



# EAO-CRC VIRTUAL SUMMIT

SUMMARY REPORT  
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<b>ACS</b>	American Cancer Society
<b>ACS CAN</b>	American Cancer Society Cancer Action Network
<b>CRC</b>	Colorectal Cancer
<b>COVID-19</b>	Coronavirus Disease-19
<b>EAO-CRC</b>	Early-Age Onset Colorectal Cancer
<b>EHR</b>	Electronic Health Record
<b>FHH</b>	Family Health History
<b>GI</b>	Gastrointestinal
<b>HHS</b>	Department of Health and Human Services
<b>HIPAA</b>	Health Insurance Portability and Accountability Act
<b>MSKCC</b>	Memorial Sloan Kettering Cancer Center



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## Opening Remarks and Framing the Conversation

The Early-Age Onset Colorectal Cancer (EAO-CRC) Virtual Summit kicked off on April 23rd, 2020, with very touching personal stories from a colorectal cancer (CRC) survivor and a CRC caregiver. Richard Fahrer, Oncology Marketing Director, Patient Solutions, Pfizer Pharmaceuticals shared his experience of being a highly active adult who was suddenly confronted with an advanced cancer diagnosis. A Stage III EAO-CRC survivor, Mr. Fahrer walked the audience through his and his family's personal fight with the disease—the emotional roller coaster of fear, anticipation, and hope. He was joined by Renay Caldwell, Director of Navigation and Screening Services, University of South Carolina, whose husband had been diagnosed with EAO-CRC and lost his fight 2 years prior to this Virtual Summit.

Cindy R. Borassi, Executive Director, Colon Cancer Foundation (CCF), then introduced the agenda for the Virtual Summit, with a particular focus on harnessing the collective knowledge, capabilities, creativity, funding, and connections of experts in the CRC space during the coronavirus disease-19 (COVID-19) pandemic. “We need to be ready and standing at the gates when they open to fight for our patients, caregivers, health care practitioners, and researchers who have been fighting and supporting CRC in the midst of a global pandemic,” Ms. Borassi told the online attendees.

# Emerging Epidemiology of EAO-CRC and Opportunities for Mitigation

Rebecca Siegel, MPH, Scientific Director, Surveillance Research, American Cancer Society, highlighted new data on the epidemiology of EAO-CRC and prospects for disease mitigation in the U.S.

Ms. Siegel pointed out that EAO-CRC is a growing global phenomenon. In a paper published late last year by Ms. Siegel and collaborators,<sup>1</sup> including Thomas Weber, MD, the founder of CCF, EAO-CRC incidence increased uniquely, or more rapidly, among young adults in 12 high-income countries across three continents based on the most recent available data. Another study published by Ms. Siegel and her colleagues in March 2020 estimated that about 17,930 individuals under age 50 will be diagnosed with CRC in the U.S. in the year 2020 alone, and 3,640 will die of the disease.<sup>2</sup>

## CRC Incidence and Mortality

Overall, CRC incidence and mortality have continued to decrease driven by trends in the oldest age groups.

- CRC incidence rates declined by 3.3% annually between 2011-2016 among those 65 years and older
- CRC incidence rates increased by 1% annually among those 50-64 years old, after declining by 2% to 3% during 2000-2010
- Incidence increased by about 2% annually for individuals under 50 years for tumors in the proximal and distal colon and in the rectum

“This very much contrasts the previous years where the increase was primarily driven by rectal tumors,” Ms. Siegel said. Overall, from 1995-2016, a 44% increase in CRC incidence has been documented among those under 50 years based on complete U.S. population coverage excluding appendiceal tumors.

A similar trend in mortality (2008-2017) was noted among these different age groups—it reduced by 3% annually among those over 65 years and

only by 0.6% in the 50-64 years age group (down from a 3% annual decline). The scenario was completely flipped in the under 50 age group: a 1.3% annual increase in mortality. Mortality has seen a slightly steeper increase among men (1.5% annual increase) than women (1% annual increase), which Ms. Siegel said may be attributed to earlier diagnosis in women: 36% of women under 50 are diagnosed at a localized stage compared to 31% of men.

## Disease Stage Characteristics of EAO-CRC

During the decade ending 2016, rising CRC incidence in the under 50 age group has been confined to the regional and distant stage diagnoses, each seeing a 2.5% annual increase, while localized CRC rates have remained stable. This establishes late stage diagnosis as a hallmark of early-onset disease, Ms. Siegel emphasized. Younger patients are also more likely to be diagnosed at an advanced stage: 26% of those under 50 years already have metastatic disease when diagnosed, as opposed to 20% of those over 50 years. This difference partly reflects the higher rate of screening in older patients compared to younger patients, but even after accounting for screening, the risk of advanced-stage CRC is 40% higher in the under 50 age group, she said.

