RARE where you lead melanoma research

The RARE Registry

Patient Voices Empowering Research

2026 DATA REPORT

Melanoma Research Alliance

RARE where you lead melanoma research

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As the largest non-profit global funder of melanoma research, MRA has dedicated over $200 million to date in support of the fight against melanoma. Learn more at curemelanoma.org

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A Letter from MRA

Sponsor of the RARE Registry

To the RARE Registry Community:

The RARE Registry has become the largest direct-to-patient registry for individuals with acral, cutaneous, and mucosal melanoma. Since launching in October 2022, nearly 700 participants across the acral, mucosal, and cutaneous melanoma subtypes have joined the registry, marking both an important milestone in building a powerful and growing resource for the melanoma community, and in advancing research for these rare and often difficult-to-treat melanoma subtypes.

This effort was driven by the challenging experiences that patients with rare melanomas face. Rare melanoma subtypes remain underrepresented and underfunded in research and suffer from limited awareness of their progression, treatment, and impact on patient lives. RARE exists to help change this.

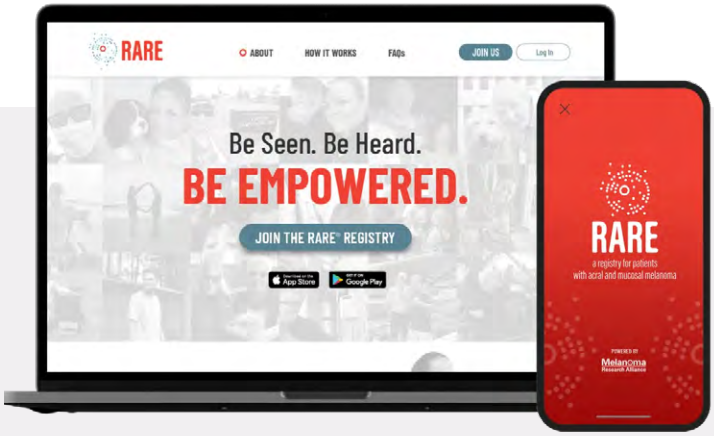
We are especially grateful to the patients and caregivers who inspired and helped shape RARE from the very beginning. Your voices and experiences continue to guide RARE's growth and impact—each individual's story holds the power to make a meaningful difference in the future of patient care in melanoma, especially for the rare melanoma subtypes.

As the registry continues to grow, so does its potential to transform our understanding of melanoma and improve patient care. We are truly appreciative to every member of the RARE community for making this important initiative possible.

Sincerely,
Joan Levy and **Jessica Scales**

Joan Levy, PhD
MRA Chief Science Officer

Jessica L. Scales, PhD
MRA Associate Director,
Rare Melanoma Research



VISIT THE REGISTRY:
raremelanoma.org

About the RARE Registry

In October 2022, the Melanoma Research Alliance (MRA) launched the first direct-to-patient registry called RARE for patients with acral, mucosal, and cutaneous melanoma. The RARE Registry is a patient-centered, web-based platform designed to advance our understanding of melanoma, particularly for rare melanoma subtypes such as acral and mucosal melanoma.

While most melanomas develop in locations where the skin is frequently exposed to the sun (cutaneous melanoma), rarer forms can develop in areas of the body that receive little to no sun exposure, including the palms of the hands, soles of the feet, and underneath nails (acral melanoma), as well as, mucosal surfaces that line areas of the body like the nasal passages, mouth, gastrointestinal tract, and genital areas (mucosal melanoma). These rare subtypes affect a relatively small number of patients each year, but are often diagnosed at more advanced stages. They do not respond as well to approved treatments for melanoma, and are associated with poorer health outcomes.

RARE was inspired by patient advocates diagnosed with acral and mucosal melanoma, and was intentionally designed as a collaborative effort involving patients, caregivers, clinicians, and researchers. The RARE Registry was created to address critical knowledge gaps in these underserved patient populations by collecting comprehensive, real-world data directly from patients.

The patient perspective is captured through multiple foundational surveys that focus on an individual's demographics, disease history, genetics and tumor biomarkers, treatment history and timeline, lifestyle, and quality of life, which are areas often underrepresented in clinical research involving these melanoma subtypes.

Through the collection of both clinical data and patient-reported experiences, RARE provides a more holistic understanding of these melanoma subtypes, the impact on those diagnosed, and real-world evidence that can support longitudinal studies. Unlike traditional registries, RARE allows participants to complete and update their surveys over time, creating a more complete and evolving picture of an individual's disease journey.

"Getting the word out about the existence and unique features of these rare melanoma subtypes is crucial," says Boris Bastian, MD, PhD, a Scientific Advisor for the RARE Registry and physician-scientist at the University of California San Francisco. "These efforts are so critical because they create a forum for people to get together and counteract these factors that otherwise impede progress."

A central goal of RARE is to generate actionable insights that can inform research, improve clinical care, and accelerate the development of effective treatments for patients with acral, mucosal, and cutaneous melanomas. Ultimately, RARE represents an opportunity towards more inclusive, patient-driven research, with the aim of reducing disparities in rare melanoma patient care and improving health outcomes for those affected by melanoma.

"We started the RARE Registry to bridge this divide and address the unmet needs of the rare melanoma community, from patients and caregivers to leading researchers and physicians. Power and strength arise in those facing a rare melanoma diagnosis who share their stories. We are so grateful to the RARE Registry participants who are already driving this critical research forward," states Joan Levy, PhD, Chief Science Officer of the MRA and Principal Investigator of the RARE Registry.

Now in 2026, we are excited to share the first RARE Registry report, which captures key insights from RARE participants and helps bring greater visibility to the voices and experiences of individuals with acral, mucosal, and cutaneous melanoma.

"Getting the word out about the existence and unique features of these rare melanomas is crucial."

DR. BORIS BASTIAN,
RARE OVERSIGHT COMMITTEE SCIENTIFIC ADVISOR

RARE Oversight Committee Scientific Advisors, Patient Advisors, and MRA Staff

The RARE Registry:

Inspired by Patients and Caregivers

The MRA's RARE Registry was inspired by and developed in close collaboration with a community of rare melanoma patient advocates and caregivers, whose lived experiences helped shape its vision and priorities. From its earliest stages, the concept and design of RARE was informed by what this patient community identified as most needed: greater representation in research, a deeper understanding of patient experiences, and a stronger emphasis on quality of life alongside clinical outcomes.

To ensure these priorities remain central as RARE continues to enroll participants and advance its mission, RARE established an Oversight Committee composed of patients and caregivers, alongside a multidisciplinary group of medical advisors, including dermatologists, pathologists, oncologists, surgeons, and scientists, with experience in these melanoma subtypes.

Together, this collaborative structure ensures that RARE continues to reflect both the patient perspective and the evolving needs of the scientific and medical communities, fostering research that is both patient-centered and clinically impactful.

MRA is incredibly grateful for the continued support of each and every member of the Oversight Committee in helping RARE achieve its mission, especially our patient advisors:

Trena Brown, Chris Carr, Judith Colin, Julie Dewey, Patricia Janiak, Amy Jardon, David Marx, Jonathan Swingle, Alfonso Waller, Eileen Walther, J.B. Ward, Janet Yannelli

Uveal (or Ocular) melanoma is another rare and aggressive melanoma subtype that develops from melanocytes in the uveal tract of the eye. Patients with uveal melanoma are encouraged to participate in established ocular melanoma registries, including through **A Cure In Sight** *and the* **Melanoma Research Foundation**.

A Lasting Legacy

This report is dedicated to the patients, caregivers, and loved ones whose lives have been forever changed by melanoma.

We remember those we have lost, including Christopher Dewey, Lisa Patel Waller, and John Janiak, whose courageous journeys with mucosal melanoma inspired the vision for the RARE Registry. Patients with rare diseases often feel alone as there are few others who understand their experience, and this challenging reality is compounded by the scarcity of effective treatments. These patients and their spouses—Julie Dewey, Alfonso Waller, and Patricia Janiak—refused to accept that future patients diagnosed with a rare melanoma should have to endure the same uncertainties.

Finding each other through the Mucosal Melanoma Warriors support community, these individuals discovered that their experiences reflected those of countless others navigating this rare disease. Together, they envisioned a way for patients and caregivers to transform their experiences into knowledge that could accelerate research and improve care—the RARE Registry, the first direct-to-patient registry dedicated to rare melanoma subtypes including mucosal and acral melanoma.

We also honor the life of Jonathan Swingle, a dedicated and fearless patient advocate for mucosal melanoma. As a founding patient advisor of the RARE Registry Oversight Committee, Jonathan helped shape the registry's patient-centered mission—ensuring the lived experiences and disease journeys of individuals with rare melanomas could be used for impactful research studies centered on the risk factors, biomarkers, standard of care, and quality of life in the setting of rare melanomas.

The legacy of Jonathan, Christopher, Lisa, and John will live on through the RARE Registry they and their spouses helped to build and nurture—a testament to their vision that continues to connect patients, inspire hope, and fuel discoveries that will impact the future of rare melanomas.

IN MEMORY

John M. Janiak

Husband of Patricia Janiak, RARE patient advisor

Author of *Surviving Mucosal Melanoma and Immunotherapy Induced Encephalitis: My Journey of Body and Soul*

Lisa Patel Waller

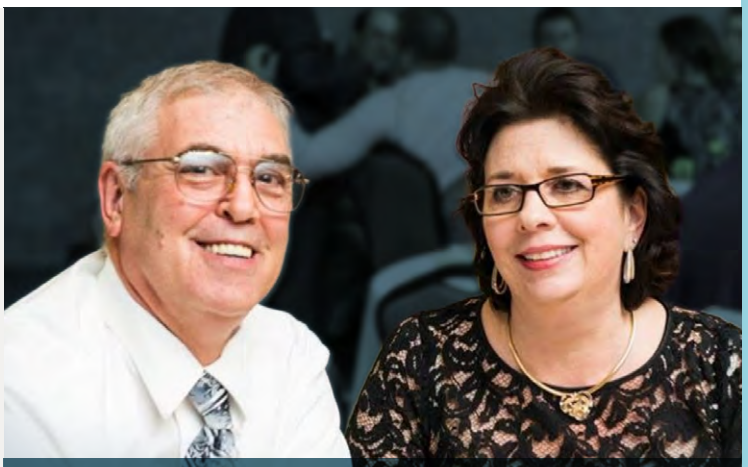
Wife of Alfonso Waller, RARE patient advisor

Christopher L. Dewey

Husband of Julie Dewey, RARE patient advisor

Jonathan Warne Swingle

RARE patient advisor



"The more common the problem, the more people that look for an answer; the more rare, not so much, but some people will force the issue. The return on investment may be small in context, but every life matters."

JONATHAN SWINGLE, PATIENT ADVOCATE AND RARE PATIENT ADVISOR

IN THEIR OWN WORDS

Joan Levy, PhD

MRA Chief Science Officer

“Through the registry, patients with these rare melanoma subtypes can partner with researchers to accelerate research by helping the field better understand their unique patient journeys.

We’re also able to return de-identified data insights back to participants in real time. This allows them to access customized data snapshots to see how they fit into the entire cohort—something that can be really powerful for a rare cancer community. It’s exciting that participants can see research as it emerges as well as get tailored educational materials, clinical trial alerts, and webinars that they might be interested in.

The registry will be critical both in helping researchers get the data they need, but just as importantly helping them understand the patient’s journey as they experience it.”

RARE Registry Insights

Demographics

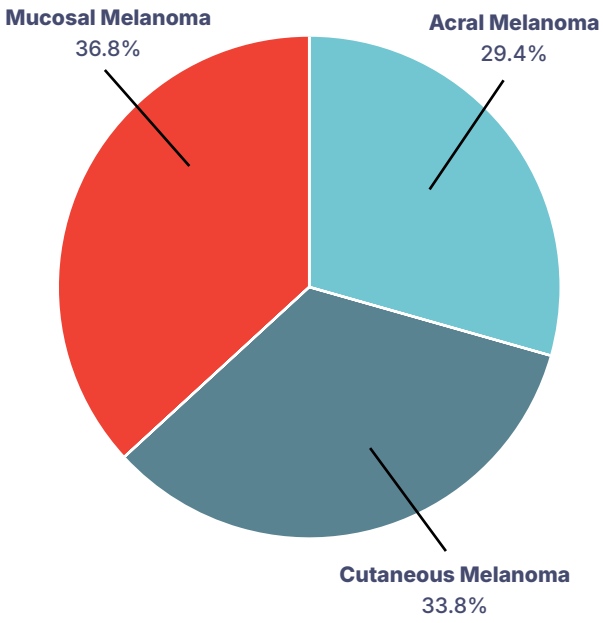
Melanoma Subtype

Since its launch in October 2022 through April 2026, RARE has enrolled 687 total participants across the acral, mucosal, and cutaneous melanoma subtypes.

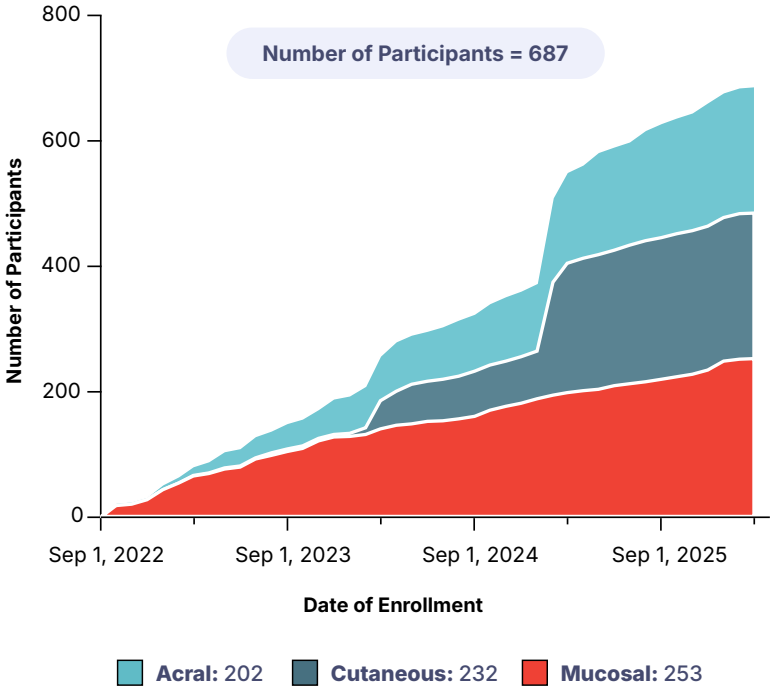
Of these, 29% of participants have acral melanoma, 37% have mucosal melanoma, and 34% have cutaneous melanoma. In the last year alone, RARE has seen a 24% increase in the number of individuals who have enrolled. The RARE Registry remains open for individuals with acral, mucosal, or cutaneous melanoma to enroll and share their lived experiences with the disease. Each and every individual's experience with melanoma is important for supporting the mission of RARE—to advance research studies on improving the care and health outcomes for patients.

Here and throughout this report, "Number of Participants" shown with each graph indicates the number of RARE Registry participants who provided a response to the associated survey question.

Enrollment by Melanoma Subtype



Enrollment by Melanoma Subtype Over Time



There are several types of melanoma: the most common subtype, known as cutaneous melanoma, forms on skin that is often exposed to the sun and accounts for nearly 90% of all melanomas. The less common or rare subtypes of melanoma, such as acral and mucosal melanoma, form in parts of the body that have limited to no exposure to the sun. Together, acral and mucosal melanoma account for approximately 3-4% of all melanoma cases, and due to their obscurity, patients often face later diagnoses and poorer health outcomes (Nowowiejska *et al.*, 2025).

Nowowiejska, J., Ordon, A. J., Purpurowicz, P., Argenziano, G., & Piccolo, V. (2025). Many Faces of Melanoma: A Comparison Between Cutaneous, Mucosal, Acral, Nail, and Ocular Malignancy. *Pigment cell & melanoma research, 38(5)*, e70051. https://doi.org/10.1111/pcmr.70051

Demographics

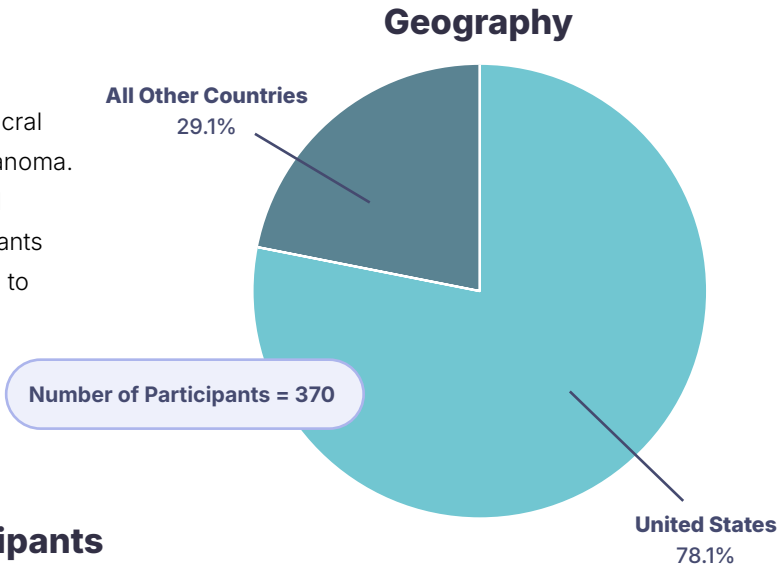
Geography

The RARE Registry features participants with acral, mucosal, and cutaneous melanoma from the United States and around the world. RARE welcomes patients from the United States and who are English-speaking residing in other countries to consent to participate in the registry. Presently, RARE is represented by participants from 24 countries, including Australia, Canada, China, Cuba, France, Ireland, Italy, Japan, Lithuania, Mexico, Nepal, Netherlands, New Zealand, Peru, Poland, Singapore, South Africa, Spain, Switzerland, Ukraine, United Arab Emirates, United Kingdom (includes England, Scotland, Wales, and Northern Ireland), United States, and Uruguay.

