

## EXECUTIVE SUMMARY

### Program Background

The burden of cancer is far greater than the diagnosis of a single tumor. When patients receive a cancer diagnosis, every facet of their life—physical, mental, emotional, social, financial—is impacted and without appropriate psychosocial support, that burden can be extremely heavy. While psychosocial distress screening is mandated in cancer programs by the American College of Surgeons Commission on Cancer,<sup>1</sup> service delivery models vary and are largely dependent on the availability of staffing and funding. Furthermore, in the post-COVID-19 healthcare landscape, the need for psychosocial care in oncology has transcended the needs of patients and their families, as supportive care to address emotional distress and burnout is urgently needed for cancer care professionals.

To explore the current state of oncology supportive care, the Association of Community Cancer Centers (ACCC)—with its partners, the Association of Oncology Social Work (AOSW), the American Psychosocial Oncology Society (APOS) and with support from BeiGene—held a multistakeholder meeting, *A Call to Action: Delivery of Psychosocial Care in Oncology Summit*, on March 8, 2023, in Washington, DC. Invitations were extended to key leadership representatives of advocacy organizations, academic medical centers, and community care programs. Its aim was to develop priorities and actions to address barriers to access and delivery of psychosocial care in oncology.

Summit goals included:

- Providing a forum for healthcare leaders, cancer care team members, and patient advocates to discuss the current state of mental health in oncology
- Building a collaborative dialogue amongst interested stakeholders to identify action plans that address ongoing mental health issues for patients, caregivers, and cancer care professionals
- Identifying effective screening tools, training, resources, and policies to address psychological distress in patients, caregivers, and cancer care professionals

- Identifying barriers to providing and accessing timely and appropriate care for patients and caregivers experiencing psychological distress
- Promoting strategies to foster resilience and a health-care culture that mitigates burnout among all members of the cancer care team.

The following executive summary highlights findings from the summit and will guide post-summit action planning efforts and the creation of enduring deliverables to support improvements to the psychosocial care in oncology landscape.

### About Psychosocial Care in Oncology

A cancer diagnosis is undeniably stressful. Patients experience fear, uncertainty, anger, sadness, and despair, and while many will recover, approximately 25 percent of survivors will have continued issues, such as anxiety, depression, and other psychological and social (psychosocial) stressors.<sup>2</sup> Moreover, in a 2022 survey conducted by Cancer Support Community as part of its Cancer Experience Registry, a research study that evaluated 600 cancer patients and survivors who self-identified as having experienced emotional or mental health concerns, 60 percent of respondents were not referred to a mental health professional by their cancer care team.<sup>3</sup> Untreated psychosocial distress can contribute to poorer treatment outcomes and a worsening of comorbidities, as well as lead to higher healthcare costs.

With the onset of the COVID-19 pandemic, existing psychosocial services became overburdened by the emotional and occupational distress experienced by providers caring for patients with cancer and helping patients and families make difficult treatment choices. During the height of the pandemic in 2021, 60 to 75 percent of clinicians reported symptoms of exhaustion, depression, sleep disorders, and post-traumatic stress disorder, and approximately 20 percent of healthcare workers quit, resulting in staffing shortages nationwide.<sup>4</sup> Existing disparities in access to services for underserved populations also worsened during this period.

In 2019, ACCC surveyed its membership to assess the level of burnout across multidisciplinary cancer care teams utilizing the American Medical Association’s clinically validated Mini Z survey; the results revealed high levels of dissatisfaction and occupational stress—pre-COVID. ACCC repeated this survey in 2022; physicians, advanced practice providers, and nurses were found to be the disciplines most at-risk. Today, cancer care providers across the multidisciplinary spectrum continue to experience record high levels of burnout, due to increasingly complex treatment options, a rapidly increasing aging population, growing financial toxicity, and an overstrained healthcare system. Social workers, who have been on the front lines of the public and mental health crisis during and post-COVID-19, continue to suffer as they struggle to support patients with job losses, housing issues, food insecurities, and other critical challenges.

