



GUIDE TO THE DEVELOPMENT OF STATE-LEVEL COLORECTAL CANCER COALITIONS



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Introduction

This guide provides 80% partners with a framework for the development of state-based coalitions focused on colorectal cancer control. The shared 80% goal requires a coordinated approach from various stakeholders committed to the implementation of strategic interventions at the patient, provider, organization, community, state, and national level. Collaborative efforts at the state level improve the focus and potential of colorectal cancer control activities and encourages multi-disciplinary and cross-sector partnerships between relevant organizations taking advantage of each contributor's area of expertise.

These organized and collaborative efforts often operate under different names (including coalitions, consortiums, collaboratives, and action groups) and can form due to the leadership of a statewide comprehensive cancer control (CCC) coalition, a health department, or another prominent and motivated community stakeholder. Regardless of variations like these, this guide is designed to accommodate the many paths of partnership.

A National Colorectal Cancer Roundtable (NCCRT) subcommittee identified the following five states as being early leaders in the establishment of successful state level colorectal cancer coalitions. The states highlighted in this guide were chosen because they are effective, well-established coalitions, and offer a range of models and approaches that can inform emerging efforts. These states demonstrated success in bringing together public health organizations, health care providers, non-profit organizations, hospital systems, political leaders, advocacy groups and other organizations committed to improving colorectal cancer screening and care in their states over a multi-year period. The highlighted states include: California, Delaware, Kentucky, Minnesota, and South Carolina.

Examples offered throughout this guide depict development models that occurred from both large funding sources, such as the Centers for Disease Control and Prevention's (CDC) Colorectal Cancer Control Program, the Prevent Cancer Foundation's state Dialogue for Action program, or individual state funding, as well as models demonstrating collaborations that faced lean initial resources, yet still found a way to succeed.

This guide is organized around the ten tasks that state coalitions need to undertake when developing a plan of action to advance colorectal cancer control efforts. Effective colorectal cancer collaborations:

1. **Prioritize colorectal cancer in your state;**
2. **Establish a structure;**
3. **Develop a vision;**
4. **Recruit leadership and staff;**
5. **Build a network of partners;**
6. **Convene partners;**
7. **Set goals;**
8. **Maintain momentum;**
9. **Get creative with funding and resources;**
10. **Hold the group accountable.**

The Appendix provides examples of materials that further illustrate how state coalitions have executed the tasks described in this guide. We hope this information will help other partners learn from the experiences outlined here as they work to develop collaborative efforts to address colorectal cancer. Additional lessons learned are also drawn from the NCCRT.

TASK 1

Prioritize Colorectal Cancer in Your State

HOW THEY CHOSE COLORECTAL CANCER

The **Minnesota Cancer Alliance** had 23 different objectives that they were working on simultaneously. However, they recognized that in order to make progress, they needed to focus on only a few.

After going through a disciplined evaluation process of all their objectives, colorectal cancer emerged as a top-three priority area and a subcommittee was established to focus on it.

The subcommittee brought together organizations across the state whose work aligned with this objective.



“If we’re really going to make an impact, let’s focus.”

- Kentucky Cancer Consortium

Make the Case to Focus on Colorectal Cancer

The state collaborations profiled in this guide made an early decision to focus efforts and resources on colorectal cancer—some embarking on this process more than a decade ago. For any collaborative (or individual partner) with limited resources, prioritizing can be difficult to do given the many competing health needs that impact the state population. Leaders in these states successfully made the case that the toll taken by colorectal cancer justified a unique investment of time and resources in order to fulfill the great potential of screening. This focus ultimately paid off in terms of long-term commitments from a diverse range of partners, and each state has documented dramatically increased screening rates.

There were three important elements that coalition leaders say contributed to their ability to convince partners of the importance of a special investment in colorectal cancer control:

1. The potential for high impact,
2. The presence of strong national support, and
3. State-specific data on colorectal cancer incidence and screening performance.

Highlight Potential for High Impact

Colorectal cancer is unique in that it is one of the few cancers which can be prevented through screening due to the detection and removal of precancerous polyps. There is clear consensus that colorectal cancer screening decreases both the numbers of cases and the number of deaths from the disease. Focusing on colorectal cancer offered states the opportunity for rapid return on investment, as even a small investment could make a significant difference in increasing colorectal cancer screening rates.

Clinical leaders and advocates in the state collaborations profiled in this guide knew that there were proven methods available to them to positively impact colorectal cancer screening, such as evidence-based practices presented in the CDC’s Community Guide, tools and resources from the NCCRT, or resources from partners, such as rtips.cancer.gov, cancer.org/colonmd, cancercontrolplanet.org, and other sites.

Leverage Strong National Support

Today, the 80% national goal aims to lead the charge in increasing colorectal cancer screening rates. However, over the past 20 years, proactive changes in the public health landscape shaped the current opportunity to invest in colorectal cancer control:

1. In 2001, Medicare began covering the full range of colorectal cancer screening tests that were recommended at the time.
2. CDC established the National Comprehensive Cancer Control Program (NCCCP) in 1998.
3. In 1999, CDC launched the Screen for Life National Action Campaign, a multiyear, multimedia campaign launched to educate and inform men and women aged 50 and older, the age group at greatest risk of developing colorectal cancer, about the importance of regular colorectal cancer screening.
4. CDC administered a colorectal cancer screening demonstration program for underinsured and uninsured men and women 50-64 years old to assess the feasibility of establishing a federally-funded colorectal cancer screening program from 2005-2009.
5. CDC launched its Colorectal Cancer Control Program (CRCCP) in 2009.
6. March was established as Colorectal Cancer Awareness Month and the Blue Star was established as the universal symbol.
7. The Prevent Cancer Foundation provided organizing support through the state Dialogue for Action program.
8. The NCCRT, CDC, NCI, ACS, and many others were studying evidence-based interventions and compiling resources for partners to determine what works and what motivates people to get screened.
9. The Affordable Care Act was passed in 2010.

The NCCCP provides a coalition-based approach for planning, prioritizing, and implementing cancer prevention and control activities in communities across the country.

CDC supplemented NCCCP grantees with additional funding from 2002-2009 for specific activities to increase colorectal cancer awareness and colorectal cancer screening.



The state-based collaborations highlighted in this guide report that their state level efforts benefit significantly from being involved at the national level with groups like the NCCRT, by operating in partnership with state comprehensive cancer control programs and coalitions, or by attending the Prevent Cancer Foundation's *Dialogue for Action*.

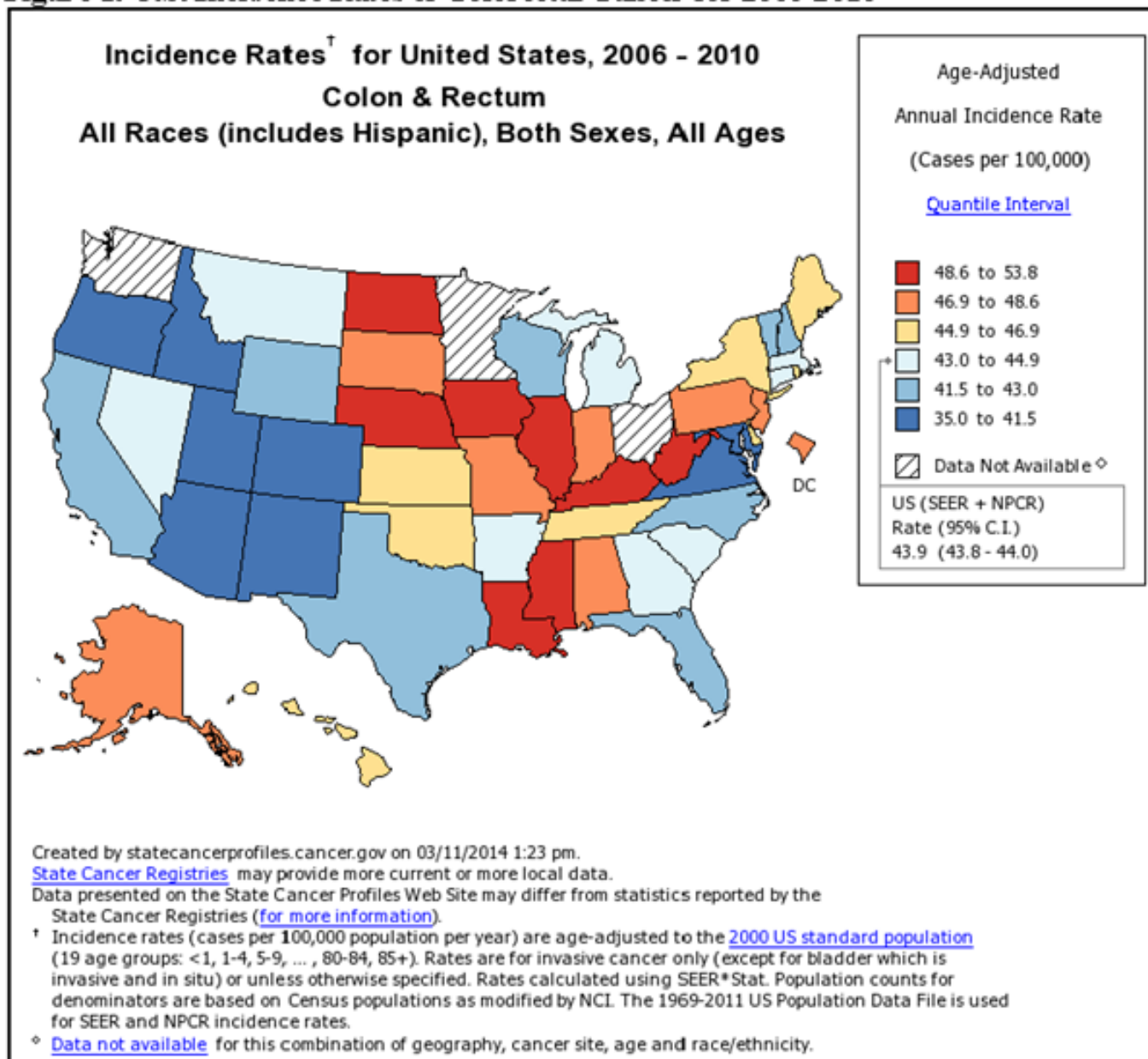
Taking advantage of these national networking opportunities enable state-based groups to learn from other states and gather ideas to execute at the local level.

Involvement at the national level also informs state level colorectal cancer collaboratives to stay up to date on important national policy developments that will impact colorectal cancer efforts, including changes to the Affordable Care Act, Medicaid expansion, and Medicare coverage.

Use State-Specific Data to Make the Case

The state colorectal collaborations highlighted in this guide report that their statewide numbers for colorectal cancer screening, incidence, and mortality were extremely poor at the start of their efforts, making it an “easy sell” and a natural priority. For those that faced some level of resistance, data on statewide rankings proved to be an influential tool. Partners demonstrated how colorectal cancer impacts their states using local morbidity and mortality statistics, as well as evidence of how disparities could be remedied through clearly defined, proven methods. Several states say that publicizing national rankings on these measures was a particularly powerful motivator for change. Some resources that provide helpful state and local data include the [United States Cancer Statistics](#), [National Cancer Institute’s county level death rates](#) and [CDC’s Behavioral Risk Factor Surveillance System \(BRFSS\)](#). Learn more about how to access and use colorectal cancer data sets by viewing NCCRT’s webinar archive of “[Colorectal Cancer Screening Data Sets: What are they and what do they tell us?](#)”.

Figure 1: U.S. Incidence Rates of Colorectal Cancer for 2006-2010⁶



STATE-SPECIFIC RESOURCES

- The American Cancer Society Statistics Center is a resource that can help communicate the toll that colorectal cancer takes on the people in your state, which allows visitors to view and download maps, graphs and charts; create custom downloadable maps, graphs and charts; and more easily share statistics: <https://cancerstatisticscenter.cancer.org/#/>
- State specific data on numbers of individuals who need to be screened for colorectal cancer and potential number of lives saved can be found here: <http://ncrt.org/resource/80-2018-impact-lives-saved-state/>
- A 2015 journal article shares cancer data by Congressional district: <http://onlinelibrary.wiley.com/doi/10.3322/caac.21292/full>
- States may also want to convene a task group focused on identifying, collecting, and disseminating data. State-based partners can include, the state's cancer registry staff, registrar association members, and epidemiologists.

Coalition leaders also explain that the case for investing in colorectal cancer is bolstered by sharing data on the consequences of not addressing the problem, including the cost of cancer treatment that states must assume for the uninsured. Whenever possible, they say these costs should be described based on local or state numbers, rather than national ones.

For example, the Kentucky Cancer Consortium includes the following detailed impact data in their coalition plan, describing the costs to Kentucky's Medicaid program:

- Each year, cancer treatment in Kentucky cost Medicaid \$132 million, private insurance companies \$836 million and cost Medicare \$718 million from 2004-2008.
- In 2010, cancer care in Kentucky costs approximately \$2.2 billion. In 2020, it is estimated to increase by 69% which would be approximately \$3.8 billion.
- The typical new cancer drug coming on the market in 2010 cost approximately \$10,000/month of treatment. Two of the new cancer drugs cost more than \$35,000 per month of treatment.

Several state-based partnerships produce fact sheets (see Appendix) and maps, like the one shown, with detailed information on colorectal cancer incidence and mortality by district or region. California's C4 coalition works with a health economist to prepare data on many aspects of colorectal cancer, including incidence of late stage cancer for each state senate and general assembly district. This type of information is shared with state assembly members and used to support a variety of advocacy efforts.

Estimated new cases and deaths, 2018		
Colorectum, by state		
State [†]	Estimated New Cases, 2018 [†]	Estimated Deaths, 2018 [†]
California	14,400	5,300
Florida	11,670	3,640
Texas	10,080	3,740
New York	9,080	2,970
Pennsylvania	6,440	2,380
Ohio	5,550	2,100
Illinois	5,340	2,080
Michigan	4,510	1,670
North Carolina	4,440	1,570
Georgia	4,120	1,580

Figure 1: American Cancer Society Interactive Cancer Statistics Map

The bottom line is that influential state leaders might not yet appreciate the toll that colorectal cancer takes in their state. Once the impact from colorectal cancer is understood, coupled with the great potential of screening to save lives, a sense of urgency develops.

