

ASSOCIATION OF COMMUNITY  
CANCER CENTERS

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Financial Advocacy Network

# FINANCIAL ADVOCACY SERVICES GUIDELINES

*A framework for oncology  
financial advocacy programs*

# INTRODUCING THE ACCC FINANCIAL ADVOCACY SERVICES GUIDELINES.

**WELCOME!** Originally, there was no guidance or playbook for delivering financial advocacy services to patients with cancer, and many of us were paving the way in our own cancer program or practice by ourselves. Then, in 2018, the Association of Community Cancer Centers (ACCC) developed an initial set of Financial Advocacy Services Guidelines. While this was an important starting point, a lot has changed since.

When I started this work ten years ago, the role of the financial advocate in oncology did not exist at my cancer program. I had to both learn the role and create a program from scratch because there were no established guidelines, processes, or workflows. It was a reactive—not proactive—approach to cancer care. When patients had financial-related problems, my team and I would do our best to help, but we lacked a well-defined programmatic approach to addressing these patient needs.

Today, the term “financial advocate” can encompass many members of the cancer care team, such as financial counselors and navigators, oncology pharmacy staff, social workers, and more. Yet patients’ need for financial advocacy services throughout the cancer care continuum is becoming more urgent as both healthcare costs and coverage complexity increase. A 2019 Patient Advocate Foundation survey shows that 63 percent of patients facing a serious illness rank financial distress as a fate worse than death.<sup>1</sup> The financial cost of treatment is a top concern among patients in limited resource and underserved populations, and their families’ financial viability is an important goal of care.<sup>1</sup> As cancer care teams prioritize symptom and side effect management to improve outcomes for their patients, including treatment effectiveness and quality of life, financial hardship is increasingly being considered a toxicity that must be proactively managed.

While financial hardship disproportionately impacts people who experience existing disparities and negative social determinants of health,<sup>1</sup> ACCC and others recognize the critical role financial advocacy plays in advancing health equity. Just a few examples include the National Patient Advocate Foundation Health Needs Navigation campaign,<sup>1</sup> National Cancer Institute financial hardship supplements<sup>2</sup> and workshop,<sup>3</sup> and American Society of Clinical Oncology 2022 Quality Care Symposium abstracts<sup>4</sup> on emerging financial navigation implementation science research.

Research shows, as financial advocates see firsthand, how incredibly impactful—and effective—financial advocacy services are for patients. *All patients deserve the right to access these services.* How do we get there? Many of us have built financial advocacy programs in our cancer program or practice without the benefit of formal training, established standards, or documented processes, but the ACCC Guidelines are an important step toward changing that. While we know there’s much work ahead of us, *ACCC and its partners see the Financial Advocacy Services Guidelines as a foundational step to improving our patients’ ability to access these critical services and receive affordable, high-quality, and comprehensive cancer care.*

*Angie Santiago*

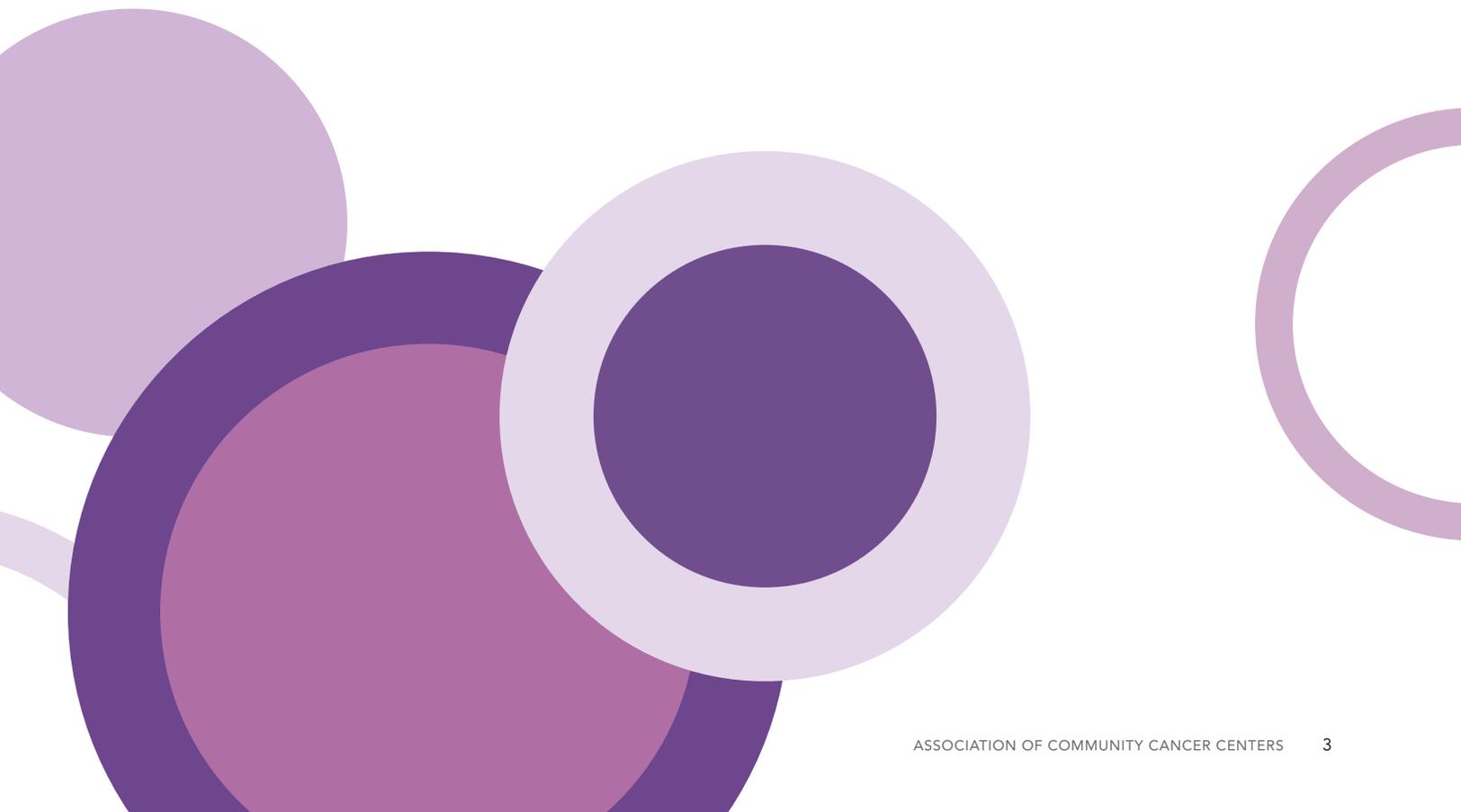
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# TABLE OF CONTENTS

<b>Background</b>	4
<b>Key Terms</b>	5
<b>Guidelines</b>	6
Domain 1: Financial advocacy services & functions	7
Domain 2: Program management functions	14
Domain 3: Partner engagement functions	18
<b>Call to Action</b>	19
<b>References</b>	20
<b>Acknowledgements</b>	24
<b>Appendix A</b>	28
<b>Appendix B</b>	34



# BACKGROUND

In 2018, the Association of Community Cancer Centers (ACCC) developed the Financial Advocacy Services Guidelines to support cancer programs and practices with proactively addressing patients' financial concerns along the cancer care continuum, so patients can access high-quality care for a better quality of life. These guidelines were developed with the input and guidance of the ACCC Financial Advocacy Network Advisory Committee and financial advocates working on the frontlines.

Over the last four years, the healthcare landscape has continued to change, and the role of oncology financial advocates has grown and evolved. Thus, the network sought to create new Financial Advocacy Services Guidelines using a collaborative, consensus-based process to promote and guide the implementation of these critical services in cancer programs and practices across the nation.

## Developing the Guidelines

*See Appendix B (page 34) for additional details about ACCC's methodology.*

ACCC convened an expert task force to guide the development of the Financial Advocacy Services Guidelines. Demonstrating a commitment to an inclusive process, the task force used the following guiding principles to serve as a North Star in decision making:

- Patient-centeredness
- Equity
- Engagement
- Value
- Feasibility
- Rigor.

ACCC and the task force also used a consensus-driven, evidence-based methodology to develop the Guidelines. Informed by a literature scan of financial advocacy-related research articles<sup>5-59</sup>, ACCC developed a list of 44 potential guidelines. It then recruited a diverse panel of 49 experts (e.g., financial advocates, oncology providers, subject matter experts, patients, and patient advocates) to review the proposed guidelines and vote on a final list. When voting, panelists selected one of the following statements for each potential guideline:

- Should not be a guideline
- Should be a minimum guideline
- Should be an enhanced guideline
- Not sure/I do not have enough information to choose.

