

# THE IMPACT OF LIVING WITH A RARE DISEASE: BARRIERS AND ENABLERS OF INDEPENDENT LIVING AND SOCIAL PARTICIPATION

A Rare Barometer survey

## Target population :

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



10 July - 8 September 2024



**10,478** respondents worldwide and  
**9,591** in Europe



**25** languages



**43** countries



**1,643** diseases represented

# DASHBOARD FOR EUROPE



## HOW TO USE THIS DASHBOARD

In this dashboard, you will find results for every 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](http://eurordis.org/voices)
- visit our newborn screening-dedicated webpage: [eurordis.org/rare-barometer-survey](http://eurordis.org/rare-barometer-survey)

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3. Disability assessment and barriers
4. Independent living: public support, personal assistance and living arrangements
5. Social participation: discrimination, employment, school participation, community participation and social environment

## MORE ON THE SURVEY

Research questions and in-depth analysis of European results are in the **full report in English**: [tiny.cc/survey/RB\\_DailyLife](http://tiny.cc/survey/RB_DailyLife)

Key results are available in the **factsheets**:  
[tiny.cc/RB\\_DailyLife\\_Results](http://tiny.cc/RB_DailyLife_Results)

Original questionnaire: [tiny.cc/DailyLife\\_questionnaire](http://tiny.cc/DailyLife_questionnaire)



# 1. SAMPLE INFORMATION

**Sociodemographic characteristics,  
diagnostic information**

### Total number of respondents

# 9,591

### Device used to answer



● PC ● Tablet ● Smartphone

### Average number of minutes to fill the questionnaire

# 21

Mean

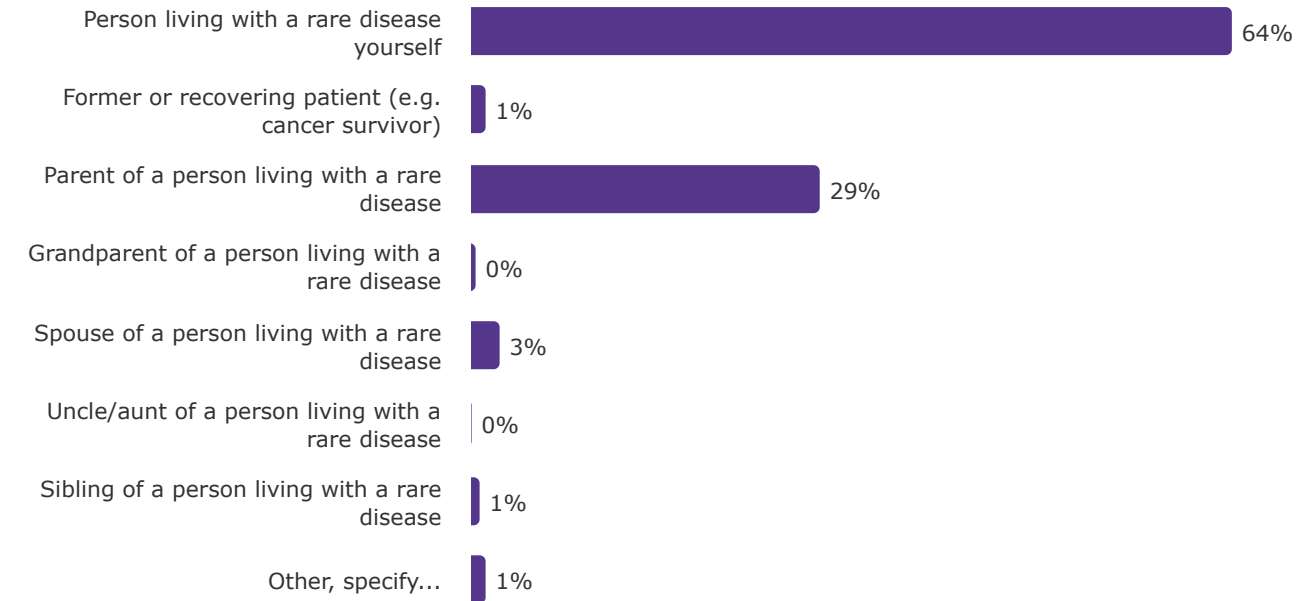
### Median number of minutes to fill the questionnaire

# 15

Median

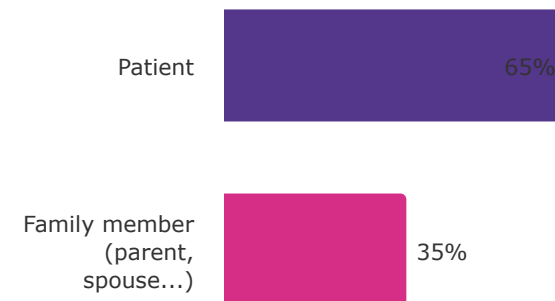
### Are you answering the questionnaire as a...?

	N
Person living with a rare disease yourself	6,136
Former or recovering patient (e.g. cancer survivor)	123
Parent of a person living with a rare disease	2,816
Grandparent of a person living with a rare disease	43
Spouse of a person living with a rare disease	240
Uncle/aunt of a person living with a rare disease	19
Sibling of a person living with a rare disease	82
Other, specify...	132
<b>TOTAL</b>	<b>9,591</b>



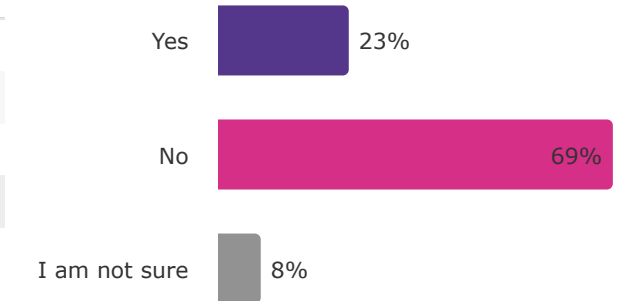
### If 'Other, specify...' specify:

	N	%
Patient	6,260	65%
Family member (parent, spouse...)	3,331	35%
<b>TOTAL</b>	<b>9,591</b>	<b>100%</b>

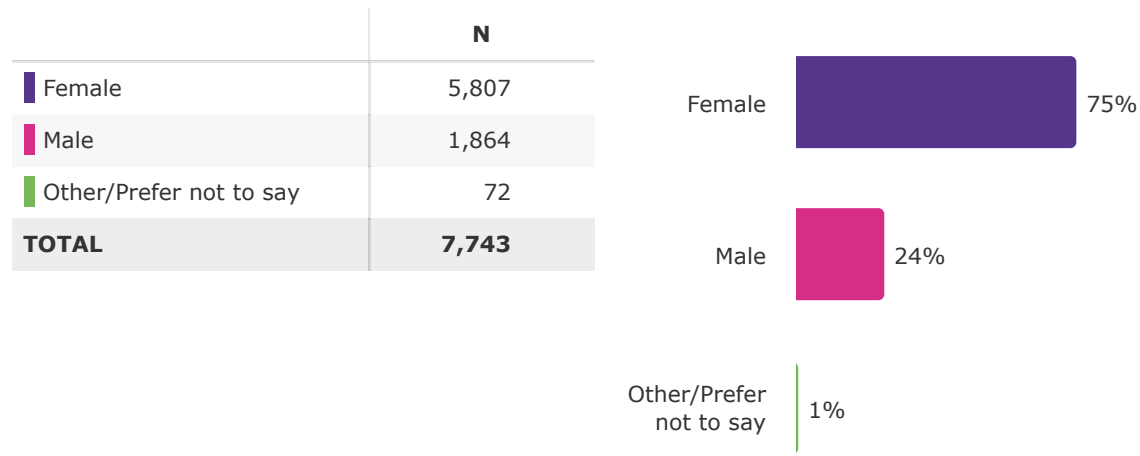


### Are you also a patient representative, i.e., involved in voluntary and/or policy activities to support the cause of rare diseases?

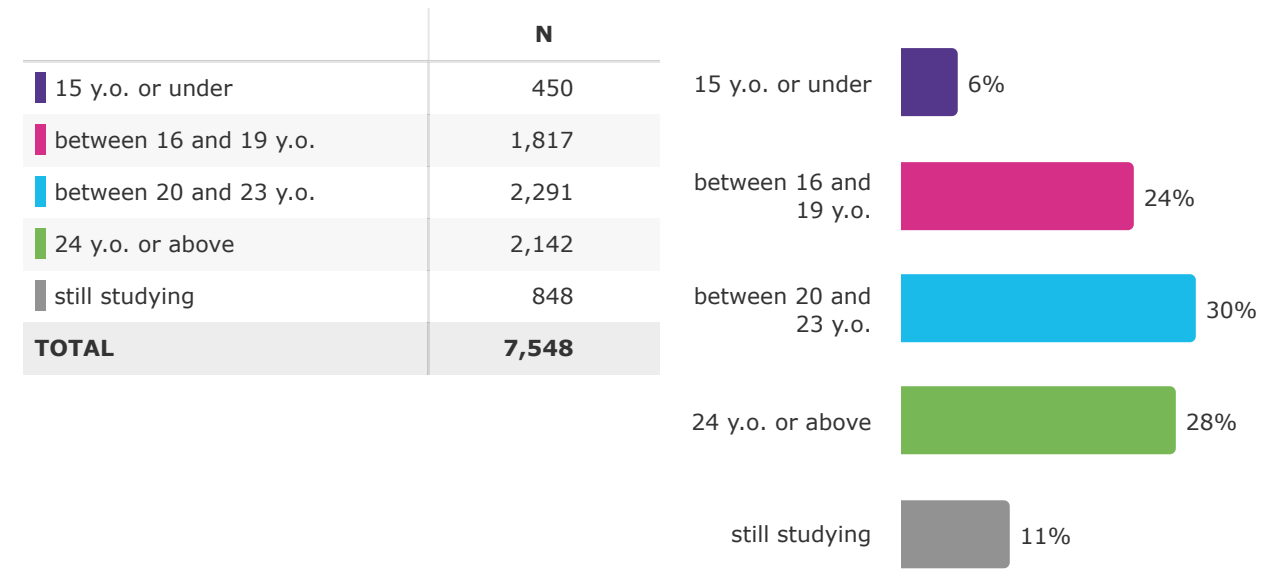
	N
Yes	2,210
No	6,643
I am not sure	738
<b>TOTAL</b>	<b>9,591</b>



### Are you:



### How old were you when you stopped full-time education?



### How old are you?

	N	%
Less than 18	31	0%
From 18 to 23	138	2%
From 24 to 29	333	5%
From 30 to 39	1,114	16%
From 40 to 49	1,833	26%
From 50 to 59	1,847	26%
60 and over	1,733	25%
<b>TOTAL</b>	<b>7,029</b>	<b>100%</b>

### Age of the person living with a rare disease

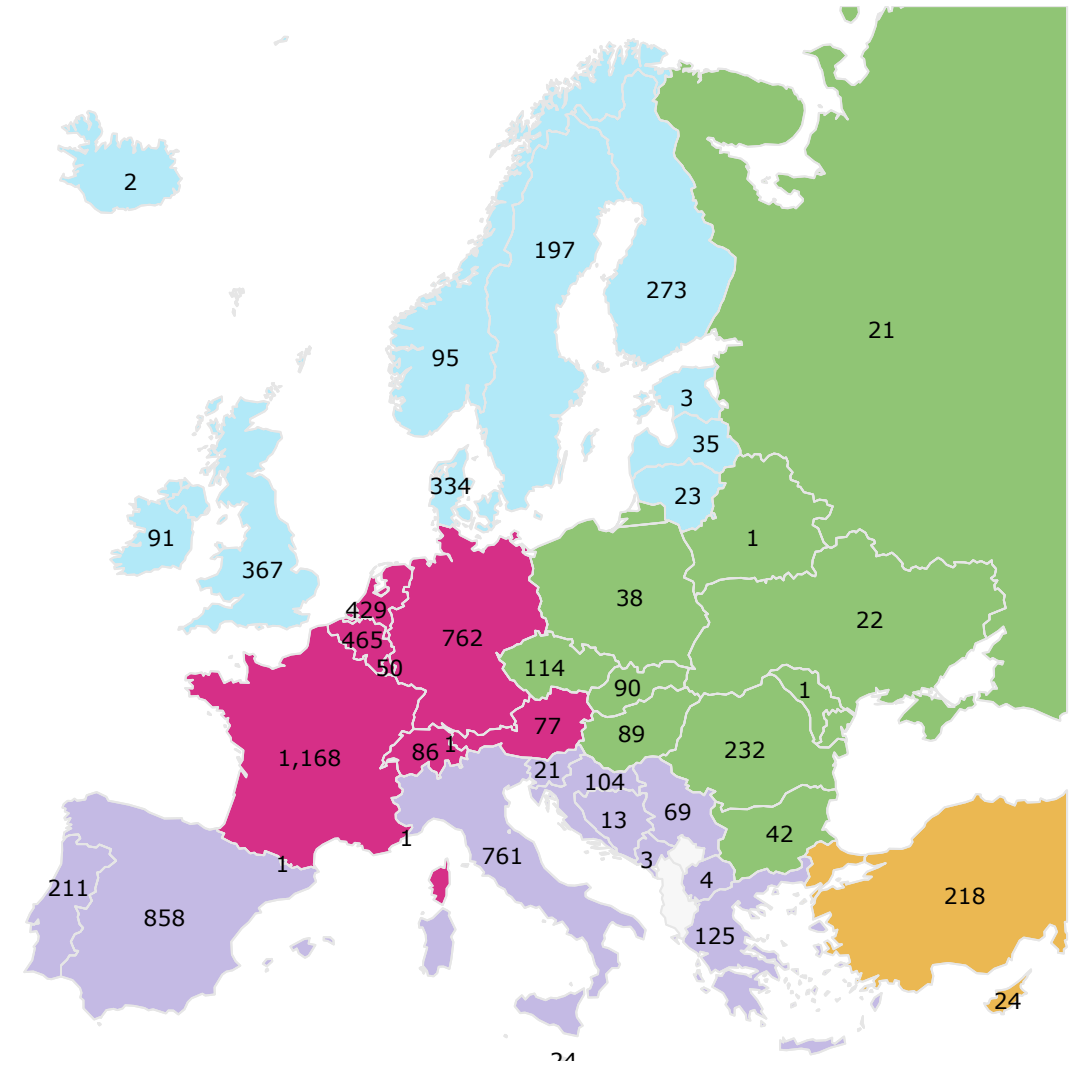
	N	%
Less than 18	1,611	21%
From 18 to 23	455	6%
From 24 to 29	431	6%
From 30 to 39	904	12%
From 40 to 49	1,277	17%
From 50 to 59	1,475	19%
60 and over	1,537	20%
<b>TOTAL</b>	<b>7,690</b>	<b>100%</b>

**In which country do you live?**

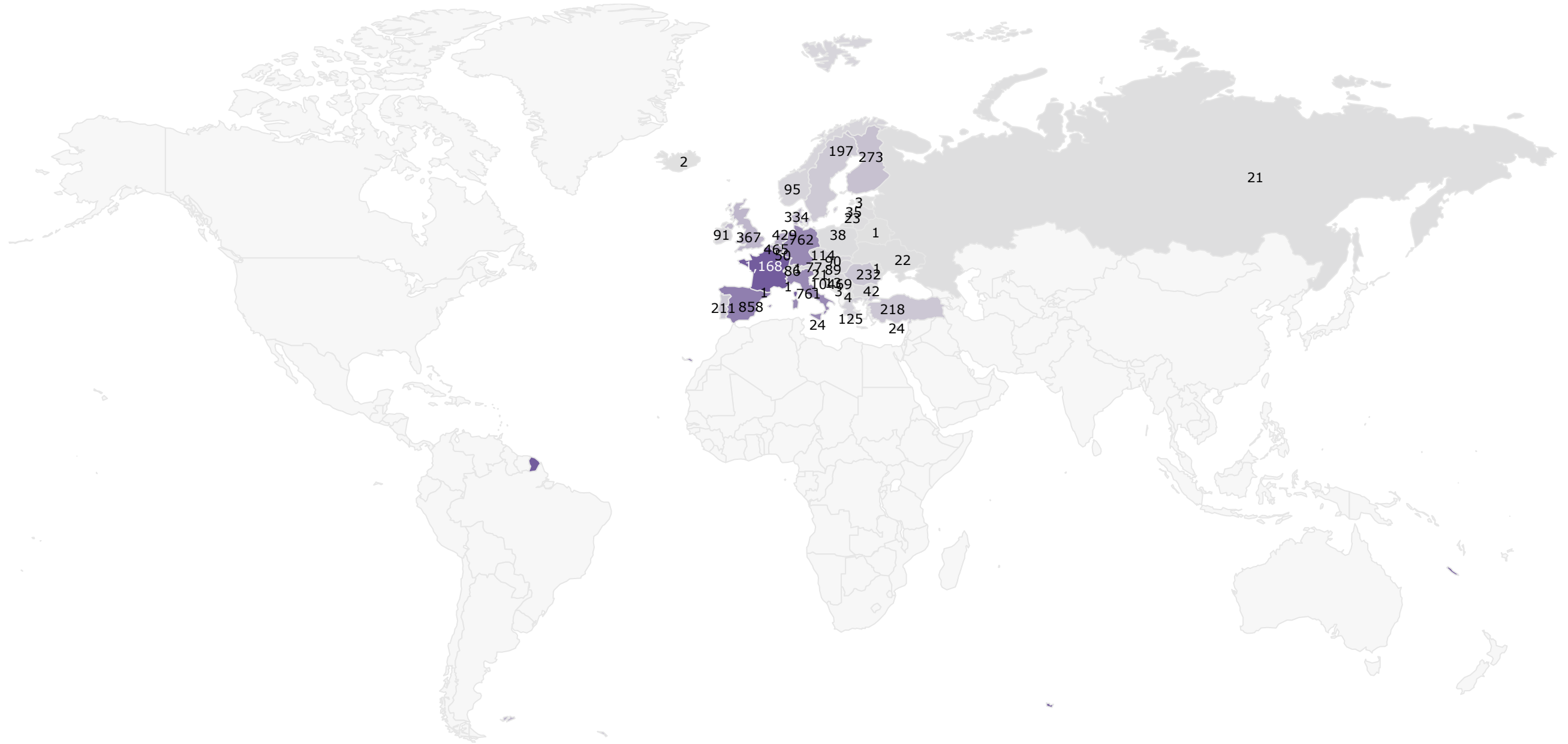
**In which country do you live?**

	<b>N</b>	<b>%</b>
France	1,168	14%
Italy	946	12%
Spain	858	11%
Germany	762	9%
Belgium	465	6%
Netherlands	429	5%
Denmark	427	5%
Romania	368	5%
Turkey	368	5%
United Kingdom	367	5%
Finland	338	4%
Portugal	274	3%
Sweden	228	3%
Czech Republic	154	2%
Greece	150	2%
Slovakia	127	2%
Norway	123	2%
Hungary	114	1%
Croatia	104	1%
Ireland	91	1%
Switzerland	87	1%
Austria	77	1%
Bulgaria	71	1%

	<b>N</b>	<b>%</b>
Serbia	69	17%
Luxembourg	50	13%
Latvia	46	12%
Poland	44	11%
Ukraine	33	8%
Lithuania	32	8%
Slovenia	27	7%
Cyprus	24	6%
Malta	24	6%
Russia	21	5%
Bosnia and Herzegovina	13	3%
Macedonia	4	1%
Estonia	3	1%
Montenegro	3	1%
Iceland	2	1%
Andorra	1	0%
Belarus	1	0%
Liechtenstein	1	0%
Moldova	1	0%
Monaco	1	0%



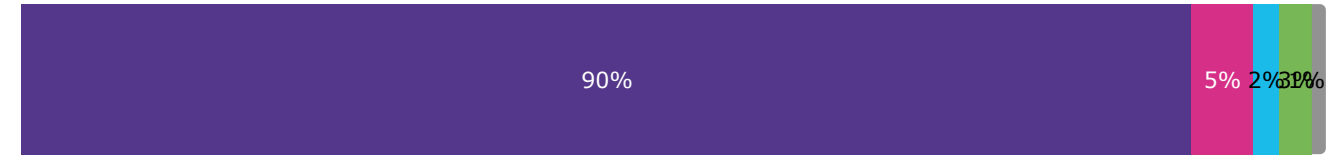
### In which country do you live?





