

# Barriers to Healthcare for Autistic Adults

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Autism in Inclusion Health

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# Autism & Healthcare

- **Trigger warning**
- Poor mental health
- Poor physical health
- Premature mortality
- Suicide

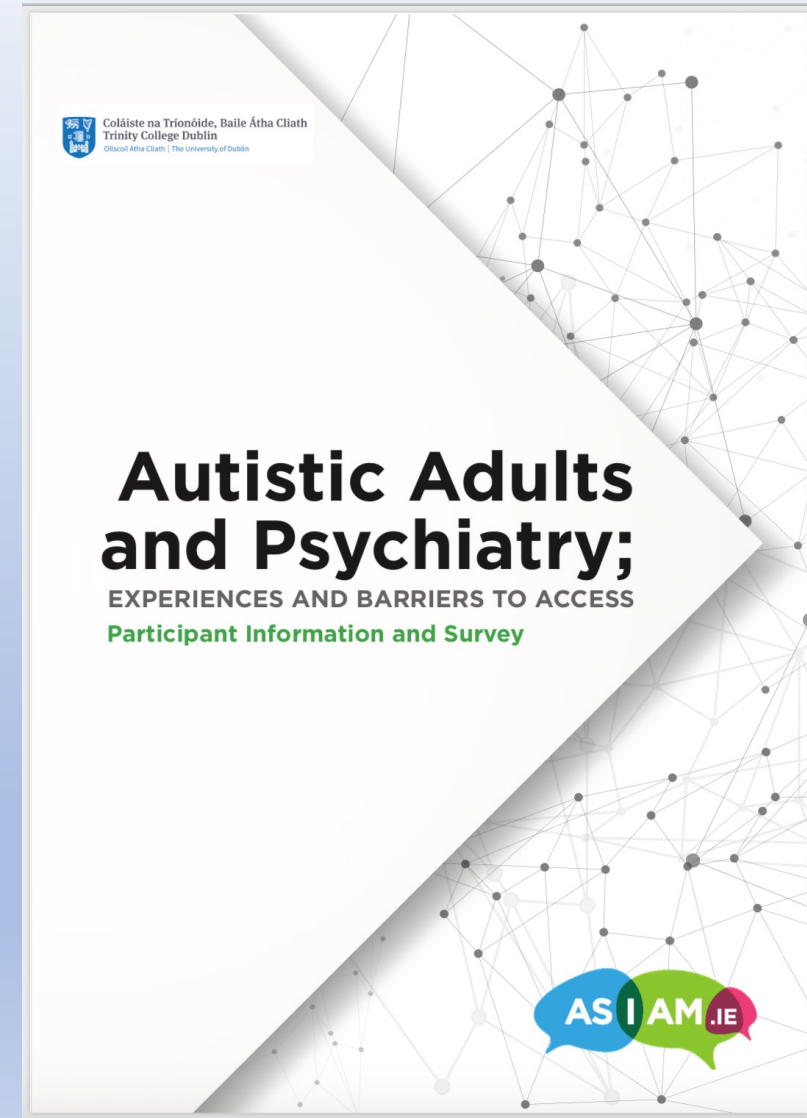
# Mental Health

- Anxiety
- Depression
- Bipolar Disorder
- OCD
- Eating Disorder
- Substance misuse
- Personality Disorder \*BPD / EUPD\*
- ADHD/Dyslexia/Dyspraxia

- Suicide – an autistic crisis
  - 66% ideation
  - 35% attempted
  - 15% of hospitalized
  - 11% of completed suicides

# Experiences in mental health services

- N = 101
- Currently attending psychiatrist 18%
- Attended in past 61%
- Difficulty attending 43%
- Male 30
- Female 39
- Non-binary 23



# Experiences in mental health services

- Suicide
  - 86% ideation
    - Inpatient 27%
    - Sectioned 11%
    - Restraint 10%
  - 47% attempted
    - Alcohol 28%
    - Illicit drugs 11%
  - 65% self harm
  - 21% medical care

# Autistic Adults and Psychiatry; Experiences and Barriers to Access

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## Introduction

Autistic people are more likely to experience mental illness than non-autistic people, including anxiety, depression, and post-traumatic stress disorder.<sup>1</sup>

Rates of anxiety and depression for are four to six times higher in the autistic community than the non-autistic community.<sup>2 3</sup>

Furthermore, autistic people are at considerably higher risk of self-harm, and both suicidal ideation and suicide attempts.<sup>4</sup>

Despite this, little is known about how or when, autistic people access psychiatry, and what acts as facilitators or barriers to their engagement.

It is important to understand these experiences in order to shape psychiatric services to promote autistic engagement and wellbeing.

## Objective

The aim of this study was to understand the experiences that autistic adults had of mental health and accessing psychiatric care.

## Method

101 autistic adults engaged in an anonymous survey at Autscope, an autistic-led social event. See figure 1. Median age at diagnosis was 32 (range 6 - 66). A questionnaire with quantitative and qualitative responses was developed. The aim of the study was to investigate:

- The prevalence of self-reported co-occurring mental health conditions in autistic adults and associated inpatient psychiatric admissions
- Experiences of self-harm, suicidal ideation and attempts
- Preferred or avoided sources of help in crisis
- Experience of inpatient psychiatric care
- Barriers experienced in accessing mental health services

Autscope is a conference specifically by and for autistic people, welcoming participants from across the spectrum of all ages, including those who are non-speaking, have high support needs or a full-time carer. Survey respondents were those able to read the survey and express themselves by writing or typing.

Ethical approval was gained from the Trinity College Dublin Faculty of Health Sciences Research Ethics Committee prior to data collection.

This poster shows the descriptive analysis of the quantitative data with some representative quotes (in speech bubbles) to provide further insight.

## Results

Many participants reported psychiatric diagnoses prior to autism (fig. 1), in-patient psychiatric care (fig. 3), self-harm and suicidal ideation (fig. 4) and would seek help from different formal and informal supports (fig 2).

