

New York State



Cancer Consortium

Working Together, Reducing Cancer, Saving Lives

ORIENTATION MANUAL

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WELCOME AND INTRODUCTION



Working Together, Reducing Cancer, Saving Lives

Thank you for your interest in the New York State Cancer Consortium. The Consortium is the network of organizations and individuals who are involved in implementing the New York State Comprehensive Cancer Control Plan.

The New York State Comprehensive Cancer Control Plan is the result of collaborations among organizations and individuals working in cancer control to coordinate activities, maximize resources and achieve desired cancer control outcomes. The Plan was developed with the participation of stakeholders throughout the state and the collection of input via community forums and surveys. The Plan has gone from the development phase, to the work group phase, and into local implementation of Plan priorities.

To continue the critical work undertaken by the Consortium, we welcome stakeholders from across the state. Whether you have a personal or professional interest in cancer control, are involved in work with a specific cancer or a broad-based issue faced by all people with cancer, work in a small community with a specific population or are part of a state-wide or national group, there is a role for you to play. You can begin by filling out our membership application where you can sign up for a Standing/Program Committee that addresses your particular interests and expertise within the cancer spectrum. You will have access to our bimonthly newsletter, the NYSCC Chronicle, providing information on what the NYSCC is doing. We will inform you of cancer-related events that are going on throughout the state, including: training opportunities, conferences, meetings, etc. Legislative happenings will be shared along with ways that you and the people you serve can affect change on a statewide level. Strategies, goals and objectives of member organizations will be shared. As a member, you can network in a much larger area, using the website, "The NYSCC Chronicle" and the NYSCC Facebook page to share your news and view the news of others.

With your help, we can make a difference in New York State. We can increase the number of New Yorkers working together, reducing cancer and saving lives.

Mark Cronin

Anita McFarlane, MPH

Co-Chairs NYSCC Steering Committee

Mission

The mission of New York State Cancer Consortium is to reduce the human and economic burden of cancer in New York State.

Vision

People concerned about cancer will work collaboratively to implement the New York State Comprehensive Cancer Control Plan, while respecting and embracing the cultural, demographic and geographic diversity within New York State.

***NEW YORK STATE COMPREHENSIVE
CANCER CONTROL PLAN***

New York State Comprehensive Cancer Control Partnership

Executive Summary

The New York State Comprehensive Cancer Control Plan (NYSCCCP) represents the collective input and commitment of hundreds of organizations and individuals throughout the State, with the goal of eliminating cancer as a major health problem for all New Yorkers. With support from the Centers for Disease Control & Prevention, stakeholders in New York have created a plan that envisions integrating the efforts of all those who care about reducing cancer in New York to enhance existing strengths in research, prevention, treatment and quality of life and build new initiatives in areas of unmet needs. The goals and strategies in the Plan are based on the principle of inclusive collaboration to ensure that all New Yorkers are reached by the best practices that are available to ultimately reduce the burden of cancer in New York State.

Why is Such a Major Effort Needed?

While we have made significant progress in New York over the last decade, primarily in reducing cancer mortality, much remains to be done to better prevent and control cancer. Cancer is one of the most common chronic diseases in New York State, and is second only to heart disease as the leading cause of death. An estimated 100,960 people will be diagnosed with cancer in New York State in 2007 — over 240 people each day of the year.¹ An estimated 35,270 New Yorkers will die from cancer — about 97 individuals each day. Four cancer sites account for 56% of the total cancer burden — lung, colorectal, breast and prostate cancers. These same four cancers are responsible for 51 percent of all cancer deaths in New York State.

What is Comprehensive Cancer Control (CCC)?

Comprehensive cancer control is defined as an integrated and coordinated approach to reducing cancer incidence, morbidity, and mortality through prevention, early detection, treatment, rehabilitation, and palliation. Comprehensive cancer control is achieved through a partnership of public and private stakeholders whose common mission is to reduce the overall burden of cancer. This partnership mobilizes support for implementing priorities, puts in place coordinated activities, monitors progress over time, and reassesses priorities periodically in light of emerging developments in cancer and related fields.

To be “comprehensive” a program must address the entire continuum of cancer services from primary prevention to end-of-life; be interdisciplinary, engaging all professions involved in cancer control; and be inclusive of all cancers, population groups, and geographic regions.

The concept of Comprehensive Cancer Control (CCC) was developed by the Centers for Disease Control, the American Cancer Society, the National Cancer Institute, and the American College of Surgeons. Statewide planning and implementation of CCC were spearheaded by these organizations and are funded through the CDC. For information on the CDC’s Comprehensive Cancer Control activities, access their web site at <http://www.cdc.gov/cancer/ncccp/index.htm>.

