### EMHA Migraine & Stigma Survey

**Final Analysis** 



**The Migraine Movement** 



#### **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

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 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** 

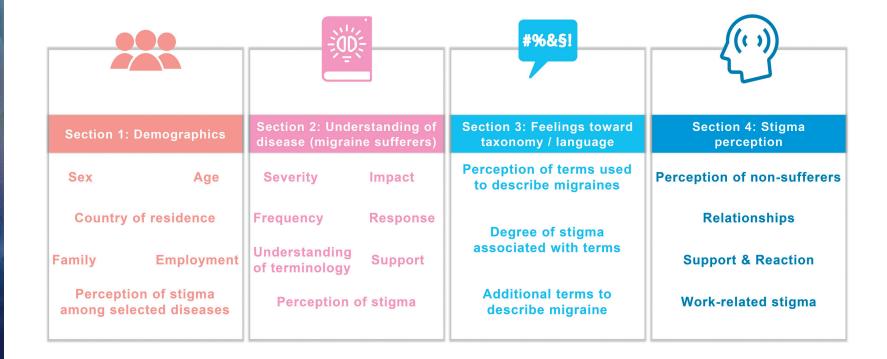
### 1. EMHA Migraine Stigma Survey





#### **1.1 EMHA Migraine Stigma Survey**

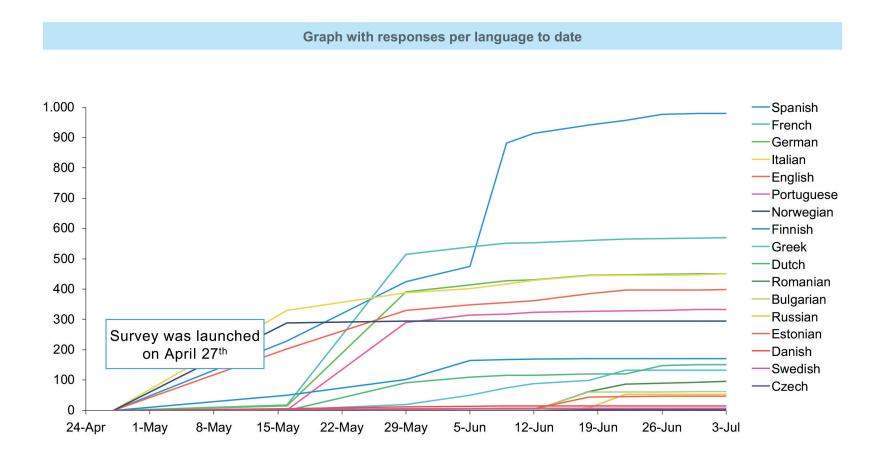
The content from "EMHA Migraine Stigma Survey" was divided into the following 4 categories





#### 1.2 Response rate per language

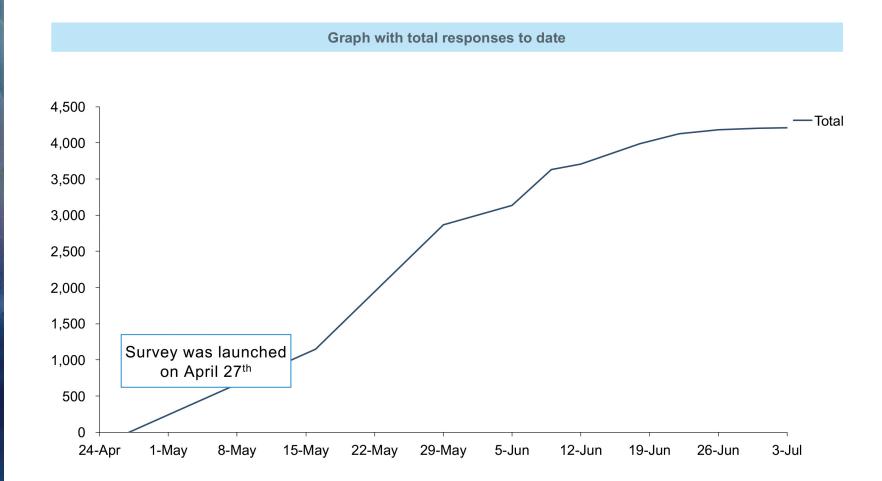
The surveys with the highest response rates have been Spanish, French, German, Italian and English