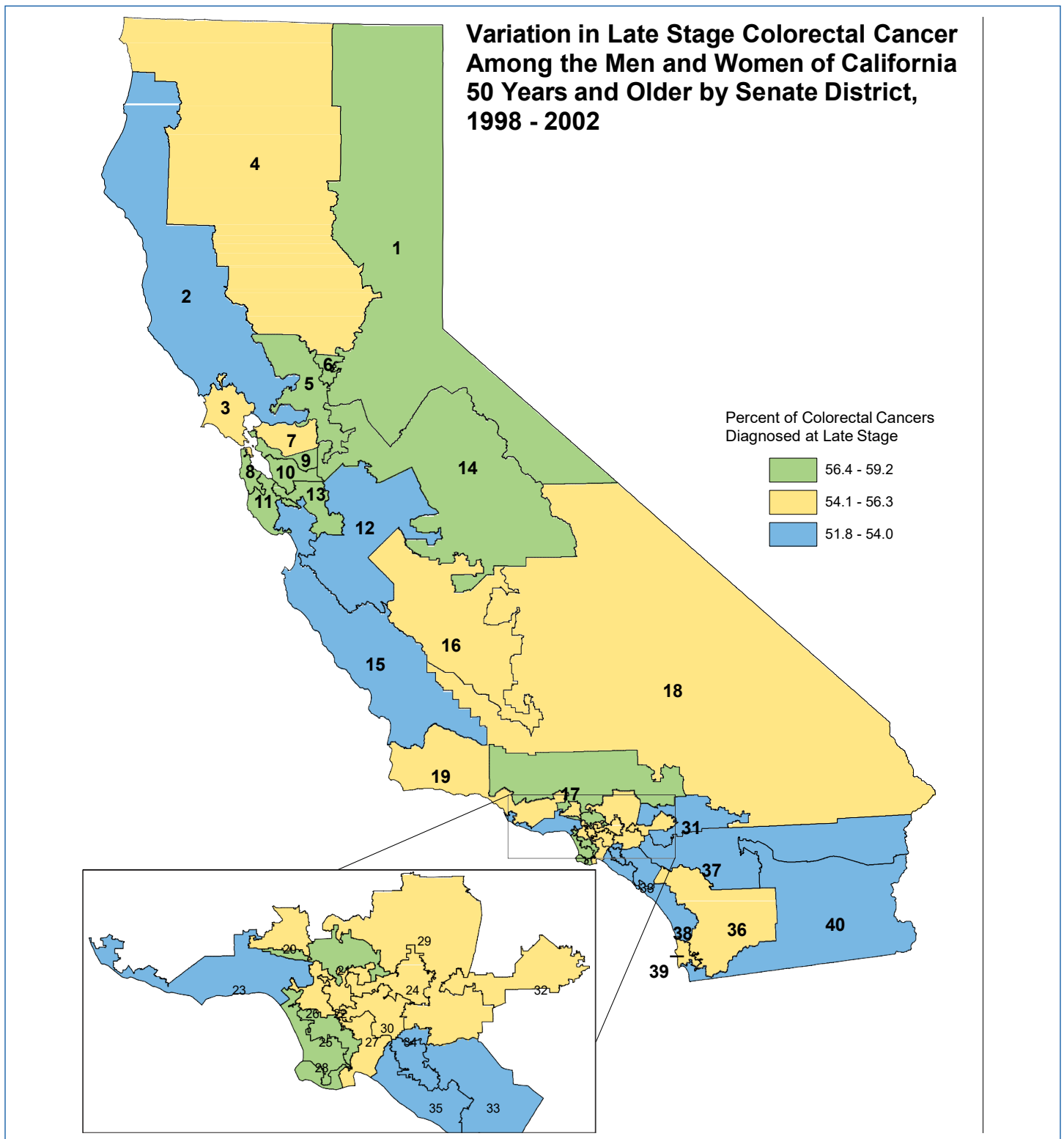


Figure 2: California Cancer Registry. October 2007 incidence data 1998-2002; 2000 Census population at block level, age-adjusted to the 2000 US Population.

TASK
2

Establish Your Structure

The state-level colorectal cancer collaborations profiled in this guide have had success operating under one of two models:

1. Task groups or committees organized within their state's comprehensive cancer control (CCC) coalition, funded by the CDC, and typically administered through the state's department of public health; or,
2. Independent, not-for-profit organizations operating in concert with their state CCC program and/or coalition.

While there are a number of ways to form a collaboration, there are many reasons to coordinate efforts with state comprehensive cancer control activities. Aligning efforts improves stakeholder inclusion, reduces the chance for duplication of planned strategies and initiatives, and displays a united front from the cancer community. The example collaborations highlighted in this guide are similar in terms of staffing structure, volunteer involvement, and the effort to advance goals.



Model 1: Colorectal Cancer Committees within Comprehensive Cancer Control Coalitions

A defining component of the CDC's NCCCP has been developing and supporting a unique cancer control infrastructure through the formation of regional and local CCC coalitions.

Advantages

CCC coalitions allow partners to maximize the impact of limited resources to achieve desired cancer prevention and control outcomes. Aligning with a state CCC program and coalition helps integrate your goals with both the state cancer plan and coalition priorities related to increasing colorectal cancer screening rates. In addition, aligning with the state CCC coalition increases your network of partners with similar priorities, provides you access to resources including professional expertise in areas such as access to and utilization of surveillance data, planning and evaluation, implementing evidence-based strategies, and helps make you aware of announcements of new funding opportunities.

Often, CCC coalitions have a strong advocacy agenda which can enhance your efforts to remove barriers to screening for particularly the underserved and uninsured population groups. In most instances, this structure allows access to staff support from the state's department of public health, as well as access to funding, potentially, from the CDC and state appropriations.

Staff support is critically important to early efforts, thus access to CCC staff, in particular, can make early implementation efforts easier. It also provides the opportunity to more closely interact with state work groups or committees that are focusing on other types of cancer, enabling cross-pollination of ideas and resources.

Disadvantages

Coalition leaders interviewed say that disadvantages to this structure are mainly related to the restrictions imposed on how funding from a state or government entity can be used. State department of health staff may face fundraising and lobbying restrictions. Funds allocated to the CCC coalition by the CDC are also restricted to specific categories of use, some of which may be allocated to prevention and early detection of other types of cancer, tobacco prevention and control, or survivorship initiatives.

Programs underneath the CCC umbrella are also generally tied to the state's cancer plan and cannot necessarily choose to pursue other initiatives. However, the operational and funding structure of CCC programs and coalitions vary in each state, so it is important to learn, discuss, and navigate how best to align with a CCC coalition, weighing the advantages and disadvantages of these models.

Model 2: Independent CRC Coalitions

Some state-level colorectal cancer collaborations began life as a work group within their state's CCC coalition, and after achieving some success, made the decision to “break off” and form an independent not-for-profit organization.

Forming a separate voluntary organization (particularly as a formalized 501c3) results in fewer constraints on the colorectal cancer collaborative's activities, the most important of which are the freedom to raise outside funds and engage in advocacy and lobbying.

If the collaborative establishes itself as a separate entity, participation as a member of the state's CCC coalition is recommended due to the advantages explained above. This type of partnership is highly encouraged and critically important to coordinate activities and avoid duplicating efforts.

While this approach has clear advantages, forming a 501c3 can be a time-consuming process. Additionally, the added responsibility and challenge of fund-raising should not be underestimated.



“They can go out and raise their own funds, run events, and such, without having to deal with any bureaucracy.”

(California Colorectal Cancer Coalition)

Example State-Level Colorectal Cancer Coalition Structures

Coalition	Structure	History
California Colorectal Cancer Coalition (C4)	Non-profit	The C4 coalition began as a subcommittee of the state's comprehensive cancer control program, the California Dialogue on Cancer (CDOC). It later formed an independent 501c3 organization known as C4; however, there is still considerable overlap in participation. C4 leaders continue to help with the development of colorectal cancer goals in California's state cancer plan, and C4 has received CDC-funded grants from CDOC. C4's independent status gives it the freedom to raise outside funds to supplement activities and establish its own goals and initiatives. California's independent C4 coalition is led by a president and a 22-member board consisting of advocacy organizations, gastroenterologists, surgeons, survivors, and representatives from the state department of public health.
Delaware Cancer Consortium	DOH staffed, chairs appointed by the governor	The Delaware Cancer Consortium began in 2001 as a one-year advisory committee established by the state legislature. Today, committee chairs are appointed by the governor, committees are comprised of volunteers, and department of health staff provide program management support.
Kentucky Cancer Consortium	CCC program affiliate	The Kentucky Cancer Consortium is the state comprehensive cancer control coalition. It works in partnership with the Kentucky Colon Cancer Screening Advisory Committee (KCCSAC), which was assembled in 2008 to provide recommendations for the implementation and conduct of the Kentucky Colon Cancer Screening Program.
Minnesota Cancer Alliance	CCC program affiliate	Minnesota's Colon Cancer Network is one of four topic-specific committees within the Minnesota Cancer Alliance—the coordinating body for the state's comprehensive cancer control efforts.
South Carolina Cancer Alliance	Non-profit	The South Carolina Cancer Alliance is a nonprofit organization led by a board of directors and staff. The Alliance has a subcommittee focused on colorectal cancer. They partner with the Center for Colon Cancer Research at the University of South Carolina to address statewide colorectal cancer issues and both have strong participation from the local academic community.



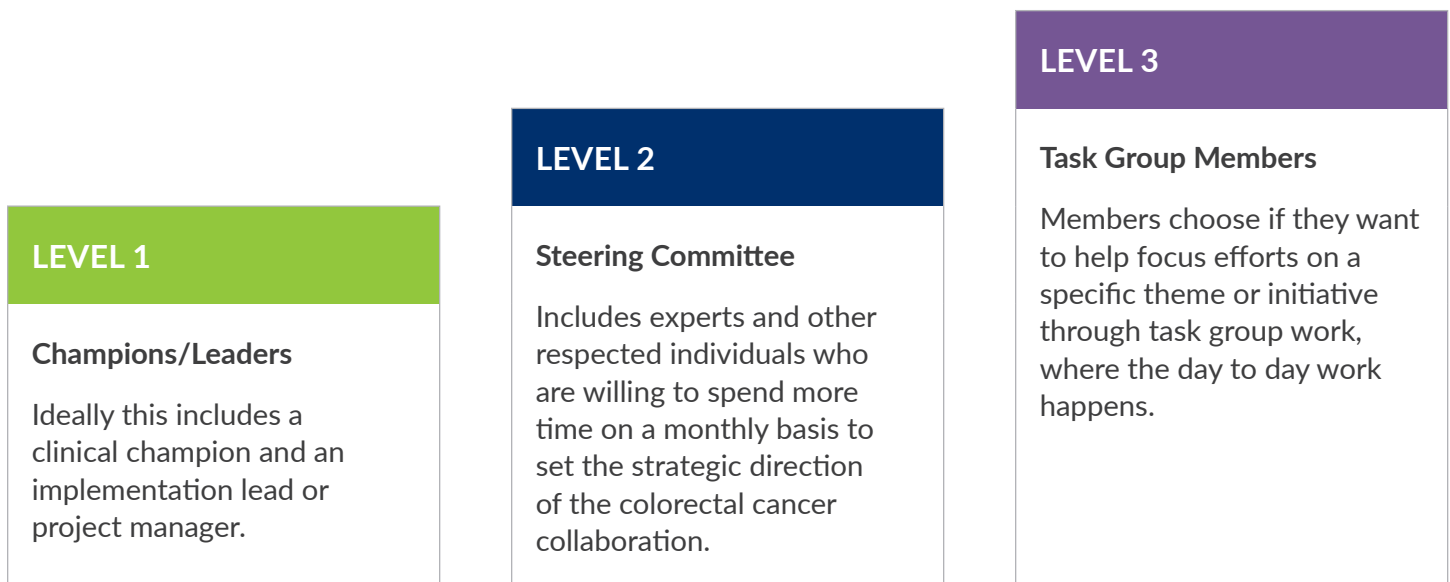
Advantages and Disadvantages of Structures

	Advantages	Disadvantages
Colorectal Cancer Collaborations within CCC Programs	<ul style="list-style-type: none"> • Established network of partners • Staff support through the CCC programs and/or coalitions • Access to CDC funds and (potentially) state appropriations • Goal alignment with both the state cancer plan and coalition priorities • Close interaction with other department of public health cancer programs • Access to resources, including professional expertise • Access to announcements of new funding opportunities • Alignment with CCC coalition advocacy agenda 	<ul style="list-style-type: none"> • Potential restrictions on fundraising • Potential restrictions on lobbying and advocacy efforts • CCC coalition scope and state cancer plan may include priorities other than CRC
Independent CRC Collaborations	<ul style="list-style-type: none"> • No restrictions on fundraising • No restrictions on engaging in lobbying and advocacy • Flexibility to focus on scope or work that is different than the CCC coalition scope and state cancer plan 	<ul style="list-style-type: none"> • Time-consuming to start a 501c3 • Time-consuming to fundraise • Need to identify paid or volunteer staff • Additional effort to coordinate with the CCC coalition

Internal Structure

Once the state-level colorectal cancer collaboration is established, choices need to be made about the type of leadership and work group structure that will be employed. As an example, the structure used by the NCCRT allows members to participate at a level that is comfortable and realistic for them. By offering different levels of involvement, no one is asked to take on more than they can handle.

For smaller colorectal cancer collaborations or those that are just getting started, a simple structure with just one or two co-chairs/champions and a small advisory group of key partners may suffice. For a larger collaborative with many members, the structure below (which mirrors the NCCRT structure) may be a good approach.



More details about the purpose of the steering committee and task groups are outlined in Task 4.



TASK GROUPS

The Kentucky Cancer Consortium found that the following division of labor was fruitful for their structure:

- Public awareness
- Providers
- Policy
- Quality

TASK 3

Develop a Vision

State-based collaborations formed to prioritize colorectal cancer can benefit from outlining their vision at the outset. A well-crafted vision aligns partner ambitions, provides inspiration, and establishes a path for future strategic planning. See the example mission statement from the California Colorectal Cancer Coalition (C4).

Building on a CCC coalition's existing vision, which takes a strategic approach to preventing or minimizing the impact of cancer in communities, has proven successful. The CCC process requires state and local health departments, community organizations, researchers, health care providers, decision makers, cancer survivors and their families, and many others, all coming together to identify and agree upon ways to address cancer concerns in their communities.



A newly established state-based colorectal cancer collaboration might benefit from developing a similar vision to that of state CCC coalitions. This vision includes:

- Building coalitions of stakeholders who are willing to share resources and expertise to fight cancer.
- Using data from cancer registries, behavioral risk factor surveys, and other sources to learn more about the cancers and risk factors that impact their communities most.
- Developing and implementing strategic plans to address the burden.
- Setting priorities and leveraging resources to implement evidence-based interventions to support behavioral lifestyle changes to prevent cancer; ensure access to screening services to detect cancers early; as well as to ensure access treatment services through policy, systems, and environmental change strategies.
- Paying special attention to the needs and concerns experienced by groups of people in their communities with poor cancer health outcomes.
- Paying special attention to the needs and concerns of the cancer survivors and their families in their communities, particularly the survivors' (and their families') physical, financial, and emotional well-being.

C4 MISSION STATEMENT

The **California Colorectal Cancer Coalition (C4)** is a nonprofit organization established to increase colorectal cancer screening rates in an effort to decrease mortality associated with the disease. The C4 mission is to save lives and reduce suffering from colorectal cancer in all Californians.

C4 plans to fulfill this mission by:

- Implementing strategies to reduce disparities in colorectal cancer screening, diagnosis and treatment among underserved populations in California.
- Increasing capacity for colorectal cancer screening.
- Advocating for colorectal cancer screening programs to serve uninsured and underinsured populations.

National Colorectal Cancer Roundtable Vision and Role

For reference, when establishing a vision, it may be helpful to align with and learn from the NCCRT.

The NCCRT is a national coalition of public, private and voluntary organizations dedicated to reducing the incidence of and mortality from colorectal cancer in the U.S., through coordinated leadership, strategic planning, and advocacy. The NCCRT serves as a forum for communication and developing consensus; stimulates collaboration on projects; and leverages the talents of the members to jointly conduct studies, create tools and identify emerging issues that can advance colorectal cancer screening.

It has been a long-standing principle that the NCCRT not compete with its member organizations or duplicate their work or missions. Rather, the NCCRT strives to stimulate collaboration and take on projects that no one else is doing but that everyone agrees needs to be done.

