

# LIVING WELL: THE MENTAL HEALTH OF PEOPLE LIVING WITH A RARE OR UNDIAGNOSED CONDITION AND THEIR FAMILY MEMBERS

## A Rare Barometer survey

### Target population :

- People living with a rare or undiagnosed condition
- Family members of those living with a rare disease



11 Sept. - 14 Dec. 2025



**10,732** respondents worldwide and  
**9,897** in Europe



**25** languages



**43** countries



**1,657** diseases represented

# DASHBOARD FOR EUROPE



## HOW TO USE THIS DASHBOARD

In this dashboard, you will find results for each question of the Rare Barometer survey on the opinion of people living with a rare disease on newborn screening.

Please do not use results of questions for which there are less than 30 respondents.

**Please refer to Rare Barometer or add the Rare Barometer logo when using the results.**



## LANGUAGES

You can change the language at the bottom left of this page and have access to the questions and modalities as they appeared to respondents in the 25 languages of the survey.

**The translation is not available for new variables that were calculated after the questionnaire was closed and for some comments added in this dashboard.**



## INFORMATION

For more information:

- contact the Rare Barometer team at [rare.barometer@eurordis.org](mailto:rare.barometer@eurordis.org)
- visit the Rare Barometer website at [eurordis.org/voices](https://eurordis.org/voices)
- visit our mental health & wellbeing-dedicated webpage: <https://www.eurordis.org/mental-wellbeing/>

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### 1. Sample information

**2. Mental health:** depressive symptoms, anxiety symptoms, loneliness, suicidal thoughts, number of difficulties, quality of life

**3. Support needed and received:** before diagnosis, at diagnosis, in the last 6-12 months

**4. The impact of living with a rare disease on mental health:** daily experiences and link with mental health

## MORE ON THE SURVEY

Research questions and in-depth analysis of European results are in the **full report in English:** [tiny.cc/RB-MH](https://tiny.cc/RB-MH)

Key results are available in the **factsheets:** [tiny.cc/RB-MH-results](https://tiny.cc/RB-MH-results)

Original questionnaire: [tiny.cc/RB-MH-questionnaire](https://tiny.cc/RB-MH-questionnaire)



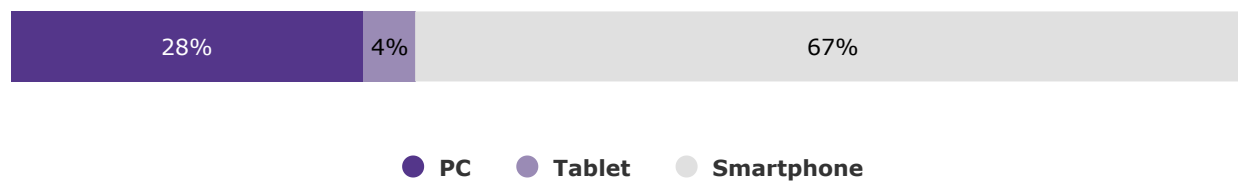
# 1. SAMPLE INFORMATION

**Sociodemographic characteristics,  
diagnostic information**

Ar klausimyną pildo... Suprantame, kad galite save atpažinti keliose iš toliau aprašytų situacijų, tačiau svarbu, kad šioje apklausoje pasirinktumėte **TIK VIENĄ SITUACIJĄ**. Tai gali būti situacija, kuri labiausiai veikia jūsų kasdienį gyvenimą.

# 9 897

## Įrenginys naudojamas atsakymui



## Vidutinis minučių skaičius užpildyti anketą

# 33

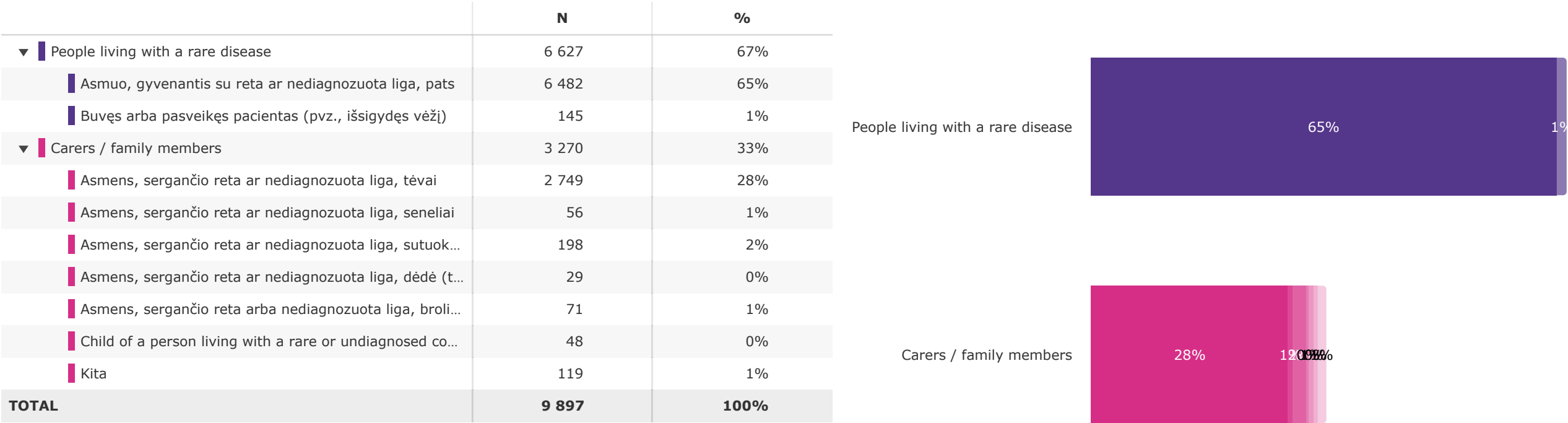
Mean

## Vidutinis minučių skaičius užpildyti anketą

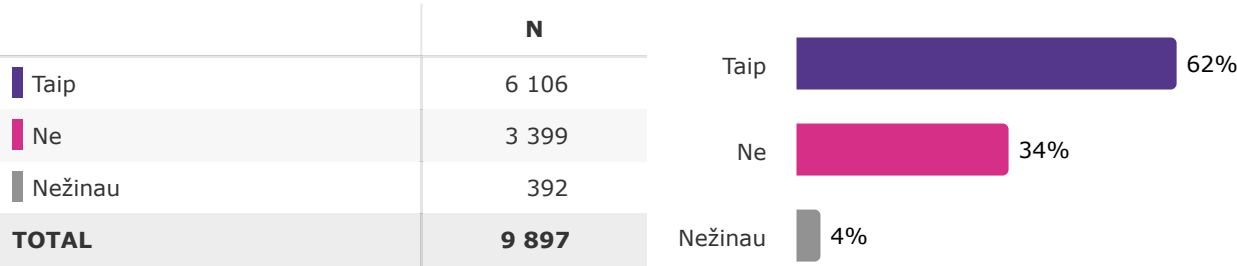
# 25

Median

Ar klausimyną pildė... Suprantame, kad galite save atpažinti keliose iš toliau aprašytų situacijų, tačiau svarbu, kad šioje apklausoje pasirinktumėte TIK VIENĄ SITUACIJĄ. Tai gali būti situacija, kuri labiausiai veikia jūsų kasdienį gyvenimą.

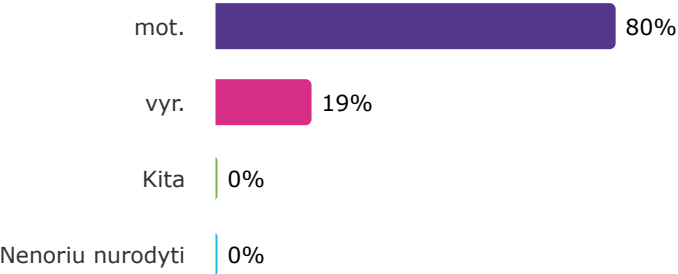


Ar esate ne pelno organizacijos, vienijančios reta ar nediagnozuota liga sergančius asmenis arba jų šeimos narius, narys?



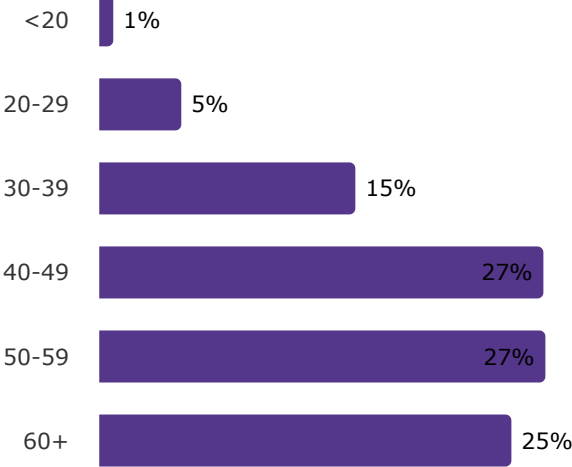
Jūsų lytis:

|                  | N            | %           |
|------------------|--------------|-------------|
| mot.             | 7 931        | 80%         |
| vyr.             | 1 898        | 19%         |
| Kita             | 32           | 0%          |
| Nenoriu nurodyti | 36           | 0%          |
| <b>TOTAL</b>     | <b>9 897</b> | <b>100%</b> |



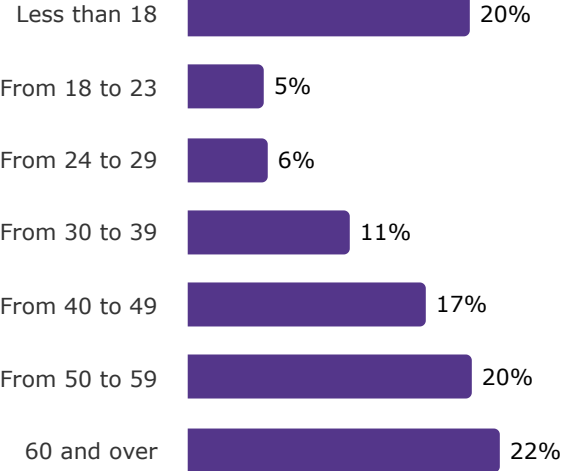
Age of the participant

|              | N            | %           |
|--------------|--------------|-------------|
| <20          | 84           | 1%          |
| 20-29        | 493          | 5%          |
| 30-39        | 1 527        | 15%         |
| 40-49        | 2 661        | 27%         |
| 50-59        | 2 665        | 27%         |
| 60+          | 2 467        | 25%         |
| <b>TOTAL</b> | <b>9 897</b> | <b>100%</b> |



Age\_PLWRD

|               | N            | %           |
|---------------|--------------|-------------|
| Less than 18  | 1 944        | 20%         |
| From 18 to 23 | 528          | 5%          |
| From 24 to 29 | 546          | 6%          |
| From 30 to 39 | 1 113        | 11%         |
| From 40 to 49 | 1 632        | 17%         |
| From 50 to 59 | 1 950        | 20%         |
| 60 and over   | 2 146        | 22%         |
| <b>TOTAL</b>  | <b>9 859</b> | <b>100%</b> |

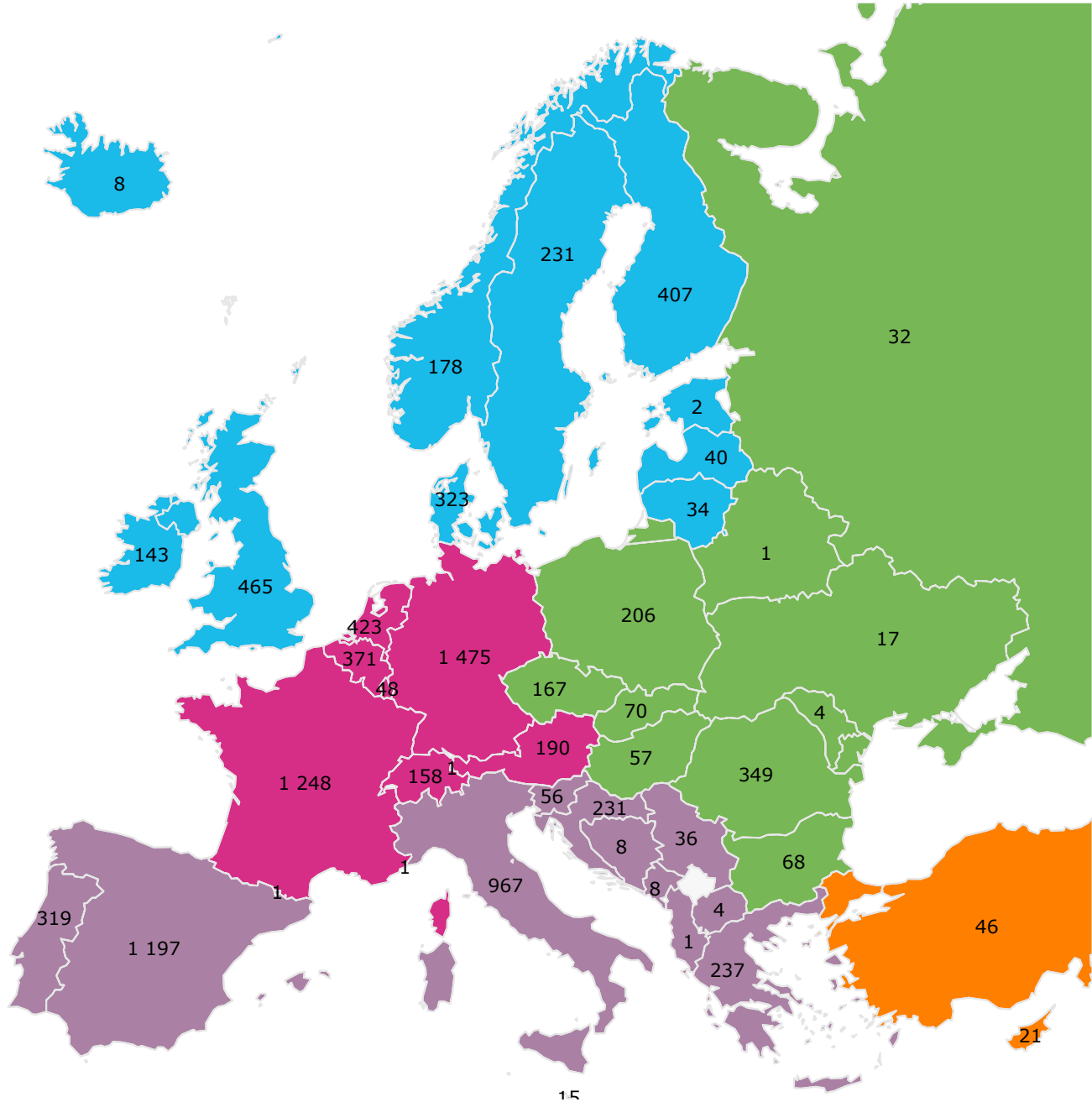


Kokioje valstybėje gyvenate?

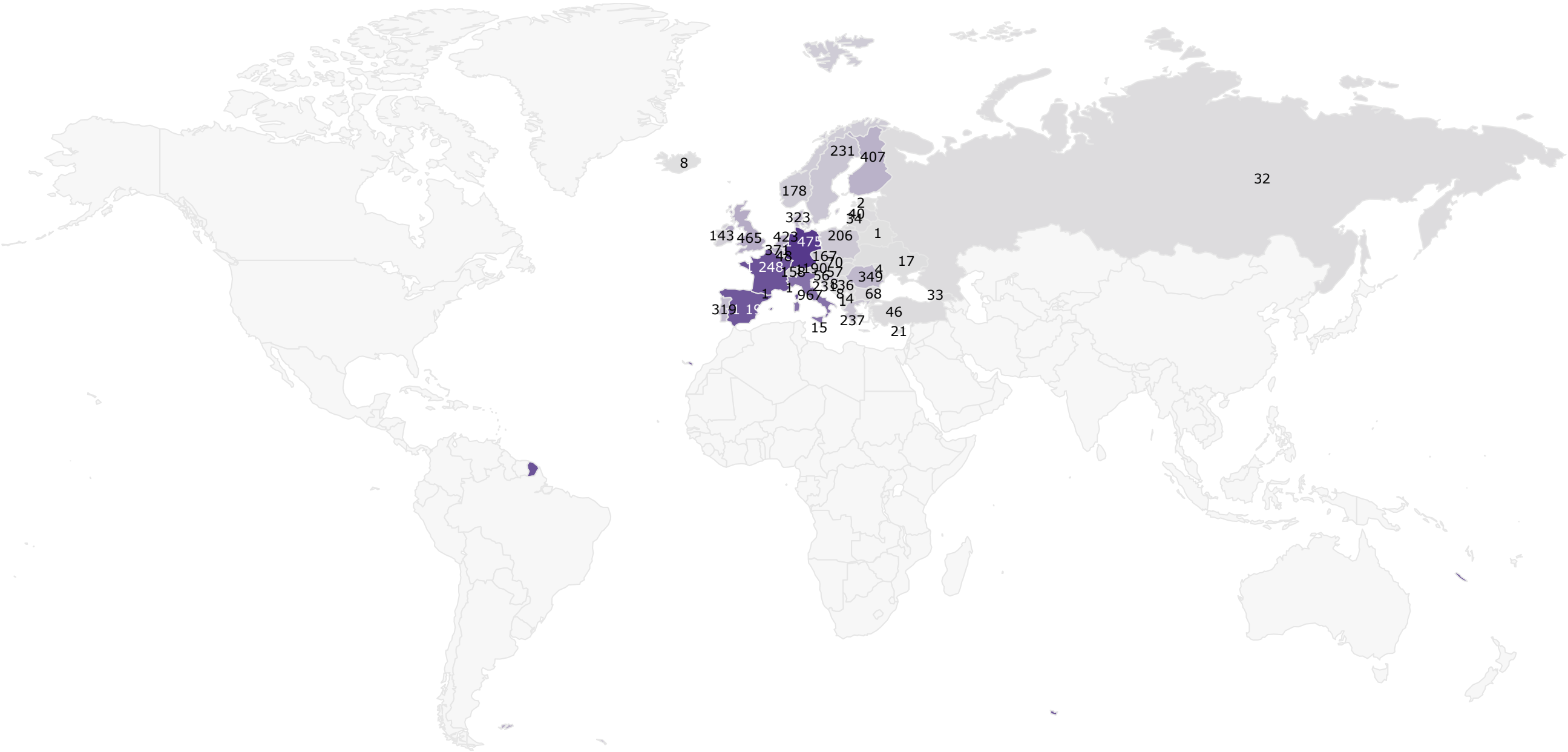
|                    | N     | %   |
|--------------------|-------|-----|
| Vokietija          | 1 475 | 16% |
| Prancūzija         | 1 248 | 13% |
| Ispanija           | 1 197 | 13% |
| Italija            | 967   | 10% |
| Jungtinė Karalystė | 465   | 5%  |
| Nyderlandai        | 423   | 5%  |
| Suomija            | 407   | 4%  |
| Belgija            | 371   | 4%  |
| Rumunija           | 349   | 4%  |
| Danija             | 323   | 3%  |
| Portugalija        | 319   | 3%  |
| Graikija           | 237   | 3%  |
| Kroatija           | 231   | 2%  |
| Švedija            | 231   | 2%  |
| Lenkija            | 206   | 2%  |
| Austrija           | 190   | 2%  |
| Norvegija          | 178   | 2%  |
| Čekijos Respublika | 167   | 2%  |
| Šveicarija         | 158   | 2%  |
| Airija             | 143   | 2%  |
| Slovakija          | 70    | 1%  |

Kokioje valstybėje gyvenate?

|                        | N  | %   |
|------------------------|----|-----|
| Slovakija              | 70 | 11% |
| Bulgarija              | 68 | 11% |
| Vengrija               | 57 | 9%  |
| Slovėnija              | 56 | 9%  |
| Liuksemburgas          | 48 | 8%  |
| Turkija                | 46 | 8%  |
| Latvija                | 40 | 7%  |
| Serbija                | 36 | 6%  |
| Lietuva                | 34 | 6%  |
| Gruzija                | 33 | 5%  |
| Rusija                 | 32 | 5%  |
| Kipras                 | 21 | 3%  |
| Ukraina                | 17 | 3%  |
| Malta                  | 15 | 2%  |
| Bosnija ir Hercegovina | 8  | 1%  |
| Islandija              | 8  | 1%  |
| Juodkalnija            | 8  | 1%  |
| Makedonija             | 4  | 1%  |
| Moldova                | 4  | 1%  |
| Estija                 | 2  | 0%  |
| Albanija               | 1  | 0%  |
| Andora                 | 1  | 0%  |

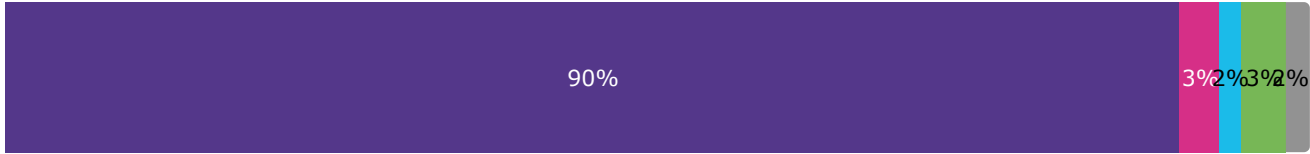


Kokioje valstybėje gyvenate?



