

EMHA Migraine Stigma Surveys

Final Analysis

November 30th, 2023

Objective of the project

The project aims to assess the **origin** and **impact** of **stigma** on migraine patients in Europe, as well as understand patients' need for a better understanding of their condition

1

Phase 1 is currently in place, and it involves a **digital survey**. The survey explores topics such as **patients' understanding of migraine terminology**, **sources** of stigma, specific **types of stigma** affecting patients, and potential **solutions**

2

Phase 2 will focus on preparing a **scientific paper** to **advocate** for a **paradigm shift** in addressing patient stigma. The Prescient team will conduct **discussions** with EMHA, experts, and partners, along with a **literature review** on **stigma's definition and impact**

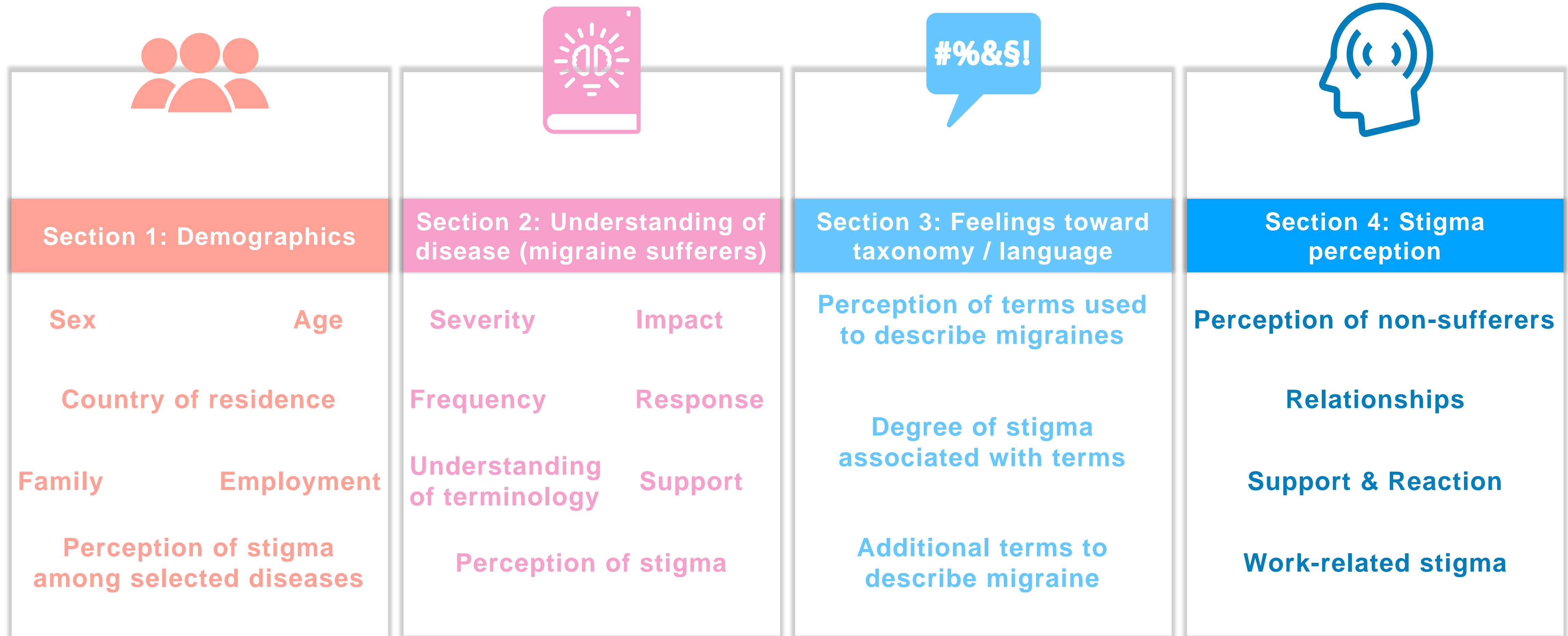


The project aims to raise awareness about **stigma associated with migraine**, drive **positive change**, and improve support for migraine sufferers

EMHA Migraine Stigma Survey

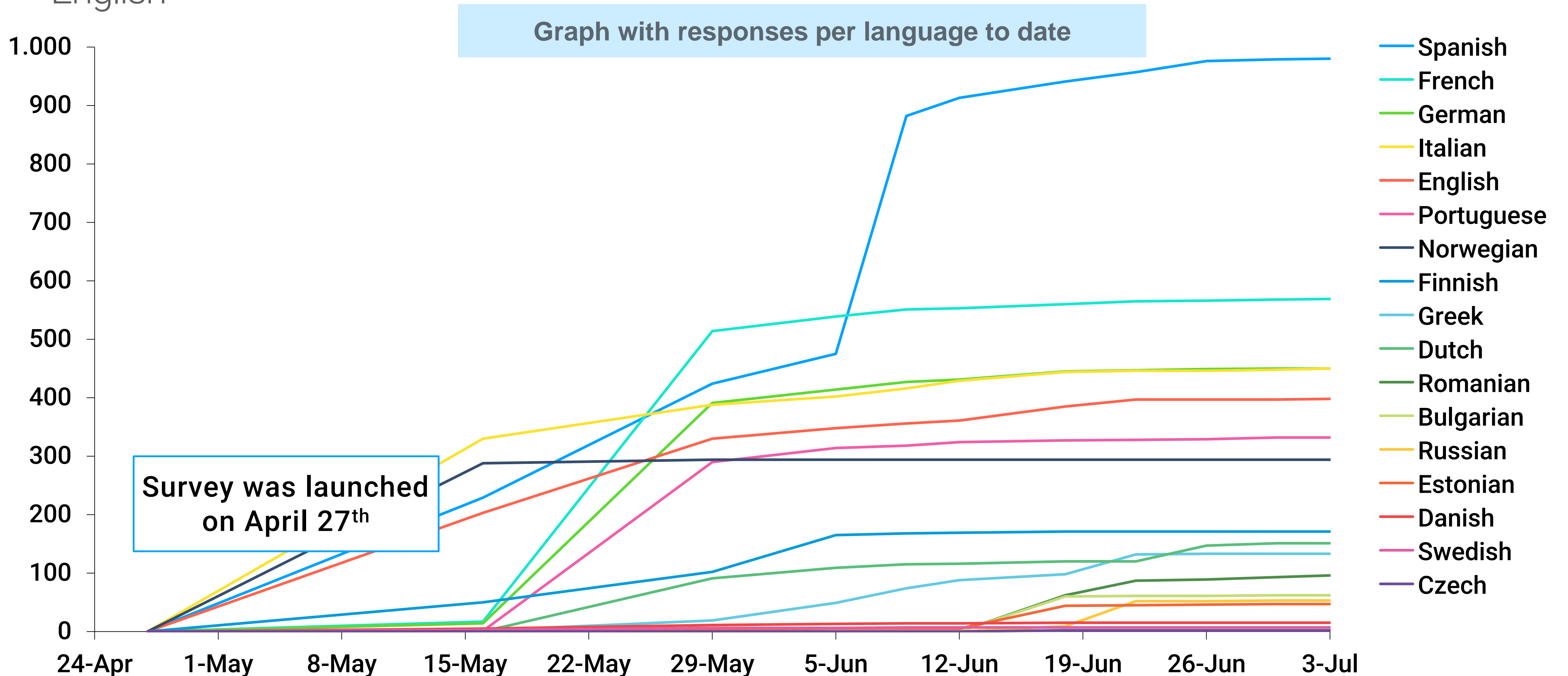
EMHA Migraine Stigma Survey

The content from “EMHA Migraine Stigma Survey” was divided into the following 4 categories



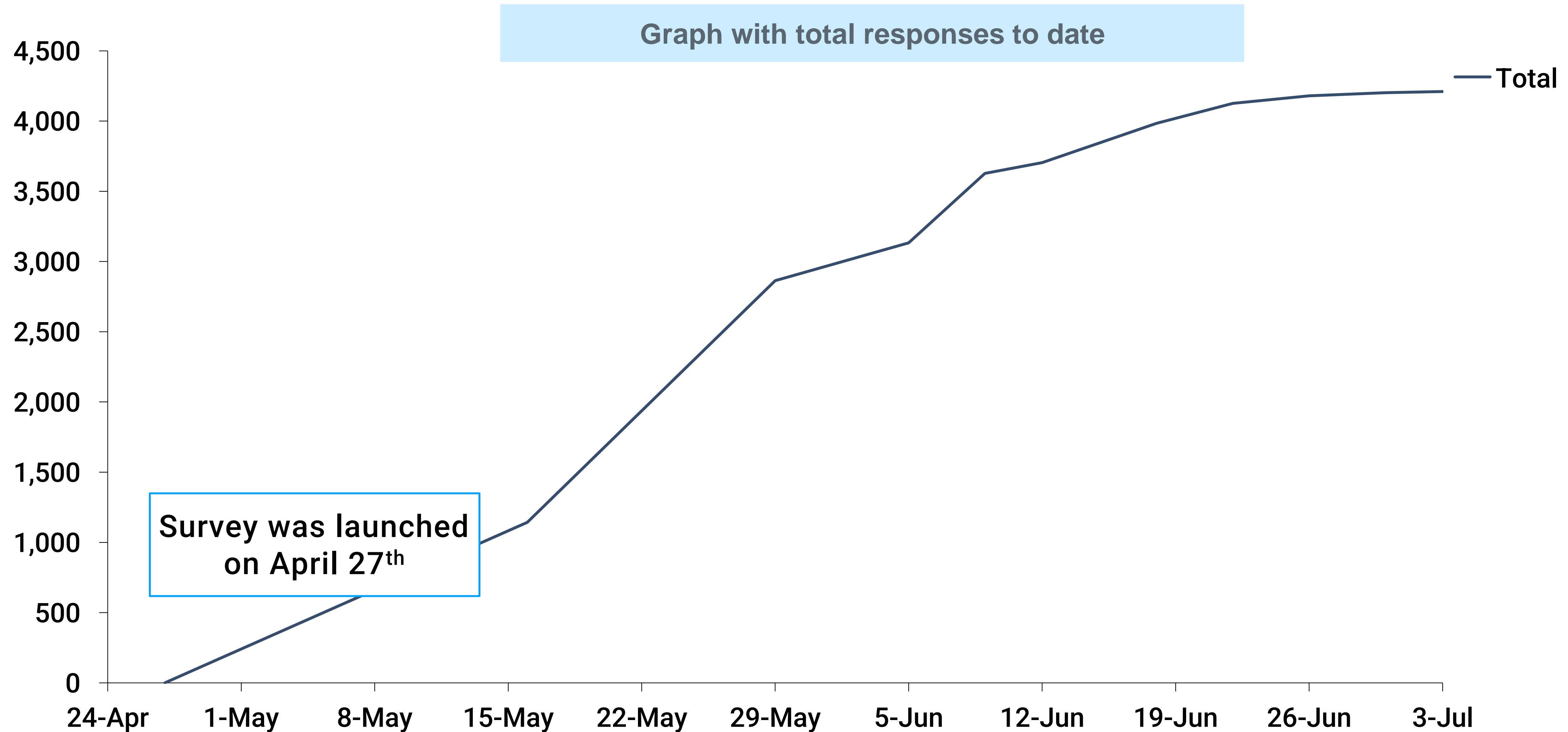
Response rate per language

The surveys with the highest response rates have been Spanish, French, German, Italian and English



Total response rate

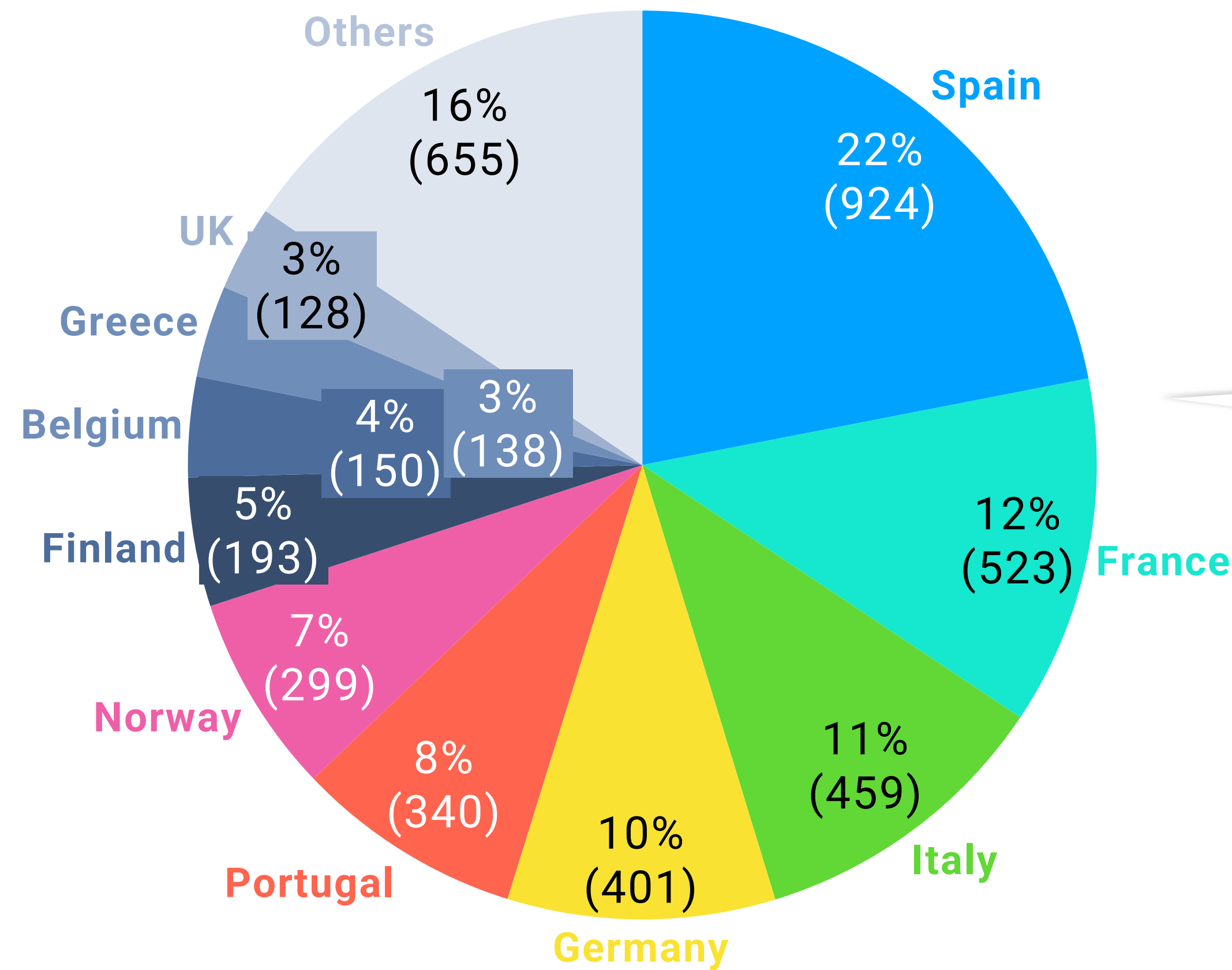
A total amount of 4.210 answers have been obtained



Countries of residence

On the other hand, if we look at the countries of residence of the respondents, the most represented ones are also Spain, France, Italy, and Germany, while Portugal emerges, and the UK loses traction

Distribution of respondents' countries of residence

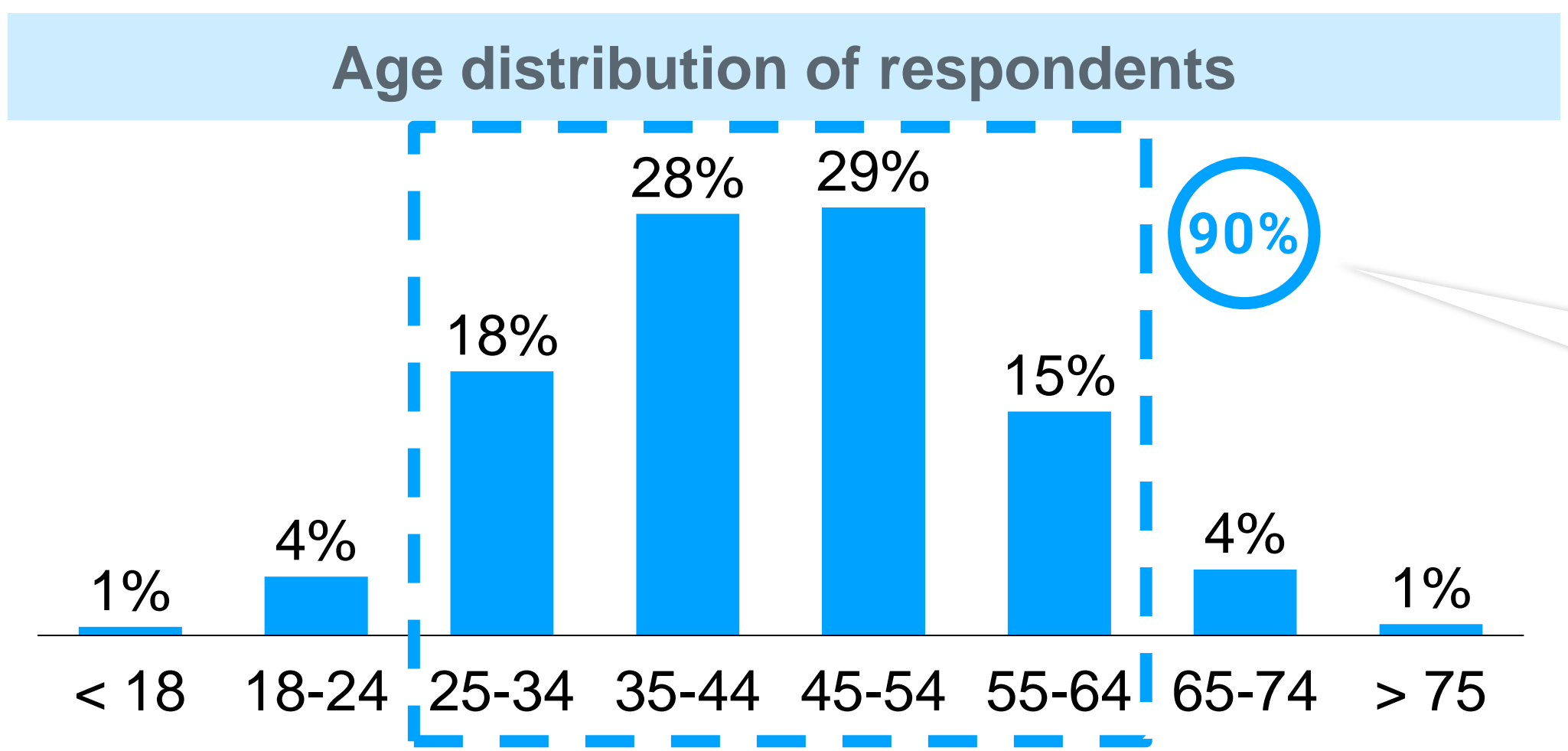
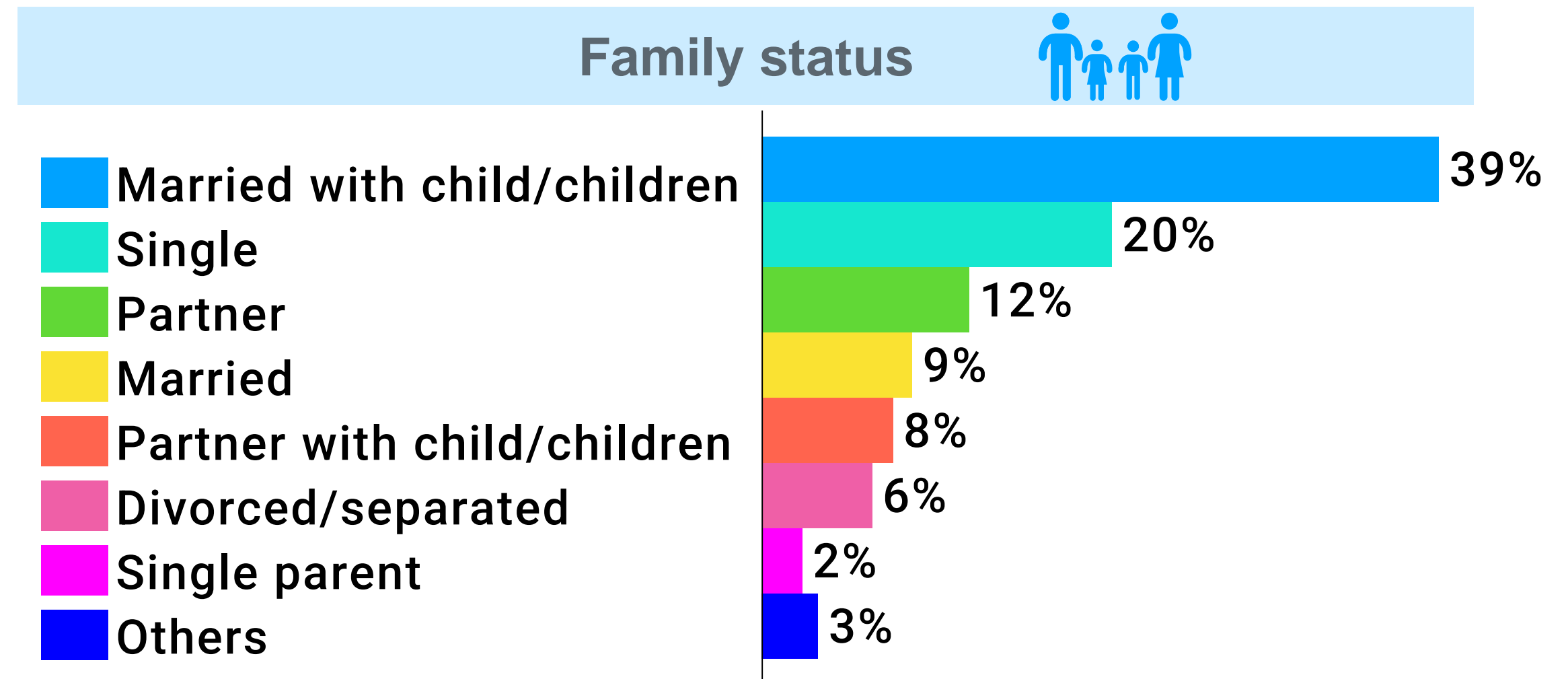
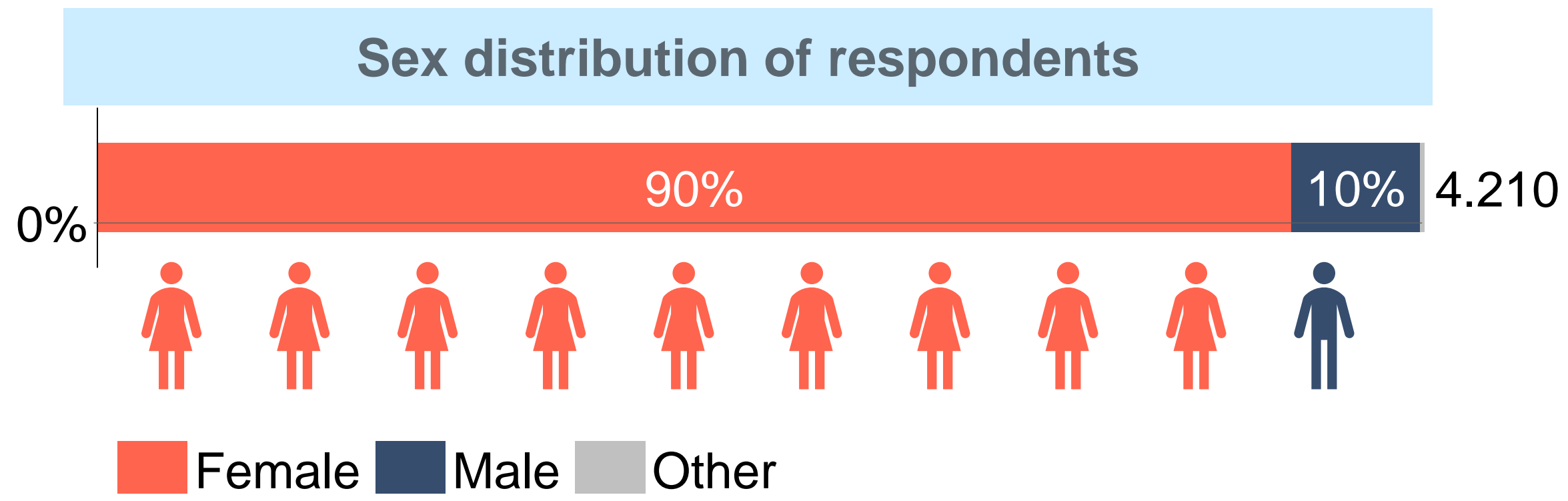


4.210 answers have been obtained, among which most of them were from people residing in Spain, France, Italy, Germany, and Portugal (63%)

Notes: Sample size for these questions: 4.210 respondents

Sociodemographic data (1/2)

Population corresponds mainly to women between 25 and 64 years of age, married with children



