RECOMMENDATIONS FOR
STATE-LEVEL COLORECTAL CANCER
COALITIONS (ROUNDTABLES)

MAY 2, 2018
3:00 PM ET

@NCCRTnews
Purpose of Today’s Webinar

• Review recommendations for developing state level CRC screening coalitions
• Introduce two new NCCRT tools: *Development of State-Level CRC Coalitions, Guide and Workbook*.
• Examine two established examples of state coalition efforts that promote CRC screening.
• Q&A
NCCRT Resource Center
Presenters

Caleb Levell
Program Manager
National Colorectal Cancer Roundtable

Katie Bathje, MA, LPCC
Program Director
Kentucky Cancer Consortium

Shauntay Davis, MPH
Program Director
Comprehensive Cancer Control Program
California Department of Public Health
State-Level CRC Coalitions:
What can we learn from early leaders in the effort to launch effective CRC coalitions?

May 2, 2018

Caleb Levell
Program Manager, NCCRT
More and More States Start CRC Coalitions

New coalitions want to know:

• What can we learn from strong existing coalition?
• What are the best practices?
• What are the lessons learned?
• How can we sustain our efforts?
New Guide on Development of State-Level CRC Coalitions

Featuring the experiences of model programs in California, Delaware, Kentucky, Minnesota and South Carolina
New Companion Workbook

Featuring summary pages with brainstorming and action planning activities.
**Prioritize Colorectal Cancer in Your State**

Addressing colorectal cancer (CRC) is a national priority. As the second leading cause of cancer death in the U.S. when men and women are combined and with more than 155,000 adults diagnosed each year, colorectal cancer is a source of considerable suffering. State-based partners are challenged with limited time and resources and must balance and prioritize the public health issues facing their unique populations.

Leaders from successful colorectal cancer collaborations have often started by clearly demonstrating to their partners and peers that the local toll taken by colorectal cancer justifies an immediate investment of local resources and a commitment to action to fulfill the great potential of screening.

**Steps for prioritizing CRC in your state**

1. **Use state-specific data to make your case**
   - Other state-based resources: State Department of Health, Universities, cancer registries

2. **Develop key messages for partner recruitment**
   - Colorectal cancer is one of the few cancers which can be prevented through screening.
   - Even though colorectal cancer can be prevented or caught early, 37% of people develop colorectal cancer in (STATE) and 57% of people will die from the disease.
   - There are proven strategies local leaders can take to increase colorectal cancer screening and reduce the toll taken by this disease.

3. **Align with national efforts**
   - Engage with your state comprehensive cancer control program and coalition, your local CDC Colorectal Cancer Control program (if applicable), and offline resources developed by the Comprehensive Cancer Control National Partnership (http://www.comprehensivepartners.org)
   - Contact your American Cancer Society state systems staff, who have unique skills and are engaged with state systems.
   - Attend national conferences focused on cancer control, such as the Prevent Cancer Foundation’s Dialogue for Action™ meeting, the CDC Cancer Conference, or the Southeast Regional Colorectal Cancer Consortium.

4. **Review key resources**

**Making the Case in Kentucky**

- Whenever possible, pioneering state collaborations use local or state costs and data to make the case.

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

- Private insurance companies spent $8.56 million and Medicare $71.8 million.

- In 2010, cancer costs in Kentucky cost approximately $2.2 billion.
- In 2010, it is estimated to increase by 20%, which would be approximately $3 billion.
- The typical new cancer drug costing on the market in 2010 cost approximately $10,000 per month of treatment.

"If we’re really going to make an impact, let’s focus." — Kentucky Cancer Consortium
### TASK 1: Worksheets

#### Identify Existing Activities

<table>
<thead>
<tr>
<th>Activity</th>
<th>Resource</th>
<th>Completed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Has your organization signed the NCCRT’s pledge to reach an 80% screening rate?</td>
<td><a href="http://nccrt.org/80-2018-pledge">http://nccrt.org/80-2018-pledge</a></td>
<td>□</td>
</tr>
<tr>
<td>Have you identified the other organizations in your state that have signed the pledge?</td>
<td><a href="http://nccrt.org/national-map-of-pledges">http://nccrt.org/national-map-of-pledges</a></td>
<td>□</td>
</tr>
<tr>
<td>Which other organizations need to sign the pledge?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Are you coordinating with your state’s CDC-funded comprehensive cancer control program or coalition?</td>
<td><a href="https://www.cdc.gov/cancer/ncccp/index.htm">https://www.cdc.gov/cancer/ncccp/index.htm</a></td>
<td>□</td>
</tr>
<tr>
<td>Does your state have funding from CDC for colorectal cancer control programming?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Are you working with your ACS state office staff?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>What national conferences focused on colorectal cancer control do you regularly attend?</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

#### Identify Available Data

<table>
<thead>
<tr>
<th>Activity</th>
<th>Resource</th>
<th>Completed</th>
</tr>
</thead>
<tbody>
<tr>
<td>How does your state rank/compare nationally?</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

#### Create three key messages to help prioritize colorectal cancer in your state:

1.
2.
3.

