



# 2013-2018 Pennsylvania Cancer Control Plan

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## WELCOME

Dear Pennsylvanians:

Significant time, talent and resources were committed over the past two years towards the development of the 2013-2018 Pennsylvania Cancer Control Plan. A new coalition of stakeholders, the Stakeholder Leadership Team (SLT), was created by the Pennsylvania Cancer Control, Prevention and Research Advisory Board (CAB) to lead the development, implementation and evaluation of cancer control activities, including the preparation of the new Plan. The CAB, the SLT, and the Department of Health teamed together to host the *Building Bridges: Pennsylvania Cancer Planning Summit*, giving stakeholders a voice in the planning process and an opportunity to connect with other organizations and agencies that address cancer issues. Hence, the Summit title of “Building Bridges” now culminates in this Plan and moves us into the crucial phase of implementation—or putting the Plan into action.

As our world changes, so does the role of public health and government. Agencies and communities can no longer rely solely on state and federal government funding to develop and sustain public health efforts. Our emphasis must change to become the “convener” of public and private partners and the “promoter” of best and promising practices of public health. Cancer continues to be a leading cause of mortality in Pennsylvania, and therefore is a priority for public health initiatives across the broad continuum from prevention to end-of-life care. Collaborative approaches must focus on developing the resources, skills and opportunities for our work in public health as we are all asked to do more with less.

Cancer prevention, like other chronic diseases, is based on eating the right kinds of foods, being physically active, avoiding tobacco, and using alcohol only in moderation. We are challenged with motivating people to change their attitudes and behaviors about these preventive measures. We all need to be part of changing those behaviors through what the Centers for Disease Control and Prevention refer to as Policy, Systems, and Environmental Approaches (PSE).

Now, get involved! Carefully review this Plan and find your role in its implementation. There is a lot of challenging work to be accomplished over the next five years to achieve a healthier Pennsylvania. We need you to join with us to be effective and successful in this endeavor.



Michael Wolf  
Secretary of Health



Joel Noumoff, MD  
Chairman, Cancer Advisory Board



Robert Durkin,  
Interim Chair, Stakeholder Leadership Team



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## ACKNOWLEDGEMENTS

The Pennsylvania Cancer Control, Prevention and Research Advisory Board thank the Stakeholder Leadership Team coalition members and the staff of the Pennsylvania Department of Health for their vision, leadership and expertise in crafting this Plan in the fight against cancer.

We also acknowledge the more than 200 individuals and organizations that participated in the Building Bridges—Cancer Planning Summit in Pittsburgh, Danville, and Philadelphia in April 2013 and provided valuable input which is reflected in the document.

### Stakeholder Leadership Team

(See Appendix 3)

### Consultants

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- Keith Chase, Planning Consultant
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- Matthew O'Donnell, Office of the Governor, Commonwealth of Pennsylvania
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- Pennsylvania Breast Cancer Coalition
- Einstein Health System
- Geisinger Health System
- Lehigh Valley Health System
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### Facility/Meeting Support

- The Alliance of Pennsylvania Councils

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  - Division of Nutrition and Physical Activity
  - Division of Health Risk Reduction
- Bureau of Epidemiology, Division of Community Epidemiology
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## PLAN INTRODUCTION

The Pennsylvania Department of Health (DOH) is funded in part by the federal Centers for Disease Control and Prevention (CDC) to conduct activities to help Pennsylvanians prevent and manage cancer. Under the CDC National Comprehensive Cancer Control Program (NCCCP), with each new grant period (historically, every five years) the Department is expected to update its strategic plan to ensure future resources are targeted in areas or population groups where they can make the greatest impact. This 2013-2018 Pennsylvania Cancer Control Plan is the first update in a decade and is unique in many ways.

First, there are unprecedented challenges from the federal Patient Protection and Affordable Care Act (ACA) and related health reforms. The Pennsylvania Cancer Control, Prevention and Research Advisory Board (Cancer Advisory Board/CAB), legislatively mandated to oversee Plan development in Pennsylvania, noted the importance early on of assessing and incorporating ACA impacts. Positive ACA outcomes include significant numbers of previously uninsured residents obtaining insurance, including 100% coverage for preventive services including cancer screenings. Initially there was concern that CDC funds to provide screening services to the uninsured would no longer be required if everyone became insured. However, it is estimated as many as 500,000 Pennsylvania residents may remain un(der)insured and still need services, including residents already facing barriers to accessing care and insurance coverage.

Another positive reform is the expansion of the Patient-Centered Medical Home (PCMH) concept, which coordinates care among multiple providers involved in a patient's care—and better includes the patient in the process. This includes an emphasis on self-care as well as primary care, while expanding primary care across teams made up of a broad spectrum of providers to reach those in need of clinical and support services. Community lay workers, routinely called Community Health Workers (CHW), have been particularly successful in reaching patients historically difficult to access due to social, economic and physical determinants of health such as access to transportation and cultural and/or language barriers. However, cost-reduction efforts under reform also may be a challenge as all care team members will

require payment for their services and few systems currently exist to share and allocate these payments appropriately. Further, patients will be held more accountable for their care, including better attention to lifestyle factors that impact their health.

The Cancer Control Plan sets the stage for the major issues Pennsylvania should address and potential actions to take; allowing the Department, in partnership with its many stakeholders, to prioritize what can realistically be accomplished in the near future. It also attempts to provide guidelines to cover the many activities undertaken every day by our statewide network of stakeholders—including the smallest, community-based organizations often reaching residents most in need.

**Vision:** Eliminate cancer burden for all Pennsylvanians, regardless of age, gender, race/ethnicity and social, economic and physical determinants of health

**Mission:** Reduce cancer burden through a collaborative process where partners pool and strategically leverage resources across the cancer care continuum, to reduce cancer risk; find cancers earlier; improve treatments; and optimize survivorship

**Burden is defined as:** *mortality, incidence, disability and suffering from cancer; including impacts from risk factors, comorbidities with other diseases and health determinants*



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Therefore, ***the vision of this Plan is to eliminate the burden of cancer for Pennsylvanians.*** “Burden” is defined as impacts from cancer incidence (or number of diagnosed cases); death rates; and flat or negative trends over time, including an aging population and comorbidities—such as, cancer combined with obesity/lack of physical activity, smoking impacts, etc. Burden can be decreased by reducing cancer risk, finding cancers earlier, improving treatments and increasing the number of cancer survivors.<sup>1</sup>

Further, the CDC expects the Department to focus resources on those residents most vulnerable or “disparate.” In addition to the social, economic and physical determinants of health noted earlier, disparities also occur among residents due to demographic indicators including, but not limited to age, gender, race or ethnicity, or geographic location. Therefore, ***the Plan mission is to eliminate cancer disparities, while reducing burden, in Pennsylvania.*** Effective comprehensive cancer control ultimately requires collaboration among partners statewide to pool their resources to reduce the burden of cancer.



<sup>1</sup> The Centers for Disease Control and Prevention

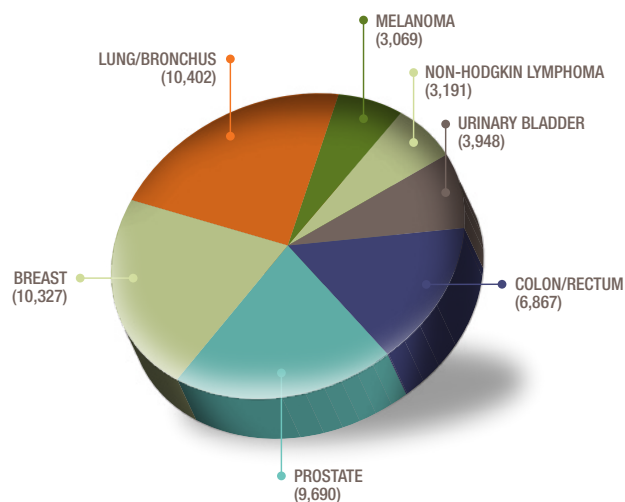
# CANCER BURDEN

## Introduction

The Centers for Disease Control and Prevention (CDC) defines cancer burden as impacts from incidence; death rates; and flat or negative trends over time, including comorbidities (e.g. cancer combined with obesity, smoking, etc.) and an aging population. As noted in the Introduction, burden is decreased by reducing cancer risk, finding—or diagnosing—it earlier, improving treatments and increasing the number of survivors. In 2013, estimates forecast just under 80,000 newly diagnosed cancer cases in Pennsylvania. An estimated 28,600 will die in 2013 from various cancers, ranking Pennsylvania fifth in the country behind California, Florida, Texas and New York.<sup>2</sup>

## Cancer Incidence—All Sites

2010 Cancer Incidence,  
All Sexes, All Races, Pennsylvania



<sup>2</sup> American Cancer Society

<sup>3</sup> National Cancer Institute



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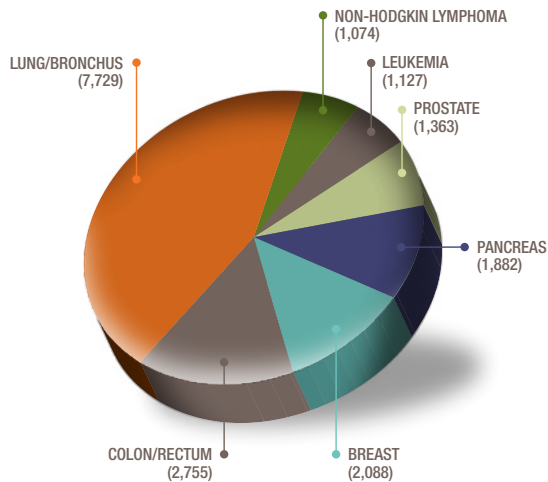
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## Cancer Mortality – Highest-Burden Cancers

### 2010 Cancer Mortality, All Ages, All Sexes, Pennsylvania



Cancer mortality refers simply to death from cancer. In 2010, as with incidence, lung/bronchus cancer caused the most cancer deaths, including all age groups and sexes, at 26.8% of total cancer mortality (28,809). Colon/rectum cancers were second,

making up 9.6% of all cancer mortalities in Pennsylvania; roughly 7.2% of all cancer deaths were from breast cancer.