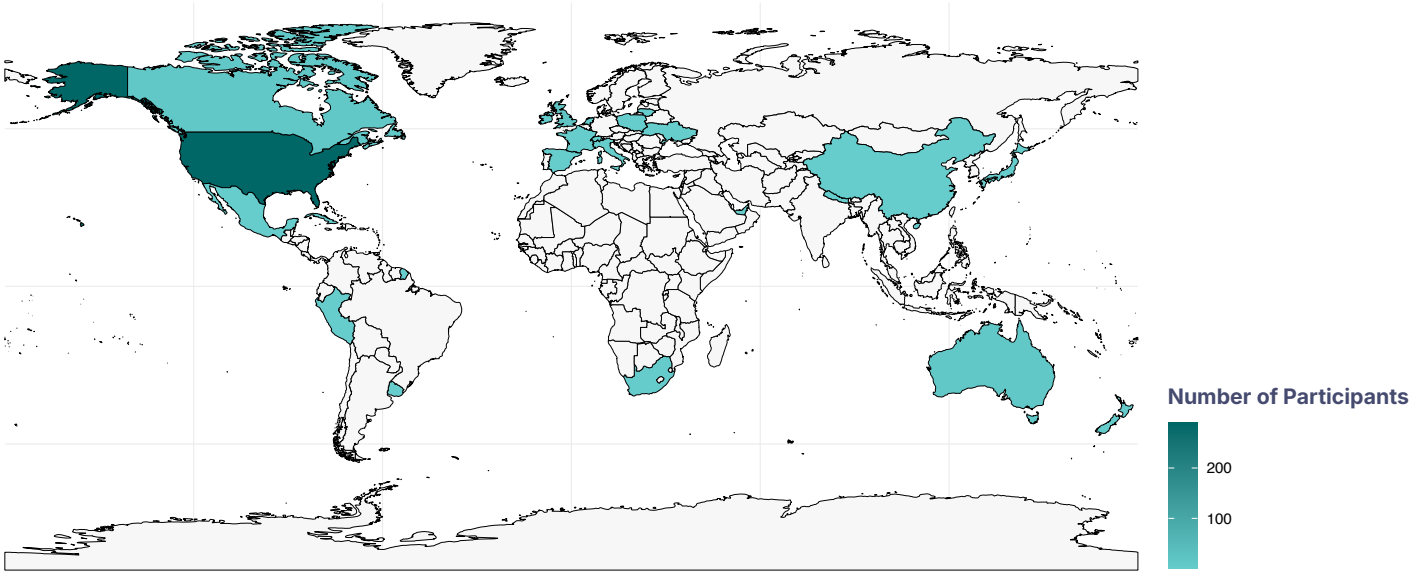
The majority of RARE participants are from or reside in the United States (78%). Over 86% of participants with cutaneous melanoma reside in the United States, compared to 76% of participants with acral melanoma and 75% of participants with mucosal melanoma. In Great Britain, Australia, and Canada, among several other countries, a higher percentage of RARE participants had acral melanoma or mucosal melanoma compared to cutaneous melanoma.

RARE is also represented by participants across all 50 states, with the most represented states including California (11%), Florida (7%), New York (6%), Minnesota (5%), and Virginia (5%).

To capture a broader range of patient experiences across acral, mucosal, and cutaneous melanoma, RARE is working to increase global participation. In addition to English, the RARE web portal will soon be available in the Spanish language, and at a later date, in the Portuguese and Chinese languages.



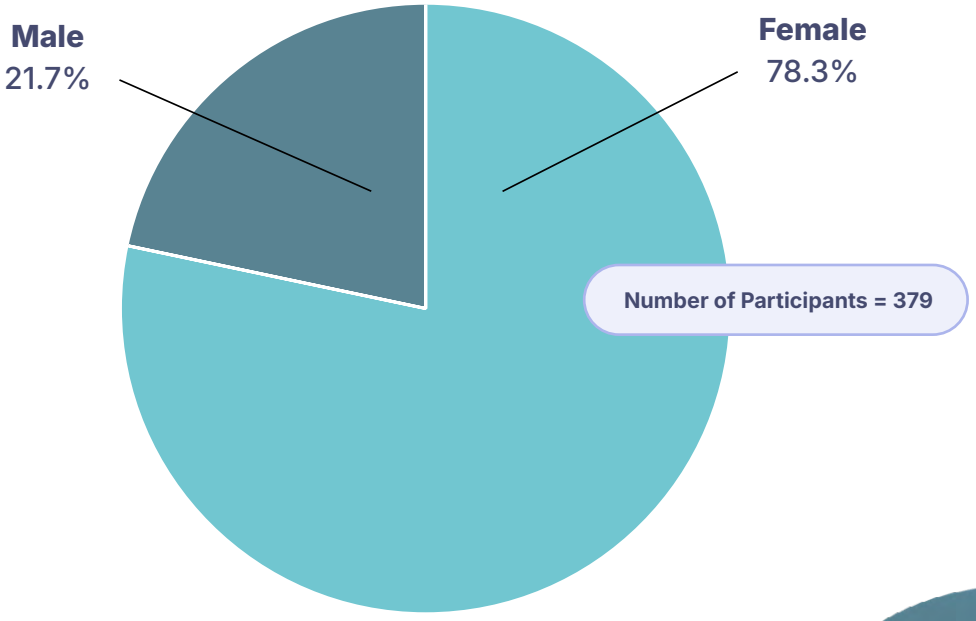
Geography of RARE Registry Participants



Demographics

Gender

The majority of RARE participants (78%) identified as female, and this trend was observed across each of the three melanoma subtypes.



IN THEIR OWN WORDS

Julie Dewey

Patient Advocate and RARE Patient Advisor

"MRA answered the call on every level.

They were the only group who could do it all. They could find the funding to support it; they had the team in place to create the surveys needed to collect the most pertinent information; and they were familiar with other cancer registries. They also had the ambition and the compassion to make it happen with the patient community. Finally, they understood the immediate need—lives were on the line."

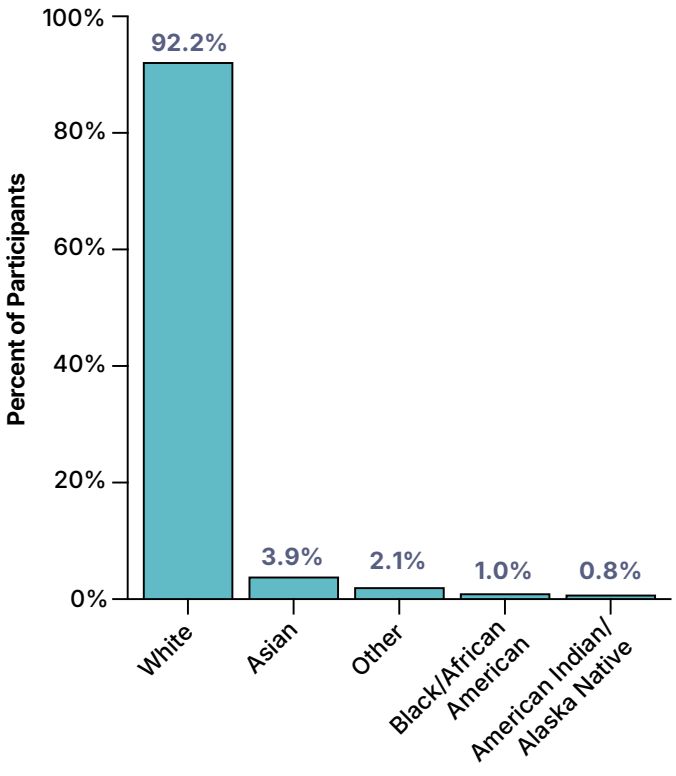
Demographics

Race and Ethnicity

Across all melanoma subtypes, the majority of RARE participants identified as White (92%), followed by Asian (4%), Black or African American (1%), and American Indian or Alaska Native (1%). For participants with acral melanoma, 91% identified as White, 4% as Black or African American, and 3% as Asian. For participants with mucosal melanoma, 90% identified as White, 7% as Asian, and 2% as American Indian or Alaska Native. Nearly all participants with cutaneous melanoma (99%) identified as White.

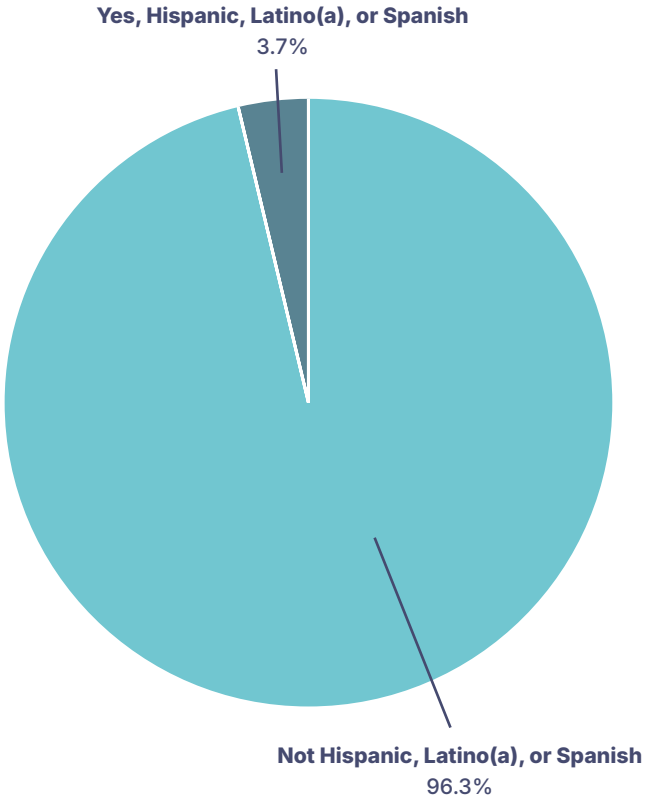
Collectively, more than 96% of RARE participants did not identify as Hispanic, Latino(a), or Spanish. A total of 2% identified as Hispanic, Latino(a), or Spanish, 1% as Mexican, Mexican American, or Chicano(a), and less than 1% as Puerto Rican or Cuban.

Race



Number of Participants = 386

Ethnicity



Number of Participants = 377

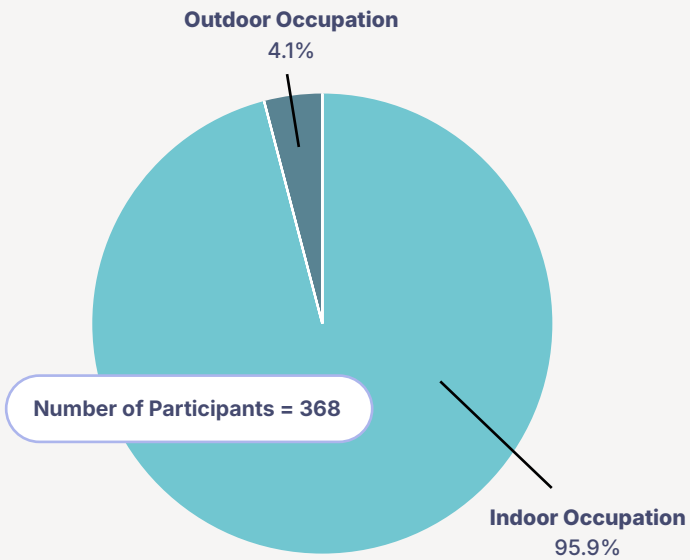
Demographics

Occupation Setting

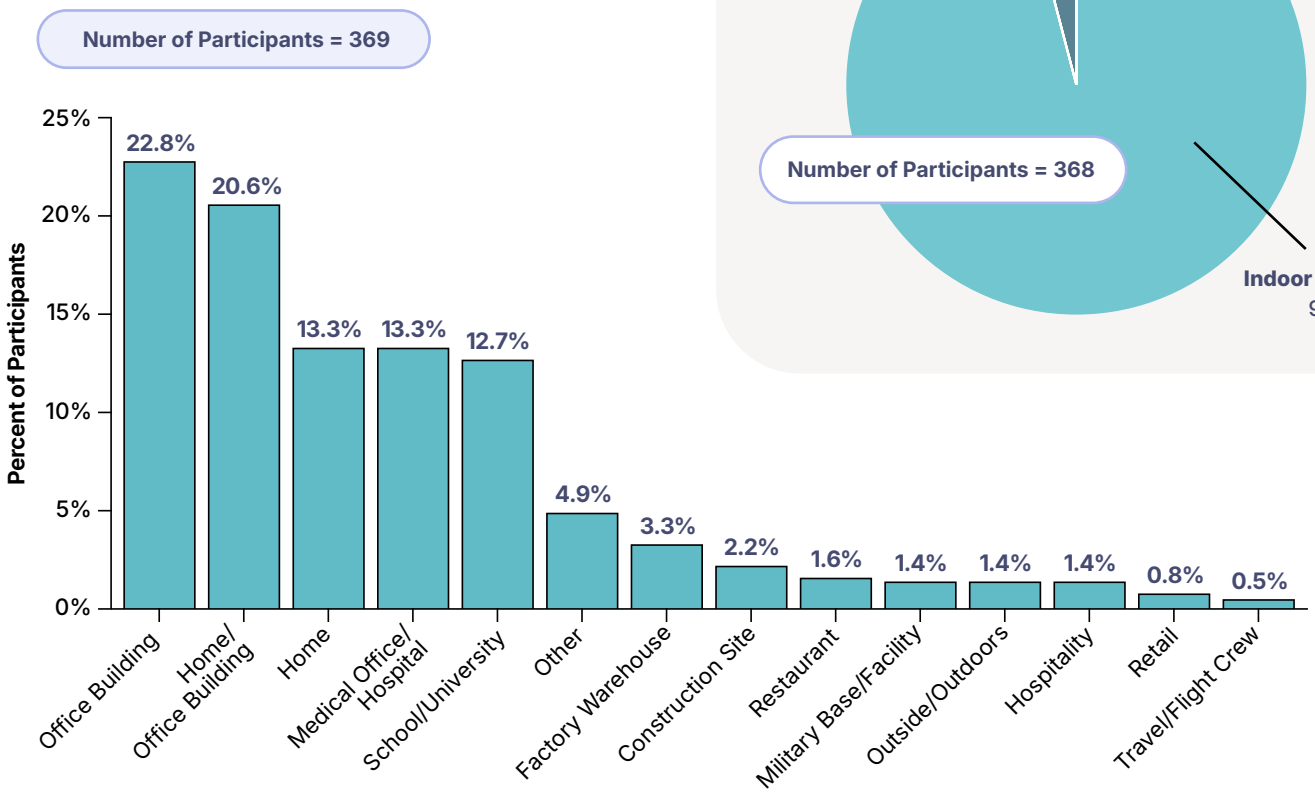
Across all three melanoma subtypes, approximately 96% identified having an indoor occupation compared to an outdoor occupation (4%). The most common occupation setting was an office building (23%) closely followed by a hybrid office/home setting (21%). A primary work setting at a factory or warehouse, construction site, or military base or facility was more common among those with acral and mucosal melanoma (8%) compared to cutaneous melanoma (4.3%).

Researchers are working towards an understanding of the risk factors, including occupational exposures, that may potentially contribute to the development of rare melanoma subtypes like acral and mucosal melanoma. The MRA was involved in a recent study that identified an increased risk of acral melanoma in U.S. Veterans with documented Agent Orange exposure (Hwang *et al.*, 2026).