Ms. Siegel attributed this finding to the delay between onset of symptoms and treatment initiation observed in the under 50 CRC population compared to those over 50: for example, one study of rectal cancer patients reported 217 days vs 29.5 days, respectively. She reiterated what has been a recurrent message at previous EAO-CRC Annual Summits: the need to raise awareness of early-onset disease and symptom recognition among young adults.

The delay between symptom recognition and treatment initiation have a significant impact on outcomes. The five-year survival for the under 50 CRC patients dropped from 78% among those with regional disease to 21% for distant stage disease. Ms. Siegel cited a study published just a few days prior to the Virtual Summit that found that 40% of cancer-related deaths could be



prevented if the disease was diagnosed earlier (Stage III) rather than later (Stage IV).<sup>3</sup>

### Need for Earlier Screening

Over a period of 15 years (2001-2016), the median age of CRC diagnosis has lowered from 72 years to 66 years, which supports the ACS recommendation to initiate screening at 45 instead of 50 years among those at an average risk of CRC.<sup>4</sup> Nearly half (48%) of patients diagnosed before 50 years are 45-49 years old and potentially could be diagnosed at an earlier stage if screened at age 45 years, as recommended by the ACS.

Another study released just days before the summit found that more than 98% of patients in their 40s with a family health history (FHH) of CRC could have been diagnosed earlier with recommended screening. Only about 25% of CRC cases in the 40-49 age group met the FHH-based screening criteria, and the authors concluded that all cases who met these criteria could have been diagnosed earlier or their disease prevented if the recommended earlier screening guideline had been followed.<sup>5</sup>

An analysis of CRC incidence in 1-year age increments found a steep rise in incidence among people in their early 50s, reflecting the large

number of preclinical CRCs detected during first screening.<sup>6</sup> “This shows that there is a great opportunity to detect these cancers earlier, maybe even prevent them, with screening at 45 [years] or earlier if at an increased risk,” Ms. Siegel said.

Based on the findings of her team, an estimated 49 EAO-CRC cases will be diagnosed per day in the U.S. in 2020, and about 10 people younger than 50 are expected to die of the disease daily. “Unfortunately, much of the medical community has not caught up with this reality,” she stated.

In closing, Ms. Siegel emphasized opportunities to mitigate the EAO-CRC burden, including promoting a healthy lifestyle, raising awareness among primary care physicians and young adults around disease symptoms and the increased risk in the younger population, and paying greater attention to documenting FHH to guide risk-based screening.

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# Impact of COVID-19 on EAO-CRC

The subsequent session provided the audience with a detailed and real-time view of the impact of the SARS-CoV-2 pandemic and its associated COVID-19 disease on cancer care overall, and CRC in particular.

## Impact of COVID-19 on Cancer

J. Leonard Lichtenfeld, MD, MACP, Deputy Chief Medical Officer, ACS, opened the session.

Dr. Lichtenfeld shared that the ACS has been developing cancer care recommendations for use during the COVID-19 pandemic, one of which is to delay elective screenings till the end of the pandemic. He pointed out, however, that elective screening for individuals at high risk is an individual decision.

In the context of EAO-CRC, access to primary care is important, and this access may vary based on the patient's geographic location. Resources have been redirected for COVID-19 care and routine care may be unavailable as health care workers—physicians, physician's assistants, nurses, and social workers, among others—are being reassigned to take care of COVID-19 patients, he explained.

Warning about the resurgence of SARS-CoV-2 infections as the country reopens, Dr. Lichtenfeld said that he personally believes that the opening will vary across the country and medical decisions will be made locally by care teams who should prioritize care based on the severity of a person's condition and their risk category. However, what actually happens with care delivery on the ground in the COVID-19 scenario remains to be seen.

One thing that is clear though is the apprehension among primary care practices, particularly those serving smaller communities, about their viability in the face of this pandemic. So, as states reopen and routine care delivery begins, these factors will impact patient outcomes, Dr. Lichtenfeld said. While millions of job losses are adding to economic pressures, those with employer-based insurance may see their coverage lapsed. ACS, he said, is advocating for extension of funds to allow for continued insurance coverage for these individuals and to reopen enrollment within the Affordable Care Act for those who may no longer have access to health insurance.

Along with patients and their family caregivers, COVID-19 has deeply distressed the primary care workforce, which will affect their ability to resume normal caregiving. Expressing his concern with the impact of reopening communities and the potential for resurgence of infections, Dr. Lichtenfeld added that we need to be able to prioritize care and ensure that those who have symptoms but have been holding back from seeking care, have the opportunity to get the care they need.

Addressing the fear in people's minds that may keep them from visiting a doctor's office, he emphasized the need to implement mitigation-to-containment strategies, along with restoring faith in the medical system so people who have care needs will not put them off.

