The Pennsylvania Comprehensive Cancer Control Plan

DECEMBER 2003

PENNSYLVANIA CANCER CONTROL CONSORTIUM PAC^3

"They came from all parts of the Commonwealth; they came from different backgrounds; they came from different professions—and they all came for the same reason: To create a common vision for the future of cancer control in Pennsylvania."

November 2001 Future Search Conference

"Together…Making our Vision a Reality"

This document summarizes the Pennsylvania Comprehensive Cancer Control Plan, which was developed for the Commonwealth by the Pennsylvania Cancer Control Consortium (PAC^3). PAC^3 is a volunteer collaborative group comprised of more than 190 stakeholders across the Commonwealth representing the healthcare community, cancer research centers, academia, community organizations, advocacy groups, insurers, state government, industry, and cancer survivors.

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Commonwealth of Pennsylvania

DEPARTMENT OF HEALTH

HARRISBURG

THE SECRETARY

December 2003

Dear Fellow Pennsylvanians:

The Pennsylvania Cancer Control Consortium (PAC^3) was formed in 2001 with the goal of developing the first statewide Comprehensive Cancer Control Plan (Plan). Comprised of health care providers, researchers, cancer survivors, advocates, insurers, and representatives from the Pennsylvania Department of Health and the American Cancer Society, PAC^3 has developed this Plan which spells out a five-year cancer control approach. The Plan will pull together people and resources from across our state to decrease the incidence of cancer among the citizens of Pennsylvania. Included in the Plan are efforts focused on eliminating cancer-related health disparities and ensuring the delivery of the highest quality of cancer care for all Pennsylvanians.

While considerable progress has been made in the fight against cancer, we all recognize that much more remains to be done. We have a wonderful opportunity to decrease the incidence and increase the survival rates of cancer through innovative, research-based cancer prevention, diagnosis and treatment. Among other strategies, this Plan will address healthy individual behaviors by providing social and environmental support in the communities, encouraging innovative tobacco research, promoting physical activity and nutrition in schools and communities, and increasing public knowledge about cancer screening.

We invite all to share the vision and the enthusiasm and to work together to implement the Pennsylvania Cancer Control Plan. By doing this, we truly can make a difference.

Sincerely,

Calvin B. Johnson, M.D., M.P.H.

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PREFACE

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In 2001, an unprecedented partnership was initiated in Pennsylvania by the Pennsylvania Department of Health to develop the Commonwealth's first-ever comprehensive cancer control plan, a plan designed to make a real difference in the lives of all Pennsylvanians. Since then, more than 190 stakeholders representing the healthcare community, cancer research centers, academia, community organizations, advocacy groups, insurers, industry, and cancer survivors joined with the Pennsylvania Department of Health and the Pennsylvania Division of the American Cancer Society (ACS) to form the Pennsylvania Cancer Control Consortium (PAC^3). PAC^3 has worked through a very deliberate process in an open dialogue among these stakeholders to assess the burden of cancer in Pennsylvania, identify issues that cut across all stages of cancer from its prevention to end-of-life, examine available resources and opportunities, and lay out a plan that represents a starting point for our work together. The work of PAC^3 members led to the creation of the Pennsylvania Comprehensive Cancer Control Plan.

The Pennsylvania Comprehensive Cancer Control Plan is a statewide blueprint for all sectors of Pennsylvania—public, academic, private, and volunteer, to work together to meet the growing challenge of cancer control. The Plan provides a clear, unifying vision of cancer related priorities and the steps that must be taken to reduce the impact of cancer on the people of Pennsylvania. Pennsylvania is a state fortunate to have a wealth of resources to meet the challenge. The focus and leadership developed by PAC^3 will be a powerful stimulus in forging public, academic, private, and volunteer partnerships as we move forward with the Plan's implementation.

We want to take this opportunity to express our deepest gratitude to the many people and organizations that so freely gave their time, talents, and energy with a commitment to work together to make this plan a reality. A special thank you to former Pennsylvania Governor Tom Ridge who challenged all states through his work with the National Dialogue on Cancer to develop comprehensive cancer control plans and to our current Governor Edward G. Rendell for his continuing support of our efforts.

The Centers for Disease Control and Prevention (CDC) has issued a very ambitious challenge – to eliminate suffering and death due to cancer by the year 2015 – and both ACS and the National Cancer Institute (NCI) have adopted equally aggressive 2015 year challenge goals. While such goals may seem far-reaching, we are energized by the possibilities that lie ahead. We recognize that by working together throughout our state and across the nation, we can make a difference. We feel strongly that through continued and focused collaborations, Pennsylvania will distinguish itself among states as having the most effective cancer plan in the nation. We are determined and steadfast in this mission.

With the unparalleled spirit of cooperation and the PAC^3 structure, we have the power to marshal our existing strengths and resources to better address the cancer problem through innovative, research-based cancer prevention, diagnostic, and treatment strategies.

As you can see in this report, much work has been done to create the Pennsylvania Comprehensive Cancer Control Plan. The hardest work, however, lies ahead – combining our state's talent, skills, and resources in collaboration with our national partners to implement the Plan. All Pennsylvanians have a role in this fight against cancer. You are urged to consider ways you or your organization can assist with the implementation of this Plan. Please visit www.pac3.org to join this collaborative effort or call the Pennsylvania Department of Health at 717-787-5251. We know that by working together, we can transform this vision into a reality.

We look forward to working with you to dramatically reduce the burden of cancer across the Commonwealth and throughout the nation.

ACKNOWLEDGEMENTS

Through the combined leadership of the Pennsylvania Department of Health and the Pennsylvania Division of the American Cancer Society, stakeholders across Pennsylvania have worked in a unique partnership to develop the state's first-ever, comprehensive cancer control plan.

Participants in the Pennsylvania Cancer Control Consortium (PAC^3) have represented many types of stakeholders that make up our Commonwealth including healthcare providers, healthcare administrators, researchers, insurers, business leaders, community leaders, manufacturers, government employees, health policymakers, community-based organizations, and healthcare consumers. The collaborative PAC^3 planning process and the resulting comprehensive cancer control plan will change the face and dynamics of cancer planning and cancer control in Pennsylvania.

OUR SPECIAL THANKS TO:

- **ORGANIZATIONS CONTRIBUTING FINANCIAL RESOURCES TO PAC^3**

  Centers for Disease Control and Prevention
  Pennsylvania Department of Health
  American Cancer Society, Pennsylvania Division Inc.

- **MEMBERS OF THE PAC^3 EXECUTIVE TEAM AND CO-CHAIRS OF THE PAC^3 WORK GROUPS**

  More than 190 participants involved in the PAC^3 Planning Process are identified in Appendix D of the full PAC^3 Plan. (Visit www.pac3.org)

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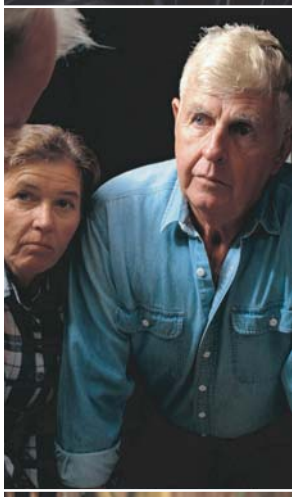
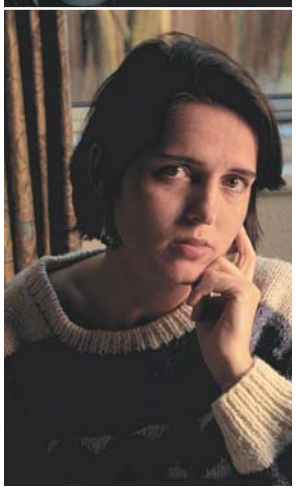
WORKING TOGETHER TO REDUCE THE BURDEN OF CANCER IN PENNSYLVANIA





The Centers for Disease Control and Prevention (CDC) defines *comprehensive cancer* control as "an integrated and coordinated approach to reducing cancer incidence, morbidity and mortality through prevention (primary prevention), early detection (secondary prevention), treatment, rehabilitation, and palliation." The American Cancer Society (ACS), National Cancer Institute (NCI), and the World Health Organization (WHO) also recognize and promote the strategy of comprehensive cancer control.

Comprehensive cancer control is achieved through a broad partnership of public and private stakeholders whose common mission is to reduce the overall burden of cancer.

The Pennsylvania Cancer Control Consortium (PAC^3) believes that collaboration is the key to successfully reducing the burden of cancer. With a shared vision, organizations and interest groups can successfully build a system that will establish priorities and identify, implement, and evaluate the most effective approaches to cancer control. True collaboration, though challenging, is recognized as being the key that will ensure long-lasting success.

We ask ourselves as a new Consortium:

What do Pennsylvanians gain if we collaborate?

- We can provide the best approaches to cancer control to more areas of our state for populations most in need.
- We can consider multiple approaches collectively, discuss the strengths and weaknesses of each, and select what will work best with each specific population and with those most in need.
- We can cover the state with a standardized approach to interventions, ensuring improved access to cancer control across the state.
- We can work through larger systems and influence larger groups of people.
- We can concentrate on gaps in research and gaps in programs for intervention.
- We can conduct research through stronger more diverse programs and contribute solutions with more efficiency.
- We can challenge complacency and inefficiency among various strategies currently used in cancer control.
- We can evaluate whether what we are doing is adequate to address the needs of those groups who carry unequal cancer burdens.
- We can enhance organizational collaboration and implement strategies of the Plan collectively.

What do Pennsylvanians lose if we do not collaborate?

- We lose the ability to evaluate the scope of our interventions and their impact.
- We will not cover the gamut of activities needed across the spectrum of cancer control, especially those activities needed by certain underserved geographic areas and populations.
- We will limit the conduct of research to our current efforts and lose time and efficiency in translating solutions to the broader citizenry.
- We will not be able to institutionalize comprehensive cancer plan activities to make them ongoing and effective.
- We will not be able to secure adequate funding to do the job right.

The Pennsylvania Comprehensive Cancer Control Plan (Plan) is the inaugural report of PAC^3. As PAC^3 grows and transitions from a Plan-writing organization to a Plan-implementing organization, this Plan serves as a reference to advocate for cancer prevention and control strategies and policies with a collective voice; a roadmap to build and enhance collaborative relationships; a recruitment device to expand collaborative activities; and, a resource to raise the "cancer IQ" among our citizens, all levels of decision-makers and change agents statewide.

Thank you for your interest in the Pennsylvania Comprehensive Cancer Control Plan. The Pennsylvania Cancer Control Consortium (PAC^3) invites you to join us in our ongoing efforts to dramatically reduce the impact of cancer across the Commonwealth.
Visit us at **www.pac3.org**.

We have much to gain by working together.

PAC^3

PENNSYLVANIA COMPREHENSIVE CANCER CONTROL PLAN

PRIORITY GOALS

CANCER PREVENTION AND HEALTHY LIFESTYLES

Tobacco Free Lifestyles & Environments

GOAL A Reduce use of tobacco by adults.

GOAL B Reduce use of tobacco by youth.

GOAL C Support innovative tobacco research.

GOAL D Improve tobacco control efforts through advocacy and education.

GOAL E Reduce exposure to tobacco smoke pollution for *all* of Pennsylvania's citizens.

Physical Activity and Nutrition

GOAL F Reduce the risk of cancer among Pennsylvanians through healthy eating practices and adequate physical activity levels in accordance with current research.

5-9 servings of fruits and vegetables daily and nutrition guidelines [1,2]
U.S. Surgeon General recommendations for physical activity [2,3]

Skin Cancer Prevention

GOAL G Reduce the incidence of malignant melanoma among all Pennsylvanians.

Cervical Cancer Screening and Follow-up

GOAL H All women in Pennsylvania at higher risk for cervical cancer will have the knowledge and the resources to have Pap smears according to evidence-based guidelines and to receive appropriate follow-up of abnormal screening results.

[1] National Cancer Institute. *5 A Day for Better Health Program.* www.5aday.gov/

[2] *The Complete Guide - Nutrition and Physical Activity.* www.cancer.org

[3] U.S. Department of Health and Human Services. *The Surgeon General's Report on Physical Activity and Health,* 1996. Rockville, MD: U.S. Department of Health and Human Services, Public Health Service, and Office of Surgeon General. http://www.cdc.gov/nccdphp/sgr/sgr.htm

CANCER SCREENING AND DIAGNOSTIC FOLLOW-UP

Awareness and Knowledge

GOAL A All Pennsylvanians will be provided information about cancer screening guidelines, what screening services are recommended in established guidelines, where screening services are available, and how to access screening services. Healthcare systems, healthcare organizations, and healthcare providers will routinely deliver information about available screening services to patients eligible for screening and facilitate informed and value-based decision making by patients about screening service utilization. Disparities in awareness of and knowledge about cancer screening services will be systematically identified and addressed.

Utilization of Screening Services

GOAL B All Pennsylvanians will have the opportunity to take advantage of cancer screening services. The availability of and access to screening services will be ensured in the Commonwealth. Healthcare systems, healthcare organizations, and healthcare providers will deliver cancer screening services as part of routine care in accordance with established guidelines. Disparities in cancer screening service utilization will be systematically identified and addressed.

Evaluation and Research

GOAL C Public and private sector support for behavioral research, epidemiological research, and health services research on screening services, along with basic and clinical science studies, will be provided to ensure that all Pennsylvanians benefit from research on cancer screening services. Cancer screening services evaluation and research can serve to identify geographic areas and populations where screening awareness and utilization are low, determine methods that are effective in enhancing screening awareness and utilization, evaluate the impact of screening programs and methods, and identify new screening technologies. Information can also be generated for use in reducing disparities in cancer screening awareness, utilization, and impact.

CANCER TREATMENT AND CARE DELIVERY

GOAL A Standardize the quality of cancer care for all Pennsylvanians.

GOAL B Recruit and retain the best cancer care providers.

GOAL C Promote patient empowerment and informed decision-making.

GOAL D Integrate and coordinate cancer resources across the state, including treatment, support, and recovery to enhance quality of care.

Being diagnosed with cancer is like being tossed alone into a stormy sea. I'm drowning, gasping for air, certain I am dying, and suddenly you are there. You bring a boat, throw me a lifeline, teach me, take care of me. You give me hope."

Jane H., a cancer survivor, to an oncology nurse

QUALITY OF LIFE: SURVIVORSHIP THROUGH END-OF-LIFE

GOAL A Improve quality of life and diminish suffering for all persons with cancer, their families, friends, and lay caregivers from the time of diagnosis through survivorship.

GOAL B Increase the use of quality of life assessment of persons with cancer and their families across all stages of disease and in all settings of cancer care.

GOAL C Increase scientific research and the adoption of interventions that researchers have found to diminish suffering and to overcome barriers to achieving quality of life among persons with cancer in Pennsylvania, their families, friends, and lay caregivers.

GOAL D Improve quality of life for all persons with cancer, their families, friends, and lay caregivers during and through the end-of-life.

ACCESS

GOAL A Every Pennsylvanian will have access to primary care, cancer prevention/screening, and cancer care by eliminating barriers (geography, transportation, income, information access, language, culture, and psychosocial).

RESEARCH

GOAL A Use existing state resources to estimate the burden and risk factors for major types of cancer in Pennsylvania and then perform research to develop more effective programs for cancer prevention, early detection, and disease management for all affected individuals in the state.

GOAL B Promote synergistic cancer research effectiveness by encouraging and facilitating research collaborations among Pennsylvania cancer centers and other research organizations; develop an infrastructure through which the Pennsylvania Cancer Alliance can effectively coordinate translational, behavioral, and clinical research opportunities and needs; and provide statewide access to joint innovative cancer research initiatives in order to fully address the needs of all people in the state who are affected by cancer.

GOAL C Implement a user-friendly statewide website with appropriate links to other relevant regional and national websites, to facilitate an effective communication mechanism for all research goals, facilitate communications and sharing of information among cancer researchers and others, and provide needed information on cancer and clinical cancer research studies to Pennsylvania citizens, health professionals, and researchers, in order to disseminate research opportunities and research advances across the Commonwealth.

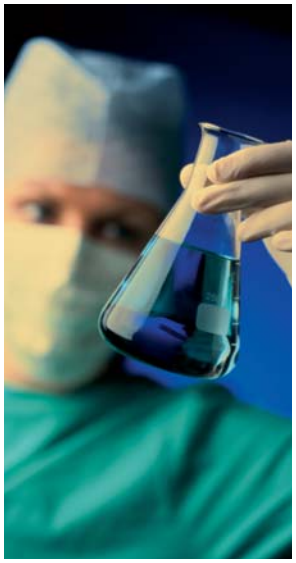
RESEARCH (*continued*)

GOAL D Establish as a subcommittee of the Pennsylvania Cancer Alliance, a collaborative group of behavioral medicine researchers and population scientists in Pennsylvania to:

(1) propose important areas of cancer research;
(2) evaluate procedures to increase awareness and improve implementation by state healthcare professionals and citizens of available and emerging guidelines for regular cancer screening and changes in lifestyle; and
(3) encourage interdisciplinary collaborations with basic cancer researchers, public health researchers, and healthcare professionals.

GOAL E Perform research to develop effective approaches to modify the behavior of most, if not all, individuals in the Commonwealth to not use tobacco, so that the deleterious effects on health are avoided.

GOAL F Ensure the accomplishment of the Consortium's Research goals by continuing the commitment of the Commonwealth for tobacco settlement formula funds to support biomedical, clinical, and health services research, marshal needed resources, and obtain sufficient additional funding and support to accomplish all high priority Research goals and objectives.



CANCER-RELATED INFORMATION MANAGEMENT AND DISSEMINATION

GOAL A Provide all Pennsylvanians with access to high-quality, accurate, and current information based on individual and population factors for all aspects of cancer, from prevention to end-of-life care.

GOAL B Provide all Pennsylvania healthcare providers with access to accurate, up-to-date, age- and culture-appropriate information about cancer prevention, risk reduction, screening, diagnosis, treatment, and end-of-life.

GOAL C Increase the usage of available cancer data by researchers and health planners for assessing the cancer burden and providing a solid foundation for cancer surveillance, research, and program planning activities in Pennsylvania.

GOAL D Influence policymakers, government, and private industry to increase funding opportunities that focus on cancer information development, management, and dissemination.

GOAL E Enhance collaboration among diverse cancer control organizations and engage other public- and private-sector organizations in the coordinated dissemination and utilization of cancer information for the public, patients, providers, researchers, program planners, and policymakers.

IMPLEMENTATION

GOAL A Work together to implement the Pennsylvania Comprehensive Cancer Control Plan, evaluate results, and identify and respond to new challenges and opportunities.

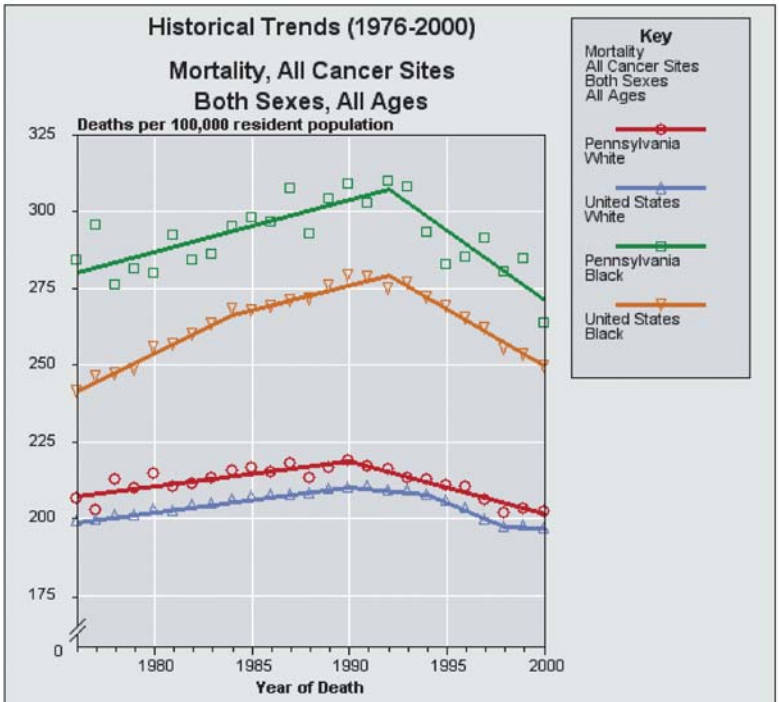
Cancer is the second leading cause of death in Pennsylvania.
Bureau of Health Statistics, Pennsylvania Department of Health

CHALLENGES AND OPPORTUNITIES IN PENNSYLVANIA

Across the Commonwealth of Pennsylvania, there is no life that goes untouched by cancer – whether coping with one's own personal struggle with cancer, caring for a loved one, offering compassionate support, working on the front lines in healthcare, or tirelessly searching for a cure.

- **One in every four deaths among Pennsylvanians is from cancer.**
- **From 1990 - 2000, over 700,000 new cases of cancer were diagnosed in Pennsylvania.**
- **Annually, approximately 30,000 Pennsylvanians will die of cancer.**

Bureau of Health Statistics
Pennsylvania Department of Health, 2003



Created by statecancerprofiles.cancer.gov on 07/05/2003 3:41pm.
Regression lines calculated using the Joinpoint Regression Program.
Source: Death data provided by the National Vital Statistics System public use data file. Death rates calculated by the National Cancer Institute using SEER*Stat. Death rates are age-adjusted to the 2000 US standard population by 5-year age groups. Population counts for denominators are based on Census 2000 as modified by NCI.

Figure 1 The APC is the Annual Percent Change over the time interval. Rates used in the calculation of APC are age-adjusted to the 2000 US standard population.

Cancer is the second leading cause of death in Pennsylvania. Although progress has been made in reducing the numbers of people who die from cancer each year, the mortality rate is still higher in Pennsylvania than for the nation as a whole. In addition, there is marked disparity between the mortality rate for Blacks and Whites in Pennsylvania (Figure 1).[4] A recent ACS report estimates that in 2003 more than 29,600 will die of this disease in our state.[5]

Within the Commonwealth, the number of people newly diagnosed with cancer has risen significantly over the last ten years. The same ACS report estimates that in 2003, more than 70,800 Pennsylvanians will be newly diagnosed with cancer.[5] This means that more people are living with cancer. Coping with the effects of cancer treatment and resuming normal routines remain significant challenges for this growing number of cancer survivors and their families.

The greatest hope in reducing the number of lives lost to cancer lies in targeting cancers that can be prevented or that can be treated effectively if detected at an early stage.

Historical trends indicate that the incidence of cancer in Pennsylvania is increasing.[6] According to health statistics published by the Pennsylvania Department of Health, lung and bronchus cancers, colorectal cancer, female breast cancer, melanoma, and prostate cancer accounted for 59% of actual new invasive cases of cancer in Pennsylvania in 2000 and for 53% of actual cancer deaths in 2001. Consequently, many of the priority goals and objectives of this Plan target these specific cancers. However, many of the policies and actions that will be implemented will affect the prevention, detection, and treatment of all cancers.

4 http://cancercontrolplanet.cancer.gov
5 *ACS Facts and Figures 2003,* Atlanta GA: American Cancer Society
6 *Cancer Facts and Figures. Pennsylvania 2002.* Pennsylvania Department of Health

CHALLENGES AND OPPORTUNITIES *(continued)*

Detailed information on the burden of cancer can be seen in Appendix A – Cancer in Pennsylvania: Facts and Figures. PAC^3 Cancer Burden Statements[7] can be found on the PAC^3 website at www.pac3.org.

PAC^3 members recognize that a variety of factors exist in the Commonwealth that affect, either positively or negatively, the success of statewide cancer prevention and control efforts. The opportunities to impact the effect of cancer span across the continuum that begins with lifestyle behaviors; continues with screening, diagnosis, treatment, recovery, potential/possible recurrence; and ends with issues related to survivorship (living with cancer) or end-of-life. By working together, Pennsylvania can leverage its vast resources to lead the nation in cancer prevention and care.

ECONOMIC BURDEN OF CANCER IN PENNSYLVANIA

Now, more than ever, in 2003 the costs of healthcare are accelerating, and cancer care is not immune to the many larger environmental factors that drive up these costs. Causes of the rise in cancer care costs include the increased use of services and use of more expert technology. Many factors combine to make cancer care less affordable. These costs are passed down to those who are insured, businesses that insure the public, organizations and centers that deliver care, the underinsured, the uninsured, and families.

At this time, the PAC^3 Plan does not directly address issues and goals related to the costs of cancer. PAC^3 recognizes, however, that improving the effectiveness of prevention efforts, screening, treatment, and cancer care can decrease economic costs. The overall vision of PAC^3 focuses on reducing the economic burden of cancer and, thus, PAC^3 does have cost consciousness and cost effectiveness in mind. Presently, the goals and objectives of PAC^3 are intended to account for some of the economic concerns; however, more specific strategies will evolve from future discussion.

Pennsylvania Cancer Control Consortium (PAC^3)

The staggering costs of cancer in the United States in 2003 is estimated at $189.5 billion, including healthcare expenditures and lost productivity from illness and death.

National Institutes of Health
National Heart, Lung and Blood Institute, 2002 Fact Book
http://nhlbi.nih.gov/about/02factbka.pdf

[7] *PAC^3 Burden Statements available for: All Cancers, Breast, Colorectal, Lung, Melanoma, and Prostate Cancers*

THE PENNSYLVANIA CANCER CONTROL CONSORTIUM

"They came from all parts of the Commonwealth; they came from different backgrounds; they came from different professions-and they all came for the same reason: To create a common vision for the future of cancer control in Pennsylvania."

November 2001 Future Search Conference

"Together...Making our Vision a Reality"

PAC^3: TOGETHER...MAKING OUR VISION A REALITY

The Pennsylvania Cancer Control Consortium (PAC^3) is made up of organizations working together to reduce the burden of cancer in Pennsylvania. PAC^3 is a unique initiative in which public, private, and voluntary organizations across the state are working together to achieve cancer control priorities.

The PAC^3 Vision, Mission, Core Goals, Core Values, and Guiding Principles guided the development of the Pennsylvania Comprehensive Cancer Control Plan.

PAC^3 VISION

It is the vision of PAC^3 that, by working together in partnership across the continuum of cancer control, the Consortium will have a significant impact on improving the health of the citizens of the Commonwealth.

Together we will ensure that research-based knowledge and understanding of the causes of cancer and its progression will allow us to develop and implement state-of-the-art prevention, early detection, treatment, and quality of life programs that are evidence-based and deliver high-quality care to citizens of the Commonwealth.

PAC^3 MISSION

The mission of the Pennsylvania Cancer Control Consortium is to reduce the human and economic burden of cancer for all citizens of the Commonwealth by working together as a collaboration of leaders from many organizations.

PAC^3 CORE GOALS

- Prevent cancer from occurring whenever possible.
- Detect cancer in its earliest stages when it occurs.
- Treat any cancer found with the most appropriate and effective treatment known.
- Assure the best possible quality of life for cancer patients, their families, and caregivers.
- Eliminate disparities in incidence, mortality, survival, and risk factors among population groups.
- Conduct and support research to continually improve cancer prevention, detection, treatment, and quality of life.
- Establish an infrastructure to support and assure the rapid transfer of research findings into practice.
- Ensure that all of these cancer prevention, detection, treatment, and quality of life plans and actions are as cost-effective as possible.

PAC^3 CORE VALUES

- We can achieve more together than we can alone.
- All Pennsylvanians will have equal access to state-of-the-art cancer resources.
- Exemplary standards in cancer care will be established among the Commonwealth healthcare providers.
- As key stakeholders, we will work together to develop a comprehensive state cancer control plan and a coordinated infrastructure to implement the plan.