Psychosocial care can be instrumental in alleviating the burden of stress not only for patients, but for the care teams that play a critical role supporting patients and their families. Psychosocial care focuses on the whole-person in addressing any social, psychological, emotional, spiritual, and functional aspects of care.<sup>5</sup> By identifying and promoting

effective distress screening tools and resources, as well as developing strategies that promote a healthcare culture of resilience, patients, caregivers, and cancer care teams can be better prepared to face the daily challenges of cancer.

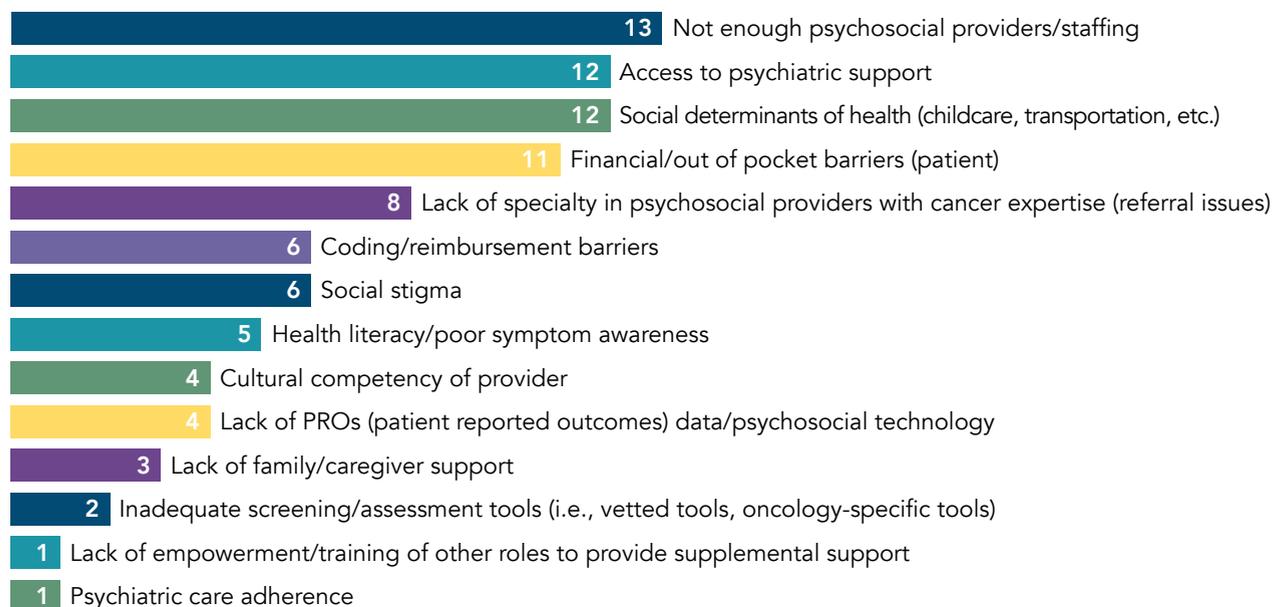
### Pre-Summit Survey

Summit participants were asked to complete a brief, pre-summit survey to provide a snapshot of the current challenges and barriers to access and delivery of psychosocial care in oncology. All participants responded to the survey (n=18). The survey explored what practices/service models have been effective, and asked respondents to identify and rank the top barriers to accessing support. Participants were also asked to consider and share feedback on what organizations, such as ACCC, AOSW, and APOS could do to advance diversity, equity, inclusion, and access in psychosocial care.

Roles represented included licensed clinical social workers (LCSWs), licensed independent clinical social workers (LICSWs), clinical psychologists, board of oncology certified social workers, nurses, advanced practice providers (APPs), and one physician.

**Figure 1. Pre-Summit Survey: Top Barriers to Access and Delivery of Psychosocial Care (n=18)**

(Participants selected their top 5 barriers.)



**Other barriers included:** poor utilization of screening tools, hierarchy of need (they present with other significant needs that their psychological distress is not often high on the scale and cannot be addressed until the others are), and poor screening adherence.