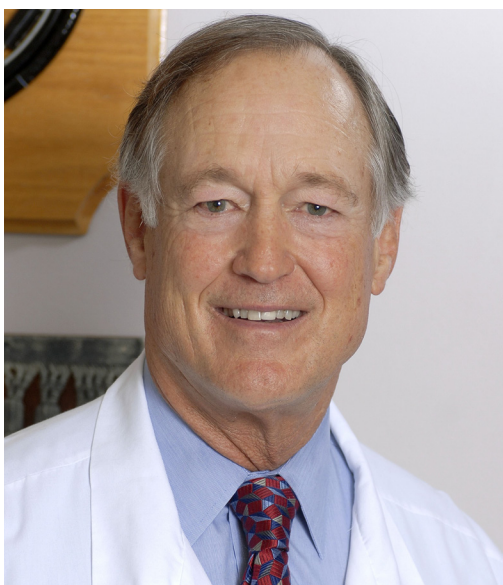
So, after articulating the need, identifying the appropriate structure, and defining the vision, what other steps should be taken to ensure success? The remainder of this guide will review a variety of tasks, funding opportunities, partnerships, and other aspects that have contributed to the creation of well-functioning and impactful collaborations.

More than 97% of National Comprehensive Cancer Control Program grantees have included colorectal cancer screening goals in their state cancer control plans. Over thirty have signed the 80% pledge (<http://nccrt.org/80-2018-pledge/>).



TASK 4

Recruit Leadership and Staff



"What led to its development and continued success is who is leading it. Nothing is more significant than the motivated individuals who lead it."

*- Daniel "Stony" Anderson, MD
California Colorectal Cancer
Coalition President*

Leadership

Successful colorectal cancer collaborations draw support from a wide network of partners, but their success often hinges upon the commitment of an expert champion and the diligence of a project manager/implementer working together to achieve goals.

In the beginning, the colorectal cancer collaboration may consist of little more than these most committed individuals and a handful of others. However, what matters most at the beginning is having people that have a true passion for the work.

Grant Applications Due Friday, December 19.

Grant submission confirmation available by request.

Message from the President

Welcome to the C4 web site and thank you for taking the time to review this site. The California Colorectal Cancer Coalition (C4) is a nonprofit organization made up of a diverse group of dedicated individuals from throughout California whose mission is to save lives and reduce suffering from colorectal cancer in all Californians.

Colorectal cancer is a common and deadly disease. Colorectal cancer is the fourth most common cancer and the second most common cause of cancer deaths in California. Both the numbers of colorectal cancers and the deaths from colorectal cancer are reduced by screening for colorectal cancer in men and women over 50. Unfortunately, the majority of Californians over age 50 have not been screened for colorectal cancer. Californians are suffering and dying from this disease because they are not getting screened.

Expert Champions

Identifying a passionate, charismatic expert champion is critical to success. The champion is often a clinician who can provide expertise and intellectual leadership, connect the colorectal cancer collaborative to a network of peers, and legitimize the effort to spur the involvement of others.

The champion is often a well-respected primary care physician, gastroenterologist, or surgeon (or a combination of these as co-chairs). Having a clinician at the helm lends credibility to the work and provides opportunities to build bridges between clinicians and other important partners such as public health advocates and state government agencies.

The five collaborations highlighted in this document all have champions that self-identified once the word was put out that a statewide colorectal cancer effort was being organized.

It is likely that these champions are already working in an advocacy role, possibly volunteering to provide free colonoscopies or serving on a charitable board.

Because the champion will often be the “face” of the collaboration, he or she should ideally have the following characteristics:

- Passionate about colorectal cancer prevention
- Strong clinical knowledge of colorectal cancer
- Leadership orientation
- Well connected with other clinical and advocacy leaders across the state

It can also be advantageous to have dual-leaders or co-chairs to share the workload. A public-private partnership, can also be a valuable means of signaling the breadth and importance of the initiative to potential new partners.

“Getting the right people in place that have a great passion for the work tends to attract other great and talented people and gets them engaged. Then it seems to just continue to grow.”

- Minnesota Cancer Alliance



LEADERSHIP

Ideally, the champion will not only be a natural leader, but also persistent about asking for help from peers and partners.

The National Colorectal Cancer Roundtable is chaired by Dr. Richard Wender, a respected primary care physician. As the face of the NCCRT in many national and state level forums, he brings attention to the NCCRT’s key initiatives through speaking engagements, public relations, and media such as a YouTube video about ten steps to reach 80%.

PROJECT MANAGEMENT SUPPORT

The colorectal cancer work group in the Delaware Cancer Consortium receives staff support from public health specialists in the Department of Public Health. These specialists are funded by the state, with their support of the consortium established through state statute. One specialist attends each committee meeting, monitors progress, reports on decisions made and follows up with attendees.

Project Managers/Implementation Leads

In addition to a clinical champion, state level colorectal cancer collaborations benefit from having staff or volunteers who can take on a project management or implementation role. Often, for colorectal cancer collaborations that are sub-committees in their state CCC coalition, this role is filled by one or more staff members of the department of public health who are able to devote part of their professional time. For independent colorectal cancer collaborations, it may be a partial FTE position contributed by a member organization (e.g. ACS) or a volunteer. Ideally, implementation staff should have the following characteristics:

- Passionate about colorectal cancer prevention;
- Possess excellent communication skills;
- Have strong organizational and management skills;
- Able to facilitate group meetings.

Implementation staff serve a coordinating role, manage the day-to-day work of maintaining the coalition's structure, and communicate with constituents. Their work is both logistical and strategic. Some of the essential tasks completed by implementation staff that lead to success include:

- Coordinating and planning calls and meetings, including drafting meeting agendas and minutes;
- Following up with committee members on assigned tasks;
- Conducting project management;
- Finding and coordinating with speakers;
- Doing background research/finding needed data;
- Confirming and orienting new members;
- Developing and maintaining a website;
- Maintaining relationships with state legislators;
- Writing grant applications;
- Managing distribution of funds;
- Managing fundraising activities;
- Gathering data to demonstrate program impact;
- Drafting annual reports; and,
- Writing and distributing news updates.

It is important to establish an effective division of labor between the champion and any staff. While there is no right or wrong way to divide the work, generally, a volunteer champion is willing to provide intellectual leadership, review draft materials, and contact other leaders. Staff should consider how to best support the volunteer champion's limited time.



Steering Committee

Though not necessarily referred to as a steering committee, champions are often supported by a core group of dedicated partners willing to contribute more time and energy to keep the collaboration moving forward. These members should ideally be influential and well networked. They will be called upon to help make strategic decisions about the direction of the collaboration, but also to make phone calls and recruit new partners and contributors. Sometimes members of this core group include individuals with additional skills that can help in key ways (e.g. researchers, experts, fundraisers, attorneys). Staff should strive to support the Steering Committee in a similar way that they support the champion.



POTENTIAL PARTNERS

- State Department of Public Health
 - Comprehensive Cancer Control Program - CDC
 - Colorectal Cancer Control Program - CDC
- American Cancer Society
- Advocacy organizations
- Health systems and hospitals
- NCI-designated cancer centers
- Cancer institutes
- Academic medical centers and affiliated universities
- State/regional medical professional societies (e.g., AGA, ACG, AAFP, ACP, SGNA)
- State Primary Care Associations
- Commission on Cancer State Chair
- Federally Qualified Health Centers
- Ambulatory surgery centers
- Large employers
- Survivors
- Medicaid leadership
- Private industry (e.g. FIT/FOBT manufacturers)
- Gastroenterologists
- Clinical quality organizations
- Health plans
- State Health Insurance Exchange
- Legislators, staffers, local political leaders
- Fraternal or business organizations
- Political leadership (e.g. mayors)
- Pharmacists
- Local celebrities touched by CRC

State Level Leadership

Steering committees or boards should be developed with diverse membership. Below is an example of California's C4 Board Members.

Name	Organization
President Daniel Anderson, MD, FACP	Staff Gastroenterologist SCPMG Clinical Professor of Medicine UCSD
Vice President Margaret Hitchcock, PhD	University of California, Davis
Secretary/Treasurer Jessica Jamison, MPH	
James Allison, MD	UCSF and Kaiser Division of Research
Taft Bhuket, MD	Division Chief, Gastroenterology & Hepatology Director, Endoscopy Unit Highland Hospital
Jennie Cook	President-Intercultural Cancer Council Caucus
Lukejohn Day, MD	Department of Gastroenterology School of Medicine San Francisco General Hospital and Trauma Center
Laura Goetz, MD	General/Oncology Surgeon, Scripps Clinic Medical Group
Jon Greif, DO, FACS	Retired
Samir Gupta, MD, MSCS	Department of Gastroenterology School of Medicine University of California, San Diego
David Hamilton, MSN, CS, ACNP-BC	US Davis Health
Gregory Idos, MD	Division of Gastroenterology and Hepatology University of Southern California
Michele Limoges-Gonzales, NP	Division of Gastroenterology UC Davis
Folasade May, MD, MPhil, PhD	UCLA School of Public Health
Meghan Nousaine	California Primary Care Association
Autumn Ogden-Smith	American Cancer Society Cancer Action Network
Michael Potter, MD	UCSF School of Medicine
Liisa Russell, M.D.	School of Osteopathic Medicine Touro University, California
Todd Setter	Colon Cancer Survival Advocate
Joan Watson-Patko, MSW	Senior Director, Primary Care Systems West Region American Cancer Society, Inc.
Joanne Wellman, RDH, MPH	Retired
Holly Whittaker	Nevada County Public Health Department
Ex-Officio Shauntay Davis, MPH	Program Director - Comprehensive Cancer Control Program CA Department of Public Health
Ex-Officio Marilyn Kempster	CA Department of Public Health
Ex-Com Emeritus Sandra Robinson, MBA	CDPH

Task Group Chairs and Members

In some colorectal cancer collaborations, day to day work happens through the work of issue specific task groups.

The NCCRT has found that a diversity of task groups provides members with the opportunity to address colorectal cancer screening, prevention, and early detection on many different fronts. This structure also allows the NCCRT to leverage the skills and expertise of the participating organizations to advance work on shared priorities. Through this spirit of cooperation, the NCCRT taps into the expertise of its partners to create tools, conduct studies, conduct outreach, and support projects. Task groups are also chaired or co-chaired by experts or leaders, who sometimes also serve on the Steering Committee. To learn more about the NCCRT task groups visit <http://nccrt.org/about/task-groups>.



TASK 5

Build a Network of Partners

Most leaders of well-established colorectal cancer collaborations relayed that the support of two key partners was critical to have from the beginning—the state department of health and the American Cancer Society. Beyond that core, coalitions have taken varied routes when it comes to engaging a network of contributing stakeholders.

Identifying Potential Partners

Existing colorectal cancer coalitions took a thoughtful, strategic approach to identifying potential partners. They started by developing a priority list of organizations and individuals who are critical to the effort based on projects that have been identified as early priorities. Partners include those who are already acting in leadership roles, those who are highly influential and well networked, and organizations whose commitment is essential to fulfilling the strategic priorities of the colorectal cancer collaborative. A secondary list may include potential partners whose participation is desirable, but not essential.

“Identify people that are really movers and shakers.”

- Minnesota Cancer Alliance

The National Colorectal Cancer Roundtable (NCCRT) is an organization of organizations, meaning that individuals participate in the NCCRT on behalf of their organizations. This set up helps extend the reach and impact of the coalition and also ensures continuity with key organizations if a respected individual retires or changes professions.

Additionally, the NCCRT has a formal application process, in which organizations must apply for membership, which helps ensure a higher level of visibility and commitment from the overall organization, which also helps to protect the NCCRT from partners who may be more interested in advancing their own agenda than promoting public health.



Some states may already have a core group of people who have been working together on colorectal cancer issues. To ensure that the new collaborative approach goes beyond what has previously been done, it is important to expand ownership of the issue beyond the original core group. Consider reaching out to potential partners who have been successful in other arenas, such as advocacy for breast or cervical cancer, as they may bring fresh ideas and energy to the group.

Valuable partners will also be found in the business community, universities, government, hospital systems, local community health centers, and the political arena. The colorectal cancer collaborations interviewed for this publication have seen significant benefits from the involvement of individuals with experience in fundraising, law, marketing, media, and public relations.

Although not all the states profiled here have partners in the political area, some have reaped significant benefits from the involvement of state legislators, staffers, and others in the public sphere. For example, Delaware's Cancer Consortium has received considerable state funding in part because the former governor of the state was involved from the beginning of the effort, and state legislators sit on the coalition itself.

The Delaware Cancer Consortium facilitates their involvement by sending information and reports to all lawmakers and giving presentations to legislators to educate them on consortium initiatives. Similarly, in Kentucky while legislators are not members of the consortium, Kentucky Cancer Consortium leaders have made a conscious effort to identify and contact all state legislators who are known to have a personal connection with cancer to ensure that they are familiar with the consortium's work.

“Focus down on what the priorities are for the state, for the organizations, for the country—like 80% by 2018—and then go find the people that are in that line of work who can come together to make specific progress.”

- California Colorectal Cancer Coalition

DELAWARE'S CANCER PROGRAM IS *getting noticed*

The hard work of the members of the Delaware Cancer Consortium, Governor Ruth Ann Minner, and the legislature, and the ongoing efforts of the Division of Public Health in the fight against cancer have been noticed and applauded in a variety of ways.



Governor Ruth Ann Minner

As a result of her leadership, Governor Minner has accepted an invitation from former President and C-Change co-chair, George H. W. Bush, to serve on C-Change, an organization comprised of the nation's key cancer leaders from government, business, and nonprofit sectors. She has shared Delaware's efforts with the committee in a presentation. These cancer leaders share the vision of a future in which cancer is prevented, detected early, and cured, or is managed successfully as a chronic illness.

In addition, both the Centers for Disease Control and the National Cancer Institute continue to use Delaware's cancer program as an example of an effective model to motivate other states.

Figure 3: Former Governor Ruth Ann Minner was an important driving force behind Delaware Cancer Consortium's (profiled in First Four Years - Year 3 Report)

Finally, cancer survivors have an important role to play in a state level colorectal cancer collaboration. Survivors may serve as patient advocates and are often able to provide insight into community-level resources and partners that might otherwise be overlooked. Survivors who are also active in the business or political community can be particularly valuable to the effort by sharing their stories and making the need to save lives from the disease both real and personal to their business or political constituency.

MAKING THE CASE WITH DATA

Types of data that can be used to make the case and define the need for involvement:

- Percent of state population up to date with screening
- Percent of people in the state without health insurance
- Number of people who would face high deductibles for screening
- Wait times for a diagnostic colonoscopy
- Locations of community health centers and share of population served by them
- Share of population served by each health plan



Prepare the Case for Participation

Before approaching potential partners, a case for commitment should be developed. This process should draw from some of the findings discussed in *Prioritizing Colorectal Cancer* on page 7, but should also include researching the potential partner's interests and activities along with describing the proposed effort in detail. Presenting the colorectal cancer collaboration as an organized, well defined effort can generate excitement for the cause.

“If you want people to respond to a challenge, you’ve got to describe the challenge.”

- American Cancer Society

Compiling the following information will help make a strong case for partners to participate:

- Data that defines and explains the population need and makes a strong case for a new/renewed statewide focus on colorectal cancer.
- Vision of the new group and how it is differentiated from what has been done before in the state.
- Specific information about who is being approached and what is being asked of each partner – action-oriented participation/particular areas of expertise and time commitment.

In Minnesota, the Department of Health provided high quality, specific data about the prevalence of colorectal cancer in the state and the needs of target audiences.

This data was used by coalition leaders when approaching partners and helped to clearly define the need and possible scope of their involvement.

“The medical groups were more comfortable having a discussion about donations when we were able to share real numbers rather than vague statements. Once they could see the real numbers, it provided them some comfort to give it a try.”

