



React19 Persistent Symptoms Survey #2

REACT¹⁹

Symptoms Progression

1047 Participants

09/30/2021 – 04/03/2022



REACT¹⁹

Survey Outline

Part 1:

- Symptoms prevalence
- Symptoms evolution
- Symptoms cluster
- Quality of Life
- Pre-Existing Conditions
- Methodology

Part 2:

- Tests
- Diagnoses



Validate findings of the previous analysis



Improve data visualisation



Find additional information, clusters, patterns, and/or trends if present



Identify flaws and issues to improve the next survey round

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Patient-Led Surveys

Prevalence of Reported Symptoms

General

Fatigue 82%

Exercise Intolerance 77%

Sleep Disorders 76%

Dizziness/Vertigo 67%

Muscle Weakness 63%

Chills 36%

Lymphadenopathy 29%

Musculoskeletal

Myalgia 60%

Arthralgia 57%

Muscle Atrophy 36%

Neurological

Brain Fog 72%

Paraesthesia 69%

Neuralgia 53%

Headaches 52%

Fasciculations 49%

Tremors 46%

Amnesia 46%

Paralysis 8%

Seizures 3%

Respiratory

Dyspnoea 56%

Cough 19%

Cardiovascular

Heart Palpitations 66%

Tachycardia 56%

Oedema Extremities 52%

Hyper/Hypotension 44%

Varicose Veins 19%

Raynaud's Phenomenon 11%

Endocrinologic

Adrenaline Surges 58%

Increased Thirst 35%

Heat Intolerance 34%

Dist. in Glucose Levels 13%

Gastrointestinal

Bowel Problems 44%

Abdominal Pain 41%

Nausea 39%

Heartburn 36%

Flatulence 24%

Melaena 8%

Jaundice 5%

HEENT

Ocular Problems 60%

Tinnitus/
Hyperacusis 59%

Xerostomia 31%

Sore Throat 22%

Genitourinary

Urinary Incontinence 37%

Menstrual Disorder 20%

Dermatology

Skin Problems 30%

Alopecia 27%

Psychiatric

Anxiety 45%

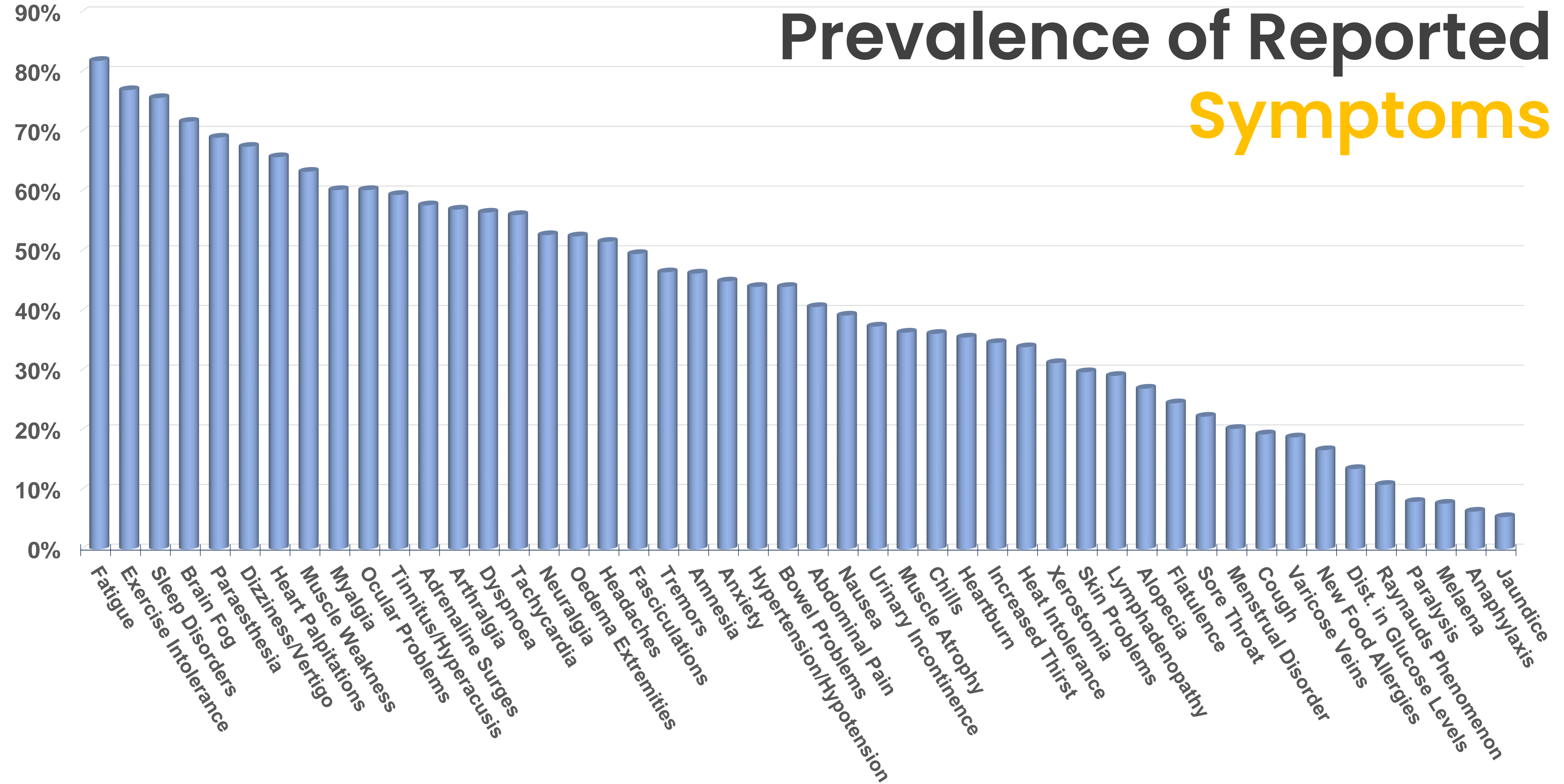
Allergies

New Food Allergies 17%

Anaphylaxis 6%

□ □ □ Patient-Led Surveys

Prevalence of Reported Symptoms



Reported Symptoms

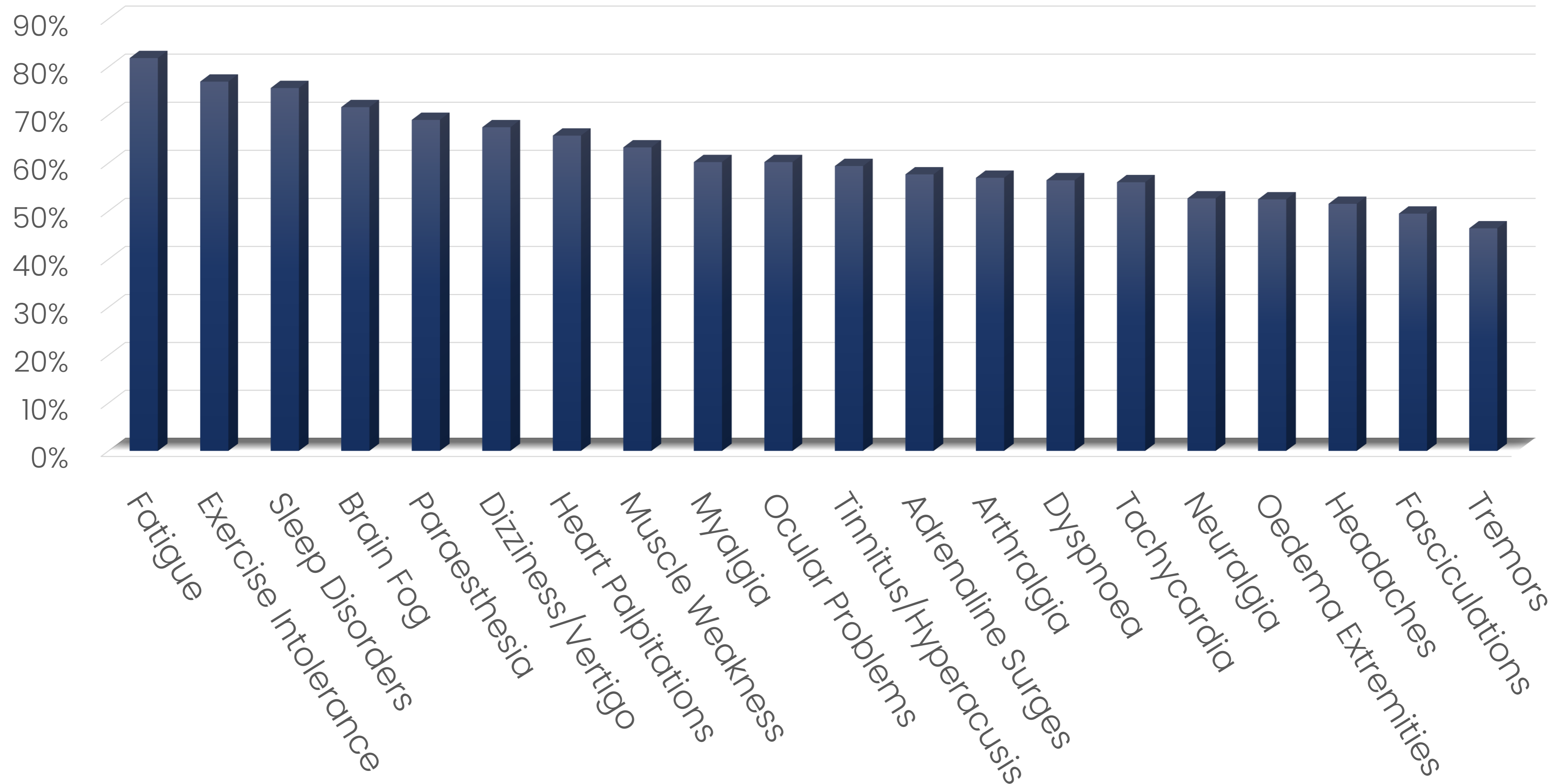
- general
- neurological
- cardiovascular
- gastrointestinal
- heent
- musculoskeletal
- endocrinologic
- respiratory
- genitourinary
- integumentary
- psychiatric
- allergy





