Brought to you with Comprehensive Cancer Control National Partnership's (CCCNP) Sustaining Coalitions Workgroup

Ask-the-Expert Session 10: Summary Discussion Notes

Sharing What Works: Comprehensive Cancer Control (CCC) Membership and Leadership

January 24, 2017

Experts

Henry Well, Executive Director for the South Carolina Cancer Alliance, has extensive experience in the realm of non-profit organizations. For over 15 years, Mr. Well has served in senior management roles with the National Kidney Foundation and the American Cancer Society. In his current position at the South Carolina Cancer Alliance, he oversees the planning, organizing and execution of Alliance initiatives. More specifically, his responsibilities include, but are not limited to, the development of the state cancer plan, public and patient education, marketing and communications, and managing daily office responsibilities.

Judy Proctor has served as the manager of the New Hampshire Comprehensive Cancer Collaboration for almost 10 years. She is a registered nurse and spent most of her nursing career in the oncology field, and ultimately managed a hospice program. Judy worked for the New Hampshire Health Department for 11 years, where she became certified as a public manager. She currently works for the Foundation for Healthy Communities, a 501(c)(3), whose mission is to improve health and health care in communities through partnerships that engage individuals and organizations.

Download the presentation slides

Use the Nine Habits of Successful Comprehensive Cancer Control Coalitions to guide your work in building an effective and efficient coalition.

Overview of the Comprehensive Cancer Control National Partnership (CCCNP)

By **Sarah Shafir**, Strategic Director, State and National Systems, American Cancer Society (ACS). Sarah also moderated the Ask-the-Expert session.

- The CCCNP mission is to facilitate CCC Coalitions to develop and sustain implementation of CCC plans at the state, territory, tribe and local levels.

- The CCCNP began informally in 1994 with just five organizations. Today, CCCNP is a formalized coalition with by-laws and a strategic plan. The current membership includes 18 leading cancer organizations with nationwide reach.
- The goals of the current strategic plan are to 1) facilitate and provide support to CCC Coalitions and 2) coordinate national CCC efforts. Together, CCC national partners leverage resources and coordinate expertise to support CCC efforts and actively build capacity for cancer control at all levels.
- There are four workgroups focusing on priority areas:
    1. Human Papillomavirus (HPV) vaccination uptake
    2. Colorectal cancer screening
    3. Tobacco cessation services for cancer survivors
    4. Sustaining coalitions
- In addition to the workgroup structure, the evaluation and communication workgroups cut across all CCCNP work.
- The current leadership group is as follows:
    - Chair: Nina Miller, American College of Surgeons Commission on Cancer (CoC)
    - Vice-Chair: Cindy Vinson, National Cancer Institute
    - Centers for Disease Control and Prevention (CDC) Representative: Ena Wanliss, CDC
    - Convener Representatives: Sarah Shafir and Lorrie Graaf, ACS
    - Technical Consultants: Karin Hohman and Leslie Given, Strategic Health Concepts
- Visit the CCCNP website for more information.

Discuss ways to establish and maintain effective structures and features of coalition membership

By **Henry Well**, Executive Director, South Carolina Cancer Alliance

- Henry became the Executive Director of the South Carolina Cancer Alliance (hereafter "the Alliance") over a year ago. It was "stagnant" when he started, with limited growth in membership and member satisfaction.
- Value-added collaboration and flexible structure
    - The first thing they did was to inventory their membership, which consisted of approximately 1,100 members and narrowed it down to 600 members: those who participated in at least one workgroup conference call, meeting or activity. Further, of the 600 members, 200 were classified as *active* members that were members of a workgroup or board and were engaged with the organization. "We lost members along the way, but that's okay." This created more energy around the Alliance and framed the scope of work, which helped engage members on specific projects.
    - **Audience question:** Why is *active* membership so important?
        - **Henry:** Some people gauge the success of their coalition on the number of members. It is better to have a smaller, well-functioning and engaged coalition than a large and bloated coalition. It is important to take the time to define what "active" participation means. For example, I found that those who were opening our emails were from smaller

hospitals in the rural areas, who said that they do not have the time to participate in workgroups and had no dedicated budget for travel to go to meetings; so, they wanted to be engaged, but they did not have the resources. What we decided to do was to convene meetings via conference calls and create sub-committees. We also made an effort to reach out to them to accommodate their schedules. For example, a hospital near Myrtle Beach told us that they would not be able to attend the meetings that we usually convened in the summer on a Friday, due to heavy traffic going to the beach. In response, the Alliance decided to convene the next meeting in January.

