

**MEETING SUMMARY**  
**PRESIDENT’S CANCER PANEL**  
**IMPROVING RESILIENCE AND EQUITY IN COLORECTAL CANCER**  
**SCREENING: LESSONS FROM COVID-19 AND BEYOND**

November 2 and 4, 2020  
Virtual Meeting

This workshop was the second in the President’s Cancer Panel’s (the Panel) 2020–2021 series on cancer screening. The workshop brought together stakeholders from several sectors, including clinical care, healthcare systems, insurance companies, government agencies, research, and advocacy. Participants discussed barriers and opportunities related to colorectal cancer screening, including those relevant to the healthcare system disruptions caused by the coronavirus disease (COVID-19) pandemic. The workshop was available to the public via live feed, and members of the public were invited to submit written comments and questions during and after the workshop. Participants were encouraged to live-Tweet at [#ImprovingCancerScreening](#).

This meeting summary was prepared to satisfy requirements established by the Federal Advisory Committee Act. The summary provides an overview of presentations and discussions occurring as part of the workshop and does not necessarily reflect the views of Panel members.

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## **WELCOME AND INTRODUCTIONS**

Dr. John Williams welcomed invited participants and other attendees, introduced the Panel members, described the history and purpose of the Panel, and provided an overview of the current Panel series of meetings. The Panel is concerned about the long-term consequences of cancer screenings missed and delayed due to massive disruptions of the healthcare system during the COVID-19 pandemic. The pandemic has created new barriers to screening and exacerbated those that already existed. The current Panel series will explore practices and barriers present before the pandemic, implications of the pandemic on screening, and opportunities to improve the equity and resilience of cancer screening in the United States.

To assist with series planning, the Panel created the Working Group on Cancer Screening During the COVID-19 Era. Cancer type-specific planning subgroups for lung, colorectal, cervical, and breast cancers were established. These subgroups—comprising clinicians, researchers, and patient advocates—helped

identify barriers, opportunities, and potential solutions in their respective areas. Several cross-cutting themes were identified across cancer types, including disparities, equity, and inclusion; telemedicine; and access and uptake issues.

Dr. Edith Mitchell introduced meeting facilitator Mr. Scott Wheeler and the co-chairs of the Colorectal Cancer Planning Subgroup, Drs. Al Benson and Richard Wender. Drs. Benson and Wender introduced subgroup members, as well as members of the colorectal cancer stakeholder panel invited to participate in the meeting. Input received at all series meetings will be considered and inform development of recommendations to be presented in the Panel's report to the President of the United States.

## **COLORECTAL CANCER WORKING GROUP PRESENTATION**

Drs. Benson and Wender provided an overview of the opportunities to improve colorectal cancer screening that were rated most highly by subcommittee and stakeholder panel members before the meeting. A noncomprehensive list of barriers and solutions related to each opportunity also was presented. Many barriers and solutions are relevant to multiple opportunities. It was noted that most discussion of the fecal immunochemical test (FIT) also is relevant to FIT-DNA.

### **OPPORTUNITY 1: GREATER PROMOTION OF STOOL-BASED TESTS**

#### **Barriers**

- Many providers recommending only colonoscopy
- Lack of acceptance and recommendation of stool-based tests.
- Concerns about quality of FIT programs and lack of quality metrics
- Financial burden of paying for colonoscopy after a positive stool-based test
- Patient beliefs about the necessity of screening
- Patient difficulty following instructions for using and returning kits
- Shame/stigma associated with the test
- Burden of yearly requirement
- Appropriate follow-up after FIT

#### **Solutions**

- Increase awareness of FIT and encourage providers to recommend it.
- Create well-organized FIT programs that include a choice of screening method.
- Track adherence to annual FIT after a negative FIT.
- Change policy to eliminate cost-sharing for colonoscopy after positive FIT.
- Develop graphical instructions for FIT.
- Develop digital navigation for FIT, similar to that for colonoscopy.

### **OPPORTUNITY 2: GREATER ACCESS TO COLONOSCOPY AND DISCUSSION OF OPTIONS**

#### **Barriers**

- Time demands for patients and providers
- Variable insurance coverage by state and limited colonoscopist acceptance of financial assistance programs

- Patients' reluctance to go to a medical facility due to COVID-19 concerns
- Lack of screening reminder systems
- Inadequate numbers of colonoscopists in rural and frontier areas
- Shame/stigma associated with the test
- Challenges to creating consistently high-quality colonoscopy programs
- Viability of procedure during COVID-19
- Fear of cancer diagnosis
- Low Centers for Medicare & Medicaid Services (CMS)/insurance reimbursement for telemedicine
- Logistical challenges (e.g., time, transportation, escort)

### **Solutions**

- Use electronic health record (EHR) alerts. These should be used uniformly to reduce technology-induced disparities.
- Reimburse support staff time to identify eligible individuals for outreach and contact patients for screening and follow-up.
- Promote use of noninvasive screening tests.
- Determine which cultural groups are most likely to experience shame/stigma.
- Develop targeted approaches for addressing shame and stigma among different cultural groups.