Table 1.

	Mean	SD
Female	45.5	14.8
Male	48.0	11.9
Non-Binary	35.8	11.2
Other	45.0	20.8
Prefer not to say	47.2	27.2

78% were from the UK, 20% from Europe & 2% from Australia. 99% of respondents identified as autistic, with 92% reporting a formal diagnosis, specifically Asperger Syndrome (48%), Autism Spectrum Disorder (29%), High Functioning Autism (10%) and Autism Spectrum Condition (5%).

Fig 1.

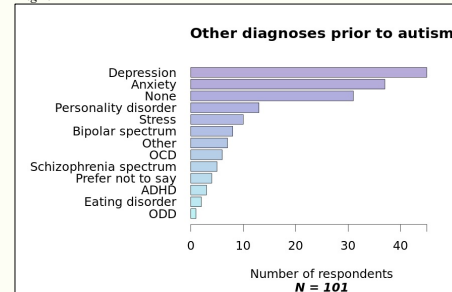
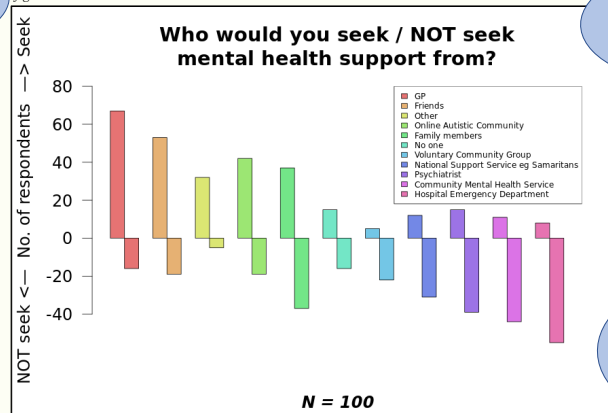


fig 3.



We don't do autism but I can offer you borderline personality disorder if you like

Restraint used during meltdowns made meltdowns worse

My communication of my symptoms will not meet their expectations

there was no one who knew about or was trained in autism

Fig 3.

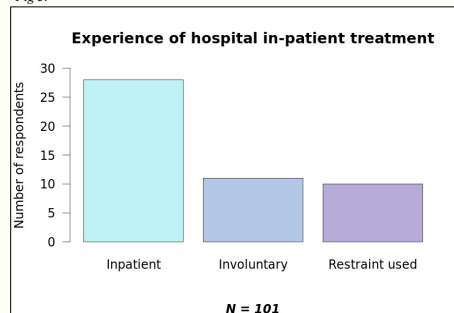


Fig 4

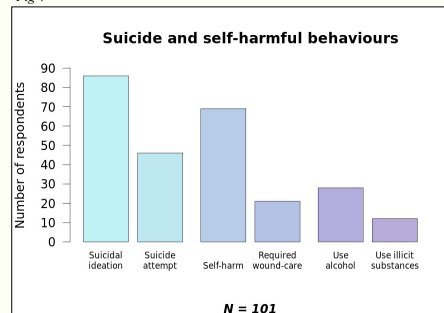


Table 2.

Use of Healthcare	
Respondents registered with a GP	94%
Currently attending psychiatrist	19%
Previously attended psychiatrist	64%
Good relationship with psychiatrist	21%
Expressed difficulty attending psychiatrist	44%

## Discussion

High rates of co-occurring mental ill health reflect findings from previous studies<sup>1</sup>.

Suicidality and self harm were higher than previously reported in an autistic cohort<sup>4</sup>.

There was a high rate of involuntary admission to psychiatric settings (10%), with multiple reports of seclusion and restraint.

Autistic people face barriers to accessing psychiatric care including prior negative experience with mental health services.

Ongoing thematic analysis will further explore experiences, barriers and facilitators to psychiatric care.

The sample was a non-probability sample limited to a specific autistic lead event. Further research on a wider and larger sample is needed.

## Conclusion

This community led study shows the range of experiences that autistic people have with psychiatric care. Further research needs to explore reducing barriers to accessing high quality psychiatric care with staff trained in autism.

