RESEARCH REPORT 2026

INSIGHT GLOBAL PATIENT REGISTRY FOR OCULAR MELANOMA

New in 2026:
Additional INSIGHTS for Researchers and BioPharma Drug Developers

aCUREINSIGHT™.org
ocular melanoma

ABOUT INSIGHT

The Insight Global Ocular Melanoma Patient Registry is the first global patient input registry for Ocular Melanoma. The idea was brought to A Cure In Sight by Dr. Bertil Damato while he was at University of California, San Francisco (UCSF) in 2015. A Cure In Sight raised funds and worked with Dr. Damato and Dr. Armin Afshar to make this registry a reality. The Insight Global Ocular Melanoma Patient Registry was launched on June 22nd 2020 after many years of hard work to bring the best registry to the ocular melanoma community.

The Insight registry is a powerful opportunity for patients to contribute directly to research. It remains the first and largest patient input registry for Ocular Melanoma. There are now over 1,100 participants who are completing surveys that provide essential demographic and biodata for OM research.

The Insight registry is possible due to a collaborative effort with USCF and access to NORD's rare disease registry platform. The amount of data available to researchers is vast, but here is a small sample you might be interested in!

In 2025, we are proud to bring an updated platform with enhanced surveys to improve the patient experience and gather the best information, to further research and understanding of ocular melanoma.

A LETTER FROM OUR INSPIRATION

Dr. Bertil Damato is an ophthalmologist specializing in ocular oncology. He has served as the President of the Europoean Ophthalmic Oncology Group, the Eurpoean Vision and Eye Research Association and the International Society of Ocular Oncology. The Insight registry was a goal of Dr. Damato's that ACIS has worked to make a reality.

"Patients with ocular melanoma want to know that any suffering caused by their treatment is not worse than the disease itself. They also want to know that they are receiving the best possible care, unsurpassed by any other healthcare services near and far. For example, if an eye is removed, they need reassurance that such loss is essential. If they lose vision after radiotherapy, they will find this side effect easier to accept if they know this was unavoidable. If they are advised to defer treatment of a suspected melanoma until growth is documented, they will be concerned about missing any chances of preventing metastatic disease. If they are offered a tumor biopsy, they will wonder whether this procedure will disseminate tumor cells to the liver and other parts of the body, with a fatal outcome. All these considerations are concerning not only to patients but also to their ocular oncologists.

For these reasons, it is essential to base clinical decisions and treatments on scientific evidence, that is, on solid data. And such data requires databases, otherwise known as registries. These registries must be secure, to guarantee patient confidentiality and

widely in influential scientific journals and at national and international conferences. However, therapeutic results achieved at these leading centers may not reflect those of healthcare providers in smaller centers. It is therefore important for quality of care to be rigorously monitored everywhere and continuously so that clinical practice can be optimized for all patients wherever they happen to live. Patients want to know their own chances of successful treatment and not only those of a distant ocular oncology center. Such knowledge will empower them to do whatever they can to retain their eyesight and remain healthy.

Patients also want to contribute to knowledge on ocular melanoma to help others who will develop this disease in the future, wherever they may be. The information that patients provide is valuable because it can complement evidence that is gathered by their ocular oncologists. This is why registries such as the one developed by A Cure in Sight are of vital importance.

Thanks to evidence-based medicine, patients with ocular melanoma are no longer being treated with venesection, leeches and starvation but there is still very much to do so that patients with this disease can benefit from all the wonderful pharmaceutical and surgical advances that are taking place.

— Dr. Bertil E. Damato, MD, PhD, FRCOphth

OUR PATIENT COMMUNITY

By Patients, For Patients

As a patient input registry, the ocular melanoma patient community is the very heart of Insight. Here is more about our growing global registry community:

1,137
Enrolled respondents with 953 signed consent forms

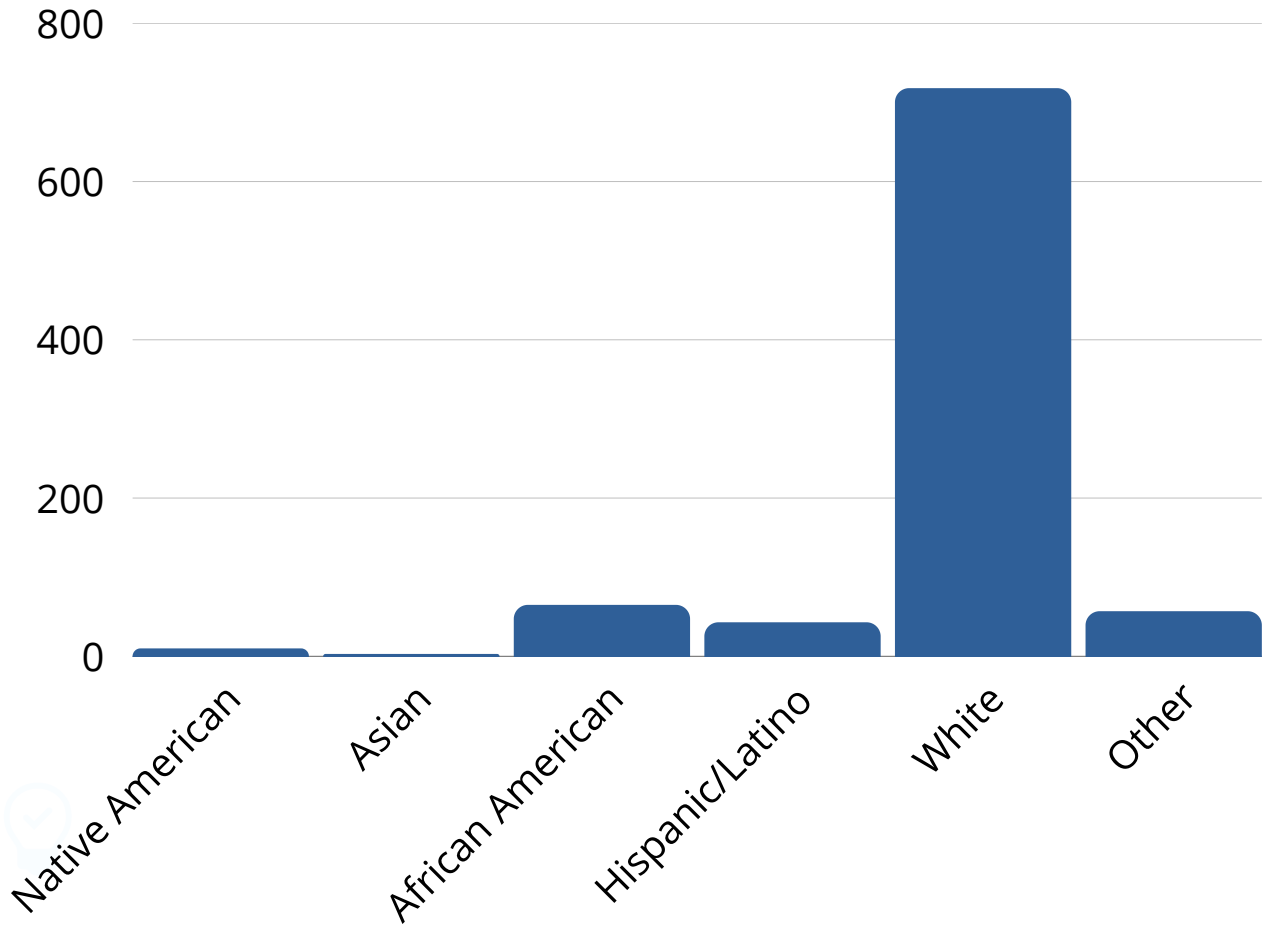
8,594
Completed surveys

66% of participants are female, 34% male, and <1% Transsexual

88% of Insight participants currently live in the United States. However, there is a growing group of individuals from countries around the world, including:

- **Canada (31)**
- **U.K., Great Britain, Ireland (24)**
- **Australia (11)**
- **Netherlands (7)**
- **South Africa (3)**
- **Spain (3)**
- **New Zealand (4)**
- **Brazil (2)**
- **Croatia (1)**
- **Georgia (1)**
- **Switzerland (1)**
- **France (1)**
- **Germany (3)**
- **Switzerland (2)**
- **Costa Rica (2)**
- **Argentina (1)**

RACE AND ETHNICITY



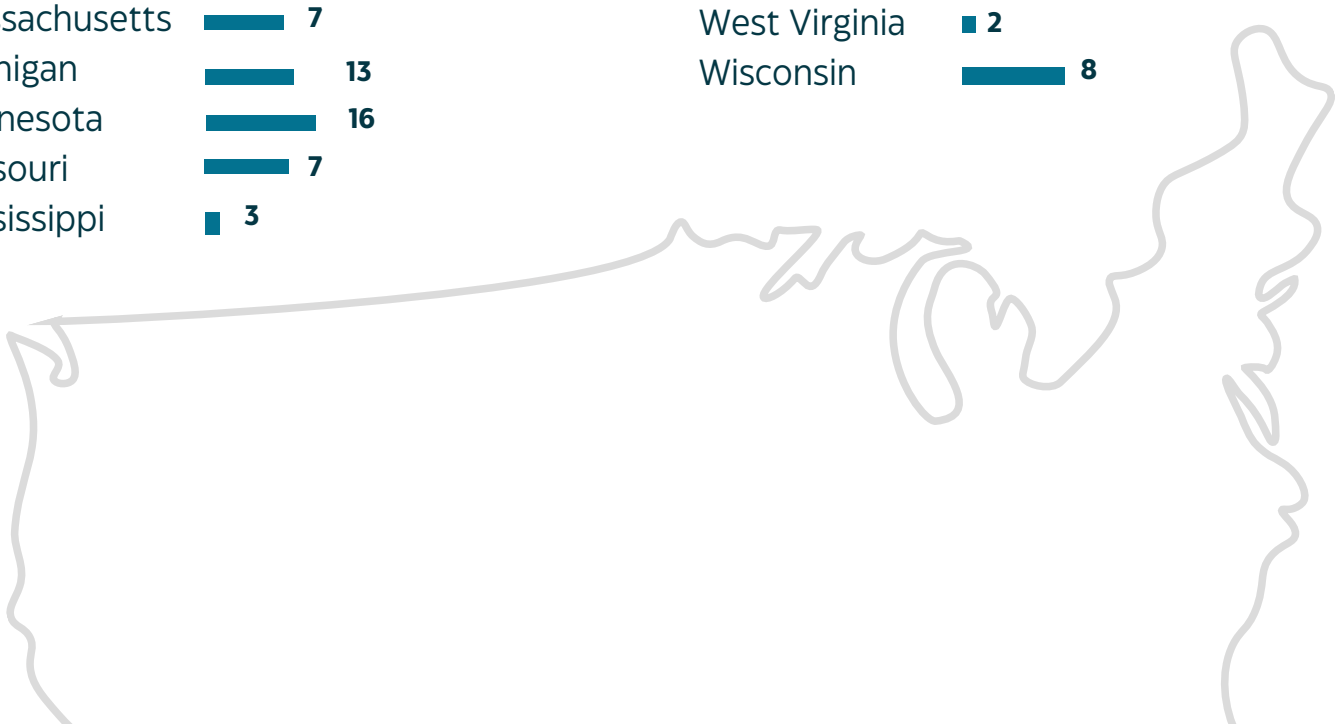
While Insight is a global registry that welcomes participants from every corner of the world, the largest concentration of the community is caucasian or of European decent. Other countries of origin (countries where the participant's biological family had previous residence or past ancestors) include:

- Latvia
- Azerbaijan
- Switzerland
- Spain
- Sweden
- New Zealand
- Nigeria
- Portugal
- Ukraine
- Slovenia
- South Africa
- Congo
- Cameroon
- Syrian Arab Republic
- Azerbaijan
- Australia
- Brazil
- Uruguay
- The Philiipines
- Indonesia
- Turkey
- Israel
- Isle of Man
- Belarus
- Romania
- Belgium
- Hungary
- Lithuania
- Finland
- Chile
- Iceland
- Denmark
- Austria
- Italy
- Croatia
- Norway
- Poland
- France
- Germany
- Greece
- Czech Rep.
- The Netherlands
- Russia
- China
- Moldova
- Ireland
- UK
- Canada
- US
- Mexico
- Israel
- Honduras
- El Salvador
- Venezuela
- South Korea
- Latvia
- Lebanon
- Luxembourg
- Malta
- Serbia

NATIONAL DEMOGRAPHICS

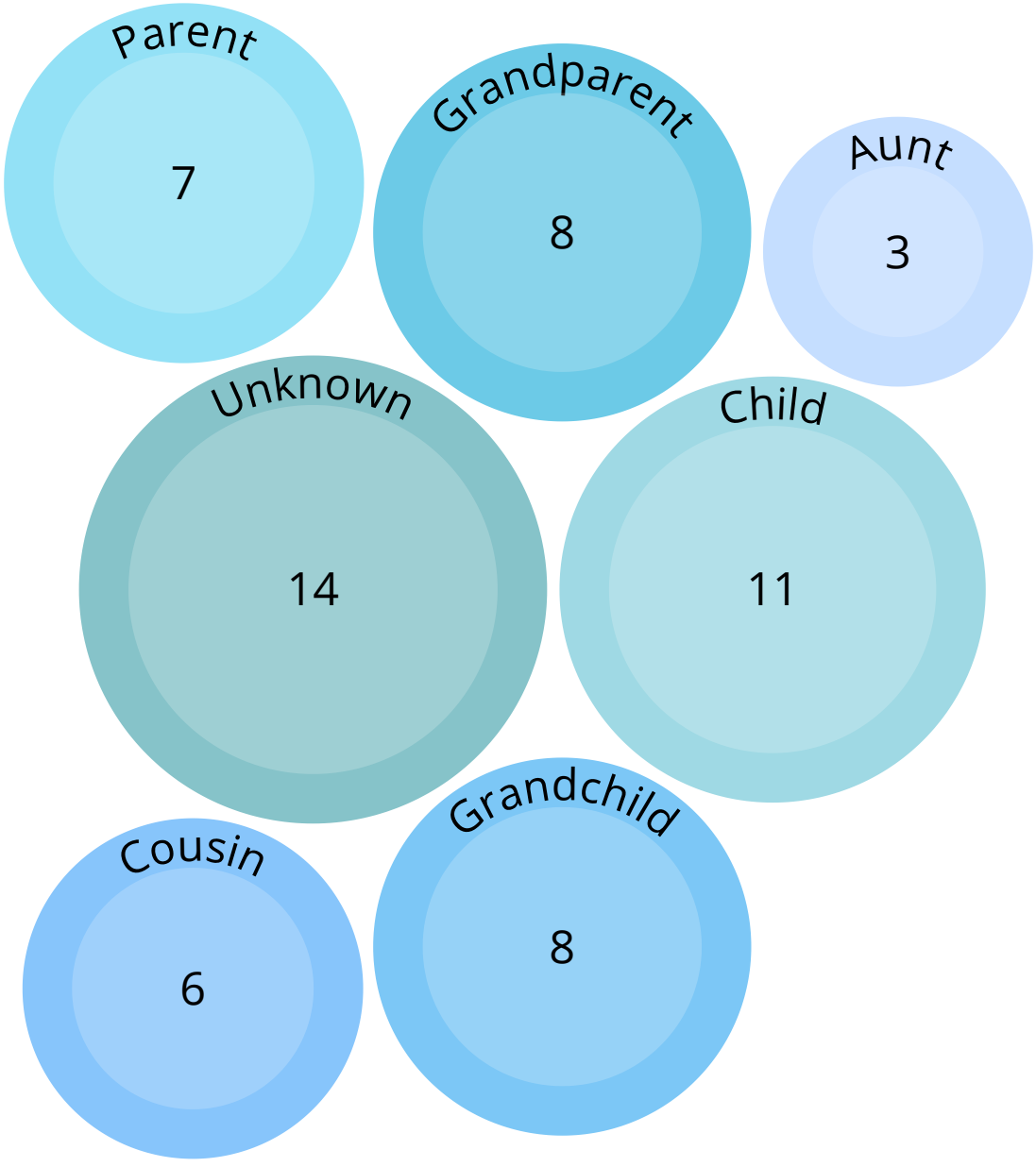
Number of US patients by state of residence

Alabama	8
Alaska	4
Arizona	16
Arkansas	1
California	74
Colorado	11
Connecticut	4
Florida	39
Georgia	18
Hawaii	3
Idaho	4
Illinois	20
Indiana	7
Iowa	5
Kansas	5
Kentucky	7
Louisiana	2
Maine	1
Maryland	7
Massachusetts	7
Michigan	13
Minnesota	16
Missouri	7
Mississippi	3
Nebraska	1
Nevada	3
New Hampshire	3
New Jersey	5
New Mexico	3
New York	84
North Carolina	29
Ohio	14
Oaklahoma	3
Oregon	11
Pennsylvania	13
Rhode Island	3
South Carolina	10
South Dakota	2
Tennessee	16
Texas	34
Utah	6
Virginia	10
Washington	15
West Virginia	2
Wisconsin	8



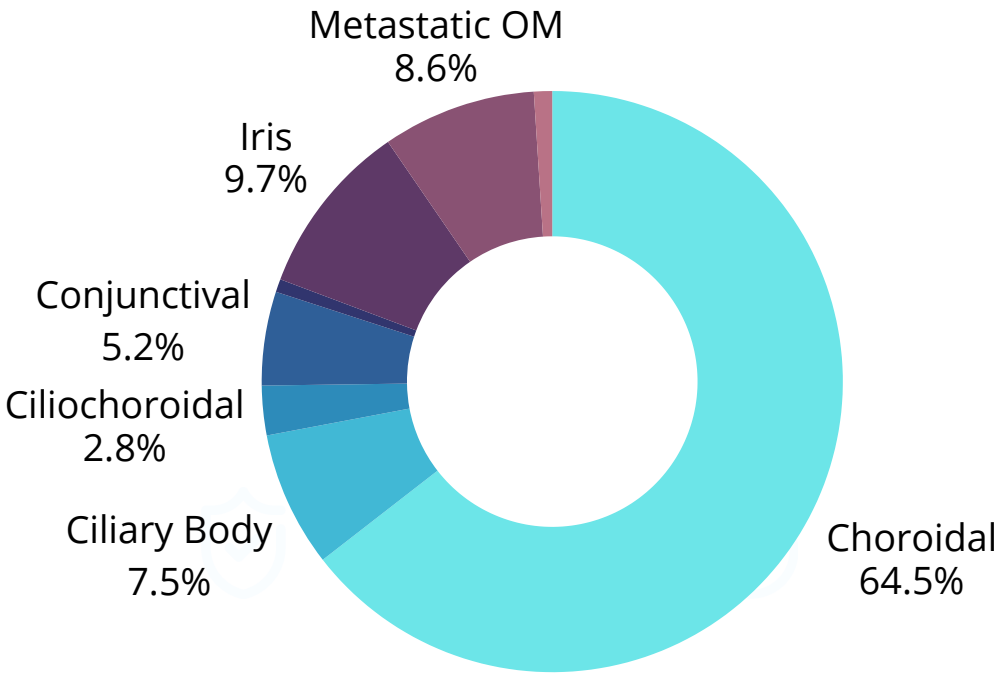
HERITAGE

While it is rare for Ocular Melanoma to be genetically passed down from one generation to another, there are some individuals with family members that have also been diagnosed.



DIAGNOSIS

There are several different diagnoses within Ocular Melanoma.
Within the Insight registry, the largest percentage of diagnosis is Choroidal, with Iris and Ciliary following.



