

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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1. Sample information
2. Disabilities: disability rates; diversity, complexity and severity of disabilities
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

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

Na ovaj upitnik odgovarate kao...?

9.591

Uređaj koji se koristi za javljanje



● PC ● Tablet ● Smartphone

Prosječan broj minuta za ispunjavanje upitnika

21

Mean

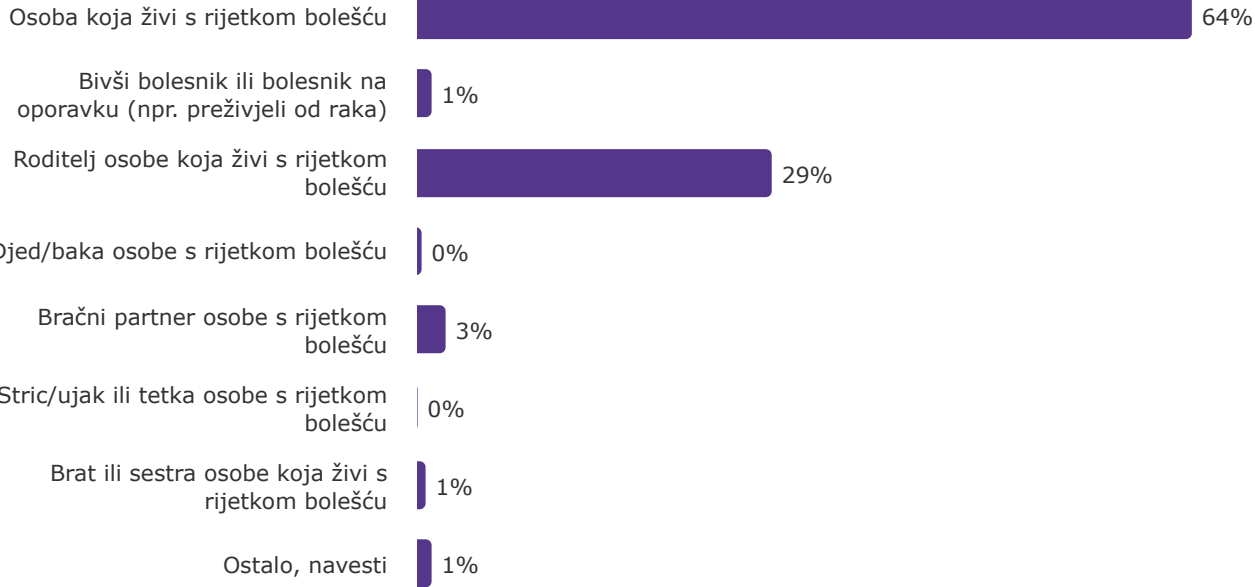
Srednji broj minuta za ispunjavanje upitnika

15

Median

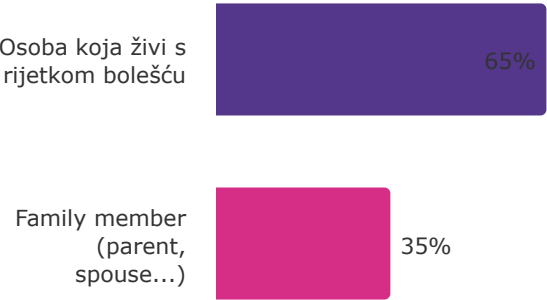
Na ovaj upitnik odgovarate kao...?

	N
Osoba koja živi s rijetkom bolešću	6.136
Bivši bolesnik ili bolesnik na oporavku (npr. preživjeli od raka)	123
Roditelj osobe koja živi s rijetkom bolešću	2.816
Djed/baka osobe s rijetkom bolešću	43
Bračni partner osobe s rijetkom bolešću	240
Stric/ujak ili tetka osobe s rijetkom bolešću	19
Brat ili sestra osobe koja živi s rijetkom bolešću	82
Ostalo, navesti	132
TOTAL	9.591



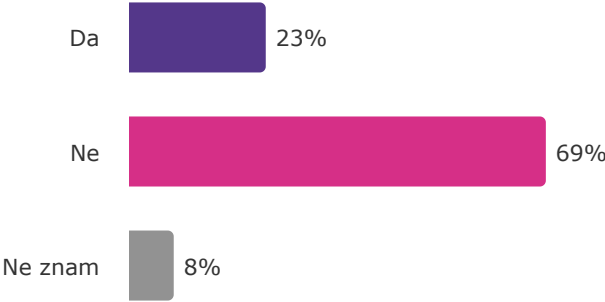
Ako je 'Drugo', navedite...

	N	%
Osoba koja živi s rijetkom bolešću	6.260	65%
Family member (parent, spouse...)	3.331	35%
TOTAL	9.591	100%

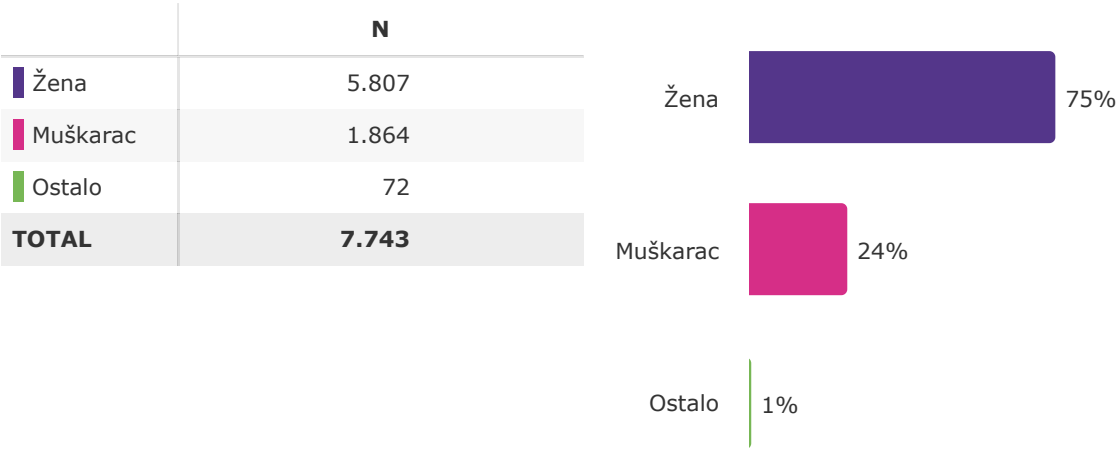


Jeste li predstavnik bolesnika, tj. uključeni u aktivnosti politike za podršku pitanja rijetkih bolesti?

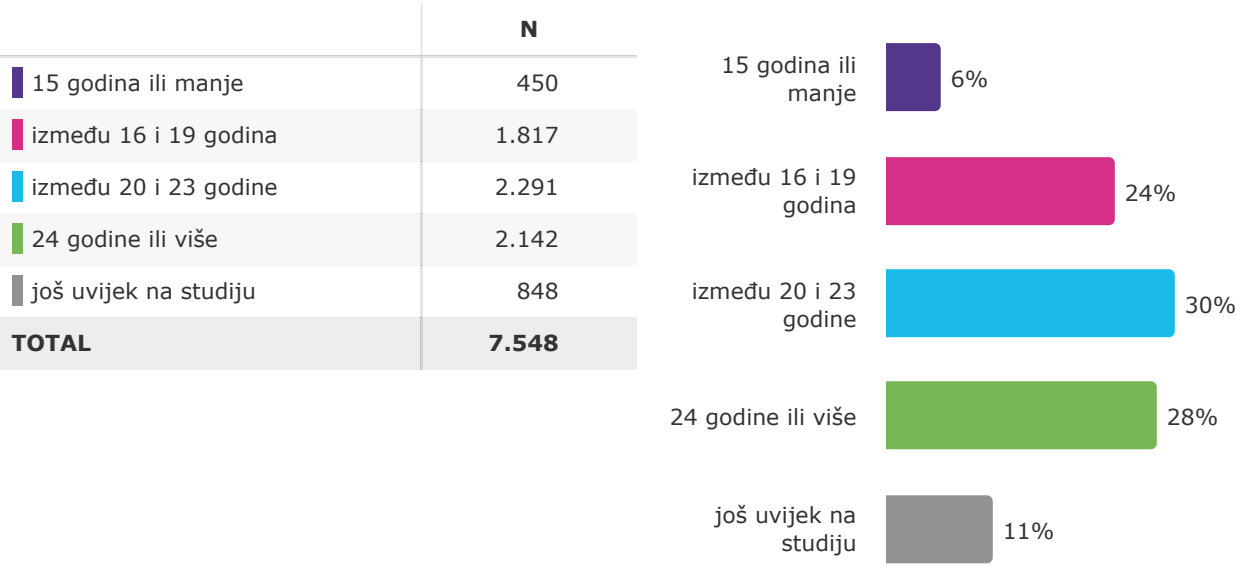
	N
Da	2.210
Ne	6.643
Ne znam	738
TOTAL	9.591



Jeste li:



Koliko Vam je bilo godina kad ste završili s redovnim obrazovanjem?



Koliko imate godina?

	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%
TOTAL	7.029	100%

Koliko godina ima osoba oboljela od rijetke bolesti?

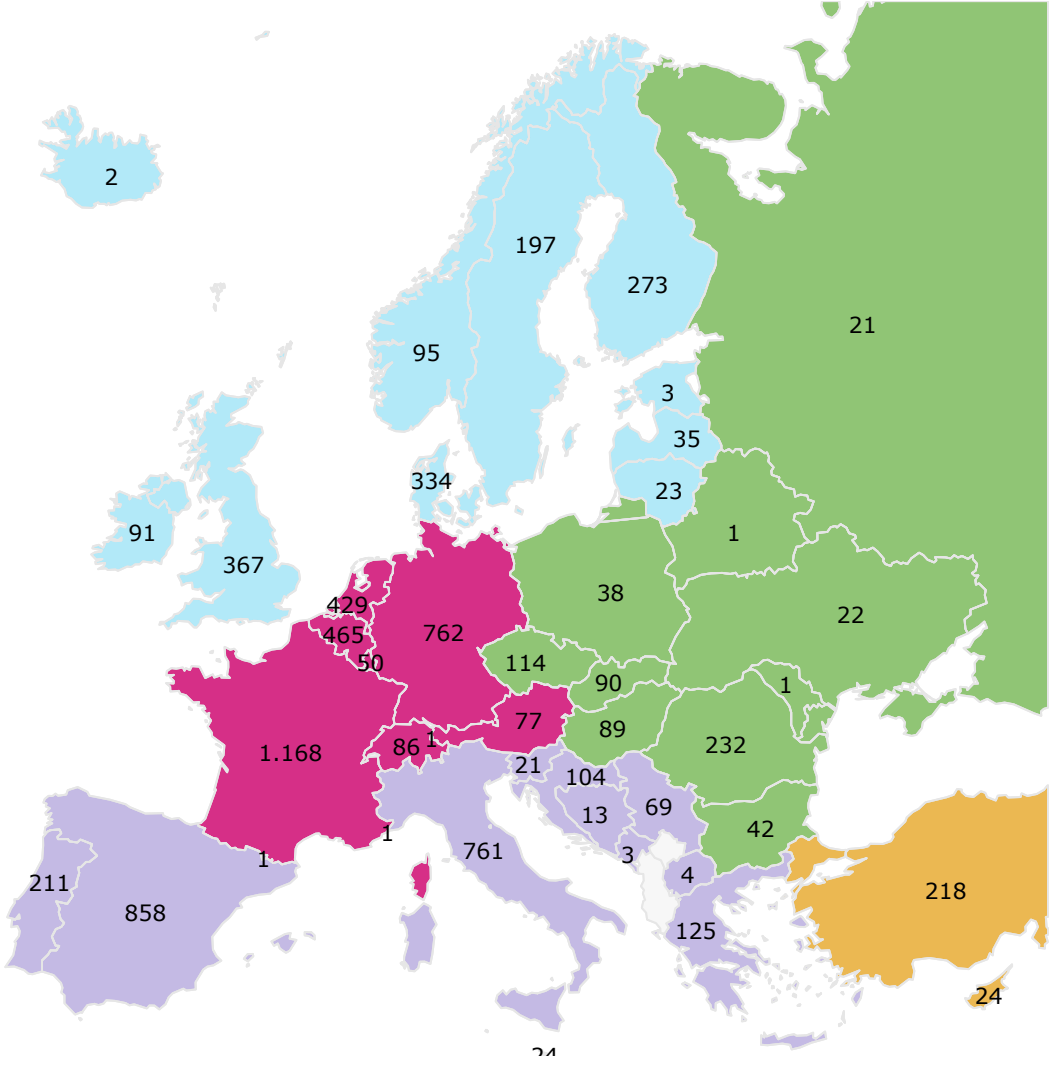
	N	%
Less than 18	1.611	21%
From 18 to 23	455	6%
From 24 to 29	431	6%
From 30 to 39	904	12%
From 40 to 49	1.277	17%
From 50 to 59	1.475	19%
60 and over	1.537	20%
TOTAL	7.690	100%

Countries with languages

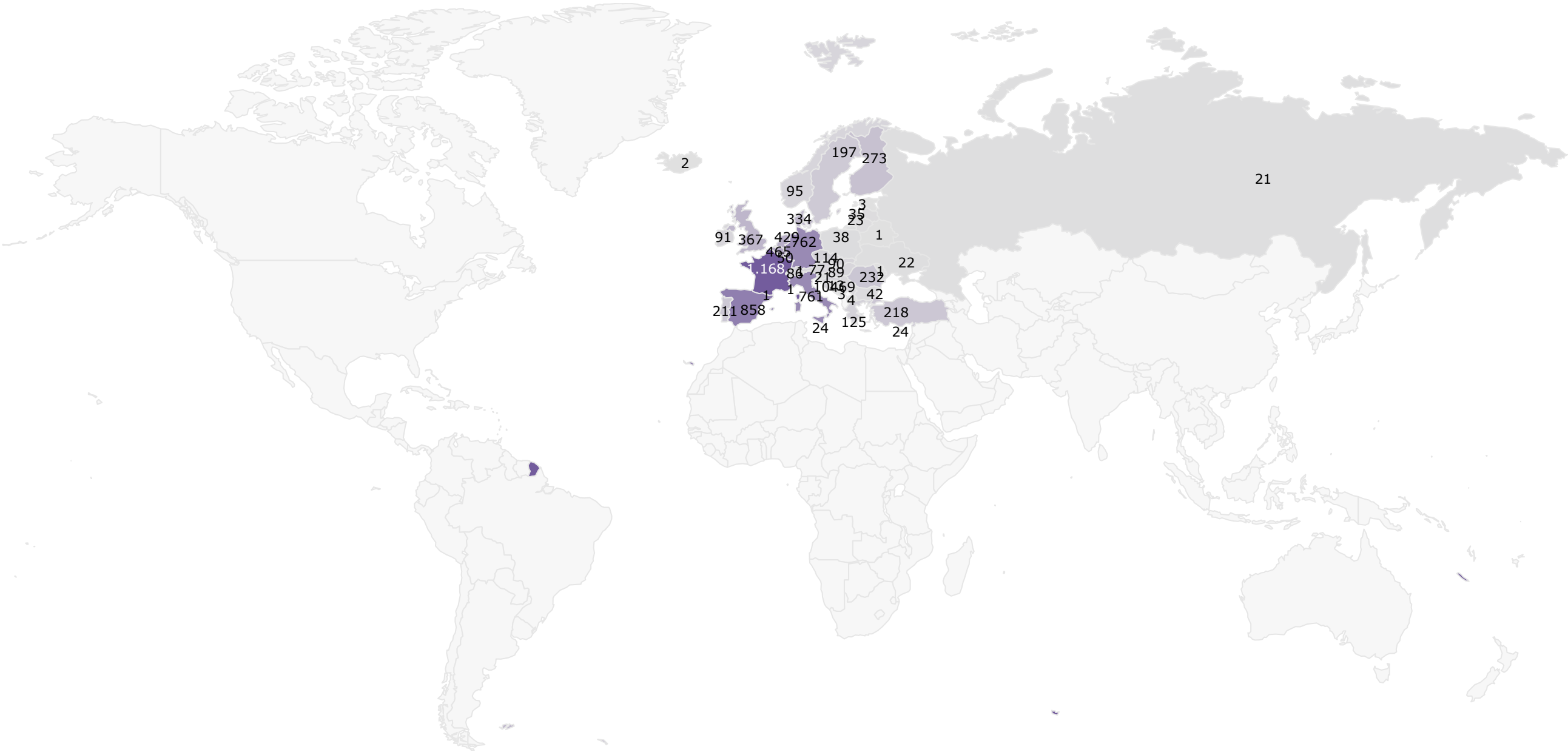
	N	%
Francuska	1.168	14%
Italija	946	12%
Španija	858	11%
Njemačka	762	9%
Belgija	465	6%
Nizozemska	429	5%
Danska	427	5%
Rumunija	368	5%
Turska	368	5%
Velika Britanija	367	5%
Finska	338	4%
Portugália	274	3%
Švedska	228	3%
Češka Republika	154	2%
Grčka	150	2%
Slovačka	127	2%
Norveška	123	2%
Mađarska	114	1%
Hrvatska	104	1%
Irska	91	1%
Švicarska	87	1%
Austrija	77	1%
Bugarska	71	1%

Countries with languages

	N	%
Srbija	69	17%
Luksemburg	50	13%
Letonija	46	12%
Lengyelország	44	11%
Ukrajina	33	8%
Litvanija	32	8%
Slovenija	27	7%
Kipar	24	6%
Malta	24	6%
Rusija	21	5%
Bosna i Hercegovina	13	3%
Makedonija	4	1%
Estonija	3	1%
Crna Gora	3	1%
Island	2	1%
Andora	1	0%
Bjelorusija	1	0%
Lihtenštajn	1	0%
Moldavija	1	0%
Monaco	1	0%

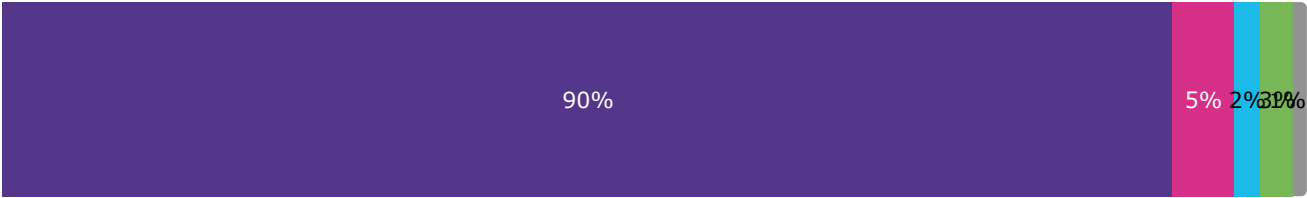


U kojoj državi živite?



Molimo odaberite rečenicu koja najbolje opisuje vašu situaciju ili situaciju osobe o kojoj se brinete:

	N
Znam NAZIV rijetke bolesti, sindroma ili deformacije, što je POTVRĐENO je odgovarajućim genetskim, kliničkim, medicinskim slikovnim, molekularnim ili biokemijskim testovima (npr. biopsija, test krvi ili urina)	8.624
Znam NAZIV rijetke bolesti, sindroma ili deformacije, što još NIJE potvrđeno odgovarajućim genetskim, kliničkim, medicinskim slikovnim, molekularnim ili biokemijskim testovima	456
Imam samo DJELOMIČNE informacije o nazivu rijetke bolesti ili s time povezanom genu ili vrsti bolesti	184
Znam da je ta bolest rijetka, no njezin naziv ili uzrok NISU PRONAĐENI	242
Ostalo, navesti	84
TOTAL	9.590



- Znam NAZIV rijetke bolesti, sindroma ili deformacije, što je POTVRĐENO je odgovarajućim genet...
- Znam NAZIV rijetke bolesti, sindroma ili deformacije, što još NIJE potvrđeno odgovarajućim gen...
- Imam samo DJELOMIČNE informacije o nazivu rijetke bolesti ili s time povezanom genu ili vrsti ...
- Znam da je ta bolest rijetka, no njezin naziv ili uzrok NISU PRONAĐENI
- Ostalo, navesti

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

This question was only asked to people with confirmed diagnosis.

Koliko se sjećate, kada ste prvi put čuli za NAZIV rijetke bolesti, sindroma ili urođenog poremećaja?

	N	
Prije manje od 6 mjeseci	43	Prije manje od 6 mjeseci 7%
Prije 6 do 23 mjeseci	76	Prije 6 do 23 mjeseci 12%
Prije 2 do 4 godine	140	Prije 2 do 4 godine 23%
Prije 5 godina ili više	362	Prije 5 godina ili više 58%
TOTAL	621	

Koliko se sjećate, kada je naziv rijetke bolesti, sindroma ili uređenog poremećaja POTVRĐEN odgovarajućim genetičkim, kliničkim, radiološkim, molekularnim ili biokemijskim pretragama (npr. biopsija, pretrage krvi ili mokraće)?