#### Notes:
10 Tasks New CRC Coalitions Should Address:

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 and objectives
8. Maintain momentum
9. Get creative with funding and resources
10. Hold the group accountable
1. Prioritize CRC in your State

Colorectal cancer is one of the few cancers which can be prevented through screening.

1. Potential for High Impact
2. Leverage national support
   - Momentum and support from 80% by 2018 (Hall of Famers)
3. Use state-specific data to make the case
   - Even though colorectal cancer can be prevented or caught early, X # of people develop colorectal cancer in [STATE] and Y# of people will die from the disease.
   - National Data Sets Webinar
1. Prioritize CRC in your State

*TIP:* Create a fact sheet to describe CRC incidence and mortality in your state.

How to create a sense of urgency in key partners in your state?

Think about your audience

“If we’re really going to make an impact, let’s focus.”  
*(Kentucky Cancer Consortium)*

[Link to Kentucky Cancer Consortium website](http://www.kycancerc.org/)
2. Establish a Structure

Common models:

1. Task groups or committees organized under their state’s CCCP, typically administered through the state’s department of public health

2. Independent, not-for-profit organizations operating in concert with their state CCC program

3. Unassociated voluntary organization

Advantages and Disadvantages discussed in Guidebook
3. Develop a Vision

What is the ideal community where a coalition like yours would not need to exist?

Guide includes tips from:

• CDC -- NCCCP
• NCCRT
  – Envision the Goal
  – Promote an inclusive solution
  – Identify your role
  – Avoid duplication
3. Develop a Vision

Example: NCCRT

- NCCRT stands united in eliminating colorectal cancer as a major public health problem.

NCCRT Role:

- Forum for communication and developing consensus
- Stimulates collaboration on projects
- Leverages the talents of the members to jointly conduct studies, create tools, and identify emerging issues that can advance colorectal cancer screening.
4. Recruit leadership and “staff”

Common models include:

1. Expert champion (typically a clinician)
   - Personality is important. Ideally, the champion will not only be a natural leader, but also persistent about asking for help from peers and partners.
   - i.e. *Expends social capital*
2. Project managers/implementation leads
3. Steering Committee members
4. Task Group members and chairs

*TIP*: Consider how to best support a volunteer champion’s limited time. It is often more realistic for a volunteer champion to provide leadership and contacts, but have a staff member from ACS or DOH do the behind-the-scenes project management.
5. Build a Network of Partners

- Involve two key collaborators from the beginning—the state department of health and the American Cancer Society.
- Start by developing a priority list of organizations and individuals who are critical to the effort.
- Consider involving state legislators, staffers and others in the public sphere.
- Non-traditional (e.g. fundraising, law, marketing, media, policy, other non-CRC oriented public health advocates)
6. Convene Partners

1. Plan a Summit/Kick-Off meeting
   - Get partners to the table to discuss the issues, agree on priorities, develop a plan, and secure commitments.

2. Follow up to define success
   - Capitalize on momentum with quick action. Tangible goals, action items, assignments and target dates should be documented and distributed to all participants.

3. Keep Momentum / Maintain volunteer investment
   - Annual Meetings, Task Groups
7. Set Goals and Objectives

- Plan strategically to set goals for coalition’s long term vision and objectives that are:
  - Concrete,
  - Action-oriented, and
  - Measurable.
- Brainstorm often, but limit to what can reasonably be accomplished.
- Align with the state cancer control plan.
- Make the process collaborative.
- Plan some early wins. Consider 3 months, 6 months, and 12 months.
8. Maintain (Build) Momentum

Tips for sustaining momentum over time:

▪ Meet in-person at least yearly and schedule regular times for calls.
▪ Focus on making meetings *interesting* and *productive*.
▪ Assign clear tasks, and identify achievable outcomes that can be completed before the next meeting.
▪ Add value to meetings by bringing in guest speakers.
▪ Offer ongoing communication through newsletters, email blasts, or social media.
9. Get Creative with Funding and Resources

- Funding from CDC, state funds, grants, private fundraising, etc.
- In kind support (e.g. ACS and DOH staffing, donated meeting space and services, etc.)
- Don’t overlook public fundraising opportunities, such as local events or sales.
- Most important ingredient for success: a passionate, committed membership.
10. Hold the Group Accountable

- Many coalition leaders say that a sense of accountability permeates their work. What sets them apart from previous efforts that may have fallen short of their objectives is the understanding among all partners that the coalition will be held accountable for what they propose to do.

