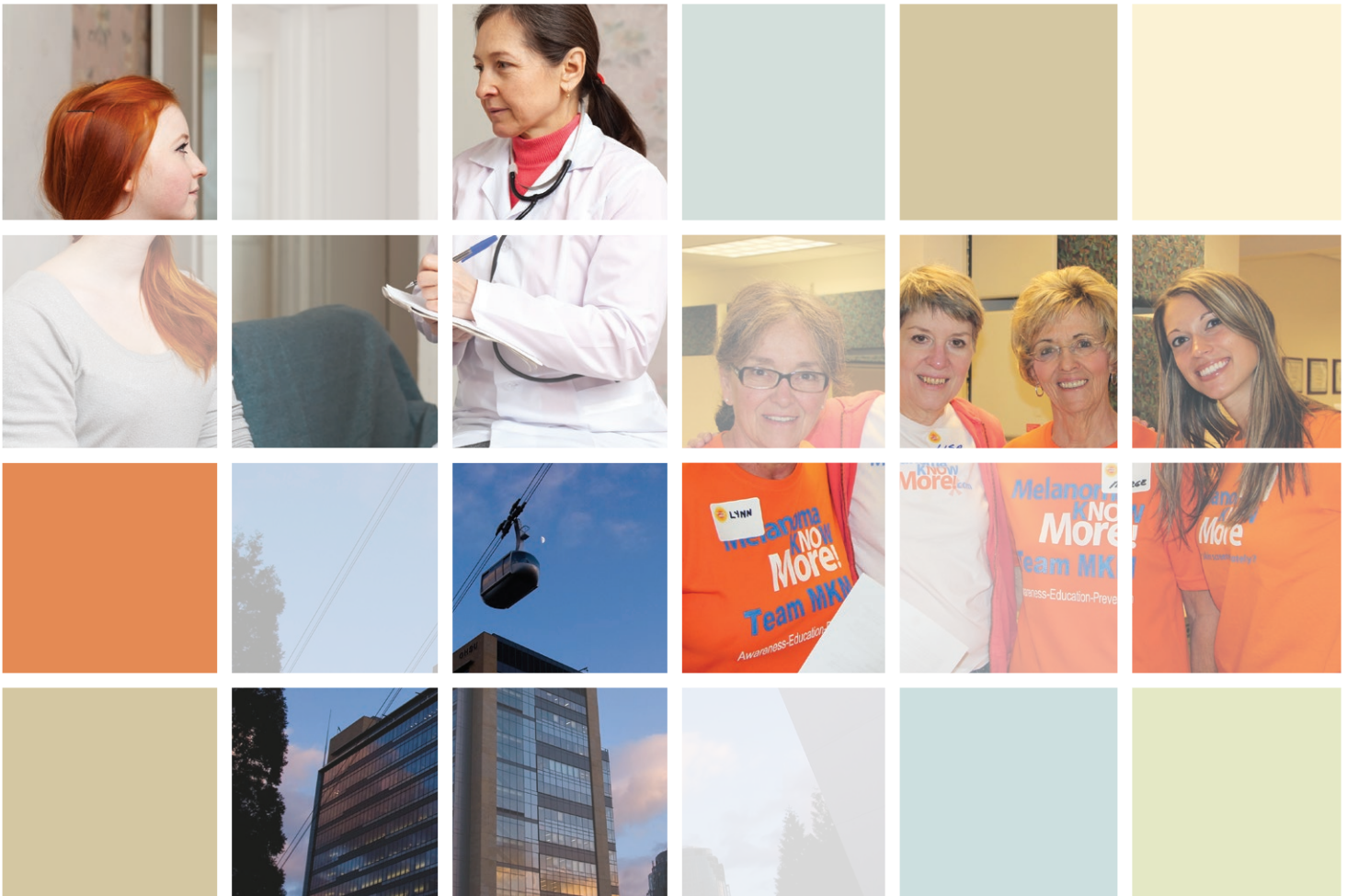


Melanoma

Improving the Patient Experience

*Practical Strategies for
Community Cancer Centers*



ASSOCIATION OF COMMUNITY CANCER CENTERS

Melanoma

Improving the Patient Experience

Practical Strategies for Community Cancer Centers

The *Melanoma: Strategies & Tools to Improve the Patient Experience* education project and this supplement are sponsored through a grant provided by Bristol-Myers Squibb.

We would like to acknowledge and thank the members of the ACCC Advisory Board who contributed their valuable time and expertise to this educational project.

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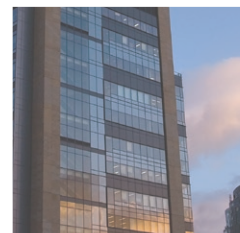
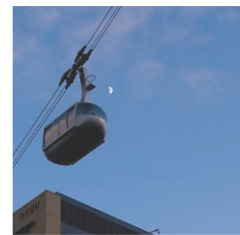
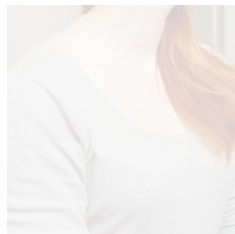
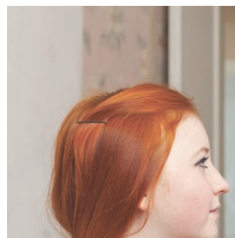
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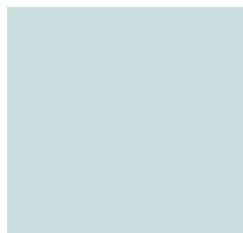
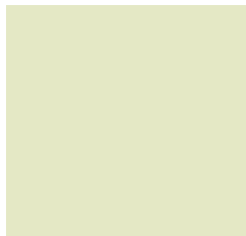
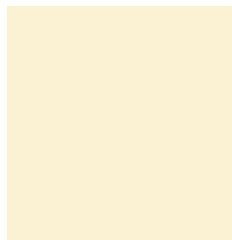
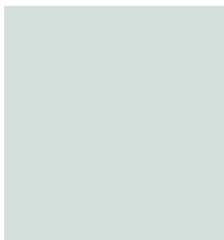


