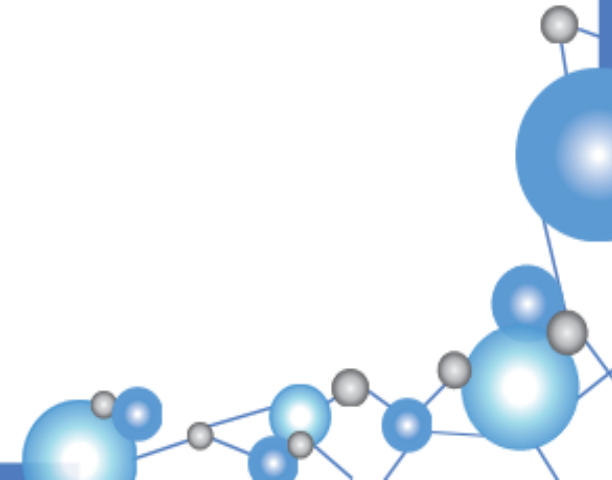


# QOL and Burden of Disease

# Who Am I?





# HI LIFE ROLLERCOASTER



# What We are Doing & Why We are Doing It

- Examining our current HIGR measures to see how we may want to adjust it
- HIGR represents the patient and family experience
- Data obtained from HIGR allows us to see where needs are being met, where gaps exist, and what changes may or may not make an impact on the lives of those living with HI



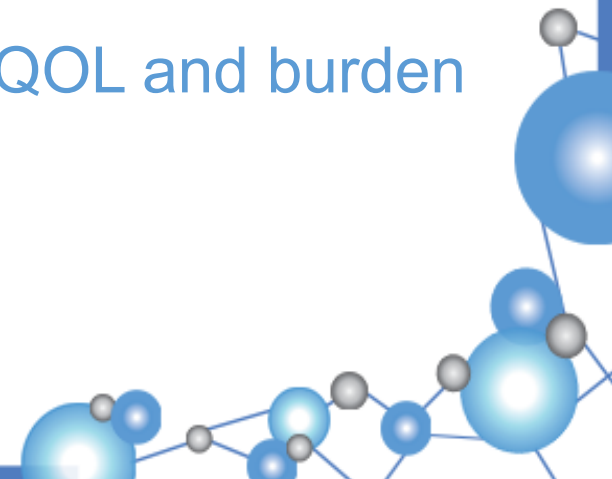


## What Does "Quality of Life" Mean?

- World Health Organization
  - An individual's **perception** of their position in life in the context of the culture and value systems in which they live and in relation to their **goals, expectations, standards, and concerns**
- It differs for each person and family
  - We want to capture trends
  - We want to capture influences, so we can help treatment help
  - What makes us feel satisfied?

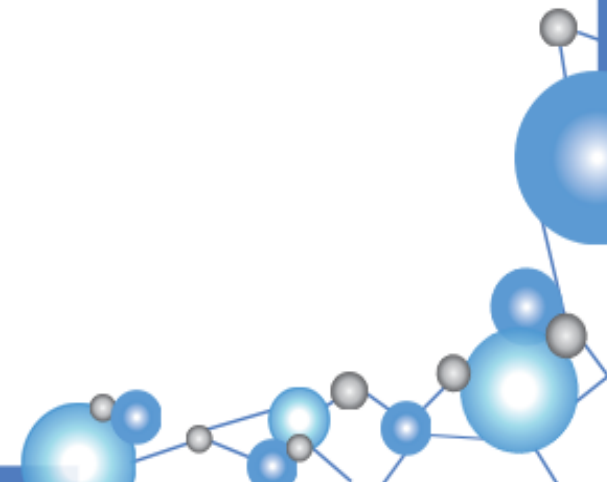
# QOL Approach

- Ongoing Process
  - Reviewing our current QOL tools and conducting the systematic steps for validation of the tool, utilizing global literature/resources
- Short-term Goals
  - Compare our tools to others
  - Adding a few items to give a more robust impression of QOL
- Long-term Goals
  - Look at adopting another tool into the system to use as a comparator as part of the validation process
  - Review listening session data to integrate aspects of QOL and burden of disease into HIGR