	N	
Prije manje od 6 mjeseci	739	Prije manje od 6 mjeseci 9%
Prije 6 do 23 mjeseci	1.001	Prije 6 do 23 mjeseci 12%
Prije 2 do 4 godine	1.502	Prije 2 do 4 godine 17%
Prije 5 godina ili više	5.366	Prije 5 godina ili više 62%
TOTAL	8.608	

1.643

Orphacode associated nomenclature (english)

	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

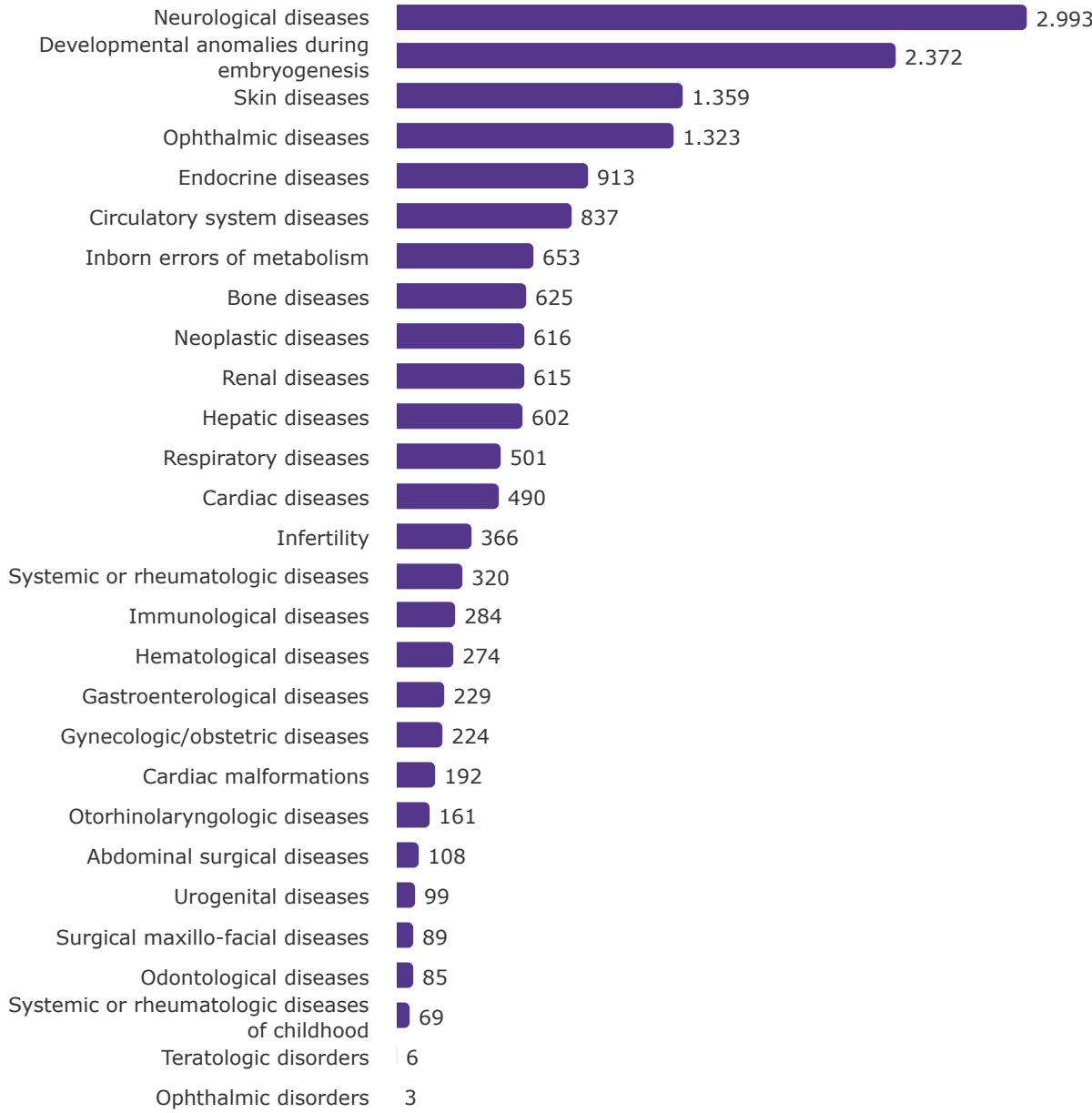
Orphacode associated nomenclature (english)

	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

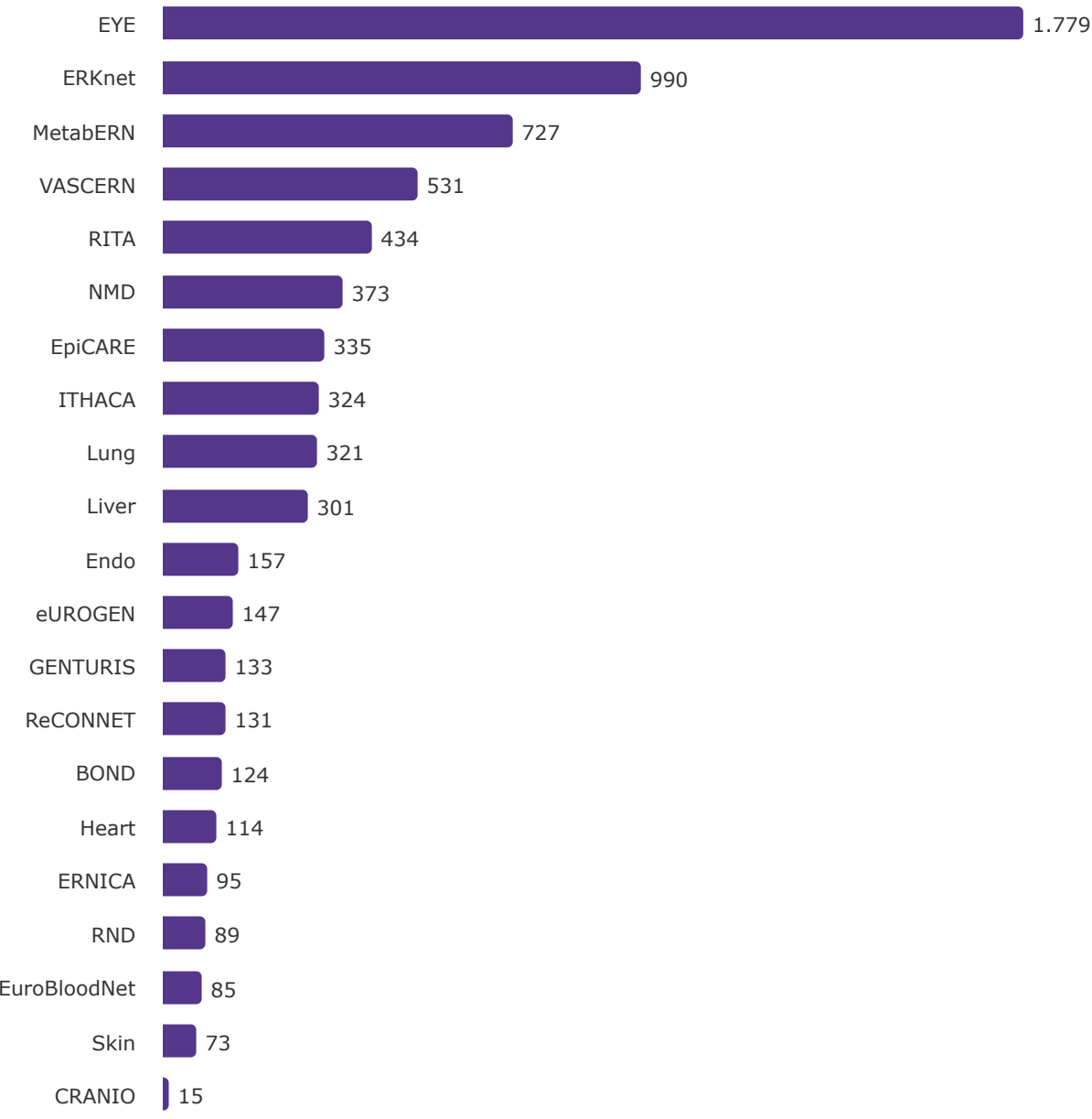
Orphacode associated nomenclature (english)

	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

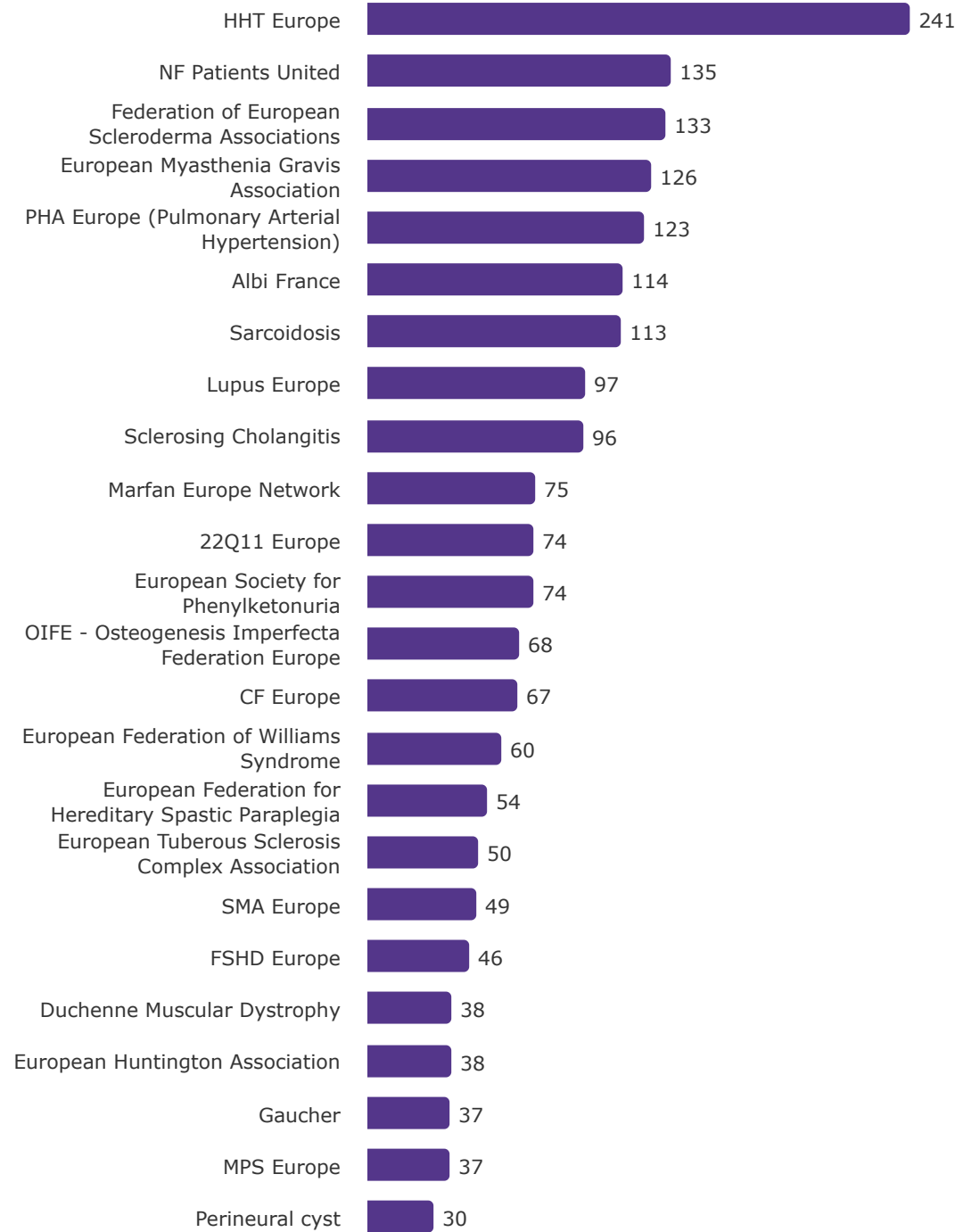
Orphanet classification of rare diseases (one disease can be classified in several categories)



tableexterne("ERNs_2024.txt",orphacode,"ePAG")



tableexterne("European Federations.txt",orphacode,"european_federation")



tableexterne("European Federations.txt",orphacode,"european_federation")

	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%

tableexterne("European Federations.txt",orphacode,"european_federation")

	N	%
European Federation of Williams Syndrome	60	14%
European Federation for Hereditary Spastic Paraplegia	54	12%
European Tuberous 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%

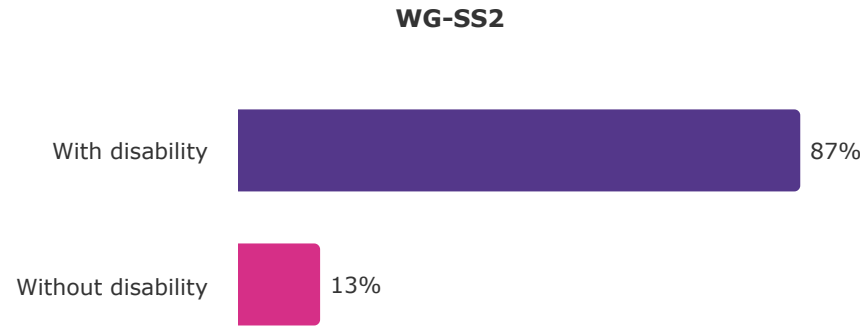


2. DISABILITIES

**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.

WG-SS2		
	N	%
With disability	8.351	87%
Without disability	1.240	13%
TOTAL	9.591	100%

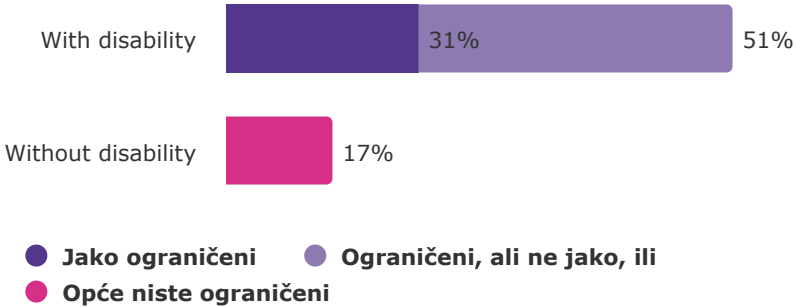


The Global Activity Limitation Index (GALI) measures disability through activity limitations that an individual experienced in the last 6 months or more due to a health problem.

Jeste li tijekom posljednjih 6 ili više mjeseci zbog zdravstvenih problema bili ograničeni u aktivnostima kojima se ljudi inače bave? Rekli biste...

	N	%
▼ With disability	7.790	83%
Jako ograničeni	2.964	31%
Ograničeni, ali ne jako, ili	4.826	51%
▼ Without disability	1.652	17%
Opće niste ograničeni	1.652	17%
TOTAL	9.442	100%

Jeste li tijekom posljednjih 6 ili više mjeseci zbog zdravstvenih problema bili ograničeni u aktivnostima kojima se ljudi inače bave? Rekli biste...

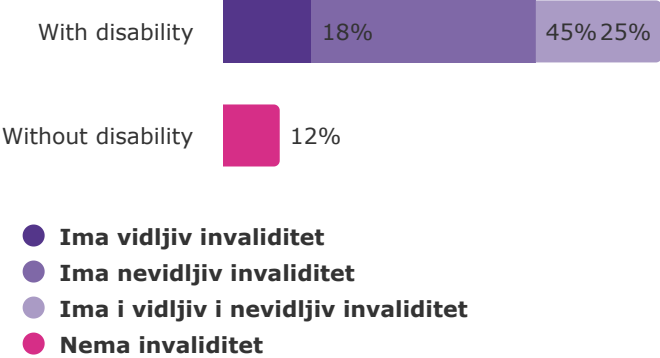


People living with rare diseases were asked if they perceive themselves as living with a disability, be it invisible, visible or both.

Smatrate li sebe osobom koja...?

	N	%
▼ With disability	8.030	88%
Ima vidljiv invaliditet	1.626	18%
Ima nevidljiv invaliditet	4.107	45%
Ima i vidljiv i nevidljiv inva...	2.297	25%
▼ Without disability	1.068	12%
Nema invaliditet	1.068	12%
TOTAL	9.098	100%

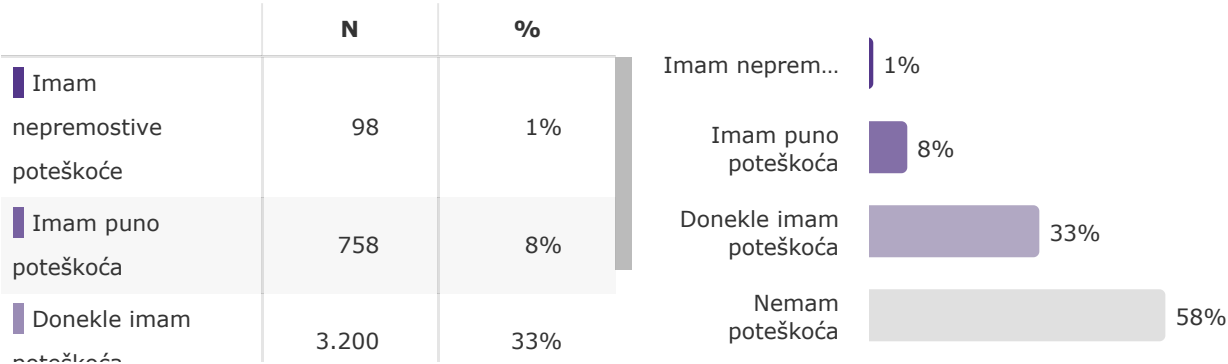
Smatrate li sebe osobom koja...?



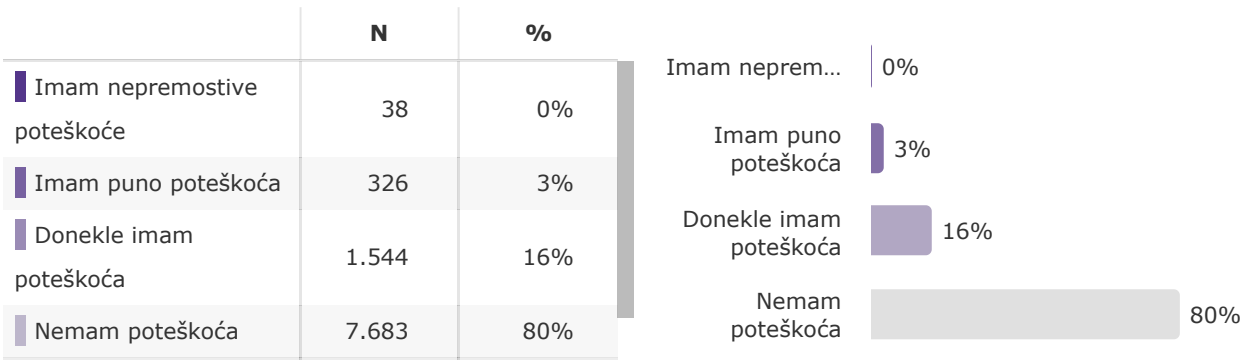
Washington Group Short Set (WG-SS)

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

Imate li poteškoća s VIDOM, čak i ako nosite naočale? Rekli biste...

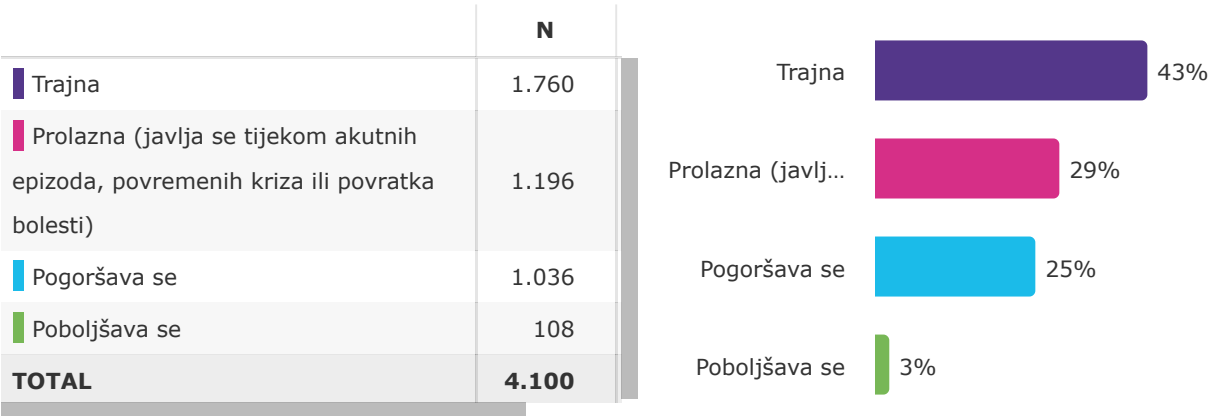


Imate li poteškoća sa SLUHOM, čak i ako nosite slušno pomagalo? Rekli biste...

