
BREAST CANCER ACTION PLAN FOR KENTUCKY - PHASE II

Report to Governor Paul E. Patton
by the
Kentucky Breast Cancer Task Force



June 30, 2000



**Governor's Mansion
Frankfort, Kentucky 40601**

Message from the First Lady

The Kentucky Breast Cancer Task Force, established by Governor Paul E. Patton in July, 1998, has just completed its second and final year. The Phase I Action Plan, issued in July, 1999, asked, what needs to be done to decrease the burden of breast cancer borne by Kentucky women? This report, the second by the Task Force, answers the follow-up question of how do we do it? Taken together, the two reports represent the Kentucky Breast Cancer Action Plan.

The Task Force of 60 members effectively represented the concerns of individual women and of organizations about this disease, as well as their collective experience and knowledge. We had the benefit of broad geographic and professional representation, and the counsel of breast cancer survivors. In addition, several consultants provided their special expertise to the Task Force. I am grateful to all of them for their commitment to this effort.

I am especially pleased to acknowledge the work of Dr. Gilbert H. Friedell, the Executive Director of the Task Force, and that of Dr. Linda H. Linville and Ms. Connie L. Sorrell, of the Kentucky Cancer Program, Co-Directors of the Task Force.

It is my hope that we can now move to implement successfully the actions proposed in the Plan. To do so we will need the best efforts of all of the individuals and organizations on the Task Force, plus many others. I am optimistic that this support will be forthcoming from the public and health care professionals in the Commonwealth, and that in the coming months and years we can together succeed in reducing the burden of breast cancer borne by the women of Kentucky.

A handwritten signature in cursive script that reads "Judi Patton".

Judi Patton

Chair, Governor's Task Force on Breast Cancer

Dedication



*This report is dedicated
to the memory of*

*Senator Paul Mason
and
Hank Bell, Jr., M.D.*

*Members of the
Breast Cancer Task Force*



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Foreword



The Phase I Action Plan of the Kentucky Breast Cancer Task Force was presented to Governor Paul E. Patton in July, 1999. It dealt with a broad range of issues related to the incidence, morbidity, and mortality of breast cancer in Kentucky. The Task Force was especially concerned that all breast cancer patients in Kentucky receive optimal care throughout the entire spectrum of the disease, including the services of a multi-disciplinary care team, the availability of second opinions, and the help of a “patient navigator” to assist women in accessing the services which are necessary for optimal care.

In that plan a second issue of major concern, and one clearly related to the accessibility of appropriate patient care, was the need for all Kentucky women to have health insurance coverage for breast cancer treatment, as well as for screening and diagnosis. A third issue of particular concern was the need for coordination across the state of programs for public education about breast cancer. The Task Force felt strongly that the same basic information about the disease and its treatment should be presented to the public by all organizations involved in providing such information. In addition, the Task Force addressed issues related to legislation, research and additional data needs. All told 18 recommendations were made at the end of Phase I about what needs to be done.

This Phase II Action Plan is concerned with how to carry out the recommendations in the first report. This Report focuses on five major subjects: standards of care in breast cancer screening, diagnosis, treatment, continuity of care, pain control, and psychosocial support; insurance coverage; the development of new approaches to public and professional education; legislation and research. In addition, conducting a feasibility study for a screening mammography registry and providing appropriate educational material for newly diagnosed cancer patients has a high priority.

Above all, the clear message in the Plan is that making progress in the fight against breast cancer will require expanded and enhanced local and regional partnerships among the many individuals and organizations concerned with this disease. As requested by the Task Force, the Kentucky Cancer Program will take a lead role in coordinating and facilitating the implementation of Task Force recommendations and in fostering these partnerships. It is hoped that members of the Task Force will continue to participate in implementing the recommendations they developed during the past two years.

In addition, the Task Force Chair, Judi Patton, has agreed to serve as Chair of an Implementation Advisory Committee. Her leadership has been an essential ingredient in the success of the Task Force and her continued interest bodes well for breast cancer control activities in the coming months and years.