### **OPPORTUNITY 3: IMPROVEMENT OF GUIDELINES (LOWER AGE FOR DISCUSSING COLORECTAL CANCER TO AGE 45)**

#### **Barriers**

- Policy changes in each state needed to uniformly lower the starting age
- Risks of overscreening (e.g., too frequent surveillance of small polyps, bottlenecks that delay diagnosis for at-risk patients, procedure complications)
- Different starting ages for risk-based screening
- Lack of guidance on upper age limits for screening

#### **Solutions**

- None noted.

### **OPPORTUNITY 4: RISK-BASED APPROACH TO SCREENING AND MANAGEMENT**

#### **Barriers**

- Low prioritization of screenings relative to other concerns
- Missed opportunities to recommend screening or order related tests (e.g., germline testing) in primary care settings
- Challenges obtaining family history
- Patient reluctance to go to a medical facility due to COVID-19 concerns
- Inadequate access to telemedicine (e.g., due to technological barriers or limited CMS/insurance reimbursement)

- Limited genetic testing in colorectal cancer screening community
- Insufficient numbers of genetic counselors

### **Solutions**

- Use EHR alerts.

## **OPPORTUNITY 5: IMPROVEMENT OF FOLLOW-UP, MANAGEMENT, AND TREATMENT**

### **Barriers**

- Patient challenges navigating the screening process (e.g., poor preps, scheduling and attending appointments, compliance)
- Lack of systems that ensure high-quality and timely treatment (e.g., EHR, documentation, reminder systems)
- Lack of digital navigation (e.g., to address patient challenges with using telemedicine and patient portals)
- Variability in care quality
- Insufficient numbers of gastroenterologists, surgeons, and oncologists

### **Solutions**

- None noted.

## **COLORECTAL CANCER SCREENING IMPROVEMENT OPPORTUNITIES**

A mind map was used to visually organize and present barriers and potential solutions identified prior to the meeting. Mr. Wheeler facilitated discussion on each of the five opportunity areas. Stakeholders elaborated on previously identified barriers and solutions and offered new suggestions for ways to improve colorectal cancer screening. Input was recorded in real time through updates to the mind map. Participants were urged to think about what screening barriers have been exacerbated during the COVID-19 pandemic and how changes created by the pandemic may provide opportunities to enhance cancer screening in the long term.

## **GREATER PROMOTION OF STOOL-BASED TESTS**

### **Provider Awareness, Behavior, and Workflow**

- More information is needed on how many and which providers are only recommending colonoscopy for colorectal cancer screening. If this is widespread, this may be a healthcare system- or payor-related issue.
- To achieve high rates of screening, multiple screening options should be made available to patients. Providers and patients often are not aware of colorectal cancer screening test options other than colonoscopy (e.g., FIT, FIT-DNA). Some providers and patients consider colonoscopy to be the gold standard for colorectal cancer screening; most are not aware of modeling data showing that the population impact of stool-based tests is almost identical to that of colonoscopy.
- Currently, stool-based tests are the only noninvasive colorectal cancer screening tests available, but other technologies may be developed. Patients and providers will need to be made aware of these as they become available.
- Physicians may feel they do not have sufficient time to present and discuss all of the available colorectal cancer screening options during a standard office visit. There are tools that present options

and help patients identify their preferences before they talk to their providers. This will allow more efficient use of time during appointments.

- Ongoing randomized clinical trials are comparing the effectiveness of colonoscopy with that of stool-based tests. Recommendations, strategies, and tools should be flexible so they can be adapted based on the data.
- Allowing nonphysician staff to provide an initial recommendation, or sign an order for screening, may relieve the burden for physicians and increase uptake. This approach has been successful for the flu vaccine. Pharmacists also could provide information about colorectal cancer screening.
- Providers may view colonoscopy as a more efficient use of their time. Colonoscopy is recommended every 10 years, while Cologuard should be done every 3 years and FIT should be done annually. Annual testing poses a greater workload for providers.
- Providers could be encouraged to offer FIT while a patient is waiting for a colonoscopy to be done.
- Medicare has approved chronic care management (CCM) codes that allow reimbursement for remote patient management. These could be leveraged to support navigation for Medicare patients. Other payors may follow suit if the codes become widely used.

### **Training**

- Physicians should receive training during their residencies and fellowships to help them promote colorectal cancer screening during their careers. They should be taught to leverage existing tools and resources and trained in shared decision-making. They also should learn to work within multidisciplinary teams, which are critical to successful screening programs.
- Many of the skills and much of the knowledge needed for providers to promote colorectal cancer screening also are relevant to screening for other cancers.
- Providers should learn to understand metrics and be encouraged to participate in quality improvement projects.

### **Stool-Based Testing Benefits and Considerations**

- Patients can collect samples for stool-based tests on their own. This is particularly valuable during the COVID-19 pandemic. Eligible patients could be identified using EHRs and FIT kits could be delivered via mail. Simple, clear instructions and other systems supports would be needed to help patients complete sample collection at home.
- The requirement for annual testing is a downside of FIT. In some cases, FIT could be a bridge to colonoscopy; patients may do FIT for a few years until they are comfortable receiving a colonoscopy.