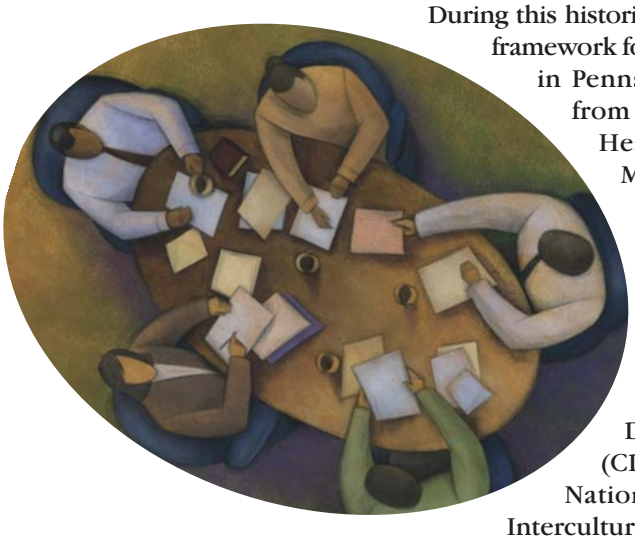
PAC^3 GUIDING PRINCIPLES

- Establish and maintain a collaborative process to identify and achieve cancer control priorities.
- Focus prevention and screening efforts on the cancers that are currently the most common, preventable, and/or detectable, and strive to expand these goals to less common malignancies.
- Support research into all aspects of cancers, as well as into the development of screening and prevention strategies for all cancers.
- Make decisions that are data driven, using the Pennsylvania Cancer Registry and other sources for planning, coordinating efforts, and stimulating action.
- Aggressively communicate the Pennsylvania Comprehensive Cancer Control Plan to the public and obtain their support to ensure plan implementation.
- Ensure that the process to identify, implement, and evaluate cancer control priorities will be sustainable.

A SUMMARY OF THE PAC^3 PROCESS

Through the vision and leadership of the Pennsylvania Department of Health (DOH), the Commonwealth of Pennsylvania embarked on a new venture to develop the first-ever, comprehensive cancer control plan.

Early in 2001, the DOH began planning for a Future Search Conference, where sixty stakeholders representing diverse backgrounds convened in Harrisburg for three days to discuss the past, present, and future of cancer control in the Commonwealth. Participants included representatives of government, healthcare delivery organizations, healthcare providers, healthcare consumers, community-based organizations, community leaders, researchers, voluntary organizations, and industry. This was the first step in the dialogue-to-action process. During this historic meeting, participants envisioned a framework for action to ease the burden of cancer in Pennsylvania. Nine areas came forward from discussion for action: Access to Healthcare, Cancer Information Management, Care Delivery, Quality of Life, Healthy Lifestyles/Prevention, Research, Screening, Technology, and Tobacco Prevention and Control. From these areas, eight work groups emerged.



Simultaneously, the Centers for Disease Control and Prevention (CDC), American Cancer Society (ACS), National Cancer Institute (NCI), Intercultural Cancer Council (ICC), and other key national stakeholder organizations sponsored a Leadership Institute on comprehensive cancer control planning for cancer control leaders throughout the country. Pennsylvania was selected as one of the regional training locations by the sponsors: ACS, NCI, ICC, American College of Surgeons (ACoS), Association of State and Territorial Health Officials (ASTHO), Chronic Disease Directors (CDD), National Conference of State Legislatures (NCSL), National Dialogue on Cancer (NDC), National Governors Association (NGA), and North American Association of Central Cancer Registries (NAACCR).

Fifteen representatives from Pennsylvania organizations such as the DOH and state agencies, the ACoS, ACS, ICC, NCI cancer centers, and state government attended the Leadership Institute and discussed how to implement a comprehensive cancer control approach within Pennsylvania. At that time, Pennsylvanian participants agreed to form a new consortium — the Pennsylvania Cancer Control Consortium (PAC^3) — to guide Pennsylvania's planning efforts and its Executive Team.

CDC provided a funding opportunity to states that were interested in developing comprehensive cancer control plans. In 2001, the DOH competed for and received a cancer strategic planning grant from CDC.

The Centers for Disease Control and Prevention (CDC) has developed the building blocks model for comprehensive cancer control planning, a strategy for building a coordinated public health response to cancer. This model provides a way to assess and then address the cancer burden within a state, territory, or tribe. It builds on the achievements of, and enhances the infrastructure created for, existing cancer programs - many of which address individual cancer sites or risk factors.

www.cdc.gov/cancer/ncccp/guidelines

SUMMARY *(continued)*

With this funding and financial support from ACS, Pennsylvania advanced its ideas and designed the strategic planning process. The 21-member Executive Team held several meetings in the first six months of 2002. In June 2002, nearly 100 stakeholders participated in the first inclusive PAC^3 meeting held in Harrisburg, Pennsylvania. Since then, more than 190 stakeholders representing the healthcare community, cancer research centers, academia, community organizations, advocacy groups, insurers, industry, and cancer survivors joined the Pennsylvania DOH and the Executive Team as members of PAC^3 to develop goals with objectives and write the first ever Pennsylvania Comprehensive Cancer Control Plan. The members, which formed eight work groups that year, accomplished these tasks:

- Reviewed issues that spanned the cancer continuum (from prevention to end-of-life).
- Focused on broad areas of importance related to cancer control.
- Assessed the influence of key cross-cutting topics (technology, disparities, advocacy, and communication).
- Deliberated and developed a set of priority goals, objectives, and related potential actions.
- Identified items for future consideration.

The products of these work groups form the backbone of this Plan and represent the collaborative nature of the PAC^3 process and a consensus view of the stakeholders involved.

COMPREHENSIVE CANCER CONTROL PLANNING LEADERSHIP CONFERENCE ✦ OCTOBER 2001 ▶

RECEIVED CDC PLANNING GRANT ✦ OCTOBER 2001 ▶

PA DEPARTMENT OF HEALTH FUTURE SEARCH CONFERENCE ✦ NOVEMBER 2001 ▶

PAC^3 EXECUTIVE TEAM FIRST MEETING ✦ JANUARY 2002 ▶

PAC^3 CONSORTIUM MEETINGS ✦ JUNE 2002 - OCTOBER 2003 ▶

PAC^3 PLAN RATIFICATION ✦ OCTOBER 2003 ▶

ACCESS TO CARE

Co-Chairs: Thomas Storey, MD and Pat Lawless, MHA

"Access is the keystone to cancer care. Geographic, financial, cultural, psychosocial, and other barriers to care must be eliminated so all Pennsylvanians are able to receive the cancer screening and care they need."

CANCER-RELATED INFORMATION MANAGEMENT AND DISSEMINATION

Co-Chairs: Linda Fleisher, MPH and Terry Hartman, PhD, MPH, RD

"Today rich and vast cancer-related data and information exist, yet are significantly underutilized. Our goal is to see that existing data and information are used to their full potential to address cancer information at all levels and across the continuum, from prevention to end-of-life."

CANCER TREATMENT AND CARE DELIVERY

Co-Chairs: Aaron Bleznak, MD, FACS and Vicki Hoak

"When considering the ideal cancer care delivery system for Pennsylvania, our work group members focused on the individual diagnosed with cancer as well as his or her family and friends, all of whom are affected by the disease. We also recognized the crucial role that oncology professionals play in empowering and caring for those affected by cancer."

CANCER PREVENTION AND HEALTHY LIFESTYLES

Co-Chairs: Sharon Manne, PhD and Barbara Terry

"There is a wealth of information suggesting that adopting a healthy lifestyle, which includes a good diet, regular physical activity, and the practice of sun protection, would significantly reduce the cancer risk for Pennsylvanians. Our goal is to outline ways that we can encourage Pennsylvanians to adopt a healthier lifestyle and thereby reduce the risk of, and in some cases, prevent cancer."

QUALITY OF LIFE

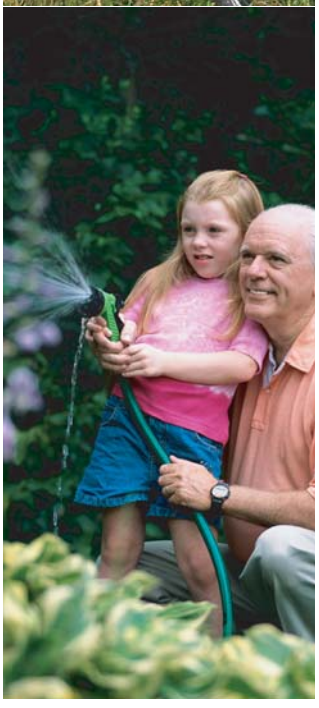
Co-Chairs: Judy Dobson, RN, MSN, CHPN and Harold Harvey, MD

"Quality-of-Life Work Group members approached their work recognizing that knowledge is the key that opens the doors to quality of life."

RESEARCH

Co-Chairs: Ronald Herberman, MD and Louise Showe, PhD

"The membership of the Research Work Group reflects the belief that research is a critical component for the establishment of a truly effective cancer control plan. In keeping with this principle, members had diverse areas of interest and expertise ranging from the basic and medical sciences to policymakers and patient advocates, and represented the major academic cancer centers and several rural centers."



CANCER SCREENING AND DIAGNOSTIC FOLLOW-UP

Co-Chairs: Ronald Myers, PhD and Paul Engstrom, MD

"A basic assumption of the Screening Work Group is that cancer screening services include not only using an early cancer detection test, but for those who have abnormal findings, having complete diagnostic follow-up. We must provide comprehensive services to realize the potential benefits of screening."

TOBACCO PREVENTION AND CONTROL

Co-Chairs: Frank Leone, MD and Nathan Mains

"Tobacco prevention and control has moved to the forefront of health policy in Pennsylvania because of the opportunities presented through the Master Settlement Agreement. Our group looked to leverage this increased awareness to help in the reduction of tobacco product use as it pertains to cancer control in the Commonwealth."

PAC^3

ABOUT THE PLAN

Throughout Pennsylvania, vast resources exist to address the fight against cancer. The vision of PAC^3 and this Plan is to pull together both people and resources across the state to significantly reduce the burden of cancer for all our citizens.

PAC^3 members recognize that the opportunity to impact the effect of cancer spans a continuum that begins with lifestyle behaviors; continues with screening, diagnosis, treatment, recovery, potential/possible recurrence; and addresses quality of life throughout the cancer experience related to survivorship or end-of-life.

> The burden of cancer is not borne equally by all populations in Pennsylvania.
>
> For the Commonwealth to develop effective cancer control strategies for the diverse members of its population, specific, targeted intervention tactics are required to address the beliefs and concerns of each population group.
>
> *Pennsylvania Cancer Control Consortium (PAC^3)*

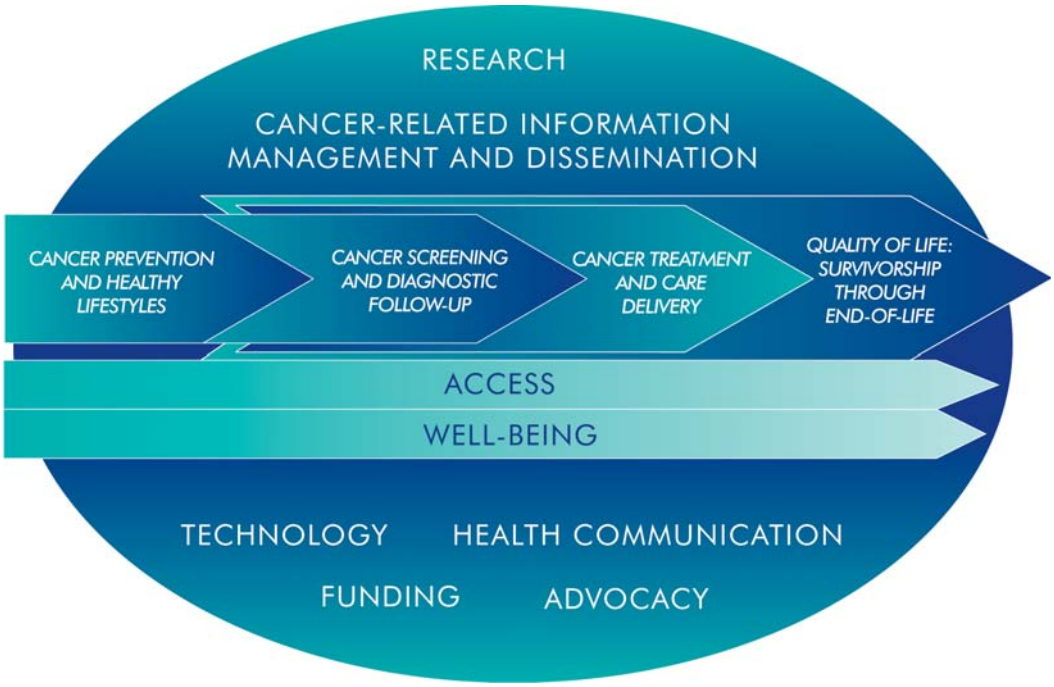
Accordingly, the ***Priority Goals and Objectives*** of the Pennsylvania Comprehensive Cancer Control Plan target this continuum and the means and methods necessary to achieve success across this continuum.

In addition, the Plan embodies two overarching principles necessary for successful implementation:

(1) Our full potential for impact will only be realized through **collaboration**, both within the Commonwealth and with national partners.

(2) We must **ensure that cancer-related health disparities are addressed** so that ALL citizens of the Commonwealth benefit from the efforts of this Plan.

THE CANCER CONTINUUM AND MEANS AND METHODS FOR EFFECTIVE CANCER CONTROL



ABOUT THE PLAN *(continued)*

The Pennsylvania Comprehensive Cancer Control Plan is intended to:

- Enhance coordination among cancer stakeholders in the Commonwealth in all aspects of cancer control – from prevention and scientific research to information management and quality of life;
- Establish consensus on priorities for the Comprehensive Cancer Control Plan;
- Increase cooperation and collaboration among PAC^3 members;
- Develop strong public-private partnerships;
- Design and implement strategies to reduce duplication of effort and increase shared resources among partners and stakeholders; and
- Coordinate dissemination of cancer-related information and education.

This Plan identifies areas of common interest and need, and it offers a **road map to guide action**. It is intended for use by people in all areas of cancer control statewide. The Plan is not static; rather, it is a dynamic document that will evolve and develop over time to respond to the changing needs of the citizens of Pennsylvania.

The **Priority Goals** in this Plan are deliberately broad and visionary, aimed at improving the lives of all Pennsylvanians and dramatically reducing the burden of cancer throughout the Commonwealth. The **Objectives** and **Potential Actions** included in this Plan are varied and are intended to provide a number of opportunities where committed stakeholders can connect and act. Collaboration is the key to success…implementation of this Plan will require local activities in communities across the state, collaborative efforts among small groups around specific areas of interest, and larger statewide efforts. It is through collaboration that we will maximize investments made in cancer control and have the greatest opportunity to achieve our goals.

Following are the ***Priority Goals and Objectives*** identified through the deliberations of the PAC^3 Work Groups, Executive Team, and other stakeholders. ▶

THE CONTINUUM OF CANCER

CANCER PREVENTION AND HEALTHY LIFESTYLES

The number of new cancer cases can be reduced considerably through actions taken by individuals, communities, government, and other groups to **prevent** the occurrence of cancer. Many of the causes of cancer morbidity and mortality are the result of health behaviors established early in life, in particular: tobacco use and addiction; inadequate physical activity; unhealthy diet patterns; unprotected sun/UV radiation exposure; and unsafe sexual practices.

As many as 50 to 75% of cancer deaths are caused by human behaviors, such as smoking and dietary choices.

National Institutes of Health, 2001

http://progressreport.cancer.gov

In America today, tobacco stands out as the agent most responsible for avoidable illness and death. Smoking causes about 30% of all U.S. deaths from cancer and is responsible for the leading cause of cancer death in both men and women. Cigarette smoking is by far the most common preventable cause of lung cancer in our society; avoiding tobacco use is the single most important step that can be taken to reduce the cancer burden in this country.[8]

Tobacco use is strongly addictive, and wreaks havoc on the health of middle-age and older adults. Dramatic repeated education about the ill effects of tobacco use and how to quit tobacco use is a central, overarching goal of all anti-tobacco programs. Unfortunately, current educational approaches fail to have long-lasting benefits for the majority of audiences. A major improvement in education benefits requires increased research to identify more effective educational approaches to behavior change and also more effective community-based dissemination of improved educational methods. The Pennsylvania Comprehensive Cancer Control Plan has included these issues in its section on Research Goals and Objectives.

For the majority of people who do not use tobacco, the most important prevention opportunities lie in the areas of dietary choices and physical activity. According to current scientific evidence, about one-third of cancer deaths that occur in the U.S. each year are due to nutritional and physical activity factors, including obesity.

Beyond the many cancers linked to tobacco use, poor nutrition, and physical inactivity, melanoma and cervical cancer are two highly preventable cancers linked to other health behaviors. Substantial evidence from numerous cohort and case-control studies confirms that malignant melanoma is associated with sun exposure. Based on these data, many professional societies recommend that the most important ways to lower individual risk of melanoma are to avoid prolonged exposure to intense sunlight and to practice sun safety when outdoors even on cloudy and cool days. In addition, cervical cancer is highly preventable; avoiding several risk factors, notably the Human Papillomavirus (HPV), can reduce individual risk for most pre-cancerous lesions of the cervix. Delaying sexual intercourse, limiting the number of sexual partners, and avoiding sexual intercourse with people who have had many other sexual partners can reduce HPV exposure risk.

Healthful individual behaviors are most likely to occur when there is social and environmental support in communities. Therefore, it is essential to work with community, school, and government systems to prioritize the establishment of policies and practices that will support healthy lifestyle choices.

The following are Pennsylvania's ***Priority Goals and Objectives*** for Cancer Prevention and Healthy Lifestyles. ▶

While the dietary causes of cancer are complex, there is general agreement that obesity is associated with higher cancer incidence.

In Pennsylvania, 60% of adults who responded to the Behavioral Risk Factor Surveillance System in 2001 were considered to be overweight and 22% were obese. The comparable figures for Black adults are 73% overweight and 36% obese. *

While it is not clear that physical activity in of itself can result in lower cancer rates, it is accompanied by higher body weight. In Pennsylvania, 25% of adults report no leisure time for physical activity.

**Health Risks of Pennsylvania Adults 2001 Harrisburg: PA Department of Health*

[8] http://progressreport.cancer.gov

PRIORITY GOALS AND OBJECTIVES

TOBACCO FREE LIFESTYLES AND ENVIRONMENTS

GOAL A Reduce use of tobacco by adults.

Objective A1
Support the developing infrastructure of Pennsylvania's comprehensive tobacco control program.

Objective A2
Improve access to, and availability of, effective cessation and prevention programs for all Pennsylvanians.

Objective A3
Ensure high-quality evaluation of existing tobacco prevention and cessation programs.

Objective A4
Identify and eliminate the disparities in both the rates of tobacco use and its untoward effects among different population sub-groups within Pennsylvania.

GOAL B Reduce use of tobacco by youth.

Objective B1
De-normalize tobacco use in Pennsylvania's youth culture.

Objective B2
Reduce illegal access to tobacco products among minors.

Objective B3
Support the developing infrastructure of Pennsylvania's comprehensive tobacco control program.

Objective B4
Improve access to and availability of effective cessation programs specifically targeting youth.

Objective B5
Ensure high-quality evaluation of existing tobacco prevention and cessation programs.

Objective B6
Identify and eliminate the disparities in both the rates of tobacco use and its untoward effects among different population sub-groups within Pennsylvania.

PRIORITY GOALS AND OBJECTIVES *(continued)*

GOAL C Support innovative tobacco research.

Objective C1
Increase the amount of external funding awarded to Pennsylvania's tobacco researchers.

Objective C2
Improve collaboration among researchers, through PAC[3] networks, in order to foster a more effective, well-leveraged research position in Pennsylvania.

GOAL D Improve tobacco control efforts through advocacy and education.

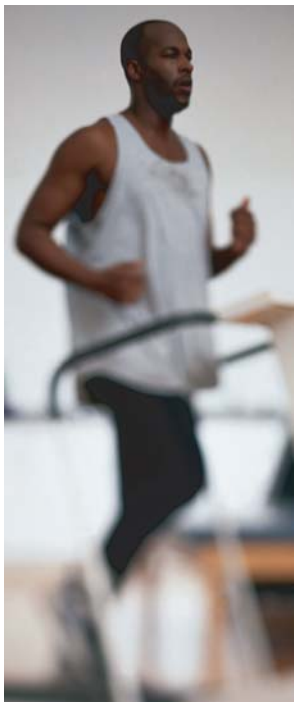
Objective D1
Improve insurance coverage for cessation treatments and reduce barriers to care across Pennsylvania.

Objective D2
Identify methods of reaching diverse, high-priority populations such as Hispanics, children, pregnant women, and smokers in the lowest socio-economic strata.

Objective D3
Engage the medical community in establishing new norms for care, and help them to provide leadership in the dissemination of new ideas about tobacco.

GOAL E Reduce exposure to tobacco smoke pollution for *all* of Pennsylvania's citizens.

Objective E1
Reduce the impact of tobacco smoke pollution (TSP) on the health of Pennsylvanians.



Objective E2
Reduce the number of venues in Pennsylvania where TSP is present.

PHYSICAL ACTIVITY AND NUTRITION

GOAL F Reduce the risk of cancer among Pennsylvanians through healthy eating practices and adequate physical activity levels in accordance with current research.

5-9 servings of fruits and vegetables daily and nutrition guidelines [1,2]
U.S. Surgeon General recommendations for physical activity [2,3]

Objective F1
Increase public awareness about the positive health effects of eating a variety of healthy foods and maintaining a physically active lifestyle, particularly the effects of reducing obesity and preventing cancer.

Objective F2
Increase the number of effective policies and practices that support and promote healthy eating and physical activity in schools and communities.

[1] National Cancer Institute. *5 A Day for Better Health Program.* www.5aday.gov/

[2] *The Complete Guide - Nutrition and Physical Activity.* www.cancer.org

[3] U.S. Department of Health and Human Services. *The Surgeon General's Report on Physical Activity and Health,* 1996. Rockville, MD: U.S. Department of Health and Human Services, Public Health Service, and Office of Surgeon General. http://www.cdc.gov/nccdphp/sgr/sgr.htm

PRIORITY GOALS AND OBJECTIVES *(continued)*

SKIN CANCER PREVENTION

GOAL G Reduce the incidence of malignant melanoma among all Pennsylvanians.

Objective G1

Increase the proportion of pre-school aged children, school-aged children and adolescents who engage in protective behaviors for ultraviolet (UV) light in accordance with evidence-based data.

Objective G2

Increase the proportion of adults who engage in UV protective behaviors in accordance with evidence-based data.

Incidence data from the Pennsylvania Cancer Registry show the number of newly diagnosed melanoma cases is increasing on an annual basis.

CERVICAL CANCER PREVENTION

GOAL H All women in Pennsylvania at higher risk for cervical cancer will have the knowledge and the resources to have Pap smears according to evidence-based guidelines and to receive appropriate follow-up of abnormal screening results.

Objective H1

Increase the proportion of women in Pennsylvania who understand the importance of being screened for cervical cancer on a regular basis throughout their lifetime and who have knowledge of cervical cancer screening guidelines.

Objective H2

Improve statewide delivery of effective health education programs to school-aged children through coordinated school health programs.

Objective H3

Promote updated educational campaigns targeting healthcare providers and family planning professionals about Human Papillomavirus (HPV)-prevention messages, new developments in testing and treatment, and patient counseling for sexually active patients, especially those with HPV infections and their partners.

Objective H4

Obtain important baseline information on risk behaviors and provide a benchmark for future intervention efforts by working with the Centers for Disease Control and Prevention to implement the Youth Risk Behavior Surveillance System in all public school districts in Pennsylvania by 2005.

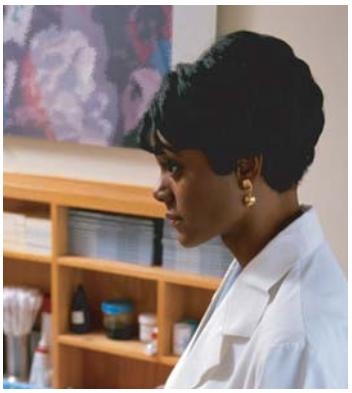
See Appendix B1 for potential actions identified by PAC^3 for achieving the Cancer Prevention and Healthy Lifestyles Priority Goals and Objectives.

CANCER SCREENING AND DIAGNOSTIC FOLLOW-UP

Cancer screening and diagnostic follow-up (cancer screening services), can identify pre-cancerous lesions and early-stage disease, resulting in reduced morbidity and mortality. Today, it is well known that screening for breast, cervical, colorectal, and skin cancer can save lives and substantially reduce the cancer burden. However, the full potential of screening for these cancers has not been fully realized in Pennsylvania. Screening for prostate cancer remains controversial because of the large number of false-positives, and the ability of the Prostate Specific Antigen (PSA) test to reduce the mortality rate have not been adequately demonstrated. In addition, lung cancer screening is not of proven benefit.

Successful treatment of many kinds of cancer depends largely on how early the cancer is detected.

Centers for Disease Control and Prevention



To achieve the benefits of proven methods for cancer screening and to assure informed choice by citizens, we must provide information and guidance in decision-making about screening services to the public, to populations at increased risk for cancer, and to primary care physicians and health professionals. In addition, proven methods of cancer screening must be made readily accessible and available. Healthcare providers must also be encouraged to provide patients with information about cancer screening services and to systematically integrate established screening guidelines into standard care. Further, state-of-the-art methods for increasing screening service awareness and for maximizing utilization must be identified and disseminated across the Commonwealth. Finally, screening-related disparities (race/ethnicity, socioeconomic, geographic) must be identified and eliminated.

Making cancer screening services readily available and accessible to all Pennsylvanians is essential to reduce high rates of cancer and cancer deaths in the Commonwealth. The following are Pennsylvania's ***Priority Goals and Objectives*** for Cancer Screening and Diagnostic Follow-up. ▶

Knowing is not enough, we must apply. Willing is not enough, we must do.

Johann Van Goethe

PRIORITY GOALS AND OBJECTIVES

AWARENESS AND KNOWLEDGE

GOAL A All Pennsylvanians will be provided information about cancer screening guidelines, what screening services are recommended in established guidelines, where screening services are available, and how to access screening services. Healthcare systems, healthcare organizations, and healthcare providers will routinely deliver information about available screening services to patients eligible for screening and facilitate informed and value-based decision making by patients about screening service utilization. Disparities in awareness of and knowledge about cancer screening services will be systematically identified and addressed.

Objective A1
Increase public knowledge about cancer screening services.

Objective A2
Increase provider knowledge of cancer screening guidelines and standards of care related to follow-up.

Objective A3
Increase provider-patient dialogue about cancer screening services.

Objective A4
Increase legislators' knowledge of cancer screening guidelines and standards of care.

Objective A5
Increase requests for cancer screening services information by the general public and populations at increased risk for cancer.

Objective A6
Decrease disparities in awareness and knowledge about cancer screening services.

UTILIZATION OF SCREENING SERVICES

GOAL B All Pennsylvanians will have the opportunity to take advantage of cancer screening services. The availability of and access to screening services will be ensured in the Commonwealth. Healthcare systems, healthcare organizations, and healthcare providers will deliver cancer screening services as part of routine care in accordance with established guidelines. Disparities in cancer screening service utilization will be systematically identified and addressed.

Objective B1
Increase provider performance of and referral for screening services.

Objective B2
Increase screening service utilization.

Objective B3
Increase detection of precursor lesions and early-stage disease in the general population and populations at increased risk for cancer.

PRIORITY GOALS AND OBJECTIVES *(continued)*

Objective B4
Increase availability of third-party payor coverage for screening services.

Objective B5
Decrease disparities related to physician referrals for and performance of screening services, screening utilization within populations, and the detection of precursor lesions and early-stage disease.

EVALUATION AND RESEARCH

GOAL C Public and private sector support for behavioral research, epidemiological research, and health services research on screening services, along with basic and clinical science studies, will be provided to ensure that all Pennsylvanians benefit from research on cancer screening services. Cancer screening services evaluation and research can serve to identify geographic areas and populations where screening awareness and utilization are low, determine methods that are effective in enhancing screening awareness and utilization, evaluate the impact of screening programs and methods, and identify new screening technologies. Information can also be generated for use in reducing disparities in cancer screening awareness, utilization, and impact.

Objective C1
Increase behavioral research, epidemiological research, health services research, and screening technology development research.

Objective C2
Integrate existing data sources and develop new data sources that can be used to create a comprehensive repository on screening services and interventions in Pennsylvania.

Objective C3
Identify and develop effective screening service behavioral interventions, health services approaches, and screening technologies.

Objective C4
Increase dissemination of screening service research findings to the public, populations at increased risk for cancer, and healthcare providers.

Objective C5
Increase the integration of research findings into routine healthcare.

See Appendix B2 for potential actions identified by PAC^3 for achieving the Cancer Screening and Diagnostic Follow-up Priority Goals and Objectives.