Pasirinkite vieną teiginį, kuris tinka jūsų ar asmens, kurį prižiūrite, situacijai apibendrinti:

|                                                                                                                         | N     | %    |
|-------------------------------------------------------------------------------------------------------------------------|-------|------|
| Žinau retos būklės PAVADINIMĄ ir ji buvo PATVIRTINTA atitinkamais medicininiais tyrimais arba klinikiniais kriterijais  | 8 904 | 90%  |
| Žinau retos būklės PAVADINIMĄ, bet ji dar nepatvirtinta atitinkamais medicininiais tyrimais ar klinikiniais kriterijais | 314   | 3%   |
| Esu tik IŠ DALIES informuotas apie retos ligos pavadinimą, su ja susijusį geną ar ligos rūšį                            | 167   | 2%   |
| Žinau, kad liga yra reta, tačiau jos sukėlėjas ar pavadinimas DAR NEBUVO NUSTATYTAS                                     | 330   | 3%   |
| Kita                                                                                                                    | 182   | 2%   |
| TOTAL                                                                                                                   | 9 897 | 100% |



- Žinau retos būklės PAVADINIMĄ ir ji buvo PATVIRTINTA atitinkamais medicininiais tyrimais arba klinikiniais kriterijais
- Žinau retos būklės PAVADINIMĄ, bet ji dar nepatvirtinta atitinkamais medicininiais tyrimais ar klinikiniais kriterijais
- Esu tik IŠ DALIES informuotas apie retos ligos pavadinimą, su ja susijusį geną ar ligos rūšį
- Žinau, kad liga yra reta, tačiau jos sukėlėjas ar pavadinimas DAR NEBUVO NUSTATYTAS
- Kita

Time SINCE diagnosis (initial or confirmed), in years

|             | N     | %    |
|-------------|-------|------|
| <4          | 2 029 | 21%  |
| 4-10        | 2 485 | 25%  |
| 10-20       | 2 396 | 24%  |
| 20+         | 2 308 | 23%  |
| Undiagnosed | 679   | 7%   |
| TOTAL       | 9 897 | 100% |



# 1 657

### Orphacode associated nomenclature (english)

|                                       | N   |
|---------------------------------------|-----|
| Hereditary hemorrhagic telangiectasia | 609 |
| Myasthenia gravis                     | 355 |
| Monosomy 22q13.3                      | 331 |
| Hypermobile Ehlers-Danlos syndrome    | 308 |
| Neurofibromatosis type 1              | 207 |
| Primary biliary cholangitis           | 118 |
| Systemic sclerosis                    | 100 |
| 22q11.2 deletion syndrome             | 94  |
| Williams syndrome                     | 92  |
| Postpoliomyelitis syndrome            | 86  |
| Sarcoidosis                           | 86  |
| Addison disease                       | 82  |
| Systemic lupus erythematosus          | 81  |
| Cystic fibrosis                       | 80  |
| Fragile X syndrome                    | 80  |
| Tuberous sclerosis complex            | 80  |

### Orphacode associated nomenclature (english)

|                                                   | N  |
|---------------------------------------------------|----|
| Primary sclerosing cholangitis                    | 77 |
| Adult-onset myasthenia gravis                     | 72 |
| Angelman syndrome                                 | 64 |
| Poliomyelitis                                     | 61 |
| Granulomatosis with polyangiitis                  | 57 |
| Behçet disease                                    | 55 |
| Chronic inflammatory demyelinating polyneuropathy | 52 |
| Friedreich ataxia                                 | 50 |
| Idiopathic intracranial hypertension              | 49 |
| Antiphospholipid syndrome                         | 47 |
| Marfan syndrome                                   | 45 |
| Primary Sjögren syndrome                          | 44 |
| Diffuse cutaneous systemic sclerosis              | 43 |
| Facioscapulohumeral dystrophy                     | 43 |
| Charcot-Marie-Tooth disease type 1A               | 42 |
| Hereditary spastic paraplegia                     | 41 |
| Vascular Ehlers-Danlos syndrome                   | 41 |
| Duchenne muscular dystrophy                       | 40 |
| Ehlers-Danlos syndrome                            | 40 |

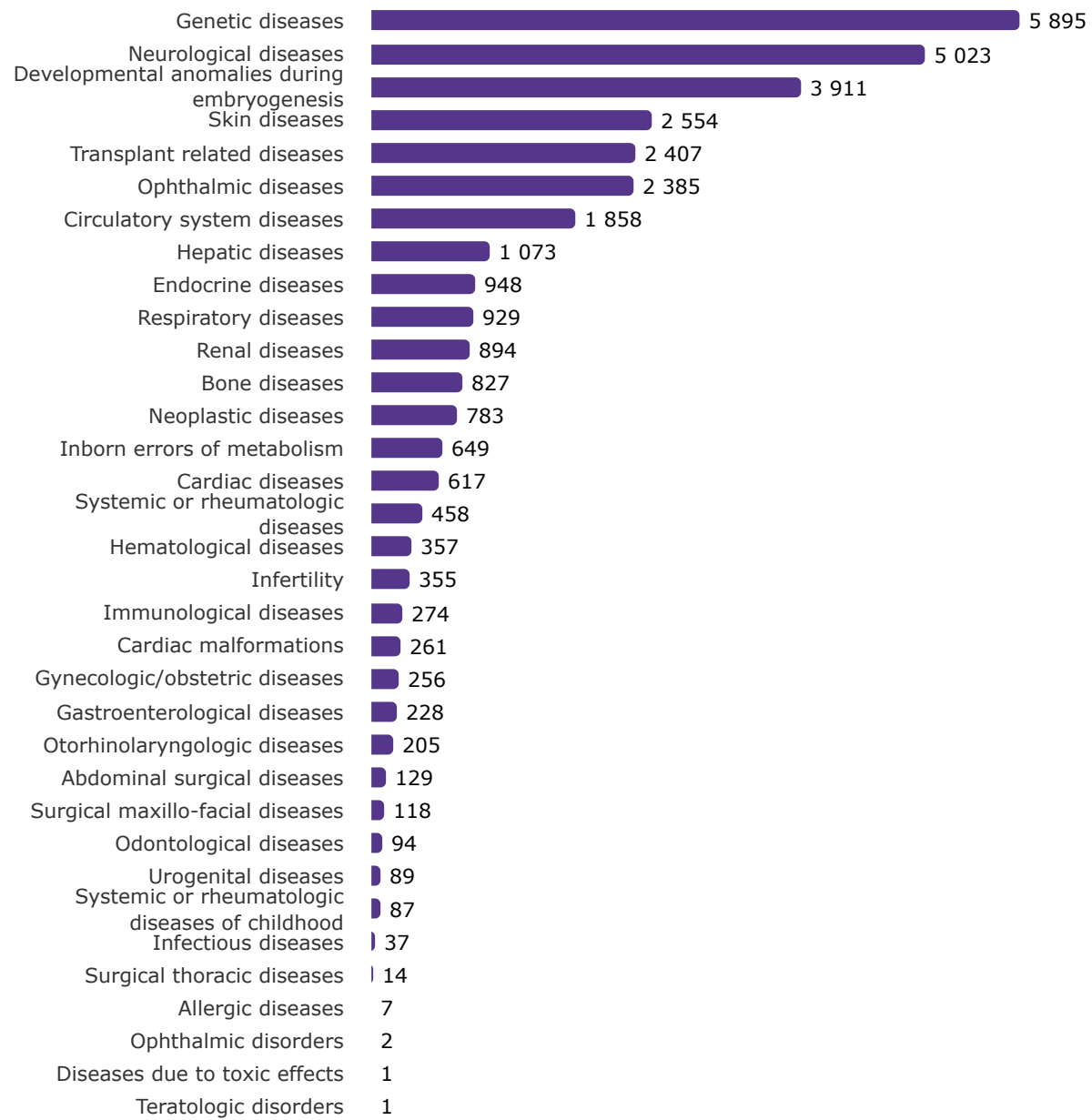
### Orphacode associated nomenclature (english)

|                                                                                                              | N  |
|--------------------------------------------------------------------------------------------------------------|----|
| Amyotrophic lateral sclerosis                                                                                | 37 |
| Rett syndrome                                                                                                | 37 |
| Wilson disease                                                                                               | 37 |
| Facial dysmorphism-developmental delay-behavioral abnormalities syndrome due to 10p11.21p12.31 microdeletion | 36 |
| Lamellar ichthyosis                                                                                          | 35 |
| Charcot-Marie-Tooth disease/Hereditary motor and sensory neuropathy                                          | 34 |
| Waldenström macroglobulinemia                                                                                | 33 |
| Autoimmune hepatitis                                                                                         | 31 |
| Classical Ehlers-Danlos syndrome                                                                             | 31 |
| Familial Mediterranean fever                                                                                 | 31 |
| Acromegaly                                                                                                   | 30 |
| Autosomal systemic lupus erythematosus                                                                       | 30 |
| Neurofibromatosis type 2                                                                                     | 30 |
| Prader-Willi syndrome                                                                                        | 30 |

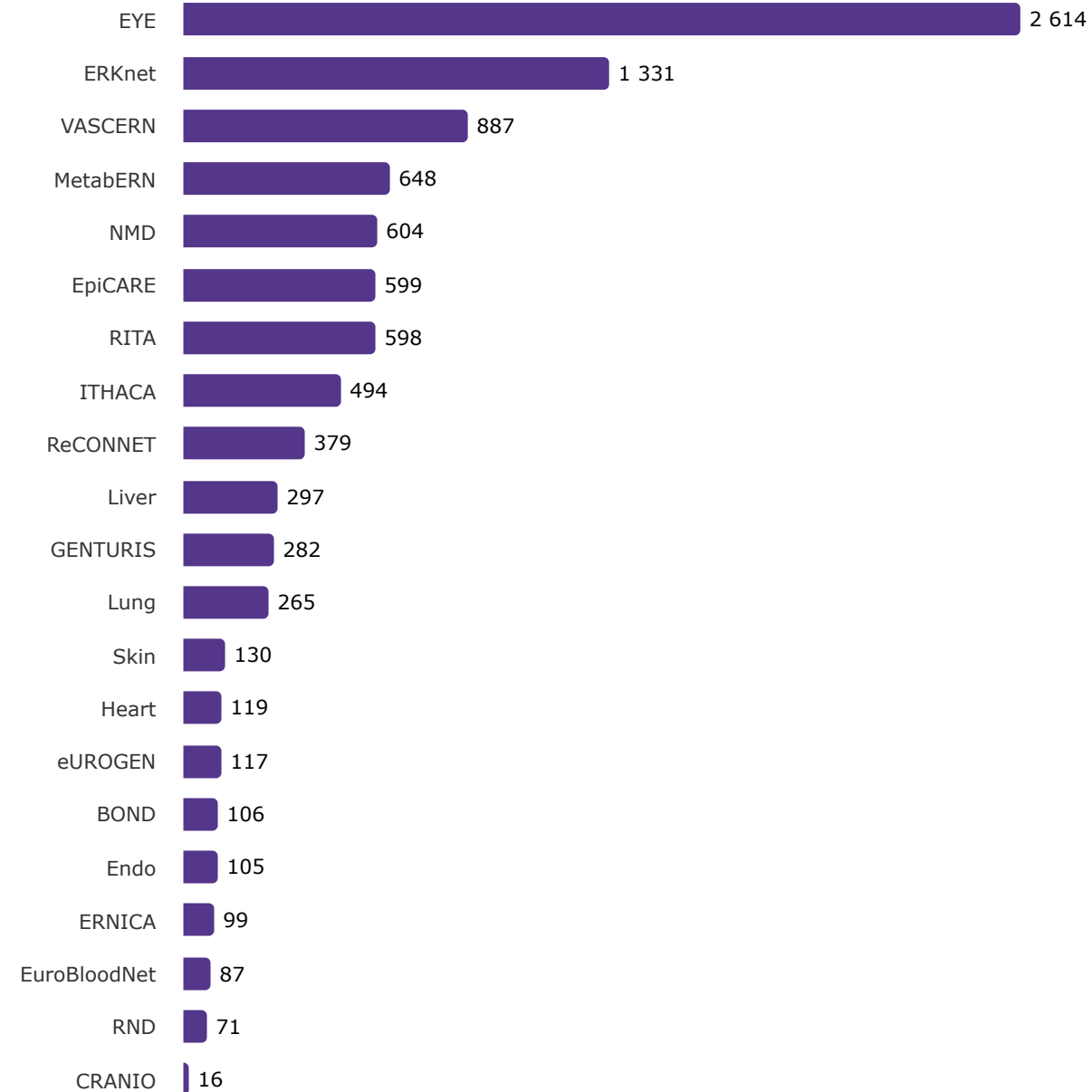
### Orphacode associated nomenclature (english)

|                                                     | N  |
|-----------------------------------------------------|----|
| Common variable immunodeficiency                    | 29 |
| Pemphigus vulgaris                                  | 29 |
| X-linked hypophosphatemia                           | 29 |
| Idiopathic pulmonary arterial hypertension          | 28 |
| Scleroderma                                         | 28 |
| Classic phenylketonuria                             | 27 |
| Fabry disease                                       | 26 |
| Hereditary angioedema                               | 26 |
| Non-acquired panhypopituitarism                     | 26 |
| Angelman syndrome due to maternal 15q11q13 deletion | 25 |
| Arnold-Chiari malformation type I                   | 25 |
| Esophageal atresia                                  | 25 |
| Idiopathic achalasia                                | 25 |
| Limited cutaneous systemic sclerosis                | 25 |
| Monosomy 5p                                         | 25 |
| Primary lymphedema                                  | 25 |

## list\_orphacodes\_classification\_updated



## ERNs 2024



EURORDIS European Federations

|                                                                                     | N     | %   |
|-------------------------------------------------------------------------------------|-------|-----|
| FEDERG - Federation of European Associations of Patients affected by Renal Diseases | 1 573 | 37% |
| EAMDA-European Alliance of Neuromuscular Disorders Associations                     | 1 248 | 29% |
| HHT Europe                                                                          | 609   | 14% |
| LGD Alliance Europe                                                                 | 513   | 12% |
| European Myasthenia Gravis Association                                              | 438   | 10% |
| Phelan McDermid                                                                     | 331   | 8%  |
| European Liver Patients Association                                                 | 306   | 7%  |
| NF Patients United                                                                  | 267   | 6%  |
| Federation of European Scleroderma Associations                                     | 222   | 5%  |
| Lupus Europe                                                                        | 195   | 5%  |
| European CMT Federation                                                             | 183   | 4%  |
| Systemic Sclerosis                                                                  | 182   | 4%  |
| European Polio Union                                                                | 162   | 4%  |
| Albi France                                                                         | 157   | 4%  |

EURORDIS European Federations

|                                                                                                                             | N   | %   |
|-----------------------------------------------------------------------------------------------------------------------------|-----|-----|
| European Network for Ichthyosis                                                                                             | 141 | 16% |
| Euro Ataxia - European Federation of hereditary Ataxias                                                                     | 140 | 16% |
| 22Q11 Europe                                                                                                                | 96  | 11% |
| European Federation of Williams Syndrome                                                                                    | 92  | 10% |
| Sarcoidosis                                                                                                                 | 92  | 10% |
| Williams syndrome                                                                                                           | 92  | 10% |
| Sarcoidosis Europe - European Association of Patients Organizations of Sarcoidosis and other Granulomatous Disorders (EPOS) | 92  | 10% |
| PHA Europe (Pulmonary Arterial Hypertension)                                                                                | 84  | 10% |
| European Fragile X Network                                                                                                  | 81  | 9%  |
| CF Europe                                                                                                                   | 80  | 9%  |
| European Tuberous Sclerosis Complex Association                                                                             | 80  | 9%  |
| Tuberous Sclerosis                                                                                                          | 80  | 9%  |
| Cystic Fibrosis Worldwide                                                                                                   | 80  | 9%  |

EURORDIS European Federations

|                                                       | N  | %   |
|-------------------------------------------------------|----|-----|
| Sclerosing Cholangitis                                | 77 | 11% |
| PSC Patients Europe                                   | 77 | 11% |
| EDINETWORK                                            | 71 | 10% |
| Marfan Europe Network                                 | 68 | 10% |
| CANPKU+                                               | 58 | 8%  |
| OIFE - Osteogenesis Imperfecta Federation Europe      | 49 | 7%  |
| European Society for Phenylketonuria                  | 48 | 7%  |
| European Federation for Hereditary Spastic Paraplegia | 47 | 7%  |
| SMA Europe                                            | 47 | 7%  |
| Rett Syndrome Europe                                  | 44 | 6%  |
| Sj gren Europe                                        | 44 | 6%  |
| FSHD Europe                                           | 43 | 6%  |
| MPS Europe                                            | 42 | 6%  |
| Duchenne Muscular Dystrophy                           | 40 | 6%  |
| European Huntington Association                       | 27 | 4%  |
| Gaucher                                               | 26 | 4%  |



## 2. MENTAL HEALTH AND WELLBEING

Poor mental health: depressive symptoms, anxiety symptoms, loneliness, suicidal thoughts

## Mental health score

# 68%

## Poor mental health

Percentage of participants who reported at least one mental health difficulty among:

- moderate to severe **depressive symptoms** (PHQ-8 score  $\geq 10$ )
- clinically significant **anxiety symptoms** (GAD-2 score  $\geq 3$ )
- **loneliness** (UCLA loneliness scale score  $\geq 9$ )
- or **suicidal thoughts** in the past six months.

**Depressive symptoms** were measured using the Patient Health Questionnaire (PHQ-8), often used to screen individuals based on eight core DSM-based symptoms by asking how often the symptoms were experienced over the past two weeks, generating a total score from 0 to 24. See the eight questions next page.

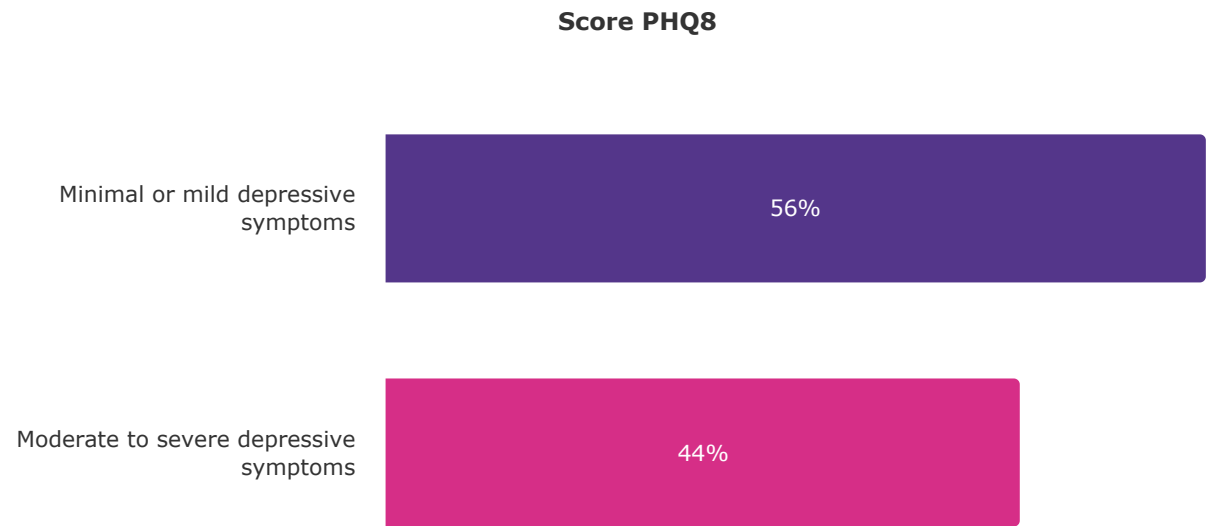
A cut-off score of 10 or more was used to identify moderate to severe depression symptoms.

