

ASSOCIATION OF COMMUNITY CANCER CENTERS

MULTIDISCIPLINARY METASTATIC BREAST
CANCER SUMMIT: ADDRESSING DISPARITIES

October 7, 2019
Washington, D.C.

EXECUTIVE SUMMARY



Association of Community Cancer Centers

It Takes a Team: Identifying, Prioritizing, and Responding to the Needs of MBC Patients

When the Association of Community Cancer Centers (ACCC)—in partnership with the Cancer Support Community and the Metastatic Breast Cancer Alliance—launched its Metastatic Breast Cancer Project in 2016, the aim was to better understand and address the communication challenges and barriers facing this often under-represented patient population. With the guidance of an expert multidisciplinary advisory committee, ACCC performed an environmental scan and conducted interviews and site visits with ACCC member programs to develop resources that can help cancer programs better identify and meet the needs of their patients with metastatic breast cancer. This work culminated in the identification of best practices in patient support described in the workbook, *Metastatic Breast Cancer: Effective Principles & Practices in Patient Support*; the development of a curated, searchable Metastatic Breast Cancer Resource Library; and a follow-up publication describing how cancer programs have implemented effective practices to improve patient care.

As the cancer community's understanding and treatment of breast cancer continue to grow, patients with metastatic breast cancer have ever-increasing informational and communication needs. To help the cancer care community respond to the full spectrum of these needs, ACCC convened a day-long Metastatic Breast Cancer Summit in Washington, D.C. The by-invitation-only summit included individuals from across the multidisciplinary cancer care team, including social workers, program managers, nurse practitioners, oncologists, chaplains, nurse navigators, patient advocates, financial navigators, and others. Also included were some of the most knowledgeable specialists—people who had themselves been diagnosed with metastatic breast cancer.

After a day rich in discussion and interaction, the participants came together to identify a series of specific actions that, if enacted, could significantly enhance patient care and reduce disparities in treatment.

Assembling a Team

Upon opening the summit, ACCC Executive Director Christian G. Downs, JD, MHA, remarked, "Everyone knows what we have to do; it's more difficult to know *how* to do it. Today is the 'how to' part." The "what," observed Downs, are the largely agreed-upon goals that must be realized before all patients with metastatic breast cancer are able to access the full spectrum of clinical and supportive care services. These goals—such as equal access to psychosocial care, clinical trials, financial resources, and treatment options—will remain lofty ideals until the actions that can make them realities are widely adopted.

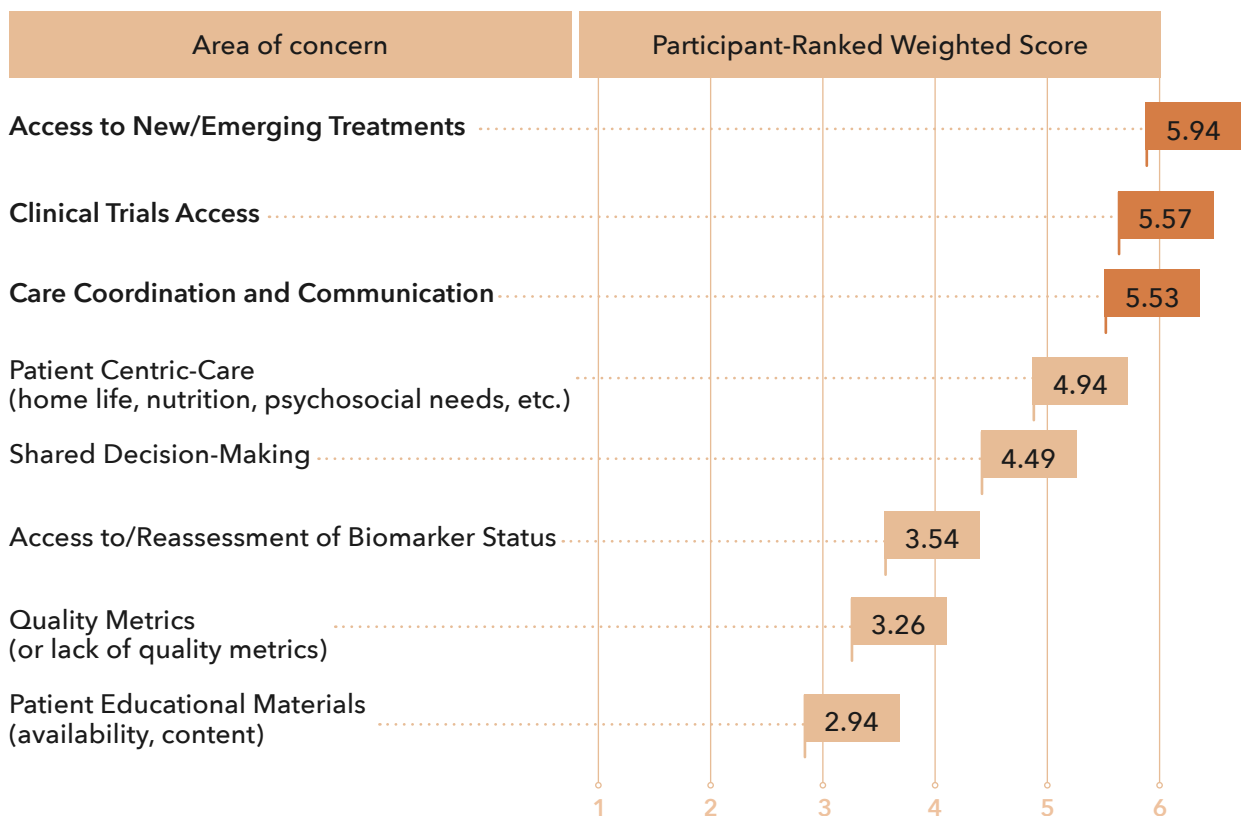
By bringing together a variety of stakeholders in the cancer care community, the day-long summit aimed to identify practical action items that cancer practices large and small can imple-

