



## Findings from the 2020 ACCC Focus Groups

The common thread uniting members of the Association of Community Cancer Centers (ACCC) is the opportunity to amplify voices in ways that support one another. Coronavirus disease 2019 (COVID-19) presented cancer programs and practices with extraordinary professional and personal challenges, disruptions, and opportunities for pause and reflection.

Rather than fielding its annual *Trending Now in Cancer Care* survey while cancer programs were experiencing unprecedented challenges due to the extended public health emergency, ACCC chose to facilitate conversations with its members to capture the lived experiences of the most pertinent issues impacting oncology practice and care delivery. ACCC convened three focus groups in November-December 2020 representing the President’s Theme Task Force, the Financial Advocacy Network Committee, and the Education Committee to discuss the following topics:

- Staffing and operational integrity.
- Service line delivery and revenue optimization.
- Telehealth and supportive technology.
- Clinical research.
- Health equity.

When we asked discussion participants how their cancer programs were impacted by COVID-19, “burnout,” “exhaustion,” “fatigue,” and “stress” were the words most frequently used across all three focus groups. Participants revealed strains that tested institutional, professional, and personal resilience and transformed the dynamics of clinical and personal communication.

Clinicians not only had fewer opportunities for hands-on clinical examination, but the absence of a second set of eyes and ears and the loss of vital details about symptoms that family members provide when they accompany patients on clinic visits made patient examination much more challenging.

But focus group participants also shared silver linings. They told us how their cancer programs and practices developed new operational approaches and workflows to minimize disruptions to staff and patients and ensure continuity of care. They shared how cancer programs and practices implemented telehealth virtually overnight to support care delivery—often without the benefit of robust infrastructure. And they underscored the remarkable resilience of cancer program staff. Figure 1 (page 42) paints a picture of the lived experience of these focus group participants.

Figure 1. The Lived Experience of COVID-19

### Cancer program staff have been tested.

- The COVID-19 pandemic strained the resources of cancer programs. Patient volume and revenue dropped dramatically in the first COVID-19 wave. Workloads increased and provider and staff roles and responsibilities expanded.
- Mandatory physical distancing contributed to social and emotional isolation for many staff and patients. Providing support for staff became a full-time occupation for many leaders and managers.
- Information flow and exchange was severely disrupted in 2020. Cancer programs and practices spent more on resources to support COVID-related safety protocols and telehealth.



### COVID-19 transformed the dynamics of clinical and operational practices.

- The shift from being in the clinic to remote work was seismic. Financial navigators, oncology social workers, genetic counselors, administrators, and other staff worked remotely more than physicians and nurses, who often had to be in clinics and infusion centers. This shift reshaped communication between clinicians, staff, and their patients and colleagues.
- Cancer programs and practices identified new operational approaches to address disruptions.
- Telehealth became more prominent in 2020, often despite lack of infrastructure and multiple implementation barriers. Members are hopeful that relaxed regulations introduced in 2020 will remain and emphasized the potential for telehealth to improve health equity by removing transportation barriers, particularly for those in rural and underserved communities.
- Flexibilities established in clinical research have long-term potential to reshape the design and conduct of clinical trials and potentially address health inequities.



### Cancer program staff have shown remarkable resilience.

- Cancer care teams acutely felt the loss of in-person social connection and the disruption of everyday professional and personal life.
- COVID-19 reinforced the importance of face-to-face communication for clinical practice and financial navigation. Oncology staff found new ways to communicate and connect—with each other and with their patients.
- To bolster this resiliency, cancer programs and practices repurposed conference rooms and other areas as designated staff spaces; got innovative with staff recognition and perks, like hosting milkshake and ice cream bars; developed robust buddy systems; sent daily supportive messaging and shared positive stories and accomplishments; and reinforced a “speak up” culture, especially when issues and challenges arose.





## Staffing and Operational Integrity

Cancer program staffing was adversely impacted at different points in the pandemic. In the first wave, staffing cuts and furloughs were widespread and many clinical staff members were re-

deployed to support COVID-19 operations or cover the shortfall for other services. An ACCC Education Committee member observed, “The ambulatory clinics closed down in March and April. Those nurses moved to the inpatient units, and the staffing just kind of moved around.”