# KEY TERMS

ACCC recognizes that the field of financial advocacy is an area of continuing research and discussions to define clearer terms and establish agreement. For the purposes of this document and the Guidelines' development process, the following terms were used:

- **Financial distress**

Used to encompass financial hardship and financial toxicity. Financial distress is a term used in medicine to characterize the issues patients may experience relating to the costs of their care: "not having health insurance or having a lot of costs for medical care [that are] not covered by health insurance can cause financial problems and may lead to debt and bankruptcy."<sup>60</sup> Financial distress can also impact individuals' access to care and quality of life. For example, they may skip their medical appointments or not adhere to their prescription treatment schedule to save money. Patients with cancer "are more likely to have financial distress than people without cancer. [Financial distress is] also called economic burden, economic hardship, financial burden, financial hardship, financial stress, and financial toxicity."<sup>60</sup>

- **Financial advocacy**

Used to comprise financial navigation and financial counseling. Financial advocacy is dedicated to proactively integrating financial health into the cancer care continuum, while helping patients gain access to affordable, high-quality care for improved quality of life. Financial advocacy ensures the identification and mitigation of financial distress for patients with cancer, their caregivers, and their families. A cancer program or practice may have one or more associates on staff who focus on varying aspects of financial advocacy for their patients. At this time, no single job title is associated with these roles. Members of a financial advocacy team often have diverse education and knowledge levels, as well as other responsibilities within their cancer program or practice.

- **Guidelines**

Statements that include recommendations for all cancer programs and practices (no matter their geographic location or size) to optimize patient care by addressing financial distress through financial advocacy services. These

guidelines are informed by an evidence-based process and offer the opportunity for programs and practices to review their current services and identify best practices for implementation to meet the needs of their patient population.<sup>61</sup> The Financial Advocacy Services Guidelines reflect the suite of services that should be delivered to patients with cancer to reduce financial distress, regardless of who is delivering the service or medical care. ACCC understands that cancer programs and practices, clinics, hospitals, and health systems vary greatly in their structures and resources for delivering financial advocacy services.

- **Minimum guideline**

A fundamental service that is necessary to provide to patients with cancer to help reduce risk of financial distress. Minimum guidelines should be feasible for most cancer programs and practices, clinics, hospitals, or health systems of any size or resource level to implement.

- **Enhanced guideline**

Financial advocacy services that go beyond the agreed upon basic services to proactively prevent financial distress among patients with cancer and improve their decision making and quality of life. Enhanced guidelines may only be feasible for well-resourced cancer programs and practices, clinics, hospitals, and health systems or more established financial advocacy programs to implement.

- **Established practice**

Activities, services, or functions that are *routinely* performed and understood to be part of a team or department's scope of work.

- **Process**

A guideline-concordant service or function is being delivered, but the guideline does not dictate *how* it needs to be delivered. This does not mean that there must be a detailed procedural manual to get the identified service or function done, but processes should be documented in some way to facilitate knowledge transfer and continuity in the cancer program or practice, clinic, hospital, or health system (e.g., staffing changes). A *standardized process* means that multiple staff know how to complete the service or function in the same way.

# GUIDELINES

Below are the resulting ACCC Financial Advocacy Services Guidelines that reached consensus through the Delphi process. These guidelines are organized into three domains:

- Domain 1. Financial Advocacy Services & Functions\*
- Domain 2. Program Management Functions\*
- Domain 3. Partner Management Functions

\*Domains 1 and 2 include subdomains with multiple guidelines. A summary table with all the guidelines can be found in Appendix A (page 28).

## Guideline Indicators

Providing all of the services and functions listed in these guidelines is the ideal future state of oncology financial advocacy. ACCC recognizes that this may not be immediately feasible for all healthcare organizations. Additionally, the association aims to identify the minimum baseline services needed, so healthcare organizations can focus on building these first, as well as services that will enhance their ability to maximize impact for patients and the organization overall.

## Implementation Considerations

In addition to the Financial Advocacy Services Guidelines, ACCC extracted implementation considerations from Delphi panelists' as well as input from the task force, which are included throughout this manuscript.

The Delphi panelists and task force agreed that successful implementation of the Guidelines require a supportive environment, including recognition from leadership, decision-makers, and provider champions that financial advocacy services are a key component of comprehensive, high-quality cancer care. Institutional-based financial resources, including budget for staffing, physical office/desk space, training, technology (hardware and software), and other resources, are another ubiquitous factor to enable effective implementation of the Guidelines.

The following indicators are used to show the expert-driven Delphi panel's level of agreement to whether each guideline should be—at the least—a minimum guideline or an enhanced guideline. To meet the minimum or enhanced guideline threshold, panel agreement must have reached a 75 percent or higher consensus.

### Trending toward a minimum guideline

A majority of the expert panel (60 percent to 74 percent) agreed that the guideline is a minimum service, but the consensus threshold was not met.

### Minimum guideline

The expert panel reached consensus (75 percent agreement) that the guideline is a minimum service, meaning it is fundamental to reduce the risk of financial distress for people with cancer. Minimum guidelines should be feasible for most cancer programs or practices, clinics, hospitals, or health systems of any size or resource level to implement.

### Split between a minimum and enhanced guideline

The expert panel reached consensus that the service is a guideline but were split between rating it as minimum or enhanced.

### Trending toward an enhanced guideline

A majority of the expert panel (60 percent to 74 percent) agreed that the guideline is an enhanced service, but the consensus threshold was not met.

### Enhanced guideline

The expert panel reached consensus (75 percent agreement) that the guideline is an enhanced service, meaning it goes a step beyond the identified basic services that are necessary to reduce the risk of financial distress. Enhanced guidelines may only be feasible for larger and/or well-resourced cancer programs or practices, clinics, hospitals, or health systems and/or more established financial advocacy programs to implement.

# DOMAIN 1. FINANCIAL ADVOCACY SERVICES & FUNCTIONS

## 1.1 Patient Education & Communication



Minimum



Trending toward minimum



Split



Trending toward enhanced



Enhanced



1.1.1 Established practice of meeting with patients *upon request* to answer questions about financing the costs of their cancer care.



1.1.2 Established practice of meeting with all patients and their families/caregivers during an initial consult or prior to the start of treatment to discuss the financial advocacy services that are available to them and who to contact to receive these services.



1.1.3 A process of maintaining contact with patients regarding the available financial advocacy services along the continuum of care and, as part of patients' plan of care, scheduling regular meetings or touchpoints with them and their families/caregivers to discuss at minimum:

- Does their current insurance coverage meet their immediate and future needs?
- Are there continued or new financial (or other) barriers to getting treatment?
- Is the patient adhering to treatment or avoiding care due to financial concerns and mounting payments?



1.1.4 Established practice of working with patients and their families/caregivers *upon referral or request* to identify anticipated "other" costs, such as expenses related to transportation, childcare, partner care, eldercare, and/or lodging.



1.1.5 Established practice of working with patients and their families/caregivers to establish a flexible payment plan for the costs of treatment if viable for the healthcare organization and agreeable to the patient.

### Implementation Considerations

Guideline 1.1.1 is the only guideline that reached consensus as a minimal guideline, meaning it is fundamental to reducing the risk of financial distress. This guideline should be feasible for most cancer programs and practices, clinics, hospitals, and health systems of any size or resource level to implement. Guideline 1.1.2 can be seen as taking guideline 1.1.1 further, where each new patient meets with a member of the financial advocacy team to discuss any available services.

A cross-cutting recommendation from the panel for the implementation of any patient education and

communicating these guidelines is to apply health literacy best practices (e.g., use of plain language, elementary reading level, breaking down complex numbers, etc.) in print, online, and verbal communications for patients and their families/caregivers. Healthcare organizations should, whenever possible, provide information that is shared verbally with patients and their families/caregivers in writing as well. Further, organizations should ensure that all information and tools are available in various languages to meet the needs of their communities.