#### **1.3 Total response rate**

A total amount of 4.210 answers have been obtained



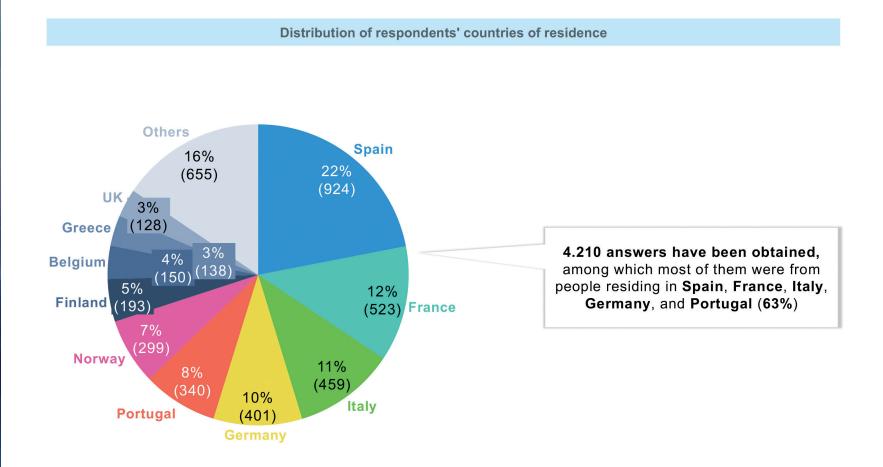


ALL

PARTICIPANTS

#### **1.4 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

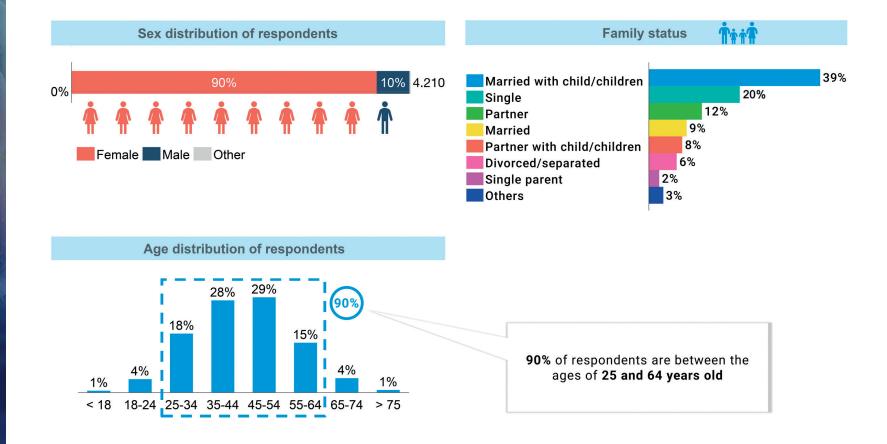




ALL PARTICIPANTS

### 1.5 Sociodemographic data (1/2)

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



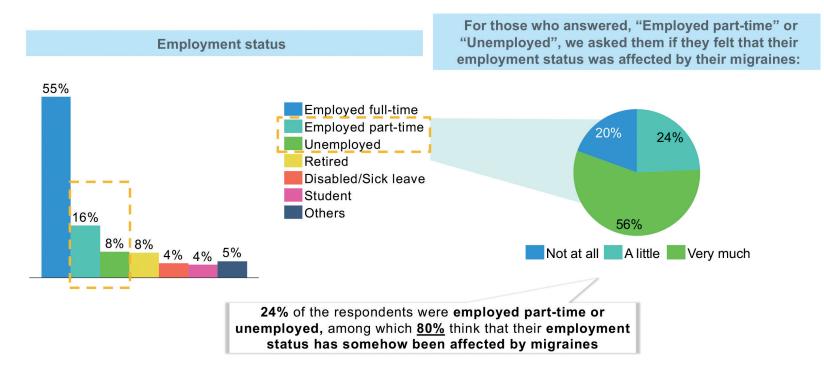


ALL

PARTICIPANTS

### 1.6 Sociodemographic data (2/2)

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

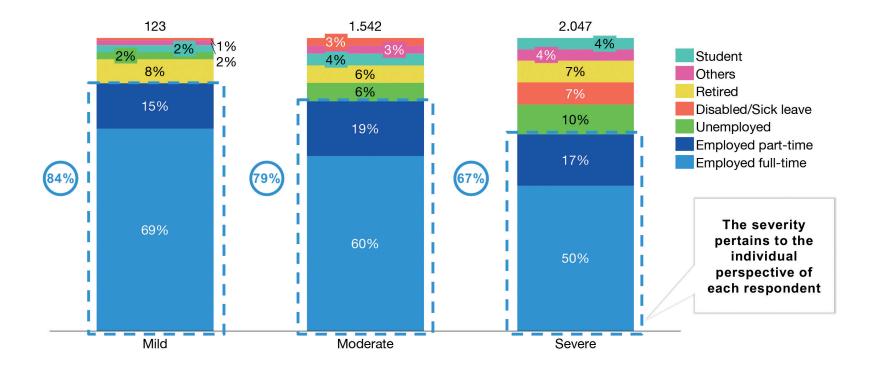




**SUFFERERS** 

#### 1.7 Employment status vs severity of the disease

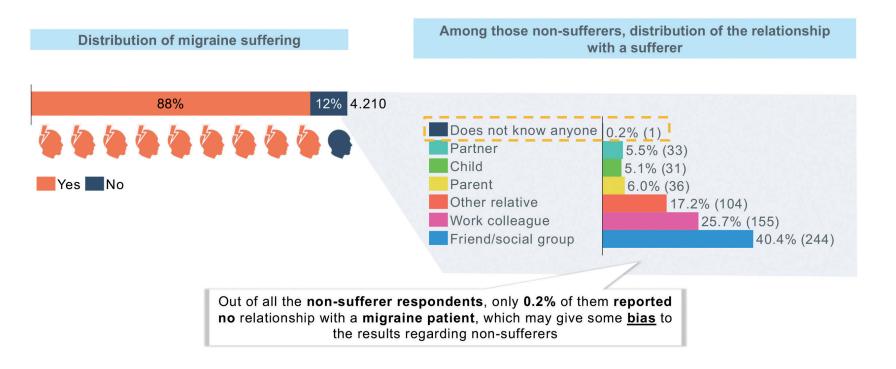
The level of employment exhibits a distinct correlation with the severity of the disease: as the severity increases, the employment rate declines proportionally.





#### **1.8 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.



### 2. Migraine disease

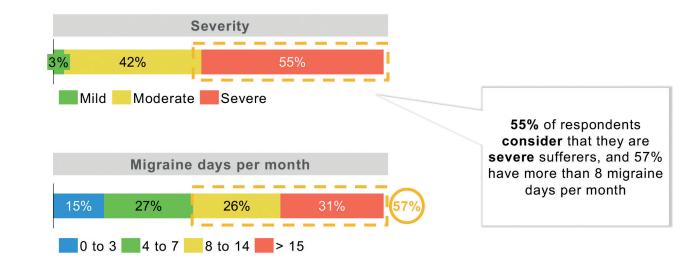




# 2.1 Migraine sufferers' perception of their disease

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:

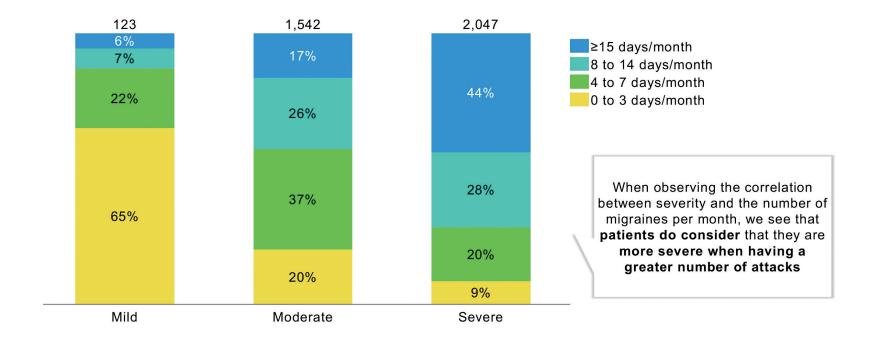




**SUFFERERS** 

### 2.2 Migraine sufferers' perception of their disease

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

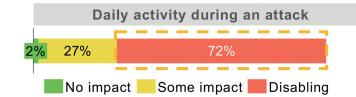




### 2.3 Migraine sufferers' perception of their disease

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:





Response to treatment with medicines



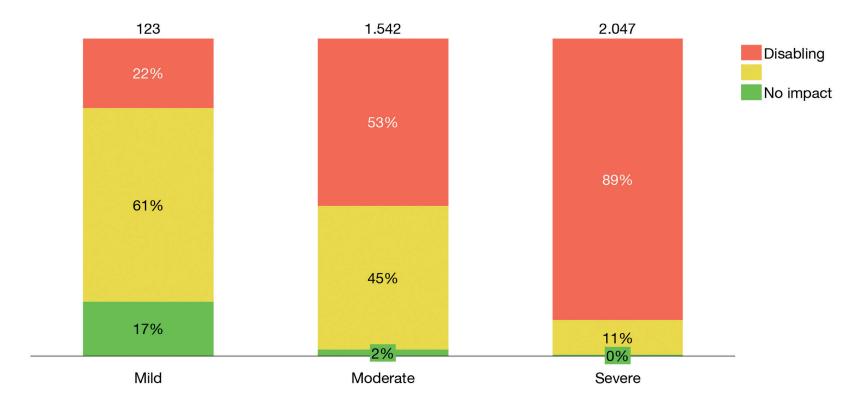
My medicines usually resolve the episodes I need to take my medicines for several days Episodes persist even if taking my medicines