# QOL Tools Reviewed

- *Caregiver Strain Questionnaire*
- *Perceived Stress Scale*
- *Quality of Life Scale (QOLS-16)*
- *Satisfaction with Life Scale*
- *Clinical Global Impression Scale*
- *Patient's Global Impression of Change Scale (PGIC)*
- *Pediatric Quality of Life Inventory (PedsQL)*
- *Meaning in Life Scale*
- *Fear of Hypoglycemia Scale*
- *DISABKIDS questionnaires*
- *EQ-5D*
- *Dyadic Adjustment Scale (DAS – measures satisfaction in relationships)*
- *Family Needs Assessment Tool (FNAT assessing family coping/functioning and support in caring for a chronically-ill child)*
- *Tennessee Self-Concept Scale (TSCS)*
- *KINDL (Kiddy-KINDL, Kid-KINDL, Kiddo-KINDL, KINDL)*



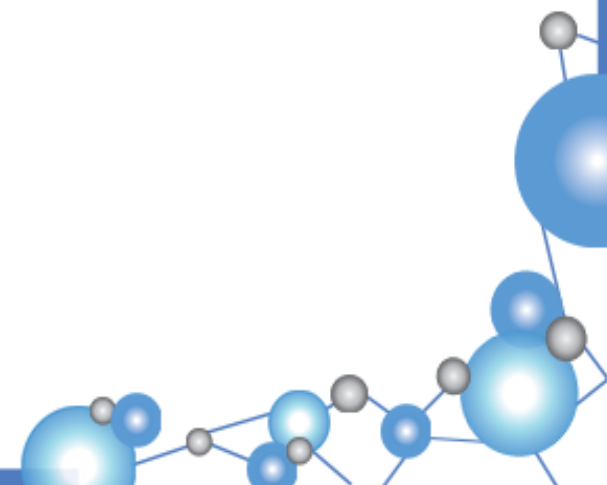
# HIGR QOL Domains

## Currently covered:

- Physical Well-Being
- School/Work Well-Being
- Financial Impact
- Social Support/Family Impact
- Emotional Well-Being
- Burden of Care
  - Fear of Hypoglycemia (newly added)
- Satisfaction with Diagnosis Process

## Identified in other QOL Tools:

- Self-Esteem/Self-concept Impact
- Spiritual Well-Being





# HIGR QOL – Change Over Time

- Campaigns will promote completion of HIGR items at regular intervals
  - Allows for longitudinal studies
  - Captures change over time
    - How do the needs of families and individuals change as time progresses?
    - At what stage might certain domains thrive or become impaired?



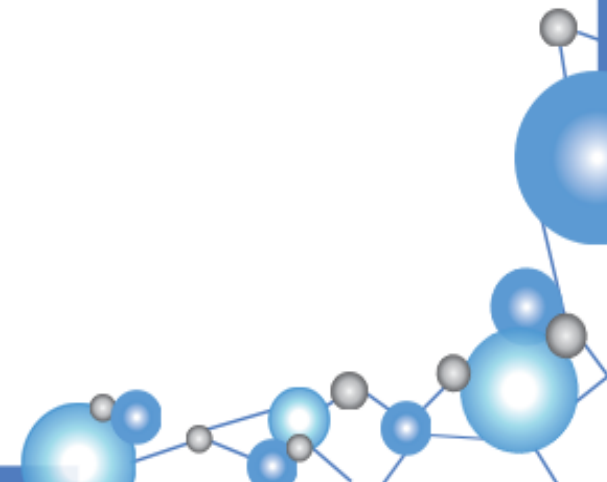
Gabriel, 6 months



Gabriel, 6 years

# QOL Considerations

- What matters to our key audiences:
  - The patient community, etc.
  - Researchers,
  - Regulatory agencies
- Want to ensure we could capture if a change would be measurable
- How well are we covering the key components of QOL now?
- Introducing a validated tool as a comparator