### **Suggested areas to cover in financial-related patient education include the following:**

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- Patients' health insurance benefits
- Estimated out-of-pocket costs for the prescribed treatment regimen
- Common insurance-related terms and their definitions
- Patients' out-of-pocket costs (coinsurance, deductible, and co-pay)
- How billing for their treatment and medical appointments works (e.g., timing of bills, who to expect bills from, understanding bills and explanation of benefits, who to contact with questions)
- Patients or families/caregivers' ability to access financial education tools and materials (e.g., digital literacy, internet access, need for no-cost consultation on practical or legal issues, etc.)
- Patients use of tools, such as cost calculators and other websites, to compare their prescription costs across pharmacies and manufacturers
- Patients' employment situation, preferences and goals, and risk of losing their commercial/employer-sponsored insurance
- Common financial concerns patients may face
- Common ways patients may attempt to cope with financial hardship (e.g., skipping treatment appointments or not taking their prescriptions), the importance of treatment adherence for positive health outcomes, and resources to support adherence to their treatment plan
- Financial assistance—why apply for funding, how funding will be allocated, what is not covered by the fund, details on what to expect when applying for funding (e.g., determination timeframe, which documents are needed and why, etc.)
- Patient expectations regarding their involvement and responsibilities in partnership with the financial advocacy team.

## Benefits Verification, Prior Authorization, & Insurance Optimization



Minimum



Trending toward minimum



Split



Trending toward enhanced



Enhanced



1.2.1 A process for ensuring patients' insurance and pharmacy benefits information is obtained at first encounter and that they are asked at each visit if changes have occurred.



1.2.2 A process for ensuring structured documentation of comprehensive demographic, insurance, and pharmacy benefits information in the electronic health record (EHR).



1.2.3 A process for performing insurance benefits verification with third-party payers, including network status, referral requirements, patients' out-of-pocket responsibilities, deductible, and accumulations to date.



1.2.4 A process for re-verifying insurance benefits at least every three to six months during active treatment, depending on patients' insurance type.



1.2.5 A process for obtaining and documenting medical necessity and prior authorization (also known as precertification or prior approval) for required therapies to ensure all treatments have approved

authorization that is accurate, within the date range, and of the appropriate quantity for the therapy to be received before treatment initiation; otherwise, patients are rescheduled in a timely manner.



1.2.6 Established practice of completing all prior authorizations as quickly as possible (less than 72 hours in advance for urgent and less than 14 days in advance for non-urgent outpatient care) to avoid treatment- or medication-related delays.



1.2.7 Established practice of providing patient referrals to reputable resources for insurance navigation and assistance.



1.2.8 Established practice of performing a comprehensive health insurance assessment to identify patients' coverage eligibility for, but not limited to, Medicare (A, B, C, D, and Medigap supplements), Medicaid, Marketplace, commercial/employer-sponsored plans, Tricare/Veterans Administration, and COBRA (Consolidated Omnibus Budget Reconciliation Act) plans and providing insurance navigation and enrollment support.

### Implementation Considerations

Benefits verification and prior authorization are important financial advocacy services that should be completed in a timely manner after a treatment plan is established to enable informed decision-making for patients and their families/caregivers. Ideally, patients' insurance verification should be performed at least 24 hours before any appointment to ensure no unnecessary out-of-pocket costs are taken and reduce loss of revenue for the healthcare organization. Prior authorization(s) should also be completed prior to treatment initiation, and care must be taken to ensure the prior authorization aligns with the treatment plan, especially for costly radiation

treatments, to avoid delay. Note: any clinical changes (i.e., port/angles, boost, total dose, fractions, therapy type, etc.) to a radiation treatment plan can negatively impact authorization reimbursement by the payer. Delphi panelists' responses identify guideline 1.2.8 as trending toward an enhanced service, with the rest (1.2.1 to 1.2.7) trending toward minimum services.

Benefits verification and insurance education go hand-in-hand, as many patients are not fully aware of their insurance benefits, may not understand common insurance-related terms, or how insurance and medical

billing work. Providing a transparent and written summary of patients' responsibilities for any planned care and services after completing a benefits review—and discussing it with them—supports informed decision-making. Further, benefits verification and prior authorization proactively identify gaps in patients' insurance coverage prior to their starting treatment and can lead to enhanced identification of resources for assistance that can lessen the financial burden of their care.

### Panelist Insight

"Financial advocacy should feel personalized to the patient [and] consistently deliver guidance on available resources that help minimize the harms [of financial toxicity]. Who provides counseling [or navigation] may not be the same for every patient, but the screening can be a check list to get to the best solution for the patient. Services should not just be educational but intervening on the patient's behalf. Listening [to a patient's needs after]...screening is critical; people do not always see or express what is happening, or [they] avoid sharing in fear of not getting treated."

Delphi panelists provided input on how often re-verification of insurance benefits should occur, with responses ranging from every encounter to on an annual basis. Ultimately, benefits re-verification *should occur* as often as feasible for the healthcare organization to ensure patients' continuous coverage of services and avoid disruptions in their care. It is also important to re-verify patients' benefits any time there is a change in their treatment plan. Delphi panelists noted that benefits re-verification should occur when a patient reports a change in insurance, for example, if they had a change in employment or disability status. Further, benefits re-verification may need to happen more

regularly for patients with Medicaid (e.g., every two to four weeks) and Medicare (e.g., monthly) than for those with commercial/employer-sponsored insurance (e.g., every 90 days). The months of January and July may be ideal timepoints to re-verify patients' benefits, as some plans change mid-year and keeping in mind that re-enrollment for Marketplace plans occurs annually in the fall.

Insurance optimization helps patients maximize their insurance benefits and assists in identifying resources to address coverage inadequacy. For example, during a benefits verification or re-verification, asking if the patient is on Social Security can help a financial advocate identify the patient's unique eligibility timelines for Medicare, Supplemental Security Income (SSI), and Medicaid. Further, during an individual's initial Medicare enrollment period (not the annual Open Enrollment period), patients can sign up for a Medigap plan without underwriting, which can help with accessing coverage for their 20 percent co-insurance responsibility.

### Panelist Insight

"Financial advocacy is a compliment to the care patients are getting. It is getting to the root cause(s) and leading people to vetted, direct financial assistance programs, uncovering and addressing insurance challenges, [and] connecting [them] to social programs/safety-net solutions to alleviate current and future financial stress that present because of a cancer diagnosis...Taking a proactive approach to help patients get approved for grants and other... [financial]assistance they may be eligible for is a win-win for...the patient...[and the healthcare organization's] revenue integrity."

## 1.3 Financial Distress Screening



Minimum



Trending toward minimum



Split



Trending toward enhanced



Enhanced



1.3.1 A process for screening patients *upon referral* for potential financial distress using a standard set of questions.



1.3.2 An electronic process for screening all patients for current and potential financial distress prior to beginning treatment, using a comprehensive and validated questionnaire that covers the three domains of financial hardship (material, psychological, behavioral),<sup>63,23</sup> as well as key social needs or social determinants of health. Examples of commonly used questionnaires include the:

- Comprehensive Score for Financial Toxicity (FACIT-COST)<sup>64</sup>
- National Comprehensive Cancer Network (NCCN) Distress Thermometer<sup>65</sup>
- Social determinants of health questionnaire that may be available in an EHR.



1.3.3 A process for re-screening patients who are found to be at risk of financial distress, at key milestones during their treatment (e.g., when treatment regimen changes) and at least every six to 12 months.



1.3.4 An electronic process for re-screening all patients for financial distress at key milestones during treatment (e.g., when treatment regimen changes) and at least every three to six months.



1.3.5 Processes for further assessing patients' needs, identifying resources and interventions, and making proper referrals and follow-up to minimize the harms identified through financial distress screening.

### Implementation Considerations

While there is presently no agreement in the field of financial advocacy on clear distinctions between financial distress screening and assessment, screening in this sub-domain refers to a relatively brief check for red flags that indicate more extensive assessment may be warranted. Methods for screening are not yet standardized in the field either. Feasibility and workflow for financial distress screening will vary by healthcare organization and financial advocacy team. Delphi panel responses identify guidelines 1.3.1 and 1.3.5 as trending toward minimum services and 1.3.4 as trending toward an enhanced service. Critically, guideline 1.3.5 illustrates that it is not enough to just screen for risk of or one's current financial distress, rather processes must be in place to act on the information that is collected via screening to best address patients' needs.

