of the core indicators was signed in May 2004. Meanwhile, the National Cancer Institute contracted for a set of papers from RAND Health for the purpose of informing the effort to develop quality-of-cancer-care measures, and these were also helpful for this report (McGlynn and Malin, 2002; McGlynn, 2002). The overlapping membership of the steering committee and the committee for this report allowed the NQF and IOM to stay informed of each other's activities and progress in a coordinated way. This background will be discussed more fully in Chapter 2, *Concepts, Methods, and Data Sources,* insofar as it is relevant to the conceptual framework and method for this report.

ORGANIZATION OF THIS REPORT

Chapter 2, *Concepts, Methods, and Data Sources,* describes how the measures were identified and supported by evidence. It also briefly reviews potential sources of data and benchmarks for measuring the quality of cancer care. (Appendixes A and B provide additional details on potential data sources and benchmarks.)

Chapter 3, *Preventing Cancer*, begins a series of four chapters that present recommended quality measures organized by the stage in the continuum of cancer care for the four major sites of adult cancer—breast, colorectal, lung, and prostate—which comprise over half the cancer cases and deaths in Georgia. The four chapters include detailed one-page summaries of the measures containing a description of the measure, the originator or source of the measure, an explanation of the underlying evidence, an explanation of the gap between the evidence and current practice, the method for calculating the measure, potential sources of data and benchmarks, and key references in the literature. Following Chapter 3, Chapter 4 (*Detecting Cancer Early*) covers measures of cancer early detection; Chapter 5 (*Diagnosing Cancer*), measures of cancer diagnosis; and Chapter 6 (*Treating Cancer*), measures of cancer treatment, including palliative and end-of-life care.

Chapter 7, *Crosscutting Issues in Assessing the Quality of Cancer Care*, addresses two questions: first, how to capture cancer patients' experience in assessing the quality of care; and, second, how to evaluate and address disparities in cancer care. In the concluding chapter, Chapter 8, *Looking Ahead to the Implementation of Quality-of-Cancer-Care Measures*, the IOM committee offers GCC advice on implementing the quality-of-cancer-care measures recommended in this report.

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2

Concepts, Methods, and Data Sources

". . . the Coalition is committed to measuring its efforts and showing quantifiable progress towards its goals."
Mobilizing Georgia, Immobilizing Cancer
Georgia Cancer Coalition, 2003

"Quality health care means doing the right thing, at the right time, in the right way, for the right person—and having the best possible results."
Agency for Healthcare Research and Quality, 2001

The Institute of Medicine (IOM) Committee on Assessing Improvements in Cancer Care in Georgia began its work by developing a conceptual framework and approach for the selection of quality measures that could be used by states—Georgia in particular—to assess progress in improving the quality of cancer care and in reducing cancer-related morbidity and mortality. The committee assumed it would recommend a rather slim set of measures. Ultimately, as the state's data collection and reporting system proves its workability and value to funding sources, GCC can invest in expanding the scope and type of measures it employs. At a minimum, the state should regularly revisit the measure set to make adjustments. Oncology is a dynamic field of medicine; today's indicators of quality care may become irrelevant in a few years.

The committee's conceptual framework and approach to selecting quality-of-cancer-care measures for Georgia, including the expert panel process and other methods, are described in this chapter. The final section

of the chapter identifies and discusses the strengths and weaknesses of key sources of data for the quality measures recommended in this report.

KEY CONCEPTS

The committee began by establishing some basic definitions and concepts. As discussed below, these included what constituted good quality health care, how to define quality measures, and what principles and criteria the committee should use to select quality measures for cancer care.

It is important to note that the concepts and methods used by the IOM committee were built on important foundational work by others—most notably Avedis Donabedian's classic body of work on quality of care; IOM's National Roundtable on Health Care Quality and subsequent IOM inquiries into quality of care, including the IOM National Cancer Policy Board's research on the quality of cancer care; RAND Health's groundbreaking work in developing indicators of quality health care and in documenting basic deficits in U.S. health care; and the developmental work of the Strategic Framework Board of the National Quality Forum (Donabedian, 1980; IOM, 1998, 1999, 2000a,b, 2001a,c; Asch et al., 2000; McGlynn, 2002, 2003a,b; McGlynn and Malin, 2002; McGlynn et al., 2003; NQF, 2003). Also important was the work of the Comprehensive Cancer Control Program of the Centers for Disease Control and Prevention (CDC) and the Outcomes Research Branch of the Cancer Control and Population Sciences Division of the National Cancer Institute.

What Is Good Quality Health Care?

The IOM committee defined good quality care as care that makes desired health outcomes more likely and more consistent with current professional knowledge, a definition first put forth by IOM in 1990 (IOM, 1990). In other words, as articulated by the federal Agency for Healthcare Research and Quality, good quality care is "doing the right thing, at the right time, in the right way, for the right person—and having the best possible results" (AHRQ, 2001).

Several important concepts are implicit in the perspectives on health care quality adopted by the committee. One is that the roots of poor quality health care are systemic. Health care systems, along with many individual and institutional participants, determine the quality of care—and considering these systems and participants is essential to quality improvement. Moreover, some factors are beyond the control of health care providers. A person's health is a result of many forces—genetic, environmental, behavioral factors, exposure to risk, and health history, as well as the person's personal preferences regarding such things as the invasiveness of medical or

surgical procedures or desire for extreme life-saving procedures (Palmer, 1997). Furthermore, the quality of health care is multidimensional and continuous. As shown in Figure 2-1, "the cancer control continuum"—which includes the domains of prevention; early detection; diagnosis; treatment (delivering evidence-based treatment); minimizing pain and providing humane, end-of-life care; and maintaining the health of survivors—is a useful framework for assessing the impact of the GCC initiative or similar state-level cancer initiatives. This framework takes the broad view that an integrated and coordinated approach is key to reducing cancer incidence, morbidity, and mortality (Richard-Lee and Rochester, 2003). It also recognizes that for many patients, cancer is a life-altering, chronic illness with a prolonged course.

What Are Health Care Quality Measures?

This section reviews how the committee chose quality measures using a process which was the same for all four cancers considered in this report. The IOM committee adopted the classification of health care quality measures suggested by Donabedian's framework (Donabedian, 1980) for measuring quality of care: (1) *structural measures*—the features of health care facilities, equipment, staffing, and organization of delivery of care that establish the capacity to provide good quality care; (2) *process measures*—what health care providers do to or for patients in both a technical and interpersonal way; and (3) *outcome measures*—what happens to patients, their health status, functional status, and quality of life that can be directly

Prevention	Early Detection	Diagnosis	Treatment	Survivorship	End-of-Life Care
Tobacco control	Colorectal cancer screening	Biopsy	Chemotherapy	Surveillance	Hospice care
Diet	Breast cancer screening	Histological assessment	Hormone therapy	Psychosocial care	Palliation
Physical activity	Cervical cancer screening	Pathology reporting	Pain management	Management of long-term effects	
Sun exposure		Tumor stage documented	Psychosocial care		
Alcohol use			Radiation		
			Surgery		

FIGURE 2-1 Domains of the cancer control continuum with selected examples of activities in each domain.
SOURCE: Adapted from National Cancer Institute figure on the "Cancer Control Continuum": http://cancercontrol.cancer.gov/od/continuum.html.

attributed to the health care they have received. The committee found it useful to think of measures in this way for at least two reasons: when possible, measures should deal with outcomes, that is, assess what good care actually achieves for patients; and thinking of measures in terms of structure, process, or outcomes focuses attention on the part of the health system that may require attention. But, as indicated in Figure 2-2, the committee evaluated measures as described in that figure and the accompanying text.

The committee also agreed with the classification, first suggested by the National Roundtable on Health Care Quality, that there are three types of quality *problems* in cancer care: too little care; too much care; and the wrong care (IOM, 1998). *Too little care ("underuse")* is when patients do not receive evidence-based preventive care, diagnostic tests and procedures, treatment, or palliative care. *Too much care ("overuse")* is when patients receive unnecessary diagnostic tests, medications, surgeries, or other health care services that may cause side effects or pose other health risks. The *wrong care ("misuse")* is when diagnoses are missed or delayed, ineffective treatments are used, effective procedures are done poorly, or errors are made. This classification is useful to have in mind as a concept because it may bear on the feasibility or utility of a measure, but, as noted above, the committee focused on scoring as shown in Figure 2-2 and used the excellent work of Donabedian and the Roundtable only as background.

Finally, the committee took the view that patient-centeredness is a fundamental attribute of high-quality health care (IOM, 2001a). Thus, measuring patients' perspectives, experiences, and preferences regarding

	Characteristics of the measure							Feasibility and utility of the measure						
Measure	Variation in factor	Improvable factor	Specifiable measure	Valid measure	Adaptable measure	Measures trends, groups	Culturally acceptable	Currently available	Ease of measurement	Potential to develop	Improve decisions	Compelling	Leverage point	Overall yes, no, or maybe
Rate each measure on the criteria above on a scale of 1 to 5. 1 = poor 3 = moderate 5 = ideal NA = Not applicable														

FIGURE 2-2 Sample scoring sheet used to evaluate potential quality measures.

the structure, process, and outcomes of cancer care is fundamental to measuring quality. This important attribute led the committee to discuss, and strongly urge Georgia to survey patients as described in Chapter 7. The committee often referred to patient-centeredness in evaluating potential measures, although clearly not every measure focuses on this attribute.

KEY METHODS

Guiding Principles and Criteria Used to Select Quality Measures for Cancer Care

In deciding which quality-of-cancer-care measures to recommend, the committee adapted the guiding principles and selection criteria of the National Quality Forum's Strategic Framework Board (McGlynn, 2002). Thus, the committee's decisions about the selection of quality-of-cancer-care measures were guided by the following five general principles:

1. Each measure should relate directly to a GCC strategic goal (Box 2-1).
2. Each measure should have a clear and compelling use.
3. Each measure should avoid imposing an undue burden on those providing data (with the understanding that important improvements to Georgia's cancer information infrastructure may be necessary).
4. Each measure should be actionable so that Georgia providers and other stakeholders can use the measure for making decisions or taking steps to improve the state's cancer care.
5. Each measure should help GCC lead the improvement of cancer care in Georgia.

Additional criteria the committee used as ideals to guide its decisions about whether to accept or reject specific quality-of-cancer-care measures were each measure's importance, scientific acceptability, and feasibility/utility (NQF, 2003); they were part of the discussions and were reflected in the scoring sheet used to evaluate potential measures and in the one-page descriptions defined below and presented in Chapters 3-6:

- *Importance*. Candidate quality-of-cancer-care measures were considered important if, from the perspective of GCC, they represented one or more of the following: a significant leverage point for improving the quality of cancer care; an aspect of cancer care where current practice does not meet the best available, evidence-based standards of care; a standard of care that is inconsistently practiced throughout the state, varying by location of care, region of the state, socioeconomic factors, race and ethnicity, or other

BOX 2-1
Strategic Goals of the Georgia Cancer Coalition (GCC)

GCC GOALS THAT ARE THE FOCUS OF THIS IOM STUDY

1. Prevent Cancer and Detect Existing Cancers Earlier. Reduce the number of deaths due to cancer through a focused cancer prevention and early detection effort; and provide education to and screen Georgians for cancer, emphasizing the cancers that are the major causes of death.

- Make all Georgians aware that death from some of the most common cancers can be reduced through prevention and early detection.
- Educate health care providers about the importance and availability of early detection programs and the value of counseling patients about cancer prevention behaviors.
- Provide education to Georgians about how to prevent cancer.
- Increase participation in early detection programs.
- Provide accurate and useful data to guide the planning and evaluation of cancer prevention and early detection programs.

2. Improve Access to Quality Care for All Georgians with Cancer. Increase access to quality care and upgrade the availability of world-class medical care for Georgians with cancer through state-of-the-art technology and methods.

- Implement a cancer treatment delivery system that provides statewide access to a full range of quality cancer treatments for all Georgians.
- Implement an information system that allows cancer-related data to be shared among all cancer treatment programs.

OTHER GCC GOALS

3. Save More Lives in the Future. Create a new leading body of knowledge and leading products that contribute to the ultimate eradication of cancer in Georgia and for humankind.

4. Train Future Cancer Researchers and Caregivers. Leverage the overall effort to benefit future generations by training the next wave of cancer researchers and caregivers.

5. Turn the Eradication of Cancer into Economic Growth. Create and enhance existing partnerships with pharmaceutical and biotechnology companies that will provide quality jobs to Georgians and environmentally clean additions to the economy.

SOURCE: GCC Strategic Plan, 2001.

factors; and an area of cancer care that GCC could realistically act on and improve.

- *Scientific acceptability*. Candidate measures were judged to be scientifically acceptable if they were (1) precisely specified and described in a standard format including explicit specifications for the numerator and denominator (where applicable); (2) valid—that is, clearly able to reflect the concept being evaluated and to discern good from bad quality; and (3) adaptable—that is, useful in a variety of real-world circumstances where patient preferences often differ, clinical scenarios vary, and similar services are provided in different organizational settings.
- *Feasibility/utility*. Candidate quality-of-cancer-care measures had to be both feasible and usable to be selected by the IOM committee. A measure was judged to be feasible if it could be produced using data that are currently available or data that could be developed with reasonable improvements to Georgia's cancer information infrastructure (e.g., by enhancing registry data or expanding or introducing new patient- or population-based surveys). A measure was judged to have utility if it had practical and compelling applications (e.g., as potential management tools to drive quality improvements). GCC and other users of the quality indicators would have to be able to use the measure to track statistical trends and group disparities and also to present findings that could be easily interpreted by key audiences, including the governor, state legislature, providers of cancer care services, patients, and the public.

Consideration of Levels of Evidence for Quality-of-Cancer-Care Measures

In addition to using the selection criteria just described, the IOM committee considered the strength of the evidence underlying the candidate quality measures when deciding on acceptance or rejection. The committee adopted the U.S. Preventive Services Task Force's (USPSTF) three-level hierarchy of evidence (Box 2-2). The committee's gold standard, referred to as Grade I evidence by USPSTF, is evidence from a properly conducted randomized controlled trial. Grade II refers to evidence from well-designed, nonrandomized controlled trials; well-designed cohort or case-control studies; or multiple-time series. Grade III, the least reliable type of evidence, includes expert opinion, descriptive studies, and case reports. Of course, the strength of evidence varied for different measures, but the committee assigned great importance to evidence-based measures, and this almost always meant at least some Grade I support.

BOX 2-2
Levels of Evidence Applied to Clinical Research

The "hierarchy of evidence" applied to clinical research (e.g., examining whether a given treatment is effective in patients with a specific type of cancer) is well established and agreed upon. The following version is taken from the well-respected U.S. Preventive Services Task Force, proceeding from the most reliable to the least reliable type of evidence (i.e., from Grade I to Grade III):

Grade I Evidence—Evidence obtained from at least one properly randomized controlled trial.

Grade II Evidence

II-1 Evidence obtained from well-designed controlled trials without randomization.

II-2 Evidence obtained from well-designed cohort or case-control (epidemiologic) studies.

II-3 Evidence obtained from multiple time series with or without the intervention dramatic results in uncontrolled experiments (e.g., the results of the introduction of penicillin treatment in the 1940s could be regarded as this type evidence).

Grade III Evidence—Opinions of respected authorities, based on clinical experience, descriptive studies and case reports, or reports of expert committees.

SOURCE: USPSTF, 1996.

Focus on Clinical Indicators of the Quality of Cancer Care

The IOM committee chose to focus primarily on potential measures of clinical quality, that is, measures useful in assessing the quality of preventive, diagnostic, or therapeutic patient care, because of earlier IOM reports that identified a "wide gulf" between what is known about cancer care and what is actually experienced by many Americans (IOM, 1999). A series of reports by IOM's National Cancer Policy Board have found extensive evidence that the public can not depend on receiving even the most basic elements of quality care, such as cancer prevention and early detection, appropriate diagnosis and treatment, palliative care, and follow-up of survivors (IOM, 2001c, 2003a,b).

Focus on Four Common Cancers in Adults

The IOM committee limited its review to potential quality measures that might be used to track progress in controlling the four most common cancers in Georgia and the United States—namely, breast, colorectal, lung, and prostate cancers. Together these cancers account for approximately 58 percent of cancer incidence and 53 percent of cancer-related mortality in Georgia (Table 2-1). In 2000, these four cancers contributed 18,194 of the state's 31,591 new cases of cancer and 7,213 of the 13,628 cancer-related deaths (NCI and CDC, 2004; GDPH, 2004).

The overwhelming majority of cancers are diagnosed in adults, so the committee chose to focus exclusively on adult cancers. This focus on the most common cancers in adults is a pragmatic one. Almost 9 in 10 incident cancer cases are diagnosed among adults aged 45 and older (Ries et al., 2004). In fact, cancers of the breast, colon and rectum, lung, and prostate almost never occur in children. In Georgia, only an estimated 150 children are diagnosed with cancer each year (McNamara et al., 2002).

Expert Panel Process

A technique that is used widely to define the attributes of good quality health care and to review and select measures of health care quality is an expert panel process (Brook, 1994; Shekelle et al., 1998; Asch et al., 2000). The IOM Committee on Assessing Improvements in Cancer Care in Georgia was constituted so that the committee could function as an expert panel.

TABLE 2-1 Incidence and Mortality in Georgia from the Four Most Common Cancers, 2000

	Incidence		Mortality	
Cancer site	No. of cases/ year	Percent of all sites	No. of deaths/ year	Percent of all sites
Lung and bronchus	5,060	16	4,143	30
Female breast	4,953	16	996	7
Colorectal	3,452	11	1,293	9
Prostate	4,729	15	781	6
Subtotal	18,194	58	7,213	52
All sites	31,591	100	13,628	100

SOURCE: NCI and CDC, 2004; GDPH, 2004.

Members of the committee were recruited to ensure national-level leadership in the following disciplines:[1]

- Academic-based cancer care
- Cancer epidemiology
- Community cancer care
- Consumer and patient perspective
- Disparities in care
- Evaluation methods
- Health policy/health services research
- Management/academic cancer centers
- Medical informatics
- Oncology nursing
- Outcomes research
- Palliative care
- Prevention
- Primary care
- Quality measurement/improvement
- Radiation therapy
- State cancer control
- Tumor registries

In a series of six monthly sessions, the IOM committee held conference calls to individually review and vote on more than 80 candidate measures. The committee's review process began with cancer prevention- and early detection-related quality measures, followed by diagnosis and treatment measures, and then palliative and end-of-life measures.

Before each review session, IOM staff sent committee members a one-page description of each potential quality measure. Each summary description included the following:[2]

- a one- or two-line description of the measure;
- the origin or source of the measure;
- capsule summaries of the consensus on care, including the level of evidence supporting the underlying process to be measured and what is known about the gap between the consensus on care and actual care delivery;
- the method for calculating the measure (including the numerator, denominator, population for whom the measure should be constructed, and comments;

[1]A list of committee members with their affiliations is presented at the front of the report.
[2]The summary descriptions are presented in Chapters 3, 4, 5, and 6.

- potential sources of data and performance benchmarks, including any known data limitations; and
- key references for the capsule summaries.

The staff also sent committee members a scoring tool to facilitate their evaluation of the potential quality measures (Figure 2-2). Committee members were asked to examine each summary and complete the scoring tools in advance of each review session. The scoring tool served as a decision aid and device for organizing the committee's review—scores and numerical grades were tallied for discussion purposes only. The review process was iterative. During the first round of reviews, the committee discussed and voted "yes, no, or maybe" on each individual measure. "Maybe" measures were revisited in subsequent review sessions. "No" measures were discarded.

SOURCES OF QUALITY-OF-CANCER-CARE MEASURES CONSIDERED

The IOM committee drew its pool of candidate quality-of-cancer-care measures for Georgia from the cancer-related quality measures and clinical guidelines of more than 20 leading organizations—including the federal Agency for Healthcare Research and Quality's newly released National Healthcare Quality Report, the U.S. Preventive Services Task Force, the Foundation for Accountability, the National Quality Forum, the National Committee for Quality Assurance, selected state cancer control programs, and RAND Health (Box 2-3). Descriptions of selected sources of cancer-related clinical guidelines and quality measures are presented in Appendix A, *Sources of Cancer-Related Clinical Guidelines and Quality Indicators*.

DATA FOR RECOMMENDED QUALITY-OF-CANCER-CARE MEASURES IN GEORGIA

The IOM committee strongly urges that Georgia make the necessary investment required to generate reliable data inputs into its quality-of-cancer-care information system. If the state's cancer information system includes accurate, complete, and timely data, it will enable the state to identify where quality problems exist, to stimulate quality improvements, and to measure progress. The integrity of Georgia's quality-of-cancer-care information system will depend on how the quality data inputs are defined and collected (Kahn et al., 2002). Methods must be uniform across multiple health care providers and settings throughout the state.

The data inputs to the state's quality-of-cancer-care information system will originate in a variety of subsidiary information systems, including tumor registries; administrative claims databases (e.g., for Medicare benefi-

BOX 2-3
Principal Sources of Candidate Quality-of-Cancer-Care Measures Considered by the IOM Committee

Accreditation Organizations
- Joint Commission on Accreditation of Healthcare Organizations
- National Committee on Quality Assurance (especially its Health Plan Employer Data and Information Set [HEDIS])

Federal Health Agencies
- Agency for Healthcare Research and Quality (including National Healthcare Quality Report, National Quality Measures Clearinghouse)
- Centers for Disease Control and Prevention
- National Cancer Institute
- Surgeon General's office
- U.S. Preventive Services Task Force

Provider Groups and Professional Associations
- American College of Radiology
- American College of Surgeons
- American Society of Clinical Oncology
- College of American Pathologists
- National Comprehensive Cancer Network

State Cancer Control Programs
- Colorado
- Kansas
- Michigan
- New Mexico
- Vermont

Others
- Foundation for Accountability
- National Quality Forum
- RAND Health

ciaries and Medicaid enrollees); the medical records of hospitals, physician offices, and pathology laboratories; patient- and population-based surveys, state and national datasets; and linkages between registry data and other data sources on, for example, comorbidities and use of cancer-related services (IOM, 2000a; McGlynn, 2003b).

As described in the discussion that follows, four types of data will be integral to Georgia's quality monitoring system:

- cancer registries,
- medical records,
- administrative claims (Medicare claims in particular), and
- surveys.

Table 2-2 lists the potential data sources for selected quality-of-cancer-care measures recommended for Georgia. Table 2-3 summarizes the strengths and weaknesses of these critical data sources. Although it is beyond the scope of this report to provide more than this brief summary of these or other relevant data sources, additional information on potential data sources can be found elsewhere (see, for example, IOM, 2000a; Malin et al., 2002a; Howe et al., 2003; Clarke et al., 2003).

Cancer Registries

Cancer registries play a critical role in cancer surveillance and are also a vital resource for measuring the quality of cancer care (IOM, 2000a; Kahn et al., 2002; McGlynn, 2002; Malin et al., 2002b; Wingo et al., 2003). Population-based cancer registries maintain a complete enumeration of cancer cases in a specific geographic area, thereby providing the data that are integral to determining the risk of developing and dying from cancer in that area and to building an information base for studying the impact of cancer on important subgroups (Howe et al., 2003).

In Georgia, hospitals and outpatient facilities including pathology laboratories, radiation therapy and medical oncology centers, and physicians' offices, are required by law to report information on newly diagnosed cancer patients to the state's population-based cancer registries (GCCR, 2003). These include (1) the Georgia Comprehensive Cancer Registry (GCCR), where data on more than 60 percent of Georgia's cancer cases are submitted; and (2) the Surveillance, Epidemiology, and End Results (SEER) registry, which covers an estimated 37.1 percent of Georgia's population—35.6 percent in the five-county metropolitan Atlanta region and 1.5 percent in 10 rural counties with substantial African-American populations (NCI, 2004b). These and several other cancer registries are discussed further below.

Georgia Comprehensive Cancer Registry

The GCCR is a unit of the Georgia Department of Human Resources, in the state's Division of Public Health. The GCCR's data collection is managed by the Georgia Center for Cancer Statistics, a research division of the Rollins School of Public Health of Emory University, under contract with the state. In addition to collecting, editing, and processing the GCCR

TABLE 2-2 Potential Sources of Data for Quality-of-Cancer-Care Measures and Benchmarks

	Georgia-Based Data Sources							National Data Sources			
Quality Measures	Vital records	Cancer registries	BRFSS, YRBSS	Claims	Medical records	NVSS	NHQR	BRFSS, YRBSS	Medicare claims	HP 2010	SEER
Preventing cancer											
—Helping smokers quit			●		●		●	●		●	
—Smoking			●		●			●		●	
—Incidence		●			●		●				●
Detecting cancer early											
—Cancer screening			●	●	●		●	●	●	●	
—Stage at diagnosis		●			●		●				●
Diagnosing cancer											
—Timely diagnosis		●		●	●						●
—Tumor stage documented		●			●						●
—Adequate lymph node dissection		●			●						●
—Pathology reports meet standards of care					●						
Treating cancer											
—Timely primary and adjuvant therapy		●		●	●						●
—Survival		●			●					●	●
—Mortality	●					●	●			●	
—Pain management					●						
—Hospice use				●	●		●		●		

NOTE: NVSS = National Vital Statistics System; BRFSS = Behavioral Risk Factor Surveillance System; YRBSS = Youth Risk Behavior Surveillance System; NHQR = National Healthcare Quality Report; SEER = Surveillance, Epidemiology, and End Results; HP 2010 = Healthy People 2010.

TABLE 2-3 Strengths and Weaknesses of Key Sources of Data for Quality-of-Cancer-Care Measures and Benchmarks

Data source	Purpose	Strengths	Weaknesses
Population-based tumor registries	To track new cases of cancer, analyze cancer incidence, and monitor cancer trends	—Complete enumeration of incident cancer cases —Detailed information on cancer stage, survival —Data on hospital-based services —Records can be linked with claims databases to provide a more complete picture of patient care	—Relevant only to persons with confirmed cancers —Data on ambulatory care may be incomplete —Time lag can be 2 years —Secondary treatment data less reliable than data on initial treatment —Incomplete death ascertainment
SEER registries	To collect information on newly diagnosed cancers in nine U.S. regions, including metro Atlanta and 10 rural Georgia counties	—High-quality data —Detailed public use datasets are available —Includes demographics, anatomic/histologic details, stage, diagnostic techniques, first course of treatment, stage-specific survival —98 percent completeness in case ascertainment	—Time lag greater than 2 years —In Georgia, not representative of state overall. In United States, not representative of racial/ethnic makeup —Treatment data are limited in scope —Provides no information on quality of life —Lacks staging data to correlate services with stage at diagnosis
Claims	To generate bills for health care services	—Available in electronic format —Some can be linked with registry data —Data on discrete, billable services	—Poor detail on patient diagnosis, comorbidities, unreimbursable services (e.g., provider advice on treatment options, bundled services) —Excludes persons without health insurance

BRFSS	To monitor behavioral risk factors related to cancer and other preventable disease	—Designed for state-level estimates —Custom questions can be added —Oversampling is feasible —Useful source of benchmark data	—Households without telephones are excluded —Self-reported data are subject to recall error —Low response rates —Sampling frame may be insufficient for subgroup analyses or regional comparisons
Custom surveys	Can be designed to meet specific research needs	—Captures the perspective of patients and their family members, individuals with limited access to health care system	—Expensive —May need multiple languages, e.g., Spanish —Difficult to link with other data sources —Self-reported data are not reliable for certain aspects of care (e.g., medications) —Low response rates
Medical records	To document patient comorbidities, disease progression, treatment, test results, medications, other clinical details	—Extensive documentation of clinical details of disease, treatment, and comorbidities —Includes diagnostic details for those who do and do not end up with a confirmed cancer diagnosis	—Records may be incomplete or missing —Data abstraction is costly and time consuming —Multiple records must be consulted to obtain complete documentation of patient history

NOTE: SEER = Surveillance, Epidemiology, and End Results; BRFSS = Behavioral Risk Factor Surveillance System.

data, the Georgia Center for Cancer Statistics manages Georgia's other central population-based registry—Georgia's SEER registry.

The GCCR meets and exceeds the highest standards—gold certification—of the North American Association of Central Cancer Registries (NAACCR) (GCC, 2003). It is also a participant in the National Program of Cancer Registries. GCC is to be lauded for its early attention to improving the GCCR. GCC's investment in the GCCR is largely responsible for the registry's current high level of performance. Currently, GCCR data are 97 percent complete—a dramatic improvement from the pre-GCC era of 75 percent. NAACCR gold certification requires that the GCCR identify at least 95 percent of its region's cancer cases; record all required data within 23 months of the diagnosis year; and meet other NAACCR standards for internal consistency, timeliness, minimal duplication of records, minimal reports by death certificate only, and minimal missing data fields (NAACCR, 2004).

The GCCR collects data on patient demographics (gender, age at diagnosis, race, Hispanic ethnicity, county of residence, etc.); cancer site (tumor topography and histology); SEER tumor stage (in situ, local, regional, or distant); SEER extent of disease;[3] initial course of treatment including type and date of surgery and radiation therapy; reason for no surgery (if none); date and cause of death, if applicable; and other data elements (Bayakly, 2003).

Surveillance, Epidemiology, and End Results (SEER) Registries

The SEER registries are the nation's most complete source of cancer incidence and survival data, and are considered the standard of quality for cancer registries worldwide (NCI, 2002). SEER registries, like Georgia's, are considered superior for three important reasons. First, unlike other registry data, SEER data can be used to determine cancer survival rates because the registries actively follow up at least 95 percent of cancer cases to determine vital status and cause of death (if applicable). Second, the SEER program conducts extensive quality assurance that includes annual audits of data quality and completeness (Warren et al., 2002b). Third, SEER data are routinely linked with Medicare claims data, and this linkage greatly enhances the usefulness of SEER data, as discussed below.

SEER/Medicare Database

The SEER/Medicare database is a collaborative program of the National Cancer Institute, the SEER registries, and the Centers for Medicare and

[3]SEER extent of disease includes tumor size, lymph node involvement, regional nodes positive, regional nodes examined, extension, and tumor markers.

Medicaid Services.[4] It is a unique and indispensable resource for investigating the quality of cancer care. Unlike any other information source, SEER/Medicare combines SEER's patient-level information on cancer site, tumor pathology, stage, and cause of death with Medicare's longitudinal data on services before, during, and after diagnosis (Warren et al., 2002b).

Although this combined SEER/Medicare database is greater than the sum of its parts, it carries some of the key deficits of its component parts. One problem is that with the combined SEER/Medicare database, as with SEER, there is a significant time lag, because registry data are approximately 2 years behind and the linkage is updated only every 3 years. The next linkage update, consisting of data on cases diagnosed in 2000 to 2002, is scheduled for completion in 2005 (Riley and Warren, 2005). Another problem with the combined SEER/Medicare database, like the Medicare database, is that the data are not useful for studies of cancers that are common to the under-65 age group and cannot be used to assess the unique concerns of individuals without health insurance.

Limitations of GCCR and SEER Registry Data

Both GCCR and SEER registry data have several limitations:

- Registry data for a given year are not available for almost 2 years after the end of the diagnosis year (Clarke et al., 2003; Bayakly, 2003).
- Registry records contain no information on patients' comorbidities, therapy beyond the first course of cancer treatment, adjuvant therapies that are not completed (regardless of date received), and recurrence and long-term disease status. For patients with multiple surgical procedures, only the most definitive surgery is reported in registry records (Warren et al., 2002b).
- Registry data may be incomplete unless vigorous attempts are made to ensure that all eligible patients and data are included.
- Registries have limited value for studying the diagnostic process because they only maintain data on *confirmed* cancer cases. Assessing the quality of diagnosis requires data on people whose possible cancer is ruled out and people who get "lost" in the midst of the diagnostic process.
- Cancer-related care is more likely to be documented in registries if it is hospital-based than if it is provided in an ambulatory setting (Bickell and Chassin, 2000; Malin et al., 2002b). This observation holds especially true for early-stage breast and prostate cancers and skin melanomas, compared with other types of cancer, because they are typically identified and treated in physician's offices (Wingo et al., 2003). SEER registries appear to

[4]Extensive information about SEER is available at http://seer.cancer.gov.

do a better job of documenting treatment than do non-SEER cancer registries (Brown et al., 2000).

- NAACCR-certified registries, including the GCCR, are not required to actively follow registered cancer cases. Consequently, neither vital status nor other follow-up information is available for many registered cases (Wingo et al., 2003; Howe et al., 2003). However, most registries, including the GCCR, do passive follow-up by linking with vital records to obtain death information.

Special Cancer Registries That Focus on Specific Cancers or Aspects of Cancer Care

Elsewhere in the nation, there are special cancer registries that focus on specific types of cancer or aspects of cancer care and collect extensive data to support a wide range of research. Such registries include, for example, seven mammography data collection and research sites that collaborate as part of the National Cancer Institute's Breast Cancer Surveillance Consortium (BCSC).[5] The BCSC registries and data centers link mammography data with local SEER registry data and collect extensive follow-up data on women who undergo screening mammography. The result is an especially rich database and powerful tool for studying how breast cancer screening relates to changes in stage at diagnosis, survival, or breast cancer mortality. Approximately 150 papers, published in peer-reviewed journals, have used the BCSC data to address a wide array of questions about screening mammography (NCI, 2004a). GCC should consider expanding its own registry operations to foster this kind of research.

Medical Records

Medical record data have been used extensively in health services research, including research into the quality of care. Much of the available research on the quality of cancer care draws from detailed abstracts of medical records (see, for example, Asch et al., 2000; McGlynn, 2002; Malin et al., 2002b). Medical records are an important data source because they contain extensive documentation of patients' characteristics, comorbidities, and descriptions of the disease, its progression, the recommended course of treatment, and other important clinical details.

[5]The seven data collection and research sites are the Carolina Mammography Registry, the Colorado Mammography Project, the Group Health Cooperative Breast Cancer Surveillance project, the New Hampshire Mammography Network, the New Mexico Mammography Project, the San Francisco Mammography Registry, and the Vermont Breast Cancer Surveillance System.

The obstacles to relying on medical records as a routine source of quality monitoring information are substantial (McGlynn, 2002). Data usually have to be manually abstracted from handwritten, paper records by trained personnel with clinical expertise, often nurses. The process is labor intensive and costly. Furthermore, the content and format of medical records is not standardized. Multiple records may have to be consulted to develop one episode of patient care, and some records are frequently missing. Considerable travel time in going from delivery site to delivery site is sometimes required, particularly in a state as large as Georgia (photocopying or scanning and transmitting encrypted electronic records may be a workable alternative if privacy issues can be appropriately handled). Some medical records may be inaccurate or incomplete. In light of these factors, the IOM committee recommends that GCC limit its use of paper medical records to occasional, high-priority studies.

An electronic health record system could help Georgia effectively and efficiently use medical records to assess the quality of cancer care. Perhaps more importantly, an electronic record system could also be a potent force for quality improvement (IOM, 2003c). Electronically managing the diagnostic phase of cancer care would have several advantages over paper-based reporting. With computerized recordkeeping, results from biopsies and radiology procedures, for instance, might be more readily obtained by providers at the time and place they are needed and thus reduce waiting time for results, expedite treatment, and ameliorate patient anxiety (Overhage et al., 2001; Olivotto et al., 2001; Schiff et al., 2003; Bates et al., 2003).

At present, few, if any, of Georgia's cancer care providers use electronic health records. It should be noted, however, that a key aspect of the Georgia Center for Oncology Research and Education—one of GCC's most significant initiatives—is to introduce electronic recordkeeping for its patients in clinical trials. Plans are now underway to expand the availability of cancer clinical trials in urban and rural areas throughout Georgia (GCC, 2003). GCC estimates that the percentage of Georgians with cancer who participated in a clinical trial in 2000 was under 2 percent (Russell, 2004).

Administrative Claims

Administrative claims are a relatively inexpensive, electronic data source for measuring quality of care. Administrative claims exist for payment purposes and are best used for determining patients' receipt of particular services that are likely to generate a bill for a reimbursable service (e.g., for certain cancer screening tests, diagnostic procedures, or treatments) (McGlynn, 2002). Claims data are least useful for obtaining clinical details such as tumor stage or test results and most valuable when claims are linked with registry data as in the SEER/Medicare dataset.

Medicare claims have been used extensively in studies of cancer care and validated as a data source for information on use of cancer-related surgery, chemotherapy, and radiation treatments as well as home health and hospice care (Du et al., 1999, 2000; Cooper et al., 2002; Warren et al., 2002a). The Medicare program covers most adults aged 65 and older, as well as some other adults with a disability or end-stage renal disease. Because cancer occurs most frequently among older adults, Medicare claims are an important data source for quality assessments of cancer care. Nationwide, almost 57 percent of all cancer cases, from 1997 to 2001, occurred among persons aged 65 or older (Ries et al., 2004). In Georgia, 955,000 persons (11.2 percent of the total population) were Medicare beneficiaries in 2002 (CMS, 2003).

Medicare claims do have limitations. They tend to be less useful for studies of cancers that occur more frequently among younger people such as testicular cancer, leukemia, and lymphoma (Warren et al., 2002b). In addition, Medicare claims cannot be used to assess services which are not reimbursed by Medicare, such as long-term care outside of skilled nursing facilities. Accurate determination of doses of drugs is difficult, if not impossible from administrative data. It is also sometimes difficult to tell recurrent cases from follow-up cases in the absence of longitudinal patient files.

Patient and Population Surveys

Surveys are the one data source that can capture the perspective of cancer patients, their families, health care providers, and the public on many aspects of quality of care (McGlynn, 2002).[6] Surveys that target patients and their families provide critical insights into issues such as patient involvement in treatment decisions, satisfaction with health care after a cancer diagnosis, access to recommended services, pain management, and quality of life including health and functional status. Surveys that target the broader Georgia population are also important because they offer insights into persons who are well and unwell, insured and uninsured, and users and nonusers of health care services. There are a number of ongoing population-based surveys, sponsored by the federal government and private sources, which collect data that are relevant to the quality of cancer care.

Unfortunately, most population-based surveys are not designed to provide state-level statistics. An important exception is the Behavioral Risk Factor Surveillance System (BRFSS).[7] The BRFSS is an ongoing survey

[6]See Chapter 7, *Crosscutting Issues in Assessing the Quality of Cancer Care*, for the IOM committee's recommendations on how to use surveys to capture the experience of cancer patients.

[7]Further details on the BRFSS are provided in Appendix B.

research collaborative of the CDC and U.S. states and territories (CDC, 2004). BRFSS field operations are managed by state health departments in accordance with CDC guidelines.[8] The core activity of the BRFSS is a computer-assisted telephone-interview survey of a sample of each state's adult population. The survey is designed to collect uniform, state-specific data on preventive health practices and risk behaviors that are linked to cancer and other chronic diseases, injuries, and preventable infectious diseases. States may oversample regional populations to ensure adequate sample size for smaller geographically defined populations of interest. Aggregate, national-level findings are available on the CDC website and provide useful benchmarks for each state to assess its progress in, for example, reducing smoking and advancing preventive health practices. The BRFSS design also allows for comparisons between individual states.

The BRFSS survey instrument has three parts—a core module used by all states, optional modules, and state-added questions. The core module includes questions on health-related perceptions, conditions, and behaviors. In 2004, several sections of the core module had direct relevance to the quality of cancer care, including series of questions on tobacco use, alcohol consumption, excessive sun exposure, breast, colorectal, and prostate cancer screening.

The BRFSS optional modules are sets of standardized survey questions on a variety of topics. In 2004, there were three cancer-related, optional modules—smoking cessation, other tobacco products, and secondhand smoke policy. States may add their own questions to the BRFSS, but state-added questions, unlike the core and optional modules, are not edited or evaluated by CDC.

BRFSS data do have limitations. Telephone surveys underrepresent households without telephones (approximately 8 percent in Georgia) and households that use only mobile telephones. In addition, telephone surveys tend to have low participation rates. Also, like other survey data, BRFSS data are self-reported and thus subject to recall error. Individual recollections have been found to be accurate for certain health care services, such as surgery, but less so for medications used or others aspects of health care (Kahn et al., 2002). Recent research raises some concerns about the reliability of mammography self reports in the BRFSS (IOM, 2004).

In addition, although the BRFSS sampling frame is designed to generate state-level estimates, it is insufficient for comparing regions of the states or for assessing trends among subgroups in the state. GCC must oversample

[8]The responsible entity in Georgia is the Epidemiology Branch of the Chronic Disease, Injury, and Epidemiology Section of the state's Division of Public Health (Martin et al., 2004).

regional populations to ensure adequate sample size for smaller geographically defined populations of interest.

Finally, BRFSS does not collect diagnostic data. Even if Georgia were to add cancer-related questions to the survey, the sample is too small to collect sufficient numbers of respondents with a cancer diagnosis.

Issues in Interpreting Quality-of-Cancer-Care Data

Quality monitoring must be an ongoing, iterative process. First-time results can be used to identify problems and to establish baseline results. Subsequent measures will track progress over time, providing comparisons with past performance to help determine the impact of the GCC initiative. The significance of the quality measures will be clearer when the measures are presented along with a corresponding reference point or benchmark (McGlynn, 2003b; AHRQ, 2004). Using benchmarks or other standards makes information on quality more meaningful by providing a context for understanding the information (IOM, 2001b). Benchmarks can be drawn from past or baseline performance, clinical guidelines, expert groups, and other sources. Potential sources for performance benchmarks—for the quality measures recommended in this report—are detailed in the one-page measure descriptions that appear at the end of Chapter 3 through Chapter 6.

Quality measures are often reported as simple proportions that are calculated with a *numerator* equal to the number of individuals who received a recommended service and a corresponding *denominator* equal to the number of individuals who should have received the recommended service (Figure 2-3). Robust sample size is fundamental to this calculation, and it becomes an increasingly important and limiting factor if the analysis focuses on smaller subgroups or specific geographic areas such as adults with lung cancer in rural counties or African-American men with prostate cancer who reside in southwest Georgia (Clarke et al., 2003). The analytic challenge is further exacerbated when the objective is to compare the performance of hospitals or regions within the state or to assess subgroup disparities.[9] In such cases, it may be necessary to pool data over several years in order to develop reliable estimates.

Quality measures, particularly health outcome measures, may need to be risk-adjusted to account for individual patient factors, such as cancer stage, age, and other demographic characteristics, which would otherwise confound the results. In general, risk adjustment will be less important when monitoring progress toward specific state goals than for comparing

[9]See Chapter 7, *Crosscutting Issues for Assessing the Quality of Cancer Care,* for further discussion on addressing disparities in the quality of cancer care.

(Number of women aged 52 to 69 who had a mammogram in the past 2 years)	÷	(Number of women aged 52 to 69)	=	Percentage of women aged 52 to 69 who had a mammogram in the past 2 years

FIGURE 2-3 Sample calculation of a quality-of-cancer-care measure (breast cancer screening).

performance among Georgia's various regional cancer centers (McGlynn, 2003b).

Quality indicators, particularly process measures, often have a natural optimal standard of 100 percent (Landon et al., 2003). For example, all smokers should be offered help in quitting tobacco use. However, for some measures, optimal care does not imply a 100 percent standard because patients' comorbidities or other clinical considerations preclude using the recommended process. In other circumstances, patients may prefer a different treatment approach or other nonclinical factors, such as health insurance coverage, may impede access to care. Today's clinical guidelines, for example, recommend that women with early-stage breast cancer should receive adjuvant therapy if they undergo breast-conserving surgery (NCCN, 2004). The proportion of affected women who undergo breast-conserving surgery and receive appropriate adjuvant therapy might arguably be close to 100 percent. However, some women, after being fully informed of their treatment options, will opt for full mastectomies. Such realities must be taken into account but evaluators should also be vigilant in following up performance that falls short of a specific standard or 100 percent (whichever is appropriate).