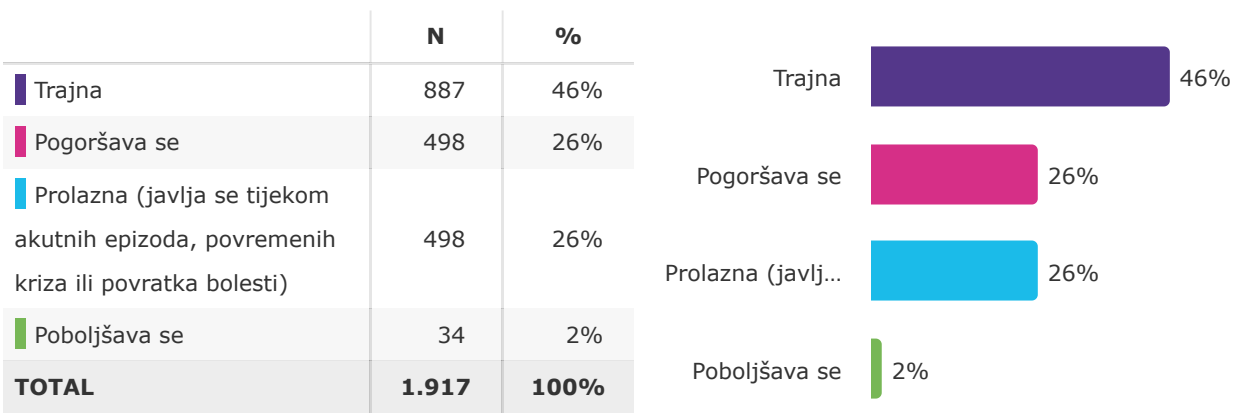


These questions were only asked to people with difficulty.

Kakva je poteškoća?



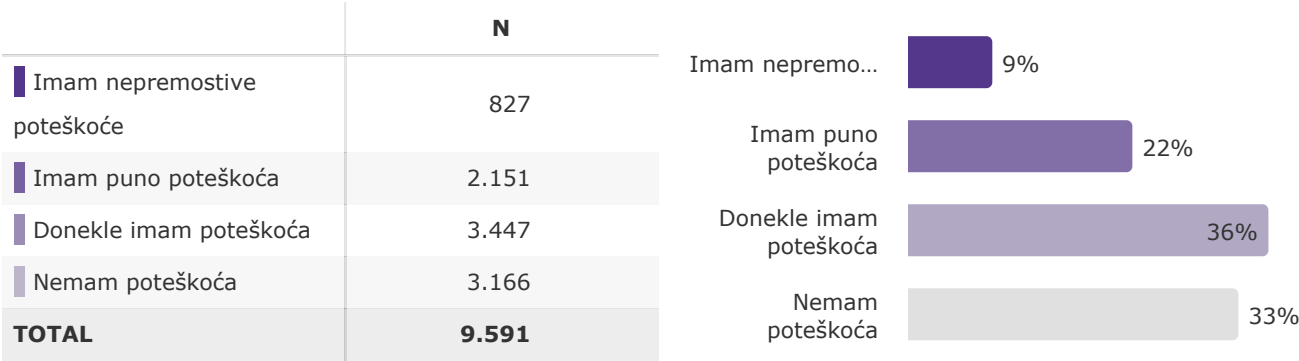
Kakva je poteškoća?



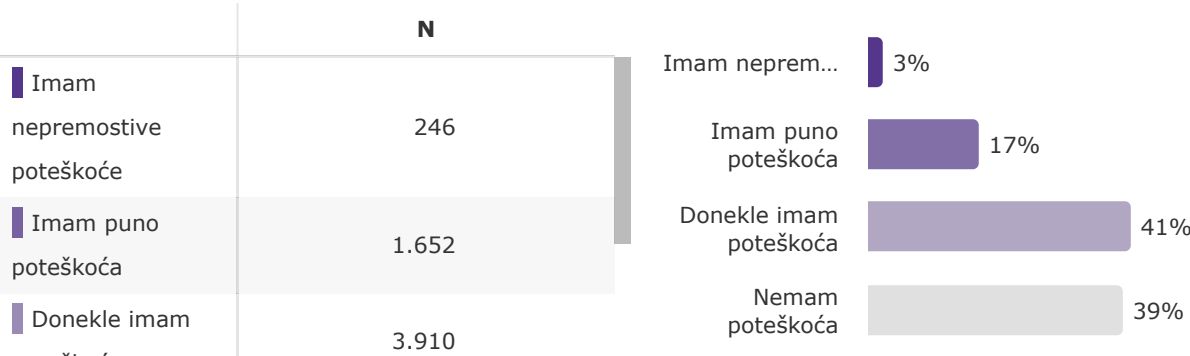
Washington Group Short Set (WG-SS)

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

Imate li poteškoća s HODANJEM ili PENJANJEM UZA STUBE? Rekli biste...

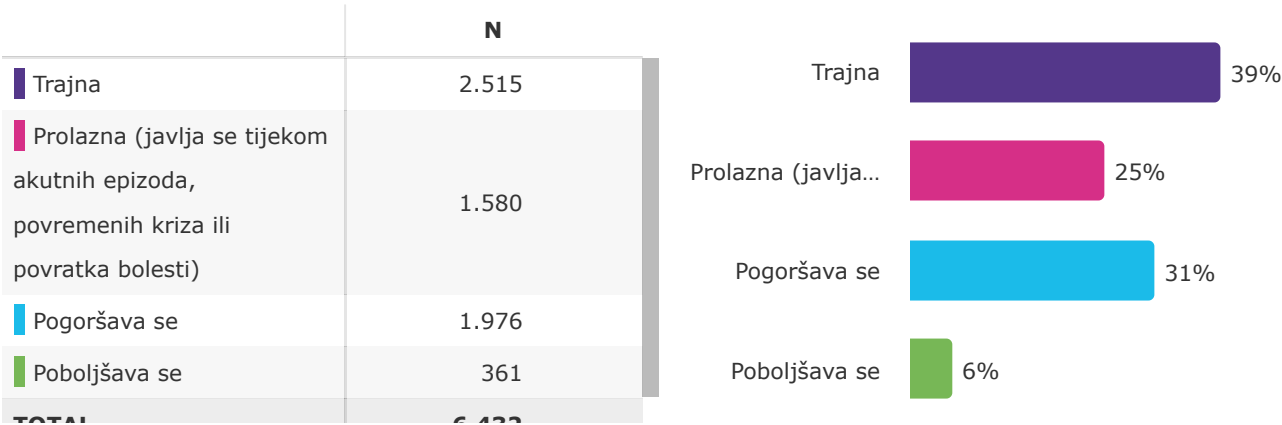


Imate li poteškoća s PAMĆENJEM ili KONCENTRACIJOM? Rekli biste...

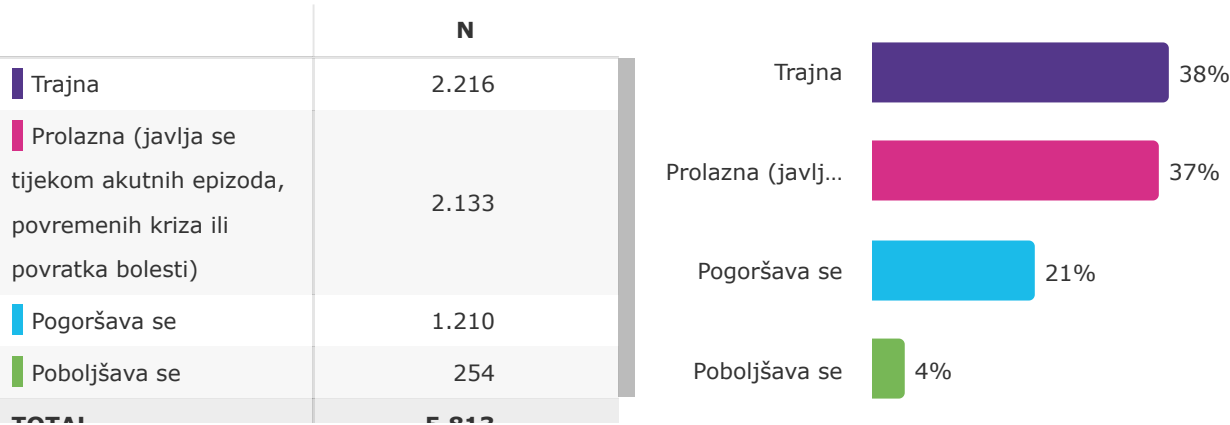


These questions were only asked to people with difficulty.

Kakva je poteškoća?



Kakva je poteškoća?

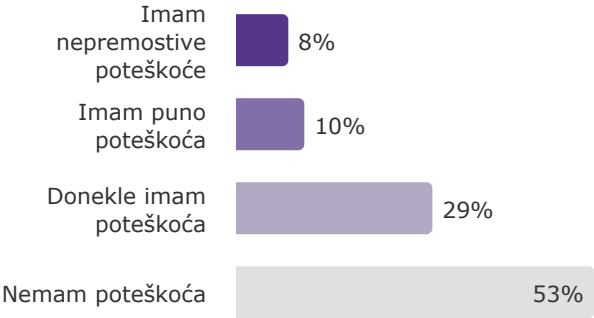


Washington Group Short Set (WG-SS)

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

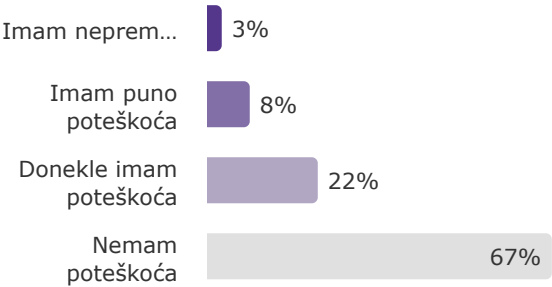
Imate li poteškoća s BRIGOM O SEBI, kao što je pranje cijelog tijela ili presvlačenje? Rekli biste...

	N
Imam nepremostive poteškoće	766
Imam puno poteškoća	989
Donekle imam poteškoća	2.783
Nemam poteškoća	5.053
TOTAL	9.591



Ako se koristite uobičajenim jezikom, imate li poteškoća u KOMUNICIRANJU, odnosno razumijete li druge i razumiju li oni Vas? Rekli biste...

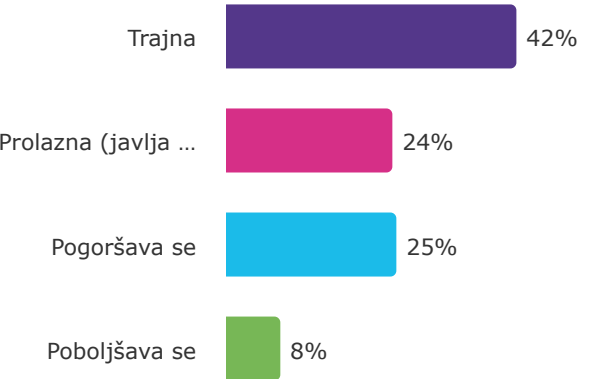
	N
Imam nepremostive poteškoće	287
Imam puno poteškoća	814
Donekle imam poteškoća	2.093
Nemam poteškoća	6.397
TOTAL	9.591



These questions were only asked to people with difficulty.

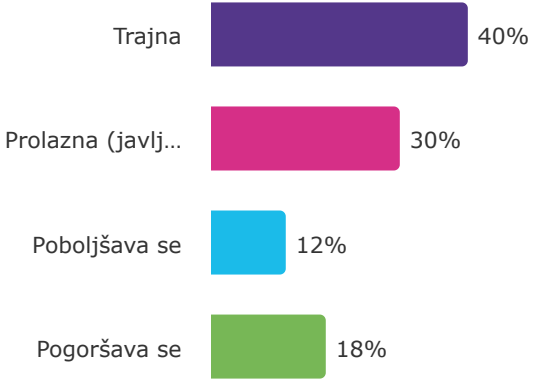
Kakva je poteškoća?

	N
Trajna	1.926
Prolazna (javlja se tijekom akutnih epizoda, povremenih kriza ili povratka bolesti)	1.108
Pogoršava se	1.142
Poboljšava se	366
TOTAL	4.542



Kakva je poteškoća?

	N
Trajna	1.294
Prolazna (javlja se tijekom akutnih epizoda, povremenih kriza ili povratka bolesti)	945
Poboljšava se	380
Pogoršava se	580
TOTAL	3.199



Washington Group Short Set (WG-SS)

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

v="WGSS2_0_1"+"Hearing_1_0"+"Walking_1_0"+"Cognition_1_0"

6.918

▼ Sample information : Number_difficulties_WGSS >= 2

Percentage of respondents who have difficulty in at least 2 activities

72%

v="WGSS2_0_1"+"Hearing_1_0"+"Walking_1_0"+"Cognition_1_0"

5.086

▼ Sample information : Number_difficulties_WGSS >= 3

Percentage of respondents who have difficulty in at least 3 activities

53%

v="WGSS2_0_1"+"Hearing_1_0"+"Walking_1_0"+"Cognition_1_0"

3.367

▼ Sample information : Number_difficulties_WGSS >= 4

Percentage of respondents who have difficulties in at least 4 activities

35%

com_prog

6.134

▼ Sample information : Index_prog >= 1

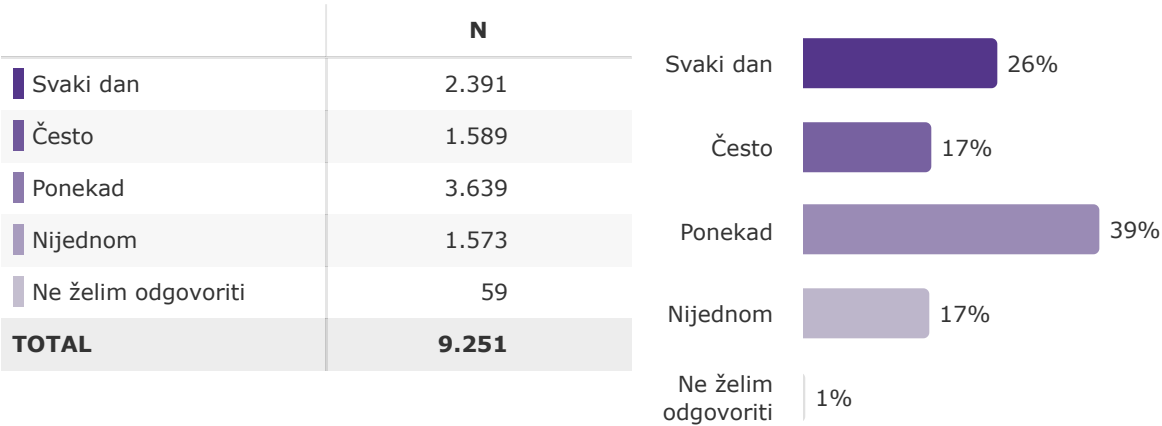
progressive_dynamic

64%

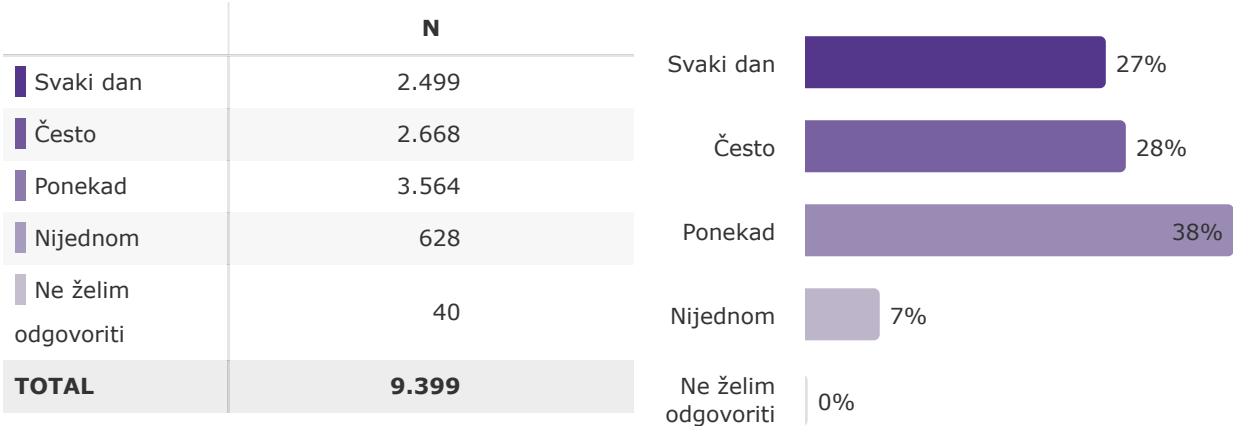
Washington Group Extended Set (WG-ES)

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

U posljednja 3 mjeseca, koliko ste često osjetili BOL? Rekli biste...

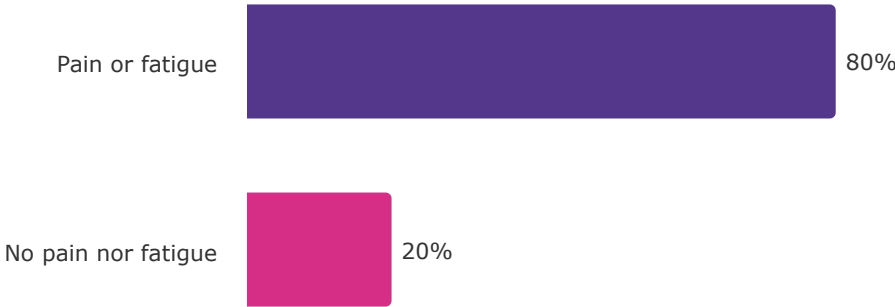


Τους τελευταίους τρεις μήνες, koliko ste često osjetili UMOR ili ISCRPLJENOST? Rekli biste...



Τους τελευταίους τρεις μήνες, koliko ste često osjetili UMOR ili ISCRPLJENOST? Rekli biste...

	N
Pain or fatigue	7.693
No pain nor fatigue	1.898
TOTAL	9.591



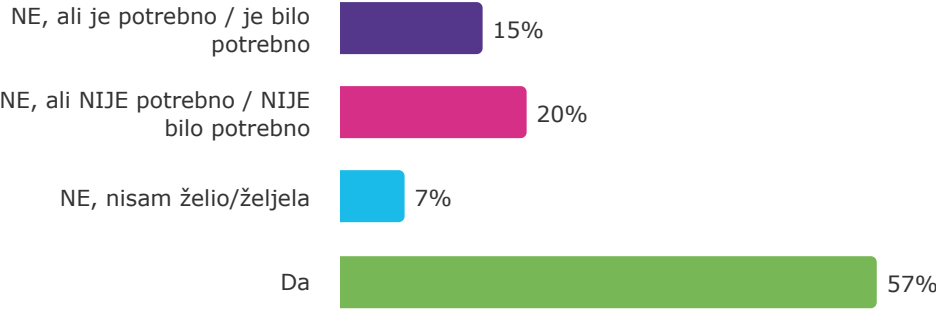


3. DISABILITY RECOGNITION

Disability assessment and barriers

Jeste li ikada bili na procjeni invaliditeta, čija je svrha procijeniti i prepoznati invaliditet?