- As coalitions set goals, they should also develop plans for assessing progress and reporting at regular intervals. (emails, newsletters, websites, annual reports, etc.)
10. Hold the Group Accountable

Finally, don’t forget to celebrate success!
Acknowledgements

• Thank you to our funders, ACS and the CDC.
• Thank you to our lead author, Tamara O'Shaughnessy of QNA Group.
• A special thank you to the state coalition leaders in California, Delaware, Kentucky, Minnesota and South Carolina who generously offered their time and expertise.
• Thank you to Nikki Hayes, Nina Miller, Anne Major, Sarah Shafir, Lorrie Graaf, Djenaba Joseph, Kaitlin Sylvester, Angela Moore, Karen Peterson, Erica Childs, Anjee Davis, Bob Smith, and Kerstin Ohlander.
• A big thank you to all of you who are working to increase CRC screening in your state!
Thank you!

- Questions? Caleb.Levell@cancer.org
COLON CANCER IN KENTUCKY
BUILDING A SUSTAINABLE COALITION
May 2, 2018

Katie Bathje
Program Director
Kentucky Cancer Consortium
In the past 17 years, Kentucky's colorectal cancer (CRC) screening rate has improved more than any other state in the country.

50% increase in screening

As screening rates have risen, incidence rates and mortality rates have declined DRAMATICALLY.

23% decrease in incidence
30% decrease in mortality

This decrease in incidence means that every year approximately 350 Kentuckians who would have gotten colorectal cancer no longer get the disease.
HOW DID KENTUCKY MAKE PROGRESS?

STORY TOLD THROUGH THE LENS OF THE NCCRT’S “DEVELOPMENT OF STATE-LEVEL COLORECTAL CANCER COALITIONS” 10 RECOMMENDED TASKS
NCCRT’S “DEVELOPMENT OF STATE-LEVEL COLORECTAL CANCER COALITIONS” 10 RECOMMENDED TASKS

1. Prioritize colorectal cancer in their state
2. Establish a structure
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4. Recruit leadership and staff
5. Build a network of partners
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7. Set goals
8. Maintain momentum
9. Get creative with funding and resources
10. Hold the group accountable
How did Kentucky make progress?

- Health dept.
- Comp cancer
- Non-profits
- Health systems
- Advocacy org
- Provider groups

- Physician
- Legislator
- Lobbyist
- Public Health official

- Comp Cancer

- Reduce financial barriers
- Increase access

Long-term cross-sector collaboration
Champions, champions, champions
Coordinated efforts to reach the public, providers and systems with best-practice messaging and interventions
Strong policies that reduce barriers and expand access
COALITION FOUNDATION: PARTNERSHIPS

- Identify dedicated staff who can be neutral conveners (Task 4)
- Establish a structure by gathering partners with similar goals & clearly defining roles (Task 2)
- Make identifying a strong policy partner a **TOP** priority (Task 3)
- Convene partners **regularly, initially** around a specific project/initiative (Task 6)
- Build on momentum of initial project to catalyze ongoing objectives/workgroups (Task 8)

- Comprehensive Cancer Control
- Ex: ACS, ACS CAN, Regional cancer control org, health department, physician org
- Work with your 501c3’s to identify a lobbyist/consultant
- Ideas: state summit, public awareness campaign, provider education event
- Providers, Public, Policy
COALITION GROWTH: A PLAN IN ACTION

- Identify resource gaps and areas of greatest need (Task 1)
- Prepare for planned and unexpected opportunities to request and acquire resources (Task 9)
- Choose top objectives from state cancer plan, and create an accompanying resource plan (Tasks 7 & 9)
- Continue convening partners regularly (Tasks 6 & 10)

- Cancer registry data, BRFSS questions, “who’s doing what?” matrix
- What would you do with a million dollars?
- How much would it cost to implement that state cancer plan objective? Or not?
- Neutral staff creating agendas, minutes, logistics of space, following up on meeting action steps
TASK 9: GET CREATIVE WITH FUNDING & RESOURCES

- **Planned:** Testify at state legislative Health & Welfare Committee hearings; make the case to Administration that CRC screening saves lives AND money; find friendly legislators.