Patient-Led Surveys

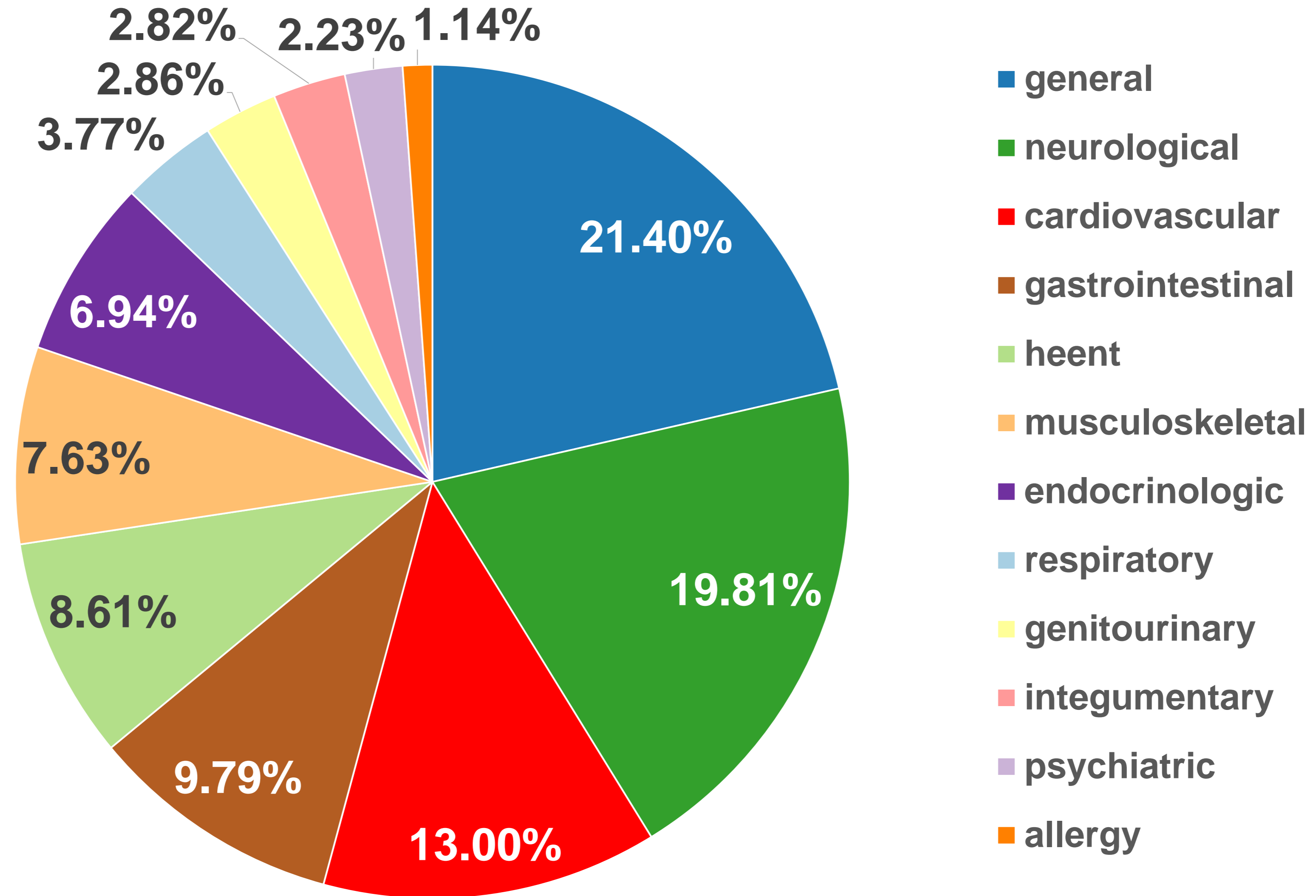
Top 20 Symptoms



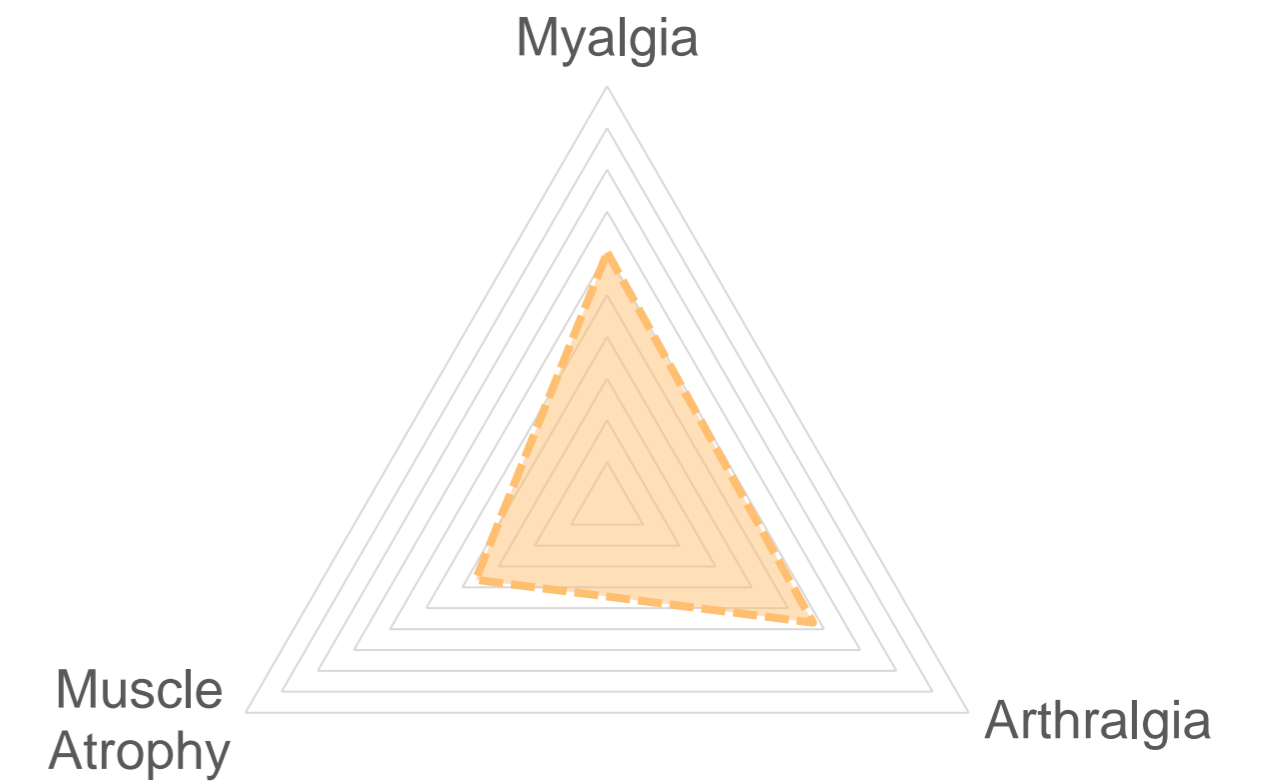
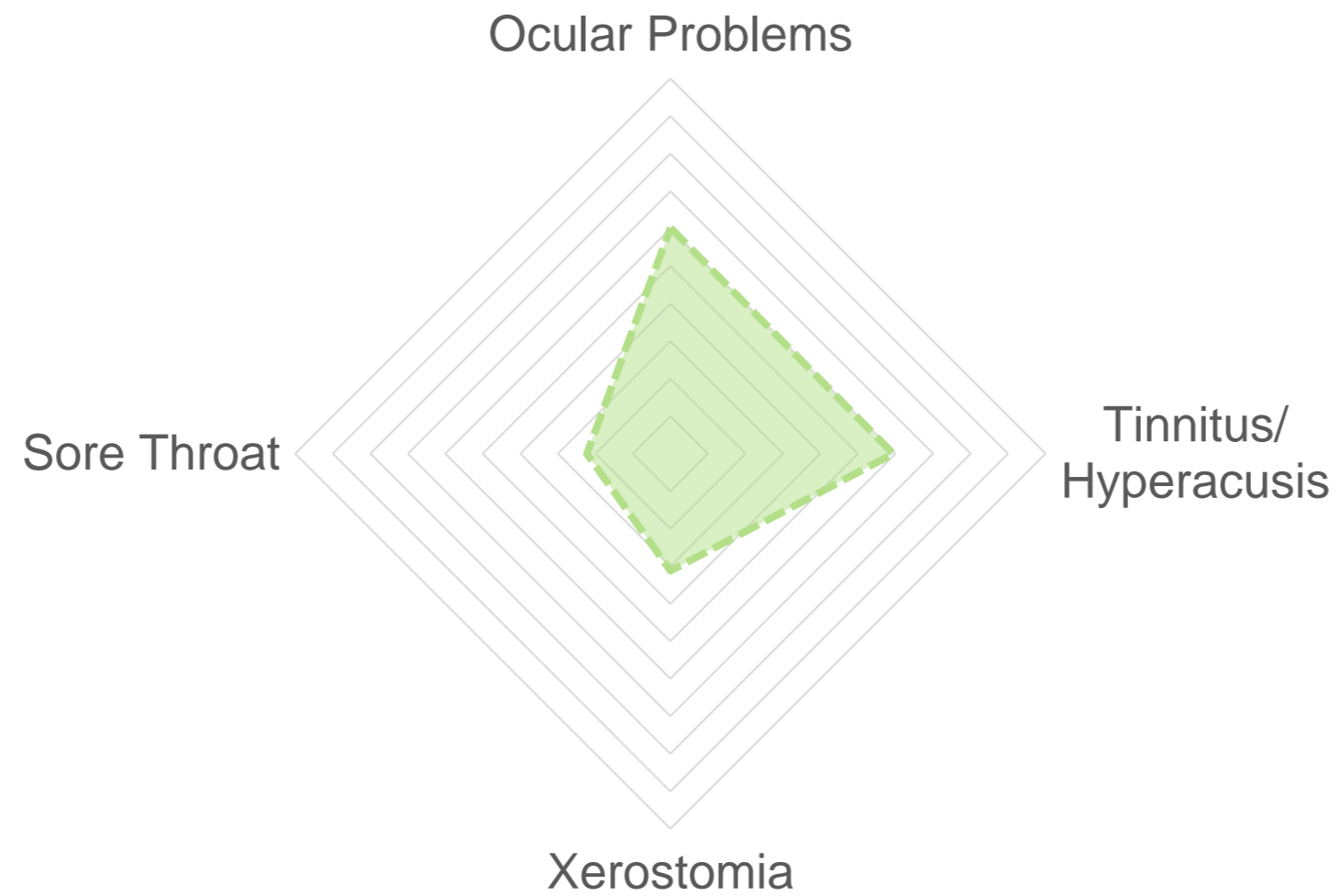
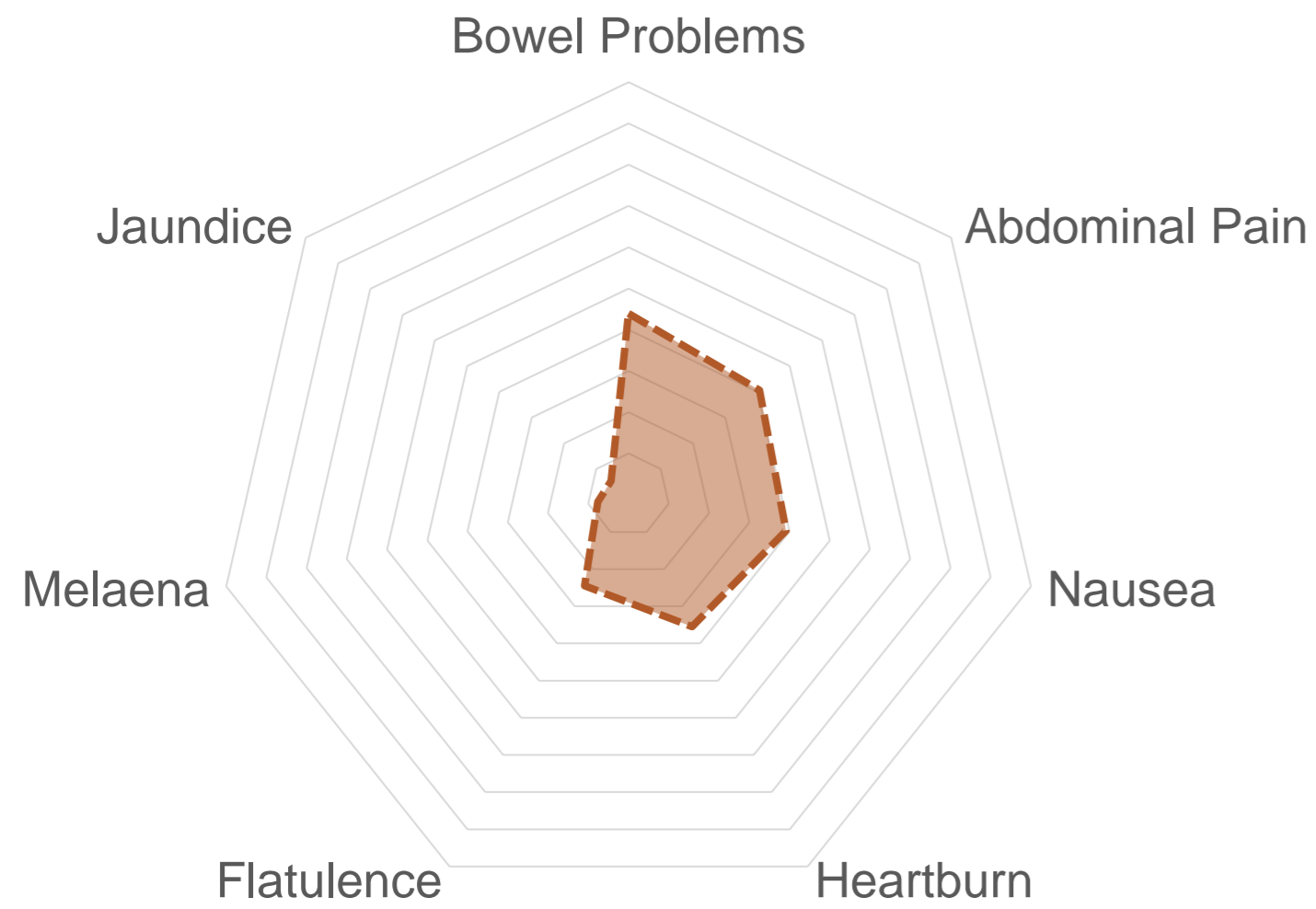
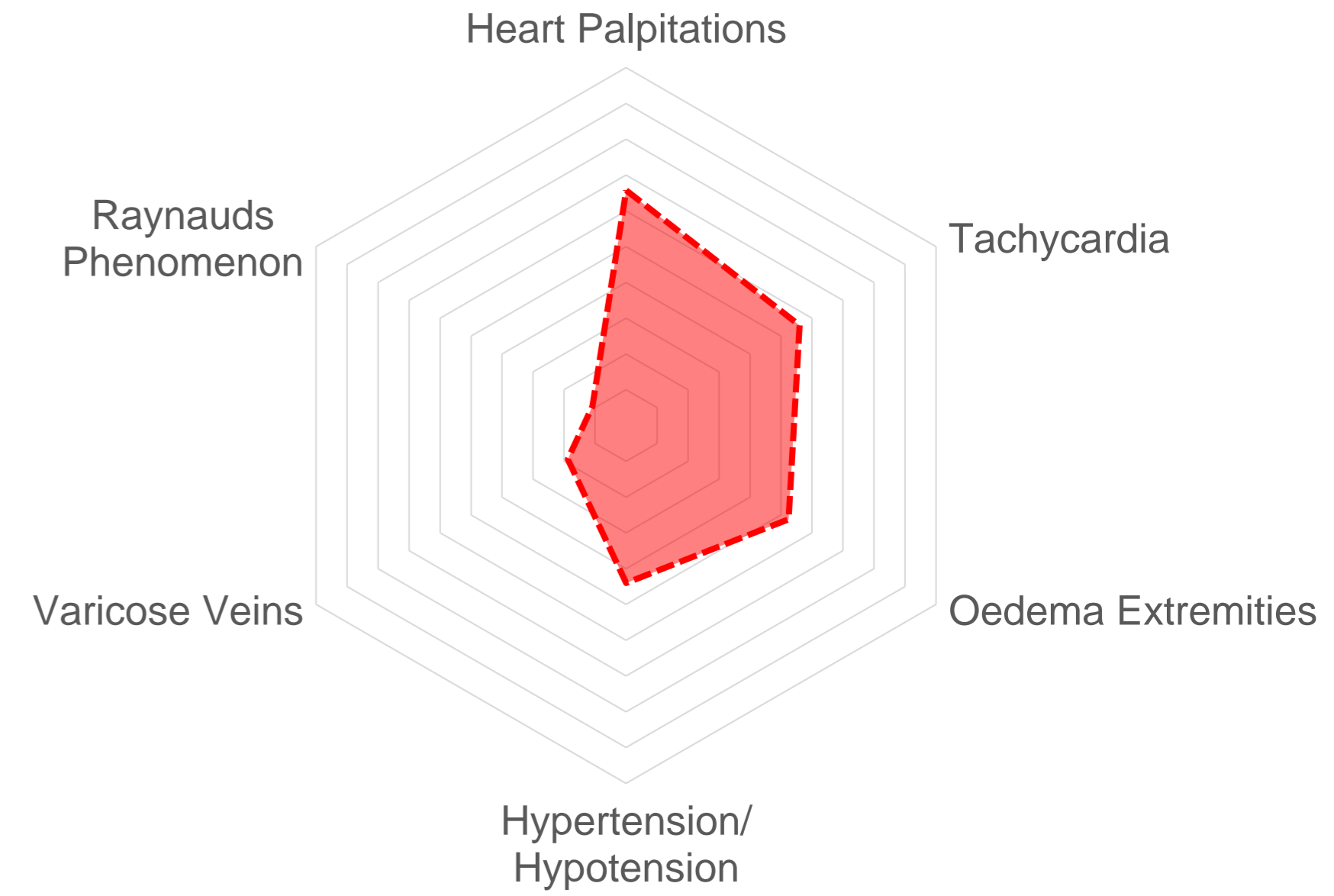
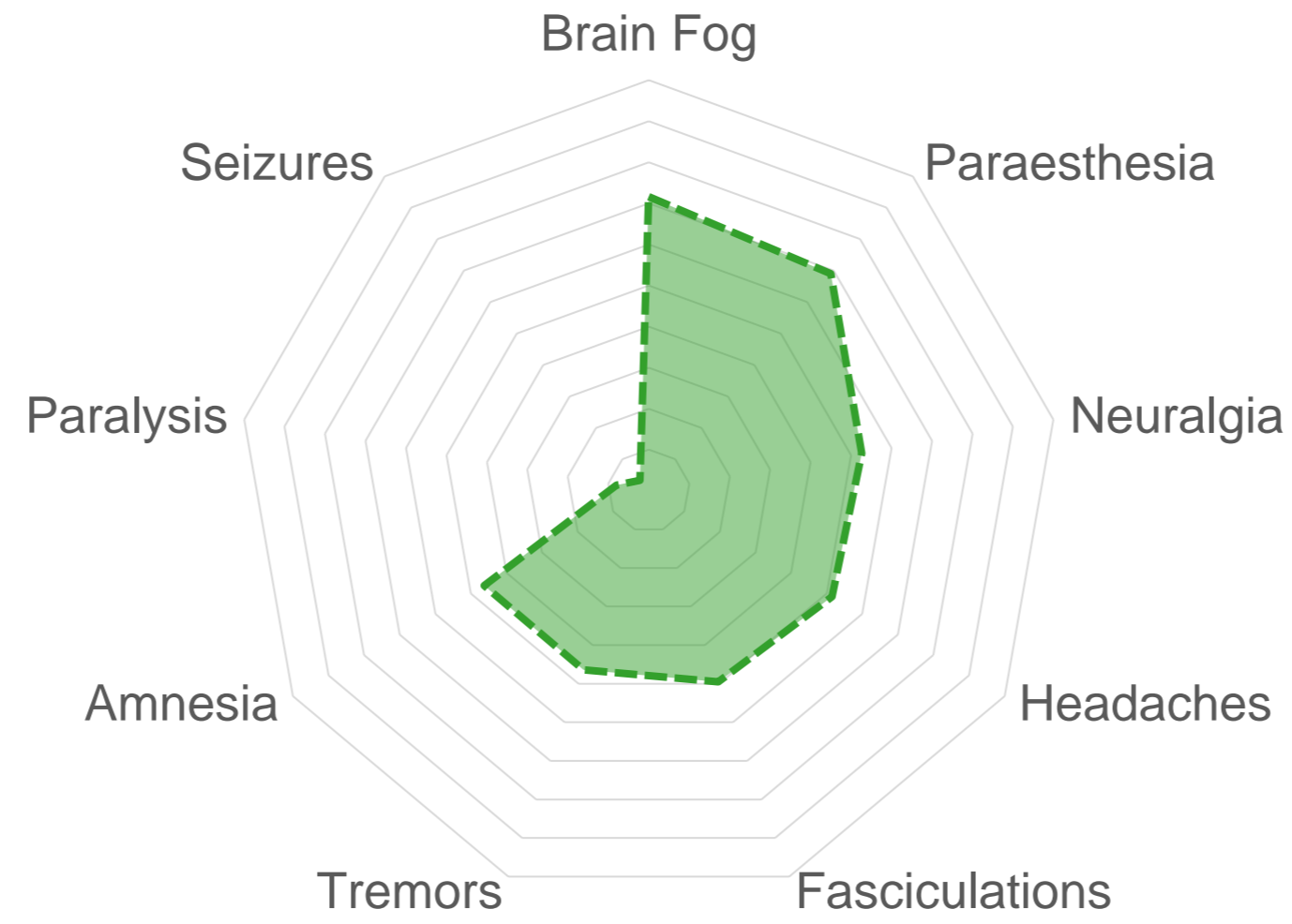
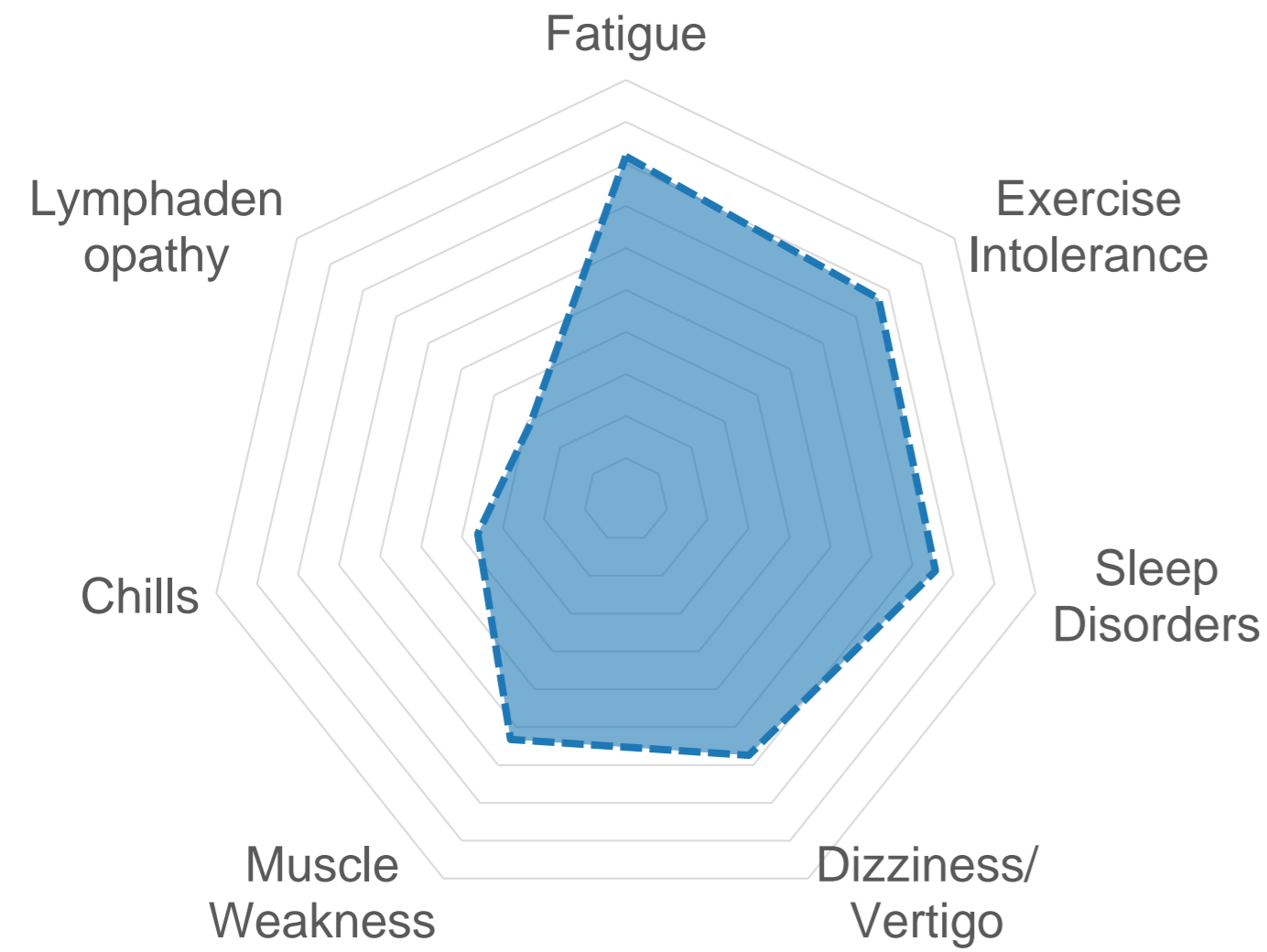