ment now to enhance and expand holistic care in their patient population. Downs observed that the collective skills of the summit’s participants represent the holistic model of care that is the ideal in oncology. By cultivating the accumulated knowledge of the multidisciplinary cancer care team, said Downs, new insights can arise and energize caregivers to pool their talents and enhance patient care.

Making a Wish List

The day’s conversation focused on the recognition that there are significant disparities in the resources available to individual patients. These disparities may be a function of geography, racial inequality, inadequate insurance coverage, limited personal finances, poor support systems, unequal access to clinical trials, and other factors mostly outside the control of individual patients.

In a continued effort to improve the care of patients diagnosed with metastatic breast cancer, ACCC conducted a Multidisciplinary Team Communication in Metastatic Breast Cancer survey of more than 100 care team members—representing 86 unique cancer programs—that measured progress and assessed areas for continued improvement in caring for patients with metastatic disease. Using data from this survey, and prior to the summit, participants were asked to prioritize the issues they believe require the most urgent attention in metastatic breast cancer care. Respondents gave the highest priority to patients’ inability to adequately access new and emerging treatments, followed by access to clinical trials, and poor care coordination and communication.



The summit began with participants introducing themselves and sharing what they perceive as the action that could have the most impact on improving the care of their patient population. Their answers included:

Enable Supportive Care

- Make essential supportive care services accessible to all patients.
- Leverage the patient data contained in EHRs to better customize supportive care.
- Promote understanding of the importance of supportive services, from palliative care to financial navigation.
- Give patients' psychosocial needs the same consideration as their clinical needs.
- Don't forget to address a patient's most basic needs. Keep in mind that patients don't know what they don't know. Teach them about diet, exercise, and wellness in addition to treating them clinically.

Address Disparities in Care

- Make comprehensive treatment choices available to all patients, regardless of geography or financial resources.
- Proactively identify disparities in knowledge of disease and treatment options and educate patients and caregivers accordingly.
- Address unconscious biases based on race, geography, and socioeconomic factors.
- Foster trust in and build relationships with groups traditionally distrustful of the medical research community.
- Give all patients access to biomarker testing.

Enhance the Doctor/Patient Relationship

- Improve shared decision-making tools and practices.
- Help patients make informed decisions in accordance with their values and beliefs.
- Address asymmetries in doctor/patient relationships.

Enable Access to Clinical Trials

- Remove obstacles to clinical trial participation for metastatic breast cancer patients.
- Remove practical obstacles to clinical trials, including transportation, childcare, and work responsibilities.

Enhance Patient Well-Being

- Provide metastatic breast cancer patients access to resources specific to their needs.
- Enhance bereavement programs for family members and caregivers.
- Increase technology use to better manage symptoms and side effects and communicate with care teams.

Learning to Ask

Throughout the summit, participants emphasized the need to recognize that breast cancer is not a monolithic disease. The many ways in which the disease manifests itself and the diversity of treatments available—many still in the clinical trial phase—mean that patients with metastatic breast cancer will not necessarily be well-served by the “survivorship mantra” often embraced by patients diagnosed with early-stage breast cancer.

Rather, participants agreed, patients with metastatic breast cancer should have access to resources that are customized to their specific needs. Participants acknowledged that while many of these resources—such as clinical navigation services and peer support groups—are already well developed and available to some patients, many others lack access to them. As one participant noted, “The future is already here, but it is not evenly distributed.”