Table of Contents

- 2** Introduction
- 3** Needs Assessment Summary & Effective Practices

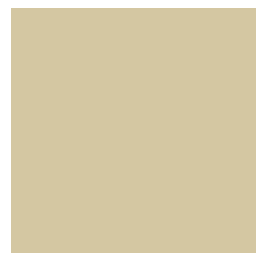
Effective Practices from Community Cancer Centers

- 5** Moffitt Cancer Center
- 7** Oregon Health & Science University Knight Cancer Institute
- 9** Spectrum Health Cancer Center
- 11** The Christ Hospital Cancer Center
- 12** The Regional Cancer Center
- 13** Wake Forest Baptist Medical Center

- 15** Assessment of Effective Practices: Pre/Post Test
- 16** Melanoma Effective Practices Pre/Post Checklist

ABOVE: AT SPECTRUM HEALTH CANCER CENTER, JACK DEKINGA, MD, A DERMATOLOGIST, AND LEON OOSTENDORP, MD, A SURGEON, DISCUSS A PATIENT'S TREATMENT PLAN DURING THE MELANOMA CLINICAL TEAM MEETING.

PHOTOGRAPHS COURTESY OF: COVER [ON RIGHT] THE CHRIST HOSPITAL CANCER CENTER; [BOTTOM LEFT] OREGON HEALTH & SCIENCE UNIVERSITY; P. 1, SPECTRUM HEALTH CANCER CENTER; P. 5,6, MOFFITT CANCER CENTER; P. 7, OREGON HEALTH & SCIENCE UNIVERSITY; P. 9, SPECTRUM HEALTH; P. 12, THE REGIONAL CANCER CENTER; P. 13, WAKE FOREST BAPTIST MEDICAL CENTER; BACK COVER, MOFFITT CANCER CENTER.



Introduction

Jennifer Bires, MSW, LICSW, OSW-C

Unlike many other cancers, the rates of melanoma have been increasing in the U.S. over the last several decades. According to the Melanoma Research Foundation, 1 in 50 Americans has a lifetime risk of developing melanoma.

Detection, diagnosis, and treatment of melanoma involves many different specialties including outreach and screening staff, primary care physicians, surgeons, dermatologists, dermatopathologists, medical oncologists, oncology nurses, and others. As part of its *Melanoma: Strategies & Tools to Improve the Patient Experience* project, ACCC has developed this non-clinical guide. It is our hope that knowledge of effective practices in care coordination and delivery can help to improve patient access to care, to the latest treatment options, and to clinical trials.

In a needs assessment survey of ACCC member cancer programs conducted for this project, respondents indicated that among the greatest challenges in treating and supporting melanoma patients in the community setting were patients' financial and/or personal barriers (46%), followed by the challenges of transition of care between a variety of healthcare settings (44%), and keeping up with the latest treatment modalities (36%).

Based on criteria developed from the needs assessment and information gleaned from follow-up interviews, from respondents six cancer programs were identified as

having effective practices in caring for patients with melanoma. In this non-clinical guide, these centers share effective programmatic strategies that have helped in improving the melanoma patient experience. These programs employ:

- A multidisciplinary approach to treating melanoma
- Processes to streamline scheduling across disciplines of patients who have been diagnosed with melanoma
- Resources that reduce barriers to care
- Successful marketing approaches for the melanoma program
- Outreach activities related to skin cancer screening.

On pages 15–16 there is an Assessment of Effective Practices: Pre/Post Test and a Melanoma Effective Practices Pre/Post Checklist that community cancer programs can use in assessing their services for patients with melanoma. For more information about the project and additional resources visit: www.accc-cancer.org/melanoma.

DID YOU KNOW ?

Approximately 9,480 people are expected to die of melanoma (about 6,280 men and 3,200 women) in 2013.

Source: American Cancer Society

Needs Assessment Summary & Effective Practices

The ACCC *Melanoma: Strategies & Tools to Improve the Patient Experience* project was launched in spring 2013 with the goal of improving the quality of care for melanoma patients being treated and cared for at community cancer centers. The project seeks to:

- Identify current methods of treatment and barriers to treating melanoma patients in the community setting
- Develop effective strategies for improving the patient experience by identifying a broad cross section of programs that are currently offering replicable “effective practices” in the treatment of melanoma
- Provide tools that allow providers to work across multiple disciplines and departments to improve the patient experience.

As a first step in this initiative, ACCC conducted a needs assessment survey of its membership. An online survey instrument was developed by consultants Meniscus Educational Institute and Spectrum Medical Education, with input and guidance from the project’s expert Advisory Board. The survey was conducted from April 17 through May 6, 2013. The survey received 255 responses.

Melanoma treatment questions focused on the following:

- Confidence levels for identifying and treating patients with melanoma
- Melanoma topics of interest for education and information

- Tools and practice-based resources currently in use and those that are needed and likely to be used
- Barriers to learning and change
- Challenges in treating and supporting melanoma patients and their families
- The presence of multidisciplinary team-based care for melanoma patients
- The existence of a library for patients with melanoma and their families
- Use of treatment guidelines
- Clinical trial involvement
- Identification of “effective practices” and what criteria constitute a strong program
- Areas in need of strengthening in the care of patients with melanoma.

Summary of Survey Results

The survey respondents included oncology nurses (20%) and cancer program administrators (13%), medical oncologists (10%), pharmacists (7%), practice managers or administrators (6%), hematologic oncologists (5%) and surgical oncologists (5%), and others, including nurse practitioners and researchers. Most respondents (46%) practice in hospital-based cancer centers, 22% work in outpatient cancer centers, and 12% work in private physician oncology practices and are not hospital employees.

Nearly half of respondents (49%) treat between 1 and 19 melanoma patients per year in their cancer program, followed by 27%

who treat 20–50 patients per year, 12% who treat 51–80 patients per year, 5% who treat 81–100 patients per year, 3% who treat 101 to 200 patients per year, and 5% who treat more than 201 patients per year.

The respondents reported being most confident in recognizing melanoma risk factors, signs and symptoms, treatment options and survival rates, providing supportive care and continuity of care between care settings, and managing side effects of therapy. Areas in which respondents reported being less confident included classification and staging, treating aggressively relapsing melanoma, discussing clinical trials with patients, and identifying and using “effective practices.”

When asked whether melanoma cases are reviewed in a multidisciplinary manner at their cancer programs, 52% of respondents said their cancer program has a multidisciplinary model of care, and 28% percent report that they have multidisciplinary care “sometimes.” Fourteen percent said no multidisciplinary team and 7% didn’t know.

