

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
- visit the Rare Barometer website at eurordis.org/voices
- visit our newborn screening-dedicated webpage: eurordis.org/rare-barometer-survey

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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

Key results are available in the **factsheets**: tiny.cc/RB_DailyLife_Results

Original questionnaire: tiny.cc/DailyLife_questionnaire



1. SAMPLE INFORMATION

**Sociodemographic characteristics,
diagnostic information**

Total number of respondents

465

Device used to answer



● PC ● Tablet ● Smartphone

Average number of minutes to fill the questionnaire

21

Mean

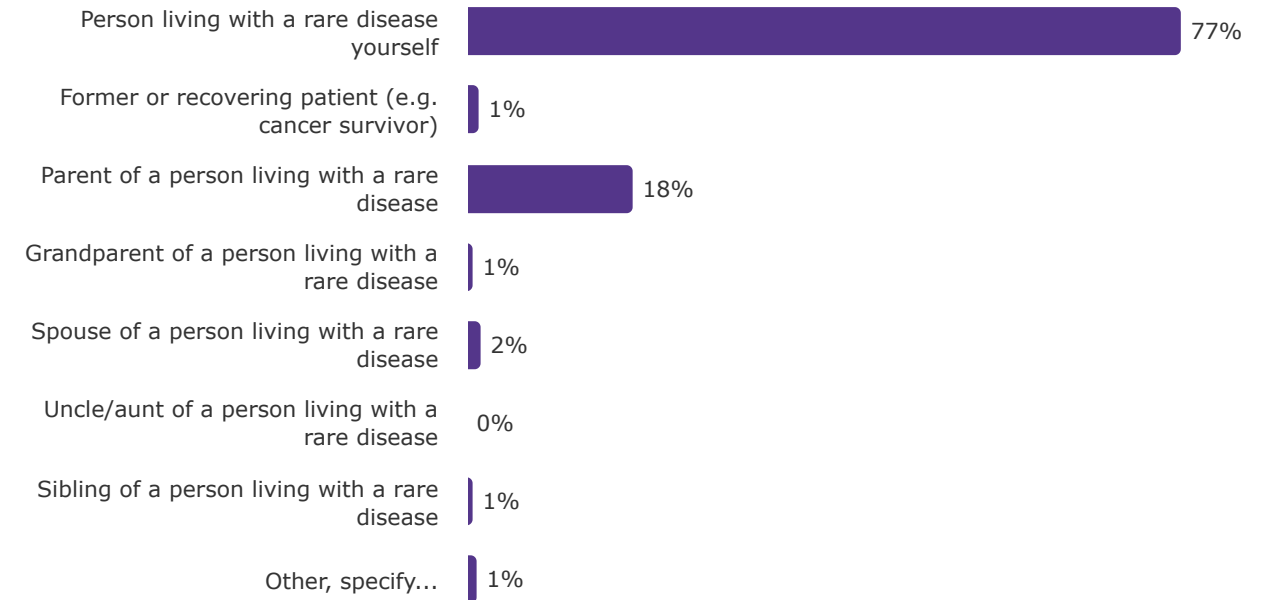
Median number of minutes to fill the questionnaire

15

Median

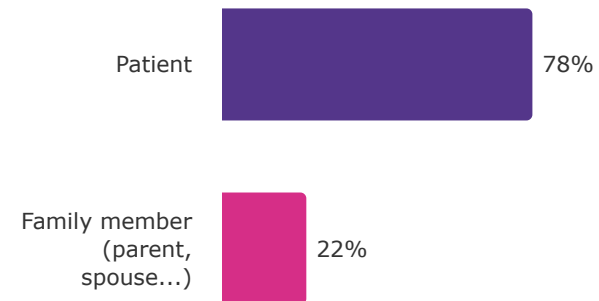
Are you answering the questionnaire as a...?

	N
Person living with a rare disease yourself	358
Former or recovering patient (e.g. cancer survivor)	6
Parent of a person living with a rare disease	83
Grandparent of a person living with a rare disease	3
Spouse of a person living with a rare disease	7
Uncle/aunt of a person living with a rare disease	0
Sibling of a person living with a rare disease	3
Other, specify...	5
TOTAL	465



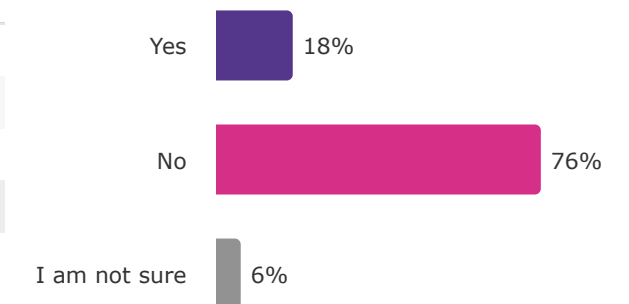
If 'Other, specify...' specify:

	N	%
Patient	364	78%
Family member (parent, spouse...)	101	22%
TOTAL	465	100%

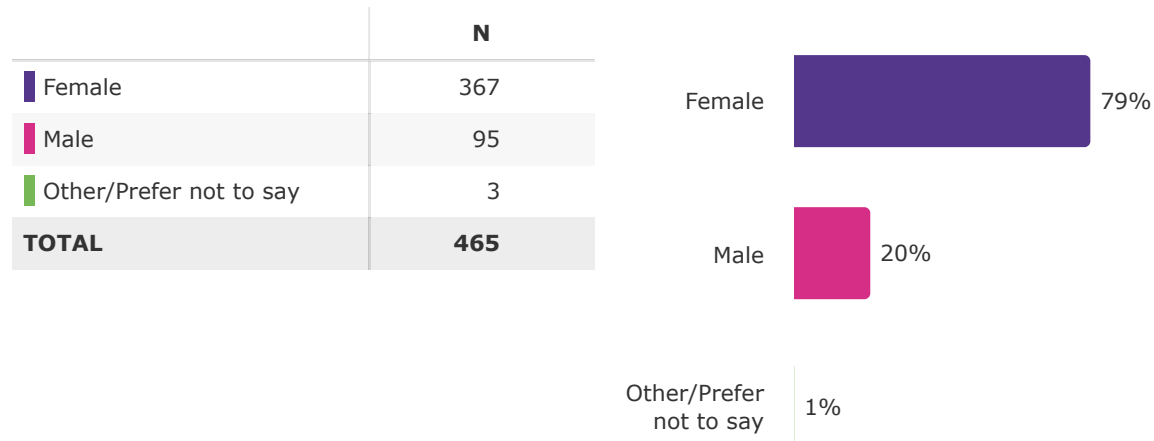


Are you also a patient representative, i.e., involved in voluntary and/or policy activities to support the cause of rare diseases?

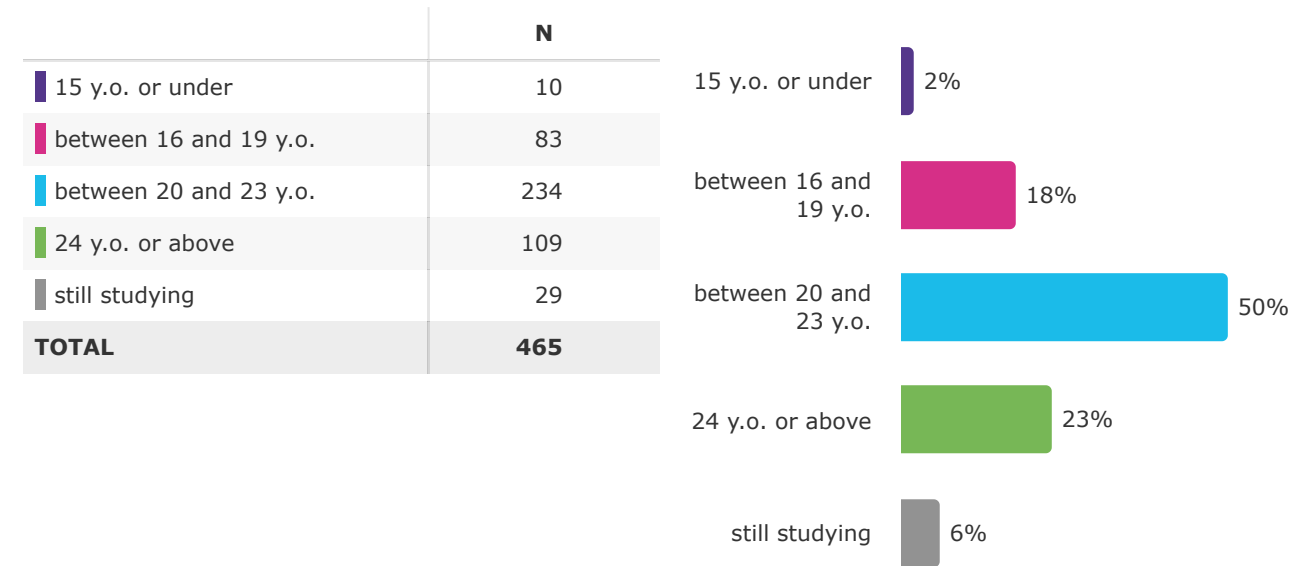
	N
Yes	85
No	352
I am not sure	28
TOTAL	465



Are you:



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



How old are you?

	N	%
Less than 18	1	0%
From 18 to 23	6	1%
From 24 to 29	27	6%
From 30 to 39	58	13%
From 40 to 49	100	22%
From 50 to 59	133	29%
60 and over	129	28%
TOTAL	454	100%

Age of the person living with a rare disease

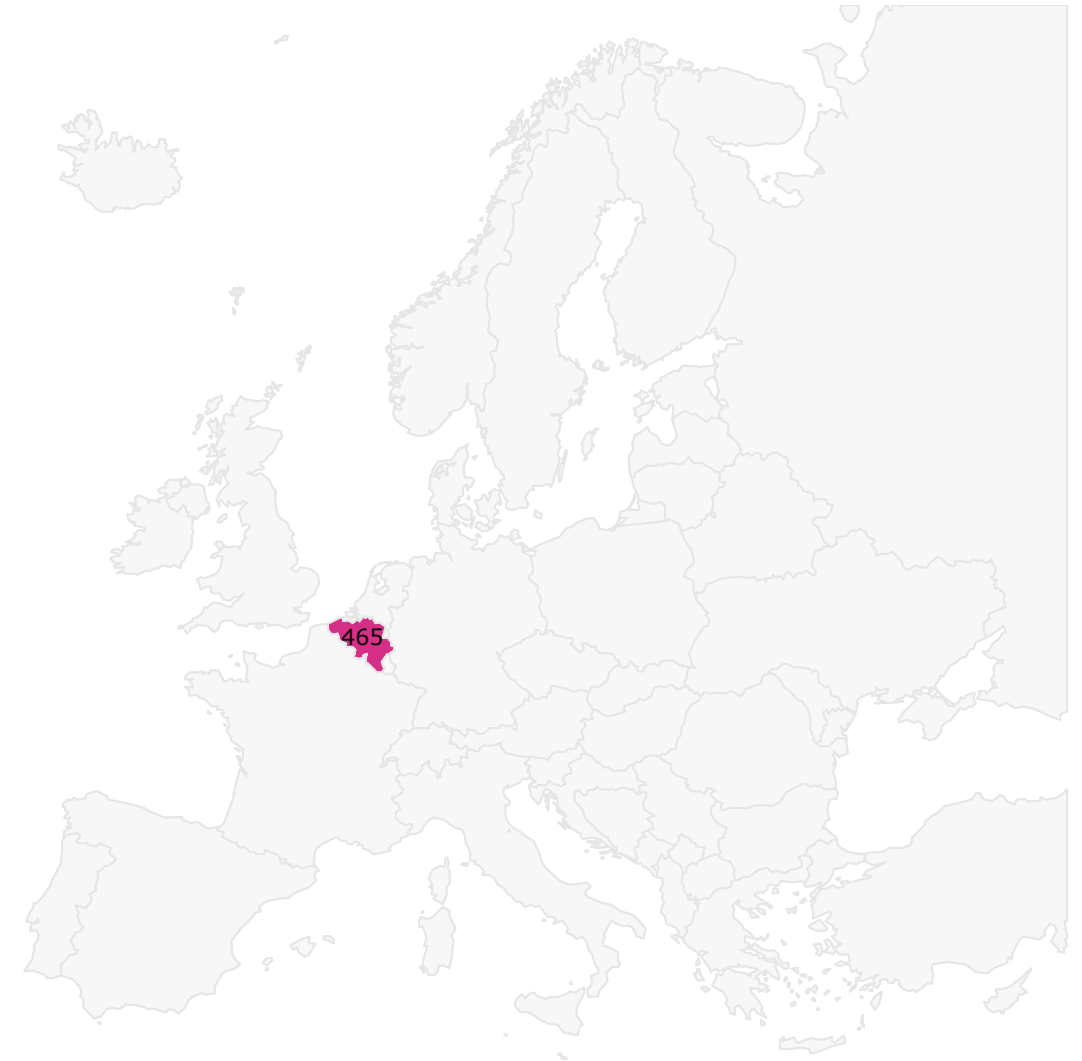
	N	%
Less than 18	60	13%
From 18 to 23	14	3%
From 24 to 29	31	7%
From 30 to 39	47	10%
From 40 to 49	76	16%
From 50 to 59	119	26%
60 and over	118	25%
TOTAL	465	100%

In which country do you live?

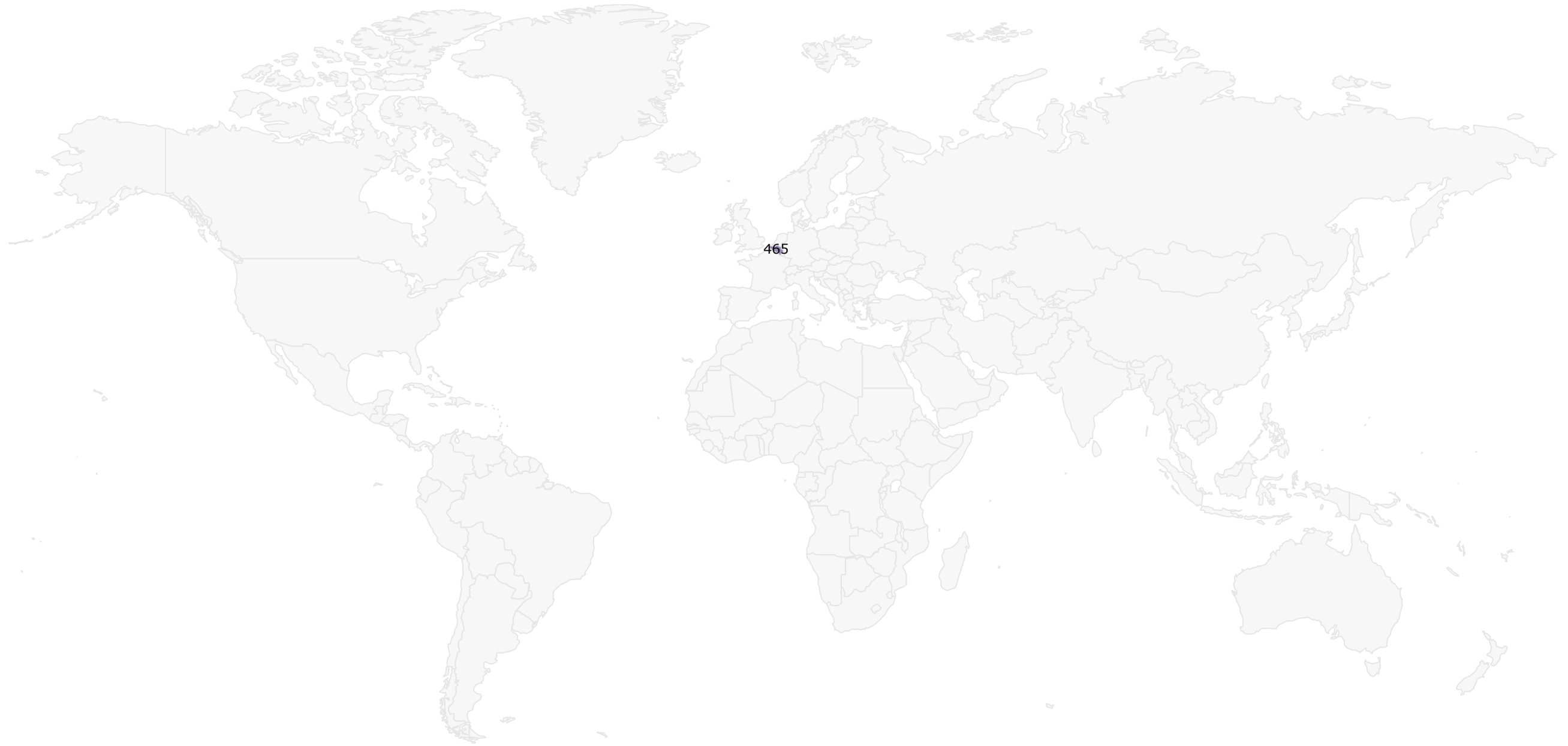
In which country do you live?

	N	%
Belgium	465	100%

	N	%
No record		

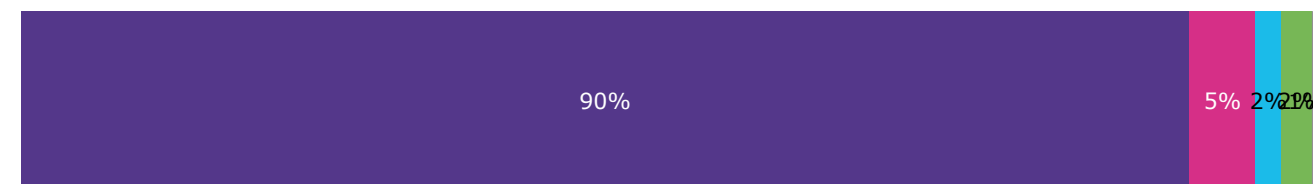


In which country do you live?



