

## Introduction

Roughly 90% of melanomas form on sun-exposed skin, while rare subtypes—such as acral and mucosal melanoma—form on parts of the body shielded from the sun. Each year, about 5,000 patients in the US are diagnosed with these subtypes. Patients facing rare melanoma subtypes are often diagnosed later and have poorer prognoses, thereby representing an area of profound unmet medical need.

In Oct. 2022, the Melanoma Research Alliance (MRA) launched the RARE Registry, the first direct-to-patient registry for those with acral and mucosal melanoma, as well as non-acral cutaneous melanoma as a comparator arm. RARE was developed and continues to be monitored by an Oversight Committee comprised of patients, caregivers and medical advisors. Through RARE, participants complete surveys and can also upload medical reports, the latter information used to validate participant reported data and provide additional clinical information. One year after launch, there are 159 participants enrolled. De-identified data generated from surveys is being analyzed in real-time with data insights being provided back to participants via their online dashboard, and soon to be released to researchers worldwide.

## Objective

The purpose of the RARE registry is to advance research into rare melanoma subtypes by creating a platform that directly enables patients with acral and mucosal melanoma to provide information about their disease and associated journey.

## Methods

- MRA, sponsor of the RARE registry, has an IRB approved protocol (NB200070; 10/22/2022) and consent. Patients must provide eConsent to be enrolled in the registry.
- Consented participants fill out a series of 8 surveys addressing: demographics, disease history, inherited genetics and tumor biomarkers, disease monitoring, overall health and lifestyle, quality of life (QOL), treatment overview and treatment timeline.
  - QOL surveys are collected every 4 months.
  - Treatment timeline information can be updated as needed.
- Participants also have the ability to upload medical reports (i.e.: pathology, tumor genomics, surgery, etc.).
- Emerging data is analyzed in a real-time manner with some common information being collected across the 3 melanoma cohorts (acral, mucosal, and cutaneous) and additional information analyzed specifically for each subtype.

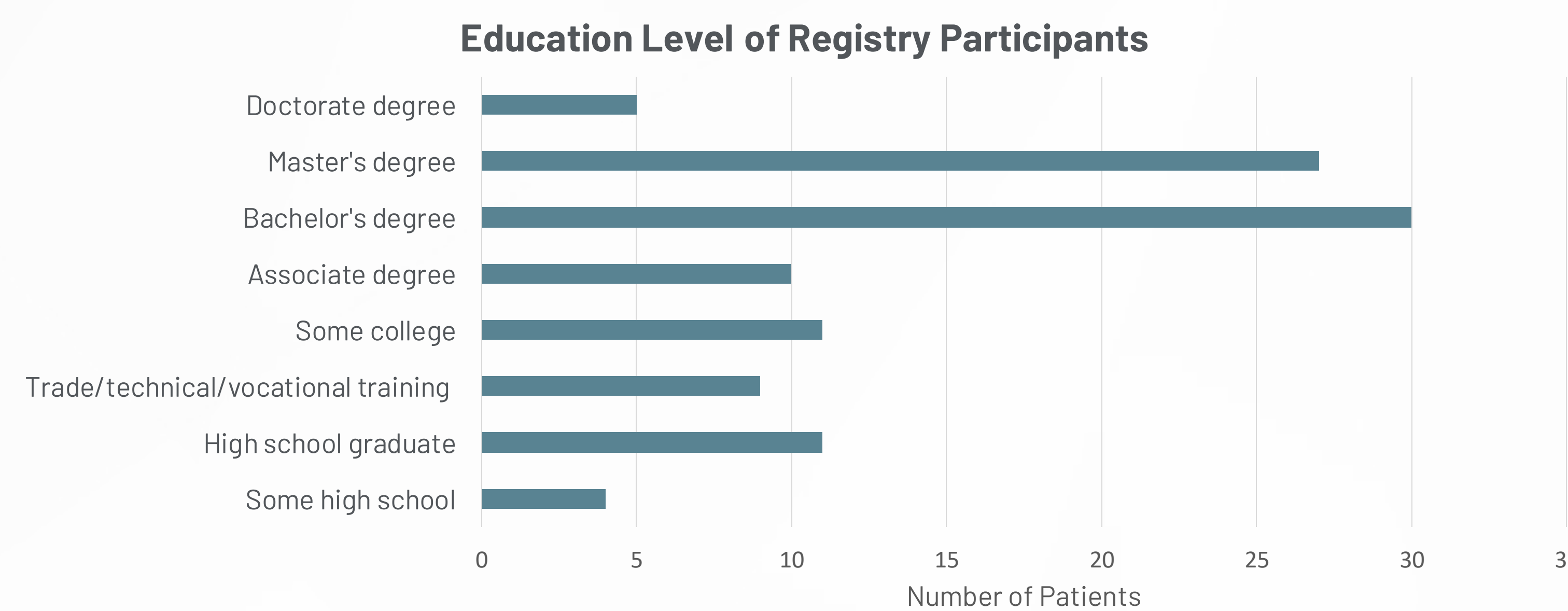
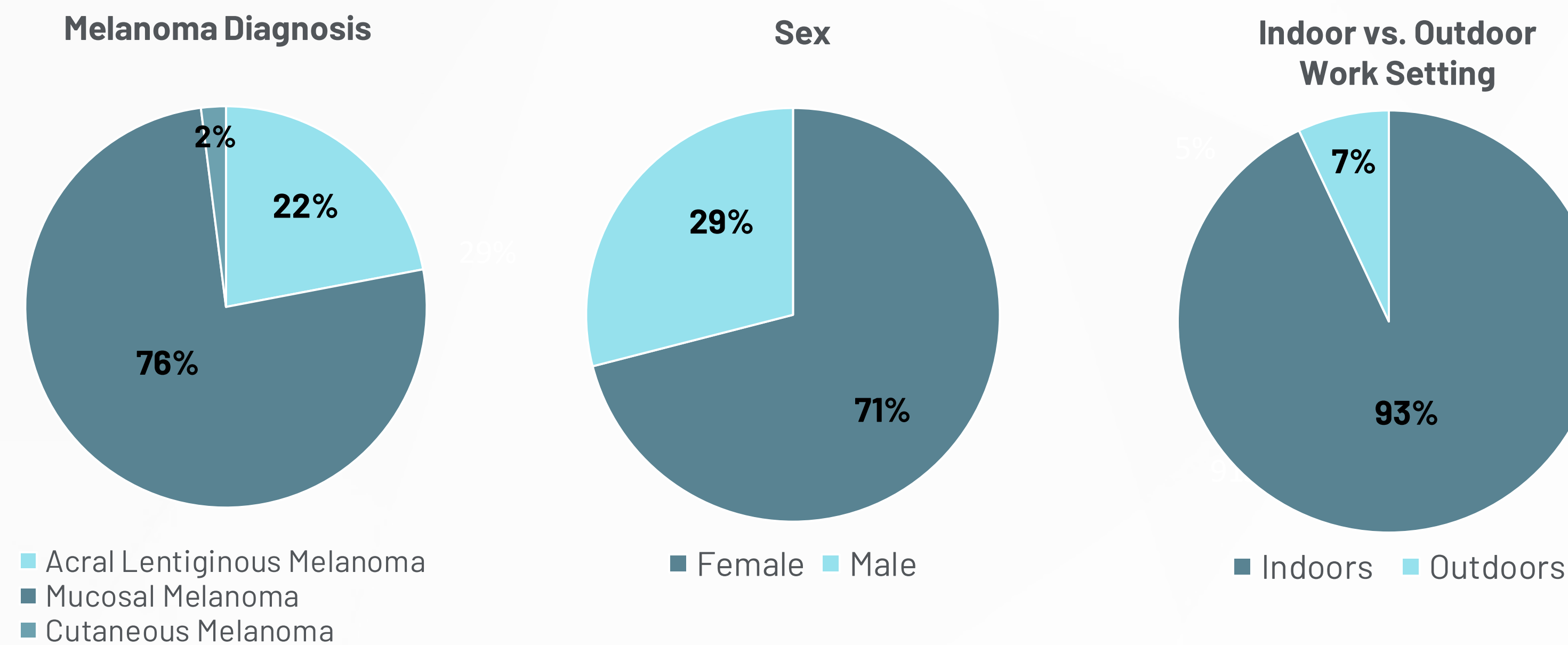
## Conclusions

