

CANCER LEADERSHIP COUNCIL

A PATIENT-CENTERED FORUM OF NATIONAL ADVOCACY ORGANIZATIONS
ADDRESSING PUBLIC POLICY ISSUES IN CANCER

June 26, 2020

The Honorable Lamar Alexander
Chairman
Committee on Health, Education, Labor and Pensions
United States Senate
Washington, DC 20510

Dear Chairman Alexander:

The undersigned organizations represent cancer patients, providers, and researchers. We are united in efforts to ensure cancer patients access to adequate health insurance, enhance the quality of care and quality of life for all cancer patients, and foster research and development of new treatments.

In separate comments, organizations that are part of the Cancer Leadership Council have offered advice on several pandemic preparedness issues, including all issues related to testing during a pandemic. In our joint comments, we will focus on actions to ensure that cancer patients receive care during a pandemic without unreasonable interruption, efforts to protect access to telehealth during pandemics and beyond, and actions to enhance accurate public health communication to the general public and vulnerable populations about the infectious diseases of the future and the potential impact on them and the nation.

Our recommendations are related primarily to one of the areas for action that you have identified, Public Health Capabilities—Improve State and Local Capacity to Respond.

Cancer Care During the COVID-19 Pandemic

The tale of cancer care during the COVID-19 pandemic is one of disruption, innovation, and restoration of care for many, but not for all. When providers were instructed to delay elective care, that triggered an evaluation of what cancer care could be safely delayed and what care should proceed even in the pandemic. The pandemic triggered evaluation and innovation regarding how to care for cancer patients safely and how to protect the cancer care workforce.

Cancer care providers have responded by shifting care that can appropriately be provided through telehealth to that mode of care. That has been possible because of the legislation passed by Congress providing the Centers for Medicare & Medicaid Services (CMS) waiver authority related to telehealth requirements in Medicare, action by CMS to detail telehealth flexibilities, and parallel action by private payers. Through telehealth, cancer care providers have been able to monitor their patients, provide important services, and forestall many disruptions in care.

Although telehealth has been a godsend for patients and providers, some care cannot be delivered by telehealth and instead must be provided face-to-face. Lab tests, imaging services, radiation therapy, and chemotherapy administration are among those elements of care. Cancer care practices – from the smallest to large cancer care centers – have re-engineered their practice of medicine so that care can be provided safely when provided in person. That has required changing everything from scheduling of appointments to the layout of the infusion center or the radiation oncology center. In addition, it is imperative that personal protection equipment (PPE) is available for practices.

We also note that facility limits, PPE supply issues, and social distancing requirements have disrupted cancer clinical trials. Some trials have been postponed, others have been interrupted, and some have been redesigned so that they can be continued or resumed. The commitment and ingenuity of clinical investigators and trial sponsors and the flexibility of clinical trial participants have permitted some trials to continue without interruption and many more trials to be resumed. However, the opportunity to receive care in a clinical trial has been lost for some patients, and the pace of clinical research has slowed during the pandemic. Clinical trial disruptions also create a grave concern about treatment advances that may be slowed or lost.¹

Through the hard work and ingenuity of cancer care providers (as with the resumption of clinical trials) there has been a resumption of much cancer care. Despite the restart of care for many, there are several long-lasting effects from the disruptions in cancer care. National Cancer Institute Director Ned Sharpless editorialized in *Science Magazine* about the impact of COVID on cancer:

“Cancer is a complex set of diseases whose prognoses are influenced by the timing of diagnosis and intervention. In general, the earlier one receives cancer treatment, the better the results. There already has been a steep drop in cancer diagnoses in the United States since the start of the pandemic, but there is no reason to believe the actual incidence of cancer