- Minnesota Cancer Alliance

Once potential partners are identified and the case for participation has been prepared, it is important to identify the right person to approach potential partners and ask for their support. A personal call from a leader or trusted member can open doors that may not be opened in other ways. While these personal contacts may be time-consuming for your leaders in the beginning, the investment will pay off in the end. Momentum will begin to build and other partners will want to be a part of something that they know has the support of leading organizations and respected peers.

Gaining the attention of clinical partners may be made easier by enlisting the support of state leaders from organizations like the American Academy of Family Physicians, the state's primary care association, or a State Chair from the American College of Surgeons. These organizations are said to play an important role in getting individual providers or practices to take notice.

“You do need someone who is a little higher up in the organizational standing who can make these calls and have more influence.”

- American Cancer Society

Meeting Partners' Needs

To attract and retain involvement from partner organizations, the coalitions profiled paid attention to meeting the strategic needs of partners as well as focusing on the public health goals of the CRC collaboration.

When it comes to approaching private and for-profit companies like health plans, health systems, or large employers, a business case can help secure participation in the CRC collaborative along with looking for unique “win-win” opportunities. For example, fundraising efforts can be paired with business leaders' desires to promote their organizations. Similarly, health systems may be encouraged to donate colonoscopies in exchange for recognition in marketing materials.



When meeting with potential partners, your leaders should explore what the partner's priorities are and what resources they need to accomplish their goals. Partners should be given ample opportunity to talk about their work and what is needed to advance their own initiatives. Areas of mutual concern that can be advanced through partnership can then be identified.

Setting Expectations for Involvement

When setting the stage for active participation from partners, it is important to clearly convey expectations at the beginning. For a volunteer coalition to be effective, partners need to know that they are signing up for a work group, not an advisory committee, and that they are being asked to contribute something concrete. At the same time, it is important to convey that their contribution is not open-ended and that if all volunteer members share the burden of effort, much can be accomplished without overwhelming any single member.

To make sure partners understand what is expected of them, some colorectal cancer coalitions ask potential members to submit formal applications and go through a review process before being admitted, as done by the NCCRT. Leaders from the Minnesota Cancer Alliance note that although their application process for steering committee members is not simple, it is a good way to signal to potential members that they are serious about this being a work group. Those who are willing to go through the application and approval process are more likely to also be committed to the effort for the long run.

“People who are part of the coalition are very passionate. They want to do the work. It’s not just a name thing...you really work when you’re part of this coalition, but people are happy to do so.”

- California Colorectal Cancer Coalition



Naturally, not all potential partners will be willing or able to contribute equally to a work group. Some may only want to join to network, share, or receive information. These members can receive key information via email lists and newsletters in the interim and can revisit their involvement at a later date. Once a few early successes are documented, it may be easier to engage organizations that expressed hesitancy in the beginning.

It may be challenging to gain participation from certain types of private organizations because of competitive interests. For example, two health systems or hospitals with overlapping service areas may be hesitant to share information in a public forum.

In other cases, such as for large health systems, it may be difficult to make contact with key leaders (e.g. CEOs, CFOs, or CMOs) who are in a position to make commitments on behalf of the organization. In these cases, it is important to find and leverage personal connections that members may have.

“Part of it is having a core group that’s really motivated and can motivate others...it’s easy to have a meeting. The hard part is getting people to do things once they leave the meeting.”

- CDC

Some approaches that have worked include networking to influential leaders in these organizations through existing business relationships or personal connections on charitable boards and moving up the ranks of the organizations by first approaching employees who are most likely to care about the cause—e.g. hospital-employed gastroenterologists or oncologists.

Once that connection is made, the coalition’s champion will need to sit down with organizational leadership to understand their mission and values, discuss the role the organization can play and the benefits to involvement.

LEVELS OF INVOLVEMENT

The Minnesota Cancer Alliance allows prospective members to choose their level of involvement. New members who are not sure about participation have the option of joining a task group that meets only a couple of times a year.

TASK
6

Convene Partners

PRODUCTIVE MEETINGS

The Prevent Cancer Foundation's *Dialogue for Action* process encouraged state coalitions to emerge from a summit meeting with three focus areas. Each state was free to develop different focus areas, depending on local resources and conditions. In Kentucky, the coalition voted and decided on the following priorities: 1) public awareness, 2) provider awareness and recommendations, and 3) policy/advocacy efforts at the state level.

(See the appendix of the guide for a more detailed description of the dialogue process.)

Summit or Kick-Off Meeting

Most established state colorectal cancer collaborations report that holding a kick off meeting or summit was a critical step in getting partners to the table to discuss the issues, agree on priorities, develop a plan, and secure commitments to move forward.

In some situations, this type of summit meeting takes place before an operational structure has been developed and before potential partners fully commit. If that is the case, key goals of the meeting should be established by the hosting organization and champions: 1) the formation of a colorectal cancer collaboration and 2) a commitment from attendees who wish to formally participate.

“We had scientists, physicians, survivors, the wife of the governor, public health advocates, government people—a wide range of people showed up, and there was this huge energy to do something across the state with regard to colorectal cancer. That’s what kicked it off.”

- South Carolina Cancer Alliance



“You need the usual suspects, but it has to be an occasion to go beyond that. Otherwise you’re not going to see something new and bigger happening.”

- Prevent Cancer Foundation



MEETING RESOURCES

The *Kentucky Cancer Consortium* relies on a rotating series of sponsors and partners (acknowledged and thanked in meeting agendas) to provide meeting space and lunches at quarterly meetings. For example, past sponsors have included the University of Kentucky College of Medicine and College of Public Health, the Kentuckiana Lung Cancer Alliance, Bristol Myers-Squibb and Humana KY.

In other situations, a summit meeting takes place after a core coalition group has formed and partners have committed. In that case, the purpose of the meeting may be to develop a set of strategic initiatives and assign responsibilities for moving forward.

Meeting Size and Scope

The size and scope of this type of summit meeting can vary dramatically. States reported having anywhere from 15 to more than 150 attendees. Although it is important to have a core group that is already committed to the colorectal cancer coalition (e.g. the steering committee), this summit does not need to be limited to those who have already agreed to a broader commitment. In many cases, individuals who attend this type of summit may not ultimately join the efforts or remain active in them. However, their participation can provide valuable input, perspective, and resources and sow the seeds of future involvement.

To carry out a successful summit meeting, it is important to plan ahead, agree in advance what it is the leaders most want to get out of the event, and figure out how to make the best use of the time of the experts who are coming together.

Conducting Initial Assessment

Initial assessments of colorectal cancer control activities prior to the meeting, can help ensure a good use of everyone’s time. This can include e.g. a pre-meeting survey of stakeholders to understand partners’ perspectives and prepare to address them or pre-meeting planning sessions with members of the steering committee. Prep for each of the yearly Dialogue for Action meetings, for example, included conducting a background survey, stakeholder interviews, and numerous planning committee calls. The NCCRT has found that short, carefully designed, pre-meeting surveys that explore problems and solutions can be especially helpful to the meeting’s success ([sample included in Appendix](#)). Pre-meeting surveys are a way to get stakeholders invested early in the process, and serve many purposes:

- Ensuring attendees give careful thought to key issues in advance;
- Assisting attendees in the organization of their thoughts;
- Preparing attendees to serve as active participants at the meeting;
- Documenting problems in advance, thus focusing the meeting agenda on solutions; and,
- Identifying best practices or pockets of success.

The NCCRT also shamelessly flags these pre-meeting surveys as a priority for attendees, sending several reminders that often come from the Chair to ensure that attendees understand the importance of participating in the process ([sample included in Appendix](#)).

Work also goes into traditional event planning tasks like speaker planning, developing the attendee list, creating the agenda, securing and prepping speakers, securing sponsors, printing materials, arranging meals and travel, and securing meeting space (a partner organization in a centrally located part of the state can be asked to donate a room).

Meeting Agenda

The most important advice that the NCCRT can offer is that the meeting must be solution-oriented.

Presentations & Speakers

While a short (30 minute or less) presentation on the problems is helpful to ensure that issues are put on the table, the meeting will not succeed if too much time is spent rehashing all the reasons that getting people screened is hard. Rather, the time should be used to focus on solutions and success.

Speakers should be selected who are leaders in the field and who can describe assets that are available through collaborative work, such as partnerships, pilot projects, data collection tools, and promising interventions.

Speakers should be pushed to analyze their work in terms of how it can inform larger efforts. What was key to their success? What were their lessons learned? What advice do they have to offer a larger strategy? How could their effort be expanded?

The NCCRT often designs “lightning round” presentation panels, asking four to six experts to deliver key information in short 8 minute presentations ([speaker template included in Appendix](#)).

While preparing a short presentation can actually be harder for a speaker than delivering a lengthier presentation, this method generates new ideas, while protecting discussion and brain-storming time that will be essential to the day’s success.

Working Groups & Breakout Sessions

Another successful approach to effective utilization of meeting time is the use of breakout groups. This tool is especially effective when a large number of people have come together. For example, the Minnesota Cancer Alliance uses this approach effectively by placing attendees in several small groups and assigning each group a task or problem on which to brainstorm.

Breakout topics at a recent roundtable meeting in Minnesota included access to screening for the uninsured, generating demand among the uninsured, and supporting provider recommendations for screening. Working collaboratively, the group had time to generate ideas and then reported back to the larger group.

“Once you have those conversations, sometimes you have to close the deal...after the strategies have been talked about, after some agreements have been made about how to proceed, then you have to get out and ask. Sometimes it’s uncomfortable to put an organization on the spot, but you just need to ask.”

- Minnesota Cancer Alliance

Meeting Outcomes

If one of the champions or a member of the steering committee has experience as a meeting facilitator, they can be tapped to direct the meeting and guide attendees to clear decisions and commitments. If there is money available, consider engaging a professional meeting facilitator.

Meeting planners and leaders must agree in advance what it is they most want to get out of the kick off meeting and prepare accordingly. Where do they want to be at the end of the day? Do they want a formal commitment from some attendees? Do they want to launch some initial projects? Do they want to create a task group structure? If so, the meeting must be designed to discuss the vision for these goals and secure commitments.

Before committing, attendees will want to know how often they will meet and what the commitment entails. Whoever is directing the meeting should be willing to make a direct ask of attendees (commitment template included in Appendix).

Sample Meeting Agenda: Minnesota Cancer Alliance

Colon Cancer Prevention: The Next Quantum Leap A Health System Roundtable Discussion	
Preliminary Agenda	
March 5, 2009 8:00 a.m. – 12:00 noon Medica Headquarters, Minnetonka	
8:00 – 8:15	Welcome: Why Colorectal Cancer? Sanne Magnan, MD, PhD, Commissioner of Health
8:15 – 9:15	Background Data Panel: “Where are we today?” Carin Perkins, PhD, Minnesota Cancer Surveillance System Jim Chase, Minnesota Community Measurement Brian Rank, MD, HealthPartners
9:15 – 9:45	Optimal Colorectal Cancer Prevention: “Where do we want to go?” John Allen, MD, MBA, Minnesota Gastroenterology
9:45 – 9:50	Introduction to Roundtable Discussions: Ken Joslyn, MD, MPH
9:50 – 10:00	BREAK
10:00 – 10:45	Roundtable Discussions: <i>Seeking systems solutions</i> “How do we take the first steps?”
10:45 – 11:15	Report out
11:15 – 11:55	Discussion: “ <i>New thinking, New processes, New Structures</i> : “How do we take the first leaps?” Kent Bottles, MD - moderator
11:55 – noon	Wrap Up and Adjourn

Launching the Follow Up

Meeting Recap

Immediately after the kick-off meeting or summit, the coalitions we talked to suggest putting the results in writing and beginning follow up. The meeting will likely generate momentum and good will, and it is important to capitalize on that momentum with quick action. Tangible goals, action items, assignments, and target dates should be documented and distributed to all participants in the form of an informal email, minutes, or a more detailed report. This follow up is important for a few reasons: it captures the momentum that is created at the meeting; ensures that the great ideas generated at the meeting are recorded; reminds participants of commitments regarding follow up activities; and underscores for attendees that this is a serious effort. Attendees should be asked to review a draft of the report, both to ensure accuracy and to maintain a sense of ownership for the launch of the effort. Finally, the planners can consider presenting the report in a follow up webinar to further maintain momentum. Sample meeting reports and minutes developed after coalition meetings can be found in the appendix.

- [Prevent Cancer Foundation Dialogue for Action State Level Digests](#)
- [Delaware Cancer Coalition Colorectal Cancer Committee – Sample Meeting Minutes \(2003\)](#)

Reconvening & Strategic Planning

The leaders and planners should arrange to reconvene by phone within a month after the kick off meeting to review ideas generated at the meeting and determine which are the best fit for the new coalition. **Again, it is the follow up from the meeting that will define success.** Thus, the leaders must quickly work to put a plan in place to make some of the ideas a reality by identifying leaders and work group members, developing a project plan, creating a project schedule, and create some quick wins for the group.

After the coalition has gotten its footing, it may be helpful to also prepare a written strategic plan. Strategic plans are helpful for providing long-term guidance and ensuring accountability. Below are two examples of planning documents developed by coalitions in Kentucky and Delaware.

- [Kentucky Cancer Consortium Resource Plan \(2013\)](#)
- [Delaware Cancer Consortium Multi-Year Strategic Plans and Progress Reports](#)



CRC Objectives and Tasks

From the 2002 Report of the Delaware Advisory Council on Cancer Incidence and Mortality

Create a comprehensive statewide colorectal cancer screening and advocacy program

- 1 Outreach to major health systems to participate in a comprehensive, community-focused colorectal cancer screening and advocacy program
- 2 Develop an evaluation plan
- 3 Hire project screening advocates
- 4 Market project and services
- 5 Project start up
- 6 Operational support

Reimburse for colorectal cancer screening of uninsured Delawareans age 50 and older

- 1 Establish a \$1.5 million annual allocation to colorectal cancer screening for the uninsured
- 2 Establish a system for billing and payment for colorectal cancer screenings whereby funds would be paid directly to health providers for reimbursable services based on Medicare rates
- 3 Provide colorectal cancer screening for uninsured Delawareans 50 and older that includes a comprehensive monitoring and evaluation program
- 4 Revise allocation based on actual costs and projections

Case manage every Delawarean with an abnormal colorectal cancer screening test

- 1 Establish a \$900,000 annual allocation for case management of Delawareans with abnormal colorectal cancer screening results
- 2 Establish a system for case managing every Delawarean with an abnormal colorectal cancer screening using current systems and models that include a comprehensive monitoring and evaluation system.
- 3 Begin case management
- 4 Revise allocation based on actual costs and projections

TASK 7

Set Goals and Objectives

EARLY COALITION ACTIONS EXECUTED WITH LIMITED FUNDING

Early in its history, the **Kentucky Cancer Consortium** devoted \$30,000 to develop a CRC screening toolkit for primary care providers.

This was accomplished through the joint contributions of the KCC and its partner, the Kentucky Cancer Program—Providers Practice Prevention.

Other early work by coalitions has included screening events, public awareness campaigns, training for primary care providers and partnering with community health centers to pilot free screening for the uninsured.



Taking a strategic approach to goal setting is important for early success, and setting firm objectives in well thought out goal areas is a common pattern of successful colorectal cancer collaborations. Goals should encompass and help realize your collaboration's long term vision. Objectives should be concrete, action-oriented, and measurable. At the same time, objectives should be limited to what can reasonably be accomplished. To this end, some state colorectal cancer collaborations have developed ways of evaluating potential objectives in a very systematic way. For example, in Delaware, leaders from their collaborative solicit ideas from stakeholders and then prioritize those ideas based on importance and feasibility.

