

FINANCIAL ADVOCACY NETWORK

ACCC 2021 Financial Advocacy Network Summit

What's Ahead

The Association of Community Cancer Centers (ACCC) Financial Advocacy Summit is an annual opportunity for members to connect and discuss the current and critical issues impacting financial advocacy. The Summit was held virtually in September 2021. Over the course of three days and three 90-minute sessions, 43 financial advocacy stakeholders gathered to tackle key issues that were identified by the ACCC Financial Advocacy Network Advisory Committee and member feedback. Discussion topics were:

- Screening for risk of financial distress
- Advocating for equitable cancer care
- Scope of financial navigation and advocacy services.

Each session comprised a facilitated large group discussion and breakout sessions to tackle specific questions and garner member feedback. After each breakout session, the groups reconvened to recap their small-group discussions.

Attendance was by invitation only and limited to facilitate active conversation. Summit participants represented a wide range of settings, such as hospital, practice, and community-based organizations. Participants included administrators, financial navigators and counselors, social workers, pharmacists, and other advocates in specialized roles like registration, patient access, and billing compliance.

Aimee Hoch, LSW, a financial navigator at Grand View Health, Sellersville, Penn., introduced the first topic (Session 1, right) by sharing about the financial navigation program at her facility. She


Session 1. Screening for Risk of Financial Distress

Description: Traditionally, underserved patient populations face increased risk of financial distress. Financial distress screening is important to identify interventions that can mitigate or prevent financial toxicity for patients with cancer, but screening practices vary. During this session, participants discussed barriers to and effective practices for implementing financial distress screening.

Objectives: Gather feedback to inform an action plan between ACCC and its partners to improve or clarify financial distress screening implementation at member institutions.

framed distress screening as assessing the various sources of patients' financial burden to intervene where needed so that patients can participate in *all* aspects of their care.

Hoch identified common financial triggers of distress, including out-of-pocket expenses, missed work or inability to work, loss of income, building medical debt, and existing prior debt(s). She and many attendees agreed that patients' psychological responses to distress can include concern or stress about their wages, income, and how to pay for their expenses, which can result in the inability to fully participate in their cancer care, shared decision-making, appointments, and/or support groups.



Together, these issues can lead to coping behaviors that interfere with optimal treatment like skipping medical appointments, supportive care opportunities, or medication due to costs.

During the breakout sessions, participants discussed how screening for financial distress happens in their facilities, as well as which tools and skills work versus those that do not.

- **Who to screen?** It often is not possible to screen every patient and defining the right subset of patients to target is challenging. Some patients may not self-identify as needing financial help because they are embarrassed, overwhelmed, or do not realize that there is a problem with covering their treatment-related costs. Additionally, some patients may need assistance later in their care and not realize that help is available. If financial navigators rely on insurance coverage or other financial indicators to determine who is at high risk for financial distress, they may miss patients who could benefit from assistance. It helps to ensure that healthcare providers and clinic staff know how to refer patients to a financial navigator if a relevant concern is indicated.
- **When to screen?** When patients are overwhelmed about their finances, they cannot fully participate in their treatment planning. Screening patients early for financial distress helps them begin treatment in a better place mentally. Continuing to assess for distress periodically throughout treatment can help proactively identify issues when changes occur in patients' treatment plan, insurance coverage, disease status, etc.
- **How to screen?** Summit attendees identified a variety of methods, including use of the COST tool,¹ National Comprehensive Cancer Network Distress Thermometer,² and Patient Health Questionnaire (PHQ)-2³ and/or PHQ-9.⁴ Participants agreed that a mixture of these tools and strategies yield the best results.
- **Importance of building trust.** Regardless of one's screening processes, building relationships with patients makes it much easier to ask difficult questions, especially for underserved patients who may struggle with their own trust in the American healthcare system. Financial navigators should help patients understand that they are not alone in

facing financial concerns related to their anti-cancer treatment and how financial navigation services can help.

- **Importance of clear communication.** Helping patients understand their insurance benefits and estimated financial burden up front is an important early step in the cancer care continuum. If patients have insurance, they may assume that paying for their care will not be a problem. This is not always the case, especially if patients do not fully understand their insurance benefits. Clarity and education may also help patients feel more comfortable with asking for help from a financial navigator.

Areas of Focus

Participants agreed that they want better tools and processes for screening patients for financial distress, no matter their cancer program or practice size or location. While there are effective elements within existing tools, these tools need to be refined. Ideas include:

- Create one concise ACCC tool using the “best” parts of identified, existing distress screening tools.
- Develop screening checklists using identified risk factors for financial toxicity and weaving checklists into a screening tool.
- Identify three to four questions that could be asked of all patients to identify their level of risk for financial toxicity.
- Create or improve access to electronic health record tools that would allow financial navigators to be notified of new consults, denials or loss of insurance, and alerts of an overage for a pre-set outstanding balance threshold.

