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Charting the New Oncology Landscape

by Donald Jewler & Cara Egan

The largest group ever to attend an ACCC-sponsored event gathered in Washington, D.C., for the Association's 23rd Annual National Meeting, held March 19-22, 1997. Close to 500 physicians, cancer program administrators, nurses, and medical directors heard dozens of expert presentations about the transformations taking place within health care and the far-reaching effects these changes will have on hospitals, oncology practices, and cancer patients. This new landscape features dramatic attempts to cut costs and threats to patient access to quality cancer care.

Concerns were voiced that HMOs are rewriting the medical standard of care without outcome studies. "The denial of hospitalization for women undergoing breast cancer surgery is a glaring example of arbitrarily rewriting the standards of medical care," said Connecticut surgeon Kristen Zarfos, M.D. She described a health care system in which market forces—not individual patient needs—shape health delivery. "In this system—in the name of cost savings—we have become a double agent. We are asked to serve two masters," said Zarfos, referring to the need to address the dictates of the HMOs and the needs of patients.

"Patients come to you as physicians, not as cost-containment agents," said Zarfos. "So, I will caution you that before you adopt a cost-saving measure, any cost-saving measure, weigh the dollar you save with potential losses it might bring either in...the well-being of your patient or in the loss of your own integrity as a physician."

Last year Zarfos faced two HMOs that refused hospitalization for women undergoing a mastectomy or lymph node removal for breast cancer. "From a medical standard of two to four days to recuperate and gain physical and emotional strength, women were faced with being sent home a few hours after losing a breast, groggy from anesthesia and in pain," she noted.

In May 1996 Zarfos sent a questionnaire to 225 of her patients, most of whom had had mastectomies, to find out their thoughts and concerns about the treatment delivered by their health maintenance organizations. "One hundred percent of the women who had undergone a mastectomy responded in outrage and anger about the pain, the concern about the drains, and their emotional and psychological needs being ignored by the HMOs."

Zarfos sought help from Rep. Rosa L. DeLauro (D-Conn.), a survivor of ovarian cancer. The result was the introduction of the Breast Cancer Patient Protection Act of 1997, which would require insurers to cover a minimum of 48 hours of hospitalization for mastectomies and 24 hours for lymph node excision. Zarfos was commended by President Clinton in his 1997 State of the Union address.

ASSURING QUALITY CARE

"Approximately one out of every seventh dollar in the U.S. economy is in health care; yet, our ability to identify the quality of what we are buying is still in a very rudimentary form," said presenter Daniel P. Perry, executive director of the Alliance for Aging Research in Washington, D.C.

Among the many groups working to encourage quality improvement and accountability within health care organizations is the Foundation for Accountability (FAcct), explained Perry, who serves as a representative of consumer interests on its board of trustees. FAcct members include public purchasers (such as the Health Care Financing Administration and the U.S. Department of Defense) private purchasers (such as AT&T, General Motors, and American Express), and consumer and patient groups (such as the AFL-CIO and the American Association of Retired Persons). The philosophy behind FAcct is that the health care system should be driven by the needs of the people it serves—consumers.

According to Perry, FAcct's role is to endorse measures that are consistent with what consumers and purchasers say they want to see as

Donald Jewler is ACCC publications director, and Cara Egan is assistant editor.

Speaking at ACCC's Governmental Affairs Forum was Mark Smith of Senator Connie Mack's (R-Fla.) office. Smith (standing before the microphone) spoke about the current financial health of Medicare as well as The Medicare Cancer Clinical Trial Coverage Act of 1996, which was introduced by Senator Mack and Senator Jay Rockefeller (D-W.V.). The bill would establish a demonstration project requiring Medicare coverage for patient care costs for people with cancer enrolled in approved clinical trials.

During the general session on major health care industry trends affecting cancer care in the 21st century, meeting participants engaged presenters in a spirited discussion about how to assure quality cancer care within a managed care environment.

Kristen Zarfos, M.D., voiced concerns that HMOs are changing the medical standard of care without outcome studies.

Dean Rosen from Senator Nancy L. Kassebaum-Baker's (R-Kans.-ret.) office addressed attendees at ACCC's award luncheon. Senator Kassebaum-Baker was honored with ACCC's Award for Outstanding Contributions to Cancer Care.