Please select the sentence that best describes your situation:

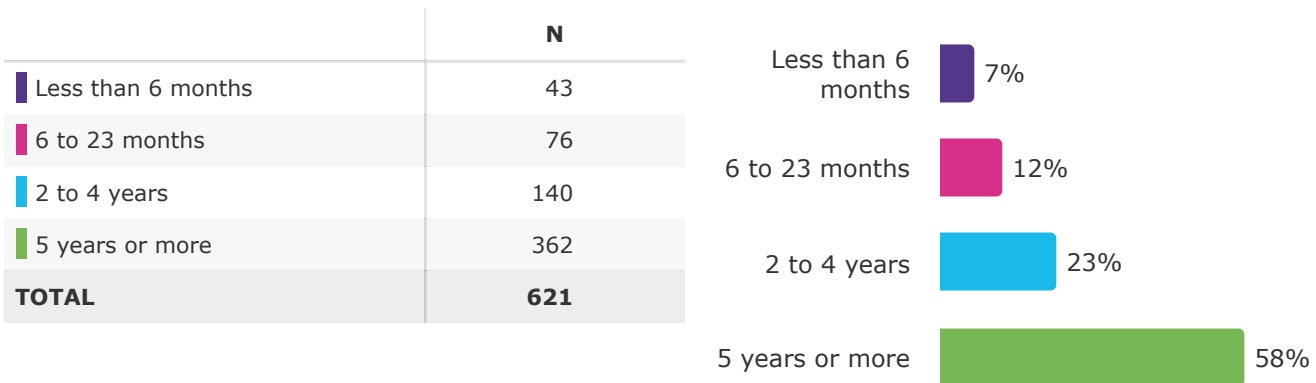
	N
I know the NAME of the rare disease, syndrome or malformation and it has been CONFIRMED by appropriate genetic, clinical, medical imaging, molecular or biochemical tests (e.g biopsy, blood or urine test)	8,624
I know the NAME of the rare disease, syndrome or malformation but it has NOT yet been confirmed by appropriate genetic, clinical, medical imaging, molecular or biochemical tests	456
I only have PARTIAL information on the name of the rare disease or the gene involved or the type of disease	184
I know that the disease is rare but the name or the cause have NOT BEEN IDENTIFIED	242
Other, specify...	84
<b>TOTAL</b>	<b>9,590</b>



- I know the NAME of the rare disease, syndrome or malformation and it has been CONFIRMED by ...
- I know the NAME of the rare disease, syndrome or malformation but it has NOT yet been confirm...
- I only have PARTIAL information on the name of the rare disease or the gene involved or the typ...
- I know that the disease is rare but the name or the cause have NOT BEEN IDENTIFIED
- Other, specify...

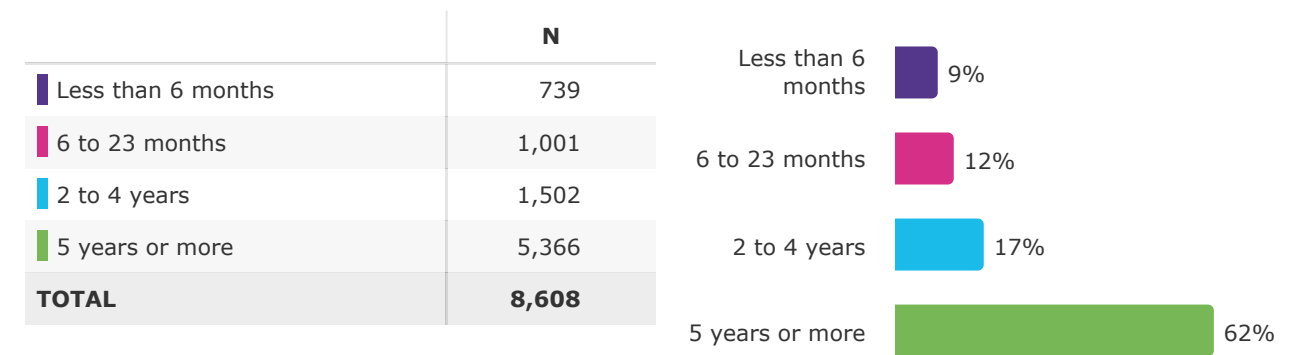
This question was only asked to people with an INITIAL diagnosis.

As far as you remember, how long has it been since you first knew the NAME of the rare disease, syndrome or malformation?



This question was only asked to people with confirmed diagnosis.

As far as you remember, how long has it been since the name of the rare disease, syndrome or malformation was CONFIRMED by appropriate genetic, clinical, medical imaging, molecular or biochemical tests (e.g. biopsy, blood or urine test)?



Number of different rare diseases represented

1,643

Rare diseases with 45+ respondents

	N
Hypermobile Ehlers-Danlos syndrome	243
Hereditary hemorrhagic telangiectasia	241
Addison disease	127
Myasthenia gravis	112
Sarcoidosis	107
Neurofibromatosis type 1	106
Primary sclerosing cholangitis	96
22q11.2 deletion syndrome	68
Autoimmune hepatitis	67
Cystic fibrosis	67
Phenylketonuria	65
Williams syndrome	60
Systemic sclerosis	52
Marfan syndrome	51
Friedreich ataxia	50
Tuberous sclerosis complex	50
Classical Ehlers-Danlos syndrome	49
Common variable immunodeficiency	48
Hereditary spastic paraplegia	48
Facioscapulohumeral dystrophy	46
Behçet disease	45
Primary lymphedema	45

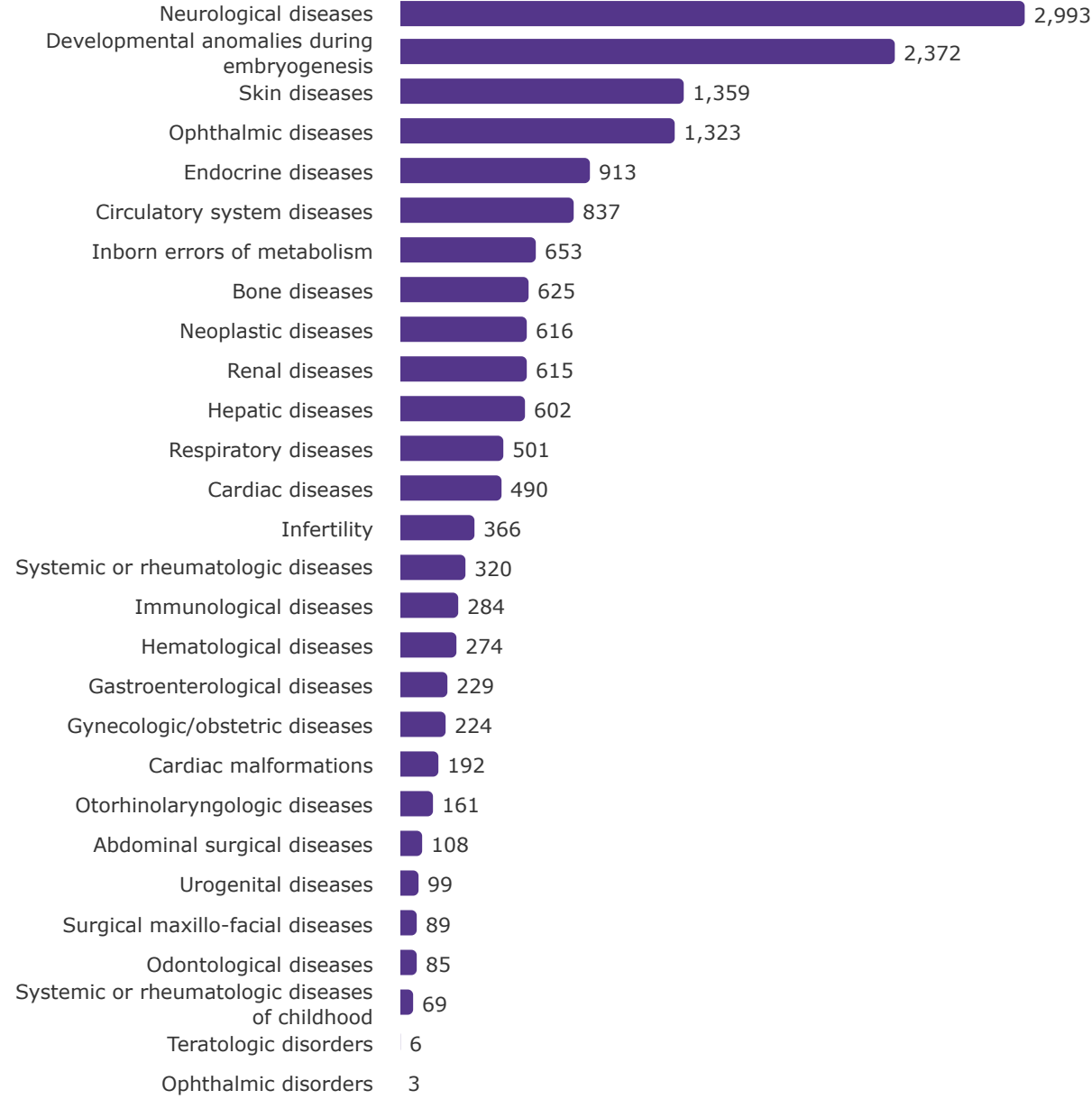
Rare diseases with 30-45 respondents

	N
Alpha-1-antitrypsin deficiency	44
Wilson disease	43
Arnold-Chiari malformation type I	41
Diffuse cutaneous systemic sclerosis	40
Primary biliary cholangitis	39
Duchenne muscular dystrophy	38
Idiopathic achalasia	38
Monosomy 5p	38
Amyotrophic lateral sclerosis	37
Chronic primary adrenal insufficiency	36
Fabry disease	35
Idiopathic pulmonary arterial hypertension	35
Pulmonary arterial hypertension	35
Autoimmune polyendocrinopathy type 1	34
Familial Mediterranean fever	33
Chronic inflammatory demyelinating polyneuropathy	32
Granulomatosis with polyangiitis	32
Angelman syndrome	31
Perineural cyst	30

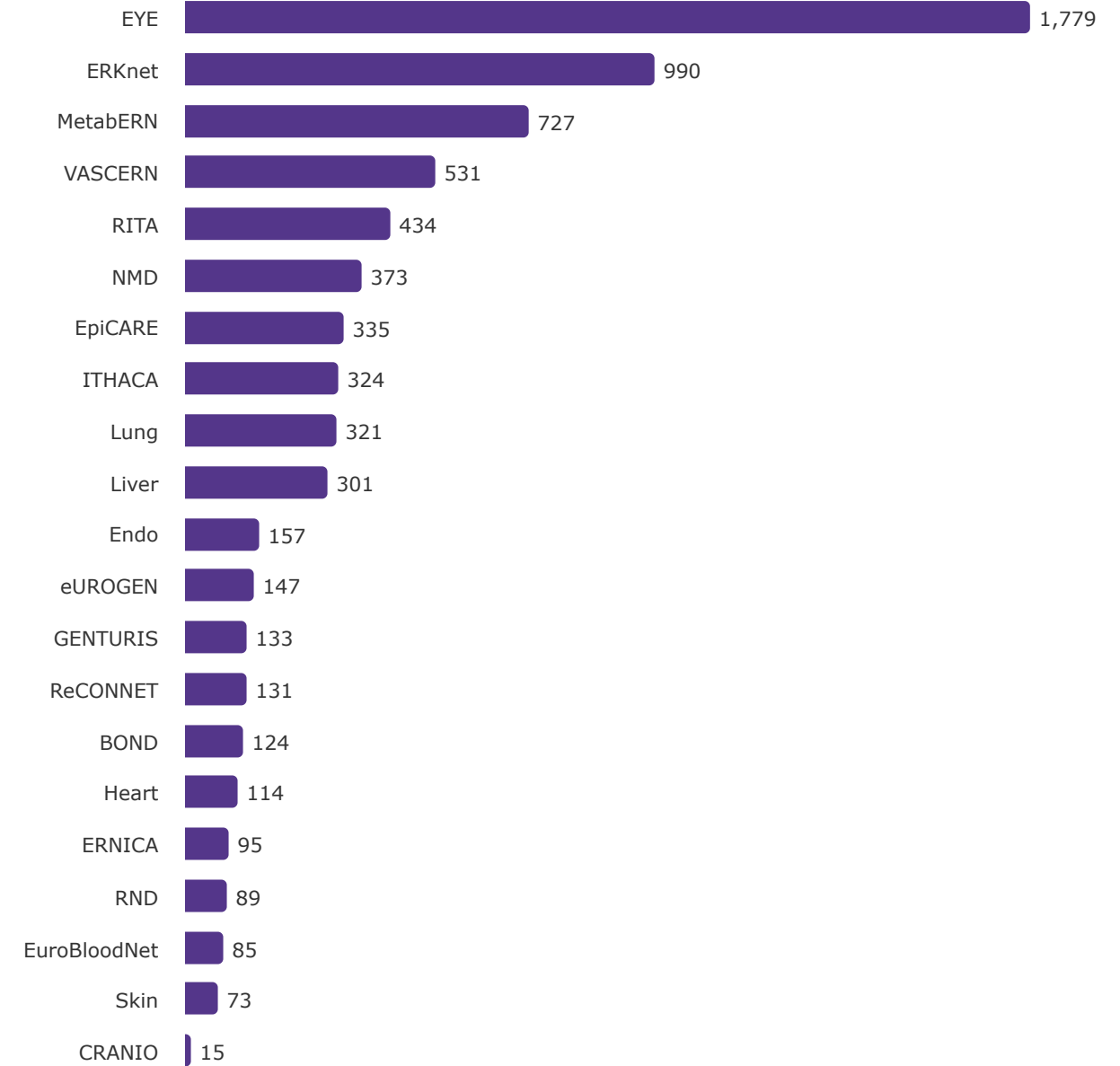
Rare diseases with 25-30 respondents

	N
Gaucher disease	29
Osteogenesis imperfecta	28
Acromegaly	27
Huntington disease	27
Large congenital melanocytic nevus	27
Neuromyelitis optica spectrum disorder	27
Prader-Willi syndrome	27
Ataxia-telangiectasia	26
Cushing disease	26
Non-acquired panhypopituitarism	26
Systemic lupus erythematosus	26
Lupus erythematosus panniculitis	25

### Orphanet classification of rare diseases (one disease can be classified in several categories)

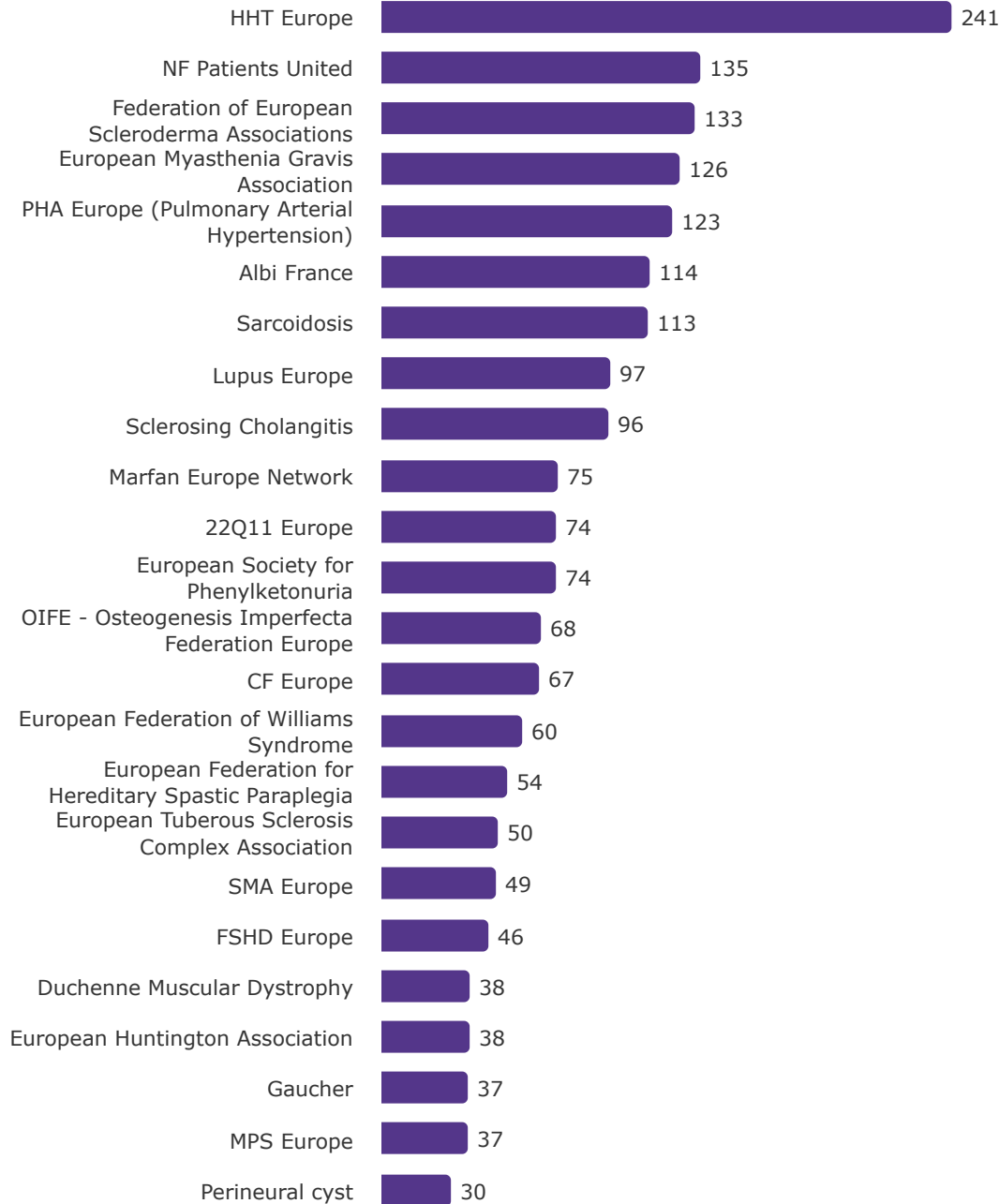


### Number of participants per European Reference Network (ERN)



### EURORDIS European Federations

<https://www.eurordis.org/who-we-are/our-members/european-or-international-federations-for-rare-diseases/>



### EURORDIS European Federations

<https://www.eurordis.org/who-we-are/our-members/european-or-international-federations-for-rare-diseases/>

	N	%
HHT Europe	241	15%
NF Patients United	135	8%
Federation of European Scleroderma Associations	133	8%
European Myasthenia Gravis Association	126	8%
PHA Europe (Pulmonary Arterial Hypertension)	123	8%
Albi France	114	7%
Sarcoidosis	113	7%
Lupus Europe	97	6%
Sclerosing Cholangitis	96	6%
Marfan Europe Network	75	5%
22Q11 Europe	74	5%
European Society for Phenylketonuria	74	5%
OIFE - Osteogenesis Imperfecta Federation Europe	68	4%
CF Europe	67	4%
European Federation of Williams Syndrome	60	4%

### EURORDIS European Federations

<https://www.eurordis.org/who-we-are/our-members/european-or-international-federations-for-rare-diseases/>

	N	%
European Federation of Williams Syndrome	60	14%
European Federation for Hereditary Spastic Paraplegia	54	12%
European Tuberos Sclerosis Complex Association	50	11%
SMA Europe	49	11%
FSHD Europe	46	10%
Duchenne Muscular Dystrophy	38	9%
European Huntington Association	38	9%
Gaucher	37	8%
MPS Europe	37	8%
Perineural cyst	30	7%

## **A** 2. DISABILITIES

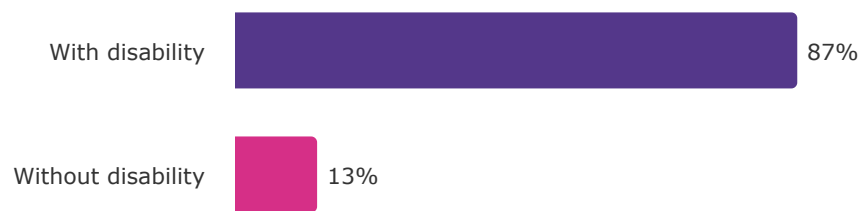
**Disability rates; diversity, complexity  
and severity of disabilities**

The Washington Group Short Set on functioning assesses the difficulty experienced by people living with rare diseases in doing six activities: seeing, hearing, walking or climbing steps, remembering or concentrating, self-care, communication.

**Disability rate: Washington group short set (WGSS)**

	N	%
With disability	8,351	87%
Without disability	1,240	13%
<b>TOTAL</b>	<b>9,591</b>	<b>100%</b>

**Disability rate: Washington group short set (WGSS)**

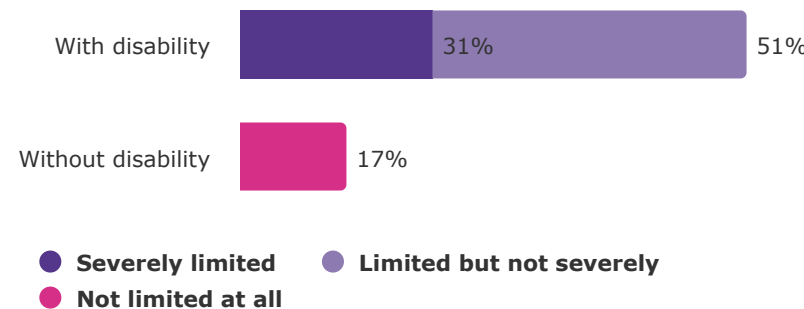


The Global Activity Limitation Index (GALI) measures disability through activity limitations that an individual experienced in the last 6 months or more due to a health problem.