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



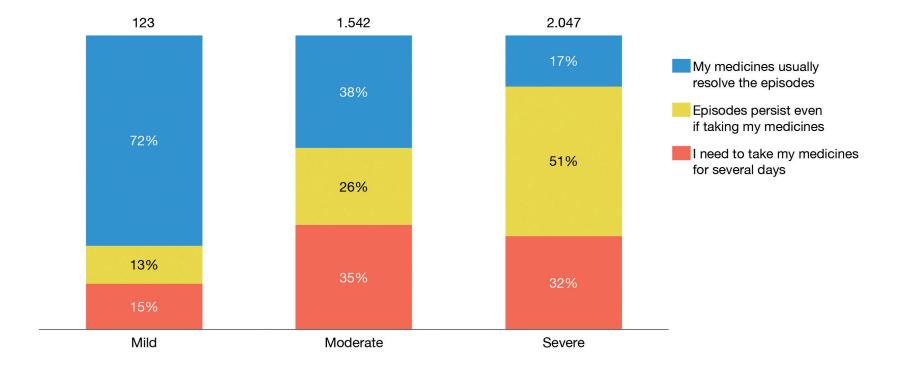
#### 2.4 Response to treatment vs severity

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





#### 2.5 Response to treatment vs severity



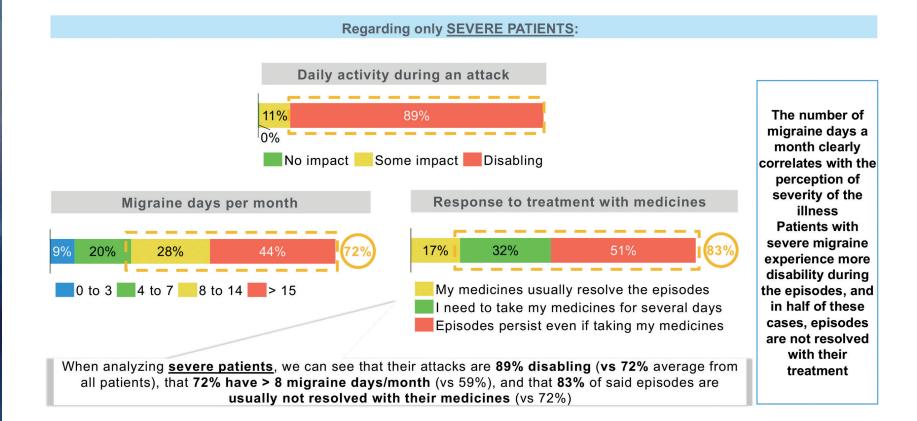


SUFFERERS

SEVERE

# 2.6 Migraine sufferers' perception of their disease

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.



### 3. Stigma



The Migraine Movement

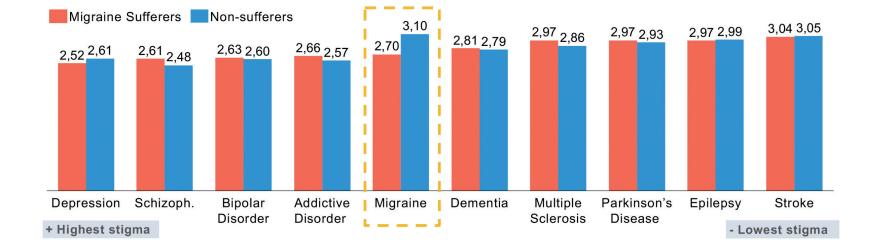


#### 3.1 Disease-related Stigma

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)



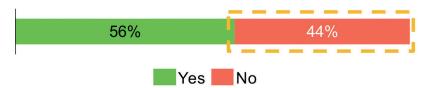
#### **3.2 Migraine stigma for sufferers**

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



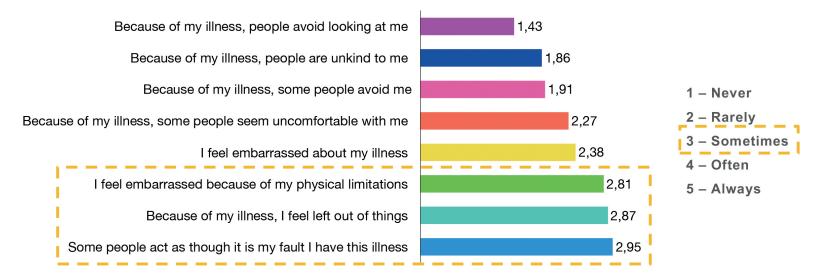


SUFFERERS

#### **3.3 Migraine stigma for sufferers**

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



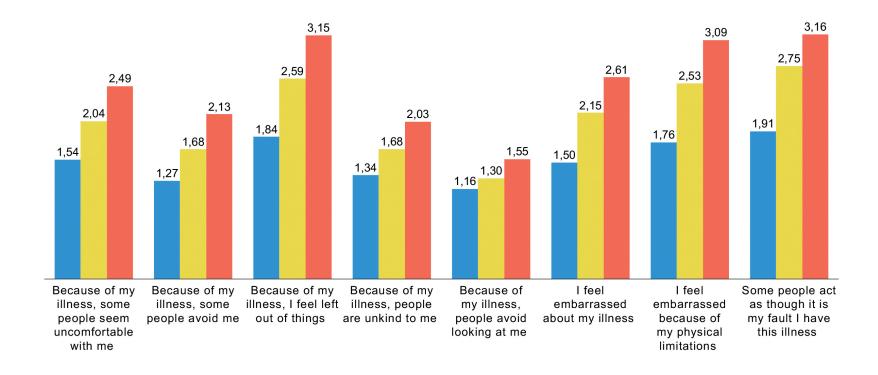




**SUFFERERS** 

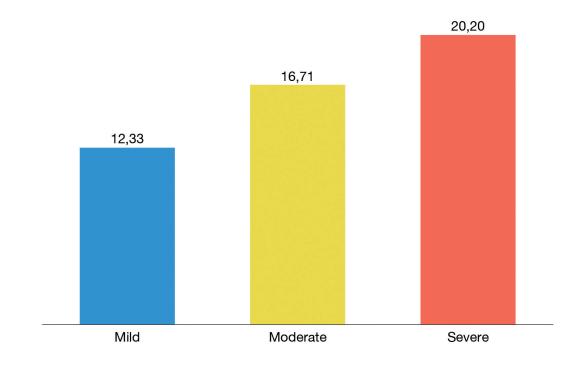
## 3.4 SSCI split per severity of the disease

Mild Moderate Severe





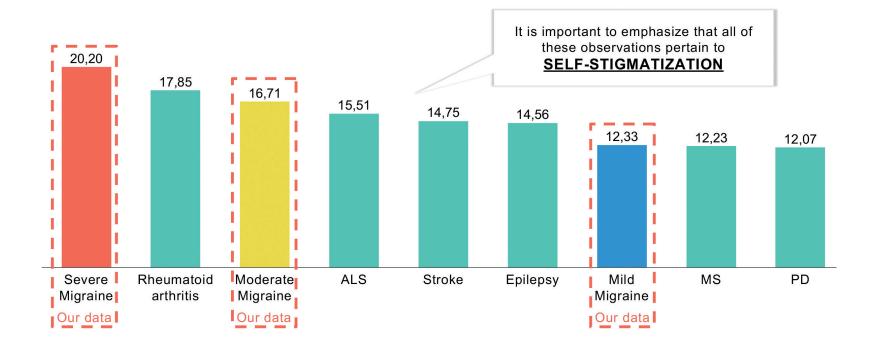
#### 3.5 Total rank of SSCI per severity of the disease