Patient-Led Surveys

Symptom Classes



Reported Symptoms



0-100% scale

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Overall Symptoms Evolution

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Patient-Led Surveys

Symptoms Evolution



Symptom Onset

Symptom Quantity

Symptom Timeline

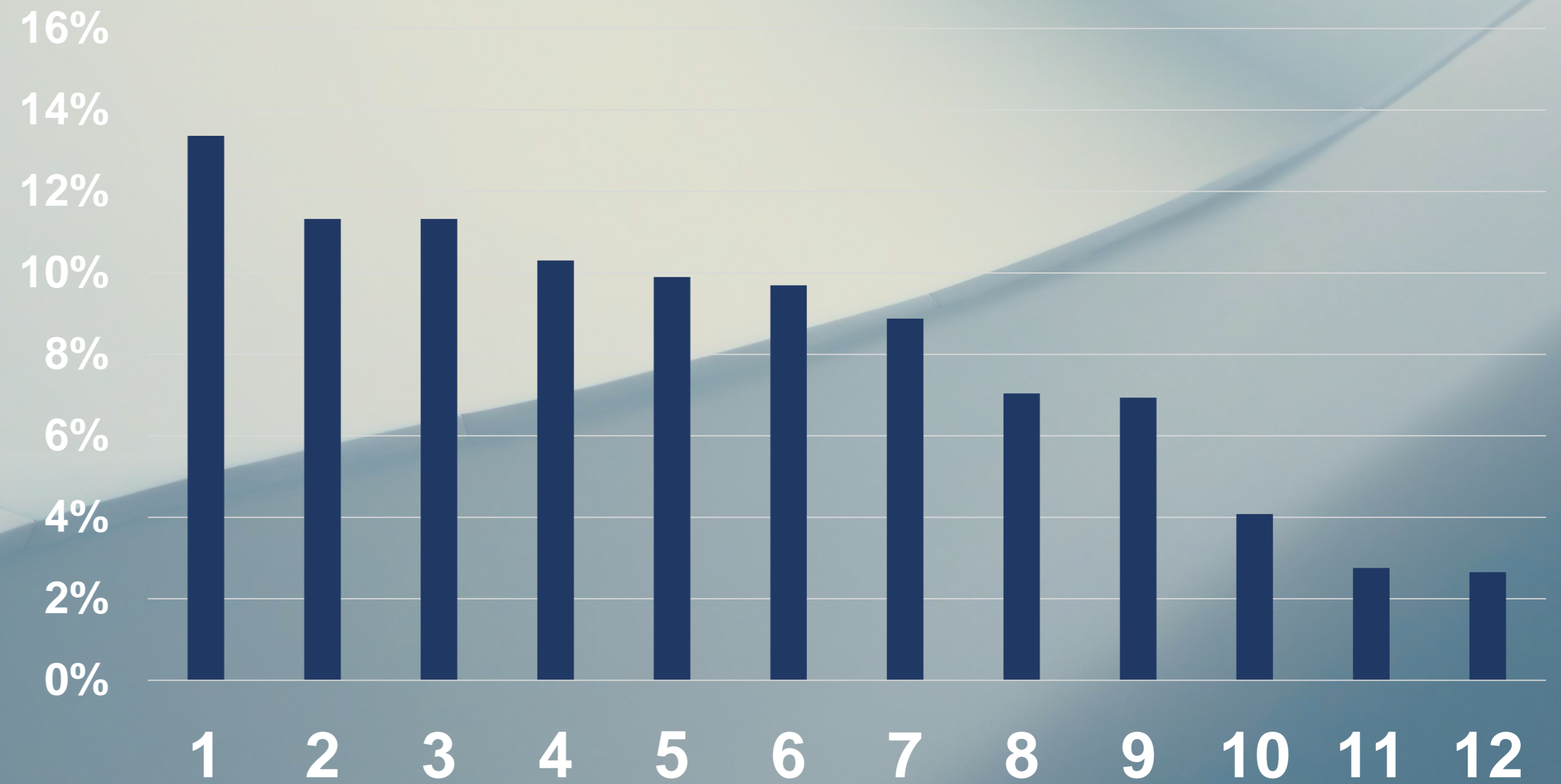
20

The average number of symptoms reported

0-5 Days

72% of participants reported symptoms began in first 5 days.

How many months since vaccination?

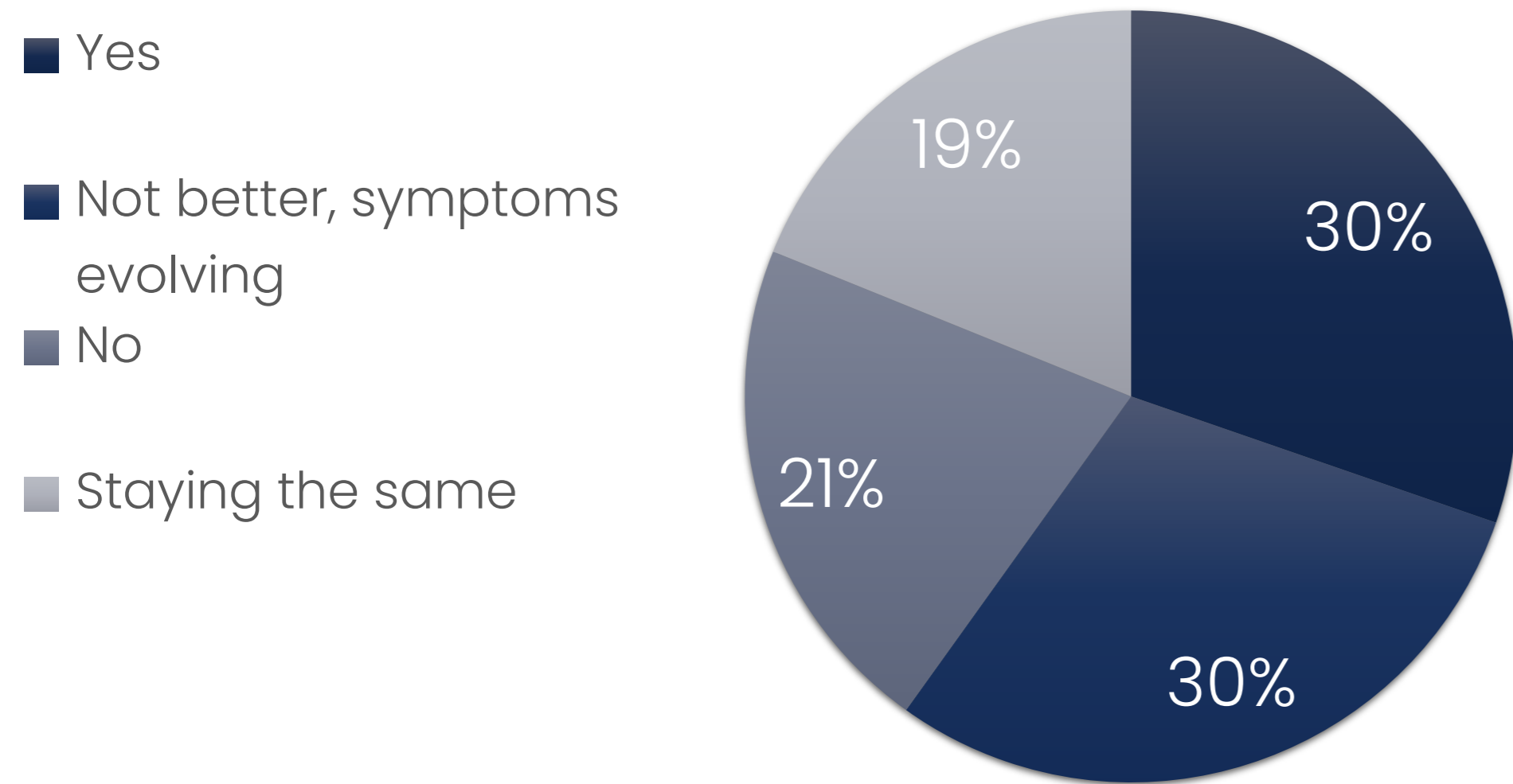


Months



Symptoms Evolution

Do you feel you are improving?