Indoor vs. Outdoor Occupation



Primary Occupation Setting



Hwang, J. C., Huhmann, L. B., Cho, K., Goryachev, S. D., Starink, N., Weinstock, M. A., Asgari, M. M., Zheng, C., Lu, C., Feldman, T. C., Do, N. V., Gaziano, J. M., Semenov, Y. R., Hurlbert, M. S., Fillmore, N. R., & Hartman, R. I. (2026). Identification of Risk Factors for Acral Melanoma in US Veterans. *JAMA dermatology,* 162(3), 279–291. https://doi.org/10.1001/jamadermatol.2025.5827

Disease History

Initial Symptoms of Melanoma

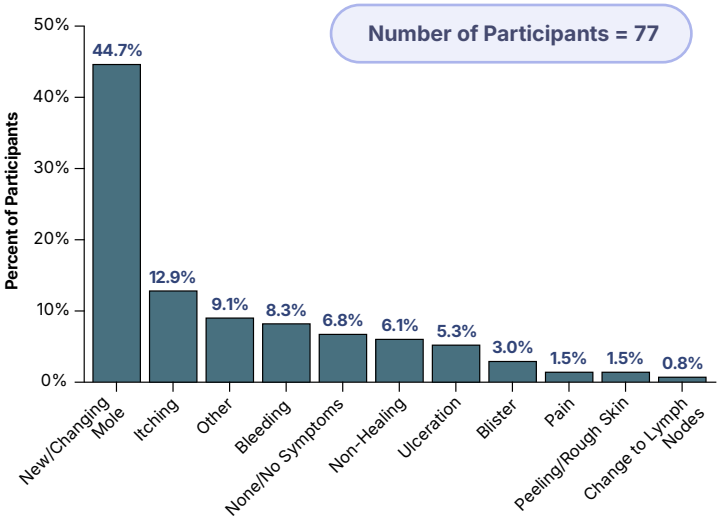
The initial symptoms of participants' melanoma varied by subtype. For participants with cutaneous melanoma, 45% reported a new or changing mole, 13% reported itching, 8% reported bleeding, and 7% reported having no symptoms. The symptoms reported by participants with acral melanoma included 18% with a new or changing mole, 13% with a nail streak, 11% with bleeding, and 11% with a non-healing wound. The most common symptoms reported by participants with mucosal melanoma included 41% with a new mass or obstruction and 38% with bleeding.

Participants with acral and mucosal melanoma reported a median number of two initial symptoms of their disease, compared to participants with cutaneous melanoma who reported a median number of one symptom.

The initial symptoms of mucosal melanoma also varied by the initial site or origin of the disease. Common symptoms of anorectal mucosal melanoma (mucosal melanoma of the anus or rectum) included anorectal masses (57%), rectal bleeding (55%), pain (20%), and painful defecation (18%). Participants with sinonasal mucosal melanoma (mucosal melanoma of the nose or sinuses) reported initial symptoms including a nasal obstruction (58%), nose bleeds (47%), and pain (23%). The most frequently reported symptoms of vulvovaginal mucosal melanoma (mucosal melanoma of the vulva, vagina, or cervix) were itching (44%), bleeding (44%), a vaginal mass (24%), and a non-healing wound (20%).

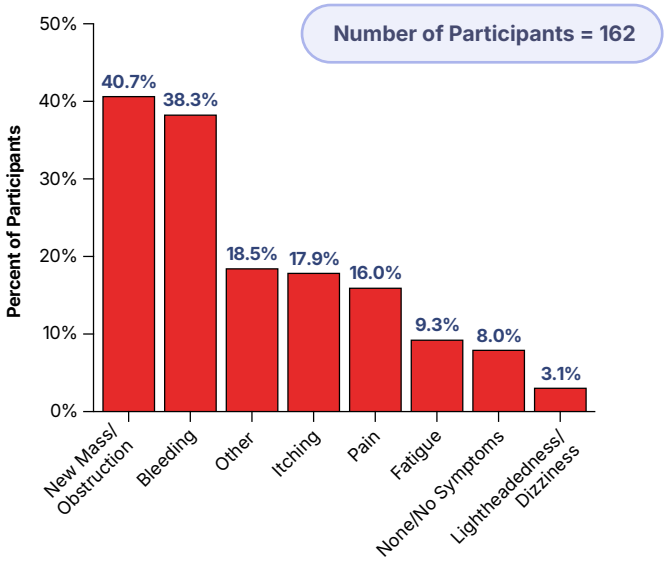
Initial Symptoms of Cutaneous Melanoma

Number of Participants = 77



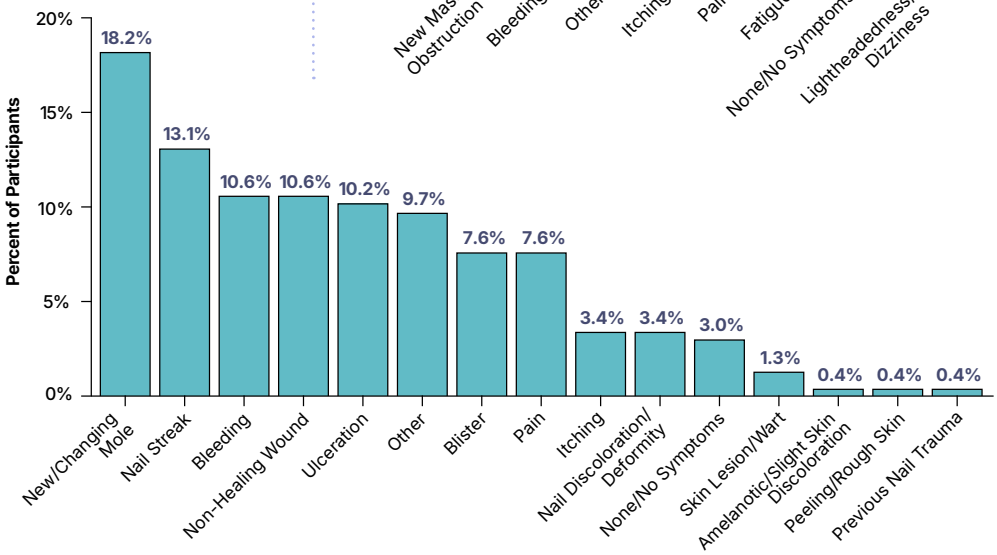
Initial Symptoms of Mucosal Melanoma

Number of Participants = 162



Initial Symptoms of Acral Melanoma

Number of Participants = 100



Disease History

Age at First Symptoms

The age (in years) at which participants noticed their first symptoms differed by melanoma subtype. **Participants with cutaneous melanoma reported initial symptoms at a younger age compared to participants with acral and mucosal melanoma.**

Participants with cutaneous melanoma reported noticing their first symptoms at an average age of 39 years old. For participants with acral and mucosal melanoma, the average age at which symptoms first appeared was 50 years old and 56 years old, respectively.

In participants with acral and cutaneous melanoma, female patients were younger than male patients when symptoms were first noticed. Initial symptoms of acral and cutaneous melanoma appeared in females that were, on average, approximately 7 and 12 years younger than males, respectively. Both females and males with mucosal melanoma reported initial symptoms at identical ages.

Average Age at Time of First Symptoms

50
years old
OVERALL

Number of Participants:
Acral Melanoma = 97
Cutaneous Melanoma = 73
Mucosal Melanoma = 152

39
years old
CUTANEOUS

50
years old
ACRAL

56
years old
MUCOSAL

Disease History

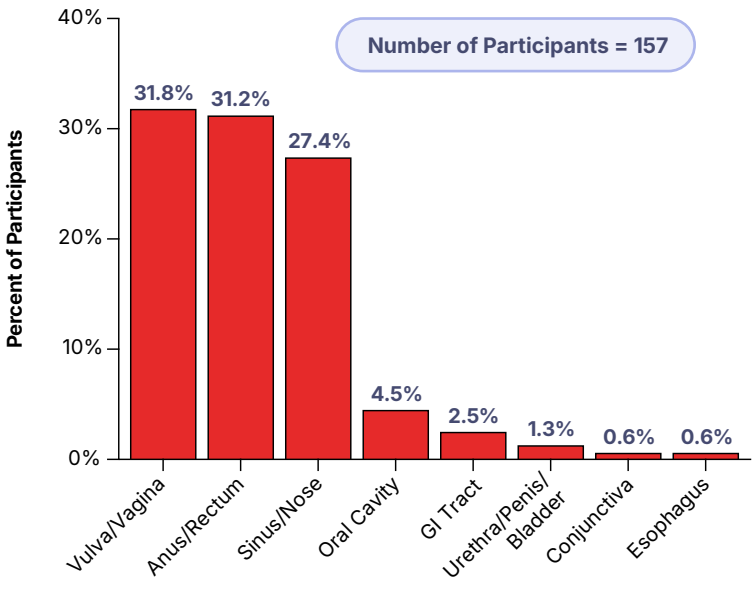
Origin Site of Melanoma

Among RARE participants with acral melanoma, the sole of the foot (63%) was the most common origin site of their disease, followed by the toenail (19%) and fingernail (17%), with fewer participants diagnosed with acral melanoma on the palm of the hand (1%). This pattern was similar between female and male participants with acral melanoma.

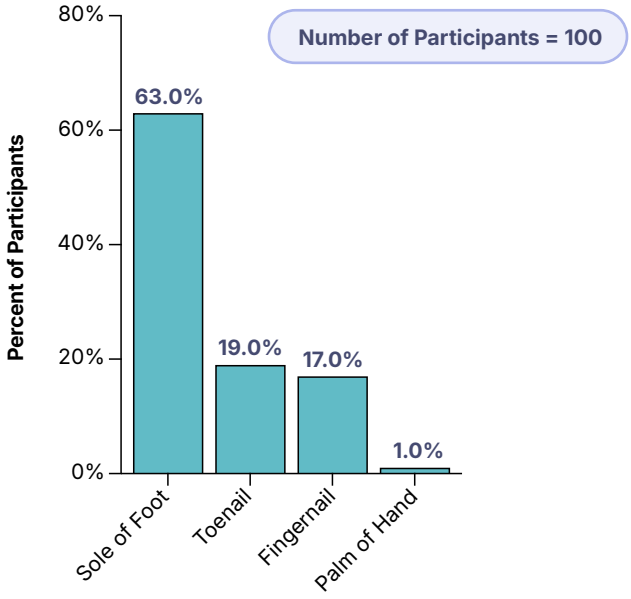
Participants with cutaneous melanoma reported an origin site of their disease including the legs or hips (35%), arms or shoulders (26%), and back (18%), with head, neck, or face (10%), chest (7%), foot (3%), and hand (1%) involvement reported by fewer participants. The predominant site of cutaneous melanoma varied by gender, with females reporting their disease originated most frequently on the legs or hips (39%) and males reporting their disease originated most frequently on the head, neck, or face (27%).

Across participants with mucosal melanoma, the origin site of the disease most often occurred in the vulva or vagina (32%), anus or rectum (31%), and sinuses or nose (27%), with fewer participants having involvement of the mouth or oral cavity (5%), gastrointestinal tract (3%), urinary tract (1%), conjunctiva (<1%), and esophagus (<1%). 39% of females reported their mucosal melanoma originated in the vulva or vagina. For males, 49% reported their mucosal melanoma originated in the anus or rectum.

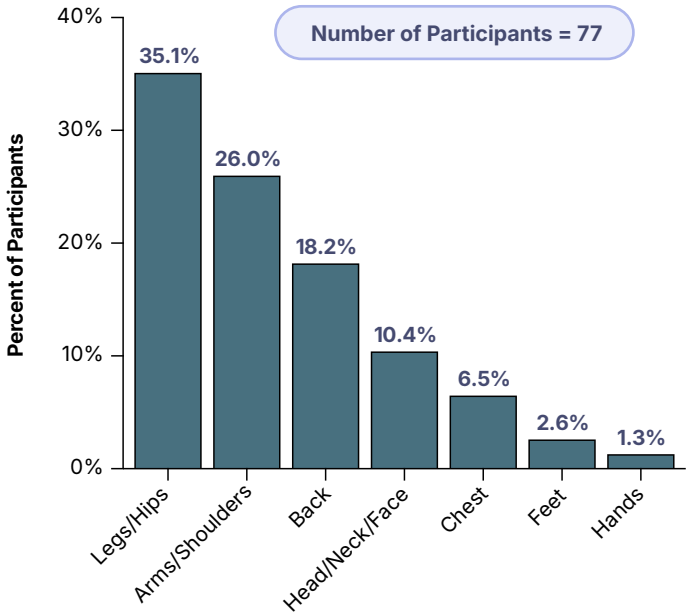
Origin Site of Mucosal Melanoma



Origin Site of Acral Melanoma



Origin Site of Cutaneous Melanoma



Unlike cutaneous melanoma, which is predominantly diagnosed on skin exposed to the sun or ultraviolet radiation, rare melanomas like acral and mucosal melanoma arise from parts of the body with limited to no sun exposure.

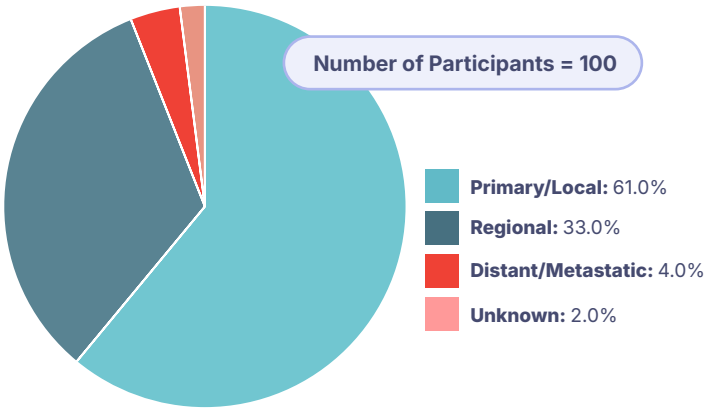
Disease History

General Stage of Melanoma at Initial Diagnosis

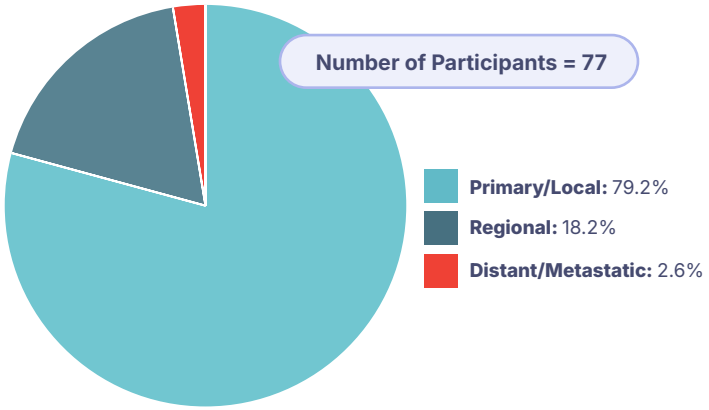
Among all RARE participants, most presented with primary or local disease at initial diagnosis. 79% of participants with cutaneous melanoma were diagnosed at this early stage compared to 61% of participants with acral melanoma and 67% of participants with mucosal melanoma.

Participants with mucosal melanoma reported a comparatively higher burden of metastatic or distant disease at initial diagnosis (13% of participants) compared to acral melanoma (4% of participants) and cutaneous melanoma (3% of participants).

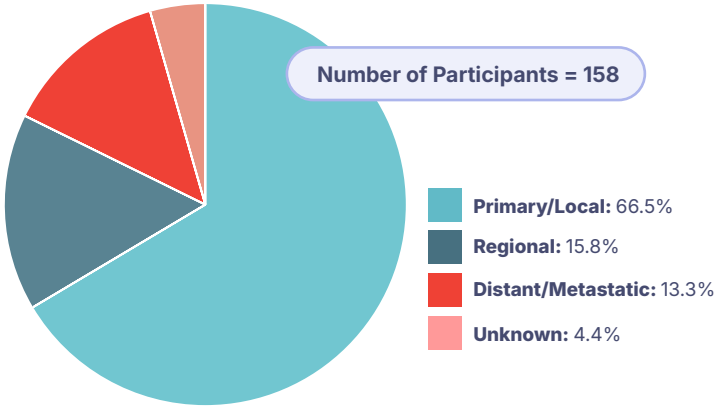
Stage of Acral Melanoma at Initial Diagnosis



Stage of Cutaneous Melanoma at Initial Diagnosis



Stage of Mucosal Melanoma at Initial Diagnosis



Real-world data reports that rare melanomas are typically diagnosed at more advanced stages of the disease.

Disease History

Age at Time of Initial Melanoma Diagnosis

The age (in years) at which participants were first diagnosed differed across melanoma subtypes, with participants being diagnosed with acral or mucosal melanoma at an older age compared to those with cutaneous melanoma. Participants with cutaneous melanoma were on average 42 years old when initially diagnosed compared to those with acral melanoma (an average of 52 years old) and mucosal melanoma (an average of 57 years old).

Females, compared to males, were younger in age when first diagnosed with acral or cutaneous melanoma. At the time of diagnosis, females with acral melanoma were on average 6 years younger than males; females with cutaneous melanoma were on average 18 years younger than males. The average age at diagnosis for female and male participants with mucosal melanoma was the same.