#### 3.6 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



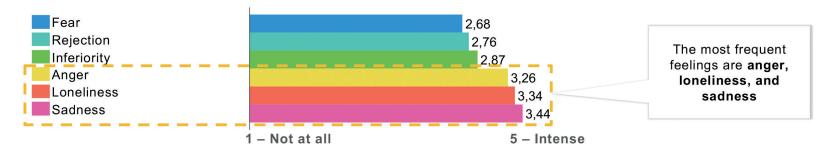
Source: The Stigma Scale for Chronic Illnesses 8-item version (SSCI-8): Development, validation, and use across neurological conditions (link); Assessment Of Stigmatization In Rheumatoid Arthritis Using The Stigma Scale For Chronic Illnesses-short Form (SSCI-8) (link)



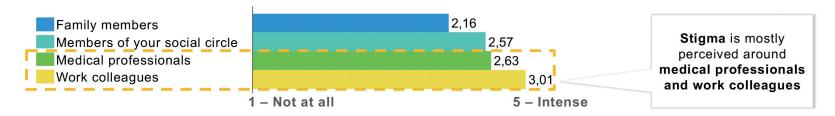
#### 3.7 Migraine stigma for sufferers

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



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



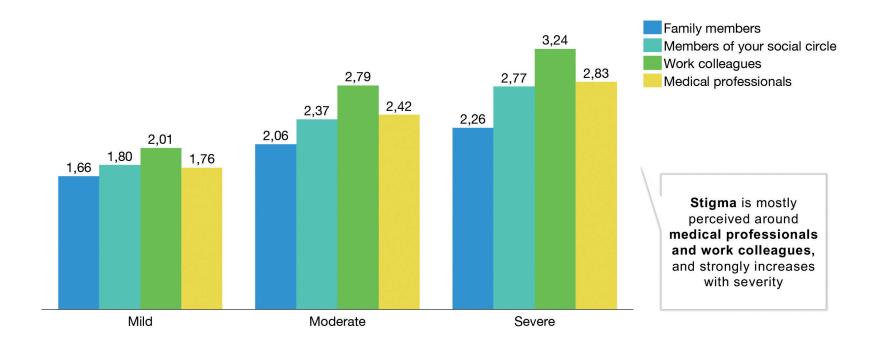


**SUFFERERS** 

### **3.8 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?

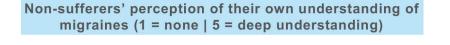


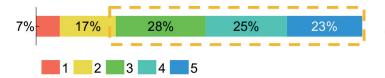


#### 3.9 Migraine stigma for non-sufferers (1/3)

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

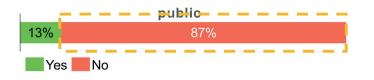






**76%** of non-sufferer respondents believe that they have a **good understanding** of migraines, which again highlights the **possible bias** in this survey

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



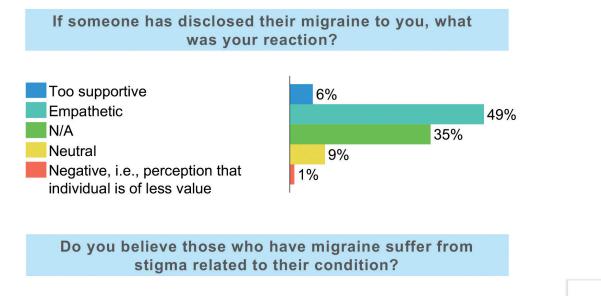
87% of non-sufferer respondents consider that migraines are not well understood by the general public, very much in line with the sufferers who rated this same question with 93%

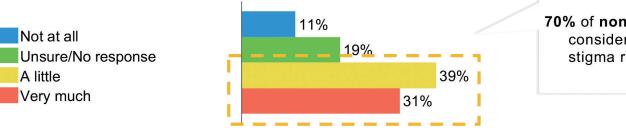


NON-SUFFERERS

#### 3.10 Migraine stigma for non-sufferers (2/3)

Non-sufferers consider that there is some kind of stigma associated with it





**70%** of **non-sufferer** respondents consider that there is some stigma related to migraines

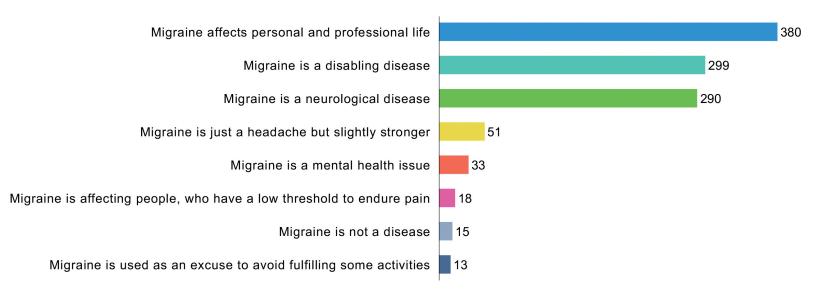


NON-SUFFERERS

#### 3.11 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)?

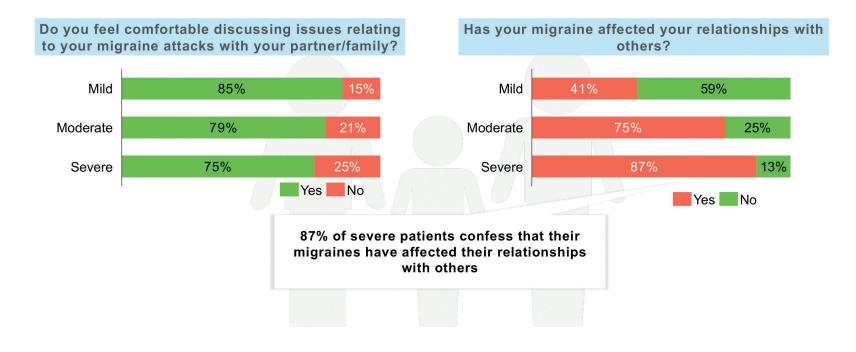


#### Non-sufferers mainly believe that migraine is a disabling neurological disease that affects personal and professional life



#### **3.12 Family stigma for sufferers**

23% of respondents don't feel comfortable discussing issues related to their migraine attacks with their partner/family and 81% believe that the disease has affected their relationship with others

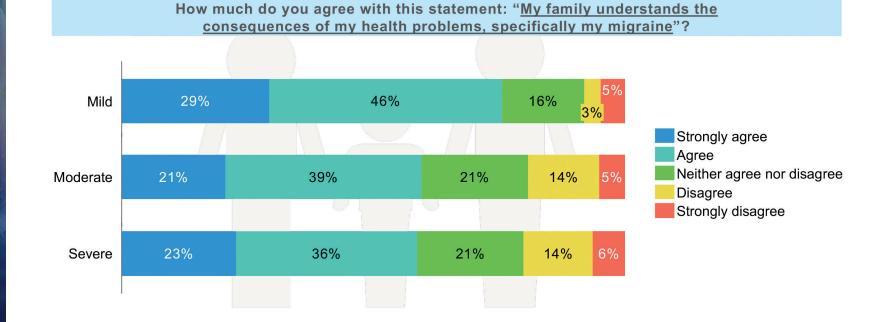




#### 3.13 Family stigma for sufferers

23% of respondents don't feel comfortable discussing issues related to their migraine attacks with their partner/family and 81% believe that the disease has affected their relationship with others