Over the summer, cancer programs continued to experience staffing shortages even as inpatient volumes rebounded and new COVID-19-related clinical and administrative roles were created to screen patients prior to clinic visits. During the second surge in late 2020, staffing shortages remained a significant problem as elective surgeries increased in volume and clinics reopened. By the fall, many staff had also contracted COVID-19 or were still furloughed.

Staff workloads increased, roles were reshaped, and many cancer program staff absorbed new responsibilities as colleagues were furloughed or redeployed.

### Impact on Clinical Staff

Virtual visits increased expectations about the volume of patients that clinicians can see in a day, and oncology team members had to absorb some tasks usually performed by colleagues. For instance, clinicians felt they spent more time ensuring that remote office staff contacted patients following office visits to schedule scans or blood draws.

As one President’s Theme Task Force member shared, “We’re not having the direct interaction within the office. In terms of workload, it means that after we see the patient, we must make other contacts to make sure things are carried out, like scheduling and scans. We want all those things done during the office visit, but that can’t happen if staff aren’t there. It means that we [clinicians] have to make sure the office contacts the patient and that the patient also knows they have to communicate with the office. It’s added to the workload—not having the whole team physically present.”

As processes for communicating with colleagues and patients shifted toward virtual channels early in 2020, clinicians keenly felt the loss of one-on-one interaction with patients and families. Clinicians not only had fewer opportunities for hands-on clinical examination, but the absence of a second set of eyes and ears and the loss of vital details about symptoms that family members provide when they accompany patients on clinic visits made patient examination much more challenging.

As one President’s Theme Task Force member shared, “You might have a husband and wife in the exam room when you ask about diarrhea. The patient knows they’re getting their scan results that day, and they don’t want to reveal all of the symptoms that might stop their therapy. So when you say, ‘Do you have any diarrhea?’ The patient says, ‘No.’ But their partner says, ‘You

were in the bathroom five times last night!’ So that other part of the assessment that comes from the honesty of their partner is missing when there’s nobody in the room.”

### Impact on Financial Navigators and Supportive Care Staff

The workload for financial navigators and supportive care staff increased considerably, both to meet an expanding volume of patient needs and to accommodate resource gaps. New COVID-19-specific programs and resources emerged for which many patients were eligible and about which financial navigators and supportive care staff had to rapidly educate themselves.

Pre-pandemic, financial navigators linked patients directly to supportive care resources, like social work, during an in-office visit. In 2020, these professionals spent more time trying to identify resources and following up with contacts themselves after talking with patients by phone. In response to these challenges, ACCC developed a COVID-19 Financial Advocacy Resource Hub ([acc-cancer.org/FAN-COVID19](http://acc-cancer.org/FAN-COVID19)) and shared tips for financial navigators via a town hall.

At the same time, many financial navigators and supportive care staff were redeployed or worked from home and it was challenging for colleagues to communicate directly with each other. Navigators and supportive care staff who worked from home had to rely on on-site staff for signatures, email, and other resources and felt that this added a layer of extra burden on their colleagues.

Financial navigators and supportive care staff were largely unable to have face-to-face conversations with patients on-site and had to rely on phone calls or virtual platforms to communicate with patients. However, technology and connectivity issues added to the challenge of having candid conversations with patients about their financial and other supportive care needs because many patients experienced technology and connectivity barriers. Patients were, in fact, harder to reach by phone—they were often unfamiliar with the cell phone numbers of navigators and cancer program staff and ignored calls. These access issues created additional workload for financial navigators and supportive care staff who had to schedule follow-up calls to reach patients, sometimes multiple times.

Even when financial navigators and supportive care staff could reach patients by phone, they found it harder to build a relationship and trust with patients, which is especially key for initial financial assistance assessment. In response to communication deficits, financial navigators and supportive care staff developed new processes. They created information packets on benefits and resources for patients to collect when they attended the hospital or clinic, combined with a follow-up phone call. To improve patient access, some staff connected their cell phones to a hospital-wide app, which identified callers as the oncology clinic versus a personal cell phone user. This approach increased patient response to calls from financial navigation and supportive care staff.