How Was the New York State CCC Plan Developed?

The New York State Comprehensive Cancer Control Plan (NYSCCCP) was developed over a period of about 18 months beginning in fall 2001. The plan development process was coordinated through the combined leadership of the American Cancer Society and the New York State Department of Health. This process involved the partnership of hundreds of people and organizations. A Core Work Group met monthly to coordinate the many facets of the Plan and to ensure broad-based participation. Other state plans were reviewed and used as models for the New York Plan. Stakeholder Surveys were sent to approximately 400 organizations and individuals to seek their ideas on key issues and solicit input on suggested goals and strategies. Nine Goal Development Teams

¹ Cancer Facts & Figures, 2007. American Cancer Society, Atlanta, GA
Created 2/07
Rev. 7/10

were created, comprised of 65 experts and advocates, around the nine goal areas of the Plan, and a preliminary set of goals and strategies were formed. Ten Community Forums were conducted across the State in which over 300 people reviewed and commented on a draft of the Plan. The forum comments were then incorporated into the Plan. A two-day Leadership Summit was held where experts and advocates met to provide a final review, comment on the Plan and indicate their commitment to the implementation process.

The Final Plan was released in September of 2003 and incorporates nine major goal areas:

- Health Promotion and Disease Prevention
- Early Detection
- Treatment
- Quality of Life
- Palliative Care
- Health Personnel
- Research
- Data and Surveillance
- Public Policy

How is the New York State Cancer Plan Being Carried Out?

Some of the accomplishments of the NYSCCCP to date are listed below:

- ❖ Statewide distribution of and communications about the Plan
- ❖ Demonstration projects in colorectal, prostate, ovarian and skin cancers carried out in various locations across the state
- ❖ Development of a Steering Committee and Implementation Workgroups (IWG) for each of the nine plan areas
- ❖ Implementation Workgroups developed work plans with local pilot projects and collaborative efforts in all the plan areas
- ❖ Quarterly meetings with the Cancer Center Directors for input and joint advocacy efforts with NYS Governor's Office
- ❖ Development of a new name, the New York State Cancer Consortium and a new governance structure which includes general membership, a steering committee, advisory committees, and standing committees
- ❖ Establishment of standing committees on Evaluation, Communications, Implementation, Membership, and Policy
- ❖ Local implementation collaborations with rural health networks and other local stakeholders throughout the state underway or in planning stages
- ❖ Collaboration on the successful "Dialogue for Action" colorectal cancer grant application which funded a statewide meeting in 2006
- ❖ In order to further the implementation phase, those involved with the NYS Comprehensive Cancer Control Plan identified the need to reorganize. Our new name, The New York State Cancer Consortium, was adopted in April 2006 and a new Governance Model and Operational Guidelines were adopted in May 2006 to further this implementation.

Where Do We Go From Here?

Many of the goals of the New York State Comprehensive Cancer Control Plan are set for 2010. As we approach that milestone, the Plan effort will include the following activities:

- ❖ Continued planning, consultation and activities throughout the state
- ❖ Collaborative efforts with the Cancer Center Directors group to advance comprehensive cancer control, especially in state government

- ❖ Expanded local implementation of the plan, including provision of guidance, two-way communication of best practices and other initiatives to enhance community efforts in reducing the burden of cancer
- ❖ Continued outreach to ensure that New Yorkers of all racial, ethnic, socioeconomic, geographic and cultural backgrounds are included as important stakeholders in Plan efforts
- ❖ Tracking, evaluation and public reporting of progress towards Plan goals

To implement these initiatives and reach the challenging goals embodied in the Plan, this effort needs the commitment of all New Yorkers. Please consider joining in the effort to eliminate cancer as a major health problem for New York.

For more information on the New York State Comprehensive Cancer Control Plan and to obtain a membership application:

- ❖ Visit on the web at: <http://www.nyscancerconsortium.org/>
- ❖ Or contact us: nyscccp@cancer.org

HISTORY

What is the Comprehensive Cancer Control Plan?

- A collaboration among organizations and individuals working to coordinate cancer control activities in order to maximize resources and achieve desired outcomes
- It addresses the continuum of cancer from primary prevention through end of life care.
- It includes all major cancers, population groups, and geographic areas in the state.
- It was created based upon the input from several professional backgrounds, including: administration, research, evaluation, health education, program development, public policy, surveillance, clinical services and health communications.