MIGRAINE SUFFERERS

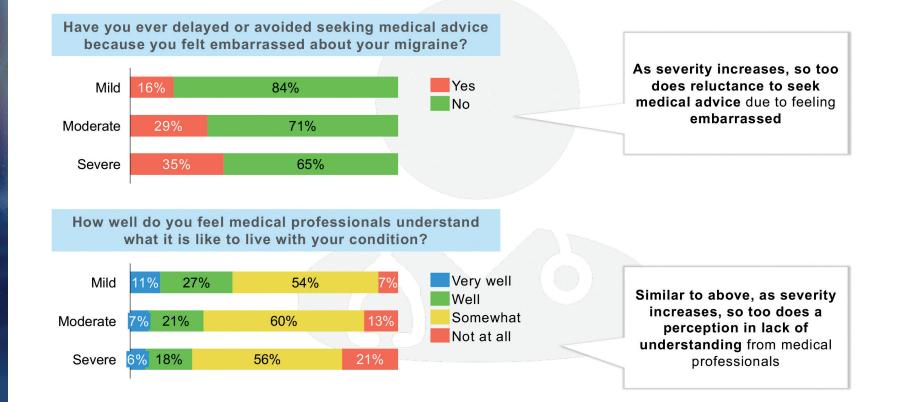




SUFFERERS

# 3.14 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** 

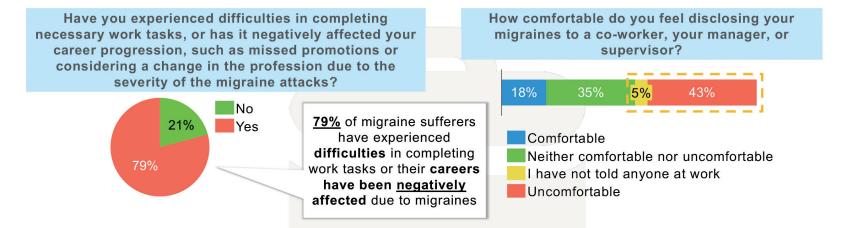




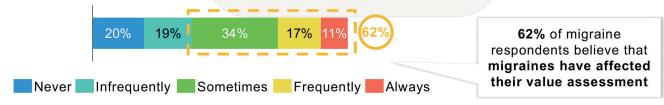
**SUFFERERS** 

#### 3.15 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



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



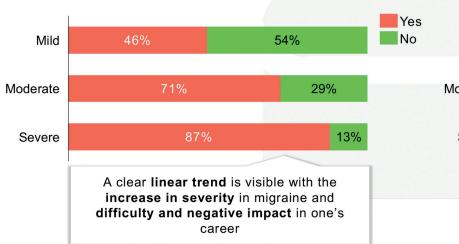


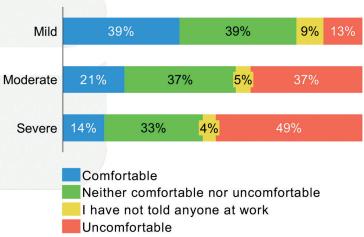
#### **3.16 Work-related stigma for sufferers**

Split per severity of the disease

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?

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



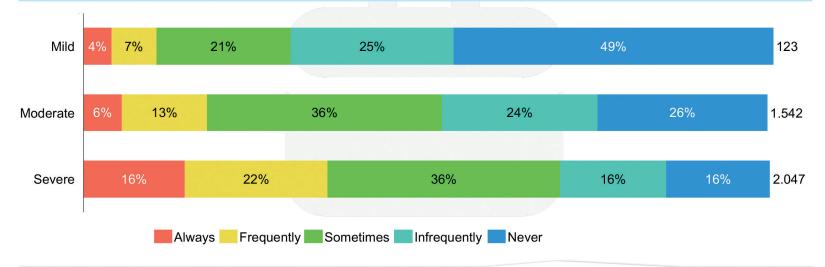




#### 3.17 Work-related stigma for sufferers

Split per severity

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



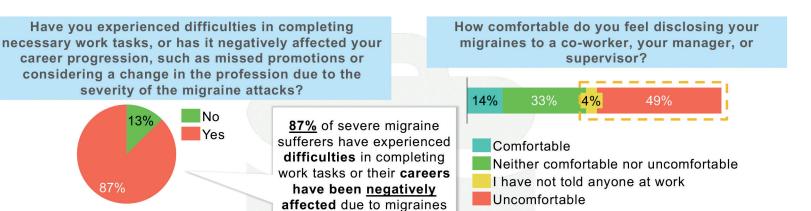
Similar to the previous slide, there is **linear correlation** within **work-related stigma**, as evident from the increased perceived affect in **how direct managers assess an individuals' value**, with the severity of migraine



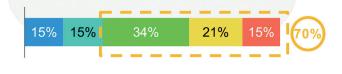
#### 3.18 Work-related stigma for sufferers

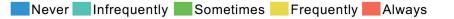
Focus only on SEVERE patients





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







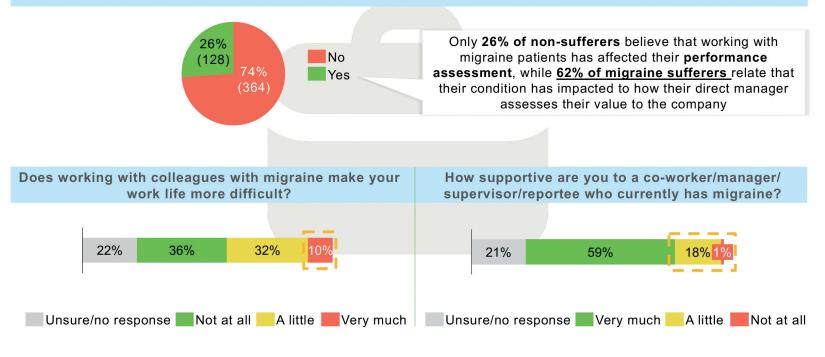
NON-

**SUFFERERS** 

# 3.19 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?



## 4. Language perception



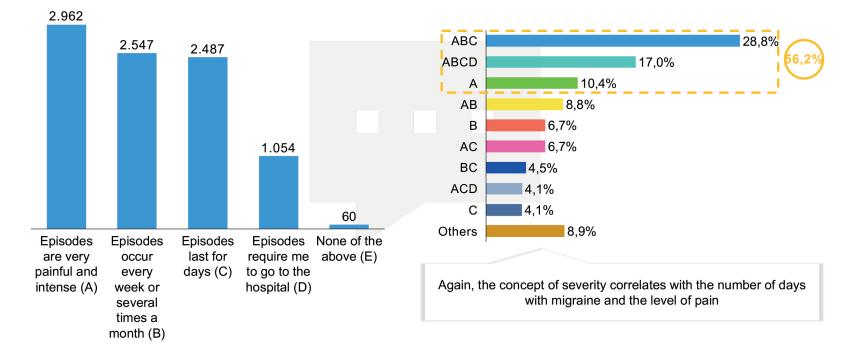


### 4.1 Migraine terminology - Severe

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)