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)	417
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	24
I only have PARTIAL information on the name of the rare disease or the gene involved or the type of disease	9
I know that the disease is rare but the name or the cause have NOT BEEN IDENTIFIED	11
Other, specify...	4
TOTAL	465

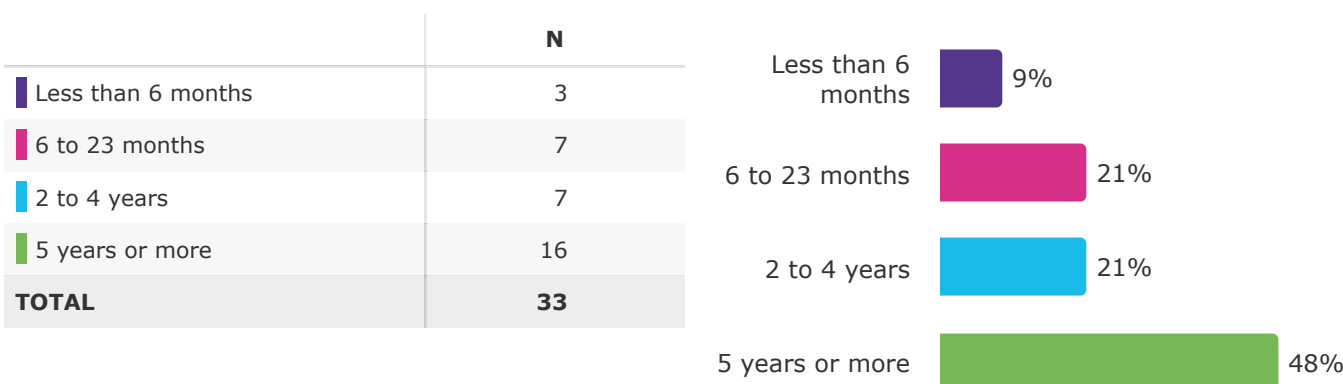


- I know the NAME of the rare disease, syndrome or malformation and it has been CONFIRMED by ...
- I know the NAME of the rare disease, syndrome or malformation but it has NOT yet been confirm...
- I only have PARTIAL information on the name of the rare disease or the gene involved or the typ...
- I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

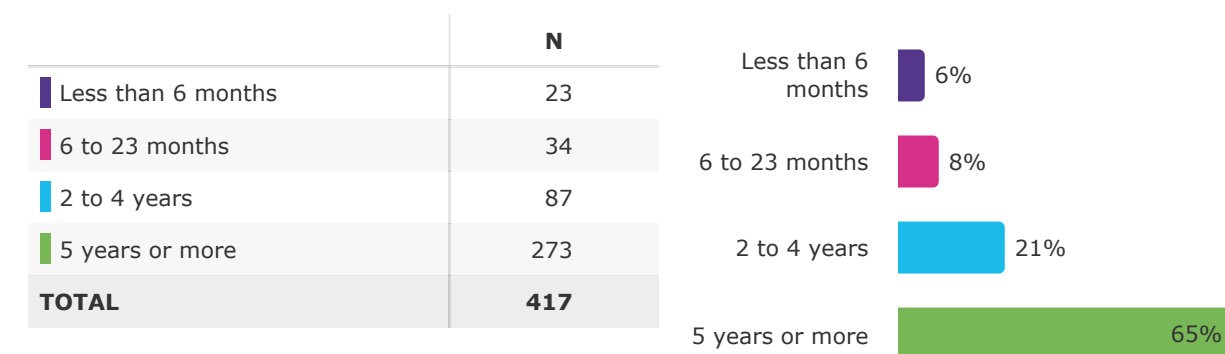
This question was only asked to people with an INITIAL diagnosis.

This question was only asked to people with confirmed diagnosis.

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



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

Rare diseases with 45+ respondents

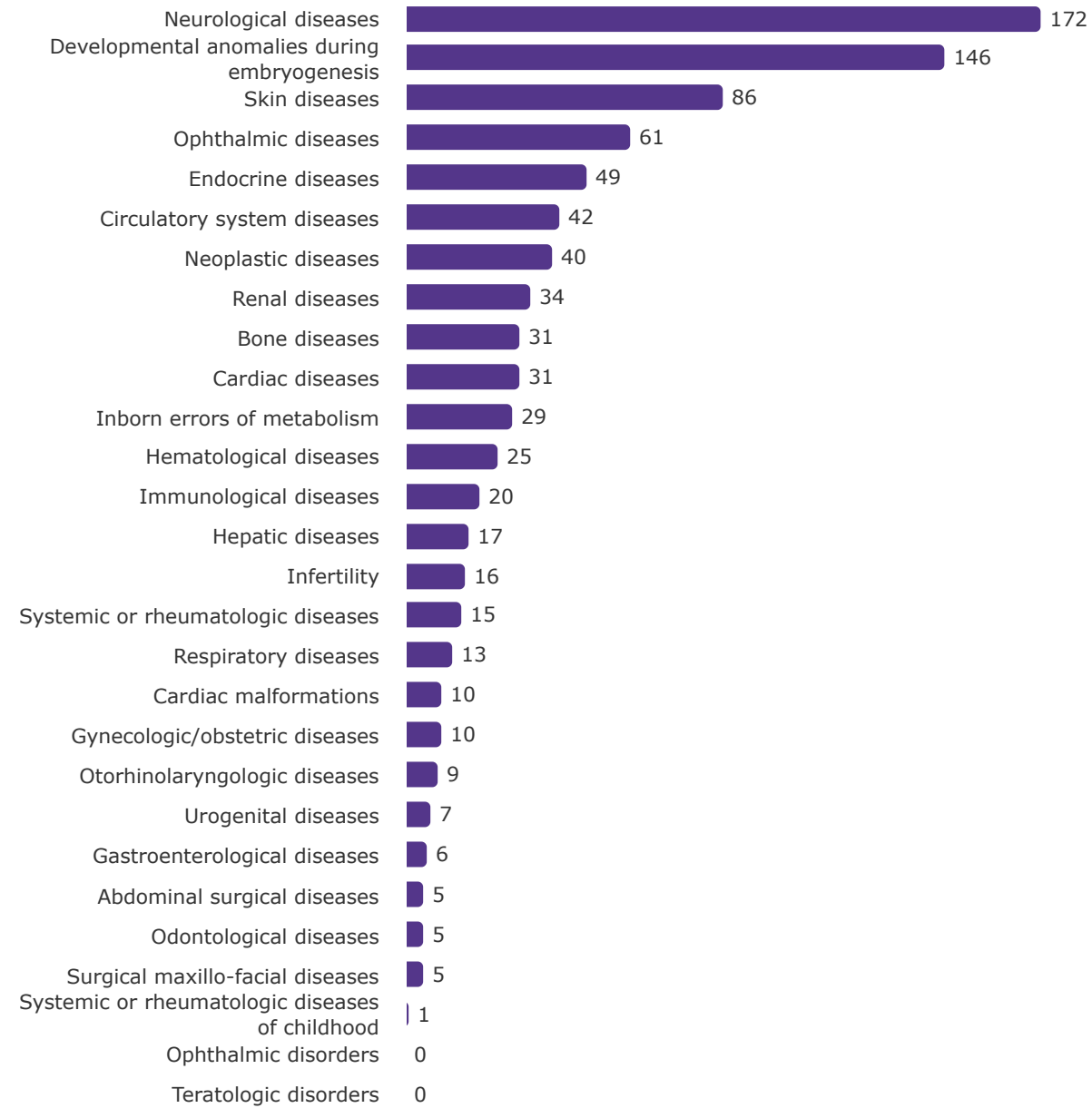
Rare diseases with 30-45 respondents

Rare diseases with 25-30 respondents

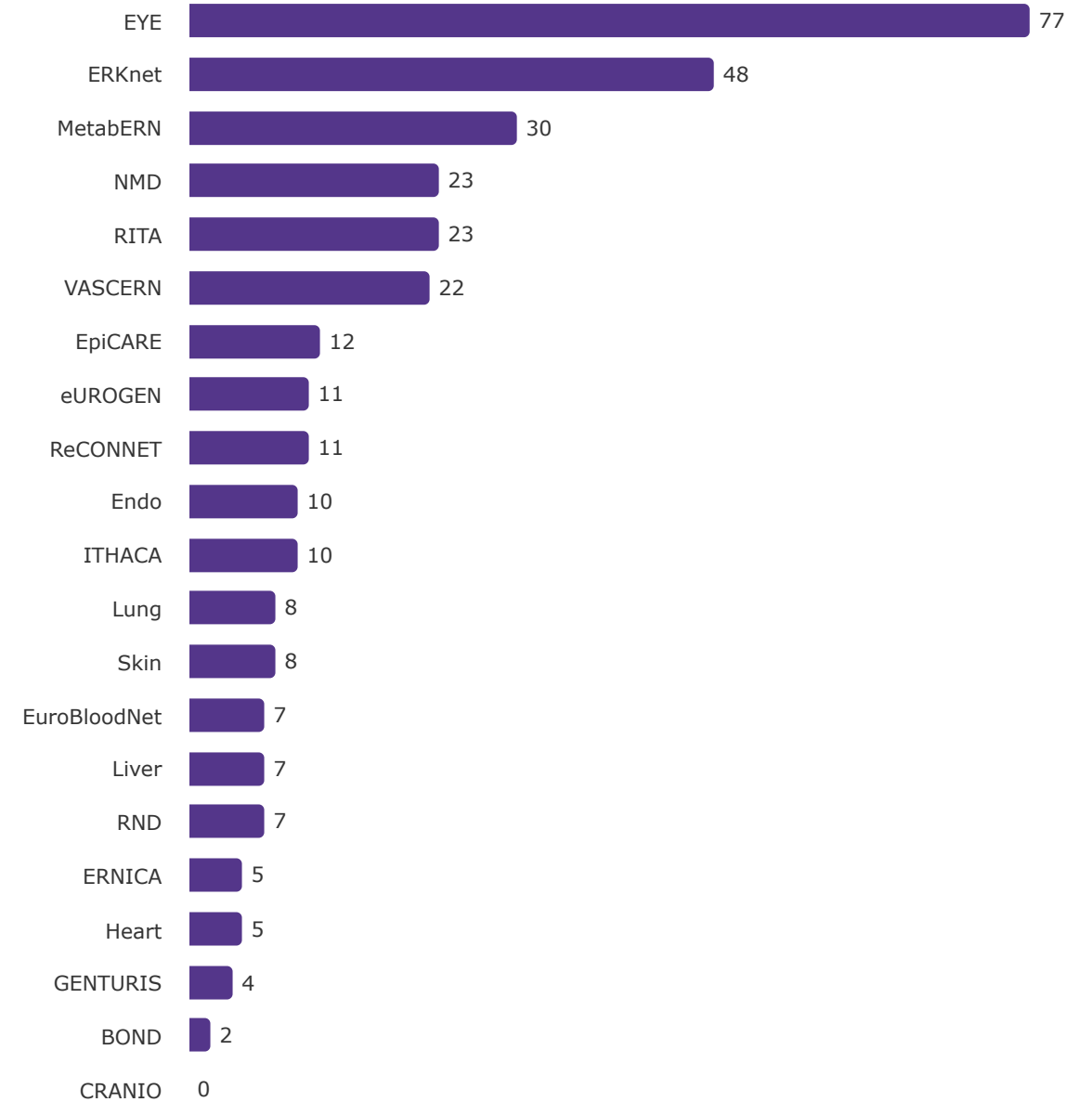
256

	N		N		N
No record		Hypermobile Ehlers-Danlos syndrome	43	No record	

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/>

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EURORDIS European Federations

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

	N	%
No record		

	N	%
No record		

A 2. DISABILITIES

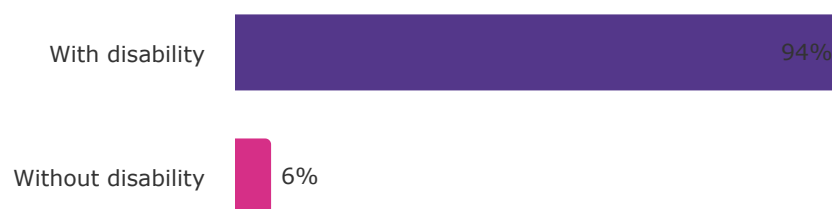
**Disability rates; diversity, complexity
and severity of disabilities**

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	438	94%
Without disability	27	6%
TOTAL	465	100%

Disability rate: Washington group short set (WGSS)

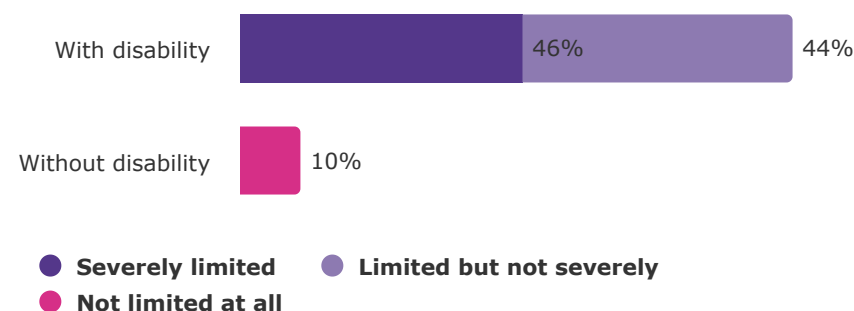


The Global Activity Limitation Index (GALI) measures disability through activity limitations that an individual experienced in the last 6 months or more due to a health problem.

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	417	90%
Severely limited	213	46%
Limited but not severely	204	44%
▼ Without disability	46	10%
Not limited at all	46	10%
TOTAL	463	100%

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...

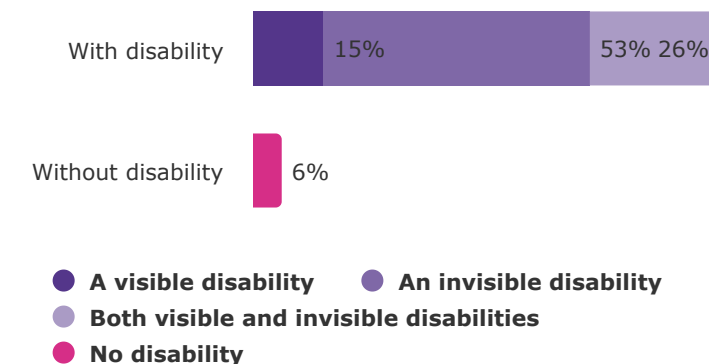


People living with rare diseases were asked if they perceive themselves as living with a disability, be it invisible, visible or both.

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

	N	%
▼ With disability	425	94%
A visible disability	66	15%
An invisible disability	241	53%
Both visible and invisible di...	118	26%
▼ Without disability	27	6%
No disability	27	6%
TOTAL	452	100%

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

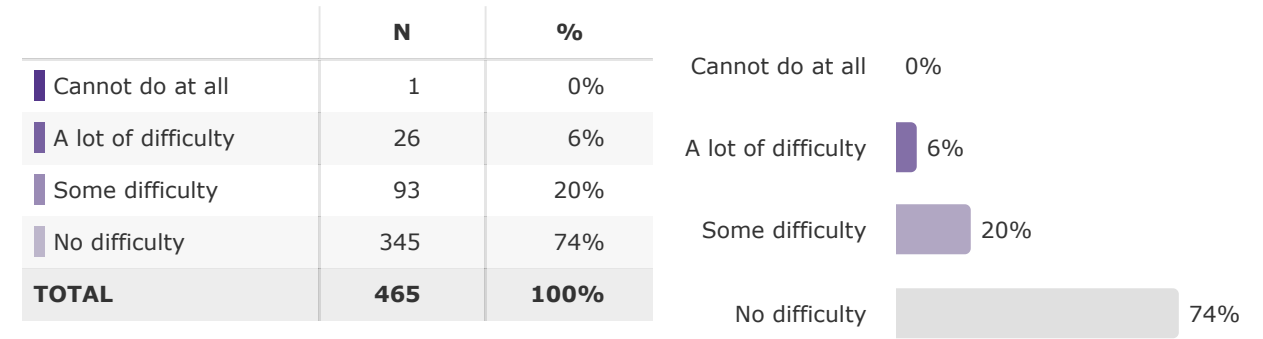
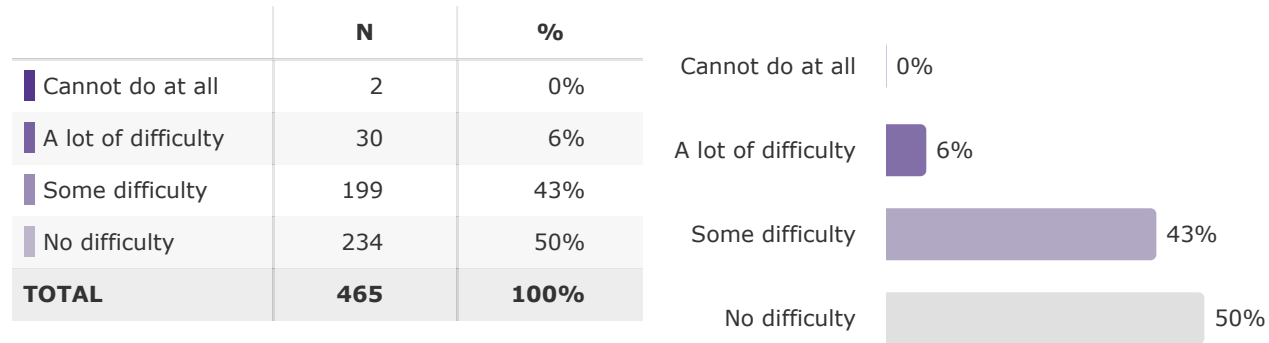


Washington Group Short Set (WG-SS)

<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...

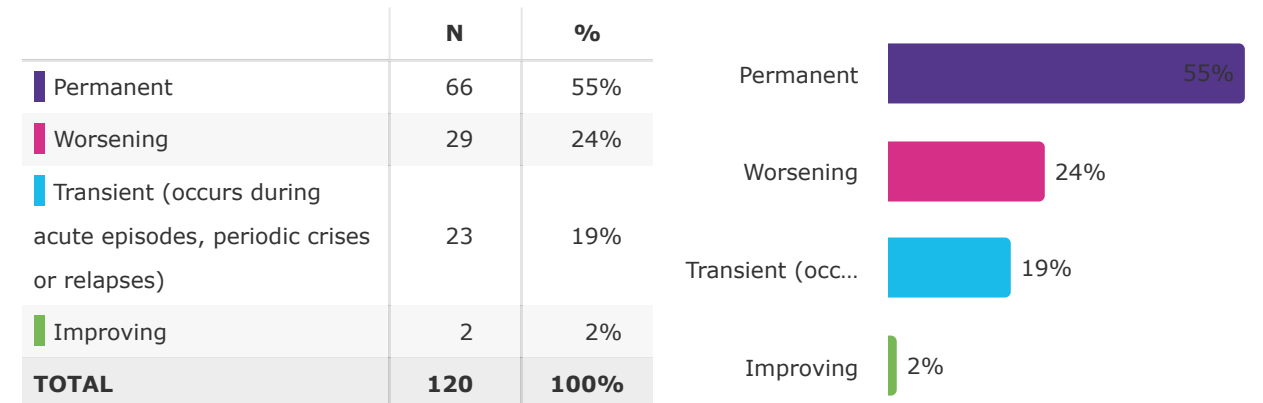
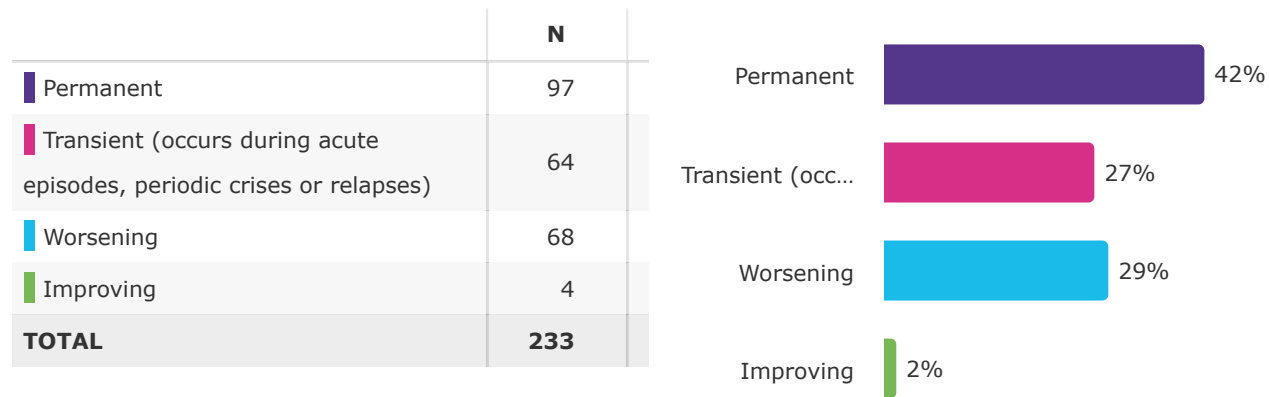
Do you have difficulty HEARING, even if using a hearing aid(s)? Would you say...