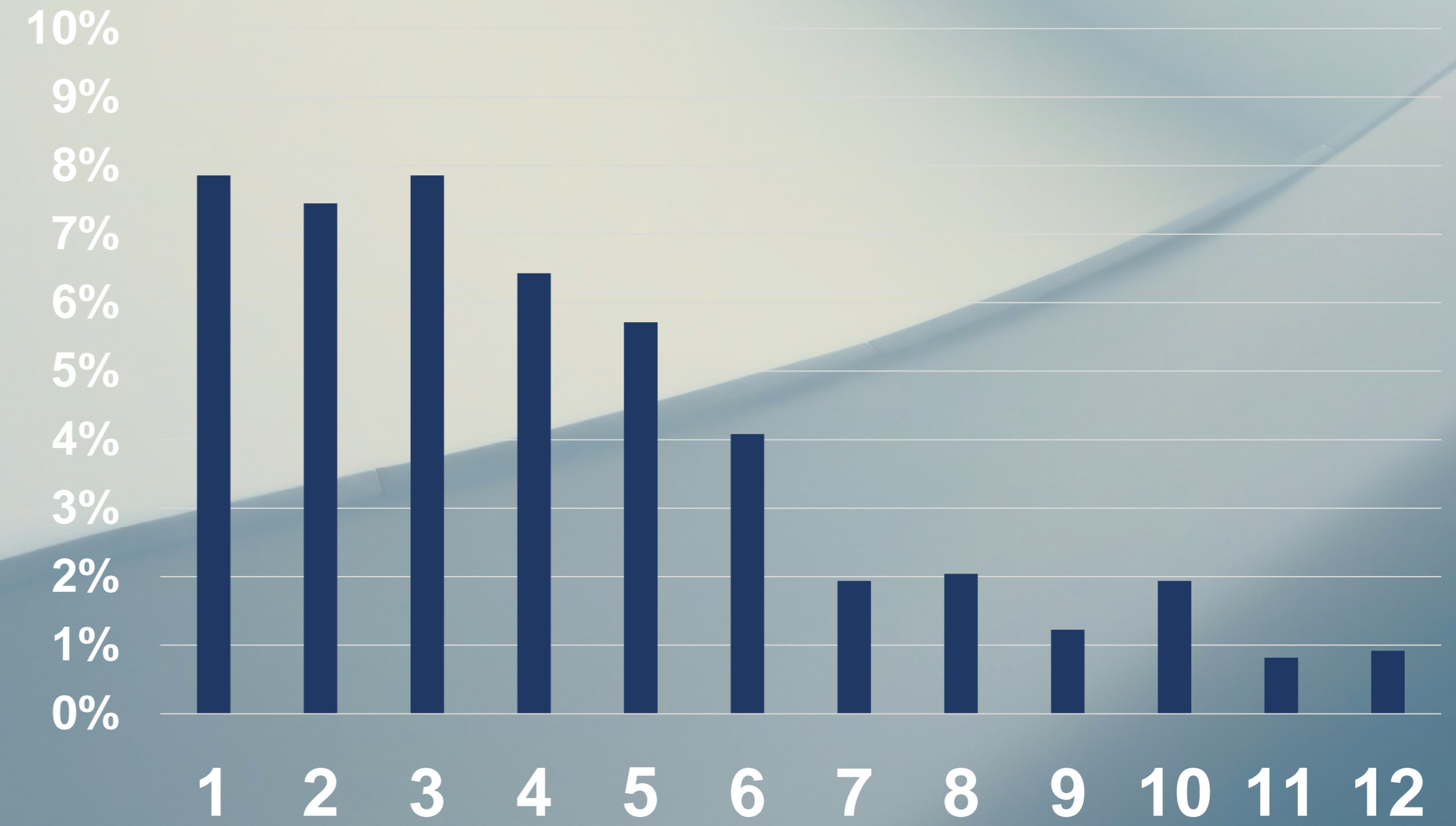


No + Staying the same 40%



52% of participants reported their symptoms never improved.

When did symptoms level off?



Average: 4 Months 1 Week

Months

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Specific Symptoms Evolution

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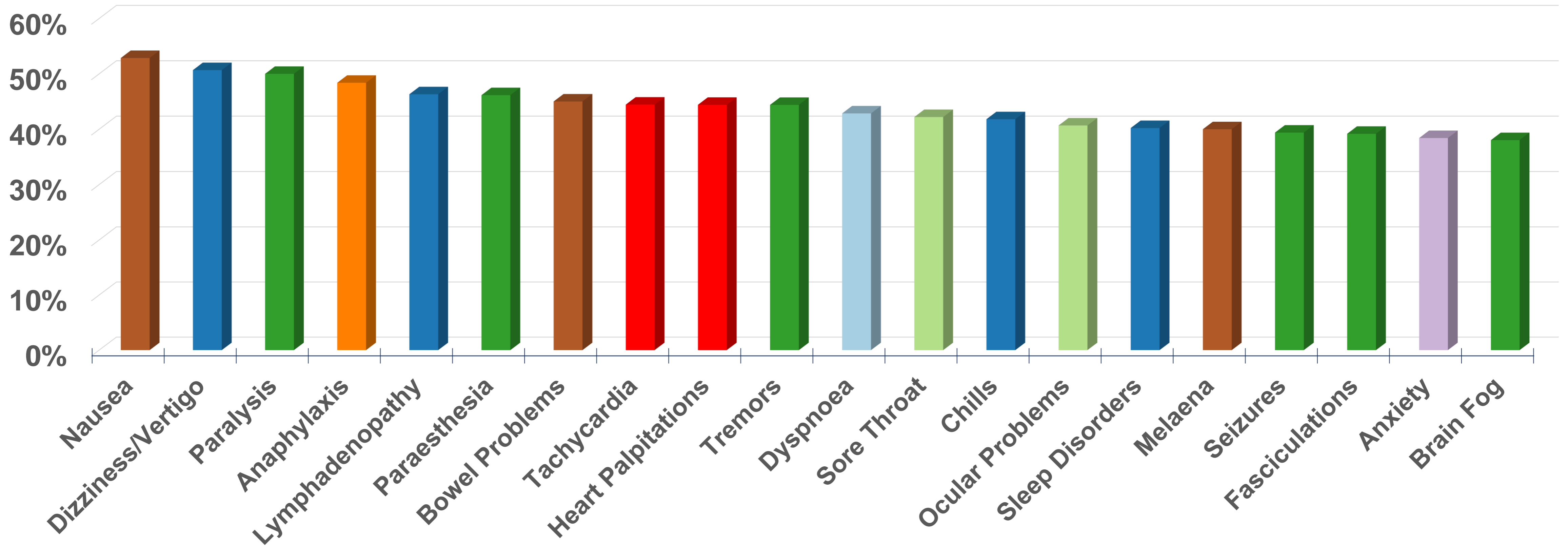


Provider Education

Symptoms Evolution

Top 20 Improving Symptoms

- general
- neurological
- cardiovascular
- gastrointestinal
- heent
- musculoskeletal
- endocrinologic
- respiratory
- genitourinary
- integumentary
- psychiatric
- allergy





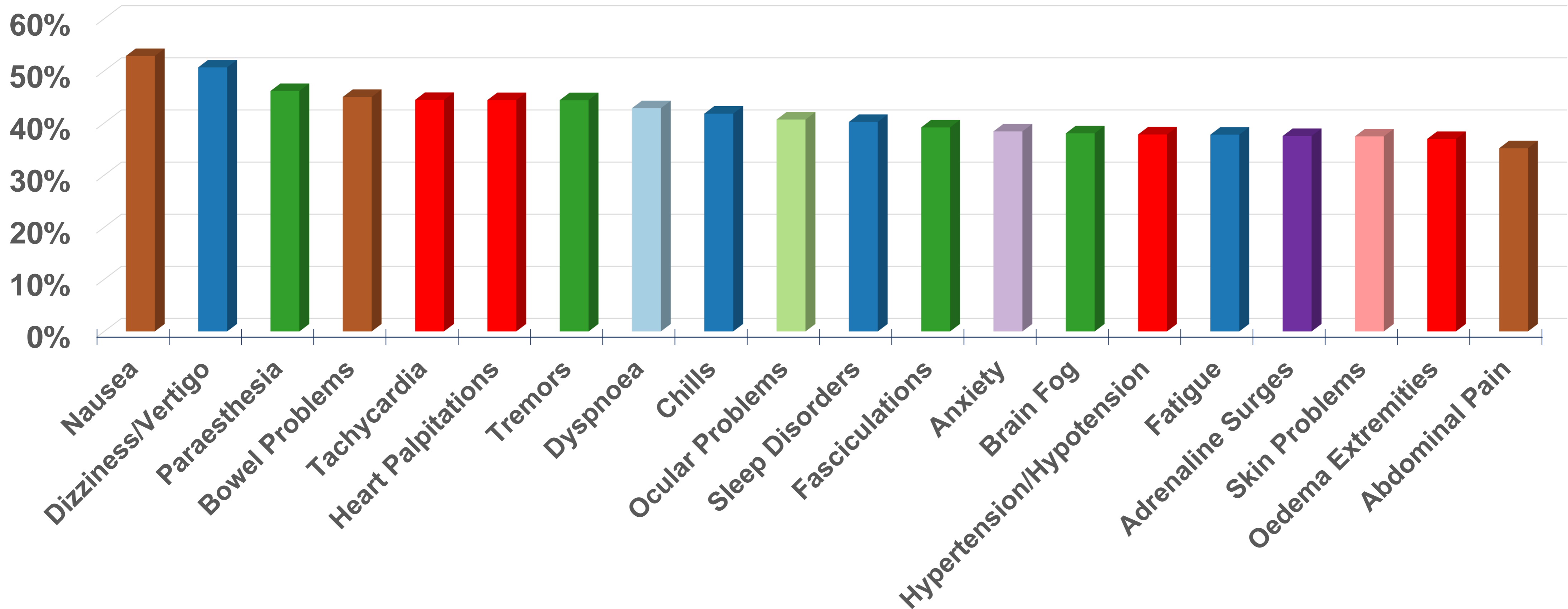
Provider Education

Symptoms Evolution

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Top 20 Affecting More than 30% of People



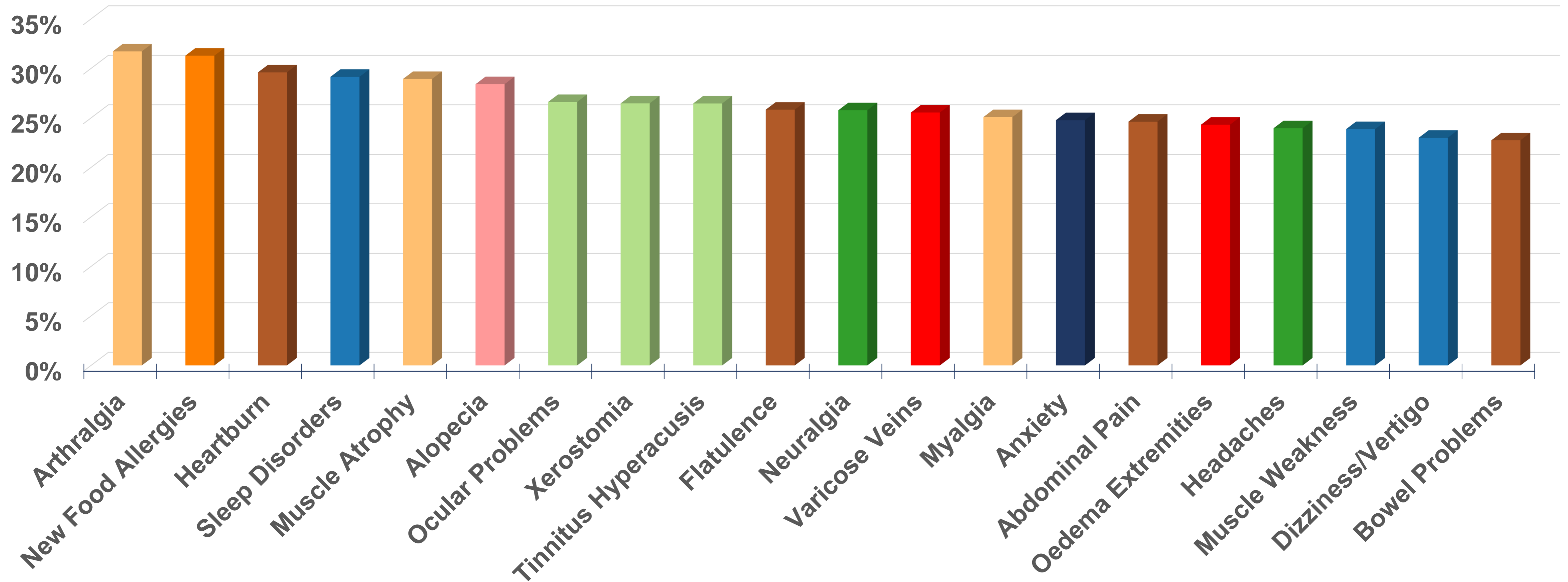


Provider Education

Symptoms Evolution

Top 20 Worsening Symptoms

- general
- neurological
- cardiovascular
- gastrointestinal
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- integumentary
- psychiatric
- allergy





