Public Value Mapping Breast Cancer Case Studies

Monica Gaughan
Center for Science, Policy, & Outcomes
And
Georgia Institute of Technology

Introduction

The federal effort to combat cancer in the United States is one of many "wars" declared in the past 30 years, following the "war on poverty" and preceding the "war on drugs" and the "war on terrorism." The main federal agency in charge of cancer research, the National Cancer Institute, is the largest and oldest of 26 Centers and Institutes of the National Institutes of Health, spending over 3.3 billion dollars in FY 2000 to study cancer. Cancer has a huge impact on the mortality profile of the nation, and is a worthy object of federal funding. From a social impact perspective, however, what has this expenditure purchased? For example, despite such massive research expenditures, breast cancer continues to be the second-leading cause of cancer death in women, and the disparities in survival between white women and women of color, and between regions, have grown over the time period.

During the last twenty years breast cancer research has become increasingly present on the domestic agenda of politicians, women's health advocates and scientists. Thanks to the enormous advocacy efforts of women's health and breast cancer organizations, breast cancer has gained its own place in cancer research. From being lumped together in the past within the generic category of "Other types of cancer", breast cancer is now receiving much needed attention both politically and scientifically. Not only have there been nationwide breast cancer awareness campaigns in the form of races and walks and the designation of a month dedicated to breast cancer awareness, but now there are entire academic research departments devoted solely to the molecular and genetic study of breast cancer.

The purpose of this analysis is to evaluate the cancer research effort in terms of its ability to ameliorate the population impact of breast cancer, with a particular emphasis on the differential impact of cancer on American subpopulations. We seek to apply a public value approach to mapping the outcomes of breast cancer related research. The public value mapping methodology has been described in greater detail elsewhere (Bozeman 2002). Therefore, in the next section of this paper I will briefly describe the components of such an analysis. The analysis itself will then follow the logic of the method using the case of breast cancer research as the source of evidence.

Public Value Mapping

The public value is defined in terms of outcomes that are specified and valued by society. They are values and outcomes in which the entire society, and each member of it, has a stake. In the context of research evaluation, public value is the extent to which science contributes to achieving valued social outcomes. As such, scientific research activity is only one institution among many that contribute to the achievement of social mileposts. Although a powerful institution, science alone neither creates nor resolves social problems. Nevertheless, it is a key institution in developing knowledge and technology that help to meet important goals. This methodology, then, seeks to situate the scientific enterprise within the larger economic and social contexts that foster scientific development and solutions to critical social needs.

Applied to problems of social interest, PVM seeks to expand the research evaluation perspective to include the entire field of scientific endeavor (rather than individual projects) focusing on a particular problem. This analysis first uses the PVM tool to evaluate federal efforts in breast cancer research, and is largely summative in its focus. The analysis of the federal effort reveals a number of institutional and capacity-based problems that limit the nation's ability to achieve meaningful population-based milestones. We also apply the PVM tools to a prospective, formative evaluation of an innovative approach to cancer research occurring in the State of Georgia. In this way, we hope to demonstrate the flexibility of the tool for evaluating past, present, and future issues of public interest.

A PVM analysis begins first with the identification of the social outcomes domain of interest, identifies measurable public values through mission statements, and understands the relationships among these values. For example, in both the federal and state cases, this involves the analysis of legislative and executive objectives for scientific achievement, and the organizational mechanisms developed to implement them. PVM analysis then moves to the domain in which the actual research occurs. Here, we apply the concept of a Knowledge Value Community (KVC) to explore the complexity of the ecology in which modern scientific research occurs (Bozeman and Rogers 2002). This includes governmental actors (which are not usually considered once funds have been encumbered) and scientists (the usual object of research evaluation). We further conceptualize other types of users that are essential to the success of large social objectives, including the business community, the nonprofit community, and consumers and beneficiaries of scientific products. In other words, we examine how policy initiatives and their implementation create and constrain opportunities for working on particular scientific problems, and how the complexity of the user community facilitates or hinders the ability to have an impact on social outcomes of interest. Specifically, attention to the characteristics of the knowledge value community allows us to examine effectiveness by considering the growth, fecundity, and capacity of the KVC to achieve the desired outcomes. In this context, capacity includes the scientific, technical, and human capital (STHC) necessary to meet the goals of the research.

In brief, Public Value Mapping seeks to identify social outcomes objectives to which science is expected to make major contributions. The critical first task is the identification and quantification of the public values and social outcomes of interest. The approach then turns to an assessment of the capacity and effectiveness of the Knowledge Value Community that develops to meet the social objectives. The analysis provides the opportunity to evaluate critical paths in the process, including those that should be there but are not. The first case study examines the federal effort; the second examines a new state-level initiative in Georgia. Comparing and contrasting the two shows the diversity of approaches to organizing scientific effort, and invites further attention to resolving key institutional barriers that hinder progress in achieving social outcomes objectives.

The Federal Case: How are prime values in health research determined?

The issue of what is or is not a public value is a thorny one in most policy domains. In the case of illness and health, however, there tends to be broad social consensus about which values are publicly cherished, and which are not. The World Health Organization defined health in 1948 as, "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity (WHO 1948)." Although there is a great deal of disagreement about how best to achieve these objectives, few disagree that longer, healthier, and more satisfying lives are in the best interest of society as a whole, and of the individuals who make up that society.

The World Health Organization philosophy represents only one multilateral organization that may not hold up well in the profit-driven US context. Nevertheless, the democratic process in the United States creates its own prime objectives, which we can consider as examples of public value codified through appropriate channels. There are two recent major political initiatives that have resulted in the specification of goals and objectives for the federal health infrastructure. That specific objectives should be identified is crucial, given that the US Department of Health and Human Services (HHS) is responsible for a FY 2000 budget of 429 billion dollars.

The HHS has fostered decennial cycles of Healthy People planning. Initiated in 1980s, these processes have yielded three prospective blueprints for federal health policy objectives: Healthy People 1990, Healthy People 2000, and Healthy People 2010. The first two iterations resulted in unwieldy collections of specific health objectives. It read as a laundry wish list for improving health outcomes. The efforts were criticized, however, for their failure to prioritize outcomes, or to specify mechanisms by which improvements in outcomes would come about. In effect the implicit causal mechanism was simple: expenditures in HHS programs would result in improvement in various collections of outcomes indicators. Clearly, this was hardly a recipe for prospective program and policy planning.

Shortly after the completion of the HP2000 process, the Clinton administration spearheaded the Government Performance and Results Act of 1993 (GPRA; PL 103-62). This act has far-reaching consequences throughout the federal government, requiring every cabinet agency to submit a three-year strategic plan, and annual performance plans that specify how the agency's programs meet the specified strategic objectives. Despite the shortcomings of HHS's previous Healthy People documents, the Department was better positioned than some of its sister agencies to adapt to these new requirements. The second, and current strategic plan claims the HHS mission is:

> To enhance the health and well-being of Americans by providing for effective health and human services and by fostering strong, sustained advances in the sciences underlying medicine, public health, and social services. HHS Strategic Plan, 1997

Note that there are two major operational domains embodied in this overall mission statement: service and research. The distinction is important because the majority of HHS funds go to service related entitlement initiatives. In FY 2001, only about 6% of the HHS budget was dedicated to research, with over 94% of the budget dedicated to entitlement, service programs, and administration. This imbalance in expenditure is mirrored in a relatively greater emphasis on health services in the 6 overarching strategic goals of the Department (See Table 1). In the breast cancer case to follow, we are most interested in the sixth goal: to strengthen the nation's health sciences research enterprise and enhance its productivity. Because HHS is such a major purchaser of both scientific research and health-related services ostensibly based on such research, it is critical that its purchases be the most effective in meeting the nation's health goals and objectives, and population needs.

At the same time that the HHS geared up through GPRA for strategic planning, the Healthy People 2010 process was underway. The two efforts informed one another, with the latter process resulting in the health outcomes indicators that are used to monitor some aspects of performance plan progress. In addition, the HP 2010 initiative created two prime objectives: to increase the quality and years of healthy life, and to reduce health disparities (HP 2010). The GPRA strategic planning process yields a mission statement that is articulated primarily in process terms. By contrast, the HP2010 process articulates outcomes-based missions. In effect, one can think of the GPRA objectives of providing services and fostering scientific advance being the inputs to achieve the HP2010 outcomes of increasing life and decreasing disparities.

Figure 1 shows a schematic of the federal policy process as it relates to the national health policy. At the highest level of the federal policy chain are the President and the Congress. The President can provide high-level leadership attention for health issues, as Nixon did with the War on Cancer and Reagan did with the War on Drugs. In this way, particular health issues can be elevated in the hierarchy of publicly defined problems and values. Congress is responsible for authorizing cabinet agencies, and for providing them with funds to achieve their objectives. The 1993 Government Performance and Results Act gave Congress additional leverage to demand policy planning and outcomes analysis.

The next policy level is the cabinet level, which includes the Department of Health and Human Services as the biggest federal health research policy player. Other federal, state, and local governmental agencies are also involved in health policy. The private sector is a huge player in the health services arena, and to a more limited extent in the health research arena. This is not to say that private organizations do not forward public values. Rather, private organizations have profit maximization as their prime goal, which is not true for governmental agencies. It is particularly appropriate in the context of PVM to evaluate the extent to which incorporation of private enterprise may in fact be an essential partner in meeting important policy objectives. Currently, however, there are few formal mechanisms for including the private sector in national health research policy planning.

The PVM methodology relies on the stated missions and strategic objectives to define the public value. In other words, we assume that the democratic process that underlies establishing policy initiatives codifies and endorses outcomes as legitimate. We claim that the following four objectives represent articulated public values at the level of federal health policy.

Process Objectives result from the GPRA planning process, and include:

—Provide health and human services.
—Foster advances in the sciences.

Outcomes Objectives result from the Healthy People process, and include:

—Increase quality and years of healthy life
—Reduce health disparities.

The first two prime objectives are the result of the Congress-induced GPRA strategic planning process, while the second two are the result of the HHS's third iteration of the Healthy People process. Taken together, they provide the best guide to identifying the public good with respect to health policy. Returning to the concept of public value mapping, we are interested in these four objectives in terms of measurable outcomes. A fairly easy and well-defined process question is, how does the government provide health and human services? A more difficult question to answer from an evaluative standpoint is, how does the governmental effort foster advances in the sciences? Much more difficult than these two process questions are those posed by the Healthy People 2010 goals. It is not enough simply to succeed in providing services, or fostering scientific advances. The public value mapping approach asks how scientific activity and capacity is specifically linked to increasing the quality and quantity of life, and decreased health disparities? Before looking more closely at the knowledge value collective responsible for achieving these objectives, we will discuss the social outcomes indicators by which we evaluate success in the two cases featured in this monograph.

Breast Cancer Social Indicators

The federal research effort on health and disease is huge in scope; therefore, we will focus on the specific disease of breast cancer for our case analyses. The massive impact of breast cancer on the longevity and health of women is an appropriate object of public concern. Following from the principles of public value just derived, one can assert with some confidence that the public value is consistent with a reduction in breast cancer incidence, prevalence, and mortality. Concomitantly, there is a public interest in increasing beneficial practices—such as screening and behavioral modification—that may reduce the impact of breast cancer. Furthermore, decreasing the racial, ethnic, and socioeconomic disparities in breast cancer is fully consistent with the prime goals of the department.

The Healthy People 2010 process articulates what social indicators are to be used to follow progress in achieving breast cancer goals. Specifically, they are:

3.3 Reduce the breast cancer death rate.
3.13 Increase the proportion of women aged 40 years and older who have received a mammogram within 2 years.
3.15 Increase the proportion of cancer survivors who are living 5 years or longer after diagnosis.

From: Tracking Healthy People 2010

These social indicators have some nice properties. First, they are based on population characteristics rather than individual level data. Second, they rely on official reporting procedures rather than individual self-report. Finally, there are good time series data available to track the historical trends in the data.

In effect, these three time series constitute the theoretical “dependent variables” in our analysis. Ultimately, we seek to evaluate the extent to which the federal science research effort may reasonably be expected to achieve the four prime goals of the Department by affecting the three specific breast cancer-related indicators. It is worth taking a few moments to examine what these indicators tell us about the American population with respect to breast cancer. We present three figures depicting the time series 1973 to 1997 and broken down to illustrate racial and ethnic disparities. Each figure breaks the indicator into data based on race, and ethnicity when available. Figure 2 depicts the breast cancer incidence rate and mortality rate over the time period; Figure 3 depicts the 5-year survivorship rate; and Figure 4 depicts the mammogram-screening rate. Overall, these data allow us the opportunity to observe “quality” and “quantity” of life over the time series, as well as disparities among groups.

Figure 2 plots breast cancer incidence and age-adjusted mortality rates for white and black women. Breast cancer incidence among white and black females has remained generally invariable based on the last 5 years of examined data (1991-1996). Incidence rates varied by an average of (+/-) 1.6% among white females and (+/-) 1.8% among blacks from 1991-1996, however there is no clear pattern of increase or decrease in the most recent period. White females have higher breast cancer incidence rates than black females, however breast cancer mortality rates are higher for black females than white females. From 1989-1996 breast cancer mortality among white females has decreased by an average of 1.9%, whereas the mortality rate for black females has remained fairly constant at 31.3 per 100,000. This trend in mortality is different from previous years. Between 1973 and 1983, the mortality rate for each race was similar. This figure illustrates several paradoxes. First, over the whole time series, breast cancer incidence is increasing for both white and black women. Second, the mortality rates have remained fairly stable, despite this increasing incidence. Finally, the disparity in mortality between white and black women is due to the differential improvement of white women’s mortality since 1984. Despite black women’s lower incidence of breast cancer, they face a much higher risk of breast cancer- related mortality.