SUMMARY

This chapter has described the conceptual framework and method for selecting quality-of-cancer-care measures to assess the progress of GCC's impressive cancer initiative. There is a well-established body of research and a sound, scientific evidence base for selecting valid and usable quality indicators for cancer care in Georgia. GCC will need a quality-of-cancer-care information infrastructure to monitor its progress. If this cancer information system includes accurate, complete, and timely data it will enable the state to identify where quality problems exist, to stimulate quality improvements, and to measure progress.

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Warren JL, Klabunde CN, Schrag D, Bach PB, Riley GF. 2002b. Overview of the SEER-Medicare data: content, research applications, and generalizability to the United States elderly population. *Med Care*. 40(8 Suppl): IV-3-18.

Wingo PA, Jamison PM, Hiatt RA, Weir HK, Gargiullo PM, Hutton M, Lee NC, Hall HI. 2003. Building the infrastructure for nationwide cancer surveillance and control—a comparison between the National Program of Cancer Registries (NPCR) and the Surveillance, Epidemiology, and End Results (SEER) Program (United States). *Cancer Causes Control*. 14(2): 175-93.

3

Preventing Cancer

"Georgia will have the lowest incidence, prevalence, and mortality rates for cancer in the nation."

Strategic Plan for the Georgia Cancer Coalition, 2001

"Failure to implement proven methods of cancer prevention leads to avoidable disease and death. A 19 percent decline in the rate at which new cancer cases occur and a 29 percent decline in the rate of cancer deaths could potentially be achieved by 2015 if efforts to help people change their behaviors that put them at risk were stepped up and if behavioral change were sustained."

Fulfilling the Potential of Cancer Prevention and Early Detection
Institute of Medicine, 2003

The objective of cancer prevention is to avoid the development of cancer through the use of interventions that eliminate or reduce exposures to the causes of cancer (e.g., tobacco and other carcinogens, obesity). In health care's arsenal of weapons to fight cancer, prevention holds tremendous potential (IOM, 2003). The Georgia Cancer Coalition (GCC) could harness much of the untapped potential of cancer prevention by working to close the gap between what is known and what is practiced in the common, everyday routines of physicians' offices. Among the first steps GCC might take to prevent unnecessary cancer morbidity and mortality are encouraging the use of evidence-based, effective means to help smokers quit smoking, as well as seeking to ensure that effective cancer screening procedures are used as recommended (see Chapter 4, *Detecting Cancer Early*) (IOM, 2003).

The Institute of Medicine (IOM) Committee on Assessing Improve-

BOX 3-1
Recommended Measures for Tracking the Quality of Cancer Prevention

Smoking Rates and Interventions

Measure 3-1	Adult smoking rate
Measure 3-2	Adolescent smoking rate
Measure 3-3	Smokers who receive advice to quit
Measure 3-4	Smokers who are recommended pharmacotherapy to assist in quitting smoking

Trend in Obesity

Measure 3-5	Adult obesity rate

Cancer Incidence Rates

Measure 3-6	Cancer incidence rate (all sites)
Measure 3-7	Breast cancer incidence rate
Measure 3-8	Colorectal cancer incidence rate
Measure 3-9	Lung cancer incidence rate
Measure 3-10	Prostate cancer incidence rate

ments in Cancer Care in Georgia recommends that Georgia adopt 10 quality indicators related to cancer prevention (Box 3-1). Four recommended measures are related to smoking rates and smoking cessation interventions. Smoking is the cause of 30 percent of all cancers, and almost one in four adults and high school students in Georgia smoke. The fifth recommended measure tracks obesity. Obesity is another major risk factor for cancer, but evidence-based solutions for reducing obesity are more elusive than those available for reducing smoking. The final five measures are measures of various cancer incidence rates. Cancer incidence rates are the ultimate indicators of the success of prevention efforts. With sustained meaningful improvement in cancer prevention, Georgia should eventually experience declining cancer incidence rates.

The 10 quality measures pertaining to cancer prevention recommended for Georgia are identified in this chapter. In addition, the rationale for the IOM committee's selection of these measures is provided. For each measure, there is a section providing a brief explanation of the evidence underlying the measure (the "consensus on care") and a description of what is known about the gap between the evidence and current practice ("knowledge vs. practice"). Also provided near the end of this chapter is a brief section on the potential data sources for the 10 recommended measures related to cancer prevention. The chapter concludes with one-page summaries of each

quality measure, including specifications for calculating the recommended measures. Chapter 4 (*Detecting Cancer Early*), Chapter 5 (*Diagnosing Cancer*), and Chapter 6 (*Treating Cancer*) are similarly organized.

RECOMMENDED MEASURES FOR TRACKING THE QUALITY OF CANCER PREVENTION

Smoking Rates and Interventions

The IOM committee recommends four measures to monitor smoking interventions in Georgia. Two of them are measures for routine surveillance of adult and adolescent smoking rates:

- Measure 3-1—*Adult smoking rate*—the proportion of adults who smoke cigarettes.
- Measure 3-2—*Adolescent smoking rate*—the proportion of adolescents who smoke cigarettes.

The other two are measures to monitor delivery of recommended smoking cessation interventions:

- Measure 3-3—*Smokers who receive advice to quit*—the proportion of adult smokers who were advised to quit smoking during a visit with a doctor, nurse, or other health professional.
- Measure 3-4—*Smokers who are recommended pharmacotherapy to assist in quitting smoking*—the proportion of adult smokers whose doctor, nurse, or other health professional recommended or discussed medication to assist quitting smoking.

Cigarette smoking accounts for at least 30 percent of cancer-related deaths and a staggering 87 percent of lung cancer deaths (ACS, 2004). Smokers are 20 times more likely than never-smokers to develop lung cancer (Alberg and Samet, 2003). Smoking is also a major cause of cancer of the larynx, oral cavity, throat, and esophagus and is a contributing cause in the development of cancers of the bladder, pancreas, liver, uterine cervix, kidney, stomach, colon and rectum, and some leukemias. An individual who quits smoking or refrains from starting smoking will experience substantial and immediate health benefits (U.S. DHHS, 2004).

If tobacco use does not begin in childhood or adolescence, it is unlikely to start in adulthood. Most adult smokers have their first cigarette before age 18, and more than half are daily smokers by age 18 (U.S. DHHS, 1994). Smokers who quit before age 50 have one-half the risk of dying in the next 15 years compared with continuing smokers. The benefit is even greater for

younger smokers who quit (Peto et al., 2000). The U.S. Surgeon General's office has estimated that after 10 years abstinence, the risk of lung cancer is 30 to 50 percent of the risk for continuing smokers (U.S. DHHS, 1990).

Consensus on Care

There is a wealth of evidence documenting how health providers can influence adult smokers to quit and an extensive body of clinical guidelines promoting the use of these interventions (U.S. DHHS, 2004). More than 100 randomized controlled clinical trials have shown modest but statistically significant reductions in tobacco use for adult smokers who receive physician counseling (Fiore et al., 2000; USPSTF, 2002). The likelihood of quitting smoking increases with the intensity of counseling (Fiore et al., 2000).

In its most recent review of the evidence on the efficacy of smoking interventions, the U.S. Preventive Services Task Force (USPSTF) concluded that, compared with no intervention, smoking-cessation interventions that include screening, behavioral counseling (as brief as 3 minutes), and pharmacotherapy delivered in primary care settings, are effective in helping adult smokers quit smoking and remain smoking-free after 1 year (USPSTF, 2002). Numerous pharmacotherapies approved by the Food and Drug Administration—including bupropion, nicotine gum, nicotine transdermal patches, inhalers, and nasal sprays—have been shown to be safe and effective for treating tobacco dependence. Success in abstaining from smoking among people who use these pharmacotherapies ranges from 18 to 31 percent, as compared with 10 to 17 percent among people who do not use them (Fiore et al., 2000).

In addition to the literature on clinical interventions, there is a substantial literature on community-based strategies for reducing exposure to environmental tobacco smoke, encouraging tobacco-use cessation, and discouraging the onset of tobacco use in children and adolescents (CDC, 2000).[1] Increasing the cost of tobacco and tobacco control programs that include mass media campaigns are among the strategies that have been shown to reduce the initiation of tobacco use among children and adolescents (Hopkins et al., 2001).

Unfortunately, little is known about the effectiveness of physician

[1]Given this report's focus on clinical indicators of quality care, it was beyond the scope of this study to assess potential indicators of community-based approaches to cancer prevention. GCC should consult the work of the U.S. Community Preventive Services Task Force for further information and evidence (see, for example, http://www.thecommunityguide.org/cancer/default.htm).

TABLE 3-1 Cigarette Smoking by Adults and Adolescents in Georgia

	Estimated smoking rate (%)		
Population group	Female	Male	Both sexes
Adults, ages 18 and older (2002)	20.1	26.6	23.2
Adolescents			
—Grades 9-12 (2001)	19.9	27.4	23.7
—Grades 6-8 (2001)	7.1	10.5	8.9

SOURCE: Martin et al., 2004; Kanny et al., 2002.

counseling of children and adolescents in preventing smoking initiation or promoting cessation (USPSTF, 2002).

Knowledge vs. Practice

Smoking is common in Georgia, as it is elsewhere in the United States. About 23 percent of the state's adults and high school students smoke cigarettes (Table 3-1). More than 10 percent of Georgia's sixth- to eighth-grade boys say they smoke cigarettes.

Despite the persuasive body of evidence supporting interventions to help smokers quit, many health providers do not follow the well-established guidelines for helping their smoking patients quit the habit. Nationwide, for example, in 2000 only 62 percent of adult smokers reported that their doctor had advised them to quit during a routine office visit in the previous year (AHRQ, 2003).

Smoking prevention and cessation has been recognized by GCC as an essential part of the fight against cancer. Approximately 37 percent of GCC's funds since 2001 have been invested in tobacco use prevention (GCC, 2003). Tracking smoking rates and the delivery of smoking cessation interventions will help GCC monitor its impact on the leading preventable cause of cancer.

Trend in Obesity

The IOM committee recommends that GCC regularly monitor rates of adult obesity in the state:

- Measure 3-5—*Adult obesity rate*—the proportion of adults who are obese.

Obesity is commonly defined using the formula based on weight and height known as the body mass index (BMI). Persons with a BMI of 30 or higher are considered obese. BMI is calculated as weight (in pounds) divided by height (in inches squared) multiplied by 703.[2] The chief causes of obesity are a sedentary life style and a high-calorie diet (Friedenreich, 2001; Kritchevsky, 2003).

Reporting adult obesity trends will be fundamental to tracking Georgians' risk for developing cancer. There is evidence that weight control may play an especially important role in the metabolic conditions amenable to carcinogenesis (Friedenreich, 2001). Numerous studies of cancer incidence show a relationship between increasing weight gain and the onset of cancer (IOM, 2003; Key et al., 2004). Recent estimates indicate that about 10 percent of breast and colorectal cancers can be attributed to overweight and obesity, and 25 to 40 percent of kidney, esophageal (adenocarcinoma), and endometrial cancers (Vainio and Bianchini, 2002).

Weight loss of only 5 to 10 percent of total weight provides health benefits such as improved lipid levels and blood pressure rate. However, it is not known if weight reduction in adult life meaningfully reduces one's risk of developing cancer.

Consensus on Care

Despite growing scientific evidence on the role of obesity in the epidemiology of cancer, there is a little evidence on the efficacy of any specific approach to preventing or treating obesity. The USPSTF recommends that clinicians screen all adults for obesity and offer intensive counseling and behavioral interventions for optimal weight loss (USPSTF, 2003). In its 2003 review of the evidence, the USPSTF found that the most effective interventions combine nutrition education and diet and exercise counseling with behavioral strategies to increase physical activity and help change eating habits.

Knowledge vs. Practice

Adult obesity rates have been steadily increasing in Georgia, rising from under 11 percent in 1990 to almost 24 percent in 2002 (Figure 3-1) (CDC, 2003). Despite this epidemic of obesity in Georgia and elsewhere in the United States, it appears that health care providers rarely counsel their patients regarding weight issues. In Georgia, the vast majority (81.8 percent) of adults in 2000, overweight or not, reported that they did not get

[2]A BMI calculator is available at www.nhlbisupport.com/bmi.

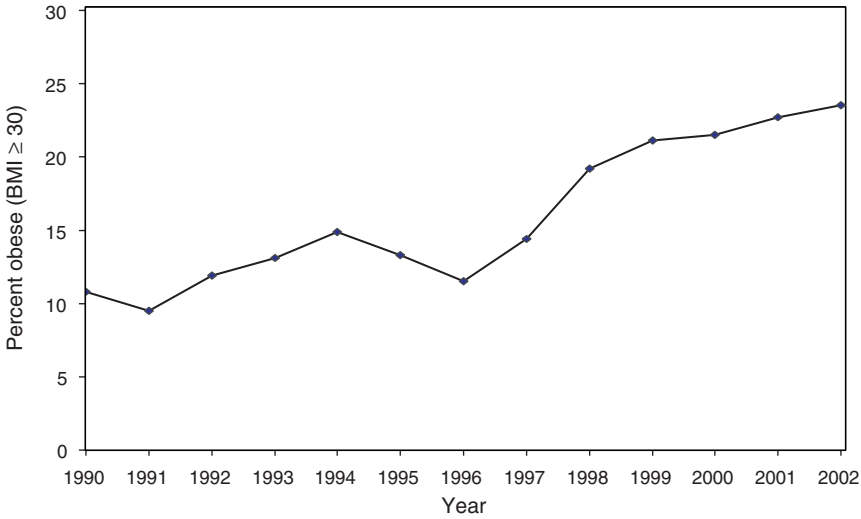

FIGURE 3-1 Obesity by body mass index, Georgia, 1990-2002.
SOURCE: CDC, 2003.

professional advice about weight control in the previous year (CDC, 2004a). It is not known whether Georgians were more likely to receive professional advice about their weight if they were obese. Nationally, about 43 percent of obese persons say that a health care professional had advised them to lose weight during a routine checkup in the previous year (Mokdad et al., 2001).

Cancer Incidence Rates

The IOM committee recommends that GCC routinely monitor the overall incidence of cancer as well as the specific incidence of breast, colorectal, lung, and prostate cancers (see below).

- Measure 3-6—*Cancer incidence rate (all sites)*
- Measure 3-7—*Breast cancer incidence rate*
- Measure 3-8—*Colorectal cancer incidence rate*
- Measure 3-9—*Lung cancer incidence rate*
- Measure 3-10—*Prostate cancer incidence rate*

Cancer incidence rates are important measures of the burden of cancer in a population, usually expressed as the number of newly diagnosed cancers

TABLE 3-2 Incidence of the Four Leading Cancers in Georgia, by Sex, 2000

Cancer site	Incidence rate (per 100,000)[a]	Number of cases	Percent
Lung and bronchus			
Male	108.8	3,095	10
Female	51.5	1,965	6
Breast (female)	125.6	4,953	16
Colorectal			
Male	62.2	1,762	6
Female	43.6	1,690	5
Prostate	164.5	4,729	15
Subtotal	—	18,194	58
All cancers		31,591	100
Male	558.1	16,388	52
Female	388.0	15,203	48

[a]Age-adjusted to year 2000 population.
SOURCE: U.S. Cancer Statistics Working Group, 2003; NCI and CDC, 2004.

per 100,000 population at risk.[3] The population used depends on the rate to be calculated. For cancer sites that occur in only one sex, the sex-specific population (e.g., males for prostate cancer) is used. Table 3-2 shows the estimated incidence of the four leading types of cancers in Georgia in 2000: breast, colorectal, lung, and prostate.

Incidence data are fundamental to planning and evaluating cancer control programs. If, for example, Georgia succeeds in significantly reducing smoking rates, real progress, over the long term, will be evident in the state's cancer incidence data, especially for lung cancer. Similarly, if Georgia markedly improves the quality and prevalence of colorectal cancer screening, this will ultimately be apparent in a corresponding decline in the incidence of colorectal cancer. Some caution is required in interpreting incidence rates since, in the short term, incidence may appear to increase in underscreened populations or with the introduction of more sensitive screening techniques.

[3]Incidence refers to the rate of new cases of a disease, whereas prevalence refers to the proportion of a specified population that has the disease at a given point (or period) in time.

DATA SOURCES

The data for the 10 prevention-related quality-of-cancer-care measures recommended for Georgia may be drawn from two sources: population surveys and tumor registries. As shown in Table 3-3, some data sources are Georgia based and others are national.

The Behavioral Risk Factor Surveillance System (BRFSS), sponsored by the Centers for Disease Control and Prevention (CDC), will be an essential source of information on Georgians who are at risk for cancer because of smoking or dietary habits. The BRFSS is specifically designed to produce annual, state-level estimates of population trends in behaviors related to cancer and other diseases. BRFSS field operations are managed by state health departments, so Georgia will have considerable flexibility to exploit the full potential of the survey. Furthermore, national-level findings are available on the CDC website and will provide useful benchmarks for Georgia to assess its progress. The Georgia Youth Tobacco Survey will be essential to monitoring adolescent smoking rates. At present, the survey only targets adolescents enrolled in school. Georgia should consider expanding the survey to reach an especially vulnerable population, teenagers who do not attend school. Tumor registries are the principal data source for computing cancer incidence rates. Further information about potential data sources is presented in Chapter 2, *Concepts, Methods, and Data Sources* and in Appendixes A and B.

SUMMARY

The application of evidence-based preventive services could help reduce the burden of cancer in Georgia. A considerable body of research has shown, for example, that smoking cessation interventions such as brief, behavioral counseling and pharmacotherapy are effective in helping adult smokers quit and remain smoking-free for 1 year. In this chapter, the IOM committee has recommended 10 quality-of-cancer-care measures to gauge GCC's success in closing the gap between what is known about cancer prevention and what is practiced in the common, everyday routines of Georgia's physician offices.

TABLE 3-3 Potential Data Sources for Recommended Measures of the Quality of Cancer Prevention in Georgia[a]

	Potential Georgia-Based Data Sources			Potential National Data Sources for Benchmarking and Comparison				
Quality Measure	Georgia BRFSS	GCCR and Georgia SEER	Georgia Youth Tobacco Survey	BRFSS	Healthy People 2010	NHQR	SEER	YRBSS
Smokers receive advice to quit	❍			●				
Pharmacotherapy to quit smoking	❍			●				
Adult smoking rate	●			●	●	●		
Adolescent smoking rate			●		●			●
Adult obesity rate	●			●				
Cancer incidence rates		●			●	●	●	

[a]See Chapter 2, *Concepts, Methods, and Data Sources,* and Appendixes A and B for descriptions of data sources.
NOTE: BRFSS = Behavioral Risk Factor Surveillance System; GCCR = Georgia Comprehensive Cancer Registry; SEER = Surveillance, Epidemiology, and End Results; NHQR = National Healthcare Quality Report; YRBSS =Youth Risk Behavioral Surveillance System. The symbol ● indicates data are currently available. The symbol ❍ indicates that enhancements to current data collection are required. A blank indicates that the data source is not appropriate for that measure.

QUALITY MEASURE SPECIFICATIONS: PREVENTING CANCER

The following section contains summary descriptions of the quality indicators presented in this chapter. These quality indicators were drawn from a variety of clinical practice setting organizations, federal programs, provider groups, and other sources. See Appendix A for descriptions of each of these organizations, including their classification schemes for grading clinical recommendations and characterizing evidence.

Measure 3-1.	Adult Smoking Rate
Measure 3-2.	Adolescent Smoking Rate
Measure 3-3.	Smokers Who Receive Advice to Quit
Measure 3-4.	Smokers Who Are Recommended Pharmacotherapy to Assist in Quitting Smoking
Measure 3-5.	Adult Obesity Rate
Measure 3-6.	Cancer Incidence Rate (All Sites)
Measure 3-7.	Breast Cancer Incidence Rate
Measure 3-8.	Colorectal Cancer Incidence Rate
Measure 3-9.	Lung Cancer Incidence Rate
Measure 3-10.	Prostate Cancer Incidence Rate

MEASURE 3-1: PREVENTING CANCER—Adult Smoking Rate

Description	Adult smoking rate
Source	Healthy People 2010
Consensus on care	Cigarette smoking is a major risk factor for lung cancer and contributes to the development of other types of cancer. Nonsmokers should be discouraged from starting. Intensive tobacco counseling and pharmacotherapy have been shown to be safe and effective in helping current smokers to quit. The U.S. Preventive Services Task Force strongly recommends that clinicians screen all adults for tobacco use and provide tobacco cessation interventions for those who use tobacco products (Category A recommendation).
Knowledge vs. practice	Tobacco use accounts for at least 30 percent of all cancer deaths and 87 percent of lung cancer deaths in Georgia. In 2002, 23.2 percent of adults in Georgia smoked cigarettes.

Approach to calculating the measure

Numerator	Number of adults who smoke cigarettes
Denominator	Number of adults
Potential data source(s)	Behavioral Risk Factor Surveillance System
Comments	Adjusted to year 2000 population standard. Adults include all persons age 18 and older.

Limitations	Potential response bias.
Potential benchmark source(s)	Behavioral Risk Factor Surveillance System; Healthy People 2010

Key references

GDPH. 2004. *OASIS Web Query—Death Statistics*. [Online] http://oasis.state.ga.us/webquery/death.html [accessed April 2004].

IOM. 2003. *Fulfilling the Potential of Cancer Prevention and Early Detection*. Washington, DC: The National Academies Press.

Martin LM, et al. 2004. *Georgia Behavioral Risk Factor Surveillance System, 2002 Report*. Atlanta, GA: Georgia Department of Human Resources. Publication Number DPH04-158HW.

U.S. DHHS. 2000. *Healthy People 2010: Understanding and Improving Health. Chapter 27. Tobacco Use*. 2nd ed. Washington, DC: U.S. GPO. [Measure 27-1a.]

USPSTF. 2002. *Guide to Clinical Preventive Services. Counseling to Prevent Tobacco Use and Tobacco-Caused Disease*. Rockville, MD: AHRQ.

MEASURE 3-2: PREVENTING CANCER—Adolescent Smoking Rate

Description	Adolescent smoking rate
Source	Healthy People 2010
Consensus on care	Smoking should be discouraged among adolescents. Most adult smokers had their first cigarette before age 18, and more than half were daily smokers by age 18. There is evidence that if tobacco use does not begin in childhood or adolescence, it is unlikely to start in adulthood. The U.S. Preventive Services Task Force finds limited evidence that counseling adolescents in the primary care setting is effective in preventing adolescent smoking or in helping adolescents to quit.
Knowledge vs. practice	In 2001, 23.7 percent of Georgia high school students and 8.9 percent of Georgia middle school students reported smoking cigarettes in the last 30 days.
Approach to calculating the measure	
Numerator	Number of students in grades 9 through 12 who smoked cigarettes on one or more of the previous 30 days
Denominator	Number of students in grades 9 through 12
Potential data source(s)	Youth Risk Behavior Surveillance System; Youth Tobacco Survey
Comments	—
Limitations	Data only reflect the subset of adolescents enrolled in high school; thus, adolescents at greatest risk are missed (i.e. high school dropouts, younger or older teens). Potential response bias.
Potential benchmark source(s)	Youth Risk Behavior Surveillance System; Healthy People 2010

Key references

ASCO. 2003. American Society of Clinical Oncology policy statement update: tobacco control—reducing cancer incidence and saving lives. *J Clin Oncol.* 21(14): 2777-86.

Kanny D, et al. 2002. *Georgia Youth Tobacco Survey, 2001.* Atlanta, GA: Georgia Department of Human Resources. Publication Number DPH02.72HW.

National Center for Chronic Disease Prevention and Health Promotion. 2003. *YRBSS Youth Risk Behavior Surveillance System.* [Online] Available: http://www.cdc.gov/nccdphp/dash/yrbs/index.htm [accessed August 26, 2004].

U.S. DHHS. 2000. *Healthy People 2010: Understanding and Improving Health*. 2nd ed. *Chapter 27. Tobacco Use.* Washington, DC: U.S. GPO. [Measure 27-2b.]

USPSTF. 2002. *Guide to Clinical Preventive Services. Counseling to Prevent Tobacco Use and Tobacco-Caused Disease.* Rockville, MD: AHRQ.

MEASURE 3-3: PREVENTING CANCER—Smokers Who Receive Advice to Quit

Description	Smokers who receive advice to quit
Source	National Healthcare Quality Report; Health Employer Data Information Set
Consensus on care	Many of the health risks associated with smoking are reduced after quitting. The U.S. Preventive Services Task Force strongly recommends that clinicians screen all adults for tobacco use and provide tobacco cessation interventions for those who use tobacco (Category A recommendation). USPSTF found "good evidence" that, compared with no intervention, brief smoking cessation interventions, including screening, brief behavioral counseling (< 3 minutes), and pharmacotherapy delivered in primary care settings, are effective in helping smokers quit smoking and remain smoking-free after 1 year. The U.S. Department of Health and Human Services Public Health Service reports that quit rates are directly related to the intensity of counseling (Strength of Evidence grade A).
Knowledge vs. practice	In 2002, 23.2 percent of adults in Georgia smoked cigarettes. National data indicate that in 2000, 62 percent of smokers who had a routine office visit reported that their doctors had advised them to quit.
Approach to calculating the measure	
Numerator	Number of adult smokers who were advised to quit smoking during a visit with a doctor, nurse, or other health professional in the past year
Denominator	Adults who smoke and who saw a doctor, nurse, or other health professional in the past year
Potential data source(s)	Behavioral Risk Factor Surveillance System
Comments	—
Limitations	Potential recall and response bias.
Potential benchmark source(s)	National Healthcare Quality Report; Behavioral Risk Factor Surveillance System

Key references

AHRQ. 2003. *National Healthcare Quality Report*. Rockville, MD: U.S. Department of Health and Human Services.

Fiore MC, et al. 2000. *Treating Tobacco Use and Dependence. Clinical Practice Guideline*. Rockville, MD: U.S. Department of Health and Human Services, Public Health Service.

GDPH. 2004. *OASIS Web Query—Death Statistics*. [Online] http://oasis.state.ga.us/webquery/death.html [accessed April 2004].

Martin LM, et al. 2004. *Georgia Behavioral Risk Factor Surveillance System, 2002 Report*. Alanta, GA: Georgia Department of Human Resources. Publication Number DPH04/158HW.

NCQA. 2004. *Advising Smokers to Quit*. [Online] Avaiable: http://www.ncqa.org/programs/radd/expanded%20web%20version/advising_smokers_to_quit.htm#Measure [accessed August 2004].

MEASURE 3-4: PREVENTING CANCER—Smokers Who Are Recommended Pharmacotherapy to Assist in Quitting Smoking

Description	Smokers who are recommended pharmacotherapy to assist in quitting smoking
Source	U.S. Preventive Services Task Force (USPSTF); U.S. Department of Health and Human Services, Public Health Service (Strength of Evidence grade A)
Consensus on care	Many of the health risks associated with smoking are reduced after quitting. The USPSTF strongly recommends that clinicians screen all adults for tobacco use and provide tobacco cessation interventions for those who use tobacco (Category A recommendation). USPSTF found "good quality" studies documenting higher quitting rates among people who use nicotine replacement products compared with people who do not. There are numerous Food and Drug Administration-approved pharmacotherapies, such as nicotine gum, nicotine transdermal patches, inhalers, and nasal sprays that have been shown to be safe and effective for treating tobacco dependence.
Knowledge vs. practice	In 2002, 23.2 percent of adults in Georgia smoked cigarettes.
Approach to calculating the measure	
Numerator	Number of adult smokers whose doctor, nurse, or other health professional recommended or discussed medication to assist quitting smoking in the past year
Denominator	All adult smokers
Potential data sources	Behavioral Risk Factor Surveillance System
Comments	Adults include all persons aged 18 and older.
Limitations	It is uncertain whether tobacco cessation pharmacotherapy is safe and effective for pregnant women, nursing mothers, children, and adolescents. The measure does not capture advice given to younger smokers. Potential recall and response bias.
Potential benchmark source(s)	Behavioral Risk Factor Surveillance System

Key references

CDC. 2004. *Behavioral Risk Factor Surveillance System: Questionnaires*. [Online] Available at http://www.cdc.gov/brfss/questionnaires/questionnaires.htm [accessed November 26, 2004.

Fiore MC, et al. 2000. *Treating Tobacco Use and Dependence. Clinical Practice Guideline*. Rockville, MD: U.S. Department of Health and Human Services, Public Health Service.

GDPH. 2004. *OASIS Web Query—Death Statistics*. [Online] http://oasis.state.ga.us/webquery/death.html [accessed April 2004].

Martin LM, et al. 2004. *Georgia Behavioral Risk Factor Surveillance System, 2002 Report*. Atlanta, GA: Georgia Department of Human Resources. Publication Number DPH04/158HW.

NCQA. 2004. *Advising Smokers to Quit*. [Online] Avaiable: http://www.ncqa.org/programs/radd/expanded%20web%20version/advising_ smokers_to_quit.htm#Measure [accessed August 2004].

USPSTF. 2002. *Guide to Clinical Preventive Services. Counseling to Prevent Tobacco Use and Tobacco-Caused Disease*. Rockville, MD: AHRQ.

MEASURE 3-5: PREVENTING CANCER—Adult Obesity Rate

Description	Adult obesity rate
Source	Healthy People 2010
Consensus on care	Body mass index (BMI) is defined as weight in kilograms divided by square of the height in meters (BMI = weight[kg]/height[m^2]). Obesity is defined as a BMI of 30 or more. Obesity is a risk factor for some types of cancers, including breast and colorectal cancer. According to the International Agency on Research in Cancer, about 10 percent of breast and colorectal cancers may be attributable to overweight and obesity. The U.S. Preventive Services Task Force recommends that all clinicians screen all adults for obesity and offer intensive counseling and behavioral interventions (Category B recommendation). It is a goal of Healthy People 2010 to reduce the proportion of adults who are obese.
Knowledge vs. practice	In Georgia, 23.5 percent of adults are obese, and obesity rates vary by race, 20.7 percent of whites compared with 31.2 percent of blacks.
Approach to calculating the measure	
Numerator	Number of adults aged 18 and older who have a BMI ≥ 30 kg/m^2
Denominator	Number of adults aged 18 and older
Potential data source(s)	Behavioral Risk Factor Surveillance System
Comments	BMI is calculated from self-reported height and weight.
Limitations	Cancer-related health risks from obesity past age 74 are unclear. Potential recall and response bias.
Potential benchmark source(s)	Behavioral Risk Factor Surveillance System; Healthy People 2010
Key references	IOM. 2003. *Fulfilling the Potential of Cancer Prevention and Early Detection*. Washington, DC: The National Academies Press. Martin LM, et al. 2004. *Georgia Behavioral Risk Factor Surveillance System, 2002 Report*. Atlanta, GA: Georgia Department of Human Resources. Publication Number DPH04/158HW. McTigue KM, et al. 2003 Screening and interventions for obesity in adults: summary of the evidence for the U.S. Preventive Services Task Force. *Ann Intern Med*. 139(11):933-949. U.S. DHHS. 2000. *Healthy People 2010: Understanding and Improving Health*. 2nd ed. *Chapter 19 Nutrition and Overweight*. Washington, DC: U.S. GPO. [Measure 19-2.] USPSTF. 2003. Screening for Obesity in Adults. *What's New from the U.S. Preventive Services Task Force*. Rockville, MD: AHRQ.

MEASURE 3-6: PREVENTING CANCER—Cancer Incidence Rate (All Sites)

Description	Cancer incidence rate (all sites)
Source	Routine surveillance statistic
Consensus on care	Incidence statistics are key to monitoring overall cancer burden and the health care system's capacity to meet the need for services.
Knowledge vs. practice	In 2000, Georgia's cancer incidence rates were 558.1 per 100,000 and 388.0 per 100,000 for males and females, respectively. Nationally they were 546.9 per 100,000 and 409.4 per 100,000.
Approach to calculating the measure	
Numerator	Number of new cancer cases
Denominator	Total Georgia population
Potential data source(s)	Georgia Comprehensive Cancer Registry
Comments	Incidence rate = (New cancers/Population) × 100,000. Estimate should be age-adjusted to allow comparisons.
Limitations	Increasing incidence may reflect improvements in screening rates and technologies rather than a real increase in cancer. Incidence is a long-term indicator; substantial time must pass before GCC would have any impact on breast cancer incidence. Incidence is not a full measure of the burden of cancer and ignores duration, mortality, quality of life, and other factors.
Potential benchmark source(s)	Surveillance, Epidemiology, and End Results Program, U.S. Cancer Statistics publications
Key references	U.S. Cancer Statistics Working Group. 2003. *United States Cancer Statistics: 2000 Incidence.* Atlanta, GA: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention and National Cancer Institute.

MEASURE 3-7: PREVENTING CANCER—Breast Cancer Incidence Rate

Description	Breast cancer incidence rate
Source	Routine surveillance statistic
Consensus on care	Incidence statistics are key to monitoring cancer burden and the health care system's capacity to meet the need for services.
Knowledge vs. practice	In 2000, Georgia's breast cancer incidence rate was 125.6 per 100,000; nationally it was 128.9 per 100,000.
Approach to calculating the measure	
Numerator	Number of new breast cancer cases
Denominator	Number of females in Georgia
Potential data source(s)	Georgia Comprehensive Cancer Registry
Comments	Incidence rate = (New cancers/Population) × 100,000. Estimate should be age-adjusted to allow comparisons.
Limitations	Increasing incidence may reflect improvements in screening rates and technologies rather than a real increase in breast cancer, so incidence statistics may need to be interpreted with stage and mortality statistics. Incidence is a long-term indicator; substantial time must pass before GCC would have any impact on cancer incidence.
Potential benchmark source(s)	Surveillance, Epidemiology, and End Results Program; U.S. Cancer Statistics publications
Key references	U.S. Cancer Statistics Working Group. 2003. *United States Cancer Statistics: 2000 Incidence.* Atlanta, GA: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention and National Cancer Institute.

MEASURE 3-8: PREVENTING CANCER—Colorectal Cancer Incidence Rate

Description	Colorectal cancer incidence rate
Source of measure	Routine surveillance statistic
Consensus on care	Recent studies show an association between colorectal cancer screening and decreased incidence of and mortality from colorectal cancer. Survey data suggest that colorectal cancer screening rates in Georgia fall far short of recommended levels.
Knowledge vs. practice	In 2000, Georgia's colorectal cancer incidence rates were 62.2 per 100,000 and 43.6 per 100,000 for males and females, respectively. Nationally, they were 65.0 per 100,000 and 47.0 per 100,000.
Approach to calculating the measure	
Numerator	Number of new colorectal cancer cases
Denominator	Total Georgia population
Potential data source(s)	Georgia Comprehensive Cancer Registry
Comments	Incidence rate = (New cancers/Population) × 100,000. Estimate should be age-adjusted to allow comparisons.
Limitations	Increasing incidence may reflect improvements in screening rates and technologies rather than a real increase in colorectal cancer, so incidence statistics may need to be interpreted with stage and mortality statistics. Incidence rates are long-term indicators; substantial time must pass before GCC would have any impact on colorectal cancer incidence.
Potential benchmark source(s)	Surveillance, Epidemiology, and End Results Program; U.S. Cancer Statistics publications
Key references	CDC. 2004. *Behavioral Risk Factor Surveillance System, Prevalence Data: Georgia 2002 Colorectal Cancer Screening*. [Online] Available: http://apps.nccd.cdc.gov/brfss/display.asp?cat=CC&yr=2002&qkey=7400&state=GA [accessed November 26, 2004]. IOM. 2003. *Fulfilling the Potential of Cancer Prevention and Early Detection*. Washington, DC: The National Academies Press. U.S. Cancer Statistics Working Group. 2003. *United States Cancer Statistics: 2000 Incidence*. Atlanta, GA: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention and National Cancer Institute.

MEASURE 3-9: PREVENTING CANCER—Lung Cancer Incidence Rate

Description	Lung cancer incidence rate
Source	Routine surveillance statistic
Consensus on care	More than 80 percent of lung cancers can be attributed to smoking. Lung cancer incidence in Georgia should drop if GCC succeeds in lowering smoking rates.
Knowledge vs. practice	In 2000, Georgia's lung cancer incidence rates were 108.0 per 100,000 and 51.5 per 100,000 for males and females, respectively. Nationally, they were 87.9 per 100,000 and 51.5 per 100,000.
Approach to calculating the measure	
Numerator	Number of new lung cancer cases
Denominator	Total Georgia population
Potential data source(s)	Georgia Comprehensive Cancer Registry
Comments	Incidence rate = (New cancers/Population) × 100,000. Estimate should be age-adjusted to allow comparisons.
Limitations	Incidence rates are long-term indicators; substantial time must pass before GCC would have any impact on lung cancer incidence.
Potential benchmark source(s)	Surveillance, Epidemiology, and End Results Program; U.S. Cancer Statistics publications
Key references	IOM. 2003. *Fulfilling the Potential of Cancer Prevention and Early Detection*. Washington, DC: The National Academies Press. Martin LM, et al. 2004. *Georgia Behavioral Risk Factor Surveillance System, 2002 Report*. Atlanta, GA: Georgia Department of Human Resources. Publication Number DPH04/158HW. U.S. Cancer Statistics Working Group. 2003. *United States Cancer Statistics: 2000 Incidence*. Atlanta, GA: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention and National Cancer Institute.

MEASURE 3-10: PREVENTING CANCER—Prostate Cancer Incidence Rate

Description	Prostate cancer incidence rate
Source	Routine surveillance statistic
Consensus on care	Incidence statistics are key to monitoring cancer burden and the health care system's capacity to meet the need for services.
Knowledge vs. practice	In 2000, Georgia's prostate cancer incidence rate was 164.5 per 100,000; nationally, it was 160.4 per 100,000.
Approach to calculating the measure	
Numerator	Number of new prostate cancer cases
Denominator	Number of males in Georgia
Potential data source(s)	Georgia Comprehensive Cancer Registry
Comments	Incidence rate = (New cancers/Population) × 100,000. Estimate should be age-adjusted to allow comparisons.
Limitations	Increasing incidence may reflect improvements in screening rates and technologies rather than a real increase in prostate cancer, so incidence statistics may need to be interpreted with stage and mortality statistics. Incidence rates are long-term indicators; substantial time must pass before GCC would have any impact on prostate cancer incidence.
Potential benchmark source(s)	Surveillance, Epidemiology, and End Results Program; U.S. Cancer Statistics publications
Key references	U.S. Cancer Statistics Working Group. 2003. *United States Cancer Statistics: 2000 Incidence*. Atlanta, GA: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention and National Cancer Institute.

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4

Detecting Cancer Early

"Because early detection remains the best guarantee for successful treatment, the Coalition will develop a statewide screening and early detection network of public and private healthcare providers so that every Georgian will have access to cancer screenings."

Strategic Plan for the Georgia Cancer Coalition, 2001

"In summary, one of the safest, simplest, and most cost-effective ways to reduce cancer morbidity and mortality is to raise the screening rates for selected cancers. There is considerable consensus among experts about high quality screening practices."

National Healthcare Quality Report,
Agency for Healthcare Research and Quality, 2003

The early detection of cancer refers to the use of screening tests to identify cancer or premalignant disease in persons without signs or symptoms of the disease. It is well established that finding breast cancer and colorectal cancer at an early stage and promptly beginning appropriate treatment—before symptoms develop—improves health outcomes and saves lives (IOM, 2003; NCI, 2004a).

Unfortunately, though, what is known about the potential of early cancer detection is not reflected in current practice (Roetzheim et al., 1999; Breen et al., 2001).

Regular mammography screening for early detection of breast cancer may be a routine in many women's lives, but far too many women are still

BOX 4-1
Recommended Measures for Tracking the Quality of Early Cancer Detection

Use of Cancer Screening Interventions
Measure 4-1 Breast cancer screening rate
Measure 4-2 Colorectal cancer screening rate

Cancer Stage at Diagnosis
Measure 4-3 Early-stage breast cancer diagnosis
Measure 4-4 Advanced-stage breast cancer diagnosis
Measure 4-5 Advanced-stage colorectal cancer diagnosis

not screened as recommended (Coughlin et al., 2004).[1] Large proportions of low-income and uninsured women are especially at risk of not being screened for breast cancer (Rao et al., 2004; Taplin et al., 2004). Rates of colorectal cancer screening fall far short of recommended levels across the board (Swan et al., 2003). If the Georgia Cancer Coalition (GCC) raises breast and colorectal cancer screening rates in Georgia to recommended levels, the state is likely to experience significant declines in cancer-related morbidity and mortality (assuming newly identified cases are promptly followed with appropriate treatment).

The Institute of Medicine (IOM) committee recommends that Georgia adopt five quality indicators to assess the state's progress in achieving the full potential of early cancer detection (Box 4-1). Two of the indicators would be used to monitor cancer screening rates and three would track cancer stage at diagnosis to gauge the impact of improvements in cancer screening and other means of early detection.

The five recommended quality measures pertaining to cancer early detection are discussed further below, along with the rationale for their selection. For each measure discussed, there is a section providing a brief explanation of the evidence underlying the measure (the "consensus on care") and a description of what is known about the gap between the evidence and current practice ("knowledge vs. practice"). Potential data sources for measures in the early detection domain are briefly discussed, as

[1]See Chapter 7, *Crosscutting Issues in Assessing the Quality of Cancer Care*, for a discussion about using quality indicators to address disparities in the behaviors and conditions that lead to cancer, as well as in the incidence, diagnosis, treatment, and outcomes of cancer.

well. Summaries of each recommended quality measure in the early detection domain appear at the end of the chapter.

RECOMMENDED MEASURES FOR TRACKING THE QUALITY OF EARLY CANCER DETECTION

Use of Cancer Screening Interventions

The IOM committee recommends two quality measures to monitor use of screening services for breast cancer and colorectal cancer:

- Measure 4-1—*Breast cancer screening rate*—the proportion of women aged 52 to 69 with one or more mammograms in the past 2 years.
- Measure 4-2—*Colorectal cancer screening rate*—the proportion of adults aged 52 to 80 who have received either a fecal occult blood test within the past year, flexible sigmoidoscopy within the past 5 years, colonoscopy within the past 10 years, or double-contrast barium enema within the past 5 years.

Lung and prostate cancer screening measures are not recommended. A cost-effective screening method for lung cancer has yet to be developed (Mahadevia et al., 2003). Prostate screening is controversial. Although the prostate-specific antigen (PSA) screening test detects very early cancers, some of these cancers might not cause any harm if left untreated and, if treated, might lead to impotence and incontinence (Harris and Lohr, 2002; USPSTF, 2002d; Clark et al., 2003). PSA screening is also associated with false positive results and unnecessary anxiety, biopsies, and follow-up diagnostic procedures (Sirovich et al., 2003).

Breast Cancer Screening Rate

Early detection of breast cancer saves women's lives (Fletcher and Elmore, 2003; IOM, 2005; NCI, 2004b). Strong evidence from numerous randomized clinical trials has shown that routine mammography screening, by detecting cancers sufficiently early for curative treatment, cuts the risk of death from breast cancer by as much as 30 percent (USPSTF, 2002b; IOM, 2003).

In Georgia, breast cancer is the most commonly diagnosed cancer and the second leading cause of cancer death for women—4,953 women were diagnosed with breast cancer and 996 women died of the disease in 2000 (NCI and CDC, 2004; GDPH, 2004b). The American Cancer Society estimates that 6,080 new cases of breast cancer will be diagnosed in Georgia in 2004 (ACS, 2004).