Though the volume of patient financial needs increased in 2020, access to financial and other supportive care resources decreased. Many patients with cancer experienced economic hardships in 2020. Accordingly, financial navigators noticed an

uptick in patients asking about care costs prior to even scheduling a clinical consult.

Patients' financial situations are now more complex or precarious than pre-COVID-19. For example, unemployed patients are having to make decisions between COBRA or purchasing health insurance on state exchanges. Cancer program staff are also reporting seeing more patients struggling with food insecurity. Underserved and non-English-speaking populations had less access to COVID-related information, which was often only available in English.

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### **Elevated Personal Stress**

Across the board, personal stress levels increased dramatically in all members of the cancer care team—clinical and non-clinical. By the end of 2020, staff exhaustion had reached a zenith. The terms most frequently used by focus group participants to describe the toll of COVID-19 were “burnout,” “exhaustion,” “fatigue,” and “stress.” In addition to increased workloads, cancer program staff had their own personal health concerns to contend with, as well as home responsibilities, such as school-age children participating in virtual learning.

Institutional support for remote work varied and was mostly used for service line leadership and supportive care staff. These staff experienced considerable uncertainty around work schedules and acutely felt the push-pull nature of moving on- and off-site at different points over the year in response to infection rates. This uncertainty demanded significant personal flexibility and a forward-thinking mindset to ensure that cancer program staff were prepared to meet patient needs.

One Financial Advocacy Network Advisory Committee member said this about the ongoing uncertainty, “Am I going to work? Am I not? Do I have everything I need at home? Do I have enough stamps and envelopes so that at least I can mail resources?”

Institutional strategies to address the impact of low patient volume and reduced procedures on revenue also had direct financial consequences for cancer program staff. Many programs, or the health systems of which they are part, established revenue-protecting strategies that included:

- Placing holds on 2021 merit raises, 403(b) contributions, or IRA matches.
- Staff furloughs.

- Workforce reductions of five to ten percent (as reported by focus group participants).
- Flexing staff to patient volume, productivity levels, or remote work.
- Reducing or eliminating personal time off.

### **New Ways to Inform and Support Staff**

Service line leaders often stepped in to respond to inconsistent COVID-19-related information, especially at the beginning of the pandemic. The absence of widely shared science in a rapidly evolving situation created an information vacuum all too often filled by mixed messages and misinformation. To combat mounting staff anxiety, service line leaders initiated their own communication processes to keep staff informed and up to date; for example, virtual COVID-19 huddles and team-specific Facebook pages.

As the pandemic evolved, service line leaders also developed a heightened awareness of the potential for staff burnout. They sought ways to provide emotional support to mitigate the loss of social contact that resulted from remote work or redeployment policies and the frustration around reduced remuneration (see Figure 1, page 42). But providing support for staff also took a toll on leadership morale and energy and became increasingly challenging in the context of dwindling public recognition of health professionals and loss of pay and/or vacation time.