## Telemedicine in the Era of COVID-19

With social distancing becoming a norm during the COVID-19 epidemic, telemedicine has proven extremely important to ensure patient access to care. Jordan Karlitz, MD, Associate Clinical Professor of Medicine and Director, GI Hereditary Cancer and Genetics Program at Tulane University, provided an update on the how telemedicine and telehealth allow remote administration of clinical services in the times of COVID-19.

Providing a perspective on the burgeoning growth of the field, Dr. Karlitz said that while 2016 saw more telemedicine sessions than all previous years combined, these sessions doubled in 2017. This increase prepped the health system to handle the 4000% increase seen in March 2020 alone due to restrictions placed on in-person appointments during the COVID-19 pandemic.

He then shared some important facts regarding telehealth services:

- Parity laws in 41 states and Washington, D.C. require payers to reimburse for telehealth in addition to in-person services



- Majority of states recognize the diversity among eligible providers of telehealth: physicians, nurse practitioners, physician assistants, certified nutrition specialists, advanced practice registered nurses, and others
- Many states do not require any special license to practice telemedicine
- Malpractice coverage for telehealth is determined by individual policy

## Medicare

Medicare has traditionally restricted telemedicine delivery based on the originating site, which is the site where the patient is located. Dr. Karlitz said historically this could include the doctor's office, hospital, critical access hospital, rural health clinic, federally qualified health center, hospital-based dialysis facility, and skilled nursing facility but did not include the patient's home. However, the COVID-19 pandemic has eased some of these restrictions, including allowing the originating site to be at a patient's home. A distant site, where the provider is located, has fewer restrictions.

## Medicaid

Medicaid telemedicine settings vary by state and many states may accept the home as an acceptable originating site.

## Private Payers

Telemedicine policies can vary significantly among private insurance payers, and it's best to contact them for specific policies.

## Health Policy and Telehealth

The 4000% increase in telehealth utilization seen in March 2020, Dr. Karlitz said, "is equivalent to six years of growth within just a few weeks." This required rapid changes in policies at all levels of telehealth delivery for safe interactions between patients and health care providers, he added. He shared a direct quote pulled from the [Medicare website](#)<sup>7</sup> on changes to how CMS would reimburse providers. In response to the COVID-19 pandemic, Medicare's "services expand the current telehealth covered services, to help you have access from more places (including your

home), with a wider range of communication tools (including smartphones), to interact with a range of providers (like doctors, nurse practitioners, clinical psychologists, licensed clinical social workers, physical therapists, occupational therapists, and speech language pathologists). During this time, you will be able to receive a specific set of services through telehealth including evaluation and management visits (common office visits), mental health counseling and preventive health screenings without a copayment if you have Original Medicare. This will help ensure you are able to visit with your doctor from your home, without having to go to a doctor's office or hospital, which puts you and others at risk of exposure to COVID-19."

Access from home and using a smartphone for this interaction are important changes, Dr. Karlitz pointed out.

In the context of COVID-19, HIPAA-related changes are also being implemented, he said, noting that the Office for Civil Rights at HHS is exercising enforcement discretion to not impose penalties for noncompliance with HIPAA rules associated with telehealth delivered via non-public facing audio or video communication products such as Skype or Zoom. This discretion is for COVID-19-related as well as other consults.

However, he emphasized the importance of informing patients and providers of privacy risks with using these platforms.

## Telemedicine, EAO-CRC, and COVID-19

In the COVID-19 setting, EAO-CRC patients, and those in need of CRC screening or diagnostic evaluations, are seeing a large shift from in-office to out-of-office visits. Concerning symptoms, such as rectal bleeding, can be assessed via telemedicine along with documenting family history of CRC and other cancers so that patients can be stratified for screening or diagnostic colonoscopy. Importantly, with limited access of health care professionals to personal protective equipment—such as masks, goggles, gowns, etc.—telemedicine is vital to risk stratify patients based on the urgency for scheduling a colonoscopy. GI procedure capacity can potentially be limited in certain areas due to the pandemic and providers are urged to understand

any such limitations in their local areas. Telemedicine can be used to discuss other CRC screening options, including stool-based testing and can also help manage CRC-associated health conditions such as Crohn's disease and ulcerative colitis, he said. Dr. Karlitz then shared a list of telemedicine platforms that are successfully being utilized by GI practices:

- GI OnDEMAND: HIPAA compliant, includes secure video, dedicated to the practice of gastroenterology, and waived subscription fee. They charge a \$1 per session fee.
- Doxy.me: HIPAA compliant, includes secure video, and has a free or subscription model
- FaceTime or Skype with the practice's own EHR: Not historically HIPAA-compliant (however, see above regarding HIPAA compliance restrictions in setting of COVID-19) and free

## Impact of COVID-19 on EAO-CRC Diagnostics and Screening

David A. Greenwald, MD, Director of Clinical Gastroenterology and Endoscopy, Mount Sinai Hospital, and Mark Pochapin, MD, Director, Division of Gastroenterology & Hepatology, Department of Medicine, NYU Langone Health, together provided an overview of how COVID-19 has affected CRC care in their respective hospitals.