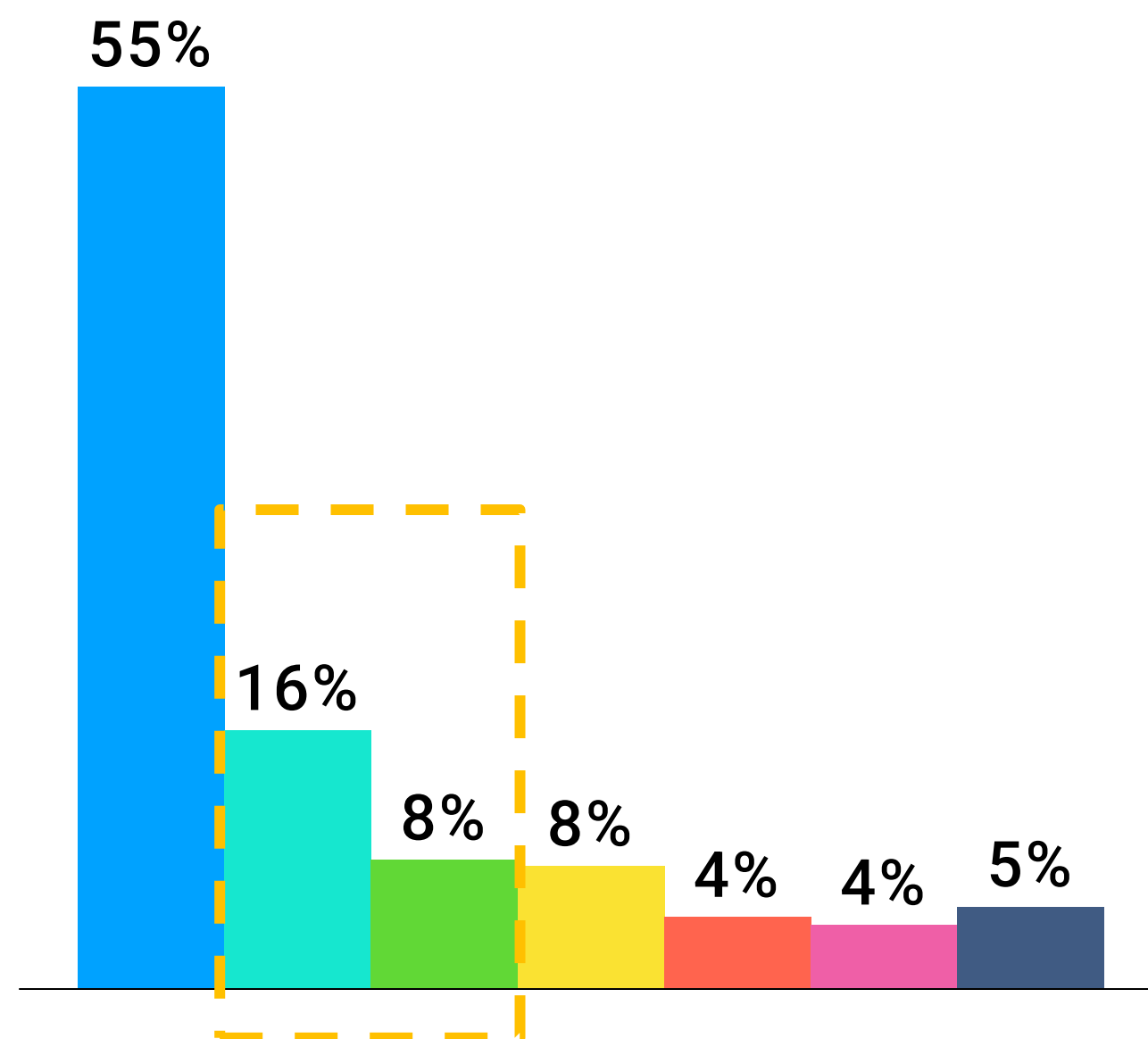
Notes: Sample size for these questions: 4.210 respondents

Sociodemographic data (2/2)

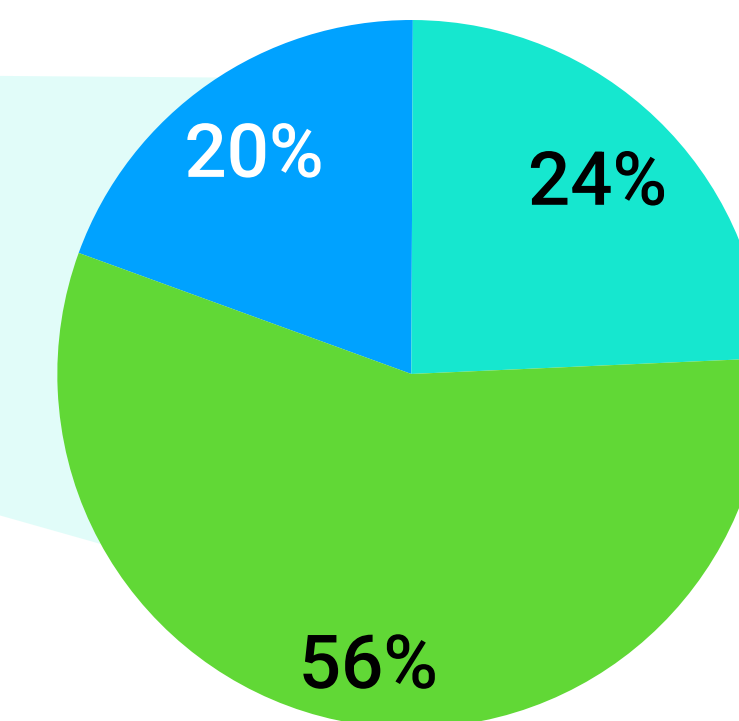
In addition, most of them (71%) are employed full or part-time, followed by 16% unemployed or retired

Employment status

For those who answered, “Employed part-time” or “Unemployed”, we asked them if they felt that their employment status was affected by their migraines:



- Employed full-time
- Employed part-time
- Unemployed
- Retired
- Disabled/Sick leave
- Student
- Others



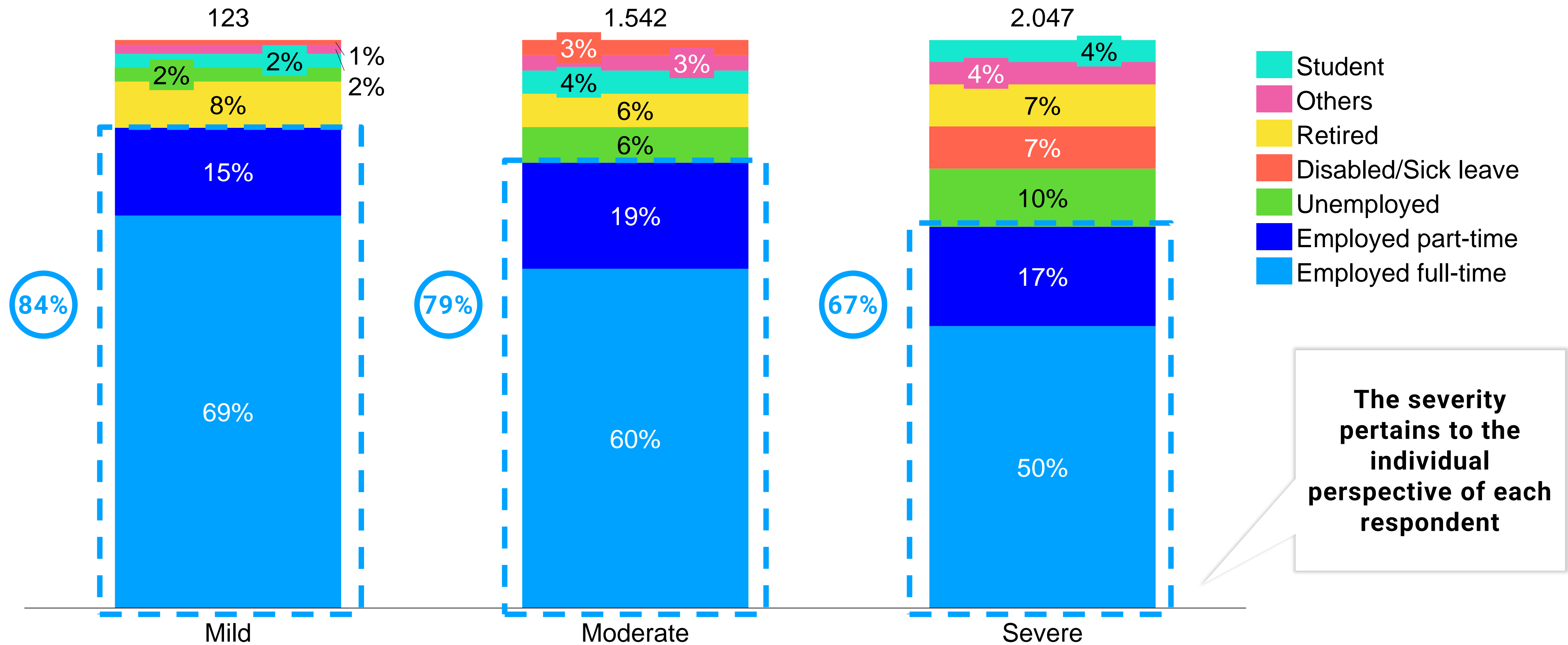
■ Not at all ■ A little ■ Very much

24% of the respondents were employed part-time or unemployed, among which 80% think that their employment status has somehow been affected by migraines

Notes: Sample size for these questions: 4.210 respondents

Employment status vs severity of the disease

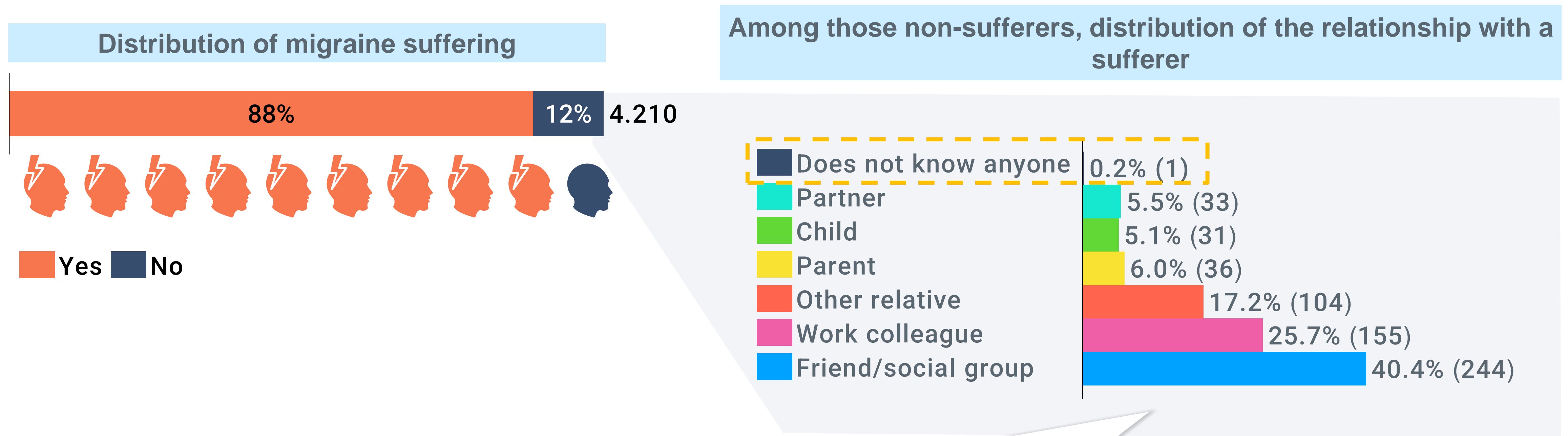
The level of employment exhibits a distinct correlation with the severity of the disease: as the severity increases, the employment rate declines proportionally



Notes: Sample size: 3.712

Sufferers vs non-sufferers

Within the sample, 88% of the respondents suffer from migraines. In addition, among non-sufferers, only 0.2% do not have any relationship with sufferers



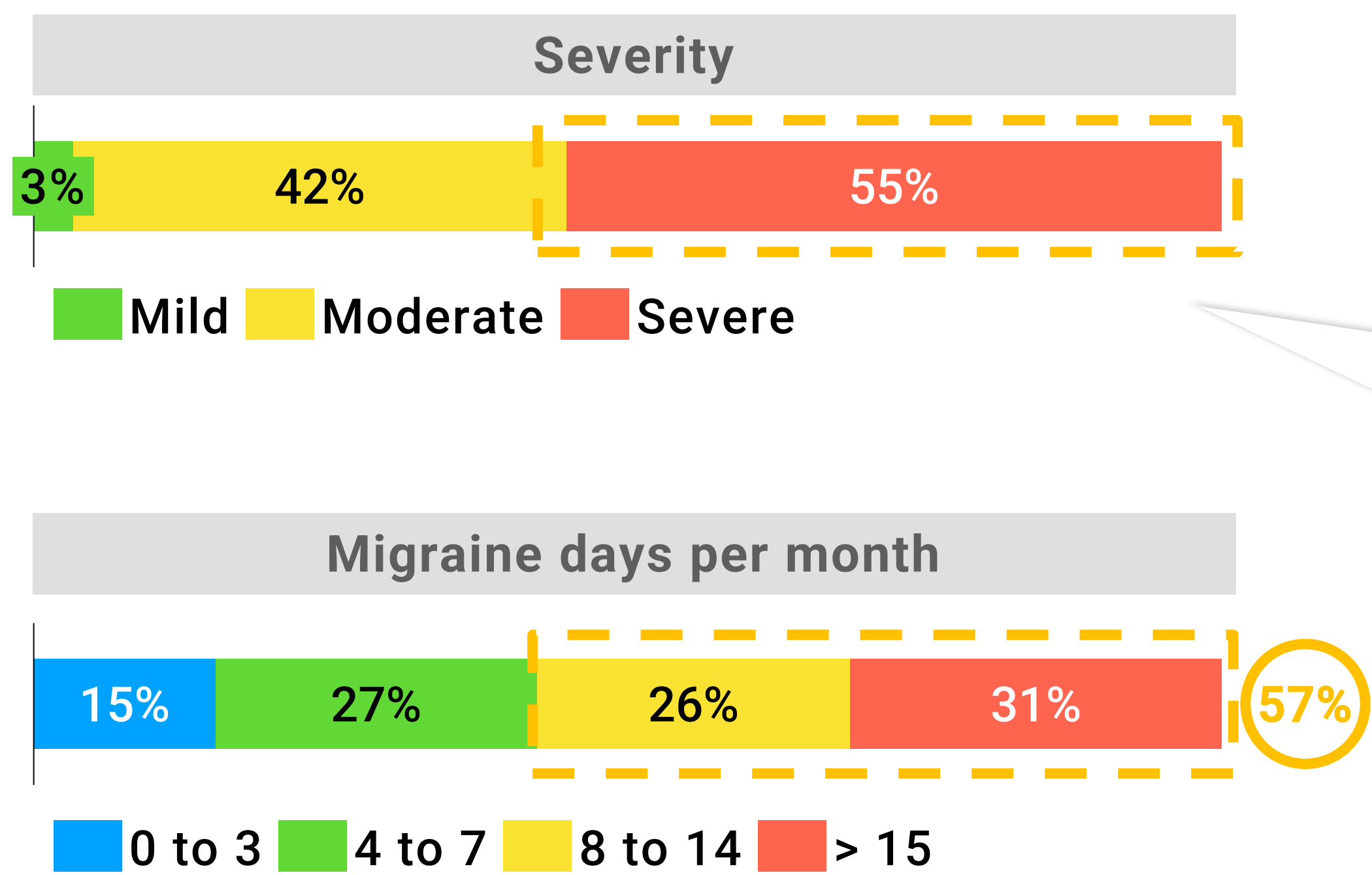
Out of all the **non-sufferer respondents**, only **0.2%** of them **reported no** relationship with a **migraine patient**, which may give some **bias** to the results regarding non-sufferers

2. Migraine disease

Migraine sufferers' perception of their disease

Most respondents are considered severe patients, with more than 8 migraine days per month

Regarding migraine sufferers, they were asked to describe their attacks (most frequent ones, those representing >60%) according to different parameters and these were the results:

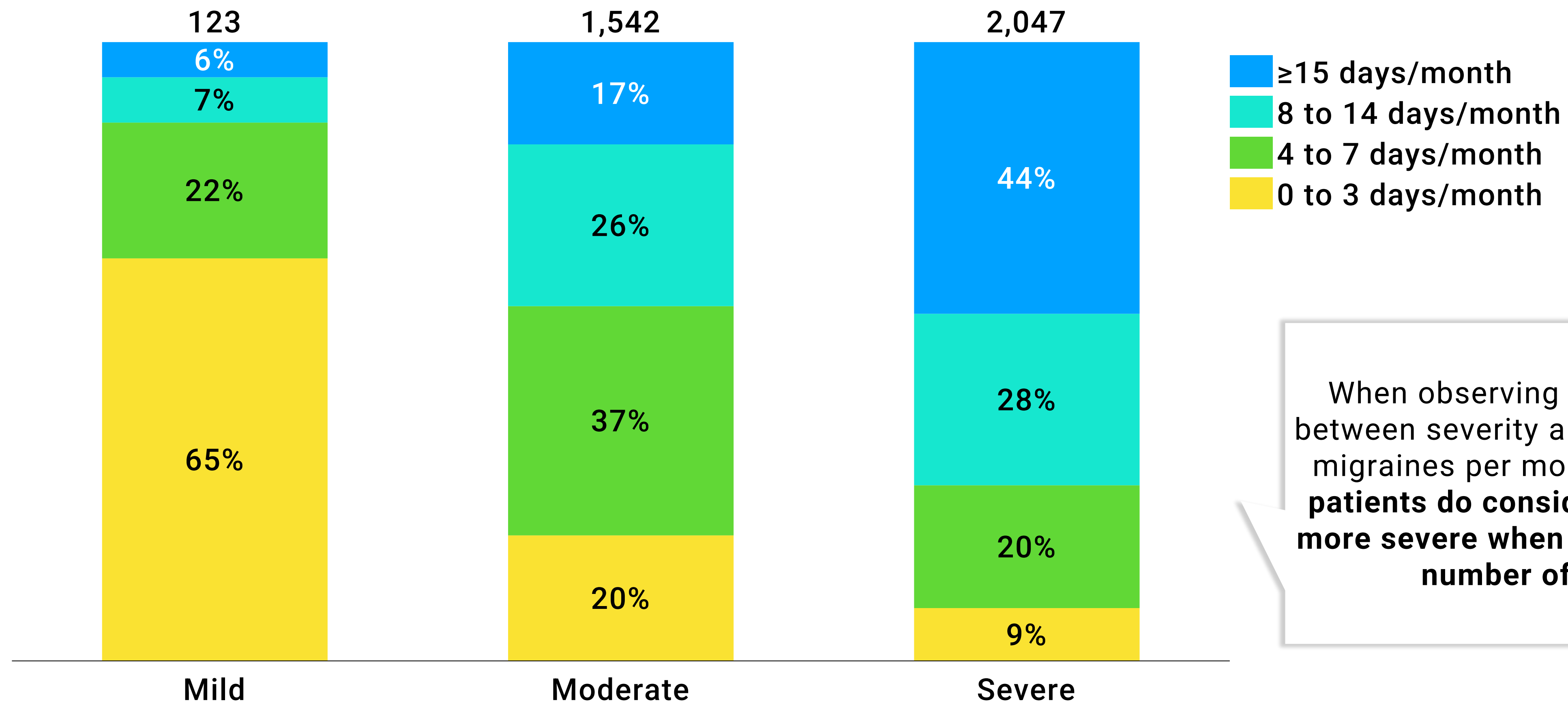


55% of respondents consider that they are **severe** sufferers, and 57% have more than 8 migraine days per month

Notes: Sample size: 3.712

Migraine sufferers' perception of their disease

Correlation between the severity and the number of migraine days per month



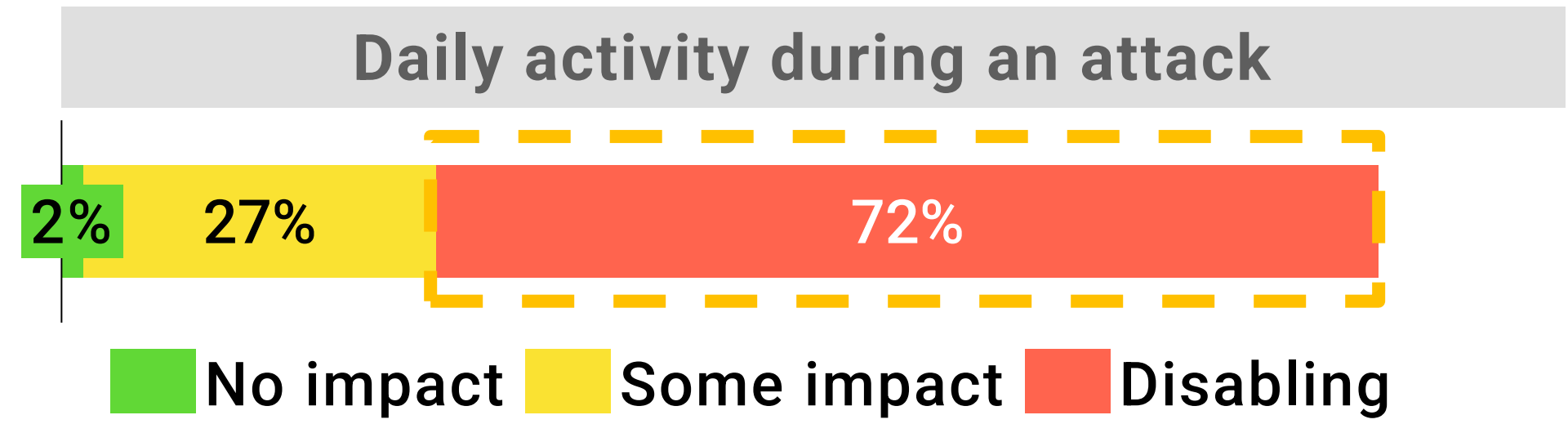
When observing the correlation between severity and the number of migraines per month, we see that **patients do consider** that they are **more severe when having a greater number of attacks**

Notes: Sample size: 3.712

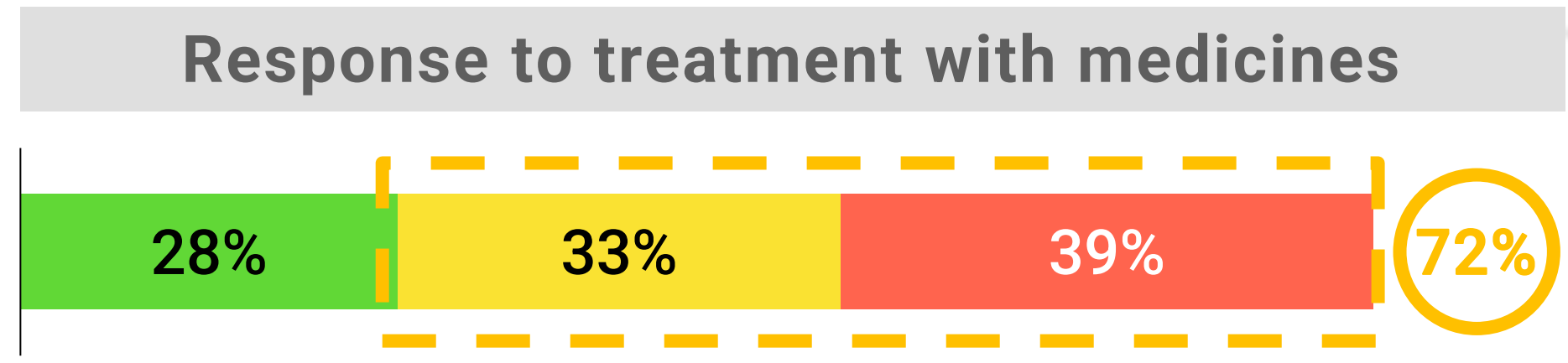
Migraine sufferers' perception of their disease

Most respondents are considered severe patients, with more than 8 disabling attacks per month

Regarding migraine sufferers, they were asked to describe their attacks (most frequent ones, those representing >60%) according to different parameters and these were the results:



■ No impact ■ Some impact ■ Disabling



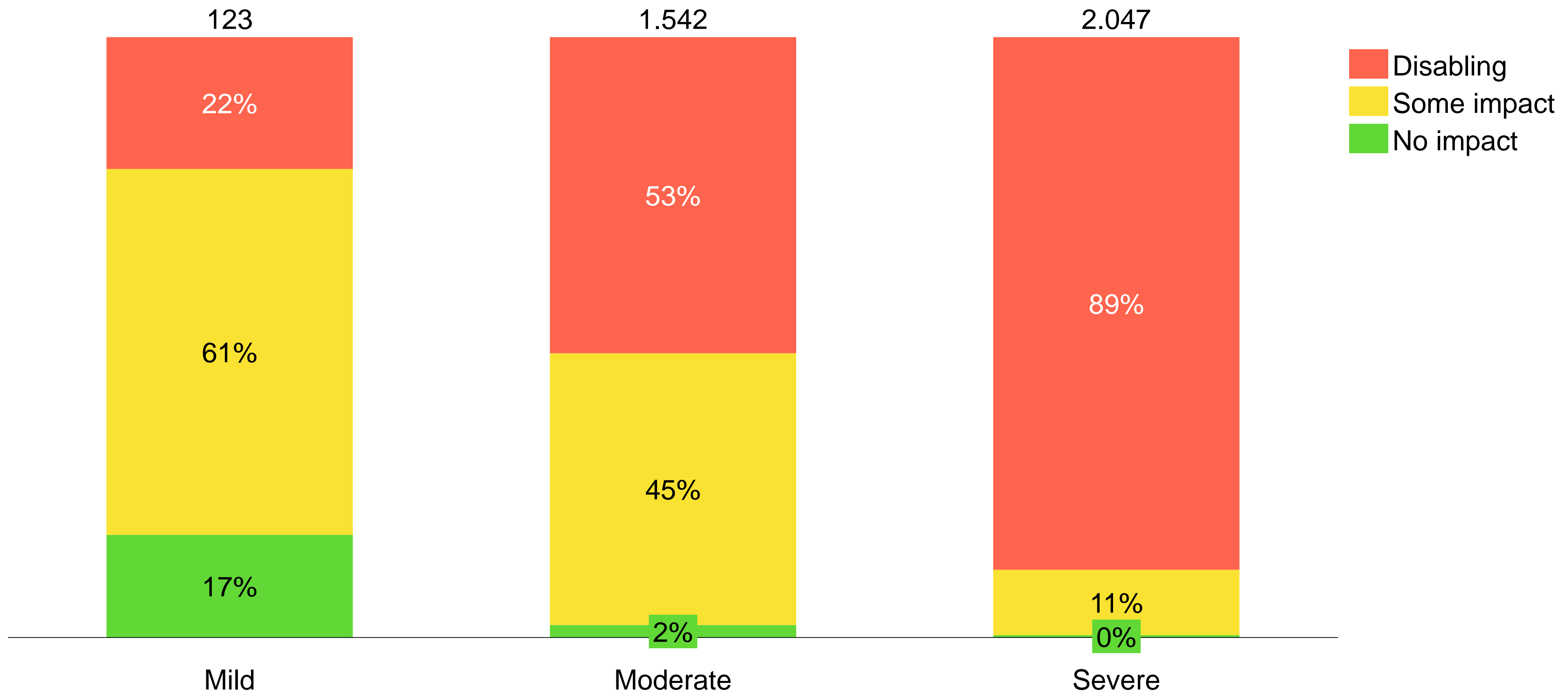
■ My medicines usually resolve the episodes
 ■ I need to take my medicines for several days
 ■ Episodes persist even if taking my medicines