Of the participants, the majority (72 percent) identified the lack of psychosocial providers/staffing as the most critical barrier to care. Social determinants of health (e.g., child-care, transportation, internet access), access to psychiatric support, and financial and out-of-pocket barriers were also identified by participants (approximately 60 percent) as major hurdles, among numerous other barriers (see Figure 1).

## Strategies That Work

Raising awareness about psychosocial services, incorporating community health workers, and utilizing technology were among the strategies and service models that participants were most proud of. In one cancer program, oncology psychology services are introduced during meet and greet sessions with physician and clinical team members during their onboarding week. Another cancer program raises awareness among oncology providers about clinical social work training and skills set, which has enabled LCSWs to practice at the top of their license.

Utilizing telehealth, one cancer program has been successfully conducting telehealth therapy groups for the last three years. Some cancer programs have integrated distress screening within their electronic health record (EHR) systems and others utilize private messaging through the EHR to communicate and consult on patients' needs.

Another important strategy to expand access has been collaboration with community health workers. Several cancer programs are incorporating community health workers to address the need for adequate staffing, which has proven helpful, and in one program, has even served to increase the diversity of its team.

## Key Challenges

The obstacles and barriers current cancer programs face are numerous. Funding and under-staffing topped the list, as nearly all participants highlighted challenges surrounding adequate financial and leadership support to ensure psychosocial programs are equipped with the necessary staff and funds needed for operations. As a result, LCSWs are often asked to take on additional roles and functions that limit their ability to work at the top of their license and contribute to role strain and burnout. Logistics around distress screening is also compounded by these challenges, as screening workflows are difficult to maintain due to frequent staff turnover and space limitations.

Lack of understanding and awareness of the scope and functions of psychosocial services among hospital administration was also reported as a key barrier. Often seen as extensions of outpatient behavioral therapy, psychotherapists, and/or care managers have presented challenges related to clinical expectations and billing and/or reimbursement issues.

The pre-summit survey also explored the greater challenge of advancing diversity, equity, inclusion, and access in psychosocial care, which was later identified as one of the key priorities for discussion during the summit. **Opportunities and suggestions shared by survey participants were numerous, and included:**

- Forging partnerships with communities and advisory groups to target outreach programming for communities
- Identifying funding to support specialty training and creating scholarships for Black, Indigenous, and People of Color (BIPOC)/people from diverse backgrounds to pursue the field of oncology
- Increasing advocacy, public policy work, and changing the national conversation around psychosocial care, cultural humility, and other diversity, equity, and inclusion topics
- Integrating cultural humility and competence in patient care and interdisciplinary team communication and collaboration
- Acknowledging the ways (direct and indirect) that structural racism, implicit bias, and other inequities continue to impact care
- Increasing equity, diversity, and inclusion training for providers, integrating cultural humility and competence in patient care, increasing diversity of staff, and advocating for diverse and inclusive leadership
- Advocating for healthcare payment models that include psychosocial care and clinical social work
- Supporting research dedicated to assessing social determinants of health, as well as evidenced-based interventions appropriate for minority groups.

## Summit Highlights

The summit included a general session, two 30-minute breakout sessions, and a call-to-action wrap-up. The framework was designed to utilize experts to develop priorities and potential actions while onsite, then use these recommendations as a catalyst for a greater, national discussion over the coming months. Prior to the summit, participants were provided with a series of pre-read materials and resources (see box on last page) to supplement the discussion. A visual recorder was also provided onsite to capture the ideas and strategies voiced during the summit.

To open the dialogue, participants were asked to share their vision for psychosocial care in a perfect world. Overarching themes that emerged were a call to change the national conversation around psychosocial care and to build awareness among providers, hospital leadership, and administrators on what psychosocial care means and the impact it can make when fully funded and integrated. There was also a resounding call for increased diversity, equity, and inclusion in psychosocial care staffing, as well as ensuring greater access to care for underserved populations.