With New York State being the epicenter of the pandemic in March and April, Dr. Greenwald shared the massive increase in hospital beds, both regular and intensive care unit (ICU), that were required as a result of the crisis, in New York City and in the state overall. The situation could have been much worse if social distancing measures had not been implemented. "The tsunami [of COVID-19 infected patients] affected the way hospitals were staffed in New York City," he said, sharing a stacking plan that showed nearly all floors of NYU Langone converted to COVID-19 patient care units at the beginning of April, similar to many other hospitals in the New York City area.

Tracing the conversation back to EAO-CRC, Dr. Greenwald said reopening would require planning, preparing, and performing. All GI procedures were categorized as elective, semi-elective, and urgent needs. While urgent and semi-elective procedures were still being conducted during the pandemic, elective GI procedures were delayed or put on hold. Dr. Greenwald emphasized that under guidance from the American College of Gastroenterology and other GI organizations, personal protective equipment will play a vital role in conducting endoscopy procedures going forward.

Dr. Pochapin, who spoke next, described the reassignment of gastroenterologists as internists within what he described as the "COVID army." While new cases of infected patients were leveling off at the time of the Virtual Summit, ICUs were still busy and patients with semi-urgent needs were still not being seen. "If we open in mid-May or June, that would be when we can consult with these patients," Dr. Pochapin hoped.

The process will not be easy, though, and both the patients and the staff caring for them will need to be tested for the coronavirus to reduce the overall burden on the care delivery system, he added. Patients with semi-urgent needs would get priority, followed by symptomatic patients, and those with a positive fecal immunochemical test.

Dr. Pochapin then shared some of the learnings from the COVID-19 experience that could influence the future care of EAO-CRC patients:

- Telemedicine works well: He believes this will be a critically important factor for screening. This may especially be true for younger patients who may have inhibitions about coming to the doctor's office. Dr. Pochapin urged the participants to consider telemedicine consults as a better option for reaching out to younger EAO-CRC patients.
- The ethos of the medical profession is caring for others
- Medical care will be altered for the next few years until we:
  - Have effective COVID-19 treatment
  - Have antibody tests that demonstrate patient immunity
  - Have an effective vaccine

Screening recommendations for EAO-CRC, and CRC in general, will need to be altered in the context of this altered medical care delivery.

**“While recognizing this as a crisis, we cannot disregard our progress till date in other health care fields such as EAO-CRC.” –Dr. Pochapin**

## Impact of COVID-19 on Patient Flows, Clinical Trials, and Therapeutics

Kimmie Ng, MD, MPH, Associate Professor of Medicine, Harvard Medical School, and Director, Young-Onset Colorectal Cancer Center, Dana-Farber Cancer Institute, described her experiences as she and her team continue delivering care for their patients with CRC during the COVID-19 pandemic.

“The pandemic has disrupted the fabric of how we care for our CRC patients,” Dr. Ng said, “with having to minimize our on-site staff and converting in-person patient visits to telemedicine visits.” Patients are impacted at various levels, as revised protocols preclude hospitalized patients from having visitors or family members accompany them during outpatient care. “These changes have probably had the biggest impact on the care our patients receive,” she added, because social distancing is shielding patients from the human interaction when they receive both good news and bad related to their well-being. Dr. Ng stressed that the absence of in-person compassionate interactions has proven difficult for both providers and patients.

Recognizing the vulnerability of cancer patients to infections, especially those who receive immune-suppressing treatments, she explained that cancer patients are at a heightened risk during the COVID-19 pandemic. Dr. Ng and her team at the Dana Farber Cancer Institute have modified their patient care guidelines to keep patients safe during the pandemic while delivering effective care. This often meant:

- Switching to oral therapies from intravenous therapies whenever possible
- Switching to treatment regimens that require less frequent visits to ensure continued social distancing
- Switching to maintenance chemotherapy or taking treatment breaks when safe to do so

Patients have been an important part of this conversation as decisions are being made with the aim of balancing their treatment with their safety.

Patient access to CRC clinical trials is vital and Dr. Ng said that while trial sponsors have been amenable to changes that ensure patient safety, several trials have shut down primarily due to challenges associated with collecting patient samples. With respect to non-interventional banking studies she said, “We are focused on collecting stool, blood samples, and tumor samples to understand underlying causes of EAO-CRC, but several labs have shut down now, so non-essential research studies have temporarily been put on hold during the pandemic.”