**During the last 6 or more months, have you been limited in performing activities that people usually do because of a health problem? Would you say...**

	N	%
▼ With disability	7,790	83%
Severely limited	2,964	31%
Limited but not severely	4,826	51%
▼ Without disability	1,652	17%
Not limited at all	1,652	17%
<b>TOTAL</b>	<b>9,442</b>	<b>100%</b>

**During the last 6 or more months, have you been limited in performing activities that people usually do because of a health problem? Would you say...**

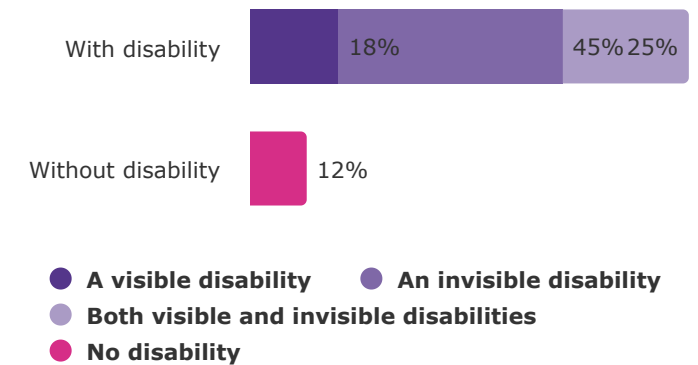


People living with rare diseases were asked if they perceive themselves as living with a disability, be it invisible, visible or both.

**Do you consider yourself as a person with...?**

	N	%
▼ With disability	8,030	88%
A visible disability	1,626	18%
An invisible disability	4,107	45%
Both visible and invisible di...	2,297	25%
▼ Without disability	1,068	12%
No disability	1,068	12%
<b>TOTAL</b>	<b>9,098</b>	<b>100%</b>

**Do you consider yourself as a person with...?**

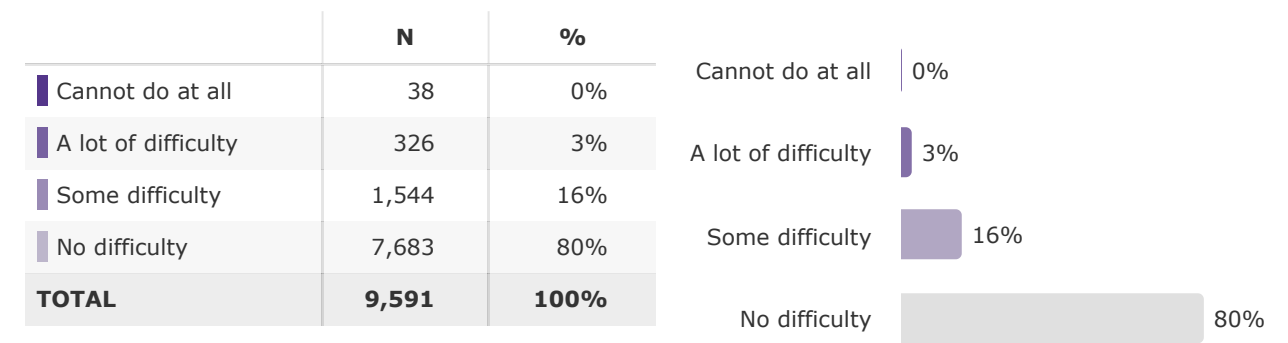
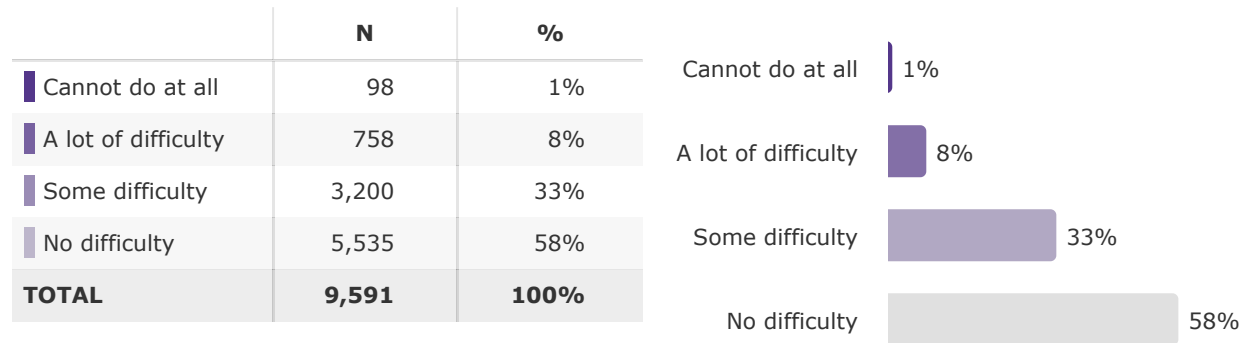


## Washington Group Short Set (WG-SS)

<https://www.washingtongroup-disability.com/question-sets/wg-short-set-on-functioning-wg-ss/>

Do you have difficulty SEEING, even if wearing glasses? Would you say...

Do you have difficulty HEARING, even if using a hearing aid(s)? Would you say...

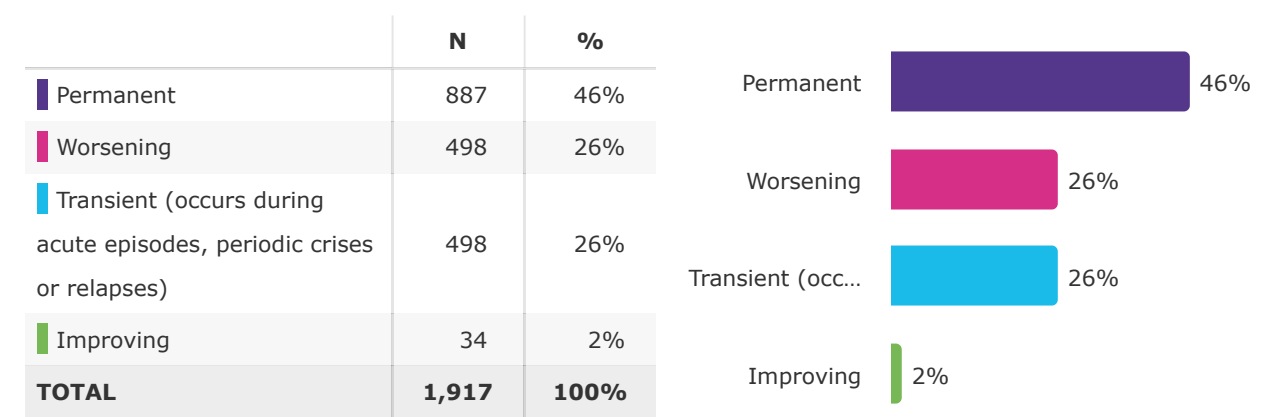
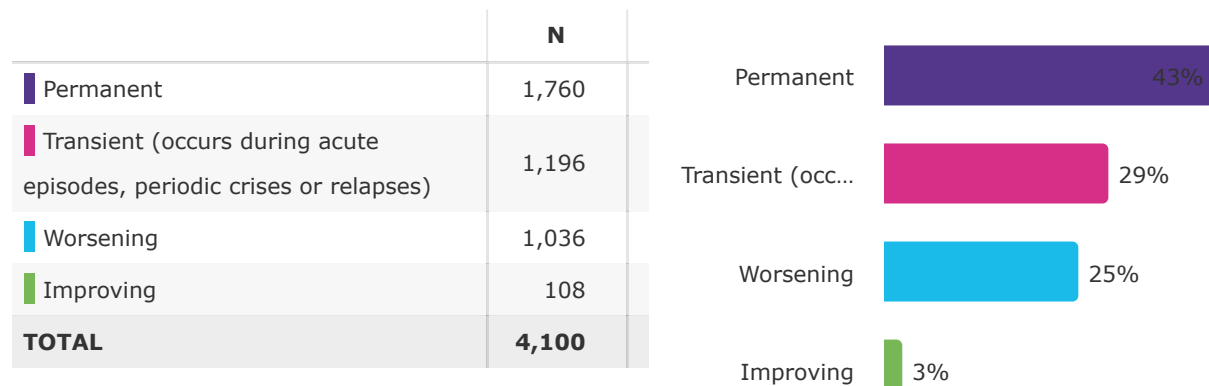


These questions were only asked to people with difficulty.



Is the difficulty...?

Is the difficulty...?

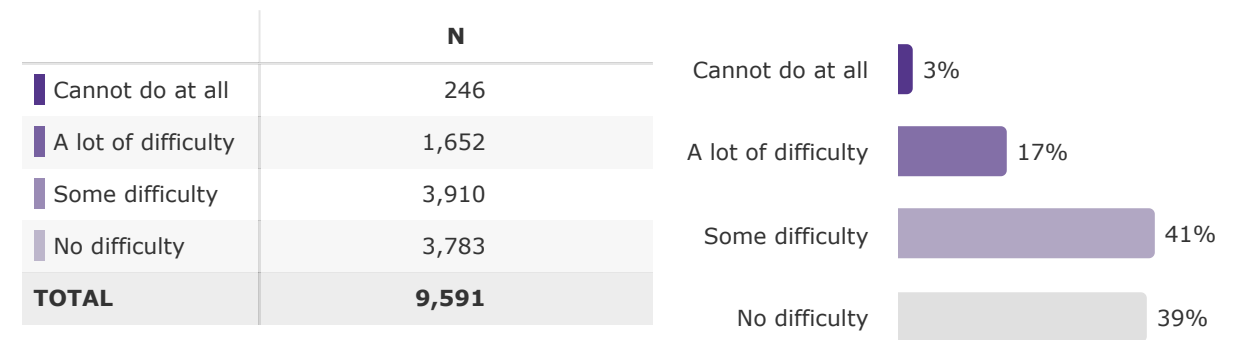
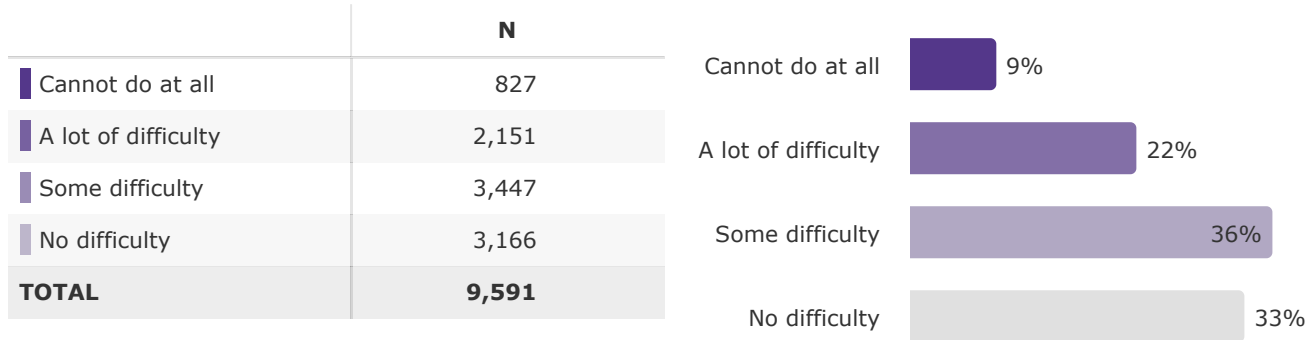


## Washington Group Short Set (WG-SS)

<https://www.washingtongroup-disability.com/question-sets/wg-short-set-on-functioning-wg-ss/>

Do you have difficulty WALKING or CLIMBING STEPS? Would you say...

Do you have difficulty REMEMBERING or CONCENTRATING? Would you say...

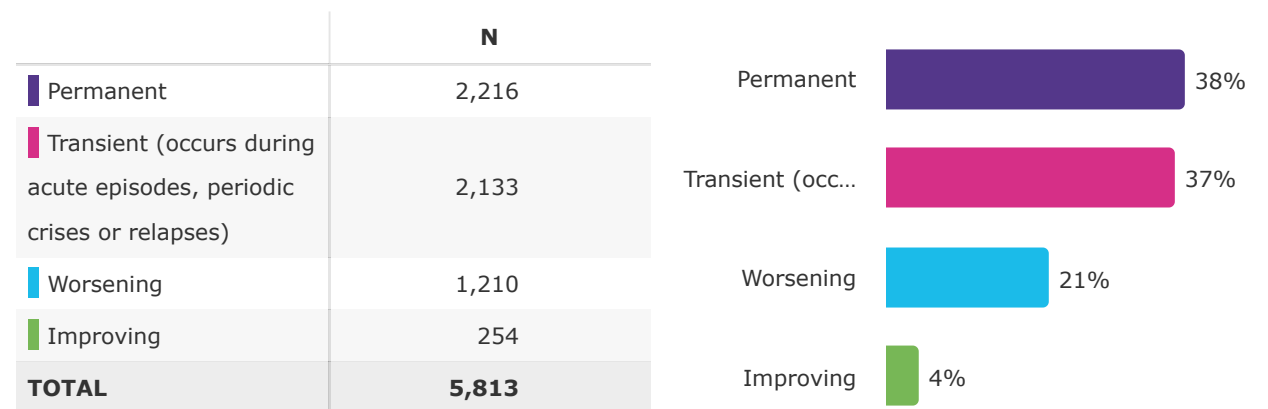
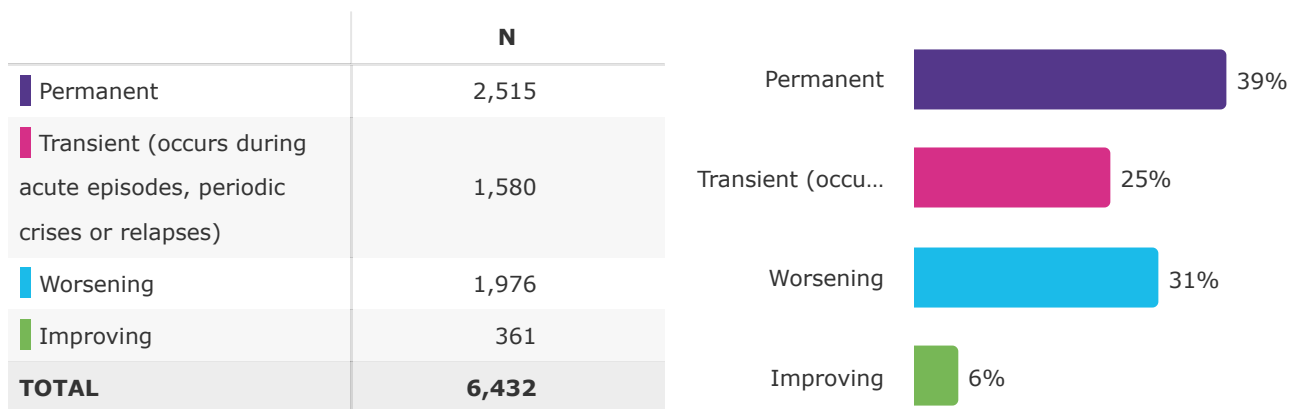


These questions were only asked to people with difficulty.



Is the difficulty...?

Is the difficulty...?





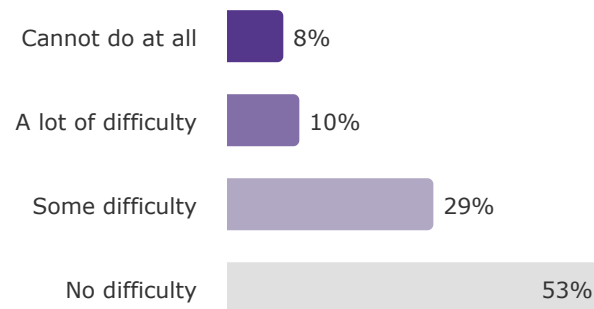
## Washington Group Short Set (WG-SS)

<https://www.washingtongroup-disability.com/question-sets/wg-short-set-on-functioning-wg-ss/>

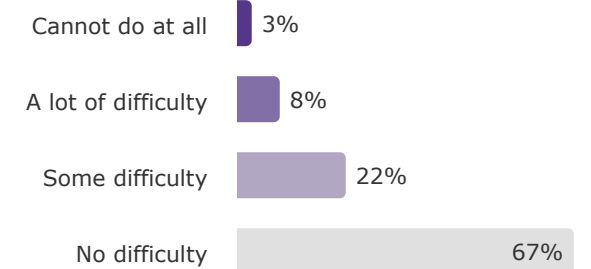
Do you have difficulty with SELF-CARE, such as washing all over or dressing? Would you say...

Using your usual language, do you have difficulty COMMUNICATING, for example, understanding or being understood? Would you say...

	N
Cannot do at all	766
A lot of difficulty	989
Some difficulty	2,783
No difficulty	5,053
<b>TOTAL</b>	<b>9,591</b>



	N
Cannot do at all	287
A lot of difficulty	814
Some difficulty	2,093
No difficulty	6,397
<b>TOTAL</b>	<b>9,591</b>

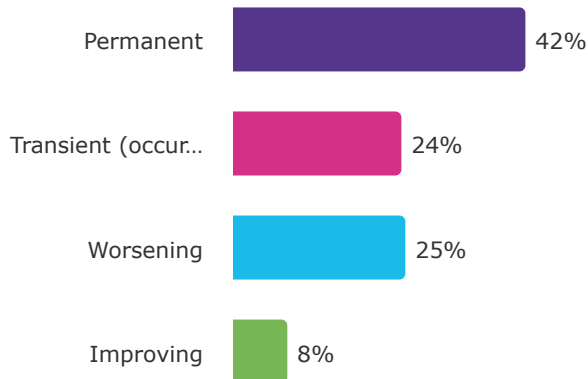


These questions were only asked to people with difficulty.

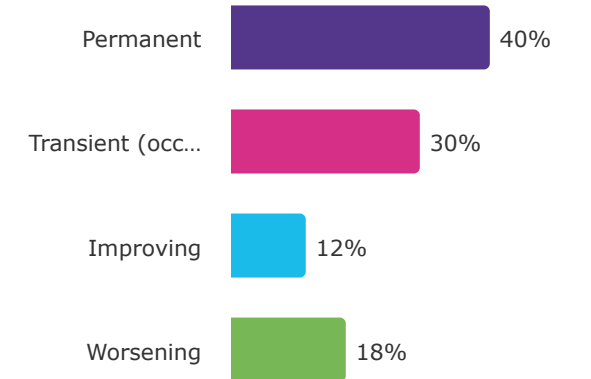
Is the difficulty...?

Is the difficulty...?