The PHQ-8 score does not correspond to a clinical diagnostic and as such, estimates based on a cut-off score of 10 or more should be interpreted as reflecting the prevalence of elevated depressive symptoms, rather than clinically confirmed major depressive symptoms.

**Comparison with general population in the EU and per EU country (Eurostat):**

[https://ec.europa.eu/eurostat/databrowser/view/hlth\\_ehis\\_mh2e\\$defaultview/default/lang=en](https://ec.europa.eu/eurostat/databrowser/view/hlth_ehis_mh2e$defaultview/default/lang=en)

| Score PHQ8                               |       |      |
|------------------------------------------|-------|------|
|                                          | N     | %    |
| ▼ Minimal or mild depressive symptoms    | 5 579 | 56%  |
| Minimal depression                       | 2 239 | 23%  |
| Mild depression                          | 3 340 | 34%  |
| ▼ Moderate to severe depressive symptoms | 4 318 | 44%  |
| Moderate depression                      | 2 390 | 24%  |
| Moderately severe depression             | 1 239 | 13%  |
| Severe depression                        | 689   | 7%   |
| TOTAL                                    | 9 897 | 100% |



Combined analysis

|                                                                                                                                                                                               | BEVEIK<br>KIEKVIE...<br>DIENĄ | DAUGIAU<br>NEI PUSĖ<br>IŠ VISŲ<br>DIENŲ | KELETĄ<br>DIENŲ | VISAI<br>NEKAMA... | TOTAL |                                                                                                                                    |                                                                     |
|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------|-----------------------------------------|-----------------|--------------------|-------|------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------|
| Mažas susidomėjimas ar malonumas atliekant dalykus                                                                                                                                            | 1 062                         | 1 485                                   | 4 547           | 2 803              | 9 897 | Mažas susidomėjimas ar malonumas atliekant dalykus                                                                                 | <div><div>11%</div><div>15%</div><div>46%</div><div>28%</div></div> |
| Jautimasis nusiminusiam (-ai), prislėgtam (-ai) ar beviltiškam (-ai)                                                                                                                          | 1 077                         | 1 333                                   | 4 514           | 2 973              | 9 897 | Jautimasis nusiminusiam (-ai), prislėgtam (-ai) ar beviltiškam (-ai)                                                               | <div><div>11%</div><div>13%</div><div>46%</div><div>30%</div></div> |
| Sunkumas užmigti ar išmiegoti, arba per ilgas miegojimas                                                                                                                                      | 2 640                         | 1 896                                   | 3 431           | 1 930              | 9 897 | Sunkumas užmigti ar išmiegoti, arba per ilgas miegojimas                                                                           | <div><div>27%</div><div>19%</div><div>35%</div><div>20%</div></div> |
| Jautimasis pavargusiam (-ai) ar energijos trūkumas                                                                                                                                            | 3 533                         | 2 237                                   | 3 440           | 687                | 9 897 | Jautimasis pavargusiam (-ai) ar energijos trūkumas                                                                                 | <div><div>36%</div><div>23%</div><div>35%</div><div>7%</div></div>  |
| Prastas apetitas arba persivalgymas                                                                                                                                                           | 1 530                         | 1 553                                   | 3 230           | 3 584              | 9 897 | Prastas apetitas arba persivalgymas                                                                                                | <div><div>15%</div><div>16%</div><div>33%</div><div>36%</div></div> |
| Prasta savijauta – pojūtis, kad esate nevykėlis (-ė) arba kad nuvylėte save ar savo šeimą                                                                                                     | 1 304                         | 1 201                                   | 3 234           | 4 158              | 9 897 | Prasta savijauta – pojūtis, kad esate nevykėlis (-ė) arba kad nuvylėte save ar savo šeimą                                          | <div><div>13%</div><div>12%</div><div>33%</div><div>42%</div></div> |
| Sunkumas susikoncentruoti ties tokiais dalykais, kaip laikraščio skaitymas arba televizoriaus žiūrėjimas                                                                                      | 1 312                         | 1 400                                   | 3 820           | 3 365              | 9 897 | Sunkumas susikoncentruoti ties tokiais dalykais, kaip laikraščio skaitymas arba televizoriaus žiūrėjimas                           | <div><div>13%</div><div>14%</div><div>39%</div><div>34%</div></div> |
| Judėjimas ar kalbėjimas taip lėtai, kad kiti žmonės galėjo pastebėti? Arba atvirkščiai – buvimas tokiam (-ai) neramiam (-ai) ar nenustygstančiam (-ai), kad judėjote daug daugiau nei įprasta | 798                           | 861                                     | 2 603           | 5 635              | 9 897 | Judėjimas ar kalbėjimas taip lėtai, kad kiti žmonės galėjo pastebėti? Arba atvirkščiai – buvimas tokiam (-ai) neramiam (-ai) ar... | <div><div>8%</div><div>9%</div><div>26%</div><div>57%</div></div>   |

● Beveik kiekvieną dieną ● Daugiau nei pusė iš visų dienų ● Keletą dienų  
● Visai nekamavo

Cross: Status for MH / Score PHQ8

| STATUS FOR MH  | SCORE PHQ8                          |            |                                        |            |       |      |
|----------------|-------------------------------------|------------|----------------------------------------|------------|-------|------|
|                | MINIMAL OR MILD DEPRESSIVE SYMPTOMS |            | MODERATE TO SEVERE DEPRESSIVE SYMPTOMS |            | TOTAL |      |
|                | N                                   | %          | N                                      | %          | N     | %    |
| PLWRD          | <u>3 633</u>                        | <u>55%</u> | <u>2 994</u>                           | <u>45%</u> | 6 627 | 100% |
| Parent         | <u>1 600</u>                        | <u>58%</u> | <u>1 149</u>                           | <u>42%</u> | 2 749 | 100% |
| Spouse/partner | <u>128</u>                          | <u>65%</u> | <u>70</u>                              | <u>35%</u> | 198   | 100% |
| Other FM       | <u>218</u>                          | <u>67%</u> | <u>105</u>                             | <u>33%</u> | 323   | 100% |
| TOTAL          | 5 579                               | 56%        | 4 318                                  | 44%        | 9 897 |      |

Under-represented elements  Over-represented elements

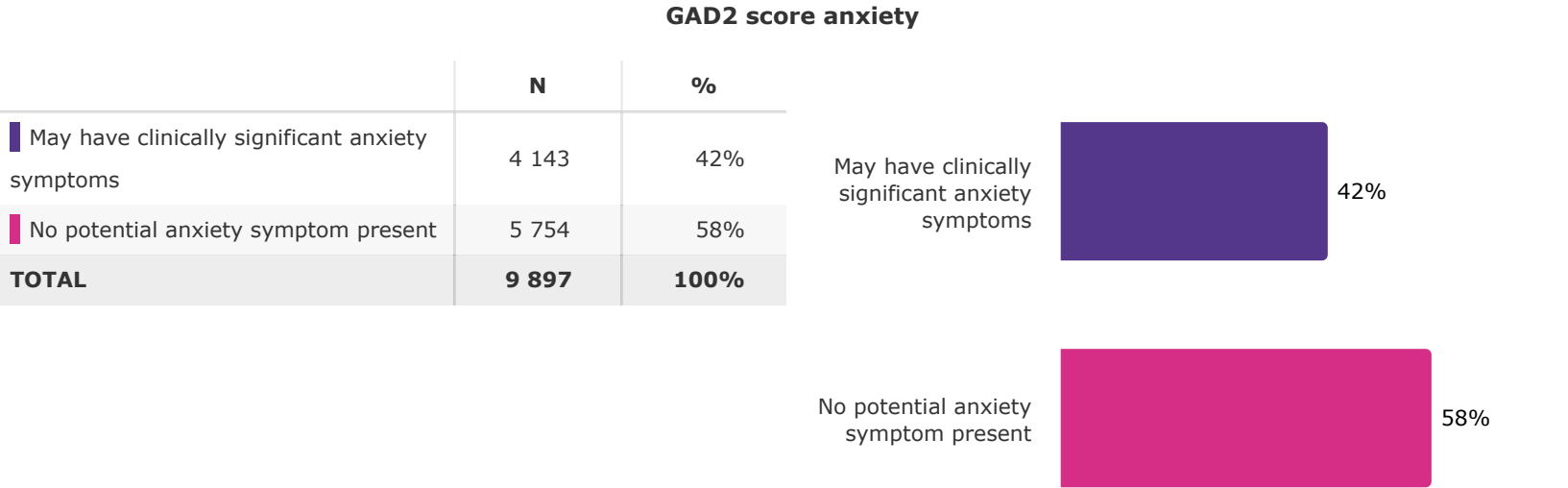
The relationship is very significant.  $p\text{-value} = < 0,01$  ;  $\text{Chi}^2 = 32,0$  ;  $\text{dof} = 3$ .

**Anxiety symptoms** were measured using the Generalised Anxiety Disorder scale (**GAD-2**), a brief screening tool recommended in population surveys and clinical settings. It captures two core symptoms of generalised anxiety (see next page).

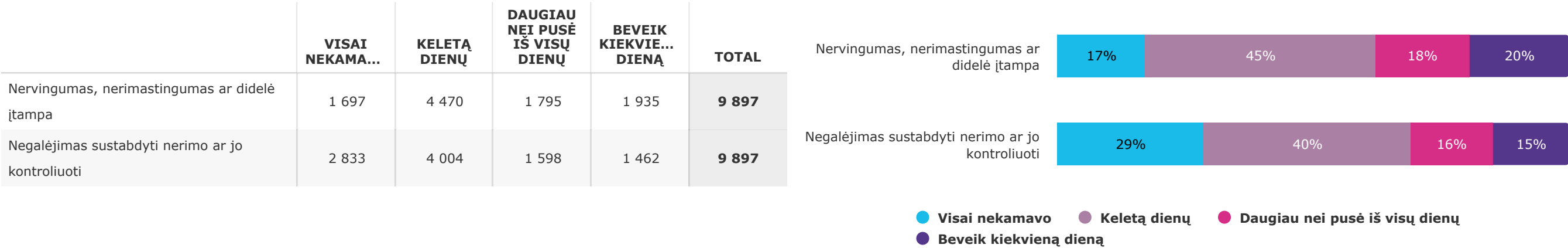
A cut-off score of 3 is widely applied in community and clinical settings to identify individuals who may have clinically significant anxiety symptoms.

**Comparison with general population in the EU and per EU country (IHME estimates for WHO):**

[doi.org/10.1787/health\\_glance\\_eur-2018-en](https://doi.org/10.1787/health_glance_eur-2018-en)



**Combined analysis**



Cross: Status for MH / GAD2 score anxiety

| STATUS FOR MH  | GAD2 SCORE ANXIETY                                     |     |                                         |     |       |      |
|----------------|--------------------------------------------------------|-----|-----------------------------------------|-----|-------|------|
|                | MAY HAVE CLINICALLY<br>SIGNIFICANT ANXIETY<br>SYMPTOMS |     | NO POTENTIAL ANXIETY<br>SYMPTOM PRESENT |     | TOTAL |      |
|                | N                                                      | %   | N                                       | %   | N     | %    |
| PLWRD          | 2 497                                                  | 38% | 4 130                                   | 62% | 6 627 | 100% |
| Parent         | 1 442                                                  | 52% | 1 307                                   | 48% | 2 749 | 100% |
| Spouse/partner | 87                                                     | 44% | 111                                     | 56% | 198   | 100% |
| Other FM       | 117                                                    | 36% | 206                                     | 64% | 323   | 100% |
| TOTAL          | 4 143                                                  | 42% | 5 754                                   | 58% | 9 897 |      |

Under-represented elements  Over-represented elements

The relationship is very significant.  $p\text{-value} = < 0,01$  ;  $\chi^2 = 179,0$  ;  $\text{dof} = 3$ .

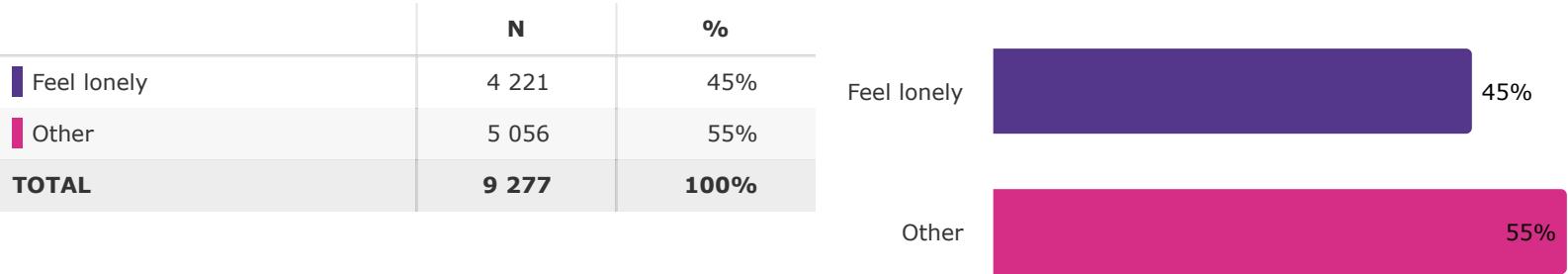
**Loneliness** is commonly defined as the subjective feeling of a discrepancy between desired and actual relationships. It was measured in this survey using the 3 items version of the **UCLA-loneliness scale** (see questions below), widely used and validated in population health research.

A cut-off score of 9 was used to identify people who felt lonely.

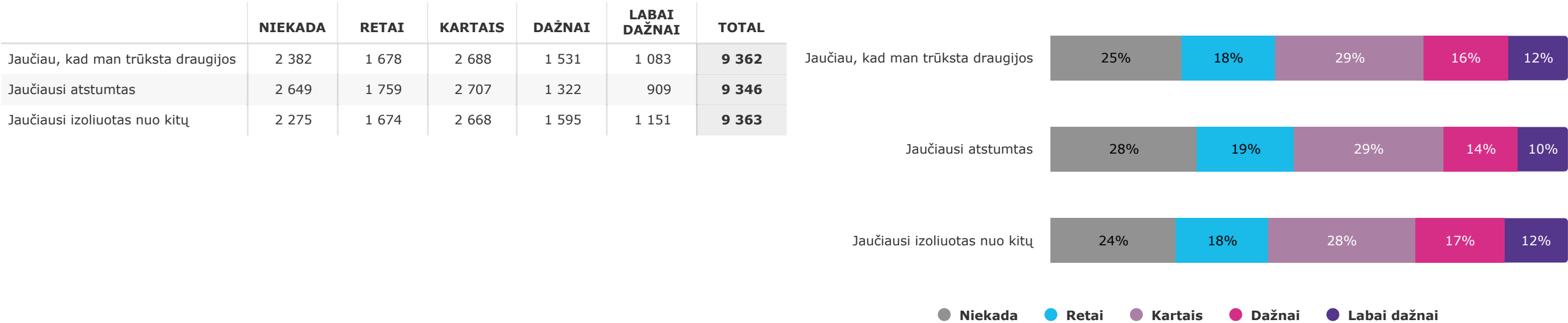
**Comparison with other populations (literature review):**

[doi.org/10.1136/bmj-2021-067068](https://doi.org/10.1136/bmj-2021-067068)

Participants who feel lonely (UCLA loneliness scale >= 9)



Combined analysis



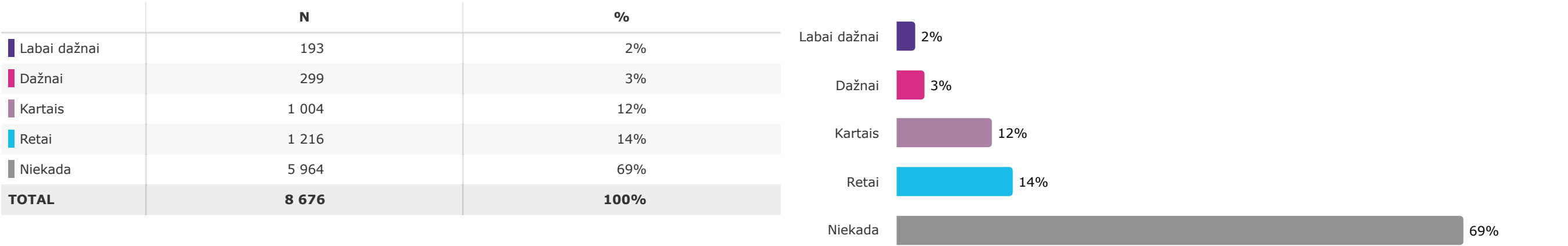
Cross: Status for MH / Participants who feel lonely (UCLA loneliness scale >= 9)

| STATUS FOR MH  | PARTICIPANTS WHO FEEL LONELY (UCLA LONELINESS SCALE >= 9) |     |       |     |       |      |
|----------------|-----------------------------------------------------------|-----|-------|-----|-------|------|
|                | FEEL LONELY                                               |     | OTHER |     | TOTAL |      |
|                | N                                                         | %   | N     | %   | N     | %    |
| PLWRD          | 2 756                                                     | 44% | 3 537 | 56% | 6 293 | 100% |
| Parent         | 1 292                                                     | 51% | 1 229 | 49% | 2 521 | 100% |
| Spouse/partner | 89                                                        | 47% | 99    | 53% | 188   | 100% |
| Other FM       | 84                                                        | 31% | 191   | 69% | 275   | 100% |
| TOTAL          | 4 221                                                     | 45% | 5 056 | 55% | 9 277 |      |

Under-represented elements Over-represented elements

The relationship is very significant. p-value= < 0,01 ; Chi2= 66,0 ; dof= 3.

Pagalvodavau apie savižudybę



Prevalence of suicidal thought for other populations (literature reviews):

[doi.org/10.1017/S003329171900391X](https://doi.org/10.1017/S003329171900391X), [doi.org/10.1080/13811118.2020.1765928](https://doi.org/10.1080/13811118.2020.1765928)

Cross: Status for MH / Pagalvodavau apie savižudybę

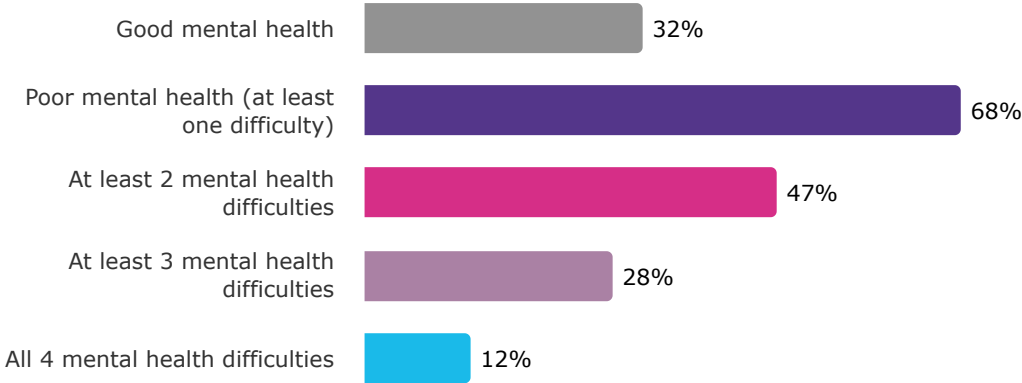
| STATUS FOR MH  | PAGALVODAVAU APIE SAVIŽUDYBĘ |    |        |    |         |     |       |     |         |     |       |      |
|----------------|------------------------------|----|--------|----|---------|-----|-------|-----|---------|-----|-------|------|
|                | LABAI DAŽNAI                 |    | DAŽNAI |    | KARTAIS |     | RETAI |     | NIEKADA |     | TOTAL |      |
|                | N                            | %  | N      | %  | N       | %   | N     | %   | N       | %   | N     | %    |
| PLWRD          | 166                          | 3% | 224    | 4% | 759     | 13% | 883   | 15% | 3 851   | 65% | 5 883 | 100% |
| Parent         | 19                           | 1% | 65     | 3% | 212     | 9%  | 296   | 13% | 1 761   | 75% | 2 353 | 100% |
| Spouse/partner | 3                            | 2% | 2      | 1% | 7       | 4%  | 19    | 11% | 146     | 82% | 177   | 100% |
| Other FM       | 5                            | 2% | 8      | 3% | 26      | 10% | 18    | 7%  | 206     | 78% | 263   | 100% |
| TOTAL          | 193                          | 2% | 299    | 3% | 1 004   | 12% | 1 216 | 14% | 5 964   | 69% | 8 676 |      |

Under-represented elements  Over-represented elements

The relationship is very significant.  $p$ -value= < 0,01 ; Chi2= 120,1 ; dof= 12.