CANCER TREATMENT AND CARE DELIVERY

Cancer Treatment and Care Delivery recognizes the importance of providing the highest quality care for all individuals in Pennsylvania affected by cancer, at all stages of disease, and in all care settings.

Cancer is a complex disease; different cancers behave differently and respond to different treatments. Treatment choices depend upon the type and stage of cancer as well as other individual factors such as age, health status, and personal preferences. Cancer care and treatment often require exhaustive healthcare services, resources, and technologies.[9]

To effectively reduce the burden of cancer, state-of-the-art treatment options must be available, affordable, and accessible to our diverse citizenry across the state. It is critical to integrate and coordinate treatment and support programs and services in order to make the best use of these resources throughout Pennsylvania. We also must recruit and retain the best professionals to provide the care needed, and those professionals must empower patients to make informed decisions about their care.

The following are Pennsylvania's ***Priority Goals and Objectives*** for addressing Cancer Treatment and Care Delivery issues for all Pennsylvanians affected by cancer, and to ensure that all Pennsylvanians who are diagnosed with cancer receive optimal treatment.

PRIORITY GOALS AND OBJECTIVES

GOAL A Standardize the quality of cancer care for all Pennsylvanians.

Objective A1

Create a delivery system for cancer care that provides timely, high-quality core services at facilities close to people's homes and facilitates access to more specialized care. Core cancer care services are those as defined by the American College of Surgeons' (ACoS) Commission on Cancer (CoC).

Objective A2

Promote evidence-based treatment practices.

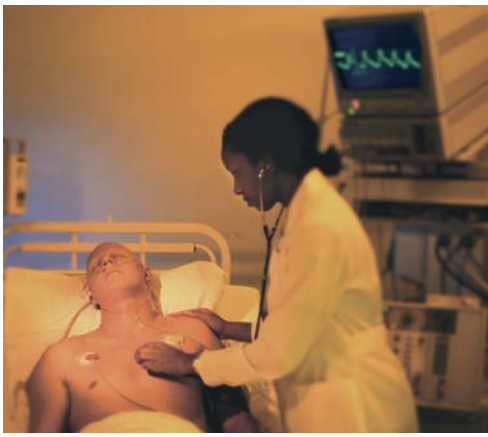
GOAL B Recruit and retain the best cancer care providers.

Objective B1

Create an environment that attracts and retains high-quality physicians, nurses, and other healthcare providers.

Objective B2

Integrate cancer prevention and treatment information and issues related to cancer survivorship into the professional healthcare curriculum for the initial training of healthcare providers, continuing education, certification examinations, and other competency-based assessments.



Objective B3

Offer more advanced and ongoing training for cancer providers.

Objective B4

Provide financial support for career development in oncology.

[9] http://www.cancer.org

PRIORITY GOALS AND OBJECTIVES *(continued)*

GOAL C Promote patient empowerment and informed decision making.

Objective C1

Obtain an endorsement from medical professional associations, medical schools, and other oncology disciplines to adopt a "patient first" philosophy recognizing patient empowerment.

Objective C2

Increase Pennsylvanians' knowledge of cancer, healthcare providers, treatments, and how to live with the disease.

Objective C3

Develop decision-making tools to assist patients with their treatment options.

Objective C4

Adopt a Cancer Patient Bill of Rights.

GOAL D Integrate and coordinate cancer resources across the state, including treatment, support, and recovery to enhance quality of care.

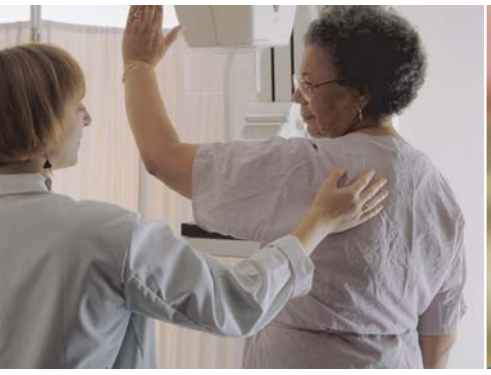
Objectives D1

Enhance collaboration among cancer programs, including hospital-based cancer providers, community cancer providers, and privately funded outreach programs.

Objectives D2

Facilitate utilization of the leadership and resources of the NCI-designated comprehensive cancer centers in Pennsylvania as a means for disseminating evidence-based treatment strategies and improving communication throughout the Commonwealth, thereby reducing disparity in cancer treatment and improving access to appropriate therapies.

See Appendix B3 for potential actions identified by PAC^3 for achieving the Cancer Treatment and Care Delivery Priority Goals and Objectives.



QUALITY OF LIFE: SURVIVORSHIP THROUGH END-OF-LIFE

Health-related quality of life begins with diagnosis and continues through survivorship and issues related to end-of-life.

Health-related quality of life is multidimensional by nature and includes perceptions of persons with cancer about their well-being, and their physical, spiritual, and psychological functioning. Quality of life measures a variety of experiences, such as role functioning, pain, other distressing symptoms, emotional status, satisfaction with treatment and care, and concerns about the future. The concept of quality of dying, currently less fully developed in our healthcare systems, focuses on the experiences of living with a terminal illness. Quality of life and quality of dying topics include the concerns and experiences of persons with cancer, their families, their friends, and their lay caregivers.

The following are Pennsylvania's ***Priority Goals and Objectives*** for addressing Quality of Life issues for individuals and families affected by cancer.

PRIORITY GOALS AND OBJECTIVES

GOAL A Improve quality of life and diminish suffering for all persons with cancer, their families, friends, and lay caregivers from the time of diagnosis through survivorship.

Objective A1
Increase knowledge among the public and healthcare providers about quality of life resources and services.

Objective A2
Develop and implement an information dissemination best practices model and approaches to support programs and initiatives focused on cancer survivorship.

Objective A3
Promote the highest level of activities of daily living, social function, and role function among all persons with cancer from the time of diagnosis through survivorship.

Objective A4
Promote palliative care practice among all medical professionals.

GOAL B Increase the use of quality of life assessment of persons with cancer and their families across all stages of disease and in all settings of cancer care.

Objective B1
Identify and analyze current research pertaining to the use of quality of life assessment instruments that are completed by persons with cancer in clinical practice settings.

Objective B2
Increase the numbers of clinical facilities that adopt the routine use of a patient quality-of-life assessment instrument on scheduled oncology visits.

Objective B3
Develop a compendium of useful quality of life instruments with annotations about their evaluation, strengths, weaknesses, and how best to use them in specific settings, such as outpatient clinics, hospitals, or home care.

PRIORITY GOALS AND OBJECTIVES *(continued)*

GOAL C Increase scientific research and the adoption of interventions that researchers have found to diminish suffering and to overcome barriers to achieving quality of life among persons with cancer in Pennsylvania, their families, friends, and lay caregivers.

Objective C1
Utilize longitudinal data from current studies of the unmet needs of persons with cancer to improve their quality of life with appropriate interventions.

Objective C2
Identify, through existing and future research, the education needs among providers, institutions, and agencies to promote quality of life interventions for persons with cancer.

Objective C3
Monitor the impact of prospective payment on persons with cancer who reside in skilled nursing facilities or who are unable to enter skilled nursing facilities and nursing homes due to their diagnosis and need for cancer treatment and care.

GOAL D Improve quality of life for all persons with cancer, their families, friends, and lay caregivers during and through the end-of-life.

Objective D1
Increase access to a full array of palliative care interventions and supportive services at the end-of-life to ease the burden of care on family members and friends despite their ability to pay for such services.

Objective D2
Increase public and health provider awareness about the hospice concept so that persons with cancer and their family and lay caregivers are equipped with knowledge and more willing to use hospice services.

Objective D3
Evaluate the availability of hospice services and referrals to hospice services across all geographic regions of Pennsylvania, especially in nursing homes.

Objective D4
Maximize participation in hospice services.

Objective D5
Increase the numbers of healthcare providers who have additional certifications in hospice care.

Objective D6
Relieve physical pain and distressing symptoms.

PAC^3

See Appendix B4 for potential actions identified by PAC^3 for achieving the Quality of Life: Survivorship Through End-of-Life Priority Goals and Objectives.

ACCESS

The Commonwealth's burden of cancer is not borne equally by all population groups. There are significant measurable differences in cancer status related to health behaviors, such as smoking or use of cancer screening and treatment resources for specific populations in our state. However, the reasons for these differences in cancer extend beyond differences in individual behaviors. Different groups have different access to those goods and services that create or maintain a healthy life, such as access to nutritious foods, primary healthcare, or healthcare systems that provide early detection services and cancer treatments. These differences, referred to as disparities, are found in minority populations and extend to uninsured non-minority populations, those challenged by low literacy, and those living in rural areas who have limited access to healthcare services.

Concerns about access often address disparities in health outcomes according to social inequalities. A review of Pennsylvania's cancer rates for any recent time period shows that incidence and mortality rates will nearly always be higher for Blacks than for Whites for nearly all cancers. Unfortunately mortality, incidence, and health behavior data for low-income populations and all other ethnic minority groups (beyond Blacks, Whites, and Latinos) are not readily available for all Pennsylvania citizens. Gathering and understanding such data is a high priority for PAC^3.

Differences in known cancer rates across populations in Pennsylvania appear to be related to individual risk factors such as smoking and diet, as well as use of early detection services. These behavior differences often correlate with ethnicity, income, and education levels. For example; according to the Pennsylvania Behavioral Risk Factor Surveillance System (PA-BRFSS) for 2000, individuals with a college education were more likely to eat fruits and vegetables five or more times a day than those with only a high school education. Additionally, breast cancer tends to be diagnosed more often at later stages in Black women than in White women. Also, women with no high school diploma are much less likely to have a Pap test in the past three years (66 %) compared to those with more education.[10]

According to the 2000 census, education levels in Pennsylvania were similar to adults nationwide, but at least 22% of adults (age 16 +) have low literacy.[11] According to the Pennsylvania Literacy Survey, nearly 2 million adults (age 16+) could fall into this category.

Literacy levels are significant predictors of poor health status. Research has shown that poor readers misinterpret physician instructions, fail to obtain or follow through on medical care, and fail to take advantage of preventive health measures. They may be the most vulnerable patient population in the Commonwealth.[12]

Access to healthcare is also limited in specific areas of Pennsylvania for two primary reasons – geographic distribution of services and insurance coverage. Urban areas of the Commonwealth have at least twice as many primary care physicians per population than rural areas, where limited public transportation and road conditions already limit access. Approximately 2.5 million Pennsylvanians live in regions of the state that are federally designated as "health profession shortage areas" or "medically underserved areas". Additionally, the 2000 PA-BRFSS reports that 11% of all adults

DIMENSIONS OF ACCESS:

Availability
The relationship of volume and type of existing services (and resources) to the number of clients and types of needs. Refers to the adequacy of the supply of providers, facilities and specialized programs and services.

Accessibility
The relationship between the location of supply and the location of clients, taking account of transportation resources, travel time, distance, and cost.

Accommodations
The relationship between the manner in which supply resources are organized to accept clients and the client's ability to accommodate to these factors and the clients' perception of their appropriateness.

Affordability
The relationship of prices of services and providers' insurance or deposit requirements to the client's income, ability to pay, and existing health insurance.

Acceptability
The relationship of client's attitudes toward provider personal characteristics and characteristics of the provider's practice, as well as to provider attitudes about acceptable personal characteristics of clients.

Penchansky, Roy D.B.A. and J. William Thomas, PhD, "The Concept of Access: Definition and Relationship to Consumer Satisfaction" Medical Care, February. 1981, Vol. XIX, No. 2, pp. 127-140

[10] *2000 Pennsylvania Behavioral Risk Factor Surveillance System (BRFSS).* http://www.health.state.pa.us

[11] U. S. Census Bureau. www.cencus.gov

[12] Weiss B. D., Coyne C. 'Communicating With Patients Who Cannot Read'. *New England Journal of Medicine,* 1997: 337:272-274

ACCESS *(continued)*

under age 65 have no healthcare coverage while 24-33% of adults whose annual incomes are $24,999 and lower had no healthcare coverage – significantly higher than all the other income brackets.[10] A large proportion of our population is uninsured and a large proportion live at or just above the poverty line.

Other populations are easily overlooked in our state. There are approximately 25,000 seasonal farm workers employed each year in Pennsylvania. According to the Keystone Farm Worker Program, 89% of those receiving healthcare through its primary care clinic had incomes below the poverty level, with 96% being Latino. Additionally, there are approximately 35,200 Old Order Amish living in Pennsylvania. Known for their separateness from modern society, they are less likely to make use of preventive screening services.

Other examples of differences in health status outcomes reported in Pennsylvania that are suggested to be related to issues of access include:

- Higher rates of lung cancer among those with lower socioeconomic status, particularly among men in Appalachia who have higher rates of poverty, lower education levels, and more limited access to healthcare.
- Higher rates of death from breast cancer among Black women than among White women and greater likelihood that Black women are diagnosed at regional or distant stages (33.8%) compared to White women (27.6%).
- Lower five-year relative survival rates for prostate cancer among Black men compared to White men.
- Lower rates of five-year survival with colorectal cancer among Black women (52%) compared to White women (62%) with higher rates of death in southeast Pennsylvania (35.8 deaths per 100,000) compared to central parts of the state (approximately 20 per 100,000).
- Greater average annual age-adjusted incidence and mortality rates for melanoma in men regardless of race.

The reasons for these differences span the cancer continuum from prevention to survivorship, and many are related to issues of access.

Pennsylvania is unique because significant federal dollars are being invested in research and intervention to address the burden of cancer for its special populations. For more information and for sources of all data cited above, please refer to the PAC^3 Burden Statement on Disparities (www.pac3.org). This report summarizes disparity and access issues of geography, numbers of primary healthcare providers, numbers of or distance to cancer care providers or other specialists, insurance coverage, lack of employment, education, literacy, and poverty.

The following are Pennsylvania's ***Priority Goal and Objectives*** for ensuring that all Pennsylvanians have access to the information and services necessary for healthy lifestyles and prevention to cancer detection, care, survivorship, and those resources that help them with end-of-life concerns. ▶

[10] 2000 Pennsylvania Behavioral Risk Factor Surveillance System (BRFSS). http://www.health.state.pa.us

PRIORITY GOAL AND OBJECTIVES

GOAL A Every Pennsylvanian will have access to primary care, cancer prevention/screening, and cancer care by eliminating barriers (geography, transportation, income, information access, language, culture, and psychosocial).

Objective A1

Eliminate barriers to receiving optimal cancer-related services by:

1. identifying and maximizing use of effective currently available resources; and
2. developing new resources as needed.

Objective A2

Ensure a reliable transportation infrastructure for cancer patients to and from treatment.

Objective A3

Expand existing state agency services for cancer detection and care.

Objective A4

Reduce the number of uninsured and underinsured Pennsylvanians between the ages of 0-64 years.

Objective A5

Align financial/regulatory systems with expectations for standards of care.

Objective A6

Streamline eligibility and regulatory requirements and reimbursement.

Objective A7

Adapt cancer-related information to address differences in culture, age, gender, etc., as needed.

See Appendix B5 for potential actions identified by PAC^3 for achieving the Access Priority Goals and Objectives.

WELL-BEING

PAC^3 members acknowledge that more general concerns regarding well-being and overall quality of life extend across the continuum of prevention to end-of-life. Issues and concerns related to well-being and overall quality of life are broader than health-related or disease-specific quality of life concerns. Well-being and overall quality of life address the concerns of community and family life even when a family is not facing cancer. One example is concern about local safety, which influences how much activity children and adults freely seek. Additional examples are the actual and perceived health and safety of the physical and occupational environment. Yet another example is the family's access to goods, resources, and services. This way of thinking about well-being and overall quality of life emphasizes the perceptions of community members about what types of community factors support or inhibit quality of life. These perceptions are supplemented by those concerns of service providers and elected representatives and the information and data that they analyze. As such, these broader concerns of well-being and overall quality of life primarily concentrate on social and economic well-being.

The Pennsylvania Comprehensive Cancer Control Plan does not directly address all of these concerns, but recognizes the influence of these broader sets of issues on well-being and overall quality of life. To this end, this Plan includes a research objective "to determine the prevalence of known risk factors, including occupational and environmental factors, and the extent to which they may account for high or disproportionate levels of incidence, delayed detection, and mortality from major types of cancer".

While *specific* goals and objectives for well-being and overall quality of life have not been developed during the first phase of the planning process, PAC^3 has identified this set of issues as very important and will pursue more detailed planning in this area in the future.

RESEARCH

An important thread that runs through the major goals across the cancer continuum is research. Thorough and thoughtful research will provide the insights and guidance for implementing new and promising approaches to cancer control and for revising, restructuring, or abandoning those approaches that have not been effective. This pertains to goals related to "quality of life" or "healthy lifestyle" issues as well as to those related to the development and application of better diagnostics or new targets for cancer prevention or therapy. Rapid progress and success in all areas will depend on harnessing all of the impressive research expertise in the Commonwealth. To do this, we must establish strong collaborative relationships and continuous communication among the research institutions and investigators. Sufficient funding for these important initiatives will be required. If we are to make a truly major impact on Pennsylvania's cancer statistics, research is needed to not only develop better diagnostic, preventive, and treatment methods, but also identify and track *what* people are doing, *why* they are doing it, and *which* interventions are most effective to improve cancer-related behaviors and outcomes. We must follow then by finding ways to provide the most promising approaches to all relevant people throughout the state.

"Research is the cornerstone upon which the greatest progress can be made in identifying strategies to improve how cancer is prevented, diagnosed, and treated in the Commonwealth."

Pennsylvania Cancer Control Consortium (PAC^3)

PAC^3 identified two overarching research goals that drive the Plan's Research agenda:

1. To make Pennsylvania "THE" national leader in cancer research.
2. To focus the research expertise in the state on efforts to reduce the cancer burden and optimize cancer care by improving the "bench-to-bedside" transfer of information.

To this end, the following are Pennsylvania's ***Priority Goals and Objectives*** for Research.

PRIORITY GOALS AND OBJECTIVES

GOAL A Use existing state resources to estimate the burden and risk factors for major types of cancer in Pennsylvania and then perform research to develop more effective programs for cancer prevention, early detection, and disease management for all affected individuals in the state.

PROVIDE THE BASIS FOR MORE EFFECTIVE INTERVENTIONS

Objective A1

Identify problems of high incidence, high mortality, and degree of late-stage diagnosis among the major cancer types that may exist throughout the Commonwealth for the major cancers, and determine whether the need for more effective approaches to early detection, screening, and access to treatment and care is related to these factors.

Objective A2

Determine the prevalence of known risk factors, including occupational and environmental factors, and the extent to which they may account for high or disproportionate levels of incidence, delayed detection, and mortality from major types of cancer statewide and regionally throughout the Commonwealth.

PRIORITY GOALS AND OBJECTIVES *(continued)*

DETERMINE BEST PRACTICES FOR CANCER CONTROL INTERVENTIONS AND THEN DISSEMINATE THROUGHOUT PENNSYLVANIA

Objective A3

Determine effective approaches for facilitating the adherence to recommended clinical cancer prevention and screening/early detection practices of individuals in geographic areas with relatively high proportions of late-stage diagnosis of certain major types of cancer.

Objective A4

Evaluate access to, and outcomes of, state-of-the-art practices for cancer prevention, early diagnosis, and management for common cancers (e.g., breast cancer, colon cancer, prostate cancer); measure access in all regions of Pennsylvania to best practices; and determine the effect the *use of best practices* has on health outcomes (e.g., stage of disease at diagnosis and length of survival after diagnosis).

GOAL B Promote synergistic cancer research effectiveness by encouraging and facilitating research collaborations among Pennsylvania cancer centers and other research organizations; develop an infrastructure through which the Pennsylvania Cancer Alliance can effectively coordinate translational, behavioral, and clinical research opportunities and needs; and, provide statewide access to joint innovative cancer research initiatives in order to fully address the needs of all people in the state who are affected by cancer.

FORM AN ORGANIZATION FOR COORDINATING CANCER RESEARCH AMONG THE CANCER RESEARCH CENTERS

Objective B1

Establish an effective and stable infrastructure for: (1) facilitating and coordinating joint research efforts to share expertise and special resources; and (2) planning and carrying out a joint program to achieve more rapid and effective progress in basic, translational, behavioral, health outcome studies, and clinical cancer research across all of Pennsylvania.

PARTNER BETWEEN CANCER RESEARCH ORGANIZATIONS AND ALL OTHER RELEVANT ORGANIZATIONS

Objective B2

Develop an effective Pennsylvania cancer research coalition between the Pennsylvania Cancer Alliance and other organizations of relevance, including state government, academic, and private-sector organizations (e.g., pharmaceutical and biotech companies and insurers), and cancer research support and advocacy organizations to jointly plan and implement important research initiatives to reduce death and suffering from cancer throughout Pennsylvania.

Objective B3

Determine the current status of capabilities, participation in, and access to clinical research across the state; develop and establish more extensive and effective translational and clinical research collaborations across Pennsylvania; and provide the entire population with access to innovative and potentially more effective approaches to the treatment, early diagnosis, and prevention of cancer.

PRIORITY GOALS AND OBJECTIVES *(continued)*

GOAL C Implement a user-friendly statewide website with appropriate links to other relevant regional and national websites to facilitate an effective communication mechanism for all Research goals, facilitate communications and sharing of information among cancer researchers and others, and provide needed information on cancer and clinical cancer research studies to Pennsylvania citizens, health professionals, and researchers, in order to disseminate research opportunities and research advances across the Commonwealth.

MAKE CLINICAL RESEARCH STUDIES AVAILABLE TO ALL

Objective C1

Establish a website that will immediately begin to provide user-friendly, searchable information to the public and to healthcare professionals on all clinical cancer research studies in Pennsylvania and where they are available, along with links to national websites that provide information on clinical research studies available at other locations throughout the United States.

FACILITATE COMMUNICATIONS AMONG ALL PENNSYLVANIA CANCER RESEARCHERS

Objective C2

Develop an intranet website for communications among cancer research organizations in Pennsylvania and cancer researchers to share plans for joint research studies and results of cancer research studies.

EFFECTIVELY COMMUNICATE RESEARCH RESULTS AND ADVANCES

Objective C3

Develop a public website to provide the public and healthcare professionals with information collected from the research programs described in other Research Goals.

RESEARCH EXPERTISE IN PENNSYLVANIA

Pennsylvania is fortunate to be the home of rich and diverse research expertise. Across the state there are five NCI-designated Cancer Centers, a variety of community cancer centers, the headquarters for three NCI-funded clinical oncology cooperative groups, a statewide bioinformatics consortium and a number of other cancer research organizations, all working to impact the burden of cancer.

Developing effective research collaborations among these organizations will not only maximize the investments made in cancer research, but will ensure that by working together Pennsylvania can make a significant contribution to the national (NCI, ACS, CDC) goal of eliminating death and suffering due to cancer by the year 2015.

NCI-designated cancer centers in Pennsylvania:

- Abramson Cancer Center of the University of Pennsylvania ..... http://pennhealth.com/cancer/penn
- Fox Chase Cancer Center ..... http://www.fccc.edu
- Kimmel Cancer Center of Thomas Jefferson University ..... http://www.kcc.tju.edu
- University of Pittsburgh Cancer Institute ..... http://www.upci.upmc.edu
- The Wistar Institute ..... http://www.wistar.upenn.edu

Visit the PAC^3 website at www.pac3.org to review the document "Research Expertise in Pennsylvania"

PRIORITY GOALS AND OBJECTIVES *(continued)*

GOAL D Establish as a subcommittee of the Pennsylvania Cancer Alliance, a collaborative group of behavioral medicine researchers and population scientists in Pennsylvania to: (1) propose important areas of cancer research; (2) evaluate procedures to increase awareness and improve implementation by state healthcare professionals and citizens of available and emerging guidelines for regular cancer screening and changes in lifestyle; and (3) encourage interdisciplinary collaborations with basic cancer researchers, public health researchers, and healthcare professionals.

Objective D1

Define a list of priorities to identify strategies that will result in the greatest immediate impact on having Pennsylvanians begin to assume more personal responsibility for effective cancer prevention behaviors.

Objective D2

Research and evaluate: (1) available educational tools for promoting cultural sensitivity and culturally appropriate education in terms of their ability to provide best practice cancer treatments, early detection procedures, and prevention approaches to under-educated and other underserved populations (e.g., racial and ethnic minority populations); and (2) promote useful tools, including those that measure literacy level, to all relevant healthcare professionals in Pennsylvania.

GOAL E Perform research to develop effective approaches to modify the behavior of most, if not all, individuals in the Commonwealth to not use tobacco, so that the deleterious effects on health are avoided.

PREVENT TOBACCO USE

Objective E1

Conduct basic and applied research on the elements of effective tobacco prevention programs.

Objective E2

Identify and then deliver the community-based tobacco control programs that are most effective in targeting high-risk populations in Pennsylvania.

Objective E3

Increase the impact of Pennsylvania's community and state tobacco control program by developing effective mechanisms to communicate advances in tobacco control and basic research, to translate those results into action in Pennsylvania's diverse communities.

Objective E4

Conduct prospective, long-term research to evaluate the impact of new policies and approaches on tobacco use patterns in the state (e.g., these analyses might track the impact of legislative events, and if increases in tobacco taxes are found to decrease use by minors, a decision will be made as to whether an additional increase can further reduce tobacco use).

PRIORITY GOALS AND OBJECTIVES *(continued)*

PROMOTE CESSATION OF TOBACCO USE

Objective E5

Perform research to identify the basis of tobacco addiction and allure, the barriers to successful addiction treatment, and the most effective means of achieving abstinence from tobacco.

Objective E6

Investigate mechanisms for optimal dissemination of proven interventions for specific populations at the community and state levels.

Objective E7

Perform tobacco treatment research to develop new and innovative strategies to effectively influence a high proportion of high-risk youth.

GOAL F Ensure the accomplishment of the Consortium's Research goals by continuing the commitment of the Commonwealth for tobacco settlement formula funds to support biomedical, clinical, and health services research, marshal needed resources, and obtain sufficient additional funding and support to accomplish all high priority Research goals and objectives.

FUND IMPLEMENTATION

Objective F1

Educate the Pennsylvania Administration and General Assembly on the importance of investing in cancer research.

Objective F2

Through collaborative partnerships across the state, compete for a substantially higher level of federal funding for Pennsylvania cancer research.

Objective F3

Develop strategies and cultivate opportunities to access non-governmental funds.

Objective F4

Ensure adequate financial support for all aspects of clinical care associated with clinical trials.

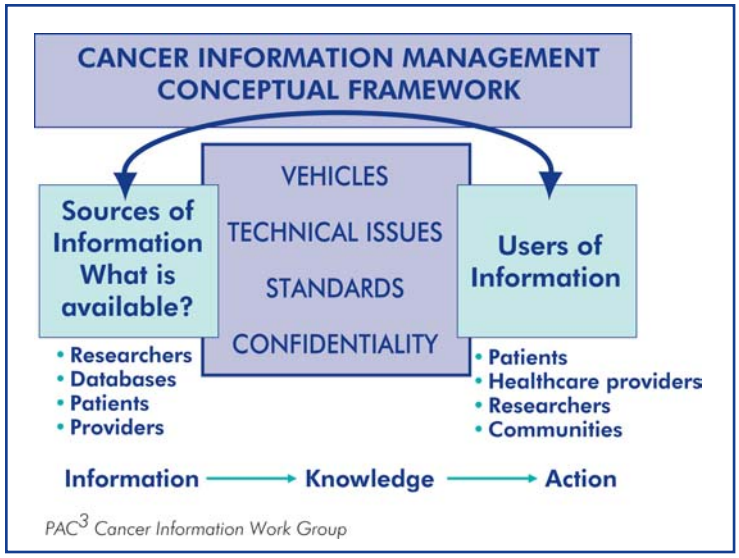
See Appendix B6 for potential actions identified by PAC^3 for achieving the Research Priority Goals and Objectives.

CANCER-RELATED INFORMATION MANAGEMENT AND DISSEMINATION

The rapid advancement of information technology has created rich cancer-related data and information. However, these existing data sources and information are not being used to their full potential by a variety of users including researchers, planners, healthcare providers, patients, and the general public. PAC^3 realizes that to fully benefit from these diverse resources, we need to develop and carry out dissemination strategies to address cancer information at all levels and across the continuum, from prevention to end-of-life. These strategies need to address the diversity of populations in the state, must be coordinated with various organizations and stakeholders, and should be based on health communication best practices. In addition, it is critical to support and utilize new technologies to facilitate the efficient collection, dissemination, and management of cancer-related data and information.