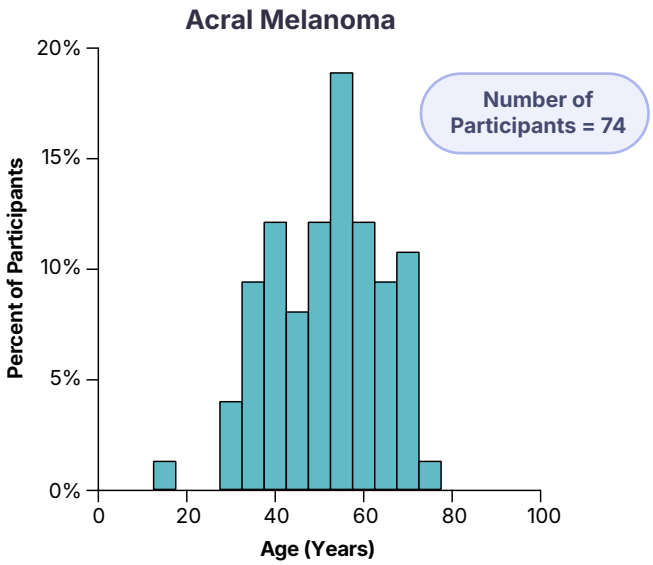
The average time (in years) between when symptoms first appeared and a diagnosis was made differed by melanoma subtype: an average of 3 years for participants with cutaneous melanoma, 2 years for participants with acral melanoma, and 1 year or less for participants with mucosal melanoma.

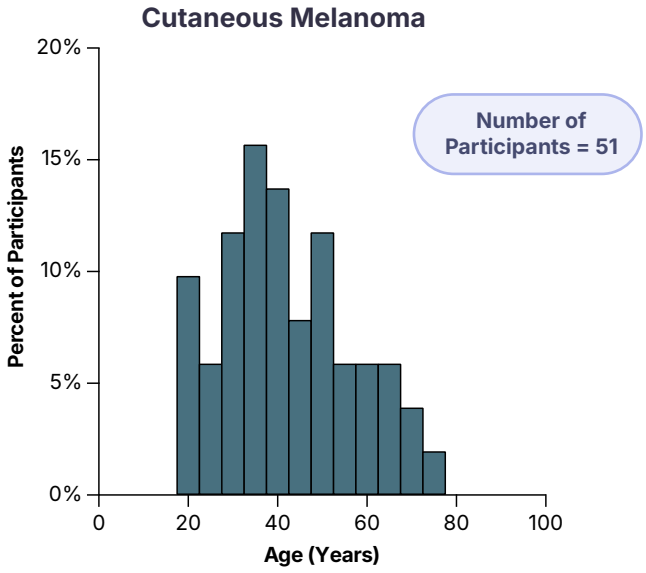
Melanoma of the skin is one of the ten most common cancers in young adults between the ages of 15-39 years old, especially in young women (SEER 21, 2019–2023; https://seer.cancer.gov/statfacts/).

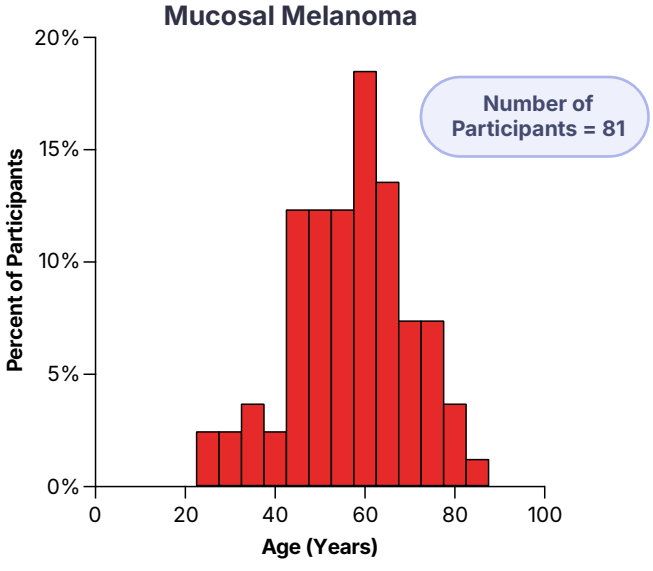
For some melanoma subtypes, the incidence of melanoma varies by age. In mucosal melanoma, more than half of patients are diagnosed in older adults over the age of 60 years old (Sergi *et al.*, 2023).

Sergi, M. C., Filoni, E., Triggiano, G., Cazzato, G., Internò, V., Porta, C., & Tucci, M. (2023). Mucosal Melanoma: Epidemiology, Clinical Features, and Treatment. Current oncology reports, 25(11), 1247–1258. https://doi.org/10.1007/s11912-023-01453-x

Age at Diagnosis





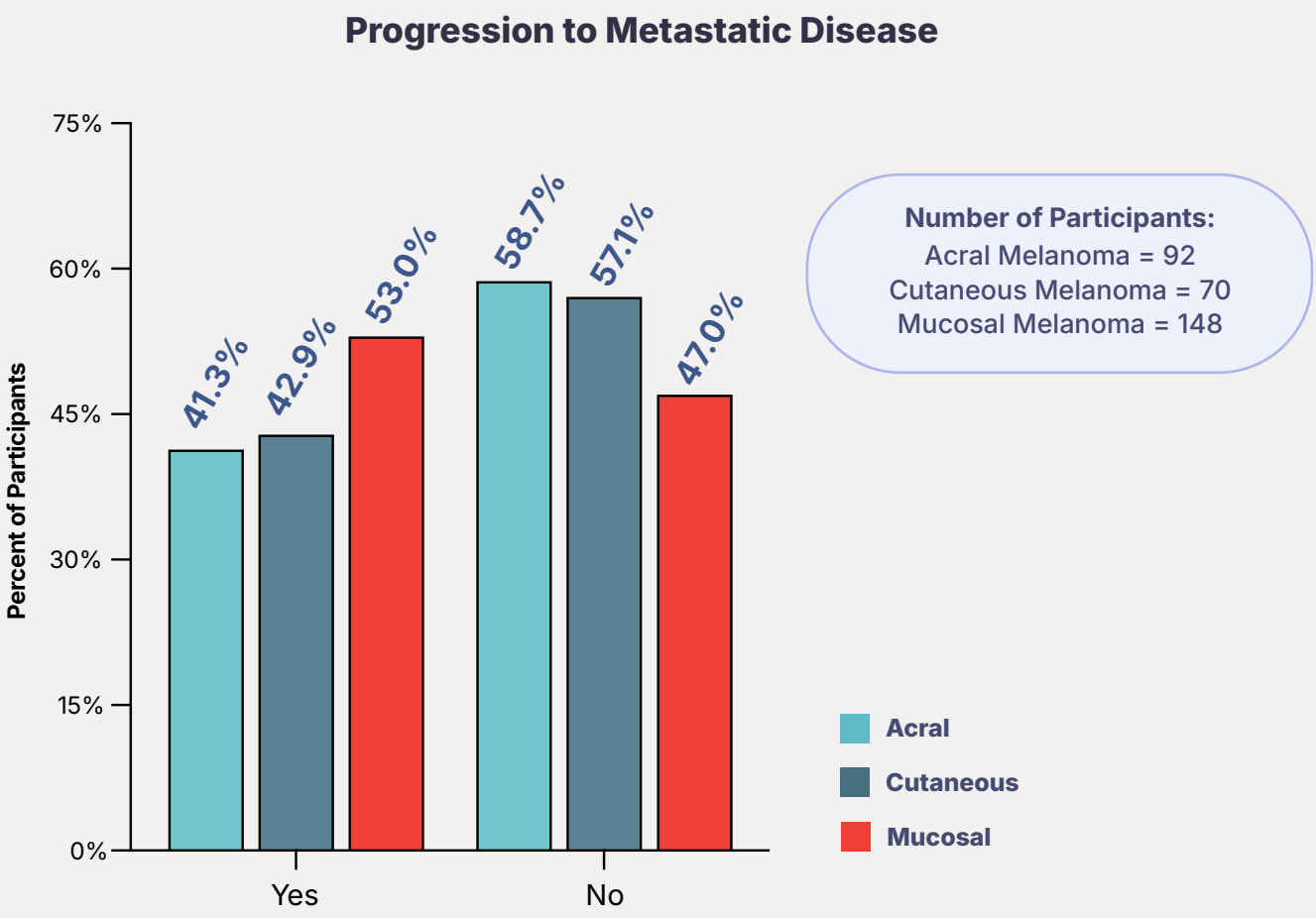


Disease History

Progression to Metastatic Melanoma

Overall, 52% of RARE participants reported their melanoma had progressed to metastatic disease. Higher rates of metastatic progression occurred in participants with mucosal melanoma (53%) compared to participants with acral melanoma (41%) and cutaneous melanoma (43%). Among all RARE participants with metastatic disease, 70% were male and 30% were female.

Routine imaging-based testing accounted for the majority of metastatic disease detection (47%) before symptoms were noticed by the participant. 28% of participants noticed symptoms or changes that led to the detection of metastatic disease.



Disease History

Anatomic Sites of Metastatic Melanoma

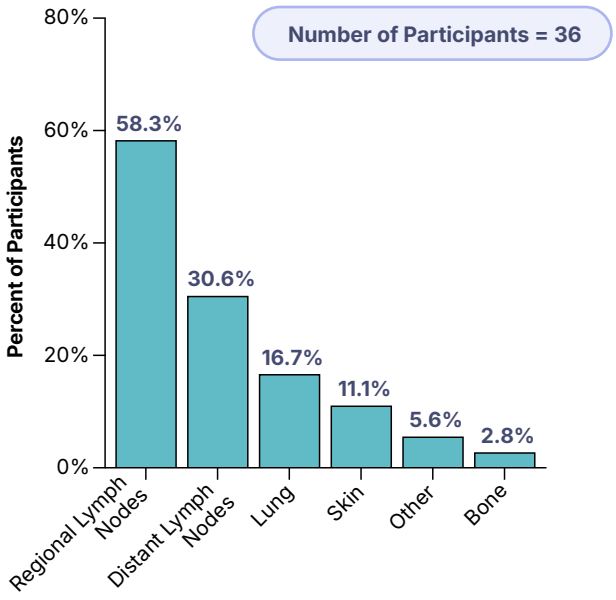
Melanoma progression in RARE participants was frequently characterized by involvement of multiple body sites. Across all melanoma subtypes, RARE participants identified that the most common sites their melanoma spread to involved the regional lymph nodes (58%), lungs (29%), distant lymph nodes (15%), liver (13%), and bones (11%). Less frequent sites included the head and neck (6%), adrenal gland (3%), and gastrointestinal tract (3%).

Of the participants with metastatic acral melanoma, the sites of metastasis involved the regional lymph nodes (58%), distant lymph nodes (31%), lungs (17%), skin (11%), bones (3%), and other sites (6%) like the gastrointestinal tract.

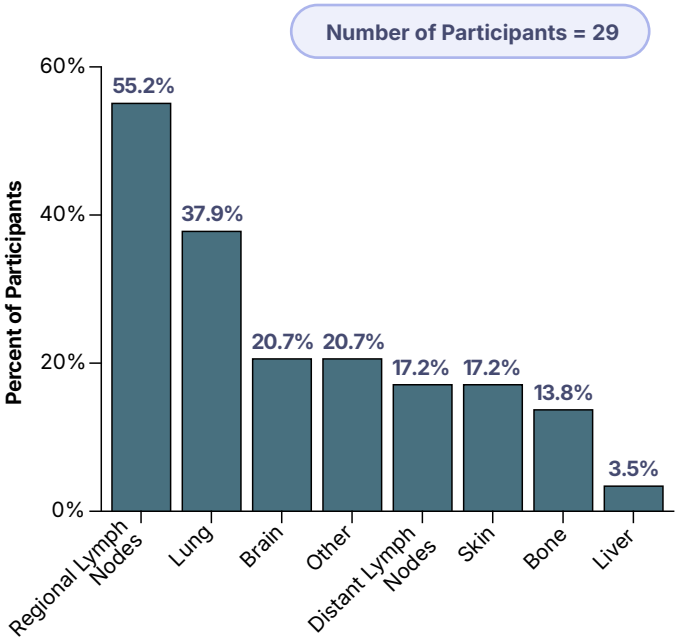
Participants with cutaneous melanoma reported their disease had spread to the regional lymph nodes (55%), lungs (38%), brain (21%), distant lymph nodes (17%), and other sites (21%) such as the adrenal gland, head and neck region, breasts, and gastrointestinal tract.

Metastatic mucosal melanoma was identified to spread to the regional lymph nodes (40%), lungs (31%), liver (23%), bones (13%), distant lymph nodes (7%), and other sites (31%). Other sites, less frequently, included the head and neck region, adrenal gland, breasts, gastrointestinal tract, and kidneys.

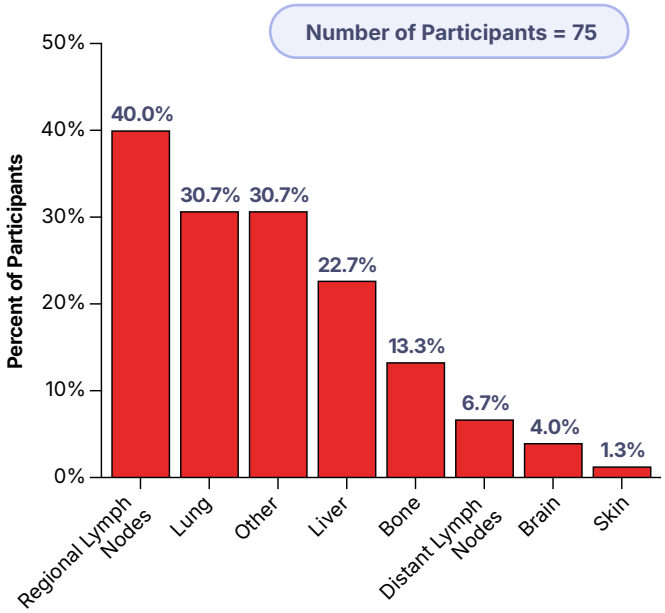
Sites of Metastatic Acral Melanoma



Sites of Metastatic Cutaneous Melanoma



Sites of Metastatic Mucosal Melanoma



Disease History

Age at Diagnosis of Metastatic Melanoma

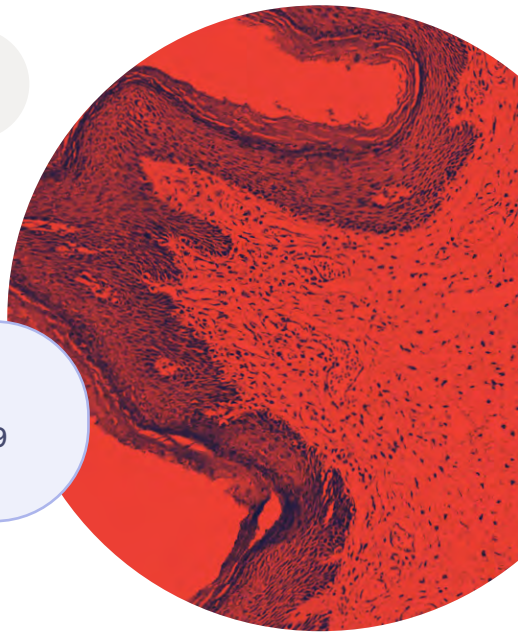
RARE participants reported an average age of 54 years old at the time of metastatic progression. Participants with cutaneous melanoma were of a younger age (average of 44 years old) than those with acral melanoma (average of 57 years) and mucosal melanoma (average of 56 years old).

For participants whose melanoma progressed to metastatic disease, the time from initial diagnosis to metastatic disease varied by melanoma subtype, with mucosal melanoma progressing the quickest (an average difference of less than 1 year), followed by acral melanoma (an average difference of 2 years) and cutaneous melanoma (an average difference of 4 years).