The RARE registry is fully open and enrolling patients with acral, mucosal, and cutaneous melanoma. Our efforts to date suggest that RARE is a realistic way to capture meaningful information from patients with rare melanomas. Emerging data also indicates that additional efforts are needed to broaden representation from all races and ethnicities affected by acral and mucosal melanoma. MRA is working to implement strategies to increase awareness of RARE and maintain engagement of enrolled participants.

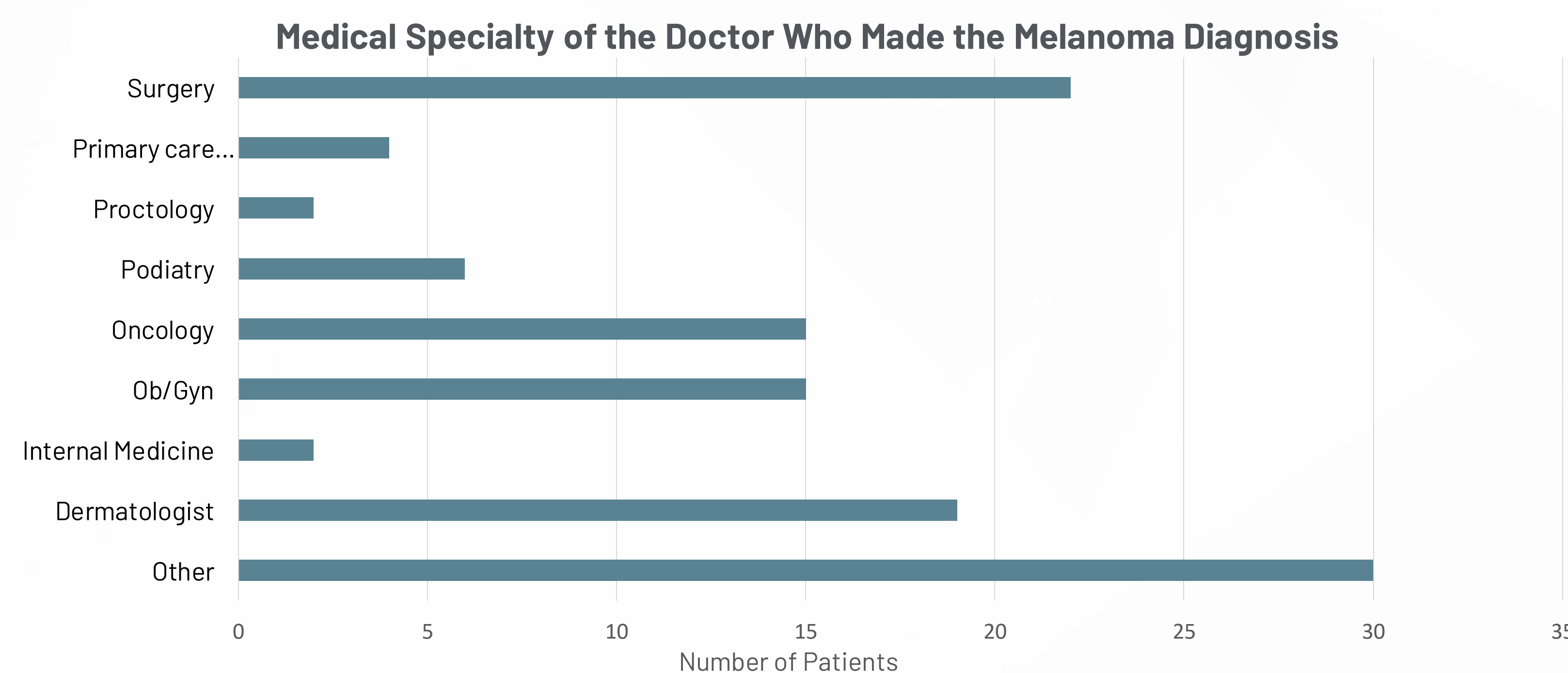
### Future Directions include:

- Establishing a research portal for researchers and clinicians to enable access to de-identified patient-reported, clinically abstracted and molecular data.
- Developing a biorepository to collect archived and prospective samples from RARE participants for future research studies.
- Launching the RARE Registry internationally to include a more representative population of patients worldwide.

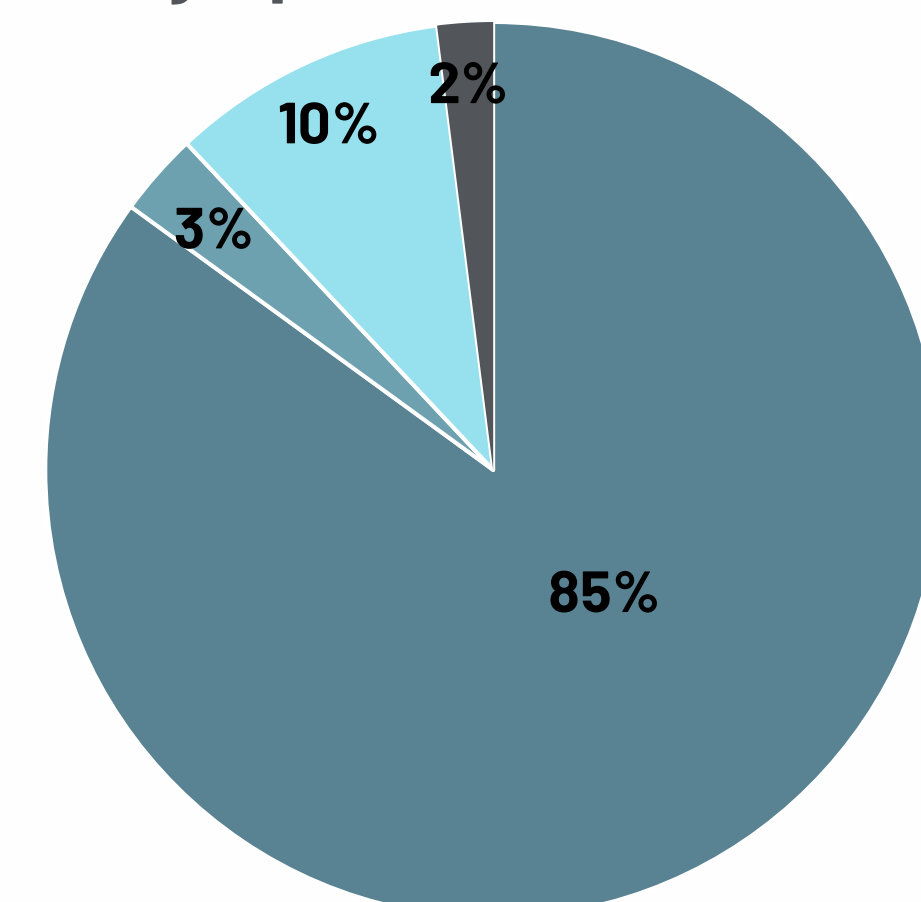
## Demographics



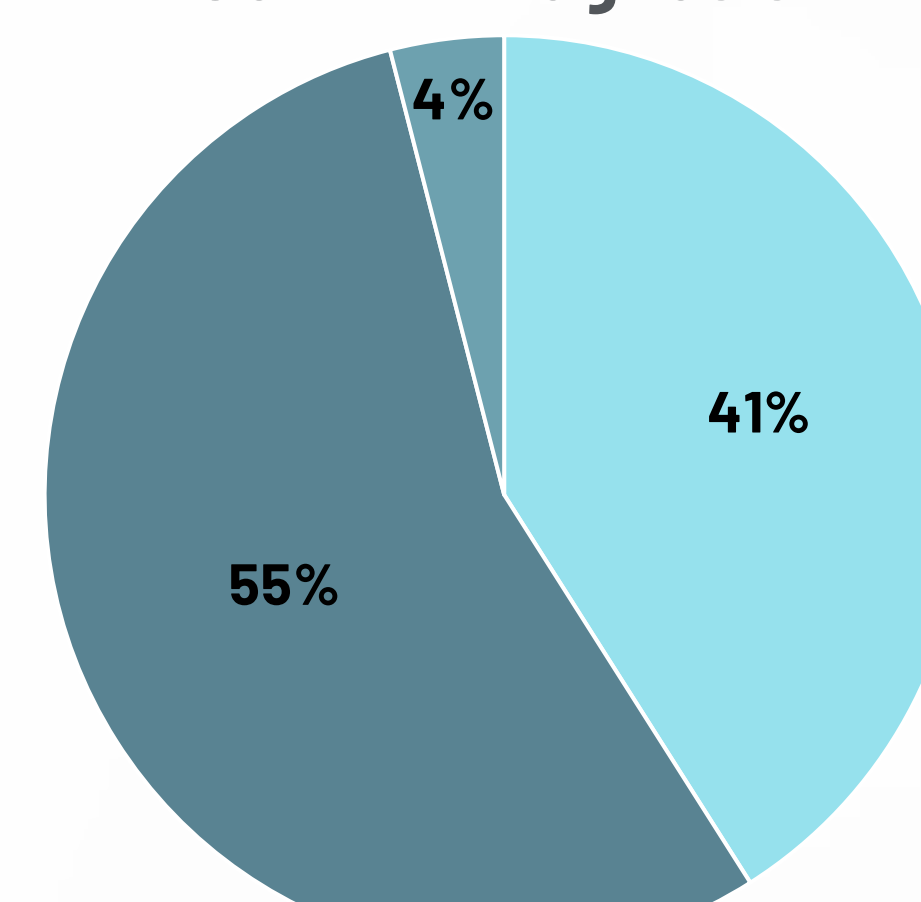
## Disease History



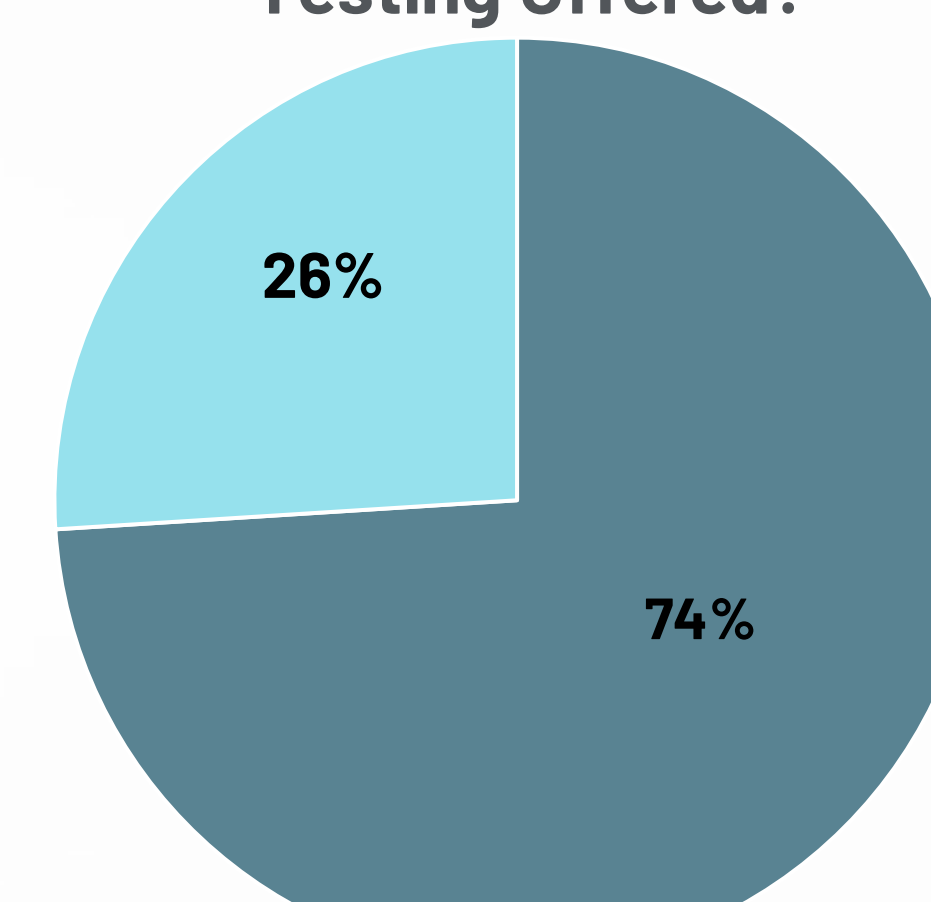
### First Person to Notice Signs or Symptoms of Melanoma