In general, the multidisciplinary care team includes the medical oncologist (97%), radiation oncologist (85%), pathologist (80%), oncology nurse (70%), surgical oncologist (65%), radiologist (58%), and dermatologist (44%), followed by genetics counselor, pharmacist, and cancer program administrator.

Clinical practice guidelines (National Comprehensive Cancer

About 76,690 new melanomas will be diagnosed in the U.S. in 2013.

Source: American Cancer Society

Network, American Society of Clinical Oncology, and American Academy of Dermatology) are the most widely used resources, followed by patient education brochures and clinical trial information.

Challenges and Barriers

Respondents reported that the biggest challenges in treating and supporting melanoma patients and their families in the community setting were patients' structural, financial, and/or personal barriers such as transportation and insurance (46%). This was followed by the challenges of transition of care between numerous healthcare settings (44%), keeping current on the latest treatment modalities (36%), and translating clinical trial information into practice (28%).

The "other" challenges noted were financial resources of patients, insurance covering new treatments, primary care physicians not screening for melanoma, difficulty getting appointments with dermatologists, and use of multiple EMRs across the treatment team (i.e., lack of EMR integration).

Survey respondents indicated a need for additional clinical practice resources and tools including practice guidelines, patient education brochures, and clinical trial information.

Effective Practices

Of those respondents reporting a strong clinical program for melanoma patients, availability of clinical trials, including strong recruitment

for trials; a multidisciplinary approach to treatment and care; and qualified, knowledgeable, passionate providers were ranked as the top three criteria. The following effective practices criteria were identified through the survey:

- Access to clinical trials
- Multidisciplinary approach to care
- Qualified "top notch" providers (knowledgeable and passionate)
- Oncologists with melanoma specialty
- Clinical research support for trials
- Presence of a patient navigator
- Availability of regional experts
- Use of clinical guidelines (NCCN, ASCO, AAD)
- Supportive, holistic program.

Based on survey responses, the following criteria were used to identify respondents as having strong, effective programs:

- Number of patients treated for melanoma per year
- High confidence levels
- Involvement in clinical trials
- Use of practice guidelines
- Qualified providers (knowledgeable and passionate about caring for patients with melanoma)

- A multidisciplinary team
- Supportive care for patients
- Use of resources and tools
- Self-reported strong program.

This guide features six ACCC member programs identified from among survey participants as having effective programs for melanoma:

The Christ Hospital Cancer Center
Cincinnati, Ohio

Moffitt Cancer Center
Tampa, Florida

Oregon Health & Science University Knight Cancer Institute
Portland, Oregon

The Regional Cancer Center
Erie, Pennsylvania

Spectrum Health Cancer Center
Grand Rapids, Michigan

Wake Forest Baptist Medical Center
Winston-Salem, North Carolina

In this publication, these programs share replicable models, practical strategies, and insight into effective practices for improving the delivery of quality care to patients with melanoma and their families. More project resources are available online at www.accc-cancer.org/melanoma.

Moffitt Cancer Center

The H. Lee Moffitt Cancer Center & Research Institute in Tampa, Florida, is the only National Cancer Institute Comprehensive Cancer Center based in Florida. The Florida State Legislature created Moffitt, which opened in 1986, to address the burden of cancer in the state. The cancer center is a private, nonprofit, freestanding academic institution affiliated with the University of South Florida. The hospital has more than 5,000 cancer discharges per year and the outpatient clinics see more than 324,000 visits annually. The clinical care services and research activities are organized into 13 interdisciplinary clinical programs.

According to Moffitt's 2011 Annual Report, in 2010 skin cancer (excluding basal cell and squamous cell carcinoma) was the second most frequently seen cancer (11.6%), after breast cancer (11.7%).

Moffitt Cancer Center's Cutaneous Oncology Program specializes in the evaluation and treatment of patients with melanoma and other skin cancers. The program of care includes screening, diagnosis, staging, treatment, and long-term follow-up, both at Moffitt and in coordination with the patient's primary care physician. Moffitt offers the latest investigational treatments for melanoma. Physicians at Moffitt have helped pioneer the development and understanding of the role of lymphatic mapping and sentinel node biopsy for staging of patients with clinically negative nodes, as well as investigating adjuvant

therapy for node-positive patients.

A leading focus of melanoma research at Moffitt is on developing more effective therapies for patients with metastatic disease. This is a collaborative effort of scientists and clinical investigators involved in Moffitt's Total Cancer Care™, the Comprehensive Melanoma Research Center, and the recently awarded NIH Specialized Programs of Research Excellence (SPORE) grant.

Streamlining Access to Multidisciplinary Care for Diagnosis and Treatment Planning

A key effective practice exemplified at Moffitt Cancer Center is providing patients with timely access to the multidisciplinary care team for initial diagnosis and treatment planning. Melanoma patients are able to see all the healthcare providers involved

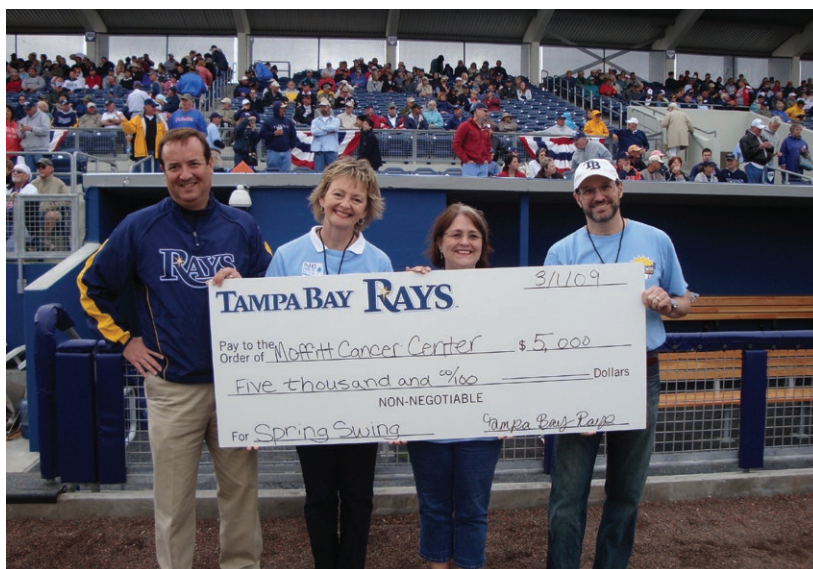
in their diagnosis, staging, and treatment planning in one to two visits to the Moffitt Cancer Center. Prior to the patient's first visit, the team reviews the patient's pathology report to ensure consensus on the diagnosis and the range of treatment options available. Moffitt pathologists review the slides before discussing the patient at a weekly multidisciplinary conference because "treatment is only as good as the diagnosis," said surgical oncologist Vernon K. Sondak, MD, chair of the Department of Cutaneous Oncology.