A handwritten signature in black ink that reads "G. H. Friedell".

Gilbert H. Friedell, M.D.
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Introduction



In February, 1998, Governor Paul E. Patton issued an Executive Order establishing the Kentucky Breast Cancer Task Force (KBCTF) with instructions to begin July 1, 1998 to assess and make recommendations to him regarding the:

- Availability, accessibility, quality, utilization, and outcome of public and private breast cancer screening and treatment services, including continuity of care and rehabilitation.
- Adequacy of health insurance coverage with regard to breast cancer related issues.
- Services needed and received by uninsured and under-served women with breast cancer.
- Availability and allocation of state and federal dollars for breast cancer and areas of need.
- Effectiveness and adequacy of educational/outreach programs throughout the state, including an inventory of such programs and the materials and approaches used.
- Availability and utilization of data from private and public sources on breast cancer screening, diagnoses, treatment, and outcomes.

The Governor appointed Judi Patton, First Lady of the Commonwealth, to chair the KBCTF and Dr. Gilbert H. Friedell, Director Emeritus of the Markey Cancer Center, to serve as Executive Director. At the Governor's request, the Kentucky Cancer Program (KCP), represented by Dr. Linda Linville at the University of Kentucky (UK) and Connie Sorrell at the University of Louisville (UL), assumed responsibility for KBCTF coordination and management.

Although the KBCTF initially believed it could respond to the governor's request in one year, it became apparent at the end of the year that more time would be needed to complete the task. Indeed, it was recognized that the work of the Task Force would be conducted in two phases. Phase I would deal with what needs to be done, and Phase II would consider how to do it.

The work of the KBCTF has been accomplished through the active participation of its members, including radiologists, medical oncologists, radiation therapists, surgeons, and other practicing physicians; nurses; breast cancer survivors; local/county public health officials; medical social workers; and representatives of the Kentucky Department for Public Health (KDPH), the American Cancer Society (ACS), KCP, the Kentucky African Americans Against Cancer (KAAAC), the Kentucky Breast Cancer Advisory Committee, the Kentucky Breast Cancer Coalition (KBCC), the Kentucky Medical Association (KMA), local breast cancer coalitions, and the health insurance community.

The Phase I Action Plan, published in June 30, 1999, after a year of activity, presented a profile of breast cancer in Kentucky, with sections focused on prevention,



detection, treatment, and quality of life. The KBCTF reviewed this material, then made 18 recommendations about what needs to be done. Some of them stressed the need for collecting additional data. Others spoke to the need for improving the availability, accessibility and utilization of breast cancer-related services, the necessity of providing quality services, and the need to monitor effectively the outcomes of the interventions.¹

These recommendations were addressed by the KBCTF in developing the Phase II Action Plan. Work was conducted through numerous meetings and conference calls with staff, consultants, and KBCTF members including First Lady Judi Patton.

Workgroups focused particularly on:

- Standards of Care (including Professional Education)
- Insurance Coverage and Cost of Care
- Public Education and Outreach
- Legislation
- Research
- Data Issues

This Phase II Action Plan is presented in sections containing a brief discussion and a grid in which columns refer to desired outcomes, actions to be taken, designated partners, responsible organizations, monitoring entities, and specific references to the recommendations in the Phase I Action Plan. Rows indicate specific issues which working group members felt to be of importance. As implementation progresses, it will be essential to evaluate both process and outcomes in order to assure that strategies provide appropriate solutions to the identified issues.

The adoption of this Phase II Action Plan concludes the formal activities of the KBCTF. Much remains to be done before optimal breast cancer care will be available for all women in Kentucky, but a path for progress has been clearly marked. It will be up to the organizations and individuals who have participated on the KBCTF, and to others concerned with reducing the incidence, morbidity, and mortality of breast cancer in Kentucky, to support both the implementation of the recommendations in the Phase I and II Plans and the evaluation of the outcomes.

To facilitate and coordinate these efforts the KBCTF recommends that this responsibility be vested in the KCP and the KMA, working with the Brown Cancer Center at UL and the Markey Cancer Center at UK. The KBCTF also recommends that an advisory committee be formed, chaired by First Lady Judi Patton, to provide advice and support in these ongoing efforts.

