

# ***Exploring Breast Cancer Patterns of Care in Central Appalachia***

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## **ABSTRACT**

Several recent national studies have highlighted growing concerns about the quality of cancer care, particularly in health disparity populations. Many factors influence the potential patterns of care. Poor or underinsured patients or patients from racial or ethnic minorities may not receive the same level of care. Adoption of and adherence to national care guidelines may vary among providers and institutions. In rural areas the scarce distribution of key diagnostic and treatment resources may impact the quality of cancer care. Central Appalachia is potentially affected by all these factors. As a result, questions related to patterns of care (detection, diagnosis, treatment) continuously arise in discussions about cancer in the region. **Objective 2** was directed at exploring regional patterns of care for breast cancer, and evaluating ways in which observed patterns of care may be impacting on Central Appalachian cancer outcomes.

**This material is a copy of a program report to the Centers for Disease Control and Prevention intended for the purposes of dissemination of results. This report has not been peer reviewed for the purposes of publication. This Program was supported in whole by grant # H57-CCH420134.**

## BACKGROUND

In order to explore regional patterns of care for Objective 2, our intent as outlined in our proposal to CDC was: *to develop an electronic medical record system using two complementary organizing approaches that improves physician-patient cancer care planning and communication among health professionals involved in a patient's care.* This planned approach to implementation of Objective 2 involved two key components – the use of an electronic tracking system, and the comparison of two different models for patient data collection.

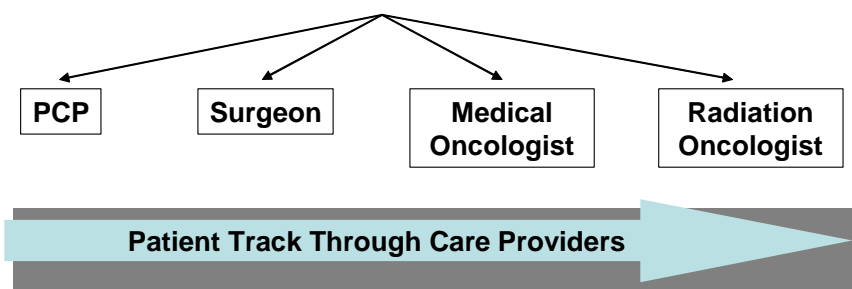
### ***Electronic Tracking System***

It is generally agreed that before initiating primary treatment for cancer there should be, if possible, a multi-specialty consultation among healthcare personnel concerned with the case. Primary care physicians would be involved in considering available management options, together with the patient and family. Concurrent pre-treatment consultation is recommended, but when not possible, consecutive opinion from all of the above individuals should be obtained. To facilitate this kind of communication, we proposed to use a multi-provider patient tracking system that provides access to the patient's record by healthcare professionals involved with planning and implementing each patient's care. The system was to be modeled on an existing patient record system already in place at several sites in eastern Kentucky.

### ***Models of Patient Data Collection***

Our initial intent was to test two different approaches to capturing patient data. As Figure 1 shows, it is theoretically possible to capture patient data beginning with any of the data providers' patients encounter in their cancer treatment process.

**Figure 1: Potential Points of Entry for Study Data Collection**



In Kentucky, we planned to identify cases at the time of diagnosis, with data gathered from primary care providers, and then following the patient through their referral to cancer treatment providers and institutions. In Tennessee and Virginia, the planned starting point for record linkage was through cancer care specialists, and then following back to make communication links with the involved primary care physicians and patients and their families.

## IMPLEMENTATION

Objective Two's research was to be conducted with patients from all three states, using cancer centers and primary care practices as recruitment points for patient participants. We have experienced significant challenges in recruiting participant institutions and practices. The following sections outline the approaches taken in the three states and a summary evaluation of our implementation efforts.

### ***Approaches Taken***

#### *Kentucky*

In Kentucky the rural primary physicians contacted were willing to pursue this approach. However, at each of four sites where efforts to implement the program were made, various obstacles put forward by surgeons and oncologic specialists prevented implementation.

At one site the surgeons were unwilling to participate. The radiotherapist and medical oncologist were reluctant but would have participated if the surgeons had been willing.

At another site the surgeons were quite willing as was the medical oncologist, but the off-site radiotherapist was not. She was concerned that the plan would increase her workload and that of her staff, although staff support would have been provided.