David Nexon (left) of Senator Edward M. Kennedy's office accepts an award from then-ACCC President John E. Feldmann, M.D. Senator Kennedy was honored with ACCC's Award for Outstanding Contributions to Cancer Care. He and Senator Kassebaum-Baker (R-Kans.) were recognized for their successful efforts to provide portability of insurance coverage and ban exclusions for preexisting conditions, including cancer.

PHOTOGRAPHS BY JAMES TWATCH

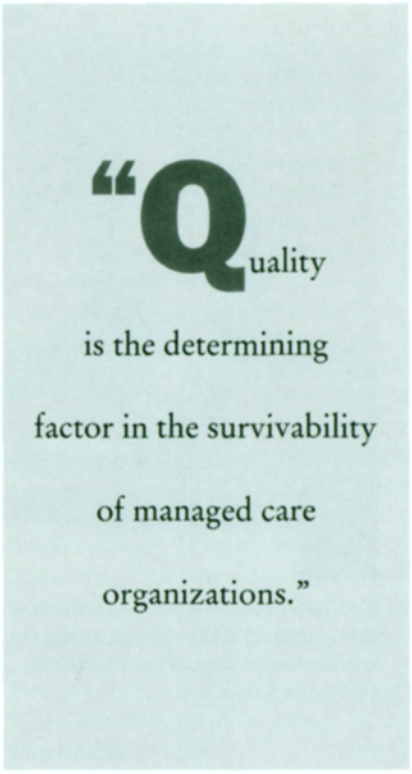
quality. It then advocates widespread adoption of these measures by large purchasers, including the government. FAcct extends and complements the National Committee for Quality Assurance's report card on managed care plans, the Health Plan Employer Data Information Set, better known as HEDIS. It does so by translating data to information useful to consumers, measuring quality in non-HMO plans and systems, and evaluating quality comprehensively across a number of diseases, including diabetes, asthma, and breast cancer.

FAcct's breast cancer measures attempt to provide consumers and purchasers information about the health systems' ability to screen and detect disease, deliver effective medical treatments, and help patients with physical and psychological difficulties that accompany the disease. According to FAcct, said Perry, a quality cancer program should be able to provide answers to the following questions.

- How many older women have regular mammograms to test for breast cancer?
- How many patients' breast cancers were detected early when the chances of recovery are greater?
- Do patients with less advanced breast cancer receive necessary information before deciding about surgery options?
- How many patients with less advanced cancer undergo conservative breast surgery instead of full breast removal, and did they receive the needed radiation treatment after surgery?
- How satisfied are patients with their communications with doctors and nurses, their involvement in treatment decisions, and the timeliness of getting test results?
- How satisfied are patients with being able to see specialists and getting support services?
- How many patients are treated successfully without a return of cancer after five years?
- How well do patients continue their routine activities and cope with cancer and its treatment one year after treatment?

The National Committee for Quality Assurance picked up some of FAcct's breast cancer measures in its HEDIS 3.1. The Health Care Financing Administration (HCFA) has a contract with the RAND, Corp., to implement FAcct measures in a set of Medicare markets.

How does HCFA see its role in quality performance measures? "Twofold," said Roy A. Harris, R.N., M.S.N., a member of the HCFA's Quality and Performance Standards Team, "to create standardized and reliable measurement systems and to collect plan-specific clinical performance data to enhance accountability." HCFA's focus is on data collection, noted Harris. Data-driven monitoring can yield plan-to-plan comparison and enhance the quality improvement process within plans. "This data will help plans improve themselves."



"We envision a future where Medicare and Medicaid beneficiaries are empowered through the information developed through purchaser groups," said Harris. "Beneficiaries need information to make choices about how health care is delivered, by whom, and in what setting."

According to Harris, HCFA plans to assist its beneficiaries in making informed health care choices by first providing them with basic HMO plan data on benefit packages, premiums, and copayments. Next, HCFA will incorporate member satisfaction information into a plan comparability chart, and then incorporate quality measurement data to enable rating of different plans.

Harris noted that enrollment of managed care has increased in the Medicare population. At the end of 1996, 12 percent of Medicare beneficiaries, almost 4.8 million people, were in HMOs. HCFA now contracts with 336 HMOs.

"HCFA sees an increased partnership with managed care plans and advocacy groups as well as an evolution from the role of regulator to purchaser. Although the reality is we will always be regulators, we will work hard to be cost-effective and quality-oriented purchasers."

