

# The CCC National Partnership: an example of organizations collaborating on comprehensive cancer control

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**Abstract** The landscape of cancer control has changed throughout the past 12 years and continues to change even more so as health reform is implemented in the United States. With the advent of health reform, coalitions, such as comprehensive cancer control (CCC) coalitions, are more important than ever if the intended benefits of reform are to be realized. Comprehensive cancer control (CCC) coalitions in state, tribe, territory, and Pacific Island Jurisdictions are “engines of change” and form a network that can facilitate important cancer control progress throughout this country. Since the onset of CCC efforts, the vitality of this network of coalitions and their sustainability has been the primary focus of a group of national organizations, now known as the Comprehensive Cancer Control National Partnership (CCCNP). The CCCNP is national organizations who come together voluntarily to develop strategies and resources that support implementation of CCC coalition plans across the nation.

**Keywords** Comprehensive cancer control · Coalitions · National Partnership

## Introduction

The landscape of cancer control has changed throughout the past 12 years and continues to change even more so as health reform is implemented in the United States. With the advent of health reform, coalitions, such as comprehensive cancer control (CCC) coalitions, are more important than ever if the intended benefits of reform are to be realized.

Comprehensive cancer control (CCC) is a process through which communities and partner organizations pool resources to reduce the burden of cancer. These combined efforts help to reduce cancer risk, find cancers earlier, improve treatments, and increase the number of people who survive cancer [1]. There are specific parts of the health reform package that impact directly on the goals of CCC as well as many CCC coalitions across the nation. In addition, there are new opportunities under health reform that will provide CCC coalitions with an increased likelihood they can achieve these goals. Many health reform provisions could provide opportunities to further CCC efforts, such as:

- New rules for coverage for clinical trials participants.
- A new national public–private partnership for prevention and health promotion outreach.
- New coverage provisions for payment for preventive health services.
- State demonstration projects for employer run wellness programs.
- Standardized data collection across states to address health disparities.

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- Coverage provisions to assist many of the Nation's uninsured seeking care.
- Multiple workforce provisions including training opportunities for both public health and clinical specialties.
- Testing and demonstration of innovative models for payment and service delivery [2].

Changes that are needed require not only good national policy and leadership but also “engines of change” that spark collective action at all levels of society. Comprehensive cancer control coalitions in state, tribe or tribal organizations, territory, and Pacific Island Jurisdictions are such engines of change.

Since the beginning of CCC efforts in the United States, the vitality of this network of coalitions and their sustainability has been the primary focus of a group of national organizations, now known as the Comprehensive Cancer Control National Partnership (CCCNP). The CCCNP today is made up of 15 national organizations that voluntarily develop strategies and resources that support implementation of CCC coalition plans across the nation. The National Partner member organizations as of July 2010 are:

1. American Cancer Society (ACS)
2. American Cancer Society Cancer Action Network (ACS-CAN)
3. American College of Surgeons Commission on Cancer (ACOS)
4. Association of State and Territorial Health Officers (ASTHO)
5. C-Change
6. Centers for Disease Control and Prevention (CDC)
7. Health Resources and Services Administration (HRSA)
8. Intercultural Cancer Council (ICC)
9. Lance Armstrong Foundation (LAF)
10. Leukemia and Lymphoma Society (LLS)
11. National Association of Chronic Disease Directors (NACDD)
12. National Association of County and City Health Officials (NACCHO)
13. North American Association of Central Cancer Registries (NAACCR)
14. National Cancer Institute (NCI)
15. Susan G. Komen for the Cure

Assisting CCC coalitions as they respond to the changing landscape of health care systems is a priority of the CCCNP. CCC coalitions face challenges that the CCCNP must continue to help address. These include:

- identifying and addressing opportunities and challenges with health care reform,
- identifying new strategies to assure resourcing for implementing CCC plans,

- updating and revising CCC plans to reflect changes in evidence-based interventions, and
- managing the typical coalition development issues associated with sustaining member interest, membership recruitment and retention over long periods of time.