### **Financial Considerations**

- Financial considerations influence provider screening recommendations and patient decision-making.
- If a positive FIT result is received, a colonoscopy must be done. The current draft United States Preventive Services Task Force (USPSTF) guideline for colorectal cancer screening refers to the colonoscopy following a positive FIT test as “diagnostic.” Patients may be responsible for substantial cost-sharing if insurance companies consider the colonoscopy to be a diagnostic rather than screening service. Addressing this issue should be a high priority. Colorectal cancer screening should not be considered a single procedure but an episode of care that includes all steps from initial test to diagnosis. USPSTF should define FIT-based screening as a two-step process—FIT (or another stool-based test) followed by any necessary colonoscopy follow-up—and payors should cover the follow-up colonoscopy without patient copay, regardless of whether a polyp is found. Major medical groups, including the American Medical Association (AMA), have advocated for this. USPSTF may reconsider if they receive strong feedback to their current draft.

- Patients may be charged if there are positive findings during a screening colonoscopy.
- CMS has signaled it may be able to make administrative changes to eliminate copays for colonoscopy after a positive FIT; however, they are resistant to making this change unless legislative changes are made to eliminate copays when a polyp is found during colonoscopy. The increased cost to CMS of fully covering the diagnostic colonoscopies is substantial; more than 60 percent of Medicare-covered screening colonoscopies end up as diagnostic colonoscopies.
- Cost is one of the most significant barriers to colorectal cancer screening on a population scale, particularly in communities with high numbers of uninsured people and in states that have not expanded Medicaid. Promoting FIT rather than colonoscopy may be a way to reduce overall costs.
- Younger people could potentially gain more quality-adjusted life years through screening than older people; however, those aged 45 to 65 years are less likely than older people to have health insurance. It may be beneficial to advocate for and create policies to address screening deficits among this younger population.
- Anesthesia can account for a significant proportion of colonoscopy cost. One option to increase access to colonoscopy may be to recommend/use moderate rather than full sedation for some patients; however, gastroenterology societies may not support this idea.
- There are evidence-based strategies to increase colorectal screening uptake, but these activities are usually not funded in a sustainable way. Providing funding for these efforts should be a high priority. The availability of billable codes would be helpful in this regard.

### **Leveraging Existing Resources**

- The Centers for Disease Control and Prevention (CDC) colorectal cancer screening program should be expanded. CDC-supported programs in every state pay for breast and cervical cancer screening, but this is not the case for colorectal cancer.
- Commission on Cancer (CoC)-accredited programs are required to address barriers to care and conduct screening. The National Colorectal Cancer Roundtable (NCCRT) has recommended that CoC-accredited programs provide a certain number of colonoscopies free of charge for uninsured people, including through the NCCRT Links of Care program. CoC-accredited programs could collaborate with nonprofit hospitals to do this. This approach has successfully increased screening rates at some community health centers.
- State cancer plans and NCI-designated Cancer Center Offices of Outreach and Engagement should promote standards and opportunities for colorectal cancer screening. State roundtables also should be involved in the process.

### **Population-Based Screening**

- Health plans or health centers could perform population-based outreach for screening. For example, UnitedHealthcare used claims data to identify and mail test cards to health plan members who were not up to date on screening. Community health centers also have mailed FIT cards to patients; however, it can be challenging to ensure patients return the cards. One health center found it took an average of three calls from a navigator to achieve a 70 percent return rate. This type of program requires resources.
- Direct-to-patient outreach may help relieve the burden on provider time, but providers should not be completely removed from the process. Patients generally consider their providers to be the most trusted source for health-related information.

## **Communications Campaign**

- A national campaign could be conducted to inform the public about colorectal cancer screening options. This would help reach people who do not have a relationship with a provider or healthcare system. CDC and/or advocacy organizations could conduct a national campaign.
- Clear messaging would be needed for any national campaign, including messaging about age of screening initiation and recommended tests for different age groups. Recommending FIT for people 45 to 50 years of age may help address concerns about capacity.
- CDC has experienced resistance from providers when educational interventions are delivered by public health staff. Peer-to-peer education may be more effective.
- Changes in guidelines often are not effectively communicated to providers or patients. It is important to develop a unified message that can be delivered to stakeholders in communities. Social media may be helpful in this regard.
- Professional societies can partner with communication campaigns and help develop targeted messages that can be disseminated to providers through EHRs.
- Patients, particularly those with family history of colorectal cancer, need to understand their risk well before they reach the recommended screening age. Younger patients also should be informed about early signs of colorectal cancer.

## **Shared Decision-Making and Navigation**

- The Colorectal Cancer Alliance (the Alliance) has developed a navigation tool for colorectal cancer screening that will be launched in January 2021. The tool can connect to scheduling functions and health information within EHRs. Patients or providers can use the system to access screening recommendations by completing a questionnaire that has been validated by an expert advisory committee. Third-party full-service navigation is provided to help patients make appointments, understand colonoscopy preparation, and coordinate follow-up of a positive screening test, among other things. The service will be funded by the Alliance initially. A one-time cost would be incurred to connect the navigation system to an EHR system.
- Shared decision-making tools must be flexible so they can accommodate changes in knowledge, guidelines, and technology. Tools also should take patient preferences into account. For example, even if colonoscopy is found to be superior to stool-based tests, some patients may still choose the latter based on their personal preference.
- Colorectal cancer screening tools would not necessarily need to be developed directly by EHR vendors. The Epic App Orchard provides opportunity for EHR users to incorporate third-party add-ons into their systems.
- Lessons should be gleaned from breast cancer screening. Breast radiology programs excel at care coordination. They often utilize navigators to ensure that patients receive the care they need in a timely manner.