The IOM committee recommends that Georgia monitor mammography rates among women aged 50 to 69, with the goal of increasing the rate statewide. The choice of this age group is a pragmatic one. The evidence supporting regular mammography is strongest for women aged 50 to 69 compared with either younger or older women (USPSTF, 2002b). The measure focuses on a starting age of 52, rather than age 50, because it will be applied retrospectively and should allow for the full 2 years to receive recommended screening. This age group is also targeted by the National Committee for Quality Assurance through its HEDIS program (NCQA, 2004). HEDIS, the Health Plan Employer Data and Information Set, is one of the most widely-used, standardized approaches for assessing the quality of health plans, especially with respect to preventive services.[2]

Consensus on care. Clinical guidelines with respect to the age at which women should begin regular mammography screening vary. One reason is that the risk of developing breast cancer is age-related. Breast cancer is rare among younger women but incidence increases steadily beginning at age 40 and continues to rise until it peaks in women aged 70 to 79. Among Georgia women under age 40, for example, only 14 per 100,000 were diagnosed with breast cancer from 1999 to 2000 (ACS et al., 2003) (Figure 4-1). During the same period, there were 270 breast cancer cases per 100,000 women aged 50 to 59 and 402 breast cancer cases per 100,000 women aged 70 to 79.

Although there is a strong consensus that all women should receive mammograms every 1 to 2 years beginning at age 50, some groups urge that screening begin at age 40 (IOM, 2003). Earlier screening is advised for those with an increased risk for the disease. The U.S. Preventive Services Task Force (USPSTF) has concluded that the evidence is strongest for women aged 50 to 69, although many studies also indicate a mortality benefit for women aged 40 to 49 (USPSTF, 2002b). Most groups have not issued specific recommendations for women older than age 70 because so few studies have included this age group (Fletcher and Elmore, 2003). Only two randomized trials have enrolled women over age 69, and no trials have enrolled women over age 74 (Humphrey et al., 2002; USPSTF, 2002b; Fletcher and Elmore, 2003).

Knowledge vs. practice. A substantial proportion of Georgia women report having had a mammogram in the past 2 years—81.8 percent of women aged 55 to 64 and 77.5 percent of women over age 64 (Martin et al., 2004). Nevertheless, two vulnerable groups of women—those with lower incomes

[2]See Appendix A for additional information on HEDIS.

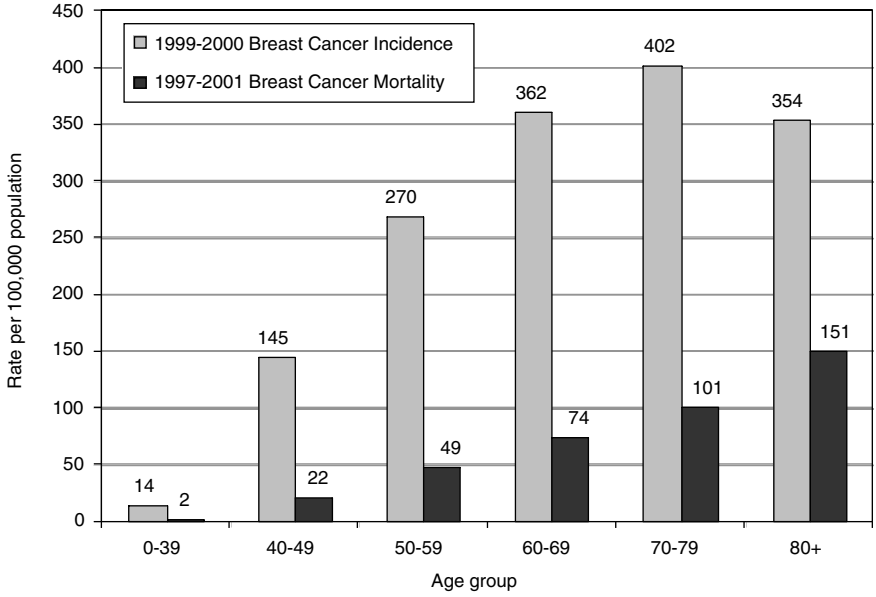

FIGURE 4-1 Breast cancer incidence and mortality in Georgia, by age group, 1997-2001.
NOTE: Rates are annualized and age-adjusted to the 2000 U.S. standard population.
SOURCE: ACS, 2003.

and those who report that they did not have health insurance or they were unable to see a doctor "because of cost" in the previous year—are significantly less likely to be screened. In 2002, as shown in Table 4-1, mammography screening rates for women aged 40 and older with incomes under $25,000 were 15 percentage points lower than the rates for women with incomes of at least $35,000 (65.9 percent or lower vs. 81.7 percent or higher) (Martin et al., 2004). Lacking health insurance and difficulties with medical care costs were particularly significant barriers to getting a mammogram. Almost half of Georgia women aged 40 and older (i.e., 49.7 percent) who cited these difficulties with access to care also reported not having been screened for breast cancer.

Colorectal Cancer Screening Rate

Screening for colorectal cancer substantially improves one's chances of surviving the disease. It has also been credited with preventing the disease, because when precancerous (referred to as adenomatous) polyps are

TABLE 4-1 Breast Cancer Screening Rate Among Women over Age 40 in Georgia, by Income and Access to Medical Care, 2002

Population of Women	Mammogram in the Past 2 Years (%)
All women	75.5
By income group	
—Less than $15,000	63.8
—$15,000 to $24,999	65.9
—$25,000 to $34,999	72.8
—$35,000 to $49,999	81.7
—$50,000 to $74,999	82.2
—$75,000 or more	85.6
By access to medical care	
—No health insurance or unable to see a doctor "because of cost"	49.7
—All others	79.5

SOURCE: Martin, et al. 2004.

detected during screening, they can be removed during the procedure (Mandel et al., 2000; Winawer et al., 2003). More than 80 percent of colorectal cancers begin as adenomatous polyps (USPSTF, 2002c).

Colorectal cancer is the second leading cause of cancer death for males and females in the United States. Almost 3,300 Georgians were diagnosed with and 1,260 died of the disease in 2000 (Landis et al., 2004). The risk of developing colorectal cancer increases with age, rising sharply beginning at age 50 (Figure 4-2).

The IOM committee recommends that Georgia monitor colorectal screening rates for all adults aged 50 to 80. The measure focuses on adults starting at age 52, rather than age 50, to allow for the first 2-year period during which recommended screening should occur.

Consensus on care. USPSTF and most other guidelines recommend that, starting at age 50, all people should be periodically screened for colorectal cancer using one of the available options (USPSTF, 2002b; Winawer et al., 2003; IOM, 2003). As shown in Box 4-2, several types of procedures with different frequency are recommended for colorectal cancer screening: the home fecal occult blood test (FOBT), flexible sigmoidoscopy, the combination of home FOBT and flexible sigmoidoscopy, colonoscopy, and double-

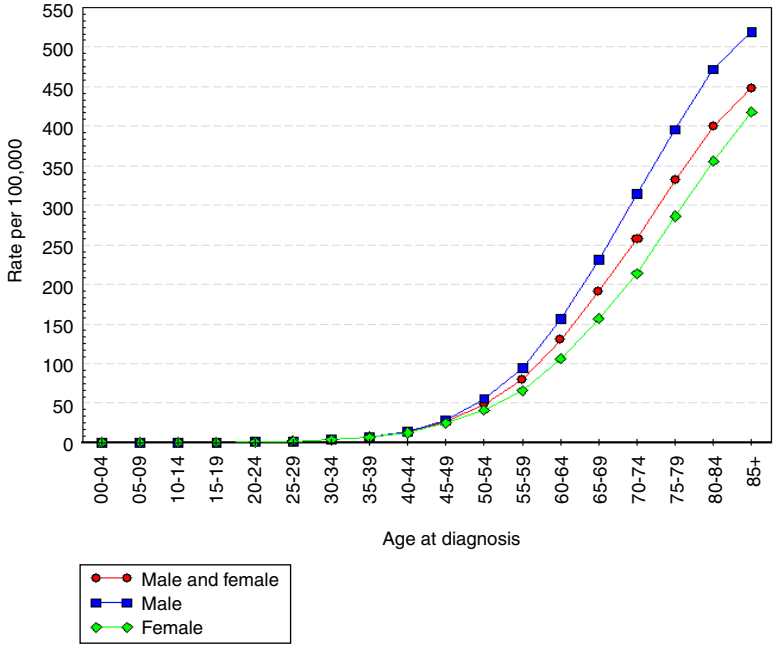

FIGURE 4-2 Incidence of colorectal cancer by age at diagnosis and sex, United States, 1997-2001.
SOURCE: NCI SEER, 2004.

contrast barium enema (USPSTF, 2002c). USPSTF has concluded that while there is insufficient evidence to determine which particular screening strategy is best, colorectal cancer screening is likely to be cost-effective regardless of the type of screening method.

Knowledge vs. practice. Colorectal cancer screening rates in Georgia fall far short of recommended levels (Figure 4-3). In 2002, 47 percent of men and 51 percent of women, over aged 50, reported *ever* having a sigmoidoscopy or colonoscopy (Martin et al., 2004). An even smaller proportion of adults were screened via an FOBT. In 2001, about 32 percent of all Georgia adults, over age 50, said they had an FOBT in the past 2 years (Martin et al., 2003). Lacking health insurance and difficulties with medical care costs were important barriers to being screened either by FOBT (21.5 percent) or by sigmoidoscopy/colonoscopy (34.3 percent) (Table 4-2).

BOX 4-2
Colorectal Cancer Screening Procedures and Recommended Frequency

Four types of tests can be used to detect premalignant polyps and early-stage colorectal cancers, as discussed below.

Fecal Occult Blood Test (FOBT)
An FOBT is used to find occult (i.e., hidden) blood in the stool. Blood vessels at the surface of colorectal polyps, adenomas, or cancers often release a small amount of blood into the stool. For an FOBT, a small sample of stool is applied to a chemically treated card; then a chemical developer solution is added. If the card changes color, there is blood in the stool. Blood in the stool can be caused by cancer, but it may also be due to a number of conditions including hemorrhoids, anal fissures, polyps, peptic ulcers, and ulcerative colitis. Recommended annually.

Flexible Sigmoidoscopy
Sigmoidoscopy enables the physician to view the lining of the large intestine from the rectum through the last part of the colon, called the sigmoid colon. A sigmoidoscope is a slender, flexible, hollow, lighted 2-foot tube. It is inserted through the rectum into the lower part of the colon and transmits an image via a tiny video camera. Recommended every 5 years.

Colonoscopy
A colonoscope is a longer version of a sigmoidoscope that provides a complete view of the colon. Colonoscopy not only detects but also prevents colorectal cancer because, during the screening procedure, any identified premalignant polyp can be removed. Recommended every 10 years.

Double-Contrast Barium Enema
A double-contrast (or air-contrast) barium enema is an X-ray examination of the colon and rectum. Using a tube inserted into the rectum, the colon is filled with a contrast material containing barium and is then drained out, leaving only a thin layer of barium on the wall of the colon. Next, the colon is filled with air, providing a detailed X-ray view of the inner surface of the colon including any small polyps, colorectal cancer, or inflammation. Recommended every 5 years.

SOURCE: USPSTF, 2002b.

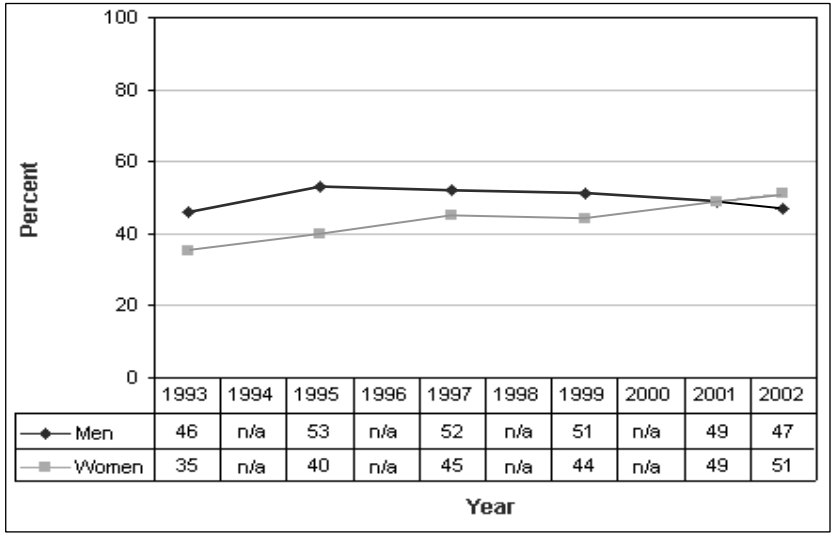

FIGURE 4-3 Percentage of adults aged 50 and older in Georgia who ever had a colonoscopy or sigmoidoscopy, by sex, 1993-2002.
SOURCE: GDPH, 2004a.

TABLE 4-2 Colorectal Cancer Screening Rate Among Adults over Age 50 in Georgia, by Age and Access to Medical Care, 2001

Population	FOBT in the Past 2 Years (%)	Ever Had a Sigmoidoscopy or Colonoscopy (%)
All adults aged 50+	32.4	48.4
By age		
—Aged 50 to 54	NA	34.3
—Aged 55 to 64	NA	47.0
—Aged 65+	NA	59.2
By access to medical care		
—No health insurance or unable to see a doctor "because of cost"	21.5	34.3
—All others	33.9	50.4

NOTE: FOBT = fecal occult blood test; NA = not available.
SOURCE: Martin et al., 2003.

TABLE 4-3 Survival of Breast Cancer and Colorectal Cancer in the United States, by Stage at Diagnosis, 1995-2000

	5-Year Survival (%)	
Cancer Stage at Diagnosis	Breast cancer	Colorectal cancer
All stages	87.7	63.4
By stage		
In situ	100.0	NA
Localized	97.5	89.9
Regional	80.4	67.3
Distant	25.5	9.6

NOTE: NA = not applicable.
SOURCE: Ries et al., 2004.

Cancer Stage at Diagnosis

Cancer stage describes the extent and severity of an individual's cancer (NCI, 2005).[3] If the cancer has spread, the stage describes how far it has spread from the original site to other parts of the body. As illustrated in Table 4-3, cancer stage *at diagnosis* determines an individual's prognosis and chance for cure (Compton, 2003). With expansion of breast and colorectal cancer screening, diagnosis of these two cancers should increasingly occur at an earlier, more treatable stage.

In the past, tumor registries typically recorded cancer stage using three different staging systems: (1) Tumor, Regional Lymph Nodes, and Distant Metastasis method (commonly referred to as TNM); (2) Surveillance, Epidemiology ,and End Results (SEER) Summary Stage; and (3) SEER Extent of Disease. Each system had a different purpose, data set, and algorithm for translating medical record information into a coded stage. More recently, a unified data set referred to as *Collaborative Stage* has come into use. Collaborative staging was developed to meet the needs of the three staging systems by combining and standardizing the information needed to assign the stage (AJCC, 2004). NAACCR and SEER registries (including Georgia's registries) have been required to follow the collaborative method for cases diagnosed from January 2004 forward. Nevertheless, the other staging systems can be derived from the collaborative data elements and they continue to be useful for epidemiological and longitudinal studies.

[3]Some cancers, such as acute leukemia, may not be staged.

The IOM committee recommends that GCC adopt the following three quality measures for tracking cancer stage at diagnosis:

- Measure 4-3—*Early-stage breast cancer diagnosis*—the proportion of new breast cancer cases that are diagnosed at an early stage
- Measure 4-4—*Advanced-stage breast cancer diagnosis*—the number of newly diagnosed advanced-stage breast cancers per 100,000 women aged 40 and older
- Measure 4-5—*Advanced-stage colorectal cancer diagnosis*—the number of newly diagnosed advanced-stage colorectal cancer cases per 100,000 adults aged 50 and older

The terms "early stage" and "advanced stage" refer to the SEER summary stage (Box 4-3). SEER summary staging is based on how a cancer grows (Young et al., 2001). Early-stage cancers are noninvasive "in situ" and "localized" tumors that have not spread beyond the organ of origin.

BOX 4-3
The SEER Summary Staging System for Cancer

The SEER summary stages are described below.

Early-Stage Cancers

- *In situ*—refers to a malignancy that has not invaded the supporting structure of the organ on which it arose. Also referred to as Stage 0, noninvasive, preinvasive, and noninfiltrating.

- *Localized*—refers to a malignancy that is limited to the organ of origin; it has not spread beyond that organ. The tumor can be invasive and show metastases within the organ.

Advanced-Stage Cancers

- *Regional*—refers to a malignancy that extends beyond the limits of the organ of origin. A cancer is regional when it has the potential to spread by more than lymphatic or vascular supply route.

- *Distant*—refers to a malignancy in which tumor cells have broken away from the primary tumor, traveled to other parts of the body, and begun to grow at the new location. Also referred to as remote, diffuse, disseminated, metastatic, or secondary disease. The liver, lung, brain, and bones are common sites of distant-staged cancer because they receive blood flow from all parts of the body.

SOURCE: Young et al., 2001.

Advanced-stage cancers include "regional" tumors that extend beyond the organ of origin and "distant" cancers in which tumor cells have spread to other parts of the body remote from the original tumor.

Monitoring stage at diagnosis for lung and prostate cancer is not recommended. As noted earlier in the chapter, a cost-effective method for detecting early lung cancer is not currently available (Mahadevia et al., 2003). Although PSA screening detects very early prostate cancers, not treating some of these cancers might be harmless while treating them can lead to serious complications (Harris and Lohr, 2002; USPSTF, 2002d; Clark et al., 2003).

Breast Cancer Stage at Diagnosis

Early-stage breast cancer diagnosis. The first recommended measure related to cancer stage at diagnosis, as noted above, tracks the overall proportion of new breast cancer cases that are at an early, treatable stage.

Consensus on care. Breast cancer is a progressive disease and early detection is life-saving because there are effective treatments for early breast cancer (USPSTF, 2002b; IOM, 2003; NCCN, 2004). Early detection also means that patients have a greater choice of treatments, including the option for breast conserving surgery (Freedman et al., 2003). The available treatment options for advanced-stage breast cancer are much less successful in saving women's lives.

Knowledge vs. practice. Early-stage breast cancer was relatively rare before the advent of widespread mammography screening, but it has climbed since the 1970s (Fletcher and Elmore, 2003). The most recent data available for Georgia indicate that more than two-thirds of the state's breast cancer cases (68.5 percent) are diagnosed at an early stage (Table 4-4) (GCCR, 2004). Yet, the likelihood of early-stage diagnosis is considerably

TABLE 4-4 Early- and Advanced-Stage Breast and Colorectal Cancers at Diagnosis in Georgia as a Percentage of Total Cases, 1999-2000

	Breast Cancer		Colorectal Cancer	
Stage at Diagnosis	Number	Percent	Number	Percent
Early	7,541	68.5	2,734	41.3
Advanced	3,460	31.5	3,886	58.7
Total	11,001	100.0	6,620	100.0

NOTE: Early stage refers to in situ and localized cancers. Advanced stage refers to regional and distant cancers.
SOURCE: GCCR, 2004. Unpublished data.

lower among certain groups including African-American women, women who are uninsured, and women who live in high-poverty areas (Li et al., 2003; ACS, 2003; Ghafoor et al., 2003; Gwyn et al., 2004; Ward et al., 2004).

Advanced-stage breast cancer diagnosis. The second recommended quality measure related to cancer stage at diagnosis, as noted above, tracks the incidence of advanced-stage breast cancer (calculated as the number of newly diagnosed advanced-stage breast cancers per 100,000 women aged 40 and older).

Consensus on care. The proportion of women who survive 5 years after a breast cancer diagnosis dramatically declines with advanced-stage disease; from 97.5 percent for localized cases, to 80.4 percent for regional-stage cases, and down to 25.5 percent for distant-stage cases (Table 4-3 above) (Ries et al., 2004). In the previous chapter, the committee recommended that GCC track the overall incidence rates of breast, cervical, and colorectal cancers to evaluate the success of Georgia's prevention interventions. In this chapter, the committee recommends that GCC monitor another dimension of cancer incidence—the incidence of advanced-stage disease—which should decline as the state draws more women into breast cancer screening and other early breast cancer detection programs.

Knowledge vs. practice. Stage-specific breast cancer incidence rates are not available for Georgia. Nationally, there was little change in the incidence of advanced-stage breast cancer during the 1980s to 1990s (Ghafoor et al., 2003). Yet there are marked differences in the incidence of advanced-stage breast cancer by age. In 2000, for example, there were 125.8 cases per 100,000 women aged 40 to 64 compared with 204.9 cases per 100,000 women aged 65 and older (Table 4-5) (AHRQ, 2003). Although the incidence of breast cancer is highest among white women, the rate of advanced-

TABLE 4-5 Incidence of Advanced-Stage Breast and Colorectal Cancers by Age, in the United States, 2000

Type of Cancer	Age at Diagnosis	Incidence (per 100,000)
Breast cancer	Aged 40 and older	149.7
	40 to 64	125.8
	65 and older	204.9
Colorectal cancer	Aged 50 and older	95.6
	50 to 64	43.4
	65 and older	157.1

SOURCE: AHRQ, National Healthcare Quality Report, 2003.

stage breast cancer is consistently higher among African-American women (ACS, 2003).

Advanced-Stage Colorectal Cancer Diagnosis

The incidence of advanced-stage colorectal cancer will be an indicator of Georgia's success in ensuring that adults are screened as recommended. If the state succeeds in significantly increasing routine colorectal cancer screening, the incidence of advanced-stage colorectal cancer in Georgia will decline (USPSTF, 2002c; IOM, 2003).

Consensus on care. Colorectal cancer is most likely to be successfully treated if diagnosed early (NCCN, 2003). If diagnosed with early-stage colorectal cancer, adults have an 89.9 percent survival rate at 5 years compared to 67.3 percent for regional-stage colorectal cancer and only 9.6 percent for distant-stage colorectal cancer (Table 4-3) (Ries et al., 2004). There is also strong evidence that if premalignant polyps are removed during the screening procedure, the patient is far less likely to ever develop colorectal cancer (USPSTF, 2002c).

Knowledge vs. practice. Almost 60 percent of Georgians with colorectal cancer are diagnosed with advanced-stage disease (Table 4-4 above) (Martin et al., 2004). From 1999-2000, 7.1 percent of colorectal cancer cases were in situ, 34.2 percent were localized, 41.6 percent were regional, and 17.1 percent were distant. U.S. incidence of advanced-stage colorectal cancer was 95.6 per 100,000 adults aged 50 and older in 2000 (Table 4-5 above) (AHRQ, 2003).

DATA SOURCES

The data sources for the measures presented in this chapter, with one exception, are already currently available in Georgia (Table 4-6). Georgia should expand the prostate cancer screening section of the annual Behavioral Risk Factor Surveillance Survey to include questions regarding men's awareness of the risks and benefits of the PSA test. Further information about the data sources is presented in Chapter 2, *Concepts, Methods, and Data Sources* and Appendixes A and B.

SUMMARY

In this chapter, the IOM committee has recommended six cancer quality indicators that GCC should use to gauge its progress in promoting early detection of cancer. There is sound scientific evidence showing that finding

TABLE 4-6 Potential Data Sources for Recommended Measures of the Quality of Cancer Early Detection in Georgia[a]

	Potential Georgia-Based Data Sources			Potential National Data Sources for Benchmarking and Comparison					
Quality Measure	GCCR and Georgia SEER	Georgia BRFSS	Georgia SEER/ Medicare	BRFSS	HEDIS	HP 2010	SEER	SEER/ Medicare	NHQR
Mammography screening		●	❍	●	●	●		●	●
Colorectal cancer screening		●	❍	●	●	●		●	●
Early-stage breast cancer diagnosis	●							●	
Advanced-stage breast cancer diagnosis	●					●	●		●
Advanced-stage colorectal cancer diagnosis	●					●	●		●

[a]See Chapter 2, *Concepts, Methods, and Data Sources,* and Appendixes A and B for descriptions of data sources.

NOTE: BRFSS = Behavioral Risk Factor Surveillance System; GCCR = Georgia Comprehensive Cancer Registry; HEDIS = Health Employer Data Information Set; HP 2010 = Healthy People 2010; NHQR = National Healthcare Quality Report; SEER = Surveillance, Epidemiology, and End Results. The symbol ● indicates data are currently available. The symbol ❍ indicates that enhancements to current data collection are required. A blank indicates that the data source is not appropriate for that measure.

breast cancer and colorectal cancer at an early stage, and beginning treatment early, improves health outcomes and saves lives (IOM, 2003). Unfortunately, what is known about the potential of early detection is not reflected in current practice, especially among many men and women who are poor or uninsured. If GCC succeeds in raising breast and colorectal cancer screening rates to recommended levels, with prompt, appropriate treatment, Georgia is likely to experience significant declines in cancer-related morbidity and mortality. In the shorter term, the state's progress will be evident in a declining incidence of advanced-stage breast and colorectal cancer.

QUALITY MEASURE SPECIFICATIONS: DETECTING CANCER EARLY

The following section contains summary descriptions of the quality indicators presented in this chapter. These quality indicators were drawn from a variety of clinical practice setting organizations, federal programs, provider groups, and other sources. See Appendix A for descriptions of each of these organizations, including their classification schemes for grading clinical recommendations and characterizing evidence.

Measure 4-1.	Breast Cancer Screening Rate
Measure 4-2.	Colorectal Cancer Screening Rate
Measure 4-3.	Early-Stage Breast Cancer Diagnosis
Measure 4-4.	Advanced-Stage Breast Cancer Diagnosis
Measure 4-5.	Advanced-Stage Colorectal Cancer Diagnosis

MEASURE 4-1: DETECTING CANCER EARLY—Breast Cancer Screening Rate

Description	Breast cancer screening rate
Source	Health Plan Employer Data and Information Set (HEDIS); U.S. Preventive Services Task Force (USPSTF)
Consensus on care	Clinical guidelines vary with respect to the age at which women should begin regular mammography screening. Although there is a strong consensus that all women should receive mammograms at least every 2 years beginning at age 50, some groups urge that screening begin at age 40 and be repeated annually. Earlier screening is advised for those with an increased risk for the disease. Most groups have not issued specific recommendations for women older than age 70 because so few studies have included this age group. USPSTF recommends screening mammography every 1-2 years for women aged 40 and older but concludes that the evidence is strongest for women aged 50 to 69 (Category B recommendation). Evidence from randomized controlled trials indicates that screening mammography reduces the risk of death from breast cancer for women aged 50 and older.
Knowledge vs. practice	Most women over age 54 in Georgia report having had a mammogram in the past 2 years. In 2002, 81.8 percent of women aged 55 to 64 and 77.5 percent of women aged 65 and older in Georgia had a mammogram in the past 2 years. However, mammography rates among low-income women (<$15,000 per year) and women with no access to medical care were lower; around 66 percent and 50 percent, respectively, for women aged 40 and older.
Approach to calculating the measure	
Numerator	Number of women aged 52 to 69 with one or more mammograms in the past 2 years
Denominator	Number of women aged 52 to 69
Potential data source(s)	Behavioral Risk Factor Surveillance System; Medicare claims and enrollment files; census data; Medicaid claims and enrollment files
Comments	Although monitoring should begin at age 50, the measure starts at age 52 because it will be applied retrospectively and should allow for the full 2 years to receive recommended screening.
Limitations	—
Potential benchmark source(s)	BRFSS; Breast Cancer Surveillance Consortium; National Committee on Quality Assurance/HEDIS reports; Surveillance, Epidemiology, and End Results/Medicare dataset

Key references

Martin LM, et al. 2004. *Georgia Behavioral Risk Factor Surveillance System, 2002 Report*. Atlanta, GA: Georgia Department of Human Resources. Publication Number DPH04/158HW.

NCQA. 2002. *The State of Health Care Quality: 2002*. Washington, DC: NCQA.

USPSTF. 2002. *Guide to Clinical Preventive Services*. Third ed. Rockville, MD: AHRQ.

MEASURE 4-2: DETECTING CANCER EARLY—Colorectal Cancer Screening Rate

Description	Colorectal cancer screening rate
Source	Health Plan Employer Data and Information Set (HEDIS)
Consensus on care	Recent studies show an association between colorectal cancer screening and decreased incidence of colorectal cancer. There is also evidence that screening may reduce colorectal cancer mortality. Screening for colorectal cancer is strongly recommended for men and women aged 50 and older (U.S. Preventive Services Task Force category A recommendation). There are several screening options but insufficient evidence on which strategy is best: (1) annual fecal occult blood test (FOBT); (2) flexible sigmoidoscopy every 5 years; (3) annual FOBT plus flexible sigmoidoscopy every 5 years; (4) double-contrast barium enema; and (5) colonoscopy every 10 years.
Knowledge vs. practice	Screening for colorectal cancer lags far behind screening for other cancers. In 2002, an estimated 49.2 percent of Georgia adults reported having had a sigmoidoscopy or colonoscopy.
Approach to calculating the measure	
Numerator	Number of adults aged 52 to 80 who have received either a FOBT within the past year, flexible sigmoidoscopy within the past 5 years, colonoscopy within the past 10 years, or double-contrast barium enema within the past 5 years
Denominator	Number of adults aged 52 to 80
Potential data source(s)	Behavioral Risk Factor Surveillance System (BRFSS); Medicare and Medicaid claims and enrollment files; commercial datasets
Comments	Although monitoring should begin at age 50, the measure starts at age 52 because it will be applied retrospectively and should allow for the full 2 years to receive recommended screening
Limitations	HEDIS measures are routinely collected by National Committee for Quality Assurance—accredited managed care organizations; however, HMO enrollment in Georgia is relatively minor outside the Atlanta metropolitan area and minimal among the Medicare population in general.
Potential benchmark source(s)	HEDIS; BRFSS; Surveillance, Epidemiology and End Results/ Medicare dataset

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GDPH. 2004. *OASIS Web Query—Death Statistics.* [Online] http://oasis.state.ga.us/webquery/death.html [accessed April 2004].

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USPSTF. 2002. *Guide to Clinical Preventive Services.* 3rd edition. Rockville, MD: AHRQ.

MEASURE 4-3: DETECTING CANCER EARLY—Early-Stage Breast Cancer Diagnosis

Description	Proportion of breast cancer cases diagnosed at an early stage
Source	Vermont Cancer Center
Consensus on care	Screening mammography reduces mortality from breast cancer because it detects cancers at an early stage. Five-year relative survival of early-stage, localized breast cancer is 97.5 percent. In contrast, 5-year relative survival of regional-stage breast cancer is 80.4 percent; distant stage is 25.5 percent. Increased breast cancer screening should ultimately increase the proportion of breast cancer cases diagnosed at an early stage.
Knowledge vs. practice	In Georgia, from 1999-2000, 68.5 percent of breast cancers were diagnosed at an early stage; 31.5 percent at an advanced stage.
Approach to calculating the measure	
Numerator	Number of new breast cancer cases diagnosed at an early stage (see comments below)
Denominator	Number of new breast cancer cases
Potential data source(s)	Surveillance, Epidemiology, and End Results Program (SEER), Georgia Comprehensive Cancer Registry
Comments	*Early stage* refers to SEER summary stage of in situ or localized disease. *In situ stage* refers to a neoplasm that has not invaded the supporting structure of the organ on which it arose. *Localized stage* refers to a neoplasm that is limited to the organ of origin; it has not spread beyond that organ.
Limitations	—
Potential benchmark source(s)	SEER; U.S. Cancer Statistics publications

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USPSTF. 2002. *Guide to Clinical Preventive Services*. 3rd edition. Rockville, MD: AHRQ.

MEASURE 4-4: DETECTING CANCER EARLY—Advanced-Stage Breast Cancer Diagnosis

Description	Incidence of advanced-stage breast cancer
Source	National Healthcare Quality Report; Surveillance, Epidemiology, and End Results Program (SEER)
Consensus on care	Detection of tumors at an early stage significantly reduces mortality. Five-year relative survival of early-stage, localized breast cancer is 97.5 percent. In contrast, 5-year relative survival of regional-stage breast cancer is 80.4 percent; distant stage is 25.5 percent. Increased breast cancer screening should ultimately reduce the incidence of advanced-stage breast cancer.
Knowledge vs. practice	The U.S. incidence of advanced-stage breast cancer was 149.7 per 100,000 for women aged 40 and older in 2000. In Georgia, 31.5 percent of breast cancers were diagnosed at an advanced stage from 1999-2000.
Approach to calculating the measure	
Numerator	Number of females, aged 40 and older, with new breast cancer diagnosed at advanced-stage (see comments below)
Denominator	Number of females, aged 40 and older
Potential data source(s)	SEER; Georgia Comprehensive Cancer Registry
Comments	Incidence rate = (New advanced-stage breast cancers diagnosed among women aged 40 and older) ÷ (Female population aged 40 and older) x 100,000. Estimate should be age-adjusted to allow comparisons. Advanced stage refers to SEER summary stage of regional or distant disease. *Regional stage* refers to a neoplasm that has extended beyond the limits of the organ of origin (i.e., into surrounding organs or tissues or into regional lymph nodes). *Distant stage* refers to a neoplasm that has spread to parts of the body remote from the primary tumor.
Limitations	—
Potential benchmark source(s)	National Healthcare Quality Report; Healthy People 2010; U.S. Cancer Statistics publications

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MEASURE 4-5: DETECTING CANCER EARLY—Advanced-Stage Colorectal Cancer Diagnosis

Description	Incidence of advanced-stage colorectal cancer
Source	National Healthcare Quality Report; Surveillance, Epidemiology, and End Results Program (SEER)
Consensus on care	Colorectal cancer screening detects premalignant polyps and early stage cancers. It can also guide removal of premalignant polyps thus preventing cancer from developing. Detection of tumors at an early stage significantly reduces mortality. Five-year relative survival of localized-stage colorectal cancer is 89.9 percent. In contrast, 5-year relative survival of regional-stage colorectal cancer is 67.3 percent; 9.6 percent, distant stage. Increased colorectal cancer screening should ultimately reduce the incidence of advanced-stage colorectal cancer.
Knowledge vs. practice	The U.S. incidence of advanced-stage colorectal cancer was 95.6 per 100,000 for adults aged 50 and older in 2000. In Georgia, 58.7 percent of colorectal cancers were diagnosed at an advanced stage from 1999-2000.

Approach to calculating the measure

Numerator	Number of adults, aged 50 and older, with new colorectal cancer diagnosed at an advanced stage (see comments below)
Denominator	Adult population aged 50 and older
Potential data source(s)	Georgia Comprehensive Cancer Registry, SEER
Comments	Incidence rate = (New advanced-stage colorectal cancers diagnosed among adults aged 50 and older) ÷ (Adult population aged 50 and older) × 100,000. Estimate should be age-adjusted to allow comparisons. *Advanced stage* refers to SEER summary stage of regional or distant disease. *Regional stage* refers to a neoplasm that has extended beyond the limits of the organ of origin (i.e., into surrounding organs or tissues or into regional lymph nodes). *Distant stage* refers to a neoplasm that has spread to parts of the body remote from the primary tumor.

Limitations	—
Potential benchmark source(s)	National Healthcare Quality Report; Georgia Comprehensive Cancer Registry; SEER; U.S. Cancer Statistics publications

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5

Diagnosing Cancer

"The key to a continued reduction in mortality is early detection and accurate diagnosis made in a cost-effective manner."

Breast Cancer Screening and Diagnosis Guidelines
National Comprehensive Cancer Network, 2004

"Decisions regarding adequacy of surgical resection, need for adjuvant therapy, and appropriate surveillance protocols are often predicated on tumor characteristics and propensity for disease recurrence. Ambiguity or underreporting of important pathologic features may adversely influence clinical outcomes."

Quality of Colon Carcinoma Pathology Reporting: A Process of Care Study
Wei et al., 2004

Whatever Georgia may achieve by expanding cancer screening and early detection could be compromised if the state fails to adequately address the next stages in the continuum of cancer care—diagnosis and treatment. Cancer diagnosis is the critical first step in ascertaining the tumor biology or characteristics and extent of disease, as well as in determining the optimal clinical strategy for combating the disease. Several aspects of the diagnostic process are fundamental to quality cancer care: (1) the timely gathering of appropriate diagnostic and surgical specimens for histological assessment, (2) clear, reliable, and standardized pathology reporting on surgical specimens, and (3) documenting the stage of disease before initiating treatment.

The Institute of Medicine (IOM) committee recommends that the Georgia Cancer Coalition (GCC) adopt 14 quality measures related to

BOX 5-1
Recommended Measures for Tracking the Quality of Cancer Diagnosis

Adequacy of Diagnostic and Surgical Specimens

Measure 5-1 Timely breast cancer biopsy
Measure 5-2 Use of needle biopsy in breast cancer diagnosis
Measure 5-3 Tumor-free surgical margins in breast-conserving surgery
Measure 5-4 Appropriate histological assessment of breast cancer
Measure 5-5 Appropriate histological assessment of colorectal cancer

Adequacy of Pathology Reports on Surgical Specimens

Measure 5-6 Pathology laboratories' compliance with reporting standards for cancer surgical specimens
Measure 5-7 Adequacy of pathology reports on breast cancer surgical specimens
Measure 5-8 Adequacy of pathology reports on colorectal cancer surgical specimens
Measure 5-9 Adequacy of pathology reports on lung cancer surgical specimens
Measure 5-10 Adequacy of pathology reports on prostate cancer surgical specimens

Documentation of Cancer Pathologic Stage Before Chemotherapy or Radiation Treatment Begins

Measure 5-11 Breast cancer stage determined before treatment
Measure 5-12 Colorectal cancer stage determined before treatment
Measure 5-13 Lung cancer stage determined before treatment
Measure 5-14 Prostate cancer stage determined before treatment

cancer diagnosis (Box 5-1). The first five measures will help Georgia ensure that adequate diagnostic and surgical specimens are available for timely, pathologic assessment or evaluation of breast and colorectal cancers. The next five measures can be used by Georgia to track the quality of the pathology reports on cancer surgical specimens, which clinicians depend on to assess the extent of the cancer and to advise patients on treatment options. The final set of four measures will help the state ensure adequate treatment planning by monitoring whether health care providers document patients' cancer stage before initiating chemotherapy or radiation treatment.

The 14 recommended quality measures pertaining to cancer diagnosis are discussed further below. For each measure discussed, there is a section providing a brief rationale for the selection of the measure, explanation of the evidence underlying the measure (the "consensus on care") and a description of what is known about the gap between the evidence and current practice ("knowledge vs. practice"). Also provided near the end of the chapter is a brief section on the potential data sources for measures in

the diagnostic domain. The chapter concludes with summaries of each quality measure.

RECOMMENDED MEASURES FOR TRACKING THE QUALITY OF CANCER DIAGNOSIS

Adequacy of Diagnostic and Surgical Specimens

Two of the five recommended quality-of-cancer-care measures related to the adequacy of diagnostic and surgical specimens pertain to the use of biopsies in breast cancer diagnosis. During a breast biopsy, either a small sample of suspicious breast tissue (i.e., an incisional core biopsy) or an entire lump or suspicious area is removed (i.e., an excisional biopsy) for histological assessment. When the tissue sample is removed with a needle, the procedure is referred to as a needle biopsy or fine-needle aspiration. To track the timeliness of biopsy after a suspicious, abnormal mammogram and the use of needle biopsy before breast cancer surgery, the committee recommends that Georgia adopt the following measures:

- Measure 5-1—*Timely breast cancer biopsy*—the proportion of women who receive a biopsy within 14 days after first documentation of a category 4 or 5 abnormal mammogram.
- Measure 5-2—*Use of needle biopsy in breast cancer diagnosis*—the proportion of women who have a needle biopsy of the breast at least 1 day prior to breast cancer surgery.

The remaining three measures pertain to the collection and histological assessment or evaluation of surgical specimens taken from patients who undergo surgery for breast or colorectal cancer. To monitor the appropriate collection and histological assessment or evaluation of breast and colorectal cancer surgical specimens, the committee recommends that the GCC adopt the following measures:

- Measure 5-3—*Tumor-free surgical margins in breast-conserving surgery for breast cancer*—the proportion of patients undergoing breast-conserving surgery whose surgical margins are free of tumor after the last surgical procedure.
- Measure 5-4—*Appropriate histological assessment of breast cancer*—the proportion of Stage I and Stage II breast cancer cases with sentinel node biopsy *or* with histological assessment of 10 or more axillary lymph nodes.
- Measure 5-5—*Appropriate histological assessment of colorectal cancer*—the proportion of colorectal cancer surgery patients with documented histological assessment of 12 or more lymph nodes.

The rationale for the IOM committee's decision to recommend each of these measures is discussed further below.

Breast Cancer Biopsies

The first two recommended quality-of-cancer-care measures pertaining to the adequacy of diagnostic and surgical specimens are the timeliness of biopsy after a suspicious, abnormal mammogram and the use of needle biopsy before breast cancer surgery. A strong evidence base shows that screening mammography reduces breast cancer deaths by finding cancer at an early, treatable stage (USPSTF, 2002).[1] Mammography can only improve breast cancer outcomes, however, if follow-up of abnormal findings is timely and appropriate. Screening mammography findings should be documented according to the Breast Imaging and Reporting Data System (BI-RADS) (Box 5-2). Women with abnormalities that are suspicious or suggestive of malignancy—BI-RADS categories 4 and 5—should be followed up with a biopsy according to the National Comprehensive Cancer Network (NCCN) breast screening and diagnosis guidelines (ACR, 2003; NCCN, 2004c).

Timely breast cancer biopsy.

Consensus on care. There is no consensus on the ideal interval between finding a category 4 or 5 abnormal mammogram and the follow-up biopsy; however, the available evidence suggests that the interval should be brief (Olivotto et al., 2001). The Institute for Clinical Systems Improvement recommends that the biopsy be completed in less than 14 days after first documentation of a category 4 or 5 mammogram; RAND, Inc. recommends no more than 6 weeks (Gifford and Schmidt, 2000; ICSI, 2003). Delayed diagnosis of breast cancer is associated with later stage at diagnosis and poorer prognosis. A recent, multivariate analysis of 4,465 women with invasive breast cancer suggests that 6- to 12-month delays to diagnosis of asymptomatic breast cancer are associated with increased risk of lymph node metastases and larger tumor size (Olivotto et al., 2002).

Timeliness is a basic attribute of high-quality health care (IOM, 2001). The IOM committee feels strongly that women with suspicious or highly suggestive abnormal mammograms should not have to wait longer than 14 days for a biopsy. Delays in diagnosis are associated with substantial anxiety and distress for the patient (IOM, 2004).

Knowledge vs. practice. The proportion of women who have a needle biopsy before breast cancer surgery is not known. There are only limited

[1]See Chapter 4, *Detecting Cancer Early*, for further discussion of breast cancer screening.

BOX 5-2
The Breast Imaging and Reporting Data System (BI-RADS)

Breast abnormalities that are identified through screening mammography are categorized according to a taxonomy established by the American College of Radiology in collaboration with the Centers for Disease Control and Prevention, the U.S. Food and Drug Administration, the American Medical Association, the American College of Surgeons, and the College of American Pathologists.

The six BI-RADS reporting categories represent gradations of the likelihood that a cancer exists, from lowest to highest probability.

BI-RADS category	BI-RADS assessment	Description and recommended follow-up
0	Assessment is incomplete	Temporary category; additional imaging evaluation is needed. Most are benign.
1	Negative	Breasts appear normal; follow routine screening schedule
2	Benign	Negative finding (includes noncancerous lesions such as cysts and calcifications); follow routing screening schedule
3	Probably benign	High probability of being benign; follow up with mammography after a short interval
4	Suspicious abnormality	Biopsy
5	Highly suggestive of malignancy	Biopsy

SOURCE: ACR, 2003. *Breast Imaging Reporting and Data System.*

data on the extent of delays in follow-up biopsies after a suspicious mammogram. Studies assessing follow-up of all types of cancer screening indicate that about 25 percent of patients with a suspicious finding do not receive needed follow-up care (Yabroff et al., 2003). Racial and ethnic minorities, as well as uninsured and low-income persons, are especially at risk. A 2001 survey of medical directors of community health centers in 10 states found that about 40 percent of uninsured patients had difficulty getting specialty referrals, including referrals for follow-up of abnormal screening tests (Gusmano et al., 2002).

Use of needle biopsy in breast cancer diagnosis.