**Eucharía Borden, MSW, LCSW, OSW-C, FAOSW**, and vice president of Programs and Health Equity at Family Reach, stated, **"It's time to change the national conversation. We need a movement—it should not take a tragedy to get action."**

**Kauser Ahmed, PhD**, and director of Psychosocial Care at the University of California Los Angeles-Simms Mann Center added, **"In my ideal world, administrators would recognize psychosocial care as necessary and valued in the same way physicians and nurses are viewed, moving [psychosocial care] out of the realm of charity and into necessity."**

Following a high-level discussion of the current state of care, participants were divided into four groups to explore the following barriers (selected as key priorities based on survey results) during the first breakout session:

- Social determinants of health (e.g., transportation, childcare, internet access)
- Financial barriers and/or out of pocket expenses for patients
- Lack of psycho-oncology specialists

- Cultural competency; diversity, equity, inclusion, and access.

Groups were instructed to brainstorm and develop actionable solutions related to their designated barrier and rate these solutions in terms of impact and level of difficulty to implement. Groups were then asked to select the top three actionable ideas to share during their report-out to the general session.

Key action ideas that emerged included:

### Group 1. Social Determinants of Health

- Partner across organizations to access and/or obtain federal funds (underutilized funds)
- Collaborate on research; influence = policy change
- Ensure all patients have adequate Internet access so that they can receive telemedicine
- Address transportation needs
- Provide psychosocial support that is proactive vs. reactive (for example, distress screening catches issues reactively)
- Share best practices across multiple platforms, like webinars and podcasts
- Standardize licensure to have reciprocity across the U.S.
- Work with standard setting organizations to improve equity and access; lobby Medicare.

### Group 2. Financial Barriers

- Provide more cost transparency to patients; track and address indirect costs
- Engage policymakers to address inconsistent insurance coverage from state to state and lack of knowledge on how other states are handling coverage
- Measure health-related outcomes; high impact but difficult to find quantitative measurements for qualitative metrics.

### Group 3. Lack of Psycho-Oncology Specialists

- Advocate for national supervision hours
- Develop additional training opportunities
- Create short-term national programs

- Launch a marketing campaign to educate people about these professions
- Institute a national licensure, rather than a state licensure, to allow professionals to work across state lines.

#### **Group 4. Cultural Competency, Diversity, Equity, Inclusion, and Access**

- Build advocacy/policy training and methods/skills training into the curriculum across disciplines (R25 Sim Lab could be a pathway)
- Utilize professional societies and accrediting bodies to support/influence changes to the curriculum
- Train early and often—take a proactive approach, rather than reacting when psychosocial practitioners are already in the role
- Change the national conversation through macro efforts like Cancer Moonshot and the state of education across various professions
- Develop a structure to hold organizations and providers accountable for diversity, equity, and inclusion in the workplace.

#### **During the second breakout session, participants were divided into three action groups:**

- Screening tools (e.g., use of technology, telemedicine, PROs)
- Delivery models, reimbursement, and billing and coding
- Provider and healthcare team burnout.

Groups used this breakout session to develop actionable ideas related to the question, “What could our associations produce that would address [the designated barrier] that would have an impact on institutions, policies, or providers?” Again, groups were instructed to rate actionable ideas in terms of impact and level of difficulty to implement. Groups were then asked to select the top three action ideas to share during their report-out to the general session.

Key themes that emerged included:

#### **Group 1. Screening Tools**

- Create screening goals: organizations can work together to do research on why, when, how, and where screening should be done
- Further develop standards for policies and procedures for screenings
- Develop guidelines for responding to screenings.

#### **Group 2. Delivery Models**

- Unify organizations to promote collaborative care and integrated behavioral health models
- Conduct training to help providers be more engaged in psychosocial care
- Create a playbook with education around billing codes for psychosocial staff so that administrators have more transparency on costs and financial implications of psychosocial care.