Figure 3 shows the trend in 5-year survivorship by race. First, there has been some increase in the survival rate for both white and black women. Eighty-six percent of white women survive breast cancer 5 years or more in the period 1989 to 1995, compared with 75 percent in 1974 to 1979. Black women’s survival also improved, from 63 percent to 71 percent. This greater survival may be due to earlier detection, although the role of screening in reducing mortality is currently a topic of great controversy. For some breast cancers, improved treatment may also be responsible for the improvement. Nevertheless, across the time series, white women’s survivorship exceeds black women’s. Furthermore, white women’s survivorship is increasing at a faster rate than black women’s.

In Figure 4, data on mammogram screening is depicted compared by race, including Hispanic ethnicity. United States mammogram usage has steadily increased from 1987 to 1998 among white, black, and Hispanic females. Mammography in white females doubled from 1987-1998, while mammography usage tripled among blacks and Hispanics during this time. Similarly, mammography usage tripled for individuals below poverty and those without a high school education, while it doubled for those at or above poverty and those with a high school education and/or some college. This time series is heartening because it shows that improvement in screening rates can be achieved in all groups, and that differential improvement by traditionally disadvantaged groups may narrow the health disparity gap. As already noted, however, the contribution of improved screening to decreasing mortality is a matter of great scientific debate (see the ongoing debate in successive issues of The Lancet, 2001 – 2000).

In an earlier section, we articulated public value on the basis of public documents created by the Department of Health and Human Services. In this section, we described the data that HHS has chosen to use to mark its Healthy People 2010 progress. Up to this point, we have merely articulated the end points of the policy objectives. In our larger analysis, we are interested in evaluating how federal health policy practices such as providing services and fostering scientific research have an impact on reducing breast cancer mortality, increasing survivorship, and expanding breast screening. To begin to address this question, it is necessary to describe the federal health infrastructure to identify likely sources of help and hindrance in this endeavor.

The Federal Organizational Context

The federal players and processes at the highest levels have already been discussed. When the political process is codified, however, it is up to the cabinet agency to interpret and implement the law. We have examined the GPRA and Healthy People processes that the Department of Health and Human Services used to arrive at its strategic objectives. These processes were led at the Secretary level, with input from the operating and staff divisions of the department. Ultimately, however, delivery on the strategic objectives is the responsibility of these divisions. Therefore, an overview of how the Department is organized will help to frame the institutional context through which general social health outcomes are to be met. In the language of PVM, we seek to evaluate the extent to which the infrastructure of the Department can reasonably be expected to forward realization of its articulated public values.

Figure 5 depicts the current organizational chart of the Department of Health and Human Services. The Staff Divisions are the outer columns, while the Operating Divisions are the inner columns. What is immediately striking is how flat this organization is: with the exception of the immediate Office of the Secretary, there are no hierarchical reporting relationships. This democratization of the Department occurred during the Clinton administration, effectively eliminating higher-level integrative policy-making functions of the department. This statement may seem to be at odds with the strategic planning process I have already described. In the past, the Public Health Service ostensibly oversaw the key public health functions of the department. Now, each reports directly to the Secretary, using the staff divisions as appropriate. In some cases, as in the National Cancer Institute, constituent agencies of the Department can bypass the Secretary, going directly to the President and Congress. Since meeting outcomes objectives in most contexts relies on means-ends relationships, it is noteworthy that hierarchical or sequential relationships are not present in the cancer context in the federal government. This latter phenomenon will be discussed in greater detail subsequently.

The flat, democratic depiction of the organizational chart belies the diversity of functions and inequalities of fiscal, programmatic, and bureaucratic power within the agency. Briefly, the Administration for Children and Families (ACF) is primarily a welfare service agency. Similarly, the Administration on Aging (AoA) is a welfare service agency for older adults. The Centers for Medicare and Medicaid Services (CMS, formerly Health Care Financing Administration) administer these two critical entitlement programs. The Agency for Healthcare Research and Quality (AHRQ) evaluates research on health care quality and costs. The Centers for Disease Control and Prevention (CDC) is in charge of monitoring epidemics and implementing prevention programs through the states. Its Director also oversees the Agency for Toxic Substances and Disease Registry (ATSDR). The Food and Drug Administration (FDA) monitors the safety of food, medical devices, and pharmaceuticals. The Health Resources and Services Administration (HRSA) provides health services to medically underserved populations and areas. The Indian Health Service (IHS) provides health services to Native Americans. The National Institutes of Health (NIH) conduct basic and applied scientific research. The Substance Abuse and Mental Health Services Administration (SAMHSA) administers block grants to the states to improve mental health and substance abuse services. The Program Support Center is a fee-for-service administrative structure available to the entire Department.

Together, these operating divisions briefly described above collectively address the public health needs of the nation's populace. Ostensibly, the various components of the Department use scientifically and medically appropriate treatment developed in large part through its research functions. However, to think of the various organizational units as equally influential within the Department or equally important to large segments of the US populace is a mistake, despite the egalitarian organizational chart. Table 2 lists the agencies, with key organizational characteristics in the columns to their right. Column 2 shows the percentage distribution of the 63,000 employee-strong HHS labor workforce. Several statistics are noteworthy. First, the entire Office of the Secretary and all of the Staff Divisions comprise only 8 percent of the Department's labor force. While there may be some who would decry this as "too much bureaucracy," it is relatively small given the size, importance, and complexity of the Department as a whole. Second, several of the agencies are quite tiny: AoA has 121 employees, AHRQ has 294, and SAMHSA has 624. Finally, the National Institutes of Health are by far the biggest employer in the Department, having a workforce of over 17,000 people, and comprising over one-fifth of the work force. This is particularly noteworthy given that NIH makes awards to thousands of scientists in hundreds of universities across the country. This strong multiplier will be explored in greater detail later. Suffice it to say at this point that the Operating Divisions differ substantially in the size of the labor force mobilized to accomplish missions, and that the National Institutes of Health have the greatest investment in human capital to address health problems.

Using the size of the labor force to evaluate relative power within the department is only one indicator, however, and in some instances is inappropriate. For example, CMS (formerly HCFA) consumes the lion's share of the HHS resources: $339.4 billion, or 79% of the total. By contrast, it employs only 7% of the workforce. This apparent contradiction is explained by the fact that CMS provides administrative support for two efficient entitlement programs: Medicare and Medicaid. On the other hand, IHS is allocated less than one percent of the HHS budget (Column 4), but employs almost one-quarter of the work force. This is because IHS employs health professionals to provide primary health care to Native Americans: it is a labor intensive, resource poor enterprise. Therefore, it is important to consider how labor and resources mix in the Operating Divisions to achieve core missions. In the case of NIH, which is predominantly responsible for forwarding the research component of the nation's health objectives, the scientific and human capital investment component is considerable and appropriate.

An additional indicator of organizational capacity in the nation's effort is the amount of discretionary annual appropriations. Returning to FY 2001 appropriations, I exclude CMS Medicare and Medicaid entitlements from the distribution in Column 5. Examined this way, almost half of the HHS expenditures go to ACF, which administers Aid to Families with Dependent Children and other welfare programs. ACF has a high funding-to- labor ratio, and for the same reasons as the case of CMS. Excluding ACF in Column 6, NIH emerges as the key recipient of discretionary (i.e. non-entitlement) funding in the department, garnering 44% of the resources. This tendency is further reinforced in Column 7, which excludes the service programs of HRSA, IHS, and SAMHSA from consideration. Fully 60% of discretionary resources go to the National Institutes of Health, 12% go to Centers for Disease Control and Prevention, and almost one-fifth to the administrative functions of the Department that serve all agencies. In brief, the large majority of discretionary expenditures in the Department are those devoted to health research.

The point of the preceding analysis is two-fold: first, the apparent democratic organization of the Department on paper belies enormous differences in mission, size, complexity, span of control, and appropriation level. Second, the majority of the Department's appropriation is non-discretionary entitlement and service program provision. In effect, the majority of discretionary activity takes place in just three major areas: the Staff Divisions, CDC, and most important, NIH. It is in these realms where the most policy discretion is possible. For this reason, we zero in more specifically on the most important of these entities, and further focus our analysis on the question of how it affects Department level goals and objectives, especially with respect to breast cancer research.

National Institutes of Health

The preceding organizational domain analyses support the following conclusion: the National Institutes of Health is by far the most influential public or private institutional entity conducting medical research. As noted earlier, it is the largest employer among the twelve operating divisions of the HHS. It enjoys the largest discretionary appropriations. Furthermore, its scientific research effort dwarfs those of private industry or other governmental sectors. In this section, I will briefly explain how NIH works so that we can further situate the National Cancer Institute in its most immediate organizational milieu.

In 1930, the National Institute of Health was established by the Ransdell Act. Although a federal health research laboratory had been established in 1887, its functions were not separate from the general functions of public hygiene, which were formally codified in 1912 as the Public Health Service. The National Cancer Institute, founded in 1937, was the first formal Institute of what would become the National Institutes of Health in 1944 (Harden 2001). Over the years, the Institutes have expanded to include 19 Institutes, 7 Centers, and the Library of Medicine, all ostensibly overseen by the Office of the Director.

NIH is a critical component of the nation's research infrastructure investment. In FY 2001, the NIH budget was 20.3 billion dollars. The principal function of NIH, as stated on its main overview page is:

The NIH mission is to uncover new knowledge that will lead to better health for everyone. NIH works toward that mission by:

1. Conducting research in its own laboratories;
2. Supporting the research of non-Federal scientists in universities, medical schools, hospitals, and research institutions throughout the country and abroad;
3. helping in the training of research investigators; and
4. fostering communication of medical information

http://www.nih.gov/about/NIHoverview.html

In the language of public value mapping, we consider these four strategic goals to be elaborations of the HHS strategic objective relating to enhancing research capacity to achieve public health goals. The Extramural Research Program of grants and contracts to scientists and research institutions constitutes the largest effort at NIH, consuming 82 percent of resources. The most common mechanism for being awarded a grant is an "RO1," or individual investigator-initiated. A scientist, usually based in a university, writes a grant proposal to the NIH. The competition is stiff, and awards are made to a minority of applicants after a rigorous process of peer review. Over 50,000 principal investigators are supported by NIH; this figure does not include the scientists and students who may work on the research project. The American research university depends on NIH for its scientific and institutional vitality. An additional 10 percent funds the Intramural Research Programs, which are run in NIH laboratories by NIH scientists. As already noted, the NIH has a very large workforce, approximately one-quarter of which holds medical or doctoral degrees.

Just as the Operating Divisions of HHS are not equally well endowed, there is a high degree of inequality among the Institutes in terms of their longevity, budget size, and magnitude and breadth of their portfolios. Figure 6 includes a key to the 19 Institutes of Health. The names indicate the major disease or process emphasis of the research portfolio in each Institute. As can be seen, there are differences in the amount of investment in various areas. For example, NICHD, the Institute devoted to child development and fertility research garnered

6% of the NIH research dollar. Together, the addiction agencies NIDA and NIAAA also commanded 6% of the NIH research dollar. In general, the Institutes with an explicit focus on a particular phase of the life cycle—like NICHD and NIA—or diseases with strong social and behavioral components—like NIMH, NIDA, and NIAAA—are dwarfed by the expenditures on chronic diseases. For example, the National Heart, Lung, and Blood Institute is the second largest Institute of the NIH, receiving 12% of the research support. The biggest Institute by far is its oldest: the National Cancer Institute, which commanded 21% of the FY 2000 appropriation.

National Cancer Institute

The National Cancer Institute is a unique Institute of NIH and the Department as a whole. Most interesting, NCI has bypass budget authority, which means that its budget proposals are submitted directly to Congress. NCI is in the position to request increases in its budget without reference to other areas of NIH or the Department as a whole. For example, the FY 2003 budget request is almost 5.7 billion dollars, one and one-half billion dollars above last year's budget. It is hard to imagine any other Institute putting a claim on 36% more resources than the prior year. Since, however, NCI does not need to respond to other organizational priorities, it can, and does, create fantastic budgets year after year. Figure 7 depicts the meteoric rise in NCI appropriations. After steady modest increases in the post-war period, there was an upward spike in the early 1970s in response to President Nixon's declaration of the War on Cancer. There were additional sharp increases in the mid-1980s and the early 1990's in response to Presidential and Congressional initiatives to increase funding for NIH. At this rate of increase in NCI, a cure for cancer must be close at hand.

According to the NIH Almanac, the four goals of cancer research are:

1. understanding cancer biology;
2. identifying who is at risk for cancer and why;
3. developing interventions to prevent, detect, diagnose, treat, and enhance survivorship from cancer; and
4. translating research discoveries to the public and to medical practice.

http://www.nih.gov/about/almanac/organization/NCI.htm

Figure 8 depicts these goals as components of the overarching cancer research mission of the agency. It cannot be emphasized enough that this is an idealistic vision of the prioritization process, which presupposes a hierarchy in political authority and policy making. In fact, because of its independence, NCI is able to operate independently of its parent agencies, and to set the priorities itself. In other words, there is evidence to suggest that NCI is not bound to the policy-making and prioritization processes just described. Rather, NCI is in the enviable position of determining its own research priorities. Therefore, the most appropriate place to look is the composition of its research portfolio to see if it is structured in a way that could reasonably be expected to meet the social objectives identified by democratic institutions.