Consensus on care. NCCN recommends that breast tissue samples be obtained by needle biopsy if feasible (NCCN, 2004c). Needle biopsy is preferred because it is quick, accurate, and less invasive, and produces a better cosmetic outcome than alternative approaches do (Liberman, 2000; Morrow et al., 2001; Collins et al., 2004; Baxter et al., 2004; NCCN, 2004c). Needle biopsy techniques include core needle biopsy, vacuum-assisted biopsy, or fine-needle aspiration. The biopsy may be performed with or without image guidance depending on the location of the lesion, its visibility at ultrasound, equipment availability, and radiologist's expertise. For about 10 to 20 percent of women, however, a needle biopsy is not technically feasible because of the location and nature of their breast lesion (NCCN, 2004c). Thus, a standard of 70 to 80 percent rather than 100 percent would be appropriate.

Knowledge vs. practice. Data on the use of needle biopsy before breast cancer surgery are not available.

Cancer Surgical Specimens

Three of the recommended quality measures pertain to the collection and histological assessment or evaluation of surgical specimens taken from patients who undergo surgery for breast or colorectal cancer.

One measure is the proportion of breast cancer surgery patients whose surgical margins are free of tumor after the last surgical procedure. The histological assessment of surgical margins is fundamental to cancer diagnosis (Bland et al., 1999; Stocchi et al., 2001; Weir et al., 2002; Trocha and Giuliano, 2003; Le Voyer et al., 2003; Compton, 2003; Krag and Single, 2003; Fitzgibbons et al., 2004). The outer edge of the surgical specimen—referred to as the surgical margin—is considered free of tumor if there is no tumor at the line of resection. If the margin contains cancer or is too small to be fully analyzed, the extent of the patient's cancer may be underestimated and undertreated.

The other two measures pertain to the histological assessment of lymph nodes in patients with breast cancer or colorectal cancer. Lymph node evaluation is central to determining the stage of cancer at diagnosis. About one-third of persons have metastases detected at the time of their first cancer diagnosis (Eyre et al., 2002). If a cancer spreads, the lymph nodes are usually affected. In breast cancer, the axillary (armpit) nodes are the main passageway that cancer cells use to spread to other parts of the body. In colorectal cancer, the regional lymph nodes are the main passageway.

Consensus on care.

Tumor free-breast cancer surgical margins. The goal of breast cancer surgery is to completely remove the tumor and to obtain clear surgical margins. There is extensive evidence that positive surgical margins are associated with significant morbidity and cost, including higher rates of local tumor recurrence and further surgical or medical treatment (Silverstein et al., 1999; Fredriksson et al., 2003; NCCN, 2004b). With lumpectomy, a positive margin often leads to additional surgery with either re-excision of additional tissue at the positive margin, or total mastectomy. If it is not possible to obtain a negative margin with re-excision, then mastectomy is usually required, although it may be appropriate to treat cases with a microscopic focally-positive margin with breast conservation by increasing the dose of a radiation therapy boost (NCCN, 2004b). NCCN guidelines indicate that while margins greater than 1 centimeter are "widely accepted" as negative, such margin width may be excessive causing a less acceptable cosmetic result. Margins less than 1 millimeter are considered inadequate. However, the NCCN guidelines state that data are insufficient to make definitive statements about margins between 1 and 10 mm.

Assessment of lymph nodes after breast cancer surgery. Histological assessment of axillary nodes is critical to diagnosing Stage I and II breast cancer and to determining the appropriate course of treatment (Weir et al., 2002; Fitzgibbons et al., 2004; NCCN, 2004b). In Stage I breast cancer, the tumor is less than 2 centimeters in diameter with no spread beyond the breast (axillary nodes are clear). In Stage II, the tumor is 2 to 5 centimeters in size or the tumor has spread to the axillary nodes (Box 5-3). Several studies suggest that examining an insufficient number of lymph nodes leads to poorer survival after breast cancer surgery (Bland et al., 1998; Bland et al., 1999; Weir et al., 2002; Krag and Single, 2003). If too few nodes are removed, the patient's cancer may be understaged and thus undertreated. NCCN guidelines recommend two options: (1) dissection of 10 or more axillary lymph nodes for histological assessment or (2) sentinel node biopsy for patients with unicentric tumors smaller than 5 centimeters with no prior treatment or large excisions *if* an experienced sentinel lymph node team is available (NCCN, 2004b). Either procedure may be optional in patients who have particularly favorable tumors, patients for whom the selection of adjuvant systemic therapy is unlikely to be affected, elderly patients, and patients with serious comorbid conditions.

Assessment of lymph nodes after colorectal cancer surgery. Most colorectal cancer patients undergo surgical resection—an estimated 92 percent of colon cancer patients and 84 percent of rectal cancer patients (Compton, 2003). Diagnosing the extent of colorectal cancer requires histological assessment of the regional lymph nodes that are retrieved during surgery. There is an extensive literature showing that survival of colorectal

BOX 5-3
TNM Stages of Breast Cancer

- **Stage 0**—Noninvasive; cancer cells remain inside the breast duct and have not invaded the normal adjacent breast tissue. Includes *ductal carcinoma in situ* or *lobular carcinoma in situ*.
- **Stage I**—Tumor is less than 2 cm in diameter with no spread beyond the breast (lymph nodes are clear).
- **Stage IIA**—Includes tumors 2 to 5 cm in diameter without spread to axillary nodes, and tumors less than 2 cm with spread to axillary nodes
- **Stage IIB**—Includes tumors 2 to 5 cm in diameter with spread to axillary nodes where the nodes are unattached to each other or other structures, and tumors greater than 5 cm without spread to axillary nodes.
- **Stage IIIA**—Locally advanced cancer; includes tumors larger than 5 cm, and tumors less than 5 cm in diameter with spread to the axillary nodes where the nodes are attached to each other or to other structures.
- **Stage IIIB**—Locally advanced cancer; includes tumors with spread to the lymph nodes near the breast (skin or chest wall, including the ribs and the muscles in the chest) or inside the chest wall along the breast bone.
- **Stage IV**—Metastatic or recurrent carcinoma; tumor has spread beyond the breast and chest wall, such as to liver, bone, or lungs.

NOTE: TNM = Tumor, Node, Metastasis.
SOURCE: American Joint Committee on Cancer (Greene et al., 2002); NCCN *Breast Cancer* (NCCN, 2004b).

cancer increases with the number of recovered lymph nodes, regardless of the number of positive nodes that are found (Stocchi et al., 2001; Le Voyer et al., 2003; Compton, 2003). While there is no consensus on the specific number of nodes that should be analyzed, the range in the recommendations is small. For example, NCCN advises at least 14 nodes, while the College of American Pathologists (CAP) advises at least 12 nodes and urges that additional techniques such as visual enhancement be considered if fewer than 12 nodes are found (Compton, 2004a, NCCN, 2004f).

Knowledge vs. practice. It is difficult to discern from the available research whether shortcomings in pathology data are due to poor documentation

practices or poor surgical technique. Most research on the collection of breast cancer and colorectal cancer surgical specimens has focused on reporting practices rather than the adequacy of the specimens themselves. However, there is evidence that older women are less likely than younger women to undergo an axillary node dissection despite clinical guidelines to the contrary (Malin et al., 2002).

Numerous studies indicate that surgical and pathology reporting practices are of variable quality and, in fact, information on margins and the number and status of nodes is often missing from pathology reports (Weir et al., 2002; Imperato et al., 2002; Compton, 2003; White et al., 2003; Wilkinson et al., 2003; Wei et al., 2004). Stocchi et al. (2001) examined the surgery and pathology reports of 673 patients who were enrolled in a U.S. cooperative group clinical trial for Stage II or III rectal cancer. The researchers found that the operative and pathology notes were poorer than expected; 18 percent of patients had fewer than five lymph nodes examined and 68 percent had fewer than 12 nodes examined.

Adequacy of Pathology Reporting on Cancer Surgical Specimens

The IOM committee recommends five quality measures to monitor the adequacy of pathology reports on cancer surgical specimens. The first measure tracks pathology laboratories' compliance with the American College of Surgeons' Commission on Cancer reporting standards for breast, colorectal, lung, and prostate cancers.

- Measure 5-6—*Pathology laboratories' compliance with reporting standards for cancer surgical specimens*—the proportion of pathology laboratories that report CAP data elements as required by the Commission on Cancer.

The remaining four measures track whether pathology reports include the key data elements currently mandated by the Commission on Cancer for breast, colorectal, lung, and prostate cancers:

- Measure 5-7—*Adequacy of pathology reports on breast cancer surgical specimens*—the proportion of pathology reports on invasive breast cancer surgical specimens that include CAP data elements as required by the Commission on Cancer.
- Measure 5-8—*Adequacy of pathology reports on colorectal cancer surgical specimens*—the proportion of pathology reports on colorectal cancer surgical specimens that include CAP data elements as required by the Commission on Cancer.

- Measure 5-9—*Adequacy of pathology reports on lung cancer surgical specimens*—the proportion of pathology reports on invasive lung cancer surgical specimens that include CAP data elements as required by the Commission on Cancer.
- Measure 5-10—*Adequacy of pathology reports on prostate cancer surgical specimens*—the proportion of pathology reports on prostate cancer surgical specimens that include CAP data elements as required by the Commission on Cancer.

The rationale for the IOM committee's decision to recommend each of these measures is discussed further below.

Consensus on Care

Pathologists examine surgical specimens to identify the tumor size, histology, and other tumor characteristics—findings that are needed to properly stage the disease, to formulate treatment decisions, and to determine prognosis. The pathology report communicates these findings to the clinician. It is essential that the report is clear and comprehensive. Traditionally, pathologists have used an unstructured, narrative style to complete their reports. Research in the last decade has suggested, however, that standardized reporting templates yield more comprehensive and readable information than free-text pathology reports (Appleton et al., 1998; Cross et al., 1998; Branston et al., 2002). In response, CAP has developed a set of reporting templates, called checklists, for reporting pathology findings for cancer specimens (CAP, 2003). There is a specific checklist for each tumor site and type of surgical specimen. CAP recommends, but does not require, that its certified laboratories use the checklist.

As of 2004, the Commission on Cancer, a multidisciplinary program of the American College of Surgeons, has required that pathology laboratories at Commission on Cancer-certified cancer centers report the scientifically validated data elements in the CAP checklists for cancer-directed surgical specimens. The CAP checklist itself is optional. The mandatory data elements include the histologic type and grade, pathologic staging including distant metastasis, margins and lymph nodes, and other cancer-specific data items (Gal et al., 2004; Srigley et al., 2004; Fitzgibbons et al., 2004; Compton, 2004a).

Figure 5-1 illustrates the data elements required by the Commission on Cancer in a pathology report on a prostate cancer specimen. Only cancer-directed surgical resection specimens must meet the Commission on Cancer's requirement to report the scientifically validated data elements in the CAP checklists; cytologic specimens, diagnostic biopsies, and palliative resections are exempt (Paxton, 2004). In 2005, the Commission on Cancer will begin auditing its certified pathology laboratories to ensure that they comply with

FIGURE 5-1 Pathology report checklist for a prostate cancer surgical specimen, College of American Pathologists

Surgical Pathology Cancer Case Summary (Checklist)
Protocol revision date: January 2004
Applies to invasive carcinomas only
Based on AJCC/UICC TNM, 6th edition

PROSTATE GLAND: Radical Prostatectomy

Patient name:
Surgical pathology number:

Note: Check 1 response unless otherwise indicated.

MACROSCOPIC (rarely applicable; see microscopic)

MICROSCOPIC

Histologic Type
___ Cannot be determined
___ Adenocarcinoma (conventional, not otherwise specified)
___ Prostatic duct adenocarcinoma
___ Mucinous (colloid) adenocarcinoma
___ Signet-ring cell carcinoma
___ Adenosquamous carcinoma
___ Small cell carcinoma
___ Sarcomatoid carcinoma
___ Other (specify): _____
___ Undifferentiated carcinoma, not otherwise specified

Histologic Grade
Gleason Pattern:
(if 3 patterns are present, record the most predominant and second most common patterns; the tertiary pattern should be recorded if higher than primary and secondary patterns)
___ Not applicable
___ Cannot be determined

Primary Pattern
___ Grade 1
___ Grade 2
___ Grade 3
___ Grade 4
___ Grade 5

Secondary Pattern
___ Grade 1
___ Grade 2
___ Grade 3
___ Grade 4
___ Grade 5

Figure continues

FIGURE 5-1 Continued

*Tertiary Pattern
*___ Grade 3
*___ Grade 4
*___ Grade 5

Total Gleason Score: ____

***Tumor Quantitation**
*Proportion (percent) of prostate involved by tumor: ____%
*Tumor size (dominant nodule, if present):
*Greatest dimension: ___ cm
*Additional dimensions: ___ × ___ cm

Pathologic Staging (pTNM)
Primary Tumor (pT)
___ Not identified
pT2: Organ confined
___ pT2a: Unilateral, involving one-half of 1 side ("lobe") or less
___ pT2b: Unilateral involving more than one-half of 1 side ("lobe") but not both sides ("lobes")
___ pT2c: Bilateral disease
pT3: Extraprostatic extension
___ pT3a: Extraprostatic extension
___ pT3b: Seminal vesicle invasion
___ pT4: Invasion of bladder and/or rectum

Regional Lymph Nodes (pN)
___ pNX: Cannot be assessed
___ pN0: No regional lymph node metastasis
___ pN1: Metastasis in regional lymph node or nodes
Specify: Number examined: ___
Number involved: ___

Distant Metastasis (pM)
___ pMX: Distant metastasis cannot be assessed
pM1: Distant metastasis
___ pM1a: Distant metastasis, non-regional lymph node(s)
___ pM1b: Distant metastasis, bone(s)
___ pM1c: Distant metastasis, other site(s)

Note: When more than 1 site of metastasis is present, the most advanced category (pM1c) is used.

Margins (check all that apply)
___ Cannot be assessed
*___ Benign glands at surgical margin
___ Margins uninvolved by invasive carcinoma
___ Margin(s) involved by invasive carcinoma
*___ Unifocal
*___ Multifocal
___ Apical

continues

FIGURE 5-1 Continued

___ Bladder neck
___ Anterior
___ Lateral
___ Postero-lateral (neurovascular bundle)
___ Posterior
___ Other(s) (specify): _____

Extraprostatic Extension (check all that apply)
___ Absent
___ Present
*___ Unifocal
*___ Multifocal
___ Indeterminate

Seminal Vesicle Invasion (invasion of muscular wall required)
___ Absent
___ Present
___ No seminal vesicle present

***Perineural Invasion**
*___ Absent
*___ Present

***Venous (Large Vessel) Invasion (V)**
*___ Absent
*___ Present
*___ Indeterminate

***Lymphatic (Small Vessel) Invasion (L)**
*___ Absent
*___ Present
*___ Indeterminate

***Additional Pathologic Findings (check all that apply)**
*___ None identified
*___ High-grade prostatic intraepithelial neoplasia (PIN)
*___ Inflammation (specify type): _____
*___ Atypical adenomatous hyperplasia
*___ Benign prostatic hyperplasia
*___ Other (specify): _____

***Comment(s)**

*Data elements *with asterisks* are not required for accreditation purposes for the Commission on Cancer. These elements may be clinically important, but are not yet validated or regularly used in patient management. Alternatively, the necessary data may not be available to the pathologist at the time of pathologic assessment of this specimen.

SOURCE: Reprinted with permission from the College of American Pathologists (Srigley et al., 2004).

the mandate to report the scientifically validated data elements for surgical specimens.

Knowledge vs. Practice

Pathology laboratories' compliance with reporting standards for cancer surgical specimens. The quality of pathology reporting in Georgia has not been studied. There are 39 Commission on Cancer-approved cancer programs in Georgia (Table 5-1). Presumably, once the Commission on Cancer reporting mandate is fully enforced, it will improve pathology reporting at these Georgia institutions. Numerous studies have documented generally poor compliance with guidelines on reporting cancer-related pathology findings (Weir et al., 2002; Malin et al., 2002; Imperato et al., 2002; IOM, 2003; Compton, 2003; White et al., 2003; Wilkinson et al., 2003; Wei et al., 2004). Recent evidence indicates that the quality of cancer-related pathology reporting has improved since the problems were first identified in the mid- to late-1980s.

Adequacy of pathology reports on breast cancer surgical specimens. Researchers assessed concordance with breast cancer pathology reporting guidelines in 1998 and 1999 at the Roswell Park Cancer Center, a National Cancer Institute-designated comprehensive cancer center. One hundred patient records were reviewed and most lacked at least one required data element. Only 77 percent of the breast surgery reports documented margin status (Wilkinson et al., 2003). An earlier study of breast pathology reporting by hospitals in New York state found wide variation in quality (Imperato et al., 2002). Overall, performance was less than 70 percent on 9 of 16 data elements, including tumor margin status. Distance to closest margin was reported in 69 percent of the cases, but the margin orientation was noted in only 25 percent. A large-scale national study of 7,097 women who underwent lumpectomy in 1994, found significant variation in the content of pathology reports (White et al., 2003). Substantial proportions of the reports were missing key pathologic data, including lymph node invasion (46 percent), ductal carcinoma in situ (43 percent), and macroscopic margin (27 percent). The researchers found that geographic location and type of cancer program were important predictors of compliance with reporting standards; women who were treated in the Midwest or by a community hospital were the most likely to have incomplete records.

Adequacy of pathology reports on colorectal cancer surgical specimens. Although data are limited, there are studies showing considerable variability in colorectal cancer pathology reporting including failure to document critical data. There is also evidence that the quality of colorectal cancer

TABLE 5-1 Cancer Programs in Georgia That Are Certified by the Commission on Cancer

Institution Name	City	Institution Name	City
Phoebe Putney Memorial Hospital	Albany	Dwight D. Eisenhower Army Medical Center	Fort Gordon
Sumter Regional Hospital	Americus	Northeast Georgia Medical Center	Gainesville
Athens Regional Medical Center	Athens	Spalding Regional Medical Center	Griffin
Atlanta Medical Center	Atlanta	West Georgia Health System	LaGrange
Emory Crawford Long Hospital	Atlanta	Gwinnett Hospital System	Lawrenceville
Emory University Hospital	Atlanta	Coliseum Medical Centers	Macon
Northside Hospital	Atlanta	Medical Center of Central Georgia	Macon
Piedmont Hospital	Atlanta	WellStar Health System	Marietta
Saint Joseph's Hospital of Atlanta	Atlanta	WellStar Kennestone Hospital	Marietta
Medical College of GA Hospital & Clinics	Augusta	Southern Regional Medical Center	Riverdale
University Health Care System	Augusta	Floyd Medical Center	Rome
VA Medical Center	Augusta	Redmond Regional Medical Center	Rome
WellStar Cobb Hospital	Austell	Memorial Health	Savannah
Southeast Georgia Regional MC	Brunswick	St. Joseph's/Candler Health System	Savannah
The Medical Center	Columbus	Emory Eastside Medical Center	Snellville
Rockdale Medical Center	Conyers	Henry Medical Center	Stockbridge
Hamilton Medical Center	Dalton	John D. Archbold Memorial Hospital	Thomasville
DeKalb Medical Center	Decatur	Tift Regional Medical Center	Tifton
VA Medical Center	Decatur	South Georgia Medical Center	Valdosta
South Fulton Medical Center	East Point		

SOURCE: American College of Surgeons Commission on Cancer (ACoS CoC, 2005).

pathology reports varies with a laboratory's affiliation and hospital case volume. Wei et al. studied the pathology records of 438 North Carolina patients diagnosed with colorectal cancer between 1997 and 2000 (Wei et al., 2004). Compared with contract pathology labs and community hospitals, high-volume hospitals and teaching facilities were more likely to report recommended pathology data including macroscopic depth of penetration and margin status.

Adequacy of pathology reports on lung cancer surgical specimens. Surgical resection is the primary treatment for lung cancer (NCCN, 2004d). Few studies have been done on the quality of pathology reporting for lung cancer specimens. A 1991 CAP study of pathology reports of lung cancer resection specimens found poor documentation of some key data elements. Venous invasion was reported in only 22.6 percent of cases and regional lymph nodes were described in 74.7 percent of the reports (Gephardt and Baker, 1996).

Adequacy of pathology reports on prostate cancer specimens. Radical prostatectomy was the primary treatment for an estimated 41 percent of prostate cancer patients from 1995 to 2003 (Cooperberg et al., 2004). Little is known about the quality of pathology reports on prostate surgical specimens.

Documentation of Cancer Pathologic Stage Before Chemotherapy or Radiation Treatment Begins

Cancer stage describes the extent and severity of an individual's cancer. The stage of a cancer is determined by a number of diagnostic factors, including location of the primary tumor, tumor size, regional lymph node involvement, cell type and tumor grade, and presence or absence of distant metastasis (Greene et al., 2002). Cancer staging information is the most important indicator of a patient's prognosis (Bland et al., 1999; Stocchi et al., 2001; Weir et al., 2002; Trocha and Giuliano, 2003; Le Voyer et al., 2003; Krag and Single, 2003; Compton, 2003; Fitzgibbons et al., 2004; Compton, 2004b). Information about the stage of a cancer patient's cancer gives clinicians a roadmap for determining a patient's treatment options. It also helps cancer patients understand the extent of their disease, their prognosis, and their treatment choices (Brierley et al., 2002; Compton, 2004b).

Cancer stage may be referred to as *clinical* or *pathologic* depending on the timing. *Clinical stage* is based on what has been learned about a patient's cancer through, for example, physical exams, imaging tests, biopsies, and blood tests—up to the time of initial definitive treatment which is often surgery (NCI, 2005). *Pathologic stage* combines the clinical staging infor-

mation with surgical findings, incorporating data not only from before the initial definitive treatment but also from pathologic examination of resected primary and regional lymph nodes.

In addition to being important for the provision of treatment to individual patients, stage data are essential to building a sound infrastructure for cancer research, quality improvement, and population cancer control. Stage data are basic inputs to tumor registries; to evaluating screening and early detection programs, treatment interventions, and quality improvement efforts; to developing, implementing, and monitoring clinical guidelines; and to identifying patients who might benefit from a clinical trial; and to computing survival statistics (Chamberlain et al., 2000; Brierley et al., 2002; Woodward et al., 2003; Compton, 2004b). Clearly, clinical outcomes can be understood only in the context of the stage of the disease.

The IOM committee recommends that the GCC adopt four quality measures to help Georgia ensure that patients' cancers are appropriately staged before chemotherapy or radiation treatment begins:

- Measure 5-11—*Breast cancer stage determined before treatment*—the proportion of new breast cancer cases with medical chart documentation of pathologic stage before chemotherapy or radiation treatment is initiated.
- Measure 5-12—*Colorectal cancer stage determined before treatment*—the proportion of new colorectal cancer cases with medical chart documentation of pathologic stage before chemotherapy or radiation treatment is initiated.
- Measure 5-13—*Lung cancer stage determined before treatment*—the proportion of new lung cancer cases with medical chart documentation of pathologic stage before chemotherapy or radiation treatment is initiated.
- Measure 5-14—*Prostate cancer stage determined before treatment*—the proportion of new prostate cancer cases with medical chart documentation of pathologic stage before chemotherapy or radiation treatment is initiated.

The rationale for the IOM committee's decision to recommend these measures is discussed further below.

Consensus on Care

Every cancer patient's treatment regimen should be tailored to his or her stage of disease. Most treatment guidelines cannot be followed until the tumor stage has been determined (ASCO, 2002; ACR, 2004; NCCN, 2004a). Chemotherapy and radiation treatment of most cancers, including breast, colorectal, lung, and prostate cancers, should not be initiated until

the pathologic stage has been determined and documented in the medical record (NCCN, 2004a).[2]

Knowledge vs. Practice

Little is known about the extent to which cancer treatment is initiated *before* the stage has been determined and documented. Likewise, little is known about the completeness of staging or its documentation. Nonetheless, a plethora of evidence documenting serious underreporting of pathology information suggests that many cancer patients are treated in advance of, or in the absence of, appropriate documentation of the stage of their disease (Weir et al., 2002; Imperato et al., 2002; White et al., 2003; Wilkinson et al., 2003; Wei et al., 2004; Compton, 2004b).

DATA SOURCES

The data for 12 of the 14 measures pertaining to quality of cancer diagnosis must be abstracted from pathology reports and medical records (Table 5-2). Data for the remaining two measures—measures 5-1 (timely breast cancer diagnosis) and 5-2 (use of needle biopsy in breast cancer diagnosis)—can be drawn from the Surveillance, Epidemiology, and End Results (SEER)-Medicare dataset and might also be in a mammography registry (should Georgia develop one). Further information about the strengths and weakness of data sources is presented in Chapter 2, *Concepts, Methods, and Data Sources,* and Appendix A.

SUMMARY

Accurate and timely diagnosis is basic to combating cancer and is the essential first step in quality care. If diagnostic practice is poor, treatment and outcomes are likely to be less than optimal. A substantial body of research has documented that the process of cancer diagnosis in the United States is often incomplete and inadequately documented. This situation probably exists in Georgia as well, although specific evidence is not currently available. If Georgia is to meaningfully improve cancer outcomes for its residents, it must address the conduct of cancer diagnosis statewide. This chapter has recommended 14 quality measures that GCC should use to gauge its progress in ensuring that cancer treatment in Georgia draws from comprehensive and clearly documented diagnostic and histological records.

[2]Some cancers, such as acute leukemia, may not be staged.

TABLE 5-2 Potential Data Sources for Recommended Measures of the Quality of Cancer Diagnosis in Georgia[a]

	Potential Georgia-Based Data Sources				Potential National Data Sources for Benchmarking and Comparison				
Quality Measure	GCCR and Georgia SEER	Georgia mammography registry	Georgia SEER/ Medicare	Medical records	CoC	BCSC	CAP	SEER	SEER/ Medicare
Biopsy after abnormal mammogram		❍	❍			●			●
Breast needle biopsy		❍	❍			●			●
Breast cancer surgical margins				❍	●		●		
Histological assessment of lymph nodes	❍			❍	●			●	
Pathology reporting				❍	●		●		
Cancer stage determined before treatment				❍					

[a]See Chapter 2, *Concepts, Methods, and Data Sources,* and Appendixes A and B for descriptions of data sources.
NOTE: GCCR = Georgia Comprehensive Cancer Registry; BCSC = Breast Cancer Surveillance Consortium; SEER = Surveillance, Epidemiology, and End Results; CoC = American College of Surgeons Commission on Cancer; CAP = College of American Pathologists. The symbol ● indicates data are currently available. The symbol ❍ indicates that enhancements to current data collection are required.

QUALITY MEASURE SPECIFICATIONS: DIAGNOSING CANCER

The following section contains summary descriptions of the quality indicators presented in this chapter. These quality indicators were drawn from a variety of clinical practice setting organizations, federal programs, provider groups, and other sources. See Appendix A for descriptions of each of these organizations, including their classification schemes for grading clinical recommendations and characterizing evidence.

Measure 5-1.	Timely Breast Cancer Biopsy
Measure 5-2.	Use of Needle Biopsy in Breast Cancer Diagnosis
Measure 5-3.	Tumor-Free Surgical Margins in Breast-Conserving Surgery
Measure 5-4.	Appropriate Histological Assessment of Breast Cancer
Measure 5-5.	Appropriate Histological Assessment of Colorectal Cancer
Measure 5-6.	Pathology Laboratories' Compliance with Reporting Standards For Cancer Surgical Specimens
Measure 5-7.	Adequacy of Pathology Reports on Breast Cancer Surgical Specimens
Measure 5-8.	Adequacy of Pathology Reports on Colorectal Cancer Surgical Specimens
Measure 5-9.	Adequacy of Pathology Reports on Lung Cancer Surgical Specimens
Measure 5-10.	Adequacy of Pathology Reports on Prostate Cancer Surgical Specimens
Measure 5-11.	Breast Cancer Stage Determined Before Treatment
Measure 5-12.	Colorectal Cancer Stage Determined Before Treatment
Measure 5-13.	Lung Cancer Stage Determined Before Treatment
Measure 5-14.	Prostate Cancer Stage Determined Before Treatment

MEASURE 5-1: DIAGNOSING CANCER—Timely Breast Cancer Biopsy

Description	Timely breast cancer biopsy after a category 4 or 5 abnormal mammogram
Source	Institute for Clinical Systems Improvement, RAND, Vermont Cancer Center
Consensus on care	There is no consensus on the ideal interval between an abnormal mammogram and confirmed diagnosis. Delayed diagnosis of breast cancer is associated with later stage at diagnosis and poorer prognosis. A recent, multivariate analysis of 4,465 women with invasive breast cancer suggests that 6- to 12-month delays to diagnosis of asymptomatic breast cancer are associated with increased risk of lymph node metastases and larger tumor size. Delays are also associated with significant anxiety for the patient. Timeliness is fundamental to high-quality health care.
Knowledge vs. practice	Data on delays in follow-up of abnormal mammograms are limited. Most studies indicate that follow-up rates after abnormal mammogram, in general, fall below 75 percent. High rates of advanced disease at diagnosis persist among some groups—especially for racial minorities, uninsured, and low-income persons, suggesting that follow-up after an abnormal screening may be a problem. A 2001 survey of medical directors of community health centers in 10 states found that about 40 percent of uninsured patients had difficulty getting specialty referrals, including referrals for follow-up of abnormal screening tests.
Approach to calculating the measure	
Numerator	Number of women who have a completed biopsy within 14 days after first documentation of a category 4 or 5 abnormal mammogram (see comments below)
Denominator	Number of women with a category 4 or 5 abnormal mammogram
Potential data sources(s)	Surveillance, Epidemiology, and End Results (SEER)/ Medicare dataset; Georgia Comprehensive Cancer Registry (with enhancements); mammography registry
Comments	Breast Imaging Reporting and Data System (BI-RADS) category 4 and 5 mammograms are suspicious or highly suggestive of malignancy, respectively.
Limitations	—
Potential benchmark source(s)	Breast Cancer Surveillance Consortium; SEER/Medicare dataset

Key references

Gifford D, Schmidt L. 2000. Breast Cancer Diagnosis and Treatment. In: Asch, et al. *Quality of Care for Oncologic Conditions and HIV*. Santa Monica, CA: RAND. Pp. 33-45.

Gusmano MK, et al. 2002. Exploring the limits of the safety net: community health centers and care for the uninsured. *Health Affairs (Millwood)*. 21(6): 188-94.

Institute for Clinical Systems Improvement. 2003. *Health Care Guideline: Diagnosis of Breast Cancer*. 10th edition. [Online] Available: http://www.icsi.org/Knowledge/detail.asp?catID-298itemID-154 [accessed 2004].

Littenberg B, et al. 2003. *Methodologic Issues in Measuring the Quality of Cancer Care in the Community*. Burlington, VT: University of Vermont.

Olivotto IA, et al. 2002. Influence of delay to diagnosis on prognostic indicators of screen-detected breast carcinoma. *Cancer*. 94(8): 2143-2150.

Yabroff KR, et al. 2003. Is the promise of cancer-screening programs being compromised? Quality of follow-up care after abnormal screening results. *Med Care Res Rev*. 60(3): 294-331.

MEASURE 5-2: DIAGNOSING CANCER—Use of Needle Biopsy in Breast Cancer Diagnosis

Description	Needle biopsy is performed before breast cancer surgery
Source	American College of Surgeons; Institute for Clinical Systems Improvement; National Comprehensive Cancer Network (NCCN)
Consensus on care	Needle biopsy is the NCCN-preferred diagnostic follow-up to an abnormal mammogram (Category 2a recommendation). Needle biopsy is preferred because it is quick, accurate, and less invasive than the alternative approach (i.e., needle localization excisional biopsy). Needle biopsies often save patients an additional surgical procedure and thus reduce cost and improve quality of life. Women who undergo needle biopsy and ultimately opt for reconstruction after breast cancer surgery often have a better cosmetic outcome because the biopsy avoids an incision and scarring. Note that for 10 to 20 percent of women with abnormal mammograms, needle biopsy is not technically feasible because of the location and nature of the lesion.
Knowledge vs. practice	Unknown
Approach to calculating the measure	
Numerator	Number of women who have a needle biopsy of the breast at least 1 day prior to breast cancer surgery
Denominator	Number of women who undergo breast cancer surgery
Potential data source(s)	Surveillance, Epidemiology and End Results (SEER)/ Medicare dataset; mammography registry
Comments	Measurement goal should be 80 to 90 percent (some breast lesions are not amenable to needle biopsy). Needle biopsy techniques include core needle biopsy, vacuum-assisted biopsy, or fine-needle aspiration. The biopsy may be performed with or without image guidance depending on the location of the lesion, its visibility at ultrasound, equipment availability, and radiologist's expertise. The equipment for stereotactic biopsy is costly and may not be available throughout Georgia.
Limitations	—
Potential benchmark source(s)	SEER/Medicare dataset; Breast Cancer Surveillance Consortium

Key references

Collins LC, et al. 2004. Diagnostic agreement in the evaluation of image-guided breast core needle biopsies: results from a randomized clinical trial. *Am J Surg Pathol*. 28(1): 126-31.

CSI. 2003. *Health Care Guideline: Diagnosis of Breast Cancer*. 10th edition. [[Online] Available: http://www.icsi.org/Knowledge/detail.asp?catID-298itemID-154 [accessed 2004].

Liberman L. 2000. Centennial dissertation: Percutaneous imaging-guided core breast biopsy: State of the art at the millennium. *AJR Am J Roentgenol*. 174(ES): 1191-9.

Morrow, et al. 2001. Prospective comparison of stereotactic core biopsy and surgical excision as diagnostic procedures for breast cancer patients. *Ann Surg*. 233(4): 537-41.

NCCN. 2004. *Clinical Practice Guidelines in Oncology v.1.2004. Breast Cancer Screening and Diagnosis Guidelines*.

MEASURE 5-3: DIAGNOSING CANCER—Tumor-Free Surgical Margins in Breast-Conserving Surgery

Description	Tumor-free surgical margins in breast-conserving surgery
Source	College of American Pathologists (CAP); American College of Surgeons
Consensus on care	The goal of breast-conserving cancer surgery is to completely remove the tumor and to obtain clear surgical margins. Positive margins with breast-conserving surgery result in higher rates of local tumor recurrence. With lumpectomy, a positive margin often leads to additional surgery with either re-excision of additional tissue at the positive margin, or total mastectomy. Assuring appropriate treatment of breast cancer depends on high-quality pathology, including analyses of surgical margins. CAP guidelines require reporting gross margin status of all surgical margins.
Knowledge vs. practice	There are numerous reports that clear surgical margins are often lacking or that related documentation is missing from patient records.
Approach to calculating the measure	
Numerator	Number of breast-conserving cancer surgery patients whose surgical margins are free of tumor after their last surgical procedure
Denominator	Number of breast-conserving cancer surgery patients
Potential data source(s)	Special studies of pathology reports and medical records.
Comments	Clear surgical margin is defined as no tumor at the line of resection. Measurement goal should be 100 percent.
Limitations	—
Potential benchmark source(s)	CAP; baseline special studies

Key references

Commission on Cancer. 2003. *Cancer Program Standards, 2004. Standard 4.6*. Chicago, IL: American College of Surgeons. [Online] Available: http://www.facs.org/cancer/coc/cocprogramstandards.pdf.

Fitzgibbons PL, et al. (CAP). 2004. *Breast: Protocol applies to all invasive carcinomas of the breast*. [Online] Available: http://www.cap.org/apps/docs/cancer_protocols/breast04_pw.pdf [accessed August 30, 2004].

Imperato PJ, et al. 2002. Breast cancer pathology practices among Medicare patients undergoing unilateral extended simple mastectomy. *J Womens Health Gender Based Med*. 11(6): 537-47.

Silverstein MJ, et al. 1999. The influence of margin width on local control of ductal carcinoma in situ of the breast. *New Engl J Med*. 340(19): 1455-61.

White J, et al. 2003. Compliance with breast-conservation standards for patients with early-stage breast carcinoma. *Cancer*. 97: 893-904.

Wilkinson NW, et al. 2003. Concordance with breast cancer pathology reporting practice guidelines. *J Am Coll Surg*. 196: 38-43.

MEASURE 5-4: DIAGNOSING CANCER—Appropriate Histological Assessment of Breast Cancer

Description	Appropriate histological assessment of Stage I and Stage II breast cancer
Source	National Comprehensive Cancer Network (NCCN); Vermont Cancer Center
Consensus on care	Axillary lymph node status is a critical factor in determining the appropriate treatment for Stage I and II breast cancer. The axillary (armpit) lymph nodes are the main passageway that breast cancer cells use to spread to other parts of the body. Removing too few nodes may lead to undertreatment. NCCN guidelines emphasize that 10 or more axillary lymph nodes should be provided for histological assessment (Category 2a recommendation). Numerous studies show that survival markedly improves with the number nodes that are assessed. Sentinel node biopsy is an acceptable alternative to axillary dissection in some patients with unicentric tumors smaller than 5 cm with no prior treatment or large excisions *if* an experienced sentinel lymph node team is available.
Knowledge vs. practice	Numerous studies have documented that histological assessments are not performed as recommended and that use declines with patients' age.
Approach to calculating the measure	
Numerator	Number of Stage I and Stage II breast cancer cases with sentinel node biopsy *or* with histological assessment of 10 or more axillary lymph nodes
Denominator	Number of Stage I and Stage II breast cancer cases
Potential data source(s)	Surveillance, Epidemiology, and End Results Program (SEER); Georgia Comprehensive Cancer Registry (GCCR); pathology reports and medical records
Comments	NCCN guidelines indicate that axillary dissection or sentinel node biopsy may be optional in patients who have particularly favorable tumors, patients for whom the selection of adjuvant systemic therapy is unlikely to be affected, elderly patients, and patients with serious comorbid conditions. Thus, the goal for this measure should be less than 100 percent. Stage I refers to tumors less than 2 cm in diameter with no spread beyond the breast. Stage II includes tumors 2 to 5 cm in size with or without lymph node involvement, tumors less than 2 cm with spread to axillary nodes, and tumors greater than 5 cm without spread to axillary nodes.
Limitations	—
Potential benchmark source(s)	SEER; GCCR; baseline studies of pathology reports and medical records

Key references

Edge SB, et al. 2003. Emergence of sentinel node biopsy in breast cancer as standard-of-care in academic comprehensive cancer centers. *J Natl Cancer Inst.* 95(20):1514-21.

Littenberg B, et al. 2003. *Methodologic Issues in Measuring the Quality of Cancer Care in the Community*. Burlington, VT: University of Vermont.

NCCN. 2004. *Clinical Practice Guidelines in Oncology v.1.2004. Breast Cancer*.

Trocha SD, Giuliano AE. 2003. Sentinel node in the era of neoadjuvant therapy and locally advanced breast cancer. *Surgical Oncology.* 12(4): 271-6.

Weir L, et al. 2002. Prognostic significance of the number of axillary lymph nodes removed in patients with node-negative breast cancer. *J Clin Oncol.* 20(7): 1793-9.

MEASURE 5-5: DIAGNOSING CANCER—Appropriate Histological Assessment of Colorectal Cancer

Description	Appropriate histological assessment of colorectal cancer
Source	National Comprehensive Cancer Network (NCCN); College of American Pathologists (CAP)
Consensus on care	Histological assessment of regional lymph node status is integral to pathologic staging and treatment of colorectal cancer. There is an extensive literature showing that survival of colorectal cancer increases with the number of recovered lymph nodes, regardless of the number of positive nodes. NCCN recommends that a minimum of 14 regional lymph nodes be removed during surgical resection (Category 2a recommendation). CAP recommends removal of at least 12 nodes and urges that additional techniques (i.e., visual enhancement) be considered if fewer than 12 nodes are found.
Knowledge vs. practice	Numerous studies indicate that surgical and pathology reporting practices are of variable quality. Information on margins and the number and status of nodes is often missing. In one study, researchers examined the surgery and pathology reports of 673 patients who were enrolled in a U.S. cooperative group clinical trial for Stage II or III rectal cancer; 18 percent of patients had fewer than five lymph nodes examined and 68 percent had fewer than 12 nodes examined.
Approach to calculating the measure	
Numerator	Number of colorectal cancer surgery patients with a surgical resection that included at least 12 lymph nodes
Denominator	Number of colorectal cancer surgery patients
Potential data source(s)	Surveillance, Epidemiology, and End Results Program (SEER); Georgia Comprehensive Cancer Registry (GCCR) (with enhancements); pathology and surgical reports in medical records
Comments	—
Limitations	—
Potential benchmark source(s)	SEER; GCCR; baseline studies of pathology reports and medical records.

Key references

Compton CC. 2003. Colorectal carcinoma: diagnostic, prognostic, and molecular features. *Mod Pathol.* 16(4):376-88.

Compton CC (CAP). 2004. *Colon and Rectum: Protocol applies to all invasive carcinomas of the colon and rectum. Carcinoid tumors, lymphomas, sarcomas, and tumors of the vermiform appendix are excluded.* [Online] Available: http://www.cap.org/apps/docs/cancer_protocols/ColonRectum04_pw.pdf. [accessed September 1, 2004].

Le Voyer TE, et al. 2003. Colon cancer survival is associated with increasing number of lymph nodes analyzed: a secondary survey of intergroup trial INT-0089. *J Clin Oncol.* 21(15): 2912-9.

NCCN. 2004. *Clinical Practice Guidelines in Oncology v.2.2004. Colon Cancer.*

Stocchi L, et al. 2001. Impact of surgical and pathologic variables in rectal cancer: a United States community and cooperative group report. *J Clin Oncol.* 19(18): 3895-902.

MEASURE 5-6: DIAGNOSING CANCER—Pathology Laboratories' Compliance with Reporting Standards for Cancer Surgical Specimens

Description	Pathology laboratories that report College of American Pathologists (CAP) data elements as required by the American College of Surgeons' Commission on Cancer
Source	CAP; Commission on Cancer
Consensus on care	Appropriate treatment for solid tumors depends on the pathology of the primary tumor, surrounding tissues, and regional lymph nodes. Clear, standardized, and complete pathology reporting is integral to quality cancer care. CAP has developed detailed templates or "checklists" for reporting findings on cancer specimens. There are specific checklists for each organ site and type of surgical specimen, each with a series of mandatory and optional data elements. The purpose of the checklists is to ensure that information—essential to diagnosis, prognosis, and treatment—is always included. The Commission on Cancer mandates that pathology laboratories at Commission on Cancer-approved cancer programs report the mandatory data elements in the CAP checklists for cancer-directed surgical specimens (the CAP checklist reporting format is optional). The Commission on Cancer mandate does not apply to cytologic specimens, diagnostic biopsies, and palliative resection specimens.
Knowledge vs. practice	There are limited data documenting the extent of variation in pathology reporting. Selected studies have assessed reporting of some solid tumor types (e.g., breast, colorectal) and documented generally poor compliance with CAP guidelines.
Approach to calculating the measure	
Numerator	Number of pathology laboratories that report all Commission on Cancer-required CAP data elements for cancer specimens
Denominator	Number of pathology laboratories that assess breast, prostate, lung, and colorectal cancer specimens
Potential data source(s)	Special studies
Comments	—
Limitations	—
Benchmark source	CAP; Commission on Cancer; baseline special studies

Key references

CAP. 2003. *Required Data Elements from CAP Cancer Checklists Mandated for Use by the American College of Surgeons Commission on Cance, Effective January 1, 2004*. [Online] Available: http://www.cap.org/apps/docs/cancer_protocols/protocols_intro.html#1 [accessed September 1, 2004].

Commission on Cancer. 2003. *Cancer Program Standards, 2004. Standard 4.6*. Chicago, IL: American College of Surgeons. [Online] Available: http://www.facs.org/cancer/coc/cocprogramstandards.pdf.

Paxton. 2004. Cancer protocols: leaner, later, more lenient. *CAP Today*. [Online] Available: http://www.cap.org/apps/docs/cap_today/feature_stories0604Cancer_Protocols.html [accessed 2004].

White J, et al. 2003. Compliance with breast-conservation standards for patients with early stage breast carcinoma. *Cancer*. 97(4): 893-904.