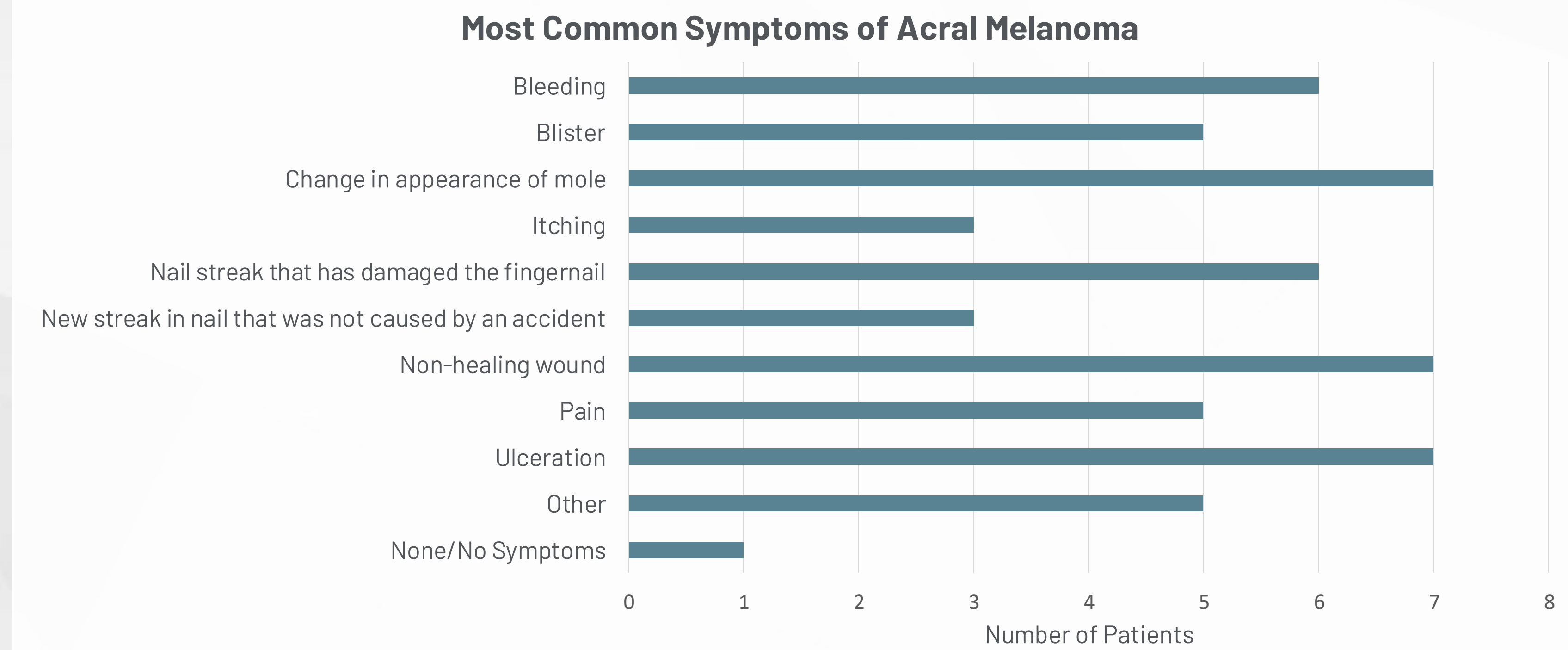
### Type of Biopsy Performed to Confirm Diagnosis



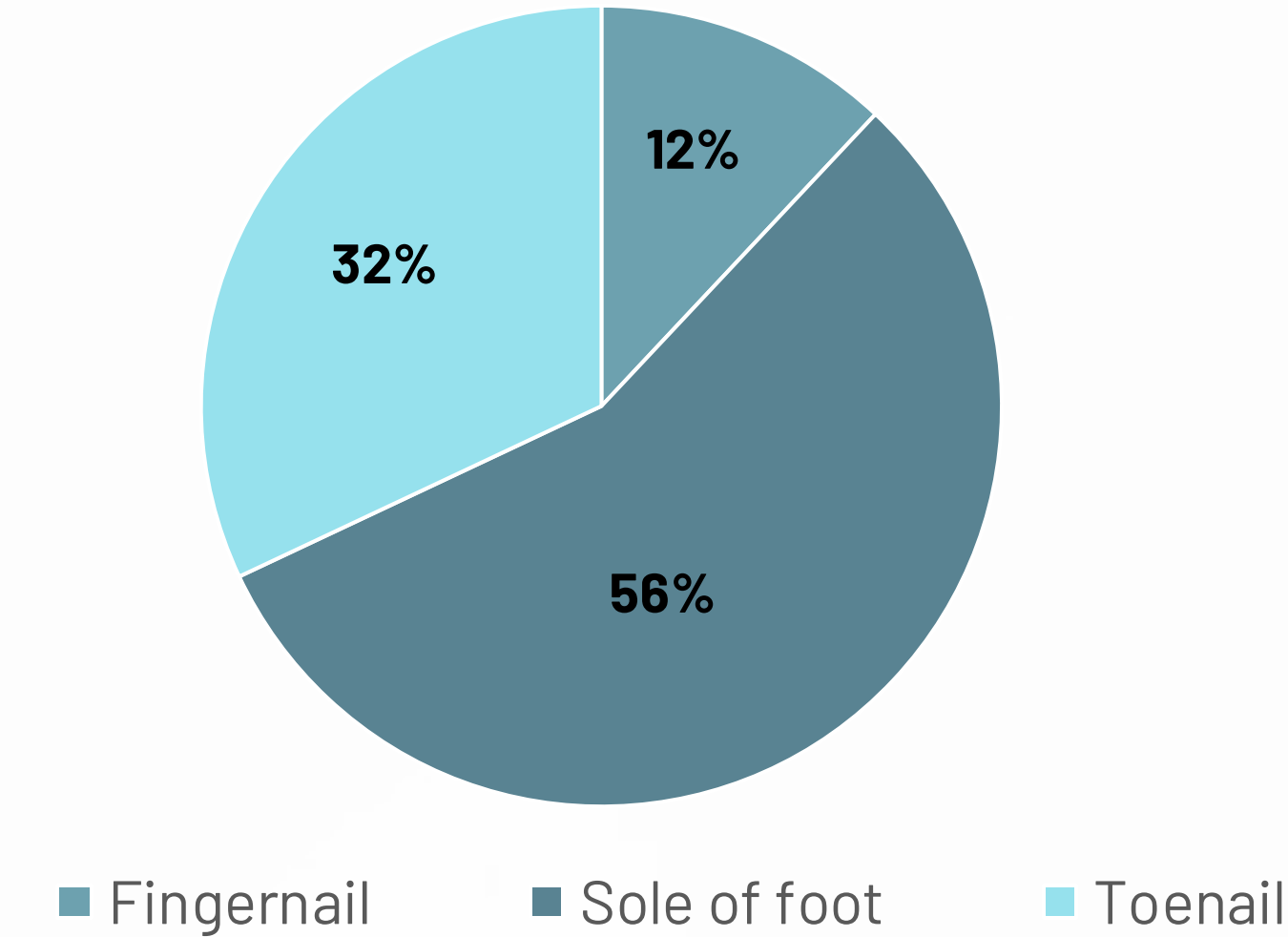
### Was Genetic or Biomarker Testing Offered?