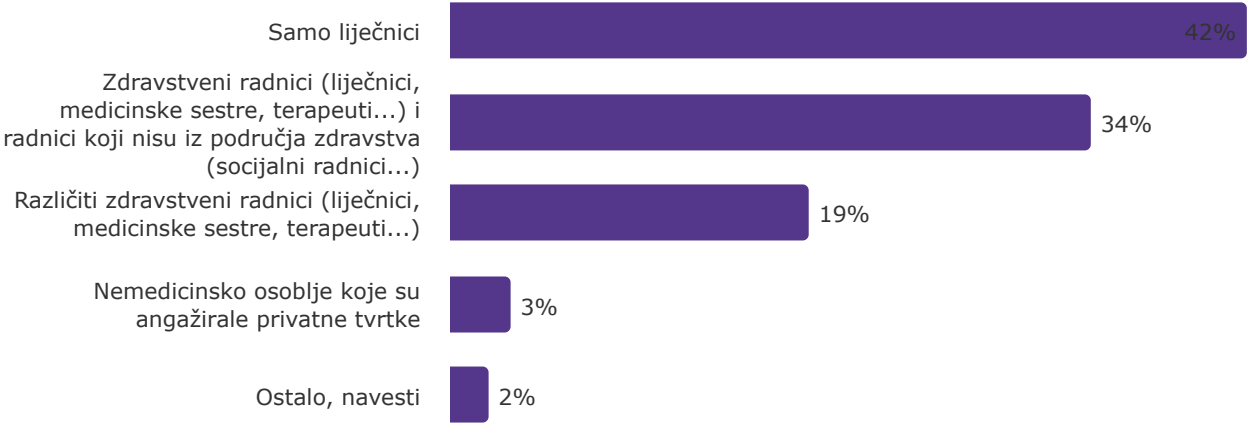
	N	%
NE, ali je potrebno / je bilo potrebno	1.435	15%
NE, ali NIJE potrebno / NIJE bilo potrebno	1.878	20%
NE, nisam želio/željela	655	7%
Da	5.364	57%



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

Koji su stručnjaci bili uključeni u procjenu?

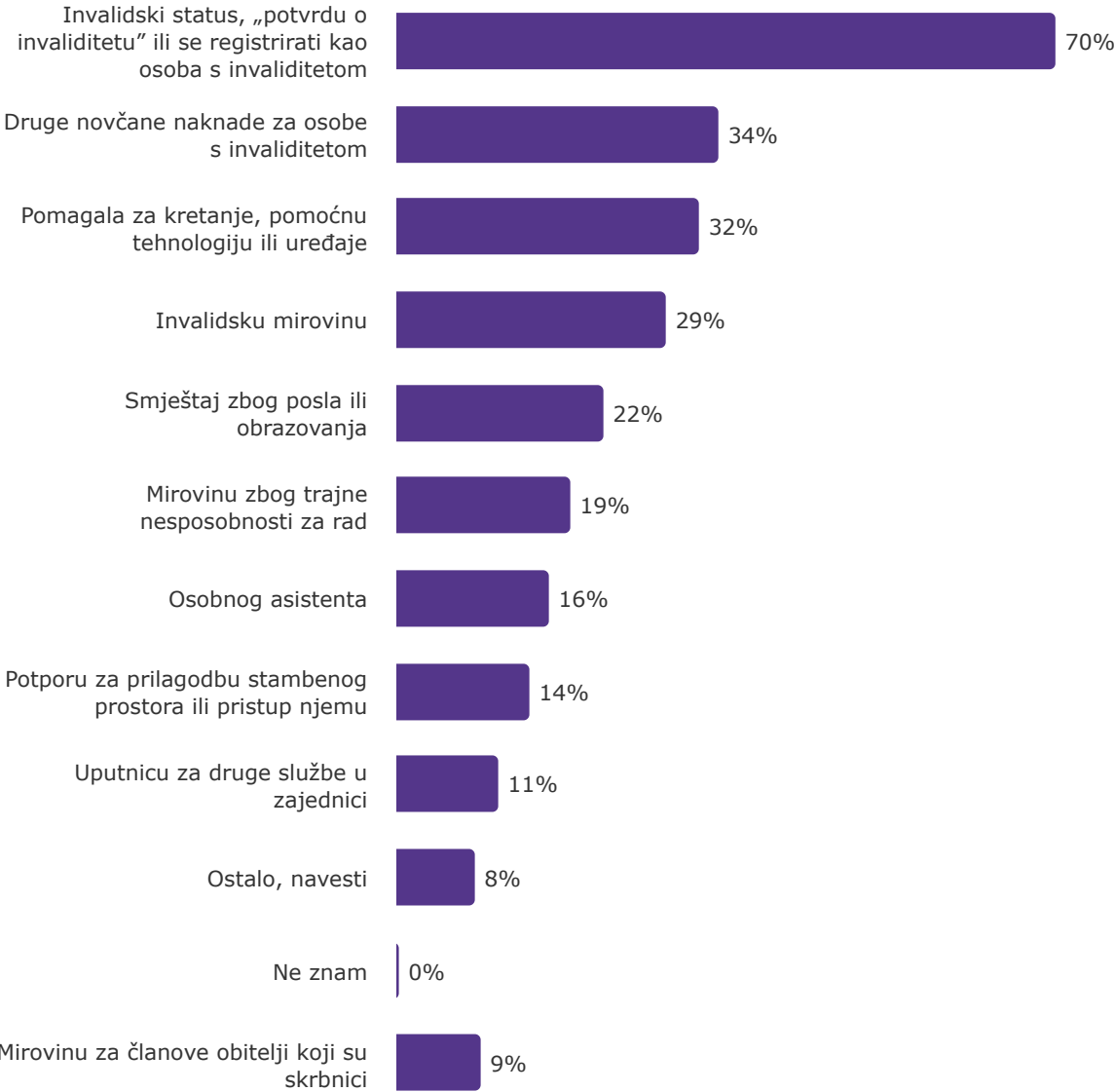
	N	%
Samo liječnici	2.164	42%
Zdravstveni radnici (liječnici, medicinske sestre, terapeuti...) i radnici koji nisu iz područja zdravstva (socijalni radnici...)	1.742	34%
Različiti zdravstveni radnici (liječnici, medicinske sestre, terapeuti...)	979	19%
Nemedicinsko osoblje koje su angažirale privatne tvrtke	168	3%
Ostalo, navesti	106	2%
TOTAL	5.159	100%



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

Što ste željeli dobiti procjenom invaliditeta?

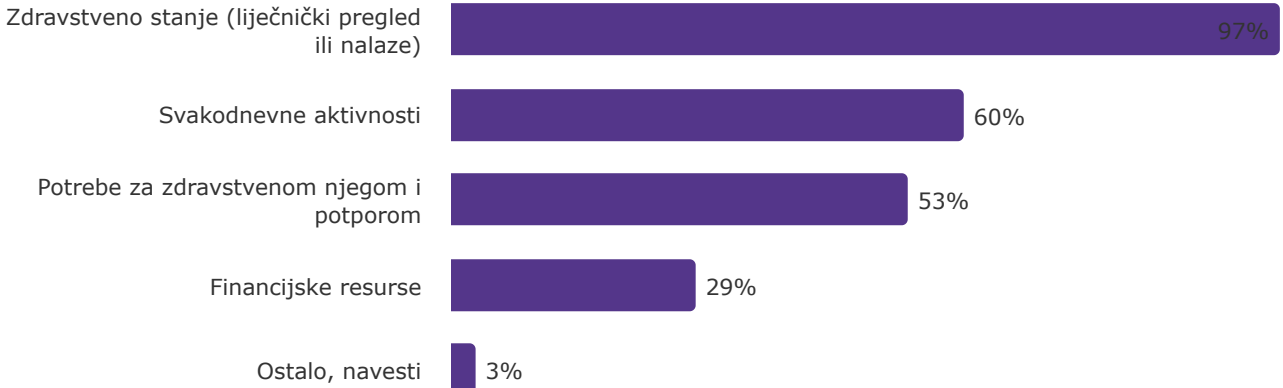
	N	%
Invalidski status, „potvrdu o invaliditetu” ili se registrirati kao osoba s invaliditetom	1.157	70%
Druge novčane naknade za osobe s invaliditetom	565	34%
Pomagala za kretanje, pomoćnu tehnologiju ili uređaje	533	32%
Invalidsku mirovinu	476	29%
Smještaj zbog posla ili obrazovanja	364	22%
Mirovinu zbog trajne nesposobnosti za rad	307	19%
Osobnog asistenta	271	16%
Potporu za prilagodbu stambenog prostora ili pristup njemu	234	14%
Uputnicu za druge službe u zajednici	180	11%
Ostalo, navesti	140	8%
Ne znam	6	0%
Mirovinu za članove obitelji koji su skrbnici	149	9%
TOTAL	1.651	



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

Jeste li tijekom procjene trebali navesti sljedeće podatke?

	N	%
Zdravstveno stanje (liječnički pregled ili nalaze)	5.128	97%
Svakodnevne aktivnosti	3.176	60%
Potrebe za zdravstvenom njegom i potporom	2.834	53%
Financijske resurse	1.524	29%
Ostalo, navesti	155	3%
TOTAL	5.306	



Koliko ste procjena invaliditeta prošli?

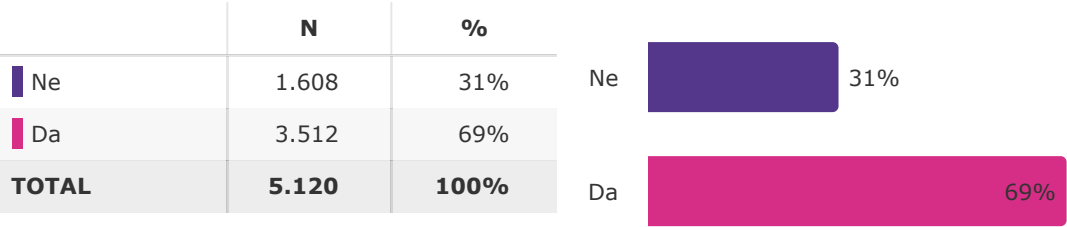
	N	
Više od jedne procjene	3.268	61%
Jednu procjenu	2.089	39%
TOTAL	5.357	

Jeste li na kraju procjene invaliditeta imali pristup očekivanim pravima i potpori?

	N	
Ne	872	16%
Djelomično	2.553	47%
Potpuno	1.955	36%
TOTAL	5.380	

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

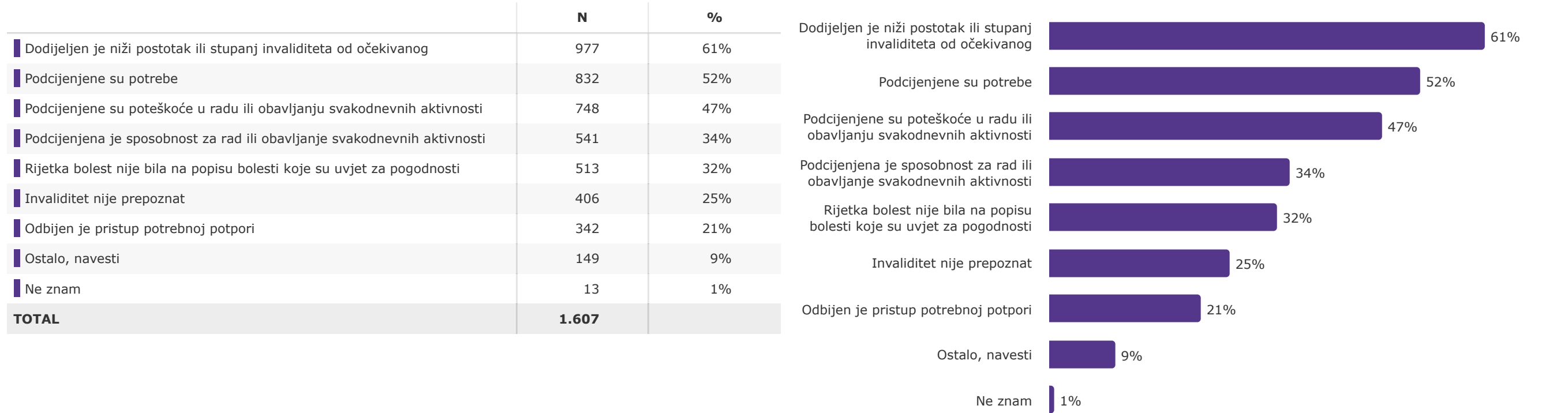
Je li rezultat procjene bio u skladu s Vašim očekivanjem?



This question was only asked to people who answer NO.

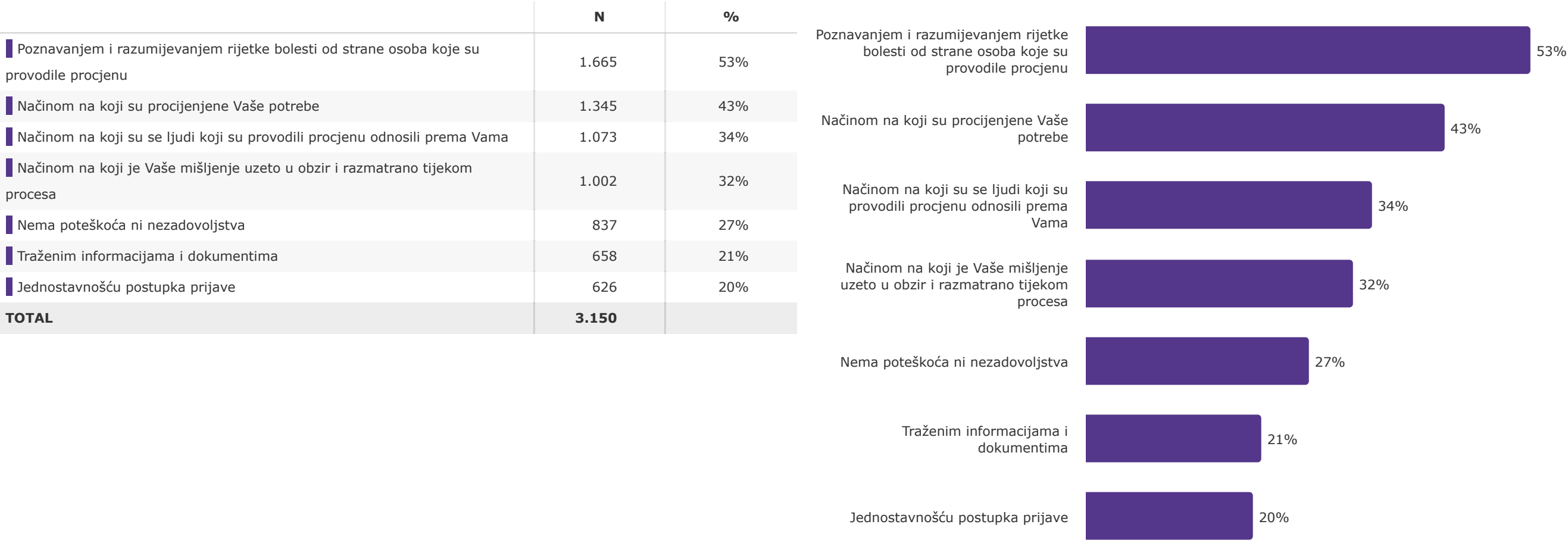


Što mislite zašto?



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

Satisfaction with Disability Assessment Process



Sample information : PATIENTvsCARER among "Osoba koja živi s rijetkom bolešću"

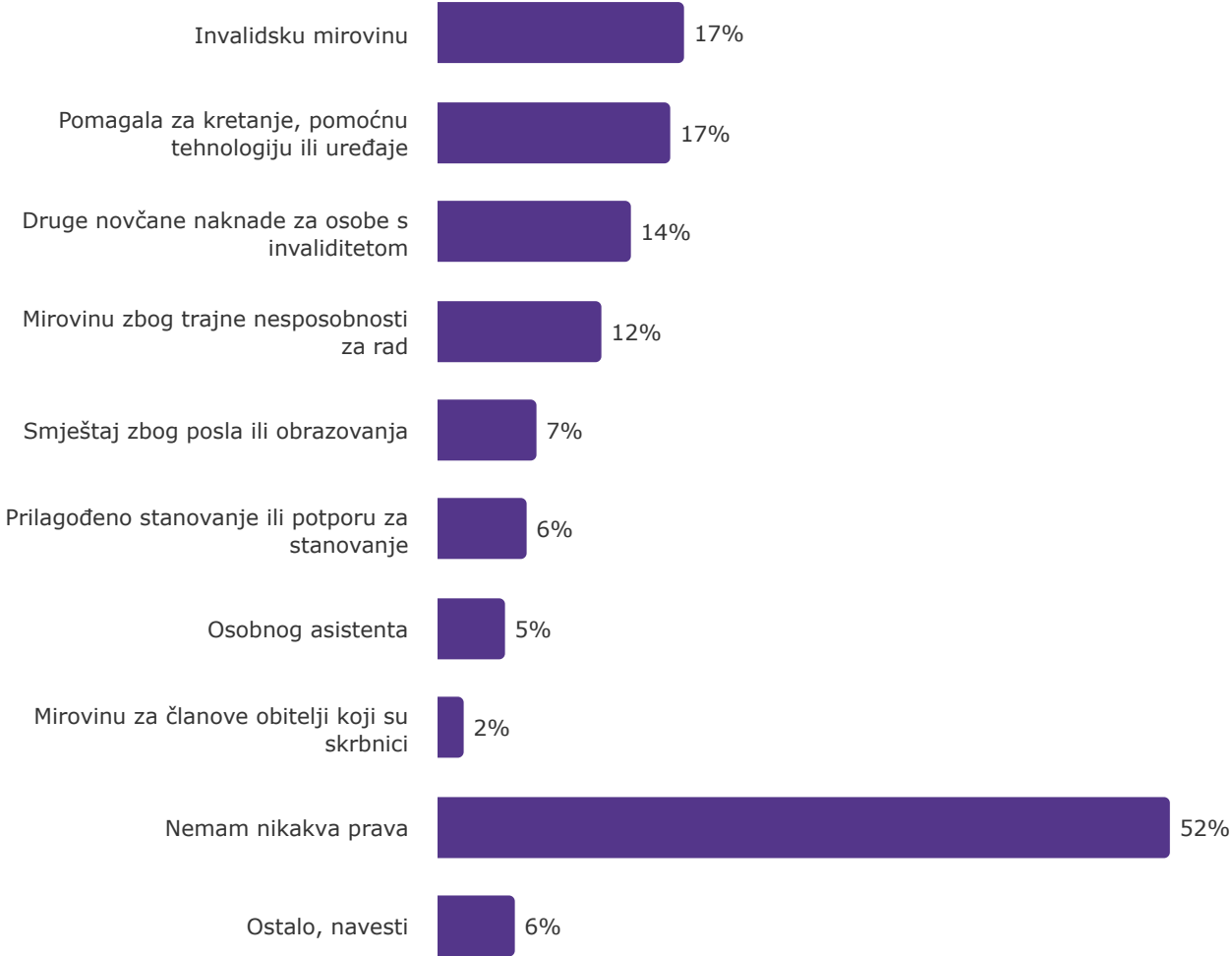


4. INDEPENDENT LIVING

Public support, personal assistant,
living arrangements

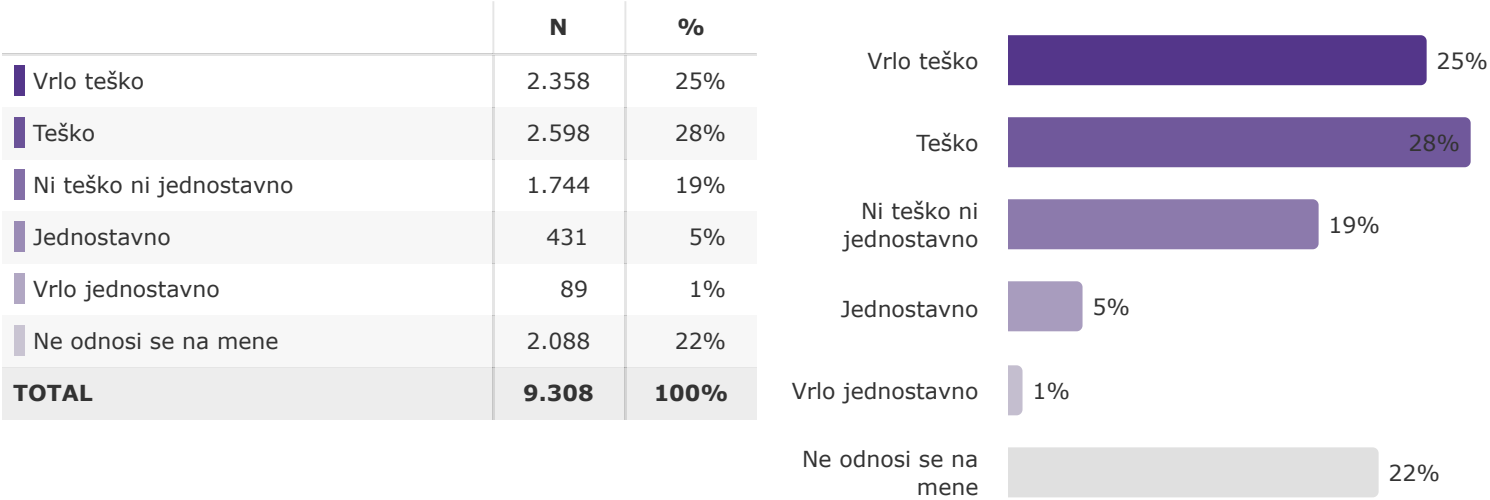
Imate li trenutno pravo na...?