The Quality Improvement System for Medicaid and Medicare Managed Care (QISMC) is a HCFA initiative to design, develop, and implement a unified quality oversight system for Medicaid and Medicare managed care plans. Its goal is to achieve a sensible, coordinated use of tools currently available in the public and private sectors, at the national and state levels, to achieve greater efficiency and effectiveness in Medicaid and Medicare managed care quality oversight. QISMC will build on HCFA's Quality Assurance Reform Initiative for Medicaid managed care and parallel activities undertaken for Medicare.

"Quality is the determining factor in the survivability of managed care organizations," said Harris. "Quality and value are of critical importance. We cannot afford to spend the kind of money we are spending without knowing it is buying the best, most appropriate, and most effective health care."

Also addressing the issue of how to improve the quality of managed care was Joseph S. Bailes, M.D., member of the Practicing Physicians Advisory Council of the National Committee for Quality Assurance (NCQA), which accredits its managed care plans through its report card standards, or HEDIS. Bailes is also chair of the Clinical Practice Committee of the American Society of Clinical Oncology (ASCO).

According to Bailes, ASCO submitted a number of comments and suggestions on the draft HEDIS 3.0 in September 1996.

- The draft requires reporting the number of female enrollees age 52-

69 with at least one mammogram in the past two years and the number of women age 21-64 with Pap smears in the past three years. Data on colorectal screening are also considered. Because of the controversy over timing of the start of tests, ASCO recommended disclosing coverage rules for each test and reporting the proportion of eligible enrollees who were screened.

- The draft includes tests of timely follow-up after abnormal Pap smears and mammograms: 60 days for mammograms, no specific time period for Pap smears. ASCO suggested collecting two data points: 1) the number of abnormal tests as a proportion of total tests to indicate whether abnormalities are being detected and 2) the average number of days between an abnormal screening result and the first visit to discuss results.
- The draft states that patient surveys should be required to assess breast cancer patients' experience with pain, quality of life, and physical functioning. ASCO supported this requirement but suggested its application to all cancer patients to obtain a larger sample size and a better picture of the quality of cancer care.
- The draft contains open-ended questions to patients about access problems. ASCO suggested adding specific examples to elicit information on access to second opinions, state-of-the-art diagnostic tests, specialists, and psychosocial, hospice, and other supportive care.
- The draft would require reporting the proportion of physicians who are board certified, but not by subspecialty. ASCO supported reporting by subspecialty to gauge a plan's ability to handle certain diseases. ASCO also recommended reporting the proportion of cancer patients treated by a certified oncology nurse or other certified oncology professional.

According to Bailes, additional measures proposed by ASCO to the draft HEDIS 3.0 document include reporting on 1) the timeliness of referral to a cancer specialist after an abnormal pathology report and the proportion of children referred to a pediatric specialist, 2) the proportion of patients who receive radiotherapy for whom simulators were used, 3) the proportion of cancer patients enrolled in clinical trials, and 4) the use of psychosocial services by cancer patients and the availability of supportive care services.

CONTROLLING COSTS, ASSURING QUALITY

"Outpatient mastectomy can mean better care for patients," argued William C. Dooley, M.D., director of the Johns Hopkins Breast Center within the Johns Hopkins Oncology Center in Baltimore, Md. "But not as it has been done in the past 100 years. We have to devise better ways." Since 1994 Johns Hopkins has performed mastectomies on a growing percentage of patients who choose treatment in the outpatient setting.

Outpatient mastectomies evolved from new management strategies for treating patients, including:

- merging the medical, radiation, and surgical oncology clinics, which allows patients to set multidisciplinary appointments with physicians on the same day. An integrated, multidisciplinary educational curriculum is also established for each patient.
- developing critical pathways that involve everyone who interacts with the patient from diagnosis through long-term follow-up across both inpatient and outpatient settings, including the patient and the patient's support team. Pathway variation is monitored, and each team member is held accountable for variation.
- monitoring clinical and satisfaction outcomes. A serious commitment is made to address patient concerns and respond directly to them. This practice has resulted in higher patient satisfaction and lower morbidity.

"Our duty is to educate patients and empower them to make their own decisions," Dooley said. "Once they have made their decision, everything we do must support that decision."