The comprehensive multidisciplinary melanoma team consists of oncologists, dermatologists, plastic surgeons, dermatopathologists, radiologists, nurses, and other providers. At Moffitt, members of this interdisciplinary group are teaching faculty, and all see patients.

Part of streamlining the care

NEW CASES ARE PRESENTED AT THE WEEKLY MULTIDISCIPLINARY MELANOMA CONFERENCE.





process is reducing patient wait times for appointments. Two new patient appointment schedulers work exclusively on scheduling cutaneous patients. All external referrals for appointments flow through them. The goal is for team members to see the patient within two weeks, and if surgery is needed, to schedule it within two weeks of the initial visit. New patients are presented at the weekly Multidisciplinary Melanoma Conference, which also involves discussion of intervention results and response to treatment for established patients.

For community-based programs, Dr. Sondak advises that establishing a process for scheduling and coordinating timely patient access is essential to effective care. To do so may require commitment to creating a clinic coordinator or navigator role to ensure insurance verification, slide review by pathology, and that necessary evaluations and testing have been completed before scheduling the patient. Organizational commitment is necessary for an effective melanoma program.

Multidisciplinary care for melanoma patients involves cross-discipline involvement including such specialties as dermatology, plastic surgery, surgical oncologists, pathologists, and others. If specialists are not available in the community or resources are limited, a program's capacity to see greater volumes of melanoma patients is likely to be hampered. Access to melanoma specialists and resources are key elements to providing effective care of patients with melanoma.

Community Outreach Programs for Prevention, Detection, and Education

Among Moffitt's annual outreach activities providing skin cancer screenings and education are the Mole Patrol® and Spring Swing®, Moffitt's Sun Safety Tour. For nearly 20 years, Moffitt's Mole Patrol® skin cancer screening program has traveled across the state to offer free skin cancer screenings and education to the public. The Mole Patrol® includes medical doctors and midlevel practitioners (physician assistants and nurse practitioners) who specialize in skin cancer and/or dermatology, as well as RNs and support staff. Moffitt experts work with providers from affiliated institutions and practices in the community. If suspicious lesions are found, patients are provided follow-up recommendations that they can take to their primary care provider or Moffitt affiliate.

Since 2008, Moffitt has partnered with the Tampa Bay Rays baseball team for the Spring Swing® Sun Safety Tour. The program provides free skin cancer screenings and sun safety tips to thousands of baseball fans attending spring training games in Florida. The event has

provided over 3,000 free skin cancer screenings in the past five years.

Support Services to Address Barriers to Care

At Moffitt Cancer Center, the main patient barriers to care stem from patients' needs for support services. These barriers include insurance issues, lack of transportation, the cost of travel to treatment, and similar challenges. Moffitt has dedicated social work support staff to help melanoma patients address these barriers to care.

Effective Practice: Leadership and Commitment to Caring for Patients with Melanoma

For community cancer centers, an important takeaway is that a strong degree of multidisciplinary involvement is needed in diagnosing, treating, and caring for patients with melanoma. "It is not enough to just have a committee," said Dr. Sondak. "There must be a strong, committed leader who will champion the program. A leader who can coordinate patient care and can make this coordination happen. Someone who says, 'I am going to make this team concept successful' and who will recruit like-minded team members."

Oregon Health & Science University Knight Cancer Institute

Oregon Health and Science University (OHSU) Knight Cancer Institute in Portland, Oregon, is the only National Cancer Institute-designated cancer center between Sacramento and Seattle. Knight Cancer Institute employs more than 650 doctors, nurses, scientists, and staff. The Institute's research efforts comprise four research programs: cancer biology, solid tumors, hematologic malignancies, and cancer prevention and control. These interdisciplinary and collaborative programs encompass the full spectrum of translational research. The cancer program sees more than 3,000 new cancer patients annually; of these, approximately 420 are patients with melanoma.

Processes to Streamline Patient Access to Care

Both internal and external referrals to the melanoma program at the Knight Cancer Institute start with an intake interview. The intake process involves two navigators, the front desk scheduling navigator (non-clinical staff) and the clinical RN melanoma nurse navigator. The scheduling navigator gathers all the necessary patient information, including imaging, and identifies any clinical information gaps (such as labs or imaging). The program has designed a template for this process, which includes a standardized information packet that the patient completes. The goal is to assess the patient's needs and to schedule the



patient's first clinic appointment within 1 to 2 weeks. If the patient needs staging, that appointment is scheduled within 1 to 2 weeks, and then the patient is again scheduled for a clinic visit in 7 to 10 days. Usually within 2 to 3 weeks, patients are staged (including surgically staged) and either triaged back to their own dermatologist or, if they do not have a provider, to an Institute dermatologist. Patients can enter or exit the melanoma program as the need arises. Patients with node positive or advanced disease are triaged directly to the multidisciplinary melanoma conference, which is held twice monthly. The nurse navigator guides the patient through

the clinic process and answers any questions that may arise. The process is customized to the patient's individual needs and disease stage, and to provide timely access to the appropriate providers.

Prospective Multidisciplinary Treatment Planning

The twice monthly multidisciplinary melanoma-specific conference is attended by medical oncology, radiation oncology, surgical oncology, pathology, dermatology, genetics staff, nuclear medicine, the cancer program data manager, and other interested residents and researchers. Patients with advanced disease are presented for prospective

Melanoma is the most common form of cancer for young adults 25–29 years old and the second most common for young people 15–29 years old.

Source: www.skincancer.org

treatment planning. Patients may be presented to the conference more than once.

