ARC TALKS

WEBINAR SERIES

# Understanding Living with Amyloidosis:

## Insights from the ARC Annual Community Survey

May 14 | 12pm - 1pm ET

**Sabrina Rebello**

**Senior Research Manager**
Amyloidosis Research Consortium

# About ARC

ARC's mission is to improve and extend the lives of those with amyloidosis

## OUR FOCUS

**IMPROVING** the speed and accuracy of diagnosis

**INCREASING** our understanding of the genetics, biology and natural history of amyloidosis to identify new treatments

**ACCELERATING** regulatory approval and reimbursement of effective treatments for patients

**ENHANCING** care and quality of life of patients and caregivers throughout their amyloidosis journey

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# Before We Begin

This webinar is recorded. We will post the webinar on our website so you can view it again later.

Submit your questions anytime via the Q&A box. We will try to answer them at the end.

If you are having trouble with the audio using your computer, you can dial in (check your email for info).

# Understanding Living with Amyloidosis: Insights from the ARC Annual Community Survey

# Overview

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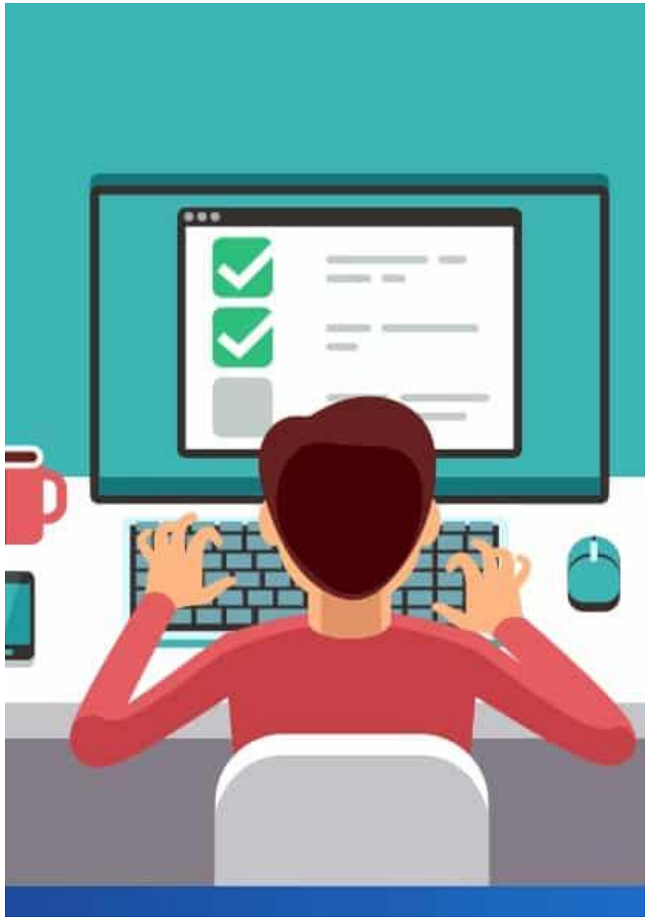

- •**Why this research matters:** improving care and support for everyone in our community
- •**Our annual survey:** hearing your experiences and using them to shape our work
- •**What patients have told us:** highlights from your experiences
- •**What caregivers have told us:** highlights from your experiences
- •**Putting results into action:** what the survey results mean for you and your care
- •**Next steps:** moving forward together with your voice guiding us

# Why Research Matters

## Understanding Experiences and Outcomes

- Personal Insight
- Real-world Evidence

## Empowerment and Decision-Making

- Informed Choices
- Advocacy

## Identification of Resources and Support

- Access to Resources
- Community Building

## Awareness of Scientific Progress

- Therapeutic Advances
- Research Participation

## Validation of Concerns

- Shared Experiences
- Understanding Variability

# Our Annual Survey

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**What:** online survey on your experiences with diagnosis, treatment, and the journey of living with amyloidosis

**Who:** people living with amyloidosis and their caregivers

**When:** annually

**Why**: to better understand the real-life experiences of people living with amyloidosis and their caregivers

**We want to understand how these experiences have evolved over time and how we can better support our community.**

# How We Use Our Annual Survey

Publications

Presentations

Online summaries

# How We Use Our Annual Survey

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## ARC 2022 Community Survey Results

for Amyloidosis Patients and Caregivers

### About this Study

The Amyloidosis Research Consortium (ARC) conducted an online survey of individuals with amyloidosis and their caregivers to collect data and gather information on the experience with diagnosis and treatment of those affected by amyloidosis. With newly available treatments since 2018 and with initiatives to increase disease awareness, there have been rapid changes within the amyloidosis community. ARC plans on conducting the survey each year to see how the experience changes over time.

Over 1200 responses were completed for the 2022 ARC Annual Community Survey during April and May of that year. 79% of participants identified as amyloidosis patients, and 21% identified as caregivers. Responses were submitted from around the world, including North and South America, Europe, and Asia.

Their responses, summarized below, shed a light into the needs of those living with amyloidosis and the work that still needs to be done to improve their lives as we work towards a cure. They are the reason the team at ARC continues Pushing Research Forward to support patients and their families.

### What We Measured

ARC asked amyloidosis patients and their caregivers about the journey to an amyloidosis diagnosis and treatment experience.

### Diagnosis Stories

*ER visits are difficult as local hospital ER physicians are unfamiliar with the disease and unwilling to contact Amyloidosis doctors at [the] Amyloidosis center for guidance...I need to be a strong advocate for myself by explaining the effects of my disease on body organs.*

*— AL patient*

***It seems to be an all over the place disease with symptoms that crop up and can be severely debilitating. Particularly the GI Issues.***

*— Wild-type ATTR amyloidosis patient*

***[It's] very difficult to get many doctors to listen to you and what's actually happening with your body.***

*— AL patient*

***Looking back in my life I had things going on that could not be explained; for years before I was diagnosed I knew that something was wrong.***

*— Wild-type ATTR amyloidosis patient*

https://arci.org/arc-2022-community-survey/

# How We Use Our Annual Survey

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## ARC 2023 Community Survey Results

for Amyloidosis Patients and Caregivers

About This Study | What We Measured | What We Learned

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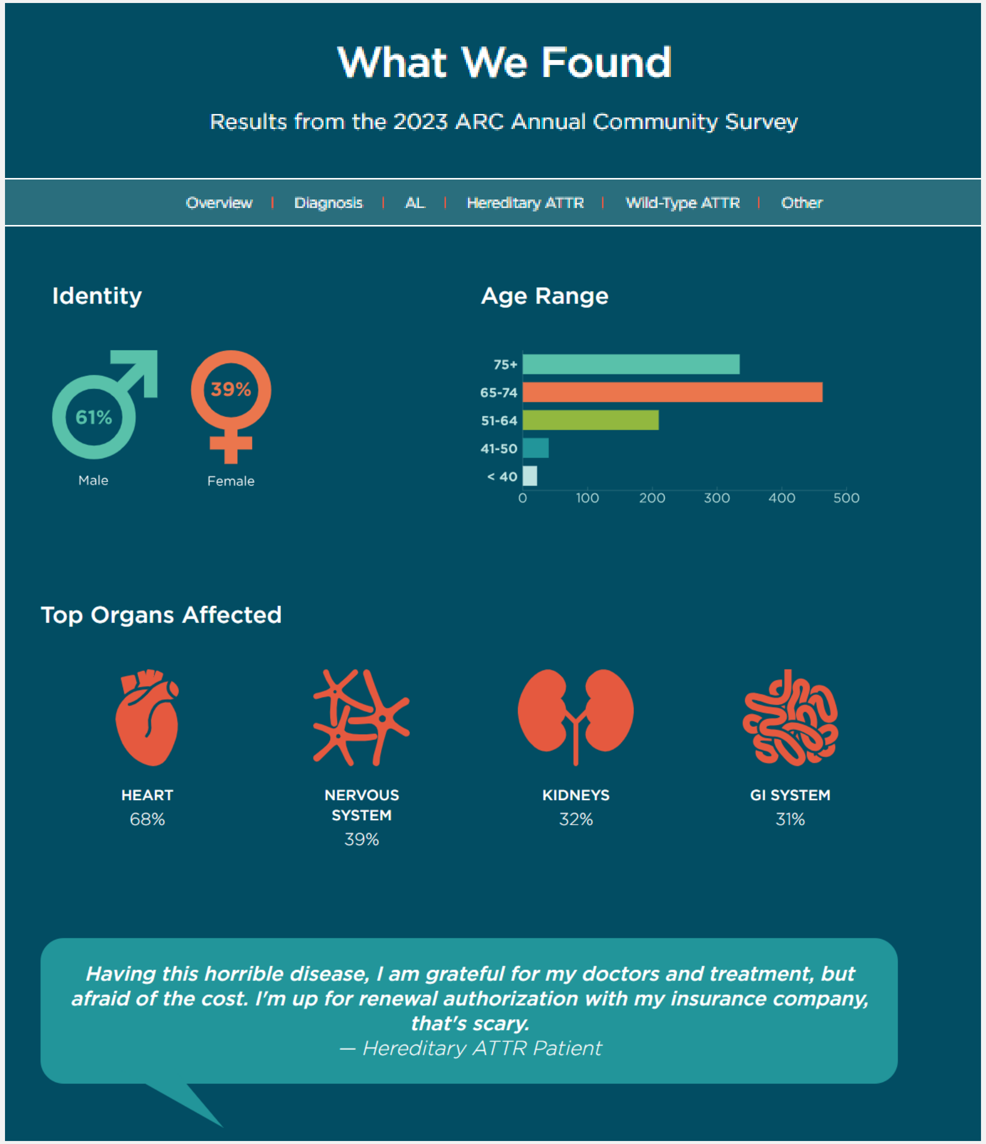


## What We Found

Results from the 2023 ARC Annual Community Survey

Overview | Diagnosis | AL | Hereditary ATTR | Wild-Type ATTR | Other

**Identity**

61% Male

39% Female

**Age Range**

**Top Organs Affected**

HEART 68%

NERVOUS SYSTEM 39%

KIDNEYS 32%

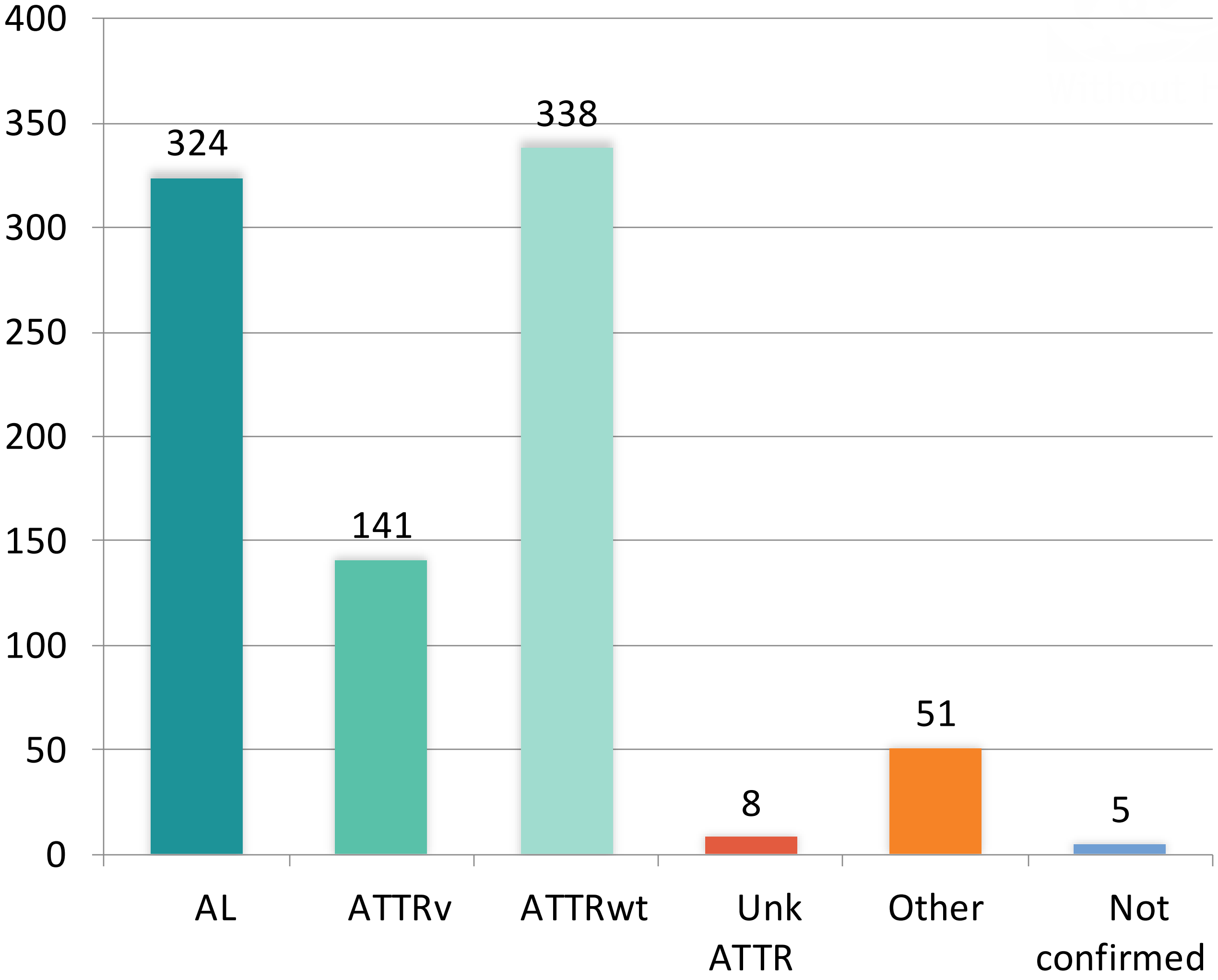
GI SYSTEM 31%

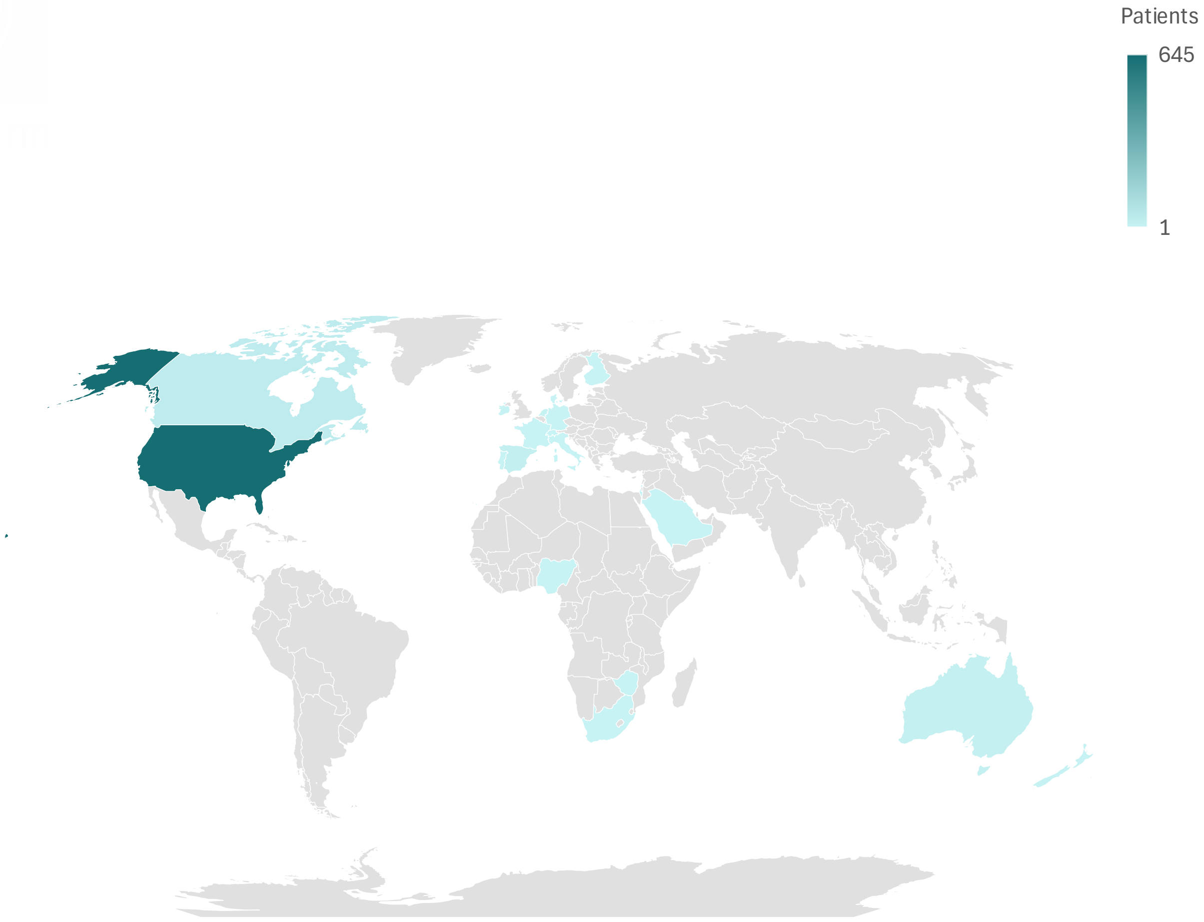
> ***Having this horrible disease, I am grateful for my doctors and treatment, but afraid of the cost. I'm up for renewal authorization with my insurance company, that's scary.***
> *— Hereditary ATTR Patient*

https://arci.org/arc-2023-community-survey/

# What Patients Told Us

## Who took the most recent survey?





# What Patients Told Us

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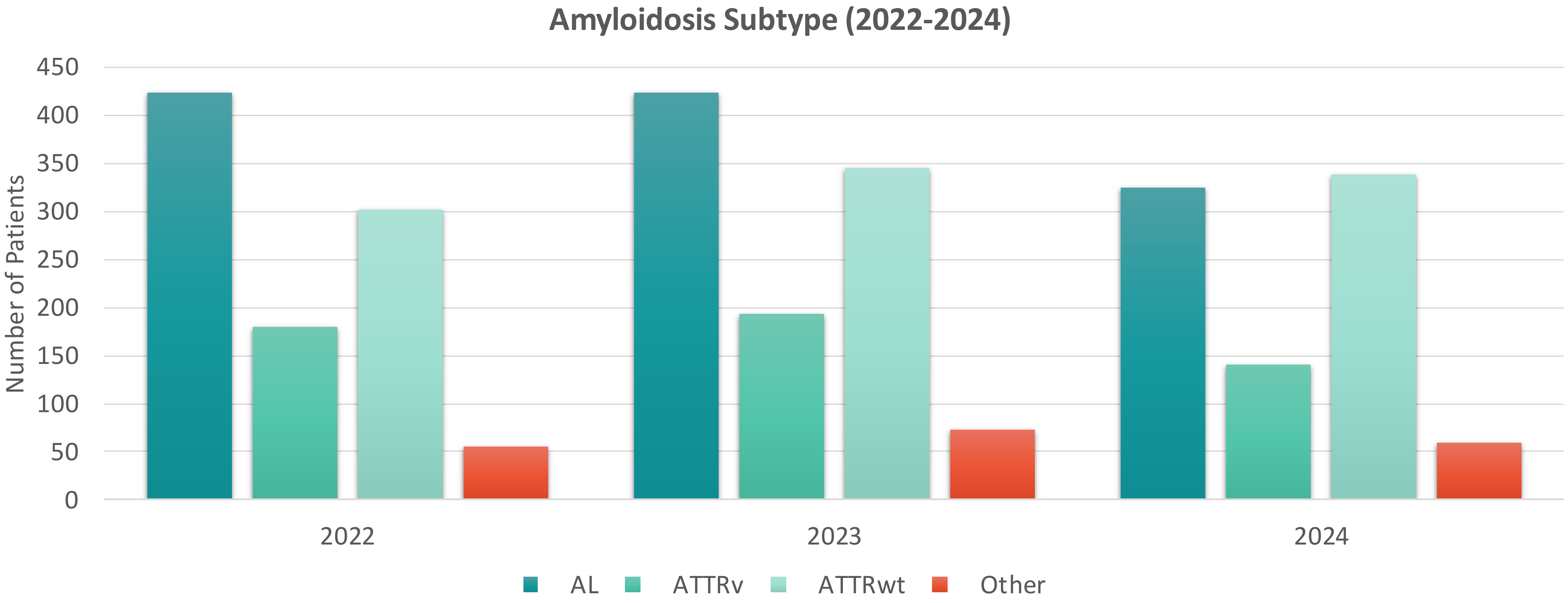
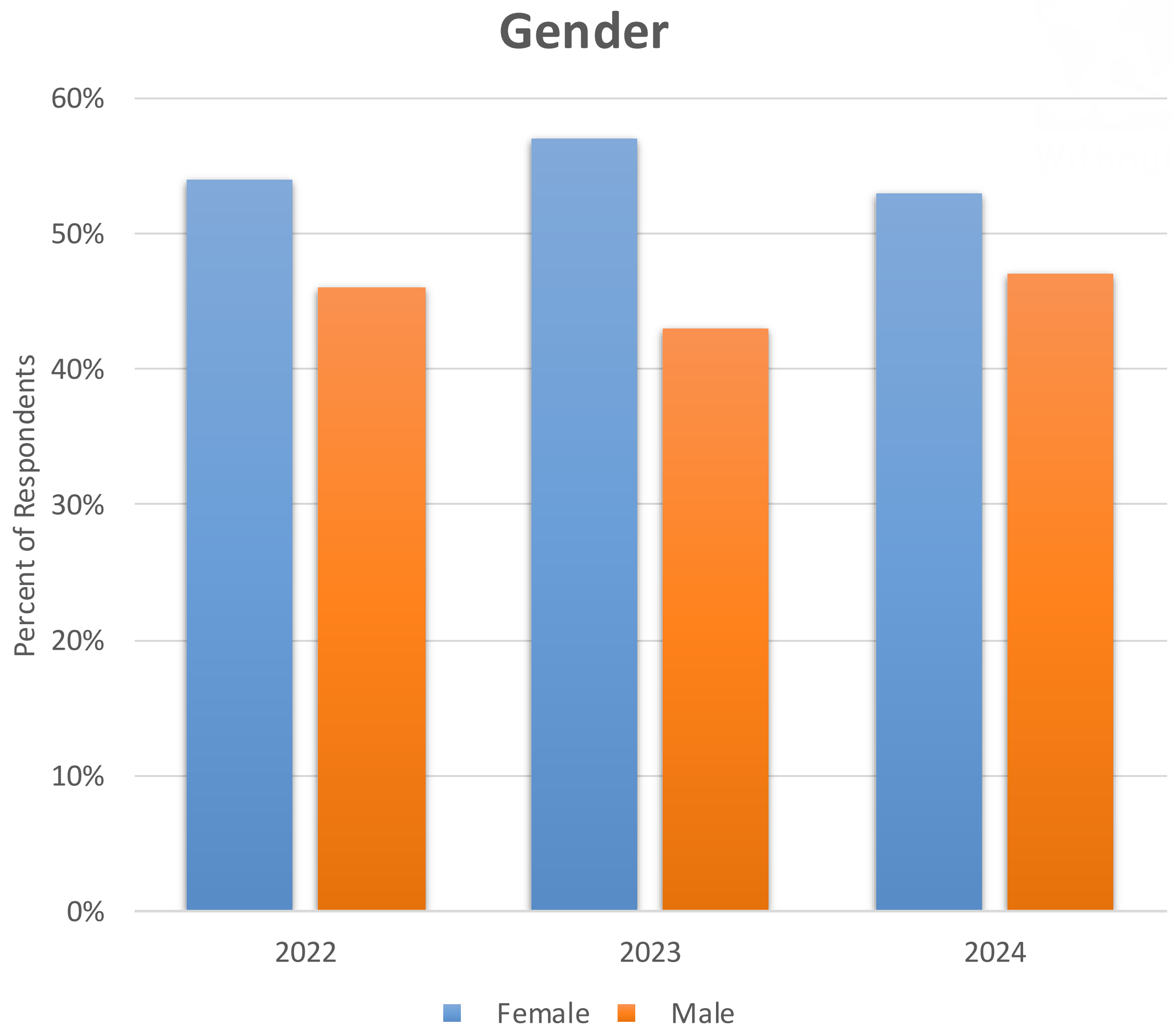
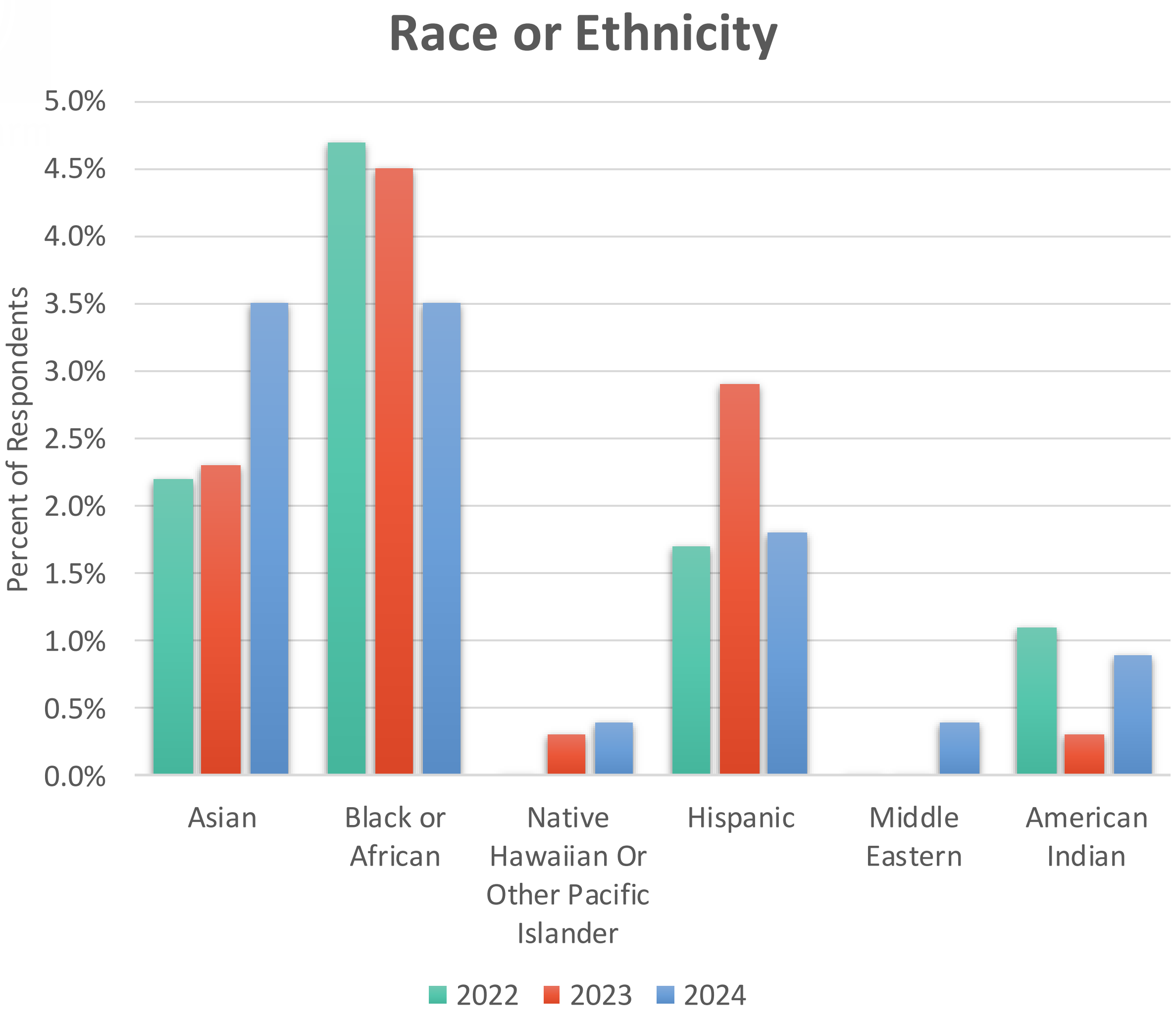
## Who took the surveys?



