Removing Out-of-Pocket Costs for Colonoscopy Following a Positive Non-Invasive Screening Test

STATE POLICY ACTION PLANNING SESSION
AUGUST 27, 2020
On August 27th, 2020, Fight Colorectal Cancer (Fight CRC), the American Cancer Society Cancer Action Network (ACS CAN), the Prevent Cancer Foundation and the National Colorectal Cancer Roundtable (NCCRT) hosted a State Policy Action Planning Session on removing out-of-pocket costs for colonoscopy following a positive non-invasive screening test.

The goal of the three-hour meeting was to bring together leaders in the colorectal cancer (CRC) community including advocacy organizations, public policy professionals, researchers, clinicians and others to discuss what can be done together to help address the challenges around enacting policy at the state level to increase access to colorectal cancer screening.

This work is also an important piece of the goal of the National Colorectal Cancer Roundtable (NCCRT) to achieve 80% screening in every community. The meeting was led by Dr. Darrell Gray, Deputy Director of the Center for Cancer Health Equity at the Ohio State University Comprehensive Cancer Center and member of Fight CRC’s Health Equity Committee.

The Problem

Out-of-pocket costs create a barrier for patients needing a colonoscopy following a positive non-invasive screening test (stool or blood). While it is important for people to consult their doctor about which test is best for them, non-invasive, at-home tests such as high sensitivity guaiac-based fecal occult blood test (hs-gFOBT), fecal immunochemical tests (FIT), and multitarget stool DNA test (i.e., Cologuard) are an important option, particularly in light of the challenges associated with COVID-19.

According to data from Komodo Health, the total number of colonoscopies and biopsies performed declined nearly 90% by mid-April 2020 compared to the same period last year due to the COVID-19 pandemic. New CRC diagnoses declined more than 32% over the same time period. Furthermore, research estimates there will be over 4,500 excess deaths from CRC due to delays in CRC screening and treatment.
State Successes

Several states have successfully addressed this issue by passing legislation to remove out-of-pocket costs for patients needing a colonoscopy following a positive non-invasive screening test.

Kentucky, Maine and Oregon all serve as models that we can learn from and build off of to advance legislation elsewhere.

**KENTUCKY**

Kentucky has passed multiple pieces of CRC-related legislation including one to create a Colorectal Cancer Advisory Committee made up of legislators, public health officials, and others that has been integral to help keep the focus on CRC in Kentucky.

In 2015, Kentucky passed legislation to amend their state statute to require that health plans cover the complete spectrum of CRC screening without deductible or coinsurance, including colonoscopy following a positive non-invasive screening test.

**MAINE**

In May of 2019, Maine’s Governor signed into law legislation updating Maine’s CRC screening statute to require coverage for all CRC examinations and laboratory tests recommended by a health care provider in accordance with published guidelines.

The ACS CAN team in Maine was able to work with a conservative, Republican lawmaker as a champion to advance the legislation by emphasizing the importance of this policy to increasing access to CRC screening in rural areas. It ultimately passed both chambers unanimously.

**OREGON**

Oregon passed legislation to ensure coverage without cost-sharing for all colorectal cancer screening examinations and laboratory tests with either a grade A or B from the United States Preventive Services Task Force (USPSTF).

The legislation specifically referenced coverage for a colonoscopy if the patient has a positive result on a non-invasive test.
States in Progress

Several states are currently in the process of advancing legislation to remove out-of-pocket costs for colonoscopy following a non-invasive screening test. In addition to the work being done by ACS CAN and others, late last year Fight CRC launched the Catalyst State-by-State Advocacy Program which aims to increase access and reduce barriers to CRC screening including addressing patient costs for follow-up colonoscopy.

A number of states are currently working to advance policy at the state level to remove out-of-pocket costs for colonoscopy following a positive non-invasive screening test.

**COLORADO** and **RHODE ISLAND** both introduced legislation in early 2020 that passed the Colorado House and Rhode Island Senate, respectively.

**ARKANSAS** intends to introduce legislation on this issue in 2021.

**LOUISIANA** is pursuing a small “p” policy approach by working directly with the largest health insurers in the state to remove cost-sharing for follow-up colonoscopies for their beneficiaries.

Landscape

As we look to advance policy at the state level, it is important to consider the broader context both within and beyond the CRC community. COVID-19 has had a significant impact on just about every aspect of life, including CRC screenings. The significant drop off in CRC screening that occurred in the first several months of the pandemic is likely to have lasting consequences. Research estimates over 4,500 excess deaths from CRC due to delays in CRC screening and treatment.

