**JULY 2026**
BUFFALO, NEW YORK

# CReWS: Lessons from the Journey and Future Directions

## Insights from the *Quality of Life* Survey


**PRESENTED BY**

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Presented by INNERSENSE ORGANIC BEAUTY

WSA 2026 CONVENTION

# Presenters

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Collaborative Registry for Williams Syndrome

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*Psychologist,* Nationwide Children's Hospital
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*Genetic Counselor,* Children's Hospital of Philadelphia
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CReWS Collaborative Registry for Williams Syndrome

***Mission: Foster collaboration to support people with Williams syndrome***

GOALS:

1. Understand long-term outcomes in WS
2. Foster & facilitate research
3. Establish "Best Practices" in care for WS

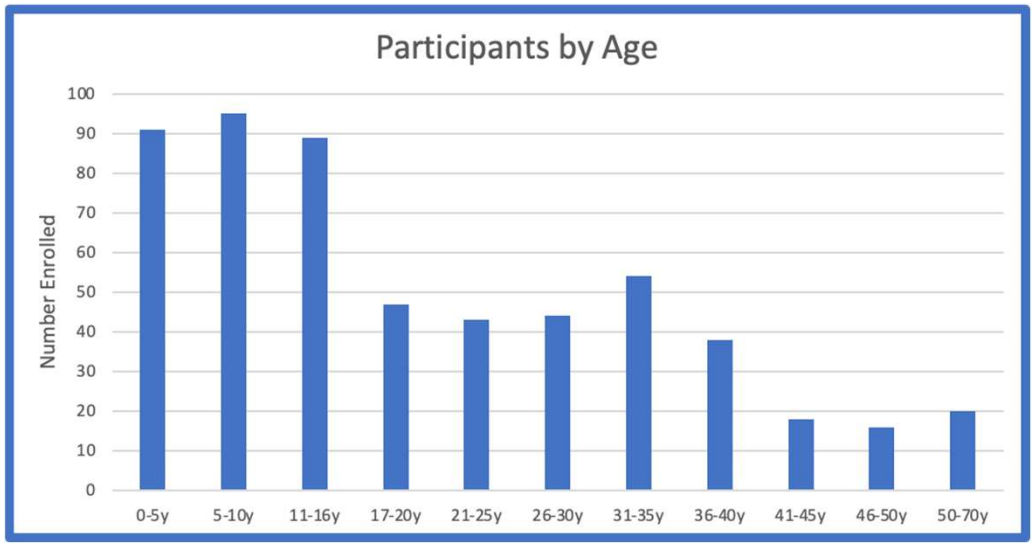


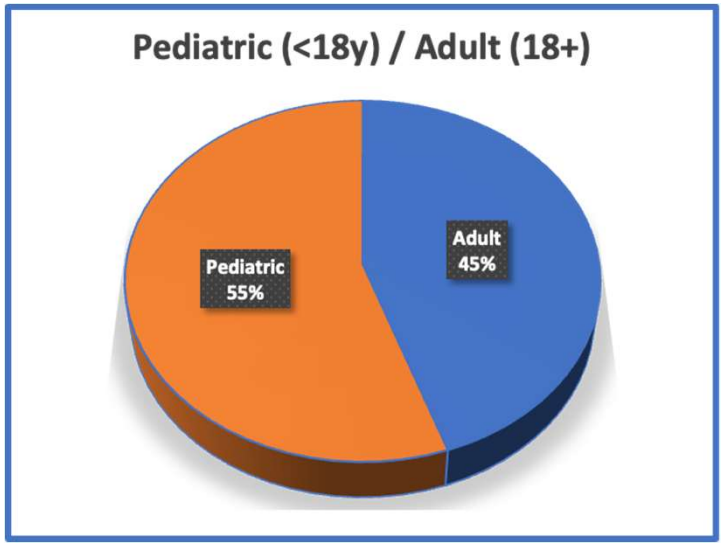
- **Answer surveys** about living with WS, including medical and developmental concerns
- **Receive invitations to new studies** for which an individual with WS may qualify.  Reply as they wish.
- **Receive information back from CReWS - like this!**

# Who is in CReWS?

Are you?

Enrolled members = 555



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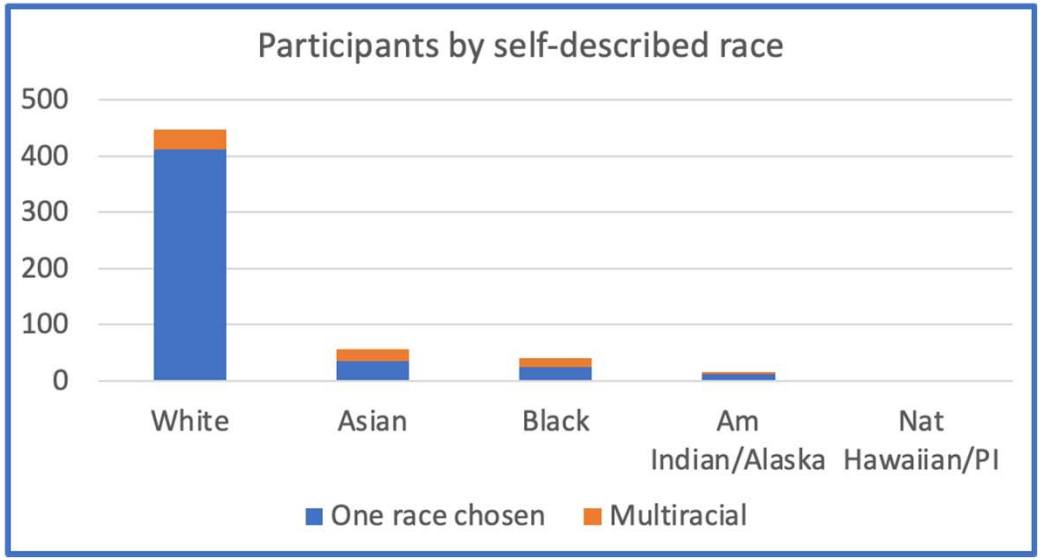
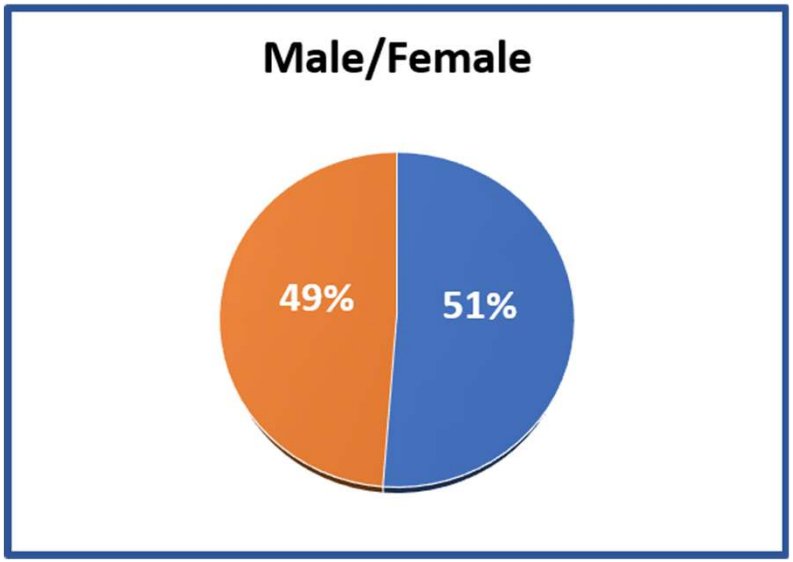
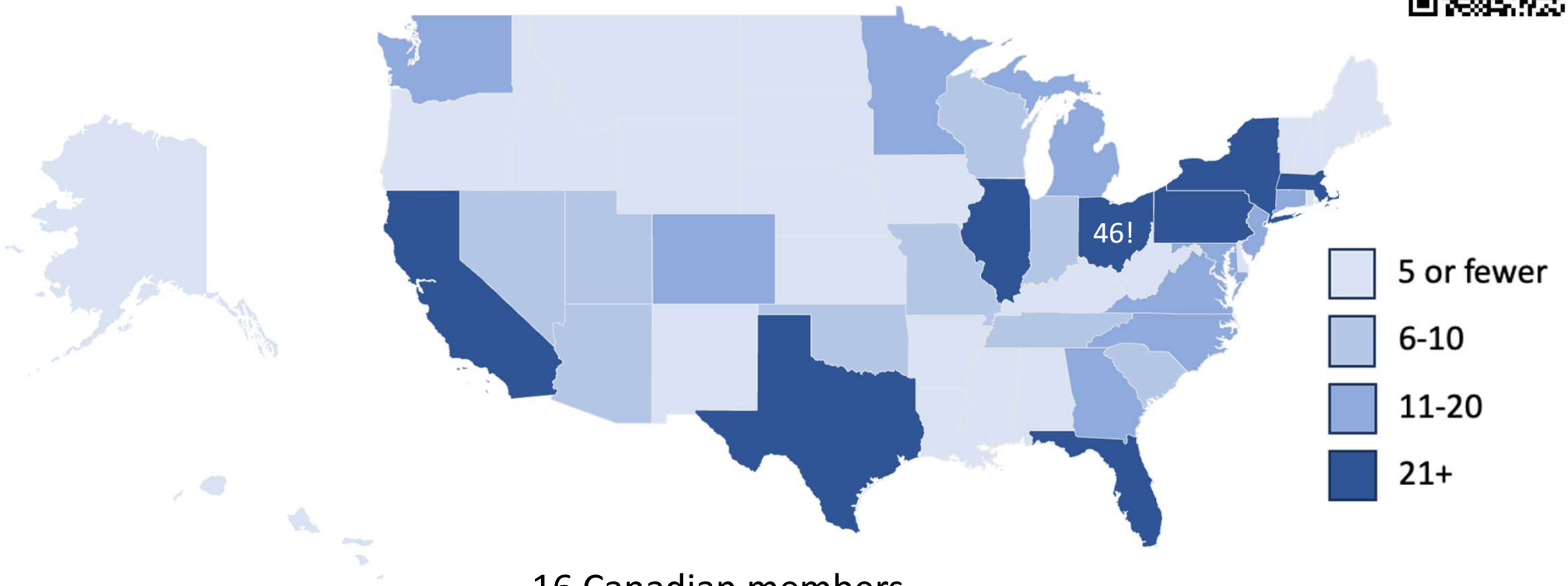