	N
Permanent	1,926
Transient (occurs during acute episodes, periodic crises or relapses)	1,108
Worsening	1,142
Improving	366
<b>TOTAL</b>	<b>4,542</b>



	N
Permanent	1,294
Transient (occurs during acute episodes, periodic crises or relapses)	945
Improving	380
Worsening	580
<b>TOTAL</b>	<b>3,199</b>



## Washington Group Short Set (WG-SS)

<https://www.washingtongroup-disability.com/question-sets/wg-short-set-on-functioning-wg-ss/>

Number of participants who have difficulty in at least 2 activities

6,918

▼ Sample information : Number\_difficulties\_WGSS >= 2

Percentage of participants who have difficulty in at least 2 activities

72%

Number of participants who have difficulty in at least 3 activities

5,086

▼ Sample information : Number\_difficulties\_WGSS >= 3

Percentage of participants who have difficulty in at least 3 activities

53%

Number of participants who have difficulty in at least 4 activities

3,367

▼ Sample information : Number\_difficulties\_WGSS >= 4

Percentage of participants who have difficulty in at least 4 activities

35%

Number of participants with progressive or dynamic disabilities

6,134

▼ Sample information : Index\_prog >= 1

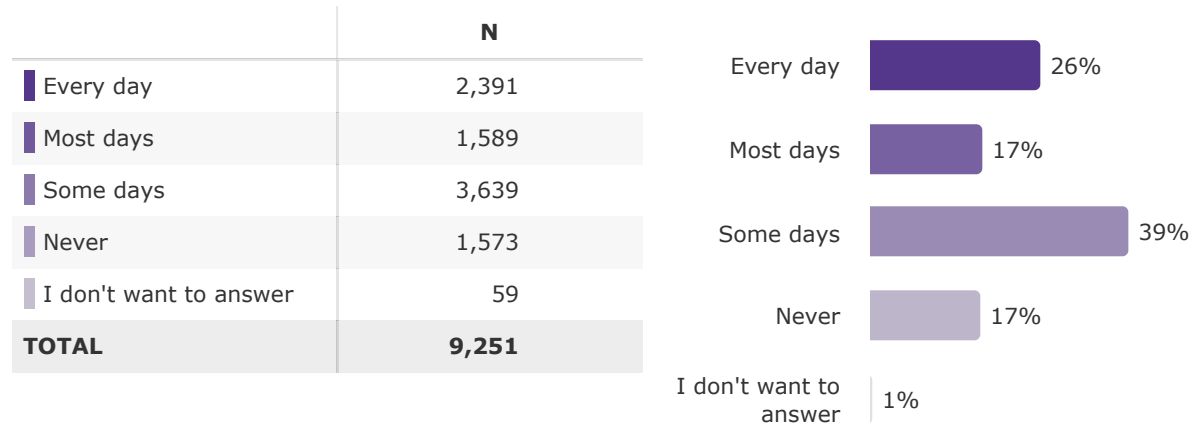
Percentage of participants with progressive or dynamic disabilities

64%

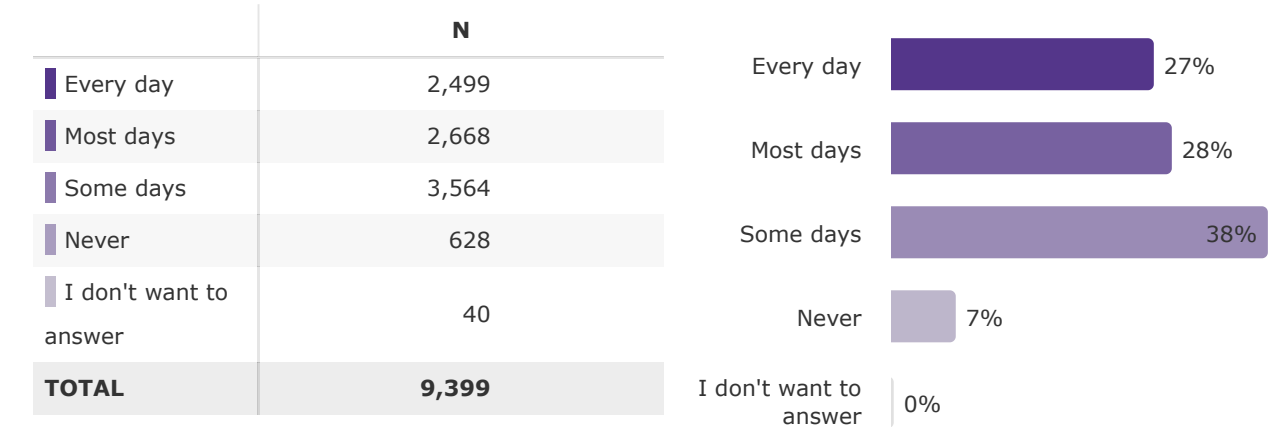
## Washington Group Extended Set (WG-ES)

<https://www.washingtongroup-disability.com/question-sets/wg-extended-set-on-functioning-wg-es/>

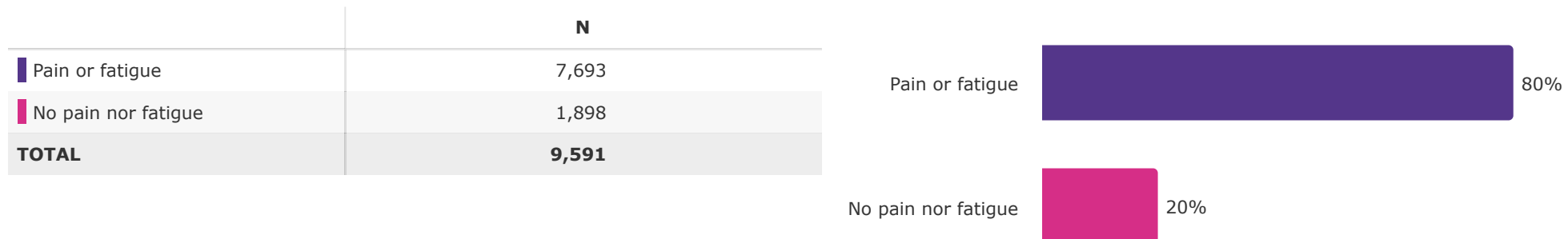
In the past three months, how often did you have PAIN? Would you say...



In the past three months, how often have you felt very TIRED or EXHAUSTED? Would you say...



In the past three months, how often have you felt very TIRED or EXHAUSTED? Would you say.../ OR  
 In the past three, how often did you have PAIN or FATIGUE? Would you say...



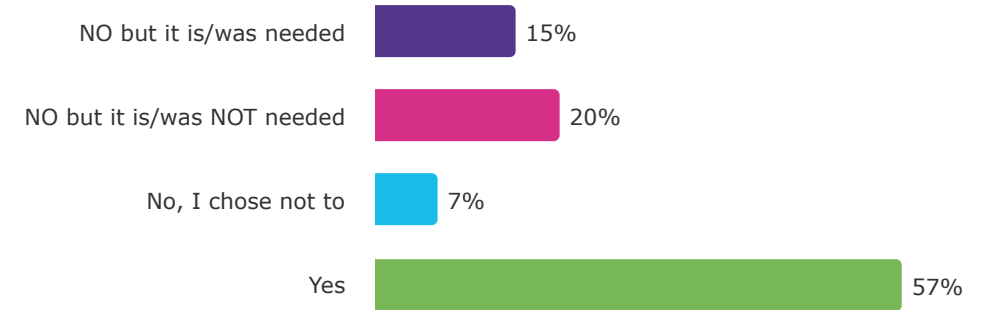


## 3. DISABILITY RECOGNITION

Disability assessment and barriers

### Have you ever undergone a disability assessment, which aims to assess and recognise disabilities?

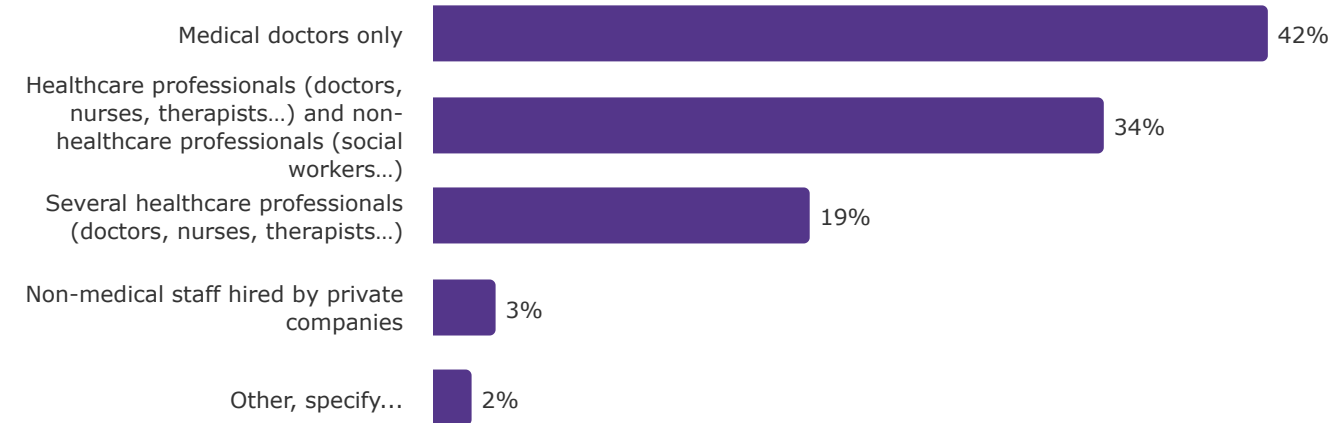
	N	%
NO but it is/was needed	1,435	15%
NO but it is/was NOT needed	1,878	20%
No, I chose not to	655	7%
Yes	5,364	57%
<b>TOTAL</b>	<b>9,332</b>	<b>100%</b>



These questions were only asked to people who underwent a disability assessment.

### What kind of professionals were involved in the assessment?

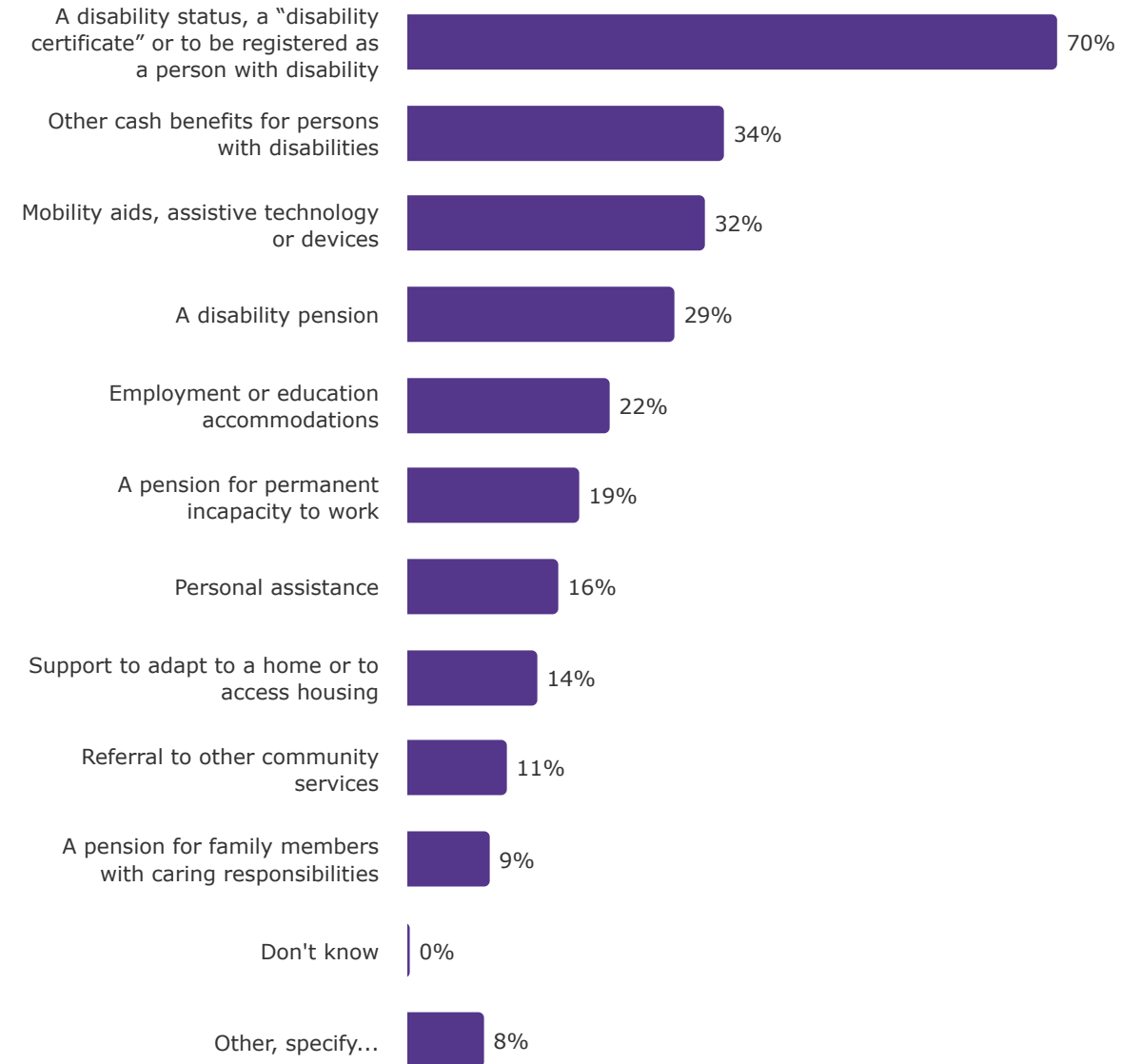
	N	%
Medical doctors only	2,164	42%
Healthcare professionals (doctors, nurses, therapists...) and non-healthcare professionals (social workers...)	1,742	34%
Several healthcare professionals (doctors, nurses, therapists...)	979	19%
Non-medical staff hired by private companies	168	3%
Other, specify...	106	2%
<b>TOTAL</b>	<b>5,159</b>	<b>100%</b>



**These questions were only asked to people who underwent a disability assessment.**

**Was (or were) the purpose(s) of the disability assessment(s) to obtain...?**

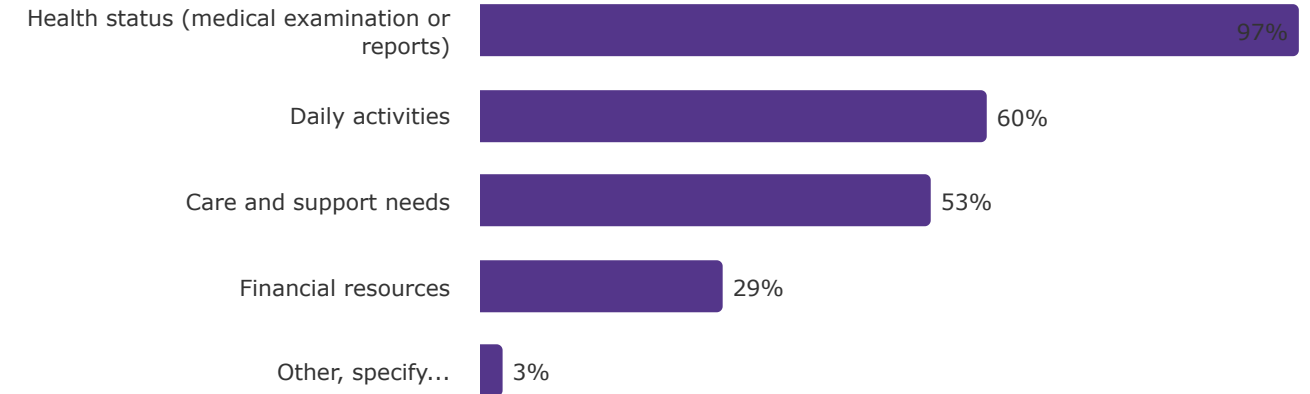
	N	%
A disability status, a "disability certificate" or to be registered as a person with disability	1,157	70%
Other cash benefits for persons with disabilities	565	34%
Mobility aids, assistive technology or devices	533	32%
A disability pension	476	29%
Employment or education accommodations	364	22%
A pension for permanent incapacity to work	307	19%
Personal assistance	271	16%
Support to adapt to a home or to access housing	234	14%
Referral to other community services	180	11%
A pension for family members with caring responsibilities	149	9%
Don't know	6	0%
Other, specify...	140	8%
<b>TOTAL</b>	<b>1,651</b>	



**These questions were only asked to people who underwent a disability assessment.**

**During the assessment, were you required to provide information on...?**

	N	%
Health status (medical examination or reports)	5,128	97%
Daily activities	3,176	60%
Care and support needs	2,834	53%
Financial resources	1,524	29%
Other, specify...	155	3%
<b>TOTAL</b>	<b>5,306</b>	



**How many disability assessments have you undergone?**

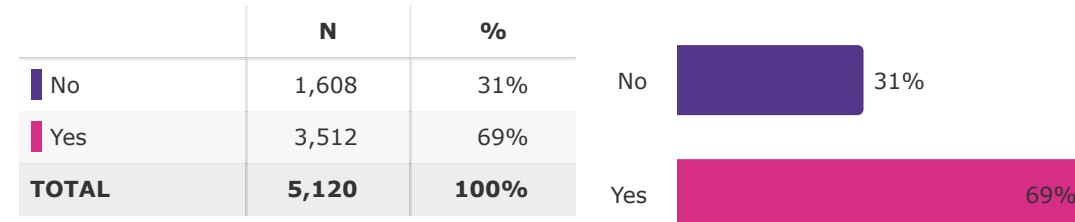
	N	Percentage
More than one assessment	3,268	61%
One assessment	2,089	39%
<b>TOTAL</b>	<b>5,357</b>	

**At the end of the disability assessment, did you have access to the expected rights and support?**

	N	Percentage
No access	872	16%
Partially	2,553	47%
In full	1,955	36%
<b>TOTAL</b>	<b>5,380</b>	

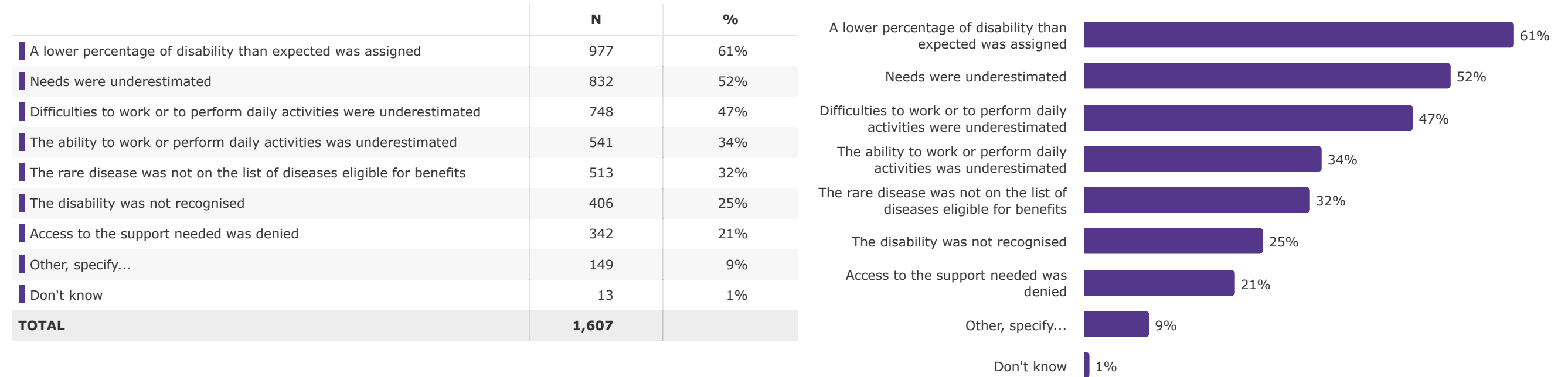
This question was only asked to people who underwent a disability assessment

Was the result of the assessment what you expected?



This question was only asked to people who answer NO.

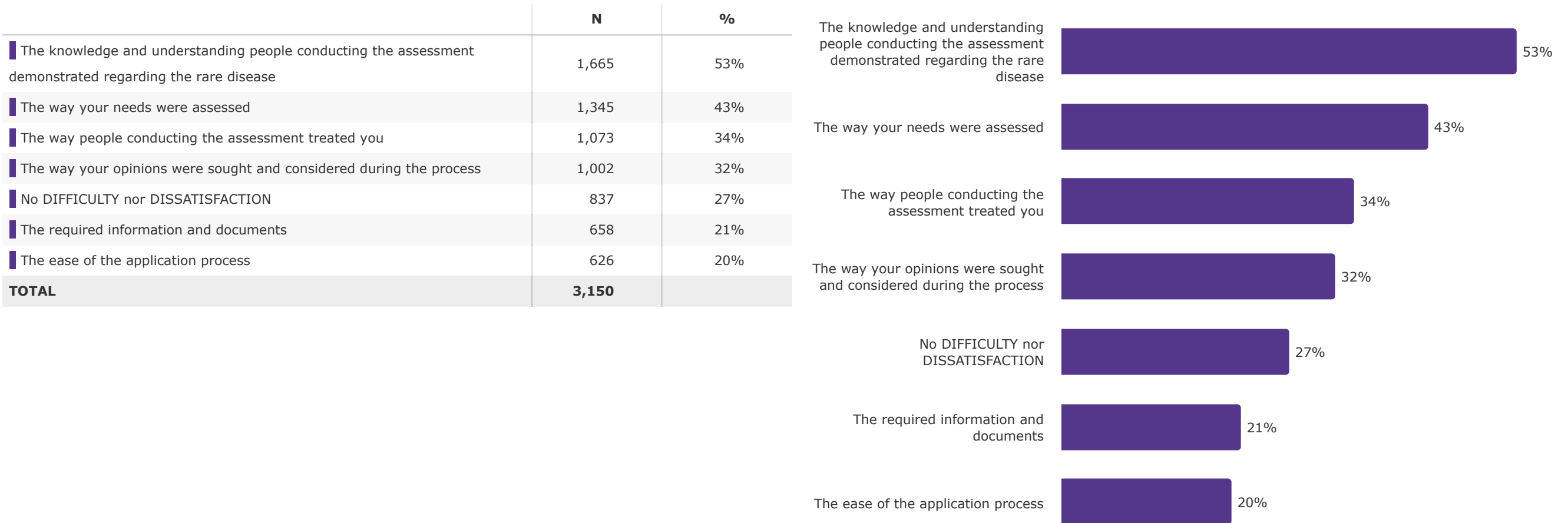
In your opinion, was it because...?