Goals and objectives can also be closely aligned with state cancer control plans. Even among colorectal cancer collaborations that are non-affiliated with the state CCC coalition, leaders are intimately involved in the development of their state cancer control plans. In essence, the cancer control plan is the common ground between the organized colorectal cancer collaborative and the state CCC program or coalitions.

For example, California's C4 collaborative began as a group of individuals who came together to write the colorectal cancer chapter in California's state cancer control plan. Although C4 and similar colorectal cancer groups may have strategic objectives that go above and beyond the cancer control plan, they typically are developed in cooperation with one another.

“We write the cancer plan here at public health, in collaboration with the consortium members. We provide ideas to them or suggestions and they come up with their own, and then we put it all together. They review it and approve it before it ever gets published.”

- Delaware Cancer Consortium

SAMPLE CRC GOALS

The following goals emerged from South Carolina's Dialogue for Action colorectal cancer summit meeting held in 2007, which was attended by more than 130 leaders from around the state.

- Champion, encourage and assist public, private and nonprofit employers and other decision makers to adopt insurance and workplace policies that encourage prevention and early detection, incorporating worksite screening and/or education programs.
- Develop, implement and evaluate a clear, culturally sensitive multimedia campaign that presents colorectal cancer as preventable and treatable for all populations.
- Review existing programs and identify health services and educational gaps to develop innovative, nontraditional strategies to overcome the barriers and unmet needs for all populations (especially those with the worst general health outcomes, such as the uninsured/underinsured, poor, less educated and non-white).



The goal and objective setting process should be a genuinely collaborative effort among partners. Goals must not be imposed upon the group in a top-down fashion. Instead, the group should work together to examine the strengths and assets of the participants and allow them to decide what they can reasonably contribute.

This means that the work of the state colorectal cancer collaboration will be aligned to the member organizations, rather than the other way around.

State colorectal cancer collaborations are comprised of volunteers, with members being asked to take on work on top of their "day jobs." As such, requests have the best chance of success if they are an extension of what members are already doing.

"We tend to traditionally think about these intervention efforts as top-down. We think of the intervention and then we tell people to go out there and do it. But you almost need to do the opposite.

You need to have the people who are participating look at what they have, think about what they can do, and then figure out how that fits into the initiative. That way, you're asking people to do things that are within their reach."

- CDC

First Year Objectives

The types of goals that a colorectal cancer coalition will set in their first year will differ substantially depending on members, resources, and where the state is in its colorectal cancer efforts. The group must assess its assets, talents, energy, and know-how, and then consider what feels right and what projects seem “winnable.”

By planning to “hit some home runs” in the beginning, the group can build momentum and a positive track record that will set the stage for recruiting new partners/volunteers, obtaining donations or grants, garnering state support, and feeding further successes that will advance the ultimate goal of increasing colorectal cancer screening rates.

In some states, looking for this low hanging fruit might mean targeting efforts at the unscreened insured population, rather than tackling difficult populations with significant access and affordability issues.

For example, focusing on newly insured Medicaid recipients or large state employers to boost screening rates might provide measurable positive outcomes in the first year.

Or it could mean starting small on a tougher problem, such as creating a screening program for the uninsured, but starting it as a pilot project with just a few community health centers, gastroenterology practices, and a local hospital.

Choosing achievable goals and objectives in the first year also allows members to “practice collaboration” and build trust among the different partners. This is particularly important for groups that have not historically partnered successfully.

For example, it may be important to build bridges between competing health systems or between public health agencies and physicians. A skilled project director/implementer will be particularly valuable to engage partners in constructive collaboration during their first year working together.

FIRST YEAR ACTIONS

One of the things that brought the Kentucky coalition together in its early stages was acting as an advisory board for the distribution of 16 mini-grants that were funded by the CDC.

Coalition members were involved in decisions about where the funds were directed and approving plans for regional initiatives across the state.

Once the project was complete, the group wanted to continue working together and developed a new purpose for the group moving forward.



“We were very time sensitive. We wanted to deliver change as soon as possible... people do not want to bang their head for years, come up with plans and then nothing ever happens. You really have got to have some success, small successes the first time, before you can get on to big problems”

- Delaware Cancer Consortium

Goals can be process-related or focused on clinical outcomes, or some combination of both. Established coalitions and national leaders from the CDC and ACS contributed to the list of sample goals below, but it is important to note that the selection of an initial project is nothing that an outsider can choose. Another state colorectal cancer collaboration may have had great success screening the insured, but that may have been built on existing strong relationships with both payers and primary care groups that not every state has. Alliances such as these must do their homework, consider their own assets and talents, and decide.

Sample Clinical Goals	Sample Process-Related Goals
Work with primary care practices to create a provider reminder or patient reminder system	Obtain commitments from a clinical champion and project manager/implementation leader
Work with community health centers to improve performance on UDS measures by a specific percentage	Take a census of colorectal cancer initiatives across the state
Work with community health centers and other primary care practices to offer high sensitivity stool tests in a quality way	Gather baseline data and demographics to inform decision-making
Engage hospital systems or other major employers in increasing the colorectal cancer screening rates of their employees	Build an infrastructure of engaged coalition partners who are committed to action
Obtain commitments from state health plans to notify doctors of their screening rates on a regular schedule	Develop a structure for regular meetings/calls and dissemination of information to partners
Use funds to provide screening for a targeted number of uninsured residents	Member organizations agree on and document targets/goals for the coalition
Screen “x number” of individuals by a target date	Prepare a detailed action plan and timeline for implementation
Work with local gastroenterologists to increase access to screening or diagnostic colonoscopies for the uninsured	Raise funds to support a key initiative (e.g. screening event, media campaign)
Use funds to hire a phone-based screening navigator who can support practices across the state.	Engage with state primary care organizations; conduct outreach
	Obtain legislative support for a proposed initiative
	Develop a strategy for addressing disparities
	Deliver training/education for primary care providers

TASK 8

Maintain Momentum

MAKING THE MOST OF MEETINGS

The C4 coalition in California holds their call-in meetings on the same day and time each month so that members can attend whenever possible and do not need to consult a schedule that changes monthly.

Their calls are efficient -- they last one hour and make the most of everyone's time. The executive committee holds a separate meeting one week in advance to discuss progress and plans for the call.



The state level colorectal cancer collaborations described in this guide have been highlighted in part because of their ability to engage a statewide network of partners on this issue and maintain momentum over time.

Leaders attribute their success to a combination of factors, including paying attention to the needs and interests of partners and a strong focus on efficient, productive mechanisms for participation.

Design Action-Oriented Meetings

Most commonly, colorectal cancer collaborations have a regular schedule for meetings or calls. Some meet monthly or bi-monthly, with more frequent communication among members of the leadership team or steering committee. Some meet by conference call; others participate in person. However, partners should meet in-person on at least a yearly basis.

“People really trusted us as conveners not to waste their time.”

- Kentucky Cancer Consortium

To facilitate efficient, productive meetings that are well attended, start by making it convenient for partners to attend. In large states, this means selecting a location that is central or easy to reach from all regions.

In many cases, they ask members for only a half day of time. Others plan their meetings to coincide with other related meetings taking place in the same location (e.g. the state capital).

EFFICIENCY IN COMMUNICATION

The Kentucky coalition structures meeting minutes with the most important information at the top, including decisions made, action items, and assignments.

The least important information is at the end. Critical information is repeated in the body of the email so that busy participants see it even if they do not take time to open the attachment.

Delaware public health specialists meet before and after each committee meeting to ensure that information is shared about progress and decisions made.

After attending meetings, they document the results, post them online, and do follow up on action items.

BUILDING A COMMUNITY OF PARTNERS

The **Minnesota Cancer Alliance** uses their monthly newsletter to inform members about what the Alliance is doing, but also connects them by using it as a forum to share information about what member organizations are doing on their own, including events and educational opportunities that coalition members can attend.

A top priority should be making meetings interesting and productive. During the meeting, facilitators are realistic about new ideas that are proposed, focusing on how they can be operationalized and who will take responsibility for them.

To promote engagement among attendees and promote concrete progress, some colorectal cancer collaborations assign tasks to working groups to develop strategies around specific goals (e.g. developing common messaging around test choice, screening barriers, survivorship, or patient navigation).

“Everything is documented in the minutes, so I know who volunteered to do what, and if it hasn’t been done yet, I know who to follow up with.”

- Delaware Cancer Consortium

Successful colorectal cancer collaborations use time during the meeting to assign clear tasks to attendees and identify achievable outcomes that can be completed before the next meeting. This type of accountability helps keep all partners engaged because when attendees see that something is always accomplished during meetings, they want to participate and do more.

Successful colorectal cancer collaborations also have clear plans for consistent follow through and communication. Decisions are documented immediately after the meeting, along with who agreed to complete each task. Implementation staff then follow up with members if tasks are not completed.



Provide Value to Members

In order to achieve established goals, it is important to also provide value to members so that they want to continue participating. Often, meetings can be used to deliver value by bringing in guest speakers, sharing new research, or presenting case studies. The Minnesota Cancer Alliance books nationally recognized presenters at their annual summit to attract interest and attendance from new organizations that might otherwise not attend. This in turn allows the Minnesota Cancer Alliance the opportunity to showcase their activities and engage new partners.

In Kentucky, each quarterly, full-membership meeting has a theme (“Quarterly Hot Topics”) or topic of interest to engage members. Past topics have included Medicaid issues, informed decision-making, childhood cancer, hospice care, and environmental carcinogens. Value is also delivered by providing partners with opportunities to engage with one another, forge relationships, and share what they are working on outside of the colorectal cancer collaboration’s efforts. This acknowledges partners’ independent roles and may spark new ideas or collaborative efforts that further entrench the value of participating in the coalition.

Conduct Ongoing Communications

Regular communication such as newsletters, email blasts, Facebook posts, or annual reports delivers timely updates on activities, but also maintains momentum, creates new connections, and boosts enthusiasm among partners. Communications also provide a means of thanking donors and volunteers and celebrating interim successes.

Colon Cancer	<ul style="list-style-type: none"> • Documentary Debut: The Colon Cancer Prevention Project is debuting their next edition of “Catching a Killer”, a 30-minute documentary on colon cancer and the importance of colon cancer screening. This documentary features people from Kentucky. Please invite your partners, friends and family to attend a FREE viewing at one of the following locations: <ul style="list-style-type: none"> ○ Louisville, KY; Clifton Center (click here for map/directions) <ul style="list-style-type: none"> ▪ Date/Time: June 18th; 7:00pm-8:00pm EST ▪ Click here to RSVP ○ Lexington, KY; Lexington Public Library Downtown (click here to find directions & parking info) <ul style="list-style-type: none"> ▪ Date/Time: June 23rd; 7:00pm-8:00pm EST ▪ Click here to RSVP ○ Eastern, KY; Perry County Library, 289 Black Gold Blvd., Hazard, KY <ul style="list-style-type: none"> ▪ Date/Time: July 20th; 6:00pm-8:00pm EST ▪ Click here to RSVP • Clarification on the recent Colon Legislation passed in March 2015: This past legislative session, a bill was passed seeking to ensure that appropriately recommended colorectal screenings were not susceptible to co-pays or deductibles. Recently, the Kentucky Department of Insurance released an Advisory Opinion interpreting the term “<i>complete colorectal cancer screening</i>” in SB 61 as it amended KRS 304.17A-257. The Advisory Opinion memo stresses that “<i>no deductible or coinsurance amount shall be collected for colorectal examinations specified in current American Cancer Society screening guidelines</i>” and gives the following example for clarity: “<i>...if a Fecal Immunochemical Test (FIT) result indicates that the insured needs further testing, such as a colonoscopy, then the FIT and the colonoscopy shall be covered as preventive and no deductible or coinsurance amount will be collected.</i>” Read the one-page memo from KY
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Figure 4: Excerpt from KCC Wednesday’s Word Newsletter

The Kentucky Cancer Consortium keeps partners updated through Wednesday’s Word, a bi-weekly e-newsletter that summarizes recent state and national cancer control articles, resources, events, and tools. The newsletter includes brief sections on individual cancers, as well as broader issues that impact health care, such as the Affordable Care Act, health equity, and patient navigation. Partners can also contribute their own information that they want to share with the broader network.

TASK
9

Get Funding and Resources

SOURCES OF SEED MONEY FOR EARLY EFFORTS

- CDC
- American Cancer Society
- State Department of Public Health
- Individual donors/survivors
- Health systems
- Foundations



The established state colorectal cancer collaborations report highly varied sources of funding and resources, both at the outset of their efforts and today. For example, the Delaware Cancer Consortium is funded entirely through a combination of state appropriations and CDC CCC program funding.

In contrast, California's C4 coalition currently receives no state funding, but engages in private fundraising and receives significant contributions from individuals.

South Carolina's colorectal cancer collaboration, which includes both an independent 501c3 organization and a research group at the University of South Carolina, has pursued and received numerous grants from both public sources and private foundations.

The lesson to be learned from these differing approaches is that the best funding source that is most productive for a given colorectal cancer collaboration depends largely on the abilities, experience, and connections of its members, good timing, air tight funding proposals, and a bit of luck.

The South Carolina Coalition leveraged the political connections of a colorectal cancer survivor who was both a respected businessman and a former state legislator. Similarly, the Kentucky coalition capitalized on the election of a physician to the state legislature. These connections positioned the collaboratives to work toward state budget allocations for colorectal cancer.

In contrast, a colorectal cancer collaboration with members who have experience developing grant applications should logically pursue that avenue. If a member of the leadership team has a background in individual fundraising, that resource should be exploited. For example, the California coalition included a volunteer attorney; the Kentucky coalition found assistance from a volunteer who had previously conducted fundraising for the Leukemia and Lymphoma Society.

The reality is that everyone in public health struggles with funding. While some state colorectal cancer collaborations were fortunate to have money come from outside sources relatively quickly, others needed to create and doggedly pursue a way to get the work done on a lean budget. The important thing was that they did not let lack of funding create inertia.

Funding

The most important ingredient for success is not necessarily funding, but rather a passionate, committed membership. At the same time, some level of funding is important to cover basic costs and extend the reach of the collaborative efforts. In the beginning, more seed money is needed to support efforts such as hosting summit meetings/kick-off events for partners or producing materials to describe colorectal cancer needs in the state.

Some colorectal cancer collaborations interviewed for this guide reported that they did not need a large amount at this early stage, but a small amount to cover meeting facilities and pay for attendees' meals or travel made their early efforts easier.

Also, when money is available to fund some type of outreach action, such as a media campaign or small screening effort, it helps to energize members and reassure them that their participation will lead to a concrete result. For example, the Kentucky Cancer Coalition had \$8,000 in seed money from the CDC which was spent on a public awareness campaign. Although this was not a large amount of money, it was enough to generate interest among new members and reassure them that tangible results were coming, thus keeping the members engaged.

FUNDRAISING APPROACHES USED BY STATE CRC COLLABORATIONS

- Races/walks
- Golf outings
- Black tie galas/dinners
- Pub crawls
- Direct mailings
- Sponsorships
- Amazon Smile donations



“There’s something to be said for even just a little seed money that people can rally around.”

- Kentucky Cancer Consortium



In some cases, fundraising efforts may start out small, but gain momentum as the word gets out. The Center for Colon Cancer Research in South Carolina has seen the success of their annual Unmasking Colon Cancer Gala grow dramatically, going from raising \$35,000 eight years ago to more than \$116,000 in recent years.

The Gala leverages high-level sponsorship categories, which are filled by insurance companies, medical centers, gastroenterology groups, pharmaceutical companies, local businesses, and individuals.