Standardization of treatment was key to providing mastectomy care in an outpatient setting, according to Dooley. Within five months of initiating the pathways, provider variability in the cost of mastectomy or lumpectomy was reduced from 300 percent to 5 percent. Changing the levels of anesthesia has reduced the occurrence of nausea and pain in patients after mastectomy from 85 percent to 3 percent. Within two hours of leaving the recovery room, most patients are able to walk, eat, and go to the bathroom. The majority of patients decide in the recovery room whether to remain in the hospital.

Not everyone was convinced that the Johns Hopkins program of outpatient mastectomy could be implemented at community cancer centers at locations away from that venerable institution.

"You've heard about Dr. Dooley's outpatient breast cancer surgery program at Johns Hopkins," responded Connecticut surgeon Kristen Zarfos, M.D. "Dr. Dooley has done a wonderful job putting the program together.

"Oh, that the rest of us out in the hinterlands had the resources of Johns Hopkins! But, we do not."

State-of-the-art therapy mandates standardization of care to control costs, stated William P. Peters, M.D., Ph.D., M.B.A., director and chief executive officer of the Barbara Anne Karmanos Cancer Institute in Detroit, Mich. The costs of bone marrow transplantation are staggering, with a typical transplant costing more than $100,000. Peters cited national estimates of 20,000 to 25,000 breast cancer patients who are potential candidates for the procedure. Third-party payers are balking at assuming these costs. "If reimbursement of high-dose therapy is a problem for payers because of cost, we must decrease the cost to eliminate the issue of coverage," Peters said.

By standardizing the way high-dose therapy is administered to patients, the Karmanos Cancer Institute has reduced the number of inpatient hospital days for a bone marrow transplant from thirty-seven to five days. Charges have dropped from $140,000 per BMT in 1990 to about $55,000 today. Using the current outpatient model, the patient is admitted to the hospital for high-dose chemotherapy only.

The rapid decline in toxicity, morbidity, and mortality levels associated with transplant within the past several years has contributed to the Karmanos Cancer Institute's ability to treat patients in the outpatient setting. Karmanos has also instituted a prophylactic

treatment regimen of ciprofloxin and rifampin for all patients undergoing transplant to ward off infection. As a result of this treatment, 40 percent of transplant patients are reporting having no fever at any time during their treatment.

The economics of outpatient bone marrow transplant are powerful, but must not overshadow concern for the patient, Peters said. However, as the costs of bone marrow transplants come down, physicians and patients will benefit from its more widespread availability.

HEREDITARY RISK ASSESSMENT

Among the trends discussed at this year's meeting was the advent of hereditary risk analysis and genetic testing at community cancer centers, which will both have long-reaching effects on the delivery of health care.

"There is a need in the community to describe an individual's hereditary risk, ultimately empowering people in their pursuit of health-promoting activities and participation in cancer screening guidelines," said Tonyce Williams, M.N., director of oncology services development at Hoag Cancer Center in Newport Beach, Calif. She discussed goals, components, and models for risk assessment programs, highlighting the Hoag Cancer Center's experience over the past six years.

According to Williams, an effective hereditary risk assessment program is an information-sharing service. Its goals are to identify and educate high-risk individuals and recommend increased screening surveillance aimed at early detection. Among the questions that planners at community hospitals must address when developing such a program are:

- Will the program consider all types of cancer, or be site specific, i.e., breast cancer?
- Will the program be independent or in collaboration with another group?
- Will the program involve only risk counseling or also include genetic testing?
- What program model or resources will be used for risk counseling and genetic testing?

Special Interest Group (SIG) Round-Up

Administrator SIG. Four sessions were offered.

- "Disease Management." Kent Giles, M.P.P.M., presented his views on disease management, a more patient-focused alternative to managed care that seeks to treat patients based on the best available clinical pathways and reduces costs through prevention, early detection, and more efficient use of resources.
- "Genetic Risk Management Programs in the Community Setting." Tonyce Williams, M.N., O.C.N., director of oncology services development at the Hoag Cancer Center in Newport Beach, Calif., presented the challenges of establishing community genetic risk programs. (See accompanying article for more information.)
- "Community-Based Oncology Pain Management Programs." June Dahl, Ph.D., professor of pharmacology at the University of Wisconsin Medical School in Madison, Wisc., discussed the importance of building an institutional commitment to pain management.
- "Complementary Therapies: How to Manage Them." Barrie R. Cassileth, Ph.D., adjunct professor of medicine at the University of North Carolina in Chapel Hill, N.C., enlightened attendees about the plethora of alternative cancer therapies, from shark cartilage to Chinese herbs to colonic therapy. She was careful to distinguish between alternative medicine, which purports to cure cancer without chemotherapy and surgery, and complementary therapies, which are in addition to standard treatments and include meditation, massage, selected teas, counseling, and acupuncture for pain and symptom control.