    - **Audience question:** How did you get rural stakeholders engaged?
        - **Henry:** We worked with our cancer registry to create a map indicating areas with higher burdens of cancer, which, in South Carolina, are the rural counties. These data were persuasive when we talked to rural stakeholders. We also presented the data to the board and challenged them to have representation from rural counties. We reached out to stakeholders by visiting them and keeping them up-to-date with meeting minutes. It takes persistence: you may not get an immediate response from small hospitals. However, if you communicate that you are willing to accommodate their schedules and unique needs and show them the data, they will be more likely to engage with your coalition.
    - The Alliance reworked their bylaws to reflect the scope of the smaller organization. They also reorganized the board and workgroups to include better communication and representation. For example, workgroups are responsible for appointing one of their members of the board.
    - The Alliance relaunched the website and published a one-page fact sheet about the Alliance and its role in South Carolina.
- Clear roles and accountability/dedicated staff
    - The Alliance kicked off a workgroup to develop the 2021 cancer plan, which included a meeting featuring a motivational speaker.
    - The Alliance removed administrative work, such as taking meeting notes, from the responsibilities of workgroup members and assigned them to coalition staff. This way, the members can focus their time and expertise on the work at hand.
    - **Audience question:** How are you staffing your coalition?
        - **Henry:** We are a private non-profit and have a contract with the South Carolina Department of Health and Environmental Control that provides funding to implement the cancer plan. Currently, we have two staff: I am the full-time Executive Director and we have a part-time Program Manager. We use graduate assistants and interns to support our work—currently we have four of them.
- Priority work plans
    - The Alliance also developed an engagement plan with past, present and potential members and asked them to sign a letter of support.
    - The Alliance invited Dr. Fran Butterfloss to present on the steps of developing a successful coalition at the Annual Meeting (her book is *Ignite: Getting Your Community Coalition "Fired Up" for Change*).

- The Alliance is currently working on conducting a gap analysis and an organizational five-year plan that outlines action items to build organizational capacity and visibility.
- Tip: "if you believe in your organization, have a realistic vision and are excited, your board and members will follow your lead."

Discuss ways to establish and maintain effective structures and features of coalition leadership

By **Judy Proctor**, Manager, New Hampshire Comprehensive Cancer Collaboration

- Dedicated staff/diversified funding
  - The New Hampshire Comprehensive Cancer Collaboration (hereafter "the Collaboration") is an initiative of The Foundation for Healthy Communities, a 501(c)(3) non-profit agency, and is primarily funded by the CDC National Comprehensive Cancer Control Program via a contract with the state of New Hampshire. As mentioned in the Nine Habits of Successful Cancer Coalitions, having a dedicated staff member is "one of the most critical elements."
  - **Audience question:** What are the implications of a 501(c)(3) versus volunteer-run organizations?
    - **Judy:** The Collaboration researched becoming a 501(c)(3) and interviewed several other states, and determined that they will forgo it at this time. The biggest reason for this decision was that the Collaboration wanted to remain a neutral organization that did not compete for funding with the member organizations.
    - **Audience input:** We have decided to become a 501(c)(3). This provides the opportunity to have dedicated staff, foster a neutral environment (non-government) for membership engagement and activity, apply for other funding opportunities and organize fundraisers.
    - **Audience input:** We have been a 501(c)(3) for several years, and the main reason we did this is for sustainability: the coalition will still survive in the case that state or federal funding are eliminated.
  - **Audience question:** We used to be a non-profit coalition; however, the state has administered the coalition since 2012. This has led to a loss of engagement and our cancer plan has been under the state approval process for over a year. Therefore, we would like to become a 501(c)(3), but are having a hard time finding someone to lead the tax paperwork. How do you recommend we do this?
    - **Judy:** The Collaboration is unique in that although we are not a 501(c)(3) entity, we are an initiative of a 501c3 that can accept funds on our behalf. Our annual meeting has become a revenue stream for us, and the 501(c)(3) can accept that money and keep it in a separate bank account that can be tapped to supplement state contract funds; essentially this supports our sustainability efforts.
    - **Audience input:** We are going in a similar direction, where we are working with a fiscal agent to which the state can give a sub-grant. This way, the coalition does not assume the work associated with setting up their own 501(c)(3). I recommend doing this, especially to smaller non-profits.