CORPORATE LEVELS	Corporate/Individual sponsors will receive:	MARQUEE LEVELS	Marquee sponsors will receive:
	<ul style="list-style-type: none"> Your name and link on the website and social media for the Center for Colon Cancer Research Special acknowledgment and recognition at the Gala 		<ul style="list-style-type: none"> Sponsorship Recognition: Your name/logo on some print and promotional materials for the Gala (posters, banner, and program) Your name and link on the website and social media for the Center for Colon Cancer Research Special acknowledgment and recognition at the Gala
	<p>\$2,500 Contributor Sponsor</p>		<p>\$25,000 Platinum Sponsor</p>
	<ul style="list-style-type: none"> 6 invitations to the Gala 		<ul style="list-style-type: none"> 14 invitations to the Gala
	<p>\$1,200 Supporter Sponsor</p>		<ul style="list-style-type: none"> 4 invitations to the VIP brunch that will take place on March 7, prior to the Gala
	<ul style="list-style-type: none"> 4 invitations to the Gala 		<p>\$15,000 Gold Sponsor</p>
INDIVIDUAL LEVELS	<p>\$1,000 Donation</p>		<ul style="list-style-type: none"> 12 invitations to the Gala
	<ul style="list-style-type: none"> 4 invitations to the Gala 		<ul style="list-style-type: none"> 4 invitations to the VIP brunch to occur prior to the Gala
	<p>\$500 Donation</p>		<p>\$10,000 Silver Sponsor</p>
	<ul style="list-style-type: none"> 2 invitations to the Gala 		<ul style="list-style-type: none"> 10 invitations to the Gala
	<p>\$300 Donation</p>		<ul style="list-style-type: none"> 2 invitations to the VIP brunch to occur prior to the Gala
	<ul style="list-style-type: none"> 2 invitations to the Gala 		<p>\$5,000 Bronze Sponsor</p>
	<p>\$100 Donation</p>		<ul style="list-style-type: none"> 8 invitations to the Gala
	<ul style="list-style-type: none"> 1 invitation to the Gala 		<ul style="list-style-type: none"> 2 invitations to the VIP brunch to occur prior to the Gala

Figure 5: Sponsorship Levels for Center for Colon Cancer Research 2015 Gala

Advancing Goals on a Limited Budget

The NCCRT report on Coverage of Colonoscopies under the Affordable Care Act's Prevention Benefit was developed by multiple partners working together with no underlying budget to support the work.

The issue of the "colonoscopy surprise" was a key concern identified at the 2011 NCCRT annual meeting. The ACA required private health plans to cover colonoscopy screening free of cost-sharing, but there was confusion among both health plans and providers on how to implement the benefit. As such, cost-sharing was often applied if a polyp was discovered and removed during screening, angering patients who went into the exam believing it to be free, but waking up to find they were responsible for a hefty co-pay. The NCCRT Policy Action Task Group set out to document the problem.

The Policy Action Task Group Co-Chairs from the Colorado School of Public Health and AARP Public Policy Institute provided project leadership. A senior fellow from the Kaiser Family Foundation (KFF) provided both intellectual leadership to the project and also authorized researchers from the Georgetown School of Public Health to conduct stakeholder interviews to better understand the confusion over implementation.

The Georgetown School of Public Health brought a nuanced understanding of insurance law to the table that was matched by the NCCRT's expertise in CRC guidelines and coverage. Partners from the American Gastroenterological Association (AGA) and the Maryland Department of Health helped the researchers understand nuances around coding and why the law was much harder to implement than would first seem.

NCCRT partners from ACS CAN and the insurance industry connected the researchers with insurance executives to document the wide variety of insurance coding and billing practices. Other partners from Fight Colorectal Cancer and the Center for Colon Cancer Research secured interviews with physicians and their billing staff.

The Colon Cancer Alliance recruited patients who had experienced the surprise of receiving these post-polypectomy bills to provide the consumer voice to the problem.

In the end, the report was a thorough documentation of the issue that made the case that further guidance was needed to improve clarity and standardize the cancer screening benefit. Several news organizations covered the report when it was released in September of 2012, and it was promoted by the ACS, KFF and AGA.

Most importantly, by February of 2013, the Center for Consumer Information and Insurance Oversight (CCIIO) issued clarifying guidance definitively stating that health plans or issuers may not impose cost-sharing with respect to a polyp removal during a colonoscopy performed as a screening procedure.

This was an excellent example of how many dedicated partners could come together and create changes in advancing colorectal cancer control with the underlying costs limited to the staff time provided by all the partners involved.



EASY FUNDRAISING IDEAS FROM THE COLON CANCER PREVENTION PROJECT

- Organize a fundraising event at a local restaurant or other business that might be willing to donate part of its proceeds that night.
- Ask businesses or individuals to donate items for gift baskets that are raffled off. It is great publicity for the businesses.
- Create a calendar or other creative items to sell to supporters.
- Ask employers to match donations or go Casual for a Cause, where employees make a donation in exchange for a dress down day.
- Ask your place of worship to address the congregation and take up a special collection.



Finding Funding Sources

When just getting started, small donations or allocations from a few sources may be sufficient to get the effort underway. Larger partners—such as health systems or advocacy groups—may be a good source of these small donations.

Some colorectal cancer collaborations report using leftover funds from other state cancer initiatives, after petitioning funders for permission. Others were able to find matching grant opportunities and combine these with small amounts of money from their state health department and the ACS or CDC.

It is important not to overlook small scale opportunities to fundraise from the general public, such as local events or sales. The C4 coalition encourages partners and supporters to support them through the Amazon Smile donation program.

For those groups that are able to conduct independent fundraising on a larger scale, the collaborations interviewed for this guide recommend taking a strategic look at the state and drawing up a list of possible donors. These might include large employers in the state, pharmaceutical companies, health systems, local charitable foundations, gastroenterology and oncology groups, and insurance companies.



California Colorectal Cancer Coalition - C4

July 15, 2015 · 🌐

When you shop at Amazon, please go through [Smile.Amazon.com](https://www.amazon.com/smile) (you can even do this if you have a Prime account) and designate C4 as your beneficiary. Amazon donates money to our nonprofit if you do so (no additional cost to you). This is a completely painless to help support us in our mission to improve screening and treatment for Californians.



Support California Colorectal Cancer Coalition by shopping at AmazonSmile.

When you shop at AmazonSmile, Amazon will donate to California Colorectal Cancer Coalition. Support...

[SMILE.AMAZON.COM](https://www.smile.amazon.com)

Donors should be prioritized and contacted by an organizational champion with a personal message about the state colorectal cancer collaboration's plans and the important role that the organization can play as a donor.

The down side of launching donation-based fundraising efforts is that it can be seen as competing with some of the member organizations, such as small nonprofits that rely on donors. If so, it is important to put these issues on the table.

Partners may support certain fund-raising activities that are clearly advancing the shared public health goal, such as raising funds to launch a screening navigation program or pay for colonoscopies for the uninsured. Each state colorectal cancer collaboration must weigh these pros and cons, be transparent and sensitive to the needs of its partners, and decide accordingly.

“They really need to have a good relationship with their state government’s administration and make sure the administration sees the importance of this work. That’s the only way they’ll get state dollars.”

- Delaware Cancer Consortium

States that have strong ties between their state colorectal cancer collaboration, CCC coalition, and state government—such as Delaware—have had remarkable success at obtaining state appropriations to support colorectal cancer control efforts.

As early as 2003, the Delaware Cancer Consortium was receiving significant state budget allocations for dedicated staff support, colorectal cancer screening programs, nurse navigators and public education campaigns.

Statewide summit meetings themselves can also be an opportunity for raising funds. The Prevent Cancer Foundation, which facilitated colorectal cancer coalition building activities in many states over a period of several years, reports that the cost of these activities ranged from \$15,000 to \$80,000 per state, depending on the in-kind resources available in each location.

FUNDING THROUGH GRANTS

South Carolina's coalition obtained funding from two foundations who sought to fund complementary components of their program.

One funder was only interested in funding clinical services, while another restricted its funds to infrastructure (e.g. administration, patient navigation, and evaluation).

By pairing these together, the coalition was able to support many of its critical activities and provide reassurance to both funders that their goals would be met.





The summit meetings not only kicked off successful colorectal cancer collaborations, but provided a forum for actually raising money. California's C4 coalition raised approximately \$75,000 from sponsorships and exhibits at their state summit of which \$60,000 was used as seed money to implement the colorectal cancer screening strategies of the C4 coalition.

Similarly, the Minnesota Cancer Alliance raises money each year at their statewide summit. Although the Alliance is part of the CCC program, summit funds are important because they can be used at their discretion, unlike CDC funds.

Some colorectal cancer collaborations have had significant success obtaining public and private grants to support statewide colorectal cancer efforts (e.g. CVS, Blue Cross/Blue Shield, Duke Endowment, NIH).

In South Carolina, they have found that funders want to know about other funders with "skin in the game" (i.e., Blue Cross/Blue Shield is more likely to fund their efforts because they know funding is also coming in from respected source such as the Duke Endowment).

They also emphasize outcomes with funders (i.e., increased screening rates, saving lives and health care costs) and are able to clearly articulate the impact and benefit of the work in increasing colorectal cancer screening rates.

One key to success in obtaining these kinds of grants is significant experience with grant writing. If possible, states should partner with a school of public health or other academic partner that has experience in this arena. Additionally, it is valuable to meet with grant-making foundations before submitting an application in order to better understand how their funding priorities are aligned and whether their needs change from year to year.

The South Carolina colorectal cancer collaboration found many of its funders through its strong network of partners, which also turned out to be a particular strength of its grant applications. Funders are more likely to give to coalitions that have demonstrated the support of an influential network of partners.

In South Carolina's case, this included over half of the gastroenterologists in the state, the University of South Carolina's School of Public Health, pharmaceutical companies, the State Department of Public Health, and community health centers.

In-Kind Resources

Particularly in the beginning, it is just as important to have in-kind resources and contributed staff time as it is to have funding. A lot can be done by bringing the right minds together, even if funding is lean. The ACS or the state department of health often play a critical “convener” role by offering meeting space, and importantly, the man power that is responsible for implementation and follow through, which is critical to getting the effort off the ground.

Not all partners will be able to provide direct funding, but many will be able to provide support through intellectual leadership, networking, a formal allocation of partial FTEs for selected staff members or informal assistance with some of the meeting planning and project planning responsibilities.

The ACS health systems staffing structure can be a real benefit, in that all ACS Divisions have staff dedicated to supporting health systems cancer control efforts in each state and are specially trained to work with other state systems to deliver evidence-based interventions.

“Something as simple as having a space to meet in proved to be important so that the group had a sense of where they were going to go next and they literally had a place to meet to do so.”

- Prevent Cancer Foundation

Some colorectal cancer collaborations recognized in this guide experience great success because their partners have strong connections that can deliver much needed resources, such as expertise in law, grant writing, fundraising, lobbying, or public relations.

Others have in-kind resources that are primarily clinical in nature, allowing them to directly deliver screening to the uninsured and underinsured that comprise their target audience. For example, securing commitments from gastroenterologists who donate a specified number of colonoscopies, with the colorectal cancer collaboration needing to cover only facility costs.

IN-KIND STAFF RESOURCES

The work of the colorectal cancer committee at the **Minnesota Cancer Alliance** is supported by contributed staff time from the Minnesota Department of Public Health and the ACS State Health Systems Manager, which are positions that exist in all ACS Divisions.

The in-kind staff support from these individuals makes it possible for the committee to do its work without a paid project manager.



TASK 10

Hold the Group Accountable

ACCOUNTABILITY OF WORK GROUPS

The colorectal cancer committee at the **Minnesota Cancer Alliance** reports back to the steering committee on a quarterly basis. In both written and verbal reports, they answer questions addressing:

- Progress made by the project team to date
- Significant successes or accomplishments
- Greatest challenges or barriers faced
- Lessons learned
- Organizations or partners that have become involved in the work
- Resources needed to ensure forward progress
- Ways the steering committee can assist



A sense of accountability permeates the work of a successful colorectal cancer collaboration. What sets them apart from previous efforts that may have fallen short of their goals and objectives is the understanding among all partners that the collaborative will be held accountable for what they propose to do. This orientation instills a sense of urgency into the process and creates regular opportunities to reflect on activities, make course corrections, and celebrate achievements.

A system of accountability is something that is usually best planned from the start. As a colorectal cancer collaboration sets up goals and objectives for themselves, they should simultaneously develop plans for assessing progress and reporting on those goals and objectives at regular intervals. Publicizing progress at these intervals can also help keep the issue of colorectal cancer in the public eye and on the radar screen of influential lawmakers and public leaders. This in turn helps motivate members to keep working on it.

Reports on the progress of shared goals and objectives can be through both formal and informal communications efforts, including monthly email newsletters, websites, annual reports, and yearly meetings.

Outcome Measures

Types of outcomes that should be measured will naturally depend on where the effort started. However, following are possible outcome measures that might be considered, which can help demonstrate the impact of a coalition's efforts:

- Changes in overall screening rates/progress toward 80% by 2018;
- Improvements in disparities;
- Increased volunteer participation from physicians/specialists;
- Increased contributions from health systems/hospitals;
- Numbers of polyps found in the targeted population;
- Numbers of early cancers detected in the targeted population; and
- Policy changes/successful legislation passed.

Where we were	Where we are now
Colorectal cancer screening rate was 57%.	Colorectal cancer screening rate is 74.0%
No comprehensive navigation program.	Screening Nurse Navigators in five health systems.
Excess mortality rate versus U.S. was: <ul style="list-style-type: none"> - Males +2.7% - Females +7.7% 	Case management is provided for every abnormal screening.
Mortality disparity gaps were: <ul style="list-style-type: none"> - Male African-American versus Caucasian +23.5% - Female African-American versus Caucasian +71.8% 	22 colorectal cancers detected through Screening for Life -1.3% detection rate.
	More than 2,000 uninsured or underinsured people have been screened through Screening for Life: <ul style="list-style-type: none"> - 2,184 colorectal cancer screenings; of these 74% were colonoscopies - 978 clients had polyps removed - 18% of clients were male - 82% of clients were female - 88% of clients were over the age of 50 - 17% were racial/ethnic minorities

Figure 6: Delaware Cancer Consortium CRC Committee Report - June 2007

While guidance on developing an evaluation program to measure impact is beyond the scope of this handbook, the CDC has produced a detailed program evaluation toolkit that provides excellent guidance for cancer coalitions. This toolkit was developed for evaluating state CCC programs; however, its advice is valuable for carrying out any type of program evaluation. Similarly, the NCCRT has developed a Colorectal Cancer Screening Evaluation 101 Toolkit that can provide assistance to those with little to no evaluation experience: <http://nccrt.org/resource/evaluation-toolkit/>



Progress Reports and Annual Reports

Some established collaborations evaluate their progress in more formal annual reports. The reports below provide examples of how to document progress. These examples are not necessarily solely focused on colorectal cancer efforts, but all include updates on what their statewide cancer coalitions have accomplished.

While some of these examples are more professionally produced than others, the content is what is most important. Some collaborations have been able to create attractive reports and infographics showing their impact because they have received donated services to do so. Any type of report that documents efforts and outcomes on a regular basis is ultimately going to be valuable for future progress.

[The Kentucky Colon Cancer Screening Advisory Committee Annual Report July 2012 through June 2013](#)

[The Colon Cancer Prevention Project \(KY\)](#)

[Minnesota Cancer Alliance 2013 Annual Report](#)

[Delaware Cancer Consortium Progress Reports and Multi-Year Plans](#)

[Evaluation of Delaware Cancer Consortium's Progress—the First Four Years](#)

Create a comprehensive statewide colorectal cancer screening and advocacy program.