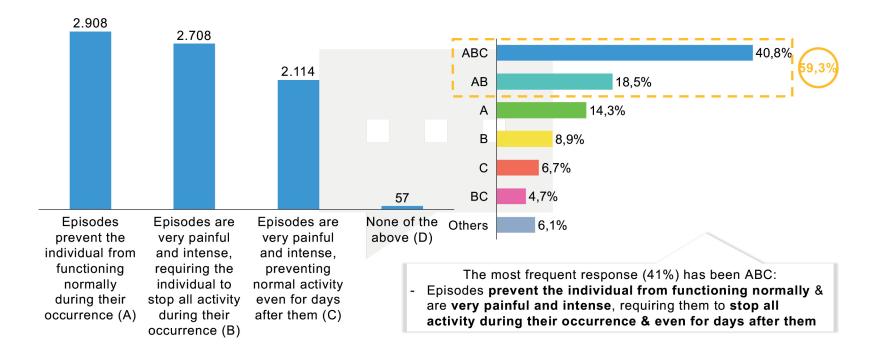
MIGRAINE

**SUFFERERS** 

#### 4.2 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)



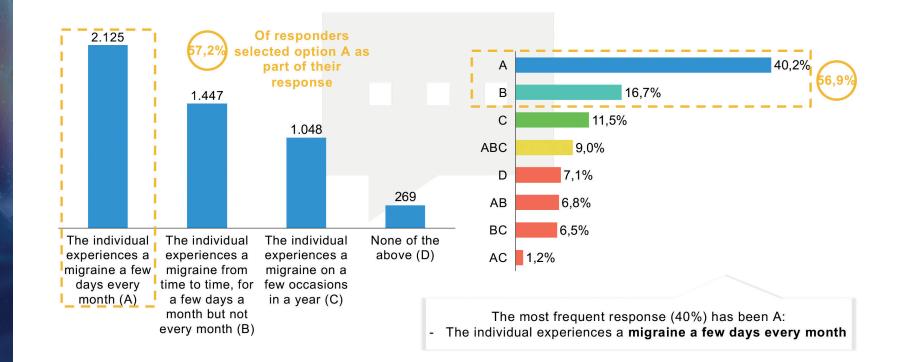


MIGRAINE SUFFERERS

### 4.3 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

42



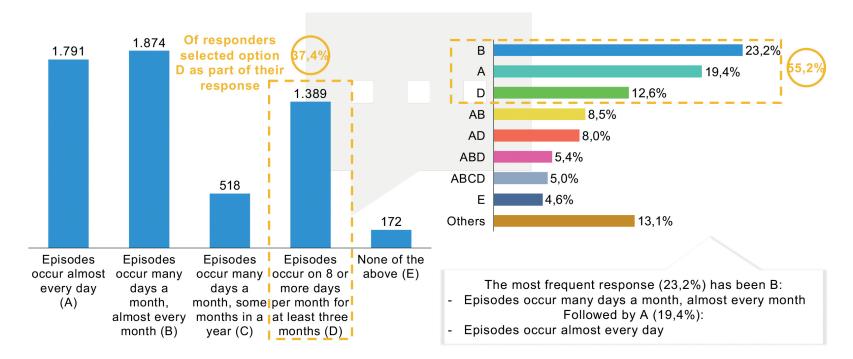
MIGRAINE

SUFFERERS

### 4.4 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)



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



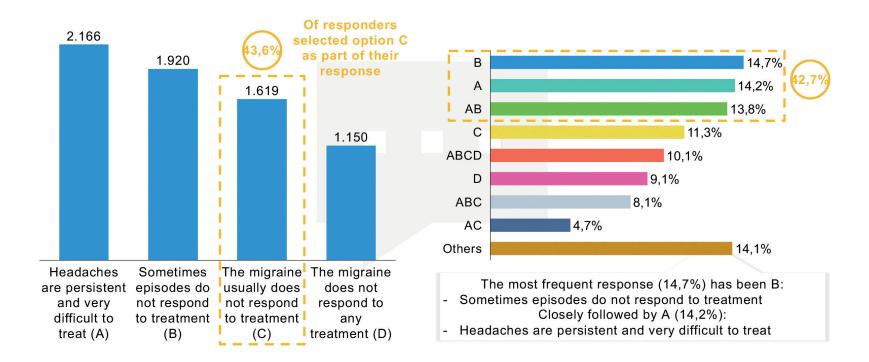
MIGRAINE SUFFERERS

#### 4.5 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)



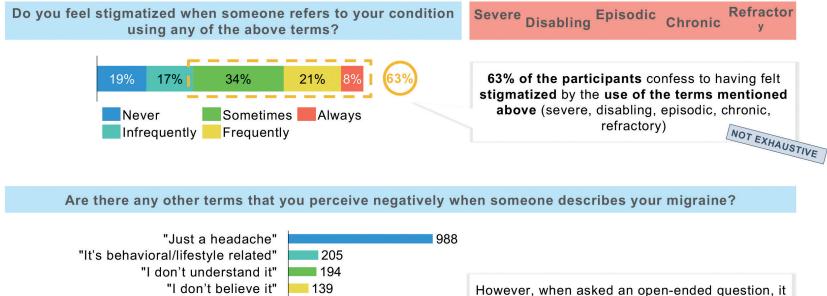
Notes: Sample size for these questions: 3.712 respondents. Source: European headache federation consensus on the definition of resistant and refractory migraine (link)



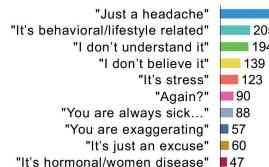
MIGRAINE SUFFERERS

#### 4.6 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



is striking that what is **perceived as the worst** is when the **severity of the disease** is <u>minimized</u> by comparing it to something like a headache





MIGRAINE

SUFFERERS

#### 4.7 Language stigma





MIGRAINE

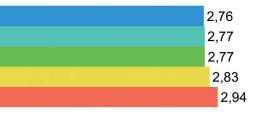
SUFFERERS

#### 4.8 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

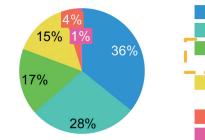
What do you believe is the <u>root cause of stigma toward your illness?</u> (please rank them from 1 to 5, with 1 representing the most significant cause of stigma)?

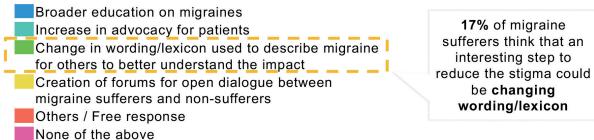
Lack of understanding
Its invisible nature
Misconceptions/myths
Symptoms
Name of condition



1 – Most significant cause of stigma

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









### 4.9 Cause of stigma (2/2)

What steps would you take to reduce the stigma related to migraines (free response option)?