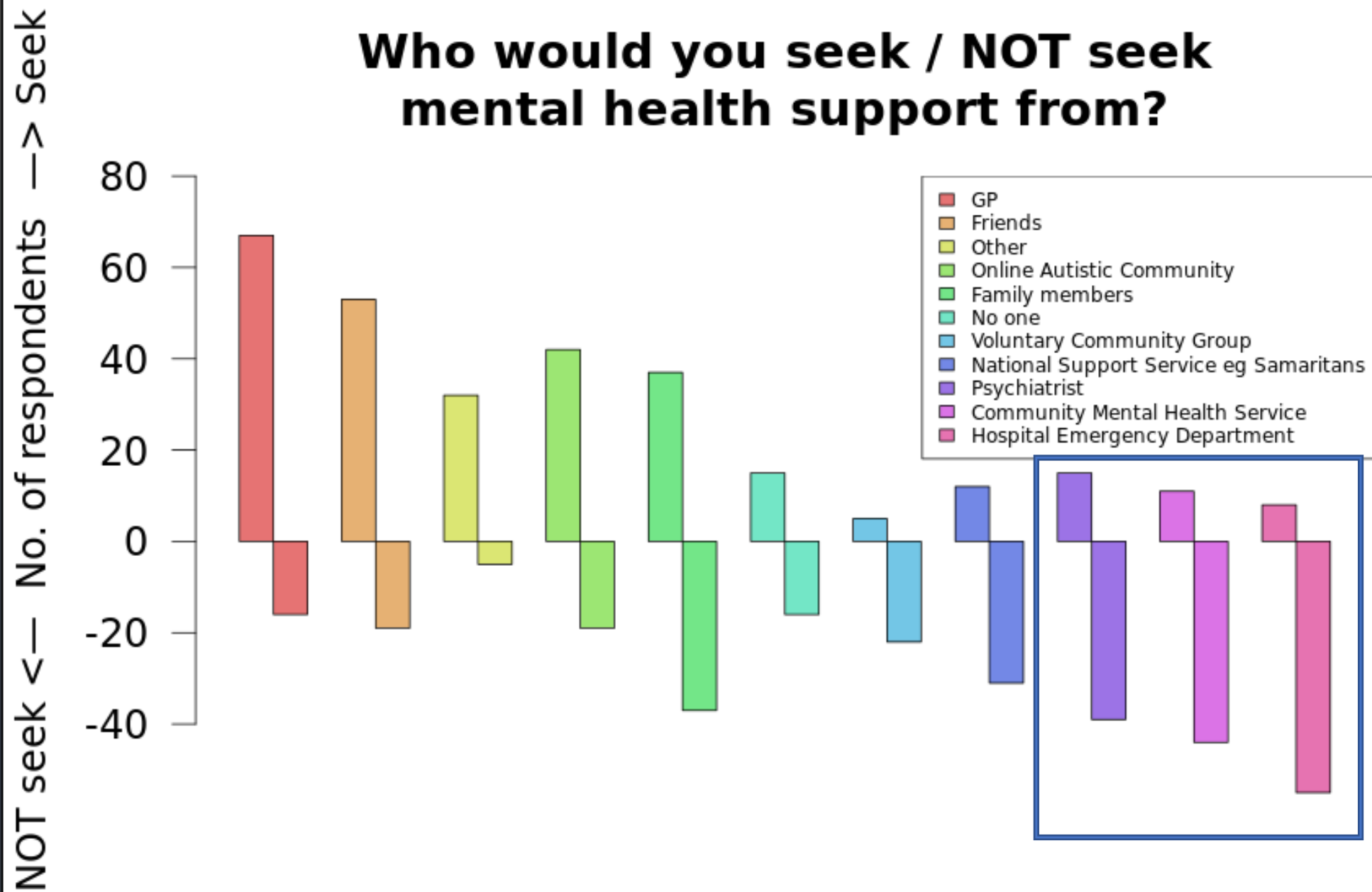
My psychiatrist is autistic and one of the best mental health experts I know

Autistic people can thrive

## References

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- 3 Kerns, C. M., Raab, J. E., & Shattuck, P. T. (2020). Prevalence and Correlates of Caregiver-Reported Mental Health Conditions in Youth With Autism Spectrum Disorder in the United States. *The Journal of Clinical Psychiatry*, 82(1). doi: 10.4088/JCP.20m13242
- 4 Cassidy, S., Bradley, P., Robinson, J., Allison, C., McHugh, M., & Baron-Cohen, S. (2014). Suicidal ideation and suicide plans or attempts in adults with Asperger's syndrome attending a specialist diagnostic clinic: A clinical cohort study. *The Lancet Psychiatry*, 1(2), 142-147. doi: 10.1016/S2215-0366(14)70248-2

## Who would you seek / NOT seek mental health support from?



***N = 100***

# Premature mortality in autism spectrum disorder

- 27,000 people in Sweden diagnosed with ASD
- To examine all-cause and cause-specific mortality in ASD
- To investigate moderating role of gender and intellectual ability
- General population mortality rate 0.91%
- Mortality rate for the ASD group was 2.56%
  - 2.60%; OR = 2.56; 95% CI 2.38–2.76

Hirvikoski, T., Mittendorfer-Rutz, E., Boman, M., Larsson, H., Lichtenstein, P., & Bölte, S. (2016). Premature mortality in autism spectrum disorder. *British Journal of Psychiatry*, 208(3), 232-238



# Premature mortality in autism spectrum disorder

- Average life expectancy for the general population was about **70 years**
- In the autistic group it was **54 years**
- For those with co-occurring cognitive disabilities it was just under **40 years**
- Leading causes of death were heart disease, suicide, and epilepsy
- Cause-specific analyses showed elevated mortality in ASD for all diagnostic categories (except infections)

Hirvikoski, T., Mittendorfer-Rutz, E., Boman, M., Larsson, H., Lichtenstein, P., & Bölte, S. (2016). Premature mortality in autism spectrum disorder. *British Journal of Psychiatry*, 208(3), 232-238

# Physical Health

- Diabetes
- Obesity
- Hypertension
- High cholesterol
- Stroke
- Epilepsy
- Parkinson's
- Sleep disorders
- Digestive disorders
- EDS / Hypermobility
- Known healthcare disparities
- Known access barriers
- Patient/provider communication
- Sensory sensitivities
- Executive function/planning issues
- Prior negative experience

# Emergency Department Use among Adults with Autism Spectrum Disorders (ASD)

- One-third of ED visits among adults with ASD led to an inpatient admission (34%) as compared to one-tenth of ED visits among adults without ASD
- Approximately one percent of adults with ASD had a mortality event after an ED visit as compared to 0.3% adults without ASD
- Three times as likely to have a serious condition, three times as likely to die

Vohra, R. et al, J Autism Dev Disord (2016) 46: 1441.

- Because autistic people delay seeing their own doctor, or have no doctor?



# What do you wish your doctor (GP) knew about autism?



## Barriers to Accessing Healthcare in the Autism Community

There are 3 versions to choose from:

If you are autistic please complete the following survey:

<https://go.gl/forms/2ce9m723-2b1e252>

If you are not autistic but you are a parent of an autistic child, please complete the following survey:

<https://go.gl/forms/2ce9m723-2b1e252>

If you are not autistic and not a parent of an autistic child please continue to the next section

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Google Forms

 **AUTSCAPE 2018**  
Exploring Inclusion



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## Barriers to healthcare for autistic adults: Consequences & policy implications. A cross-sectional study

Mary Doherty, Stuart D Neilson, Jane D O'Sullivan, Laura Carravallah, Mona Johnson, Walter Cullen,  
Louise Gallagher

**doi:** <https://doi.org/10.1101/2020.04.01.20050336>

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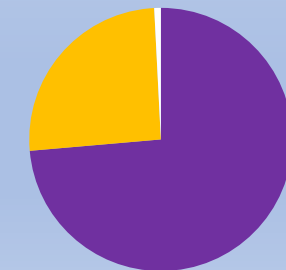
196