Wilkinson, NW, et al. 2003. Concordance with breast cancer pathology reporting practice guidelines. *J Am Coll Surg*. 196(1): 38-43.

MEASURE 5-7: DIAGNOSING CANCER—Adequacy of Pathology Reports on Breast Cancer Surgical Specimens

Description	Pathology reports on invasive breast cancer surgical specimens that include College of American Pathologists (CAP) data elements as required by the American College of Surgeons' Commission on Cancer
Source	CAP; Commission on Cancer
Consensus on care	Appropriate treatment of breast cancer depends on clear, standardized, and comprehensive reporting on the pathology of the primary tumor, surrounding tissues, and regional lymph nodes. CAP has developed a detailed template or "checklist" for reporting findings on invasive breast cancer specimens. The purpose of the checklist is to ensure that information—essential to diagnosis, prognosis, and treatment—is always included. The Commission on Cancer mandates that pathology laboratories at Commission on Cancer-approved cancer programs report the scientifically validated data elements in the CAP checklist for cancer-directed surgical specimens (the CAP checklist reporting format is optional). The Commission on Cancer mandate does not apply to cytologic specimens, diagnostic biopsies, and palliative resection specimens.
Knowledge vs. practice	Available research indicates that the quality of pathology reports for breast cancer surgical specimens is variable; documentation of key data elements is often poor.
Approach to calculating the measure	
Numerator	Number of pathology reports on invasive breast cancer surgical specimens that include CAP data elements as required by the Commission on Cancer
Denominator	Number of pathology reports on invasive breast cancer surgical specimens
Potential data source(s)	Special studies of pathology reports; medical records
Comments	Measurement goal should be 100 percent. Findings should be reported in the aggregate and individually by pathology laboratory.
Limitations	—
Potential benchmark source(s)	CAP; Commission on Cancer; baseline special studies

Key references

Commission on Cancer. 2003. *Cancer Program Standards, 2004. Standard 4.6*. Chicago, IL: American College of Surgeons. [Online] Available: http://www.facs.org/cancer/coc/cocprogramstandards.pdf.

Fitzgibbons, et al. (CAP). 2004. *Breast: Protocol applies to all invasive carcinomas of the breast*. [Online] Available: http://www.cap.org/apps/docs/cancer_protocols/breast04_pw.pdf [accessed August 30, 2004].

Imperato PJ, et al. 2002. Breast cancer pathology practices among Medicare patients undergoing unilateral extended simple mastectomy. *J Womens Health Gender Based Med*. 11(6): 537-547.

White J, et al. 2003. Compliance with breast-conservation standards for patients with early-stage breast carcinoma. *Cancer*. 97: 893-904.

Wilkinson NW, et al. 2003. Concordance with breast cancer pathology reporting guidelines. *J Am Coll Surg*. 196(1): 38-43.

MEASURE 5-8: DIAGNOSING CANCER—Adequacy of Pathology Reports on Colorectal Cancer Surgical Specimens

Description	Pathology reports on colorectal cancer surgical specimens that include College of American Pathologists (CAP) data elements as required by the American College of Surgeons' Commission on Cancer
Source	CAP; Commission on Cancer
Consensus on care	Surgical resection is the primary treatment for colorectal cancer and the pathologic characteristics of resection specimens are the most powerful predictors of health outcomes. Complete and accurate pathology reports on surgical specimens are integral to treatment decisions. CAP has developed a detailed template or "checklist" for reporting findings on colorectal cancer specimens. The purpose of the checklist is to ensure that information—essential to diagnosis, prognosis, and treatment—is always included. The Commission on Cancer mandates that pathology laboratories at Commission on Cancer-approved cancer programs report the scientifically validated data elements in the CAP checklist for cancer-directed surgical specimens (the CAP checklist reporting format is optional). The Commission on Cancer mandate does not apply to cytologic specimens, diagnostic biopsies, and palliative resection specimens.
Knowledge vs. practice	Available research indicates that the quality of pathology reports for colorectal cancer surgical specimens is variable; documentation of key data elements is often poor.
Approach to calculating the measure	
Numerator	Number of pathology reports on colorectal cancer surgical specimens that include CAP data elements as required by the Commission on Cancer
Denominator	Number of pathology reports on colorectal cancer surgical specimens
Potential data source(s)	Special studies of pathology reports; medical records
Comments	Measurement goal should be 100 percent. Findings should be reported in the aggregate and individually by pathology laboratory.
Limitations	—
Potential benchmark source(s)	CAP; Commission on Cancer; baseline special studies

Key references

Commission on Cancer. 2003. *Cancer Program Standards, 2004. Standard 4.6.* Chicago, IL: American College of Surgeons. [Online]Available: http://www.facs.org/cancer/coc/cocprogramstandards.pdf.

Compton CC. 2003. Colorectal carcinoma: diagnostic, prognostic, and molecular features. *Mod Path.* 16(4): 376-88.

Compton (CAP). 2004. *Colon and Rectum: Protocol applies to all invasive carcinomas of the colon and rectum. Carcinoid tumors, lymphomas, sarcomas, and tumors of the vermiform appendix are excluded.* [Online] Available: http://www.cap.org/apps/docs/cancer_protocols/ColonRectum04_pw.pdf [accessed September 1, 2004].
— COLON and RECTUM: Polypectomy.
— RECTUM: Local Excision (Transanal Disk Excision).
— COLON AND RECTUM: Resection.

Stocchi L, et al. 2001. Impact of surgical and pathologic variables in rectal cancer: a United States community and cooperative group report. *J Clin Oncol.* 19(18): 3895-902.

MEASURE 5-9: DIAGNOSING CANCER—Adequacy of Pathology Reports on Lung Cancer Surgical Specimens

Description	Pathology reports on lung cancer surgical specimens that include College of American Pathologists (CAP) data elements as required by the American College of Surgeons' Commission on Cancer
Source	CAP; Commission on Cancer
Consensus on care	Surgical resection is the initial treatment for most types of lung cancer. Complete and accurate pathology reports on surgical specimens are integral to treatment decisions. CAP has developed a detailed template or "checklist" for reporting findings on lung cancer specimens. The purpose of the checklist is to ensure that information—essential to diagnosis, prognosis, and treatment—is always included. The Commission on Cancer mandates that pathology laboratories at Commission on Cancer-approved cancer centers report the mandatory data elements in the CAP checklist for cancer-directed surgical specimens (the CAP checklist reporting format is optional). The Commission on Cancer mandate does not apply to cytologic specimens, diagnostic biopsies, and palliative resection specimens.
Knowledge vs. practice	Available research indicates that the quality of pathology reports for lung cancer surgical specimens is variable; documentation of key data elements is often poor.
Approach to calculating the measure	
Numerator	Number of pathology reports on lung cancer surgical specimens that include CAP data elements as required by the Commission on Cancer
Denominator	Number of pathology reports on lung cancer surgical specimens
Potential data source(s)	Special studies of pathology reports; medical records
Comments	Measurement goal should be 100 percent. Findings should be reported in the aggregate and individually by pathology laboratory.
Limitations	—
Potential benchmark source(s)	CAP; Commission on Cancer; baseline special studies

Key references

Chamberlain DW, et al. 2000. Pathological examination and the reporting of lung cancer specimens. *Clin Lung Cancer*. 1(4): 261-8.

Commission on Cancer. 2003. *Cancer Program Standards, 2004. Standard 4.6*. Chicago, IL: American College of Surgeons. [Online] Available: http://www.facs.org/cancer/coc/cocprogramstandards.pdf.

Gal AA, et al. (CAP). 2004. *Lung: Protocol applies to all invasive carcinomas of the lung*. [Online] Available: http://www.cap.org/apps/docs/cancer_protocols/lung04_pw.pdf [acccessed September 1, 2004].

Gephardt GW, Baker PB. 1996. Lung carcinoma surgical pathology report adequacy: a College of American Pathologists Q-Probes study of over 8300 cases from 464 institutions. *Arch Pathol Lab Med*. 120(10): 922-7.

NCCN. 2004. *Clinical Practice Guidelines in Oncology-v.1.2004. Small Cell Lung Cancer*.

NCCN. 2004. *Clinical Practice Guidelines in Oncology-v.1.2004. Non-Small Cell Lung Cancer*.

MEASURE 5-10: DIAGNOSING CANCER—Adequacy of Pathology Reports on Prostate Cancer Surgical Specimens

Description	Pathology reports on prostate cancer surgical specimens that include College of American Pathologists (CAP) data elements as required by the American College of Surgeons' Commission on Cancer
Source	CAP; Commission on Cancer
Consensus on care	A large proportion of prostate cancer patients are treated surgically. Appropriate follow-up to prostate cancer surgery depends on clear, standardized, and comprehensive reporting on the pathology of the primary tumor, surrounding tissues, and regional lymph nodes. CAP has developed a detailed template or "checklist" for reporting findings on prostate cancer specimens. The purpose of the checklist is to ensure that information—essential to diagnosis, prognosis, and treatment—is always included. The Commission on Cancer mandates that pathology laboratories at Commission on Cancer-approved cancer programs report the scientifically validated data elements in the CAP checklist for *cancer-directed surgical specimens* (the CAP checklist reporting format is optional). The Commission on Cancer mandate does not apply to cytologic specimens, diagnostic biopsies, and palliative resection specimens.
Knowledge vs. practice	Little is known about the quality of pathology reports on prostate cancer surgical specimens.
Approach to calculating the measure	
Numerator	Number of pathology reports on prostate cancer surgical specimens that include CAP data elements are required by the Commission on Cancer
Denominator	Number of pathology reports on prostate cancer surgical specimens
Potential data source(s)	Special studies of pathology reports; medical records
Comments	Measurement goal should be 100 percent. Findings should be reported in the aggregate and individually by pathology laboratory.
Limitations	—
Potential benchmark source(s)	CAP; Commission on Cancer; baseline studies of pathology reports

Key references

Commission on Cancer. 2003. *Cancer Program Standards, 2004. Standard 4.6.* Chicago, IL: American College of Surgeons. [Online] Available: http://www.facs.org/cancer/coc/cocprogramstandards.pdf.

NCCN. 2004. *Clinical Practice Guidelines in Oncology-v.1.2004. Prostate Cancer.*

Srigley JR, et al. (CAP). 2004. *Prostate Gland: Protocol applies to invasive carcinomas of the prostate gland.* [Online] Available: http://www.cap.org/apps/docs/cancer_protocols/prostate04_pw.pdf [accessed September 1, 2004].

— PROSTATE GLAND: Radical prostatectomy

— PROSTATE GLAND: Needle Biopsy, transurethral prostatic resection, enucleation specimen.

MEASURE 5-11: DIAGNOSING CANCER—Breast Cancer Stage Determined Before Treatment

Description	Breast cancer cases in which pathologic staging preceded chemotherapy and radiation treatment
Source	American College of Surgeons; American College of Radiology; American Society of Clinical Oncology; National Comprehensive Cancer Network
Consensus on care	Chemotherapy and radiation treatment of breast cancer should not be initiated until the pathologic stage has been determined and documented in the medical record. *Clinical stage* is based on what has been learned about a patient's cancer up to the time of initial definitive treatment. *Pathologic stage* combines clinical staging information with surgical findings, incorporating pathologic examination of resected primary and regional lymph nodes. Every cancer patient's treatment regimen should be tailored to his or her stage of disease. Most treatment guidelines cannot be followed until the tumor stage has been determined.
Knowledge vs. practice	Few studies have reported on documentation of cancer stage before treatment. The proportion of Georgia women with breast cancer that is treated *before* the stage is determined is not known. Baxter et al. (2004) analyzed more than 25,000 breast cancer patients diagnosed with ductal carcinoma in situ from 1992 through 1999. The researchers found that tumor grade was not documented in the charts of more than half of the cases.
Approach to calculating the measure	
Numerator	Number of new breast cancer cases with medical chart documentation of pathologic stage before chemotherapy or radiation treatment is initiated
Denominator	Number of new breast cancer cases with chemotherapy or radiation treatment
Data source	Medical records
Comments	—
Limitations	—
Potential benchmark source(s)	Baseline studies of medical records

Key references

ACR (American College of Radiology). 1999. *ACR Practice Guideline for Communication: Radiation Oncology*. [Online] Available: http://www.acr.org/dyna/?doc=departments/stand_accred/standards/standards.html [accessed 2004].

Baxter NN, et al. 2004. Trends in the treatment of ductal carcinoma in situ of the breast. *J Natl Cancer Inst*. 96(6): 443-8.

Commission on Cancer. 2003. *Cancer Program Standards 2004*. Chicago, IL: American College of Surgeons. [Online] Available: www.facs.org/cancer/coc/cocprogramstandards.pdf.

Greene FL, et al. (AJCC). 2002. *The AJCC Cancer Staging Manual*. 6th Edition. New York: Springer-Verlag.

NCCN. 2004. *Clinical Practice Guidelines in Oncology-v.1.2004. Breast Cancer*.

MEASURE 5-12: DIAGNOSING CANCER—Colorectal Cancer Stage Determined Before Treatment

Description	Colorectal cancer cases in which pathologic staging preceded chemotherapy and radiation treatment.
Source	American College of Radiology; American Society of Clinical Oncology; Commission on Cancer; National Comprehensive Cancer Network
Consensus on care	Chemotherapy or radiation treatment of colorectal cancer should not be initiated until pathologic stage has been determined and documented in the medical record. *Clinical stage* is based on what has been learned about a patient's cancer up to the time of initial definitive treatment. *Pathologic stage* combines clinical staging information with surgical findings, incorporating pathologic examination of resected primary and regional lymph nodes. Every cancer patient's treatment regimen should be tailored to his or her stage of disease. Most treatment guidelines cannot be followed until the tumor stage has been determined.
Knowledge vs. practice	Few studies have reported on documentation of stage of colorectal cancer before treatment. The proportion of Georgians with colorectal cancer that is treated *before* the stage is determined is not known.
Approach to calculating the measure	
Numerator	Number of new colorectal cancer cases with medical chart documentation of pathologic stage before chemotherapy or radiation is initiated
Denominator	Number of new colorectal cancer cases with chemotherapy or radiation treatment
Potential data source(s)	Medical records
Comments	—
Limitations	—
Potential benchmark source(s)	Baseline studies of medical records

Key references

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MEASURE 5-13: DIAGNOSING CANCER—Lung Cancer Stage Determined Before Treatment

Description	Lung cancer cases in which pathologic staging preceded chemotherapy and radiation treatment
Source	American College of Radiology; American Society of Clinical Oncology; Commission on Cancer; National Comprehensive Cancer Network
Consensus on care	Chemotherapy or radiation treatment of lung cancer should not be initiated until the pathologic stage has been determined and documented in the medical record. *Clinical stage* is based on what has been learned about a patient's cancer up to the time of initial definitive treatment. *Pathologic stage* combines clinical staging information with surgical findings, incorporating pathologic examination of resected primary and regional lymph nodes. Every cancer patient's treatment regimen should be tailored to his or her stage of disease. Most treatment guidelines cannot be followed until the tumor stage has been determined.
Knowledge vs. practice	Few studies have reported on documentation of lung cancer stage before treatment. The proportion of Georgians with lung cancer that is treated *before* the stage is determined is not known.
Approach to calculating the measure	
Numerator	Number of new lung cancer cases with medical chart documentation of pathologic stage before chemotherapy or radiation treatment is initiated
Denominator	Number of new lung cancer cases with chemotherapy or radiation treatment
Potential data source(s)	Medical records
Comments	—
Limitations	—
Potential benchmark source(s)	Baseline studies of medical records

Key references

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MEASURE 5-14: DIAGNOSING CANCER—Prostate Cancer Stage Determined Before Treatment

Description	Prostate cancer cases in which pathologic staging preceded chemotherapy and radiation treatment
Source	American College of Radiology; American Society of Clinical Oncology; Commission on Cancer; National Comprehensive Cancer Network
Consensus on care	Chemotherapy and radiation treatment of prostate cancer should not be initiated until the pathologic stage has been determined and documented in the medical record. *Clinical stage* is based on what has been learned about a patient's cancer up to the time of initial definitive treatment. *Pathologic stage* combines clinical staging information with surgical findings, incorporating pathologic examination of resected primary and regional lymph nodes. Every cancer patient's treatment regimen should be tailored to his or her stage of disease. Most treatment guidelines cannot be followed until the tumor stage has been determined.
Knowledge vs. practice	Few studies have reported on documentation of prostate cancer stage before treatment. The proportion of Georgians with prostate cancer that is treated *before* the stage is determined is not known.
Approach to calculating the measure	
Numerator	Number of new prostate cancer cases with medical chart documentation of pathologic stage before chemotherapy or radiation treatment is initiated
Denominator	Number of new prostate cancer cases with chemotherapy or radiation treatment
Potential data source(s)	Medical records
Comments	—
Limitations	—
Potential benchmark source(s)	Baseline studies of medical records

Key references

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6

Treating Cancer

". . . knowledge of treatments with proven efficacy do not translate directly to the optimal delivery of such treatments to patients."
Developing a System to Assess the Quality of Cancer Care: American Society of Clinical Oncology National Initiative on Cancer Care Quality
Schneider et al., 2004

"More advanced treatment, utilizing cutting-edge technology, will be available at several key medical centers throughout the state, making it unnecessary for Georgians to go elsewhere in the nation. All Georgia cancer providers will become part of the Coalition's efforts."
Mobilizing Georgia, Immobilizing Cancer: Annual Report
Georgia Cancer Coalition, 2003

Once cancer is diagnosed, ensuring the best possible treatment is paramount. The Institute of Medicine (IOM) committee recommends that the Georgia Cancer Coalition (GCC) adopt 23 quality measures related to cancer treatment (Box 6-1). Four of the measures will allow Georgia to track cancer patients' receipt of appropriate primary therapy, focusing on patients' participation in clinical trials and primary therapy for prostate cancer. Six of the measures will enable the state to track breast and colorectal cancer patients' receipt of appropriate adjuvant treatment and follow-up. Four other measures will allow the state to assess the extent to which pain management and hospice care are used to minimize cancer patients' suffering. The final nine measures are routine measures of cancer survival and mortality.

BOX 6-1
Recommended Measures for Tracking the Quality of Cancer Treatment

Receipt of Appropriate Primary Therapy for Cancer
Measure 6-1 Cancer patients' participation in clinical trials
Measure 6-2 Inappropriate hormonal therapy before radical prostatectomy
Measure 6-3 Appropriate external beam radiation therapy (EBRT) doses for prostate cancer
Measure 6-4 Appropriate hormonal therapy with EBRT for prostate cancer

Receipt of Appropriate Adjuvant Therapy for Cancer
Measure 6-5 Adjuvant radiation after breast-conserving surgery
Measure 6-6 Adjuvant hormonal therapy for invasive breast cancer
Measure 6-7 Adjuvant combination chemotherapy for breast cancer
Measure 6-8 Adjuvant chemotherapy after colon cancer surgery

Receipt of Appropriate Follow-Up After Treatment for Cancer
Measure 6-9 Follow-up mammography after treatment for breast cancer
Measure 6-10 Follow-up colonoscopy after treatment for colorectal cancer

Minimization of Cancer Patients' Suffering
Measure 6-11 Cancer pain assessment
Measure 6-12 Prevalence of pain among cancer patients
Measure 6-13 Cancer deaths in hospice
Measure 6-14 Cancer patients' hospice length of stay

Cancer Survival and Mortality Rates
Measure 6-15 Breast cancer 5- and 10-year survival rates
Measure 6-16 Colorectal cancer 5- and 10-year survival rates
Measure 6-17 Lung cancer 5- and 10-year survival rates
Measure 6-18 Prostate cancer 5- and 10-year survival rates
Measure 6-19 Breast cancer mortality rate
Measure 6-20 Colorectal cancer mortality rate
Measure 6-21 Lung cancer mortality rate
Measure 6-22 Prostate cancer mortality rate
Measure 6-23 All cancers mortality rate

The 23 recommended quality measures pertaining to cancer treatment are discussed further below, along with the rationale for their selection. Brief explanations of the evidence underlying the measures (the "consensus on care") and a description of what is known about the gap between the evidence and current practice ("knowledge vs. practice") are also provided. At the end of the chapter, potential data sources for measures in the treat-

ment domain are briefly described. Summaries of each quality measure appear at the end of the chapter.

RECOMMENDED MEASURES FOR TRACKING THE QUALITY OF CANCER TREATMENT

Receipt of Appropriate Primary Therapy for Cancer

As noted above, four of the 23 recommended quality-of-cancer-care measures in the cancer treatment domain pertain to cancer patients' receipt of appropriate primary therapy, focusing on patients' participation in clinical trials and primary therapy for prostate cancer.

The first measure is a measure of cancer patients' participation in clinical trials:

- Measure 6-1—*Cancer patients' participation in clinical trials*—the proportion of newly diagnosed cancer patients in treatment who are participating in a clinical trial.

Expanding clinical trial participation is a principal, strategic goal of GCC (GCC, 2003). Towards this end, GCC has collaborated with many of Georgia's cancer care providers to establish the Georgia Clinical Oncology Research and Education, Inc., a nonprofit corporation dedicated to developing a statewide cancer clinical trial and research network (GCC, 2004). The IOM committee recommends that GCC monitor the progress of this significant statewide venture by tracking Georgia residents' enrollment in cancer trials by adopting this quality measure. In the future, GCC should consider expanding its monitoring of clinical trial participation. For example, it will be important to know whether low participation in trials is due to physicians not asking, patients refusing, or lack of appropriate trials even when physicians ask and patients agree.

In addition, the IOM committee recommends three quality indicators to track whether Georgia's prostate cancer patients receive evidence-based care if they opt for surgical or radiation treatment:

- Measure 6-2—*Inappropriate hormonal therapy before radical prostatectomy*—the proportion of prostate cancer patients who receive hormonal therapy before undergoing radical prostatectomy.
- Measure 6-3—*Appropriate external beam radiation therapy (EBRT) for prostate cancer*—the proportion of intermediate and high-risk prostate cancer patients who undergo external beam radiation and receive central axis doses of at least 75 Grays (Gy).

- Measure 6-4—*Appropriate hormonal therapy with EBRT for prostate cancer*—the proportion of high-risk prostate cancer patients who are treated with external beam radiation therapy and receive hormonal therapy for at least 2 years.

The rationale for the IOM committee's decision to recommend adoption of these measures is discussed further below.

Cancer Patients' Participation in Clinical Trials

The first recommended measure is the proportion of cancer patients in treatment in Georgia who participate in clinical trials.

Consensus on care. Clinical trials are essential to developing new cancer therapies and, as a result, they benefit countless numbers of persons with cancer. National Cancer Comprehensive Network (NCCN) guidelines strongly encourage cancer patients to participate in clinical trials (NCCN, 2004a). The conventional wisdom is that trial participants, compared with other cancer patients, have better access to medical professionals, are more closely monitored, and receive more timely interventions when necessary (NCI, 2001; CancerCare, 2003; Scalliet, 2004; Seattle Cancer Care Alliance, 2004). Yet demonstrating a causal relationship between trial participation and improved outcome is difficult (Peppercorn et al., 2004). Recent reviews of the literature have raised some doubts about the true benefit of trial participation largely because the available studies are flawed and data are insufficient to make the case that patients in cancer trials receive better care than other cancer patients (Peppercorn et al., 2004).

Knowledge vs. practice. Many cancer patients are not medically eligible to participate in a clinical trial either because of comorbid conditions and other clinical factors or because there are no ongoing trials relevant to their specific disease (Ruckdeschel, 1997). Definitive counts of participants in cancer clinical trials are elusive. GCC estimates that less than 2.0 percent of Georgians with cancer participated in a clinical trial in 2000 (Russell, 2004). Nationally, approximately 1.7 percent of lung, prostate, breast and colorectal cancer patients diagnosed in 2000-2002 enrolled in nonsurgical clinical trials sponsored by National Cancer Institute (NCI) Clinical Trials Cooperative Groups. Clinical trial enrollment is lower among Hispanic and Black persons, and declines with increasing age (Murthy et al., 2004). Estimates of enrollment in non-NCI sponsored trials are not available.

Primary Therapy for Prostate Cancer

Three of the quality measures track whether prostate cancer patients receive evidence-based care. In determining the appropriate course of treatment for prostate cancer, it is essential that the patient's risk of recurrence be accurately classified. NCCN practice guidelines recommend that clinicians determine each prostate cancer patient's risk of a recurrence at the time of the individual's prostate cancer diagnosis (NCCN, 2004f). As shown in Box 6-2, the risk of recurrence is classified into one of four categories—low, intermediate, high, and very high—and is determined by the patient's tumor stage, Gleason Score (an indicator of tumor grade), and prostate-specific antigen (PSA) level.

A man diagnosed with prostate cancer faces an array of possible treatment options (Litwin et al., 2000; Potosky et al., 2000; Spencer et al., 2003). The major therapeutic options include various combinations of radical prostatectomy, external beam radiation therapy, brachytherapy, and hormonal therapy. Evidence on which treatment works best is sparse (Litwin et al., 2000; Potosky et al., 2000). Thus, for many prostate cancer patients, the treatment decision is based to a great extent on the potential side effects and long-term complications of the alternative approaches rather than any demonstrated differences in treatment effectiveness (Potosky et al., 2000; Cooperberg et al., 2004).

There is good evidence, however, on the optimal *delivery* of the alternative treatments for prostate cancer (Litwin et al., 2000; Spencer et al., 2003). The three quality measures related to therapy for prostate cancer, discussed further below, are based on this body of evidence.

Inappropriate hormonal therapy before radical prostatectomy. The first recommended measure is the proportion of prostate cancer patients who receive inappropriate hormonal therapy before undergoing radical prostatectomy.

Consensus on care. Radical prostatectomy—the removal of the prostate and surrounding tissue—is recommended for localized prostate cancer (NCCN, 2004f). Nationally, it is the most common procedure used to treat prostate cancer and was the primary treatment for approximately 41 percent of men diagnosed with prostate cancer between 1995 and 2003 (Cooperberg et al., 2004).

NCCN guidelines do not recommend hormonal therapy before radical prostatectomy (NCCN, 2004f). Yet analyses of recent treatment data indicate that hormonal therapy is sometimes provided to patients undergoing radical prostatectomy in advance of their surgery (Cooperberg et al., 2003; Holzbeierlein et al., 2004). This misuse is worrisome given that several randomized, controlled trials have clearly shown no benefit to this treat-

BOX 6-2
Determining the Risk of Recurrence in Prostate Cancer Patients

Accurate classification of prostate cancer patients' recurrence risk is essential to determining the appropriate course of treatment. The risk categories are described below:

- *Low recurrence risk*—tumor Stage T1-T2a and Gleason score 2-6 and prostate-specific antigen level (PSA) < 10 ng/mL
- *Intermediate recurrence risk*—tumor Stage T2b-T2c or Gleason score 7 or PSA 10-20 ng/Ml
- *High*—tumor Stage T3a or Gleason score 8-10 or PSA > 20 ng/mL
- *Very high recurrence risk*—tumor Stage T3b-T4 or any T and N1

Three clinical variables determine a patient's risk classification:

- *Tumor stage*—based on information from laboratory tests, digital rectal exam, pathology reports, and imaging studies. The TNM staging typology is used; although only the T-values are used for classifying risk. TNM is based on the size and extent of the tumor (T), extent of spread to the lymph nodes (N), and metastasis (M). Higher numbers and letters indicate greater tumor size or more spread to lymph nodes and/or organs.
  - TX: primary tumor cannot be evaluated
  - T0: no evidence of primary tumor
  - T1 a, b, c; T2 a, b, c; T3 a, b; or T4: size and extent of the primary tumor
  - NX: regional lymph nodes were not assessed
  - N0: no regional lymph node metastasis
  - N1: metastasis in regional lymph nodes
  - MX: distant metastasis cannot be assessed
  - M0: no distant metastasis
  - M1: distant metastasis
- *Gleason score*—based on microscopic analysis, the Gleason score represents the tumor grade and the likelihood of spread. Scores range from 2 to 10; the higher the value, the higher the risk of spread.
- *Prostate-specific antigen (PSA) level*—determined by a blood test that measures the PSA level, a protein produced by the prostate. Men with prostate cancer usually have PSA levels above 4 ng/Ml with values up to 20 ng/ml and higher. Increases in PSA levels are associated with prostate cancer as well as benign prostatic hyperplasia and infection or inflammation of the prostate.

SOURCES: NCCN, 2004f; AJCC Staging Manual (Greene et al., 2002).

ment approach (Schulman et al., 2000; Aus et al., 2002; Soloway et al., 2002; Klotz et al., 2003). Furthermore, there is evidence documenting that hormonal treatment for prostate cancer has serious side effects, including hot flashes, anemia, and fatigue (Holzbeierlein et al., 2004). In addition, presurgical hormonal therapy may unnecessarily delay the tumor's removal and raise the overall costs of treatment.

Knowledge vs. practice. Even though the use of hormonal therapy before radical prostatectomy is inappropriate, the practice appears to be increasing. CaPSURE is a national, longitudinal database documenting the care of prostate cancer patients at 35 academic- and community-based urology practices. A recent CaPSURE study found that hormonal therapy use before radical prostatectomy had risen from 2.9 percent of patients diagnosed in the years 1989-1992 to 7.8 percent of patients diagnosed in the years 1999-2001 (Cooperberg et al., 2003). While this trend may reverse as the trial findings from 2002-2003 become more widely known, monitoring should help end the use of this inappropriate therapy.

Appropriate external beam radiation therapy for prostate cancer. The second recommended measure is the proportion of intermediate- and high-risk prostate cancer patients who undergo appropriate external beam radiation and receive central axis doses of at least 75 Gy.

Consensus on care. NCCN recommends three-dimensional conformal or intensity-modulated external beam radiation treatment with doses of 75-80 Gy for intermediate- or high-risk prostate cancer patients (NCCN, 2004f). Doses in this range have been shown to be more effective than the former standard dose of 70 Gy.

An M.D. Anderson Cancer Center randomized, controlled study, for example, compared the efficacy of 70 Gy vs. 78 Gy in controlling intermediate- and high-risk prostate cancer. The researchers found that the higher radiation dose significantly improved "freedom from failure," defined as three increases in the patients' PSA levels (Pollack et al., 2002). After 6 years, 62 percent of patients treated with 78 Gy were "free of treatment failure" compared with only 43 percent of patients treated with 70 Gy. In comparison with the lower dosage group, however, the higher dosage group experienced more rectal complications—a finding that indicates that rectal exposure to radiation treatment should be limited.

Preliminary results from another randomized trial, as well as numerous nonrandomized and retrospective studies, similarly support the higher radiation dose in treating prostate cancer patients (Zelefsky et al., 1998, 2001; Lyons et al., 2000; Hanks et al., 2000; Kuban et al., 2003; Kupelian et al., 2004; Zietman et al., 2004).

Knowledge vs. practice. Available evidence suggests that a substantial proportion of prostate cancer patients who undergo external beam radia-

tion therapy receive inadequate doses. A study of 392 patients at 58 radiation facilities, for example, found that only 38 percent of intermediate-risk patients and 60 percent of higher-risk patients received doses above 72 Gy (Zelefsky et al., 2004). Patients treated at academic medical centers were more likely to receive higher doses compared with patients treated at non-academic centers.

Appropriate hormonal therapy with external beam radiation therapy for prostate cancer. The third recommended measure is the proportion of high-risk prostate cancer patients who are treated with appropriate external beam radiation therapy and receive hormonal therapy for at least 2 years.

Consensus on care. External beam radiation therapy combined with hormonal therapy is a standard treatment for high-risk prostate cancer patients. NCCN's prostate cancer guidelines recommend that external beam radiation treatment be accompanied by 2 to 3 years of hormonal therapy for most prostate cancer patients at high recurrence risk (NCCN, 2004f).

Randomized trials have demonstrated that high-risk prostate cancer patients who undergo external beam radiation treatment have a substantial survival advantage with long-term hormonal therapy (Pilepich et al., 1997; Bolla et al., 2002; Hanks et al., 2003; Roach, 2003). An analysis of 412 patients in a randomized Phase III trial, for example, found dramatic differences between the patients who had external beam radiation treatment alone compared with the patients who had 3 years of hormonal therapy beginning on the first day of external beam radiation treatment. The hormonal therapy regimen resulted in 5-year, clinical disease-free survival rates of 74 percent, compared to 40 percent when hormonal therapy was not provided (Bolla et al., 2002). It also led to substantial improvements in overall survival and disease-specific survival.

Similarly, another Phase III randomized trial compared 2 years vs. 4 months of hormonal treatment with external beam radiation treatment and found marked improvement with the longer-term prostate cancer hormonal therapy (Hanks et al., 2003).

Knowledge vs. practice. Analyses of the CaPSURE cohorts indicate that combined use of hormonal therapy with external beam radiation is increasing. Most of the cohort diagnosed between 1999 and 2001, 74 percent of intermediate-risk and 90 percent of high-risk patients, received hormonal therapy before external beam radiation treatment—30 percentage points higher than the 1996-1998 cohort (Cooperberg et al., 2003). By monitoring the use of these prostate cancer treatments, Georgia can help to ensure that prostate cancer patients are receiving treatment that is appropriate to their disease.

Receipt of Appropriate Adjuvant Therapy for Cancer

Surgical resection is the primary course of treatment for most breast and colon cancers (NCCN, 2004b, 2004g). Adjuvant treatments—typically regimens of hormonal therapy, chemotherapy, and/or radiation administered after a cancer is removed surgically—are designed to eradicate or prevent growth of any cancer cells which may not have been surgically removed (Adjuvant therapy, 2000; NCCN, 2004b). When used appropriately, adjuvant therapies reduce the risk of recurrence and improve chances of long-term survival.

The IOM committee recommends four quality indicators to monitor the appropriate use of adjuvant therapy for cancer. Three of the measures pertain to adjuvant therapy after surgery for breast cancer:

- Measure 6-5—*Adjuvant radiation after breast-conserving surgery (BCS)*—the proportion of selected women who receive radiation treatment within 8 weeks of BCS or after post-BCS chemotherapy, if chemotherapy is given.
- Measure 6-6—*Adjuvant hormonal therapy for invasive breast cancer*—the proportion of selected women who receive adjuvant hormonal therapy for hormone-receptor positive invasive breast cancer.
- Measure 6-7—*Adjuvant combination chemotherapy for breast cancer*—the proportion of selected women who receive adjuvant combination chemotherapy for hormone-receptor negative Stage I to Stage III breast cancer.

The fourth recommended measure pertains to adjuvant therapy for colon cancer:

- Measure 6-8—*Adjuvant chemotherapy after colon cancer surgery*—the proportion of Stage III colon cancer patients who receive adjuvant chemotherapy after surgery.

The rationale for the IOM committee's decision to recommend these particular measures is discussed further below.

Adjuvant Therapy for Breast Cancer

As just noted, three of the recommended measures pertain to adjuvant therapy after surgery for breast cancer.

Adjuvant radiation treatment after breast-conserving surgery for breast cancer. The first recommended measure is the proportion of patients under

age 70 who undergo breast-conserving surgery for invasive cancer and receive adjuvant radiation treatment within 8 weeks of their surgery, or following post-surgery chemotherapy, if chemotherapy is given.

Consensus on care. Adjuvant radiation is the standard of care for most women with invasive cancer who undergo breast-conserving surgery (Adjuvant therapy, 2000; NCCN, 2004b). An established, high-level evidence base shows that radiation after breast-conserving surgery markedly reduces the risk of cancer recurrence in the same breast compared with surgery alone (Early Breast Cancer Trialists' Collaborative Group, 2000; Fisher et al., 2002; Veronesi et al., 2002; Goldhirsch et al., 2003). Recent randomized trial evidence strongly suggests that women, aged 70 and older, may not need adjuvant radiation if they receive a recommended course of hormonal therapy for estrogen-receptor-positive (ER-positive) tumors that are no larger than 2 cm in diameter (see discussion below) (Hughes et al., 2004).

Although there is no consensus on how soon radiation treatment should begin after breast-conserving surgery, the available evidence suggests that the interval should be brief. A meta-analysis of 10 retrospective studies involving 7,401 breast cancer patients found that the 5-year local recurrence rate was significantly higher in patients whose adjuvant radiation treatment began more than 8 weeks after surgery (Huang et al., 2003).

NCCN recommends radiation after breast-conserving surgery for most Stage I or Stage II breast cancers, as well as for all noninvasive breast cancers (i.e., ductal carcinoma in situ, or DCIS) patients with tumors that are 0.5 cm in diameter or larger (NCCN, 2004b). If the patient also requires adjuvant chemotherapy, the radiation treatments should follow the chemotherapy.

Knowledge vs. practice. Breast-conserving surgery has become the most common surgical treatment for women with early-stage breast cancer (Morrow et al., 2002; Singh et al., 2003). In Georgia's Commission on Cancer-certified hospitals, however, only 51 percent of women with Stage 0 to Stage II breast cancers undergo breast-conserving surgery (NCDB, 2002). Numerous studies have shown that not all women treated with breast-conserving surgery receive radiotherapy as recommended, especially older women, African-American women, women who live longer distances from radiation therapy facilities, and women who did not consult with a radiation oncologist before surgery (Nattinger et al., 2000; Roetzheim et al., 2000; Gilligan et al., 2002; Mandelblatt et al., 2002; Baldwin et al., 2004).

Adjuvant hormonal therapy for Stage I and Stage II breast cancer. The second recommended measure is the proportion of Stage I and Stage II breast cancer patients who are hormone-receptor positive and receive adjuvant hormonal therapy after surgery.

Consensus on care. Adjuvant hormonal therapy is a standard component of early-stage breast cancer treatment for women with cancers that express the estrogen or progesterone receptors (NCCN, 2004b). The objective of hormonal therapy is to prevent estrogen from stimulating further tumor growth. Tumor cells that contain receptors for the hormones are more likely to grow and spread with the presence of the hormones. A cancer is called "ER-positive" if it has receptors for the hormone estrogen and "PR-positive" if it has receptors for the hormone progesterone. Randomized clinical trials have shown that, as the number of ER-positive and PR-positive tumor cells increases, hormonal therapy is more likely to be effective (Adjuvant therapy, 2000; Cole et al., 2001).

There is a plethora of evidence showing that adjuvant hormonal therapy reduces the risk of tumor recurrence and significantly improves survival for women with Stage I or Stage II hormone-receptor positive breast cancer (Early Breast Cancer Trialists' Collaborative Group, 1998; Adjuvant therapy, 2000; Baum et al., 2002; Winer et al., 2002; Goldhirsch et al., 2003).

Tamoxifen has long been established as effective adjuvant hormonal therapy for women with ER-positive and PR-positive invasive breast cancer. More recently, aromatase inhibitors such as anastrozole have been shown to be effective at reducing the risk of tumor recurrence, and are now recommended as part of an adjuvant hormonal therapy regimen for postmenopausal women (Baum et al., 2002; Winer et al., 2005). In postmenopausal women, estrogen is no longer produced by the ovaries, but is converted from androgen, another hormone. Aromatase inhibitors inhibit the androgen to estrogen conversion.

Knowledge vs. practice. There are numerous reports showing that adjuvant hormone therapy is used less often than well-established clinical guidelines recommend. Failure to undergo hormonal treatment is associated with advancing age as well as age under 45, being nonwhite, and not having seen an oncologist before treatment was initiated (Guadagnoli et al., 1997; Malin et al., 2002; Du et al., 2003).

Adjuvant combination chemotherapy after surgery for Stage I to Stage II breast cancer. The third recommended measure is the proportion of Stage I to Stage III breast cancer patients under age 71 who receive adjuvant combination chemotherapy after surgery.

Consensus on care. There is an extensive body of research, based on randomized trials, showing that combination chemotherapy—the administration of two or more pharmaceutical agents—substantially increases relapse-free survival and survival overall for women under age 71 with operable breast cancer (Adjuvant therapy, 2000; Cole et al., 2001). NCCN recommends adjuvant combination chemotherapy for women under age 71

with Stage I, II, or III breast cancer if their tumor is larger than 1 centimeter in diameter and both ER-negative and PR-negative (NCCN, 2004b). The optimal time for initiating chemotherapy is not known (NCI, 2004a). There are insufficient data to either support or discourage adjuvant chemotherapy for women over age 70.

Knowledge vs. practice. There is a clear divergence between consensus recommendations and clinical practice (Harlan et al., 2002; Du et al., 2003). Chemotherapy use declines substantially with increasing age. In addition, older women who undergo chemotherapy are more likely to experience treatment delays and to receive lower than recommended dosages, compared with others (Lyman et al., 2003).

Adjuvant Therapy for Colon Cancer

As noted above, one of the measures recommended is the proportion of Stage III colon cancer patients who receive adjuvant chemotherapy. The rationale for the IOM committee's decision to recommend this measure is presented below.

Consensus on care. For most colon cancer patients, primary treatment involves surgical removal of the tumor and regional lymph nodes (NCCN, 2003). For patients with Stage III colon cancer—tumors that have spread through the wall of the colon into regional lymph nodes and nearby tissues or organs—adjuvant chemotherapy has been the established standard of care for over a decade (Moore and Haller, 1999). Numerous randomized trials have shown that adjuvant chemotherapy substantially increases disease-free and overall survival of Stage III colon cancer (Moertel et al., 1995; IMPACT Investigators, 1995; Wolmark et al., 1999; Potosky et al., 2002). NCCN specifically recommends 6 months of adjuvant 5-fluorouracil plus leucovorin or FOLFOX[1] for all Stage III colon cancer patients (NCCN, 2004g).

Knowledge vs. practice. Despite the well-documented benefits of adjuvant chemotherapy for Stage III colon cancer, numerous reports show that its use varies by a wide range of patient and provider characteristics including patients' age, race, ethnicity, marital status, health insurance status (i.e., being uninsured) and type of health insurance coverage, Medicaid coverage, hospital volume and individual hospital (Roetzheim et al., 2000; Hodgson et al., 2001; Potosky et al., 2002; Ayanian et al., 2003; Oliveria et al., 2004).

[1]FOLFOX refers to infusional 5-FU/leucovorin/oxaliplatin.

Receipt of Appropriate Follow-Up After Treatment for Cancer

After initial cancer treatment, patients are at risk for a recurrence. Mammography after breast cancer and colonoscopy after colorectal cancer are routinely recommended to assure early detection of a recurrence or new cancer (Smith et al., 1999; Benson et al., 2000; NCCN, 2004b, 2004g). The IOM committee recommends two quality indicators to monitor appropriate follow-up of breast and colorectal cancer patients.

- Measure 6-9—*Follow-up mammography after treatment for breast cancer*—the proportion of women with Stage 0 to Stage III breast cancer who have a mammogram by 19 months after diagnosis.
- Measure 6-10—*Follow-up colonoscopy after treatment for colorectal cancer*—the proportion of patients with Stage I to Stage III colorectal cancer who undergo a colonoscopy within 1 year of surgery.

The rationale underlying the IOM committee's recommendations is discussed further below.

Follow-Up Mammography After Treatment for Breast Cancer

The first recommended measure is the proportion of women with Stage 0 to Stage III breast cancer who have a mammogram by 19 months after diagnosis.

Consensus on care. Women with a history of breast cancer are at significant risk of recurrence especially if they had breast-conserving surgery without adjuvant radiation. The National Surgical Adjuvant Breast and Bowel Project conducted a 20-year follow-up of women who had breast-conserving surgery and adjuvant radiation. The researchers found that 14.3 percent of the women experienced a recurrent tumor in the same breast; without adjuvant radiation, 39.2 percent of the patients experienced a recurrence (Fisher et al., 2002). Age under 45 years is also a major risk factor for local recurrence of breast cancer (Elkhuizen et al., 1998).

The American Society of Clinical Oncology (ASCO) and NCCN recommend that women treated with breast-conserving therapy have a first post-treatment mammogram of the preserved and contralateral breast approximately 6 to 12 months after radiotherapy is complete and yearly mammograms thereafter (Smith et al., 1999; NCCN, 2004b).