These questions were only asked to people with difficulty.

Is the difficulty...?

Is the difficulty...?

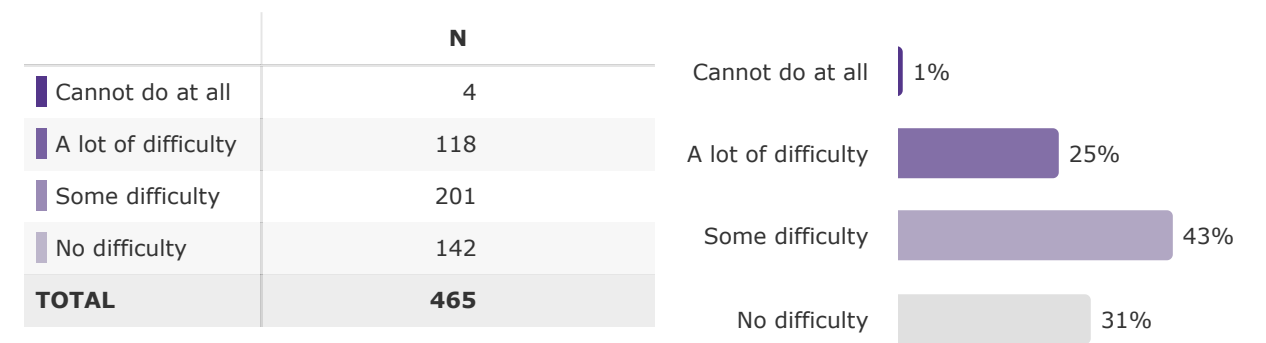
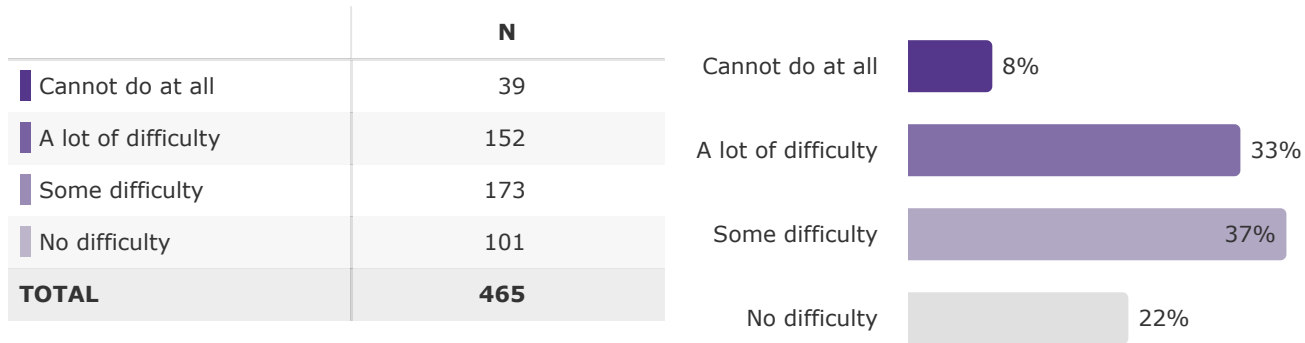


Washington Group Short Set (WG-SS)

<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...

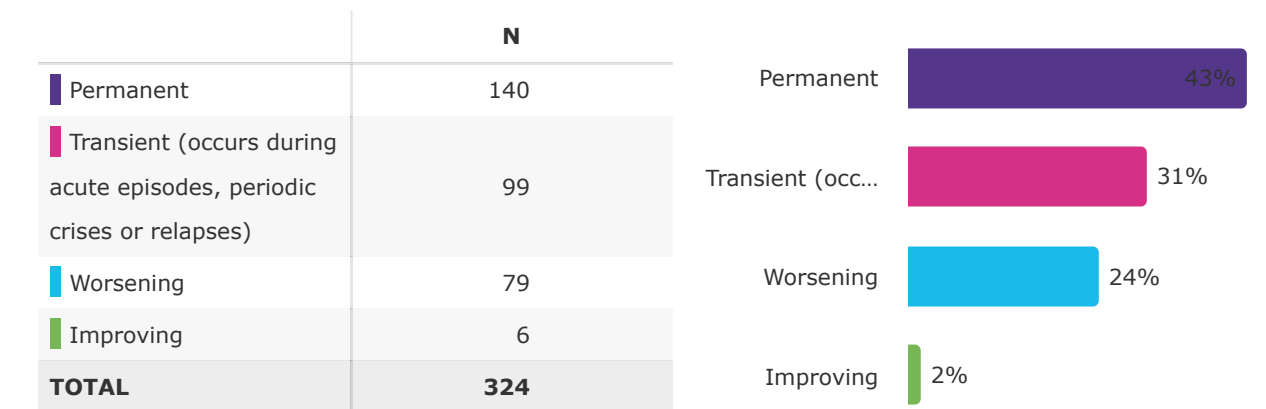
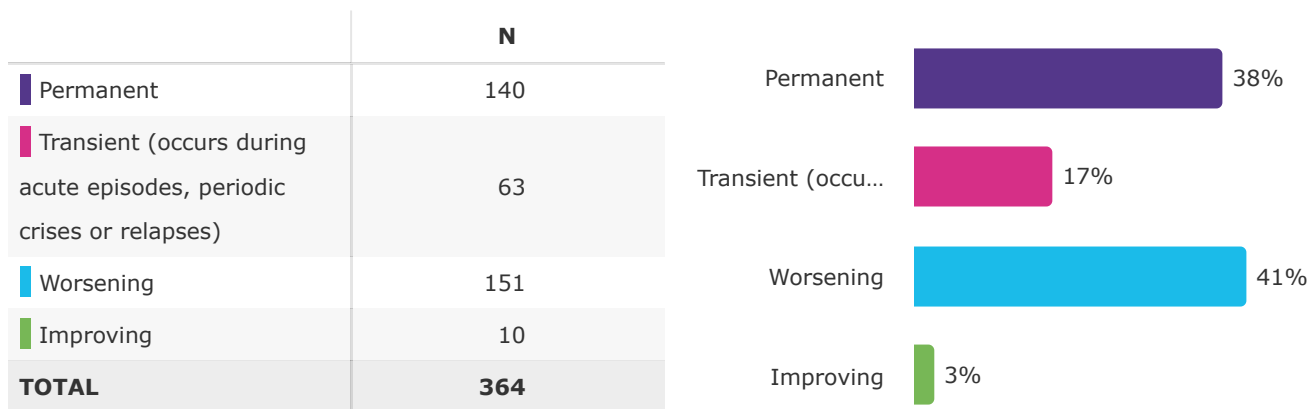


These questions were only asked to people with difficulty.



Is the difficulty...?

Is the difficulty...?



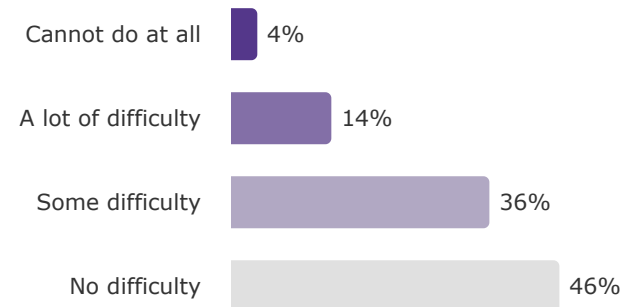
Washington Group Short Set (WG-SS)

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

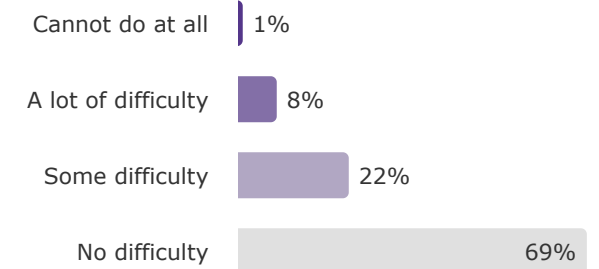
Do you have difficulty with SELF-CARE, such as washing all over or dressing? Would you say...

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

	N
Cannot do at all	18
A lot of difficulty	66
Some difficulty	168
No difficulty	213
TOTAL	465



	N
Cannot do at all	5
A lot of difficulty	37
Some difficulty	103
No difficulty	320
TOTAL	465

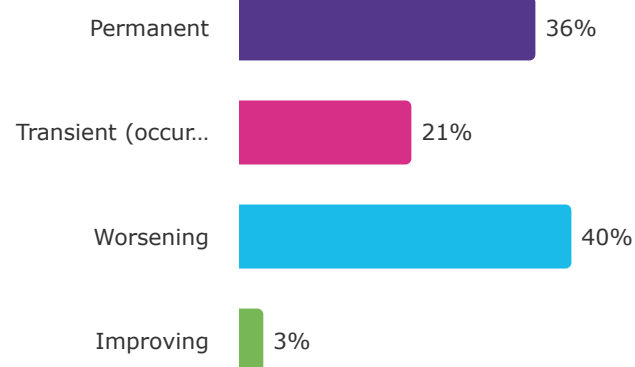


These questions were only asked to people with difficulty.

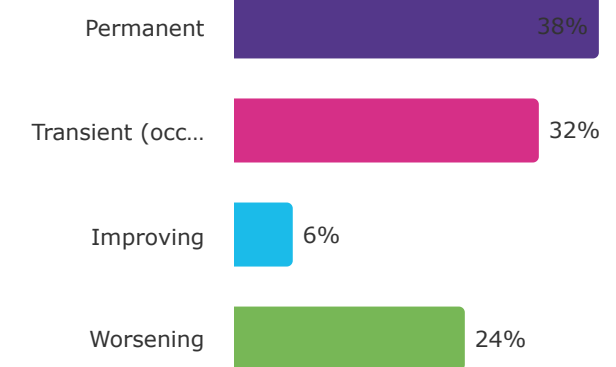
Is the difficulty...?

Is the difficulty...?

	N
Permanent	90
Transient (occurs during acute episodes, periodic crises or relapses)	53
Worsening	101
Improving	8
TOTAL	252



	N
Permanent	55
Transient (occurs during acute episodes, periodic crises or relapses)	46
Improving	9
Worsening	35
TOTAL	145



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

390

▼ Sample information : `Number_difficulties_WGSS >= 2`

Number of participants who have difficulty in at least 3 activities

288

▼ Sample information : `Number_difficulties_WGSS >= 3`

Number of participants who have difficulty in at least 4 activities

192

▼ Sample information : `Number_difficulties_WGSS >= 4`

Percentage of participants who have difficulty in at least 2 activities

84%

Percentage of participants who have difficulty in at least 3 activities

62%

Percentage of participants who have difficulty in at least 4 activities

41%

Number of participants with progressive or dynamic disabilities

328

▼ Sample information : `Index_prog >= 1`

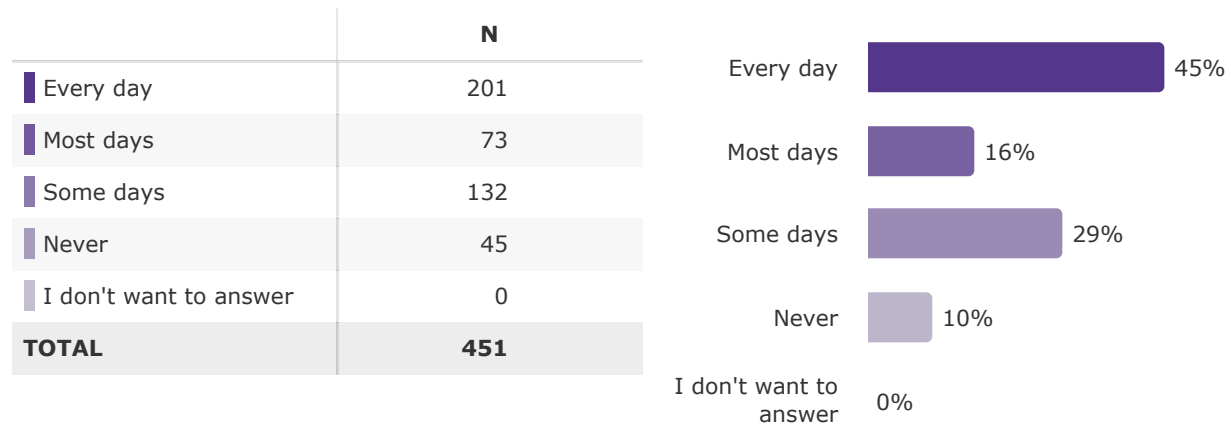
Percentage of participants with progressive or dynamic disabilities

71%

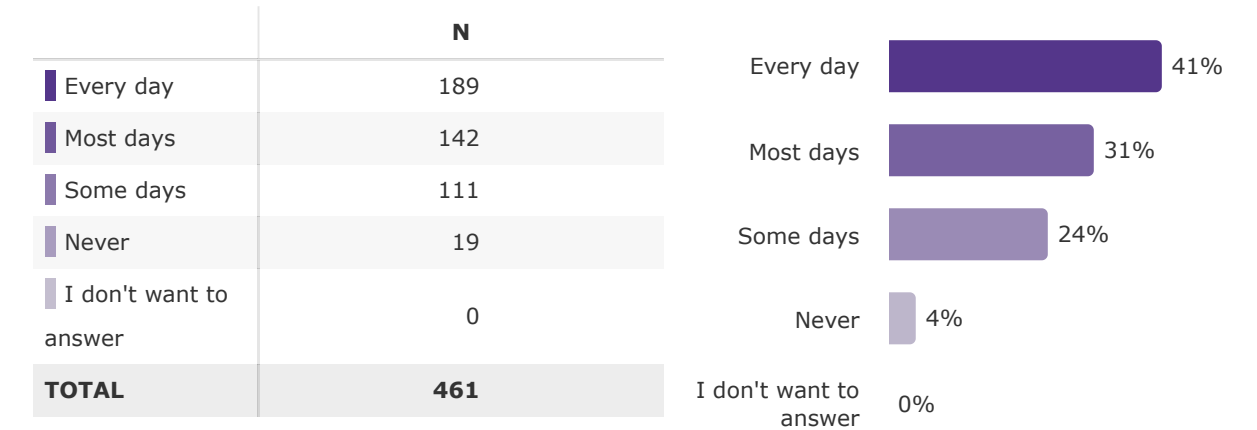
Washington Group Extended Set (WG-ES)

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

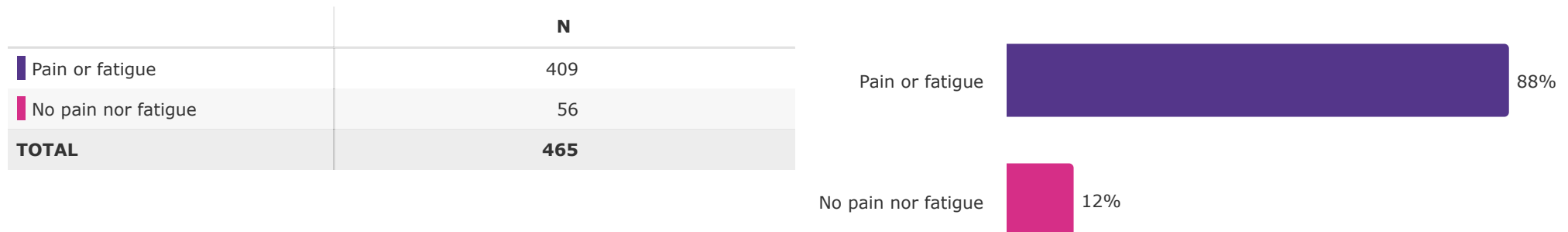
In the past three months, how often did you have PAIN? Would you say...



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...



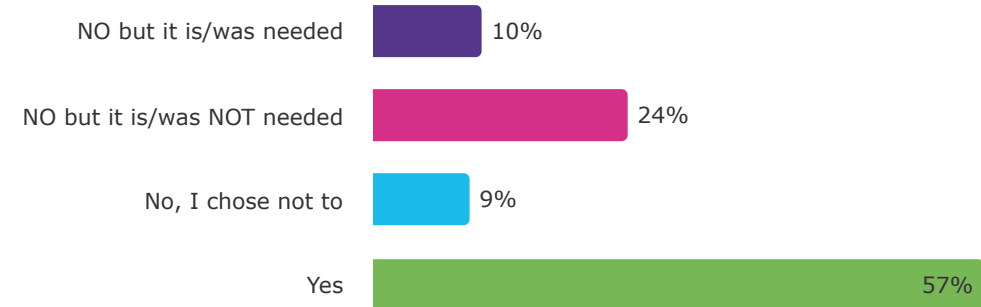


3. DISABILITY RECOGNITION

Disability assessment and barriers

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

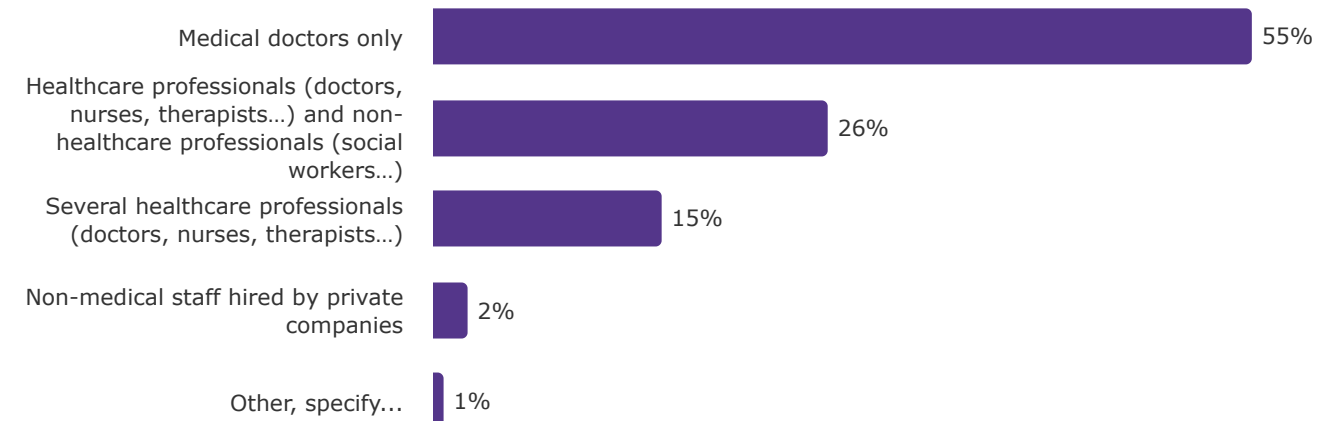
	N	%
NO but it is/was needed	46	10%
NO but it is/was NOT needed	107	24%
No, I chose not to	41	9%
Yes	256	57%
TOTAL	450	100%



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

What kind of professionals were involved in the assessment?