One of the most critical issues is the lack of a centralized access point for the diverse resources that already exist for both professionals and the public. The concept of a "web portal" is a critical strategy to address the following ***Priority Goals and Objectives***. This concept is an approach to combine these resources and increase the dissemination of existing data and information. PAC^3 envisions this portal as a diffusion and dissemination mechanism, not a mechanism to recreate existing resources and programs. Two important caveats are:

1. building on existing new cancer portals, such as Cancer Control PLANET developed by NCI, ACS, and CDC, and
2. creating parallel access points to reach those who have limited or no access or ability to use Internet based resources.



The following are ***Pennsylvania's Priority Goals and Objectives*** for Cancer-Related Information Management and Dissemination. They focus primarily on the efficient and effective use and management of existing cancer data and information by all stakeholders (e.g. public, patients, researchers, program planners, healthcare providers, and policymakers). ▶

PRIORITY GOALS AND OBJECTIVES

GOAL A Provide all Pennsylvanians with access to high-quality, accurate, and current information based on individual and population factors for all aspects of cancer, from prevention to end-of-life care.

Objective A1

Develop and implement a dissemination model and approaches to provide all patients going through cancer diagnostic testing or having received a diagnosis of cancer with information on how to obtain cancer information through a variety of communication channels.

Objective A2

Develop and implement a dissemination model and approaches to provide specific age groups and populations with information about cancer prevention, prevention trials and studies, cancer risk, and cancer risk reduction through a variety of communication channels.

Objective A3

Identify pilot programs focused on creating personalized clinical records to assist patients and the public for tracking and accessing their own cancer-related behaviors, risks, and treatment.

Objective A4

Identify and implement a process to evaluate cancer information sources and disseminate this information through cancer control initiatives and the PAC^3 web portal.

Objective A5

Encourage Medicare, Medicaid, commercial, and other health insurers to make pertinent benefit information available to their members (e.g., concerning covered and non-covered services, provider directories, and other benefit information).

Objective A6

Identify and implement pilot programs for on-line management of individual health risk assessment based on standardized and validated risk factor surveys. (The measurable outcome is more readily available risk factors and functional data to enable epidemiologists to identify and study the effectiveness of cancer treatment interventions).

PRIORITY GOALS AND OBJECTIVES *(continued)*

GOAL B Provide all Pennsylvania healthcare providers with access to accurate, up-to-date, age- and culture-appropriate information about cancer prevention, risk reduction, screening, diagnosis, treatment, and end-of-life.

Objective B1
Provide healthcare providers with access to current, high-quality, and accurate information on the basis of specific information needs and risk factors.

Objective B2
Ensure that every healthcare provider has access to the latest evidence-based guidelines.

Objective B3
Promote the use of information sources on the availability and outcomes of clinical trials for cancer prevention and treatment.

Objective B4
Encourage and support compliance with current laws and regulations regarding patient confidentiality, security, and privacy, and foster the sharing of best practices among health entities.

GOAL C Increase the usage of available cancer data by researchers and health planners for assessing the cancer burden and providing a solid foundation for cancer surveillance, research, and program planning activities in Pennsylvania.

Objective C1
Coordinate and disseminate existing cancer data/information by establishing, maintaining, and promoting a website and a portal with links to various sources of cancer data and cancer-related information.

Objective C2
Create and promote use of a user-friendly interactive website that provides current and historical cancer incidence statistics (numbers, rates, graphs, maps, and profiles) for various geographic areas (counties and municipalities).

Objective C3
Promote use of geocoded cancer incidence data and collaboration with other databases for conducting GIS/spatial analyses to facilitate more comprehensive cancer surveillance, research, and program planning activities.

Objective C4
Increase access and utilization of existing cancer incidence and other pertinent data for use in cancer surveillance and program planning activities.

PRIORITY GOALS AND OBJECTIVES *(continued)*

GOAL D Influence policymakers, government, and private industry to increase funding opportunities that focus on cancer information development, management, and dissemination.

Objective D1

Develop a method for tracking funding opportunities for cancer information development, management, and dissemination activities through governmental and private sources.

Objective D2

Develop a mechanism (e.g., Listserv, website, etc.) to notify interested persons about new and existing funding opportunities related to cancer information development, management, and dissemination activities through governmental and private sources.

GOAL E Enhance collaboration among diverse cancer control organizations and engage other public- and private-sector organizations in the coordinated dissemination and utilization of cancer information for the public, patients, providers, researchers, program planners, and policymakers.

Objective E1

Create and implement a process for a centralized location of an information clearinghouse of cancer information and communications resources including print, electronic, and distance education resources.

Objective E2

Identify the cancer information infrastructures, both data and information, of PAC^3 organizations.

Objective E3

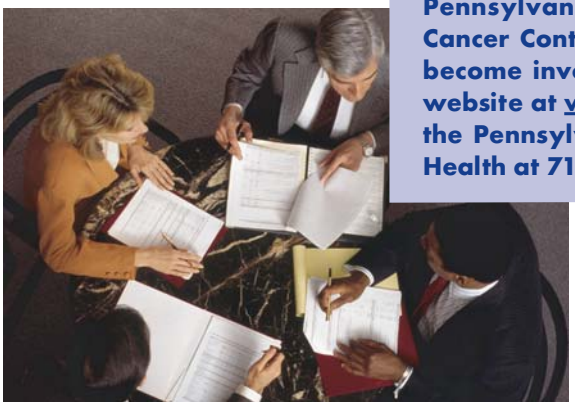
Encourage and foster research in the management and dissemination of cancer information between PAC^3 and other organizations within Pennsylvania.

See Appendix B7 for potential actions identified by PAC^3 for achieving the Cancer-Related Information Management and Dissemination Priority Goals and Objectives.

IMPLEMENTATION

To learn more about the Pennsylvania Comprehensive Cancer Control Plan and how to become involved, visit the PAC^3 website at www.pac3.org or call the Pennsylvania Department of Health at 717-787-5251.

The capacity to seize the opportunity for change lies with the collaborative efforts of all stakeholders across the Commonwealth. While the Consortium (PAC^3) that created this Plan is committed to its implementation, the Consortium must be *expanded* to include the resources and expertise of the many agencies, organizations, and individuals already working along the cancer continuum.



To ensure that the ***Priority Goals and Objectives*** of this Plan are implemented and that the principles of collaboration and addressing cancer disparities are predominant in all implementation efforts, PAC^3 recommends the following:

GOAL A Work together to implement the Pennsylvania Comprehensive Cancer Control Plan, evaluate results, and identify and respond to new challenges and opportunities.

Objective A1

Re-establish the Pennsylvania Cancer Control Consortium (PAC^3) as the body to coordinate implementation of the Plan.

Objective A2

Implement the Plan:

- Within the first 100 days after Plan ratification, PAC^3 will:
  - Convene to initiate Plan implementation.
  - Identify teams and champions to lead initiative areas, goals and objectives.
- Identify the ***Priority Goals and Objectives*** to be implemented first.
- Establish definitive strategies and measurable outcomes for *Priority Goals and Objectives*.
- Develop an evaluation mechanism.
- Identify advocacy priorities and coordinate advocacy efforts.
- Identify, coordinate, and secure funding opportunities.
- Help forge and expand partnerships and collaborations.
- Continuously review progress by tracking activities and measuring results, with particular emphasis on addressing cancer disparities.
- Convene an annual summit to review progress and set new goals.

Through the PAC^3 process, members identified a range of potential actions that represent starting points for implementation. These Potential Actions, which can be seen in Appendix B, are products of the PAC^3 work group process. Each work group identified ideas and examples of how the ***Priority Goals and Objectives*** of this Plan might be achieved. As PAC^3 moves to implementation, these action ideas will be the starting point for discussing and developing strategies and measurable outcomes.

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APPENDIX A: CANCER IN PENNSYLVANIA

SOME BASIC FACTS[13]

What is Cancer?

- Group of diseases related to the uncontrolled growth and spread of abnormal cells.
- Death can occur if growth of abnormal cells spreads.
- If detected early and treated promptly, many cancers can be cured.

What Causes Cancer?

- Environmental factors include chemicals, radiation (ultraviolet, x-rays, gamma rays), viruses, and lifestyle (tobacco use, diet, alcohol consumption).
- Internal factors include hormones, immune status, and inherited conditions.

How is Cancer Prevented?

- Primary prevention includes avoiding oncogenic exposures (tobacco, sun exposure, excess dietary fat).
- Secondary prevention includes early detection and treatment of benign precursor lesions.

How is Cancer Treated?

- Surgery, radiation, chemotherapy, hormones, and immunotherapy.

Who Gets Cancer?

- Cancer strikes all segments of the state's population.
- Occurrence of cancer rises with age and exposure to risk factors.

What Are the Most Common Cancers?

- Female Breast
- Bronchus and Lung
- Prostate
- Colon and Rectum
- Urinary Bladder

How Many New Cancer Cases and Deaths Will There Be in 2003?

- About 71,960 Pennsylvanians are projected to be diagnosed with invasive cancer in 2003.
- 69,065 Pennsylvania residents were diagnosed with invasive cancer in 2000.
- About 29,955 Pennsylvanians are projected to die from cancer in 2003.
- 29,853 Pennsylvania residents died as a result of cancer in 2001.

Why Is the Number of Cancer Cases Increasing in Pennsylvania?

- Larger percentage of early-stage detection.
- Aging population.
- Better awareness of symptoms/signs.

Are Cancer Death Rates Declining in Pennsylvania?

- Although total cancer deaths have averaged 30,000 per year since 1990, the age-adjusted rates have been declining since 1990.
- Similarly, cancer deaths among men and women have remained steady, while corresponding rates have declined.

[13] Pennsylvania Department of Health - *Cancer Facts and Figures, Pennsylvania,* 2003

APPENDIX A *(continued)*

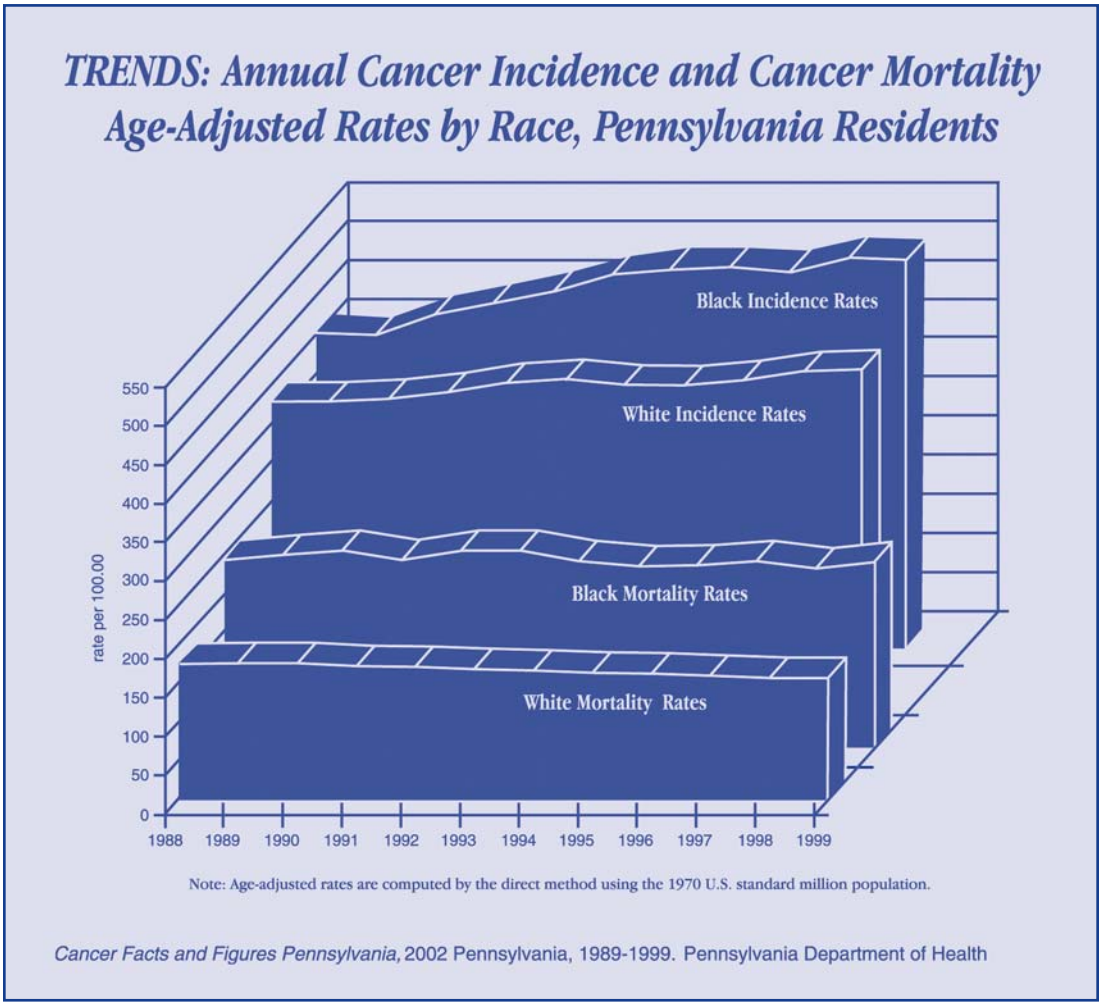
The description of the cancer burden for each of the major cancers was supplied by the Pennsylvania Department of Health Statistics in 2002 for use by the work groups in creating the first Comprehensive Cancer Control Plan for Pennsylvania. This burden statement is a historical document and should not be considered current.

Additional and updated cancer statistics for Pennsylvania are found at the Pennsylvania Department of Health website at www.health.pa.us/stats/ (click on the "Cancer Incidence and Mortality" link), the NCI/CDC combined website Cancer Control PLANET at http://cancercontrolplanet.cancer.gov, and the American Cancer Society website, www.cancer.org.

INCIDENCE AND MORTALITY

The American Cancer Society estimates that in 2002, Pennsylvania had 68,900 new cancer cases and 29,800 cancer deaths. The average annual age-adjusted mortality rate for cancer deaths per 100,000 persons in Pennsylvania is estimated to be 174.7. This is slightly higher than the national recorded death rate per 100,000 of 168.3. Pennsylvania ranks 21st highest overall in cancer mortality rates among the 50 states and Washington, D.C.

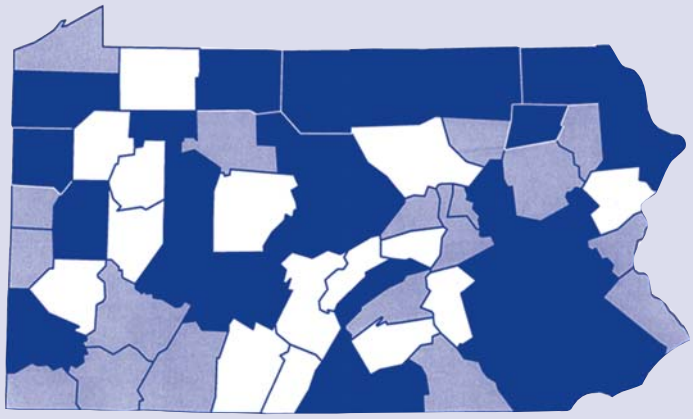
According to health statistics published by the Pennsylvania Department of Health, lung and bronchus, colorectal, female breast, melanoma, and prostate cancer accounted for 59% of actual new invasive cases of cancer in Pennsylvania in 2000 and 53% of actual cancer deaths in 2001. Because lung cancer, colorectal cancer, breast cancer, and prostate cancer account for 56% of all new cancer cases in 2000 and 51% of estimated cancer deaths in 2001, it is reasonable for the current Pennsylvania Cancer Control Plan to emphasize these cancers in recommendations for prevention, screening, and treatment.



2001 Projected and 1999 Observed Cancer Deaths Percent Change 1999 to 2001 by Pennsylvania County of Residence

County	2001 Projected	1999 Observed	Percent Change
ALL COUNTIES	30,045*	30,136	-0.3
ADAMS	190	187	1.6
ALLEGHENY	3,490	3,692	-5.5
ARMSTRONG	135	184	-26.6
BEAVER	530*	540	-1.9
BEDFORD	105*	111	-5.4
BERKS	825*	813	1.5
BLAIR	350*	343	2.0
BRADFORD	140*	131	6.9
BUCKS	1,225	1,236	-0.9
BUTLER	395	386	2.3
CAMBRIA	420	417	0.7
CAMERON	20*	13	53.8
CARBON	185	174	6.3
CENTRE	195	186	4.8
CHESTER	770*	735	4.8
CLARION	85*	96	-11.5
CLEARFIELD	200*	216	-7.4
CLINTON	95*	91	4.4
COLUMBIA	135*	125	8.0
CRAWFORD	250	232	7.8
CUMBERLAND	430*	458	-6.1
DAUPHIN	525	560	-6.3
DELAWARE	1,410*	1,367	3.1
ELK	95*	99	-4.0
ERIE	620*	629	-1.4
FAYETTE	415*	435	-4.6
FOREST	30	20	50.0
FRANKLIN	325	313	3.8
FULTON	15	17	-11.8
GREENE	105	106	-0.9
HUNTINGDON	80	88	-9.1
INDIANA	190*	189	0.5
JEFFERSON	110*	108	1.9

County	2001 Projected	1999 Observed	Percent Change
JUNIATA	65	57	14.0
LACKAWANNA	620*	650	-4.6
LANCASTER	980	947	3.5
LAWRENCE	260*	271	-4.1
LEBANON	310	308	0.6
LEHIGH	705*	699	0.9
LUZERNE	975*	1,013	-3.8
LYCOMING	250	284	-12.0
MCKEAN	130*	116	12.1
MERCER	345	329	4.9
MIFFLIN	105*	111	-5.4
MONROE	270*	307	-12.1
MONTGOMERY	1,670*	1,666	0.2
MONTOUR	50*	50	0.0
NORTHHAMPTON	610*	627	-2.7
NORTHUMBERLAND	240	251	-4.4
PERRY	85*	88	-3.4
PHILADELPHIA	4,275*	4,138	3.3
PIKE	85	75	13.3
POTTER	45	39	15.4
SCHUYLKILL	4608	459	0.2
SNYDER	65	69	-5.8
SOMERSET	185	185	0.0
SULLIVAN	25*	26	-3.8
SUSQUEHANNA	125	116	7.8
TIOGA	110	109	0.9
UNION	45	47	-4.3
VENANGO	120	128	-6.3
WARREN	110*	118	-6.8
WASHINGTON	575*	570	0.9
WAYNE	130*	129	0.8
WESTMORLAND	965	1,001	-3.6
WYOMING	75	64	17.2
YORK	775*	792	-2.1



Percent Change 1999-2001

-5.0 or lower | -4.9 to 0.0 | 0.1 to 4.5 | 4.6 or higher

NOTE: Projections were rounded to the nearest whole five.

* The arithmetic mean for the five-year period of 1995-99 was used to estimate the number of deaths. See Technical Notes for additional information.

APPENDIX A *(continued)*

POPULATIONS

Pennsylvania is the 6th most populous state in the nation. However, Pennsylvania has the second highest percentage (15.6%) of elderly citizens. The Commonwealth of Pennsylvania has very high-density population in its large metropolitan areas in Southeast Pennsylvania, Western Pennsylvania, the Lehigh Valley, and Harrisburg area, but rural populations through much of the rest of the state.

This factor may account for differences in cancer rates, differences in stage of disease at the time of diagnosis, and differences in projected cancer deaths per 100,000. National data show that average annual incidence and mortality rates differ by race, ethnicity, and gender. Because rates of cancer increase with age, one would expect that Pennsylvania has somewhat higher cancer incidence and mortality rates than states with generally younger populations such as Nevada, Arizona, and California.

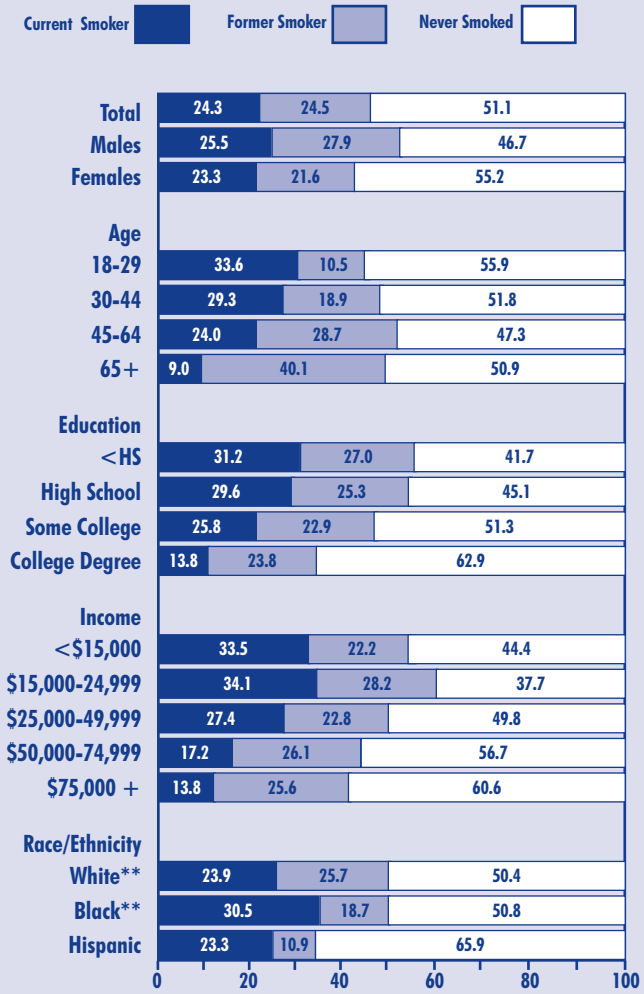
GEOGRAPHIC AREA

The figures on the left show that some counties have experienced an increase in the percentage of deaths from cancer between 1999 to 2001. Generally, these are the densely populated areas of the state, and include potentially underserved rural areas.

CHANGES OVER TIME

Although there is a decrease in annual age-adjusted-cancer death rates in the U.S. and in Pennsylvania, there is an overall increase in the incidence of female cancer. This is primarily due to the fact that more women are smoking and thus experiencing increased incidence from tobacco-related cancers. See chart on the right.

Tobacco Use
Percent of Current and Former Smokers and By Selected Demographic Characteristics
Pennsylvania Adults, 2000 BRFSS*



*Behavioral Risk Factor Surveillance System
** Non-Hispanic

NOTE: Percents may not add to 100.0 due to rounding.

APPENDIX A *(continued)*

ETIOLOGY

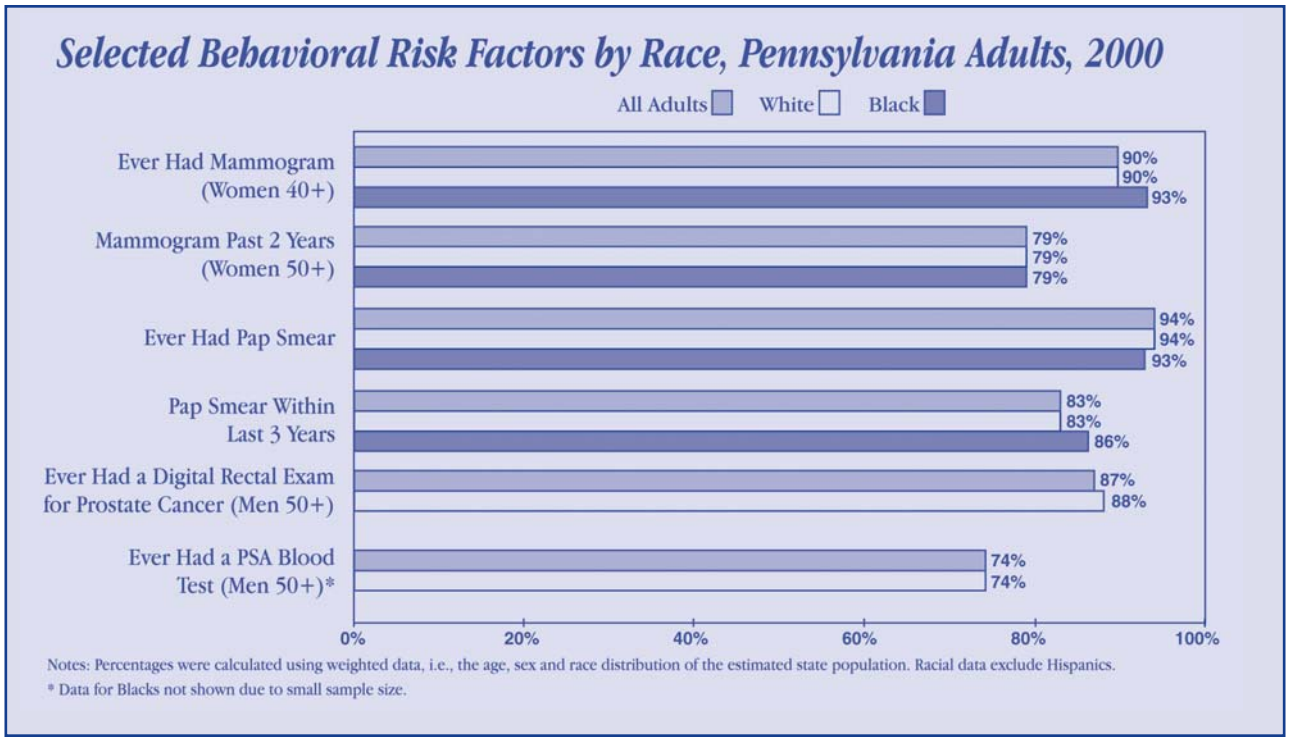
Cancer causation can be due to individual factors or to environmental factors. The primary individual factors include heredity, which probably accounts for no more than 5% of cancer risk and is due to familial inheritance of a cancer gene mutation. Endogenous hormone levels are a factor in breast, ovarian, and endometrial cancer in women, and prostate and testicular cancer in men. The endogenous hormones do not initiate the cancer but may accelerate progression of cancer. While not a factor in most people, immune deficiency plays a role in patients who are on immunosuppressive drugs to maintain an organ transplant or in patients with acquired immune deficiency (AIDS).

Lifestyle or health-related behavior accounts for 75% of environmentally-associated cancer: diet, 35%; tobacco use, 30%; alcohol consumption, 3%; and sexual practices, 7%. Cancer caused by community-based exposures include infectious agents, 10%; workplace exposures, 4%; natural physical exposure such as ultraviolet and gamma radiation, 3%; human pollution in the air and the water, 2%; medicines and medical procedures, 1%; and consumer products such as food additives, 1%.

Because tobacco is such an important cause of cancer, further data about smoking is as follows: 24% of all Pennsylvania adults and 31% of Black adults indicate that they were regularly smoking cigarettes in 2000. This compares to a national average of 15% and 18% respectively. The age group 18-29 has the highest percentage of smokers. With increasing age, cigarette use decreases to only 9% among 65 years of age and older. In Pennsylvania, 25% are adult former smokers (28% males, 22% females). Pennsylvania is lagging behind the rest of the nation in quit-smoking rates – 45% vs. 50% nationally.

While the dietary causes of cancer are complex, there is general agreement that obesity is associated with higher cancer incidence. In Pennsylvania, 58% of adults who responded to a recent statewide survey were considered to be overweight and 21% were obese. The comparable figures for Black adults are 74% overweight and 30% obese. While it is not clear that physical activity in and of itself can result in lower cancer rates, cancer incidence is related to higher body weight. In Pennsylvania, 23% of adults report no leisure time physical activity.

There are no well-documented geographic cancer "hot spots" in Pennsylvania. However, statewide data do suggest that urban counties with greater minority and low-income populations tend to have higher cancer death rates. In general, this is because there is a strong correlation between low socioeconomic status and increased cancer death rates.



