CANCER SUPPORT
COMMUNITY
COMMUNITY IS STRONGER THAN CANCER

March 20, 2023

The Honorable Bernie Sanders
Chair, Senate HELP Committee
United States Senate
Dirksen Senate Office Building
Washington, DC 20510

The Honorable Bill Cassidy
Ranking Member, Senate HELP Committee
United States Senate
Dirksen Senate Office Building
Washington, DC 20510

Dear Senator Sanders and Senator Cassidy,

On behalf of the Cancer Support Community (CSC), I would like to thank you for the opportunity to submit feedback to the Senate Committee on Health, Education, Labor, and Pensions (HELP Committee) about the growing healthcare workforce shortage in the United States and its impact on patients and caregivers.

CSC is a global non-profit network of 175 locations, including CSC and Gilda's Club centers, hospital and clinic partnerships, and satellite locations that deliver more than $50 million in free support and navigation services to patients and families. In addition, we administer a toll-free helpline, 888-793-9355, and produce award-winning educational and digital resources that, together with the locations, reach more than one million people each year. We also conduct cutting-edge research on the emotional, psychological, and financial journey of cancer patients and advocate at all levels of government for policies to help individuals whose lives have been disrupted by cancer.

We are most grateful to you for for drawing attention to the growing healthcare workforce crisis. In the following comments, we hope to demonstrate that the issue of healthcare workforce must be considered from multiple perspectives to be fully understood. On behalf of the cancer patients and caregivers whom we represent, we would argue that the patient perspective should be considered among the most important.

Workforce Trends

In reading the Medicare Payment Advisory Commission’s (MedPAC) annual report to Congress[1], one might conclude that there is not presently a healthcare workforce crisis because MedPAC’s standardized survey tool did not demonstrate what they deemed to be significant access issues. While the strategy of looking at the current environment and deciding that it has not gotten bad enough, yet, may appear to make sense from a health economics perspective, the Committee can likely appreciate that the patient community would rather not wait until *more* patients report access issues – resulting in more advanced disease, more expensive treatments, and poorer patient outcomes, and the potential for health system collapse – before taking action.

MedPAC reports that 11% of Medicare beneficiaries looked for a new primary care provider in the past year and most did so because their previous primary care provider had retired or stopped practicing. Approximately half of those looking for a new provider reported having trouble finding one. The

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[1] The Medicare Payment Advisory Commission, Physician and Other Health Professional Services, *MedPAC March 2023 Report to the Congress: Medicare Payment Policy*. https://www.medpac.gov/wp-content/uploads/2023/03/Ch4_Mar23_MedPAC_Report_To_Congress_SEC.pdf

MedPAC report also states that 26 percent of Medicare beneficiaries reported looking for a new specialist in 2022, and a third of them reported a problem finding one. Left unaddressed, the trends beginning to develop in the MedPAC data would be alarming. However, the fact that baby boomers are not just starting to leave the healthcare workforce, they are also starting to need more healthcare services should be a call to action. A separate MedPAC report estimates that, by 2030, when the entire baby boom generation is eligible for Medicare, there will be 77 million Medicare beneficiaries—up from 62 million beneficiaries in 2020[2]. In addition, the number of cancer survivors, many of whom have multiple chronic conditions that need management by both by physician specialists and primary care providers, is estimated to increase from16.9 million in 2019 to 22.1 million in 2030[3].

Although MedPAC would suggest that these findings are consistent, if not only slightly worse than usual, when viewed in the context of the alarming number of physicians who say they are experiencing extreme burnout, along with the knowledge that our aging physician workforce is beginning to retire, it seems to indicate that we are seeing the beginning of a dangerous trend in supply of healthcare providers. Therefore, we hope that the Committee will focus, not only on policy solutions that increase the opportunities for healthcare professional training and the number of people seeking to go into healthcare professions, but also those that will help to ensure that talented and caring providers are still able to practice. This means addressing sources of emotional and psychological stress in addition to providing additional resources and support. It means acknowledging that the cost of misapplied utilization management tools and clumsy and poorly informed reimbursement models is not only worse for patient care, it is causing health professionals to leave the workforce or consolidate with larger hospitals and health systems so they can hand off some of the overhead and, in some cases, avoid reporting requirements.