During the pandemic, responding to COVID-19 has understandably been the central focus of most state legislatures and state public health agencies. Furthermore, COVID-19 has had a significant impact on state budgets which will create a challenge for any policy that could have additional costs. But cancer has not stopped for COVID-19, and it is important that we work together to remind policymakers that ensuring people have access to CRC screening needs to remain a priority.

Additionally, the future of the Affordable Care Act is in question due to a lawsuit questioning the constitutionality of the law. Should the law be struck down, the requirement to cover preventative services would fall with it, making state policy all the more important.

In an effort to better understand how Americans were handling cancer screenings during the pandemic, the Prevent Cancer Foundation conducted a survey as part of a new program, Back on the Books, which encourages people to resume routine screenings.

**THE SURVEY FOUND THAT:**

- **43%** of Americans missed these appointments because of COVID-19.
- **35%** missed a cancer screening that had been scheduled during the pandemic.
- **22%** said they planned to cancel or postpone a routine medical appointment or screening scheduled within 3 months.

*As of May 2020*
Discussion

During the meeting, attendees were put into three breakout groups and tasked with identifying 3-5 priorities or issues the group can address to help advance state policy efforts to remove out-of-pocket costs for colonoscopy following a positive non-invasive screening test. **Each group discussed the following questions:**

- What are the main challenges with advancing state policy around follow-up colonoscopy?
- What are the main opportunities with advancing state policy around follow-up colonoscopy?
- What data/resources do we currently have to support these efforts? What do we need?

Each group included at least one representative from a state who has successfully advanced policy on this issue to provide first-hand knowledge of what worked, what didn’t, and what is needed. Following the breakout sessions, one person from each group presented on their discussion and several key themes emerged:

### STATE POLICY BEST PRACTICES

Throughout the discussion the group was able to hear from those who are currently working to advance policy change and those who have successfully passed legislation. A number of best practices and strategies for success emerged from the discussion.

- Identify and develop engaged CRC patient advocates
- Identify and develop engaged physician champions (primary care & GI)
- Collect patient & physician stories to illustrate and support policy ask
- Work with a high-quality government relations professional
- Develop a targeted public relations strategy including social media to highlight patient & physician stories
- Utilize legislation from other states as a model
- Build strong state coalitions
- Create State CRC Advisory Committee
- Once legislation is passed, continue to work with physicians, insurers and others to ensure proper implementation

**NEXT STEPS:** Compile a best practice guide that can serve as a resource for states currently working or looking to begin work on advancing policy around the follow-up issue.

### SUPPORTING DATA

Another theme from the discussion was the importance of state-specific data to support policy efforts. Policymakers need to understand the specific burden of CRC in their state and in the communities they serve. Specifically:

- State-level outcomes on screening, follow-up, and diagnosis (who gets screened, when, how & short-term vs. long-term costs)
- Data on impact of COVID-19 (drop in screening & disease progression)
- Health disparities data (racial, ethnic, rural/urban)
- Data from states that have successfully passed legislation on the follow-up colonoscopy issue to illustrate impact
- Data illustrating the cost of screening vs. cost of cancer care to make the case for a positive return on investment for screening

**NEXT STEPS:** Bring together stakeholders to determine what data currently exists, what data needs to be gathered, and what data is most compelling to support these policy efforts. Create a template or guide for states to direct them towards where to find the most compelling data and how to present it.

### COVID-19

It is also important to note that over the next year if not longer, COVID-19 will continue to be a major focus of state legislatures. Furthermore, as time goes on we will begin to see in greater detail the impact of drop in CRC screening due to COVID-19.

We have the opportunity to help mitigate some of that impact through advancing policy at the state level. Another theme that emerged from the discussions was the need to frame policy in the context of COVID-19 to leverage the legislative focus as well as the public affairs opportunity.

**NEXT STEPS:** Develop talking points on COVID-19 and the follow-up issue that states can use in their engagement with policymakers.

### ADDITIONAL RECOMMENDATIONS

Several other key action items and strategies emerged from the discussion to help advance policy efforts around the follow-up issue. These are largely complementary to the recommendations mentioned above.

- Develop case studies from health plans that already cover follow-up colonoscopy without cost-sharing and compile language around their rationale for such coverage
- Develop consensus/clarity across stakeholders on messaging/terminology for materials, engagement with policymakers, social media, etc
- Compile a database to identify what organizations have what expertise and help connect states to needed resources

**NEXT STEPS:** Convene a working group to engage with health plans and develop case studies. Leverage NCCRT to bring together key stakeholders to develop consensus around language and messaging. Identify most-needed resources for states and where they can access them.