### **Safety-Related Operational Changes**

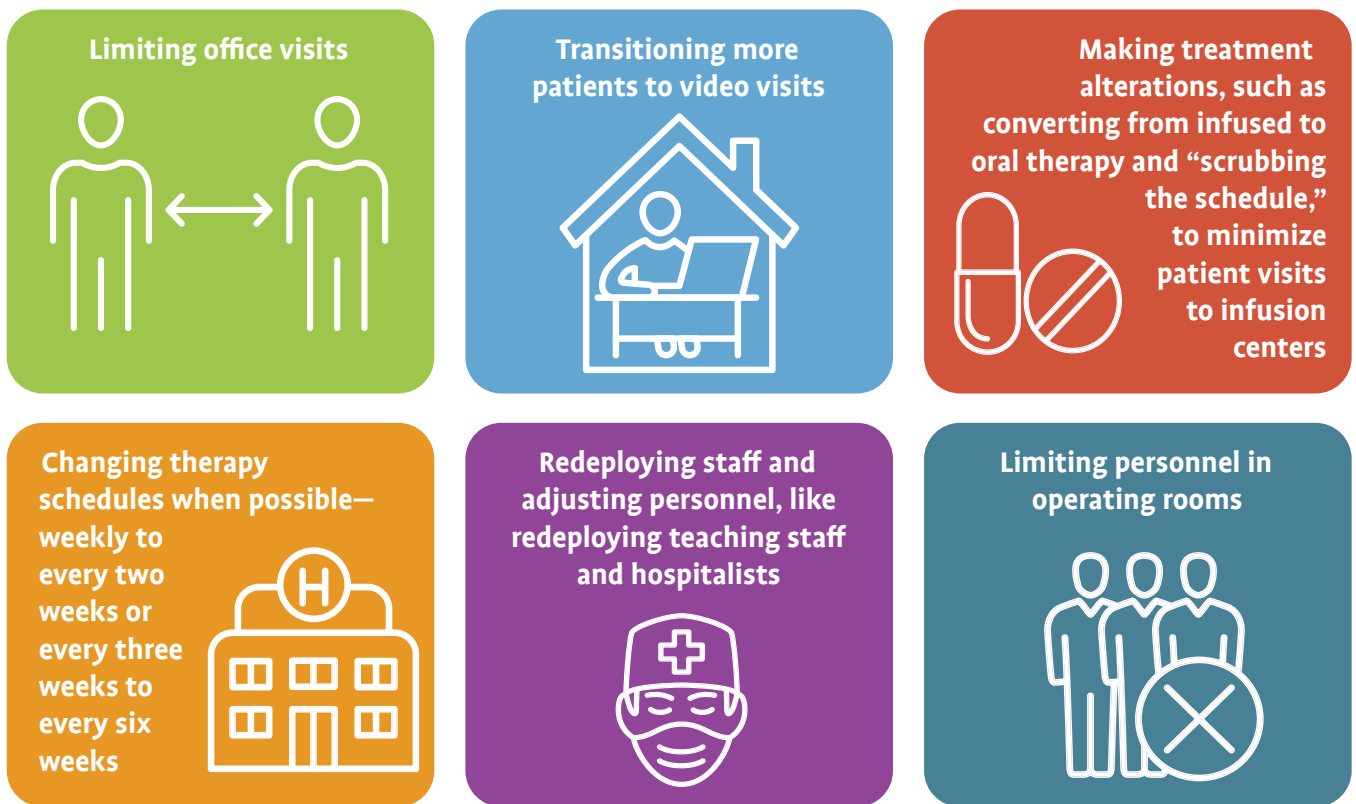
Cancer programs and practices devised operational changes to expedite cancer treatment and minimize risk of exposure to coronavirus for patients and staff, many of which continue (see Figure 2, right). These changes included transitioning more patients to video visits or changing therapy schedules when possible (e.g., from weekly to every two weeks or from every three weeks to every six weeks). As one member of the President's Theme Task Force reflected, these changes amounted to an “endless list of disruptions.”

Patients and their families were affected by safety protocols set in place to reduce the risk for COVID-19 exposure. Inpatients were restricted from having visitors and many were scared and alone and lacked personal advocates or support systems. In turn, family members experienced increased anxiety because they were unable to be with their loved ones in hospital and worried that they might not be contacted in a timely manner if their loved one's condition changed.

### **Pharmacy Operational Changes**

Some operational changes were extensive, especially in the oncology pharmacy setting. For instance, new protocols were necessary to ensure cleanroom compliance with certain compounding mandates (e.g., USP 797 and 800) in a context of diminishing supplies (e.g., gowns, masks) and budgetary constraints. Some oncology pharmacy service lines also created new safety protocols for staff working on-site to address emergent needs (e.g., drug shipments) and established formal expectations about home office setup for offsite employees (e.g., having a shredder, a secure location, adequate Internet speed) to ensure compliance with the Health Insurance Portability and Accountability Act and to protect sensitive data.