### The history of the national partnership

In the early 1990s, the idea emerged that a comprehensive approach to cancer control may enhance and coordinate the efforts of programs that focus on individual types of cancer. A group of national organizations, including the Centers for Disease Control and Prevention (CDC), the American Cancer Society (ACS), the National Cancer Institute (NCI), the American College of Surgeons (ACOS), and the North American Association of Central Cancer Registries (NAACCR), took on the challenge of defining, promoting, and supporting a collaborative and integrated approach to the full spectrum of cancer prevention and control. This concept is now called comprehensive cancer control. A major force that accelerated the acceptance of the concept and moved the concept from ideas to reality was the National Comprehensive Cancer Control Program (NCCCP) funded by the Centers for Disease Control and Prevention since 1998. The NCCCP has provided significant leadership and resources in the development, growth and ongoing support for the infrastructure of coalitions at the state, tribe, territory, and Pacific Island Jurisdiction levels. These resources have assisted CCC coalitions in their efforts to effectively develop and implement their CCC plans [3].

As the CCC movement gained acceptance and momentum, the national organizations that were initially involved in creating the concept began meeting to continue and expand their support for CCC. This group has grown and evolved into the Comprehensive Cancer Control National Partnership (CCCNP). The CCCNP has existed since 1999 as a collaborative group of diverse national organizations working together to build and strengthen comprehensive cancer control efforts across the nation.

As described in the report commissioned by the CCCNP, “The Comprehensive Cancer Control Movement, Ten Years of Success 1998–2008” [4], the partnership has enjoyed a collegial relationship that has resulted in multiple successful collaborative initiatives that have directly benefited U.S. state, tribe or tribal organizations, territory, and Pacific Island Jurisdictions in their CCC efforts.

The CCCNP has grown and matured over the past several years. Examples of this include the number of members has increased, there has been an increase in the frequency and systematic methods used to assess CCC

needs across the nation, the process for identification and allocation of resources from member organizations to CCCNP initiatives has become more established, and planning and evaluating the CCCNP's efforts has become further formalized, as evidenced by the development of a CCCNP 5-year strategic plan. Throughout this evolving partnership, a constant factor has been collegial respect, trust and the commitment to communicate directly and honestly with each other while working on the shared goal of supporting a strong CCC movement.

For several years, the partnership functioned on an informal basis. In 2008, it was agreed that the ongoing success of the partnership would be enhanced and strengthened by creating a simple operational and strategic framework in which the partners would work together. Two documents were created for this, the CCC National Partnership Operating Guidelines, and the CCC National Partnership 2008–2013 Strategic Plan.

The CCCNP is similar to the coalitions it supports. Like CCC coalitions across the nation, the CCCNP is comprised of diverse partners who believe that their work together can achieve outcomes they cannot achieve on their own. The CCCNP and CCC coalitions face similar challenges such as maintaining and sustaining partners, setting agreed upon partnership priorities among organizations that have differing individual agendas and organizational priorities, tracking progress and impact, being responsive to their constituents and demonstrating tangible value to their involvement in the partnership when their individual organizational resources are strained and scarce. All CCC coalitions from the national level to the community level can learn from each other's successes as well as how they approach their challenges.

### The strategic direction of the national partnership

In 2008, the National Partnership embarked on a strategic planning process in which informal thinking and ways of working together were identified, discussed, and agreed to and documented [5]. A vision and mission and 5-year plan were created over a 6-month timeframe. The CCCNP vision and mission are:

*Vision:* A national movement of states, tribes, territories, U.S. Pacific Island Jurisdictions, and local communities working together to reduce the burden of cancer for all people.

*Mission:* The CCC National Partnership facilitates CCC coalitions to develop and sustain implementation of Comprehensive Cancer Control plans at the state, tribe, territory, U.S. Pacific Island Jurisdictions and local levels.

In addition, six goals and corresponding strategies to achieve those goals were identified. The 2008–2013 goals for the CCCNP are:

- Provide technical assistance and training to coalitions on implementing their CCC plan priority strategies
- Identify policy approaches to assist in the implementation of CCC plans.
- Establish communication mechanisms on CCC National Partnership initiatives
- Facilitate the exchange of information between CCC Coalitions.
- Summarize and report on progress made through the CCC movement
- Sustain the CCC National Partnership as a model for collaboration.

### How the national partnership works

The following section describes how the National Partnership is structured and describes basic operating approaches and mechanisms.