Pancreatic cancer, although not among the seven highest incidence cancers, resulted in the fourth highest (6.5%) reported cancer deaths throughout the Commonwealth. Prostate (4.7%), leukemia (3.9%), and non-Hodgkin lymphoma (3.7%) were the fifth, six, and seventh most fatal cancers. In line with incidence, these top seven cancers in 2010 were responsible for 62.5% of all reported cancer deaths for all sexes and races in the Commonwealth of Pennsylvania.

Like incidence rates, mortality rates are often age-adjusted and calculated per 100,000 (population). In addition to disease risk, treatment success is the next largest contributor to survival; type and quality of care are also important determinants. Mortality rates generally vary only slightly over time, and improvements are often difficult to interpret or attribute to Department interventions.

For more specific information regarding Cancer Burden, please go to [PA.org](http://PA.org)



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## PLANNING PROCESS

### Pennsylvania Cancer Control, Prevention, and Research Advisory Board (CAB)

The Pennsylvania Cancer Control, Prevention and Research Advisory Board (Cancer Advisory Board/CAB) is the legislatively mandated board established to advise the Pennsylvania Secretary of Health and report to the Governor and the General Assembly with respect to cancer control, prevention and research in Pennsylvania. The CAB approves all Pennsylvania cancer plans and oversees the implementation of cancer-related prevention, education, training and research through the Department of Health (Department). The 11 members are distinguished professionals in the fields of medicine, oncology nursing, health care administration, public health, and community

health nursing; and also includes consumers, as established by law. Ten members are appointed by the Governor with the consent of the Senate; the remaining position is held by the Secretary of Health.

The CAB operational structure includes four standing committees to implement the mission, goals, and functions of the Board. In addition to the Stakeholder Leadership Team, which operates as Pennsylvania's Comprehensive Cancer Control Coalition and oversaw Plan development; these are the Data Advisory Committee, the Breast and Cervical Cancer Medical Advisory Committee, and the Colorectal Cancer Advisory Committee.

### Stakeholder Leadership Team (SLT)

After Pennsylvania's former cancer coalition dissolved, the CAB assembled a small committee of board members to develop a strategy for developing a new cancer plan. This committee engaged additional key partners and has since grown into the coalition, the Stakeholder Leadership Team (SLT). Fully operational as of August 2012, the SLT's membership now encompasses a diverse group of volunteer organizations, agencies, institutions, and individuals with the expertise and willingness to work collaboratively to plan, develop, implement, communicate and evaluate cancer activities in Pennsylvania. The SLT has created an infrastructure of workgroups to carry out its mission with administrative support provided by the Department of Health's Division of Cancer Prevention and Control. The SLT Chairperson attends CAB meetings to keep board members informed on committee activities.

During its first year of operation, SLT members dedicated time and expertise to the development of the Pennsylvania Cancer Plan. Members formed workgroups and drafted Plan goals, objectives and strategies supporting policy, system, and environmental approaches to manage chronic disease and efforts to link clinical interventions with community resources. The SLT opted

to structure the Plan based on the federal Centers for Disease Control and Prevention (CDC) Chronic Disease and Health Promotion Domains and to address the key provisions of the Patient Protection and Affordable Care Act (ACA) focused on improving healthcare outcomes and streamline the delivery of care. Another goal focused on sustainability, the idea that working together to pool resources and coordinate cancer control activities was needed.

As part of the Plan development process, the SLT and the CAB organized the *Building Bridges Pennsylvania Cancer Planning Summit* to give concerned stakeholders a voice into the statewide planning process and the opportunity to provide input into the new Cancer Plan. The day-long Summit was highlighted by presentations addressing both federal and state perspective for cancer control strategies with panel discussions highlighting promising practices currently underway in communities across the state. The Summit was held at the University of Pittsburgh Cancer Institute, with satellite locations at the Einstein Health System, Philadelphia, and the Geisinger Health System, Danville.



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## Integration of the CDC Chronic Disease Prevention and Health Promotion Domains

Controlling chronic disease improves quality of life, increases life expectancy and productivity and controls health care spending. The SLT structured the Pennsylvania Cancer Control Plan around the four key action areas identified by the CDC to give Americans even greater opportunity to take charge of their health. This approach integrates the public health infrastructure with health care providers, clinicians, local communities, business and industry, and academia.

### The Four Domains are:

**Epidemiology and Surveillance** to provide states and communities with the necessary expertise to collect data and information and to develop and deploy effective interventions, identify and address gaps in program delivery, and monitor and evaluate progress in achieving Plan goals. Data and information can inform decision makers and the public on whether preventive interventions are effective and demonstrate the return on investment.

**Environmental Approaches** or strategies that support and reinforce healthy choices and healthy behaviors in schools, worksites, and communities. Examples include working to expand access to and availability of healthy foods and beverages; promoting increased physical activity; reducing tobacco use, prevent youth initiation, and eliminating exposure to secondhand

smoke; and increasing the proportion of the U.S. population served by community water systems with optimally fluoridated water. Improvements in social and physical environments make healthy behaviors easier and more convenient.

**Health System Interventions** to improve the effective delivery and use of clinical and other preventive services to prevent disease, detect diseases early, and reduce or eliminate risk factors and mitigate or manage complications. Health system and quality improvement changes such as electronic health records and systems prompt clinicians for screening and follow-up or referral and encourage physicians and health plans to focus on preventive services.

**Strategies to improve Community-Clinical Linkages** so that communities support and clinics refer patients to programs that improve management of chronic conditions. Such interventions ensure those with or at high risk for chronic diseases have access to quality community resources to best manage their conditions or risk factors. Community-clinical linkages give people with or at high risk of cancer access to local resources and the support for managing chronic conditions once they occur through targeted outreach and appropriate follow up care. Cancer survivorship is addressed by ensuring appropriate follow-up care and promoting lifestyle interventions to reduce risk of recurrence.

### Cross-Cutting Issues

Early in the planning process, the SLT coalition identified high-level, “cross-cutting” issues they determined would be critical to Plan success. These issues are cross-cutting since they apply across the entire scope of the Plan and represent key processes required particularly for effective implementation statewide, from state to local levels and in the public and private sectors.

Comprehensive cancer control is the integrated approach to reducing cancer incidence, morbidity, and mortality throughout the cancer care **continuum**—from prevention and early detection, through treatment and end-of-life care. While the Plan is built around CDC’s Chronic Disease Prevention and Health

Promotion Domains, it still identifies specific, strategic priorities across the continuum as follows: preventing future cancers; detecting new cancers early; increasing access to optimal treatment and follow-up care; improving quality of life for cancer survivors; and improving palliative, i.e. pain management, and end-of-life care.

Integration in cancer control also requires bi-directional **communication** between partners—communication in its many forms is central to effective, high quality cancer care across the continuum from prevention to survivorship. Communication will reach specific internal and external audiences such as the newly diagnosed, survivors, family



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members and caregivers, present and new program partners, health care professionals, public agencies and organizations, educational institutions, policy makers, other stakeholders, and various media. Targeted outreach to these audiences will promote effective and evidence-based Policy, Systems and Environmental (PSE) approaches; health provider system changes; and community-based linkages to reduce cancer burden across Pennsylvania.

The CAB noted early on the importance of incorporating the impacts of **health reform** in the Plan. While these concepts are incorporated throughout the document, the CAB further noted the value of including reform-based education when communicating with stakeholders. This is particularly important as many of the elements of health reform still are to be resolved and implemented.

Another cross-cutting issue the SLT Coalition felt was critical is ensuring the Plan, although developed at the state level, will be **“translatable”** or flexible enough to apply in all areas of Pennsylvania, particularly local communities. As noted earlier, the Plan was intentionally developed at a high level, providing broad guidance useful to stakeholders at various levels statewide to utilize as they see fit to best impact their programs. The ultimate outcome is to implement comprehensive and collaborative efforts at the community level to foster change and action toward reducing cancer disparities and burden through lifestyle

changes by individuals and community support of initiatives and programs. An integrated, comprehensive cancer control strategy also allows for a more balanced, efficient and equitable use of limited resources at the community level. (See *Goal 4, Community-Clinical Linkages, for more information.*)

This local community discussion is also a key component in Plan **implementation**. As Plans in many fields may end up “collecting dust on a shelf”; SLT Coalition members and funders have expressed the importance of effective Plan implementation statewide over the Plan period and beyond. The major planning themes already are being incorporated into Department activities, in part to ensure a comprehensive and timely implementation process. (See the *Implementation Section for more information.*)

Hand-in-hand with implementation is **evaluation** of the progress in achieving Plan goals and objectives. Not only did the SLT Coalition identify this as a critical activity; the CDC, the primary funder for Comprehensive Cancer Control activities, mandates ongoing evaluation as well as development of performance measures. An Evaluation Workgroup of interested and qualified Coalition members and stakeholders has been convened to guide the ongoing evaluation process; finalize the evaluation strategy; and develop performance measures for ongoing utilization. (See the *Evaluation Section for more information.*)



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## Plan Framework

Beyond the cross-cutting issues, and based on the CDC domains, the SLT Coalition developed and refined a Plan framework of goals, objectives and strategies; in some cases, members suggested specific activities to be considered upon Plan implementation (see *Plan Implementation for additional detail*). Early in the planning process, high-level goal concepts began to gel that cut across all the CDC domains; when it became evident certain concepts also focused primarily on one of the domains, a framework of four such goals was decided upon. Finally, it was recognized how critical sustainability would be in a future environment of change in many aspects of cancer prevention and control; therefore, a fifth goal of sustainability in programs, research and stakeholder engagement was added.