	N	%
Invalidsku mirovinu	1.082	17%
Pomagala za kretanje, pomoćnu tehnologiju ili uređaje	1.024	17%
Druge novčane naknade za osobe s invaliditetom	855	14%
Mirovinu zbog trajne nesposobnosti za rad	719	12%
Smještaj zbog posla ili obrazovanja	443	7%
Prilagođeno stanovanje ili potporu za stanovanje	395	6%
Osobnog asistenta	303	5%
Mirovinu za članove obitelji koji su skrbnici	120	2%
Nemam nikakva prava	3.205	52%
Ostalo, navesti	347	6%
TOTAL	6.194	



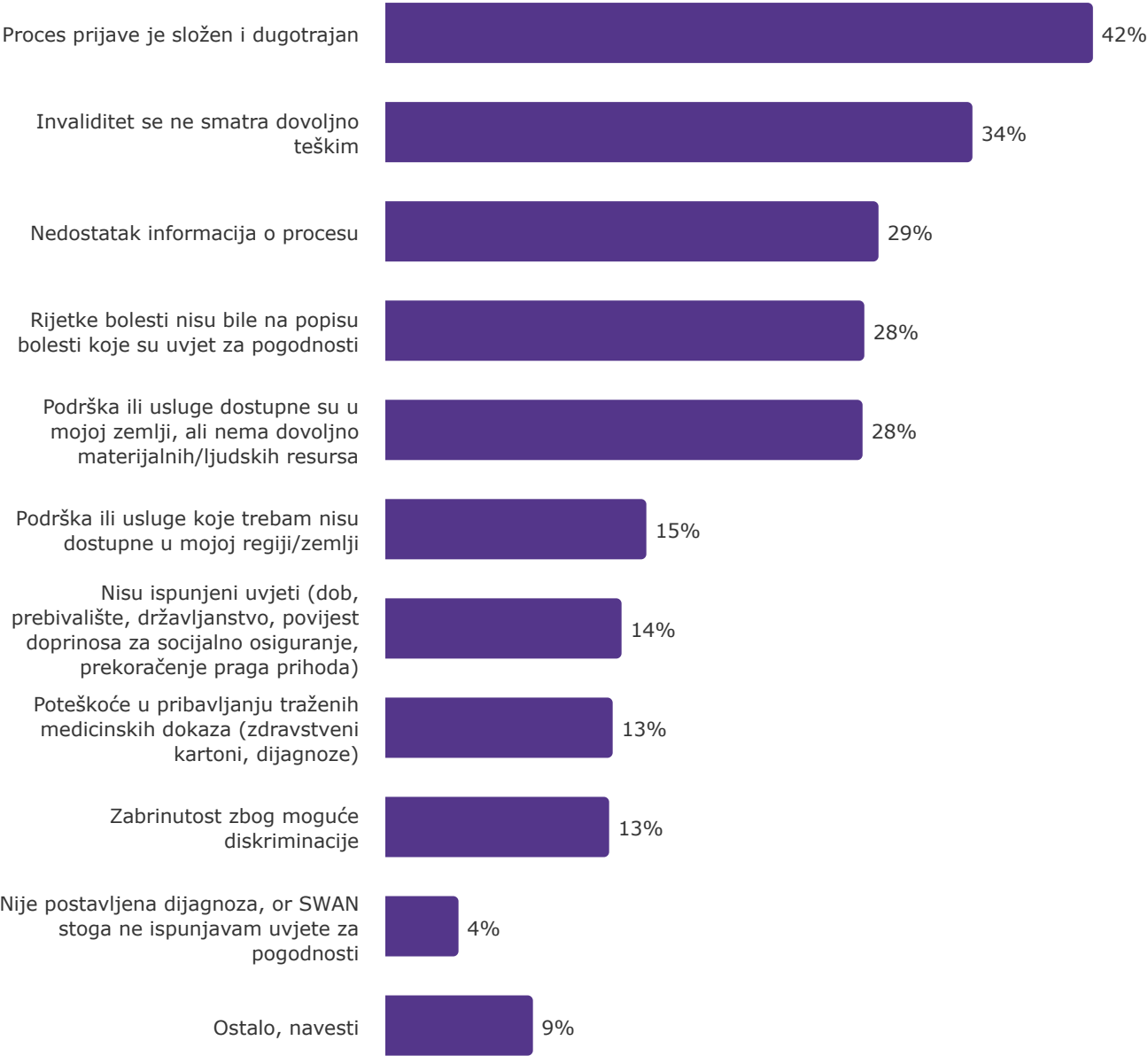
▼ Sample information : PATIENTvsCARER among "Osoba koja živi s rijetkom bolešću"

Koliko Vam je teško dobiti državnu potporu kao što je zdravstvena njega, pomoć kod kuće, financijska potpora, pomoćna tehnologija, pomagala za kretanje itd.?



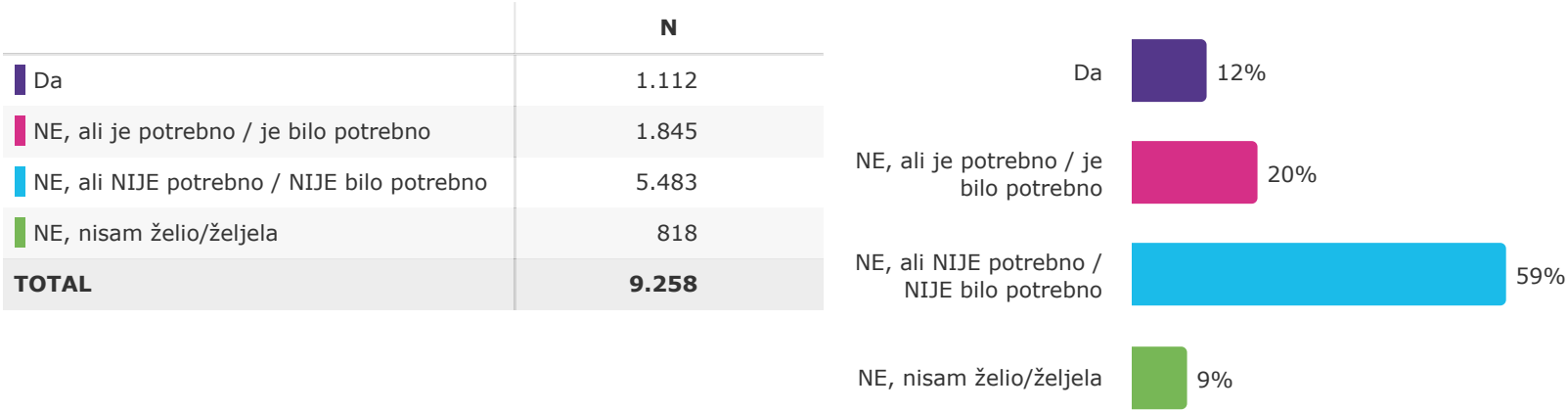
S kojim se problemima suočavate pri traženju potpore kao što je zdravstvena njega, pomoć kod kuće, financijska potpora, pomoćna tehnologija, pomagala za kretanje itd.?

	N
Proces prijave je složen i dugotrajan	2.923
Invaliditet se ne smatra dovoljno teškim	2.421
Nedostatak informacija o procesu	2.038
Rijetke bolesti nisu bile na popisu bolesti koje su uvjet za pogodnosti	1.977
Podrška ili usluge dostupne su u mojoj zemlji, ali nema dovoljno materijalnih/ljudskih resursa	1.970
Podrška ili usluge koje trebam nisu dostupne u mojoj regiji/zemlji	1.079
Nisu ispunjeni uvjeti (dob, prebivalište, državljanstvo, povijest doprinosa za socijalno osiguranje, prekoračenje praga prihoda)	982
Poteškoće u pribavljanju traženih medicinskih dokaza (zdravstveni kartoni, dijagnoze)	945
Zabrinutost zbog moguće diskriminacije	930
Nije postavljena dijagnoza, or SWAN stoga ne ispunjavam uvjete za pogodnosti	305
Ostalo, navesti	613
TOTAL	7.042



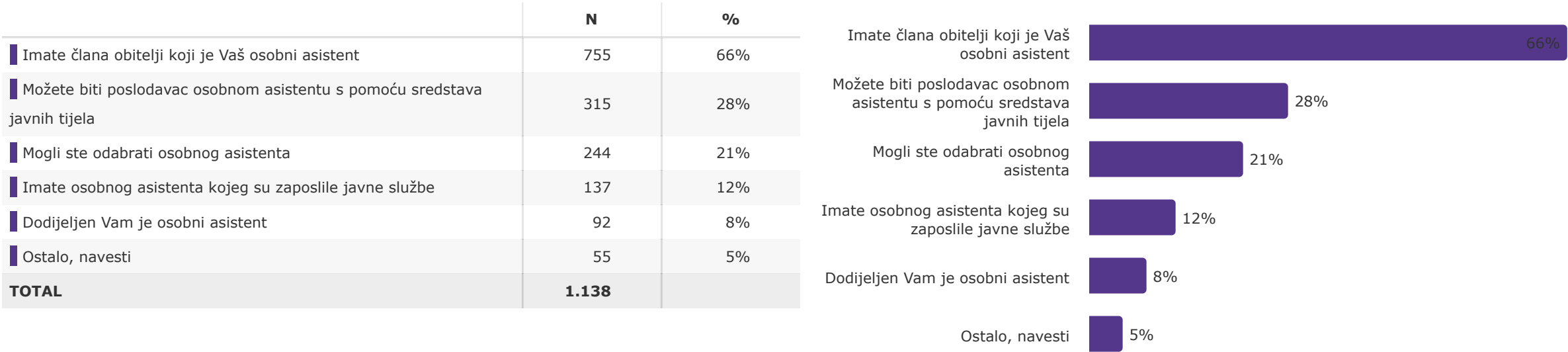
This question was only asked to people who didn't find it very easy to obtain state support.

Imate li osobnog asistenta koji Vam pomaže samostalno živjeti?



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

Koja se situacija odnosi na Vas?



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

Koliko sati osobne asistencije dobiva trenutačno u jednom danu?

10,9

Mean

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

5,4

Mean

Koliko sati osobne asistencije dobiva trenutačno u jednom danu?

7,0

Median

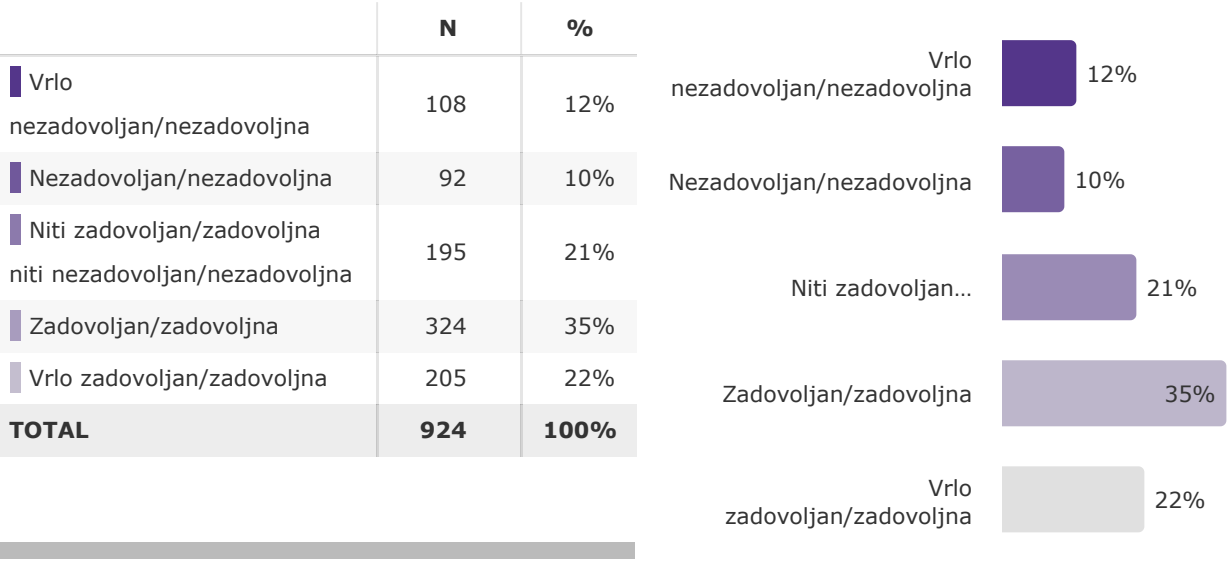
How many days of personal assistance do they currently have per week?

7,0

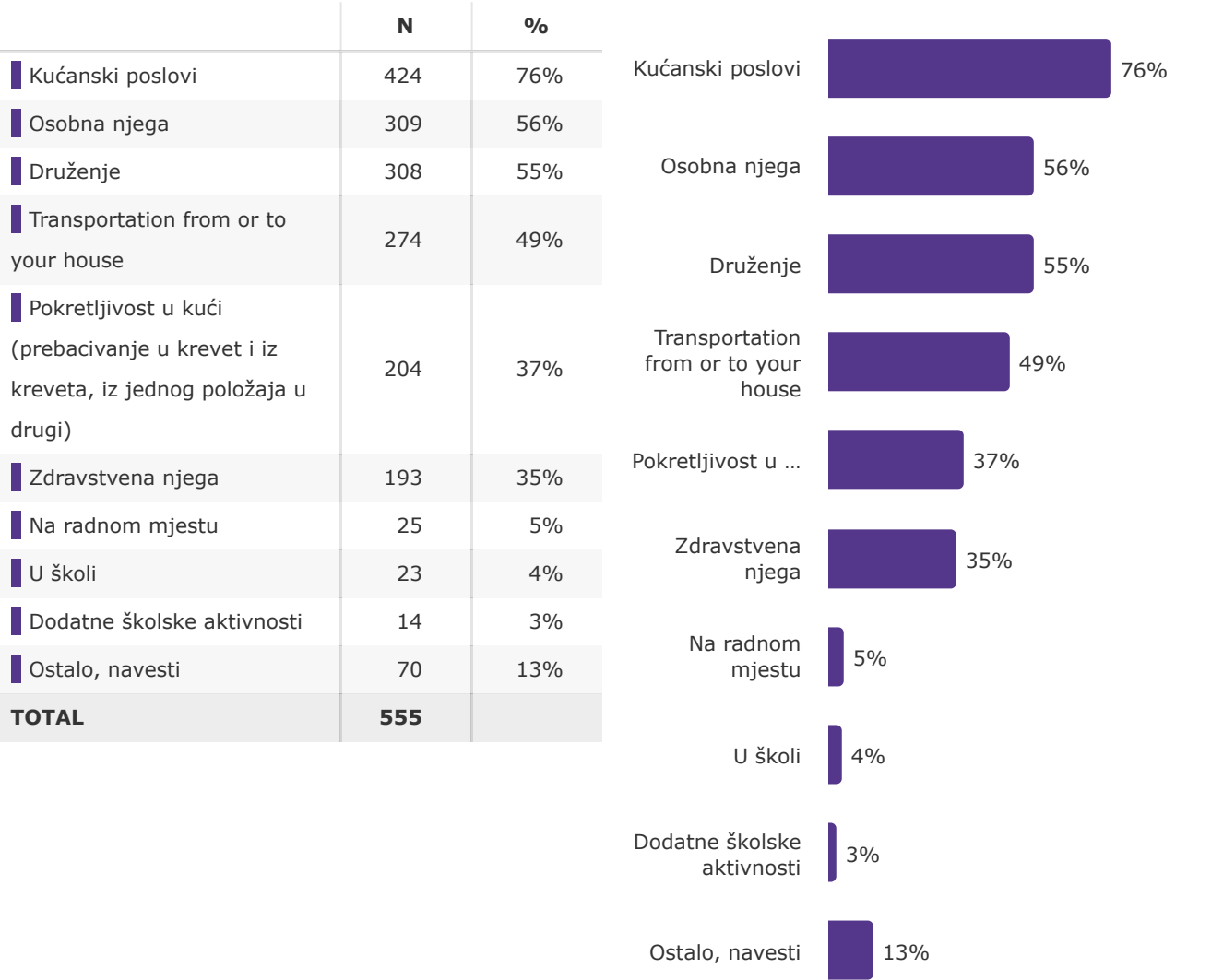
Median

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

Jeste li zadovoljni brojem sati osobne asistencije?



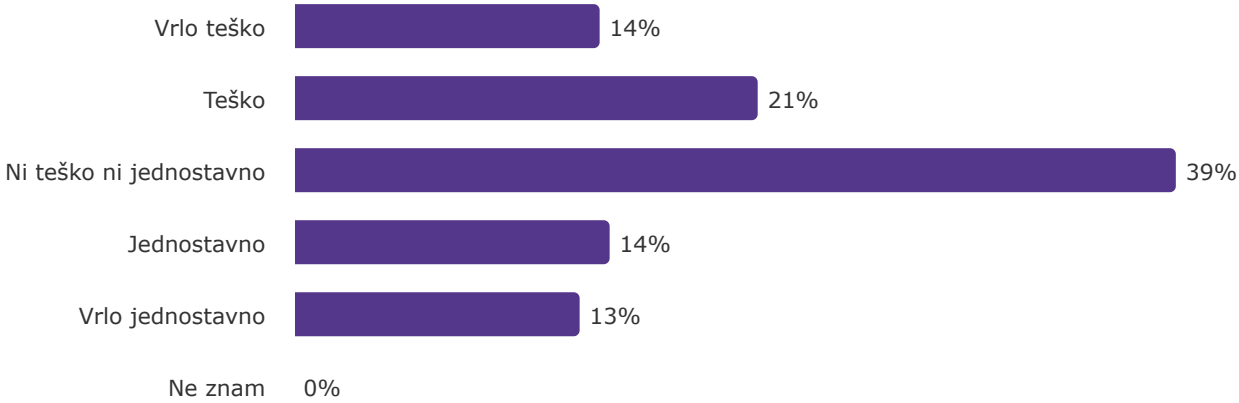
S kojim zadacima trenutno pomaže osobni asistent?



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

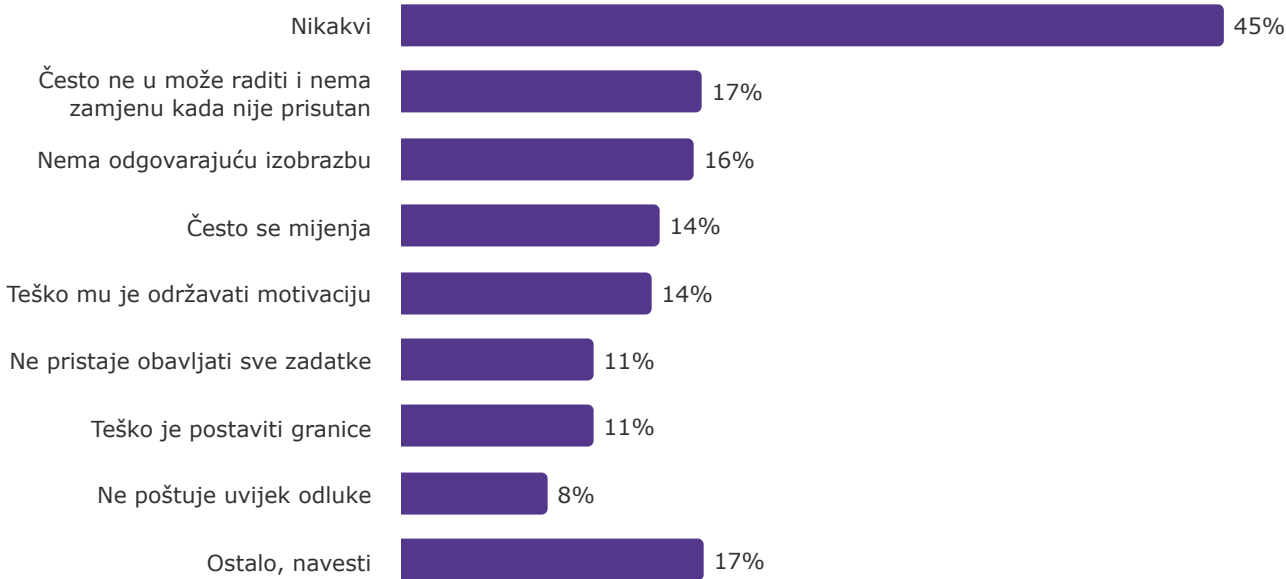
Koliko Vam je teško rukovoditi osobnim asistentom (zapošljavanje, rad, plaćanje)?