The IOM committee recommends 19 months after diagnosis to allow for a 12-month follow-up period after a 7-month therapeutic period. The goal for this measure may be less than 100 percent to account for those women who refuse follow-up or who undergo bilateral total mastectomies.

Knowledge vs. practice. It appears that many women treated for breast cancer—especially women at high-risk of a recurrence—do not get needed follow-up care. Geller and colleagues analyzed 2,503 breast cancer cases in the NCI's Breast Cancer Surveillance Consortium registries and found that, by 12 months after diagnosis, about half the women had a first follow-up mammogram (Geller et al., 2003). By 30 months, 78 percent of women had returned for a mammogram. Women who did not receive adjuvant radiation after breast-conserving surgery were less likely to return for follow-up despite being at significant risk of recurrence.

Follow-Up Colonoscopy After Treatment for Colorectal Cancer

The second recommended measure—follow-up colonoscopy after treatment for Stage I to Stage III colorectal cancer—is the proportion of Stage I to Stage III colorectal cancer cases who undergo a colonoscopy within 1 year of surgery.

Consensus on care. The recurrence rate after colorectal cancer surgery is not known; estimates of the rate of recurrence range from as low as 2 percent to about 33 percent, at 5 years post-surgery (Green et al., 2002; Fisher et al., 2003). Colonoscopy can detect recurrences, as well as new polyps or new primary cancers. A recent retrospective study of 3,546 Veterans Administration patients strongly supports a mortality benefit for follow-up colonoscopy in patients with a history of nonmetastatic colorectal cancer (Fisher et al., 2003). The researchers compared 5-year mortality rates and found that risk of death was decreased by 43 percent in the group of patients who had at least one follow-up colonoscopy compared with the group of patients who had no follow-up.

NCCN recommends that Stage I to Stage III colorectal cancer patients have a follow-up colonoscopy within 1 year of resection. The colonoscopy should be performed 3 to 6 months after surgery if an obstruction had prevented a preoperative colonoscopy. ASCO guidelines call for a preoperative or perioperative colonoscopy followed by colonoscopy every 3 to 5 years (Benson et al., 2000).

Knowledge vs. practice. The use of colonoscopy to follow up colorectal cancer surgery patients appears to vary with patients' characteristics and local practice patterns (Cooper et al., 2000; Rulyak et al., 2004). Cooper and colleagues used a national Surveillance, Epidemiology, and End Results (SEER)/Medicare dataset to study the use of endoscopy by 5,716 patients aged 65 and older, following surgery for nonmetastatic colorectal cancer. Colonoscopy was performed in 58 percent of patients who had survived through the end of the 6-year study period. The likelihood of a colonoscopy

after surgery was associated with patients' age, tumor location (colon or rectum), and local provider practice patterns.

Minimization of Cancer Patients' Suffering

Many cancer patients experience intense pain at some time during the course of their disease (Cleeland et al., 1997; Benedetti, 2001). Furthermore, for many people who ultimately die of cancer, the period before death is characterized by unnecessary pain, distress, nausea, and other physical and psychological symptoms (IOM, 2001). The objective of palliative care is to relieve the symptoms and suffering caused by cancer—starting at diagnosis and continuing through treatment, survivorship, recurrent or advanced disease, and the end of life.

The IOM committee recommends four quality indicators that GCC should use to monitor the quality of palliative care. Two of the recommended measures pertain to the assessment of pain among cancer patients:

- Measure 6-11—*Cancer pain assessment*—proportion of cancer patient encounters where patient was assessed for pain.
- Measure 6-12—*Prevalence of pain among cancer patients*—proportion of cancer patients who report more than minor pain.

The other two measures track cancer patients' use of hospice care:

- Measure 6-13—*Cancer deaths in hospice*—Rate of cancer deaths in hospice.
- Measure 6-14—*Cancer patients' hospice length of stay*—proportion of hospice cancer patients with a length of stay of at least 7 days.

The rationale underlying each of these measures is discussed further below.

Assessment of Cancer Patients' Pain

As noted above, the IOM committee recommends two measures pertaining to the assessment of pain among cancer patients: one measure of pain assessment (proportion of cancer patient encounters where patient was assessed for pain) and one measure of the prevalence of pain among cancer patients.

Consensus on care. Regular reassessment of patients' pain is integral to effective cancer pain management (IOM, 2001; Goudas et al., 2001; ONS, 2002; Balducci, 2003; NCCN, 2004d). The American Pain Society recommends that health providers view pain as the "fifth vital sign"™ so that

pain is routinely checked with pulse, blood pressure, core temperature, and respiration in every patient encounter (APS, 1995a).

Several studies have found that the most important predictor of inadequate pain relief is a discrepancy between the patient's and the physician's assessment of the severity of pain (Jacox et al., 1994; Reifel, 2000). Consequently, numerous clinical guidelines advise that patients be directly queried regarding their level of pain (Jacox et al., 1994; WHO, 1996; ONS, 2002; National Consensus Project for Quality Palliative Care, 2004; JCAHO, 2004; NCCN, 2004d).

NCCN, for example, recommends that clinicians screen cancer patients for pain every time they are seen and that patients should use one of several available rating scales to quantify their pain (NCCN, 2004d). The Joint Commission for the Accreditation of Healthcare Organizations (JCAHO) has established standards for inpatient pain management including a documentation requirement stipulating that assessed pain be recorded in a way that facilitates appropriate follow-up and reassessment (Center to Advance Palliative Care, 2003). JCAHO, in a recent collaboration with the American Medical Association and the National Committee for Quality Assurance, has also developed a standardized performance measure for tracking the proportion of cancer patients who are assessed for pain (JCAHO, 2004). The IOM committee drew from this effort to develop the measure on the assessment of cancer patients' pain (Measure 6-11).

The World Health Organization (WHO) has developed an approach to treating cancer pain that is widely endorsed in the United States and around the world (WHO, 1996). WHO outlines a step-by-step algorithm that suggests patients be started on acetaminophen or a nonsteroidal anti-inflammatory drug. If insufficient, the patient should then receive a "weak" opioid, such as codeine, and, if necessary, progress to a "strong" opioid such as morphine.

Knowledge vs. practice. There are no definitive estimates of the prevalence of pain among cancer patients and survivors (Symptom management, 2002). Estimates range from 14 percent to 100 percent. Regardless, the research literature makes clear that severe pain is often characteristic of the cancer experience not only for patients in the advanced stages of disease but also for patients during the course of successful treatment and afterwards (Goudas et al., 2001; Allard et al., 2001; IOM, 2003b). Nevertheless, cancer pain is often untreated or undertreated (Cleeland et al., 1997; Benedetti, 2001; Goudas et al., 2001; IOM, 2001; Symptom management, 2002; IOM, 2003b). Several studies suggest that some groups of cancer patients are more likely to be inadequately treated for pain, especially members of racial or ethnic minorities, women, and elderly persons (Cleeland et al., 1997; Goudas et al., 2001; Green et al., 2003). Cleeland and colleagues

(1997) conducted a prospective study of the Eastern Cooperative Oncology Group's management of outpatients who had pain and recurrent or metastatic cancer. The researchers found poor pain care overall and significant disparities in care; 65 percent of nonwhite and Hispanic patients did not receive guideline-recommended analgesic prescriptions compared with 50 percent of nonminority patients.

Cancer Patients' Use of Hospice Care

As noted above, the IOM committee recommends two measures pertaining to the cancer patients use of hospice care: one measure of cancer deaths in hospice and one measure of cancer patients' hospice length of stay.

Consensus on care. Hospice—the gold standard of care for dying persons, their families, and other loved ones—is a home-based or inpatient program of palliative and supportive care services that provides physical, psychological, social, and spiritual care (ASCO, 1998; NCCN, 2004e). NCCN recommends that patients with *months to weeks to live* be offered palliative or hospice care and that patients with *weeks to days to live* should be given intensive palliative care—not more anticancer treatments. There is no consensus on how long cancer patients should stay in hospice to receive maximum benefit.

Knowledge vs. practice. Hospice use among cancer patients is increasing. However, most patients are referred to hospice too late to fully benefit from it (MedPAC, 2002; NCCN, 2004e). Some dying cancer patients are not referred at all. Lackan and colleagues analyzed the SEER/Medicare records of more than 170,000 Medicare beneficiaries who had been diagnosed with breast, colorectal, lung, or prostate cancer and died (Lackan et al., 2004). Thirty percent of the study population used hospice services before they died.

The median hospice length of stay for adult cancer patients was 15.4 days in 2000 (AHRQ, 2003). However, a substantial proportion of cancer patients receive hospice care just days before death. An analysis of 28,777 Medicare beneficiaries who died of various cancers found that, among those who ultimately died in hospice, 17.0 percent had exceedingly short stays of only 3 or fewer days (Earle et al., 2004).

Several studies indicate that access to hospice care varies with patient's age, race and ethnicity, supplemental Medicare coverage, income, urban vs. rural residence, managed care enrollment, and other factors (MedPAC, 2002; Lackan et al., 2004).

Cancer Survival and Mortality Rates

Cancer survival and mortality rates are surveillance measures used by epidemiologists to analyze the impact of cancer on a population. Survival rates are generally viewed as indicators of treatment effectiveness while mortality rates may be influenced also by prevention and early detection. If GCC succeeds in narrowing the gap in Georgia between *what is known* about effective cancer prevention, early detection, and treatment and *what is practiced*, the change will eventually become evident in survival and mortality rates.

The IOM committee recommends that Georgia track the following cancer survival rates:

- Measure 6-15—*Breast cancer 5- and 10-year survival rates*
- Measure 6-16—*Colorectal cancer 5- and 10-year survival rates*
- Measure 6-17—*Lung cancer 5- and 10-year survival rates*
- Measure 6-18—*Prostate cancer 5- and 10-year survival rates*

In addition, the IOM committee recommends that Georgia monitor mortality rates for the state's four most common cancers and track the mortality rate for all types of cancer as indicators of quality of cancer care:

- Measure 6-19—*Breast cancer mortality rate*
- Measure 6-20—*Colorectal cancer mortality rate*
- Measure 6-21—*Lung cancer mortality rate*
- Measure 6-22—*Prostate cancer mortality rate*
- Measure 6-23—*All cancers mortality rate*

The cancer survival and mortality rates recommended as quality measures are discussed further below.

Cancer Survival Rates

Currently, Georgia monitors cancer mortality rates but the state does not track cancer survival rates. The IOM committee recommends that GCC continue to include cancer mortality monitoring in Georgia's quality-of-cancer-care measurement activities and also build the capacity to track cancer survival trends. Although cancer epidemiologists typically use 5-year survival as the standard statistic for defining when a cancer has been successfully treated, the IOM committee recommends that Georgia plan to track 10-year survival rates as well. Measurable progress will only be apparent over the long-term for most cancers.

Cancer survival may be measured in two ways, observed survival and relative survival. *Observed survival* is the percentage of cancer patients still alive at some specified time after diagnosis, including deaths from cancer and all other causes. *Relative survival* adjusts the observed rate to account for death due to causes other than cancer. It thus provides a more accurate estimate of the likelihood that a patient will survive the cancer in the specified time period.

There are stark disparities in survival rates by type of cancer; in part, reflecting differences in the availability of early detection methods and effective treatments. Most breast, colorectal, and prostate cancer patients survive 5 years after diagnosis; in Atlanta, 84.6 percent; 61.6 percent; and 97.5 percent, respectively. In contrast, just 16.5 percent of lung cancer patients are living 5 years after diagnosis.

Table 6-1 shows the relative survival rates for breast, colorectal, lung, and prostate cancers in Georgia's Atlanta SEER registry alone, as well as in the combined U.S. SEER registry areas, including Atlanta, Connecticut, Detroit, Hawaii, Iowa, Los Angeles, New Mexico, San Francisco-Oakland, Seattle-Puget Sound, and Utah.

Cancer survival statistics are subject to bias and should therefore be interpreted with caution. When interpreting cancer survival measures, it is important to keep in mind the potential for lead-time bias and length bias (Box 6-3). Apparent increases in cancer survival rates may reflect advances in early detection rather than true improvements in delivering state-of-the-

TABLE 6-1 Relative Survival Rates for Breast, Colorectal, Lung and Bronchus, and Prostate Cancers

	Survival rates (by percent)		
	Atlanta SEER registry	U.S., SEER registries[a]	
Cancer site	5 years[b]	5 years[c]	10 years[d]
Breast (female)	84.6	86.8	77.3
Colorectal	61.6	63.7	57.4
Lung and bronchus	16.5	15.2	10.2
Prostate	97.5	98.7	92.1

[a]Includes Atlanta, Connecticut, Detroit, Hawaii, Iowa, Los Angeles, New Mexico, San Francisco-Oakland, Seattle-Puget Sound, and Utah.

[b]Cancers diagnosed from 1992-1999.

[c]Cancers diagnosed in 1996.

[d]Cancers diagnosed in 1991.

SOURCE: Ries et al., 2004; Liff, 2004.

BOX 6-3
Caveat Emptor: Interpreting Cancer Survival Statistics

Cancer survival measures can sometimes be misleading because of two types of biases in the statistics: lead-time bias and length bias. It is important to keep these in mind when interpreting survival statistics.

Lead-Time Bias
Measured improvements in survival may be due to a statistical artifact called lead-time bias rather than to any deliberate intervention to improve the quality of care. As progress is made in improving early detection of new cancers, cancer diagnosis is pushed back in time. Because of this longer "lead time," patients can seem to live longer after their diagnosis. Consider a man who is destined to develop prostate cancer symptoms at age 65, to survive 5 years, and to die at age 70. His survival rate can be doubled to 10 years simply by detecting the cancer before symptoms appear, at age 60, even if he still dies from that same cancer at age 70.

Length Bias
Length bias is another statistical artifact that may cause improvements in survival rates to be overestimated for cancers that can be detected early through screening. As early detection becomes more commonplace, relatively more slow-growing cancers are detected. Fast-growing cancers exist in screening populations for a comparably shorter period of time because they tend to lead more hastily to death. Thus, as the proportion of slower-growing cancers increases, the measurable survival period may appear to be lengthening.

SOURCE: Adapted from http://cancer.gov/statistics/glossary.

art cancer treatments to patients. Early cancer detection pushes back the timing of diagnosis—and that, in turn, may artificially lengthen the survival period.

Cancer Mortality Rates

Cancer mortality rates are measured by the number of people who die of cancer within a year, expressed in terms of number of deaths per 100,000 people. Mortality rates are developed from death statistics based on the underlying cause of death—the disease or injury that initiated the sequence of events leading directly to death. Georgia's mortality rates for the four leading types of cancers and all cancers combined are shown in Figure 6-1 and Figure 6-2.

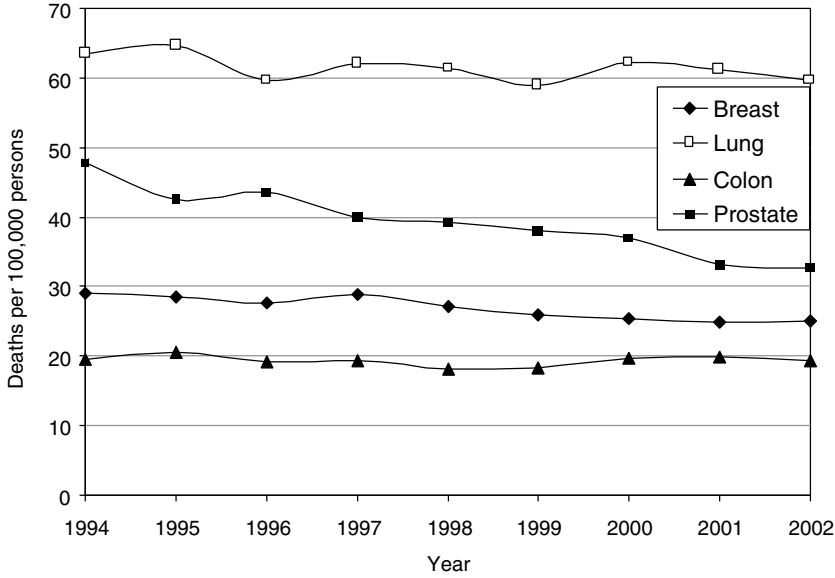

FIGURE 6-1 Mortality rate for each of four leading cancers in Georgia, 1994-2002.
NOTE: Rates are age-adjusted to the year 2000 population.
SOURCE: GDPH, 2004.

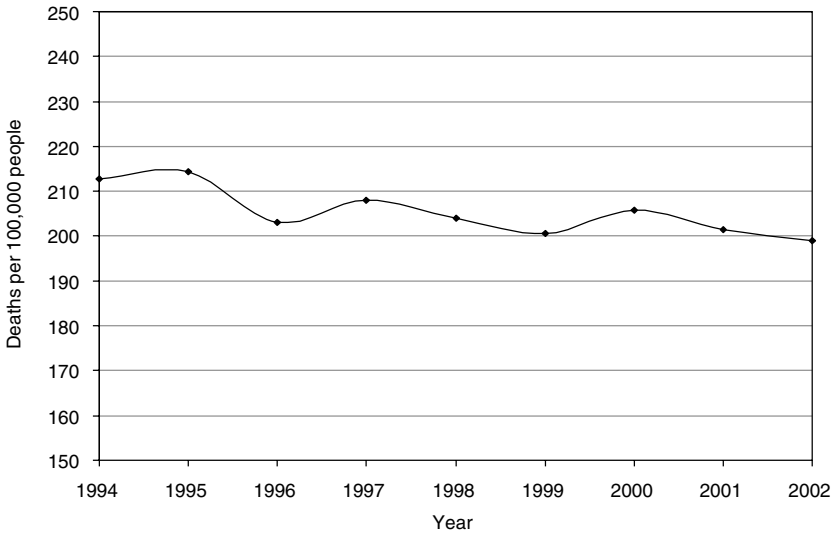

FIGURE 6-2 Mortality rate for all cancers in Georgia, 1994-2002.
NOTE: Rates are age-adjusted to the year 2000 population.
SOURCE: GDPH, 2004.

DATA SOURCES

The data for treatment-related quality measures may be drawn from a variety of sources (Table 6-2):

- Georgia Clinical Oncology Research and Education, Inc. will be essential to tracking trends in clinical trial enrollment.
- Medicare and other claims databases—if linked with tumor registry data—are key to primary and adjuvant treatment quality measures. The linked Medicare claims and SEER dataset is an already available, critical information source. The Georgia Comprehensive Cancer Registry must be upgraded to SEER standards in order to generate survival statistics and conduct analyses of adult populations younger than Medicare age. GCC should explore using and linking commercial claims to registry data for adults under age 65.
- Medical records will be an essential though costly data source because they contain extensive documentation of patients' treatments and other important clinical details.
- Surveys of cancer patients and family members are the best way to capture the patient experience. They will be an indispensable means to assessing the quality of palliative and end-of-life care.

Further information about the strengths and weakness of data sources is presented in Chapter 2, *Concepts, Methods, and Data Sources,* and Appendixes A and B.

SUMMARY

When a patient is diagnosed with cancer, ensuring the best possible treatment is paramount. Far too often, however, cancer patients do not receive treatments with proven efficacy and their cancer experience is one of unnecessary pain. If Georgia is to meaningfully improve cancer outcomes for state residents, it must encourage the delivery of evidence-based cancer treatment statewide. In this chapter, the IOM committee has recommended four sets of measures to assess the quality of cancer treatment. GCC should use these quality indicators to gauge Georgia's progress in improving the quality of cancer treatment in the coming years.

TABLE 6-2 Potential Data Sources for Recommended Measures of the Quality of Cancer Treatment in Georgia[a]

	Potential Georgia-Based Data Sources							Potential National Data Sources for Benchmarking and Comparison				
Quality Measures	Claims	GA-CORE	GCCR, GA-SEER	GA-SEER/ Medicare	Medical records	Patient surveys	Vital statistics	BCSC	NHHCS	NHQR	SEER	SEER/ Medicare
Clinical trials		❍										
Primary treatment	❍	❍	●	❍	❍						●	●
Adjuvant radiation	❍	❍	❍	❍	❍						●	●
Adjuvant hormonal therapy	❍	❍	❍		❍						●	●
Adjuvant chemotherapy	❍	❍	❍	❍	❍						●	●
Treatment follow-up	❍	❍		❍	❍			●			●	●
Pain assessment and prevalence					❍	❍						
Cancer deaths in hospice				❍			●		●	●		
Hospice length of stay	❍			❍					●	●		●
Survival rates			❍								●	
Death rates			❍				●			●		

[a]See Chapter 2, *Concepts, Methods, and Data Sources,* and Appendixes A and B for descriptions of data sources.
NOTE: GCCR = Georgia Comprehensive Cancer Registry; GA-CORE = Georgia Clinical Oncology Research and Education, Inc.; BCSC = Breast Cancer Surveillance Consortium; SEER = Surveillance, Epidemiology, and End Results Program and Patterns of Care Studies; NHQR = National Healthcare Quality Report; NHHCS = National Home and Hospice Care Survey. The symbol ● indicates data are currently available. The symbol ❍ indicates that enhancements to current data collection are required.

QUALITY MEASURE SPECIFICATIONS: TREATING CANCER

The following section contains summary descriptions of the quality indicators presented in this chapter. These quality indicators were drawn from a variety of clinical practice setting organizations, federal programs, provider groups, and other sources. See Appendix A for descriptions of each of these organizations including their classification schemes for grading clinical recommendations and characterizing evidence.

Measure 6-1.	Cancer Patients' Participation in Clinical Trials
Measure 6-2.	Inappropriate Hormonal Therapy Before Radical Prostatectomy
Measure 6-3.	Appropriate External Beam Radiation Therapy Doses for Prostate Cancer
Measure 6-4.	Appropriate Hormonal Therapy with External Beam Radiation Therapy for Prostate Cancer
Measure 6-5.	Adjuvant Radiation After Breast-Conserving Surgery
Measure 6-6.	Adjuvant Hormonal Therapy for Invasive Breast Cancer
Measure 6-7.	Adjuvant Combination Chemotherapy for Breast Cancer
Measure 6-8.	Adjuvant Chemotherapy After Colon Cancer Surgery
Measure 6-9.	Follow-Up Mammography After Treatment for Breast Cancer
Measure 6-10.	Follow-Up Colonoscopy After Treatment for Colorectal Cancer
Measure 6-11.	Cancer Pain Assessment
Measure 6-12.	Prevalence of Pain Among Cancer Patients
Measure 6-13.	Cancer Deaths in Hospice
Measure 6-14.	Cancer Patients' Hospice Length of Stay
Measure 6-15.	Breast Cancer 5- and 10-Year Survival Rates
Measure 6-16.	Colorectal Cancer 5- and 10-Year Survival Rates
Measure 6-17.	Lung Cancer 5- and 10-Year Survival Rates
Measure 6-18.	Prostate Cancer 5- and 10-Year Survival Rates
Measure 6-19.	Breast Cancer Mortality Rate
Measure 6-20.	Colorectal Cancer Mortality Rate
Measure 6-21.	Lung Cancer Mortality Rate
Measure 6-22.	Prostate Cancer Mortality Rate
Measure 6-23.	All Cancers Mortality Rate

MEASURE 6-1: TREATING CANCER—Cancer Patients' Participation in Clinical Trials

Description	Cancer patients in treatment who participate in clinical trials
Source	National Comprehensive Cancer Network (NCCN); Healthy People 2010
Consensus on care	NCCN encourages participation in clinical trials to ensure the best management of cancer care. Increased participation in clinical trials is a strategic goal of the Georgia Cancer Coalition. It is commonly accepted, although no systemic evidence exists, that participation in clinical trials is associated with excellent medical care as well as improving the standard of care through research.
Knowledge vs. practice	Less than 2 percent of Georgia cancer patients currently participate in clinical trials.
Approach to calculating the measure	
Numerator	Number of newly diagnosed cancer patients in treatment participating in clinical trials
Denominator	Number of newly diagnosed cancer patients in treatment
Potential data source(s)	Georgia Center for Oncology Research and Education
Comments	—
Limitations	—
Potential benchmark source(s)	Baseline participation rates
Key references	NCCN. 2003. *National Comprehensive Cancer Network Clinical Practice Guidelines in Oncology*-v.1.2004. Russell K. 2004. *Georgia Clinical Trials*. Personal communication to Jill Eden. U.S. DHHS. 2000. *Healthy People 2010: Understanding and Improving Health*. 2nd edition. *Chapter 3 Cancer*. Washington, DC: U.S. Government Printing Office.

MEASURE 6-2: TREATING CANCER—Inappropriate Hormonal Therapy Before Radical Prostatectomy

Description	Inappropriate hormonal therapy before radical prostatectomy for prostate cancer
Source	Several prospective randomized trials
Consensus on care	Hormonal therapy should be used infrequently prior to radical prostatectomy. Randomized trials have shown that hormonal therapy prior to radical prostatectomy does not improve progression-free survival. It is an expensive and morbid therapy. Potential side effects include anemia, impotence, fatigue, and hot flashes.
Knowledge vs. practice	A study of 3,439 patients found that use of hormonal therapy before radical prostatectomy increased from 2.9 percent of patients diagnosed in 1989-1992 to 7.8 percent of patients diagnosed in 1999-2001.
Approach to calculating the measure	
Numerator	Number of men with prostate cancer undergoing hormonal therapy prior to radical prostatectomy
Denominator	Number of men with prostate cancer undergoing radical prostatectomy
Potential data source(s)	Surveillance, Epidemiology, and End Results (SEER)/ Medicare dataset; medical records
Comments	—
Limitations	Some patients opt for hormonal therapy while deciding which other therapies to choose.
Potential benchmark source(s)	SEER/Medicare dataset
Key references	Cooperberg MR, et al. 2003. National practice patterns and time trends in androgen ablation for localized prostate cancer. *J Natl Cancer Inst*. 95(13): 981-9. Holzbeierlein JM, et al. 2004. Complications of androgen deprivation therapy for prostate cancer. *Curr Opin Urol*. 14(3): 177-83. Soloway MS, et al. 2002. Neoadjuvant androgen ablation before radical prostatectomy in cT2bNxMo prostate cancer: 5-year results. *J Urol*. 167(1): 112-6.

MEASURE 6-3: TREATING CANCER—Appropriate External Beam Radiation Therapy Doses for Prostate Cancer

Description	Appropriate doses of external beam radiation therapy (EBRT) for intermediate- and high-risk prostate cancer
Source	National Comprehensive Cancer Network (NCCN)
Consensus on care	NCCN recommends that prostate cancer patients who are at intermediate or high recurrence risk receive EBRT central axis doses of ≥ 75 Gy (Category 2a recommendation). Several studies suggest that doses < 70 Gy are associated with a higher risk of recurrence. An M.D. Anderson randomized trial showed that for patients with prostate-specific antigen (PSA) levels > 10 ng/mL, treatment with 78 Gy resulted in significantly fewer recurrences than a dose of 70 Gy (62 percent vs. 43 percent at 6 years).
Knowledge vs. practice	Limited evidence suggests that many patients are not given appropriate doses of radiation, especially at nonacademic medical centers.
Approach to calculating the measure	
Numerator	Number of men with intermediate- or high-risk prostate cancer receiving EBRT central axis doses ≥ 75 Gy
Denominator	Number of men with intermediate- or high-risk prostate cancer receiving EBRT
Potential data source(s)	Surveillance, Epidemiology, and End Results (SEER)/ Medicare dataset, medical records
Comments	Intermediate recurrence risk is defined by the NCCN as tumor Stage T2b-T2c or Gleason score 7 or PSA 10-20 ng/mL. High recurrence risk is defined as tumor Stage T3a or Gleason score 8-10 or PSA > 20 ng/mL.
Limitations	—
Potential benchmark source(s)	SEER/Medicare dataset

Key references

Kupelian PA, et al. 2004. Radical prostatectomy, external beam radiotherapy < or =72 Gy, external beam radiotherapy >72 GY, permanent seed implantation, or combined seeds/external beam radiotherapy for Stage T1-T2 prostate cancer. *Int J Radiat Oncol Biol Phys.* 58(1): 25-33.

NCCN. 2004. *Clinical Practice Guidelines in Oncology-v.1.2004. Prostate Cancer.*

Pollack A, et al. 2002. Prostate cancer radiation dose response: results of the M.D. Anderson phase III randomized trial. *Int J Radiat Oncol Biol Phys.* 53(5): 1097-105.

Zelefsky MJ, et al. 2004. Changing trends in national practice for external beam radiotherapy for clinically localized prostate cancer: 1999 Patterns of Care survey for prostate cancer. *Int J Radiat Oncol Biol Phys.* 59(4): 1053-61.

MEASURE 6-4: TREATING CANCER—Appropriate Hormonal Therapy with External Beam Radiation Therapy for Prostate Cancer

Description	Appropriate hormonal therapy with external beam radiation therapy (EBRT) for high-risk prostate cancer
Source	National Comprehensive Cancer Network (NCCN)
Consensus on care	Randomized trials show high-risk prostate cancer patients have a substantial survival advantage with long-term hormonal therapy. NCCN guidelines recommend EBRT with 2-3 years of hormonal therapy for most high-risk prostate cancer patients (Category 1 recommendation).
Knowledge vs. practice	Use of hormonal therapy combined with external beam radiation is increasing. An analysis of prostate cancer patients diagnosed from 1999-2001 found that 74 percent of intermediate-risk and 90 percent of high-risk patients received adjuvant hormonal therapy with EBRT.
Approach to calculating the measure	
Numerator	Number of high-risk prostate cancer patients who are treated with EBRT and receive hormonal therapy for at least 2 years
Denominator	Number of high-risk prostate cancer patients treated with EBRT
Potential data source(s)	Surveillance, Epidemiology, and End Results (SEER)/ Medicare dataset; medical records
Comments	High risk is defined as tumor Stage T3a or Gleason score 8-10 or PSA > 20 ng/ml.
Limitations	Some patients may refuse hormonal therapy because of potential side effects such as osteoporosis, anemia, impotence, fatigue, and hot flashes.
Potential benchmark source(s)	SEER/Medicare dataset

Key references

Bolla M, et al. 2002. Long-term results with immediate androgen suppression and external irradiation in patients with locally advanced prostate cancer (an EORTC study): a phase III randomized trial. *Lancet*. 360(9327): 103-8.

Cooperberg, et al. 2003. National practice patterns and time trends in androgen ablation for localized prostate cancer. *J Natl Cancer Inst*. 95(13): 981-9.

Hanks GE, et al. 2003. Phase III trial of long-term adjuvant androgen deprivation after neoadjuvant hormonal cytoreduction and radiotherapy in locally advanced carcinoma of the prostate: the Radiation Therapy Oncology Group Protocol 92-02. *J Clin Oncol*. 21(21): 3972-8.

Holzbeierlein JM, et al. 2004. Complications of androgen deprivation therapy for prostate cancer. *Curr Opin in Urol*. 14(3): 177-83.

NCCN. 2004. *Clinical Practice Guidelines in Oncology-v.1.2004. Prostate Cancer*.

MEASURE 6-5: TREATING CANCER—Adjuvant Radiation After Breast-Conserving Surgery

Description	Adjuvant radiation after breast-conserving surgery (BCS) for women under age 70 with invasive breast cancer
Source	National Comprehensive Cancer Network (NCCN)
Consensus on care	Numerous clinical trials conclude that adjuvant radiation after breast-conserving surgery markedly reduces recurrence. NCCN recommends radiation therapy for patients with negative axillary nodes (category 2A recommendation) or positive nodes (category 1 recommendation). A meta-analysis of 10 studies involving 7,401 cases indicates that recurrence is significantly higher in patients who receive radiation more than 8 weeks after surgery. If the patient also requires chemotherapy, radiation treatment should be given after chemotherapy is completed. Women aged 70 and older who have breast-conserving surgery do not require adjuvant radiation if they have hormonal therapy.
Knowledge vs. practice	Adjuvant radiation for breast cancer is used less often than clinical guidelines recommend. Numerous studies show receipt of adjuvant radiation varies with the patient's age, health insurance status, geographic access to services, Medicaid coverage, race, ethnicity, and other socioeconomic factors.
Approach to calculating the measure	
Numerator	Number of women who undergo radiation treatment within 8 weeks of BCS, or after post-BCS chemotherapy, if chemotherapy is given. Limit to women under age 70 with invasive breast cancer who undergo BCS.
Denominator	Number of women under age 70 with invasive breast cancer who undergo BCS
Potential data source(s)	Special studies of medical records; Surveillance, Epidemiology and End Results (SEER)/Medicare dataset (for 65- to 69-year-olds)
Comments	—
Limitations	—
Potential benchmark source(s)	Baseline studies of medical records; SEER/Medicare dataset

Key references

Early Breast Cancer Trialists' Collaborative Group. 2000. Favourable and unfavourable effects on long-term survival of radiotherapy for early breast cancer: an overview of the randomized trials. *Lancet.* 355(9217): 1757-70.

Fisher B, et al. 2002. Twenty-year follow-up of a randomized trial comparing total mastectomy, lumpectomy, and lumpectomy plus irradiation for the treatment of invasive breast cancer. *New Engl J Med.* 347: 1233-41.

Huang J, et al. 2003. Does delay in starting treatment affect the outcomes of radiotherapy? A systematic review. *J Clin Oncol.* 21(3): 555-63.

Hughes KS, et al. 2004. Lumpectomy plus Tamoxifen with or without irradiation in women 70 years of age or older with early breast cancer. *N Engl J Med.* 351(10): 971-7.

NCCN. 2004. *Clinical Practice Guidelines in Oncology-v.1.2004. Breast Cancer.*

MEASURE 6-6: TREATING CANCER—Adjuvant Hormonal Therapy for Invasive Breast Cancer

Description	Adjuvant hormonal therapy for hormone-receptor-positive invasive breast cancer
Source	National Comprehensive Cancer Network (NCCN); American Society of Clinical Oncology; National Institutes of Health Consensus Statement
Consensus on care	NCCN recommends a 5-year course of adjuvant tamoxifen for premenopausal women with hormone-receptor-positive invasive breast cancer followed by 5 years of letrozole (Category 1 recommendation). For postmenopausal women with hormone-receptor-positive invasive breast cancer, NCCN recommends various combinations of aromatase inhibitors and tamoxifen for at least 5 years (Category 1 recommendation). An analysis of 37,000 women in 55 trials found that, after 10 years, 5-year use of adjuvant tamoxifen reduced recurrence and mortality by 47 percent and 26 percent respectively.
Knowledge vs. practice	There are numerous reports showing that adjuvant hormone therapy is used less often than well-established clinical guidelines recommend and that use declines markedly with advancing age.
Approach to calculating the measure	
Numerator	Number of women who receive adjuvant hormonal therapy for hormone-receptor-positive invasive breast cancer greater than 1 cm in size
Denominator	Number of women with hormone-receptor-positive invasive breast cancer greater than 1 cm in size
Potential data source(s)	Special studies of medical records
Comments	Hormone-receptor-positive refers to tumors that are estrogen receptor positive or progesterone receptor positive.
Limitations	—
Potential benchmark source(s)	Baseline studies of medical records

Key references

Adjuvant therapy for breast cancer. 2000. *NIH Consensus Statement 2000*. 17(4): 1-35.

Du XL, et al. 2003. Discrepancy between consensus recommendations and actual community use of adjuvant chemotherapy in women with breast cancer. *Ann Intern Med*. 138(2): 90-97.

Early Breast Cancer Trialists' Group. 1998. Tamoxifen for early breast cancer: an overview of the randomized trials. *Lancet*. 351(9114): 1451-67.

Goldhirsch A, et al. 2003. Meeting highlights: updated international expert consensus on the primary therapy of early breast cancer. *J Clin Oncol*. 21(17): 3357-65.

Holmes CE, Muss HB. 2003. Diagnosis and treatment of breast cancer in the elderly. *CA Cancer J Clin*. 53: 227-244.

NCCN. 2004. *Clinical Practice Guidelines in Oncology-v.1.2004. Breast Cancer*.

MEASURE 6-7: TREATING CANCER—Adjuvant Combination Chemotherapy for Breast Cancer

Description	Adjuvant combination chemotherapy for women under age 71 with hormone-receptor-negative Stage I to Stage III breast cancer
Source	National Comprehensive Cancer Network (NCCN); National Cancer Institute Consensus Statement
Consensus on care	NCCN recommends that after local surgical treatment, adjuvant combination chemotherapy should be given to all women under age 71 with Stage I, Stage II, or Stage III breast cancer who have hormone-receptor-negative tumors greater than 1 cm (Category 1 recommendation).
Knowledge vs. practice	There are numerous reports showing that combination chemotherapy is used less often than well-established clinical guidelines recommend, especially among older women.
Approach to calculating the measure	
Numerator	Number of women under age 71 who receive combination chemotherapy after surgery for a hormone-receptor-negative Stage I to Stage III breast cancer
Denominator	Number of women under age 71 who undergo surgery for hormone-receptor-negative Stage I to Stage III breast cancer
Potential data source(s)	Special studies of medical records; Surveillance, Epidemiology, and End Results (SEER)/Medicare dataset
Comments	For Stage I cancers, include only those cases with tumors larger than 1 cm. Hormone-receptor-negative refers to tumors that are both estrogen-receptor-negative and progesterone-receptor-negative.
Limitations	—
Potential benchmark source(s)	Baseline studies of medical records; SEER/Medicare dataset
Key references	Cole BF, et al. 2001. Polychemotherapy for early breast cancer: an overview of the randomized clinical trials with quality-adjusted survival analysis. *Lancet.* 358(9278): 277-86. Goldhirsch A, et al. 2003. Meeting highlights: updated international expert consensus on the primary therapy of early breast cancer. *J Clin Oncol.* 21(17): 3357-65. Harlan LC, et al. 2002. Adjuvant therapy for breast cancer: practice patterns of community physicians. *J Clin Oncol.* 20(7): 1809-17. NCCN. 2004. *Clinical Practice Guidelines in Oncology-v.1.2004. Breast Cancer.*

MEASURE 6-8: TREATING CANCER—Adjuvant Chemotherapy After Colon Cancer Surgery

Description	Adjuvant chemotherapy after surgery for Stage III colon cancer
Source	National Comprehensive Cancer Network (NCCN)
Consensus on care	NCCN guidelines recommend 6 months of adjuvant chemotherapy for patients with node-positive colon carcinoma (Category 1 recommendation). There is evidence from randomized clinical trials that adjuvant chemotherapy decreases colon cancer mortality by about one-third.
Knowledge vs. practice	Numerous studies indicate that older patients are less likely to receive recommended adjuvant chemotherapy despite evidence that chemotherapy is well tolerated by older patients. Race, marital status, hospital volume, and individual hospitals are also associated with receipt of adjuvant chemotherapy.

Approach to calculating the measure

Numerator	Number of patients with Stage III colon cancer who receive a full course of adjuvant chemotherapy after surgery
Denominator	Number of patients with Stage III colon cancer who undergo surgery
Potential data source(s)	Surveillance, Epidemiology and End Results (SEER)/ Medicare dataset; special studies of medical records
Comments	Stage III colon cancer refers to tumors that have spread through the wall of the colon or rectum into 1 to 4 regional lymph nodes and nearby tissues or organs. The current standard for chemotherapy is a 6-month course.

Limitations	—
Potential benchmark source(s)	SEER/Medicare dataset; baseline studies of medical records

Key references

Ayanian JZ, et al. 2003. Use of adjuvant chemotherapy and radiation therapy for colorectal cancer in a population-based cohort. *J Clin Oncol.* 21(7): 1293-300.

Moore HC, Haller DG. 1999. Adjuvant therapy of colon cancer. *Semin Oncol.* 26: 545-55.

NCCN. 2004. *Clinical Practice Guidelines in Oncology-v.2.2004. Colon Cancer.*

Neugut AI, et al. 2002. Use of adjuvant chemotherapy and radiation therapy for rectal cancer among the elderly: a population-based study. *J Clin Oncol.* 20(11): 2643-50.

MEASURE 6-9: TREATING CANCER—Follow-Up Mammography After Treatment for Breast Cancer

Description	Follow-up mammography after treatment for Stage 0 to Stage III breast cancer
Source	American Society of Clinical Oncology (ASCO); National Comprehensive Cancer Network (NCCN)
Consensus on care	ASCO and NCCN recommend that women treated with breast-conserving therapy have a first post-treatment mammogram about 6 months after radiotherapy is complete (ASCO Level of evidence I, Grade of recommendation A; NCCN Category 2a recommendation). Women treated for breast cancer are at risk of recurrence. The 20-year findings of the National Surgical Adjuvant Breast and Bowel Project indicate that 14.3 percent of women experienced a recurrent tumor in the same breast after lumpectomy and adjuvant radiation. Recurrence was 39.2 percent among women with no adjuvant radiation.
Knowledge vs. practice	An analysis of data from the national Breast Cancer Surveillance Consortium found that 78 percent of women had returned for a mammogram 30 months following a breast cancer diagnosis. Within 12 months of diagnosis, about half the women had a first follow-up mammogram. Women who did not receive radiation treatment after breast-conserving surgery were less likely to return for follow-up despite being at significant risk of recurrence.
Approach to calculating the measure	
Numerator	Number of women with a return mammogram by 19 months after a Stage 0 to Stage III breast cancer diagnosis
Denominator	Number of women with Stage 0 to Stage III breast cancer
Potential data source(s)	Georgia Comprehensive Cancer Registry (with enhancements); Surveillance, Epidemiology, and End Results (SEER)/Medicare dataset, special studies medical records; mammography registry (if available).
Comments	The 19-month period in the numerator is based on a 12-month follow-up period after a 7-month therapeutic period. The goal for this measure should be less than 100 percent to account for those women who undergo bilateral total mastectomies.
Limitations	—
Potential benchmark source(s)	Breast Cancer Surveillance Consortium; SEER/Medicare dataset; baseline studies of medical records

Key references

Fisher, B et al. 2002. Twenty-year follow-up of a randomized trial comparing total mastectomy, lumpectomy, and lumpectomy plus irradiation for the treatment of invasive breast cancer. *New Eng J Med.* 347(16): 1233-41.

Geller BM, et al. 2003. Mammography surveillance following breast cancer. *Breast Cancer Res Treat*. 81(2): 107-15.

NCCN. 2004. *Clinical Practice Guidelines in Oncology-v.1.2004. Breast Cancer*.

Smith, et al. 1999. American Society of Clinical Oncology 1998 update of recommended breast cancer surveillance guidelines. *J Clin Oncol.* 17(3): 1080-2.

MEASURE 6-10: TREATING CANCER—Follow-Up Colonoscopy After Treatment for Colorectal Cancer

Description	Follow-up colonoscopy after treatment for Stage I to Stage III colorectal cancer
Source	National Comprehensive Cancer Network (NCCN)
Consensus on care	NCCN recommends that Stage I to III colorectal cancer patients have a follow-up colonoscopy by 1 year after resection (Category 2A recommendation). A study of 3,546 VA patients strongly supports a mortality benefit for follow-up colonoscopy in patients with nonmetastatic colorectal cancer. The researchers compared 5-year mortality rates and found that risk of death was decreased by 43 percent in the group of patients who had at least one follow-up colonoscopy compared with the group of patients who had no follow-up.
Knowledge vs. practice	Use of endoscopic procedures after potentially curative resection for local- or regional-stage colorectal cancer varies with patient-related factors and local practice patterns.
Approach to calculating the measure	
Numerator	Number of Stage I to Stage III colorectal cancer cases with a colonoscopy within 1 year of surgery
Denominator	Number of Stage I to Stage III colorectal cancer cases
Potential data source(s)	Surveillance, Epidemiology, and End Results (SEER)/ Medicare dataset; special studies of medical records
Comments	—
Limitations	—
Potential benchmark source(s)	SEER/Medicare dataset; baseline studies of medical records

Key references

Cooper GS, et al. 2000. Patterns of endoscopic follow-up after surgery for nonmetastatic colorectal cancer. *Gastrointest Endosc.* 52(1): 33-8.