IMPROVE EDUCATION AND TRAINING FOR HEALTHCARE PROFESSIONALS

EDUCATE EMPLOYERS AND SUPERVISORS
MORE SUPPORT FROM DOCTORS

RAISE AWARENESS THROUGH PUBLIC CAMPAIGNS, MEDIA COVERAGE AND ADVERTISING
ENCOURAGE OPEN DISCUSSIONS

ADDRESS STIGMA AND MISCONCEPTIONS
ENHANCE RECOGNITION OF MIGRAINES AS NEUROLOGICAL DISEASE

**IMPROVE REIMBURSEMENT** 

MORE EFFECTIVE AND NEW TREATMENTS

**CONDUCT MORE RESEARCH** 

**MORE LABOR PROTECTION** 

**INCLUSION OF MIGRAINE AS A DISABILITY** 

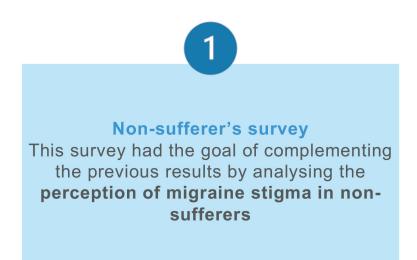
### **5. Non-sufferers Survey**





#### **5.1 Additional survey**

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





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



#### **5.2 Response tracker**

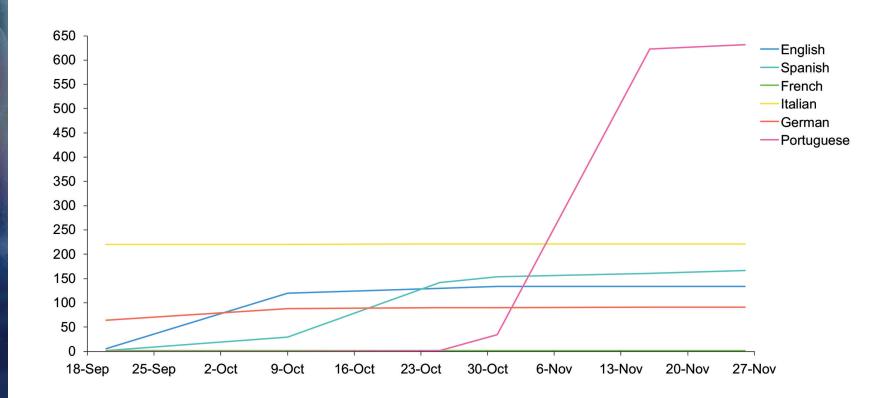
We obtained a total of 1.245 answers, mainly from Portuguese, Italian, Spanish, and English-speaking people

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



#### **5.3 Response tracker**

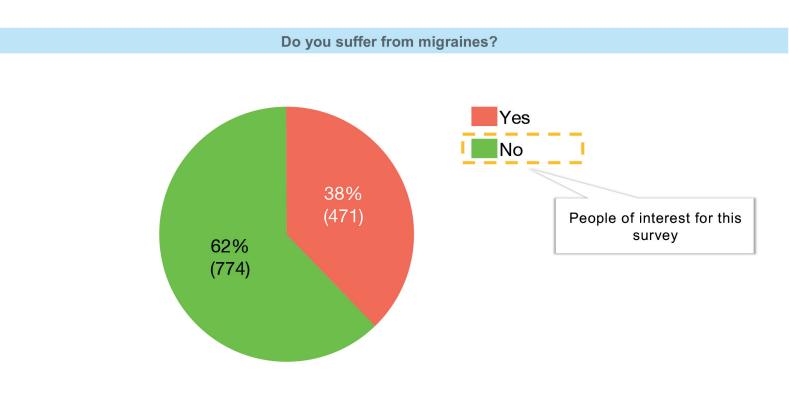
We obtained a total of 1.245 answers, mainly from Portuguese, Italian, Spanish, and English-speaking people





#### 5.4 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

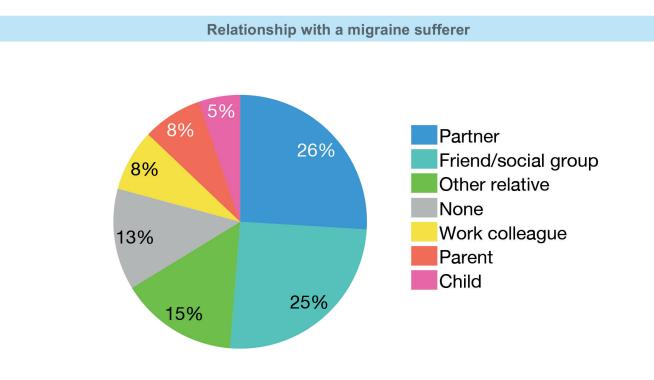


Sample size: 1.245



#### 5.5 Question 2

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



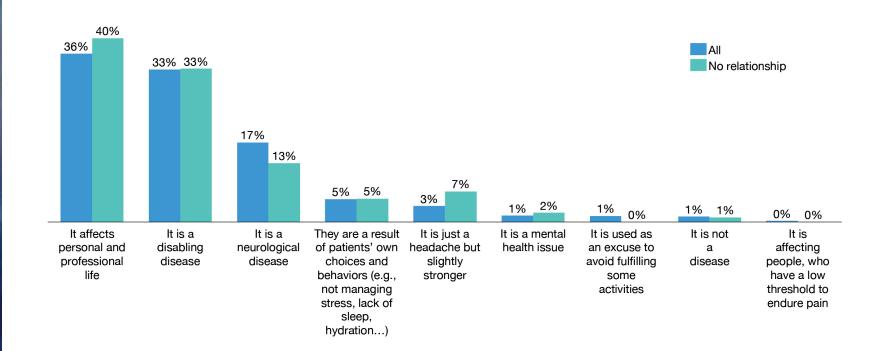
Sample size: 774



#### 5.6 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...



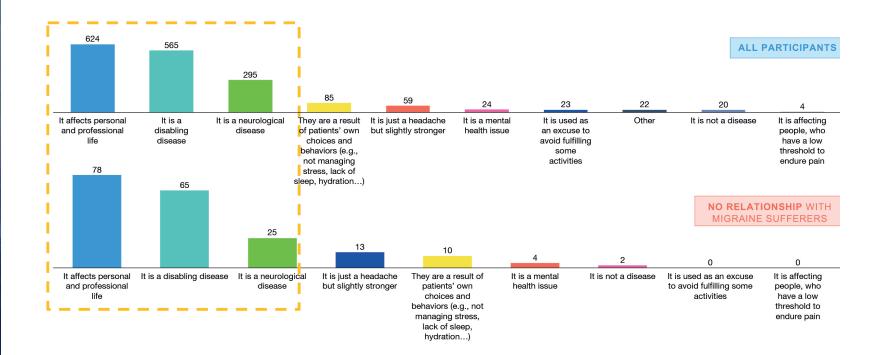
Notes: Sample size: 774 (All); 100 (No relationship)



#### 5.7 Question 3 – with combinations

When asking respondents to describe migraines, their answers are similar to those with relationship with migraine sufferers