¹Kentucky Breast Cancer Task Force, *Kentucky Breast Cancer Action Plan, Phase I*. Lexington, KY: Kentucky Cancer Program, University of Kentucky. 1999.

Guide to Partners



ACLU	American Civil Liberties Union
ACoS	American College of Surgeons
ACS	American Cancer Society
CIS	Cancer Information Service
EPEC	Educating Physicians about End of Life Care
FEHBP	Federal Employee Health Benefit Plan
FDA	Food & Drug Administration
HCFA	Health Care Financing Association
HEDIS	Health Plan Employer Data and Information Set
JCAHO	Joint Commission on Accreditation of Health Organizations
KAHP	Kentucky Association of Health Plans
KBCC	Kentucky Breast Cancer Coalition
KCP	Kentucky Cancer Program
KCPI	Kentucky Cancer Pain Initiative
KCR	Kentucky Cancer Registry
KCW	Kentucky Commission on Women
KDPH	Kentucky Department for Public Health
KHA	Kentucky Hospice Association
KHA	Kentucky Hospital Association
KMA	Kentucky Medical Association
KMIC	Kentucky Medical Insurance Company
KNA	Kentucky Nurses Association
NCCN	National Comprehensive Cancer Network
NCRA	National Cancer Registration Association
NAACCR	North American Association of Central Cancer Registries
NCI	National Cancer Institute
TRIAD	Cooperative Collaboration between ACS, ACoS and NCRA
TRICARE	Federal Employee/Military Insurance