#### Members

Roles and expectations are set forth in the Operational Guidelines for the CCC National Partnership. CCCNP members are expected to contribute to the overall mission and goals of the partnership as well as make specific commitments to support implementation of the CCCNP strategic plan. The implementation of CCCNP initiatives is dependent on members' ability and willingness to commit their organization to provide expertise, staff time, resources, and opportunities to leverage existing efforts within their organization. The tangible commitment from partner organizations has evolved from attending meetings once a year to providing both in-kind and direct funding contributions. Once cost estimates and budgets are developed to carry out specific CCCNP initiatives, each member organization is asked to contribute through in-kind and/or direct funds as appropriate for their organization.

Currently, the CCCNP has liaisons and advisors representing tribe and tribal organizations and Pacific Island Jurisdictions. These liaisons and advisors provide guidance to the CCCNP in their efforts to ensure ongoing inclusion, collaboration and communication between CCC National Partners, tribe or tribal organizations, and Pacific Island Jurisdictions. (Unpublished document: Comprehensive Cancer Control National Partnership Operating Guidelines).

#### Workgroups

The CCCNP's work is done primarily through member workgroups. These workgroups are formed based on current and upcoming needs and priorities and are led by a

designated national partner. 2009–2010 workgroups include:

- June 2010 Comprehensive Cancer Control Leadership Institute (CCCLI)
- Policy Agenda Development
- Evaluation of CCCNP Initiatives
- National Partnership Internal and External Communications

#### Leadership and decision making

Leadership of the National Partnership is informal. Major decisions are made by consensus of the National Partnership members. A convener of the National Partnership is identified from one of the member organizations and is responsible for assuring that all National Partners have the opportunity to provide input into major decisions, work products, communications to the field and the development of meeting and conference call agendas. Since 2008, the National Partnership Convener has been The American Cancer Society.

#### Progress

The CCCNP with CCC coalition assistance has developed strategies and initiatives to improve the way organizations coordinate and collaborate in the fight against cancer. Building on work of individual organizations, a focus to work collaboratively to address the cancer burden has resulted in a strong cancer control movement that is stakeholder and data driven. Critical factors that facilitated the growth of CCC include:

- Expanded cancer data, such as registry and survivorship Behavioral Risk Factor Surveillance System (BRFSS) data, and evidence-based interventions utilized as a basis to inform cancer plans and to motivate action;
- The CCCNP and other national organizations with common goals vigorously promoting, supporting and coordinating with the “promise” of CCC as an approach and making comprehensive cancer control a priority within their organizations and with the staff who work at local and regional levels;
- CDC funding the National Comprehensive Cancer Control Program to provide basic infrastructure for states, tribes, and territories to establish coalitions and develop and implement CCC plans;
- Organizational partners from different sectors in the community with diverse resources and expertise coming together and working toward the same CCC goals.

With tireless work from individuals and organizations across the country, including the CCCNP, major milestones

have been achieved in CCC including CDC funding steadily increasing since 1998; the inclusion of CCC in strategic planning of several National Partner organizations; and the development and delivery of technical assistance materials, meetings, and communication to address the needs of CCC programs and coalitions. This is pictured graphically in Fig. 1.

The CCC National Partners routinely identify specific needs of the CCC coalitions to help support the development and implementation of their CCC plans. A few examples of CCC National efforts to develop resources and provide technical assistance include:

#### Comprehensive Cancer Control Leadership Institute

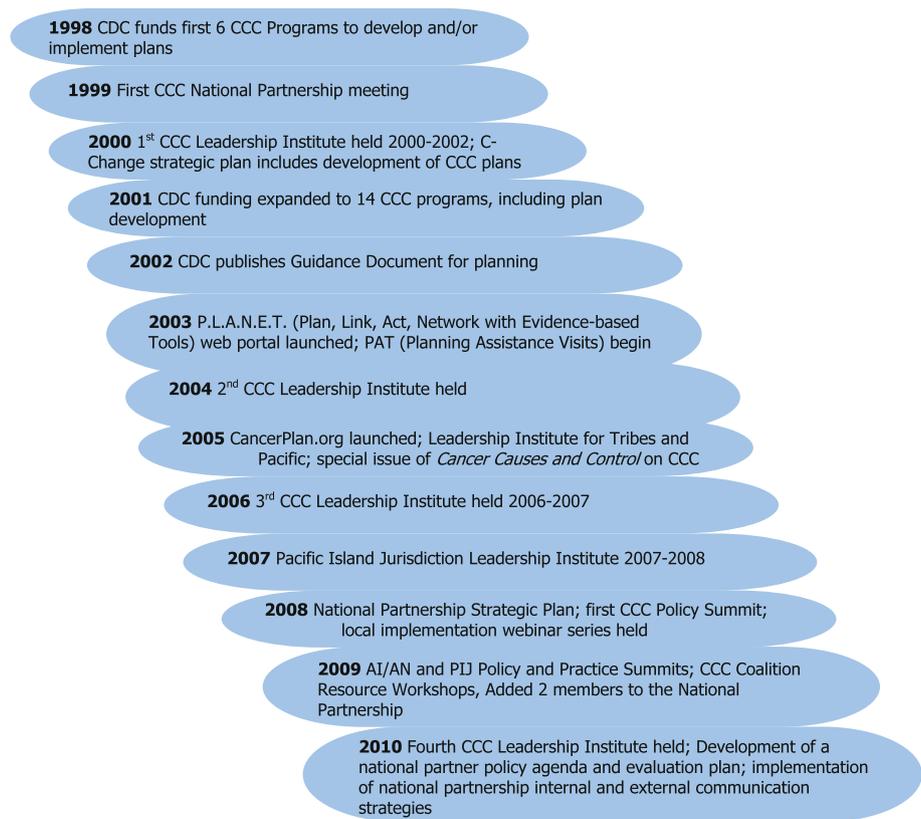
Beginning in the year 2000, a series of forums for teams of leaders from states, tribes, territories, and Pacific Island Jurisdictions were held to learn, share, and set strategic direction for their CCC initiatives. Four phases of the Institute have been held as of 2010, each with a specific purpose, first aimed at encouraging development of CCC plans and moving in CCCLI Phases III and IV to supporting implementation of CCC plans.

Focused Leadership Institutes were held for tribes, tribal organizations, territories, and Pacific Island Jurisdictions. The first American Indian and Alaska Native Leadership Institute was held in 2005 and attended by over 200 individuals from tribes and tribal organizations who were developing or implementing CCC plans or who were interested in getting involved in CCC efforts. As a result of this Leadership Institute, an American Indian and Alaska Native (AI/AN) Advisory Group was formed to advise the CCC National Partnership on how to enhance CCC efforts within the AI/AN population. In addition, three Leadership Institutes were held for the ten Pacific Island Jurisdictions in 2005, 2007 and 2009, with topics ranging from data collection and evaluation to identifying and adapting best practices in cancer control. Altogether, thousands of CCC coalition members have attended the Leadership Institutes and as a result have moved forward with completing CCC plans, have identified priority strategies for implementation, have learned about best practices in cancer control, and have put these practices into action in their communities to address the cancer burden.

Cancer control P.L.A.N.E.T. (Plan, Link, and Network with evidence-based tools)

The Cancer Control P.L.A.N.E.T. (<http://cancercontrol.planet.cancer.gov>) web portal was launched in April 2003 and is an online data and planning tool to assist CCC practitioners. This collaborative web portal is sponsored by several of the CCC National Partners (NCI, CDC, ACS,

**Fig. 1** Graphic taken from: The Comprehensive Cancer Control Movement, Ten Years of Success 1998–2008 and updated



ACOS) as well as the Substance Abuse and Mental Health Services Administration and the Agency for Healthcare Research and Quality. The portal provides access to data and resources that can help planners, program staff, and researchers design, implement and evaluate evidence-based cancer control plans and programs.

#### Comprehensive cancer control policy and practice summits

In 2008–2009, the CCC National Partnership, with leadership from C-Change, provided a series of opportunities for CCC coalition leaders and CCC National Partners to identify and discuss key issues and corresponding policy solutions that have the potential to enhance their CCC efforts. As a result, the CCC National Partners developed a policy agenda and corresponding plans to respond to the specific recommendations raised during the summits. CCC National Partnership policy priorities are further described in the article titled “Public Policy Action and CCC Implementation: Benefits and Hurdles” in this special issue.

#### Webinars and workshops to support implementation of CCC plans

In the fall of 2008, the CCC National Partnership hosted a series of three web-based interactive discussions and

sharing of information and resources among CCC practitioners related to implementation of CCC priority strategies at a local level. Over 300 individual CCC coalition members from states, tribes, territories, Pacific Island Jurisdictions, and local communities participated in this first webinar series which was focused on describing approaches to local implementation and the partnerships and resources necessary to support local implementation.