It seems worth nothing that the Patient Protection and Affordable Care Act authorized the creation of a National Healthcare Workforce Commission. Commissioners were named but, because Congress has never appropriated funds for its work, the Commission has never met. Issues like those briefly mentioned above, the well-documented nursing workforce strain, clinician scope of practice, and the impact of federal reimbursement policies are all topics that a Workforce Commission might examine[4].

Patient Perspectives

This year's MedPAC survey also showed that urban respondents were more likely to look for a new specialist than rural respondents, and higher income respondents were more likely to look for a new specialist than lower-income respondents. Alarmingly, clinicians in MedPAC focus groups reported that some patients could wait up to six months to see certain specialists.

Someone newly diagnosed with cancer does not have six months to find a specialist, especially if that cancer is diagnosed at a late stage. Decades of experience with access to various cancer screening modalities have demonstrated that a patient whose cancer is caught early is more likely to have better treatment options and better outcomes. For many, that annual screening, covered by Medicare and other insurers, may only be available at a hospital. Yet 136 rural hospitals closed between 2010 and

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[2] https://www.medpac.gov/wp-content/uploads/2022/03/Mar22_MedPAC_ReportToCongress_Ch1_v2_SEC.pdf

[3] Miller, K. D., Nogueira, L., & et. al. (2019). Cancer treatment and survivorship statistics, 2019. CA: A Cancer Journal for Clinicians, 69(5), 363-385. doi:https://doi.org/10.3322/caac.21565

[4] The Patient Protection and Affordable Care Act, Public Law 111–148, § 5001 https://www.hhs.gov/sites/default/files/v-healthcare-workforce.pdf

2021. 19 of those closures occurred in 2020, the most of any year in the past decade.[5] Even worse, it does not appear that the tapering of the COVID-19 pandemic has eased the economic burden. A report commissioned by AHA showed that 2022 was the worst financial year for hospitals since the start of the COVID-19 pandemic.[6] 76% of health system leaders participating in a recent Deloitte survey cited inflation as a significant factor in their planning for 2023. They also listed affordability issues for patients, shrinking margins, and ongoing supply chain disruptions as chief concerns.[7] 85% of those surveyed said staffing challenges would have a major impact on their strategy for 2023. We know that healthcare workforce shortages could mean disaster in underserved communities that already struggle to recruit new providers.

Importantly, supply and demand are not the only ways to measure the adequacy of the healthcare workforce. Taking proactive steps to increase racial, ethnic, cultural, and geographic diversity in the healthcare workforce cannot be relegated to a secondary priority. In general, Native American, Black, and Hispanic people are significantly underrepresented in the healthcare workforce[8]. Increasing diversity in the healthcare professions will help to ameliorate the potential for not only individual racism but also structural racism as well[9]. The American Medical Association has asserted that they are committed to not only addressing the healthcare workforce shortage, but also to increasing the diversity of physicians because of the impact that this will have on health equity and enhancing the patient experience[10].

We would like to highlight for the Committee some of the comments that we have heard from patients regarding the diversity of the healthcare workforce:

Patient A – "I am currently a retired Veterans Affairs Healthcare Administrator. I also served over 20 years in Psychiatry at the VA. The other admins did not look like me (Patient A is a Black woman) and I noticed. I didn't leave the workforce but it made it harder to work there."

Patient B - "My concerns regarding the healthcare workforce shortage, also has to do with the lack of diversity. Sometimes I'm uncomfortable discussing or even explaining the symptoms that I'm experiencing for fear of being misunderstood or not being taken seriously. Not sure what the solution would be, but it sure would help if I was able to be treated by someone who looks like me.