At the conclusion of the conference, the patient is called and informed of the team’s treatment recommendation. Clinic nurses then schedule the patient for the next appropriate appointment.

Developing an Algorithm for Melanoma Clinical Trials

The melanoma team at Knight Cancer Institute meets regularly with cancer center staff to develop an algorithm for clinical trials, which goes through the Clinical Research Review Committee—the clinical part of the Institutional Review Board (IRB). This provides a process for consistently updating OHSU clinical trials for melanoma with an algorithm for stages of disease, open trials by disease stage, and when studies are closing.

Provider-to-Provider Outreach to Improve Patient Access to Clinical Trials

The melanoma program at Knight Cancer Institute has fostered a city-wide collaborative approach to facilitate matching melanoma patients with appropriate clinical trials. The two other hospitals in the city that see a large number of melanoma patients work with the Knight Cancer Institute melanoma team to assess cases within a city-wide central algorithm of open trials. By attending each other’s conferences and putting the patients first, “everyone sits down and, regardless

of hospital affiliation, can figure out the best place for the patient to go,” said John Vetto, MD, FACS, Professor of Surgery, Division of Surgical Oncology and Director of the Department of Surgery Cutaneous Oncology Program at the Knight Cancer Institute. “Unfortunately, it is the nature of melanoma that patients will fail one study and then go into another study.” By taking a city-wide approach to clinical trial accrual, “patients can get into the right study in the right order without having to leave their home community.”

Identifying Resources Close to Home for Patients

Oregon is a largely rural state. This means that travel for care can be a significant burden for patients. “We have to be cognizant of what resources are available where the patient lives, so that they can be home [for care when appropriate] and can come to Portland when they need a clinical study,” said Dr. Vetto. To this end, the melanoma program at OHSU strives to help patients find appropriate care close to home when possible.

The Knight Cancer Institute provides a range of support services for patients, including psychosocial counseling, financial counseling, and social work services. Support is available to patients, even by phone, when they are off site.

Spreading the Word

Dr. Vetto and colleagues from the Knight Cancer Institute melanoma

program are active in reaching out to other providers with education and information, including traveling around the state to speak with dermatology programs. In March 2014, the Knight Cancer Institute will present a program for dermatologists on what to do when melanoma is diagnosed for the American Academy of Dermatology. Cancer centers need to promote their melanoma programs both internally and externally. “In any medical center, there’s a silo effect with satellite clinics or in labs or departments where they are not aware of [the melanoma] program,” said Dr. Vetto. OHSU conducts Grand Rounds on melanoma and provides ongoing education on advances in melanoma diagnosis, treatment, and care.

Bringing the Stakeholders—Those Who Are Passionate About Melanoma—to the Table

For cancer programs considering developing a disease-specific melanoma program, it’s important to identify providers who want to cut across barriers—departmental barriers, specialty barriers, inter-institutional barriers, inter-hospital system barriers—to just focus on patient problems and be very open minded about who their colleagues are across the whole realm, recommended Dr. Vetto. “Recognize those providers in your area that have the same passion for melanoma that you do. Bring those people into the same room and the program practically builds itself.”

Spectrum Health Cancer Center

SPECTRUM HEALTH OFFERS WEST MICHIGAN'S ONLY MELANOMA TREATMENT CLINIC STAFFED BY A MULTIDISCIPLINARY TEAM OF EXPERTS.



Spectrum Health's Cancer Center is a Michigan-based American College of Surgeons Commission on Cancer-accredited program that diagnoses approximately 3,500 new cancer patients annually. Lemmen-Holton Cancer Pavilion in downtown Grand Rapids serves as the comprehensive center for outpatient cancer care. Inpatient cancer care is provided at the Lettinga Cancer Center at Spectrum Health Butterworth Hospital, located across the street. Select outpatient cancer services are also offered at Spectrum Health locations throughout West Michigan. Clinical research is available through the Spectrum Health Oncology Research team, the Grand Rapids Clinical Oncology Program, and CCOP, RTOG, ACoSOG, industry-related trials, and university-related trials.

Improving the Patient Experience by Bringing Services Close to Home

The melanoma program at Spectrum Health was developed with the goal to provide care for patients with melanoma in their home community. Previously, only two sites in Michigan had offered care for melanoma patients—one in East Michigan and the other in Southeastern Michigan.

A key to success in developing the new melanoma program was engaging physician participants early in the process. Physicians were involved in initial discussions on whether the timing was right for establishing the program and ways to improve care for patients with melanoma. The planning group included physicians from all involved specialties including dermatology,

medical oncology, radiation oncology, and surgery. The group came together with a common goal to better serve patients with melanoma and to offer patients an alternative to having to travel for care.

With strong physician support for the program, Spectrum Health was able to leverage its experience in developing other multidisciplinary team clinics and identify successful features that could be replicated. In this instance, Spectrum Health was able to replicate the role of a combined nurse navigator/clinic coordinator that had been successfully implemented in the breast cancer program. There was consensus from the planning group on the value of the nurse navigator for the melanoma patient population, which gave strong support for the combined role (nurse navigator/clinic coordinator) and the importance of having a primary point person for the patient and family from referral through the continuum of care.

Designing a One-Stop Melanoma Multispecialty Team Clinic

Spectrum Health now provides a melanoma treatment clinic staffed by a multidisciplinary team of

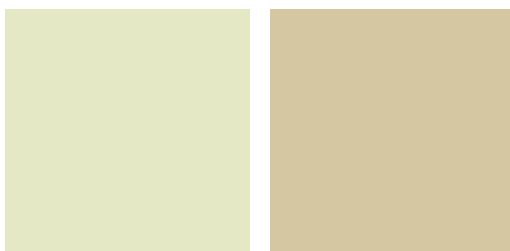
experts. The clinic is designed so that patients who have been diagnosed with melanoma can receive a complete evaluation and treatment plan or a second opinion in a single visit. Patients are referred to the clinic by their primary care physician or they may self refer. Team members participating in the clinic include dermatologists, medical oncologists, dermatopathologists, surgeons, radiologists, a nurse navigator, genetic counselors, a medical social worker, and other specialists as needed. The melanoma multispecialty team clinic visit includes:

- A comprehensive evaluation by all specialists in one day
- Clinical team meeting to determine the best treatment options or a second opinion
- Discussion of the treatment plan between the patient and the clinical team
- Connection to a nurse navigator who will guide the patient through the treatment process
- Written treatment plan provided to the patient with a copy sent to the referring or primary care physician.