In 2008–2009, the CCC National Partnership developed and delivered a series of CCC Resources Workshops designed to assist CCC coalitions with the creation of a resource strategy to support implementation of their CCC plan priorities. Two to three coalition members per state, tribe or tribal organization, territory, and Pacific Island Jurisdiction attended the in-person workshops held in Atlanta, GA. Participants left with a set of tools and decisions made about how to develop their own resource strategy for funding implementation of their plan priorities.

#### Lessons learned

Over the course of the past 11 years, the CCCNP partnership has experienced a variety of challenges to achieving its goals. Table 1 summarizes those issues and briefly identifies the actions taken to address each challenge.

**Table 1** CCCNP challenges and actions taken

National partnership component	Challenge	Action taken
Assessing membership	When, who and how to add additional organizations to the membership	Created member criteria, a written process and supporting materials for recruiting and responding to potential new members
Member relationships	Key individual members unable to continue active involvement in the partnership	Worked with those members leaving to identify someone within their organization who would remain actively involved
Internal communications	A core group of members kept in regular contact, but not all members had this regular communication. Therefore when full partnership calls or meetings occurred some members felt out of the loop on some decisions and efforts	Monthly conference calls were established. It is understood that decisions will be made on those calls, and therefore full participation is desired An internal website has been developed for internal communication and document storage
External communications	Feedback from the CCC field indicated there was confusion and a lack of understanding regarding the purpose and ongoing efforts of the National Partnership	A set of “standardized” National Partnership communication materials were developed for distribution and use during presentations and meetings. The “Link” newsletter was established to communicate to the field. (The link has just recently been changed from a bi-annual newsletter, to more frequent “blast” email communications.)
Support from members’ organizational leadership	As individual organizations looked to cut programs and identify cost saving measures, questions about the value of being actively involved in the National Partnership were coming from members’ leadership	An evaluation plan of CCCNP efforts has been developed and is underway. The results of the ongoing evaluation can be shared with organizations to demonstrate value in an organization’s participation in the partnership

### Evaluation of national partnership efforts

As can be seen from the long and varied history of providing strategic direction, technical assistance and coordination, the CCC National Partners have developed ongoing and long-standing relationships, first with each other as individuals and as organizations and then extending to stakeholders among the states, tribe and tribal organizations, and the territories, and Pacific Island Jurisdictions. These relationships have been positive and productive in developing activities to address the cancer burden.

Yet, in order to systematically assess how well these relationships are working, the CCCNP in 2010 began a process to evaluate both the internal workings of the National Partnership and the extent that they have provided helpful technical assistance, appropriate resources, and quality communication to CCC stakeholders. The 2010 Evaluation Plan will be developing information on the processes and workings of each national partner workgroup active in 2010 and 2011; evaluation data from coalitions on how the national partners can best meet the needs of CCC coalitions; and an evaluation of the national partners’ satisfaction with the operation and functioning of national partner processes. The purpose of this evaluation effort is to improve national partner work and to begin to document the impact of these activities—crucial information that

documents to what extent the national partners contribute to reducing the burden of cancer in the country.

With the development of a more formal partnership structure and operations in 2008 and the evaluation initiated in 2010, the National Partners have been able to grow from a group of individual organizations informally working together to alleviate the cancer burden, to a group of organizations systematically committed to extending their collective efforts under a common, strategic framework.

### Conclusion

The CCC National Partnership is an example of a group of people and organizations who are committed to cancer control, who are willing to work on comprehensive cancer control in a coordinated and collaborative manner, and have persevered in building and sustaining relationships with each other and their stakeholders for a unified purpose. This commitment to “do the right thing” has carried this group to where they are today—a strong effective partnership.

Today, the CCC National Partnership can look back at multiple, successful initiatives that have assisted CCC coalitions across the nation in their efforts in cancer control, as well as look forward to the continuing collaborative efforts among partners. The CCCNP will continue to strive

to support CCC coalitions across the nation as they combat cancer on the front line; in our communities where our families, our friends, and our neighbors live.

The CCC National Partnership can serve as encouragement and an example to others, both in the cancer control field as well as other health-related areas. The CCCNP demonstrates that despite today's economic and political challenges, organizational barriers and at times pessimistic attitudes, it is possible to develop collaborative, supportive, and impactful relationships and efforts that can achieve both individual organizational and collective goals and objectives as well as significant accomplishments that could not have been achieved alone.

**CDC Disclaimer** The finding and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

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