History

- *Comprehensive Cancer Control Plan Leadership Institute* (October 2001)
 - NYS DOH, ACS, ACoS State Chairs and Others
- *Stakeholder Surveys* (June 2002)
 - Over 400 Surveys Distributed
- *Goal Development Teams* (June – November 2002)
- *Community Forums* (January 2003)
 - Ten Statewide
- *Draft Plan* (February – March 2003)
- *Leadership Summit* (March 21 & 22)
- *Developed Evaluation Component* (January – April 2003)
- *Revise/Finalize Plan* (by October 2003)
- *Implementation Workgroups (IWG) developed work plans* (June 2004 – September 2004)
- *Implementation* (September 2004 – 2010)

Structure

- The plan is broken down into nine different plan areas
 - **Health Promotion and Disease Prevention** addresses environmental and behavioral factors (i.e. smoking, diet, etc) leading to cancer, as well as genetics
 - **Early Detection** works to increase identification of cancers at an early stage to increase likelihood of successful treatment.
 - **Treatment** focuses on providing effective, high quality, accessible and affordable cancer treatment
 - **Quality of Life** focuses on improving the lives of individuals with cancer and their families through psychosocial services, self-advocacy, teenage and children's services, etc.
 - **Palliative Care** focuses on maintaining culturally sensitive and competent care in pain management, symptom control and spiritual care
 - **Health Personnel** addresses the need for recruiting and maintaining trained and qualified personnel to provide cancer related care
 - **Research** works to ensure that New York State continues to lead the way in cancer research
 - **Data & Surveillance** works to strengthen the existing surveillance systems in NYS to support greater collaboration between clinical, public health, and research professionals, and to disseminate data relevant to cancer control.
 - **Public Policy** encourages the creation of policies that supports efforts in prevention and response to acute care needs on levels such as family, employer, community and government.

TIMELINE

Pre-plan strategizing	Plan Development		Plan Implementation		
2001	2002	2003	2004	2005	2006
<p><u>October</u> CCCLI-I* New York State begins planning process. Core Work Group is formed.</p>	<p><u>April/May</u> Potential stakeholders identified and contacted about joining the NYSCCCP</p> <p><u>June</u> Over 400 surveys distributed to stakeholders across NYS.</p> <p><u>June – November</u> Goal Development Teams meet; develop initial goals and strategies for the Plan.</p>	<p><u>January</u> Community Forums: 10 held statewide to gather input on goals and strategies developed.</p> <p><u>January – April</u> Evaluation component developed</p> <p><u>February</u> Initial Draft Plan created.</p> <p><u>March 21 & 22</u> Leadership Summit: draft Plan reviewed by stakeholders.</p> <p><u>October</u> Plan content is finalized. Plan is sent out for graphic design and printing.</p> <p>NYSDOH Commissioner of Health and ACS Chief Executive Officer hold press conference and release Plan.</p>	<p><u>January</u> Plan is published and distributed to stakeholders statewide.</p> <p><u>January – June</u> Core Work Group reorganizes as the Steering Committee.</p> <p>Steering Committee develops implementation plan, orientation materials for workgroups, and plans for coming year.</p> <p><u>June – September</u> Implementation Workgroups meet; develop work plans for implementation of each of the nine goal areas of the Plan.</p> <p><u>October</u> CCCLI-II New York State convenes team to review Plan and strategize implementation priorities.</p>	<p><u>September 2004 – December 2005</u> Workgroups continue to undertake implementation activities. Steering Committee meets bi-monthly to guide process.</p> <p><u>June</u> 1st Annual Stakeholders Summit held.</p> <p><u>December</u> Steering Committee convenes ad hoc Governance Committee to revise implementation process to allow for growth and create concrete identity.</p>	<p><u>January – March</u> Governance Committee develops Mission and Vision statements, operational guidelines and organizational structure. Presents to Steering Committee for review. Steering Committee accepts recommendations.</p> <p><u>March – August</u> Governance Committee develops membership application, finalizes proposed structure, develops transition plan. Steering Committee accepts.</p> <p><u>April</u> New name, NYS Cancer Consortium adopted. 1st meeting of the Central New York Cancer Coalition.</p> <p><u>May</u> New Governance Model adopted. 2nd Annual Stakeholders Summit held.</p> <p><u>June</u> CCCLI-III New York State team convenes to align goals with priorities defined by national partners, develop strategies for coming year.</p> <p><u>August</u> 1st meeting of the Dutchess Co. Cancer Coalition.</p> <p><u>September</u> Membership applications sent to stakeholders across NYS.</p> <p><u>October</u> 2nd Meeting of the Central New York Cancer Consortium.</p> <p>Recommendations for new members, new Steering Committee are proposed. Steering Committee accepts.</p> <p><u>December</u> Transition of existing Steering Committee and new Steering Committee occurs. Transition to new structure complete, implementation continues.</p>

*CCCLI– Comprehensive Cancer Control Leadership Institute, sponsored by the CDC.