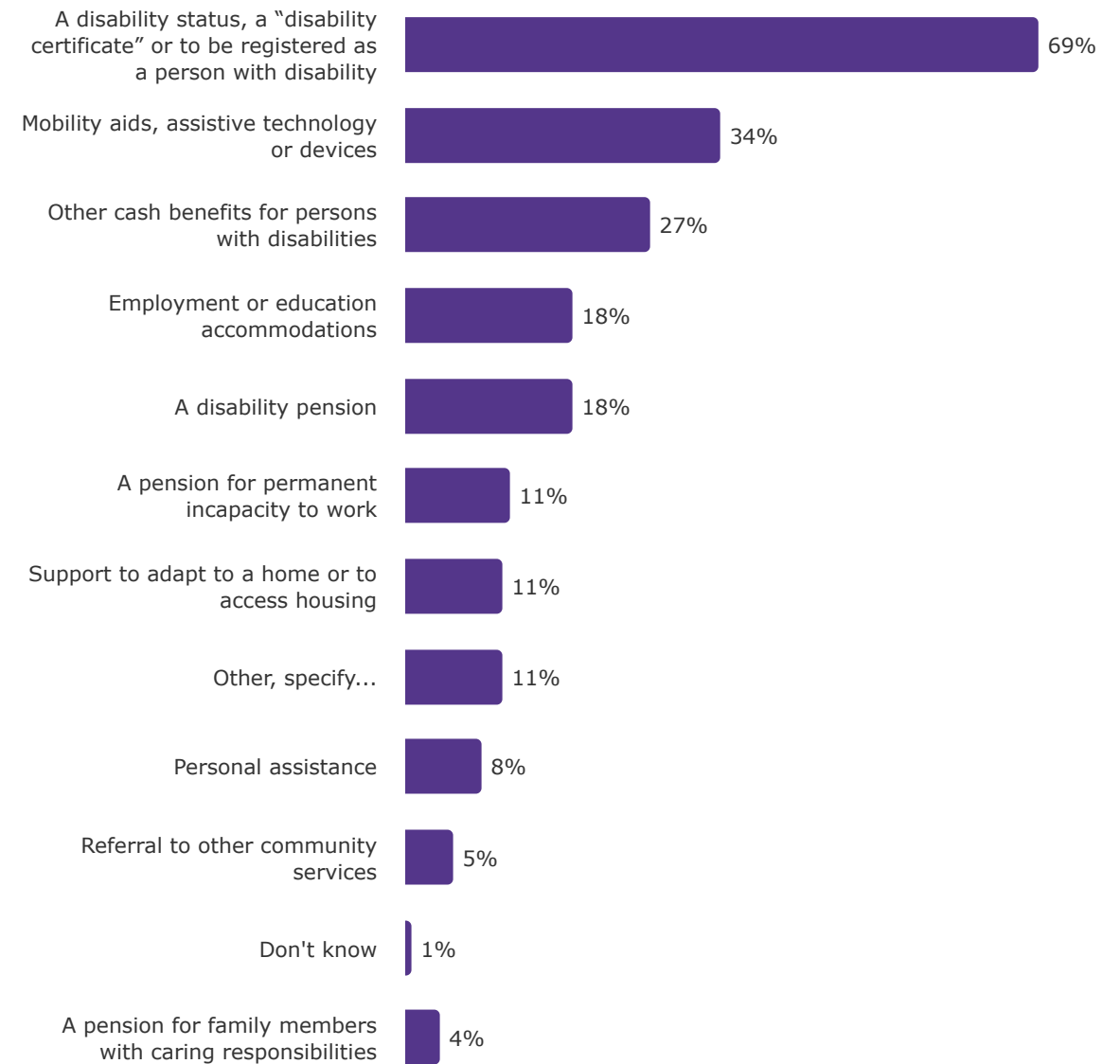
	N	%
Medical doctors only	139	55%
Healthcare professionals (doctors, nurses, therapists...) and non-healthcare professionals (social workers...)	67	26%
Several healthcare professionals (doctors, nurses, therapists...)	39	15%
Non-medical staff hired by private companies	6	2%
Other, specify...	2	1%
TOTAL	253	100%



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...?

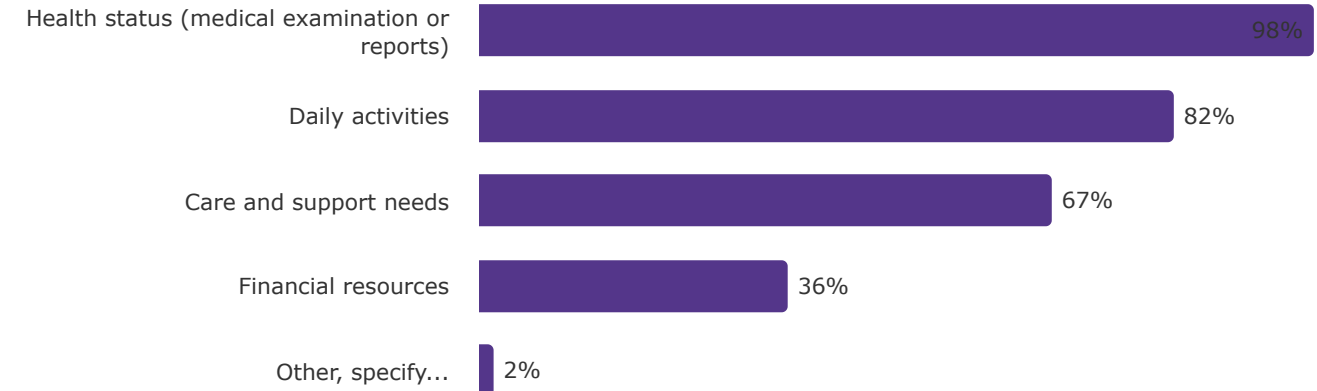
	N	%
A disability status, a "disability certificate" or to be registered as a person with disability	90	69%
Mobility aids, assistive technology or devices	45	34%
Other cash benefits for persons with disabilities	35	27%
Employment or education accommodations	24	18%
A disability pension	24	18%
A pension for permanent incapacity to work	15	11%
Support to adapt to a home or to access housing	14	11%
Other, specify...	14	11%
Personal assistance	11	8%
Referral to other community services	7	5%
Don't know	1	1%
A pension for family members with caring responsibilities	5	4%
TOTAL	131	



These questions was 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)	251	98%
Daily activities	209	82%
Care and support needs	172	67%
Financial resources	93	36%
Other, specify...	5	2%
TOTAL	255	



How many disability assessments have you undergone?

	N	Percentage
More than one assessment	165	64%
One assessment	91	36%
TOTAL	256	

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

	N	Percentage
No access	49	19%
Partially	117	46%
In full	90	35%
TOTAL	256	

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

Was the result of the assessment what you expected?

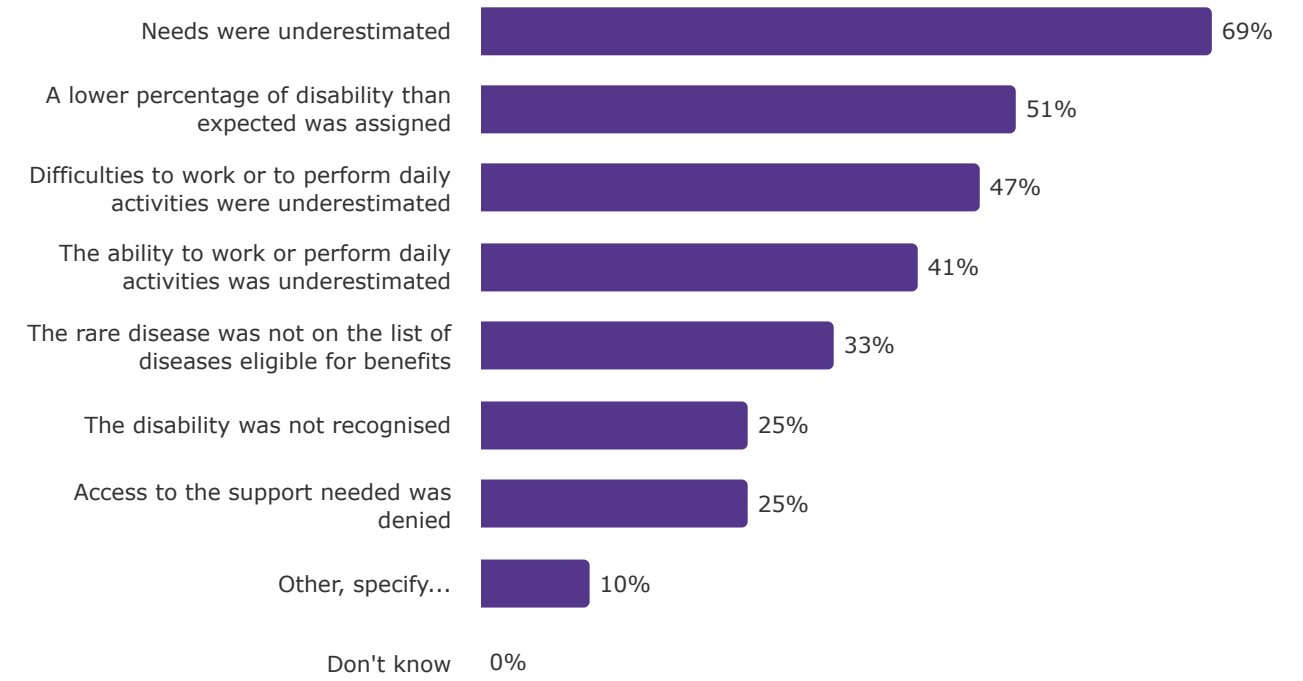
	N	%
No	87	35%
Yes	163	65%
TOTAL	250	100%

This question was only asked to people who answer NO.



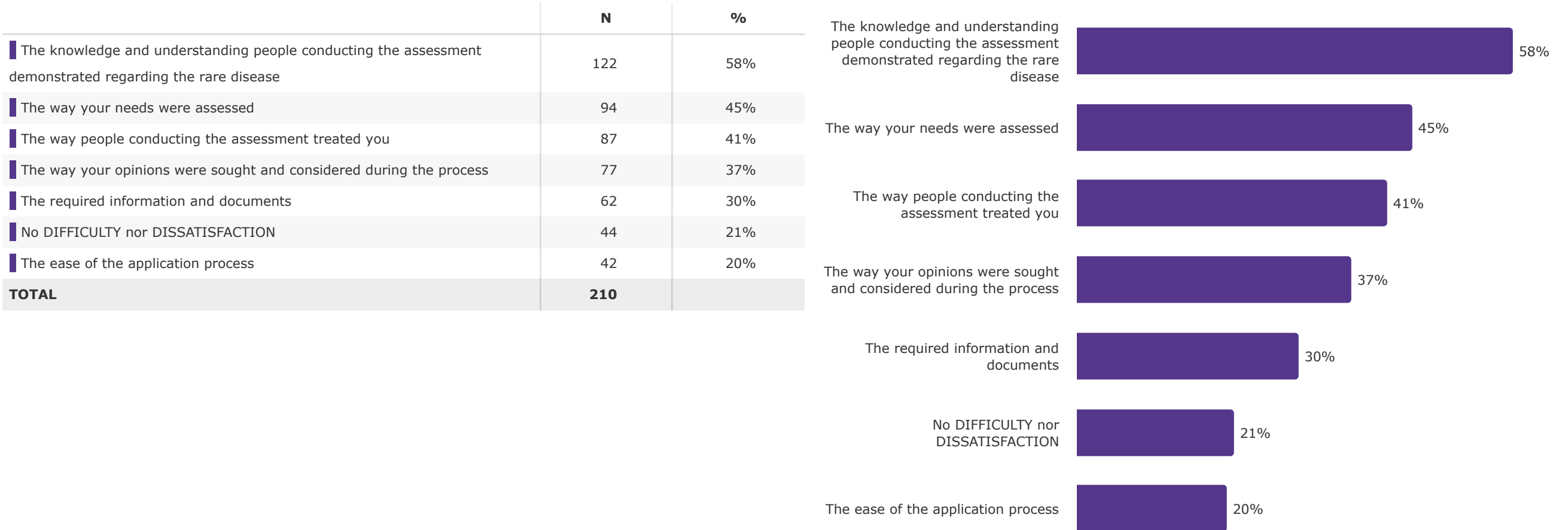
In your opinion, was it because...?

	N	%
Needs were underestimated	60	69%
A lower percentage of disability than expected was assigned	44	51%
Difficulties to work or to perform daily activities were underestimated	41	47%
The ability to work or perform daily activities was underestimated	36	41%
The rare disease was not on the list of diseases eligible for benefits	29	33%
The disability was not recognised	22	25%
Access to the support needed was denied	22	25%
Other, specify...	9	10%
Don't know	0	0%
TOTAL	87	



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"

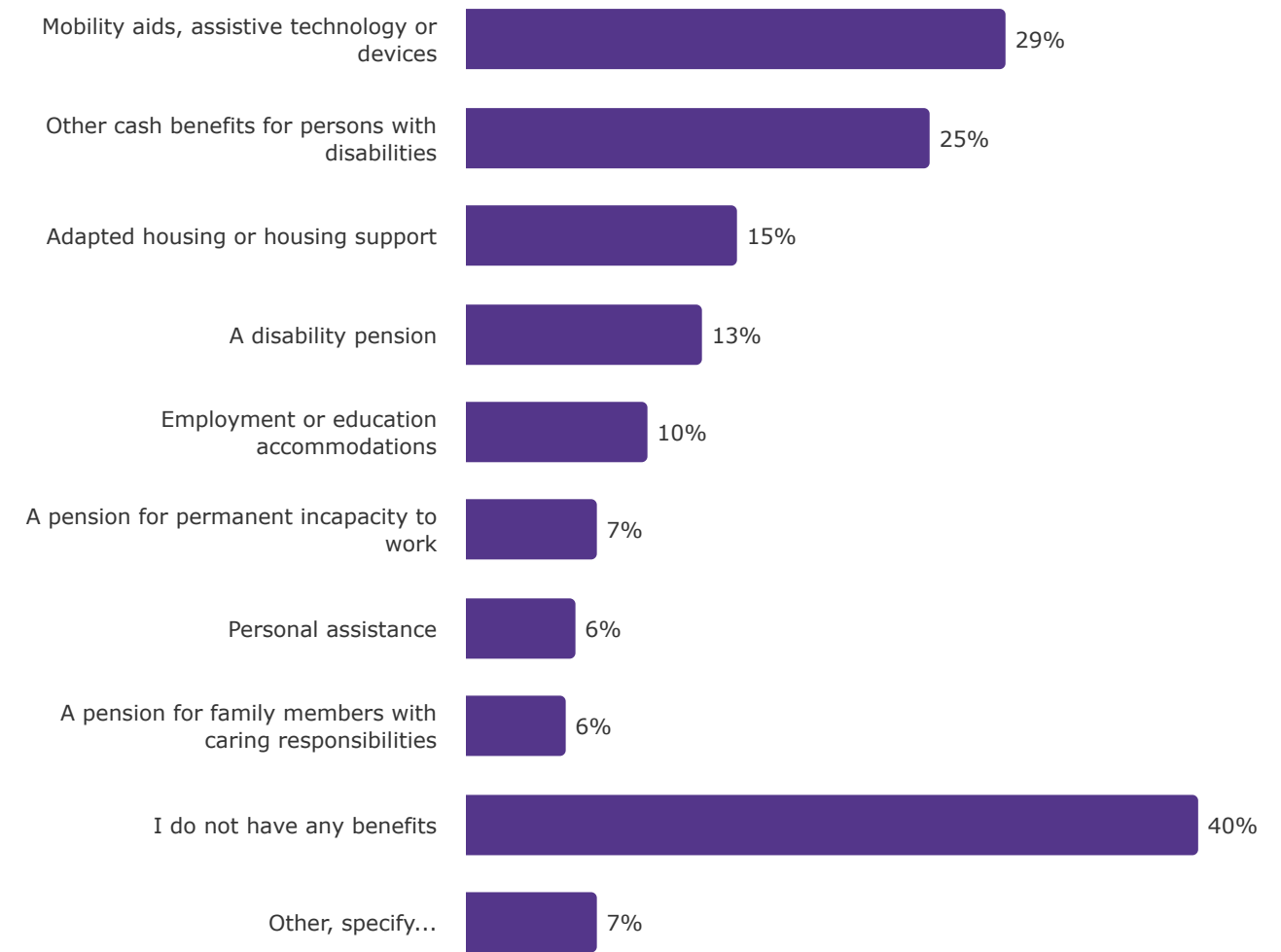


4. INDEPENDENT LIVING

Public support, personal assistant,
living arrangements

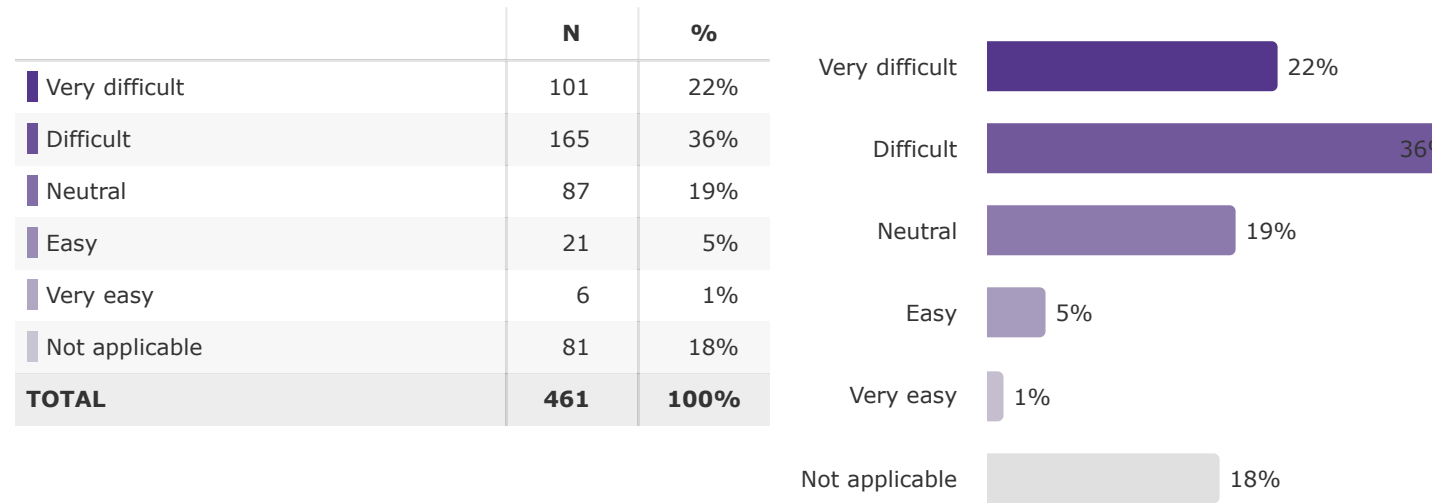
Do you currently benefit from...?