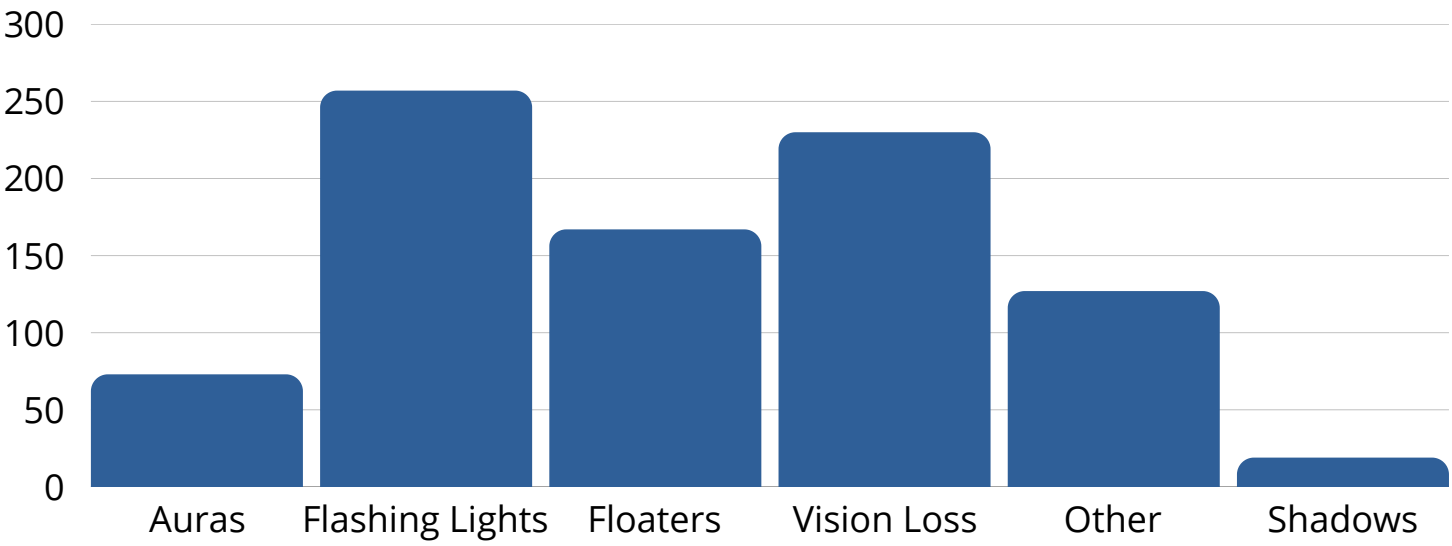
27%

of participants were diagnosed with a Nevus prior to the OM diagnosis

90%

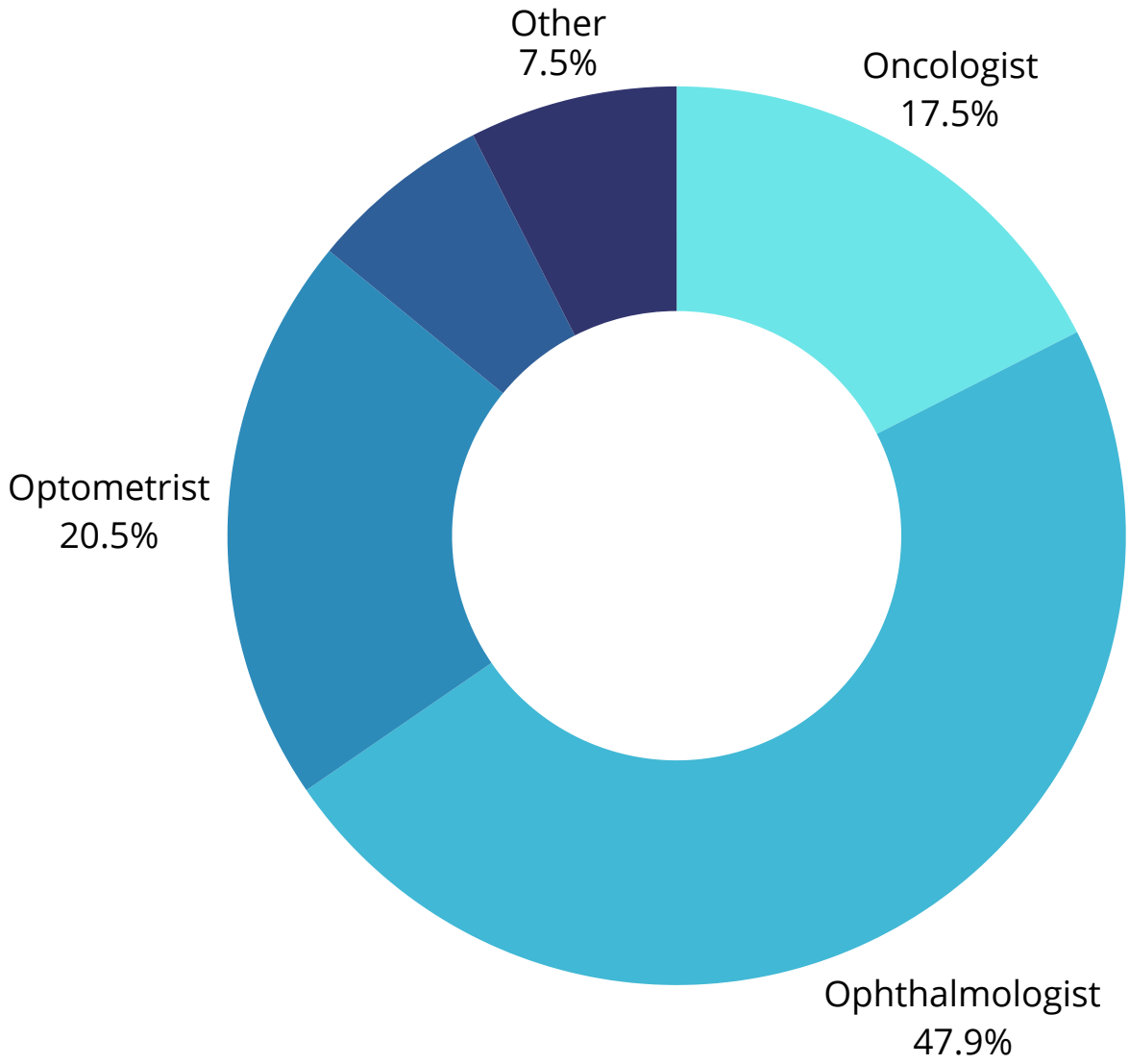
of respondents reported they did not receive a biopsy

Some patients experienced symptoms prior to an OM diagnosis.
Here is the breakdown of those symptoms:



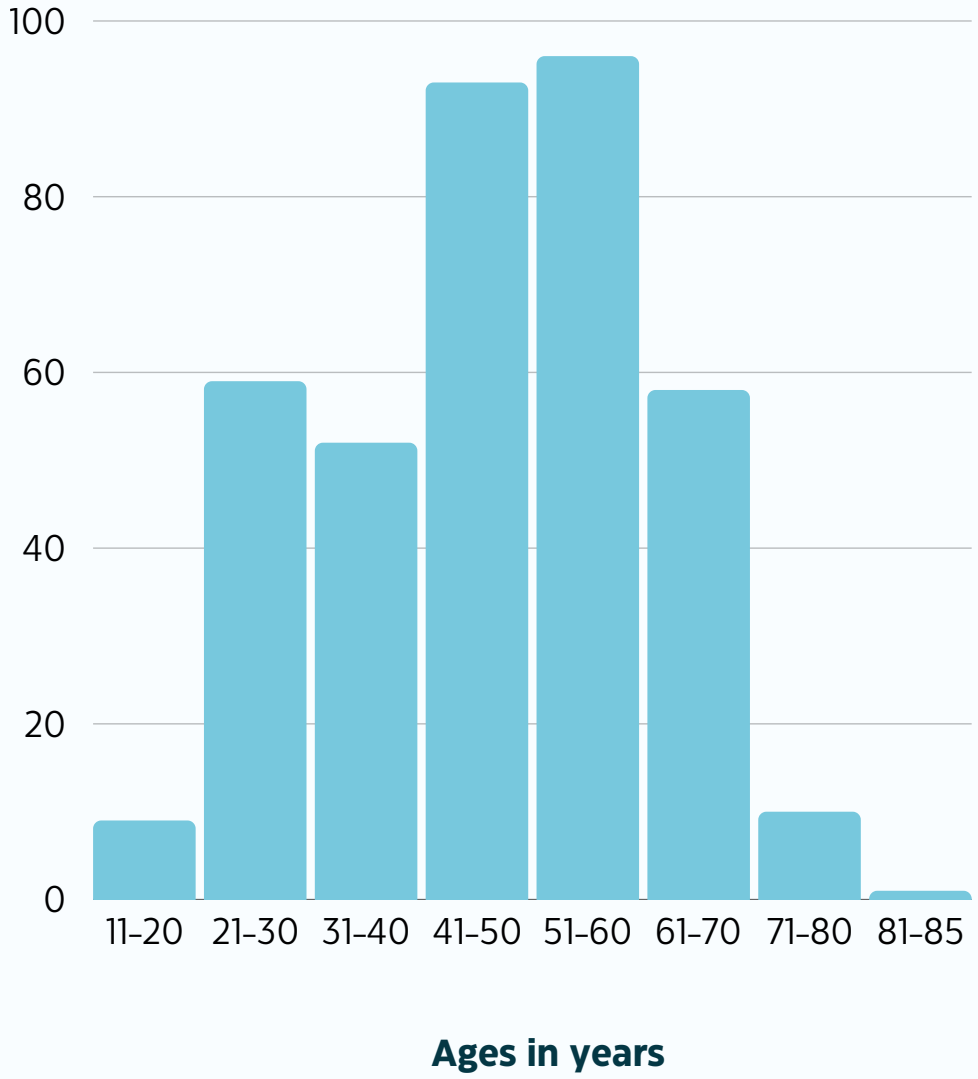
DIAGNOSIS

Ophthalmologists generally diagnose Ocular Melanoma, but occasionally a diagnosis comes from another medical provider:



