Melanoma
Specialty Registry Report 2017

What is the Melanoma Specialty Registry?

In 2017, approximately 87,000 people will be newly diagnosed with melanoma (American Cancer Society, 2016). Given the diverse nature of melanoma presentation and the many treatment modalities available to patients, it is vitally important that the patient experience is understood and documented.

The Melanoma Specialty Registry, which began accepting participants in December 2014, documents the experiences of a cross-section of people living with melanoma. The Melanoma Advisory Council— made up of melanoma specialists and other oncologists, behavioral scientists, patient advocates, and industry representatives—supports the efforts of the Registry by providing continued support and guidance on outreach, research, and the dissemination of findings (see a list of Advisory Council members at **www.cancersupportcommunity.org/RegistryIndexReport2017**).

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KEY FINDINGS

THIS REPORT CONTAINS NUMEROUS INSIGHTS
INTO THE MELANOMA EXPERIENCE. KEY FINDINGS INCLUDE:

QUALITY OF LIFE

43% OF MELANOMA SURVIVORS RATE THEIR OVERALL HEALTH AS VERY GOOD OR EXCELLENT

69% ARE CONCERNED ABOUT INSURANCE AND FINANCIAL COSTS OF CARE

57% ARE AT RISK FOR CLINICAL DEPRESSION

TREATMENT DECISION-MAKING

31% WERE PREPARED TO DISCUSS TREATMENT OPTIONS WITH THEIR DOCTOR

25% DID NOT FEEL AT ALL PREPARED TO DISCUSS TREATMENT OPTIONS WITH THEIR DOCTOR

44% FELT THEY WERE KNOWLEDGEABLE ABOUT TREATMENT OPTIONS

BODY IMAGE

46% WERE DISSATISFIED WITH APPEARANCE OF A SCAR

30% FELT LESS PHYSICALLY ATTRACTIVE BECAUSE OF MELANOMA AND TREATMENT

26% AVOID PEOPLE BECAUSE OF THE WAY THEY FEEL ABOUT THEIR APPEARANCE

FINANCIAL IMPACT

28% DID NOT TALK ABOUT COSTS OF TREATMENT WITH A MEMBER OF THE CARE TEAM

16% SPENT OVER $1,000 IN MONTHLY OUT-OF-POCKET COSTS RELATED TO THEIR MELANOMA CARE

40% REPORT SIGNIFICANT LEVELS OF INTRUSIVE THOUGHTS AROUND MANAGING THE COSTS OF CANCER CARE

Who is in the Registry?

This 2017 report presents analysis from 111 melanoma patients who reside in the United States and completed survey questions from the opening of the Registry in December 2014 to December 31, 2016 (in the tables below, the number of responses is 111 unless otherwise noted).

FIGURE 1 **MELANOMA SPECIALTY REGISTRY SURVEY DEMOGRAPHICS**

	NUMBER OF PARTICIPANTS (n)	PERCENT
AGE	(n = 77)	
Mean age	52.5 years, SD = 13.1	Range: 24 to 83
18-44	20	26%
45-64	47	61%
>=65	10	13%
GENDER	(n = 64)	
Male	18	28%
Female	46	72%
RACE	(n = 64)	
White	57	89%
NON-HISPANIC ETHNICITY	(n = 64)	
	60	94%
EDUCATION	(n = 64)	
High school or less	8	13%
Associate degree or some college	26	40%
Bachelor degree	17	27%
Graduate degree or higher	13	20%
REGION	(n = 68)	
Urban	9	13%
Suburban	31	46%
Rural	24	35%
EMPLOYMENT STATUS	(n = 59)	
Full-time	26	44%
Part-time	6	10%
Retired	10	17%
Not employed due to disability	11	19%
Not employed (reason not specified)	6	10%
ANNUAL INCOME	(n = 60)	
<$40K	13	21%
$40-59.9K	8	13%
$60-79.9K	12	20%
$80-99.9K	3	5%
$100K+	14	24%
Prefer not to share	9	15%

FIGURE 2 **CANCER STAGE, TIME SINCE DIAGNOSIS AND CANCER STATUS OF SURVEY PARTICIPANTS**

	NUMBER OF PARTICIPANTS (n)	PERCENT
STAGE AT DIAGNOSIS	(n = 56)	
Stage 0	3	5%
Stage I	13	23%
Stage II	10	18%
Stage III	16	29%
Stage IV	11	20%
I don't know	3	5%
TIME SINCE DIAGNOSIS	(n = 58)	
<1 year	10	17%
1–1.9 years	11	19%
2–4.9 years	22	38%
>=5 years	15	26%
METASTATIC	(n = 57)	
	28	49%
RECURRENCE	(n = 56)	
	18	32%

What are we learning?