Delphi panelists provided input on which patients should be screened for financial distress and the frequency of this

screening. The consensus is that even in cancer programs and practices, clinics, hospitals, and health systems with limited resources, all patients should be screened for financial distress at least once. Universally screening patients, ideally built into paper or electronic intake forms, would help reduce the bias on the healthcare organization in deciding who to screen and any stigma on the patient side that is associated with reporting financial concerns and discussing finances with financial advocacy team members. Patients must be assured that the quality of their care will not depend on their financial distress screening responses. Additionally, those with identified risks in an initial brief screening should be referred to an in-depth assessment of needs and referrals for support.

Like the re-verification of insurance benefits, the recommended interval for re-screening for financial distress varies, with some completing it at every encounter and

others doing it annually. If healthcare organizations do not implement universal screening for financial distress, re-screening might depend on patients' initial screening results, insurance type, and/or financial stability. The patients that should be prioritized for more frequent screening include those with anticipated higher out-of-pocket costs, such as those who are uninsured, underinsured, with public benefits or government-funded insurance plans, unhoused, or who have undocumented immigration status.

Delphi panelists were also asked which screening tool(s) they recommend as patient-friendly, easy to use in practice, and most effective at screening for risk of financial distress. They commented on the complexity of financial distress screening. The top four most used resources include the Comprehensive Score for Financial Toxicity (FACIT-COST),<sup>65</sup> NCCN Distress Thermometer,<sup>66</sup> social determinants of health questionnaires (which may be pre-built in the EHR), or a financial distress questionnaire that is developed in-house. Panelists emphasize that financial distress screening needs to be actionable and feasible to administer. Some screening tools that are validated in research studies were felt to be too long for regular in-person screening and lack guidance on actions to take based on patients' scores. Expert-driven consensus determined that it matters less which screening tool is used, but rather that some form of screening is occurring. More critically, patients' needs must be met through any in-house developed resources or via referrals to external resources.

Patient education and communication also goes hand-in-hand with screening. Patients should understand:

- Why the financial advocate is reaching out to them and how they can help
- Why the specific questions are being asked
- What follow-up will look like
- How to reach out to the financial advocacy team if there is a change in their situation, they have questions, or they need support (instead of waiting for the healthcare organization's next financial distress screening cycle).

## Panelist Insight

"Ideally, you [should] build a trusted team specific to the cancer program (not outsourced to a central billing department) to answer and/or help facilitate all billing/financial questions that a patient may have. Key components are:

1. Financial advocate(s) to address insurance coverage issues and questions
2. Oncology social worker(s) to assess psychosocial needs and connect patients with community resources
3. Financial and co-pay assistance with dedicated staff to help patients apply for [this] assistance
4. Nurse navigator(s) to assess for barriers to care and refer patients to [a] financial advocate, social worker, [or] psychologist as needed
5. Educational resources for patients/caregivers to better understand the financial aspects of receiving oncology care."

## 1.4 Financial Assistance



Minimum



Trending toward minimum



Split



Trending toward enhanced



Enhanced



1.4.1 Established practice of evaluating patients' eligibility for and enrolling them into assistance or submitting claims that can help with direct treatment-related costs, for example, through:

- Federal- and state-funded benefits programs or subsidies
- Manufacturer-based (i.e., pharmaceutical company) financial assistance programs, such as co-pay cards or programs, patient assistance programs, or drug reimbursement programs
- National, independent foundation-funded and disease-specific assistance programs
- Hospital-based charity programs, scholarships, or grant funds
- Reduced or no-interest loan or financing options
- Local community resources (e.g., local foundation assistance).



1.4.2 Established practice of working with patients and their families/caregivers to identify and provide enrollment assistance or refer them to national and local community-based assistance programs that can help with:

- Supportive care and non-treatment-related costs (e.g., transportation, lodging, childcare, fertility preservation, scalp cooling, in-home care, hospice/end-of-life care)
- Workplace accommodations (e.g., Americans with Disabilities Act [ADA], Family and Medical Leave Act [FMLA])

- Income replacement (e.g., short-term or long-term disability, Supplemental Security Income [SSI] and Social Security Disability Insurance [SSDI], unemployment)
- Essential needs (e.g., housing, food, personal hygiene, utilities, etc.).



1.4.3 An established cancer program or practice, clinic, hospital, or health system assistance fund with clear, transparent, and publicly available eligibility and enrollment criteria to assist those who may otherwise be unable to receive support through other financial assistance programs.



1.4.4 Established practice of tracking patients' financial assistance application(s) status; liaising between the patient, cancer care team, and assistance program; and following up until a determination is made by the program.



1.4.5 Established practice of processing approved assistance program applications for medication(s) and other costs, ensuring the removal of patients' billing charges for approved medication(s) or other costs, and fund collecting for co-pay assistance.



1.4.6 Established practice of re-enrolling patients in qualifying financial assistance programs on time to avoid a lapse in assistance, as required.

### Implementation Considerations

Helping patients access financial assistance is a core service of financial advocacy programs. This ensures financial advocacy teams are meeting patients' needs and capturing the maximum reimbursement amount for their healthcare organization. For guidelines 1.4.1 through 1.4.5, Delphi panelists are split on identifying these as minimum or enhanced services, whereas panelists agree that

guideline 1.4.6 is trending toward a minimum service. While many understand that cancer care is complex and expensive, panelists emphasize the importance of securing financial assistance for patients, especially for treatments and supportive care medications with higher out-of-pocket costs like some oral chemotherapies, immunotherapies, and other medications.

## DOMAIN 2. PROGRAM MANAGEMENT FUNCTIONS

### 2.1 Staffing Roles & Responsibilities



Minimum



Trending toward minimum



Split



Trending toward enhanced



Enhanced



2.1.1 Established practice of setting clear expectations that clinical, non-clinical, and administrative (e.g., front desk, health information management, etc.) multidisciplinary cancer care team members, who interact with patients and their families/caregivers, refer patients for financial advocacy services when signs of financial distress are evident.



2.1.2 Dedicated financial advocacy position(s) specific to serving patients and their families/caregivers. (Position titles vary and might include financial counselor, financial navigator, or financial advocate.)

### Implementation Considerations

ACCC understands that cancer programs and practices, clinics, hospitals, and health systems vary greatly in their structure and available resources for delivering financial advocacy services, therefore, it is not appropriate for it to prescribe a specific staffing guideline. The guidelines in this section reflect the suite of services that should be delivered to patients with cancer to reduce financial distress, regardless of who is delivering the service.

Delphi panelists submitted comments indicating that awareness and concern for financial distress is the responsibility of the entire multidisciplinary cancer care team. Guidelines 2.1.1 and 2.1.2 trend among panelists as being minimum required services of financial advocacy programs. The panel recommends that cancer programs and practices, clinics, hospitals, and health systems staff a dedicated position focused on serving patients with cancer and their families/caregivers and not solely rely on services that may be available centrally, such as through a billing department. The panel also recognizes that other staff, who are not in dedicated financial advocacy roles, will play an important part in the delivery of these services. The expert panel suggests that financial advocacy teams include various roles to provide the complementary services reflected in these guidelines, such as financial counselors, financial navigators, or financial advocates; social workers; nurse navigators; and case managers.

Panelists indicate that, as is the case for the healthcare organization as a whole, financial advocacy team members

should reflect the communities they serve, including representing diversity in race, ethnicity, language, culture, and educational background. .2 Benefits Verification, Prior Authorization, & Insurance Optimization and building relationships with local interpretation services or community organizations that can further help patients of diverse backgrounds in their language(s). In addition, all team managers should ensure thorough assessment of a candidate pool to provide a selection of potential interviewees that represent the communities being served, and, if necessary, hold job fairs that promote a diverse workforce.

Additionally, Delphi panelists commented on the appropriate caseload each financial advocacy team member should have, noting that caseloads may depend on the complexity of patients' needs and treatment plans, available technology to help manage caseloads, format for service delivery (e.g., in person or virtual), and individuals' skills and level of training. Caseloads may also vary by financial advocate, based on how much one can handle. When one's caseload is too much, they cannot effectively advocate for their patients and program metrics, such as time to resolution, will suffer. While consensus on caseload was not reached, some panelists provided estimates based on their own experiences. They suggest defining caseloads based on the number of providers on staff, by the cancer program or practice's total patient volume, or by service line (e.g., radiation, medical, or surgical oncology), whereas others offer measuring caseload in terms of number of patients per financial advocate per day, week, month, or year.