Number of mental health difficulties

|                                              | N     | %   |
|----------------------------------------------|-------|-----|
| Good mental health                           | 3 152 | 32% |
| Poor mental health (at least one difficulty) | 6 745 | 68% |
| At least 2 mental health difficulties        | 4 652 | 47% |
| At least 3 mental health difficulties        | 2 802 | 28% |
| All 4 mental health difficulties             | 1 195 | 12% |
| TOTAL                                        | 9 897 |     |



Cross: Status for MH / Number of mental health difficulties

| STATUS FOR MH  | NUMBER OF MENTAL HEALTH DIFFICULTIES |     |                                              |     |                                       |     |                                       |     |                                  |     |       |   |
|----------------|--------------------------------------|-----|----------------------------------------------|-----|---------------------------------------|-----|---------------------------------------|-----|----------------------------------|-----|-------|---|
|                | GOOD MENTAL HEALTH                   |     | POOR MENTAL HEALTH (AT LEAST ONE DIFFICULTY) |     | AT LEAST 2 MENTAL HEALTH DIFFICULTIES |     | AT LEAST 3 MENTAL HEALTH DIFFICULTIES |     | ALL 4 MENTAL HEALTH DIFFICULTIES |     | TOTAL |   |
|                | N                                    | %   | N                                            | %   | N                                     | %   | N                                     | %   | N                                | %   | N     | % |
| PLWRD          | 2 166                                | 33% | 4 461                                        | 67% | 3 103                                 | 47% | 1 850                                 | 28% | 865                              | 13% | 6 627 |   |
| Parent         | 784                                  | 29% | 1 965                                        | 71% | 1 354                                 | 49% | 849                                   | 31% | 307                              | 11% | 2 749 |   |
| Spouse/partner | 59                                   | 30% | 139                                          | 70% | 87                                    | 44% | 44                                    | 22% | 7                                | 4%  | 198   |   |
| Other FM       | 143                                  | 44% | 180                                          | 56% | 108                                   | 33% | 59                                    | 18% | 16                               | 5%  | 323   |   |
| TOTAL          | 3 152                                | 32% | 6 745                                        | 68% | 4 652                                 | 47% | 2 802                                 | 28% | 1 195                            | 12% | 9 897 |   |

Under-represented elements    Over-represented elements

The relationship is very significant.  $p\text{-value} = < 0,01$  ;  $\chi^2 = 109,1$  ;  $\text{dof} = 12$ .

Cross: Status for MH / Kaip vertintumėte savo gyvenimo kokybę?

| STATUS FOR MH  | KAIP VERTINTUMĖTE SAVO GYVENIMO KOKYBĘ? |    |           |     |                          |     |         |     |               |     |       |      |
|----------------|-----------------------------------------|----|-----------|-----|--------------------------|-----|---------|-----|---------------|-----|-------|------|
|                | 1-LABAI PRASTAI                         |    | 2-PRASTAI |     | 3-NEI PRASTAI, NEI GERAI |     | 4-GERAI |     | 5-LABAI GERAI |     | TOTAL |      |
|                | N                                       | %  | N         | %   | N                        | %   | N       | %   | N             | %   | N     | %    |
| PLWRD          | 312                                     | 5% | 1 495     | 23% | 2 424                    | 37% | 2 135   | 32% | 261           | 4%  | 6 627 | 100% |
| Parent         | 58                                      | 2% | 400       | 15% | 987                      | 36% | 1 121   | 41% | 183           | 7%  | 2 749 | 100% |
| Spouse/partner | 8                                       | 4% | 28        | 14% | 73                       | 37% | 74      | 37% | 15            | 8%  | 198   | 100% |
| Other FM       | 6                                       | 2% | 24        | 7%  | 89                       | 28% | 162     | 50% | 42            | 13% | 323   | 100% |
| TOTAL          | 384                                     | 4% | 1 947     | 20% | 3 573                    | 36% | 3 492   | 35% | 501           | 5%  | 9 897 |      |

Under-represented elements  Over-represented elements

The relationship is very significant. p-value= < 0,01 ; Chi2= 271,5 ; dof= 12.

Comparison with the general population in the EU and EU countries (Eurostat):

[https://ec.europa.eu/eurostat/databrowser/view/ilc\\_pw05\\$dv\\_2768/default/table](https://ec.europa.eu/eurostat/databrowser/view/ilc_pw05$dv_2768/default/table)

Cross: Kaip vertintumėte savo gyvenimo kokybę? / Mental health score

| KAIP VERTINTUMĖTE SAVO GYVENIMO KOKYBĘ? | MENTAL HEALTH SCORE |     |                    |     |       |      |
|-----------------------------------------|---------------------|-----|--------------------|-----|-------|------|
|                                         | POOR MENTAL HEALTH  |     | GOOD MENTAL HEALTH |     | TOTAL |      |
|                                         | N                   | %   | N                  | %   | N     | %    |
| 1-Labai prastai                         | 376                 | 98% | 8                  | 2%  | 384   | 100% |
| 2-Prastai                               | 1 815               | 93% | 132                | 7%  | 1 947 | 100% |
| 3-Nei prastai, nei gerai                | 2 733               | 76% | 840                | 24% | 3 573 | 100% |
| 4-Gerai                                 | 1 689               | 48% | 1 803              | 52% | 3 492 | 100% |
| 5-Labai gerai                           | 132                 | 26% | 369                | 74% | 501   | 100% |
| TOTAL                                   | 6 745               | 68% | 3 152              | 32% | 9 897 |      |

Under-represented elements  Over-represented elements

The relationship is very significant. p-value= < 0,01 ; Chi2= 1 868,0 ; dof= 4.

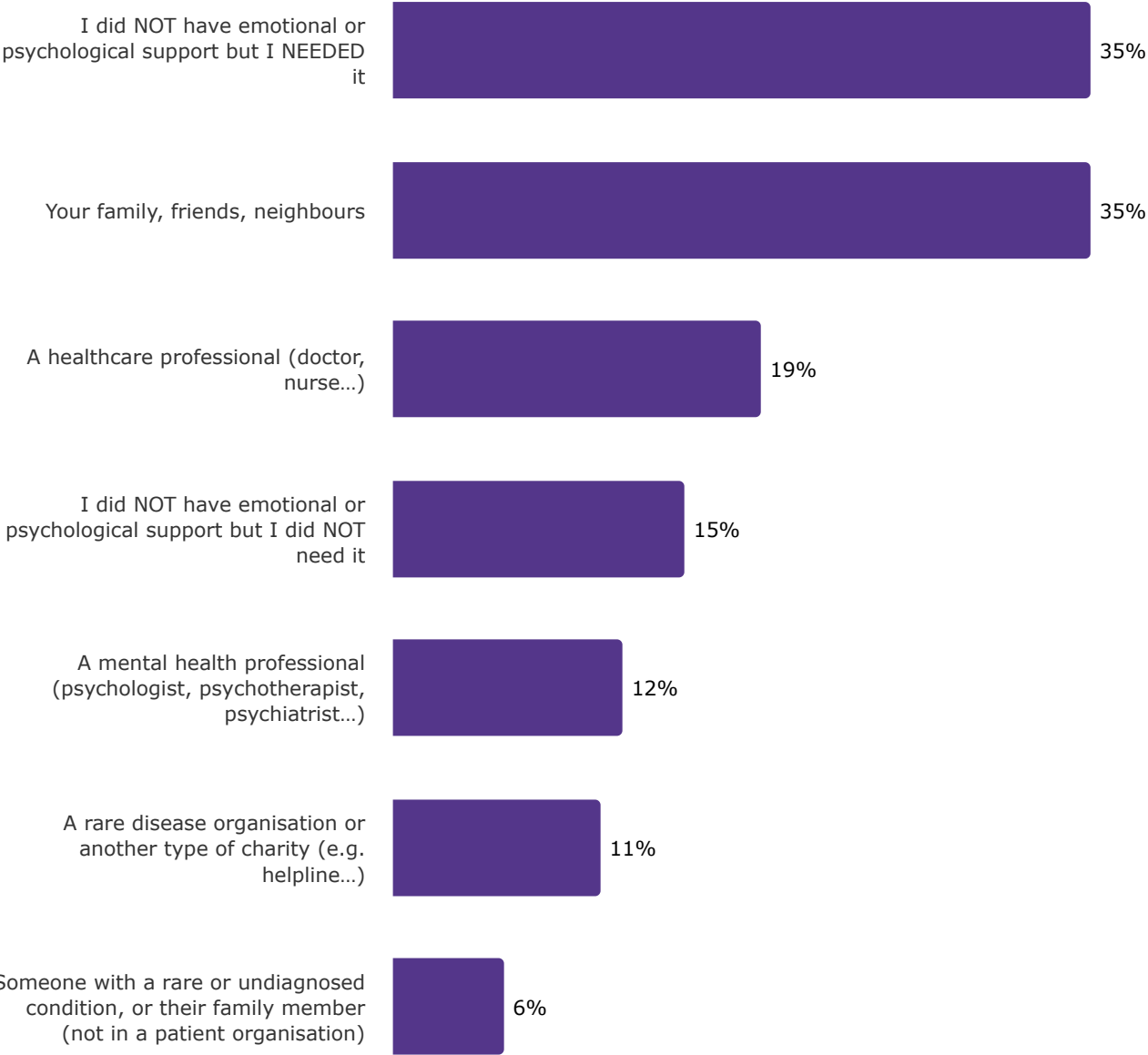


### 3. SUPPORT NEEDED AND RECEIVED

Before diagnosis, at diagnosis, in the last 6-12 months

Since the first symptoms were noticed (while you were still searching for a diagnosis for the rare condition), did YOU receive emotional or psychological support from:

|                                                                                                      | N     | %   |
|------------------------------------------------------------------------------------------------------|-------|-----|
| I did NOT have emotional or psychological support but I NEEDED it                                    | 3 418 | 35% |
| Your family, friends, neighbours                                                                     | 3 417 | 35% |
| A healthcare professional (doctor, nurse...)                                                         | 1 798 | 19% |
| I did NOT have emotional or psychological support but I did NOT need it                              | 1 430 | 15% |
| A mental health professional (psychologist, psychotherapist, psychiatrist...)                        | 1 123 | 12% |
| A rare disease organisation or another type of charity (e.g. helpline...)                            | 1 018 | 11% |
| Someone with a rare or undiagnosed condition, or their family member (not in a patient organisation) | 542   | 6%  |
| TOTAL                                                                                                | 9 631 |     |



Cross: Since the first symptoms were noticed (while you were still searching for a diagnosis for the rare condition), did YOU receive emotional or psychological support from: / Time from first symptoms to initial OR confirmed diagnosis

| SINCE THE FIRST SYMPTOMS WERE NOTICED (WHILE YOU WERE STILL SEARCHING FOR A DIAGNOSIS FOR THE RARE CONDITION), DID YOU RECEIVE EMOTIONAL OR PSYCHOLOGICAL SUPPORT FROM: | TIME FROM FIRST SYMPTOMS TO INITIAL OR CONFIRMED DIAGNOSIS |       |
|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------|-------|
|                                                                                                                                                                         | MEAN                                                       | N     |
| I did NOT have emotional or psychological support but I NEEDED it                                                                                                       | <u>5,3</u>                                                 | 3 042 |
| Someone with a rare or undiagnosed condition, or their family member (not in a patient organisation)                                                                    | 4,9                                                        | 445   |
| A mental health professional (psychologist, psychotherapist, psychiatrist...)                                                                                           | 4,6                                                        | 920   |
| I did NOT have emotional or psychological support but I did NOT need it                                                                                                 | 4,2                                                        | 1 255 |
| Your family, friends, neighbours                                                                                                                                        | <u>3,6</u>                                                 | 2 987 |
| A healthcare professional (doctor, nurse...)                                                                                                                            | <u>3,5</u>                                                 | 1 531 |
| A rare disease organisation or another type of charity (e.g. helpline...)                                                                                               | <u>3,4</u>                                                 | 834   |

Under-represented elements Over-represented elements

The relationship is very significant.  $p\text{-value} = < 0,01$  ; Fisher= 10,9.  
Inter variance= 1 084,3. Intra variance= 99,4.

Cross: Since the first symptoms were noticed (while you were still searching for a diagnosis for the rare condition), did YOU receive emotional or psychological support from: / Time from first symptoms to initial OR confirmed diagnosis

| SINCE THE FIRST SYMPTOMS WERE NOTICED (WHILE YOU WERE STILL SEARCHING FOR A DIAGNOSIS FOR THE RARE CONDITION), DID YOU RECEIVE EMOTIONAL OR PSYCHOLOGICAL SUPPORT FROM: | TIME FROM FIRST SYMPTOMS TO INITIAL OR CONFIRMED DIAGNOSIS |       |
|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------|-------|
|                                                                                                                                                                         | MEAN                                                       | N     |
| I did NOT have emotional or psychological support                                                                                                                       | <u>5,0</u>                                                 | 4 298 |
| A healthcare professional or a mental health professional                                                                                                               | 3,8                                                        | 2 035 |
| The rare disease community (organisation or individual) or a charity                                                                                                    | 3,8                                                        | 1 118 |
| Your family, friends, neighbours                                                                                                                                        | <u>3,6</u>                                                 | 2 987 |

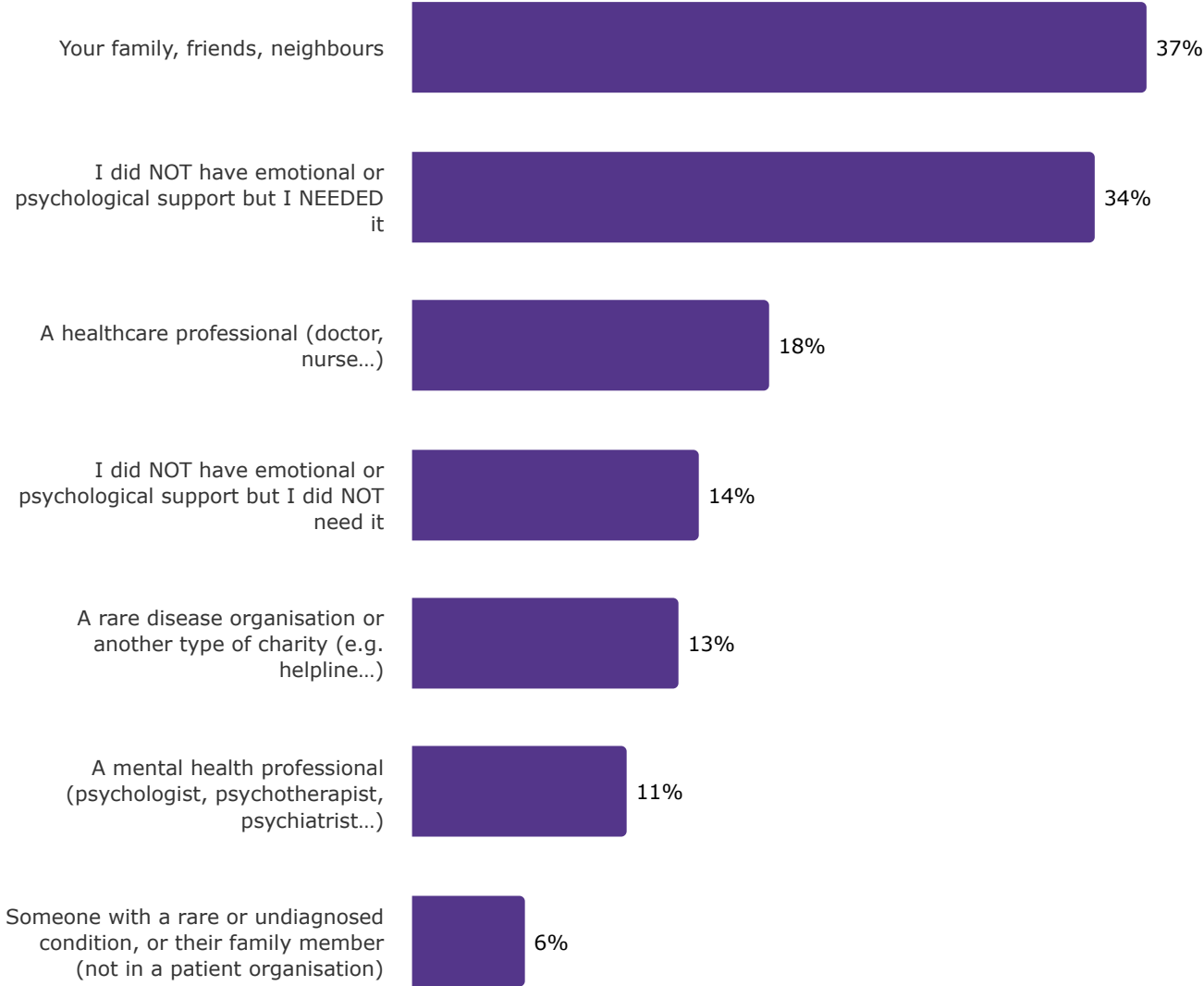
Under-represented elements Over-represented elements

The relationship is very significant.  $p\text{-value} = < 0,01$  ; Fisher= 14,3.  
Inter variance= 1 413,4. Intra variance= 98,6.

This question was only asked to people with a diagnosed rare disease

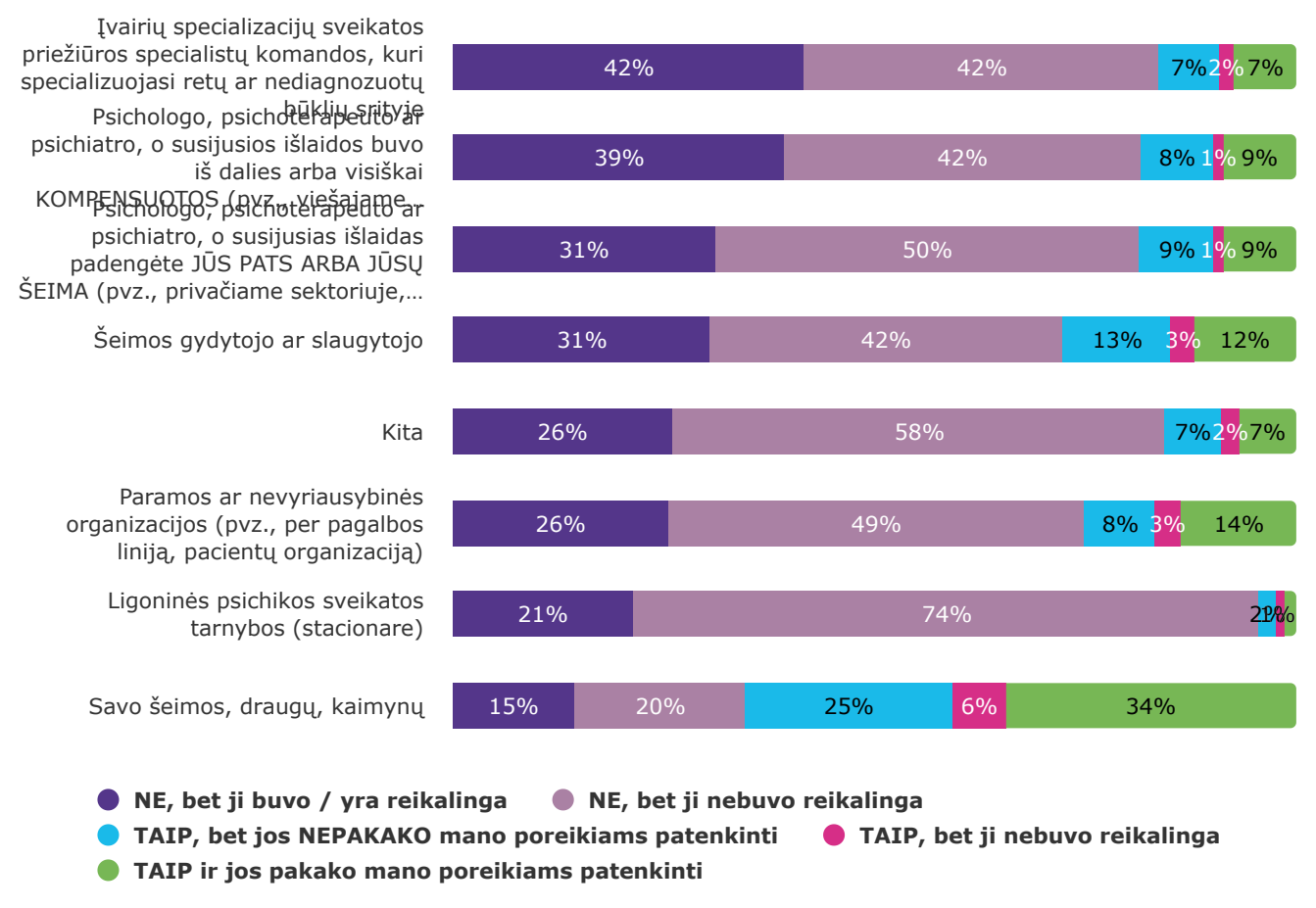
When the diagnosis was announced, did YOU receive emotional or psychological support from:

|                                                                                                        | N            | %   |
|--------------------------------------------------------------------------------------------------------|--------------|-----|
| ■ Your family, friends, neighbours                                                                     | 3 308        | 37% |
| ■ I did NOT have emotional or psychological support but I NEEDED it                                    | 3 078        | 34% |
| ■ A healthcare professional (doctor, nurse...)                                                         | 1 610        | 18% |
| ■ I did NOT have emotional or psychological support but I did NOT need it                              | 1 292        | 14% |
| ■ A rare disease organisation or another type of charity (e.g. helpline...)                            | 1 202        | 13% |
| ■ A mental health professional (psychologist, psychotherapist, psychiatrist...)                        | 968          | 11% |
| ■ Someone with a rare or undiagnosed condition, or their family member (not in a patient organisation) | 507          | 6%  |
| <b>TOTAL</b>                                                                                           | <b>9 010</b> |     |