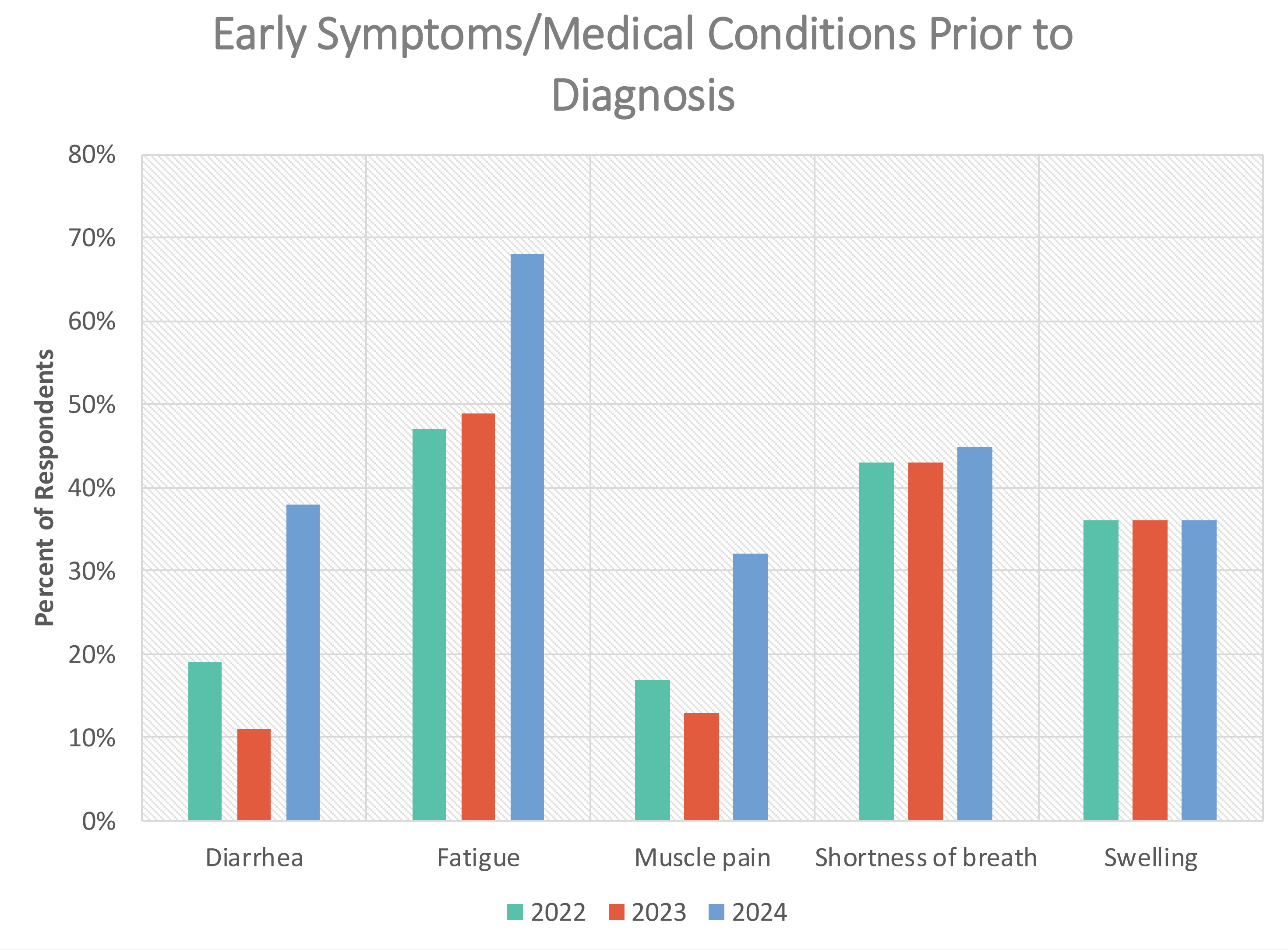
# AL Amyloidosis

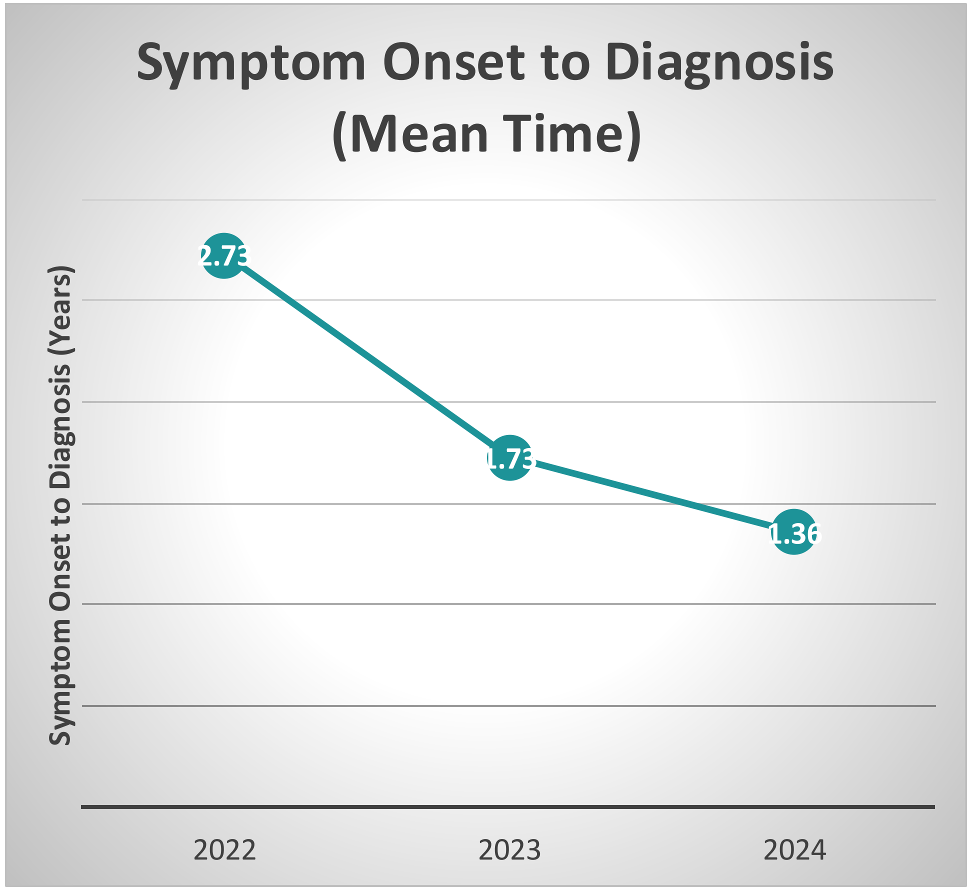
# Demographics – AL Amyloidosis





# Pathway to Diagnosis – AL Amyloidosis


Early Symptoms/Medical Conditions Prior to Diagnosis


Symptom Onset to Diagnosis (Mean Time)

# Pathway to Diagnosis – AL Amyloidosis

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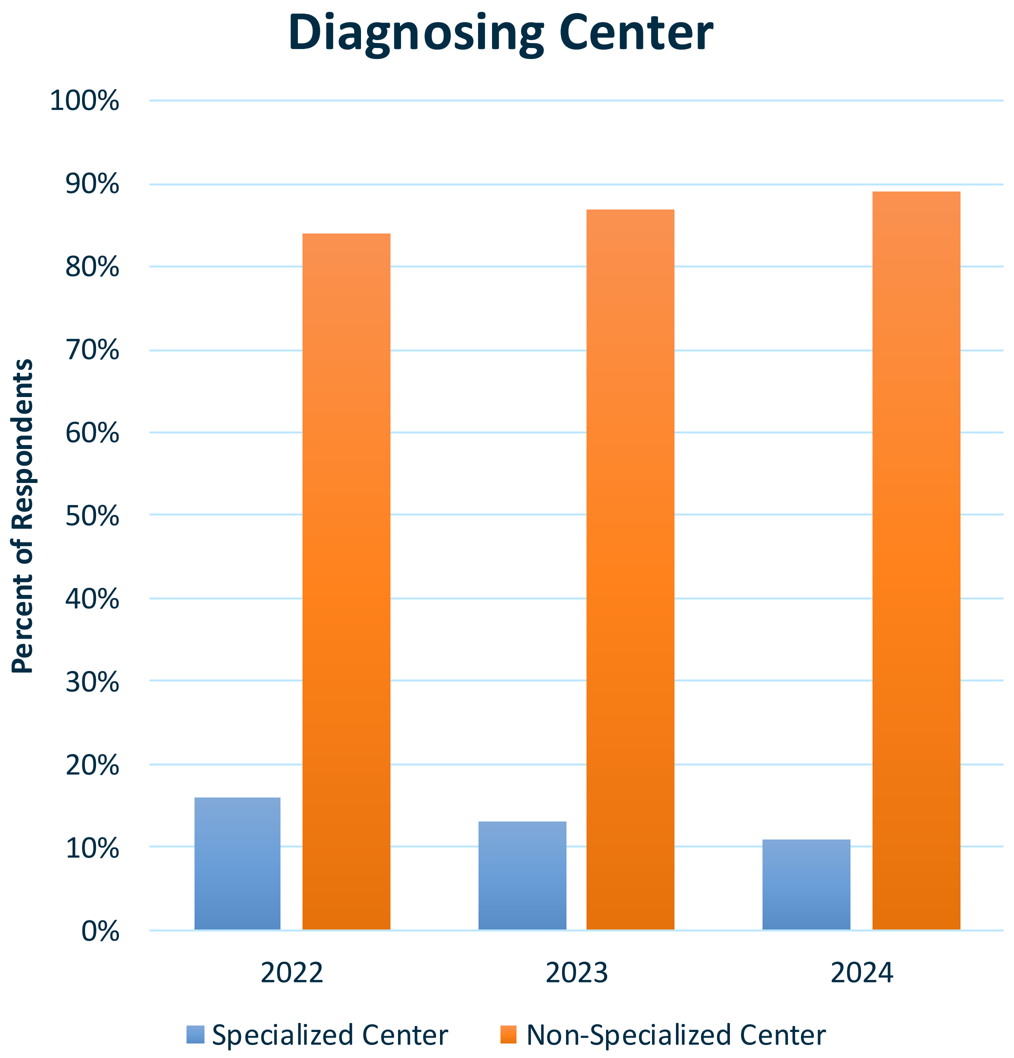

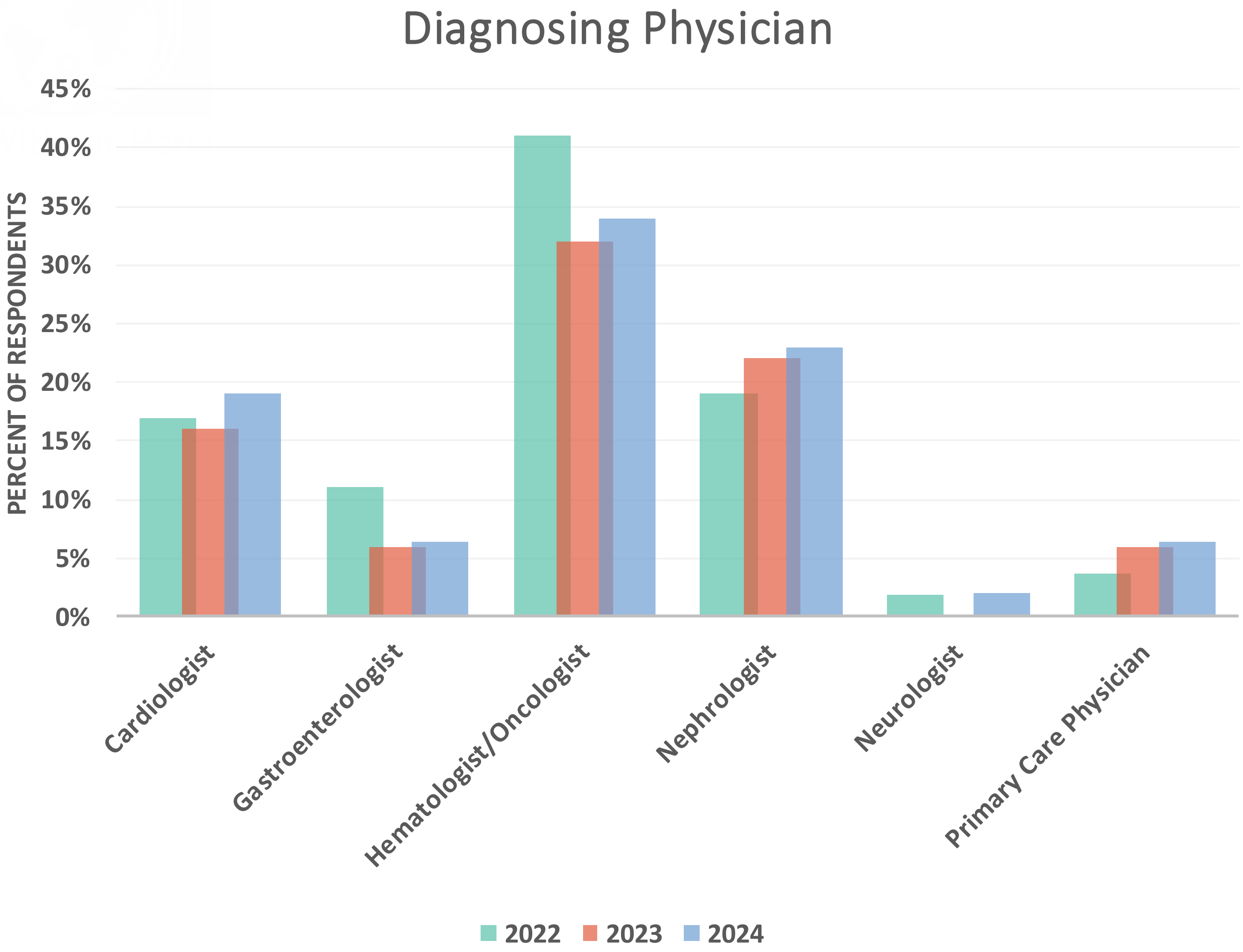

# Health Snapshot – AL Amyloidosis

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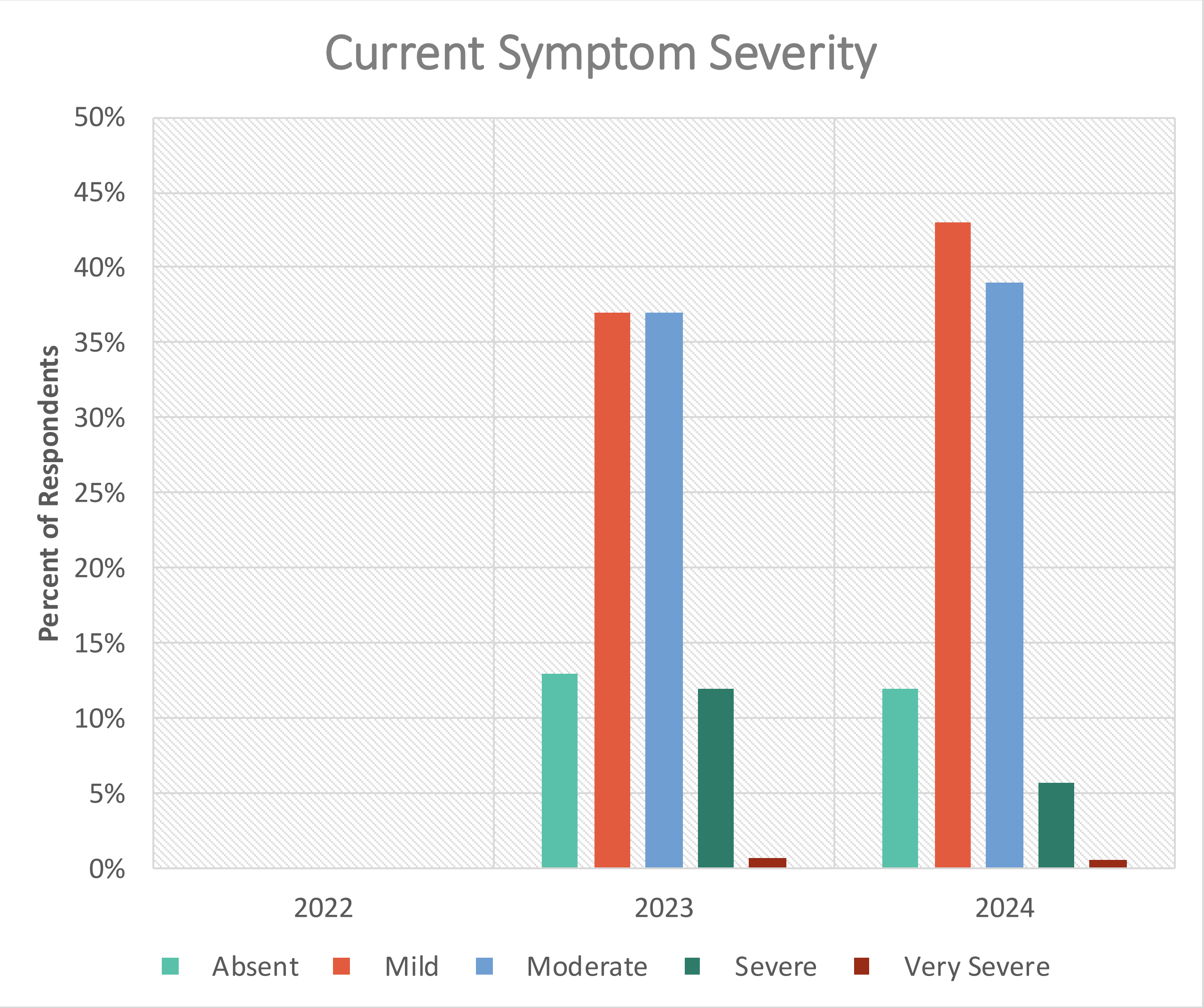