Figure 2. COVID-19 Safety-Related Operational Changes Made by Cancer Programs



### COVID-19-Related Operational Changes

COVID-19 testing is required for oncology patients prior to beginning chemotherapy. Cancer programs and practices are using text messaging, automated screening and tracking, or phone calls from physician assistants or registered nurses to identify whether patients have been exposed to coronavirus or have COVID-19 symptoms prior to treatment or clinic appointments. Oncology patients who test positive for COVID-19 are treated in separate units or isolated in the infusion center—placing additional demand on already strained space, time, and staffing resources. An additional challenge is that many cancer or treatment-related symptoms (e.g., fever, diarrhea, shortness of breath, cough) overlap with COVID-19 symptoms. Some cancer programs and practices have instituted secondary screening by the infusion provider and testing for patients with new or worsening symptoms. This additional layer of testing further delays initiation of cancer treatment.



### Service Line Delivery and Revenue Optimization

Patient volume and revenue fluctuated according to pandemic surges. In March and April, many cancer programs and practices experienced reductions in patient volume and revenue. Elective surgeries were delayed because intensive care unit beds were required for COVID-19 patients and additional space was also required for transfusions. Cancer screening volume decreased because either screening sites closed down or primary care providers stopped offering screening to their patients. At the same time, patients avoided regular physical exams, which reduced the potential for incidental findings. Some health systems suspended outpatient scheduled appointments and entire service lines. Oncology inpatient volume also dipped for some

cancer programs, as one member of the Education Committee noted: “I had an average daily census of five to six patients from about the end of March until the first of August. And I could not meet productivity, of course, because I didn’t have any patients.”

These reductions in overall patient volume and procedures adversely impacted health system revenue and contributed to significant financial losses for cancer programs and practices.<sup>1</sup> One focus group participant noted a \$128 million loss for their cancer program in the first COVID-19 surge when elective surgeries were stopped. The staffing required for COVID-19 screening has also increased the overall costs of providing care. Screening is a highly paid activity with no associated revenue, the cost for personal protective equipment remains high, and the steps involved in operationalizing safety protocols require time and reduce efficiency.

### **Cancer Service Lines Shored Up Health System Revenue**

Cancer programs and practices shored up health system revenues diminished by reduction in other service lines, as one Education Committee member described, “As far as oncology care went, chemo infusions, radiation treatments, there was really no drop in volume in March, April, or May. In some ways we were holding up the health system a little bit financially.” Another Education Committee member shared, “We have our own specialty pharmacy. We also have home infusion services. And revenue has gone up about 40 percent in both of those areas.”

Although government assistance (e.g., Paycheck Protection Programs) helped defray revenue losses, some cancer programs and practices adjusted their approaches to managing accounts receivable. Financial navigators became even more vital to the process of maintaining the integrity of revenue cycles through effective communication with patients about the availability of financial assistance resources.

As one Financial Advocacy Network Advisory Committee member said, “I noticed our revenue business office zeroing in more on the money...looking for payment...coming back and asking us [about payments] where before they would be more lenient to adjustments. I feel like the revenue department itself is more conscious of asking, ‘Are we getting every dollar from the insurance?’”



### **Telehealth and Supportive Technology**

Though telehealth use in oncology surged in 2020, some cancer programs and practices were better prepared to accelerate than others. Sites with access to existing telehealth infrastructure or a “strategic roadmap” for telehealth experienced more rapid implementation and moved “from 0 to 60”

in a short timeframe. As one member of the President’s Theme Task Force said, “We had a telemedicine platform, and we had a handful of people who knew how to use it. We were able to pivot in a minute. We went from doing zero percent telemedicine visits to 46 percent in less than a month.”

Cancer programs and practices that were able to accelerate their use of telehealth during the first COVID-19 surge were supported by some or all these infrastructural components:

- Telehealth platforms embedded in workflows.
- Visit types integrated in electronic health records.
- Organizational commitment to telehealth.
- Dedicated telehealth staff and/or clinical information liaisons.
- Information technology support.
- Prior education and training for providers and non-clinical staff.
- Robust patient accounts and scheduling teams able to integrate virtual and real-time visits and support patients with technical questions.
- Patient education, training, and real-time troubleshooting on technology requirements and use.

Yet telehealth expansion was not linear but fluctuated with COVID-19 surges. The first surge saw rapid expansion. In the summer, however, there was less urgency to keep patients and personnel out of clinics and hospitals, and telehealth use receded. By July or August, many cancer programs and practices had established protocols and processes for mitigating infection and acquired personal protective equipment that was largely absent at the beginning of the pandemic, so people felt more comfortable being physically in clinic space. The second surge in the fall ramped up telehealth again for many programs, with telehealth accounting for about 40 to 50 percent of patient visits.