- Migraine episodes have **some degree of impact on daily activity almost always**
- **Treatment seems to provide good control of episodes in less than 1/3 of respondents**

Notes: Sample size: 3.712

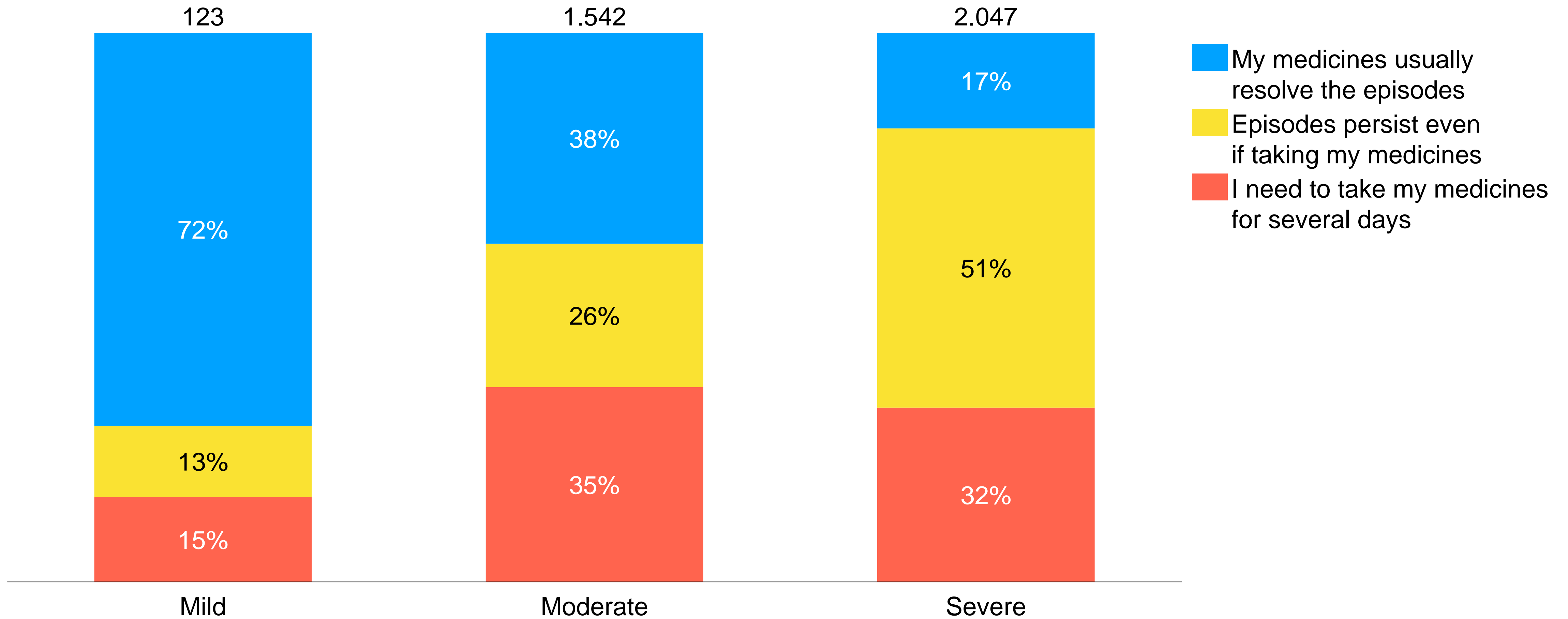
Response to treatment vs severity

The impact on their daily activity exhibits a distinct correlation with the severity of the disease: as the severity increases, the level of disability increases proportionally



Notes: Sample size: 3.712

Response to treatment vs severity



Notes: Sample size: 3.712

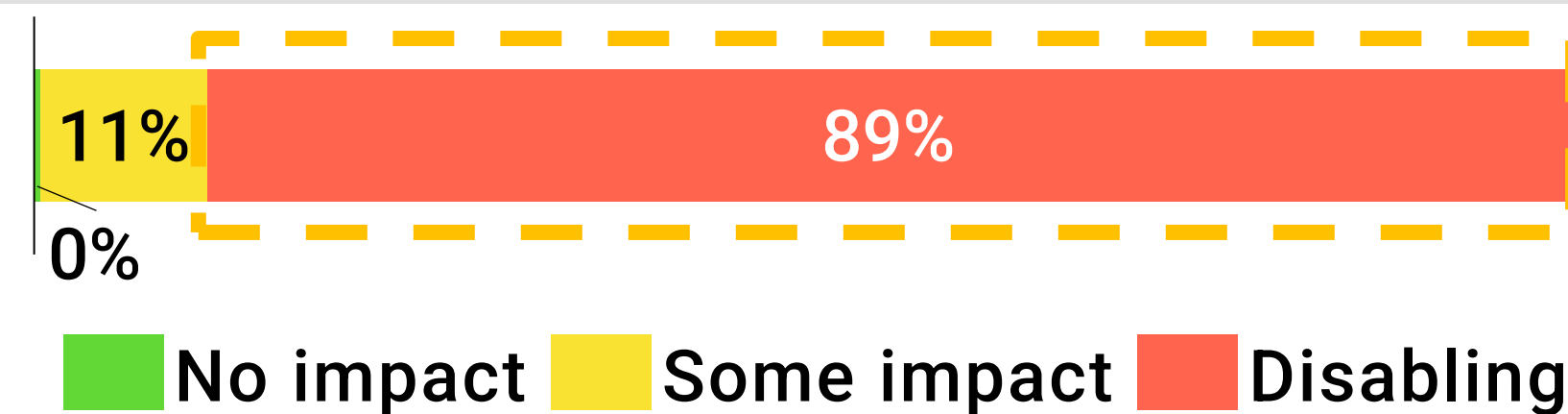
Migraine sufferers' perception of their disease

MIGRAINE SUFFERERS 
SEVERE 

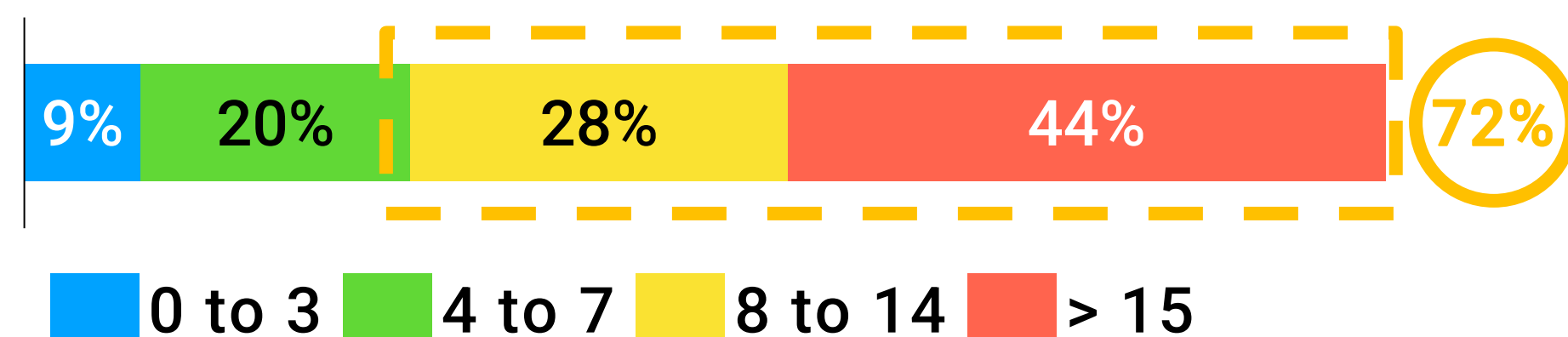
On the other hand, if we focus on the SEVERE PATIENTS, we can see that 89% are completely disabled during an attack and that 72% have more than 8 migraine days per month

Regarding only SEVERE PATIENTS:

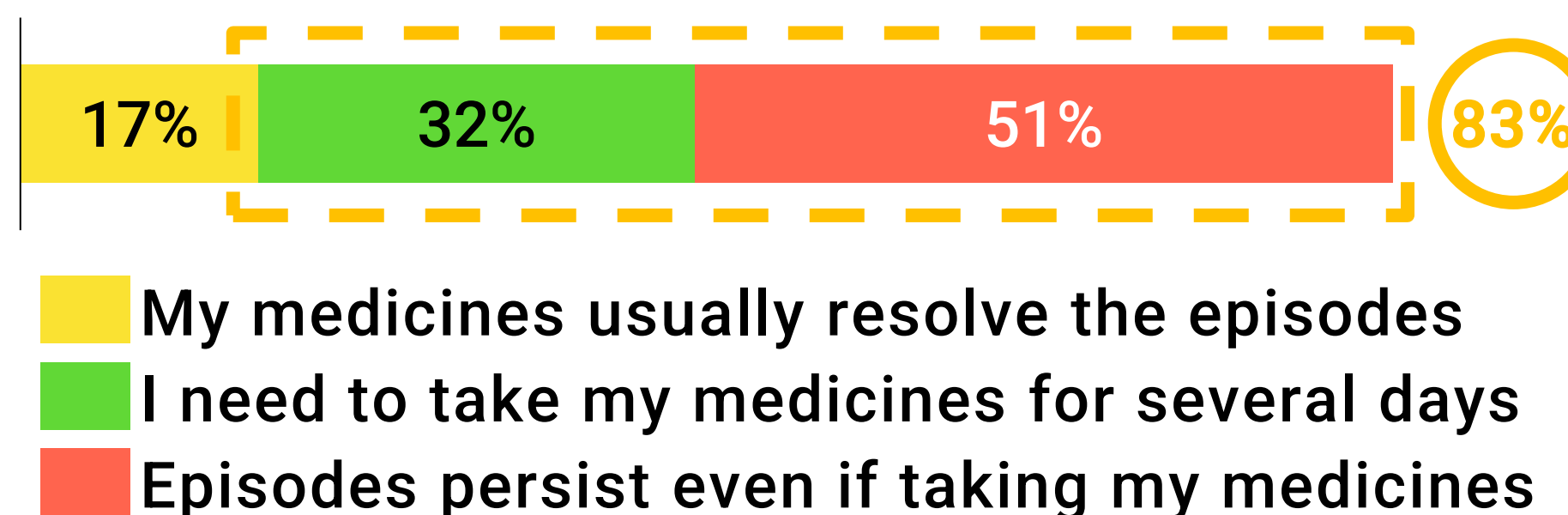
Daily activity during an attack



Migraine days per month



Response to treatment with medicines



When analyzing severe patients, we can see that their attacks are **89% disabling** (vs 72% average from all patients), that **72% have > 8 migraine days/month** (vs 59%), and that **83% of said episodes are usually not resolved with their medicines** (vs 72%)

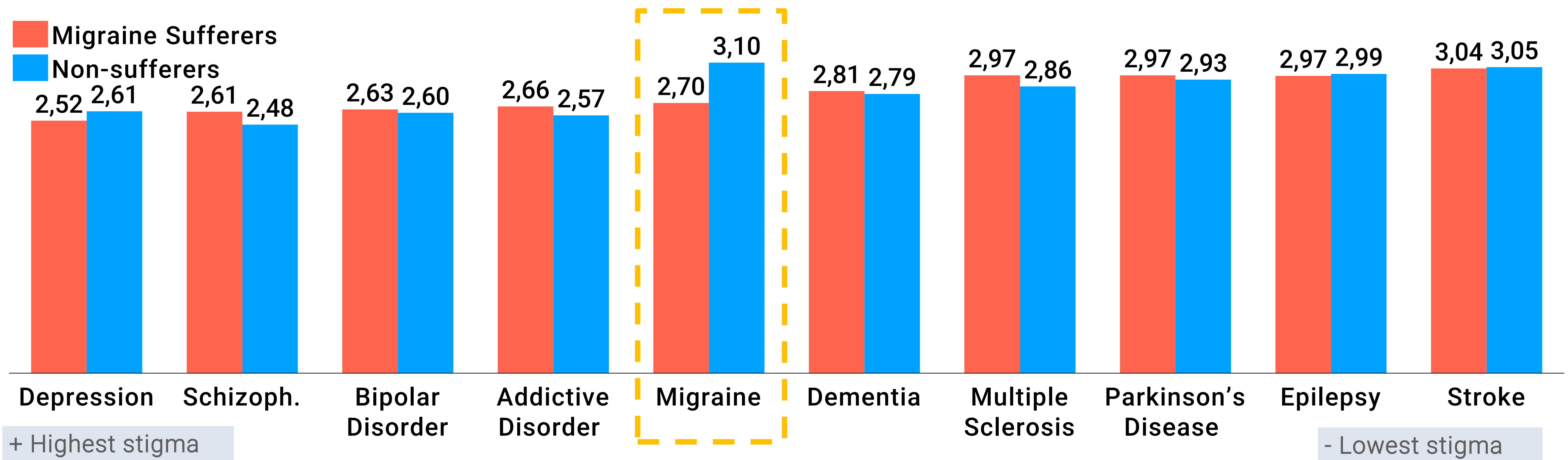
The number of migraine days a month clearly correlates with the perception of severity of the illness
Patients with severe migraine experience more disability during the episodes, and in half of these cases, episodes are not resolved with their treatment

3. Stigma

Disease-related Stigma

Mental diseases are considered more stigmatizing than other neurological diseases, migraine sufferers consider their disorder to be more stigmatizing than dementia, Parkinson's or stroke

Level of stigma associated with a mental or neurological disease, with 1 indicating the most significant cause of stigma



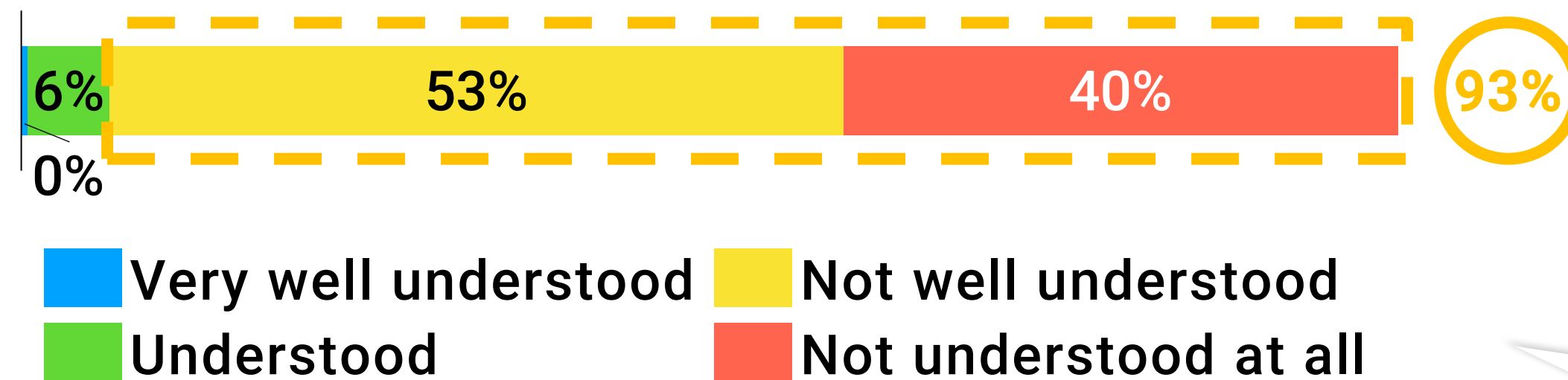
Non-sufferers, despite the bias of most of them having a relationship to a migraine-sufferer, have given migraines the lowest stigma rating (3,10)

Notes: Sample size for these questions: 4.210 respondents

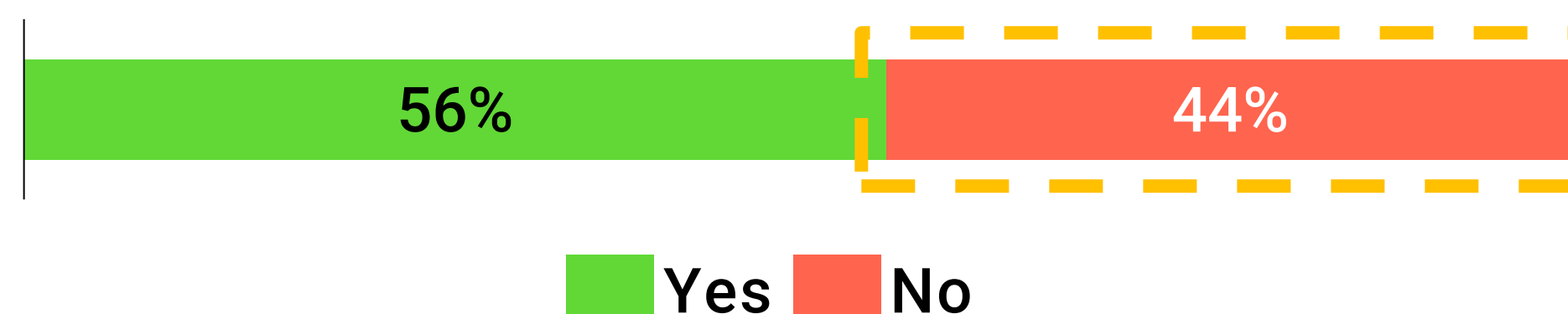
Migraine stigma for sufferers

The focus now turns to the stigma associated with migraines: migraine sufferers were asked to rate their perception of people with their disease

Perception by sufferers of how migraines as a disease, is well-known and understood by the general public



Perception of how mild patients are supportive of those very severe ones



93% of migraine sufferers consider that migraines are not well understood by the general public

Notes: Sample size for these questions: 3.712 respondents

Migraine stigma for sufferers

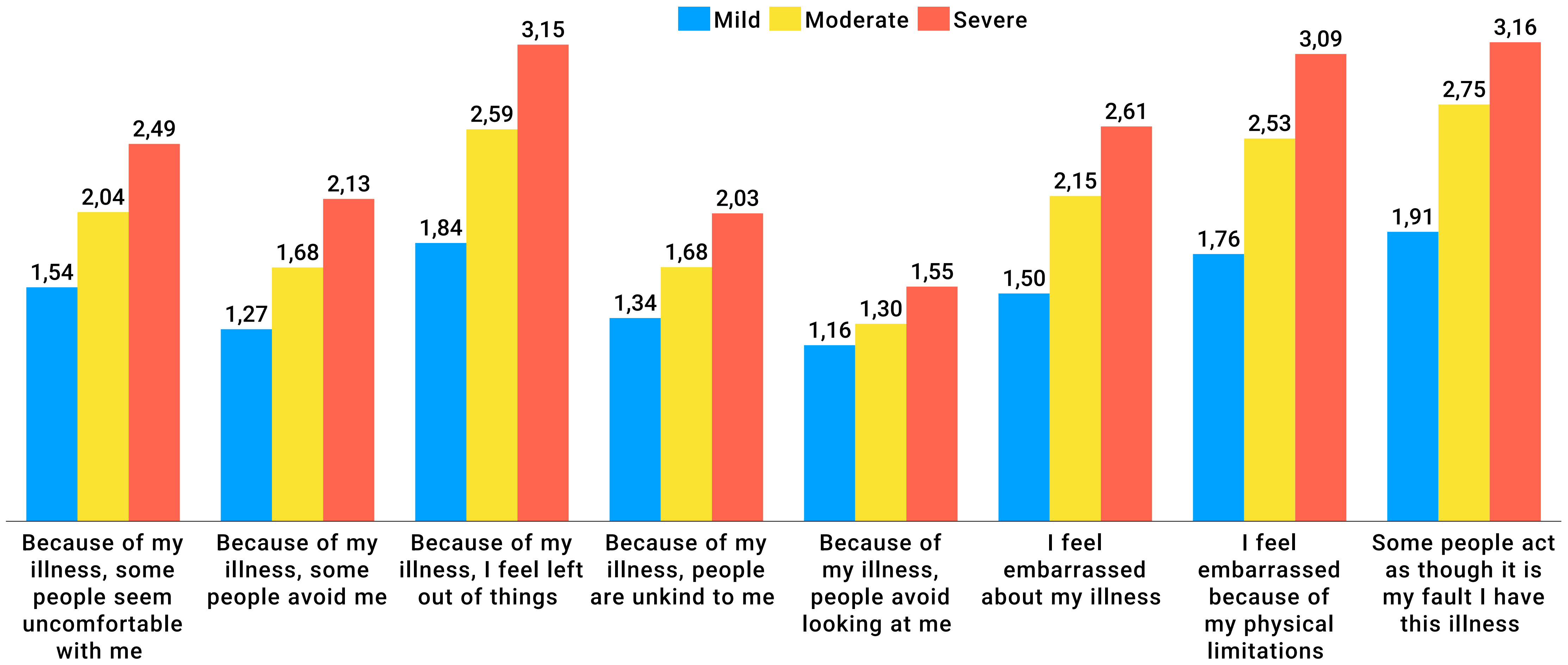
The focus then turned to the self-stigma associated with migraines: migraine sufferers were asked to rate their feelings

Stigma Scale for Chronic Illness (SSCI) 8-item:



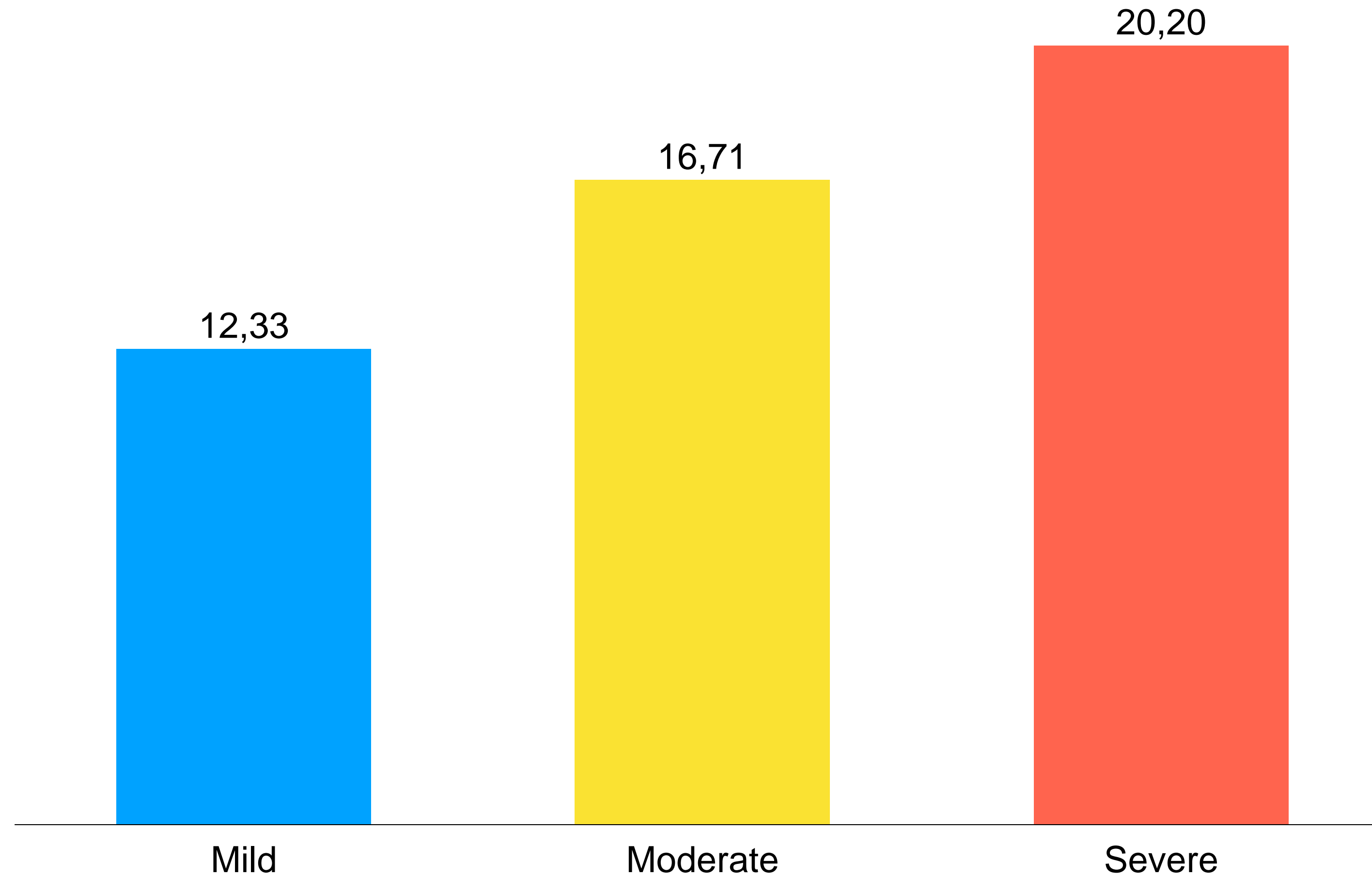
Notes: Sample size for these questions: 3.712 respondents