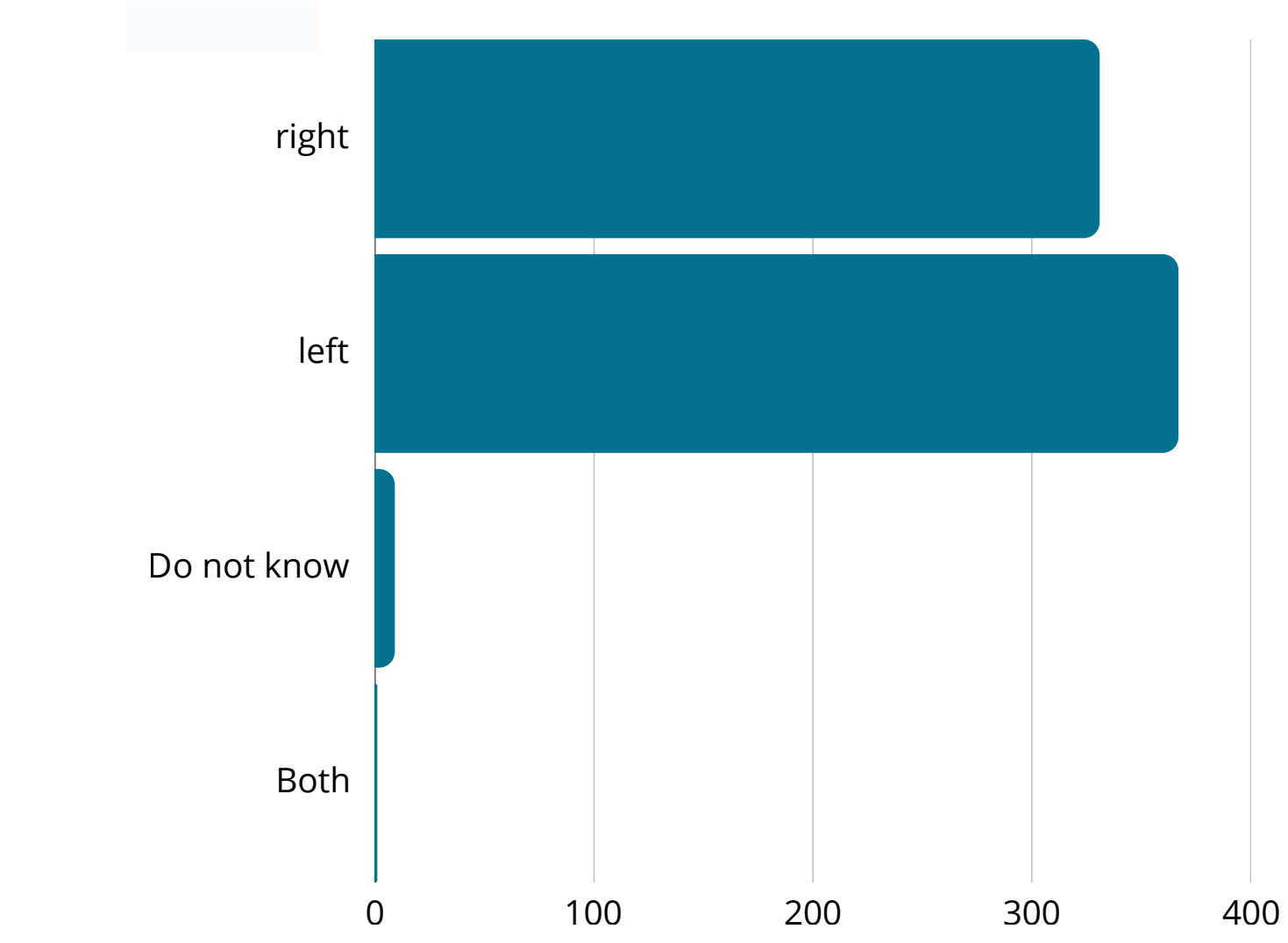
DIAGNOSIS BY AGE GROUP

While Ocular Melanoma can occur at any age, the median age of diagnosis is about 55 years old. The Insight Registry data reflects this statistic, with the two largest age groups being 41-50 and 51-60.



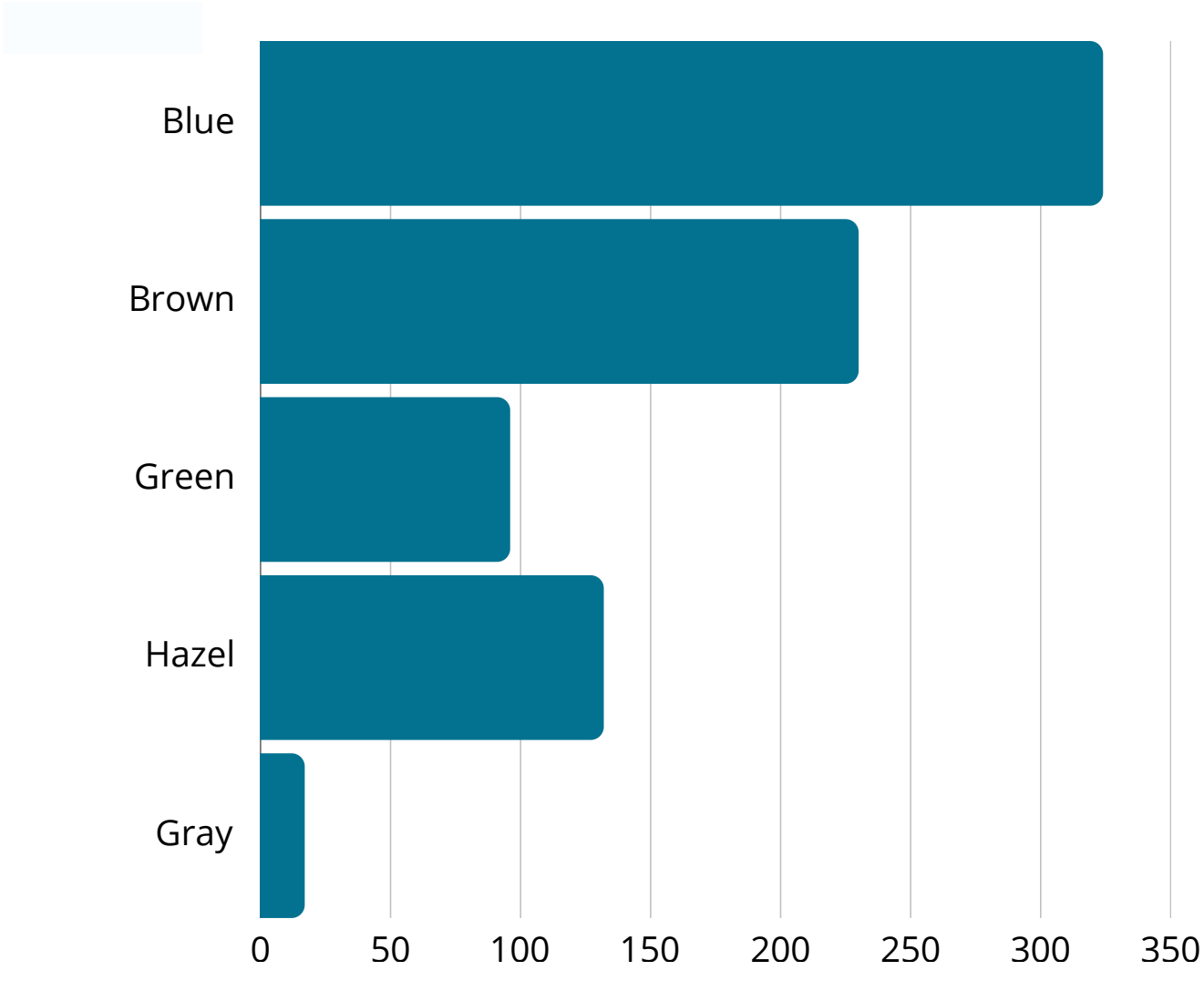
EYE WITH OM

Respondents listed which eye their ocular melanoma was located in.
The majority of respondents are showing as left eye.



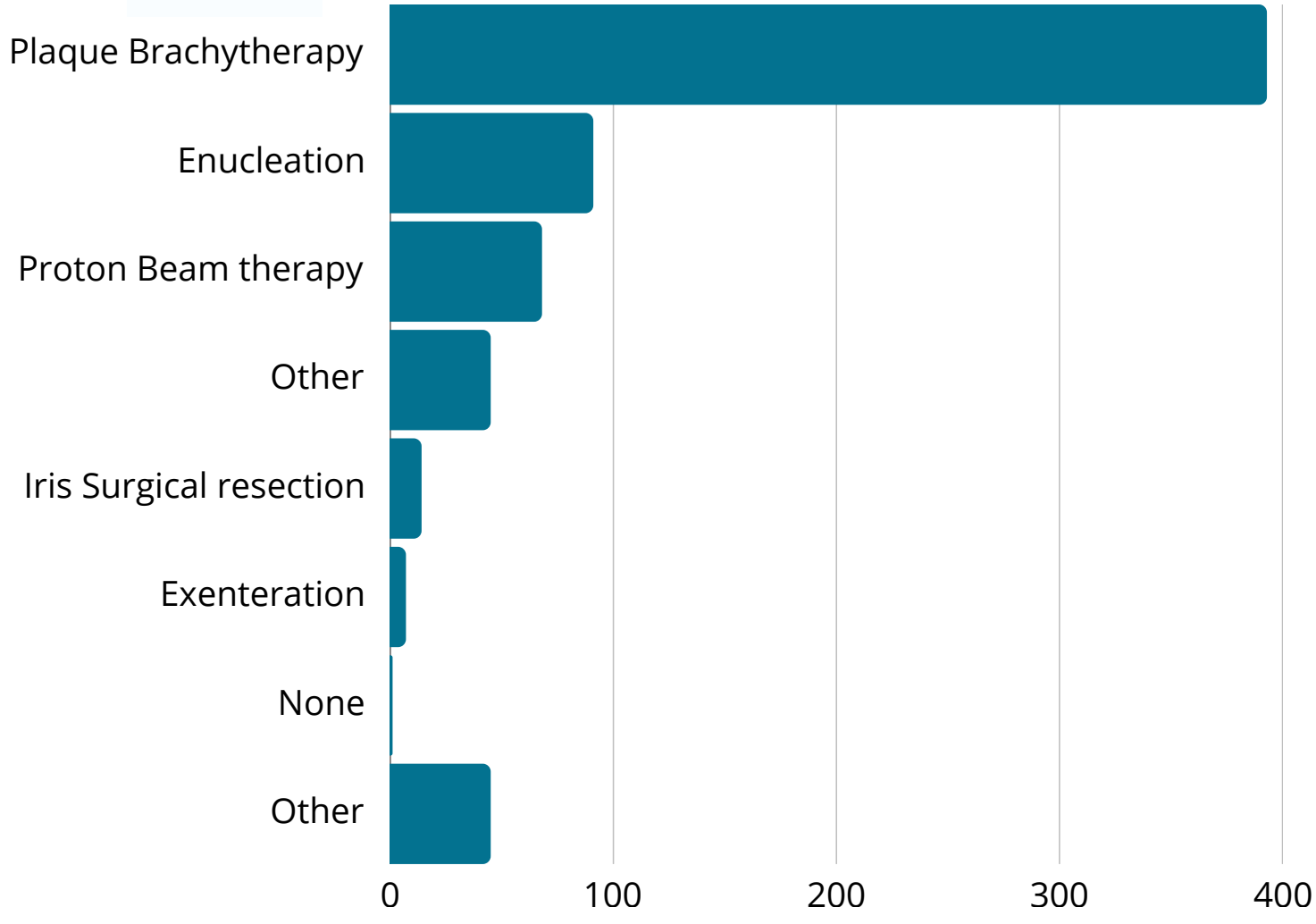
EYE COLOR

The most prevalent eye color for ocular melanoma is blue. This correlates with the light eyed, light skin risk factor. We can see that not having blue eyes does not protect you from ocular melanoma as all eye colors are represented.