***NYS CANCER CONSORTIUM
OPERATIONAL GUIDELINES***

NYS Cancer Consortium Operational Guidelines
Adopted May 9, 2006
Revised Dec. 12, 2007

Mission

The mission of New York State Cancer Consortium is to reduce the human and economic burden of cancer in New York State.

Vision

People concerned about cancer will work collaboratively to implement the New York State Comprehensive Cancer Control Plan, while respecting and embracing the cultural, demographic and geographic diversity within New York State.

I. MEMBERSHIP

- a. Membership is open to individuals and organizations that support the goals of the New York State Comprehensive Cancer Control Plan.
- b. All members will receive communications and updates on Plan activities, and will be given an opportunity to participate in all aspects of NYS Comprehensive Cancer Control activities.
- c. Levels of Membership
 - General
 - Steering Committee Member
 - Standing/Program Committee Member
- d. Applying for Membership
 - All members shall complete and sign a Membership Application and Disclosure Statement for any potential conflicts of interest.
 - Membership will be granted at the discretion of the Steering Committee.

II. STEERING COMMITTEE MEMBERSHIP

- a. Steering Committee shall be made up of 20 to 25 members
- b. Principles of Representation
 - The Steering Committee may include individuals, and public and private organizations that represent the voices of their constituency to the Consortium.
 - Steering Committee membership will reflect the cultural, demographic and geographic diversity of New York State.
- c. Number of meetings/year
 - Six meetings per year: 3 conference calls and 3 in-person meetings.
- d. Participation Requirements
 - Minimum of 4 meetings annually.

III. STEERING COMMITTEE RESPONSIBILITIES

Purpose: Steering committee of the New York State Cancer Consortium is responsible for overseeing the implementation and evaluation of the Plan. This will be accomplished by a review of the emerging policy issues, development of a Consortium advocacy agenda and education of the membership through the Consortium Standing Committees, website, Chronicle and other communication venues.

- a. Leadership responsibilities include:
 - Strategic planning & review of progress
 - Liaison with committees
 - Develop policy
 - Review actions and committee recommendations
 - Review recommendations of Membership Committee

- b. Decisions will occur by consensus

IV. OFFICERS

a. Positions

- Chair or Co-Chairs
- Vice Chair (if there is no co-chair)
- Secretary
- Immediate Past Chair(s)

b. Process for appointment

- Membership Committee to solicit recommendations for officers.
- Officers must be current members of the Steering Committee and have served on the Steering Committee for at least one full year.
- Steering Committee to appoint officers using consensus model.
- Term of office is two years.

V. ADVISORY COMMITTEES

Purpose: Committees created to assist the Steering Committee in providing direction and focus for the NYSCC.

a. Cancer Center Directors

- Provide expertise and priority guidance
- Serve as advocates for key cancer control issues

b. Policy Committee

- Provides updates on relevant legislation relative to the New York State Cancer Consortium
- Develops legislative policy/advocacy agenda
- Develops policy/procedures for statewide communications
- Acts as a resource to all committees.

VI. STANDING COMMITTEES

Purpose & Membership

Committees created to support the infrastructure and ensure progress of the New York State Cancer Consortium. Each Standing Committee shall include a representative from the Steering Committee (designee/alternate) and at least four other persons representing either organizational or individual membership.

Each Standing Committee shall ensure that members represent the diversity of the State and that the Committee's activities reflect a commitment to supporting the NYSCC mission and vision.

a. **Communications Committee**

- Provides statewide oversight of communications, promotional materials, press releases, etc. related to the New York State Cancer Consortium
- Develops policy/procedures for statewide communications
- Resource to other committees as needed

b. **Evaluation Committee**

- Provides oversight on measuring progress toward achieving plan goals.
- Provides quality assurance of implementation activities.
- Collaborates with Implementation Committee to develop framework for process and outcome evaluation of local implementation activities.

c. **Membership Committee**

- Develops policies/procedures
- Solicits recommendations for Chair(s), Vice Chair and Secretary

- Develops process for membership recruitment/orientation/retention
- Reviews membership applications and disclosure statements and make recommendations to Steering Committee for approval

d. Ad Hoc Committees

- Steering committee may create ad hoc committees as needed; short term committee to be dissolved when assignment completed