Fisher DA, et al. 2003. Mortality and follow-up colonoscopy after colorectal cancer. *Am J of Gastroenterol.* 98(4): 901-6.

NCCN. 2004. *Clinical Practice Guidelines in Oncology-v.2.2004. Colon Cancer.*

Rulyak SJ, et al. 2004. Clinical and sociodemographic factors associated with colon surveillance among patients with a history of colorectal cancer. *Gastrointest Endosc.* 59(2): 239-47.

Winawer S, et al. 2003. Colorectal cancer screening and surveillance: clinical guidelines and rationale-update based on new evidence. *Gastroenterology.* 124(2): 544–60.

MEASURE 6-11: TREATING CANCER—Cancer Pain Assessment

Description	Cancer patients who are regularly assessed for pain
Source	National Comprehensive Cancer Network (NCCN); Joint Commission on Accreditation of Healthcare Organizations, (JCAHO); Oncology Nursing Society; American Pain Society (APS)
Consensus on care	Cancer patients—at all stages of the disease—frequently experience severe pain. Regular reassessment of patients' pain is integral to effective cancer pain treatment. Patients (or family members) should be directly queried regarding their level of pain. Several studies indicate that an important predictor of inadequate pain relief is a discrepancy between the patient's and physician's assessment of the severity of pain. NCCN advises clinicians to screen cancer patients for pain every time they are seen and that patients should use a rating scale to quantify their pain (Category 2A recommendation). APS encourages health providers to view pain as "the fifth vital sign" so that patients' pain is routinely checked with pulse, blood pressure, core temperature, and respiration in every patient encounter.
Knowledge vs. practice	The proportion of cancer patients who receive routine pain assessments is not known. Cancer pain is often untreated or undertreated. Several studies suggest that some groups of cancer patients are more likely to be inadequately treated for pain, especially racial or ethnic minorities, women, and elderly persons.
Approach to calculating the measure	
Numerator	Number of cancer patient encounters where patient was assessed for pain
Denominator	Number of cancer patient encounters
Potential data source(s)	Special patient surveys; studies of medical records
Comments	This measure should be used in all health care settings (hospital, physician office, nursing homes, hospice, etc.) for all patients who are not comatose. It will require different sampling and monitoring approaches depending on the health care setting.
Limitations	—
Potential benchmark source(s)	Baseline patient surveys and studies of medical records; JCAHO

Key references

APS. 1995. *Pain: The Fifth Vital Sign™*. [Online] Available: http://www.ampainsoc.org/advocacy/fifth.htm [accesseed November 30, 2004].

JCAHO. 2004. *Pain Management Performance Measurement Final Report, JCAHO Inpatient Cancer Pain Management Measures*. A collaboration of the American Medical Association, JCAHO, and the National Committee on Quality Assurance. Unpublished.

NCCN. 2004. *Clinical Practice Guidelines in Oncology-v.1.2004. Cancer Pain*.

ONS. 2002. *[ONS Position]. Cancer Pain Management*. Pittsburgh, PA: ONS. [Online] Available: http://www.ons.org/Positions/Cancer_Pain.pdf.

Symptom management in cancer: pain, depression, and fatigue. 2002. *NIH Consens State Sci Statements*. 19(4):1-29.

MEASURE 6-12: TREATING CANCER—Prevalence of Pain Among Cancer Patients

Description	Prevalence of more than minor pain among cancer patients
Source of measure	National Comprehensive Cancer Network; Joint Commission on Accreditation of Healthcare Organizations; Oncology Nursing Society; American Pain Society
Consensus on care	Unrelieved pain has debilitating adverse physical and psychological effects. Regular reassessment of patients' pain is integral to effective cancer pain treatment. Most cancer pain can be treated safely and effectively. The World Health Organization (WHO) has developed an approach to treating cancer pain that is widely endorsed in the United States and around the world. WHO outlines a step by step algorithm that suggests patients be started on acetaminophen or a nonsteroidal anti-inflammatory drug. If insufficient, the patient should then receive a "weak" opioid, such as codeine, and, if necessary, progress to a "strong" opioid such as morphine.
Knowledge vs. practice	Cancer pain frequently goes untreated or undertreated. There are no definitive estimates of the prevalence of pain among cancer patients and survivors; estimates range from 14 percent to 100 percent.
Approach to calculating the measure	
Numerator	Number of cancer patients who report being in more than minor pain
Denominator	Number of cancer patients who are not comatose
Potential data source(s)	Special patient surveys; studies of medical records
Comments	This measure should be used in all health care settings (hospitals, physician offices, nursing homes, hospice, etc.). It will require different sampling and monitoring approaches depending on the health care setting. A validated pain scale that defines "minor pain" must be used in each care setting. The threshold for minor pain should be reported along with the measure.
Limitations	Low prevalence estimates may be due to poor medical record documentation.
Potential benchmark source(s)	Baseline patient surveys and studies of medical records

Key references

APS. 1995. Quality improvement guidelines for the treatment of acute pan and cancer pain. *JAMA*. 274(23): 1874-80.

Goudas J, et al. 2001. *Management of Cancer Pain:* Volume 1. Evidence Report/Technology Assessment Number 35. AHRQ Publication Number 02-E002. Rockville, MD: AHRQ.

NCCN. 2004. *Clinical Practice Guidelines in Oncology-v.1.2004. Cancer Pain.*

ONS. 2002. *Cancer Pain Management [ONS Position].* Pittsburgh, PA: ONS. Available: http://www.ons.org/publications/positions/CancerPainManagement.shtml.

Symptom management in cancer: pain, depression, and fatigue. 2002. *NIH Consens State Sci Statements.* 19(4):1-29.

WHO. 1996. *Cancer Pain Relief.* 2nd edition. Geneva: WHO.

MEASURE 6-13: TREATING CANCER—Cancer Deaths in Hospice

Description	Cancer deaths in hospice per 100 cancer deaths
Source of measure	National Healthcare Quality Report
Consensus on care	Hospice is the gold standard of care for dying persons, their families, and other loved ones. NCCN recommends that patients with *months to weeks to live* be offered palliative or hospice care and that patients with *weeks to days to live* should be given intensive palliative care—not more anticancer treatments (Category 2A recommendation).
Knowledge vs. practice	Hospice use among cancer patients is increasing although substantial numbers of dying cancer patients are not referred at all. In one study of more than 170,000 Medicare beneficiaries who had breast, colorectal, lung, or prostate cancer and had died, only 30 percent of the study population had used hospice services before they died. Several studies indicate that access to hospice care varies with patient's age, race and ethnicity, supplemental Medicare coverage, income, and other socioeconomic factors.

Approach to calculating the measure

Numerator	Number of adults discharged (disposition = dead) from hospice care with cancer as the underlying cause of death (see comment below)
Denominator	Number of deaths where cancer is the underlying cause of death (see comment below)
Potential data source(s)	Surveillance, Epidemiology and End Results (SEER)/ Medicare dataset; vital statistics (mortality)
Comments	Rate = (Cancers deaths in hospice/All cancer deaths) × 100. Estimate should be age-adjusted to allow comparisons. Cancer diagnoses include ICD-10 codes C00-C97, ICD-9 codes 140-208.

Limitations	—
Potential benchmark source(s)	National Healthcare Quality Report; National Home and Hospice Care Survey; Outcome and Assessment Information Set.

Key references

AHRQ. 2003. *National Healthcare Quality Report*. Rockville, MD: U.S. DHHS.

Lackan NA, et al. 2004. Decreasing variation in the use of hospice among older adults with breast, colorectal, lung, and prostate cancer. *Med Care*. 42(2):116-22.

NCCN. 2004. *Clinical Practice Guidelines in Oncology-v.1.2004. Palliative Care*.

MEASURE 6-14: TREATING CANCER—Cancer Patients' Hospice Length of Stay

Description	Cancer patients who receive hospice care for at least 7 days
Source	National Healthcare Quality Report; National Comprehensive Cancer Network (NCCN) (Category 2a recommendation)
Consensus on care	Hospice is the gold standard of care for dying persons, their families, and other loved ones. NCCN recommends that patients with *months to weeks to live* be offered palliative or hospice care and that patients with *weeks to days to live* should be given intensive palliative care—not more anticancer treatments. There is no consensus on how long cancer patients should stay in hospice to receive maximum benefit.
Knowledge vs. practice	A substantial proportion of cancer patients who receive hospice care, receive it just days before death. An analysis of 28,777 Medicare beneficiaries who died of breast cancer, lung cancer, or colorectal or other gastrointestinal cancers found that, among those who died in hospice, 17 percent had exceedingly short stays of only 3 or fewer days. Several studies indicate that access to hospice care varies with patient's age, race and ethnicity, supplemental Medicare coverage, income, and other socioeconomic factors.
Approach to calculating the measure	
Numerator	Number of adults who are discharged from hospice (disposition = dead) with cancer listed as the underlying cause of death with a length of stay of at least 7 days
Denominator	Number of adults with a cancer diagnosis who are discharged from hospice (disposition = dead) with cancer listed as the underlying cause of death
Potential data source(s)	Surveillance, Epidemiology and End Results (SEER)/ Medicare dataset
Comments	Cancer diagnoses include ICD-10 codes C00-C97, ICD-9 codes 140-208. Because hospice length of stay differs depending on the care setting, separate rates should be reported for inpatient and outpatient settings.
Limitations	—
Potential benchmark source(s)	SEER/Medicare dataset

Key references

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MEASURE 6-15: TREATING CANCER—Breast Cancer 5- and 10-Year Survival Rates

Description	Breast cancer 5- and 10-year relative survival rates (females)
Source	Surveillance, Epidemiology, and End Results Program (SEER)
Consensus on care	Not applicable
Knowledge vs. practice	Early detection, improved quality of care, and better access to care should increase breast cancer survival. Many studies show consistently poorer breast cancer survival rates among lower-income women and women without health insurance. The 5-year relative breast cancer survival rate in metropolitan Atlanta was 84.6 percent for cancers diagnosed from 1992 to 1999.
Approach to calculating the measure	
Numerator	Proportion of women diagnosed with breast cancer in the past 5 (or 10) years who are still alive (*see comments below*)
Denominator	Proportion of women from the general population of comparable age to those diagnosed with breast cancer expected to be alive (based on mortality rates from all causes)
Potential data source(s)	SEER; Georgia Comprehensive Cancer Registry (with enhancements)
Comments	Relative survival adjusts for causes of death besides cancer. It is the ratio of the number of cancer patients alive at a point in time to the number of people expected to be alive from a comparable, cancer-free population. Georgia should also consider monitoring stage-specific breast cancer survival rates.
Limitations	Breast cancer survival rates are subject to lead-time bias and length bias, and should be interpreted with caution. Early cancer detection pushes back the timing of diagnosis which can artificially lengthen the survival period.
Potential benchmark source(s)	SEER
Key references	Bradley CJ, et al. 2002. Race, socioeconomic status, and breast cancer treatment and survival. *J Natl Cancer Inst*. 94(7): 490-6. Liff J (Georgia Center for Cancer Statistics). 2004. Unpublished data. Ries LAG, et al., Editors. 2004. *SEER Cancer Statistics Review, 1975-2000*. Bethesda, MD: NCI. [Online] Available: http://seer.cancer.gov/csr/1975_2000. Singh GH, et al. 2003. Area Socioeconomic Variations in U.S. Cancer Incidence, Mortality, Stage, Treatment, and Survival, 1975-1999. *NCI Cancer Surveillance Monograph Series*, Number 4. NIH Publication Number 03-5417. Bethesda, MD: NCI.

MEASURE 6-16: TREATING CANCER—Colorectal Cancer 5- and 10-Year Survival Rates

Description	Colorectal cancer 5- and 10-year relative survival rates
Source	Surveillance, Epidemiology, and End Results Program (SEER)
Consensus on care	Not applicable
Knowledge vs. practice	Early detection, improved quality of care, and better access to care should increase colorectal cancer survival. Many studies show consistently poorer colorectal cancer survival rates among lower-income patients and people without health insurance. The 5-year relative colorectal cancer survival rate in metropolitan Atlanta was 61.6 percent for cancers diagnosed from 1992-1999.
Approach to calculating the measure	
Numerator	Proportion of adults diagnosed with colorectal cancer in the past 5 (or 10) years who are still alive (*see comments below*)
Denominator	Proportion of adults from the general population of comparable age to those diagnosed with colorectal cancer expected to be alive (based on mortality rates from all causes)
Potential data source(s)	SEER; Georgia Comprehensive Cancer Registry (with enhancements)
Comments	Relative survival adjusts for causes of death besides cancer. It is the ratio of the number of cancer patients alive at a point in time to the number of people expected to be alive from a comparable cancer-free population. Georgia should also consider monitoring stage-specific colorectal cancer survival rates.
Limitations	Colorectal cancer survival rates are subject to lead-time bias and length bias and should be interpreted with caution. Early cancer detection pushes back the timing of diagnosis and can thereby artificially lengthen the survival period.
Potential benchmark source(s)	SEER

Liff J (Georgia Center for Cancer Statistics). 2004. Unpublished data.

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MEASURE 6-17: TREATING CANCER—Lung Cancer 5- and 10-Year Survival Rates

Description	Lung cancer 5- and 10-year relative survival rates
Source	Surveillance, Epidemiology and End Results Program (SEER)
Consensus on care	Not applicable
Knowledge vs. practice	Early detection, improved quality of care, and better access to care should increase lung cancer survival. Many studies show consistently poorer lung cancer survival rates among lower income patients and people without health insurance. The 5-year relative lung cancer survival rate in metropolitan Atlanta was 16.5 percent for cancers diagnosed from 1992 to 1999.
Approach to calculating the measure	
Numerator	Proportion of adults who were diagnosed with lung cancer in the past 5 (or 10) years and are currently alive (*see comments below*)
Denominator	Proportion of adults from the general population of comparable age to those diagnosed with lung cancer expected to be alive (based on mortality rates from all causes)
Potential data source(s)	SEER; Georgia Comprehensive Cancer Registry (with enhancements)
Comments	Relative survival adjusts for causes of death besides cancer. It is the ratio of the number of cancer patients alive at a point in time to the number of people expected to be alive from a comparable cancer-free population. Georgia should also consider monitoring stage-specific lung cancer survival rates.
Limitations	—
Potential benchmark source(s)	SEER
Key references	Liff J (Georgia Center for Cancer Statistics). 2004. Unpublished data. Ries LAG, et al., Editors. 2004. *SEER Cancer Statistics Review, 1975-2000*. Bethesda, MD: NCI. [Online] Available: http://seer.cancer.gov/csr/1975_2000. Singh GH, et al. 2003. Area Socioeconomic Variations in U.S. Cancer Incidence, Mortality, Stage, Treatment, and Survival, 1975-1999. *NCI Cancer Surveillance Monograph Series*, Number 4. NIH Publication Number 03-5417. Bethesda, MD: NCI.

MEASURE 6-18: TREATING CANCER—Prostate Cancer 5- and 10-Year Survival Rates

Description	Prostate cancer 5- and 10-year relative survival rates
Source	Surveillance, Epidemiology, and End Results Program (SEER)
Consensus on care	Not applicable
Knowledge vs. practice	Early detection, improved quality of care, and better access to care should increase prostate cancer survival. Uninsured, low-income, and African-American men are at greater risk for delayed diagnosis and death from prostate cancer. The 5-year relative prostate cancer survival rate in metropolitan Atlanta was 97.5 percent for cancers diagnosed from 1992-1999.
Approach to calculating the measure	
Numerator	Proportion of men diagnosed with prostate cancer in the past 5 (or 10) years who are still alive (*see comments below*)
Denominator	Proportion of men from the general population of comparable age to those diagnosed with prostate cancer expected to be alive (based on mortality rates from all causes)
Potential data source(s)	SEER; Georgia Comprehensive Cancer Registry (with enhancements)
Comments	Relative survival adjusts for causes of death besides cancer. It is the ratio of the number of cancer patients alive at a point in time to the number of people expected to be alive from a comparable cancer-free population. Georgia should also consider monitoring stage-prostate cancer survival rates.
Limitations	Prostate cancer survival rates are subject to lead-time bias and length bias and should be interpreted with caution. Early cancer detection pushes back the timing of diagnosis which can artificially lengthen the survival period.
Potential benchmark source(s)	SEER
Key references	Clegg LX, et al. 2002. Cancer survival among US whites and minorities. *Arch Intern Med*. 162(17): 1985-93. Liff J (Georgia Center for Cancer Statistics). 2004. Unpublished data. Ries LAG, et al., Editors. 2004. *SEER Cancer Statistics Review, 1975-2000*. Bethesda, MD: NCI. [Online] Available: http://seer.cancer.gov/csr/1975_2000. Singh GH, et al. 2003. Area Socioeconomic Variations in U.S. Cancer Incidence, Mortality, Stage, Treatment, and Survival, 1975-1999. *NCI Cancer Surveillance Monograph Series*, Number 4. NIH Publication Number 03-5417. Bethesda, MD: NCI.

MEASURE 6-19: TREATING CANCER—Breast Cancer Mortality Rate

Description	Breast cancer deaths per 100,000 females per year
Source	National Healthcare Quality Report; Healthy People 2010
Consensus on care	Improving the effectiveness of Georgia breast cancer care should ultimately reduce related mortality.
Knowledge vs. practice	Not applicable
Approach to calculating the measure	
Numerator	Number of female deaths due to breast cancer (ICD-10 code C50) per year
Denominator	Number of females in Georgia
Potential data source(s)	Georgia Division of Public Health Vital Statistics System
Comments	Death rate = (Deaths/Population) × 100,000. Data should be age-adjusted to 2000 standard population. Age-adjusted rates are weighted sums of age-specific rates.
Limitations	Substantial time must pass before GCC would have any impact on mortality rates.
Potential benchmark source(s)	National Healthcare Quality Report; Healthy People 2010; National Vital Statistics System
Key references	AHRQ. 2003. *National Healthcare Quality Report*. Rockville, MD: U.S. DHHS. GDPH. 2004. *OASIS Web Query—Death Statistics*. [Online] Available: http://oasis.state.ga.us/webquery/death.html [accessed April 2004]. IOM. 2003. *Fulfilling the Potential of Cancer Prevention and Early Detection*. Washington, DC: The National Academies Press. U.S. DHHS. 2000. *Healthy People 2010: Understanding and Improving Health*. 2nd edition. *Chapter 3 Cancer*. Washington, DC: U.S. Government Printing Office. [Measure 3-5.]

MEASURE 6-20: TREATING CANCER—Colorectal Cancer Mortality Rate

Description	Colorectal cancer deaths per 100,000 persons per year
Source	National Healthcare Quality Report; Healthy People 2010
Consensus on care	Improving the effectiveness of Georgia colorectal cancer care should ultimately reduce related mortality.
Knowledge vs. practice	Not applicable
Approach to calculating the measure	
Numerator	Number of deaths due to colorectal cancer (ICD-10 codes C18-C21) per year
Denominator	Total Georgia population
Potential data source(s)	Georgia Division of Public Health Vital Statistics System
Comments	Death rate = (Deaths/Population) × 100,000. Data should be age-adjusted to 2000 standard population. Age-adjusted rates are weighted sums of age-specific rates.
Limitations	Substantial time must pass before GCC could have any impact on mortality rates.
Potential benchmark source(s)	National Healthcare Quality Report, Healthy People 2010; National Vital Statistics System
Key references	AHRQ. 2003. *National Healthcare Quality Report*. Rockville, MD: U.S. DHHS. CDC. 2004. *Behavioral Risk Factor Surveillance System, Prevalence Data: Georgia 2002 Colorectal Cancer Screening*. [Online] Available: http://apps.nccd.cdc.gov/brfss/display.asp?cat=CC&yr=2002&qkey=7400&state=GA [accessed November 26, 2004]. GDPH. 2004. *OASIS Web Query*. [Online] http://oasis.state.ga.us/webquery/death.html. IOM. 2003. *Fulfilling the Potential of Cancer Prevention and Early Detection*. Washington, DC: The National Academies Press. U.S. DHHS. 2000. *Healthy People 2010: Understanding and Improving Health*. 2nd edition. *Chapter 3 Cancer*. Washington, DC: U.S. Government Printing Office. [Measure 3-5.]

MEASURE 6-21: TREATING CANCER—Lung Cancer Mortality Rate

Description	Lung cancer deaths per 100,000 persons per year
Source	National Healthcare Quality Report; Healthy People 2010
Consensus on care	Improving the effectiveness of Georgia lung cancer care should ultimately reduce related mortality.
Knowledge vs. practice	Not applicable
Approach to calculating the measure	
Numerator	Number of deaths due to lung cancer (ICD-10 codes C33-34) per year
Denominator	Total Georgia population
Potential data source(s)	Georgia Division of Public Health Vital Statistics System
Comments	Death rate = (Deaths/Population) × 100,000. Data should be age-adjusted to 2000 standard population. Age-adjusted rates are weighted sums of age-specific rates
Limitations	Substantial time must pass before GCC would have any impact on mortality rates.
Potential benchmark source(s)	National Healthcare Quality Report; Healthy People 2010; National Vital Statistics System
Key references	AHRQ. 2003. *National Healthcare Quality Report*. Rockville, MD: U.S. DHHS. IOM. 2003. *Fulfilling the Potential of Cancer Prevention and Early Detection*. Washington, DC: The National Academies Press. Martin LM, et al. 2003. *Georgia Behavioral Risk Factor Surveillance System, 2001 Report*. Atlanta, GA: Georgia Department Human Resources. Publication Number DPH03-069HW. U.S. DHHS. 2000. *Healthy People 2010: Understanding and Improving Health*. 2nd edition. *Chapter 3 Cancer*. Washington, DC: U.S. Government Printing Office. [Measure 3-2.]

MEASURE 6-22: TREATING CANCER—Prostate Cancer Mortality Rate

Description	Prostate cancer deaths per 100,000 males per year
Source	National Healthcare Quality Report; Healthy People 2010
Consensus on care	Improving the effectiveness of Georgia prostate cancer care should ultimately reduce related mortality.
Knowledge vs. practice	Not applicable
Approach to calculating the measure	
Numerator	Number of deaths due to prostate cancer (ICD-10 code 61) per year
Denominator	Number of males in Georgia
Potential data source(s)	Georgia Division of Public Health Vital Statistics System
Comments	Death rate = (Deaths/Population) × 100,000. Data should be age-adjusted to 2000 standard population. Age-adjusted rates are weighted sums of age-specific rates.
Limitations	Substantial time must pass before GCC would have any impact on mortality rates.
Potential benchmark source(s)	National Healthcare Quality Report; Healthy People 2010; National Vital Statistics System
Key references	AHRQ. 2003. *National Healthcare Quality Report*. Rockville, MD: U.S. DHHS. GDPH. 2004. *OASIS Web Query—Death Statistics*. [Online] Available: http://oasis.state.ga.us/webquery/death.html [accessed April 2004-. Jemal A, et al. 2003. Cancer statistics, 2003. *CA Cancer J Clin.* 53:5-26. U.S. DHHS. 2000. *Healthy People 2010: Understanding and Improving Health*. 2nd edition. *Chapter 3 Cancer*. Washington, DC: U.S. Government Printing Office. [Measure 3-7.]

MEASURE 6-23: TREATING CANCER—All Cancers Mortality Rate

Description	Cancer deaths (all sites) per 100,000 persons per year
Source	National Healthcare Quality Report; Healthy People 2010
Consensus on care	Improving the effectiveness of Georgia cancer care should ultimately reduce related mortality
Knowledge vs. practice	Not applicable
Approach to calculating the measure	
Numerator	Number of deaths due to cancer (ICD-10 codes C00-C97) per year
Denominator	Total Georgia population
Potential data source(s)	Georgia Division of Public Health Vital Statistics System
Comments	Death rate = (Deaths/Population) × 100,000. Data should be age-adjusted to the year 2000 standard population. Age-adjusted rates are weighted sums of age-specific rates.
Limitations	Substantial time must pass before GCC would have any impact on mortality rates.
Potential benchmark source(s)	National Healthcare Quality Report; Healthy People 2010; National Vital Statistics System
Key references	AHRQ. 2003. National Healthcare Quality Report. Rockville, MD: U.S. DHHS. GDPH. 2004. *OASIS Web Query*. [Online] Available: http://oasis.state.ga.us/webquery/death.html. NCHS. 2003. *Deaths, Age-adjusted Death Rates, and Comparisons by State for Selected Leading Causes of Death*. [Online] Available: [http://www.cdc.gov/nchs/releases/03facts/ mortalitytables.htm#Georgia] U.S. DHHS. 2000. *Healthy People 2010: Understanding and Improving Health*. 2nd edition. *Chapter 3 Cancer*. Washington, DC: U.S. Government Printing Office. [Measure 3-1.]

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7

Crosscutting Issues in Assessing the Quality of Cancer Care

"Quality-of-life research has taught us the central role of the patient as the most important person in the assessment process. Although proxies and health care professionals can provide substitute judgment, the patient's own preferences or values are most highly regarded."
What Outcomes Matter to Patients: A Physician-Researcher Point of View
Patricia A. Ganz, 2002

"Numerous scientific studies provide the evidence that certain U.S. populations experience significant disparities in risk, incidence, disease-stage diagnosis, care received, and disease outcomes for cancer."
Making Cancer Health Disparities History
Trans-HHS Cancer Health Disparities Progress Review Group
(U.S. DHHS, 2004)

As the Georgia Cancer Coalition (GCC) establishes its system for monitoring the quality of cancer care, the Institute of Medicine (IOM) Committee on Assessing Improvements in Cancer Care in Georgia recommends that it carefully develop the capacity to assess the experience of cancer patients and to measure disparities in the quality of cancer care. This chapter provides guidance on these two important crosscutting issues.

CAPTURING CANCER PATIENTS' EXPERIENCES

Responsiveness to patient-centered needs, preferences, and outcomes is a fundamental attribute of high-quality care (IOM, 2001; AHRQ, 2003). The IOM committee believes that evaluating patients' experiences will be as

critical to assessing the quality of cancer care as deploying any of the quality indicators recommended in this report. Georgia should implement a quality-of-cancer-care patient-centered survey research program as soon as it is technically feasible. No other source of information can substitute for patients' self reports on their preferences, outcomes, satisfaction, health care experiences and overall well-being (Cleary and Edgman-Levitan, 1997; IOM, 1999a, 2000, 2004; Ganz, 2002; Lawrence and Clancy, 2003; AHRQ, 2003; Drain and Clark, 2004).

Georgia's effort in this area is likely to be groundbreaking. GCC will face numerous and complex survey design decisions and should obtain expert advice. The use of patient surveys to assess the quality of community-based cancer care is a developing field of research (Schulman and Seils, 2003; Drain and Clark, 2004; Ayanian et al., 2004). There is an extensive literature validating numerous patient surveys, multi-symptom assessment tools, and quality-of-life instruments for cancer patients in clinical trials (Schag et al., 1991; Ware and Sherbourne, 1992; Cella et al., 1993, 1995; Esper et al., 1997; Brady et al., 1997; Cleary and Edgman-Levitan, 1997; Safran et al., 1998; McLachlan et al., 1998; Cleary, 1999; Ward et al., 1999). Unfortunately, few if any of these instruments have been tested in clinical settings where most patients seek care (Berry et al., 2004).

The discussion of patient surveys that follows offers guidance on two aspects of developing an approach to capture cancer patients' experiences: (1) the design of surveys of cancer patients; and (2) potential topics for cancer patient surveys.

Designing Surveys of Cancer Patients

When designing a survey to capture patients' experiences, GCC should carefully consider its sampling methods to ensure, depending on the focus of the survey, that the sample population is representative of Georgia (IOM, 2000). Special attention should be given to sample size so that the surveys have sufficient statistical power to detect racial, ethnic, socioeconomic, and other subgroup differences. Uninsured and low-income patients may be particularly hard to reach, but they must be included in the survey because they are the patients most likely to be undertreated.

GCC can learn and draw from the many published surveys on symptoms, quality of life, and satisfaction with cancer care (Table 7-1). A number of instruments have been developed for use with cancer patients and survivors (although, as noted above, few have been tested outside of clinical trials). Some surveys have modules tailored to specific cancers. The Functional Assessment of Cancer Therapy, for example, has individual modules for collecting data on physical, social/family, emotional, and functional well-being for breast, colorectal, lung, and prostate cancers (Cella et al., 1993,

TABLE 7-1 Examples of Survey Instruments That Measure the Patient Experience and Quality of Life

Survey	Sponsor/Developer	Focus
	Cancer-specific instruments	
Assessment of Patients' Experience of Cancer Care Study (currently under development)	National Cancer Institute; Northern California Cancer Center	Experience and perceptions of cancer survivors, including services received, access, communication, symptoms, pain and other side effects.
Cancer Rehabilitation Evaluation System	A. Coscarelli, R. Heinrich, and P. Ganz	Physical, psychosocial, medical interaction, marital, and sexual quality of life
Functional Assessment of Cancer Therapy (FACT), includes: —FACT-G, general; FACT-B, breast; FACT-C, colorectal; FACT-L, lung cancer; FACT-P, prostate	D. Cella Institute for Health Services Research and Policy Studies, Northwestern University	Physical, social/family, emotional, and functional well-being
National Quality of Life Study	American Cancer Society	Needs and concerns of cancer survivors
Quality of Life Questionnaire (QLQ), includes: —QLQ-C30, core module; QLQ-BR23, breast cancer module	European Organization for Research and Treatment of Cancer	Quality of life of cancer patients in clinical trials including physical, psychosocial, medical interactions, pain, sexual and other side effects
	General health instruments	
Ambulatory Care Experiences Survey (ACES), includes: —PCP-ACES, primary care; SF-ACES, primary care short form	The Health Institute, Tufts-New England Medical Center	Patients' experiences with their primary care physician, specialist physicians, and health plan
Consumer Assessment of Health Plan Survey (CAHPS), includes: —A-CAHPS, ambulatory care; H-CAHPS, hospital care; G-CAHPS, group practice care	Agency for Health Care Research and Quality; Center for Medicare and Medicaid Services (CMS)	Interpersonal aspects of health care

continues

TABLE 7-1 Continued

Survey	Sponsor/Developer	Focus
Doctors' Office Quality (pilot instrument under development)	CMS	Quality of ambulatory care for chronically ill patients, including patient's experience of care
Medical Outcomes Study, Short Form (SF)-12 and SF-36	CMS; The Health Institute, Tufts-New England Medical Center	Functional status, well-being, and self-perceived health
Primary Care Assessment Survey	The Health Institute, Tufts-New England Medical Center	Quality of physician-patient interactions and structural features of care

1995). The National Cancer Institute and the Northern California Cancer Center are currently testing a cancer-specific survey, called the Assessment of Patients' Experience of Cancer Care, which draws upon the Consumer Assessment of Health Plans (CAHPS), the Primary Care Assessment Survey, and other primary care surveys (Arora, 2004; NCCC, 2004).

More generic instruments, such as the Ambulatory Care Experiences Survey and the Primary Care Assessment Survey, collect data on patients' experiences with their physicians and health plan independent of diagnosis. CAHPS, although first developed to determine health plan members' satisfaction with their managed care organization, is now being adapted to assess the interpersonal aspects of health care in a variety of clinical settings (AHRQ, 2004).

Target Population

The target population is the group of people about whom the researcher wishes to draw conclusions; it should be clearly defined and standardized across surveys to allow comparisons. The committee recommends that GCC select population-based samples of persons with the most common types of cancer (i.e., breast, colorectal, lung, and prostate) and, within these groups, two subgroups: (1) *recently diagnosed cancer patients* (i.e., those diagnosed within the previous 6 to 18 months), because they are most likely to remember the details of their clinical care experiences; and (2) *cancer survivors 5 to 6 years after diagnosis* in order to capture the experiences of survivors. Survivors are a rapidly growing population whose needs have significant public health implications.

Sampling Frame

A sampling frame is a list or other organized record of a population from which a survey sample is drawn. The committee recommends that Georgia sample patients from its central, population-based cancer registries.[1] This will require careful consideration of patient confidentiality issues in light of the Health Insurance Portability and Accountability Act (HIPAA) of 1996. Under HIPAA regulations, central cancer registries are considered public health authorities with the legal authority "to collect or receive such information for the purposes of preventing or controlling disease, injury, vital events such as birth or death, and the conduct of public health surveillance, public health investigations, and public health interventions."[2] Nevertheless, the committee urges GCC to explore the legal implications of using Georgia's central registries for quality-of-care research. It is beyond the scope of this study to evaluate this issue further.

Georgia's registries currently find at least 97 percent of all incident cancer cases in the state and, for each case, collect patient demographic information including residence, standardized racial and ethnic data, cancer site, tumor stage and extent of disease, initial course of treatment, and other data elements (Bayakly, 2003).

Substantial delays in data collection are characteristic of registry operations nationwide—up to 2 years may elapse from the time cancer cases are diagnosed until all required patient data are entered into a registry's database (IOM, 2000). Georgia must invest in expanding registry capacity to identify and follow up cancer cases soon after diagnosis. For special studies of cancers with relatively short survival times, such as lung cancer, GCC could use an expedited process—rapid case ascertainment—to accelerate reporting of new cancer diagnoses (NCI, 2003). Another method is to have the registry's data collection effort interface with the electronic medical records that many hospitals and practices are beginning to adopt.

Oversampling

By oversampling specific subpopulations of interest, GCC will ensure sufficient statistical power to measure differences in outcomes (NRC, 2004). This will be particularly critical to analyses of disparities (see discussion below). For example, a study of prostate cancer outcomes may be especially concerned with the experiences of African-American men living in rural

[1]See Chapter 2, *Concepts, Methods, and Data Sources*, for a description of the Georgia registries.

[2]45 CFR 164.512.

versus metropolitan areas. If so, a disproportionately larger subsample of rural African-American men may be needed.

GCC should use patient surveys only to collect data that are best collected from patients themselves. The costs of obtaining survey data for small or geographically concentrated racial and ethnic groups will make it infeasible to collect such data on a regular basis (NRC, 2004). On the other hand, GCC could conduct periodic targeted studies on specific groups in specific areas. Doing this would be a feasible way of collecting meaningful data on important subgroups over time. In addition, the Centers for Disease Control and Prevention-sponsored Behavioral Risk Factor Surveillance System provides an affordable option for oversampling selected subpopulations in its survey on risk behaviors (CDC, 2004). GCC should take advantage of this option to obtain additional, more representative data from the cancer-related components of that survey.

Potential Topics for Cancer Patient Surveys

The IOM committee recommends that GCC seek direct patient input on the quality of cancer care. By analyzing and reporting the findings from well-designed patient surveys and quality-of-life instruments, GCC can inform providers, policy makers, and consumers about how well cancer patients are being served across the continuum of care. There are critical insights into the needs and preferences of those affected by cancer—beyond considerations of treatment efficacy—that can only be gained by asking cancer patients and survivors (Schulman and Seils, 2003). Furthermore, patients have been shown to be the best source of information on their functional status, treatment-related symptoms, satisfaction and interpersonal issues, and access to needed services (Ayanian et al., 2004).

Important domains for patient survey research (Table 7-2) include the following:

- **Functional status.** Functional status refers to the ability of patients to do what they need and want to do, and encompasses a wide variety of patient-focused outcomes including physical functioning (e.g., walking and climbing stairs), emotional well-being (e.g., role-limiting anxiety or fear of recurrence), and social functioning (e.g., isolation, ability to work) (Ganz, 2002).
- **Symptoms.** Symptom experiences—what the patient feels—are basic to quality of life (Cella et al., 2002). Cancer patients' symptoms may be due to physiologic changes related to their cancer or to the treatment for cancer. Pain, nausea, fatigue, depression, and anxiety are commonplace among cancer patients regardless of the cancer site (IOM, 2004). Treatments for some cancers, including prostate and breast cancer, cause signifi-

TABLE 7-2 Potential Domains and Topics for Cancer Patient Surveys

Domain	Potential Topics
Functional status	Physical, emotional, spiritual, and social functioning
Treatment-related symptoms	
—All cancers	Pain, nausea, depression, anxiety
—Breast	Lymphedema
—Colorectal	Diarrhea
—Lung	Shortness of breath
—Prostate	Incontinence, impotence
Satisfaction	Interpersonal care including patient preferences, patient-provider relationship, treatment decisions, feeling informed especially with respect to treatment decision making, coordination of care, expectations
Access	Out-of-pocket costs, barriers to needed services, timeliness

cant morbidity. The longitudinal Prostate Cancer Outcomes Study, for instance, found that after radical prostatectomy, radiation treatment, or hormone therapy, substantial proportions of patients with localized prostate cancer reported having problems related to impotence, incontinence, or bowel function (Potosky et al., 2000).

- **Satisfaction and interpersonal issues.** Patients' health care experiences have been linked to clinically important, intermediate outcomes such as adherence to treatment regimens and following instructions after a hospital stay—underscoring the significance of monitoring satisfaction and interpersonal experiences, such as patient preferences, patient-provider communication, adequate information for treatment decision making, knowledge of diagnostic and treatment expectations, and coordination of care (DiMatteo et al., 1993; Weinfurt, 2003; Schulman and Seils, 2003; Wickizer et al., 2004; DiMatteo, 2004).
- **Access to care.** Patient surveys that ask patients to report on the timeliness, financial burdens, and other barriers to cancer-related services will provide GCC important direction in how to approach quality improvement. There is a well-established literature showing that access to health care is integral to survival and quality of life (Ayanian et al., 1993; IOM, 1999b, 2002, 2003b; Roetzheim et al., 2000b; Bradley et al., 2003; McDavid et al., 2003; Gornick et al., 2004).

EVALUATING DISPARITIES IN CANCER CARE

Gross disparities exist in the behaviors and environmental conditions that lead to cancer, as well as in the incidence, diagnosis, treatment, and outcomes of cancer (IOM, 1999b, 2003b; Landis et al., 2004; Jemal et al., 2004). The IOM committee believes that the quality of Georgia's cancer care cannot improve meaningfully without addressing the state's unequal cancer burden.

What Causes Disparities in Health and Health Care?

The reasons for disparities in health and health care are not well understood. Race, ethnicity, and socioeconomic status are correlated with one another and each has been shown to independently contribute to an individual's health (NRC, 2004). It is clear, for example, that socioeconomic factors, early cancer detection, and cancer survival are closely linked (Gorey et al., 2000; Ponce et al., 2003). Health insurance coverage and family income, in particular, are critical determinants of cancer outcomes largely because of barriers to access and delays in diagnosis (Ayanian et al., 1993; Roetzheim et al., 2000a; Gonzalez et al., 2001; McDavid et al., 2003). An extensive literature has made clear that patient's age is often associated with the type of cancer care received (Hodgson et al., 2001; Harlan et al., 2002; Ayanian et al., 2003; Lyman et al., 2003; Richardson, 2004). Numerous studies have also shown that cancer survival is worse for Medicaid enrollees compared with other insured persons (Ayanian et al., 1993; Bradley et al., 2003).

Health insurance and poverty, however, do not fully explain cancer disparities. There is also a profound and unequal burden of cancer associated with race and ethnicity (IOM, 1999b). The disproportionate burden of cancer among African Americans, for example, is well documented (IOM, 1999b, 2003b; U.S. DHHS, 2004; Ward et al., 2004). African Americans, compared with all other racial or ethnic groups in the United States, have the highest mortality rate from all cancer sites combined and from breast, colorectal, lung, and prostate cancers individually (Table 7-3) (ACS, 2004). Compared with cancer death rates for white men and women, the cancer death rate is 43 percent higher for African-American men and 19 percent higher for African-American women.

Data Infrastructure Needed to Reduce Cancer Disparities

The IOM committee urges Georgia to improve its cancer information systems so that high-quality racial, ethnic, and socioeconomic data are readily available. The importance of building a data infrastructure to under-

TABLE 7-3 Incidence and Mortality Rates for Four Leading Cancers in Georgia, by Gender, Race, and Ethnicity, 2001[a]

	Incidence, by Race/Ethnicity (per 100,000)			
Cancer	All Races	White	African American	Hispanic-Latino[b]
All sites				
Male	570.9	548.0	687.8	337.0
Female	385.9	399.5	351.4	344.3
Breast, female				
In situ	27.5	28.9	24.4	NA
Invasive	124.6	131.6	105.4	101.3
Colorectal				
Male	61.0	57.8	76.4	39.4
Female	41.7	39.2	49.9	45.8
Lung and bronchus				
Male	108.1	105.7	123.0	55.0
Female	51.8	56.2	37.5	37.8
Prostate	173.8	152.4	270.4	103.9

	Mortality, by Race/Ethnicity (per 100,000)			
Cancer	All Races	White	African American	Hispanic-Latino[b]
All sites				
Male	263.4	246.9	343.9	NA
Female	164.1	161.1	175.6	NA
Breast[c]	24.9	23.8	29.1	NA
Colorectal				
Male	23.2	21.0	33.0	NA
Female	17.7	15.2	27.1	NA
Lung and bronchus				
Male	91.7	90.6	101.2	NA
Female	40.8	44.3	29.7	NA
Prostate	33.5	25.2	71.5	NA

[a]Age-adjusted to the 2000 U.S. standard population.
[b]All races.
[c]Invasive female breast cancer only.
NOTE: NA = Not available.
SOURCE: U.S. Cancer Statistics Working Group, 2004.

take the challenge of reducing cancer disparities is underscored by Georgia's rapid growth and increasing diversity. Georgia was the fastest growing southern state in the 1990s and, mirroring trends elsewhere in the United States, the state is becoming ever more racially and ethnically diverse (Box 7-1).

These demographic trends are inextricably linked with health insurance and poverty. In Georgia and throughout the nation, insurance and poverty status vary considerably by race and ethnicity (Table 7-4 and Table 7-5).

Two aspects of building a state data infrastructure for understanding and addressing health disparities require particular attention and action: (1) standardizing race and ethnicity data; and (2) creating the capacity to

BOX 7-1
Rapidly Changing Demographics in Georgia

Georgia's population is rapidly growing and becoming increasingly diverse. During the 1990s, the state population grew by more than 26 percent to total 8.2 million in 2000. Part of this growth was due to an astonishing migration of African Americans to Georgia that led to an almost 35 percent increase in the state's African-American population. African Americans now make up an estimated 28.7 percent of Georgia's residents while white persons represent 65.1 percent.

Georgia's Asian population doubled during the 1990s. Although only 2.1 percent of Georgians are Asian, most Asians live in metropolitan Atlanta. In 2000, more than 7 percent of Gwinnett County, just outside Atlanta, was Asian.

The state's ethnic makeup is also changing, mirroring trends across the United States. The Hispanic population is the fasting growing minority group in the state. From 1990 to 2000, there was an almost 300 percent rise in the number of Hispanic residents in Georgia, an increase from 108,922 to 435,227 persons. In 2000, Hispanic persons were just 5 percent of Georgia residents but their presence varies dramatically by county. In two northern counties (i.e., Hall and Whitfield), for example, one in five residents is Hispanic.

Race and Ethnicity of Georgia's Population in 2000

White	65.1%
Black	28.7%
Asian	2.1%
Other[a]	4.2%
Hispanic or Latino origin (any race)	5.3%

[a]Other includes American Indians and Alaskan Natives, Native Hawaiians and other Pacific Islanders, and respondents who belong to two or more racial categories.

SOURCE: Office of Planning and Budget, 2004; U.S. Census Bureau, 2004.

TABLE 7-4 Percentage of Nonelderly Persons in Georgia Who Are Uninsured, by Race and Ethnicity, 2002-2003

	Percentage Uninsured
Nonelderly Georgia residents	18
White, non-Hispanic	15
Black, non-Hispanic	20
Hispanic	43
Other	NA

NOTE: Nonelderly includes persons under age 65. Hispanic persons may be of any race. NA = Not available.
SOURCE: Urban Institute and Kaiser Commission on Medicaid and the Uninsured, based on pooled March 2002-2003 Current Population Surveys. Kaiser Family Foundation, 2004.