	N	%
Vrlo teško	62	14%
Teško	94	21%
Ni teško ni jednostavno	179	39%
Jednostavno	64	14%
Vrlo jednostavno	58	13%
Ne znam	0	0%
TOTAL	457	100%



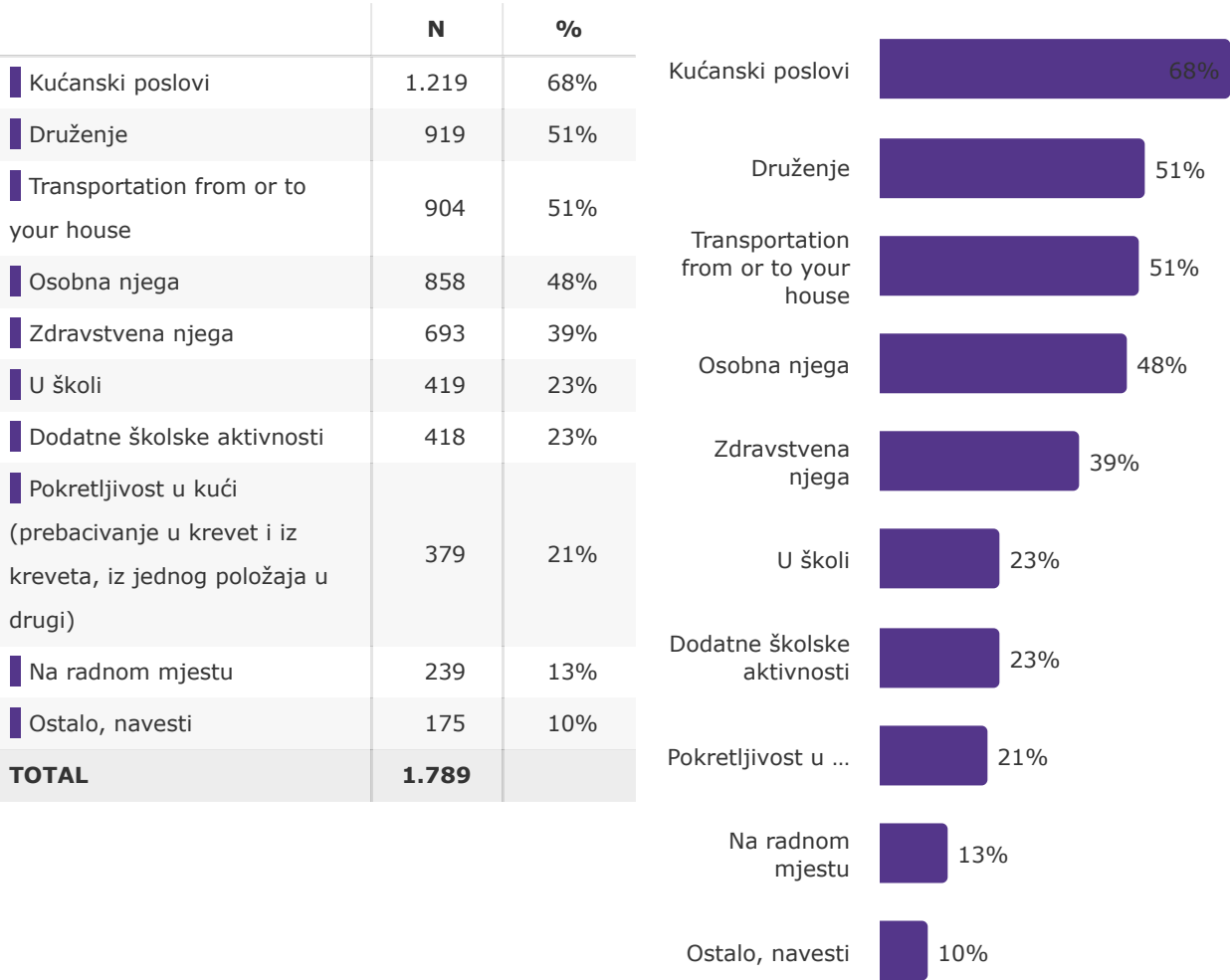
Kakvi su sve izazovi povezani s osobnim asistentom?

	N	%
Nikakvi	456	45%
Često ne u može raditi i nema zamjenu kada nije prisutan	167	17%
Nema odgovarajuću izobrazbu	163	16%
Često se mijenja	144	14%
Teško mu je održavati motivaciju	140	14%
Ne pristaje obavljati sve zadatke	107	11%
Teško je postaviti granice	107	11%
Ne poštuje uvijek odluke	82	8%
Ostalo, navesti	168	17%
TOTAL	1.006	

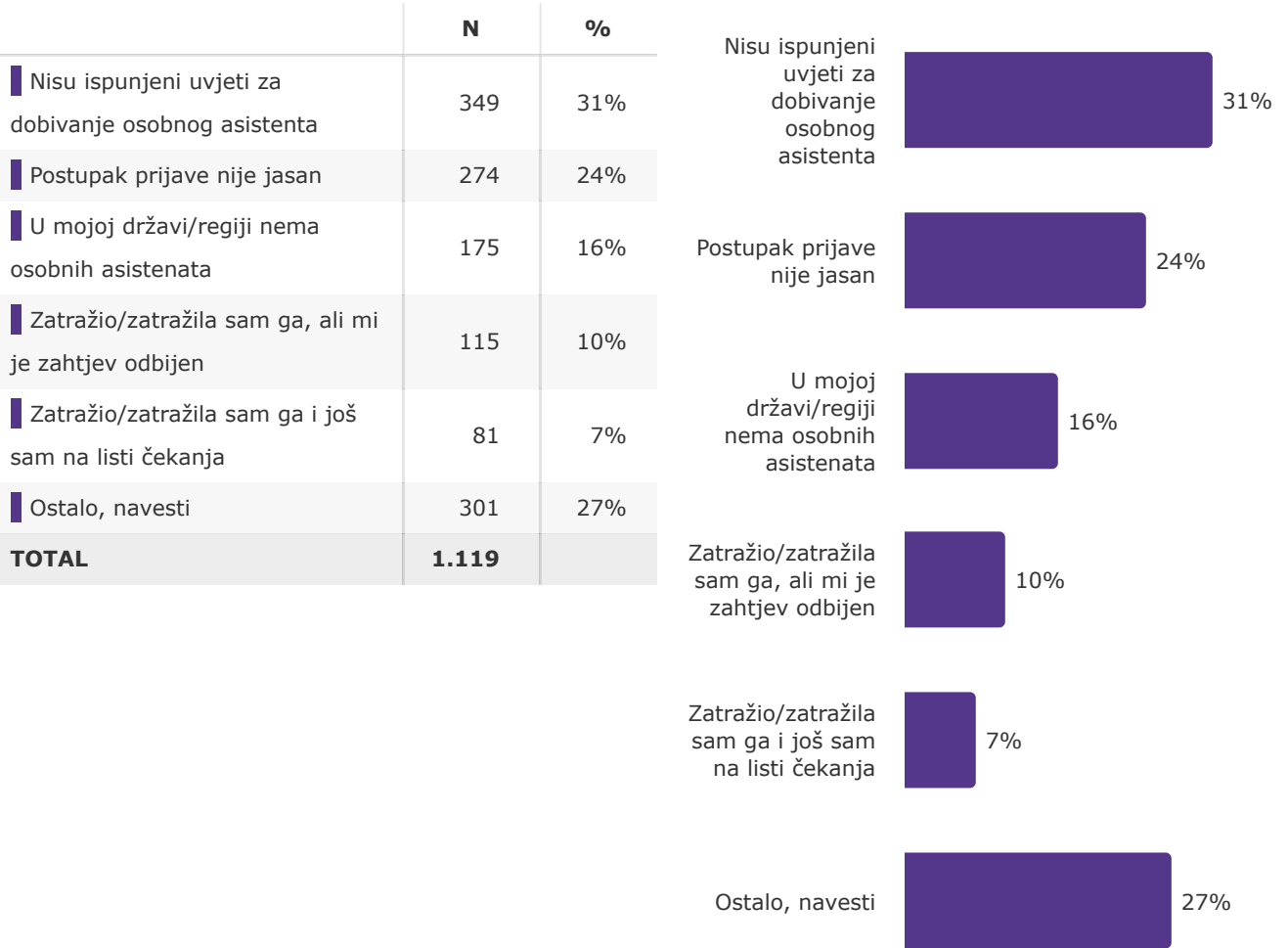


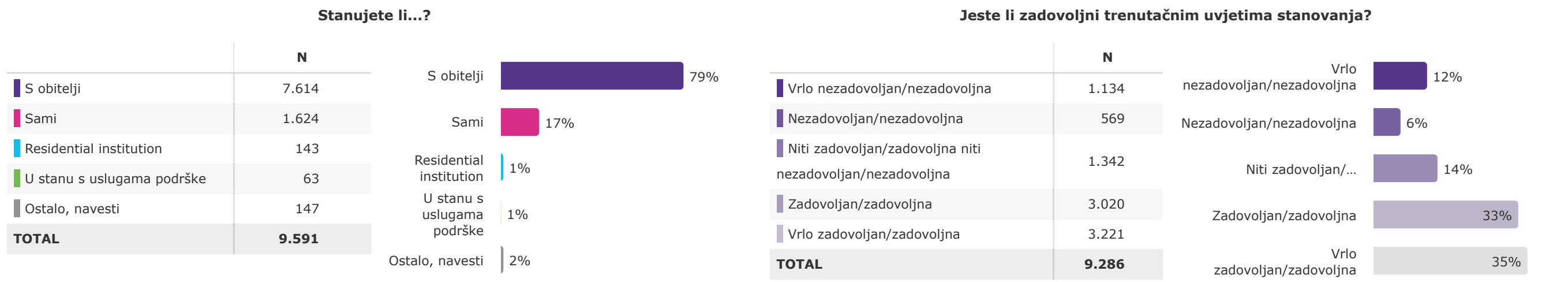
This question was only asked to people who do not have a personal assistant but need one.

Za koje biste zadatke trebali pomoć?



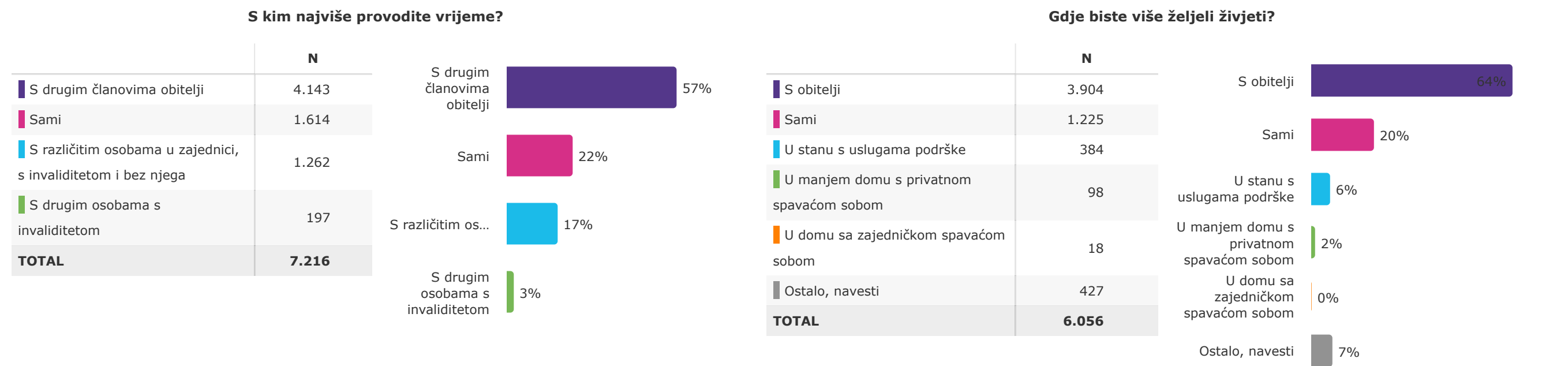
Zašto nemate osobnog asistenta?





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.



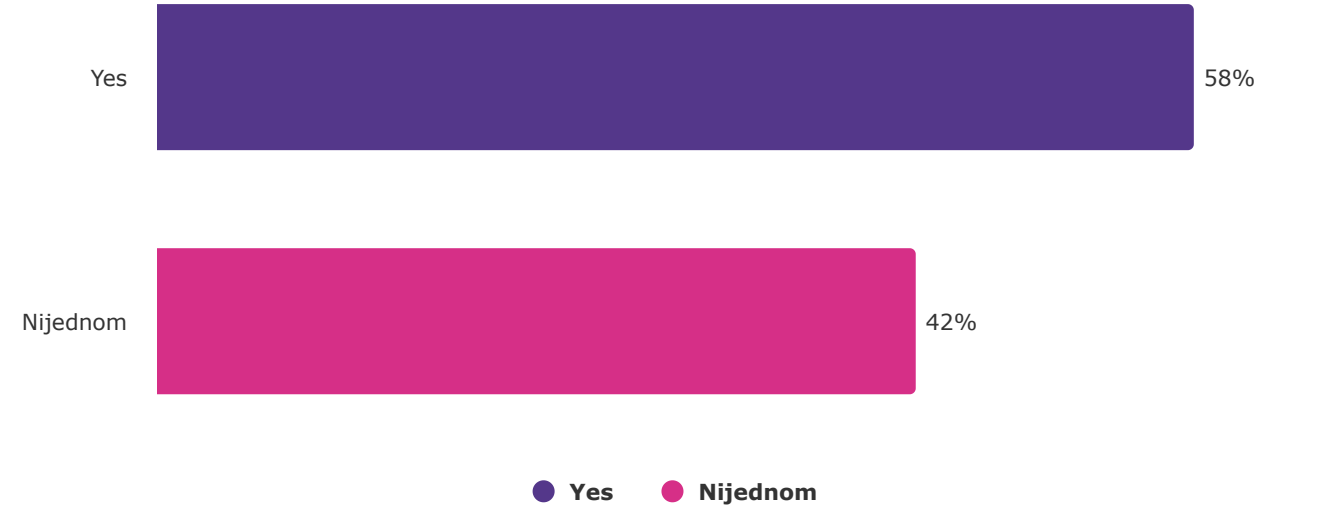


5. SOCIAL PARTICIPATION

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

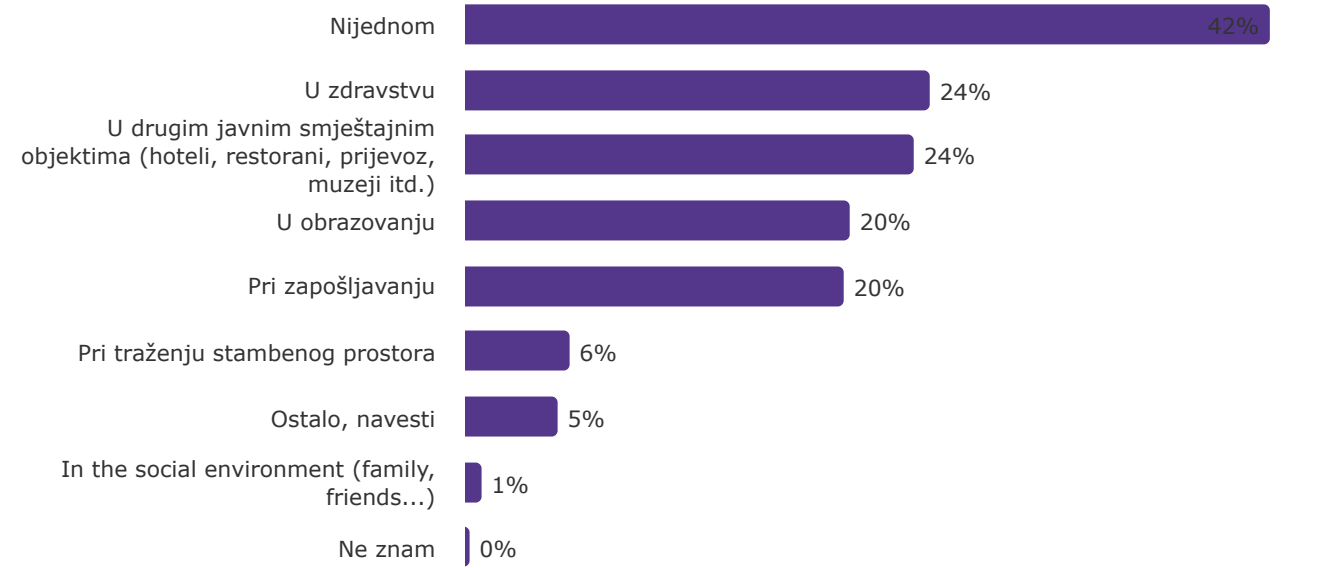
Jeste li ikada doživjeli diskriminaciju zbog rijetke bolesti ili invaliditeta?

	N	%
▼ Yes	5.270	58%
U zdravstvu	2.234	24%
U drugim javnim smještajnim objektima (hoteli, restorani, prijevoz, muzeji ...	2.158	24%
U obrazovanju	1.850	20%
Pri zapošljavanju	1.822	20%
Pri traženju stambenog prostora	506	6%
Ostalo, navesti	454	5%
In the social environment (family, friends...)	83	1%
■ Nijednom	3.860	42%
TOTAL	9.126	



Jeste li ikada doživjeli diskriminaciju zbog rijetke bolesti ili invaliditeta?

	N	%
■ Nijednom	3.860	42%
U zdravstvu	2.234	24%
U drugim javnim smještajnim objektima (hoteli, restorani, prijevoz, muzeji itd.)	2.158	24%
U obrazovanju	1.850	20%
Pri zapošljavanju	1.822	20%
Pri traženju stambenog prostora	506	6%
Ostalo, navesti	454	5%
In the social environment (family, friends...)	83	1%
Ne znam	25	0%
TOTAL	9.150	



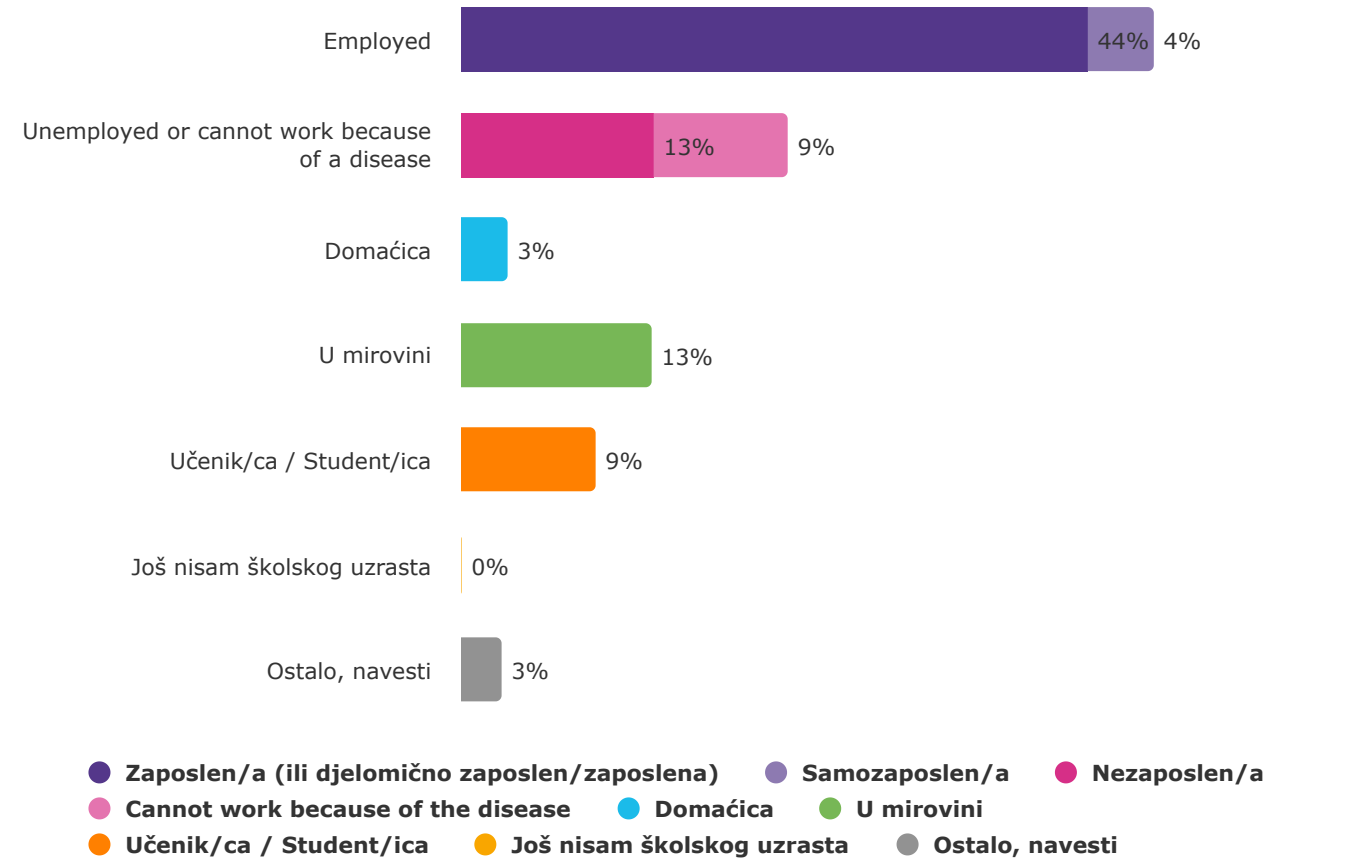


5.2. EMPLOYMENT

Employment and unemployment

Kakav je Vaš trenutajući status?

