



Transition Document to the Biden-Harris Administration from the Cancer Support Community

The Cancer Support Community (CSC) looks forward to working with the Biden-Harris Administration in a collaborative and transparent manner to put patients first. In order to accomplish this, particularly during a time when many policy decisions are being made at a rapid pace in order to address the COVID-19 pandemic, economic fallout, and associated health care challenges, CSC asks the administration to consider the following guiding principles:

- Policy changes should be considered in a **broad context** which places patients and their loved ones at the center, including policies that expand coverage and make care more affordable. It is vital to understand the implications that each policy change will have on the health care system and in the lives of individual patients.
- Policy changes should honor patient-provider **shared decision-making**.
- Policy changes should address **affordability and stability** in the overall health care system as well as in the lives of individual patients.
- Policy changes should be **transparent** to all stakeholders while they are being negotiated and include stakeholders in any final decision making.
- Policy changes should **improve patient access** to appropriate therapies.
- Policy changes should **improve affordability** for patients.
- Policy changes should be accompanied by information to **help patients understand** the potential impact to them and their caregivers.
- Patients should be given **ample opportunity and time to understand policy changes**, ask questions, and seek assistance necessary to maintain access to care.

Cancer and COVID-19

Access and Affordability: The impact of COVID-19 on all individuals, particularly those impacted by cancer and other chronic illnesses, must be understood and addressed. Individuals must have access to no- or low-cost services and resources to prevent, diagnosis, and manage the impacts of COVID-19.

There is evidence that people impacted by cancer are more vulnerable to COVID-19. One study found that COVID-19 patients with cancer had higher risks in all severe outcomes, with those with hematologic (such as leukemia, lymphoma, and myeloma), lung, or metastatic cancer with the highest frequency of severe events (such as being admitted to intensive care units and needing mechanical ventilation) (Dai et al., 2020). Further, there is evidence that cancer screenings have plummeted during the pandemic, with one study (Mast & Munoz, 2020a) showing screening for cancers of the breast, colon, and cervix down between 86% and 94% in March of 2020 alone. By July 2020, rates of cancer screenings were still between 29% and 35% lower than their pre-COVID-19 levels for breast, colon and cervical cancer (Mast & Munoz, 2020b). There are concerns that delayed or missed screenings will result in some cancer cases diagnosed later or with a poorer prognosis. National Cancer Institute (NCI) Director Norman Sharpless recently referenced the “steep drop in cancer diagnoses” and stated that “cancer is a complex set of diseases whose prognoses are influenced by the timing of diagnosis and intervention” (2020).

In our comprehensive study regarding the impact of COVID-19 on cancer patients, CSC preliminary findings revealed the following: 56% of respondents indicated that COVID-19 has very or somewhat negatively affected their ability to obtain needed health care; 42% of respondents have experienced a disruption to their cancer-related health care because of COVID-19; 44% of respondents were somewhat, very, or extremely concerned about diagnostic tests being delayed or canceled; and 73% had at least one telehealth session during the COVID-19 pandemic and 43% of these were specifically for a cancer-related health appointment.

As we continue to care for the millions of Americans impacted by COVID-19, we also must brace for the potential swell in the number of individuals diagnosed with cancer. We must be aware of how COVID-19 will impact this group of people and what resources and services will be available to help them most successfully treat and attend to their cancer as well as mitigate their chances of contracting COVID-19. Services to prevent, diagnosis, and treat COVID-19 should be offered at no- or low-cost to anyone impacted by the virus. This includes COVID-19 vaccinations that, once approved, should be made available in the first wave of dissemination to cancer patients in active treatment, cancer survivors with compromised immune systems, and caregivers actively caring for these individuals. We must prioritize individuals at highest risk of infection and serious negative outcomes. Patient advocacy groups, like CSC, can be important education outlets to disseminate vaccine information to stakeholders.