These questions were only asked to people who underwent a disability assessment.

During the assessment, did you have DIFFICULTY or DISSATISFACTION in:



Sample information : PATIENTvsCARER among "Patient"

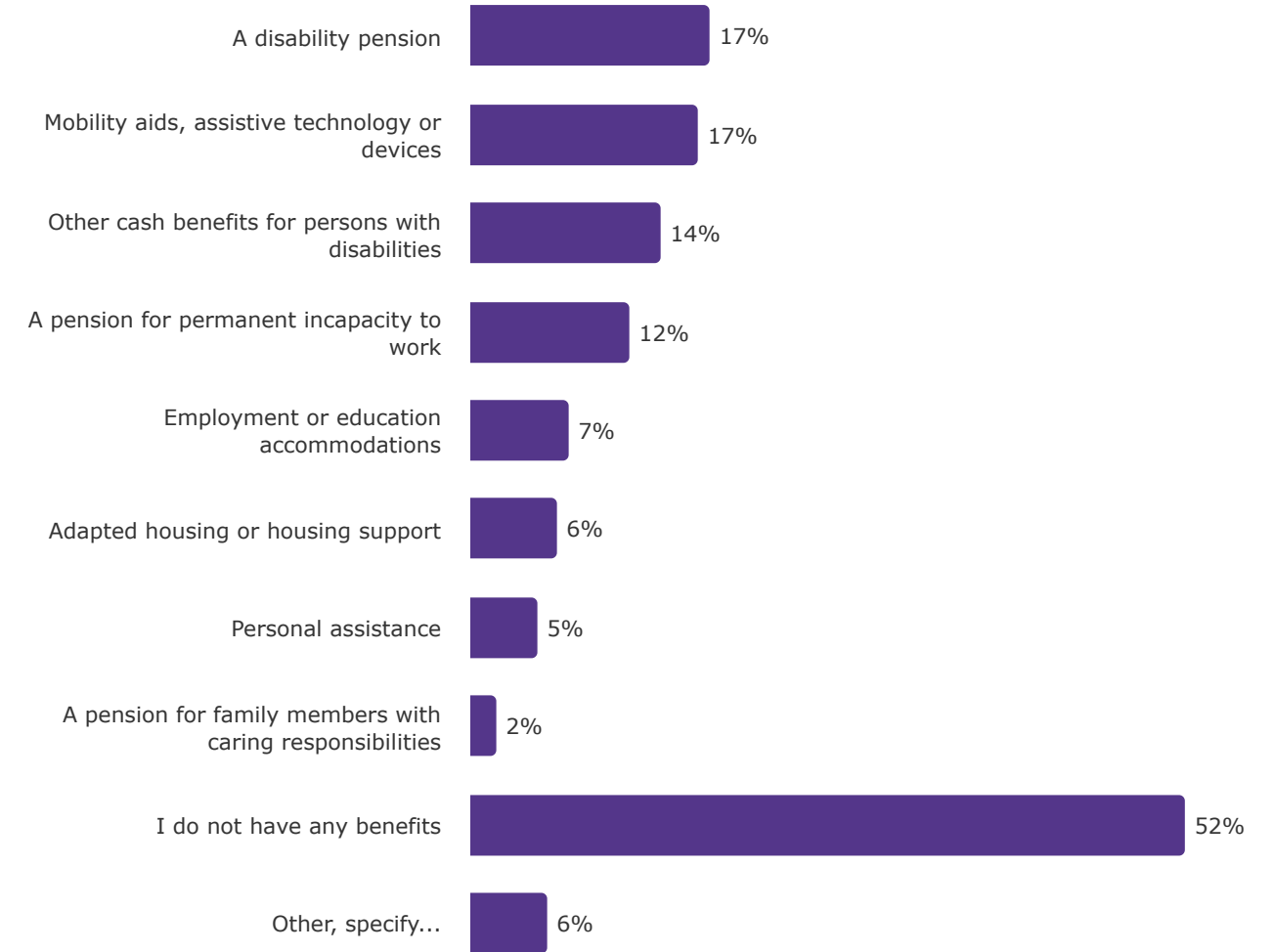


## 4. INDEPENDENT LIVING

Public support, personal assistant,  
living arrangements

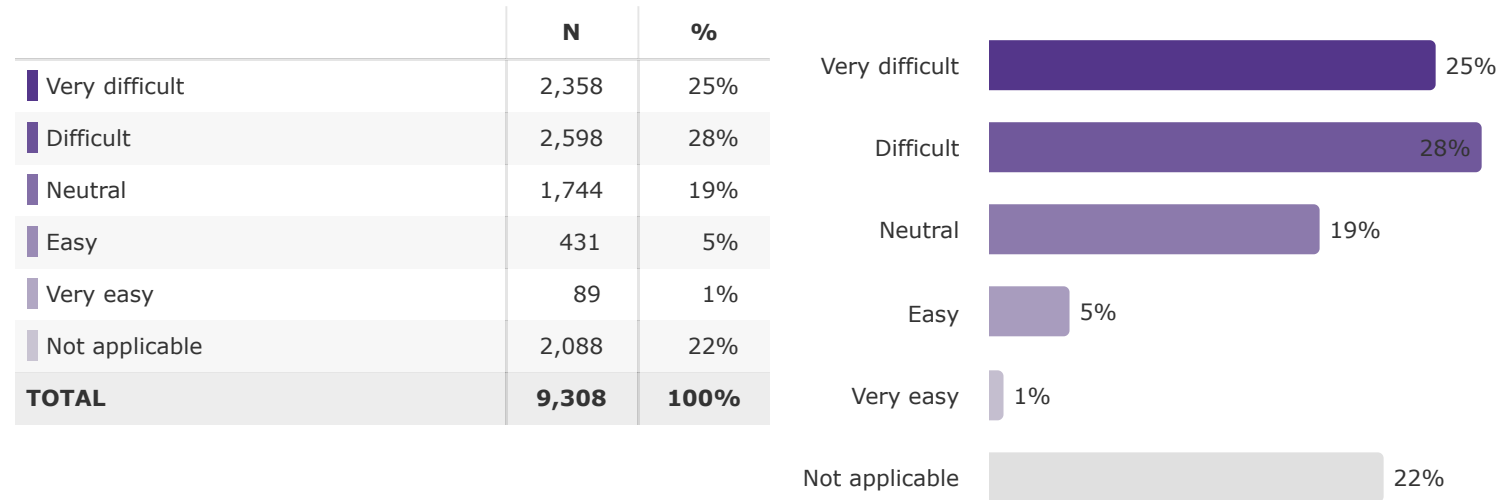
**Do you currently benefit from...?**

	<b>N</b>	<b>%</b>
A disability pension	1,082	17%
Mobility aids, assistive technology or devices	1,024	17%
Other cash benefits for persons with disabilities	855	14%
A pension for permanent incapacity to work	719	12%
Employment or education accommodations	443	7%
Adapted housing or housing support	395	6%
Personal assistance	303	5%
A pension for family members with caring responsibilities	120	2%
I do not have any benefits	3,205	52%
Other, specify...	347	6%
<b>TOTAL</b>	<b>6,194</b>	



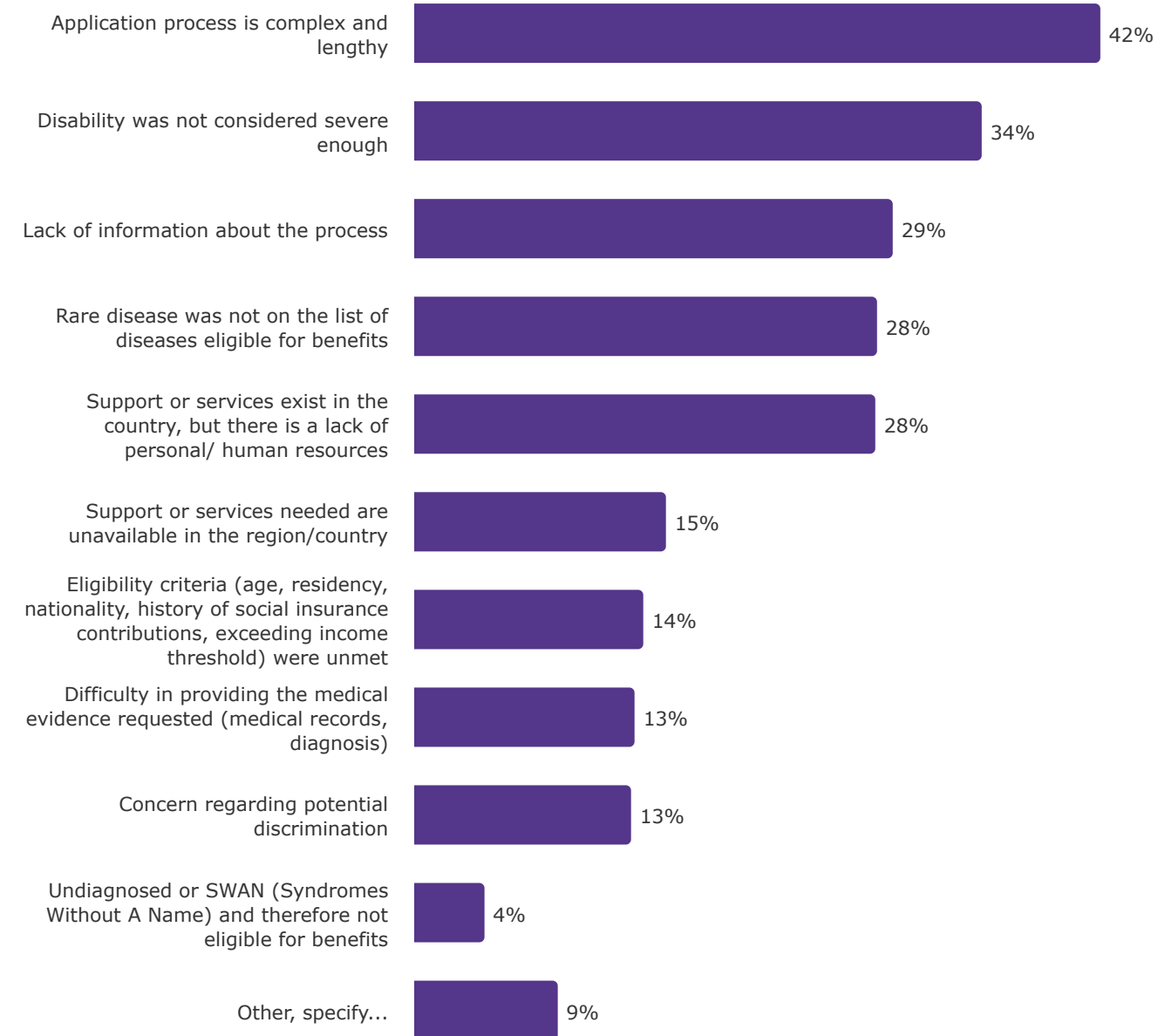
▼ Sample information : PATIENTvsCARER among "Patient"

**How difficult do you find it to obtain state support such as attendant care, home support, financial support, assistive technology, mobility aids, etc.?**



**What barriers are you facing in obtaining support such as attendant care support, home support, financial support, assistive technology, mobility aids, etc.?**

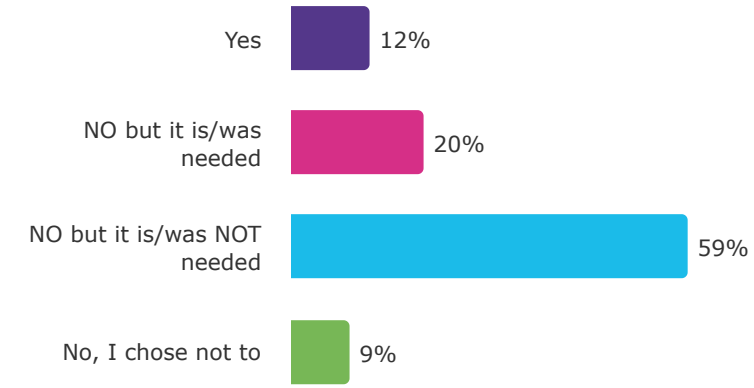
	N
Application process is complex and lengthy	2,923
Disability was not considered severe enough	2,421
Lack of information about the process	2,038
Rare disease was not on the list of diseases eligible for benefits	1,977
Support or services exist in the country, but there is a lack of personal/ human resources	1,970
Support or services needed are unavailable in the region/country	1,079
Eligibility criteria (age, residency, nationality, history of social insurance contributions, exceeding income threshold) were unmet	982
Difficulty in providing the medical evidence requested (medical records, diagnosis)	945
Concern regarding potential discrimination	930
Undiagnosed or SWAN (Syndromes Without A Name) and therefore not eligible for benefits	305
Other, specify...	613
<b>TOTAL</b>	<b>7,042</b>



**This question was only asked to people who didn't find it very easy to obtain state support.**

### Do you have a personal assistant to help you live independently?

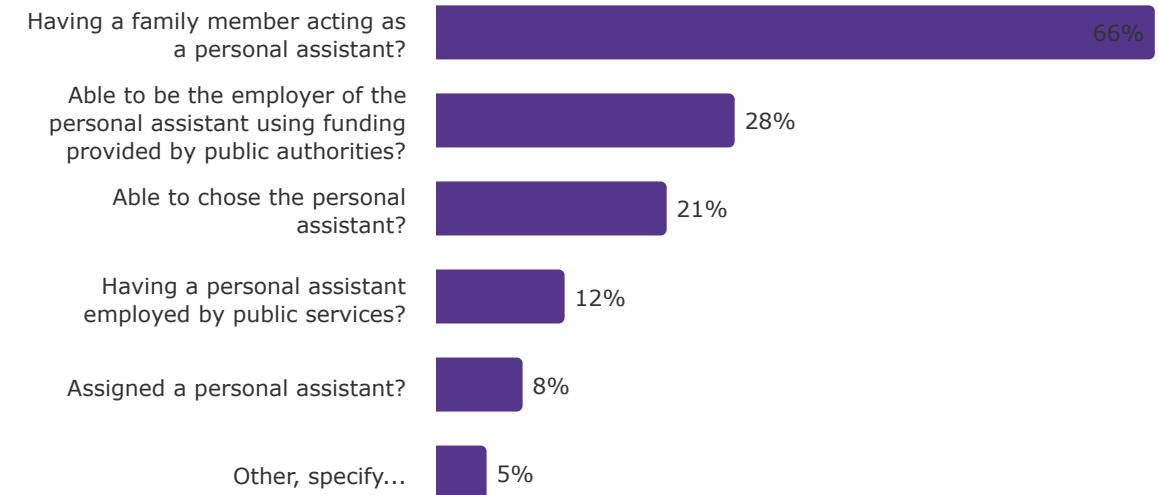
	N
Yes	1,112
NO but it is/was needed	1,845
NO but it is/was NOT needed	5,483
No, I chose not to	818
<b>TOTAL</b>	<b>9,258</b>



This question was only asked to people who have a personal assistant.

### Were you...?

	N	%
Having a family member acting as a personal assistant?	755	66%
Able to be the employer of the personal assistant using funding provided by public authorities?	315	28%
Able to chose the personal assistant?	244	21%
Having a personal assistant employed by public services?	137	12%
Assigned a personal assistant?	92	8%
Other, specify...	55	5%
<b>TOTAL</b>	<b>1,138</b>	



**These questions were only asked to people who have a personal assistant.**

How many hours of personal assistance do they currently have per day?

**10.9**

Mean

How many days of personal assistance do they currently have per week?

**5.4**

Mean

How many hours of personal assistance do they currently have per day?

**7.0**

Median

How many days of personal assistance do they currently have per week?

**7.0**

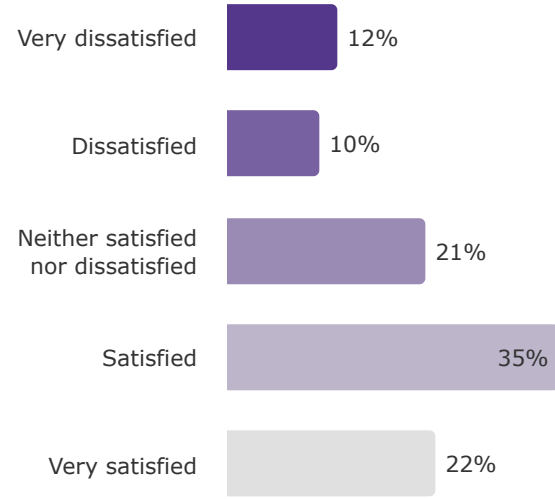
Median

These questions were only asked to people who have a personal assistant.

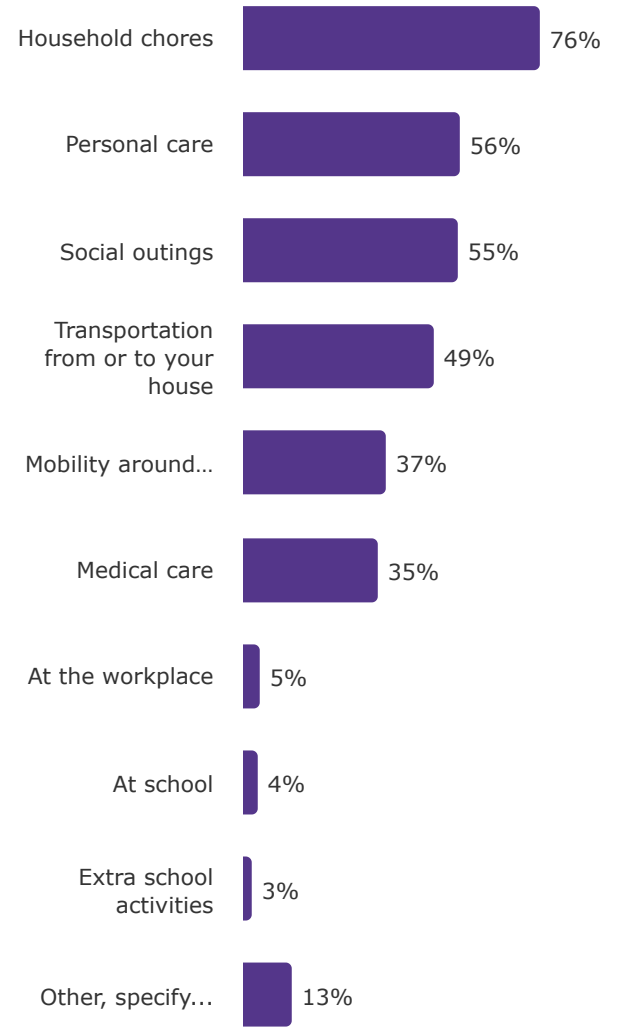
**Are you satisfied with the number of hours of personal assistance?**

**What tasks is the personal assistant currently assisting with?**

	N	%
Very dissatisfied	108	12%
Dissatisfied	92	10%
Neither satisfied nor dissatisfied	195	21%
Satisfied	324	35%
Very satisfied	205	22%
<b>TOTAL</b>	<b>924</b>	<b>100%</b>



	N	%
Household chores	424	76%
Personal care	309	56%
Social outings	308	55%
Transportation from or to your house	274	49%
Mobility around your place (transferring in and out of bed, from a position to another)	204	37%
Medical care	193	35%
At the workplace	25	5%
At school	23	4%
Extra school activities	14	3%
Other, specify...	70	13%
<b>TOTAL</b>	<b>555</b>	

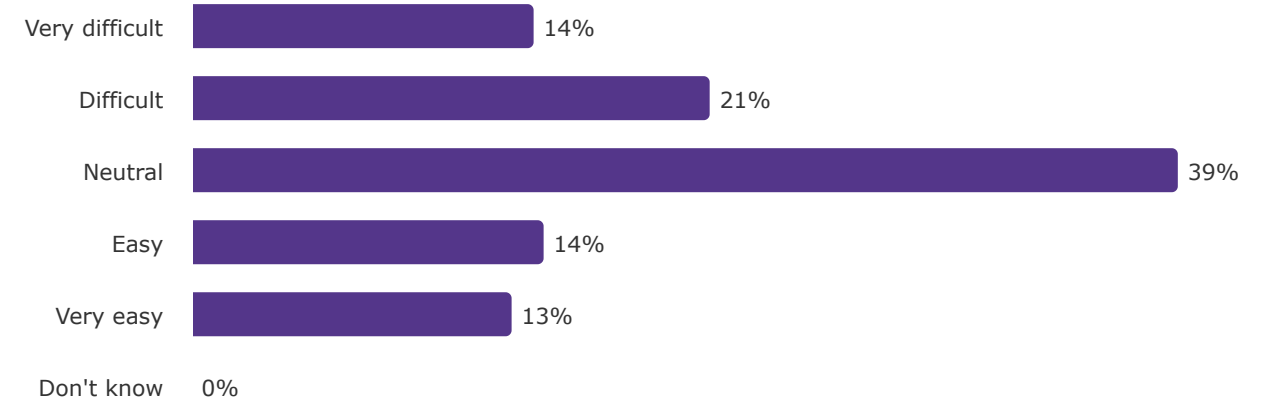




This question was only asked to people who have a personal assistant.

