

National Breast Cancer Coalition Fund
Breast Cancer Quality Care Summit
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Charting a Course Toward Quality Breast Cancer Care

Framing and Answering the Most Fundamental Questions

After a century of progress in health care, a quarter century of unprecedented progress in breast cancer research, and a lengthy national discussion of health care reform, America still cannot answer one fundamental question: What is quality breast cancer care?

Meanwhile, the growth of managed care has raised important questions about how quality health care in general is described. The National Breast Cancer Coalition Fund (NBCCF) has been among the leaders in pursuing answers in these arenas for breast cancer.

NBCCF believes that a necessary step in achieving quality care for women with breast cancer is determining the components that make up “quality.” To initiate this process, NBCCF convened a Breast Cancer Quality Care Summit in January 1999, in Phoenix, Arizona. We brought together nearly 50 participants, including patient advocates, managed care and insurance representatives, government officials, policymakers and members of the scientific and medical communities. Participants shared their ideas in an interactive forum that included small working groups and larger group discussions.

The Summit identified several key questions that must be answered in order to guide the development of sound public policy, and also suggested a number of ways in which the nation can begin obtaining answers. Following is a distillation of these ideas. By

building on these suggestions at a time when Congress is moving forward on health care legislation, NBCCF intends to:

- Advance public policies that move the country toward an evidence-based health care system that delivers quality breast cancer care to all women
- Develop tools that will enable women to assess the quality of breast cancer care they are receiving

What Would Quality Breast Cancer Care Look Like?

At present NBCCF simply cannot develop a clear and complete vision of quality breast cancer care. Too many questions must first be answered.

We can sketch portions of the picture: nationally uniform breast cancer insurance coverage, universal access to the best care available, timely and integrated care provided by a coordinated multidisciplinary team, systemwide accountability, patient-responsive care that respects women's preferences for information and involvement in determining the course of treatment, a systemwide emphasis on quality of life issues, etc.

But these ideals – and many more – are of limited use if the care at the heart of the system is not quality care. Much remains unknown about what care is currently being delivered for breast cancer, let alone how well that care is being delivered, how well it is working, or what care *should* be delivered.

A key component of this discussion is evidence. There are many types of evidence that are used for very different purposes. For example, a clinical trial may test the efficacy of a particular breast cancer treatment, a survey may explore the experience of individual breast cancer patients, and a national databank may collect survival rates of a specific patient population. Thus, the first challenge is to define “evidence” and to determine what types of evidence are necessary for various types of breast cancer care decision making.

One important type of evidence in determining the quality of care is the evidence used by patients when choosing their care and treatments, and by clinicians when recommending specific care and treatments. Yet there is no consensus on what constitutes sufficient “evidence” in this context. At this point, NBCCF would like to:

- Develop a description of quality breast cancer care that is based on existing evidence (and other components of quality),
- Identify areas where adequate evidence does not exist,
- Develop strategies to ensure that the evidence that is needed is obtained.

We also need a system for evaluating existing evidence. There is insufficient and inconsistent consensus among clinicians and other stakeholders on how to evaluate the strength of evidence. We do not understand how evidence is currently used by decision-makers, or what types or strength of evidence patients, providers, payers and policymakers are using to make breast cancer care decisions.

Thus, we cannot yet recommend changes in the types of evidence that *should* be used to make breast cancer care decisions. At the core of the problem is a serious lack of crucial information. We need:

- 1) More data collection and valid systems for analyzing the data to measure quality
- 2) More information about our current models of breast cancer care, in order to design better models of care

With both 1 and 2, we can move to a consensus understanding of what evidence supports quality care. The following recommendations start addressing each of these needs.

1) Better Measures and Data Systems

Obtaining more information requires more research, and America needs better information focusing on the quality of today’s breast cancer care. The nation needs a means of capturing and collecting more and better information about the care being delivered.

In short, our country must create an information infrastructure that collects the data needed to produce quality of care measures across the spectrum of care. On the national and state levels, we must establish uniform, systematic collection and aggregation of clinical, demographic and insurance data about breast cancer patients and their care. These data must be made available for public use with appropriate patient protections.