Domain-based workgroups were developed from the SLT Coalition, which further refined the framework for the Plan. While public health stakeholders traditionally have been process-oriented—for instance, primarily focused only on awareness and education—SLT members were challenged to develop a more outcome-focused Plan framework to better demonstrate future results and Policy, Systems and Environmental (PSE) changes. This was primarily accomplished by utilization of the Specific, Measurable, Achievable, Realistic and Time-Based (SMART) template.<sup>4</sup>

<sup>4</sup> The Centers for Disease Control and Prevention

### PLAN GOALS

1. Advocate for state and federal policies, practices, reform and community-based systems that promote consumer access to affordable and quality health care
2. Reduce cancer health disparities, defined as populations disproportionately burdened by disease and its contributing factors
3. Support evidence-based health provider practices across the cancer care delivery continuum, while incorporating health reform concepts
4. Develop and expand community support system linkages to improve cancer control, while addressing the impacts of social, economic and physical health determinants
5. Build capacity for sustainable cancer control programs, research and stakeholder engagement

### SMART Template

**Specific** – What is the specific task?

**Measurable** – What are the standards or parameters?

**Achievable** – Is the task feasible?

**Realistic** – Are sufficient resources available?

**Time-Based** – What are the start and end dates?

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## PLAN COMPONENTS



### Goal 1 – Advocate for state and federal policies, practices, reform and community-based systems that promote consumer access to affordable and quality health care

As noted earlier, the Cancer Advisory Board (CAB) was designated by the Pennsylvania General Assembly (legislature) to oversee Department cancer control activities. The CAB has led the planning process, including incorporating impacts from health reform, particularly the Patient Protection and Affordable Care Act (ACA). While reform concepts have been incorporated throughout the Plan, it was determined this approach was primarily consistent with the Policy, Systems and Environmental (PSE) approaches domain.<sup>5</sup>

PSE approaches promote good health, including primary prevention of cancer and supporting and reinforcing healthful behaviors in schools, worksites, and communities; while removing barriers that interfere with Americans' attempts to take charge of their health. Improvements in social and physical environments make healthy behaviors easier and more convenient; and a healthier society delivers healthier students to our schools, healthier workers to our businesses and employers, and a healthier population. These types of interventions have broad reach, sustained health impact and are "best buys" for public health. Accordingly, the Stakeholder Leadership Coalition established the first Plan goal to: "advocate for state and federal policies, practices, reform and community-based systems that promote consumer access to affordable and quality health care."

The first objective under this goal is to "institute a coordinated approach that engages public agencies and private organizations to promote access to affordable health care." Community stakeholders and leaders will be better engaged to facilitate consumer engagement, as these local efforts often have the best outcomes.

Communication strategies need to be enhanced to include a web portal for stakeholders statewide to promote activities, share information, and link to initiatives at local, regional, state and federal levels. Beyond engagement, consumers need to be educated not only on public health issues but also the complexities surrounding health reform. Department cancer interventions must be coordinated with other chronic disease initiatives, including but not limited to tobacco prevention and control, obesity and diabetes; to eliminate barriers and address comorbidities, in line with current Centers for Disease Control and Prevention (CDC) efforts toward coordination. While these PSE approaches traditionally have applied only to public-sector agencies, partnerships developed with private-sector entities (as appropriate) will help to accomplish this objective.

#### **OBJECTIVE 1.1: Institute a coordinated approach that engages public agencies and private organizations to promote access to affordable health care**

**STRATEGY:** Coordinate interventions with other chronic diseases to eliminate barriers and address comorbidities

**STRATEGY:** Develop communication strategies to facilitate consumer education and engagement

**STRATEGY:** Support healthcare delivery transformation, consistent with the State Health Care Innovation Plan

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<sup>5</sup> Centers for Disease Control and Prevention



**OBJECTIVE 1.2: Link consumers to initiatives that help them navigate the health care system and reduce barriers to obtain coverage, care and services**

**STRATEGY:** Eliminate barriers to accessing quality and affordable cancer care

**STRATEGY:** Support sustained, data-driven legislative advocacy to reduce burden and disparities

**STRATEGY:** Develop multi-media approaches to connect audiences to beneficial resources

The second objective aims to “link consumers to initiatives that help them navigate the healthcare system and reduce barriers to obtain coverage, care, and services.” In order to provide services across the continuum of cancer care, access to education, prevention, screening and treatment as well as certain individual-level disease stage and social, economic and physical “health determinants” such as socioeconomic status need to be addressed to eliminate barriers presented to vulnerable populations. Data-driven legislative advocacy needs to be supported to sustain Department and partner funding and other resources. Consistent with health reform, the un(der)insured should be identified and assisted with accessing safety nets through education, awareness and access to health services. These examples of “healthcare delivery system transformation” will be accomplished in conjunction with the Governor’s State Health Care Innovation Plan (SHCIP).

**OBJECTIVE 1.3: Empower consumers to actively participate in their health and care**

**STRATEGY:** Promote the Patient Centered Medical Home (PCMH) model, facilitating enhanced relationships with primary providers

**STRATEGY:** Support Health Information Exchanges and Pennsylvania’s eHealth Partnership Authority, allowing consumer access to information portals and active participation in their care

**STRATEGY:** Provide information and intervention to recipients across the lifespan, **with a focus on younger ages**

The third objective will “empower consumers to actively participate in their health and care,” including participation with a regular healthcare provider under the Patient-Centered Medical Home (PCMH) model. Under this model, self-care best practices need to be supported and promoted, as well as a shift in emphasis and resources from treatment to preventive services. Consistent with reform and Pennsylvania’s eHealth Partnership Authority, the support of Health Information Exchanges (HIE) including access through online portals, allows consumers to be active in their own care. This includes information provided to recipients at younger ages, for example middle and even elementary school children, as a portal to family health promotion. Health education in schools must be further improved through an increased focus on reducing high-incidence risk factors, particularly tobacco use and physical inactivity/obesity; and including community leaders or “champions” as presenters.

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# **OBJECTIVE 1.4: Reduce policy, system, and environmental (PSE) gaps in the cancer continuum of care**

**STRATEGY:** Promote emerging, innovative models of health promotion and care delivery, e.g. Community Health Workers (CHW)

**STRATEGY:** Support patient-focused care models, including Patient Centered Medical Home (PCMH)

**STRATEGY:** Incorporate palliative care into school curricula of all health care professionals

curricula for medical and nursing schools and training for allied health providers and social workers.

# **OBJECTIVE 1.5: Simplify health insurance administration by promoting a uniform set of rules to verify eligibility, determine claim status, and pay for services**

**STRATEGY:** Support Health Information Exchanges (HIE) and Pennsylvania's eHealth Partnership Authority, e.g. initiatives aligning systems and incentives

**STRATEGY:** Support joint quality improvement opportunities, consistent with State Health Care Innovation Plan (SHCIP) initiatives

The fourth objective seeks to “reduce policy, system, and environmental (PSE) gaps in the cancer continuum of care” (see *Goal 3 regarding clinical care gaps*). Innovative and effective current (including PCMH) and emerging models of health promotion and care delivery such as Community Health Workers (CHW) need to be promoted and utilized for care coordination and to close gaps in cancer care. Communication must also be improved among providers, consumers, families and caregivers to close the gaps. The utilization of financial counselors, particularly in large provider institutions such as hospitals, must be encouraged to facilitate needed care across the continuum particularly for disparate populations. Finally, efforts should be supported to incorporate palliative, as well as end-of-life care into health provider

The fifth and final objective under this goal seeks to “simplify health insurance administration by promoting a uniform set of rules to verify eligibility, determine claim status, and pay for services.” To accomplish this, patient, provider, and payer systems must be aligned, including joint quality improvement opportunities, consistent with SHCIP efforts. These initiatives must again be supported by Health Information Exchanges (HIE) and other reform-based information technologies. Efforts to streamline provider reimbursement and establish incentives to provide high-quality, affordable care are strongly encouraged.

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## Goal 2 – Reduce cancer health disparities, defined as populations disproportionately burdened by disease and its contributing factors



By primarily addressing the Epidemiology and Surveillance domain,<sup>6</sup> this goal highlights key components of the Plan mission and vision to: “reduce cancer health disparities, defined as populations disproportionately burdened by disease and its contributing factors.” Public health surveillance refers to the collection, analysis, and use of data to target public health prevention.<sup>7</sup> Disparities are defined as the disproportionate impacts on certain populations from factors including, but not limited to: age; gender; race/ethnicity; geographic location; and social, economic and physical determinants of health.

CDC places high priority on ongoing, data-driven decision making and continuous improvement of interventions and outcomes. Multiple, high-quality data collection and analysis resources are readily available to the Department. The Pennsylvania Cancer Registry (PCR) is a national gold-standard, population-based central cancer data repository. Further, comprehensive analyses on PCR death, incidence, and related data are conducted routinely and ad hoc within the Department of Health’s Bureau of Health Statistics and Research, as well as by staff in the Bureau of Epidemiology, for ultimate consideration in decision-making.

This goal’s first objective will sustain and “improve rates for key cancer surveillance

indicators and measures for high burden cancers,” particularly mortality (deaths); cancer incidence, or new diagnoses; and, more recently, stage of disease diagnosis—generally early or late stage. Continuing and developing data trends, or changes in data over time, are also important; mortality trends, since the numbers are smaller, take much longer to develop and change as compared to these other indicators. The SLT Coalition has emphasized the importance of expanding state-level data sharing with stakeholders, particularly community-based care providers and those populations disproportionately bearing the cancer burden including patients, survivors, families and caregivers.

Current CDC priorities focus on breast, cervical and colorectal cancers, the highest-burden cancer types—or “sites”—in Pennsylvania and nationwide, for which evidence-based screening is available. These cancer sites will continue to be addressed, while building capacity with our partners to address additional high-burden cancers. These efforts will initially focus on PSE approaches including improving awareness and access to existing services, particularly community-based; and promoting evidence-based screening and other clinical guidelines (see Goal 3 regarding evidence-based practice).