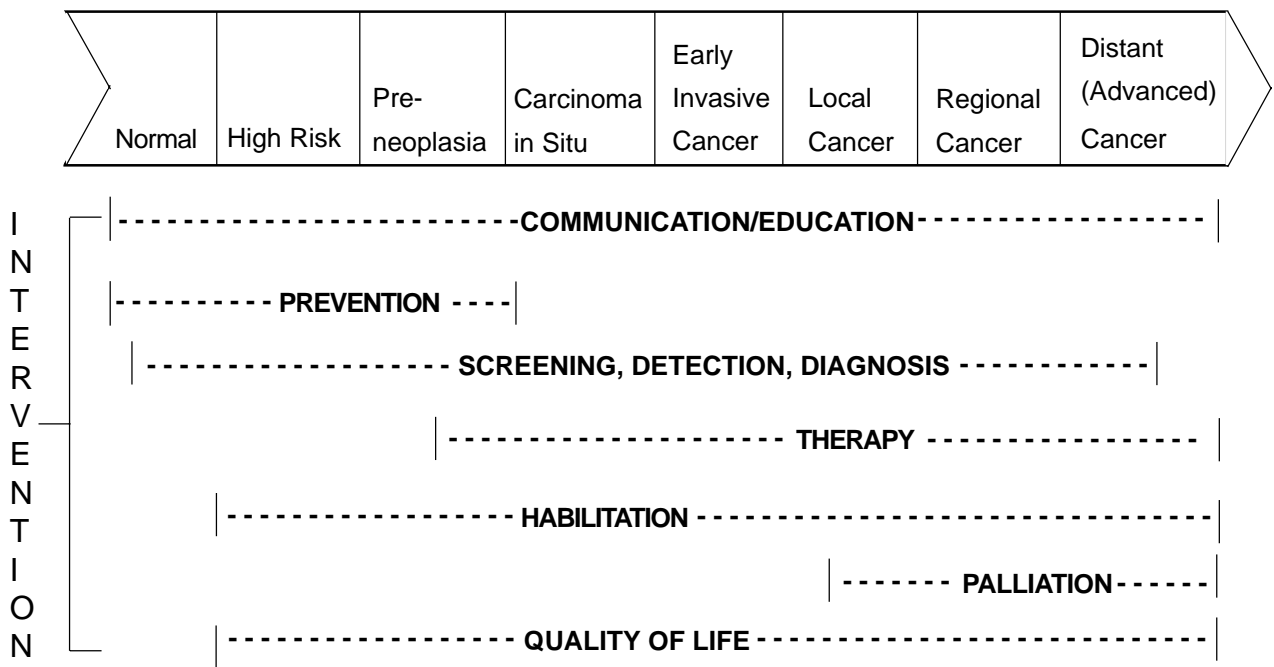


Standards of Care

One of the most important recommendations of the Phase I Action Plan was to promote universal adherence to professionally-accepted standards of care for breast cancer early detection, diagnosis, treatment, and rehabilitation.¹ Consideration of this issue was one of the most challenging activities in developing the Phase II Action Plan.

The report of the Standards of Care workgroup underscored the necessity of having high quality breast cancer care available for all Kentucky women across the spectrum of this disease (Figure 1). In addition to specific breast cancer treatment, the workgroup was concerned about psychosocial support and adequate pain control in all stages of the disease. Working issues are summarized in Table 1 at the end of this section.

Figure 1. Relationship of Breast Cancer Interventions to the Course of Disease



Screening Mammography

Based on incidence data from the Kentucky Cancer Registry (KCR), as well as published consensus guidelines from ACS and the National Cancer Institute (NCI), the KBCTF recommends beginning annual mammography screening at age 40, although 75% of all cases occur in women over the age of 50 years, and 50% of all cancers occur in women over age 65. For those women with significant family histories of breast cancer, earlier onset of screening should be discussed with their physicians. Women of any age, with symptoms, should promptly seek medical advice.



Treatment

The workgroup, after careful consideration, decided to recommend adoption of the excellent and already available basic or Category I Guidelines for breast cancer treatment, promulgated by the NCCN². These practice guidelines were developed by a large group of national health care professionals with particular expertise in dealing with the treatment of breast cancer in all stages. In addition to treatment guidelines, NCCN has also established guidelines for pain management and psychosocial support protocols, covering all phases of the disease continuum. Joint Commission future mandates will include standards for pain control. The KBCTF Standards of Care workgroup and the KBCTF has endorsed the adoption of these guidelines as well.

Second Opinions

The KBCTF has emphasized that second opinions should be available to all patients, and covered by health insurance, concerning the interpretation of mammograms and pathologic material, and when definitive treatment decisions are being considered. At this time coverage is available only under some policies.

Multidisciplinary Care

The KBCTF agrees with the NCCN emphasis on multidisciplinary approaches to patient management decisions, with the management team varying in membership depending on the issue under consideration. For example, the KBCTF recommends that when primary treatment decisions are being considered, the optimal multidisciplinary team participants should be a surgeon, radiation therapist, medical oncologist, and the primary care physician as well as an oncology nurse and, if at all possible, psychosocial and spiritual counselors. At other points along the spectrum of disease, the NCCN guidelines indicate which health care professionals should be involved for multidisciplinary case management. At a minimum, the team should include a surgeon and a medical or radiation oncologist when the definitive treatment plan is being decided.

Professional Education

Professional Education is essential for the effective implementation of the NCCN Practice Guidelines. It is necessary for KMA, the Kentucky Nurses Association (KNA) and other health professional organizations to encourage and facilitate the development and utilization of continuing medical education (CME) programs in this regard. It is incumbent on health professional schools to integrate the concept of multidisciplinary care and the use of NCCN guidelines in their educational programs regarding breast cancer patient care and to monitor practice during training. Other cancer control partners should participate in continuing professional education activities as well.

²Winn, R.J. National Comprehensive Cancer Network, Oncology Practice Guidelines. *Oncology NCCN Proceedings*, 13:11A. 1999.



Patient Navigator

To assure that the individual patient care plan is followed after a diagnosis has been made, the KBCTF strongly recommends the involvement of a patient navigator. The navigator could be either a health care professional or a non-professional, including a survivor, experienced in working with the management team. This is the task generally accomplished by the “research assistant” in organized clinical trials, i.e., the individual who assures that what is supposed to be done is in fact done, and that reports from each activity are promptly made available to members of the management team.