157

Autistic Parent Control

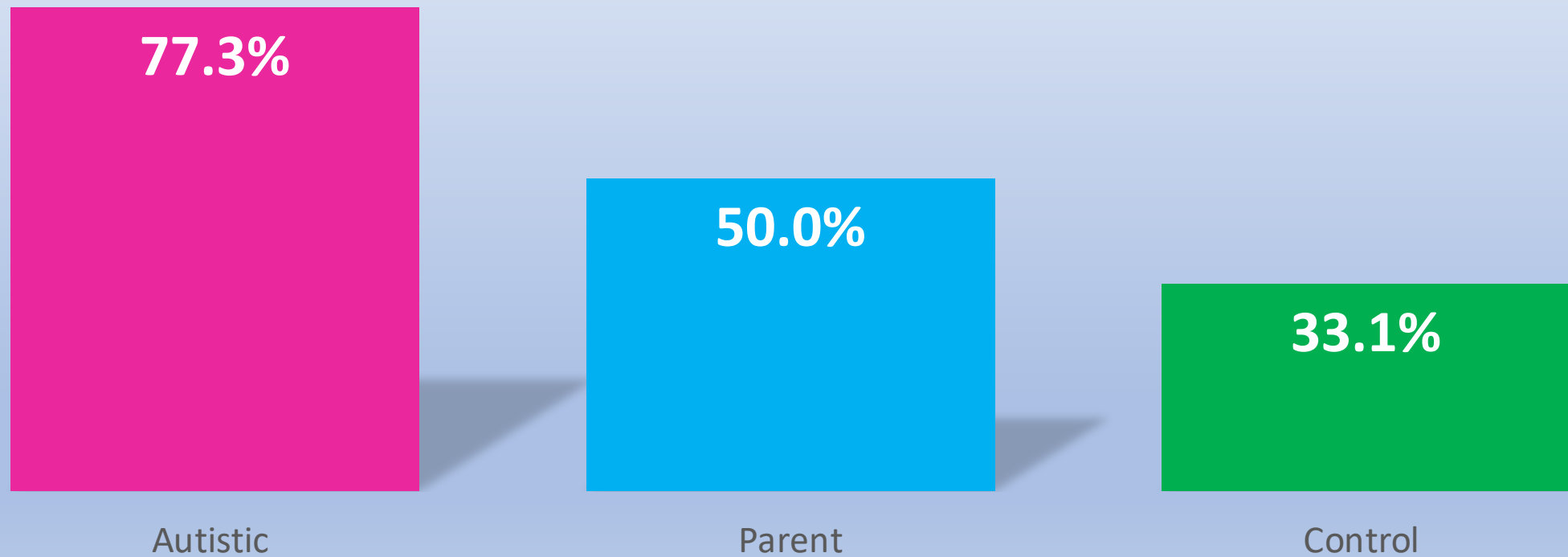
Respondents  
n = 860

Formal diagnosis



■ Yes ■ No

# Do you have difficulty visiting your doctor when you need to?



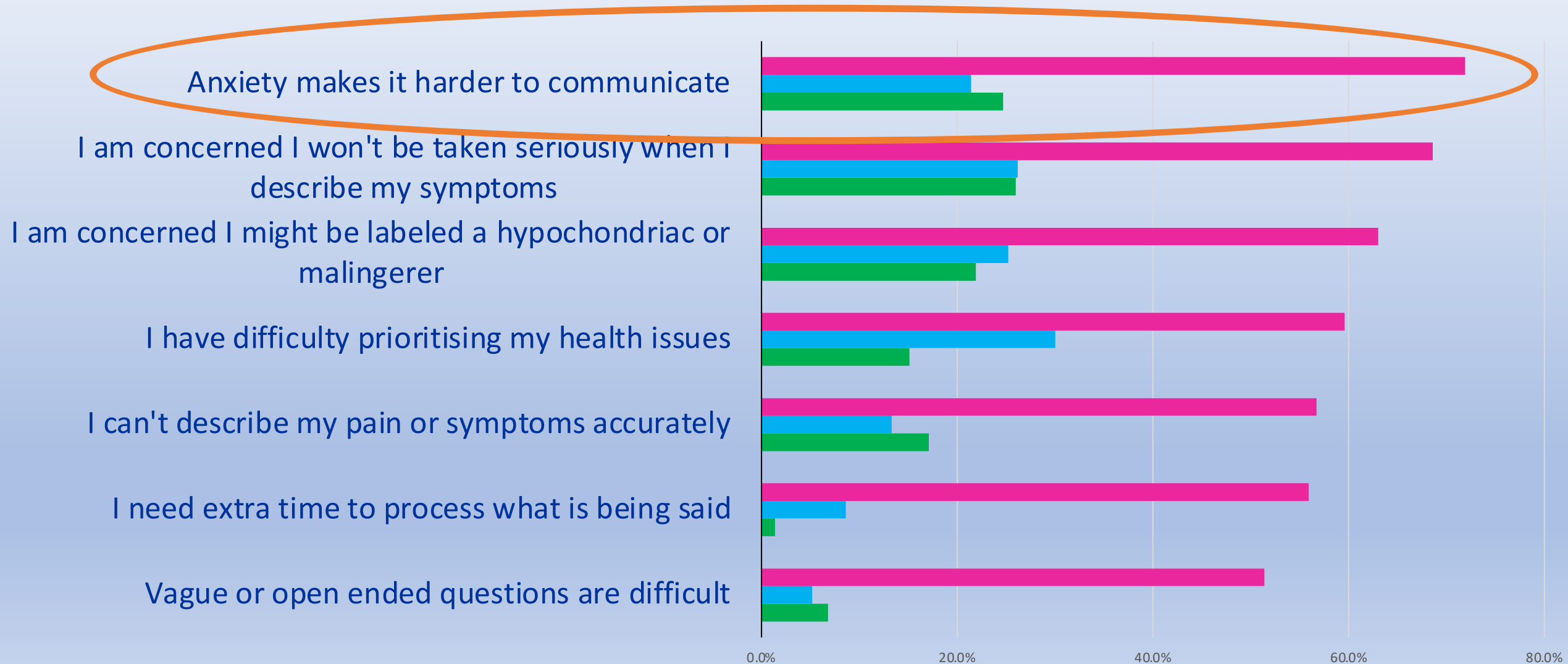
# Key Findings

- 78% of autistic respondents avoid using telephone
- Most common barrier to healthcare access (60%)
- 55% of autistic respondents avoid or delay a GP visit because of not feeling understood
- Sensory difficulties in waiting room
- Executive functioning / planning difficulties
- Concerns around disclosure of diagnosis