SSCI split per severity of the disease



Notes: Sample size for these questions: 3.712 respondents

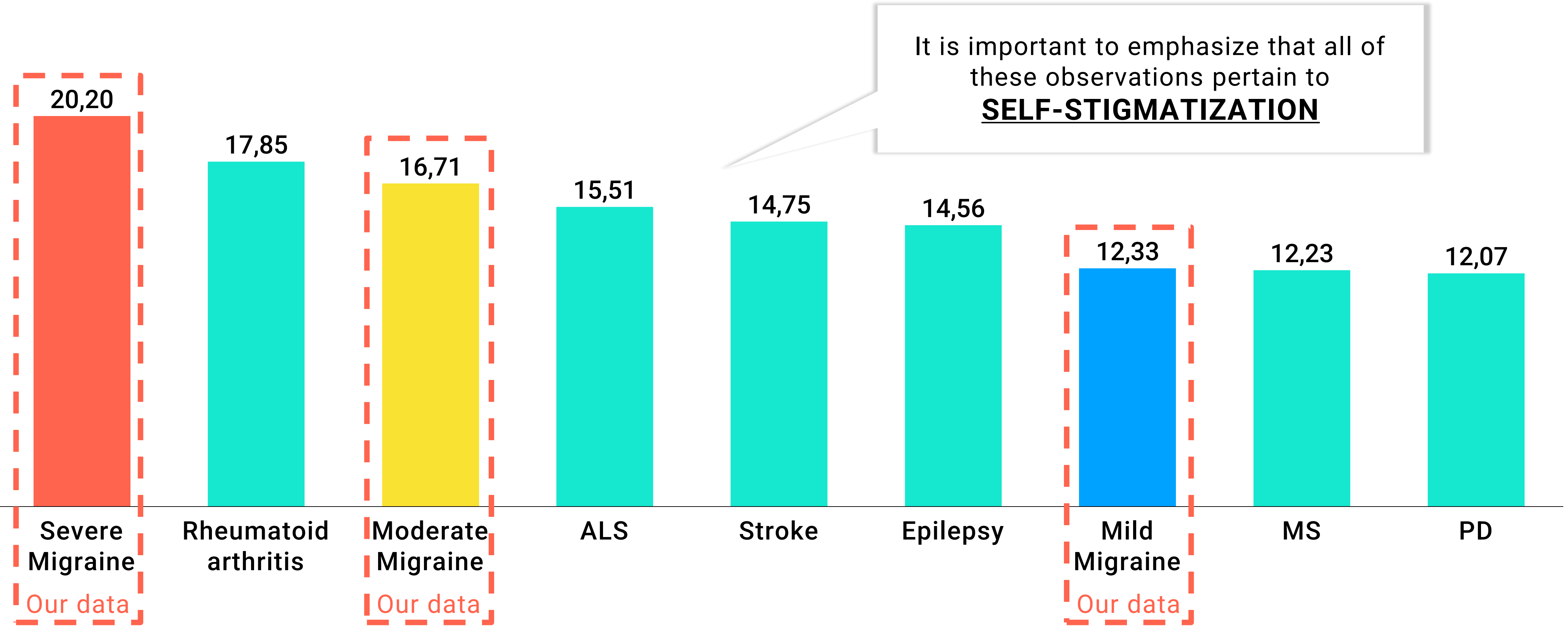
Total rank of SSCI per severity of the disease



Notes: Sample size for these questions: 3.712 respondents

Stigma Scale for Chronic Illness (SSCI) 8-item:

Based on the responses to the SSCI-8 items questionnaire, migraine is ranked as more stigmatizing than other chronic diseases, but strongly varies according to the severity

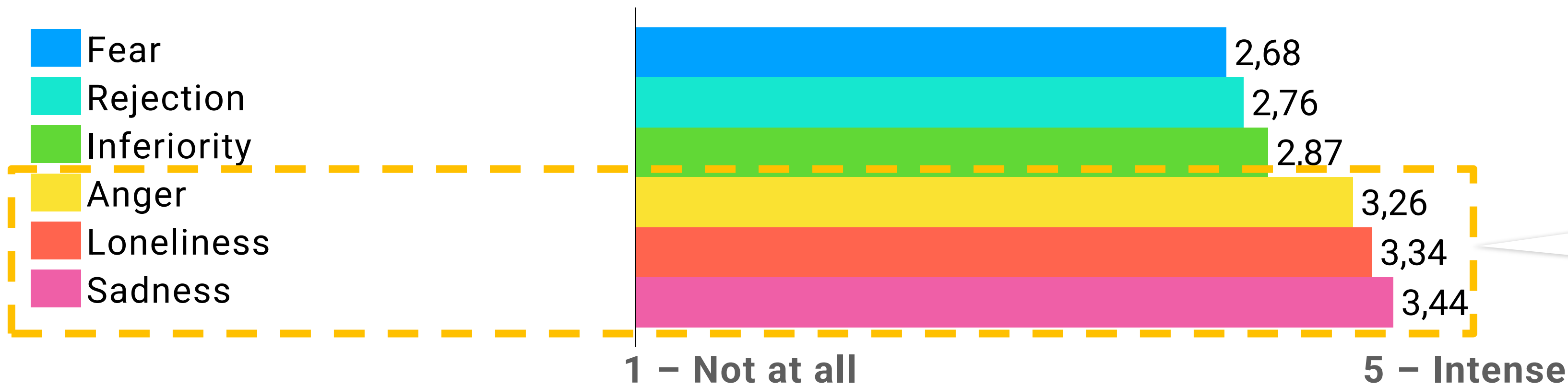


Source: The Stigma Scale for Chronic Illnesses 8-item version (SSCI-8): Development, validation, and use across neurological conditions ([link](#)); Assessment Of Stigmatization In Rheumatoid Arthritis Using The Stigma Scale For Chronic Illnesses-short Form (SSCI-8) ([link](#))

Migraine stigma for sufferers

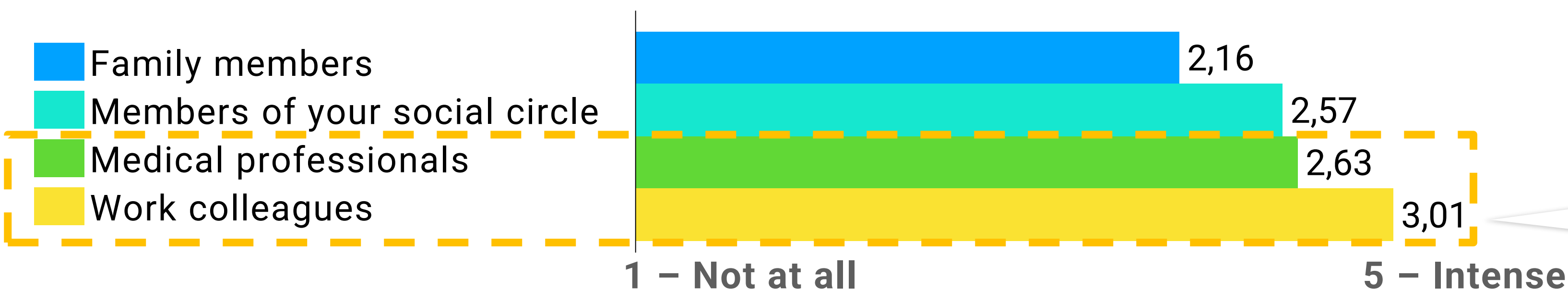
Stigma produces anger, loneliness, and sadness and is mostly perceived within the work environment and among medical professionals

How strongly do you feel the following emotions when experiencing stigma related to your migraine



The most frequent feelings are **anger, loneliness, and sadness**

How strongly do you feel stigma with the following people in your life?



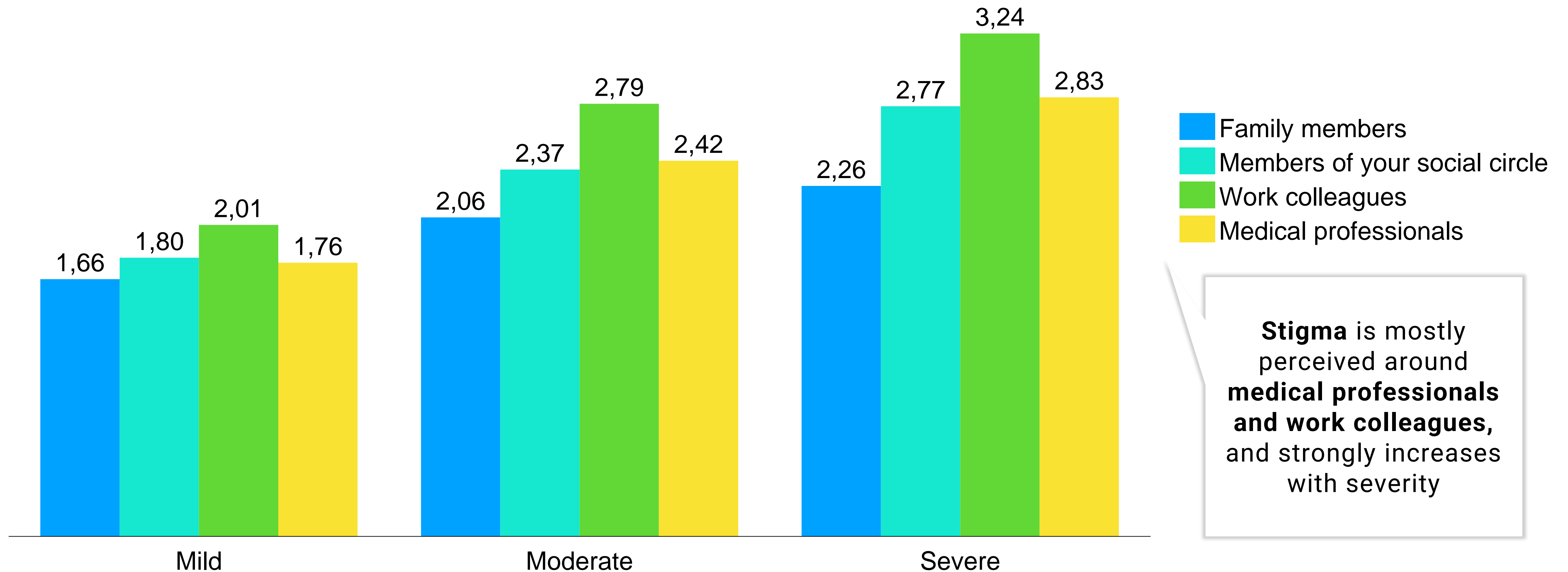
Stigma is mostly perceived around **medical professionals and work colleagues**

Notes: Sample size for these questions: 3.712 respondents

Migraine stigma for sufferers

Stigma is mostly perceived within the work environment and among medical professionals, especially in moderate and severe patients

How strongly do you feel stigma with the following people in your life?



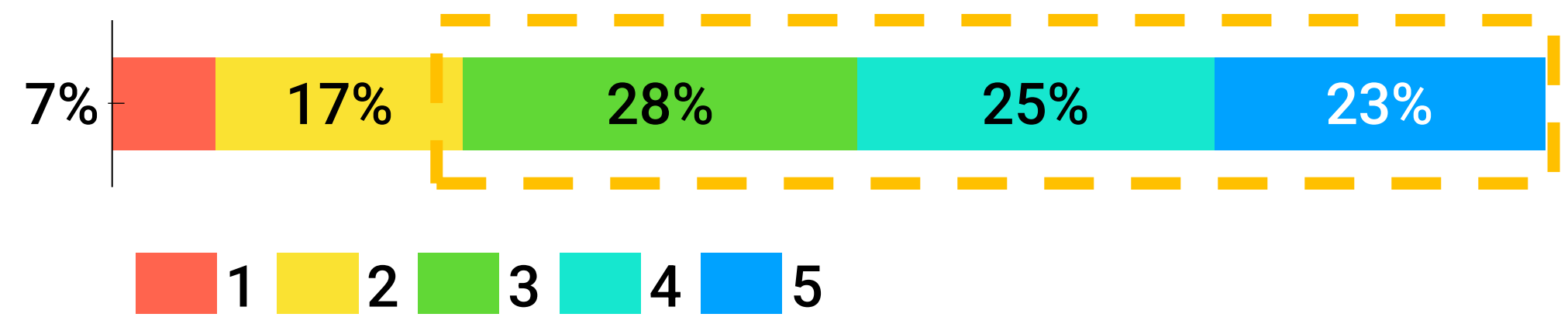
Stigma is mostly perceived around **medical professionals and work colleagues**, and strongly increases with severity

Notes: Sample size for these questions: 3.712 respondents

Migraine stigma for non-sufferers (1/3)

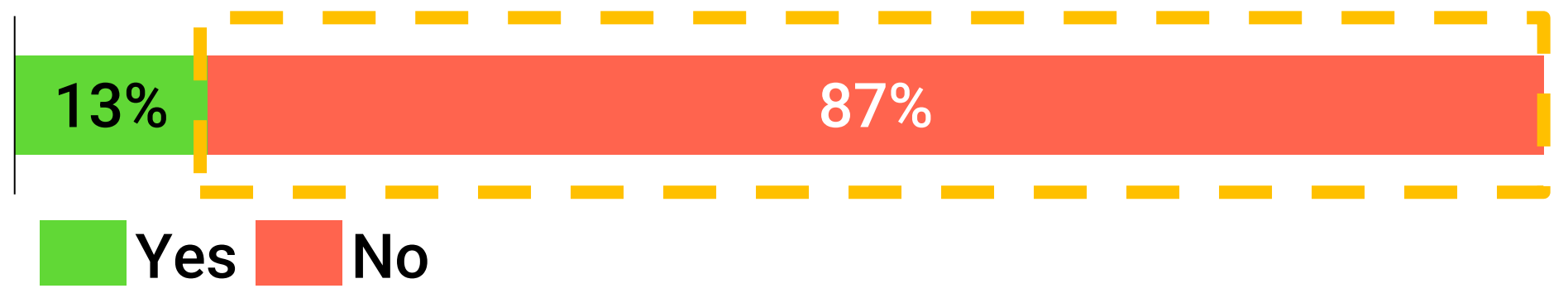
Non-sufferers consider the disease is not well understood by general public

Non-sufferers' perception of their own understanding of migraines (1 = none | 5 = deep understanding)



76% of non-sufferer respondents believe that they have a **good understanding** of migraines, which again highlights the **possible bias** in this survey

Perception by non-sufferers of how migraines as a disease is well-known and understood by the general public



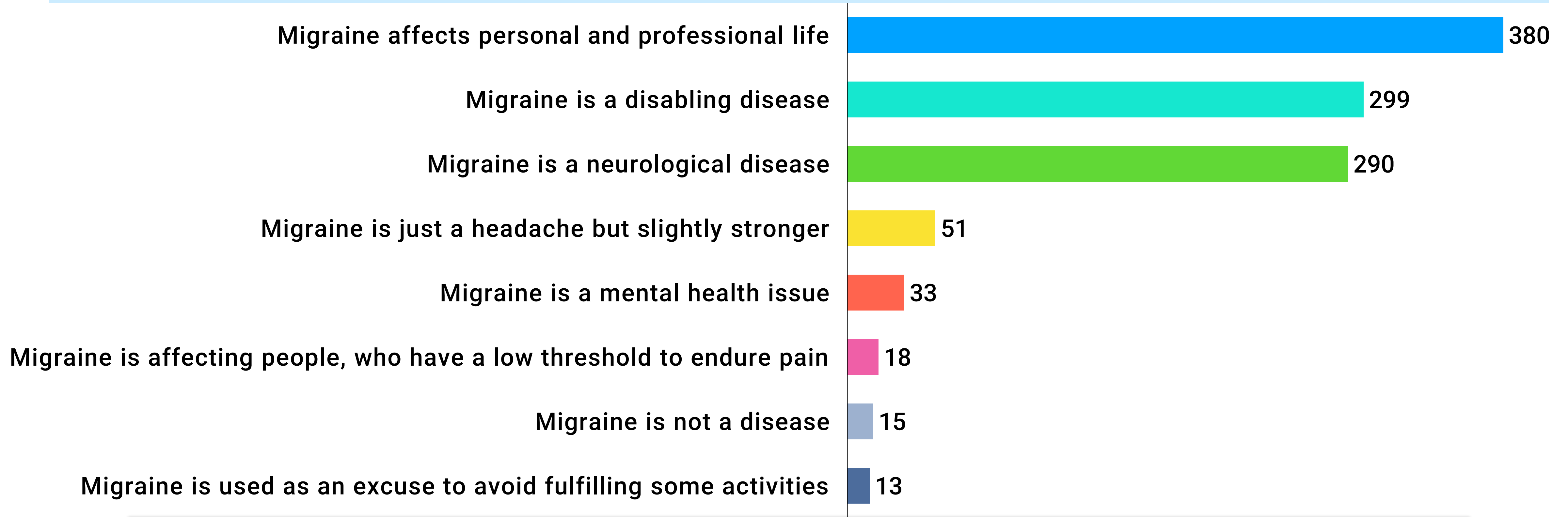
87% of **non-sufferer** respondents consider that migraines are **not well understood** by the general public, **very much in line with the sufferers** who rated this same question with 93%

Notes: Sample size for these questions: 498 respondents

Migraine stigma for non-sufferers (3/3)

Majority of responders know migraine is a neurological disease with an impact in daily activity and in personal and professional life

Among the following statements, which one describes migraine the best (multiple choice)?



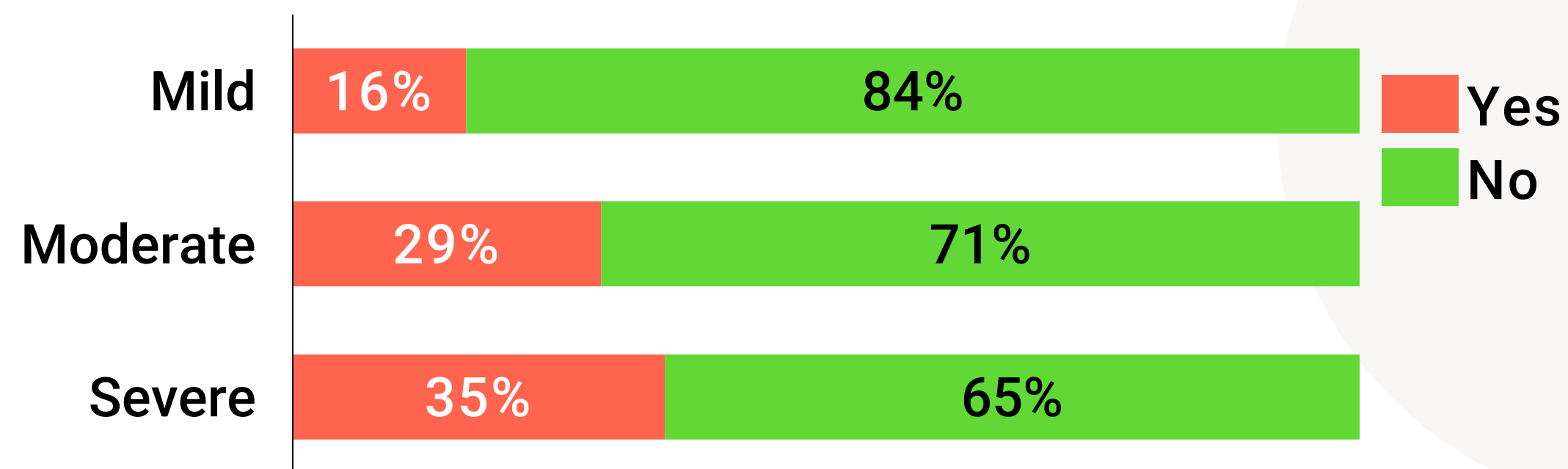
Non-sufferers mainly believe that migraine is a disabling neurological disease that affects personal and professional life

Notes: Sample size for these questions: 498 respondents

Medical professionals' stigma for sufferers

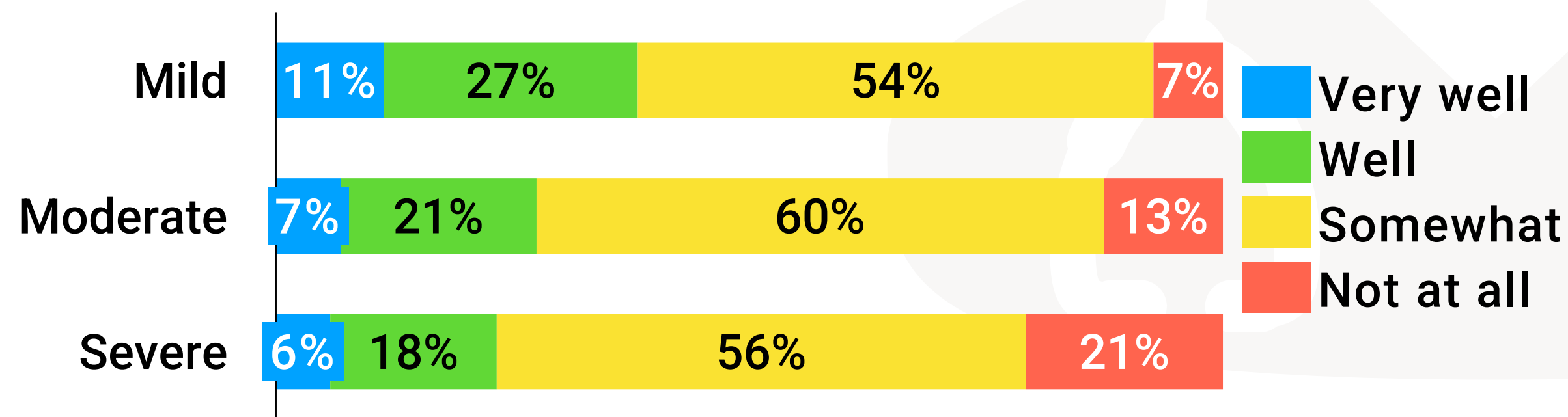
Regarding medical professionals, there is a clear linear relationship between the severity of migraine and their perception of medical professionals' understanding of what it is like to live with migraines

Have you ever delayed or avoided seeking medical advice because you felt embarrassed about your migraine?



As severity increases, so too does reluctance to seek medical advice due to feeling embarrassed

How well do you feel medical professionals understand what it is like to live with your condition?



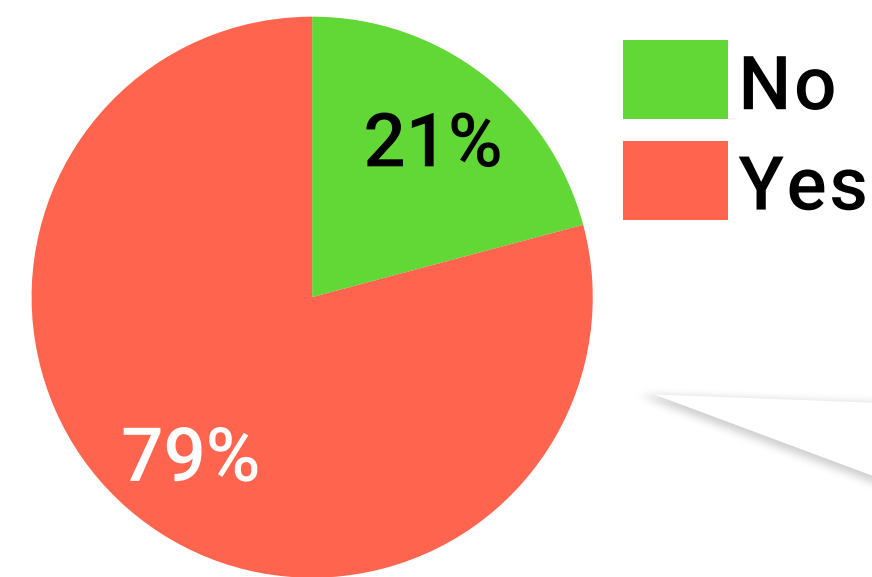
Similar to above, as severity increases, so too does a perception in lack of understanding from medical professionals

Notes: Sample size for these questions: 3.712 respondents

Work-related stigma for sufferers

80% of migraine sufferers have experienced difficulties in completing work tasks or their careers have been negatively affected due to migraines

Have you experienced difficulties in completing necessary work tasks, or has it negatively affected your career progression, such as missed promotions or considering a change in the profession due to the severity of the migraine attacks?



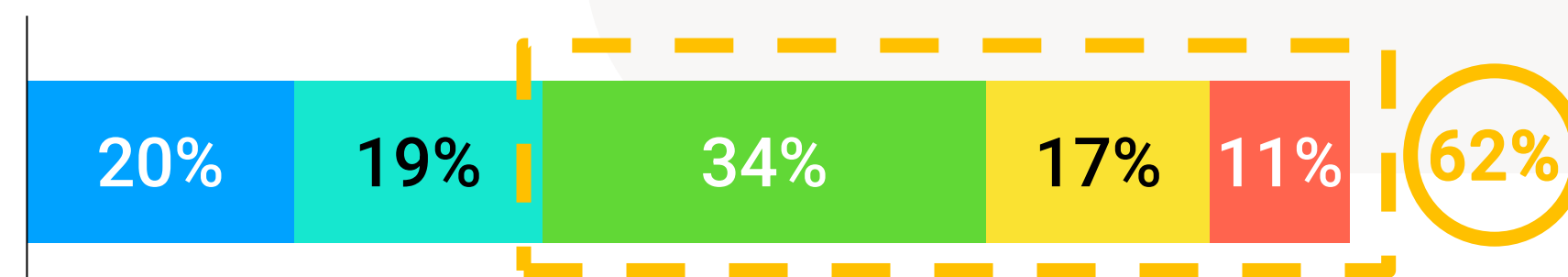
79% of migraine sufferers have experienced **difficulties** in completing work tasks or their **careers have been negatively affected** due to migraines

How comfortable do you feel disclosing your migraines to a co-worker, your manager, or supervisor?