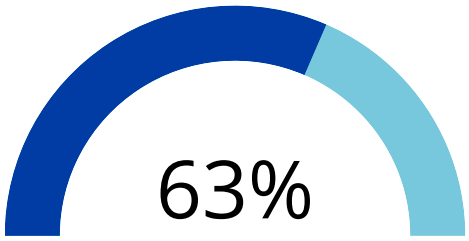
PRIMARY TREATMENT

There are many different treatment options for Ocular Melanoma.
Plaque Brachytherapy (radiation) is the most common.
64% of Insight respondents listed this as their main treatment.



GENETIC TESTING

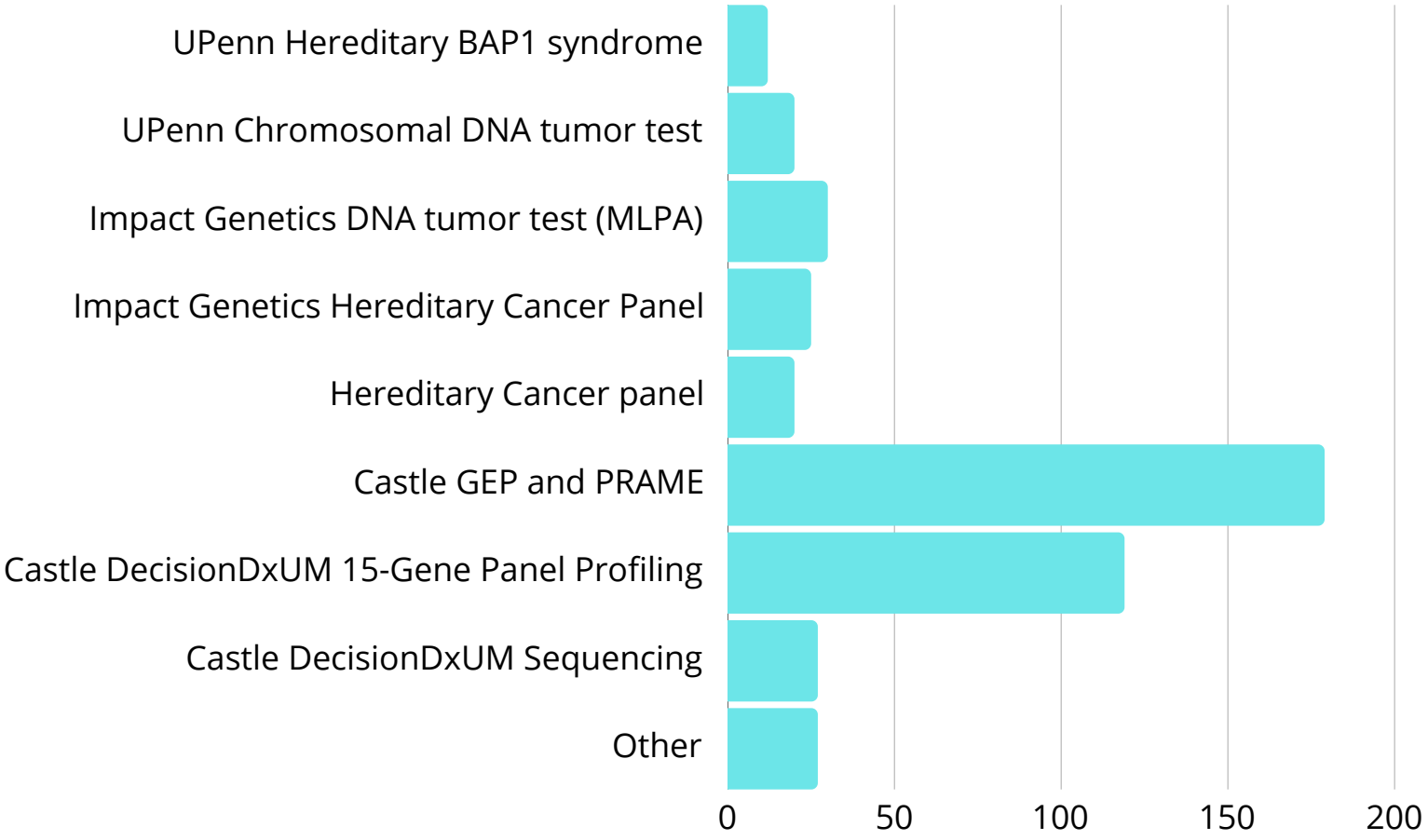
Out of **690** participants who responded to the question about genetic testing, just ***half (347)*** said they had testing done.



of respondents said they had ***not*** been initially offered genetic testing

49% of respondents said they wish they had been offered genetic testing.

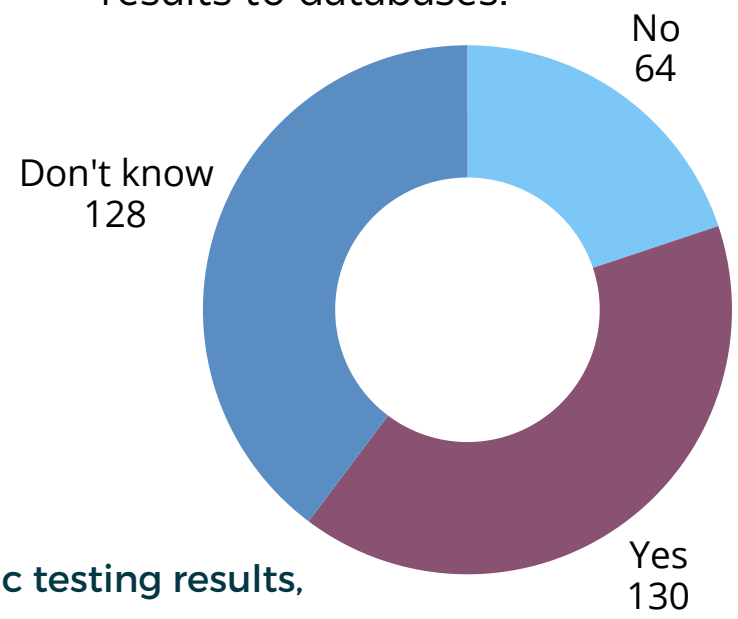
Type of test done



GENETIC TESTING

39% of respondents said they authorized sending their test results to one or more databases for future research

Authorized sending results to databases:



Here's a look at actual genomic testing results, based upon the Castle Biosciences Uveal Melanoma DecisionDx UM 15-gene GEP and PRAME tests:

73 Respondents were Class 2

- **31** of them were PRAME positive
- **42** of them were PRAME negative

45 Respondents were Class 1b

- **27** of them were PRAME negative
- **18** of them were PRAME positive

57 Respondents were Class 1a

- **39** of them were PRAME negative
- **18** of them were PRAME positive

MORE RESULTS FROM OTHER TESTS

Impact genetics Hereditary cancer panel

Negative (no mutation found): 63%
Positive (damaging mutation found): 13%
Variant of uncertain significance (VUS) - unclear mutation found: 25%

SNP test

BAP1 normal: 17%
GNA11 mutation: 8%
GNA11 normal: 25%
GNAQ mutation: 25%
GNAQ normal: 25%

MLPA test

EIF1AX mutation: 13%
EIF1AX normal: 16%
GNA11 mutation: 19%
GNAQ mutation: 10%
GNAQ normal: 13%
SF3B1 mutation: 23%
SF3B1 normal: 6%

UPenn Hereditary BAP1 syndrome

Normal (no mutation found): 73%
Positive (damaging mutation found): 9%
Variant of uncertain significance (VUS) - unclear mutation found: 18%

Chromosome 6

6q gain: 43%
Disomy 6 (normal): 57%

Chromosome 3

Disomy 3 (normal): 47%
Monosomy 3: 33%
Borderline Monosomy 3: 20%

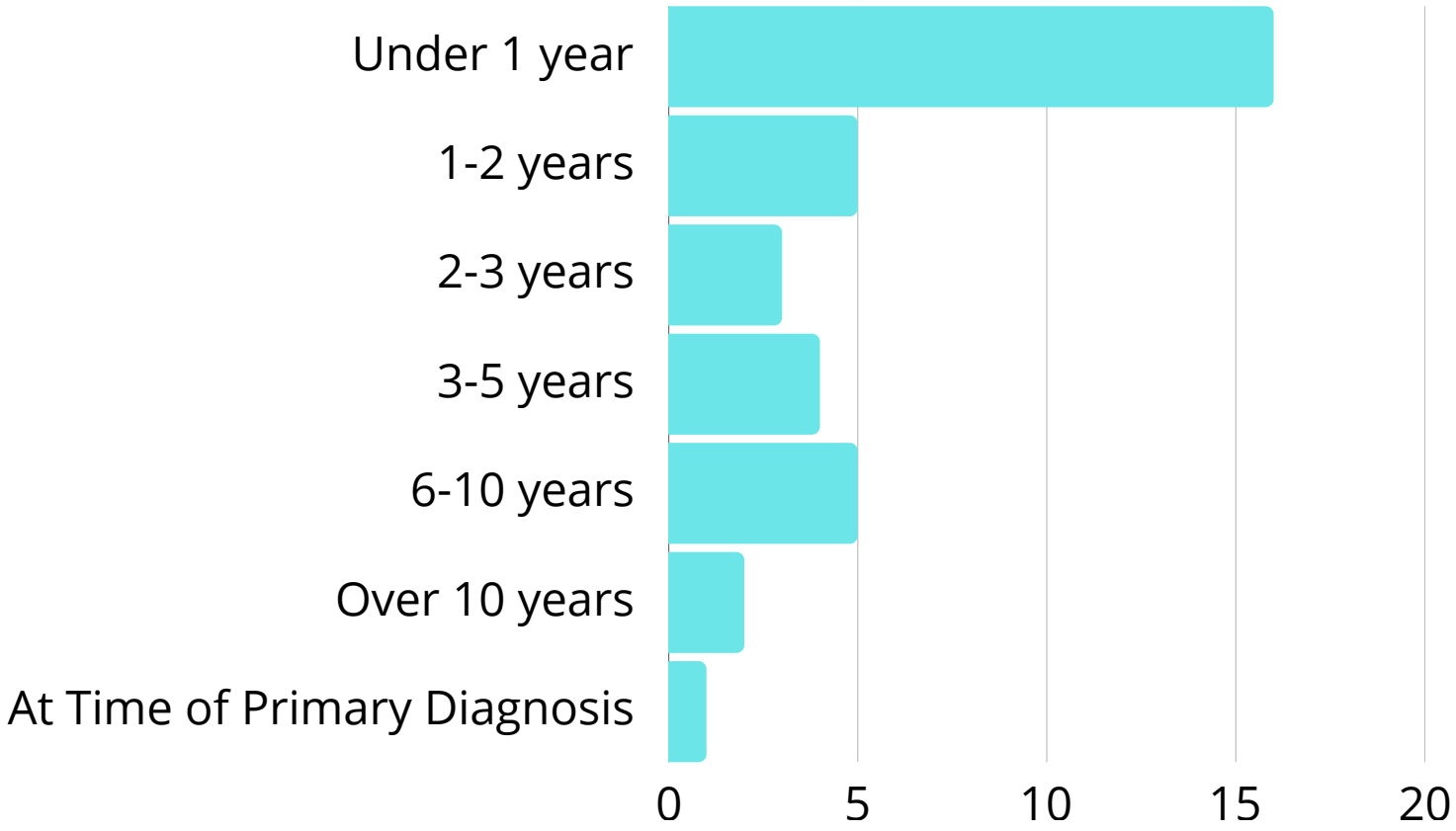
Chromosome 8

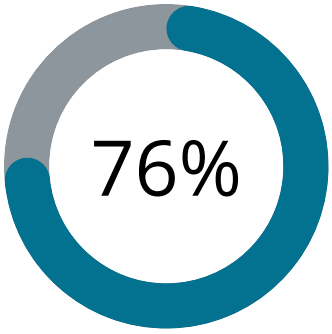
8p gain: 6%
8p loss: 6%
8q gain: 38%
Disomy 8 (normal): 50%