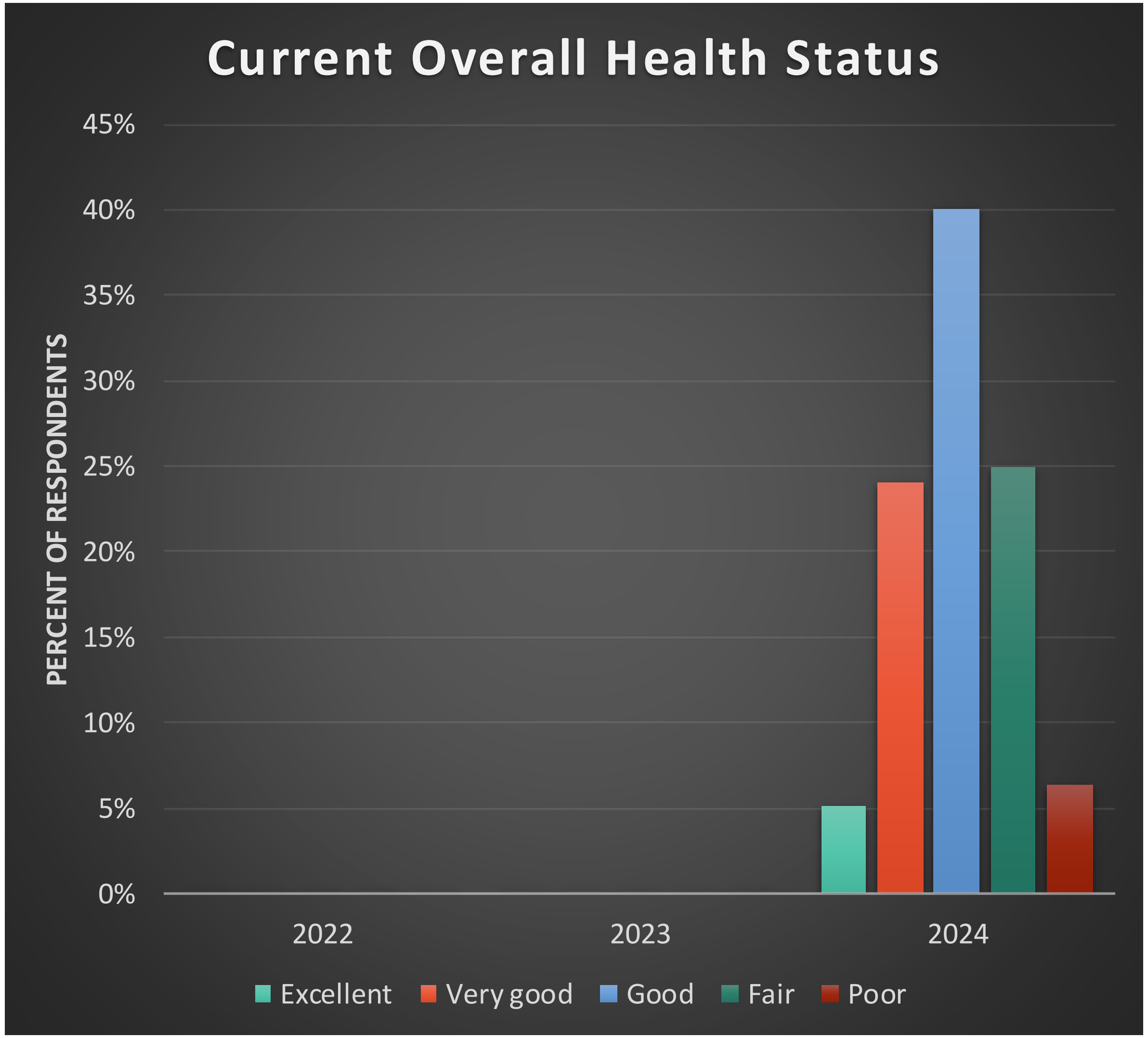

# How Patients Feel About Their Treatment

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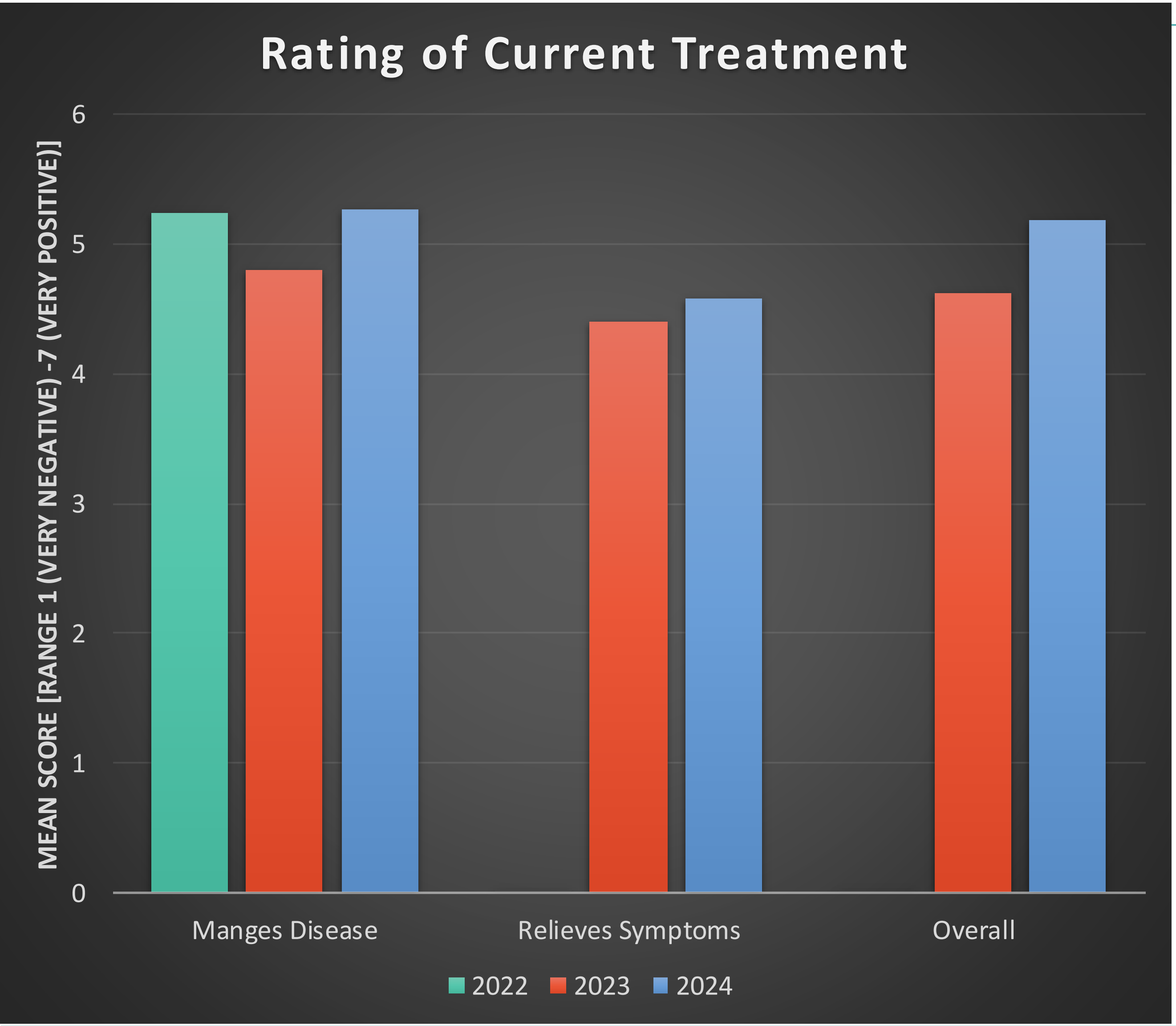
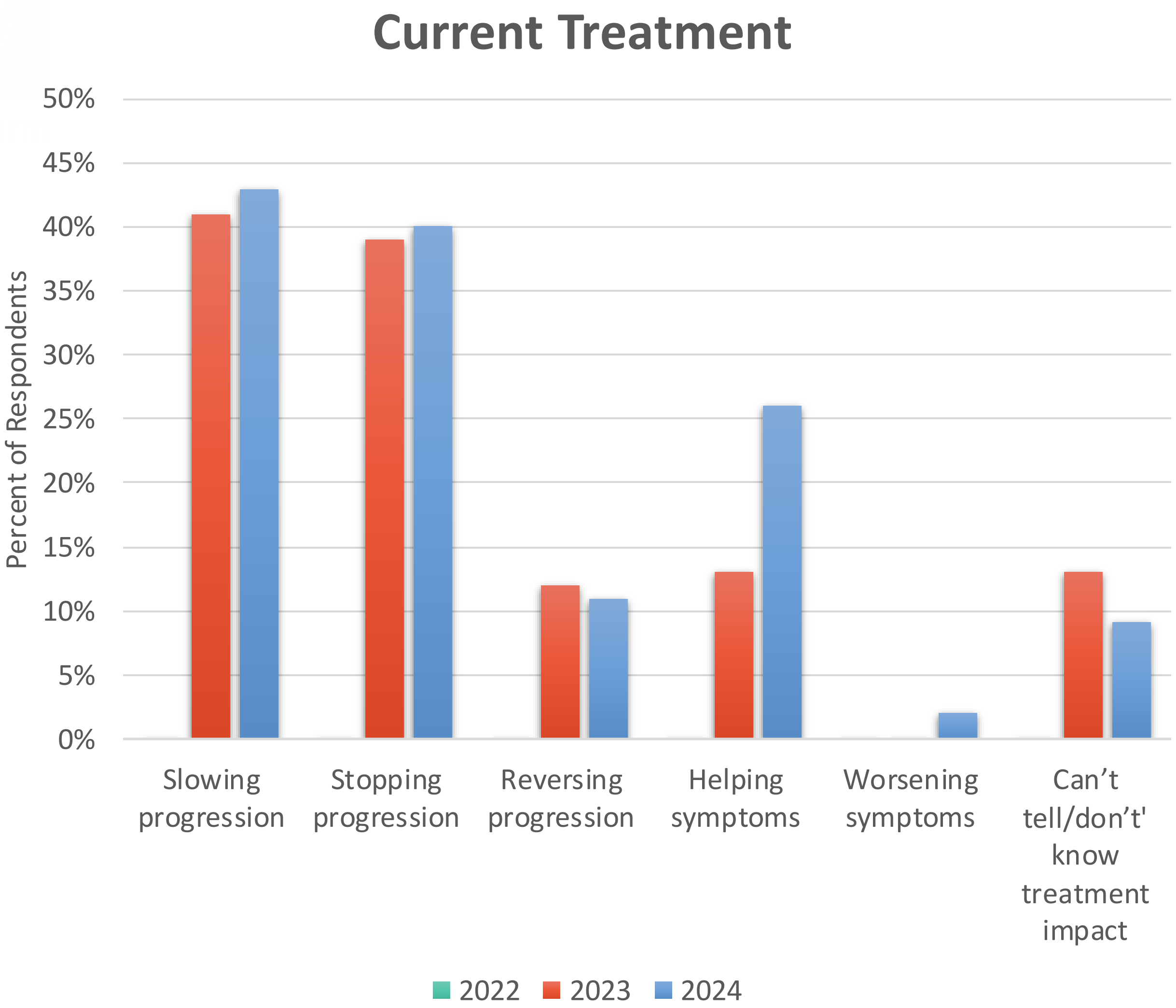
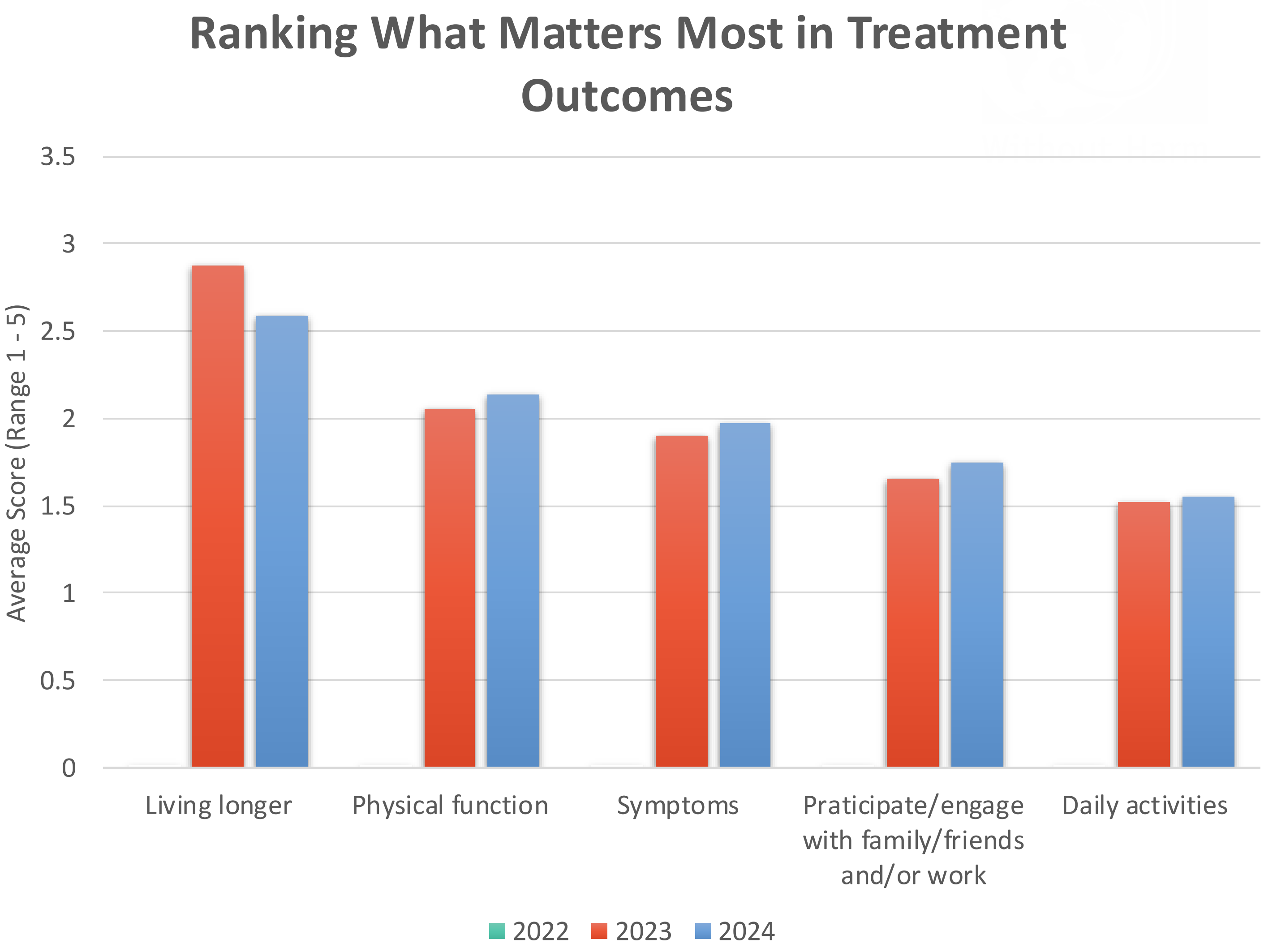
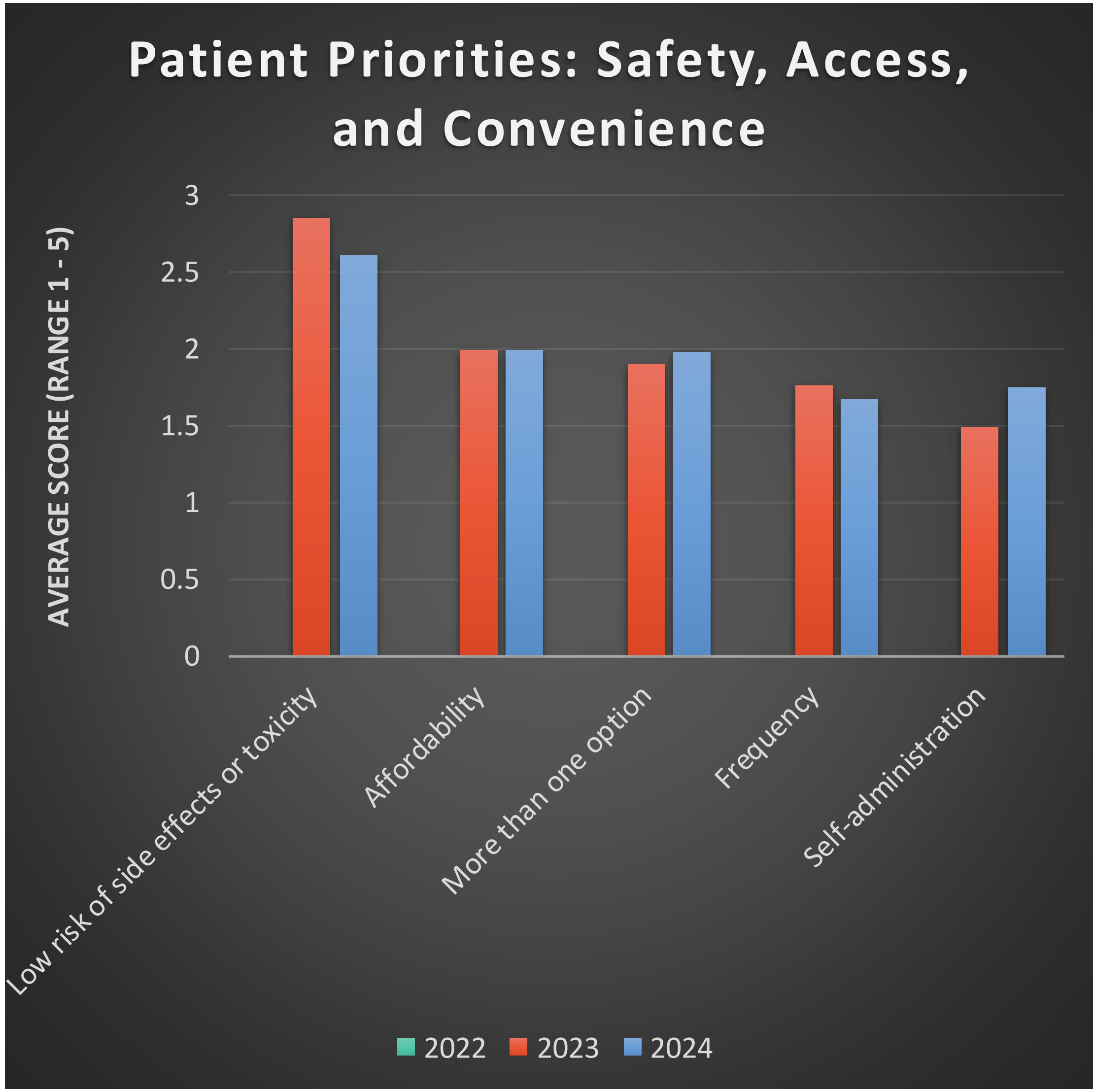




# Goals That Matter: A Patient Perspective





# Patient Feedback on Ongoing Care

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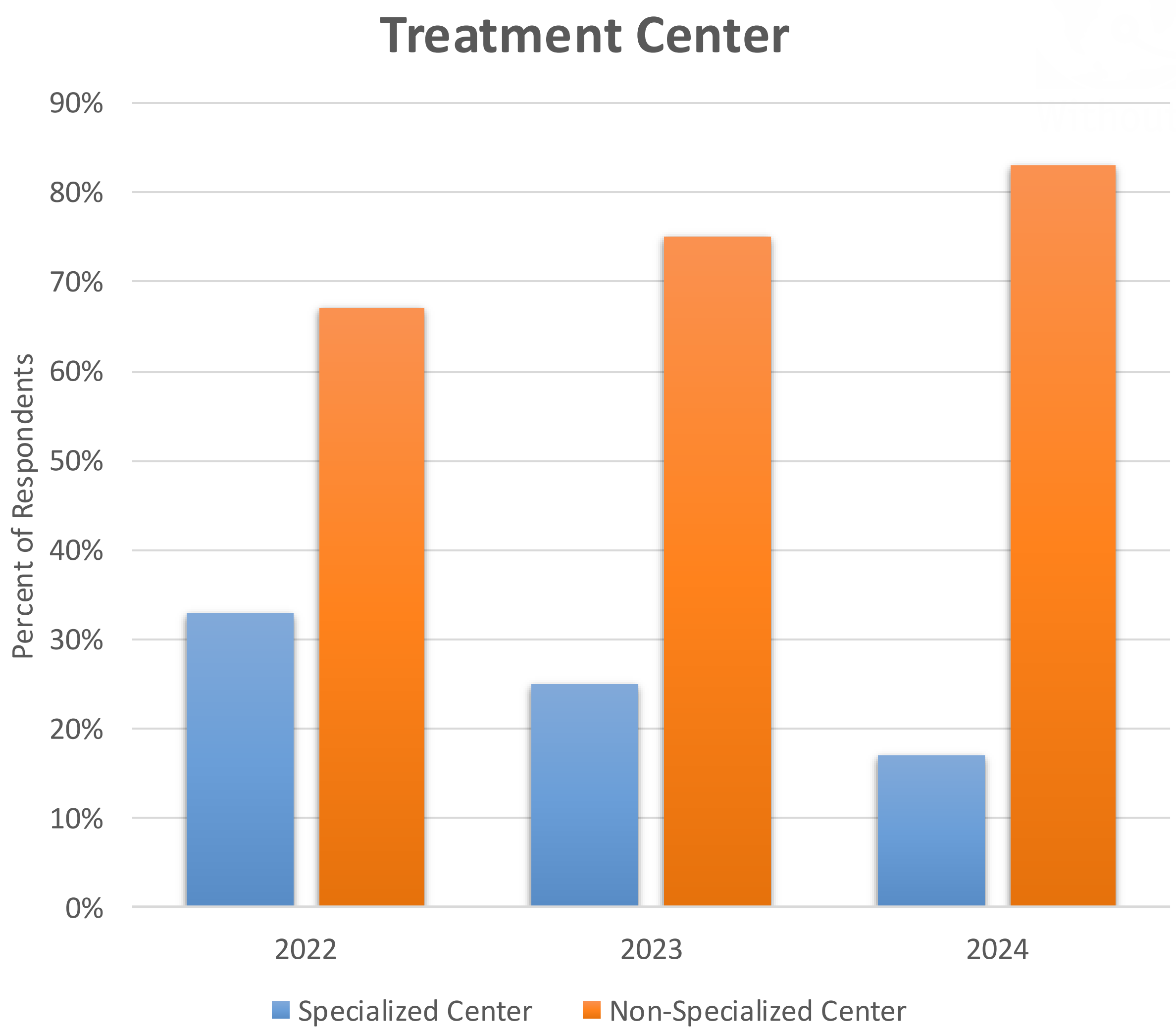
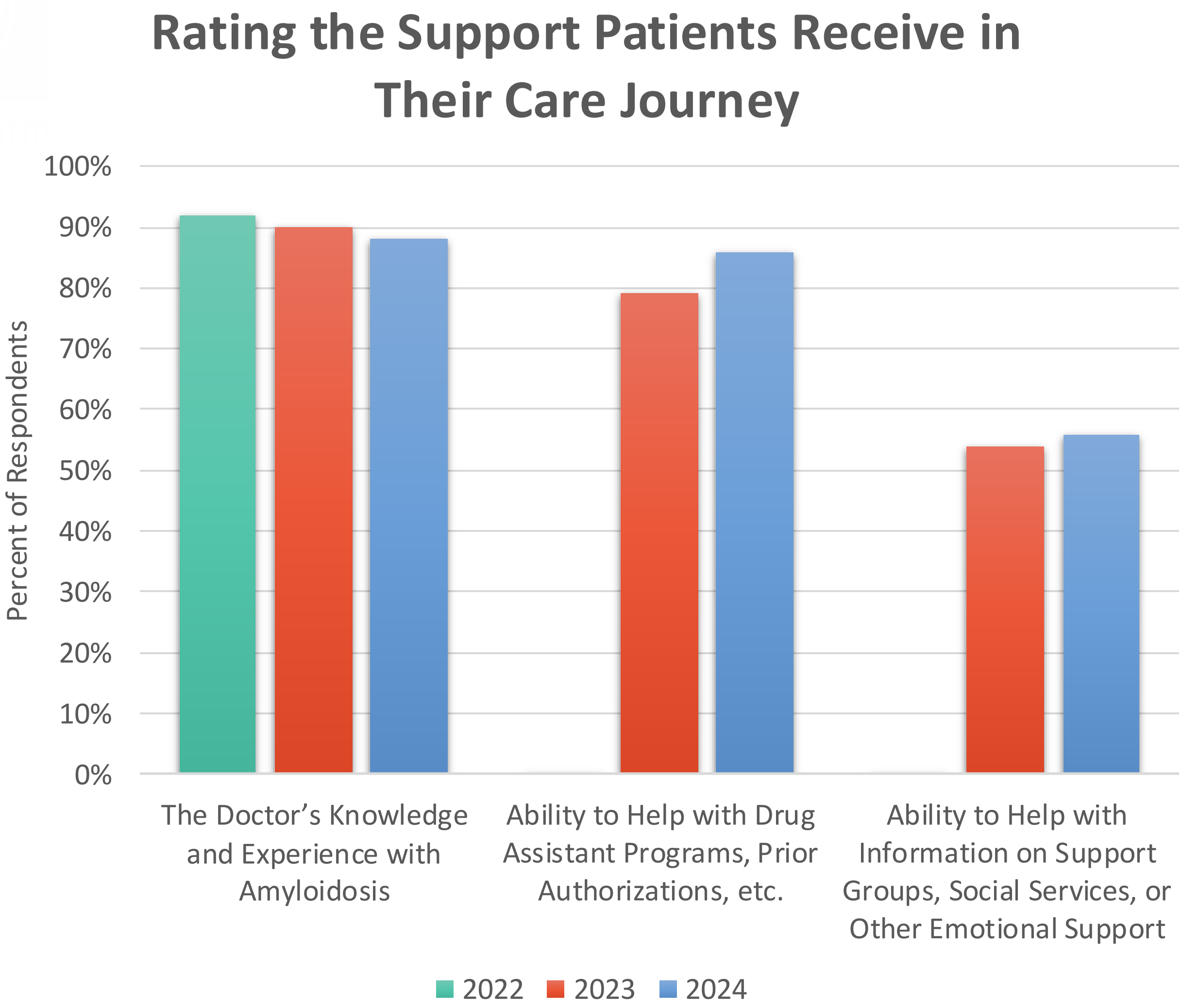
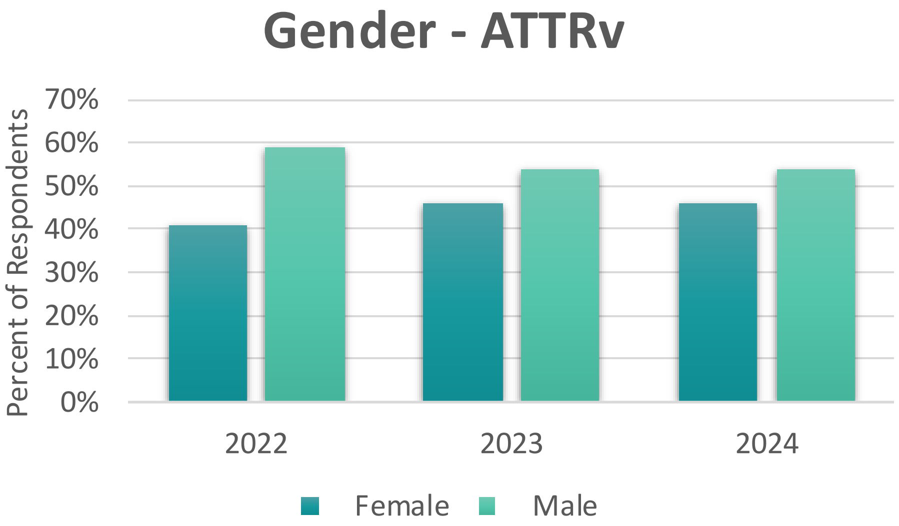
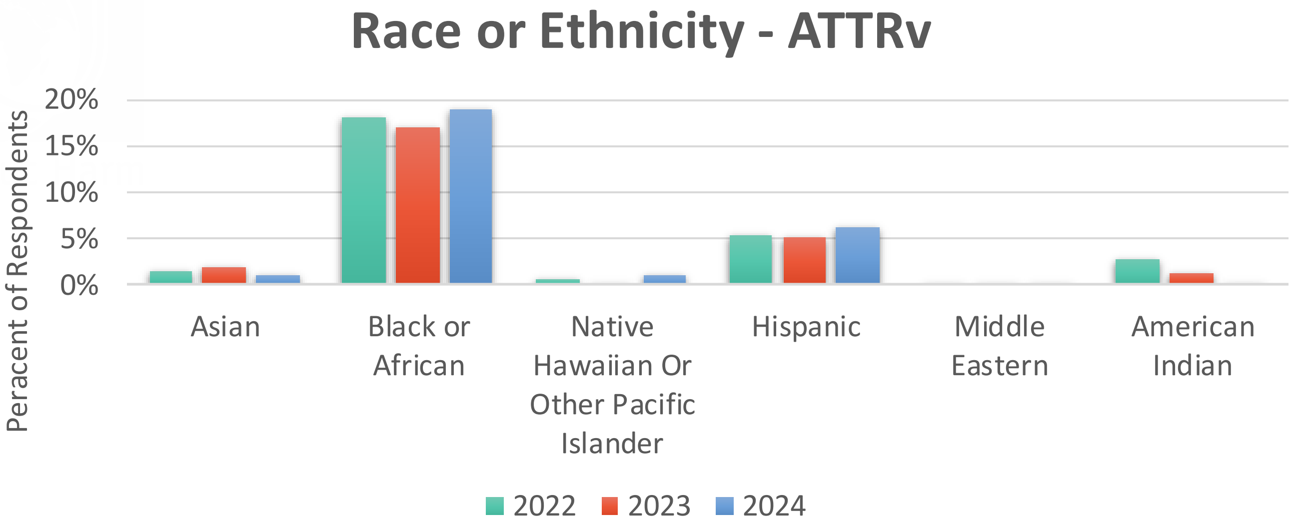