The role of the patient navigator in Kentucky is particularly important in the current health care system in which health professionals may be physically separated from one another by variable distances, with communication systems that may not be linked. At the same time, many patients will be uncertain of the steps to be taken in achieving optimal care and may be fearful of the diagnostic studies, the specific treatments and the disease. Patients and families should be provided with readily available and understandable information about treatment options and community resources. Whether the navigators are health care professionals, e.g. case managers, or lay persons working closely with health care professionals, they should be characterized by sensitivity to patient concerns and expertise in assuring that individuals move successfully along the path to appropriate care. The Task Force encourages the development of a standardized training program and piloting of a navigator system in selected communities. This patient navigator program will be linked to existing statewide networks.

Evaluation

The ultimate test of the value of practice guidelines is in their acceptance and use by physicians and other health professionals along with the achievement of improvements in patient care and disease outcomes. As Yates and Edge point out, “Free standing patient management guidelines have had a minimal effect on physician behavior. Their passive distribution and implementation have proven to be no more effective than conventional medical education programs. Evaluating compliance with guidelines, providing feedback to physicians, and assessing the impact on clinical, social, and economic outcomes is critical to optimal use of the guidelines.”² They suggest that “methods for evaluating guidelines may include (1) conducting patient and physician surveys, (2) measuring general compliance to recommendations on major points, (3) abstracting information from clinical records, (4) using payor data to determine resource use, and (5) using cancer registry data to follow outcomes.”² It is expected that compliance will be monitored by ACoS and JCAHCO.



NCCN cautions that “the success of clinical management guidelines is a complex effort that varies greatly depending on local conditions. Improvements in guideline compliance will require the use of multiple interventions tailored to the local practice environment.”² Evaluation methodology will necessarily also be tailored to “the local practice environment”² although the same underlying methodology must be constant across the state.

The KBCTF recommends pilot projects in implementing and evaluating the use of the basic NCCN guidelines for breast cancer treatment, psychosocial support, and pain control. These pilot projects would be under the aegis of the Kentucky Medical Association and the University of Louisville and University of Kentucky cancer centers, with the KCP serving to facilitate and coordinate the efforts. Hospital cancer registries and the KCR would be key participants in these activities, together with liaison fellows of the ACoS, the Kentucky Association of Health Plans (KAHP), and representatives of other health professional organizations and institutions. Appropriate administrative and other support for these activities is essential to success.



Table 1. Standards of Care

ISSUES	DESIRED OUTCOMES	ACTION	WHO	MONITOR	DATA NEEDS	REFER-ENCES
Universal adherence to professionally-accepted standards of care for breast cancer early detection, diagnosis, treatment, rehabilitation, and palliation.	Adherence to NCCN Category I Practice Guidelines for Tx, Pain Control, Psychosocial Support	Disseminate and encourage implementation, pilot projects	KMA, KNA, KHA, KHA, KDPH, KAHP, Health profession, schools	Hospital Registries, KCR, HEDIS, EPEC, ACoS, JCAHO	Imple-mentation data	4.1-4.6
Patient navigation through system	Available to all patients	Establish navigator process	Patient care team and facilities, KDPH, hospital auxiliaries, ACS Reach to Recovery, Kentucky Homeplace	Patient Care Team	Utilization	7, 8
<i>Pathfinders*</i> (also in education grid)	Available to all patients	Revise, distribute, and web access	KCP, KMA, KDPH Patient care team		Utilization	8
Treatment options booklet	Available to all patients	Revise and expand	KDPH, Patient care team, KMIC, KMA	ACS Reach to Recovery, CIS	Utilization	8
Second Opinions - Mammography - Pathology - Treatment	Available to all patients	Assure patients have information, Provide ins. coverage	KMA, KAHP, consumers	HEDIS, HCFA	Utilization	4.7
Professional education regarding practice guidelines (treatment, pain control, psychosocial support)	Adherence to practice guidelines	CME provision, Insurance reduction	Health profession schools, EPEC, KCPI, KCP, Journey's Ebd	EPEC, Health Profession Schools, KMA, KNA, other health prof org., KCP	Edu-cation and out-comes	4.1-4.6, 4.8-4.9,5