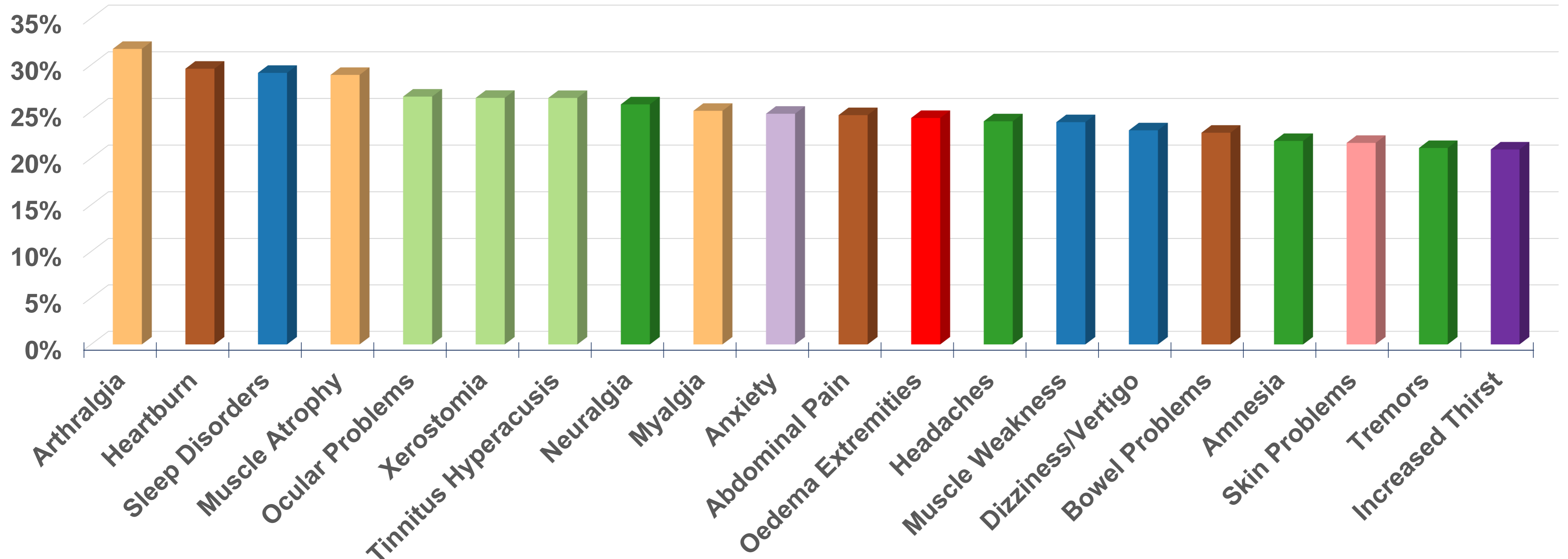
Provider Education

Symptoms Evolution

Top 20 Worsening Symptoms

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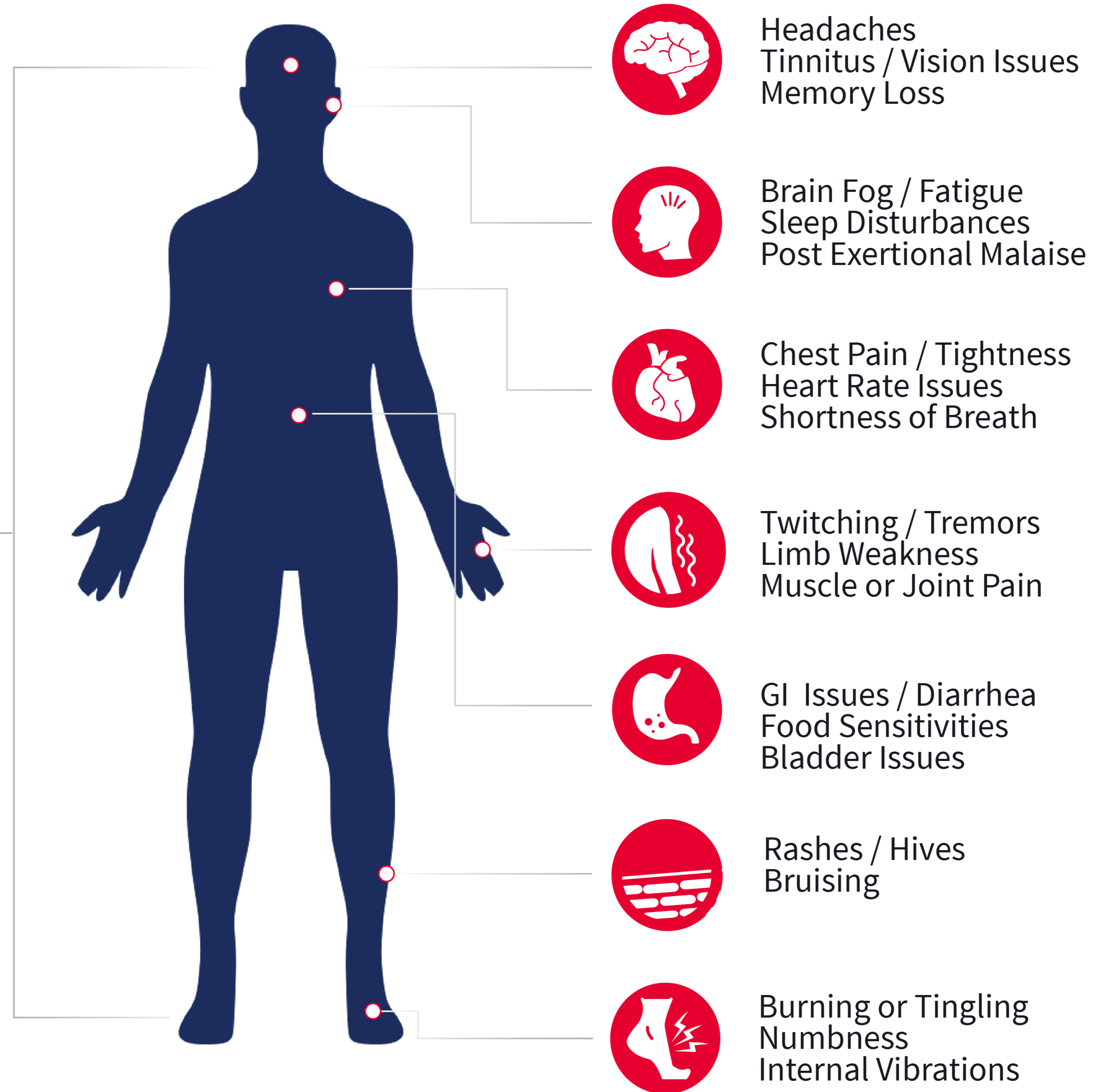
Top 20 Affecting More than 30% of People



Post Covid Vaccine Syndrome

Common Diagnoses

- Inflammation
- Pericarditis
- Myocarditis
- Dysautonomia
- Neuropathy
- Autoimmunity
- POTS (Postural Orthostatic
Tachycardia Syndrome)
- Guillain Barre Syndrome
- Transverse Myelitis
- Stroke / Clots
- ME/CFS
- CIDP
- MCAS



Survey 2

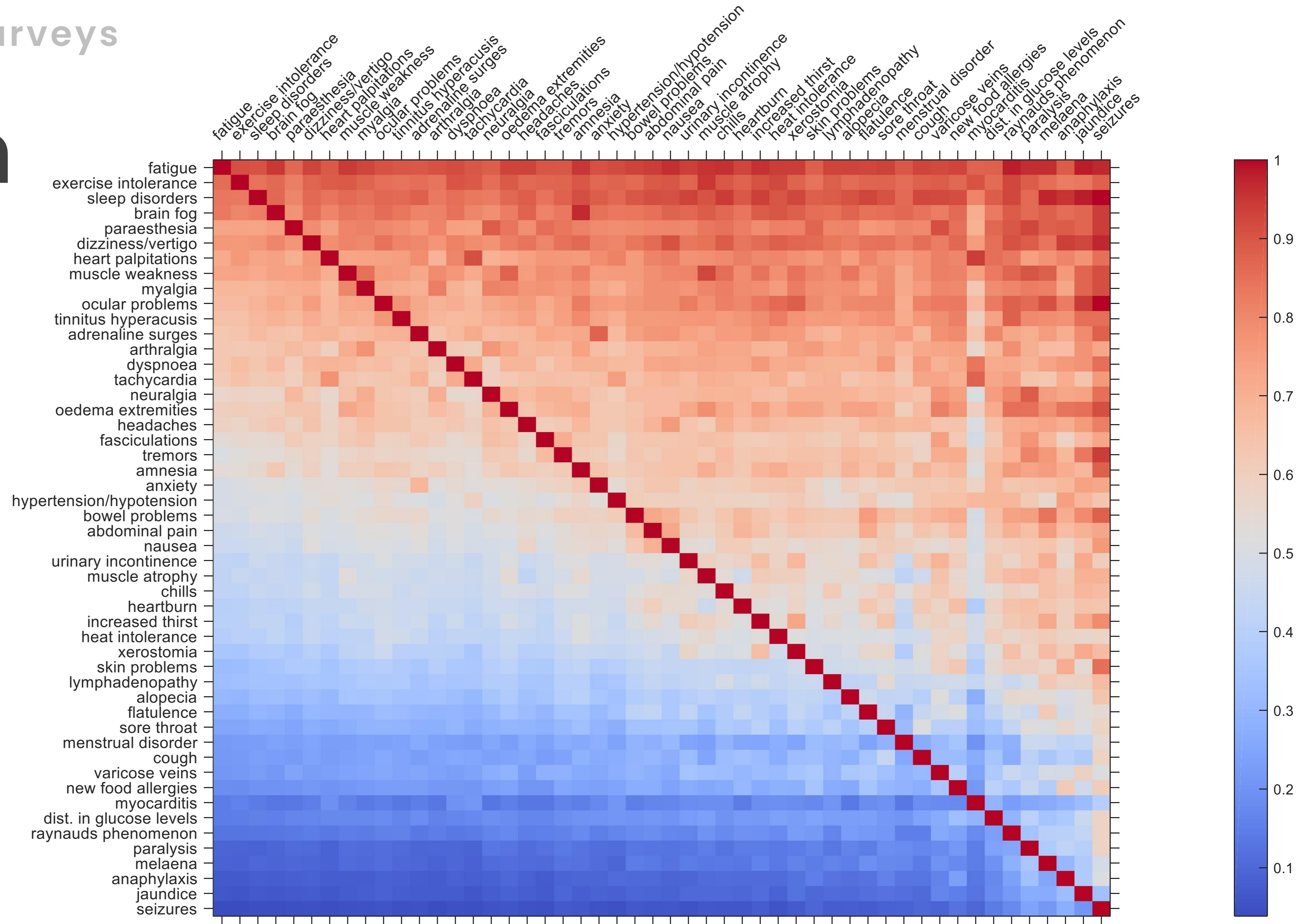
Clusters of Symptoms

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Symptom Clusters

Each column shows % of how many people have reported the other symptoms

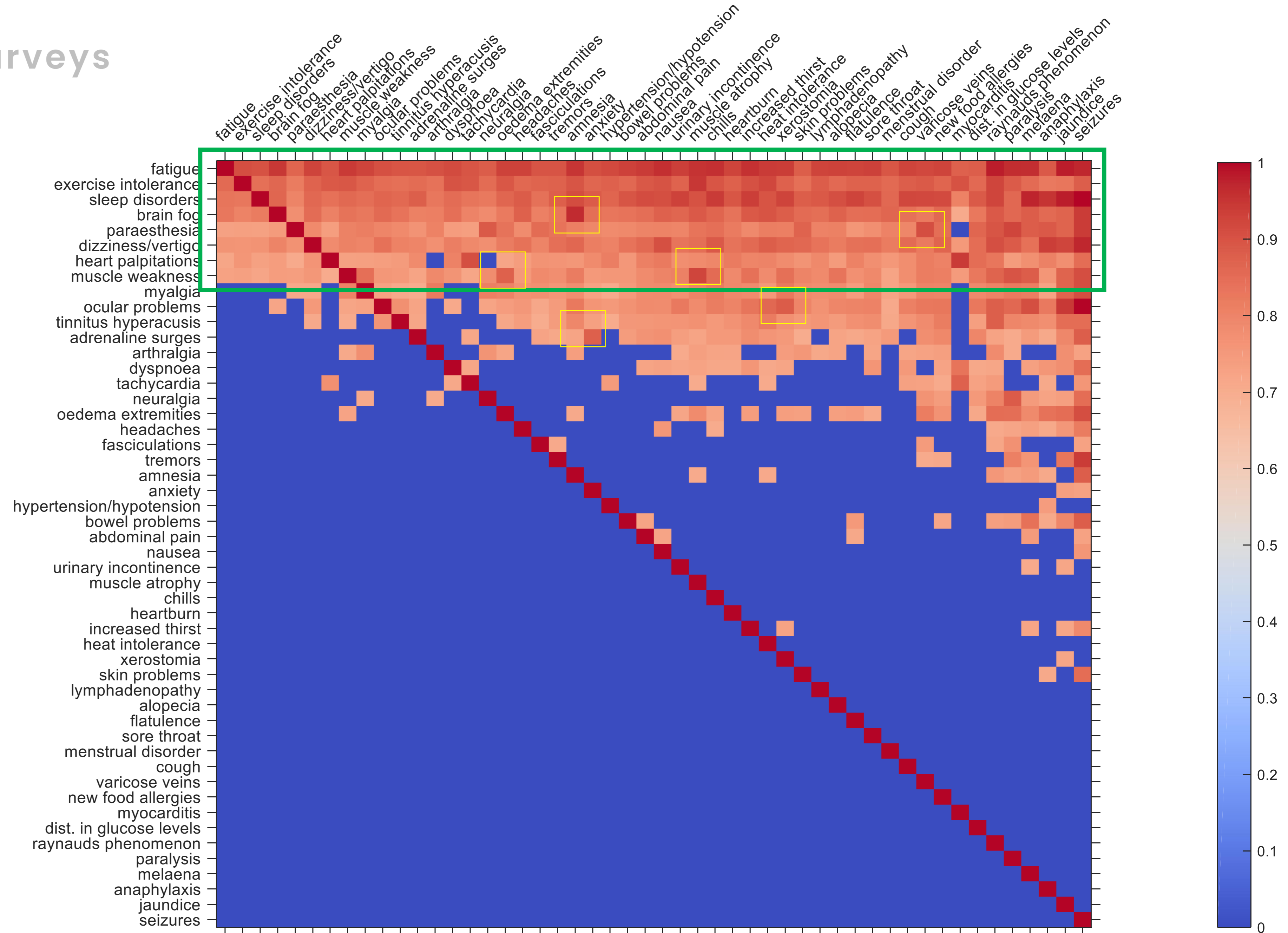
Less reported symptoms are more likely to be coupled with other more generic symptoms



Symptom Clusters

Zero anything below 0.7 to spot clear patterns

- Top 10 symptoms are very often reported with any of the other symptoms
- Symptoms that affect the same organ/system are often coupled together



