

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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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



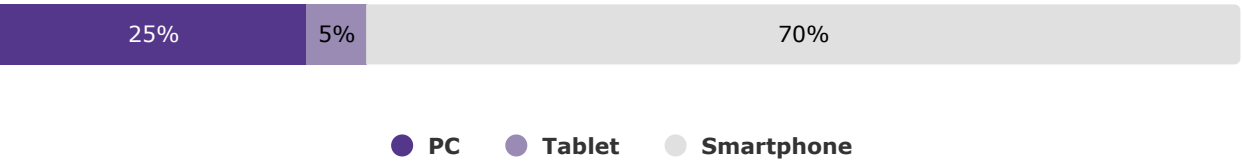
1. SAMPLE INFORMATION

**Sociodemographic characteristics,
diagnostic information**

Ali na vprašalnik odgovarjate kot ...?

9.591

Naprava za odgovor



Povprečno število minut za izpolnjevanje vprašalnika

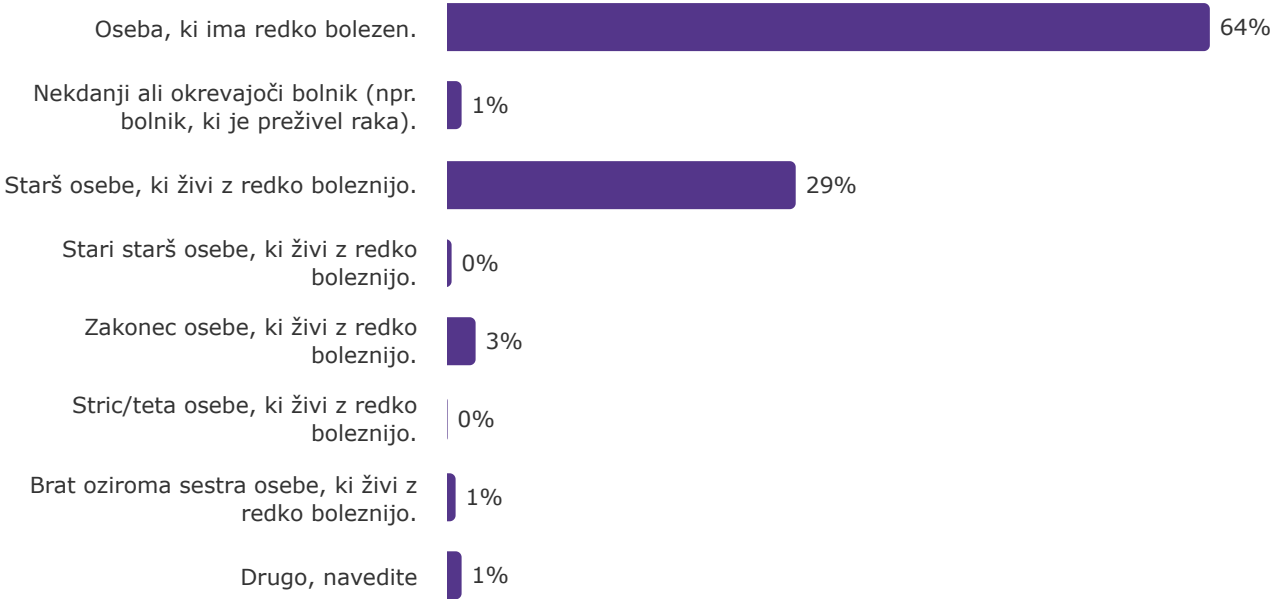
21
Mean

Srednje število minut za izpolnjevanje vprašalnika

15
Median

Ali na vprašalnik odgovarjate kot ...?

	N
Oseba, ki ima redko bolezen.	6.136
Nekdanji ali okrevajoči bolnik (npr. bolnik, ki je preživel raka).	123
Starš osebe, ki živi z redko boleznijo.	2.816
Stari starš osebe, ki živi z redko boleznijo.	43
Zakonec osebe, ki živi z redko boleznijo.	240
Stric/teta osebe, ki živi z redko boleznijo.	19
Brat oziroma sestra osebe, ki živi z redko boleznijo.	82
Drugo, navedite	132
TOTAL	9.591



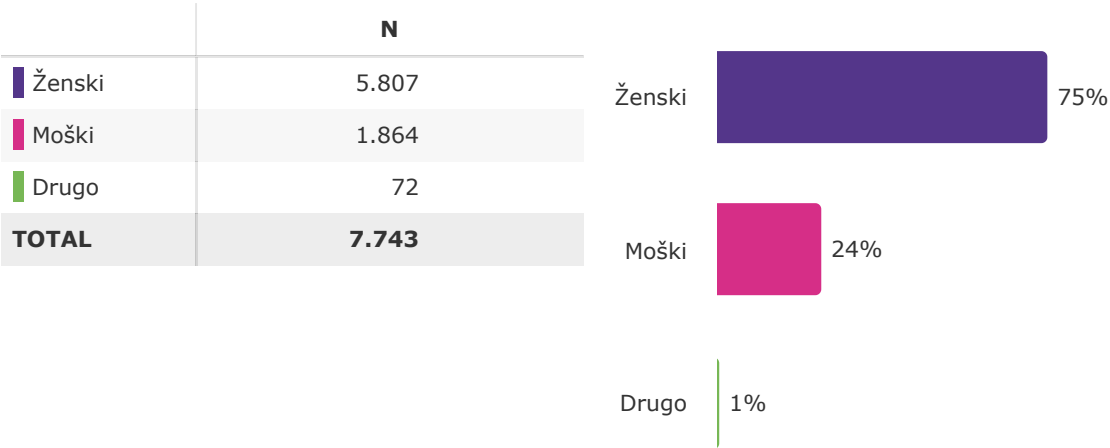
Če se izbrali »Drugo«, navedite ...

	N	%	
Oseba, ki ima redko bolezen.	6.260	65%	Oseba, ki ima redko bolezen. 65%
Family member (parent, spouse...)	3.331	35%	
TOTAL	9.591	100%	Family member (parent, spouse...) 35%

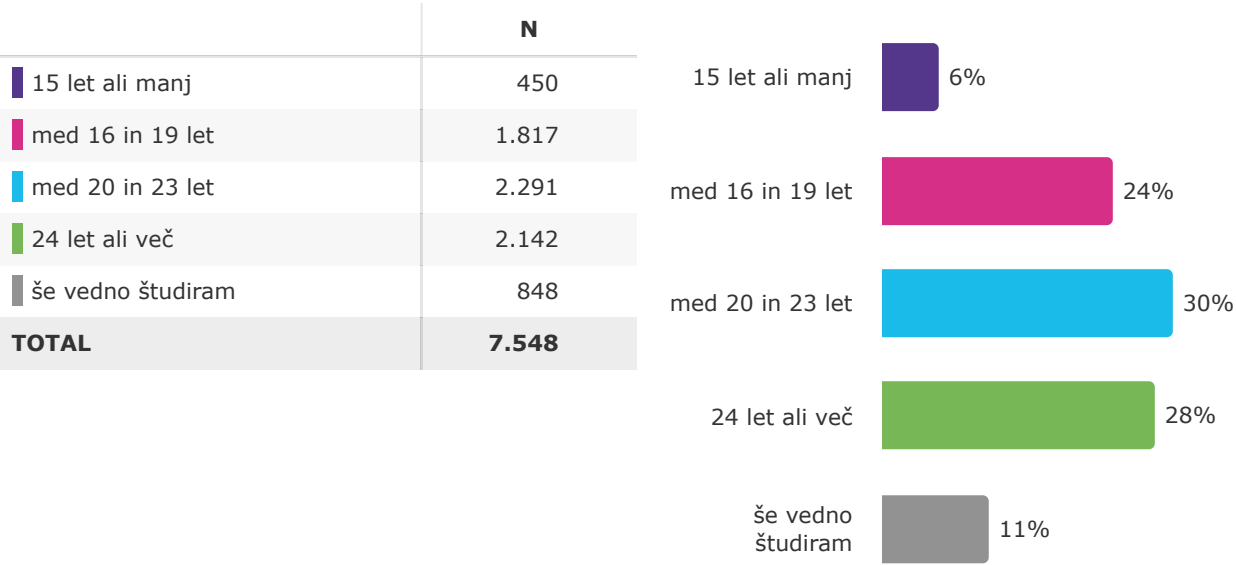
Ali ste predstavnik bolnikov, npr. ste vključeni v širše aktivnosti za podporo redkim boleznim?

	N	
Da	2.210	Da 23%
Ne	6.643	Ne 69%
Ne vem	738	Ne vem 8%
TOTAL	9.591	

Označite svoj spol:



Koliko ste bili stari, ko ste zaključili redno izobraževanje?



Označite svojo starost.

	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 je stara oseba, ki jo je prizadela redka bolezen?

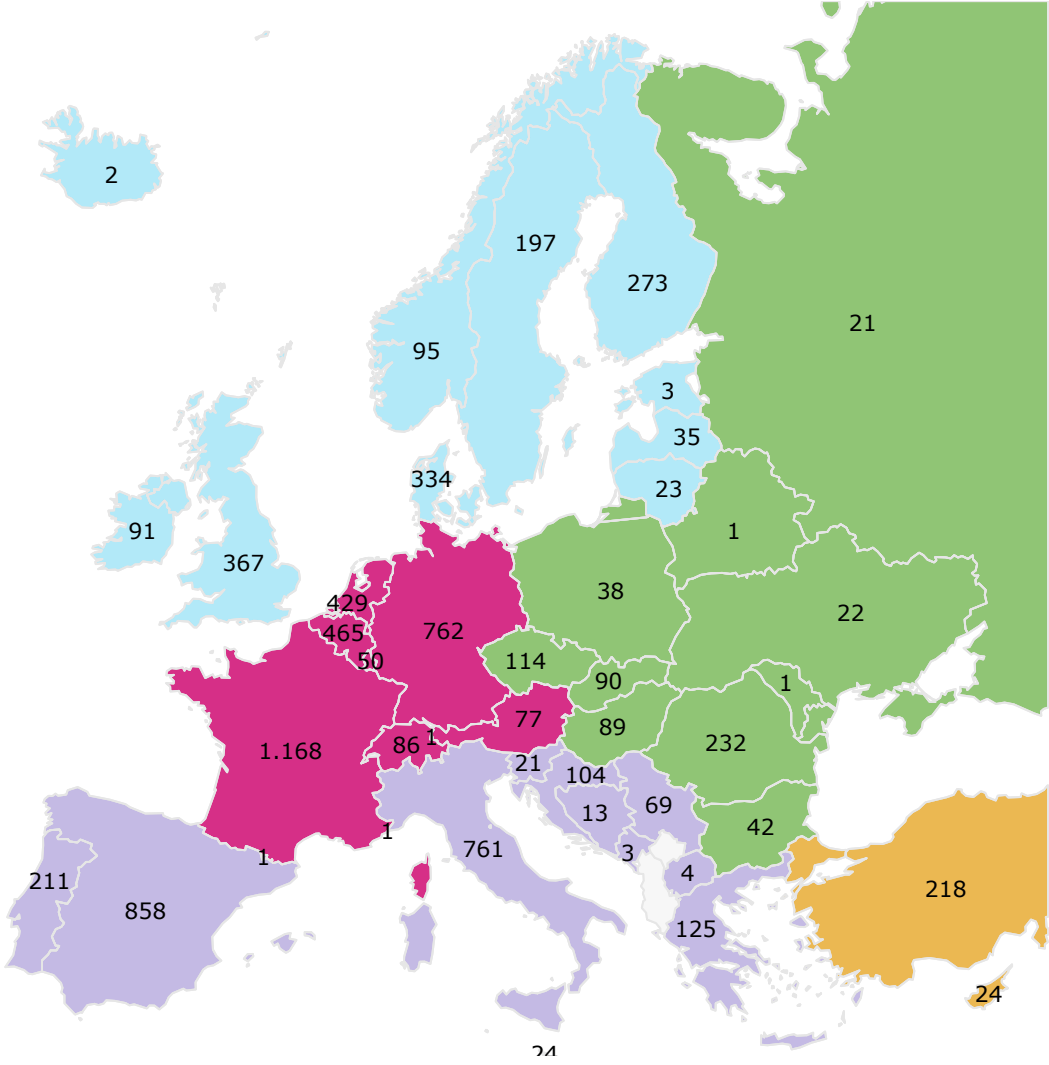
	N	%
Less than 18	1.611	21%
From 18 to 23	455	6%
From 24 to 29	431	6%
From 30 to 39	904	12%
From 40 to 49	1.277	17%
From 50 to 59	1.475	19%
60 and over	1.537	20%
TOTAL	7.690	100%

Countries with languages

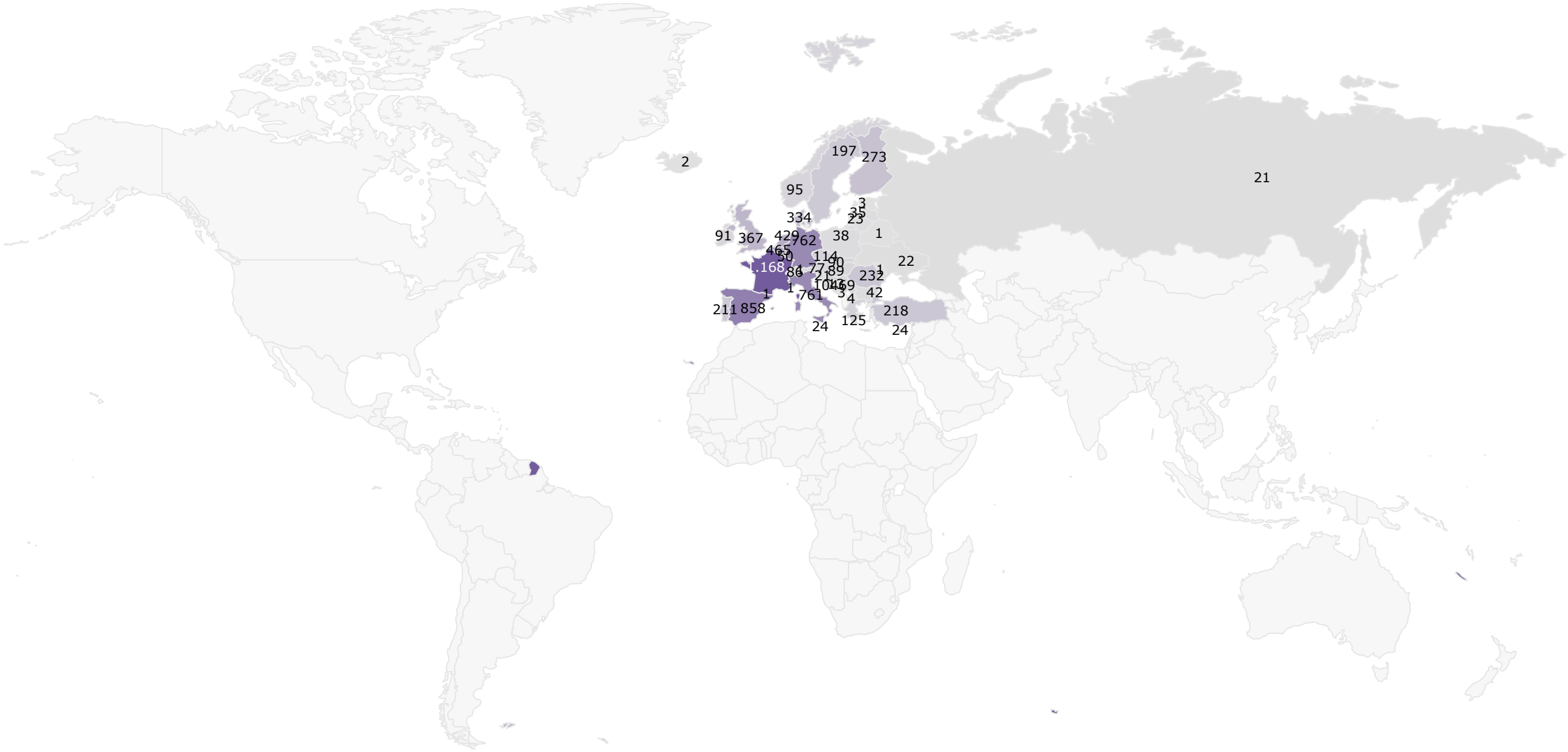
	N	%
Francija	1.168	14%
Italija	946	12%
Španija	858	11%
Nemčija	762	9%
Belgija	465	6%
Nizozemska	429	5%
Danska	427	5%
Romunija	368	5%
Turčija	368	5%
Velika Britanija	367	5%
Finska	338	4%
Portugalska	274	3%
Švedska	228	3%
Češka	154	2%
Grčija	150	2%
Slovaška	127	2%
Norveška	123	2%
Madžarska	114	1%
Hrvaška	104	1%
Irska	91	1%
Švica	87	1%
Avstrija	77	1%
Bolgarija	71	1%

Countries with languages

	N	%
Srbija	69	17%
Luksemburg	50	13%
Latvija	46	12%
Poljska	44	11%
Ukrajina	33	8%
Litva	32	8%
Slovenija	27	7%
Ciper	24	6%
Malta	24	6%
Rusija	21	5%
Bosna in Hercegovina	13	3%
Makedonija	4	1%
Estonija	3	1%
Črna gora	3	1%
Islandija	2	1%
Andora	1	0%
Belorusija	1	0%
Lihtenštajn	1	0%
Moldavija	1	0%
Monako	1	0%

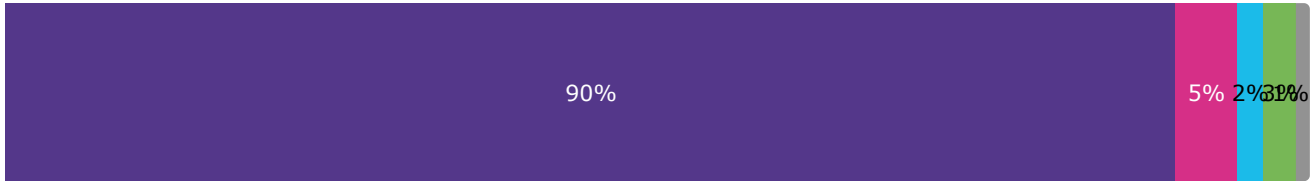


V kateri državi živite?



Izberite stavek, ki najbolje opisuje vaš položaj ali položaj osebe, za katero skrbite:

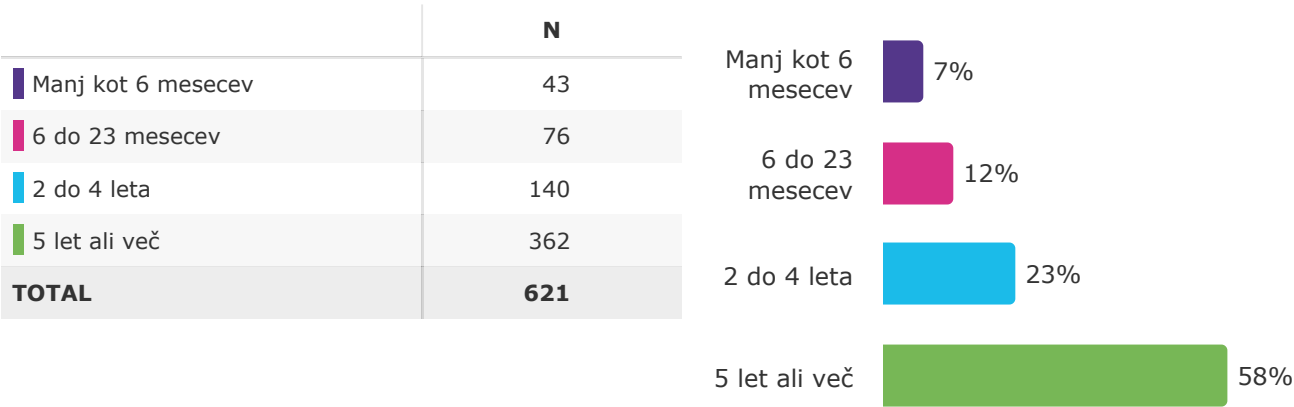
	N
Poznam IME redke bolezni, sindroma ali malformacije in bilo je POTRJENO z ustreznimi genetskimi, kliničnimi, medicinskimi slikovnimi, molekularnimi ali biokemičnimi preiskavami (npr. biopsija, preiskava krvi ali urina)	8.624
Poznam IME redke bolezni, sindroma ali malformacije, vendar še NI bilo potrjeno z ustreznimi genetskimi, kliničnimi, medicinskimi slikovnimi, molekularnimi ali biokemičnimi preiskavami	456
Imam le DELNE informacije o imenu redke bolezni ali prizadetega gena ali vrsti bolezni	184
Vem, da gre za redko bolezen, vendar ime ali vzrok NISTA BILA UGOTOVLJENA	242
Drugo, navedite	84
TOTAL	9.590



- Poznam IME redke bolezni, sindroma ali malformacije in bilo je POTRJENO z ustreznimi genetskimi, kliničnimi, medicinskimi slikovnimi, molekularnimi ali biokemičnimi preiskavami (npr. biopsija, preiskava krvi ali urina)
- Poznam IME redke bolezni, sindroma ali malformacije, vendar še NI bilo potrjeno z ustreznimi genetskimi, kliničnimi, medicinskimi slikovnimi, molekularnimi ali biokemičnimi preiskavami
- Imam le DELNE informacije o imenu redke bolezni ali prizadetega gena ali vrsti bolezni
- Vem, da gre za redko bolezen, vendar ime ali vzrok NISTA BILA UGOTOVLJENA
- Drugo, navedite

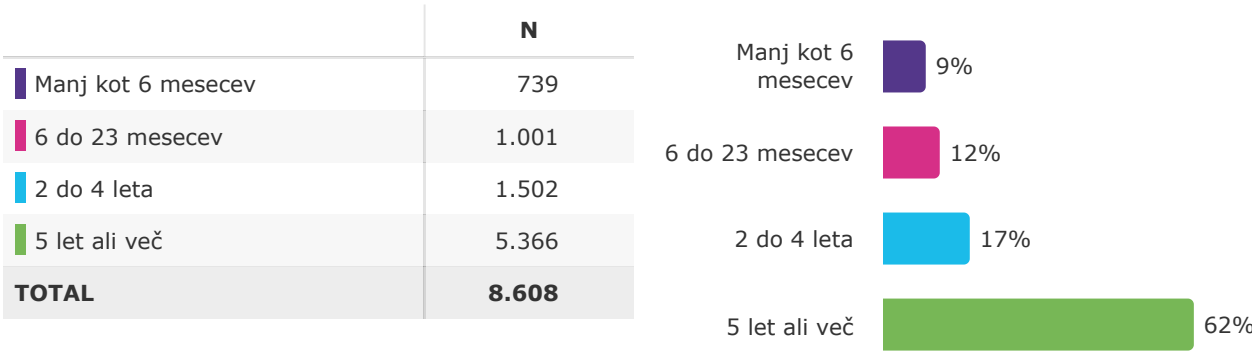
This question was only asked to people with an INITIAL diagnosis.