The patchwork character of health insurance coverage for breast cancer screening, detection, diagnosis, treatment, rehabilitation, and continuity of care is quite evident from Table 2. Regrettably, insufficient data is available to make a definitive statement about the number of women who are uninsured or under insured. Only Medicare, available for all women over the age of 65 and to many women with disabilities, covers all cases in the same way. As indicated in Table 2, there is considerable variation in what different policies cover. Most policies cover diagnosis and treatment, but some have limitations on the type of treatment, or may lack coverage of second opinions, coverage of breast reconstruction, or coverage of professional psychosocial support services. Other concerns have been addressed in recent congressional legislation, including portability of coverage with and without employer coverage. The coverage of participation in clinical trials has not been generally available, even though such participation might be the best option for some patients. Coverage for durable medical equipment is quite uneven.

Table 2. Insurance Payor Source (NCCN Category I)

Payor	Screening	Diagnosis	Second Opinions	Treatment	Psycho-Social	Hospice
Medicaid	✓	✓	✓	✓	✓	✓
Medicare	✓	✓	✓	✓	✓	✓
Ky Employer Self-Insured	Policy Varies	Policy Varies	Policy Varies	Policy Varies	Policy Varies	Policy Varies
Ky Employer Purchased	✓	✓	✓	✓	Optional Service	✓
Out of State, Employer Self-Insured	Policy Varies	Policy Varies	Policy Varies	Policy Varies	Policy Varies	Policy Varies
Out of State, Employer Purchased	Policy Varies	Policy Varies	Policy Varies	Policy Varies	Policy Varies	Policy Varies
Uninsured	KDPH program <250% poverty	✓		✓		
Federal Employees including Military Personnel	✓	✓	✓	✓	✓	✓



The active participation on the KBCTF by representatives of the insurance industry has been most helpful in clarifying issues and suggesting ways to solve problems of paying for necessary care (Table 3). Moreover, their participation has focused attention on the need to evaluate outcomes and look at costs as well as benefits. The KAHP is expected to be instrumental in addressing gaps in care. The workgroup recommendations include coverage for all women across the continuum of disease and activation of the state’s screening fund.

In the interim, the KBCTF recommends the continued development of community capacity to meet the cost of durable medical equipment and those services which enhance the quality of life.

Evaluation of insurance issues will first require determining: (1) the number of women over age 40 for whom screening mammography is covered by some form of health insurance and changes in the proportion of the population covered over a period of time; (2) baseline information about current coverage of NCCN Category I treatment and changes in the proportion of the population with this coverage over time; and (3) the proportion of the population with health insurance coverage for pain control and psychosocial support as provided by NCCN guidelines, with assessment of the changes in these figures over time. With these data, recommendations can be made to improve insurance coverage as needed.

Table 3. Insurance

ISSUE	OUTCOMES DESIRED	ACTION	WHO	MONITOR	DATA NEEDS	REFERENCES
Variations in health insurance coverage*	Coverage for all NCCN Category I related services	Provide health insurance for all breast health care	KAHP, consumers, KBCC	Department of Insurance	Patterns of coverage via patient surveys	4.7 6.2 9-9.3 12 17
Activation of KDPH screening fund	Increase availability/ access to screening for medically indigent	Secure funding	KDPH and contributors	KDPH (annual reports)	Determine magnitude of problem	13.1
Disparity in charges for breast cancer care	Comparable charges for insured and under-insured patients	Review Charges	KAHP, KHA, KMA, consumers	KDPH, KAHP		17

*Indigent health care, including breast cancer treatment is funded jointly by state and county appropriations in Jefferson County only.



Developing a statewide coordinated public breast cancer education plan poses a great challenge for Kentucky (Table 4). This can best be accomplished through regional networks of cancer control partners working together to build community capacity and linkages across the state. In each community, partners will work to assess concerns regarding availability and accessibility of patient care services and to explore possible community solutions to specific problems. Partners will also provide meaningful, understandable information regarding screening and treatment options, including clinical trials, and resources available to the community for newly diagnosed patients and their families.