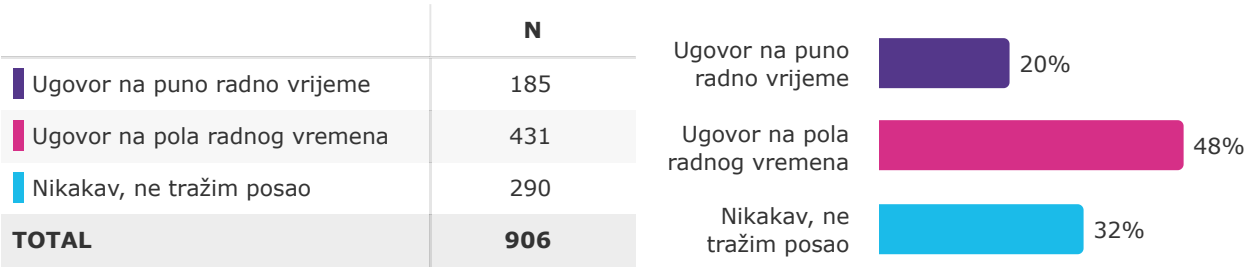
	N	%
▼ Employed	2.567	48%
Zaposlen/a (ili djelomično zaposlen/zaposlena)	2.329	44%
Samozaposlen/a	238	4%
▼ Unemployed or cannot work because of a disease	1.216	23%
Nezaposlen/a	716	13%
Cannot work because of the disease	500	9%
Domaćica	177	3%
U mirovini	714	13%
Učenik/ca / Student/ica	500	9%
Još nisam školskog uzrasta	4	0%
Ostalo, navesti	154	3%
TOTAL	5.332	100%



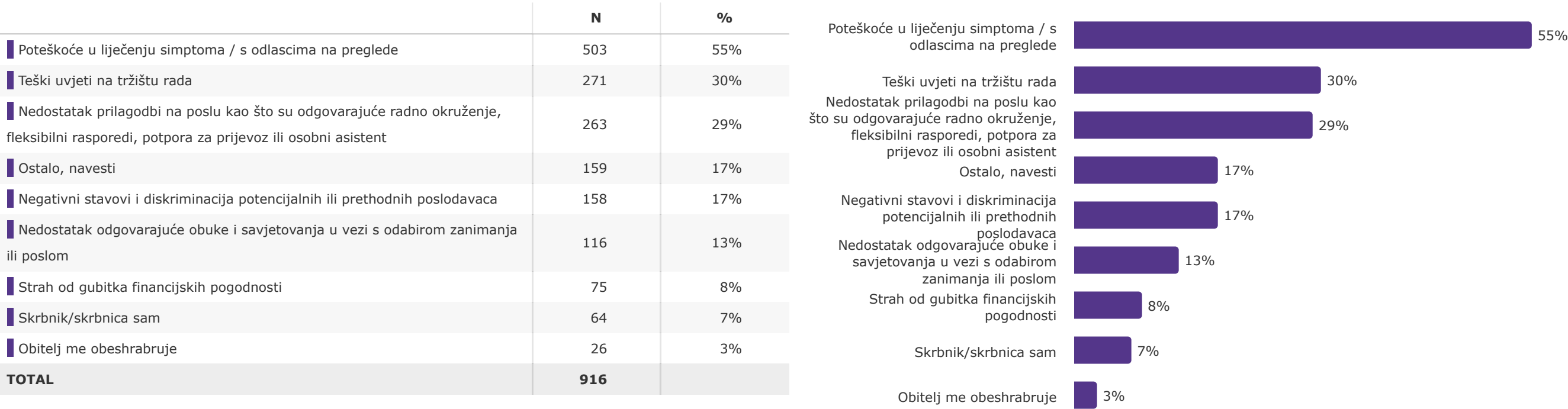
▼ Sample information : Age_patient between 16 and 64

These questions were only asked to unemployed respondents.

Koju biste vrstu ugovora o radu željeli kada biste se zaposlili?



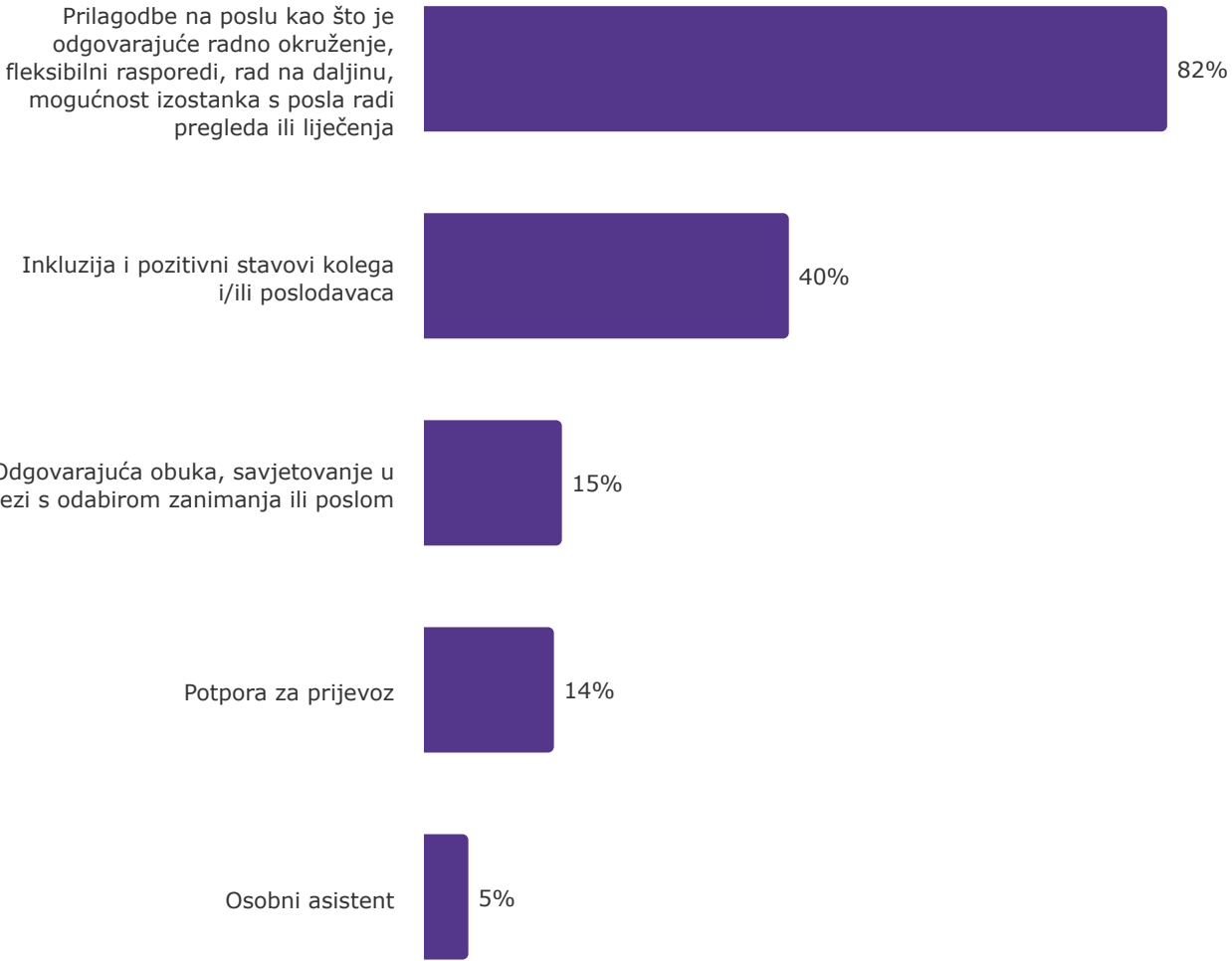
Zbog čega ste trenutno nezaposleni?



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

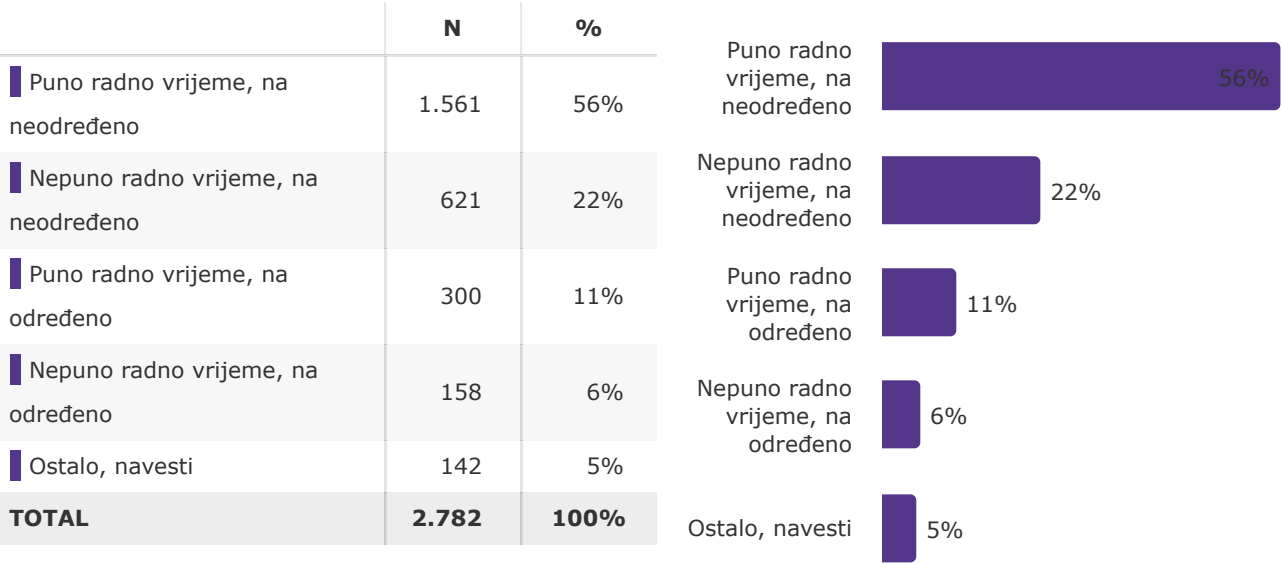
Što mislite, kakva bi potpora pri zapošljavanju i prilagodba na radnom mjestu mogla poboljšati Vaš poslovni život?

	N
Prilagodbe na poslu kao što je odgovarajuće radno okruženje, fleksibilni rasporedi, rad na daljinu, mogućnost izostanka s posla radi pregleda ili liječenja	2.463
Inkluzija i pozitivni stavovi kolega i/ili poslodavaca	1.211
Odgovarajuća obuka, savjetovanje u vezi s odabirom zanimanja ili poslom	459
Potpora za prijevoz	432
Osobni asistent	151
TOTAL	3.005

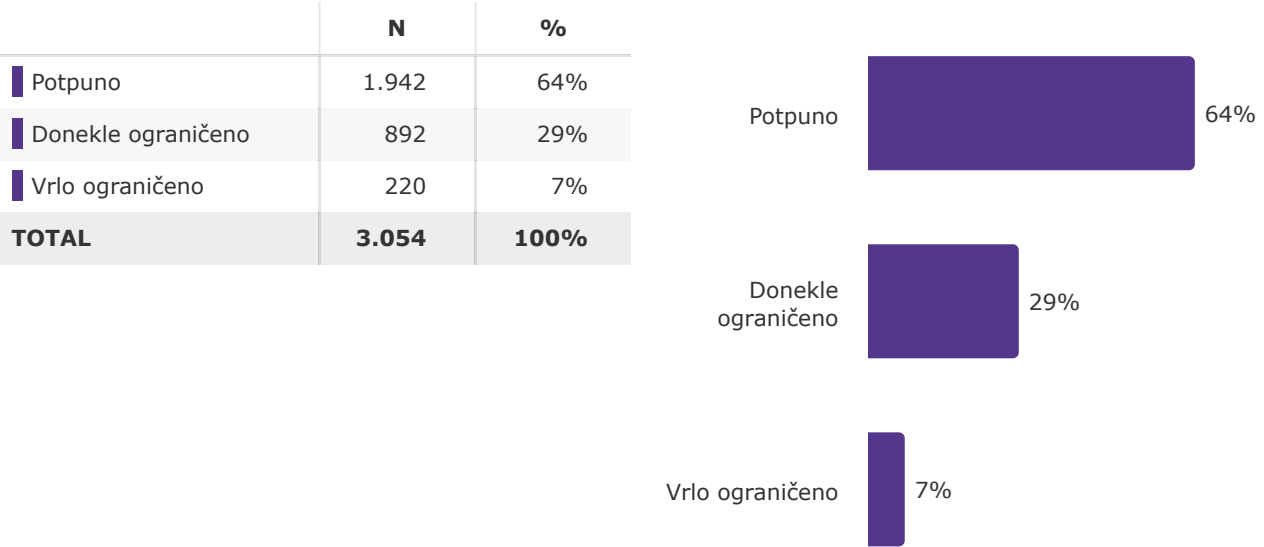


This question was only asked to respondents who are currently employed.

Koju vrstu ugovora imate?



Koliko ste trenutno uključeni na poslu?



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

Jeste li?

	N	%
U redovnom radnom odnosu (rad u organizaciji koja zapošljava osobe s invaliditetom i bez njega, bez podrške ili prilagodbe na radnom mjestu)	2.199	73%
U redovnom radnom odnosu uz podršku i prilagodbu na radnom mjestu (rad u organizaciji koja zapošljava osobe s invaliditetom i bez njega, uz podršku ili prilagodbu na radnom mjestu prema osobnoj situaciji)	735	24%
U zaštićenom radnom odnosu (organizacije koje zapošljavaju uglavnom osobe s invaliditetom)	75	2%
TOTAL	3.009	100%

U redovnom radnom odnosu (rad u organizaciji koja zapošljava osobe s invaliditetom i bez njega, bez podrške ili prilagodbe na radnom mjestu)

U redovnom radnom odnosu uz podršku i prilagodbu na radnom mjestu (rad u organizaciji koja zapošljava osobe s invaliditetom i bez njega, uz podršku ili prilagodbu na radnom mjestu prema osobnoj situaciji)

U zaštićenom radnom odnosu (organizacije koje zapošljavaju uglavnom osobe s invaliditetom)



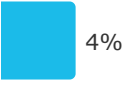
Željeli biste raditi...

	N	%
U redovnom radnom odnosu (rad u organizaciji koja zapošljava osobe s invaliditetom i bez njega, bez podrške ili prilagodbe na radnom mjestu)	990	33%
U redovnom radnom odnosu uz podršku i prilagodbu na radnom mjestu (rad u organizaciji koja zapošljava osobe s invaliditetom i bez njega, uz podršku ili prilagodbu na radnom mjestu prema osobnoj situaciji)	1.175	39%
U zaštićenom radnom odnosu (organizacije koje zapošljavaju uglavnom osobe s invaliditetom)	120	4%
Nemam posebnih želja	732	24%
TOTAL	3.017	100%

U redovnom radnom odnosu (rad u organizaciji koja zapošljava osobe s invaliditetom i bez njega, bez podrške ili prilagodbe na radnom mjestu)

U redovnom radnom odnosu uz podršku i prilagodbu na radnom mjestu (rad u organizaciji koja zapošljava osobe s invaliditetom i bez njega, uz podršku ili prilagodbu na radnom mjestu prema osobnoj situaciji)

U zaštićenom radnom odnosu (organizacije koje zapošljavaju uglavnom osobe s invaliditetom)



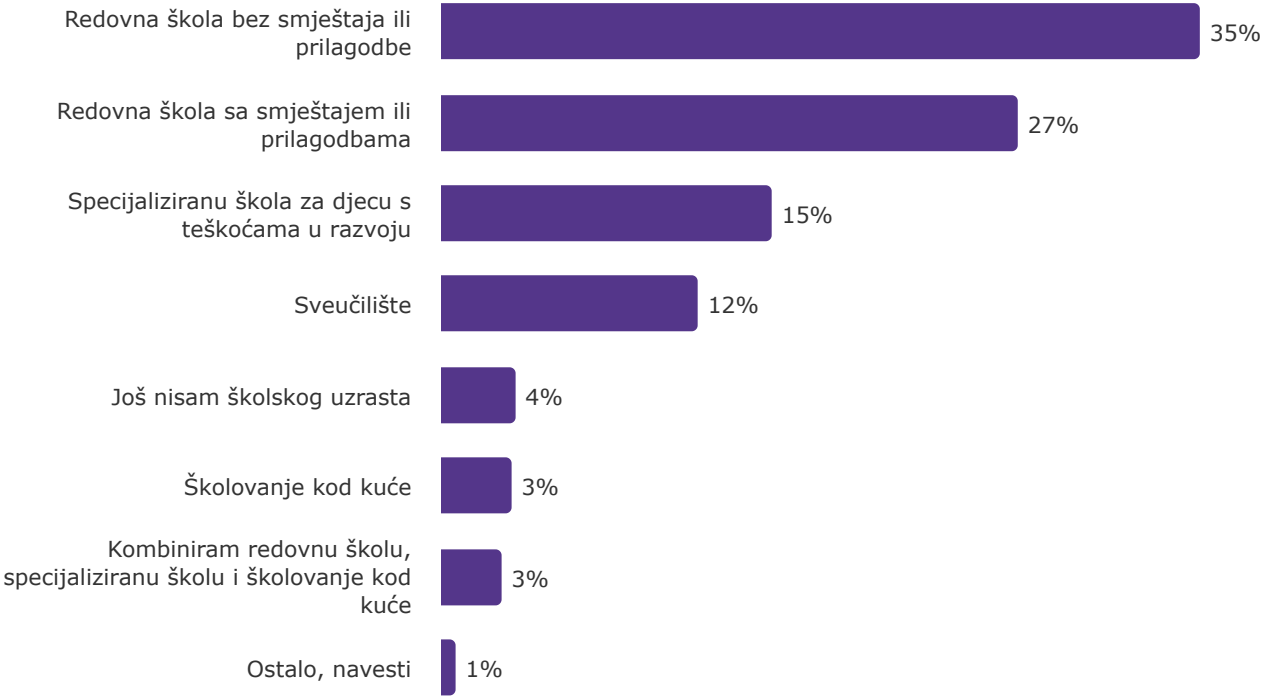


5.3. SCHOOL PARTICIPATION

This question was only asked to students/pupils

Kakvu školu pohađate?

	N
Redovna škola bez smještaja ili prilagodbe	662
Redovna škola sa smještajem ili prilagodbama	504
Specijaliziranu škola za djecu s teškoćama u razvoju	290
Sveučilište	224
Još nisam školskog uzrasta	67
Školovanje kod kuće	62
Kombiniram redovnu školu, specijaliziranu školu i školovanje kod kuće	54
Ostalo, navesti	14
TOTAL	1.877



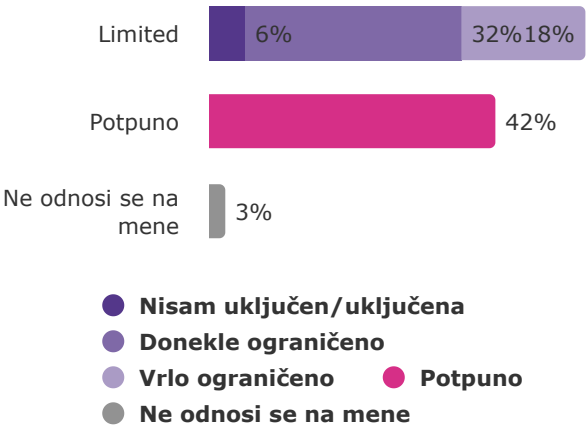


5.4. COMMUNITY PARTICIPATION

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

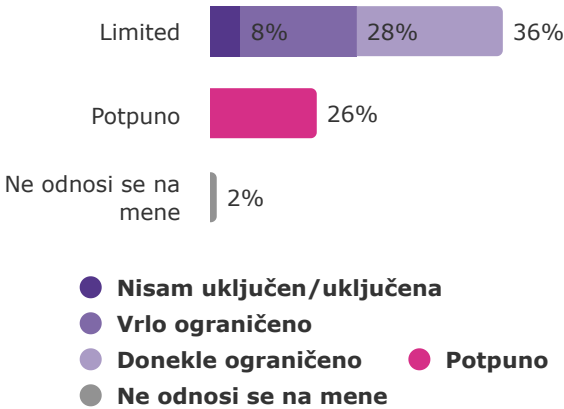
Compared to other people the same age, what is your current level of participation in educational (academic) activities with other students in the classroom?