Koliko časa je minilo, odkar ste prvič izvedeli za IME redke bolezni, sindroma ali malformacije?



This question was only asked to people with confirmed diagnosis.

Koliko časa je minilo, odkar je bilo ime redke bolezni, sindroma ali malformacije POTRJENO s pomočjo ustrezne genetske, klinične, medicinsko-slikovne, molekularne ali biokemične preiskave (npr. biopsije, krvne preiskave ali preiskave urina)?



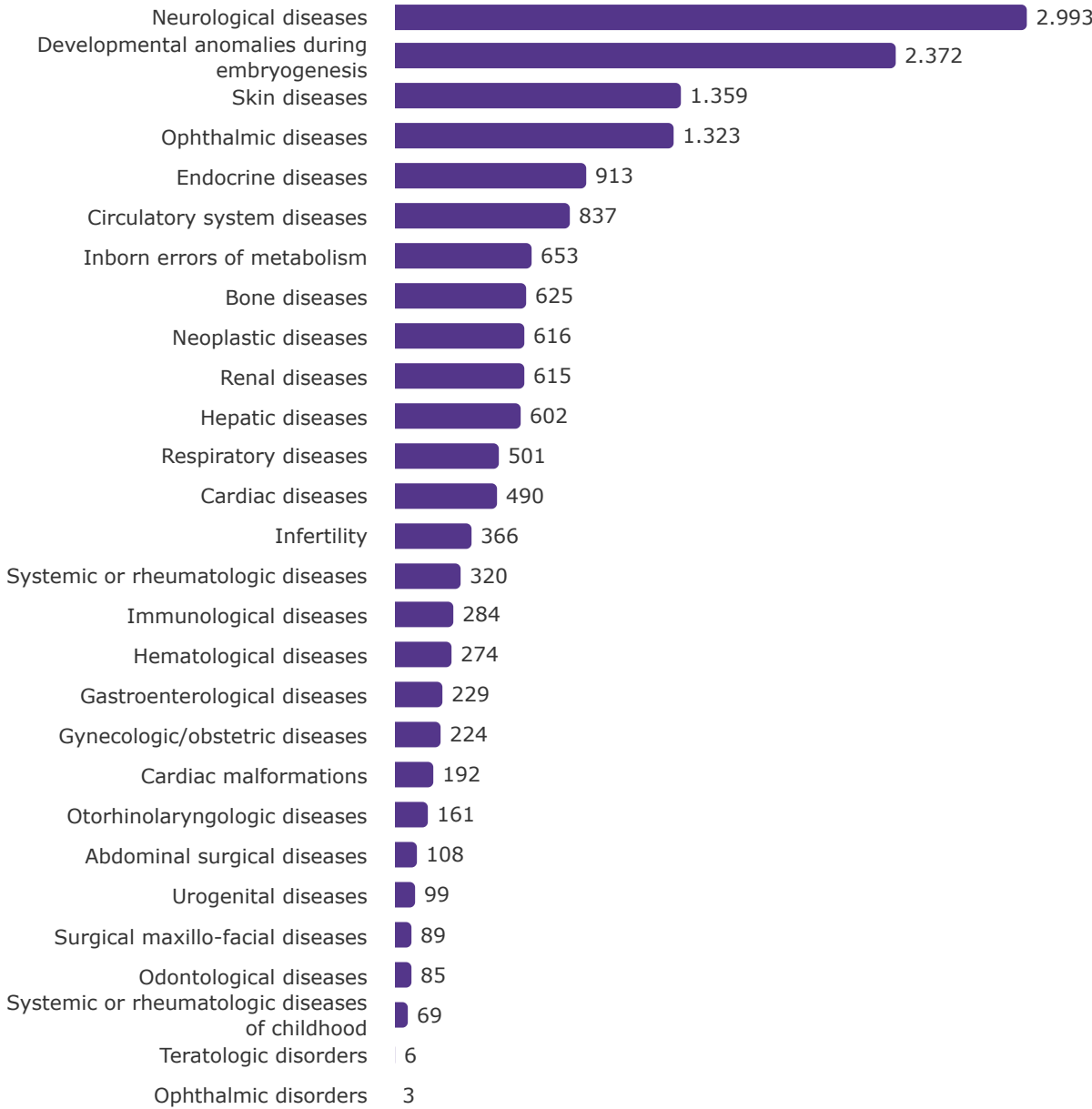
1.643

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

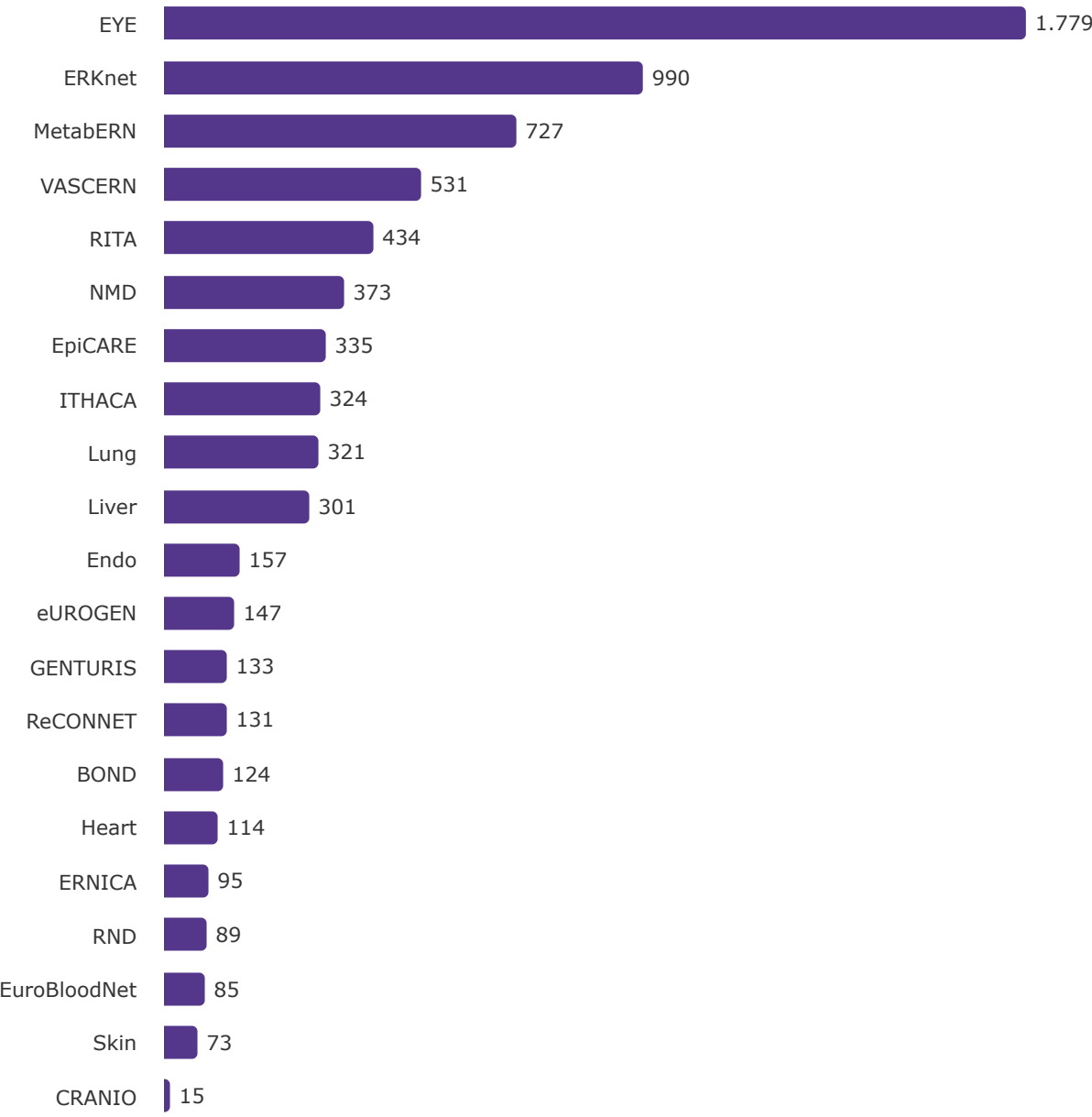
Orphacode associated nomenclature (english)	N
Alpha-1-antitrypsin deficiency	44
Wilson disease	43
Arnold-Chiari malformation type I	41
Diffuse cutaneous systemic sclerosis	40
Primary biliary cholangitis	39
Duchenne muscular dystrophy	38
Idiopathic achalasia	38
Monosomy 5p	38
Amyotrophic lateral sclerosis	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

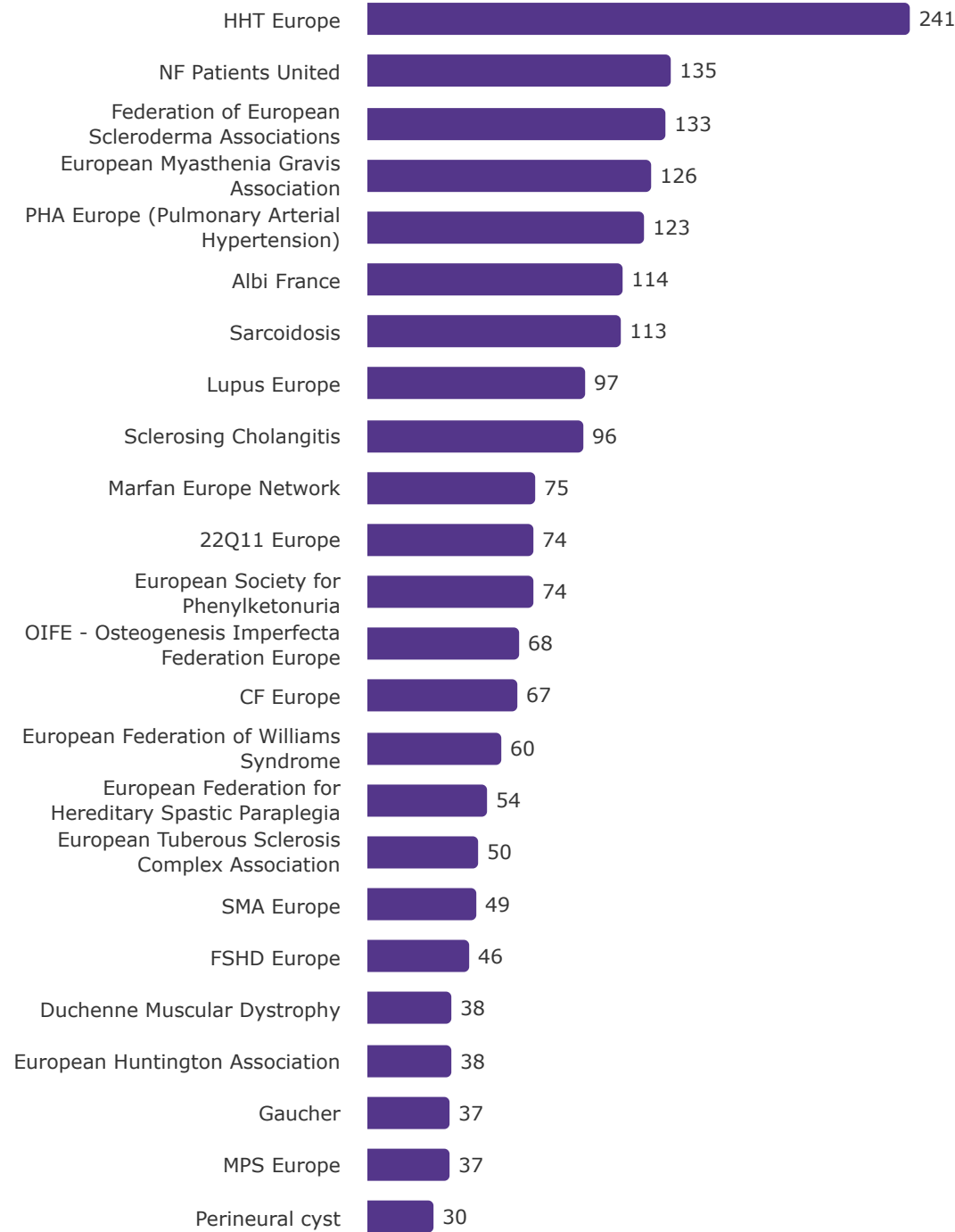
Orphanet classification of rare diseases (one disease can be classified in several categories)



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

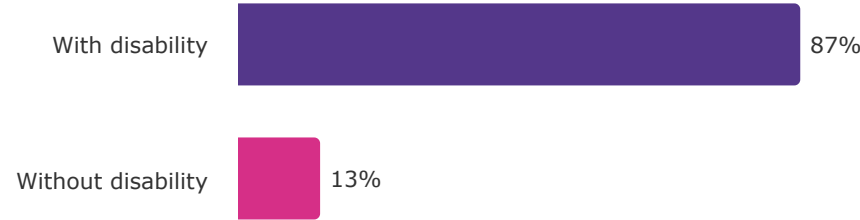
**Disability rates; diversity, complexity
and severity of disabilities**

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%

WG-SS2

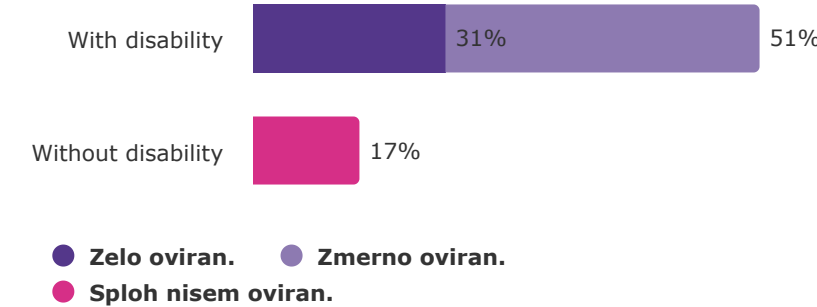


The Global Activity Limitation Index (GALI) measures disability through activity limitations that an individual experienced in the last 6 months or more due to a health problem.

Ali ste bili v zadnjih 6 ali več mesecih zaradi zdravstvenih težav omejeni pri dejavnostih, ki jih ljudje običajno opravljajo? Odgovorili bi ...

	N	%
▼ With disability	7.790	83%
Zelo oviran.	2.964	31%
Zmerno oviran.	4.826	51%
▼ Without disability	1.652	17%
Sploh nisem oviran.	1.652	17%
TOTAL	9.442	100%

Ali ste bili v zadnjih 6 ali več mesecih zaradi zdravstvenih težav omejeni pri dejavnostih, ki jih ljudje običajno opravljajo? Odgovorili bi ...

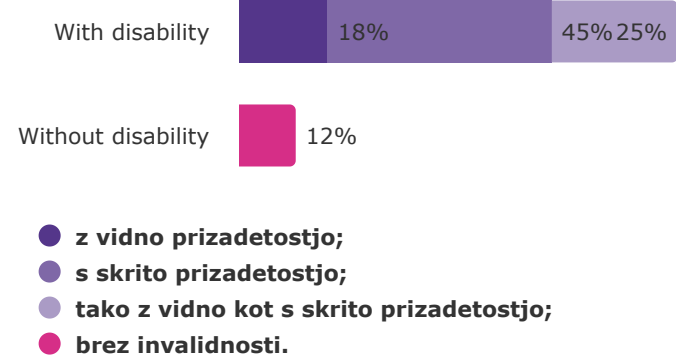


People living with rare diseases were asked if they perceive themselves as living with a disability, be it invisible, visible or both.

Ali menite, da ste posameznik ...?

	N	%
▼ With disability	8.030	88%
z vidno prizadetostjo;	1.626	18%
s skrito prizadetostjo;	4.107	45%
tako z vidno kot s skrito pr...	2.297	25%
▼ Without disability	1.068	12%
brez invalidnosti.	1.068	12%
TOTAL	9.098	100%

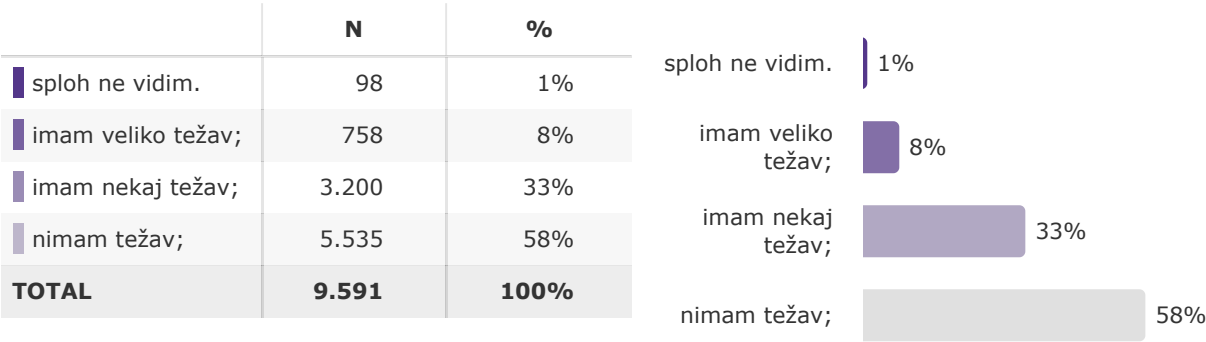
Ali menite, da ste posameznik ...?



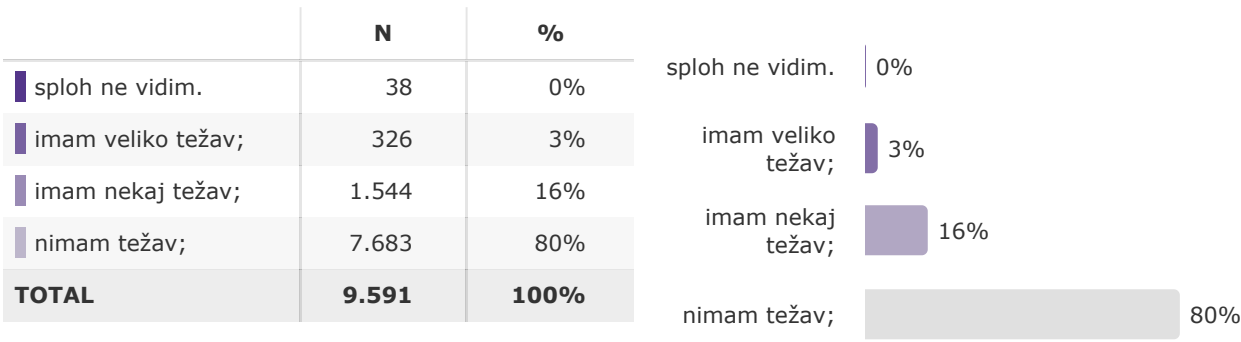
Washington Group Short Set (WG-SS)

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

Ali slabo VIDITE, tudi če nosite očala? Odgovorili bi ...

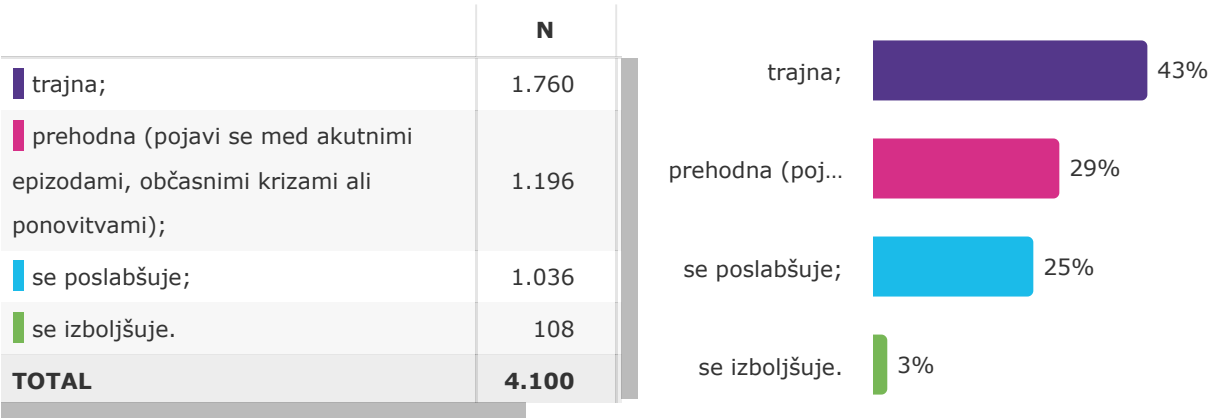


Ali slabo SLIŠITE, tudi če uporabljate slušni aparat? Odgovorili bi ...