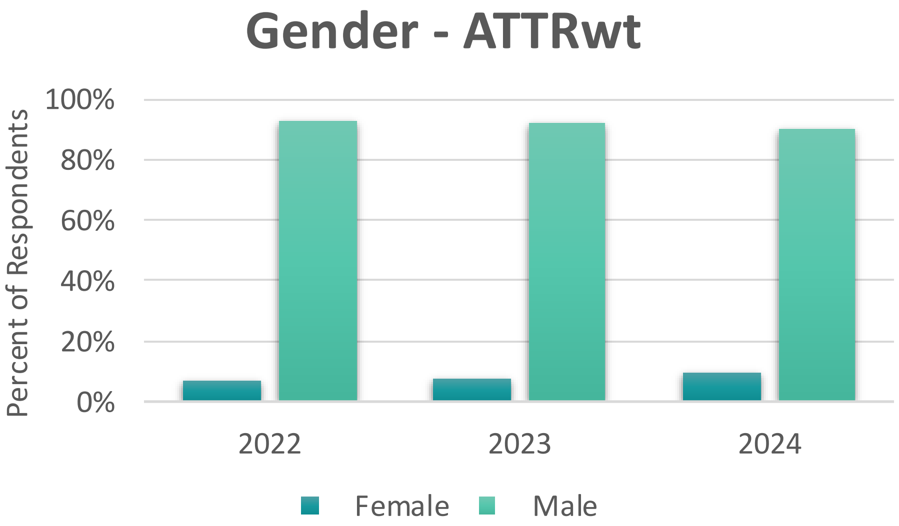


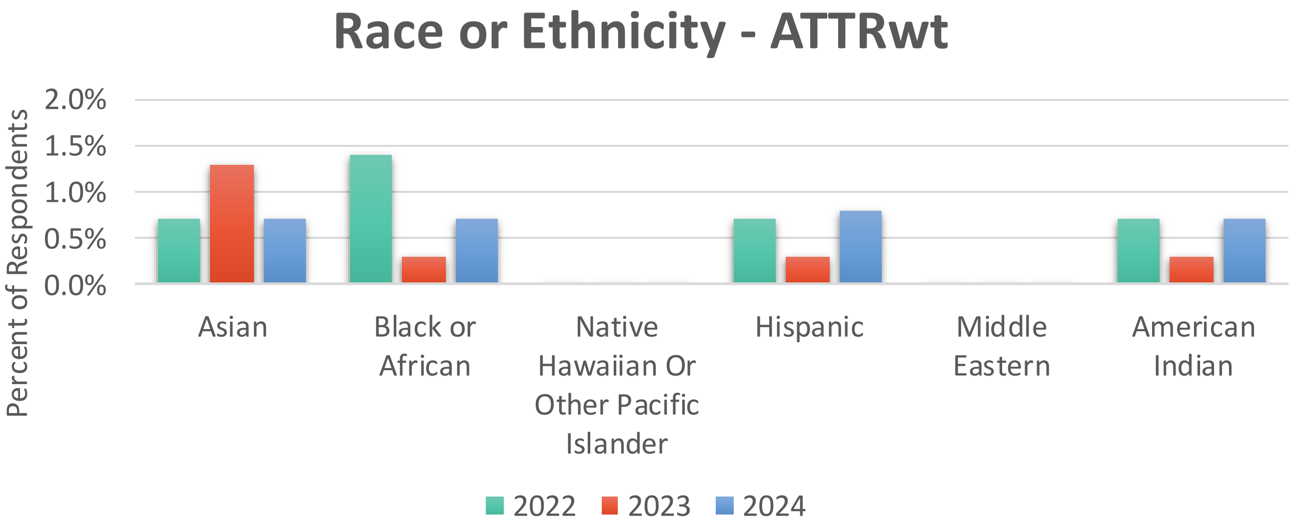
# ATTR Amyloidosis

# Demographics – ATTR Amyloidosis

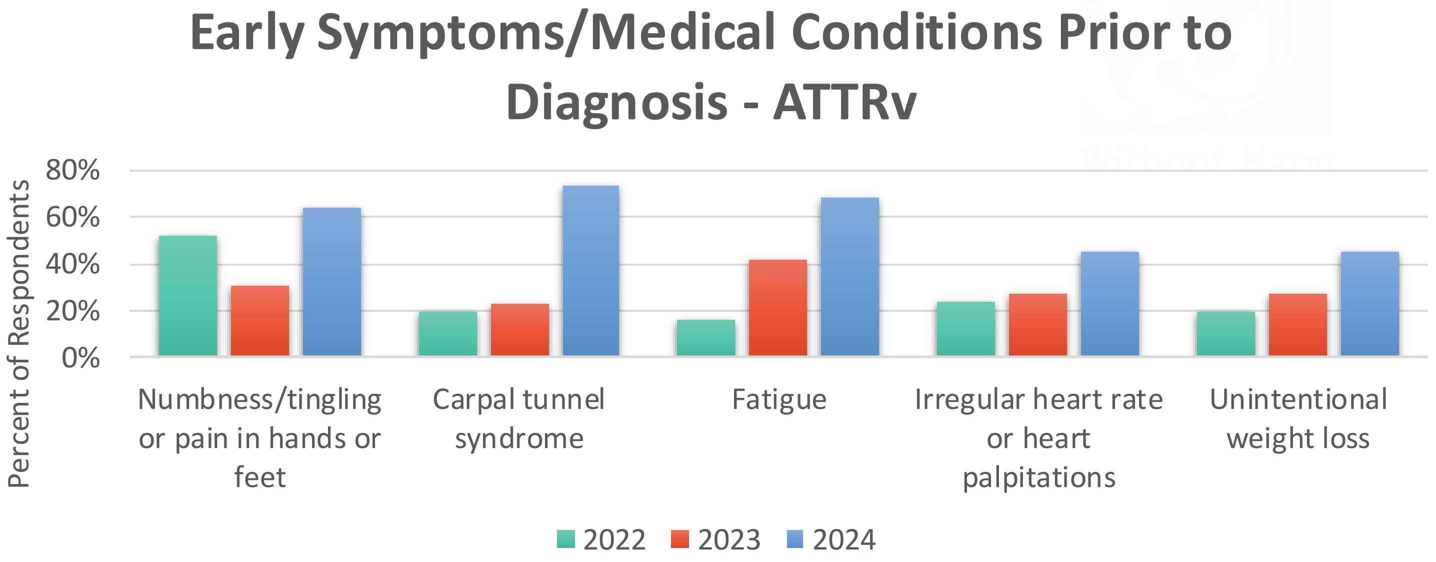


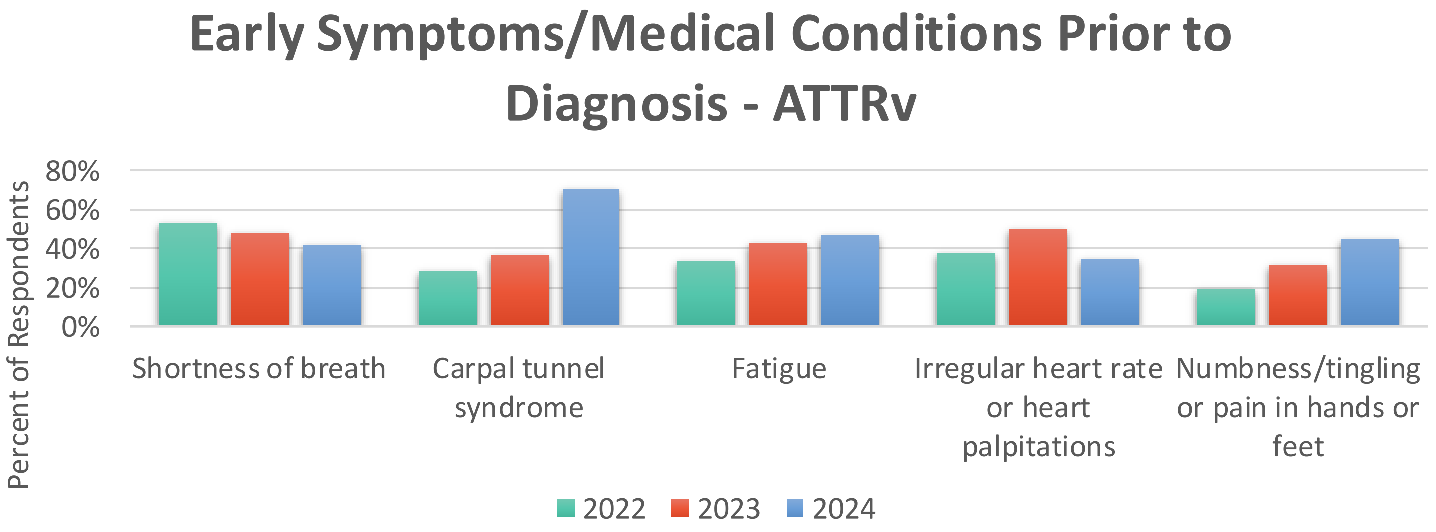


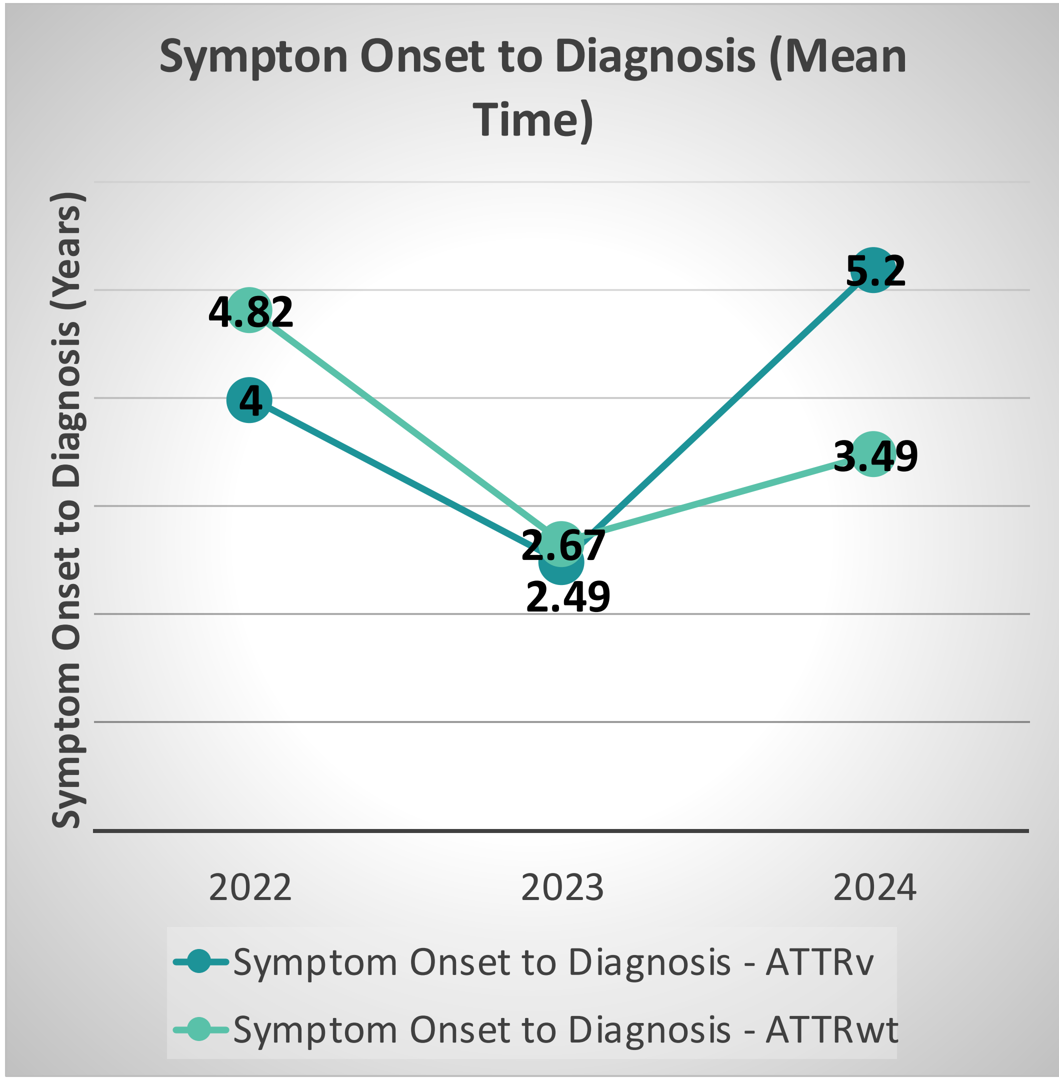




# Pathway to Diagnosis – ATTR Amyloidosis

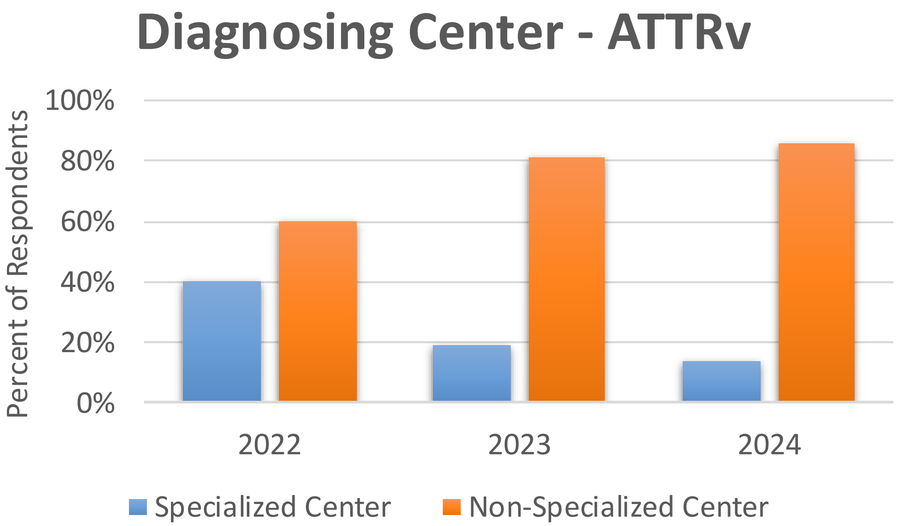


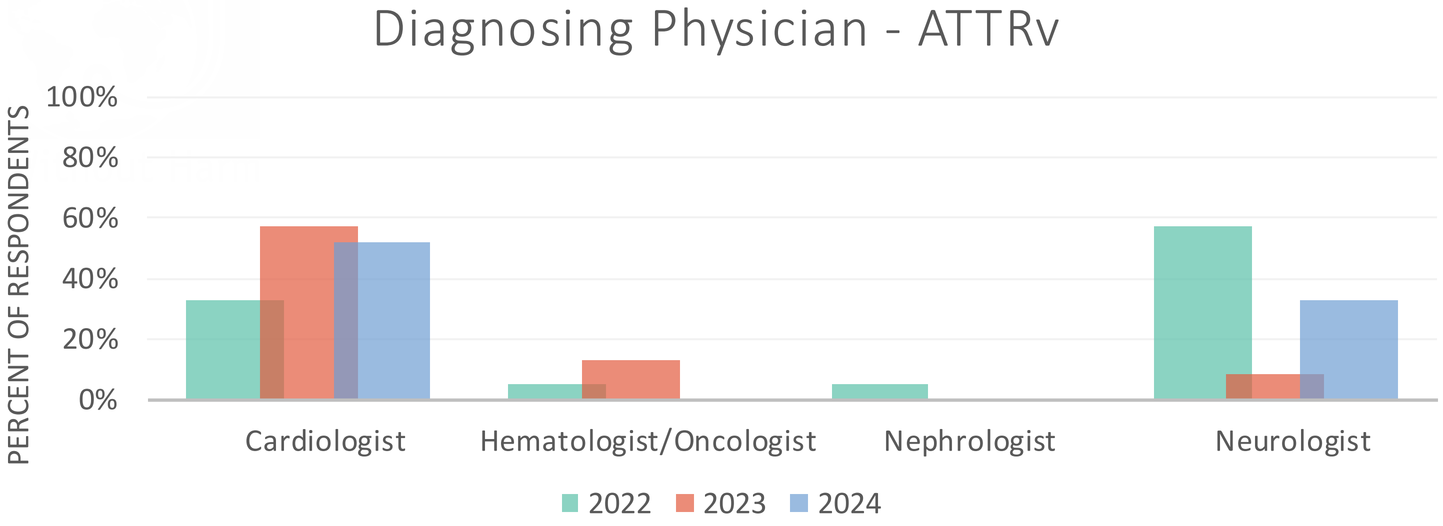


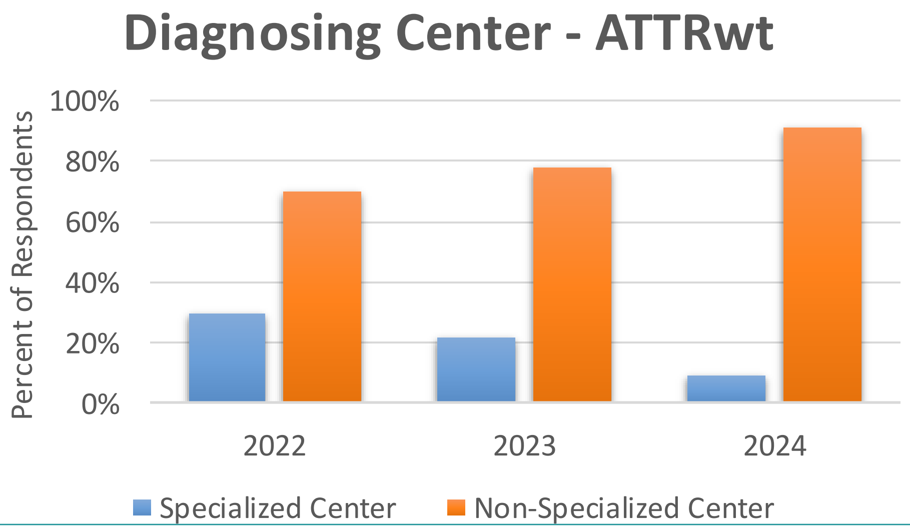


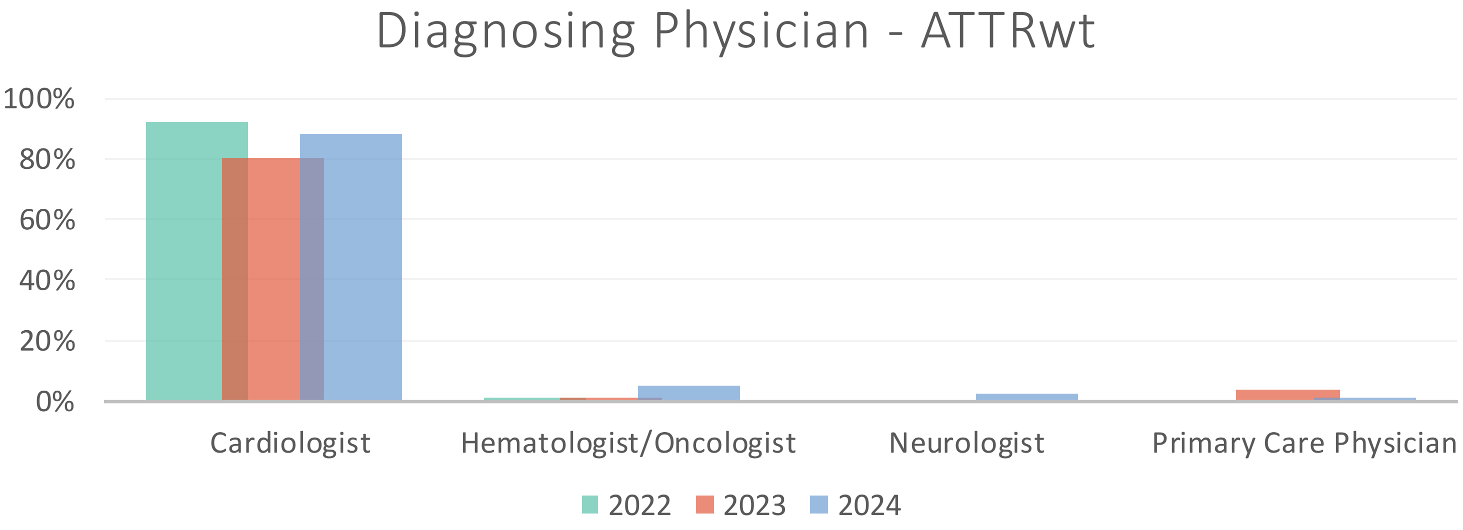
# Pathway to Diagnosis – ATTR Amyloidosis

Amyloidosis Research Consortium









# Health Snapshot – ATTR Amyloidosis

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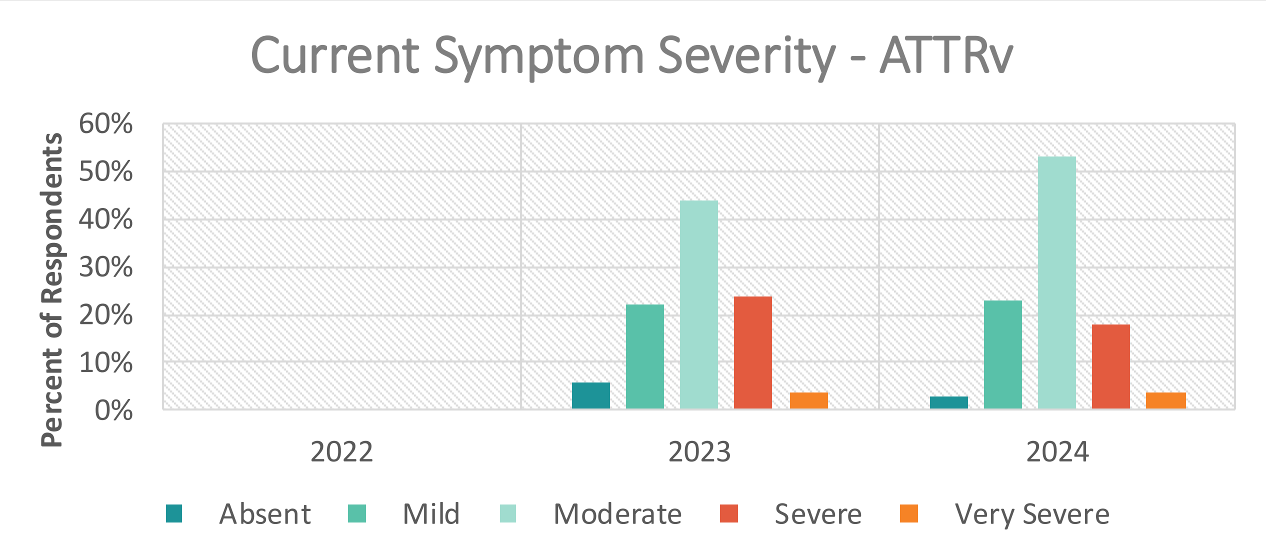