# Who is in CReWS?




16 Canadian members
27 International members

# Surveys sent to participants, to date

Health History Survey (HHS) – All participants at sign-up

- Screen for health concerns across the lifespan to date
- Screen for health concerns across body systems

Targeted Surveys (time-specific) - All participants

- 2024 Quality of Life with WS-specific addendum
- 2024 Yearly updates:  Anxiety, Cardiac, Gastrointestinal
- 2025 Yearly updates:  Medication, Anxiety, Depression
- 2026 Quality of Life with WS-specific addendum
- 2026 Yearly updates:  ???

# Baseline: Health History Survey

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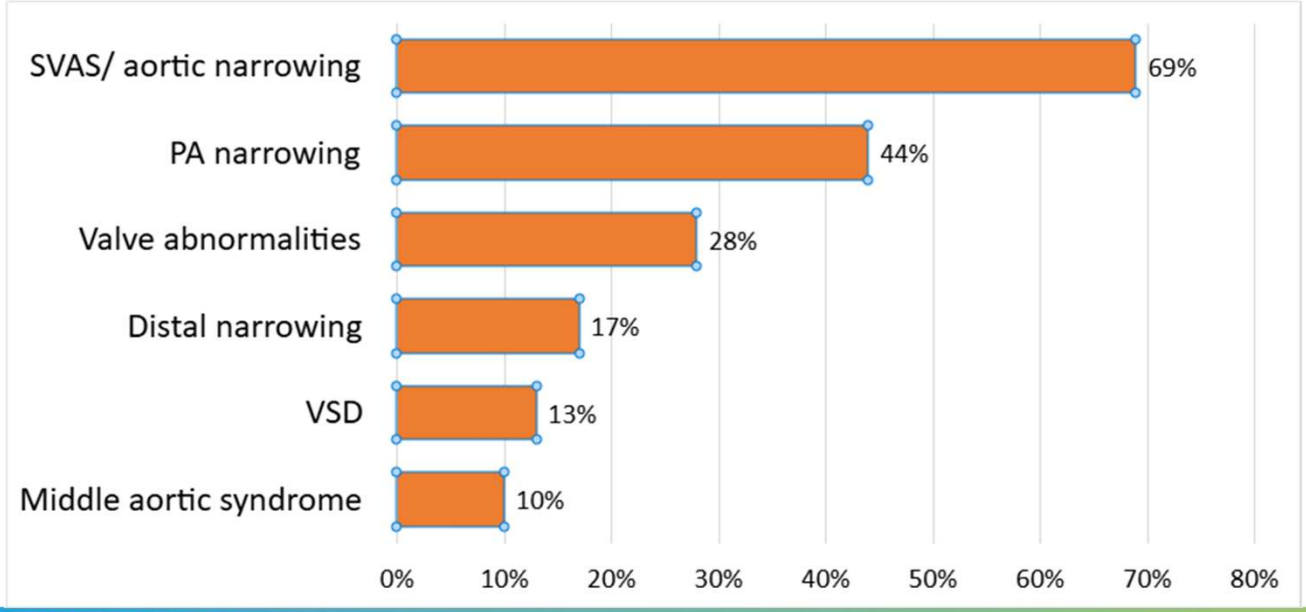
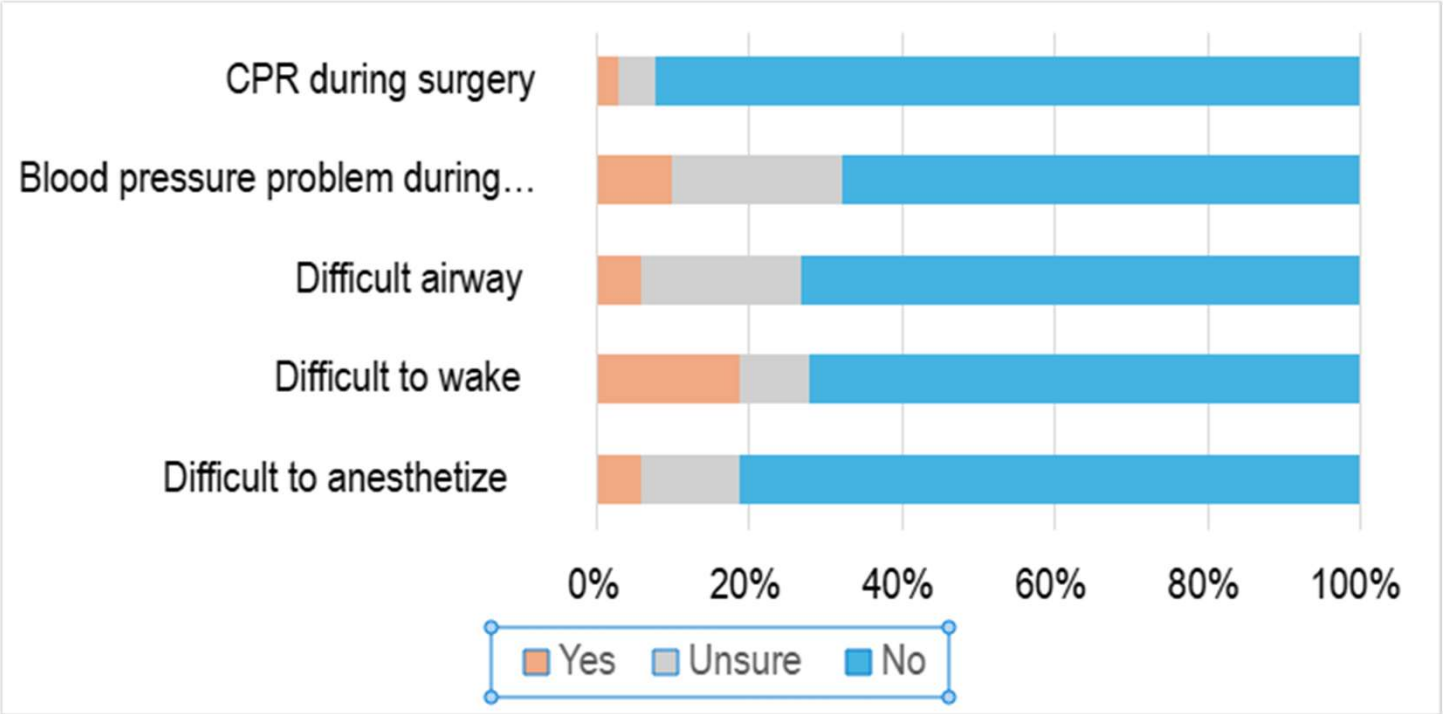