APPENDIX A *(continued)*

SECONDARY PREVENTION OR SCREENING

Screening is effective for early detection of some cancers. In general, the rate of mammography participation in Pennsylvania is consistent with the national average in 2000; over 90% of women 40+ indicate they had a mammogram, and 79% of women age 50 + had a mammogram in the last two years. Also, 94% of women had a Pap smear, 83% within the last three years. In men over age 50, 87% had a digital rectal exam (DRE) for prostate cancer, and about 74% had at least one Prostate Specific Antigen (PSA) blood test. The 2001 data showed that 30% of female adults and 32% of male adults had a fecal occult blood test (FOBT) for colon cancer in the previous two years and that 45% of all adults had ever had this screening test.

TREATMENT

Recently published data from the National Medicare Claims Database (Birkmeyer et al., 2002), shows that mortality decreased as volume increased for cancer surgery. The figure below shows that absolute differences in adjusted mortality rates between very-low-volume hospitals and very-high-volume hospitals were over 12% for pancreatic resection (16.3% vs. 3.8%) and greater than 5% for esophagectomy and pneumonectomy. The authors conclude that, in the absence of other information about quality of surgery at the hospitals near them, Medicare patients undergoing cancer procedures can significantly reduce their risk of operative death by selecting a high-volume hospital.

RESEARCH ISSUES

On a statewide basis, there is a need for more timely data about cancer care delivery, both for prevention, screening, and treatment.

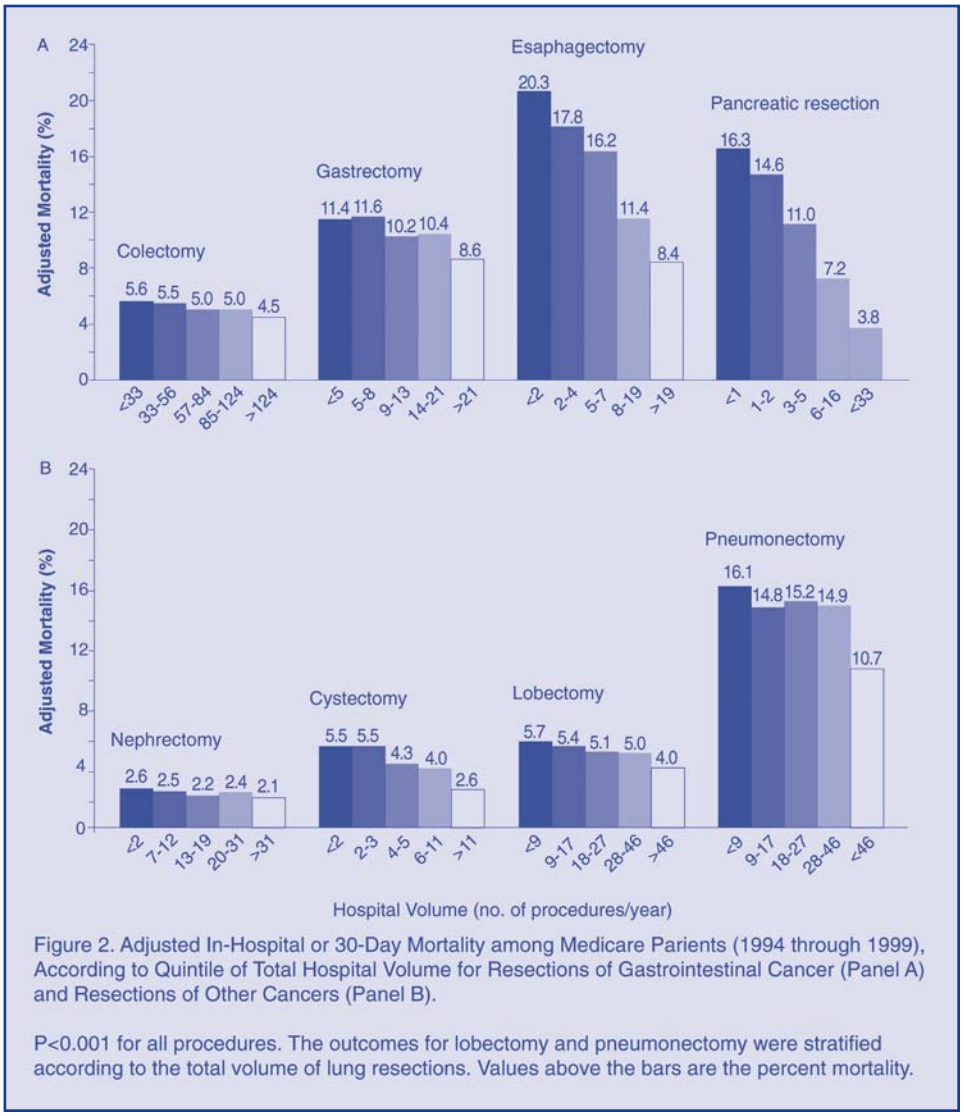


Figure 2. Adjusted In-Hospital or 30-Day Mortality among Medicare Parients (1994 through 1999), According to Quintile of Total Hospital Volume for Resections of Gastrointestinal Cancer (Panel A) and Resections of Other Cancers (Panel B).

P<0.001 for all procedures. The outcomes for lobectomy and pneumonectomy were stratified according to the total volume of lung resections. Values above the bars are the percent mortality.

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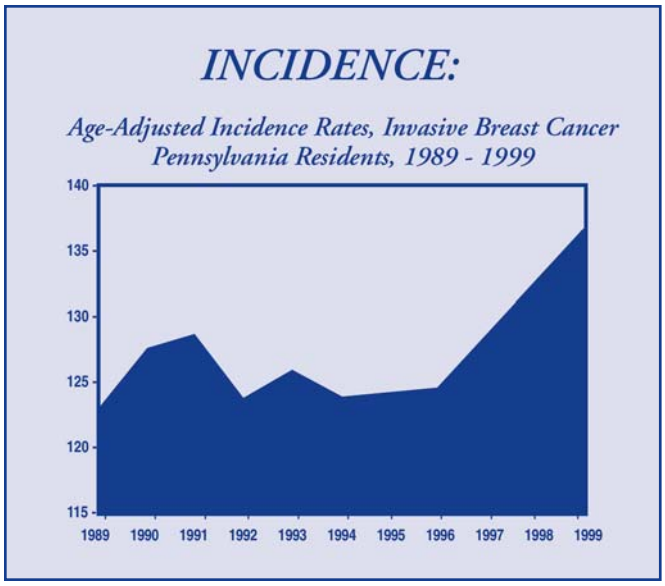
APPENDIX A *(continued)*

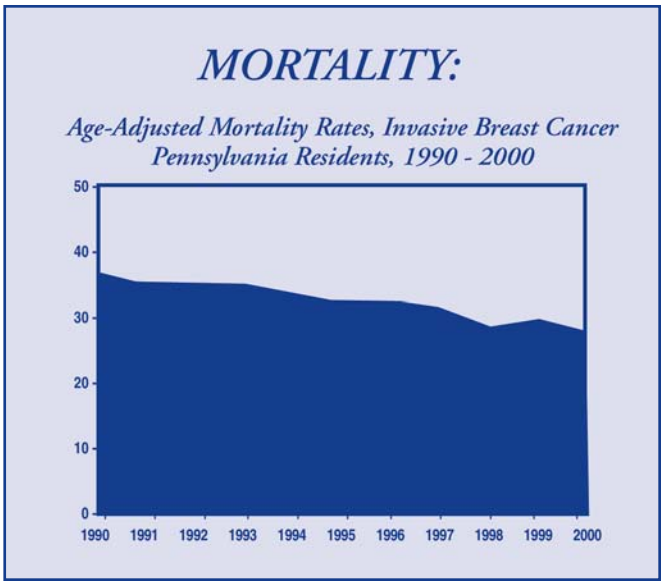
The burden of cancer in Pennsylvania is depicted below in charts based on incidence and mortality data per 100,000 age-adjusted to the 2000 U.S. standard million population.

BREAST CANCER IN PENNSYLVANIA

Breast cancer is the most common form of cancer diagnosed among women in Pennsylvania, and it is the second most frequent cause of cancer mortality among Pennsylvania women (surpassed only by lung cancer).

The age-adjusted incidence rate for invasive female breast cancer among residents has fluctuated between 122.5 in 1989 and 136.6 in 1999 (see chart below). The 1999 rate was the highest rate recorded during the eleven-year period. That year, 10,158 cases of invasive female breast cancer were reported among residents. This rate has been on the increase between 1995 and 1999 among Pennsylvania women. In 2000, there were 2,267 deaths due to female breast cancer among residents. This resulted in an age-adjusted mortality rate of 27.5 per 100,000 (see chart below). In 1990, there were 2,690 deaths reported, for a rate of 36.6. The annual age-adjusted mortality rates have declined between 1990 and 2000. In fact, the 2000 rate was the lowest recorded during this eleven-year period.





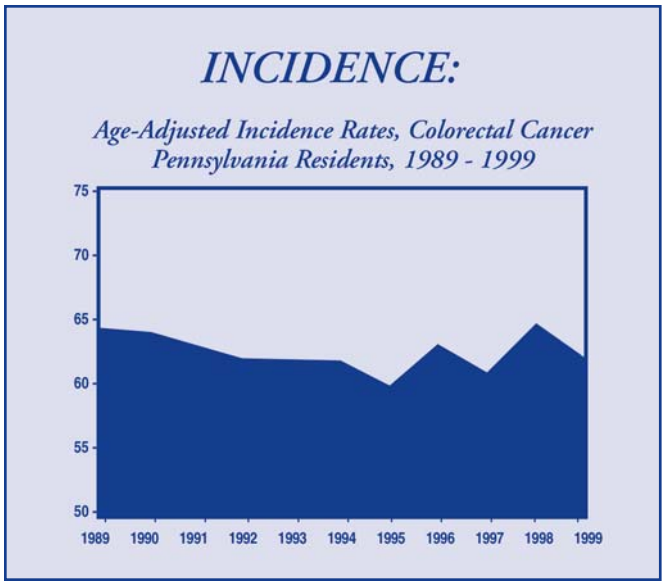
Additional information on the burden of breast cancer in Pennsylvania can be found on the PAC^3 website at www.pac3.org; at the Pennsylvania Department of Health website at www.health.state.pa.us/stats/ (click on the "Cancer Incidence and Mortality link); the NCI/CDC combined website Cancer Control PLANET at http://cancercontrolplanet.cancer.gov; and the American Cancer Society website, www.cancer.org.

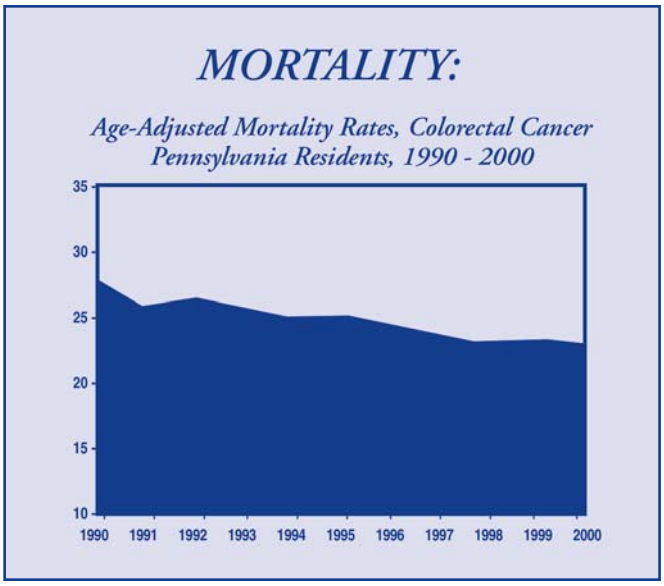
APPENDIX A *(continued)*

COLORECTAL CANCER IN PENNSYLVANIA

Colorectal cancer is the third most common type of cancer diagnosed among men and the second most common among women in Pennsylvania. Colorectal cancers are the third most common cause of cancer deaths among both men and women in Pennsylvania.

In 1999, there were 8,918 cases of invasive colorectal cancer diagnosed among residents and reported to the Pennsylvania Cancer Registry, for an age-adjusted incidence rate of 61.9 per 100,000. In 1989, there were 8,502 cases reported, for a rate of 64.2. As shown in the chart below, age-adjusted rates have not changed much in recent years. In 2000, there were 3,414 deaths due to colorectal cancer among residents. This resulted in a mortality rate of 23.0 per 100,000 age-adjusted to the 2000 United States standard million population. In 1990, there were 3,707 deaths reported, for a rate of 28.0. The annual number of deaths and age-adjusted mortality rates have been on the decline during the eleven-year period of 1990-2000.



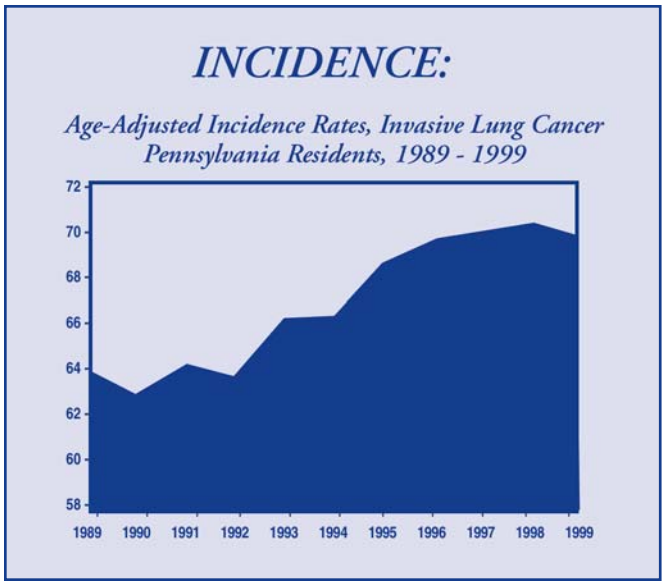


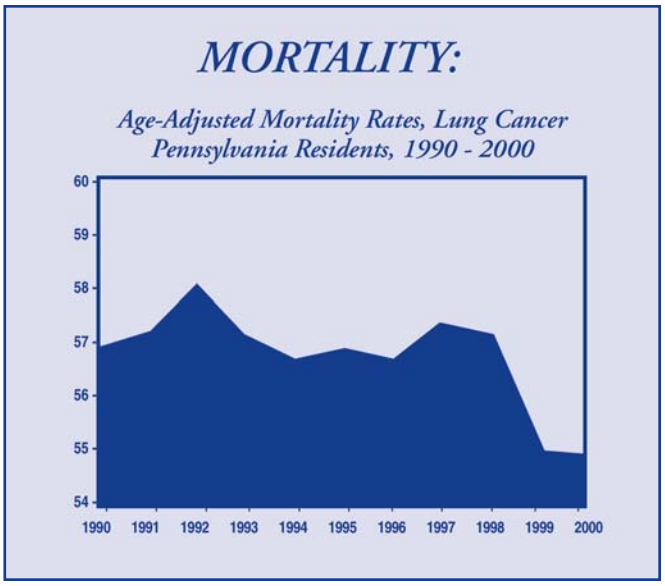
Additional information on the burden of colorectal cancer in Pennsylvania can be found on the PAC^3 website at www.pac3.org; at the Pennsylvania Department of Health website at www.health.state.pa.us/stats/ (click on the "Cancer Incidence and Mortality link); the NCI/CDC combined website Cancer Control PLANET at http://cancercontrolplanet.cancer.gov; and the American Cancer Society website, www.cancer.org.

APPENDIX A *(continued)*

LUNG CANCER IN PENNSYLVANIA

Lung cancer is the second most common form of cancer diagnosed in Pennsylvania. In 1999, there were 9,815 cases of invasive lung and bronchus cancer diagnosed. The age-adjusted incidence rate in 1999 was 69.6 per 100,000. In 1989, there were 8,392 cases reported, for a rate of 63.9. Total numbers and rates have been on the increase since 1989. The highest rate was recorded for 1998 at 70.2. Lung cancer is the most common cause of cancer deaths among both men and women in Pennsylvania. In 2000, there were 8,014 deaths due to lung and bronchus cancer among Pennsylvania residents. The 2000 age-adjusted mortality rate was 54.9 per 100,000. In 1990, there were 7,749 deaths reported for a rate of 56.9. Annual age-adjusted mortality rates have generally declined during the period of 1990-2000. However, female mortality rates have been increasing, while male rates have been decreasing.





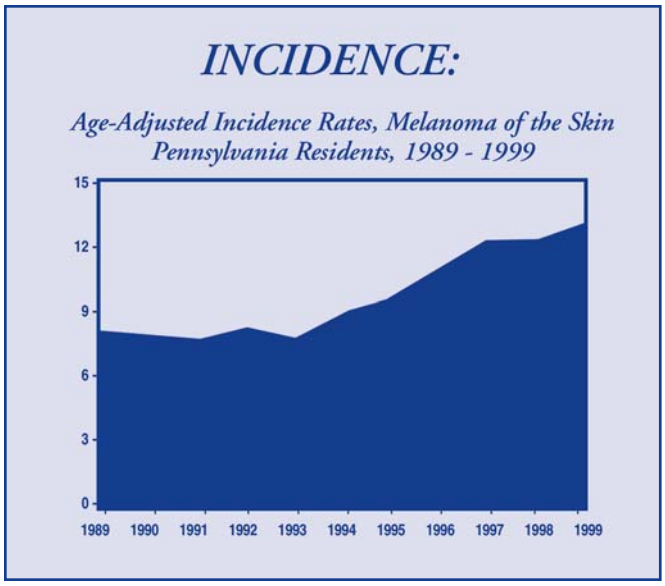
Additional information on the burden of lung cancer in Pennsylvania can be found on the PAC^3 website at www.pac3.org; at the Pennsylvania Department of Health website at www.health.state.pa.us/stats/ (click on the "Cancer Incidence and Mortality link); the NCI/CDC combined website Cancer Control PLANET at http://cancercontrolplanet.cancer.gov; and the American Cancer Society website, www.cancer.org.

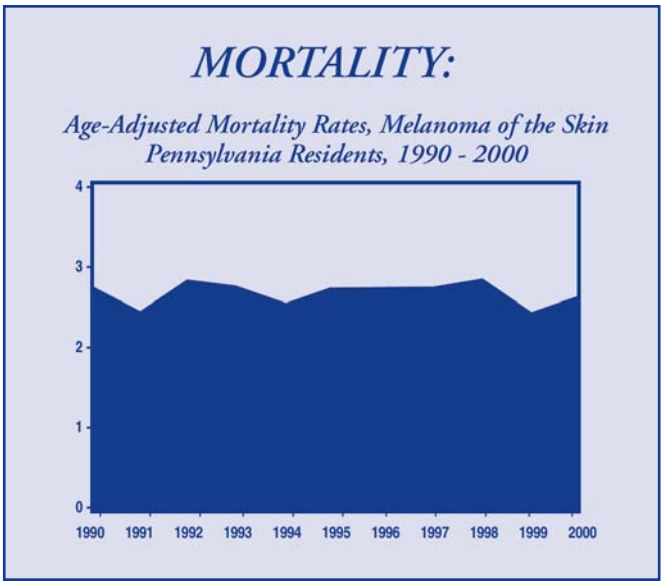
APPENDIX A *(continued)*

MELANOMA IN PENNSYLVANIA

Among Pennsylvania residents, 1,702 men and women were diagnosed with melanoma of the skin in l999. This is the largest number of cases reported in any single year in the decade from l989 through l999 and represents an increase of nearly 70% from the number of cases reported in l989.

Annual age-adjusted incidence rates for invasive melanoma of the skin, between 1989 and 1999 (see chart below) have been increasing, especially since 1994. There were 1,702 cases diagnosed in 1999 (up 70 percent from 999 cases reported to the Pennsylvania Cancer Registry in 1989). The vast majority of skin melanomas occur among Whites and excess exposure to sunlight is a major risk factor. Incidence rates have been on the increase for both males and females. The annual age-adjusted mortality rates for melanoma of the skin during the period of 1990 to 2000 have not changed much (see chart below). The highest rate was 2.9 (in 1992 and 1998), while in 2000 there were 382 deaths for a rate of 2.7. In 1990, there were 362 deaths reported for a rate of 2.8. Age-adjusted mortality rates among both males and females have also shown no trends between 1990 and 2000.





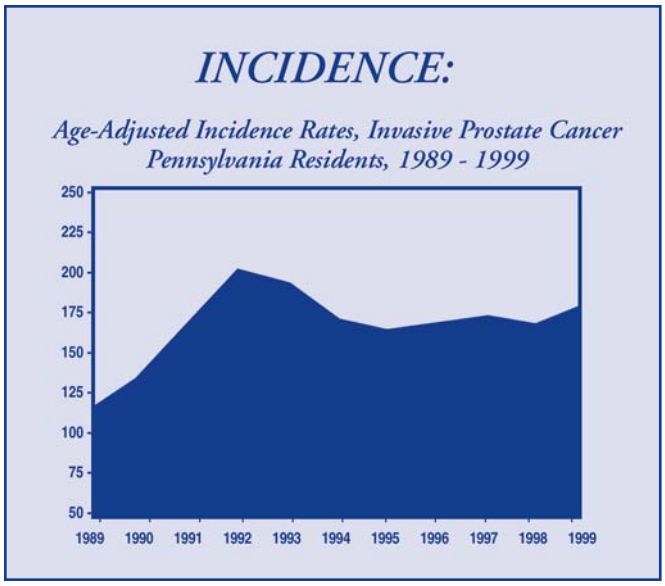
Additional information on the burden of melanoma in Pennsylvania can be found on the PAC^3 website at www.pac3.org; at the Pennsylvania Department of Health website at www.health.state.pa.us/stats/ (click on the "Cancer Incidence and Mortality link); the NCI/CDC combined website Cancer Control PLANET at http://cancercontrolplanet.cancer.gov; and the American Cancer Society website, www.cancer.org.

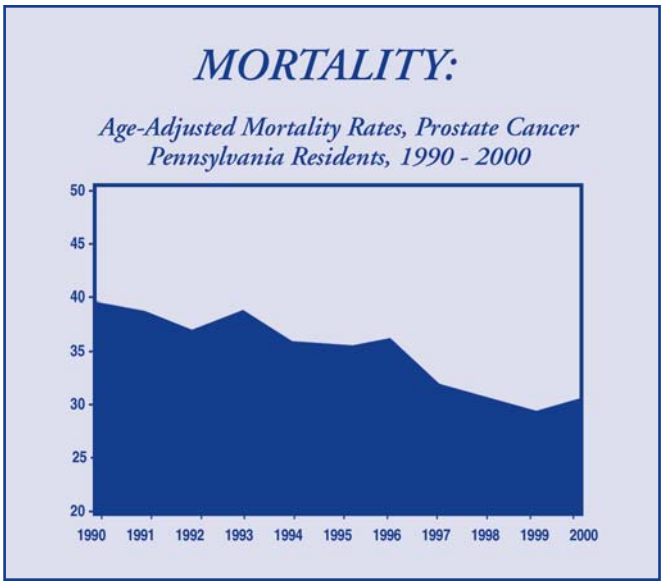
APPENDIX A *(continued)*

PROSTATE CANCER IN PENNSYLVANIA

Prostate cancer is the most common cancer among males in Pennsylvania. It is also the second most frequent cause of cancer death in males, following lung cancer.

The age-adjusted incidence rate for invasive prostate cancer increased dramatically between 1989 (109.9) and 1992 (191.1), probably due to more widespread use of a screening procedure (PSA blood test). In 1992, there were 11,078 cases reported, compared to 5,888 in 1989: an increase of 88%. However, the rates have stabilized between 1994 (162.6,) and 1999 (169.9). There were 10,158 invasive prostate cancers among Pennsylvania residents in 1999. In 2000, there were 1,674 deaths due to prostate cancer among Pennsylvania residents. This resulted in an age-adjusted mortality rate of 30.7. In 1990, there were 1,850 deaths reported for an age-adjusted rate of 39.5. The annual age-adjusted mortality rates have generally been on the decline since 1990. The 2000 rate was over 22 percent lower than the 1990 rate of 39.5 – the highest recorded during the eleven-year period of 1990-2000.





Additional information on the burden of prostate cancer in Pennsylvania can be found on the PAC^3 website at www.pac3.org; at the Pennsylvania Department of Health website at www.health.state.pa.us/stats/ (click on the "Cancer Incidence and Mortality link); the NCI/CDC combined website Cancer Control PLANET at http://cancercontrolplanet.cancer.gov; and the American Cancer Society website at www.cancer.org.

Bureau of Health Statistics and Research, Pennsylvania Department of Health, www.health.state.pa.us/stats/

APPENDIX B: GOALS, OBJECTIVES, AND POTENTIAL ACTIONS

The PAC^3 process identified a range of possibilities to achieve the Priority Goals and Objectives of the Pennsylvania Comprehensive Cancer Control Plan. Actual actions to implement the Plan will be revised and carried out over time through an ongoing and evolving process. The following Potential Actions correspond to the goals and objectives outlined in the Plan and reflects ideas and examples that flowed out of the many discussions among work group members. These Potential Actions represent a starting point for action planning.

Actual implementation strategies will be developed through the partnerships and collaborations that form as PAC^3 moves from a planning phase to an implementation phase. As such, some of these ideas may very well change and new ideas may evolve as the implementation phase begins.

APPENDIX B1: **CANCER PREVENTION AND HEALTHY LIFESTYLES**

Tobacco Free Lifestyles and Environments

PREVENTION GOAL A Reduce use of tobacco by adults.

Prevention Objective A1
Support the developing infrastructure of Pennsylvania's comprehensive tobacco control program.
Prevention Objective A2
Improve access to, and availability of, effective cessation and prevention programs for all Pennsylvanians.
Prevention Objective A3
Ensure high-quality evaluation of existing tobacco prevention and cessation programs.
Prevention Objective A4
Identify and eliminate the disparities in both the rates of tobacco use and its untoward effects among different population sub-groups within Pennsylvania.

Potential Actions

- Seek new/additional funds for tobacco control through innovative public/private partnerships, foundation grants, federal funds, etc.
- Support additional tobacco excise taxes, including taxes indexed to inflation, on all tobacco products.
- Create a statewide tobacco prevention and cessation delivery system.
- Investigate, implement, and evaluate new and more effective ways to help people stop smoking.
- Identify ways of supporting collaboration among Pennsylvania's researchers dedicated to the investigation of tobacco cessation and prevention.
- Engage employers in development of workplace tobacco policies while providing access to cessation resources.

PREVENTION GOAL B Reduce use of tobacco by youth.

Prevention Objective B1
De-normalize tobacco use in Pennsylvania's youth culture.
Prevention Objective B2
Reduce illegal access to tobacco products among minors.
Prevention Objective B3
Support the developing infrastructure of Pennsylvania's comprehensive tobacco control program.
Prevention Objective B4
Improve access to, and availability of effective cessation programs specifically targeting youth.
Prevention Objective B5
Ensure high-quality evaluation of existing tobacco prevention and cessation programs.

APPENDIX B1 *(continued)*

Prevention Objective B6

Identify and eliminate the disparities in both the rates of tobacco use and its untoward effects among different population sub-groups within Pennsylvania.

Potential Actions

- Seek new/additional funds for tobacco control through innovative public/private partnerships, foundation grants, federal funds, etc.
- Build popular support for laws tightening the regulation of sales, strengthening compliance checks, and providing merchant education, training, and support.
- Support additional tobacco excise taxes, including taxes indexed to inflation, on all tobacco products.
- Create a statewide tobacco prevention and cessation delivery system.
- Investigate, implement, and evaluate new and more effective ways to help young people stop smoking.
- Identify ways of supporting collaboration among Pennsylvania's researchers dedicated to the investigation of tobacco cessation and prevention.
- Engage education leadership in development of campus tobacco policies while providing access to cessation resources.
- Support Pennsylvania's BUSTED! youth movement.

PREVENTION GOAL C Support innovative tobacco research.

Prevention Objective C1

Increase the amount of external funding awarded to Pennsylvania's tobacco researchers.

Prevention Objective C2

Improve collaboration among researchers, through PAC^3 networks, in order to foster a more effective, well-leveraged research position in Pennsylvania.

Potential Actions

- Conduct a systematic health-services evaluation of current programs offered by the Pennsylvania Department of Health, including variables such as utilization, treatment delivery models, effectiveness, and cost.
- Use identified deficiencies to develop a strategic plan for future priorities for growth, and utilize targeted Requests for Applications to foster growth in those areas.
- Conduct field evaluation of the reach and effectiveness of statewide counter-marketing campaigns.
- Focus research priorities on identifying novel biologic and behavioral targets for intervention.

PREVENTION GOAL D Improve tobacco control efforts through advocacy and education.