Against the COVID-19 backdrop, Dr. Ng stressed the importance of continued conversations and collaborations to keep up the momentum gained within the EAO-CRC care space.



## Impact of COVID-19 on Genetic Testing

Zsofia Stadler, MD, Associate Professor, Clinical Director, Clinical Genetics Service, Memorial Sloan Kettering Cancer Center (MSKCC), shared how having a functional telemedicine program allowed her team to successfully deliver genetic counseling services to EAO-CRC patients during the COVID-19 pandemic.

“This is important as 20% of our patients have a genetic mutation that predisposes younger patients to colorectal cancer and some other cancers,” Dr. Stadler said, adding that genetic testing can significantly influence their treatment plan, including surgery and chemotherapy.

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Explaining the collaborative relation between genetics and telemedicine, Dr. Stadler said that clinical geneticists can efficiently conduct a lot of their work without physically examining the patient.

Under her guidance, MSKCC’s Clinical Genetic Services team has increased its ability to deliver telemedicine consults over the last 2-3 years and 28% of their total volume used telemedicine technology to deliver clinical genetic services largely to the regional networks of MSKCC. “We were fortunate that over one weekend, we were able to convert our entire genetic service to a telemedicine-only service to adapt to new safety guidelines associated with the COVID-19 pandemic. We were very successful with this quick transition,” she said, adding that patients were appreciative of not having to expose themselves to the risk of a potential infection by coming into the hospital in New York City, which remained the epicenter of the COVID-19 pandemic for several weeks.

Since patients are referred to genetic counselors following medical or surgical oncology consults that may have been scheduled a few weeks earlier, her team had not seen a drop in the volume of consults at the time of the Virtual Summit (April 23, 2020). With the help of over 20 MSKCC genetic counselors, she herself has conducted as many as 23-24 telemedicine consults in one day.

“It’s been an enlightening experience and we have learnt so much from this,” Dr. Stadler said. Expressing her faith in telemedicine as a means to improve access to care, she said it can also ease the involvement of family members particularly in the context of cancers that have a strong correlation with FHH. While technology challenges with using the telemedicine platform exist, such as audio and video issues, they can definitely be overcome.

The convenience and ease of telemedicine means that Dr. Stadler’s group is not in a hurry to conduct in-patient appointments. In the context of COVID-19, she explained that the pandemic will not be going away very soon, and telemedicine is a safe option for patients to continue receiving their care in an efficient and timely manner.

## Impact of COVID-19 on EAO-CRC and Surgical Procedures

Yi-Qian Nancy You, MD, MHSc, FACS, Department of Surgical Oncology, Division of Surgery, MD Anderson Cancer Center, addressed the impact of COVID-19 on surgical procedures among EAO-CRC patients. She identified three major issues that were impacting patients at her Cancer Center:

- Access to care: Travel restrictions led to their Cancer Center limiting access to in-state and local (within 150 miles radius) patients. Consequently, individuals—especially younger CRC patients—seeking additional referrals to specialized centers or access to EAO-CRC centers were encountering a challenge. Reiterating the importance of telemedicine in the current scenario, Dr. You said that at the time of the Summit, their telemedicine services were restricted to follow-up visits, but she expected these to expand to new patients and consultations.



- Lack of contact in surgery: There were early concerns about the safety of conducting open versus minimally invasive surgery—would minimally invasive surgery cause more aerosolization of the coronavirus? With an improved understanding of the virus, this concern had reduced, and most patients were able to benefit from newer surgical techniques like minimally invasive surgeries. Additionally, surgeries at their institution were being prioritized for COVID-19–negative patients. Her major concern was the virtual post-op care and follow-up visits, and the lack of physical interaction with recovering patients.
  - Sequencing surgical care and treatment during COVID-19: Patients are recovering alone in the hospital without any family support structure, in addition to being exposed to in-hospital care. Dr. You said that to be able to delay these surgeries to a safer time window, patients are being given neo-adjuvant therapy and maybe a few more cycles of chemotherapy, in coordination with the patient’s medical oncologist.
- “It’s been a challenging time for everyone, but we believe we are all in it together, and it’s brought people together,” Dr. You added.

## Impact of COVID-19 on the Cancer Care Health Care Ecosystem: A Policy Perspective

Phylicia L. Woods, Esq., Director, Federal Relations at American Cancer Society Cancer Action Network (ACS CAN) shared the policy work being conducted by her organization and others to improve cancer care delivery during the COVID-19 pandemic.

Referring to the coronavirus relief packages released by the federal government, Ms. Woods said the three packages that were approved—the [Coronavirus Preparedness and Response Supplemental Appropriations Act](#),<sup>8</sup> the [Families First Coronavirus Response Act](#),<sup>9</sup> and the [Coronavirus Aid, Relief, and Economic Security Act](#)<sup>10</sup>—have brought about significant changes in cancer care delivery.