# Baseline:  Health History Survey

**Anesthesia:  87% of respondents have had anesthesia**



# Yearly Modules - 2024 Insights

Health History Survey (HHS) – All participants at sign-up

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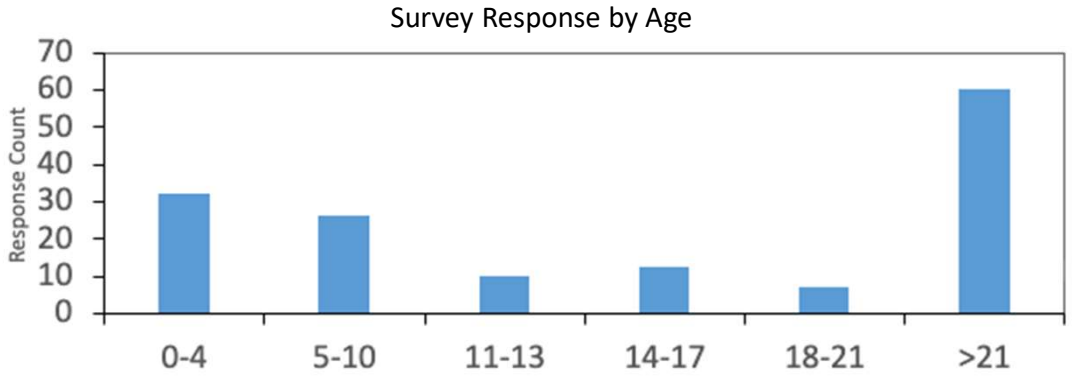
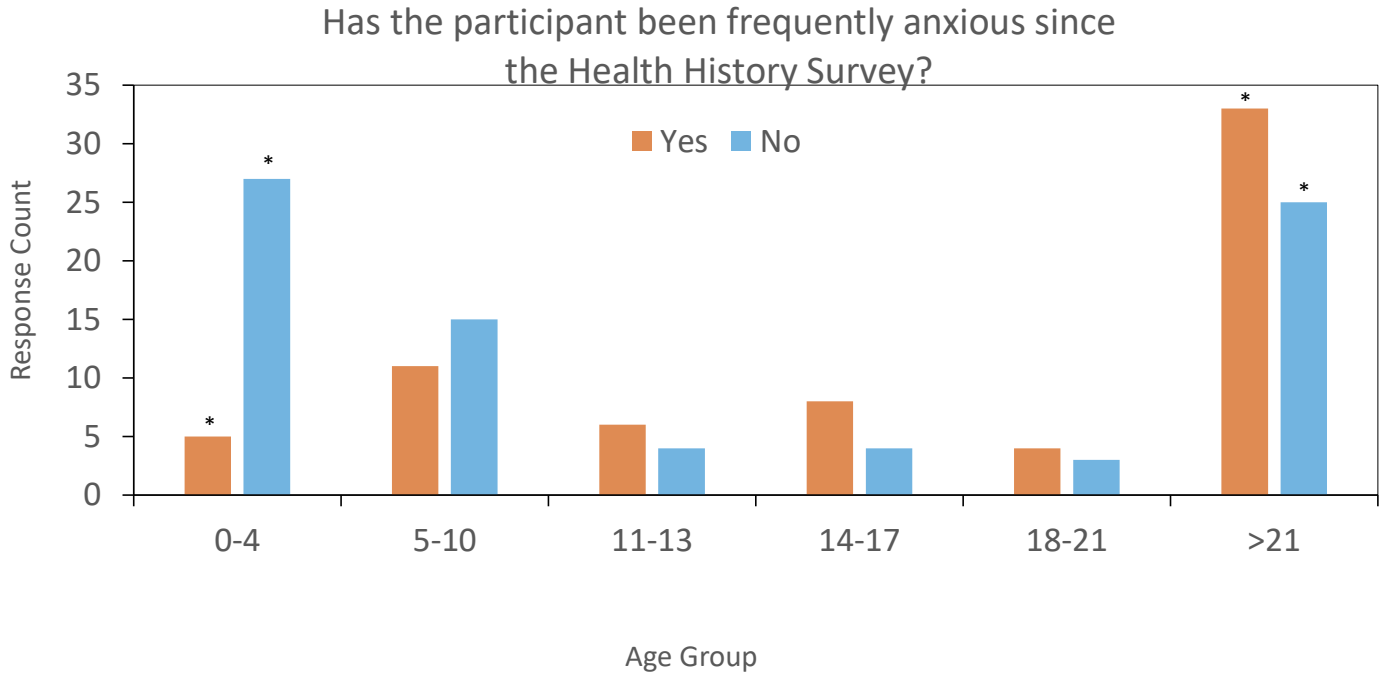
- 2026 Quality of Life with WS-specific addendum
- 2026 Yearly updates: ???

# 2024 Yearly - Anxiety Module

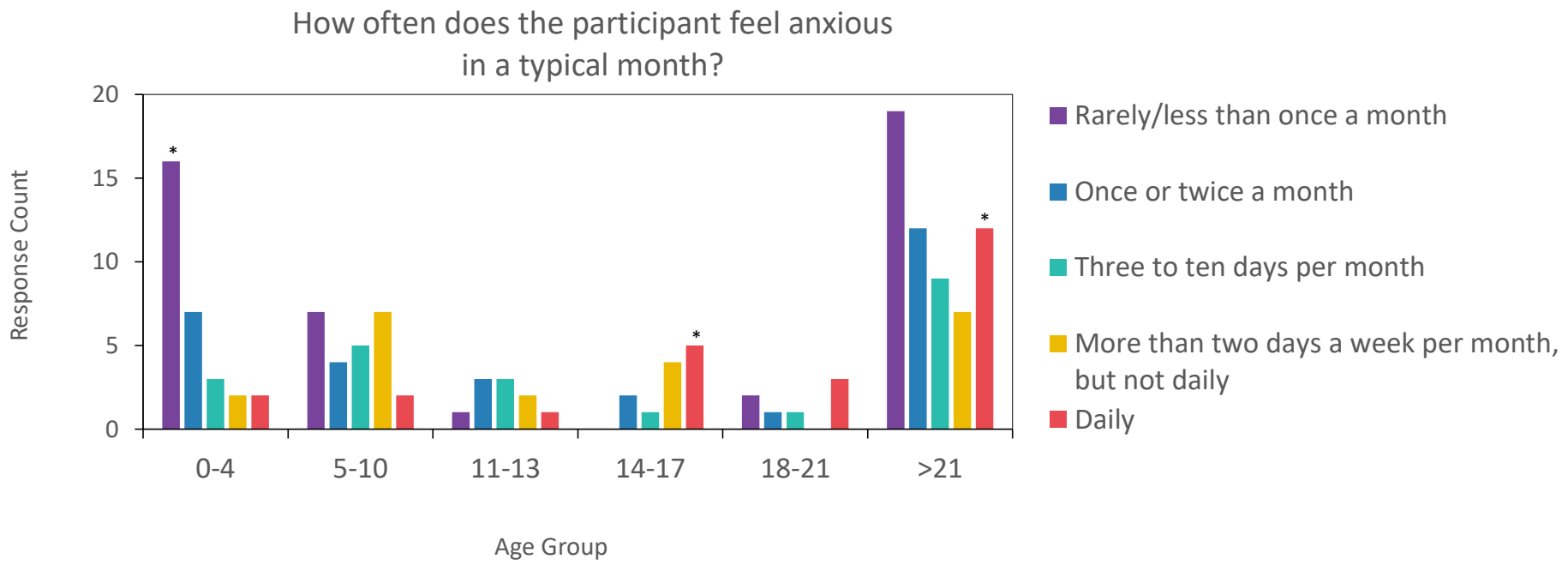
- 307 yearly surveys sent with three modules (GI, Cardiac, and Anxiety)
- 147 complete responses (47.9%) to Anxiety Module
- 94% of responses completed by caregiver