Survey 2

Quality of Life

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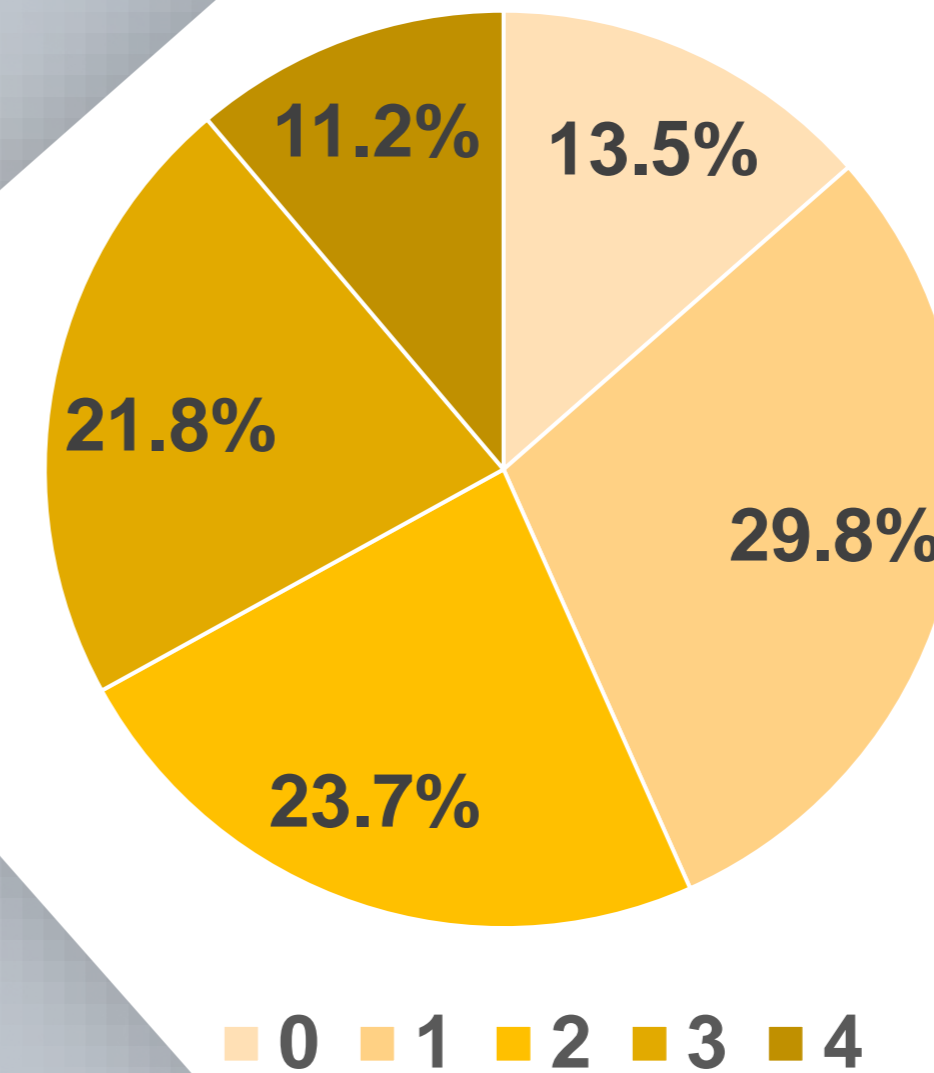
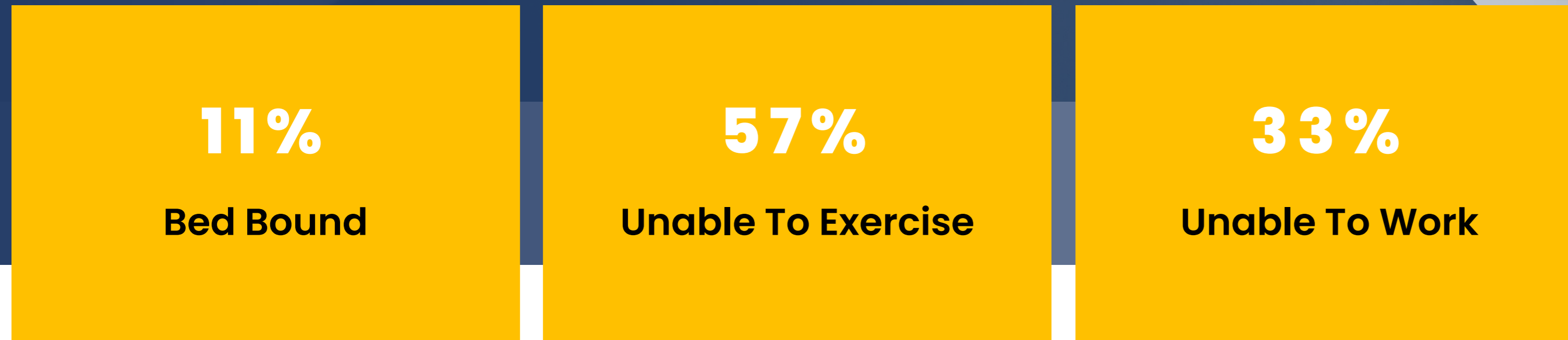


Patient-Led Surveys

Quality Of Life



Previously healthy, working individuals report a dramatic change in their daily living.



- 0** I can live life like I did before
- 1** I work or do chore and do light exercise
- 2** I work or do chores but can't exercise
- 3** I am unable to work but can't do chores
- 4** I am unable to work and bedridden most days

Average Severity
1.87

Respondents with pre-existing conditions may be more likely to be unable to work → higher reported severity



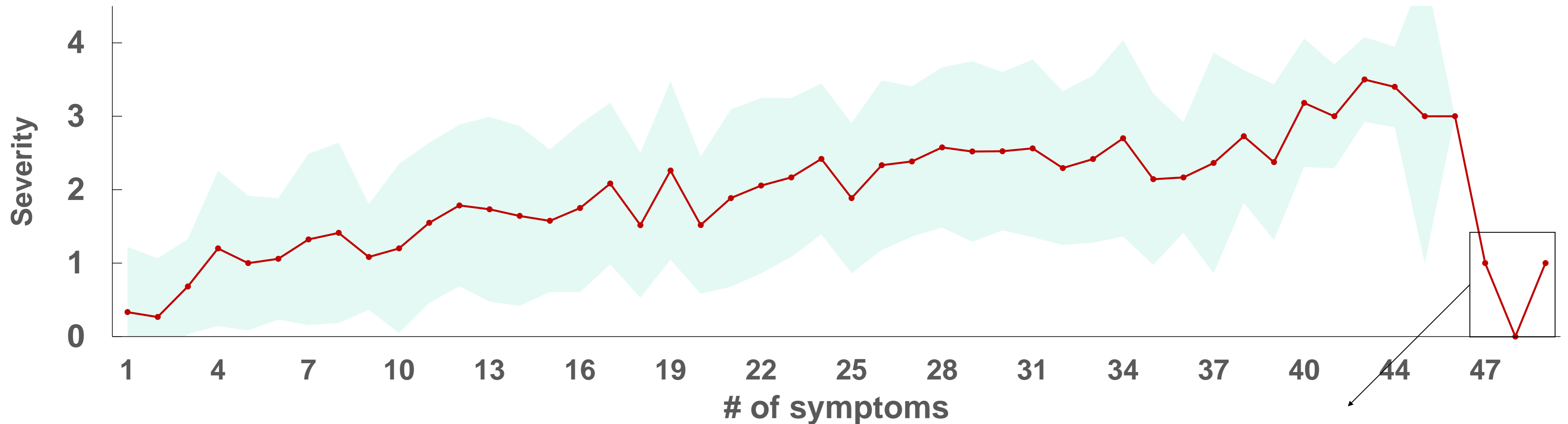
Patient-Led Surveys

Quality Of Life

Symptoms and Severity

- 0** I can live life like I did before
- 1** I work or do chore and do light exercise
- 2** I work or do chores but can't exercise
- 3** I am unable to work but can't do chores
- 4** I am unable to work and bedridden most days

Reported severity is correlated with reported number of symptoms



Only 3 respondents out of 930 reported >45 symptoms



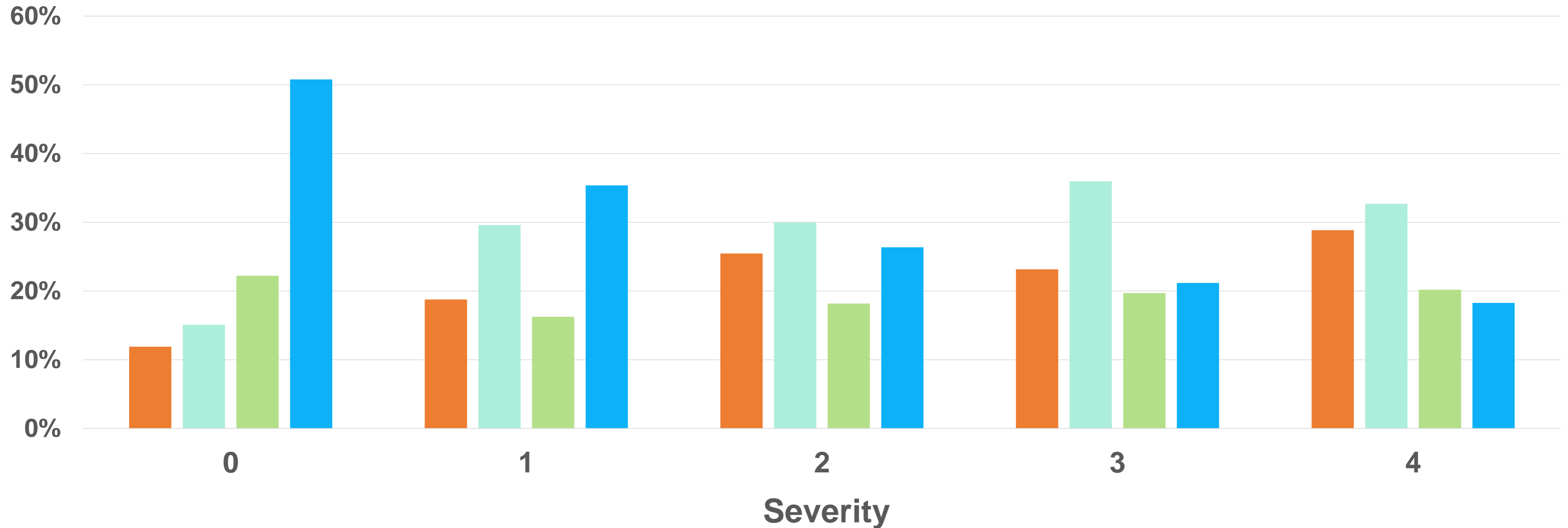
Patient-Led Surveys

Quality Of Life

Status Evolution and Severity

Ratio of people reporting that they are improving decreases monotonically with increasing severity.

- Not improving
- Symptoms evolving
- Staying the same
- Improving



Survey 2

Pre-Existing Conditions

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Medical History

Previous Vaccine Reaction?



Prior to Covid vaccination, have you ever reacted to any previous vaccine you had received?

NO - 94%

History of Covid Infection



Have you ever had a positive Covid infection?

NO - 76%

Pre-Existing Conditions



Do you have any pre-existing health conditions?

NO - 42%



Patient-Led Surveys

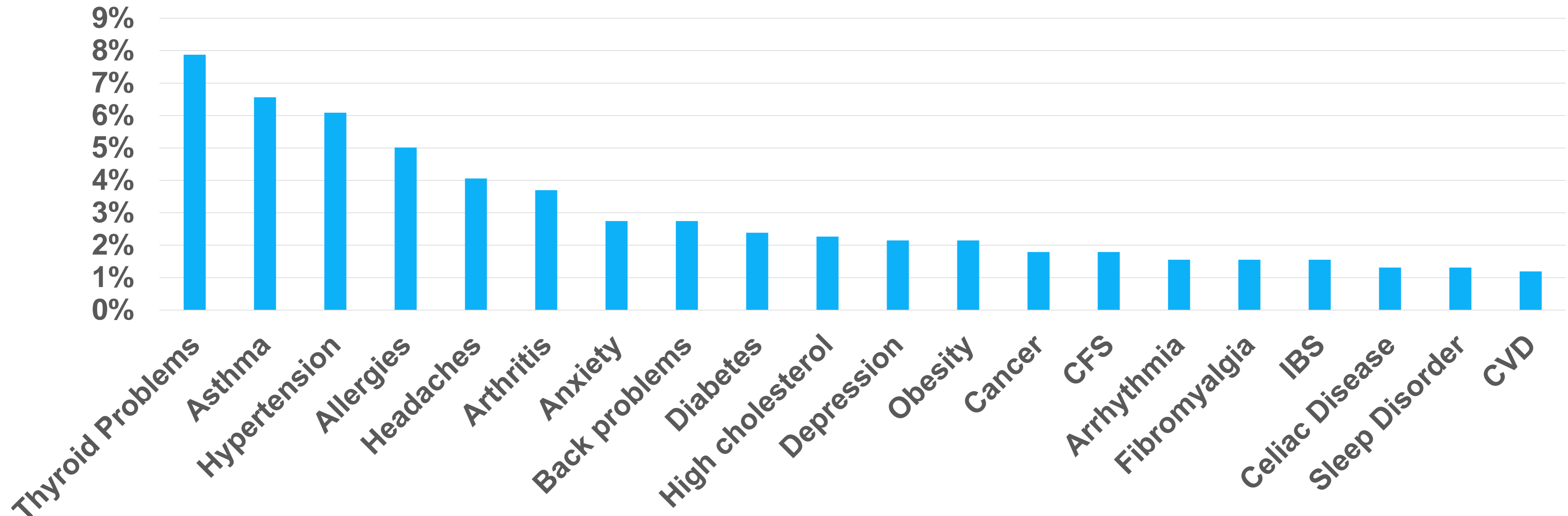
Pre-Existing Conditions

Status Evolution and Severity

Pre-existing conditions reported by more than 1% of respondents.

(More specific data collection is needed in next survey.)