	N	%
Mobility aids, assistive technology or devices	107	29%
Other cash benefits for persons with disabilities	92	25%
Adapted housing or housing support	54	15%
A disability pension	47	13%
Employment or education accommodations	36	10%
A pension for permanent incapacity to work	26	7%
Personal assistance	22	6%
A pension for family members with caring responsibilities	20	6%
I do not have any benefits	145	40%
Other, specify...	26	7%
TOTAL	363	



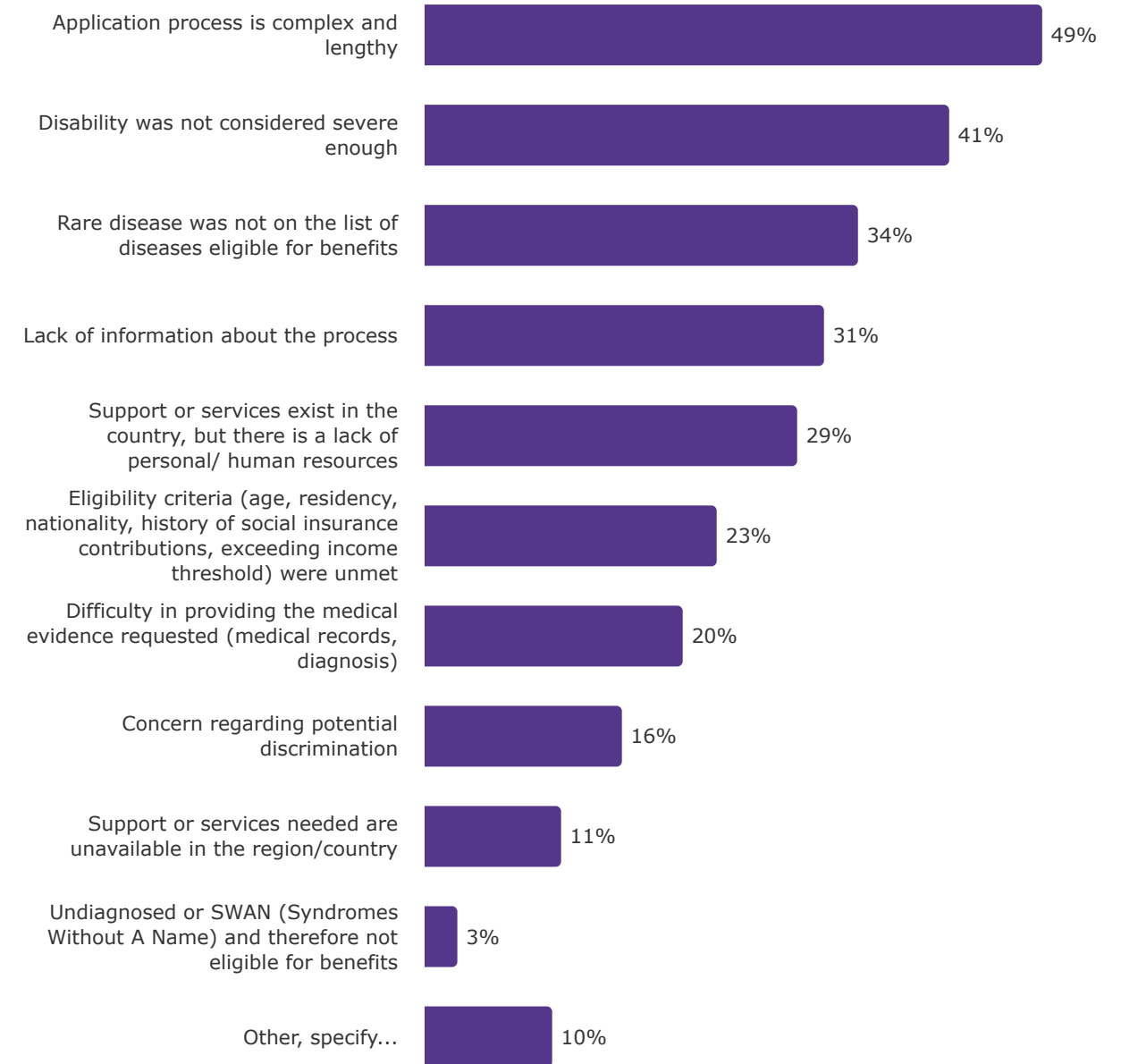
▼ Sample information : PATIENTvsCARER among "Patient"

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.?

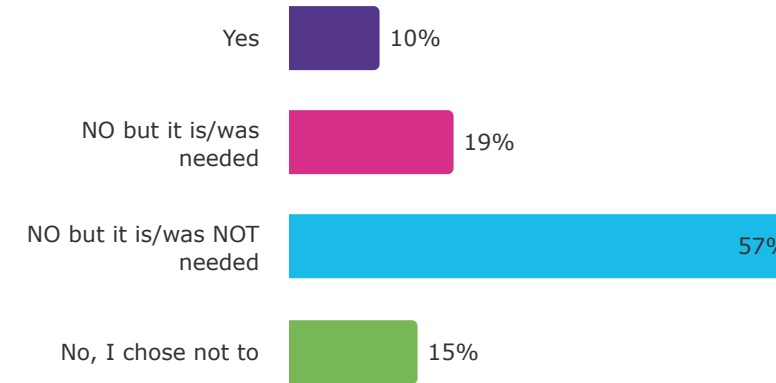
	N
Application process is complex and lengthy	184
Disability was not considered severe enough	156
Rare disease was not on the list of diseases eligible for benefits	129
Lack of information about the process	119
Support or services exist in the country, but there is a lack of personal/ human resources	111
Eligibility criteria (age, residency, nationality, history of social insurance contributions, exceeding income threshold) were unmet	87
Difficulty in providing the medical evidence requested (medical records, diagnosis)	77
Concern regarding potential discrimination	59
Support or services needed are unavailable in the region/country	41
Undiagnosed or SWAN (Syndromes Without A Name) and therefore not eligible for benefits	10
Other, specify...	38
TOTAL	378



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?

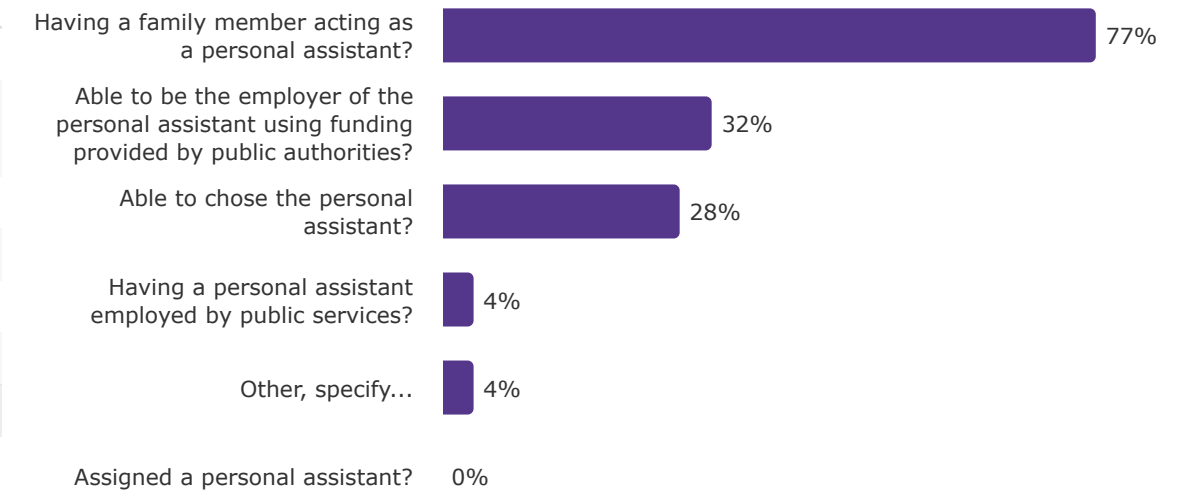
	N
Yes	46
NO but it is/was needed	84
NO but it is/was NOT needed	258
No, I chose not to	66
TOTAL	454



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

Were you...?

	N	%
Having a family member acting as a personal assistant?	41	77%
Able to be the employer of the personal assistant using funding provided by public authorities?	17	32%
Able to chose the personal assistant?	15	28%
Having a personal assistant employed by public services?	2	4%
Other, specify...	2	4%
Assigned a personal assistant?	0	0%
TOTAL	53	



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

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

9.5

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?

4.0

Median

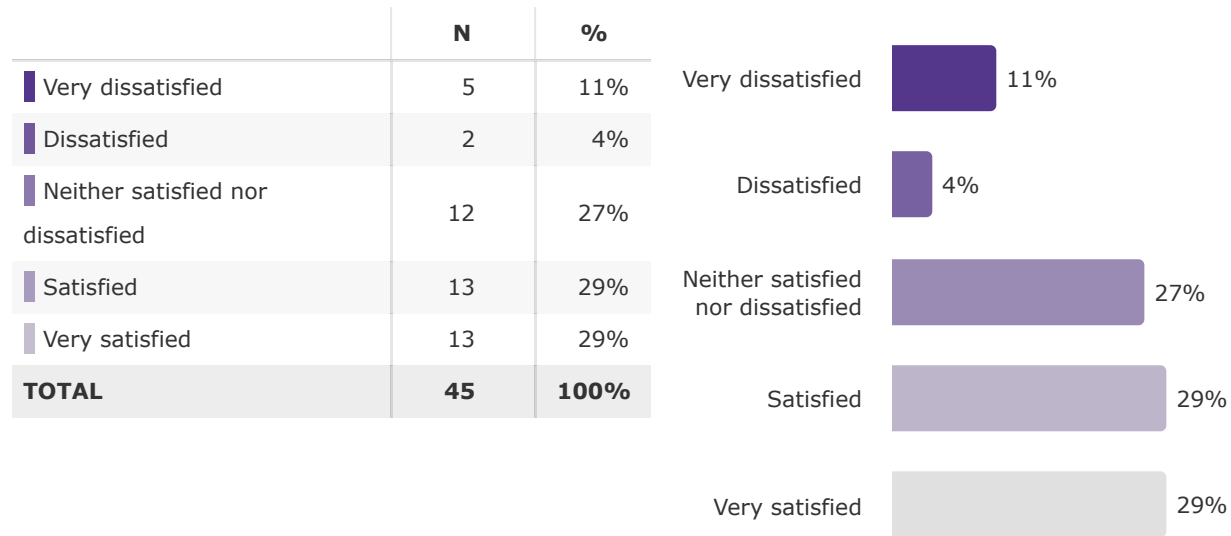
How many days of personal assistance do they currently have per week?

7.0

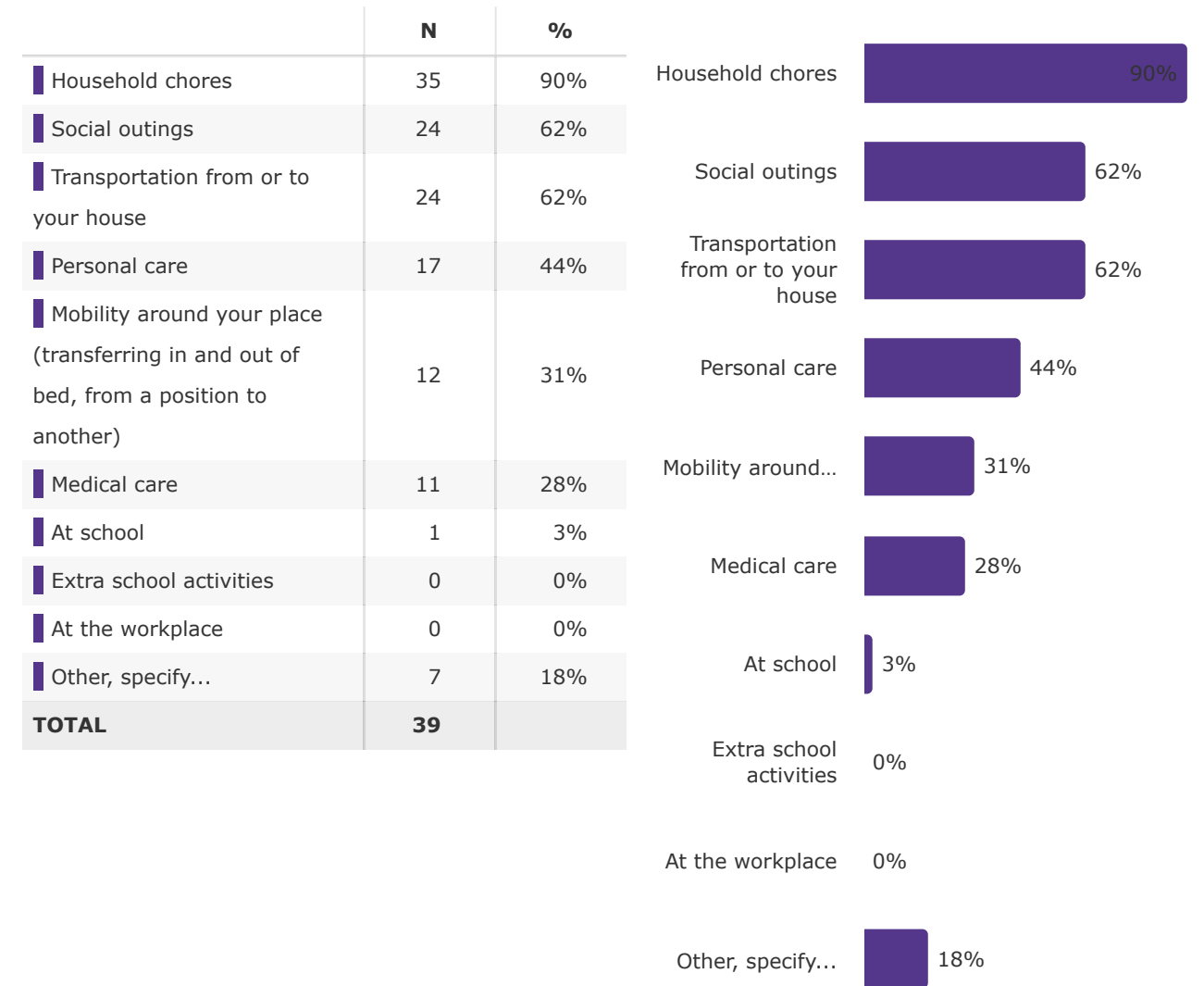
Median

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

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



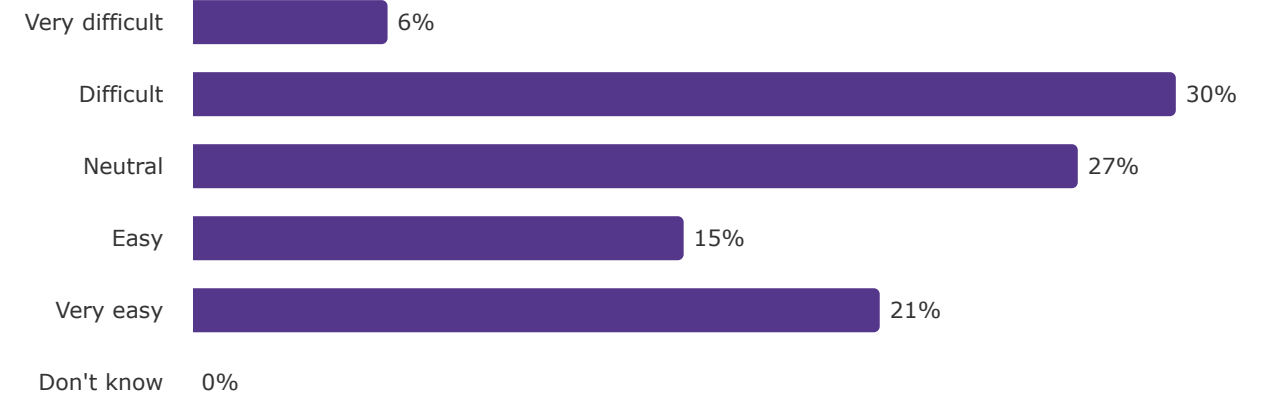
What tasks is the personal assistant currently assisting with?



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

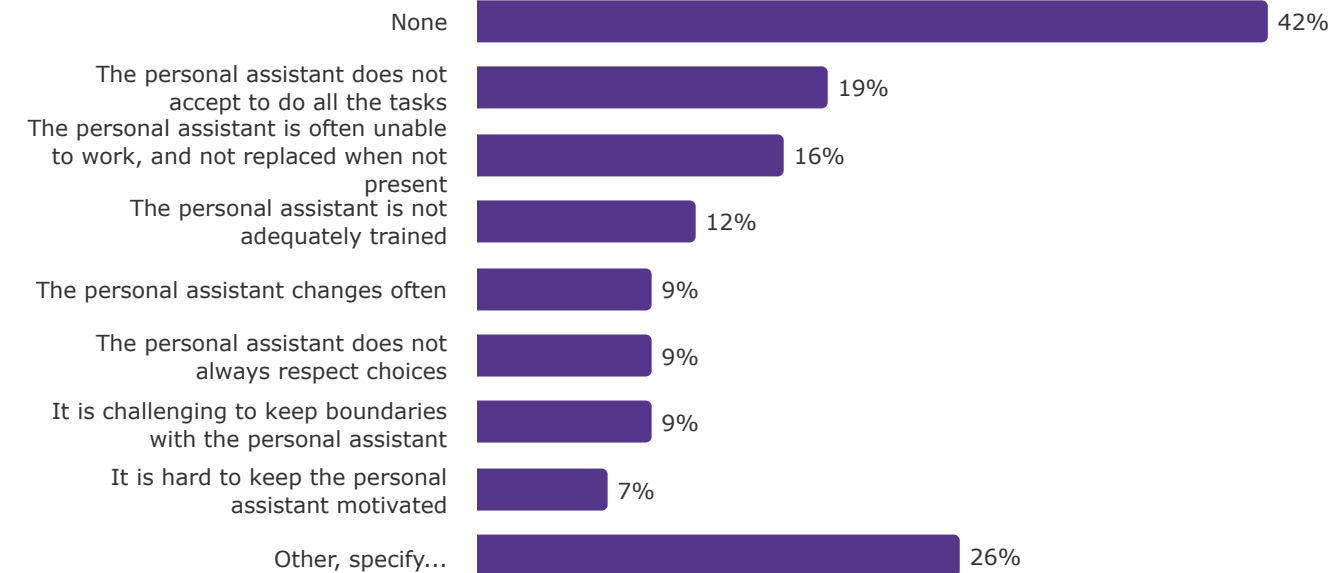
How difficult do you find it to manage the personal assistant (hiring, managing, paying)?