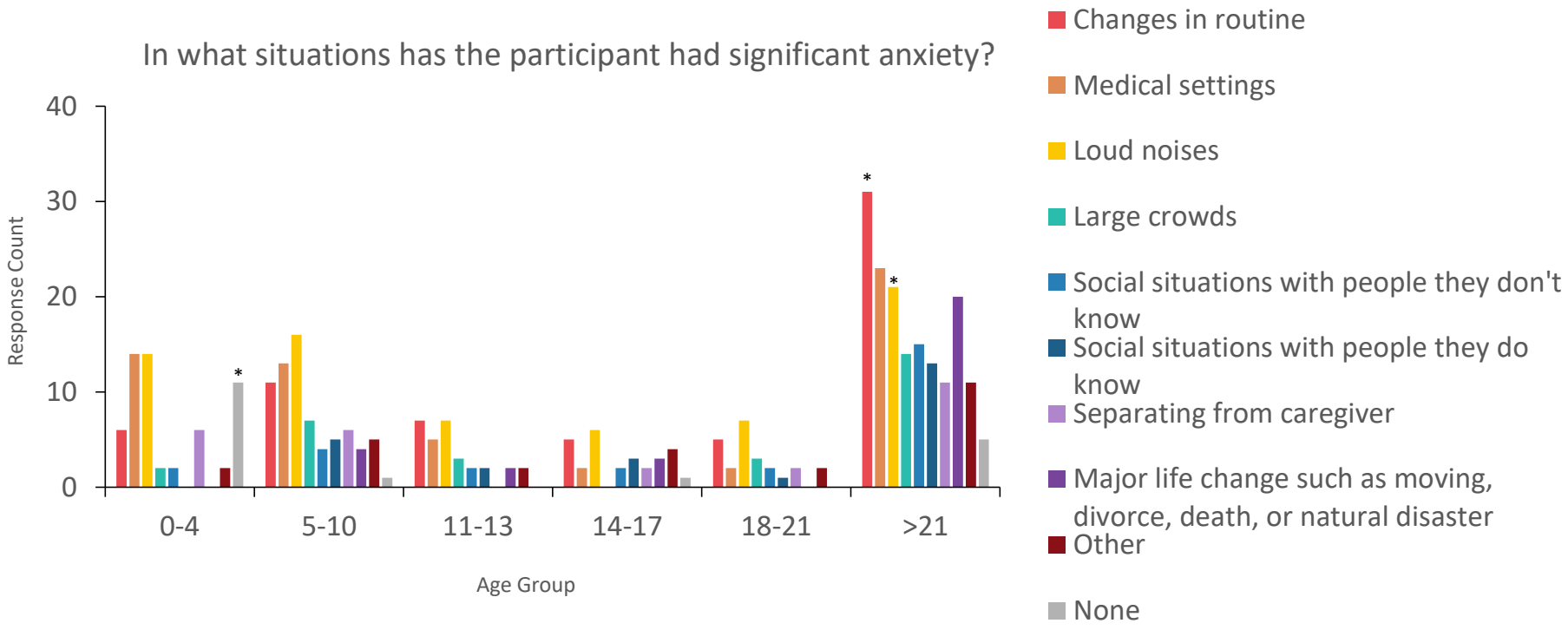
# Age has a statistically significant effect on anxiety
## (p<0.05)



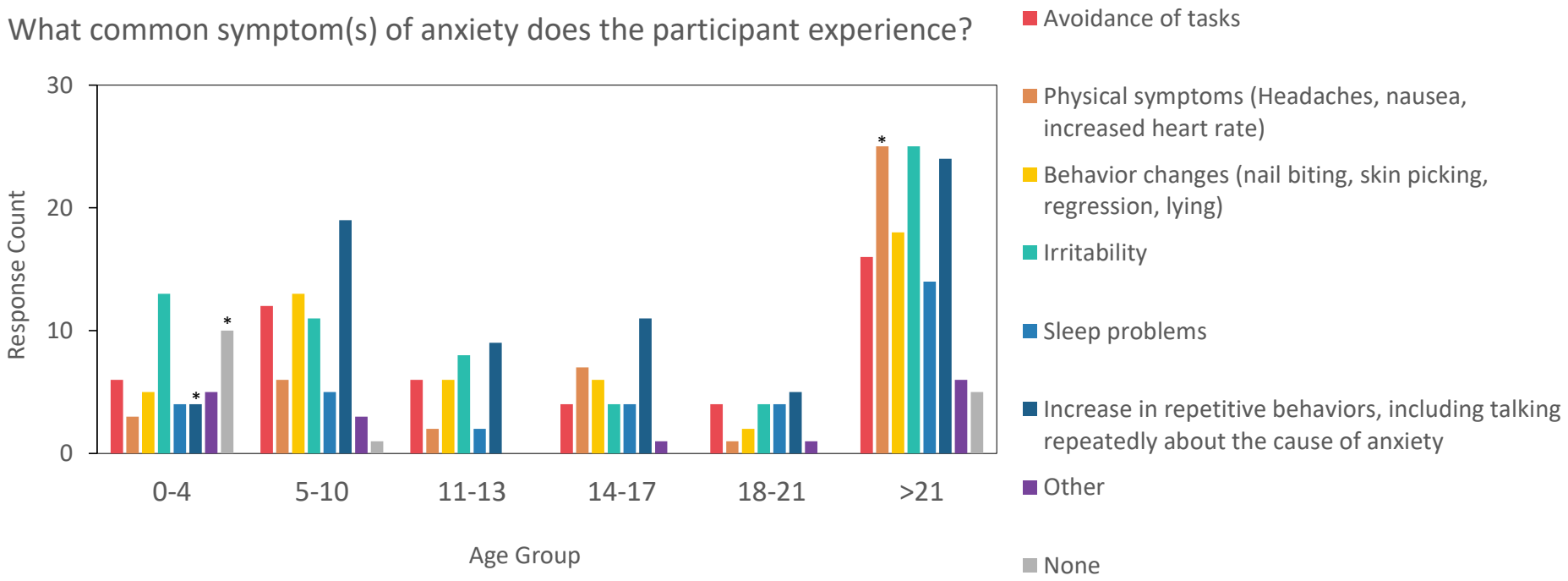
# Age affects how often in a month individuals report anxiety
## (p<0.05)



# Age affects what situations cause anxiety
## (p<0.05)



# Age affects the type of anxiety symptoms experienced
## (p<0.05)

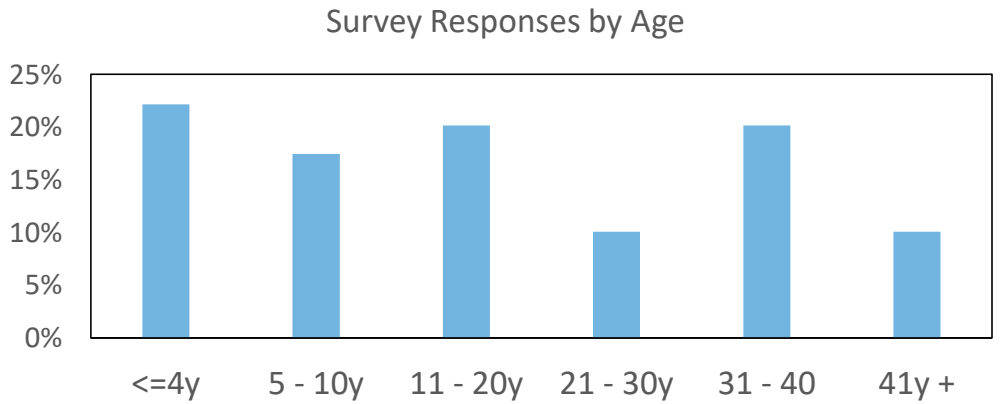


# 2024 Anxiety Module - Key Findings

- Age plays a role in diagnosis of anxiety, more likely for adults (> 21)
- People age 14-17 and over 21 are more likely to have daily anxiety. (More respondents needed 18-21.)
- People over age 21 are more likely to experience anxiety due to changes in routine and loud noises than people at younger ages.
- People over age 21 are more likely to have somatic symptoms as a result of anxiety, such as headaches, nausea or increased heart rate.
- Future work to assess mental health/anxiety for school-aged patients (ages 5-21) – more participants needed for statistical power

# 2024 Yearly - Cardiac Module

- 307 yearly surveys sent with three modules (GI, Cardiac, and Anxiety)
- 149 complete responses (48.5%) to Cardiac Module
- 94% of responses completed by caregiver
- Focus on conditions: VSD, narrowing of aorta, narrowing (stenosis) of blood vessel, heart valve problems and high blood pressure