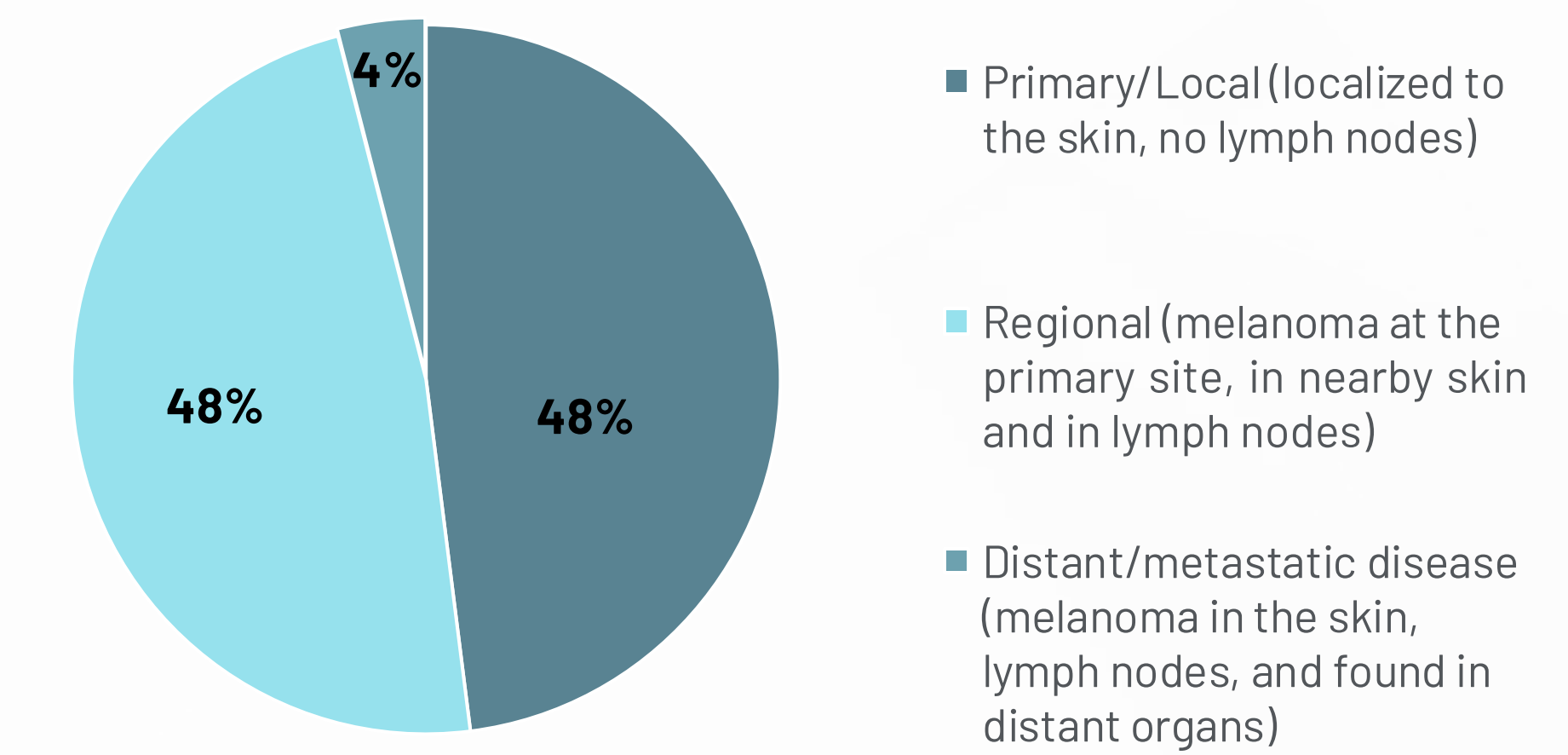
## Acral Melanoma



### Acral Melanoma Origin Site

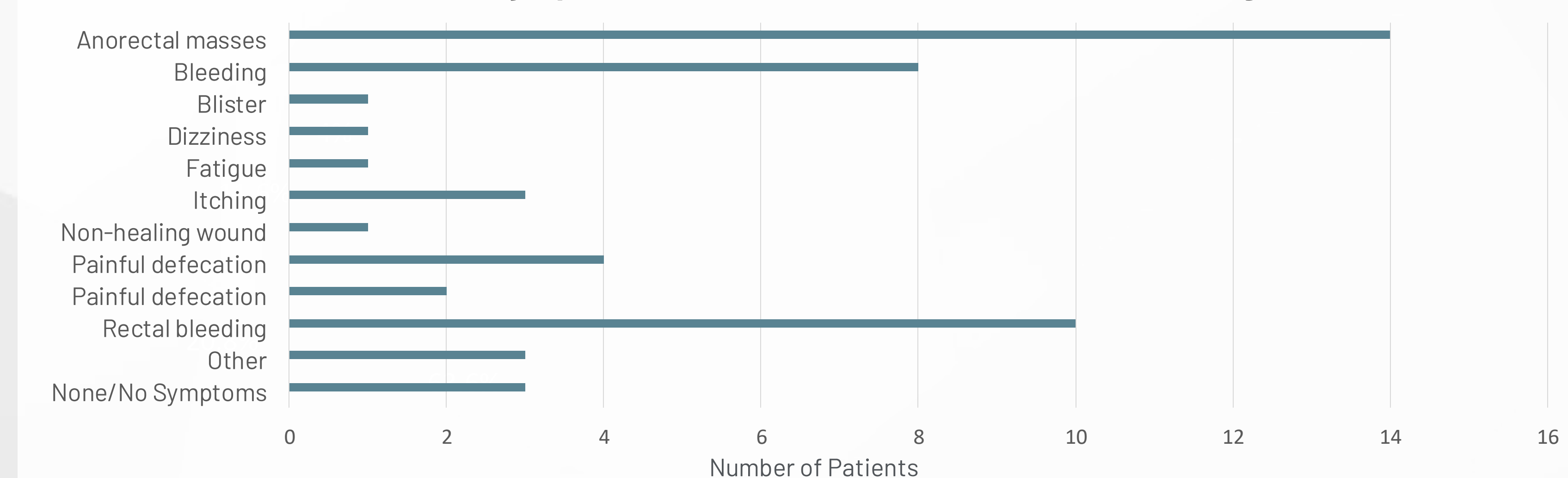


### General Stage When First Diagnosed

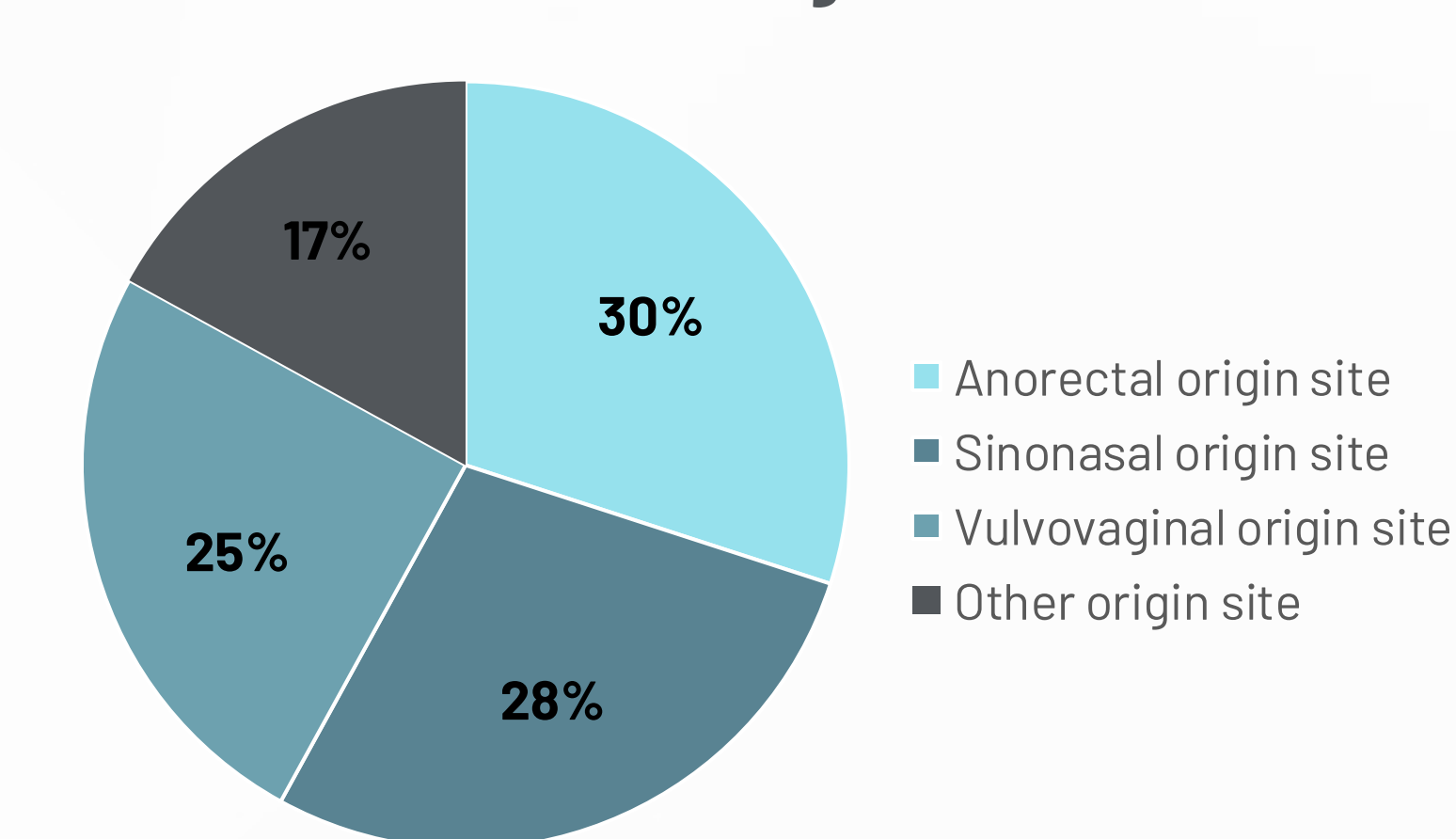


## Mucosal Melanoma

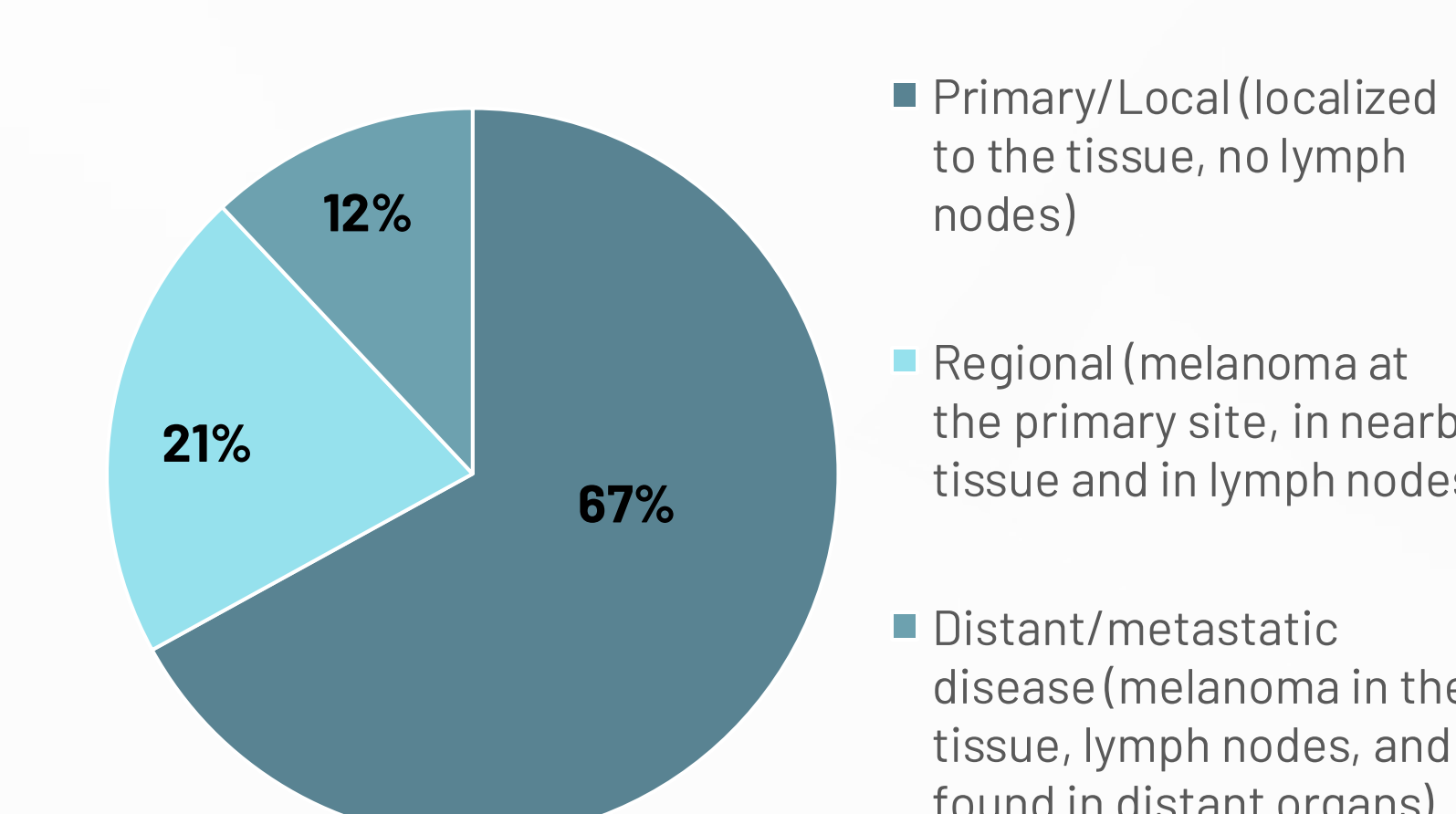
### Most Common Symptoms of Mucosal Melanoma on Anorectal Origin Site



### Mucosal Melanoma Origin Sites



### General Stage When First Diagnosed



## Get Involved

- Request IRB-approved educational material containing information about RARE from MRA.
- Discuss the RARE Registry with MRA staff to learn more.
- Visit [RareMelanoma.org](http://RareMelanoma.org) for an overview of RARE.
- Contact:** Joan Levy at [jlevy@curemelanoma.org](mailto:jlevy@curemelanoma.org)



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