The telehealth provisions, for example, provide greater flexibility to patients and providers, which is especially important for immunocompromised cancer patients. In addition to providing funding support to the Food and Drug Administration and the Centers for Disease Control & Prevention, Congress has also taken steps to ensure paid emergency medical leave for individuals infected with—or caring for someone infected with—coronavirus. Money has also been directed to the development of SARS-CoV-2 vaccines and treatments and toward community health centers.

Ms. Woods said that ACS CAN, in collaboration with 50 cancer organizations, is focused on moving their mission forward and preserving access to care for cancer patients and survivors. “Access to care is a primary focus, it is even more important now,” she added. Disparities in access to care for underserved populations, which have always existed in the cancer care continuum, are being highlighted currently as populations of color are disproportionately affected by the virus. Using the COVID-19 lens, ACS CAN and partners are working to develop policy solutions to reduce disparities in the health care system, overall.

ACS CAN is also evaluating access issues related to clinical trials, many of which have been halted because of the pandemic. “We want to make sure that novel treatments are being developed and that patients continue to have access to these trials.” With this goal, ACS CAN and other cancer organizations are advocating with members of Congress to ensure that additional grant funding is given to the National Institutes of Health and that ongoing studies continue to see progress even during the pandemic.

Ms. Woods concluded that ACS CAN will continue addressing issues related to access to care and highlighting the importance of cancer care through the COVID-19 lens.





## Attending to Emotional Wellbeing During COVID-19

A profoundly serious concern that has emerged during the COVID-19 pandemic is the mental wellbeing of the patients as well as health care providers and workers. For individuals with underlying conditions such as cancer, the constant threat of the virus, social isolation, and maybe even job loss [may be overwhelming](#).<sup>11</sup> Among health care providers, the sheer number of infections, the high mortality, and the feeling of helplessness toward their patients has [increased their stress levels](#) way beyond the usual.<sup>12</sup> For those who are constantly exposed to the virus, there is the danger of being infected themselves while trying to keep their family members safe.

The American Medical Association has [developed a resource guide](#) to assist health care organizations develop policies to support their staff's wellbeing during these times while efficiently providing care for patients.<sup>13</sup> One of the final sessions during the EAO-CRC Virtual Summit addressed this developing aspect of the COVID-19 pandemic.

Susan K. Peterson, PhD, MPH, Department of Behavioral Science, Division of Cancer Prevention and Population Sciences, MD Anderson Cancer Center, shared a flowchart of the unique set of stressors related to COVID-19 on cancer survivors and their families, in the context of their exposure, risk, and access to COVID-19 testing. While cancer survivors are familiar with many of the issues that we are currently facing, such as isolation and hospitalization, it is exacerbated by the potential loss of family and friends. Financial concerns and social distancing have augmented the stress, creating an additional layer of fear and anxiety, Dr. Peterson explained, adding that individuals can improve their resiliency by drawing support from their family members and social network. Improved resiliency, combined with the individual's personal (age, race, insurance status) and clinical (date of diagnosis, cancer type, treatment status) traits can influence their health-related quality of life, she said.

ACS CAN commissioned a survey to analyze the impact of COVID-19 on 1,200 U.S. cancer patients and survivors who were within 5 years of diagnosis or treatment; 51% of those surveyed were in active treatment.<sup>14</sup> The focus of this assessment, Dr. Peterson explained, was the influence of the

COVID-19 pandemic on respondents' experiences accessing health care—access to appointments and services, ability to pay for care, and concerns with being safe when receiving care and treatment in the future. The survey found that,

- 50% had experienced a change in their care due to COVID-19
  - 27% in active treatment reported delayed care
  - 13% in active treatment with delayed care had no knowledge on when their treatment would be rescheduled
- 38% had experienced a financial impact of the pandemic, which affected their ability to pay for their care, either due to reduced work hours, reduced investment value, inability to work from home, or job loss
- About 50% of those with an annual household income of \$30,000 or less were worried that COVID-19 would reduce their ability to afford care

She also shared results of a survey published in JAMA among health care workers—nurses, physicians, and frontline workers—in 34 hospitals across China who were caring for patients with COVID-19. A significant number of the 1,257 workers who participated reported feelings of depression (50%), anxiety (45%), insomnia (34%), and distress (72%), with nurses, women, and frontline workers experiencing more severe symptoms.<sup>15</sup>

April D. Barry, L.S.W., M.S.W, Evaluation and Performance Improvement Manager, Pennsylvania Department of Health, Bureau of Health Promotion and Risk Reduction, Division of Cancer Prevention and Control, spoke next, stressing the importance of identifying the mental state and wellbeing of frontline health care workers. She explained that many may be isolating themselves, socially or from at-risk family members within their own home, to lower the risk of spreading the infection to their loved ones. "This significant disruption in social support in the name of helping and protecting others, may go on for an undetermined amount of time," Ms. Barry said, "and can impact the wellbeing of health care workers."