### Objective 2.1: Improve rates for key cancer surveillance indicators and measures for high burden cancers

**STRATEGY:** Positively impact rates for CDC priority cancers: breast, cervical and colorectal

**STRATEGY:** Calculate rates and monitor trends for additional high burden cancers including preventable cancers, e.g. tobacco-related

**STRATEGY:** Optimize use of Pennsylvania Cancer Registry data in order to recommend realistic interventions

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<sup>6</sup> The Centers for Disease Control and Prevention

<sup>7</sup> The Centers for Disease Control and Prevention

## Objective 2.2: Optimize impacts of health reform to eliminate cancer health disparities

**STRATEGY:** Target primary care providers to track data on screening, early detection and prevention

**STRATEGY:** Facilitate development of data-driven patient navigation systems

**STRATEGY:** Support the Moral Imperative to advance equity and eliminate disparities

Health reform places a high priority on prevention, creating a need to further address preventable cancer sites. This goal's second objective seeks to "optimize impacts of health reform to eliminate cancer health disparities." These are identified primarily by identifying and tracking risk factors, with tobacco use topping the list and suggesting priority for lung and other tobacco-related cancers. Men's health may warrant a higher profile, including promoting evidence-based prevention and care for prostate cancer. Health care reform further supports the Patient-Centered Medical Home (PCMH) concept, which facilitates patient care coordination with a primary provider—usually a physician/practice. The objective promotes utilization of future care teams including Community Health Workers (CHWs) which would benefit patients requiring assistance with navigation of the health care system. This includes facilitating provider access to surveillance, care quality and other supporting data to improve provider-patient communication, provider accountability and patient outcomes. Prevention, including tobacco cessation and referral services, as well as coordinated chronic disease management, need to be integrated into provider training as well as practice to reinforce their importance. These data not only need to be translated into multiple

languages; but also into materials that are culturally and linguistically appropriate,<sup>8</sup> including multiple outreach media that best target diverse audiences.

## Objective 2.3: Link registry data to other reliable data sources to improve outcomes; and share appropriately with partners and audiences

**STRATEGY:** Expand linkages to existing state-level resources to improve outcomes

**STRATEGY:** Reduce burden of multiple chronic diseases through newly identified data sources

**STRATEGY:** Pennsylvania's eHealth Partnership Authority to improve outcomes and optimize data-driven decision-making

To complement Goal 1, this goal also supports reform-based measures including the Health in All Policies (HiAP) Moral Imperative to advance equity; and reduce disparities and "disempowering situations."<sup>9</sup> This objective specifically aims to "link registry data to other reliable data sources to improve outcomes; and share appropriately with partners and audiences," including care providers such as physicians and hospitals. Increasing data integration and quality improvement provide a more accurate picture of the nature of burden and disparities, which informs more effective interventions with potential to improve outcomes. Department analysts already have linked other state-level sources with Registry data, including Pennsylvania Health Care Cost Containment Council<sup>10</sup> (PHC4)

<sup>8</sup> United States Department of Health and Human Services

<sup>9</sup> World Health Organization

<sup>10</sup> Pennsylvania Health Care Cost Containment Council

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hospital data, resulting in improved data integration and “mapping” to show areas of need and gaps in service. Future public sector datasets for potential linkage include federal programs—including Medicare/Medicaid, Federally Qualified Health Centers and Rural Health Clinics—that will continue to serve the un(der)insured. Prevention data needs to be incorporated globally to traditional, future stand-alone, and integrated datasets. These initiatives must again be supported by Health Information Exchanges (HIE) and other reform-based information technologies.

Private sector datasets will be more difficult to access due to privacy issues. As our

community-based partnerships expand, their data should be more accessible, although data reliability will need to be assessed. School-based data is currently being collected to manage chronic diseases like asthma, however, scope and quality tends to vary widely by location. Workplace data collection and sharing has significant potential for analyzing the impact of workplace wellness initiatives on cultural and individual behavioral change, particularly regarding prevention; despite significant privacy hurdles. Data collection, sharing technologies and priorities under reform may facilitate these opportunities in the future.



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### Goal 3 – Promote evidence-based health provider practices across the cancer care delivery continuum, including reform-based transformation models



The continuum of cancer care spans risk assessment, primary prevention (e.g. risk factors), screening, detection, diagnosis, treatment, survivorship, and end-of-life care. Movement across the continuum involves several types of care, as well as transitions between these types. Health System Interventions, the primary domain addressed here, assist in the improvement of the delivery and use of clinical and other services in order to prevent disease, detect diseases early, reduce or eliminate risk factors, and mitigate or manage complications across the continuum of cancer care.<sup>11</sup> These interventions can facilitate effective delivery of quality cancer services and help Pennsylvanians more effectively use and benefit from those services. Health system changes and quality improvement can encourage providers and health systems to focus more on preventive services. Effective outreach and reducing barriers to accessing these services, as addressed elsewhere in the Plan, is crucial; as health care coverage and availability alone may not ensure use of quality cancer services.

This goal seeks to: “promote evidence-based health provider practices across the cancer care delivery continuum, including reform-based transformation models.” Such models include care increasingly provided by collaborative healthcare teams—consisting of primary care and specialist physicians, community-based providers such as screening entities and community lay workers, community-based pharmacists and ancillary providers. Efforts to grow and sustain primary care resources, including more community-focused and oncology-based care in medical provider education must continue. Finally, reform promotes Accountable Care Organizations (ACO), which link team providers with joint quality improvement initiatives to improve patient outcomes while reducing costs; providers and payers can also be linked through reimbursements that include incentives for providing higher-quality care.

A key objective under this goal is to “promote evidence-based best clinical practices across all elements of the cancer care continuum” to providers and partners, through improved communication links and multi-media portals such as the LiveHealthyPA.org website. In conjunction with our partners, promotion and development of ongoing practice improvements to cancer care, particularly clinician-designed approaches, are important. Current best practices focus on the Patient-Centered Medical Home (PCMH) model, which increases consistent, coordinated, more patient-focused care often resulting in improved outcomes. Future clinical practice promotion also will be in line with Pennsylvania’s State Health Care Innovation Plan (SHCIP), developed in conjunction with federal-level health reform. Future clinical practices and protocols also need to better address comorbidities, or treating multiple chronic diseases concurrently in the same patient.

#### **Objective 3.1: Promote evidence-based best clinical practices across all elements of the cancer care continuum**

**STRATEGY:** Assess existing clinical care practices to promote best current practices

**STRATEGY:** Support development of new, and improvements in existing, practices

**STRATEGY:** Incorporate impacts of comorbidities in recommendations of clinical guidelines



<sup>11</sup> The Centers for Disease Control and Prevention



### Objective 3.2: Increase attention to prevention, early detection and reduction of risk factors

**STRATEGY:** Promote evidence-based screening as appropriate by site and population, while reducing disparities in screening awareness and access

**STRATEGY:** Facilitate the reform-based shift from treatment to prevention when promoting allocation of care resources

**STRATEGY:** Support development of a sustainable, community-focused cancer care workforce e.g. primary care providers

Guidelines,<sup>12</sup> which encourage early provider-patient discussion of care values and goals should be promoted; as well as supporting ongoing training and availability of the spectrum of primary care providers.

### Objective 3.3: Facilitate collaboration to increase attention to appropriate use of palliative care and improve quality of life

**STRATEGY:** Promote CDC National Action Plan for Cancer Survivorship to reduce burden on cancer survivors, their families and caregivers

**STRATEGY:** Promote National Consensus Project for Quality Palliative Care, Clinical Practice Guidelines

The other end of the care continuum involves efforts to “facilitate collaboration to increase attention to appropriate use of palliative care and improve quality of life,” as cancer survivors seek and manage to live longer, higher-quality lives. Traditional hospice care should continue to be enhanced, as well as expansion of its availability and scope to include diverse care settings and expanded palliative care. The CDC National Action Plan for Cancer Survivorship promotes these concepts as well as “psycho-oncology”: addressing psychosocial factors, or the effects of cancer on a person’s psychological health as well as the social and behavioral factors that may affect disease process and/or remission; and the additional burden

<sup>12</sup> National Consensus Project for Quality Palliative Care

Other key objectives influenced by reform include allocating more resources at both “ends” of the care continuum, in an attempt to “increase attention to prevention, early detection and reduction of risk factors,” while focusing resources on the disproportionate cancer burden in vulnerable populations, including factors such as race/ethnicity; gender; age; and social, economic and physical determinants of health. At the front end of the care continuum, prevention further includes reducing or eliminating risk factors, such as obesity and substance abuse, particularly tobacco; and detecting disease early, primarily through screening and including genetic testing. Evidence-based prevention suggests unique screening protocols for each cancer site, including more and less frequently recommended screenings in the future. National Consensus Project for Quality Palliative Care Clinical Practice

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placed on survivor families and caregivers.<sup>13</sup> The National Consensus Project again plays a role here, as patients are made aware of potential treatment risks and toxicities and given a larger role in treatment decisions.

**Objective 3.4: Facilitate Policy, Systems and Environmental (PSE) changes to improve cancer diagnosis and treatment**

**STRATEGY:** Promote health care reform concepts to improve cancer outcomes

**STRATEGY:** Support reform-based information technology and cost-effective clinical technology

**STRATEGY:** Increase awareness and consideration of risk factors, symptoms and toxicities associated with cancer treatments

Objective 3.4 will “facilitate Policy, Systems and Environmental (PSE) changes to improve cancer diagnosis and treatment.” Key PSE approaches to improve cancer care and outcomes include increased focus on

relieving and preventing cancer patient suffering, or palliative care. As noted previously, the National Consensus Project for Quality Palliative Care promotes increased palliative resources throughout the care continuum, not just in later stages, including early patient involvement in care choices.<sup>14</sup> Additional PSE approaches include: promoting reform-based, cost-effective technology improvements, including electronic medical records and telemedicine; and better linking public health with community-based care, including federal and state-level community and rural health centers. Interventions and activities should be consistent with provisions of the Governor’s State Health Care Innovation Plan (SHCIP).