## **Quality Metrics for Stool-Based Screening Tests and Programs**

- Many programs and/or institutions track patient participation in an initial screening test, but this is an incomplete assessment of program quality. An important quality metric for noninvasive colorectal screening programs (e.g., FIT, FIT DNA, other stool-based tests) is the percentage of patients with a positive test who undergo colonoscopy within a prescribed time (e.g., 6 to 9 months). Timely follow-up of an abnormal finding via colonoscopy is essential for high-quality screening. Screening should not be considered complete until abnormal findings are resolved.
- Quality metrics can drive improvements in care, particularly if they are tied to reimbursement. A metric for appropriate completion of screening should be created (e.g., percentage of patients 50 to 75



years of age with an abnormal screen test who completed colonoscopy within 6 months). This metric would be relevant for programs focused solely on FIT as well as institutions/programs that perform stool-based screening as part of a broader set of services. Metrics could be developed and implemented through the Healthcare Effectiveness Data and Information Set (HEDIS), the Federally Qualified Health Center (FQHC) Uniform Data System, and/or the Medicare Star Ratings program.

- Medicaid currently does not have a national quality metric for up-to-date colorectal cancer screening or percentage of people with abnormal test who completed coloscopy. CMS has been resistant to adopting these metrics because the Medicaid population is, on average, younger than the recommended age for colorectal cancer screening; however, Medicaid expansion may change this.
- U.S. Food and Drug Administration (FDA) approval of stool-based tests depends on the test's ability to detect blood in stool not necessarily its effectiveness in detecting cancer. Use of a high-quality FIT could be a metric for FIT programs. Other metrics could include timely processing of FIT results and adherence to an annual schedule for FIT.
- High-quality FIT programs should have a patient education component.
- The FIT-DNA test includes navigation support to help patients complete the test; however, this navigation does not extend to coordination of follow-up screening if the test is positive. Both FIT and FIT-DNA programs should create processes to ensure appropriate colonoscopy follow-up is done for all positive noninvasive screening test results.
- The National Committee for Quality Assurance (NCQA) recognizes patient-centered medical homes that meet certain criteria. A similar model could be developed for FIT programs to encourage adherence to quality standards.

## **GREATER ACCESS TO COLONOSCOPY AND DISCUSSION OF OPTIONS**

### **Limited Access to Colonoscopy**

- Changes in colorectal cancer screening guidelines that expand the eligible population may exacerbate disparities if screening capacity is used for low-risk people with high access to services.
- Promotion of FIT could help address the barrier of inadequate access to colonoscopy, particularly for low-risk individuals and/or those living in communities with too few endoscopists. Patients living in remote areas who receive a cancer diagnosis following colonoscopy may need assistance accessing surgical or oncology care.
- NCCRT is developing a web-based needs calculator to help programs estimate how many follow-up colonoscopies they will need to provide as part of a FIT program. This will facilitate planning and coordination with partner organizations that may be able to provide the procedures free of charge for some patients.

### **Expansion of Providers Who Perform Colonoscopy**

- One way to expand access to colonoscopy would be to expand the number of providers trained to perform the procedure (e.g., primary care physicians, nurses, physician assistants). Some specialties do include endoscopy in their training, but most trainees do not perform sufficient numbers of procedures to qualify to perform colonoscopy independently.
- Sigmoidoscopy can be performed by a broader set of providers (e.g., nurse practitioners, physician assistants). Although the procedure is effective, it only detects abnormalities in the lower colon. There was a suggestion that sigmoidoscopy may be appropriate for younger people, who are less likely to be diagnosed with cancers of the upper colon. However, sigmoidoscopy has fallen out of favor in the United States because of insufficient reimbursement and coverage of only part of the colon. It seems

unlikely that sigmoidoscopy will be widely adopted, particularly given the availability of noninvasive screening tests.

- For rural and frontier areas with lack of colonoscopy services, it is not sufficient to recruit a colonoscopist. Several types of support staff—medical technicians, navigators, etc.—are needed to successfully perform colonoscopy.
- Efforts must should focus on expanding access to *high-quality* colonoscopy. All providers performing endoscopy should measure the quality of their exams.