Average Age at Time of Metastatic Progression

54
years old
OVERALL

Number of Participants:
Acral Melanoma = 35
Cutaneous Melanoma = 29
Mucosal Melanoma = 74



44
years old
CUTANEOUS

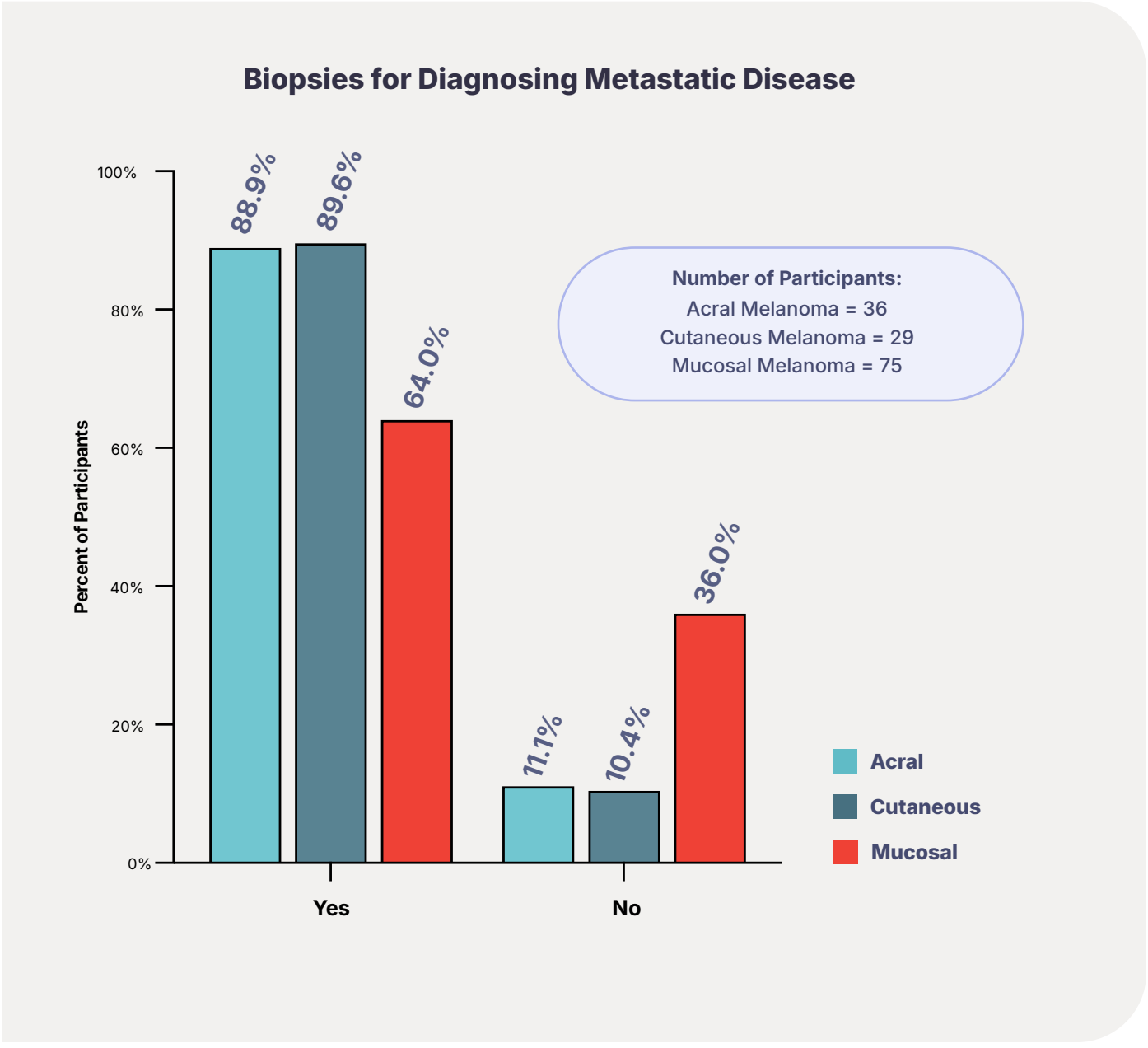
57
years old
ACRAL

56
years old
MUCOSAL

Disease History

Biopsies for Diagnosing Metastatic Melanoma

Most RARE participants (76%) underwent a biopsy to diagnose metastatic melanoma. Biopsy rates were similarly high among those with acral melanoma (89%) and cutaneous melanoma (90%), but considerably lower among participants with mucosal melanoma (64%). Across melanoma subtypes, the median number of biopsies was two, with greater variability in the number of biopsies for participants with mucosal melanoma. Across subtypes, the common biopsy sites for diagnosing metastatic melanoma involved the lymph nodes (39%) and less frequently the skin (14%), lungs (11%), liver (7%), head and neck region (3%), and bone (2%). Other biopsy sites reported by participants included the gastrointestinal tract, adrenal gland, kidneys, and breasts.



Disease History

Concerns About Metastatic Melanoma

RARE participants shared concerns about being diagnosed with metastatic melanoma. Length of life was the most commonly reported concern (91%), followed by treatment side effects (59%), burden of disease on family and friends (46%), ability to continue working (32%), financial concerns (29%), and access to care (20%). Participants also reported worries about melanoma recurrence, lack of effective treatments, and mental health.

Disease History

Current Disease Status

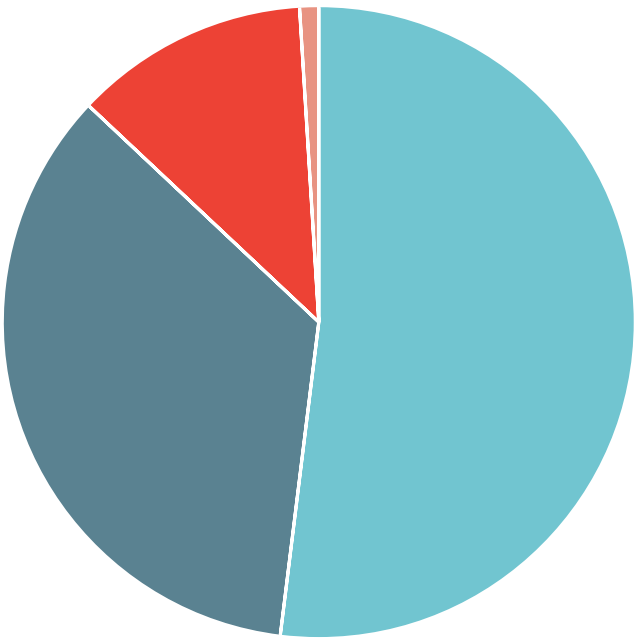
At the time of survey completion, 52% of RARE participants reported they had no evidence of disease, followed by 35% on therapy with active disease, and 12% on observation with active disease. 1% of all participants had passed away from their disease.

Active disease, whether on therapy or on observation, was highest among participants with mucosal melanoma (57%), followed by acral melanoma (42%), and cutaneous melanoma (33%). Among participants reporting no evidence of disease at the time of survey completion, the highest proportion had cutaneous melanoma (67%), followed by acral melanoma (57%), and mucosal melanoma (42%).

Current Disease Status

- **No Evidence of Disease:** 51.9%
- **Active Disease, On Therapy:** 35.0%
- **Active Disease, On Observation:** 12.1%
- **Deceased:** 1.0%

Number of Participants = 306



Disease History

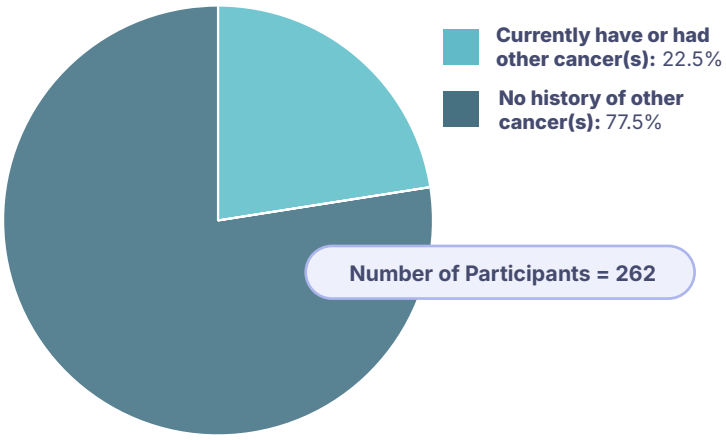
History of Cancer

Among all participants of RARE, 23% identified having been diagnosed with cancer either before or after their melanoma diagnosis. A history of cancer was most commonly reported among participants with acral melanoma (27%) and mucosal melanoma (24%) than those with cutaneous melanoma (15%).

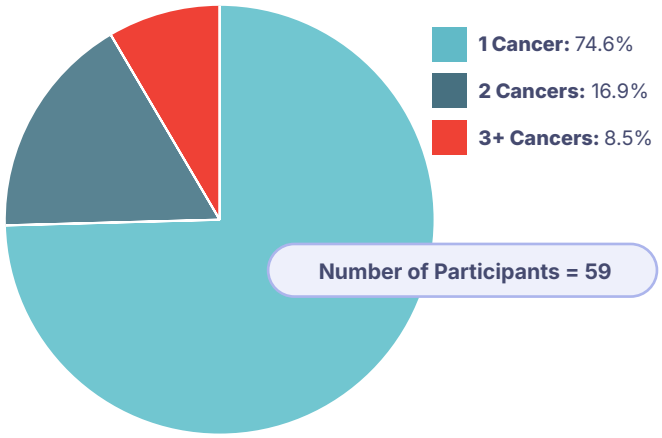
Most participants with a history of cancer reported one other cancer diagnosis (75%), followed by two (17%) or three or more (9%) other cancer diagnoses. Collectively, the majority of these cancer diagnoses (72%) occurred prior to a diagnosis of melanoma for participants, especially for participants with acral melanoma (82%) and mucosal melanoma (76%). In contrast, only 40% of participants with cutaneous melanoma reported a history of cancer prior to their melanoma diagnosis.

For participants with acral melanoma with a history of cancer, the most frequently reported cancers were basal cell carcinoma, breast cancer, and squamous cell carcinoma. Among participants with cutaneous melanoma reporting a history of cancer, common cancer types included basal cell carcinoma and squamous cell carcinoma. Basal cell carcinoma, breast cancer, and non-Hodgkin lymphoma were the most frequent cancers reported by participants with mucosal melanoma.

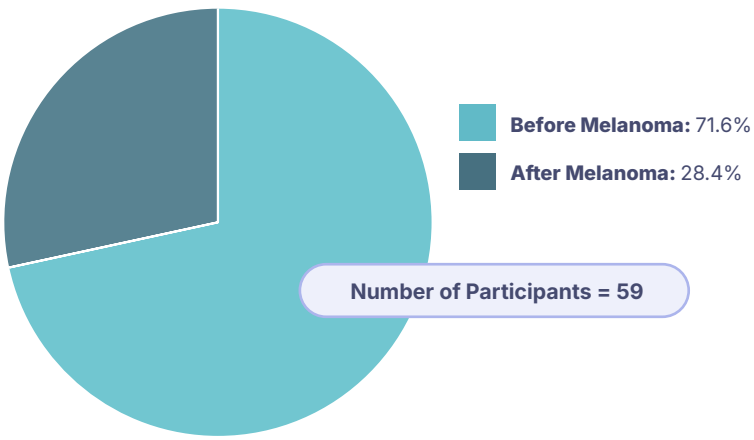
Personal History of Cancer



Number of Personal Cancer Diagnoses



Timing of Personal Cancer Diagnoses



Disease History

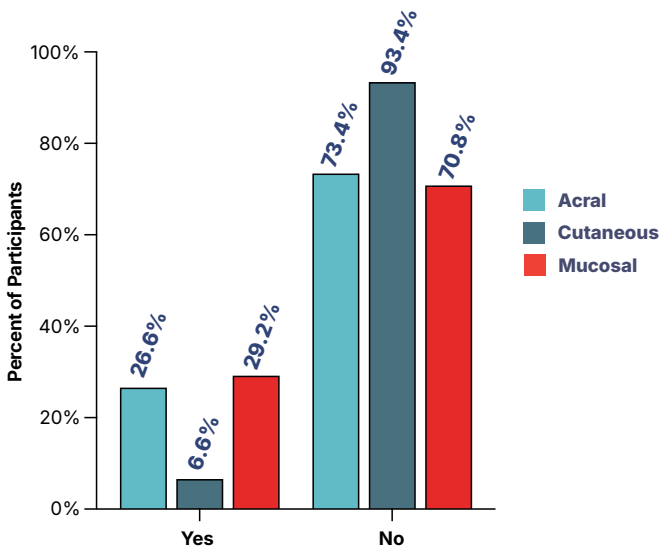
History of Chronic Disease or Illness

A history of chronic disease or illness prior to melanoma diagnosis was reported by 29% of participants with mucosal melanoma, 27% with acral melanoma, and 7% with cutaneous melanoma. Among participants with a prior chronic disease or illness, the most common conditions were high blood pressure (42%), autoimmune disease (35%), high cholesterol (30%), diabetes (17%), and thyroid disease (17%), among others. Participants with acral melanoma identified having other chronic diseases or illnesses such as asthma, migraine, irritable bowel disease, gastroesophageal reflux disease, gout, and long COVID. For participants with mucosal melanoma, other prior chronic diseases or illnesses reported included alopecia, endometriosis, asthma, chronic sinusitis, irritable bowel disease, among others.

Of participants with a prior chronic disease or illness, 38% had one condition, 32% had two conditions, and 30% had three or more conditions. Participants with acral melanoma most frequently reported having three or more prior chronic diseases (43%) compared to those with cutaneous melanoma (25%) or mucosal melanoma (23%).

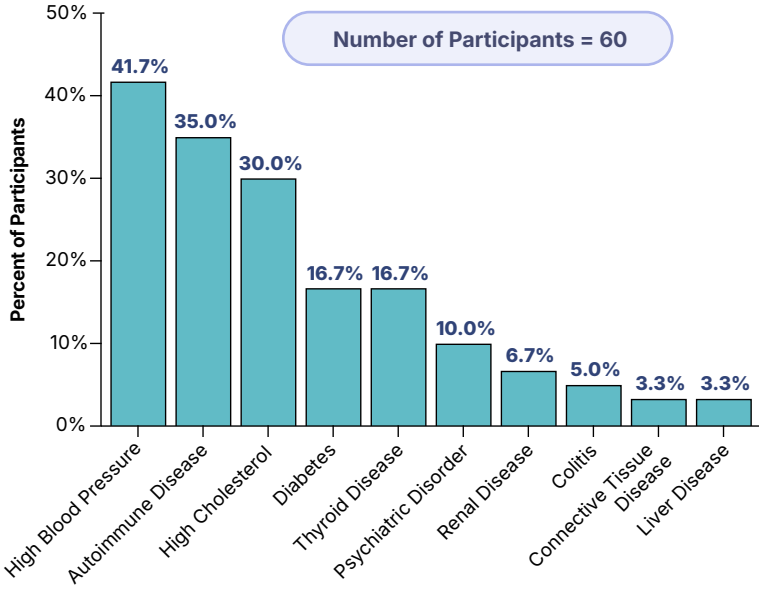
Across all melanoma subtypes, approximately 26% of participants reported developing a chronic illness or disease following their melanoma diagnosis (whether from treatment side effects or not).

History of Prior Chronic Disease

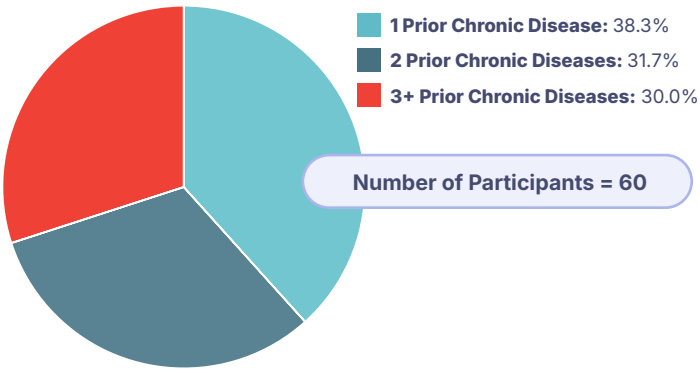


Number of Participants
Acral Melanoma = 79
Cutaneous Melanoma = 61
Mucosal Melanoma = 120

Prior Chronic Disease(s)



Number of Prior Chronic Disease(s)



IN THEIR OWN WORDS

Chris Carr

Patient Advocate and RARE Patient Advisor

“When I was diagnosed with acral melanoma in 2019, I found it very difficult to gather accurate information pertaining to survivor rates, recurrence, treatment options, and stories from people who had been through a similar situation. In general, rare melanomas receive very little attention.

The development of the RARE Registry audaciously attempts to mitigate some of the ‘lack of information’ problems. Working with other patient advocates, the registry was developed with a patient-first ethos, informed by world-class researchers and oncologists. It continues on the path toward aggregating and analyzing massive data sets to make the information available to those in the field.

There is the scientific aspect, by which the registry has gathered some of the most prolific and proficient minds to work on a highly complex problem. The directed focus and diverse backgrounds have led to new insights and approaches that I’ve witnessed firsthand. On a personal level, it feels good to be seen as a patient, as a human, and not just a number in a data table. The patient advisors are actively involved in all levels of activity within the registry, which I find highly encouraging. I am excited to continue my work with the RARE Registry and fully support its mission.”