ACCOMPLISHED

YEAR

1

- Reached out to the six major health systems serving adult populations (Nanticoke, Beebe, Bayhealth, Christiana Care, Veterans Hospital, and St. Francis) to participate in a comprehensive, community-focused colorectal cancer screening and advocacy program.
- DHSS continues to provide staff support for the CRC committee and oversight for the screening coordinators and advocates (ongoing).

ACCOMPLISHED

YEAR

2

- Evaluation tools to measure operations and quality/outcomes have been fine-tuned and implemented (ongoing).
- Screening for Life reimbursed providers for 241 colonoscopies—early cancer was detected and polyps were removed from 60 patients in FY '05. Coordinators scheduled 10 colonoscopies through Screening for Life, 9 through Medicare, and 6 through private insurance. Screening coordinators assisted in getting 225 patients screened.
- In addition to ongoing marketing efforts to inform the public and health care professionals, we reached hundreds of citizens with a special promotion featuring The Colossal Colon in New Castle and Kent counties.

ACCOMPLISHED

YEAR

3

- Recruitment of additional physicians and facilities continues (ongoing).
- In FY '06 coordinators assisted 528 patients who were screened, enrolled 241 patients in Screening for Life, and had one-on-one contact with 17,410 individuals to educate them about colon cancer and testing.
- In FY '06 early cancer or polyps were detected and removed from 191 patients.
- Developed a customized web-based case management program to track and monitor screenings.

TO BE ACCOMPLISHED

YEAR

4

- Expand program to include high-risk patients under 50 years old.
- Continue to increase the capabilities of the web-based case management monitoring system.

*Figure 7:
Excerpt from
Delaware Cancer
Consortium
Progress Report -
April 2007*

Promoting and Celebrating Success

Annual reports are one way of promoting success; however, self-promotion in other ways can also be valuable. Publicizing or celebrating success is a way of thanking partners and donors, attracting the interest of new partners, and keeping the issue in the public eye. One state CRC collaboration even found that their track record of success brought them unsolicited assistance when they were approached by a private corporation who wanted to fund their work.

The involvement of survivors is another important means of making success tangible through case stories, personal videos, or public talks.

THANKING SUPPORTERS AND MEMBERS

In South Carolina, the coalition hosts a legislative “thank you event” to show appreciation for legislators who have helped support the CRC cause over the past year.



Figure 8: Outreach video featuring CRC survivors (produced by South Carolina Colon Cancer Prevention Network)

Appendix

Following are links to reports and data sheets that make the case for an increased state focus on colorectal cancer.

Links to the websites of the five state colorectal cancer collaborations described in this guide:

- California: <http://www.cacoloncancer.org>
- Delaware: <https://www.healthdelaware.org/Consortium>
- Kentucky: <http://www.kycancerc.org>
- Minnesota: <http://mncanceralliance.org>
- South Carolina: <http://www.sccanceralliance.org>

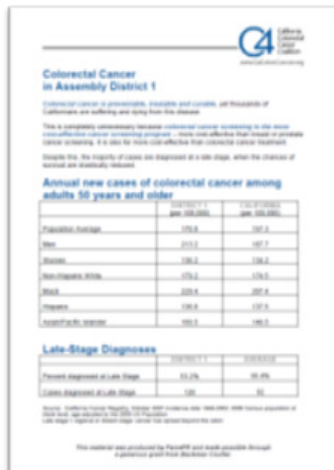
Links to websites of other state colorectal cancer collaborations:

- Colorado: <http://www.coloradocancercoalition.org/task-forces/colorectal-cancer>
- Maryland: <https://phpa.health.maryland.gov/cancer/cancerplan/Pages/collaborative.aspx>
- New York City: <http://c5nyc.org/>



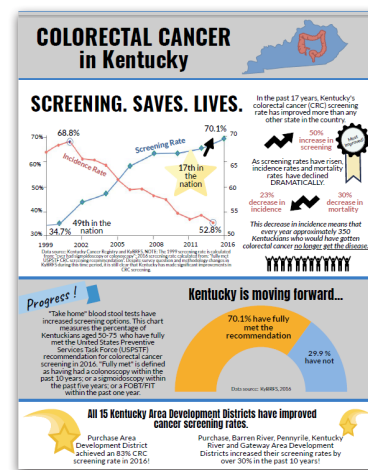
Four-page summary providing factual information about the incidence of colorectal cancer in Minnesota with selected demographic information.

<http://mncanceralliance.org/wp-content/uploads/2013/05/MN-FF-Colon-122013-FINAL.pdf>



Fact sheet describing colorectal cancer prevalence for each state assembly district. Includes data by gender and ethnicity.

http://www.cacoloncancer.org/advocacy_factsheets.php#Senate



Fact sheet describing colorectal cancer incidence and mortality in Kentucky, including comparisons to other states and progress over time.

<http://www.kycancerc.org/committees/coloncancerpreventioncommittee/CRC%20in%20Kentucky%202018%20FINAL.pdf>



Timeline

May 2005

Start of Project

June 2005

Pre-Orientation

Dialogue core team completed a background survey for the *California Dialogue*.

August 2005

Stakeholder Interviews

The core team conducted interviews with individuals from diverse occupations and specialties.

October 2005

Orientation

Planning committee members began planning the summit and completed a satisfaction survey regarding the orientation and their expectations for the process.

June 1-2, 2006

Leadership Summit

Held at the *San Diego Marriott Hotel and Marina*, in San Diego, CA, and 130 attended. Feedback was collected from participants and organizers.

August - September 2006

Post-Summit Activities

August 2007

1-Year Post Summit

September 2007

Follow-up Phone Call

Glossary, References and Notes: Page 4

Californians Taking Action To Conquer Colorectal Cancer: *A Dialogue for Action*™

A Program of the Prevent Cancer Foundation

The *Dialogue for Action*, a signature program of the Prevent Cancer Foundation (formerly the Cancer Research and Prevention Foundation), offers a unique opportunity for a state to develop a working consensus to increase colorectal cancer (CRC) screening rates. The process brings together a diverse group of individuals and organizations united by their dedication to decrease morbidity and mortality from CRC. Working within a state's comprehensive cancer control plan, *Dialogue* identifies collaborative solutions to increase screening, provides the tools participants need to take action and stimulates the building and maintaining of statewide partnerships.

The *Dialogue* process culminates in an innovative and interactive leadership summit that provides a creative forum for identifying collaborative strategies. The summit concludes with tangible outcomes. The process serves as a catalyst for increased activity around CRC screening. State outcome activities have included: updating CRC objectives in the state plan, creating or revitalizing a statewide coalition, creating a media campaign, agreeing on a universal message regarding screening modalities, conducting provider or pharmacist outreach and initiating legislative activities.



California *Dialogue* Planning Committee (See page 3 for a complete list of Core Team and Planning Committee members.)

California Selected for *Dialogue*

California was one of three states funded in the third year of *Dialogue* as part of a 5-year cooperative agreement with the Centers for Disease Control and Prevention (CDC).

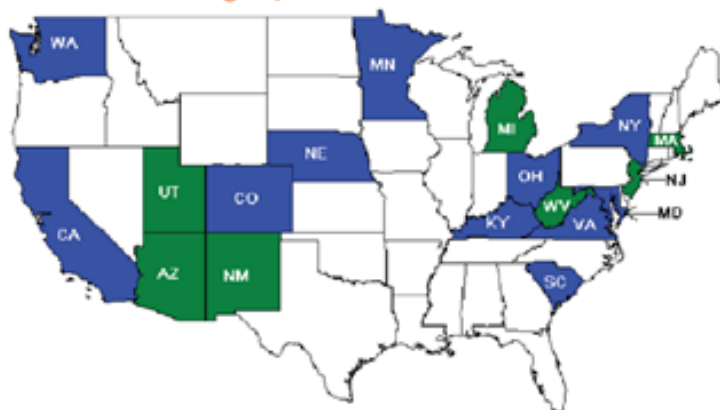
A Picture of California

At the start of the Dialogue process:

- 34,650,690 residents
- 20% over the age of 55
- 19% uninsured
- Ethnicity: 45% White (non-Hispanic), 35% Hispanic/Latino(a), 12% Asian, 6% African American/Black, 1% American Indian/Alaska Native, 0.5% Native Hawaiian/Pacific Islander and 3% Other, including mixed ethnicity

See Reference #1 on Page 4

State-Level *Dialogue for Action*™ 2002-2008



LEGEND

■ CDC/Prevent Cancer Project States
■ States with Other Funding

2008	2006	2004
AI/AN	CA	CO
WA	MA	MI
KY	NE	WV
	NY	
	VA	2003
	WV	WV
2007		AZ/NM
AI/AN		
NJ		
MN	2005	
SC	MD	2002
	NE	UT
	OH	
	WV	



CA Cancer Plan

Goal

- By 2010, reduce the colorectal cancer mortality rate in California by 40 percent, from a baseline of 17.6 per 100,000 persons.

Objectives

- By 2010, increase the percent of Californians over age 50 who have had a flexible sigmoidoscopy or a colonoscopy within the past 5 years from 40 percent to 58 percent including women, Asian/Pacific Islanders, African Americans, Latinos, and those of low income.
- By 2010, increase the percent of colorectal cancer diagnosed at an early stage from 42 percent to 65 percent.

From the *California Comprehensive Cancer Plan*
(See Reference #2 on Page 4.)

Financial Contributors

Platinum Level

- American Cancer Society
- Beckman Coulter Inc.

Gold Level

- Blue Cross of California

Silver Level

- EXACT Sciences
- NCI – Cancer Information Service of California
- Quest Diagnostics

Bronze Level

- American College of Surgeons
- California Medical Association
- ConMed
- Fleet Laboratories
- Hemosure
- Kaiser Permanente
- Olympus

Californians Taking Action To Conquer Colorectal Cancer:

A Dialogue for Action™

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Before the Dialogue

Prior to the *Dialogue* summit, the California Department of Health Services had initiated several projects to reduce CRC incidence and mortality in the state. Recognizing the needs of patients and providers in California, the department had launched a number of activities to raise public awareness, and to enhance vital collaborative partnerships in order to build capacity for CRC screening and treatment.

Among these efforts was the passing of a resolution in March 2003 proclaiming March "Colorectal Cancer Awareness Month." In addition, the California Department of Health Services' Comprehensive Cancer Control (CCC) Program requested funding from the CDC to implement a statewide CRC screening and prevention program targeting Asian, Pacific Islander and Latino populations. The program was designed with a focus on provider and patient education and collaborations at the community, state and national levels. A core planning team was formed to implement these efforts.

The California Dialogue on Cancer (CDOC), the official name of California's comprehensive cancer control coalition, was formed to develop and implement the state's cancer plan. CDOC's greatest challenge was addressing CCC program goals related to access to care, data and surveillance, disparities, early detection and treatment, prevention, research, and survivorship. Organizers believed the CDOC could play a role in conducting outreach and expanding statewide involvement in the process by identifying additional funding sources, and engaging the community and key stakeholders. As a result, collaborations, such as one between the California Department of Public Health and the California Division of the American Cancer Society, have

maximized scarce resources and increased CRC awareness activities in California.

The CDOC took on three projects specific to CRC prevention:

- Adapting a Vietnamese instructional video for fecal occult blood testing to a Spanish language version.
- Conducting research on community-based programs on CRC screening for Asian and Latino populations.
- Using state cancer registry data, CDOC "mapped" areas of the state where CRC is routinely presented in advanced stages (a surrogate for inadequate CRC screening). Eighteen such areas were identified. In each of these areas, more than 80 percent of CRC cases were Stage III (regionally advanced) or Stage IV (distally spread).

CDOC hoped that the *Dialogue* summit would serve as a springboard for reviewing existing CRC screening efforts and for developing strategies that were delineated in the state cancer plan. Organizers also hoped the summit would help to determine the next steps toward implementing a comprehensive plan.

The Dialogue Summit

Californians Taking Action to Conquer Colorectal Cancer: a Dialogue for Action took place in San Diego on June 1–2, 2006, and attracted more than 130 people. The goal of the summit was to establish a new a 501(c)3 coalition for increasing CRC screening rates in California. Several distinguished speakers presented on issues related to this goal, including the role of primary care in CRC screening and treatment for at-risk groups, the current state of CRC prevention efforts in California, and best practices for screening among diverse populations. Participants also engaged in interactive conversations designed to establish key branches of a proposed statewide colorectal cancer coalition.

Californians Taking Action To Conquer Colorectal Cancer:

A Dialogue for Action™

A Program of the Prevent Cancer Foundation



Dialogue Summit continued

Dr. Harold P. Freeman, the Medical Director of the Ralph Lauren Center for Cancer Care and Prevention, gave the keynote address in which he discussed early detection and treatment of CRC for all at-risk populations as a means to significantly reduce mortality from the disease. Dr. Janet Bates from the California Cancer Registry presented data identifying those areas of the state at greatest risk for advanced stage presentation of CRC. It was proposed to target screening demonstration projects to these areas. To read more about the summit, go to: <http://www.thecdoc.com/dfa/index.php>.

Impact of the Dialogue

Participants in the breakout conversations developed recommendations that have already resulted in the following outcome activities:

- A statewide CRC coalition, named California Colorectal Cancer Coalition (C4), was formed.



- Approximately \$75,000 was raised from sponsorships and exhibits at the Dialogue, of which \$60,000 was used as seed money to implement the CRC screening strategies of the C4 coalition.

CRC screening demonstration projects are being developed for at least one urban and one rural area identified by the registry-mapping project as at-risk for late-stage presentation of CRC.

More than a year later, the C4 coalition continues to be very active. The newly formed coalition board of directors meets monthly. Currently, there are 21 board members and approximately 50 coalition members.

The coalition plans to raise more funds and develop demonstration and advocacy projects for the underserved. In addition, the coalition plans to play a key role in the implementation of a national CRC screening program in California, pending federal legislation.

Planning Committee

Core Team

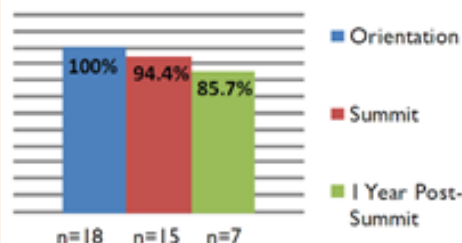
- Jon M. Greif, DO, FACS
Dialogue Co-Chair
Kaiser Permanente Medical Center
- Alexander K. Chen, MD
Dialogue Co-Chair
Sutter Medical Group
- Debbie Hintz
Dialogue Coordinator
CA Department of Health Services
- Allyn Fernandez-Ami, MPH
CA Department of Health Services
- Greta Hicks
CA Department of Health Services
- Margaret McCusker, MD
FACPM, CA Department of Health Services
- Sandra Robinson, MBA
American Cancer Society
- Kurt Snipes, MS, PhD
CA Department of Health Services

Planning Committee

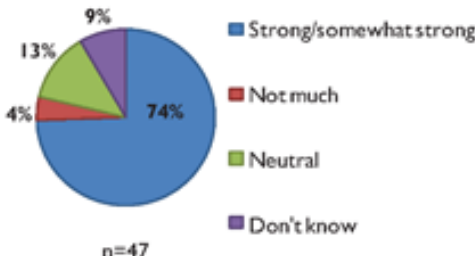
- Daniel S. Anderson, MD
Kaiser Permanente Medical Center
- Rynda Clark, MPA
University of California, San Diego
- Jennie R. Cook
Intercultural Cancer Council
- Chrysten E. Cunningham, DO
American College of Obstetricians and Gynecologists
- Marilyn Murry
American Cancer Society
- Anna M. Napoles-Springer, PhD
Univ. of California—San Francisco
- Merel Grey Nissenberg, JD
CA Prostate Cancer Coalition
- Jill Olmstead, MSN, NP-C
St. Jude Heritage Medical Group
- Ralph Peterson, MD
100 Black Men of America, Inc.
- Miyoko Sawamura, CA
Department of Health Services
- S. Todd Stolp, MD, Tuolumne
County Public Health Department
- Nicole Vazquez
Senate Health Committee
- Judith Walsh, MD, MPH
UCSF Women's Health Clinical Research Center

Impact of Dialogue: One-Year Post-Summit

Strong or Somewhat Strong Impact on Advancing State CRC Objectives



Impact of Dialogue on Identifying New Partners



When planning committee members were asked about the impact Dialogue had on advancing the state's CRC objectives, the majority saw a strong or somewhat strong impact. Across the three evaluation periods, confidence in the Dialogue process remained high.