The Cancer Research Portfolio

The National Cancer Institute classifies its research projects into 7 major categories: Biology; Etiology; Prevention; Early Detection, Diagnosis, and Prognosis; Treatment; Cancer Control, Survivorship, and Outcomes Research; and Scientific Model Systems. In Figure 9, these priority areas are arranged from a macro, population-based level of analysis, to a micro, organism and smaller level of analysis. The figure, which excludes Scientific Model Systems, shows the distribution of 3,991 breast cancer relevant studies being undertaken as of October, 2002. Overall, there were 2,826 unique breast cancer research projects, but some of these addressed scientific issues that spanned common scientific classifications. Among all of these studies, there are 37 clinical trials.

It is clear that breast cancer research has benefited from the infusion of resources into NCI during the last decade. This supports NCI's claim that it is being responsive to the criticism levied against it in the early 1990s from breast cancer activists who charged that NIH was ignoring breast cancer research. Although one could argue about levels of funding relative to disease incidence and prevalence, NCI has established a large group of research projects working on breast cancer. It is the distribution of these efforts that are of concern in this monograph.

It is our proposition that to achieve population outcomes called for in various strategic planning documents, research needs to address all levels of analysis, and be integrated across levels so as to inform further research. Considered in this way, the breast cancer research portfolio is concentrated at micro levels of analysis, and sparser at the macro levels of analysis. Indeed, even at the macro levels of analysis, there is a significant tilt toward micro-level solutions. For example, two of 6 priority areas within prevention are chemoprevention and vaccine development. Furthermore, even at the most macro-level, research is concentrated in areas that deal with the consequences of cancer. For example, the Control, Survivor, and Outcomes priority area, which is present in only 10 percent of research projects, includes care giving, healthcare and other costs, and end-of-life issues. These are all important topics, but focus on issues related to combating the disease, and not on larger population issues related to breast cancer.

Analysis of strategic plans, budgets, policy documents, grant patterns, and National Academy of Science panel recommendations suggests that federal cancer efforts continue to emphasize the search for a socially-neutral molecular bullet, and to de-emphasize research on environmental, social, and behavioral determinants that may ultimately prove more useful in reducing the overall demographic impacts of breast cancer. One of the most interesting discoveries of this study is the proliferation of organizations focused on breast cancer research. For some, the research programs have developed as a response to NCI's limited success in addressing population based needs. It is to these organizations that we now turn.

The Expanding Organizational Domain of Breast Cancer Research

The heart of the federal analysis focuses on activity of the National Institutes of Health, and specifically on the National Cancer Institute. Its FY 2002 breast cancer research expenditures were $629 million, dwarfing the efforts of other funding agencies. Although it is the most significant player in breast cancer research, it is critical to consider the extent of involvement and roles that other public and private institutions play. The proliferation of various public and private entities devoted to breast cancer research is an unobtrusive indicator of the "public failure" of the NCI to meet important research objectives. There are two major federal governmental agencies involved with breast cancer research, and multiple private foundations and industries. In effect, these are elements of the national Knowledge Value Community that seeks to make scientific progress on the topic of breast cancer research. Furthermore, including them allows one to see how even small members of KVCs can leverage resources and create the critical momentum necessary for shaping research to be more conducive to improving the social outcomes.

Public Institutions

In addition to the programs of NIH, there is one other major federal player in the breast cancer research domain: the Department of Defense. The DoD Breast Cancer Research Program is the result of a fascinating case of legislative activism. Dissatisfied with NCI's response to breast cancer research advocacy, Congress established the program in FY92 to extend research funding taking place in the National Institutes of Health. There was a volatile appropriations history as the program took hold, followed by steadily increasing appropriations since 1996. The Department of Defense's Breast Cancer Research Program appropriations from 1992 to 2001 totaled $1.218 billion dollars. This is a remarkable example of a Congressionally Directed Medical Research Program. However, a 1997 Institute of Medicine review of breast cancer research in the Department of Defense found that it had focused primarily on genetic, cellular, and molecular functions despite recommendations in a 1993 report to include additional research priorities (IOM 1997, 1993). This is especially noteworthy given that the Department of Defense was starting the program in 1993, and had considerable ability to affect research allocations. Indeed, one of the reasons Congress made a breast cancer research program within Defense was a desire to break NCI's stronghold on scientific priorities. Unfortunately, its original purpose of improving the range of the federal breast cancer research portfolio is largely unrealized, relying instead on defining problems in ways similar to the NCI basic research program (IOM 1997).

In 1993 the California Legislature established the Breast Cancer Act which created two programs responsible for the administration of breast cancer research funding, the Breast Cancer Research Program and the Breast Cancer Early Detection Program. Both programs are funded with tobacco state tax revenues. Forty-five percent of the tax revenues are allocated into the BRCP, which is administered by the University of California. Its purpose is to allocate the resources into the research for the cure, cause, treatment, early detection, and prevention of breast cancer in California. The California State Department of Health Services administers the Breast Cancer Early Detection Program, which receives 55% of the tax revenue. Its purpose is to provide funding to early detection services for uninsured and underinsured women in California. The remaining 5% is allocated into the California Cancer Registry responsible for the collection and compilation of data on cancer survival rate and, deaths in California.

Although funds for the BRCP are allocated in universities, research institutes, hospitals and cancer centers exclusively in California, scientific advances will be in the public domain. Unlike the DoD BCRP, the California BCRP is attempting to fill important gaps in breast cancer research. It has identified 7 priority research areas: biology of the normal breast, earlier detection, etiology, Innovative treatment modalities, health policy and health services, pathogenesis, prevention and risk reduction, and socio-cultural, behavioral, and psychological issues of breast cancer. The mission of the health policy and health services research area, which comprised 17% of funding in 2001, is to eliminate the emotional, cultural and health service barriers to treatment, focusing on breast cancer prevention and detection in underserved populations, among others. Another area of rapid growth is early detection, whose funding increased from 9% in 2000 to 15% in 2001. Besides researching on technology, biopsy and other screening methods, more researchers funded by BRCP are turning their attention to the attitudes, beliefs and physicians' approach to the patient that may affect compliance with screening recommendations. Where NCI ignored, and DoD failed to address, California is leveraging important resources to create a broader KVC that will improve scientific knowledge and, it is hoped, affect population outcomes.

Private Institutions

In addition to governmental entities, breast cancer has also sparked the interest of many philanthropic entities, those seemingly bottomless pockets of goodwill money eager to fund worthy causes. In part, the private sector is mirroring public concern with how NCI has been disbursing funds and developing scientific knowledge. However deep these pockets might be, their contribution to breast cancer activities is minimal compared to contributions disbursed by the NIH and other government entities. Private foundations distributed grants to non- profit organizations, universities, research hospitals, grass roots organizations and health clinics. Although not as large a financial effort as governments can afford, these ongoing contributions are important for the support of breast cancer activities nationwide, and in some important cases can leverage additional funds or new directions in breast cancer research.

Foundations have recently been diversifying their philanthropy investments to include medical research. Many are interested in supporting research but cannot possibly identify those researchers and institutions in need. Instead, they give the money to intermediary organizations that redirect the money to the most needed sectors. In the data studied, most of the funds disbursed by directly by foundations were awarded to hospitals and universities for building and equipping science laboratories. By contrast, grants awarded through intermediary organizations tend to go to particular research projects and researchers.

The Susan Komen Breast Cancer Foundation, the largest non-profit recipient of grant money for breast cancer, is a perfect example. The Komen Foundation and its hundreds of Affiliates receive money from foundations, individual donations, corporate sponsorships and Race for the Cure. It allocates almost 85% of its funds to breast cancer research, education, prevention, screening and treatment programs. In 1999 alone, the Foundation had $85 million in gross revenues, out of which $44 million were allocated into the grants programs. Although all four areas are a priority in the fight against the disease, more grants go to research and education than to any other area. In 1999, 31% and 30% went to research and education respectively. Since 1982, almost $68 million dollars have been granted to breast cancer research. Research grants have increased both in grant amount and in the scope of topics. In 1995, 33 research grants were awarded in contrast with the 102 research grants awarded in 1999, and averaging $176,000 per grant. Research topics have also diversified over time, from focusing exclusively on basic research support, to expanding into clinical, translational, behavioral and community-based studies. Grants have also supported dissertation research, imaging technology, and postdoctoral fellowships. Most importantly, grants have increasingly been given for the population specific research. The latest research in this category has studied populations such as the Amish, Hispanics, Native Americans, Lesbians, and African Americans, among others.

Another important intermediary organization is the Breast Cancer Research Foundation, founded in 1993 by Evelyn Lauder. To date, BCRF has allocated 30 million dollars into breast cancer research projects focusing primarily on clinical and genetic research. In 2001, almost $8 million dollars were distributed as grants alone. The funds are collected from corporate partners, fundraising events, foundations and individual donations, and are distributed to numerous research entities. Universities and research hospitals, such as Georgetown University-Lombardi Cancer Center, the Memorial Sloan-Kettering Cancer Center, University of Texas, University of Pennsylvania, The Wistar Institute and Mayo Clinic are among many other prestigious research institutions that have recently received BCRF funds.

The Estee Lauder Company has significantly contributed to BCRF through the Pink Ribbon Program, and helped to broker additional funding for the BCRF. Aventis Oncology, a division of Aventis Pharmaceuticals recently agreed to donate to BCRF $725,000 over a three year period for breast cancer research. General Mills/Yoplait “Save lids to Save lives” campaign renewed their commitment to BCRF awarding $4.4 million dollars over a three year period to fund clinical and genetic research placing special emphasis on nutrition/diet and breast cancer. United Airlines has also partnered with BCRF in a mileage donation campaign. So far United Airlines has donated 7 million miles to BCRF to support the travel of researchers in the field.

In addition to cash disbursements by private foundations and companies, one must also consider corporations’ contributions in the form of in-kind donations, collaborative fundraising, monetary donations from the sale of their products and free advertisement. Corporations such as Avon, Estée Lauder, Clinique, Lee Co. (Lee jeans) have been very committed to breast cancer awareness. Some of their activities have included: national month for Breast Cancer awareness have included: lighting up monuments in pink worldwide, the sale of pink bows, cosmetics gift sets, among many other creative strategies. Even the Ladies Professional Golf

Association (PGA) made Susan Komen Breast Cancer Foundation their national charity to which tournament proceeds will go.

For an interesting take on the commercialization of breast cancer, see social commentator Barbara Ehrenreich's recent article, "Welcome to Cancerland" (Ehrenreich 2001). Herself a breast cancer survivor, Ehrenreich describes the survivor's rallies she has attended, which include stands for pink decorations, wigs, chemo makeup, prostheses, hair wraps, and other must-haves for women with breast cancer. Given the prevalence of breast cancer, American marketers have rightly recognized the demographic importance of addressing breast cancer in some way. Obviously, many of these products are useful, but Ehrenreich also suggests that the breast cancer philanthropy movement serves just as much public relations and profit-making functions as it does trying to solve the problem.

The most fascinating example of private sector foundation support for breast cancer research is the Avon Foundation. Through its Breast Cancer Crusade, Avon has targeted biomedical research conducted to understand racial and ethnic disparities in care. This approach is unique in that the organization requires grantees to fulfill social as well as biomedical missions. The results, which are just beginning to emerge, are remarkable: the Foundation is using its money to leverage change in the way breast cancer research is done, who is doing the research, and the populations that are being included. Through grants to individual researchers and its own Centers of Excellence program, Avon insists on the inclusion of underrepresented groups in research protocols, and the development of women scientists working on breast cancer research. To do so, the research institutions have had to address such novel issues as transportation, translation, and child care. With relatively small amounts of money, Avon is helping the biomedical research community to address institutional factors that have traditionally limited its ability to address important population-based questions.

More astonishing still is Avon's use of its funds to jump-start new approaches to breast cancer research at various levels of government. The oldest of its efforts has included the development of grassroots and community service providers. For several years, Avon has been implementing institutional change in the research process through its Centers of Excellence. Most recently, Avon undertook two unprecedented steps in 2001. The first astonishing move was to give 20 million dollars to the federal National Cancer Institute. The funding was earmarked for spending to increase underrepresented group participation in clinical research trials. Although NCI had nominally supported such a goal, few resources were expended to address the barriers to involvement. The Avon funding bombshell obliterated the funding excuse.

Another example of Avon sponsorship of government breast cancer research efforts is its 7.5 million dollars of support for the new Georgia Cancer Coalition. The Georgia effort and its Coalition are discussed in great detail in the next case study. Briefly, Avon provided seed money to the Coalition to help it develop cancer research infrastructure explicitly tailored to addressing population needs, including disparities in research. In effect, Avon is sponsoring the development of a knowledge value collective that conceptualizes the cancer research enterprise broadly, including various actors in addition to scientists and funding agencies.

To summarize, there are a variety of funding agencies devoted to breast cancer research. In particular, the last ten years has seen a remarkable proliferation of federal, state, and private institutions that are devoted to such research. In most cases, funding agencies are following the lead of the National Cancer Institute in defining cancer in primarily biomedical terms, sponsoring research at the biological and molecular level over environmental, social, or behavioral levels of analysis. Some new initiatives, such as that in California, have taken the opportunity to push and expand breast cancer research into new disciplines, and to address the needs of special populations. Foundations have generally followed the lead of the biomedical research community, deferring to the priorities and processes established by academic scientists. A distinct exception is that of the Avon Foundation, which conceptualizes biomedical research as occurring within a social and institutional matrix that can hinder or help progress on breast cancer. Its funding strategy is explicit in its requirement that researchers address the population issues as a fundamental part of the research design strategy.