Treatment History

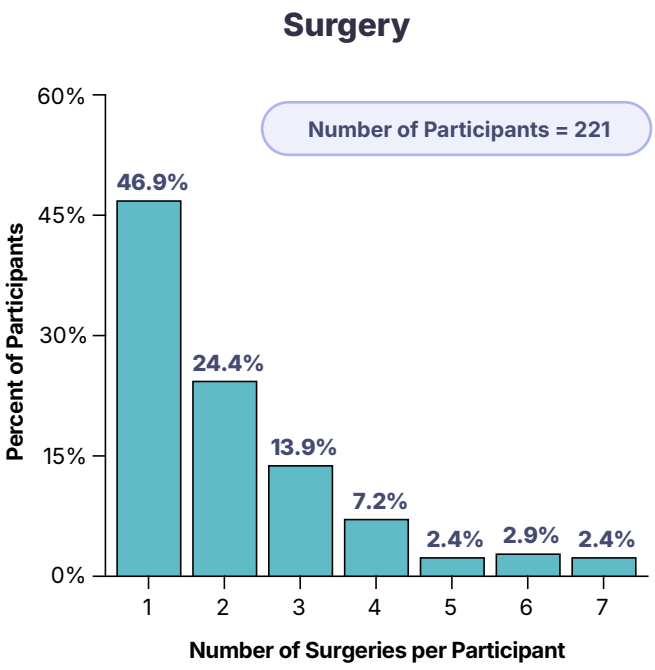
Surgery

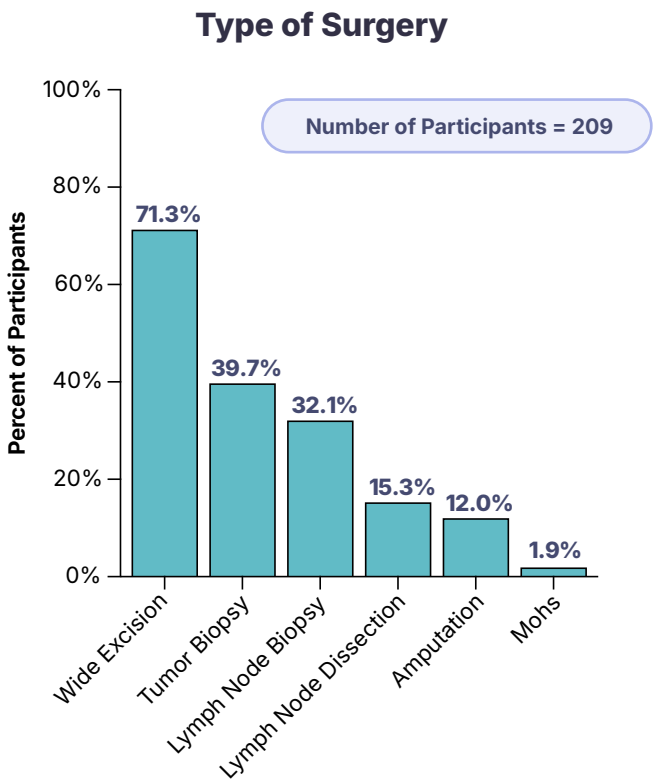
Approximately 95% of participants reported having undergone surgery for their melanoma. On average, participants underwent two surgeries for their melanoma (minimum of one surgery, maximum of seven surgeries), and this was largely consistent across melanoma subtypes.

The majority of RARE participants reported having a wide excision surgery (71%), tumor biopsy (40%), sentinel lymph node biopsy (32%), complete lymph node dissection (15%), amputation (12%), or Mohs (2%). Amputation was most frequently indicated by participants with acral melanoma (34%) than those with mucosal melanoma (2%) and cutaneous melanoma (0%).

The first surgical procedure was most often a wide excision surgery (50%) or a tumor biopsy (29%). Most wide excision surgeries were followed by a lymph node biopsy or dissection. Tumor biopsies were most often followed by wide excision surgery.

Generally, RARE participants viewed surgical interventions as highly effective and valuable, and often times as curative, especially in early-stage melanoma.





Treatment History

Radiation Therapy

Approximately 29% of RARE participants reported having radiation for treating their melanoma. The most common type of radiation therapy reported was intensity modulated radiation therapy or IMRT (52%), followed by stereotactic radiosurgery or SRS (30%), proton therapy (11%), and intraoperative radiation therapy (6%), among other types of radiation therapy. On average, these participants underwent one course or type of radiation therapy.

Among participants who underwent IMRT, 47% received treatment to the head and neck region, 30% received IMRT as a part of a planned surgery, and 70% received IMRT in conjunction with immunotherapy. Side effects were reported by 81% of participants. 65% reported that the treatment was valuable in treating their melanoma.

Among participants who received SRS, 79% received treatment to the brain, head and neck region, or spine, and 65% received SRS as a part of a planned treatment with immunotherapy. 59% of participants reported side effects and 82% found this type of radiation therapy to be valuable in treating their melanoma.

Percentage of Participants Receiving Radiation Treatment

29%

OVERALL

52%

INTENSITY MODULATED RADIATION THERAPY

30%

STEREOTACTIC RADIOSURGERY

11%

PROTON THERAPY

Treatment History

Medications

Over the last two decades, there have been 19 approved treatments for melanoma. These include immunotherapies such as the immune checkpoint inhibitors, oncolytic viral therapy, and more recently a cell-based immune therapy called tumor infiltrating lymphocyte (TIL) therapy. The new approvals also include drugs targeted to inhibit an acquired alteration or tumor biomarker in melanoma called BRAF and drugs that target another protein controlling cell growth in melanoma called MEK. The approved therapies are used to treat advanced and metastatic melanoma, and some treat melanoma in the adjuvant setting (after surgical removal of the tumor) in patients that are at higher risk for disease progression.

Infused and Injected Medications

Approximately 63% of RARE participants across all subtypes reported being administered an infused or injected medication as a part of their treatment for melanoma. These included the immune checkpoint inhibitors given as monotherapy, Keytruda (Pembrolizumab), Opdivo (Nivolumab), and Yervoy (Ipilimumab), as well as the immune checkpoint drugs given in combination, Yervoy + Opdivo (Ipilimumab + Nivolumab) and Opdualag (Nivolumab + Relatlimab). Therapeutics such as Intron A (Interferon alfa-2b), among others, were also used. Participants reported receiving approximately two infused or injected medications for treating their melanoma.

Intralesional and Topical Medications

Nearly 10% of participants reported using intralesional or topical medications, including Aldara/Imiquimod, the oncolytic viral therapy Imlygic (T-VEC), TICE BCG (BCG Live), and Intron A (Interferon alfa-2b). On average, these participants indicated using one type of intralesional or topical medication as a part of their melanoma treatment.

Oral Medications

The use of oral medications was reported by 16% of RARE participants. Drugs that are BRAF and MEK inhibitors were used across melanoma subtypes in participants presumably who tested positive for the BRAF tumor biomarker. The oral medications to treat these patients included the BRAF drugs, Braftovi (Encorafenib), Tafinlar (Dabrafenib), and Zelboraf (Vemurafenib), and MEK drugs including Mekinist (Trametinib) and Mektovi (Binimetinib), as well as combinations of BRAF and MEK drugs. Other oral medications given to some participants included Gleevec (Imatinib Mesylate) and Temodar (Temozolomide), among others.

COMING SOON: Participants will be able to connect to their Electronic Health Records (EHRs) and upon consent, transfer specific medical information to the RARE Registry. MRA registry staff will abstract clinical data from the EHRs, such as treatment information, which will be linked to the participant's reported survey responses.

The MRA is committed to supporting research that aims to identify new therapeutic approaches for treating melanoma. Since its founding in 2007, the MRA has dedicated over **$31 million** to rare melanoma research.

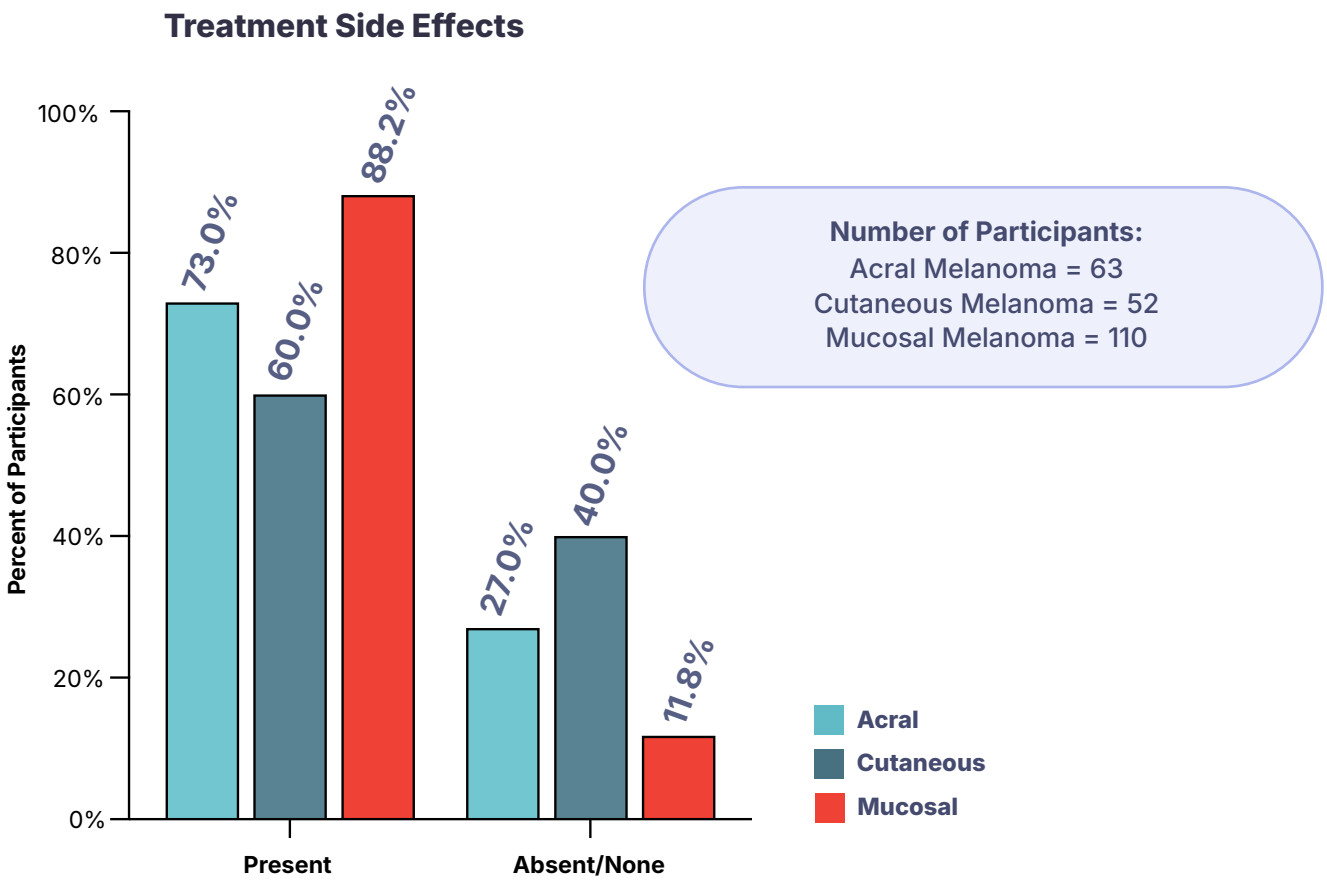
Treatment History

Treatment Side Effects

Across melanoma subtypes, most participants (78%) reported experiencing treatment side effects, with the highest proportion having mucosal melanoma (88%), followed by acral melanoma (73%), and cutaneous melanoma (60%).

Collectively, RARE participants reported a wide range of treatment-related side effects, with fatigue being the most consistently described and characterized as severe, persistent, and functionally limiting. Gastrointestinal toxicities such as diarrhea, nausea, vomiting, and colitis, were also commonly noted and described as being disruptive to daily life, and in some cases, requiring long-term management or hospitalization. In addition, participants reported endocrine-related complications, particularly in the context of immunotherapy, highlighting side effects like thyroid disfunction, adrenal insufficiency, and diabetes.

Skin-related complications were also described and included rash, vitiligo, itching or pruritus, blistering, and burns, in some cases resulting from radiation therapy. Neurological symptoms were frequently identified and spanned headache, neuropathy, vision or hearing loss, and brain fog or reduced cognitive function. For participants who underwent surgery, post-surgical complications included poor wound healing, infections, and nerve injury, with some participants reporting long-term or permanent functional limitations and the need for assistive mobility devices.



Treatment History

Value of Treatment

RARE participants generally described their melanoma treatment(s) as valuable and in some cases, life-saving, even when enduring a treatment with challenging side effects or a long recovery period. Some viewed treatment as a way to delay progression, valuing the time gained to explore emerging treatment options. Many participants expressed willingness to undergo the same treatment(s) again as the benefits of the therapy outweighed the burdens.

However, participants emphasized that while melanoma treatment(s) extended life, they reduced quality of life. Participants described feeling a lack of involvement in treatment decisions and called for clearer communication about treatment efficacy and side effects.

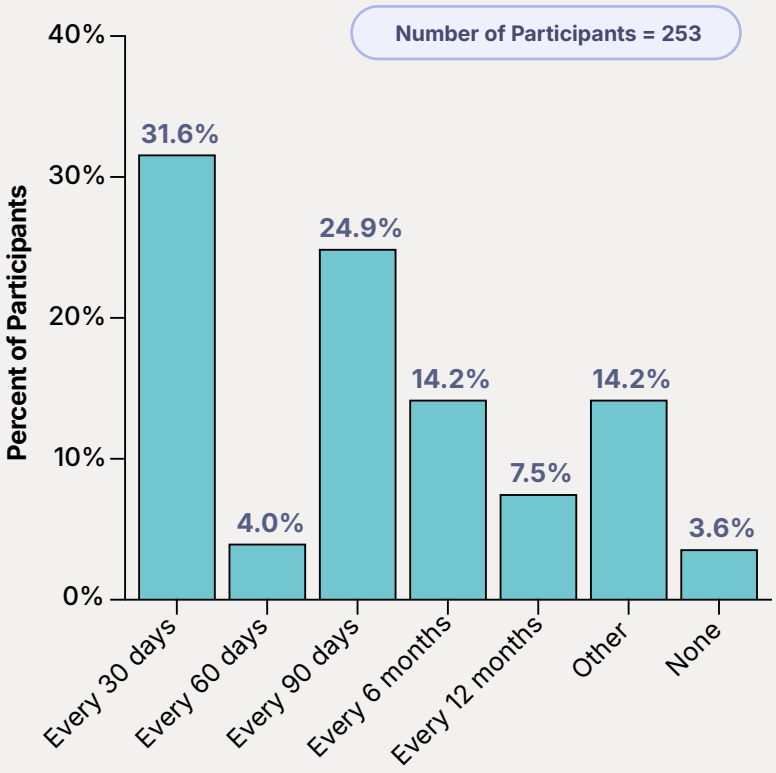
Treatment History

Monitoring and Frequency of Visits with Medical Care Team

The majority of RARE participants visited their medical care team every 30 days (32%) or every 90 days (25%). Participants with mucosal melanoma (40%) were most likely to visit their medical care team every 30 days compared to those with acral melanoma (25%) or cutaneous melanoma (22%).

Most participants (87%) indicated satisfaction with the frequency of medical monitoring, whereas 12% felt monitoring was too limited and 1% felt it was too much. Visits were most frequently with medical oncologists (68%), dermatologists (65%), surgeons (32%), and primary care physicians (27%), among other physician specialties.

Frequency of Visits with Medical Care Team



Treatment History

Clinical Trial Participation

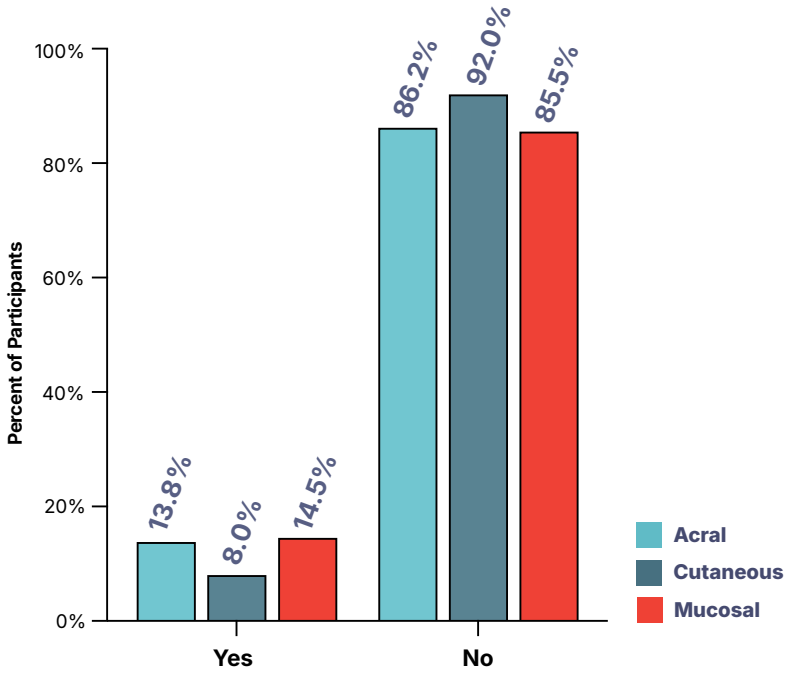
Participants' interest in participating in a clinical trial varied across melanoma subtypes. Those with acral melanoma (37%) and mucosal melanoma (34%) expressed the greatest interest in participating in clinical trials compared to those with cutaneous melanoma (22%).