VII. PROGRAM COMMITTEES

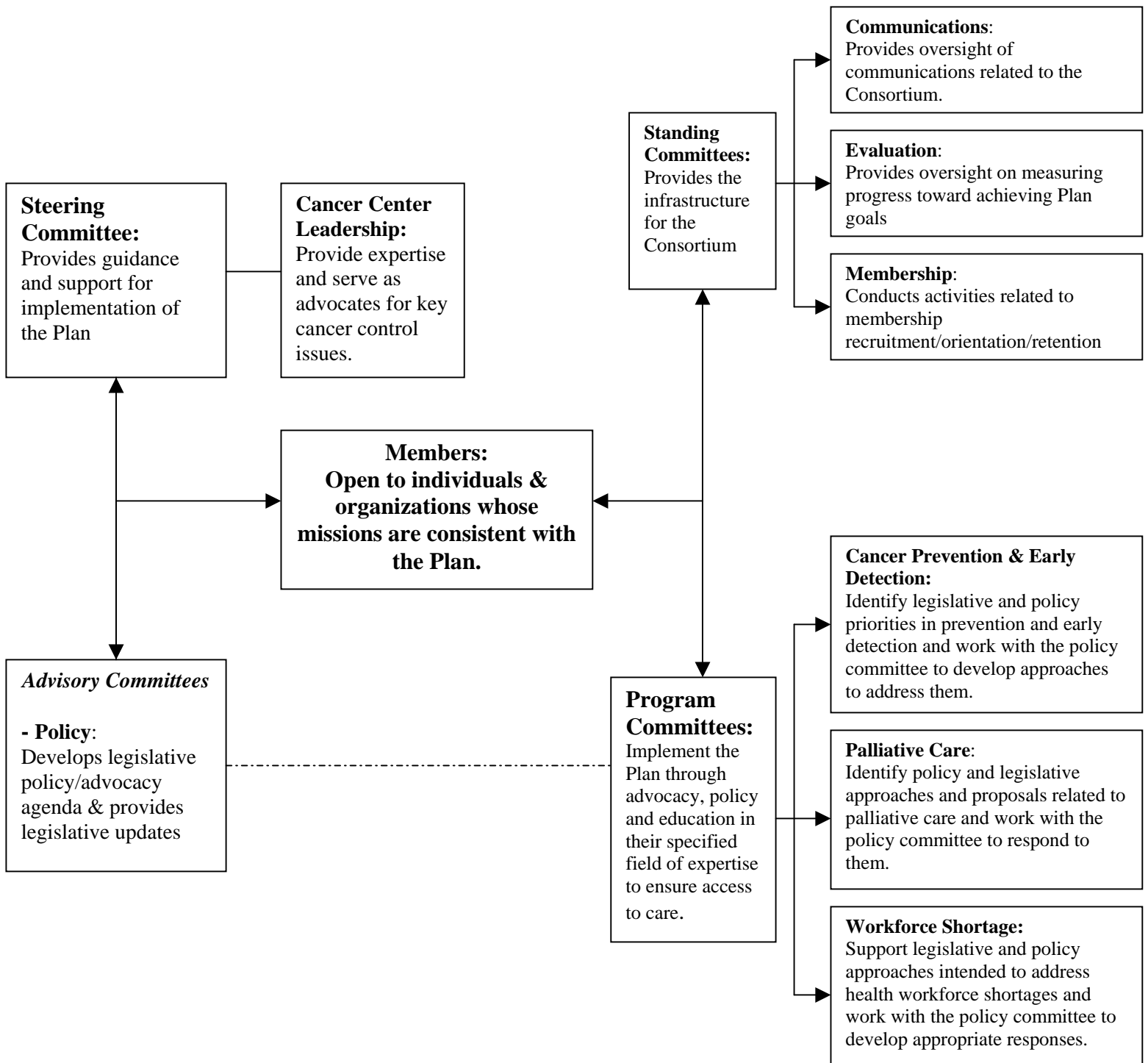
Purpose and Membership

Committees created to implement the Plan through advocacy, policy and education in their specified field of expertise to ensure access to care for all New Yorkers. Each Program Committee shall include a representative from the Steering Committee (designee/alternate) and at least four other persons representing either organizational or individual membership.

Program Committees are not permanent committees and will be altered according to the focus of the NYSCC determined by the Steering Committee.

ORGANIZATIONAL CHART

**New York State Cancer Consortium
Organizational Chart 2009**



MEMBERSHIP INFORMATION

Membership in the NYS Cancer Consortium is open to individuals and organizations that support the goals of the New York State Comprehensive Cancer Control Plan. All members will receive communications and updates on Plan activities, and will be given an opportunity to participate in all aspects of NYS Comprehensive Cancer Control activities.

Levels of Membership

- General
- Steering Committee Member
- Standing/Program Committee Member

Applying for Membership

- All members shall complete and sign a Membership Application and Disclosure Statement for any potential conflicts of interest.
- Membership will be granted at the discretion of the Steering Committee.

For more information, please contact Kristina Hawes by e-mail at nyscccp@cancer.org, or at 585-224-4915. Thank you for joining the NYS Cancer Consortium in its fight against cancer!