Lessons from the Federal Effort in Breast Cancer Research

In the federal case study, we have sought to evaluate the nation's breast cancer research effort in its ability to meet articulated public values. In brief, we discovered that the flagship institution of cancer research, the National Cancer Institute, has done little to change its simple input-output model of science by and for scientists. The analysis shows four particular areas of weakness that have led to a fragmented and only partially responsive national research effort in cancer research. These weaknesses are: a lack of integration into publicly accountable bodies; a concentration on micro level perspectives to the virtual exclusion of meso and macro level perspectives that may have greater potential for population impact; the lagged effect of over 60,000 scientists nationwide responding to the flawed prioritization process of scientific peer review and the NCI; and a public failure in fostering a diverse national knowledge value collective, resulting in a proliferation of funding agencies devoted to research.

First, the National Cancer Institute is not integrated into the publicly sanctioned hierarchy for articulating and meeting social goals. Its bypass budget authority makes it independent of the efforts of the National Institutes of Health, and the Department of Health and Human Services to prioritize cancer-related efforts. The meteoric rise in the National Cancer Institute has occurred in a policy vacuum in which there have been few democratic or bureaucratic demands for performance accountability. Congress and the executive branch must insist on accountability from the National Cancer Institute, and should begin by making it subject to the same laws, policies, and procedures—including GPRA—that govern every other aspect of the national health effort.

Second, the National Cancer Institute has persisted in investing the lion's share of its resources in the search for cellular (and smaller) solutions to cancer. While this micro perspective is useful and interesting, it is limited in its ability to address cancer-related issues at larger levels of aggregation. It is unlikely that micro approaches can inform us much about organs, systems, organisms, individuals, groups, populations, or environments, each of which is a poorly understood component of the disease process. As a result of this scientific bias, the scientific community devoted to cancer research has tended to develop and maintain peer review and work norms that privilege micro perspectives over others. This has led to an anemic knowledge value community, which fails to incorporate relevant disciplinary perspectives, or diverse social institutions and actors that could help solve some of the cancer mysteries. Given the massive increases in the NCI budget, there are sufficient resources to be expended to expand research into new areas, and to invest in developing scientific talent at various levels of analysis.

Finally, multiple public failures in the established cancer research community have resulted in an interesting proliferation of policies and organizations that attempt to address some of the issues. In most cases, attempts to broaden cancer research topics and knowledge value communities have failed because new institutions have tended to look to NCI for guidance to model the new efforts, and because the scientists qualified to conduct cancer research are limited by the system that privileges certain forms of inquiry over others. Nevertheless, a couple of institutions have succeeded in questioning some of these basic premises, and have succeeded in expanding the scope of cancer research. The confluence of two of these entities—Avon Foundation and the State of Georgia—is the subject of the next case study.

New Institutional Research Approaches in Georgia

In the federal case study, we determined that there is too much reliance on the simple model of research effectiveness articulated by Bozeman in the theoretical monograph. The simple model suggests that undirected expenditures in basic science will ultimately result in positive social impacts. What we observed, however, is that scientific expenditures based on scientific priorities alone resulted in a proliferation of organizational forms attempting to redress the problems with that approach. The result was an uncoordinated system of funding agencies contributing to a fragmented cancer research Knowledge Value Community defined almost entirely in terms of the basic scientific research community itself. Although other actors and funding agencies are involved, there is a lack of integration at various levels that would allow a focused approach to affecting social outcomes. Importantly, members of the national KVC identified some of the problems, and are seeking to establish new models for directing scientific research toward acknowledged public values. In this next case, we examine the efforts of Georgia over the last three years, and apply PVM methodology to a prospective evaluation of its prospects. In this way, we hope to demonstrate that PVM may also be used as a tool to identify areas for improvement in complex plans to link science to social objectives. Specifically, we hope to identify stress points in the current system, and to evaluate plans for strengthening them. Furthermore, we will assess what links are not present, but should be, and to evaluate links that are not working as effectively as planned. Ultimately, the chief objective is to identify aspects of the system design that can be modified during the developmental stages to meet social objectives more effectively.

Political Leadership

As with Nixon’s national “War on Cancer,” the State of Georgia has a strong executive advocate in its former Governor, Roy Barnes.[1] The focal organization of this case study is the innovative Georgia Cancer Coalition, the outcome of a fascinating interplay of elite activism, economic opportunity, and populist appeal. One of the early important players is one of Georgia’s native sons, Hamilton Jordan, who served as President Carter’s Chief of Staff. A survivor of bouts with three different cancers, Jordan is influential within the Democratic Party, but utterly compelling in his advocacy for cancer prevention, research, and treatment (Jordan 2000). The imminent windfall of the national tobacco settlement presented the fiscal opportunity to conceptualize and implement a comprehensive cancer plan for the state. Jordan’s personal and political charisma joined forces with entrepreneur Michael Johns and renowned oncologist Jonathan Simons to develop a population-based research and economic development plan. Barnes’s own expertise in health care policy and financing was an important component of this “kitchen cabinet” (Wahlberg 2002).

Barnes is particularly astute in balancing the desires of a rapidly expanding economy and its participants with the needs of a marginalized poor population that is largely credited with providing him his margin of victory in the 1998 election. In cancer, Barnes identified a threat to Georgians in the disproportionate impact of cancer in Southerners, and to poor, rural, and minority Southerners in particular. At the same time, he identified an opportunity to attract biotechnology investments in research and industry. His twin objectives of reducing the burden of cancer in all Georgia populations, and developing the economy through biotechnology are better defined and more easily assessed than President Nixon’s naïve hope to defeat can-

---

[1] Although the new Governor, Sonny Perdue, opposed Roy Barnes on most issues, he agreed that the Georgia Cancer Coalition should remain a top priority in the state. It is not likely that the momentum of the GCC will be lost in the new administration.

cer through more research. What distinguishes Georgia's approach from the national effort is a more developed critical understanding of the limits of academic research alone to realize social impacts.

As in the national effort in the early seventies, Georgia is poised to make substantial investments in the development of cancer-related scientific infrastructure. What makes this effort exciting is the intentionality with which the planners are addressing the task of helping the research and service infrastructure meet the population's needs, a linkage that has been explicitly recognized as critical only recently. The case study begins with an evaluation of the social objectives, as codified in legal and policy documents, and in organizational mission statements. As with the national assessment, this application of Public Value Mapping (PVM) assumes that such statements are codified outcomes of socially-sanctioned deliberative processes for articulating social objectives in a democratic society.

Cancer-Related Public Values in Georgia

In the past, cancer certainly has been a focus of concern in Georgia. The headquarters of the Centers for Disease Control and Prevention and the American Cancer Society, as well of the location of several top research and medical universities, translate into good coverage of cancer-related epidemiology and research. As a political and economic focus, however, cancer has only recently come to command concerted attention. A convergence of elite attention to the issue translated into a will to create the institutional infrastructure to address the cancer problems in the State.

In a recent Atlanta Journal Constitution interview (AJC 2002), Barnes recounted a presentation given by several prominent Georgia citizens. Hamilton Jordon, President Carter's former Chief of Staff and three-time cancer survivor joined forces with Dr. Jonathan Simons, an internationally renowned cancer researcher, and Dr. Michael Johns of Emory University to articulate the case for attracting more talent and resources to Georgia to fight cancer. Over the course of the year, the idea was further developed into a well-articulated plan to be implemented through the Georgia Cancer Coalition. As in the National Cancer Institute case, we take the articulated goals and objectives to be a codification of the public process of values clarification.

The mission of the Georgia Cancer Coalition, the central institution devoted to cancer in the State is, "To make Georgia a national leader in cancer treatment and research by accelerating research, prevention, early detection, and treatment." Specific goals of the Coalition include:

1. To prevent cancer and detect existing cancers earlier.
2. To improve access to quality care for all Georgians with cancer.
3. To save more lives in the future [by developing research infrastructure]. And
4. To realize economic benefits from eradicating cancer.

The first goal implies the need for attention to environmental, social, and behavioral factors, and to improved access to an participation in screening. The second goal, related to the second part of the first, is to improve access to treatment. The fourth goal relates to economic benefits from eliminating cancer (but which also may be conceptualized to include those economic development activities that result from the effort, even without the elimination of cancer).

The third goal, the one of greatest interest to this monograph, is the least well articulated. The causal logic of the Georgia initiative is that improving research infrastructure—broadly defined—will bring about a reduction in the cancer burden in the population. At the national level, this "trickle-down" research logic has not led to improvement of health outcomes, or uneven improvement at best. However, the planning and implementation of the Georgia Cancer Coalition is being conducted differently than traditional biomedical research efforts, and may in fact succeed where other research outcomes paradigms have had limited to no success. Before a more detailed examination of the institutional and organizational forces arrayed to improve outcomes, I will discuss specific cancer-related health indicators as they relate to Georgia.

Social Impacts in Georgia

The key feature of PVM is the explicit analytic objective of tying public values to measurable social outcomes. The articulated public value in Georgia's cancer plan is to reduce population cancer burden and disparities, to develop the economic and research infrastructure to support this objective, and to improve economic development in the state. In this section, the incidence, prevalence, and distribution of cancer in the population is described. This is followed by a description of the current status of biotechnology-related investment in Georgia.

According the American Cancer Society, there will be an estimated 31,600 new cases of cancer in Georgia, and 13,700 deaths during 2002 (ACS 2002). These numbers translate into an age-adjusted mortality rate of 211.8 per 100,000, substantially higher than the national average of 206. Overall, Georgia ranks in the middle of states in the burden of cancer in its population (CDC 2000). The incidence of breast cancer in Georgia is 5,200; 1,000 will die of breast cancer this year (ACS 2002). As with the national data, there has been an upward trend in breast cancer incidence in the state since the 1970's. In marked contrast to the national profile, in which white women are more likely to develop breast cancer, Georgia black women are equally likely to develop breast cancer. This pattern, which is depicted in Figure 10 has developed only during the last decade; prior to 1992, black Georgians followed the national tendency for lower breast cancer incidence (GCCS 2000).

Overall Georgia cancer mortality rates tend to mask important racial disparities in mortality. Georgia Whites are 27% less likely to die from cancer than Blacks (Guthrie 2002). For example, the overall breast cancer mortality rate in Georgia is 28.3 per 100,000, somewhat below the national average of 28.8. For whites, the rate is 25.9, better than the national rate of 28.2. For blacks, however, the rate is 36.4. Although this is better than the average national black mortality rate of 37.1, blacks in Georgia are much more likely to die of breast cancer than whites (CDC 2002). Black women in Georgia are 36% more likely to die of breast cancer then whites (PHA 2000). The racial parity in incidence rates stands in marked contrast to the racial disparity in breast cancer mortality. Simply put: whites in Georgia are more likely to be cancer survivors.

In addition to racial disparities, there are substantial regional disparities in cancer incidence and mortality in Georgia. Figure 11 shows the overall cancer mortality profiles by Georgia County (GCCS 2000). There are two distinct patterns: first, the most rural and underdeveloped areas of the state have higher than state average cancer mortality rates, and the Atlanta metropolitan area as a whole does better than the state average. Even within the 20 county Atlanta region, however, there are rural and income related disparities in mortality. For example, Fulton County, which encompasses the City of Atlanta's predominantly African American and poor population, has a higher than average cancer mortality rate. By contrast, the affluent white Atlanta counties of Cobb, Gwinnett, Rockdale, Cherokee, and Forsyth have lower than average cancer mortality rates (GCCS 2000). Importantly, the affluent and majority black DeKalb County also has lower than average cancer mortality rates, suggesting that poverty may be more important than race in determining mortality rates.

The demographic outcomes variables are easy to measure and track. By contrast, the social outcomes indicators to mark success in developing the biotechnology sector in the state are more indirect. For example, a critical objective of the Georgia initiative is to improve the scientific and human capital stock related to cancer research. The program logic is to attract top researchers to the state, which will in turn attract research investments from other public and private institutions. Georgia's Universities already are investing in improved human capital in these areas. In particular, Emory University has attracted top national talent to the cancer initiative, including some who were previously committed to the health disparities project housed at National Cancer Institute. In addition, Georgia Institute of Technology and the University of Georgia continue to invest in genetic, biotechnology, and bioengineering programs, including developing faculty and research infrastructure. Therefore, indicators of scientific and technical human capital success include such factors as faculty growth in the area, university programs, laboratory infrastructure, and ability to attract top scientific talent and to develop career and training ladders to develop such talent in-state. Success in these areas is likely to translate into greater ability to garner research funds from the National Cancer Institute and other cancer research funding organizations. Therefore, another indicator to track is the growth in outside funding for cancer-related scientific research.

Early evidence shows that Georgia is making progress attracting top talent to the state. By the beginning of August 2002, the Coalition had recruited 40 clinicians and researchers to the State; the overall goal is to attract 150 new scientists. Will the talent being drawn to and developed in Georgia attract funding from the National Cancer Institute and others? Will the scientific research cover the range of population-related objectives, or will it target molecular magic bullets like its federal cousin? Suggestions for prospective assessment of these questions are included in the lessons section of the case study.

In addition to attracting basic research dollars to the state, the concentration of scientific talent is also expected to attract greater investment by the biotechnology industry. Furthermore, concentrations of scientific intellectual talent are also expected to create new biotechnology firms within the state. Current baseline indicators include the number of life sciences companies (169), which has grown from 69 in 1993. Furthermore, 4,000 new life sciences jobs have been added over the same period (Bryant 2001). Georgia is currently ranked 11th by Ernst & Young in the biotechnology presence. Clearly, there is a promising foundation for biotechnology to flourish in the state. It is critical for the GCC to create additional baselines for assessing progress in developing biotechnological investments in the State. There are a number of trade organizations that could help develop such indicators as the number of scientists and technicians, current laboratory capacity, scope of research problems and projects, and linkages with universities and government laboratories.