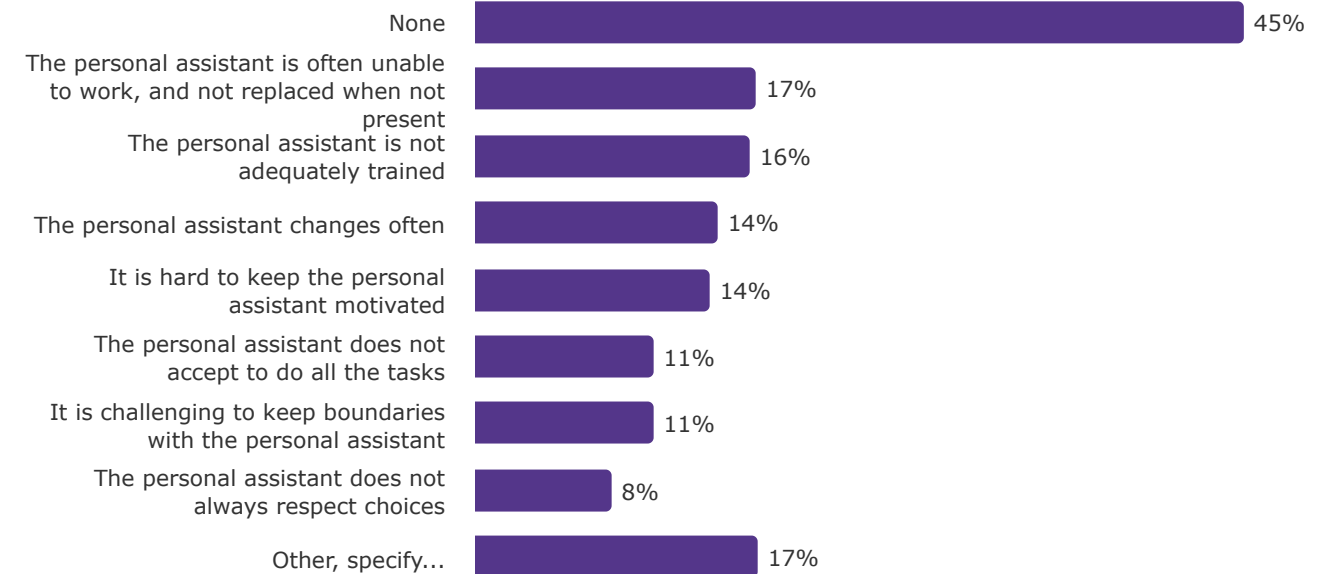
How difficult do you find it to manage the personal assistant (hiring, managing, paying)?

	N	%
Very difficult	62	14%
Difficult	94	21%
Neutral	179	39%
Easy	64	14%
Very easy	58	13%
Don't know	0	0%
<b>TOTAL</b>	<b>457</b>	<b>100%</b>



What are the difficulties faced managing the personal assistant?

	N	%
None	456	45%
The personal assistant is often unable to work, and not replaced when not present	167	17%
The personal assistant is not adequately trained	163	16%
The personal assistant changes often	144	14%
It is hard to keep the personal assistant motivated	140	14%
The personal assistant does not accept to do all the tasks	107	11%
It is challenging to keep boundaries with the personal assistant	107	11%
The personal assistant does not always respect choices	82	8%
Other, specify...	168	17%
<b>TOTAL</b>	<b>1,006</b>	

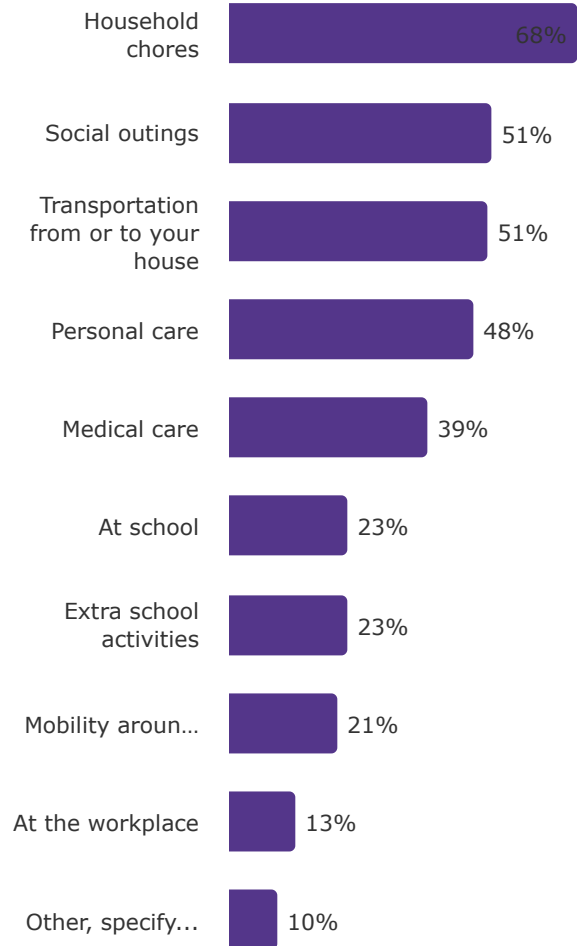


This question was only asked to people who do not have a personal assistant but need one.

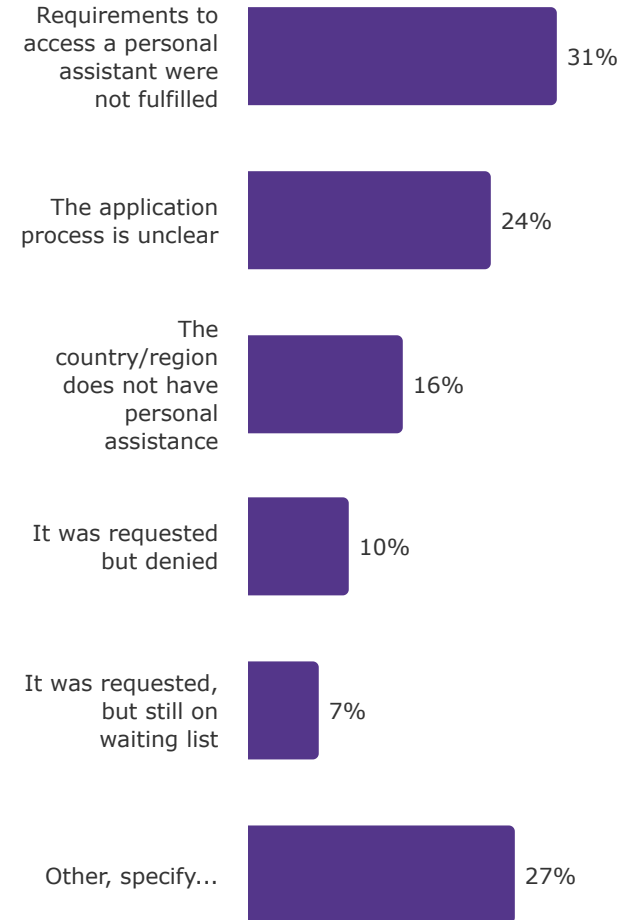
What tasks would you need assistance with?

What are the reasons for not having a personal assistant?

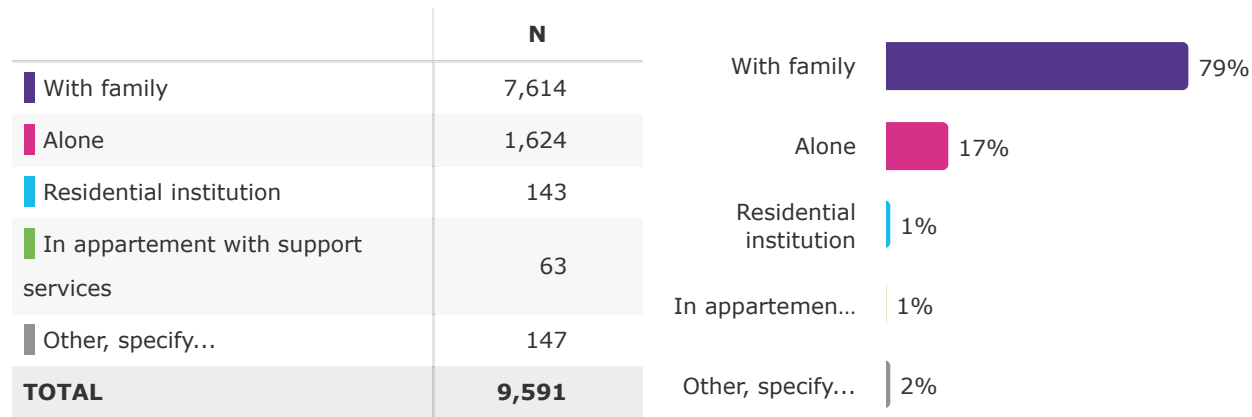
	N	%
Household chores	1,219	68%
Social outings	919	51%
Transportation from or to your house	904	51%
Personal care	858	48%
Medical care	693	39%
At school	419	23%
Extra school activities	418	23%
Mobility around your place (transferring in and out of bed, from a position to another)	379	21%
At the workplace	239	13%
Other, specify...	175	10%
<b>TOTAL</b>	<b>1,789</b>	



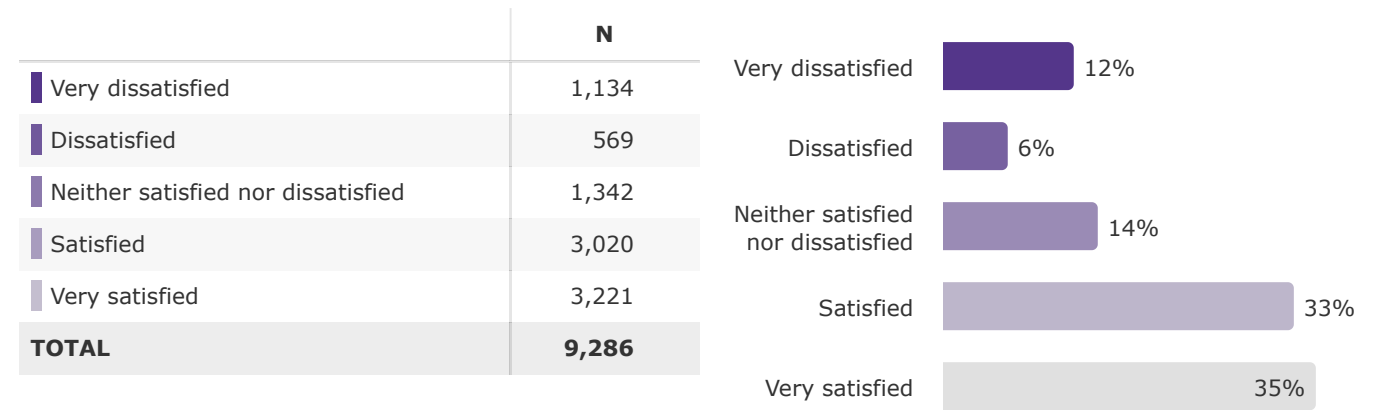
	N	%
Requirements to access a personal assistant were not fulfilled	349	31%
The application process is unclear	274	24%
The country/region does not have personal assistance	175	16%
It was requested but denied	115	10%
It was requested, but still on waiting list	81	7%
Other, specify...	301	27%
<b>TOTAL</b>	<b>1,119</b>	



### Do you live...



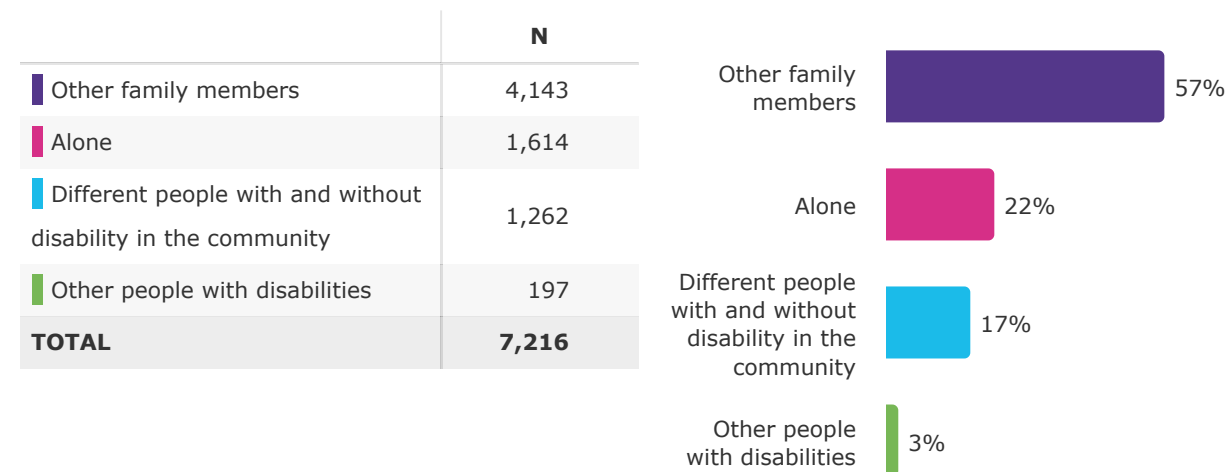
### Are you satisfied with your current living arrangements?



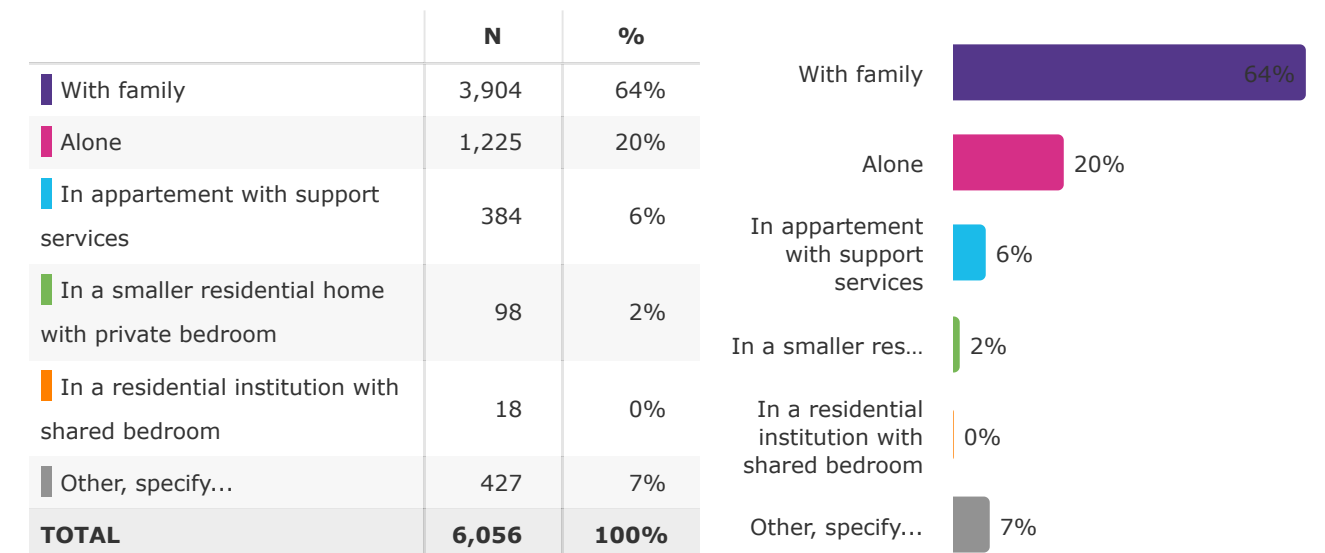
This question were only asked to people that consider themselves as living with disabilities.

This question were only asked to people that are not very satisfied of their current living arrangements.

### Do you spend most of your day with...?



### Would you prefer to live...?



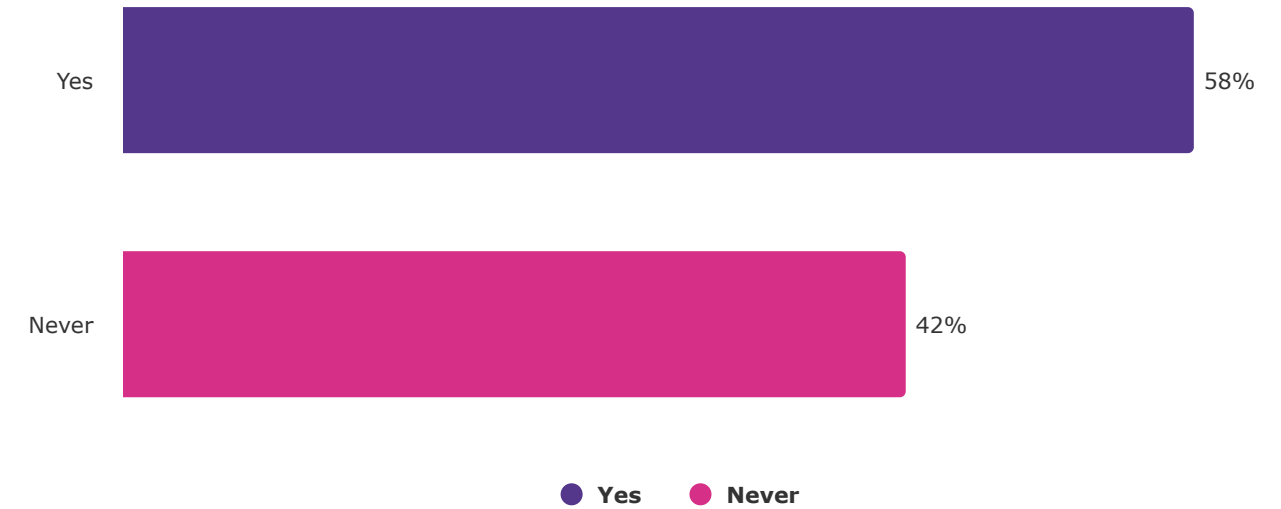


## 5. SOCIAL PARTICIPATION

**Discrimination, employment, school participation, community participation, social environment**

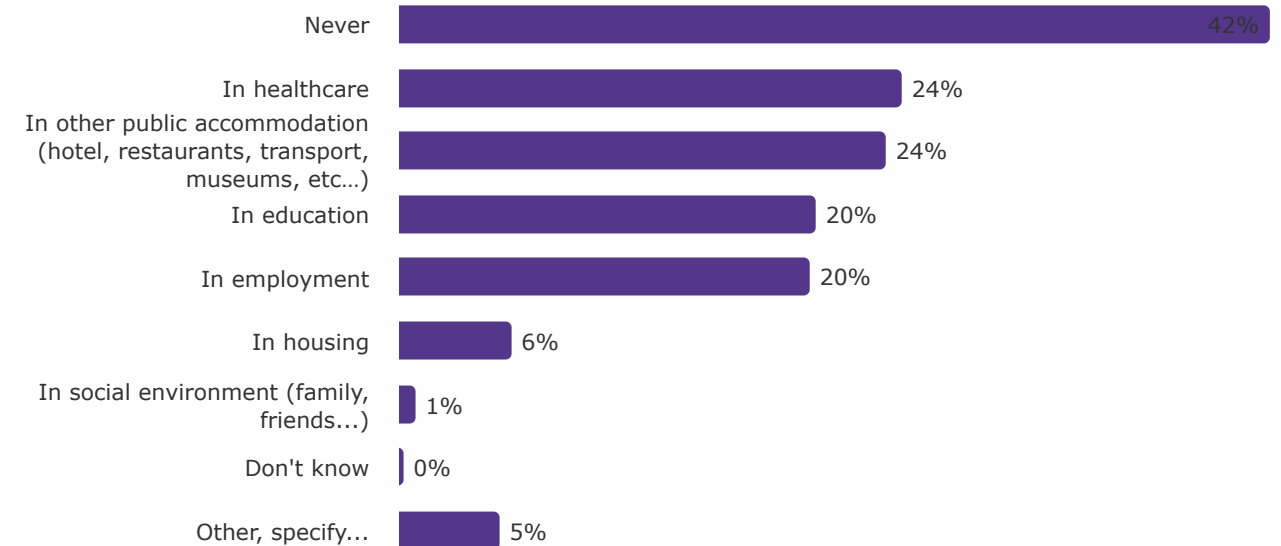
### Have you ever experienced discrimination related to the rare disease or disability?