DIAGNOSTIC EXPERIENCE

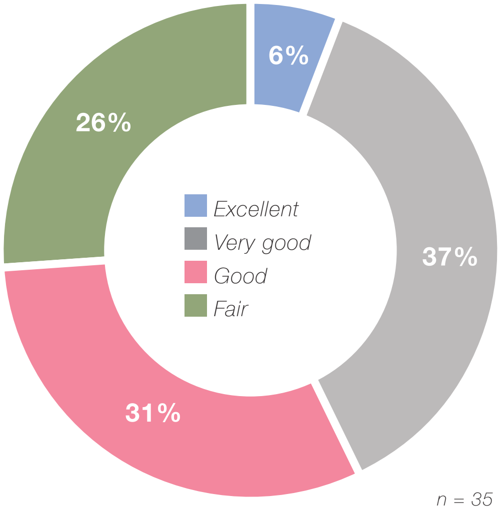
There are a variety of types of melanoma, which might affect treatment plans and quality of life. Nearly three quarters (74%) of respondents reported cutaneous melanoma; of those, 37% had superficial spreading. Nodular melanoma, the most aggressive of the cutaneous melanomas and largely considered invasive at diagnosis, was reported by 22% of respondents. Acral lentiginous melanoma and lentigo maligna melanoma—which can advance more quickly than other cutaneous types—were each reported by approximately 4% of respondents. Eight percent of respondents were diagnosed with mucosal melanoma, and 3% with ocular (in and around the eye) melanoma.

To test the severity of disease, doctors often perform two common tumor assessments: Breslow Depth, which measures in millimeters, the vertical depth of the tumor, and Clark Level, which classifies tumors according to penetration into deeper skin layers. In the survey, 70% reported a Breslow depth of more than 1mm, while 18% did not know their depth reading. Clark levels ranged across the spectrum. Clark Level II (penetration into the dermis, the second layer of skin) and Clark Level III (penetration deep into the dermis) melanomas were reported by 46% of respondents, while Level IV (penetration into the reticular dermis) and Level V (penetration below the dermis, into the fat of the skin) were each reported by 11%. Approximately 11% of patients described their cancer as Clark Level I, the least invasive, in which the melanoma is confined to the epidermis. Twenty-one percent of respondents reported that they did not know their Clark Level.

PERCEPTIONS OF HEALTH

In the survey, nearly half (43%) described their overall health as excellent or very good, and 31% described it as good (Figure 3). No respondents indicated they were in poor health.

FIGURE 3 **SURVEY PARTICIPANTS' PERCEIVED OVERALL HEALTH**



n = 35

CANCER-RELATED DISTRESS

Melanoma can be accompanied by emotional distress, either because of the treatment, complications, or other factors. Figure 4 presents the 10 items that most respondents were moderately, seriously, or very seriously concerned about according to CancerSupportSource®,