<sup>13</sup> The Centers for Disease Control and Prevention

<sup>14</sup> National Consensus Project for Quality Palliative Care



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## Goal 4 – Develop and expand community support system linkages to improve cancer control, while addressing the impacts of social, economic and physical health determinants



Community-Clinical Linkages (CCL) is the CDC domain that helps ensure individuals at high risk for chronic disease have access to health care, community resources and support to prevent, delay or manage chronic conditions. Strategies to improve CCLs ensure communities support, and clinics refer, patients to programs that improve disease management.<sup>15</sup> The Plan goal is to: “develop and expand community support system linkages to improve cancer control, while addressing the impacts of social, economic and physical health determinants.” An evidence-based strategy utilizing patient navigators such as Community Health Workers (CHW) and/or allied health providers is the bridge to the care system to improve outcomes and reduce disparities in access and quality across the continuum of care.

### **Objective 4.1: Align community-based cancer care with clinical care across the full continuum**

**STRATEGY:** Promote chronic disease self-education and self-management programs to positively impact cancer risk and lifestyle factors

**STRATEGY:** Incorporate survivorship plans and care into community-based services and interventions

The first objective seeks to identify and “align community-based cancer care with clinical care across the full continuum.” Consistent

<sup>15</sup> The Centers for Disease Control and Prevention

with reform, prevention will be promoted through chronic disease self-education and management programs designed to reduce cancer risk and positively impact lifestyle factors, with an emphasis on disparate populations. Department interventions and activities need to be coordinated with partners, including Patient-Centered Medical Home (PCMH) care team members based inside and outside physician practices. Community partners need to be connected to facilitate provision, and prevent duplication, of community-based services. Another priority will be to incorporate survivorship plans and care into community-based services and interventions, consistent with similar clinical approaches to improve services at the tail end of the care continuum. Further, the earlier in the care continuum that patient care values, goals and risks are discussed, care and outcomes are often improved.

### **Objective 4.2: Promote primary care and patient navigation for disparate populations**

**STRATEGY:** Promote the use of community lay workers, e.g. Community Health Workers (CHWs)

**STRATEGY:** Support Patient-Centered Medical Home collaboratives that incorporate CHWs, practice-based health coaches and other patient navigators as part of the care team

This objective aims to “promote primary care and patient navigation for disparate populations,” including training and utilization of community-based primary care providers, beyond physicians, consisting of physician practice-based health coaches and patient navigators, including CHWs—often trusted members of the community with a passion for

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helping fellow members prevent and manage chronic disease while providing access to resources. They may have minimal formal training in health care, yet provide education, support, and skills to individuals, families, and caregivers in medically underserved communities. CHWs help patients overcome barriers to accessing health care—including transportation, scheduling, and compliance with appointments, prescriptions, preventive services, and financing—by serving as a member of the PCMH health care team, bridging the health care system. The Department conducted an environmental scan (Spring 2013) to assess the current capacity of CHWs in Pennsylvania toward developing effective future interventions. Successful interventions should be shared with medical schools, academic institutions and students through health provider and system trainings if clinical linkages are to be strengthened. Finally, connections should be made with local stakeholders and consumers to serve as local CHWs and other lay workers in clinics and communities where possible.

**Objective 4.3: Reduce barriers to availability of, and access to, community-based care**

**STRATEGY:** Expand outreach to underserved populations through community lay workers

**STRATEGY:** Increase state-local linkages to coordinate services and promote resource efficiencies

The final objective under this goal seeks to “reduce barriers to availability of, and access to, community-based care;” particularly for populations that are disparate or difficult to reach. There are a number of strategies to accomplish this: one is to make information and services available at recipient “entry points”, or bringing information and services to people at home, work, school, events, etc. Outreach to non-compliant patients, or patients missing appointments, assists in identifying access difficulties or uncertainty—such as fear of certain procedures—that can be rectified and care resumed. Partners also may develop innovative strategies, such as barter or trade and time banking systems already developed by some partners, to access those in need who are difficult to reach.

Some systemic approaches for potential longer-term benefits include enhancing or integrating existing, as well as developing new, community-based partnerships such as faith-based organizations, individual cancer survivors and the business community. State-level linkages should also facilitate coordination with and between community-based services to promote resource efficiencies and reduce duplication. Quality health data, information and resources from local, regional, state and federal sources may be collected; then assessed for cultural and linguistic appropriateness to facilitate understanding and effective use by diverse populations.





## Goal 5 – Build capacity for sustainable cancer control programs, research and stakeholder engagement

Stakeholder Leadership Team (SLT) discussions early in the planning process noted sustainability as a key theme for all aspects of cancer prevention and control moving forward. To highlight its importance, it became the fifth and final Plan goal, cutting across all Plan domains and activities, to: “build capacity for sustainable cancer control programs, research and stakeholder engagement.” As traditional public-sector funding may be less available in the future, identifying other supporting resources will be critical to sustain cancer control activities. Cancer research was considered important as traditional cancer care costs continue to skyrocket while outcomes have shown much more modest improvement and some decline. Finally, sustaining stakeholder engagement is increasingly important as resources are challenged; while, at the same time, acknowledging stakeholder work responsibilities and schedules have become more demanding and travel budgets constrained.

### Objective 5.1: Optimize and expand existing resources to sustain cancer control programs

**STRATEGY:** Advocate for sustained public-sector program funding for state-level and partner programs

**STRATEGY:** Obtain supplemental resources through non-traditional sources, e.g. private sector sources

**STRATEGY:** Link to existing and future prevention programs, e.g. tobacco cessation, obesity reduction

Objective 5.1 addresses the potential limited longevity of programs by seeking to “optimize and expand existing resources to sustain cancer control programs.” Sustaining funding is a logical first step in addressing sustainability, including advocating for maintaining current public-sector resources,

i.e. CDC (federal) and state-level public health—particularly chronic disease—funding. It will be important to better leverage current and future laws and regulatory requirements to sustain this public-sector funding at federal, state, regional and local levels. Other opportunities must be identified and supplemental, non-traditional funding should be secured from the public and private sectors. Regarding the latter, corporations including pharmaceutical companies are increasingly interested in partnering with the public sector to increase consumer awareness and improve health outcomes. A better job of sharing, if not leveraging, funding opportunities with partners statewide needs to be applied. Finally, initiatives that support adequate reimbursement for care providers at all levels, including community-based workers should be promoted. Health reform suggests future bundled payments for coordinated provider care teams; it will be important to reimburse and incentivize team members appropriately while focusing on patient outcomes.

Sustainability strategies should be pursued beyond funding, particularly linking with and promoting community-based programs that most effectively reach those in need. As traditional media are being supplanted by social media, strategies should include promoting and linking of local programs through ongoing, state-level, multimedia outreach and educational efforts. As health reform shifts public health focus increasingly to prevention, increased resources also need to be dedicated to education and awareness, including early detection and evidence-based screening. This includes increased emphasis on self-care programs: much less costly and often more effective approaches to manage chronic disease than traditional clinical services. Technical assistance should be provided to local programs, including activity and intervention planning, implementation and evaluation.

Next, the CDC is increasingly requiring grantees to coordinate their chronic disease efforts wherever possible, providing opportunities for sharing and leveraging educational, programmatic and promotional



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resources. This also suggests improved state-level, inter-agency collaboration as the interwoven physical, social and behavioral aspects of health are explored. An example of improved collaboration could be working with the Pennsylvania Department of Environmental Protection (DEP), the agency primarily responsible for impacts of lead and radon exposure, as issues surrounding lung cancer are further addressed. Finally, data collection and analysis resources must be sustained, as well as increased data sharing and connectivity, to better monitor and continually seek to improve individual and population-based health outcomes.

**Objective 5.2: Support sustainable cancer research to inform, support and validate best available evidence and improve outcomes**

- STRATEGY:** Promote research across the care continuum for high-burden cancers
- STRATEGY:** Support patient-centered outcomes research consistent with health care reform
- STRATEGY:** Promote research collaborations among cancer centers and other organizations

In an effort to further combat issues of sustainability, objective 5.2 will “support sustainable cancer research to inform, support and validate best available evidence and improve outcomes.” While clinical research traditionally has centered on high-cost ventures at individual academic institutions, sustainable quantitative and qualitative collaborative cancer research targeting the highest-burden cancers will be increasingly important. As with programmatic funding, research funding is also at risk; stable research funding is needed, while encouraging availability of, and facilitating patient access to, high-quality, outcome-focused clinical research trials. Members of high-burden populations historically

have been underrepresented in research, and efforts to increase exposure to and participation of disparate populations in research opportunities must be supported.

The SLT Coalition supports the recommendations of the President’s Cancer Panel on future cancer research, including: 1) promoting increased public-private sector research collaborations; 2) consistent with reform, shifting funding toward early-stage disease and prevention, including carcinogens and infectious agents; 3) reducing traditional research aversion to innovation, risk and patient-centered outcomes; and, 4) expanding research scope beyond clinical trials to include translational, behavioral and health services research should be supported.<sup>16</sup> Efforts to facilitate collaboration among cancer centers and other research organizations; promote availability of cancer registries’ data to research institutions; and attract and support diverse young people in research and data-related careers also are encouraged.

**Objective 5.3: Develop and sustain an effective stakeholder engagement strategy**

- STRATEGY:** Translate Plan into local action through equitable resource allocation and aligned support
- STRATEGY:** Conduct ongoing education and evaluation to sustain stakeholder engagement
- STRATEGY:** Develop and implement stakeholder commitment recognition program

<sup>16</sup> National Cancer Institute



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From 2012-2013, a dynamic stakeholder engagement strategy was implemented to sustain stakeholder involvement in the Department's cancer planning and programming, which coincides with the last objective to "develop and sustain an effective stakeholder engagement strategy." This is a high CDC priority as well as a proven sustainability approach under many state-level and community-based cancer control programs. As noted earlier, the SLT Coalition has been the primary entity driving the planning process. Resources were made available by the Department of Health to enable SLT members to attend bi-monthly in-person meetings; regional meetings and web-based media will be available in the future to enable interested parties to continue to participate in stakeholder meetings. Outreach was further expanded at the Cancer Planning Summit in April 2013 at multiple locations statewide, triggering an expansion of stakeholder networks to prepare for Plan implementation.