Participants identified several barriers to clinical trial participation, including most frequently that clinical trials were not mentioned as a medical care option (54%), and that individuals with acral and mucosal melanoma often did not meet eligibility criteria for available trials (40% and 48%, respectively). Participants also described difficulties finding a trial that was right for them (8%) and had concerns about side effects (7%). Concerns about receiving placebo in a clinical trial (6%) were also noted.

Approximately 15% of participants with mucosal melanoma, 14% with acral melanoma, and 8% with cutaneous melanoma had enrolled in a clinical trial. Of the participants that enrolled in clinical trials, the average distance traveled to participate in the trial was 370 miles.

Participation in Clinical Trials

Number of Participants:
Acral Melanoma = 65
Cutaneous Melanoma = 50
Mucosal Melanoma = 110



Through RARE, participants have the opportunity to receive announcements for clinical trials. To learn more about clinical trials and the critical role they play in advancing research and patient care, visit curemelanoma.org/clinicaltrials.

In order to have productive discussions with medical providers and be able to make informed care decisions, every patient should have clear information on all treatment possibilities, including clinical trials. Educational material such as webinars and FAQs can be found at curemelanoma.org, as well as, across other advocacy sites and clinicaltrials.gov.

IN THEIR OWN WORDS

Amy Jardon

Patient Advocate and RARE Patient Advisor

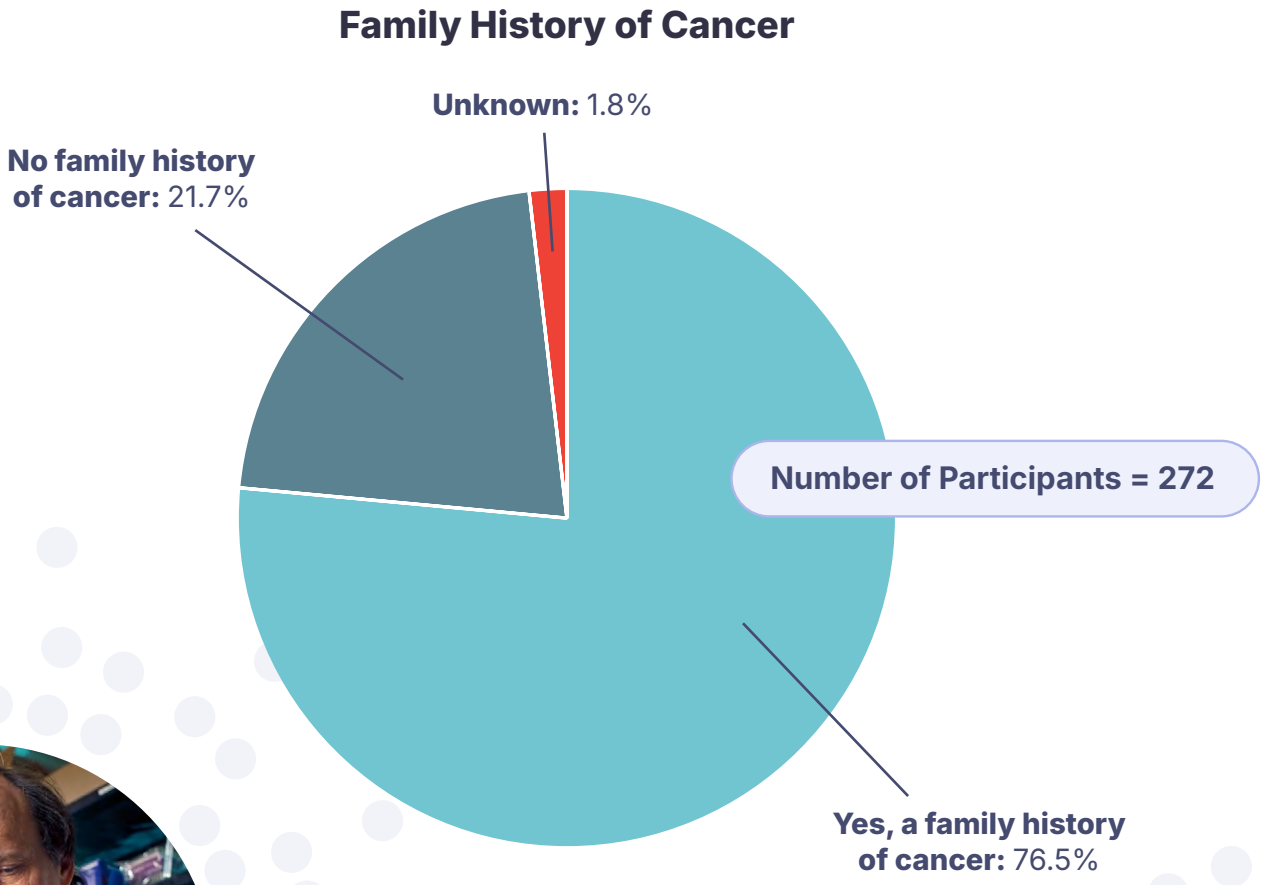
"For myself—and many—healing after melanoma is more in-depth than just physical healing. Finding an answer as to why the rare subtypes occur, and to contribute to science in a small way is exciting. With the RARE Registry, we can help make a difference for today, and for more tomorrows. The RARE Registry gives patients a way to make a change in the lens of research, treatment, and patient living.

When I was asked to be a part of the RARE Registry, to help expand our understanding of the rare melanoma subtypes, I was excited to help enact change for acral melanoma and to make a difference for those newly or yet to be diagnosed. From survey questions to being able to upload medical records, the RARE Registry allows patients to have an avenue to help and for researchers to gain insight into the medical lives of patients, including their appointments, treatments, and adverse or positive effects of therapy. The RARE Registry is building a bridge to the tomorrows for researchers and patients, bringing meaningful change to a rare melanoma diagnosis."

Genetics & Tumor Biomarkers

Family History of Cancer

Across all melanoma subtypes, approximately 77% of participants reported a family history of cancer, excluding any type of melanoma. The most common types of cancer affecting family members included breast cancer (22%), lung cancer (13%), prostate cancer (11%), colon cancer (8%), pancreatic cancer (5%), leukemia (5%), and bladder cancer (4%), among several others. Participants reported a history of cancer involving one family member (37%), two family members (32%), or three or more family members (31%). Of the family members affected by cancer, 49% were grandparents, 38% were parents, and 13% were siblings.



Genetics & Tumor Biomarkers

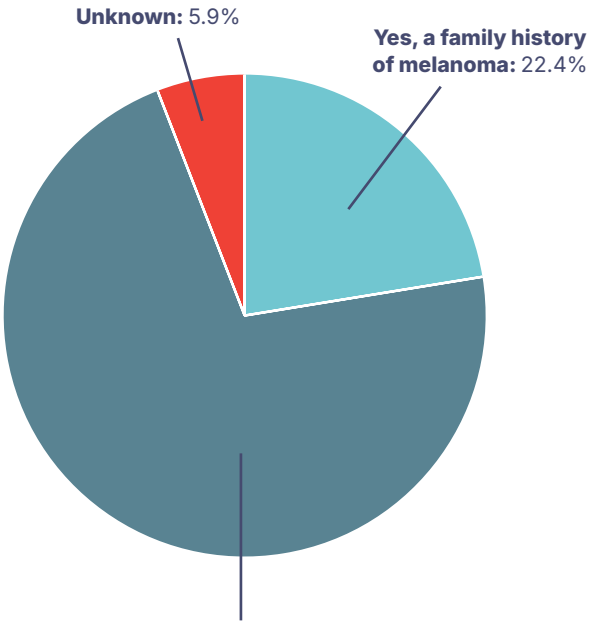
Family History of Melanoma

Among all RARE participants, 22% reported a family history of melanoma. A family history of melanoma was the most common among participants with cutaneous melanoma (32%), followed by mucosal melanoma (20%), and acral melanoma (19%).

The majority of these participants reported having one family member with a history of melanoma (76%), followed by two or more family members with a history of melanoma (24%). Of the family members affected by melanoma, 51% were parents, 29% were grandparents, and 20% were siblings.

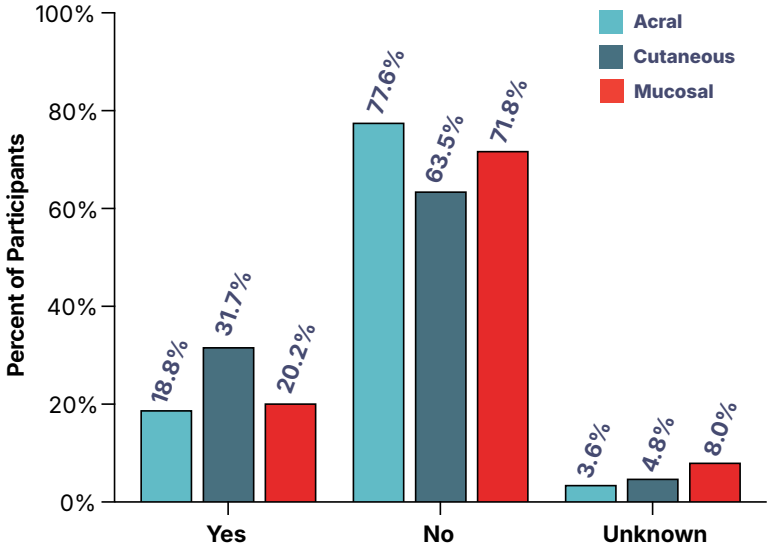
The average age of family members diagnosed with melanoma was 60 years (median of 65 years, minimum of 21 years, and maximum of 94 years).

Family History of Melanoma



Number of Participants = 272

Family History of Melanoma by Subtype



Number of Participants:
Acral Melanoma = 85
Cutaneous Melanoma = 63
Mucosal Melanoma = 124

Genetics & Tumor Biomarkers

Genetic Testing: Inherited Gene Mutations

Genetic testing enables the detection of inherited gene changes in healthy (non-cancerous) cells that may predispose individuals to a higher risk of developing cancer, such as melanoma. In a subset of melanomas, these inherited changes can contribute to an individuals' lifetime risk of developing the disease.

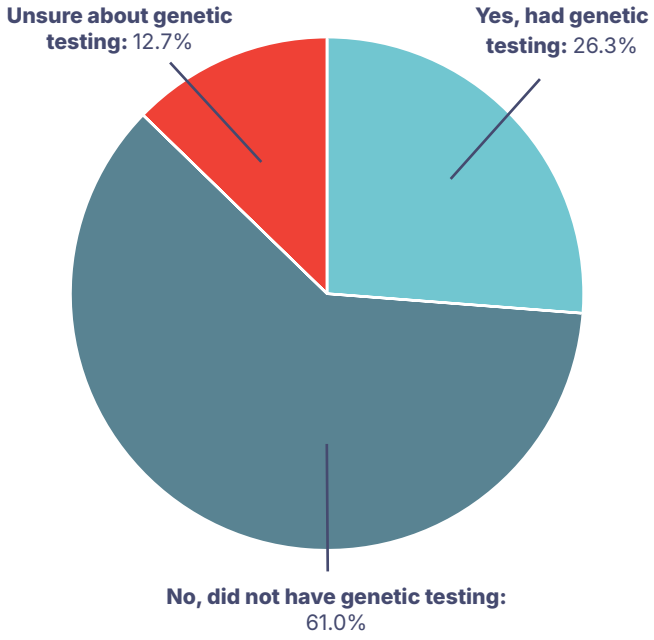
Among all RARE participants, 26% underwent genetic testing while the majority (61%) did not have genetic testing performed. 13% of participants were unsure of whether genetic testing had been performed. Genetic testing was most frequently performed among participants with cutaneous melanoma (32%), followed by acral melanoma (27%), and mucosal melanoma (23%).

Of participants who underwent genetic testing, the hospital laboratory (30%) was the most frequent site for testing to be performed, followed by Invitae (22%), and Ambry (16%). Other less frequent sites included Blueprint Genetics, Color Genomics, Myriad, and Tempus.

The presence of inherited gene mutations was reported by 42% of participants with cutaneous melanoma, 30% of participants with mucosal melanoma, and 14% of participants with acral melanoma. The percentage of inherited mutations in RARE participants may be higher than what has been reported in the literature for patients with cutaneous and rare melanoma subtypes (Toussi *et al.*, 2020; Amouzegar *et al.*, 2026). This may be explained by the relatively low number of RARE participant responses to this question.

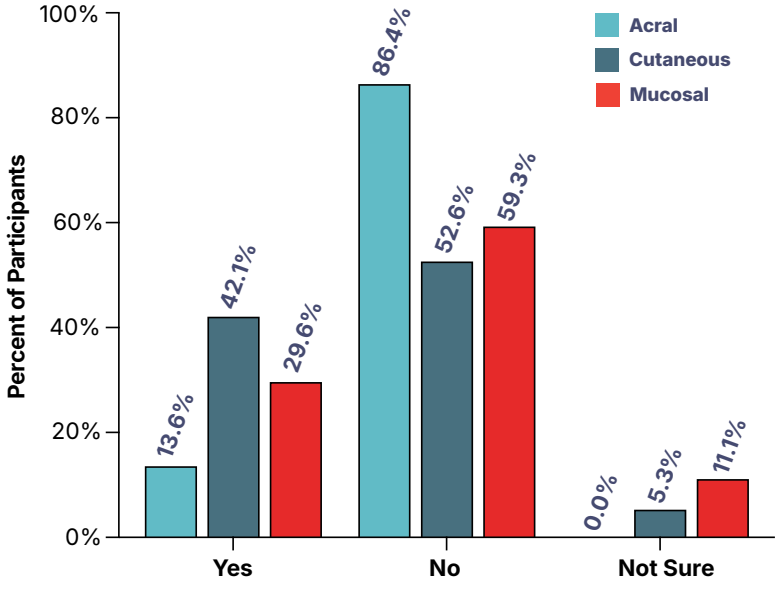
Participants with acral melanoma identified inherited gene mutations in *CDKN2A*. Participants with cutaneous melanoma reported inherited gene mutations in *BAP1*, *BRCA2*, *CDK4*, *CDKN2A*, *MITF*, *PTEN*, and *TERT*. Inherited gene mutations were identified in *ATM*, *CDK4*, *CDKN2A*, *MDM2,* and others, among participants with mucosal melanoma.

Genetic Testing



Number of Participants = 267

Presence of Inherited Gene Mutations



Number of Participants
Acral Melanoma = 22
Cutaneous Melanoma = 20
Mucosal Melanoma = 28

Toussi, A., Mans, N., Welborn, J., & Kiuru, M. (2020). Germline mutations predisposing to melanoma. *Journal of cutaneous pathology*, 47(7), 606–616. https://doi.org/10.1111/cup.13689

Amouzegar, A., Wu, X., Long, J. P., Chen, G. W., Wong, J. W., Prabhakaran, S., Little, L., Gumbs, C., Bota, N., Malke, J., Simon, J., Zhang, J., Nagarajan, P., Davies, M. A., Tawbi, H., Amaria, R. N., Oliva, I. C. G., Ikeguchi, A. P., Su, S., Hanna, E. Y., ... Futreal, P. A. (2026). Germline variants in cancer susceptibility genes among patients with mucosal melanoma. *NPJ genomic medicine*, 10.1038/s41525-026-00583-y. Advance online publication. https://doi.org/10.1038/s41525-026-00583-y

Genetics & Tumor Biomarkers

Biomarker Testing: Acquired Gene Mutations in Melanoma

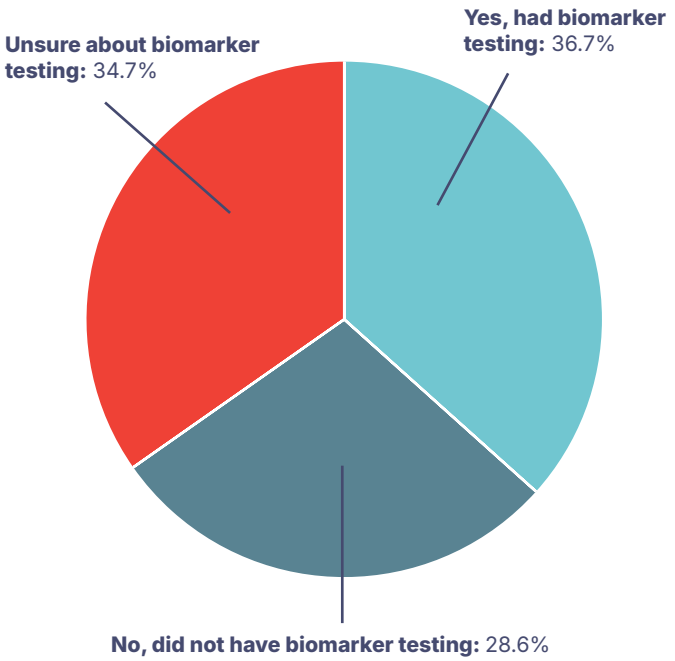
Biomarker testing often involves looking at the genetic alterations to DNA or genes present in cancer cells—these are known as acquired mutations and represent a type of tumor biomarker. Understanding the acquired mutations found in melanoma can help physicians understand more about how an individual's melanoma may behave and respond to certain treatments.