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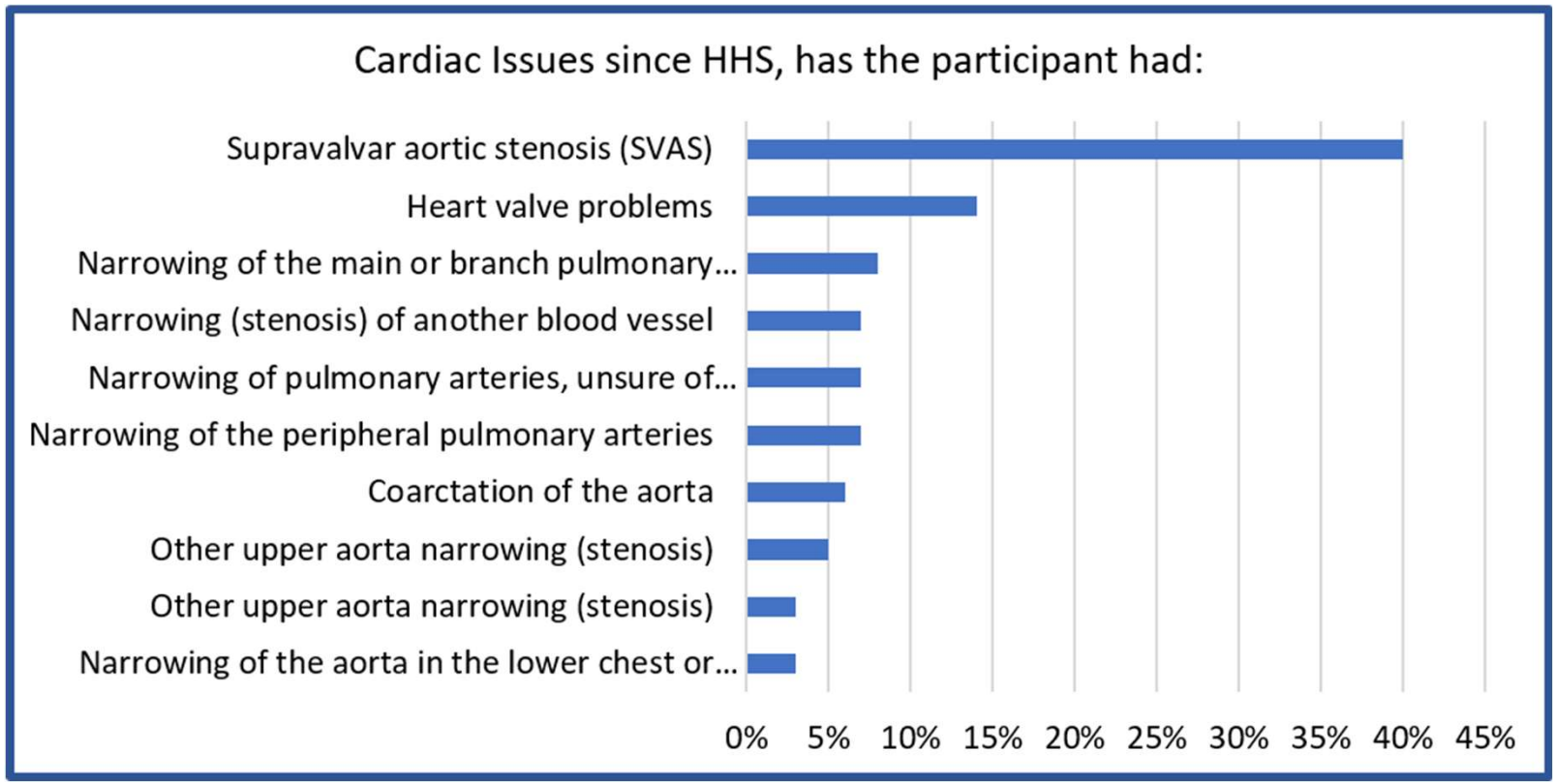
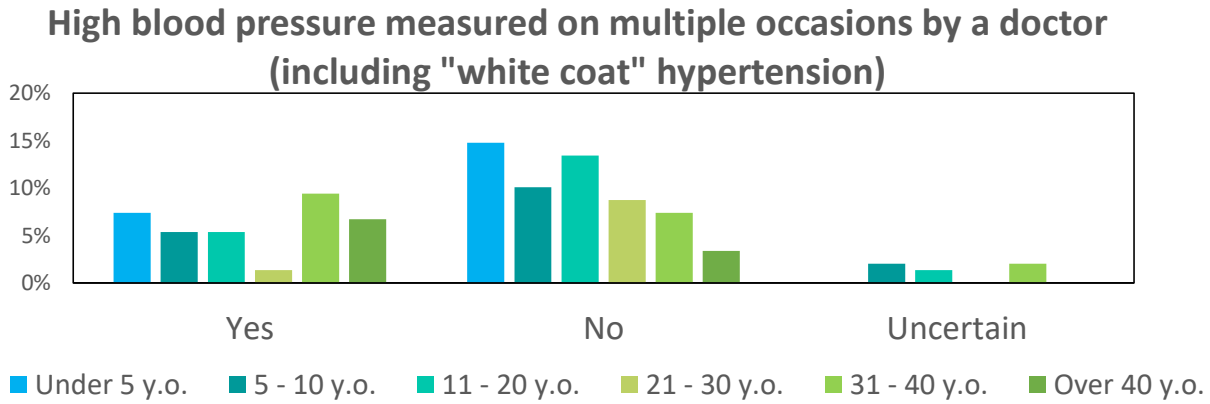
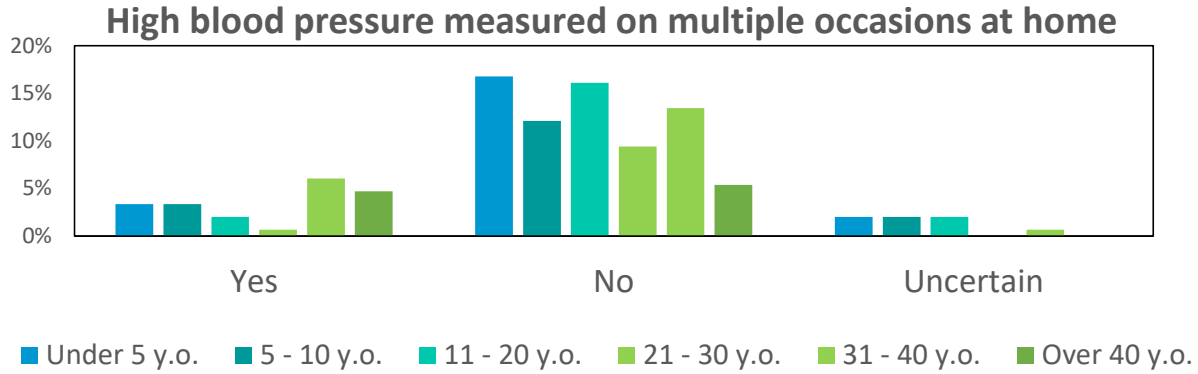


# 2024 Yearly - Cardiac Module

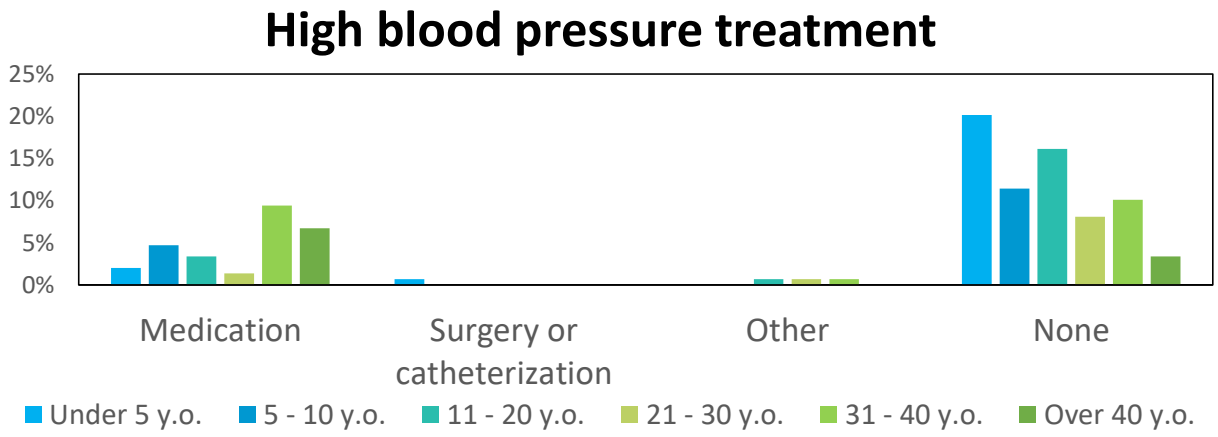
**44%** of respondents reported high blood pressure measured by a doctor