I'm afraid if the GP finds out I'm autistic she'll decide I'm a bad parent

# Communication during consultation (1)





# Communication during consultation (1)

Anxiety makes it harder to communicate

I am concerned I won't be taken seriously  
when I describe my symptoms

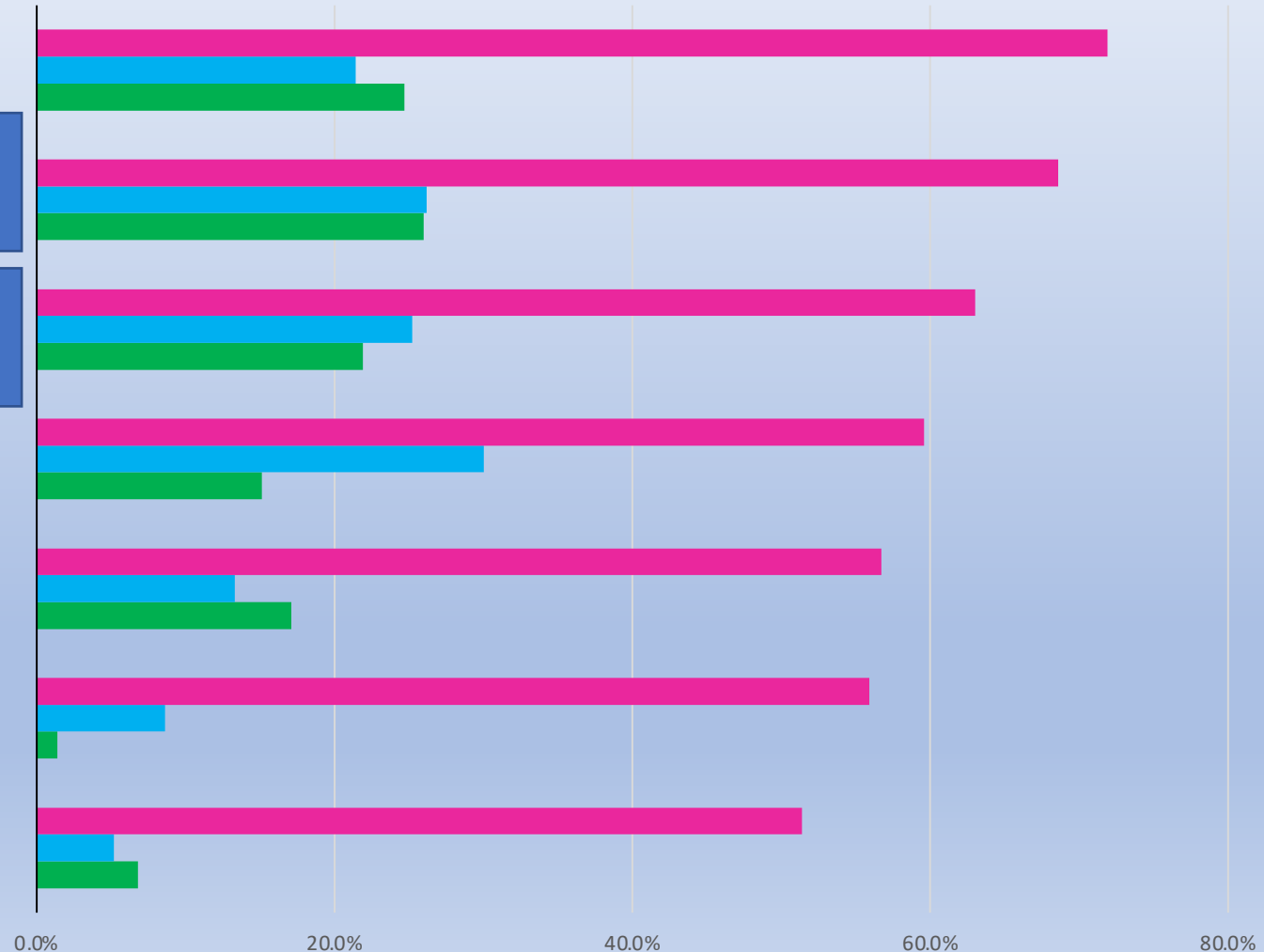
I am concerned I might be labelled a  
hypochondriac or malingerer