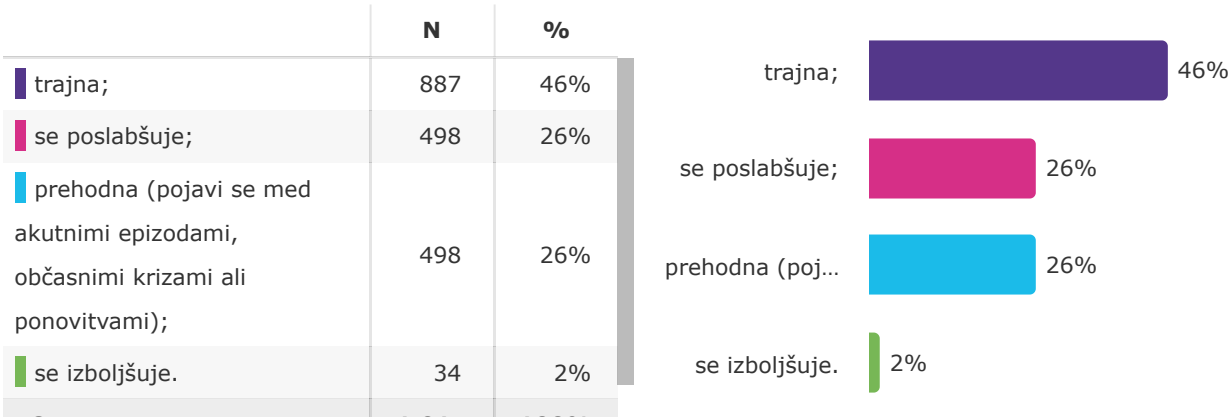


These questions were only asked to people with difficulty.

Ali je težava ...?



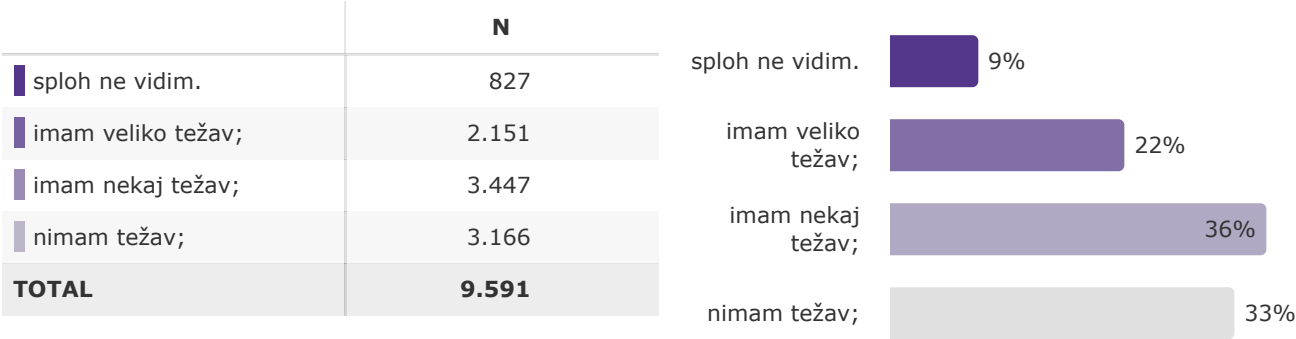
Ali je težava ...?



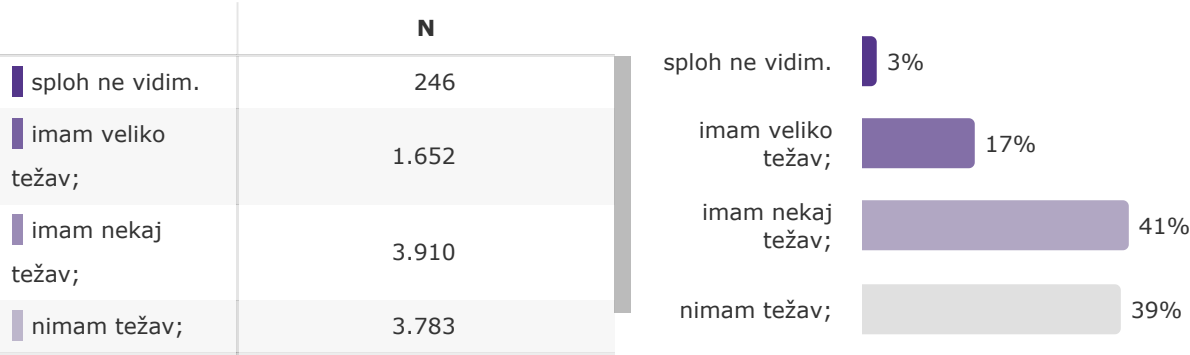
Washington Group Short Set (WG-SS)

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

Imate težave PRI HOJI ali VZPENJANJU PO STOPNICA? Odgovorili bi ...

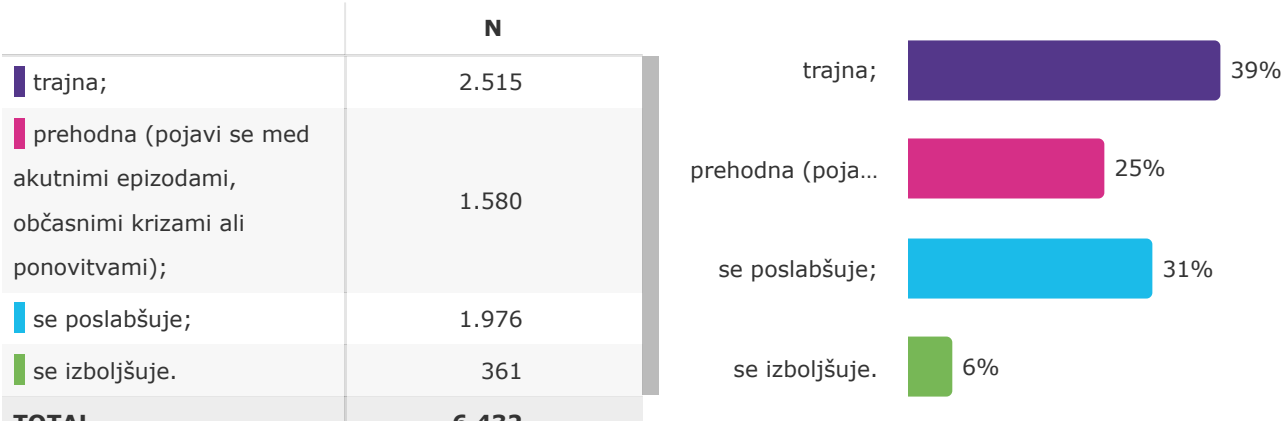


Imate težave s SPOMINOM ali KONCENTRACIJO Odgovorili bi ...

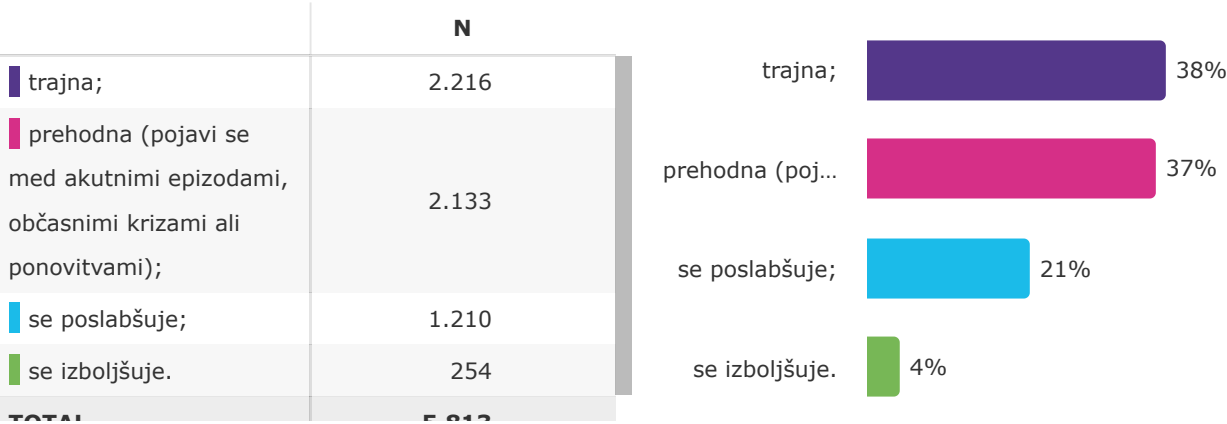


These questions were only asked to people with difficulty.

Ali je težava ...?



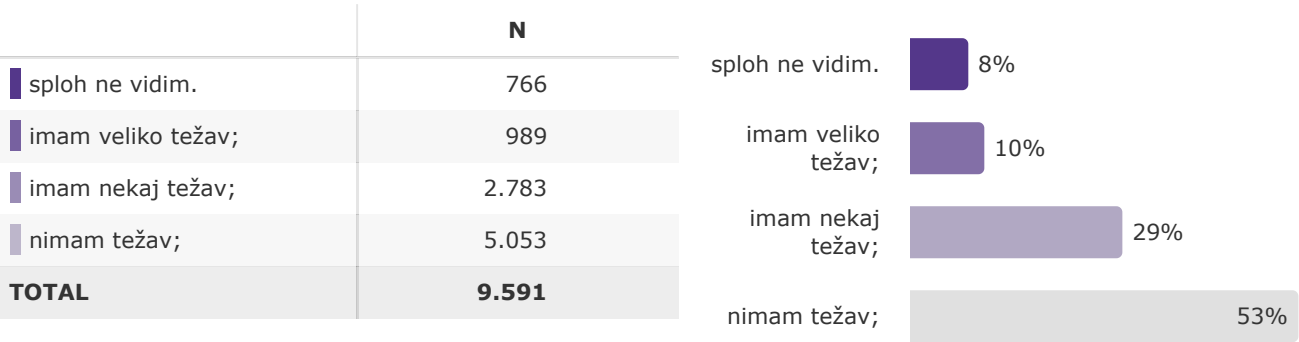
Ali je težava ...?



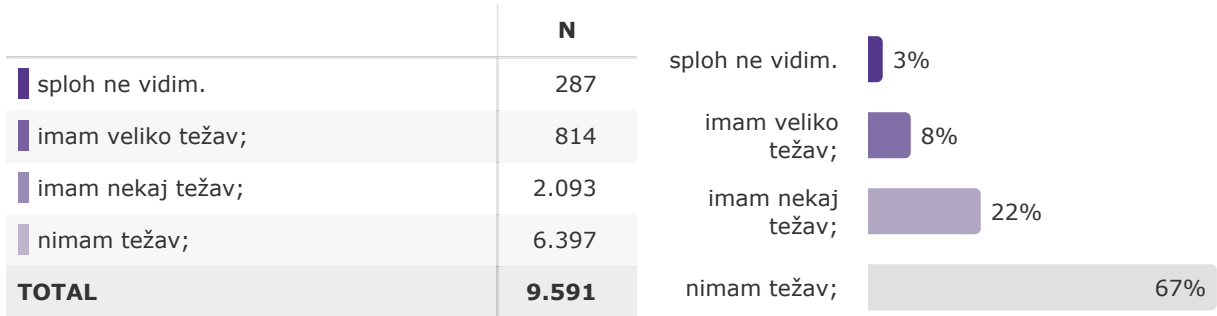
Washington Group Short Set (WG-SS)

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

Imate težave s SKRBJO ZASE, kot so težave z umivanjem ali oblačenjem? Odgovorili bi ...

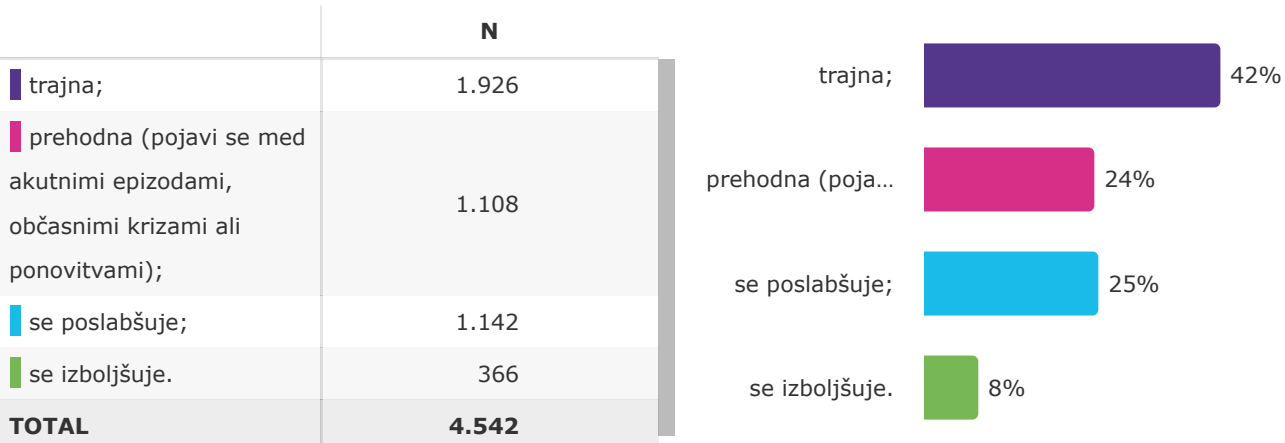


Ali imate pri uporabi svojega jezika težave PRI KOMUNICIRANJU, na primer z razumevanjem ali z biti razumljeni? Odgovorili bi ...

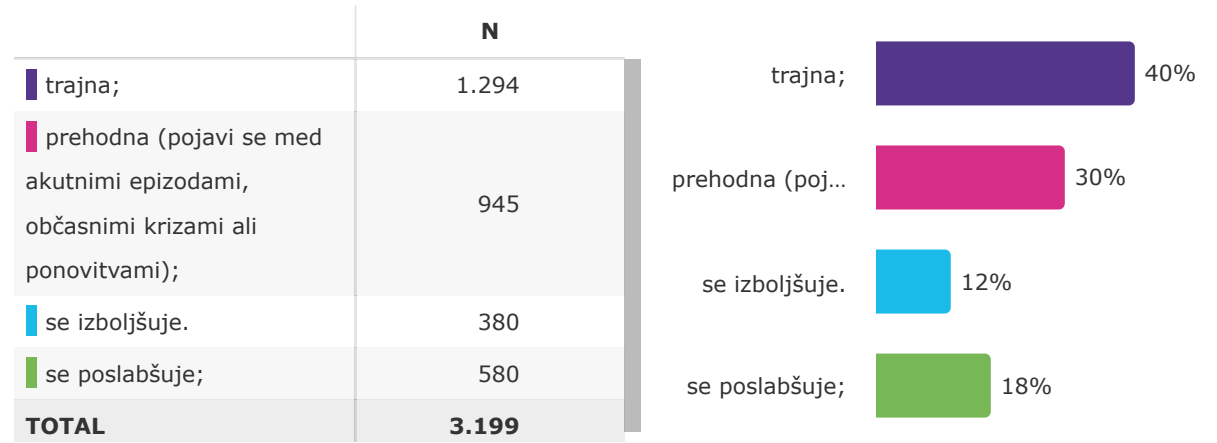


These questions were only asked to people with difficulty.

Ali je težava ...?



Ali je težava ...?



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

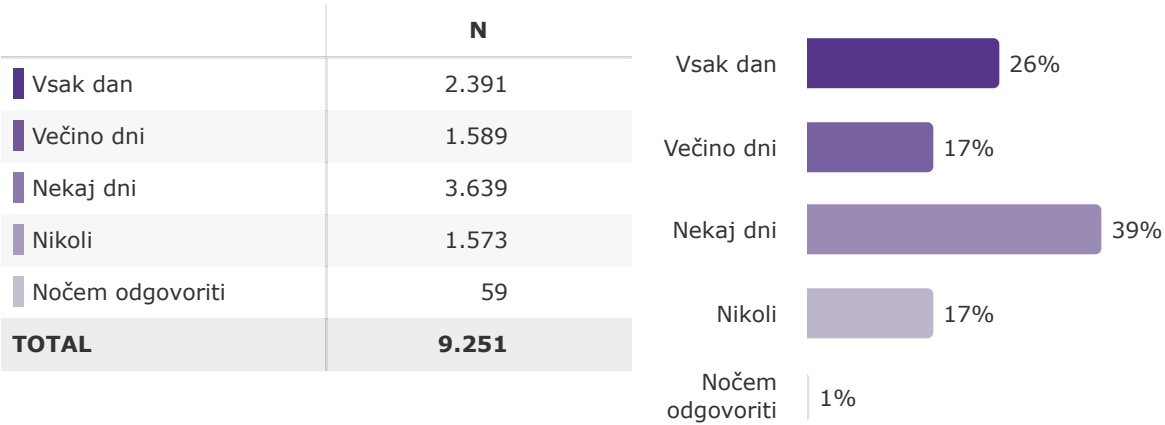
progressive_dynamic

64%

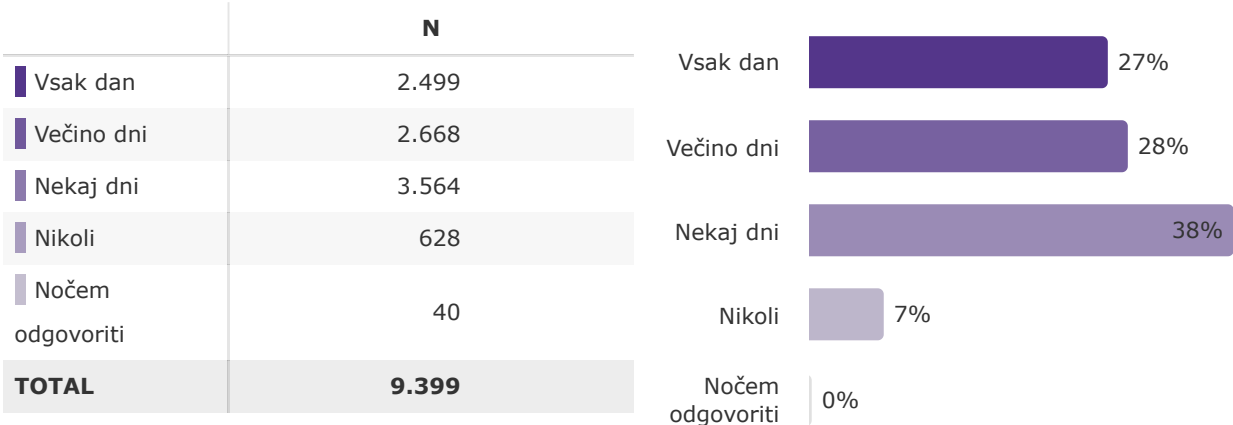
Washington Group Extended Set (WG-ES)

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

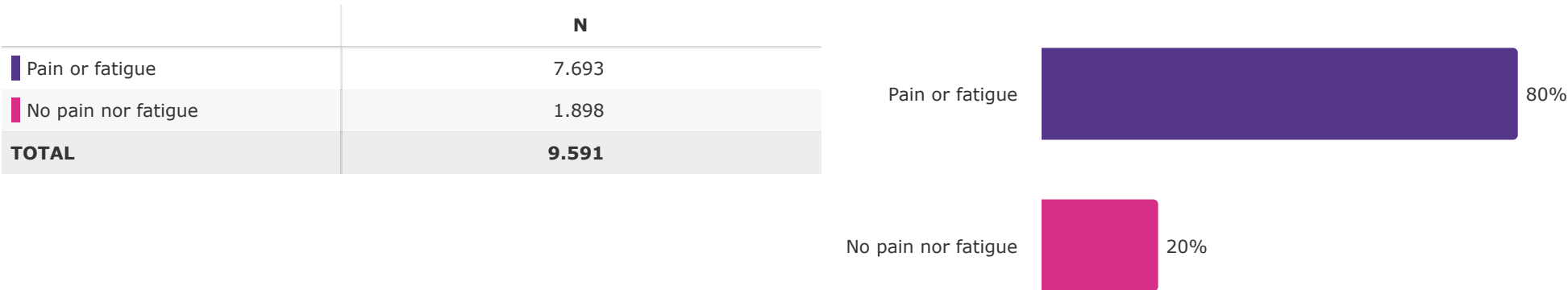
Kako pogosto ste v zadnjih 3 mesecih trpeli **BOLEČINE**? Odgovorili bi ...



Kako pogosto ste se v zadnjih 3 mesecih počutili zelo **UTRUJENI** ali **IZČRPANI**?



Kako pogosto ste se v zadnjih 3 mesecih počutili zelo **UTRUJENI** ali **IZČRPANI**?



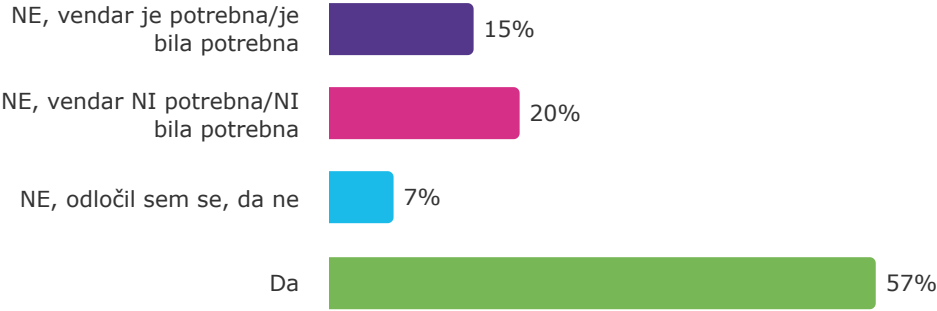


3. DISABILITY RECOGNITION

Disability assessment and barriers

Ali ste že kdaj opravili oceno invalidnosti, katere namen je bil oceniti in prepoznati invalidnost?