    - **Audience question:** What kinds of fundraising are you doing and to what kinds of grants are you applying?
        - **Audience input:** We seek sponsorships, sometimes from corporations, for our events and donations from the board. Our long-term goal is to secure enough unrestricted funds to hire a development manager. These funds would allow us to grow and conduct activities that state government dollars do not allow.
- Empowering leadership/clear roles and accountability
    - The Collaboration has an active governing board of directors with 20 members, which is a separate board from The Foundation for Healthy Communities 501(c)(3). Board members are obligated to join a taskforce or active committee within the organization. The leadership group consists of a Chair, Vice-Chair and Immediate Past Chair. There are four core appointed members from the Department of Health, state liaison from CoC, ACS and the state contract agent in addition to the remaining elected members.
    - Having a governing body has given the Collaboration more respect and authority. People want to serve on the board of directors.
    - The Collaboration has a structured orientation program provided to new board members.
    - The board developed and recently updated the Guiding Principles on leadership structure. It defines responsibilities, authorities and meeting requirements.
    - A facilitator helped the Collaboration write role descriptions for board members, officers, task force leaders and general members, which was surprisingly useful and necessary, especially for new members. It also adds professionalism and credibility to the organization.
- Value-added collaboration
    - The nominating committee reviews the terms of the board and gaps in expertise annually. They also recruit key stakeholders that have missions and deliverables that align with the Collaboration.
    - The Collaboration also looks for representation from non-cancer-specific organizations, such as the New Hampshire Healthy Eating Active Living, New Hampshire Health & Equity Partnership and New Hampshire Hospice and Palliative Care Organization.
    - **Audience question:** What other non-traditional partners are engaged in your coalition?
        - **Judy**: We have engaged a lawyer who is also a cancer survivor. She helped us modify our Guiding Principles. We also brought on a local business partner, who helped us understand that it would be beneficial to charge more for registration to our annual meeting in order to increase revenue.
        - **Henry**: We have Blue Cross Blue Shield as part of the Alliance, and I think they joined because it was beneficial to them, because all cancer stakeholders in the state are in the Alliance. For example, they serve on workgroups to increase insurance utilization and organize colorectal and breast cancer screenings through state health plans and employers. As we are looking more to tackle health equity in our work, we are looking to engage more faith-based organizations. We have also reached out to the state's Office of Minority Health (OMH). With the mutual understanding of the benefits of collaboration, OMH agreed to share their listserv, and the Alliance began outreach efforts. Now, we have a Health Equity workgroup of 22 people.

- Effective communication
    - The Collaboration conducts bi-weekly phone calls between the Chair, Vice-Chair, the immediate past Chair and the Manager. The liaison from the state comprehensive cancer control program joins the call once a month.
    - Board members serve as a taskforce or committee co-leaders.
    - The Collaboration continuously updates their dedicated website and produces newsletters.

Expert and participant-recommended resources:

- Comp Cancer 101 Wiki: A portal designed to help cancer control professionals with the details of various coalition tasks. Topics include coalition organization and leadership structure; comprehensive cancer control plan development; and membership, communication and engagement.
- All Hands on Deck: Making the Case for Comprehensive Cancer Control
- Building Local Comprehensive Cancer Control Coalitions: Lessons Learned from Local Health Departments
- Collaboration Guide for Pacific Island Cancer and Chronic Disease Programs
- Engaging Businesses in Comprehensive Cancer Control Coalitions: The Value Proposition for Comprehensive Cancer Control