Ar per pastaruosius 6 mėn. sulaukėte emocinės ar psichologinės pagalbos iš:

|                                                                                                                                                                                               | NE, BET<br>JI BUVO<br>/ YRA<br>REIKAL... | NE, BET<br>JI<br>NEBUVO<br>REIKAL... | TAIP, BET<br>JOS<br>NEPAK...<br>MANO<br>POREIK...<br>PATENK... | TAIP, BET<br>JI<br>NEBUVO<br>REIKAL... | TAIP IR<br>JOS<br>PAKAKO<br>MANO<br>POREIK...<br>PATENK... | TOTAL |
|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------|--------------------------------------|----------------------------------------------------------------|----------------------------------------|------------------------------------------------------------|-------|
| Įvairių specializacijų sveikatos priežiūros specialistų komandos, kuri specializuojasi retų ar nedidelių būklių srityje                                                                       | 3 847                                    | 3 920                                | 655                                                            | 157                                    | 686                                                        | 9 265 |
| Psichologo, psichoterapeuto ar psichiatro, o susijusios išlaidos buvo iš dalies arba visiškai KOMPENSUOTOS (pvz., viešajame sektoriuje, pagal bazinės sveikatos priežiūros nuostatas ir pan.) | 3 649                                    | 3 924                                | 781                                                            | 116                                    | 796                                                        | 9 266 |
| Psichologo, psichoterapeuto ar psichiatro, o susijusias išlaidas padengėte JŪS PATS ARBA JŪSŲ ŠEIMA (pvz., privačiame sektoriuje, už bazinės sveikatos priežiūros sistemos ribų ir pan.)      | 2 891                                    | 4 654                                | 813                                                            | 107                                    | 801                                                        | 9 266 |
| Šeimos gydytojo ar slaugytojo                                                                                                                                                                 | 3 833                                    | 3 867                                | 1 103                                                          | 263                                    | 1 111                                                      | 9 265 |



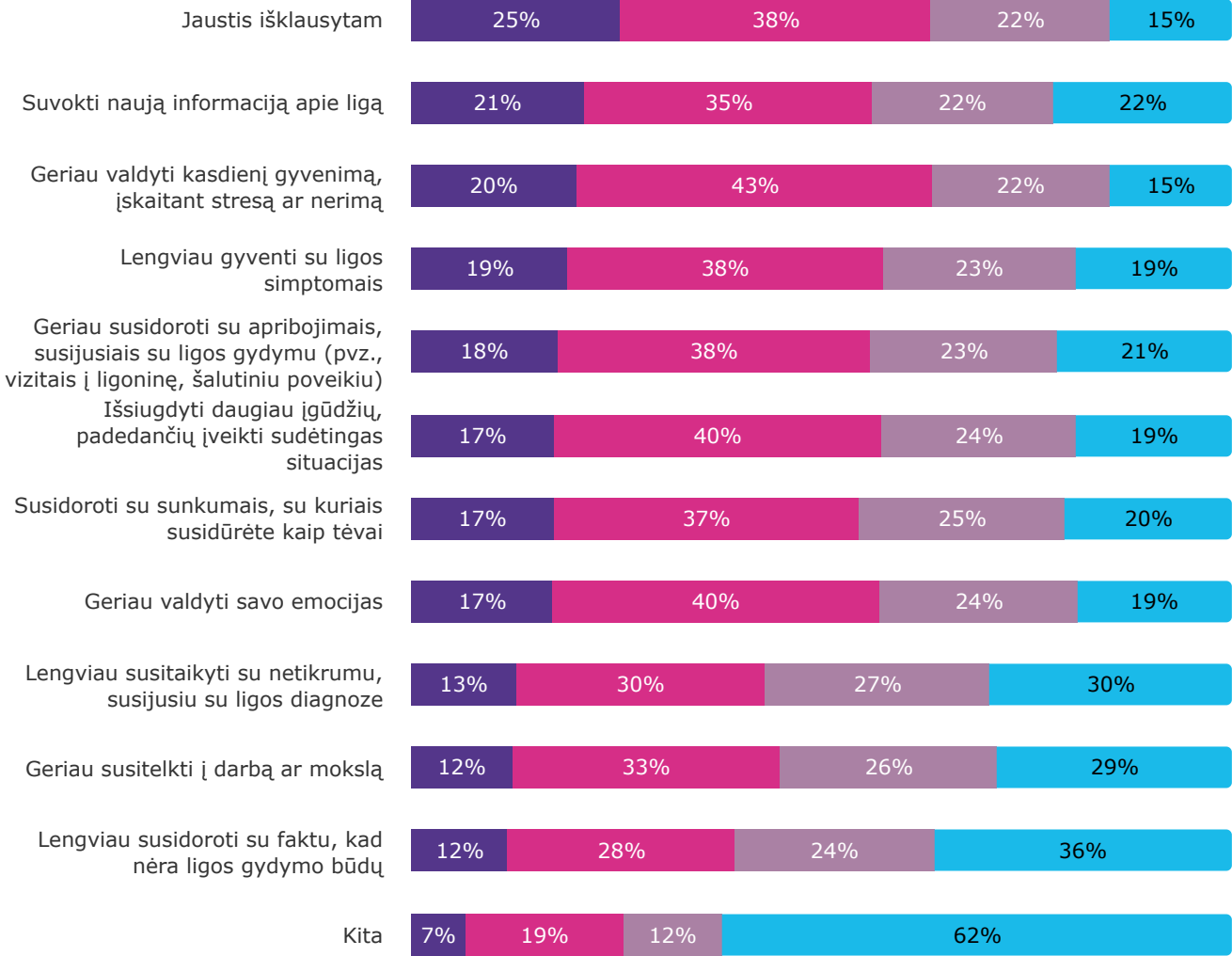
| Needs from professional psychological support over the past six months |       |      |
|------------------------------------------------------------------------|-------|------|
|                                                                        | N     | %    |
| NEEDS professional psychological support                               | 6 799 | 73%  |
| NO need for pro psy support                                            | 2 466 | 27%  |
| TOTAL                                                                  | 9 265 | 100% |

| Professional psychological support in the last six months |       |      |
|-----------------------------------------------------------|-------|------|
|                                                           | N     | %    |
| Professional psychological support                        | 4 529 | 49%  |
| NO pro psy support                                        | 4 736 | 51%  |
| TOTAL                                                     | 9 265 | 100% |

Only people who received emotional or psychological support

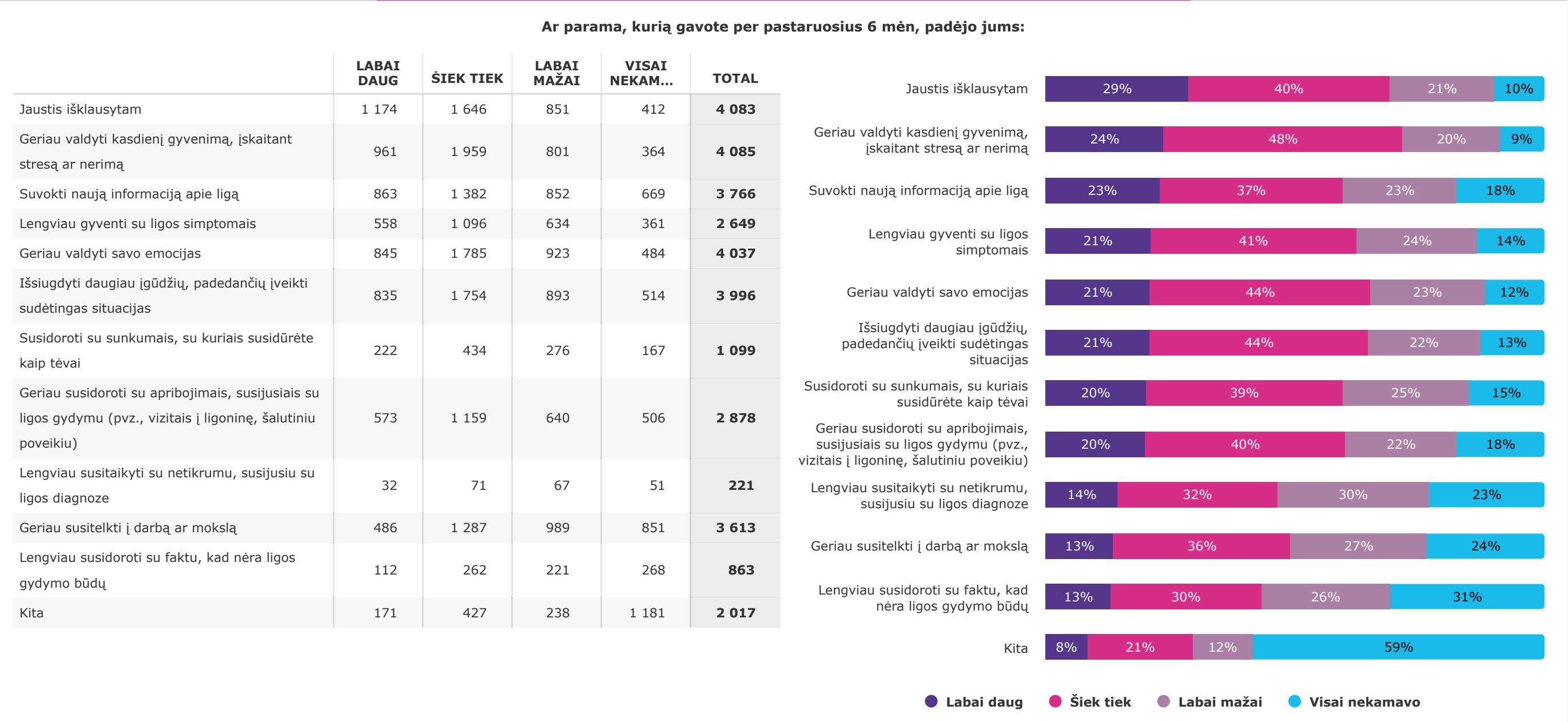
Ar parama, kurią gavote per pastaruosius 6 mėn, padėjo jums:

|                                                                                                                | LABAI DAUG | ŠIEK TIEK | LABAI MAŽAI | VISAI NEKAM... | TOTAL |
|----------------------------------------------------------------------------------------------------------------|------------|-----------|-------------|----------------|-------|
| Jaustis išklausytam                                                                                            | 1 843      | 2 762     | 1 577       | 1 088          | 7 270 |
| Suvokti naują informaciją apie ligą                                                                            | 1 423      | 2 361     | 1 479       | 1 475          | 6 738 |
| Geriau valdyti kasdienį gyvenimą, įskaitant stresą ar nerimą                                                   | 1 438      | 3 105     | 1 545       | 1 066          | 7 154 |
| Lengviau gyventi su ligos simptomais                                                                           | 887        | 1 791     | 1 092       | 885            | 4 655 |
| Geriau susidoroti su apribojimais, susijusiais su ligos gydymu (pvz., vizitais į ligoninę, šalutiniu poveikiu) | 890        | 1 903     | 1 136       | 1 062          | 4 991 |
| Išsiugdyti daugiau įgūdžių, padedančių įveikti sudėtingas situacijas                                           | 1 213      | 2 783     | 1 654       | 1 326          | 6 976 |
| Susidoroti su sunkumais, su kuriais susidūrėte kaip tėvai                                                      | 349        | 748       | 500         | 411            | 2 008 |
| Geriau valdyti savo emocijas                                                                                   | 1 208      | 2 807     | 1 689       | 1 322          | 7 026 |
| Lengviau susitaikyti su netikrumu, susijusiu su ligos diagnoze                                                 | 49         | 115       | 104         | 113            | 381   |
| Geriau susitelkti į darbą ar mokslą                                                                            | 779        | 2 073     | 1 666       | 1 823          | 6 341 |
| Lengviau susidoroti su faktu, kad nėra ligos gydymo būdų                                                       | 191        | 458       | 403         | 596            | 1 648 |
| Kita                                                                                                           | 247        | 723       | 446         | 2 316          | 3 732 |



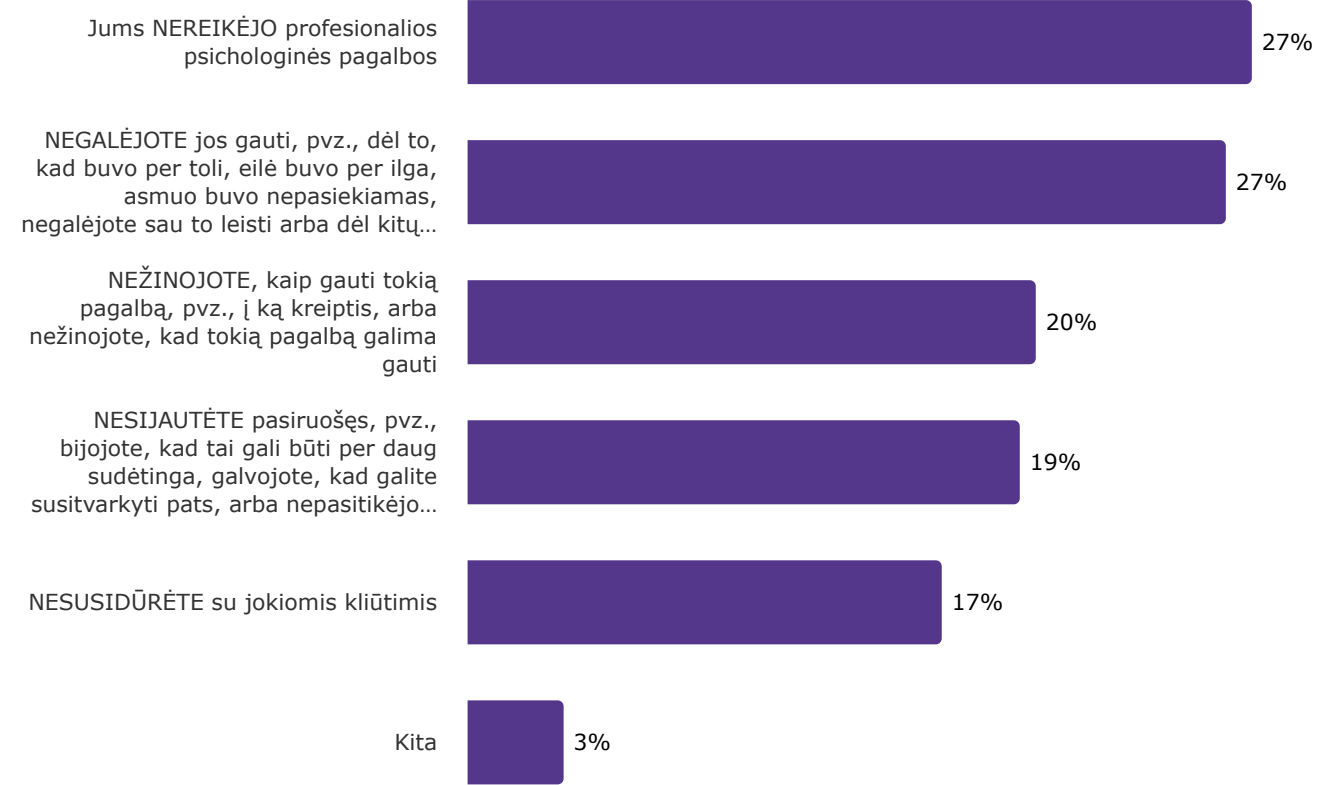
● Labai daug ● Šiek tiek ● Labai mažai ● Visai nekamavo

Only people who received PROFESSIONAL PSYCHOLOGICAL support



Ar kuris nors iš šių dalykų kada nors jus sustabdė nuo profesionalios psichologinės pagalbos?

|                                                                                                                                                                | N     | %   |
|----------------------------------------------------------------------------------------------------------------------------------------------------------------|-------|-----|
| Jums NEREIKĖJO profesionalios psichologinės pagalbos                                                                                                           | 2 463 | 27% |
| NEGALĖJOTE jos gauti, pvz., dėl to, kad buvo per toli, eilė buvo per ilga, asmuo buvo nepasiekiamas, negalėjote sau to leisti arba dėl kitų logistinių kliūčių | 2 382 | 27% |
| NEŽINOJOTE, kaip gauti tokią pagalbą, pvz., į ką kreiptis, arba nežinojote, kad tokią pagalbą galima gauti                                                     | 1 781 | 20% |
| NESIJAUTĖTE pasiruošęs, pvz., bijojote, kad tai gali būti per daug sudėtinga, galvojote, kad galite susitvarkyti pats, arba nepasitikėjote asmeniu             | 1 731 | 19% |
| NESUSIDŪRĖTE su jokiais kliūtimis                                                                                                                              | 1 486 | 17% |
| Kita                                                                                                                                                           | 301   | 3%  |
| TOTAL                                                                                                                                                          | 8 979 |     |



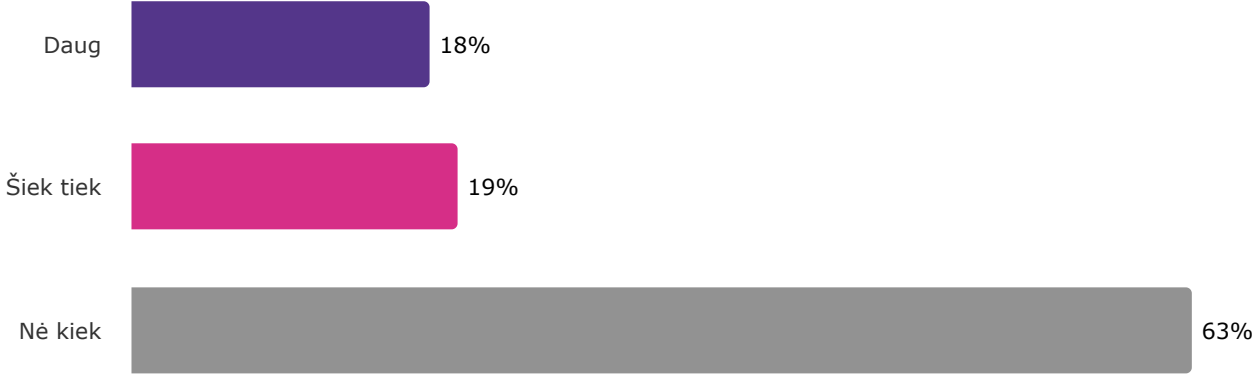
| Mental health score |       |      |                    |
|---------------------|-------|------|--------------------|
|                     | N     | %    |                    |
| Poor mental health  | 1 008 | 41%  | Poor mental health |
| Good mental health  | 1 455 | 59%  | Good mental health |
| TOTAL               | 2 463 | 100% |                    |

Sample information : [Limit\_access\_psy\_support] In "4"

Only participants who accessed  
professional psychological support:

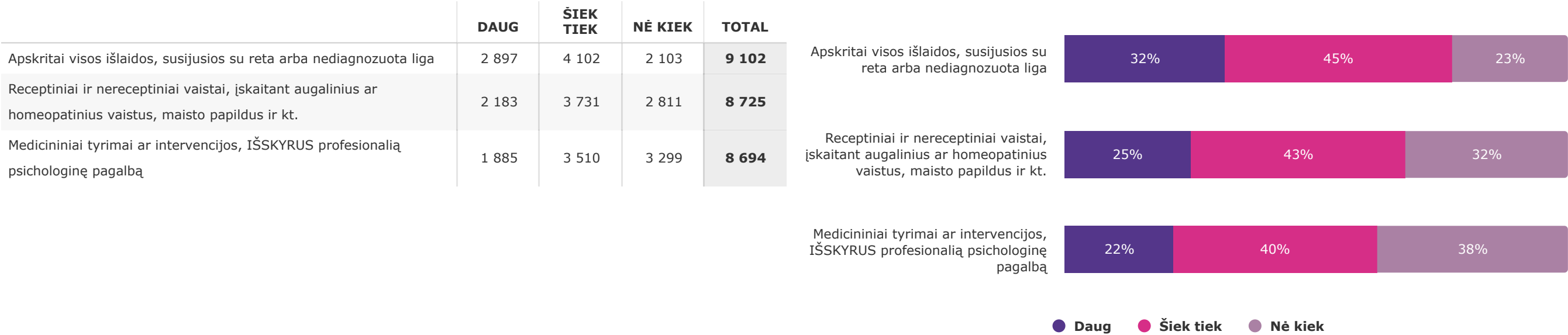
Profesionali psihologinē pagalba

|              | N            | %           |
|--------------|--------------|-------------|
| Daug         | 393          | 18%         |
| Šiek tiek    | 430          | 19%         |
| Nē kiek      | 1 401        | 63%         |
| <b>TOTAL</b> | <b>2 224</b> | <b>100%</b> |



▼ Sample information : [Pro\_psy\_support] = "2"

Combined analysis



Comparison with the general population in the EU and EU countries (Eurostat):

[https://ec.europa.eu/eurostat/databrowser/view/ilc\\_hch01\\_custom\\_21139489/default/table](https://ec.europa.eu/eurostat/databrowser/view/ilc_hch01_custom_21139489/default/table)

Question on reported-experience of discrimination was only asked to people living with a rare disease themselves (not to their family members)

Ar kada nors patyrėte diskriminaciją dėl retos ligos arba negalios?