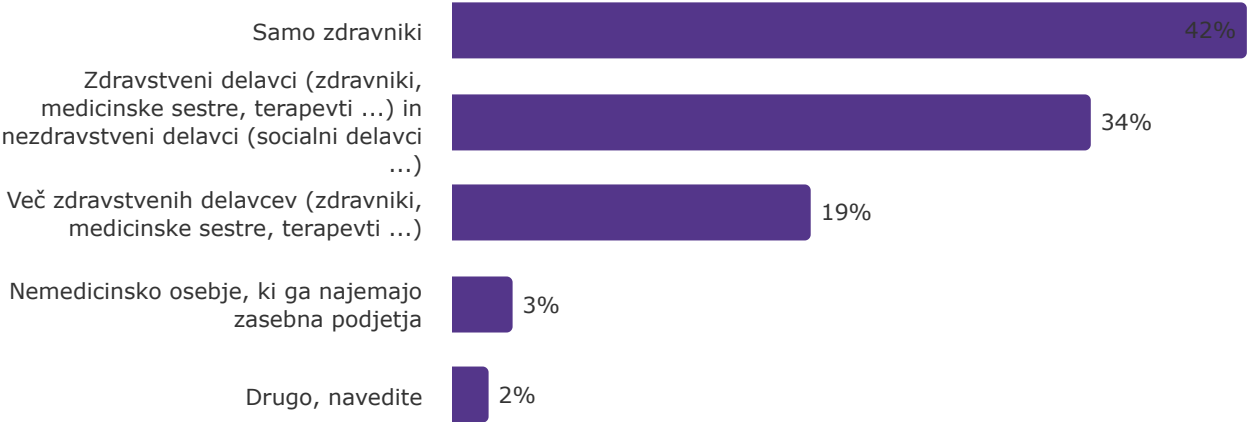
	N	%
NE, vendar je potrebna/je bila potrebna	1.435	15%
NE, vendar NI potrebna/NI bila potrebna	1.878	20%
NE, odločil sem se, da ne	655	7%
Da	5.364	57%



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

Kateri strokovnjaki so sodelovali pri ocenjevanju?

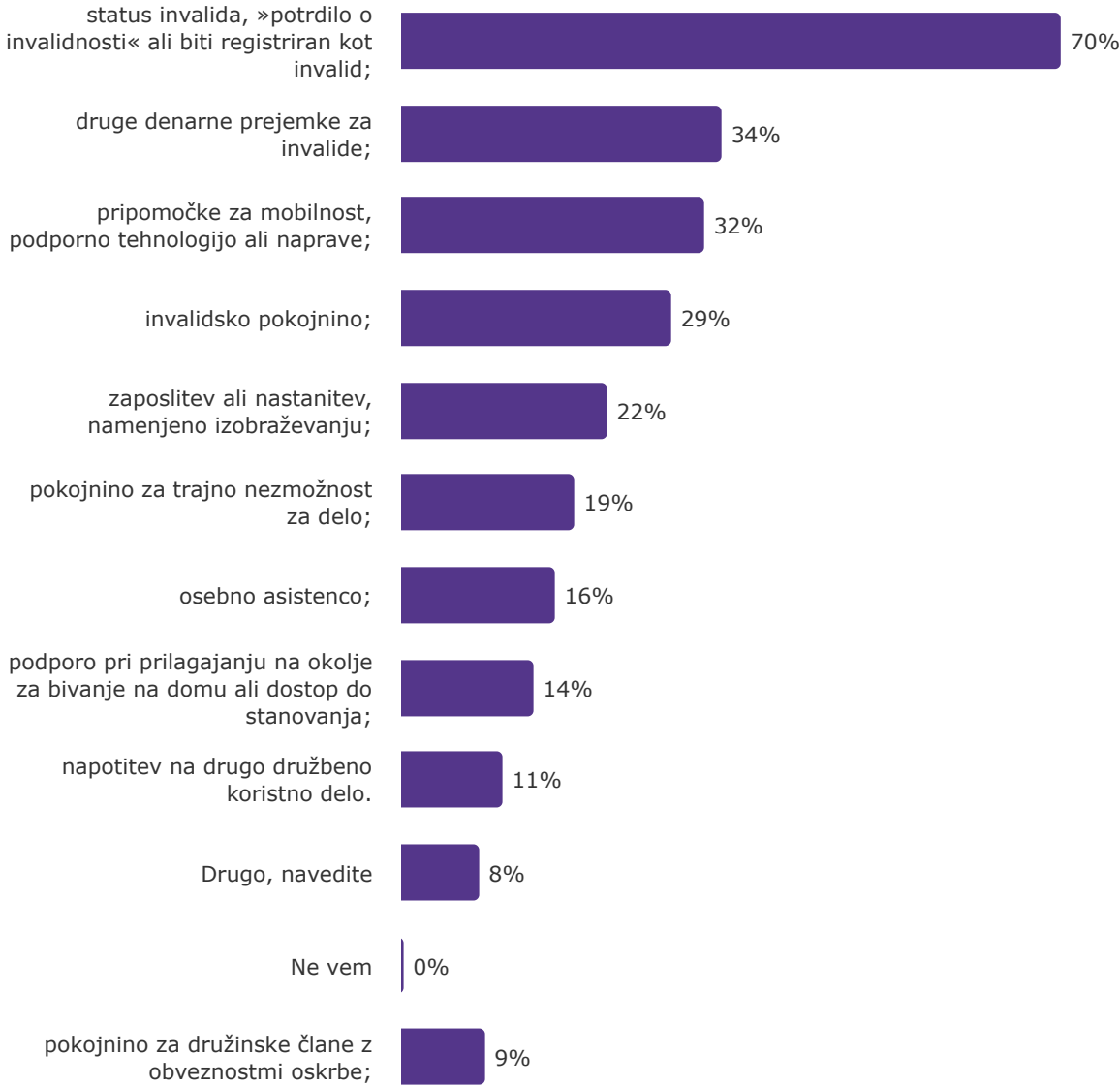
	N	%
Samo zdravniki	2.164	42%
Zdravstveni delavci (zdravniki, medicinske sestre, terapevti ...) in nezdravstveni delavci (socialni delavci ...)	1.742	34%
Več zdravstvenih delavcev (zdravniki, medicinske sestre, terapevti ...)	979	19%
Nemedicinsko osebje, ki ga najemajo zasebna podjetja	168	3%
Drugo, navedite	106	2%
TOTAL	5.159	100%



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

Ali je bil (ali so bili) namen(i) ocene invalidnosti pridobiti ...?

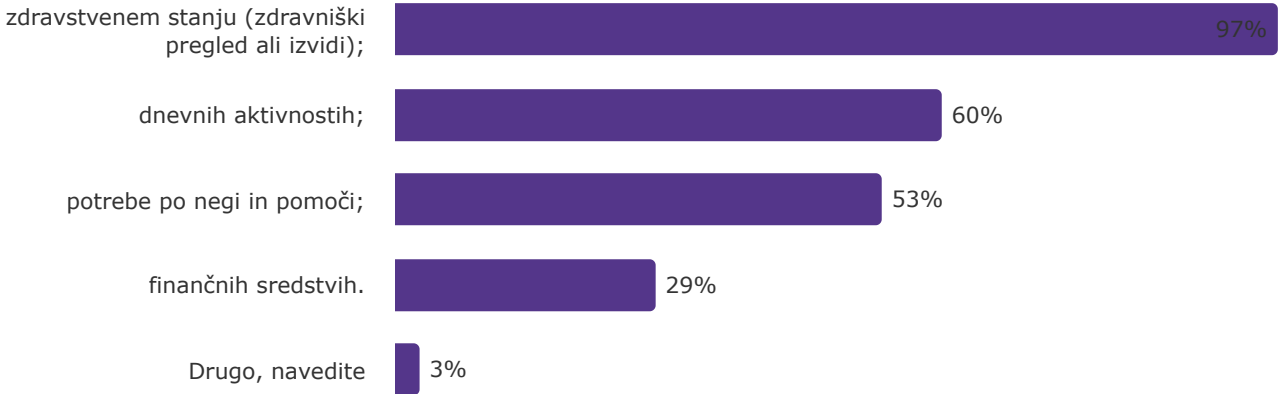
	N	%
status invalida, »potrdilo o invalidnosti« ali biti registriran kot invalid;	1.157	70%
druge denarne prejemke za invalide;	565	34%
pripomočke za mobilnost, podporno tehnologijo ali naprave;	533	32%
invalidsko pokojnino;	476	29%
zaposlitev ali nastanitev, namenjeno izobraževanju;	364	22%
pokojnino za trajno nezmožnost za delo;	307	19%
osebno asistenco;	271	16%
podporo pri prilagajanju na okolje za bivanje na domu ali dostop do stanovanja;	234	14%
napotitev na drugo družbeno koristno delo.	180	11%
Drugo, navedite	140	8%
Ne vem	6	0%
pokojnino za družinske člane z obveznostmi oskrbe;	149	9%
TOTAL	1.651	



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

Ali ste morali med ocenjevanjem predložiti podatke o...?

	N	%
■ zdravstvenem stanju (zdravniški pregled ali izvidi);	5.128	97%
■ dnevnih aktivnostih;	3.176	60%
■ potrebe po negi in pomoči;	2.834	53%
■ finančnih sredstvih.	1.524	29%
■ Drugo, navedite	155	3%
TOTAL	5.306	



Koliko ocen invalidnosti ste opravili?

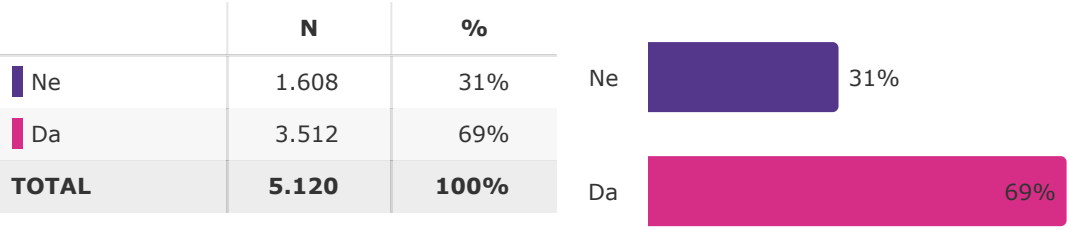
	N	
■ Več kot eno oceno	3.268	Več kot eno oceno 61%
■ Eno oceno	2.089	
TOTAL	5.357	Eno oceno 39%

Ali ste ob zaključku ocene invalidnosti imeli dostop do pričakovanih pravic in pomoči?

	N	
■ Brez dostopa	872	Brez dostopa 16%
■ Delno	2.553	Delno 47%
■ V celoti	1.955	
TOTAL	5.380	V celoti 36%

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

Je bil rezultat ocenjevanja tak, kot ste pričakovali?



This question was only asked to people who answer NO.



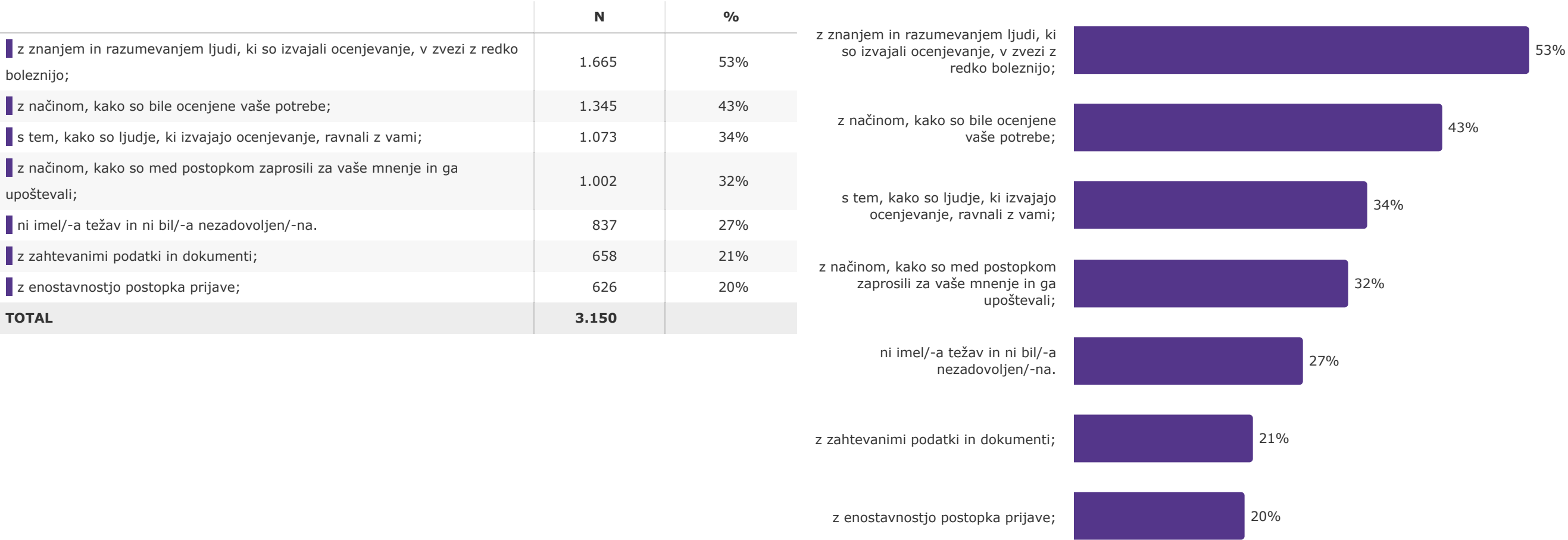
Je bilo po vašem mnenju to zato, ker ...?

	N	%
je bil določen nižji odstotek ali stopnja invalidnosti od pričakovane;	977	61%
so bile potrebe podcenjene.	832	52%
so bile težave pri delu ali opravljanju vsakdanjih dejavnosti podcenjene;	748	47%
je bila zmožnost za delo ali opravljanje vsakdanjih dejavnosti podcenjena;	541	34%
redka bolezen ni bila na seznamu bolezni, upravičenih do ugodnosti;	513	32%
invalidnost ni bila priznana;	406	25%
je bil dostop do potrebne podpore zavrnen;	342	21%
Drugo, navedite	149	9%
Ne vem	13	1%
TOTAL	1.607	



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

Satisfaction with Disability Assessment Process



Sample information : PATIENTvsCARER among "Oseba, ki ima redko bolezen."

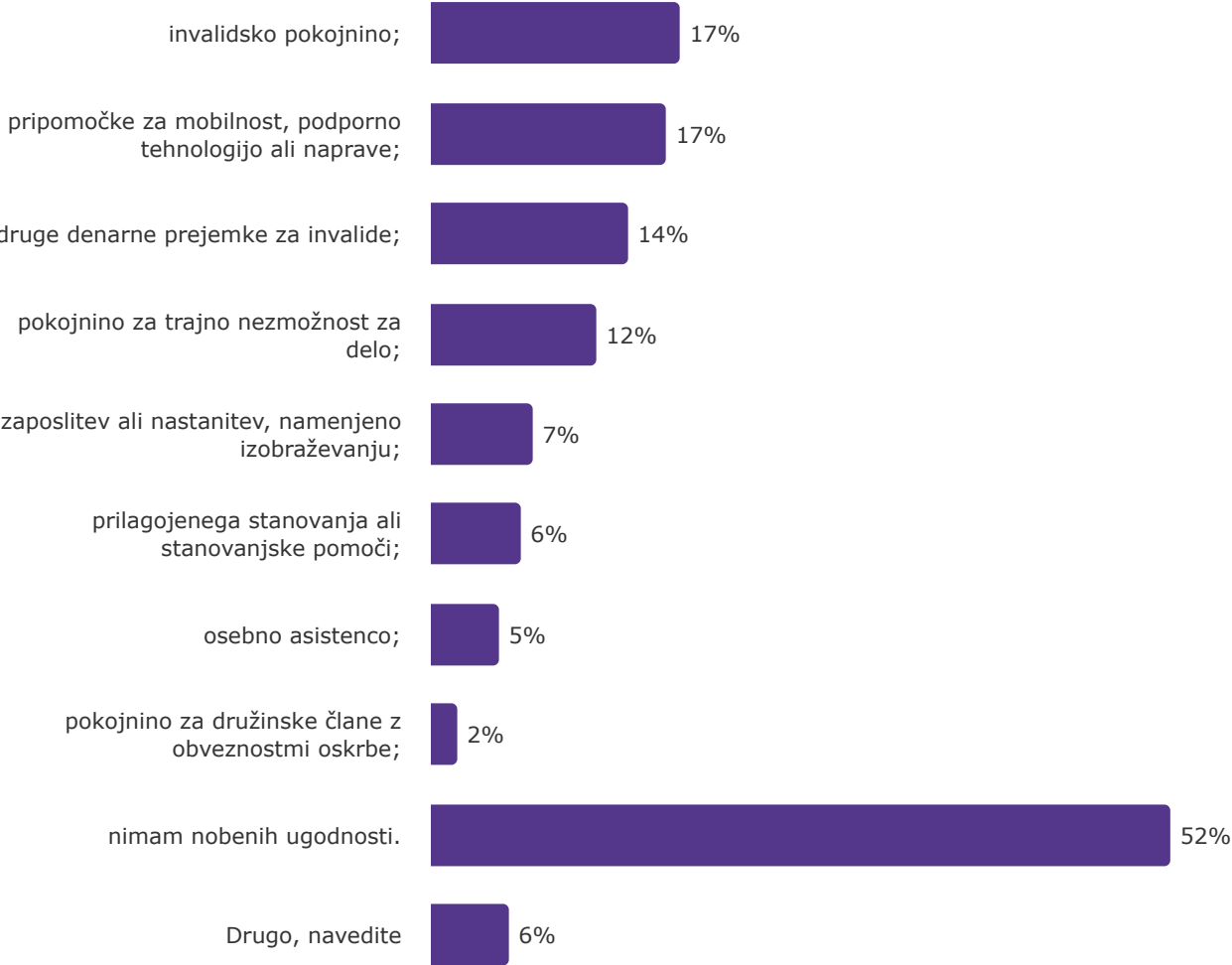


4. INDEPENDENT LIVING

Public support, personal assistant,
living arrangements

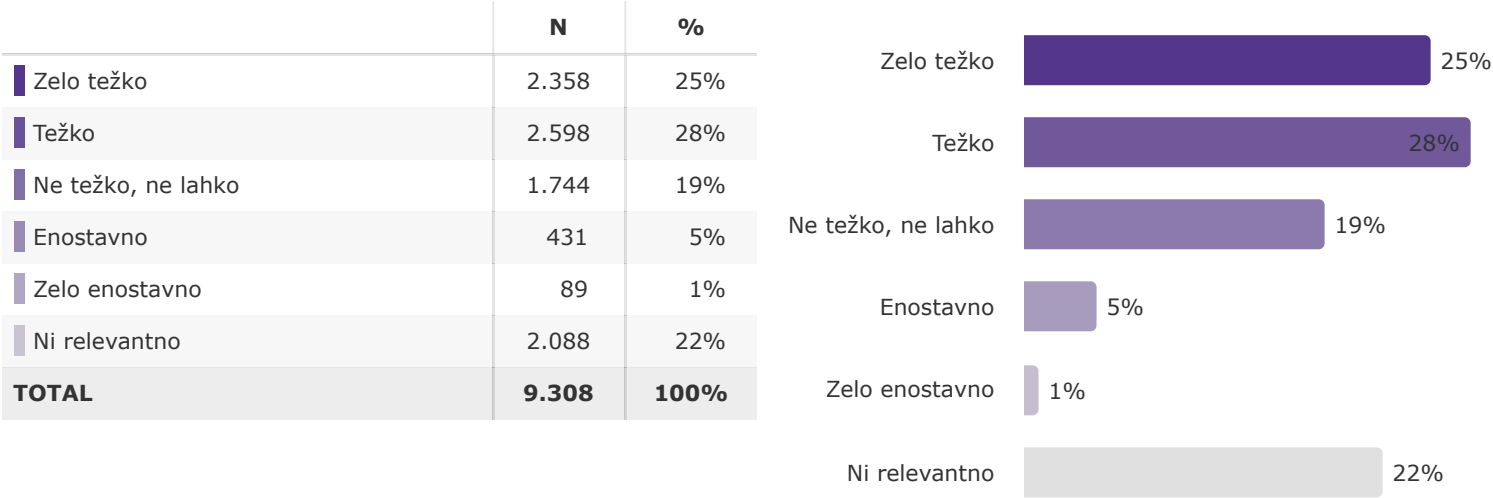
Ali trenutno koristite ugodnosti ...?