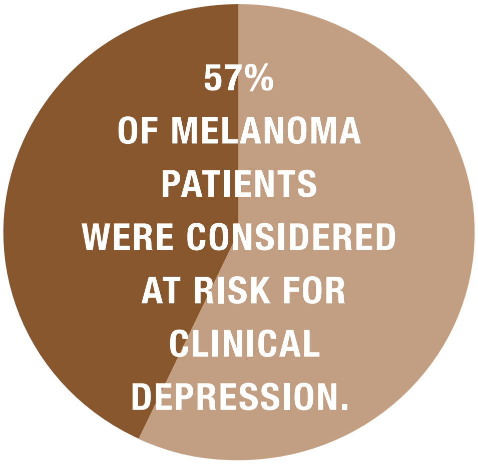
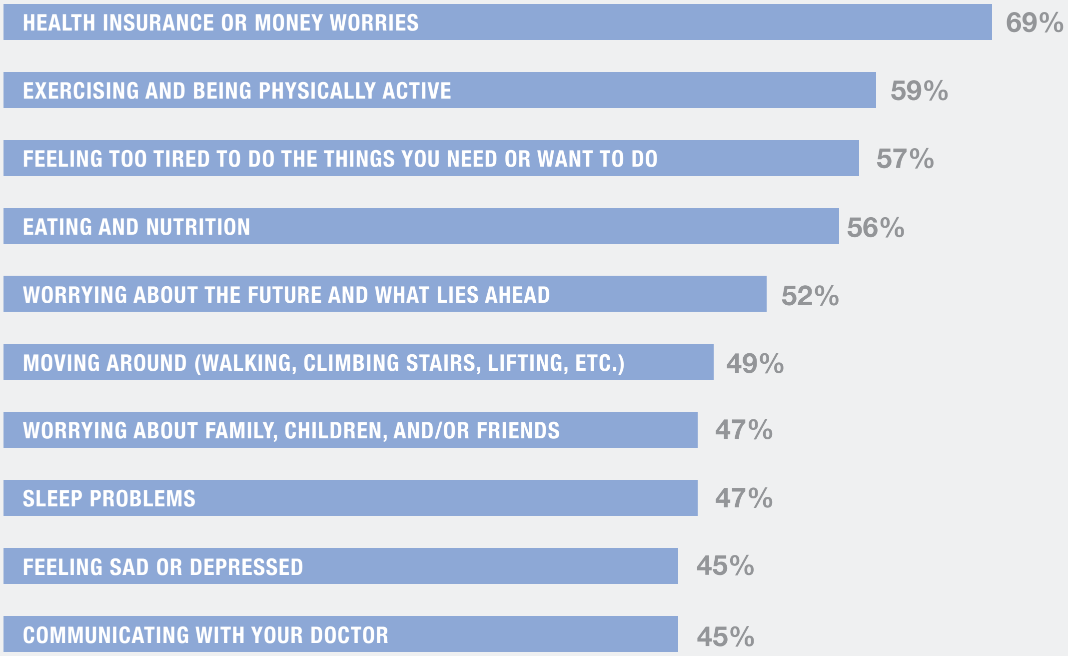


FIGURE 4 **TOP 10 CONCERNS OF MELANOMA PARTICIPANTS**



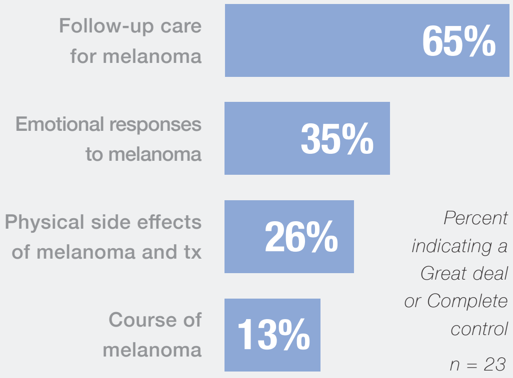
Percent of Patients Moderately to Very Seriously Concerned

n = 53

The Melanoma Specialty Registry also examines concerns unique to the melanoma experience. All respondents (100%) said they were at least somewhat concerned about continued exposure to the sun, and 95% were somewhat, quite a bit, or very concerned about the sun exposure of their family and friends. Nearly all (95%) were at least somewhat concerned about a recurrence and metastasis (95%). Body image issues, not uncommon in people with skin cancers, were cited by 52% of survey respondents.

For some survivors, distress can take the form of a loss of control—over their health, their bodily functions, and their day-to-day activities. Figure 5 describes how much control respondents felt they had over elements of their cancer and cancer treatment (response options included "no control," "only a little," "moderate amount," "great deal," or "complete control").

FIGURE 5 **PERCEIVED CONTROL AMONG MELANOMA PARTICIPANTS**



Percent indicating a Great deal or Complete control

n = 23

a validated distress screening instrument.[1] CancerSupportSource features a depression subscale that demonstrated that more than half (57%) of melanoma patients were at risk for depression.

DISTRESS RELATED TO BODY IMAGE

Melanoma tumors may be visible on the skin, and surgery often leaves scars. Approximately 43% of melanoma respondents reported their body image as either slightly or much worse now than when they were first diagnosed. Figure 6 highlights respondents' body image views and satisfaction.