She explained that the current disruption has exposed those in the health care field to an unprecedented amount of sickness and death, beyond what they may have ever witnessed in their professional careers. As a result, they are experiencing a range of emotions from fear, anxiety, powerlessness, and anger, to physical fatigue, guilt, emotional fatigue, and sadness. She emphasized the importance of self-care—

staying connected with family and friends, eating healthy, engaging in activities that help one feel energized, taking naps, and getting adequate sleep—as a means of ensuring they can continue taking care of others. Ms. Barry also recommended mindfulness, guided meditation, and connecting with a counselor as additional ways of coping with work-related stress.

## Introduction of EAO-CRC Working Groups

The Virtual Summit ended with an introduction to the various working groups by Whitney Jones, MD, Founder, Colon Cancer Prevention Project, that will continue to move the field forward and prepare for the EAO-CRC annual summit to be held later in the year. Introducing the four gaps that were identified at the 5th Annual EAO-CRC Summit in 2019, along with a 5th gap that addressed the impact of the COVID-19 pandemic, Dr. Jones said, “Crisis is a change agent, and we are learning what the gaps are in our system with COVID-19.”

- **Gap 1: Documenting FHH.** We continue to struggle with documenting FHH, and the objective of this gap is to translate FHH into an actionable pedigree, effectively utilizing the EHR in the process. Referencing two studies that were recently published, he emphasized the important role of gastroenterologists in ensuring timely screening:
  - Dr. Karlitz and his team published a guide that recommends surveillance intervals for patients with advanced colorectal polyps, and early screening (40 years) for their first-degree relatives<sup>16</sup>
  - The study by Gupta et al, published just a couple of days prior to the Summit, found that over 98% of those who met the early screening criteria for colon cancer should have been screened at an earlier age based on their family history<sup>5</sup>
- **Gap 2: Earliest diagnosis of sporadic disease.** How can we reduce the gap between the time a patient visits the doctor and gets a definite diagnostic test? A major concern here is being able to integrate this gap in the national message because the focus for CRC screening has been age 50 years. Dr. Jones believes there is need for aligning with screening guideline developers, including the U.S. Preventive Services Task Force and the ACS.
- **Gap 3: Improving the state-of-the-art treatment modalities.** We need effective and timely treatments that improve patients’ quality of life and are fertility preserving, Dr. Jones said, emphasizing the need to raise awareness around the centers that provide such care.
- **Gap 4: Investigating the Causes of EAO-CRC.** While we know a lot about this disease, a lot remains to be discovered, Dr. Jones said, adding that messaging is vital. Improving our own understanding of this issue and ensuring timely communication with the younger population on CRC prevention would be key.
- **Gap 5: Navigating the new landscape of healthcare, post COVID-19.**

## **GAP 1:** **Family History Ascertainment in the U.S.**

Dr. Stadler, who will be leading this working group, highlighted the following key measures for improved identification of those at risk for CRC:

- Optimizing and clarifying screening guidelines, such as the ideal age to initiate screening
- Improving access to genetic testing. Dr. Stadler warned of financial barriers that could arise for patients who may have lost their insurance coverage due to unemployment, consequent to the COVID-19 pandemic.
- Cascade testing and facilitative genetic testing to maximize the number of family members who can be tested. She spoke of carving out a path to ensure that unaffected individuals have access to genetic testing. As we think of ways to facilitate this, telemedicine will play an important role, she said.
- Leveraging novel tools and technologies
- Identifying barriers and opportunities at the legislative level

## **GAP 2:** **Earliest Possible Diagnosis and Treatment Through Timely Recognition of the Symptoms and Signs of Young Adult CRC**

Dr. Karlitz and Erin Peterson, EAO-CRC Virtual Summit co-host, Communications Director, Colon Cancer Coalition, will be leading this working group.

Dr. Karlitz shared the focus on ensuring earliest stage diagnosis.

Gap 2A: Focus on evidence to transition to age 45 for average-risk screening, with the objective of preventing cancer or diagnosing it at an earlier stage.

Gap 2B: Assuring those at risk for CRC prior to 45 or 50 years are risk stratified for earlier testing.

- Patients and providers should make sure that family history is well documented to ensure risk stratification before a person reaches the average-risk screening age. Those with advanced polyps undergoing colonoscopy should inform family members that earlier screening is required.
- Assuring that hereditary CRC syndromes are not missed. Dr. Karlitz pointed out a few studies that highlight deficiencies in the diagnosis of hereditary CRC syndromes, including a national cohort study that found only 43% of those under age 50 undergo tumor testing. Another found gastroenterologists were not ordering tumor testing due to their inability to interpret results and lack of access to genetic counselors who can assist with interpretation.