	N	%
Very difficult	2	6%
Difficult	10	30%
Neutral	9	27%
Easy	5	15%
Very easy	7	21%
Don't know	0	0%
TOTAL	33	100%



What are the difficulties faced managing the personal assistant?

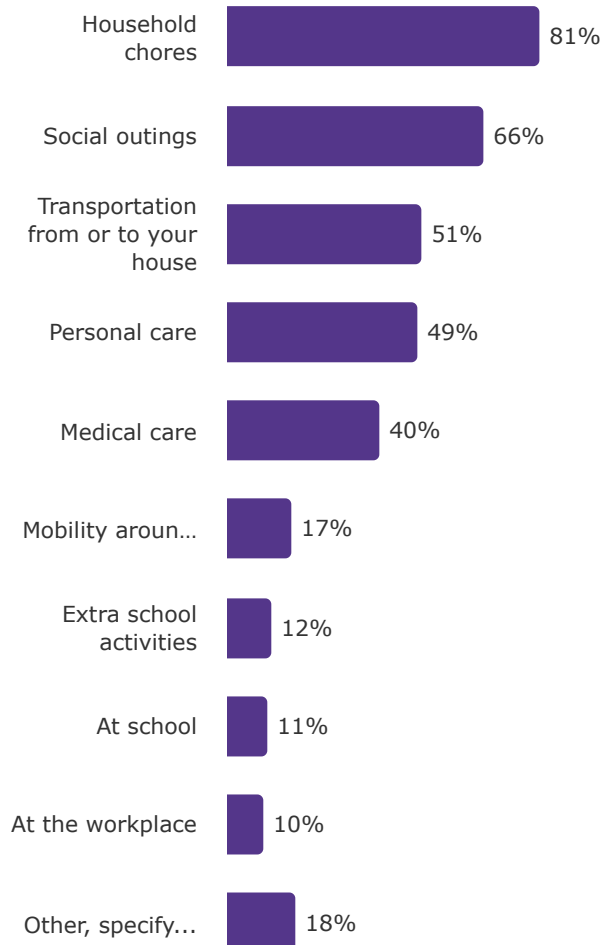
	N	%
None	18	42%
The personal assistant does not accept to do all the tasks	8	19%
The personal assistant is often unable to work, and not replaced when not present	7	16%
The personal assistant is not adequately trained	5	12%
The personal assistant changes often	4	9%
The personal assistant does not always respect choices	4	9%
It is challenging to keep boundaries with the personal assistant	4	9%
It is hard to keep the personal assistant motivated	3	7%
Other, specify...	11	26%
TOTAL	43	



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

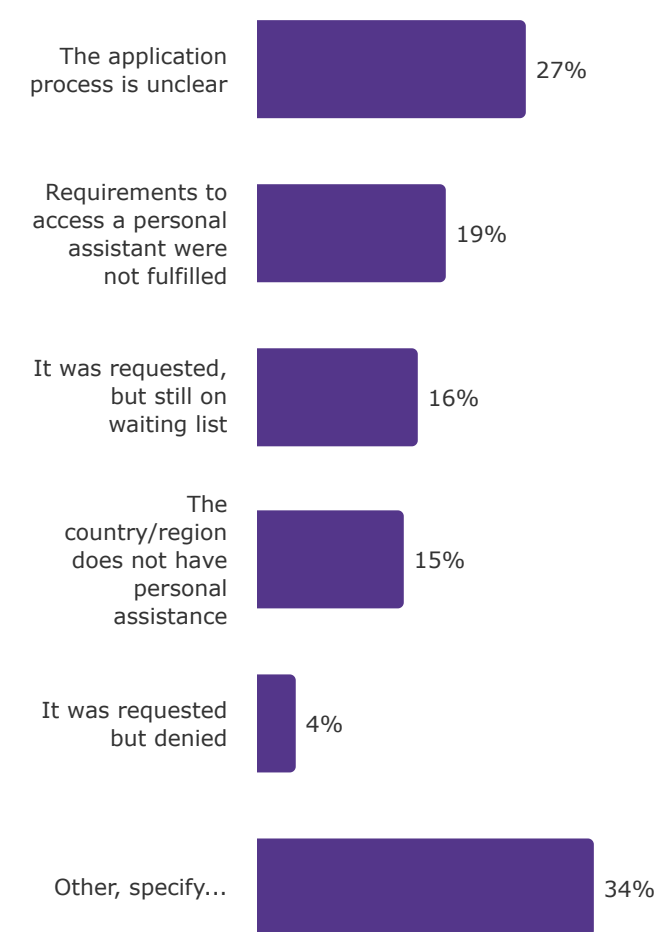
What tasks would you need assistance with?

	N	%
Household chores	67	81%
Social outings	55	66%
Transportation from or to your house	42	51%
Personal care	41	49%
Medical care	33	40%
Mobility around your place (transferring in and out of bed, from a position to another)	14	17%
Extra school activities	10	12%
At school	9	11%
At the workplace	8	10%
Other, specify...	15	18%
TOTAL	83	

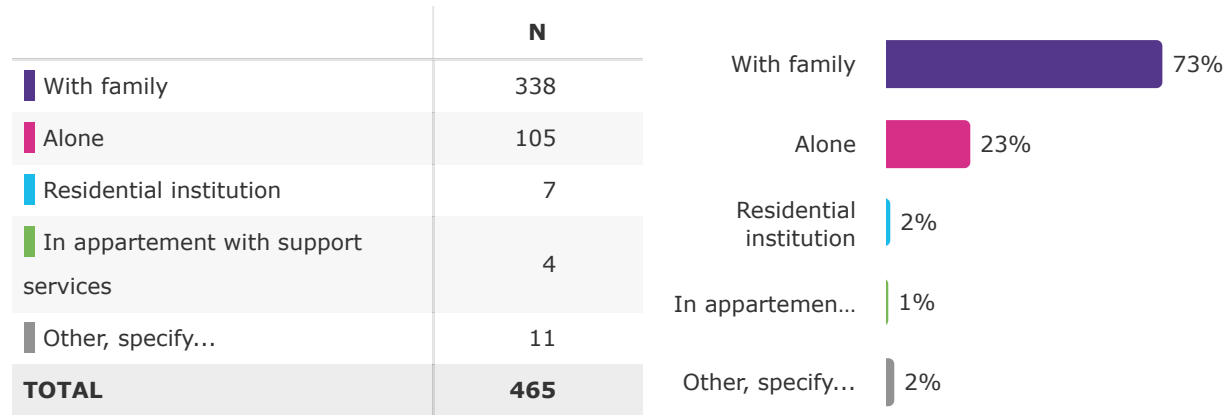


What are the reasons for not having a personal assistant?

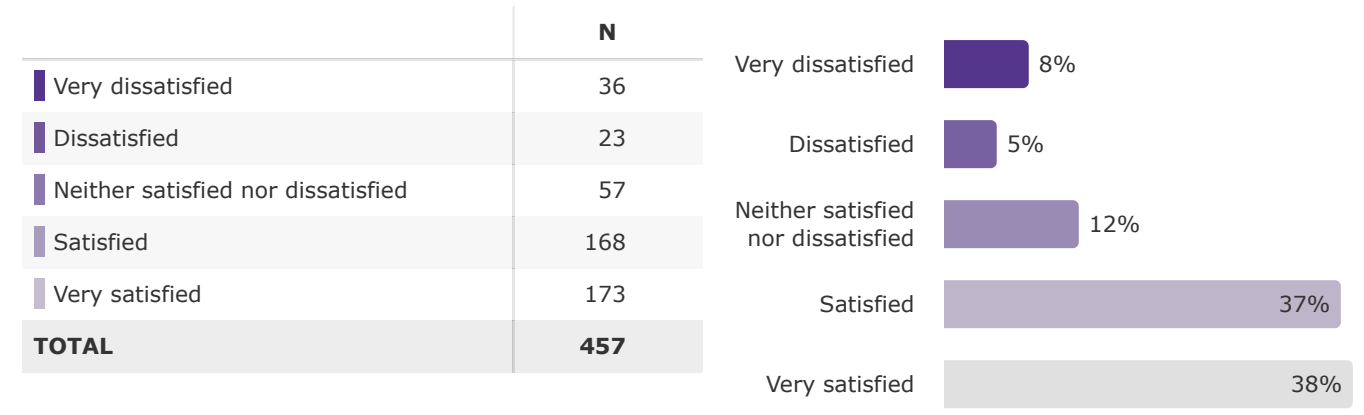
	N	%
The application process is unclear	20	27%
Requirements to access a personal assistant were not fulfilled	14	19%
It was requested, but still on waiting list	12	16%
The country/region does not have personal assistance	11	15%
It was requested but denied	3	4%
Other, specify...	25	34%
TOTAL	74	



Do you live...



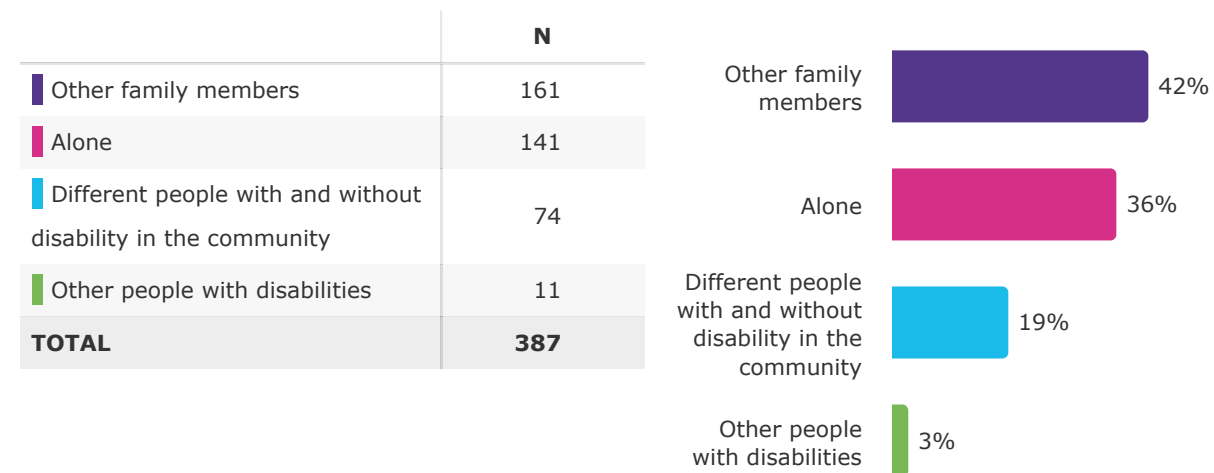
Are you satisfied with your current living arrangements?



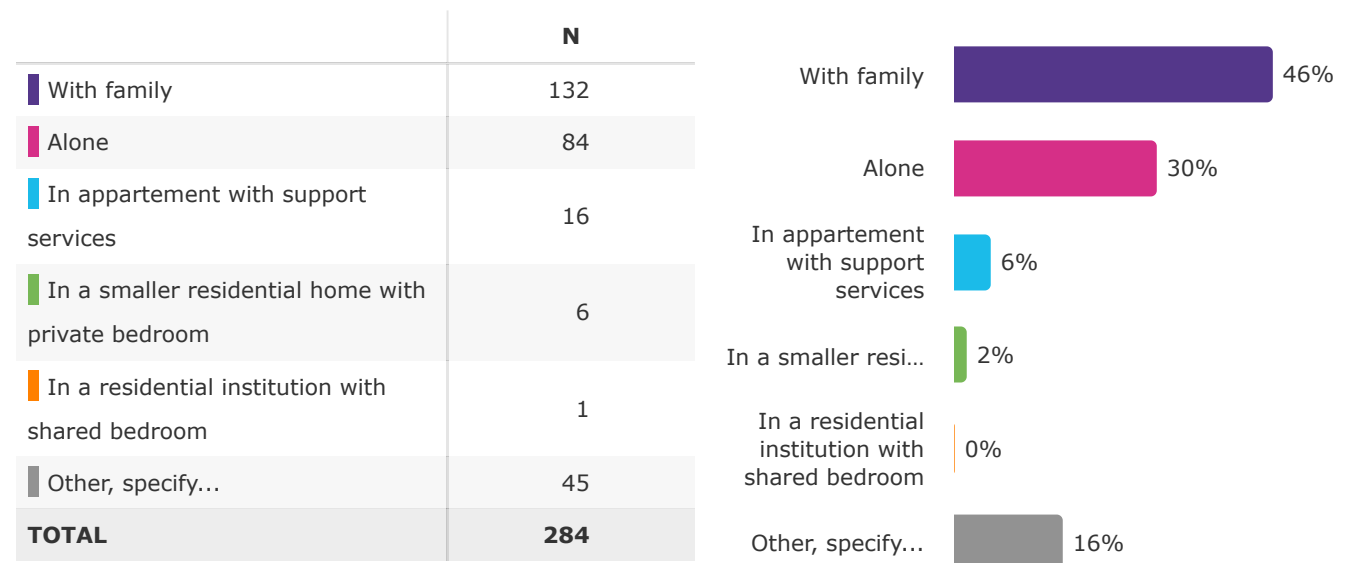
This question were only asked to people that consider themselves as living with disabilities.

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...?



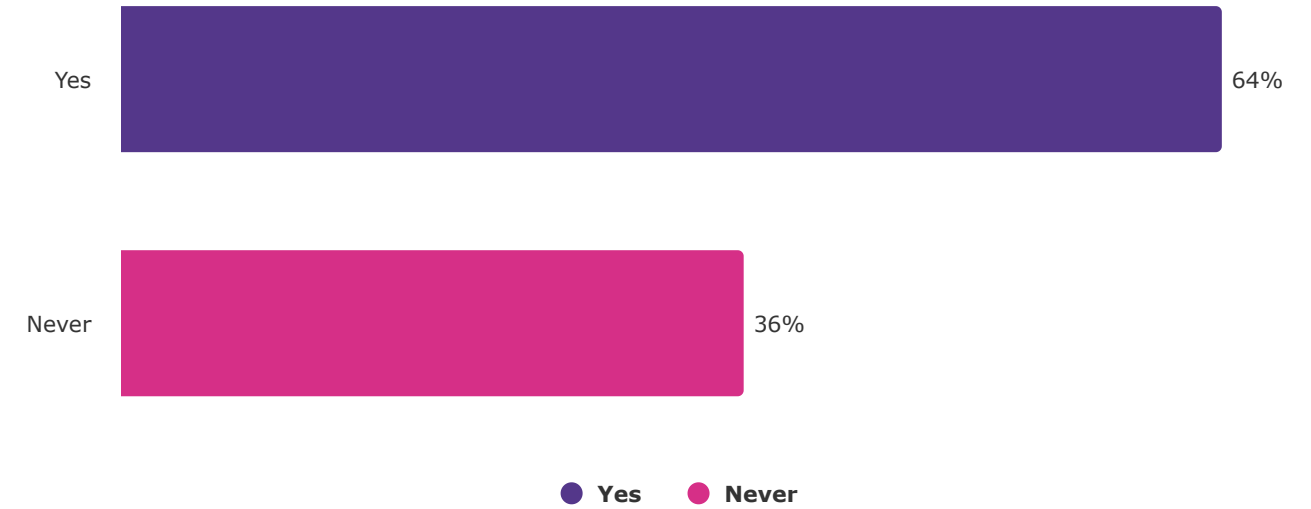


5. SOCIAL PARTICIPATION

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

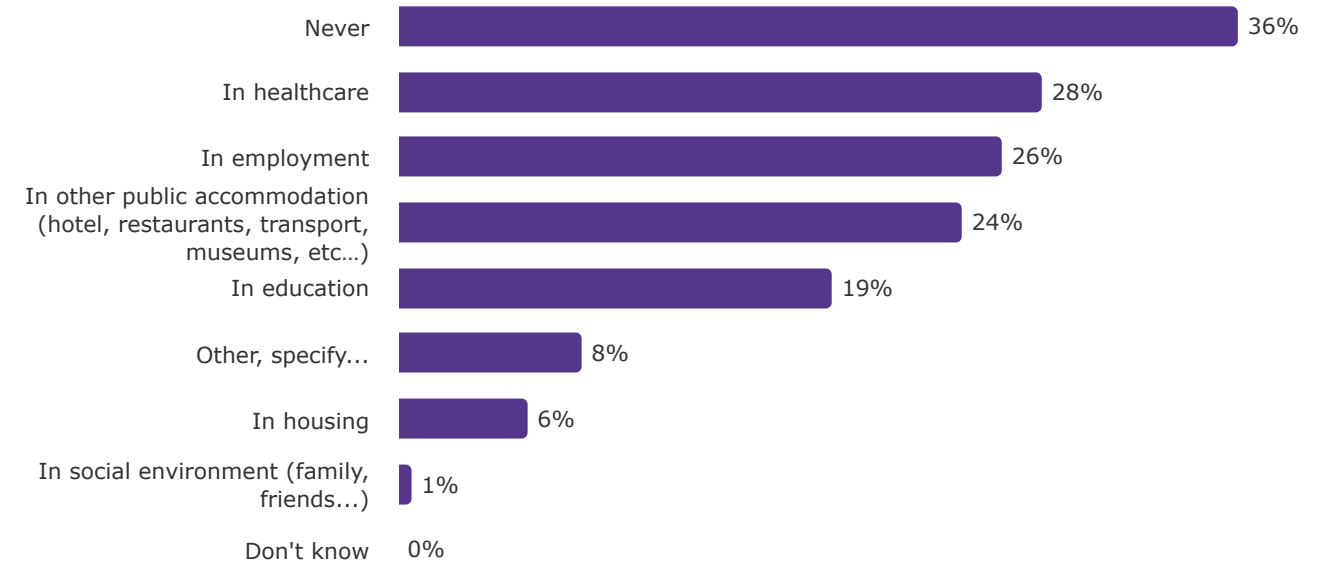
Have you ever experienced discrimination related to the rare disease or disability?