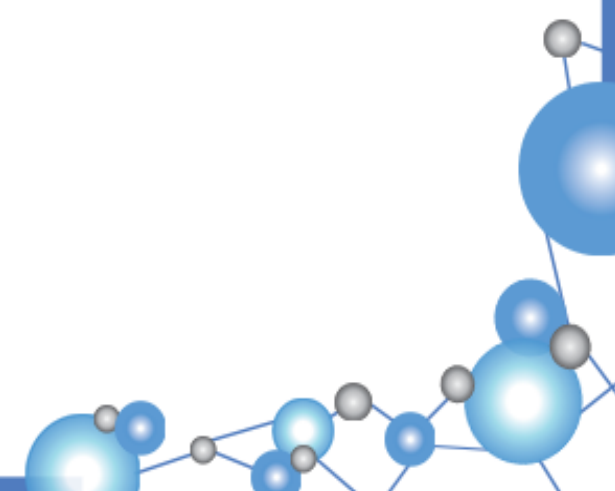
# HIGR QOL DATA

# Characteristics of HIGR Respondents Represented in Parent QOL Data

There are a total of 186 participants represented in this parent QOL data. The total N for some questions varies as respondents can choose to skip certain questions.

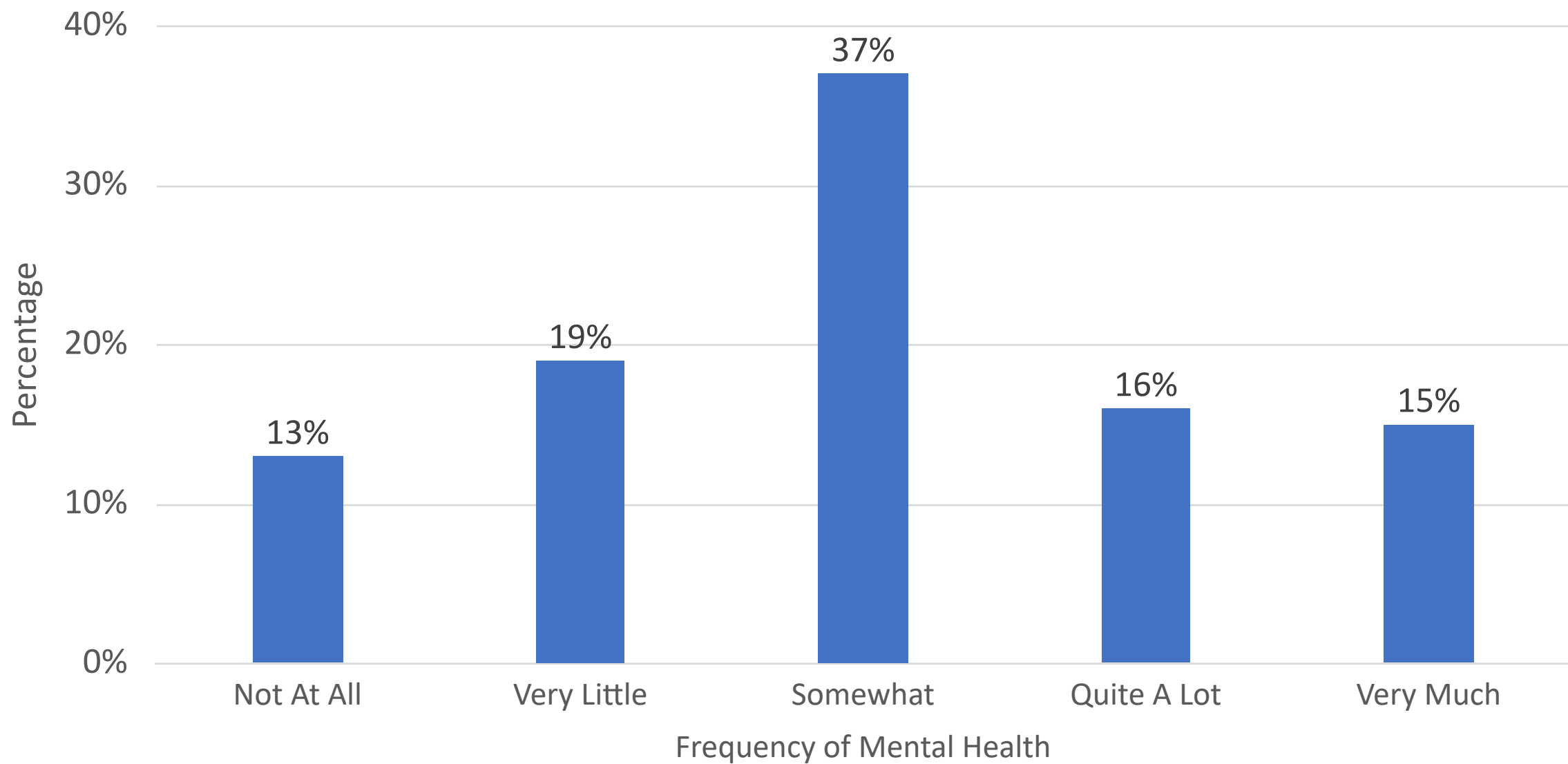
Age	Participants
0-2 years	65
3-5 years	50
6-9 years	26
10-12 years	15
13-17 years	12
18+ years	18
Youngest	18 days old
Oldest	57 years old