TABLE 7-5 Percentage of Persons in Georgia Who Are Living in Poverty, by Race and Ethnicity, 2002-2003

	Percentage in Poverty
All Georgia residents	13
White, non-Hispanic	11
Black, non-Hispanic	26
Hispanic	30
Other	9

NOTE: Persons in poverty defined as those with family incomes less than 100 percent of the federal poverty level. The federal poverty level for a family of three was $15,260 in 2003. Hispanic persons may be of any race. NA = Not available.
SOURCE: Urban Institute and Kaiser Commission on Medicaid and the Uninsured, based on pooled March 2002-2003 Current Population Surveys. Kaiser Family Foundation, 2004.

analyze socioeconomic factors through standardized geographical data. These are discussed below.

Standardizing Race and Ethnicity Data

If Georgia is to mitigate racial and ethnic disparities in the quality of cancer care, it must produce high-quality, standardized, race and ethnicity data. Without this capability, GCC will be unable to either monitor the disparity problem or develop adequate solutions.

The IOM committee recommends that GCC use standardized categories of race and ethnicity in its cancer registries, medical records, claims, patient- and population-based surveys, and other cancer-related data col-

lection. GCC should adopt the federal Office of Management and Budget (OMB) minimum standards for categorizing race and ethnicity and apply the standards in all patient data collection (Box 7-2). The OMB standards are flexible enough to serve state as well as federal information needs (NRC, 2004).

With Georgia's growing Hispanic population, some attention to Hispanic cancer data is also recommended. There is some research suggesting that registries and vital records under-ascertain or misclassify cancer incidence among Hispanics (Swallen et al., 1997; Coronado et al., 2002). Bias in the cancer registry data collection methods is thought to contribute to the problem. The North American Association of Central Cancer Registries

BOX 7-2
Standardizing Racial and Ethnic Categories for Public Policy Uses

Federal and some state data collection systems use standard categories of race and ethnicity to comply with the requirements of the federal Office of Management and Budget (OMB). Since 1977, OMB has required these minimum standards to promote consistency in defining race and ethnicity for civil rights legislative use, monitoring equal treatment, and other public policy uses.

OMB currently mandates the use of five racial categories and two ethnic categories. Subjects are simultaneously tabulated by race and ethnicity. In the U.S. Census, respondents may also select more than one race, allowing for very many combinations.

OMB-Mandated Racial and Ethnic Categories

Racial Categories	*Ethnic Categories*
(1) Black or African American	(1) Hispanic or Latino
(2) White	(2) Non-Hispanic or Latino
(3) Asian	
(4) American Indian and Alaska Native	
(5) Native Hawaiian and other Pacific Islander	

OMB standards are required in all federal census and survey data, federal administrative records, federally sponsored research, as well as in data collected by states for federal purposes. States collect much of the data that the federal government uses to study health and health care services, including the Vital Statistics Cooperative Program for vital statistics, the Healthcare Cost and Utilization Program for hospital discharge data, the Surveillance, Epidemiology, and End Results Program for cancer, the Behavioral Risk Factor Surveillance System, and the Medicaid program.

Many privately sponsored surveys also use the OMB classifications.

SOURCE: NRC, 2004; OMB, 1977.

(NAACCR) has developed a computerized algorithm to address the problem (NAACCR Expert Panel on Hispanic Identification, 2003; Howe, 2004). Registries in California have had some experience with this issue (Stewart et al., 1999).

Creating the Capacity to Analyze Socioeconomic Factors

Socioeconomic status is associated with high-risk behaviors such as tobacco use, poor nutrition, physical inactivity, and obesity as well as barriers to appropriate cancer screening, early detection, treatment, and palliative care (IOM, 2003a). As a consequence, socioeconomic factors are also correlated with cancer and other health outcomes (IOM, 1999b; Freeman, 2003; NRC, 2004; Ward et al., 2004). These interrelationships imply that racial and ethnic disparities should be viewed in the context of social and economic conditions (NRC, 2004). GCC must therefore have the ability to analyze how cancer care quality varies not only by race and ethnicity but also by gender, age, income, geographic location, health insurance status, and other socioeconomic factors. If racial and ethnic groups can be disaggregated into more socially and culturally homogeneous subgroups, researchers will be better equipped to assess disparities and identify effective interventions (Braveman, 2003; U.S. DHHS, 2004).

Historically, state-based collection of health-related data has been uneven and not standardized (NRC, 2004). Furthermore, since most health-related data systems draw from health records, little information on socioeconomic status has been collected. In social science research, socioeconomic status is commonly ascertained by developing indices combining measures of education, occupation, and income, but the routine collection of such information by cancer registries has not been possible because it usually cannot be found in medical records.

Geocoding is the assignment of a code to a geographical location by matching an individual address to a census tract or other geographic unit, such as a county, public health district, or region. It can be an inexpensive and reliable way to capture socioeconomic variables for monitoring the cancer burden if the cancer registry maintains reliable records of patients' addresses (Braveman, 2003; U.S. DHHS, 2004). Georgia should consider using currently available software to geocode its cancer registry records as each new cancer case is entered into the state's surveillance database. Geocoded registry-based cancer cases could then be linked with geographic-specific data such as area-based socioeconomic variables, environmental data, and health care resources. With this step, Georgia's cancer control professionals and researchers would have unprecedented capacity to assess the impact of social and contextual level variables on cancer incidence, diagnosis, treatment, and outcomes (Krieger et al., 2003; Singh et al., 2003).

Thus, GCC's quality monitoring could discern disparities between, for example, rural and urban African Americans. Otherwise, grouping the two populations in one racial group could well obscure poor outcomes in rural African-American populations.

Implementing geocoding of cancer data would also put Georgia in step with the U.S. Healthy People 2010 call for increased use of geocoding in all major national, state, and local health data systems (U.S. DHHS, 2000).

SUMMARY

In this chapter, the IOM committee has addressed two related cross-cutting issues in assessing the quality of cancer care—first, the use of cancer patient surveys, and second, the conduct of health disparities research. Evaluating cancer patients' experiences will be as critical to assessing the quality of cancer care as deploying the 53 quality-of-cancer-care measures recommended in this report. Moreover, cancer outcomes will not improve for Georgians unless disparities in the quality of cancer care are addressed.

The IOM committee recommends that Georgia expand and enhance its cancer information systems to include a patient survey research program that focuses on functional status, symptoms, satisfaction, and access to care and build the data infrastructure needed to develop high-quality racial, ethnic, and socioeconomic data that can be used to address health disparities. Building the capacity to survey patients and measure disparities will be costly and should be carefully planned. Patient surveys should be used only to collect data that are best collected from patients themselves. Periodic, targeted studies on specific groups in specific areas would be a feasible way of collecting meaningful data on important subgroups over time.

Socioeconomic data will be essential to better understanding racial and ethnic disparities. Geocoding is an inexpensive and reliable way to capture socioeconomic variables for monitoring the cancer burden. Georgia should consider using currently available software to geocode its cancer registry records as each new cancer case is entered into the state's surveillance database.

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8

Looking Ahead to the Implementation of Quality-of-Cancer-Care Measures

In this report, the Institute of Medicine (IOM) committee has recommended several types of measures to monitor cancer outcomes in Georgia. The committee's main focus has been on the selection of evidence-based quality indicators that can help the Georgia Cancer Coalition (GCC) direct and evaluate progress in cancer prevention, early detection, diagnosis, and treatment (including palliative and end-of-life care). GCC will now be faced with the challenging job of organizing a system to implement the quality-of-cancer-care measures identified in previous chapters. Precisely how implementation should best occur is a question that is well beyond the scope of this report, but implementation of the recommended measures is a very important challenge.

In this chapter, the IOM committee offers advice about some principles and approaches to implementing the complex set of cancer measures. Specifically, it presents six principles to guide GCC:

1. The use of quality-of-cancer-care measures has a dual purpose: evaluating progress and motivating change.
2. GCC should develop a cancer surveillance, monitoring, and evaluation plan that incorporates a strategy for promotion and dissemination.
3. Georgia's quality-of-cancer-care monitoring system should be transparent and very public.
4. Monitoring of the quality-of-cancer-care indicators should be managed by the highest level of GCC.
5. GCC's quality-of-cancer-care infrastructure should build on Georgia's existing measurement and reporting systems.

6. Credibility of the system will be paramount: collect, interpret, and present the results carefully.

Each of these principles is discussed further below. In addition, the committee recommends that GCC look to the growing literature examining lessons learned from numerous quality measurement and improvement projects around the nation (California HealthCare Foundation, 2001; Hermann et al., 2002; Lorenzi, 2003; Mills and Weeks, 2004; McGlynn, 2004; Kanouse et al., 2004; Landon et al., 2004; Murphy-Smith et al., 2004; Bradley et al., 2004a; Bradley et al., 2004b).

1. The use of quality-of-cancer-care measures has a dual purpose: evaluating progress and motivating change.

GCC's quality-of-cancer-care monitoring system will both evaluate progress in improving outcomes and fuel interest in investigating explanations for observations. The emphasis on outcome assessment should not outweigh the other important purpose of motivating change. Fear of slowness in progress will tend to reduce investments in monitoring. However, the measurement process itself can often serve to raise awareness to levels that can lead, even indirectly, to improvements apart from the direct indicator that is being assessed. There need not be an expectation, therefore, that all indicators will improve with every evaluation. In other words, surveillance is not just a "report card" on how much progress has been made. Rather, surveillance should be viewed as a process of push, pull, give, and take, which will serve to enlighten many interested parties, across many sectors, about the needs and opportunities for improving cancer care in Georgia.

2. GCC should develop a cancer surveillance, monitoring, and evaluation plan that incorporates a strategy for promotion and dissemination.

That plan should be a blueprint for a cancer surveillance, monitoring, and evaluation unit, with a strategic plan to assure both oversight and independence. See Figure 8-1 for a proposed schematic of a GCC Quality Monitoring, Surveillance, and Evaluation Unit. This unit will need to have long-term, sustainable funding support. The unit will require a full-time director who understands data systems, epidemiology, and health communications, and an adequate support staff. This unit will need to work closely with other surveillance systems, such as those in the State Health Department, cancer registries, and medical data systems, who should be full partners in the plan. The unit could be commissioned to be located within an organization or a university, but it is important that it be an independent unit answerable to GCC to assure credibility.

Outputs of the monitoring system should be well defined by the plan. In most instances the outputs will be annual reports. All outputs will be

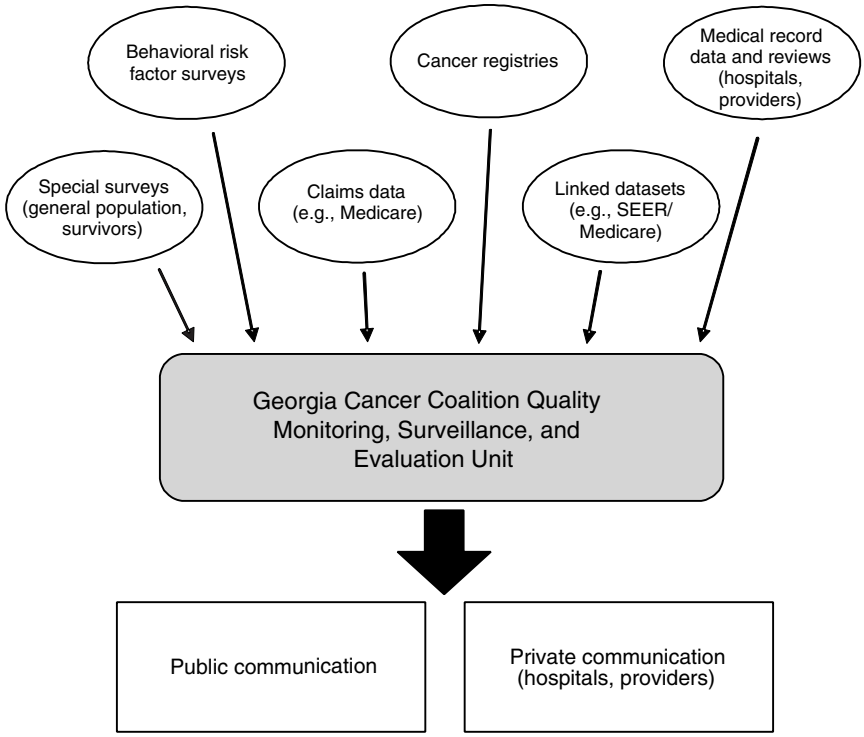

FIGURE 8-1 Schematic of the Georgia Cancer Coalition Quality Monitoring, Surveillance, and Evaluation Unit.

public reports, with the exception of some provider-specific data that will best remain confidential to the providers and health care systems.

3. Georgia's quality-of-cancer-care monitoring system should be transparent and very public.

The assessment process needs to be clearly described and well understood by GCC collaborators, and the general public should come to expect regular annual reports of the state of cancer in Georgia. The experience of several quality monitoring projects around the country suggests that credible reporting and data feedback will be key to achieving "buy-in" from clinical leaders, medical groups, health plans, business leaders, consumers and other stakeholders (California HealthCare Foundation, 2001; Lorenzi, 2003; Kanouse et al., 2004; Mills and Weeks, 2004; Bradley et al., 2004a, 2004b). The National Cancer Institute's (NCI's) annual cancer progress report and

the Cancer Control PLANET are two models worth considering.[1] The collateral improvements that can occur with monitoring are best optimized by a very open and public process of monitoring and surveillance. The general public may not directly act on the reports, but the reports' presence in the public domain could stimulate quality improvement among providers. Surveillance that is not understood, or that is not respected, or that is too private, cannot be effective in fostering change. Findings from the monitoring system should be disseminated on a regular schedule, and widely publicized, though some of the information in the system (e.g., provider-specific findings) will need to remain confidential.

Georgia's quality-of-cancer-care monitoring system will yield an increasingly rich and unique dataset. As it will be beyond GCC's means to fully exploit this new treasure trove of information, the state should consider making the data available to researchers for a wide range of health services and scientific research. Outside funding sources, including the federal government, might be willing to support such an effort as it is likely to be a valued resource for the nation. GCC should establish a standing scientific review committee to develop and oversee the implementation of a carefully considered policy for public access to Georgia's quality-of-cancer-care data. There are numerous models for such an activity; see, for example, the national Consumer Assessment of Health Plans (CAHPS) benchmarking database, New York state's Statewide Planning and Research Cooperative System (SPARCS), and the American College of Surgeons' National Cancer Database (NCDB), among others.[2]

4. Monitoring of the quality-of-cancer-care indicators should be managed by the highest level of GCC.

Monitoring and surveillance should not be regarded as a secondary activity to be delegated to a low-level unit. Although various elements of the monitoring system will likely be implemented by organizations or entities that are themselves independent of GCC, the overall system should be managed by GCC as a high-profile public activity.

5. GCC's quality-of-cancer-care infrastructure should build on Georgia's existing measurement and reporting systems.

The building blocks of the system will include routinely collected data

[1]See these websites for further information: NCI annual progress reports, www.cancer.gov/nci-annual-report/. NCI Cancer Control PLANET, cancercontrolplanet.cancer.gov/index.html.

[2]See these websites for further information: CAHPS, www.ncbd.cahps.org/Home/index.asp. NCDB, www.facs.org/cancer/ncdb/index.html. SPARCS, www.health.state.ny.us/nysdoh/sparcs/sparcs.htm.

from the central cancer registries, state Behavioral Risk Factor Surveillance System (BRFSS), the linked Surveillance, Epidemiology, and End Results (SEER)/Medicare dataset, and state vital records systems. Parties principally responsible for collecting those data will be the current operators of those systems. In some cases, special data elements might be included (e.g., BRFSS special questions or oversampling of special populations), or special contractual arrangements may be needed to assure data timeliness and completeness. However, in most cases the data inputs will be routinely collected data, compiled on a once-per-year basis. Other data inputs will be specifically constructed for the monitoring system, such as the data from hospital records and special samples of clinical data collected for the treatment and outcomes monitoring elements that will be specially designed for this system. Those special inputs might well be more frequent than annual.

6. Credibility of the system will be paramount: collect, interpret, and present results carefully.

Quality monitoring and surveillance will require careful interpretation and presentation. The data inputs and the results must be perceived as valid to motivate change. Some data sources will be more reliable and complete than others. Case-mix or risk adjustment of some measures will be needed to compare providers fairly. Furthermore, the measures should be periodically reviewed and updated as needed. It will be important to have a basis for considering new quality measures over time and retiring existing measures if they prove to be ineffective or no longer relevant.

SUMMARY

In this chapter, the IOM committee has offered six principles to guide GCC as it takes on the daunting challenge of implementing a quality-of-cancer-care monitoring system in Georgia. In addition, the committee has recommended that GCC look to the growing literature on lessons learned from numerous quality measurement and improvement projects around the country as it undertakes the challenge of implementing the quality-of-cancer-care measures recommended in this report (California HealthCare Foundation, 2001; Hermann et al., 2002; Lorenzi, 2003; Mills and Weeks, 2004; McGlynn, 2004; Kanouse et al., 2004; Landon et al., 2004; Bradley et al., 2004a, 2004b).

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APPENDIX A

Sources of Cancer-Related Clinical Guidelines and Quality Indicators

The quality measures recommended in this report draw from a variety of clinical practice setting organizations, federal health agencies, provider groups, and others. This appendix describes the following organizations that were key to the IOM committee's work (including how each organization grades levels of evidence and categorizes the strength of its clinical recommendations):

- American Society of Clinical Oncology;
- College of American Pathologists;
- Commission on Cancer;
- Healthy People 2010;
- Institute for Clinical Systems Improvement;
- National Comprehensive Cancer Network; and
- U.S. Preventive Services Task Force.

American Society of Clinical Oncology

Sponsor	American Society of Clinical Oncology
Description	Professional organization of clinical oncologists, oncology nurses, and other health care professionals with a focus in oncology. Publishes guidelines and technology assessments produced by panels of experts based on the research literature. Topics are selected for clinical or economic importance, variations in patterns of or access to care, availability of data, and ethical considerations.
Primary Focus	Breast cancer, colorectal cancer, hematology, lung cancer, myeloma, and crosscutting topics related to cancer treatment, such as the use of antiemetics.
Levels of Evidence	Level I: Evidence obtained from meta-analysis of multiple, well-designed, controlled studies. Randomized trials with low false-positive and low false-negative errors (high power). Level II: Evidence obtained from at least one well-designed experimental study. Randomized trials with high false-positive and/or negative errors (low power). Level III: Evidence obtained from well-designed, quasi-experimental studies such as nonrandomized, controlled, single group, pre-post, cohort, and time or matched case-control series. Level IV: Evidence from well-designed, nonexperimental studies such as comparative and correlational descriptive and case studies. Level V: Evidence from case reports.
Strength of Recommendation	Grade A: There is evidence of type I or consistent findings from multiple studies of type II, III, or IV. Grade B: There is evidence of type II, III, or IV, and findings are generally consistent. Grade C: There is evidence of type II, III, or IV, but findings are inconsistent. Grade D: There is little or no systematic empirical evidence.
Years	Since 1993
Schedule of Updates	New literature reviewed annually; guidelines updated as necessary
Website	www.asco.org

College of American Pathologists

Sponsor	College of American Pathologists (CAP)
Description	Principal organization of board-certified pathologists concerned with the practice of pathology and laboratory medicine.
Primary Focus	CAP produces standardized templates, referred to as protocols or checklists, for reporting findings on cancer specimens for each organ site and type of surgical specimen.
Levels of Evidence	NA
Strength of Recommendation	NA
Years	Since 1998
Schedule of Updates	Updated as needed
Website	www.cap.org

NA = not applicable.

Commission on Cancer

Sponsor	American College of Surgeons
Description	The Commission on Cancer (CoC) is a multi-disciplinary consortium that establishes quality standards for cancer care programs and accredits programs according to those standards. Although most CoC-accredited programs are hospital-based, freestanding treatment facilities and health care networks can also apply for CoC accreditation.
Primary Focus	CoC standards cover the full range of cancer center activities including clinical and pathology data and reporting, tumor registries, clinical management, research, community outreach, professional education, and quality improvement. CoC-certified pathology laboratories must comply with the College of American Pathologists' reporting requirements for cancer-directed surgical specimens.
Levels of Evidence	NA
Strength of Recommendation	NA
Years	Since 1975
Schedule of Updates	Updated as needed
Website	http://www.facs.org/cancer/coc/coc.html

NA = not applicable.

Healthy People 2010

Sponsor	U.S. Department of Health and Human Services (DHHS)
Description	Healthy People 2010 is a statement of national health objectives designed to identify the most significant preventable threats to health and to establish national goals to reduce these threats. It includes specific, measurable objectives across 28 focus areas with target goals and national baseline.
Primary Focus	The cancer-related objectives of Healthy People 2010 relate to: • Mortality (overall, lung, breast, cervical, colorectal, oropharyngeal, prostate, and melanoma) • Sun exposure and skin cancer • Provider counseling about cancer prevention • Pap tests • Colorectal cancer screening • Mammograms • Statewide cancer registries • Survival • Fruit and vegetable intake • Fat intake • Oral and pharyngeal cancers • Tobacco use including smoking cessation and insurance coverage of tobacco cessation treatment
Levels of Evidence	NA
Strength of Recommendation	NA
Years	Healthy People 2000, Healthy People 2010
Schedule of Updates	New objectives developed every 10 years. Each focus area is reviewed at least twice during the decade.
Website	www.healthypeople.gov

NA = not applicable.

Institute for Clinical Systems Improvement

Sponsors	Six Minnesota health plans; Blue Cross and Blue Shield of Minnesota, Health Partners, Medica, PreferredOne, UCare Minnesota, and Metropolitan Health Plan
Description	A nonprofit collaborative that provides health care quality improvement services to its 54 member groups, including more than 7,400 physicians.
Primary Focus	More than 55 guidelines for the prevention or treatment of specific health conditions. Cancer-related guidelines address colorectal cancer screening, tobacco use prevention and cessation, diagnosis of breast disease, and breast cancer treatment.
Levels of Evidence	*Primary Reports of New Data Collection* Class A: Randomized, controlled trial Class B: Cohort study Class C: Nonrandomized trial with concurrent or historical controls; Case-control study; Study of sensitivity and specificity of a diagnostic tests; Population-based descriptive study Class D: Cross-sectional study; Case series; Case report *Reports that Synthesize or Reflect upon Collections of Primary Reports* Class M: Meta-analysis; Systematic review; Decision analysis; Cost-effectiveness analysis Class R: Consensus statement; Consensus report; Narrative review Class X: Medical opinion
Strength of Recommendation	Grade I: The evidence consists of results from studies of strong design for answering the question addressed. The results are both clinically important and consistent with minor exceptions at most. The results are free of any significant doubts about generalizability, bias, and flaws in research design. Studies with negative results have sufficiently large samples to have adequate statistical power. Grade II: The evidence consists of results from studies of strong design for answering the question addressed, but there is some uncertainty attached to the conclusions because of inconsistencies among the results from the studies or because of minor doubts about generalizability, bias, research design flaws, or adequacy of sample size. Alternatively, the evidence consists solely of results from weaker designs for the question addressed, but the results have been confirmed in separate studies and are consistent with minor exceptions at most.

	Grade III: The evidence consists of results from studies of strong design for answering the question addressed, but there is substantial uncertainty attached to the conclusion because of inconsistencies among the results from different studies or because of serious doubts about generalizability, bias, research design flaws, or adequacy of sample size. Alternatively, the evidence consists solely of results from a limited number of studies of weak design for answering the question addressed.
Years	Since 1992
Schedule of Updates	Reviewed every 12-18 months and updated as necessary
Website	www.icsi.org

National Comprehensive Cancer Network

Sponsor	National Comprehensive Cancer Network (NCCN)
Description	An alliance of 19 leading cancer centers. NCCN Clinical Practice Guidelines in Oncology are the most widely used guidelines in oncology practice.
Primary Focus	NCCN guidelines cover treatment of more than 95 percent of all cancers and also address cancer detection; risk assessment and reduction; and supportive care for nausea and vomiting, distress management, cancer-related fatigue, and cancer pain.
Levels of Evidence	NA
Strength of Recommendation	The strength of the recommendations provided in NCCN guidelines is indicated by the Categories of Consensus, which are based on both the strength of the evidence for the recommendation and the degree of committee consensus. Category 1: There is uniform NCCN consensus, based on high-level evidence, that the recommendation is appropriate. Category 2A: There is uniform NCCN consensus, based on lower-level evidence including clinical experience, that the recommendation is appropriate. Category 2B: There is nonuniform NCCN consensus (but no major disagreement), based on lower-level evidence including clinical experience, that the recommendation is appropriate. Category 3: There is major NCCN disagreement that the recommendation is appropriate.
Years	Since 1995
Schedule of Updates	Updated at least annually
Website	www.nccn.org

NA = not applicable.

U.S. Preventive Services Task Force (USPSTF)

Sponsor	U.S. Department of Health and Human Services, Agency for Healthcare Research and Quality
Description	An independent panel of private-sector experts appointed by the Agency for Healthcare Research and Quality.
Primary Focus	The appropriate use of preventive services in primary care settings, including cancer screening, counseling, chemoprevention, and immunizations. Cancer-related recommendations concern screening for 12 cancers, including breast, lung, prostate, and colorectal and counseling for gynecologic cancers, skin cancer; tobacco use, and vitamin supplementation for cancer prevention.
Levels of Evidence	Good: Evidence includes consistent results from well-designed, well-conducted studies in representative populations that directly assess effects on health outcomes. Fair: Evidence is sufficient to determine effects on health outcomes, but the strength of the evidence is limited by the number, quality, or consistency of the individual studies, generalizability to routine practice, or indirect nature of the evidence on health outcomes. Poor: Evidence is insufficient to assess the effects on health outcomes because of limited number or power of studies, important flaws in their design or conduct, gaps in the chain of evidence, or lack of information on important health outcomes.
Strength of Recommendation	A: The USPSTF strongly recommends that clinicians provide [the service] to eligible patients. The USPSTF found good evidence that [the service] improves important health outcomes and concludes that benefits substantially outweigh harms. B: The USPSTF recommends that clinicians provide [this service] to eligible patients. The USPSTF found at least fair evidence that [the service] improves important health outcomes and concludes that benefits outweigh harms. C: The USPSTF makes no recommendation for or against routine provision of [the service]. The USPSTF found at least fair evidence that [the service] can improve health outcomes but concludes that the balance of benefits and harms is too close to justify a general recommendation. D: The USPSTF recommends against routinely providing [the service] to asymptomatic patients. The USPSTF found at least fair evidence that [the service] is ineffective or that harms outweigh benefits.

	I: The USPSTF concludes that the evidence is insufficient to recommend for or against routinely providing [the service]. Evidence that the [service] is effective is lacking, of poor quality, or conflicting and the balance of benefits and harms cannot be determined.
Years	Since 1984
Schedule of Updates	Updated as needed
Website	www.ahrq.gov/clinic/uspstfix.htm

APPENDIX B

Sources of Data: Surveys and Datasets

The data sources for the measures recommended in this report include a variety of established surveys and datasets. This appendix describes the following:

- Behavioral Risk Factor Surveillance System;
- Consumer Assessment of Health Plans Study;
- Health Plan Employer Data and Information Set;
- National Home and Hospice Care Survey;
- National Vital Statistics System—Mortality; and
- Youth Risk Behavior Survey.

Behavioral Risk Factor Surveillance System (BRFSS)

Sponsor	U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, National Center for Chronic Disease Prevention and Health Promotio
Description	Population-based survey. Objective is to collect uniform, state-specific, data on preventive health practices and risk behaviors that are linked to chronic diseases (including cancer), injuries, and preventable infectious diseases in the adult population
Mode of administration/ data collection	Telephone interview. Data are collected separately by each state.
Sample design	State-level, random-digit-dialed probability samples
Primary survey content	A rotating core of questions asked every other year in all states, standardized optional questions on selected topics that are administered at the state's discretion, and state-added questions developed to address state-specific needs. Questions cover behavioral risk factors (e.g., alcohol and tobacco use), preventive health measures including cancer screening, health status, limitation of activity, and health care access and utilization.
Population targeted	U.S. civilian, noninstitutionalized population 18 years of age and older in households with telephones
Demographic data	Gender, age, education, race/ethnicity, household income, employment status, and marital status
Years	Since 1984
Schedule	Annual
Geographic estimates	National; state; smaller area estimates possible in some states
Contact information	http://www.cdc.gov/brfss

Consumer Assessment of Health Plans Study (CAHPS)

Sponsors	U.S. Department of Health and Human Services, including the Agency for Healthcare Research and Quality; Center for Medicare and Medicaid programs, State Medicaid agencies, and State Children's Health Insurance Programs; public and private employers, individual health plans, and the U.S. Department of Defense
Description	Survey designed to develop and test questionnaires that assess health plans and services, to produce easily understandable reports for communicating survey information to consumers, and to evaluate the usefulness of these reports for consumers in selecting health care plans and services
Mode of administration/ data collection	Mail or telephone questionnaire
Sample design	Random sample of health plan members by independent survey vendors following standardized procedures
Primary survey content	Consumer experiences in obtaining health care, including five major areas: getting needed care; getting care without long waits; how well doctors communicate; courteous and helpful office staff; customer service.
Population targeted	Surveys are tailored for various groups, including adults; children; children with chronic conditions; insured populations including commercial, Medicaid, Medicare, and Medicare managed care.
Demographic data	Age, gender, education, race, ethnicity, region, insurance coverage, health status
Years	Since 1998
Schedule	Annual
Geographic estimates	State, census bureau regions
Contact information	http://ncbd.cahps.org
Other	The National CAHPS Benchmarking Database is a national repository of CAHPS survey data that is available to researchers and others interested in using comparative CAHPS survey results for benchmarking and research. Information available at http://ncbd.cahps.org/Home/index.asp.

Health Plan Employer Data and Information Set (HEDIS)

Sponsor	National Committee for Quality Assurance (NCQA)
Description	A set of standardized performance measures designed to provide purchasers and consumers with the ability to evaluate the quality of different health plans.
Mode of administration/ data collection	NCQA collects and maintains HEDIS data directly from its member managed-care organizations and preferred provider organizations. All HEDIS data are maintained in a central database.
Sample design	NA
Primary survey content	Effectiveness of care (e.g. cancer screening, immunization status, etc.), access/availability of care, member satisfaction with the experience of care, cost of care, health plan stability, informed health care choices, use of services
Population targeted	Health plan members including children and adults enrolled in Medicaid, Medicare, and commercial health plans
Demographic data	Age, sex, race, education
Years	Since 1993
Schedule	Annual
Geographic estimates	By health plan
Contact information	http://www.ncqa.org/Programs/HEDIS/

NA = not applicable.

National Home and Hospice Care Survey

Sponsor	U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, National Center for Health Statistics
Description	Survey of home and hospice care agencies concerning agency management and current and discharged patients
Mode of administration/ data collection	Personal interviews with administrators and staff are used to complete questionnaires for samples of current and discharged patients.
Sample design	Stratified two-stage probability sample of patients served by Medicare- or Medicaid-certified agencies
Primary survey/ database content	Referral and length of service, diagnoses, number of visits, patient charges, health status, reason for discharge, and types of services provided
Population targeted	Patients of U.S. home health and hospice care agencies
Demographic data	Gender, age, educational attainment, race/ethnicity, marital status and health status
Years	For individual years from 1992-1994, 1996, 1998, and 2000
Schedule	Periodically, based on funding availability
Geographic estimates	U.S. Bureau of Census regions and metropolitan statistical areas
Contact information	http://www.cdc.gov/nchs/about/major/nhhcsd/nhhcsd.htm

National Vital Statistics System—Mortality

Sponsor	U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, National Center for Health Statistics
Description	An intergovernmental collaboration between the National Center for Health Statistics and the 50 states, two cities, and five territories organized to collect and disseminate mortality statistical information from death certificates
Mode of administration/ data collection	Death certificates are completed by physicians, coroners, medical examiners, and funeral directors and filed with state vital statistics offices.
Sample design	All deaths (nationally, about 2.2 to 2.3 million annually)
Primary survey/ database content	Year of death, underlying and multiple causes of death, place of decedent's residence, place death occurred, age at death, day and month of death, selected demographic data
Population targeted	U.S. deaths
Demographic data	Detailed race and ethnicity, marital status, place of birth, gender, educational attainment for selected states, and occupation and industry for selected states
Years	Complete since 1933
Schedule	Annual
Geographic estimates	National, regional, and state. Selected data are available for counties with more than 100,000 persons.
Contact information	http://www.cdc.gov/nchs/about/major/dvs/mortdata.htm

Youth Risk Behavior Survey (YRBS)

Sponsor	U.S. Department of Health and Human Services, Centers for Disease Control and Prevention (CDC)
Description	YRBS, a component of the Youth Risk Behavior Survey Surveillance System, is a national school-based survey of high school students that is conducted by CDC. It is designed to monitor national progress toward achieving the Healthy People 2000 and 2010 objectives and to track health risk behaviors among youth. States can receive federal funding to conduct the YRBS for state and local purposes. The state version of the survey uses different sampling and other procedures.
Mode of administration/ data collection	Self-administered questionnaire. Students record their responses on a computer-scannable booklet or answer sheet.
Sample design	Three-stage, cluster sample design
Primary survey content	Risk behaviors such as tobacco use, inadequate physical activity, alcohol and drug use, and sexual behavior
Population targeted	9th–12th grade students. States have the option of also surveying middle school students or those in juvenile justice facilities.
Demographic Data	Gender, age, grade in school
Years	Since 1991
Schedule	The national YRBS is conducted every 2 years.
Geographic estimates	National-level estimates only from the national survey
Contact information	http://www.cdc.gov/HealthyYouth/yrbs/

NA = not applicable.

APPENDIX C

Glossary, Abbreviations, and Acronyms

GLOSSARY OF TERMS

Adjuvant therapy: Treatment given after the primary treatment to increase the chances of a cure. Adjuvant therapy may include chemotherapy, radiation therapy, hormone therapy, or biological therapy.

Ambulatory care: The use of outpatient facilities—doctors' offices, home care, outpatient hospital clinics, and day-care facilities—to provide medical care without the need for hospitalization. Often refers to any care outside a hospital.

Axillary nodes: Lymph nodes in the armpit. In breast cancer, cancer cells usually spread to the axillary lymph nodes before the rest of the body.

Biopsy: Refers to a procedure that involves obtaining a tissue specimen for microscopic analysis to establish a precise diagnosis.

Breast-conserving surgery: Surgery to remove a breast cancer and a small amount of tissue around the cancer, but without removing the entire breast or surrounding tissues.

Cancer: A general term for more than 100 diseases that are characterized by uncontrolled, abnormal growth of cells. Cancer cells can spread locally or through the bloodstream and lymphatic system to other parts of the body.

Cancer registry: A system that monitors cancer cases that have been diagnosed or treated in one institution or a specific geographic area.

Chemotherapy: The treatment of disease by means of chemicals that have a

specific toxic effect upon the disease-producing microorganisms (antibiotics) or that selectively destroy cancerous tissue (anticancer therapy).

Claims data: Information on health care services provided that is generated from billing and reimbursement records.

Clinical outcome: The end result of a medical intervention (e.g., survival or improved health).

Clinical practice guidelines: Systematically defined statements to assist practitioner and patient decisions about appropriate health care for specific clinical circumstances.

Clinical trial: A formal study carried out according to a prospectively defined protocol that is intended to discover or verify the safety and effectiveness of procedures or interventions in humans. The term may refer to a controlled or uncontrolled trial.

Cohort study: An observational study in which outcomes in a group of patients that received an intervention are compared with outcomes in a similar group, that is, the cohort, either contemporary or historical, of patients that did not receive the intervention. In an adjusted- (or matched-) cohort study, investigators identify (or make statistical adjustments to provide) a cohort group that has characteristics (e.g., age, gender, disease severity) that are as similar as possible to the group that experienced the intervention.

Colonoscopy: An endoscopic (fiber optic) investigation of the large intestine (colon).

Comorbidity: A disease occurring in an individual in addition to the index disease being treated or studied.

Diagnosis: Definitive confirmation of a specific disease, usually by imaging procedures and from the use of laboratory findings.

Double-contrast barium enema: Procedure in which x-rays of the colon and rectum are taken after a liquid containing barium is put into the rectum. Barium is a silver-white metallic compound that outlines the colon and rectum on an x-ray and helps show abnormalities. Air is put into the rectum and colon to further enhance the x-ray.

Ductal carcinoma in situ (DCIS): A very early form of breast cancer confined to cells lining the breast ducts, as opposed to the glandular tissue of the breast.

Early detection: Identifying disease at an early stage, before it has grown large or spread to other sites.

Epidemiology: Science concerned with defining and explaining the interrelationships of factors that determine disease frequency and distribution.

External beam radiation therapy (EBRT): Radiation therapy that uses a machine to aim high-energy rays at the cancer.

Fecal occult blood test (FOBT): A test to check for blood in the stool.

Flexible sigmoidoscopy: Inspection of the lower colon using a thin, lighted tube called a sigmoidoscope.

Functional status: A measure of an individual's ability to perform normal activities of life. Encompasses a wide variety of patient-focused outcomes including physical functioning (e.g., walking and climbing stairs), emotional well-being (e.g., anxiety, fear of recurrence), and social functioning (e.g., isolation, ability to work).

Gleason score: Grade of tumor of the prostate; based on glandular differentiation

Histology: The study of the microscopic structure of tissue.

Hormonal therapy: Treatment that adds, blocks, or removes hormones. To slow or stop the growth of certain cancers (such as prostate and breast cancer), synthetic hormones or other drugs may be given to block the body's natural hormones. Sometimes surgery is needed to remove the gland that makes hormones. Also called hormone therapy, hormone treatment, or endocrine therapy.

Hormone receptor: Protein on the surface of a cell that binds to a specific hormone.

Hospice: A discrete site of care in the form of an inpatient hospital or nursing home unit or a free-standing facility; an organization or program that provides, arranges, and advises on a wide range of medical and supportive services for dying patients and their families and friends; an approach to care for dying patients based on clinical, social, and metaphysical or spiritual principles.

Incidence: The number of new cases of a disease that occur in the population per unit of time.

Lead-time bias: Overestimation of survival time because of the backward shift in the starting point for the measurement of survival as a result of early detection.

Length bias: The tendency of screening to detect slowly growing cancers more readily than aggressive cancers.

Mammogram: X-ray image of the breast produced for screening or diagnostic purposes in detecting or diagnosing cancer.

Margin: Border between a tumor and regular tissue.

Mastectomy: Excision of all or part of the breast.

Medicare: A program that provides health insurance to people aged 65 and over, those who have permanent kidney failure, and people with certain disabilities.

Metastasis: Spread of cancer from its original site to one or more additional body sites.

Morbidity: A diseased condition or state, the incidence of a disease or of all diseases in a population.

Mortality rate: Expresses the number of deaths in a unit of population within a prescribed time and may be expressed as crude death rates or as death rates specific for diseases and, sometimes, for age, sex, and other attributes.

Needle biopsy: Procedure in which a hollow needle is used to remove small cylinders of tissue from a suspected cancer.

Neoadjuvant therapy: Use of anticancer drugs before initial surgery or radiation treatment

Oversampling: A sampling procedure designed to give a demographic or geographic population a larger proportion of representation in the sample than the population's proportion of representation in the overall population.

Palliative care: Treatment of symptoms associated with the effects of cancer and its treatment.

Pathology report: Description of cells and tissues made by a pathologist based on microscopic evidence, and often used to make a diagnosis of a disease or determine prognosis.

Pharmacotherapy: Treatment or therapy using drugs.

Prevalence: The number of cases of disease, infected persons, or persons with some other attribute, present at a particular time and in relation to the size of the population from which drawn.

Primary cancer prevention: Prevention of the development of cancer.

Prostate-specific antigen (PSA) test: A blood test that measures the level of SA, a substance produced by the prostate and some other tissues in the body. Increased levels of PSA may be a sign of prostate cancer.

Quality measure: Quantitative indicators that reflect the degree to which care is consistent with the best available, evidence-based clinical standards.

Quality of care: The degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge.

Radical prostatectomy: The removal of the prostate and the surrounding tissue as a treatment for prostate cancer.

Randomized controlled trial: A true prospective experiment in which investigators randomly assign an eligible sample of patients to one or more treatment groups and a control group and follow patients' outcomes (also know as randomized clinical trial).

Recall bias: Bias created in survey data due to individuals' inaccurate or incomplete memory of an event.

Relative survival rate: A specific measurement of survival. For cancer, the rate is calculated by adjusting the survival rate to remove all causes of death except cancer. The rate is determined at specific time intervals, such as 2 years and 5 years after diagnosis. See also survival rate.

Response bias: Bias created in survey data when individuals do not respond truthfully (e.g., underestimate risky lifestyle behaviors such as smoking, or overestimate healthy behaviors such as exercise).

Sampling frame: List or other organized record of a population from which a survey sample is drawn.

Screening: Systematic testing of an asymptomatic population to determine the presence of a particular disease.

Staging: The determination of the anatomic extent of a cancer. Clinical stage is based on physical examination and tests done before surgery. Pathological stage is based on examination of surgical specimens.

Survival rate: The percentage of people in a study or treatment group who are alive for a given period of time after diagnosis. This is commonly expressed as 5-year survival. See also relative survival.

Tumor, node, metastasis (TNM): Standard nomenclature for the staging of tumors according to three basic components: the size of the primary tumor (T), involvement of regional lymph nodes (N), and metastasis (M). Numbers are used to denote size and degree of involvement; for example, 0 indicates undetectable and 1, 2, 3, and 4, a progressive increase in size or involvement.

Vital records: Legal records of events, such as birth, death, or marriage documents.

ACRONYMS AND ABBREVIATIONS

ACoS	American College of Surgeons
ACR	American College of Radiology
ACS	American Cancer Society
AHRQ	Agency for Healthcare Research and Quality
AJCC	American Joint Committee on Cancer
APS	American Pain Society
ASCO	American Society of Clinical Oncology
BCS	Breast-conserving surgery
BCSC	Breast Cancer Surveillance Consortium
BI-RADS	Breast Imaging and Reporting Data System
BMI	body mass index
BRFSS	Behavioral Risk Factor Surveillance System
CAHPS	Consumer Assessment of Health Plans
CAP	College of American Pathologists
CaPSURE	Cancer of the Prostate Strategic Urologic Research Endeavor
CDC	Centers for Disease Control and Prevention
CMS	Centers for Medicare and Medicaid Services
CoC	Commission on Cancer
DCIS	ductal carcinoma in situ
DHHS	Department of Health and Human Services
EBRT	external beam radiation therapy
ER	estrogen receptor
FACT	Functional Assessment of Cancer Therapy
FOBT	fecal occult blood test
GA-CORE	Georgia Center for Oncology Research and Education
GCC	Georgia Cancer Coalition
GCCR	Georgia Comprehensive Cancer Registry
Gy	gray (unit of absorbed radiation)
HEDIS	Health Plan Employer Data and Information Set
HP 2010	Healthy People 2010
ICSI	Institute for Clinical Systems Improvement
IOM	Institute of Medicine

JCAHO	Joint Commission on Accreditation of Healthcare Organizations
NAACCR	North American Association of Central Cancer Registries
NAS	National Academy of Sciences
NCCN	National Comprehensive Cancer Network
NCI	National Cancer Institute
NCPB	National Cancer Policy Board
NCQA	National Committee for Quality Assurance
NHQR	National Healthcare Quality Report
NIH	National Institutes of Health
NQF	National Quality Forum
NVSS	National Vital Statistics System
OMB	Office of Management and Budget
ONS	Oncology Nursing Society
PR	progesterone receptor
PSA	prostate-specific antigen test
SEER	Surveillance, Epidemiology, and End Results
TNM	Tumor, Node, Metastasis
USPSTF	U.S. Preventive Services Task Force
WHO	World Health Organization
YRBSS	Youth Risk Behavior Surveillance System