It is also a CDC requirement to provide education to SLT and CAB members, partners, and statewide stakeholders regarding cancer prevention and control. Ongoing education and training programs must be conducted to sustain stakeholder

buy-in throughout Plan development and implementation. Ongoing evaluation will enable the Department to continually improve and facilitate stakeholder satisfaction and ensure continued engagement in cancer control efforts. Attention must be given to developing and implementing (and evaluating again), corrective action plans in areas needing improvement, an often overlooked element in an effective evaluation program. Finally, a recognition program for stakeholder engagement should be implemented, based on a variety of factors including commitment, collaboration, impact and outcomes.

Perhaps the SLT's highest priority regarding its own sustained engagement is to ensure effective Plan implementation to local—including county, municipal and community—levels. This includes, at minimum: 1) multimedia outreach targeted to our diverse stakeholder audiences; 2) more closely aligning local stakeholders to state and regional coalitions; 3) facilitating resource allocation statewide, focusing on disparate and vulnerable populations; and 4) linking to ongoing community and provider-based community needs assessments to target resources where the need is greatest and avoiding duplication of services.



## IMPLEMENTATION

### Implementation—Why/How

The Centers for Disease Control and Prevention (CDC), National Comprehensive Cancer Control Program (NCCCP) primary program objectives note the larger importance, once the Plan has been developed, of effective **implementation**. One objective requires the Department to develop and implement evidence-based interventions, in conjunction with key partners, which improve long-term outcomes toward reducing cancer burden and disparities. Further, priority must be given to implementation at the community level, to expand capacity and outreach and strengthen partner relationships. Another NCCCP objective notes the importance of utilizing, “high-quality, accurate and representative cancer burden data” to improve the quality, and justify prioritization, of implementation activities. Yet another objective cites the importance of SLT and other stakeholder participation and leadership

### Coalition/Workgroup Process

This Plan will primarily provide guidelines for the more important phase: **implementation of Plan strategies**. The Stakeholder Leadership Team (SLT/Coalition), the committee to which the Cancer Advisory Board (CAB) delegated primary responsibility for Plan development, will also drive the implementation process. The SLT Coalition was built from a combination of previous and newer stakeholders; and developed the Plan framework with a dedicated, efficient and diverse group of 30-40 members. This group will be expanded during Plan implementation, at minimum to ensure adequate statewide representation (including geographic); including urban, suburban and rural communities; and representing the dozens of stakeholder types, sectors and organizations statewide.

During Plan development, SLT members routinely broke into workgroups based on the CDC coordinated chronic disease domains forming the Plan framework: policy/ systems/ environmental (PSE) approaches, epidemiology/surveillance (data), health system interventions and community-clinical linkages. While some of these workgroups will transition to the implementation stage,

in successful Plan implementation.

The primary NCCCP objective guiding Plan implementation is to: “maintain, implement and periodically revise a comprehensive cancer control plan.” A key goal here is implementing Plan strategies that support Policy, Systems and Environmental (PSE) approaches, including prevention and community-clinical linkages (see *Plan Goals 1 and 4 for additional detail*). These approaches again need to consider surveillance data toward reducing burden and disparities; as well as utilize evidence-based interventions, already existing if possible, with potential for broad implementation. Examples include client reminders for cancer screening; smoke-free policies to reduce tobacco use; and food procurement policies and practices. Linkages with other chronic disease programs aids in reducing duplication and increase efficiency and effectiveness.

some may not; and some may be replaced by others as the SLT determines Plan priorities. For example, the Community-Clinical Linkages workgroup will assist in developing the Department’s Community Health Worker (CHW) strategy (see Goal 4 for additional detail). Concurrent with Plan development, the Department conducted an environmental scan of current CHW initiatives and resources statewide; from the results a state-level strategy will be determined. The PSE workgroup will also transition to implementation, with the primary responsibility of prioritizing and driving reform-based initiatives. The data workgroup will work with, or possibly transition to, the Data Advisory Committee of the CAB. As the SLT develops short (1-2 year), medium (3-4 year) and long-term (5+ year) priorities under Plan implementation, the need for additional work or advisory groups will be determined.

Permanent workgroups were convened during planning, involving two of the important cross-cutting issues discussed previously: **evaluation** and **communication**. The Evaluation Workgroup has already begun to meet and develop a Plan evaluation strategy, and will be ready to operate concurrently with



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the implementation process (see *Evaluation section for more details*). Communication is also an ongoing priority; particularly with expected future funding challenges, it will be critical to improve and sustain communication with the many statewide cancer control

partners. With the significant recent expansion in media outlets and methods, the ideal media will need to be identified, if not developed, to reach each of our many target audiences (see *Cross-Cutting Issues section for more details*).



## Moving Into Implementation: “What Can You Do”?

If planning is the map or the key to the treasure, then implementation must be the treasure itself. The Plan development paperwork is done; time to roll up the sleeves and get to work!

Our hope is that all of the people who spent so much time helping to develop this Pennsylvania Cancer Control Plan will remain involved in the actual implementation moving forward. But certainly there are other essential partners/players who need to be involved in actually getting the work of the Plan done. Who are they? Where are they? How do we find them? What can they do?

### ***What are the basic steps for successful implementation?***

1. Identify the key processes or activities required in the Plan
2. Cast a “wide net” for partners and organizations needed
3. Do a “risk analysis”—identify the tasks that need to be completed in order to achieve the objectives;
4. Assign responsibility for tasks
5. Prioritize activities and tasks
6. Forecast a reasonable timeline, which will also provide a total project time
7. Budget costs required
8. Take action!
9. Review and evaluate

### ***What can our partners and other organizations do to help attain the goals of the Plan?***

#### ***Community-based Organizations:***

- Provide cancer awareness information to your employees and constituents
- Promote cancer screenings among clients and link them to a Patient-Centered Medical Home (PCMH)
- Encourage participation in clinical trials
- Collaborate to provide community prevention programs

#### ***Employers/Businesses:***

- Provide healthy foods in vending machines and cafeterias
- Encourage employees to increase physical activity
- Collaborate with health care providers to host screening events
- Incentivize healthy behaviors

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### **Faith-based Organizations:**

- Provide cancer prevention information to members, including PCMH
- Encourage healthy potlucks and meeting meals/snacks
- Open your building for walking clubs in cold weather
- Promote compliance with recommended cancer screening guidelines

### **Hospitals and Healthcare Systems:**

- Provide cancer awareness information to your employees and patients
- Ensure your cancer cases are reported in a timely manner
- Provide meeting space for cancer support groups
- Collaborate to sponsor community screening programs/events
- Acquire or maintain American College of Surgeons certification

### **Insurance Companies/Payers:**

- Provide for tobacco addiction treatments
- Reimburse for nutrition and physical activity counseling and interventions
- Provide incentives to members who get recommend cancer screenings
- Provide full coverage for recommended cancer screenings
- Provide full coverage for cancer risk assessments and genetics testing

### **Local/State Public Health Agencies:**

- Provide cancer awareness information to your employees and community
- Facilitate healthy lifestyle campaigns
- Work with physicians to promote screening programs and case reporting
- Provide space for survivor support groups

### **Physicians and other health care providers:**

- Ensure patients get appropriate cancer screening tests
- Refer patients to smoking cessation resources/programs
- Be sure your cancer cases are reported in a timely manner
- Encourage patients to enroll in clinical trials
- Make earlier referrals to hospice for end of life care

### **Legislators/Polymakers:**

- Ensure appropriate funding for comprehensive cancer control
- Sponsor or support legislation that promotes cancer prevention and control
- Advocate for a statewide comprehensive smoke-free air bill
- Ensure that all Pennsylvanians have access to quality affordable health care

### **Professional Organizations:**

- Provide cancer awareness information to employees and constituents
- Promote cancer screening among clients
- Encourage participation in clinical trials
- Collaborate to provide community prevention programs

### **Survivors/Caregivers:**

- Share your experience to help educate the public about the needs of survivors and families
- Mentor survivors and families to be active participants in the medical decision making process
- Consider joining an advocacy group or organization working to improve survivors' quality of life

### **Educational Institutions (universities, colleges, school systems):**

- Include cancer prevention messages in health classes
- Provide healthy foods in vending machines and cafeterias
- Increase physical education requirements
- Make your entire campus smoke-free

### **Residents of Pennsylvania:**

- Stop using tobacco products or never start
- Eat more fruits and vegetables to help maintain a healthy weight
- Increase your daily physical activity
- Know when to be screened and do it on schedule
- If diagnosed, consider enrolling in a clinical trial
- Volunteer with your local hospital, faith community or community-based organization<sup>17</sup>

<sup>17</sup> Indiana Cancer Control Plan (2010-2014)

Texas Cancer Plan (2012)

Wisconsin Comprehensive Cancer Control Plan (2010-2015)