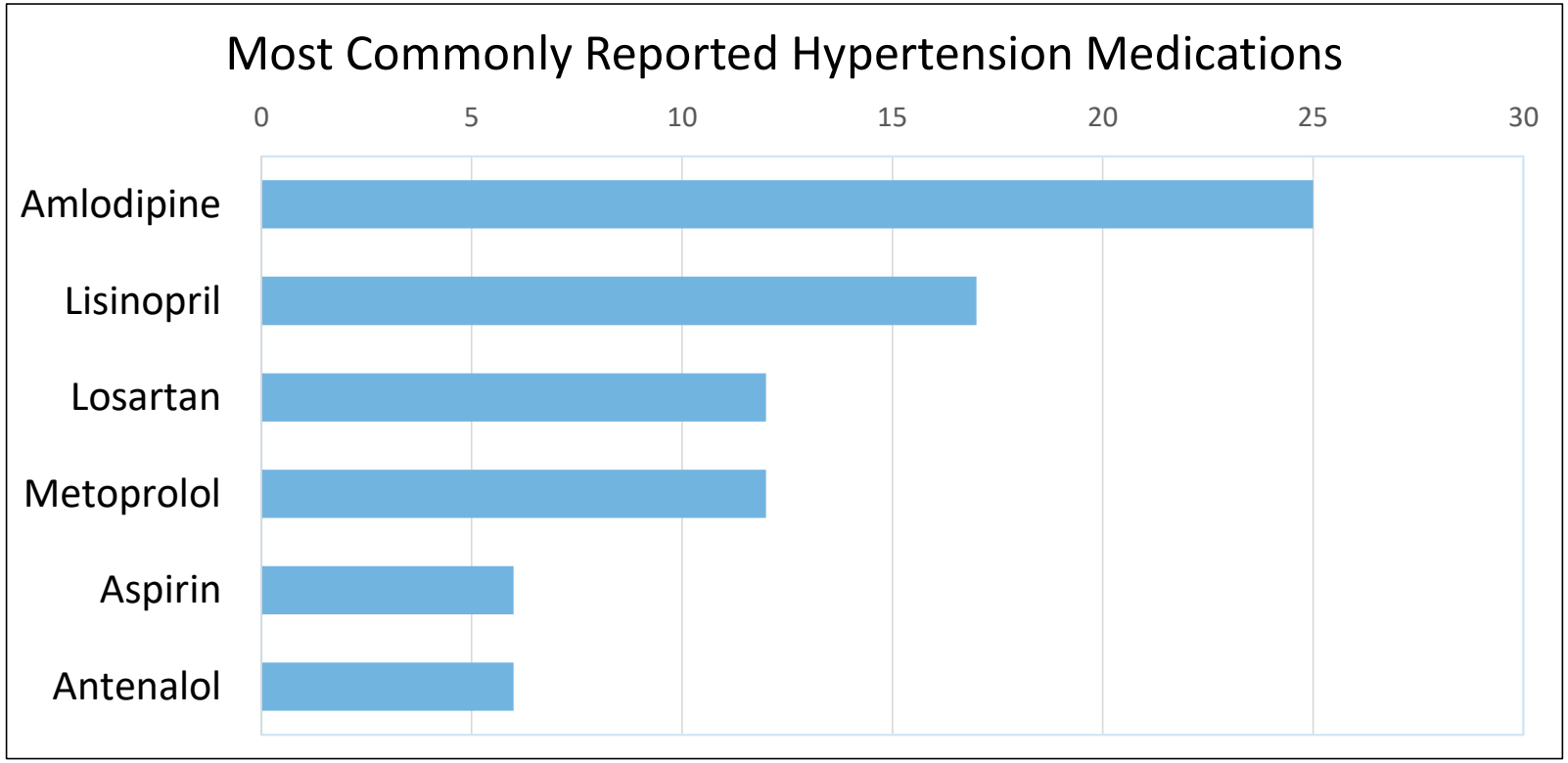

**29%** of respondents reported high blood measured at home



# 2024 Yearly - Cardiac Module



# 2024 Yearly > 2025 Yearly

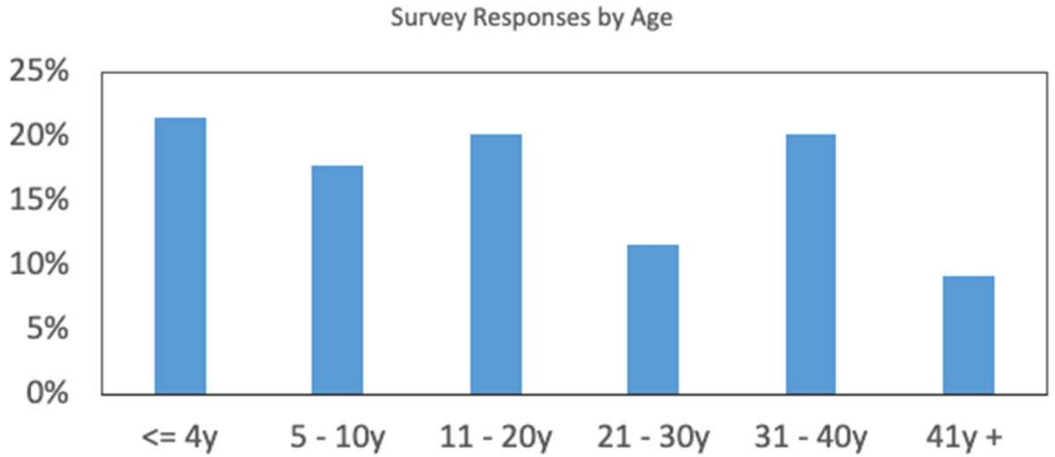


# 2024 Cardiac Module - Key Findings

- SVAS was the most common type of narrowing of upper aorta reported
- For all cardiac conditions, most reported no treatment while some took medication for high blood pressure
- 44% had HTN measured by a doctor, while it was found in only 29% when measured at home
- Medication more often used to treat older adults
- Future: Cross reference responses to Cardiac and Medication surveys. How effective were certain hypertension medications? Were they different at different ages?

# 2024 Yearly - GI Module

- 307 yearly surveys sent with three modules (GI, Cardiac, and Anxiety)
- 164 complete responses (53.4%) to GI Module
- 93% of responses completed by caregiver
- Focus on GI conditions: reflux (GERD), celiac disease, IBS, IBD, chronic constipation, diverticulitis, chronic abdominal pain, hemorrhoids, rectal prolapse



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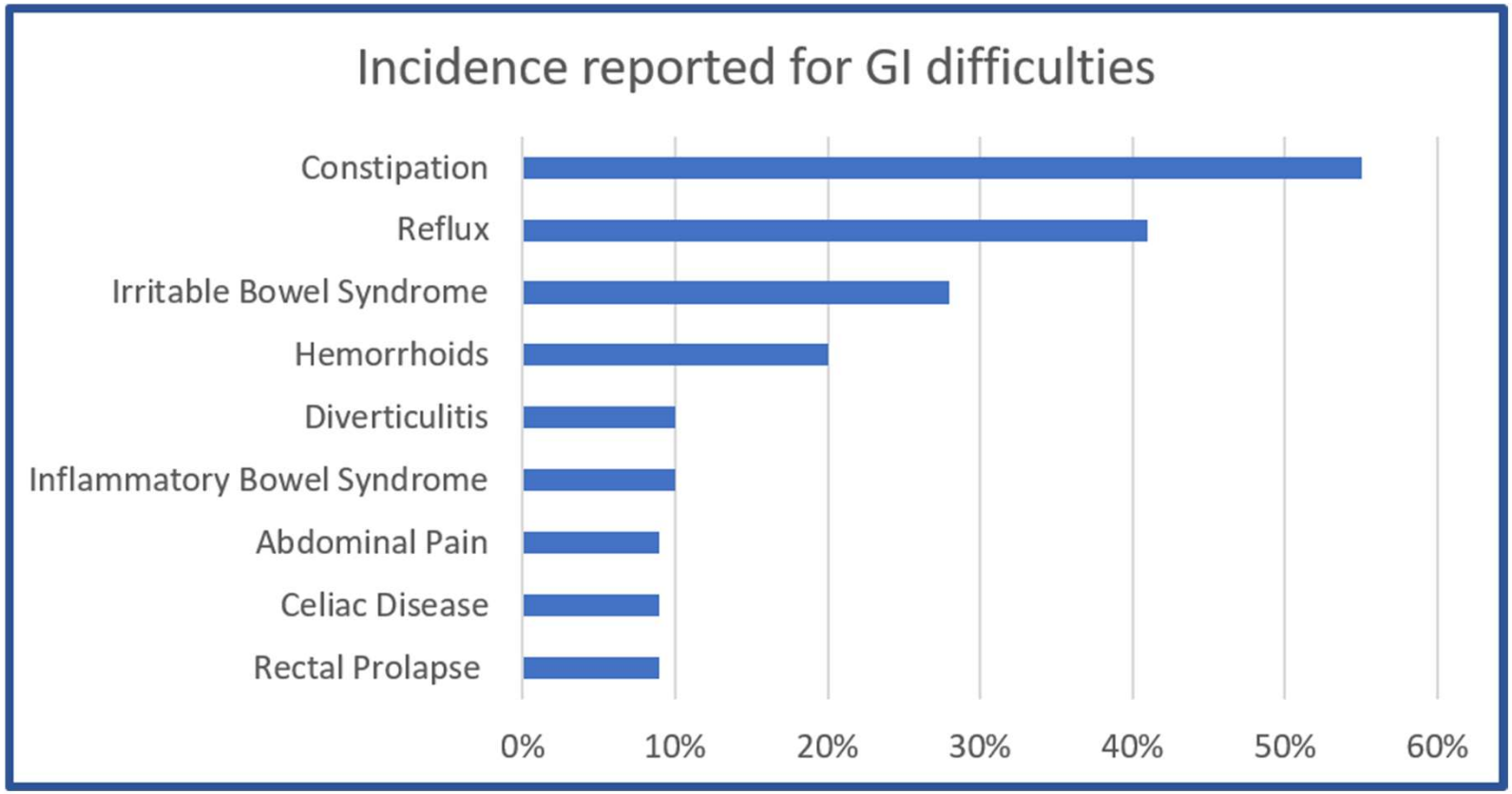
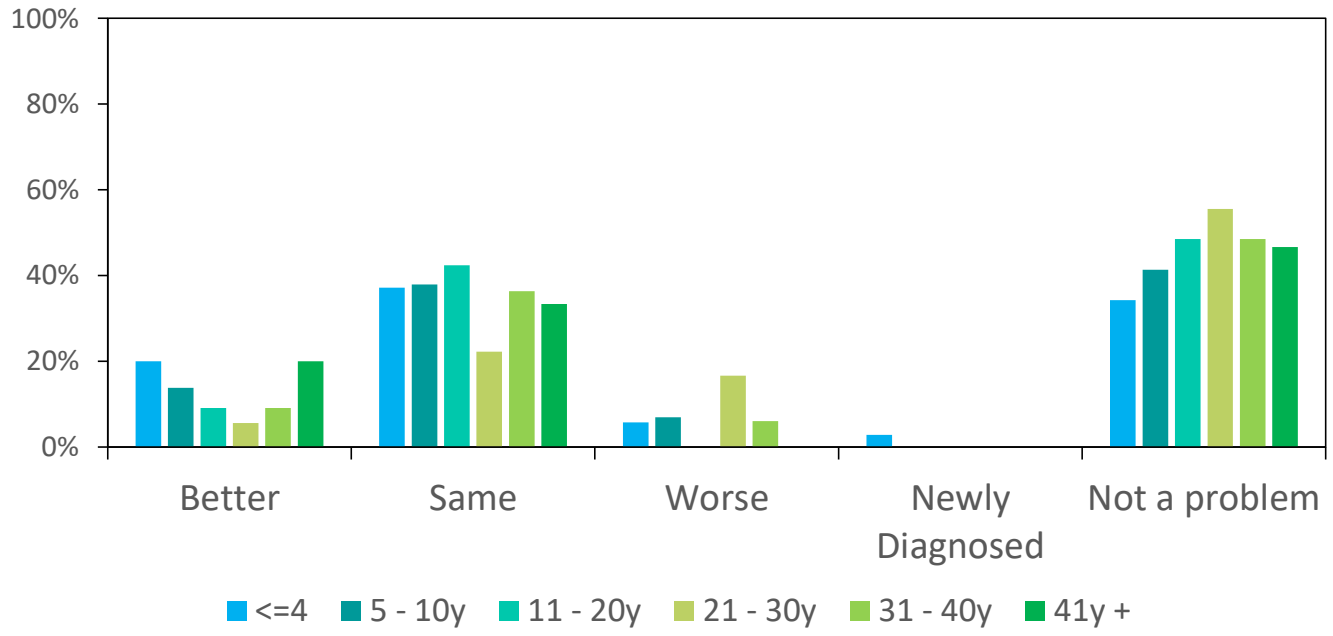