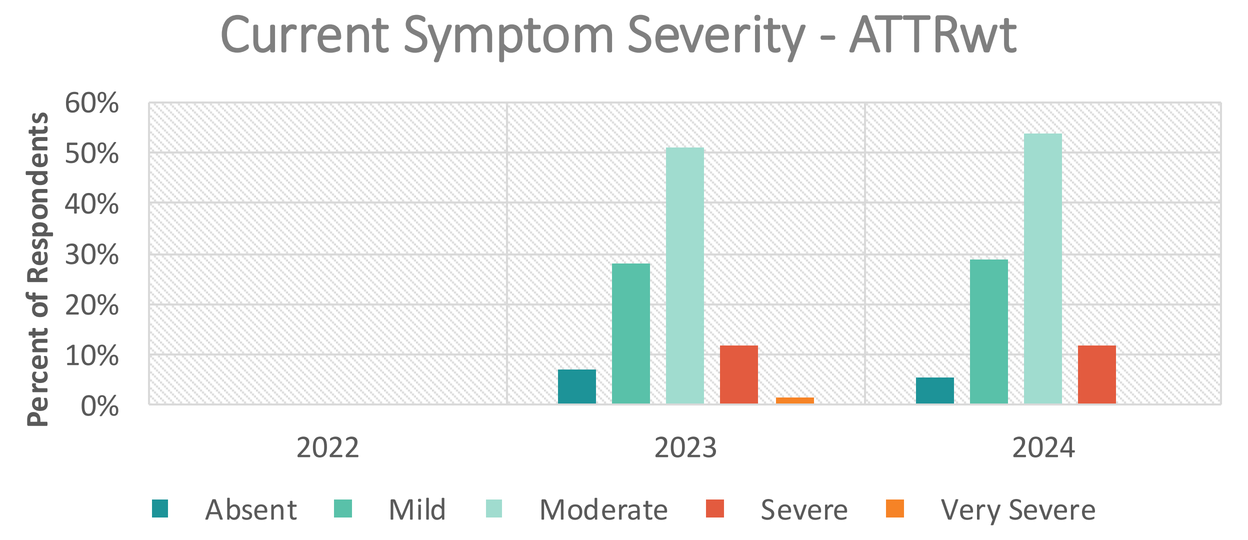

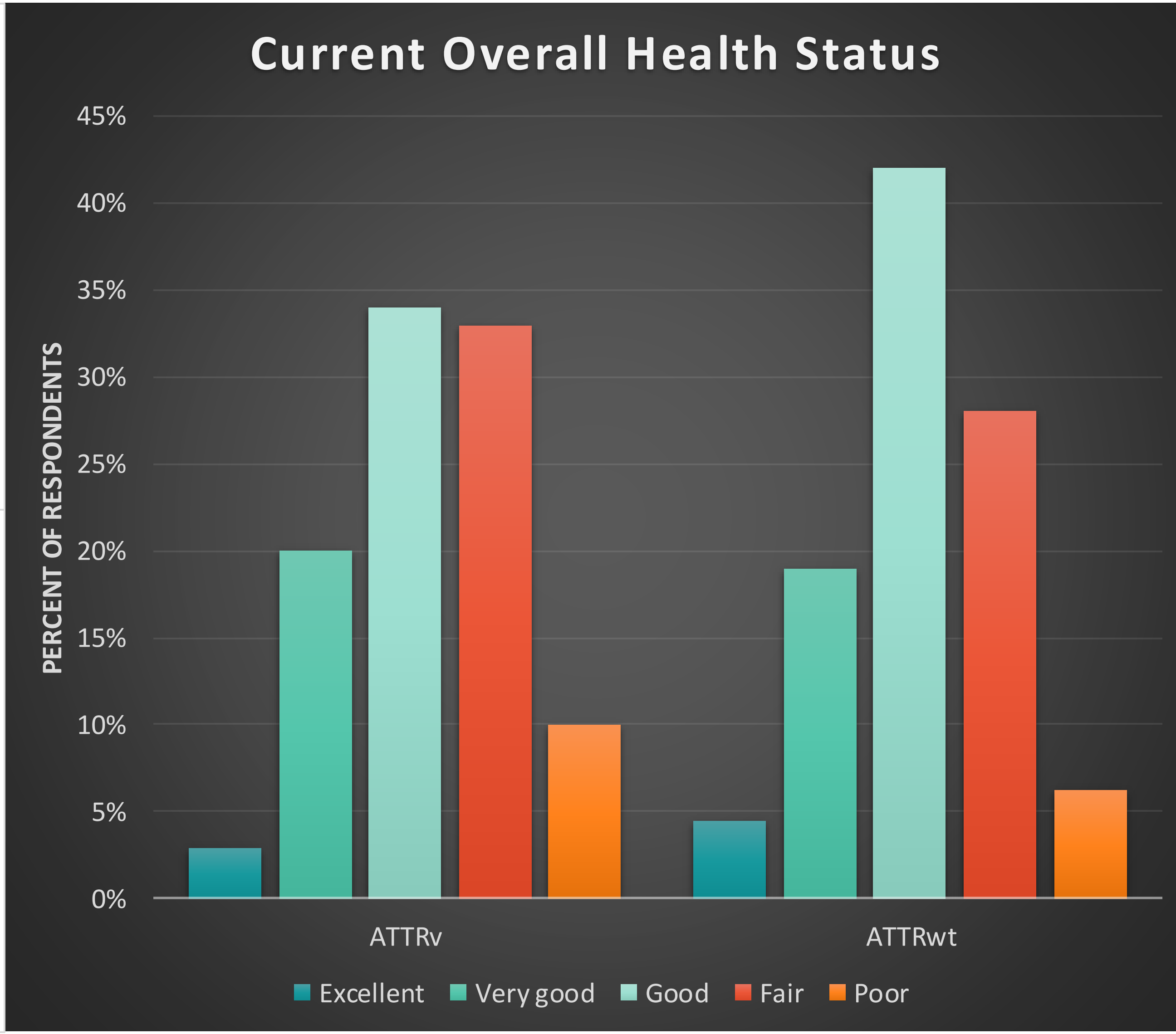

# How Patients Feel About Their Treatment

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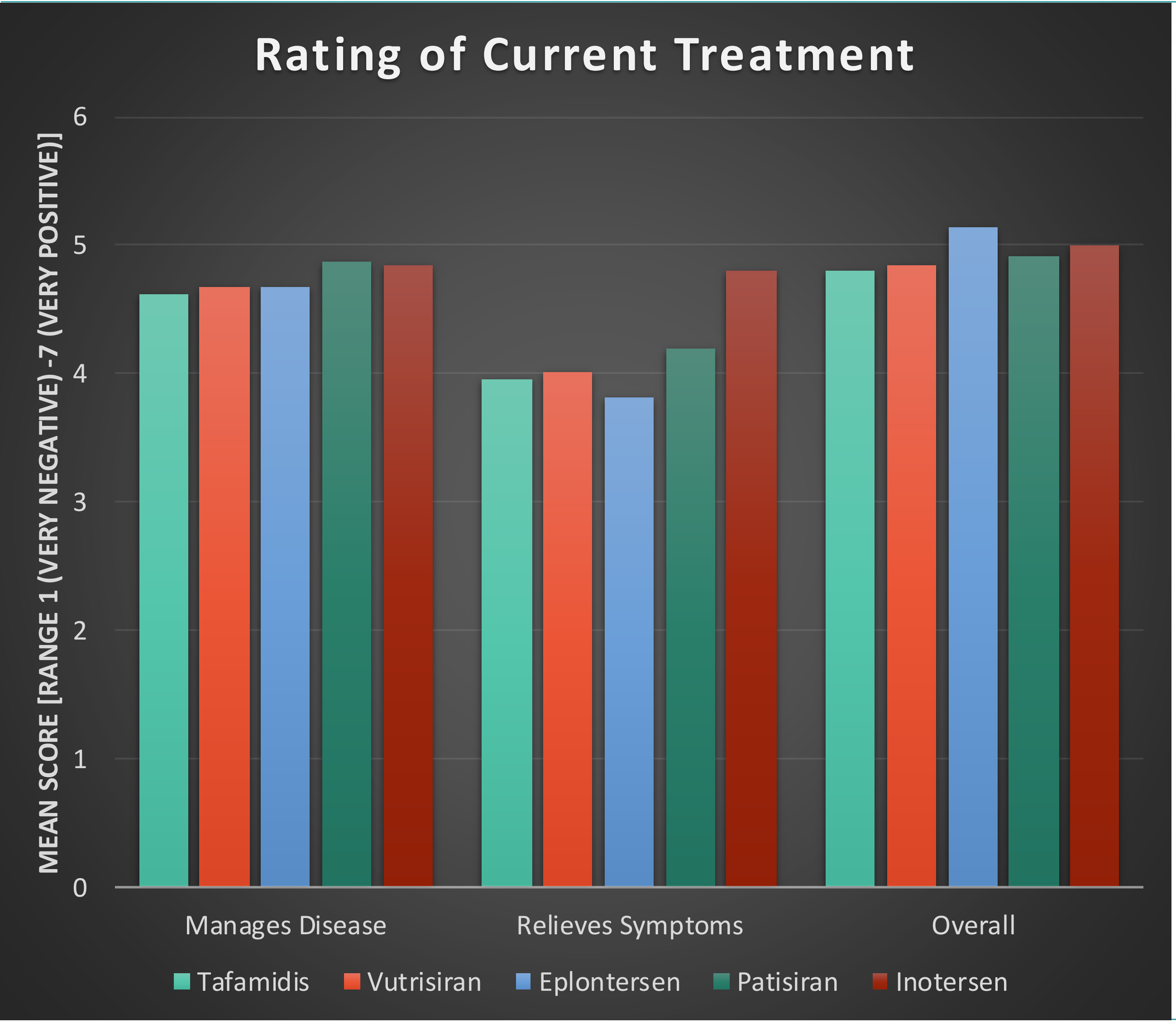

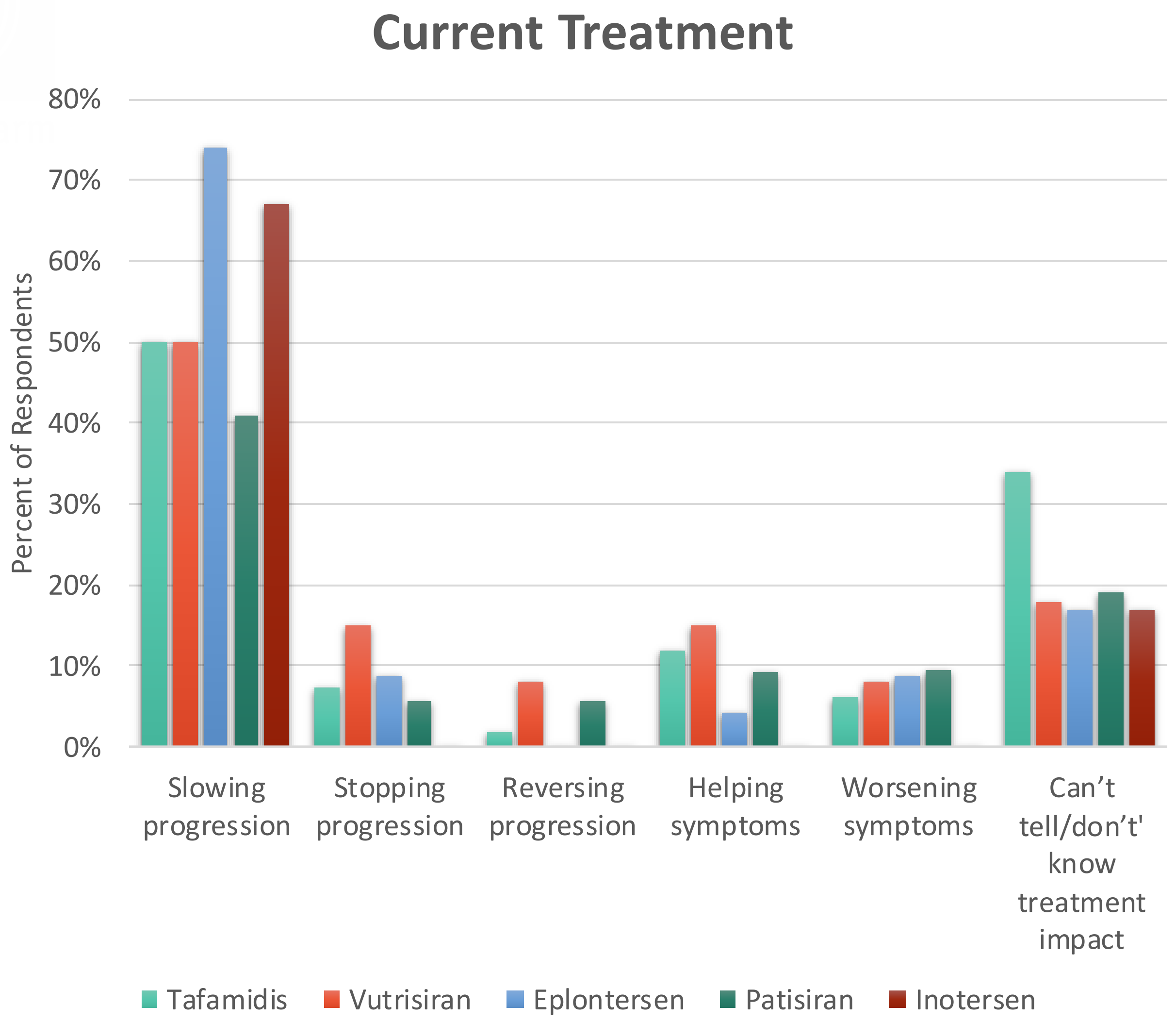

# Goals That Matter: ATTRv Patient Perspective

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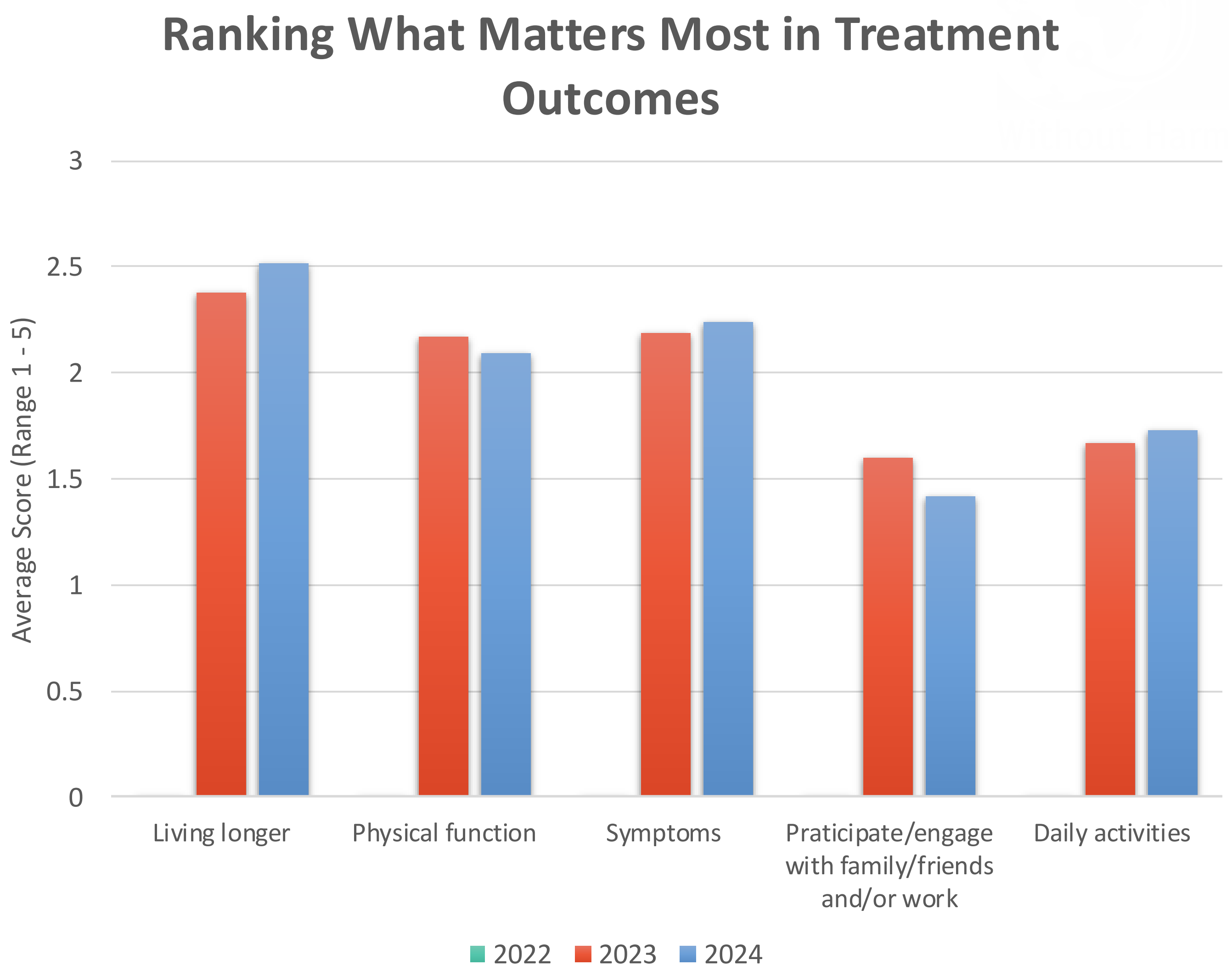

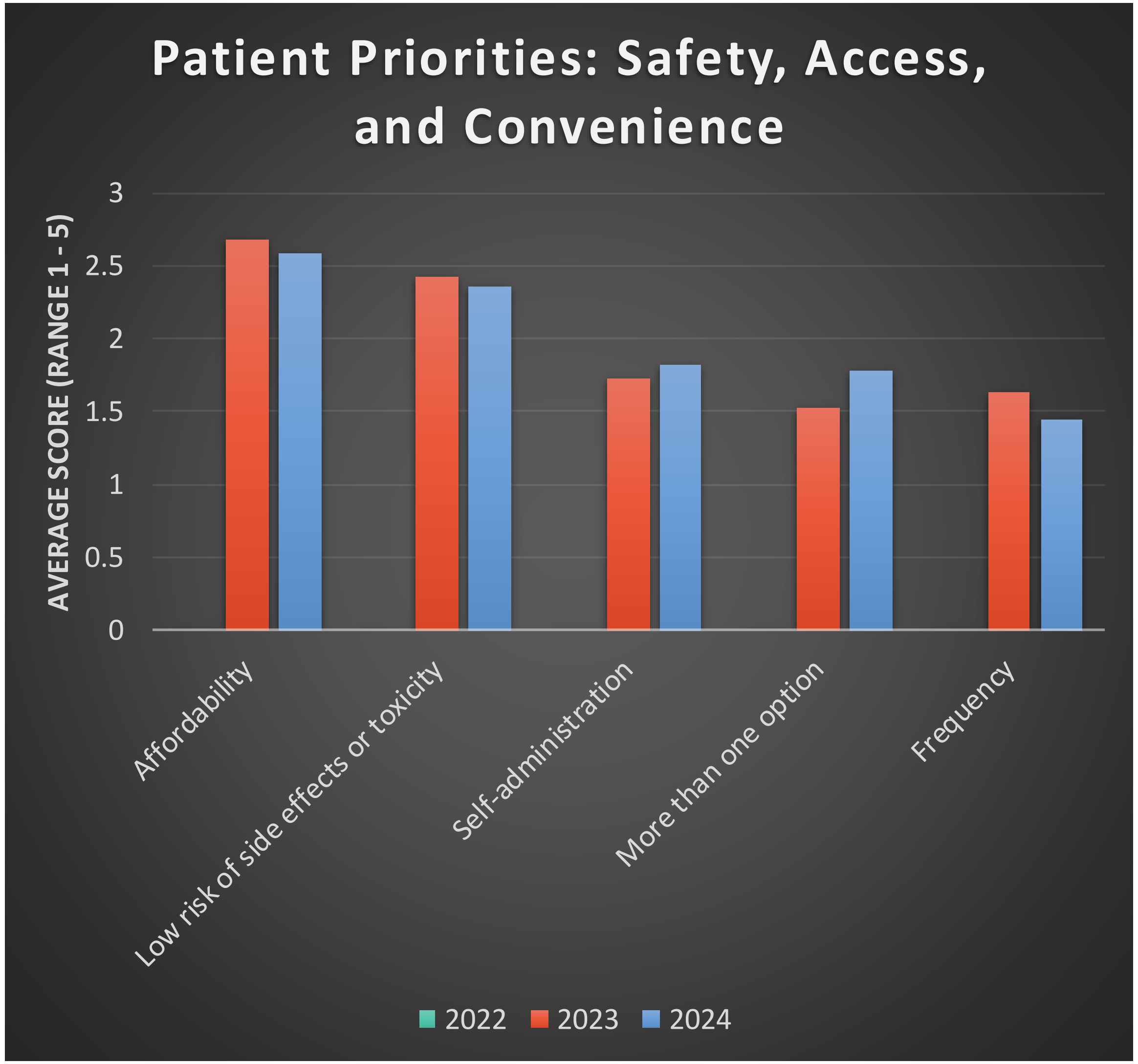

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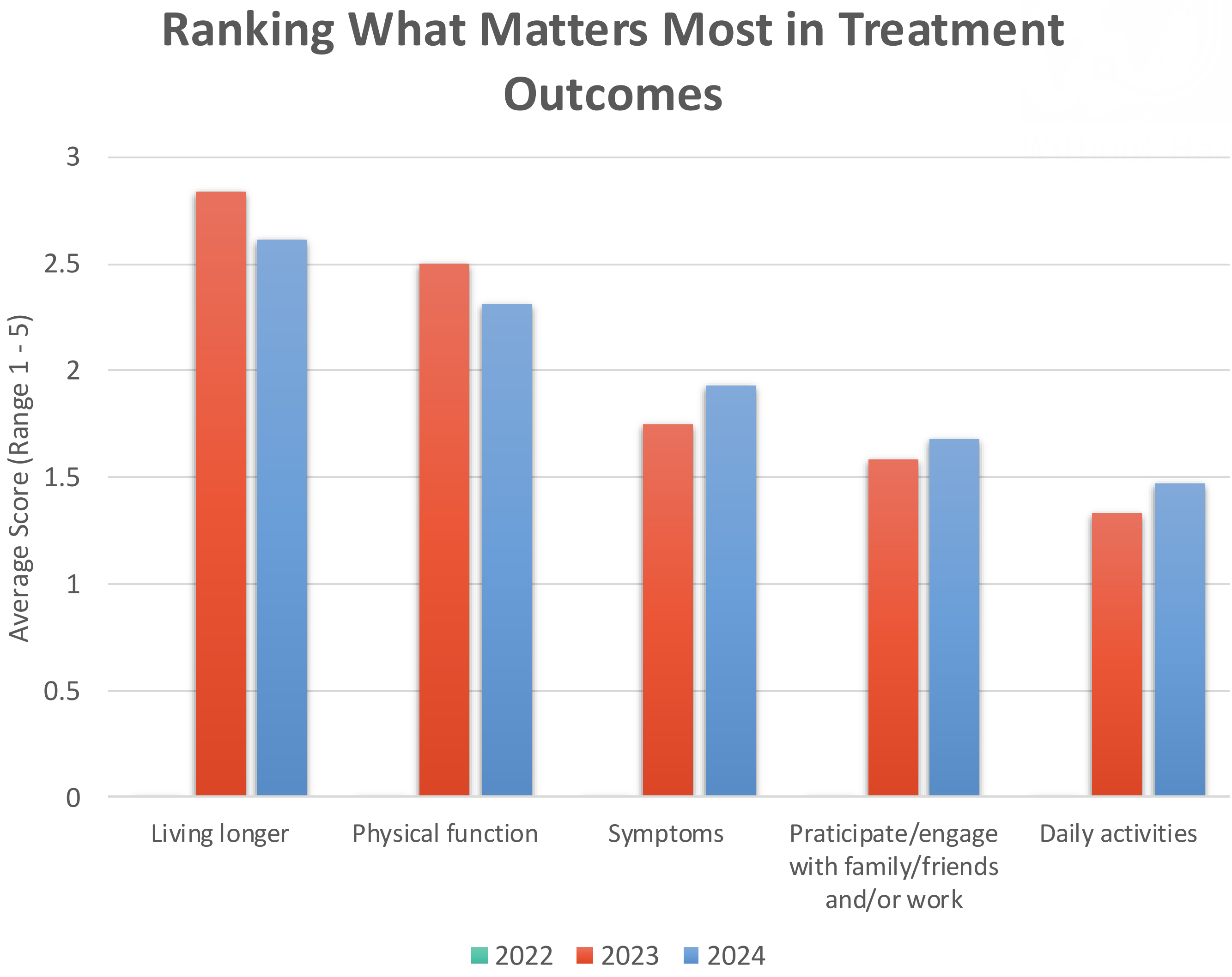