- **Unplanned:** 3-time cancer survivor and fundraiser found our plan online. Comp cancer convenes fundraiser, comp cancer coalition chair, and physician champ...a new 501c3 is founded.

Prepare for planned and unexpected opportunities to request and acquire resources.
KENTUCKY CANCER RESOURCE PLAN

What can we do for Kentucky?

• For every $100,000 invested in cancer prevention and screening....
  • 666 Smoking cessation medications can be provided
  • 135 Lung cancer screenings performed
  • 246 Colon cancer screenings performed
  • 403 Breast cancer screening performed
  • 450 Cervical cancer screening performed

Lost opportunity for Kentucky

• For every $100,000 invested in cancer treatment...
  • 0 Kentuckians can be treated for late stage lung cancer. OR...
  • 1 Kentuckian can be treated for late stage colon cancer. OR...
  • 1 Kentuckian can be treated for late stage breast cancer. OR...
  • 1 Kentuckian can be treated for late stage cervical cancer.
KENTUCKY COLORECTAL CANCER POLICY: SAVING LIVES!

Thank you for prioritizing policies that reduce cancer in Kentucky. We know what works to prevent colorectal cancer and how to find it early when it is most treatable. Enacting data-driven practices at the policy level give you, our state policymakers, a unique opportunity to join our efforts.
COALITION PARTNERS PUT POLICIES & PLANS INTO ACTION

• KCP develops “Get the FIT Facts” provider education campaign, disseminates to PCPs statewide.

• Kentucky Cancer Registry, Ky Behavioral Risk Factors Surveillance System Program and KCC gather CRC data and create factsheets and presentations for use by KCP & Local HDs in health education.

• KCCSP trains local HD staff as patient navigators in CRC screening programs.

• C2P2 takes CRC screening lunch-n-learn to staffs of all FQHCs and community health centers in Kentucky.

• 7 Inflatable colons travel around Kentucky for CRC screening awareness events.

• Kentucky Cancer Link partners with NCI designated Markey Cancer Center to distribute FIT kits and navigate patients.
2016 Colorectal Cancer Screening Rates by Area Development District, KyBRFS

Purchase - 83%
Green River - 78%
Bluegrass - 77%
Barren River - 72%
Northern Kentucky - 74%
FIVCO - 74%
KIPDA - 72%
Pennyville - 71%
Lincoln Trail - 71%
Buffalo Trace - 67%
Kentucky River - 64%
Gateway - 63%
Cumberland Valley - 63%
Lake Cumberland - 62%
Big Sandy - 60%

Purchase ADD achieved **80% by 2018**!

And many ADDs increased their screening rates **by over 30%** in the past 10 years.
Despite our progress, there is more to be done. 21 percent of colorectal cancer cases in Kentucky are still diagnosed at a late stage. Blacks have a higher incidence rate and mortality rate from colorectal cancer than whites. The highest incidence and mortality rates in Kentucky are in the Appalachian region of the state, and they are declining much more slowly compared to the non-Appalachian area of the state.
COALITION WORK – ALL ABOARD!
NCCRT’S “DEVELOPMENT OF STATE-LEVEL COLORECTAL CANCER COALITIONS” 10 RECOMMENDED TASKS

1. Prioritize colorectal cancer in their state
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THANK YOU!

KATIE BATHJE
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KCC Colon Cancer Committee organizations:

- American Cancer Society
- American Cancer Society Cancer Action Network
- Colon Cancer Prevention Project
- Kentucky African Americans Against Cancer
- Kentucky Cancer Foundation
- Kentucky Cancer Program at the University of Kentucky
- Kentucky Cancer Program at the University of Louisville
- Kentucky Cancer Registry
- Kentucky CancerLink
- Kentucky Department for Public Health
- Kentucky Homeplace
- University of Kentucky Rural Cancer Prevention Center
- University of Kentucky, Markey Cancer Center
- University of Louisville, Brown Cancer Center
National Colorectal Cancer Roundtable State CRC Coalition Guide and Workbook
California’s Experience

Shauntay Davis, MPH
Program Director
California’s Comprehensive Cancer Control Program
California Department of Public Health

National Colorectal Cancer Roundtable Webinar
May 2, 2018
California’s Comprehensive Cancer Control Program