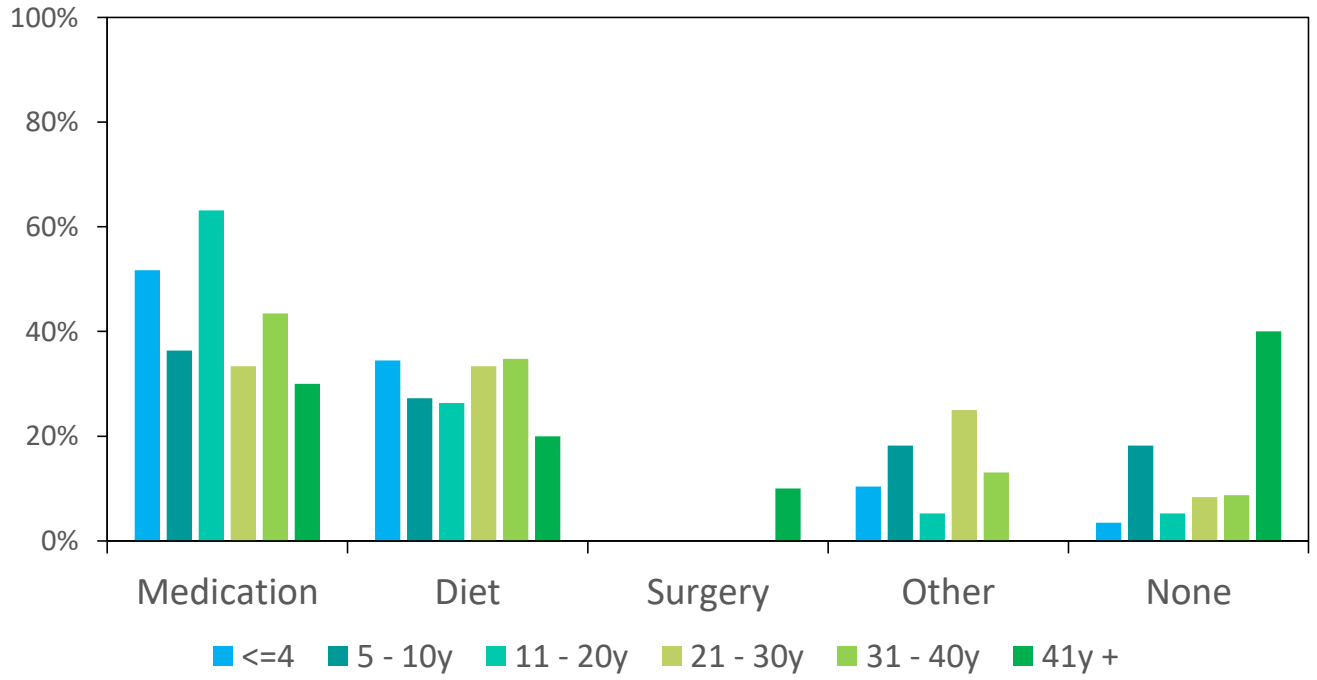
# 2024 Yearly - GI: Chronic Constipation

Since Health History Survey (HHS) completion, constipation has been:



# 2024 Yearly - GI: Chronic Constipation

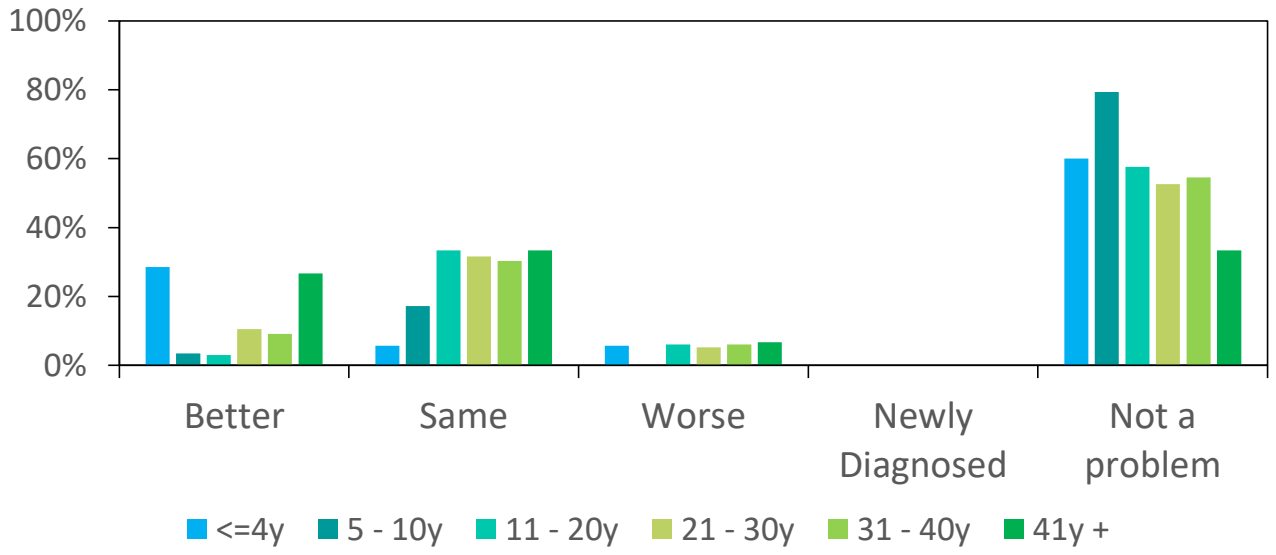
Since Health History Survey (HHS) completion, how has constipation been treated?




"Other" treatments primarily OTC medication or supplements; Also, pelvic floor PT/exercise

# 2024 Yearly - GI: Reflux (GERD)

Since Health History Survey (HHS) completion, reflux has been:



# 2024 Yearly – GI Module - Key Findings

- Most participants, >70% per condition, reported no problems with GI conditions (celiac disease, IBS, IBD, diverticulitis, chronic abdominal pain, hemorrhoids, and rectal prolapse)
- Most common were reflux and constipation
- Medication was the most common treatment for reflux and chronic constipation.
- Future: Were any specific medications helpful?