	N	%
invalidsko pokojnino;	1.082	17%
pripomočke za mobilnost, podporno tehnologijo ali naprave;	1.024	17%
druge denarne prejemke za invalide;	855	14%
pokojnino za trajno nezmožnost za delo;	719	12%
zaposlitev ali nastanitev, namenjeno izobraževanju;	443	7%
prilagojenega stanovanja ali stanovanjske pomoči;	395	6%
osebno asistenco;	303	5%
pokojnino za družinske člane z obveznostmi oskrbe;	120	2%
nimam nobenih ugodnosti.	3.205	52%
Drugo, navedite	347	6%
TOTAL	6.194	



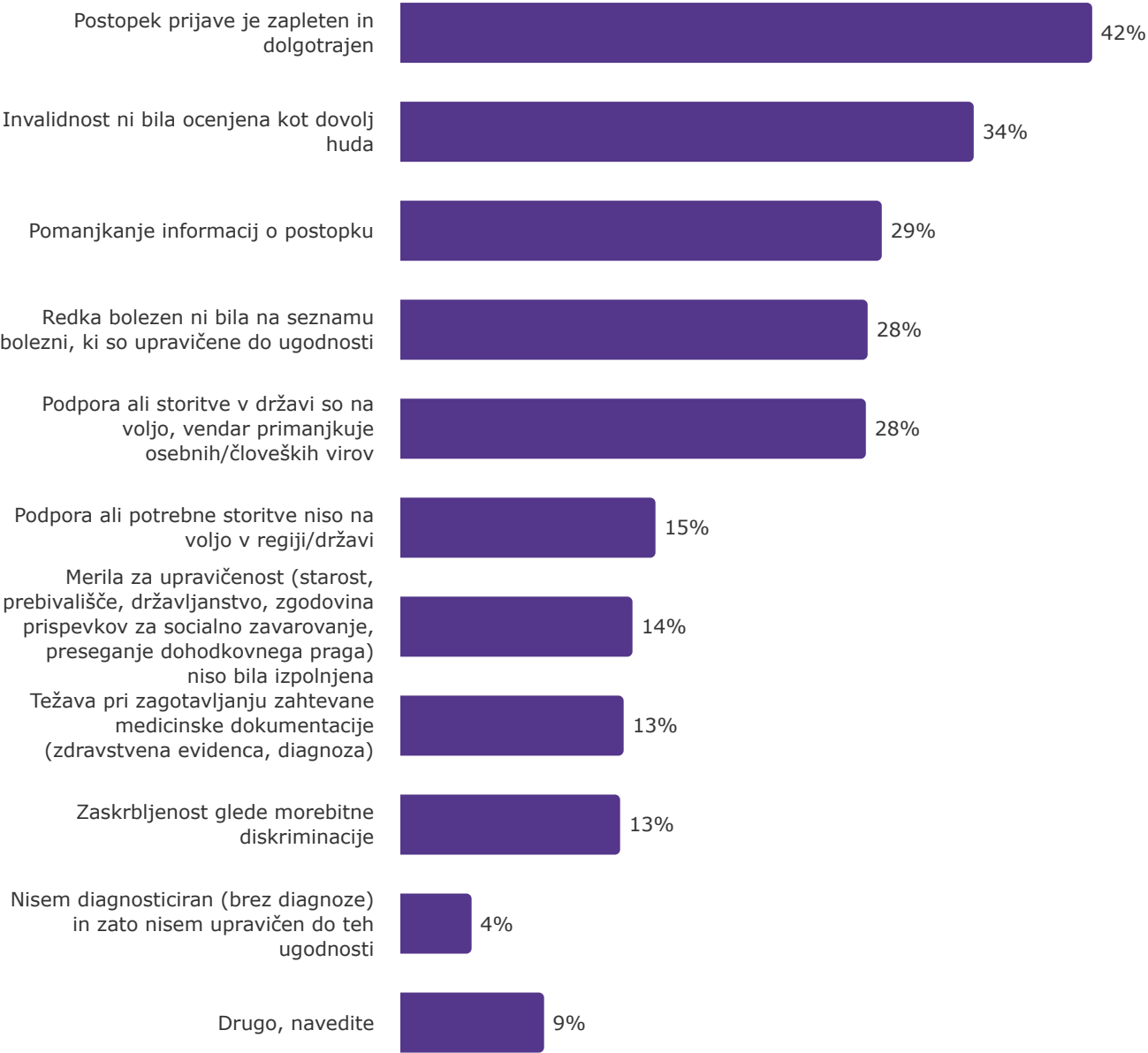
▼ Sample information : PATIENTvsCARER among "Oseba, ki ima redko bolezen."

Kako težko se vam zdi pridobiti državno podporo, kot je oskrba, pomoč na domu, finančna podpora, podporna tehnologija, pripomočki za mobilnost itd.?



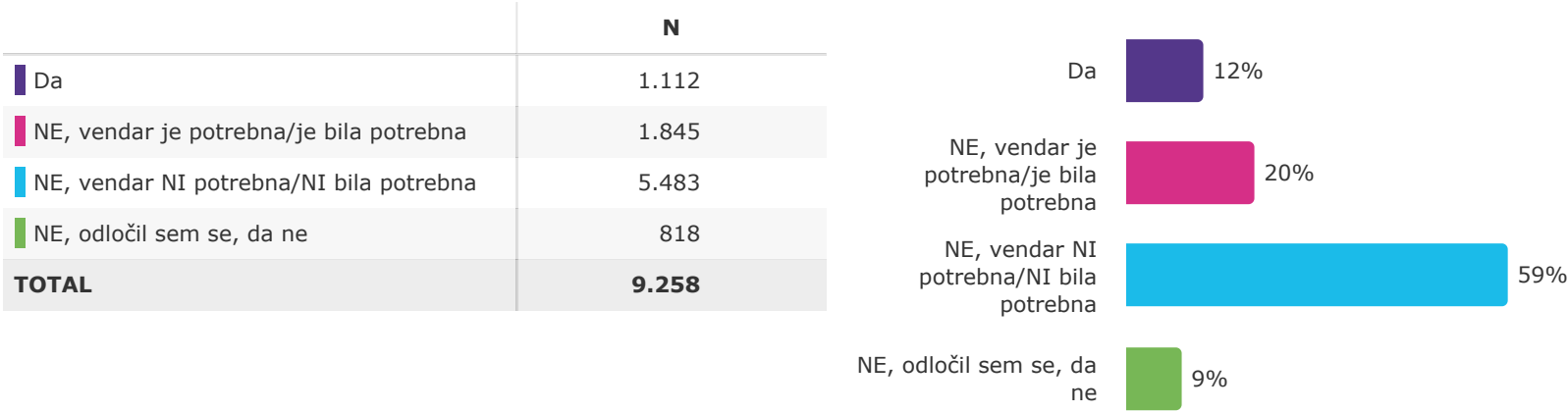
S kakšnimi ovirami se soočate pri pridobivanju podpore, kot je oskrba za nego, pomoč na domu, finančna podpora, podporna tehnologija, pripomočki za mobilnost itd.?

	N
Postopek prijave je zapleten in dolgotrajen	2.923
Invalidnost ni bila ocenjena kot dovolj huda	2.421
Pomanjkanje informacij o postopku	2.038
Redka bolezen ni bila na seznamu bolezni, ki so upravičene do ugodnosti	1.977
Podpora ali storitve v državi so na voljo, vendar primanjkuje osebnih/človeških virov	1.970
Podpora ali potrebne storitve niso na voljo v regiji/državi	1.079
Merila za upravičenost (starost, prebivališče, državljanstvo, zgodovina prispevkov za socialno zavarovanje, preseganje dohodkovnega praga) niso bila izpolnjena	982
Težava pri zagotavljanju zahtevane medicinske dokumentacije (zdravstvena evidenca, diagnoza)	945
Zaskrbljenost glede morebitne diskriminacije	930
Nisem diagnosticiran (brez diagnoze) in zato nisem upravičen do teh ugodnosti	305
Drugo, navedite	613
TOTAL	7.042



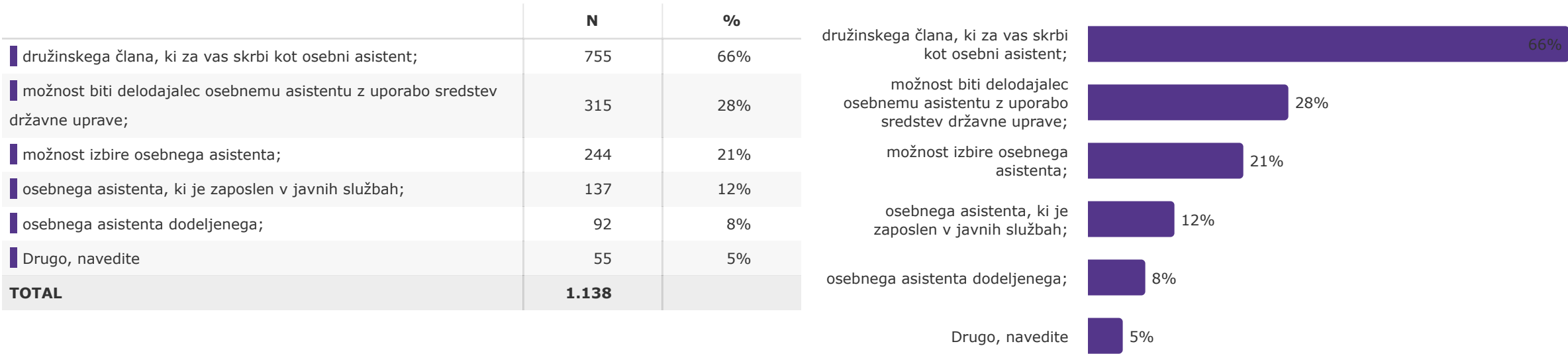
This question was only asked to people who didn't find it very easy to obtain state support.

Ali imate osebnega asistenta, ki vam pomaga živeti samostojno?



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

Ste imeli oz. imate ...?



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

Koliko ur osebne asistence trenutno prejema na dan?

10,9

Mean

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

5,4

Mean

Koliko ur osebne asistence trenutno prejema na dan?

7,0

Median

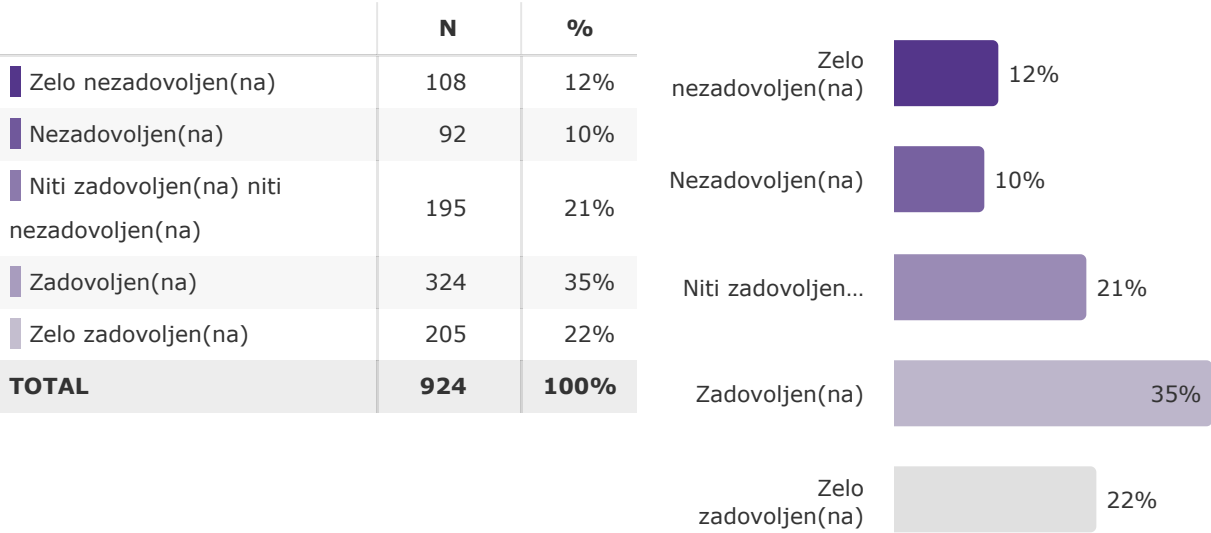
How many days of personal assistance do they currently have per week?

7,0

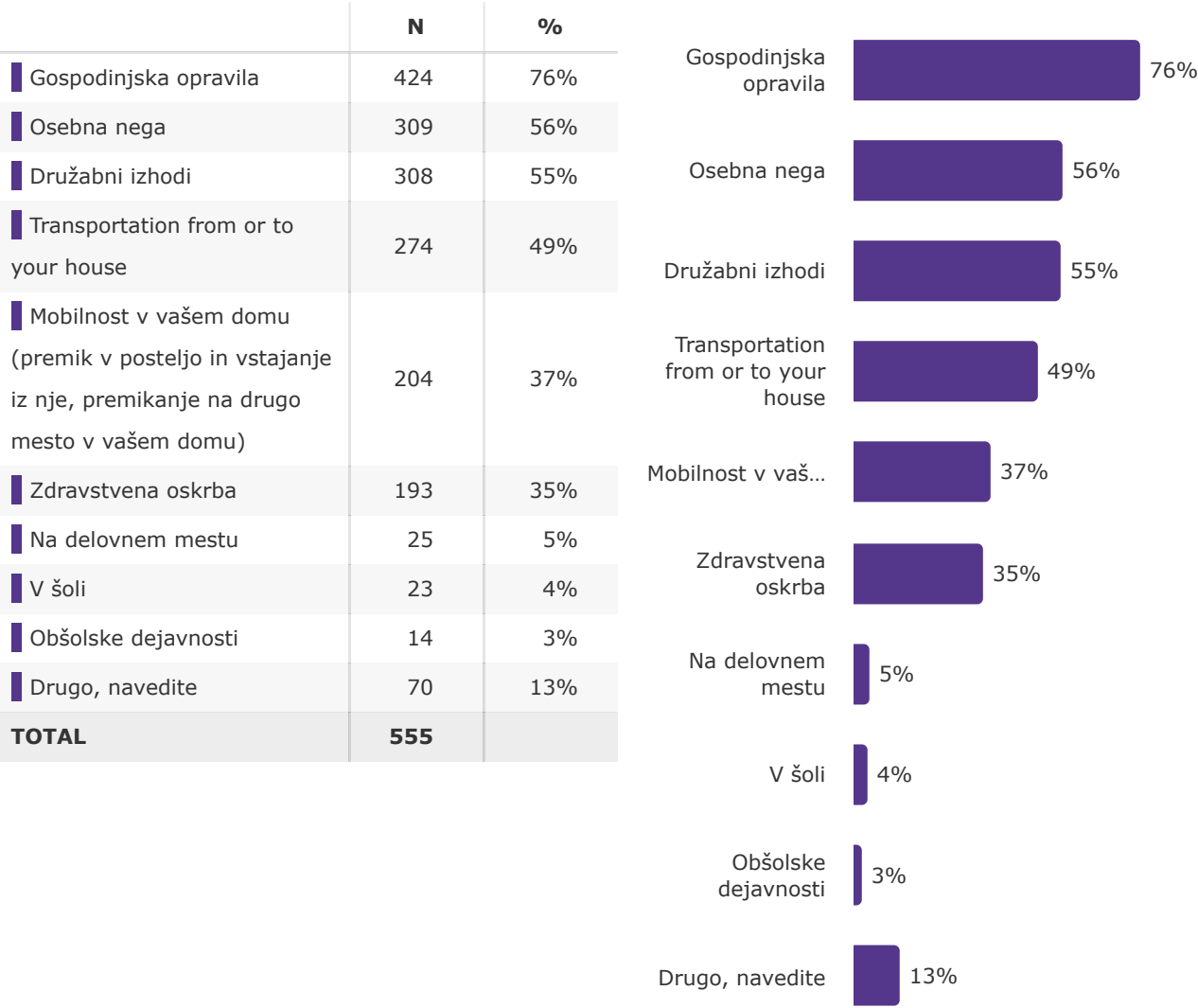
Median

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

Ali ste zadovoljni s številom ur osebne asistence?



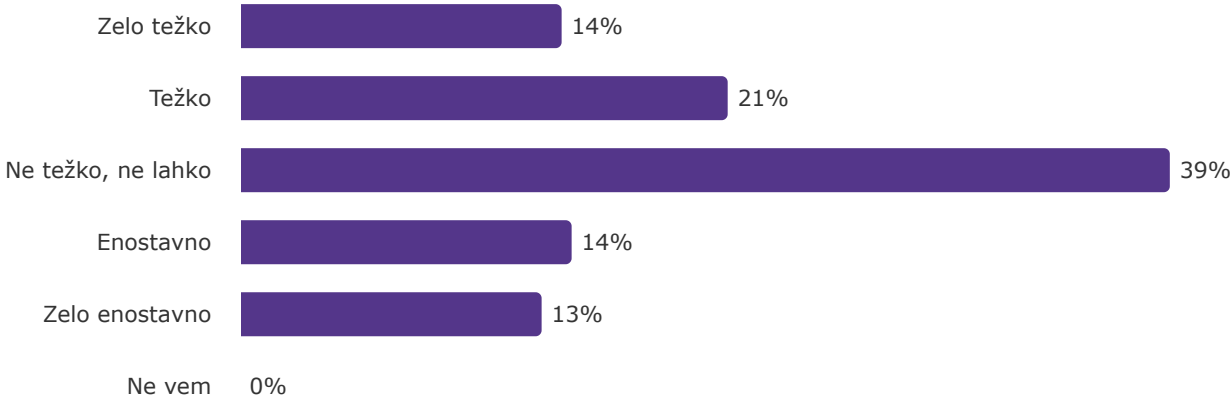
Pri katerih nalogah trenutno pomaga osebni asistent?



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

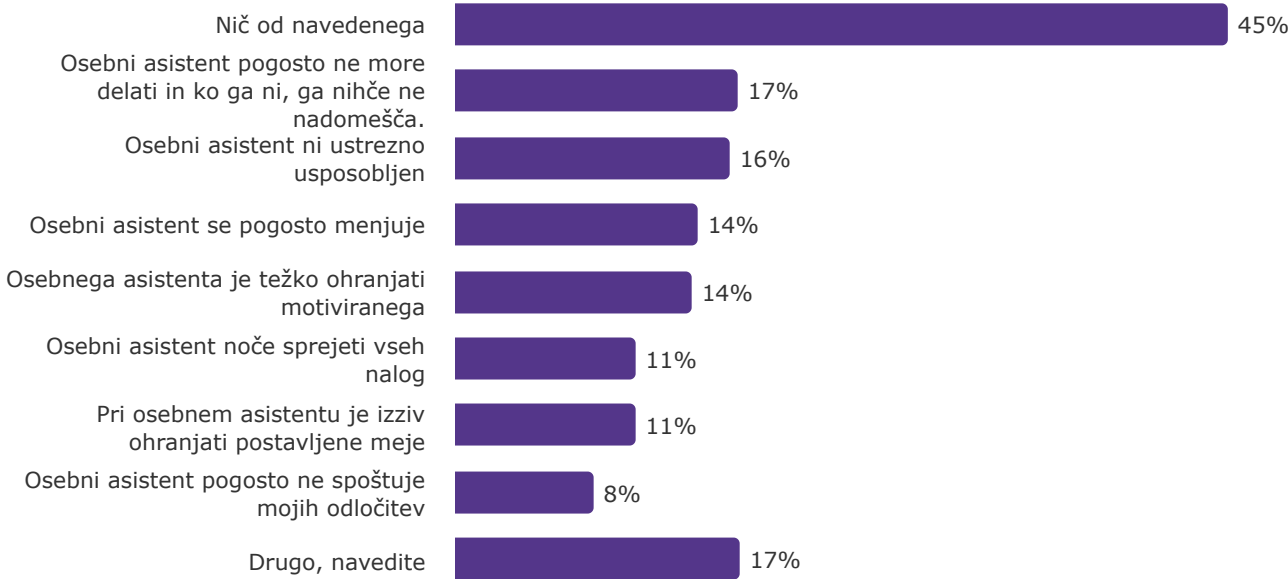
Kako težko se vam zdi delo z osebnim asistentom (zaposlovanje, upravljanje, plačilo)?

	N	%
Zelo težko	62	14%
Težko	94	21%
Ne težko, ne lahko	179	39%
Enostavno	64	14%
Zelo enostavno	58	13%
Ne vem	0	0%
TOTAL	457	100%



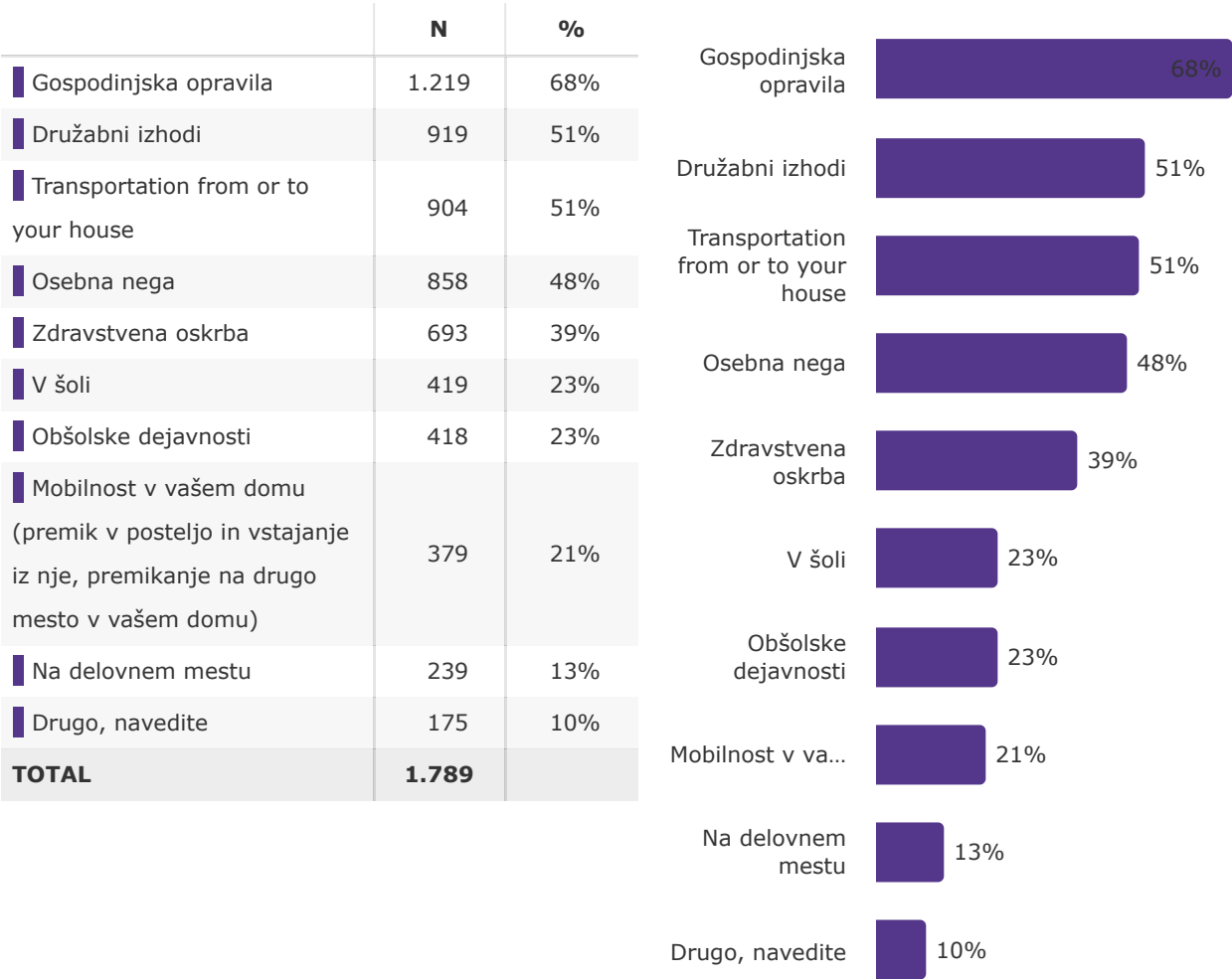
Kakšne izzive prinaša osebni asistent?