## 2.2 Staff Training



Minimum



Trending toward minimum



Split



Trending toward enhanced



Enhanced

 2.2.1 A process for training all clinical, non-clinical, and administrative staff (e.g., front desk, health information management, etc.), who interact with patients and their families/caregivers, on how to identify financial distress, share the available financial advocacy services, and refer patients for support from the financial advocacy team (i.e., as part of in-service requirements and new staff onboarding).

 2.2.2 A process (e.g., through a hiring evaluation of prior experience or on-the-job training) to ensure financial advocacy team members can identify, are knowledgeable on, and skilled in:

- The basics of healthcare billing, insurance, and patient assistance options, especially benefits verification, federal- and state-based programs, workplace accommodations, and FMLA and ADA regulations
- The basic clinical knowledge of the most common cancer diagnoses they will be working with
- Understanding sources of evidence-based practice (e.g., U.S. Food and Drug Administration [FDA], NCCN) and justifying medical necessity (i.e., on-label treatment)
- How cancer impacts patients, as well as their families/caregivers, especially when considering potential financial toxicity

- Health literacy and numeracy best practices (general health literacy and financial literacy)
- Implicit bias and cultural humility
- Empathy, compassion, and how to have difficult conversations within the scope of practice
- How to help build patients' skills to empower them in managing their finances and navigating insurance-related issues
- How to work effectively as a member of the cancer care team
- Scope of practice and who/where to refer patients for additional services or resources (e.g., psychosocial support, social needs navigation, legal and financial navigation, occupational medicine).

 2.2.3 The requirement and mechanism(s) to provide ongoing/continuing training and professional development for every member of the financial advocacy team to support their career growth.

 2.2.4 The requirement and processes for financial advocacy team leadership or management to stay abreast of any national, local, and/or institutional policy issues that directly impact their organization's financial advocacy services or likelihood of financial distress among patients and to communicate any relevant information or required actions to the team.

## Implementation Considerations

Delphi panelists recognize that training resources and the ability to recruit staff with existing expertise in financial advocacy will vary by cancer program or practice, clinic, hospital, or health system. They also highly recommended building general awareness among all oncology staff about financial distress risks, its warning signs, and how to refer

patients for support. Panelists identify guideline 2.2.1 as trending toward a minimum service. Empathy, humility, and good communication skills are considered foundational to the success of financial advocacy team members, while much of the technical content and skills can be taught through training or mentoring if necessary.

## 2.3 Infrastructure & Information Exchange



Minimum



Trending toward minimum



Split



Trending toward enhanced



Enhanced



2.3.1 A process for documenting and communicating concerns about financial distress and steps to resolve in the health record.



2.3.2 A HIPAA-compliant database or tool, integrated in the EHR, to enable financial advocacy service delivery, including:

- Standardized screening and referrals
- Inventory or database of available financial assistance programs
- Documenting and tracking all communication with patients, payer(s), and assistance programs to ensure patients have their needs met and do not fall through cracks
- Bi-directional communication between cancer care team members.



2.3.3 Dedicated on-site space for financial advocacy team members to hold private conversations with patients and their families/caregivers via telephone or in person.



2.3.4 Processes for integrating financial advocacy into existing cancer care planning and services (i.e., comprehensive care planning, survivorship care planning) and facilitating regular multidisciplinary cancer care team communication regarding patients' financial concerns and resulting psychosocial/emotional or medical impacts (e.g., tumor boards).

### Implementation Considerations

Expert panelists identify guideline 2.3.1 as trending toward a minimum service. While panelists agree that electronic solutions greatly support financial advocacy service delivery, it is recognized that not all cancer programs and practices, clinics, hospitals, or health systems can feasibly afford or implement these technology solutions at present. Guideline 2.3.4 is the only guideline to reach consensus among panelists as being an enhanced service.

A key consideration in this sub-domain is patient confidentiality—patients may vary in their willingness to have a financial advocacy team member share details about their financial situation with the rest of the cancer care team. As in any sensitive clinical situation, seek the patient's consent and only disclose what is necessary for supporting clinical decision-making and through private or secure communication channels.

## 2.4 Monitoring & Evaluation



Minimum



Trending toward minimum



Split



Trending toward enhanced



Enhanced



2.4.1 A process, with clear metrics, to track and evaluate the impact of the financial advocacy program on an annual basis at least, including, but not limited to:

- Number of patients served
- Number of insurance denials mitigated.



2.4.2 A process, with metrics in addition to those identified in guideline 2.4.1, to track and evaluate the impact of the financial advocacy program on an annual basis at least, including, but not limited to:

- Total funding secured for patients
- Total funding secured for the cancer program or practice, clinic, hospital, or health system
- Financial return on staff investment
- Improvements in patient-reported outcomes or care quality metrics, including patient satisfaction.



2.4.3 Established practice of conducting quality improvement activities to enhance efficiency, effectiveness, and equity of financial advocacy service delivery.



2.4.4 Established accountability or quality standards for equitable financial advocacy service delivery, monitored at least quarterly, for continuous improvement, including, but not limited to:

- A process for identifying inequities in the provision of financial advocacy programs and services (e.g., comparing financial distress indicators by race and/or ethnicity or other patient demographic data)
- A process for monitoring the effectiveness of the proactive strategies used to address the unique needs of the patient populations that are at increased risk of financial distress
- Assessment of non-solvables to monitor if a barrier absorbs time but has no resolution
- Review of partner referral organizations to assess their ongoing resources, capacity, and how well patients' needs are met.



2.4.5 Established practice of financial advocacy team members engaging in professional development activities to advance the field of financial advocacy (e.g., research, participation in external working groups, conferences, etc.).

### Implementation Considerations

Monitoring and evaluating financial advocacy services and programs within a cancer program or practice, clinic, hospital, and health system is important to determine if patients' needs are being met and document the value of these services to the organization. As written, guideline 2.4.2 is in addition to guideline 2.4.1, and guideline 2.4.4 is in addition to guideline 2.4.3. Additionally, Delphi panelists identify guideline 2.4.1 as trending toward a minimum required service.

Program evaluation can illuminate service gaps and offer opportunities for quality improvement, as well as to seek external funding to meet outstanding needs. Program monitoring against accountability standards can support individual-level staff performance management and program-level quality metrics, ensuring all patients benefit equitably from available services. Additional

ideas for evaluation metrics include assessing for reduced missed appointment rates due to the provision of financial advocacy services (e.g., transportation support) or reduced use of internal charity funds because of increased secured funding or enrollment of patients in eligible, external sources of financial assistance.

Evaluation activities do not need to be the sole responsibility of the financial advocacy program, as cancer program or practice management or administrative leadership can provide support as well. A manager or leader overseeing the financial advocacy team should be given regular opportunities to translate outcome metrics and communicate the value of financial advocacy services to internal and external partners (e.g., donors, board members) to justify continued or expanded support and investment for the program.

## DOMAIN 3. PARTNER ENGAGEMENT FUNCTIONS



Minimum



Trending toward minimum



Split



Trending toward enhanced



Enhanced



3.1 Processes for obtaining up-to-date knowledge of requirements for enrolling patients in:

- Health insurance (e.g., Medicaid, Marketplace, etc.)
- Manufacturer, state, and local medication assistance programs
- Disease-specific assistance programs from non-profit, independent foundations
- Medicare prescription benefits
- Medicare Low-Income Subsidy and any federal, state, and local benefits (e.g., unemployment benefits, disability benefits, etc.).



3.2 Processes for identifying and developing relationships with contacts at important organizations to become familiar with available resources, policies, and procedures for working with them, including, but not limited to:

- In-network insurance plans
- Local pharmacies, including specialty pharmacies
- Local diagnostic service companies
- Local non-profits and independent foundations
- External patient advocacy groups and community-based organizations that offer education, direct assistance, navigation, and/or other services.



3.3 A process for making referrals to legal service organizations to assist patients with legal issues that arise after a cancer diagnosis (e.g., employment, disability benefits, housing, consumer rights, estate planning, medical decision-making, etc.).



3.4 Processes for working with patients and their families/caregivers' employers to advocate for issues related to insurance benefits, accommodations, and protections.

### Implementation Considerations

This domain addresses how financial advocacy team members can become aware of available resources and build relationships with external organizations and key contacts to ensure the smooth delivery of financial advocacy services. Some commercial databases of national and local resources exist, but many financial advocacy teams build their own internal databases organically over time, sharing resource leads and contacts within their local networks.

Delphi panelists identify guideline 3.1 as trending toward a minimum service. Guidelines 3.2 through 3.4 reached split consensus among panelists, with guideline 3.2's split likely indicating the capacity for and priority of offering these

processes varying by a healthcare organization's resources and patient population's needs.