	N	%
▼ Limited	958	55%
Nisam uključen/uključ...	99	6%
Donekle ograničeno	547	32%
Vrlo ograničeno	312	18%
Potpuno	732	42%
Ne odnosi se na mene	46	3%
TOTAL	1.736	100%



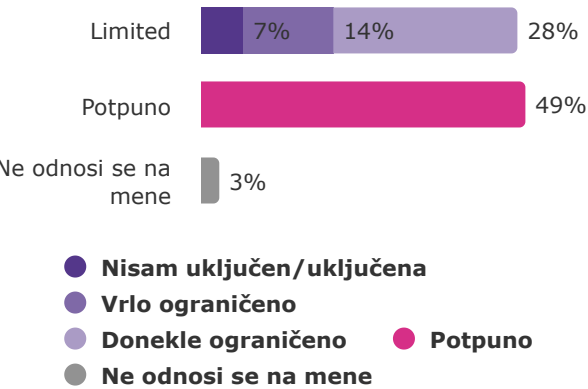
Compared to other people the same age, what is your current level of participation in social, play and recreational activities with other students (e.g., "hanging out", sports, clubs, hobbies, creative arts, lunchtime or recess activities)?

	N	%
▼ Limited	1.250	72%
Nisam uključen/uključ...	134	8%
Vrlo ograničeno	494	28%
Donekle ograničeno	622	36%
Potpuno	454	26%
Ne odnosi se na mene	36	2%
TOTAL	1.748	100%



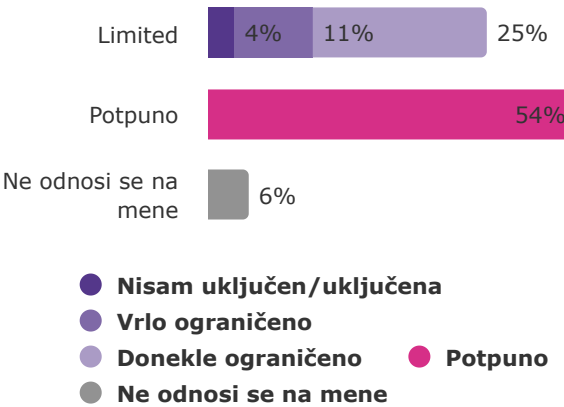
Compared to other people the same age, what is your current level of participation in moving around at school/university (e.g., to get to and use the bathroom, playground, cafeteria, library or other rooms and things that are available to other students the same age)?

	N	%
▼ Limited	834	48%
Nisam uključen/u...	116	7%
Vrlo ograničeno	237	14%
Donekle ograničeno	481	28%
Potpuno	855	49%
Ne odnosi se na mene	54	3%
TOTAL	1.743	100%



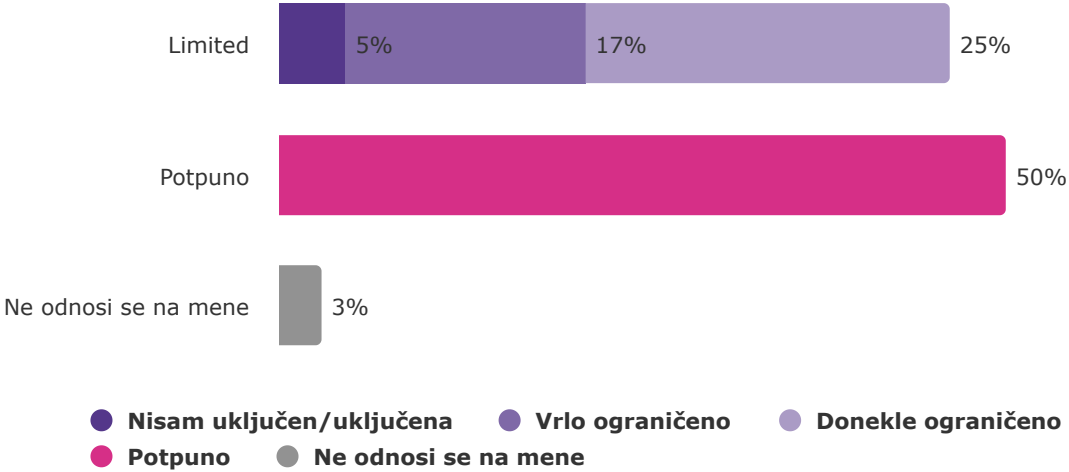
Upotreba obrazovnih materijala i opreme koji su dostupni drugim učenicima u učionici ili koji su modificirani za Vas (npr. knjige, računala, stolice i stolovi)?

	N	%
▼ Limited	698	41%
Nisam uključen/uklj...	68	4%
Vrlo ograničeno	197	11%
Donekle ograničeno	433	25%
Potpuno	922	54%
Ne odnosi se na mene	103	6%
TOTAL	1.723	100%



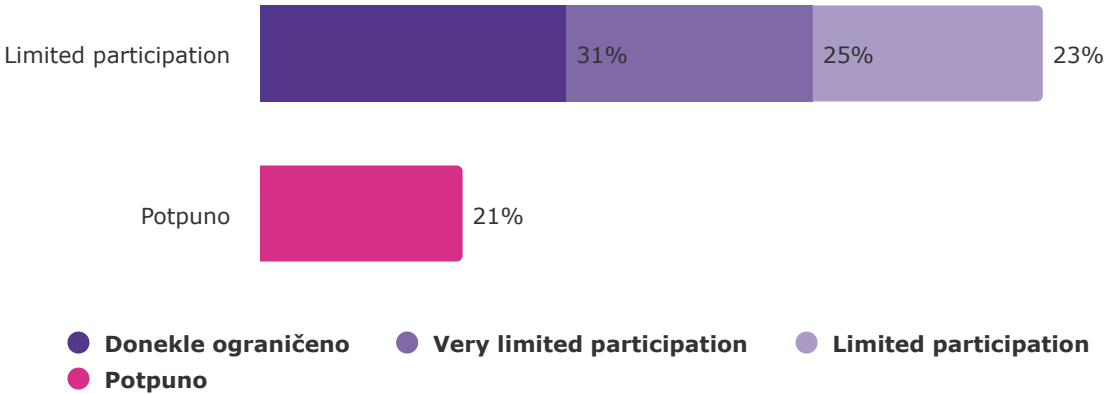
Komunikacija s drugim studentima i odraslima u školi ili na sveučilištu?

	N	%
▼ Limited	813	47%
Nisam uključen/uklj...	82	5%
Vrlo ograničeno	291	17%
Donekle ograničeno	440	25%
Potpuno	880	50%
Ne odnosi se na mene	54	3%
TOTAL	1.747	100%



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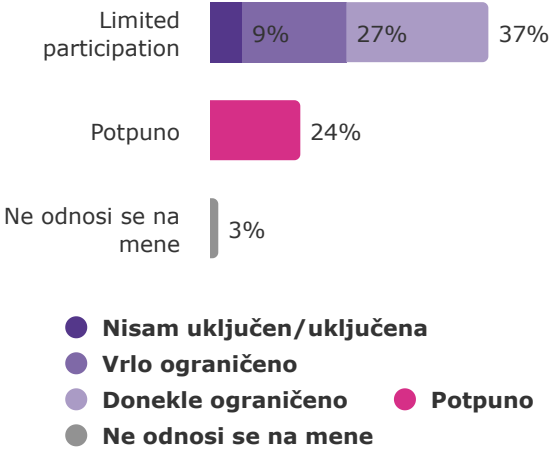
	N	%
▼ Limited participation	1.229	79%
Donekle ograničeno	484	31%
Very limited particip...	386	25%
Limited participation	359	23%
Potpuno	319	21%
TOTAL	1.548	100%



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

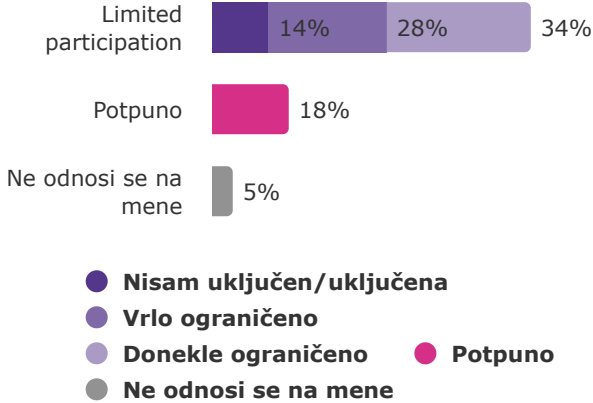
Društvene aktivnosti, zabava ili slobodne aktivnosti s prijateljima u susjedstvu i zajednici (npr. zabavne igre, „druženja“, odlasci na javna mjesta kao što je kino, park ili restoran)?

	N	%
▼ Limited participation	7.008	73%
Nisam uključen/uključ...	838	9%
Vrlo ograničeno	2.608	27%
Donekle ograničeno	3.562	37%
Potpuno	2.283	24%
Ne odnosi se na mene	270	3%
TOTAL	9.561	100%



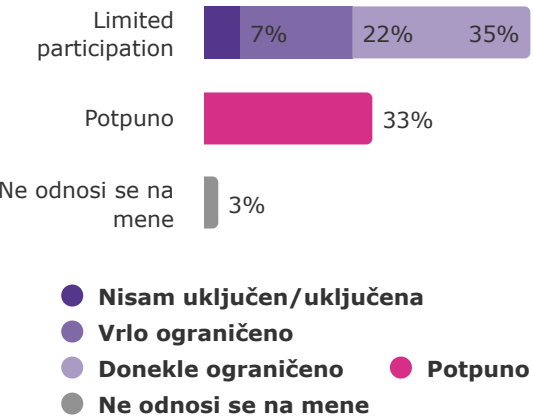
Strukturirani događaji i aktivnosti u susjedstvu i zajednici (npr. timski sportovi, klubovi, blagdanski ili vjerski događaji, koncerti, parade i sajmovi)?

	N	%
▼ Limited participation	7.280	76%
Nisam uključen/u...	1.339	14%
Vrlo ograničeno	2.677	28%
Donekle ograničeno	3.264	34%
Potpuno	1.760	18%
Ne odnosi se na mene	504	5%
TOTAL	9.544	100%



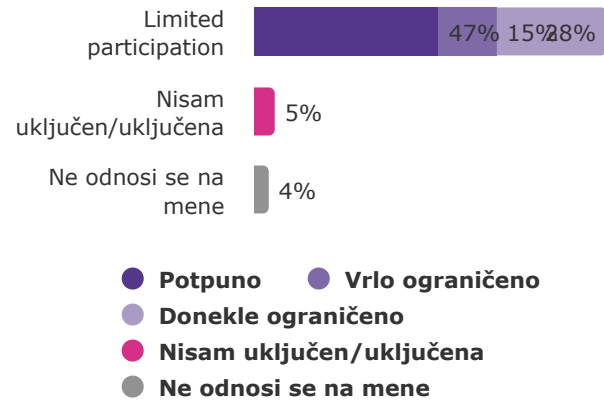
Kretanje po susjedstvu i zajednici (npr. javne zgrade, parkovi, restorani, kina)?

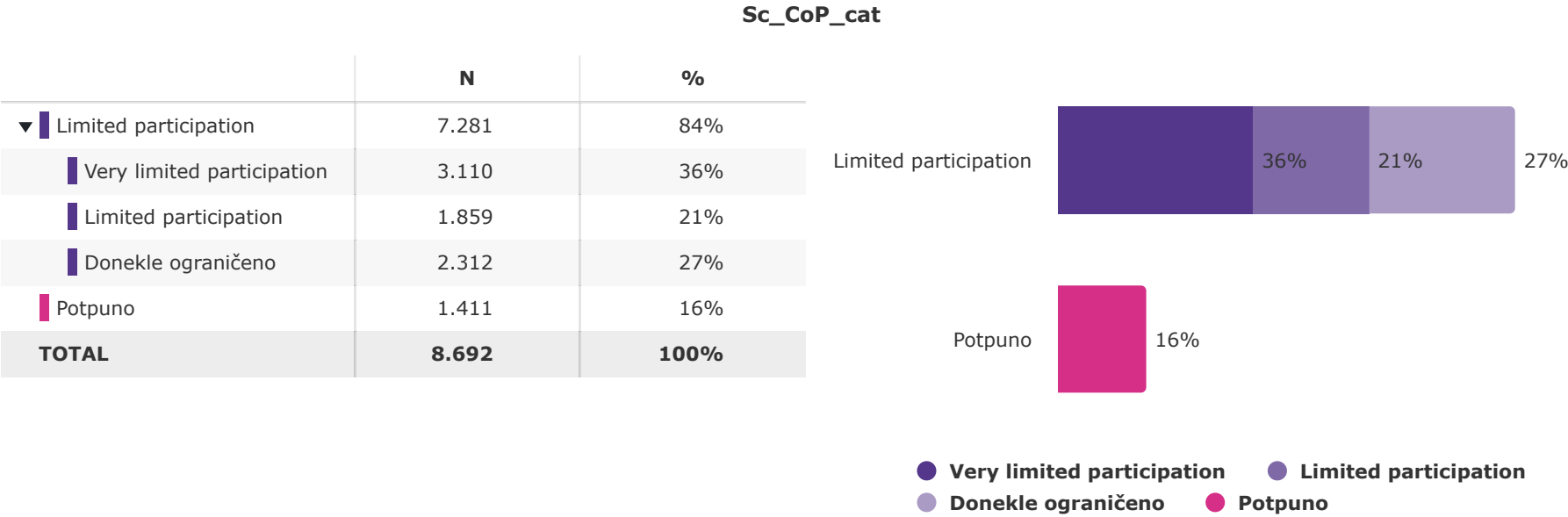
	N	%
▼ Limited participation	6.085	64%
Nisam uključen/u...	711	7%
Vrlo ograničeno	2.066	22%
Donekle ograničeno	3.308	35%
Potpuno	3.178	33%
Ne odnosi se na mene	303	3%
TOTAL	9.566	100%



Komunikacija s drugima u susjedstvu i zajednici?

	N	%
▼ Limited participation	8.648	91%
Potpuno	4.523	47%
Vrlo ograničeno	1.448	15%
Donekle ograniče...	2.677	28%
Nisam uključen/uklj...	512	5%
Ne odnosi se na mene	395	4%
TOTAL	9.555	100%

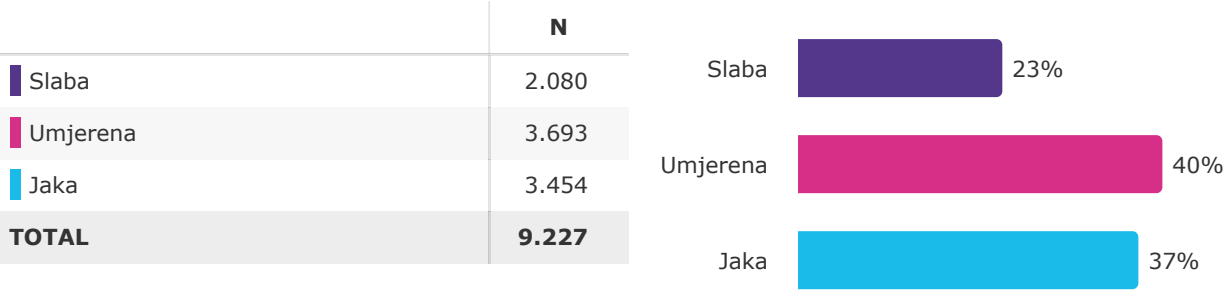




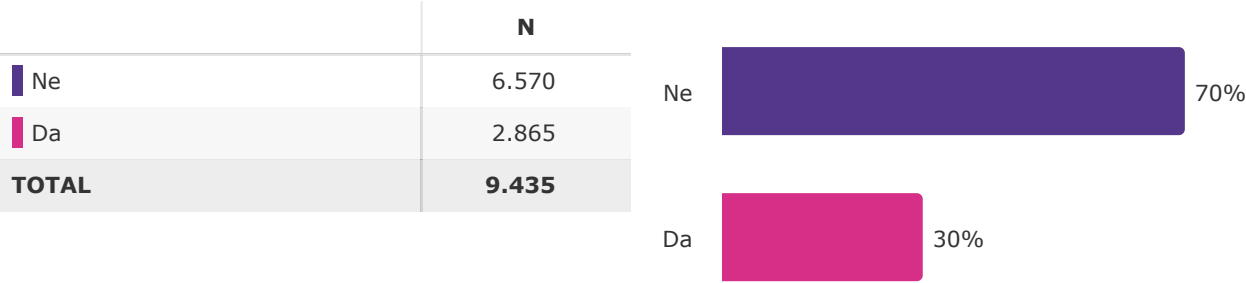


5.5. SOCIAL ENVIRONMENT

Kako biste kvalificirali društvenu podršku koju dobivate od ljudi (bliske osobe na koje možete računati, bržnost drugih ljudi, praktična pomoć susjeda u slučaju potrebe)?

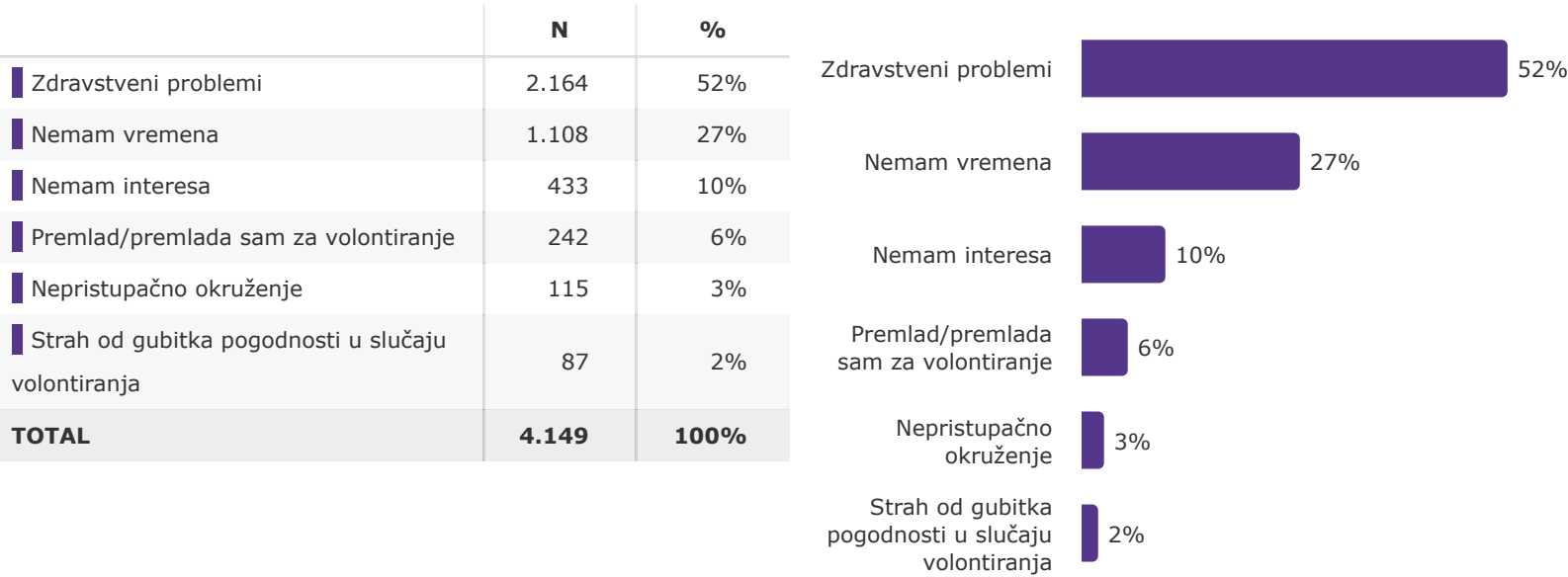


Jeste li tijekom posljednjih 12 mjeseci za neku organizaciju obavljali bilo kakav neplaćeni, neobavezan posao ili neformalne aktivnosti (npr. pomoć drugim ljudima, pomoć životinjama)?



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

Zašto niste? Navedite samo najvažniji razlog.



Hvala vam!

Za sva pitanja obratite se timu Rare Barometra na
rare.barometer@eurordis.org

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