Nursing SIG. "Maintaining the Balance: Oncology Staffing Across Multiple Settings of Care" was presented by Barbara R. Medvec, R.N., M.S.A., M.S.N., O.C.N. She examined methods for evaluating workload, acuity, and skill mix requirements in oncology.

Medical Director SIG. This session, which was combined with Saturday's general session, featured representatives from national and regional alliances of both hospital and physician group practices. Pat Stanfill, R.N., M.S., M.B.A., president of Columbia/HCA Cancer Centers, Nashville, Tenn.; Richard Larison, president, M.D. Anderson Network, Fort Worth, Tex.; and Ronald Conheim, regional vice president of development, Phymatrix Corporation, Baltimore, Md., discussed strategies for improving cancer services across hospital systems.

Radiation Oncology SIG. Walter J. Curran, Jr., M.D., professor and chairman of the Department of Radiation Oncology at Thomas Jefferson University in Philadelphia, Pa., discussed opportunities and threats facing clinical research.

Community Research/CCOP SIG. Leslie Ford, M.D., associate director of the Division of Cancer Prevention and Control at the National Cancer Institute (NCI) presented an update of the CCOP program. Robert E. Wittes, M.D., director of the Division of Cancer Treatment, Diagnosis, and Centers at NCI offered an overview on the future of CCOPs.

SIGN UP NOW!

The Association of Community Cancer Centers currently recognizes five special interest groups (SIGs): Administrator, Community Research/CCOP, Medical

- How will referrals be obtained? Via physicians or self-selection?
- Where will the program be located? The environment should promote a sense of trust and safety.
- Who will operate the program? Will staff include a nurse, physician, health educator, and/or genetic counselor? The answer depends on the kind of program that is being developed.
- What is the budget for the program? Are there innovative ways to obtain funding, such as an endowment?
- What types of information will be tracked?
- How will quality assurance and evaluation be handled?
- How will confidentiality be assured?

Williams noted that the benefits of genetic testing include the identification of a mutation and further defining of an individual's cancer risk. She also noted the limitations of genetic testing in 1997, including the potential for discrimination and the possibility that test results may provide no clear answer to a participant's concerns.

OF ALLIANCES AND NETWORKS

As hospitals continue to merge, form alliances, and join regional networks, administrators are increasingly assuming responsibility for cancer programs that encompass multiple sites.

"The challenges of directing a cancer program with multiple settings can be formidable—long-established referral patterns and territorialism threaten to undermine the best efforts of any administrator," according to presenter Marija Bjegovich, M.S.N., director of cancer services, St. Luke's Medical Center in Milwaukee, Wisc. However, with careful planning and communication at all levels, administrators can lead multi-institutional cancer programs to greater efficiency and improved cost savings, according to Bjegovich.

Reduced duplication of services and decreased costs are perhaps the most tangible benefits of multi-institutional programs, stated Nancy A. Haas, R.N., B.S.N., O.C.N., corporate director for the Meridia Cancer Institute in Mayfield Village, Ohio. The Meridia Cancer Institute is the center of cancer activity for four hospitals within the Meridia system. Previously, for example, each hospital had printed its own annual report. The unnecessary duplication, along with the lack of uniformity, convinced Haas to combine the documents into one polished annual report. As a result, printing costs dropped from about $5,000 per hospital to about $6,000 for the entire system.

The administrator of a multi-institutional cancer program must have the flexibility to cope with the unexpected, stated Diane M. Otte, R.N., M.S., O.C.N., operations director, oncology services for Alegent Health in Omaha, Nebr. "Don't assume that the hospital leaders who brokered these alliances from the beginning planned the details of how oncology services would be provided across the system—they probably didn't." As a result, she said, the administrator is often confronted with unforeseen barriers that require creative strategies to overcome. Otte recommends keeping a positive attitude through constant networking with colleagues and professional development.

The changing health care landscape requires inventive strategies of everyone involved in oncology care. The challenge, according to William Dooley, M.D., is to view today's demands as an invitation to develop unique solutions. "As Hannibal said in 900 B.C. as he crossed the Alps, 'We will find a way or we will make one.'"