After much deliberation, the KBCTF recommends that those involved in disseminating information about screening, treatment options, risk, and other issues, distribute the same basic information in communities across the state. This approach will minimize the dissemination of conflicting information by different organizations.

The KBCTF suggests the following basic messages for dissemination within communities:

Screening Messages

- Beginning at age 40, women should have a screening mammogram and clinical breast exam every year.
- Mammography is available to all women in Kentucky.
- Early detection increases the chance for successful treatment.

These screening messages will target women age 40 and over, but special emphasis should be focused on women who are over age 50, low income, uninsured, African American, or non-English speaking, as well as women with limited literacy skills and those residing in geographic regions with disproportionate incidence of late stage disease.

Treatment Option Messages

- Providers should discuss treatment options with newly diagnosed women.
- Written information discussing treatment options, e.g. *Choices*, should be provided to newly diagnosed women.
- Newly diagnosed women should seek information about treatment options and their availability.

Risk Message

- All women are at risk for breast cancer.



Quality of Life Message

Patients and families should seek information and support services from community resources.

Advocacy

The KBCTF was concerned that many issues of importance to breast cancer patients and their families were not being addressed. As a consequence, the KBCTF recommends that regional cancer control partners:

- Encourage health care providers to distribute *Pathfinders* (regional guides to community resources produced by the KCP) to all breast cancer patients and their families.
- Mobilize the community to reduce the disparities in treatment charges.
- Mobilize communities and consumers to encourage out-of-state insurers to comply with Kentucky coverage mandates.
- Encourage women to participate in clinical trials.
- Encourage mammography facilities to accept self-referrals for screening mammography.
- Mobilize communities to obtain services not readily available or accessible.
- Develop a patient navigator system and pilot it in selected communities.

Education Plan Implementation

The Plan will be implemented through the regional networks of cancer control partners headed by team leaders. An agreed upon packet of information will be developed and distributed to regional cancer control partners. The packet would contain the following:

- An outline of the key public education messages and the secondary community outreach messages.
- A copy of the regional *Pathfinder*, a community resource guide produced by the KCP.
- A copy of *Understanding Treatment Options and/or Choices*, a publication which Kentucky providers are legally mandated to distribute to newly diagnosed women.
- A summary of *Treatment Guidelines for Patients*².
- A summary of best community practice ideas, including media campaigns, for successful public education and community outreach activities.

Partners will be asked to integrate basic messages and community outreach strategies into their organizational program plans and designate staff to be responsible for implementation. Collaboration will be encouraged between local partners.



Evaluation

A team leader would organize at least one regional meeting per year with community partners to discuss progress and would conduct a partner survey annually to monitor activities. Partners would be asked to complete a report, describing successful public education or community outreach strategies implemented by their organizations. Copies of the report would be distributed to regional and statewide partners for possible implementation by other organizations and groups.



Table 4. Public Education

ISSUE	DESIRED OUTCOME	ACTION	WHO	MONITOR	REFERENCES
Statewide integrated public education	Increase best practices for all	Integrated basic messages used by all	KCP, ACS, KBCC, KDPH	KBCC KCP	1.1-1.6
Survivor celebrations	Increase awareness	Survivor Celebration	KBCC		1.9-1.10
Standards for access to care (i.e. distance, cost, mobile services, etc.)	Guidelines recommended	Create Guidelines	KBCC Patient Navigators		2.1
Self-referral for screening mammogram	Self-referral availability	Provider adoption	KHA, KMA, Radiologists	Mammography Registry	2.3
Screening for low income women	Increase utilization	Utilization and Expansion of KDPH Screening Program	KDPH	Breast Cancer Advisory Board	3.1
Media campaign	Increase screening	Media Campaign	KDPH, Local Mammography Facilities		3.3
Patient summary of NCCN Guidelines	Understandable NCCN guidelines	ACS/NCCN/KCP to develop	ACS, NCCN, KCP	KBCC	1
Patient navigator	All patients have access to patient navigator	Establish protocol and standardize training	KBCC	KBCC	7 8