Access to Health, Mental Health, and Cancer Care

More people are living with cancer than ever before, with over 16.9 million survivors in the U.S. today. That number is expected to increase to 22.1 million by 2030 with 41% of Americans

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receiving a cancer diagnosis in their lifetime (American Cancer Society, 2020). Cancer patients, survivors, and caregivers must have access to affordable, comprehensive, high-quality, timely health care. As such, CSC supports the following policy principles as the United States health care system continues to evolve:

Access: Individuals impacted by cancer must have access to timely, high-quality, and comprehensive health care.

The Affordable Care Act (ACA) was a critical policy shift in improving our nation's health care coverage landscape. The expansion of Medicaid is at the heart of the ACA, and any barriers that have been constructed to restrict access to Medicaid must be lifted. The gains made by the ACA must be protected and improved upon. Any changes should not disrupt the care or coverage patients are currently receiving. Barriers must be addressed so that patients can find an appropriate health care provider in their geographic area and efficiently enter and navigate the health care system. Patients should be able to access the full range of essential health benefits without any restrictions on access due to a pre-existing condition. Young adults should be eligible to remain covered on their parents' insurance plan until the age of 26. Patients should also have access to clinical trials without the risk of losing insurance as a result of participation.

Affordability: Individuals impacted by cancer must be able to afford and maintain their health insurance coverage and prescription medications.

It is particularly important that cancer patients and survivors are not discriminated against through higher premiums and exorbitant out-of-pocket costs. The patient-provider shared decision-making process should be respected by ensuring all patients have affordable access to the most appropriate and effective medication(s) to treat their disease without burdensome barriers that impede patient care and outcomes. It is also vital that people of a lower socioeconomic status or those who have historically been underserved in the health care system are provided with subsidies or other economic exceptions to ensure that they can afford care. The Medicaid program and subsidies are several key ways for these individuals to access health insurance coverage and care.

Racial Justice, Health Equity, and Non-Discrimination: Individuals impacted by cancer must receive equitable treatment within the U.S. health care system.

CSC strongly supports efforts to eliminate health inequities. Underrepresented and disenfranchised communities (including people of color, women, and people living with lower incomes, etc.) must always have a seat at the decision-making table. There must also be significant efforts to enhance confidence in government and scientific institutions as reputable, evidence-based, trustworthy resources for all people.

Health disparities can only be meaningfully addressed when all individuals have access to, and can afford, health care insurance and services. Individuals impacted by cancer should not be discriminated against based on health status, age, gender, ability level, race, ethnicity, sexual orientation, gender identity, disability, or any other characteristic. Further, it is imperative that health insurance companies not deny coverage to individuals based upon pre-existing conditions

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or catastrophic illness. Additionally, insurance companies should not be able to place annual or lifetime caps on coverage, rescind coverage (except in cases of fraud), or drastically raise premiums (or other out-of-pocket costs) for cancer patients or survivors, or those at risk for cancer.

Additionally, once approved, COVID-19 vaccinations should be made available in the earliest waves to individuals from communities that have both historically been underserved and those who have borne an unequal share of illness and death as a result of COVID-19 (such as racial and ethnic minority groups).

Patient-Centered Care: Individuals impacted by cancer must receive patient-centered care that is aligned with their needs and preferences.

Patient-centered care is respectful of, and responsive to, individual patient preferences, needs and values, and ensures that patient values guide all clinical decisions. Patients engage in shared decision-making with their health care team in order to develop a plan of care that supports the patient's goals and wishes.

Prevention and Early Detection Services: Individuals should have access to no- or low-cost preventive care including, at a minimum, coverage that provides for well services, cancer screenings and testing, immunizations, nutrition services, and opportunities to engage in an active lifestyle.

Preventive services can help individuals not only prevent chronic illness, including cancer, but can help them to detect and treat disease as soon as possible. The COVID-19 pandemic has reemphasized the importance of cancer prevention and early detection as screening rates have plummeted for much of 2020. Single tumor screening and forthcoming innovative resources and services in screening and early detection must be available to all people, particularly those at risk for specific cancers and those from historically disenfranchised populations. Enhanced efforts to ensure access to screening and early detection is not only important to our nation's approach to cancer control overall, it is also one key way to tackle disparities in cancer outcomes because we can find and treat cancer at earlier stages when patients are more likely to survive.