Prevention Objective D1

Improve insurance coverage for cessation treatments and reduce barriers to care across Pennsylvania.

Prevention Objective D2

Identify methods of reaching diverse, high-priority populations such as Hispanics, children, pregnant women, and smokers in the lowest socio-economic strata.

Prevention Objective D3

Engage the medical community in establishing new norms for care, and help them to provide leadership in the dissemination of new ideas about tobacco.

PREVENTION GOAL E Reduce exposure to tobacco smoke pollution for *all* of Pennsylvania's citizens.

Prevention Objective E1

Reduce the impact of tobacco smoke pollution (TSP) on the health of Pennsylvanians.

Prevention Objective E2

Reduce the number of venues in Pennsylvania where TSP is present.

APPENDIX B1 *(continued)*

Potential Actions

- Work to repeal statewide preemption laws, which limit the effectiveness of local regulation of TSP.
- Support the strengthening of statewide clean indoor air regulations governing the exposure to TSP in public spaces.
- Seek new/additional funds for TSP reduction/research programs through innovative public/private partnerships, foundation grants, federal funds, etc.
- Support ongoing educational campaigns designed to increase awareness of the adverse health consequences of TSP exposure.
- Provide healthcare professionals with targeted information that encourages them to more actively engage in TSP interventions.
- Establish a PAC^3 grassroots network to further a policy agenda targeting TSP in the workplace and among pregnant women, infants, and youth.

Physical Activity and Nutrition

PREVENTION GOAL F Reduce the risk of cancer among Pennsylvanians through healthy eating practices and adequate physical activity levels in accordance with current research.

5-9 servings of fruits and vegetables daily and nutrition guidelines [1,2]

U.S. Surgeon General recommendations for physical activity [2,3]

Prevention Objective F1

Increase public awareness about the positive health effects of eating a variety of healthy foods and maintaining a physically active lifestyle, particularly the effects of reducing obesity and preventing cancer.

Potential Actions

- Determine populations least likely to be aware of the link between healthy eating and physical activity and cancer prevention.
- Develop and implement targeted awareness campaigns in accordance with evidence-based data for healthy eating and physical activity in the prevention of cancer.
- Working in collaboration with organizations and institutions, educate healthcare providers about the importance of discussing healthy lifestyle choices, including nutrition and physical activity with their patients.

Prevention Objective F2

Increase the number of effective policies and practices that support and promote healthy eating and physical activity in schools and communities.

Potential Actions

- Increase public awareness of the importance of policies and environments that support healthy eating and physical activity.
- Solicit statewide support for a coordinated communications strategy to promote healthy eating and physical activity and the need for policy and environmental changes.
- Develop a statewide surveillance system to track the status of policies and practices that support healthy eating and physical activity in schools and communities.
- Support Pennsylvania Advocates for Nutrition and Physical Activity (PANA) as a vehicle for implementing strategies.
- Increase the Commonwealth's statewide capacity to implement policy and environmental changes that support and promote healthy eating and physical activity (training, education, technical assistance, resources).
- Increase the number of new and existing collaborative partnerships that are working to promote and support healthy eating and physical activity. For example: Healthy Community Partnerships/SHIP partners, school-related partnerships (e.g., School Health Councils), interagency/organization initiatives (PANA, PAC^3, the Pennsylvania Cardiovascular Health Consortium, government agreements, etc.).

[1] National Cancer Institute. *5 A Day for Better Health Program.* www.5aday.gov/

[2] *The Complete Guide - Nutrition and Physical Activity.* www.cancer.org

[3] U.S. Department of Health and Human Services. *The Surgeon General's Report on Physical Activity and Health,* 1996. Rockville, MD: U.S. Department of Health and Human Services, Public Health Service, and Office of Surgeon General. http://www.cdc.gov/nccdphp/sgr/sgr.htm

APPENDIX B1 ***Potential Actions*** *(continued)*

- Increase the number of institutions that implement changes to promote and support healthy eating and physical activity through:
  - Schools (e.g., the School Health Index).
  - Community Planning (e.g. health impact assessments, pedestrian planning activities).
  - Other potential institutions such as worksites and healthcare, faith-based, community, and non-profit organizations.
- Increase the number of organizations and institutions that assess environments and policies that impact healthy eating and physical activity through:
  - Schools (e.g. coordinated school health program).
  - Community and non-profit organizations.
  - State and local government (e.g. policy changes, funding guidelines, and incentives, such as traffic calming, walkable/bikeable routes, community design, and accessible and affordable recreation).
  - Grant funding institutions that support environmental and policy changes for healthy eating and physical activity.
- Enhance and expand 5-A-Day for Better Health initiatives in Pennsylvania, specifically targeting those age 2 and above least likely to eat 5 to 9 servings of fruits and vegetables daily.
- Support implementation of 5-A-Day for Better Health initiatives targeting preschools and daycare facilities.
- Reduce barriers to all populations' capacity to eat 5 to 9 servings of fruits and vegetables daily.
- Advocate for the implementation of the Youth Risk Behavior Surveillance System to obtain baseline data and tracking of youth healthful eating and physical activity behaviors.

Skin Cancer Prevention

PREVENTION GOAL G Reduce the incidence of malignant melanoma among all Pennsylvanians.

Prevention Objective G1

Increase the proportion of preschool-aged children, school-aged children, and adolescents who engage in protective behaviors for ultraviolet (UV) light in accordance with evidence-based data.

Potential Actions

- Increase the awareness of school-aged youth about the link between UV light exposure and risk for skin cancer as an adult.
- Increase the awareness of parents, particularly mothers, about the link between UV exposure in their children prior to age 18 and the increased risk for skin cancer as an adult.
- Increase parent engagement in UV protection habits (reduced sun exposure, use of consistent sun protection, avoidance of sunburns) for their children under age 18, particularly infants and preschool-aged children.
- Increase sun protection habits among youth (reduce sun exposure, use of consistent sun protection, avoidance of tanning beds).
- Obtain baseline information of youth sun protection habits by expanding the Youth Risk Behavior Surveillance System to measure sun protection habits among school-aged children.

Prevention Objective G2

Increase the proportion of adults who engage in UV protective behaviors in accordance with evidence-based data.

Potential Actions

- Increase the awareness of adults about the link between UV light exposure and risk for all types of skin cancer.
- Increase awareness of adults of the increasing incidence of malignant melanoma and all types of skin cancer among adults.
- Increase the use of UV protection habits (reduced sun exposure, avoidance of tanning beds, use of consistent sun protection) on a regular basis.

APPENDIX B1 *(continued)*

Cervical Cancer Prevention

PREVENTION GOAL H All women in Pennsylvania at higher risk for cervical cancer will have the knowledge and the resources to have Pap smears according to evidence-based guidelines and to receive appropriate follow-up of abnormal screening results.

Prevention Objective H1

Increase the proportion of women in Pennsylvania who understand the importance of being screened for cervical cancer on a regular basis throughout their lifetime and who have knowledge of cervical cancer screening guidelines.

Potential Actions

- The most important risk factor for cervical cancer is infection by Human Papillomavirus (HPV). HPV DNA is present in 93% of cases involving cervical cancer and its precursor lesions.
- Increase awareness among Pennsylvania women that certain types of sexual behavior increase a woman's risk of becoming infected with HPV. Among these are having intercourse at an early age, having numerous sexual partners, and having unprotected sexual contact at any age.
- Increase access to cervical cancer screening and follow-up services within the state. This can be done with a combination of public funding, employee groups, etc., that would help to address geographic and cultural boundaries to cervical cancer screening. (This would be monitored by appropriate survey tools administered within diverse at risk groups).

Prevention Objective H2

Improve statewide delivery of effective health education programs to school-aged children through coordinated school health programs.

Potential Actions

- Increase statewide training and support for the implementation of coordinated school health programs designed to increase knowledge of the risk associated with sexually transmitted diseases and cervical cancer by:
  - Collaborating and partnering with the American Cancer Society's School Health Leadership Institutes.
  - Sharing information on sexual health education curriculum best practices.
  - Increase to 50 percent the proportion of school districts with active school health councils by conducting targeted awareness campaigns and implementing school-related partnerships.
  - Develop culturally relevant and age-appropriate educational approaches addressing healthy lifestyles issues and disparities by accessing relevant information from the Pennsylvania Department of Health, the American Cancer Society, the Department of Education, and other organizations.

Prevention Objective H3

Promote updated educational campaigns targeting healthcare providers and family planning professionals about Human Papillomavirus (HPV)-prevention messages, new developments in testing and treatment, and patient counseling for sexually active patients, especially those with HPV infections and their partners.

Potential Actions

- Increase healthy lifestyles recommendations for office practices by developing materials/tools for state healthcare professionals to use in their practices and providing applicable training and education, technical assistance, and resources.

Prevention Objective H4

Obtain important baseline information on risk behaviors and provide a benchmark for future intervention efforts by working with the Centers for Disease Control and Prevention to implement the Youth Risk Behavior Surveillance System in all public school districts in Pennsylvania by 2005.

APPENDIX B1 *(continued)*

Potential Actions

- Disseminate survey-derived research and evaluation information.
- Incorporate survey data in efforts to seek state and national funding for sexual health programs.
- Target increased awareness in specific high-risk populations.

PAC^3

APPENDIX B2: **CANCER SCREENING AND DIAGNOSTIC FOLLOW-UP**

Awareness and Knowledge

SCREENING GOAL A All Pennsylvanians will be provided information about cancer screening guidelines, what screening services are recommended in established guidelines, where screening services are available, and how to access screening services. Healthcare systems, healthcare organizations, and healthcare providers will routinely deliver information about available screening services to patients eligible for screening and facilitate informed and value-based decision-making by patients about screening service utilization. Disparities in awareness of and knowledge about cancer screening services will be systematically identified and addressed.

Screening Objective A1
Increase public knowledge about cancer screening services.
Screening Objective A2
Increase provider knowledge of cancer screening guidelines and standards of care related to follow-up.
Screening Objective A3
Increase provider-patient dialogue about cancer screening services.
Screening Objective A4
Increase legislators' knowledge of cancer screening guidelines and standards of care.
Screening Objective A5
Increase requests for cancer screening services information by the general public and populations at increased risk for cancer.
Screening Objective A6
Decrease disparities in awareness and knowledge about cancer screening services.

Potential Actions

- Establish partnerships (involving the public and private sectors, media, advocacy, and community groups) to disseminate information on screening guidelines and screening services.
- Disseminate information on cancer risk, screening guidelines, and screening services to healthcare providers, the public, and legislators.
- Identify, develop, and deliver model educational programs to increase awareness of and knowledge about screening guidelines and screening services in the general public, populations at increased risk for cancer, and areas where disparities exist.
- Identify, develop, and deliver healthcare provider education programs on screening services, informed and shared decision making, third-party coverage, and disparities.
- Establish a center to develop effective informed decision-making methods for use in healthcare settings.
- Sponsor statewide cancer screening educational workshops and an annual cancer screening educational summit.

APPENDIX B2 *(continued)*

Utilization of Screening Services

SCREENING GOAL B All Pennsylvanians will have the opportunity to take advantage of cancer screening services. The availability of and access to screening services will be ensured in the Commonwealth. Healthcare systems, healthcare organizations, and healthcare providers will deliver cancer screening services as part of routine care in accordance with established guidelines. Disparities in cancer screening service utilization will be systematically identified and addressed.

Screening Objective B1
Increase provider performance of and referral for screening services.
Screening Objective B2
Increase screening service utilization.
Screening Objective B3
Increase detection of precursor lesions and early-stage disease in the general population and populations at increased risk for cancer.
Screening Objective B4
Increase availability of third-party payor coverage for screening services.
Screening Objective B5
Decrease disparities related to physician referrals for and performance of screening services, screening utilization within populations, and the detection of precursor lesions and early-stage disease.

Potential Actions

- Establish partnerships (involving the public and private sectors, media, and advocacy and community groups) to make cancer screening services readily accessible and available.
- Identify or develop existing population-based screening service data sources to guide screening service planning, implementation, and evaluation activities.
- Identify, develop, and finance the implementation of cancer screening services "best practices" in healthcare settings (healthcare systems, healthcare organizations, and healthcare practices) in accordance with screening guidelines.
- Initiate programs to increase screening utilization in the general population, populations at increased risk, and populations experiencing disparities.
- Extend the reach of existing screening programs (e.g., HealthyWoman Program) and ensure diagnostic follow-up for screenees with abnormal results (e.g., Breast and Cervical Cancer Prevention and Treatment (BCCPT) Program).
- Encourage legislative action to engage third-party payors in developing policies that cover screening services and to address malpractice issues related to screening services.
- Establish a center to promote screening services utilization in healthcare settings.
- Sponsor statewide cancer screening service utilization workshops and an annual cancer screening utilization summit.

Evaluation and Research

SCREENING GOAL C Public and private sector support for behavioral research, epidemiological research, and health services research on screening services, along with basic and clinical science studies, will be provided to ensure that all Pennsylvanians benefit from research on cancer screening services. Cancer screening services evaluation and research can serve to identify geographic areas and populations where screening awareness and utilization are low, determine methods that are effective in enhancing screening awareness and utilization, evaluate the impact of screening programs and methods, and identify new screening technologies. Information can also be generated for use in reducing disparities in cancer screening awareness, utilization, and impact.

Screening Objective C1
Increase behavioral research, epidemiological research, health services research, and screening technology development research.

APPENDIX B2 *(continued)*

Screening Objective C2

Integrate existing data sources and develop new data sources that can be used to create a comprehensive repository on screening services and interventions in Pennsylvania.

Screening Objective C3

Identify and develop effective screening service behavioral interventions, health services approaches, and screening technologies.

Screening Objective C4

Increase dissemination of screening service research findings to the public, populations at increased risk for cancer, and healthcare providers.

Screening Objective C5

Increase the integration of research findings into routine healthcare.

Potential Actions

- Create a centralized registry of screening service availability and utilization, which would include information from public, private, and community-based programs and would be updated continuously.
- Increase public- and private-sector funding for behavioral research, epidemiological research, health services research, and screening technology research.
- Increase public and private sector funding to support the training of screening researchers and healthcare providers.
- Provide incentives for screening service researchers to participate in collaborative projects.
- Develop standard methods for measuring changes in screening service awareness, utilization, and impact in the general population, populations at increased risk for cancer, and healthcare providers.
- Produce a screening service annual report to assess changes in screening service awareness, utilization, and impact in the general population, populations at increased risk for cancer, and healthcare providers.
- Establish a center for cancer screening services research.
- Sponsor an annual cancer screening services research summit.

APPENDIX B3: **CANCER TREATMENT AND CARE DELIVERY**

TREATMENT GOAL A Standardize the quality of cancer care for all Pennsylvanians.

Treatment Objective A1

Create a delivery system for cancer care that provides timely, high-quality core services at facilities close to people's homes and facilitates access to more specialized care. Core cancer care services are those as defined by the American College of Surgeons' (ACoS) Commission on Cancer (CoC).

Potential Actions

- Obtain baseline data by surveying all Pennsylvania hospitals to assess:
  - Current participation in the American College of Surgeons' (ACoS) Commission on Cancer (CoC).
  - The availability of core cancer care services as defined by the CoC.
  - The availability of specialized cancer care services as defined by the CoC.
  - The availability of support services.
- By 2005, establish a Statewide Hospital Cancer Services Database housed within the Department of Health. Contents of the statewide database would include the above information and would use existing data from the CoC Facility Information Profile System (FIPS), as well as other current databases as appropriate.

APPENDIX B3 *(continued)*

- Work with the Pennsylvania Medical Society and other physician organizations to develop a survey instrument for physicians directly involved in cancer care to determine certification status, scope of practice, treatment modalities offered, location(s) of practice, and methods of contact. By 2006, collect and enter data from 80% of all Pennsylvania physicians involved in cancer care into a database and make this information available via the PAC^3 website and the Cancer Patient Information Packet.
- Form alliances with professional organizations to solicit their support and assistance in promoting CoC designation and to determine the feasibility of creating affiliate accreditation programs between CoC and non-CoC approved hospitals as a condition for approval by the PAC^3 as a participating cancer care institution.
- By 2007, increase the percentage of CoC-approved hospitals by 20% from 2003 level.

Treatment Objective A2

Promote evidence-based treatment practices.

Potential Actions

- Create a PAC^3 committee to collaborate with the Department of Health, Pennsylvania Cancer Control, Prevention and Research Advisory Board (CAB) to evaluate and recommend for adoption existing treatment guidelines.
- In 2006, hold six regional Best Practices Forums to discuss cancer treatment by forming a partnership with various professional oncology groups.

TREATMENT GOAL B Recruit and retain the best cancer care providers.

Treatment Objective B1

Create an environment that attracts and retains high-quality physicians, nurses, and other healthcare providers.

Potential Actions

- By 2004, create a PAC^3 Professional Recruitment and Retention Committee responsible for tracking the vacancy and turnover rate of oncology practitioners in selected Pennsylvania hospitals.
- Have the Professional Recruitment and Retention Committee evaluate hospitals in Pennsylvania and the nation that attain "Workplace Magnet Status" because one criterion is a high employee retention rate. (To attain such magnet status, an institution must meet many criteria. In Pennsylvania, there are only three hospitals with this designation).
- Participate in discussions regarding medical insurance costs.
- Promote and support continuing education programs to enhance the management and supervisory skills of healthcare professionals.
- Use data from reliable sources, to assess best approaches for recruiting high school and college graduates into the healthcare field and to determine if recruitment from high schools and colleges into the healthcare field, specifically oncology, is increasing over time.
- Provide more opportunities for minorities to develop careers in cancer research and treatment by developing a targeted media campaign.
- Assess the percent of minority oncology professionals in hospitals, and increase by 10% from baseline by 2006 by developing a special outreach campaign that encourages individuals to enter the oncology specialty.
- Promote efforts to optimize global reimbursement for providers and cancer institutions.
- Enhance the value of collaborative efforts by fostering networking opportunities for healthcare providers.
- Design and conduct periodic patient satisfaction surveys that address the care given by oncology practitioners.
- Support professional oncology certification.

Treatment Objective B2

Integrate cancer prevention and treatment information and issues related to cancer survivorship into the professional healthcare curriculum for the initial training of healthcare providers, continuing education, certification examinations, and other competency-based assessments.

APPENDIX B3 *(continued)*

Potential Actions

- Conduct a survey of basic medical, nursing, pharmacy, social work, nutrition, and other academic programs to assess course content related to cancer prevention, detection, and treatment.
- Identify model education programs that incorporate cancer prevention and treatment into academic curricula and those that utilize new teaching and learning innovations.
- Develop an integrated core curriculum in both didactic and clinical content for basic medical, nursing, pharmacy, and social work academic programs to include both community-based health education, screening techniques, physical diagnosis, treatment, and cancer survivorship to address current deficiencies in content.
- Develop training modules for adaptation to specific disciplines and level of training.
- Identify pre-existing learning modules and obtain funding to purchase, disseminate, and implement these models into academic settings.
- Coordinate statewide continuing education programs with state and local American Cancer Society groups to address issues in cancer prevention and treatment, recurrence, survivorship, and social supports.
- Create a speakers bureau of experts who can address specific cancer care topics.
- Encourage the participation of cancer experts in professional healthcare societies to establish standards for continuing education and certification in various specialties that relate to cancer.
- Establish links to electronic databases through the PAC^3 website to enable easy access to current scientific information.

Treatment Objective B3

Offer more advanced and ongoing training for cancer providers.

Potential Actions

- In cooperation with oncology professional organizations, determine best practices in recruitment and retention by conducting periodic job satisfaction surveys.
- Conduct periodic employee job satisfaction surveys for oncology practitioners.
- Assess percentage of healthcare professionals who are oncology certified and by 2006, increase professional oncology certification by 10% from baseline.
- Assess existing educational programs and determine gaps in training among cancer specialists including physicians, surgeons, and oncology nurses. Offer advanced continuing education activities to meet identified needs.
- Advocate for mandatory continuing education for registered nurses.
- Document and assess the effectiveness of telemedicine as a means for retaining professionals.
- Provide support for existing and new degree programs emphasizing cancer care and research.
- Assess current training guidelines for oncology nurses and medical assistants to determine their appropriateness and promote a statewide guideline for standardized training.

Treatment Objective B4

Provide financial support for career development in oncology.

Potential Actions

- Identify and facilitate access to foundations that currently offer funds for scholarships.
- Research and collect information on scholarships currently offered by professional organizations and other institutions.
- Assess current oncology specialty programs for licensed practical nurses (LPNs) and duplicate or create one for Pennsylvania's licensed practical nurses.

TREATMENT GOAL C Promote patient empowerment and informed decision-making.

Treatment Objective C1

Obtain an endorsement from medical professional associations, medical schools, and other oncology disciplines to adopt a "patient first" philosophy recognizing patient empowerment.

APPENDIX B3 *(continued)*

Potential Actions

- Conduct an intensive physician outreach campaign supported by professional organizations and the Department of Health that, by 2005, results in at least 70% of physicians endorsing the PAC^3 philosophy of patient empowerment.
- Develop, implement, and document continuing medical education (CME) and other continuing education programs to reinforce the patient empowerment philosophy among persons working in all disciplines related to cancer care such as nursing, nutrition, social work, psychology, and pharmacology.

Treatment Objective C2

Increase Pennsylvanians' knowledge of cancer, healthcare providers, treatments, and how to live with the disease.

Potential Actions

- Convene a PAC^3 Patient/Public Education Committee to determine the course of action needed to conduct and maintain a comprehensive inventory of all cancer-related patient education materials.
- Convene a PAC^3 Quality Care Committee composed of patients, advocates, family members, and healthcare professionals to design a treatment quality report card that includes:
  - Board certification of physicians.
  - Established quality care indicators such as CoC accreditation.
  - Data collected from base-line surveys of all Pennsylvania hospitals.
- By 2005, the PAC^3 Patient/Public Education Committee will review, evaluate, and endorse use of currently available educational materials for all newly diagnosed patients who have yet to make decisions about their treatment. In addition, the Committee will create new materials as needed and either distribute or monitor the distribution of these educational materials.

Treatment Objective C3

Develop decision-making tools to assist patients with their treatment options.

Potential Actions

- By 2005, the PAC^3 Patient/Public Education Committee will assess existing decision-making tools such as software and programs, including the "care navigator" model, and make recommendations for offering the most successful decision-making tools and programs to cancer patients throughout the Commonwealth.
- By 2006, develop educational materials and hold at least six care navigator-training sessions for healthcare professionals based in a healthcare facility and outside the hospital setting.
- Work with the Departments of Health and Public Welfare to assess the type of cancer care offered in institutional settings to ensure that individuals who are unable to evaluate care quality for themselves, such as those residing in nursing homes or other institutions, receive the same standard of care as persons residing in the community.
- By 2006, develop a state-endorsed website and launch a media campaign that directs the public to go to the site to learn about cancer detection, provider/facility qualifications, prevention, treatment, health insurance coverage, clinical trial information, support groups, and outcome data. A state-endorsed Cancer Patient Information Kit will be designed and offered to individuals unable to access the internet. The website and patient information kit will include information on the use of complementary and alternative medicine in cancer care.
- By 2005, implement a model in four or more regions of the state for evaluating, the outcomes of patients supported with decision-making tools compared to patients who have not received such support.

Treatment Objective C4

Adopt a Cancer Patient Bill of Rights.

Potential Actions

- By 2005, have a PAC^3 Quality Care Committee review existing Bill of Rights documents and work closely with patient advocacy groups to endorse an existing Bill of Rights or develop a new document for cancer patients.
- By 2006, working with various stakeholder groups, establish an ombudsman to advocate for cancer patients.

APPENDIX B3 *(continued)*

TREATMENT GOAL D Integrate and coordinate cancer resources across the state, including treatment, support, and recovery to enhance quality of care.

Treatment Objective D1

Enhance collaboration among cancer programs, including hospital-based cancer providers, community cancer providers, and privately funded outreach programs.

Treatment Objective D2

Facilitate utilization of the leadership and resources of the NCI-designated comprehensive cancer centers in Pennsylvania as a means for disseminating evidence-based treatment strategies and improving communication throughout the Commonwealth, thereby reducing disparity in cancer treatment and improving access to appropriate therapies.

Potential Actions

- By 2004, form a consortium consisting of various stakeholders from medical professionals to cancer patients and their families to assess and identify current cancer programs in Pennsylvania and promote interaction and joint planning between specialized cancer centers and other healthcare institutions.
- Following the initial assessment, consolidate the information into a single website that provides: (1) information on treatments available for specific cancers; (2) information on clinical trials available for specific cancers; and (3) links to comprehensive cancer programs. (All information provided by individual programs should be in a standardized format).
- Investigate and create incentives (federal, state, and private sector) for collaborative activities that would be evaluated on the basis of cost effectiveness and patient outcomes.
- In 2005, hold the first conference of cancer care providers to provide a forum for discussions of best practices and care standards.
    - Establish a planning committee of various stakeholders (to include CoC, CAB, ACS) to consider a conference agenda.
    - Solicit conference sponsorships from pharmaceutical firms and other related entities to underwrite conference costs.
    - Work with professional organizations such as the Pennsylvania Medical Society, the American Hospital Association, the Commission on Cancer, and the American Cancer Society to offset costs and assist with the promotion of the conference.
- Support and encourage utilization of the following resources and options: The mandate for NCI-designated comprehensive cancer centers to provide both educational and treatment support to individuals and institutions in their area and the Commission on Cancer provision for "cancer networks" as a membership option.

APPENDIX B4: **QUALITY OF LIFE: SURVIVORSHIP THROUGH END-OF-LIFE**

QOL GOAL A Improve quality of life and diminish suffering for all persons with cancer, their families, friends, and lay caregivers from the time of diagnosis through survivorship.

QOL Objective A1

Increase knowledge among the public and healthcare providers about quality of life resources and services.

Potential Actions

- Assess quality of life education and training programs attended by the public and for health providers across the state of Pennsylvania over the previous five years and identify gaps in educational offerings.
- Recommend a central clearinghouse that houses approved lists of quality of life resources and services for use by the public and by health providers.

APPENDIX B4 *Potential Actions* *(continued)*

- Execute a public education campaign to link the public and healthcare providers with quality of life services and resources at a central clearinghouse.
- Create educational opportunities, for community members in local communities to find quality of life resources and services, such as seminars on internet use, and hold such programs in libraries, senior citizen centers, churches, and other settings.
- Provide access to online self-education courses for healthcare providers that provide continuing education credit or contact hours.
- Provide access to affordable or free conferences, videotapes, or audiotapes on quality of life topics for use by the public or healthcare providers.
- Identify the best place to direct persons with cancer and their families to receive telephone information and support resources (telephone clearinghouse) and printed materials (print clearinghouse) for persons who do not have home computers.

QOL Objective A2

Develop and implement an information dissemination best practices model and approaches to support programs and initiatives focused on cancer survivorship.

Potential Actions

- Assess existing survivorship programs and initiatives and identify gaps.
- Develop a white paper on key issues and information resources for PAC[3] and CAB.

QOL Objective A3

Promote the highest level of activities of daily living, social function, and role function among all persons with cancer from the time of diagnosis through survivorship.

Potential Actions

- Evaluate how major cancer treatment centers and community cancer clinics assess and monitor changes in activities of daily living, role function, and social function, and how they assist persons with cancer to restore or sustain these vital functions.
- Assess the extent that persons with cancer have full access to services at home or in the outpatient setting that promote independence in activities of daily living, such as home health nursing care, physical therapy, occupational therapy, nutritional counseling, and social services regardless of ability to pay or limitations imposed by insurance payment coverage on such services.
- Explore the use of the measure Time Without Symptoms from Disease and Therapy (TWIST) in clinical trials research and other clinical cancer research projects.

QOL Objective A4

Promote palliative care practice among all medical professionals.

QOL GOAL B Increase the use of quality of life assessment of persons with cancer and their families across all stages of disease and in all settings of cancer care.

QOL Objective B1

Identify and analyze current research pertaining to the use of quality of life assessment instruments that are completed by persons with cancer in clinical practice settings.

QOL Objective B2

Increase the numbers of clinical facilities that adopt the routine use of a patient quality of life assessment instrument on scheduled oncology visits.

QOL Objective B3

Develop a compendium of useful quality of life instruments with annotations about their evaluation, strengths, weaknesses, and how best to use them in specific settings, such as outpatient clinics, hospitals, or home care.