Spectrum Health launched the melanoma multispecialty team clinic in 2011. Currently, the clinic is held twice a month on Fridays from 8:00 am to 2:00 pm. In the morning, patients are seen by all of the clinic specialists. Then a multidisciplinary conference is held. At the conclusion of the conference, one of the physician specialists presents the team's recommendations to the patient and reviews next steps.

The clinic is currently able to see five patients; however, due to patient demand, the process is being streamlined slightly so that up to six patients can be seen during the clinic hours.

Spectrum Health Cancer Center offers a full range of support services for patients and families



Barriers

PROGRAMMATIC BARRIERS One challenge in developing Spectrum Health's Melanoma Program has been the fact that physicians must be employed or part of Spectrum Health Medical Staff. This limits participation by some of the area dermatologists who do not have privileges within the health system.

BARRIERS FOR PATIENTS In terms of patient barriers to care, a common issue is limitation on patient insurance coverage that can create a barrier to accessing treatment (i.e., the type of recommended treatment is not covered by the patient's insurance). Transportation to and from treatment is also a barrier to care for some patients in this region, which includes rural areas of the state.

Spectrum Health has access to some clinical trials for melanoma, but currently patients still need to travel to participate in these studies. Increasing access to melanoma trials for patients is a goal for this program.

including a resource library, survivorship program, hospice program, palliative care program, genetic risk assessment/counseling, lymphedema program, nutrition counseling, dedicated oncology dietitian, oncology exercise/rehabilitation program, counseling services, healing garden, integrated care (e.g., yoga, massage therapist, acupuncture), pastoral care, pain management services, and hotel/housing for patients/family.

Getting the Word Out

One reason for the clinic's success is Spectrum Health's efforts in getting the word out to community providers. The organization's physician liaisons (non-clinical staff) reach out to community providers and referring physicians within a 37-county

region with information about the melanoma program, its outcomes, and resources. These outreach staff visit physician practices and talk with community physicians about their needs for this patient population and help problem solve on any expressed needs.

Another important element is outreach to the community. To help educate the community and promote sun safety and skin cancer awareness, Spectrum Health provides an annual skin cancer screening day at three sites in the community. The free program involves dermatologists, surgeons, physician assistants, nurses, and other staff—all of whom volunteer their time. In May 2013, the program performed 193 screenings.

The Christ Hospital Cancer Center

The Christ Hospital Health Network includes the main Christ Hospital campus in Mt. Auburn, Ohio, as well as outpatient centers and physician practices in more than 100 locations in the tri-state area of Ohio, Kentucky, and Indiana.

The Cancer Center at The Christ Hospital in Cincinnati, Ohio, is an American College of Surgeons Commission on Cancer-accredited program that sees about 2,000 new cancer patients each year. The cancer program sees between 100–200 melanoma patients annually. The multidisciplinary cancer care team includes oncology-certified nurses, physicians, radiation therapists, physicists, dosimetrists, dietitians, pharmacists, social workers, and a chaplain.

Committed Physician Champion

At The Christ Hospital Cancer Center, hematologist/oncologist Philip Leming, MD, is a physician leader with a strong interest in melanoma. Dr. Leming is chair of the Cancer Committee.

A melanoma research clinic is held each Tuesday at the Cancer Center. This clinic is staffed by Dr. Leming, one nurse practitioner, and four oncology nurses, who are cross trained to staff other cancer clinics as well. The melanoma clinic has grown to a full-day clinic, and typically sees from 30 to 40 patients, some of whom are on clinical trials. Melanoma patients at The Christ Hospital have access to ECOG trials for melanoma under

Dr. John M. Kirkwood at the University of Pittsburgh.

The 30-bed inpatient oncology unit nursing staff administer high-dose IL-2 over several days of intensive nursing care. These patients are monitored by highly skilled oncology nurses and supervised by Dr. Leming. This unit is one of only a few in the country that deliver this therapy in a non-ICU setting.

Dr. Leming is a founding member of Melanoma Know More, a local non-profit organization established to promote melanoma education, awareness, and prevention in the tri-state area. The organization's board members include physicians as well as local business leaders.

Uniting Providers in Multidisciplinary Approach to Care

Because melanoma involves specialists from multiple disciplines (primary care, dermatology, surgery, dermatopathology, pathology, oncology, radiology) communication and cooperation across specialties is critical. In this community, the Melanoma Know More organization has helped bring together specialists with a common goal of community outreach for melanoma education and prevention. The organization's efforts have not only strengthened outreach to the local community on skin cancer awareness, prevention, and treatment, but also provided common ground for physicians within the community who are passionate about caring for patients with melanoma. The

organization's active board spearheads numerous events, including a signature fundraising event, the Blues Event held annually in August with proceeds going to provide resources for melanoma prevention, screening, and education programs. The organization hosts and coordinates free skin cancer screenings on the second Saturday of every month, in partnership with all five local hospital systems in greater Cincinnati. Additionally, they provide information at various corporate and community health and wellness events, Cincinnati Reds games, and other community events, and conduct outreach education programs at local schools. Melanoma Know More unites interdisciplinary providers (including hematologist/oncologist, surgeon, dermatologist, dermatopathologist, and primary care providers) in its efforts and provides opportunities for peer-to-peer outreach. For example, during skin cancer screening events, primary care providers are invited to shadow a dermatologist during screening and observe both the screening exam and the process for expediting biopsy referral if needed. For screened patients needing biopsies, appointments with dermatologists are expedited within one to four weeks from the date of the clinic.

Supportive, Holistic Care

To help patients with the psychosocial and financial issues surrounding a melanoma diagnosis, the cancer program at The Christ Hospital offers dedicated social work and financial counseling services for patients and their families. In addition, the cancer center's comprehensive support services for patients and their families include counseling services, genetic risk assessment/counseling, lymphedema program, nutrition counseling, integrative care, pain management services, and palliative and hospice care.

The Regional Cancer Center



OUTREACH ON SUN SAFETY AT LOCAL ELEMENTARY SCHOOL.