### **Barriers to Telehealth Implementation**

Initially, lack of coding for reimbursement was a major impediment to oncology telehealth expansion. Congress acted quickly to ensure compensation for most virtual visits, and the Centers for Medicare & Medicaid Services changed regulations concerning reimbursement and other requirements.<sup>2</sup> These flexibilities eased the adoption of telehealth. Nonetheless, rapid telehealth expansion demanded a concentrated learning curve from staff to design protocols “on the fly,” often in circumstances of decreasing staff numbers and little guidance about telehealth platforms.

“You felt like you were just thrown in the deep end and you had to learn to swim. I don’t think many of us had something readily available at our fingertips to identify the best way to optimize telemedicine,” shared one Education Committee member.

Cancer programs and practices had to contend with multiple other implementation barriers, such as the lack of information technology (IT) staff to provide technical support on how to use “off-the-shelf” telehealth platforms (e.g., Doximity, WebEx). Clinician comfort with telehealth varied, too, as one President’s Theme Task Force member noted: “Sometimes it’s the faculty members who have been around for a long time who have more of a problem utilizing the telehealth equipment.” Access to telehealth equipment among cancer program staff was also patchy, as another President’s Theme Task Force member shared: “I don’t have a camera in my office. I had to go and purchase one. I can use my laptop, but then the laptop doesn’t connect with the

electronic health record. There's still ongoing issues that need to be addressed.”

Other providers had reservations about using telehealth. They preferred real-time, face-to-face interactions and physical contact with patients and were surprised to find that telehealth brought them closer to patients. Some providers came to view masks as a barrier to social and emotional connection and found that virtual communication allowed them to see a patient's face, which felt more connected and intimate. “I liked the video visits because we could interact with patients without wearing a mask. Wearing a mask puts distance between us and the patient and diminishes the connection. I have patients who have never seen my face because they were new patients to me during COVID-19,” shared one Education Committee member.



### Clinical Research

COVID-19 significantly impacted cancer research. Although there was a dip in approvals for clinical trials in the March-April time frame that rebounded somewhat in the summer,<sup>3</sup> many clinical trial programs suspended studies and shifted research staff to work from home in 2020. Ongoing clinical research was affected in multiple ways. Deviation filings were common due to delays in blood tests, imaging, treatment, or the need to use telehealth versus in-person visits. Patient transportation and challenges in taking time away from work also remained significant barriers for clinical trial enrollment.

Many research programs adapted to these disruptions in response to recommendations from national regulatory authorities. The following flexibilities that emerged in 2020 offer potential as standard of care in future clinical trials:

- Decentralizing care based on U.S. Food and Drug Administration guidance.
- Clarifying protocol-required essential tests.
- Amending studies to lengthen testing intervals.
- Using telehealth for clinical assessment and patient-reported symptom collection.
- Leveraging biometric devices to support patient evaluation (e.g., sleep, movement) and mapping them to Eastern Oncology Cooperative Group Performance Status.
- Shipping oral anti-cancer drugs directly to select patients from specialty pharmacies and allowing pharmacy professionals to practice medication therapy management via telehealth.

Other emergent flexibilities have potential to reduce patient burden in clinical trial participation and increase trial retention rates, such as remote consent and trial eligibility screening and using telehealth to reduce time and travel burden for patients and the frequency of in-person visits. Involving patients upfront and early in clinical trial design could also enhance health equity and reduce disparities in participation. A wider conversation is already occurring within the oncology community about “future-proofing” cancer clinical research and clinical trials in general.<sup>4,5</sup>



### Health Equity

The pandemic exacerbated existing access disparities along socio-economic, racial, ethnic, age, gender, and geographic fault lines.<sup>6</sup>

### Telehealth Use

Access to telehealth has been especially challenging for patients in rural or impoverished areas, as well as for people of color, who are more likely than urban or White patients to lack cell phone minutes, cell phone service, connectivity, and/or privacy. Hispanic, non-Hispanic Black, and Asian people and people over 65 years are also less likely to use email or engage in telehealth activities.<sup>7</sup> Patients on Medicare struggled more with technology access than younger patients. These patients tended to want to be on-site for clinical exams and were therefore more at risk from potential COVID-19 exposure. In contrast, younger patients were more likely to use telehealth, be impacted financially through unemployment or economic changes, and more in need of financial assistance.