	N	%
▼ Yes	5,270	58%
In healthcare	2,234	24%
In other public accommodation (hotel, restaurants, transport, museums, et...	2,158	24%
In education	1,850	20%
In employment	1,822	20%
In housing	506	6%
Other, specify...	454	5%
In social environment (family, friends...)	83	1%
Never	3,860	42%
<b>TOTAL</b>	<b>9,126</b>	



### Have you ever experienced discrimination related to the rare disease or disability?

	N	%
Never	3,860	42%
In healthcare	2,234	24%
In other public accommodation (hotel, restaurants, transport, museums, etc...)	2,158	24%
In education	1,850	20%
In employment	1,822	20%
In housing	506	6%
In social environment (family, friends...)	83	1%
Don't know	25	0%
Other, specify...	454	5%
<b>TOTAL</b>	<b>9,150</b>	



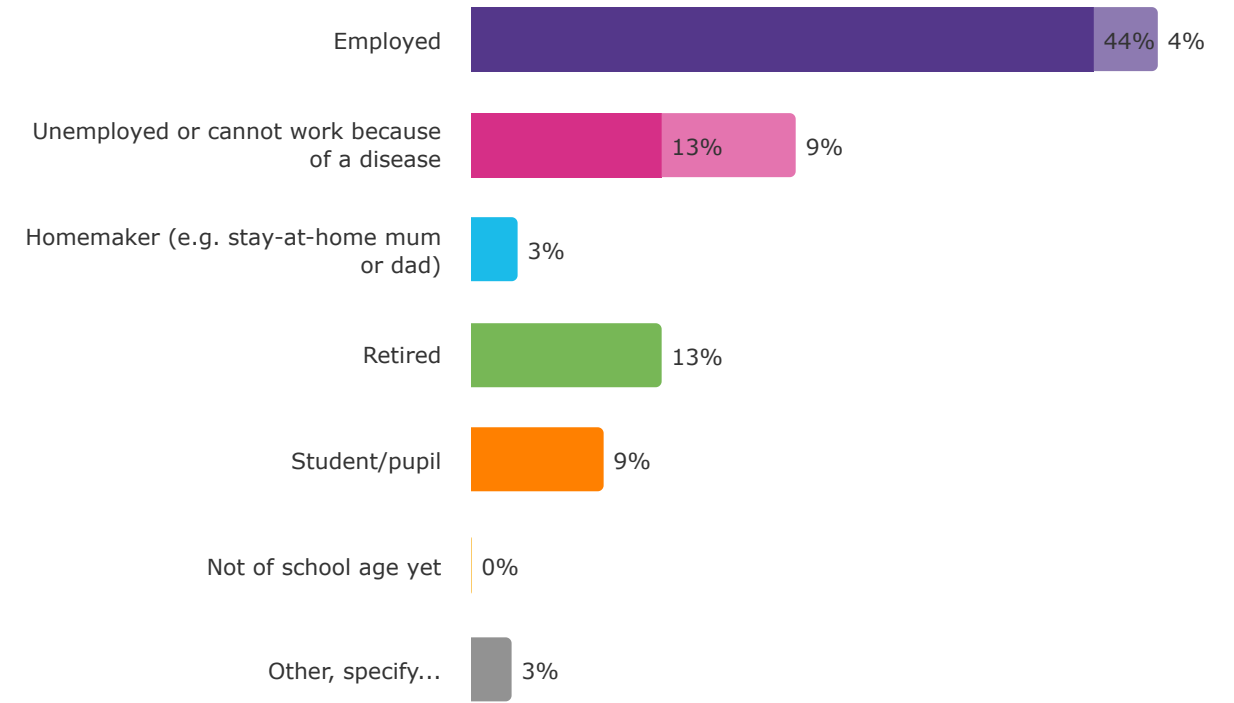


## 5.2. EMPLOYMENT

### Employment and unemployment

### What is your current situation?

	N	%
▼ Employed	2,567	48%
Employed (or partially employed)	2,329	44%
Self-employed	238	4%
▼ Unemployed or cannot work because of a disease	1,216	23%
Unemployed	716	13%
Cannot work because of the disease	500	9%
Homemaker (e.g. stay-at-home mum or dad)	177	3%
Retired	714	13%
Student/pupil	500	9%
Not of school age yet	4	0%
Other, specify...	154	3%
<b>TOTAL</b>	<b>5,332</b>	<b>100%</b>



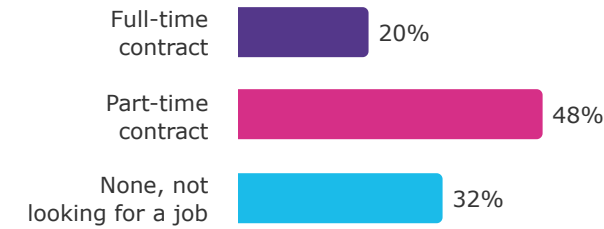
- Employed (or partially employed)
- Self-employed
- Unemployed
- Cannot work because of the disease
- Homemaker (e.g. stay-at-home mum or dad)
- Retired
- Student/pupil
- Not of school age yet
- Other, specify...

▼ Sample information : Age\_patient between 16 and 64

These questions were only asked to unemployed respondents.

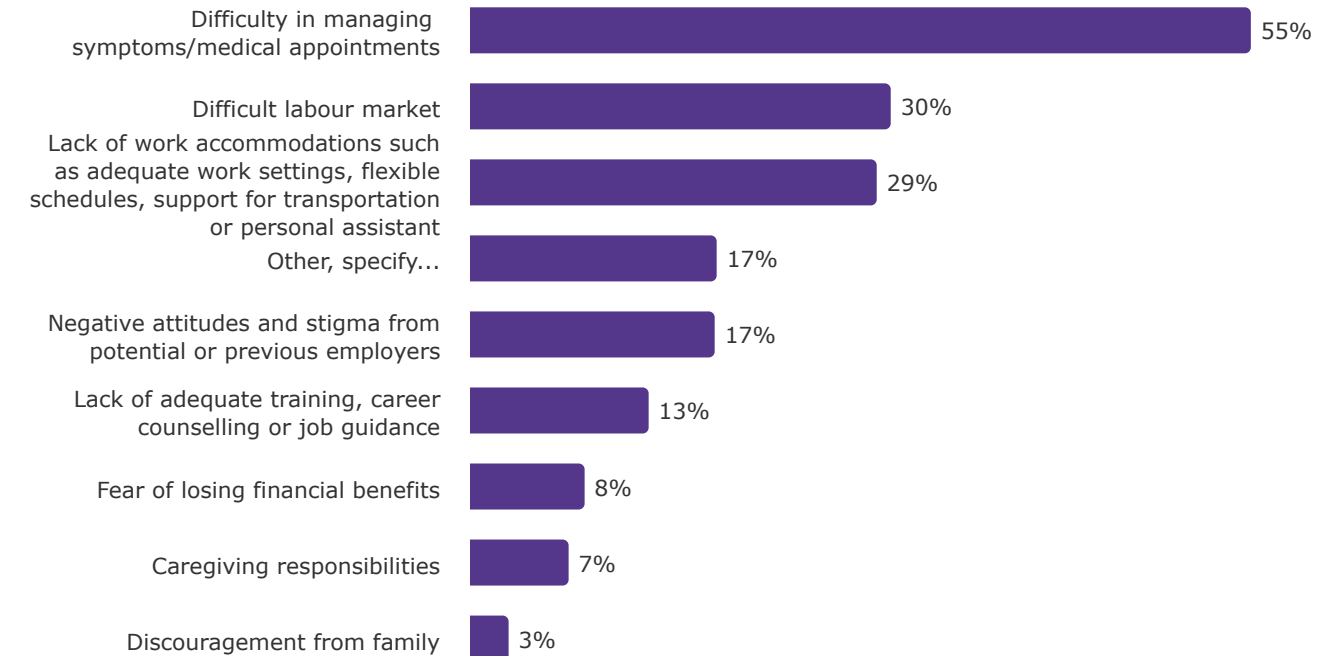
### What type of work contract would you prefer if you became employed?

	N
Full-time contract	185
Part-time contract	431
None, not looking for a job	290
<b>TOTAL</b>	<b>906</b>



### What are your reasons for currently being unemployed?

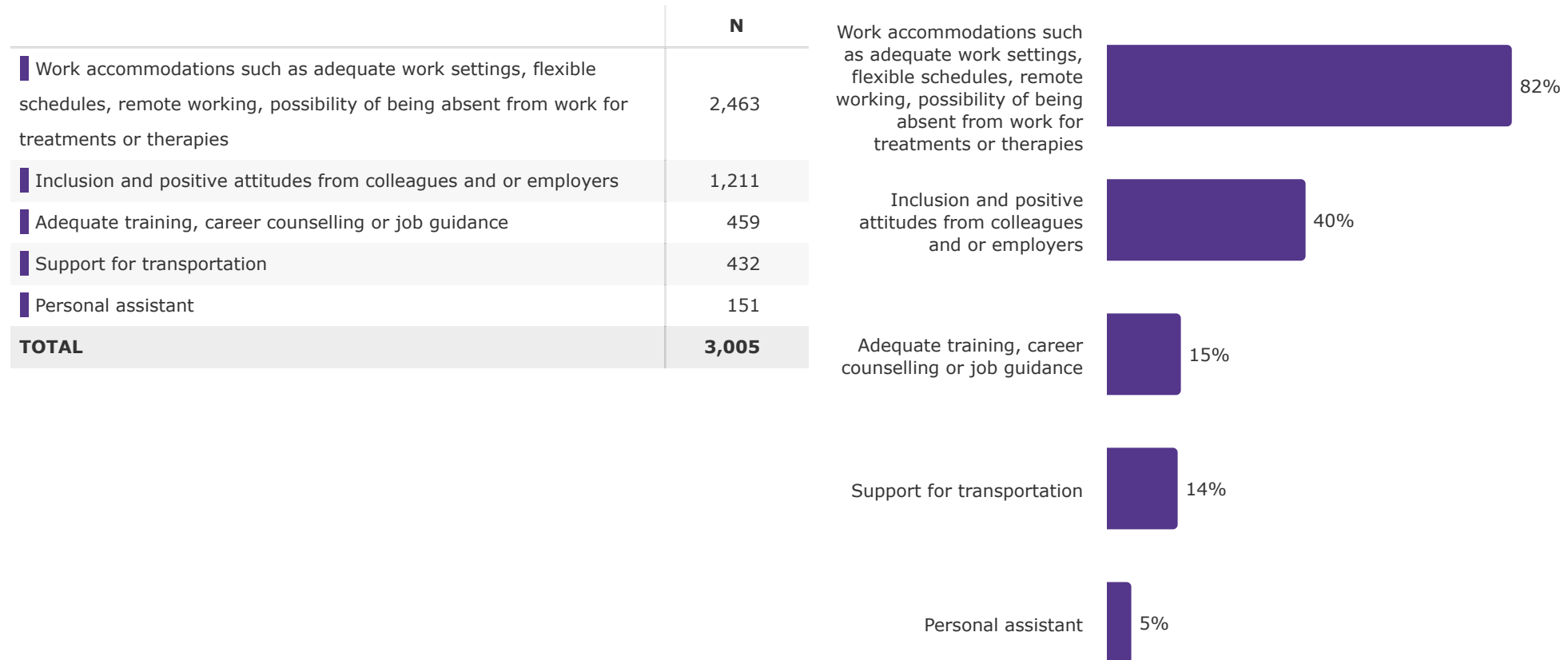
	N	%
Difficulty in managing symptoms/medical appointments	503	55%
Difficult labour market	271	30%
Lack of work accommodations such as adequate work settings, flexible schedules, support for transportation or personal assistant	263	29%
Other, specify...	159	17%
Negative attitudes and stigma from potential or previous employers	158	17%
Lack of adequate training, career counselling or job guidance	116	13%
Fear of losing financial benefits	75	8%
Caregiving responsibilities	64	7%
Discouragement from family	26	3%
<b>TOTAL</b>	<b>916</b>	





**This question was only asked to respondents who are currently employed.**

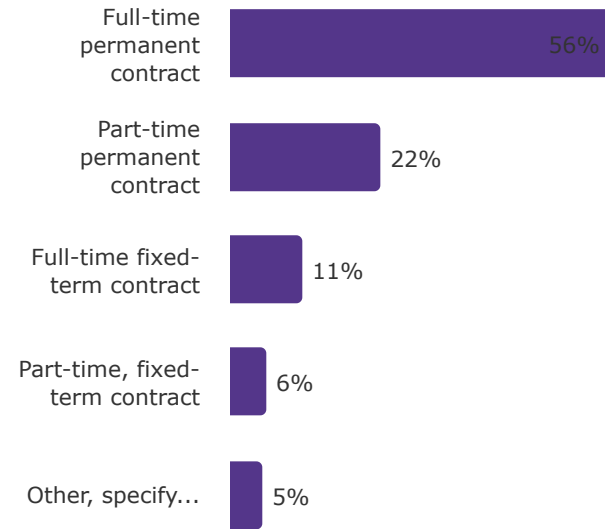
**Which employment support and workplace accommodations do you think can improve your work life?**



**This question was only asked to respondents who are currently employed.**

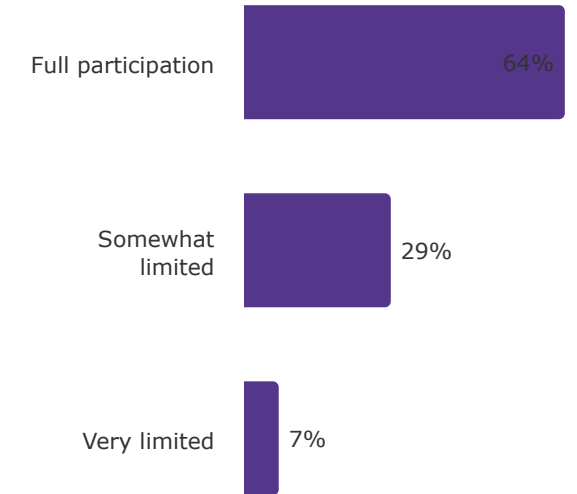
**What type of work contract do you have?**

	N	%
Full-time permanent contract	1,561	56%
Part-time permanent contract	621	22%
Full-time fixed-term contract	300	11%
Part-time, fixed-term contract	158	6%
Other, specify...	142	5%
<b>TOTAL</b>	<b>2,782</b>	<b>100%</b>



**What is your current level of participation at work?**

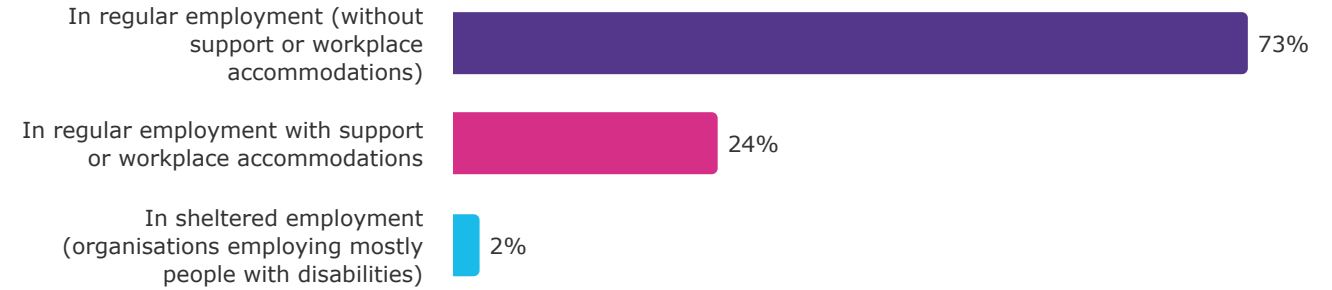
	N	%
Full participation	1,942	64%
Somewhat limited	892	29%
Very limited	220	7%
<b>TOTAL</b>	<b>3,054</b>	<b>100%</b>



**This question was only asked to respondents who are currently employed.**

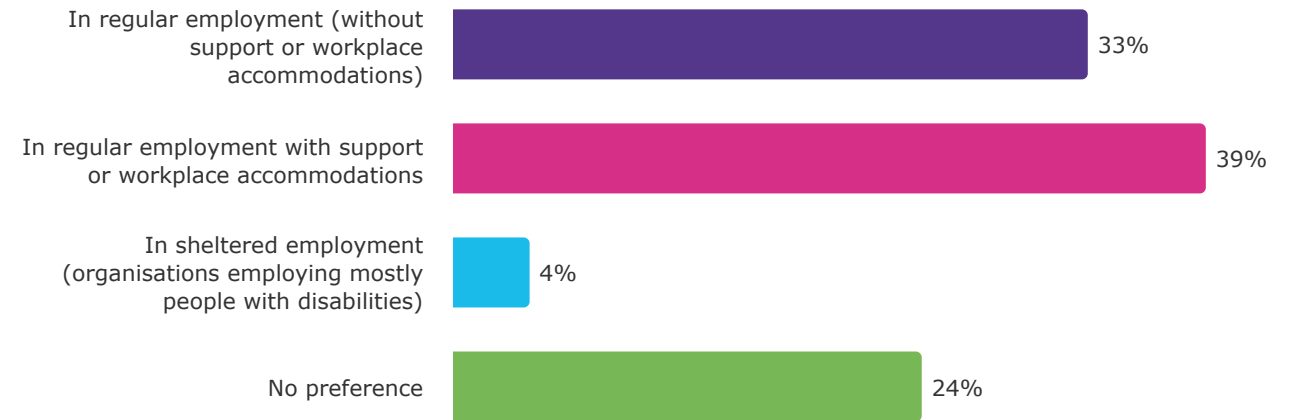
**Do you work?**

	N
In regular employment (without support or workplace accommodations)	2,199
In regular employment with support or workplace accommodations	735
In sheltered employment (organisations employing mostly people with disabilities)	75
<b>TOTAL</b>	<b>3,009</b>



**Would you prefer to work...**

	N	%
In regular employment (without support or workplace accommodations)	990	33%
In regular employment with support or workplace accommodations	1,175	39%
In sheltered employment (organisations employing mostly people with disabilities)	120	4%
No preference	732	24%
<b>TOTAL</b>	<b>3,017</b>	<b>100%</b>



▼ Sample information : Situation\_m among "Employed (or partially employed);Self-employed"

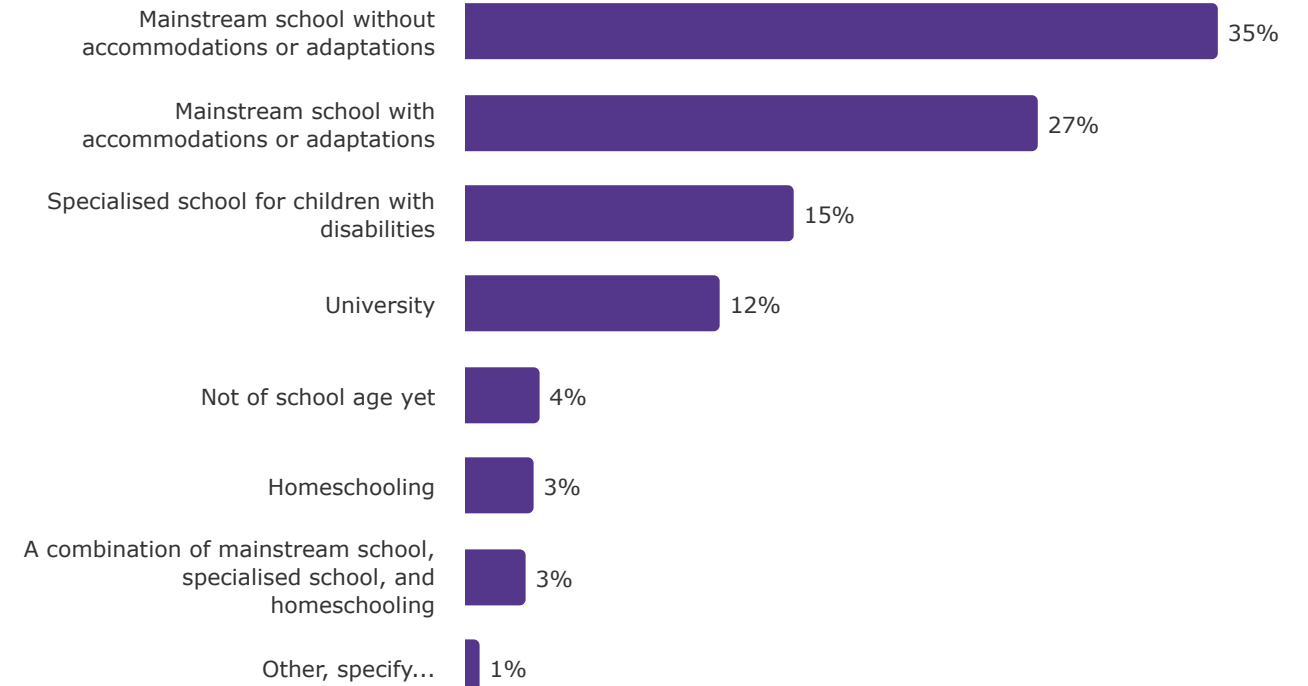


## 5.3. SCHOOL PARTICIPATION

This question was only asked to students/pupils

Do you attend...