At the healthcare organization level, a representative from the financial advocacy team should be routinely included in its community needs assessment processes to assist in identifying specific assets and vulnerabilities in the catchment area. There should also be processes or structures in place to enable authentic, diverse, and inclusive patient and community engagement that can inform financial advocacy and clinical service delivery (e.g., patient and family advisory council or community advisory board).

# CALL TO ACTION

The ACCC Financial Advocacy Network's Delphi process resulted in 43 guidelines across three domains to ensure the identification and mitigation of financial distress for patients with cancer, their caregivers, and their families, while helping patients gain access to affordable, high-quality cancer care for improved quality of life. Several clear next steps emerged through this initiative, and ACCC encourages all to join in carrying this important work forward.



**1. Healthcare organizations should assess their current oncology financial advocacy services** based on these guidelines and develop plans to expand and improve where needed. ACCC and its partners will develop a site assessment tool that cancer programs and practices, clinics, hospitals, and health systems can use to identify gaps and opportunities for improvement, and the association will share existing as well as develop new resources and tools to support this work.



**2. More research is needed to build agreement and consistency in the field** on financial distress screening (tools, integration into workflows and EHRs, periodicity); financial advocacy interventions (core services, measurable outcomes); and the role of financial advocates (competencies, job title, description, designation, certification). Only two guidelines reached consensus on whether they were a minimum or enhanced service, likely reflecting the diversity of practice settings represented on the expert panel and opportunity to develop greater agreement and standardization in the field.



**3. Commit to action to expand the United States healthcare system's overall capacity to deliver financial advocacy services** and address systemic barriers to affordable care. Examples include:

- Joining patient-driven community outreach campaigns and collaborative policy development initiatives to improve equitable access to, quality of, and sustainability for crucial financial advocacy services.
- Developing accountability measures through national bodies to promote adoption and implementation of these guidelines.
- Continuing efforts to contain out-of-pocket healthcare costs and promote affordability.



**4. Broadening financial advocacy services across the cancer care continuum.** Currently, financial advocacy services are focused mainly on treatment, with some directed toward diagnosis and survivorship care. But there are great needs among patients at increased risk of cancer, such as those with hereditary syndromes and genetic predispositions, in which financial advocacy can have a role. For example, what does financial advocacy for cancer prevention and interception services look like?

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# Appendix A.

## Financial Advocacy Services Guidelines



Minimum



Trending toward minimum



Split



Trending toward enhanced



Enhanced

### Domain 1. Financial Advocacy Services & Functions

#### Sub-Domain 1.1 Patient Education & Communication



1.1.1 Established practice of meeting with patients *upon request* to answer questions about financing the costs of their cancer care.



1.1.2 Established practice of meeting with all patients and their families/caregivers during an initial consult or prior to the start of treatment to discuss the financial advocacy services that are available to them and who to contact to receive these services.



1.1.3 A process of maintaining contact with patients regarding the available financial advocacy services along the continuum of care and, as part of patients' plan of care, schedule regular meetings or touchpoints with them and their families/caregivers to discuss at minimum:

- Does their current insurance coverage meet their immediate and future needs?
- Are there continued or new financial (or other) barriers to getting treatment?
- Is the patient adhering to treatment or avoiding care due to financial concerns and mounting payments?



1.1.4 Established practice of working with patients and their families/caregivers *upon referral or request* to identify anticipated "other" costs, such as expenses related to transportation, childcare, partner care, eldercare, and/or lodging.



1.1.5 Established practice of working with patients and their families/caregivers to establish a flexible payment plan for the costs of treatment if viable for the healthcare organization and agreeable to the patient.

#### Sub-Domain 1.2 Benefits Verification, Pre-Authorization, & Insurance Optimization



1.2.1 A process for ensuring patients' insurance and pharmacy benefits information is obtained at first encounter and that they are asked at each visit if changes have occurred.



1.2.2 A process for ensuring structured documentation of comprehensive demographic, insurance, and pharmacy benefits information in the EHR.



1.2.3 A process for performing insurance benefits verification with third-party payers, including network status, referral requirements, patients' out-of-pocket responsibilities, deductible, and accumulations to date.



1.2.4 A process for re-verifying insurance benefits at least every three to six months during active treatment, depending on patients' insurance type.

 1.2.5 A process for obtaining and documenting medical necessity and prior authorization (also known as precertification or prior approval) for required therapies to ensure all treatments have approved authorization that is accurate, within the date range, and of the appropriate quantity for the therapy to be received before treatment initiation; otherwise, patients are rescheduled in a timely manner.

 1.2.6 Established practice of completing all prior authorizations as quickly as possible (less than 72 hours in advance for urgent and less than 14 days in advance for non-urgent outpatient care) to avoid treatment- or medication-related delays.

 1.2.7 Established practice of providing patient referrals to reputable resources for insurance navigation and assistance.

 1.2.8 Established practice of performing a comprehensive health insurance assessment to identify patients' coverage eligibility for, but not limited to, Medicare (A, B, C, D, and Medigap supplements), Medicaid, Marketplace, commercial/employer-sponsored plans, Tricare/Veterans Administration, and COBRA (Consolidated Omnibus Budget Reconciliation Act) plans and providing insurance navigation and enrollment support.

### Sub-Domain 1.3 Financial Distress Screening

 1.3.1 A process for screening patients *upon referral* for potential financial distress using a standard set of questions.

 1.3.2 An electronic process for screening all patients for current and potential financial distress prior to beginning treatment, using a comprehensive and validated questionnaire that covers the three domains of financial hardship (material, psychological, behavioral),<sup>62,63</sup> as well as key social needs or social determinants of health. Examples of commonly used questionnaires include the:

- Comprehensive Score for Financial Toxicity (FACIT-COST)<sup>64</sup>
- National Comprehensive Cancer Network (NCCN) Distress Thermometer<sup>65</sup>
- Social determinants of health questionnaire that may be available in an EHR.

 1.3.3 A process for re-screening patients, who are found to be at risk of financial distress, at key milestones during their treatment (e.g., when treatment regimen changes) and at least every six to 12 months.

 1.3.4 An electronic process for re-screening all patients for financial distress at key milestones during treatment (e.g., when treatment regimen changes) and at least every three to six months.

 1.3.5 Processes for further assessing patients' needs, identifying resources and interventions, and making proper referrals and follow-up to minimize the harms identified through financial distress screening.

## Sub-Domain 1.4 Financial Assistance

 1.4.1 Established practice of evaluating patients' eligibility for and enrolling them into assistance or submitting claims that can help with direct treatment-related costs, for example, through:

- Federal- and state-funded benefits programs or subsidies
- Manufacturer-based (i.e., pharmaceutical company) financial assistance programs, such as co-pay cards or programs, patient assistance programs, or drug reimbursement programs
- National, independent foundation-funded and disease-specific assistance programs
- Hospital-based charity programs, scholarships, or grant funds
- Reduced or no-interest loan or financing options
- Local community resources (e.g., local foundation assistance).

 1.4.2 Established practice of working with patients and their families/caregivers to identify and provide enrollment assistance or refer them to national and local community-based assistance programs that can help with:

- Supportive care and non-treatment-related costs (e.g., transportation, lodging, childcare, fertility preservation, scalp cooling, in-home care, hospice/end-of-life care)
- Workplace accommodations (e.g., Americans with Disabilities Act [ADA], Family and Medical Leave Act [FMLA])
- Income replacement (e.g., short-term or long-term disability, Supplemental Security Income [SSI] and Social Security Disability Insurance [SSDI], unemployment)
- Essential needs (e.g., housing, food, personal hygiene, utilities, etc.).

 1.4.3 An established cancer program or practice, clinic, hospital, or health system assistance fund with clear, transparent, and publicly available eligibility and enrollment criteria to assist those who may otherwise be unable to receive support through other financial assistance programs.

 1.4.4 Established practice of tracking patients' financial assistance application(s) status; liaising between the patient, cancer care team, and assistance program; and following up until a determination is made by the program.

 1.4.5 Established practice of processing approved assistance program applications for medication(s) and other costs, ensuring the removal of patients' billing charges for approved medication(s) or other costs, and fund collecting for co-pay assistance.

 1.4.6 Established practice of re-enrolling patients in qualifying financial assistance programs on time to avoid a lapse in assistance, as required.