	N	%
Nič od navedenega	456	45%
Osebni asistent pogosto ne more delati in ko ga ni, ga nihče ne nadomešča.	167	17%
Osebni asistent ni ustrezno usposobljen	163	16%
Osebni asistent se pogosto menjuje	144	14%
Osebnega asistenta je težko ohranjati motiviranega	140	14%
Osebni asistent noče sprejeti vseh nalog	107	11%
Pri osebnem asistentu je izziv ohranjati postavljene meje	107	11%
Osebni asistent pogosto ne spoštuje mojih odločitev	82	8%
Drugo, navedite	168	17%
TOTAL	1.006	

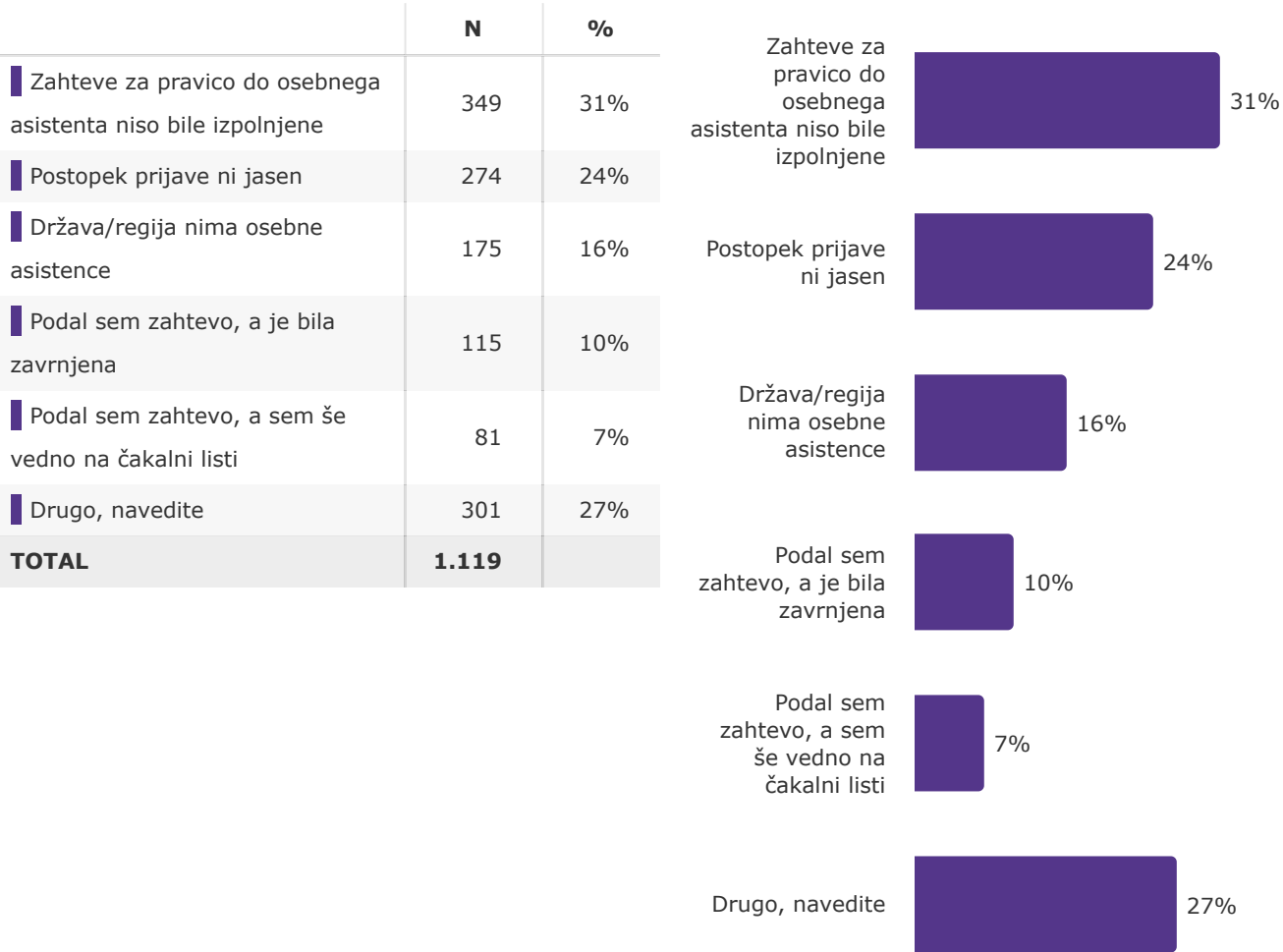


This question was only asked to people who do not have a personal assistant but need one.

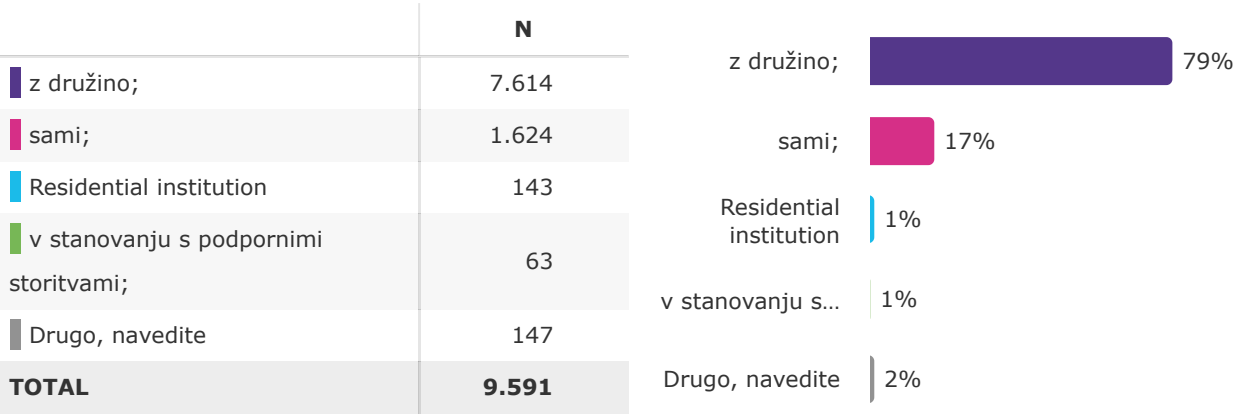
Pri katerih nalogah bi potrebovali asistenco?



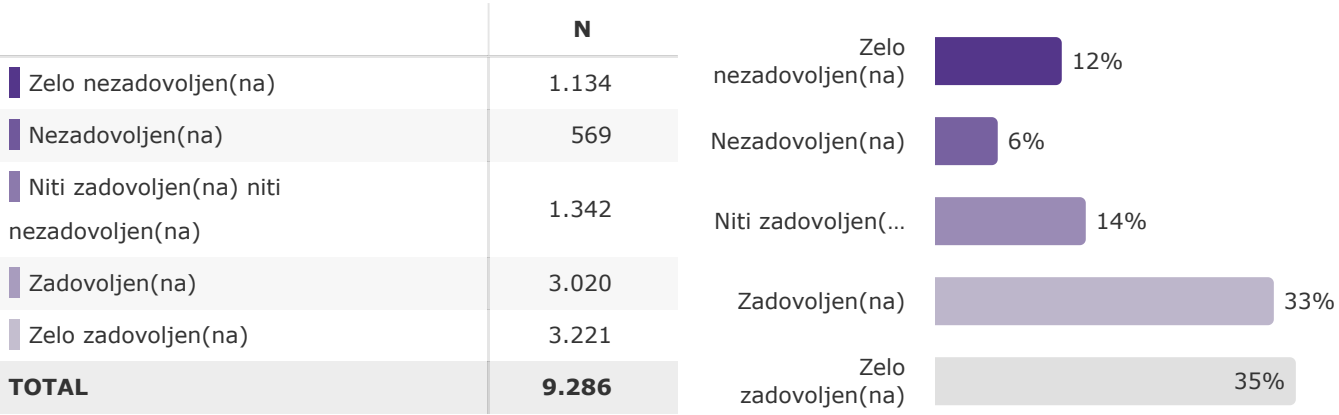
Kaj so razlogi, da nimate osebnega asistenta?



Živite ...



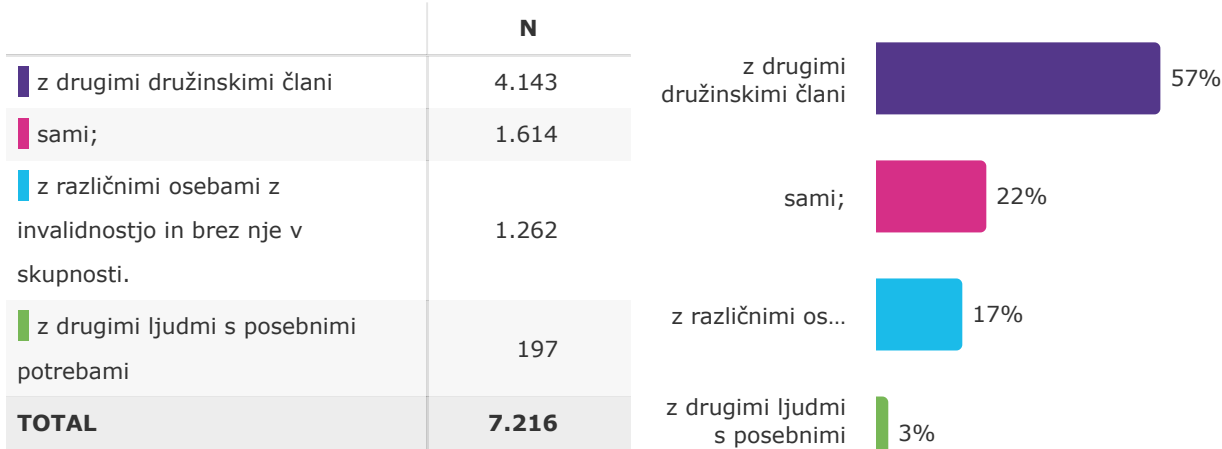
Ali ste zadovoljni s trenutno ureditvijo bivanja?



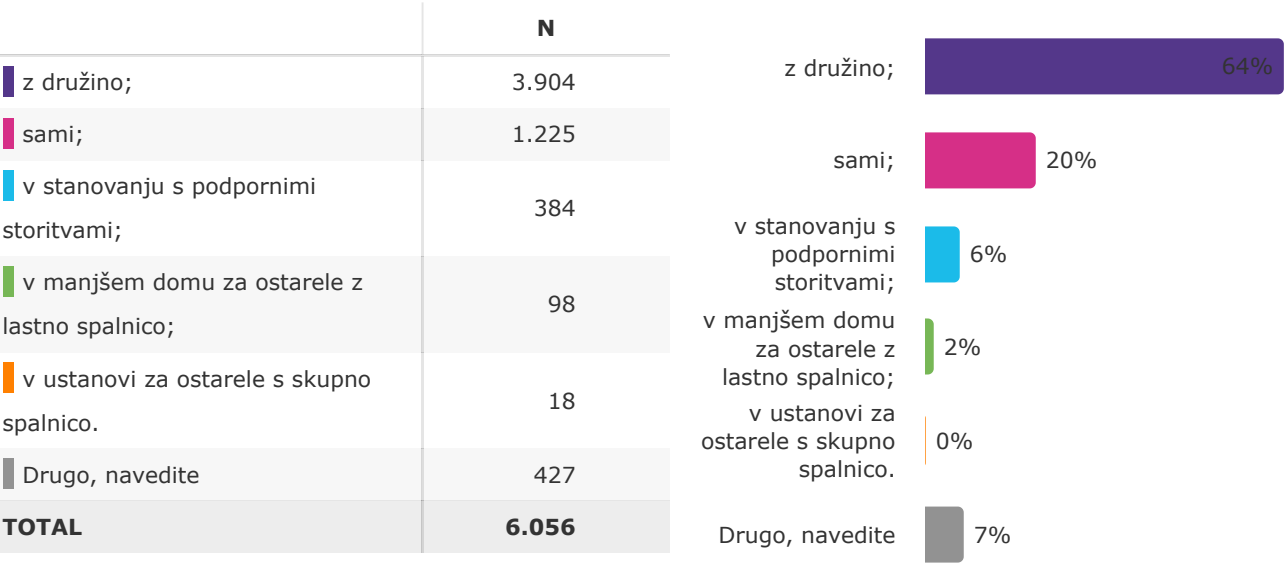
This question were only asked to people that consider themselves as living with disabilities.

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

Ali večino dneva preživite ...?



Bi raje živeli ...?



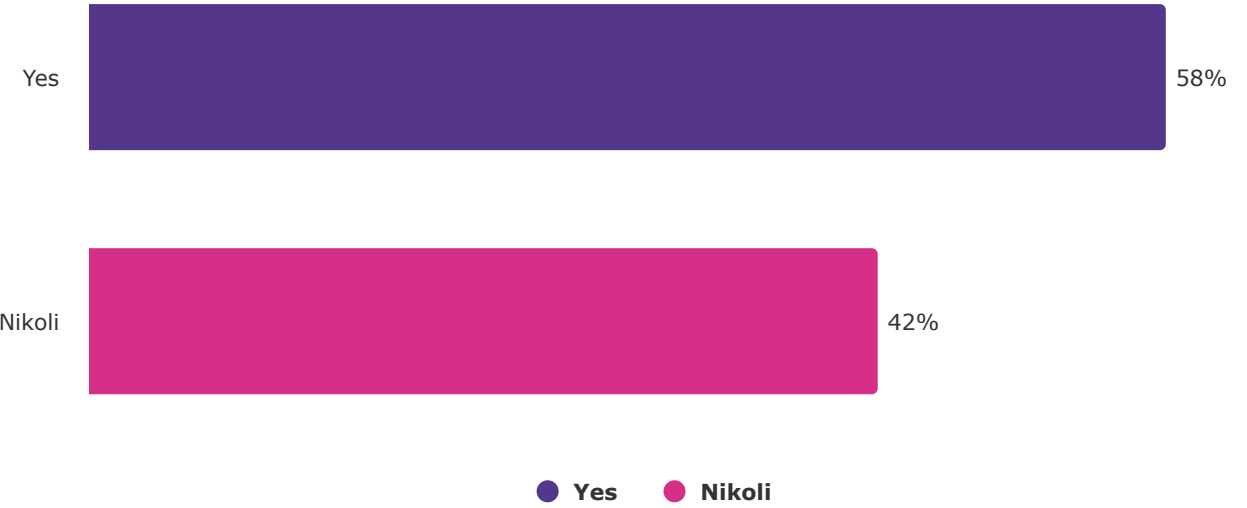


5. SOCIAL PARTICIPATION

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

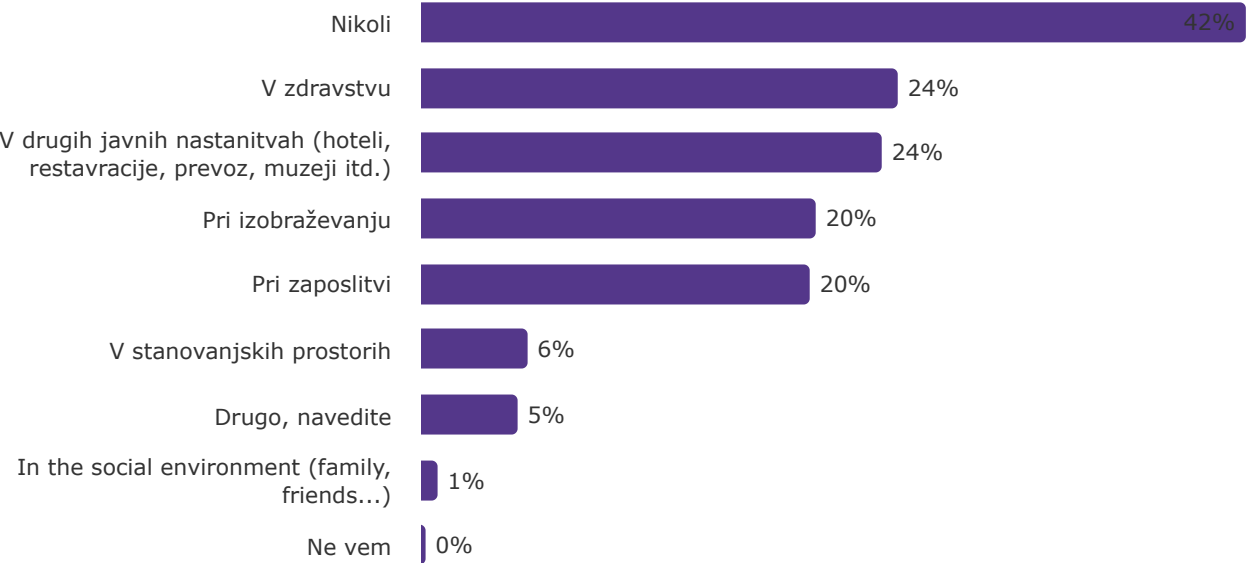
Ali ste kdaj doživeli diskriminacijo v zvezi z redko boleznijo ali invalidnostjo?

	N	%
▼ Yes	5.270	58%
V zdravstvu	2.234	24%
V drugih javnih nastanitvah (hoteli, restavracije, prevoz, muzeji itd.)	2.158	24%
Pri izobraževanju	1.850	20%
Pri zaposlitvi	1.822	20%
V stanovanjskih prostorih	506	6%
Drugo, navedite	454	5%
In the social environment (family, friends...)	83	1%
█ Nikoli	3.860	42%
TOTAL	9.126	



Ali ste kdaj doživeli diskriminacijo v zvezi z redko boleznijo ali invalidnostjo?

	N	%
█ Nikoli	3.860	42%
V zdravstvu	2.234	24%
V drugih javnih nastanitvah (hoteli, restavracije, prevoz, muzeji itd.)	2.158	24%
Pri izobraževanju	1.850	20%
Pri zaposlitvi	1.822	20%
V stanovanjskih prostorih	506	6%
Drugo, navedite	454	5%
In the social environment (family, friends...)	83	1%
Ne vem	25	0%
TOTAL	9.150	



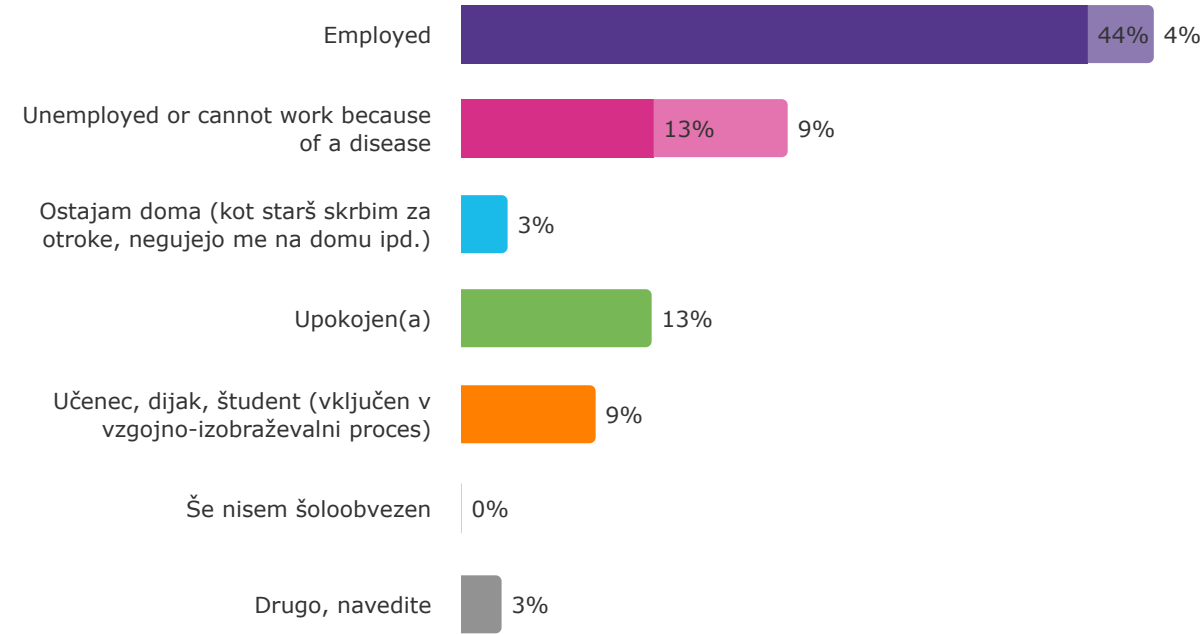


5.2. EMPLOYMENT

Employment and unemployment

Kakšna je vaša trenutna situacija?