- Comfortable
- Neither comfortable nor uncomfortable
- I have not told anyone at work
- Uncomfortable

How do you feel your condition affects the way in which your direct manager assesses your value to the company?



- Never
- Infrequently
- Sometimes
- Frequently
- Always

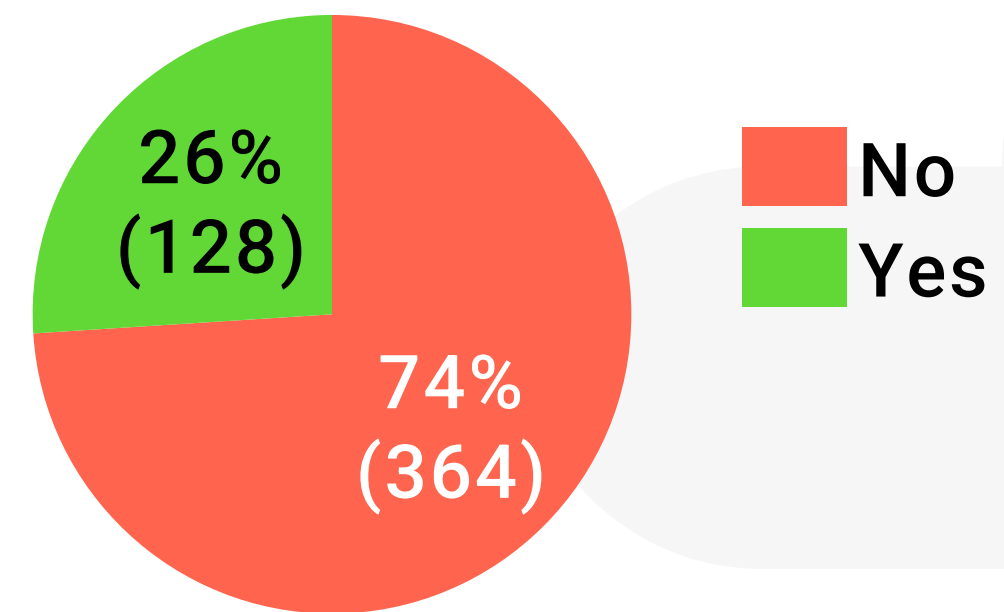
62% of migraine respondents believe that **migraines have affected their value assessment**

Notes: Sample size for these questions: 3.712 respondents

Work-related stigma for non-sufferers

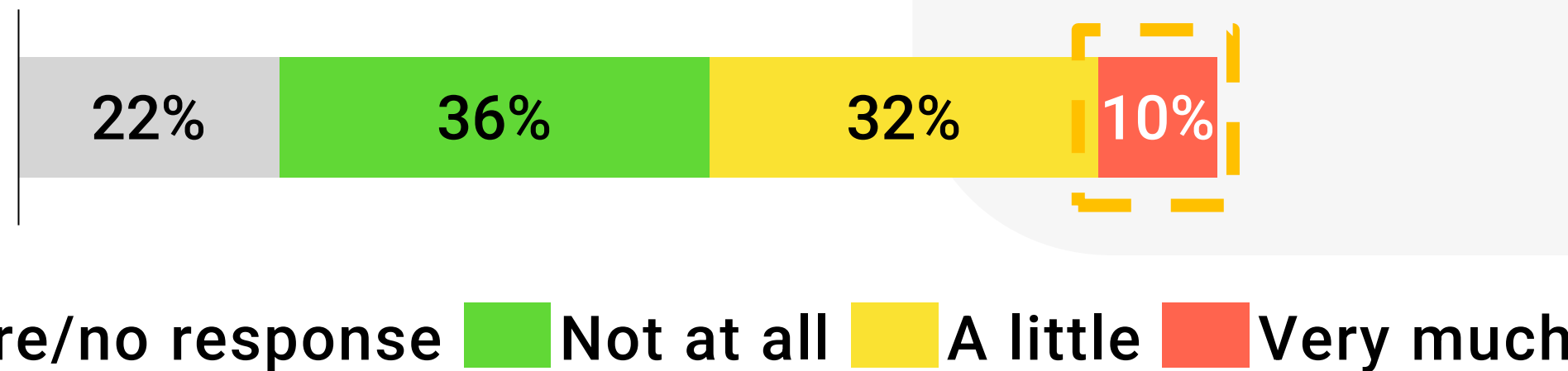
On the other hand, only 26% of non-sufferers believe that working with migraine patients affects the way in which they are evaluated, and only 10% that it makes their work life more difficult

Does working with someone who has migraine affect the way in which you assess their performance?

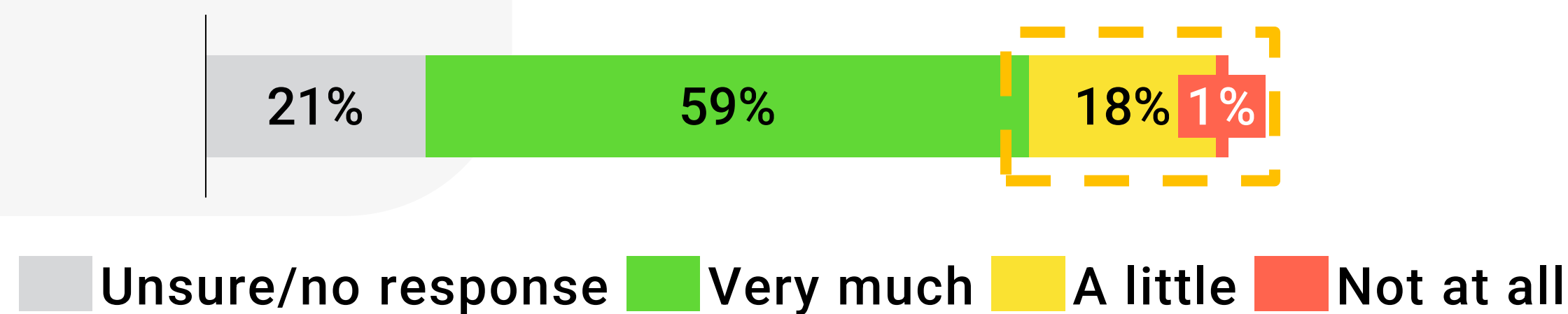


Only **26% of non-sufferers** believe that working with migraine patients has affected their **performance assessment**, while **62% of migraine sufferers** relate that their condition has impacted to how their direct manager assesses their value to the company

Does working with colleagues with migraine make your work life more difficult?



How supportive are you to a co-worker/manager/supervisor/reportee who currently has migraine?



Notes: Sample size for these questions: 498 respondents

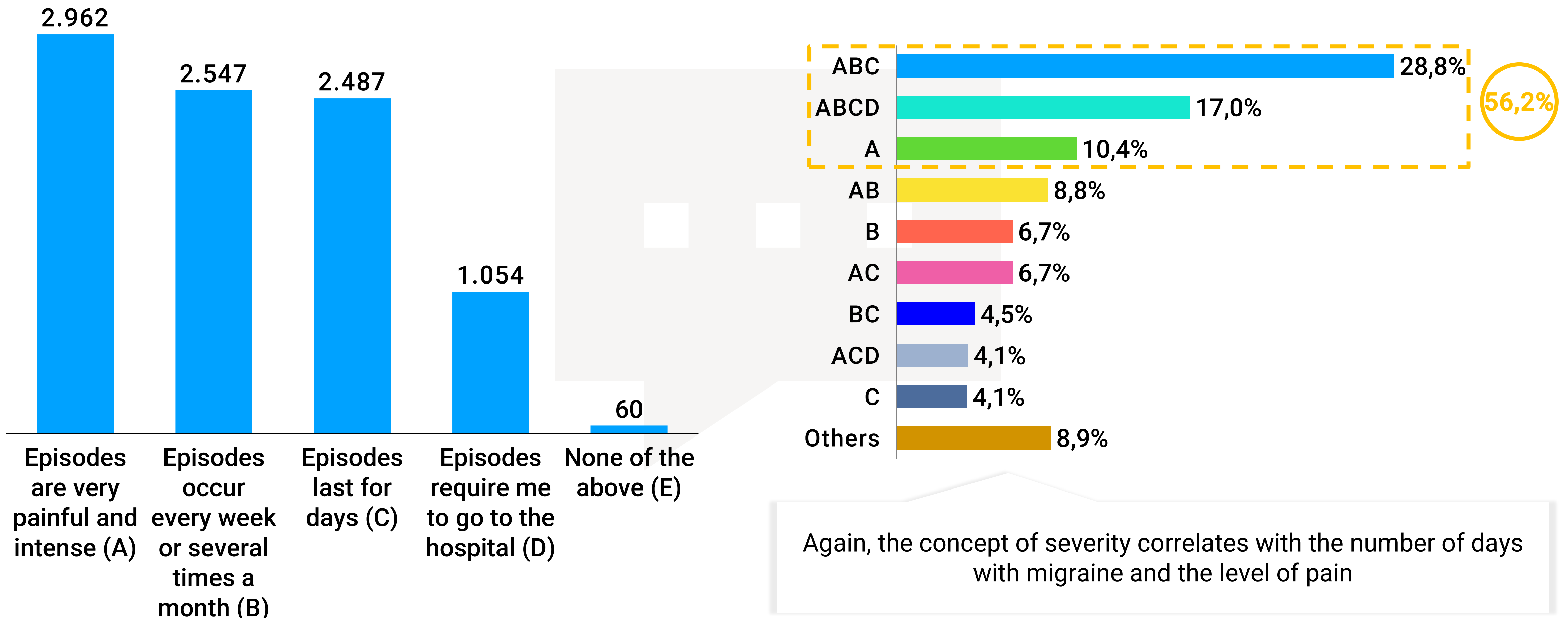
A black and white photograph of several medical professionals, likely radiologists, gathered around a computer monitor. They are looking at a series of axial brain CT scans. One person's hand is visible, pointing at a specific scan. The monitor displays a grid of scans, with one larger scan on the left side. The interface includes various controls and a menu bar at the top. The text 'Medical Research Environment v2.0.556' is visible on the right side of the monitor.

4. Language perception

Migraine terminology - Severe

When migraine sufferers were asked about their understanding of the word 'Severe', most of them agreed that it refers to very painful and intense episodes that last for days and occur every week or several times a month

Q13-17: What is your understanding of the following terms used to describe migraine (multiple choice)

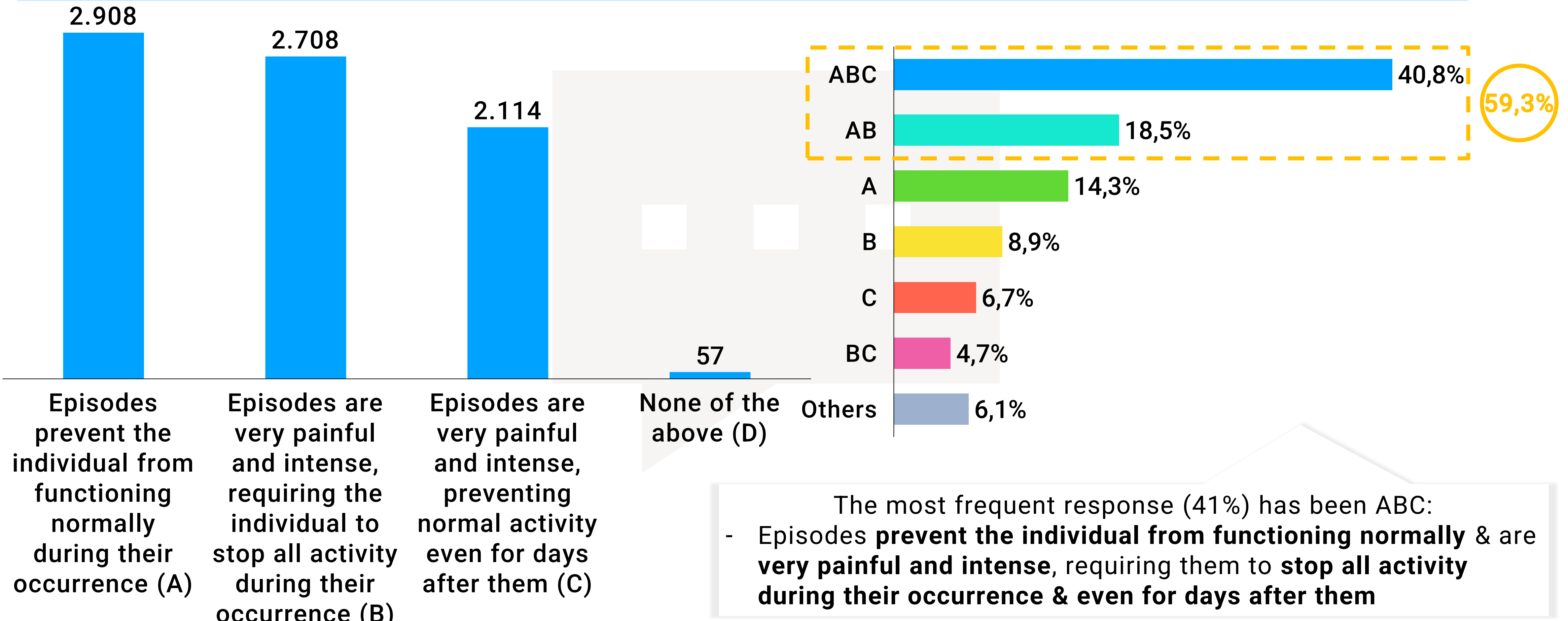


Notes: Sample size for these questions: 3.712 respondents

Migraine terminology - Disabling

In addition, when asked about the word 'Disabling', they agreed that episodes prevent the individual from functioning normally & are very painful and intense, requiring them to stop all activity

Q13-17: What is your understanding of the following terms used to describe migraine (multiple choice)



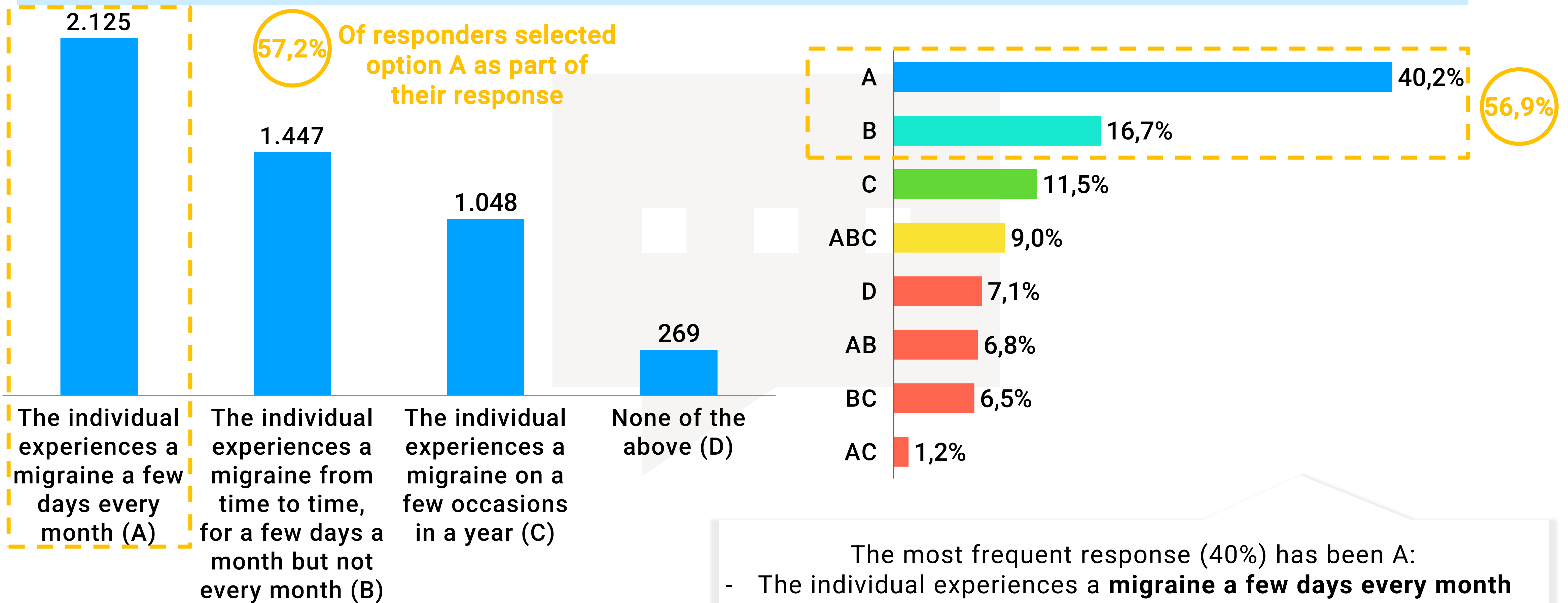
The most frequent response (41%) has been ABC:
 - Episodes **prevent the individual from functioning normally** & are **very painful and intense**, requiring them to **stop all activity during their occurrence & even for days after them**

Notes: Sample size for these questions: 3.712 respondents

Migraine terminology - Episodic

Episodic migraines according to science: Episodic migraine is defined as having a migraine on fewer than 15 days per month

Q13-17: What is your understanding of the following terms used to describe migraine (multiple choice)

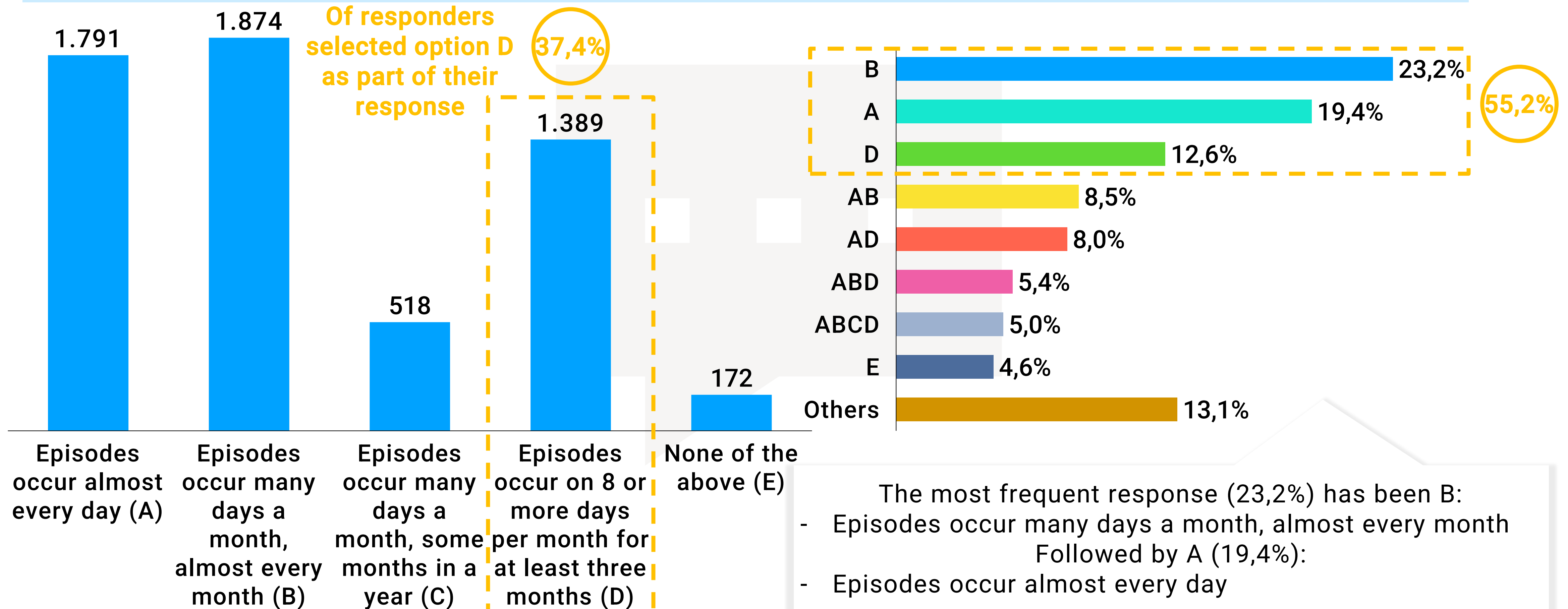


Source: Defining the Differences Between Episodic Migraine and Chronic Migraine ([link](#)). Notes: Sample size for these questions: 3.712 respondents

Migraine terminology - Chronic

Chronic migraines according to science: Having chronic migraine means you have at least 8 migraines per month for at least 3 months, or 15 or more days per month

Q13-17: What is your understanding of the following terms used to describe migraine (multiple choice)



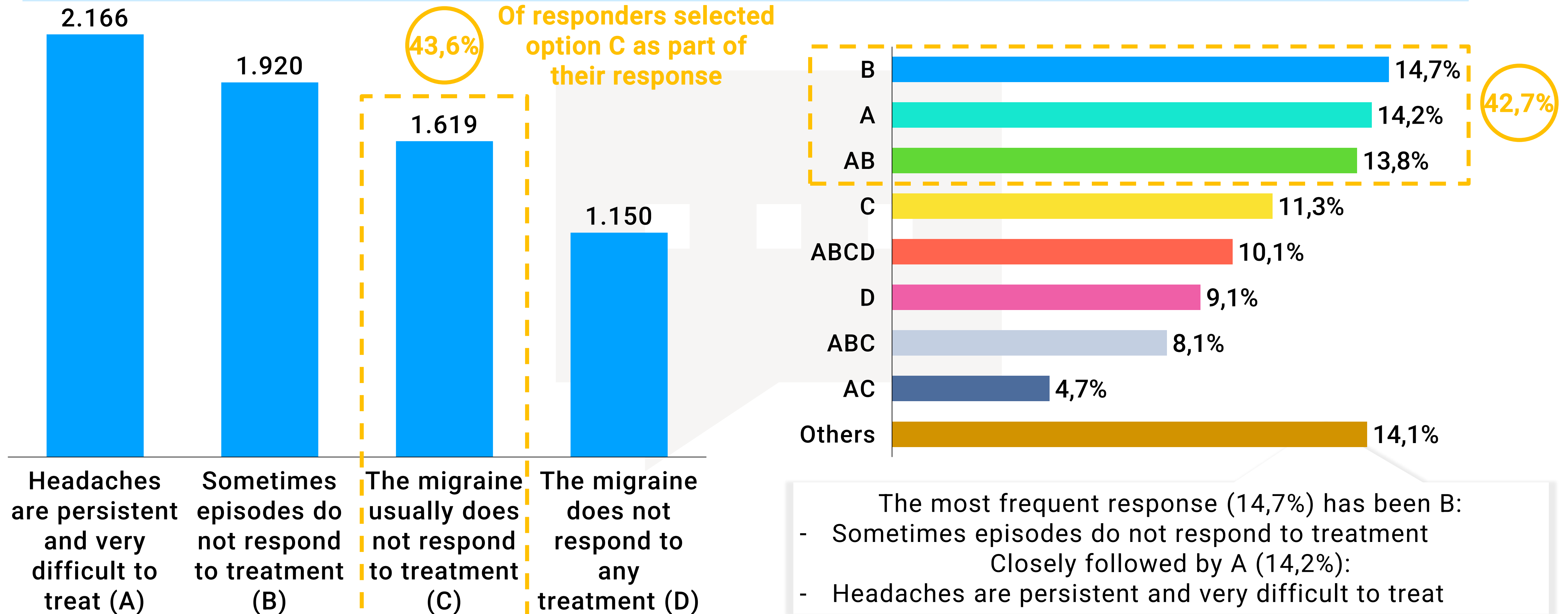
The most frequent response (23,2%) has been B:
 - Episodes occur many days a month, almost every month
 Followed by A (19,4%):
 - Episodes occur almost every day

Source: Cleveland Clinic ([link](#)) | Defining the Differences Between Episodic Migraine and Chronic Migraine ([link](#)). Notes: Sample size for these questions: 3.712 respondents

Migraine terminology - Refractory

Refractory migraines according to science: Failure to respond to 5 classes of preventive treatments

Q13-17: What is your understanding of the following terms used to describe migraine (multiple choice)



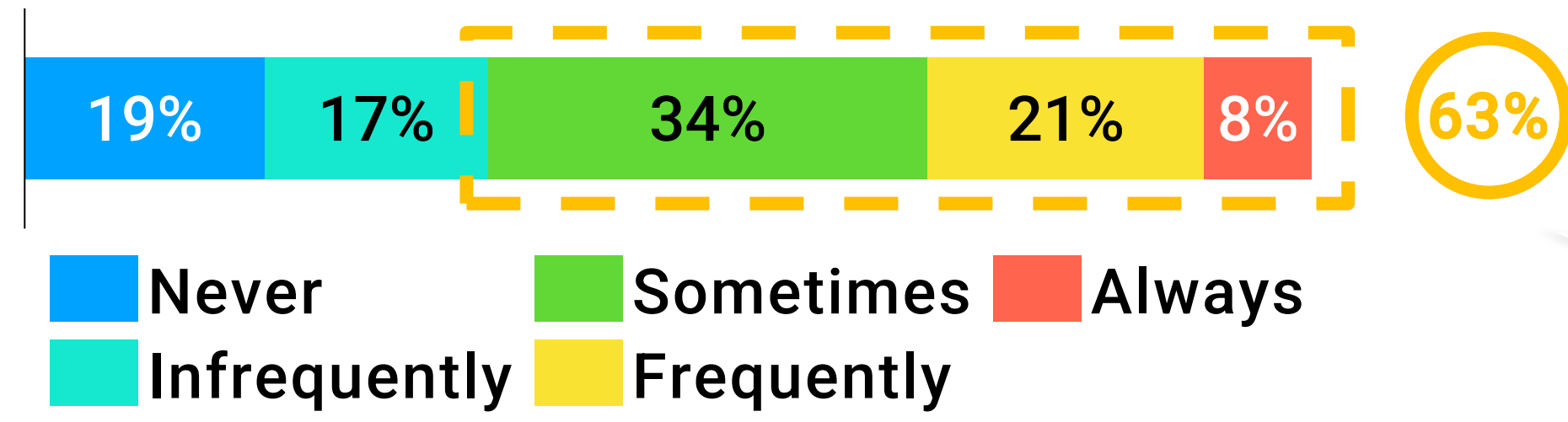
Notes: Sample size for these questions: 3.712 respondents. Source: European headache federation consensus on the definition of resistant and refractory migraine ([link](#))

Language stigma

Migraine sufferers confess feeling more stigmatized when their disease is devalued by comparing it to a simple headache due to a lack of knowledge

Do you feel stigmatized when someone refers to your condition using any of the above terms?