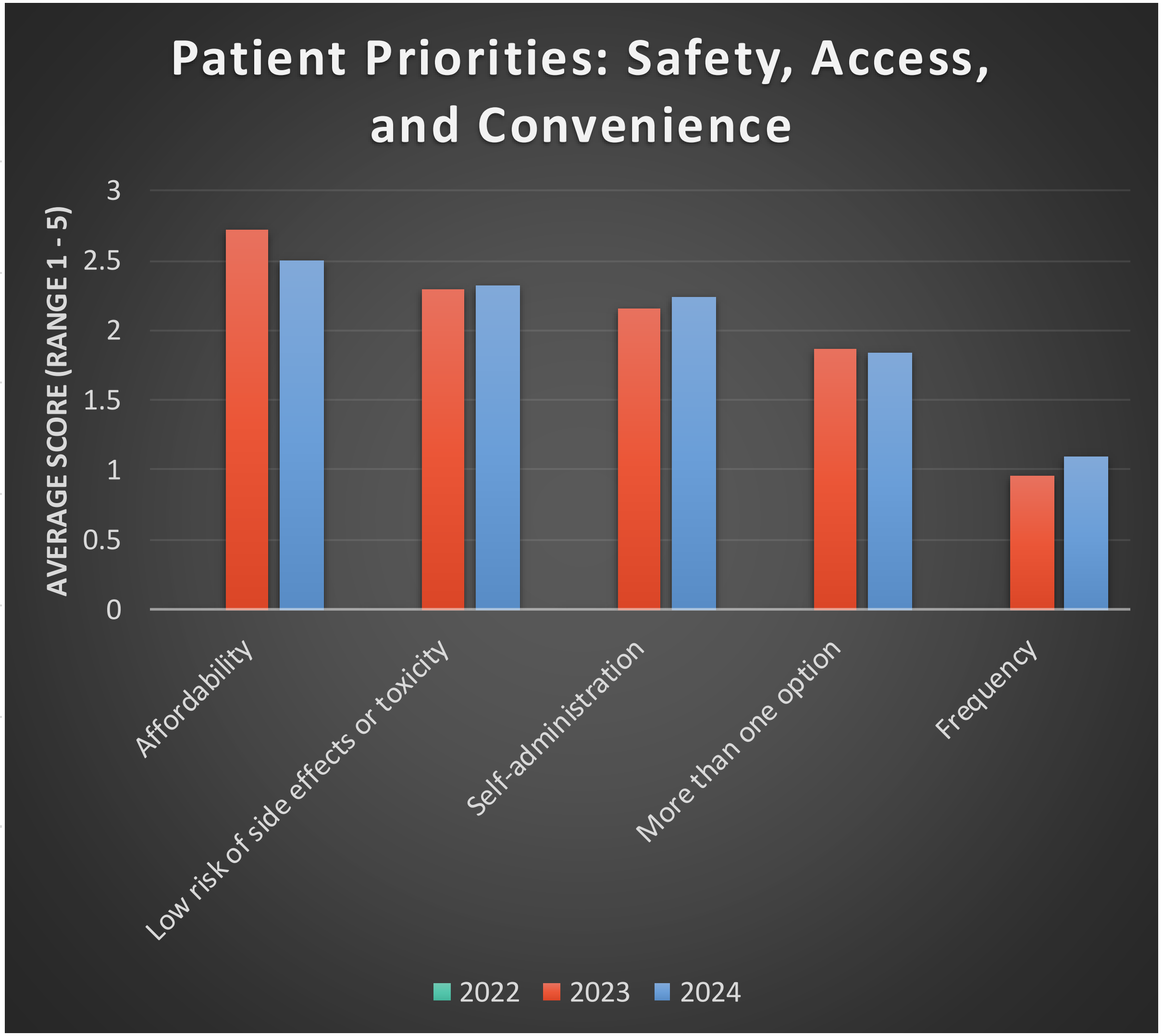

# Patient Feedback on Ongoing Care

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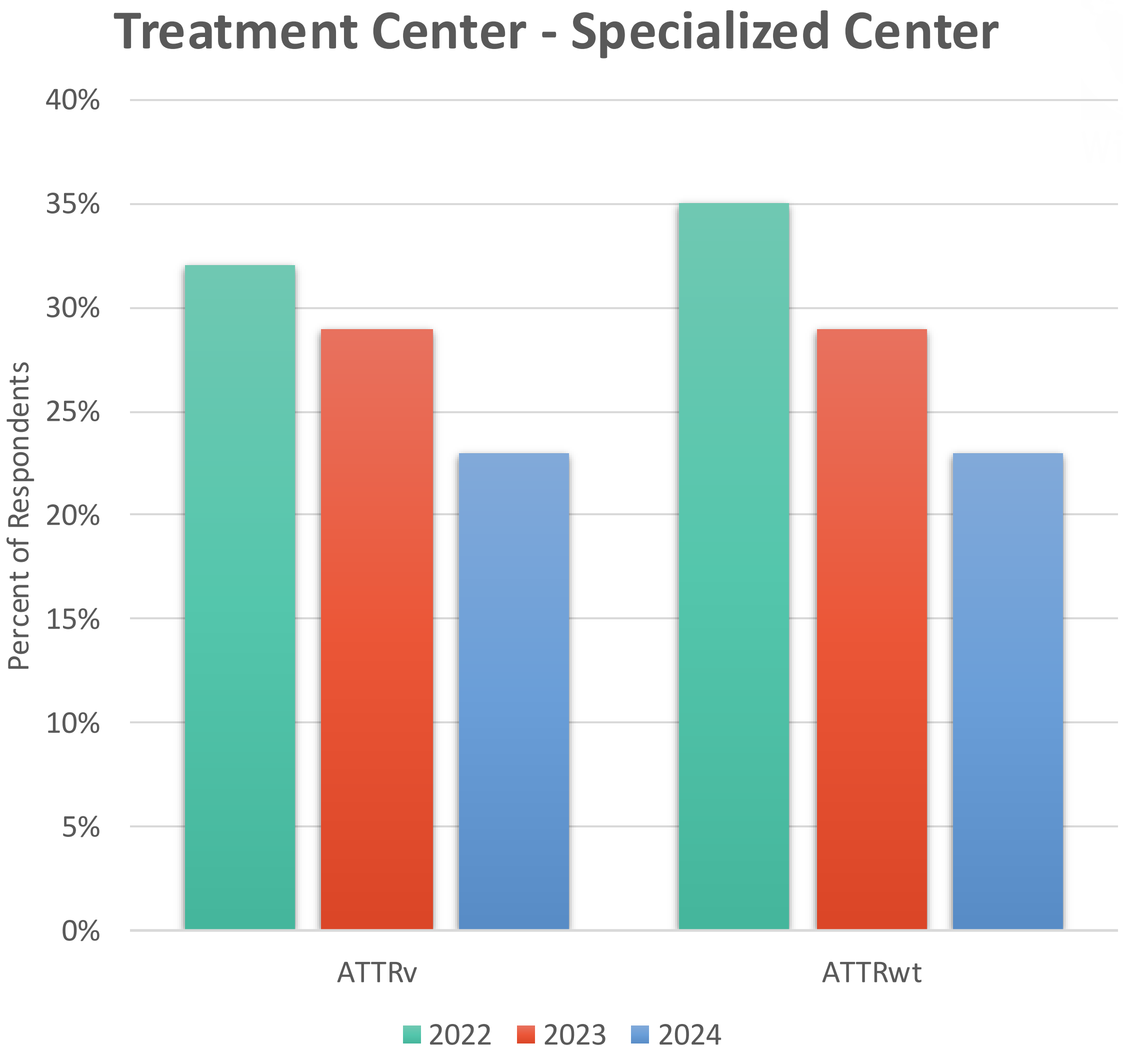
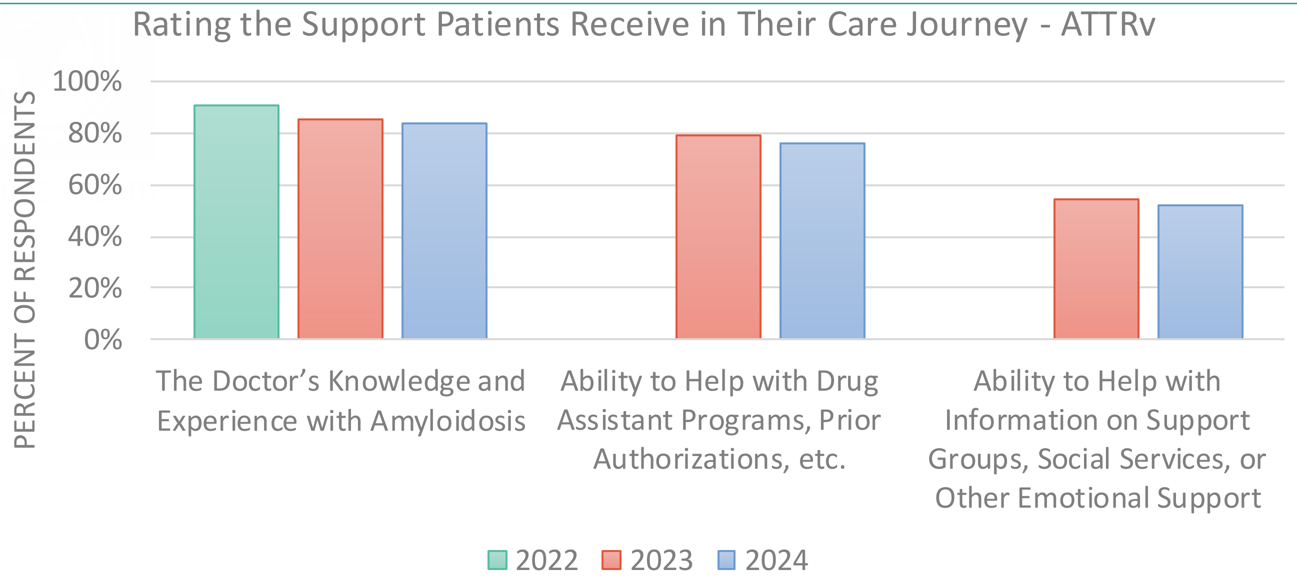
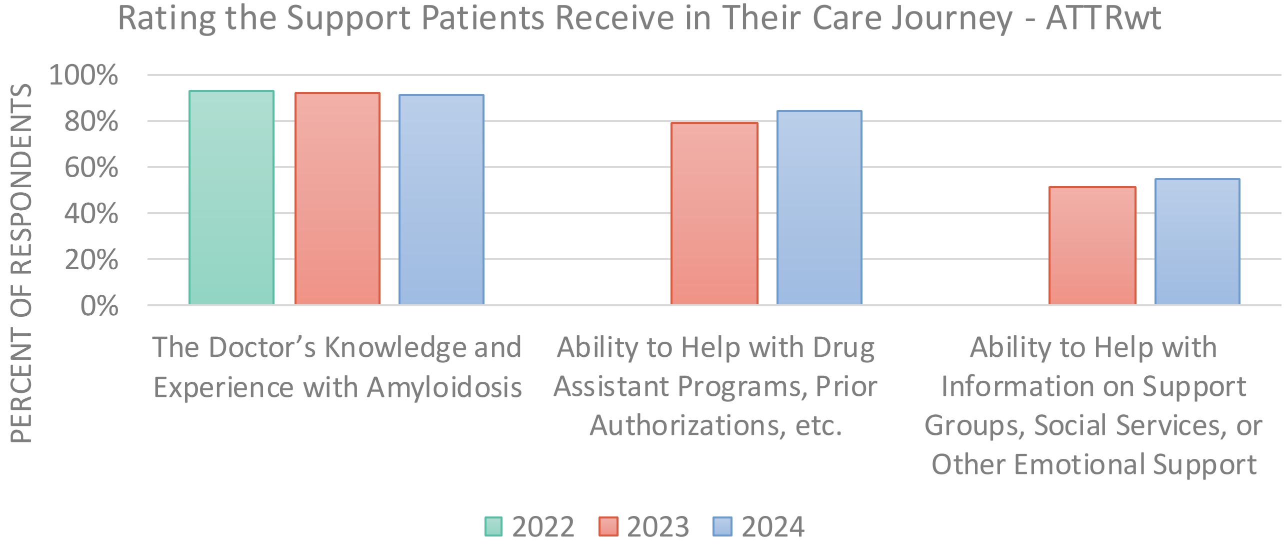
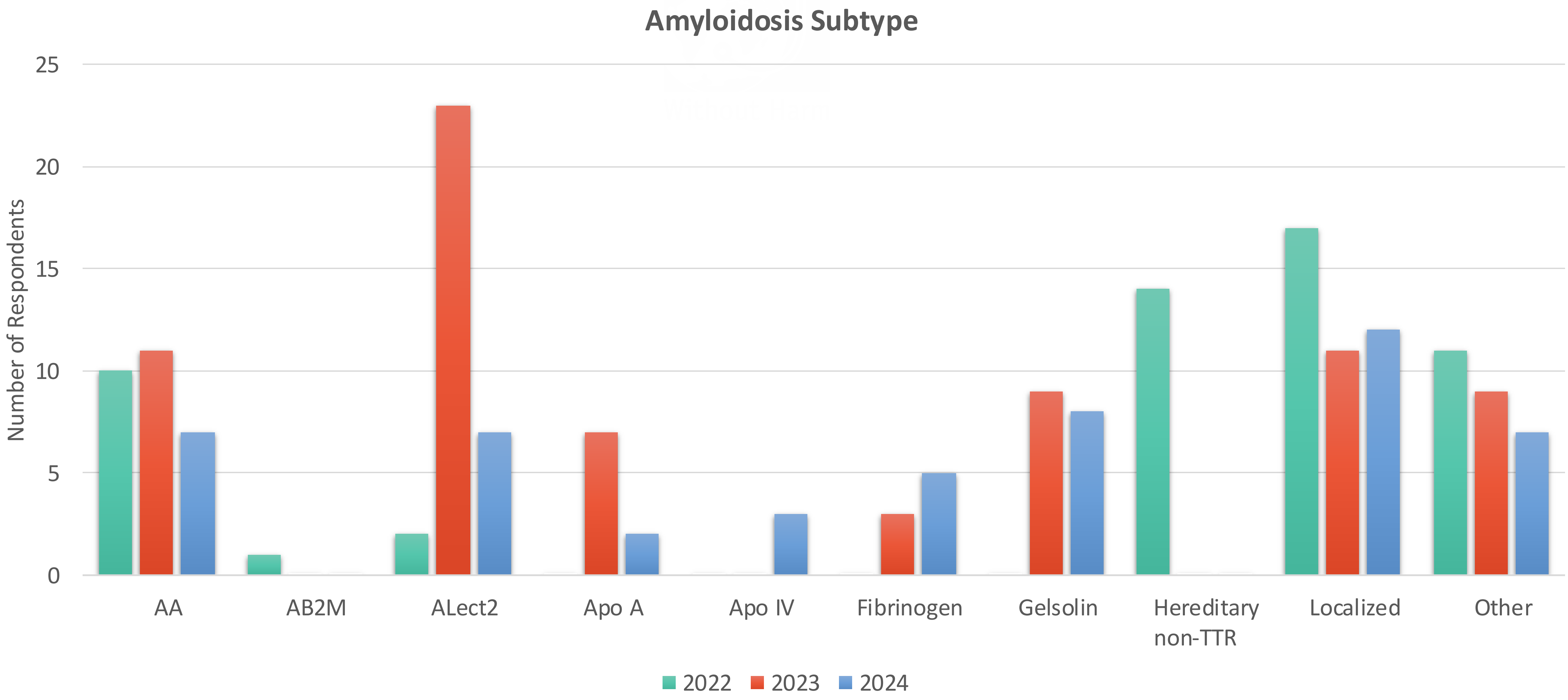