Membership Application Form

Membership Agreement:

Membership is open to individuals and organizations (and/or organizational units) whose goals are consistent with those of the New York State Cancer Consortium. Each member agrees to:

- Endorse the mission of the Consortium;
- Act in accordance with the Operational Guidelines;
- Be identified as a Consortium member, or member organization, in publications, lists or other appropriate contexts;
- Support efforts to evaluate Consortium activities, including providing information about the cancer control activities in which you and/or your organization are involved.;
- Support the commitment to respect diversity and address health disparities;
- Coordinate and collaborate with other organizations and within their own organization to implement strategies that address one or more of the Consortium's goals.

Applicant Information:

Name: _____

Title: _____

Organization: _____

Address: _____

City/State/Zip: _____

County: _____ Phone: _____ Fax: _____

E-mail: _____

Does your organization cover more than the county/geography listed above? If so, what other counties/geographies does it encompass?

Signature: _____ **Date:** _____

Alternate Contact Name and E-mail

Name: _____

E-mail: _____

Please indicate those committees on which you are interested in serving and/or have expertise, as openings arise:

INFRASTRUCTURE/STANDING COMMITTEES:

- Communications:** Provides oversight of Consortium-related communications.
- Evaluation:** Provides oversight on measuring progress toward achieving Plan Goals.
- Membership:** Conducts activities related to membership recruitment/orientation/retention.

PROGRAM COMMITTEES:

- Cancer Prevention & Early Detection:** Identify legislative and policy priorities in prevention and early detection.
- Palliative Care:** Identify policy and legislative approaches and proposals related to palliative care work with the policy committee to respond to them
- Workforce Shortages:** Support legislative and policy approaches intended to address health workforce shortages and work with the policy committee to develop appropriate responses.

If you have selected a Program or Advisory Committee, what type of experience/expertise do you have in the selected area(s)?

Conflict of Interest Policy:

New York State Cancer Consortium members shall not be financially interested in any action made by the Consortium or any action they take in their capacity as a Consortium member.

A New York State Cancer Consortium member, who maintains a direct or indirect financial interest in any action considered by the Consortium, shall disclose the interest during the Consortium meeting and have the disclosure specifically noted in the minutes of that meeting. The affected Consortium member shall not vote or debate the matter in conflict or attempt to influence any other Consortium member on the subject in question.

A member of the New York State Cancer Consortium shall not accept compensation, gifts, favors or other benefits from any individual, firm or organization for work performed as a Consortium member.

The New York State Cancer Consortium shall not endorse any person, company, product or procedure without the specific approval of the Steering Committee. Any contributions from corporations or foundations will be disclosed by the New York State Cancer Consortium to its members and the public.

New York State Cancer Consortium members shall not use their official capacity in the Consortium to solicit or otherwise influence others for personal reasons or benefits.

I have read and agree to the New York State Cancer Consortium Conflict of Interest Policy.

Signature: _____

Date: _____

COMMITTEES

Standing Committees

Communications Committee

- The Communications Committee is to provide statewide oversight of communications, promotional materials, press releases, etc. related to the NYSCC. The committee members work with the objective of informing members of the NYSCC and others interested in cancer control of activities, initiatives, opportunities, and best practices that are occurring throughout New York State.

Evaluation Committee

- The Evaluation Committee is responsible for providing oversight on measuring progress toward achieving plan goals and to develop a framework for the evaluation of implementation activities within the state. Primary activities of the evaluation committee include identifying and gathering data as well as developing documents to share outcomes with interested stakeholders.

Membership Committee

- The Membership Committee is responsible for reviewing all membership applications and disclosure statements sent to the NYSCC and making recommendations to the Steering Committee for approval of membership. From these applications, the Membership Committee solicits recommendations for Chair(s) and Secretary. The Committee also develops processes for membership recruitment/orientation/retention in order to ensure that the NYSCC represents the demographic, geographic and cultural diversity of New York State.

Program Committees

Cancer Prevention & Early Detection

- The Cancer Prevention & Early Detection Program Committee is charged with identifying legislative and policy priorities in prevention and early detection and working with the policy committee to develop approaches to address them.

Palliative Care

- The Palliative Care Program Committee is charged with identifying policy and legislative approaches and proposals related to palliative care and working with the policy committee to respond to them.

Workforce Shortages

- The Workforce Shortages Program Committee is charged with supporting legislative and policy approaches intended to address health workforce shortages and working with the policy committee to develop appropriate responses.

Program Committees are not permanent committees and will be altered according to the focus of the NYSCC as determined by the Steering Committee.