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[5] *Care in Local Communities.* American Hospital Association. Retrieved from https://www.aha.org/system/files/media/file/2022/09/rural-hospital-closures-threaten-access-report.pdf

[6] KaufmanHall. (February 2023). *National Hospital Flash Report Based on January Data from More Than 900 Hospitals.* Retrieved from https://www.kaufmanhall.com/sites/default/files/2023-02/KH-NHFR_2023-02.pdf

[7] Wheeler, T. (2022, December 13). *Deloitte: Health Forward Blog.* Retrieved from 2023 Outlook for Healthcare: https://www2.deloitte.com/us/en/blog/health-care-blog/2022/2023-outlook-for-health-care-could-margins-staffing-stall-progress-to-future-of-health.html?id=us:2ps:3gl:lshco23h:awa:lshc:030323:healthcare%20articles:b:c:kwd-98434896&gclid=Cj0KCQiAx6ugBhCcARIs

[8] Salsberg E, Richwine C, Westergaard S, et al. Estimation and Comparison of Current and Future Racial/Ethnic Representation in the US Healthcare Workforce. JAMA Netw Open. 2021;4(3):e213789. doi:10.1001/jamanetworkopen.2021.3789

[9] Togioka BM, Duvivier D, Young E. Diversity and Discrimination In Healthcare. [Updated 2022 Aug 22]. In: StatPearls [Internet]. Treasure Island (FL): StatPearls Publishing; 2022 Jan-. Available from: https://www.ncbi.nlm.nih.gov/books/NBK568721/

[10] [3] Harmon, GE. AMA Statement on Advancing Equity in Medicine. *AMA Press Releases*. 2022 Apr 25. Available from: https://www.ama-assn.org/press-center/press-releases/ama-statement-advancing-equity-medicine

> I am also concerned that the quality of care will start to diminish due to burnout in healthcare workers. For example, an increase in misdiagnosis, and/or other medical errors as a result of the current workforce shortages."

Any effort to improve access to healthcare must prioritize the needs of those who are accessing that care. Diversity, Equity, and Inclusion training and one-on-one mentorship programming should be made available for all health professionals, regardless of race or ethnicity. In addition, CSC would support efforts to increase recruitment to medical professions from among graduates of Historically Black Colleges and Universities and tribal academic institutions, and increased funding for programs like the National Health Service Corps which prioritizes funding for trainees who agree to practice in underserved communities.

We hope the Committee will consider the CSC Cancer Experience Registry® (CSC CER) as a resource to help shine light on the patient experience. An IRB-approved study listed on clinicaltrials.gov, CSC CER is an online research study to understand the experiences of those impacted by a cancer diagnosis. The Registry is a web-based platform to distribute cross-sectional and longitudinal surveys. Study surveys are designed based on input from advisor experts, including patients and caregivers, and focus on the social, emotional, physical, financial, and decision-making experiences of those who have been diagnosed with cancer and their caregivers. Findings contribute toward enhancing care for patients, survivors and caregivers via programming and policy initiatives.

By gathering the important insights of those affected by cancer through the CSC CER survey, we can create better outcomes for patients, survivors, and caregivers today, and for future generations. A CSC CER spotlight survey focusing on the mental health needs of those impacted by a cancer diagnosis yielded the following responses related to the healthcare workforce:

Q. **Which individual of your cancer care team did you feel was more compassionate and thoughtful to your mental healthcare needs?**

A. "My **palliative care doctor**, for the first time did not document that I was crying. He documented that I had a normal response to having terminal cancer. I appreciated that so much. He also took a long time to figure out who I was and how treatment would work for me. At our hospital, the **psychologists all quit during COVID, and they have not returned**. This has made mental health a pill mill. I'm not interested in that. Neither was my palliative care doctor."

Q. **What do you think are the main barriers that people with cancer experience in obtaining care for their emotional or mental health concerns?**

A. **"Lack of availability of mental health professionals <u>who deal with cancer or chronic illness</u>**, cost because some specialists don't take insurance, and limited availability because of so many people seeking help since the **pandemic**."

Because CSC has direct interactions with cancer patients and caregivers through every stage of their experiences with cancer: from diagnosis and treatment, to post-treatment survivorship, and through palliative care, and bereavement, we hear from them directly about their concerns, frustrations, challenges, and fears. As such, the recommendations above seek to mitigate the pending workforce crisis for the benefit of patients and caregivers. However, a mitigation strategy, alone, will not be sufficient to protect patients from the impact of these changes. The Committee must also consider how we will adapt to the reality of a health system that is ill-equipped to manage the coming crisis.