## Domain 2. Program Management Functions

### Sub-Domain 2.1 Staffing Roles & Responsibilities

-  2.1.1 Established practice of setting clear expectations that clinical, non-clinical, and administrative (e.g., front desk, health information management, etc.) multidisciplinary cancer care team members, who interact with patients and their families/caregivers, refer patients for financial advocacy services when signs of financial distress are evident.
-  2.1.2 Dedicated financial advocacy position(s) specific to serving patients and families/caregivers. (Position titles vary and might include financial counselor, financial navigator, or financial advocate.)

### Sub-Domain 2.2 Staff Training

-  2.2.1 A process for training all clinical, non-clinical, and administrative staff (e.g., front desk, health information management, etc.), who interact with patients and their families/caregivers, on how to identify financial distress, share the available financial advocacy services, and refer patients for support from the financial advocacy team (i.e., as part of in-service requirements and new staff onboarding).
-  2.2.2 A process (e.g., through a hiring evaluation of prior experience or on-the-job training) to ensure financial advocacy team members can identify, are knowledgeable on, and skilled in:
  - The basics of healthcare billing, insurance, and patient assistance options, especially benefits verification, federal- and state-based programs, workplace accommodations, and FMLA and ADA regulations
  - The basic clinical knowledge of the most common cancer diagnoses they will be working with
  - Understanding sources of evidence-based practice (e.g., FDA, NCCN) and justifying medical necessity (i.e., on-label treatment)
  - How cancer impacts patients, as well as their families/caregivers, especially when considering potential financial toxicity
  - Health literacy and numeracy best practices (general health literacy and financial literacy)
  - Implicit bias and cultural humility
  - Empathy, compassion, and how to have difficult conversations within the scope of practice
  - How to help build patients' skills to empower them in managing their finances and navigating insurance-related issues
  - How to work effectively as part of the cancer care team
  - Scope of practice and who/where to refer patients for additional services or resources (e.g., psychosocial support, social needs navigation, legal and financial navigation, occupational medicine).
-  2.2.3 The requirement and mechanism(s) to provide ongoing/continuing training and professional development for every member of the financial advocacy team to support their career growth.
-  2.2.4 The requirement and processes for financial advocacy team leadership or management to stay abreast of any national, local, and/or institutional policy issues that directly impact their organization's financial advocacy services or likelihood of financial distress among patients and to communicate any relevant information or required actions to the team.

### Sub-Domain 2.3 Infrastructure & Information Exchange

 2.3.1 A process for documenting and communicating concerns about financial distress and steps to resolve in the health record.

 2.3.2 A HIPAA-compliant database or tool, integrated in the EHR, to enable financial advocacy service delivery, including:

- Standardized screening and referrals
- Inventory or database of available financial assistance programs
- Documenting and tracking all communication with patients, payer(s), and assistance programs to ensure patients have their needs met and do not fall through cracks
- Bi-directional communication between cancer care team members.

 2.3.3 Dedicated on-site space for financial advocacy team members to hold private conversations with patients and their families/caregivers via telephone or in person.

 2.3.4 Processes for integrating financial advocacy into existing cancer care planning and services (i.e., comprehensive care planning, survivorship care planning) and facilitating regular multidisciplinary cancer care team communication regarding patients' financial concerns and resulting psychosocial/emotional or medical impacts (e.g., tumor boards).

### Sub-Domain 2.4 Monitoring & Evaluation

 2.4.1 A process, with clear metrics, to track and evaluate the impact of the financial advocacy program on an annual basis at least, including, but not limited to:

- Number of patients served
- Number of insurance denials mitigated.

 2.4.2 A process, with metrics in addition to those identified in Guideline 2.4.1, to track and evaluate the impact of the financial advocacy program on an annual basis at least, including, but not limited to:

- Total funding secured for patients
- Total funding secured for the cancer program or practice, clinic, hospital, or health system
- Financial return on staff investment
- Improvements in patient-reported outcomes or care quality metrics, including patient satisfaction.

 2.4.3 Established practice of conducting quality improvement activities to enhance efficiency, effectiveness, and equity of financial advocacy service delivery.

 2.4.4 Established accountability or quality standards for equitable financial advocacy service delivery, monitored at least quarterly, for continuous improvement, including, but not limited to:

- A process for identifying inequities in the provision of financial advocacy programs and services (e.g., comparing financial distress indicators by race and/or ethnicity or other patient demographic data)
- A process for monitoring the effectiveness of the proactive strategies used to address the unique needs of the patient populations that are at increased risk of financial distress
- Assessment of non-solvables to monitor if a barrier absorbs time but has no resolution
- Review of partner referral organizations to assess their ongoing resources, capacity, and how well patients' needs are met.

 2.4.5 Established practice of financial advocacy team members engaging in professional development activities to advance the field of financial advocacy (e.g., research, participation in external workgroups, conferences, etc.).

## Domain 3. Partner Engagement Functions



3.1 Processes for obtaining up-to-date knowledge of requirements for enrolling patients in:

- Health insurance (e.g., Medicaid, Marketplace, etc.)
- Manufacturer, state, and local medication assistance programs
- Disease-specific assistance programs from non-profit, independent foundations
- Medicare prescription benefits
- Medicare Low-Income Subsidy and any federal, state, and local benefits (e.g., unemployment benefits, disability benefits, etc.).



3.2 Processes for identifying and developing relationships with contacts at important organizations to become familiar with available resources, policies, and procedures for working with them, including, but not limited to:

- In-network insurance plans
- Local pharmacies, including specialty pharmacies
- Local diagnostic service companies
- Local non-profits and independent foundations
- External patient advocacy groups and community-based organizations that offer education, direct assistance, navigation, and/or other services.



3.3 A process for making referrals to legal service organizations to assist patients with legal issues that arise after a cancer diagnosis (e.g., employment, disability benefits, housing, consumer rights, estate planning, medical decision-making, etc.).



3.4 Processes for working with patients and their families/caregivers' employers to advocate for issues related to insurance benefits, accommodations, and protections.

## Appendix B.

# Methods

### Literature Scan

Research about financial distress and financial advocacy in oncology has increased in recent years, so ACCC began this initiative with a scan of financial advocacy-related research articles. This scan was then used to develop a list of potential guidelines.

A total of 55 articles were identified: 21 original research articles; 19 commentaries, editorials, or position papers; and 14 reviews.<sup>5-59</sup> Financial advocacy services described in interventions under study include:<sup>7-61</sup>

- Access to health insurance
- Access to out-of-pocket cost estimation tools
- Access to third-party case managers
- Assistance with clinical trial participation costs
- Education on cost-health literacy and financials
- Relief from debt
- Applications for disability
- Discussion of and assistance with medical care costs
- Screen for financial assistance
- Access to insurance enrollment tools for financial advocacy staff
- Institution-wide use of financial advocacy services
- Guidance with legal needs
- Access to medications
- Rapid identification of patients
- Referrals for assistance with unpaid non-medical bills
- Reimbursement for services
- Review of health insurance benefits
- Use of financial tumor boards to improve financial advocacy services.

The literature scan revealed that there is great variability in the methods used to screen patients for financial distress, as well as the types of financial advocacy services provided by cancer care teams. Standardization of how cancer programs and practices, clinics, hospitals, and health systems screen for current and potential patient financial distress and the types of financial services that are offered is needed to better understand the outcomes and impacts of oncology financial advocacy. Further, clear and common metrics are needed to evaluate the success of financial advocacy programs and the implementation of financial advocacy services.

### The Delphi Technique

ACCC chose to adapt the Delphi technique to follow a “Delphi process”<sup>66</sup> to create the new Financial Advocacy Services Guidelines since the evidence-base regarding financial advocacy programs, practices, and policies is still emerging. The Delphi technique is often used to collect expert opinions and identify consensus around the development of practice guidelines. To oversee the association’s Delphi process, ACCC convened a task force of seven experts in financial advocacy. These experts represented multidisciplinary backgrounds in healthcare, including oncology, nursing, navigation, social work, research, policy, patient advocacy, and administration.