Psychosocial Health Services: Individuals impacted by cancer must have access to high-quality, comprehensive, and timely psychosocial health care services.

As the World Health Organization Constitution states "health is a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity" (n.d.). As such, there should be mental and behavioral health care parity. Patients should have timely and sufficient access to trained and licensed mental health care providers who provide affordable care. Cancer patients should be screened for distress at all points along the cancer continuum and receive the appropriate services based on their results.

Quality: Individuals with cancer must be able to utilize high-quality health care services that are effective, efficient, and safe.

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High-quality health care supports patients' efforts to achieve desired outcomes.

Research: Individuals with cancer benefit from a well-funded, robust research infrastructure.

Institutions such as the National Institutes of Health, National Cancer Institute, and Food and Drug Administration (FDA) must have adequate and sustainable funding in order to continue to build upon the progress that has been achieved in oncology and other fields.

Triple Aim: Individuals with cancer deserve health care that achieves the goals of the triple aim.

Health care reform was targeted at improving the experience of care, improving the health of populations, and reducing per capita costs of health care. The health care system must meet these three goals in order to improve the health of Americans and be sustainable, particularly for individuals dealing with chronic illnesses such as cancer.

CSC has advocated for a host of critical, lifesaving health care and economic protections (particularly during the COVID-19 pandemic) including:

- Opportunities for individuals to seek **private and public health insurance** coverage that provides ample health care benefits;
- Enhanced access to **vital medications and health care services** at affordable prices;
- Access to permanent **telehealth and tele-mental health** services;
- Protection of patients with chronic illnesses, including cancer, from **discriminatory triage plans** in response to the pandemic;
- **Access to appropriate and affordable medications** (such as oral therapies) and options to receive health care services in the most **appropriate and preferred** settings (such as home infusion/injection) in order to safeguard health and wellbeing;
- Banning of **surprise medical billing**;
- **Expansion of health care networks** to ensure convenient and safe access to care;
- Lifting of **utilization management techniques** (such as step therapy) that prevent access to timely care and services.
- Expanded (in both time period and amount) **unemployment insurance** to ensure that individuals who are unemployed, underemployed, or unable to work due to a compromised immune system or living in the same household with an individual with a compromised immune system have access to enhanced benefits;
- Enhancements to **paid family and medical leave** for people living with chronic illnesses including cancer and their caregivers and family members living in the same home;
- Protections for **children and families at school and work**; and
- Enhanced funding for **nonprofit organizations** providing vital safety net services.

Clinical Trial Design and Enrollment

Diversity, Inclusion, and Access: Broaden eligibility criteria when scientifically and clinically appropriate and increase enrollment of underrepresented populations. Ensure Medicaid coverage

for clinical trial costs. Enhance access by meeting patients where they are and increasing clinical trial offerings at the community level nationwide.

Clinical trials provide individuals with cancer and other serious medical conditions the opportunity to participate in ground-breaking research that may bring about treatments that improve quality of life, extend survival, and even prove lifesaving. While most cancer patients express a willingness to participate in clinical trials, numerous barriers to enrollment drastically reduce the number of adult cancer patients in clinical trials to about 1 in 20, or 5%. With data being consistent with the idea that higher rates of patients enrolled in clinical trials produce faster rates of treatment advances, and concurrent survival increases and mortality reductions, CSC shares the commitment, need, and urgency to ensure the broadest and most inclusive patient participation possible in clinical trials while maintaining safety and efficacy standards. Approximately 20% of cancer clinical trials fail due to insufficient patient enrollment. Barriers to clinical trial participation, whether resulting from restrictive eligibility criteria, patient burdens, social determinants, or patient mistrust, are thwarting potential treatment advances, survival increases, and reduction in mortality. Clinical trials must be offered in communities where patients reside and be made affordable to all patients, regardless of insurance type or status.