	N	%
▼ Yes	297	64%
In healthcare	129	28%
In employment	121	26%
In other public accommodation (hotel, restaurants, transport, museums, et...	113	24%
In education	87	19%
Other, specify...	37	8%
In housing	26	6%
In social environment (family, friends...)	3	1%
Never	168	36%
TOTAL	465	



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

	N	%
Never	168	36%
In healthcare	129	28%
In employment	121	26%
In other public accommodation (hotel, restaurants, transport, museums, etc...)	113	24%
In education	87	19%
Other, specify...	37	8%
In housing	26	6%
In social environment (family, friends...)	3	1%
Don't know	0	0%
TOTAL	465	



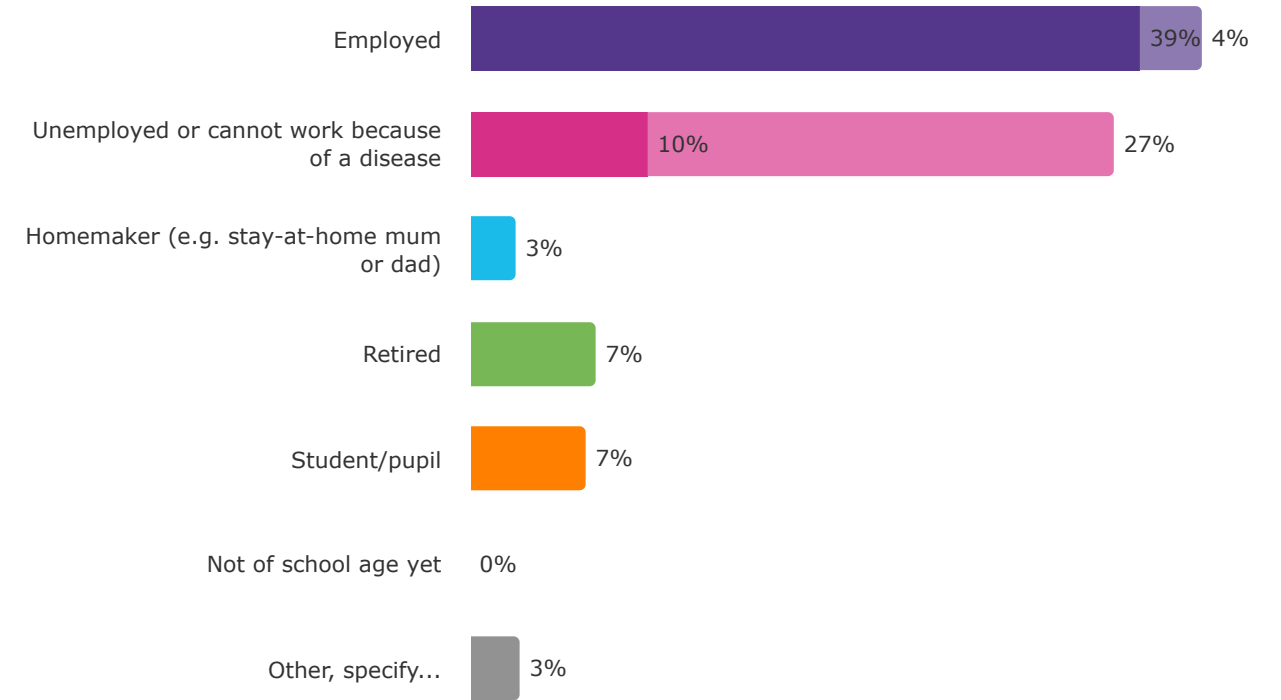


5.2. EMPLOYMENT

Employment and unemployment

What is your current situation?

	N	%
▼ Employed	144	43%
Employed (or partially employed)	132	39%
Self-employed	12	4%
▼ Unemployed or cannot work because of a disease	127	38%
Unemployed	35	10%
Cannot work because of the disease	92	27%
Homemaker (e.g. stay-at-home mum or dad)	9	3%
Retired	25	7%
Student/pupil	23	7%
Not of school age yet	0	0%
Other, specify...	10	3%
TOTAL	338	100%



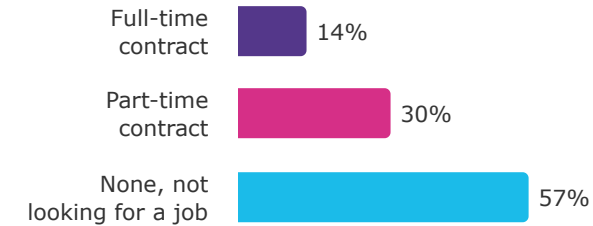
- Employed (or partially employed)
- Cannot work because of the disease
- Retired
- Self-employed
- Homemaker (e.g. stay-at-home mum or dad)
- Student/pupil
- Unemployed
- Not of school age yet
- Other, specify...

▼ Sample information : Age_patient between 16 and 64

These questions were only asked to unemployed respondents.

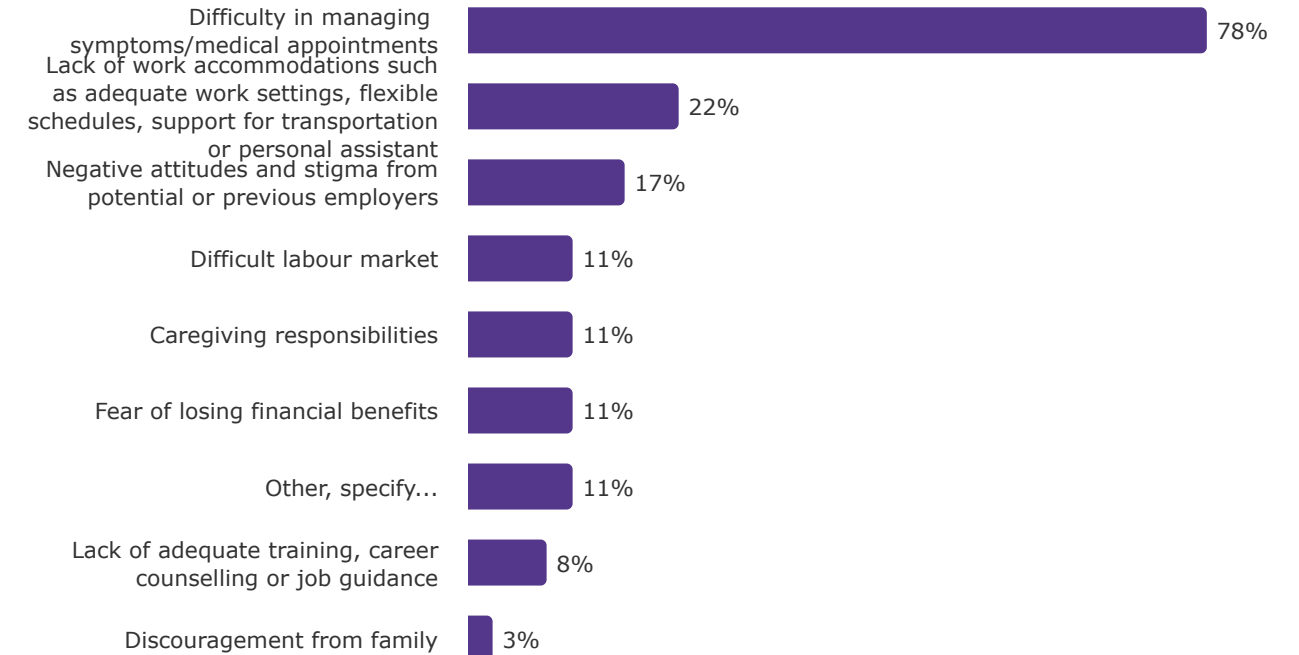
What type of work contract would you prefer if you became employed?

	N
Full-time contract	5
Part-time contract	11
None, not looking for a job	21
TOTAL	37



What are your reasons for currently being unemployed?

	N	%
Difficulty in managing symptoms/medical appointments	28	78%
Lack of work accommodations such as adequate work settings, flexible schedules, support for transportation or personal assistant	8	22%
Negative attitudes and stigma from potential or previous employers	6	17%
Difficult labour market	4	11%
Caregiving responsibilities	4	11%
Fear of losing financial benefits	4	11%
Other, specify...	4	11%
Lack of adequate training, career counselling or job guidance	3	8%
Discouragement from family	1	3%
TOTAL	36	



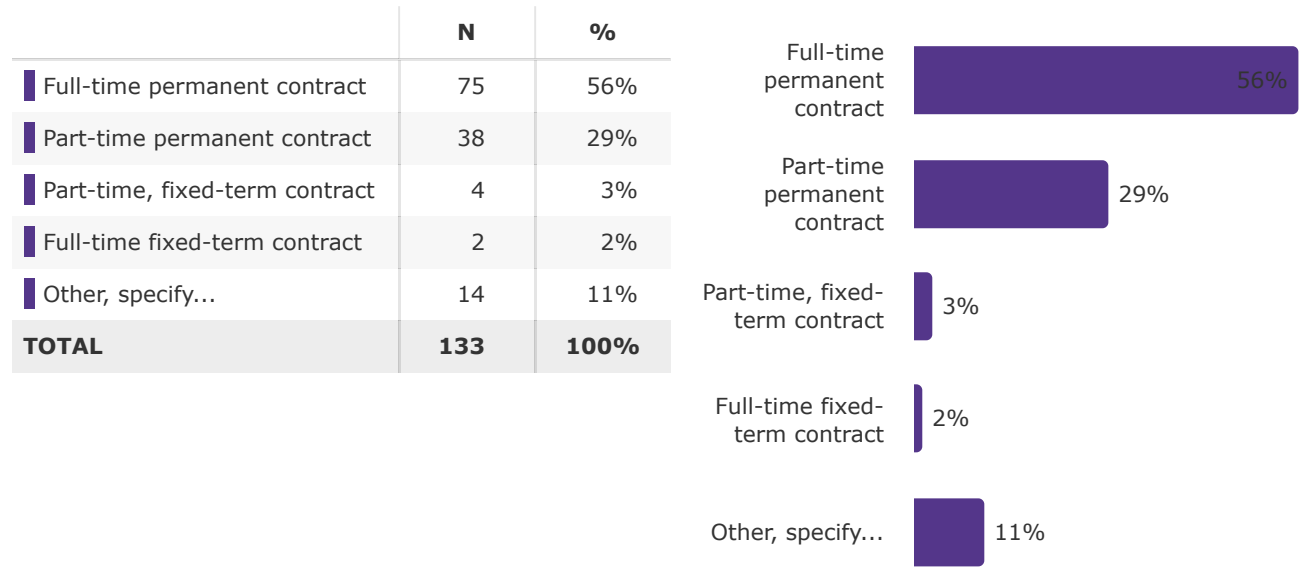
This question was only asked to respondents who are currently employed.

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

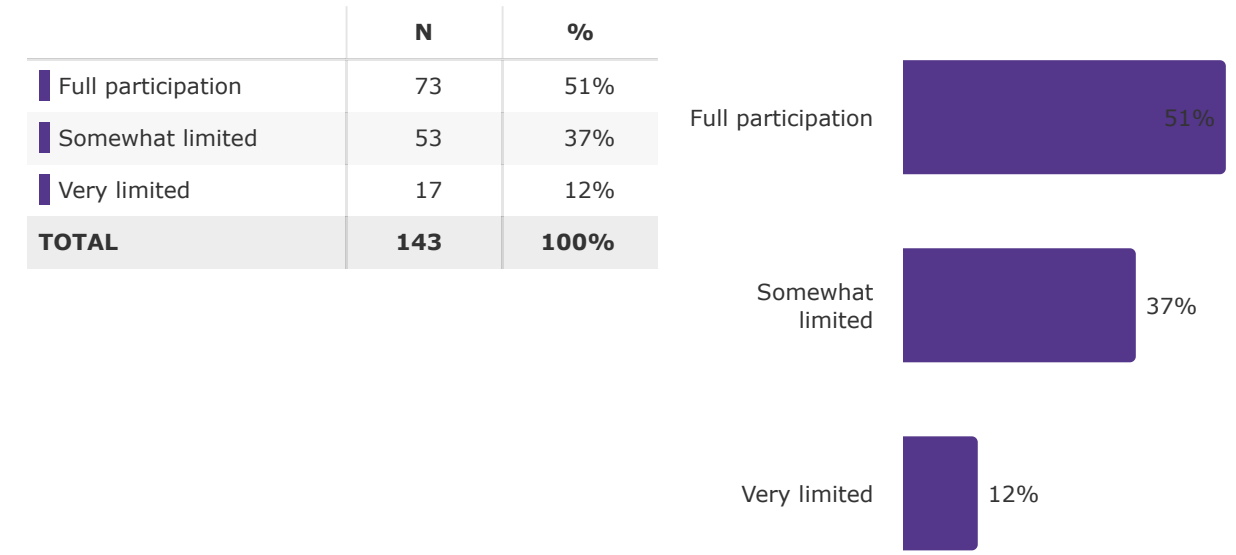


This question was only asked to respondents who are currently employed.

What type of work contract do you have?



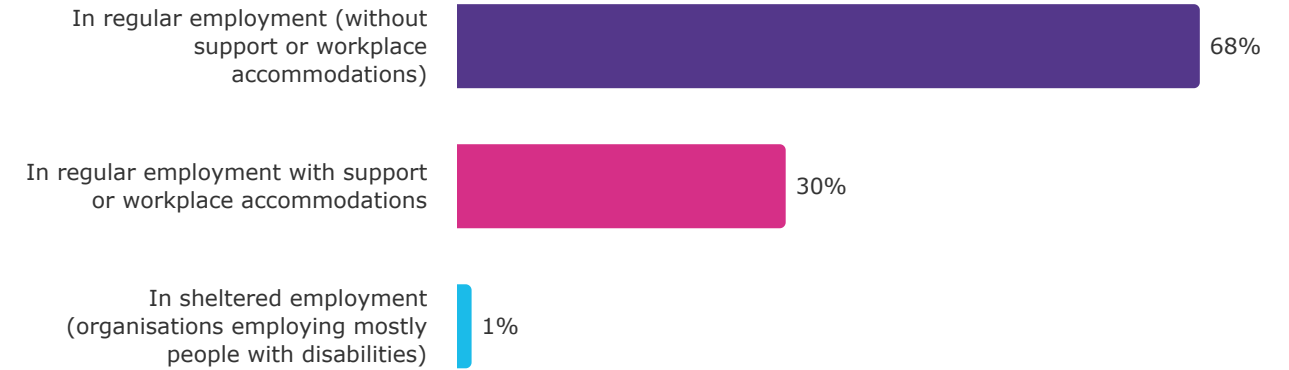
What is your current level of participation at work?



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

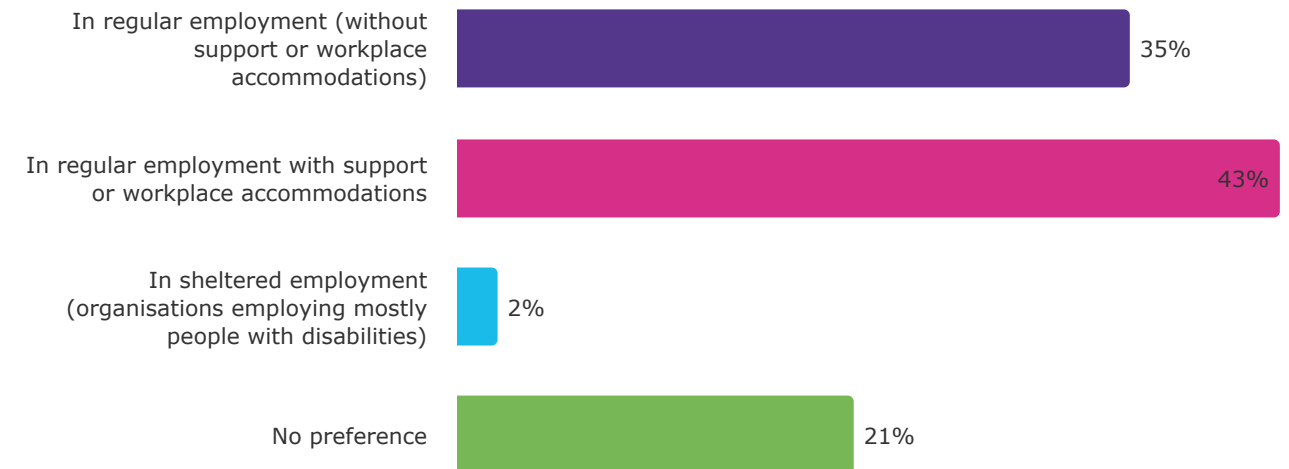
Do you work?

	N	%
In regular employment (without support or workplace accommodations)	97	68%
In regular employment with support or workplace accommodations	43	30%
In sheltered employment (organisations employing mostly people with disabilities)	2	1%
TOTAL	142	100%



Would you prefer to work...

	N	%
In regular employment (without support or workplace accommodations)	49	35%
In regular employment with support or workplace accommodations	60	43%
In sheltered employment (organisations employing mostly people with disabilities)	3	2%
No preference	29	21%
TOTAL	141	100%



▼ Sample information : Situation_m among "Employed (or partially employed);Self-employed"

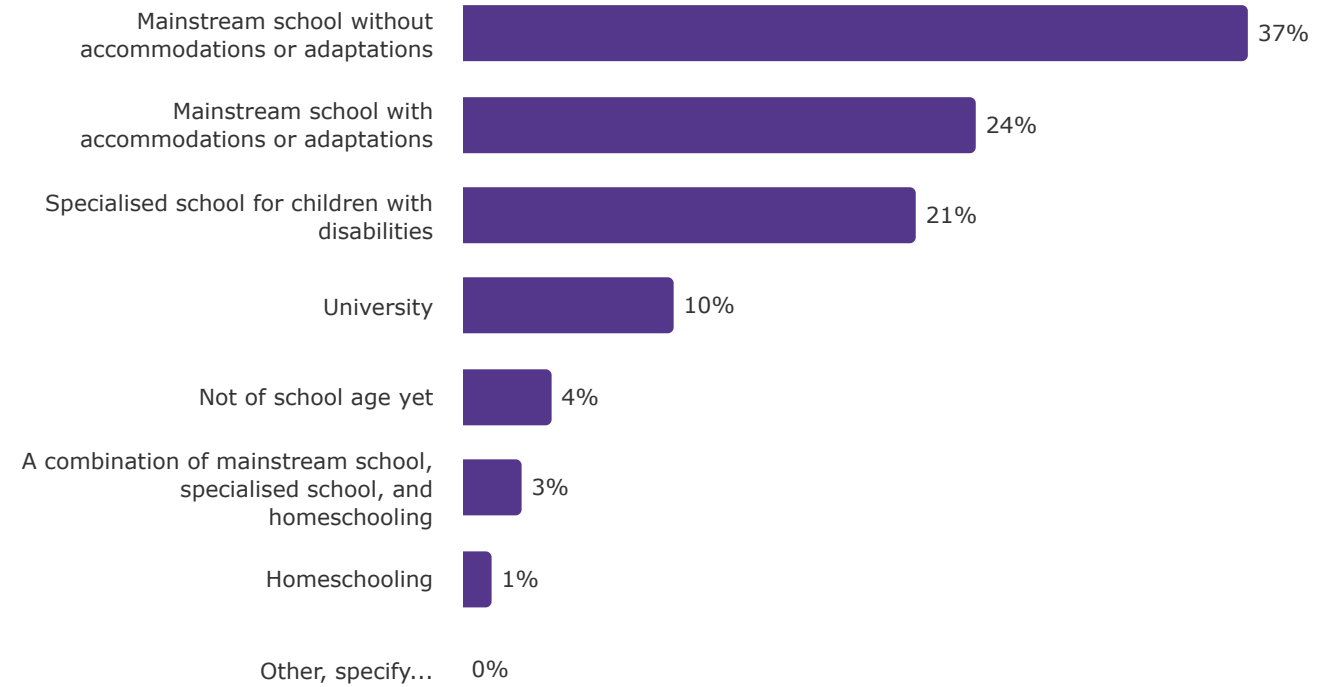


5.3. SCHOOL PARTICIPATION

This question was only asked to students/pupils

Do you attend...