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

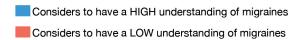


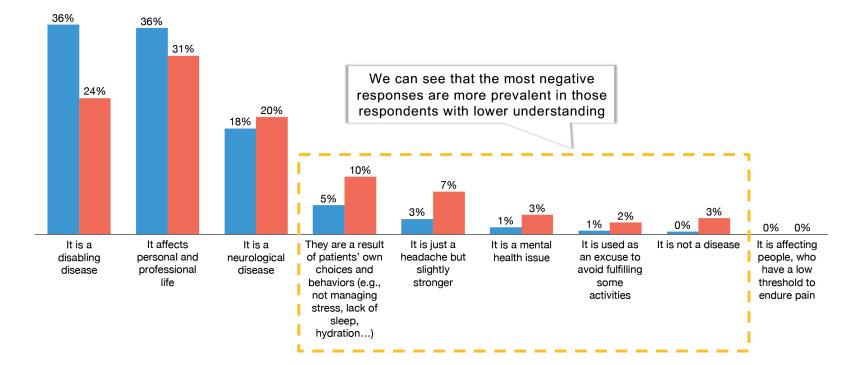
Notes: Sample size: 774 (All); 100 (No relationship)



#### **5.8 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)...

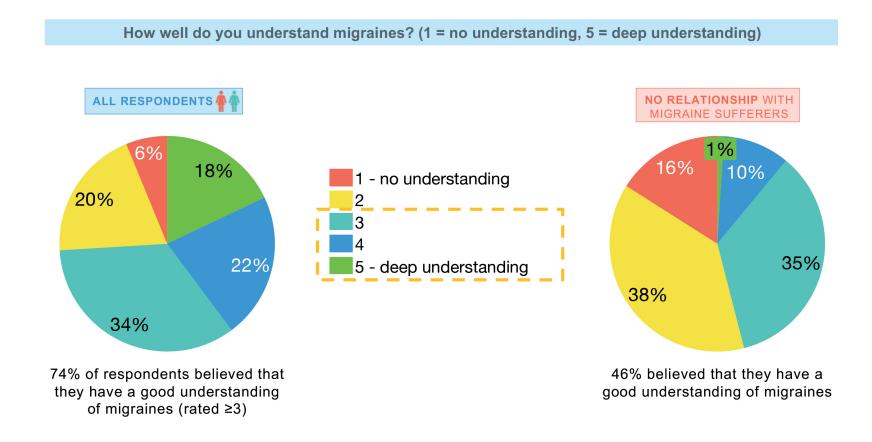






#### 5.9 Question 4

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



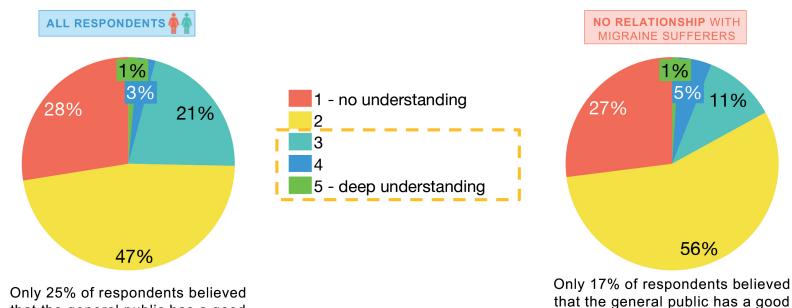
Notes: Sample size: 774 (All); 100 (No relationship)



#### 5.10 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?



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

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

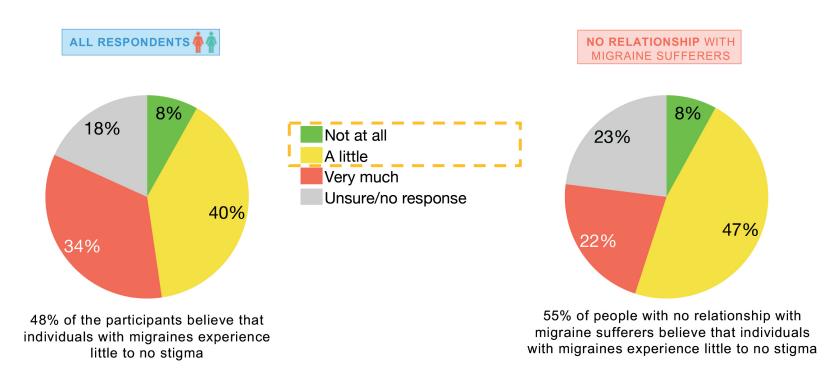
understanding of migraines



#### 5.11 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?



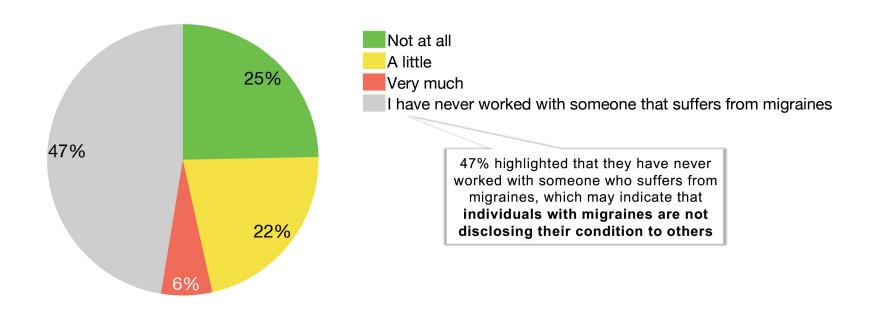
Notes: Sample size: 774 (All); 100 (No relationship)



#### 5.12 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?

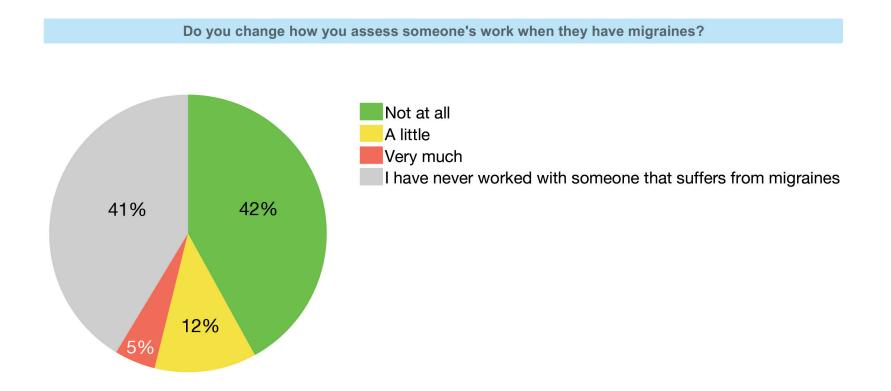


Notes: Sample size: 774



#### 5.13 Question 8

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



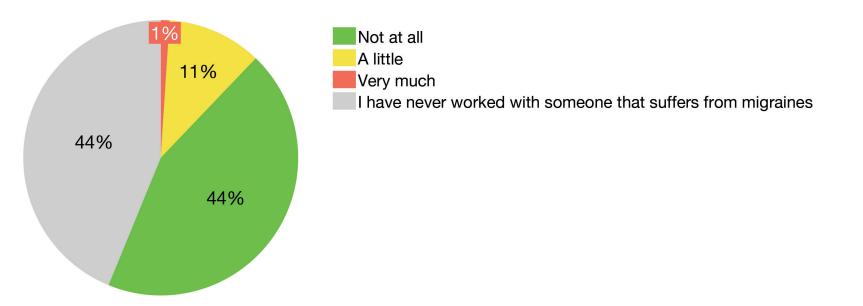
Notes: Sample size: 774



#### 5.14 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?



Notes: Sample size: 774