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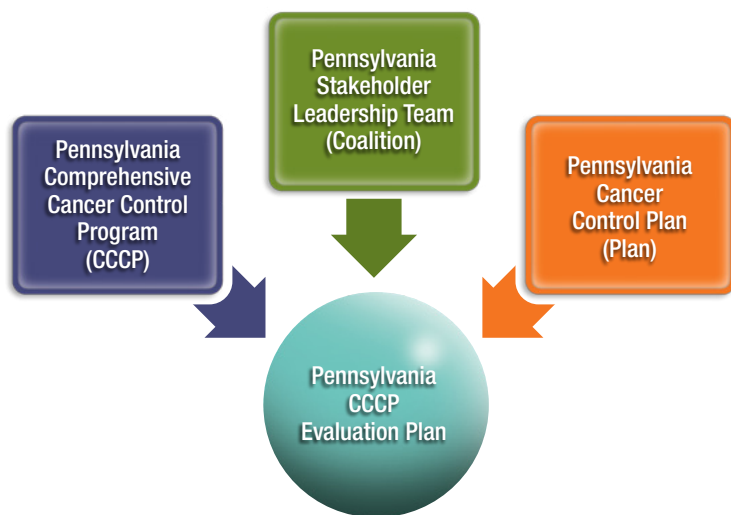
# EVALUATION

## Introduction

Program evaluation is a systematic way to improve and account for public health actions. Evaluation involves procedures to gain insight into whether strategies and interventions are achieving their desired result, improving program effectiveness, and making decisions about future planning. It allows people and organizations invested in the program to have a stake in what will be done with the results of the evaluation. Evaluation of Pennsylvania's cancer programs and initiatives stem from three powerful and integrated elements as illustrated below:

This structure supports The Centers for Disease Control and Prevention (CDC) requirement to focus upon three key aspects

of state-level cancer control activities: Program, Partnership and Planning to foster strong alliances and instill positive outcomes. Pennsylvania has an Evaluation Plan which describes the overall approach or design that guides evaluation activities. The Evaluation Plan is developed by the Evaluation Workgroup—members of the Stakeholder Leadership Team (SLT) leading evaluation efforts on behalf of the Coalition—and an external evaluator. Pennsylvania's Cancer Evaluation Plan utilizes evaluation data from these three components to promote and support an environment of ongoing quality improvement, foster data driven decisions and adapt to ever-changing program needs across the cancer care continuum.



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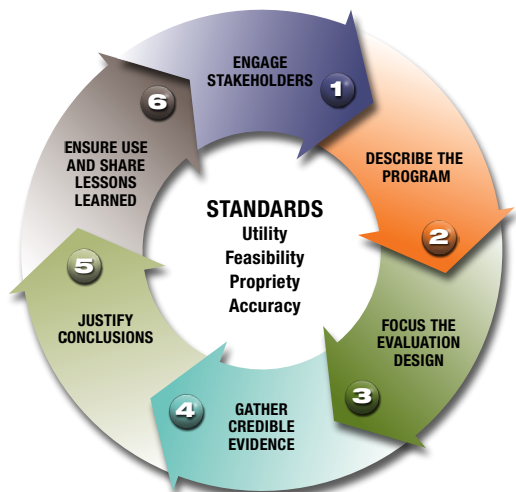
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## Evaluation Design and Methods

The evaluation design for Pennsylvania's Cancer Program includes four phases: planning, implementing, monitoring, and communicating. This phased approach ensures evaluation is utilized on an ongoing basis and strategies are purposeful, relative and sustainable throughout the process. In addition to these phases, the Evaluation Plan incorporates CDC's guiding principles via the six step framework for program evaluation in public health:



This approach focuses on CDC's key aspect of **Plan**; it ensures cancer control efforts are targeted, focused on proven science and data-driven, and available to the public. Different types of evaluation—formative, process, outcome, cost-effectiveness, comprehensive—enhance data collection, its usefulness and accuracy. The Evaluation Plan is flexible and employs the most appropriate type of evaluation within each phase according to the required need. Progression

through CDC's six step framework is not linear and occurs in tandem with the Program's existing cancer control efforts and the developmental phases of the Plan.

By focusing on the key aspects of Program, Partnership and Planning, the evaluation design generates overarching evaluation questions which, along with the SLT Coalition's input, form the foundation for Pennsylvania's cancer control efforts. On an annual basis, state-level cancer control efforts are reviewed and data-driven outcomes direct policy, systems and environmental (PSE) change. Utilizing this overarching evaluation strategy facilitates a comprehensive evaluation of chronic disease and risk factors associated with cancer. It drives Pennsylvania's ongoing cancer planning and selection of evaluation priorities and targeted activities, and sets the foundation to ensure Pennsylvania is well informed and poised for future healthcare change.

### Planning Phase:

During the initial planning phase, the SLT was formed reinforcing Pennsylvania's commitment to the key aspect of **Partnership**. To ensure evaluation was ongoing, the SLT formed the Evaluation Workgroup. Membership is voluntary but requires expertise in quality assurance/quality improvement and evaluation. Meetings occur monthly or as needed to review ongoing evaluation efforts. The Evaluation Workgroup, in collaboration with an outside evaluation contractor, is tasked to oversee evaluation efforts for all three activity areas: Plan, Partnership, and Program and be a conduit for ongoing recommendations.



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## Implementation Phase:

Utilizing the SLT and its workgroups a process evaluation method will be employed to track Plan progress via the reporting timeline (e.g. monthly, quarterly, annually). Workgroups will gather necessary data relative to their assignment, per the outlined timeline, for review and submit recommendations to the Evaluation Workgroup. The Evaluation Workgroup will receive copies of all sub-committee reports on an ongoing basis for the purpose of high-level review, comment and further recommendations, quality improvement action plans and report dissemination via the Communication Workgroup.

## Monitoring Phase:

The evaluation design incorporates Plan outcomes while interfacing with existing cancer control programs and their respective logic models to reinforce CDC's key aspect of **Program** on an ongoing basis. The monitoring phase of the Plan is continuous and ever-evolving. Cumulative Plan progress outcomes are monitored on an ongoing basis with concerns and/or questions being directed to the Evaluation Workgroup and Program

staff for collaborative resolution. Quarterly reviews by the Evaluation Workgroup will produce a quarterly communication report to all SLT workgroups on Plan status via various media. As required by CDC, the Evaluation Workgroup will design and craft an annual Evaluation Plan update outlining current and future evaluation activities and corrective actions for areas needing improvement. Pennsylvania's external contractor will develop evaluation tools for analysis and consistent tracking of Plan impact.

## Communication Phase:

Evaluation reports are released by the communications workgroup of the SLT who is responsible for creating dissemination strategies to release evaluation results and key findings, identifying targeted audiences, and selecting the type of media most appropriate. An annual report of program findings is released by the Cancer Advisory Board to the Governor and General Assembly.



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## APPENDICES

### Appendix 1 – Glossary of Terms

Click on keyword for source information.

**Accountable Care Organization (ACO)**—Groups of doctors, hospitals, and other health care providers, who come together voluntarily to give coordinated high quality care to their Medicare patients. Under health reform, ACO is expanding to include payer, i.e. insurance, organizations.

**Affordable Care Act**—A Federal health reform act intending to put individuals, families and businesses in better control of their health care (see also *Patient Protection and Affordable Care Act*)

**Bronchus**—Main branch of the trachea that goes into the lungs.

**Cancer Control**—The reduction of cancer incidence, morbidity, and mortality through an orderly sequence from research on interventions and their impact in defined populations to the broad, systematic application of the research results.

**Centers for Disease Control and Prevention (CDC)**—The federal agency increasing the national health security by conducting critical science and providing health information that protects the nation against expensive and dangerous health threats, and responds when they arise.

**Centers for Medicare & Medicaid Services (CMS)**—The federal agency that provides health coverage through Medicare, Medicaid, and the Children's Health Insurance Program (CHIP).

**Certified Rural Health Center (CRHC)**—Intended to increase primary care services for Medicaid and Medicare patients in rural communities. CRHCs can be public, private or non-profit, with the main advantage of RHC status is enhanced reimbursement rates for providing Medicaid and Medicare services in rural areas.

**Children's Health Insurance Program (CHIP)**—Provides health coverage to children in families with incomes too high to qualify for Medicaid, but can't afford private coverage. CHIP is administered by the states, but is jointly funded by the federal government and states.

**Chronic Disease**—Illness that is prolonged in duration, does not often resolve spontaneously, and is rarely cured completely.

**Chronic Disease Prevention and Health Promotion Domains (domains)**—Make measurable contributions to the prevention and control of chronic disease and by doing so, improve quality of life, increase life expectancy, improve the health of future generations, increase productivity and help control health care spending; through: 1) environmental approaches; 2) epidemiology and surveillance; 3) health system interventions; and 4) community-clinical linkages.

**Community Health Worker (CHW)**—The term Health Worker (CHW) as defined by the Department of Labor as Standard Occupational Classification means an individual who promotes health or nutrition within the community in which the individual resides: 1) By serving as a liaison between communities and health care agencies; 2) By providing guidance and



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social assistance to community residents; 3) By enhancing community residents' ability to effectively communicate with health care providers; 4) By providing culturally and linguistically appropriate health and nutrition education; 5) By advocating for individual and community health; 6) By providing referral and follow-up services or otherwise coordinating care; and 7) By proactively identifying and enrolling eligible individuals in federal, state, and local private or nonprofit health and human services programs.

**Comorbidities**—The presence of more than one disease or condition in the same person at the same time.

**Disparity (health)**—Differences in health among specific population groups that result from cumulative social disadvantages. (source: [Connecticut Department of Health](#))

**eHealth Partnership Authority**—Created through state legislation in July 2012 to improve healthcare delivery and outcomes in Pennsylvania by enabling the secure exchange of health information (see also HIE).

**Electronic Medical Record (EMR)**—Digital version of a paper chart that contains all of a patient's medical history from one practice.

**Environmental Scan**—Designed to help health system leaders better understand the health care landscape.

**Epidemiology**—The study of the distribution and determinants of health-related states in specified populations, and the application of this study to control health problems.

**Evidence-Based Practice**—The integration of best research evidence with clinical expertise and patient values to provide high-quality services reflecting the interests, values, needs, and choices of the individuals served.

**Federally Qualified Health Center (FQHC)**—community-based and patient-directed organization that serves populations with limited access to health care.