After one year, participants, including the core team and planning committee, felt that Dialogue helped them to identify new partners. More than 70% of all participants said the Dialogue process helped strengthen existing relationships.



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The Prevent Cancer Foundation's *Dialogue for Action*TM functions to bring together individuals and organizations to implement CRC objectives in the state comprehensive cancer control plan. This project is supported by Cooperative Agreement #U58/CCU323068 from the Centers for Disease Control and Prevention.



Prevent Cancer Foundation, formerly the Cancer Research and Prevention Foundation, is a national nonprofit health organization whose mission is cancer prevention and early detection through research, education and community outreach to all populations, including children and the underserved. Since 1985, the Foundation has provided more than \$97 million in support of research, education and community outreach.

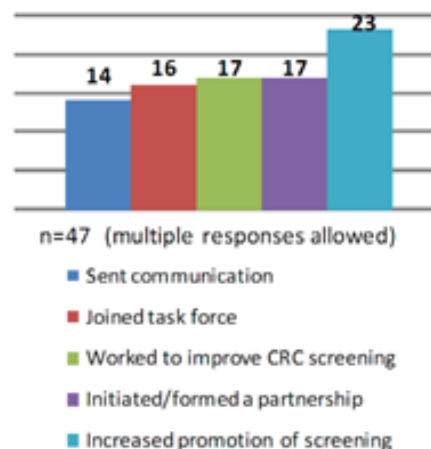
Californians Taking Action To Conquer Colorectal Cancer: *A Dialogue for Action*TM A Program of the Prevent Cancer Foundation

Impact of *Dialogue* continued

Other CRC initiatives in California include an additional mapping project to identify which counties in the state have a predominance of late-stage CRC diagnoses, and to identify this population by critical factors, such as ethnicity. Demonstration projects have also been initiated with insured populations and implemented through one of the state's large insurers, Kaiser Permanente.

The combined efforts across the state reflect sustained progress made in California to address CRC and the positive impact of the *Dialogue* process.

One Year after *Dialogue*:
CRC Activities Reported by Summit
Participants



Glossary

Core Team: small group of individuals responsible for the implementation of the California *Dialogue* process (n=8).

Participants: individuals from diverse fields who attended the California *Dialogue* summit (n=130).

Planning Committee: a group of individuals who make recommendations on the design and implementation of the *Dialogue* summit. Comprised of leaders in diverse areas and includes the core team (n=13).

Stakeholders: individuals who participate in a one-time interview at the development stage of the conference by giving feedback on the proposed meeting purpose and design (n=9).

State Coordinator: individual responsible for the management of the California *Dialogue* process.

References

- United States Census Bureau, 2003.
- CRC State Goals and Objectives retrieved from the California Comprehensive Cancer Plan located online at www.thecdoc.com/plan.php.

Methodological Notes

- Level of involvement of key groups and numbers of respondents:** The core team was most involved with the *Dialogue*, followed by the planning committee and then the summit participants (see Glossary for definition of these terms). While core team and planning committee members were involved throughout the process, summit participants' involvement was limited to the summit itself. The evaluation design reflected this difference in the intervention itself. Where all three groups responded to the same questions and the data are displayed as a combined result, the overwhelming number of respondents would be summit participants.
- Attrition:** The percentage of one-year post-summit surveys completed by summit participants was lower than the percentage completed at the summit: 38% of participants completed paper surveys at the summit, but only 28% completed electronic surveys one year later. For the planning committee members, completion rates were 76% and 54% respectively. Completion rates for the core team evaluation remained steady with about 40% of core team members consistently completing all evaluation surveys.

Delaware Cancer Consortium		September 22, 2003	
		12:30 p.m. to 1:30 p.m.	
		DTCC Terry Campus, Dover, DE	
Committee:	Colorectal	Type of meeting:	Kick-Off Meeting
Facilitator:	Management Concepts, Inc.	Note taker:	Vicki Hayden
Attendees:	Steven Grubbs, MD – Chairperson Victoria Cooke – Executive Director, Delaware Breast Cancer Coalition, Inc. Allison Gil – Cancer Control Manager, American Cancer Society Nora C. Katurakes, RN, MSN, OCN – Helen F. Graham Cancer Center		
Observers:	Paul Silverman - Chief of Health Monitoring and Program Consultation, Division of Public Health Vicki Hayden – Program Assistant, Management Concepts, Inc.		
Other Committee Members:	David J. Cloney, MD, FACS – Atlantic Surgical Associates		

Minutes

Agenda item:	Introductions
Discussion:	Self-introductions by group
Agenda item:	Brief Overview of Advisory Council History
Discussion:	Overview of the history of the Advisory Council and the intent of the Delaware Cancer Consortium (DCC).

Agenda item: Workplan Goals and Objectives

- Discussion:**
- Committee agreed that it should focus on the accomplishments that could have the most impact in a finite period of time. The goal of achieving 80% of target population screened in the next 5 years would make a definitive difference.
 - Would like to establish/work within a network of service providers, most likely hospitals.
 - Funds have already been allocated for the expansion of Screening for Life to include colorectal screening (\$443,000?). This program has the mechanism to do the tests; there are age requirements; the DCC funds will reimburse Screening for Life for price of screening.
 - The DCC has allocated \$700,000 for treatment, but the committee was uncertain of what that would entail, who would be eligible, which costs are included, etc... More questions were raised than answered.
 - Dr. James Gill of Christiana Care won the bid for evaluation (\$50,000). Need to give a description of the network to Dr. Gill for his work to commence.
 - An amount of \$900,000 has been allocated annually to cover care coordination. Coordinators role should include outreach to eligible population for colonoscopy screening, and when necessary to receive treatment. Nora Katurakes has demographic maps available indicating where outreach is needed. These maps could be useful to drill down and help focus outreach efforts.
- Conclusions:** Committee members should be prepared to discuss job description for Case Managers (Colorectal “Czar”/Patient Advocates) who would be responsible to reach out to community. Positions will be full-time. Envision Care Coordinator/Case Manager as being centrally located at the hospitals.

Action items
Person responsible
Deadline

- | Action items | Person responsible | Deadline |
|--|--------------------|----------|
| ✓ Research job description for Care Coordinators | Committee members | |

Agenda item: Roles and responsibilities

Presenter

- Discussion:** Presented a brief overview of “Roles and Responsibilities” included in meeting materials.

Agenda item: Recruitment Needs		
Discussion:	Committee discussed potential resources needed to accomplish its objectives.	
Conclusions:	The following were identified as membership needs: <ul style="list-style-type: none"> • Dr. Palekar – Gastroenterologist in Lewes, DE • H.C. Moore – Nanticoke Memorial Hospital • Alice Edgell – Screening for Life • Kate Salvato – Director of Education, Bayhealth • Eileen Schmitt, MD – Director, St. Clare Outreach 	
Action items	Person responsible	Deadline
✓ Solicit potential members for participation in committee goals.		
✓ Contact Nanticoke for Outreach Coordinator		

Agenda item: Regular Meeting Schedule		
Discussion:	Discussed time/location for next meeting.	
Conclusions:	Next meeting will be Thursday, October 23, 2003, from 8:30 a.m. to 10:00 a.m. at the Helen F. Graham Cancer Center, Room 1107A. A conference call will be set up for those unable to attend physically.	
Action items	Person responsible	Deadline
✓ Set agenda for next meeting		
✓ Schedule meeting, notify participants, and send meeting materials as necessary for next meeting	Vicki Hayden	

Agenda item: Next Steps/What to Expect	Presenter:
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Other Information

- Resources:**
- **Chairperson’s Notebook** – Committee Member List, DCC Member List, DCC Meeting Agenda, Committee Meeting Agenda, Membership Recruitment Form, Meeting Planner, Committee Member Responsibilities and Expectations, Committee Goals & Objectives, Senate Bill 102
 - **Committee Member Packet** – DCC Meeting Agenda, Committee Meeting Agenda, Committee Member List, Committee Member Responsibilities and Expectations, DCC Bylaws (draft), Senate Bill 102

“Nag” Email Example

Subject: REMINDER: Action requested: NCCRT 2017 Steering Committee retreat pre-meeting survey

We are a marvelously supportive group that always takes an upbeat encouraging approach to completing these surveys.

(pathetic)

No subliminal messages here!

(just fill out the stupid survey)

We care about each of you and know you're busy.

(America's Got Talent is back on the air)

But that's why we ask! You get the most wisdom from the busiest people!

(we'll try to find some)

SO if you get the chance, please complete the survey.

(OMG - where did we find these people?!?!?!?)

THANKS!

Richard Wender | Chief Cancer Control Officer

American Cancer Society, Inc.

Speaker Template: Colorectal Cancer Screening in Community Health Centers – Addressing the Continuum of Care

How can the lessons learned from my program help inform a national strategy to improve links of care between community health centers and the medical neighborhood?

Thank you for agreeing to share your experiences on improving links of care between community health centers and the medical neighborhood in the delivery of colorectal cancer screening and follow up care. Attached is a template meant to help guide your presentation.

1. As a framing question when you prepare your slides, please ask yourself overall, "What are the key take-aways from my program that can help inform a menu of options for community health centers looking to improve links of care?"
2. The template is a guide only. Feel free to adjust and amend in a way that works for you. Essentially, we want to know what elements from your program have been critical to improving links of care with others in the continuum and what the lessons might be.
3. Everyone on the panel will be limited to 8 to 10 slides. Think themes, lessons learned, and remaining challenges and needs.
4. These presentations should only be about 8 minutes, as we will be saving a lot of time for Q & A and follow-up discussion. We will be very firm about time and end presentations after 10 minutes.

High Performing Models: Case Studies

Populations Served and Partners	<ol style="list-style-type: none"> 1. Whom do you serve? 2. Who are your principal professional partners at each point in the cancer care continuum? E.g. primary care physicians, researchers, hospital staff, oncologists, surgeons, pathologists and anesthesiologists
Processes and Methods	<ol style="list-style-type: none"> 3. What do you do when you find a cancer? 4. How did you address the following barriers to providing quality cancer screenings, follow up care and treatment for underserved populations? <ul style="list-style-type: none"> • Garnering the support of GIs? • Garnering the support of other needed professionals, such as hospital staff, surgeons, anesthesiologists, pathologists, and oncologists? • patient costs • program funding • patient navigation • transportation • communication with patients • communication with professionals
Project Successes and Challenges	<ol style="list-style-type: none"> 5. What has been crucial to your success in delivering CRC cancer screenings and follow up care to underserved patients? 6. What issues and concerns, if addressed, would enable you to better assist patients along the full continuum of care?
Lessons Learned	<ol style="list-style-type: none"> 7. What advice do you have for expanding access to colorectal cancer screening and the full continuum of follow up care?

Meeting Pledge Form

Links of Care Next Steps

Name:	Title:
Organization:	Email/Phone:

Please select one or more options as next steps you personally, or your organization can take to advance a Links of Care program to provide colonoscopies and/or cancer treatment following a positive blood stool tests for uninsured/underinsured patients:

- I am with a medical professional society and want to promote the program to our network of providers. Please have someone contact me to discuss my organization's engagement.
- I am active in a cancer coalitions and believe the coalition will be interested in learning about Links of Care for possible replication.
- There is analysis or research that I or my organization might be able to conduct to advance the Links of Care project. Please contact me for details.
- There was a specific barrier mentioned at the meeting that I believe my organization can help overcome. Please contact me for details.
- I would like someone to present about the Links of Care effort to my organization as a way to discuss possible expansion.
- My organization might be able to offer financial resources to advance the Links of Care effort.
- I am willing to contribute to the project in this capacity: _____
- Comments:

Pre-Meeting Survey Sample:

Survey was distributed via email and responses were collected online through a third-party software application.

2018 Strategy Mapping Survey

Thank you for agreeing to attend our June 10th 80% by 2018 Strategy Mapping Session. The purpose of the meeting is to provide high level direction for the work of the NCCRT and NCCRT Task Groups on 80% by 2018. The goal is to come away with both broad and focused strategies, a work map, and clear lines of responsibility.

We are asking all participants to take this survey to help us determine where organizations are focusing their efforts for 2018, what else needs to be done and how the Roundtable can help maximize these efforts. Please allow 30 minutes to take the survey.

Please consider these important categories in achieving 80% by 2018: Public Awareness, Provider Education and Outreach, Systems Change, Health Equity, and Policy.

1. Your Name
2. Organization
3. How do you see your organization helping to achieve the 80% by 2018 goal?
4. Where do you see your organization having the most influence in terms of increasing colorectal cancer screening rates? (Select all that apply)
 - a. Public Awareness
 - b. Provider Education and Outreach
 - c. Systems Change
 - d. Healthy Equity
 - e. Policy
5. Please give a brief explanation of your work in each of the selected areas (A – E) you chose (Public Awareness, Provider Education and Outreach, Systems Change, Health Equity and Policy).
6. Are there niche audiences or channels that your organization is targeting or will be targeting to promote colorectal cancer screening? If yes, please describe.
7. There are a number of ways to influence adults to get screened for colorectal cancer. What three groups or channels are most targeted by your organization? (Please Select Three).

<ol style="list-style-type: none"> a. Health care providers b. Hospitals and Medical Centers c. Payers/Health plans d. Employers e. Public Health agencies (state or local health departments) 	<ol style="list-style-type: none"> f. Cancer Coalitions g. Cultural touchpoints or icons (celebrities, ethnic/cultural events) h. Community groups/churches i. Government j. Elected officials 	<ol style="list-style-type: none"> k. Non-profits l. Cancer Advocacy groups m. CRC Survivors n. Families o. Media p. Social media q. Other
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8. Please describe your organization's work with these three groups or channels. What insights can you share about effective ways to reach these groups? What insights do you have about what hasn't worked?
9. Are there organizational successes that you will seek to replicate?
10. How might some of your organization's efforts in the area of CRC screening benefit from collaboration? With which other organizations?
11. Are there any barriers that are preventing your organization from contributing to its fullest potential in terms of increasing CRC screening rates?
12. How might the Roundtable help address these barriers? Are there specific tools or resources that might be helpful?
13. What type of content does your organization tend to develop around colorectal cancer screening issues? Who is the audience? How is this content shared? [Click down of languages you have communicated in or think would be important to communicate in?]
14. Does your organization rely on various champions to serve as spokespeople for the effort to increase colorectal cancer screening rates? Who do they target? Would you be able to share their names?
15. Has your organization had internal discussion on how it will contribute to the shared 80% by 2018 goal?
 - a. If yes, what were some of the key outcomes? Is there a way for the Roundtable to help?
 - b. If no, are there plans for internal discussions? How might the Roundtable contribute to those discussions?