The mission of the Georgia Cancer Coalition is to meet population needs through scientific research and biotechnological development. Any one of these three legs of the triangle would have significant social impacts, by improving population health, expanding scientific and technical human capital, and by increasing the economic vitality of the State. The population focus and the availability of a majority of the populace for research have the potential to attract researchers and firms that can take advantage of the opportunity insurance coverage for research confers. Additionally, the interaction of academic researchers and the biotechnology industry can lead to new scientific developments, including new treatments of potential benefit to all people. A potential problem with this triumvirate is that it may lead to an exclusive emphasis on micro approaches, which may crowd out cancer research that has the potential to effect changes at the unprofitable social level.

Linking Research to Social Objectives in Georgia

The accompanying monograph by Bozeman discusses the limitations of traditional research evaluation in detail. In brief, research evaluation has typically focused on a simple input-output model in which resources are provided to primary investigators to pursue basic research questions; indicators of successful outcomes include publications, citations, and other academic achievements. Research assessment has not focused on how the scientific enterprise contributes to social outcomes of interest. In Public Value Mapping, these outcomes are only one part of a complex whole in which scientific researchers are but one critical component. The Georgia case is interesting because the cancer initiative from its inception has been designed to use scientific institutions to achieve progress in the population and economic development objectives just described. As such, it is an ideal case for an application of the Public Value Mapping approach to prospective, formative evaluation.

The Cancer-Related Knowledge Value Community in Georgia

As elaborated by Rogers and Bozeman (2002), the churn model of research organization applies when the scientific project has diverse knowledge objectives. The project as a whole generates a Knowledge Value Community (KVC) that evolves to encompass the complexity of the mission. For example, diverse knowledge objectives imply that parties external to the scientific community are critical. Furthermore, the incorporation of diverse actors into the enterprise makes the very nature of the knowledge development corporate, inter-organizational, and inter-institutional rather than individual or institutionally focused. A further corollary is that the broad undertaking is not easily contained in one field or discipline.

Early on, Barnes and his advisors supported the development of an entirely new, non-profit institution to develop the inter-institutional and interdisciplinary networks necessary for meeting diverse objectives. This institution, the Georgia Cancer Coalition, is conceptualized as a spoke in a wheel of diverse actors engaged in developing and using a common body of knowledge. The knowledge development is planned to occur throughout the state at multiple service-research sites, including institutions serving the underserved, minorities, and veterans. Multiple sites are involved, the most notable academic leadership coming from Emory, with important support from the University of Georgia in biochemistry and genetics. Georgia Institute of Technology and Emory continue to develop their joint program in bioengineering. It is expected that Medical College of Georgia in Macon will assume leadership in other parts of the state. The inclusion of the Medical College is likely to be critical to the success of the effort, as so much of the demographic impact of cancer is disproportionately born by the State’s rural population. The Georgia Cancer Coalition, which is effectively only a yearling organization, is poised to tie the “network” –KVC in our parlance—together. Through GCC, knowledge value alliances will emerge to develop the capacity to conduct clinical research while providing integrated care.

The Georgia cancer effort conceptualizes population outcomes and research development to be complementary objectives. As such, the project logic model is based on the premise of using population coverage to attract research and researchers, and to use research to affect cancer-related population outcomes and to further attract and foster biotechnological development in the state. In the language of a KVC, these are examples of diverse knowledge objectives that have not traditionally been conceptualized in relation to one another. The Georgia conceptualization also includes a very broad definition of the stakeholders and participants in the research. From an organizational perspective, it includes an intention to incorporate governmental (federal, state, and county), academic, medical care (hospitals, clinics), and private (insurers, pharmaceutical, philanthropic). In addition, it seeks to incorporate the ultimate “users”—in this case, the population—which are not typically conceptualized as central to other cancer research enterprises. The Georgia KVC is comprised of Georgia scientists, clinicians, funding organizations, businesses, politicians, patients, and institutions using biomedical and behavioral research to decrease cancer mortality rates in the state. The objectives are varied, from wanting to live longer, to developing networks of researchers and clinicians, to attracting top science talent, to infusing energy into the biotechnology industry. Furthermore, the activities of the planned KVC are highly varied, including: basic research, clinical trials, drug trials, publications, patient recruitment and care, procedures, drugs, services, economic development, and financing. Despite these diverse objectives and activities, all the participants belong to the KVC because they are part of a network that is developing and using a common body of knowledge, albeit for diverse instrumental objectives. The unique challenge for Georgia is how to tie formal organizations, research collaborations, industry partnerships, grants and contract agencies, patients and clinician provider together in ways that assist and inform rather than compete with one another.

Signs of Progress

The initial GCC effort includes the development of an executive board, which had its first meeting in 2002. One issue in the development of a board is its ability to represent a range of perspectives. This is critical for GCC because of the stated purpose of developing networks of diverse actors addressing cancer. Somewhat more than half of the Board is from Atlanta or its metropolitan region. The lack of widespread representation from the State as a whole suggests that the Coalition should ensure that the regional objectives of the initiative are met. Early evidence suggests that there are a number of contenders for Centers of Excellence, and geographic diversity represented among them. A key issue will be how the Coalition maintains momentum in areas that are not ultimately designated as Centers. To achieve the stated population objectives, their continued involvement will be important for success.

The Board of Directors includes a number of prominent politicians, physicians, financiers, community cancer organizations, and media personalities. As already noted, the prominence of the leaders behind Georgia Cancer Coalition is likely to be an important component of sustained effort and later success. Nevertheless, the Board does not appear to have representation by academic researchers, either biomedical or social. Because the success of the effort rests so squarely on the development of scientific talent and research infrastructure, it is important to consider developing the Board further to include members who can speak to these issues. Furthermore, because the success of the outcome will be measured in part by population indicators, it is important to have public health representation on the Board. Given Georgia’s national prominence for public health organizations, it should not be difficult to make such appointments, which will further lend national credibility to the effort.

Indeed, parties traditionally excluded from basic cancer researchers are critical components of this innovative approach. Without political leadership from the Governor, operational leadership from the Georgia Cancer Coalition, and financial leadership from Avon Foundation and the Georgia legislature, the Georgia Cancer Coalition KVC would be a more traditional type of simple-input, simple-output medical research project. The Governor and his influential “kitchen cabinet” have already been discussed. They provided the political leadership necessary to garner support for using the tobacco settlement to fund a cancer initiative, but it still left a great deal of latitude about how, precisely, such an effort would be organized.

In terms of KVC development, it will be interesting to see how effective the institutions are in working with “downstream” users, for example, rural health clinics or front-line physicians. In effect, this objective requires that a broader array of clinical actors be brought into the research enterprise, which has not always been high in the priority of the Carnegie Research Universities. Ultimately, however, the integration of clinicians, community members, and patients into the KVC may lead to research on more relevant macro-level research questions, and greater capacity for clinical and general populations to benefit from cancer research by developing linkages between researchers and community providers. Theoretically, this will lead to better understanding of clinical oncology problems, and ultimately to a systematic transformation of how research is typically conducted. In effect, the concept of linking academic researchers, clinicians, and patient populations within the research enterprise promises to widen and perhaps pave some of the “two lane country road” that the National Cancer Institute so often laments, but so rarely does anything to mitigate.

In addition, expanding bases of research require innovative and new financing. On that front, Barnes persuaded the Legislature to allow Medicaid to cover participation in clinical trials. Even more remarkable, the State’s major insurers have also agreed to cover participation in clinical trials. If successful, the Georgia initiative will expand the scientific and technical human capital capacity in the state to cover more of the population over a broader geographic area.

One of the problems with the GCC spoke and wheel analogy, however, is that it represents only one type of network model, and probably not the best one for this type of activity. It is crucial that GCC is centrally located in the network, but it is also critical that as linkages occur, it does not become an information or logistical bottleneck. Ideally, GCC should position itself to develop network linkages and to monitor the content of those linkages. Its unique contribution to the state effort then will be to understand the many components of the whole effort, and how they interact with one another. In this way, GCC will be uniquely positioned to identify new opportunities or barriers to network effectiveness. It will also be very important to leverage scarce administrative and policy resources. Currently, GCC has only three graduate-level professionals working full-time. Although additional help is likely, it is politically important that GCC not develop into the kind of normal bureaucracy that Governor Barnes wanted to avoid in the first place.

Besides the obvious interdisciplinary nature of clinical practice, one of the most interesting questions as the Georgia KVC evolves is whether it will incorporate knowledge from the social and behavioral sciences, which is critical to any success in affecting the mortality rates and, in particular, the regional and racial disparities in cancer mortality. This is a both a STHC issue and a social configuration problem. Early evidence from the composition of GCC board membership and key research actors suggests that the development of social and behavioral scientific research is not a top priority. As discussed in the National Cancer Institute case, however, the inclusion of such perspectives is important for developing a comprehensive cancer research portfolio that does more than seek the ever-elusive silver cancer bullet. Failure to address social and behavioral components of cancer incidence, prevalence, and mortality may constitute a sufficient condition for failing to meet societal outcomes objectives. At this stage in GCC development, it certainly is not too late to develop greater attention to these issues in the design of the network, and the development of the Knowledge Value Community related to cancer.

Ultimately, public value mapping and scientific and technical human capital theory (Rogers and Bozeman 2001) will provide theoretical guidance for characterizing the evolution of the cancer Knowledge Value Community and emerging alliances. First, the focal research organization, Winship at Emory worked as a “single sector sporadic exchange.” With the entry of Avon and the development of Georgia Cancer Coalition, the KVC is developing into a “multiple sector mutually adapting” KVC, with the clinical needs providing an important part—but not all—of the “industry” component. In the future, it will be interesting to see if the KVC evolves into different or more complex KVC’s. The emergence and development of the GCC is likely to result in at least one—and probably more—formal organizations to facilitate exchanges among members. One of the nice temporal properties of the Georgia case is there is a political and economic “start point” which is only a couple of years ago, and a sufficient degree of political will and financial backing to carry the project through its vulnerable early years.

Ultimate success will be measured by a reduction of cancer burden in the population, and the development of research and economic infrastructure related to biomedical research and cancer. In the course of meeting these goals, important intermediate indicators of GCC success should include an assessment of the geographic range of effort to ensure that all areas of the state are benefiting. A related issue is the population dispersion of effort. Will all groups be represented, and enjoy benefits? The research infrastructure should be evaluated at least in part by intellectual diversity and output of the effort. For example, to what degree will efforts other than biomedical be employed, and how will the multidisciplinary perspective lead to new and more elaborated research models? Although the primary focus of the Georgia effort is Georgia, there is potential for new approaches to research organization to spread in the scientific arena. Such innovation in research organization has been documented in the national laboratories, and is beginning to be documented in National Science Foundation Research Centers.

Lessons from the Georgia Effort in Cancer Research

The Georgia case is new, and it is impossible to expect measurable outcomes at this stage of its initiative. As such, this section could just as easily be conceptualized as lessons “for” Georgia. These include the need to plan for, and track, diversity of research; to broaden representation; to develop effective network models in the Coalition; and to document the organizational innovations occurring as a result of the initiative.

Efforts should be made to capture the volume and type of funding that is leveraged in the future. In particular, the Coalition should track the diversity of the research portfolio that is developed to ensure that the research mix can reasonably be expected to improve population outcomes. Portfolio planning should include explicit attention to the development of environmental, social, and behavioral research, all areas that are likely to yield benefits in cancer control and prevention. These funds are available, even from the conservative NCI, but the Coalition needs to conceptualize their importance to the overall effort. Furthermore, additional funding requests should also include attention to the population issues that make the Georgia effort unique. Although it is more difficult, research groups should explicitly address disparities issues in subsequent research. Otherwise, the portfolio as a whole may drift toward less of a population focus, and have less of an impact on desired social outcomes. Greater involvement with the national program may lead to the biomedical entrenchment that has been documented in other NCI-dominated KVCs. Hence, the national problems that plague the NCI and DoD portfolios could easily be imported to Georgia if sufficient human resource and portfolio planning is not instituted early in the process of institutionalization. Furthermore, the twin goal of strengthening the biomedical industry in the State may create additional barriers to implementing a research system that incorporates a variety of perspectives.

Second, the Coalition should broaden representation on its Board and constituent entities to include geographic, political, occupational, institutional, and disciplinary breadth. Geographic and political diversity is particularly important to protect the future of the Coalition, and its financing source, especially in light of the State’s budgetary crisis and its new leadership. Conceptually, the effort will also benefit from a broader range of representation from other professions, including academic science, public health, and government. This will yield a greater ability to address the difficult portfolio issues outlined above.

Finally, the Georgia Cancer Coalition is in a unique position to broker and monitor relationships throughout the state, across institutions, and between populations. However, because of its size, and the delicacy of its position, the spoke-and-wheel network may not be the most effective strategy. The efforts of the Coalition and its constituent parts are already leading to new organizational forms. Therefore, the Coalition should document these forms and their effectiveness, and use them for modeling effective network structures for this context.

Conclusion

Public Value Mapping methodology (Bozeman 2002) asks evaluators to examine scientific capacity to meet socially-defined scientific objectives. This is a very different outcomes focus than examining the dollar value of research, the number of articles written and cited or even particular treatment modalities. In the case of breast cancer research on which we focused here, PVM provides a tool for evaluating the extent to which the scientific community as a whole has the capacity to address population-based breast cancer outcomes objectives.