Ms. Peterson addressed the need for messaging and change on the ground. A significant challenge in the field is to encourage young adults to reach out to their physician about their symptoms, and, in turn, encouraging those physicians to pay attention to these concerns. The focus of this working group, she added, will be to create a road map to reach those individuals who are not already aware of the signs and symptoms of EAO-CRC—those who are uninformed and unengaged. The Colon Cancer Coalition, she said, can play a significant role in this.

### **GAP 3:**

## **Timely, Effective, Quality-of-Life and Fertility-Preserving State of the Art Treatment**

Andrea Cercek, MD, Memorial Sloan Kettering Cancer Center, provided an overview of the importance of lending timely and effective interventions that address patients' quality-of-life goals and fertility preservation.

- **Early intervention:** Dr. Cercek addressed the importance of bringing up sexual health and fertility early in the CRC care plan discussions, particularly for rectal cancer. Because cancer treatment takes priority, especially for patients with metastatic disease, fertility options are not commonly discussed. However, a lot can be achieved with early intervention to give patients the time to think through their options and priorities and discuss fertility preservation with their family members or partner. While fertility preservation options have improved—with uterine transposition and ovarian transposition—we continue to lack real data to inform patients about fertility risks, especially in the curative setting.
- **Psychosocial support:** It is critically important to provide these resources—access to social workers, psychologists, or psychiatrists—to EAO-CRC patients early in their care, many of whom might have just embarked on a career or a relationship. Dr. Cercek believes this can lend additional support as patients navigate their journey from treatment to survivorship. While financial barriers may exist, especially in the context of the COVID-19 pandemic, earlier interventions to provide psychosocial support can make a difference in patients' lives, Dr. Cercek added.
- **Clinician education:** Educating clinicians, even those in private practice, early and in a timely way can significantly impact patient wellbeing.

### **GAP 4:**

## **How Did This Happen? Investigating the Causes of EAO-CRC**

Jose Perea, MD, PhD, Surgery Department, Fundación Jiménez Díaz University Hospital and Research Institute, and Dr. Ng, spoke about collaborating to identify the triggers of EAO-CRC.

- **Scientific priorities for research:** Dr. Perea drew attention to environmental influences, including the microbiome and early-life exposures. He also highlighted the need to develop laboratory models of early-onset disease, in addition to research conducted in cell line and organoid cultures and utilizing CRISPR-Cas9 techniques.
- **Study design:** Since EAO-CRC is different from older-onset CRC, study designs for the two diseases should be different. Dr. Perea recommended conducting comparative studies, with control groups being healthy adults or older-onset CRC patients. Prospective studies with large patient populations should investigate possible exposures to certain environmental factors during childhood and adolescence, alongside comprehensive data collection.
- **International collaboration:** Explaining that EAO-CRC is a global issue, Dr. Ng said that collaboration is vital to ensure an adequate number of patients in large cohort studies and to have a comprehensive biobank of specimens with adequate power. She also emphasized the need to harmonize data collection methods so data can be pooled and analyzed together.
- **Leverage novel technologies:** Artificial intelligence and machine learning will allow rapid and robust analysis of a large amount of information, Dr. Ng said. Since every cancer center has access to only a small number of young-onset patients, there is potential to leverage social media channels to widen access to this patient population.

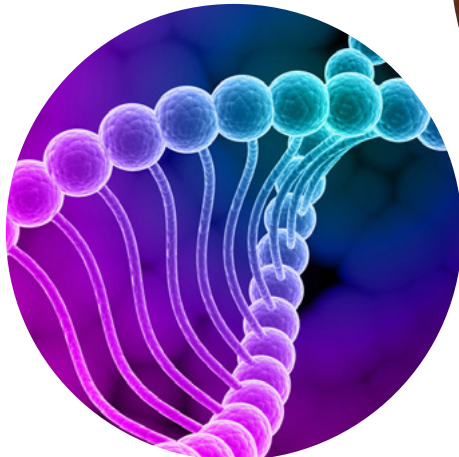


## GAP 5: Navigating the Post-COVID-19 Health Care Landscape

Ms. Borassi, who will be leading this workgroup, acknowledged the challenge with addressing this Gap since it is a completely new and dynamic terrain. Major considerations for this Gap will include:

- The impact of COVID-19 on the cancer care health care ecosystem
- Taking advantage of the new COVID-19 policies
- Leveraging novel technologies

She emphasized that the end goal would be to ensure the voice of organizations and advocates that represent EAO-CRC patients and caregivers is heard on the Hill.



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