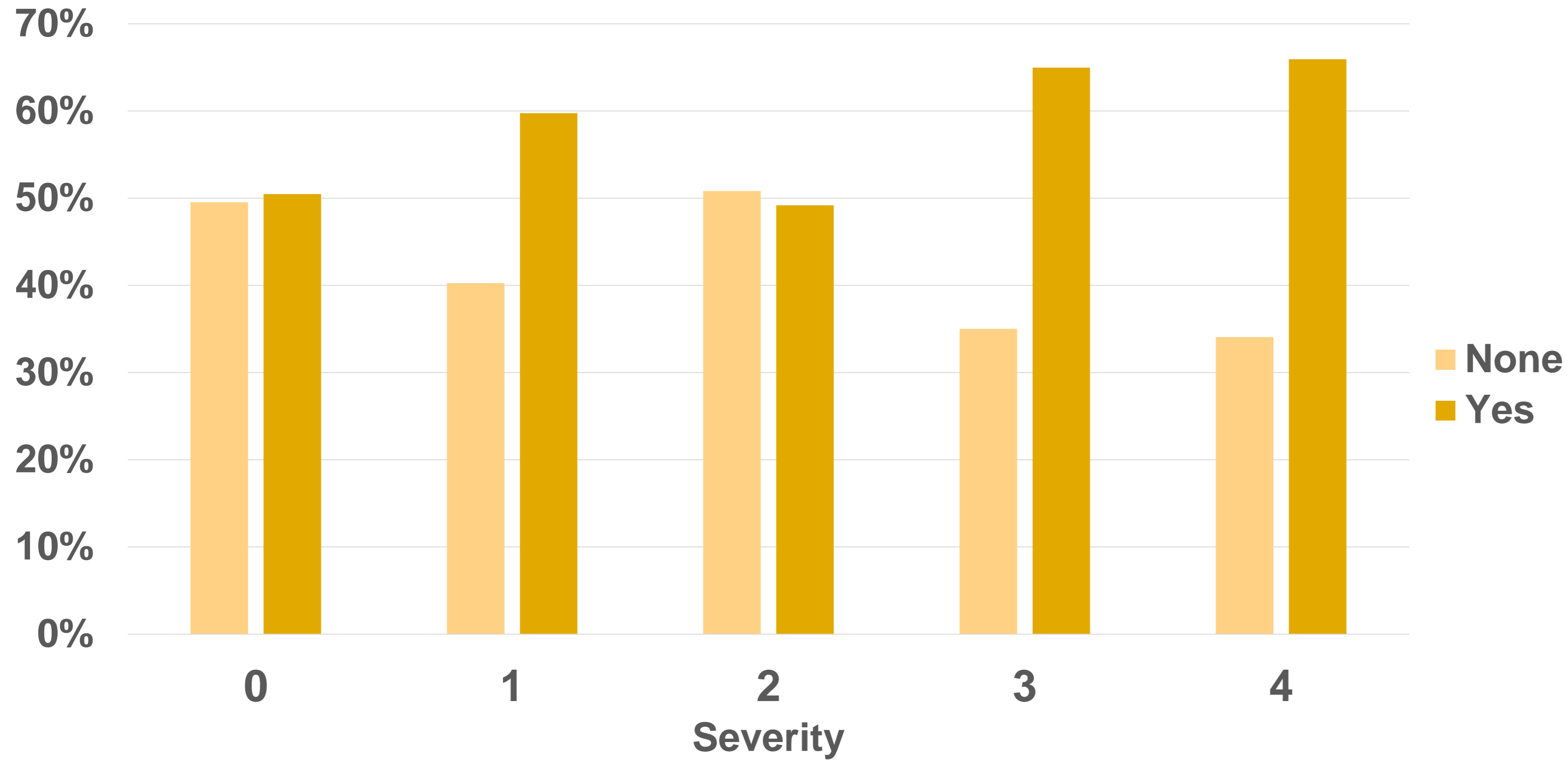
Around 16% of all reported pre-existing conditions fall in the autoimmune category





Patient-Led Surveys

Pre-Existing Conditions & Severity



Respondents with pre-existing conditions may be more likely to be unable to work → higher reported severity

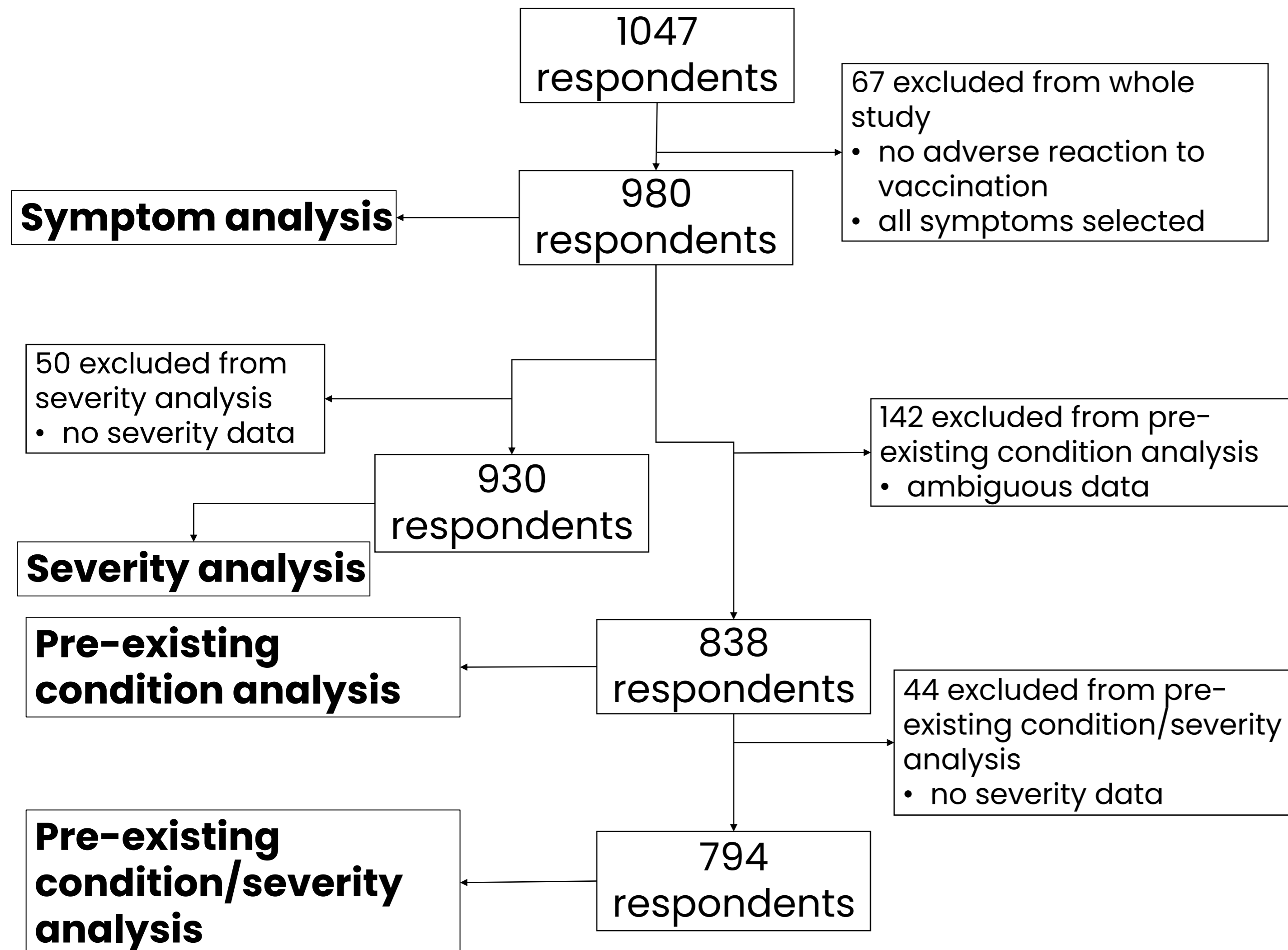
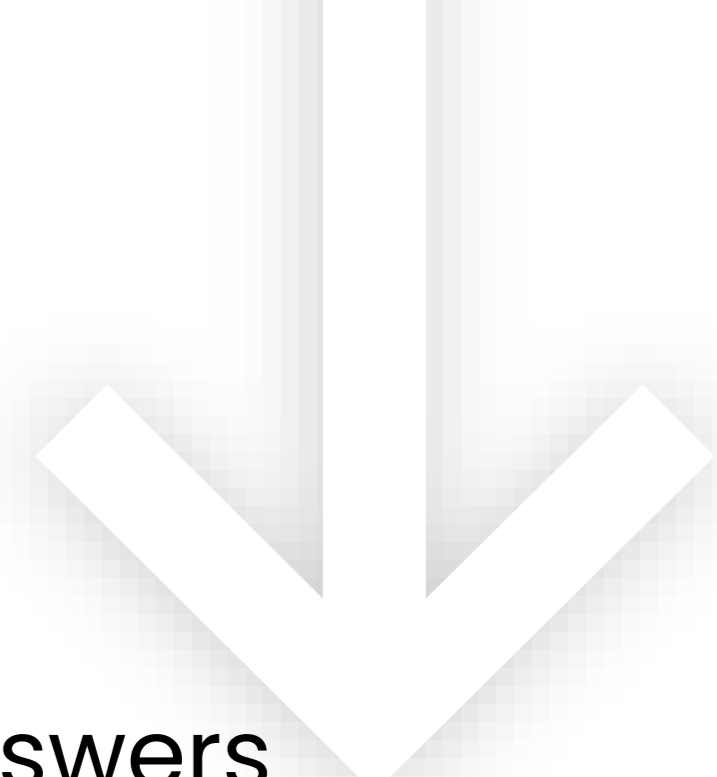
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Methodology

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Manual Checks for Data Validation



Free form answers manually checked

980 people included in the analysis:

838 people included in the pre-existing conditions analysis

930 people included in the severity analysis

794 people included in pre-existing/severity analysis.



Symptoms Grouping for Data Analysis

- Myocarditis and glaucoma are not symptoms so may need to be removed from the analysis for consistency.
- Groups of symptoms created based on general/common medical categories (WHO, NIH etc.):

General	General	Endocrinologic	Endocrinologic
Fatigue	Fatigue	Adrenaline surges	Adrenaline surges
Exercise intolerance	Exercise intolerance	Increased thirst	Increased thirst
Muscle weakness	Muscle weakness	Heat intolerance	Heat intolerance
Dizziness	Dizziness/Vertigo	Disturbances in glucose levels	Disturbances in glucose levels
Feeling off balanced or motion at rest	Sleep disorders		
Insomnia	Chills	Respiratory	Respiratory
Sleep disturbances	Lymphadenopathy	Shortness of breath	Dyspnoea
Excessive sleep		Persistent cough	Cough
Chills			
Swollen lymph nodes		Integumentary	Integumentary
		Skin redness, hives, petechia or rashes	Skin problems
		Hair loss	Alopecia

Symptoms that are very similar/often discussed together are paired to aid visualisation.



Symptoms Grouping for Data Analysis

- Myocarditis and glaucoma are not symptoms so may need to be removed from the analysis for consistency.
- Groups of symptoms created based on general/common medical categories (WHO, NIH etc.):

Cardiovascular

Heart palpitations
High heart rate
Heaviness in legs
Swelling of extremities
High blood pressure
Low blood pressure
Bulging veins
Myocarditis
White/blue finger tips

Cardiovascular

Heart palpitations
Tachycardia
Oedema in extremities
Hypertension/Hypotension
Varicose veins
Raynaud's phenomenon

Symptoms that are very similar/often discussed together are paired to aid visualisation.

Note: chest pain was missing from survey

Neurological

Brain fog
Nerve pain
Tingling, numbness in extremities
Burning sensation on skin
Headaches
Muscle twitching
Memory loss
Internal vibrations
Tremors
Paralysis
Seizures

Neurological

Brain fog
Neuralgia
Paraesthesia
Headaches
Fasciculations
Amnesia
Tremors
Paralysis
Seizures



Symptoms Grouping for **Data Analysis**

- Myocarditis and glaucoma are not symptoms so may need to be removed from the analysis for consistency.
- Groups of symptoms created based on general/common medical categories (WHO, NIH etc.):

Gastrointestinal		HEENT	
Abdominal, stomach pain		Tinnitus	}
Nausea	Gastrointestinal	Sound sensitivity	
Heartburn indigestion	Abdominal pain	Visual disturbances	}
Diarrhoea	Nausea	Light sensitivity	
Constipation	Heartburn	Dry eyes	}
Loss of bowel control	Bowel problems	Temporary blindness	
Bloody or black/tar-like stool	Melaena	Glaucoma	}
Excessive gas	Flatulence	Dry mouth	
Yellowing of skin or of the white of eyes	Jaundice	Sore throat	

Symptoms that are very similar/often discussed together are paired to aid visualisation.



Symptoms Grouping for Data Analysis

- Myocarditis and glaucoma are not symptoms so may need to be removed from the analysis for consistency.
- Groups of symptoms created based on general/common medical categories (WHO, NIH etc.).
- Medical terms preferred for conciseness and

Musculoskeletal
Muscle aches
Muscle loss
Joint pain

Musculoskeletal
Myalgia
Muscle atrophy
Arthralgia

Genitourinary
Frequent urination
Irregular menstrual cycle

Genitourinary
Urinary Incontinence
Menstrual disorder

Allergy
New food allergies
Anaphylaxis

Psychiatric
Anxiety

Symptoms that are very similar/often discussed together are paired to aid visualisation.

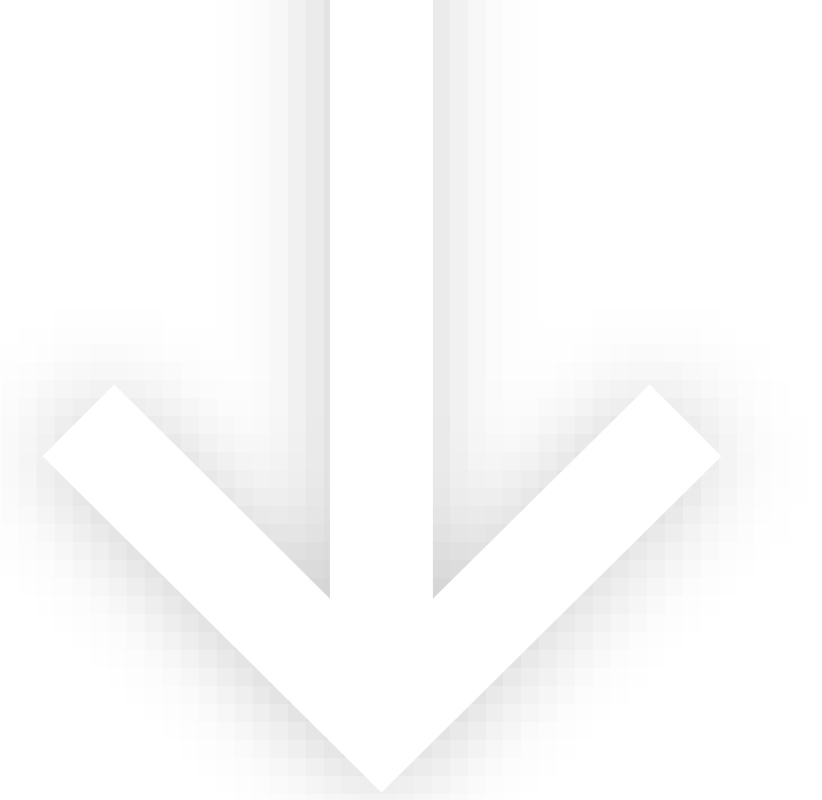
Survey 2

PART 2 Abnormal Tests, Diagnoses

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Goals



930 respondents, 4650 free form answers manually analysed

- Analysis of reported abnormal test results
- Analysis of misdiagnoses
- Analysis of formal diagnoses

Warning: results are not encouraging, but note they were from 1+ year ago.