Not surprisingly, we found that the National Cancer Institute is the primary sponsor of breast cancer research. We found that the focus of its research initiatives tends to micro-levels of analysis at the biological level and lower (cellular, molecular). This pattern persists despite massive increases in funding that would allow broader perspectives to be taken, and consistent public criticism of the composition of its research portfolios. More important, the pattern persists despite evidence that biomedical interventions do little to improve the breast health of the population. As a result, there has been a proliferation of breast cancer research funding organizations developed in the last 20 years. Because of their dependence on scientific expertise, however, few of these organizations have developed research portfolios that are substantially different from the prevailing biomedical model.

The Public Value Mapping methodology applied here allowed us to identify organizational actors in the breast cancer research domain that are behaving as innovators. The State of California, the Avon Foundation, and the Georgia Cancer Coalition are all examples of breast cancer research sponsors that seek to expand and extend research in order to address population-based objectives. The second case study of this analysis focused in particular on the Georgia Cancer Coalition, which is developing by creating linkages among academic researchers and clinicians and clinical populations in the state. Because it is designing in these linkages as part of its strategies, it is likely that the State's knowledge value community will develop new approaches for controlling and combating cancer. It is crucial that GCC maintain its population focus, and insist that research strategies meet social and population needs, as well as biomedical needs.

In effect, the application of the PVM methodology has allowed us to conduct a summative evaluation of the federal effort, and a formative evaluation of the Georgia State effort. We have used it to identify aspects of the research enterprise that limit the ability of academic science to address population objectives that are articulated by democratic institutions. We found that the National Cancer Institute is decoupled from its democratic anchors by its bypass budget authority. Why should NCI address the nation's breast cancer objectives when it is not accountable to the agency (HHS) charged with meeting them? Furthermore, it is unclear the extent to which scientific organizations are expected to meet GPRA requirements. We found that the ideology of "basic research leads to good things—just don't ask how or what" continues to thrive in the National Cancer Institute. As a result, the scientific community and the research it has the capacity to address is concentrated in areas of biomedical investigation, and sparse in social, behavioral, and population-based studies to examine how to avoid and limit cancer in the first place.

The Georgia Cancer Coalition is in the position to develop its cancer research portfolio to be broader and more population focused. The question to be answered is whether the leadership and will is present to expand research representation, especially in light of severe budgetary problems in the state, and the replacement of the GCC's executive champion by a new Governor. Despite these uncertainties, GCC is certainly heading in the right direction by conceptualizing research as an integral component of the population it must ultimately serve. Further research will seek to examine how these innovations are introduced, and the barriers and practices that hinder or help the development of an integrated cancer research knowledge value community in the State of Georgia.

REFERENCES

American Cancer Society. 2002. Breast Cancer Facts and Figures 2001-2002. Atlanta, Georgia.

Atlanta Journal Constitution. September 24, 2002. "Q & A with Governor Barnes on Cancer Care."

Avon Breast Cancer Crusade. Medical Research and Clinical Care. www.avoncompany.com/women/avoncrusade

Bozeman, Barry. 2002. Public Value Mapping Monograph. To Rockefeller Foundation via Center for Science Policy and Outcomes.

Bozeman, Barry and Juan Rogers. 2002. A Churn Model of Scientific Knowledge Value: Internet Researchers as a Knowledge Value Collective. Research Policy 31: 769- 794.

Bryant, Julie. December 7-13, 2001. "Governor Barnes Pledges to Back Biotech Industry." The Atlanta Business Chronicle.

California Breast Cancer Research Foundation. www.ucop.edu/srphome/bcrp.

Centers for Disease Control and Prevention, National Center for Health Statistics,

National Health Interview Survey, National Institutes of Health - Health, United States, 2000, Table 82.

Ehrenreich, Barbara. 2001. Welcome to Cancerland: A Mammogram Leads to a Cult of

Pink Kitsch. Harpers Magazine: November.

Georgia Center for Cancer Statistics. 2000. Downloaded from: www.sph.emory.edu/GCCS/GCCSdata/SEER7597/female%20breast.htm.

Guthrie, Patricia. 2002. Rebecca's Story. Atlanta Journal Constitution. September 29, 2002.

Harden, Victoria A. 2001. A Short History of the National Institutes of Health. Washington, DC: http://www.nih.gov/od/museum/exhibits/history/full-text.html.

Institute of Medicine. 1990. Breast Cancer: Setting Priorities for Effectiveness Research. Kathleen N. Lohr, Ed. Washington, DC: National Academy Press.

———. 1997. A Review of the Department of Defense's Program for Breast Cancer Research. Washington, DC: National Academy Press.

———.1999. The Unequal Burden of Cancer: An Assessment of NIH Research and Programs for Ethnic Minorities and the Medically Underserved. M. Alfred Haynes and Brian D. Smedley, Eds. Washington, DC: National Academy Press.

———. 1999. Ensuring Quality Cancer Care. Maria Hewitt and Joseph V. Simone, Eds. Washington, DC: National Academy Press.

———. 2000. Enhancing Data Systems to Improve the Quality of Cancer Care. Maria Hewitt and Joseph V. Simone, Eds. Washington, DC: National Academy Press.

———. 2001. Mammography and Beyond: Developing Technologies for the Early Detection of Breast Cancer. Margie Patlak, Sharyl J. Nass, I. Craig Henderson, and Joyce C. Lashof, Eds. Washington, DC: National Academy Press.

Jordan, Hamilton. 2000. No Such Thing as A Bad Day. Atlanta: Longstreet Press.

Partnership for Health and Accountability. 2000. The State of the Health of Georgia: Burden of Cancer.

Rogers, Juan and Barry Bozeman. 2002. Science, Technology & Human Values 31:769-794.

Susan G. Komen Foundation. www.komen.org. Dallas, Texas.

US Department of Health and Human Services. 2000. Healthy People 2010.

National Cancer Institute, National Institutes of Health - SEER Cancer Statistics Review 1973-96, Table IV-2, 3, & 11, and Review 1973-98, Table II-3, 4, 5, 6, 24, & 25, Table XV-3.

Wahlberg, David. 2002. Q & A with Governor Roy Barnes on Cancer Care. Atlanta Journal Constitution. September 24, 2002.

World Health Organization. 1948. Constitution of the World Health Organization (Official Records of the World Health Organization, no. 2, p. 100).

Table 1

Six Goals of the Department of Health and Human Services Strategic Plan

1. Reduce the major threats to the health and productivity of all Americans.
2. Improve the economic and social well-being of individuals, families, and communities in the United States.
3. Improve access to health services and ensure the integrity of the nation’s health entitlement and safety net programs.
4. Improve the quality of health care and human services.
5. Improve the nation’s public health systems.
6. Strengthen the nation’s health sciences research enterprise and enhance its productivity.

From: http://aspe.os.HHS.gov/hhsplan/intro.html

Table 2

HHS Operating Divisions, Labor Force, and FY ’01 Appropriations

1 Operating Division	2 % Emps	3 FY01 HHS $Bil	4 % HHS	5 % excl CMS	6 % excl CMS, ACF	7 % excl CMS,ACF IHS,HRSA SAMHSA
ACF	2	43.4	10.12	48.44	—	—
Aging	0	1.1	0.26	1.23	2.38	3.25
CMS	7	339.4	79.11	—	—	—
AHCQR 0	0.27	0.06	0.30	0.58	0.80	
CDC	12	4.2	0.98	4.69	9.09	12.43
FDA	15	1.3	0.30	1.45	2.81	3.85
HRSA	4	6.2	1.45	6.92	13.42	—
IHS	24	3.2	0.75	3.57	6.93	—
NIH	27	20.5	4.78	22.88	44.37	60.65
SAMHSA	1	3.0	0.70	3.35	6.49	—
SECRETARY	8	6.4	1.50	7.18	13.92	19.02

Total Labor Force: 63,000

Acronym Key:

ACF	Administration for Children and Families
Aging	Agency on Aging
CMS	Center for Medicare and Medicaid
AHCQR	Agency for Health Care Quality Research
CDC	Centers for Disease Control and Prevention
FDA	Food and Drug Administration
HRSA	Health Resources and Services Administration
IHS	Indian Health Service
NIH	National Institutes of Health
SAMHSA	Substance Abuse and Mental Health Services Administration
Secretary	Secretary and Staff Divisions

Source: www.hhs.gov/news/press/2001pres/01fsprofile.html
November 12, 2001

Figure 1
Strategic Vision:
Federal Health Policy

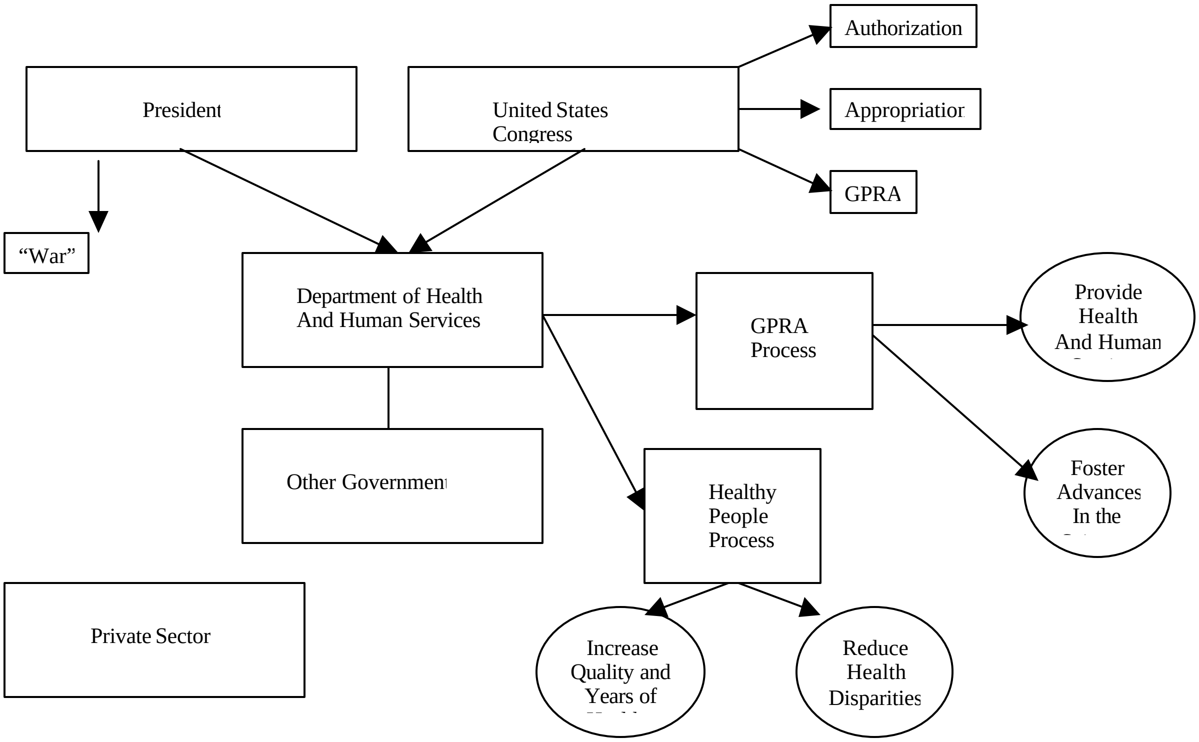


Figure 2

Breast Cancer Incidence and Mortality Rates (Age-adjusted)

Source Data: National Cancer Institute - SEER Cancer Statistics Review 1973-96, Table IV-2/3