### Cancer Outcomes

COVID-19 will likely exacerbate racial, ethnic, and socio-economic disparities in cancer outcomes, although the overall impact on new cancer diagnoses has yet to be calculated for 2020. One focus group participant noted a 50 percent reduction in new breast cancer diagnoses for their cancer program in the second quarter and a 20 percent reduction for new breast cancers in 2020 overall. This pattern of a short-term dip in incidence followed by an uptick in advanced stage disease and increased mortality will likely be widespread.<sup>8</sup>

### Transportation

Transportation support provided by the American Cancer Society and other organizations virtually disappeared due to COVID-19 restrictions. Rural communities, states with no Medicaid expansion, and underserved populations suffered especially from transportation barriers to care. Many cancer programs and practices devised alternative strategies to meet the shortfall such as gas cards or liaising with family members to provide transportation for patients. On page 30 of this issue, learn how a virtual rideshare hub developed by an ACCC member program is improving patient access and eliminating disparities.

### Strategies to Support Underserved Populations

The pandemic has shown that moving forward, cancer programs and practices must be more conscious of the role that social determinants of health play in patient access to oncology care. Strategies to pre-emptively address health inequities in access to oncology care and alleviate patient burden include:

- Creative clinic and treatment scheduling for employed patients and family members.
- Transportation support for treatment and clinical trial participation; for example, gas and public transportation vouchers and rideshare partnerships.



- Counseling and social work to address financial need, as well as additional support to address food insecurity, childcare needs, and other home support.
- Wider adoption of telehealth services.
- Partnering with community organizations to connect with and reach at-risk patient populations.
- Use of lay navigators from communities who represent the racial, ethnic, cultural, and linguistic patient populations they serve. This will support appropriate messaging and gain stakeholder buy-in for population health navigation programs.

One focus group participant suggested that comprehensive cancer centers that are renewing their National Cancer Institute designation should include engagement and community outreach in their renewal application as a foundation to address disparities and access to care.

Although cancer incidence and mortality overall are declining in the United States, certain underserved patient populations continue to be disproportionately impacted by certain cancers. The oncology community, including organizations like ACCC and the American Society of Clinical Oncology, have pledged to identify opportunities and develop programs to ensure equitable access and quality cancer care for *all* patients—regardless of race, ethnicity, age, gender identity, socio-economic status, sexual orientation, and/or geographic region.

In this edition of *Oncology Issues*, 2021-2022 ACCC President Krista Nelson, MSW, LCSW, OSW-C, FAOSW, announced her President's Theme: "Real-World Lessons from COVID-19: Driving Oncology Care Forward." One of the key lessons learned is that health equity and social justice are critical drivers of quality cancer care delivery. In this issue, ACCC shines a spotlight on two pioneering cancer programs, the Center for Indigenous Cancer

Research at Roswell Park Comprehensive Cancer Center (pages 18-24) and Cone Health Cancer Care (pages 30-39), and breast cancer advocate Reverend Tammie Denyse (pages 14-17) and the work they are doing to improve health equity and empower patients with cancer. **OI**

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The **Association of Community Cancer Centers (ACCC)** is the leading education and advocacy organization for the cancer care community. Founded in 1974, ACCC is a powerful network of 28,000 multidisciplinary practitioners from 2,100 hospitals and practices nationwide. As advances in cancer screening and diagnosis, treatment options, and care delivery models continue to evolve—so has ACCC—adapting its resources to meet the changing needs of the entire oncology care team. For more information, visit [acc-cancer.org](https://acc-cancer.org) or call 301.984.9496. Follow us on Facebook, Twitter, and LinkedIn; read our blog, ACCCBuzz; and tune in to our podcast, CANCER BUZZ.

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