Among all RARE participants, 37% had tumor biomarker testing performed to look for acquired mutations in the DNA of cancer cells. Tumor biomarker testing was most frequently reported by participants with mucosal melanoma (46%), followed by those with acral melanoma (29%) and cutaneous melanoma (29%).

The majority of participants had tumor biomarker testing performed through a hospital lab (53%), followed by Caris (7%), Tempus (5%), Foundation Medicine (4%), Guardant Health (3%), and others such as Natera and Castle Biosciences.

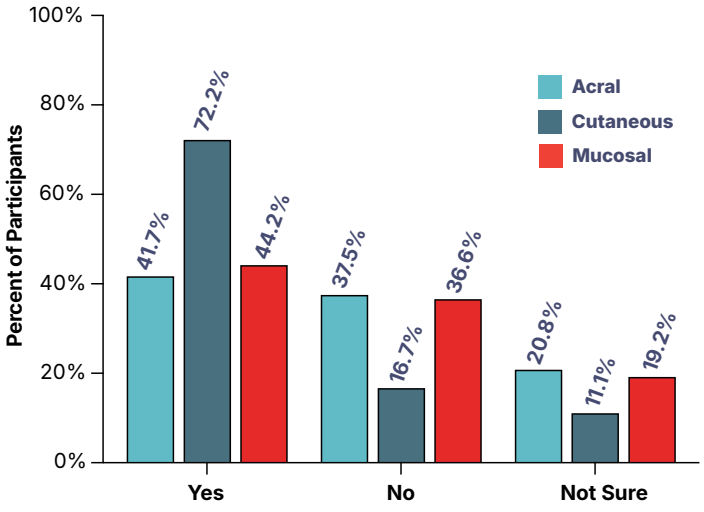
For participants that had biomarker testing performed, acquired mutations were found in 72% of those with cutaneous melanoma, 44% of those with mucosal melanoma, and 42% of those with acral melanoma. Participants with acral melanoma identified acquired gene mutations in *BRAF*, *CDK4*, *CRKL*, *FRS2*, *KIT*, *MDM2*, *NF1*, *NRAS*, *PAK1*, *RSF1*, and *YEATS4*. Among those with cutaneous melanoma, acquired gene mutations were identified in *BRAF*, *GNAQ*, *GNA11*, *NRAS*, *PTEN*, and *TP53*. Participants with mucosal melanoma reported acquired gene mutations in *ATR*, *BLM*, *BRAF*, *CDK4*, *CDKN2A-p14*, *CDKN2A-p16*, *KIT*, *KRAS*, *NF1*, *NRAS*, *RB1*, *SF3B1*, and *TP53*.

Tumor Biomarker Testing



Number of Participants = 262

Presence of Acquired Gene Mutations



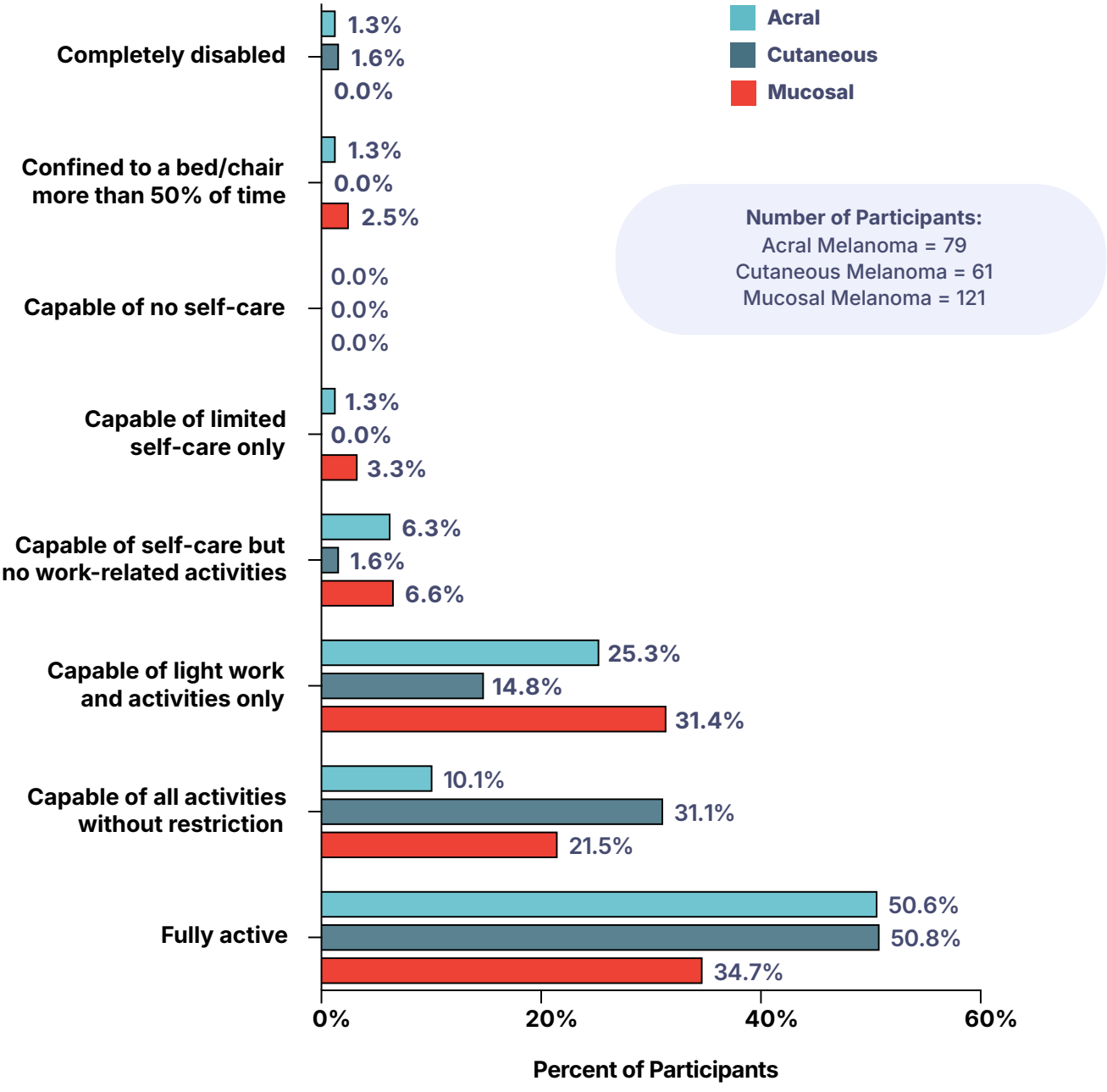
Number of Participants:
Acral Melanoma = 24
Cutaneous Melanoma = 18
Mucosal Melanoma = 54

Support & Quality of Life

Impact of Melanoma on Current Health, Lifestyle, and Quality of Life

When asked about the current status of health and physical activity, participants with cutaneous melanoma (82%) more frequently reported being fully active or capable of all activities without restriction, compared to participants with acral melanoma (61%) and mucosal melanoma (56%), indicating a generally poorer functional status in participants with these rare melanoma subtypes. A larger percentage of participants with acral and mucosal melanoma also reported greater limitations in work-related activities and self-care.

Current Status of Health & Physical Activity



RARE participants shared additional information about how melanoma has affected their current health and ability to participate in social and other activities. Several major themes emerged from their responses.

Participants described a large psychological burden of living with melanoma, whether having a common or rare subtype. Psychological distress was associated with fear of progression or recurrence, anticipation of test results, and enduring lengthy treatment trajectories. Participants also noted their disease led to emotional strains on relationships with family and friends that exacerbated feelings of loneliness and isolation.

Substantial physical burdens of melanoma and associated treatments were described, including fatigue, pain, sleep disruption, and physical weakness. These symptoms contributed to limitations in work, exercise, travel, and social activities with friends and family.

Financial challenges emerged, with participants reporting high out-of-pocket medical expenses, medical debt, and changes to health insurance coverage due to reduced work capacity. Several participants described being forced into early retirement or part-time employment due to their disease or treatments. Travel expenses associated with specialized care or clinical trials further contributed to financial strain.

Participants expressed frustrations with the healthcare system, including limited treatment options, treatments with severe and lasting side effects, delays in diagnosis and care, and barriers to accessing clinical trials.

Despite these challenges, many RARE participants described meaningful shifts in their perspectives of life following their melanoma diagnosis. Participants noted a change in priorities, focusing on more intentional, present-moment living. Some found purpose through advocacy, community involvement, spirituality, or faith. Others found hope in the future—that advances in research will lead to improved care for patients with melanoma.

Currently, the MRA is working on a study to better understand patient quality of life using data collected through RARE.

Support & Quality of Life

Social and Family Support

Overall, the majority of RARE participants expressed that they had adequate social and family support throughout their disease journey. This sentiment was greatest among participants with cutaneous melanoma (95%) and mucosal melanoma (94%), and slightly lower among participants with acral melanoma (85%).

"The RARE Registry is an opportunity for patients to help shape the future of melanoma research.

By sharing their experiences with melanoma, patients help investigators and clinicians to identify research priorities, thus accelerating efforts towards improving care and quality of life for current and future patients."

JESSICA SCALES, PHD
MRA ASSOCIATE DIRECTOR, RARE MELANOMA RESEARCH

IN THEIR OWN WORDS

J.B. Ward, PhD

Patient Advocate and RARE Patient Advisor

“Rare melanomas have remained relatively in the shadows for a long time. With so few cases per year, there hasn’t been a pathway to collecting enough information about these conditions. The RARE Registry has provided an opportunity to do meaningful research for rare melanomas.

There are many ways that rare melanomas differ from cutaneous melanomas, and we are now able to investigate some of these differences. For example, we have had the opportunity to begin to look at the impact of having a rare melanoma on an individual’s quality of life, which was previously unexplored.”

Closing

The Future of RARE: Insights from Patients, Impact for Research

RARE captures a unique and growing body of knowledge about the lived experiences of patients with acral, mucosal, and cutaneous melanomas—insights that are often not captured through research on these patient populations, especially for the rare melanoma subtypes.

RARE aims to expand by enrolling new participants and actively engaging current participants to complete registry surveys, both of which will strengthen the insights generated from RARE and enable the launch of new and more powerful research studies. To get involved in the MRA's RARE Registry, please visit raremelanoma.org or contact us at rare@curemelanoma.org.

The future of RARE depends on a growing, engaged community of patients and caregivers. In 2026 and beyond, we are advancing several key initiatives to support the mission of RARE—to deepen our understanding of melanoma and improve patient outcomes.

FOR RARE REGISTRY PARTICIPANTS

RARE is starting its **first peer-reviewed research study focused on quality of life for individuals with acral, mucosal, and cutaneous melanoma**, with additional comprehensive studies to follow. Sharing your lived experiences through RARE is pivotal in driving this work. If there are specific research questions or topics you would like to see explored, we encourage you to share your ideas with us by reaching out to rare@curemelanoma.org.

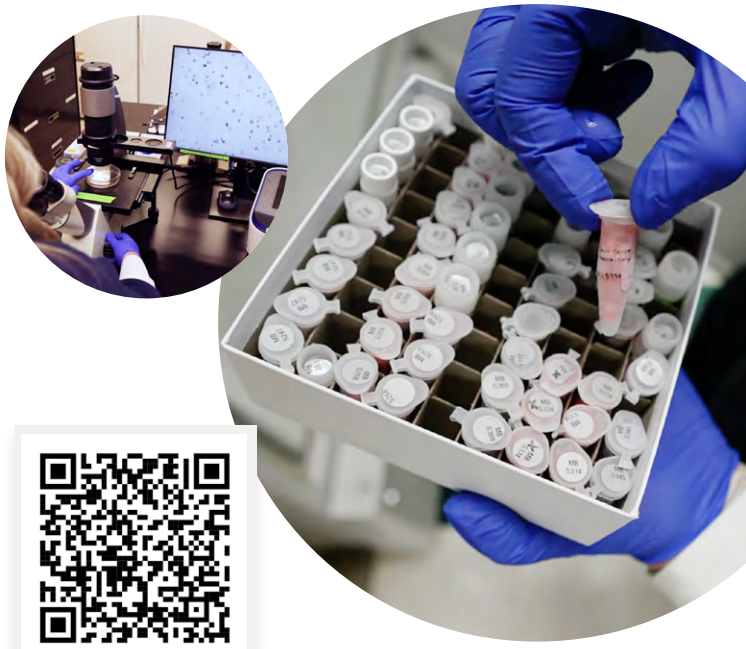
We are also introducing a new electronic health record (EHR) integration feature on RARE's web portal that will enable participants to securely connect their medical records with their RARE survey data. This will enable more detailed research on disease progression, treatments, and outcomes—amplifying the impact of each and every participant's contribution to RARE.

Lastly, we have launched the **MRA Melanoma Biorepository, which now provides patients the opportunity to donate their melanoma tumor and normal tissues from past or upcoming procedures (biopsies and surgeries).** Donated tissues will support approved research studies previously out of reach, including studies on predictive and prognostic biomarkers, as well as, treatments and treatment resistance mechanisms in melanoma. Participants enrolled in RARE may also choose to have their registry data linked with their donated samples. To learn more, visit curemelanoma.org/biorepository.

FOR CLINICIANS AND RESEARCHERS

MRA is developing a data analytics platform that will provide researchers and clinicians with access to de-identified, aggregate data from RARE to facilitate studies on melanoma that aim to improve patient care and outcomes. Feel free to contact MRA with ideas on future surveys to incorporate into RARE to collect additional data. Please let us know if there are ways that you could help us spread the word about RARE so we can continue to build a more complete understanding of melanoma, especially the rare subtypes that remain underrepresented in research.

Collectively, these efforts will strengthen RARE as an important and ongoing resource for the melanoma community and help shape the future of research and care for patients with melanoma.



To learn more about the MRA's Melanoma Biorepository, visit curemelanoma.org/biorepository or email the MRA Melanoma Biorepository team at biorepository@curemelanoma.org.

Acknowledgements

The MRA recognizes that the RARE Registry is built upon the willingness of patients to share their lived experiences and melanoma journeys. We sincerely thank the patients who have generously contributed their time and lived experiences to make this important work possible.

We are especially grateful to the RARE patient advisors, whose perspectives and advocacy helped to shape and guide the registry from its earliest stages, and to the RARE scientific advisors, whose expertise in these melanoma subtypes has been instrumental in expanding the RARE Registry's scope, depth, and long-term vision.

RARE Oversight Committee Scientific Advisors

Maryam Asgari, MD, MPH—University of Colorado Anschutz School of Medicine

Boris Bastian, MD, PhD—University of California San Francisco

Elizabeth Buchbinder, MD—Massachusetts General Hospital

Richard Carvajal, MD—Northwell Health

Kasey Couts, PhD—University of Colorado Anschutz School of Medicine

Jason Luke, MD—Strand Therapeutics, Inc.

Sapna Patel, MD—University of Colorado Anschutz School of Medicine

Vito Rebecca, PhD—Johns Hopkins University

Yevgeniy 'Eugene' Semenov, MD, MS—Massachusetts General Hospital

Alexander Shoushtari, MD—Memorial Sloan Kettering Cancer Center

Iwei Yeh, MD, PhD—University of California San Francisco

RARE Principal Investigator

Joan Levy, PhD—MRA Chief Science Officer

Registry Staff

Joan Levy, PhD—MRA Chief Science Officer

Jessica Scales, PhD—MRA Associate Director, Rare Melanoma Research

Many thanks to prior MRA staff involved in the inception and launch of the RARE Registry: **Marc Hurlbert, PhD; Rachel Fisher, PhD; Cody Barnett, MPH; Nicholas Starink, MPH**

Report Contributors

Joan Levy, PhD—MRA Chief Science Officer

Jessica Scales, PhD—MRA Associate Director, Rare Melanoma Research

Precious Ngnosse, BS—MRA Science Intern

Dana Deighton, BA—MRA Director, Communications and Engagement

Renee Orcione, BA—MRA Associate Director, Communications and Engagement

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To learn more about the MRA's RARE Registry, please visit raremelanoma.org or email the RARE Registry team at rare@curemelanoma.org.

RARE where you lead melanoma research

The **RARE Registry** is an initiative led by the **Melanoma Research Alliance** (MRA). MRA was founded in 2007 and is the largest non-profit funder of melanoma research worldwide. Since its inception, MRA has committed over $200 million, and leveraged an additional $500 million from outside sources, to fund life-saving melanoma research needed to achieve its mission of ending suffering and death due to melanoma. Learn more about the MRA at **CureMelanoma.org** and the RARE Registry at **raremelanoma.org**.

VISIT THE REGISTRY:
raremelanoma.org

Melanoma Research Alliance

curemelanoma.org

MELANOMA RESEARCH ALLIANCE
730 15th Street, NW | Washington, DC 20005 | (202) 336-8935 info@curemelanoma.org