Participants pointed out that many patients face barriers to care that can have simple solutions, if the right resources are available. One participant noted that some of the most common barriers she sees to patient participation in clinical trials are easy to alleviate. “Barriers such as lack of childcare, transportation, and flexible work schedules can be removed with simple resources,” she said. “We need to bring our community resources together and get funding for the associated expenses of participating in clinical trials. We need to prioritize what our patients tell us they most need.”

“We don’t always ask our patients what they need,” agreed a participant who organizes retreats for women with metastatic breast cancer. “We just assume what is best for them. They may be embarrassed or ashamed to ask for help, so we need to make them feel comfortable telling us what they need to best cope on a daily basis.”

A social worker shared that her cancer program regularly consults with its oncology social workers to discover what they are hearing about patient needs to better address their concerns. When they learned that the partners of patients did not feel that they were getting the support they needed, the program created an online support group for them. “Team communication is essential,” said the participant. “We don’t know what patients are thinking unless we consult with one another.”

Another participant shared that patients may have unexpected reactions to supportive services undertaken with the best of intentions. She and her coworkers were surprised to find some patients resistant to receiving financial counseling services. After asking some questions, she learned that the patients to whom they offered financial navigation services felt “singled out” due to their insurance status or financial situation.

“Now all of our patients are assigned to financial navigators,” said the participant. “Simply asking some questions enabled us to make our patients more comfortable and get them the help they need.” Others agreed. “We will never be as effective as we could be if we do not ask for patient feedback,” said another participant. “Simply asking can teach us how we can most effectively obtain the information we need without making patients feel uncomfortable or stigmatized.”

Customizing Supportive Care

Several summit participants noted that a metastatic breast cancer diagnosis can bring with it an entirely different patient experience compared to that of patients with early-stage breast cancer.

“When you are first diagnosed with breast cancer, you are sent to surgery,” said one participant. “That’s usually the ‘Pink Room’ with lots of informational brochures about the different types of support and resources available. If you are then diagnosed with metastatic breast cancer, you are sent to a clinic that treats all types of cancers. There’s no pink; it’s a completely different environment. There are no folders listing the support resources available. These patients have different needs, and there is little customized to them.”

Participants agreed that, in general, the supportive care that patients receive can be “front-loaded,” in that patients are offered resources upon diagnosis, but there is less emphasis on those resources as treatment progresses and relapses occur. “We tend to do psychosocial distress screenings only upon diagnosis,” observed one participant. “We need to screen patients throughout treatment and as their illness progresses. There are pivotal points in the cancer journey in which patient needs can change dramatically.”

Some patients receive scant resources even upon diagnosis, depending on their geographic location. Smaller rural practices may not be able to employ social workers who can oversee the supportive care patients may need. In these cases, it’s essential that providers be plugged into the resources available in their communities. Reaching out to volunteer organizations that may be able to help patients with items such as transportation or childcare and then organizing that information into resource directories can be a tremendous service for patients who are unsure of where to turn for help. Several participants suggested that cancer programs incorporate supportive care into their business models, regardless of their programs’ size.

“Providers need to partner with community support services,” said one participant. “They can tell one another what needs they are seeing in their patient communities to get a better idea of where to direct their resources.” Participants agreed that a good practice for all cancer programs is to customize patient folders specifically to meet the needs of patients at different stages in the cancer journey. “Folders should not be offered only upon diagnosis,” said one participant. “Patients are experiencing information overload at that time. Rather, customize support materials from a pool of resources that address where that patient is at that moment.” She added that practices should regularly curate and validate the resources they tell patients about to ensure they are still available and appropriate for their needs: “Folders don’t need to be reinvented each time, but they should be kept up to date.”

Identifying Obstacles to Clinical Trial Participation

Summit participants discussed a number of barriers to clinical trials for patients with metastatic breast cancer. Among them:

- **Awareness:** Patients are largely unaware of the existence of clinical trials that could be applicable to them. It’s important that education about these trials come from patients’ own oncologists. Some physicians remain reluctant to recommend patients to clinical trials if those trials are outside of their institutions.
- **Access:** Even when patients are proactive about pursuing clinical trials, it can be difficult to find information about the ones that could potentially help them. Even members of the cancer care team can have difficulty identifying trials applicable to their patients. When appropriate trials are identified, many incorporate stringent criteria that can exclude patients with metastatic breast cancer from participating.
- **Distrust:** Members of minority communities may distrust clinical research due to previous ethical violations within the research community. Summit participants pointed out that building trust within these communities is essential. Recruiting minority oncologists and support staff can help make important connections with patients.
- **Exclusion:** Clinical trials can have criteria that prevent minority groups from participating more so than other groups. These include requirements that participants are able to read and write English or prohibitions against comorbidities, from which minorities are likely to suffer.
- **Economics:** The expenses involved in participating in a clinical trial can be prohibitive for some. This can be particularly true for patients located in rural areas who must bear travel and lodging expenses to access treatment. Lost time at work and childcare expenses can also affect a patient’s ability to participate in a clinical trial and for trials that are not covered by insurance, some patients may be left out entirely.