APPENDIX B4 *(continued)*

Potential Actions

- Select one self-administered assessment instrument for use in busy clinical settings (not a hospice setting), preferably the City of Hope quality of life instrument, which is evidence-based and available without permission.
- Design a pilot intervention in a cancer center in which all patients can choose to receive a selected quality of life assessment tool to complete (self administered) while waiting for their provider visit. This tool will need to have statements or questions concerning physical (pain and symptoms), psychosocial, and existential facets of life. Ratings can be on a scale of 1-10 or a Likert scale of measurement. The form will be completed and given to the healthcare provider who will care for the patient on that visit.
- Conduct a pilot intervention and evaluate the results.
- Create a plan to widen the use of the self-administered assessment instrument across the state.
- Contract with collaborative organizations to carry out a plan for adopting and diffusing routine quality of life assessments.
- Increase emphasis on sharing information on quality of life resources at the time of diagnosis.
- Devise written guidelines to assist providers to negotiate hiring of the support staff or linking to support staff to address the different needs identified in the quality of life assessment, such as counseling, social work, financial counseling, clergy, or psychiatric help.

QOL GOAL C Increase scientific research and the adoption of interventions that researchers have found to diminish suffering and to overcome barriers to achieving quality of life among persons with cancer in Pennsylvania, their families, friends, and lay caregivers.

QOL Objective C1

Utilize longitudinal data from current studies of the unmet needs of persons with cancer to improve their quality of life with appropriate interventions.

QOL Objective C2

Identify, through existing and future research, the education needs among providers, institutions, and agencies to promote quality of life interventions for persons with cancer.

QOL Objective C3

Monitor the impact of prospective payment on persons with cancer who reside in skilled nursing facilities or who are unable to enter skilled nursing facilities and nursing homes due to their diagnosis and need for cancer treatment and care.

Potential Actions

- Design and monitor strategies to promote more surveillance research and research in general on quality of life related issues affecting cancer patients. This research should span the whole range of the cancer experience including cancer diagnosis, treatment decision-making, survivorship, and end-of-life care.
- Create a request for applications (RFA) to assess quality of life needs among Pennsylvanians across the cancer care continuum.

QOL GOAL D Improve quality of life for all persons with cancer, their families, friends, and lay caregivers during and through the end-of-life.

QOL Objective D1

Increase access to a full array of palliative care interventions and supportive services at the end-of-life to ease the burden of care on family members and friends despite their ability to pay for such services.

QOL Objective D2

Increase public and health provider awareness about the hospice concept so that persons with cancer and their family and lay caregivers are equipped with information and more willing to use hospice services.

QOL Objective D3

Evaluate the availability of hospice services and referrals to hospice services across all geographic regions of Pennsylvania, especially in nursing homes.

QOL Objective D4

Maximize participation in hospice services.

APPENDIX B4 ***Potential Actions*** *(continued)*

QOL Objective D5

Increase the numbers of healthcare providers who have additional certifications in hospice care.

QOL Objective D6

Relieve physical pain and distressing symptoms.

Potential Actions

- Establish standards for "care at the end-of-life" in all settings where patients in Pennsylvania die (especially hospitals and long-term care facilities). These standards would include: advocacy for final wishes; tasks for the end-of-life; excellent symptom and pain management; minimally invasive interventions when possible; and psychological, spiritual, and existential support of patient and family during the death trajectory.
- Use Pennsylvania "report card" statistics from the recent Last Acts-Means to a Better End: A Report on Dying in America Today, which demonstrate areas of need, as a starting point for improvement.
- Repeat the Last Acts study in two to three years to show improvements across eight measures for Pennsylvania on end-of-life care.
- Promote a set number of end-of-life continuing education hours for physicians, nurses, and physician assistants to complete for licensure maintenance.
- Educate the public and providers on the use of the Medicare Hospice Benefit.
- Collaborate with regulatory groups to create an ICD-9 code for "comfort care at the end-of-life" in both hospitals and long-term care facilities so that the death "statistic" does not penalize the institution but creates a venue where dying patients can remain to receive care needed for a quality death.
- Implement new ways to educate future providers, such as offering resident physicians and student nurses rotations on hospice home visits or internships in freestanding hospices.
- Increase the healthy public's knowledge about hospice BEFORE the need for the service arises and thus increase the likelihood of informed discussions when hospice care is needed.
- Educate hospital providers about the Federal regulation for assessing (cancer) patients for hospice care prior to discharge from the hospital.
- Promote a risk-benefit ratio for patients with far advanced cancer who are being offered aggressive clinical trials so that one of the options of the clinical trail is palliative care with aggressive symptom management.
- Educate family members on advance directives by developing a system that bridges the tension that exists between what the patient and family wishes and what the physician is able to accomplish or provide.
- Promote respect of, and compliance with, advance directives of residents in long-term care facilities.
- Promote the initiation and expansion of pain task forces in communities of all sizes. Develop pilot programs to increase public and provider knowledge about the importance of completing advanced directives.
- Promote the use of the term "Allow a natural death" as opposed to "Do not resuscitate" among care providers of all types.

APPENDIX B5: **ACCESS**

ACCESS GOAL A Every Pennsylvanian will have access to primary care, cancer prevention/screening, and cancer care by eliminating barriers (geography, transportation, income, information access, language, culture, and psychosocial).

Access Objective A1

Eliminate barriers to receiving optimal cancer-related services by (1) identifying and maximizing use of effective currently available resources, and (2) developing new resources as needed.

Potential Actions

- Identify currently available screening, diagnostic and treatment facilities and programs (including federal, state, and private initiatives) housing/lodging support systems, and caregiver/family support networks.
    - Develop additional support programs as needed.
- Develop and utilize a comprehensive navigator system to develop three pilot projects (rural, urban, and suburban) that explore navigator-programming issues at the county level.
    - Using the SHIP/community module structure, release a request for proposals (RFP) for the implementation of a comprehensive navigator system for each pilot area.
    - Incorporate into the navigator system a self-advocacy education component that takes cultural and linguistic competency issues into account.
    - Develop an evidenced-based program with a strong evaluation component and use program outcomes to disseminate findings and support clear recommendations to state agencies, legislators, etc., on statewide implementation strategies.

Access Objective A2

Ensure a reliable transportation infrastructure for cancer patients to and from treatment.

Potential Actions

- Identify existing transportation systems to determine how patients can access the systems and determine the most effective process for publicizing the availability of services.
- Establish a travel voucher system, paid for by private foundation grants, for utilization by physicians and their patients.

Access Objective A3

Expand existing state agency services for cancer detection and care.

Potential Action

- Develop a companion "healthy male" program to cover lung, colorectal, skin, prostate, and testicular cancer for all income eligible men as defined by program.

Access Objective A4

Reduce the number of uninsured and underinsured Pennsylvanians between the ages of 0 – 64 years.

Potential Actions

- Expand and streamline the HealthyWoman Program to cover lung, breast, colorectal, cervical, and skin cancer prevention services for all eligible women within three years.
- Expand Adult Basic enrollment.
- Identify both public and private existing programs that provide care for the medically underinsured and uninsured.
    - Examples for breast cancer include government funded and private initiatives such as the Mammogram Voucher Program project of the Komen Pittsburgh Race for the Cure®.

APPENDIX B5 *(continued)*

Access Objective A5

Align financial/regulatory systems with expectations for standards of care.

Potential Action

- By 2004, initiate a partnership between PAC^3, state agencies, and private insurance providers to develop standards and then to encourage their use.

Access Objective A6

Streamline eligibility and regulatory requirements and reimbursement.

Potential Actions

- Work with the state payment programs to review the process to determine eligibility to ensure that the process is expedient and equitable for low-income individuals.
- Collect measurable data from healthcare institutions and providers to formulate a PAC^3 advocacy agenda.
- Using the above data, determine regulatory and legislative priorities, and begin advocating for necessary reform.

Access Objective A7

Adapt cancer-related information to address differences in culture, age, gender, etc. as needed.

Potential Actions

- Establish a work group of advocacy and minority organizations to assist in the development and distribution of educational materials reflecting language and cultural variations within the state's population.
- Develop a communications strategy to reach disparate/community groups to assist with disseminating cancer screening and treatment information specifically aimed at language barriers as well as cultural issues.
- Provide cultural competency training with continuing education credits to healthcare professionals.
- Publicize to hospitals and physicians the availability of existing interpreter services and encourage the use of these services.
- Examine population trends and anticipate future healthcare needs.
- Create a mechanism to determine geographically isolated areas in the state that should be monitored to ensure access to care.
- Consider non-traditional approaches to disseminating educational materials and raising awareness, e.g., African-American beauty shops and barbershops.

APPENDIX B6: **RESEARCH**

RESEARCH GOAL A Use existing state resources to estimate the burden and risk factors for major types of cancer in Pennsylvania and then perform research to develop more effective programs for cancer prevention, early detection, and disease management for all affected individuals in the state.

Provide the Basis for More Effective Interventions

Research Objective A1

Identify problems of high incidence, high mortality, and degree of late-stage diagnosis among the major cancer types that may exist throughout the Commonwealth for the major cancers, and determine whether the need for more effective approaches to early detection, screening, and access to treatment and care is related to these factors.

Potential Actions

- Facilitate close interactions between epidemiologists and behavioral scientists within the Pennsylvania Cancer Alliance and at other Pennsylvania research institutions and the staff of the Department of Health in order to review and assess: (1) existing Pennsylvania Cancer Registry (PCR) data; and (2) other existing reports and published literature regarding the current status–and trends over time–of the incidence, stage of diagnosis, and mortality rates of major types of cancer within the Commonwealth.
- Determine variations in such data within regions of the state, and in comparison with national data, to identify potential problems and areas in need of special attention.
- Enhance the completeness and timeliness of PCR data by, for example, including outpatient data and outcomes as well as incidence data.

Research Objective A2

Determine the prevalence of known risk factors, including occupational and environmental factors, and the extent to which they may account for high or disproportionate levels of incidence, delayed detection, and mortality from major types of cancer statewide and regionally throughout the Commonwealth.

Potential Actions

- Review existing bodies of information (e.g., Pennsylvania Behavioral Risk Factor Surveillance System (BRFSS)) to estimate risk factor levels by age, ethnicity, income, educational level, etc., and use this information to target interventions to address key risk factors (e.g., smoking, obesity, and non-adherence to screening recommendations).
- Consider undertaking a population-based study of specific screening practices in targeted areas in which a disproportionate percentage of certain major types of cancers are diagnosed at late stages.
- Evaluate the application of cancer screening practices across the state to determine the relationship between poor adherence to recommended screening practices and areas with disproportionate levels of late-stage diagnosis and mortality from certain major types of cancer.
- Consider conducting a study to evaluate the impact of the relatively high proportion of aged individuals in Pennsylvania on the state's cancer profile.
- Assess the apparent higher incidence of colon cancer in northeast Pennsylvania compared to the rest of the Commonwealth and the nation, particularly with regard to differences in screening and treatment practices, and consider approaches for increasing colon cancer screening in that area.

Determine Best Practices for Cancer Control Interventions and then Disseminate Throughout Pennsylvania

Research Objective A3

Determine effective approaches for facilitating the adherence to recommended clinical cancer prevention and screening/early detection practices of individuals in geographic areas with relatively high proportions of late-stage diagnosis of certain major types of cancer.

Potential Actions

Identify or develop clinical cancer research studies that: (1) address approaches for improving adherence to recommended cancer prevention and screening practices for specific cancer types; and (2) provide healthcare professionals in high incidence areas with information on such research studies.

APPENDIX B6 *(continued)*

Research Objective A4

Evaluate access to, and outcomes of, state-of-the-art practices for cancer prevention, early diagnosis, and management for common cancers (e.g., breast cancer, colon cancer, prostate cancer); measure access in all regions of Pennsylvania to best practices; and determine the effect the *use of best practices* has on health outcomes (e.g., stage of disease at diagnosis and length of survival after diagnosis).

Potential Actions

- Examine baseline information (e.g., from PCR, hospital records) to determine:
  - Incidence rates in counties across the state.
  - Demographics including age, sex, and ethnicity.
  - Stage at diagnosis.
  - Treatment (by stage and possible use of biomarkers, surgery/radiation therapy, chemotherapy):
    - For breast cancer, participation in mammography screening, markers at diagnosis (e.g., ER/PR, Her2 neu status), type of surgery, use of radiation therapy and/or adjuvant chemotherapy.
    - For prostate cancer, participation in screening by prostate-specific antigen (PSA) and/or digital rectal exam; markers (e.g., PSA level at diagnosis); type of treatment – surgery, radiation therapy and, if so, what type.
    - For colon cancer, participation in screening (e.g., fecal occult blood, sigmoidoscopy, colonoscopy), markers (e.g., CEA level) at diagnosis, stage at diagnosis, use of adjuvant therapy and, if so, what type.
- Determine access to care by identifying:
  - The availability in each region of Pennsylvania of hematologists/oncologists, cancer-experienced surgeons, and radiation therapy (type of equipment and what is latest technology used, e.g., IMRT).
  - The extent of educational efforts in each region regarding cancer prevention, early detection, and state-of-the-art treatment practices.
  - Access to clinical research studies in each region of the state.
  - Access to bioinformatics programs to assess the value/clinical utility of biomarkers.
- Evaluate health outcomes in relationship to access to best practices.
  - For common cancers in each region, determine stage of disease at diagnosis.
  - Evaluate morbidity/mortality by diagnosis and stage.

RESEARCH GOAL B Promote synergistic cancer research effectiveness by encouraging and facilitating research collaborations among Pennsylvania cancer centers and other research organizations; develop an infrastructure through which the Pennsylvania Cancer Alliance can effectively coordinate translational, behavioral and clinical research opportunities and needs; and provide statewide access to joint innovative cancer research initiatives in order to fully address the needs of all people in the state who are affected by cancer.

Form An Organization for Coordinating Cancer Research Among the Cancer Research Centers

Research Objective B1

Establish an effective and stable infrastructure for: (1) facilitating and coordinating joint research efforts to share expertise and special resources, and (2) planning and carrying out a joint program to achieve more rapid and effective progress in basic, translational, behavioral, health outcome studies, and clinical cancer research across all of Pennsylvania.

Potential Actions

- Evolve the existing Pennsylvania Cancer Alliance into a formalized entity with a funded infrastructure and an expanded membership to include other relevant research organizations in Pennsylvania.
- Select an individual in each member organization to be the point person for conveying information to the membership of the Pennsylvania Cancer Alliance for identifying appropriate participants in establishing potential collaborations.

APPENDIX B6 *Potential Actions* *(continued)*

- Sponsor an annual "Cancer Research Meeting" held on a rotating basis at the major academic health centers that would include participation of all cancer research organizations throughout the Commonwealth.
- Identify key areas for workshops to bring groups together, such as a specific technology or a specific research question regarding a specific kind of cancer important in Pennsylvania.
- Identify barriers to success in effective collaborations among member organizations (e.g., geographical distance, cultural differences between academic and community investigators and between clinical and basic researchers, and competitiveness among member organizations) and develop effective strategies to overcome each of these barriers.

Partner Between Cancer Research Organizations and All Other Relevant Organizations

Research Objective B2

Develop an effective Pennsylvania cancer research coalition between the Pennsylvania Cancer Alliance and other organizations of relevance, including state government, academic and private-sector organizations (e.g., pharmaceutical and biotech companies and insurers), and cancer research support and advocacy organizations to jointly plan and implement important research initiatives to reduce death and suffering from cancer throughout Pennsylvania.

Potential Actions

- Identify relevant institutions, organizations, groups, and resources (e.g., the Pennsylvania Department of Health; especially the Pennsylvania Cancer Control, Prevention and Research Advisory Board; the Pennsylvania Cancer Registry; the Bureau of Epidemiology; pharmaceutical and biotechnology companies; the Pennsylvania Biotech Association; the Pennsylvania Life Sciences Greenhouses; cancer support and advocacy organizations and groups, including the Pennsylvania Division of the American Cancer Society; and healthcare payors), and develop linkages between these organizations and the expanded Pennsylvania Cancer Alliance.
- Establish effective interactions between the Pennsylvania Cancer Alliance and representatives from other relevant organizations to ensure that all work together on important cancer research issues in Pennsylvania.
- Identify, among all participants, areas of common interest and mutual benefit and develop research programs that: (1) most effectively utilize the strengths and resources of the participants; and (2) best address the needs of the entire population of Pennsylvania.

Research Objective B3

Determine the current status of capabilities, participation in, and access to clinical research across the state; develop and establish more extensive and effective translational and clinical research collaborations across Pennsylvania; and provide the entire population with access to innovative and potentially more effective approaches to the treatment, early diagnosis, and prevention of cancer.

Potential Actions

- Obtain baseline information about the status of clinical cancer research in the state:
  - Perform an inventory of hematologists/oncologists, radiation therapists, and cancer surgeons in Pennsylvania, of all hospitals or other organizations with an IRB that perform clinical research related to cancer, and of physicians or organizations that participate in cancer research sponsored by the National Cancer Institute, cooperative groups, or industry.
  - Identify the physicians who are actively engaged in clinical cancer research.
  - Determine the mechanism(s) by which non-academic centers and physicians are able to perform clinical research.
  - Advocate to enact legislation in Pennsylvania to require healthcare payors to cover clinical trials approved by the National Cancer Institute and those performed at NCI-designated cancer centers.
  - Survey the extent to which academic cancer center IRBs have cooperative agreements with community hospitals for the performance of clinical cancer research.
  - Determine the percentage and number of cancer patients and of individuals at risk for cancer in Pennsylvania who participate in clinical cancer research studies and the geographic distribution of such participation across the state.

APPENDIX B6 *Potential Actions* *(continued)*

- Develop a systematic, common mechanism for the collection and annotation of cancer tissue and serum samples in Pennsylvania that involves both academic and community clinical centers in all regions of the state to enhance the Pennsylvania Cancer Registry's ability to facilitate research:
  - Establish and facilitate collaborations to collect and process samples from clinical studies.
  - Endeavor to obtain revisions of the regulatory processes to increase efficiency, e.g., by arranging for a single IRB to review and approve all multi-center cancer research studies.
  - The Pennsylvania Research Alliance office will coordinate protocol planning and implementation and clinical informatics.
  - Implement an effective, common procedure to properly collect and annotate clinical samples for biomarker research studies.
- Develop a statewide early case locator network.
- Develop a protocol for identifying cases of biopsy-confirmed cancer on a "real-time" basis by enhancing the reporting requirements of the Pennsylvania Cancer Registry to include the identification of sites and sources of available tissue.
- Convert the Pennsylvania Cancer Registry from an "incidence" registry to an "outcome" registry to allow research requiring outcome information.

RESEARCH GOAL C Implement a user-friendly statewide website with appropriate links to other relevant regional and national websites, to facilitate an effective communication mechanism for all Research goals, facilitate communications and sharing of information among cancer researchers and others, and provide needed information on cancer and clinical cancer research studies to Pennsylvania citizens, health professionals, and researchers, in order to disseminate research opportunities and research advances across the Commonwealth.

Make Clinical Research Studies Available to All

Research Objective C1

Establish a website that will immediately begin to provide user friendly, searchable information to the public and to healthcare professionals on all clinical cancer research studies in Pennsylvania and where they are available along with links to national websites that provide information on clinical research studies available at other locations throughout the United States.

Potential Actions

- Identify and evaluate currently available cancer clinical trials search engines designed for both providers and the public.
- Conduct provider- and public- (e.g., cancer patients and their families) based research to identify website/search engine needs.
- Provide links to the PAC^3 website on all relevant existing health-related sites in Pennsylvania.
- Evaluate and select a web/search engines for use by Commonwealth healthcare professionals and the general public.
- Identify private and public funding sources to the selected website/search engine.
- PAC^3 will make recommendations for entity responsible to manage and update the website/search engine and clinical trial database.
- Develop and implement a communications plan to promote use by Commonwealth providers and the public.
- Develop and implement an annual evaluation plan to measure the impact of provider and public websites on cancer clinical trials accrual in Pennsylvania.

Facilitate Communication Among All Pennsylvania Cancer Researchers

Research Objective C2

Develop an intranet website for communications among cancer research organizations in Pennsylvania and cancer researchers to share plans for joint research studies and results of cancer research studies.

APPENDIX B6 *(continued)*

Potential Actions

- The newly developed Pennsylvania Cancer Alliance office will take the lead in developing a potential intranet website to serve as an effective communications tool to share research information related to all of the joint research projects performed as components of other Research Goals.
- Collaborate with minority community agencies and leading voluntary groups to increase the diversity of patients participating in clinical trials.

Effectively Communicate Research Results and Advances

Research Objective C3

Develop a public website to provide the public and healthcare professionals with information collected from the research programs described in other Research Goals.

Potential Actions

- Identify and evaluate currently available public cancer information websites/search engines designed for both providers and the public.
- Conduct provider- and public- (i.e., cancer patients and their families, etc.) based market research to identify public cancer information website/search engine needs.
- Evaluate and select a public cancer information website/search engines for use by Commonwealth healthcare professionals and the general public.
- Identify private- and public-sector funding sources to the selected public cancer information website/search engine.
- PAC^3 will make recommendations for entity responsible to manage and update the public cancer information website/search engine and clinical trial database and provide relevant and easily readable information about the research capabilities and accomplishments of each Pennsylvania research organization and the results of research goals (e.g., cancer incidence and access information).
- Develop and implement a communications plan to promote use by Commonwealth providers and the public.
- Facilitate website access to underserved individuals and communities (e.g., through public libraries, schools, and healthcare provider organizations).
- Develop and implement an annual evaluation plan to measure the impact of the website links on public knowledge about cancer and best practices for prevention, early detection, and management of cancer.

RESEARCH GOAL D Establish as a subcommittee of the Pennsylvania Cancer Alliance, a collaborative group of Pennsylvanian behavioral medicine researchers and population scientists to: (1) propose important areas of cancer research; (2) evaluate procedures to increase awareness and improve implementation by state healthcare professionals and citizens of available and emerging guidelines for regular cancer screening and changes in lifestyle; and (3) encourage interdisciplinary collaborations with basic cancer researchers, public health researchers, and healthcare professionals.

Research Objective D1

Define a list of priorities to identify strategies that will result in the greatest immediate impact on having Pennsylvanians begin to assume more personal responsibility for effective cancer prevention behaviors.

Potential Actions

- Identify key areas of research needs including quality of life, healthy lifestyles, complementary and alternative medicine, tobacco cessation and prevention, screening behavior, physical activity, and genetic cancer risk assessment.
- Identify and survey key behavioral researchers and population scientists within Pennsylvania regarding research priorities and support needs.
- Under the auspices of the Pennsylvania Cancer Alliance, develop a subcommittee of behavioral and population researchers to promote regular communications and collaboration.
- Develop a plan to educate clinicians on alternative approaches to medicine from other traditions/philosophies that may impact their ability to communicate and provide adequate treatment to individuals within ethnic communities.

APPENDIX B6 *(continued)*

Research Objective D2

Research and evaluate: (1) available educational tools for promoting cultural sensitivity and culturally appropriate education in terms of their ability to provide best practice cancer treatments, early detection procedures, and prevention approaches to undereducated and other underserved populations (e.g., racial and ethnic minority populations); and (2) promote useful tools, including those that measure literacy level, to all relevant healthcare professionals in Pennsylvania.

Potential Actions

- Compile existing published literature and reference materials concerning cultural sensitivity in medicine, particularly as they may be relevant to cancer issues, including Pennsylvania-based publications and conferences and forums on this topic. Prioritize these materials according to their applicability to cancer care and the specific cultural needs of state populations. Develop a mechanism through which to make this information available electronically so that it can be readily accessed by healthcare professionals and periodically updated.
- Plan and convene a statewide conference on possible practical approaches for integrating cultural sensitivity into existing cancer programs and increasing the awareness and sensitivity of clinical staff. Follow up by convening regional/local focus groups of cultural leaders, cancer survivors, and healthcare professionals to assess local priorities and identify locally relevant program strategies. On the basis of these discussions and input, develop research studies to evaluate the practicality and usefulness of the most promising approaches in terms of their impact on the behavior of the targeted populations.

RESEARCH GOAL E Perform research to develop effective approaches to modify the behavior of most if not all individuals in the Commonwealth to not use tobacco, so that the deleterious effects on health are avoided.

Prevent Tobacco Use

Research Objective E1

Conduct basic and applied research on the elements of effective tobacco prevention programs.

Research Objective E2

Identify and then deliver the community-based tobacco control programs that are most effective in targeting high-risk populations in Pennsylvania.

Research Objective E3

Increase the impact of Pennsylvania's community and state tobacco control program by developing effective mechanisms to communicate advances in tobacco control and basic research, to translate those results into action in Pennsylvania's diverse communities.

Research Objective E4

Conduct prospective, long term research to evaluate the impact of new policies and approaches on tobacco use patterns in the state. (e.g., these analyses might track the impact of legislative events and if increases in tobacco taxes are found to decrease use by minors, a decision will be made as to whether an additional increase can further reduce tobacco use).

Promote Cessation of Tobacco Use

Research Objective E5

Perform research to identify the basis of tobacco addiction and allure, the barriers to successful addiction, and the most effective means of achieving abstinence from tobacco.

Research Objective E6

Investigate mechanisms for optimal dissemination of proven interventions for specific populations at the community and state levels.

APPENDIX B6 *(continued)*

Potential Actions

- As different interventions are found to be effective for particular groups, larger scale dissemination and diffusion trials should be conducted to evaluate the best approaches for applying these programs at the state and community levels.

Research Objective E7

Perform tobacco treatment research to develop new and innovative strategies to effectively influence a high proportion of high-risk youth.

Potential Actions

- Introduction of non-school based programs that may be better received because they are outside of the school setting.

RESEARCH GOAL F Ensure the accomplishment of the Consortium's Research goals by continuing the commitment of the Commonwealth for tobacco settlement formula funds to support biomedical, clinical, and health services research, marshal needed resources, and obtain sufficient additional funding and support to accomplish all high priority Research goals and objectives.

Fund Implementation

Research Objective F1

Educate the Pennsylvania Administration and General Assembly on the importance of investing in cancer research.

Potential Actions

- Identify and prioritize cancer research issues for which state support is needed.
- Develop and implement an advocacy plan focused on the Pennsylvania Administration and General Assembly to secure funding for the research priorities identified. This plan should include the continued allocation of 19% of Tobacco Settlement funds to biomedical, clinical, and health services research, and a strong commitment to continue to provide formula funds to support institutions to perform high-quality biomedical, clinical and health services research. This Plan should be reviewed and updated annually.
- Identify Administration and General Assembly champions willing to facilitate the resolution of outstanding cancer research issues and convene semi-annual meetings with PAC^3 organizations and these government champions.
- Enhance communications between the governmental affairs staff of cancer centers, major academic research institutions, and cancer advocacy organizations (e.g., other PAC^3 stakeholders, the American Cancer Society, and the National Dialogue on Cancer) to gain support for common research funding goals.
- Conduct an annual or bi-annual cancer research symposium for members of the Administration and General Assembly to report on cancer research achievements and continuing challenges and needs.

Research Objective F2

Through collaborative partnerships across the state, compete for a substantially higher level of United States government funding for Pennsylvania cancer research.

Potential Actions

- Based on the identification of novel research questions and needs emanating from Research goals, encourage cancer researchers to develop and submit grant proposals for collaborative research to the National Cancer Institute, the Centers for Disease Control and Prevention, the Agency for Healthcare Research and Quality, the Health Resources and Services Administration, and other appropriate funding agencies.
- Based on the preliminary results and accomplishments of joint Pennsylvania cancer research efforts (e.g., from Pennsylvania Cancer Alliance Bioinformatics Consortium), prepare and submit joint grant proposals to the National Cancer Institute and other Federal agencies for funding on behalf of the collaborating institutions.

APPENDIX B6 *(continued)*

Research Objective F3

Develop strategies and cultivate opportunities to access non-governmental funds.

Potential Actions

- Obtain the commitment of non-government PAC^3 member organizations to annually commit substantial resources to the implementation of the Research goals of the Commonwealth's Comprehensive Cancer Control Plan.
- Identify and cultivate private research funding sources, emphasizing the combined strengths of the state's cancer centers.
- Develop and submit to these organizations joint research proposals seeking funding for collaborative research. (Such proposals may require individual Institutional Review Board approval to ensure that any potential conflicts of interest have been appropriately managed).