Researchers

# CReWS at work…

- **Mastery Motivation in Williams Syndrome and Down Syndrome**
  - Dr. Caroline Richter, University of Alabama
  - 28 participants who completed complex learning assessments, 16 recruited through CReWS!
- **Anxiety in Williams Syndrome**
  - Dr. Andrea Witwer, The Ohio State University
  - 20 participants completed, continuing to recruit at Convention!

Researchers

# CReWS invitations coming soon…

- **Executive Functioning and Adaptive Behavior in Youth with Intellectual Disability**
  - Participants Ages 6-21 and a caregiver fill out a survey, two zoom meetings with researchers
  - This kind of study will be a basis for showing if certain interventions make a difference
- **Williams Syndrome and the Transition from Adolescence to Adulthood**
  - Interviewing people with WS who are over age 18 about how they want to live in adulthood and the supports that have been helpful.

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# QUESTIONS? Come by Table 34!

Families who participate!
Williams Syndrome Association
Williams Syndrome Clinical Consortium

Dr. Wendy Chung, Primary Investigator
Winnie Chen
Candace Cameron
Yeyson Quevedo

CReWS

# Thank you!

See consent form here!

CREWS@cumc.columbia.edu

Researchers

CReWS at work…

# Insights from the Quality of Life Survey

- Collaborative project between different members of CReWS
- Looked at results from the 107 people who completed the Quality of Life (QoL) survey
  - Goal to learn more about reported QoL in people with WS in order to inform future areas of research/advocacy to improve QoL
  - Used the QoL-Disability (Downs et al., 2019) a quality of life measure developed through interviews of parents of children with intellectual disabilities

# Quality of Life - Insights

- Quality of Life: individual's physical health, psychological well-being, level of independence, social relationships, and engagement within their community
  - Gives a multidimensional perspective on someone's well-being, which is important for helping figure out supports someone may need
- However, little research has been done focusing on individuals with WS
- When thinking about QoL, important to consider both **internal factors** (e.g., physical health challenges due to hospitalizations) and **external factors** (e.g., limited opportunities for community participation)

# Who participated?

- 107 individuals completed the QoL survey

| Self-Reported Race/Ethnicity | Number of Individuals (%) |
|---|---|
| White | 99 (92.5%) |
| American Indian or Alaska Native | 4 (3.7%) |
| Asian | 5 (4.7%) |
| African American | 4 (3.7%) |
| Native Hawaiian or Other Pacific Islander | 1 (0.9%) |
| Hispanic | 7 (6.5%) |

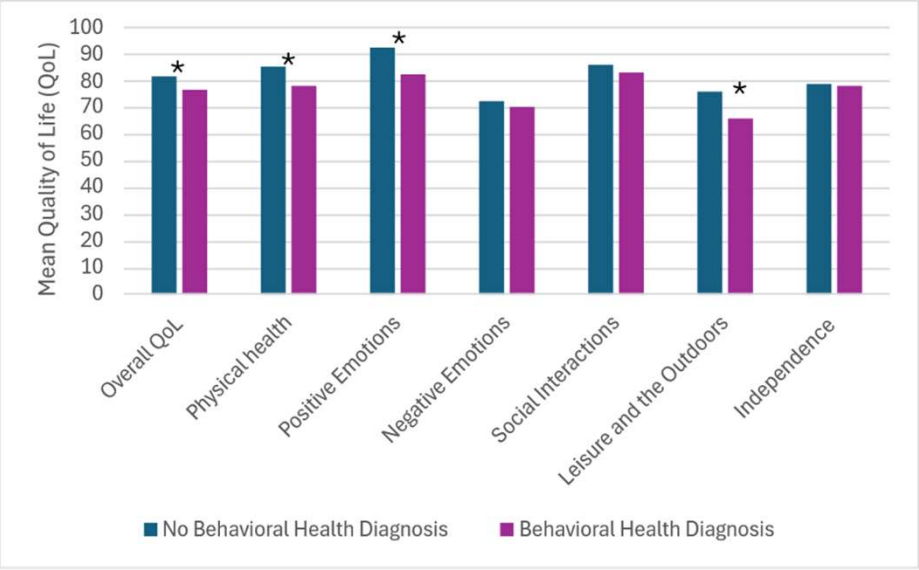
| Age | Number of Individuals (%) |
|---|---|
| 0-11 | 29 (27%) |
| 12-17 | 13 (12%) |
| 18+ | 64 (60%) |
| Age not specified | 1 (1%) |

| Sex | Number of Individuals (%) |
|---|---|
| Male | 53 (50%) |
| Female | 54 (50%) |

# What did we learn?

- Quality of life was relatively high overall

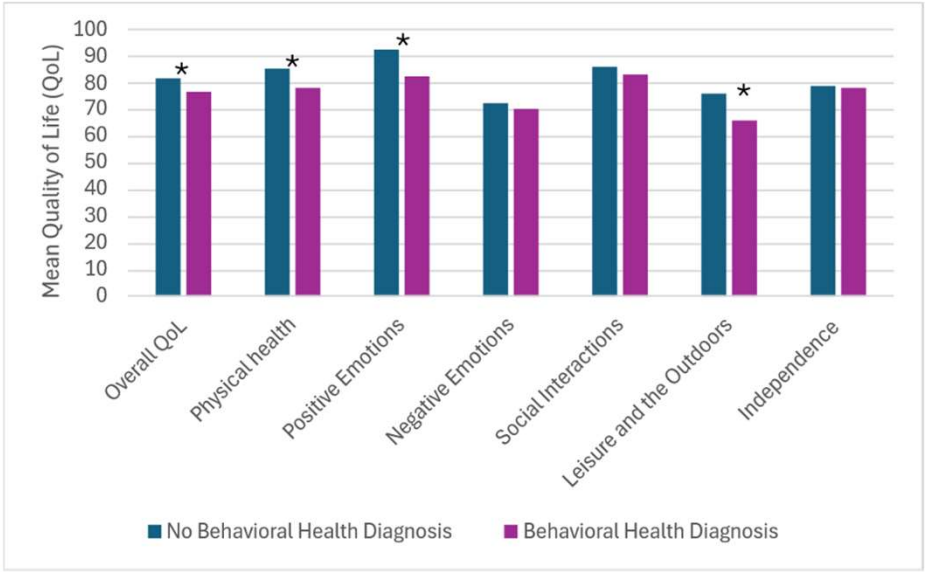
- **Average Overall QoL:** 78.5 / 100
- **Highest domain:** Positive emotions (avg 86.2 / 100)
- **Lowest domain:** Leisure and the outdoors (avg 69.9 / 100)



# What did we learn?

- We found **differences in QoL** when comparing individuals with behavioral health diagnoses to those without
  - ASD, anxiety, ADHD, depression, other

- Individuals **WITHOUT** behavioral health diagnoses had higher QoL in:
  - Overall QoL
  - Physical health
  - Positive emotions
  - Leisure and the outdoors



# Additional Findings

- As the **number** of behavioral health diagnoses increase, QoL decreased.

- However, age has a **positive effect** on QoL in several categories:
  - Improved negative emotions
  - Level of independence

# What Did This Show Us?

- Quantifies significant impact of behavioral and mental health diagnoses on QoL in WS for future focus
- Highlights cumulative and compounding nature of multiple diagnoses for daily living
- Emphasizes potential for dual diagnoses and need to understand differing lived experiences within community
- Key: Importance of recognizing symptoms, timely diagnostic evaluations, and appropriate resources/treatment

# Broader Conversations

## RECOMMENDATIONS

**2020 American Academy of Pediatrics guidelines:**

- Periodic multidisciplinary developmental and neuropsychological evaluations
- Annual behavioral assessments

## REALITY

**Access challenges for evaluations and therapeutic supports**

- Lengthy wait times for diagnostic ASD assessments
- Prolonged wait times for outpatient mental health care

Crucial given ongoing research with promising results for behavioral health interventions and better understanding of pharmacologic treatments in WS community

# Future Directions

**Internal Factors & QoL**

Assess other internal factors impacting QoL for people with WS over time and across the lifespan as people age

**Dual Diagnosis Resources**

Continue developing supports and resources for those with dual behavioral and mental health diagnoses

**WS-Specific Mental Health Management**

Further research to determine best treatments and support for mental health diagnoses for people with WS

**External & Societal Factors**

Explore resource/access disparities and how individuals' level of inclusion across different domains plays a role in QoL

# Ongoing Next Steps

- Analyze recently-collected data from **second round** of QoL surveys
  - Assess trends over time
- Validation of **empowerment** module data in collaboration with Dr. Downs
  - Guide future supports and interventions
- Further research on anxiety and depression

# Thank You!

Thank you to our presenting sponsor for
supporting the Williams Syndrome Association

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