California’s Comprehensive Cancer Control Program (CCCP) is charged with:

• Establishing a cancer control coalition  
  *California Dialogue on Cancer or CDCC*

• Assessing the burden of cancer in California

• Developing and implementing a Comprehensive Cancer Control Plan for California
Prioritizing Colorectal Cancer

- First state cancer plan adopted in 2004 that included goals and objectives to reduce the cancer burden by 2010
- Reducing colorectal cancer mortality was prioritized
  - Goal for CRC: By 2010, reduce the CRC mortality rate in California by 40%.
- CDOC formed a CRC Implementation Team
CDOC CRC Implementation Team applied for funding to further CRC screening efforts identified in the cancer plan.

- Received a grant from the Prevent Cancer Foundation to convene a California Dialogue for Action conference.
California DFA 2006 Outcome

- $60,000 raised to assist in establishing a 501c3
- In 2007, the California Colorectal Cancer Coalition (C4) is established
- C4’s mission is to save lives and reduce suffering from colorectal cancer in all Californians.

www.cacoloncancer.org
• Led by a president and a volunteer member board

• Major funders are the Colon Cancer Alliance through the UNDY Run/Walk in Sacramento and San Diego and ACS

• Close coordination with ACS, CDOC, and the state CRC CDC funded screening program

www.cacoloncancer.org
C4 Community Grants Program

• Annual community collaborative grant process initiated in 2013 with a major focus on increasing the screening rate in California’s FQHCs

• 2013 through 2018 a total of $395,660 funded 55 grants

www.cacoloncancer.org
CDOC and C4
Continued Collaboration

• CDOC and C4 continue to collaborate on CRC efforts in California

• C4’s independent status allows for more flexibility in initiating various efforts

• CDOC’s broader stakeholder base and reach allows the engagement of additional partners to address CRC efforts
CDOC’s 80 by 2018 Efforts

• 2014 - CDOC joined the 80 by 2018 movement and declared increasing CRC screening our BIG Win.

• Draft Cancer Plan Goal: By 2020, increase CRC screening among CA’s 50 and older by 24.22%, from the baseline of 64.4%* to 80%.

• 2015 - CA Comp Cancer Program was selected to participate in the first 80 by 18 Forum: *Increasing CRC Screening Rates through Enhanced Partnerships between Comp Cancer Control Coalitions & FQHCs*

*Behavioral Risk Factor Surveillance System, 2013*
CDOC’s 80 by 2018 Efforts

80% by 2018 Forum Outcome

• An action plan was developed to assist community health centers increase their CRC screening rates

• Objective: Develop a CME training that addresses specific needs and challenges of community health centers to increase CRC screening
CDOC’s 80% by 2018 Efforts

- Established Colorectal Cancer Workgroup as part of CDOC to develop training
- Engaged additional partners, including C4, California Primary Care Association (CPCA), ACS and additional SMEs
- Utilized *Steps for Increasing Colorectal Cancer Screening Rates: A Manual for Community Health Centers* to develop needs assessment and training curriculum
Increasing CRC Screening Rates
Addressing barriers and learning best practices impacting California Community Clinics & Health Centers

4.25 CME credits

Recordings of the presentations are available on the CPCA YouTube Channel and the CPCA On Demand Library

www.cpca.org
Training Curriculum

- Operational Efficiencies in CRC Screening
  - Standing orders, FluFIT

- Care Delivery & Coordination for CRC Screening
  - Patient navigation, staff coordination & patient education

- Best Practices for Financial Sustainability for CRC Screening
  - Hospital partnerships, EHR optimization, negotiating FIT prices
Collaboration is Key

- Increasing CRC screening through state level coalitions requires collaboration, commitment, and passion.

Never doubt that a small group of committed people can change the world. Indeed, it is the only thing that ever has.

Margaret Mead
Establishing a CRC Coalition
Lessons Learned

- Ensure there is a champion on board
- Utilize state cancer coalition and comprehensive cancer control program and stay engaged
- Engage stakeholders and build network – ensure there is diversity in membership (e.g. GIs, survivors, fundraisers, advocates, etc.)
Establishing a CRC Coalition Lessons Learned

- Develop a vision and goals
- Get creative with funding efforts
- Utilize existing resources
- Maintain stakeholder commitment
Please submit your questions in the chat box.
Thank You!

To follow NCCRT on social media:
Twitter: @NCCRTnews
Facebook: www.facebook.com/coloncancerroundtable

For more information contact: nccrt@cancer.org