### **COVID-19 Considerations and Telemedicine**

- The rise in unemployment due to the COVID-19 pandemic has resulted in an increase in uninsured individuals, which reduces access to colonoscopy and other cancer screening tests. The cost of colonoscopy can be prohibitive if patients do not have health insurance. Rates of screening generally are lower among the uninsured; this has been a challenging disparity to address. There should be efforts to increase access to screening and colonoscopy regardless of insurance status.
- Patients may be reluctant to go to medical facilities due to COVID-19.
- Modeling tools should be used to identify people at highest risk of colorectal cancer so they can be prioritized for screening. This would be helpful while institutions are attempting to catch up on screenings that were not done during the early months of the pandemic.
- Virtual visits during the COVID-19 pandemic have helped engage patients when in-person appointments have not been permitted or preferred. Voice-only telemedicine is important for populations in low-resource and/or remote areas that may not have access to broadband service. Reimbursement for telephone-based (audio only) telemedicine should be the same as for video-based telemedicine. CMS currently is revisiting its telemedicine guidelines. Stakeholders should provide feedback to CMS as appropriate.
- Policies should be pursued to ensure that all people in the United States have access to broadband Internet.
- Health educators at community health clinics have observed that patients in homes with school-aged children are more accessible via web-based platforms because their children need broadband access for remote schooling. It may be possible to create partnerships with schools to increase technology access.
- Some people do not have reliable access to mobile phone minutes, which may create challenges for patient-provider communication. For example, some people may deplete their mobile phone minutes before the end of the month. One solution is for health centers to ask patients to provide the phone number of a family member or trusted friend to be used if a patient cannot be reached. Another option may be for health plans to provide members with an allotment of minutes to be used for healthcare.
- Telephone-based support for outreach, education, and navigation can be provided by nonphysicians. Persistent telephone follow-up can help increase FIT return rates and completion of colonoscopy.
- Some providers have limited access to telemedicine tools and technologies.
- Many patients have become accustomed to telehealth during the pandemic and will want to continue using it. If reimbursement for and provider use of telemedicine are eliminated when COVID-19 concerns subside, patients may choose not to receive a colonoscopy rather than be inconvenienced by what they view as an unnecessary in-person appointment. Patients also have become used to being able to receive care from providers in different states while some licensing restrictions have been relaxed during the pandemic.
- Visiting nurses and mobile clinics can be used to reach patients who are reluctant or unable to attend in-person appointments. The pandemic has affected patients' support systems; family or friends who

may normally help with transportation or childcare may not be available to do so because of pandemic-related logistical or health concerns.

- During crises such as the COVID-19 pandemic, systems should be as flexible as possible and patients should be made aware of alternatives (e.g., different screening tests, different screening locations) that may make it easier for them to receive care.
- Genetic counseling services largely have shifted to telehealth platforms during the pandemic. Patients and genetic counselors have adapted easily to this change. Saliva samples for genetic testing have been collected via mail, which has precluded clinic visits for blood draws. Telemedicine also has made it easier for genetic counselors to access family members. Rules on out-of-state services have not been relaxed for genetic counseling during the pandemic, but this would be helpful to extend the reach of genetic counselors.
- FIT kits should be distributed by mail when it is difficult for people to obtain them directly from health centers. FIT kit distribution also could be coupled with in-person health services, such as influenza or COVID-19 vaccination.
- When elective procedures were halted in the early days of the pandemic, some patients got the impression that cancer screening is optional. Messaging should be developed carefully to communicate the importance of screening and the option of screening via FIT. It may be helpful to work with media outlets that serve target populations, including racial/ethnic minority communities.
- Many institutions require patients to receive a negative COVID-19 test before having a colonoscopy or other gastrointestinal (GI) procedure done. The additional time and effort required to get a COVID-19 test pose a barrier to colonoscopy.
- The risk of contracting COVID-19 during a colonoscopy visit appears to be very low. Colonoscopies and other procedures should continue as long as sufficient personal protective equipment (PPE) is available. PPE shortages were one reason procedures were cancelled or delayed in the early days of the pandemic.

### **Healthy Lifestyles for Prevention**

- Promotion and facilitation of healthy lifestyles—including physical activity and healthy diet—should be done alongside promotion of colorectal cancer screening. Some institutions work within their communities to improve food offerings through food banks and community gardens.
- CMS reimburses for nutritional counseling.
- The Healthy Homes/Healthy Families study explored interventions—including phone- and computer-based interventions—for population health management. This type of program can be used to monitor conditions such as diabetes and promote cancer screening.

### **Reminder Systems**

- Most clinics have colorectal cancer screening reminder systems, but many of these systems are cumbersome and, as a result, may not be very effective. Challenges of reminder systems include the need to incorporate family history and tailored recommendations for follow-up. An American Cancer Society (ACS) workgroup worked with several EHR vendors to try to improve reminder systems but found many vendors were reluctant to devote resources to this issue.
- Colorectal cancer screening takes place over a long period of time; colonoscopy may be done only every 10 years and FIT testing should be done annually. Thus, effective management and reminder systems must function over a long period of time. This is difficult to do when people move between health systems.
- Best practice alerts (BPA) can be useful, but providers will begin to ignore them if they are not accurate.

- It was suggested that central cancer screening registries—analogueous to state immunization registries—be created to facilitate information-sharing across providers and institutions. Creation of a central registry for cancer screening would be complicated and likely require a reporting mandate. This is likely not a practical solution.

### **Stigma**

- Colorectal cancer screening—and colonoscopy in particular—is viewed as a negative experience. The stigma may be stronger for men than women, particularly in cultures with a strong sense of masculine pride.
- Incorporating humor into messaging may help reduce fear and stigma. Marketing campaigns may be able to use stigma as a “hook” to attract attention. It is important to do this in a way that is respectful of the experiences of colorectal cancer survivors.
- The CDC Screen for Life campaign is an example of a good campaign. Advocacy and community outreach groups also can help with education and targeted messaging.
- Focus groups have suggested that messages focused on family may be effective for promoting colorectal cancer screening. Multigenerational and peer-to-peer conversations also may be helpful; these approaches have been used for prostate cancer.
- Messaging should emphasize that colorectal cancer screening can prevent cancer.
- Many groups independently develop and disseminate educational materials for colorectal cancer screening, which is inefficient.