Next Steps

Based on the needs expressed by summit participants, the Financial Advocacy Network's Education Task Force will integrate the development of tools and resources to optimize financial distress screening into its 2022 priorities. Discussion input has also been integrated into the financial distress screening portion of ACCC's Financial Advocacy Services Guidelines revision (see Session 3. Scope of Financial Navigation Services).

Session 2. Advocating for Equitable Care

Description: Financial toxicity is often driven by social determinants of health, rising costs of care, longer treatment durations, and the current health insurance landscape. Financial navigators see firsthand how these issues impact patient care and play a critical role in mitigating financial hardship. Awareness, recognition, and promotion of the role of financial navigators must be central to any health system, commercial, agency, and/or government policy that promotes equitable, affordable cancer care. ACCC members and partners identified strategies to amplify the voices of financial navigators and the patients they serve.

Objectives: Discuss the importance of cancer care and the need for policy stakeholders to understand and value the role financial navigators play in advancing health equity. Identify opportunities to align with ACCC partners on policy initiatives and identify training, resources, and/or materials needed to support members' engagement in advocacy.

Rebecca Kirch, executive vice president of Policy and Programs at the National Patient Advocate Foundation, and Becky Shipp, principal at Becky Shipp Consulting, spoke on the current advocacy landscape. They explained that United States healthcare policy typically backburners financial and social needs to focus on disease-directed treatment. Further, the federal approach to care access and affordability has historically focused on insurance reform, which does not address challenges to accessing high-quality comprehensive benefits. One potential strategy to elevating the needs for financial navigation services is to integrate these programs into existing federally funded programs, such as the Temporary Assistance for Needy Families or Social Services Block Grant, as well as targeted case management. Political advocacy plays a critical role in expanding access to financial navigation services and Congress will not make necessary changes to these programs without being asked. The same goes for state and local leaders and policymakers. Financial navigators' experience and stories can be extremely influential in building support for greater access to financial navigation services in the policy arena.

Many summit participants had advocacy experience and shared what has worked for them to amplify the role and value of financial navigation at several levels.

Advocacy Strategies

Audience: Who needs to understand financial navigation's impact on health equity?

- Health system leadership
- Cancer program leadership and department chairs
- Care team members
- Local, state, and federal legislators and health agencies
- Policy makers

- Payers
- Manufacturers.

Advocating Internally

How to effect change within a facility or health system?

- Have patience and be prepared to keep pushing. The redundancy and repetitiveness of your message for supporting financial navigation is important when trying to reach your leadership.
- Data and patient stories are effective tools to get your message across.
- Identify and involve the right champions (e.g., physicians, leadership, etc.). These people can often vouch for why financial navigation is important to your patients and institution.
- Including the patient voice in your message can be effective. For example, Press Ganey results have strong influence and are often heard loudly by cancer program or practice leadership and decision makers.

Advocating Externally

How to effect change beyond your facility or health system?

- Engage in opportunities to write letters to your local and state representatives
- Sit on advisory committees for advocacy organizations
- Submit "letters to the editor" to healthcare- and oncology-specific journals/media
- Testify at hearings.

Areas of Focus

Participants are eager to engage in policy and advocacy conversations and activities. In the summit's registration survey, 60 percent of participants indicated that they are "very interested" and 20 percent indicated that they are "slightly interested" in engaging in these conversations and activities. During the summit session, participants identified resources that they need to feel confident in their advocacy efforts:

- An "Impact of Financial Navigation" one-pager with talking points
- Education on health equity (e.g., how to assess social determinants of health in the community)
- Templates for reporting impact data to cancer program or health system leadership
- Templates for letters or presentations that broadly define financial navigation, as well as details on related, more specific topics
- 101-style training for policy-related advocacy
- Coaching and mentoring by experienced financial navigators
- Written or video stories about the unmet need for financial navigation services in cancer care.

Next Steps

ACCC is developing resources to support advocacy efforts to ignite change at multiple levels. In addition to making the case for increased investment in financial navigation services at the facility level, these resources will support broader policy engagement at the federal and state levels by engaging in ACCC's annual Virtual Hill Day and connecting with the Oncology State Societies at ACCC.

Session 3. Scope of Financial Navigation Services

Description: Cancer programs and practices, researchers, and industry look to ACCC's Financial Advocacy Services Guidelines as a primary resource for defining the scope of financial navigation services and setting the how-to on shaping formal financial navigation programs. ACCC members and stakeholders discussed the scope of financial navigation services and shared the organization's launch of a consensus-based approach for updating its guidelines.

Objectives: Gather feedback and build alignment around goals for financial navigation services, as well as identify champions and individuals who are committed to supporting this effort.