*HIGR data as of September 2023*



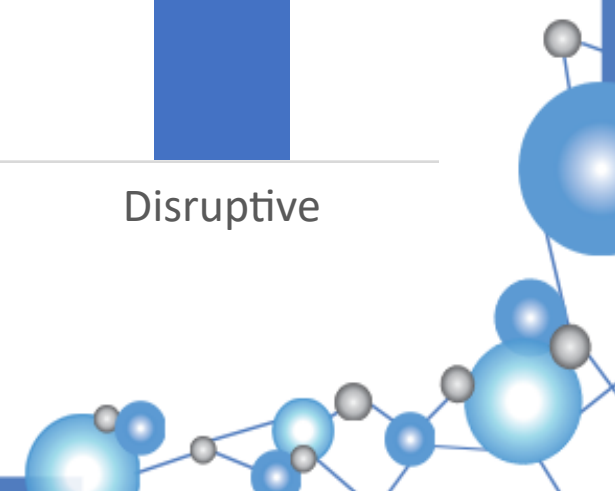
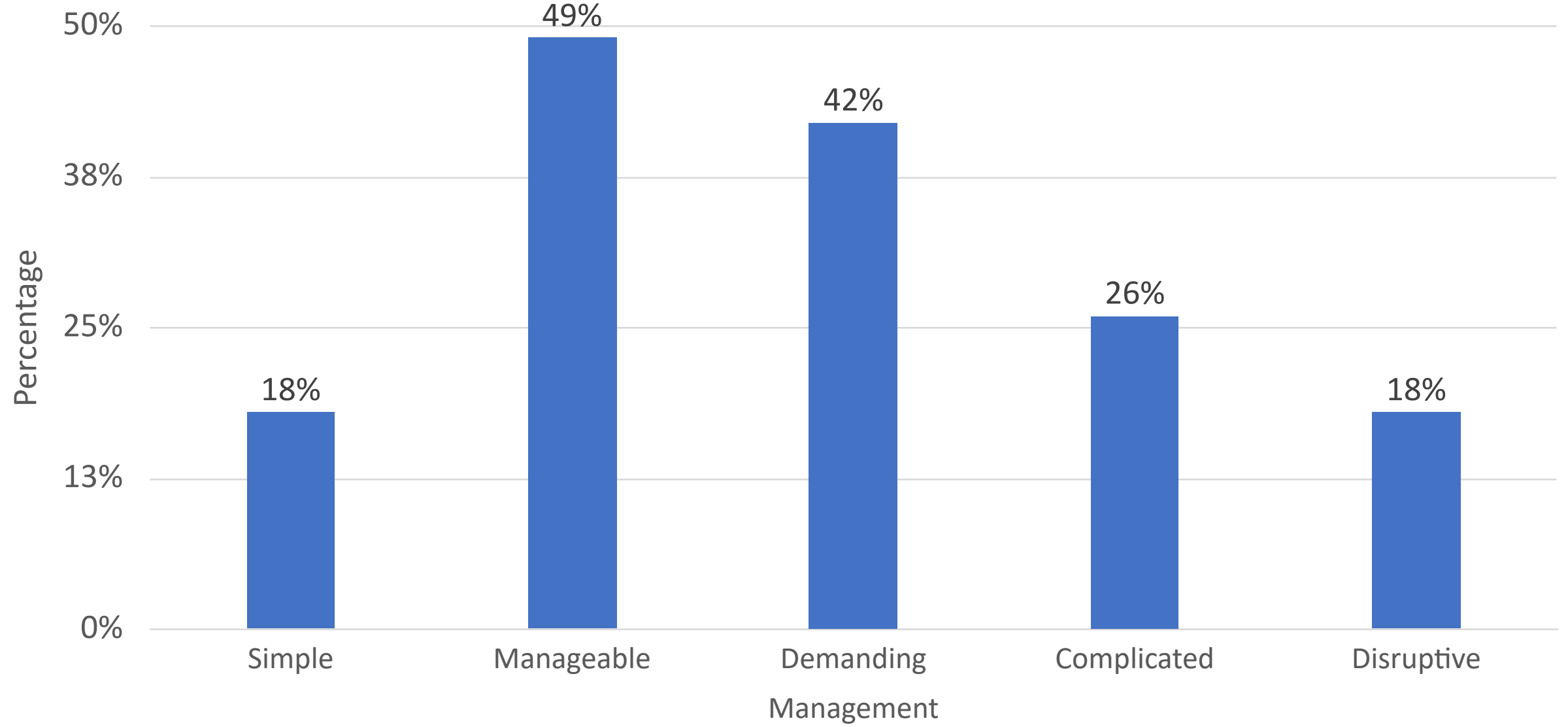
# Parent's Mental Health

n = 183



# Parent's Daily Management of HI (Choose all that apply)

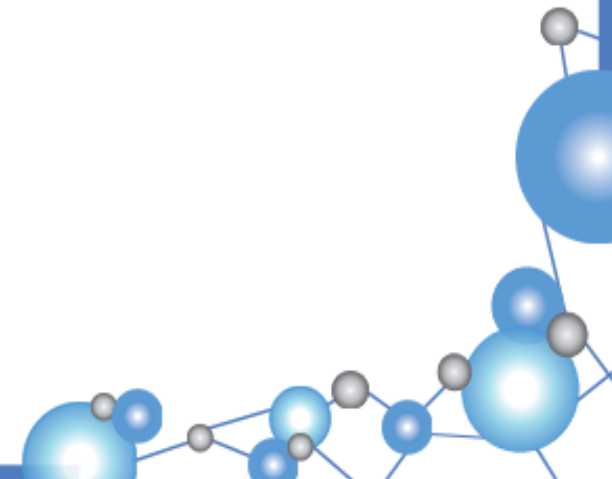
n = 180



# Characteristics of HIGR Participants Represented in Patient QOL Data

There are a total of 34 participants represented in this patient QOL data. The total N for some questions varies as respondents can choose to skip certain questions.

<b>Age</b>	<b>Participants</b>
13-17 years	6
18+ years	27
Youngest	1 year old
Oldest	57 years old



Caregiver (n = 183)

Participant (n= 34)