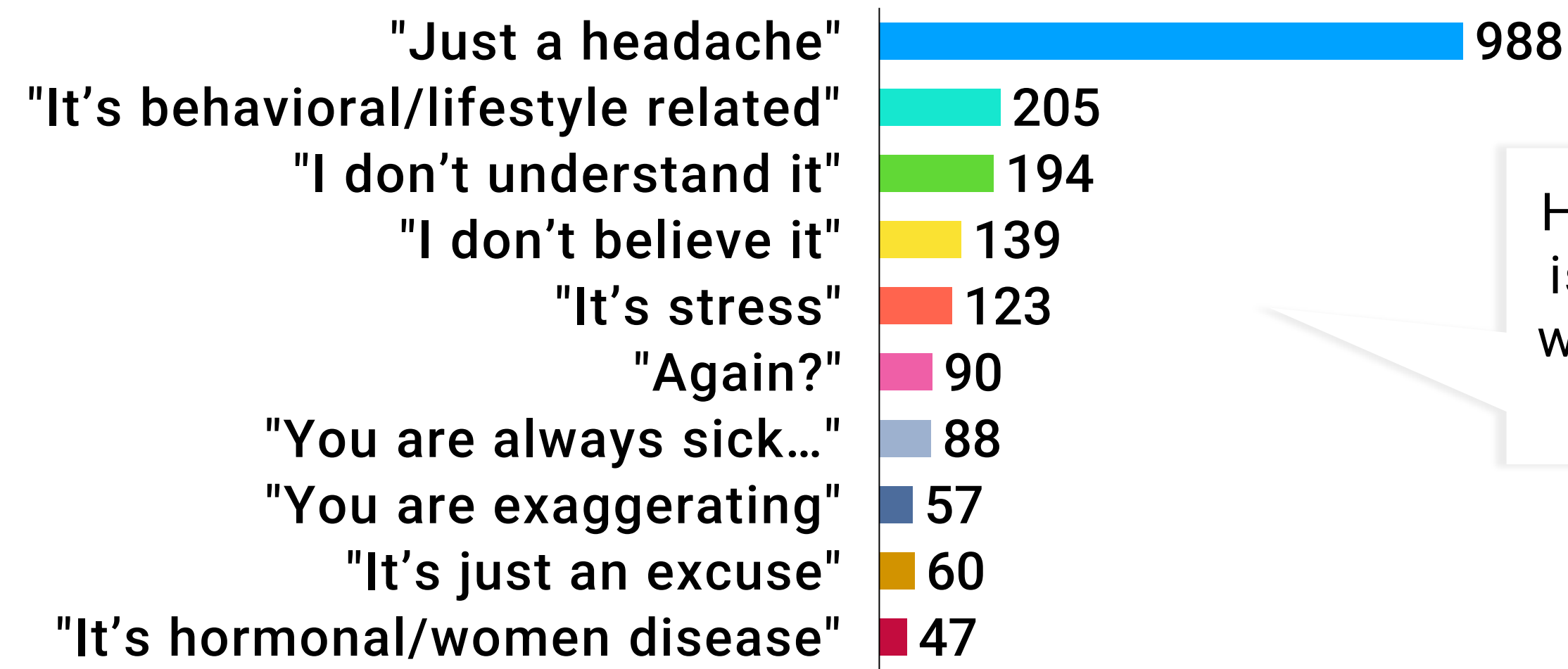
Severe Disabling Episodic Chronic Refractory



63% of the participants confess to having felt stigmatized by the use of the terms mentioned above (severe, disabling, episodic, chronic, refractory)

NOT EXHAUSTIVE

Are there any other terms that you perceive negatively when someone describes your migraine?



However, when asked an open-ended question, it is striking that what is perceived as the worst is when the severity of the disease is minimized by comparing it to something like a headache

Notes: Sample size for these questions: 3.712 respondents

Language stigma

MIGRAINE SUFFERERS 

NOT EXHAUSTIVE

“Again?!”

“You are always sick”

“I find it stigmatizing when it is toned down”

“Take a rest”

“You always cancel plans”

“It’s psychological”

“Still?!”

“Disabled”

“It’s not a big deal”

“Drama queen”

“I have headaches too... take an ibux and it’ll go away”

“IT’S JUST A HEADACHE”

“It is hormonal”

“A migraine is nothing, you are always exaggerating, I have it too and I can do my daily activities”

“Drink water”

“The term “trigger”: seems to refer to the fact that our lifestyle is not adequate”

“I don’t understand, you look good”

“It may be the weather”

“Boring”

“Unreliable”

“You can not tolerate stress”

“Any description of a mild irrelevant disorder”

“Lazy”

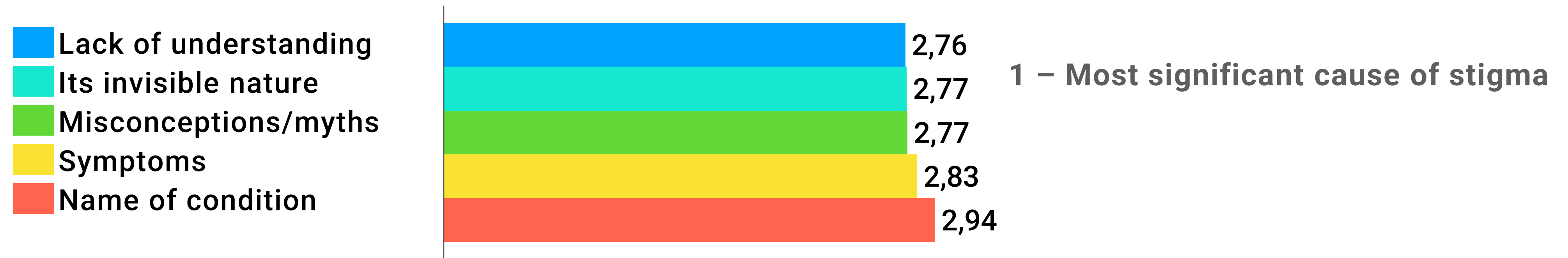
“Unpredictable”

Notes: Sample size for these questions: 3.712 respondents

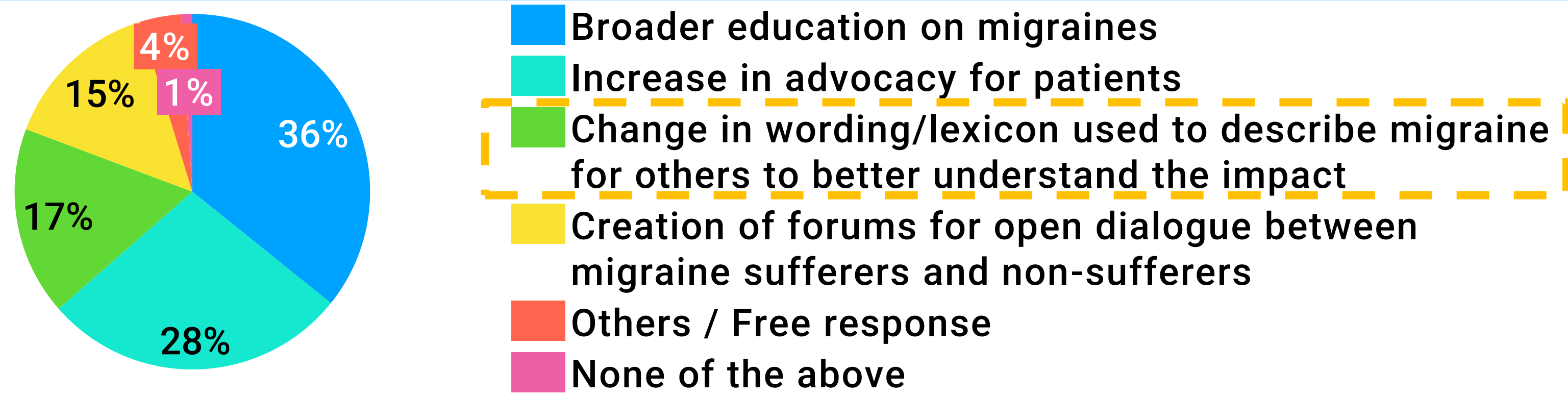
Cause of stigma

In addition to the more standard approaches to reduce stigma (education and increase in advocacy) there is a clear call for changing the medical lexicon used to describe the disease

What do you believe is the root cause of stigma toward your illness? (please rank them from 1 to 5, with 1 representing the most significant cause of stigma)?



What steps would you take to reduce the stigma related to migraines (click more than one if applicable)?



17% of migraine sufferers think that an interesting step to reduce the stigma could be **changing wording/lexicon**

Notes: Sample size for these questions: 3.712 respondents

5. EMHA Non-sufferer Survey

Additional survey

An additional survey was launched to obtain more insights regarding non-sufferers' perception of migraine stigma

1

Non-sufferer's survey

This survey had the goal of complementing the previous results by analysing the **perception of migraine stigma in non-sufferers**



The project aims to raise awareness about **stigma associated with migraine**, drive **positive change**, and **improve support for migraine sufferers**

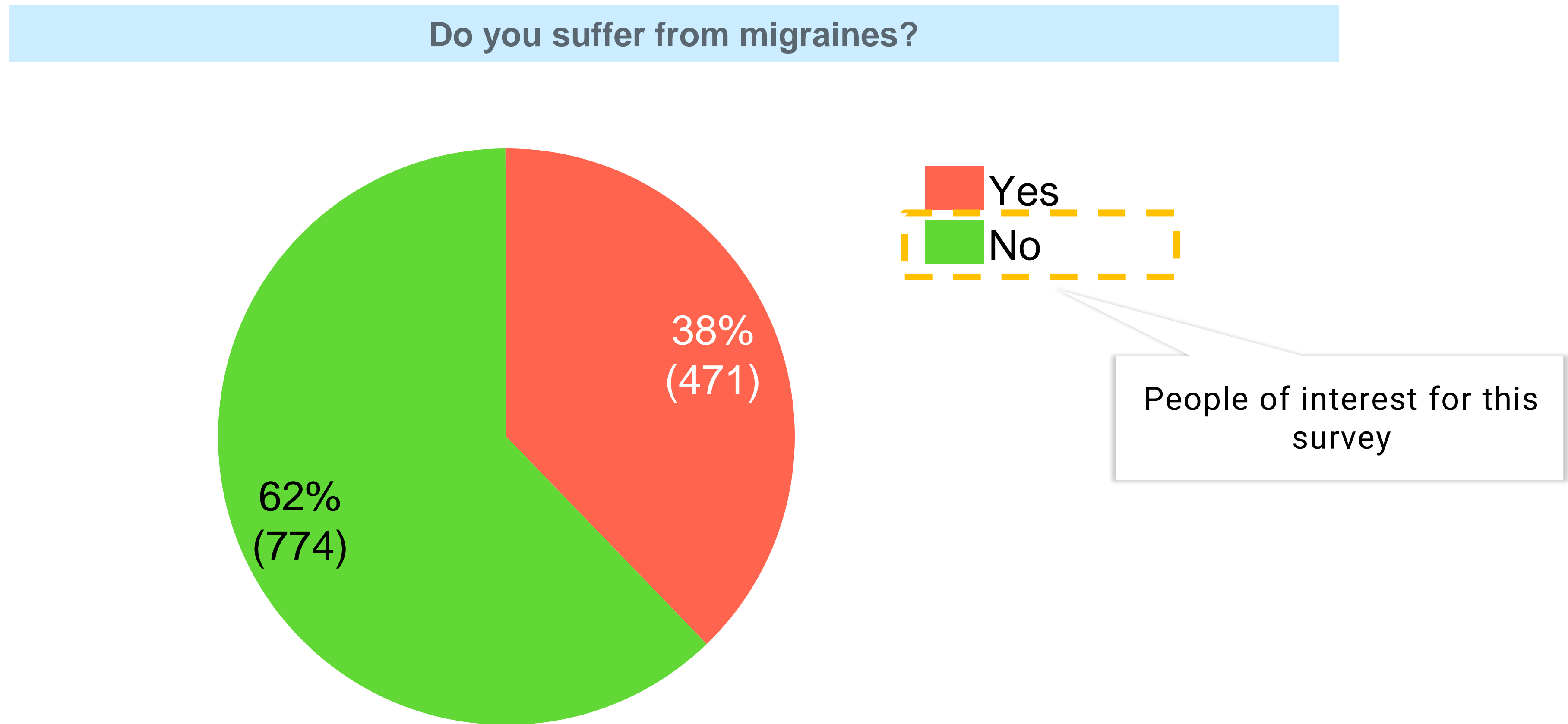
Response tracker

We obtained a total of 1.245 answers, mainly from Portuguese, Italian, Spanish, and English-speaking people

Language	Sep 20th	Oct 9th	Oct 25th	Oct 31st	Nov 16th	Nov 26th
Portuguese	0	0	1	34	623	632
Italian	220	220	221	221	221	221
Spanish	1	29	142	154	161	166
English	5	120	130	134	134	134
German	64	88	90	90	91	91
French	1	1	1	1	1	1
Total	291	458	585	634	1231	1.245

Question 1

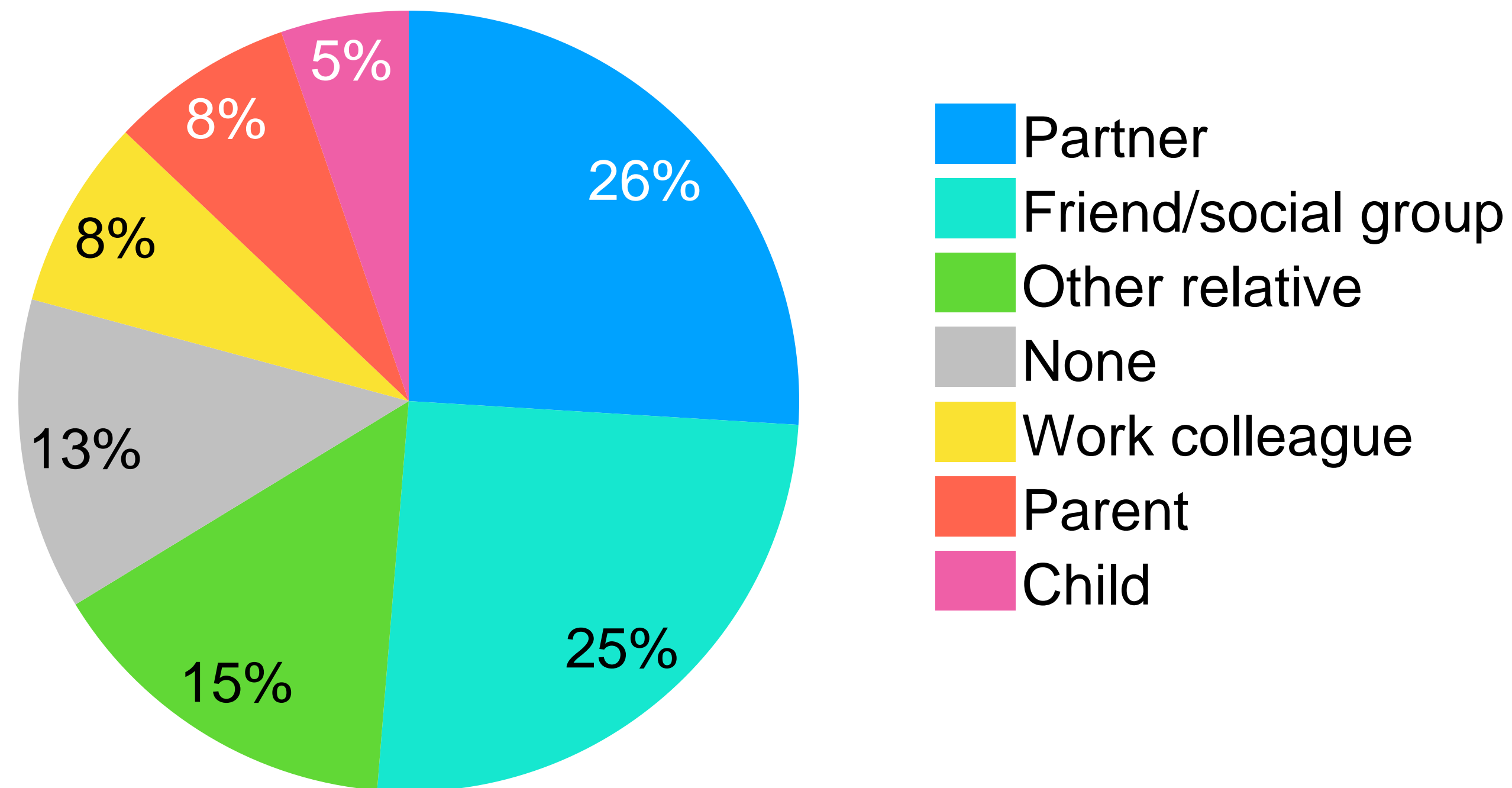
62% of people that answered the survey didn't suffer from migraines and, therefore, 774 people continued answering the rest of the questions



Question 2

Among non-sufferer respondents, 51% had connections to migraines through partners or friends, while 13% had no connections at all

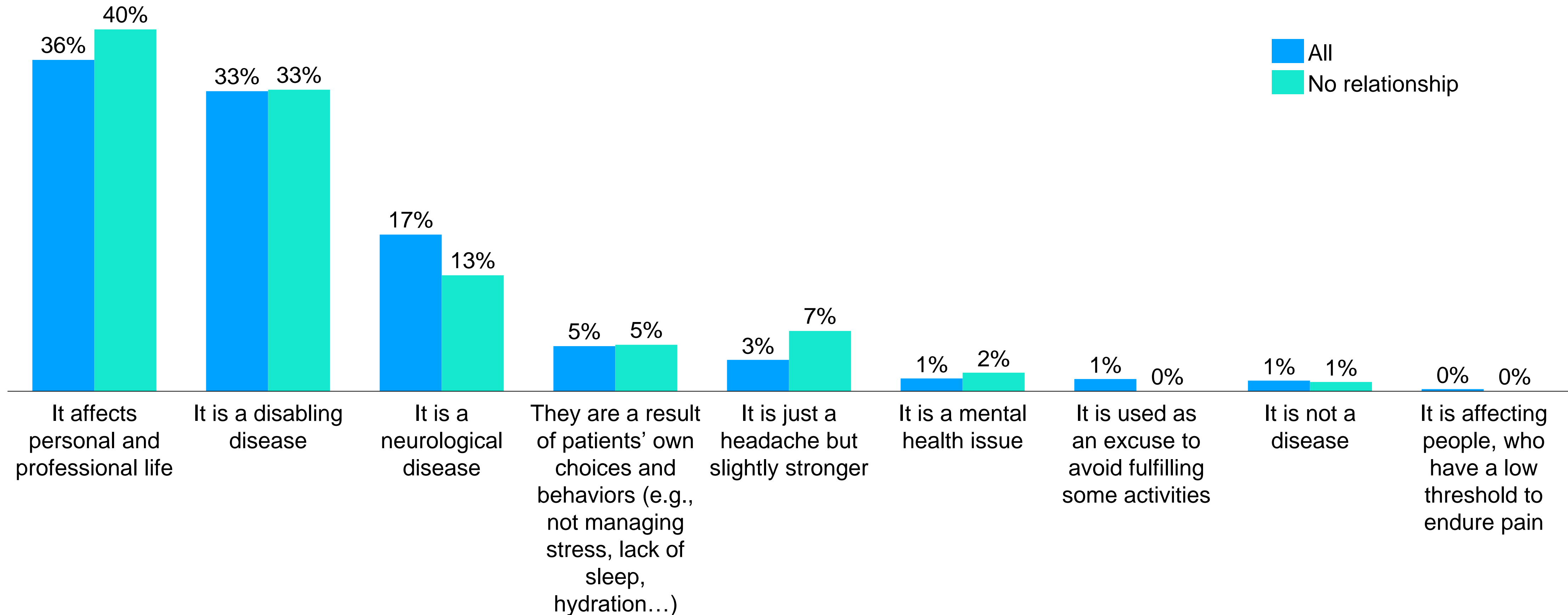
Relationship with a migraine sufferer



Question 3

When asked to describe migraines, only 20 respondents answered that it is not a disease

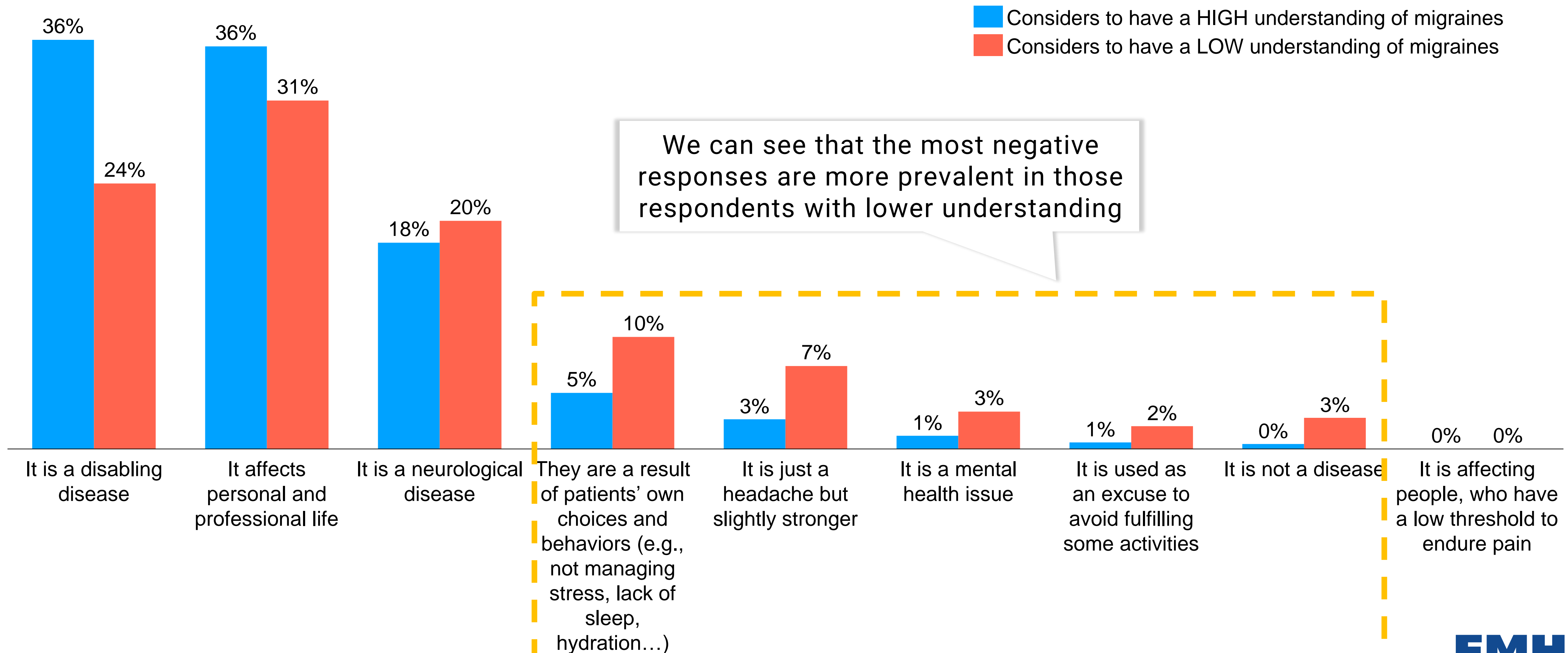
Which describes migraines best (select more than one if applicable)? Migraine...



Notes: Sample size: 774 (All); 100 (No relationship)

Comparison of migraine definition

When comparing respondents that consider to have a high understanding of migraines (rated their knowledge >3) with those with lower understanding (rated their knowledge <3)...