QUALITY OF LIFE

Cancer-related distress often leads to diminished quality of life, one of the most important factors for assessing how patients are managing their cancer. The Melanoma Specialty Registry incorporates the PROMIS-29, which compares how patients describe their quality of life to other U.S. population groups across seven different areas of life.[2] As Figure 7 illustrates, many melanoma patients reported substantially worse quality of life than the national average for fatigue (28% of respondents), anxiety (28%), depression (25%), social functioning (23%), and physical functioning (22%). In addition, 17% of respondents reported worse pain interference, and 11% reported worse sleep disturbance.

FIGURE 6 **BODY IMAGE AND SATISFACTION AMONG MELANOMA SURVIVORS**

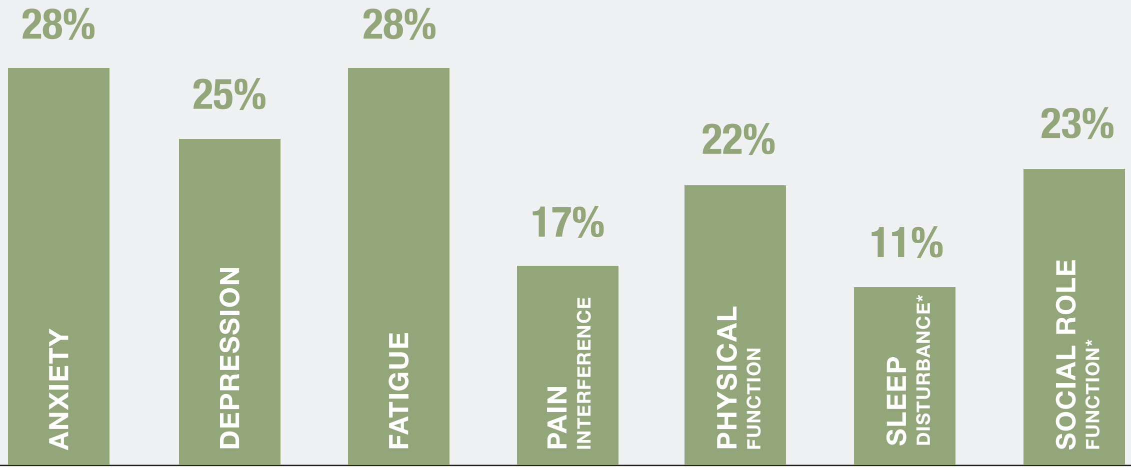
46%	35%	35%	30%	30%	30%	26%	22%	22%	22%
Dissatisfied with appearance of scar	Self-conscious about appearance	Dissatisfied with body	Difficult to look at naked	Feeling less physically attractive as a result of disease or treatment	Feeling less sexually attractive as a result of disease or treatment	Avoid people because of way felt about appearance	Feeling less feminine/ masculine as a result of disease or treatment	Dissatisfied with appearance when dressed	Feeling the treatment has left body less whole

n = 23

Percent indicating Quite a bit to Very much

FIGURE 7 **PERCENTAGE OF CANCER SURVIVORS REPORTING WORSE QUALITY OF LIFE**

n = 36



*Note: All comparisons are vs. general U.S. population, except where * denotes comparison to U.S. population group balanced to include more people with chronic illness. Worse quality of life is defined as having a score that is at least 1 standard deviation poorer than the respective comparison group.*

TREATMENT DECISION-MAKING AND PLANNING

Melanoma treatment options depend largely on a patient's disease stage and medical history: surgical excision of the tumor, targeted drug therapies, chemotherapy, and immunotherapy, primarily for advanced, high-risk cases.

Among respondents to the Melanoma Specialty Registry survey, 60% reported they had received treatment for melanoma in the past. Of these, 46% had received or were currently in first-line treatment, which describes a patient's first treatment experience. Smaller proportions were into second-line (23%) and third-line (23%) or more treatments, which occur when previous therapies—first, or second, etc.—are considered ineffective or no longer effective.

Awareness and understanding of treatment options is critical, particularly for newly diagnosed patients. For respondents with experience in second-line treatment stage or later, 90% felt they were more knowledgeable about their treatment than they were during first line of therapy, due primarily to either more experience (78%) or access to more information (89%).

More generally, 62% of all patients reported that they were quite a bit or very much involved in treatment decision-making, while only 44% felt they were knowledgeable about options, and 31% indicated they were prepared to discuss treatment options with their doctor (Figure 8).