Research Objective F4

Ensure adequate financial support for all aspects of clinical care associated with clinical trials.

Potential Actions

- Document the range of clinical care costs associated with patient participation in clinical trials.
- Survey and document the financial support practices of Pennsylvania health insurers, including the Pennsylvania Department of Public Welfare's (DPW) Medical Assistance Program (i.e., Medicaid), the Insurance Department's Children's Health Insurance Program (CHIP), and those insurers in other states.
- Develop and implement an action plan to address any barriers related to both public financial support and private insurer reimbursement of clinical care associated with clinical trials.

PAC^3

APPENDIX B7: CANCER-RELATED INFORMATION MANAGEMENT AND DISSEMINATION

INFORMATION GOAL A Provide all Pennsylvanians with access to high-quality, accurate, and current information based on individual and population factors for all aspects of cancer, from prevention to end-of-life care.

Information Objective A1

Develop and implement a dissemination model and approaches to provide all patients going through cancer diagnostic testing or having received a diagnosis of cancer with information on how to obtain cancer information through a variety of communications channels.

Potential Actions

- Create a print and web-based resource card listing NCI's Cancer Information System (CIS) and American Cancer Society telephone numbers and website addresses as a first-line resource for accurate, up-to-date cancer information.
- Develop a systematic process for printing and disseminating the Resource Card to clinics, primary healthcare providers, healthcare specialists, and community-based organizations and businesses (e.g., barbershops, primary care clinics).
- Develop a mass media campaign focused on key steps in the cancer diagnosis process and decision points linking the public to key information sources.
- Develop educational strategies to increase the public's understanding of the decision-making process in cancer diagnosis.
- Collaborate with PAC^3 website development group to encourage a "portal" approach to the PAC^3 website and ensure that it is a link to credible and reliable cancer information, including a variety of cancer sites, for the public.

APPENDIX B7 *(continued)*

- Create materials in English and Spanish and, within 5 years, in a major Asian language.
- Identify and/or create materials suitable for low-literacy audiences.

Information Objective A2

Develop and implement a dissemination model and approaches to provide specific age groups and populations with information about cancer prevention, prevention trials and studies, cancer risk, and cancer risk reduction through a variety of communication channels.

Potential Actions

- Develop a targeted mass media campaign focused on cancer prevention.
- Develop curricula and continuing education courses focused on cancer prevention for community organizations, cooperative extension agents, parish nurses, and the media.
- Create a resource card (print and web-based) with simple steps to prevent cancer and first-line resources (i.e., the NCI's Cancer Information Service and the American Cancer Society).

Information Objective A3

Identify pilot programs focused on creating personalized clinical records to assist patients and the public for tracking and accessing their own cancer-related behaviors, risks, and treatment.

Potential Actions

- Conduct an analysis of current initiatives and organizations that are using electronic personalized clinic records.
- Develop criteria for pilot selection and develop a request for applications (RFA).
- Solicit proposals and select pilot sites.

Information Objective A4

Identify and implement a process to evaluate cancer information sources and disseminate this information through cancer control initiatives and the PAC^3 web portal.

Potential Actions

- Develop an analysis of existing cancer information portals for the public focusing on successes and gaps.
- Develop a strategic plan through which to address this issue.
- Review existing website evaluations and provide recommended approaches.

Information Objective A5

Encourage Medicare, Medicaid, commercial, and other health insurers to make pertinent benefit information available to their members, (e.g., concerning covered and non-covered services, provider directories, and other benefit information).

Potential Actions

- Conduct a gap analysis to describe current practice.
- Make recommendations on appropriate language and lay terms to improve existing benefit information.
- Secure consensus on necessary benefits information.
- Secure consensus among insurers on communications strategies.
- Conduct a baseline survey to measure the current level of awareness and re-survey in two years to re-evaluate.

Information Objective A6

Identify and implement pilot programs for on-line management of individual health risk assessment based on standardized and validated risk factor surveys. (The measurable outcome is more readily available risk factors and functional data to enable epidemiologists to identify and study the effectiveness of cancer treatment interventions).

APPENDIX B7 *(continued)*

Potential Actions

- Develop a pilot project to develop a comprehensive risk factor intervention for the public. The project should:
  - Determine a direct relationship between existing risk factor surveys and cancer risks.
  - Coordinate risk factor surveillance data with known environmental and employment-related cancer health risks.
  - Develop language to describe risks from the individual consumer standpoint, including the identification and coordination of website links.
  - Create and maintain a website, available 24 hours a day, 7 days a week, for data entry and response (A data center would be required for management).
  - Create a database for analyzing aggregate data collected and analyzing the data from an epidemiological perspective.
  - Create a firewall to manage Health Insurance Portability and Accountability Act (HIPAA) concerns but, with individual patient consent, have the ability to "break the code" and allow coordination of data entered with individual patient records at participating healthcare facilities.
  - Make the surveys available to the non-internet public by evaluating paper alternatives to the proposal (associated issues include printing, dissemination, data retrieval, and data entry).
  - Create a marketing plan to enhance education about the project and publicize its collateral benefits.
  - Create standard blinded reporting strategies for the state by region, etc.
  - Implement a project evaluation and dissemination plan.

INFORMATION GOAL B Provide all Pennsylvania healthcare providers with access to accurate, up-to-date, age- and culture-appropriate information about cancer prevention, risk reduction, screening, diagnosis, treatment, and end-of-life.

Information Objective B1

Provide healthcare providers with access to current, high-quality, and accurate information on the basis of specific information needs and risk factors.

Potential Actions

- Identify, evaluate, and disseminate key existing sources of accurate published information, both web-based and print information, and media reports by professional societies, the pharmaceutical industry, consumer advocacy groups, cancer support groups, and marketing advertisements. This evaluation should include, but not be limited to, health promotion guidelines, recommendations for cancer detection and screening, drug therapy information on the treatment of cancer and management of adverse effects, and nutraceuticals.
- Identify and disseminate existing tools to assess the accuracy and reliability of national and local electronic, published, and televised media informational sources for cancer prevention/treatment.

Information Objective B2

Ensure that every healthcare provider has access to the latest evidence-based guidelines.

Potential Actions

- Facilitate an annual statewide seminar to update information on prevention and treatment.
- Collaborate with healthcare professional societies to compile lists of clinical care guidelines and consensus and position statements.
- Disseminate new evidence-based information from reputable sources (e.g., clinical trials, consensus panels, expert opinions).
- Collaborate with the National Comprehensive Cancer Center Network to list available clinical care guidelines and resources.

Information Objective B3

Promote the use of information sources on the availability and outcomes of clinical trials for cancer prevention and treatment.

APPENDIX B7 *(continued)*

Potential Actions

- Organize a statewide meeting of representatives from clinical trial offices and programs at academic medical centers and teaching hospitals.
- Create a website with links to and from credible national (National Cancer Institute) and state repositories of clinical trial information organized according to prevention and treatment protocols, geographic locations (zip codes), and site-specific cancers. Include information on:
  - Eligibility by age, site-specific cancers, and vulnerable populations.
  - Recruitment status.
  - Contact information.
- Establish alliances with cooperative clinical trial groups [e.g., the National Coalition of Cancer Cooperative Groups (NCCC), ECOG, GCOG, and SWOG] to publicize current directories of available clinical trials through the PAC^3 website.
- Disseminate electronic information with regular updates on the availability of clinical trials to primary care providers, cancer specialists, and healthcare institutions throughout the state.

Information Objective B4

Encourage and support compliance with current laws and regulations regarding patient confidentiality, security, and privacy, and foster the sharing of best practices among health entities.

Potential Actions

- Organize a statewide meeting of compliance officers from academic medical centers, teaching hospitals, community hospitals, home-health agencies, primary care practices, long-term care facilities, insurance providers, state healthcare data repositories, and other healthcare organizations to share information on how institutions are implementing the Health Insurance Portability and Accountability Act (HIPAA).
- Identify organizations with model training programs and mechanisms to monitor the confidentiality, privacy, and security of protected health information (PHI).
- Establish a site-to-site consultation network for cancer centers to benchmark practices through communication by a Listserv.
- Identify and publicize potential risks for breach of security and confidentiality of health information and consequences to patients with cancer or at risk for cancer and address these concerns on the PAC^3 website.
- Disseminate regular electronic and written materials on HIPPA regulation/mandate updates to cancer care providers.
- Conduct a statewide seminar regarding the implications for HIPAA and research on human subjects.
- Evaluate HIPAA compliance practices with privacy/confidentiality and security with state data repositories and tumor registries.

INFORMATION GOAL C Increase the usage of available cancer data by researchers and health planners for assessing the cancer burden and providing a solid foundation for cancer surveillance, research, and program planning activities in Pennsylvania.

Information Objective C1

Coordinate and disseminate existing cancer data/information by establishing, maintaining, and promoting a website and a portal with links to various sources of cancer data and cancer-related information.

Potential Actions

- Partner with a public relations or marketing company in developing a plan for designing and promoting the PAC^3 and Pennsylvania State Department of Health Bureau of Health Statistics and Research web page.
- Perform an assessment of the various sources of cancer data/information that includes an assessment of the available data sets.
- Establish guidelines/approach for the design of the website.
- Consult with the National Cancer Institute's Division of Population and Cancer Control on the developmental process of the new Cancer Control PLANET, a collaborative portal for health professionals and planners. This portal provides state-specific cancer statistics and access to proven cancer control interventions.

APPENDIX B7 *(continued)*

Information Objective C2

Create and promote use of a user-friendly interactive website that provides current and historical cancer incidence statistics (numbers, rates, graphs, maps, and profiles) for various geographic areas (counties and municipalities).

Potential Actions

- Develop a strategy for promoting the awareness and availability of this web-based data dissemination system.
- Develop a strategy to provide training for use of this data dissemination system or provide online help and video clips demonstrating how to use the Pennsylvania State Department of Health Bureau of Health Statistics and Research's EpiQMS.

Information Objective C3

Promote use of geocoded cancer incidence data and collaboration with other databases for conducting GIS/spatial analyses to facilitate more comprehensive cancer surveillance, research, and program planning activities.

Potential Actions

- Establish and document standards/procedures for geocoding (for example, how to handle records that cannot be geocoded) and provide these standards to other interested PAC^3 members.
- Re-geocode current and historical Pennsylvania Cancer Registry cancer incidence files (with 2000 census updated codes) to enable use of data for GIS/spatial analyses.
- Provide GIS software training/assistance to cancer epidemiologists for conducting spatial analyses using cancer incidence data.

Information Objective C4

Increase access and utilization of existing cancer incidence and other pertinent data for use in cancer surveillance and program planning activities.

Potential Actions

- Identify new ways to appropriately disseminate the data and results of analyses.
- Develop a procedure to incorporate the results of these discussions into Comprehensive Cancer Control planning and evaluation activities.
- Develop a format for reporting "success stories" from data use and a procedure for posting on the PAC^3 website. (Use the "success stories" format used by CDC's National Program of Cancer Registries as a model).

INFORMATION GOAL D Influence policy-makers, government, and private industry to increase funding opportunities that focus on cancer information development, management, and dissemination.

Information Objective D1

Develop a method for tracking funding opportunities for cancer information development, management, and dissemination activities through governmental and private sources.

Potential Actions

- Gather baseline data on current funding opportunities from all sources:
  - Define funding that focuses on cancer information development, management, and dissemination.
  - Define sub-categories of interest (e.g., special populations).
- Define funding that focuses on cancer information development, management, and dissemination.
- Organize and interpret baseline data for reporting and tracking purposes.
- Establish a yearly reporting mechanism for these activities to facilitate tracking.
- Establish and maintain ties with funders to facilitate lobbying for increased funding opportunities.

Information Objective D2

Develop a mechanism (e.g., Listserve, website, etc) to notify interested persons about new and existing funding opportunities related to cancer information development, management, and dissemination.

APPENDIX B7 *(continued)*

Potential Actions

- Gather baseline data on interested persons.
- Develop a system for collecting and updating funding information.
- Establish a distribution policy and plan.
- Create and implement the Listserve and/or website to allow for funding opportunities and recently funded initiatives to be posted.

INFORMATION GOAL E Enhance collaboration among diverse cancer control organizations and engage other public- and private-sector organizations in the coordinated dissemination and utilization of cancer information for the public, patients, providers, researchers, program planners, and policymakers.

Information Objective E1

Create and implement a process for a centralized location of an information clearinghouse of cancer information and communications resources including print, electronic, and distance education resources.

Potential Actions

- Determine assessment process criteria, methodology, tools, and which organizations are willing to participate.

Information Objective E2

Identify the cancer information infrastructures, both data and information, of PAC^3 organizations.

Potential Actions

- Identify a process for gathering this information, including responsibilities for collection and updating information.
- Develop a brief online survey of all partners and implement the survey.
- Share key sources of Pennsylvania cancer information and data with interested organizations across the state.

Information Objective E3

Encourage and foster research in the management and dissemination of cancer information between PAC^3 and other organizations within Pennsylvania.

Potential Actions

- Identify research area experts who are willing to work together.

APPENDIX B8: **IMPLEMENTATION**

IMPLEMENTATION GOAL A Work together to implement the Pennsylvania Comprehensive Cancer Control Plan, evaluate results, and identify and respond to new challenges and opportunities.

Implementation Objective A1

Re-establish the Pennsylvania Cancer Control Consortium (PAC^3) as the body to coordinate implementation of the Plan.

Implementation Objective A2

Implement the Plan.

Potential Actions

- Within the first 100 days after Plan ratification, PAC^3 will:
  - Convene to initiate plan implementation.
  - Identify teams and champions to lead initiative areas, goals, and objectives.
- Identify the Priority Goals and Objectives to be implemented first.
- Establish definitive strategies and measurable outcomes for priority goals and objectives.
- Develop an evaluation mechanism.
- Identify advocacy priorities and coordinate advocacy efforts.
- Identify, coordinate, and secure funding opportunities.
- Help forge and expand partnerships and collaborations.
- Continuously review progress by tracking activities and measuring results, with particular emphasis on addressing cancer disparities.
- Convene an annual summit to review progress and set new goals.

APPENDIX C: GLOSSARY OF TERMS AND ORGANIZATIONS

This glossary is provided to clarify terms and organizations cited in this Plan. It is not intended to be a complete glossary of cancer-related terms and organizations.

American College of Surgeons (ACoS) Commission on Cancer - A scientific and educational association of surgeons that was founded in 1913 to improve the quality of care for the surgical patient by setting high standards for surgical education and practice. It conducts various programs through its Commission on Cancer (CoC) (see "Commission on Cancer") to improve the care of the cancer patient, and approves hospital cancer care programs that voluntarily apply for such approval. www.facs.org.

American Cancer Society (ACS) - A community-based voluntary health organization dedicated to eliminating cancer as a major health problem by preventing cancer, saving lives from cancer, and diminishing suffering from cancer, through research, education, advocacy, and service. www.cancer.org.

Age-adjusted rate - Controls for the age structure of different populations. Age-adjustment allows rates to be compared between population groups with different age distributions. All age-adjusted rates are expressed per 100,000 individuals per year.

Biological marker (Biomarker) - A genetic, biological, chemical measurement taken from a sample of biological material used to detect preclinical disease.

Behavioral Risk Factor Surveillance System (BRFSS) - An ongoing random-digit dialed telephone survey of adults concerning health-related behaviors. The BRFSS was developed by the Centers for Disease Control and Prevention (CDC) and is conducted in all states in the U.S. The BRFSS includes questions on health behavior such as diet, weight, tobacco and alcohol use, physical exercise, preventive health screenings, and use of preventive and other healthcare services. The data are weighted to represent all adults aged 18 years and older. www.health.state.pa.us/stats.

Breast and Cervical Cancer Early Detection Program (BCCEDP) - see "HealthyWoman Program."

Bureau of Epidemiology - A multi-faceted public health surveillance and assessment program involved in the investigation of the causes of disease and injury. It is the Pennsylvania Department of Health's medical and epidemiological support entity. www.health.state.pa.us.

BUSTED! - Pennsylvania's statewide youth-led anti-tobacco movement. The primary goal of BUSTED! is to provide Pennsylvania youth, ages 14 to 17, with the necessary resources to empower them to use their own creativity and leadership to eliminate the manipulation of the tobacco industry. The BUSTED! movement provides youth with the skills and knowledge they will need to become advocates, peer educators, and community activists for key tobacco control issues in their communities.

Cancer Advisory Board (CAB) - see "Pennsylvania Cancer Control, Prevention and Research Advisory Board."

Cancer Control PLANET Web Resources (PLANET, Plan, Link, Act, Network with Evidence-based Tools) - A new web-based resource for comprehensive cancer control planning, implementation, and evaluation. PLANET serves as a doorway to cancer-related data and to new evidence-based tools that can aid communities in better understanding and addressing their cancer burden. PLANET - a joint public and private effort - was announced in spring 2003 by NCI, CDC, and the Substance Abuse and Mental Health Services Administration and was developed in collaboration with ACS. http://ccplanet.cancer.gov.

Cancer incidence - The number of newly diagnosed cases of cancer occurring in a population in a given period of time (usually one year). The incidence rate is the number of new cases of the disease expressed as a rate per 100,000 persons in the population. The incidence count is the number of new cancer cases, usually summed over one year.

Cancer Information Service (CIS) - A national cancer information and education service which is a free public service of the National Cancer Institute (NCI). www.cis.nci.nih.gov.

Cancer mortality - The number of deaths from the disease occurring in a population in a given period of time (usually one year). The mortality rate is the number of cancer deaths expressed as a rate per 100,000 persons in the population. The cancer mortality count is the number of cancer deaths, usually summed for one year.

Centers for Disease Control and Prevention (CDC) - An agency within the United States Department of Health and Human Services. CDC is recognized as the lead federal agency for protecting the health and safety of people - at home and abroad, providing credible information to enhance health decisions, and promoting health through strong partnerships. CDC serves as the national focus for developing and applying disease prevention and control, environmental health, and health promotion and education activities designed to improve the health of the people of the United States. www.cdc.gov.

Chemotherapy - Cancer treatment that uses anti-cancer drugs to cure or control the cancer.

Clinical Trial - A research study designed to evaluate new ways to prevent or treat cancer, or treat side effects of cancer or its treatment.

Commission on Cancer - Established by the American College of Surgeons (ACoS) in 1922, the multi-disciplinary commission sets standards for quality multidisciplinary cancer care delivered primarily in hospital settings; surveys hospitals to assess compliance with those standards; collects standardized and quality data from approved hospitals to measure treatment patterns and outcomes; and uses the data to evaluate hospital provider performance and develop effective educational interventions to improve cancer care outcomes at the national and local levels. Commission membership is comprised of more than 100 individuals who are either surgeons representing the ACoS or representatives from the 37 national, professional organizations affiliated with the CoC. www.facs.org/dept/cancer/coc.

Comprehensive Cancer Control - Defined by the Centers for Disease Control as an integrated and coordinated approach to reducing the cancer incidence, morbidity, and mortality through prevention, early detection, treatment, rehabilitation, and palliation.

Disparities - Refers to the condition or fact of being unequal, as in differences in age or race.

Environmental Tobacco Smoke (ETS) - Commonly referred to as secondhand smoke, comes in two forms: 1) sidestream smoke or smoke emitted between puffs on a burning cigarette, pipe, or cigar; and 2) mainstream smoke or smoke exhaled by the smoker or those in the presence of a smoker.

Future Search Conference - At the invitation of the Pennsylvania Department of Health, 60 participants from diverse organizations met for three days in Harrisburg, Pennsylvania, in November 2001, to identify and agree on a 'common ground' agenda to change the face of cancer in Pennsylvania. This agenda formed the framework that led to the eight workgroups of the Pennsylvania Cancer Control Consortium.

HealthyWoman Program - Part of the National Breast and Cervical Cancer Early Detection Program (NBCCEDP) funded by the Centers for Disease Control and Prevention (CDC) and administered through the Pennsylvania Department of Health. The purpose of the program is to provide breast and cervical cancer screening services to low income, uninsured, or underinsured women in medically underserved communities throughout the Commonwealth of Pennsylvania. The Program aims to reduce breast and cervical cancer morbidity and mortality through screening, referral, and follow-up, public education and outreach, professional education, quality assurance, surveillance, partnership development, and community involvement.

Hospice - Hospice care and hospice concepts are considered to be the model for quality, compassionate care for people facing a life-limiting illness or injury. Hospice care involves a team-oriented approach to expert medical care, pain management, and emotional and spiritual support expressly tailored to the patient's needs and wishes. Support is provided to the patient's loved ones as well. At the center of hospice is the belief that each of us has the right to die pain-free and with dignity, and that our families will receive the necessary support to allow us to do so. Hospice focuses on caring, not curing and, in most cases, care is provided in the patient's home. Hospice care also is provided in freestanding hospice centers, hospitals, and nursing homes and other long-term care facilities. Hospice services are available to patients of any age, religion, race, or illness. Hospice care is covered under Medicare, Medicaid, most private insurance plans, HMOs, and other managed care organizations.

Institutional Review Board (IRB) - A specially constituted review body established or designated by an entity to protect the welfare of human subjects recruited to participate in biomedical or behavioral research.

Intercultural Cancer Council (ICC) - Promotes policies, programs, partnerships, and research to eliminate the unequal burden of cancer among racial and ethnic minorities and medically underserved populations in the United States and its associated territories. www.icc.bcm.tmc.edu.

Malignant - Cancerous.

Mammogram Voucher Program - A project funded by the Pittsburgh Komen Race for the Cure® and administered by the American Cancer Society Southwest Region, Pennsylvania Division, and Family Health Council, Inc. that provides free mammograms and follow-up diagnostic services to medically underinsured women in 30 counties of Western and Central Pennsylvania. www.mammogramvoucher.org.

Mammography - A screening test for breast cancer in which the breast is compressed and special low-dose X-rays are taken for the purpose of detecting abnormalities in the breast tissue.

Melanoma - The most serious type of skin cancer.

Morbidity - A measurement of the extent of disease and disability.

National Cancer Institute (NCI) - A component of the National Institutes of Health (NIH), one of eight agencies that compose the Public Health Service (PHS) in the Department of Health and Human Services (DHHS). NCI, established under the National Cancer Act of 1937, is the Federal Government's principal agency for cancer research and training. The National Cancer Act of 1971 broadened the scope and responsibilities of NCI and created the National Cancer Program. www.cancer.gov.

National Dialogue on Cancer (NDC) - A forum that brings together the principal leaders of key national cancer organizations, agencies, and institutions, plus central figures from other public, private, and non-profit entities, to foster and support efforts to overcome cancer. For the first time, three sectors (public, private, and non-profit) are united with one goal: to eradicate cancer as a major public health problem at the earliest possible time. www.ndoc.org.

National Institutes of Health (NIH) - The steward for behavioral and medical research for the nation and the federal focal point for medical research in the United States. www.nih.gov.

Oncology - The study of cancer.

Palliation - The process of alleviating symptoms without curing, throughout the disease trajectory, not reserved just for the period of terminal care.

Palliative Care - Extends the principles of hospice care to a broader population that could benefit from receiving this type of care earlier in their illness or disease process. No specific therapy is excluded from consideration. An individual's needs must be continually assessed, and treatment options should be explored and evaluated in the context of the individual's values and symptoms. Palliative care, ideally, would segue into hospice care as the illness progresses.

Papanicolaou (Pap) Smear - Developed by Dr. Papanicolaou, method of examining stained cells in a cervical smear for screening and early diagnosis of cervical and uterine cancer.

Pennsylvania Advocates for Nutrition and Activity (PANA) - An organization that coordinates state-level partners in seven regional networks, including Pennsylvania Department of Health Districts and Philadelphia, to provide information and tools necessary to implement policy and environmental changes that will support and promote active lifestyles and healthy food choices. www.panaonline.org.

Pennsylvania Biotechnology Association (PABIOTECH) - A member-supported association that includes small biotechnology companies and large pharmaceutical corporations, universities, venture capital firms, and service providers who share its goal of making Pennsylvania a center for the development of biotechnology. Its mission is to advance the life sciences in Pennsylvania by creating commercial opportunities and public policy strategies that lead to greater understanding, growth, and community support of biotechnology. www.pabiotech.org.

Pennsylvania Cancer Alliance - A formal partnership formed in 1998 comprising the major academic cancer centers in Pennsylvania and unified by the joint goals of conducting groundbreaking cancer research and delivering advanced cancer care. The current membership of the Alliance is the University of Pittsburgh Cancer Institute, Kimmel Cancer Center of Thomas Jefferson University, Penn State Cancer Institute, Abramson Cancer Center of the University of Pennsylvania, The Wistar Institute, Fox Chase Cancer Center, Temple Cancer Center, and Drexel-Hahnemann University. The Alliance collaborates in efforts to secure and apply Tobacco Settlement funding to the expansion and acceleration of cancer research and other public health programs in the Commonwealth.

Pennsylvania Cancer Alliance Bioinformatics Consortium - Established in 2002 to enhance translational and clinical cancer research. The Consortium uses a bioinformatics approach to identify biomarkers useful in the diagnosis of cancer and/or for predicting cancer patients' response to treatment or the clinical course of their disease. Current activities include the selection of the most promising biomarkers for breast cancer, melanoma, and prostate cancers, and the performance of assays for these biomarkers on tumor specimens collected at the participating institutions. The results obtained will be entered into a newly developed Bioinformatics Data Warehouse in a standardized format to allow integration of data from all of the participating sites and the assessment of important clinical correlations.

Pennsylvania Cancer Control, Prevention and Research Advisory Board (CAB) - Created by Act 224 of 1980, this Board was established to advise the Secretary of Health with respect to cancer control, prevention, and research in Pennsylvania. The Board is charged with approving each year a program for cancer control, prevention, and research to be known as the "Pennsylvania Cancer Plan." In order to implement the plan, the Board recommends to the Secretary the awarding of grants and contracts to qualified associations or governmental agencies in order to plan, establish or conduct programs in cancer control or prevention, cancer education and training, and cancer clinical research. The Board reports annually to the Governor and General Assembly.

Pennsylvania Cancer Registry (PCR) - A comprehensive and responsive cancer data and information system that is used for planning, implementing, and evaluating programs, policies, and cancer research. Cancer Registry publications and data can be viewed at www.health.state.pa.us/stats; go to Health Statistics and Vital Records.

Pennsylvania Department of Public Welfare - This state department oversees all Children, Youth & Families, Mental Health, Mental Retardation, Income Maintenance, and Medical Assistance and Social Program issues in the Commonwealth. www.dpw.state.pa.us.

Pennsylvania Department of Health - This state department has the duty and power to protect the health of the people. The Department's mission is identified through it's slogan "...in pursuit of good health" and all of its activities are defined by its core functions: health needs assessment, resource development, assuring access to healthcare, promoting health and disease prevention, assuring quality, and providing leadership in the area of health planning and policy development. The Department of Health provides leadership to promote good health and healthy communities, prevent disease and injury, and assure the quality and availability of healthcare services for all citizens of the Commonwealth. www.health.state.pa.us

Pennsylvania Life Sciences Greenhouses - A state-led historic initiative established in 2002 to build upon the biotechnology research at Pennsylvania's top universities, and to capitalize on the powerful economic potential of the state's status as a world center for life science businesses. The Pennsylvania Life Sciences Greenhouse is spread among three regions of the state: Southeast (www.bioadvance.com), Southwest (www.pittsburgh-lifesciences.com), and Central Pennsylvania (www.lsgpa.com).

Prevalence - Refers to the number of existing cases of a disease or health condition in a population, including incidence (new) cases.

Prostate-specific antigen (PSA) - Blood test used to screen for prostate cancer.

State Health Improvement Plan (SHIP) - A planning process and action document adopted in 1999 by the Pennsylvania Department of Health to improve state health planning for the health of Pennsylvanians. The process enables public/private/community partnerships to develop and implement programs while sharing responsibility and accountability. This plan allows for meaningful community-based planning based on local needs, links to the extent possible the allocation of commonwealth resources addressing the full spectrum of care.

Stage of diagnosis - Stage at which a disease or health condition is identified; at diagnosis (from early to late) may be expressed as numbers (I, II, III, or IV, for example, or by A, B, or C) or by terms such as "localized," "regional," or "distant."

Ultraviolet light (UV) - Refers to solar ultraviolet radiation.

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