33%

Socialinėje aplinkoje (bendraujant šeimoje, su giminaičiais, draugais, kaimynais ir pan.)

Cross: Ar kada nors patyrėte diskriminaciją dėl retos ligos arba negalios? / Mental health score

| AR KADA NORS PATYRĖTE DISKRIMINACIJĄ DĖL RETOS LIGOS ARBA NEGALIOS?                       | MENTAL HEALTH SCORE |            |                    |            |       |      |
|-------------------------------------------------------------------------------------------|---------------------|------------|--------------------|------------|-------|------|
|                                                                                           | POOR MENTAL HEALTH  |            | GOOD MENTAL HEALTH |            | TOTAL |      |
|                                                                                           | N                   | %          | N                  | %          | N     | %    |
| Socialinėje aplinkoje (bendraujant šeimoje, su giminaičiais, draugais, kaimynais ir pan.) | <u>1 808</u>        | <u>85%</u> | <u>327</u>         | <u>15%</u> | 2 135 | 100% |
| Sveikatos priežiūros įstaigoje                                                            | <u>1 538</u>        | <u>83%</u> | <u>310</u>         | <u>17%</u> | 1 848 | 100% |
| Mieste (viešbutis, restoranai, transportas, muziejai ir pan.)                             | <u>1 248</u>        | <u>80%</u> | <u>314</u>         | <u>20%</u> | 1 562 | 100% |
| Dirbant ar mokantis                                                                       | <u>1 809</u>        | <u>80%</u> | <u>459</u>         | <u>20%</u> | 2 268 | 100% |
| Other                                                                                     | 114                 | 73%        | 43                 | 27%        | 157   | 100% |
| Niekada                                                                                   | <u>1 256</u>        | <u>51%</u> | <u>1 218</u>       | <u>49%</u> | 2 474 | 100% |
| TOTAL                                                                                     | 4 343               | 68%        | 2 080              | 32%        | 6 423 |      |

Under-represented elements Over-represented elements

The relationship is very significant. p-value= < 0,01 ; Chi2= 1 072,5 ; dof= 5.



## 4. THE IMPACT OF LIVING WITH A RARE DISEASE ON MENTAL HEALTH

Public support, personal assistant, living arrangements

| Cross: Status for MH / Iš esmės, kaip manote, ar jūsų sveikata yra |                                             |    |           |     |                          |     |         |     |               |     |       |      |
|--------------------------------------------------------------------|---------------------------------------------|----|-----------|-----|--------------------------|-----|---------|-----|---------------|-----|-------|------|
| STATUS FOR MH                                                      | IŠ ESMĖS, KAIP MANOTE, AR JŪSŲ SVEIKATA YRA |    |           |     |                          |     |         |     |               |     |       |      |
|                                                                    | 1-LABAI PRASTAI                             |    | 2-PRASTAI |     | 3-NEI PRASTAI, NEI GERAI |     | 4-GERAI |     | 5-LABAI GERAI |     | TOTAL |      |
|                                                                    | N                                           | %  | N         | %   | N                        | %   | N       | %   | N             | %   | N     | %    |
| PLWRD                                                              | 340                                         | 5% | 2 140     | 32% | 2 571                    | 39% | 1 441   | 22% | 135           | 2%  | 6 627 | 100% |
| Parent                                                             | 33                                          | 1% | 333       | 12% | 927                      | 34% | 1 230   | 45% | 226           | 8%  | 2 749 | 100% |
| Spouse/partner                                                     | 7                                           | 4% | 22        | 11% | 64                       | 32% | 86      | 43% | 19            | 10% | 198   | 100% |
| Other FM                                                           | 6                                           | 2% | 28        | 9%  | 92                       | 28% | 157     | 49% | 40            | 12% | 323   | 100% |
| TOTAL                                                              | 386                                         | 4% | 2 523     | 25% | 3 654                    | 37% | 2 914   | 29% | 420           | 4%  | 9 897 |      |

Under-represented elements

Over-represented elements

The relationship is very significant. *p-value= < 0,01 ; Chi2= 1 114,8 ; dof= 12.*

| Cross: Iš esmės, kaip manote, ar jūsų sveikata yra / Mental health score |                     |     |                    |     |       |      |
|--------------------------------------------------------------------------|---------------------|-----|--------------------|-----|-------|------|
| IŠ ESMĖS, KAIP MANOTE, AR JŪSŲ SVEIKATA YRA                              | MENTAL HEALTH SCORE |     |                    |     |       |      |
|                                                                          | POOR MENTAL HEALTH  |     | GOOD MENTAL HEALTH |     | TOTAL |      |
|                                                                          | N                   | %   | N                  | %   | N     | %    |
| 1-Labai prastai                                                          | 366                 | 95% | 20                 | 5%  | 386   | 100% |
| 2-Prastai                                                                | 2 187               | 87% | 336                | 13% | 2 523 | 100% |
| 3-Nei prastai, nei gerai                                                 | 2 586               | 71% | 1 068              | 29% | 3 654 | 100% |
| 4-Gerai                                                                  | 1 458               | 50% | 1 456              | 50% | 2 914 | 100% |
| 5-Labai gerai                                                            | 148                 | 35% | 272                | 65% | 420   | 100% |
| TOTAL                                                                    | 6 745               | 68% | 3 152              | 32% | 9 897 |      |

Under-represented elements

Over-represented elements

The relationship is very significant. *p-value= < 0,01 ; Chi2= 1 187,5 ; dof= 4.*

Cross: Status for MH / Ar per pastaruosius 3 mėnesius jus dažnai vargino SKAUSMAS? Ar sakytumėte, kad...

| STATUS FOR MH  | AR PER PASTARUOSIUS 3 MĖNESIUS JUS DAŽNAI VARGINO SKAUSMAS? AR SAKYTUMĖTE, KAD... |     |            |     |          |     |           |     |       |      |
|----------------|-----------------------------------------------------------------------------------|-----|------------|-----|----------|-----|-----------|-----|-------|------|
|                | 1-NIEKADA                                                                         |     | 2-KAI KADA |     | 3-DAŽNAI |     | 4-KASDIEN |     | TOTAL |      |
|                | N                                                                                 | %   | N          | %   | N        | %   | N         | %   | N     | %    |
| PLWRD          | 868                                                                               | 13% | 2 362      | 36% | 1 450    | 22% | 1 947     | 29% | 6 627 | 100% |
| Parent         | 460                                                                               | 17% | 1 504      | 55% | 521      | 19% | 264       | 10% | 2 749 | 100% |
| Spouse/partner | 42                                                                                | 21% | 93         | 47% | 39       | 20% | 24        | 12% | 198   | 100% |
| Other FM       | 72                                                                                | 22% | 179        | 55% | 40       | 12% | 32        | 10% | 323   | 100% |
| TOTAL          | 1 442                                                                             | 15% | 4 138      | 42% | 2 050    | 21% | 2 267     | 23% | 9 897 |      |

Under-represented elements  Over-represented elements

The relationship is very significant. p-value= < 0,01 ; Chi2= 610,1 ; dof= 9.

Cross: Ar per pastaruosius 3 mėnesius jus dažnai vargino SKAUSMAS? Ar sakytumėte, kad... / Mental health score

| AR PER PASTARUOSIUS 3 MĖNESIUS JUS DAŽNAI VARGINO SKAUSMAS? AR SAKYTUMĖTE, KAD... | MENTAL HEALTH SCORE |     |                    |     |       |      |
|-----------------------------------------------------------------------------------|---------------------|-----|--------------------|-----|-------|------|
|                                                                                   | POOR MENTAL HEALTH  |     | GOOD MENTAL HEALTH |     | TOTAL |      |
|                                                                                   | N                   | %   | N                  | %   | N     | %    |
| 1-Niekada                                                                         | 632                 | 44% | 810                | 56% | 1 442 | 100% |
| 2-Kai kada                                                                        | 2 559               | 62% | 1 579              | 38% | 4 138 | 100% |
| 3-Dažnai                                                                          | 1 635               | 80% | 415                | 20% | 2 050 | 100% |
| 4-Kasdien                                                                         | 1 919               | 85% | 348                | 15% | 2 267 | 100% |
| TOTAL                                                                             | 6 745               | 68% | 3 152              | 32% | 9 897 |      |

Under-represented elements  Over-represented elements

The relationship is very significant. p-value= < 0,01 ; Chi2= 880,4 ; dof= 3.

Cross: Status for MH / Ar per pastaruosius 6 ir daugiau mėnesių jums dėl sveikatos problemos teko riboti veiklą, kuria paprastai užsiima žmonės? Ar sakytumėte, kad...

| STATUS FOR MH  | AR PER PASTARUOSIUS 6 IR DAUGIAU MĖNESIŲ JUMS DĖL SVEIKATOS PROBLEMOS TEKO RIBOTI VEIKLĄ, KURIA PAPRASTAI UŽSIIMA ŽMONĖS? AR SAKYTUMĖTE, KAD... |     |                    |     |                     |     |       |      |
|----------------|-------------------------------------------------------------------------------------------------------------------------------------------------|-----|--------------------|-----|---------------------|-----|-------|------|
|                | LABAI APRIBOTA                                                                                                                                  |     | ŠIEK TIEK APRIBOTA |     | VISIŠKAI NEAPRIBOTA |     | TOTAL |      |
|                | N                                                                                                                                               | %   | N                  | %   | N                   | %   | N     | %    |
| PLWRD          | 2 157                                                                                                                                           | 33% | 3 779              | 57% | 691                 | 10% | 6 627 | 100% |
| Parent         | 327                                                                                                                                             | 12% | 1 328              | 48% | 1 094               | 40% | 2 749 | 100% |
| Spouse/partner | 39                                                                                                                                              | 20% | 86                 | 43% | 73                  | 37% | 198   | 100% |
| Other FM       | 32                                                                                                                                              | 10% | 131                | 41% | 160                 | 50% | 323   | 100% |
| TOTAL          | 2 555                                                                                                                                           | 26% | 5 324              | 54% | 2 018               | 20% | 9 897 |      |

Under-represented elements  Over-represented elements

The relationship is very significant. p-value= < 0,01 ; Chi2= 1 391,2 ; dof= 6.

Cross: Ar per pastaruosius 6 ir daugiau mėnesių jums dėl sveikatos problemos teko riboti veiklą, kuria paprastai užsiima žmonės? Ar sakytumėte, kad... / Mental health score

Comparison with the general population in the EU and EU countries (Eurostat):  
[https://ec.europa.eu/eurostat/databrowser/view/hlth\\_silc\\_12/default/table?lang=en&category=dsb.dsb\\_p.dsb\\_pgali](https://ec.europa.eu/eurostat/databrowser/view/hlth_silc_12/default/table?lang=en&category=dsb.dsb_p.dsb_pgali)

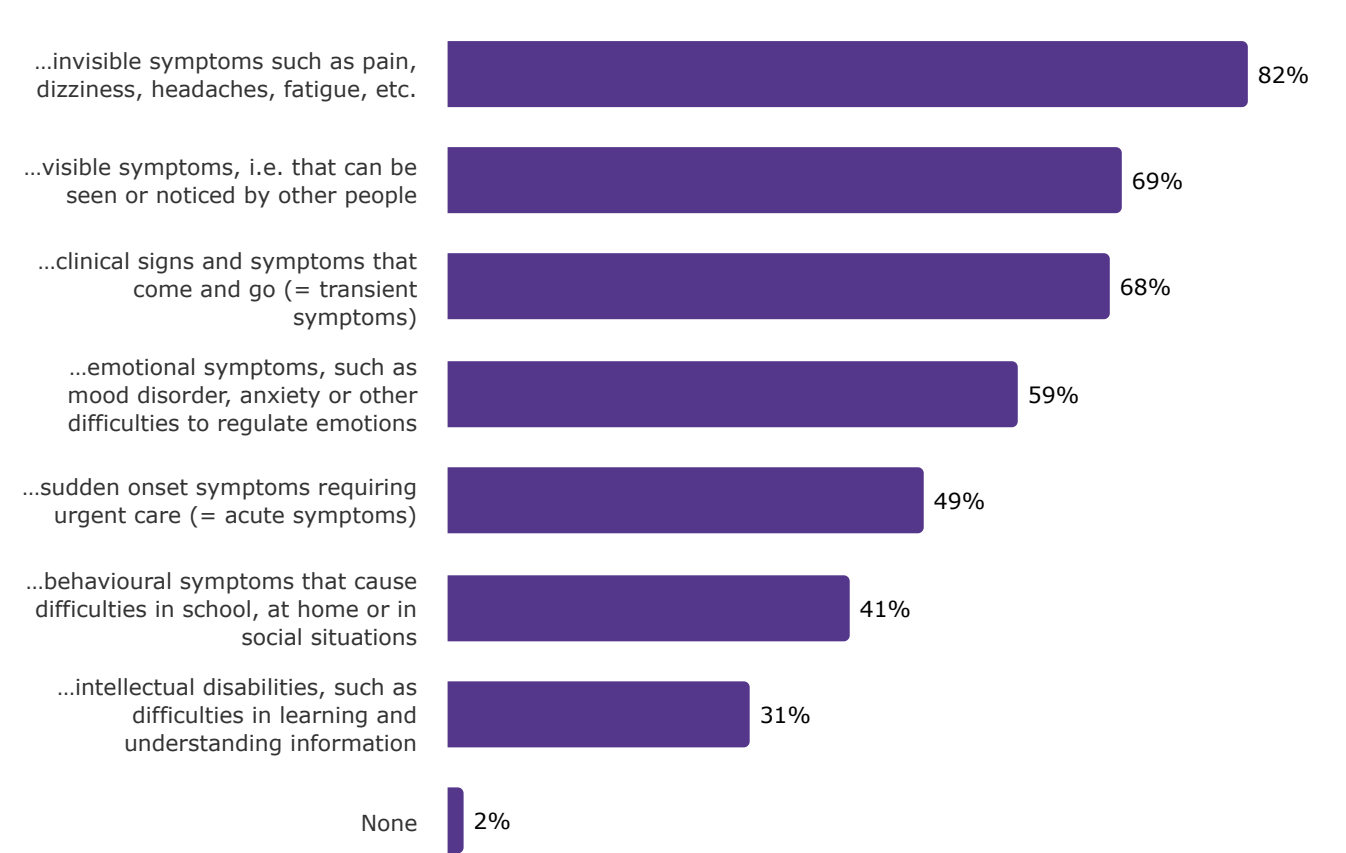
| AR PER PASTARUOSIUS 6 IR DAUGIAU MĖNESIŲ JUMS DĖL SVEIKATOS PROBLEMOS TEKO RIBOTI VEIKLĄ, KURIA PAPRASTAI UŽSIIMA ŽMONĖS? AR SAKYTUMĖTE, KAD... | MENTAL HEALTH SCORE |     |                    |     |       |      |
|-------------------------------------------------------------------------------------------------------------------------------------------------|---------------------|-----|--------------------|-----|-------|------|
|                                                                                                                                                 | POOR MENTAL HEALTH  |     | GOOD MENTAL HEALTH |     | TOTAL |      |
|                                                                                                                                                 | N                   | %   | N                  | %   | N     | %    |
| Labai apribota                                                                                                                                  | 2 197               | 86% | 358                | 14% | 2 555 | 100% |
| Šiek tiek apribota                                                                                                                              | 3 598               | 68% | 1 726              | 32% | 5 324 | 100% |
| Visiškai neapribota                                                                                                                             | 950                 | 47% | 1 068              | 53% | 2 018 | 100% |
| TOTAL                                                                                                                                           | 6 745               | 68% | 3 152              | 32% | 9 897 |      |

Under-represented elements  Over-represented elements

The relationship is very significant. p-value= < 0,01 ; Chi2= 788,3 ; dof= 2.

Symptoms multiple use

|                                                                                                  | N     | %   |
|--------------------------------------------------------------------------------------------------|-------|-----|
| ...invisible symptoms such as pain, dizziness, headaches, fatigue, etc.                          | 8 114 | 82% |
| ...visible symptoms, i.e. that can be seen or noticed by other people                            | 6 832 | 69% |
| ...clinical signs and symptoms that come and go (= transient symptoms)                           | 6 721 | 68% |
| ...emotional symptoms, such as mood disorder, anxiety or other difficulties to regulate emotions | 5 792 | 59% |
| ...sudden onset symptoms requiring urgent care (= acute symptoms)                                | 4 822 | 49% |
| ...behavioural symptoms that cause difficulties in school, at home or in social situations       | 4 086 | 41% |
| ...intellectual disabilities, such as difficulties in learning and understanding information     | 3 059 | 31% |
| None                                                                                             | 155   | 2%  |
| TOTAL                                                                                            | 9 896 |     |



Results ONLY for people living with a rare or undiagnosed condition



Cross: Symptoms multiple use / Mental health score

| SYMPTOMS MULTIPLE USE                                                                            | MENTAL HEALTH SCORE |     |                    |     |       |      |
|--------------------------------------------------------------------------------------------------|---------------------|-----|--------------------|-----|-------|------|
|                                                                                                  | POOR MENTAL HEALTH  |     | GOOD MENTAL HEALTH |     | TOTAL |      |
|                                                                                                  | N                   | %   | N                  | %   | N     | %    |
| ...intellectual disabilities, such as difficulties in learning and understanding information     | 959                 | 86% | 159                | 14% | 1 118 | 100% |
| ...emotional symptoms, such as mood disorder, anxiety or other difficulties to regulate emotions | 2 832               | 81% | 680                | 19% | 3 512 | 100% |
| ...behavioural symptoms that cause difficulties in school, at home or in social situations       | 1 644               | 81% | 396                | 19% | 2 040 | 100% |
| ...sudden onset symptoms requiring urgent care (= acute symptoms)                                | 2 320               | 72% | 916                | 28% | 3 236 | 100% |
| ...clinical signs and symptoms that come and go (= transient symptoms)                           | 3 358               | 70% | 1 439              | 30% | 4 797 | 100% |
| ...invisible symptoms such as pain, dizziness, headaches, fatigue, etc.                          | 4 128               | 70% | 1 789              | 30% | 5 917 | 100% |
| ...visible symptoms, i.e. that can be seen or noticed by other people                            | 2 873               | 68% | 1 367              | 32% | 4 240 | 100% |
| None                                                                                             | 37                  | 39% | 58                 | 61% | 95    | 100% |
| TOTAL                                                                                            | 4 461               | 67% | 2 165              | 33% | 6 626 |      |

■ Under-represented elements ■ Over-represented elements

The relationship is very significant. p-value= < 0,01 ; Chi2= 713,9 ; dof= 7.