Steering Committee

- The Steering Committee is responsible for overseeing the implementation and evaluation of the New York State Comprehensive Cancer Control Plan. The members must attend a minimum of four out of six meetings annually, with three face-to-face meetings and three conference calls. All decisions are reached by consensus. All members and officers serve a two-year term.
- Members are expected to:
 - Bring passion and commitment to the fight against cancer.
 - Discuss and debate major issues related to cancer and work together to develop, implement and promote activities that advance our identified priorities and focus areas.
 - Actively promote the New York State Cancer Consortium, connecting NYSCC to people and organizations that can help us further our mission.

- Participate in one or more committees. Participation in ad hoc committees formed to address specific issues may be requested.
- Serve as a representative from your community to the New York State Cancer Consortium.
- Participate in the development of any strategic planning activities, including revision of the Comprehensive Cancer Control Plan or documents developed to amend the original.
- Attend four of six board meetings held annually.
- Represent the Consortium at conferences, meetings, leadership institutes and other venues in which there are networking opportunities.
- Provide dynamic leadership, guidance and follow through to activities identified as critical to supporting the identified priority areas.

Advisory Committees

Policy Committee

- The **Policy Committee** develops legislative policy/advocacy agenda for the NYSCC and provides Legislative updates. It acts as an advisor to all Program Committees in their efforts to implement the plan through advocacy, policy and education in their specified field of expertise.

Cancer Center Leadership

- An important resource to the NYSCC is the advice and direction given by New York State Cancer Center Leadership Advisory Group. With the input and expertise of this group, the NYSCC prioritizes goals listed in the New York State Comprehensive Cancer Control Plan. The Cancer Center Leadership also serves as advocates for key cancer control issues.

IMPLEMENTATION TOOLS

Grants

Links to local, state and federal grant information and assistance.

Introduction to Cancer Control Data

There are a wide variety of types of data that are useful for cancer control. These data may be grouped into four basic categories: epidemiological (e.g., incidence rates); risk factors (e.g., % of adults who smoke); demographic (e.g., % population which is Hispanic); economic or cultural (e.g., median household income, % of population regularly attending religious services).

Epidemiological data such as incidence and mortality rates, percent cases detected at early stages, proportion of adults 50 and older with colorectal cancer screening are the primary sources of data used in cancer control. However, these data represent a starting point, as they focus on the burden or the problem at hand (e.g., too few adults being screened for cancer). To move further and identify barriers (e.g., language, cultural) and solutions (e.g., increased insurance coverage) require use of risk factor, demographic, economic and cultural data. Furthermore, quantitative (numerical) data must always be combined with community knowledge of how people work and how the institutions that influence them are organized and function.

Primer on Cancer-Control Data

What are the most important kinds of cancer data?

Incidence: Incidence data normally tells you how many people are newly diagnosed with cancer within a given timeframe. These figures are often averaged over a 5- year period to avoid misinterpreting a one-year random fluctuation in the number of new cases as evidence of some important new trend. By averaging over 5 years, we can be reasonably confident that any changes that occur over time represent real trends.

Mortality: Mortality data tell us how many people died from cancer within a given timeframe. These figures are also averaged over 5 years to ensure statistically relevant findings and interpretation.

Staging: Since cancers detected at an early stage in development are more treatable than those diagnosed at a later stage, knowing what proportion of cancers are caught early is very useful. Along with incidence and mortality data, the state cancer registries track the percentage of all cases, which are diagnosed at an early stage. For example, the New Jersey state cancer registry reported that for the 1995-1999 period, 39% of all cases of colorectal cancer were diagnosed at an early stage. Since we know that this cancer is highly detectable if people are screened according to ACS guidelines, this low early stage detection percentage tells us that there is great potential for saving lives by catching colorectal cancer earlier.

NOTE:

Counts vs. Rates: Incidence and mortality data are presented as either counts or rates. Counts are the **actual number** of new diagnoses of cancer, or deaths within a given year. Rates are usually presented as the number of cases or deaths per 100,000 people in the county, state or nation. Rates therefore are useful in making comparisons across geographic regions or among racial or ethnic groups of different sizes. As an example: Say Jackson county has 400 cases of cancer diagnosed in a given year and the county population is 200,000. In this case, the incidence count would be 400, but the incidence rate would be 200 per 100,000 persons. (400 cases divided by 200,000/100,000).

Age-Adjustment: Age is the number one predictor of cancer; most cases are diagnosed among people greater than 50 years of age. Since different population sub-groups and different geographic areas have different age distributions, we cannot simply compare rates. Age-adjustment corrects for age differences in populations by weighting the data by the US Standard Population from the 2000 Census. This way we can remove all effect of different age distributions and allow comparisons across different geographic areas and among different population groups. All incidence and mortality data provided by ACS is age-adjusted.