Easing Clinical Trial Access

Summit participants offered a number of ideas to circumvent the multitude of barriers that may prevent individual participation in clinical trials. Among them:

- **Reframe the conversation:** Several participants maintained that how clinicians talk to patients about clinical trials can make a big difference in whether they want to participate in them. “Inviting patients to be more active participants in their care can make a big difference,” said one participant. “Asking your patient, ‘How would you like to be a *partner* in a clinical trial?’ reframes the discussion so patients feel more empowered.” Another participant shared that her practice has created scripts to teach clinicians how to best approach conversations about clinical trials with their patients.
- **Include patients in decision-making:** Since clinical trials have not always been user-friendly for patients, participants suggested including them in decision-making about how trials are run. One participant said that her institution includes patients on their institutional review board. Another participant talked about the importance of incorporating patient feedback at every level of drug development. “Look at the quality of life of patients on treatment regimens,” she said. “Patients’ treatment decisions will not necessarily be based only on clinical factors.”
- **Connect to patients in their own communities:** Several participants talked about the importance of reaching out to historically marginalized groups in their own communities. “I’ve gone to churches and barbershops in nearby African-American communities to talk about clinical trials and cancer care, and that has sparked interest in what we do,” said one participant.
- **Consider the patient’s point of view:** “Ask yourself what a patient needs to understand before she can make an informed decision about joining a trial,” suggested one participant. “And then make sure she gets that information.” Several participants mentioned that trial protocols can be lengthy and difficult to understand. More concise, easier-to-read documents may aid in informed decision-making.
- **Educate and advise:** If patients feel they’ve made an informed decision, they will feel more empowered and be more committed to following through with a clinical trial until its conclusion. Members of the cancer care team can help patients consider all of the pros and cons by listing for them the factors they should take into consideration (e.g., time, expense, travel, clinical requirements) and helping them make the best decision for their circumstances.

Articulating a Call to Action

In the final exercise of the summit, participants worked together to evaluate the recommendations they had made throughout the day to dispel disparities in care for patients with metastatic breast cancer and move toward a more equitable distribution of clinical and psychosocial resources. Participants narrowed their recommendations down to six action items that they ranked highest in both feasibility and potential impact:

- **1. Develop comprehensive care models and pathways:** This is the foundation on which all patient care needs are articulated and addressed. Develop a steering committee composed of people who are already serving patients with metastatic breast cancer and leverage what is working for them.
- **2. Create patient care plans:** Leverage existing resources from cancer programs and practices that are already creating care plans. Ask them what is and is not working for them and apply their lessons learned to your practice.
- **3. Create patient folders:** Collect information on resources specifically tailored to the needs of patients with metastatic breast cancer. Continually update these resources to ensure their relevance and availability.
- **4. Leverage navigators:** Seek out and use clinical, financial, and lay navigators to help create a more level “playing field” among patients by ensuring everyone has access to the same resources.
- **5. Leverage telemedicine for supportive services:** Reach more patients by identifying a “mother ship” (large cancer care site) to provide virtual supportive care to rural and less-well-resourced programs.
- **6. Strengthen and maintain a resource warehouse:** Keep a large, continually updated pool of materials that physicians, nurses, social workers, navigators, and others can draw from for individual patients. Stay connected to your community to ensure you are aware of the current resources available to those you serve.

When clinicians offer the same supportive care services to all of their patients with breast cancer, they are not being mindful that, depending on when their patients are diagnosed, the progression of their disease and personal circumstances, needs can differ significantly.

Summit participants repeatedly emphasized the importance of not viewing breast cancer as a monolithic disease that everyone experiences in the same way. Rather, individuals with metastatic breast cancer have unique needs that are not always best served by the supportive care offerings made available to all breast cancer patients. Determining the most pressing needs of this patient group, prioritizing those needs, and equitably distributing supportive care services to meet those needs should be the goal of every multidisciplinary cancer care team that serves patients with metastatic breast cancer.



Association of Community Cancer Centers

1801 Research Blvd., Suite 400
Rockville, MD 20850
301.984.9496
acc-cancer.org

A publication from the ACCC education program, "Metastatic Breast Cancer Project." Learn more at acc-cancer.org/MetastaticBreastCancer.

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.

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This publication is a benefit of ACCC membership.

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This project is sponsored by Pfizer Oncology.