The current ACCC Financial Advocacy Services Guidelines were published in 2018, but the role of financial navigators has changed dramatically since. Despite progress, the field is still struggling with consistency and clarity on terms and scope of practice. Lori Schneider, 2021 Chair of the Financial Advocacy Network and oncology operations manager at Green Bay Oncology, provided background about the development of the original guidelines. She then introduced ACCC's plan to revise these guidelines in 2022. During this session, participants discussed the goals of financial navigation and provided input on priorities to drive the guidelines revision process. Participants agreed that the revised guidelines must integrate the following guiding principles:

- Patient-centeredness and value
- Health equity
- The functions of financial navigation
- Competency measurements.

Goals of Financial Navigation

Revising the financial advocacy guidelines requires consensus on the goals of financial navigation. Participants agreed on the following goals:

- Relieve or reduce patient stress and financial burden associated with cancer care

- Help patients understand their insurance benefits, financial liability for cancer care, and available resources
- Improve access to care and ensure equitable care
- Increase patient adherence to treatment plans by removing barriers to participation in their care
- Help patients make insurance coverage decisions that align with their goals, including elevating financial navigators to be part of shared decision-making conversations. This way, financial toxicity is considered as a quality-of-life factor in care decisions when appropriate
- Advocate for policy change by payers, pharmaceutical manufacturers, and other state and federal stakeholders.

Core Functions and Competencies for Financial Navigators

Regardless of current inconsistencies in the names and titles of the staff who provide financial navigation services, participants identified a few key concepts and skills that a financial navigator should be able to do:

- Understand the services provided and the system in which financial navigation work is done
- Communicate with patients in basic, non-jargon terms
- Educate patients about their insurance benefits
- Understand key concepts (e.g., prior authorization, insurance regulations and optimization, revenue cycle)
- Consider how a variety of staff can work together to create support, from social workers and pharmacy staff to clinical (nurse) and non-clinical (lay) navigators. These staff can work collaboratively with financial navigators to meet the financial navigation program's goals.

Not every cancer program or practice has the capacity to offer comprehensive financial navigation services. Summit participants discussed the benefit of establishing different levels of financial navigation services for programs and practices that correspond to their already available services and that keep in mind their size, resources, and staff experience. By using levels like gold, silver, and bronze, a gold level program could mean offering a full suite of comprehensive financial navigation services to patients, whereas a bronze level program could mean offering a standard set of necessary services.

Certification

Participants discussed the potential value of creating a formal certification focused on financial navigation, which would help standardize the role and elevate the field. Certification is a complex process that can take time, so it is critical to fully consider the value a certification holds for financial navigators. Discussion also focused on how to ensure the right stakeholders and partners are involved in the creation of a certification program to minimize redundant efforts. For example, the American Society of Clinical Oncology has a new certification related to patient-centered care, but the American College of Surgeons Commission on Cancer

accreditation could also be a place to house financial navigation credentialing.

Areas of Focus

Additional resources and needs discussed during the summit session included developing the following:

- A facility-specific, simple introduction of financial navigation services, targeting other members of the healthcare team as well as patients to clarify the role and value of financial navigators and increase utilization. This includes introducing the financial navigators on staff that are available to help patients.
- Strategies to integrate the patient perspective into ACCC's Financial Advocacy Services Guidelines. This could come directly from patients or by partnering with foundations and organizations that work directly with patient groups.
- A financial estimate tool to help patients understand what their costs may be and that can be used by financial navigators and patients alike.
- Strategies to integrate identification of disparities or gaps to accessing these services.
- Metrics and tracking to measure and communicate impact, including how to show return on investment for financial navigation services. Consider additional values that are difficult to measure like the patient experience, patient stress level, and access to care.

Next Steps

The process of revising ACCC's Financial Advocacy Services Guidelines, including the integration of the guiding principles defined above, is already underway. ACCC is leading the guidelines update process via a consensus-building methodology

known as a Delphi panel. This process will allow ACCC to collect expert-based judgments and identify consensus on the guidelines where there is little to no available and established knowledge in oncology financial navigation services.⁵ A Guidelines Development Committee has already met, and the committee has established its Delphi panel of experts who will complete questionnaires to develop the guidelines content throughout 2022.

Closing Thoughts

The ACCC Financial Advocacy Network boasts an engaged membership of financial navigators who have already begun to move actions identified during the 2021 Financial Advocacy Summit forward through task force and committee work in the coming years. ●

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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 25,000 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 or call 301.984.9496. Follow us on Facebook, Twitter, and LinkedIn; read our blog, ACCCBuzz; and tune in to our podcast, CANCER BUZZ.

The **ACCC Financial Advocacy Network** is the leader in providing professional development training, tools, and resources to proactively integrate financial health into the cancer care continuum and improve patient access to care for a better quality of life.

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