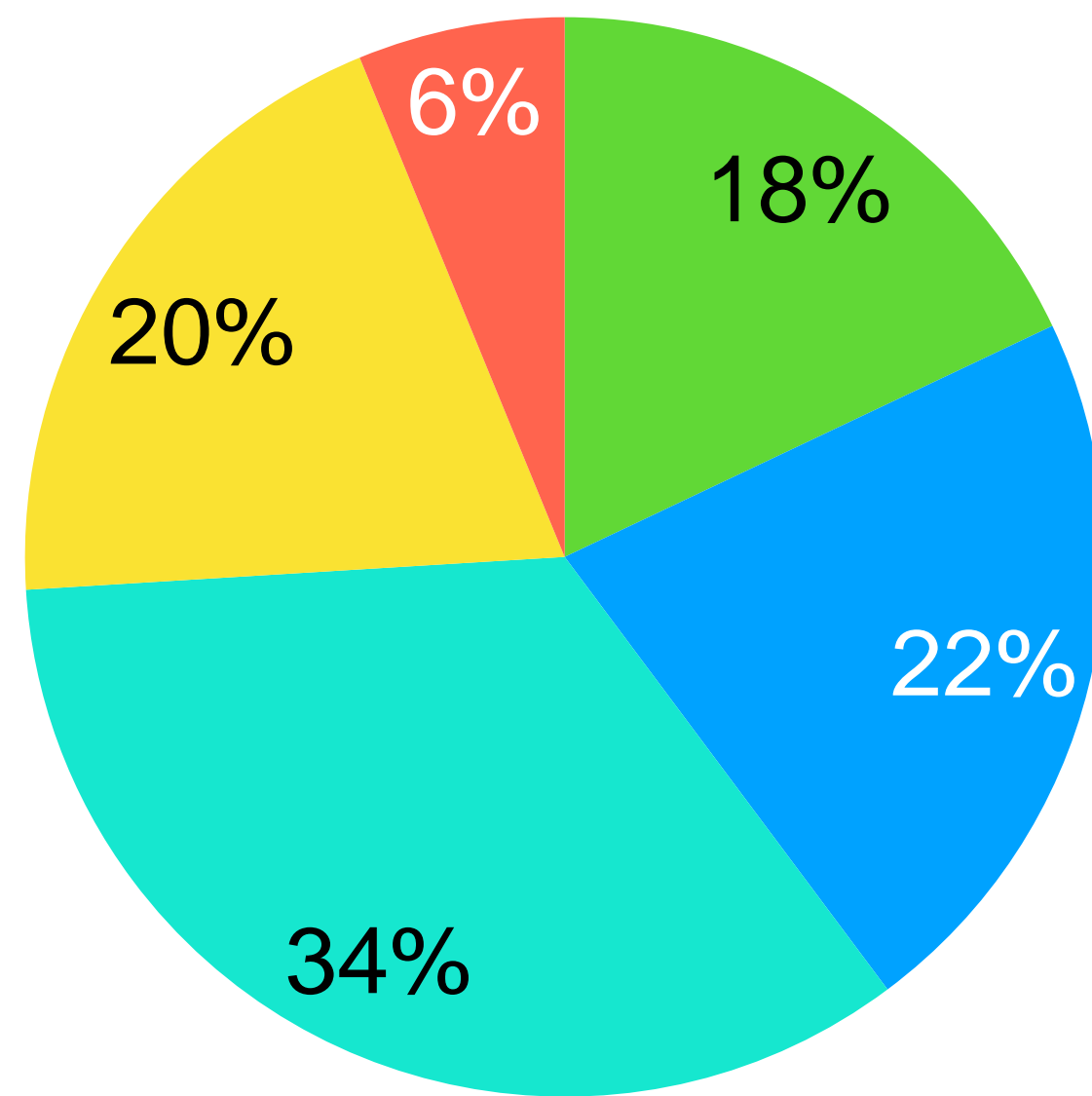


Question 4

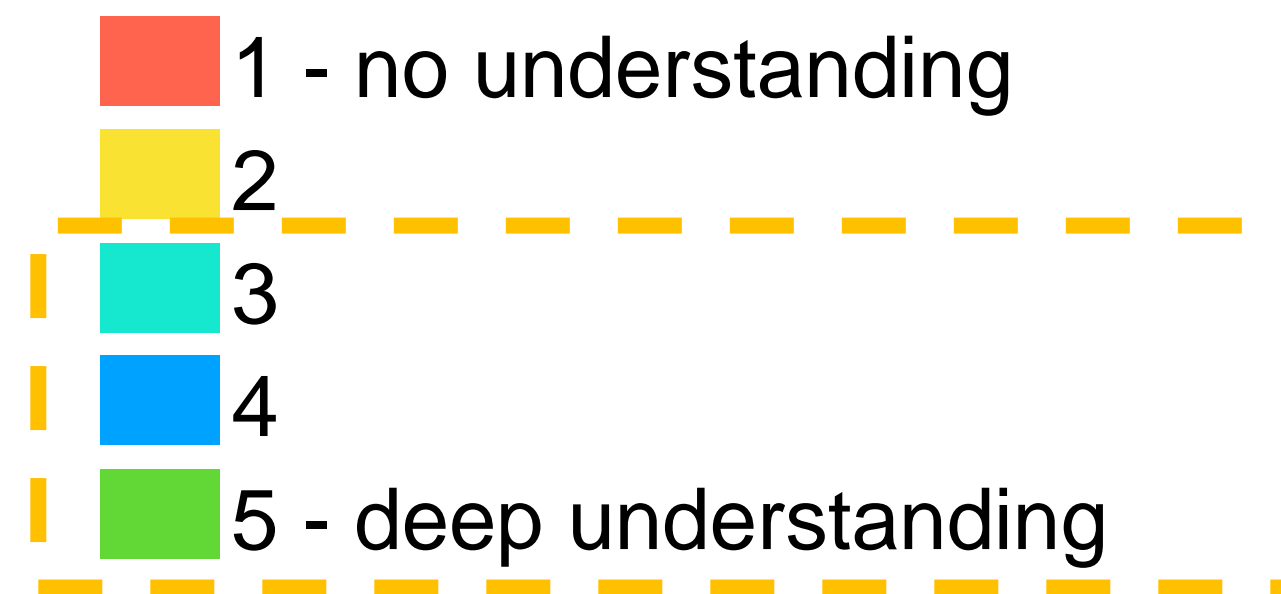
74% of respondents believe they have a good understanding of migraines, while only 46% of those with no relationship to a migraine sufferer share the same view

How well do you understand migraines? (1 = no understanding, 5 = deep understanding)

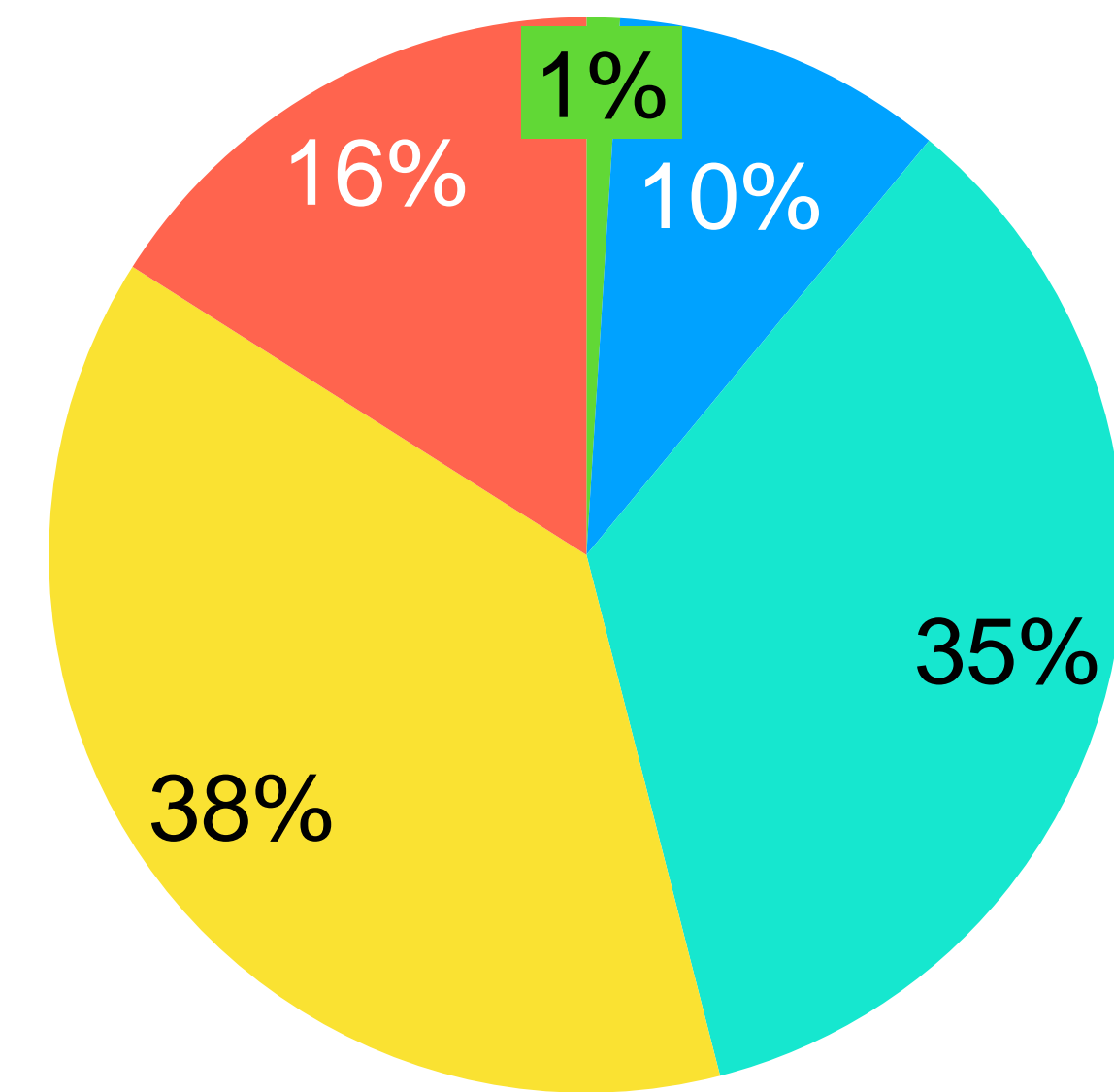
ALL RESPONDENTS 



74% of respondents believed that they have a good understanding of migraines (rated ≥ 3)



NO RELATIONSHIP WITH MIGRAINE SUFFERERS



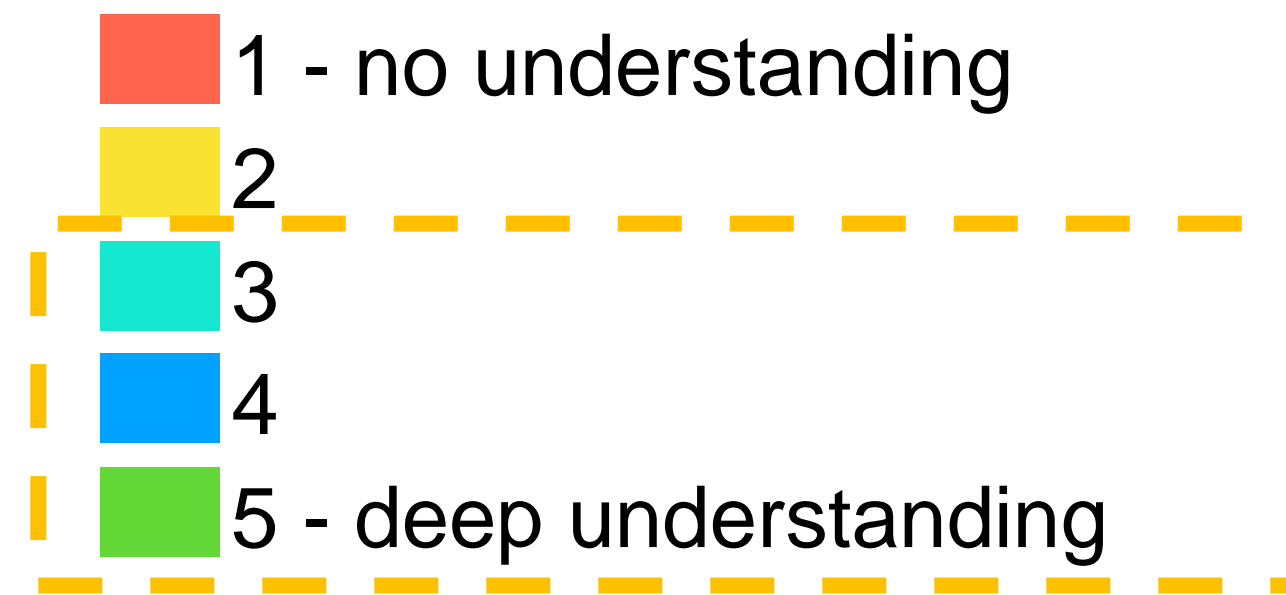
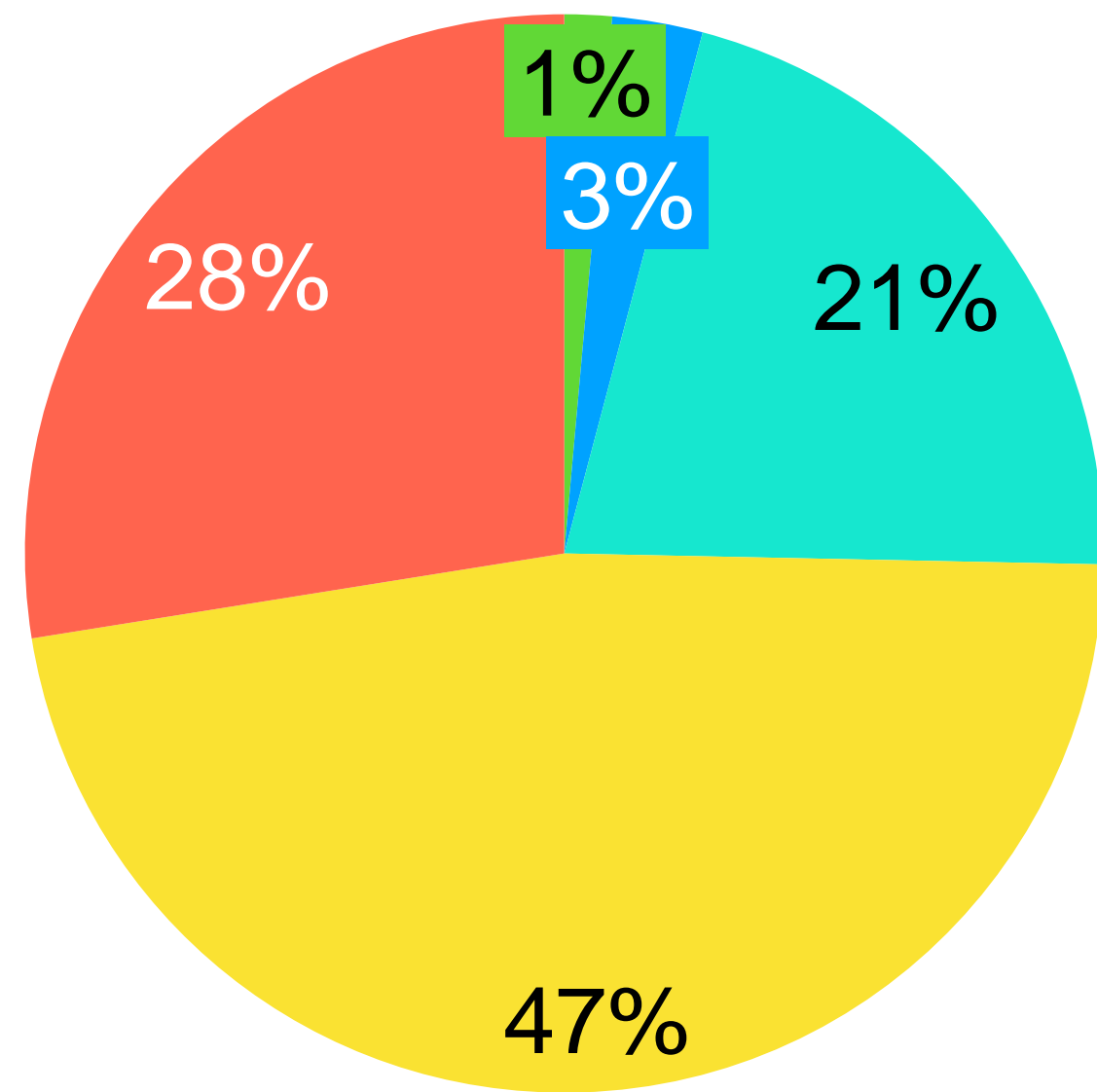
46% believed that they have a good understanding of migraines

Question 5

On the other hand, only 25% of respondents believe the general public has a good understanding of migraines

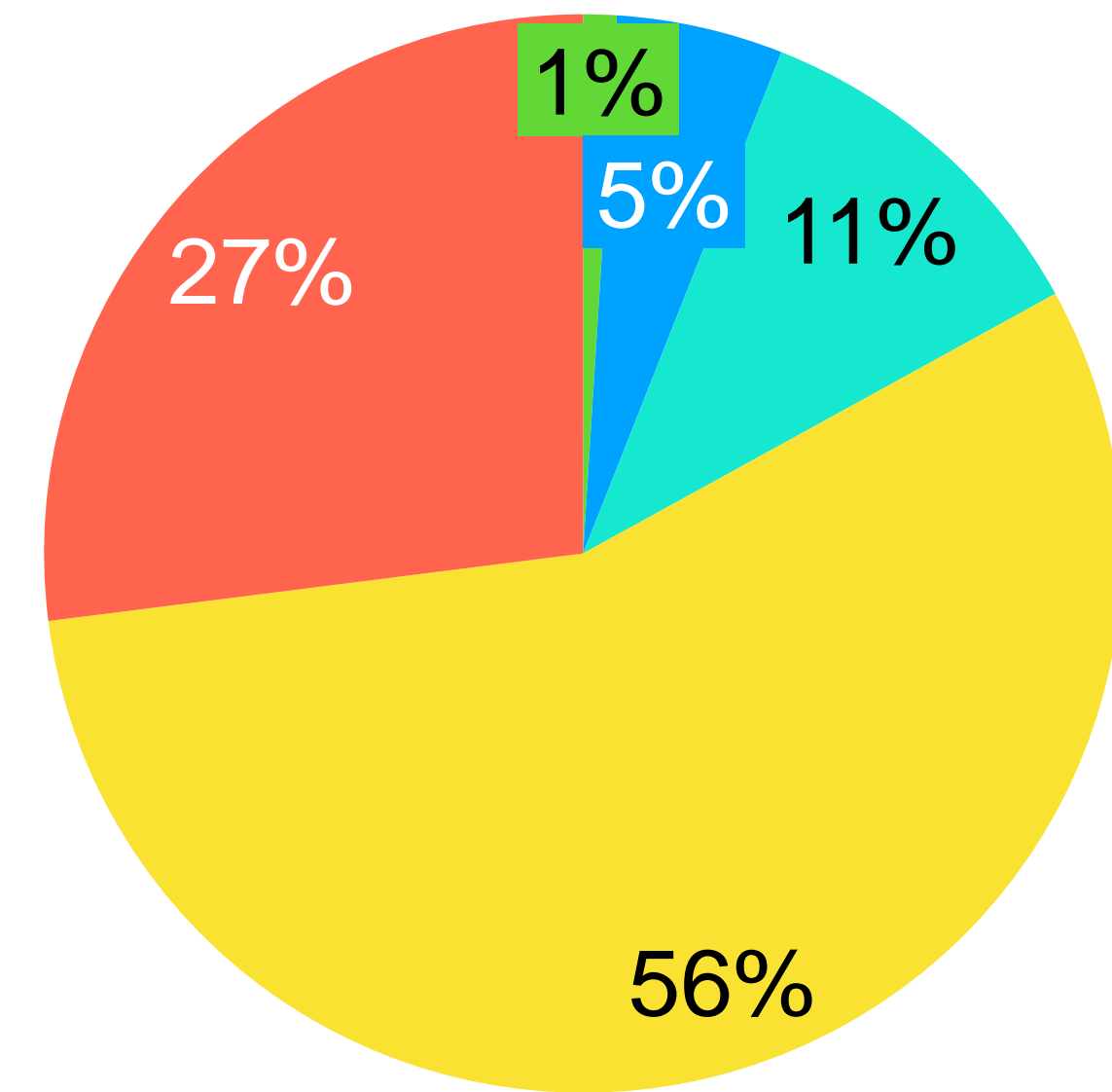
Do you think migraine is well-known and understood by the general public?

ALL RESPONDENTS 



Only 25% of respondents believed that the general public has a good understanding of migraines (rated ≥ 3)

NO RELATIONSHIP WITH MIGRAINE SUFFERERS



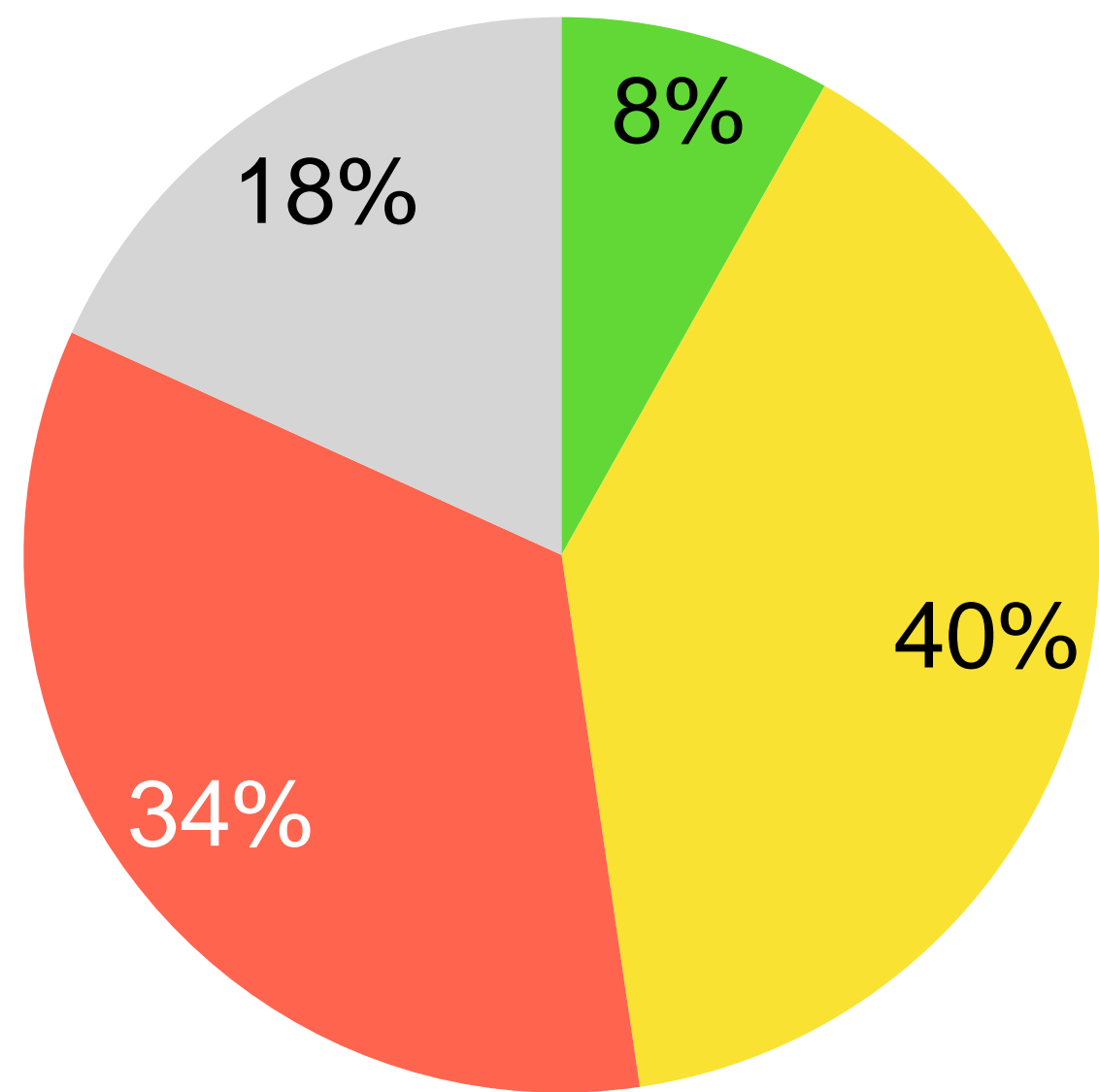
Only 17% of respondents believed that the general public has a good understanding of migraines

Question 6

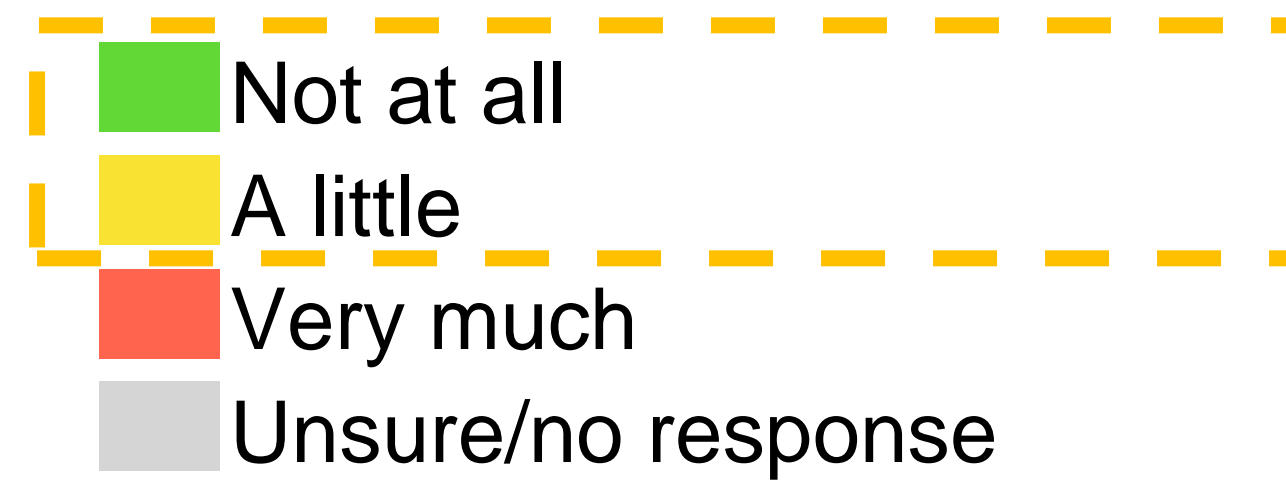
~50% of respondents believe that those with migraines experience little to no stigma

Do you believe those who have migraines suffer from stigma related to their condition?