The Regional Cancer Center (RCC) in Erie, Pennsylvania, is a joint venture of Saint Vincent Health System and UPMC Hamot, and is affiliated with UPMC Cancer Center. Accredited by the American College of Surgeons Commission on Cancer, the Center sees about 1,000 new cancer patients annually. Board-certified physicians and more than 160 staff provide leading-edge medical oncology, hematology, and radiation oncology services. Like many community cancer programs, The Regional Cancer Center does not have a disease-specific melanoma program; however, this community-based program has developed effective strategies for those with melanoma to improve the care experience for patients and their families. These strategies include:

Patient and Caregiver Advisory Panels

In 2011, The Regional Cancer Center initiated a patient advisory panel, and subsequently added a caregiver advisory panel. The groups, which have 4–5 members, meet quarterly and provide input on the care experience as well as suggestions for improvement.

Orientation for Caregivers

The cancer center offers a monthly orientation to caregiving facilitated by the cancer program's social workers. The two-hour class is also

open to patients. The orientation includes introductions to the financial counselor, dietitian, medical recordkeeping staff, and support programs. Additionally, each day in the cancer center, a caregivers' coffee break provides caregivers who are in the center with an opportunity to take a break, step back and relax, and meet with other caregivers to share stories and challenges and receive emotional support.

Option for Same-day Appointments

To streamline patient access, the cancer center has built in the scheduling option for same-day appointments if needed. The program utilizes disease-specific clinic coordinators, and has increased the number of mid-level providers. The cancer center employs one nurse practitioner and five physician assistants.

Leveraging EMR to Identify Ancillary Service Needs

In addition to the direct care provided to patients, supportive care services are also provided at The Regional Cancer Center through palliative care nurses, a dietitian, and social work services. The cancer center's electronic medical record (EMR) system will flag patients who may need these services, which increases programmatic efficiency

and streamlines patient access to these resources.

Outreach and Education

The Regional Cancer Center is located near a beautiful peninsula with a popular beach, and each year does outreach to the community on sun safety and skin cancer awareness. Last spring the cancer center partnered with local hospitals and a health insurance company to present "Can Your Tan," a program focused on educating teenage girls about the effects of tanning. In 2011, the cancer center offered an education program, "The Sunny Side of Melanoma," for nursing staff that focused on unique needs of melanoma patients.

Access to Clinical Trials Through Academic Medical Centers

The Regional Cancer Center offers some clinical trials and facilitates research participation at other facilities if necessary. Nurses on the research team review the patient's record and seek trial opportunities locally and at UPMC. They also search *clinicaltrials.gov* for other trials close to the patient's home or wherever the patient may want to travel. When a potential match is identified, if a patient is interested, the nurse works with the patient and the research sponsors to arrange for the patient's initial consult appointment. The research staff will forward the necessary information to the research study and will navigate the patient through the process.

Wake Forest Baptist Medical Center

The Comprehensive Cancer Center of Wake Forest University (CCCWFU), an NCI-designated comprehensive cancer center since 1974, is comprised of more than 121 faculty from 34 departments at Wake Forest Baptist Medical Center and Wake Forest University. The Cancer Center is the primary tertiary referral center for patients in a geographic region encompassing nearly 9 million people.

CCCWFU's multidisciplinary approach integrates consensus treatment planning that considers every possibility for the patient's health and streamlines the process to provide answers and care faster. The program's Melanoma Multidisciplinary Clinic allows patients to see an entire group of physicians who specialize in treating melanoma in one day. Through CCCFWU, patients have access to more than eight melanoma trials. CCCWFU sees more than 300 patients with melanoma each year.

The Role of a Dedicated Melanoma Nurse Navigator

The CCCWFU melanoma program is a strong proponent of utilizing a dedicated melanoma nurse navigator. The nurse navigator is the key point person for patients and families. When a referral is received, the nurse navigator contacts the patient by phone and begins to establish a relationship. During the phone interview, the nurse navigator conducts a risk assessment of each patient and family and works to help integrate the family into the



patient's care and treatment. She also gathers data and information on the patient prior to the first visit so that the visit is customized to the needs of the patient both medically and in terms of any supportive care needs, including psychosocial support.

"For these patients, it depends on where they enter the system," said Robin Petro, RN, melanoma nurse navigator at CCCWFU. "If they're referred as surgical patients or if they are referred as patients with metastatic disease—the needs of these patients are completely different. Being able to have that insight and plan for the patient before they come in has allowed us to maintain patient and family satisfaction. We treat the family as a unit." The navigator performs a risk assessment in terms of exposure to sun, chemicals, and other environmental factors, but also looks at risk in terms of potential supportive care needs. "[We] also look at the whole picture in terms of the social paradigm. What is their current role? Employment? How is their family

structure set up? This lets us start looking for needs that the patient may have that they don't even know they have yet," said Petro. This lets the program get a head start on securing resources for the patient.

"We hear from patients and families that by the time the patient comes for the first visit they feel like we are extended family members," said Petro. Most of the services patients need are located in one site on the campus, which alleviates the stress of having to travel to different locations for care.

Because the role is a clinical nurse navigator, the position also allows "portability across disciplines," said Petro. The melanoma navigator's clinical background provides physicians with a point person to communicate with as well. This model can save time and streamline communication across specialties.

The CCCWFU melanoma team is interdisciplinary and includes radiology, oncology, hematology/oncology, surgical oncology, radiation oncology, dermatology, endocrinology, plastic surgery, pain

Barriers

BARRIERS FOR PATIENTS Lack of knowledge and understanding about skin cancer and melanoma may be significant barriers to care.

Conflicting data may be a barrier (e.g., FDA recommendations for sunscreen are not consistent with AAD recommendations, for example).

Additional barriers to care include financial and access challenges. The area served by CCCWFU, from 2007 to the present, has experienced significant levels of unemployment with accompanying changes in health insurance and access. As an academic center located in relatively rural area, CCCWFU often sees patients who drive from 45 to 60 minutes to get to the cancer center. According to melanoma nurse navigator Robin Petro, RN, over the last five years there has been a reduction in patient assistance resources.