Research



Research is a vital part of the continuing care and management of all cancer patients (Table 5). The KBCTF recognizes that improvements in breast cancer prevention, detection, treatment, and rehabilitation would be dependent on clinical research in these areas. It therefore supports an increase in these activities. The KBCTF recommends participation in appropriate prevention trials and in specific clinical trials with regard to treatment when there were uncertainties about the effectiveness of state-of-the-art approaches. It would seem advisable to develop a registry of available clinical trials with information readily available to providers, breast cancer patients, and their families. It is envisioned that the cancer centers at the Universities of Kentucky and Louisville, and other institutions will increase breast cancer research and assume leadership roles in establishing linkages with providers statewide. It will be important to have results from breast cancer research communicated to health care professionals for practice integration and to the public as quickly as possible.

As the results of genetic research become available, the KBCTF wishes to encourage studies on the psychological and social implications of genetic testing.

Table 5. Research

ISSUE	DESIRED OUTCOME	ACTION	WHO	MONITOR	DATA NEEDS	REFERENCES
Information about available clinical trials (CTs)	Access to info about CTs	Establish CT Registry	UK/UL researchers, CIS, CES	UK/UL researchers	Information regarding current CTs	6.3 15.1
Increased knowledge about breast health	Increased Research	Increase research funding	Researchers (application for funds), legislators (allocate funds), foundations, ACS, Komen, CIS	UK/UL		6.1
Genetic Testing Centers Collaboration	Collaboration	UK/UL to share data on genetic testing findings	UK/UL	UK/UL	Utilization	15.2



Legislation

The KBCTF in its Phase I Report made recommendations requiring legislative actions, all of which have been reviewed and/or accomplished (Table 6). Discrimination in this sense is defined as having a cancer diagnosis or being at increased risk due to positive findings through genetic testing. An additional issue surfaced during Phase II regarding taxation of chemotherapeutic drugs administered in outpatient settings. This issue will require the possible future legislative review.

Table 6. Legislation

ISSUE	DESIRED OUTCOME	ACTION	WHO	MONITOR	DATA NEEDS	REFER-ENCES
Discrimination-Employability	No discrimination	Legislation	Legislators, consumers, KCW, Office of Women's Health	LRC ACLU	Legal interpretation of current statutes	11
Discrimination-Insurability	No discrimination	Legislation	Legislators, consumers	LRC, Dept of Insurance ACLU	Legal interpretation of current statutes	11
Chemotherapy tax in outpatient settings	Remove taxation	Legislation	Legislators, providers, consumers			17

Data Needs



Additional data needs have emerged during Phase II (Table 7). Meeting these gaps along with those identified in Phase I will help move the Breast Cancer Action Plan forward. It is likely that other organizations in the state have been pursuing these concerns and may be potential resources for these data.

Table 7. Data Needs

DATA NEEDS	References
1. What is the status of the Kentucky Resource Directory?	1.4
2. What is the status of the Office of Women's Health?	1.6
3. What are the time intervals between diagnosis and initial treatment for breast cancer?	Phase II
4. What are the latest scientific findings concerning Bone Marrow Transplantation?	Phase II
5. What are the current reimbursements for genetic testing?	Phase II
6. What medical record variables are used to record psycho-social and pain control patient interventions? What can be used?	15.3 15.5
7. What is the feasibility of a mammography registry to capture screening utilization, outcomes, etc.	15.6 15.8
8. How many breast cancer patients are untreated due to financial barriers?	14.2
9. What is the disparity in charges between those without insurance and those with charges negotiated by insurers?	17



Evaluation

The KCP will be monitoring the progress of the recommendations set forth by the KBCTF. As discussed, staff will work with a small oversight committee headed by First Lady Judi Patton. The grids presented in this report will be used as a tool to monitor the work of the respective partners (see page 8) as well as their progress in achieving the desired outcomes.