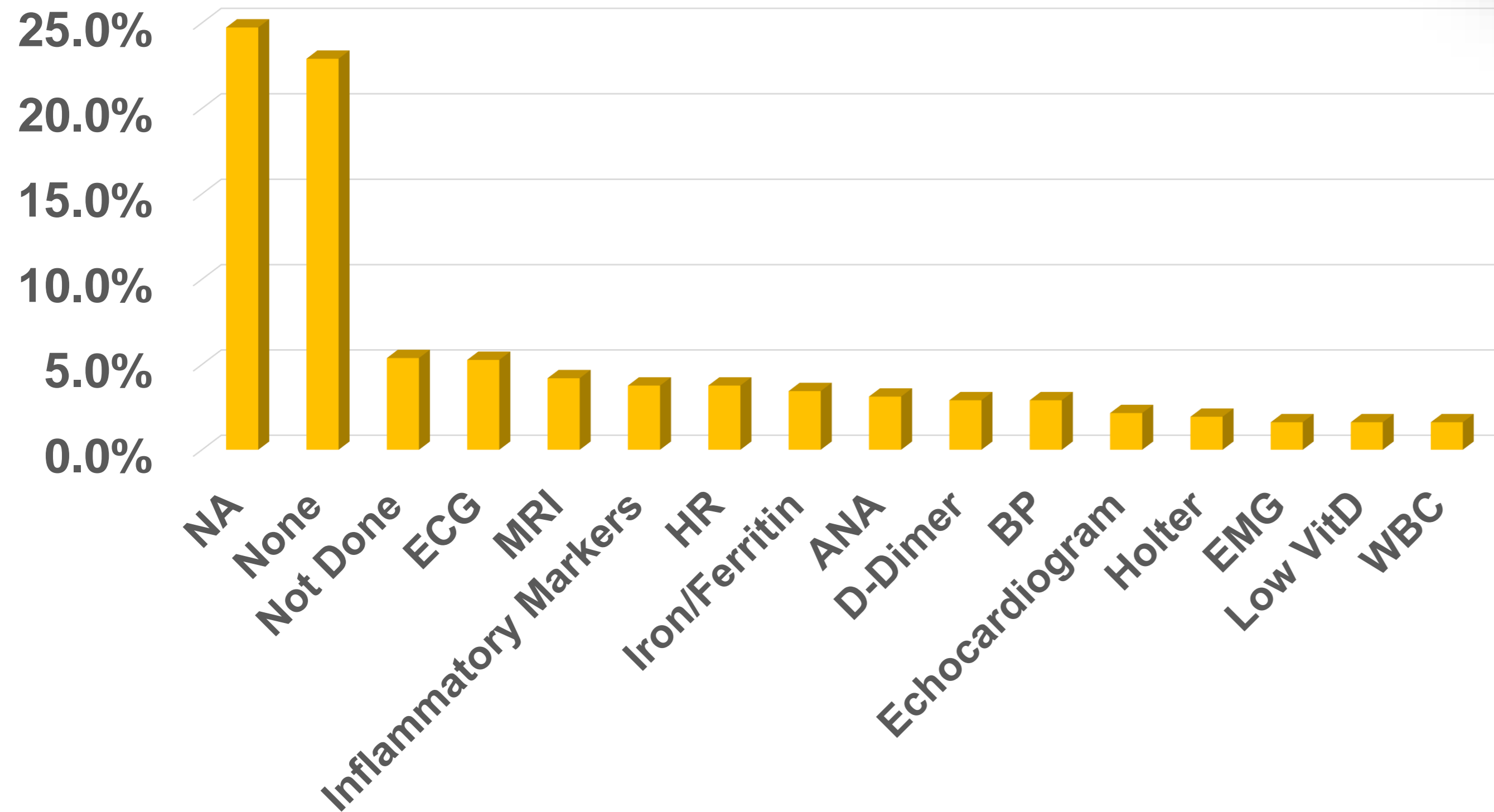
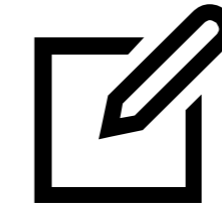
Note: we do not know the total amount of people that had a particular test, so these results and percentages have limited meaning.



Patient-Led Surveys

Abnormal Test Results

53% of respondents reports that all tests have come back normal, no test done, or not available.



Most common abnormal blood tests were:

- Inflammatory markers (3.8%)
- Iron/Ferritin (3.4%)
- ANA (3.1%)
- D-Dimer (2.9%)
- VitD (1.6%)
- WBC (1.6%)

Most common diagnostic tools

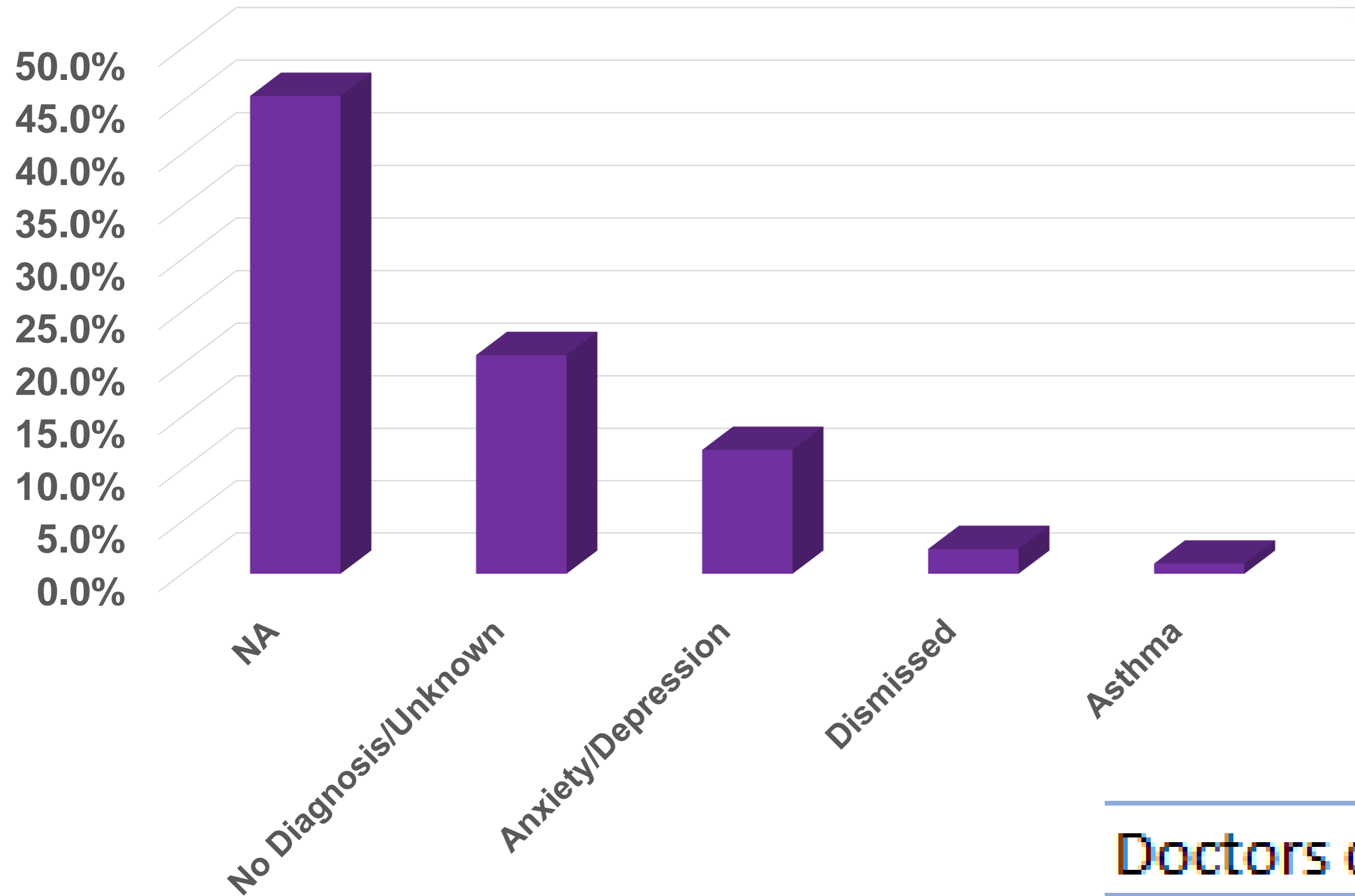
- ECG (5.3%)
- MRI (4.2%)
- Heart Rate (3.8%)
- Echocardiogram (2.2%)
- Holter (1.9%)
- EMG (1.6%)



Reported Misdiagnosis



These 4 categories make up 80.5% of respondents.



- 45.5% NA – either blank, no diagnosis yet, not visited a Dr/specialist or similar
- 20.9% unknown or no diagnosis
- 11.8% anxiety, depression, panic attacks, stress, ageing, menopause and similar
- 2.4% explicitly state they have been dismissed

Drs never admitted anything

Doctors don't know what it is

I'm making it up!

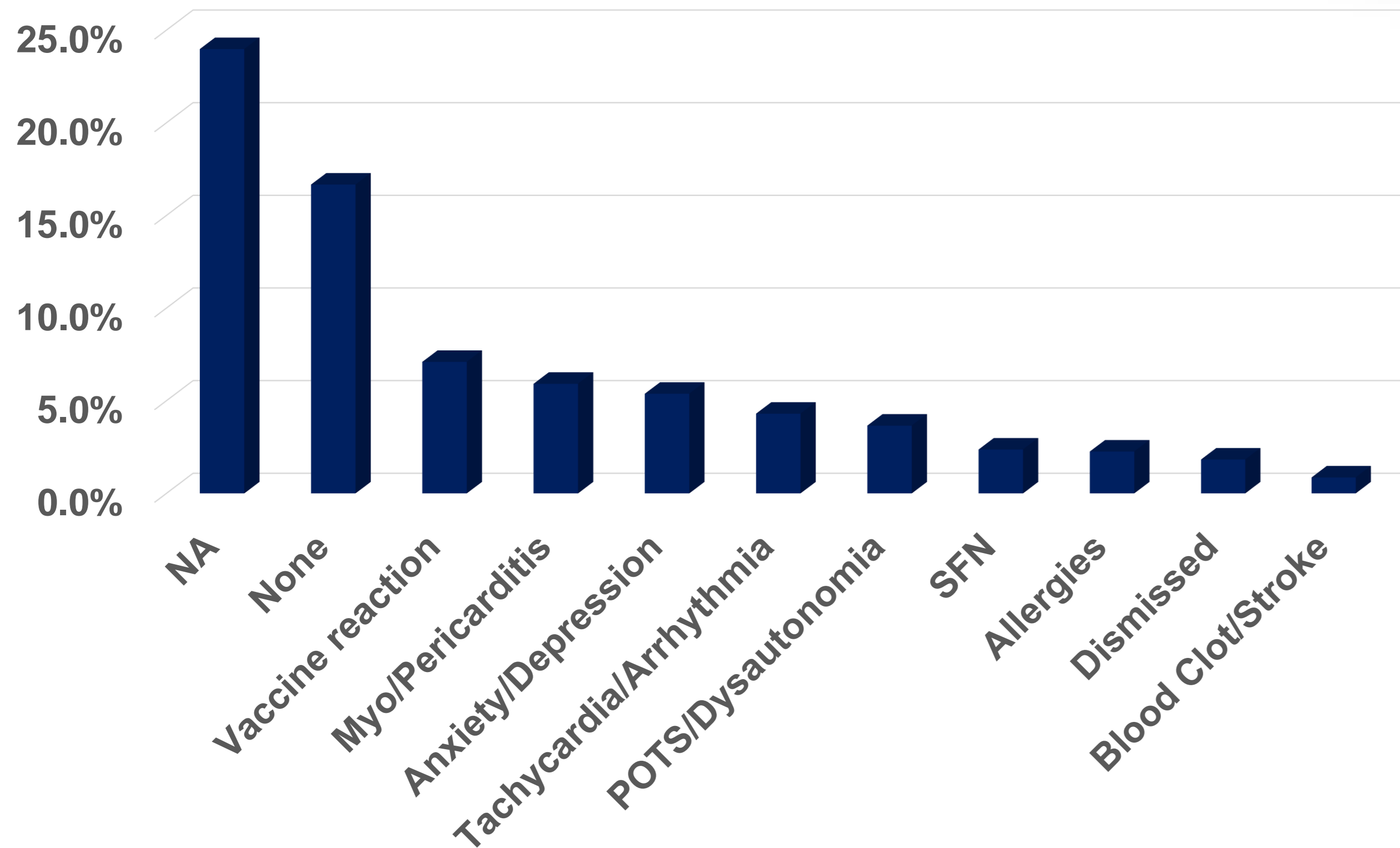
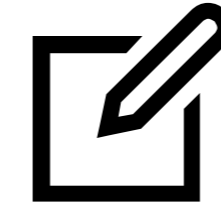
Doctors said I was imagining my symptoms, refused to treat.

My doctors doesn't know what is going on.



Reported **Diagnosis**

40.6% No formal diagnosis yet



- 7.1% doctors acknowledged some sort of vaccine adverse event
- 5.4% anxiety, depression, panic attacks, stress, ageing, menopause and similar
- Tachycardia/Arrhythmia and POTS/Dysautonomia make up around 8% of respondents
- 5.9% of respondents report being diagnosed with myocarditis, pericarditis, or myopericarditis



100%

100% of your donation to the CAREfund goes directly into the hands of the Covid vaccine-injured.



Donate Here:



REACT¹⁹
CAREfund

100% of donations go to an injured in need for medical expenses.

Patient Education

Patient Resources

We understand just how important each and every dollar is that comes into this fund. So we have setup this fund to be 100% given back to the injured community to help individuals pay for medical expenses.



Thank You

www.react19.org/get-involved