I have difficulty prioritising my health issues

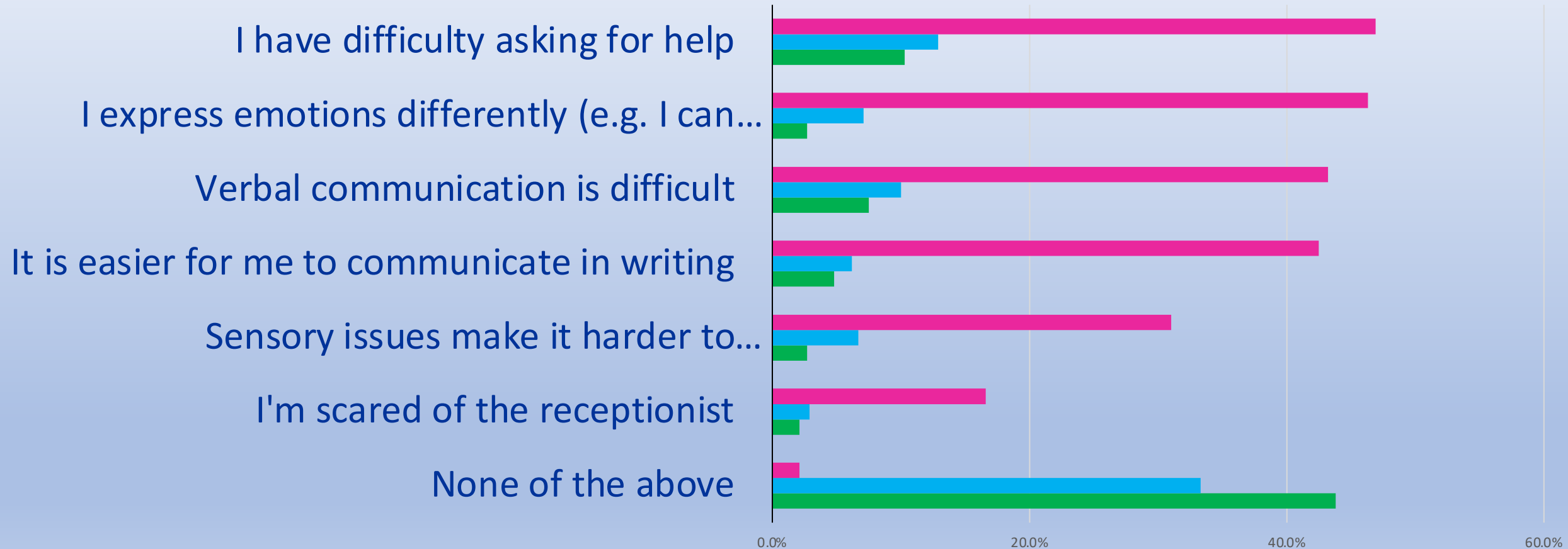
I can't describe my pain or symptoms accurately

I need extra time to process what is being said

Vague or open ended questions are difficult



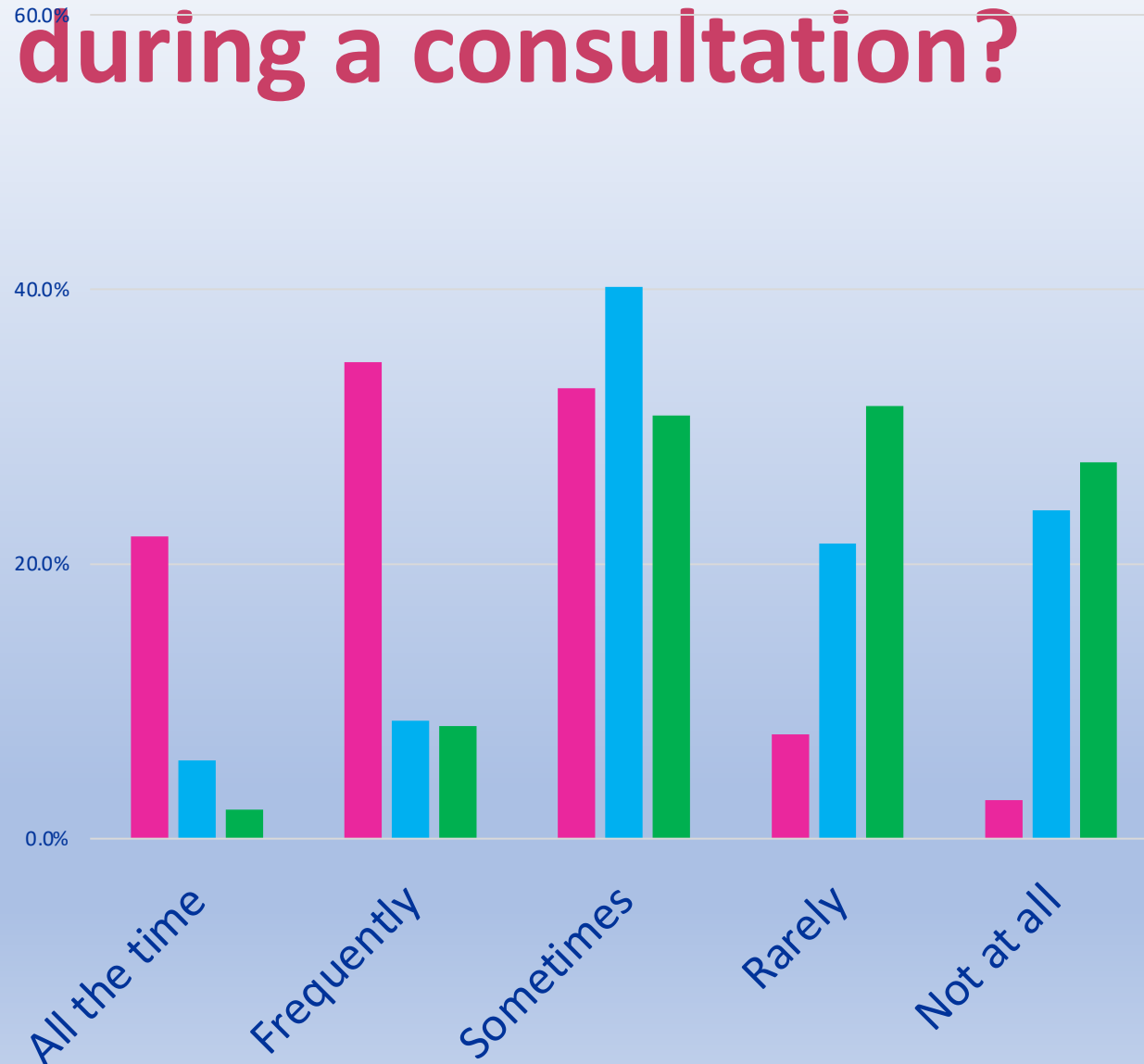
# Communication during consultation (2)