As such, CSC endorses the comments submitted on behalf of the Alliance for Connected Care. Cancer does not skip over those communities that do not have adequate access to health care and many cancer patients cannot travel long distances or are immunocompromised and unable to interact in person. During the COVID-19 public health emergency, we saw state licensure rules that have traditionally limited providers' ability to provide care across state lines, relaxed, and individuals were able access care they would have otherwise been denied. We encourage the Committee to pursue permanent policy measures codifying the use of telehealth across state lines for specific purposes. Without action on this issue, patient and caregiver outcomes will suffer.

A related and equally important adaptation strategy is creating policy that would allow for direct reimbursement for patient navigation. Complex medical terminology, insurance requirements, increasingly specific medical specialization, health system consolidation, and different sites of care are just a few of the hundreds of factors that make the American health care system a dizzying maze. Patients who are facing a potentially serious diagnosis are likely to be further hampered by fear and confusion. If these same patients are left to negotiate a health care system hobbled by workforce shortages, they may never get the care they need.

According to the Journal of Oncology Navigation Survivorship, patient navigation emerged as one solution to helping ease the burdens cancer inflicts on individuals, families, and communities impacted and to the professionals and systems charged with caring for them. Patient navigation is also an effective tool in helping to address the disproportionate impact cancer has historically had on communities of color, those with lower socioeconomic status, LGBTQ communities, and other populations who tend to experience access inequalities, lower-quality healthcare, and higher cancer death rates. In fact, the concept of patient navigation was developed by Harold P. Freeman, MD as a "strategy to improve outcomes in marginalized populations by eliminating barriers to timely diagnosis and treatment of cancer and other chronic diseases," following the 1989 American Cancer Society National Hearings on Cancer in the Poor.[11]

Pro-active, in-person and virtual navigation by qualified healthcare professionals is the single most effective tool to combat both patient access to care and anxieties around treatment. At CSC, we define our pro-active navigation model as "Empowering patients, caregivers, and families to manage the social, emotional, practical, and financial barriers to care providing them with timely access to quality individualized support, education, assistance, through all phases of their cancer experience." Our licensed mental health specialists and resource specialists navigate thousands of patients and caregivers each year through philanthropy and generous donations. This is difficult to sustain but critical in a fragmented, complex medical system. We are not alone in this endeavor and we are hopeful that one day congress will recognize that this collaborative care delivery model should be acknowledged through reimbursement.

Through a partnership with Carevive, a bi-directional EHR resource used in clinical practice for treatment care planning, clinical trial screening, symptom management, care coordination and referrals, and

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[11] https://jons-online.com/issues/2022/march-2022-vol-13-no-3/4399-oncology-navigation-standards-of-professional-practice

survivors we have demonstrated the value of proactive cancer care navigation[12]. In announcing the partnership, CSC's Chief Experience Officer Sally Werner, RN, BSN, MSHA said, "This model is the culmination of CSC's and Carevive's combined 50 years of expertise in providing emotional support and healthcare services, respectively, for people impacted by cancer. At its core, it makes it easier for patients to stay connected to their real-life cancer care team throughout their treatment. As a nurse, I can't emphasize enough that our model is remarkable because it keeps the human connection central to its design."

Supporting existing care teams is also a way to help address work-force shortages. CSC's CancerSupportSource® is a web-based distress screening, referral, and support program for adults diagnosed with cancer. The goal of the CSS programs is to rapidly identify and respond to unmet social and emotional health needs through our evidence-based program, thereby better enabling patients and caregivers to navigate care and treatment, practice self-care, and enhance well-being. PROmpt cancer care management®, is a web-based patient symptom management program for treatment care planning, symptom management, and referral for adults diagnosed with cancer. The goal of the PRO program is to improve the treatment experience of patients with cancer and survival outcomes while lowering costs.

Once again, we would like to thank the Committee for seeking feedback on this important topic. The Cancer Support Community would welcome the opportunity to continue to participate in a thoughtful dialogue on opportunities to stem this growing crisis. Please contact Courtney Yohe Savage, CSC Sr. Vice President of Policy and Advocacy at cysavage@cancersupportcommunity.org or 202-680-8985 with any questions or requests for additional feedback.

Sincerely,

Debbie Weir

Debbie Weir
CEO

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[12] https://www.globenewswire.com/en/news-release/2022/08/11/2497023/0/en/Cancer-Support-Community-and-Carevive-Partner-on-Innovative-Care-Delivery-Model.html