Note: Age-adjusted to the 1970 US population

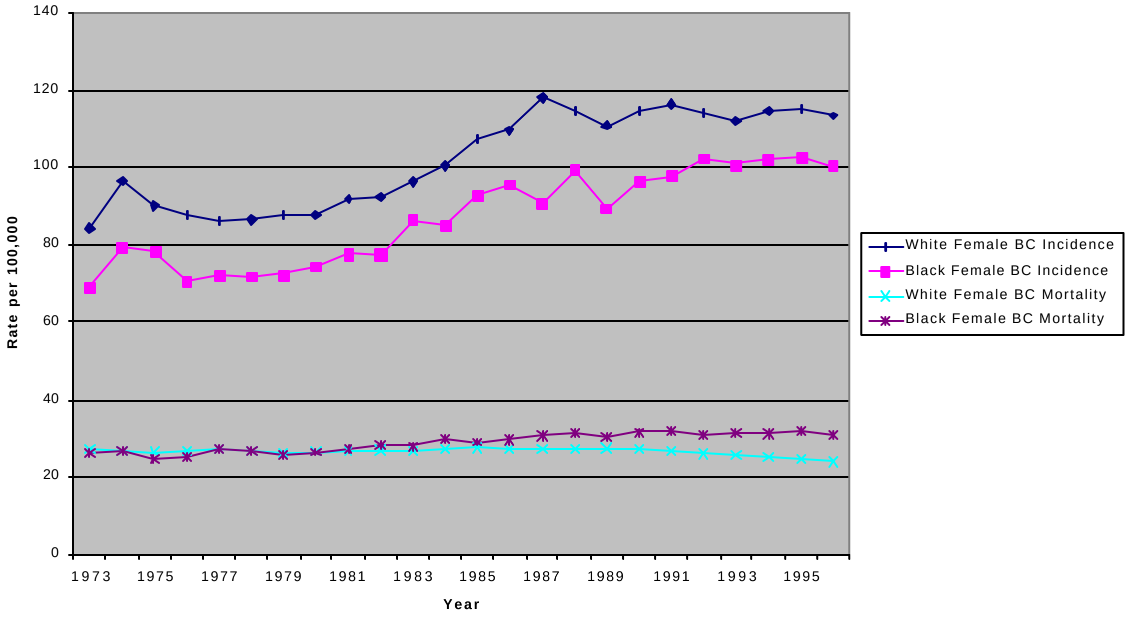


Figure 3

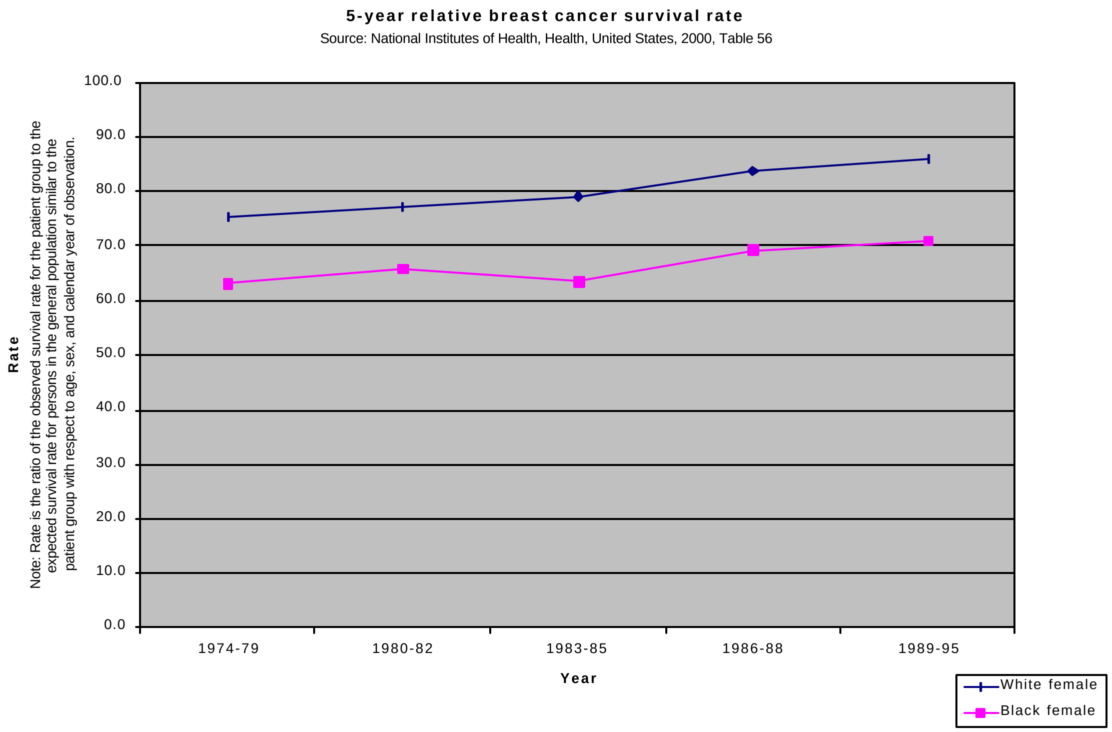

5-year relative breast cancer survival rate
Source: National Institutes of Health, Health, United States, 2000, Table 56
Rate
Note: Rate is the ratio of the observed survival rate for the patient group to the expected survival rate for persons in the general population similar to the patient group with respect to age, sex, and calendar year of observation.
100.0
90.0
80.0
70.0
60.0
50.0
40.0
30.0
20.0
10.0
0.0
1974-79
1980-82
1983-85
1986-88
1989-95
Year
White female
Black female

Figure 4

Mammography Usage by Race

Source Data: National Institutes of Health - Health, United States, 2000, Table 82

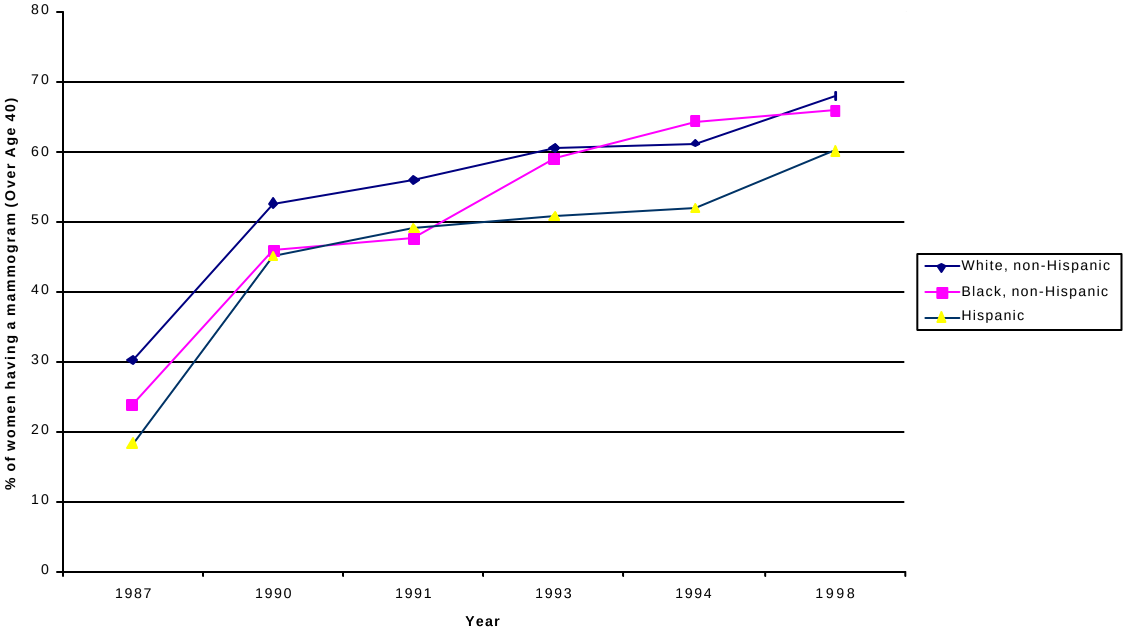


Figure 5
Department of Health & Human Services Organizational Chart

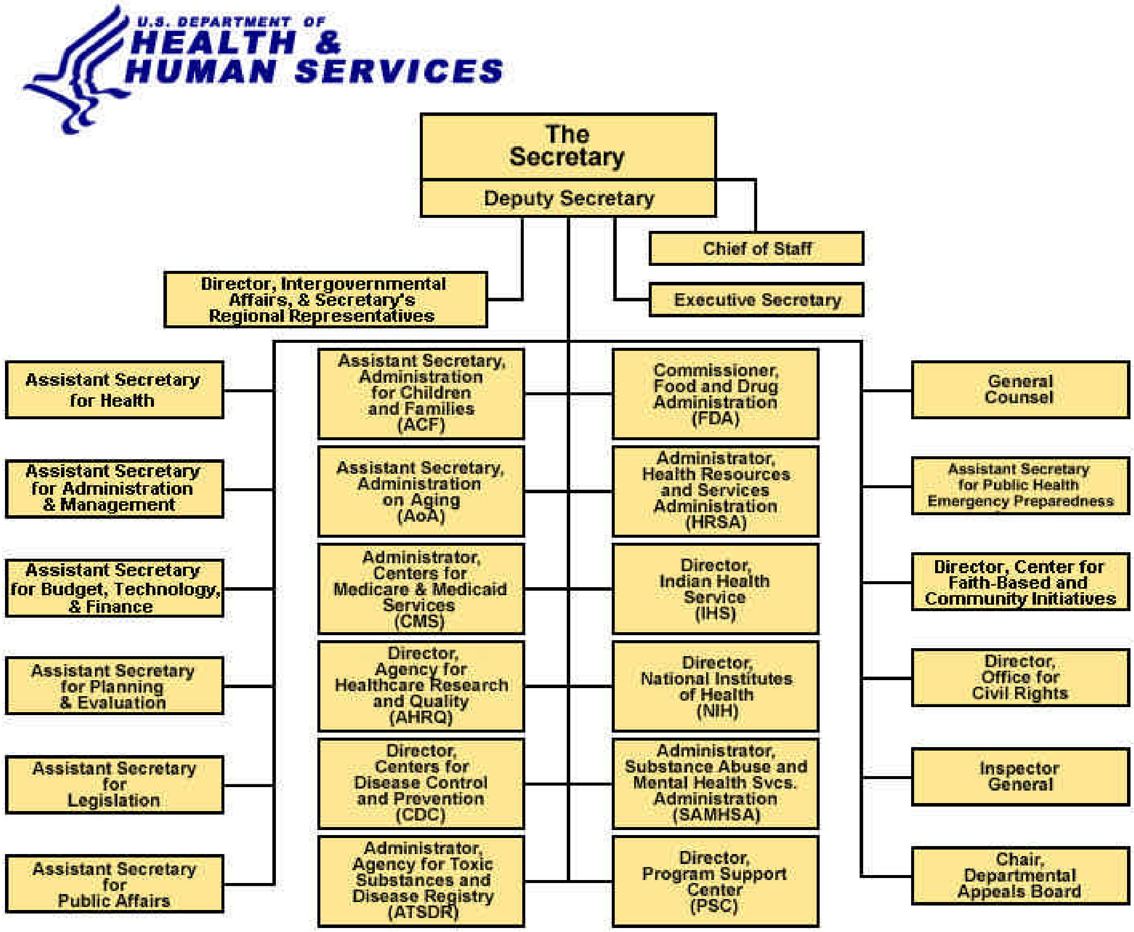
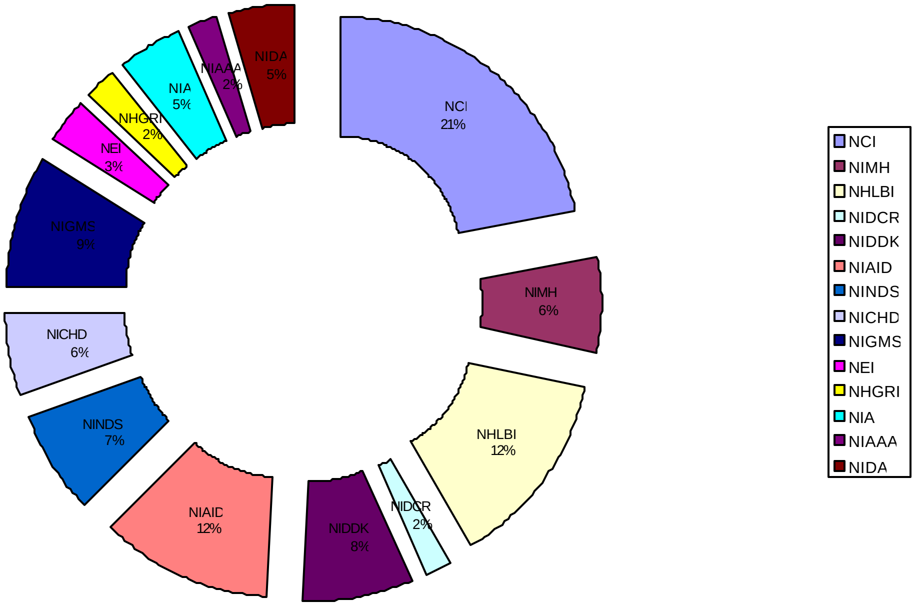


Figure 6
NIH Appropriations (FY 2000)



NCI	National Cancer Institute (1937)
NIMH	National Institute of Mental Health (1949)
NHLBI	National Heart Lung and Blood Institute (1948)
NIDCR	National Institute on Deafness and Other Communication Disorders (1988)
NIDDK	National Institute of Diabetes and Digestive and Kidney Diseases (1948)
NIAID	National Institute of Allergy and Infectious Diseases (1948)
NINDS	National Institute of Neurological Disorders and Stroke (1950)
NICHD	National Institute of Child Health and Human Development (1962)
NIGMS	National Institute of General Medical Sciences (1962)
NEI	National Eye Institute (1968)
NHGRI	National Human Genome Research Institute (1989)
NIA	National Institute on Aging (1974)
NIAAA	National Institute on Alcohol Abuse and Alcoholism (1970)
NIDA	National Institute on Drug Abuse (1973)

Not included:
National Institute of Arthritis and Musculoskeletal and Skin Diseases (1986)
National Institute of Biomedical Imaging and Bioengineering (2000)
National Institute of Dental and Craniofacial Research (1948)
National Institute of Environmental Health Sciences (1969)
National Institute of Nursing Research (1986)