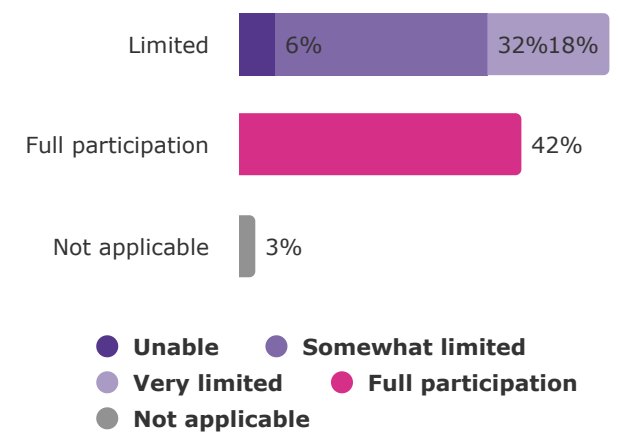
	N
Mainstream school without accommodations or adaptations	662
Mainstream school with accommodations or adaptations	504
Specialised school for children with disabilities	290
University	224
Not of school age yet	67
Homeschooling	62
A combination of mainstream school, specialised school, and homeschooling	54
Other, specify...	14
<b>TOTAL</b>	<b>1,877</b>



**This question was only asked to students/pupils who attend school/college**

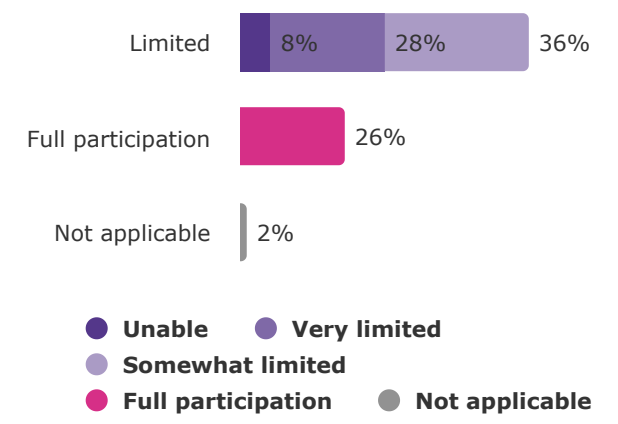
**Compared to other people the same age, what is your current level of participation in educational (academic) activities with other students in the classroom?**

	N	%
▼ Limited	958	55%
Unable	99	6%
Somewhat limited	547	32%
Very limited	312	18%
Full participation	732	42%
Not applicable	46	3%
<b>TOTAL</b>	<b>1,736</b>	<b>100%</b>



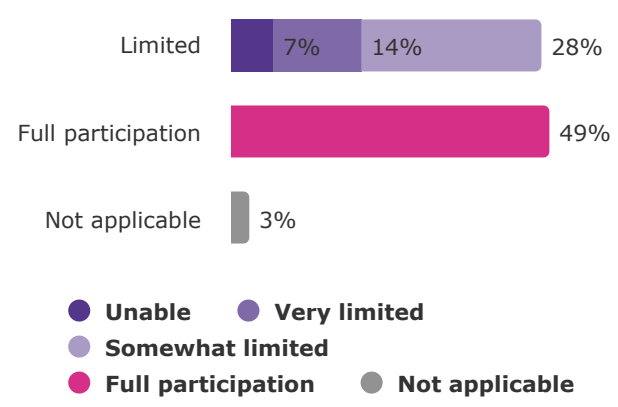
**Compared to other people the same age, what is your current level of participation in social, play and recreational activities with other students (e.g., "hanging out", sports, clubs, hobbies, creative arts, lunchtime or recess activities)?**

	N	%
▼ Limited	1,250	72%
Unable	134	8%
Very limited	494	28%
Somewhat limited	622	36%
Full participation	454	26%
Not applicable	36	2%
<b>TOTAL</b>	<b>1,748</b>	<b>100%</b>



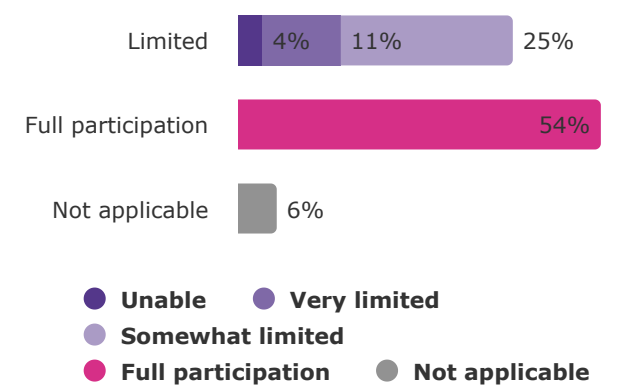
**Compared to other people the same age, what is your current level of participation in moving around at school/university (e.g., to get to and use the bathroom, playground, cafeteria, library or other rooms and things that are available to other students the same age)?**

	N	%
▼ Limited	834	48%
Unable	116	7%
Very limited	237	14%
Somewhat limited	481	28%
Full participation	855	49%
Not applicable	54	3%
<b>TOTAL</b>	<b>1,743</b>	<b>100%</b>



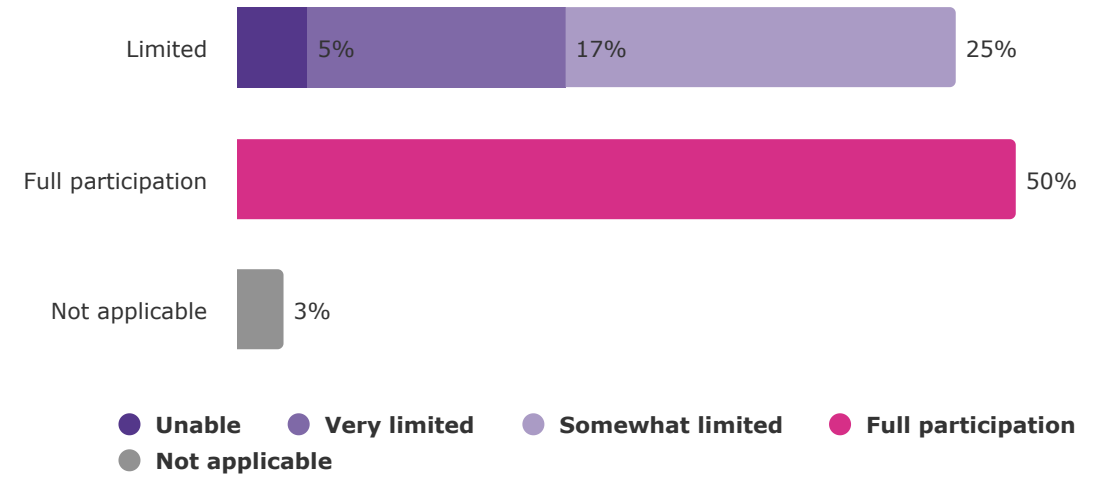
**Compared to other people the same age, what is your current level of participation in using educational materials and equipment that are available to other students in the classroom/s or that have been modified for you (e.g., books, computers, chairs and desks)?**

	N	%
▼ Limited	698	41%
Unable	68	4%
Very limited	197	11%
Somewhat limited	433	25%
Full participation	922	54%
Not applicable	103	6%
<b>TOTAL</b>	<b>1,723</b>	<b>100%</b>



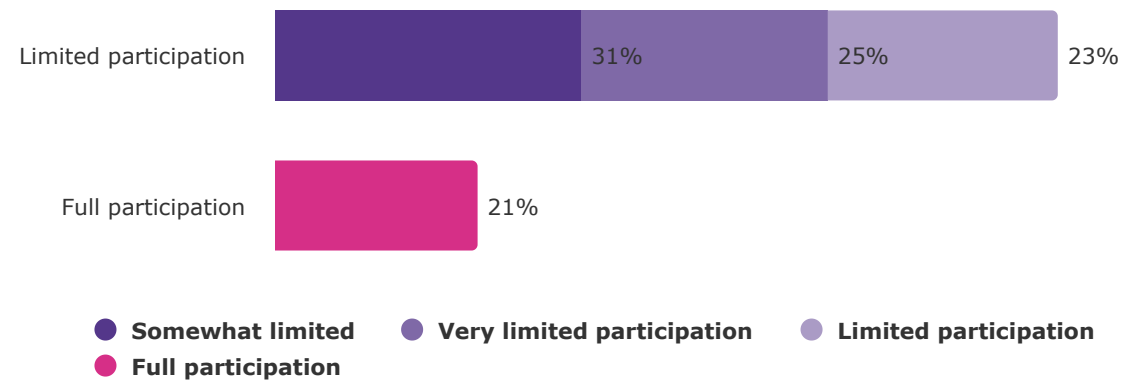
**Compared to other people the same age, what is your current level of participation in communicating with other students and adults at school/university?**

	N	%
▼ Limited	813	47%
Unable	82	5%
Very limited	291	17%
Somewhat limited	440	25%
Full participation	880	50%
Not applicable	54	3%
<b>TOTAL</b>	<b>1,747</b>	<b>100%</b>



**Total school participation measured by Child and Adolescent Scale of Participation (CASP)**

	N	%
▼ Limited participation	1,229	79%
Somewhat limited	484	31%
Very limited particip...	386	25%
Limited participation	359	23%
Full participation	319	21%
<b>TOTAL</b>	<b>1,548</b>	<b>100%</b>





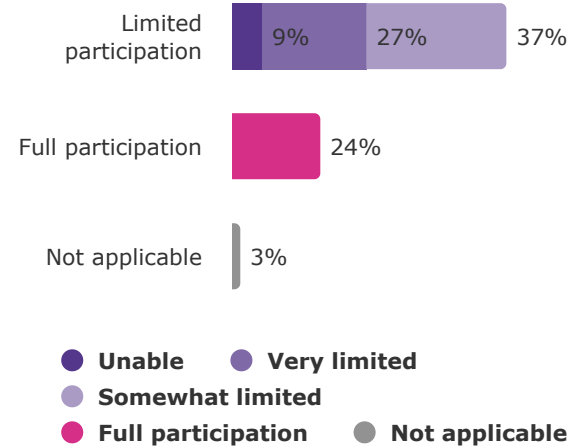
## 5.4. COMMUNITY PARTICIPATION



**Compared to other people the same age, what is your current level of participation in the following activities:**

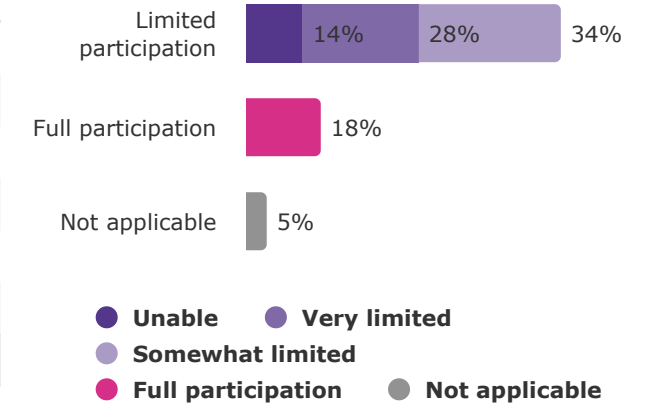
**Social, play or leisure activities with friends in the neighbourhood and community (e.g., casual games, "hanging out", going to public places like a movie theatre, park or restaurant)?**

	N	%
▼ Limited participation	7,008	73%
Unable	838	9%
Very limited	2,608	27%
Somewhat limited	3,562	37%
Full participation	2,283	24%
Not applicable	270	3%
<b>TOTAL</b>	<b>9,561</b>	<b>100%</b>



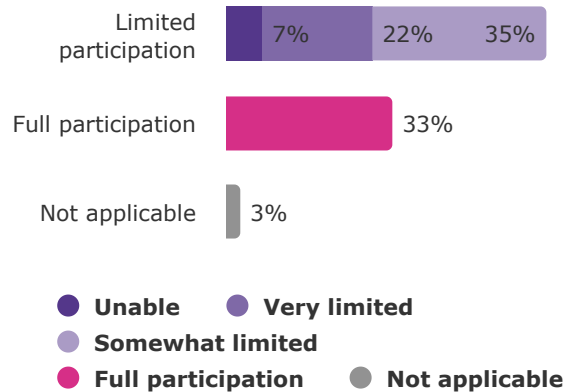
**Structured events and activities in the neighbourhood and community (e.g., team sports, clubs, holiday or religious events, concerts, parades and fairs)?**

	N	%
▼ Limited participation	7,280	76%
Unable	1,339	14%
Very limited	2,677	28%
Somewhat limited	3,264	34%
Full participation	1,760	18%
Not applicable	504	5%
<b>TOTAL</b>	<b>9,544</b>	<b>100%</b>



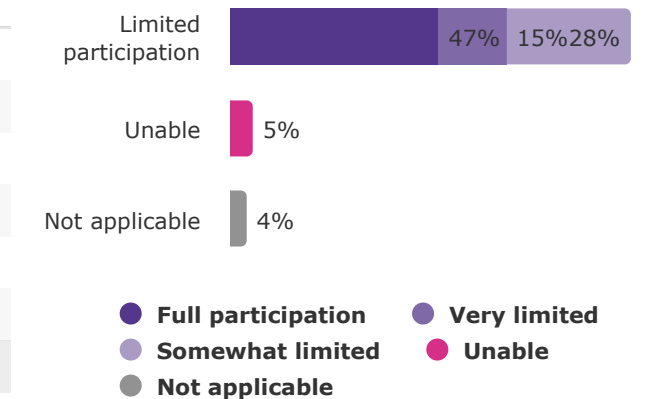
**Moving around the neighbourhood and community (e.g., public buildings, parks, restaurants, movies)?**

	N	%
▼ Limited participation	6,085	64%
Unable	711	7%
Very limited	2,066	22%
Somewhat limited	3,308	35%
Full participation	3,178	33%
Not applicable	303	3%
<b>TOTAL</b>	<b>9,566</b>	<b>100%</b>



**Communicating with others in the neighbourhood and community?**

	N	%
▼ Limited participation	8,648	91%
Full participation	4,523	47%
Very limited	1,448	15%
Somewhat limited	2,677	28%
Unable	512	5%
Not applicable	395	4%
<b>TOTAL</b>	<b>9,555</b>	<b>100%</b>



### Total community participation

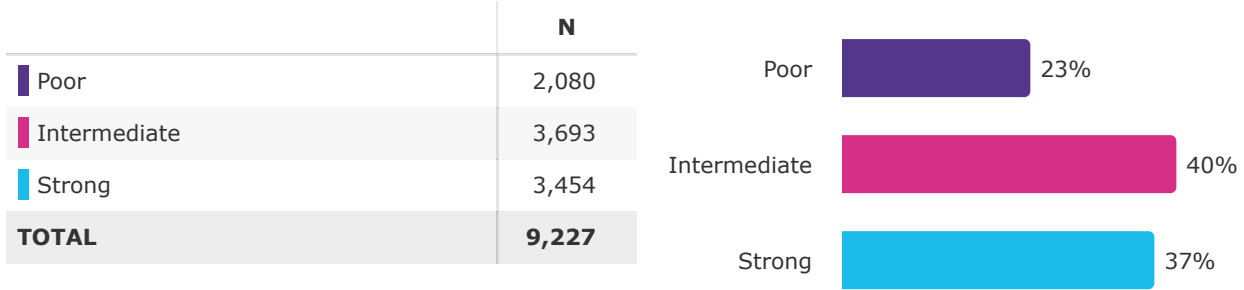
	N	%
▼ Limited participation	7,281	84%
Very limited participation	3,110	36%
Limited participation	1,859	21%
Somewhat limited	2,312	27%
Full participation	1,411	16%
<b>TOTAL</b>	<b>8,692</b>	<b>100%</b>



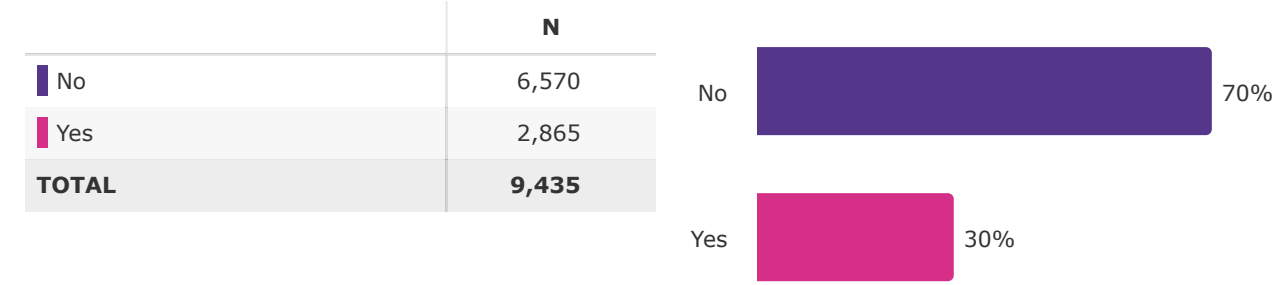


## 5.5. SOCIAL ENVIRONMENT

**How would you qualify the social support you receive from people (close people to count on, concern shown by other people, practical help from neighbours in case of need)?**

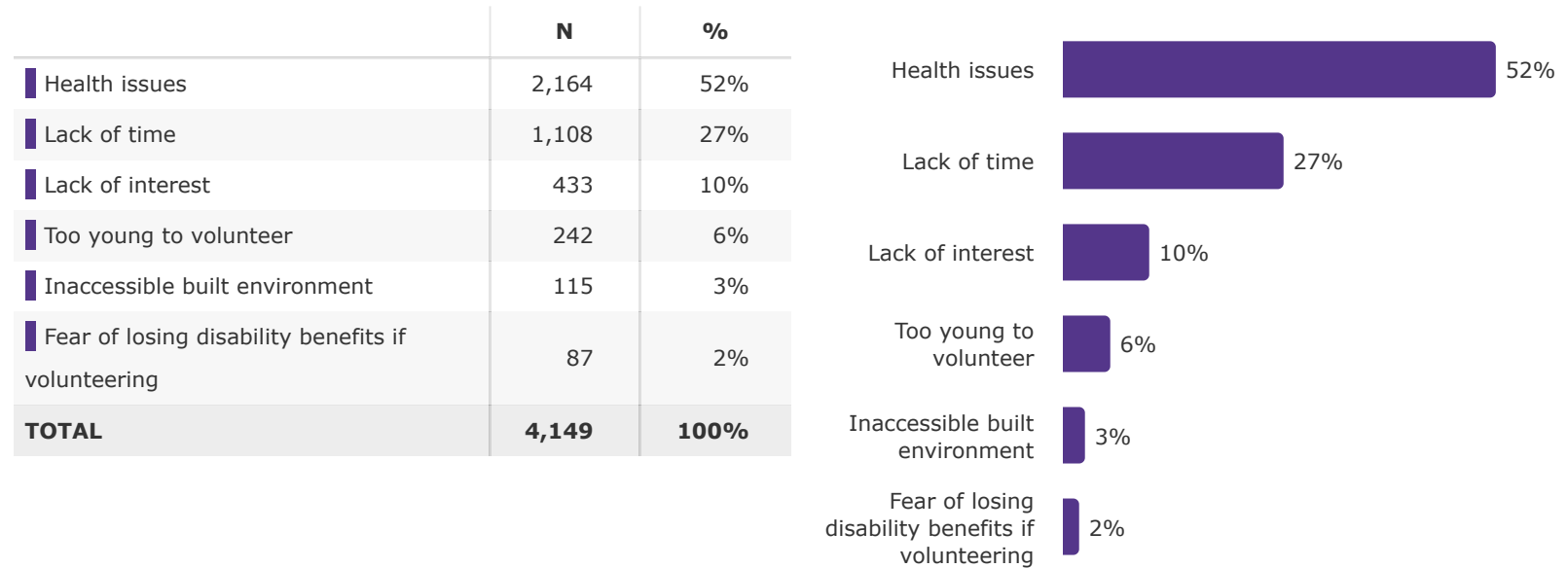


**Did you do any unpaid, non-compulsory work or informal activities (e.g., helping other people, helping animals) for an organisation during the last 12 months?**



**This question was only asked to people who don't volunteer.**

**Why not? Please give only the most important reason (for not volunteering)**



# Thank you!

to all the people with rare diseases and family members who participated in the survey, and to Rare Barometer partners

For any questions, please contact the Rare Barometer team at [rare.barometer@eurordis.org](mailto:rare.barometer@eurordis.org).