METASTASIS

67% of metastatic uveal melanoma patients first had metastasis discovered through routine surveillance. The remaining **33%** were diagnosed based on having symptoms.

Time frame for metastatic diagnosis



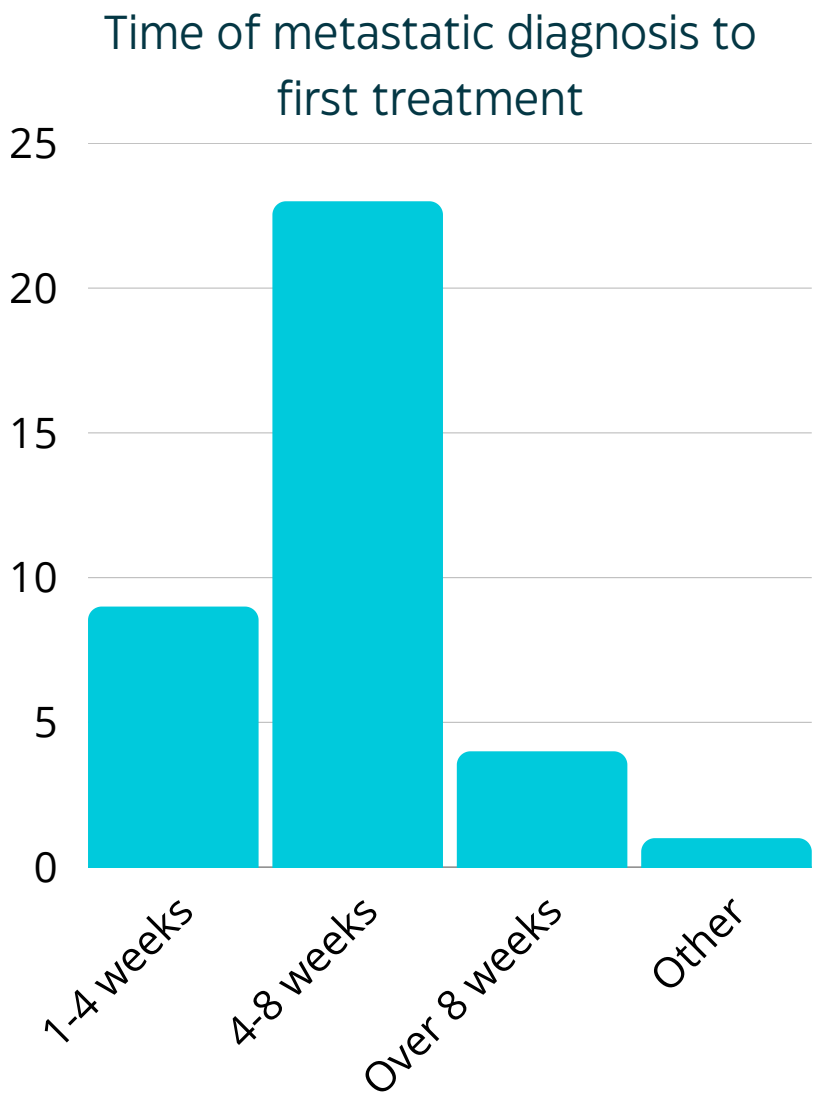


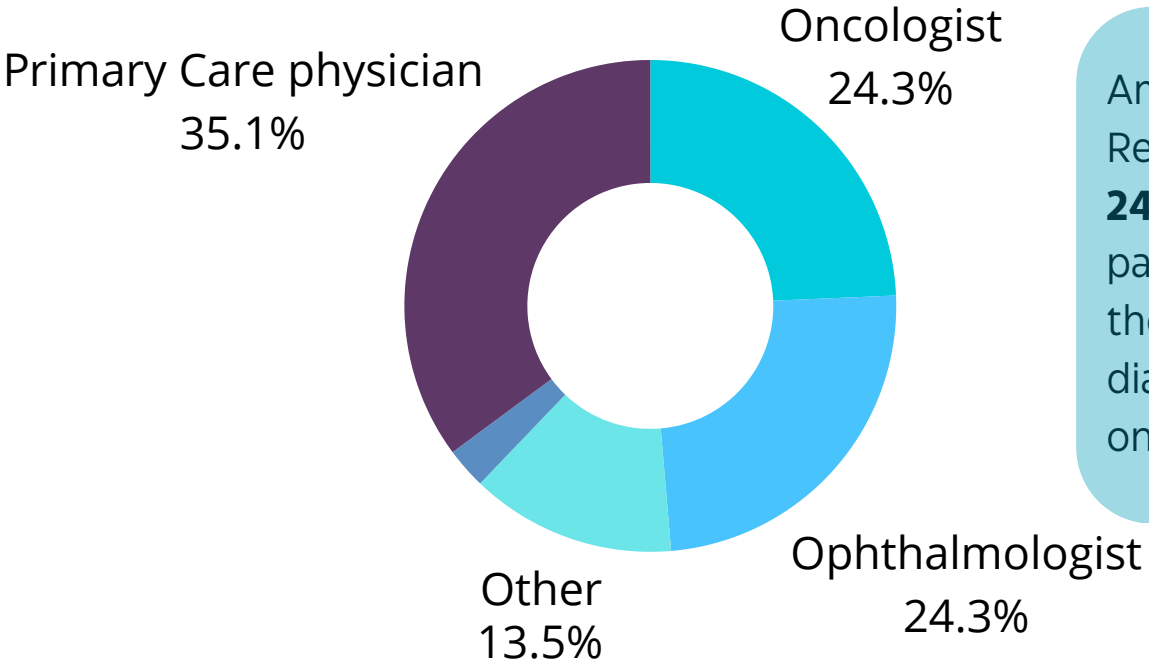
Of metastatic respondents have not yet participated in a clinical trial

METASTASIS

Location of Metastatic disease (there may be multiple sites)

- Liver — 49%
- Bone — 40%
- Lymph Node — 6%
- Lung — 6%

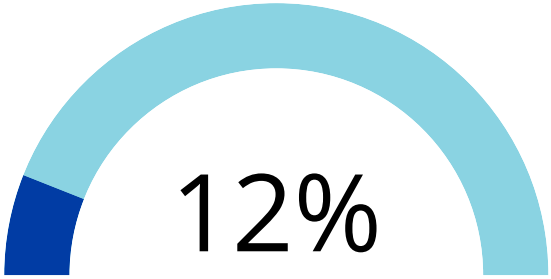




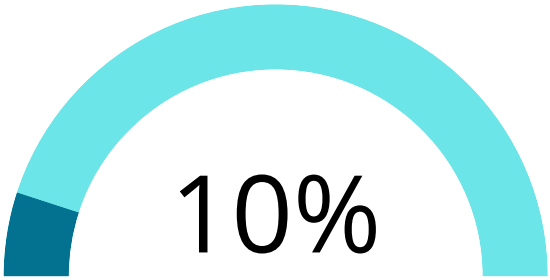
Among 39 Respondents, **24%** of Metastatic patients report they were diagnosed by an oncologist.

OTHER HEALTH CONDITIONS

Some Insight participants listed other health conditions such as:



of respondents have Autoimmune diseases

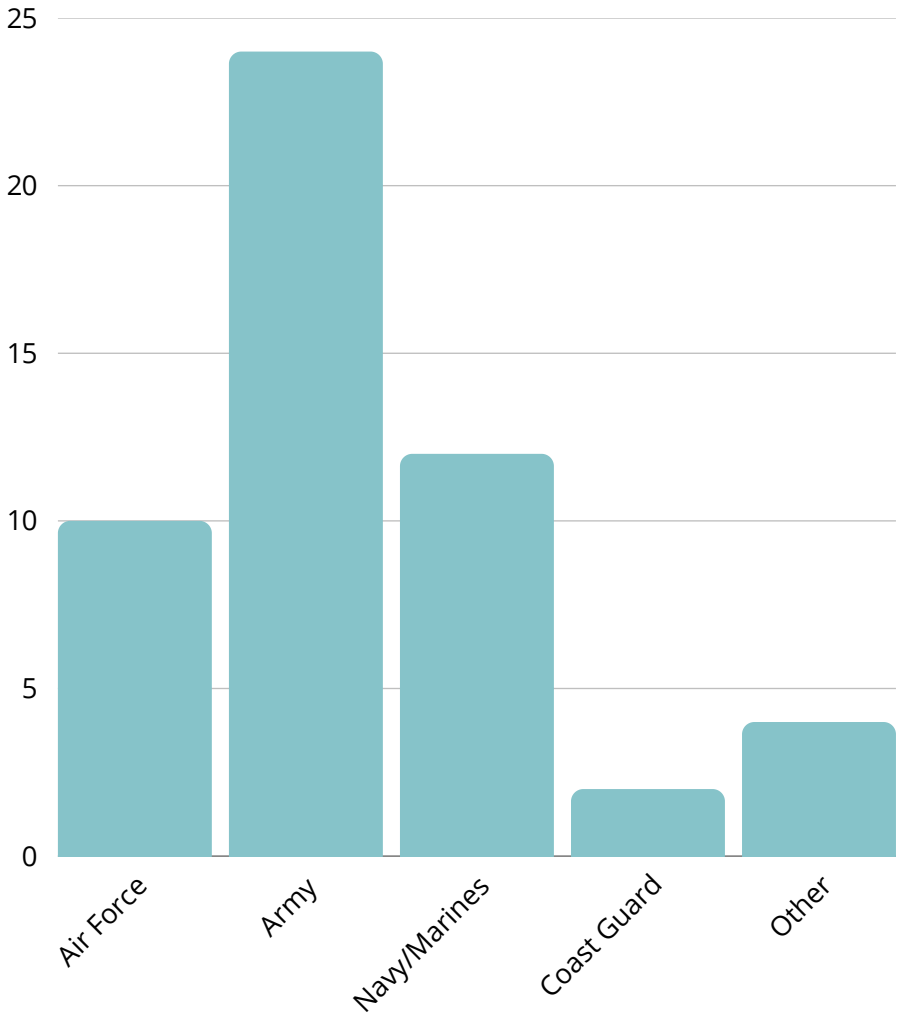


of respondents have other cancer diagnoses aside from Ocular Melanoma

RISK FACTORS

Because Ocular Melanoma is such a rare disease, there are very few conclusive studies on exposures that may increase the risk of diagnosis. However, military involvement and proximity to the 9/11 attacks are two supported theories.