# Communication during consultation (2)



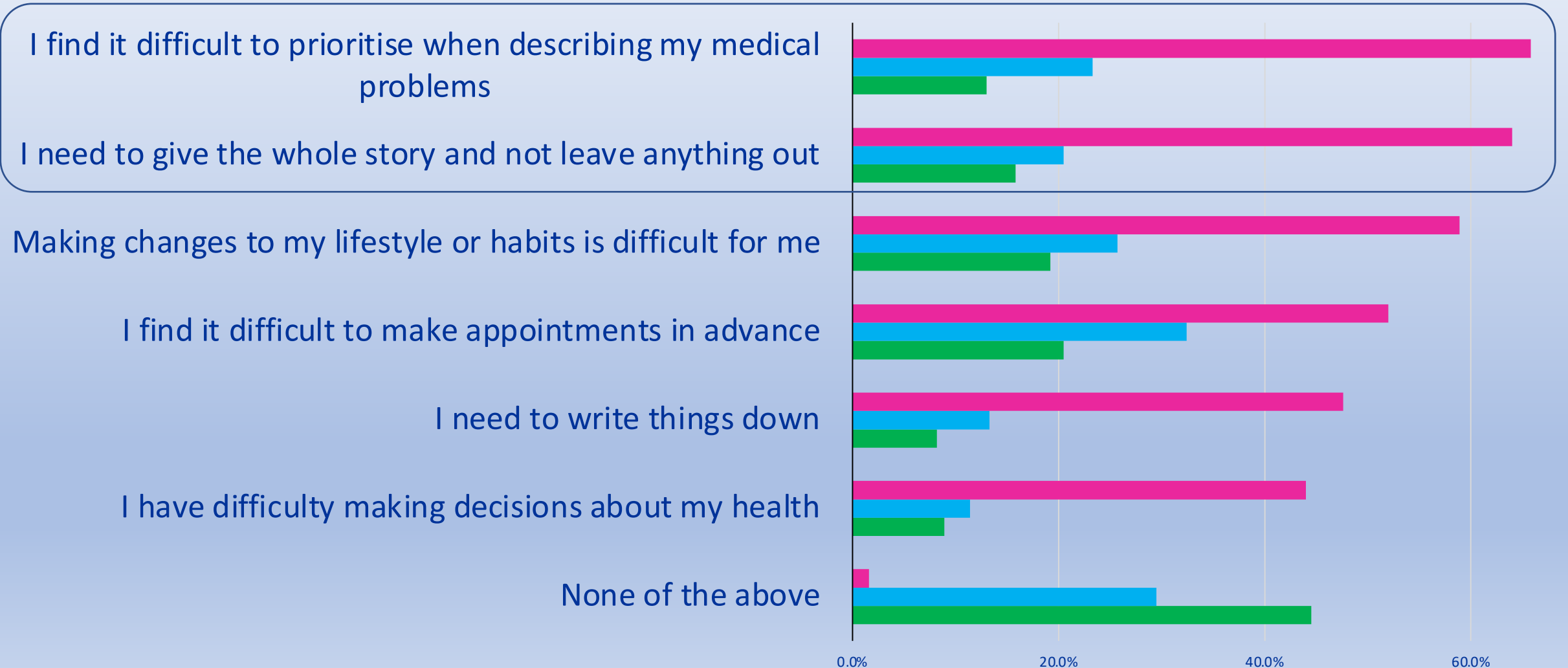
# Do you find it difficult to communicate during a consultation?



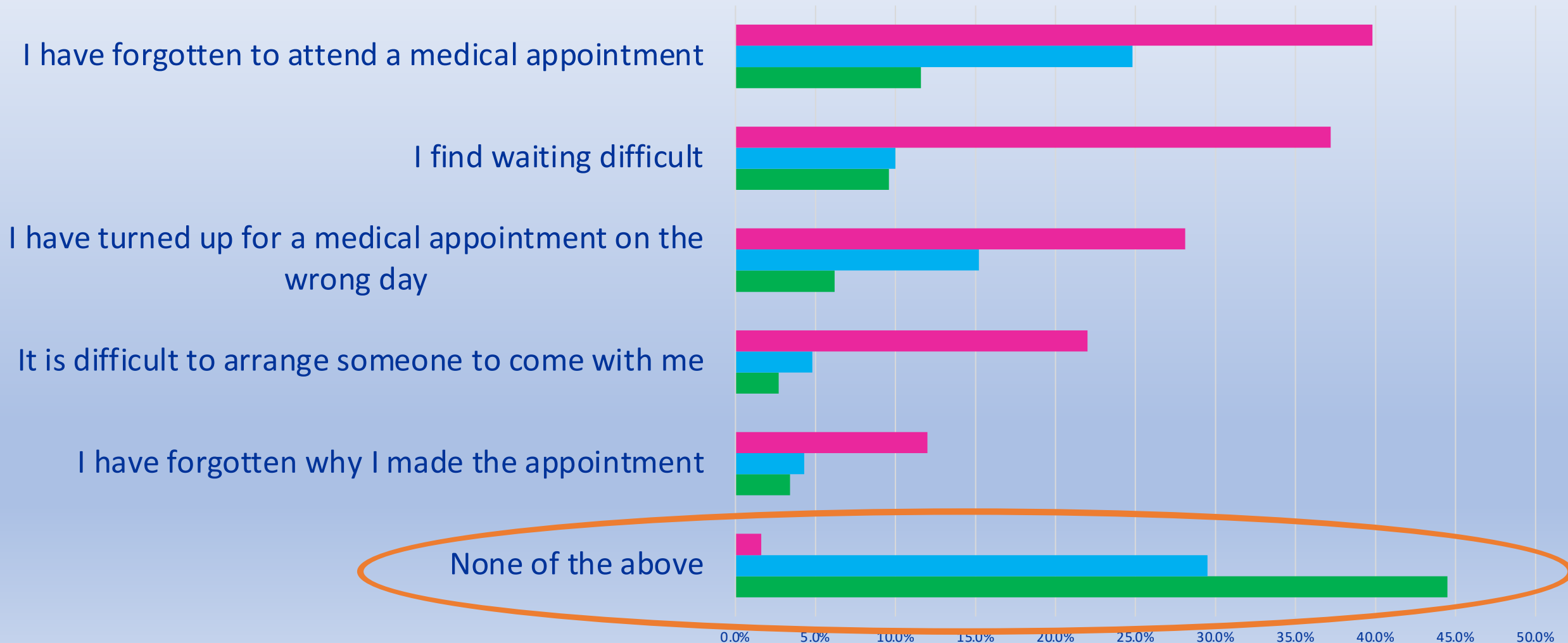
I find it hard to turn my thoughts into words. And my symptoms into language