How to Move Toward Better Measures and Data Systems

In February 1999, the National Cancer Institute's Surveillance Implementation Group released a "Cancer Surveillance Research Implementation Plan" that provides an excellent starting point for moving the nation toward more effective data systems and measures for cancer care. NBCCF's vision is compatible but somewhat broader. Specifically, we recommend the following action plan:

- Key federal agencies and national organizations that already collect cancer care information must assess and improve the compatibility and connectivity of their information systems and the sharing of their data. Among these players are the Health Care Financing Administration, the Agency for Health Care Policy and Research, the Centers for Disease Control and Prevention, the National Cancer Institute, the National Committee for Quality Assurance and the North American Association of Central Cancer Registries.
- Federal and state agencies and organizations must work together to move from our existing cancer registry network to a thoroughly transparent and universal "cancer information system," which includes a cancer registry in every state. All players must agree on which core data must be collected. Everyone must define, collect and process those data in the same format, using compatible platforms so that comparisons will be seamless and systems will be easily linked.

- A standard minimum data set must be created. Key leaders of the effort must identify supplemental data elements and decide what must be done to build on the findings.

2) Better Models of Care

In addition to improving the nation's data systems, America needs to acquire more information about today's models of breast cancer care. Specifically, we must learn which models are now delivering the highest quality care, based on our best current abilities to assess quality.

America must develop, at the national level, one core set of quality care indicators, using a set of clearly defined data elements that are uniformly collected. These indicators must cover all aspects of breast cancer care, from screening and early detection through diagnosis, treatment and end-of-life care. They must expand process measures (i.e., how care is being delivered) to include patient-responsiveness and patient involvement in determining the course of treatment, and go beyond process to address questions of how well that care is being delivered, how well that care is working (outcomes), and what care *should* be delivered, based on the highest levels of evidence and including considerations for patients' quality of life. Finally, these indicators must be validated.

The purpose of such quality care indicators would not be to create "cookie-cutter" medicine, but rather to provide consistent and accurate information to everyone involved in the health care system. It would be a tool—a set of criteria to apply—for purchasers of health care to compare plans, for patients and physicians to ensure informed decision-making, and for the federal and state governments to assess the quality of care being delivered.

Innovation is an important part of our health care system, and any national standard must encourage creative approaches to health care and reflect current scientific knowledge and data.

To make this system work, every health provider, health care organization and insurer must be held accountable for reporting these national quality indicators on an ongoing basis. Indeed, every health system should ensure accountability.

Lastly, NBCCF believes access is a vital component of any quality care system. Consequently, public policy should be designed to facilitate, not impede, access to care at the highest levels of evidence.

How to Move Toward Better Models of Care

Any approach to improving America's models of cancer care must balance the need for evidence-based standardization with the need for flexibility. One way to incorporate both concerns while assessing quality in today's models of care would be as follows.

At the national level, key stakeholders, including advocates, must work together to evaluate current standards for quality care. NBCCF recommends issuing a national request for proposals to develop new standards, establish criteria to assess successful models of care against these standards, and identify barriers to implementing high-quality systems of care and develop strategies to overcome these barriers. Key aspects of care to be studied would include prevention; access to care; patient involvement/patient responsiveness; the role of patient advocacy; patient/doctor communication; cooperation among physicians and other caregivers; care navigators; psychosocial support; treatment outcomes; quality of life; and organizational, financial or other features of care that facilitate disseminating and implementing standards for state of the art, evidence-based treatment.

Based on the results, local stakeholders would build on what is working in their systems, identify what is not working, and develop new local approaches to improving the quality of care. Applying the nationally established evaluation criteria to their local models, they

would report back to the national stakeholders and refine their models of care on an ongoing basis.

Action Now and for the Future

Obtaining the answers America needs to develop an evidence-based system that delivers quality breast cancer care to all women will clearly take time. For certain questions there may never be consensus on a single best answer.

But today's breast cancer patients and their families cannot wait until all the answers are known. They need to make choices between systems, institutions, providers and treatments right now.

While policymakers must proceed with urgency, the crucial starting point is to carefully define the core questions and terms that will guide the nation's search for answers. In doing so, policymakers must focus both on the questions that must be answered to meet current needs, and on those that must be answered to build the ideal breast cancer care system of the future. By the same token, any policies that are enacted must be sufficiently elastic to respond to future changes in health care delivery and levels of evidence, but firm enough to mandate quality care now.