6.4% of participants (50) reported having served in the military. Here is a breakdown by branches served in.



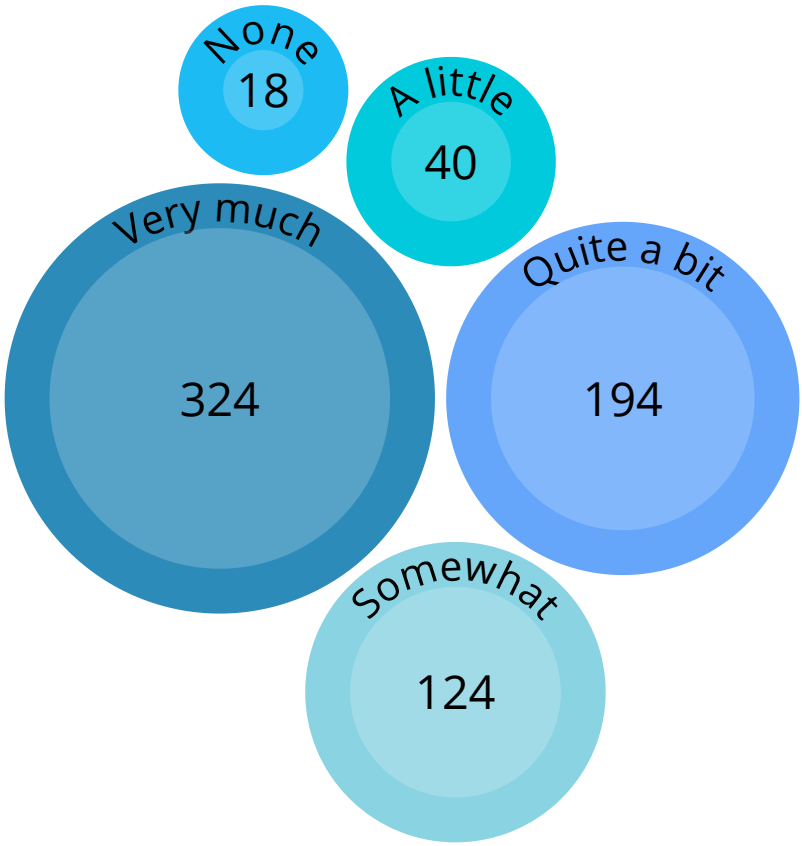
19

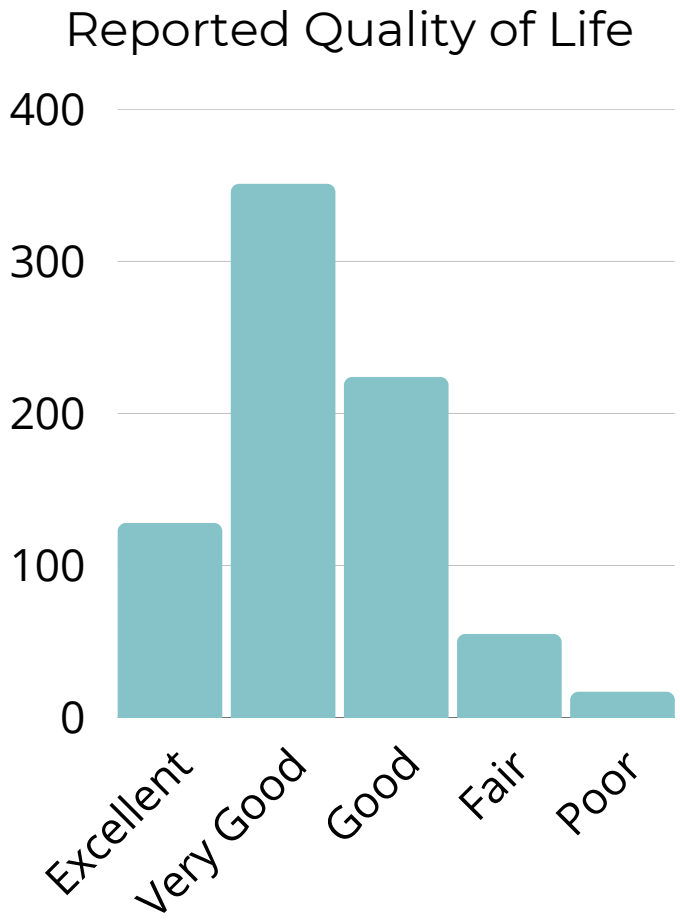
Respondents were in New York city during 9/11

QUALITY OF LIFE

Dealing with any kind of cancer diagnosis is difficult. It can be especially challenging to deal with a diagnosis like Ocular Melanoma that is so rare. There are less treatment options, less research studies, and less people around who understand.

Degree of emotional support participants receive from their family:

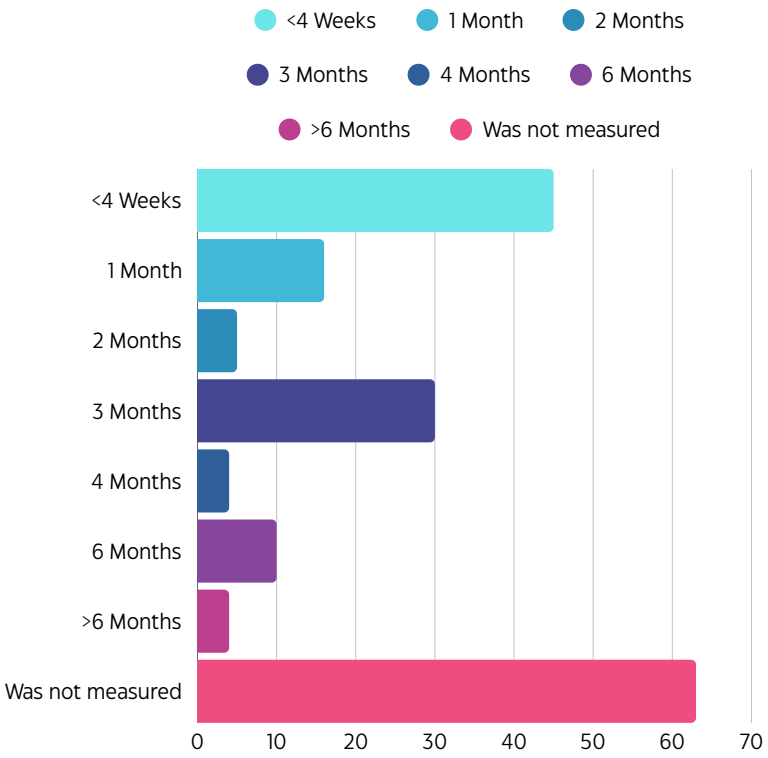




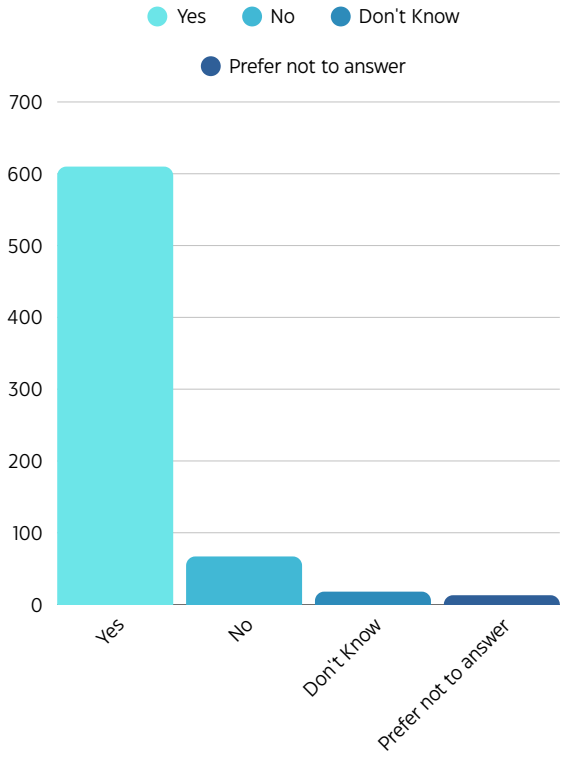
Additional INSIGHTS for Researchers and BioPharma Drug Developers

Here are additional patient survey questions which may be helpful to researchers when planning new studies

How often the primary eye tumor was measured for growth:

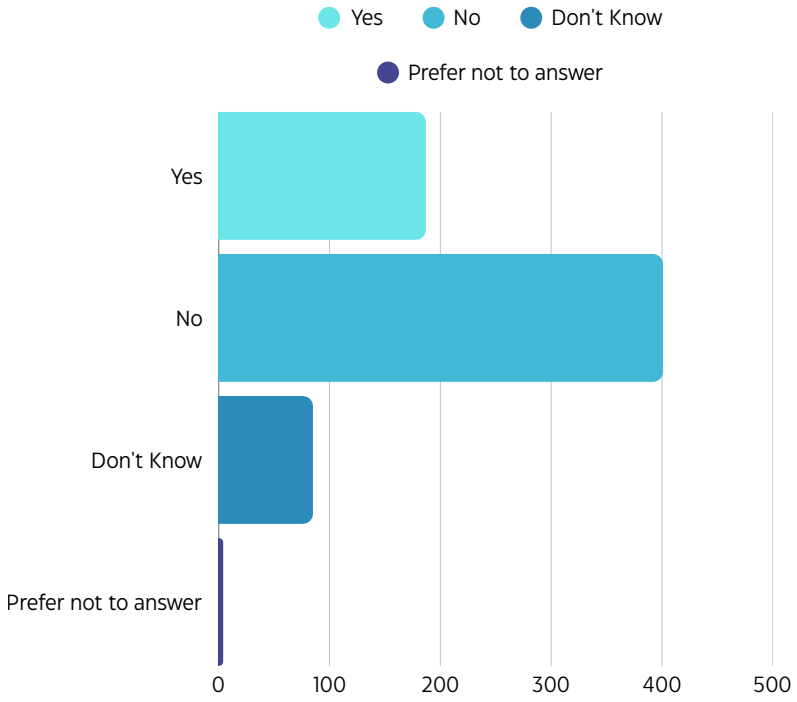


Willingness to be contacted for future research related to OM:

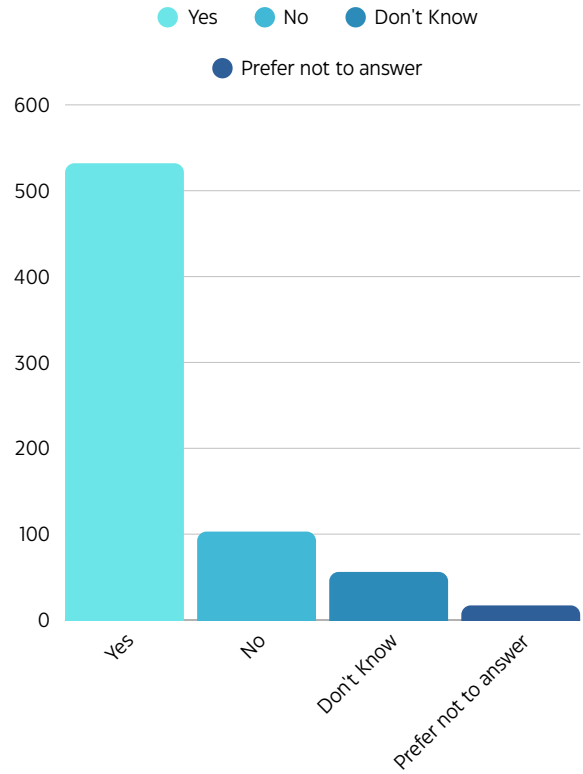


ADDITIONAL INSIGHTS FOR RESEARCHERS (2)

Patients who have previously provided a biospecimen for OM research:

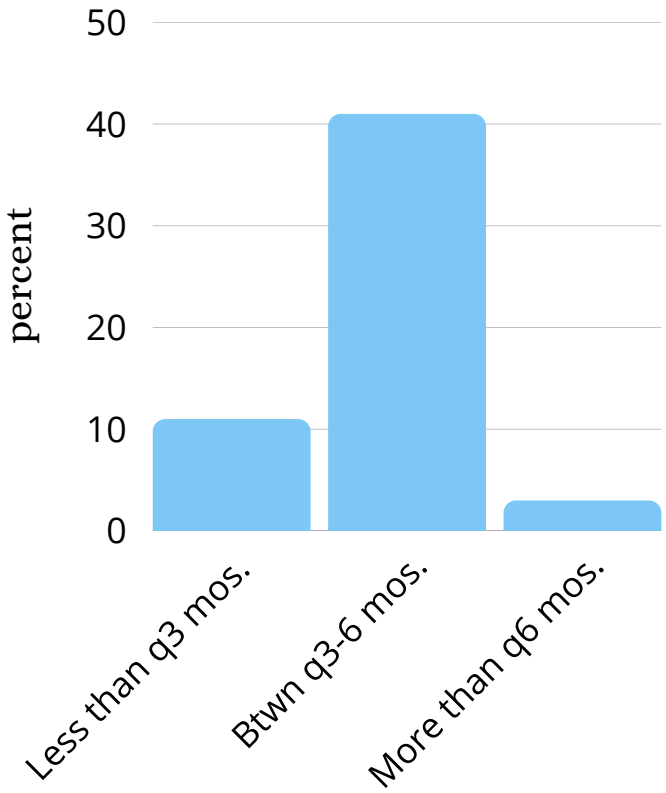


Willingness to be contacted about donating a tissue sample for research:



ADDITIONAL INSIGHTS FOR RESEARCHERS (3)

Schedule (Frequency) of Scans for Metastatic Surveillance:



Types of Treatments Received for Metastatic OM:

Hepzato® (melphalan percutaneous hepatic perfusion)
Kimmtrak® (tebentafusp)
Ablation (histotripsy ultrasound)
Chemo- or Radio- Embolization
Immune Checkpoint Inhibitors: Monotherapy & Combination
Surgical Resection of metastatic tumor
Clinical Trials (investigational drugs or immune therapy)

THANK YOU FROM A CURE IN SIGHT

Thank you to the Ocular Melanoma community for your interest and support. This registry wouldn't be possible without your interaction! When we first started working on this registry with Dr. Damato, we hoped for, but didn't expect to see the level of participation that we have. We are honored to be trusted as we work to make Dr. Damato's vision a reality.

This registry was made possible by grants from UCSF, A Cure in Sight, and many pharmaceutical companies that have supported it along the way. We are grateful to have so many wonderful individuals and companies actively engaged in furthering research.

In 2024, the Insight registry moved to an updated platform hosted by NORD. This allows us to offer more language options as we seek to expand our global outreach. We will also hope to have a greater capacity to connect with other registries. We are thrilled at the prospect of collaborating with others in ocular melanoma and creating a network of data that is undeniably powerful.

We want to especially thank the patients within our community. The importance of your experience with this disease cannot be overlooked. We appreciate your vulnerability and trust in sharing that story with us, and we promise we are putting it to good use. We are sharing the Insight registry's data with those who are working towards a cure: a cure that will be made with *you* in mind.

♥ The ACIS Team

THE REGISTRY TEAM

Melody Burchett is the founder and president of A Cure In Sight. Melody founded the organization out of frustration of the lack of patient support and education that was available. Diagnosed in 2010, the information that was available was grim at best. Before her diagnosis, Melody was an Interior and landscape designer along with a history in sales and marketing.

Bertil Damato, MD, PhD, FRCOphth, is an ophthalmologist specializing in ocular oncology. He received his undergraduate medical training in Malta, where he was born, and his post-graduate training in Glasgow, Scotland. Professor Damato is currently Senior Clinical Research Fellow at the Department of Clinical Neurosciences at the University of Oxford, Honorary Consultant Ophthalmologist at Oxford Eye Hospital, and Locum Consultant Ophthalmologist at Moorfields Eye Hospital, London, UK. He is also an Honorary Professor at the University of Liverpool and Emeritus Professor at the University of California, San Francisco. He has served as President of the European Ophthalmic Oncology Group, the European Vision and Eye Research Association and the International Society of Ocular Oncology. Professor Damato has published more than 300 peer-reviewed articles, numerous chapters and authored or co-edited several textbooks. He has received a number of awards, including the Bjerrum, Cohen, Ashton, and Watson Medals and the NHS UK Platinum Award.

Dr. Armin Afshar is a vitreoretinal surgeon and ocular oncologist with an academic career blending clinical practice, research, teaching and administration. He is an Associate Professor of Ophthalmology. Dr. Afshar serves as the Director of the Ocular Oncology Service at UCSF and the Director of Tele Ophthalmology for the San Francisco Department of Public Health. His research program is funded by the National Eye Institute at the National Institutes of Health (NIH), Research to Prevent Blindness, and That Man May See.

Dr. Afshar's specialty is in the treatment of eye tumors and disorders of the retina and vitreous. In addition to expertise in retinal diseases and surgery, he has special training and experience in the management of ocular surface tumors of the conjunctiva and cornea, as well as intra-ocular tumors involving the iris, ciliary body, choroid, retina, vitreous and optic nerves. The UCSF Ocular Oncology Service is an internationally renowned center of excellence with longstanding programs of distinction in Retinoblastoma and Uveal Melanoma, and is one of only a handful of centers world-wide offering both Ocular Proton Therapy and plaque brachytherapy.

Dr. Afshar earned his bachelor of science and medical degree in the accelerated honors medical program at the University of Illinois College of Medicine at Chicago, and a master's degree in business administration at the University of Chicago. He completed a residency in ophthalmology at the University of Chicago and fellowships in vitreoretinal surgery and ocular oncology at UCSF. He also completed a master's degree in clinical research in epidemiology & biostatistics at UCSF. He is a member of the American Academy of Ophthalmology, Association for Research in Vision and Ophthalmology, American Society of Retinal Specialists, American Association of Ophthalmic Oncologists and Pathologists and International Society of Ocular Oncology.

Dr. Afshar has served as the president of the medical board for the Insight Registry following Dr. Damato’s return to the U.K.

Amy Edgecomb has served as a volunteer on the ACIS registry board since July 2021. She currently works as an Associate Director in the US Value, Evidence and Outcomes group at GlaxoSmithKline. Her primary focus is on generating real-world research within the company's respiratory, rare diseases, and anti-infectives portfolio by using data from registries, medical and pharmacy claims, and electronic health records. She is a state registered pharmacist, holding licenses in both Florida and North Carolina and practices part-time as an emergency medicine pharmacist at Lee Health Coconut Point Hospital & Surgical Center in Estero, Florida. In prior roles, Amy has experience conducting both academic and clinical research in the areas of neurology, general medicine, infectious disease, and breast oncology at the University of North Carolina at Chapel Hill and Duke University. She holds a Doctor of Pharmacy and Master of Public Health from UNC-Chapel Hill and a Bachelor of Science in Chemical Engineering from the University of Florida.

Jeff Howard has worked in the healthcare industry for over 20 years in various imaging specialties, including radiology, oncology, and cardiology. Since being diagnosed with ocular melanoma in 2018, he has volunteered with A Cure in Sight to assist with the creation of a patient registry, partnering with the National Organization for Rare Diseases (NORD). He lives out of Sparks, NV with his wife, Rhonda and two sons.

Lucy Innes was diagnosed with uveal melanoma in 2022, during the first year of her PhD studying genomics. After her diagnosis, she dedicated her research to understanding the complex biology of uveal melanoma, in order to help improve the future of therapies for other patients like her.

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