### Selection of Experts

Delphi panel experts were defined as individuals with extensive knowledge of financial advocacy programs and services in oncology and the populations they are intended to serve. Knowledge should have been gained through employment, advocacy, academic research, and/or personal experience with receiving financial advocacy services. ACCC solicited panelists who represented the following roles:

- **Dedicated oncology financial advocacy staff (e.g., advocates, navigators, counselors, others)**—Those who are employed by a cancer program or practice, clinic, hospital, health system, or other clinical care organization, whose sole or primary professional job is to help patients with cancer through financial advocacy services to prevent or reduce financial toxicity. Services may include, but are not limited to, assisting with Medicare or Medicaid enrollment, accessing independent charity programs, optimizing insurance, leveraging co-pay or patient assistance programs, and meeting basic needs.
- **Multidisciplinary cancer care staff**—Those who serve in a clinical or non-clinical position on the multidisciplinary cancer care team, with a role in providing services related to mitigating the financial toxicity of care (e.g., physicians, advanced practice providers, nurses, pharmacy staff, social workers, revenue cycle/prior authorization specialists, patient navigators, administrators, etc.).

- **Financial advocacy subject matter experts**—Academic researchers, quality improvement specialists, and others with published or demonstrated expertise in financial advocacy in oncology.
- **Patients and patient advocates**—Individuals with direct and/or indirect expertise on patients’ lived experience with cancer and accessing financial advocacy services (e.g., non-profit organization representatives, helpline volunteers, patients serving in an advocacy role or on steering committees or boards related to cancer care, etc.).

### Panel Composition

Prior to the Delphi panel recruitment, ACCC and its task force agreed to fill out a potential roster of 40 experts to 50 experts who represent diversity in practice setting, geography, demographic background, and experience. ACCC created an online form to solicit nominations from colleagues and individual self-nominations for eligible panel participants.

Information collected included participants’ contact information, job information, practice setting, geography, patient population served, professional experience and specialty, and personal demographic data to ensure diverse perspectives were represented on the panel. ACCC and its task force members coordinated in conducting outreach to professional contacts and key voices in the field, who were identified through a scan of peer-reviewed literature and internet searches. Snowball outreach was also used, such as asking cancer advocacy organizations and associations to distribute this panel opportunity to relevant audiences through email listservs and word of mouth. To participate in the Delphi process, identified experts must:

- Be at least 18 years of age at the time of recruitment
- Have regular access to the internet for questionnaire completion
- Have a valid email address
- Be able to read, write, and understand English.

## Guiding Principles

The task force and ACCC are committed to an inclusive and consensus-based decision-making process. The following guiding principles were developed based on 2021 Financial Advocacy Network meetings and were agreed to by task force members at the start of the Guidelines’ development process to serve as a North Star in decision making:

- **Patient-centeredness**—The Delphi process and resulting Financial Advocacy Services Guidelines are respectful of and responsive to patient preferences, needs, values, support systems, and identities. This ensures that consideration for patients’ best interests guide all decisions during the Delphi process, and the resulting guidelines are communicated clearly to meet their needs.
- **Equity**—The Delphi process and resulting guidelines are designed to equalize the health outcomes of disadvantaged social groups with the outcomes of their more advantaged counterparts. This refers to the distribution and design of healthcare resources and programs, including all resources, policies, and

programs that play an important part in shaping one’s health—many of which are outside the immediate control of the healthcare sector.

- **Engagement**—The Delphi process and resulting guidelines have meaningful involvement of multiple partners (see *Selection of Experts*, below) throughout—from planning to disseminating results.
- **Value**—The Delphi process and resulting guidelines focus on improving the patient and multidisciplinary cancer care team experience, the health of populations (i.e., outcomes) overall, and the optimization of healthcare costs.
- **Feasibility**—The Delphi process and resulting guidelines are practical, with differing interests and/or views being anticipated and acknowledged, and resources (tangible and intangible) are considered.
- **Rigor**—The Delphi process and resulting guidelines are explicit, public, open to critique, and safeguarded against bias.

Recruitment took place from February to May 2022. ACCC received 77 nominations, including self-nominations, through Qualtrics—an online survey platform. For individuals who were nominated by their colleagues, ACCC followed-up with them using a personal email that requested they complete the self-nomination form. At the close of recruitment, ACCC received 66 completed self-nominations for Delphi panel participation. ACCC and its task force then reviewed the completed nominations and used the previously mentioned guiding principles and pre-determined criteria to finalize the Delphi panel invitation list.

Formal invitations were extended to potential panelists via an email from ACCC. The email included an overview document outlining the Delphi process and goals of the Guidelines. Invited experts were directed to complete a questionnaire committing their participation for the entire duration of the Delphi process or to decline participation. Forty-nine panelists accepted ACCC's Delphi panel invitation, and, while some panelists met criteria for multiple categories, they were balanced in the following manner:

- 16 dedicated oncology financial advocacy staff
- 16 multidisciplinary cancer care staff
- 6 financial advocacy subject matter experts
- 11 patients and patient advocates.

### ACCC Delphi Process

The Delphi process for creating the Guidelines took place from June and September 2022. ACCC worked with the task force to develop an initial list of financial advocacy service domains and potential guidelines that drew from the association's 2018 guidelines, as well as financial advocacy services found through the literature scan. As part of the Delphi panelists' commitment questionnaire, participating individuals were asked to respond to open-ended questions about which financial advocacy services they believed to be the most important to include as a part of formal financial advocacy programs and what resources a financial advocacy team needs to succeed in providing these services. Responses were grouped with other similar responses and used to edit or add to ACCC's existing list of proposed guidelines.

ACCC then developed a questionnaire from the list of proposed guidelines. The task force reviewed this list for clarity and flow and pilot-tested the online questionnaire,

## Implementation Considerations

With the conclusion of the final round of ratings, the **panel reached consensus that 43 proposed guidelines should be financial advocacy services guidelines.**

Of these 43 guideline guidelines:

- 1 guideline reached panel consensus (75 percent or more) on being a minimum service.
- 17 guidelines trended toward being minimum services (60 percent to 74 percent of the panel agreed).
- 22 guidelines achieved consensus but did not reach agreement on being minimum or enhanced services.
- 2 guidelines trended toward being enhanced services (60 percent to 74 percent of the panel agreed).
- 1 guideline reached panel consensus (75 percent or more) on being an enhanced service.

which was programmed in Qualtrics. Panelists were provided thorough instructions for completing the questionnaire, guiding principles, key terms, a personal link to access the questionnaire, and information on rating each proposed guideline. Panelists then selected one of the following responses for each proposed guideline:

- Should not be a guideline
- Should be a minimum guideline
- Should be an enhanced guideline
- Not sure/I do not have enough information to choose.

Panelists were able to provide comments on each of the 44 guidelines presented in the questionnaire and were asked to provide additional responses to questions regarding timing and intervals of benefits re-verification, financial distress screening, screening tools, and advocate caseloads. To support questionnaire completion, ACCC utilized Qualtrics' supported email reminders as well as personal emails and phone calls to contact panelists regularly. Forty-five panelists completed this questionnaire, representing 13 dedicated

oncology financial advocacy staff, 16 multidisciplinary cancer care staff, 10 patients and patient advocates, and 6 financial advocacy subject matter experts.

Responses were totaled across the panel for each proposed guideline. When 75 percent of panelists responded that a statement either “should be a minimum guideline” or “should be an enhanced guideline,” it was retained and revised based on feedback. Of the 44 proposed guidelines, 75 percent of panelists agreed that 38 should be financial advocacy services guidelines.

Panelists were subsequently asked to respond to a final questionnaire, where they received a summary document with the original proposed guidelines, aggregate results of the first panel’s ratings, summary of panelists’ comments and the task force’s decisions, and revised guidelines. Panelists also received additional clarifying reminders about the scope of the Financial Advocacy Services Guidelines, focusing on *the services to be provided* and

not the role or department that would be delivering these services, defining what is meant by an established practice or process, clarifying minimum and enhanced services, and reminding them to rate through the lens of the field at-large, rather than their individual experience or organizational context. All panelists (n=49) received a personal link to the final questionnaire, and ACCC utilized the same reminder tactics as used with the previous questionnaire. Forty-five panelists completed the final questionnaire, with the same representation of roles previously mentioned. However, one individual from the patients and patient advocates group, who participated in the previous round, did not complete the final questionnaire. But, another individual from the patients and patient advocates group, who did not participate in the previous round, completed the final questionnaire.

**Although ACCC’s guidelines reached panel consensus for being minimum or enhanced services, the feasibility of this will vary across cancer programs and practices.**







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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 30,000 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](http://acc-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.

The **ACCC Financial Advocacy Network** is the leader in professional development training, tools, and resources that empower providers to integrate financial health into the care continuum and help patients gain access to affordable, high-quality cancer care.

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