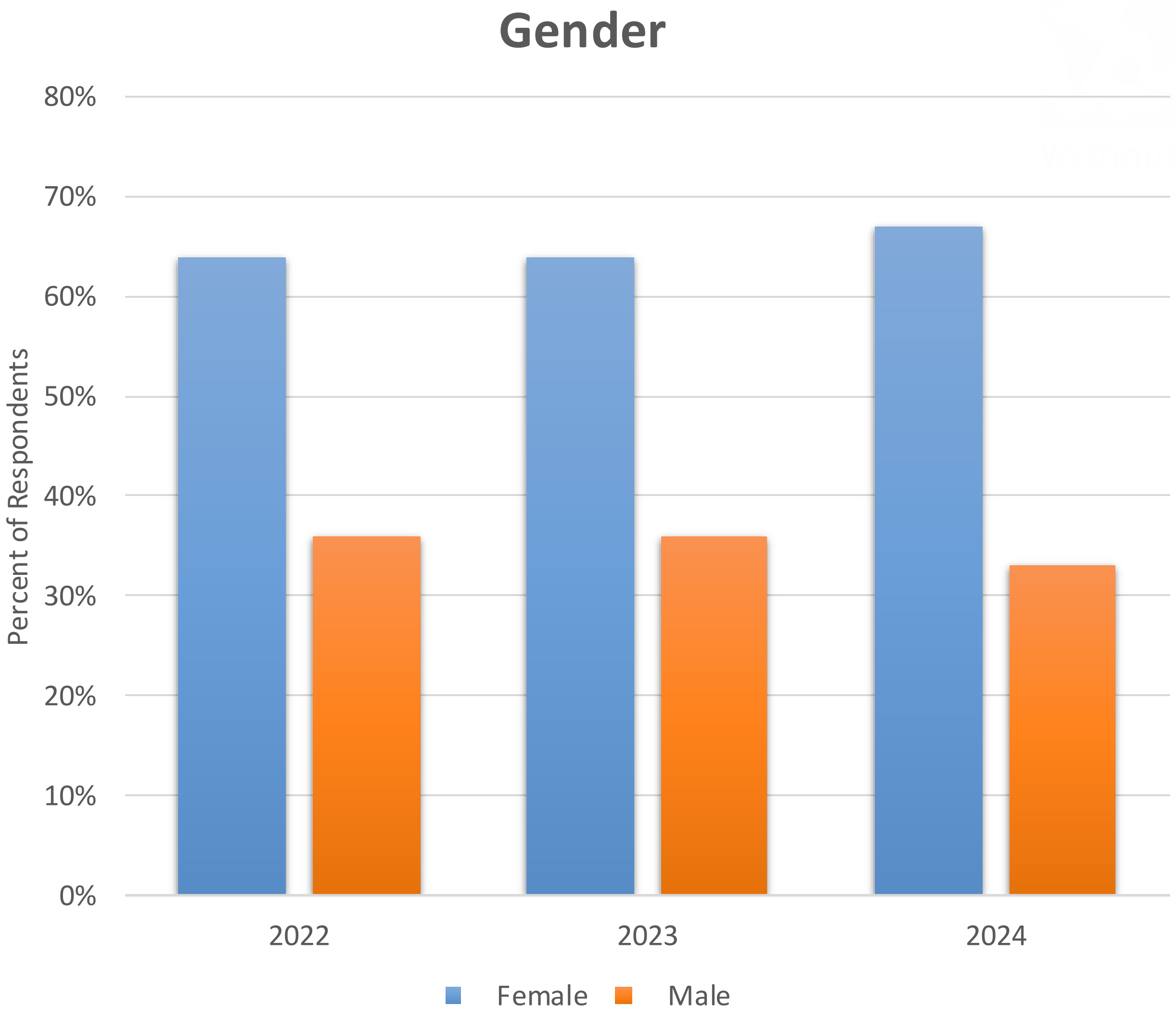


# Other Types of Amyloidosis

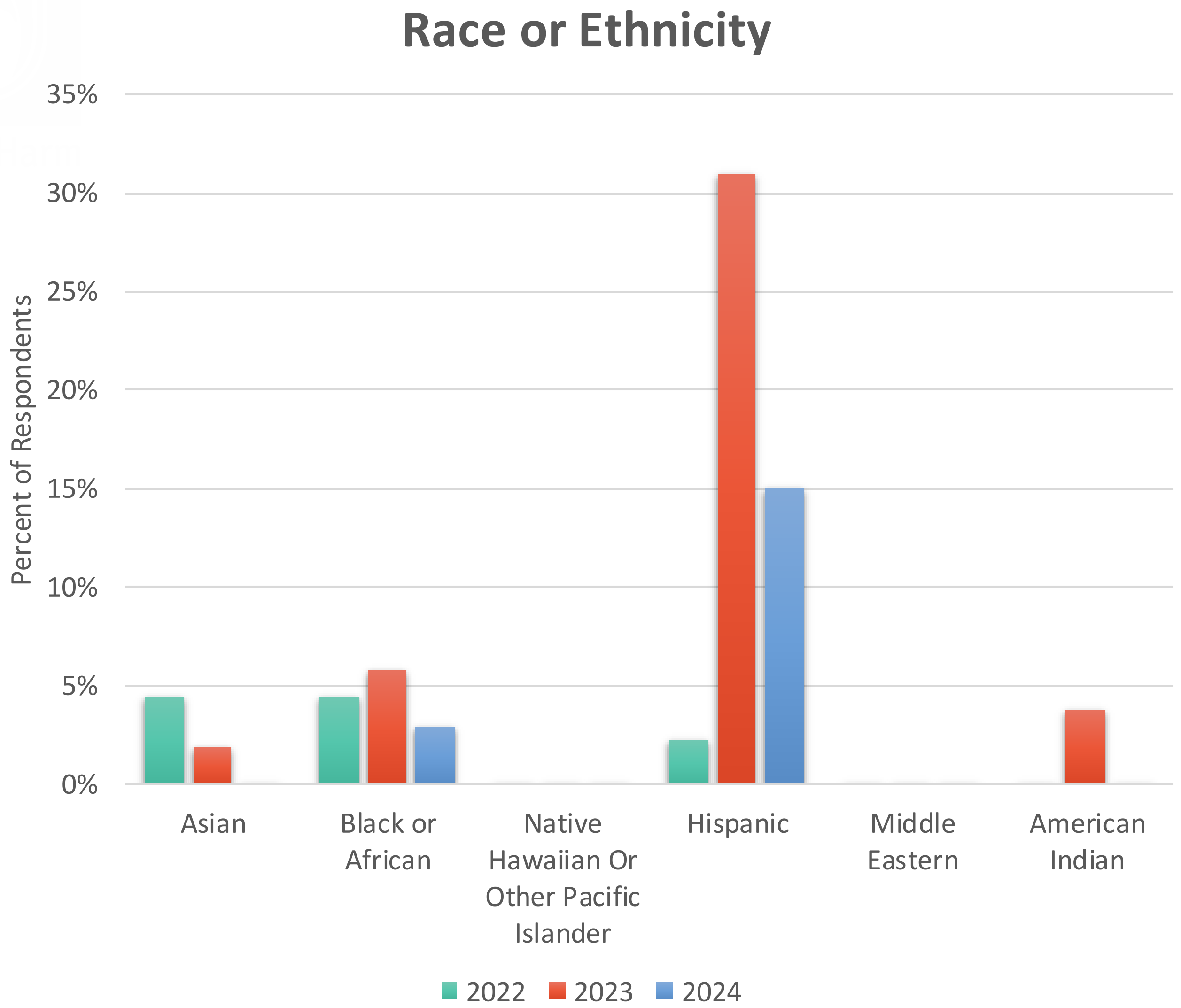
# Other Amyloidosis Subtypes



# Demographics – Other Amyloidosis Subtypes

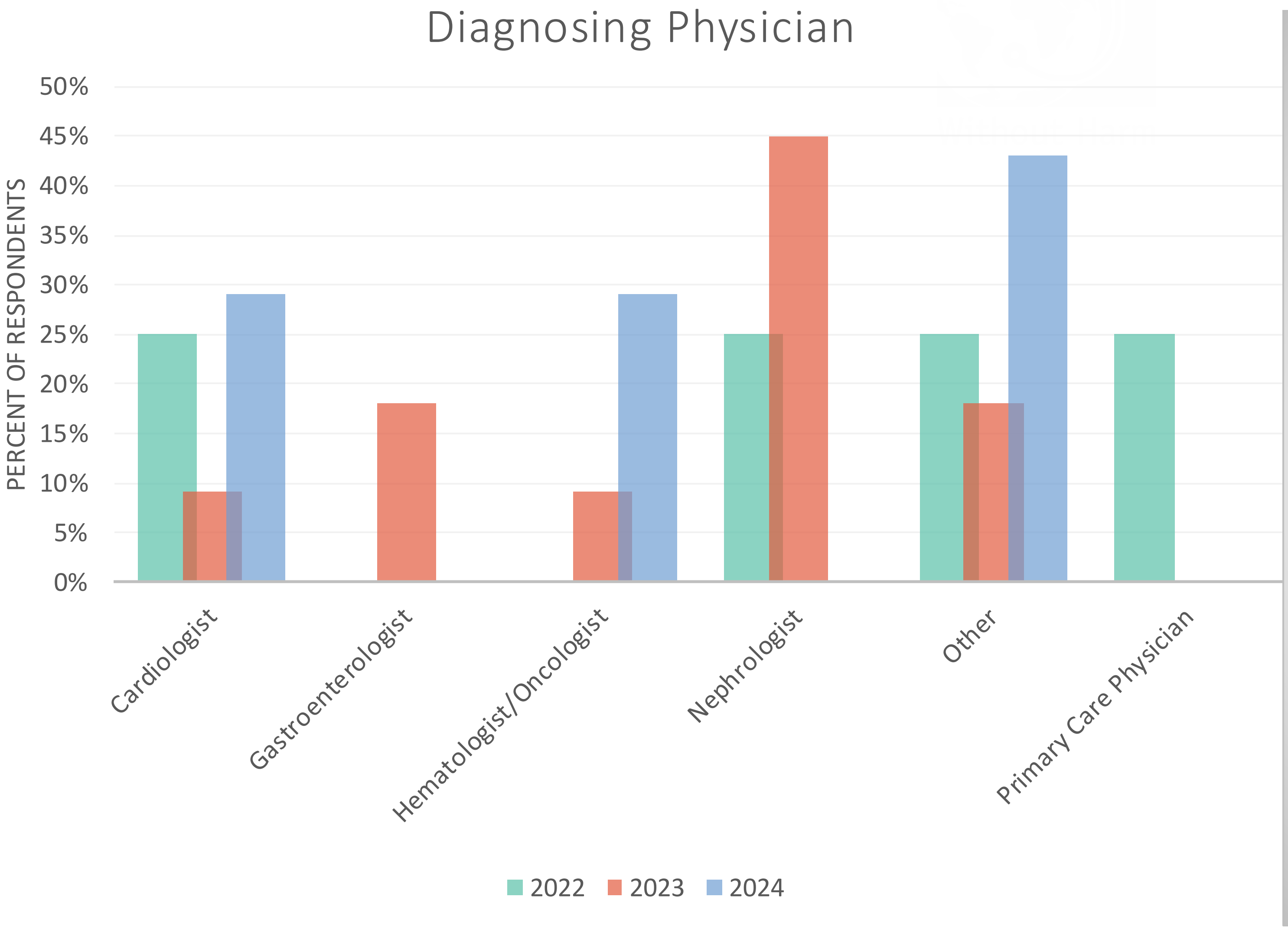


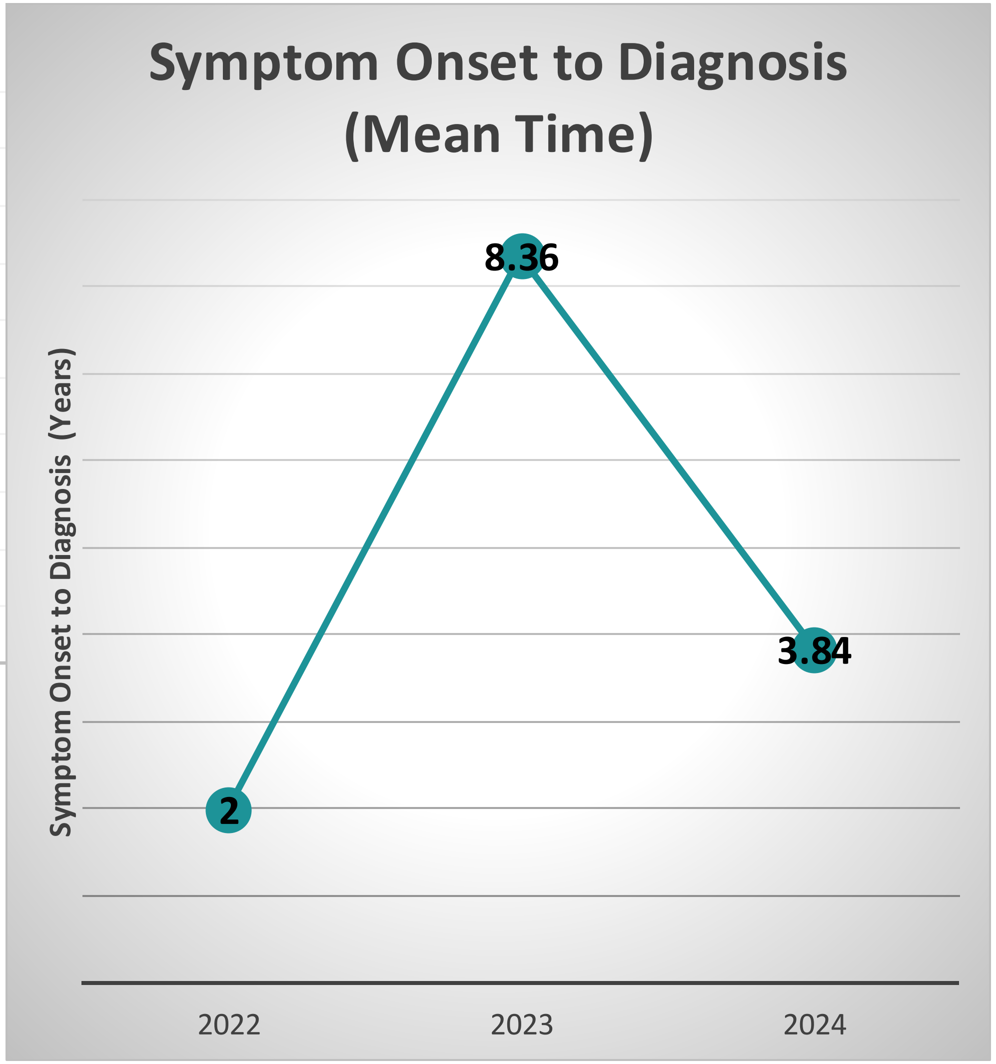
Gender



Race or Ethnicity

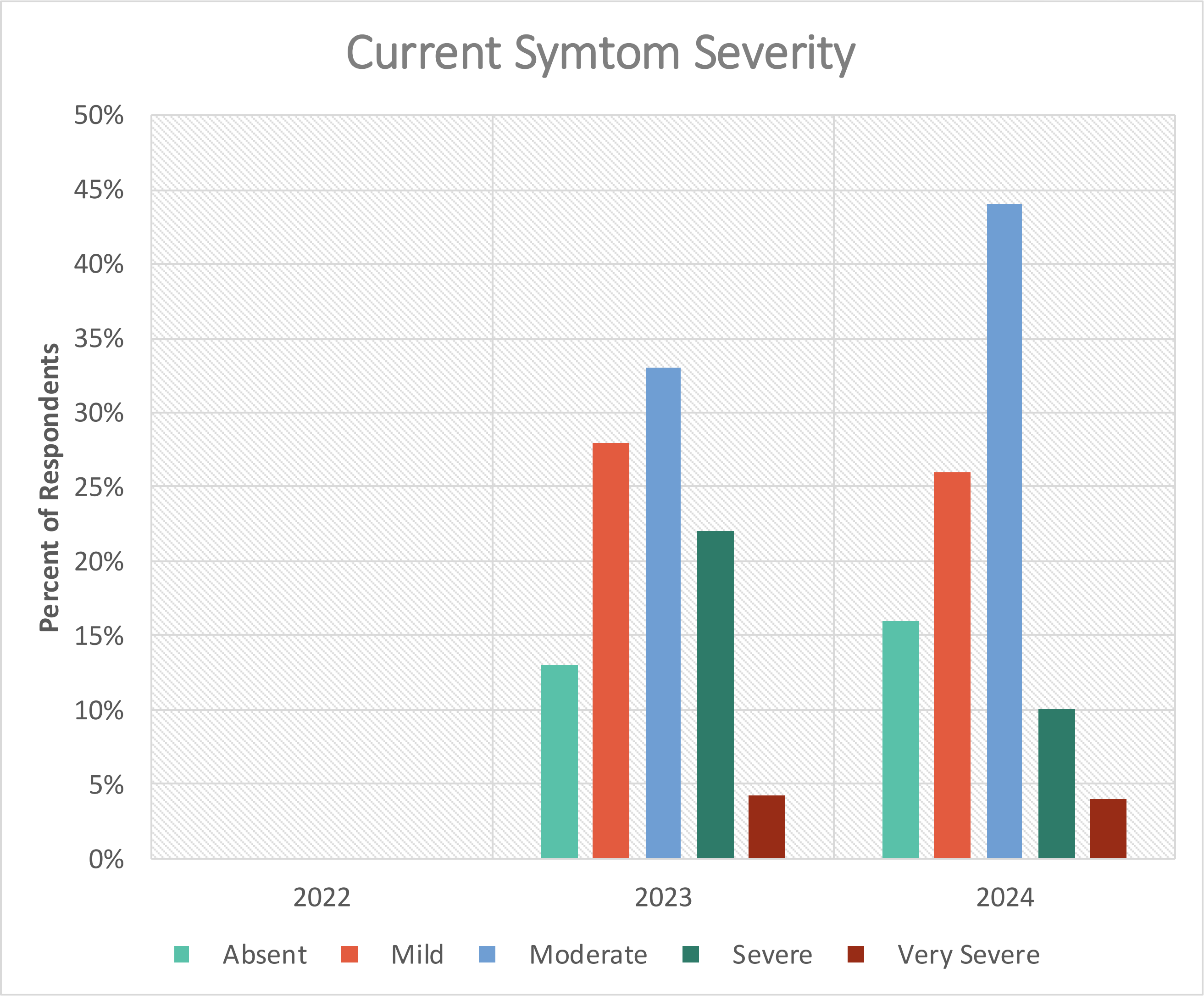
# Pathway to Diagnosis

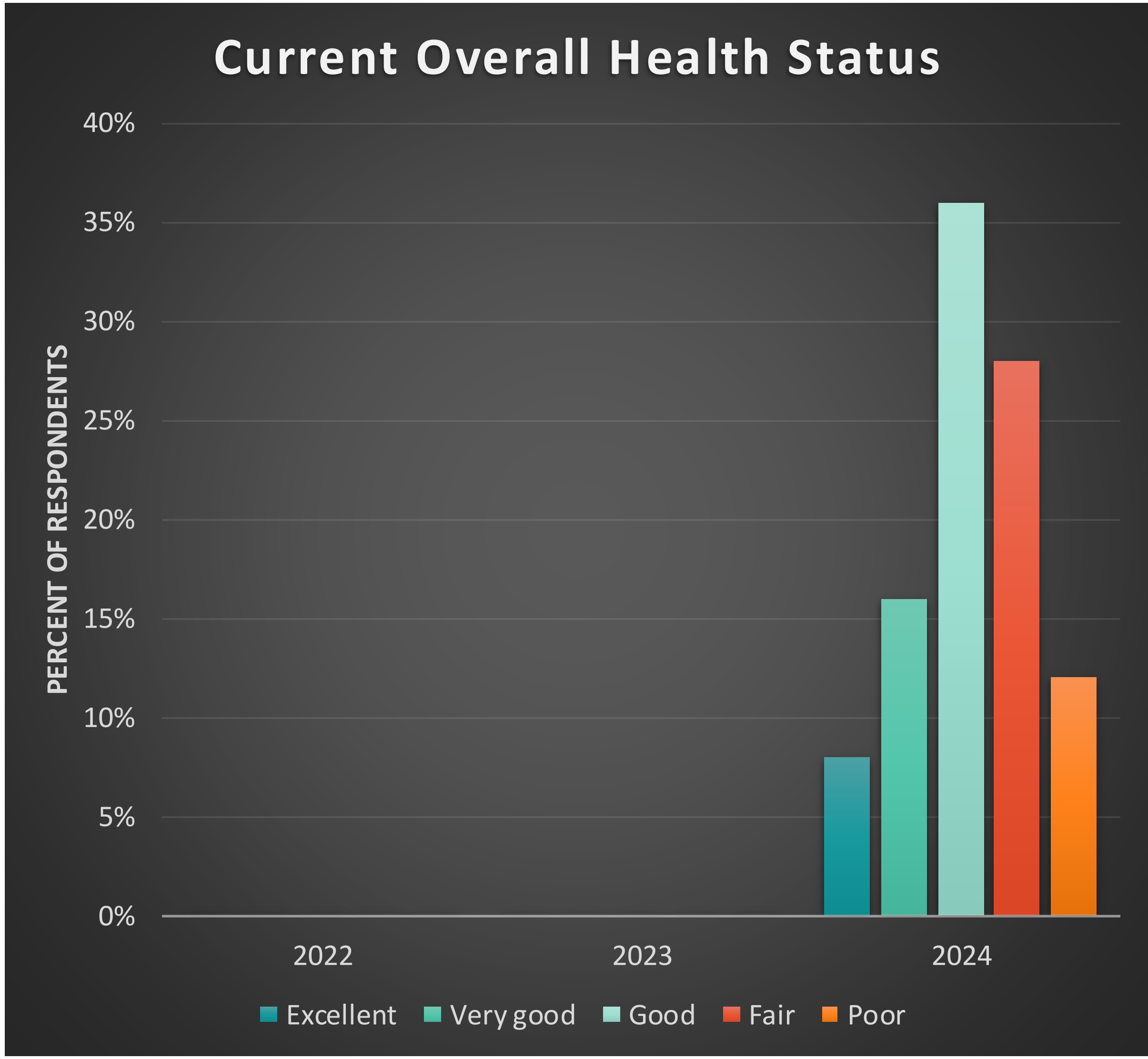




# Health Snapshot

Amyloidosis Research Consortium





# Patient Feedback on Ongoing Care

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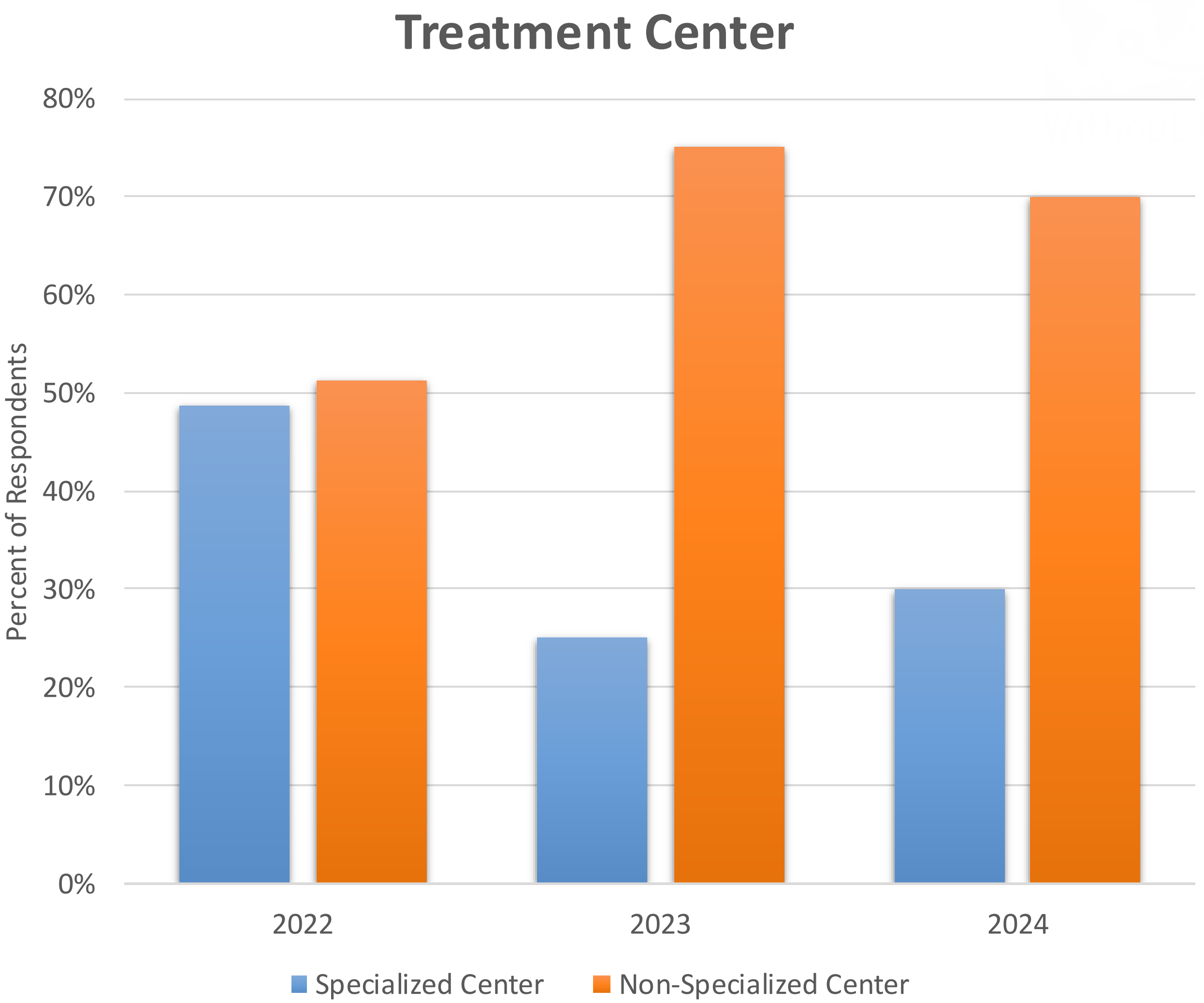