### **Logistics**

- Patients face many logistical challenges to completing colonoscopy, including transportation, time off work, and childcare.
- The time demands of colonoscopy (one day of prep and one day for the procedure) can be a hardship, particularly for the increasing number of people working nontraditional jobs. Use of telemedicine for preprocedure discussions and delivery of prep materials via mail could help address this.
- Partnerships with app-based transportation companies may help address transportation barriers. Lyft had a program to help people attend screening appointments (not specific to colorectal cancer).
- Colonoscopies must be scheduled many weeks in advance. Many people do not have their work schedules that early and/or do not feel comfortable requesting time off work. Taking time off work may mean lost income for some patients. Options to address this include providing weekend and evening clinic hours and allowing some appointments to be scheduled on a shorter timeframe. Some employers now offer health promotion days in addition to vacation and sick days.
- Childcare issues likely will become more pertinent as the age of screening eligibility is reduced to 45 years.
- Logistical challenges should be considered with respect to racial/ethnic and geographic disparities.
- Navigation services can help address many of the logistical barriers faced by patients. Navigators have been shown to increase the likelihood of colonoscopy completion. NCCRT has resources on navigation. CDC has published standards for navigation. Paying for navigation programs is a challenge. Some existing programs are supported by grants or other philanthropic support. It would be useful if navigation services were reimbursed by CMS.
- Patients who may have difficulty adhering to an annual screening schedule should be encouraged to have a colonoscopy rather than FIT.

## **IMPROVEMENT OF GUIDELINES**

### **Age of Initiation**

- There is general alignment among colorectal cancer screening guidelines that screening should begin at age 45.
- Modeling studies suggest that lowering the age of initiation of colorectal cancer screening to 45 will result in an additional lifetime colonoscopy.
- There is a risk of overscreening, particularly of younger age groups. Colonoscopists have incentive to do more surveillance than necessary of younger patients in whom low-risk adenomas were observed during an initial screen, exposing patients to excess potential harm. Policy changes may be needed to address this. Careful messaging about low-risk adenomas should be developed for patients so that they do not become overly concerned.
- It may be appropriate to do targeted screening in younger age groups. Risk-based guidelines—potentially based on polygenic or phenotypic risk scores—may help identify patients aged 45 to 50 who are at highest risk. Consideration should be given to promotion of noninvasive testing rather than colonoscopy in this age group.
- Expanded eligibility criteria will affect health center performance with respect to quality metrics. The number of eligible patients will increase, creating challenges for health centers already struggling with screening capacity. Screening rates likely will go down in many community health centers. Options to address this include allowing a grace period for health centers to increase screening of younger patients or continuing to use the current metric of screening among patients 50 to 75 years of age.
- If USPSTF rates colorectal cancer screening at age 45 as a grade A or B service, private payors and Medicare will be required to cover screening without cost-sharing under the Affordable Care Act (ACA). Medicaid coverage will depend on state policy, including whether the state participated in Medicaid expansion. Ensuring coverage of colorectal cancer screening by all payors beginning at age 45 will help address disparities. This may require policy changes, through action by Congress and/or the Executive Branch. If ACA is dismantled, policies related to screening will need to be revisited.

### **Age to Stop Screening**

- There have not been rigorous studies to inform decisions about the age at which screening should be stopped. The best approach may depend on factors other than age. Providers could use well-validated tools to estimate life expectancy to inform their recommendations. This issue will be increasingly relevant as the population ages.
- Studies have found that older patients often are hesitant or strongly resistant to stop screening.

## **RISK-BASED APPROACH TO SCREENING AND MANAGEMENT**

### **Family History and Genetic Testing**

- Current screening guidelines focus on average-risk populations. Guidance also should be provided for high-risk populations, such as those with Lynch syndrome.
- Many patients diagnosed with colorectal cancer before age 50 have a positive family history. To ensure that screening is initiated as soon as possible for people at high risk, family history information must be collected on all patients as early as possible. Age 35 would be sufficient for the average-risk population, but patients with hereditary syndromes need to be identified earlier. Patients with strong family history should be referred for genetic evaluation. It is particularly difficult to collect information from younger men; many women have contact with the healthcare system for

gynecologic care, but many young men do not have established relationships with healthcare providers or health systems.