**Gain Sharing**—Aligns the incentives of physicians and hospitals to realize and share cost savings (source: [American Medical Association](#))

**Health Information Exchange (HIE)**—Electronic movement of health-related information among organizations according to nationally recognized standards whose goal is to facilitate access to and retrieval of clinical data to provide safer, timelier, efficient, effective, equitable, patient-centered care. (source: [Health Resources and Services Administration](#))

**Incidence**—The number of new cancers of a specific site/type occurring in a specified population during a year (source: [National Cancer Institute](#))

**Intervention**—Ability to recommend to the applicable lead agency (if not public health) and implement, if applicable, strategies for disease, injury, and exposure control. (source: [The Centers for Disease Control and Prevention](#))

**Medicaid**—The federal program that provides health coverage for lower-income people, families and children, the elderly, and people with disabilities. (source: [Healthcare.gov](#))

**Medicare**—The federal health insurance program for people age 65 or older, people under age 65 with certain disabilities, and people of all ages with End-Stage Renal Disease (ESRD or permanent kidney failure requiring dialysis or a kidney transplant). (source: [Centers for Medicare and Medicaid](#))

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**Metastatic**—When cancer that originates in a certain region in the body spreads to other areas of the body. (source: [The Centers for Disease Control and Prevention](#))

**Morbidity**—Relative incidence of disease. (source: [Merriam-Webster](#))

**Mortality (cancer)**—the number of deaths, with cancer as the underlying cause of death, occurring in a specified population during a year. (source: [National Cancer Institute](#))

**National Comprehensive Cancer Control Program (NCCCP)**—CDC program to promote healthy lifestyles and recommended cancer screenings, educate people about cancer symptoms, increase access to quality cancer care, and enhance cancer survivors' quality of life to reduce the burden of cancer in the United States. (source: [The Centers for Disease Control and Prevention](#))

**Outcomes (health)**—changes in individuals attributable to the care they received, such as changes in health status, changes in behavior of patients, and satisfaction of patients.

**AMA login required** (source: [American Medical Association](#))

**Optimization**—an act, process, or methodology of making something as fully perfect, functional, or effective as possible (source: [Merriam-Webster](#))

**Palliative Care**—Care given to improve the quality of life of patients who have a serious or life-threatening disease, such as cancer. The goal of palliative care is to prevent or treat, as early as possible, the symptoms and side effects of the disease and its treatment, in addition to the related psychological, social, and spiritual problems. (source: [National Cancer Institute](#))

**Patient-Centered Medical Home (PCMH)**—A medical home that focuses on comprehensive care, patient-centered care, coordinated care, accessible services, and quality and safety. (source: [Agency for Healthcare Research and Quality](#))

**Patient Navigation**—Provides patients with information that enhances their ability to make appropriate health care choices and/or receive medical care with an enhanced sense of confidence about risks, benefits and responsibilities. Patient navigators can provide patients with guidance in the health insurance marketplace, which is especially critical for patients who have low health literacy skills. **AMA login required** (source: [American Medical Association](#))

**Patient Protection and Affordable Care Act (ACA) of 2010**—An Act of health reform that intends to put individuals, families and small business owners in better control of their health care. It has potential to reduce premium costs for millions of working families and small businesses by providing hundreds of billions of dollars in tax relief. It also reduces what families will have to pay for health care by capping out-of-pocket expenses and requiring preventive care to be fully covered without any out-of-pocket expense. (source: [United States Department of Health and Human Services](#))

**Pennsylvania Cancer Control, Prevention and Research Advisory Board**—An 11-member board that meets quarterly and advises the Pennsylvania Secretary of Health on cancer control and prevention-related issues. (source: [PA.gov](#))

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**Policy/Systems/Environmental (PSE) Approaches**—Changes in areas such as laws and regulations, institutions and systems, and the social and physical environment that promote healthier living. (source: [Minnesota Department of Health](#))

**Primary Care**—Level of a health services system that provides entry into the system for all new needs and problems, provides person-focused (not disease-oriented) care over time, provides care for all but very uncommon or unusual conditions, and coordinates or integrates care, regardless of where the care is delivered and who provides it. (source: [John Hopkins Bloomberg School of Public Health](#))

**Psycho-Oncology (cancer survivorship)**—A field of interdisciplinary study and practice concerned with aspects of cancer that go beyond medical treatment and include lifestyle, psychological and social aspects of cancer. (source: [Wikipedia](#))

**Safety Net (patients)**—The uninsured and other vulnerable patients who pay a sliding discounted fee for primary care services. (source: [Coalition of Community Health Clinics](#))

**Social, Economic and Physical Determinants of Health**—Factors that contribute to a person's current state of health. (source: [The Centers for Disease Control and Prevention](#))

**Specialty Care**—Health care focused on improving the well-being of certain specialized categories of health, as opposed to general and overall health and well-being. (source: [Robert Wood Johnson Foundation](#))

**Stakeholder**—Project stakeholders are individuals and organizations that are actively involved in the project, or whose interests may be affected as a result of project execution or project completion. They may also exert influence over the project's objectives and outcomes. (source: [Wikipedia](#))

**State Health Care Innovation Plan (SHCIP)**—Broad vision and model design for health care system and payment transformation developed by Pennsylvania Governor's Office of Administration; eHealth Partnership Authority; and Departments of Aging, Health, Insurance and Public Welfare. (source: [PA.gov](#))

**Surveillance**—The ongoing systematic collection, analysis, and interpretation of data, closely integrated with the timely dissemination of these data to those responsible for preventing and controlling disease and injury. (source: [National Institute of Health](#))

**Survivorship**—Focuses on the health and life of a person with cancer post treatment until the end of life. It covers the physical, psychosocial, and economic issues of cancer, beyond the diagnosis and treatment phases. Survivorship includes issues related to the ability to get health care and follow-up treatment, late effects of treatment, second cancers, and quality of life. (source: [National Cancer Institute](#))

**Transitions of Care**—A set of actions designed to ensure the coordination and continuity of health care as patients transfer between different locations or different levels of care within the same location. (source: [The Care Transitions Program](#))

**Underinsured**—Refers to various degrees of being insured for some real risks and uninsured for others; almost 100,000 people died in the United States each year because of lack of needed care. (source: [The Commonwealth Fund](#))

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## Appendix 2 – Pennsylvania Cancer Control, Prevention And Research Advisory Board (CAB)



CATEGORY (mandated by law)	MEMBER NAME & AFFILIATION
Physician/Scientist, Chairperson	<b>Joel Noumoff, MD, Board Chairperson</b> Department of Gynecologic Oncology Crozer-Keystone Health System
Physician/Scientist	<b>Robert P. Edwards, MD</b> , Magee Gynecologic Cancer Program, University of Pittsburgh
Physician/Scientist	<b>Susanne Gollin, PhD, FFACMG</b> , Department of Human Genetics, University of Pittsburgh Graduate School of Public Health
Consumer	<b>Frances Barg, M.Ed., PhD</b> , Associate Professor of Family Medicine and Community Health, Hospital of the University of Pennsylvania
Consumer	<b>Patricia Halpin-Murphy</b> , President and Founder, Pennsylvania Breast Cancer Coalition, Breast Cancer Survivorship
Consumer	VACANT
Health Care Administrator	<b>Ada Rivera</b> , NCI Project Director Director of Quality & Data Management Oncology Services Lehigh Valley Health Network
Oncology Nurse	VACANT
Public Health Professional-Community Health Nurse	<b>Barbara E. Jackson, RN</b> , Founder/President CATALYST, Cancer Survivorship, Retired DOH nurse
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## Appendix 3 – Stakeholder Leadership Team (SLT) Coalition



CATEGORY	MEMBER NAME & AFFILIATION
Academic Institutions	<p><b>Linda Kanzleiter,*</b> Director, Center for Primary Care/Area Health Education Center (AHEC) Penn State University College of Medicine</p> <p><b>Dr. Harriet Isom,</b> Biomedical Sciences Graduate Program, Penn State Hershey Medical Center/College of Medicine</p> <p><b>Johanna Steenrod,</b> Graduate Researcher, Health Policy Institute University of Pittsburgh</p>
Breast and Cervical Cancer	<p><b>Jennifer Pensinger,</b> Executive Director</p> <p><b>Kristen Snoke,</b> Community Outreach Director, Pennsylvania Breast Cancer Coalition</p> <p><b>Lou Ann Jeremko,*</b> Director, Statewide Cancer Programs, Alliance of Pennsylvania Councils, Inc./Adagio Health</p>
Business and Industry	<p><b>Joseph Reilly,*</b> Director Shared Service Analytics, Highmark Blue Cross Blue Shield of Pennsylvania</p>
Cancer Advocacy	<p><b>Diane Phillips,*</b> Senior Director State &amp; Federal Policy American Cancer Society–Cancer Action Network</p> <p><b>NaDa Shoemaker,*</b> Program Manager, Strategic Health Partnership American Cancer Society, East Central Division</p>
Cancer Institutes	<p><b>Robert Durkin,**</b> President Northeast Regional Cancer Institute</p> <p><b>Evelyn Gonzalez,</b> Senior Director, Health Communications/Disparities Fox Chase Cancer Center</p>
Cancer Registry	<p><b>Robin Otto,</b> Registry Manager</p> <p><b>Michelle Esterly,</b> Database Manager, Pennsylvania Cancer Registry</p>

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Health Disparities	<b>Hector Ortiz</b> , Director, DOH Office of Health Equity
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Healthy Communities/Worksites	<b>Becca Raley</b> , Executive Director, Carlisle Area Health & Wellness Foundation
Managed Medicaid Program/ Pennsylvania HealthChoices	<b>Christine Brehm</b> , Committee Coordinator, AmeriHealth Caritas Health Plan

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Minority Based Organizations	<b>Barbara E. Jackson</b> , President, Central Pennsylvania Coalition United to Fight Cancer <b>Mauricio Conde</b> , Hispanic Community Advocate
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Current as of: June 30, 2013

\*workgroup (co)chair

\*\*interim chair

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