Finding & Using Evidence-Based Initiatives

Evidence-based initiatives are based on prior research and evaluation findings. When beginning the implementation stage of cancer control, finding and using evidence-based initiatives is a very important step to the success of your implementation efforts. These initiatives have been shown to be effective in the populations and settings in which they were studied. It is more likely to ensure success from the adoption/adaptation of an evidence-based initiative, which has been systematically tested in the field, than to create a new program for the same population delivered in the same setting.

Cancer Control Planet (<http://cancercontrolplanet.cancer.gov/index.html>)

A web portal that hosts a site listing Research Tested Intervention Programs or RTIPs that can be used to find cancer related initiatives. These programs provide a catalog of best practices countrywide. The New York State Cancer Consortium has been compiling a list of suggested activities addressing cancer control from its members. While these activities are in different stages of development/implementation, the listing acts as a catalog of best practices in New York State.

Recommended Activities from NYSCC Members

The NYSCC has compiled a list of activities recommended by members of the state plan work groups. The members were asked to recommend concrete, evidence-based activities that they had been involved with or knew enough of to recommend as useful cancer control activities that can be taken on by local organizations or coalitions. Each activity has been or will be implemented in New York State. Adaptation may be necessary if activities are to be implemented in other locations or with other populations.

Research Tested Intervention Programs (RTIPs) (<http://cancercontrol.cancer.gov/rtips/>)

Sponsored by NCI and SAMHSA, the RTIPs link can be reached through the Cancer Control Planet homepage (Click on the hyperlink next to Step 4). The RTIPs site includes programs spanning the topics of tobacco control, physical activity, sun safety, breast, cervical, and colorectal cancer screening, informed decision making for cancer screening, 5 A Day, and diet. All programs listed were tested in a peer-reviewed and funded research study and were published in a

peer-reviewed journal. The website serves as a list of cancer control programs from across the United States and is updated on an ongoing basis.

Guidelines for Choosing and Adapting Programs

(http://cancercontrol.cancer.gov/rtips/adaptation_guidelines.pdf)

It is expected that once an evidence-based initiative is found, adjustments might be needed to adapt the program for your particular audience and setting. It is important to understand that each RTIP was evaluated for effectiveness within a highly controlled research study and that the recommended activities from NYSCC members were not formally evaluated for effectiveness. The [Guidelines for Choosing and Adapting Programs](#) has been made available by NCI and SAMHSA to aid in the adaptation process.

Using What Works: Adapting Evidence-Based Programs to Fit Your Need

(http://cancercontrol.cancer.gov/rtips/use_what_works/start.htm)

Using What Works: Adapting Evidence-Based Programs to Fit Your Needs is a train-the-trainer course available through Cancer Control Planet. It is designed for health promoters and educators on the national, regional, state, and local levels. This course teaches users how to plan a health program using evidence-based or research-tested programs.

Using Data Effectively

Provides an overview of cancer data, how to interpret them and how to apply them to relationships with partners.

NYSCC Website: What Can You Find?

(www.nyscancerconsortium.org)

- **About Us:** Find a listing of members and their organizations as well as a map of member distribution across the state (http://nyscancerconsortium.org/about/about_index.aspx)
- **Tools and Resources:** In order to better serve our members and all residents of New York State, the NYSCC has compiled many documents, tools and links that can be used to further cancer control efforts throughout the state. From finding cancer information and data, to planning and evaluating programs in cancer control, we have amassed a library of resources to assist in your endeavors. (http://nyscancerconsortium.org/resources/resources_index.aspx)
- **NYSCC Local Implementation Toolkit:** The NYSCC Local Implementation Toolkit is an interactive compilation created to aid those in New York State interested in local implementation efforts.

The toolkit is by no means a comprehensive document, but a starting point based upon the success of similar efforts throughout New York State. Users will be given the steps for planning and implementing the Comprehensive Cancer Control in their community. Templates of materials that can be used in this effort will also be made available.

We recognize that each community in NYS is unique and diverse, thus this toolkit is meant to serve as a guide. Sections of this toolkit will need to be modified based upon the

implementation area's demographic, cultural and geographic composition and the area's need. (http://nyscancerconsortium.org/resources/resources_toolkit.aspx)

- **Calendar:** We post Committee meetings, Conferences, Trainings and Miscellaneous Events on the Calendar on the website. Events can be submitted through the website and the calendar can be viewed on the right hand side of the homepage. (<http://nyscancerconsortium.org>)
- **News:** News is posted on our website. These items are often information about members, updates, cancer news, reminders, etc. You can also find copies of the NYSCC Chronicle. (http://nyscancerconsortium.org/News/News_Forms.aspx)