- Family history must be updated regularly to be useful. Primary care providers must cover many topics within a limited time during visits. There may not be enough time to adequately capture family history and conduct a risk assessment. Tools that determine risk for cancer and other diseases based on family history would be helpful. Risk assessment tools are available, but most do not integrate well with EHRs and/or address only one disease.
- Patient-targeted risk assessment tools should be available to patients while they are in the waiting room before medical appointments. Patients who are dealing with multiple stressors may not have time to consider cancer screening at other times.
- Approximately 25 percent of patients who test positive for genetic diseases—such as Lynch syndrome, hereditary breast and ovarian cancer, and familial hypercholesterolemia—do not have relevant family history for their disease. Population screening of these genetic conditions would help identify at-risk individuals. It is unclear when or how this would be done.
- Primary care providers will not be able to conduct sufficient population screening for genetic risk of colorectal cancer, particularly among young people. Multidisciplinary approaches are needed; however, it is useful to have primary care providers involved because their screening recommendations are influential.
- Payors could collect information on family history; this would help identify people, particularly young men, who may not have relationships with the healthcare system. Insurance companies would benefit from identifying high-risk patients and ensuring they receive proper screening and surveillance. However, there may be potential conflict of interest with respect to preexisting conditions.
- Many people are using direct-to-consumer genetic sequencing services. This may help raise awareness about leveraging family history to maintain health. It may be useful to develop messaging to inform the public which direct-to-consumer tests are highest quality and provide genetic counseling.
- Some people will be intrinsically motivated to get information about their health risks, while others will require extrinsic motivation (e.g., reduced copays or insurance premiums). Men may be less likely than women to be intrinsically motivated.
- The price of genetic testing has significantly declined over the past several years, making it more accessible. Some providers and patients may think genetic testing is prohibitively expensive. Messaging may be needed to counteract this.
- Self-reported family history is more accurate for some cancers than others. People are more likely to know the health histories of their first-degree relatives than their second- and third-degree relatives. Although many people know if their relatives have been diagnosed with cancer, few know whether there is a family history of polyps, which could inform screening and surveillance intervals. Gastroenterologists should let their patients know if they have a type of polyp that puts other family members at risk.
- Genetic counseling delivered via telemedicine can help overcome geographic access barriers to genetic counseling.
- Strategies to increase access to genetic testing and counseling were discussed. Some commercial laboratories have chatbots that collect family history and conduct risk assessment. If patients meet testing criteria, a saliva collection kit is mailed to their home. In one oncology department, nurses and nurse practitioners were trained to show patients an informed consent video and order genetic testing. Patients with positive tests then were seen by a genetic counselor. This approach increased patient access to genetic testing and helped maximize the use of genetic counselors' time.

- Patients with strong family history of cancer should be seen by a genetic counselor even if their genetic test results are negative.
- A single genetic test provides information on risk for multiple cancers.
- In some cases, genetic testing finds variants of uncertain clinical significance. There are concerns that patients will pursue aggressive interventions (e.g., preventive surgeries) based on these variants. One approach used is to include only known pathogenic variants in reports to patients. Patients or their family members can be recontacted if new information causes a variant to change from unknown significance to pathogenic.
- Genetic counselors currently are not CMS-recognized providers, which creates problems for reimbursement and access. A bill currently under consideration in the House of Representatives would change this.

### **Missed Opportunities and Systems-Based Approaches**

- Many people with relationships with healthcare providers or systems have not received recommended screenings. This represents a failure of the system, not of primary care providers. Primary care providers should not bear the full burden of screening recommendations.
- Workflows should be redesigned so screening opportunities are presented to patients before primary care appointments. Another option would be to involve other staff, such as laboratory technicians.
- It would be more efficient and effective to pursue organized screening systems rather than opportunistic screening. There are evidence-based interventions that increase screening, but they often are not implemented. Systems and workflows to identify eligible patients and move them through the screening process should be clearly defined. Ongoing assessments should be done to identify opportunities for improvement. Incentives—including reimbursement—must be put in place for all aspects of the system. Incentives have been shown to drive provider behavior.
- Patients are repeatedly asked to provide family history. This is frustrating to patients and often results in conflicting information. It would be helpful to create a single family history touchpoint for patients within a healthcare system.
- Telemedicine could play a role in organized systems to promote screening. Telemedicine must be reimbursable to make this possible.
- Reimbursement should not be structured in a way that incentivizes provider or health system use of more expensive screening tests.

### **IMPROVEMENT OF FOLLOW-UP, MANAGEMENT, AND TREATMENT**

- Health systems should be accountable for the quality of their screening programs. This would be facilitated by transparency. There should be incentives for programs to improve and maintain quality.
- It is challenging to equalize quality of care, including management and treatment. Financial accountability may be able to promote quality in diverse settings.
- Navigation programs have been successful in health systems and cancer centers.
- Chatbots could help patients navigate parts of the screening process.
- Many of the barriers and potential solutions related to providers and access are relevant to follow-up, management, and treatment, although there is an added level of complexity as more providers and steps are involved.
- Innovation could help improve follow-up, management, and treatment, but the first step should be to implement what is known to work. Cost-sharing should be eliminated for diagnostic colonoscopy,

processes should be streamlined, incentives should be aligned with quality, and navigation should be available to help all patients complete the screening process.