At another site the surgeons and the radiotherapist were very much in favor of the project, since it would create better connections between themselves and the primary physicians as well as the patient; the medical oncologist disagreed. Her refusal was on the medico-political basis that she wanted special arrangements to be made about clinical research between the Dean of the Osteopathic School of Medicine, with which she was affiliated, and ETSU, but she did not want to make those connections herself.

At the fourth site, one with an excellent, well-funded oncology program, the radiation and medical oncologists and surgeons felt they were already communicating well with the primary physicians and patients, and had both pre-treatment, multidisciplinary consultations with pathologists and diagnostic radiologists for all breast cancer cases. They saw no need for the program, although the primary care representative on the cancer committee was very much in favor of the project.

Preliminary explorations were made at two other sites, but although there was initial interest, nothing further developed. After several visits to the various sites over 9 months, and meetings with physicians, cancer registrars and others, and after meetings with computer systems developers, efforts to establish the proposed system were dropped—with great regret.

## *Tennessee and Virginia*

Successful recruitment of participant institutions: As in Kentucky, providers in Tennessee were resistant to the idea of using a tracking system as a communication facilitation tool. Providers in Virginia welcomed a tool that could be used to share patient data, but there were significant issues in designing and rolling out a system that was HIPAA compliant, and significant potential liability issues with a limited patient record such as the one we proposed being used as a sole basis for treatment decisions. Grant investigators made the decision to use an electronic system as a patient data collection tool only, with data access limited to grant personnel. By not asking providers to interact with the electronic system, and restricting our research questions to exploring patterns of care, rather than trying to influence patterns of care, we were successful in recruiting two cancer center participants, one in Tennessee and one in Virginia.

Data collection entry points: In line with the initially proposed model of data collection in Tennessee and Virginia, we primarily collected data from subspecialties located in the cancer center environment. In Tennessee, working at one of the major regional cancer treatment centers in a hospital setting, this included surgery, medical oncology, and radiation oncology. In Virginia, working at a smaller treatment center that is a satellite facility of a hospital, this included medical and radiation oncology. Because of the challenges in recruiting primary care providers in Kentucky, we also made attempts in Tennessee to collect patients at primary care practices that were in the referral stream to our participating cancer center. While two of the three primary care practices we approached agreed to participate, the limited number of breast cancer patients seen on a daily basis, and the difficulties in getting providers to broach the subject of the research study with patients, largely hampered our abilities to collect any significant number of patients from the primary care provider point of entry.

Patient recruitment: Patients have been very willing to participate, with over 90% successful recruitment amongst those approached. We have almost 80 patient participants in Tennessee, which is about 40% of the total breast cancer patient volume seen at the participating cancer center during our data collection period. We have almost 30 patient participants in Virginia, which is over half of the total breast cancer patient volume seen at the participating cancer center during our data collection period.

## ***Evaluation***

In reviewing our efforts on Objective 2 implementation, we offer the following evaluation:

1. **Our research scope had to adapt substantially to respond to realities discovered during implementation.** During the process of implementing Objective 2, it was substantially refocused. The overall research direction, to explore breast cancer patterns of care in the region, remained the same. However, we found it necessary to reduce the scope of our investigation to exploring patterns of care

through chart reviews and patient interviews, rather than using an electronic system as a tool to impact patterns of care by modifying provider and patient communication behaviors.

2. **Provider recruitment was a much more serious barrier than we initially anticipated.** Because of existing good relationships with providers in the region, we did not anticipate substantial difficulties in including them as partners on this research project. Instead, we discovered that: a) an electronic system was not viewed as an asset by many providers or institutions, particularly one designed to modify their behaviors in any way; b) although different obstacles were encountered at different sites, in general getting multiple providers (e.g. primary care providers and various cancer subspecialists) in a particular geographic area involved was very difficult unless they were all part of the same health system; and c) providers often had quite different agendas and interests related to patterns of care than we envisioned in our initial research plan.
3. **More limited research methods and approaches have still revealed useful information about patterns of care in this region.** While we had to adopt altered methods and models during the implementation of this research, we feel that the modified approaches succeeded in identifying areas where patterns of care may be contributing to less than optimal cancer outcomes in this region. The data analysis section of this report covers these findings in more detail.