#### **Group 3: Provider and Healthcare Team Burnout**

- Develop clearinghouse of best practices to reduce burnout
- Evaluate and adjust staffing to meet current needs; end practice of pulling staff to support teams, roles, and/or tasks outside of scope
- Educate administrators to develop national standard on culture of care for providers—not just patients
- Advocate self-care for providers (e.g., proposed model one-third individual’s responsibility and two-thirds the organization’s responsibility to provide time and opportunities to practice self-care)
- Develop leadership ladders for social workers in psychosocial care (i.e., social workers need to be supervised by social workers rather than nurses, administrators, or psychologists)
- Speak shared language around whole person care and delineate roles so patients understand each providers’ role in care
- Utilize tumor boards to as an opportunity to develop care plan for the whole patient—not just the tumor
- Leverage artificial intelligence to support charting.

## Call to Action

Following the breakout sessions, participants reconvened to view the results of their work: 21 actionable ideas that spanned the top challenges of access and delivery of psychosocial care in oncology. While these ideas will lay the groundwork for future planning of education and advocacy initiatives, as a group, summit participants voted and selected the following top two priorities to develop into an immediate call-to-action: **promote collaborative care and integrative models** and **develop standards for a culture of care**.

### Promote Collaborative Care and Integrative Models

Summit participants identified several initial steps that could be taken immediately to create a sense of urgency and bring attention to this need. These included issuing a joint statement by ACCC, AOSW, and APOS calling for a collaborative care model, as well as holding additional workshops and webinars (or partnering in upcoming ACCC/AOSW/APOS conferences) to target oncologists and additional medical associations to raise awareness of this need.

Identified next steps included: defining and developing the model, ensuring that the model considers the needs across all settings (e.g., rural areas, community hospitals caring for underserved populations, etc.); educating organizations and providers about the model; and developing a group of early adopters to implement the model once developed. Participants also discussed creation of an administrator engagement roadmap, recruiting the involvement of other relevant associations (e.g., American Society of Clinical Oncology, Association of Cancer Executives, patient advocacy organizations, and others) or the creation of a new consortium or alliance to guide the initiative.

The impact of the collaborative care model initiative would serve to ensure oncology patients and providers receive the appropriate psychosocial care they need, address current logistical and operational challenges with an effective model, and reduce role strain and staff burnout.

### Develop Standards for a Culture of Care

To create an effective action plan for developing standards to create a culture of care and reduce staff burnout,

participants agreed on the need to identify current best practices among cancer programs.

Suggested steps included:

- Acknowledging and broadening a greater understanding of toxicities
- Normalizing healthcare professionals seeking mental health care (e.g., virtual fireside chats modeling vulnerability, creating safety in conversations)
- Connecting patient satisfaction to provider well-being
- Including self-advocacy skills in curriculums across all disciplines
- Developing proposed reporting requirements
- Removing current licensure requirements to disclose mental health issues.

Discussions also included the need to involve multiple professional oncology associations, organizations focused on mental health and wellness, and medical schools and universities.

The impact of this initiative would create healthier staff, which in turn would reduce staff burnout and promote staff retention; it would also produce happier patients. This important work would also reduce the stigma associated with mental health in healthcare workers.

### Path Forward

This summit marks the start of a movement to create real change in psychosocial care delivery in oncology. To continue the momentum post-summit, ACCC shall disseminate a series of high-level, relevant resources to the ACCC membership and the broader oncology community across multiple platforms with the aim of beginning a national conversation on this important issue. The path forward is clear, and the improvements needed are many; however, with partnerships and collaboration with key stakeholders, the goals and actions outlined in this summary are within reach.

A publication from the ACCC education program, "Delivery of Psychosocial Care in Oncology." Learn more at [acc-cancer.org/Psychosocial-Care](http://acc-cancer.org/Psychosocial-Care).

## Acknowledgements

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## Pre-Read Resources

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Association of Community Cancer Centers



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 more than 30,000 multidisciplinary practitioners from over 2,000 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 [accc-cancer.org](https://www.accc-cancer.org). Follow us on social media; read our blog, **ACCCBuzz**; tune in to our **CANCER BUZZ podcast**; and view our **CANCER BUZZ TV channel**.

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