## **IDENTIFICATION OF STAKEHOLDER PRIORITIES**

Stakeholders were asked to identify solutions they felt should be highest priority for improving colorectal cancer screening. These included:

- Colonoscopy after positive FIT or FIT DNA test should be included within the scope of screening and covered by insurance with no cost-sharing. USPSTF guidelines should specify that colonoscopy after FIT is part of screening.
- Steps should be taken to ensure that all people—including those without health insurance—have access to screening and, if diagnosed with cancer, to treatment. This is particularly relevant for people not covered by Medicare. A public cancer insurance policy may be one approach to do this.
- Evidence-based interventions to increase cancer screening should be reimbursed by payors.
- Improved risk stratification is needed to identify people most likely to benefit from screening and determine the best screening test and schedule. Noninvasive tests should be promoted for average-risk populations. Outreach should be done to ensure high-risk individuals receive appropriate screening.
- A multifaceted campaign that includes a national communications campaign, EHR alerts, and chatbots could help address many communications challenges. A campaign should educate the public about different types of screening tests and eligibility.
- National and state cancer roundtables are excellent venues to systematize screening and should be maintained.
- Patient navigation should be incorporated into health systems.

## **PUBLIC COMMENT AND QUESTIONS**

Members of the public submitted written comments and questions, which were read and discussed by the Panel, Working Group members, and the stakeholder panel near the end of each workshop day.

- A member of the public emphasized that USPSTF guidelines should include the required colonoscopy after an abnormal stool-based test as part of the screening process. The current draft USPSTF guidelines refer to colonoscopy after FIT as diagnostic. Public comment on the draft is being received and reviewed; input from the community could potentially influence USPSTF to update this language in the final guidelines.
- A member of the public commented that patients experiencing relevant symptoms should receive a digital rectal exam. Stakeholders agreed that a full evaluation is needed to identify and document the source of symptoms such as bleeding; however, this is outside the context of screening guidelines, which apply only to individuals without symptoms.
- A member of the public urged the stakeholder panel to consider the costs of colorectal cancer screening tests. Although the tests may be cost-effective, they are still expensive. Budget constraints are likely in the postpandemic world; consideration should be given to promoting use of the least costly option among equally effective screening tests. A stakeholder panel member noted that all USPSTF-recommended screening tests for colorectal cancer are cost-effective but acknowledged that cost-sharing can create challenges for patients. Screening rates differ substantially based on whether an individual has health insurance. Out-of-pocket costs for FIT should be zero or very low for most people; it is covered by commercial health insurance under ACA and by Medicare. The cost for uninsured patients receiving care at FQHCs is covered by the health center. Cost should be considered at patient, health system, and societal levels.



- The requirement that patients be tested for COVID-19 before attending a colonoscopy appointment creates a barrier for many patients. This may necessitate additional time off work. The NCCRT website provides guidance on how to increase colorectal cancer screening in the context of COVID-19. FIT may be a good option for many of these patients; however, stakeholder panelists noted that the increase in FIT has not offset the dramatic drop in numbers of colonoscopies performed during the pandemic.
- A member of the public asked the stakeholder group to comment on how to ensure that Medicaid adopts colorectal cancer screening quality measures. CMS resistance to this may change with the lowering of the recommended age for screening initiation. It was noted that there are quality measures for colorectal cancer screening (HEDIS and Uniform Data System [UDS]); however, there are no quality measures for colonoscopy after a positive noninvasive test. Implementing such a measure may be difficult because the numbers for any given health system will be relatively low.
- A member of the public asked whether strategies for increasing outreach differ for different populations (e.g., racial/ethnic groups, immigrants, non-English-speaking groups). Stakeholders agreed that messages must be tailored for different audiences. Generic messages are less likely to motivate people to act.
- A member of the public noted that use of nurse endoscopists at Kaiser Permanente, San Francisco General Hospital, and University of California, Davis was discontinued because the nurses could not meet demand. Flexible sigmoidoscopy programs, some of which were led by nurse endoscopists, have largely been discontinued in the United States because colonoscopy is now preferred. The Medical University of South Carolina had a program through which family physicians and internists performed colonoscopies in rural areas; however, it was discontinued because the providers could not perform the volume needed to maintain accreditation. There is a small group of primary care doctors who perform screening colonoscopy, primarily in rural areas; they meticulously track quality and have good detection and safety records.
- A member of the public asked about the percentage of Medicaid recipients that are between the ages of 45 and 75. The answer to this was not known, but one stakeholder reported that 20 to 25 percent of Medicaid recipients in Oregon are between the ages of 50 and 75. Lowering the age of colorectal cancer screening initiation to 45 corresponds to about 20 million more Americans eligible for screening.

## **CLOSING REMARKS**

Panel members and Colorectal Cancer Planning Subgroup co-chairs and members thanked the stakeholder panel for its productive input and discussion. The Panel and Working Group will consider the information provided during this workshop and others in the series as they develop recommendations to be included in the Panel's report to the President. Additional written testimony and comments can be submitted at any time to the President's Cancer Panel via email ([PresCancerPanel@mail.nih.gov](mailto:PresCancerPanel@mail.nih.gov)) or the Panel website (<https://prescancerpanel.cancer.gov>).

## CERTIFICATION OF MEETING SUMMARY

I certify that this summary of the President's Cancer Panel meeting, *Improving Resilience and Equity in Colorectal Cancer Screening: Lessons from COVID-19 and Beyond*, held on November 2 and 4, 2020, is accurate and complete.

Certified by:

Date:

February 1, 2021

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John P. Williams, MD, FACS  
Chair  
President's Cancer Panel