Patient Experience: The full range of patient experience data should be collected in clinical trials and reported to the public. Patients should be partners in clinical trial design.

The need to collect and report data on the full patient experience is well-established. For example, in oncology, the Institute of Medicine concluded “it is not possible to deliver good quality cancer care without using existing approaches, tools, and resources to address patients’ psychosocial health needs.” As the comprehensive care conversation evolves and becomes more inclusive of the patient, we must expand our assessment of patients to include more than disease symptoms, treatment side effects, and physical functioning. It is incumbent upon the FDA, industry, academic institutions, members of the health care team, patient advocacy organizations, and other stakeholders to consistently and meaningfully seek robust and informative patient feedback and patient experience data at all points along the research and care continuum.

Data Sharing and Data Standards

Patient Centeredness: Ensure a patient-centered data ecosystem where silos are broken down in order to achieve the best possible outcomes for patients. Understand patient willingness to engage in data sharing.

In a 2019 study, CSC found that cancer patients and survivors were largely willing to share de-identified medical data and were most motivated by a desire to help other cancer patients (Franklin et al, 2019). Patients need to understand the purpose for sharing their data and must have complete trust that their information will be used expressly for that purpose and that purpose only. They must be assured that their identity will be kept confidential and private and that there will be no tracking without their consent. Patients should be openly acknowledged as

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practice and research partners, receiving feedback on the use of their data and results of research studies and other initiatives.

Patient Navigation

Sustainability: Patient navigation is a vital component of high-quality cancer care and should be integrated across the care continuum and reimbursed in order to ensure sustainability.

Patient navigation has a proven track record of removing barriers and improving care for cancer patients, particularly those from disenfranchised populations such as communities of color and those with lower incomes. Navigation has been shown to support more timely treatment initiation, enhanced adherence to cancer screening and care, improved quality of life, increased patient satisfaction, decreased hospital readmission, and emergency department utilization. In order to continue, and build upon, this progress, navigation services must become reimbursable.

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About the Cancer Support Community

The Cancer Support Community (CSC) is one of the largest direct provider of navigation and social and emotional support services for people impacted by cancer and the largest nonprofit employer of psychosocial oncology professionals in the United States. CSC has a unique understanding of the cancer patient experience. Overall, we deliver more than \$50 million in free, personalized services each year to individuals and families affected by cancer nationwide and internationally. CSC is dedicated to ensuring that all people impacted by cancer are empowered by knowledge, strengthened by action, and sustained by community. In addition to our direct services, our Research and Training Institute and Cancer Policy Institute are industry leaders in advancing the evidence base and promoting patient-centered public policies to ensure that the patient voice is at the center of the national dialogue.

About the Cancer Policy Institute

The Cancer Policy Institute (CPI) at the Cancer Support Community (CSC) brings together patient advocates and policy experts to ensure that the voices of cancer patients and their loved ones play a central role in federal and state legislative, regulatory, and executive policy making. The CPI works in partnership with patient advocates, the CSC affiliate network, and numerous allied health care and oncology organizations to work towards a future where 15.5 million cancer survivors have access to comprehensive, high-quality, timely, and affordable medical, social, and emotional care.

Patients are at the center of the work of the CPI. We utilize leading-edge data from our Research and Training Institute to support our policy positions with evidence that is based in the patient

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experience. Whether we are on Capitol Hill or in state legislatures, in discussions with regulators, or working in policy coalitions, our focus is always on the patient and how we can work towards a system that is truly centered around the experiences, preferences, and values of cancer patients and their loved ones.

The CPI also engages in advocacy, powered by a grassroots network of thousands of advocates across the country. Through our online platform, we provide updates on policy issues that could have an impact on the health and wellbeing of cancer patients and survivors and offer opportunities for advocates to make their voices heard with federal and state policy makers.

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