COST OF CARE

As mentioned earlier in this report, melanoma patients' biggest concern was financial matters. Forty percent of melanoma respondents reported significant levels of intrusive thoughts about their ability to manage costs of their cancer care, according to the Impact of Events Scale[3]. Seventy-two percent of respondents had discussed costs with someone on their health care team, such as a counselor, nurse, or doctor.

When health care experts study the financial burden of care, monthly out-of-pocket costs are an important lens into the disease's real, ongoing cost impact. Many respondents were able to quantify monthly out-of-pocket costs related to their cancer (Figure 9). Notably, nearly half (44%) spent over $250 and 16% spent over $1,000 per month.

FIGURE 8 **TREATMENT DECISION-MAKING PROCESS**

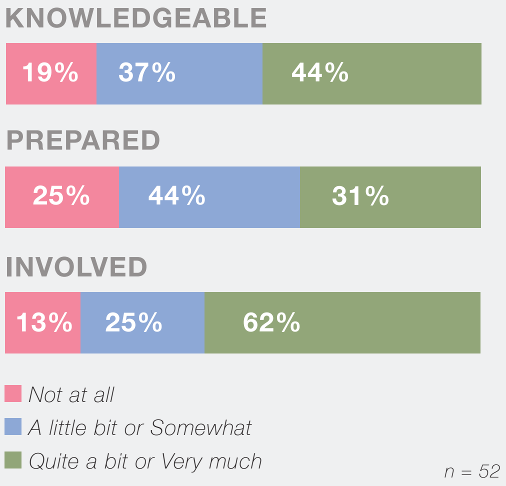
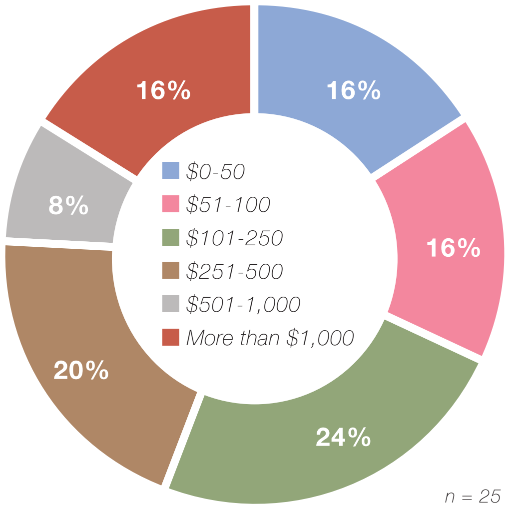


FIGURE 9 **MONTHLY OUT-OF-POCKET COSTS**



People with melanoma can experience stigma because of their illness. Forty-eight percent believed they could have prevented melanoma by not tanning or otherwise avoiding excessive sun exposure, and 61% reported that other people ask if they were diagnosed because of too much time spent in the sun. Thirty-nine percent said melanoma was generally regarded as a self-inflicted disease, and the same proportion felt that other people acted like it was their fault for developing cancer.

DONNA, Melanoma Cancer Patient

Donna was diagnosed with stage III B melanoma. While her family and friends were very supportive, she heard from others that a cancer diagnosis can be really hard on everyone. Family and friends may not always know how to respond or be supportive. Donna says, “I went to counseling for some time just to talk to someone that wasn’t related to my family just so I could really, really let my hair down, so to speak, and tell him exactly how I was feeling.” While one-on-one counseling may not be for everyone, Donna also found online communities to be very helpful. She says, “There are closed groups out there that you can get into. One woman I met, she encouraged me when I was going through a really difficult time during my treatment and I had the chance to meet her in-person recently at a melanoma walk in Houston, which was incredible.”

Learn More

For more information and to see our other specialty reports please visit:
www.cancersupportcommunity.org/RegistryIndexReport2017

- Breast Cancer Specialty Registry Report
- Caregiver Specialty Registry Report
- Chronic Lymphocytic Leukemia (CLL) Specialty Registry Report
- Chronic Myeloid Leukemia (CML) Specialty Registry Report
- General Registry Report
- Lung Cancer Specialty Registry Report
- Metastatic Breast Cancer Specialty Registry Report
- Multiple Myeloma Specialty Registry Report
- Prostate Cancer Specialty Registry Report
- Stomach Cancer Specialty Registry Report

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