	N	%
▼ Employed	2.567	48%
Zaposlen(a)	2.329	44%
Samozaposlen(a)	238	4%
▼ Unemployed or cannot work because of a disease	1.216	23%
Brezposeln(-na)	716	13%
Cannot work because of the disease	500	9%
Ostajam doma (kot starš skrbim za otroke, neguj...	177	3%
Upokojen(a)	714	13%
Učenec, dijak, študent (vključen v vzgojno-izobra...	500	9%
Še nisem šoloobvezen	4	0%
Drugo, navedite	154	3%
TOTAL	5.332	100%

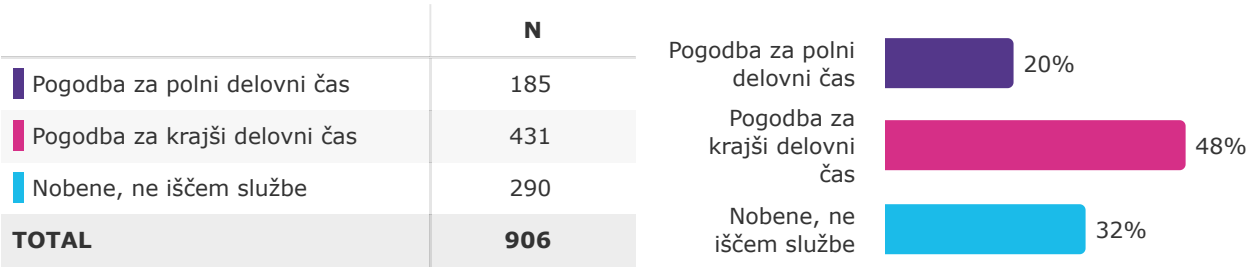


- Zaposlen(a)
- Samozaposlen(a)
- Brezposeln(-na)
- Cannot work because of the disease
- Ostajam doma (kot starš skrbim za otroke, negujejo me na domu ipd.)
- Upokojen(a)
- Učenec, dijak, študent (vključen v vzgojno-izobraževalni proces)
- Še nisem šoloobvezen
- Drugo, navedite

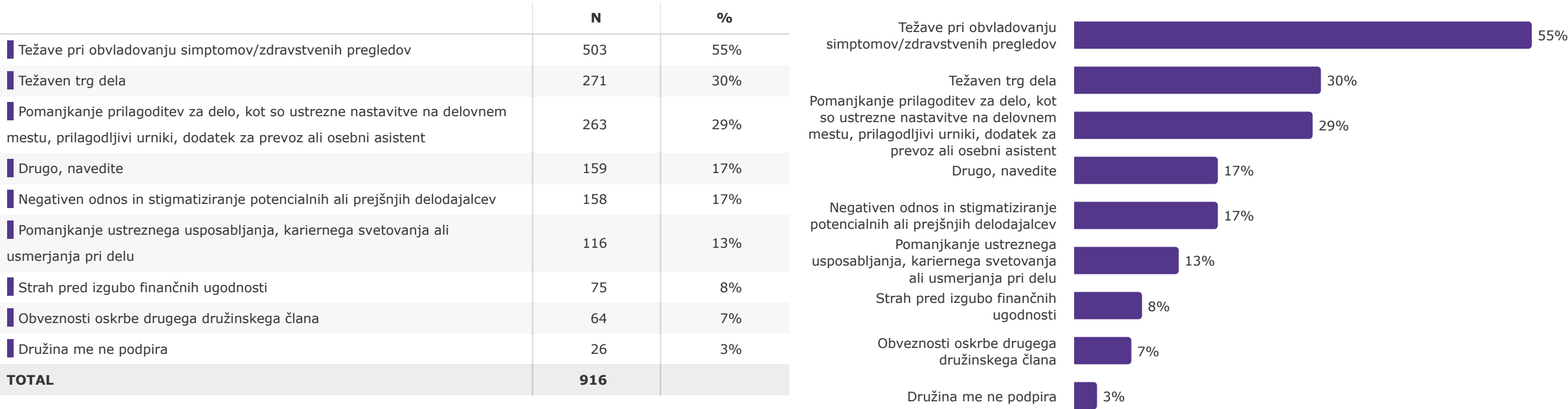
▼ Sample information : Age_patient between 16 and 64

These questions were only asked to unemployed respondents.

Kakšno pogodbo o zaposlitvi bi izbrali, če bi se zaposlili?

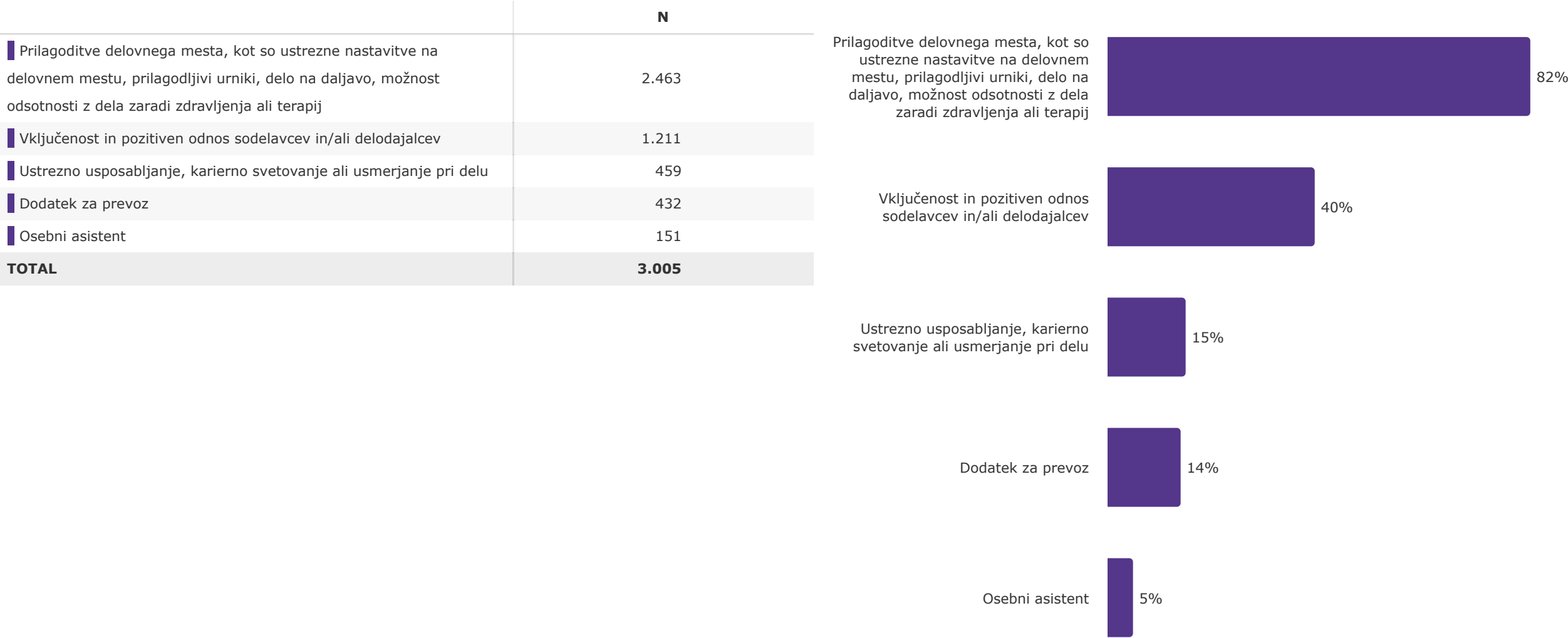


Kakšni so vaši razlogi za trenutno brezposelnost?



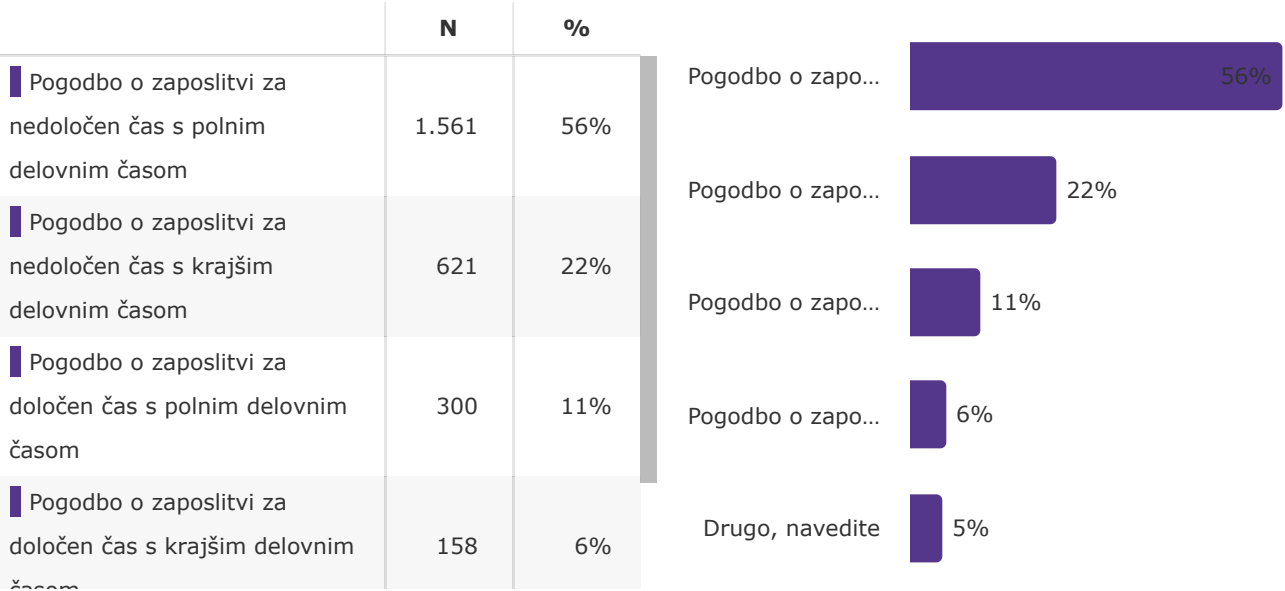
This question was only asked to respondents who are currently employed.

Katera podpora pri zaposlovanju in prilagoditve na delovnem mestu lahko po vašem mnenju izboljšata vaše poklicno življenje?

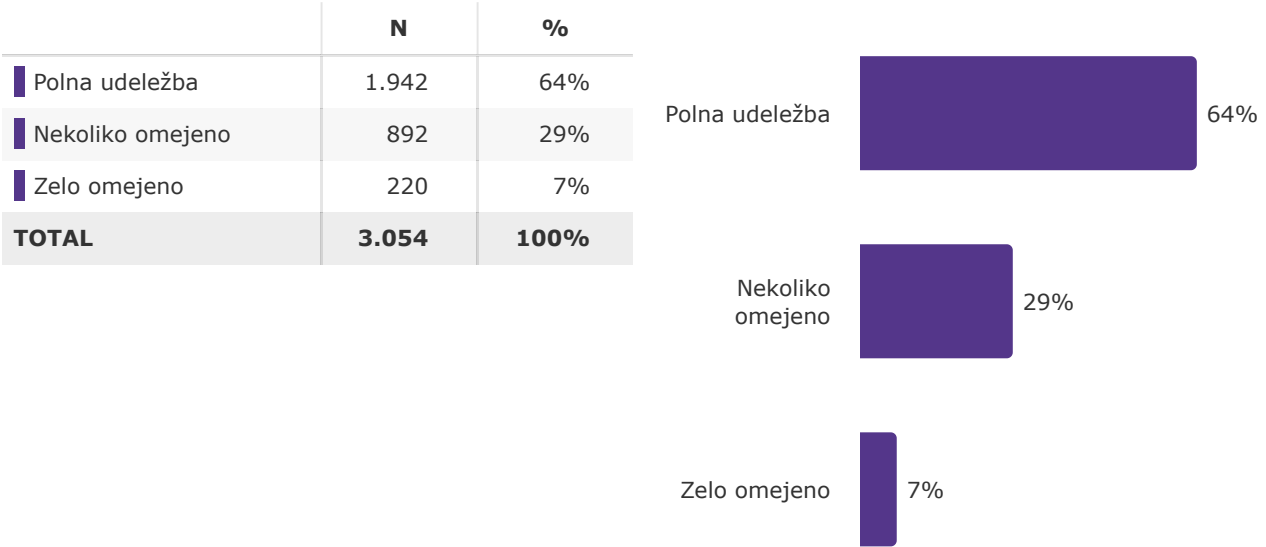


This question was only asked to respondents who are currently employed.

Kakšno vrsto pogodbe imate?



Kakšna je vaša trenutna stopnja udeležbe na delovnem mestu?



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

Ali ste zaposleni?

	N	%
Ste redno zaposleni (delo v organizaciji, ki zaposluje osebe z invalidnostjo in brez nje, brez podpore ali prilagoditev delovnega mesta)	2.199	73%
Ste redno zaposleni s podporo ali prilagoditvami delovnega mesta (delo v organizaciji, ki zaposluje osebe z invalidnostjo in brez nje, s podporo ali prilagoditvami delovnega mesta glede na osebno situacijo).	735	24%
Ste v posebni zaposlitvi (organizacije, ki zaposlujejo večinoma invalide)	75	2%
TOTAL	3.009	100%

Ste redno zaposleni (delo v organizaciji, ki zaposluje osebe z invalidnostjo in brez nje, brez podpore ali prilagoditev delovnega mesta)



73%

Ste redno zaposleni s podporo ali prilagoditvami delovnega mesta (delo v organizaciji, ki zaposluje osebe z invalidnostjo in brez nje, s podporo ali prilagoditvami delovnega mesta glede na osebno situacijo).



24%

Ste v posebni zaposlitvi (organizacije, ki zaposlujejo večinoma invalide)



2%

Bi raje delali ...

	N	%
Ste redno zaposleni (delo v organizaciji, ki zaposluje osebe z invalidnostjo in brez nje, brez podpore ali prilagoditev delovnega mesta)	990	33%
Ste redno zaposleni s podporo ali prilagoditvami delovnega mesta (delo v organizaciji, ki zaposluje osebe z invalidnostjo in brez nje, s podporo ali prilagoditvami delovnega mesta glede na osebno situacijo).	1.175	39%
Ste v posebni zaposlitvi (organizacije, ki zaposlujejo večinoma invalide)	120	4%
Ničemur ne dajem prednosti	732	24%
TOTAL	3.017	100%

Ste redno zaposleni (delo v organizaciji, ki zaposluje osebe z invalidnostjo in brez nje, brez podpore ali prilagoditev delovnega mesta)



33%

Ste redno zaposleni s podporo ali prilagoditvami delovnega mesta (delo v organizaciji, ki zaposluje osebe z invalidnostjo in brez nje, s podporo ali prilagoditvami delovnega mesta glede na osebno situacijo).



39%

Ste v posebni zaposlitvi (organizacije, ki zaposlujejo večinoma invalide)



4%

Ničemur ne dajem prednosti



24%

▼ Sample information : Situation_m among "Zaposlen(a);Samozaaposlen(a)"

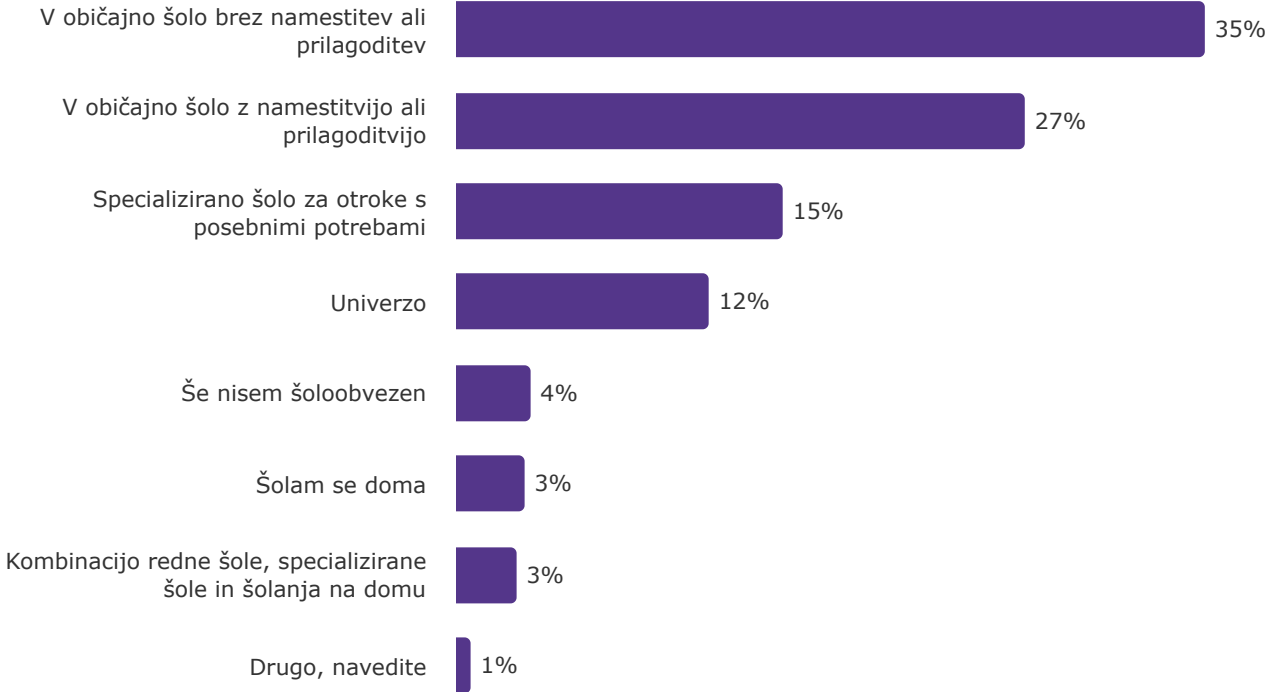


5.3. SCHOOL PARTICIPATION

This question was only asked to students/pupils

Ali obiskujete ...

	N
V običajno šolo brez namestitev ali prilagoditev	662
V običajno šolo z namestitvijo ali prilagoditvijo	504
Specializirano šolo za otroke s posebnimi potrebami	290
Univerzo	224
Še nisem šoloobvezen	67
Šolam se doma	62
Kombinacijo redne šole, specializirane šole in šolanja na domu	54
Drugo, navedite	14
TOTAL	1.877



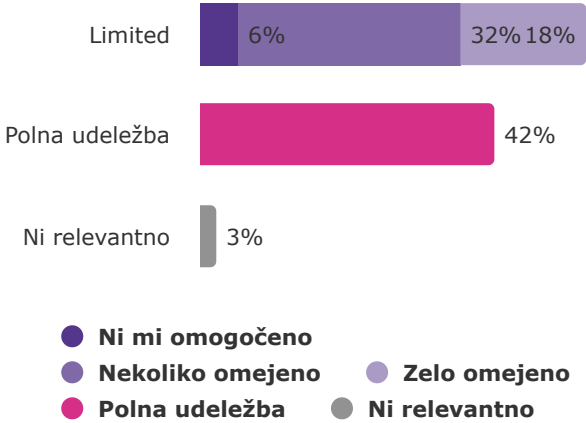


5.4. COMMUNITY PARTICIPATION

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

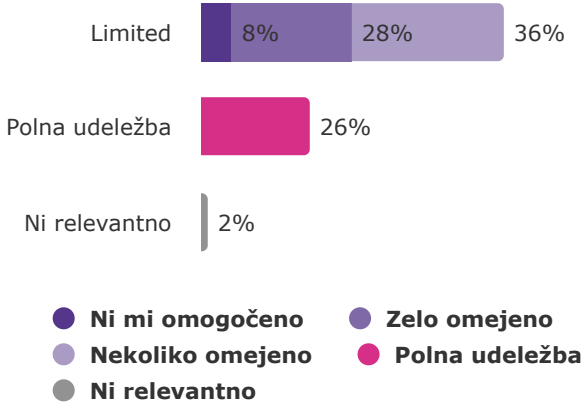
Compared to other people the same age, what is your current level of participation in educational (academic) activities with other students in the classroom?

	N	%
▼ Limited	958	55%
Ni mi omogočeno	99	6%
Nekoliko omejeno	547	32%
Zelo omejeno	312	18%
Polna udeležba	732	42%
Ni relevantno	46	3%
TOTAL	1.736	100%



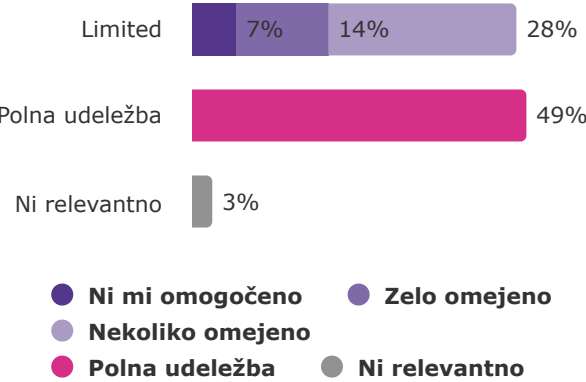
Compared to other people the same age, what is your current level of participation in social, play and recreational activities with other students (e.g., "hanging out", sports, clubs, hobbies, creative arts, lunchtime or recess activities)?