Director, Nursing, and Radiation Oncology. The SIGs provide a forum for members to discuss ongoing ACCC activities, including the annual meetings, *Oncology Issues*, strategic planning, and other critical issues. Increased SIG participation by the membership will continue to strengthen the Association's ability to be a national leader on issues of importance to all cancer care disciplines. For a SIG membership form or more information, please contact Kathleen Young, ACCC SIG Membership, 301-984-9496.

Mark your calendars. ACCC's 14th Oncology Economics Conference will be held in San Diego, Calif., at the Hyatt Regency on September 17-20, 1997. Please join us.

ACCC's new Strategic Plan was approved by the Board of Trustees on March 19, 1997.

VISION

ACCC is the leading national interdisciplinary organization that defines quality care for cancer patients and influences change to continually improve oncology care.

MISSION

ACCC is the national interdisciplinary organization that promotes the entire continuum of quality cancer care for our patients and our communities. ACCC will fulfill our mission by pursuing the following six strategies:

Policy Development and Promotion

- Proactively provide leadership for the development and enactment of policies and legislation to define support for patient care costs in clinical trials.
- Continue to coordinate the introduction of patient advocacy legislation to ensure timely patient access to off-label drugs and to support other issues of importance to cancer patients.
- Monitor legislation and regulations, and promote policies affecting timely patient access to cancer care and clinical trials (e.g., barriers to access, ambulatory patient groups [APGs]). Develop and present position statements as appropriate.
- Support the ongoing activities of regional/state oncology-related societies whose interests and issues are analogous with those of ACCC.
- Continue to develop appropriate liaison and joint planning activities with other oncology-related organizations, including patient advocacy groups.

Patient Advocacy

- Proactively provide leadership for the development and enactment of policies and legislation to define support for patient care costs in clinical trials.
- Continue to coordinate the introduction of patient advocacy legislation to ensure timely patient access to off-label drugs and to support other issues of importance to cancer patients.
- Monitor legislation and regulations, and promote policies affecting timely patient access to cancer care and clinical trials (e.g., barriers to access, ambulatory patient groups [APGs]). Develop and present position statements as appropriate.
- Communicate with the payer community on quality cancer care issues.
- Develop and distribute interdisciplinary guidelines for cancer patient management.
- Continue to provide communications and educational materials on Association policies and activities.
- Continue to develop appropriate liaison and joint planning activities with other oncology-related organizations, including patient advocacy groups.
- Promote timely patient access to appropriate cancer specialty care.

Research in the Community

- Encourage support for community research. Monitor activities of the National Cancer Institute, pharmaceutical/biotech companies, and other agencies with regard to policy for community research activities (e.g., CCOP, NCI budget). Develop and present position statements as appropriate.
- Continue surveillance for barriers to community research placed by third-party carriers; when encountered, implement national and local strategies to remove them.
- Encourage the continuing growth and development of the Collaborative Research Group.
- Assist members in promoting clinical trials.

Oncology Program Management

- Continue to review and update the ACCC *Standards for Cancer Programs*, revise appropriately, and provide this information to members and cancer programs as requested.
- Provide information on new technologies and the ethical, quality, and economic implications.
- Provide education about approaches for the effective management, delivery, and financing of comprehensive cancer care.

Membership Support

- Provide education about approaches for the effective management, delivery, and financing of comprehensive cancer care.
- Provide education and networking opportunities, encourage the development and growth of qualified members, and promote communications between ACCC leadership and membership.
- Support the activities of ACCC Committees and Special Interest Groups (SIGs).
- Support the ongoing activities of regional/state oncology-related societies whose interests and issues are analogous with those of ACCC.
- Continue to provide communications and educational materials on Association policies and activities.
- Promote utilization of the Resource Network for the ACCC membership.
- Encourage the continuing growth and development of the Collaborative Research Group.
- Assist members in promoting clinical trials.

Economic Quality Issues

- Develop and distribute interdisciplinary guidelines for cancer patient management.
- Investigate and disseminate information on models for cost-effective oncology program packaging that promote quality cancer care, competitive pricing, and appropriate outcomes.
- Provide information on new technologies and the ethical, quality, and economic implications.
- Evaluate and advise agencies that are developing quality measurement instruments for cancer care.