	N
Mainstream school without accommodations or adaptations	26
Mainstream school with accommodations or adaptations	17
Specialised school for children with disabilities	15
University	7
Not of school age yet	3
A combination of mainstream school, specialised school, and homeschooling	2
Homeschooling	1
Other, specify...	0
TOTAL	71



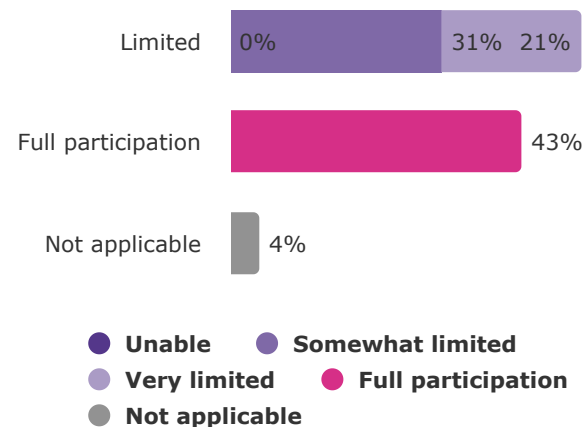


5.4. COMMUNITY PARTICIPATION

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

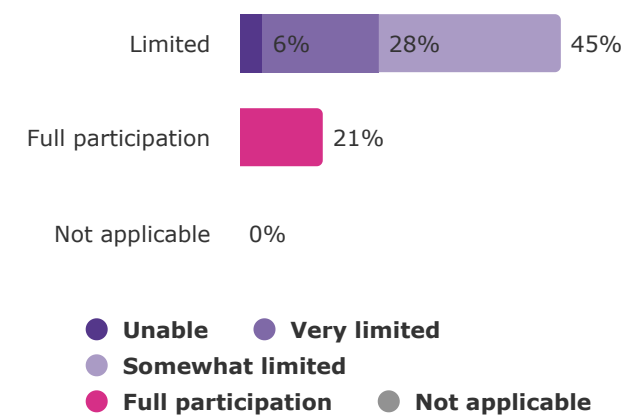
Compared to other people the same age, what is your current level of participation in educational (academic) activities with other students in the classroom?

	N	%
▼ Limited	35	52%
Unable	0	0%
Somewhat limited	21	31%
Very limited	14	21%
Full participation	29	43%
Not applicable	3	4%
TOTAL	67	100%



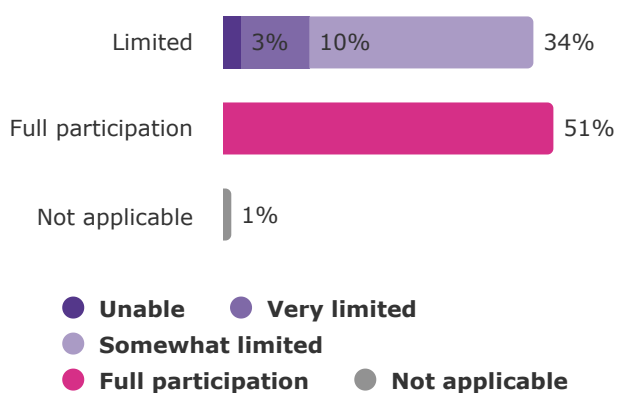
Compared to other people the same age, what is your current level of participation in social, play and recreational activities with other students (e.g., "hanging out", sports, clubs, hobbies, creative arts, lunchtime or recess activities)?

	N	%
▼ Limited	53	79%
Unable	4	6%
Very limited	19	28%
Somewhat limited	30	45%
Full participation	14	21%
Not applicable	0	0%
TOTAL	67	100%



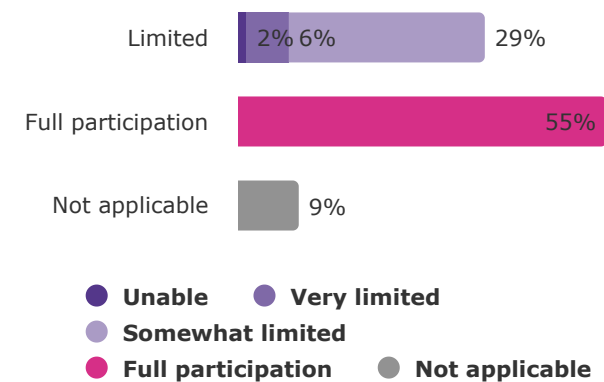
Compared to other people the same age, what is your current level of participation in moving around at school/university (e.g., to get to and use the bathroom, playground, cafeteria, library or other rooms and things that are available to other students the same age)?

	N	%
▼ Limited	32	48%
Unable	2	3%
Very limited	7	10%
Somewhat limited	23	34%
Full participation	34	51%
Not applicable	1	1%
TOTAL	67	100%



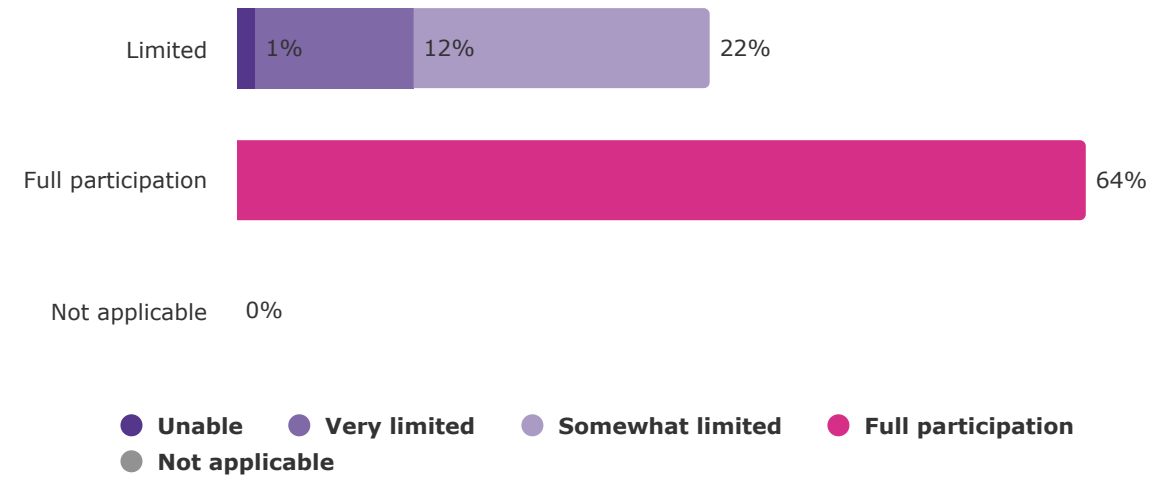
Compared to other people the same age, what is your current level of participation in using educational materials and equipment that are available to other students in the classroom/s or that have been modified for you (e.g., books, computers, chairs and desks)?

	N	%
▼ Limited	24	36%
Unable	1	2%
Very limited	4	6%
Somewhat limited	19	29%
Full participation	36	55%
Not applicable	6	9%
TOTAL	66	100%



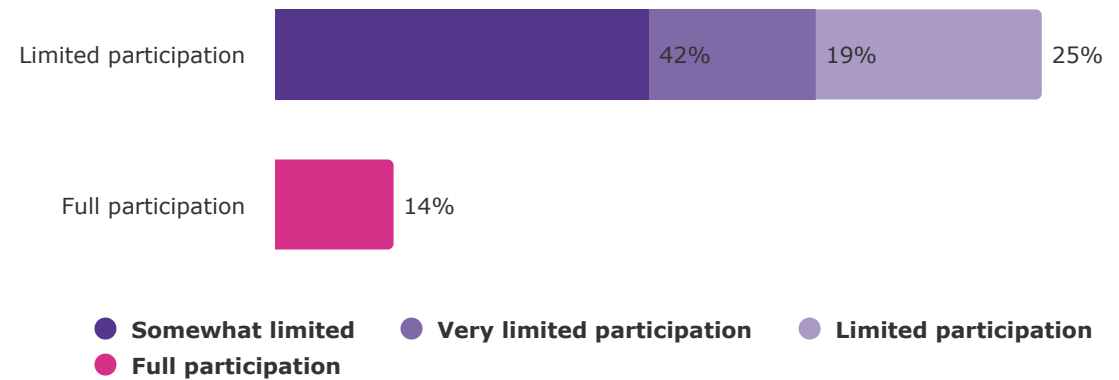
Compared to other people the same age, what is your current level of participation in communicating with other students and adults at school/university?

	N	%
▼ Limited	24	36%
Unable	1	1%
Very limited	8	12%
Somewhat limited	15	22%
Full participation	43	64%
Not applicable	0	0%
TOTAL	67	100%



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

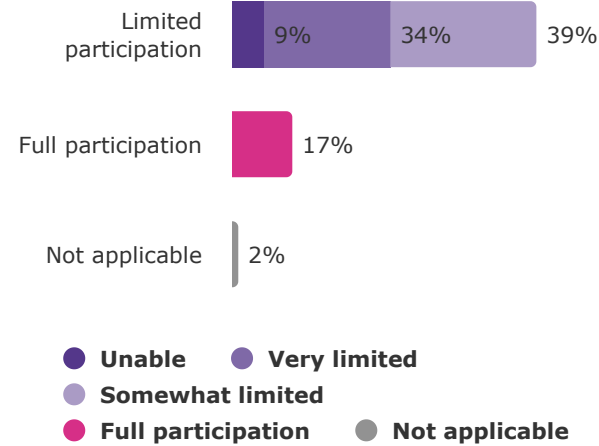
	N	%
▼ Limited participation	51	86%
Somewhat limited	25	42%
Very limited particip...	11	19%
Limited participation	15	25%
Full participation	8	14%
TOTAL	59	100%



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

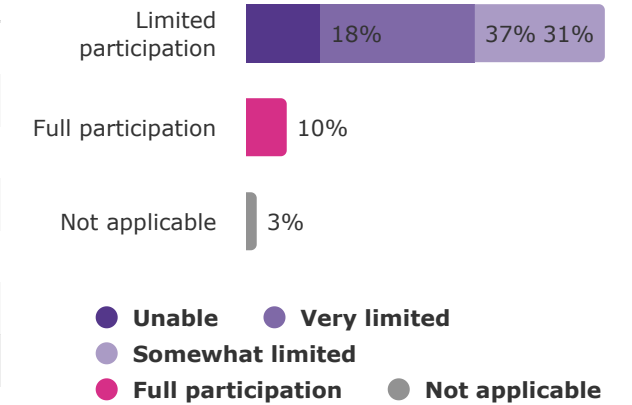
Social, play or leisure activities with friends in the neighbourhood and community (e.g., casual games, "hanging out", going to public places like a movie theatre, park or restaurant)?

	N	%
▼ Limited participation	379	82%
Unable	43	9%
Very limited	156	34%
Somewhat limited	180	39%
Full participation	77	17%
Not applicable	9	2%
TOTAL	465	100%



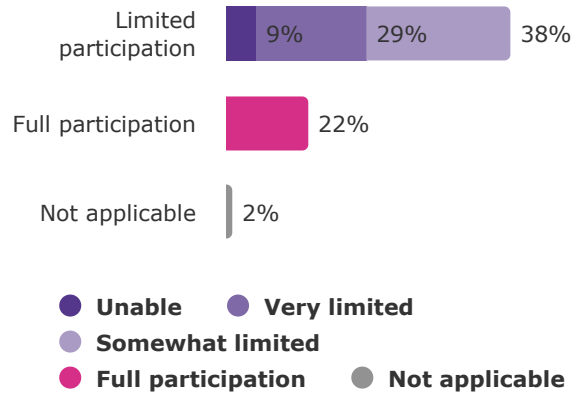
Structured events and activities in the neighbourhood and community (e.g., team sports, clubs, holiday or religious events, concerts, parades and fairs)?

	N	%
▼ Limited participation	404	87%
Unable	86	18%
Very limited	172	37%
Somewhat limited	146	31%
Full participation	47	10%
Not applicable	14	3%
TOTAL	465	100%



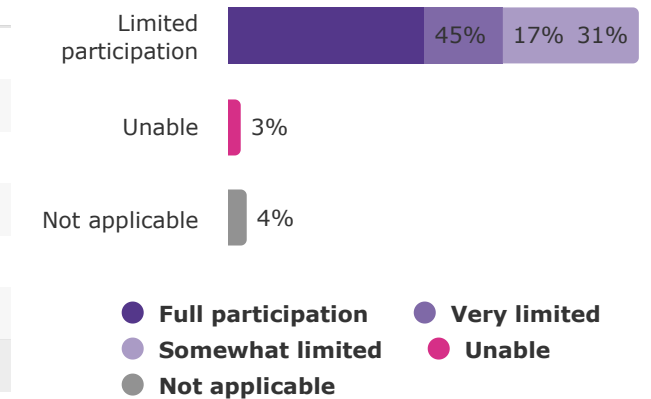
Moving around the neighbourhood and community (e.g., public buildings, parks, restaurants, movies)?

	N	%
▼ Limited participation	351	75%
Unable	40	9%
Very limited	134	29%
Somewhat limited	177	38%
Full participation	104	22%
Not applicable	10	2%
TOTAL	465	100%



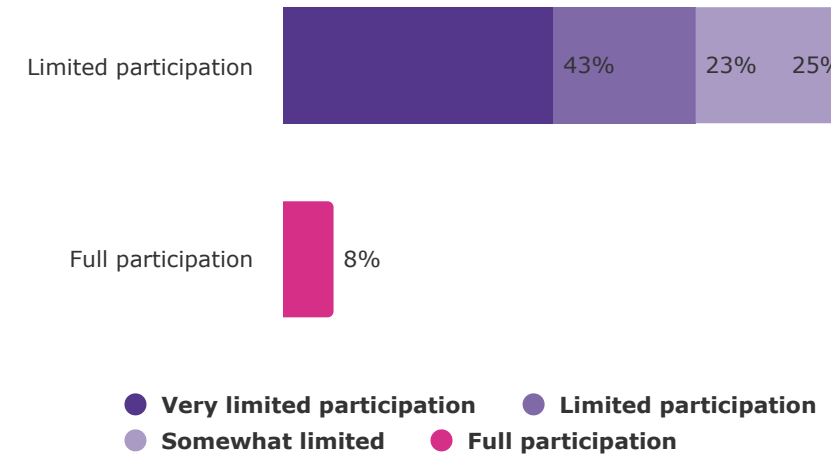
Communicating with others in the neighbourhood and community?

	N	%
▼ Limited participation	430	92%
Full participation	207	45%
Very limited	81	17%
Somewhat limited	142	31%
Unable	15	3%
Not applicable	20	4%
TOTAL	465	100%



Total community participation

	N	%
▼ Limited participation	394	92%
Very limited participation	187	43%
Limited participation	98	23%
Somewhat limited	109	25%
Full participation	36	8%
TOTAL	430	100%

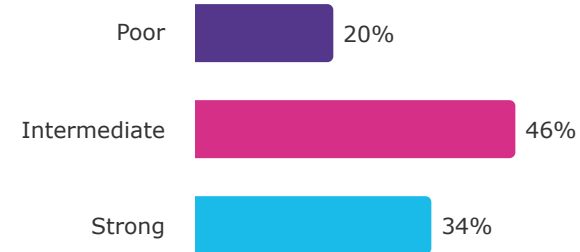




5.5. SOCIAL ENVIRONMENT

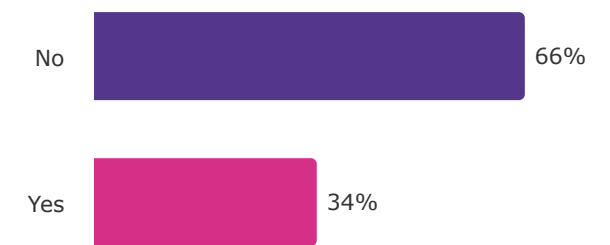
How would you qualify the social support you receive from people (close people to count on, concern shown by other people, practical help from neighbours in case of need)?

	N
Poor	90
Intermediate	208
Strong	153
TOTAL	451



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?

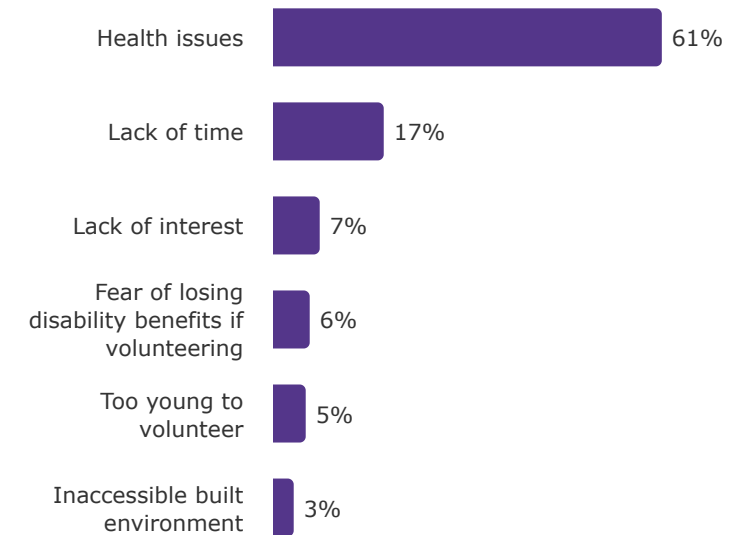
	N
No	302
Yes	157
TOTAL	459



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

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

	N	%
Health issues	146	61%
Lack of time	42	17%
Lack of interest	18	7%
Fear of losing disability benefits if volunteering	14	6%
Too young to volunteer	13	5%
Inaccessible built environment	8	3%
TOTAL	241	100%



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