▼ Sample information : Status\_for\_MH among "PLWRD"

Results ONLY for PARENTS of people living with a rare or undiagnosed condition



Cross: Symptoms multiple use / Mental health score

| SYMPTOMS MULTIPLE USE                                                                            | MENTAL HEALTH SCORE |            |                    |            |       |      |
|--------------------------------------------------------------------------------------------------|---------------------|------------|--------------------|------------|-------|------|
|                                                                                                  | POOR MENTAL HEALTH  |            | GOOD MENTAL HEALTH |            | TOTAL |      |
|                                                                                                  | N                   | %          | N                  | %          | N     | %    |
| ...sudden onset symptoms requiring urgent care (= acute symptoms)                                | <u>1 032</u>        | <u>78%</u> | <u>293</u>         | <u>22%</u> | 1 325 | 100% |
| ...behavioural symptoms that cause difficulties in school, at home or in social situations       | <u>1 382</u>        | <u>77%</u> | <u>411</u>         | <u>23%</u> | 1 793 | 100% |
| ...emotional symptoms, such as mood disorder, anxiety or other difficulties to regulate emotions | <u>1 480</u>        | <u>77%</u> | <u>446</u>         | <u>23%</u> | 1 926 | 100% |
| ...intellectual disabilities, such as difficulties in learning and understanding information     | <u>1 324</u>        | <u>75%</u> | <u>431</u>         | <u>25%</u> | 1 755 | 100% |
| ...clinical signs and symptoms that come and go (= transient symptoms)                           | <u>1 215</u>        | <u>75%</u> | <u>397</u>         | <u>25%</u> | 1 612 | 100% |
| ...invisible symptoms such as pain, dizziness, headaches, fatigue, etc.                          | <u>1 351</u>        | <u>75%</u> | <u>455</u>         | <u>25%</u> | 1 806 | 100% |
| ...visible symptoms, i.e. that can be seen or noticed by other people                            | <u>1 595</u>        | <u>73%</u> | <u>592</u>         | <u>27%</u> | 2 187 | 100% |
| None                                                                                             | <u>14</u>           | <u>44%</u> | <u>18</u>          | <u>56%</u> | 32    | 100% |
| TOTAL                                                                                            | 1 965               | 71%        | 784                | 29%        | 2 749 |      |

Under-represented elements  Over-represented elements

The relationship is very significant.  $p\text{-value} = < 0,01$  ;  $\text{Chi}^2 = 131,0$  ;  $\text{dof} = 7$ .

▼ Sample information : Status\_for\_MH among "Parent"

| Combined analysis                                                                                                                                                            |            |                |        |                |           |
|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------|----------------|--------|----------------|-----------|
|                                                                                                                                                                              | MEAN       | LOWER QUARTILE | MEDIAN | UPPER QUARTILE | FREQUENCY |
| Kokią įtaką liga daro jūsų gyvenimui?<br>0 = jokios; 10 = labai didelę                                                                                                       | <u>7,5</u> | 6,0            | 8,0    | 10,0           | 9 859     |
| Kaip manote, kiek ilgai tęsis būklė?<br>0 = labai trumpai; 10 = visada                                                                                                       | <u>9,6</u> | 10,0           | 10,0   | 10,0           | 9 859     |
| Kaip manote, kiek galite kontroliuoti savo būklę?<br>0 = visiškai nekontroliuojate; 10 = labai kontroliuojate                                                                | <u>4,2</u> | 2,0            | 4,0    | 6,0            | 9 859     |
| Kaip manote, kiek gydymas gali padėti šios būklės atveju?<br>0 = visiškai nepadeda; 10 = labai padeda                                                                        | <u>6,1</u> | 4,0            | 6,0    | 8,0            | 7 115     |
| Kiek jaučiate savo būklės simptomus?<br>0 = visiškai jokių; 10 = daug sunkių simptomų                                                                                        | <u>6,9</u> | 6,0            | 7,0    | 9,0            | 6 377     |
| Kiek nerimaujate dėl savo būklės?<br>0 = visiškai ramus; 10 = labai susirūpinęs                                                                                              | <u>7,3</u> | 6,0            | 8,0    | 10,0           | 9 859     |
| Kaip manote, ar gerai suprantate savo būklę?<br>0 = visiškai nesuprantu; 10 = labai gerai suprantu                                                                           | <u>7,6</u> | 6,0            | 8,0    | 10,0           | 9 859     |
| Kiek gyvenimas su šia liga jus veikia emociškai? (pvz., ar dėl jos pykstate, esate išsigandęs, nusiminęs ar apimtas depresijos?)<br>0 = visiškai neveikia; 10 = labai veikia | <u>6,8</u> | 5,0            | 7,0    | 9,0            | 9 859     |

Under-represented elements

Over-represented elements

Cronbach’s Alpha: 0,6

Average values

Multiple Cross

|                                                                                                                                                                              | MENTAL HEALTH SCORE |                    |
|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------|--------------------|
|                                                                                                                                                                              | POOR MENTAL HEALTH  | GOOD MENTAL HEALTH |
| Kokią įtaką liga daro jūsų gyvenimui?<br>0 = jokios; 10 = labai didelę                                                                                                       | 8,1                 | 6,1                |
| Kaip manote, kiek ilgai tęsis būklė?<br>0 = labai trumpai; 10 = visada                                                                                                       | 9,7                 | 9,6                |
| Kaip manote, kiek galite kontroliuoti savo būklę?<br>0 = visiškai nekontroliuojate; 10 = labai kontroliuojate                                                                | 3,9                 | 4,8                |
| Kaip manote, kiek gydymas gali padėti šios būklės atveju?<br>0 = visiškai nepadeda; 10 = labai padeda                                                                        | 5,8                 | 6,8                |
| Kiek jaučiate savo būklės simptomus?<br>0 = visiškai jokių; 10 = daug sunkių simptomų                                                                                        | 7,5                 | 5,8                |
| Kiek nerimaujate dėl savo būklės?<br>0 = visiškai ramus; 10 = labai susirūpinęs                                                                                              | 7,9                 | 6,0                |
| Kaip manote, ar gerai suprantate savo būklę?<br>0 = visiškai nesuprantu; 10 = labai gerai suprantu                                                                           | 7,5                 | 7,8                |
| Kiek gyvenimas su šia liga jus veikia emociškai? (pvz., ar dėl jos pykstate, esate išsigandęs, nusiminęs ar apimtas depresijos?)<br>0 = visiškai neveikia; 10 = labai veikia | 7,7                 | 5,0                |

■ Elements significantly under mean

■ Elements significantly above mean

Frequencies (number of participants)

Multiple Cross

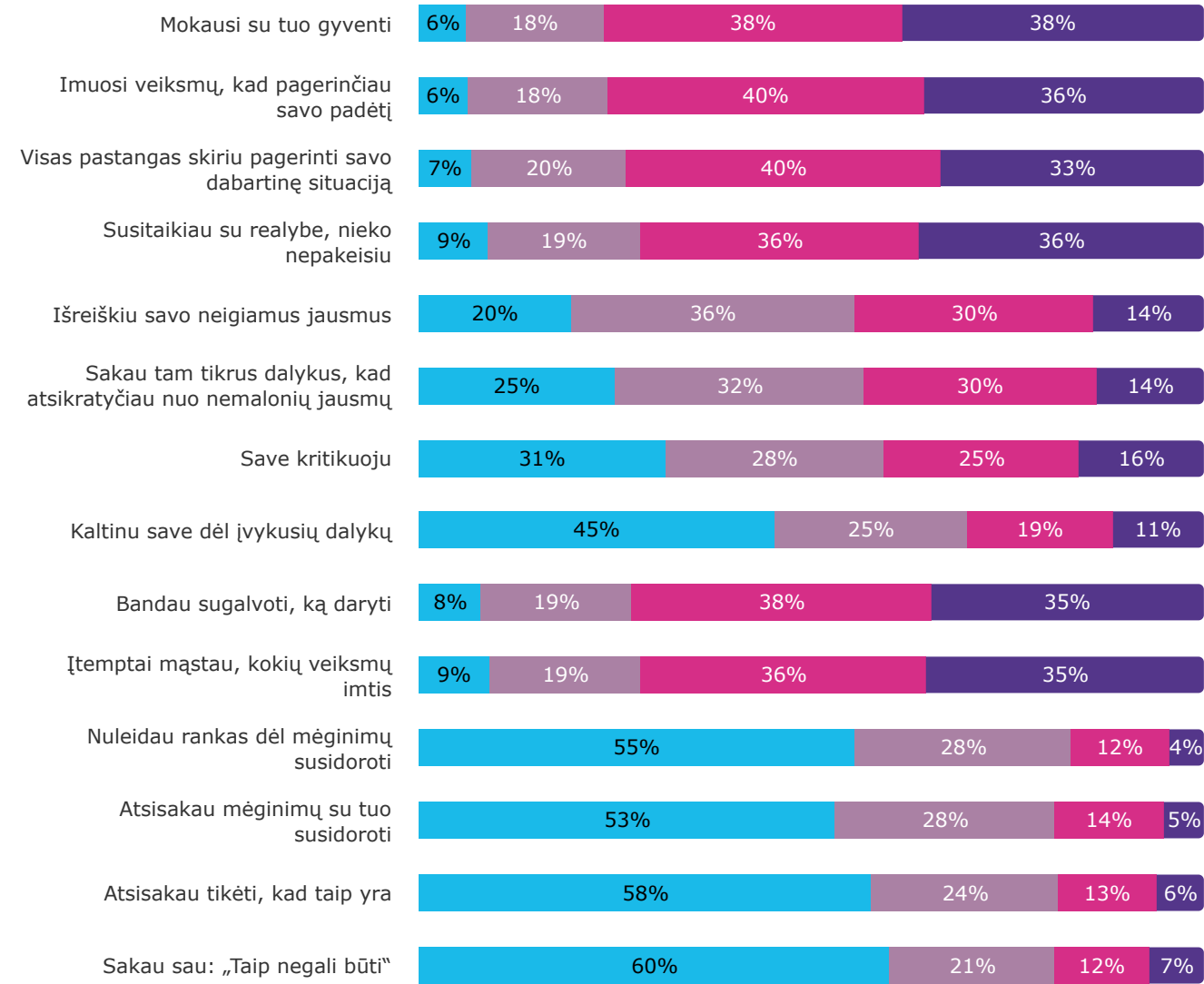
|                                                                                                                                                                              | MENTAL HEALTH SCORE |                    |
|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------|--------------------|
|                                                                                                                                                                              | POOR MENTAL HEALTH  | GOOD MENTAL HEALTH |
| Kokią įtaką liga daro jūsų gyvenimui?<br>0 = jokios; 10 = labai didelę                                                                                                       | 6 717               | 3 142              |
| Kaip manote, kiek ilgai tęsis būklė?<br>0 = labai trumpai; 10 = visada                                                                                                       | 6 717               | 3 142              |
| Kaip manote, kiek galite kontroliuoti savo būklę?<br>0 = visiškai nekontroliuojate; 10 = labai kontroliuojate                                                                | 6 717               | 3 142              |
| Kaip manote, kiek gydymas gali padėti šios būklės atveju?<br>0 = visiškai nepadeda; 10 = labai padeda                                                                        | 4 821               | 2 294              |
| Kiek jaučiate savo būklės simptomus?<br>0 = visiškai jokių; 10 = daug sunkių simptomų                                                                                        | 4 287               | 2 090              |
| Kiek nerimaujate dėl savo būklės?<br>0 = visiškai ramus; 10 = labai susirūpinęs                                                                                              | 6 717               | 3 142              |
| Kaip manote, ar gerai suprantate savo būklę?<br>0 = visiškai nesuprantu; 10 = labai gerai suprantu                                                                           | 6 717               | 3 142              |
| Kiek gyvenimas su šia liga jus veikia emociškai? (pvz., ar dėl jos pykstate, esate išsigandęs, nusiminęs ar apimtas depresijos?)<br>0 = visiškai neveikia; 10 = labai veikia | 6 717               | 3 142              |

■ Under-represented elements

■ Over-represented elements

Kiekvienas iš mūsų stresą keliančius įvykius įveikia skirtingai. Norėtume geriau suprasti, kaip paprastai elgiatės ir jaučiatės, kai patiriate stresą keliančius įvykius: Atsakykite į kitus klausimus galvodami apie tai, kiek daug ar dažnai darėte tai, kas nurodyta kiekviename punkte – teisingų ar neteisingų atsakymų nėra!

|                                                                  | 1=<br>VISIŠ...<br>NEDAR... | 2     | 3     | 4=<br>DARAU<br>DAUG | TOTAL |
|------------------------------------------------------------------|----------------------------|-------|-------|---------------------|-------|
| Mokausi su tuo gyventi                                           | 603                        | 1 735 | 3 766 | 3 793               | 9 897 |
| Imuosi veiksmų, kad pagerinčiau savo padėtį                      | 617                        | 1 756 | 3 989 | 3 535               | 9 897 |
| Visas pastangas skiriu pagerinti savo dabartinę situaciją        | 660                        | 1 948 | 3 977 | 3 312               | 9 897 |
| Susitaikiau su realybe, nieko nepakeisiu                         | 865                        | 1 922 | 3 523 | 3 587               | 9 897 |
| Išreiškiu savo neigiamus jausmus                                 | 1 933                      | 3 574 | 2 989 | 1 401               | 9 897 |
| Sakau tam tikrus dalykus, kad atsikratyčiau nuo nemalonių jausmų | 2 465                      | 3 138 | 2 935 | 1 359               | 9 897 |
| Save kritikuoju                                                  | 3 114                      | 2 751 | 2 451 | 1 581               | 9 897 |
| Kaltinu save dėl įvykusių dalykų                                 | 4 486                      | 2 426 | 1 850 | 1 135               | 9 897 |
| Bandau sugalvoti, ką daryti                                      | 778                        | 1 893 | 3 799 | 3 427               | 9 897 |
| Įtemptai mąstau, kokių veiksmų imtis                             | 903                        | 1 902 | 3 590 | 3 502               | 9 897 |
| Nuleidau rankas dėl mėginimų susidoroti                          | 5 491                      | 2 742 | 1 227 | 437                 | 9 897 |
| Atsisakau mėginimų su tuo susidoroti                             | 5 243                      | 2 780 | 1 379 | 495                 | 9 897 |
| Atsisakau tikėti, kad taip yra                                   | 5 698                      | 2 370 | 1 238 | 591                 | 9 897 |
| Sakau sau: „Taip negali būti“                                    | 5 941                      | 2 077 | 1 189 | 690                 | 9 897 |



● 1= Visiškai nedarau    ● 2    ● 3    ● 4= Darau daug

Participants' coping mechanisms were captured through the BRIEF-COPE scale, in which two items code for a sub-scale, presented below.

The score for each sub-scale is the sum of the score of the two items that compose the sub-scale. The scores range from 0 to 6.

Combined analysis

|                                | MEAN | LOWER QUARTILE | MEDIAN | UPPER QUARTILE | FREQUENCY |
|--------------------------------|------|----------------|--------|----------------|-----------|
| Active coping                  | 4,1  | 3,0            | 4,0    | 5,0            | 9 897     |
| Planning coping                | 4,0  | 3,0            | 4,0    | 5,0            | 9 897     |
| COPE acceptance                | 4,1  | 3,0            | 4,0    | 6,0            | 9 897     |
| COPE behavioural disengagement | 1,4  | 0,0            | 1,0    | 2,0            | 9 897     |
| COPE denial                    | 1,3  | 0,0            | 1,0    | 2,0            | 9 897     |
| COPE venting                   | 2,7  | 2,0            | 3,0    | 4,0            | 9 897     |
| COPE self-blame                | 2,2  | 0,0            | 2,0    | 4,0            | 9 897     |

Under-represented elements Over-represented elements

Cronbach's Alpha: 0,5

Average values for each sub-scale of the BRIEF-COPE, depending if participants reported 'poor mental health'(at least one mental health difficulty) or 'good mental health' (no mental health difficulty).

|                                | Multiple Cross      |                    |
|--------------------------------|---------------------|--------------------|
|                                | MENTAL HEALTH SCORE |                    |
|                                | POOR MENTAL HEALTH  | GOOD MENTAL HEALTH |
| Active coping                  | 4,1                 | 4,0                |
| Planning coping                | <u>4,1</u>          | <u>3,7</u>         |
| COPE acceptance                | <u>3,9</u>          | <u>4,4</u>         |
| COPE behavioural disengagement | <u>1,6</u>          | <u>0,8</u>         |
| COPE denial                    | <u>1,6</u>          | <u>0,8</u>         |
| COPE venting                   | <u>2,9</u>          | <u>2,3</u>         |
| COPE self-blame                | <u>2,7</u>          | <u>1,2</u>         |

Elements significantly under mean Elements significantly above mean

Cross: When the first symptoms were noticed, I was under 18 years old (merge PLWRD and proxy from family members) / Mental health score

| WHEN THE FIRST SYMPTOMS WERE NOTICED, I WAS UNDER 18 YEARS OLD (MERGE PLWRD AND PROXY FROM FAMILY MEMBERS) | MENTAL HEALTH SCORE |     |                    |     |       |      |
|------------------------------------------------------------------------------------------------------------|---------------------|-----|--------------------|-----|-------|------|
|                                                                                                            | POOR MENTAL HEALTH  |     | GOOD MENTAL HEALTH |     | TOTAL |      |
|                                                                                                            | N                   | %   | N                  | %   | N     | %    |
| Yes                                                                                                        | 3 797               | 71% | 1 570              | 29% | 5 367 | 100% |
| No                                                                                                         | 2 554               | 64% | 1 426              | 36% | 3 980 | 100% |
| Unsure                                                                                                     | 168                 | 73% | 61                 | 27% | 229   | 100% |
| No symptoms yet                                                                                            | 226                 | 70% | 95                 | 30% | 321   | 100% |
| TOTAL                                                                                                      | 6 745               | 68% | 3 152              | 32% | 9 897 |      |

Under-represented elements

Over-represented elements

The relationship is very significant.  $p\text{-value} = < 0,01$  ;  $\chi^2 = 49,3$  ;  $\text{dof} = 3$ .

Cross: Physical or psychological misdiagnosis / Mental health score

| PHYSICAL OR PSYCHOLOGICAL MISDIAGNOSIS | MENTAL HEALTH SCORE |     |                    |     |       |      |
|----------------------------------------|---------------------|-----|--------------------|-----|-------|------|
|                                        | POOR MENTAL HEALTH  |     | GOOD MENTAL HEALTH |     | TOTAL |      |
|                                        | N                   | %   | N                  | %   | N     | %    |
| Misdiagnosis                           | 4 186               | 74% | 1 480              | 26% | 5 666 | 100% |
| No misdiagnosis                        | 2 333               | 60% | 1 577              | 40% | 3 910 | 100% |
| No symptoms yet                        | 226                 | 70% | 95                 | 30% | 321   | 100% |
| TOTAL                                  | 6 745               | 68% | 3 152              | 32% | 9 897 |      |

Under-represented elements

Over-represented elements

The relationship is very significant.  $p\text{-value} = < 0,01$  ;  $\chi^2 = 216,1$  ;  $\text{dof} = 2$ .

Cross: Other people in the family have been diagnosed with the same condition (merge PLWRD and proxy from family members) / Mental health score

| OTHER PEOPLE IN THE FAMILY HAVE BEEN DIAGNOSED WITH THE SAME CONDITION (MERGE PLWRD AND PROXY FROM FAMILY MEMBERS) | MENTAL HEALTH SCORE |     |                    |     |       |      |
|--------------------------------------------------------------------------------------------------------------------|---------------------|-----|--------------------|-----|-------|------|
|                                                                                                                    | POOR MENTAL HEALTH  |     | GOOD MENTAL HEALTH |     | TOTAL |      |
|                                                                                                                    | N                   | %   | N                  | %   | N     | %    |
| Yes                                                                                                                | 1 326               | 63% | 774                | 37% | 2 100 | 100% |
| No                                                                                                                 | 4 640               | 69% | 2 099              | 31% | 6 739 | 100% |
| Unsure                                                                                                             | 280                 | 74% | 99                 | 26% | 379   | 100% |
| Undiagnosed                                                                                                        | 499                 | 73% | 180                | 27% | 679   | 100% |
| TOTAL                                                                                                              | 6 745               | 68% | 3 152              | 32% | 9 897 |      |

Under-represented elements

Over-represented elements

The relationship is very significant.  $p\text{-value} = < 0,01$  ;  $\chi^2 = 40,4$  ;  $\text{dof} = 3$ .