	N	%
▼ Limited	1.250	72%
Ni mi omogočeno	134	8%
Zelo omejeno	494	28%
Nekoliko omejeno	622	36%
Polna udeležba	454	26%
Ni relevantno	36	2%
TOTAL	1.748	100%



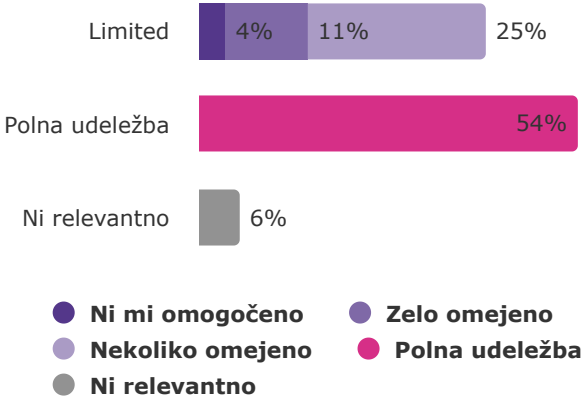
Compared to other people the same age, what is your current level of participation in moving around at school/university (e.g., to get to and use the bathroom, playground, cafeteria, library or other rooms and things that are available to other students the same age)?

	N	%
▼ Limited	834	48%
Ni mi omogočeno	116	7%
Zelo omejeno	237	14%
Nekoliko omejeno	481	28%
Polna udeležba	855	49%
Ni relevantno	54	3%
TOTAL	1.743	100%



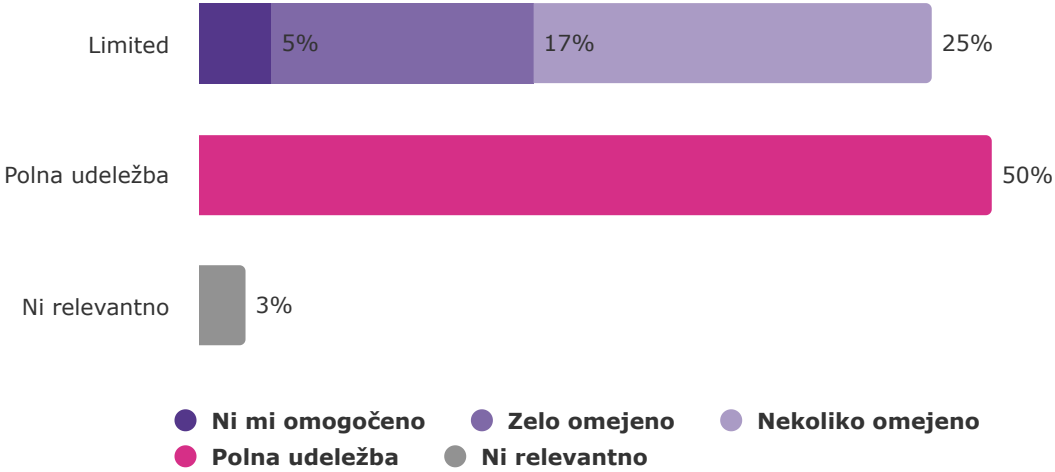
Uporaba izobraževalnih gradiv in opreme, ki je na voljo drugim sošolcem ali ki je bila prirejena za vas (npr. knjige, računalniki, stoli in mize)?

	N	%
▼ Limited	698	41%
Ni mi omogočeno	68	4%
Zelo omejeno	197	11%
Nekoliko omejeno	433	25%
Polna udeležba	922	54%
Ni relevantno	103	6%
TOTAL	1.723	100%



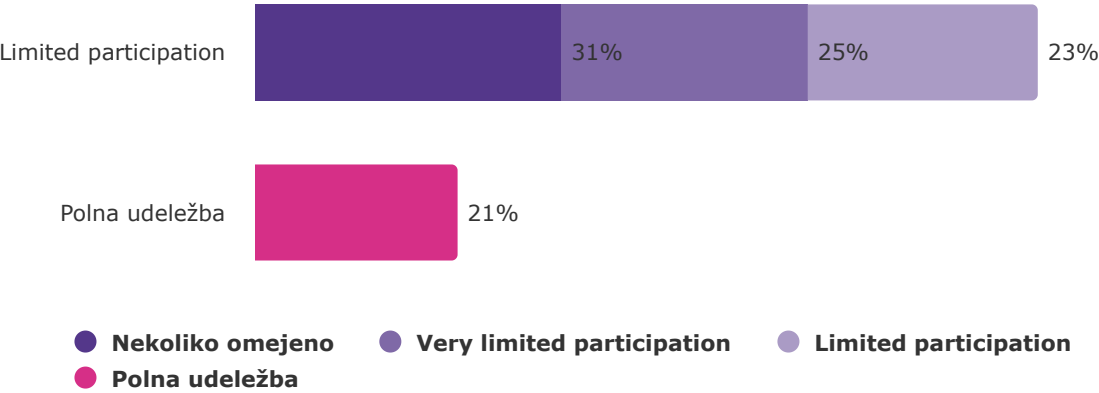
Komunikacija z drugimi študenti in odraslimi v šoli/na univerzi?

	N	%
▼ Limited	813	47%
Ni mi omogočeno	82	5%
Zelo omejeno	291	17%
Nekoliko omejeno	440	25%
Polna udeležba	880	50%
Ni relevantno	54	3%
TOTAL	1.747	100%



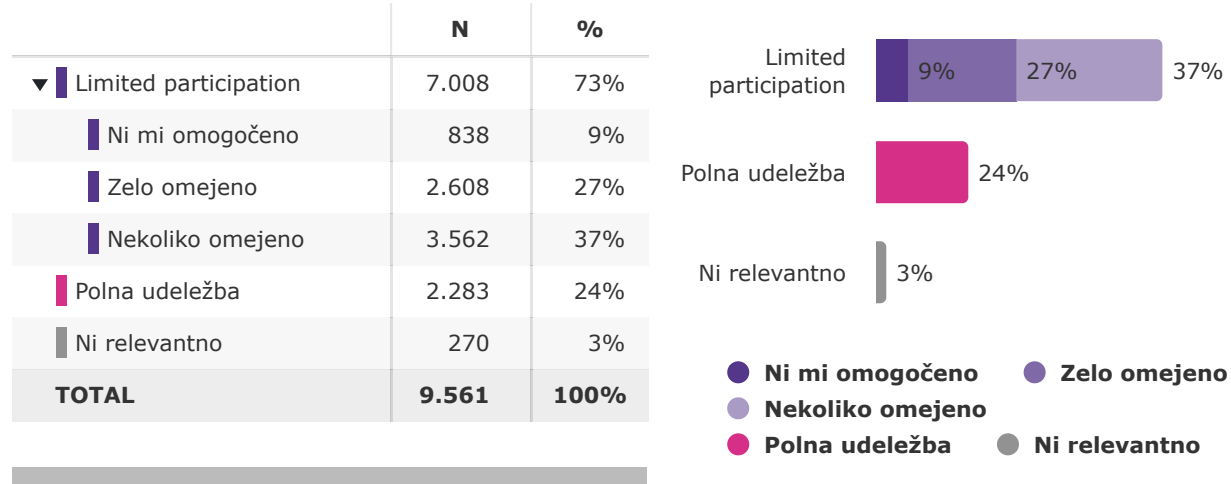
Sc_ScP_cat

	N	%
▼ Limited participation	1.229	79%
Nekoliko omejeno	484	31%
Very limited particip...	386	25%
Limited participation	359	23%
Polna udeležba	319	21%
TOTAL	1.548	100%

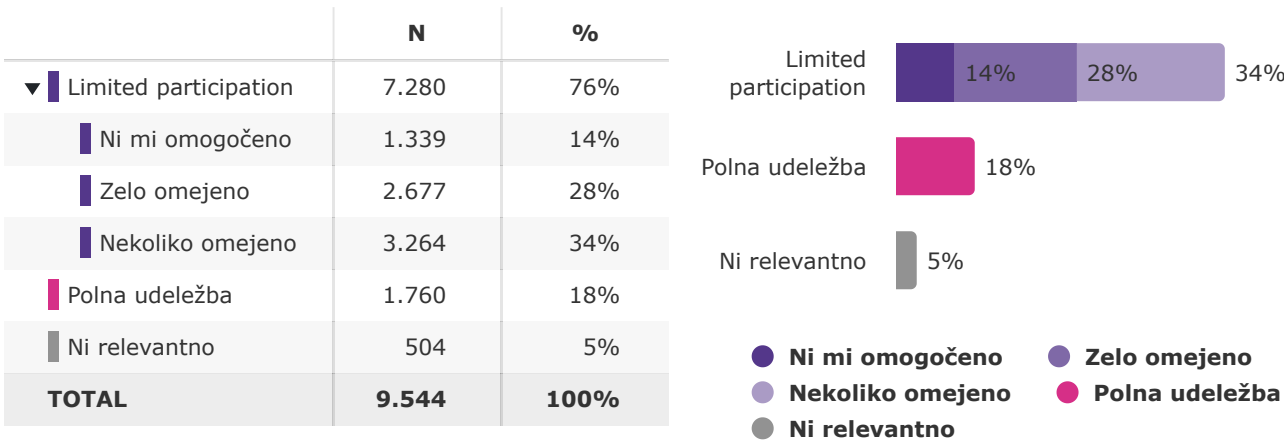


Compared to other people the same age, what is your current level of participation in the following activities:

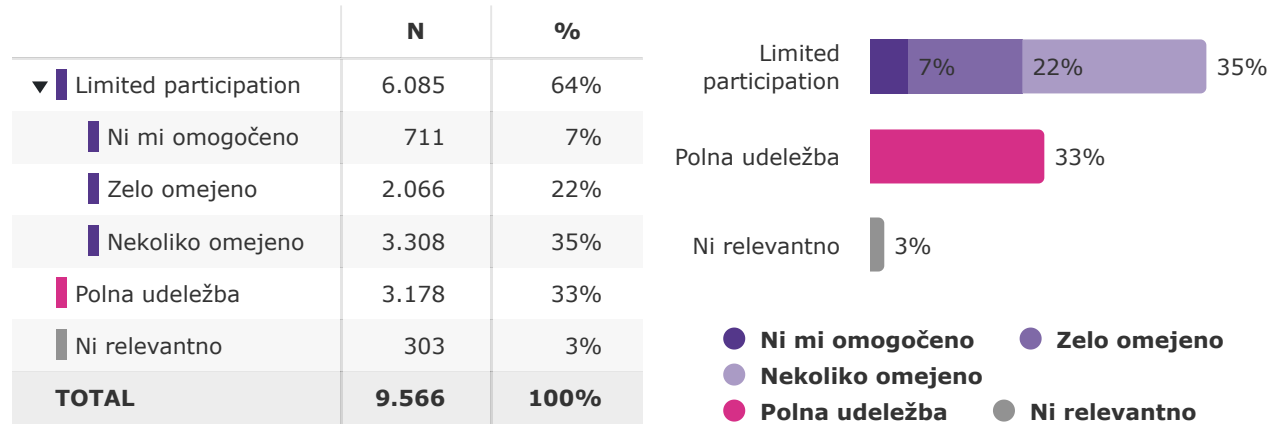
Družabne, igralne ali prostočasne dejavnosti s prijatelji iz sosesčine ali skupnosti, v kateri živite (npr. videoigre, »druženja«, obiskovanje javnih mest, kot so kinodvorane, parki ali restavracije)?



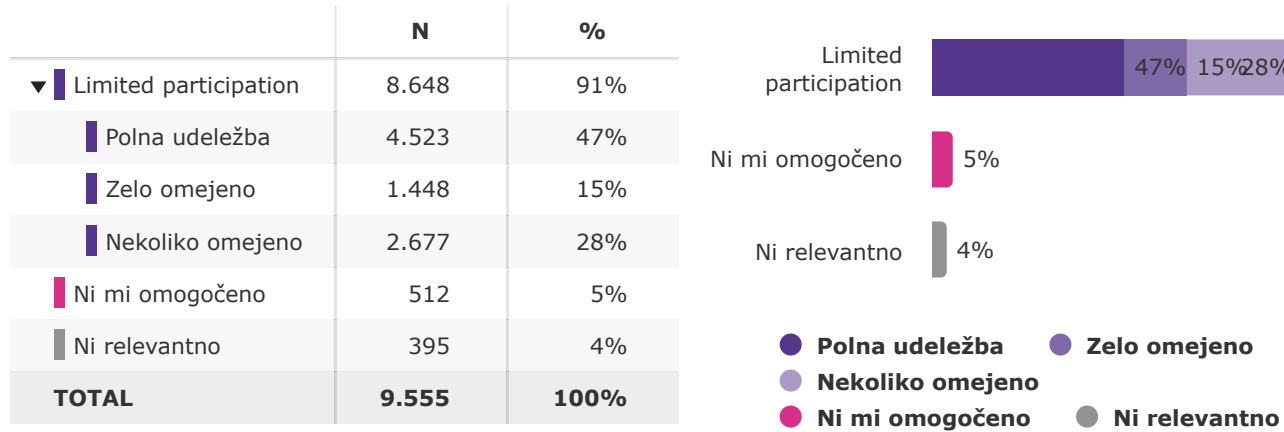
Strukturirani dogodki in dejavnosti v sosesčini ali skupnosti, v kateri živite (npr. ekipni športi, klubi, praznični ali verski dogodki, koncerti, parade in sejmi)?

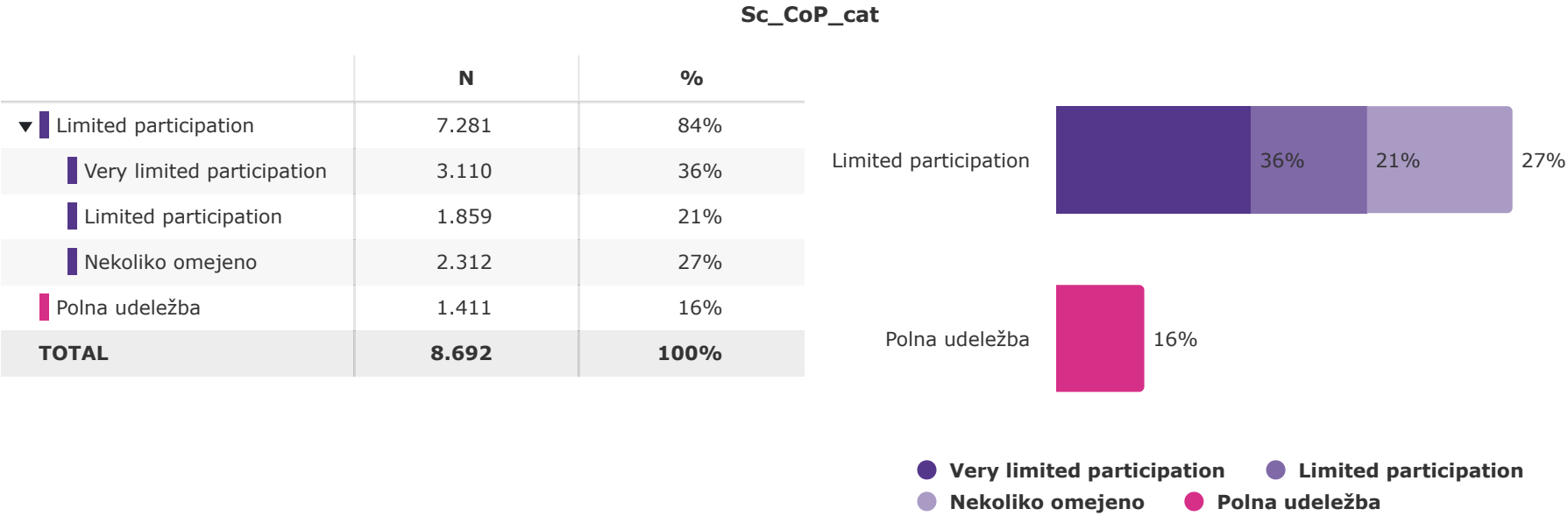


Mobilnost v sosesčini in skupnosti, v kateri živite (npr. javne zgradbe, parki, restavracije, kino)?



Komuniciranje z drugimi v sosesčini in skupnosti, v kateri živite?

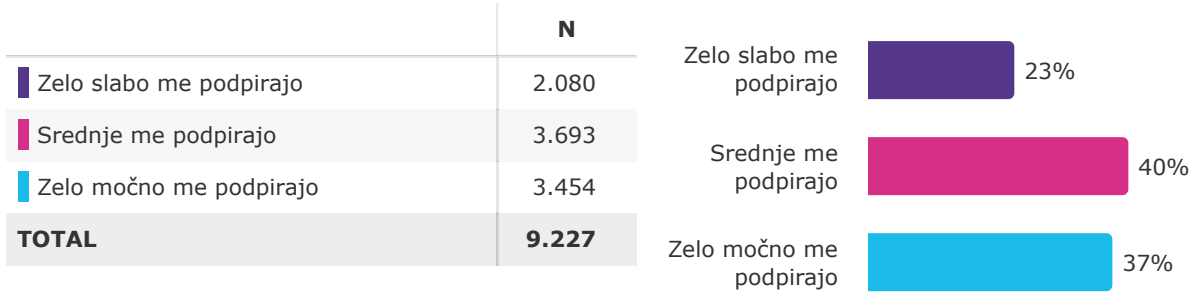




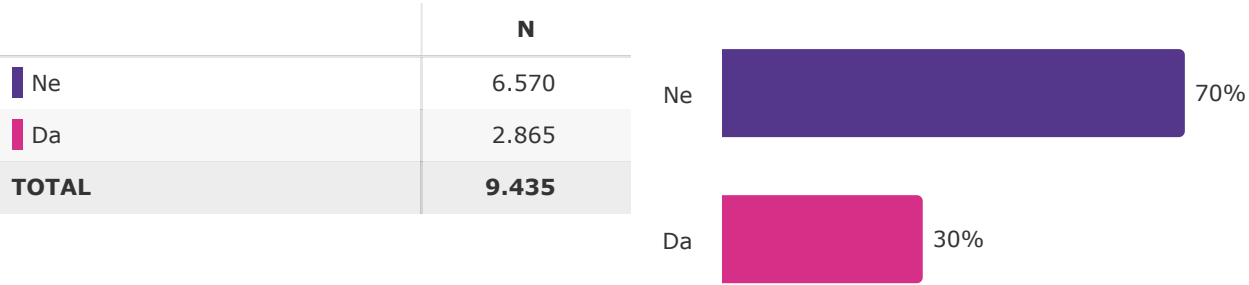


5.5. SOCIAL ENVIRONMENT

Kako bi kvalificirali podporo, ki jo prejimate od ljudi (bližnji, na katere se lahko zanesete, skrb drugih ljudi, praktična pomoč sosedov v primeru, da pomoč potrebujete)?

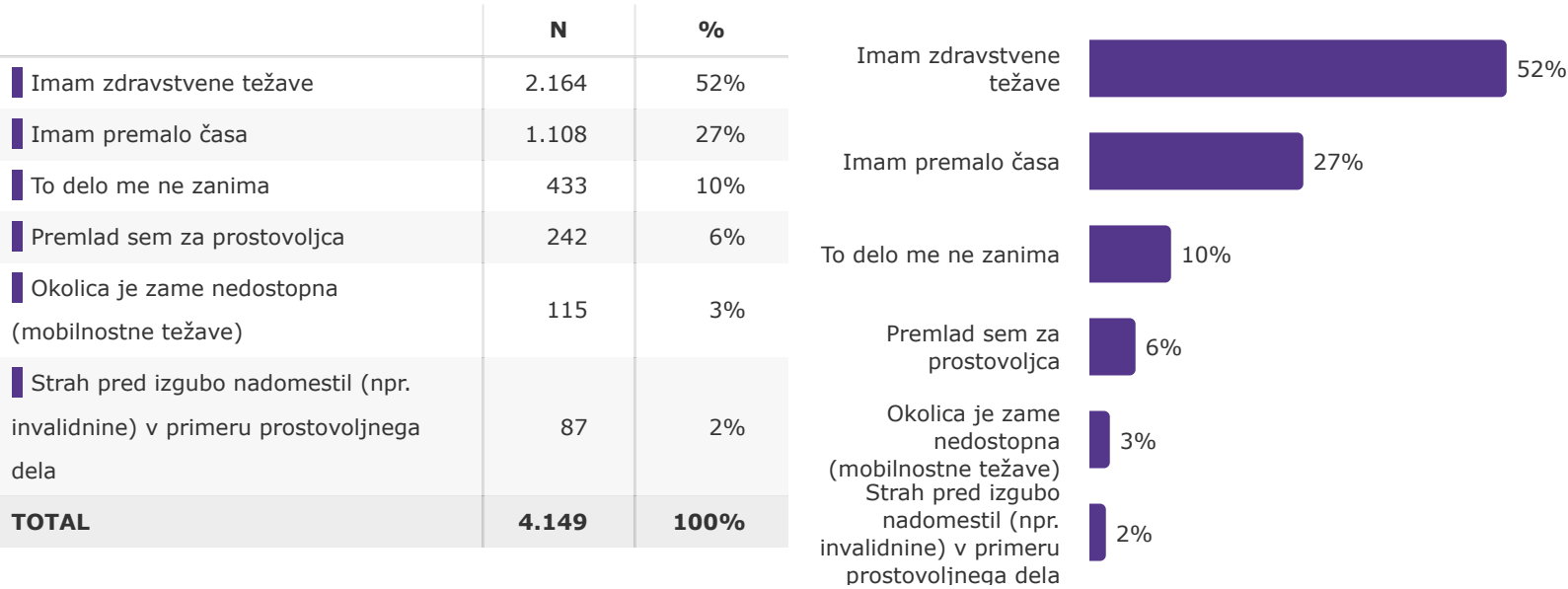


Ali ste v zadnjih 12 mesecih za kakršno koli organizacijo opravljali neplačano, neobvezno delo ali neformalne dejavnosti - prostovoljno delo (npr. pomoč drugim ljudem, pomoč živalim)?



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

Zakaj ne? Navedite samo najpomembnejši razlog.



Hvala vam!

Za vsa vprašanja se obrnite na ekipo Rare Barometer na
rare.barometer@eurordis.org

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