¹ Although in this letter we are focused on clinical care and clinical trial interruptions due to the COVID pandemic, we also direct attention to disruptions in basic and translational research. Research projects have been discontinued, research animals have been lost, and progress has been slowed. Of great concern to us is the potential loss of talented young investigators, who may have pursued other important work during the pandemic. It is difficult to be prepared for this sort of research disruption, but we urge that in any future pandemic (and in response to the ongoing COVID pandemic) that Congress provide resources to address the research interrupted and lost.

has dropped. Cancers being missed now will still come to light eventually, but at a later stage (“upstaging”) and with worse prognoses. At many hospitals, so-called “elective” cancer treatments and surgeries have been deprioritized to preserve clinical capacity for COVID-19 patients. For example, some patients are receiving less intense chemotherapy and/or radiotherapy, and in other cases, patients' operations to remove a newly detected tumor are being delayed. There can be no doubt that the COVID-19 pandemic is causing delayed diagnosis and suboptimal care for people with cancer.”²

Claims data tell us that routine cancer screenings have plummeted during the current pandemic. According to the EPIC Health Research Network:

“EHR data show a recent abrupt drop – between 86% and 94% – in preventive cancer screenings performed across the United States, presumably due to access disruptions caused by COVID-19. This study compares the number of screenings for cervical, colon, and breast cancer completed each week in 2020 to the average number of screenings completed during equivalent weeks from 2017–2019. The data set includes 2.7 million patient records from 39 organizations that represent 190 hospitals spanning 23 states.”³

This decline in screening explains in part the decline in cancer diagnoses that Dr. Sharpless identifies. In addition, cancer care providers say that Americans are delaying visits to the doctor to discuss symptoms that could be early signs of cancer, thereby delaying their cancer diagnosis. That tendency of patients and the decline in screening have created a perfect storm of delayed cancer diagnoses and a potential for excess cancer deaths in years to come, compared to what we expected prior to the COVID pandemic.

Protecting Access to “Routine” Health Care

As we assess the impact of the COVID-19 pandemic on cancer care in the United States, we have learned some lessons that we need to heed to address the disruptions of cancer care that have occurred in connection with COVID-19 and to be prepared for other pandemics in the future.

² Sharpless NE. COVID-19 and Cancer. *Science*; June 19, 2020.

³ EPIC Health Research Network, Original Article: Data Analysis, May 4, 2020. Accessed online on June 25, 2020: <https://ehrn.org/delays-in-preventive-cancer-screenings-during-covid-19-pandemic/>.

We recommend:

- Continued regulatory and reimbursement flexibility for telehealth, so that providing care in this manner is economically viable and a pathway to quality care.
- Additional research and policy development to encourage the delivery of multi-disciplinary care and coordination of care through telehealth.
- Flexibility regarding the site for providing cancer care. Institutions have been innovative in shifting site of care (including to driveways, parking lots, and other sites) to protect patients and health care professionals during the pandemic, and regulatory authorities and payers should show flexibility about these arrangements if quality of care can be protected.
- Flexibility about the site for screening services. If these services are considered elective and therefore will be delayed during a pandemic, there must be innovation (with appropriate financial support) for other sites for screening services.
- Research and policy development to identify options for providing cancer care at home. This effort must focus on what elements of cancer care can be provided at home (beyond telehealth), patient preferences about cancer care at home, and regulatory and reimbursement changes that would be necessary to permit and encourage this model of care, while also protecting cancer care quality.
- Emergency financial support to providers during a pandemic must be directed not just to those providers and institutions affected by heavy caseloads related to the pandemic disease. Relief is also necessary for those who are forced to make significant changes to continue to provide routine care. These changes include the ability to obtain PPE, shift site of care, purchase technology, and hire appropriate staff for a changing cancer care system. This emergency financial support must also include resources to continue clinical trials.