It's hard to answer general questions because I want to give very precise answers otherwise I feel like I am lying

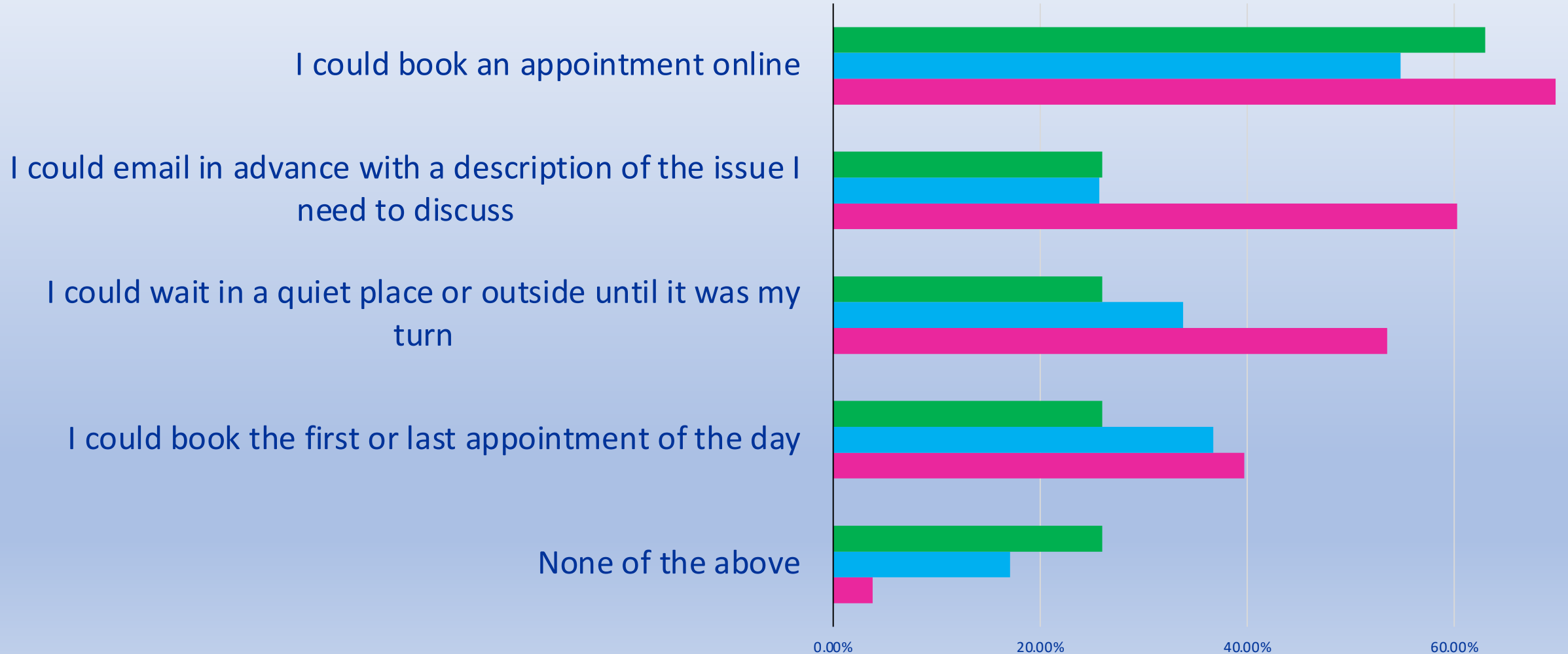
# Executive functioning / planning issues



# Executive functioning / planning issues



# Visits to my doctor would be easier if...



# Consequences

	Autistic	Parent	Control
Mental health condition remain untreated	65%	31%	17%
Physical health condition remain untreated	65%	41%	26%
Did not attend referral to a specialist	51%	32%	20%
Told you should have seen a doctor sooner	63%	49%	38%
More extensive treatment or surgery	38%	22%	14%
Potentially serious or life threatening condition untreated	32%	14%	6%
Do not attend on schedule for screening programmes	42%	21%	19%



# Lack of support

It should not be assumed that people have friends/partners/families who are willing and able to provide unpaid assistance

Who would be available to...	Autistic Nobody available	Control Nobody available
Bring your personal belongings to you in hospital	14%	6%
Collect you after a day case surgical procedure	17%	6%
Assist you at home after an operation	24%	8%
Care for your child if you were unable due to illness	5%	3%

“The one question this survey does not address: I simply do NOT go to doctors for all the reasons listed”

“I don't "have" a GP or a doctor”

“I don't go to doctors”

“I avoid seeing any doctor as far as possible”

“I don't really go to a doctor at all”

“I don't know how to find a doctor”

# Key Findings - Consequences

- The consequences of access barriers to healthcare include
  - Untreated physical conditions
  - Untreated mental health conditions
  - Late presentations
  - Emergency admissions
  - More extensive treatment or surgery
- Many autistic adults have no access to primary healthcare
- No difference between those self identified or formally diagnosed

# Summary

- Alternatives to telephone
- Strengths based approach
- Resist the tragedy narrative
- Education and training for healthcare providers
- Autism Friendly Healthcare – for autistic staff as well as patients