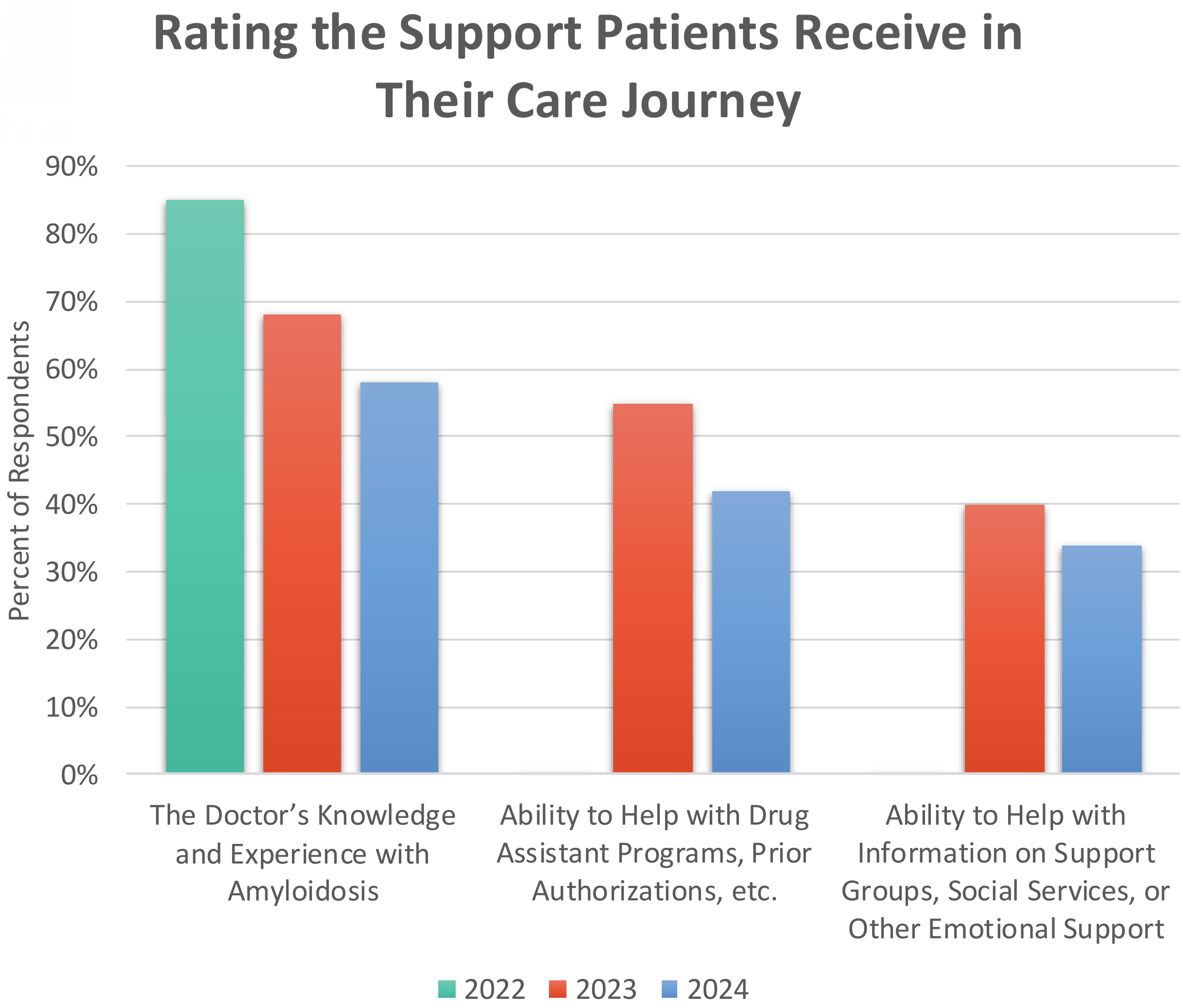

# What Caregivers Told Us

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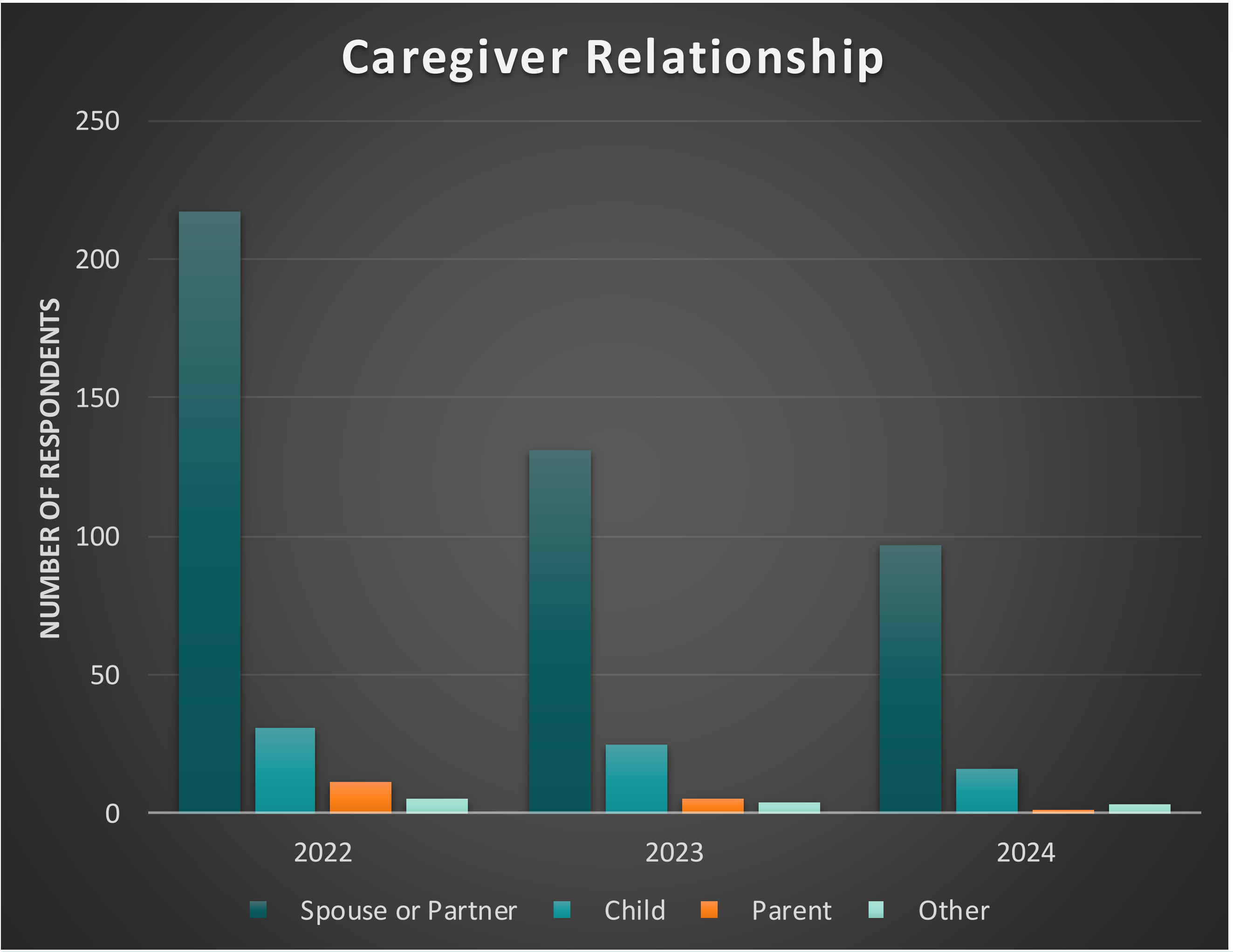
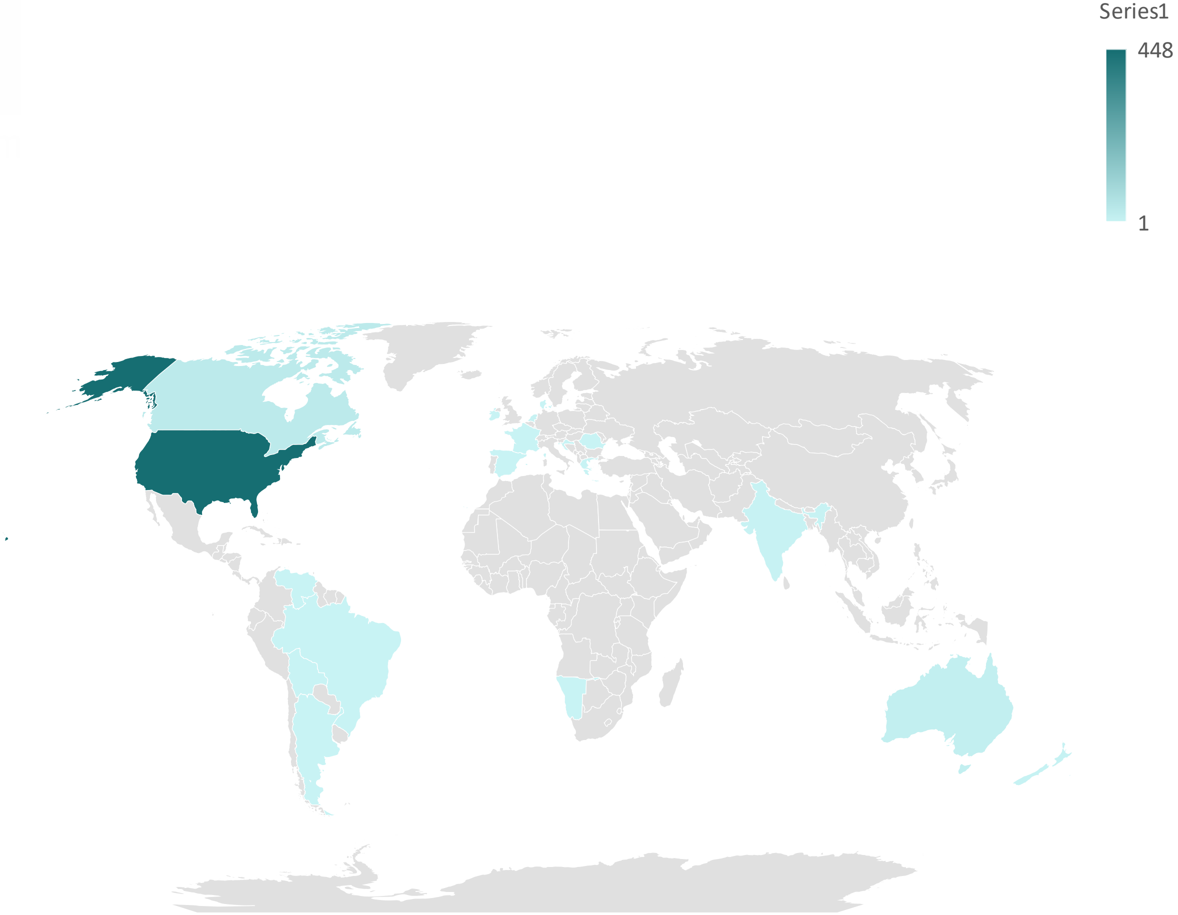
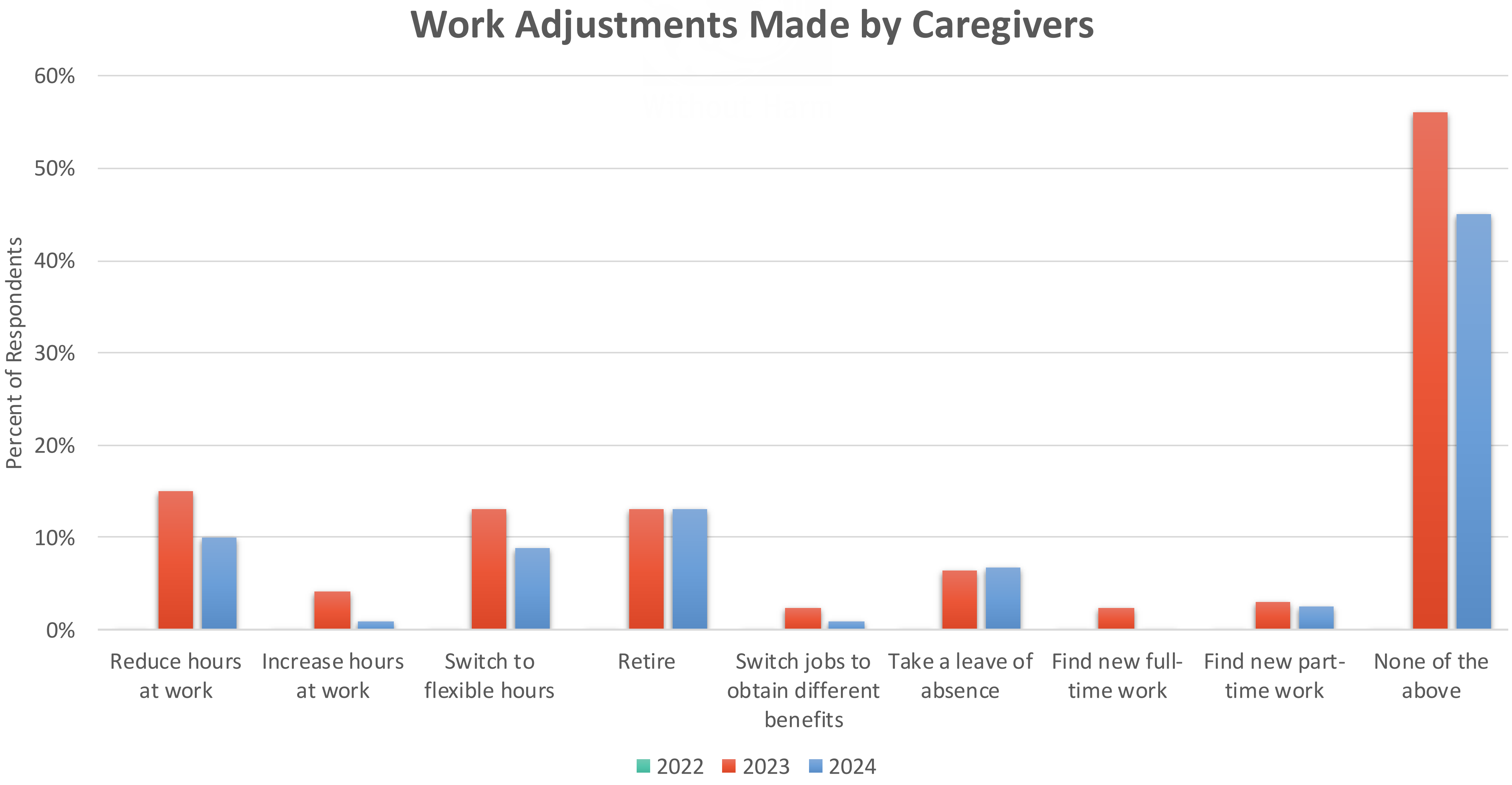
## Who took the survey?





# Balancing Work and Care: The Role of Family Caregivers in Amyloidosis

Amyloidosis Research Consortium



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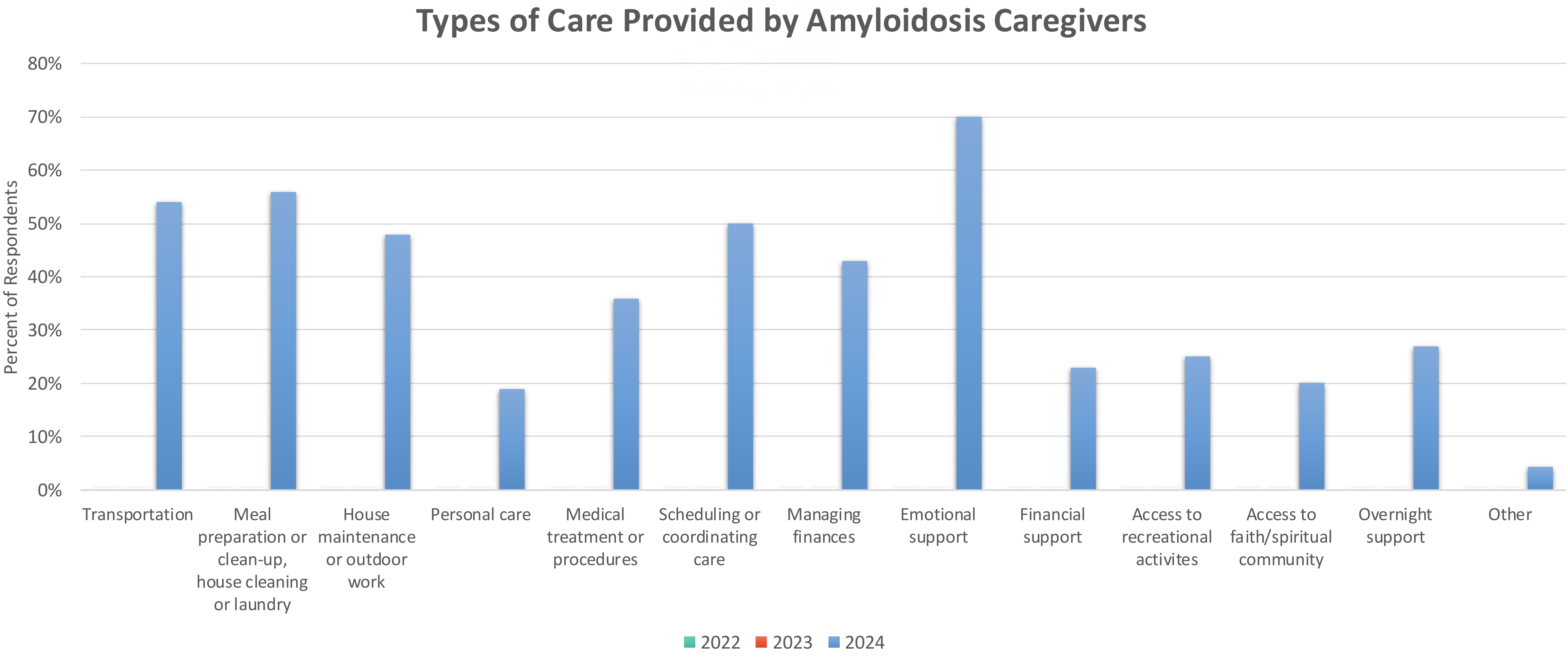

# Caring Under Pressure: The Emotional Impact on Amyloidosis Caregivers

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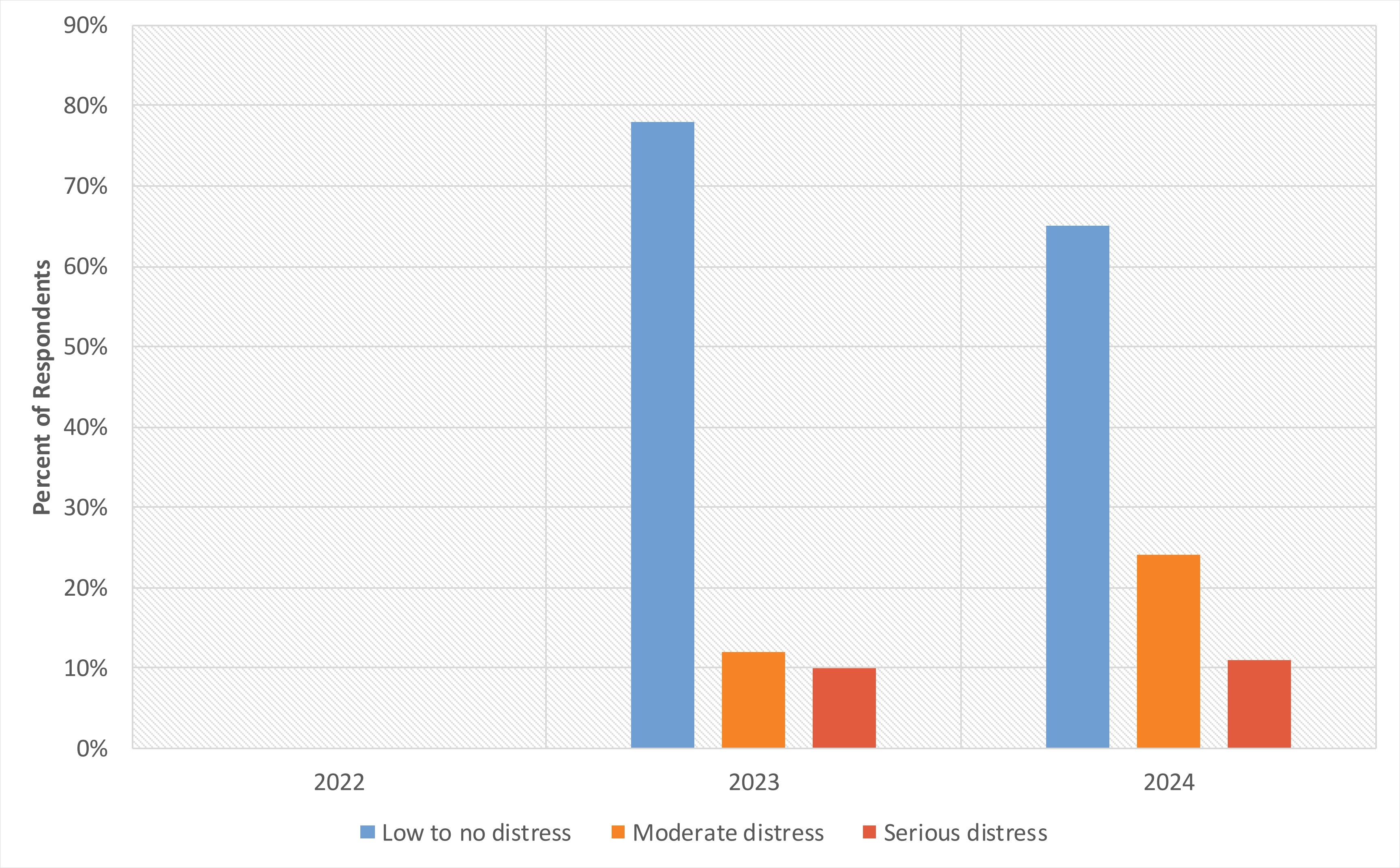
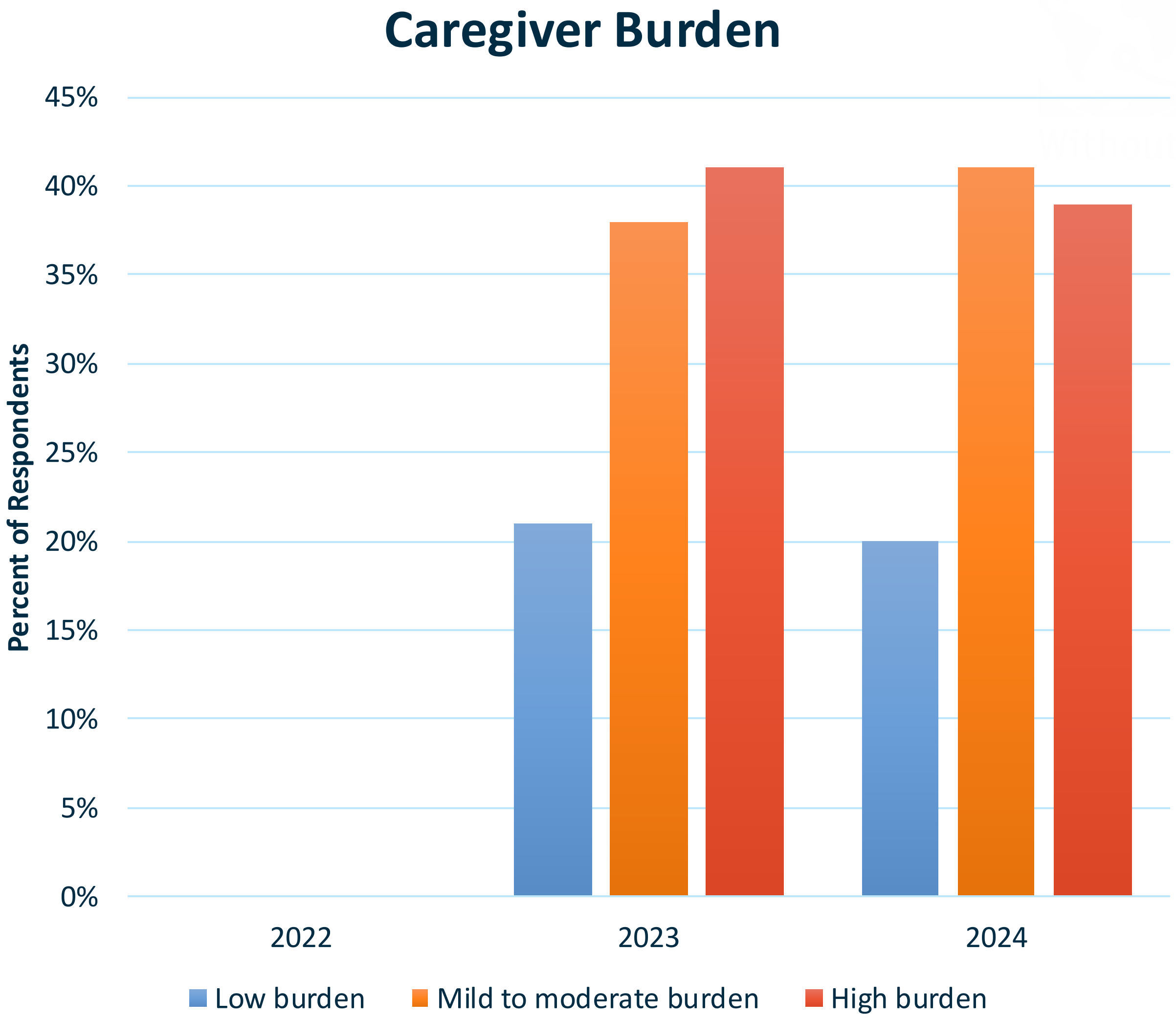
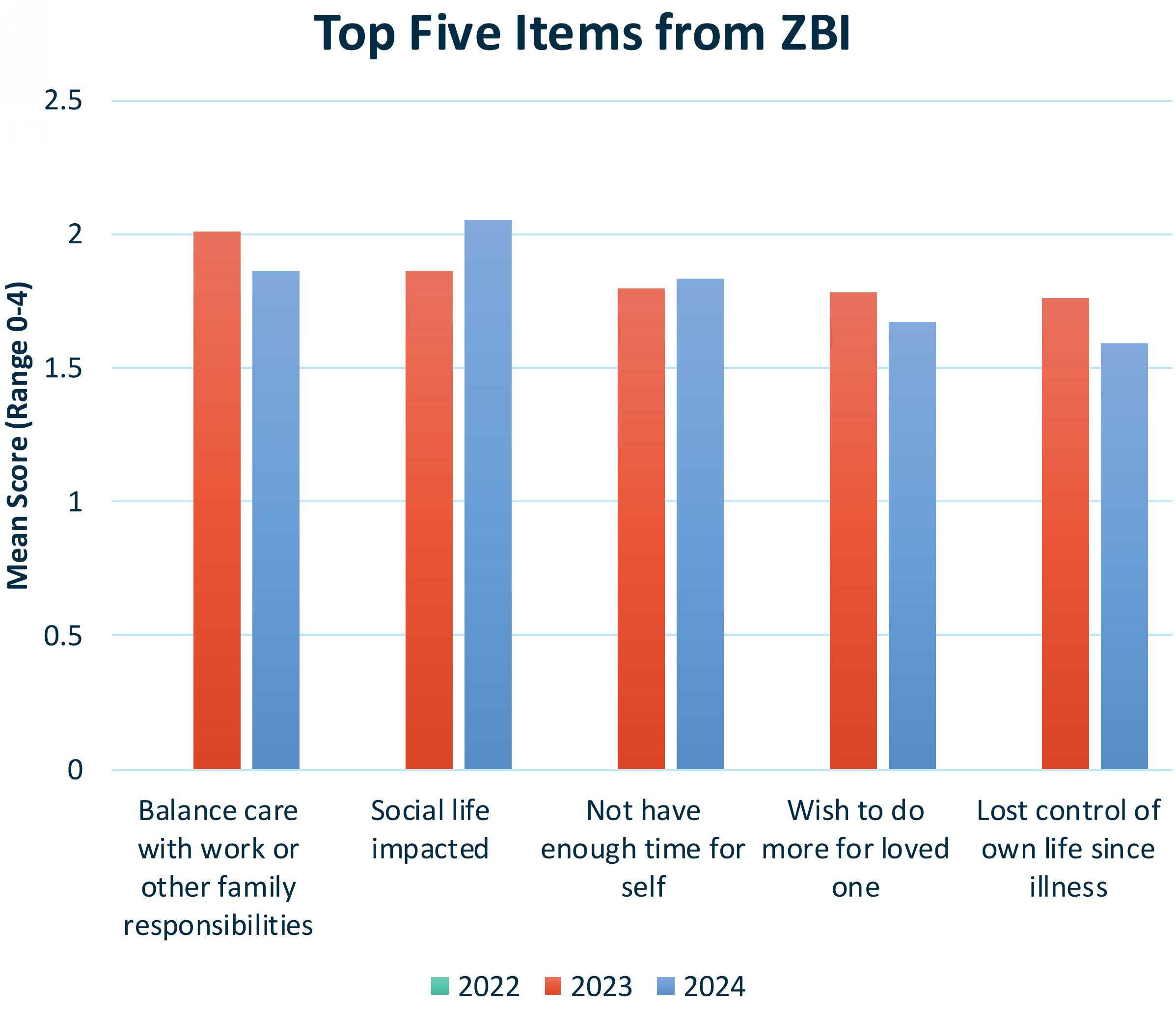


# The Weight of Care: Insights from the Zarit Burden Interview

Amyloidosis
Research
Consortium





# What The Results Mean

## AL Amyloidosis

- **Shorter time to diagnosis**: ↓ from 2.7 to 1.4 years
- **Moderate+ health status** reported by majority
- **Satisfaction with treatment increasing**, esp. in symptom relief
- **Care outside specialized centers growing**
- **Patient priorities**: Living longer, physical function, safety, affordability

## ATTR Amyloidosis (ATTRv & ATTRwt)

- **Diagnosis delays fluctuate**, still long for many
- **Vutrisiran (**AMVUTTRA) shows strongest patient-reported benefit;
  **Tafamidis** (Vyndaqel and Vyndamax) has most users, but many uncertain about its impact
- **Treatment satisfaction moderate** across all options
- **Affordability & safety** top treatment concerns
- **Non-specialized care increasing**; support services lag

## Other Amyloidosis Subtypes

- **Small but vital voices**—mostly white, female participants
- **Wide variability in diagnosis time & diagnosing specialty**
- **Declining provider expertise ratings**
- **Only 40% feel supported with services & info**
- **Need to amplify these voices and improve care equity**

## Caregivers

- Caregivers of amyloidosis patients face **emotional, practical, and economic strain**.
- There is an urgent need for:
- **Respite and support services**
- **Mental health care**
- **Policies to support working caregivers**
- Continued tracking will help **target interventions**

# What Comes Next: Turning Your Voices into Action

## 🩺 Faster, More Accurate Diagnoses

- Educate more doctors on amyloidosis signs
- Focus on all types — common *and* rare

## 🏥 Better Care Everywhere

- Give local doctors better tools
- Expand access to expert care

## 🧬 Shining a Light on Rare Types

- Hear more from AA, ALECT2, and other groups
- Advocate for their unique needs

## 💊 Improving Treatments and Relief

- Push for treatments that manage symptoms better
- Use real patient feedback to guide change

## 🤝 Stronger Support Along the Way

- Help connect patients to support and resources
- Ensure care includes emotional & community support
- Provide routine mental health screenings for caregivers
- Offer access to counseling and peer support groups

## 🎯 Focusing on What Matters Most

- Center care on *your* priorities (longevity, function, affordability, choice)

Thank you to all the patients and caregivers who have participated in ARC’s research efforts over the years!

ARC TALKS
WEBINAR SERIES

# Understanding Living with Amyloidosis:

## Insights from the ARC Annual Community Survey

Thank you for joining us today. Please take a few minutes to fill out the post webinar survey.