Racial Disparities in the COVID Pandemic

The COVID-19 pandemic has had a disproportionate impact on racial minorities. As we analyze the data from city after city and many states, we find that COVID has had a disproportionate impact on African Americans and Hispanics in both numbers of cases and deaths. The disparities in the impact of COVID-19 sadly echo persistent disparities in cancer outcomes for African Americans. As the American Cancer Society reports, “African Americans have the highest death rate and shortest survival of any racial and ethnic group in the US for most cancers.”⁴

⁴ American Cancer Society. Cancer Facts and Figures for African Americans, 2019-2021. Accessed online on June 25, 2020: <https://www.cancer.org/research/cancer-facts-statistics/cancer-facts-figures-for-african-americans.html>.

There are some glimmers of hope in the statistics on cancer in African Americans, with larger drops in deaths from lung, colorectal, and prostate cancers in African Americans than in whites since 1990. There is also important research showing that the Affordable Care Act, which provides access to health insurance through health insurance exchanges and through Medicaid in expansion states, has improved access to cancer care for African Americans.

As we are in the midst of responding to the COVID-19 pandemic and thinking ahead to future pandemic planning, it is critical that we protect access to health insurance for African Americans, as a critical first step for protecting access to cancer care. Access to exchange plans, Medicaid, or employment-based insurance must be protected, through special enrollment periods, support for Medicaid expansion, and COBRA premium assistance. But protecting health insurance access is only a first step. Other steps include:

- Increasing diversity in the cancer care workforce.
- Addressing provider bias in delivery of care, through medical training and continuing medical education.
- Enhancing African American participation in clinical trials. Two concrete policy actions may encourage this action. Congress should enact both the CLINICAL TREATMENT Act (HR 913) to require Medicaid coverage for routine patient care costs for those enrolled in clinical trials and the Henrietta Lacks Enhancing Cancer Research Act (S 946 and HR 1966) mandating a study to identify the barriers to clinical trials participation to those currently underrepresented in clinical trials. Participation in clinical trials may represent a pathway to quality cancer care, and disparities in access must be addressed. These two measures represent a step forward.

Accurate and Consistent Communication about Future Infectious Disease Threats

Cancer patients who are immune-compromised are at higher risk of contracting COVID-19 than other Americans, and studies during the pandemic have shown that cancer survivors who are diagnosed with COVID have worse outcomes than those without a cancer diagnosis. In short, a cancer diagnosis may be a risk factor both for contracting COVID and dying from COVID.

Cancer survivors face significant challenges in determining their risk in the COVID pandemic. To determine whether they can work at a frontline job or see their families or leave their homes (and for what reasons), these patients need reliable information about the pandemic – information about community spread, the latest knowledge about the disease and how to contain it and treat it, and any data about their special risk from the disease. The federal government has not provided candid and up-to-date information about COVID, information that at-risk individuals desperately need to live during and through a pandemic. We encourage honest and timely public health updates for the remainder of this pandemic and in the future. This recommendation relates to your fifth inquiry, “Who is on the Flagpole?” For cancer survivors, it is critical that an agency be in charge and that the spokesperson for that agency be a trusted medical professional who can convey accurate and blunt information about the pandemic to the public. Cancer patients can handle the truth during a pandemic. In fact, their lives depend on it.

If cancer survivors receive accurate information about the pandemic, they and their doctors may make the determination that working in a workplace with others puts them and their families at risk. If that is the situation – based on the best available information about the patient and the pandemic – it is important that these individuals have the protection of a paid leave program that is triggered by the pandemic and that is phased out when the pandemic is under control.

Thank you for the opportunity to provide reflections from the cancer community regarding COVID-19 and cancer and planning for the next pandemic.

Sincerely,

Cancer Leadership Council

Academy of Oncology Nurse & Patient Navigators
American Society for Radiation Oncology
Association for Clinical Oncology
CancerCare
Cancer Support Community
Children’s Cancer Cause
Fight Colorectal Cancer
Hematology/Oncology Pharmacy Association
LUNgevity Foundation
Lymphoma Research Foundation
National Coalition for Cancer Survivorship
Ovarian Cancer Research Alliance
Prevent Cancer Foundation
Sarcoma Foundation of America
Susan G. Komen