Cross: I was referred to a hospital service specialising in the rare condition or group of rare conditions TO OBTAIN A DIAGNOSIS (initial & confirmed diagnosis - merge from PLWRD & FM) / Mental health score

| I WAS REFERRED TO A HOSPITAL SERVICE SPECIALISING IN THE RARE CONDITION OR GROUP OF RARE CONDITIONS TO OBTAIN A DIAGNOSIS (INITIAL & CONFIRMED DIAGNOSIS - MERGE FROM PLWRD & FM) | MENTAL HEALTH SCORE |     |                    |     |       |      |
|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------|-----|--------------------|-----|-------|------|
|                                                                                                                                                                                   | POOR MENTAL HEALTH  |     | GOOD MENTAL HEALTH |     | TOTAL |      |
|                                                                                                                                                                                   | N                   | %   | N                  | %   | N     | %    |
| Yes                                                                                                                                                                               | 3 624               | 65% | 1 926              | 35% | 5 550 | 100% |
| No                                                                                                                                                                                | 2 450               | 71% | 977                | 29% | 3 427 | 100% |
| Unsure                                                                                                                                                                            | 172                 | 71% | 69                 | 29% | 241   | 100% |
| Undiagnosed                                                                                                                                                                       | 499                 | 73% | 180                | 27% | 679   | 100% |
| TOTAL                                                                                                                                                                             | 6 745               | 68% | 3 152              | 32% | 9 897 |      |

Under-represented elements

Over-represented elements

The relationship is very significant.  $p\text{-value} = < 0,01$  ;  $\chi^2 = 48,5$  ;  $\text{dof} = 3$ .

Cross: I regularly attend follow-up visits at a hospital unit specialised in the rare condition or group of rare conditions(all PLWRD - merge from PLWRD & FM) / Mental health score

| I REGULARLY ATTEND FOLLOW-UP VISITS AT A HOSPITAL UNIT SPECIALISED IN THE RARE CONDITION OR GROUP OF RARE CONDITIONS(ALL PLWRD - MERGE FROM PLWRD & FM) | MENTAL HEALTH SCORE |     |                    |     |       |      |
|---------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------|-----|--------------------|-----|-------|------|
|                                                                                                                                                         | POOR MENTAL HEALTH  |     | GOOD MENTAL HEALTH |     | TOTAL |      |
|                                                                                                                                                         | N                   | %   | N                  | %   | N     | %    |
| Yes                                                                                                                                                     | 4 110               | 65% | 2 206              | 35% | 6 316 | 100% |
| No                                                                                                                                                      | 2 480               | 74% | 882                | 26% | 3 362 | 100% |
| Unsure                                                                                                                                                  | 127                 | 70% | 54                 | 30% | 181   | 100% |
| TOTAL                                                                                                                                                   | 6 717               | 68% | 3 142              | 32% | 9 859 |      |

Under-represented elements  Over-represented elements

The relationship is very significant. p-value= < 0,01 ; Chi2= 76,7 ; dof= 2.

Cross: I have received or I am currently receiving MEDICAL TREATMENT(S) OR INTERVENTION(S) to lessen or control the effects of the rare condition (all PLWRD - merge from PLWRD & FM) / Mental health score

| I HAVE RECEIVED OR I AM CURRENTLY RECEIVING MEDICAL TREATMENT(S) OR INTERVENTION(S) TO LESSEN OR CONTROL THE EFFECTS OF THE RARE CONDITION (ALL PLWRD - MERGE FROM PLWRD & FM) | MENTAL HEALTH SCORE |     |                    |     |       |      |
|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------|-----|--------------------|-----|-------|------|
|                                                                                                                                                                                | POOR MENTAL HEALTH  |     | GOOD MENTAL HEALTH |     | TOTAL |      |
|                                                                                                                                                                                | N                   | %   | N                  | %   | N     | %    |
| No                                                                                                                                                                             | 1 769               | 69% | 791                | 31% | 2 560 | 100% |
| Unsure                                                                                                                                                                         | 127                 | 69% | 57                 | 31% | 184   | 100% |
| Yes                                                                                                                                                                            | 4 821               | 68% | 2 294              | 32% | 7 115 | 100% |
| TOTAL                                                                                                                                                                          | 6 717               | 68% | 3 142              | 32% | 9 859 |      |

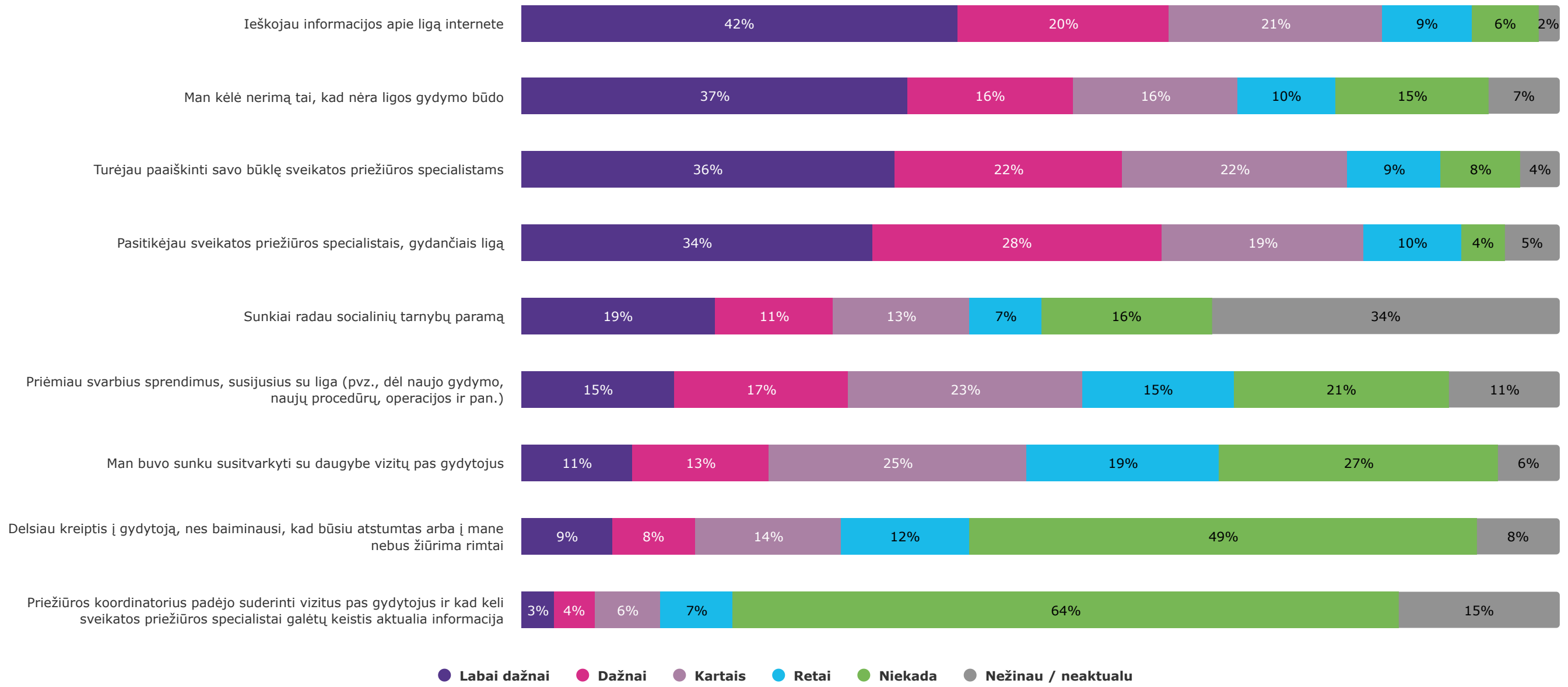
Under-represented elements  Over-represented elements

The relationship is not significant. p-value= 0,4 ; Chi2= 1,6 ; dof= 2.

Kaip dažnai per pastaruosius 6 mėn. susidūrėte su šiomis situacijomis:

|                                                                                                                                                   | LABAI<br>DAŽNAI | DAŽNAI | KARTAIS | RETAI | NIEKADA | NEŽINAU /<br>NEAKTUA... | TOTAL |
|---------------------------------------------------------------------------------------------------------------------------------------------------|-----------------|--------|---------|-------|---------|-------------------------|-------|
| Ieškojau informacijos apie ligą internete                                                                                                         | 3 994           | 1 934  | 1 951   | 822   | 612     | 193                     | 9 506 |
| Turėjau paaiškinti savo būklę sveikatos priežiūros specialistams                                                                                  | 3 418           | 2 080  | 2 068   | 850   | 727     | 364                     | 9 507 |
| Pasitikėjau sveikatos priežiūros specialistais, gydančiais ligą                                                                                   | 3 217           | 2 645  | 1 847   | 905   | 387     | 507                     | 9 508 |
| Sunkiai radau socialinių tarnybų paramą                                                                                                           | 1 775           | 1 075  | 1 256   | 655   | 1 559   | 3 185                   | 9 505 |
| Priėmiau svarbius sprendimus, susijusius su liga (pvz., dėl naujo gydymo, naujų procedūrų, operacijos ir pan.)                                    | 1 400           | 1 587  | 2 156   | 1 381 | 1 972   | 1 011                   | 9 507 |
| Man buvo sunku susitvarkyti su daugybe vizitų pas gydytojus                                                                                       | 1 010           | 1 258  | 2 356   | 1 764 | 2 548   | 569                     | 9 505 |
| Man kėlė nerimą tai, kad nėra ligos gydymo būdo                                                                                                   | 921             | 395    | 391     | 236   | 364     | 169                     | 2 476 |
| Delsiau kreiptis į gydytoją, nes baiminausi, kad būsiu atstumtas arba į mane nebus žiūrima rimtai                                                 | 828             | 760    | 1 340   | 1 176 | 4 642   | 761                     | 9 507 |
| Priežiūros koordinatorius padėjo suderinti vizitus pas gydytojus ir kad keli sveikatos priežiūros specialistai galėtų keistis aktuala informacija | 304             | 369    | 593     | 668   | 6 100   | 1 472                   | 9 506 |

**Kaip dažnai per pastaruosius 6 mėn. susidūrėte su šiomis situacijomis:**



● **Labai dažnai** ● **Dažnai** ● **Kartais** ● **Retai** ● **Niekada** ● **Nežinau / neaktualu**

Multiple Cross

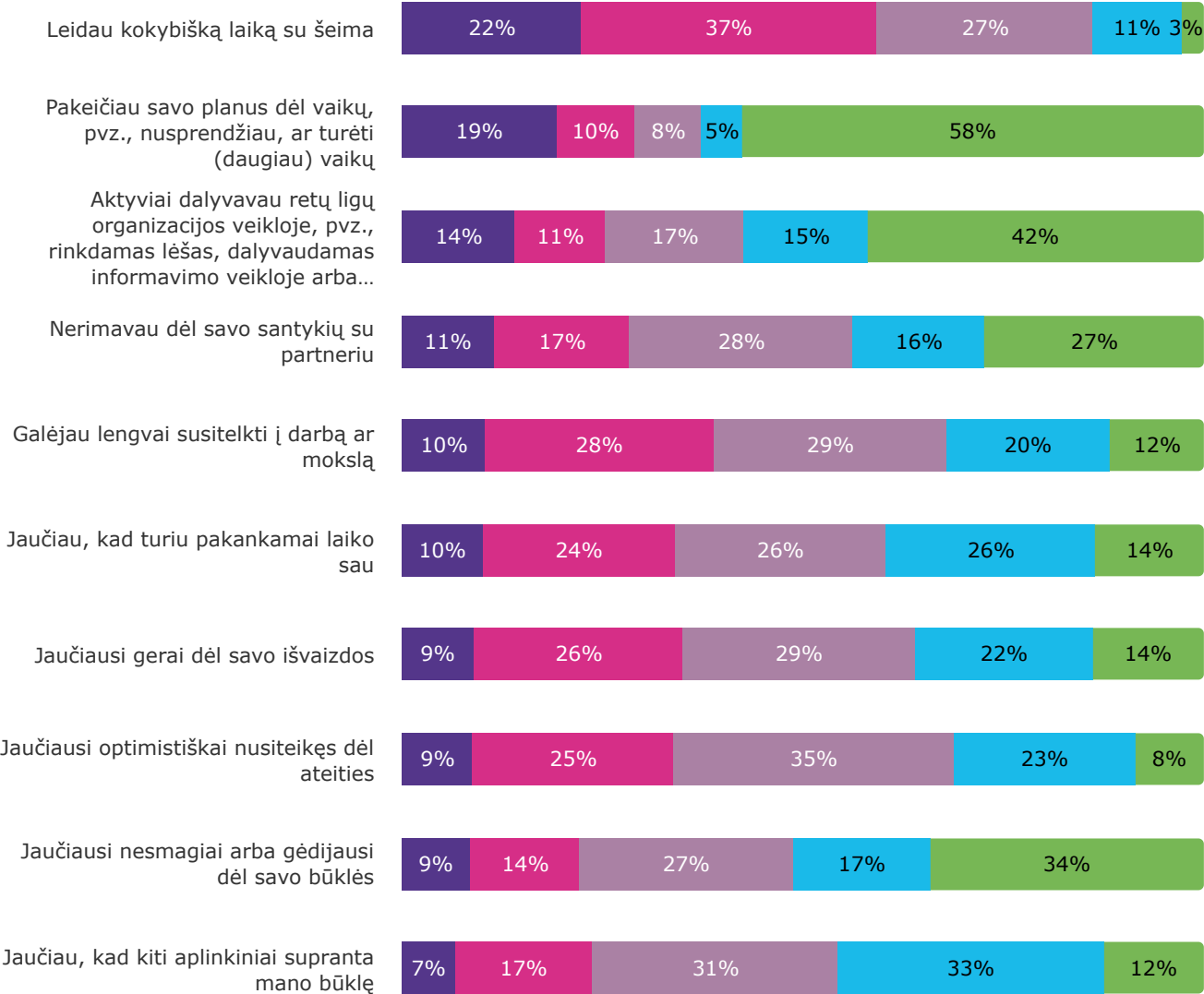
|                                                                                                                                                   | MENTAL HEALTH SCORE |                    |       |
|---------------------------------------------------------------------------------------------------------------------------------------------------|---------------------|--------------------|-------|
|                                                                                                                                                   | POOR MENTAL HEALTH  | GOOD MENTAL HEALTH | TOTAL |
| Ieškojau informacijos apie ligą internete                                                                                                         | 4,0                 | 3,5                | 3,8   |
| Turėjau paaiškinti savo būklę sveikatos priežiūros specialistams                                                                                  | 3,9                 | 3,3                | 3,7   |
| Man kėlė nerimą tai, kad nėra ligos gydymo būdo                                                                                                   | 3,9                 | 2,7                | 3,6   |
| Pasitikėjau sveikatos priežiūros specialistais, gydančiais ligą                                                                                   | 3,7                 | 4,1                | 3,8   |
| Sunkiai radau socialinių tarnybų paramą                                                                                                           | 3,5                 | 2,3                | 3,1   |
| Priėmiau svarbius sprendimus, susijusius su liga (pvz., dėl naujo gydymo, naujų procedūrų, operacijos ir pan.)                                    | 3,1                 | 2,5                | 2,9   |
| Man buvo sunku susitvarkyti su daugybe vizitų pas gydytojus                                                                                       | 2,9                 | 1,9                | 2,6   |
| Delsiau kreiptis į gydytoją, nes baiminausi, kad būsiu atstumtas arba į mane nebus žiūrima rimtai                                                 | 2,3                 | 1,5                | 2,1   |
| Priežiūros koordinatorius padėjo suderinti vizitus pas gydytojus ir kad keli sveikatos priežiūros specialistai galėtų keistis aktuala informacija | 1,5                 | 1,5                | 1,5   |
| TOTAL                                                                                                                                             | 3,1                 | 2,6                | 3,0   |

■ Elements significantly under mean    ■ Elements significantly above mean

Average values; 'non-responses' and responses 'don't know' not considered in the average value.

Combined analysis

|                                                                                                                                     | LABAI<br>DAŽNAI | DAŽNAI | KARTAIS | RETAI | NIEKADA | TOTAL |
|-------------------------------------------------------------------------------------------------------------------------------------|-----------------|--------|---------|-------|---------|-------|
| Leidau kokybišką laiką su šeima                                                                                                     | 2 081           | 3 461  | 2 513   | 1 027 | 269     | 9 351 |
| Pakeičiau savo planus dėl vaikų, pvz., nusprendžiau, ar turėti (daugiau) vaikų                                                      | 1 729           | 863    | 734     | 445   | 5 146   | 8 917 |
| Aktyviai dalyvavau retų ligų organizacijos veikloje, pvz., rinkdamas lėšas, dalyvaudamas informavimo veikloje arba savišvietos būdu | 1 302           | 1 064  | 1 621   | 1 433 | 3 912   | 9 332 |
| Nerimavau dėl savo santykių su partneriu                                                                                            | 759             | 1 118  | 1 841   | 1 086 | 1 817   | 6 621 |
| Galėjau lengvai susitelkti į darbą ar mokslą                                                                                        | 957             | 2 600  | 2 670   | 1 853 | 1 069   | 9 149 |
| Jaučiau, kad turiu pakankamai laiko sau                                                                                             | 955             | 2 231  | 2 445   | 2 423 | 1 266   | 9 320 |
| Jaučiausi gerai dėl savo išvaizdos                                                                                                  | 565             | 1 646  | 1 824   | 1 384 | 874     | 6 293 |
| Jaučiausi optimistiškai nusiteikęs dėl ateities                                                                                     | 823             | 2 342  | 3 267   | 2 117 | 786     | 9 335 |
| Jaučiausi nesmagiai arba gėdijausi dėl savo būklės                                                                                  | 543             | 855    | 1 682   | 1 077 | 2 141   | 6 298 |
| Jaučiau, kad kiti aplinkiniai supranta mano būklę                                                                                   | 617             | 1 603  | 2 885   | 3 107 | 1 158   | 9 370 |



● Labai dažnai ● Dažnai ● Kartais ● Retai ● Niekada

Multiple Cross

|                                                                                                                                     | MENTAL HEALTH SCORE |                    |       |
|-------------------------------------------------------------------------------------------------------------------------------------|---------------------|--------------------|-------|
|                                                                                                                                     | POOR MENTAL HEALTH  | GOOD MENTAL HEALTH | TOTAL |
| Leidau kokybišką laiką su šeima                                                                                                     | 3,4                 | 4,1                | 3,6   |
| Nerimavau dėl savo santykių su partneriu                                                                                            | 3,1                 | 1,9                | 2,7   |
| Jaučiausi nesmagiai arba gėdijausi dėl savo būklės                                                                                  | 2,8                 | 1,8                | 2,5   |
| Galėjau lengvai susitelkti į darbą ar mokslą                                                                                        | 2,8                 | 3,7                | 3,1   |
| Jaučiausi optimistiškai nusiteikęs dėl ateities                                                                                     | 2,7                 | 3,7                | 3,0   |
| Jaučiau, kad turiu pakankamai laiko sau                                                                                             | 2,7                 | 3,4                | 2,9   |
| Jaučiausi gerai dėl savo išvaizdos                                                                                                  | 2,7                 | 3,5                | 2,9   |
| Jaučiau, kad kiti aplinkiniai supranta mano būklę                                                                                   | 2,5                 | 3,1                | 2,7   |
| Pakeičiau savo planus dėl vaikų, pvz., nusprendžiau, ar turėti (daugiau) vaikų                                                      | 2,5                 | 1,7                | 2,3   |
| Aktyviai dalyvavau retų ligų organizacijos veikloje, pvz., rinkdamas lėšas, dalyvaudamas informavimo veikloje arba savišvietos būdu | 2,4                 | 2,5                | 2,4   |
| TOTAL                                                                                                                               | 2,8                 | 3,0                | 2,8   |

Elements significantly under mean   Elements significantly above mean

Average values; 'non-responses' and responses 'don't know' not considered in the average value.

# Ačiū!

Jei turite klausimų, susisiekite su Rare Barometer komanda  
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