Figure 7

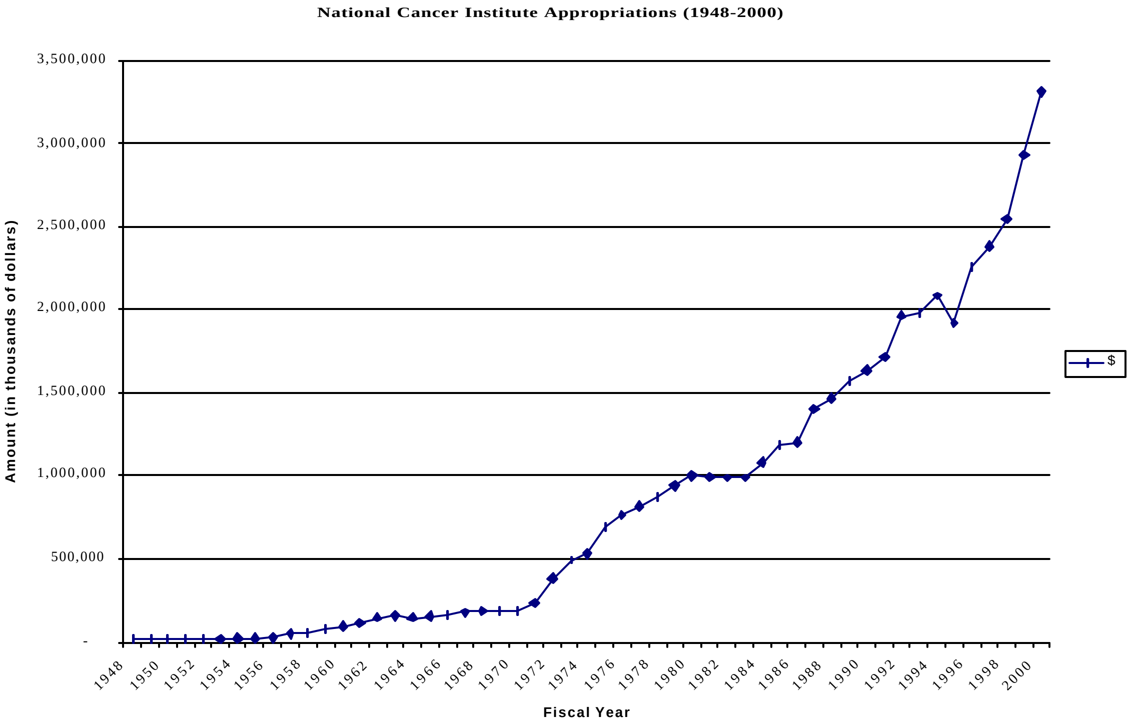

National Cancer Institute Appropriations (1948-2000)
3,500,000
3,000,000
2,500,000
2,000,000
1,500,000
1,000,000
500,000
-
Amount (in thousands of dollars)
1948
1950
1952
1954
1956
1958
1960
1962
1964
1966
1968
1970
1972
1974
1976
1978
1980
1982
1984
1986
1988
1990
1992
1994
1996
1998
2000
Fiscal Year
$

Figure 8: Strategic Vision and Social Outcomes: The Case of Breast Cancer

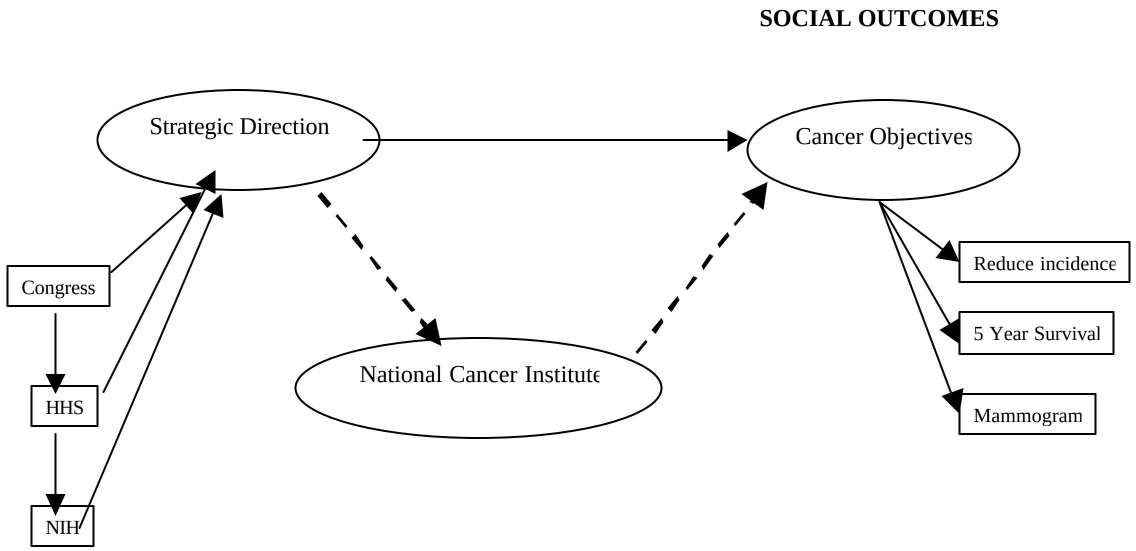


Figure 9: Opportunities in Cancer Research
Distribution of Breast Cancer Projects, by NCI Common Scientific Outline

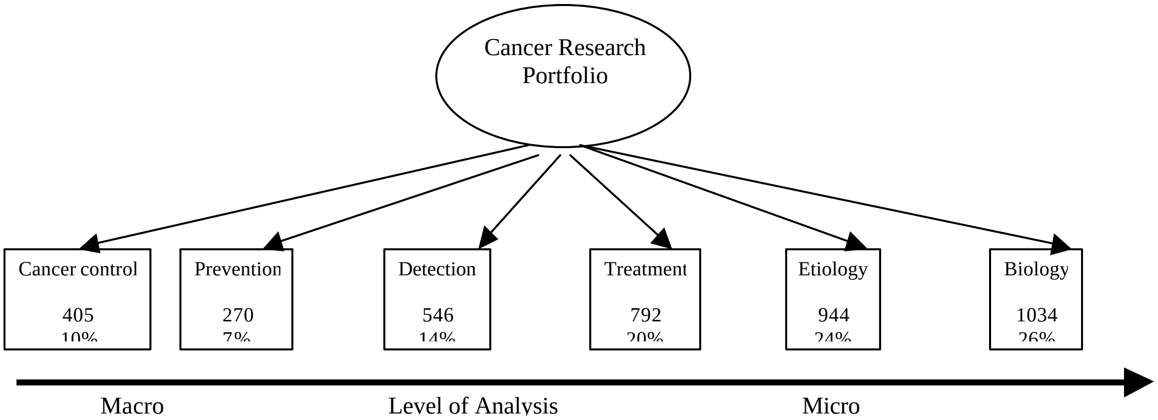


Figure 10

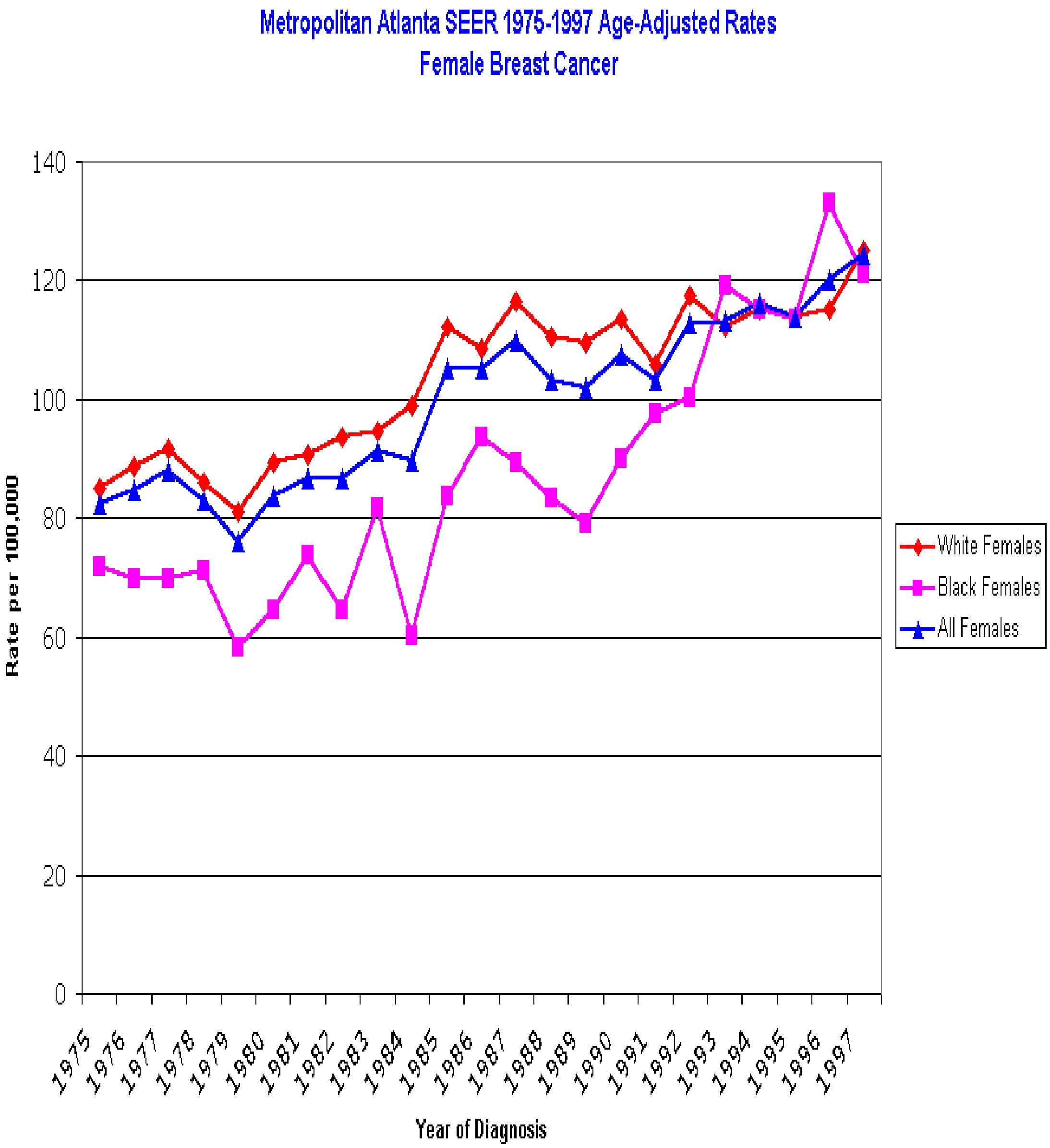
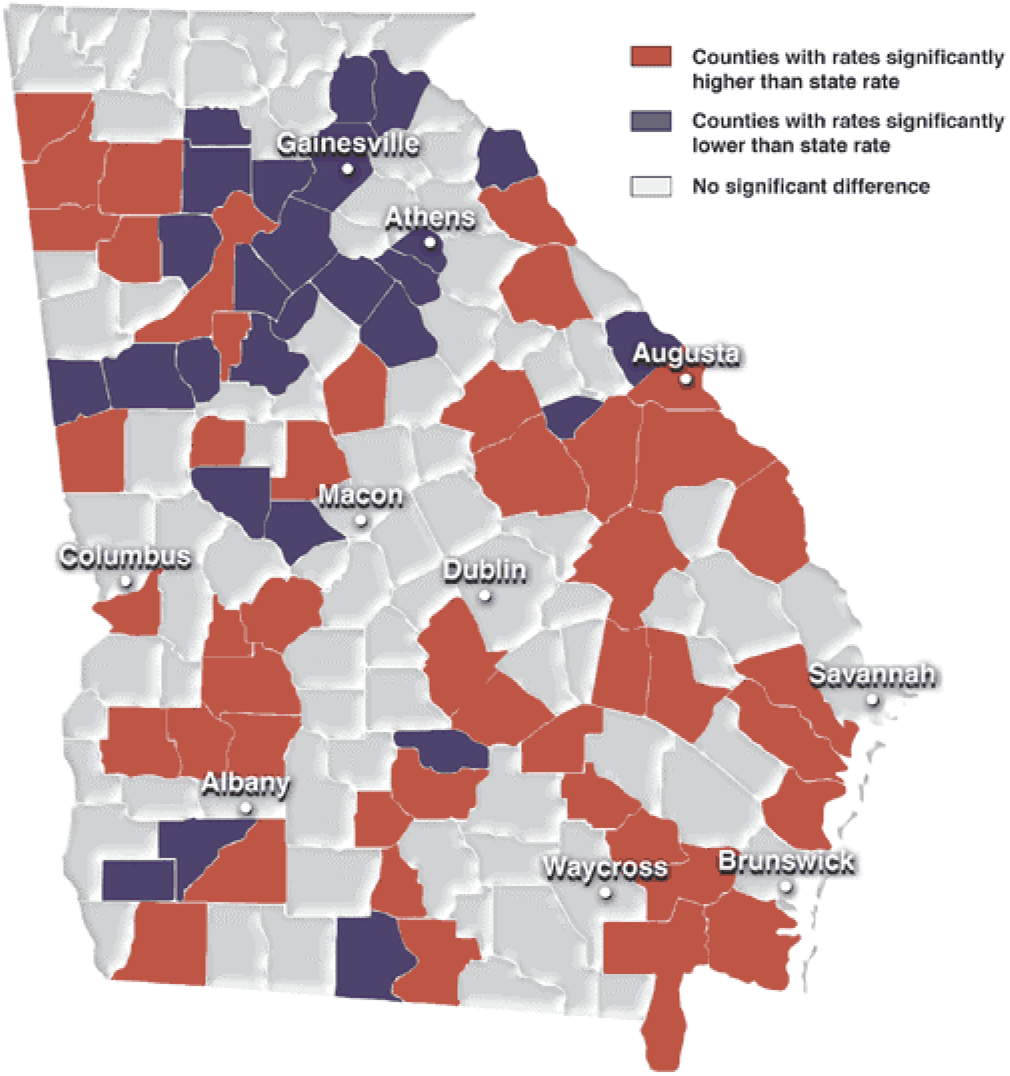

Metropolitan Atlanta SEER 1975-1997 Age-Adjusted Rates
Female Breast Cancer
Rate per 100,000
140
120
100
80
60
40
20
0
1975
1976
1977
1978
1979
1980
1981
1982
1983
1984
1985
1986
1987
1988
1989
1990
1991
1992
1993
1994
1995
1996
1997
Year of Diagnosis
White Females
Black Females
All Females

Figure 11

Counties with Significantly* High or Low Cancer Mortality Rates, 1994 - 1998



Source: Georgia Center for Cancer Statistics, August 2000
Rollins School of Public Health of Emory University