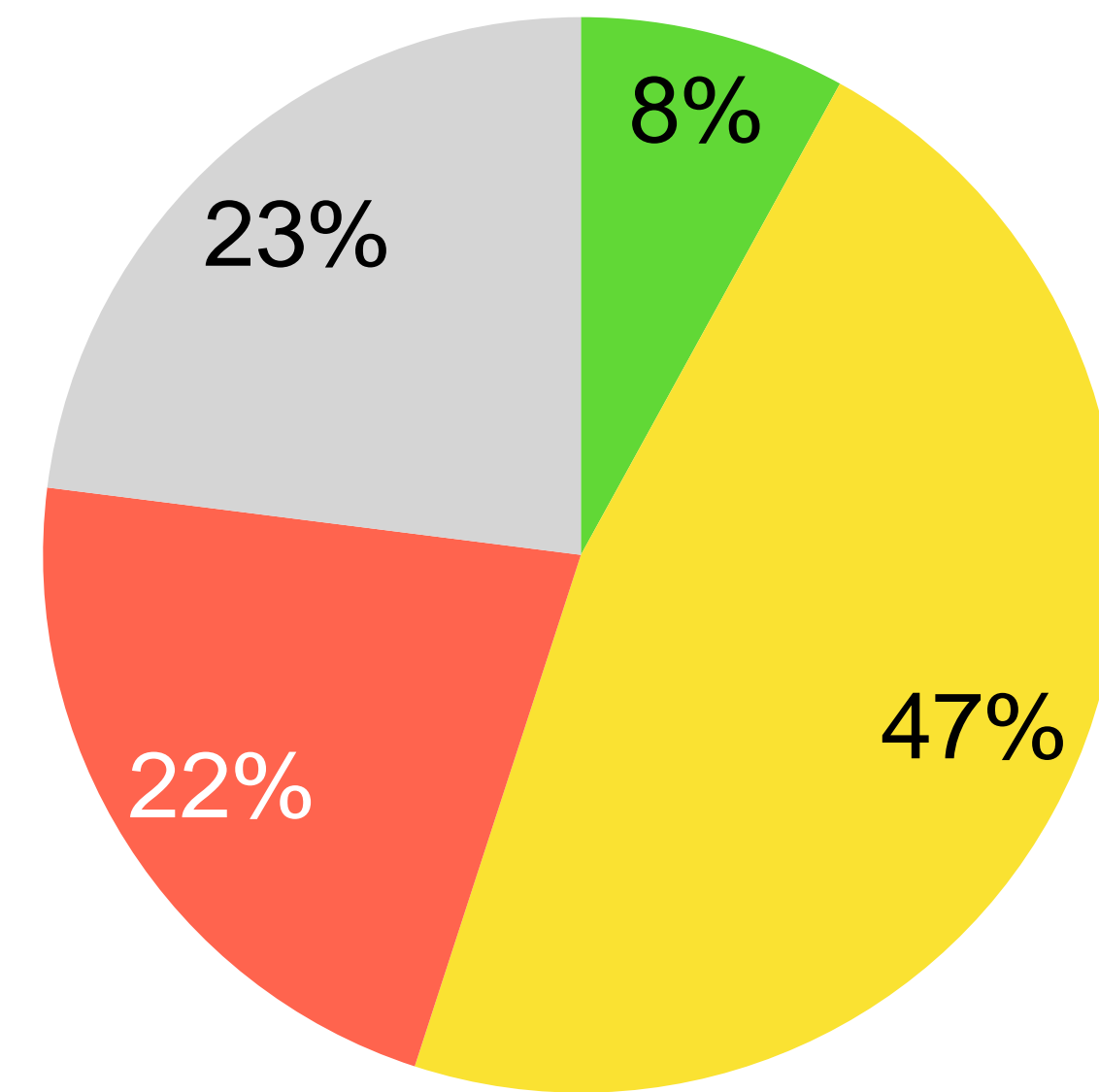
ALL RESPONDENTS 



48% of the participants believe that individuals with migraines experience little to no stigma



NO RELATIONSHIP WITH MIGRAINE SUFFERERS



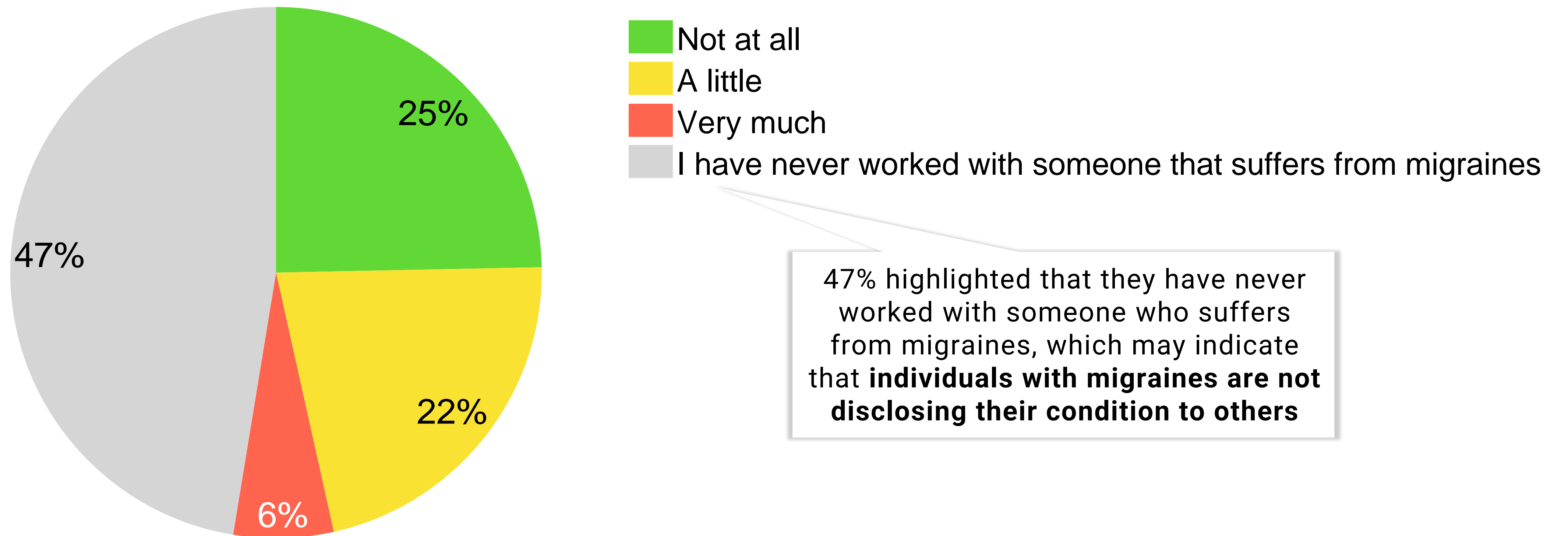
55% of people with no relationship with migraine sufferers believe that individuals with migraines experience little to no stigma

Notes: Sample size: 774 (All); 100 (No relationship)

Question 7

28% of respondents believe that working with someone who suffers from migraines makes their work life somewhat or significantly more difficult

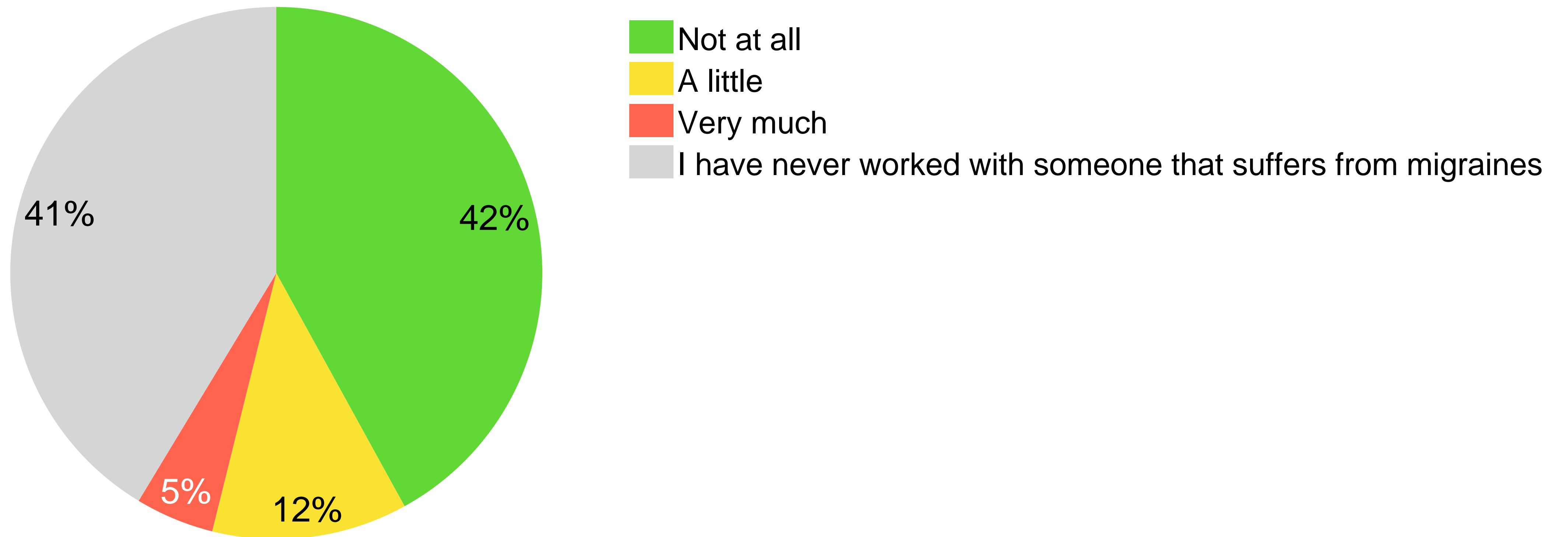
Does working with colleagues with migraines make your work life more difficult?



Question 8

17% of respondents admitted to changing how they assess someone's work when they have migraines

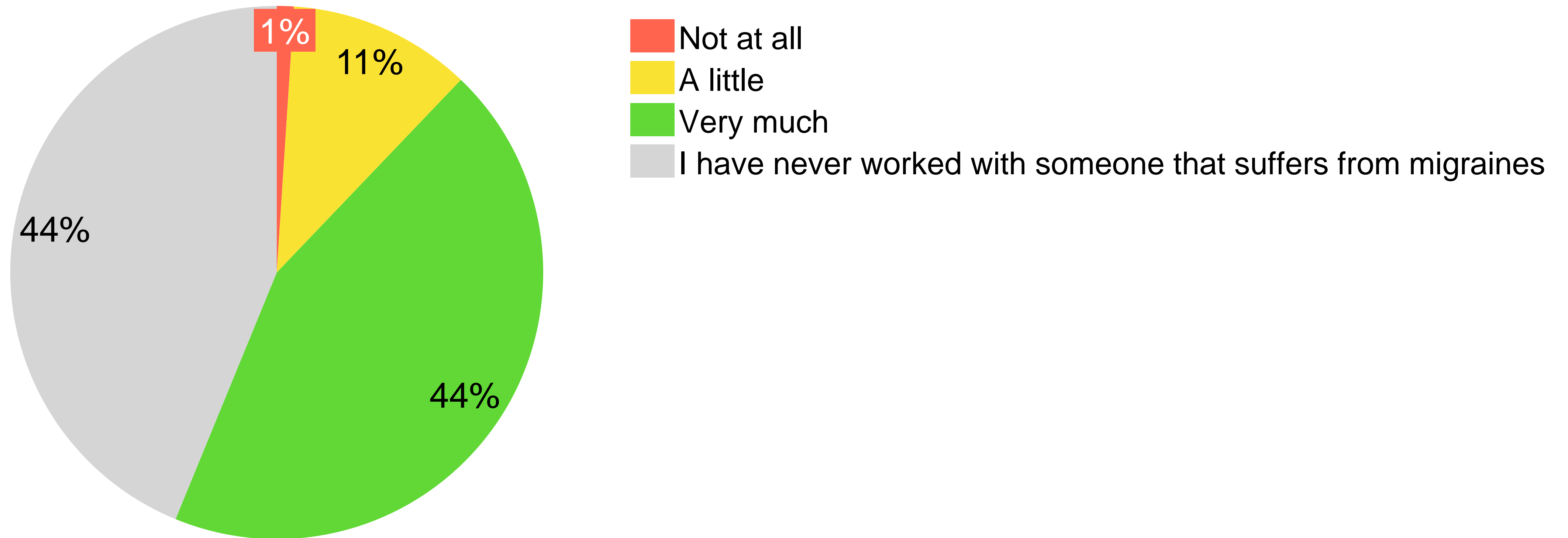
Do you change how you assess someone's work when they have migraines?



Question 9

12% admitted to not providing particularly strong support to colleagues who are currently experiencing migraines

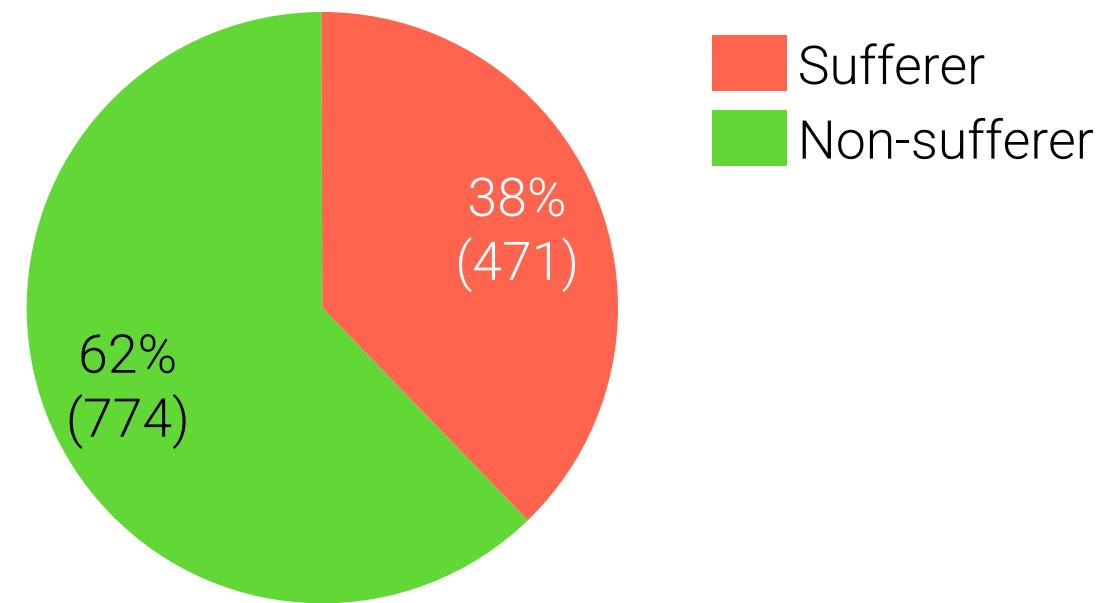
How supportive are you to a co-worker/manager/supervisor/reportee who currently has migraines?



Main findings – non-sufferer survey

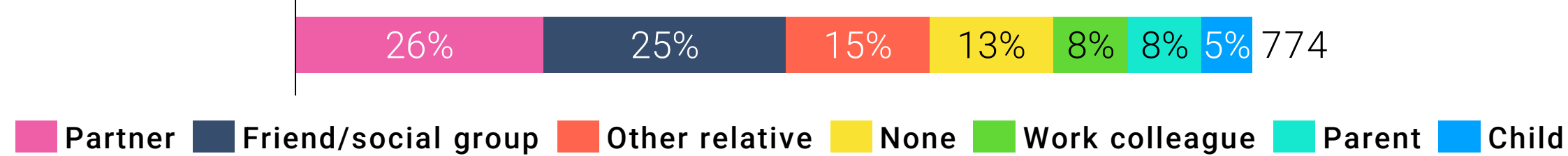
Demographics

- **1.245 answers have been obtained**, Most were from **Portuguese, Italian, Spanish and English-speaking** people
- **62% (774)** of respondents answered that they do not suffer from migraines, of which these are the people of interest in this survey, i.e., the survey is complete if someone answered they suffer with migraines



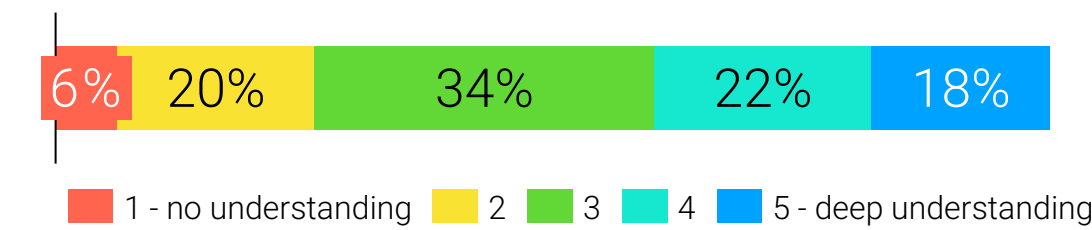
- Within the non-sufferers, **51% had a connection to migraines through partners or friends**
- **13%** had no connection at all to migraine

Distribution of relationships with a migraine sufferer of respondents:

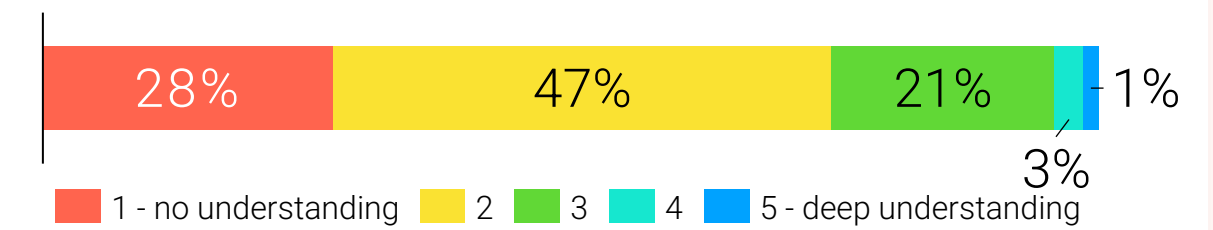


Understanding & Stigma

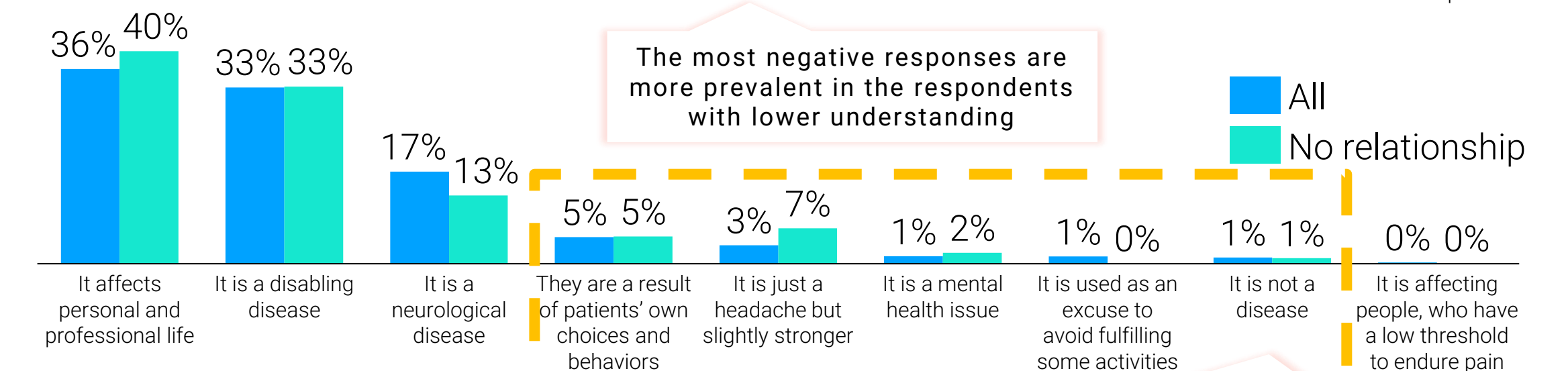
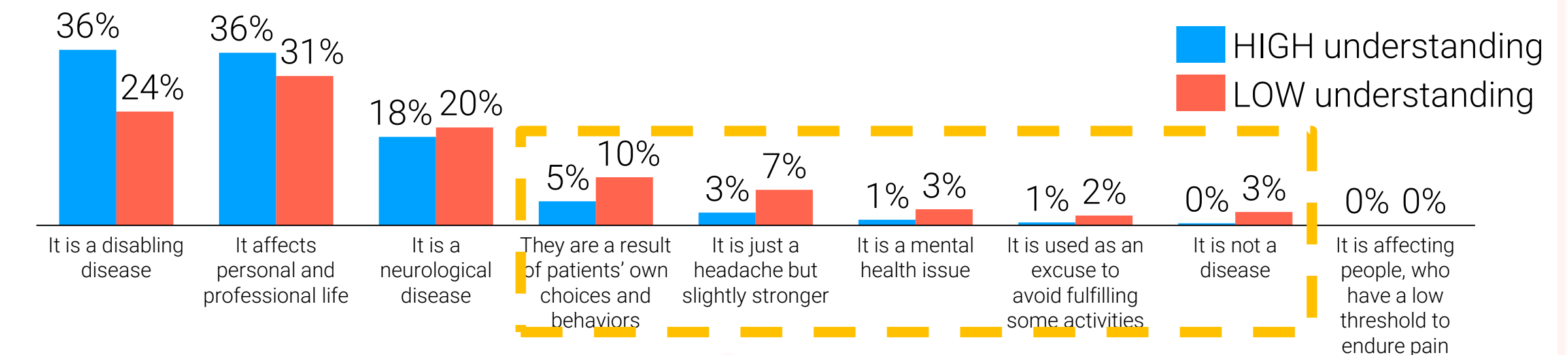
Respondents



General Public



74% of respondents believe they have a good understanding of migraines, while only 46% of those with no relationship to a migraine sufferer share the same view. However, only 25% of respondents believe the general public has a good understanding of migraines, which drops to 17% in those with no relationship to migraine



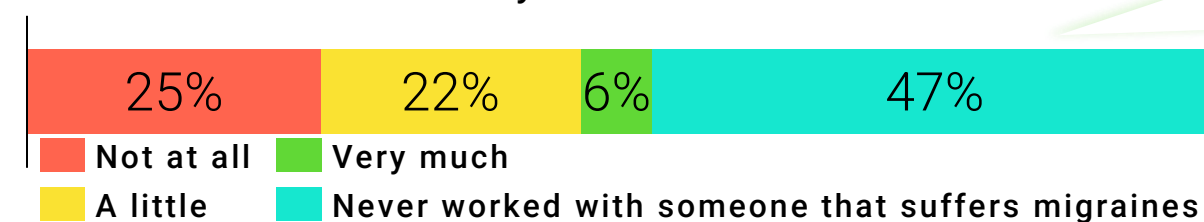
The most negative responses are more prevalent in the respondents with lower understanding

Only 20 respondents answered that migraine is not a disease at all.

Workplace Setting

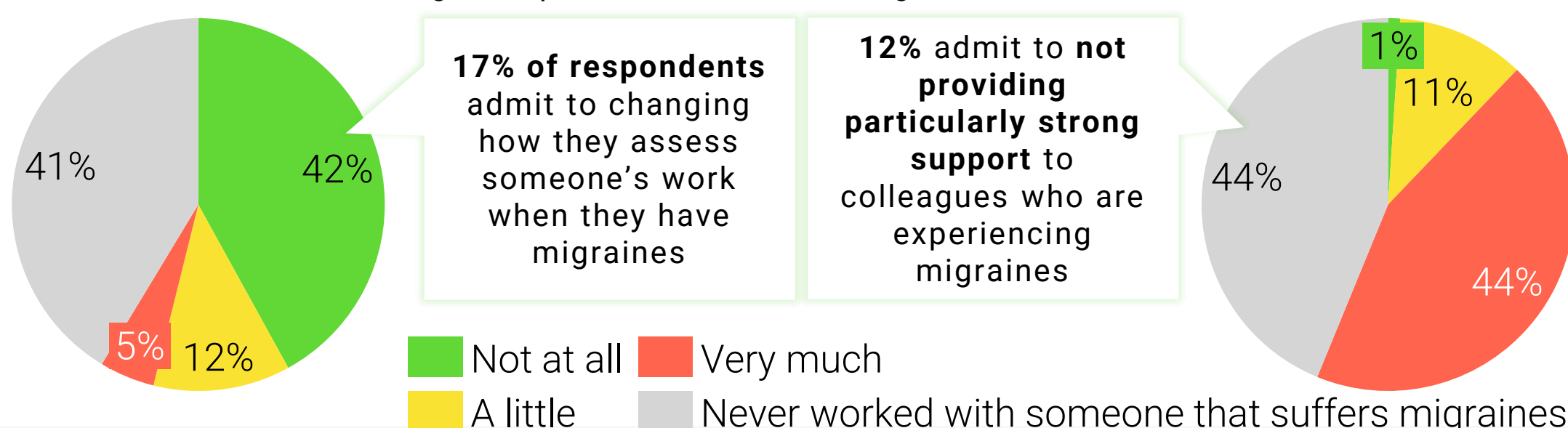
- **Stigma** is mostly perceived around **medical professionals** and **work colleagues**

Do medical professionals understand what it is like to live with your condition?



28% of respondents think that that working with someone who suffers from migraines **makes their work life somewhat or significantly more difficult**

Migraine patients' understanding of medical terms:



- **48% of all respondents** believe that those with migraines experience **little to no stigma**
- This increases to **55%** for respondents with **no relationship** to a sufferer