BARRIERS FOR PROVIDERS Lack of effective screening can be a barrier. While many dermatologists believe that the primary care physicians can perform screenings for melanoma, not all primary care physicians are educated to perform the screening and assessment effectively and these providers may have different levels of commitment to performing this screening. There is a need for a more strategic approach to these assessments and consistent access for patients.

management, ENT, physical therapy/occupational therapy for lymphedema, and support staff including psychosocial support and a survivor program.

Fostering Communication Across Specialties and Provider Groups

For programs interested in building a disease-specific melanoma program to better serve patients, physician buy-in is key and physician champions are essential. “There need to be strong champions who will embrace the program from each discipline,” said Petro. Because melanoma is a less prevalent cancer, justifying the dedicated melanoma navigator position was an initial challenge at CCCWFU.

The melanoma program was launched by Dr. Paul Savage in the

early 1990s. In 2006, the Tumor Immunotherapy Program was added under the direction of Dr. John Stewart, associate professor of Surgery and associate dean of Clinical Research and Innovation, vice chair of Surgery. The synergy between the programs identified a need for a nurse navigation component in 2006.

As the melanoma-specific program took shape, the navigator was also able to serve as a central contact point for referrals. Centralizing referrals allowed the program to gain a clearer picture of the patient population, which in turn has been important for future planning. The navigator also serves as a bridge to the patient’s primary care physician throughout the care continuum, and provides outreach to community

providers with information about the melanoma program at CCCWFU.

Individualized Support for Unique Needs of Melanoma Patients

Patients with melanoma face some stressors that are due to the nature of the disease itself. Unlike some other types of cancer, melanoma patients do not have a stable disease and face the stress of living with a disease that could progress at any time. Because many melanoma patients do not fit the image of a cancer patient popularized by the media, it may be difficult for employers and even family members to understand that they are quite sick.

When stage IV patients are referred to the program, it requires a different connection with the patient, Petro said. “For some patients, it may be necessary to address treatment and the potential for palliative care and hospice in the same visit. It is a hallmark of this cancer program that extensive communication with the patient and family has already taken place, so the patient can get the most from his or her first appointment,” she said.

This happens through a streamlined referral process. Once the referral is received, the navigator makes a personal call to the patient introducing herself, the program, and the physician she is representing at that time.

The navigator then has a conversation with the patient that may last 45 to 60 minutes at the patient’s discretion, covering the following:

- How the patient learns best
- How the patient wants to communicate
- Best times to communicate with the patient
- Review of risk assessment
- Behavioral changes that may take place in families because of family member’s diagnosis.



ASSESSMENT OF EFFECTIVE PRACTICES: PRE/POST TEST

Cancer programs can use this pre/post test in assessing implementation of effective practices.

Listed below are effective practices criteria identified through the ACCC needs assessment survey associated with effective melanoma practice. Rate each criteria using two scales.

Cancer program self-assessment: Assess your cancer program’s level with respect to each criteria, using a rating scale from “1” to “5,” where “1” is “not present” and “5” is “significant presence.”

Importance: Assess the importance of each criteria at your center, using a rating scale from “1” to “5,” where “1” is “not important” and “5” is “very important.”

CANCER PROGRAM SELF-ASSESSMENT	EFFECTIVE CRITERIA	IMPORTANCE
1 = Not Present 5 = Significant Presence		1 = Not Important 5 = Very Important
1 2 3 4 5	Access to clinical trials	1 2 3 4 5
1 2 3 4 5	Multidisciplinary approach to care	1 2 3 4 5
1 2 3 4 5	Qualified “top notch” providers (knowledgeable and passionate)	1 2 3 4 5
1 2 3 4 5	Oncologists with melanoma specialty	1 2 3 4 5
1 2 3 4 5	Clinical research support for trials	1 2 3 4 5
1 2 3 4 5	Presence of a patient navigator	1 2 3 4 5
1 2 3 4 5	Availability of regional experts	1 2 3 4 5
1 2 3 4 5	Use of guidelines (NCCN, ASCO, AAD)	1 2 3 4 5
1 2 3 4 5	Supportive, holistic program	1 2 3 4 5

DID YOU KNOW ?

Survivors of melanoma are about nine times as likely as the general population to develop a new melanoma.

Source: www.skincancer.org



✓ MELANOMA EFFECTIVE PRACTICES PRE/POST CHECKLIST

Cancer programs can use this checklist in implementing effective practices.

Directions: The following items have been identified as indicators of effective practices for the care of patients with melanoma. Indicate the degree to which your cancer program has these practices in place using the following scale:

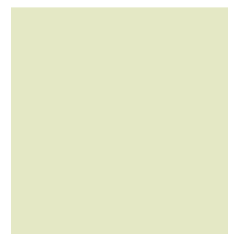
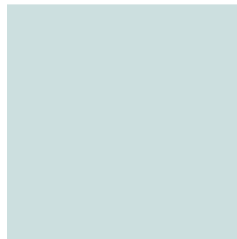
1 = not in place 5 = very effectively established

	1	2	3	4	5	COMMENTS
Physician champion on staff (e.g., melanoma expertise, commitment to caring for patients with melanoma, support for multidisciplinary approach to care)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Process to expedite scheduling appointments from screening to diagnosis to treatment planning (e.g., through effective use of EMR)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Process for frequent and effective communication with, and outreach to, referring physicians	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Streamlined, effective communication across different specialties and providers through a disease-site specific conference or clinic	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Processes in place to smooth patient transition between different settings of care (e.g., through patient navigator or care coordinator)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Support services for patients to address barriers to care (e.g., financial barriers, transportation barriers, knowledge barriers and psychosocial needs unique to this patient population)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Process to address clinical barriers such as limited space and resources, limited access to providers with melanoma expertise, limited clinical trials availability, etc.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Process in place to help patients access clinical trials	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Patient navigation services to follow patient from diagnosis through treatment and into survivorship	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Staff training on advancements in melanoma treatment and care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

Get Involved!

ACCC is seeking representatives from community cancer programs to participate in an assessment of this publication. Participants will be asked to complete two short surveys so that ACCC can evaluate whether the information included in this publication has helped other cancer programs improve the melanoma patient experience.

Your participation will help ACCC improve its educational services. If you would like to participate or need more information, visit www.accc-cancer.org/melanoma or email: providereducation@acc-cancer.org.



A publication of the Association of Community Cancer Centers
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This project is sponsored through a grant provided by Bristol-Myers Squibb.

